

The long tale: public services and Web 2.0

Paul Hodgkin and James Munro discuss how Web 2.0 can be harnessed by public services to use patients' experiences as a catalyst for change

Public services have to date remained relatively untouched by the World Wide Web. However this is about to change as the technologies loosely known as 'Web 2.0' enable all citizens with access to the web, to have a public voice. This democratisation of voice creates a new, long tale of conversations about public services. These numerous public conversations have the potential to help us access our collective wisdom and drive improvements. They also have the potential to become toxic for both staff of these services and civil society.

The web may be revolutionising banking and tearing the travel and music industries to bits, but so far the UK's health service, the NHS – that great Dowager Duchess of the public services – has sailed on unperturbed.

But the mice are getting bolder. Look on YouTube and you can find video clips of the NHS in action, while on Flickr people are posting pictures of NHS toilets, food and infrastructure.

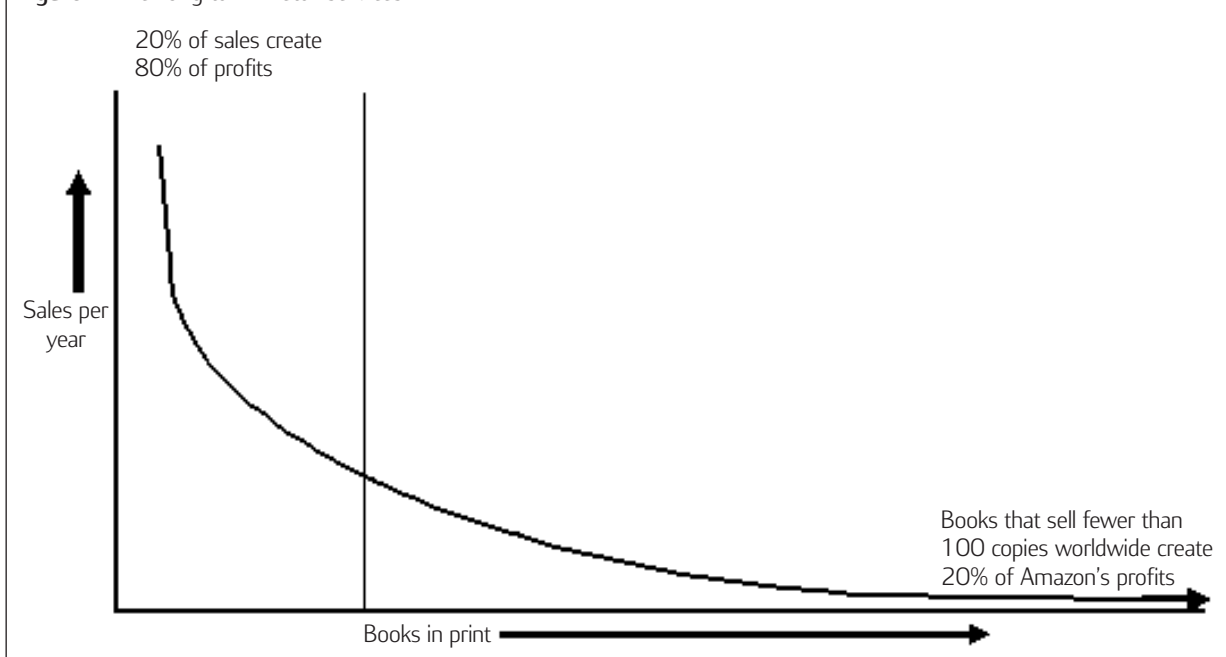
The retail sector uses Chris Andersen's concept of the Long Tail¹ to make sense of what's happening. In the past shelf space was limited, so shops stocked only what was popular. By contrast shelf space on the web is infinite, so suddenly the real shape of consumer desires is revealed: people still want blockbusters, but they also want the most obscure of things. And when viewed through the panopticon of the web, the most arcane of niches becomes profitable: Amazon makes 20 per cent of its profits from books that sell fewer than 100 copies per year worldwide (see Figure 1).

