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Title

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Journal

Neurology Clinical Practice, 6(4)

ISSN

2163-0402

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Publication Date

2016-08-01

DOI

10.1212/cpj.0000000000000250

Peer reviewed

Knowledge translation of an online tool to determine candidacy for epilepsy surgery evaluation

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Abstract

Background: Guidelines recommend that surgery be considered in patients with drug-resistant epilepsy, yet delays to epilepsy surgery still exist. A Web-based, evidence-informed clinical decision tool (www.toolsforepilepsy.com) was developed to help physicians determine which patients are appropriate for an epilepsy surgery evaluation. We evaluated the usability and feasibility of the tool with the intended end users in order to improve implementation into practice. **Methods:** Usability testing was conducted with relevant end users. After the tool was modified based on usability results, another group of end users trialed the tool in their clinical practice. This

latter group of end users then participated in focus groups and semi-structured interviews to address barriers and facilitators to tool implementation. Finally, a stakeholder meeting was held with domain experts and end users to discuss further changes to the tool and implementation strategies. **Results:** Six overall themes were identified through usability testing, and an additional 11 themes were identified through the focus groups and interviews. The tool was modified based on these findings, which were then presented at the stakeholder meeting of experts and end users for further refinement. The findings were also used to guide discussions of potential implementation strategies at the meeting. **Conclusion:** This study provides guidance on how to improve the usability of clinical decision tools by engaging end users, experts, and other key stakeholders. The modifications to the tool should facilitate its implementation in clinical practice and ultimately enhance the quality of care persons with epilepsy receive. *Neurol Clin Pract* 2016;6:304-314



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Funding information and disclosures are provided at the end of the article. Full disclosure form information provided by the authors is available with the **full text of this article at Neurology.org/cp**.

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Editorial, page 291

Epilepsy is a chronic neurologic condition that can be very disabling and associated with premature mortality.^{1,2} The condition consequently contributes substantially to the global burden of disease^{3,4} and high health care utilization.^{5,6} It is commonly managed by family medicine and general neurology specialists.⁷

The diagnosis and management of epilepsy can be challenging for physicians because of its diverse presentations, resulting in evidence–care gaps.^{8–11} One such gap is the delayed referral of persons with epilepsy for a surgical evaluation. It has been estimated that the length of time for an appropriately selected person with epilepsy to be referred to an epilepsy center for a surgical evaluation is around 20 years.^{12–15} This is despite recommendations, based on the highest level of evidence, suggesting that persons with epilepsy with disabling seizures who have failed adequate trials of antiseizure medications should be referred for an epilepsy surgery evaluation.¹⁶ The referral patterns for these patients remain unchanged over time,¹⁴ highlighting poor implementation of guidelines through passive dissemination alone. In an effort to address this particular gap, a Web-based, evidence-informed clinical decision tool was developed by a group of national experts using the rigorous RAND/UCLA Appropriateness Method.¹⁷

Initial testing of this tool (www.toolsforepilepsy.com) in clinical practice found high concordance between the tool's ratings and clinical judgment of experts (84.6%).¹⁸ In addition, the tool has been found to have reasonable generalizability in other countries such as Germany¹⁹ and Sweden (in progress, personal communication with N. Jette). Although the tool has been developed using rigorous scientific methodology and the initial validity appears sound,¹⁸ the usability of the tool, and consequently the adoption of the tool in clinical practice, remains unclear.

Clinical decision tools can assist physicians in making clinical decisions by using patient-level variables and algorithms. Such tools often synthesize and distill the available evidence, which can be particularly useful in an era in which the amount of medical research and knowledge is growing exponentially. Optimizing the usability of such tools is crucial because adoption of “best practices” in many areas, such as epilepsy, remains elusive.²⁰ There has recently been a call for studies examining usability of clinical decision tools, as usability has been identified as a key factor to their success.²¹

The overarching long-term goal of the present study is to improve the referral of appropriately selected people with drug-resistant epilepsy for surgical evaluation in order to increase the quality of care of people with epilepsy. The specific objectives of the present study were 2-fold: (1) to identify barriers and facilitators to the usability of the tool in order to optimize its implementation into clinical practice, and (2) to identify methods to further disseminate the Web-based decision tool in order to increase the number of physicians using it in clinical practice.

