

Chapter 10

Boundaries

**They constantly try to escape
From the darkness outside and within
By dreaming of systems so perfect that no one will need to be good**
– TS Eliot

**Anything your computer can do for you it can potentially do for
someone else.**
– Alan Cox

You have zero privacy anyway. Get over it.
– SCOTT MCNEALY

10.1 Introduction

When we restrict information flows to protect privacy or confidentiality, a policy goal is usually not to prevent information flowing ‘down’ a hierarchy but to prevent it flowing ‘across’ between smaller groups.

1. If you give the million US Federal employees and contractors with a Top Secret clearance access to too much Top Secret data, then you get a whistleblower like Ed Snowden if you’re lucky, or a traitor like Aldrich Ames if you’re not.
2. As mobile phones spread round the world, they’ve made wildlife crime easier. Game rangers and others who fight poaching face organised crime, violence and insider threats at all levels, but unlike in national intelligence there’s no central authority to manage clearances and counterintelligence.
3. If you let too many people in a health service see patient records, you get scandals where staff look up data on celebrities. And the existence of big central systems can lead to big scandals, such as where a billion English medical records going back a decade were sold to multiple drug companies.

4. Similar issues arise in social care and in education. There are frequent calls for data sharing, yet attempts to do it in practice cause all sorts of problems.
5. If you let everyone in a bank or an accountancy firm see all the customer records, then an unscrupulous manager could give really good advice to a client by looking at the confidential financial information of that client's competitors.

The basic problem is that if you centralise systems containing sensitive information, you create a more valuable asset and simultaneously give more people access to it. Just as the benefits of networks can scale more than linearly, so can the harms.

A common mitigation is to restrict how much information any individual sees. In our five example cases above:

1. Intelligence services put sensitive information into compartments, so that an analyst working on Argentina might see only the Top Secret reports relating to Argentina and its neighbouring countries;
2. Systems that support game conservation have to do something similar, but access control has to be a federated effort involving multiple conservancies, researchers, rangers and other actors;
3. Many hospital systems limit staff access to the wards or departments where they work, to the extent that this is reasonably practical, and patients have a right to forbid the use of their data outside their direct care. Both are becoming more difficult to implement as systems get more complex and their operators lack the incentive to make the effort;
4. In 2010, the UK parliament closed down a system that was supposed to give doctors, teachers and social workers shared access to all childrens' data, as they realised it was both unsafe and illegal. Yet there's constant pressure for information sharing, and all sorts of issues with schools and other institutions using dubious cloud services;
5. Financial firms have 'Chinese walls' between different parts of the business, and bank staff are now often limited to accessing records for which they have a recent customer authorisation, such as by the customer answering security questions over the phone.

We will discuss these kinds of access control in this chapter. There are several aspects: what sort of technical designs are feasible, the operational costs they impose on the organisation, and – often the critical factor – whether the organisation is motivated to implement and police them properly.

In the last chapter, we discussed multilevel security and saw that it can be hard to get the mechanisms right. In this chapter, we'll see that when we go for fine-grained access controls, it's also hard to get the policy right. Are the groups or roles static or dynamic? Are they set by national policy, by commercial law, by professional ethics, or – as with your group of Facebook

friends – by the system’s users? What happens when people fight over the rules, or deceive each other? Even where everyone is working for the same boss, different parts of an organisation can have quite different incentives. Some problems can be technically complex but simple in policy terms (wildlife) while others use standard mechanisms but have wicked policy problems (healthcare).

To start with a simpler case, suppose you’re trying to set security policy at the tax collection office. Staff have been caught in the past making improper access to the records of celebrities, selling data to outsiders, and leaking income details in alimony cases [183]. How might you go about stopping that?

TOP SECRET
SECRET
CONFIDENTIAL
OPEN

Fig. 9.1 – multilevel security

Your requirement might be to stop staff looking at tax records belonging to a different geographical region, or a different industry – except under strict controls. Thus instead of the information flow control boundaries being horizontal as we saw in the classic civil service model in Figure 9.1, we actually need the boundaries to be mostly vertical, as shown in Figure 9.2.

A	B	C	D	E
<i>shared data</i>				

Fig. 9.2 – multilateral security

Lateral information flow controls may be organizational, as when an intelligence agency keeps the names of agents working in one foreign country secret from the department responsible for spying on another. They may be relationship-based, as in a law firm where different clients’ affairs, and the clients of different partners, must be kept separate. They may be a mixture of the two, as in medicine where patient confidentiality is based in law on the rights of the patient but may be enforced by limiting access to a particular hospital department or medical practice. They may be volumetric, as when a game conservancy doesn’t mind declassifying a handful of leopard photos but doesn’t want the poachers to get the whole collection, as that would let them work out the best places to set traps.

Doctors, bankers and spies have all learned that as well as preventing overt information flows, they also have to prevent information leakage through side-channels such as billing data. The mere fact that patient X paid doctor Y suggests that X suffered from something in Y’s speciality.

10.1.1 Compartmentation and the lattice model

The United States and its allies restrict access to secret information by *codewords* as well as classifications. These are pre-computer mechanisms for expressing an access control group, such as the codeword *Ultra* in World War 2, which referred to British and American decrypts of messages that had been enciphered using the German Enigma machine. The fact that the Enigma had been broken was worth protecting at almost any cost. So Ultra clearances were given to only a small group of people – in addition to the cryptologists, translators and analysts, the list included the Allied leaders and their senior generals. No-one who had ever held an Ultra clearance could be placed at risk of capture; and the intelligence could never be used in such a way as to let Hitler suspect that his principal cipher had been broken. So when Ultra told of a target, such as an Italian convoy to North Africa, the Allies would send over a plane to ‘spot’ it an hour or so before the attack. This policy was enforced by special handling rules; for example, Churchill got his Ultra summaries in a special dispatch box to which he had a key but his staff did not. (Ultra security is described by David Kahn [975] and Gordon Welchman [1939].)

Much the same precautions are in place today. Information whose compromise could expose intelligence sources or methods is marked TS/SCI for ‘Top Secret – Special Compartmented Intelligence’ and may have one or more codewords. A classification plus a set of codewords gives a *compartment* or security context. So if you have N codewords, you can have 2^N compartments; some intelligence agencies have had over a million of them active. This caution was a reaction to a series of disastrous insider threats. Aldrich Ames, a CIA officer who had accumulated access to a large number of compartments by virtue of long service and seniority, and because he worked in counterintelligence, was able to betray almost the entire US agent network in Russia. The KGB’s overseas operations were similarly compromised by Vassily Mitrokhin – an officer who’d become disillusioned with communism and who was sent to work in the archives while waiting for his pension [116]. There was an even earlier precedent in the Walker spy case. There, an attempt to keep naval vessels in compartments just didn’t work, as a ship could be sent anywhere without notice, and for a ship to have no local key material was operationally unacceptable. So the US Navy’s 800 ships all ended up with the same set of cipher keys, which the Walker family sold to the Russians [854]. You clearly don’t want anybody to have access to too much, but how can you do that?

Attempts were made to implement compartments using mandatory access controls, leading to the *lattice model*. Classifications together with codewords form a lattice – a mathematical structure in which any two objects A and B can be in a dominance relation $A > B$ or $B > A$. They don’t have to be: A and B could simply be incomparable (but in this case, for the structure to be a lattice, they will have a least upper bound and a greatest lower bound). As an illustration, suppose we have a codeword, say ‘Crypto’. Then someone cleared to ‘Top Secret’ would be entitled to read files classified ‘Top Secret’ and ‘Secret’, but would have no access to files classified ‘Secret Crypto’ unless he also had a crypto clearance. This can be expressed as shown in Figure 10.3.

As it happens, the Bell-LaPadula model can work more or less unchanged.

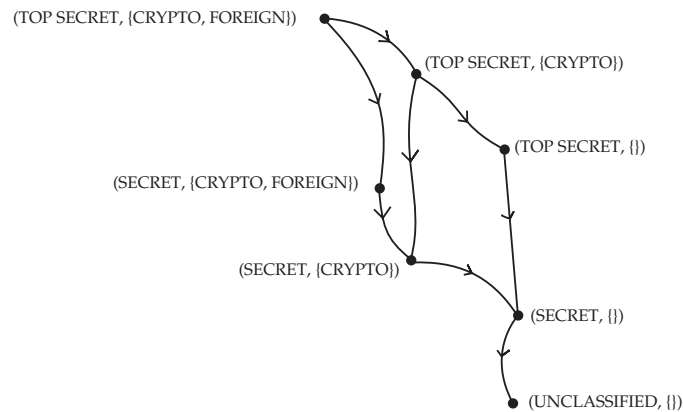


Figure 10.3: – a lattice of security labels

We still have information flows between High and Low as before, where High is a compartment that dominates Low. If two nodes in a lattice are incompatible — as with ‘Top Secret’ and ‘Secret Crypto’ in figure 10.3 — then there should be no information flow between them at all. In fact, the lattice and Bell-LaPadula models are essentially equivalent, and were developed in parallel. Most products built in the 20th century for the multilevel secure market could be used in compartmented mode. For a fuller history, see the second edition of this book.