All well and good for the retail sector, but shelf space is definitely not unlimited in the all too real world of hernias and herceptin. For health care, desire will always be trumped by the affordable. But this does not mean that nothing is changing, merely that explanations from the commercial web rarely translate well to what is happening in health care.

Web 1.0 created the huge informational universe that we know today – more than 1 trillion web pages and counting. For medicine, the singular effect of Web 1.0 was to end the esoteric nature of medical knowledge – patients come to consultations grounded in up to date knowledge in a way that previously was impossible. But this is old fare and everyone (patients and professionals) is pretty comfortable now with everyone knowing much more about everything.

Web 2.0 is a different matter. This article explores the democratisation of voice, an aspect of web 2.0 that is as disrupting to health services as Napster and peer-to-peer file sharing was for the music industry.

Figure 1 The 'long tail' in retail services



Democratisation of voice

In the old days of the twentieth century the world ran under an industrial information economy. It took a cast of thousand and several millionaires to produce a newspaper, film or CD. As a result, having a public voice was reserved for elites. But in the new, networked economy, the costs of having a digital voice that can potentially be heard by the world have become trivial. Anyone can blog or upload their clip to You Tube ,or post a comment about their recent hotel stay on Trip Advisor. Voice is available for all.

What's more, the same searchable nature of the internet means that those with minutely matched affinities can find each other. If you've got renal failure, rheumatoid arthritis and have just lost your job, somewhere out there is an e-discussion group that will be filled with people who really understand you, because within the tolerances of conversation, they have experienced the same problems. And a problem shared is not only a problem halved, it is also, given the right circumstances, a problem transformed into a pressure group.

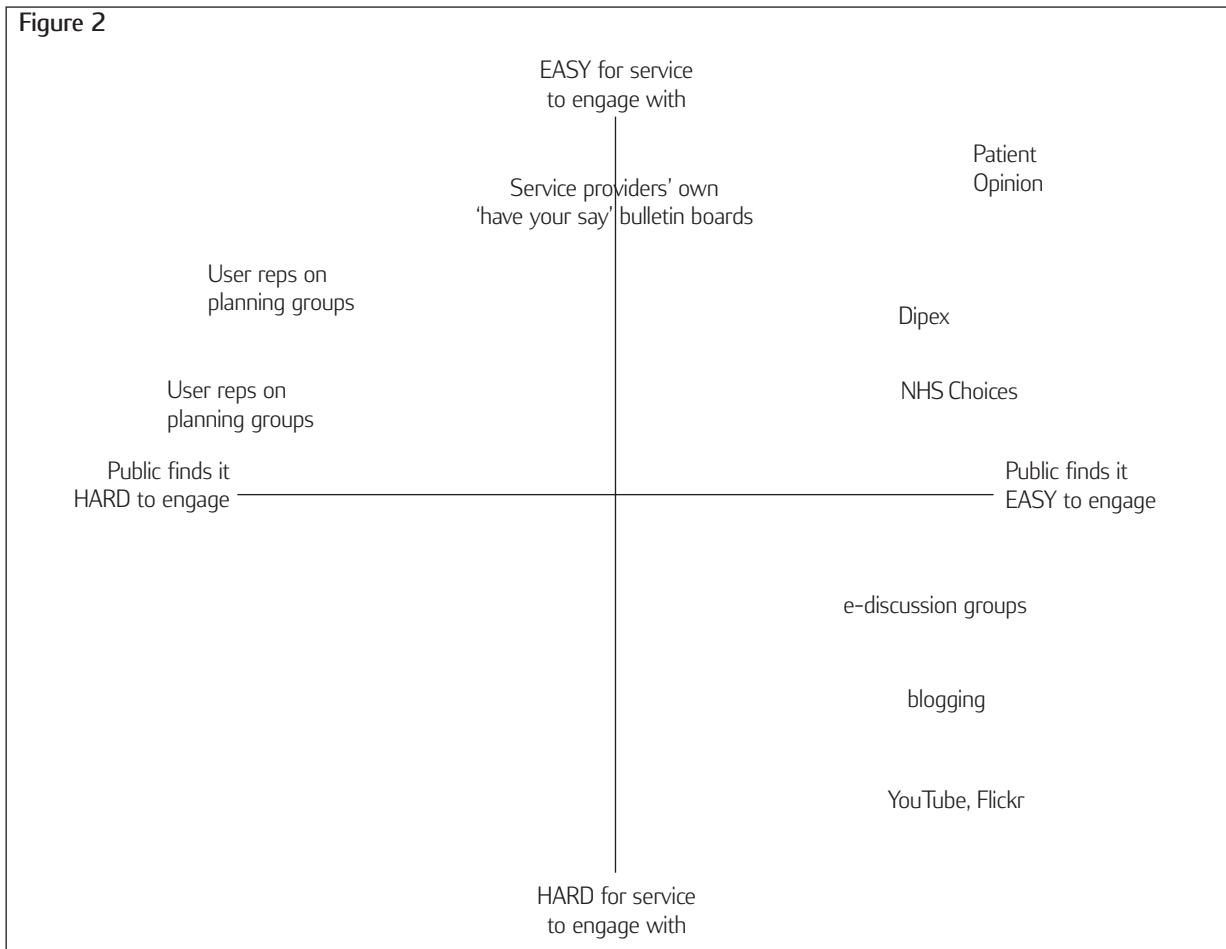
But having a choice is not the same as being heard. For most people, You Tube is an anarchic cacophony; an ego-driven place that shouts 'Look at me and mine'. Its purpose is itself. Unsurprisingly this makes it

