

Speech: Protecting confidentiality and improving care: not a zero sum game

Dr Mark Taylor writes about how NDG principle of 'no surprises' in the context of genetic and genomic medicine.

Protecting the confidentiality of personally identifiable patient data, and using that same information to improve care outcomes, is sometimes seen as a zero-sum game. Either the information is protected or it is used to improve care.

During my time on the National Data Guardian's panel I've come to see it a little differently.

There is not always a conflict between respecting an individual's right to exercise control over the use of her information and using information about her to improve care. What matters is whether the use is consistent with what she expects, accepts as reasonable, and whether it respects her wishes. I've come to recognise it to be central to the work of the National Data Guardian (NDG) to ensure that the health and care system has the right controls in place to stop inappropriate uses of data but also to ensure that it is used so that people get the care they need.

The tension, between stopping data flow and making it flow, may be perceived to be acute particularly in case of new technologies and innovative opportunities to deliver high quality health care. Genomics and genetics is a case in point.

In her most recent Annual Report, the Chief Medical Officer (CMO), Dame Sally Davies, makes clear the promise of genomic medicine and science for the UK. In Generation Genome, Dame Sally notes the importance of holding patient data securely and of standards to protect from inappropriate disclosure. She also says that "the emphasis on confidentiality must be balanced against the interests of other family members and broader society, especially where genomic information may prevent serious disease".

Dame Fiona Caldicott, as the NDG, has established authoritative principles to guide appropriate use of confidential patient data for a wide range of purposes associated with the delivery and improvement of care. Dame Fiona has been approached by the genomics and genetics community to help them think through how these principles, such as the principle that there should be 'no surprises' to patients about how their data has been used, may be applied in the context of genetic and genomic medicine.

As none of the previous NDG Reviews specifically considered these challenges in detail, we have been undertaking some work to examine the issues in collaboration with others. As a panel member, I have been supporting Dame Fiona in this work. This work has been very much an attempt to help the

genomics and genetics community move forward and is not, at this point, a policy position or official advice from the NDG.

A key challenge we've looked at is whether it is necessary for genetic and genomic data about individuals to be shared more widely than is traditional for medical data in order to ensure that people get the best diagnoses and care. We have heard that when a doctor or scientist gets a result of a genetic test for patient A, they won't necessarily know whether the result indicates a problem or not, whether possession of that gene variant by that person might contribute toward disease or if it could indicate what the best treatment might be for her. This is partly because there are so many possible gene variations and partly because the significance of a variation for an individual can depend upon other variables. We are nowhere near having seen or understood them all. So where should a doctor start to help their patient?

One place is to look at the records of as many other patients as possible to see if anyone else has ever had the same test result, what their symptoms and other characteristics were, and what treatment they had. So to most effectively diagnose and/or treat patient A, a clinician might need to look at the records of patients B, C, D, E, F etc. This is a challenge to conventional understandings of medical confidentiality – a doctor would not normally be looking at the personally identifiable patient data of people they were not treating. Our thinking has principally been around this challenge. If doctors and scientists need to access data about others to give the best care to the patient in front of them, how can this happen in a way that patients can be comfortable with and maintains trust in a confidential health service?

We've come up with some [suggestions for next steps in the paper we have published today](#). Crucial will be exploring with the relevant patient population how acceptable they consider such use to be. While the opportunities may not always exist within clinical practice for an in-depth conversation, if time and space is made for such a discussion/dialogue outside a clinical setting, then do people consider this to be a reasonable use of personally identifiable patient data? If so, then how can awareness of this use be raised to the point that patients in general would not be surprised to learn of it? How do we move toward it being a general expectation?

If it were established that access to personally identifiable patient data by other health care professionals, to help them understand genetic variants for the benefit of the care received by all, was seen by patients to be both reasonable and expected, then there are various ways in which such 'reasonable expectations' might be related to existing Caldicott and legal principles. It also relates to other work on 'reasonable expectations' being undertaken by the NDG and her panel.

We are not the only people looking at this, we know that the genetics and genomics community, NHS England, the CMO, Genomics England and others are also doing this. We look forward to playing our role in ensuring that patient confidentiality is protected consistent with patient expectation and at the same time genetic data may be used to support and improve the delivery of care. That doesn't have to be a zero sum game.

News story: Testing wider rejection for first registrations

During the trial, we will widen our rejection criteria of first registration applications to cover incorrect fees being quoted, and points that we think our customers should get right first time, such as:

When we reject applications, we will explain why we rejected them.

Between 20 and 31 March, we applied wider rejection criteria to some of the registration applications we received. You can see the areas we trialed for rejection and our reasons for testing in [our customer blog from 17 March](#).

The trial broadly told us that customers were able and willing to adapt to a wider rejection policy, but that they would need a long lead in time to update their processes. The trial also told us the wider rejection has potential to improve our overall speed of service, which we know our customers want.