In practice, mandatory access control products turned out to be not that effective for compartmentation. It is easy to use such a system to keep data in different compartments separate — just give them incompatible labels (‘Secret Tulip’, ‘Secret Daffodil’, ‘Secret Crocus’, ...). But the operating system has now become an isolation mechanism, rather than a sharing mechanism; and the real problems facing users of intelligence systems have to do with combining data in different compartments, and downgrading it after sanitization. Lattice security models offer little help here.

There was a sea change in the US intelligence community after 9/11. Leaders claimed that the millions of compartments had got in the way of the war on terror, and that better information sharing might have enabled the community to forestall the attack, so President Bush ordered more information sharing within the intelligence community. There was a drive by NSA Director Keith Alexander to ‘collect it all’, and rather than minimising data collection to maximise it instead and make everything searchable. So nowadays, government systems use mandatory access control to keep the Secret systems apart from the unclassified stuff, and the Top Secret systems from both, using data diodes and other mechanisms that we discussed in the previous chapter. The stuff above Top Secret now appears to be mostly managed using discretionary access controls.

The Snowden revelations have told us all about search systems such as XKeyscore, which search over systems that used to have many compartments. If a search can throw up results with many codewords attached, then reading that result would require all those clearances. In such a world, local labels just get in the way; but without them, as I asked in the second edition of this book, how do you forestall a future Aldrich Ames? Perhaps the US intelligence community

was lucky that the failure mode was Ed Snowden instead. As a system administrator he was in a position to circumvent the discretionary access controls and access a large number of compartments.

We later learned that at the CIA, too, compartmentation was not always effective. In 2017, its hacking tools were leaked in the Vault 7 incident, and a redacted version of the internal report into that was published in 2020 after the trial of the alleged leaker. It revealed that most sensitive cyberweapons were not compartmented, users shared sysadmin passwords, there was no user activity monitoring and historical data were available indefinitely. They did not notice the loss until the tools ended up on Wikileaks a year later. In fact, the Joint worldwide Intel Communications System (JWICS), which the intel community uses for Top Secret data, did not yet use two-factor authentication [1983].

There are a few compartments Ed Snowden didn't get to, such as the details of which cryptographic systems the NSA can exploit and how – this was marked 'extremely compartmented information' (ECI). Commercial firms may also have special mechanisms for protecting material such as unpublished financial results; at my university we compile exam papers on machines that are not even attached to the network. In such cases, what's happening may be not so much a compartment as a whole new level above Top Secret.

10.2 Privacy for Tigers

People involved in fighting wildlife crime face a fascinating range of problems. The threats range from habitat encroachment through small-scale poaching for bushmeat to organised crime gangs harvesting ivory, rhino horn and tiger body parts on an industrial scale. The gangs may be protected by disaffected communities; even heads of government can be a threat, whether by undermining environmental laws or even by protecting poaching gangs. And often the best poacher is a former ranger.

Even where sovereign threats are absent, public-sector defenders often work for mutually suspicious governments; protecting the snow leopard from poachers involves rangers in India, Pakistan, China, Nepal and Tajikistan, while the illegal ivory trade in East Africa spills over borders from Kenya down to South Africa. And technology is making matters worse; as mobile phone masts have gone up in less developed countries, so has poaching. Its military, insider-threat and political aspects are thus similar in many ways to traditional security and intelligence work. The critical difference is that the defenders are a loose coalition of NGOs, park rangers and law-enforcement agencies. There isn't a central bureaucracy to manage classifications, clearances and counterintelligence.

We had a project with Tanya Berger-Wolf, the leader of Wildbook, an ecological information management system that uses image recognition to match and analyse data collected on animals via tourist photos, camera traps, drones and other data sources [90]. Her idea was that if we could link up the many photographs taken of individual wild animals, we could dramatically improve the science of ecology and population biology, together with the resource management, biodiversity, and conservation decisions that depend on them. Modern

image-recognition software makes this feasible, particularly for large animals with distinctive markings, such as elephants, giraffes and zebras. Wildbook is now deployed for over a dozen species at over a dozen locations.

In 2015, two Spanish citizens were arrested in Namibia's Knersvlakte nature reserve with 49 small succulent plants; a search of their hotel room revealed 2000 more, of which hundreds were threatened species. It turned out that they sold these plants through a website, had made numerous collecting trips, and found rare specimens via botanical listservs and social networks. They pleaded guilty, paid a \$160,000 fine and were banned from the country for life. It turned out that they had also used another citizen-science website, iSpot [1941]. Incidents like this showed that wildlife aggregators need access control, and are also leading to a rethink among botanists, zoologists and others about open data [1133]. So what should the policy be?

What one needs to protect varies by species and location. With rare plants, we don't want thieves to learn the GPS location of even a single specimen. With endangered Coahuilan box tortoises, we don't want thieves stealing them from the wild and selling them as pets with false documents claiming they were bred in captivity. There, the goal is a public database of all known tortoises, and conservators are busy photographing all the wild specimens in their range, a 360 km² region of Mexico. This will enable the US Fish and Wildlife Service to check shipments. With the snow leopard, Wildbook had three years of camera-trap data from one Nepal conservancy, and wanted a security policy to help this scale to five locations in Nepal, India and Pakistan. This is a Red List species with only a few hundred individuals in each of these three countries. In Africa the picture is similar; Wildbook started out by tracking zebras, of which the Grévy's zebra is endangered. Animals cross borders between mutually suspicious countries, and tourists post tagged photos despite leaflets and warnings that they should not geotag [2006]. Some tourists simply don't know how to turn off tagging; some are so dumb they get out of their cars and get eaten. The protection requirements also vary by country; in Namibia the authorities are keen to stop tourists posting tagged photos of rhino, while in Kenya the rhinos all have their own armed guards and the authorities are less bothered.

The new wildlife aggregation sites can use image recognition to identify individual animals and link up sightings into location histories; other machine-learning techniques then aggregate these histories into movement models. We rapidly find sensitive outputs, such as which waterhole has lots of leopards, or which island has lots of breeding whales. This is one of the ways animal privacy differs from the human variety: highly abstracted data are often more sensitive rather than less. In effect, our machine-learning models acquire the 'lore' that an individual ranger might learn after a decade working at a conservancy. As such individuals make the best poachers if they go over to the dark side, we need to keep models that learn their skills out of the poachers' hands. And we need to be smart about sensitivity: it's not enough to protect only the data and movement models of snow leopards, if a poacher can also track them by tracking the mountain goats that they eat.

Our primary protection goal is to not give wildlife criminals actionable intelligence, such as "an animal of species A is more likely to be at location X at time T". In particular, we don't want the citizen-science data platforms we build

to make the situation worse. Our starting point is to use an operations-research model as a guide to derive access rules for (a) recent geotagged photos, (b) predictive models and (c) photo collections. And we need to be able to tweak the rules by species and location.

There are four levels of access. The core Wildbook team maintains the software and has operational access to almost everything; we might call this level zero. At level one are the admins of whom there might be maybe 20 per species; as access control is delegated there will be further admins per conservancy or per reserve. At level two are hundreds of people who work for conservancies collecting and contributing data, and who at present are sort-of known to Wildbook; as the system scales up, we need to cope with delegated administration. At level three there are thousands of random citizens who contribute photos and are rewarded with access to non-sensitive outputs. Our threat model is that the set of citizen scientists at level 3 will always include poachers; the set of conservancy staff at level 2 will include a minority who are careless or disloyal; and we hope that the level 1 admins usually won't be in cahoots with poachers.

The focus of our insider threat mitigation is conservancy staff who may be tempted to defect. Given that conservancies often operate in weak states, the threat of eventual detection and imprisonment can seem remote. The most powerful deterrent available is the social pressure from conservancy peers: loyalty to colleagues, a sense of teamwork and a sense of mission. The task is to find a technical means of supporting group cohesion and loyalty. The civil-service approach of having a departmental security officer who looks over everyone's shoulder all the time is not feasible anyway in a financially-stretched conservancy employing ten or twenty people on low wages in less-developed country (LDC) conditions.

