

Empowering Consumers and Advocates for Chronic Disease Management

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The Consumer Role

- In the ICU, the consumer (as ICU patient) does not serve a very crucial role in their own survival
- In the community, however...
 - They must remember to take their medication
 - They may need to monitor and adjust their dosage
 - They must implement exercise programs and make reasonable diet choices
 - They must choose to return to the GP (and not try to confound the system with excessive ‘doctor shopping’)
 - ... and they must maintain hope

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Time to 'tech up' the consumer role

- Rise in chronic component of global burden of disease
 - It's gonna break the system if we don't do something
 - And, as stated, there is much the consumer can do
- Ubiquity of IT has risen to a critical enabling level
 - The GPs all have a computer on their desk with patient management software running, and increasingly with broadband
 - They're ready to link with consumer/advocate
 - The patient usually has a cell phone (at least when newly diagnosed)
 - The patient (or someone near them) increasingly has Internet and knows how to use it

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Empowerment

- Focus on the **cognitive** role of the consumer
 - Contrasts with putting sensors on the patient or in their environment
- Areas where the consumer can contribute to their own health outcome in chronic disease management include both adherence to a care plan and the broader issue of becoming an active partner in *care planning*
- This transition from compliance to partnership can be identified with *empowerment*

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Activities and Advocates

- Set of patient-led activities should include
 - Medication adherence
 - Contribution to monitoring
 - Participation in lifestyle improvements
 - Contribution to schedule adherence
 - Lifelong learning (both of a practical and theoretical nature)
 - Includes 'personal learning' (how *I* can do what *I* want/need)
 - Participation in consultations with healthcare professionals (especially the GP)
- The role of the *advocate* comes most strongly into play where the consumer wishes or needs someone else to take on significant components of these activities
 - However, the availability of one or more advocates to create a social context for chronic disease management is always desirable
 - 'Advocates' may be family, clergy or other non-clinical volunteers

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Relevant technology areas

1. Internet search support
2. Agenda support
3. Lifestyle support
4. Social forums
5. Patient role in the EHR

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Consumer Health Information

- Can include
 - Information by societies (e.g., online facts, as well as information about **face-to-face events/activities**)
 - Information by companies (e.g., **selling products** or services)
 - Online communities (for people to inform and educate each other, as well as gain emotional support)
 - Gadgets – quizzes and risk calculators
 - Games
 - Some on-line health records

1. Internet Search Support

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Quality Problem

- Consumer use of Internet is concerning to health professionals
 - Is the information accurate?
 - Is it leading patients to not see a doctor when they should?
 - Is it encouraging alternative and self medication in a safe fashion?
- Consumers armed with Web information challenge doctor's authority (esp. if doctor is not computer-literate)

1. Internet Search Support

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drkoop.com well illustrates the double-edged nature of a consumer oriented site from the .com domain

Some terrific resources

But also a ‘magazine’ inspired format

Including ads

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The “Safe” Web

- In Australia, doctors are advised by the AMA to recommend *HealthInsite* as a hub of approved consumer information links
 - Also includes online quizzes (“Are you looking after your ears?”)
- There are of course also many high-quality sources, but they are not aimed for correct interpretation by patients (Medline, Cochrane reviews, etc.)
 - US National Library Medicine also provides a ‘For the Public’ portal that is much different from online journal abstracts

1. Internet Search Support

Managing meta-data

- Maintaining a resource like *HealthInsite* requires staffing
 - And the job never ends; sources change, and more is always required
- BCKOnline – Breast Cancer Knowledge Online provides a mechanism where the resources are critiqued by volunteers
 - Helps to take the load off of a government body
 - Alleviates consumer suspicion about ‘the establishment’
 - Uses profiles to match by style of content (e.g., emphasis on first-person accounts) and stage of disease

1. Internet Search Support

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The screenshot shows the BCKOnline search interface. At the top, there are navigation links: Home, Personalised Search, Breast Cancer Topics, Simple Search, and Help. Below this is a search bar with the text "Personalised Search" and a magnifying glass icon. The main section is titled "You may select all, some or none of the following categories" and contains several filter categories:

- Enter Search Term:** A text input field with the example "e.g. breast reconstruction".
- I want information for a woman aged:** Four radio button options with icons: Under 40, 40-49, 50-70, and Over 70.
- I want information on:** Three radio button options with icons: Early Breast Cancer, Recurrent Breast Cancer, and Advanced Breast Cancer.
- I want information for:** Five radio button options with icons: Self, Partner-Spouse, Friend, Parent, and Child.
- I want information which is:** Four radio button options with icons: Plain Brief, Plain Detailed, Scientific Brief, and Scientific Detailed.
- The type of information I'm looking for is:** Three radio button options: MEDICAL, SUPPORTIVE, and PERSONAL.

At the bottom of the filter section are "Search" and "Clear Search" buttons. To the right of the screenshot, there is a text box with the following text:

Resources are reviewed and given metadata encodings by breast cancer sufferers trained to use a custom reviewing interface

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Going further

- Query expansion
 - Re-render or suggest new/additional keywords for user query based on domain knowledge
- Automated quality assessment
 - So we can help the user with live queries - some patients want to *search*

1. Internet Search Support

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A patient's questions are important

- Getting 'the answer' online might not be the best thing, or the only thing
 - Should support patients to identify *questions* and issues to raise with providers
 - These provide a pathway to removal of barriers to adherence and promotion of self-care
- A patient's questions should be managed as important data (like blood pressure readings)
 - However, it's requires a different system to get a good 'reading' of patient questions

2. Agenda Support

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Violet Technology

A consumer diabetes portal with extensive patient profile for customized learning and agenda formulation support

