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Citation  Kaufman, B. G., S. Kim, K. Pieper, L. A. Allen, B. J. Gersh, G. V. Naccarelli, M. D. Ezekowitz, et al. 2018. “Disease understanding in patients newly diagnosed with atrial fibrillation.” Heart 104 (6): 494-501. doi:10.1136/heartjnl-2017-311800. http://dx.doi.org/10.1136/heartjnl-2017-311800.

Published Version  doi:10.1136/heartjnl-2017-311800

Citable link  http://nrs.harvard.edu/urn-3:HUL.InstRepos:35982158

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Disease understanding in patients newly diagnosed with atrial fibrillation

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ABSTRACT

Objective To describe self-reported disease understanding for newly diagnosed patients with atrial fibrillation (AF) and assess (1) how disease understanding changes over the first 6 months after diagnosis and (2) the relationship between patient understanding of therapies at baseline and treatment receipt at 6 months among treatment-naïve patients.

Methods We analysed survey data from SATELLITE (Survey of Patient Knowledge and Personal Priorities for Treatment), a substudy of patients with new-onset AF enrolled in the national Outcomes Registry for Better Informed Treatment of Atrial Fibrillation (ORBIT) II registry across 56 US sites. Patients were surveyed at the baseline and 6-month follow-up clinic visits using Likert scales.

Results Among 1004 baseline survey responses, patients’ confidence in their understanding of rhythm control, ablation, anticoagulation and cardioversion was suboptimal, with ‘high’ understanding ranging from 8.5% for left atrial appendage closure to 71.3% for rhythm therapy. Of medical history and demographic factors, education level was the strongest predictor of reporting ‘high’ disease understanding. Among the 786 patients with 6-month survey data, significant increases in the proportion reporting high understanding were observed (p<0.05) only for warfarin and direct oral anticoagulants (DOACs). With the exception of ablation, high understanding for a given therapeutic option was not associated with increased use of that therapy at 6 months.

Conclusions About half of patients with new-onset AF understood the benefits of oral anticoagulant at the time of diagnosis and understanding improved over the first 6 months. However, understanding of AF treatment remains suboptimal at 6 months. Our results suggest a need for ongoing patient education.

Clinical trial registration Clinicaltrials.gov. Identifier: NCT01701817.

INTRODUCTION

Atrial fibrillation (AF) is the most common sustained arrhythmia and is associated with high mortality and morbidity. Although oral anticoagulation (OAC) has been shown to reduce stroke risk by two-thirds among patients with AF, approximately half of patients with AF and risk factors for stroke do not receive this treatment, and of those treated, many discontinue anticoagulation. Patients’ confidence in their knowledge of available pharmacological and non-pharmacological therapeutic therapies for AF is essential to shared medical decision making and long-term medication adherence. Yet, there is a paucity of data regarding the extent to which patients newly diagnosed with AF in routine community practice feel they understand their treatment options and how this perception evolves over time.

Patients may have limited knowledge of the risks and therapeutic benefits associated with a diagnosis of AF, and evidence suggests that patients’ lack of knowledge surrounding their condition and treatment options presents a key barrier to the use of medications and adherence to recommendations. Some information is available via the internet and other public sources; however, the potential for misinformation from internet sources may adversely impact patient compliance. Interventions providing information about the need for warfarin, the risks and benefits associated with OAC therapy, potential interactions and the importance of monitoring international normalised ratio significantly improves time in therapeutic range in patients with AF initiating warfarin during the first 6 months. The treatment options for AF have become more complex over the past decade as additional therapeutic options are introduced including direct oral anticoagulants (DOACs), such as dabigatran, rivaroxaban, edoxaban and apixaban.

In addition to actual knowledge, patients’ confidence in their disease understanding is associated with self-efficacy and health literacy, which are prerequisites for changing patient behaviour. Understanding how patients’ perceived knowledge of AF therapeutic options impacts treatment decision may inform strategies to increase initiation and adherence to AF treatment. To meet this need, a survey was administered to participants of SATELLITE (Survey of Patient Knowledge and Personal Priorities for Treatment), a substudy of the national Outcomes Registry for Better Informed Treatment of Atrial Fibrillation (ORBIT) II registry, to collect data on patients’ self-reported risk perception as well as the patient’s confidence in their understanding of the role, options and benefits of existing and novel AF therapies. The goal of this study was to describe the level of understanding for newly diagnosed patients with AF and assess how patient...
understanding changes over the first 6 months for patients newly diagnosed with AF. Finally, we explored the relationship between patient understanding of therapeutic options at baseline and treatment rates at 6 months.