The problem is not just one of providing analytics so that we can alarm if a member of staff starts looking at lots of records of rhino, or lots of records at a Serengeti waterhole. We already have admins per species and per location. The problem is motivating people to pay attention and take action. Our core strategy is local public auditability for situational awareness and deterrence, based on two-dimensional transparency. All conservancy staff are in at least one group, relating to the species of interest to them or the park where they work. Staff in the rhino group therefore see who's been looking at rhino records – including individual sighting records and models – while staff working in the Serengeti see who's interested in data and models there. In effect it's a matrix system for level 2 staff; you get to see Serengeti rhinos if you're there or if you're a rhino expert, and in either case you share first-line responsibility for vigilance. Level 1 staff can enrol level 2 staff and make peering arrangements with other conservancies, but their relevant actions are visible to level 2 colleagues. We will have to see how this works in the field.

10.3 Health record privacy

Perhaps the most complex and instructive example of security policies where access control supports privacy is found in clinical information systems. The healthcare sector spends a much larger share of national income than the mili-

tary in all developed countries, and although hospitals are still less automated, they are catching up fast. The protection of medical information is thus an important case study for us all, with many rich and complex tradeoffs.

Many countries have laws regulating healthcare safety and privacy, which help shape the health IT sector. In the USA, the Health Insurance Portability and Accountability Act (HIPAA) was passed by Congress in 1996 following a number of privacy failures. In one notorious case, a convicted child rapist working as an orthopedic technician at Newton-Wellesley Hospital in Newton, Massachusetts, was caught using a former employee's password to go through the records of 954 patients (mostly young females) to get the phone numbers of girls to whom he then made obscene phone calls [307]. He ended up doing jail time, and the Massachusetts senator Edward Kennedy was one of HIPAA's sponsors.

The HIPAA regulations have changed over time. The first set, issued by the Clinton administration in December 2000, were moderately robust, and based on assessment of the harm done to people who were too afraid to seek treatment in time because of privacy concerns. In the run-up to the rulemaking, HHS estimated that privacy concerns led 586,000 Americans to delay seeking cancer treatment, and over 2 million to delay seeking mental health treatment. Meanwhile, over 1 million simply did not seek treatment for sexually transmitted infections [851]. In 2002, President Bush rewrote and relaxed them to the 'Privacy Rule'; this requires *covered entities* such as hospitals and insurers to maintain certain security standards and procedures for *protected health information* (PHI), with both civil and criminal penalties for violations (although very few penalties were imposed in the first few years). The rule also gave patients the right to demand copies of their records. Covered entities can disclose information to support treatment or payment, but other disclosures require patient consent; this led to complaints by researchers. The privacy rule was followed by further 'administrative simplification' rules in 2006 to promote healthcare systems interoperability. This got a further boost when President Obama's stimulus bill allocated billions of dollars to health IT, and slightly increased the penalties for privacy violations; in 2013 his administration extended the rules to the business associates of covered entities. But grumbling continues. Health privacy advocates note that the regime empowered health data holders to freely and secretly aggregate and broker protected health information, while hospitals complain that it adds to their costs and patient advocates have been complaining for over a decade that it's often used by hospital staff as an excuse to be unhelpful – such as by preventing people tracing injured relatives [807]. Although HIPAA regulation gives much less privacy than in Europe, it is still the main driver for information security in healthcare, which accounts for over 10% of the U.S. economy. Another driver is local market effects: in the USA, for example, systems are driven to some extent by the need to generate billing records, and the market is also concentrated with Epic having a 29% market share for electronic medical record systems in 2019 while Cerner had 26% [1313].

In Europe, data-protection law sets real boundaries. In 1995, the UK government attempted to centralise all medical records, which led to a confrontation with the doctors' professional body, the British Medical Association (BMA). The BMA hired me to devise a policy for safety and privacy of clinical informa-

tion, which I'll discuss later in this chapter. The evolution of medical privacy over the 25 years since is a valuable case study; it's remarkable how little the issues have changed despite the huge changes in technology.

Debates about the safety and privacy tradeoffs involved with medical information started around this time in other European countries too. The Germans put summary data such as current prescriptions and allergies on the medical insurance card that residents carry; other countries held back, reasoning that if emergency data are moved from a human-readable MedAlert bracelet to a smartcard, this could endanger patients who fall ill on an airplane or a foreign holiday. There was a series of scandals in which early centralised systems were used to get information on celebrities. There were also sharp debates about whether people could stop their records being used in research, whether out of privacy concerns or for religious reasons – for example, a Catholic woman might want to forbid her gynaecological records being sold to a drug company doing research on abortion pills.

European law around consent and access to records was clarified in 2010 by the European Court of Human Rights in the case *I v Finland*. The complainant was a nurse at a Finnish hospital, and also HIV-positive. Word of her condition spread among colleagues, and her contract was not renewed. The hospital's access controls were not sufficient to prevent colleagues accessing her record, and its audit trail was not sufficient to determine who had compromised her privacy. The court's view was that health care staff who are not involved in the care of a patient must be unable to access that patient's electronic medical record: "What is required in this connection is practical and effective protection to exclude any possibility of unauthorised access occurring in the first place." This judgment became final in 2010, and since then health providers have been supposed to design their systems so that patients can opt out effectively from secondary uses of their data.

10.3.1 The threat model

The appropriate context to study health IT threats is not privacy alone, but safety and privacy together. The main objective is safety, and privacy is often subordinate. The two are also intertwined, though in many ways.

There are various hazards with medical systems, most notably safety usability failures, which are reckoned to kill about as many people as road traffic accidents. I will discuss these issues in Part 3 in the chapter on System Evaluation and Assurance. They interact directly with security; vulnerabilities are particularly likely to result in the FDA mandating recalls of products such as infusion pumps. The public are much more sensitive to safety issues if they have a security angle; we have much less tolerance of hostile action than of impersonal risk.

A second hazard is that loss of confidence in medical privacy causes people to avoid treatment, or to seek it too late.

1. The most comprehensive data were collected by the US Department of Health and Human Services prior to the HIPAA rulemaking under Pres-

ident Clinton. HHS estimated that privacy concerns led 586,000 Americans to delay seeking cancer treatment, and over 2 million to delay seeking mental health treatment. Meanwhile, over 1 million simply did not seek treatment for sexually transmitted infections [851];

2. The Rand corporation found that over 150,000 soldiers who served in Iraq and Afghanistan failed to seek treatment for post-traumatic stress disorder (PTSD), which is believed to contribute to the suicide rate among veterans being about double that of comparable civilians – a significant barrier being access to confidential treatment [1800];
3. The most authoritative literature review concluded that many patients, particularly teenagers, gay men and prostitutes, withheld information or simply failed to seek treatment because of confidentiality concerns. Anonymised HIV testing more than doubled the testing rate among gay men [1598].

So poor privacy is a safety issue, as well as a critical factor in providing equal healthcare access to a range of citizens, from veterans to at-risk and marginalised groups. The main privacy threat comes from insiders, with a mix of negligence and malice, in roughly three categories:

1. There are targeted attacks on specific individuals, ranging from creepy doctors looking up the records of a date on a hospital computer, to journalists stalking a politician or celebrity. These cause harm to individuals directly;
2. There are bulk attacks, as where governments or hospitals sell millions of records to a drug company, sometimes covertly and sometimes with the claim that the records have been ‘anonymised’ and are thus no longer personal health information;
3. Most of the reported breaches are accidents, for example where a doctor leaves a laptop on a train, or when a misconfigured cloud server leaves millions of people’s records online [748]. These are reported at five times the rate of breaches at private firms, as healthcare providers have a reporting duty. Sometimes accidental leaks lead to opportunistic attacks.

The resulting press coverage, which is mostly of bulk attacks and accidents, causes many to fear for the privacy of their health data, although they may not be directly at risk. The bulk attacks also offend many people’s sense of justice, violate their autonomy and agency, and undermine trust in the system.

So how big is the direct risk? And how much of the risk is due to technology? As things get centralised, we hit a fundamental scaling problem. The likelihood that a resource will be abused depends on its value and on the number of people with access to it. Aggregating personal information into large databases increases both these risk factors at the same time. Over the past 25 years, we’ve moved from a world in which each doctor’s receptionist had access to maybe 5,000 patients’ records in a paper library or on the practice PC, to one in which the records of thousands of medical practices are hosted on common

platforms. Some shared systems give access to data on many patients and have been abused. This was already a concern 25 years ago as people started building centralised systems to support emergency care, billing and research, and it has become a reality since. Even local systems can expose data at scale: a large district hospital is likely to have records on over a million former patients. And privacy issues aren't limited to organizations that treat patients directly: some of the largest collections of personal health information are in the hands of health insurers and research organizations.

