The Midlands Health Literacy Project: Findings from research and implications for practice

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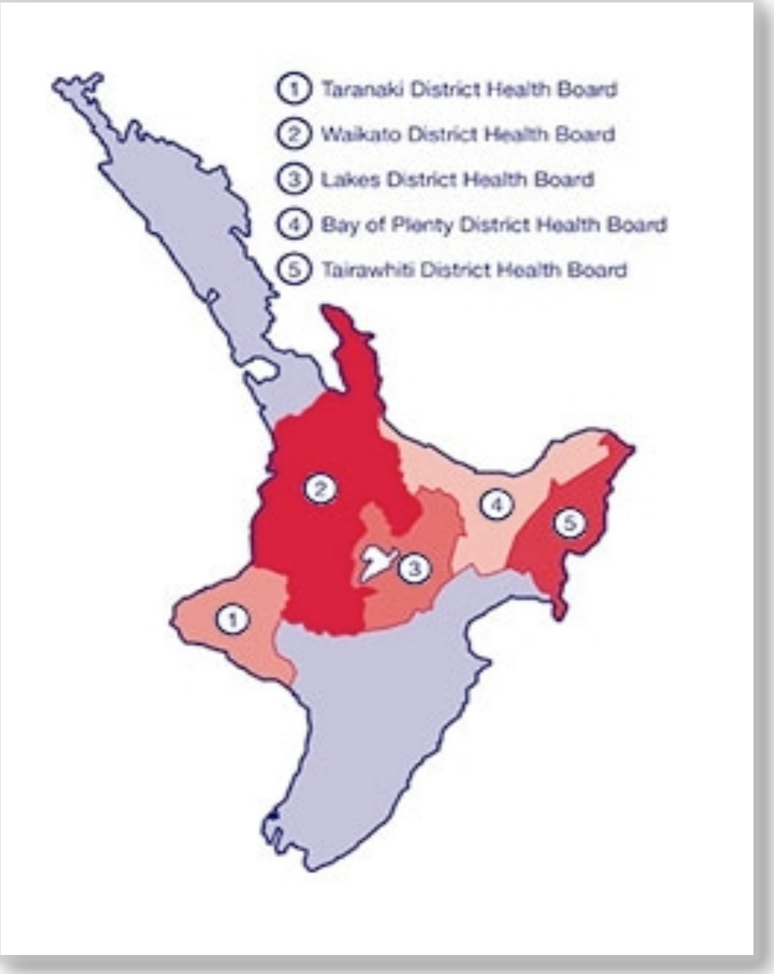
The project

A partnership with Midlands Health Network (MHN), a not-for-profit health management organisation that supports the delivery of primary and community health care in the Midlands region.

Initiated March 2010; planned completion July 2012.



What is health literacy?

“Reading level alone does not explain the complex human skills involved in becoming a health literate citizen” (Pleasant & Greer, 2005, p.196).

“Health literacy is the ability to understand, access, and use health-related tools and services in a given location” (Papen & Walters, 2008, p.10).

What does this look like?

A patient may not attend an appointment because they may not be able to follow directions to the practice.

Once at reception, they may not be able to complete forms proficiently, may be ashamed to ask for assistance in filling out forms, may leave with unanswered questions, or may sign a document they have not understood.

The may not be able to understand the doctor as they turn their back on the patient and read the screen. This may unsettle them and make them feel as if the doctor is not very engaged.

The doctor may begin by asking the patient what the problem is. They may not understand and answer the doctor’s questions adequately, or understand a lot of what the doctor said.

The doctor may have prescribed them with new medication, the name of which is unclear. They may not feel they can ask about how this medication interacts with other medication. And whether or or not they need to cease using the previously prescribed one.

They may be given brochures about their condition and care but they may only be able to read small parts of them.

They may feel that the brochure is not written for them because they can’t relate to the images in it. They throw the brochure in the bin when they get home.

Once the appointment is over, the patient may not know when to return or how to follow up on the visit.

On receiving their medication, they may not be able to read and interpret the information on how and when to take it. They may not feel confident to ask the pharmacist for clarification.

They are likely to feel that they are not in control of their condition and care. Their condition is likely to worsen.