 METHODS
 Design and setting
 The ORBIT-AF study, the largest outpatient registry of patients with AF in the USA includes two prospective outpatient disease registries. ORBIT I assessed treatment and outcomes in patients with incident or prevalent AF across 176 sites; ORBIT II included patients across 56 sites who were aged 21 years or older and diagnosed within the 6 months preceding the baseline visit or patients with AF who had initiation or transition to a factor Xa inhibitor or a direct thrombin inhibitor within the preceding 3 months. ORBIT II excluded patients with atrial flutter only, anticipated life expectancy less than 6 months, short lasting AF secondary to a reversible condition (eg, hyperthyroidism, pulmonary embolism and postcardiothoracic surgery), participation in a randomised trial of anticoagulation for AF at the time of enrolment or enrolment in the ORBIT-I Registry.

This analysis used data from the SATELLITE substudy, which surveyed a subset of patients participating in the ORBIT II registry. Only patients with an AF diagnosis within 6 months of enrolment and the ability to complete baseline and follow-up surveys in English were included in SATELLITE. Of 13415 patients enrolled in ORBIT II, 1004 participated in the SATELLITE substudy. A representative sample of cardiologists, electrophysiologists and primary care practices were selected for SATELLITE participation based on quality of registry data. Each site enrolled a convenience sample of patients meeting eligibility criteria until the 1000 patient enrolment target was reached. All Survey of Patient Knowledge and Personal Priorities for Treatment (SATELLITE) study participants gave written informed consent before enrolment. The Duke Institutional Review Board (IRB) approved the ORBIT II Registry, and all participating sites obtained approval from local IRBs before consenting.

Data collection for ORBIT II occurs at 6-month intervals over 2 years and includes demographics, medical history, cardiovascular risk factors, treatment strategies, clinical events and provider information. In addition, SATELLITE patients completed self-administered paper surveys at the baseline visit (12 March 2015–30 September 2016) and a follow-up survey at the 6-month clinic visit.

 Measures
 Survey questions were developed and refined by a panel of cardiologists, epidemiologists and electrophysiologists with subject matter expertise and experience conducting observational research in AF populations. Content validity was evaluated and confirmed by ORBIT-AF principal investigators. The scale was pilot-tested by 10 non-clinicians for readability and comprehension prior to deployment. This testing resulted in combination of several questions for parsimony and minor edits in question stem wording for clarity.

The survey assessed self-reported understanding of three disease concepts from the patient perspective using Likert scales: AF understanding, stroke risk understanding and understanding of therapeutic options, including rhythm control, ablation, warfarin, DOACs and cardioversion. General AF and stroke risk understanding were only assessed at baseline, while the understanding of therapeutic options was assessed at baseline and at 6 months.

In order to compare responses at baseline and at 6 months, the five response categories were used to define three levels of understanding for each question as shown in table 1. For questions with response categories strongly agree to strongly disagree, high understanding was defined as strongly or somewhat agree; neutral understanding was defined as a response of neutral; and low understanding was defined as a response of somewhat or strongly disagree. High understanding of stroke risk was defined as a response of somewhat or strongly agree to the question ‘The major risk of atrial fibrillation is stroke’. For questions with response categories completely understand to never heard of the therapy, high understanding was defined as a response of completely or mostly understand; low understanding was defined as a response of somewhat understand or understand very little; and no understanding was defined as never heard of the therapy.

AF treatment was defined using the forms completed by the sites at baseline and 6 months. For each time period, use of OACs was defined as use of warfarin, dabigatran, rivaroxaban, apixaban or edoxaban; rhythm control was defined as use of any