To prevent abuses scaling, lateral information flow controls are needed. Early hospital systems that gave all staff access to all records led to a number of privacy incidents, of which the most notable was the one that led to the *I v Finland* judgment of the European court; but there were similar incidents in the UK going back to the mid-1990s. All sorts of ad-hoc privacy mechanisms had been tried, but by the mid-1990s we felt the need for a proper access control policy, thought through from first principles and driven by a realistic model of the threats.

10.3.2 The BMA security policy

By 1995, most medical practices had computer systems to keep records; the suppliers were small firms that had often been started by doctors whose hobby was computing rather than golf or yachting, and they were attuned to doctors' practical needs. Hospitals had central administrative systems to take care of billing, and some were moving records from paper to computers. There was pressure from the government, which pays for about 90% of medical care in Britain through the National Health Service; officials believed that if they had access to all the information, they could manage things better, and this caused tension with doctors who cared about professional autonomy. One of the last things done by Margaret Thatcher's government, in 1991, had been to create an 'internal market' in the health service where regional commissioners act like insurers and hospitals bill them for treatments; implementing this was a work in progress, both messy and contentious. So the Department of Health announced that it wanted to centralise all medical records. The Internet boom had just started, and medics were starting to send information around by private email; enthusiasts were starting to build systems to get test results electronically from hospitals to medical practices. The BMA asked whether personal health information should be encrypted on networks, but the government refused to even consider this (the crypto wars were getting underway; see 26.2.7.3 for that story). This was the last straw; the BMA realised they'd better get an expert and asked me what their security policy should be. I worked with their staff and members to develop one.

We rapidly hit a problem. The government strategy assumed a single electronic patient record (EPR) that would follow the patient around from conception to autopsy, rather than the traditional system of having different records on the same patient at different hospitals and doctors' offices, with information flowing between them in the form of referral and discharge letters. An attempt to devise a security policy for the EPR that would observe existing ethical norms became unmanageably complex [801], with over 60 rules. Different people have

access to your record at different stages of your life; your birth record is also part of your mother's record, your record while you're in the army or in jail might belong to the government, and when you get treatment for a sexually transmitted disease you may have the right to keep that completely private.

The Department of Health next proposed a multilevel security policy: sexually transmitted diseases would be at a level corresponding to Secret, normal patient records at Confidential and administrative data such as drug prescriptions and invoices at Restricted. But this was obviously a non-starter. For example, how should a prescription for anti-retroviral drugs be classified? As it's a prescription, it should be Restricted; but as it identifies a person as HIV positive, it should be Secret. It was wrong in all sorts of other ways too; some people with HIV are open about their condition while others with minor conditions are very sensitive about them. Sensitivity is a matter for the patient to decide, not the Prime Minister. Patient consent is central: records can only be shared with third parties if the patient agrees, or in a limited range of legal exceptions, such as contact tracing for infectious diseases like TB.

Medical colleagues and I realised that we needed a security context with finer granularity than a lifetime record, so we decided to let existing law and practice set the granularity, then build the policy on that. We defined a record as the maximum set of facts to which the same people have access: patient + doctor, patient + doctor plus surgery staff, patient + patient's mother + doctor + staff, and so on. So a patient will usually have more than one record, and this offended the EPR advocates.

A really hard problem was the secondary use of records. In the old days, this meant a researcher or clinical auditor sitting in the library of a hospital or medical practice, patiently collecting statistics; consent consisted of a notice in the waiting room saying something like 'We use our records in medical research to improve care for all; if you don't want your records used in this way, please speak to your doctor.' By 1995, we'd already seen one company offering subsidised computers to General Practitioners (GPs)¹ in return for allowing remote queries by drug companies to return supposedly anonymous data.

The goals of the BMA security policy were therefore to enforce the principle of consent, and to prevent too many people getting access to too many records. It did not try to do anything new, but merely to codify existing best practice, and to boil it down into a page of text that everyone – doctor, engineer or administrator – could understand.

Starting from these principles and insights, we proposed a policy of nine principles.

1. Access control: each identifiable clinical record shall be marked with an access control list naming the people who may read it and append data to it.
2. Record opening: a clinician may open a record with herself and the patient

¹Britain's GPs are the equivalent of family doctors in the USA; they have historically acted as gatekeepers to the system and as custodians of each patient's lifetime medical record. They also act as the patient's advocate and join up care between medical practice, hospital and community. This helps keep healthcare costs down in the UK, compared with the USA.

on the access control list. Where a patient has been referred, she may open a record with herself, the patient and the referring clinician(s) on the access control list.

3. Control: One of the clinicians on the access control list must be marked as being responsible. Only she may alter the access control list, and she may only add other health care professionals to it.
4. Consent and notification: the responsible clinician must notify the patient of the names on his record's access control list when it is opened, of all subsequent additions, and whenever responsibility is transferred. His consent must also be obtained, except in emergency or in the case of statutory exemptions.
5. Persistence: no-one shall have the ability to delete clinical information until the appropriate time period has expired.
6. Attribution: all accesses to clinical records shall be marked on the record with the subject's name, as well as the date and time. An audit trail must also be kept of all deletions.
7. Information flow: Information derived from record A may be appended to record B if and only if B's access control list is contained in A's.
8. Aggregation control: there shall be effective measures to prevent the aggregation of personal health information. In particular, patients must receive special notification if any person whom it is proposed to add to their access control list already has access to personal health information on a large number of people.
9. Trusted computing base: computer systems that handle personal health information shall have a subsystem that enforces the above principles in an effective way. Its effectiveness shall be subject to evaluation by independent experts.

From the technical viewpoint, this policy is strictly more expressive than the Bell-LaPadula model of the last chapter, as it contains an information flow control mechanism in principle 7, but also contains state. In fact, it takes compartmentation to the logical limit, as there are more compartments than patients. A discussion for a technical audience can be found at [58]. The full policy dealt with a lot more issues, such as access to records by vulnerable patients who might be coerced [57].

Similar policies were developed by other medical bodies including the Swedish and German medical associations; the Health Informatics Association of Canada, and an EU project (these are surveyed in [1049]). The BMA model was adopted by the Union of European Medical Organisations (UEMO) in 1996, and feedback from public consultation on the policy can be found in [59].

10.3.3 First practical steps

Feedback from the field came from a pilot implementation in a medical practice [849], which was positive, and from a hospital system developed in Hastings,

which controlled access using a mixture of roles and capabilities, rather than the ACLs in which the BMA model was expressed. It turned out that the practical way to do access control at hospital scale was by rules such as ‘a ward nurse can see the records of all patients who have within the previous 90 days been on her ward’, ‘a junior doctor can see the records of all patients who have been treated in her department’, and ‘a senior doctor can see the records of all patients, but if she accesses the record of a patient who has never been treated in her department, then the senior doctor responsible for that patient’s care will be notified’².

The technical lessons learned are discussed in [522, 523, 849]. With hindsight, the BMA model was a lossless compression of what doctors said they did while the role-based model was a slightly lossy version but which implemented what hospitals do in practice and worked well in that context. One of the BMA rules, though, created difficulty in both contexts: the desire for a small trusted computing base. GPs ended up having to trust all the application code that they got from their suppliers, and while they could influence its evolution, there was no useful trusted subset. The hospital records system was much worse: it had to rely on the patient administrative system (PAS) to tell it which patients, and which nurses, are on which ward. The PAS was flaky and often down, so it wasn’t acceptable to make a safety-critical system depend on it. The next iteration was to give each hospital staff member a smartcard containing credentials for their departments or wards.

The policy response from the Department of Health was to set up a committee of inquiry under Dame Fiona Caldicott. She acknowledged that some 60 established flows of information within the NHS were unlawful, and recommended the appointment of a responsible privacy officer in each healthcare organisation [356]. This was at least a start, but it created a moral hazard: while the privacy officer, typically a senior nurse, was blamed when things went wrong, the actual policy was set by ministers – leading to the classic security-economics gotcha we discussed in chapter 8, of Bob guarding the system while Alice pays the cost of failure. Anyway, the government changed, and the new administration of Tony Blair went for a legal rather than a technical fix – with a data-protection law that allowed data controllers to pretend that data were anonymous so long as they themselves could not re-identify them, even if others could re-identify them by matching them with other data³. We will discuss the limits of anonymisation in the following chapter.