METHODS

Usability testing

Usability testing with a focus on identifying barriers and facilitators to using the Web site and tool was conducted using the original tool.¹⁷ This study was conducted after the development and initial feasibility testing of the original tool.^{17,18} Six to 8 participants have been found to be sufficient to obtain saturation (i.e., to capture 80% of usability issues) when performing usability testing.^{22,23} Therefore, 8 end users (family medicine physicians, pediatricians, child and adult neurologists, and residents in each of these disciplines) were identified through purposeful sampling and were invited to participate in the usability testing.

For usability testing, the participants were asked a short list of demographic questions before beginning the usability session. They were then asked to apply the tool/Web site to 5 epilepsy cases that were created by the epileptologists on the research team based on commonly encountered clinical scenarios. The purpose of these clinical scenarios was to provide participants with readily available cases as they used the tool (rather than relying on recollection of previous

cases), and they were not intended as a means of evaluating the participants' decision process. A "think-aloud" technique was used to investigate any potential usability issues with the tool/Web site, as this technique has been found to be an appropriate method for examining usability and can provide powerful data even when using a small sample size.²⁴ In the "think-aloud" technique, participants were asked to talk aloud, vocalize their thoughts, and give their opinions about the usefulness of the tool/Web site as they prospectively applied it to the case scenarios provided. The usability testing expert also probed deeper into the opinions as they were vocalized by asking clarifying or follow-up questions when needed. The usability sessions took approximately 1 hour and were audio recorded for analysis.

The results were analyzed thematically²⁵ to identify recurring relevant themes, focusing on usability difficulties, reactions to advice given, feedback on the content, and general presentation of the tool and Web site. The tool and Web site were revised based on this feedback.

Focus groups and interview

Focus groups and one-on-one interviews were conducted using the same end user groups (family medicine physicians, pediatricians, child and adult neurologists, and residents in each of these disciplines) but different participants in order to explore the functionality, usability, and practicality of the revised tool. Focus groups and interviews were chosen in order to compare and contrast the views of the end users in a systematic manner while still providing a dynamic environment that did not limit potential responses. Focus groups and interviews differed from the usability testing in that the tool was not used in real time and the focus of the discussion was on barriers and facilitators to the implementation of the tool in clinical practice.

Participants were identified using purposive sampling based on their diverse background (participants at different stages of their training or career, sex differences, and multidisciplinary) in order to generate a variety of responses and to improve generalizability of the findings.

Before participating in the focus group and interviews, participants were asked to use the tool/Web site in their clinical practice for at least 3 months when seeing persons with epilepsy. They were also asked to complete a brief demographic questionnaire (e.g., age, sex, specialty/subspecialty, number of persons with epilepsy in their clinics) that also asked about their use of and experience with the tool during the 3-month period.

Topics relating to the tool/Web site explored during the focus groups and interviews included barriers and facilitators to using the tool and Web site, associated educational needs, perceived effect on patient care, and suggestions for implementation and dissemination strategies. The focus group script is provided in appendix e-1 at Neurology.org/cp.

The focus groups and interviews were audio recorded and transcribed. The transcripts were thematically analyzed to identify themes elicited from the end users related to the feasibility of using the tool in their clinical practice. The original transcriber reviewed the transcript for accuracy before the transcript was included in the analysis by another researcher. This second researcher used nVivo software to code the transcripts. These coding "nodes" were then consolidated into themes to create a thematic analysis that was used as a basis for the final report in which the key issues were highlighted.²⁵

The tool was further modified based on the feedback from the focus groups and interviews. In addition, the focus groups and interviews were used to guide the future development of supporting implementation materials for the targeted end users, including educational materials (e.g., educational materials for resident curricula).

Stakeholder meeting

Once the tool and Web site were updated based on the findings from the usability testing, focus groups, and interviews, they were presented at a stakeholder meeting that included investigators who developed the original tool (the Canadian Appropriateness Study for Epilepsy Surgery), members of the International League Against Epilepsy (ILAE) pediatric epilepsy surgery task force, other international epilepsy experts, end users (adult neurologists, child neurologists, pediatricians, family medicine physicians, residents), knowledge translation experts, and patient

Supplemental Data

Neurology.org/cp

The discussion surrounding dissemination of the tool led to the development of a podcast and continuing medication education courses.

representatives and advocates. The meeting participants were asked to discuss the current evidence base related to epilepsy surgery to ensure that the recommendations made by the tool were in keeping with current knowledge and that the modifications from the usability testing and focus groups/interviews had not changed the scientific credibility of the tool and Web site. The meeting was also used to address additional identified barriers to the use of the tool (e.g., concerns about increased surgical referrals). The supporting implementation materials developed from the focus group findings were reviewed during this meeting. Finally, the attendees were asked to provide input into potential implementation and dissemination plans for the tool.