| Table 1  | SATELLITE survey questions and response categories |
|----------|--------------------------------------------------|
| Understanding of AF | High understanding | Moderate understanding | Low understanding |
| I feel I understand what atrial fibrillation is.* | Strongly agree | Somewhat agree | Neutral | Somewhat disagree | Strongly disagree |
| The major risk of atrial fibrillation is stroke.* | Strongly agree | Somewhat agree | Neutral | Somewhat disagree | Strongly disagree |
| Understanding of therapeutic options | | | |
| I understand the role of (rhythm control/ablation) in the treatment of AF.* | Strongly agree | Somewhat agree | Neutral | Somewhat disagree | Strongly disagree |
| I understand the various options for (rhythm control/ablation) in the treatment of AF.* | Strongly agree | Somewhat agree | Neutral | Somewhat disagree | Strongly disagree |
| I understand the role of blood thinners in the treatment of AF.* | Strongly agree | Somewhat agree | Neutral | Somewhat disagree | Strongly disagree |
| I understand the various options for blood thinners in the treatment of AF.* | Strongly agree | Somewhat agree | Neutral | Somewhat disagree | Strongly disagree |
| Understanding of therapeutic benefits | High understanding | Low understanding | No understanding |
| How well would you say you understand the benefits of using the following therapies for AF† | Completely understand | Mostly understand | Somewhat understand | Understand very little | Never heard of the therapy |

*Data collected at baseline only.
†Therapies included: warfarin/direct oral anticoagulants/left atrial appendage closure/cardioversion.
AF, atrial fibrillation.
antiarhythmic medication; cardioversion was defined as any cardioversion procedure; and ablation was defined as utilisation of a catheter ablation for AF, specifically pulmonary vein isolation (PVI).

Analysis

Due to small sample sizes, the five response categories were collapsed into three levels of understanding for assessment of the change in understanding from baseline to 6 months. To test agreement between baseline and 6-month responses, weighted kappa statistics with 95% CIs were generated for each outcome, with kappa < 0.2 indicating poor agreement/substantial change, 0.21–0.4 indicating fair agreement/moderate change, 0.41–0.6 indicating moderate agreement/little change and >0.6 indicating good agreement/very little change. For the presentation in figures, the three levels of understanding were collapsed into two for the assessment of agreement between baseline and 6-month responses and the relationship between understanding at baseline and treatment at 6 months. Agreement between time points for binary measures was assessed with the McNemar test. To avoid bias due to the impact of treatment at baseline on understanding at baseline, the relationship between patient understanding and treatment at 6 months was assessed only for the subset who have not had a given treatment or procedure at baseline. SK had full access to all the data in the study and takes responsibility for its integrity and the data analysis.

RESULTS

Among 1004 patients with baseline survey data, 86% used OACs, 34% used antiarhythmic medications and 20% had catheter ablation of AF at baseline. Among the 786 completing the 6-month survey, the median age was 69.0 years (IQR 63.0–76.0) and 92.1% (724 of 786) were white. Compared with the SATELLITE participants with baseline data only, those completing the survey at 6 months were older, more likely to smoke or have hypertension, more likely to have prior cardioversion and had a higher risk of stroke as measured by the CHA2DS2-Vasc score.

Self-reported patient understanding at baseline

At the baseline visit, 81.8% of SATELLITE patients reported high understanding of AF with a response of somewhat or strongly agree following the statement ‘I feel I understand what Atrial Fibrillation is’. Nearly 9 in 10 patients (87.2%) reported a high understanding of the role of ablation, ranging from 8.5% to 71.3% reporting a high understanding of the benefits for left atrial appendage closure and role of rhythm control, respectively. About half reported a high understanding of the benefits of warfarin and DOACs (45.6% and 50.0%, respectively). Patients receiving care from cardiologists and electrophysiologists were more likely to report a high understanding of the various therapies at baseline than patients receiving care from a primary care physician; however, due to the small numbers of patients receiving care from primary care physicians, the statistical significance of this difference was not assessed. Full results for the baseline and follow-up surveys are presented in online supplementary material.

Changes in patient understanding of AF from baseline to 6 months

Moderate change (kappa < 0.4) in patient understanding of therapeutic options from baseline to 6-month follow-up visit occurred for all therapies except cardioversion (kappa = 0.42, CI = 0.36 to 0.47) (table 4). For example, about half of those who reported low or moderate understanding of the role of rhythm control therapies at baseline reported high understanding at 6 months (50.0% and 53.9%, respectively). About one-third of patients reporting low or moderate understanding of the role of ablation therapies at baseline reported high understanding at 6 months (32.8% and 31.4%, respectively). Of patients reporting low or no understanding of the benefits of DOACs at the baseline visit, 59.1% and 32.1% improved to high understanding at 6 months, respectively. Improvement in understanding of warfarin benefit was similar. After 6 months, two-thirds of patients report low understanding of the benefits of LAAC (63.6%), one-third report low understanding of the role of ablation (37.1%) and one quarter report low understanding of the role of rhythm control (25.8%).

