



BIG MOTHER'S DEADLY NEW WORLD:

HOW THE GOVERNMENT IS GOING TO DESTROY PATIENT'S HEALTH RECORDS AND KILL PEOPLE



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“IRREPARABLE DAMAGE TO THE RELATIONSHIP BETWEEN CLINICIANS AND THEIR PATIENTS”

It is often said that the road to hell is paved with good intentions. Yet, every now and then politicians of all parties do something so thoughtless and so damaging to the longterm public interest it stands out from the usual wash of regrettable phenomena that is politics.

In the dying days of the last parliament, the government made such a mistake. The catastrophe that will follow from the Health and Social Care Act's nationalisation of health records currently draws little public attention. But make no mistake, the horror and cost in terms of human suffering will be truly colossal in the decades to come.

While the Act covers many aspects of health and social care, one particular section allows the government to open people's newly computerised records to any organisation they consider to be in the public interest — requiring neither the consent nor knowledge of the individual. It virtually destroys two thousand years of Hippocratic oath.

The highly respected Conservative peer Earl Howe warned the House of Lords that the measure “more than any other clause in any other Bill that I have ever dealt with, has incurred the alarm,

anger and condemnation of virtually the entire medical community”.¹ Counselling against the Act's erosion of patient confidentiality, he warned against a system that will cause “irreparable damage to the relationship between clinicians and their patients”.²

Today, at the hands of all departments of state, people's liberties are being undermined not so much by big brother, but by big mother. The establishment's desire to control, categorise, profile and investigate ordinary folk's every action chimes with a deep-rooted human desire to be mothered and mollycoddled.

Under the recent Regulation of Investigatory Powers Act, agents of the state can now investigate people's private financial affairs in a way that the KGB could only have dreamed of.³ Under other legislation, the National Criminal Intelligence Service has now placed duties on lawyers and accountants to spy on their clients and hand on information without them being informed.⁴

THE DATA WILL BE INCREASINGLY UNRELIABLE AND DANGEROUS

Let us be clear, if we thought such measures would help in the fight against crime then we might support them. If we believed that the government's version of electronic patient records would help provide better health data and thereby outcomes, we would be persuaded. But instead the opposite will happen.

In the years ahead, a parallel universe will be created. As already exists in many other places two types of conversation will become the norm when dealing with professionals — the truth and the official version.

The person who goes to the doctor with depression might well be worried about how this information will play out in other arenas. How will it be used in terms of career development or even a court of law? Will it stop them becoming a care worker? Might it persuade a potential employer to go with another candidate? Could it be a factor used by an opponent in a court of law, even though it is irrelevant to a case in hand? On being proscribed amitriptyline, the patient might well want the official health record to read headache — not depression (it can treat both).

Instead of an ambulance crew arriving at the scene of an accident in 2020 and immediately swiping a patient's bar code to reveal an accurate health record and thereby make sound clinical judgments, the data will be increasingly unreliable and dangerous. If an individual has diabetes, epilepsy or is receiving anti-coagulant therapy that is not shown on their health record, treatments might be initiated or surgery undertaken that could cause further complications or even death. Again, unrecorded allergies, intolerance to antibiotics and even substances such as latex could all entail unacceptable risks.

In a world where joined up government increasingly means joined up big mother the incentives for people to connive and avoid the truth becomes immense. In a society that erodes consent and confidentiality, people go out of their way to defend their profiles and reputations — as never before. The unintended consequence of



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uninvited monitoring is that over time individuals debase the public record. A huge feed-back loop is created whereby the 'garbage in, garbage out' axiom really begins to bite.

In health, the more information is gathered and utilised without patient consent, the more people will find they live in a world where the incentives to avoid the recording of the whole truth becomes overwhelming. Lies, obfuscation and partial truths become common currency in any culture that replaces consent with coercion.

At the end of the Soviet Union, the KGB held vast amounts of information on citizens, most of it increasingly inaccurate and therefore meaningless. As official records progressively failed to match reality over the decades, so state plans and projections came to be based on a cycle of ever-weaker analysis.

BE VERY AFRAID

In health, the argument for privacy is not simply about people's liberty, for liberty is a prerequisite for accurate information and good decision making. As big mother pries into every corner of our lives, slowly, people will rediscover an urge to leave the nursery. As people die as a result of clinical decisions being made on the back of bad health records, so people will again begin to rediscover and value the collective benefits of consenting confidentiality.

In the longer term, we believe that experience will be the best teacher. In the short term, we are not optimistic.⁵ At a time when Earl Howe has condemned the coming "Sovietisation of British medicine",⁶ the prospect of big mother's brave new world should cause us all to be very afraid.

NOTES AND REFERENCES

1. House of Lords debate, *Hansard*, March 22, 2001: Column 1679.
2. House of Lords debate, *Hansard*, May 3, 2001: Column 1994. Earl Howe was particularly robust in this debate and his prophetic words are worthy of record. During the Bill's third reading on May 3, 2001 he said:

One of the fundamental principles of professional medical practice is that of patient confidentiality. That principle is enshrined in GMC guidance. It is also a legal right for patients. Common law, the Data Protection Act 1998 and the Human Rights Act 1998 all safeguard patient privacy.

The law means that, wherever possible, patients should have control of medical information about themselves and that doctors must respect that right. In 1998 doubts were raised on the legality of supplying named patient data to cancer registries in the light of current law. Over the next two years, following consultations and further legal advice, the Government accepted that there was a real issue to be addressed. The GMC could not advise doctors to break the law. The logical outcome was that only Parliament could decide in what circumstances patients rights to confidentiality should be breached. That is the background to the part of Clause 68 that we are now considering.

