CADTH Symposium
Measuring Value in Theory and the Real World
April 23-25, 2017 - Ottawa, Ontario

Below is a report back of major themes gleaned from the CADTH Symposium and some recommendations for consideration.

HIGHLIGHTS

I. Shift to Health Technology Management (HTM) from Health Technology Assessment (HTA)

CADTH announced a shift to HTM from HTA, although it is not entirely clear all that this will entail. The development of processes that suggest a broader role for CADTH including the Scientific Advice Process early in the research development process, the recently created Provincial Advisory Group process post-review to provide advice to provinces on areas of confusion in prescribing algorithms, combinations and sequencing and class reviews and the growing number of patient advisory meetings gives a sense of the expansion direction. CADTH also announced a growing role in such important areas as mental health and has received an increase in funding in the recent federal budget to expand its activities. It is clearly a move to a more policy role than a technical role.

II. Health Systems Alignment

There was recognition in numerous sessions that there could be efficiencies to the overall systems that review drugs/ biologics for sale, value to the public systems and reimbursement. A first step was announced of a pilot project for concurrent and joint reviews between Health Canada and CADTH. Hopefully this will mean time gained in the aggregate time these two agencies take to review a treatment.

III. Meaningful Patient Engagement

Although there was much said about this throughout the Symposium, the Opening Plenary set a very poor tone for the rest of the discussions and certainly left many wondering if the other stakeholders understand what that means. The patient voice on that Panel was represented by (1) a carer not a patient (the carer perspective is very important but discreet from the patient experience) (2) a European not a Canadian (also an interesting but different perspective) and (3) a medical doctor (not an additional lens through which many in either group see). The session was about measuring value in theory and the real world, which for instance, Barry Stein (who was at the Symposium so obviously available) is working on internationally from a patient perspective so it is not credible to suggest we had no one to speak about this.

The Plenary on Day 2 was on meaningful stakeholder engagement and MJ DeCoteau from Rethink Breast Cancer represented the patient position clearly, articulating our expectations of engagement throughout decision-making processes. Too bad this Plenary hadn't at least come first to set the tone. It was fighting the credibility gap left by the reality of what happened in terms of patient engagement at the Opening Plenary.

IV. Real World Evidence

All government systems spoke of the importance of real world evidence for their procedures. Health Canada is interested both from its role in monitoring and evaluating drug safety and efficacy post approval but even in the approval stage, as the age of personalized and precision medicine expands and more drugs for rare diseases are discovered. CADTH also recognizes the importance of real world evidence in understanding patient value for the treatments they are taking and the role of companion diagnostics in those decisions and outcomes. pCPA also is most interested in real world data to support its negotiation conditions as it bargains for the best price for its plans. (CAPCA, the association of cancer agencies, have not said that they are gathering real world evidence in a systematic way. The only decision we know it has influenced has neither been supported by scientific evidence or real world evidence.)

Of course, other stakeholders also have a need for real world evidence, including patients, patient groups and the pharmaceutical industry. (We are not sure what the private insurer perspective is on this since, like CAPCA, they are a black box).

A problem is that there is no common accepted definition by all stakeholders about what real world evidence actual consists of and thus no common baseline data being collected by all stakeholders or by data collection groups that all stakeholders can rely on and share. Of course, in addition there may be specific data required for different diseases but there is at least a baseline that would be relevant to all. Another problem is that even what is being collected is not being shared by those collecting it so we could have a central repository of what is known.

Without the numbers to support what we know anecdotally we cannot present cogent arguments to support the patient position in relation to treatments to the various decision makers nor can we use those data to inform ourselves and patients about the treatments.

V. Sustainability and Affordability

These themes were addressed in different ways throughout sessions at the Symposium. One practical session dealt with the **use of generics and biosimilars** to save money in public drug budgets. While there certainly is a place in the treatment armamentarium for these products, it is not necessarily the case that they are always interchangeable with brand or originator products for all purposes and all people. The key is an evidence-based, nuanced approach as there should be for treatment decision making. Anything else is false savings since ineffective drugs, either because of safety issues or lack of effectiveness, leads to additional costs either in the drug budget or elsewhere in the health care system as people deal with the fallout.

Another problem is that government policy does not dedicate drug budget savings back to the drug budget but returns them to general revenues.

Another practical session dealt with the problem of **inappropriate prescribing** creating wasteful spending to the system in many ways including non-compliance, ineffective treatments, overprescribing especially in certain populations, and unnecessary diagnostic testing. What is interesting about every discussion of this is the solution always ends up as the removal of tests and treatments from public reimbursement plans rather than tackling the real problem of medical education and continuing education to keep them current with the latest guidelines for tests including the use of genetic testing and companion diagnostics, and treatments, both new drugs/biologics and those already on the market. Another area that is rarely discussed is how little doctors understand about drug interactions and poly-pharmacy. Every time I have

anything prescribed by one of my many specialists, except my infectious disease specialist who has the most amazing nurse practitioner working with her, I have to do the checking around with all my other doctors and two pharmacists about the potential drug interactions of the medications. This has proved very important in many instances and saved me potentially serious medical problems.

RECOMMENDATIONS

1. It is essential that patient groups urge all decision makers to come to a common definition of real world evidence and to determine at least baseline information that would be relevant for each of them to collect. They must agree to make systems changes to be able to collect those data and processes, to share and amalgamate them. Ideally, they should be doing this with internationally cooperation whenever feasible since much of the data are comparable and therefore relevant to Canadian decision making processes.
2. Oncology groups need to develop a discreet position on the use of biosimilars in this disease area as they move into use in this area. A patient group has formed and new members are welcome.
3. Patient groups must continue to be vigilant in ensuring that drug policy intended to improve affordability and sustainability is made based on sound evidence and leaves exceptions for those for whom it is not appropriate.
4. Patient groups must continue to advocate for the breakdown of health budget silos and rewards based on overall health budget performance not separate budget performance.
5. Patient groups must advocate for Treasury Board policies that return drug budget savings to the drug budget.
6. Patient groups need to be advocating with medical schools and continuing education programs to ensure that doctors are kept informed about medicines rather than punishing patients by removing medically necessary treatments to deal with inappropriate prescribing.
7. Patient groups need to ensure that they monitor the impact of the pilot project on concurrent, joint Health Canada and CADTH reviews to determine the impact of this collaboration on efficiencies in review times and outcomes.
8. Patient groups must monitor the expanding role of CADTH to ensure patient engagement throughout the processes.

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