



The Royal Academy
of Engineering

Privacy and prejudice:

Young people's views on the development
and use of Electronic Patient Records





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The cartoons in this report are credited to Caricatures by Luke Warm.





Breathing Country: *The play*

1. Executive summary

Breathing Country was a nationwide public engagement programme about Electronic Patient Records (EPRs) and their use in medical research. A suite of activities were delivered as part of the programme, including the development and UK tour of a play and post-performance debate about EPRs, the provision of online supporting materials and a public attitudes research project. The play's audiences were predominately school pupils (typically 14 to 18 years old), but the tour also included some special adult-only performances.

This report presents the findings of the public attitudes research project that was embedded within the wider engagement programme to explore young people's views on the development of an EPR system in the UK and its use in medical research. Some information was also collected on adult views. The research was conducted using electronic polling, focus groups, a two-day deliberative conference and a community researchers activity.

The aim of the research project was to gather the views and disseminate the findings to the relevant stakeholders and policy makers to give young people a voice regarding the development of this potentially powerful, yet controversial, tool for improving health services and medical research – the EPR system.

Growing up in an era of the *Big Brother* television series and the expansion of social networking sites such as *Facebook* does not mean that young people do not care about privacy or what happens to their personal information. Privacy is indeed extremely important to young people.



Deliberative conference cartoon: privacy and young people

The findings show that there was a spread of opinions, attitudes and views regarding EPRs. So although the majority of young people feel one way or the other about a particular issue, in most cases there was a significant minority that strongly opposed the majority view. This was demonstrated in the electronic-polling results, the community researchers' discussions, the focus groups and the deliberative conference. This should be considered when reading this report and its conclusions.

Young people's views on sharing personal information and EPRs is summarised below.

The findings

If personal medical information is to be stored electronically and be more widely available, young people expressed a strong need to be in control of their own record (at least from the age of 14). The level of (perceived) control affected the level of acceptability. For example, *Facebook* was not deemed to be an invasion of privacy because the young people felt in control of what information was posted and who could get access to that information. For young people to be in control, or at least have the option to be so, requires a system that will allow them to:

- have access to own their record;
- have a say as to who else gets access to their record and for what purposes;
- be assured of privacy from certain groups (for example, parents and potential employers);
- make informed decisions by being kept fully up to date about EPR system developments, data security and safety, who gets access and for what purposes in addition to what the implications might be.

Young people have significant concerns regarding EPRs. These arise due to the perceived inherent weaknesses of an EPR system, including both the robustness (or not) of the technology and the potential errors that will be made by the users. Young people noticed that this could lead to incorrect data within a patient's record, data loss (massive or individual) or the data reaching the 'wrong hands'. The consequences were deemed to be very serious and include the improper treatment of patients, fundamental breaches in privacy, the misuse and inappropriate exploitation of the data, prejudice and discrimination.

The 'wrong hands' were those organisations or individuals that young people felt had 'no right' to the data, irrespective of whether they had achieved 'official' access (ie by the EPR regulators) or by using improper methods such as hacking or bribing the system users. The 'wrong hands' included commercial companies, marketing and advertising agencies, insurance companies, employers or potential employers, and the media. Young people frequently mentioned that parents should not automatically have access to their records, while adults also considered the Government to be the 'wrong hands'.

Apart from EPR use in helping to improve health service administration, young people were more supportive of giving access to medical researchers over any other groups in order to develop better medicines, improve health and save lives. However, some reservations, concerns and outright objections were raised over access being given to 'private research' or pharmaceutical companies. The majority of young people were not fundamentally against the idea of utilising anonymous data from EPRs for medical research. However, this is inextricably linked with how secure and safe the EPR system will be, who will have control and who else will be allowed access.

Conclusions, questions and recommendations

A number of questions emerged and recommendations made based on the findings of this report. These need to be addressed by the National Health Service (NHS), the commissioners and regulators of EPRs, the engineers and developers that will design and build the records systems and databases, and the users and medical researchers that will have access to the data if the system is to be one that has wide support amongst the younger generation. Furthermore, the responses to these questions and recommendations need to be communicated to young people, so that they can make an informed choice about their records.

Analysis shows that young people’s views on EPRs are grounded on **one core question**, which in turn is dependent on **seven central questions** and underpinned by a **key risk** and an **underlying concern**:

Core Question: How private will electronic patient records be?								
Central Questions								
Key risk: The data will get into the ‘wrong hands’	How secure is the EPR system and how safe is the data?	How much say and control will young people have over their records?	Who will be given access to the data and why?	How accurate will records be?	How will you engage young people and keep them up to date on developments?	Who will develop, control, maintain and regulate the database?	How will you protect young people from suffering from prejudice and discrimination?	Underlying concern: The consequences of young people’s health and medical information reaching the ‘wrong hands’ could be very detrimental to them.

More detailed **recommendations** are provided in section 6.3, but in summary:

Control: Provide as many individuals as possible with as much control as possible over their own record.

Access: Deep consideration must be given to young people’s opinions on who should be allowed access to the data and for what purposes; what the consequences will be if records or data reaches the ‘wrong hands’; and how young people will be protected from any prejudice and discrimination that could arise.

Security: Ensure that all EPR databases and systems are developed to be as secure and robust as technically possible alongside a realistic understanding of how users will interact with the system, and what the weak points and vulnerabilities might be.

Communications: Regularly communicate, engage and inform young people on the development of EPRs.

2. Introduction

Background and context

Technology has enabled an exponential rise in our ability to gather, store and share large quantities of data. However, as noted in The Royal Academy of Engineering's report, *Dilemmas of Privacy and Surveillance* (2007)¹, the balance between the benefits and drawbacks of such engineering and IT advances must be carefully thought through.

Electronic Patient Record (EPR) systems store health and medical information of individuals on national or local electronic databases. They are being introduced in developed countries around the world and their potential benefits include better support for patient care and health service administration alongside potential secondary uses of the data, for example, by medical researchers for epidemiological studies.

The use of EPRs for medical research is a multi-faceted and complex issue. The potential benefits are evident as research using the data within EPRs can be used to identify disease causes, for the control of epidemics and to monitor drug effectiveness. However, there are various issues related to the use of such data for both society and the individual, including civil liberties, privacy, consent and who gets access to the data.

In 1998 the National Health Service (NHS) Executive set a target for all NHS trusts to have EPRs in place by 2005². In 2002 the UK's Department of Health published the national strategic programme for the NHS which launched the National Programme for Information Technology (NPfIT)³. One of the main aims was to introduce the NHS Care Records Service which would create a national Summary Care Record (SCR), containing basic information, and local Detailed Care Records (DCRs), containing more comprehensive clinical information. The Secondary Uses Service (SUS) would provide access to data for other purposes, such as medical research.

In 2007 the Health Committee published a report⁴ on the progress of the EPRs which highlighted several issues including: clarification over what information should be contained in the SCR; that the system should require patient consent; the importance of security and the balance between privacy and the opportunities for research. Recommendations were made and, following the report, trials of the SCR were started in GP practices around the country.

Public engagement

Several organisations claimed that too little was done by the Government to gauge the views and attitudes of the public towards the EPR system before it was initiated. Strong objections were demonstrated by campaigns such as the *The Big Opt Out*.

1. *Dilemmas of Privacy and Surveillance – Challenges of Technological Change*. The Royal Academy of Engineering, 2007.

2. *Information for health. An information strategy for the modern NHS 1998-2005*. Leeds: NHS Executive, 1998.

3. *Delivering 21st century IT support for the NHS. National strategic programme*. London: Department of Health, 2002.

4. *The Electronic Patient Record. Sixth report of session 2006 – 2007*. House of Commons Health Committee, 2007.

The Medical Research Council conducted a general public consultation regarding the use of health information in medical research (2007)⁵ and the NHS launched a public consultation⁶ for adults on additional uses of patient data in 2008.

In 2008 the Wellcome Trust along with three of the Research Councils funded a number of projects to undertake health and medical research utilising electronic patient data in addition to supporting public engagement projects that aimed to raise wider awareness and debate on the topic. As part of this funding stream, the Y Touring Theatre Company, in partnership with The Royal Academy of Engineering, were funded to produce a nationwide public engagement programme on EPRs for young people.

