



**Consumer  
Focus**  
Campaigning for a fair deal

# **Consumer Focus response to Conservative Party consultation on the personal ownership of health records**

**October 2009**

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## About Consumer Focus

Consumer Focus is a statutory body that champions the needs of consumers across England, Wales, and Scotland and, for postal services, Northern Ireland. We operate across the whole of the economy, persuading businesses and public services to put consumers at the heart of what they do. Consumer Focus has the power to take action where markets are failing consumers and to ensure a fair deal for all – especially the vulnerable and disadvantaged. As well as highlighting problems for consumers, we work with a range of organisations to champion creative solutions that improve consumers' lives.

We have a strong work programme focused on the consumer agenda in the digital economy, and work to the principles of a Charter of Digital Rights<sup>1</sup> for consumers which includes things like the right to access digital media and information and the right to secure networks and services. We are pleased to contribute to the debate on personal ownership of health records in the digital era. Our response begins with a general outline of consumer issues relating to electronic health records generally, followed by some more specific comments on the proposals to use third party providers to manage data. Much of our comments on data protection draw on work by our predecessor body, the National Consumer Council. We would very much welcome the opportunity to discuss these issues, and our larger programme of work on the consumer in the digital economy with you.

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<sup>1</sup> TACD Charter of Consumer Rights in the Digital World, March 2008

## Electronic Health Records and personal ownership: general consumer issues

Moves to make our health records available in electronic format across different health and other public services have long been promoted as a way of increasing efficiency, reducing clinical risk by having more information on patients, and ultimately, making health services work better for the people for whom they are designed. These fit with the principles of the transformational government agenda which purports to make public services deliver better outcomes for consumers by being: more personalised, more efficient and providing for more joined-up service delivery.<sup>2</sup>

The system of hard copy records can be frustrating for people as it involved: retelling different health professionals the same information in different encounters, appointments not going ahead because key records have not arrived in time for the referral, and individuals being unable to easily check the accuracy of their records. The potential benefits of making all health records available in secure and individually controllable electronic form are: the ability to more easily check information is correct and exert control over who sees your information. This has the potential to make services more responsive and personalised for individuals.<sup>3</sup>

Wider benefits have also been documented by Consumer Focus' predecessor body, the National Consumer Council. Health Records are used to make sure health services are well managed, effectively targeted and accessible to the right people at the right time, this could be greatly improved if these were based on a more effective and secure digital system. However, as well as health service planning, there are numerous other parties interested in accessing health data such a medical research organisations and commercial operators wanting to segment their market and advertise products and services directly to consumers. On the other side, the social marketing of health-related behavioural change (which will become of greater importance as we face up to major public health issues such as obesity) will be able to target campaigns better by using such data.<sup>4</sup>

Research from the Institute for Insight into the Public Services (IIPS) shows that consumers are generally willing for their data to be shared across public services, as long as there are demonstrable benefits.<sup>5</sup> This willingness to share data relies heavily on the confidence and trust of people that their data is being properly protected. This is echoed by consumer surveys and focus groups which, while generally positive about the benefits of electronic health records, consistently put issues of privacy and security at the forefront of their concerns.<sup>6</sup> Consumer Focus argues that the benefits of sharing electronic records between services have been emphasised over the more critical issue of data protection and privacy over the past few years, and that we need to refocus the debate so that data security and protection is at the heart of plans for electronic health records.

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<sup>2</sup> HM Government, *Transformational Government: enabled by technology* (2005)

<sup>3</sup> Montgomery, J 'Personal information in the NHS' in Lace, S (eds) *The Glass Consumer*, NCC/Policy Press, 2005

<sup>4</sup> *ibid*

<sup>5</sup> IIPS, *Data and Privacy: how concerned are citizens about data sharing in the public services?* May 2008

<sup>6</sup> See for example, *Health On-line: public attitudes to data sharing in the NHS*, Scottish Consumer Council 2005 or *The Public View on Electronic Health Records*, Department of Health/Health Which? 2003

## Conservative Party proposals: a new model of personal ownership via a third party provider

The Electronic Health record debate so far has taken place on the assumption that personal health data would be held by state institutions (ie NHS), with various levels of access given to citizens and relevant parties (eg other primary care professionals or social workers where necessary). The proposals from the Conservative Party to delegate ownership and control to individuals move this debate on significantly from questions of rights to access and control one's own record to taking more complete responsibility for owning records, which would be managed by a software system of their choice.