Initial aims in March 2010

- To document the literacy and numeracy demands of primary healthcare **texts**, and **interactions** within the context of the practice, other clinics, and the home.
- To assess successful and unsuccessful uptake of healthcare texts with reference to literacy demands and contextual factors.
- To develop a ‘manageable’ way of assessing patients’ level of literacy and numeracy knowledge and need so that primary health care professionals can match need with the appropriate types of texts, and appropriate interactions.
- To develop materials to inform and support primary healthcare providers to reflect on and improve how they support patient access to information, and patient agency.

Phases of the project

Phase one: Scoping	Literature review	International trends, approaches; issues and challenges for patients
	Text and document analysis	An analysis of challenges in in healthcare brochures
	Recount related prompts with practitioners	Healthcare practitioners' views of what constitutes health literacy
Phase two: Research	Patient focus groups	Reported health literacy challenges
	Observations and interviews with GPs and pharmacists	Observed strategies for dealing with challenges
	Research report	Summary and implications
Phase three: Development	Guidelines for practitioners and patients	Provision of theoretical understandings; analysis of challenges related to knowledge, text and interactions; strategies for understanding, access and uptake

Our approach to health literacy

- The analysis of the situated nature of health literacy
- The importance of representing the patients’ voice and experience
- Considering both interaction and written text
- Capturing the complexity of text and spoken language
- A universal precautions approach
- From theory to practice

Our approach to our relationship with MHN, patients and practitioners

- Engagement with all: MHN, practitioners, patients and affiliated patient support organisations e.g. Raukawa, The Pacific Trust
- A respectful and enabling relationship with patients
- An open and responsive approach to practitioner feedback
- A flexible and negotiated approach to contract outcomes

Patient focus groups

Reported health literacy challenges for patients

The doctors need to simplify their medical terms to patients. If they could simplify that, maybe we would know then what they are talking about. But they’re all using big medical words.

A: You’re very interested in what’s going on, and you don’t really understand. They use words that you’ve never heard before --

B: They’ve got a bad habit of doing that –

C: and they never seem to be the same ones.

I got my prescription, a big bag of pills, but he didn’t explain to me, ‘Oh that’s for that, that’s for that.’ I’m too scared to take the wrong one.

Observations and interviews with GPs and pharmacists

Observed strategies for dealing with challenges

I: How did you find out what INR means?
P: It's an international blood register. I just asked questions: What the hell is INR?

GP: Do you feel this bit of a lump here on the scar?... It's something called a [celoma?] that gets reabsorbed in the system.
P: Yeah I understand that part from the surgery, it's a cut isn't it? if you cut a tree it gets a big lump on it doesn't it? it must do that in your body…

If I feel that you know I get the sense that maybe you know, I'm not getting the message across what I try to do is I try to google it and like 'everyday.co.nz' and 'everyday.co.uk' where the medical conditions are simplified and I just print it out and give it to them and ask them to read about it and get back to me if there are any questions.

English is not my first language, when I pronounce certain words, you know, I may pronounce it in a different way so sometimes they will struggle or they will ask a question about, 'sorry, what did you say?' and things like that and I can clarify it.

Guidelines for practitioners

Strategies for improving understanding, access and uptake

- Explain the meaning of specialised medical vocabulary
- Substitute general low frequency words with easier and more familiar ones
- Scan the brochure or text for medical terms the patient needs to know and explain these first.
- Explain the symbols, conventions, concepts and vocabulary of the text forms such as laboratory test results.
- Provide print outs with explanatory information for patients.
- Ask patients to explain how they understand and use their medication.
- Encourage questions and feedback on your advice.

Guidelines for patients

Strategies for improving understanding, access and uptake

Doctors control the consultation by using questions. You can ask questions too….

- Could you explain the word you used for my condition?
- I've changed my diet and I exercise, but I seem to be getting worse. Why is that?

The conversation you have with your pharmacist is quite different from your doctor. Your pharmacist deals with the medication. They may ask you if you would like them to explain how to take the medication, but not always. This is why you may need to have some questions you can ask.

- This prescription tells me how many times I need to take it, but **when** should I take it?

An emergent health literacy policy?

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