A suite of activities was delivered as part of this public engagement programme, including the development and UK tour of a play (*Breathing Country*) and debate about EPRs, online supporting materials and an embedded public attitudes research project. The play's audiences were predominately school pupils (typically 14 to 18 years old), but the tour also included some special adult-only performances.

Recent updates

Independent evaluations of the SCR were carried out by University College London in 2010⁷. Evidence was found to suggest that the SCR had improved the quality of consultations but the benefits were overall judged to be subtle, hard to articulate and difficult to isolate from other aspects. The report highlighted that the debate surrounding what information should be recorded had not yet been resolved and that a reasonable and realistic expectation of the inputs and outputs produced needs to be defined.

In July 2010 the new Conservative-Liberal Democrat coalition presented the white paper *Liberating the NHS*⁸ which set out the long term vision for the future of the NHS. No direct reference was made to the NPFIT but it did promise an 'information revolution' where patients would be given full control of their own health records. The paper recognised the importance of medical and scientific research and stated that anonymised data would be made available to university and research sectors. The details of the new proposals are expected to be set out in the Health Bill, to be introduced in Parliament in Autumn 2010, and in the information strategy, to be published before the end of the same year.

Aims of the report

This report presents the findings from a public attitudes research project, in which young people were encouraged to explore the topic of EPRs and their use in medical research.

This report is being made available to raise awareness of young people's views, questions, concerns, hopes and recommendations in order to influence the decisions and plans made for the future development of EPR systems.

5. *The Use of Personal Health Information in Medical Research*. Medical Research Council/Ipsos MORI, 2007.

6. *Consultation on public, patients, and other interested parties views on additional uses of patient data*. NHS Connecting for Health/ Department of Health, 2008.

7. Greenhalgh, T. et al. *The devil's in the detail. Final report of the independent evaluation of the Summary Care Record and HealthSpace programmes*. University College London, 2010.

8. *Equity and excellence: liberating the NHS*. Secretary of State for Health, 2010.

3. Research questions

The questions which guided this public attitudes research project are as follows:

What are young people's pre-existing knowledge of and attitudes towards EPRs and the use of personal information for medical research?

What are the aspirations and concerns behind these attitudes to EPRs?

*Which groups do audiences feel are responsible for developments in this area?
Medical researchers? Healthcare professionals? Engineers? Government?
Citizens?*

Once informed, what are the perceived risks, aspirations and moral implications of developing and using such EPR systems?

4. Methodology

Three methods were used to gather EPR awareness, views and attitudes of predominately teenage audiences (typically 14 to 18 years old), although some adults were also involved:

- community researchers' projects
- electronic-polling and focus groups with the *Breathing Country* audiences
- a two day deliberative conference.

Y-Touring's play, *Breathing Country*, was central to this research project and was used as an engaging and creative way to generate debate and stimulate discussion with young people.

The *Breathing Country* performance was toured twice during the 2009/10 academic year. In the autumn term 2009 the pilot toured London, and the main tour took place across the UK in the spring term of 2010. Audiences were predominately school pupils and their teachers, in addition to a few special adult-only performances. Each one hour performance was followed by a 30 to 45 minute facilitated debate between the actors (who stay in character) and the audience.

4.1 About the play - Breathing Country

Breathing Country - a synopsis of the play

Award winning playwright, Ben Musgrave was commissioned in early 2009 to write the play, *Breathing Country*, to explore the issues surrounding the use of EPRs in medical research. The drama and debate aimed to raise awareness about the topic and connect the arguments regarding the pros and cons of EPRs to emotional human issues. There were four main characters:

Simon, 18, lives his life online. Every detail, every thought, every action is documented and published on *Facebook*.

Lizzie, his troubled 17 yr old girlfriend is grappling to deal with the death of her mother, feels her privacy is threatened by the NHS asking her to take part in a clinical trial for her panic attacks. She feels she is crashing...

Lizzie's father, Richard, Communications Director for the Department of Health, is too wrapped up in his struggle to promote the new EPR system to deal with his daughter's issues.

Meanwhile Janet, an NHS clinical psychiatrist is desperate to advance research by using the valuable data available in EPRs to find people with mental health issues. But with so much to do and so little time how can she be expected to remember all these passwords?

Breathing Country throws open questions about privacy and security and asks "are we prepared to sacrifice our privacy for the greater good?"

A full synopsis is available from: www.ytouring.org.uk/productions/Trustme/synopsis.html



Breathing Country: Simon and Lizzie

The evaluation findings revealed that *Breathing Country* was very well-received by the majority of young people and adults (an evaluation report is available from www.raeng.org.uk/eprviews). Many felt that the play presented a balanced view of the issues, although some adults and older teenagers felt that the play and debate showed some evidence of bias in favour of the EPR system. Most importantly, the evaluation demonstrated that the play and debate were able to stimulate a fairly deep consideration of the issues and development of informed attitudes in its audiences. There was evidence that opinions changed in some individuals as a result of observing the play, but in many cases both the young people and adults noted that their attitudes towards EPRs had developed rather than changed.

It definitely made my opinions stronger but I don't think it necessarily like swayed my decision ... (Focus group participant, age group 14 to 15 years)

Well I was like opposed to it from the start because I thought it's my personal information but even seeing the play it just confirms my opinions (Focus group participant, age group 18 to 19 years)

Before I were undecided about it, but after watching it I'd opt in for it. (Focus group participant, age group 14 to 15 years)

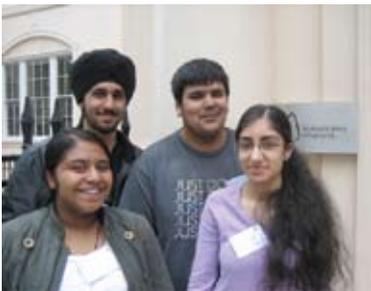
I don't think it changed my views at all, but I'm with.... I think everyone else – in theory I agree but on a personal level I have some reservations. (Adult focus group)

4.2 Community researchers

Prior to commissioning the play, four 'community researcher' groups were recruited to design, deliver and analyse their own public attitudes research projects on the development and use of EPRs, within their own communities. The community researchers consisted of three groups from different schools in Greater London (13 to 16 years old, each with three to five students and teacher support) and one group of five adult patient representatives.

The first part of the process involved the community researchers attending an Introductory Workshop (November 2008) where they listened to presentations from five different experts from the *Breathing Country* project's advisory group, who each had different views on the benefits, drawbacks and risks of EPRs.

The community researchers then attended a Research Skills Workshop (January 2009) to learn about conducting qualitative and quantitative research and analysis, which was followed up by ongoing support as they developed and delivered their projects.



Community researchers: school groups

All three of the school groups and one of the patient representatives completed and submitted research reports. A summary of each of the projects is provided below:

Community Researchers	Research focus	Methodology and Respondents
Camden Girls' School	Who gets access; opt-in/out; usage and consent.	Electronic survey (91 teachers and students)
Robert Clack School	The impact of EPRs on patient openness and honesty with their doctor.	Interviews and case studies (30 teachers, students and family members)
Guru Nanak Sikh Secondary School	Opt-in/out; who gets access and usage.	Electronic survey (44 respondents over a wide age range)
Adult patient-representative	Who gets access; opt-in/out; usage; consent and security.	Electronic survey (209, majority of which were adults, 55yr+)

The three school community researcher groups attended a Presentation Workshop (April 2009) to present their results to the project organisers, the *Breathing Country* playwright and one of the projects advisory group members from the NHS *Connecting for Health* programme. At this event, structured group conversations were held to explore the informed views of the student community researchers on EPRs.

Further information about this community researchers' project is available; www.raeng.org.uk/eprviews.

4.3 Electronic polling and focus groups

Electronic polling (e-polling) was taken with the *Breathing Country* audiences using voting handsets (Quizdom) by gathering the responses on a number of statements before each performance and following the performance as part of the debate.