10.3.4 What actually goes wrong

In his second term as Prime Minister, Tony Blair announced a £6bn plan to modernise health service computing in England. The National Programme for IT (NPfIT), as it came to be known, turned out to be the world’s most expensive

²The Hastings system was initially designed independently of the BMA project. When we learned of each other we were surprised at how much our approaches coincided, and reassured that we had captured the profession’s expectations in a reasonably consistent way.

³The UK law was supposed to transpose the EU Data Protection Directive (95/46/EC) into UK law to provide a level playing field on privacy; this loophole was one of several that allowed UK firms a lot of wriggle room, annoying the French and Germans [582]. The EU eventually pushed through the stricter General Data Protection Regulation (2016/679).

civilian IT disaster. After David Cameron came to power in 2010, an inquiry from the National Audit Office noted of a total expenditure of about £10bn, some £2bn spent on broadband networking and digital X-ray imaging resulted in largely working systems, while the rest didn't give value for money, and the core aim that every patient should have an electronic care record would not be achieved [1349]. Cameron formally killed the project, but its effects continued for years because of entrenched supplier contracts, and health IT was held up for a decade [1511].

NPfIT had called for all hospital systems to be replaced during 2004–2010 with standard ones, to give each NHS patient a single electronic care record. The security policy had three main mechanisms.

1. There are role-based access controls like those pioneered at Hastings.
2. In order to access patient data, a staff member also needs a *legitimate relationship*. This abstracts the Hastings idea of 'her department'.
3. There was a plan that patients would be able to seal certain parts of their records, making them visible only to a particular care team. However, the providers never got round to implementing this. It wasn't consistent with the doctrine of a single electronic health record, which had been repeated so often by ministers that it had become an article of religious faith. As late as 2007, Parliament's Health Committee noted that suppliers hadn't even got a specification yet [901].

As a result, patients receiving outpatient psychiatric care at a hospital found that the receptionist could see their case notes. Formerly, the notes were kept in paper in the psychiatrist's filing cabinet; all the receptionist got to know was that Mrs Smith was seen once a month by Dr Jones. But now the receptionist role had to be given access to patient records so that they could see and amend administrative data such as appointment times; and everyone working reception in the hospital wing where Dr Jones had his office had a legitimate relationship. So they all got access to everything. This illustrates why the doctrine of a single record with a single security context per patient was a bad idea. Thanks to project mismanagement, less than ten percent of England's hospitals actually installed these systems, though the doctrine of 'RBAC + relationship' has affected others since. It now looks like the failure to support multiple security contexts per patient is about to become an issue in the USA as firms start pushing health apps supported by the FIHR standard, to which I'll return in section 10.3.5.

10.3.4.1 Emergency care

The next thing to go wrong was emergency medical records. One of the stories used by politicians to sell NPfIT had been 'Suppose you fall ill in Aberdeen and the hospital wants access to your records in London ...'. This was, and remains, bogus. Paramedics and emergency-room physicians are trained to treat what they see, and assume nothing; the idea that they'd rely on a computer to tell the blood group of an unconscious patient is simply daft. But policy was policy, and

in Scotland the government created an ‘emergency care record’ of prescriptions and allergies that is kept on a central database for use by emergency room clinicians, paramedics and the operators of out-of-hours medical helpline services. Sensitive information about 2.5 million people was made available to tens of thousands of people, and the inevitable happened; one doctor of Queen Margaret Hospital in Dunfermline was arrested and charged for browsing the health records of then Prime Minister Gordon Brown, First Minister Alex Salmond and various sports and TV personalities. The case was eventually dropped as ‘not in the public interest’ to prosecute [1679]. Patients had been offered the right to opt out of this system, but it was a very odd opt-out: if you did nothing, your data were collected from your GP and made available to the Department of Health in Edinburgh and also to the ambulance service. If you opted out, your data were still collected from your GP and made available to the Department of Health; they just weren’t shared with the ambulance crew.

This was also policy in England where it was called ‘consent-to-view’: the state would collect everything and show users only what they were allowed to see. Everybody’s records would be online, and doctors would only be allowed to look at them if they claimed the patient had consented. Officials assured Parliament that this was the only practical way to build NPfIT; they described this as ‘an electronic version of the status quo’ [901]. The English emergency system, the Summary Care Record (SCR), also has sensitive data on most citizens, is widely accessible, but is little used; if you end up in an ambulance, they’ll take a medical history from you en route to hospital, just as they always have⁴. Something similar also happened in the Netherlands, where a database of citizens’ medical insurance details ended up being accessible not just by doctors and pharmacists but alternative healers and even taxi firms, with entirely predictable results [181].

10.3.4.2 Resilience

The move to centralised systems typically makes failures rarer but larger, and health systems are no exception. The NPfIT’s only real achievement was to standardise all X-ray imaging in England using digital machines and cloud storage. An early warning of fragility came on 11th December 2005, when a leak of 250,000 litres of petrol at the Buncefield oil storage depot formed a vapour cloud and detonated – the largest peacetime explosion in Europe. Oil companies were later fined millions of pounds for safety breaches. Our local hospital lost X-ray service as both the primary and backup network connections to the cloud service passed nearby. A further warning came when the Wannacry worm infected machines at another nearby hospital in 2017; managers foolishly closed down the network, in the hope of preventing further infection, and then found that they had to close the emergency room and send patients elsewhere. With no network they could do no X-rays (and get no pathology test results either, even from the hospital’s own lab). There have been further incidents of hospitals closed by ransomware since, particularly in the USA.

⁴In the coronavirus crisis, the SCR was ‘enriched’ by adding a lot of data from the GP record, making it available to planners, and making it opt-out by default. It’s still not clear that any worthwhile use has been made of it.

10.3.4.3 Secondary uses

Databases relating to payment usually don't allow a real opt-out, and the UK example is the Hospital Episode Statistics (HES) database, which collects bills sent by hospitals to the commissioning bodies that pay them, and has extensive information on every state-funded hospital visit and test in England and Wales since 1998 – about a billion records in total⁵. These records have proved impossible to protect, not just because anonymisation of complete records is impractical but because of the intense political pressure for access by researchers. More and more people had got access under the 1997–2010 Labour government; and after David Cameron became Prime Minister in 2010, the floodgates opened. Cameron hired a 'transparency tsar' who'd previously run a health IT business, and announced 'Open Data measures' in 2011 which the goal that every NHS patient would be a research patient, in order to make Britain a world leader in pharmaceutical research. Officials claimed that 'All necessary safeguards would be in place to ensure protection of patients' details – the data will be anonymised and the process will be carefully and robustly regulated' [1746]. Anonymisation meant that your personal details were redacted down to your postcode and date of birth; this is quite inadequate, as we'll discuss in the next chapter.

In 2013 the government announced that records would also be harvested from GP systems; GPs were given eight weeks to inform their patients of the impending upload. This caused enough disquiet that privacy campaigners, GPs and others got together to set up a medical privacy campaign group, medConfidential.org. The initial impetus was consent, and in particular that patients who tried to exercise their European-law rights to opt out of such systems have ended up being ignored or even de-registered from the health service. Campaigners pushed for the government to obey the newly clarified European law on consent; the government wriggled and evaded. How could doctors' bonuses be calculated if some of their records could not be uploaded?

In January 2014, some digging revealed that the HES data had been sold to over 1000 drug companies, universities and others round the world – often in the form of a set of DVDs containing a billion episodes going back to 1998. A medic revealed that the data had appeared online; it was quickly taken down [1738]. This 'care.data' scandal, as it became known after the proposal to collect all the GP data, went mainstream. Surveys show that most people are prepared to let their data be used in academic research, so long as they're asked; but most are not prepared to share it with for-profit researchers, and most object to having it simply taken. On inspection, it turned out to be easy to re-identify patients, even if their postcode and date of birth had not been included in the dataset; we'll discuss the technical details in the following chapter. There was a financial scandal: despite ministers talking of the huge value of research data to the health service, the data had been sold on a cost-recovery basis, for a

⁵HES is advertised as 'a data warehouse containing details of all admissions, outpatient appointments and A and E attendances at NHS hospitals in England' including private and foreign patients treated at NHS hospitals, and treatments at private hospitals for which the NHS pays. It is now claimed that 'We apply a strict statistical disclosure control in accordance with the NHS Digital protocol, to all published HES data. This suppresses small numbers to stop people identifying themselves and others, to ensure that patient confidentiality is maintained.'. See <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics>.

few thousand dollars a set. There was also an issue of jurisdiction: it turned out that PA Consulting had loaded the HES data to a Google cloud system for resale to its clients, as at 20Gb it was too big for Excel.