We now need more information about rejecting first registration applications to clarify which aspects of fees customers have difficulties with, and to improve our understanding of any impacts to customers and our organisation over a sustained period of time. We will, therefore, review the trial in November.

We continue to work with customers to improve the quality of applications we receive. We have met customers to discuss improvements while investigating other ways of helping, such as improving the way we report requisition (a formal request for the applicant to supply the information) data and testing a webinar that will help customers avoid requisitions.

Our customers can avoid requisitions and rejections by following:

News story: Defence Minister announces £3M to be saved as part of a new deal to supply the Royal Navy

Defence Equipment and Support (DE&S), part of the UK Ministry of Defence (MOD), has signed an innovative contract which will supply the Royal Navy with more than 10,000 different types of consumable items – covering

everything from fittings and fixtures to pistons and pumps.

Having [already announced](#) that the dredging of three million metres of mud at Portsmouth harbour has now given the new Queen Elizabeth aircraft carrier a clear route into its new home, the Defence Minister said that the award, given to Babcock International Group, will keep the Royal Navy's current and future warships, including the new Queen Elizabeth Class aircraft carriers, supplied with items essential for day-to-day maintenance and operations.

Minister for Defence Procurement Harriett Baldwin said:

The route is clear for the Navy's largest and most powerful ship to dock at its home in Portsmouth, but even ships as impressive as our magnificent new aircraft carriers need nuts and bolts to keep them running smoothly. This new contract will provide all the supplies our ships and personnel require to be effective on operations.

This also brings the previous contract under one deal, delivering improved efficiencies and highlighting how we are being smarter about support. These efficiencies are ensuring that our £178 million Defence equipment plan is going towards the state-of-the-art kit our Armed Forces deserve.

The new contract is estimated to be worth around £107 million over the next seven years, during which time it is expected to deliver around a million individual items to all current and future Royal Navy vessels. All items being supplied – including electrical cable, straps, small valves, bearings, gaskets, pipes, pistons, pumps, motors and electrical components – are 'consumable' in that they are impractical or impossible to repair.

Two of the contracts announced support the Sampson Multi-Function Radar, operational on board the RN's Type 45 Destroyers. Crown Copyright

The signature secures seven jobs at Babcock International with additional jobs secured at 11 companies across the wider UK supply chain. The contract is also set to generate savings of around £3 million for the taxpayer by bringing together eight older contracts under a new overarching management arrangement. That comes as part of the MOD's commitment to deliver efficiencies and reinvest those savings back into the cutting edge equipment our service men and women need now and in the future.

Companies within the UK supply chain include Liberty Dynamics and Andersalso, based in the West Midlands, Eriks and Edmundson, based in the South West and SPX Clyde Union in Scotland.

Chief of Materiel (Ships) for DE&S, Sir Simon Bollom, said:

The Royal Navy relies on expert, sustained support through

partnerships across UK Defence in order to protect the nation's interests at home and abroad.

This contract is not only excellent news for the Royal Navy and our partners across the Defence industry, but also for the taxpayer due to substantial negotiated savings and incentivised contract performance.

Whilst speaking in Portsmouth, the Defence Minister also announced that BAE Systems have been awarded contracts worth £72m to support cutting-edge radar systems on board the Royal Navy's ships.

Two of the contracts support the Sampson Multi-Function Radar. Operational on board the Type 45 Destroyers, the radar provides surveillance and dedicated tracking in a single system, enabling the ship to defend itself and other ships in its company from attack.

A five-year contract covering technical support was amongst the announcements. That involves on-board maintenance, spares and repairs management at BAE Systems' Cowes site on the Isle of Wight, supporting 255 jobs. The radar will also have its processing hardware updated as part of the announcements.

BAE Systems has also won the Commander T101 radar support extension project for the next four years. Deployable by land, sea and air, Commander Type 101 radars are in service across UK territories at home and abroad.

Press release: UK Armed Forces star in global show

Returning for a 68th season, the Royal Edinburgh Military Tattoo is a thrilling display of music, dance, and military entertainment from around the world, rooted firmly in Scottish culture and history. It will take place on the Esplanade of Edinburgh Castle from 4-26 August 2017.

In recognition of this being the Year of the Royal Navy, and Scotland's unique role in building UK warships, the finale will see the Esplanade transformed into an aircraft carrier flight deck, featuring a Lynx Mk III maritime aircraft, and a CGI projection onto the Castle walls of an aircraft taking off from the deck. As the audience arrives they will also walk under a life-sized model of the new F-35B fighter, with Royal Navy personnel providing a warm welcome too.

Defence Secretary Sir Michael Fallon said:

The Royal Edinburgh Military Tattoo represents all that is best in the UK's Armed Forces – talented, professional, and engaging internationally with our global allies.

This Tattoo helps showcase our Armed Forces and has raised over £10m through its Charitable Trust, and it contributes £77m a year to the Scottish economy.

