Guiding the World in Cancer Care

By Dr Jeremy Lim, Editorial Board Member

In 1995, the US National Comprehensive Cancer Network (NCCN) began an ambitious journey to develop a comprehensive set of clinical practice guidelines in Oncology. Today the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines™) are recognised as the standard for clinical policy in Oncology not only in America, but also in many parts of the world.

Dr Jeremy Lim sat down with Dr William T McGivney, Chief Executive Officer (CEO) of the NCCN, when he was in Singapore this year for the first South-East Asia Cancer Care Access Network (SEACCAN) meeting.

Dr McGivney obtained his undergraduate degree from Boston College, his PhD from the University of North Carolina at Chapel Hill, and did a postdoctoral fellowship at Harvard Medical School.

He was with the American Medical Association from 1982 to 1991, and left as the Director of the Division of Health Care Technology. In 1989, Dr McGivney was awarded the Food and Drug Administration (FDA) Commissioner's Medal of Appreciation.

In 1991, he joined Aetna Health Plans, an American health insurance company, and left as Vice President for Clinical and Coverage Policy in 1997. Later that year, he joined NCCN and is currently its CEO.

Dr Jeremy Lim – JL: Can you tell us a little about the NCCN?

Dr William T McGivney – WM: The NCCN is an alliance of 21 of the world's leading cancer centres. The NCCN is a not-for-profit organisation itself, and all our cancer centres are also not-for-profit. Comprehensive cancer centres in the US have three basic missions: education, research and patient care specifically.

The NCCN seeks to facilitate just incrementally what these large and great institutions do. We are best known for our guidelines. Earlier on, there was a focus particularly on the need for evidence-based guidelines in the US, so the establishment of the guidelines programme at NCCN was timely. There were things leading up to it, such as the famous Weinberg study about the variation in care, studies that show that there is significant levels of unnecessary use of procedures generally, and the call by the *New England Journal of Medicine* for an era of accountability. I think especially in Oncology, it's timely as the discipline is so rapidly advancing. It's far more difficult for clinicians, particularly in the community setting who treat multiple tumour types, to keep up with what the evidence is saying is appropriate care for patients.

One of our guidelines is already in its fourth edition for 2011. We have a process that we made more formal and systematic over the years to ensure we can provide guidelines based on the latest evidence. It's not perfect but on the other hand we have to balance that with the ability to stay current. Again, with almost 4000 pages of guidelines, to keep up with the literature across cancer treatments, prevention screenings and also supportive care, are huge tasks which we've been able to carry out.

JL: In your term as CEO, what has the NCCN done that gives you the most pride and satisfaction?

WM: One is the fact that I'm sitting in Singapore talking with you. The global reach of the NCCN guidelines is amazing. It's not something that we aspire to, but people need good information and NCCN guidelines are only a portion of the information people around the world use, but we're happy to provide that portion. Secondly, they're clearly recognised as the standard of care in the US. Thirdly, what we've been able to do is really make sure that the expert clinicians in the US have an influence on public policy, particularly payment policy and making sure that appropriate drugs, devices, procedures or techniques are available to patients in the US.

JL: You generally don't have methodologists in the various committees. What sort of training do you provide to the clinicians who sit on your panels, so that they are well-informed on how to read and understand evidence?

WM: Our panels are made up of the experts in the US. We have heads

Dr McGivney giving a presentation at the SEACCAN meeting

of cooperative groups, principal investigators of national studies, some of the most prominent oncologists in the US to sit on these panels and they themselves are experts in clinical trial design, analysis and interpretation. Then from a staff perspective, we have highly skilled and experienced individuals who develop the agendas, guide the presentations that are evidence-based and the discussions specifically, and provide a general format under which the discussions and the in-person meetings take place. We also do a lot of meetings by phone as we have 44 different panels.

JL: It's been said that managing doctors is worse than herding cats. What is your secret to keeping the panelists engaged, since you've mentioned that you don't pay them any money to sit on the panels, and they are some of the most brilliant people in the country?

WM: Yes, the process is totally voluntary, but I think our panelists are used to evaluating evidence-based trials and this is one thing that they enjoy doing. When they see the impact of these guidelines on clinicians, patients and insurance companies in the US, that makes them feel that their voluntary gift of time is very fruitful. And then when they come and they sit with their expert colleagues from China, as we did recently in Shanghai, Beijing and Guangzhou, and have this extended global reach – I think that is even more gratifying.

NCCN's global reach

JL: Can you tell us more about what the NCCN is doing in China?

WM: With regard to China, we have responded to requests to collaborate. China is one of our three international collaborations, the other two being the Middle East/North Africa and Latin America. We just finished our sixth Asian summit in China. It goes far beyond the presentations or seminars. NCCN experts and expert colleagues from China will present on NCCN guidelines issues they are interested in. After that, there will be a three- or four-hour meeting between the experts from China using a US panel chair to discuss, for example, what changes we are going to implement this year for the China edition of the NCCN guidelines that we have. So that meeting takes place, a new date is discussed, and so on. So the China editions are arrived at. We've had leadership exchange programmes, we're also interested in adding international institutions into our outcomes database.

So this is what we're approaching with an institution in China and one in Saudi Arabia, and that will probably be a start to enter

international institutions. The collaboration with China will become more formal. It appears, based on a meeting that we had last week, that we will formalise a collaboration and work more directly with the government in China to build guidelines for very sophisticated centres in major cities: how they practice, what is needed there, what resources are available, as well as how to contextualise and apply these guidelines into other resource settings, such as rural areas. It is ultimately a collaboration that is fruitful for NCCN and our experts and the people of China through the good work of the China clinicians.

