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F. Reed Johnson: When it Comes to Health Economics, He's In It for Life

Don't expect F. Reed Johnson, PhD, ISPOR's 2018 Avedis Donabedian Outcomes Research Lifetime Achievement Award winner—a professor of medicine and in Population Health Sciences at Duke University, and a Duke senior research scholar, Duke Clinical Research Institute (DCRI) Preference Evaluation Research—to be retiring anytime soon.

"I tell everyone that they'll have to take me out feet first," jokes Dr. Johnson, a professor in Population Health Sciences at Duke University and a Duke senior research scholar, Duke Clinical Research Institute Preference Evaluation Research. "My friends keep asking me why I haven't I retired and I say I don't have a lot of outside interests. I have no interest in playing golf, for example. I like what I'm doing."

From Environmental Health Economics to Human Health

Dr. Johnson has more than 40 years of academic and research experience in health and environmental economics. As a staff member in the US Environmental Protection Agency's (EPA) environmental economics research program during the 1980s, he helped pioneer development of nonmarket valuation techniques. These methods are now widely used in federally mandated regulatory impact studies, for estimating the value of improved health outcomes, and for quantifying patients' tolerance for treatment-related risks.

He has more than 140 publications in books and peer-reviewed journals. He led the first US Food and Drug Administration's (FDA) sponsored study to quantify patients' willingness to accept benefit-risk tradeoffs for new health technologies. The study was used to inform recent FDA guidance on submitting patient-preference data to support regulatory reviews of medical devices. He has coauthored a book on techniques for using existing environmental and health value estimates for policy analysis. He is a founding member of the International Academy of Health Preference Research. He currently serves on the editorial board for The Patient, the Science Advisory Board for the EPA, and is an active participant on the ISPOR Health Science Policy Council.

"I think it's rather puzzling to people that I showed up [in the healthcare field] late in my career," Dr. Johnson told Value & Outcomes Spotlight. "I was an environmental economist for the first half of my career. It turns out that one of the largest benefit categories of reducing pollution is health."

He recalls that the challenge back in the 1980s was trying to do cost-benefit analysis for environmental services for which there are no markets.

"There's nobody buying and selling clean air or clean water," Dr. Johnson says. "During the Reagan Administration, they were requiring the EPA do benefit/cost analysis on all major regulations,

and we had no good way really of coming up with a monetary estimate of the value of reducing air and water pollution. The government made resources available to us, and to environmental economists in general, to start trying to figure out how to value what we called 'non-market goods' or nonmarket valuation. We developed some stated preference methods that eventually became widely accepted and are now just standard practice in government regulatory impact statements."

Eventually, Dr. Johnson found himself doing more studies about health and fewer about the environment, and ended up at Research Triangle Institute, now RTI International, conducting studies in health economics.

"When I started doing work in health, I kind of thought I was going to do the same thing," he says. "I knew there was reluctance to monetize health benefits, but if you are going to compare benefits with cost, you're going to need a monetary value, which is the same problem we had in environmental economics. As it turns out, though I thought we'd just fight that fight and win it again, it turned out to be a lot harder to persuade people that we ought to attach prices to outcomes. So, we continued to transfer the methods we used in environmental economics to health, but not so much for monetizing benefits but just to understand the relative importance >

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of benefits and harms of new treatment. That's what we did for quite a long time and still are doing."

THE COLLEAGUES WHO HAVE HELPED ALONG THE WAY

In the '90s, Dr. Johnson left RTI with some other colleagues to work in their consulting firm. But he was later persuaded to come back to RTI by Josephine Mauskopf, PhD, vice president, Health Economics Solutions.

In addition to Dr. Mauskopf, Dr. Johnson says there are others who have helped him achieve professional success. These colleagues include Brett Hauber, PhD, senior economist and VP, Health Preference Assessment, at RTI, who Dr. Johnson has worked closely with for more than a decade; John F.P. Bridges, PhD, at Health Solutions at RTI; and more recently, Shelby Reed, PhD, former president of ISPOR and professor in Population Health Sciences at Duke University; Deborah Marshall, PhD, MHSA, Canada Research Chair, Health Services and Systems Research; associate professor, Department of Community Health Sciences, Faculty of Medicine, University of Calgary; and director, Health Technology Assessment, Alberta Bone and Joint Health Institute, Calgary, who also is a past president of ISPOR; and Dr. Ben Craig, who has founded a new professional organization for stated preference research in health, the International Academy of Health Preference Research (IAHPR).

Dr. Johnson is also a member of in the Duke Clinical Research Institute. "Shelby managed to find a place for me at Duke 4 or 5 years ago, and we've managed to attract a few of my former colleagues from RTI and are doing much the same thing that I've been doing all my career," Dr. Johnson says.

"All of these people, I have to say, have made it possible for me to do what I'm better at," Dr. Johnson says. "And what I'm not better at is all of the, I guess you could call it, watering and weeding that has to go on in any sort of research activity. We must function in a complicated institutional framework, and I'm not very good with dealing with bureaucracies and making things happen. And so, I've been lucky in that people like Brett and Shelby are willing to clear the way for me, so I could do what I'm better at, while they dealt with a lot of the management aspects of our research. It's really, really important, and I couldn't have done anything that I've been able to do without them."

