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Marlene Winfield

Left: *Breathing Country*, 2009 © Robert Workman
Below: *Breathing Country*, 2010 © Robert Workman



Breathing Country: A Breath of Fresh Air

By Marlene Winfield

I have been in the public engagement business for a long time. I'm always on the lookout for imaginative ways to air important and tricky issues and get the people whose lives they impact to think about them. When you are working in the area of electronic health records, it is vital that people do think about the choices they make.

When Y Touring asked me to come along to speak to a group of young people and playwrights about the benefits and risks of electronic health records in preparation for writing a play, I was intrigued. A play about electronic health records to tour schools? Reaching a notoriously hard to interest audience (most being very healthy, possessing the invulnerability of youth) would be a real challenge. Could it work?

The first briefing day was in turns taxing and enlightening. Y Touring had assembled a group of 'experts' with a range of opinions. We 'experts' presented to, and were grilled by, a tough audience. Are electronic records useful for research; is

the information in them accurate, is it safe? How much control can patients have over what information goes into them and how it is used? A particularly riveting discussion was whether the Facebook generation had a different notion of privacy than older people. The resounding message from the young people was that they were as concerned about their privacy as anyone else.

One of the most important things to come out of the day was that it was very feasible indeed to get young people interested enough in the topic to debate it. Through imaginative games as well as the discussion, Y Touring engaged the audience to say the least. Passions at times ran high.

But the play's the thing, as they say. Once the playwright was chosen, the next stage for me was to brief him in depth about the issues from my point of view. I come at this as someone developing electronic health records to improve healthcare, empower patients, and enable patient data to be used safely and anonymously for research and health service

management. This was met by a certain healthy scepticism. It was not the last time we were to exchange information during the creative process.

I was impressed by the thoroughness of the process and even more impressed by how so much complex detail was distilled into a very watchable and moving play. I remember one IT journalist's review: "I never expected to go to a play about electronic health records and come out crying".

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Young researcher

What also impressed me was how young people were involved at various stages of the play's development. A partnership with the Royal Academy of Engineering resulted in several schools being supported to do some research with pupils, staff, and parents about their attitudes to health records and privacy. I went to a workshop where the results were presented by the young researchers to the playwright and others. I remember one of the young presenters saying: 'we need to get this right, not only for ourselves, but for those born after us, who will live with these decisions for their entire lives'.

My next involvement was briefing the cast for the discussions that would take place before and after each performance. The cast would answer questions in role: a teenager with a family secret and privacy concerns, her techie boyfriend, her department of health official father, and a doctor doing mental health research. That to me was the most challenging part of my involvement, preparing people coming new to what is a complex topic to answer questions in all the directions the debate might take.

I also had a role in assuring the factual accuracy of a suite of educational materials that schools could use in conjunction with the play.

Opening night was exciting and nerve-racking. Performed for an adult audience of opinion-formers, it did stimulate a lively debate. There was pre- and post-viewing voting, with hand held voting machines and the results instantly visible on a screen. It was a clever way to kick the debate off and inform it as it went along. I've seen the play several times now with two casts and very different audiences, younger and older. It is a tribute to the play that opinions are very forthcoming and always divided. There is, after all, no one right answer in this debate. The

challenge for the NHS is to give people the ability to choose what works for them and enough information to make good individual choices.

As a way of stimulating debate among younger and older people, *Breathing Country* has worked a treat. Its mix of pros and cons, woven into the twists and turns of an engaging plot, does what it set out to do. One or two people in the evaluation thought it was biased in favour of sharing data for research. The fact that the climax is a spectacular data leak would suggest the risks have been given plenty of air time too. The strong feelings the play provokes on both sides in the debate also suggests that. But in the end, the fact that a majority want their data to be used for research, with appropriate control over the process, probably reflects public opinion.

If I could think of improvements, I'd say more time and attention needs to be devoted to getting the actors - or someone else present - up to speed with the very basic information about electronic health records and how they are used in research. That was perhaps not seen as a core enough activity. It is always a tough call about how much factual information to introduce. Too little misses opportunities to have truly informed debate, too much risks hijacking it.