The meeting consisted of 2 “World Cafés,”²⁶ or round table discussions, to generate feedback on the tool. The first “World Café” addressed the current state of the tool (Is the tool up-to-date? Who are the target end users? Future directions for the tool?), and the second “World Café” addressed the implementation and dissemination of the tool (How can the tool be disseminated? What resources would help support the tool and improve dissemination and implementation? How can the tool be maintained?).

Standard protocol approvals, registrations, and patient consents

The University of Calgary Conjoint Health Research Ethics Board has approved the use of human participants for this study. Informed consent was obtained from all participants (physicians) before participation in the study.

RESULTS

Usability testing

Six overall themes were identified through usability testing: (1) clearly defining the target end user, (2) making the home page introduction more concise, (3) clearly defining terminology, (4) providing more response options, (5) improving clarity of the final report, and (6) providing guidance on next steps in the referral process. The tool was modified based on the results of the usability testing (table 1) while ensuring the scientific integrity of the tool was maintained.

Focus groups

Two focus groups and 3 one-on-one interviews were conducted with end users of the tool after they had used it in their clinical practice for a minimum of 3 months. One-on-one interviews were conducted instead of additional focus groups because of difficulties in trying to accommodate the schedules of participants. The participants included 3 pediatric neurologists, 2 pediatric neurology residents, 2 adult neurologists, and 2 adult neurology residents.

The pre-focus group questionnaires revealed that the participants used the tool an average of 4.8 (± 3.6) times in the 3 months before the focus groups (the proportion of epilepsy patients to whom the participants applied the tool is unknown). Furthermore, 71.4% of the participants found the tool useful and 66.7% responded that they will continue to use it.

Eleven general themes emerged as a result of the focus groups and one-on-one interviews. These themes were (1) content, (2) credibility, (3) content clarity and brevity, (4) matters related to other types of epilepsy or surgery, (5) presentation and visual considerations, (6) risks, (7) suggestions, (8) target audience confusion, (9) technology platform considerations, (10) tool impact, and (11) sample case scenarios for tool use (i.e., examples of cases and the results of the tool for these cases) (table 2). Although there are no concrete means of determining

Table 1 Usability themes and example feedback and changes

Theme	Example feedback	Example modifications to tool
Clearly define the target user	One of the themes identified was that the target user should be explicitly and clearly defined as several of the variables may be unfamiliar to family physicians	The following statement was added to the home: "Are you a physician caring for a person with epilepsy? If yes, use our referral rating tool to determine if your patient should be evaluated for epilepsy surgery"
Make the introduction more concise	"It's a bit wordy right off the bat, it almost reads as an end user license agreement ... I tend to think 'oh that's a license agreement' and skip through it... I would say that this would put me off using this right off the bat"	The introduction was abridged and was moved to a separate page so as not to distract from important information on this page
Clearly define the terminology	"...unless AEDs is coming up frequently, rather than having a side definition, why not just 'how many epilepsy drugs has your patient tried? Why turn it into an acronym?"	The abbreviations were removed and terminology was updated to reflect the changes in terminology that had occurred since the development of the tool
Provide more response options	"hmm non-disabling and disabling... if I'm comparing with the previous case, I think he was less disabled than this lady. If we can add moderately disabling or severely disabling, because how would you differentiate between this patient and that patient?"	Altering the response options would affect the validity of the tool because the methodology required to develop the tool. The definitions of disability were further clarified for the end users
Improve clarity of final report	"... it's worded fine, it's just too much. It's lawyer speak, 'surgery is not recommended at this time but you should still monitor your patient'"	The final report was significantly simplified, clearly emphasizing the results and their interpretation
Provide guidance on the next steps in the referral process	"... For your tool, it would be nice 'your patient should be referred to' hit a link to 'here are the local referrals and this is how you do it.' If you could tie that in, it would get your acceptance up lots because otherwise it would be like 'who could I refer to? And how could I do that?'"	Referral resources will be added, and additional resources (contact information for epilepsy centers) will continue to be updated

saturation with such a small number of participants, it was observed that participants frequently reported the same themes during the focus groups and interviews.