The graphs (Figures 1 – 7) shown in this report are from the e-polling data collected from 30 performances at 21 schools during the main tour in Spring 2010.

The sample included approximately 2900 students and where possible, the audiences were asked to vote on seven attitudinal statements before and after the play. Sometimes the questions after the play were cut short due to timing, but generally a good response rate was achieved.

In addition six focus groups (five school groups of different age groups; and one adult focus group) were conducted with a selection of the pilot and main tour play's audiences to complement the quantitative data collected through the electronic-polling, and to discuss the issues in more depth.

4.4 Deliberative conference

The two-day deliberative conference, entitled *Mind your Own Business*, took place on 5 and 6 March 2010 in London and involved 31 15 to 17 year-olds from 10 schools and colleges (from different parts of England) in discussions about privacy, electronic information and EPRs. The conference provided this group of young people with more time to think about the topic, to become very informed about the issues involved and to develop more thought-out views. The conference was based on a *Vision Conference* format⁹.

The conference was split into two phases:

The first part of the conference was the 'divergent phase', whereby the participants took part in plenary and workgroup activities and were exposed to a number of stimulus materials and information resources in order to open up debate and discussion on a wide range of issues and concerns on privacy, record keeping and EPRs. A performance of *Breathing Country* was included as part of the programme in addition to four expert presentations, which were followed by 'Q and A' sessions.

The latter part of the conference was the 'convergent phase' where the students started to focus on the issues, topics and themes that were of most importance to them and to explore each of the selected topics in more depth. At the end of the second day, the conference participants worked in groups to document their aspirations and concerns for the future of EPRs and their use in medical research by each producing a poster together with a short oral presentation.

9. Vidal, R. V. *The Vision Conference: Facilitating Creative Processes, Systemic Practice And Action Research*, Vol. 17; Number 5, 385-405, 2004.



Deliberative conference poster: recommendations

More information about the conference can be found at www.raeng.org.uk/eprviews.

4.5 Collecting data, reporting and evaluation

The data was collected using a variety of methodologies: voting handsets (Quizdom), observations, audio-recording, video-recording in addition to written notes on flipcharts and post-it notes. A conference cartoonist was also present at the deliberative conference to capture a flavour of the young people's discussions.

As well as gathering young people views on EPRs, the research also included an evaluation to explore the impact of the play and gather participants' views on the play and debate, the community researchers' project and the deliberative conference. A separate evaluation report is available www.raeng.org.uk/eprviews.

5. Research findings – views of young people

The findings below are predominately those of the views of young people, 14 to 18 years old. A small percentage of adults were involved in the research project (< 10%), however many of the issues, hopes and concerns raised by adults resonated with those of the young people described below. There were a small number of points made by adults that were not brought up by the young people during their discussions and these views are pointed out below.

5.1 Sharing personal information

During the qualitative research (ie the focus groups, community researchers' project and the deliberative conference) many of the young people demonstrated their views about privacy through other instances where they share personal information, such as social networking, and in particular drew comparisons with *Facebook*.

While some information is definitely considered to be private, young people do see benefits in sharing certain personal data with particular groups. For example, sharing photos and music tastes on *Facebook* was seen as a way of expressing identity and for social benefit, such as providing conversation topics and finding friends with common interests. Furthermore, both young people and adults did not perceive *Facebook* to be an invasion of privacy because individuals had made a choice to be part of it, were in control of the information that was posted onto their page and who gets access to that information.

I used to be like having it [ie Facebook] all where people can see everything but that makes you more aware when weird people started messaging me and I didn't like it and so I had to put it on private. (Focus group participant, age group 15 to 16 years)

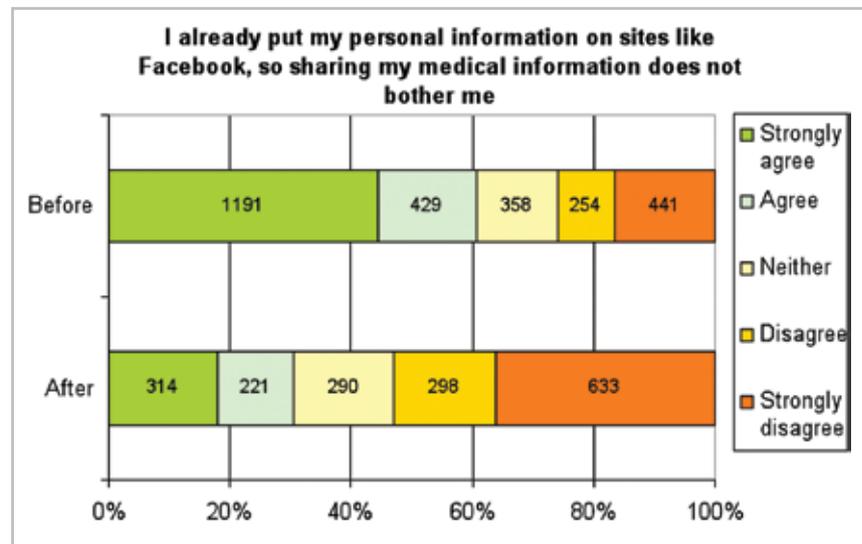
There are certain measures that I take on Facebook for example, it's not everything I want someone to know about me on Facebook, not everyone can see my pictures because I have control of that and I think with this as well you should be able to have control over exactly what people are able to see. (Adult focus group)

Other examples noted by the young people of where sharing data could bring benefits included EPRs, which could save your life, and school records which demonstrate you have good grades for university and job applications.

After becoming a bit more informed about the risks and security issues regarding personal electronic information, young people seemed far less comfortable with the idea that sharing information on social networking sites and sharing medical information were linked (Figure 1). The differences between *Facebook* and EPRs were also raised in some of the focus groups.

When you're using it you don't think about that really whereas if it's like your medical details its different because you know it's more to do with you whereas Facebook's just a bit of fun. (Focus group participant, age group 15 to 16 years)

Figure 1. Electronic-polling results: Facebook and medical records



Whether young people’s personal information should be shared or kept private was dependent upon the type of information, who the information would be shared with and whether there would be personal benefits to sharing. There was also an inherent feeling of unease with sharing personal data because of the consequences that might arise (for example, that might result in prejudice, further details in section 5.9) and a strong feeling for the need to have access to one’s own records and control who else gets access. Just because something is private, does not mean young people are not willing to share the information with particular groups, provided the information is not disseminated more widely.



Deliberative conference flipchart: exploring information sharing

5.2 Awareness and understanding

Findings from the focus groups show that both young people and adults had very low levels of awareness about EPRs prior to the seeing the performance and consequently did not have existing views and attitudes to EPRs and their potential use for medical research. The exception was one adult who had tried (with difficulty) to obtain a copy of her paper record from her GP and another who had a professional interest through her work for a charity.

*...you didn't know anything about your medical records and that was it....
(Focus group participant, age group 14 to 15 years)*

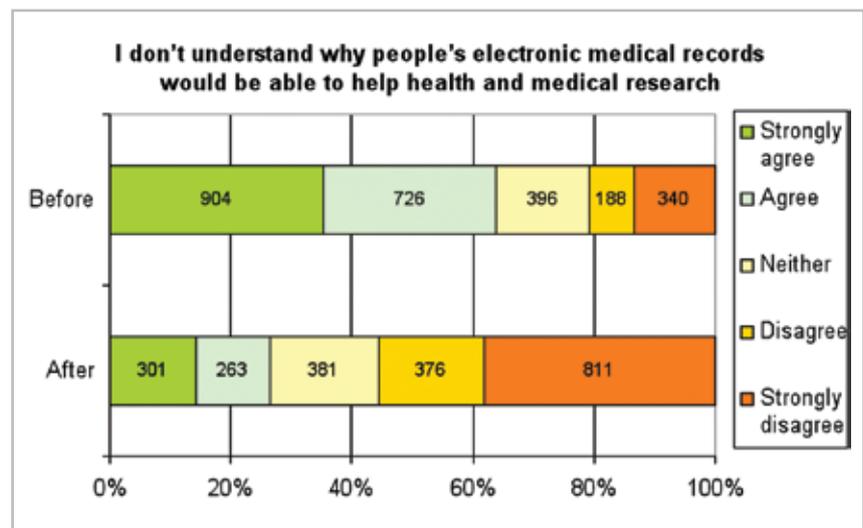
Indeed, several of the young people and adults said they had assumed that patient records were already kept electronically and that an EPR-like system was already in place:

I've always thought that records were on computers (Focus group participant, age group 14 to 15 years)

...I was....well I was assuming that it was online (Adult focus group)

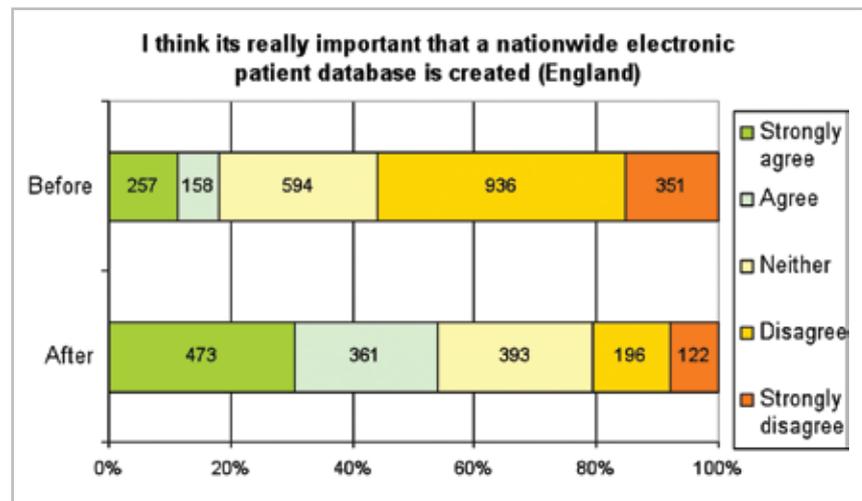
Furthermore, understanding how EPRs could be used for health and medical research is not immediately apparent to all young people, until they become more informed about the issue. Over 60% of young people agreed or strongly agreed that they did not understand how EPRs could be beneficial to health and medical research prior to the watching the *Breathing Country* performance (Figure 2).

Figure 2. Electronic-polling results: understanding EPRs and medical research



Improved understanding of the potential use of EPRs and databases after the play (Figure 2) lead to a much larger proportion of young people agreeing that it was important to create a nationwide electronic patient database (Figure 3).

Figure 3. Electronic-polling results: creating a nationwide EPR database



5.3 Security - technical vulnerability



Deliberative conference poster: EPR security was frequently mentioned

Young people’s opinions are divided over whether data kept electronically is safer than paper records (Figure 4) and have very evident concerns about the security of EPRs.

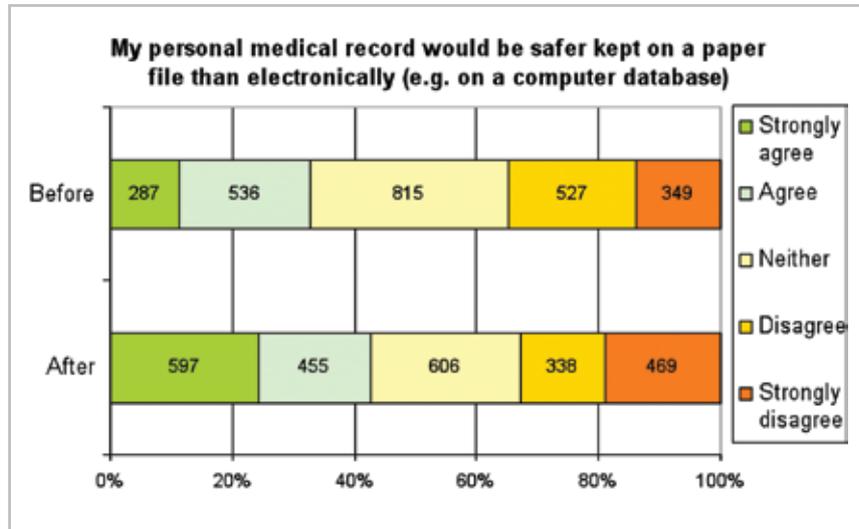
With the EPR – will the records themselves be any safer? (Deliberative conference participant, age group 15 to 17 years)

Should the paper records just be better looked after? (Deliberative conference participant, age group 15 to 17 years)

This includes the inherent technical weaknesses within the software and vulnerability to ‘attacks’ from external sources such as hackers and viruses.

With EPRs what are the chances of a patient file being lost or leaked? (Deliberative conference participant, age group 15 to 17 years)

Figure 4. Electronic-polling results: safety of paper versus electronic records



Examples of inherent technical weaknesses that were discussed included: errors during data transfer; system crash resulting in massive or individual record loss in addition to records becoming mixed up. The young people noted that the consequences would be serious, including patients being unable to be treated due to missing data; the mistreating of patients due to incorrect information; and the permanent loss of patient data that cannot be recovered, because no paper back-ups exist.



Deliberative conference cartoon: EPRs and patient data availability

*When the electronic system is in place do you have a back-up in case it fails?
(Deliberative conference participant, age group 15 to 17 years)*

Hackers were frequently mentioned as a highly significant risk and area of concern due to the inevitable loss of privacy that would result, in addition to the data being misused.

*You shouldn't put your details on the computer cause it is true people can hack into it yeah... they can take... they can like... they can just read your details ...
(Focus group participant, age group 14 to 15 years)*

What are you using to defend the database to people getting in? (Deliberative conference participant, age group 15 to 17 years)

Is it possible to tell if something is being hacked? And how long would it take to hack? (Deliberative conference participant, age group 15 to 17 years)

Adults also had additional concerns regarding the perceived Government and the civil service's poor track record in large IT projects.

In principle, I think that access to patient records for medical research is a good idea but I worry about patient confidentiality and security. In this connection I feel that the Civil Service has an extremely poor reputation... (Adult respondent to the patient-representative community researcher survey)

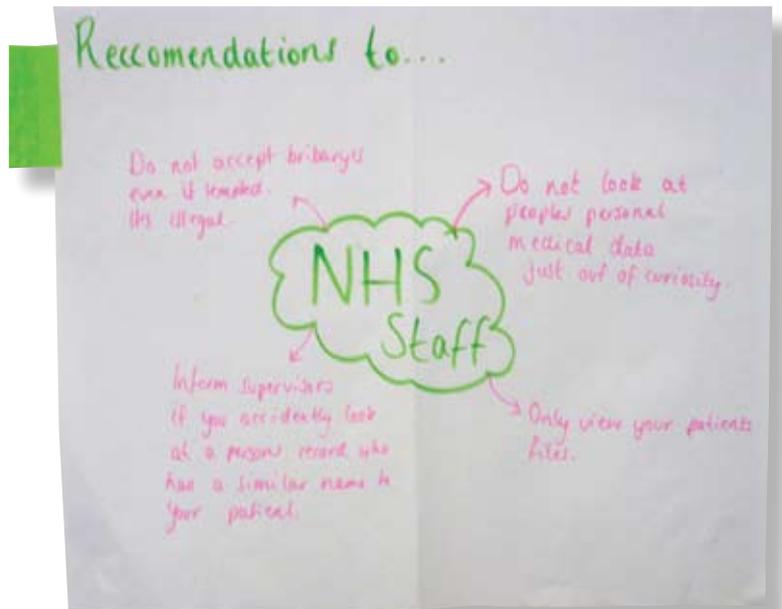
What bothers me is the fact that it's the Government doing it because they've got an appalling track record of projects this big. (Adult Focus Group)

5.4 Security - human fallibility

The young people noted that the IT infrastructure and software together with the users create the 'EPR system'. Therefore, the security and safety of the data is also subject to human fallibility and the IT abilities and understanding of the users. As such, concerns were raised that errors will occur due to a lack of IT skills and incorrect data entry. In addition young people were concerned over users misplacing or losing devices with EPR data on such as memory sticks and purposefully or inadvertently sharing PIN numbers and passwords, which would not only result in a loss of privacy but increase the opportunities for others to exploit the data.