Though perceived understanding improved between the baseline and 6-month visit for some patients, others reported less understanding at the 6-month visit than at baseline. Overall, the net increase in the proportion reporting high understanding was significant for warfarin (p < 0.0001) and DOACs (p < 0.0001) from 45.6% and 50.0% at baseline to 59.1% and 68.7% at 6 months, respectively (figure 1), but not for rhythm control, ablation or cardioversion.

Relationship between patient understanding and treatment

At the baseline visit, over 80% of SATELLITE patients used OACs, two-thirds used rhythm control and less than a quarter had a PVI. Use of a treatment at baseline was positively associated with baseline understanding of the role of that therapy (p < 0.001). For example, over 90% of patients using an OAC at baseline reported a high understanding of the role of blood thinners at baseline as compared with less than 80% among non-users. Patients reporting a high baseline understanding of ablation are more likely to receive PVI; however, patients’ understanding of OAC or rhythm control was not associated with initiation of OAC or rhythm control, respectively, within 6 months (figure 2). Patients with high understanding of the benefits (p = 0.0005) of ablation and options for ablation (p = 0.0093) at baseline were more likely to initiate PVI within 6 months (n = 799). Improved perceived understanding of therapeutic options at baseline was not associated with increased initiation of blood thinners including DOACs and warfarin (n = 132) or rhythm control (n = 577) within 6 months.

DISCUSSION

Among patients with new-onset AF, patients’ confidence in their understanding of rhythm control, ablation, anticoagulation and cardioversion was suboptimal, with 30%–60% of...
Arrhythmias and sudden death

Kaufman BG, et al. Heart 2018;104:494–501. doi:10.1136/heartjnl-2017-311800

patients reporting uncertainty about the role, benefits and options for these therapies at both the baseline and follow-up visits. Although understanding of DOACs and warfarin benefits improved over the first 6 months from diagnosis, routine care in community practices did not result in improved patient understanding of other treatment options. With the exception of ablation, patient reported understanding of therapeutic benefits and options was not associated with initiation of treatment within the first 6 months.

The finding that patients’ perceived understanding of AF is suboptimal is consistent with prior research demonstrating gaps in knowledge. However, only 13% of SATELLITE patients were unsure whether stroke is a risk of AF, compared with over 30% in prior studies. This difference is likely because this study specifically sought to assess understanding from the patient’s perspective, and patients may have overestimated their understanding of AF and stroke risk. Studies comparing self-rated knowledge to actual knowledge of AF have found gaps in knowledge relative to perceived understanding, although there was a correlation between the two measures.

The inconsistent association between perceived treatment understanding and uptake in this study contrasts with evidence suggesting that patients’ understanding influences uptake of OACs. One explanation may be the exclusion of prevalent OAC users at baseline. The 14% of SATELLITE patients not on OACs at baseline may be more likely to have a contraindication or a strong personal preference preventing OAC use. However,
Arrhythmias and sudden death

The similar baseline rates and increases in perceived understanding of warfarin and DOACs indicate that patients’ access to information about the newer DOACs may be similar to access to information about warfarin. No systematic communication was required from physicians to educate patients about specific therapeutic options, and differences in physician preference and practice patterns likely played a role in the observed changes in understanding.

Patient understanding is likely to be a stronger indicator for uptake of procedures used more selectively, including cardioversion or ablation. For example, the association found between a high understanding of ablation and PVI within 6 months may be a result of electrophysiologists or proablation physicians introducing patients to ablation early in the disease trajectory relative to physicians with different preferences.

Table 4  SATELLITE patient understanding of atrial fibrillation therapies at baseline and at 6 months