But hang on, said members of parliament, how can that be legal? Google didn't have any data centres in the UK, and there are all sorts of regulations against taking NHS data overseas [1523]. Also, officials had promised that UK data wouldn't be sold overseas, yet they were advertised in the USA; and it turned out that even the regulator, the Medicines and Healthcare Regulatory Authority (MHRA)⁶, had been selling personal data [1591]. Ministers went into damage-containment mode; the privacy regulator was persuaded to believe that the exported data were anonymous enough, and the UK website of a firm claiming to be able to identify patients from these records was taken offline [1524]. Ministers talked of lessons being learned, and a review of all data releases was commissioned; but when this appeared, it only investigated whether internal guidelines had been followed, not whether they were legal [1450].

UK health privacy scandals have continued at the rate of about once a year since then:

- In 2015, Google Deepmind obtained a copy of all the 1.6m patient records from the Royal Free Hospital in London, claiming that it wanted to develop an app to detect acute kidney injury (it took all the records, not just those of kidney patients). Patient consent was not sought, the deal was later found to be unlawful, and when the app was developed using US data obtained from the VA instead, it was unimpressive [1495]. The Information Commissioner reprimanded the hospital but failed to order Google Deepmind to delete the data. Eventually Deepmind transferred the records to Google, contrary to previous assurances [1244].
- Also in 2015, a tabloid newspaper discovered the online pharmacy Pharmacy2U selling thousands of patients' details to predatory marketers, including lottery fraudsters who targeted unwell elderly men and a healthcare supplement vendor that had already been sanctioned for misleading advertising and unauthorised health claims [644]. The firm was fined £130,000 and its commercial director suspended by the General Pharmaceutical Council. A major backer, the UK's largest GP software supplier EMIS, sold its shareholding.
- SCR data were also sold to Boots, a high-street pharmacy chain that pressures its staff to market aggressively, leading to regulatory hearings [394].
- In 2017, leading GP software supplier TPP which has 6,000 customers including 2,700 GP practices – a third of all practices in England, with records on 26 million patients – switched on 'enhanced data sharing' so that records could be seen by doctors at local hospitals. It was soon noticed that records could be seen at all other practices that were TPP customers; GPs had not been aware of this [563]. The records were also visible to

⁶The MHRA had also been a lot less keen about making data about adverse clinical trial results available to medics who wanted it. The essence of the complaint against it was that it been repeatedly acting in the interests of the drug companies and medical device makers rather than in the interest of patients, becoming in effect a captured regulator.

TPP customers in care homes, prisons and immigration detention centres. TPP failed to answer questions about whether any of its customers in India, China and the UAE had access.

- In 2018, the records of all 180,000 lung cancer patients diagnosed in England from 2008-2013 were given to a tobacco company by Public Health England, which had claimed that cancer registry data would only be sold for a ‘medical purpose’.

Standard central systems do have real advantages. In the USA, the Veterans’ Administration runs such systems for its hospital network; after Hurricane Katrina, veterans from Louisiana who’d ended up as refugees in Texas or Florida, or even Minnesota, could go straight to local VA hospitals and find their notes there at the doctor’s fingertips, when patients of many other hospitals in New Orleans lost their notes altogether.

But there have also been controversies in the USA. In November 2019, it emerged that Google had done an outsourcing deal to process the medical records of 50 million Americans on behalf of Ascension, and a whistleblower revealed that the data were not even being lightly de-identified; staff at both Google and Ascension had full access to patient data. A federal inquiry was started into whether the arrangement was HIPAA compliant [119].

Google also got VA data from the USA, which it used in place of the London data once the ICO ruled against it there. With a few such exceptions in egregious cases, policymakers find it hard to resist lobbying from marketers and researchers for access. The EU General Data Protection Regulation has a convenient exemption for ‘research’, put there by the pharma lobby, which doesn’t exclude market research. And, of course, law enforcement and intelligence agencies demand access. This started off in the 1990s with the collection of opiate prescribing records and has greatly expanded.

10.3.5 Confidentiality – the future

What can we say about healthcare privacy now, almost a quarter of a century after the BMA policy? Well, some things change, but a surprising number of things stay the same. We noted in chapter 2 that the cybercrime ecosystem had not been changed much by the huge technological changes of the past decade; much the same holds for the health privacy ecosystem. The move to cloud-based medical records is hard to resist as it saves individual care providers the trouble and expense of maintaining servers and backups. The move to ever more complex outsourcing also seems inexorable; we can expect that specialist firms will handle X-ray images, pathology tests and the like, while subject specialists will support care for specific diseases such as diabetes.

Since 2014, there has emerged a draft standard for Fast Healthcare Interoperability Resources (FHIR, pronounced ‘fire’) which describes how two systems talk to each other, once you’ve allowed them to do so. The security engineering is outside this standard; Deepmind’s smartphone apps, for example, use OAuth 2. FHIR has been mandated in the NHS from 2021. In America, new federal information-sharing rules may require providers to send your record to third-

party apps, like Apple's Health Records, after you have authorized the data exchange. The details alarm doctors who note that once you do that you'll be open to serious abuse, as the data will fall outside HIPAA and the apps can sell it off as they please. Data such as substance abuse could not only limit access to insurance but even be demanded by employers and others. The government responds that opening up health data will enable people to manage their care better and understand costs, while opening the sector up to competitive innovation [1754]. Quite apart from whether people would trust Microsoft, Amazon and Google with their health data, you have to share it all or not at all; there is no provision for finer-grained access control than your whole lifetime record. The last 25 years' experience suggests that this will not be satisfactory.

In the UK, the medical professors and drug companies are having another push to collect all the GP data, talking about three big new health industries, based on medical records, AI and genomics. Research policy is that while R&D should be 2% of GDP, only a third of that should be from the state and the rest from industry. It was announced in 2019 that five hospitals had done deals with a pharmaceutical company run by a former minister: they supply 'anonymised' data for research in return for an equity stake [487]. On the other hand, the UK's biggest medical-research charity, the Wellcome Trust, is predicting that as many as 40% of patients might opt out of having their data being used in research if there's another scandal on the scale of care.data. Certainly the data show that while about 80% of people trust doctors with their health data, this falls to just over 50% for health insurers and pharmacies, around 40% for researchers, 20% for drug companies and 10% for tech [1070]. How can we navigate this thicket?

The view of the UK campaign group medConfidential is that three things are needed.

1. First, to enable us to enforce our rights under European law, there must be real patient consent. This means a single opt-out from secondary uses, rather than the current Facebook-like approach of changing the opt-out mechanisms every year or two and forcing people to opt out all over again.
2. Second, it should not be the patient's job to defend their data, so both the privacy architecture and the security engineering must be safe by default. People must not be quietly opted in to secondary data uses that are misdescribed or not mentioned at all; and there must be appropriate security mechanisms about which patients are told the truth, particularly when they fail.
3. Third, there must still be real transparency. At present my GP can see who has had access to my record, but I want to see too. If tens of millions of patients can audit access, then even if only a few hundred thousand actually do so, this should deter most of the abuse.

History should have taught us that it's best to be honest with patients. In the UK we've wasted 20 years: a decade with NPfIT and a further decade trying to sell data while pretending not to. Yet hospitals that set out to get positive consent for the use of data in research get it 70–80% of the time, and we have had large collaborative research projects such as UK Biobank where 500,000

people not only consented in 2006–10 to lifetime monitoring but also provided blood samples, so that researchers could sequence their DNA and correlate that with health outcomes. There's a further research database of 100,000 genomes collected from other patients who consented.

Another development is the OpenSAFELY collaboration, which has been pioneering rapid analysis of the Covid-19 epidemic by working in situ with the live medical records held by TPP, a large provider of cloud electronic health record services which supports about 40% of GPs in England. They imported a list of death notifications and were able to analyse mortality not just by age and sex, as in official statistics, but by social deprivation, race, smoking history, body mass index and specific comorbidities, establishing risk factors over more than 17 million patients and over 6,000 deaths over February to April 2020 [1958]. They were first to establish, for example, that the excess mortality observed in black and Asian patients was significantly greater than could be explained by social deprivation alone. The speed and scale of this study were unprecedented and make the case for taking ethically-approved queries directly to the live data and taking away only statistics, rather than abstracting anonymised subsets for offsite use that still carry privacy hazards (as we'll discuss at length in the next chapter). The privacy risks may be more controllable as there are fewer copies of the data and as patient opt-outs can be enforced. And although this might be seen as a 'new' research technique, enabled by the emergence of cloud-based medical records, it's actually a very old technique. In the days before computers, observational epidemiology meant sitting in the library of a hospital or surgery, sifting through thousands of paper records, looking for diagnoses of interest, and departing after weeks or months of work with statistical tables rather than with identifiable personal information.

