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Dr Martyn Thomas

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



Breathing Country

By Dr Martyn Thomas

It is quite an achievement to hold the attention of school students for more than an hour on the subject of electronic patient records. To be able to do it in a way that also leaves medical research professionals wiping away tears is remarkable. With *Breathing Country*, the unique Y Touring did much more than this.

A decade ago, the Government decided that the NHS should invest in new, national computer systems. At the heart of the National Programme for IT (NPFIT) were electronic patient records (EPRs) to replace the millions of paper records that were too often elsewhere when they were needed. EPRs are obviously a good idea: copies can be held cheaply in two or more places to eliminate the risk of loss in a fire or flood, and they can be stored easily, passed between GPs and hospital clinics instantly, read in several places at once, updated remotely with test results, and quickly made available to a new doctor if you move house or fall ill on holiday. There are other, less obvious benefits too: having the medical records of a whole nation available electronically would be of incalculable value for research into the links between genetic

or environmental factors and disease, drug interactions and side-effects, for example.

On the negative side, EPRs raise serious privacy issues because personal medical information is particularly sensitive and electronic records are far easier to search, copy, leak and lose than paper records. It is inconceivable that anyone could leave ten thousand paper health records on a train. With EPRs you could easily leave a million, if they were on a memory stick or a DVD. There are many losses of personal medical data reported on the Datalossdb website (www.datalossdb.org), many involving thousands of records in a single incident.

Despite the many protections implemented or planned in NPFIT, half of all GPs have said they will opt out themselves and their families from the NPFIT Summary Care Record. Having your medical records made public can be more damaging than having your online bank account hacked, because lost money can be restored whereas privacy, once lost, cannot be recovered. Recent research by computer

scientists has shown that even records that have supposedly been “anonymised” for medical research can be reidentified quite easily by comparing the remaining details with widely-available other data such as electoral registers and social networking sites.

This is the dilemma that the Wellcome Trust asked Y Touring to explore with school students, so that they could make informed decisions about their own records and influence national policy. *Breathing Country* and the Theatre of Debate project was Y Touring's response.

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The Royal Academy of Engineering were partners with Y Touring in the project. The Academy is the UK's leading institution for engineers (just as the Royal Society is for scientists) and has a particular interest in the way that engineering projects affect society. The development of a national EPR system is a major engineering project and the Academy were able to contribute technical expertise and to take the lead in evaluating the impact on the thousands of students and adults who saw the play, discussed the issues and gave their opinions.

I was asked by the Academy if I would help Y Touring to brief the playwrights on the technology and vulnerabilities of large-scale database systems and to provide technical input into some

of the debates. Other experts agreed to talk about medical issues and about privacy.

I'm a 62 year old software engineer and consultant. I'm used to talking to professional and academic conferences, journalists and TV cameras, so the prospect of standing up in front of a few playwrights and others to give a briefing about the engineering and security issues in building large, networked database systems didn't worry me at all. Y Touring had other plans.

At Y Touring's London base, 1KX, I found an audience that mainly comprised teenage students. Then, to get the relationships on an equal footing, we were directed to join in a series of ice-breaking exercises. To an ageing geek, being asked to tell a succession of teenagers “an unusual fact about yourself” is a far more daunting prospect than a Newsnight interview! It works, though, and by the time we started discussing technology and privacy any barriers to questions and discussions had gone. There were several of us “experts” talking about technology, privacy, medical research, EPRs within NPfIT and the benefit to clinicians. The students and playwrights heard all sides of a complex subject and showed by the questions and comments that they understood the issues. I suppose students are used to absorbing information because they do it at school all the time, but I was surprised and impressed by the way that many of the questions went to the heart of the dilemmas that EPRs present in balancing individual and public benefits against (mostly) individual risks of harm.

There were four playwrights in the group and each of them wrote an outline for a play. How can you write an interesting play about EPRs? Yet each of them did so. Ben Musgrave's *Breathing Country*

From Left to Right:
Breathing Country,
2009
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Breathing Country,
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was selected to be developed into a full script and he contacted me a few times to explore points of detail.

I saw the play twice, once at 1KX in front of students and again at a special performance at the Wellcome Trust with an audience that was half young people and half medical researchers and other professionals. Each performance followed the Theatre of Debate format, with the audience voting electronically on a range of questions before the performance and again right at the end, after the play and an extended discussion between audience and cast. At both performances, I saw members of the audience, adults and students, wiping away tears as the abstract tension between privacy and medical benefit became life-changing events just a few feet in front of us.

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Of course, theatre can be used to persuade as well as to inform, and the question of balance was important. The Royal Academy of Engineering has evaluated the impact of *Breathing Country* through questionnaires and a two-day workshop with teachers and their students. The results are encouraging. The young people have no difficulty in seeing the different and conflicting issues about

EPRs and forming mature and nuanced opinions about whom they are willing to allow to see their medical records and what use should be made of them for research. The evaluation will be published later this year, with an analysis of the underlying data.

I found my involvement with Y Touring enjoyable and educational. Nigel Townsend and his team are extraordinary and creative professionals, able to create magic from the most unpromising material. It was a privilege to work with them.

From left to right:

The Projectionist,
2008
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Breathing Country,
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