What procedures are in place to make sure records aren't just altered maliciously or by mistake? (Deliberative conference participant, age group 15 to 17 years)

Furthermore, young people raised the point that humans are also vulnerable to prying (for example on colleagues or famous people) and bribery, and could therefore be persuaded to release data into the 'wrong hands' (see section 5.8 for more details) that could then be exploited by the likes of the media or commercial companies.



Deliberative conference poster: NHS staff and patient privacy

One other factor discussed was in the case of the public accessing their own patient records, and the need to be aware that the interface will need to be intuitive and user-friendly and some groups will require training and support in order to access their records online.

Being in control was also linked to being kept well-informed and up to date with EPR developments, which is further discussed in section 5.10.

The age at which you are in control of your own record was also discussed, including at what age young people should be able to choose whether to opt-in or opt-out of the database, have access to their own record and whether to allow consent to its use by medical researchers. All the young people that participated in the focus groups and the deliberative conference felt that they were old enough to make their own decisions, rather than having their parents decide for them. They felt that parents should obviously decide for younger children, but could not agree on an age limit for this.

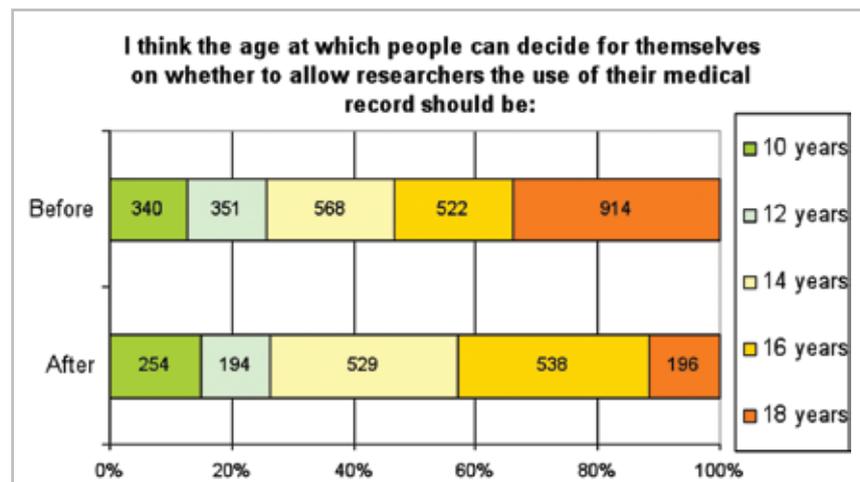
Maybe if you're like under a certain age of like 11 or 12 or something like that because you wouldn't understand like what's going on... like if you're like... its hard to set the age limit because now in this time of age like I think that I should be allowed to make my own decision... (Focus group participant, age group 14 to 15 years)

Some of the focus group participants commented that by becoming more informed about the issue (ie by seeing the play and taking part in the debate) encouraged them to take more responsibility.

Like before I would think I want my parents to look after all that stuff but now I've gone more in depth in to it I think I don't really want them to. (Focus group participant, age group 15 to 16 years)

Findings from the electronic-polling demonstrate that after seeing the play, young people favour the ages 14 or 16 years old as the most appropriate for giving consent to medical research, compared to an older average age before the play.

Figure 5. Electronic-polling results: the age of control and consent



One of the community researcher projects that surveyed both staff and students revealed that the vast majority of staff felt the age of control should be 18, while students provided a range of responses, mostly between 12 and 18, indicating that adults are more likely to favour an older age of control.

The young people that took part in the community researcher projects and focus groups also discussed what would happen to people's records when they die, and whether consent would have to be gained before death or whether next-of-kin would have the decision-making powers.

The adults and the older students that took part in the focus groups also felt that there should be the potential to change your mind over time, as people's opinions are likely to change based on factors such as age or whether they are affected by a serious disease.

They need to ask at different stages in your life as well because for say children under 16 right, when I was 17 I would have made a different choice than I'd be making now and you know, like the Facebook thing for example. So you may not have known at 17 that's really not what you want now. (Adult focus group)

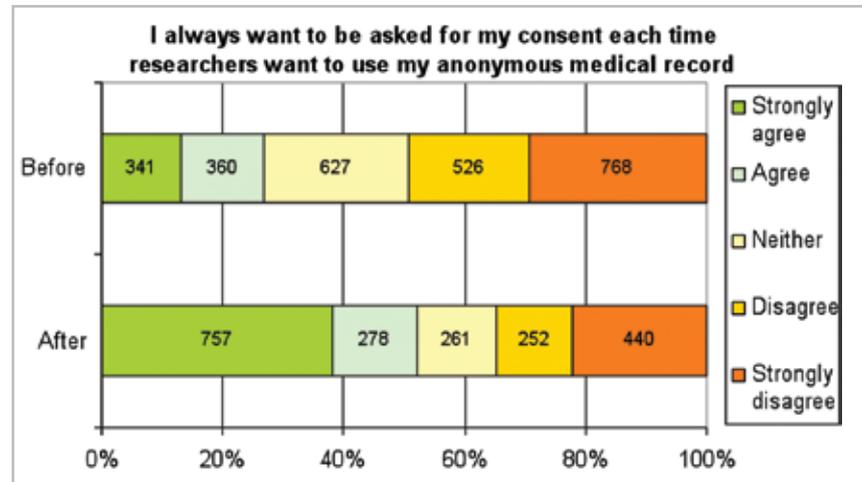
Yeah and then ask again when you do have cancer and then you might change your mind. (Adult focus group)

5.6 Choices and consent

Findings from the community researcher groups and the focus groups show that young people have divided opinions on whether the EPR system should be opt-in or opt-out, and no final majority views or consensus emerged.

Regarding consent to use data for medical research, a strong finding from the electronic polling data was that while the play and debate engendered a greater level of support for EPRs, more young people wanted to be asked for consent every time their information was used by medical researchers (Figure 6). However, the play looked at a very particular case whereby a teenager was contacted to take part in a clinical trial (ie and not using large anonymous datasets for epidemiological research), so while this result is interesting, it should be interpreted with some caution.

Figure 6. Electronic-polling results: consent and medical research



The issue of consent for data from EPRs to be used for medical research was further explored in the focus groups:

I don't think that they [ie the public] should actually have a choice to be honest but at the end of the day what you're doing is going to save lives. It's going to improve research. It matters more than your identity and why... but they'd have to make sure that it can't get stolen. (Focus group participant, age group 15 to 16 years)

It really depends like what the information's going towards helping. Because if it's something like the person believes in then they're going to give the consent, but if it's something they might not necessarily agree with then they might not want to give consent for it. (Focus group participant, age group 14 to 15 years)

5.7 NHS and medical research

Young people's discussions about the pros and cons of EPRs were strongly influenced by which groups would be able to get access, and who would be denied. The need for control and privacy from specific groups is reflected in the repeated significant reservations and concerns that the data would be allowed to get into the 'wrong hands' (see section 5.8).

There was support for the set-up of the EPR system and for access to be given to the NHS for patient care and administrative purposes. The benefits of such a system included convenience, increased efficiency and reduced bureaucracy in surgeries and hospitals, better care and more effective treatments in the case of emergencies across the country.

Yeah I probably think positives outweigh it because it's a lot quicker so doctors can access the information when they need it rather than searching for files. (Focus group participant, age group 14 to 15 years).

The only thing, like in the play like they didn't mention about how if say you got rushed into hospital and you were unconscious and no-one knew your medical records, that would really be beneficial. (Focus group participant, age group 18 to 19 years)



Deliberative conference poster: EPRs and research

Furthermore, results from the community researchers' projects indicate that many of their respondents had fairly high levels of trust in the NHS, and therefore would prefer the data to be held, maintained and controlled by NHS (as opposed to, for example, the Government). However, even though the NHS might be trusted, there was scepticism evident in some of the adults surveyed that the NHS had the IT capability to effectively manage the EPR system.

