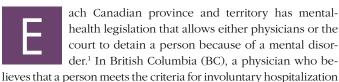
Codesigning Mental-Health-Rights Information with Patients

An Example from British Columbia

By Iva Cheung

This is the fourth in our series on the importance of plain language for access to justice. -JK



can sign a medical certificate to hospitalize them against their will.²

Involuntary patients under BC's Mental Health Act lose their right to freedom of movement and the right to make decisions about their psychiatric treatment. For example, they can be given psychiatric medications or electroconvulsive therapy without their consent.

But involuntary patients don't lose all their rights. For example, they have the right:

- to know the name and location of the hospital where they're being detained,
- to know how long they can be held,
- to challenge their detention through a review-panel hearing,
- to apply to the court for a discharge, and
- to challenge their treatment plan by asking for a second medical opinion.³

According to BC's Mental Health Act, involuntary patients must be notified, orally and in writing, of all these rights upon admission. Yet in a 2011 survey commissioned by the Ministry of Health, when involuntary patients were asked, "Were your rights under the Mental Health Act explained in a way you could understand?," 43 percent said no.⁴

One reason why involuntary patients report not understanding their rights might be that the document used to notify them is not effective.

"Plain Language," edited by Joseph Kimble, has been a regular feature of the *Michigan Bar Journal* for 37 years. To contribute an article, contact Prof. Kimble at WMU-Cooley Law School, 300 S. Capitol Ave., Lansing, MI 48933, or at kimblej@cooley.edu. For an index of past columns, visit www.michbar.org/plainlanguage.

Form 13 of the Mental Health Act

In BC, a statutory document, Form 13, is used to notify involuntary patients of their rights under the Mental Health Act.^{5,6} (Pages 1 and 2 of Form 13 appear on the facing page.)

Think-aloud user testing of Form 13

Form 13's effectiveness had never previously been user-tested. I interviewed 18 people who had experienced involuntary hospitalization in BC, using think-aloud testing⁷ to elicit opinions about the form's language, format, and design. I also showed these participants samples of other types of rights documents used in different jurisdictions for comparison. I audiorecorded these interviews, transcribed them, and analyzed them thematically.⁸

The analysis uncovered these themes:

- Form 13 on its own was not enough. Participants wanted information in more than one format, repeated at different times. Patients may not be in a state of mind to understand written material especially when first hospitalized.
- Participants wanted information about *how* to exercise their rights. For example, the form tells them that they have the right to contact a lawyer, and most participants immediately asked, "How do I contact a lawyer?"
- The language on the form was overly legal. Participants found legalese, like the term *habeas corpus*, confusing and intimidating.
- **The language was disempowering.** Participants said that phrases like "You are a person with a mental disorder" left them feeling dismissed and helpless.
- The language was unclear. Participants found the description of the certification renewal periods, and the distinction between "review panel" and "judicial review," confusing.
- The format was intimidating. Certain design features, like the bolding and the signature line, provoked anxiety among some participants. The patient's signature is meant to show only that they've been given their rights information, but some participants believed that by signing the form, they were giving up their rights or entering into an agreement. Participants wanted a friendlier format, with many asking for color.

Codesign with patients

Armed with this feedback, I began working with a patientoriented research team9 that included two former patients who had experienced involuntary hospitalization and a psychiatric nurse, with the goal of producing a new suite of patient-centered Mental Health Act rights communication tools. The team received supervisory support from researchers with expertise in severe mental illness, knowledge translation (also called implementation science), and patient-oriented research. A mental-health lawyer attended some of our meetings and agreed to review our tools for legal accuracy.

The suite of full-color tools includes:

- a pamphlet the most comprehensive and detailed of the documents
- an animated video to offer the information in an audiovisual format
- posters to be posted in the hospital for patients to read

• a wallet card - for patients to receive at discharge to remind them of their rights if they're involuntarily hospitalized again

Because the Mental Health Regulation still requires patients to receive Form 13,10 the suite of tools was designed to supplement, rather than replace, that form.

Codesign meant handing control over to patients: our team's patient partners weren't merely consultants or testers. Based on the feedback from Form 13 user testing and on their own experiences, they developed the first draft of the communication tools, with my support as a plain-language professional. They gave input at every stage, including when the images in the video were composed, and at each round of revisions.