Celebrating the theme 'Splash of Tartan', these Armed Forces musicians will make up a cast of 1,200 artists performing to a live audience of 220,000, and a global TV audience of more than 100 million.

Performers from 48 countries have taken part in the extravaganza with this year's top international acts including the United States Naval Forces Europe Band and the Japan Ground Self-Defence Force Central Band.

Royal Navy involvement

- The Massed Bands of HM Royal Marines (Portsmouth, Scotland, and Commando Training Centre)
- There will be a 24 strong Royal Navy Guard of Honour welcoming the audience every night
- The 90 strong Royal Navy and Royal Marines Tattoo Support Group have taken the lead in making the arrangements for the involvement of the UK Armed Forces this year
- Type 23 frigate HMS Somerset will berth in Leith for the last week of the Tattoo and host a number of capability demonstrations

Army involvement

- The Band of The Royal Regiment of Scotland
- The Pipes and Drums of the 1st Battalion Scots Guards
- The Pipes and Drums of The Royal Highland Fusiliers, 2nd Battalion The Royal Regiment of Scotland
- A contingent from 154 Regiment Royal Logistics Corps (Army Reserves)
- Pipes and Drum of the combined Scottish Universities Officer Training Corps

RAF involvement

- The Royal Air Force Regiment Band
- Royal Air Force Queen's Colour Squadron
- Flypasts by RAF aircraft (weather dependent)

Royal Edinburgh Military Tattoo facts:

- The Tattoo was first conceived in 1949 with the 1st performance in 1950
- 25 performances over August to a live audience of 8,800 each evening – 220,000 across the season
- HRH The Princess Royal, Princess Anne, is the Patron of The Royal Edinburgh Military Tattoo
- It has a VIP capacity of 148 each performance (3,700 including nightly

salute takers)

- Now into its 68th season, it has sold out for 18 years consecutively
 - Over 50 countries have taken part
 - The Show has been seen live by more than 14m people over the years
 - Filmed by the BBC in 'High Definition' for 59 and 90 minute programmes
 - Peak TV viewing figures of 5.3m in the UK and 100 – 300m globally
 - One of 11 Edinburgh Festivals delivering £280m to the City of Edinburgh and £313m to the national economy
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Press release: Highways England **'suited and booted' for hazardous** **concrete repairs at Spaghetti Junction**

As part of the £4.7m vital repairs to damaged concrete and waterproofing, Highways England is using high-performance jet washers that break up parts of existing concrete. The technique is known as hydrodemolition.

"Safety is always our top priority so our repair crews are wearing special body suits to protect them from flying debris which when it breaks off, can actually travel faster than a bullet," explains Highways England project manager Jessica Kenny.

"In fact, the water is so highly pressurised that operatives have to lean forward to about 45 degrees to counter the effects of the water jetting otherwise it would knock them off their feet.

"To put it into context, if you imagine the pressure washers that you use to clean the patio at home and multiply that by about ten times, you're still not even close to the water pressure we're using in this instance to complete this vital work."

As well as wearing the protective suits, those operating the machinery also need to work inside a special green cage which is designed to contain flying debris to a confined space.

Last weekend saw more than 356 people and 100 vehicles work on the 45-year-old structure that carries more than 220,000 vehicles a day.

Motorists travelling into Birmingham are still being reminded that key link roads will remain closed until 4 September.

For the duration of the scheme there is no access to the A38(M) from Gravelly Hill or Tyburn Road, with local diversions in place.

The M6 itself remains fully open during the work.

Local routes into the city centre are likely to be busier than usual. Drivers are advised to plan their journey and allow extra time.

Highways England provides live traffic information [via its website](#), local and national radio travel bulletins, electronic road signs and mobile apps. Local Twitter services are also available at @HighwaysWMIDS

Traffic management

Weekday restrictions:

- repairs to the inter-city route will be undertaken from Monday through to early Friday evening
- there will be traffic management on the A38(M) Aston Expressway – the tidal flow lane will be closed for the duration of the work
- three narrow lanes on A38(M) out of city with a 30mph speed limit for safety reasons
- 24/7 closure of the Gravelly Hill and Tyburn Road approaches to the A38(M) into city carriageway – diversions will be in place
- Park Circus on-slip will remain open
- Salford Circus will remain open
- free recovery will be available

Weekend restrictions:

We also need to fully close the A38(M) Aston Expressway and the exit slips at M6 junction 6 each weekend until 25 August. The closures will be in place from 8pm on Friday to 6am on Monday.

No traffic will be able to access the Expressway to either enter or leave Birmingham during these closures.

General enquiries

Members of the public should contact the Highways England customer contact centre on 0300 123 5000.

Media enquiries

Journalists should contact the Highways England press office on 0844 693 1448 and use the menu to speak to the most appropriate press officer.