The results of the focus groups and one-on-one interviews were used to make further modifications to the tool.

Stakeholder meeting

After updating the tool based on the usability testing results and the focus groups and interviews, a meeting of 27 key stakeholders and study investigators was held. The participants of the meeting included the investigators of the current grant, the investigators involved with the development of the original tool (n = 9), the chair of the ILAE pediatric epilepsy surgery task force (n = 1), other international epilepsy experts (n = 2), end users (adult neurologists n = 10; child neurologists n = 3; family medicine physicians n = 3; family medicine residents n = 3), knowledge translation experts (n = 2), and patient representatives and advocates (n = 3).

The results of the first "World Café" on the current state of the tool suggested that the tool was still consistent with current knowledge and could even be applied to children as young as 5 years old and that the modifications made to the tool had not changed its scientific credibility. The target end users of the tool were clarified in an effort to help focus dissemination interventions and to improve the tool for these users (minimize barriers and maximize facilitators to its use). Finally, some suggestions regarding future directions of the tool were discussed, with a particular focus on accessibility and visibility of the tool to overcome a common barrier to the use of such tools, awareness. The results of this discussion prompted a change in the domain name from www.epilepsycases.com to www.toolsforepilepsy.com in order to increase Internet and search traffic to the site. Also, professional organizations for the

Table 2 Feasibility issues identified through focus groups and one-on-one interviews

Theme	Explanation of theme	Example modifications to the tool
Content	Various aspects of the tool's content were raised as barriers to its use. These included (1) terminology—old vs new terminology, and (2) final report—results and their interpretation, privacy issues related to e-mail, referral resources	The revised terminology and classification of epilepsy have been used, although the old terminology is available in the definitions section on the same page
Credibility	Credibility was not a concern in our population but there was discussion about having the tool endorsed by organizations to increase the credibility	Currently seeking endorsement by epilepsy-related organizations
Content clarity and brevity	Most participants felt that the clarity and brevity of the tool was a facilitator to its use in clinical practice	No changes were required
Matters related to other types of epilepsy or surgery	There was some discussion around the inclusion of other types of epilepsy, seizures, and epilepsy surgery. A concern regarding the use of the tool for inappropriate patients was also raised	A checklist was added as an initial screening before launching the tool to exclude any patients who do not fit the tool eligibility criteria and to make sure that patients who require an expert epilepsy evaluation are referred regardless of the tool. Definitions for the seizure types were elaborated to improve clarity. Because the tool is for the referral of patients to an epilepsy center for evaluation, no changes regarding the type of surgery were made
Presentation and visual consideration	Several issues related to the presentation of material and visual appeal of the tool were raised as potential barriers to its use in clinical practice. These included navigation using the progress bar and the presentation of the "panel ratings" on the results page	The progress bar was not changed because if users do not complete the tool in sequence it will affect the results, which could invalidate them. The panel ratings on the results page are now viewed by clicking on a link to make the results page more visually appealing
Risks	The participants were asked to discuss any potential risks to using the tool that may influence its use. The risks identified included not reassessing patients at a later date as candidates for epilepsy surgery, unnecessary referrals and surgeries, and use of the tool as an excuse to do surgery. After discussion, the participants did not feel that these risks would outweigh the benefits	No changes were made to the tool based on these comments. A disclaimer does currently exist in the tool to alert physicians that even if the patient is not appropriate for evaluation for epilepsy surgery at the time of completion he or she should be re-evaluated at each visit
Suggestions	The participants were asked to provide suggestions on information they thought would improve tool usability in clinical practice. The suggestions included patient brochures, a practice case history, patient history form, general epilepsy information and links, a side effects link, and validation information	A "Patient" tab and a "Physician" tab have been added with information targeted to each of these users. In addition, the "Links" tab has been populated with additional resources, including a link to side effects for antiseizure drugs (this link is also provided on the page that asks about side effects from antiseizure drugs). A practice case will be included on a podcast that is being developed and will be added to the tool. The "Funding and Publications" tab has been updated to include studies that have been conducted to validate the tool
Target audience confusions	Much discussion occurred around whom the end user of the tool should be and whether this is clear. The participants believed that the end user should be physicians who see fewer epilepsy patients than an epileptologist and therefore are less certain about when to refer patients to an epilepsy center	No changes were required
Technology platform considerations	The participants felt that the tool platform (Web-based) could be a barrier to use because many were using old computers that made using online tools slow and tedious. It was suggested that creating an app for the tool would facilitate its use	The Web site has been updated to be formatted in a "responsive design" so that it looks similar on a smartphone and a computer

