

News Review & Comment

News Review p35

Good-time girls

Don't ruin the fun that is
Ladies Day at Aintree

News Review p33

That's the right answer

More Highbrow TV shows

Comment p32

Charles Moore Does

Cameron want it enough?

ENGAGED AND EMPOWERED

As doctor's role in the decision-making process is gradually changing from "God" to "Guide", **Artjoms Saposnikovs** investigates how patients' involvement is altering the image of modern healthcare system.

Although 60% of the GP surgeries are using the so-called EMIS software that allows patient to check his medical record, test results, medication and order repeat prescription drugs online, getting your health information can still be a bit of a painful quest.

In most practices, getting a full paper copy of your records takes time, possibly several weeks and you may be charged as much as £50. What the NHS has just agreed however, is that you will be able to get access to a summary care record,

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containing headline information and basic details, by the end of the year.

As patients can now get ready access to health information online there has been a considerable increase in the number of empowered patients, some of whom are finding a voice through networked online communities. We can also spot the emergence of patient leaders who are increasingly seeking dialogue with health professionals and policy makers. They are keen to promote shared decision-making in healthcare and to extend shared decision-making beyond their own care. They also want to share decision making about the design and delivery of services, participation in defining the research agenda and even in the debates on rationing, if it will be required.

This is part of a shift in healthcare which is also seeing patients slowly been given — and demanding, more power to self-manage their health and medical conditions, reducing the need to rely as heavily

on healthcare professionals. When these patients do get their standard 10-minute GP appointment, this should provide the opportunity for them to have a more constructive dialogue with their GP and reduce wasted time.

The British Medical Journal launched a strategy to promote patient partnership in June 2014. As a part of this initiative, the BMJ committed to setting up an international panel of patients, patient advocates, and clinicians to advise the journal on steps to take which might help its readers in the universal aspiration to make health services more responsive, efficient and more closely aligned to patients' needs and priorities.

Tessa Richards has worked in the NHS as a general physician and rheumatologist and subsequently a general practitioner. Now she works as a Senior Editor at the British Medical Journal and is at the helm of the BMJ's Patient Partnership Initiative. Richards describes the current UK health system as "rather impersonal at times" and, in common with all health systems, as being driven by all sort of considerations as well as the patients' agenda.

"We've had a health system that's influenced by a wide range of considerations including the interests of health professionals, the academic community and commercial companies," Richards points out.

"The influence of pharmaceutical companies is particularly pervasive and, of course, includes an impact on patients and patient groups that not infrequently get support from industry. It's a complicated business." According to Richards, looking to the future, concern is high about the sustainability of health systems and, in particular, the pressure on health systems associated with the growing number of people living with long-term diseases.

The patient involvement and shared decision-making movement has



been going on for several decades, and the BMJ has drawn on the expertise and experience of a wide number of people to select members of its patient advisory panel. It first overtly signalled its strong interest in patient partnership in 1999, when it released a patient-themed issue. The experiment continued with a patient-themed and patient written issue, released in 2001. Now things have developed further: patients are able to contribute to the BMJ editorial processes and submit blogs and other contributions for publication, and



Tessa Richards

the journal is encouraging medical authors to include patients as co-authors.

However, the journal's longstanding editorial policy remains strong — all scientific content is only published after rigorous "peer review".

Rosamund Snow, the Patient Editor at the BMJ says: "We want to be able to teach doctors, so in the pieces patient submit to us there must be something in that patients want to teach health professionals, we are not just looking

for them to tell their own story. In our "What your patient is thinking" series, we ask the patients to include three or four key messages in bullet points. These have to be something that the doctors can understand and personally change to do better tomorrow as a result of reading them."

In such a situation, the question of trust holds particular importance, in case a potential contributor writes on behalf of someone else or simply makes up his experience. "How do we actually check whether what they say is true?" Snow smiles. "It's very obvious. If someone is talking about their own feelings versus talking about something they haven't experienced — it's really easy to see."

Rosamund Snow herself has a background in dealing with long-term health conditions, as she has type 1 diabetes since her teenage years. She was building a career as a Press Officer in various fields of communication such as private, public and charity sectors for almost 20 years until she was offered a National Institute of Health Research grant in 2009. The NIHR funded a PhD for people with a particular interest in patient involvement in research in healthcare. Now, in addition to the Patient Editor job at the BMJ, she is tutoring students at King's College London. She also explores the possibility of patient involvement in the medical education, working as researcher at the Department of Primary Care Health Sciences at the University of Oxford.