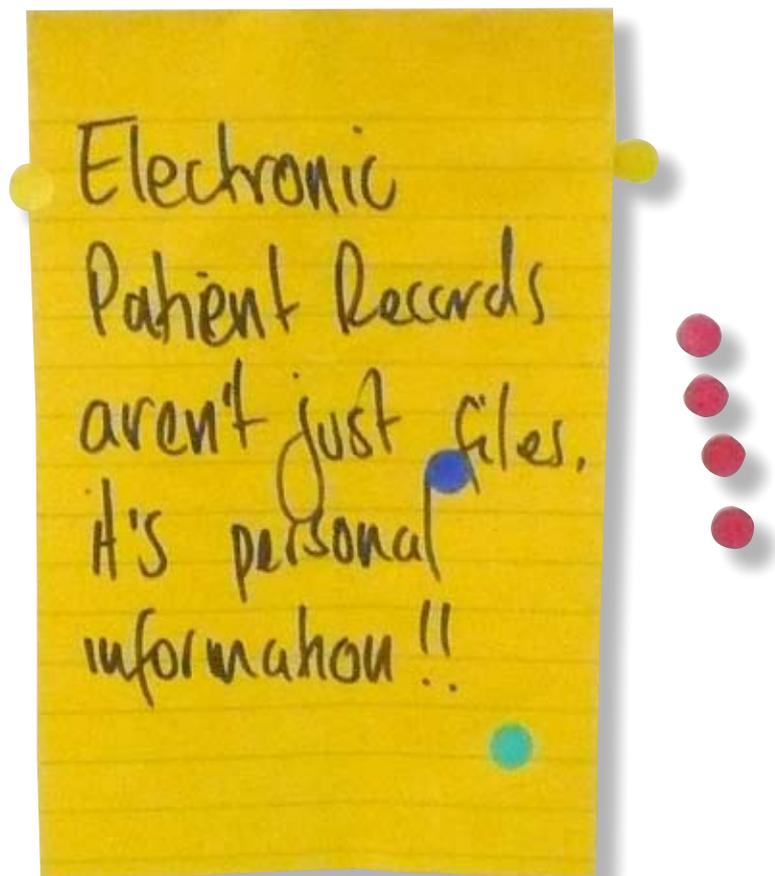
Medical records are the intimate details of patients and should not be widely available. Data is notoriously insecure within the NHS – if it is sent to universities and private companies there is no control. Private companies should not have access to publicly held, sensitive data. (Adult respondent to the patient-representative community-researcher survey)

A majority of young people support, in principle, the use of anonymous data to be used for medical research, albeit with significant conditions in place relating to the EPR data regarding security, safety, consent, access and control.

The benefits are huge to be fair in comparison to the flaws because it's... faster treatment, more research, the faster the research the faster we're going to advance the technology and more lives are going to be saved. (Focus group participant, age group 14 to 15 years)

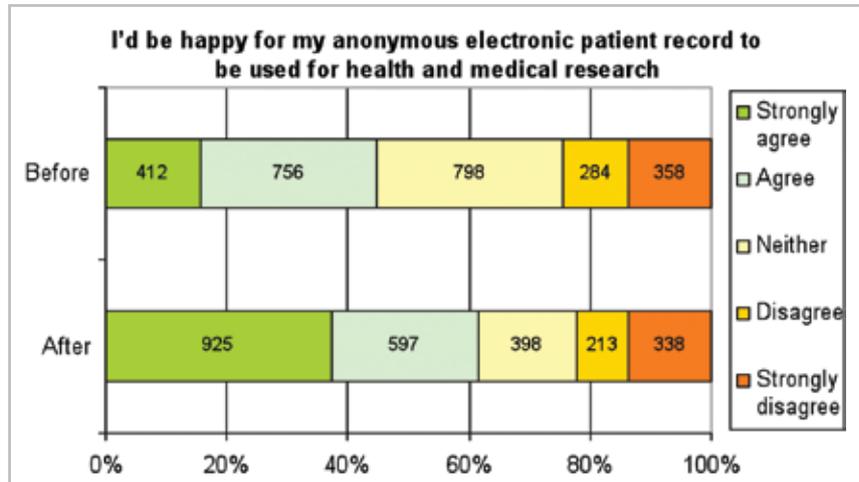
The findings from the electronic polling indicate that one impact from the performance was to engender a greater level of support for the use of anonymous EPRs in medical research among students (Figure 7). However, becoming more informed about the issue also appeared to influence a larger proportion that wanted to be asked consent each time their data is used for medical research, even if the data was anonymous (Figure 6). However, as mentioned previously (section 5.6), this finding should be treated with some caution.

The deliberative conference participants also raised the issue that medical researchers should treat information within the records with the utmost respect, and not just a dataset:



Deliberative conference 'post-it' note: EPRs are people's personal information

Figure 7. Electronic-polling results: EPRs and medical research



The importance of anonymisation was re-enforced in the focus groups and deliberative discussions:

They shouldn't send their personal information they should keep them anonymous but send their medical information instead so that would stop identity theft but they'd still know what problems they've got wrong with them and their medical history. (Focus group participant, age group 15 to 16 years)

If it's to help people it should be used but like it should be anonymous so like instead of having your name it should have a list of codes on it saying your name so only the person can see the codes and not your name. (Focus group participant, age group 14 to 15 years)

How anonymised can you make the data and will it truly anonymous? (Deliberative conference participant, age group 15 to 17 years)

However, this should not be taken to assume that all young people are supportive of giving access to medical researchers. As shown in Figure 7, there is a significant proportion of young people who remain unsure, or disagree/ strongly disagree that “I'd be happy for my anonymous electronic patient record to be used in health and medical research”.

More in-depth discussions that took place in the focus group and deliberative conference revealed that concerns and objections to allowing medical researchers access were because it was considered an invasion of privacy, concerns about the safety of the data and concerns that the data would be accessed or sold to 'private' research companies. One suggestion included having a system where it was possible to choose what types of research you would be happy for your information to be used for when you opt in:

Yeah I agree with [classmate] because like if you can say no to things that you've got a strong opinion about, but then you can say yes to everything else that you don't mind your information being used for and it doesn't take a lot of time (Focus group participant, age group 14 to 15 years)

One adult focus group participant was concerned over the implications of extending life expectancy through improved medical research using EPR data:

It's not a nice thing to say but it's something that we will actually have to think about when we're actually looking at a system where the average age used to be 65 or 70 which is now 85 to 90, how are you going to keep those...people that would have stayed alive until they were 70, who are now living an extra 20 years, how are you then going to support them when we've just turned around and went you can't actually work past the age of 65 but we're going to close down all the retirement homes? (Adult focus group)

The community researchers pointed out that the benefits of using EPRs for health and medical research are more likely to be for future generations and the current generation would need to sacrifice some of their privacy for this.

5.8 Getting into the 'wrong hands'

Data and records getting into the 'wrong hands' was a frequently mentioned concern of the young people. The 'wrong hands' were considered to be those individuals or organisations that had 'no right' to the data (whether it was anonymous or not) and/ or would misuse the data. The 'wrong hands' include those who might gain access by illegal means (for example, by hacking, fraudulent means or coercion) in addition to those who might be given 'official access' by the EPR regulators.



Deliberative conference cartoon: hackers and data misuse

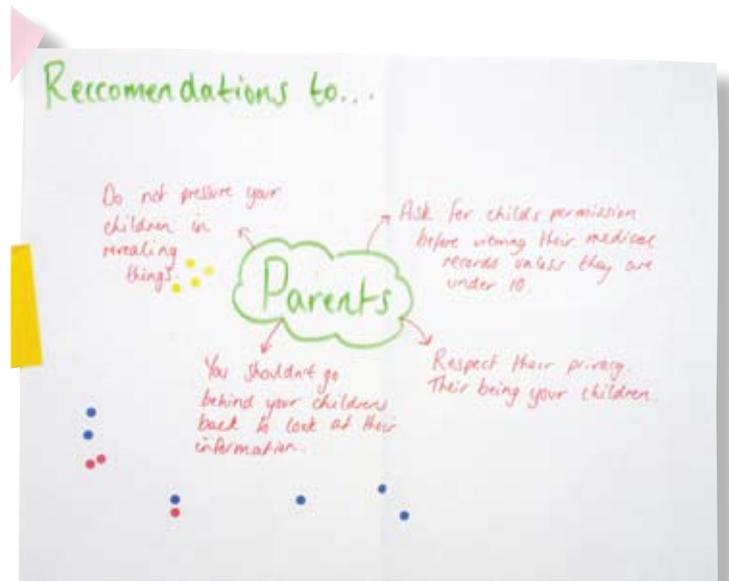
The set of organisations that made up the 'wrong hands' were commercial companies, 'private' companies, organisations that wanted to sell your data, advertising agencies, insurance companies, employers or potential employers, the media and in some cases, the Government. As mentioned above, opinion was divided over whether to allow access to pharmaceutical companies for 'private research'. It is important to re-emphasise that giving the data to organisations that are considered to be the 'wrong hands' would be considered a breach in privacy, irrespective of whether they had achieved 'official' access or not.