10.3.5.1 Ethics

So researchers working with health data had better pay attention to ethics. In 2014–5, the Nuffield Bioethics Council commissioned a dozen of us from a variety of backgrounds in tech, genetics, medicine, insurance and ethics to write a detailed report on what happens to medical ethics in a world of cloud-based medical records and pervasive genomics [1550]. Historically, it was a series of ethical abuses in medical research that drove the development of research ethics more generally.

- In the Tuskegee syphilis experiment, US doctors studied the progression of untreated syphilis in rural African-American men who were led to believe they were getting free healthcare. The experiment ran from 1932 to 1972, but even after effective antibiotic treatments became available in 1947, infected men were not treated.
- Dr Karl Brandt was Hitler's personal physician, and ran a euthanasia program from 1939. He also did human experiments on prisoners of war and the civilians of occupied countries without their consent, as did his colleague Dr Josef Mengele who experimented on twins at Birkenau from 1943–5; subjects were often killed and dissected afterwards. Brandt was convicted at the Nuremberg trials and hanged in 1948.

- In the UK Alder Hey scandal, the press discovered that pathologists were routinely saving ‘interesting’ body samples from patients living and dead, without any kind of consent. Parents discovered that body parts of their dead children had been kept without their knowledge. This did serious damage to public trust and the consequences impaired research in pathology in the UK. There was a similar scandal in Ireland.

The Nazi doctors’ trial led to the Nuremberg code in 1948, under which the voluntary and informed consent of subjects is essential. The subject must have the freedom to choose, without deceit or duress, and must be able to exit from the experiment at any time. This led later to the Declaration of Helsinki on ethics in medical research in 1964, which was revised in 1975 after Tuskegee to incorporate the need for an independent institutional review board or ethics committee, and subsequently in 1983, 1989, 1996, 2000 and 2008. The Declaration is managed by the World Medical Association and is ethically binding on physicians. The Declaration upholds the right of patients to make informed decisions about participation in research, both initially and afterwards.

Until about the mid-1990s, the main ethical debates were related to drug trials: was it wrong to give placebos to HIV sufferers once effective anti-retroviral drugs existed? And was it ethical to test drugs in less developed countries if their citizens or health services could not afford them? Since then, the growing issues have been informational: is it ethical to use whole populations as subjects in observational epidemiology and research, without giving them a right to opt out? And what are the ethical issues arising from low-cost sequencing of the human genome?

After spending a year considering in detail the history and issues I’ve summarised in this section, we concluded that, when working in such a complex and fast-moving ethical field, that holds a lot of promise but is also riven with vested interests and political chicanery, it’s not enough for researchers to hide behind the law or just act in accordance with this year’s government guidelines. A morally reasonable set of expectations should embody four principles. To quote the report:

1. The set of expectations about how data will be used in a data initiative should be grounded in the principle of respect for persons. This includes recognition of a person’s profound moral interest in controlling others’ access to and disclosure of information relating to them held in circumstances they regard as confidential.
2. The set of expectations about how data will be used in a data initiative should be determined with regard to established human rights. This will include limitations on the power of states and others to interfere with the privacy of individual citizens in the public interest (including to protect the interests of others).
3. The set of expectations about how data will be used (or re-used) in a data initiative, and the appropriate measures and procedures for ensuring that those expectations are met, should be determined with the participation of people with morally relevant interests. This participation should involve giving and receiving public account of the reasons for establishing,

conducting and participating in the initiative in a form that is accepted as reasonable by all. Where it is not feasible to engage all those with relevant interests – which will often be the case in practice – the full range of values and interests should be fairly represented.

4. A data initiative should be subject to effective systems of governance and accountability that are themselves morally justified. This should include both structures of accountability that invoke legitimate judicial and political authority, and social accountability arising from engagement of people in a society. Maintaining effective accountability must include effective measures for communicating expectations and failures of governance, execution and control to people affected and to the society more widely.

In short, you have to treat people as ends rather than means, and not just treat their data as an industrial raw material; you have to tell people in advance what you're doing, and if you can't tell everyone you must tell a good sample, not just some friends on your ethics committee; you have to obey the law, including the difficult bits of human-rights law; and you have to tell people what you've done afterwards – which includes public breach disclosure [1550]. Beware, though, that there is a lot of moral hazard around ethics processes; big firms who abuse data routinely set up ethics bodies to excuse what they do. I'll return to this ethics washing in section 11.4.4.

Since then we have used this model to guide our own research in cybercrime, which is similar in a number of ways. For example, we may sometimes use data that may be of questionable origin and from which it may be possible to draw inferences about living people who did not give consent. However, in many cases, an ethical case for an investigation can be made but the processes for taking and recording such decisions need careful thought. Transparency is vital; we put all the papers we write on our website, so everyone can see what's been done with the data.

The same principles may be a good starting point for thinking about the ethics of machine learning. Many if not most of the AI ethics controversies in the real world so far have been around health data.

10.3.6 Social care and education

The same issues have spilled over into education and social care. While building the NHS national programme for IT, the UK government also started to build a national database of all children, for child-protection and welfare purposes, containing a list of all professionals with which each child has contact. In 2006, the UK Information Commissioner asked a group of us to study the safety and privacy aspects of this. Now the fact that child X is registered with family doctor Y may be innocuous, but a child's registration with a social work department is different; teachers have lower expectations of children whom they know to have been in contact with social workers. And a record of contact with drug-addiction services or prostitution services is highly stigmatizing. We concluded that the failure to keep such metadata private is both unsafe and unlawful [99].

This became an even hotter political issue in November 2007, when the tax

authorities lost two DVDs containing the UK's entire child benefit database – personal information on every family in Britain with children. A charity associated with the Liberal Democrat party commissioned a further report entitled 'Database State' on the safety, privacy and legality of a range of public-sector systems [100]; the coalition government of which the Liberal Democrats were part after the 2010 election killed the children's database as well as discontinuing NPfIT, repealing the previous Labour government's legislation to make ID cards compulsory, and destroying the data and hardware associated with that project. After a further review, it also abandoned a plan for a new 'eCaf' system to organise social workers involved in child protection. There the issue was not just privacy but also poor design, as eCaf demanded so much information that social workers were starting to spend more time 'feeding the beast' than they did actually talking to children and their families [1316].

Attempts to share data between medicine and social care by direct electronic access threw up issues of integrity as well as privacy. As an example, when social workers in Oxford were given access to GP records, a social worker could enter 'diabetic?' directly into a GP system – which would interpret this as a diagnosis and start trying to schedule all the rest of the diabetes care machinery. The GP would have their work cut out stopping this, as medical records are append-only; and they might start failing to meet their targets for scheduling eye tests for diabetics, which would cut their income. There are also problems with automating exchanges between care services and schools; in fact, any automated interaction between different types of professional practice needs to be designed with extensive consultation and exploration of a lot of edge cases.

The 'Database State' report also highlighted privacy in education. In England, the Department for Education had set up a National Pupil Database that initially held census data but gradually accreted test results, behaviour and attendance data, whether the child was poor enough to get free school meals and whether they were in care. In addition, schools started adding further surveillance ranging from fingerprint scanners to record attendance and library book loans, to CCTV recording the classroom continuously (with the sales pitch that teachers could defend themselves against false accusations by children).

In Scotland, the government proposed a 'named person' scheme in 2014, whereby each child would be allocated one public-sector worker (typically a teacher or health visitor) to promote and safeguard their wellbeing. Rather than stigmatising the poor children who have a social worker, why not give everybody one? This aroused widespread opposition, was defeated in the Supreme Court in 2016, and finally abandoned in 2019 after ministers couldn't figure out a way to do it that was both legal and politically acceptable. A body set up to devise a statutory code of practice decided it 'would not be desirable as the complexity of this would mean it would not be easy to understand or apply in practice' [508].

Following sporadic protests by parents, there is now at least one NGO working for children's rights⁷. Concerns range from biometrics to the widespread adoption of cloud services in education, with numerous small providers selling a huge range of teaching support and other services, and children's data getting everywhere. Even the privacy regulator, the Information Commissioner, has

⁷<https://www.defenddigitalme.org>

been criticised for being blind to children's issues, for example using Vimeo to make instructional videos available on her website, when its terms of service prohibit use by under-13s. If even the regulator can't manage her own website, what chance does the average school have? More fundamentally, should a school treat each pupil as a citizen/customer – responsible and in control – or as a suspect/recidivist to be tracked, scanned and fingerprinted? The temptation with young people is the latter.