There are however, several issues of concern with the proposals outlined in the consultation document which we believe require further discussion if consumers are to benefit from this type of service transformations:

- Privacy and security concerns

Consumer Focus is concerned that Britain has gone a long way down the road towards the database state with little regard for safety and security. The trend continues with a commitment to increased surveillance and data sharing as evidenced by the Regulation of Investigatory Powers Act and the proposed Communications Data Bill which will modify the procedures for acquiring communications data and allow this data to be retained. The Conservative Party has opposed these levels of surveillance but proposals to move records from public to private ownership will not necessarily mean an end to this level of collection and use of data.

Generally, privacy protection on the internet is poor, and incidences of fraud are high. The black market and white market for personal information is growing, with information having significant value for fraudsters and advertisers alike. And with an increase in handling and storing of information, particularly electronically, the risks are very much alive. The latest Symantec report for the UK indicates that 'Hackers can access personal emails and the sensitive information often stored in them, including passwords and codes, through Internet Service Providers. Email accounts are the third most-sold item on the online black market.'<sup>7</sup>

A great deal of wealth generated on the internet comes from the value of personal information and companies are keen to get and keep data on people, as the Glass Consumer explains, "in the private sector, personal information underpins attempts to increase sales... by customising and personalising goods and services."<sup>8</sup> However, a near monopoly of the internet by certain companies means their stance and values are imposed on the whole system.

The companies cited in the consultation, Microsoft and Google, are also likely to hold data on other aspects of our lives, and consumers would need to be assured that health data is stored separately from this and there was no information provision to third parties. However, it is hard to see how their models will be profitable if there is no selling of information. As indicated earlier, successful electronic health record systems depend to a large extent on trust between consumer and provider and the poor record of both state and private providers in this area will do little to engender trust in citizens.

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<sup>7</sup> Symantec, Symantec Global Internet Security Threat Report, Trends for 2008, Volume XIV, April 2009, [http://eval.symantec.com/mktginfo/enterprise/white\\_papers/b-whitepaper\\_internet\\_security\\_threat\\_report\\_xiv\\_04-2009.en-us.pdf](http://eval.symantec.com/mktginfo/enterprise/white_papers/b-whitepaper_internet_security_threat_report_xiv_04-2009.en-us.pdf)

<sup>8</sup> Lace, S (eds) The Glass Consumer, NCC/Policy Press, 2005, p3

There is also a real question about vulnerable consumers and children controlling their data or others potentially having access to their data. The sensitivity of the issues involved may require privacy from parents and carers but the question would then be whether these consumers had the understanding necessary to control their own records.

- Disconnect between the online and regulatory world

The increasingly fast-moving online environment, has proved difficult for the 'real' world of regulation to keep up with. The current debate over copyright and file sharing is a good example of this, where legislation from another era is being applied unsuccessfully to contemporary circumstances. In the case of health record management services provided by a third party several issues are unresolved, not least the reach of individual nation's jurisdiction (for example, what would happen if records managed by multinational companies left the UK or were stored outside the UK and UK law was unenforceable?).

In order to take advantage of new technology, people need to understand the technology and the risks involved, or the risks need to be minimised externally, either through building in privacy protection or prescribing and enforcing privacy standards through legislation and other regulation.

Consumer Focus believes that the current legal framework does not meet these challenges. In the UK the Digital Britain report acknowledged that our frameworks for online protection have not kept pace with 200 years' development of consumer protection law and enforcement in the offline world<sup>9</sup>, and there has been criticism that some countries, notably the UK, have failed to fully implement the current EU Data Protection Directive.<sup>10</sup>

The enforcement body in the UK, the Information Commissioner's Office (ICO), is under-resourced both in powers and finances. The Commissioner's office appears to have fewer abilities to investigate and enforce the law than their counterparts in other EU countries, although they do now have the power to audit government departments.<sup>11</sup> Less than full implementation and lack of enforcement powers have allowed many of the data breaches that have undermined public trust.