One of the projects Snow is currently connected with is called 'Clinical Teaching Associates'. It started in

London and now this is happening in more and more in medical schools all over the UK. "It's where we have laywomen who are teaching doctors how to perform intimate vaginal examinations, but they teach it on their own bodies," Snow explains. "So, they will tell the doctor, whether they're in the right place, whether it's comfortable, whether they're feeling respected." As a result of this, instead of practicing on a plastic mannequin, the aspiring doctors will hone their skills on real women. And there is a clear opportunity that this experiment can actually be turned into exam as well, with those women giving the final mark and saying whether the students can pass or fail that particular part. "I think it will be hugely more useful in terms of education," Snow continues. "You cannot train on a plastic model, because it can't tell you that it hurts, it doesn't have accurate anatomical features, you can't easily talk to it and make it feel safe. So, all of those skills aren't being taught or trained or assessed unless you have real people doing it."

This system is currently being adopted in University of Oxford, University of Cambridge, King's College Hospital and Birmingham and Manchester universities. University of Birmingham had even made a step forward towards expanding this experience from the field of intimate health to the other parts of the body. "In Birmingham they as well teach breast examination, and in Cambridge there are men who teach prostate examination.

Continued on Page 30

AD SPACE

Feature

Continued from Page 29

If someone is doing an intimate examination on you, it really matters that they know what they're doing and it can put people off getting screening at all if their experiences are poor or painful," Snow explains.

So, for example, people with heart problems will teach on their own bodies, so that students can learn what the heartbeat sounds like in someone who's ill. "And they'll teach, again, the same sort of things alongside, such as respect and the context that the patient is bringing to that consultation," Snow says. "And, of course, that's got huge health implications: if it is frightening for patients to come for screening, then we can't cure their cancer, we have no chance. So, it's really important that these skills are told properly to doctors."

The driving force behind the patients participating in this kind of curricular experiments is nothing surprising: according to Rosamund Snow, in general, they just enjoy taking on a teaching role. Of course, like every teaching staff, the involved patients are being paid (although they sometimes volunteer), but they mostly have several different jobs and only consider it as a useful way of making some money out of ordinary hours. Besides that, the economic benefit for the teaching patients seems rather questionable, especially in comparison with the experience of the colleagues overseas. "In America they've had Gynaecological Teaching Associates for a long time and they are paid extremely well, much more than we are paid in the UK," Rosamund admits. "So, I think, in UK people volunteer for ideological reasons more than for economic gain: women patients are absolutely passionate about their health and making sure that doctors are trained well to make women feel comfortable about getting screening and being treated with respect."

Anne-Marie Boylan is a researcher with a background in psychology who has been working as a qualitative researcher for almost five years now, focusing mostly on disability and brain injury. Now she works with the Health Experiences Research group at the University of Oxford where she is responsible for doing qualitative research that is published on healthtalk.org website — a patient experience database. The involvement of patients in her research is expanding on two levels: on the first one she is actually involving patients and on the second she is doing a research about patient and public involvement in healthcare.

One of the main reasons of the patients being involved in her previous research is that they were published for the lay audience and, in this case, the presence of lay people was particularly important. In her latest research about patient and public involvement in healthcare from the last two years, she has conducted more than 40 interviews with patients and members of the public. These are people who have been involved in the decision-making process in healthcare for a various length of time and she has asked them all about the experience of their involvement. The second stage of the research will include interviews with the researchers with exactly the same questions about involving patients in their work.

However, involving patients in the research is also connected with a lot of concerns, for example the problem of paying people. Of course, there are still a certain type of patients who regard medical research as something they would feel privileged and honoured to do, completely unconcerned about the financial aspect.

But among other patients very common are the views that pretty much fit the logic 'If patients' knowledge and expertise is deemed to be valuable why should they

remain unpaid?' Unsurprisingly, it is reasonable that professionals are cautious about the response to such statements. "Some researchers think: if you pay people, you'll get the certain kind of person and that's not necessarily the kind of person you want all the time," Anne-Marie Boylan explains.

Boylan's personal attitude to this idea is overwhelmingly positive, for a variety of reasons. "Firstly, it is a marker of respect," she says. "It's a sign that you take things seriously and value their expertise. It's also a good way to get people who wouldn't ordinarily be involved to become involved. So, if you want younger people of working age — you should pay them because they have to take time out of work."

Other concern, mentioned by Anne-Marie, is related to the problem of representativeness, the right of patients to speak on the behalf of the wider group of the patients and how it could possibly affect the research.

"I think there are some researchers who see it as a 'tick box' exercise, so they think that it's something that we've been told that we have to do," Boylan says. "Therefore, they do it tokenistically, they don't necessarily see that there's any value in it, but they go through the motions of speaking to patients. I think they can be very dismissive. On the one hand, they can justify their reasons for doing things because they have a patient who is supportive of them and what they are doing, but, on the other hand, if the patient disagrees with them, they can say: 'But you're only one patient, so we don't have to listen to you.' It's a bit of a contradiction."