hard for bureaucratic organisations like hospitals to make sense of the information it displays. So people are posting pictures of the dirty toilets on ward 15, but does anyone care? And if we clean them up and post about it, will that be seen as cool or irremediably '404'² to You Tube users?

By contrast the idiom and assumptions of surveys and focus groups are essentially about You, and the tools that organisations use to discover the predilections of users, those weird people out there, are rubbed smooth by institutional needs not the needs of citizens. These two dialogues, one based on dissecting You, the other on shouting about Me, are equally ill-matched for productive conversations. What we need is to enable newly democratised voices to speak in ways that organisations can make sense of and respond to. What we need are dialogues about Us (see Figure 2).

Patient Opinion³ uses a variety of tools to do this. Patients and carers generate content by sharing their stories on the site, and by rating the service they have received. Anyone can then view this feedback to find out what local people thought about a particular department, ward, service or procedure. To make the system into a genuine conversation Patient Opinion then offers several new Web 2.0 twists:

Figure 2



- Organisations that subscribe to Patient Opinion can post responses. At first we thought that only hospital themselves would want to do this and would limit themselves to critical postings. As we have learnt more about these systems it is – of course – obvious that others having things to add to the conversations. Groups that can comment currently include Primary Care Trusts (PCTs), Practice-based Commissioning Groups, patient organisations like Asthma UK, and MPs.
- Feedback is targeted to just the right manager. Subscribers have up to 100 RSS (Really Simple Syndication) feeds that allow them to direct postings to staff or Board members. This means that the manager responsible for women’s services at Portsmouth General can receive just those postings relevant to her responsibilities as a weekly email. She can then discuss these with staff, post responses and benchmark the ratings her service has received against comparator sites.

If it works – and it is still relatively early days – Patient Opinion plans to direct several hundred thousand patient comments per year each to just the right manager across the NHS. Add in comments from other organisations, and democratised voice turns into thousands of democratic conversations, each focusing on some micro aspect of service. Comments and suggestions from patients are typically small scale, easy to rectify and highly important to the experience of care. *‘The ward orderlies never knocked’, ‘The consultant never once washed his hands before examining me’, ‘My father could only eat liquids but was at the end of the ward and the soup was always finished by the time they got to him’.* These things are central to good care. The NHS concentrates on efficacy and efficiency but these aesthetic aspects of care – what

did it feel like? Were you included in decisions? Did staff make you feel precious or worthless? – are also essential to outcomes, and to staff satisfaction, that feeling at the end of the day of having done a good and worthwhile days work.