What I particularly welcomed about the 'Theatre of Debate' approach was the power to continually surprise. In the project's Vision Conference, which took place at the Royal Academy of Engineering, a post-viewing workshop with several schools, one group of students was asked to write letters to senior people in the Department of Health addressing issues raised by the play. One of the group's key messages related to the doctor in the play who had been sacked for leaving a memory stick unprotected in her office with the names of young people taking part in a mental health related study. What issue did the group raise? Their letter to the Chief Executive of the NHS urged him not to sack people too hastily, to give them a second chance!

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Given that the 'Theatre of Debate' has showed itself to be effective in this area of policy-making, what does that suggest to me? A few things come immediately to mind. First of all, what other audiences might *Breathing Country* be used with?

An obvious one is medical and nursing students. To get those who have to make it all work thinking in new ways about issues such as privacy versus data sharing, public good versus private interest could only be valuable.

What about other topics that might be amenable to the 'Theatre of Debate' treatment? In health it would be helpful to air some of the issues in passing more control to patients, the power sharing model of health care that the coalition government has described in its recent health white paper. The play and debate could explore what patient control means and what responsibilities go with control, what areas people most want to be in control of, how best to prepare all parties for this power shift, and its impact on patients and clinicians.

Another area that is ripe for exploration is risk. Do we as a public know how to weigh up risks and benefits, for example of vaccinating our children? Are we given - or can we find out - enough unbiased information about the pros and cons of the decisions we make so that we feel able to make informed decisions? Are the media helpful or not? Understanding risk is not just about health though. It is relevant to the crucial decisions we make in many parts of our lives such as financial decisions we make about our future. Are we well enough equipped? Many issues about public good versus private interest could also lend themselves to 'Theatre of Debate' treatment.

Finally, there is fertile ground to be explored about the role of the media in society generally. Are we well served by our current media culture, where the only news worth publicising is bad news? Do journalists owe a duty of care to their audiences when they present information on which people

might base health or financial decisions or other decisions where harm might result from wrong choices?

Y Touring's 'Theatre of Debate' methodology, when supported by good recording and analysis of issues from the debates, can be an effective tool for policy-makers. So let's turn briefly to the results of the evaluation.

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Evaluation of the voting at performances plus focus groups produced some interesting findings. There was a low level of understanding of electronic health records in general, despite some people assuming that their records were already largely electronic. Clearly, before the play, people on the whole (with some notable exceptions) hadn't given the topic much thought. Before seeing the play, young people in particular didn't understand how the information in their health records might be of useful in research.

After seeing the play, both young people and adults had a better understanding of the use of patient data for research. And with that understanding came a desire to have more say over how their data is used.

With better understanding also came more concern about privacy. We should all take steps

From Left to Right:

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to protect our privacy in every aspect of our lives and our health records are no exception. Given the coalition government's intention to put people in control of their records, it is important that as many people as possible are able to make informed decisions about who sees their records and what information they see. This first step towards raising awareness among young people can only help that process. Perhaps *Breathing Country* needs to be aired in prime time on national television and radio with the Dimblebys and younger presenters facilitating the discussion!

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The evaluation also highlighted some basic confusion that needs to be addressed in any future performances, particularly over whether data used for research normally identifies individuals (as in the play) or has much of the identifying information stripped out (as is most often the case). Some of the debate would have been better if basic facts had been given to the audience about how data is processed and used for research and how research is regulated.

I am sharing with my colleagues the results of the evaluation of the *Breathing Country* exercise, which will certainly inform our thinking. I know it is informing the thinking of others like the Wellcome Trust, who provided much of its funding.

I commend 'Theatre of Debate' as a way of

bringing to life topics that people might otherwise feel are too complex, have nothing to do with them, or are outright boring. I also commend the process by which Y Touring put the centrepiece play together, with hands-on involvement at every stage by those whom it set out to reach. They had help in this from a very expert partner, the Royal Academy of Engineering, who also helped with the evaluation.

I thoroughly enjoyed taking part. It took me out of my comfort zone. I learned a lot. I had great fun. I recommend it to others, be you funders, playwrights, or prospective audiences.

Breathing Country,
2009
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