Driving those revisions was additional feedback from user testing with 16 people who had experienced involuntary hospitalization. I conducted think-aloud user testing of our suite of rights materials over three cycles. Participants gave their opinions on our communication tools in interviews that I audiorecorded, transcribed, and analyzed thematically.

FORM 13	MORE INFORMATION
MENTAL HEALTH ACT [Section 34, R.S.B.C. 1996, c. 288]	REASONS FOR INVOLUNTARY ADMISSION
()	A medical doctor signed a medical certificate for your involuntary admission because the doctor is of the opinion that
NOTIFICATION TO INVOLUNTARY PATIENT OF RIGHTS UNDER THE MENTAL HEALTH ACT	 (a) you are a person with a mental disorder that seriously impairs your ability to react appropriately to your environment or associate with other people,
OF RIGHTS UNDER THE MENTAL HEALTH ACT	(b) you require psychiatric treatment in or through a designated facility,
The information in bold type must be read to the patient.	(c) you should be in a designated facility to prevent your substantial mental or physical deterioration or to protect yourself or other people, and
I am here to tell you about your legal rights under the Mental Health Act as an involuntary patient.	(d) you cannot be suitably admitted as a voluntary patient.
I will read you a summary of these rights. You may ask me questions at any time. I will give you a copy of this form, which contains information for you to read.	The reasons why the medical doctor thinks you should be here are written on the medical certificate.
You have the right:	You may have a copy of the medical certificate unless the hospital believes that this information will cause serious harm to you or cause harm to others.
1. to know the name and location of this facility. It is	As an involuntary patient, you do not have a choice about staying here. The staff may give you medication or other treatment for your mental disorder even if you do not want to take it.
at	CONTACTING A LAWYER
	You may contact any lawyer or advocate you choose at any time.
 to know the reason why you are here. You have been admitted under the Mental Health Act, against your wishes, because a medical doctor is of the opinion that you meet the conditions required by the Mental Health Act for involuntary admission. (see Reasons for 	BENEWAL CERTIFICATES
Involuntary Admission)	If a second medical certificate is completed within 48 hours of your admission, you may be required
3. to contact a lawyer. (see Contacting a Lawyer)	to stay in hospital for up to one month depending on your response to treatment. Before the end of
 to be examined regularly by a medical doctor to see if you still need to be an involuntary patient. (see Renewal Certificates) 	the month a medical doctor must examine you and your involuntary certificate may be renewed, if necessary, for up to another month. After this, the certificates must be renewed at the end of three months and then every six months. Every time a new certificate is filled out, you have the right to ask
 to apply to the Review Panel for a hearing to decide if you should be discharged. (see Review Panel) 	for a hearing by a review panel. REVIEW PANEL
 to apply to the court to ask a judge if your medical certificates are in order. A lawyer is normally required. (see Judicial Review (Habass Corpus)) 	You or someone on your behalf may apply to the review panel by filling in a Form 7, Application for Review Panel Hearing. This form is available in the nursing unit. The review panel must decide within
 to appeal to the court your medical doctor's decision to keep you in the facility. A lawyer is normally required. (see Appeal to the Court) 	14 days to continue your hospitalization or discharge you. There is no cost. Information about how a reveiw panel works can be provided by your nurse or you can contact the Mental Health Law Program directly at (604) 685-3425 or toll free at 1-888-685-6222.
to request a second medical opinion on the appropriateness of your medical treatment. (see Second Medical Opinion)	JUDICIAL REVIEW (HABEAS CORPUS)
	You may ask the court to look at the documents used in your involuntary admission to see whether you should be kept in this facility. You will need a lawyer to assist you and there may be a cost.
	APPEAL TO THE COURT
name of patient (please print)	Your may ask the Supreme Court of British Columbia to decide whether you must continue to be an involuntary patient. You will need a lawyer to assist you and there may be a cost.
	SECOND MEDICAL OPINION
patient's signature date signed (dd i mm i yyyy)	At any time after the second medical certificate is completed, you, or a person on your behalf, may request a second medical opinion about the appropriateness of your medical treatment. The second opinion is NOT about about whether you should continue to be an involuntary patient. You may ask to be seen by a medical doctor of your choice or ask the director to pick a medical doctor. There may be a cost to you depending on the distance the doctor has to travel. When the director receives the
name of person who provided information Give the patient a blank copy and file the named copy in the chart	second opinion, the director does not have to change the treatment; it is only an opinion.
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Figures 1 and 2 - Front and back of Form 13