The Long Tail makes sense of the disruptive effect that the web is having on commerce. Given that health services will always be about bodies not bits, there will never be unlimited shelf space, so this metaphor does not work. But while services will always be anchored in the real world of money and flesh what is changing is this new blossoming of conversations about services. It not a Long Tail but a Long Tale (see Figure 3).

Currently there is a paucity of conversations about the NHS. From a citizen perspective there are individual consultations, complaints and then just the elephantine re-organisational dances indulged in at regional and national level. To date this vacuum has been conceived of in terms of a democratic deficit which leads to solutions like Scrutiny Committees. What is emerging however is a Long Tale of Conversation to match the long tail of retail sector (see Figure 4).

Existing behaviour on the net tells us that what drives people is the desire for relationship that are focused on particular interests or problems. Formal mechanisms like Scrutiny Committees need to link into this but cannot themselves create and foster the sort of loose, conversational dialogue and cooperation that builds Linux or drives MySpace.

Running Patient Opinion has convinced us that the state or public sector providers themselves are likely to be poor hosts for these conversations. Citizens instinctively distrust government websites, suspecting them, rightly or wrongly, of spin. It is also improbable that

Figure 3 The current conversations about the NHS

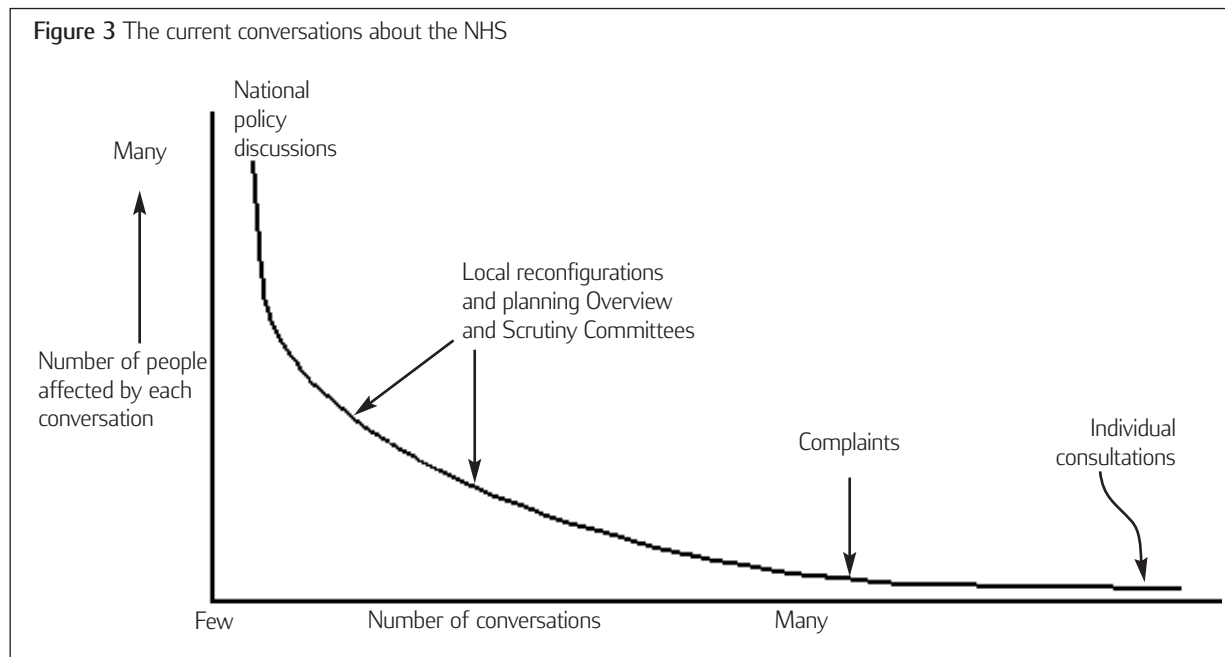
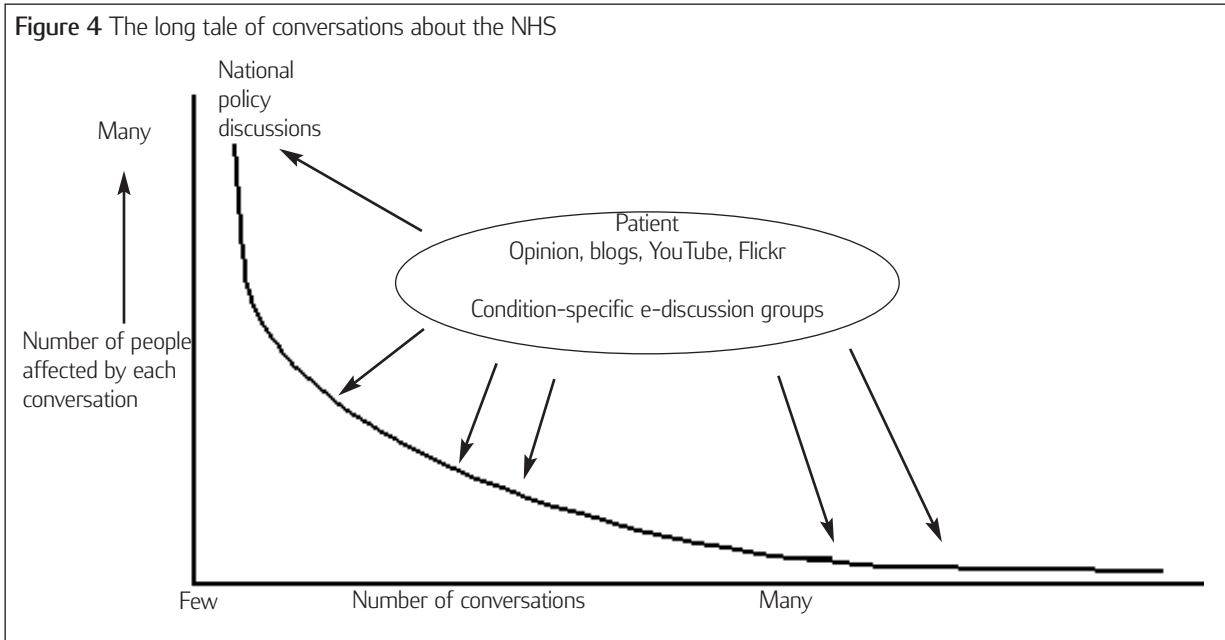


Figure 4 The long tale of conversations about the NHS



citizens will want to give email addresses and other demographic identifiers to the state, NHS or provider organisations when they may be users of those services in the future. Finally, democratised voice can easily create firestorms like the Downing Street petition over road taxing. For health these are likely to be around hospital closures or access to new treatments like herceptin, and the NHS is likely to find these easier to handle if they are not directly responsible for managing the dialogue platform. By contrast (and in parallel perhaps with organisations like Which?) we believe that independent social enterprises are in principle, much better placed to mitigate these problems of trust and democracy.

These arguments are about to be put to the test with the development of the NHS Choices website. This national website is due to go live in June 2007 and has been funded at a cost of £8 million by the Department of Health, with the aim of providing a single space where patients and citizens can find all the information they require about health. In many respects it is an admirable and much needed innovation. However one of its five work streams is Patient Voice, where amongst other things patients will be able to give feedback about their care, and for this to be shared by others. Initially NHS Choices wanted Patient Opinion to provide this facility and we were keen to do this. However during the very rushed six month development phase it became clear that there was no consensus about the principles of how citizen-donated feedback should be handled (see Table 1).