Continued

Table 2 Continued

Theme	Explanation of theme	Example modifications to the tool
Tool impact	The participants were asked to comment on the impact the tool could have on their clinical practice. The responses varied from little impact to confirmation of clinical decisions. It was felt that the tool would have more impact for general practitioners than for neurologists	No changes were required
Cases of tool use	The manner in which physicians would use the tool was discussed. The variety of platforms through which to use the tool (e.g., online, iPad) was seen as a facilitator to its use in clinical practice. For example, some participants thought that it would be good to assist patients in making decisions about referral for a surgical evaluation by completing it with their patients. It could also be used as a means of confirming the physician clinical care after patient visits, as an educational tool with residents, and as a patient exercise	In light of the discussion about the potential for patients using the tool (although they are not the end users), some patient resources were added, as well as a statement before launching the tool that states “The questions for this tool should be answered by the physician with input from the patient (or the patient’s caregiver)”

target audience have been engaged to promote the tool on their Web sites. Furthermore, by including stakeholders at the meeting, they will be more informed about the tool and could therefore be leveraged to be champions for the use of the tool at their institutions and with colleagues and collaborators.

The second “World Café” focused on implementation and dissemination strategies that would minimize barriers to the use of the tool and ways to facilitate the utilization of the tool. The use of supporting materials such as podcasts and sample cases directly on the tool Web site was suggested as a method of facilitating tool usability. Dissemination of the tool through professional and patient-led organizations was again suggested. The discussion surrounding dissemination of the tool led to the development of a podcast, continuing medication education courses, and additional resources available on the Web site. The experts and end users who attended the meeting were encouraged to be local champions of the tool within their practice settings. Overall, the stakeholder meeting resulted in further improvements to the tool and Web site (figure). The meeting also helped to start to develop implementation and dissemination strategies for the tool.

DISCUSSION

The present study identified barriers and facilitators to the use of the Web-based clinical decision tool for epilepsy surgery referral (www.toolsforepilepsy.com) and resulted in an updated tool that should improve adoption of the tool in the clinical setting.

Although the methods used in this study were not novel, their application to evaluating a clinical decision tool in neurology is new and has not been previously described in the clinical decision tool literature. Therefore, our study provides a feasible methodologic framework that could be easily applied to the development of other clinical decision tools in the field of neurology.

The think-aloud method used in the present study has been found to provide rich data regarding usability issues^{24,27}; however, like many other methodologies, it has also been criticized. The criticisms of the think-aloud method are primarily related to its applicability and ability to adequately tease out the decision-making process²⁷; these criticisms are often related to the process of conducting the think-aloud technique. To minimize these criticisms, a trained usability expert with experience conducting the think-aloud technique performed the usability testing. Another criticism of the think-aloud technique for usability testing is that it is sensitive to the cultural background of the participants.²⁸ For this reason, the target

