

Debating the Future OF Clinical Practice Guidelines

A Report on Meetings in Six Ontario Cities

Hamilton London
Peterborough Sudbury
Ottawa Toronto

The decisions made today about the development and use of clinical practice guidelines (CPGs) will have a lasting impact on all those who receive, deliver and administer health care in Canada. Should CPGs, which have traditionally been used to reinforce best practices, be used by health care administrators as a tool for managing costs? Who should be involved in developing CPGs? How can their quality be assured? These are questions that require thorough exploration by all stakeholders.

A summit on clinical practice guidelines was held in Toronto in June 1999, bringing together health professionals, administrators and patient representatives primarily from the Metro Toronto area. The proceedings were published in the summer of 1999, and included nine principle recommendations about how CPGs should be developed and used. Summit participants felt that 1) CPGs are an educational tool and must not be used to regulate medical practice; 2) CPGs must be flexible enough to meet the needs of individual patients; 3) The CPG process must be truly multidisciplinary; 4) Patient representatives must have meaningful input at all stages of CPG development; 5) A standardized process for developing and evaluating CPGs should be employed; 6) The CPG process must be visible and accountable to health care professionals and patient groups; 7) CPGs should facilitate treatment choices; 8) Strategies to encourage adoption of CPGs must be shared; and 9) Many identified the need for a central body to oversee CPG development, funding and use.

To determine whether the Summit findings remained valid and relevant outside the greater Toronto area, as well as explore additional issues related to CPGs, input was then recruited from health care stakeholders in six regions of Ontario. They were invited to respond by mail and/or participate in meetings held in Hamilton, London, Peterborough, Sudbury, Ottawa and Toronto during January/February, 2000. Penny Marrett, Director of Health Issues at the Coalition of National Voluntary Organizations, chaired each of the sessions. Dr. John Stewart, a family physician from Port Perry, Ontario and member of the Anti-infective Review Panel of Ontario, opened each of the meetings with a summary of the 1999 Summit and comments on his own experience with guidelines.

This report summarizes regional views on how CPGs should be developed and used, and explores some of the issues raised at the six meetings.

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Regional recommendations on clinical practice guidelines:

On the top of the list in all regions was that guidelines should aim primarily to improve patient care, as well as reduce variability in practice. Many were concerned that cost control was coming to dominate the guidelines process.

Regional respondents felt that guidelines should be educational and should not be used to regulate or restrict practice; even if high quality was achieved, guidelines would never apply to all patients and physicians had to be able to deviate from the guidelines and use professional judgment in these instances.

The guideline process had to include all disciplines: “If we’re not all working towards the same goal, we’re just going to confuse our patients.”

Many felt that patients or patient representatives should have input into the process, and that innovative ways to get meaningful patient participation had to be explored.

All saw a need for quality assurance that ensured regular updates and revisions.

Guidelines had to be accessible, both physically and in terms of the simplicity of the information they contain.

The guideline development process had to be accountable, transparent, and outcomes oriented.

Guidelines should aim to be practical and feasible, and should facilitate access to treatments that are needed, as well as help caregivers identify what tests and treatments are most appropriate.

In all regions there were calls for some form of national body to coordinate guideline development activities and promote consistency and quality.

would not accept this use of guidelines. “I want guidelines to tell me what works 20% of the time, 40% of the time, and what a treatment is going to mean for my quality of life,” said one. However, some participants felt that guidelines have already become rules in some sectors.

One physician who was involved in developing immunization guidelines considered that when guidelines are well developed, with input from all relevant bodies, they stop being guidelines and become standards of care. “Physicians had better be prepared to document why they varied from them,” he warned. The catch, another said, was that physicians are also held responsible for not straying from the guidelines when the situation required it.

Many participants felt that there had to be enough flexibility in guidelines to ensure that patients could still determine their own course of treatment according to their own values. “I’m hoping that my doctor will be open-minded enough that he will know me as a patient, recognize that we might not share the same values, and give me all my choices,” said one patient representative. Physicians felt they had a responsibility to provide good treatments so that the best outcomes could be achieved. Yet, they acknowledged that patients were entitled to make different choices, so long as they understood the differences, had up-to-date information, and a firm comprehension of the risks.

It was further suggested that the degree of flexibility should depend on the specific area addressed in the guideline, while others thought flexibility referred more to how the guideline was used than to what it said. Was it used to inform the decision-making process or was it the decision itself? Caregivers had to be able to move outside the guideline when the situation warranted.

“At best, a guideline may apply to 60-80% of the population, but never to everyone,” said one physician.

1 Regional views on how CPGs should be developed and used

Guidelines should be flexible and not restrictive

Regional participants identified a growing fear among physicians and members of the public that guidelines were going to become rules imposed by a third party. Patient representatives stated they

2 There should be broad-based input into CPG development

Most of the regional participants thought the CPG process should be multidisciplinary, including health professionals from the entire spectrum of

The quality of clinical practice guidelines was seen as a significant problem by most participants at the regional meetings



care, as well as patient groups and administrators. Broad participation at the development stage was considered key to ensuring successful implementation. However, some thought that reliance on evidence from randomized clinical trials (RCTs) in guideline development necessarily made them physician-centred.