Let me say straightaway that I am entirely sympathetic to the objective of safeguarding both cancer registries and other research-based activities which are clearly essential for the protection of patients and the public. I understand the Government's position on this as I understand that of the GMC. There is a legal difficulty which has to be sorted out. Where I part company with the Government is in the way that they have chosen to set about doing this.

In this clause we have an almost ludicrously broad permissive power which effectively transfers responsibility for healthcare privacy from doctors to the Secretary of State for Health. Ministers have repeatedly assured us that they understand the need to protect patient rights and to stand by the fundamental principle of informed patient consent for any disclosures of personal medical data. However, their actions, as evidenced by this clause, are diametrically opposite.

Nowhere in the clause is there mention of informed consent or proportionality. The model of patients as shareholders and cust-omers of the NHS, much espoused by this Government, is absent. Instead we have literally the language of expediency and the well-worn phrase "in the public interest". The whole starting point of the clause is therefore wrong.

Earlier I referred to alarm and dismay in medical circles on what this clause contains. Much of that concern could have been avoided if

first there had been proper public consultation and, secondly, if the intended uses of the powers and the basis on which they would be used had been included on the face of the Bill.

Amendments have been made to the clause by the Government, which are undoubtedly welcome. But we are still left with a sweeping power to breach patient confidentiality; a power that depends for the circumstances of its use on the wishes of the Secretary of State. The most disturbing long-term consequence of using the powers proposed in the clause, especially subsection 4(c), is that it will destabilise public trust in medical confidentiality. When confidentiality is compromised it has a knock-on effect on trust. A shift in the relationship of trust between patients and their doctors, nurses and therapists will lead to one thing: patients who go to their doctor will no longer be open with them. It is that openness which underpins the quality of patient care, clinical governance and, ultimately, medical research.

If the clause is passed into law in its present form, with or without a statutory advisory committee, it will cause irreparable damage to the relationship of trust between clinicians and their patients. Never mind that there are "ifs" and "buts" and affirmative resolution procedures. The mere existence of this power, not to mention the exercise of it, will start the rot. Once doctors and nurses have ceased to be the guardians of the most private information that any of us possess, and once that guardianship has been transferred to a politician in Whitehall, you no longer have a system that will command public trust. That is a process that we should not even countenance.

Why is it that the Government, with over a year of their mandate still to run, are rushing through this measure? Why is it that they are trying to pressurise us into swallowing whole this hugely significant change in the law when they have not even conducted a basic consultation exercise? I was amazed to hear the other day that the Data Protection Commissioner had not formally been consulted on these proposals. Once again we hear the cry from Ministers, "Trust us; we will not abuse these powers." I say again that that is not an argument. However much we may trust Ministers and their undertakings — I trust the Minister implicitly — these are powers which Ministers in a future government could in theory exploit for their own purposes. As the noble Earl, Lord Russell, reminded us so powerfully last week, sweeping, general powers such as these make bad law.

Those are the reasons why I am deeply disturbed by the clause as currently drafted. We should not allow it to go through as it stands. We should say to the Government, "Withdraw it; reconsider; consult and in due course come back to Parliament with a clause that is specific and clear. But when you do that, please let see exactly what we are signing-up to."

The Government have resisted all calls to do that. That is why I propose in this amendment that we should hold them to their word. We should ensure that this clause, and the power conferred under it, takes as its starting point the central principal of informed patient consent. We should insist that the power to transfer responsibility for patient privacy to the Secretary of State should be exercised only where it is not practicable or reasonable to obtain the consent of patients. Indeed, no regulation on the exercise of the power should be made unless the possibility of informed consent has been excluded. I believe that that is the minimum for which we should be looking as we see these worrying provisions pass into law. Not long ago, the Secretary of State for Health said that the patient is king. My reply to him now is, "Prove that you mean it." I beg to move.

(House of Lords debate, *Hansard*, May 3, 2001: Columns 1993, 1994, 1995)

3. The Regulation of Investigatory Powers (RIP) Bill was introduced in the House of Commons on 9th February 2000 and completed its Parliamentary passage on July 26. The Bill received Royal Assent on July 28, 2000. The Regulation of Investigatory Powers Act 2000 (RIPA) updates the law on the interception of communications in the age of the Internet. It puts many intrusive investigatory techniques on a statutory footing for the first time and provides the police and various agents of the state with new powers to combat use of strong encryption.
4. For more on the sweeping powers of the National Criminal Intelligence Service and the legislative environment in which it is empire building, see: David J. K. Carr (2001), *Don't Trust Me, I'm a Lawyer: The Operation, Scope and Possible Effects of the Government's War on Money Laundering*, Legal Notes No. 35, Libertarian Alliance, London.
5. In many of these matters we respect and share the views of the Libertarian Alliance writer and editor of *Free Life*, Dr Sean Gabb. We particularly recommend his following Libertarian Alliance writings: *The Full Coercive Apparatus of a Police State: Thoughts on the Dark Side of the Thatcher Decade*, Legal Notes No. 6 (1989), *The New Tyranny of Global, European and British State Control of Financial Transactions*, Legal Notes No. 23 (1995).
6. House of Lords debate, *Hansard*, March 22nd 2001: Column 1680