JL: NCCN has 21 partner hospitals and cancer centres. There's a moratorium on the number of centres. What happens if centres start to dip in performance or there are new ones that start to show tremendous promise?

WM: Presently we do have a process to review practice data from our institutions specifically. But with respect to the moratorium, our 21 institutions are pretty well-distributed geographically across the US. I don't think the moratorium will last forever but if you look at our map, there's probably only room for two to three more institutions. We are more interested in more formal relationships with international institutions – I've left the topic of the US now – so we'll focus specifically on international growth.

JL: If we fast forward to 2020, what would global success for NCCN look like?

WM: I think global success is beginning to be realised for me right now. It's just that organisations or even individuals who develop organisations whether in Southeast Asia, China or Middle East to look at our guidelines either as a platform from which to proceed, either as an example to develop their own complete set of guidelines to look at evidence-based medicine. The guidelines are the foundation of what we do, but the ability and commitment to collect data to see how you practice and to see the concordance between guidelines and actual practice, see if you follow the guidelines do you get better outcomes – is it more efficient care? That's what's important in terms of the next steps to take. The third component is the electronic information decision assist tools. You have electronic health records, and need to develop decision assist tools that allow you to integrate recommendations with the clinical logic of the guidelines, so you can help clinicians make decisions.

JL: Coming back to the issue of outcomes, are we confident that the 21 NCCN centres have the best outcomes in the most efficient manner among the hundred odd centres around the world?

WM: We know, from on published studies that major academic centres, based on the volume of patients seen there, generally have more accurate diagnoses and staging. Secondly, there is a relationship between volume of surgery and patients' outcomes. The more pancreatectomies and oesophagectomies you do, the better the outcomes for the patients. It's undeniable – there are a multitude of studies in that area. With respect to efficiency, we're not sure whether we have proven ourselves. There are two sides. Some studies have shown that academic centres, not just NCCN, are more efficient in some ways. I think that it is an important aspect that needs to be further studied.

Reflecting on his time at Aetna

JL: In Aetna, you were responsible for major coverage decisions, and essentially dealt with a lot of decisions at the individual level. You were really playing God. What sort of feelings went through your mind when you had to make a tough coverage decision?

WM: That was the big issue obviously. We set a process to establish coverage policy. We had a programme that looked at the whole issue of usage of investigational technologies in terminal illnesses. In the US, most insurance companies have what they call investigation exclusions – there's not enough evidence or not approved by the FDA, so whether it's a drug, device, procedure or technique, it won't be covered by insurance companies. Since clinical care is a risk-benefit analysis, we actually developed a process and a programme to look at potential exceptions of individuals with life threatening diseases.

As a result, what happened was, even though we had a national policy for our companies across the US, individually, medical directors would send in cases that were to be denied, for confirmation or for review by me. To turn away or not, we had to say yes or no. The reason was, in those days, denials and

Dr McGivney giving a presentation at the SEACCAN meeting

Dr McGivney (front row, third from right) with the other SEACCAN meeting participants

major decisions were obviously highly sensitive. There were major TV shows about this even before I got there, and there were major lawsuits. There were a number of things going on that made it critical that we had a fair and equitable decision making process and we established that.

But on a personal level, for a PhD who was really unprepared to do that, to be honest, it was extremely difficult. When you have 20 million lives, you're always dealing with a case, driving back and forth to work thinking about it, all cases look like your father, your mother, your brother, your sister and so on.

JL: Were there any particularly difficult decisions you had to make?

WM: Probably one of the more interesting cases that I ever got was that I was called one day and asked if I would cover a heart transplant for a foetus. Now of course when the foetus was born it would be placed on the waiting list. But my question actually was to the hospital: "Can you put a foetus on a national transplant organ waiting list in the US?" Actually I knew you couldn't, because I had been on the national transplant organ board. There were always cases like this. There were always these cases that needed very quick approval. This was the real world. This wasn't sitting in an office and trying to figure out what the best system was. You had to do it then, you could be on TV or you could be in court, you could have people yelling at you or happy with you the next day.

JL: With the benefit of hindsight, what sort of training or experiences would you like to have had before stepping into the job?

WM: First of all, I probably should have been a physician. Second of all, I was really thrust into this position at Aetna without warning, I thought I was just coming in to generate coverage policies and generate data. When I left after seven years, after over a thousand cases, my thinking was really shaped in the sense that, one can say, "Okay we need evidence to support a particular policy,", but that's not enough. There are thousands of patients at the margin. Special exceptions were not rare; in fact, actually they are fairly frequent. I always talk about how I had general academic book learning, what I call "commandments of decision making". But after seven years I added two more, and one was "Always set up a decision making processes that you can live with as if for your mother, your brother or your sister", and the second was "In close calls, always err on the side of the patient".

Parting words

JL: As one of the most successful persons involved in a healthcare organisation but is not a physician, what would you advise a non-physician who wants to step into NCCN or any other clinician-dominated sector or organisation?

WM: That's a tough question. What I've been able to do over the years is come to understand the healthcare system somewhat and the need to advance it through evidence. I've also learnt of a saying while at NCCN: "The perfect is the enemy of the good". While our processes may not be perfect, there is nobody right now in this world who has better processes. The conclusion of many studies may be "more research is needed", but a physician is sitting there across the table from a patient and his or her family, and needs to say, "Is this the best evidence?" Here's the guideline or recommendation, here's my judgement. This is what I can offer you today, now, because you need it today, now. That's critical, that sense of understanding that care will improve three to four years from now, ten years from now it will be better, but that patient needs those three things I talked about: evidence, judgement, and what's best for the patient. SMA

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