The benefits of obtaining patient input into guidelines were acknowledged by some but not all of the regional participants. There was uncertainty about whether and where patients should be involved in the guideline process, and one participant dismissed patients' role in developing guidelines as complicating an already complicated process. "Keep the guideline development as a medical process, but then use them to educate patients and the public," he said. Others thought patients had a definite contribution to guideline development as they could identify important aspects of care, and contribute insight into how a given treatment protocol would affect lifestyle, family relationships and daily life. However, it was considered important to bring patients into the process at a point where there was a specific issue for them to address.

There was some discussion about whether actual patients or advocates should be involved and many participants felt that from a practical viewpoint, experts had to sit down and process the scientific data before inviting input from patient groups and others. It was acknowledged that people needing acute episodes of care may not be able to contribute as much to guidelines as those with more chronic illnesses.

3 Enhance the quality of CPGs

The quality of clinical practice guidelines was seen as a significant problem by most participants at the regional meetings. One physician stated: "You could probably prescribe anything for your patient and get your librarian to find a guideline to support it." Factors seen as working against quality included the biases of developers and the lack of coordination and standards in guideline development. One participant felt that many consensus-based guidelines represented a lowest-common-denominator

approach to treatment, including only the options that nobody in the development group objected to rather than reflecting what any one of them would do in practice.


Centralization of guidelines was widely viewed as one prerequisite to improving quality; only then could standards be imposed on the process and responsibility assumed for keeping guidelines up to date. Many regional participants were optimistic about the efforts of the Ontario Guideline Implementation Network (OGIN), which is developing a Website to score existing guidelines. Scores will be calculated according to a process-based scale, with points awarded for openness, transparency, who developed the guideline, and how the process was chosen.

The issue of achieving quality took a back seat to two overriding concerns: we still don't know to what extent higher quality guidelines are more likely to be used in practice; and no matter how good guidelines become, we need to preserve the flexibility of practice to treat the percentage of patients who do not fit into the guidelines' profile.

Accountability was also considered a prerequisite to improving guideline quality, though opinion was split between those who regarded the group responsible for a guideline as key to its credibility, and those who felt that origins did not matter so long as there was some objective way to judge guideline quality. There was also debate about whether there was a conflict of interest when funders of care also funded guideline development. One participant suggested that because all parties had biases, the only safeguard was to make better patient care the prime target of guideline development. Participants also felt it was important to make guideline developers accountable for releasing every guideline they developed, even those advocating measures that would increase costs. There was widespread consensus on the need for an arms-length process in guideline development to clearly separate funders from decision-makers.

4 Define outcomes

Outcomes referred to two things in regional meeting discussions: the evidence used as a basis for guide-



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line development and the net result of introducing a guideline. Important issues were raised on both fronts. A certain level of evidence was recognized as a prerequisite to guideline development, and participants pointed to sources like the Cochrane Collaboration for evaluations of evidence available in a particular area. However, these sources mainly evaluate evidence generated through randomized clinical trials (RCTs). “We have to be very careful that we don’t fall into the trap of thinking that RCTs are the only valuable evidence,” warned one participant. “There are solid biological, social principles that have not been subject to randomized controlled trials but still have a lot of value in guiding care,” said another. Some regarded evaluating outcomes as an almost philosophical problem because the definition of outcomes is so value-laden.

5 Improve coordination and accessibility

The benefits of national standards were pitted against the need for local input in regional discussions over the desirability of a centralized body to oversee the guideline process. A clearinghouse could work to control the proliferation of guidelines, reduce duplication of effort, and alleviate the current burden on front-line health professionals.

In imagining what such a body might look like, some described a network through which new guidelines could be distributed, while others favoured an authoritative central repository, potentially one with representation from the various professional Colleges, to assume responsibility for guidelines. However, many were concerned about the government becoming overly involved in overseeing guideline activity, and the Colleges were considered unlikely to pick up the mandate of endorsing guidelines when past attempts to step into areas of clinical management had met with considerable opposition.

Information technology was viewed as the only way to ensure that guidelines reflected the most recent evidence. “That’s the only way to have very

fast updates, to keep current, to get evaluation and feedback,” said one participant. Great admiration was expressed at the pharmacists’ ability to convert to computers very quickly, developing systems that could flag drug interactions and highlight relevant patient information. However, it was felt that physicians were still a long way from achieving a similar system. “The primary care reform committee in Ontario estimated that it would cost between fifteen and twenty thousand dollars per GP in information technology to bring them up to speed,” one participant reported.

Accessibility also meant a guideline had to be useable in the context of practice, i.e. the equipment and therapies mentioned in the guideline must be available throughout the province.

An ongoing discussion

The regional consultation on clinical practice guidelines largely supported the recommendations generated by the June 1999 Toronto Summit, but also reinforced the need for further discussion. Regional participants clearly felt that CPGs should pursue the main goals of improving clinical practice and reducing variations in practice, but emphasized that they had to remain flexible enough to permit appropriate and acceptable care for all patients. Participants saw much room for improving CPGs, through broader-based input into their development, quality control measures and accountability, better coordination of efforts and more thoughtful definition of outcomes. Many participants considered patient involvement in the guidelines’ process essential to assuring guideline quality and acceptability, though there was little consensus on who should represent patients and how meaningful participation could be assured.

Health care stakeholders are becoming more and more conscious of the need to examine our use of clinical practice guidelines, and to question the principles and assumptions on which we develop them. A few new initiatives are making people optimistic that the situation can be improved, even as they recognize just how many unresolved issues remain. If one message can be extracted from these six meetings, it is that Canadian caregivers do not want to grow more reliant on, or more responsible to, clinical practice guidelines until these issues can be satisfactorily resolved. ●