| Survey question (N) | Understanding at baseline | Understanding at 6-month follow-up |
|---------------------|---------------------------|-----------------------------------|
| **Panel A: role of rhythm control (n=589)** | | |
| Baseline understanding | High understanding | Moderate understanding | Low understanding |
| High understanding | 71.3 | 79.8 | 12.6 | 7.6 |
| Moderate understanding | 15.4 | 53.9 | 27.5 | 18.7 |
| Low understanding | 13.2 | 50.0 | 19.2 | 30.8 |
| Weighted kappa=0.26 (0.18, 0.33) | | |
| **Panel B: options for rhythm control (n=581)** | | |
| Baseline understanding | High understanding | Moderate understanding | Low understanding |
| High understanding | 44.8 | 63.5 | 19.2 | 17.3 |
| Moderate understanding | 26.9 | 43.6 | 30.8 | 25.6 |
| Low understanding | 28.4 | 28.5 | 24.9 | 46.7 |
| Weighted kappa=0.27 (0.20, 0.34) | | |
| **Panel C: role of ablation (n=546)** | | |
| Baseline understanding | High understanding | Moderate understanding | Low understanding |
| High understanding | 44.3 | 66.1 | 12.4 | 21.5 |
| Moderate understanding | 22.2 | 31.4 | 36.4 | 32.2 |
| Low understanding | 33.5 | 32.8 | 15.9 | 51.4 |
| Weighted kappa=0.30 (0.23, 0.37) | | |
| **Panel D: options for ablation (n=578)** | | |
| Baseline understanding | High understanding | Moderate understanding | Low understanding |
| High understanding | 35.3 | 55.4 | 22.1 | 22.6 |
| Moderate understanding | 25.4 | 30.6 | 34.0 | 35.4 |
| Low understanding | 39.3 | 22.9 | 19.4 | 57.7 |
| Weighted kappa=0.30 (0.23, 0.36) | | |
| **Panel E: benefits of cardioversions (n=743)** | | |
| Baseline understanding | High understanding | Low understanding | No understanding |
| High understanding | 47.1 | 78.9 | 16.6 | 4.6 |
| Low understanding | 38.2 | 34.9 | 53.9 | 11.3 |
| No understanding | 14.7 | 22.9 | 41.3 | 35.8 |
| Weighted kappa=0.42 (0.36, 0.47) | | |
| **Panel F: benefits of warfarin (n=724)** | | |
| Baseline understanding | High understanding | Low understanding | No understanding |
| High understanding | 45.6 | 77.9 | 19.1 | 3.0 |
| Low understanding | 41.4 | 47.0 | 49.0 | 4.0 |
| No understanding | 13.0 | 31.9 | 44.7 | 23.4 |
| Weighted kappa=0.32 (0.26, 0.37) | | |
| **Panel G: benefits of DOACs (n=738)** | | |
| Baseline understanding | High understanding | Low understanding | No understanding |
| High understanding | 50.0 | 84.0 | 14.6 | 1.4 |
| Low understanding | 39.4 | 59.1 | 38.5 | 2.4 |
| No understanding | 10.6 | 32.1 | 44.9 | 23.1 |
| Weighted kappa=0.30 (0.24, 0.36) | | |
| **Panel H: benefits of left atrial appendage closure (n=734)** | | |
| Baseline understanding | High understanding | Low understanding | No understanding |
| High understanding | 8.5 | 32.3 | 22.6 | 45.2 |
| Low understanding | 25.3 | 13.4 | 41.9 | 44.6 |
| No understanding | 66.2 | 6.0 | 20.8 | 73.3 |
| Weighted kappa=0.26 (0.20, 0.33) | | |

DOACs, direct oral anticoagulants.
in patient understanding over the first 6 months. In addition, one quarter of SATELLITE patients reported their top source of information was the internet and other non-physician sources that may have contributed to the increase in knowledge of OACs following diagnosis.27

AF patients’ lack of confidence in their understanding of AF represents an opportunity to improve outcomes with interventions targeting patient perceptions and health literacy, particularly among those with low educational attainment. Low health literacy is consistently associated with disease-related knowledge and self-efficacy, which are prerequisite to establishing behaviours necessary for effective self-management of AF.16 The integrated care approach to AF management includes components targeting health literacy and has reduced hospitalisation and mortality; for example, interventions including postdischarge management and an AF chronic care clinic improved outcomes relative to standard care.28–30

**Limitations**

The study was limited to participating sites and patients volunteering to complete the surveys, which may limit the external validity of these data. These results are based on self-reports of patient understanding and should be interpreted with more caution than validated measures of disease knowledge. This study describes patient’s perception of disease understanding rather than demonstrated knowledge. The analysis of the relationship between understanding at baseline and treatment initiation was restricted to patients not on therapy at baseline, which resulted in a limited sample in which to assess OAC initiation due to the high rates of use at baseline. Finally, in this descriptive analysis, the associations between patient understanding and treatment decisions may be confounded by other factors, including physician practices, clinical presentation and patient socioeconomic factors.