In light of these concerns, the question of the so-called 'professional patients' comes to the fore. But how should we actually define the term 'professional patient'? If we try to consider a 'professional patient' as someone who routinely does this as his work, then this term may become a bit tricky. However, from her point of view, Anne-Marie Boylan sees a role for the professional patients. "As far as I'm concerned as a researcher, I think that a professional patient is someone who is very reflective about his experience and who understands enough about research to be able to contribute almost on the same terms as you, as you are not constantly justifying why you are doing something to him," she explains.

Alexander Silverstein, 27, fits into the abovementioned cohort perfectly. His constant involvement and undying interest in exploring various aspects of his long-term health conditions helped him to obtain a full-time job in healthcare. Alex had type 1 diabetes diagnosed

The first meeting of my disease support group was named 'How to manage your own funeral'

at age 18 months. In addition to this, he has celiac disease associated with an adverse reaction to gluten and Crohn's disease and inflammatory bowel disease, which was diagnosed when he was 25.

At the age of 18, when health management became more and more his own responsibility, Alex was asked by his nurse in hospital, if he wanted to take a week-long education course with other people who have diabetes. "Within that five days I learned more about how to treat my diabetes that I had done in 16 years," he says. "And for me that felt wrong — I didn't understand, why I had not been told how to do this earlier. It's like being given a car, told I have to start driving without having any lessons. It's not safe."

Having received a necessary impetus, Alexander began volunteering for a Diabetes UK charity, and then on one of the international conferences

he met other patients who were using the internet to speak to other communities online about their diabetes. That's how he discovered the thing called the DOC (the diabetes online community). "As soon as I accessed that, I learned something new every day. I learned where the best research was happening, what I should expect from my care... All this kind of thing that I would never have learned in the clinic, ever," he admits.

But Alex didn't stop at this point. His interest in exploring his disease stepped forward towards the International Diabetes Federation — 'United Nations' for diabetes charities that makes up 130 charities from around the world, with Diabetes



Top: Alexander Silverstein at the *i3 Diabetes* conference; right, Anne-Marie Boylan

UK being one of them. Now Alex is a president of IDF Young Leader's programme. His current job in the NHS is related to the patient experience, as he explains, "making sure that patients are using NHS in a way that is suitable and most advantageous for them".

Apart from this, in his consulting projects he is teaching healthcare professionals how to engage with young people and how to use things like social media to reach patients that aren't coming to clinic. "The ability for patients to share experience with other patients in social media is only the first stage," he says. "The second stage is conversations happening between patients and healthcare professionals online. But, ideally, patients need to understand that not all they read on the internet is reliable information — they need to find which has been quality assured by a well-known and respected source."

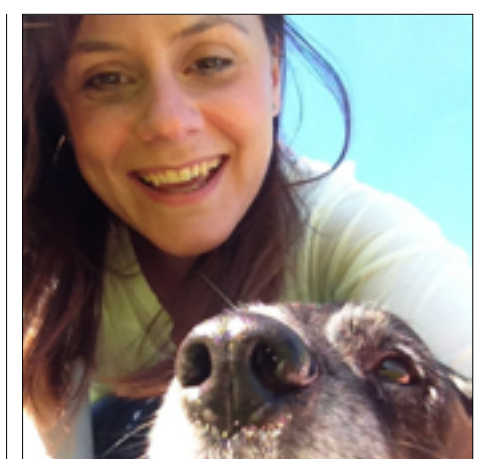
However, Alex is far from completely neglecting the necessity of visiting doctors face-to-face. According to him, he still goes to hospital minimum once a year, even if he's not sick. The point is that the outcome he wants to get out of this visit is now subject to change. "The NHS weirdly in a way is no longer just about 'illness' — it's about 'wellness'," Silverstein says. "It's about treating you when you're well, when you're OK, about giving you the stuff to look after yourself and advice where to go."

The case that pretty much backs up the fact that Internet has hugely stimulated the development of patient empowerment and changed the relationship between patients and doctors is the story of Amanda Greene, 47, from Los Angeles, US. 32 years ago she was diagnosed with lupus disease, which now is widely known due to its frequent mentions in the House M.D. TV series. In fact, it is particularly rare and horrid disease, usually with a bad outcome.

In the latest BMJ Spotlight series of articles on patient centred care, Greene wrote a column about her experience of health management at a time when social media did not exist and the only option of exploring your disease was to attend the so-called 'support group'. The result of this visit was disappointing.

