



User-generated safety

Recruiting one hundred thousand eyes and selling what they see

Dr Paul Hodgkin FRCGP




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User-generated web content


Blogs, YouTube, MySpace, Face Book, Flickr, wikipedia

A major component of 'Web 2.0'

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Elective surgery for asymptomatic, unruptured, intracranial aneurysms

Posting on Flickr.com



My dad was worried about something happening that would hurt other people, such as the unruptured aneurysm bursting while driving.

The surgeon NEVER said there was a 50% chance of permanent brain damage by going ahead with this elective procedure. He NEVER admitted the actual risk of rupture was less than 2%.

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Watford General Hospital - Toilet cleaning countdown - Red is bad

Flickr.com



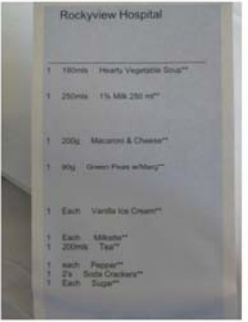
Red is bad Green is good - Green numbers are the count-down to the next clean - red numbers are the minutes over-due - the clock stops at 9:00 - these toilets haven't been cleaned for over 15 hours. They look it too.

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hospital menu

Flickr.com



Rockyview Hospital

- 1 100ml Hearty Vegetable Soup**
- 1 250ml 1% Milk 250 ml**
- 1 200g Macaroni & Cheese**
- 1 90g Green Pineapple**
- 1 Each Vanilla Ice Cream**
- 1 Each M&B**
- 1 220ml Tea**
- 1 each Raisin**
- 1 2% Soda Crackers**
- 1 Each Sugar**

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...and the resulting meal

Flickr.com




well... it's green and yellow.

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Last month traffic to user-generated sites became the biggest source of web traffic displacing sex-related sites for the first time

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So what are the deep drivers here?

Exit – providing people with a choice about where to go

Competition and markets

Voice – complaints, surveys, user-involvement, litigation


Mintzberg et al

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Industrial information economy

.... It took millions and a cast of thousands to have a voice

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Networked Information economy

.... anyone can publish

Blogs, Flickr, YouTube, e-discussion, wiki-pedia, Face Book

Ref:
Benkler Y. The Wealth of Networks
Cassells J. Internet Galaxy


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Cost of voice is now close to zero

The democratisation of voice


Voice will be a major policy driver of the next decade

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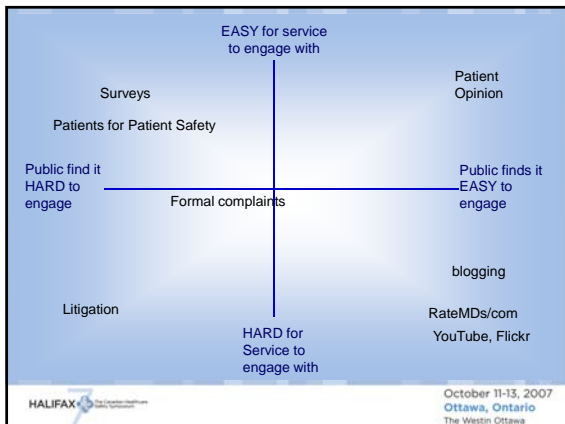
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How is the safety movement going to respond to democratised voice?

What opportunities are there?

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- Patient Opinion**
- patients and carers post stories and rate care
 - output
 - previewed and free for anyone to view
 - posted to 'just the right person' as RRS feed
 - Responses from subscribers
 - 3rd party payers, MPs etc
 - public conversations about micro-aspects of care

What's the business model?

Independent

Not-for-profit social enterprise

Advertising-free

50 organisations subscribe ~ 20% UK population

Usage:
6,000 postings or ratings to date;
500,000 page views per month


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What are subscribers buying?

Hospitals
ability to respond
patient feedback to 'just the right person'
tools to portray their values on-line
culture change

3rd party funders
- performance management tools that reach micro-care
- user testing panels

Regional/national funders
a scalable, national, self-improving system

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So does it work?

People post thoughtful, useful material
50% positive, 20% critical, 30% mixed

8% get a response of some kind

Generates improvements in service


Business model holds up

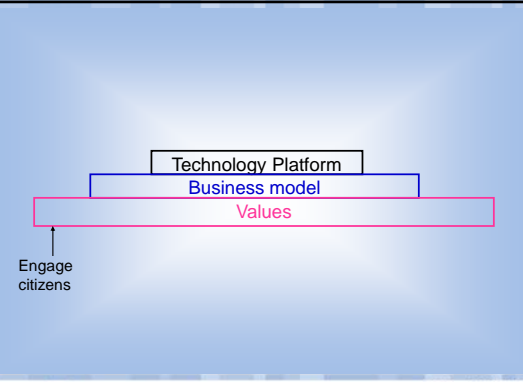
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But....

Generating postings from the public is hard work

It's a significant culture change for hospitals and staff

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Technology Platform

Business model

Values

Engage citizens

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Through our torment, NNU team was Outstanding

20 July 2007 , 14:49 PM

Our baby Dexter was born full term weighing 8lb 6oz. He had to be put on a ventilator straight away and was immediately transferred to the Neonatal Unit. Over the next few days various investigations and tests were done which gave us hope that he could make a full recovery. But then the results of his MRI scan came through; it showed that he was severely brain-damaged due to oxygen starvation. We then made the hardest decision of our lives –to ask the doctors not to resuscitate Dexter if he was unable to breathe on his own. He was just twelve days old when he died.