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The analysis uncovered these themes:

- Participants vastly preferred the new communication tools to Form 13 (15 out of 16 participants).
- Participants were able to name most of their rights. Their recall was evaluated using teach-back.¹¹
- The new suite of tools addressed only one aspect of their understanding of their rights: clinicians would still have to commit to using these tools and to create an environment where patients could feel safe in discussing their rights with staff. Participants also expressed concern that the tools might replace conversation with their health-care providers. Our team aimed to convey these concerns to clinicians in a subsequent research project to implement these tools in hospitals within the province.

Patient involvement improved the design

Patient involvement in creating the suite of tools was essential to its success. For example, one of our posters (Figure 3) has far more text than I (as a document designer) would typically put on a poster.

The design decision came from one of the team's patient partners, who recalled that when he was hospitalized, he had no books or other reading material to keep himself busy. When he became bored, he read everything on the walls. Several of the user-testing participants agreed with the text-heavy approach, underscoring the importance of our patient partner's contextspecific insight.

That said, a minority of participants did tell us that the poster had too much information. In response, our team created a second poster (Figure 4) that had only basic rights information and referred readers to the pamphlet for more details.

After the final revisions to the tools, we posted them to our website, bcmentalhealthrights.ca,¹² and developed a program to train clinicians on their use.

What did we learn from this project?

Power sharing by codesigning with patients results in a more patient-centered product. Participants identified specific expressions that they found problematic but that people who'd never been involuntarily hospitalized may not have minded.

Also, even with patient engagement on our team, user testing was still necessary to uncover issues with design and language that our team had not considered. Having several perspectives made our documents stronger.

Finally, the clarity of the documents is important, but more important is how they make readers feel, especially if the readers are people who've had disempowering interactions with the mental-health system. Complex language is problematic not just because it's confusing but also because it exacerbates power differences¹³ between patients and the health-care providers responsible for detaining them.

Figure 3 – Large poster

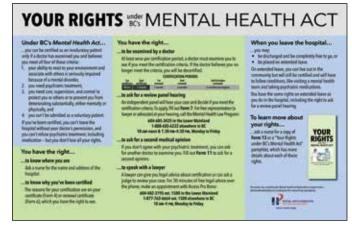
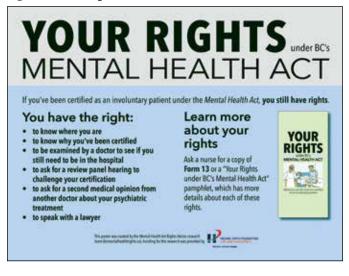


Figure 4 – Small poster



Empowering patients is key

Ensuring that patients understand their rights is crucial from an access-to-justice perspective. As former Canadian Chief Justice Beverley McLachlin said, "There is truth in the proposition that if we cannot understand our rights, we have no rights."¹⁴ It's also critical from the perspective of therapeutic jurisprudence, a field of study based on the notion that agents and structures of the law can have either therapeutic or antitherapeutic effects.¹⁵

Research about patient empowerment has shown that patients' experiences with the mental-health system are more likely to be positive if they feel less coercion. And giving involuntary patients a sense of procedural justice by telling them their rights and helping them exercise their rights can reduce feelings of coercion and learned helplessness and engage them in their own recovery.¹⁶

Many of our participants said that they weren't necessarily going to exercise their rights, but they were comforted to know that they had rights and that there were limits to what the law allowed the hospital to do.

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Acknowledgments

This research was funded by the Michael Smith Foundation for Health Research and the Canadian Institutes of Health Research. The author thanks members of her PhD supervisory committee — Drs. Diego Silva, Kimberly Miller, Erin Michalak, and Charlie Goldsmith — for their advice and support, and Laura Johnston for the legal review of our tools. She also acknowledges members of her patient-oriented research team, including J. Wang, Andrew Woods, and Vanessa Bland, and her research participants, whose identities are confidential.

This article is reprinted from The Clarity Journal, No. 80 (2019).

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