In our view these differences arise because large volumes of citizen-donated feedback about public services represent a new class of data that the state has not had to deal with before. Getting the balance right between citizen and state whilst providing a business model that is sustainable and ensures indepen-

dence, requires imaginative solutions. For example, during our negotiations with the Department of Health, we proposed that data should be held and owned entirely separately from the state in an escrow database controlled by a Community Interest Company representing a range of civil society interests, together with the Department of Health. However this was unacceptable to the Department of Health, which views all feedback arising through the NHS Choices site as its property.

From the consumer's point of view, the resolution of these issues is of immense importance. As web-based feedback grows, it will become a crucial quality driver, as well as determining how the public perceives services. Who owns, controls and quality assures the data presented will determine whether it is trusted, and whether the great potential of citizen-donated feedback is realised or thrown away. From the experience of Patient Opinion to date, we would suggest that all proposals for data ownership and control of citizen-donated feedback should be judged against the following criteria:

- all data, including personal ID, be held independently of the state by a trusted third party;
- citizens need to know the published data is unbiased and complete (subject to legal constraints);
- data should be held so as to maximise use and creativity of civil society, state, and provider organisations
- access costs to data sets low;
- no monopolistic control of data; and
- data needs to be held in ways that maximise the utility of emerging web technologies, rather than ways determined by administrative convenience of state or provider organisations.

Whilst existing data handling models, such as the Office of National Statistics, provide some useful guid-

Table 1 Comparing and contrasting the visions and approaches by the Department of Health and Patient Opinion

	Department of Health view of NHS Choices patient feedback module	Patient Opinion
Aim	Enable patient feedback via the web	Enable patient feedback via the web
Fundamental goal	Collection of data to inform patients, healthcare commissioners and providers	Radical transformation of the relationship between citizens and their health services
Ownership of patient feedback	Owned by the NHS	Held 'in trust' by Patient Opinion or other independent body for public benefit
Feedback is seen as:	A commercial or state asset	The gift of past patients to future patients
A successful patient voice on NHS Choices means	Building the site Analysing feedback data	Building and holding the trust of patients, public, healthcare professionals, government Engaging these groups to see how they might engage with patient feedback
How should citizen-donated feedback be shared?	State licenses, approved organisations for approved use	Data sets exposed to authorised organisations to mash up as they wish.
Skills required	IT and analytical skills	Clear communication, networking, building trust and sharing vision
Benefits of this approach	Public sector standards applied Rapid development possible Government ownership of data and site assets	Harnessing the vision and energy of civil society groups and individuals New ideas and areas can be pursued rapidly Relationships between citizens and services begin to change
Risks of this approach	Citizen apathy or cynicism Feedback has complaining or hostile tone High risk of vexatious postings Patients and staff lose faith in the site and potential	Unpredictable level of citizen engagement Reliance on business success

ance, the much more personal and citizen-led nature of this kind of data means that the distance from the state arguably needs to be greater than for official statistical sets.

What next?

The democratisation of voice holds great promise for the consumer. For the first time the gaze of the state is returned by the insouciant stare of thousands of users interacting on their own terms in their own time.

Learning how to handle this new, massive, flow of feedback in ways that promote civil society is not easy,

and getting it right is not a foregone conclusion. 'asbestos' is the most expensive Adword on Google due to its appeal for US attorneys. It is possible to imagine highly profitable and very destructive feedback platforms based on servers in unscrupulous jurisdictions that are driven by advertising from personal litigation lawyers and purveyors of therapeutic snake oil. Avoiding this and achieving the best for citizens will require vision, balance and coordinated effort between all those concerned for the consumer in this new wage of democratised voice.

REFERENCES

- [1] www.longtail.com
- [2] In the world of text messaging 404 means stupid, broken. From the web message 'Error 404. File not found'
- [3] Patient Opinion is a not-for-profit social enterprise that generates income via subscriptions from Trusts, Primary Care Trusts and Strategic Health Authorities.