The field of medicine is rushing headlong into a new, information-intensive era of practice and research. As medicine learns to wield the tools of “big data,” there is growing confidence that physicians and researchers will be able to obtain, measure, and analyze information from multiple sources, including the directly solicited views and preferences of patients.

In this week’s issue of Circulation, Stolker and colleagues provide insight into where this major trend may be headed. Using a simple questionnaire administered to patients in a cardiovascular clinic, they uncovered several intriguing findings. First, they noted a difference between clinical trialists and patients in terms of the importance ascribed by each group to preventing different specific outcomes that make up the classic major adverse cardiovascular event end points used to assess the safety and efficacy of cardiovascular therapies. Second, they found that among the patient respondents to their survey, these weightings also varied as a function of demographic factors. From these findings, Stolker and colleagues propose that weighted composites could be used to personalize evidence assessment to inform healthcare delivery on the basis of these differences.

The measurement of patient preferences has a long history that nevertheless seems to undergo perpetual rediscovery. Yet the key issues in this arena have received scant attention from funding agencies, and very little support has been directed toward research aimed at elucidating patient preferences and decision-making processes. As a result of this inattention, the framing of questions is of critical importance in survey-based research.

The very brief questionnaire that the authors administered does not provide vignettes describing the range of disability that might be expected from nonfatal cardiovascular events; furthermore, it frames the question in terms of reducing the risk of each outcome. One could assume that reducing the risk of stroke or myocardial infarction (MI) would also reduce the risk of death, and it is unclear what summative considerations went into the responses. The finding that patients rated reducing the risk of MI as important as or more important than reducing the risk of death seems to run counter to previous reports, whereas the clinical trialists’ responses, which rated death as much more severe than nonfatal events, were consistent with prior data. Other literature indicates that after more framing, patients weight nonfatal MI as less important than stroke, whereas they tend to assign similar importance to stroke and death. Studies using questionnaires that provided more detailed descriptions of the physical manifestations of mild or severe MI or stroke have tended to elicit much more finely grained preferences. Clearly differentiating nonfatal MI and nonfatal stroke from fatal events is a critical issue for future research.

The subgroup findings from Stolker and colleagues support a narrative that many would find pleasingly consistent with conventional wisdom. Older patients valued reducing the risk of death relative to stroke as much less important than did younger patients (possibly reflecting differences in the relative valuation of quality of life), and wealthier patients valued reducing the risk of death more than lower-income patients (possibly reflecting differential concerns about the costs of nonfatal events). Future work should aim at further development of techniques and systems for eliciting preferences. In particular, the massive National Patient-Centered Clinical Research Network (PCORnet) program of the Patient-Centered Outcomes Research Institute presents a significant opportunity to interact with patient groups on a national scale and to evolve a better understanding of risk and outcomes for people with specific diseases. Furthermore, as patients learn more about the possible future states entailed by diseases and

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conditions (and by their treatments), it is likely that thought-
ful, effective use of Internet-based tools and resources can
help individuals and groups iterate toward realistic and accu-
rate estimates of preferences.

Methods for depicting findings when weighting schemes
are applied to composite outcomes also deserve further articu-
lation. Distinguishing any effect from random variation is
difficult enough, given the modest benefit of most effective
therapies. However, because these weighted comparisons will
involve more stratification based on preferences for different
weights for different outcomes, there exists the great risk of
introducing considerable false-positive evidence into the deci-
cision-making matrix. However, a massive increase in sample
sizes is achievable if we can successfully create a learning
health system in which patients and families interact with
providers and electronic records on a more continuous basis.
The access of PCORnet to millions of interested research par-
ticipants will make possible comparative effectiveness studies
on a sufficiently large scale to produce a “consumer reports”
outcome assessment that enables different patients and prac-
titioners to make choices based on the array of predicted
outcomes.

Stolker and colleagues have made a solid contribution
to this novel but increasingly important field. As larger and
more rigorous systems for assessing preferences are devel-
oped and become commonplace, the relevant outcomes for
clinical and outcomes trials will be optimized by the ability
to appropriately match the preferences of patients, their care-
givers, providers, and health systems. The most fertile ground
for detailed work awaits the finding of true differences among
types of people and roles in the system (patients, caregivers,
providers, administrators, etc). Deeper dives will often reveal
issues with the framing of preferences, but differences that
persist after framing and cognitive biases are accounted for
can lead to true personalization of health care.

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