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Always ensuring Dexter was as comfortable as possible, the staff made us feel that his life was as significant to them as it was to us. Nurse Jan Edwards made a print of his feet and hands and put them together in a card with some clippings of his hair. On Father's Day there was some chocolate for me that was labelled from Dexter.

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As Dexter had spent his whole life in an incubator with various lines going into his little body we asked that he be able to spend his final moments outside in the daylight. The staff arranged for us to sit outdoors in a fragrant garden with our son for his last moments. For the first time, he was not attached to lots of machines but in our arms like an ordinary baby. We cradled him in our arms as he died and then wandered over to a wooded part of the hospital grounds where we spent some time alone with him. This was important for us and the staff at the NNU did their utmost to ensure he spent his final moments in the way that we wanted.

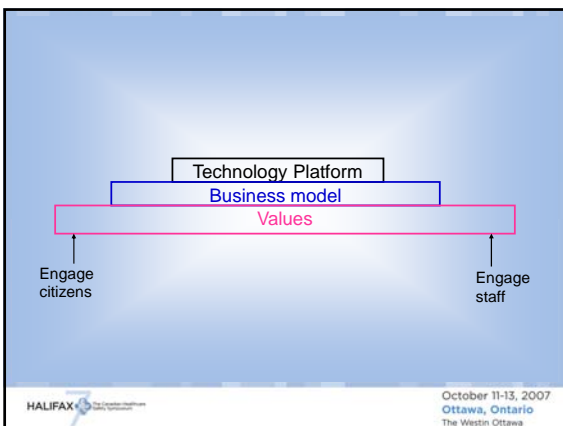
During his time on the NNU it often felt like we were powerless to help our little boy and it was humbling to see these highly skilled professionals do their work. We have the highest regard for these committed and dedicated people, who cared for our family in our moments of greatest anguish. They are an extraordinary team and a credit to the NHS.

Contributed by [Rog](#) about [Royal Devon and Exeter Hospital \(Worford\)](#)

Keywords : [Centre for Women's Health](#) | [NNU](#) | [Neonatal](#) | [anguish](#) | [baby](#) | [death](#)

View ratings for : [Royal Devon and Exeter Hospital \(Worford\)](#)

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What could this kind of platform do for safety?

New tools – including online video and pictures from patients

Patient-led initiatives

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International interest

Spain, Netherlands, USA, Estonia

Shared software platforms for not-for-profits
shared software costs
'open source' for future developments
IP held in common

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Summary

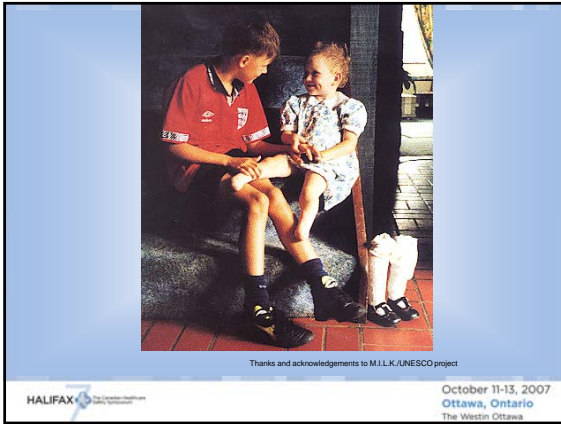
Democratisation of voice means patient contribution to safety will become highly significant

There are both useful and toxic forms of voice

Values and business model are crucial to realising full public benefits of democratised voice

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Lack of nutrition
18 October 2006 , 09:03 AM

My father in law developed throat cancer. Because his throat was sore and obstructed he couldn't eat properly. He was admitted to Manchester Royal Infirmary for rehabilitation as he had become to weak for the oncologist to consider any treatment. That was 18 days ago.

Since then he has been waiting for minor surgery to insert a feeding tube. He is often given a sandwich to eat in the evening which is sealed in a plastic packet which he cannot open. Even if he could open the sandwich he has great difficulty in eating it because of the obstruction to his throat.

His breakfast includes toast which he cannot eat properly. Because he is in bed 25 he never gets soup, which he could eat, because there is never any left by the time the trolley reaches him. He says it always starts at bed 1.

He is given diet yoghurt, which he can eat, but given his problems seems inappropriate. The food which he orders from the menu does not appear to reach him. The ward staff say that there isn't really a system to ensure that the meals patients order are actually provided.

Each time his daughter alerts the staff to these problems the staff provide suitable nutrition, but there does not appear to be any effective strategy for ensuring that appropriate food is provided.

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4 month wait for brain scan at Royal Preston Hospital
14 September 2006 , 16:31 PM


My husband went to the doctor with a suspected TIA (a mini stroke) at the beginning of August 2006. His doctor sent him to the fast track TIA service to see a stroke specialist, but the appointment took 2 weeks.

He had the appointment and the specialist recommended he have a brain scan but we were then told there is 4 month waiting list for this in Preston. I think this is terrible.

I was reading [Stroke News](#) (page 13) and found an article reporting that the Public Accounts Committee report says that "a brain scan is vital following a stroke", so why does it take 4 months to be seen? This makes me think that a suspected stroke patient is not being given the proper treatment.

I wonder if the hospital could reply here on Patient Opinion so that others in the same situation can find out what's happening.

Patient Opinion has forwarded this comment to Preston Royal Hospital to see if they wish to respond.

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Controversies in Healthcare Safety

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