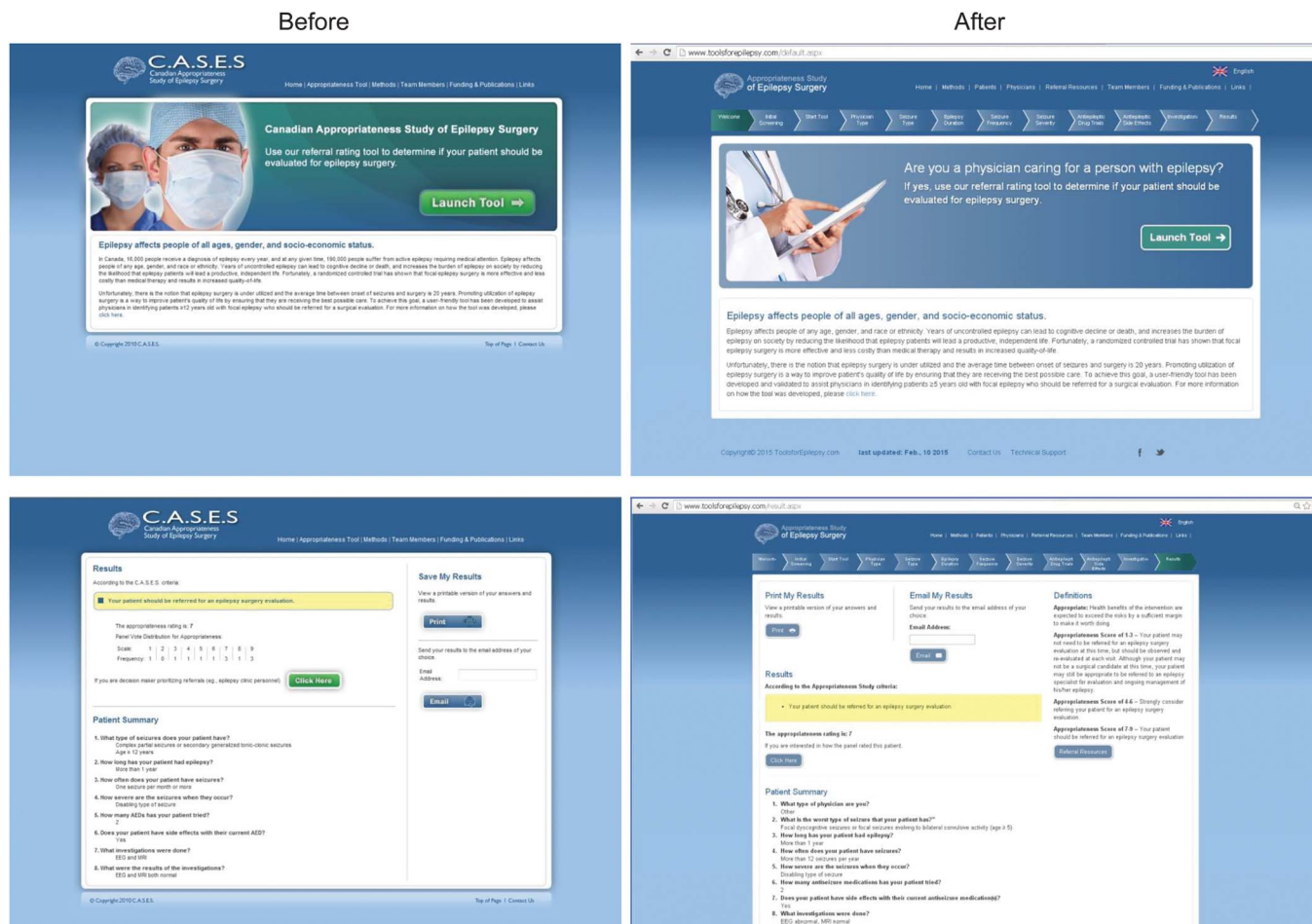
A strength of the study is that key stakeholders who were engaged in evaluating the online tool included both content experts and end users.

audience, which was relatively heterogeneous with regard to cultural background, was purposefully sampled.

A strength of the study is that key stakeholders who were engaged in evaluating the online tool included both content experts and end users. This enabled the development of a tool with scientific integrity and credibility while balancing the needs of the end users. Perhaps the greatest limitation of this study is that the objectives and scope of the study prevented us from examining the implementation of the tool in clinical practice and the potential effect on the process of care and clinical outcomes. This topic is an important area of future research that should be pursued, and such research should take into consideration the complexity of the referral process for epilepsy surgery by controlling for demographic factors of the patient, physicians, and the settings.

A gap exists between clinical practice guidelines and their application in actual clinical care.^{14,20,29} Clinical decision support tools, such as the one examined in this study, are a potential means of closing this gap and improving quality of care delivered.³⁰⁻³⁴ They tend to

Figure Examples of the tool before and after knowledge translation activities conducted throughout this study



be more effectively implemented if they are part of regular workflow, provide recommendations rather than assessments, provide support at the location and time of the clinical encounter, and are computer-based.³¹ The tool presented here contains many of these features. The changes made to the tool, as outlined here, should improve its usability, thus providing a clinical decision tool with the capability to improve the quality of care of people with epilepsy.

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Received November 12, 2015. Accepted in final form February 4, 2016.