"At her first visit," Tessa Richards, who commissioned the column from Greene, says. "She went expecting that she would get the chance to talk

to other patients about her disease, only to discover that the planned topic for discussion was 'How to manage your own funeral', even down to what clothes you wanted to be buried in. Imagine what that might do to you, especially if you're aged 15?" But fast forward 32 years, and in today in her article Greene writes about how things have changed for her and fellow patients with lupus. The situation has improved considerably, as patients are now sharing their experience on line soon after diagnosis via network communities instead of going along to formal patients support groups. Amanda Green, whose life plans didn't include an option of dying at age 15, is now a health activist, known



in the internet as "Lupus Lady" with more than 8.000 people following her twitter account.

The big problem related to the development of patient self-management and shared decision-making is that it remains virtually unnoticed to the politicians and the policy makers, although they frequently big this problem up and consider it very important.

The same situation applies to the patient involvement in various medical conferences. The BMJ has joined others who are seeking to draw wide attention to the case for including patients in key meetings where medical issues and policies are discussed including those run by the NHS. Tessa Richards is excited about the developments which are pushing patients to be included in medical conferences both as members of planning committees and as speakers as well as in the audience but acknowledges that there are challenges ahead. "Conference organisers may find it hard to know how to involve patients in a meaningful way which promotes mutual understanding and brings benefit to all parties. Conference organisers also have to stick to tight budgets, so they will say: 'We can't do it, or can't invite more than a handful of patients as we don't have a budget for patient delegates.' Health professionals who go to conferences such as doctors and managers are usually funded to attend by the institutions that they work for," Richards explains.

The International Forum on Quality and Safety in Healthcare will take place at ExCel London from 21 to 24 April. According to Richards, it considered as one of the first major international healthcare forums that has put in place a good plan to involve patients. The patients are being paid to attend the whole conference and will be invited to take notes. At the end, there will be a session devoted to them where they will put over their views about the conference and their impressions. Patients' experience and views are expected to help the

organisers understand how to make patient involvement as systematic and meaningful as possible at the next Forum in 2016. "But, if you think about it, you could see this as a small start," Richards argues. "This is a forum, discussing health and safety for patients, and there's 3.000 delegates coming. And we only have six patients on our panel. It's not the number that counts, but their influence and impact and having patients on the steering committee for the 2016 meeting is a great step forward."

Alexander Silverstein, who was presenting at the Diabetes UK Professional Conference that also happened at the ExCel London this March, claims that people now are more interested in conferences if they include a "human element", so, the patients with their stories are the ideal candidates for this. However, he also cites another, more practical reason for such involvement. "The clinical tools we have, the knowledge, the equipment — it's not progressing that fast anymore," he admits. "The research that's being done is happening a lot slower than it was in the past. That's why conference organisers want more and more patients, because there's less to present about advances in technology and treatment therapies."

One of the initiatives that could possibly strengthen the bridge between doctors and patients is called "Patient Opinion". It is a non-for profit social enterprise that provides patients with internet platform where they can leave feedback on any healthcare they've received across the range of services. 2/3 of NHS trusts are currently signed up to this initiative. Every patient or carer can write about their experience, and this query or comment can be responded to directly by a person or persons appointed by the particular Trust. The advantage of this particular system is that allows patients and the public to track the progress of a query, as it has 4 stages, from "Read" to "Change Planned", and, once the question is responded to by the trust representative, they will then have to provide another update with a response.

Another advantage of Patients Opinion is that the feedback it provides is essentially real-time, especially comparing to the standard NHS complaints process that can take months and months and also can be really stressful for the people involved. In this regard, Patient Opinion seems as a much more direct way of connecting with sometimes senior staff.

Ricky Derisz, a Subscriber Support Officer at "Patient Opinion" and a recent journalism graduate thinks that the main problem of establishing this sort of direct contact is the fact that it is difficult for healthcare professional to overcome their fears. "That's quite a common thing that we see that people are fearful having an online public feedback about them," he explains. "And they're also a bit fearful about responding, because they used to sort complaints before, and they dealt with them in a really formal way. I would admit, however, that people who express this fear are in a minority."

Interestingly the main concern expressed by the patients who feedback about their experience has proven that one of the biggest things that patients want is simply to be listened to. And a lot of the time, just having doctors and other health staff listening to their concerns is enough to relieve their anger and frustration. "We've had stories, when the patients left a really frustrated message originally," Derisz says. "The organisation responded in a really open and honest way, and the patient has then actually came back on and left a response saying: 'I'm really pleased that I feel valued, I feel so much better now'. And that is the biggest testament to how we can make a change. That's just fantastic, that's we're all about."