The screenshot displays the Violet Technology web portal. On the left is a navigation menu with links: Welcome, Top Information, Quiz, Generate Agenda, Browse Information, View/Update Profile, and Log Out. The main content area is titled 'Potential Agenda Questions' and includes a date '7/06/04 21:36'. Below this is a table with two columns: 'Questions' and 'Your Status'. The table lists two questions: 'membership of NDSS' and 'Hyperglycaemia symptoms'. The 'Your Status' column contains text indicating whether the user has joined the NDSS and if they have hyperglycaemia symptoms. Below the table are sections for 'Information you have selected' (with checkboxes for 'Symptoms of high blood glucose' and 'Foot Care and Foot Wear'), 'Agenda questions you have created' (with a checkbox for 'travel'), and 'Your previous agenda list' (with checkboxes for 'know the importance of managing diabetes' and 'Symptoms of low blood glucose level'). A 'Done' button is visible at the bottom left of the browser window.

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Ubiquitous future

- **Txt 2 hlp u quit smoking trial**
 - STOMP (Stop Smoking with Mobile Phones trial)
 - The University of Auckland Clinical Trials Research Unit trialed a service to prepare young people to quit smoking
 - And then provide them SMS services as ‘chewing gum for your fingers’
 - Personalized messages include tips for healthy eating (since young people are more concerned about weight gain than long-term health issues)
- Promising future for more interventions in hand-held devices and integrating devices as computing becomes ‘ubiquitous’ (who thinks of their phone as ‘a computer’?)
 - Need to get the computer into kitchen and grocery store **with an integrated plan**

3. Lifestyle Support

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You are not alone

- Despite concerns, consumer forums are found to give accurate advice (inaccurate advice is rapidly pointed out by other users)
- A chronic illness diagnosis should come with access rights to a 'portal of peers'
 - Portals allow exchange of tacit knowledge (survival tips and practicalities not especially well-known to doctors)
 - Provide a place for expression and sharing for emotional Transition (how to cope spiritually and have a 'good' outlook)
- The discussions are also amenable to automated analysis through semantic space models such as HAL (hyperspace analogue to language)
 - For research, and perhaps to monitor

4. Social Forums

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Patient-Held Records

- Smartcards or USB memory sticks
 - As Cache – hold a set of most relevant facts (like a MedicAlert bracelet, but with a lot more space – actually they have it, the MedicAlert E-HealthKEY; see <http://www.medicalert.org/E-Health/>)
 - As Hub – hold links to sites where patient has had service
 - As Key – hold digital certificate to access a cache or hub website (perhaps this is best, since the card itself could be lost or damaged and hence needs a backup)

5. Patient Role in EHR

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The screenshot shows the MedicAlert website with a navigation bar at the top containing links for HOME, LOGIN, CONTACT US, and FAQS. Below the navigation bar is a banner for E-HealthKEY with the tagline "Can simply save your life" and a "Join Now!" button. The main content area features a large image of a woman and a USB device. Text on the page describes the E-HealthKEY as a self-contained USB-enabled tool for emergency medical information. It also mentions a desktop version and provides a list of features such as recording medical history, tracking medications, and creating emergency wallet cards. A sidebar on the left contains links for E-HealthKEY, Demo, Flash-140k, Highlights, FAQs, and Whitepaper PDF-450k. A right sidebar contains a "Now Available!" section with a "JOIN NOW" button and a "LOGIN" button. The page number "19" is visible in the bottom right corner.

Probably not a bad idea (at least in theory)

But seems a very commercial 'sell'

PHR – Personal Health Record

- The PHR contains an “ongoing, longitudinal and life-long record of information that bridges both wellness and illness” [Markle Personal Health Working Group]
- Each person controls their own PHR: individuals decide which parts of their PHR can be accessed, by whom and for how long
- Slightly different than allowing a patient view of an EHR (in which case ‘the system’ owns and controls the record)
 - PHR requires more initiative from the consumer
 - EHR may have stronger advantage with respect to patient observing errors (or verifying a lack of errors for ‘buy in’)

Direct Consumer Involvement in EHRs

- Patient reviewing the record may **correct errors** or raise questions that lead to **productive discussions**
- IT can make a patient **part of the process**
 - Patients logging observations (e.g., blood sugar)
 - Any good EHR architecture should track source of ANY observation, so patient-entered observations are easily differentiated from provider observations from a quality viewpoint
 - Patients having online access to their care plans and sometimes taking the action to fulfill the plan (e.g., scheduling their own recommended monitoring activities such as annual podiatry in Diabetes)
- Aim for a view where the patient feels they are **holding and owning** the plan (albeit jointly with the provider)
 - By the way, the *plan* has to be part of the 'record'

5. Patient Role in EHR

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Need for Evidence

- Evidence for consumer health information systems is thin and needs improving
 - Consumer use of Internet is best studied, but least part of 'the system' of the technical possibilities
 - Exceedingly poor track record of consumer programs being sustained (lots of pilots, not much further)
- New Zealand is a fantastic environment for trialing and sustaining consumer information systems
 - Tech'ed up GPs, fairly techie populace, plenty of chronic illness, great privacy legislation framework, NHI numbers, high expectations of 'the system', PHO/DHB framework

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Planning for Empowerment

- National EHR architecture plans and regional programs need to *really* include the consumer
 - The consumer view is usually the first thing to get dropped
- Need to plan for the ‘consumer-distinct’ features
 - Forums, agenda/question support, profile-based query expansion – not just a view of the provider-oriented EHR
 - Opportunity to re-invent the healthcare system with the consumer (and nominated advocates) actually ‘in’ the system