AUTHOR CONTRIBUTIONS

KMS contributed to the interpretation of the data, prepared the initial draft of the manuscript, contributed to the revisions, and agrees to the publication of this draft of the manuscript. JH-L obtained funding for the study, contributed to the conceptualization and design of the study, the interpretation of the data, and the revisions of the manuscript, and agrees to the publication of this draft of the manuscript. SW contributed to the conceptualization and design of the study and the revisions of the manuscript and agrees to the publication of this draft of the manuscript. HQ contributed to the conceptualization and design of the study and the revisions of the manuscript and agrees to the publication of this draft of the manuscript. LC contributed to the conceptualization and design of the study and the revisions of the manuscript and agrees to the publication of this draft of the manuscript. JHC contributed to the conceptualization and design of the study and the revisions of the manuscript and agrees to the publication of this draft of the manuscript. GWM contributed to the conceptualization and design of the study and the revisions of the manuscript and agrees to the publication of this draft of the manuscript. HA contributed to the conceptualization and design of the study and the revisions of the manuscript and agrees to the publication of this draft of the manuscript. JS contributed to the acquisition and interpretation of the data and the revisions of the manuscript and agrees to the publication of this draft of the manuscript. NJ obtained study funding, contributed to the conceptualization and design of the study, contributed to the interpretation of the data, preparation of the initial draft of the manuscript, and the revisions of the manuscript, and agrees to the publication of this draft of the manuscript.

STUDY FUNDING

The study was funded by a Canadian Institute for Health Research grant awarded to NJ and JH-L.

DISCLOSURES

K. M. Sauro receives research support from Alberta Innovates - Health Solutions, International League Against Epilepsy, and Canadian League Against Epilepsy. J. Holroyd-Leduc serves as a member of the Research Management Board and Chair of the KT Committee for Technology Evaluation in the Elderly; serves as an Associate Editor for *Canadian Medical Association Journal*; and receives research support from the Canadian Institute of Health Research, Alberta Innovates - Health Solutions, and Alberta Health Services. S. Wiebe serves on DSMB for NINDS; has received funding for travel from International League Against Epilepsy; serves on the Editorial Boards of *Epileptic Disorders*, *Epilepsy & Behavior*, and *Canadian Journal of Neurological Sciences*; receives research support from Canadian Institutes of Health Research and Alberta Innovates Health Solutions; and is the recipient of a Hopewell professorship of clinical neurosciences research from University of Calgary. H. Quan receives salary support from Alberta Innovation Health Solutions. L. Cooke reports no disclosures. J. H. Cross holds an endowed Chair through the University College, London; has served on scientific advisory boards for Eisai, Sanofi, Viropharma, Zogenix, and UCB; serves on the Editorial Board for *Epilepsy Research*; is author on a patent re: Betashot (Vitaflo), a C10 compound developed for nutritional purposes; receives

research support from GW Pharma, Zogenix, National Institute for Health & Research, European Union, Epilepsy Research UK, SPARKS, and the Great Ormond Street Hospital Children's Charity; and works as Clinical Advisor to the National Children's Epilepsy Surgery Service for which remuneration is made to her department. G. W. Mathern serves on the Data Monitoring Committee for NeuroPace Inc.; has received funding for travel from International League Against Epilepsy; serves as Editor-in-Chief of *Epilepsia* and on the Editorial Boards of *Neurology*, *Surgical Neurology International*, *Epilepsy Research*, and *Epileptic Disorders*; devotes 100% of his clinical effort to UCLA's Pediatric Epilepsy Surgery Program; receives research support from NIH and RE Children's Project; and is the Davies endowed chair for epilepsy research at UCLA. H. Armson reports no disclosures. J. Stromer receives salary support from Alberta Innovation - Health Solutions and has received research support from Ministry of Economic Development and Trade, Alberta, Canada and University of Calgary. N. Jetté has received funding for travel from Bial Neurology; serves as an Associate Editor for *Epilepsia* and on the Editorial Board of *Neurology*; and receives research support from Pfizer Canada, the University of Calgary Hotchkiss Brain Institute, Canada Research Chair Tier 2 in Neuroscience Health Services Research (salary support), Canadian Institutes for Health Research, Alberta Innovates - Health Solutions, Alberta Health Services, and Alberta Spine Foundation. Full disclosure form information provided by the authors are available with the **full text of this article at Neurology.org/cp**.

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