**CONCLUSIONS**

Physician and patient factors that influence AF disease understanding and shared decision making should be a priority in future research. In routine community practice, patients’ perceived understanding of AF therapeutic options is suboptimal at diagnosis and remains so at 6 months, suggesting a role for ongoing patient education. Future work should focus on elucidating specific factors contributing to low health literacy, such as socioeconomic status, multimorbidity and suboptimal patient–provider communication. Such knowledge could support development of targeted interventions to improve disease understanding and support better communication about stroke risk and available therapies in vulnerable patient populations.
Arrhythmias and sudden death

Figure 2  SATELLITE patient understanding of role or options for atrial fibrillation therapies at baseline and use of therapy at 6 months. Notes: the relationship between patient understanding and therapy at 6 months was assessed only for the subset of patients not on the treatment at baseline. Ablation therapy was defined as use of pulmonary vein isolation (PVI). Rhythm control therapy was defined as antiarrhythmic medication.

Use of Therapy at Six Months  ▲ No  ● Yes

Key messages

What is already known on this subject?
Patients’ confidence in their understanding of available pharmacological and non-pharmacological therapeutic therapies for atrial fibrillation is essential to shared medical decision making and long-term medication adherence.

What might this study add?
This study provides evidence regarding extent to which patients newly diagnosed with AF in routine community practice understand existing and novel therapeutic options, how this understanding evolves over time and the association with treatment initiation.

How might this impact on clinical practice?
In routine community practice, patient understanding of AF therapeutic options is suboptimal at baseline and remains so at 6 months, suggesting a role for ongoing patient education.

Acknowledgements

The authors would like to thank the staff and participants of the ORBIT-II AF registry and Tony Schibler for their important contributions to this work.

Contributors

BGK, SK, KP and ECO: conception, analysis and interpretation of data. LAA, BfG, GVN, MDE, GGC, KWM, DES, PSC, JVF, JA, PRK, JAR, JP, EP and ECO: conception, acquisition and interpretation of data. All authors participated in critically revising the manuscript for important intellectual content, provided final approval of the version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Competing interests

BGK, SK and KP: none. LAA: consultancy from Novartis (significant) and Janssen. JP: significant research support from Boston Scientific, ResMed, ARCA Biopharma, St. Jude Medical Center, Gilead Sciences, Johnson&Johnson, Spectranetics and Janssen and consultancies to Janssen (significant), Spectranetics (significant), Medtronic (significant), Forest Laboratories (modest), Pfizer (modest) and GlaxoSmithKline (modest). EP: significant research support from Eli Lilly & Company, Daiichi Sankyo and Janssen. ECO: significant research grant from Janssen, BMS, Novartis and Pfizer. BfG: consultancies to Janssen Scientific Affairs (significant) and Cipla Limited Data Safety Monitoring Board (modest) for: Mount Sinai St. Lukes, Boston Scientific Corporation, Teva Pharmaceutical Industries, St. Jude Medical, Janssen Research & Development, Baxter Healthcare Corporation, Thrombosis Research Institute, Duke Clinical Research Institute, Duke University, Kowa Research Institute and Cardiovascular Research Foundation. PRK: consultant to Johnson&Johnson (significant). GCF: consultant to Johnson&Johnson (modest). JAR: consultant and/or speaker’s bureau for Boehringer-Ingelheim, Janssen (significant), Pfizer, BMS, Portola (modest) and Daiichi Sankyo. JVF: consultant to Janssen (modest) and salary support from the American College of Cardiology National Cardiovascular Data Registry. JA: consultancy/advisory board to Bristol-Myers Squibb; Pfizer; Janssen; Daiichi Sankyo; Boehringer Ingelheim; Instrumentation Laboratories; Perosphere; Roche Diagnostics. Equity in Perosphere. MDE: consultancies to Boehringer Ingelheim and Daiichi Sankyo (modest) and Bristol-Myers Squibb, Pfizer, Johnson&Johnson and Janssen Scientific Affairs (significant). GVN: consultant/advisory board to Janssen, Daiichi Sankyo, GlaxoSmithKline, Astra Zeneca; research support from Janssen. PSC: funding from the NHLBI (R01HL123980). DES: consultant/advisory board to Boehringer Ingelheim, Bristol-Myers Squibb, Merck, Johnson&Johnson, Medtronic, Pfizer; research grants from Boehringer Ingelheim, Bristol-Myers Squibb and Medtronic. KWM: financial disclosures can be viewed at http://med.stanford.edu/profiles/kenneth-mahaffey.

Ethics approval

Duke Institutional Review Board.

Provenance and peer review

Not commissioned; externally peer reviewed.
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