*With the EPR, can people get your information - is it easier to get or buy information from the NHS for marketing purposes?
(Deliberative conference participant, age group 15 to 17 years)*

*If you were to hack a database how would you go about it?
(Deliberative conference participant, age group 15 to 17 years)*

*What effect will EPR have on selling personal details to newspapers?
(Deliberative conference participant, age group 15 to 17 years)*

Keeping personal data such as medical records private from parents was considered to be paramount to young people, and a frequently mentioned view (see overleaf and section 5.9).



Deliberative conference poster: parents and privacy

Could parents do Freedom of Information to look at their son/ daughters school record? (Deliberative conference delegate, age group 15 to 17 years)

It was also noted giving people access to their own data might be detrimental to their privacy and well-being as they could be forced to share their record with a parent, partner or other relative against their will.

Adults also noted that the Government itself could be considered a pair of 'wrong hands' with questions raised over whether it would have access and therefore would be able to misuse or exploit the data.

5.9 Prejudice and judgements

Young people frequently expressed a strong underlying concern that individuals or organisations that get access to records, such as EPRs, would make judgements and assumptions that would result in prejudice. The young people also noted that prejudice could arise because the observer might (mis)judge someone from the data in their record or due to the information being incorrect (for example, mixed up with someone else's EPR or that the data was entered incorrectly).

This issue was raised a number of times throughout the deliberative conference and the community researchers' conversations. A number of examples given by the young people are provided below regarding the consequences of such prejudice from having access to personal data more generally (for example, on *Facebook*) and that specific to EPRs:

- you could be misjudged by people thinking that just because you like 'rap and grime' music you are also into violence and guns (for example, *Facebook*)
- you could be treated differently, such as being outcast or discriminated against (for example, *Facebook*, school records and EPRs)
- if a potential or current employer accessed your record you may not be offered a job or may be sacked (for example, *Facebook*, EPRs)
- you could be discriminated against by insurance companies (EPRs)

Once again the subject of parental access arose and the prejudicial consequences that could arise:

But your family could use it to spy on you, like say for example a religious conservative family, say for example a Muslim teenage girl and she got pregnant and she had an abortion and the family if they were spying on you it could create all sorts of problems. So it's just there's loads of implications but I think there's more negative than there is positive. (Focus group participant, age group 18 to 19 years)

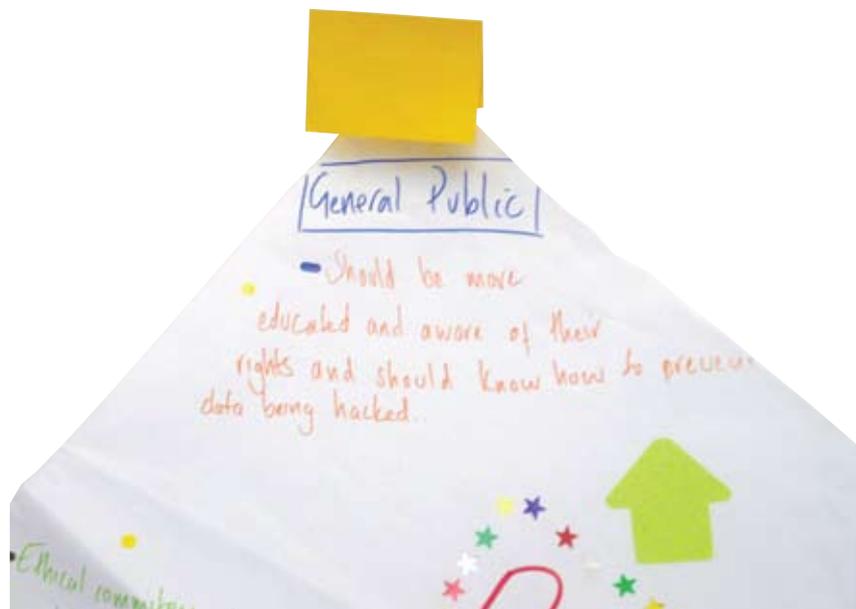
Young people also expressed a feeling that records are forever and so people will be 'labelled for life' and never get to escape their records and therefore their past.

The young people in the deliberative conference noted that the frequency of recorded personal information was an important issue to consider in regard to judgements and prejudice. An example was given that someone finding out that you had pizza last Friday night would not be an issue. Nevertheless, if your eating habits were repeatedly recorded, and it was found that you consumed pizza on a frequent basis, a judgement could be made that you were fat, greedy and/or unhealthy. The same could be said about frequently recorded information within your EPR.

5.10 Communications and engagement

The importance of communicating with young people was frequently mentioned. This was also linked in many ways to having control where the young people noted to be in control you also need to be kept up to date, to know what you are signing up to, or opting out of, and therefore able to make an informed choice.

A number of communication mechanisms were mentioned that would reach young people, rather than letters sent through the post which would be read by the adults in the household. These included *Facebook* (which was also thought to be an appropriate mechanism given the topic in question) and free papers with a young readership such as the *Metro*.



Deliberative conference poster: public engagement and education

The student community researchers proposed an alternative to the proposition of 'one way engagement' ie where the NHS or EPR regulators requested your permission to use your data. It was proposed that the wider public could be asked to enter into a partnership agreement with the NHS regarding their EPR; with each partner clearly stating how the data will be used, what each partners roles and responsibilities will be and their duty to each other.

5.11 Doctor-patient relationships

Both young people and adults questioned whether EPRs would affect doctor-patient relationships.

There's going to be 10 or 20 times more people available to my information now and I don't know who's taking care of the confidentiality clause. That's going to make me a bit more apprehensive to speak to the doctor if I've actually got something private that I need to say, do you know what I mean? (Adult focus group)

Findings from one of the community researcher's project indicated that young people are not fully aware of their rights regarding the confidentiality of their existing records, and whether their parents will be entitled to access, never mind what their rights might be regarding the new EPRs.

Is it unethical for two GPs to discuss a patient? (Deliberative conference participant, age group 15 to 17 years)

The community researchers discussed whether the development of an EPR system, in which other people will get access to the data, might result in young people being less open with their doctors over sensitive issues such as sexually-transmitted infections and pregnancy. One of the community researchers also noted that as the focus on patient health becomes increasingly about the electronic record, then GPs will look at the screen, rather than looking at and engaging with the their patient sitting opposite them. This was linked to a concern about over-reliance on the data in the electronic record, which may take precedence over a patient's knowledge about themselves, or doctor's intuition.

5.12 Money

Questions were raised during the deliberative conference over the cost of setting up and maintaining the EPR system and whether this would offer value for money, and whether the money could have been spent better elsewhere in the NHS.

Do you think the money will be well spent; do you think it could be spent more practically? (Deliberative conference participant, age group 15 to 17 years)

6. Conclusions

6.1 In response to the research questions

Pre-existing knowledge and attitudes towards the use of personal information for medical research

There was little public awareness among young people and adults regarding EPRs and their potential use in medical research. As such, prior to the play the audiences did not have conscious pre-existing attitudes towards EPRs and their use by medical researchers. Furthermore, it was not immediately apparent to younger audiences that EPRs could be used for health and medical research.