LOOKING TOWARD THE FUTURE

Dr. Johnson says while stated preference research and its methods have come a long way, there is still much more progress to be made.

He points out that there are some barriers to the establishment of stated preference data as a routine element in both regulatory decision making and drug and device product development. "There is maybe a little bit of mistrust in patients' ability to think clearly and logically about the tradeoffs that are involved in healthcare," Dr. Johnson says. "It's hard for clinicians to see stated preference data as data in the same sense as trial data are viewed. And one of the primary goals of our research has been to make these studies, as much as possible, look like the kinds of controlled data collection efforts that are the basis of events-based decision making in health. I think we've made some progress in establishing some standards for doing these kinds of studies, in establishing validity tests that establish whether the data we have could stand up to the standard expectations about evidence. But it's hard to do this well—it's hard to do it at all. There aren't the resources available that are obviously available for other kinds of data collection in health."

According to Dr. Johnson, he was "honestly surprised" to be selected for the ISPOR Avedis Donabedian Award. "I felt in some ways that we weren't ready for that kind of recognition," he says. "But we have in fact made quite a bit of progress in the last few years, which has been gratifying."

This progress is reflected in the growing popularity of stated preference method topics for ISPOR's conferences. "It feels different than it did for many years when it was hard to get on the ISPOR program," Dr. Johnson says. "It's not so hard anymore, there seem to be a lot of people who are signing up for the conference courses and attending sessions. But still, I see a surprising—well, I guess surprising to me, considering how much attention stated preference work and specifically patient centricity in healthcare has had in the last few years—people still don't quite understand what we do and get confused between stated preference studies and patient-reported outcomes studies. But we're making progress."

One sign of this progress Dr. Johnson points to is the adoption of guidance for submitting patient preference data, specifically for benefit-risk assessments, at FDA's Center for Devices and Radiological Health. "But the Center for Drug Evaluation and Research (CDER) is moving in that direction much more slowly," he says. "And until we can get actual guidance from CDER, it's still going to be hard to see much of a role that quantitative patient preferences are going to have in regulatory assessments of drugs."

However, Dr. Johnson believes that CDER will get there, and sooner rather than later. "Becky Noel [Global Leader for Benefit-Risk Assessment at Eli Lilly] once said to me about 15 years ago when we were working on the Tysabri studies, that it took 10 years for any major changes to take place at the FDA," he says. "A few years ago I asked Becky whether she thought the clock had started yet. But it had, it had. So maybe we are about 5 years away, 4 years away from seeing those kinds of changes in the CDER."

His current research involves quantifying patients' willingness to accept side-effect risks in return for therapeutic benefits and estimating general time equivalences among health states.

"We are actively involved in adapting these general population or general patient population surveys for use in a clinical setting," Dr. Johnson says. "And the idea is to come up with a preference diagnostic tool that can be used quickly, efficiently, and in a clinical setting—maybe when patients are in the waiting room before an

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appointment—that would provide the physician with diagnostics roughly like vital signs diagnostics that they routinely receive." Physicians already try and obtain that information informally but have very limited time and resources to do so. "It's the informally part that makes us all nervous, because there's just limited time and resources to spend with patients," Dr. Johnson says. "We'd like to formalize that to some extent with a validated instrument that would actually produce, in a more structured way, what physicians and other caregivers do more informally."

A LOVE FOR SINGING AND SCANDINAVIAN CULTURE

Although Dr. Johnson focuses mostly on his work, he does enjoy choral singing, being part of the first tenor section in various local groups. His wife is a choral conductor, which he says allows them to share that interest.

He admits he does not perform as often as he used to. "I've actually slowed down a little bit," Dr. Johnson says. "A couple of years ago, between church and the various community groups I sang with, I was doing maybe 10 or 12 concerts a year, with about 5 or 6 with them during the Christmas season. But now it's more like 4 in total. That's a little more reasonable!"

As a Mormon missionary in the 1960s in Sweden, Dr. Johnson developed an affinity for the country. He learned Swedish and has brought his family back to Sweden several times, and they share his love of Scandinavian culture.

One of his family's traditions is holding a traditional Swedish "Other Day of Christmas" celebration, which is the day after the holiday. "We have a big party every year in our home, with Swedish music and a Christmas tree decorated in a traditional Swedish way, and we do dancing around the Christmas tree," Dr. Johnson says.

As he has cut back his choral group involvement, Dr. Johnson has concentrated on work. He continues to establish ways to validate preference data.

"I think we've made some progress in establishing some standards for doing these kinds of studies, in establishing validity tests that establish whether the data we have could stand up to the standard expectations about evidence," he says. "But it's hard to do this well, it's hard to do it at all—there aren't the resources available that are obviously available for other kinds of data collection in health.

So yes, it feels good to have gotten this far but it really feels like we have a long way to go."