It is currently very difficult for consumers to identify and correct errors, which often only become apparent when something has gone seriously wrong. Further, there is little that consumers can do if their data is disclosed deliberately, hacked into or lost through negligence. The ICO currently has limited power to deal with data breaches and provide the opportunity for redress for consumers. Their powers to issue sanctions are also limited, they have the ability to impose fines but these tend not to be of a high enough value to act as a deterrent.

- Consumer choice

It is not clear whether private record stores would be free to access for everyone, if it is provided at no direct cost to consumers then it is reasonable to interrogate the motivations of providers, and question whether they will be looking to make a profit via

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<sup>9</sup> Digital Britain, Final Report, June 2009, p189

<sup>10</sup> Europe Claims UK botched one-third of Data Protection Directive, Out-law News, 17 September 2007. Available at [www.outlaw.com](http://www.outlaw.com)

<sup>11</sup> Data Sharing and data protection – National Consumer Council's response to the Data Sharing Review, February 2008, p4

advertising (as Google Health does in the USA) or even by selling on data from individuals to other parties.

It is also debatable whether there would be a real choice for people; it is likely that there will be one or two large providers which may not offer vastly different levels of service. There may be additional implications for conditions of use and privacy if companies were to change hands, or if a consumer wished to change companies. In the digital arena, there are still key international issues to be finalised over issues like interoperability and net neutrality and without definite commitments to these, people may be unable to switch and transfer data. In addition, the terms and conditions of use for such services and privacy policies are notoriously complex and difficult for consumers to understand.

- Personal ownership

Consumer Focus would agree that, in theory, the principle of greater personal ownership of information could have a potentially positive impact for consumers. Our work on public services over the years has campaigned for services built around individuals playing an active role in meeting their own needs on their own terms, facilitated by professionals. We would expect that personal ownership of records might encourage people to take greater responsibility for their health as they would be much closer to their information. Greater familiarity with their records could make it easier to communicate effectively with a mix of providers and allow for patients to be on a more even footing with professionals or advocates. Although we haven't undertaken research in this particular area, research into the Personal Child health records (aka The Red Book) which became standardised nationally in 2004 shows that it has been successful in enhancing communication between parents and health professionals, with very high levels of usage (98 per cent).<sup>12</sup>

However, being a consumer should not be a full time job and personal ownership should not add a further burden to lives and time. Any system must provide real control and usability and significant work would need to be undertaken before it was truly accessible to all and there was no discrimination in level of services.<sup>13</sup>

## Conclusion

Finally, we would advise caution in drawing too many conclusions from what works in other countries. The companies cited are working in the USA which has a very different health system to the UK. Similarly, even between countries with more comparable public services, there is a great degree of difference in people's trust in their government and state services and the extent to which they are willing to engage in new relationships with the state and their data.

This leads us to our final point which is that such a fundamental rethink in the way people manage and take responsibility for their data will need to be accompanied by an equally fundamental rethinking of the role of the citizens, the private sector, third sector and state in delivering and managing services. There will need to be much greater transparency in how data is collected and used, and a much more open and honest debate about the risks and opportunities of the personal information economy.

With current pressures on public spending, it is tempting to look for quick gains in efficiency, but it is important that efficiency is not emphasised at the expense of an effective, long-term service for consumers.

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<sup>12</sup> Watson, S and Bedford, H 'Parents' use and views of the national standard Personal Child Health Record', Child Care Health Development, 2007 November; 33 (6) 744-8

<sup>13</sup> See Recommendations 4 and 5, The Digital Divide; Universal service and broadband, Consumer Focus, May 2009 , p4

### **Consumer Focus response to Conservative Party consultation on the personal ownership of health records**

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Published: October 2009

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