For the majority of audiences, watching the play and taking part in the debate resulted in strengthening existing opinions (ie about privacy and data security) and helping to shape and form opinions. For a minority there was some evidence that opinions changed more dramatically.

The play, electronic polling and post-performance debate proved to be a very engaging way in which to inform and stimulate young people to consider EPRs, which might seem a rather dry and un-interesting issue at first, especially to teenagers. The young people were able to express empathy with the characters and the evaluation findings show that the drama enabled audiences to explore the issue from different people's perspectives and to stimulate a fairly deep consideration of the issues.

Responsibilities of different groups

There were a number of groups whom young people declared were accountable for the responsible development of the EPR system.

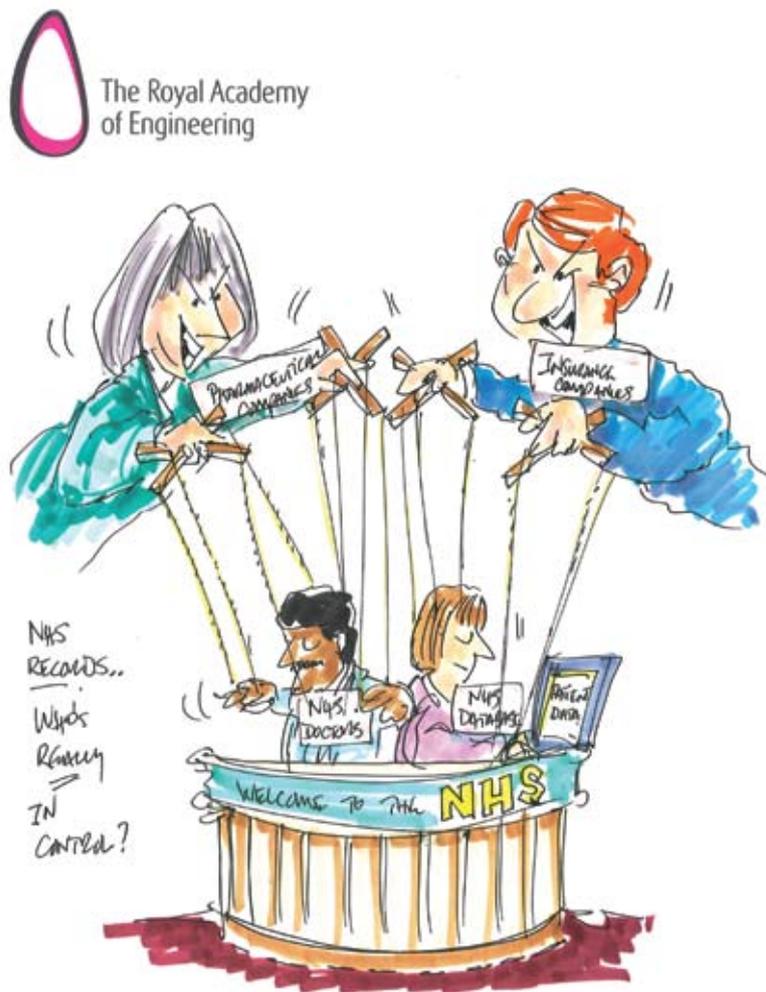
The findings indicate that young people showed a preference for the NHS to be the information keepers and managers. Adults had serious concerns over the Government having control of the information, due to its perceived poor track record regarding large IT databases and anxieties over what the data would be used for.

In regards to engineers, a number of the seven central questions that emerged (see section 6.2) were underpinned by the technical vulnerability of the system. In addition the young people noted that the 'EPR system' would consist of both the technology and its users, and the interaction between them. So the technology must be designed and developed in a way that is not only robust and usable but centres around how people will interact with the system. The latter not only refers to IT capabilities and skills of the users but also considers the human errors (in judgement or due to a lack of IT skills) that will occur, such as prying; sharing the data with the 'wrong hands'; losing and sharing smartcards and PINs and mixing up patient data.

It was not apparent to young people exactly which organisation or individuals would be responsible for the EPR system.

Perceived risks, aspirations and consequences of EPRs

The majority of young people were supportive of the idea of EPRs in principle. The major perceived risk was that privacy will be breached and that the data will be seen by those individuals or groups that have no right to access. This includes those that have gained access through users' errors (for example, losing memory sticks); by hacking the system in addition to those that may be given 'official' rights to the data (by the EPR regulators) but which young people consider to be the 'wrong hands'.



Deliberative conference cartoon: Who will really be in control? Who will have access?

The main aspirations for EPRs were that the wider public (including young people) were kept extremely well-informed about the EPR system, in control of their own record with full access to the data, to have a say on who will get access to what data and for what purposes.

The consequences of EPRs were frequently discussed rather than the implications *per se* (as per the original research question). The beneficial consequences included the increased efficiency regarding health service administration and potential advances in health and medical research. The detrimental consequences were serious indeed and included fundamental breaches in privacy; inappropriate use and exploitation of the data; and discrimination and prejudice to the individuals in which their privacy has been breached, which could result in social or family difficulties or exclusion, loss of employment and inability to get insurance.

6.2 Questions, risks and concerns

A set of seven central questions emerged from the young people's discussions, that underpin their core question of privacy and are shaped by the key risk and underlying concern (see table opposite).

These questions and concerns must be carefully considered and addressed by the policy makers, regulators, developers and engineers before progressing with the design, development and implementation of EPR record keeping systems and the linking of any databases.

Furthermore, the responses to these seven central questions need to be communicated to young people, and the wider public, so that they can make an informed choice about their participation.

Core Question: How private will electronic patient records be?

Central Questions

Key risk: The data will get into the 'wrong hands'	How secure is the EPR system and how safe is the data?	How much say and control will young people have over their records?	Who will be given access to the data and why?	How accurate will records be?	How will you engage young people and keep them up to date on developments?	Who will develop, control, maintain and regulate the database?	How will you protect young people from suffering from prejudice and discrimination?	Underlying concern: The consequences of young people's health and medical information reaching the 'wrong hands' could be very detrimental to them.
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6.3 Recommendations

6.3.1. Control: Provide as many individuals as possible with as much control as possible over their own record.

Specific recommendations included:

- Provide individuals with as much access to their recorded health and medical information as possible (this therefore includes both the SCR and the DCR).
- Allow individuals to have a say over their privacy settings to determine who else they would allow to have access to their medical data.
- Allow young people to have control of their record.
- Allow people to change their minds over time regarding whether to be part of the database, and their privacy settings.

6.3.2. Access: Deep consideration must be given to young people's opinions on who should be allowed access to the data and for what purposes; what the consequences will be if records or data reaches the 'wrong hands'; and how young people will be protected from any prejudice and discrimination that could arise.

Specific recommendations included:

- Listen to young people regarding which individuals and organisations should have access to their records and for what purposes.
- In addition to the media; commercial companies and insurance companies etc, it is important that young people's records are kept private from their parents, unless they choose to share access.

6.3.3 Security: Ensure that all EPR databases and systems are developed to be as secure and robust as technically possible alongside a realistic understanding of how users will interact with the system, and what the weak points and vulnerabilities might be.

Specific recommendations included:

- The engineers and others responsible for the development of the system need to fully consider not only the technical vulnerabilities but the weaknesses in the users regarding IT capabilities and susceptibility to bribery and nosiness. A full understanding of how the two will interact is required to ensure that the data can be kept as safe and secure as possible.
- Provide users with excellent guidance (for example, ensuring respect for peoples personal data), information and training.

6.3.4. Communications: Regularly communicate, engage and inform young people on the development of EPRs.

Specific recommendations included:

- A wide variety of communication and engagement mechanisms could be used such as social networking sites, such as *Facebook*, and newspapers that young people read such as the *Metro*.
- EPR systems and databases will not be fail-safe and the risks to the safety and security of the data should be fully acknowledged.
- Excellent communications, and possibly training, is required for those that are less 'IT savvy' on how to access their record, and to keep it secure.
- In order to feel engaged, and make an informed choice about having an EPR, information should include clear and specific answers to the seven central questions (see page 39).

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