Looking back at almost a quarter century of tussles around the safety and privacy of health IT, and the related subjects of IT in education and social care, one can see the failures conforming to political stereotypes. Britain's Labour governments from 1997–2010 failed in a typical left-wing way. They were well-meaning but naïve; they could only think in terms of bureaucratic centralism and billion-pound contracts (some with firms that hired ministers before or after their term of office); they had no idea how to write the specifications; they lied like mad when things went wrong; and they were suckers for special interests such as medical researchers demanding access to everything. The Conservative governments since 2010 have failed in a typical right-wing way⁸: talking about rights and freedoms but cynically selling off data to their friends in the drug companies, and for a pittance; lying like mad when things went wrong; while undermining regulators and appointing leaders disposed to turn a blind eye to both safety and privacy failures.

10.3.7 The Chinese Wall

Our final flavour of multilateral security is the Chinese Wall model, formalised by David Brewer and Michael Nash [309]. Financial services firms from investment banks to accountants are required by their regulators to have internal rules designed to prevent conflicts of interest wherever two of their clients are competitors, and these controls are called Chinese Walls.

The model's scope is wider than finance. There are many service firms whose clients may be in competition with each other: advertising agencies are another example. A typical rule is that 'a partner who has worked recently for one company may not see the papers of any other company in the same sector'. So once a copywriter has worked on the Shell account, they will not be allowed to work on another oil company's account for some fixed period of time.

The Chinese Wall model thus mixes free choice and mandatory access control: a partner can choose which oil company to work for, but once that decision is taken their actions in that sector are constrained. It also introduces the concept of *separation of duty* into access control; a given user may perform transaction A or transaction B, but not both. Access controls thus become stateful.

Part of the attraction of the Chinese Wall model to the security research community comes from the fact that it's easy to formalise; in fact, it can be expressed in terms similar to Bell-LaPadula. If we write, for each object c , $y(c)$ for c 's company and $x(c)$ for c 's conflict-of-interest class, then like BLP it can

⁸This was despite the fact that the 2010–15 government had Liberal Democrat coalition partners

be expressed in two properties:

- The *simple security property*: a subject s has access to c if and only if, for all c' which s can read, either $y(c) \notin x(c')$ or $y(c) = y(c')$
- The **-property*: a subject s can write to c only if s cannot read any c' with $x(c') \neq \emptyset$ and $y(c) \neq y(c')$.

The Chinese Wall model sparked a debate about the extent to which it is consistent with the BLP tranquility properties, and some work on the formal semantics of such systems⁹. There are also some interesting new questions about covert channels. For example, could an oil company find out whether a competitor which used the same investment bank was planning a bid for a third oil company, by asking which specialists were available for consultation and noticing that their number had dropped suddenly?

In practice Chinese Walls still get implemented using manual methods. One large software consultancy has each of its staff maintain an ‘unclassified’ CV containing entries that have been sanitized and agreed with the customer. A typical entry might be:

Sep 17 – Apr 18: consulted on security requirements for a new branch accounting system for a major US retail bank

This is not the only control. A consultant’s manager should be aware of possible conflicts and not forward the CV to the client if in doubt; if this fails, the client can spot potential conflicts himself from the CV; and if this also fails then the consultant is duty bound to report any potential conflicts as soon as they appear.

There remains the issue of micro-level access. What if a bank manager simply looks at the bank statements of his best customer’s competitors? Here, modern systems tend to limit access except where the staff member has established a security context for that customer, for example by getting the customer to answer some authentication questions. I’ll discuss this further in the chapter on Banking and Bookkeeping.

One conspicuous failure mode of Chinese walls is where the conflict period is too short. Governments typically have conflict rules that prevent a minister working in any sector that they have regulated for six months after leaving office. This is way too little. Someone who was an energy minister six months ago still knows all the top people in the industry, and anyone who’s benefited from their policy may express their gratitude by hiring them. Five years might be more sensible, but if you think you can get your local legislature to pass such a law, good luck.

⁹See, for example, Foley [682] on the relationship with non-interference. The practical resolution of tranquility is usually a cooling-off period: having worked for one oil company, you might be forbidden to work for another for two years

10.4 Summary

In this chapter, we looked at the problem of setting boundaries when systems scale up to collect large amounts of sensitive information, to which many people need access in order to do their jobs. This is an issue in many information security problems, ranging from the protection of national intelligence data and data about wildlife at risk from poaching, through the privacy and confidentiality of medical and social-care information, to professional practice in general.

We looked at medical records in the greatest detail, and found that the easy problem is setting up access controls in a direct care setting so that access to each record is limited to a sensible number of staff. Such systems can be designed by automating existing working practices, and role-based access controls are a natural way to implement them. However, the incentives in health-care systems are such that the implementation is often poor, and needs regulation to enforce compliance. The traditional approach to privacy, which might be summarised as ‘consent or anonymise’, is being undermined by growing complexity with many outsourced systems that are often opaque even to doctors (let alone patients). The harder problems are the growing number of central systems, particularly those related to payments, from which opt-outs aren’t available; the growing use of genetic data, and the effects of social media from which sensitive personal health information can often be inferred. Here, too, the governance problems are even less tractable than the technical ones. The only realistic solution lies in regulation, and here the USA and the EU are moving ever further apart. Europe gives its citizens the right to restrict their personal health information to the clinicians involved directly in their case; America does not. However it can be hard for Europeans to enforce our rights. Both America and Europe have huge lobbying and financial pressures from drug firms and others who want all our data; politicians tend to side with the industry and undermine the regulators.

Since the 1990s, health providers and services have tried to have their cake and eat it by building ‘anonymised’ databases of medical records (or school records, or census returns) so as to allow researchers to make statistical enquiries without compromising individuals’ privacy. There are some applications where this is a complete non-starter, such as in fighting wildlife crime; there, the aggregate data are even more valuable to poachers than individual sightings. In the case of medical records, computer scientists have known since the 1980s that anonymising rich data is a lot harder than it looks, and in recent years we’ve acquired a robust theory of this that lets us work out when it can work and when it won’t. I’ll discuss this in the next chapter.

Another takeaway message is this. Just as multilevel security was the ‘hedgehog’ approach to information security, where you hope to get a good result by just getting one big thing right, multilateral security requires the ‘fox’ approach; you need to understand your application in detail, learn what’s gone wrong in the past – and also be good at adversarial thinking if you want to anticipate what’s likely to go wrong in future.

Research Problems

The coronavirus pandemic is likely to make health surveillance much more pervasive so personal health information will become more widespread and the conflicts discussed here will spread way beyond the healthcare sector. What will that entail, and how should technical and policy mechanisms evolve to cope?

Also, in the near future, more and more medical treatment will involve genetic information. Is there any sensible way in which privacy models can be extended to deal with multiple individuals? For example, in many countries you have the right not to know the outcome of a DNA test that a relative has for an inheritable disease such as Huntington's Chorea, as it may affect the odds that you have it too. Your relative does have a right to know, and may tell others – so unwelcome news might reach you indirectly. As I write, there are cases going through the courts in the UK and Germany that push in different directions on the rights of the children of people diagnosed with Huntington's [592]. Such tensions over information rights long predate the Internet and cannot be managed purely by technological mechanisms. But social media change the scaling factors in such a way as to make them more widespread and acute. The long-term solutions may well involve some mix of laws, social norms and technology support; but they are likely to take years to work out, and we may well end up with different solutions in different cultures. For example, East Asian countries have tolerated much more intrusive surveillance, and have suffered far fewer deaths in the pandemic, at least so far. Might that change attitudes elsewhere?

Further Reading

The literature on compartmented-mode security is scattered: most of the public-domain papers are in the proceedings of the NCSC/NISSC and ACSAC conferences, while Amoroso [47] and Gollmann [760] cover the basics of the lattice and Chinese-wall models. For a survey of privacy failures in health, social care and education in the UK in 2009, see '*Database State*' [100]. For a case study of the NHS National Programme for IT, see [370], and for a later report on total costs by the UK Parliament's Public Accounts Committee, see [1511]. For the BMA model see the policy itself [57], the Oakland version [58], the proceedings of a conference on the policy [62], and the papers on the pilot system at Hastings [522, 523]. For a National Research Council study of medical privacy in the USA, see [1370]; there is also an HHS report on the use of de-identified data in research at [1157]. But the best sources for up-to-date news on medical privacy issues are the websites of the relevant lobby groups: medConfidential for the UK, and Patient Privacy Rights for the USA.