care.data: why are Scotland and Wales doing it differently?

NHS England has delayed the launch of its national system to link general practice and hospital records after concerns about patients’ privacy. Care.data should look to the devolved nations, says Margaret McCartney

The Health and Social Care Act 2012 gives the Health and Social Care Information Centre, an executive non-departmental public body, the power to require all general practices to upload their data. Citizens can opt out by asking their general practitioner—but only if they know they are otherwise opted in.

A rich and accurate dataset of referral patterns, diagnosis, treatment episodes, drug allergies, and trends in admissions has advantages for research and planning health services. But negative publicity may mean many people opting out and less accurate and useful data.

The scheme will allow approved researchers to obtain raw, identifiable, “red data,” including diagnosis codes, prescription details, and demographic information, without the consent of individual patients. Such data can be released only in a public health emergency or with the secretary of state for health’s approval after scrutiny by the independent Confidentiality Advisory Group.

So far, most of the applications have been from NHS researchers, but applications have also been made by commissioning organisations to facilitate payments; more applications are expected once care.data is rolled out.

Aggregated “green data” are fully anonymised and available freely. Pseudonymised “amber data” have the main patient identifier changed and access has to be approved by the independent Data Access Advisory Group. Requests have so far been mainly from academics but also from the Institute of Fiscal Studies and the private commercial healthcare data companies Dr Foster and Civil Eyes Research.

Different approaches

There has been much less controversy in Scotland and Wales. The Welsh system does not hold any fully identifiable data, and researchers need consent from individual patients to access red data. And, unlike in England, there is no law forcing practices to participate; each practice chooses, and almost half have voluntarily signed up.

In Wales data are split at source. Demographic data are “pseudonymised” by the National Wales Information Service (NWIS), with fields such as postcodes removed. The Secure Anonymised Information Linkage project (SAIL, www.saildatabank.com) combines them with clinical data without demographic identifiers so that neither SAIL or NWIS can independently decrypt patients’ identity.

The Scottish Primary Care Information Resource (SPIRE), due to launch at the end of 2014, stipulates pseudonymisation at source before data can be transmitted to NHS National Services Scotland. SPIRE will be able to use “reversible” pseudonymisation, which can identify the patient and link—for example, GP and hospital records. The resulting information will then have “one way” pseudonymisation performed before it is used for research. Unlike in England, general practices will be able to opt out—entirely, from specific uses, or case by case. Practices can review each request before data are released to SPIRE, with no response taken to mean no. When asked about identifiable, red data, a spokesman for the Scottish government said, “This will only be extracted with the approval of the SPIRE steering group and the explicit consent of each patient.”

In Northern Ireland, the new electronic care record (NIECR) makes clear in an information leaflet to patients that “only the staff caring for you will be able to look at your information on the NIECR and you will be asked for your permission first. An audit trail will check this.”

Currently, researchers throughout the UK, including marketing and drug companies, can access aggregated, green data for free. For red data, individual consent must be obtained from Scottish and Welsh patients—but not those in England.

So what of amber data? The chief data officer of the NHS, Geraint Lewis, has said that “a determined analyst could attempt to re-identify individuals within amber data by linking them to other data sets.” This risk is to be mitigated by access being governed by the Data Access Advisory Group and a contract which states that it is illegal to attempt to identify individuals.

SPIRE recognises that even pseudonymised individual records may contain sufficient detail to risk disclosure of patients’ identities, so limits access to users and purposes approved by a steering group.

So why has NHS England done things differently? A spokesperson for NHS England told me that because “organisations across these different care settings use different information sources, pseudonymisation at source is not currently possible.”

But Scotland plans to do it, and Wales already does, so why is it not possible in England? And why was a law passed in England that allows for fully identifiable data to be made available to researchers without individual consent, when this will not be allowed in Scotland or Wales?

In 2011, when announcing the intention to change the NHS Constitution to enable care.data, Prime Minister David Cameron said, “The end-game is for the NHS to be working hand-in-glove with industry as the fastest adopter of new ideas in the world.” This would act as a “huge magnet to pull new innovations through, right along the food-chain—from the labs, to the boardrooms, to the hospital bed.” If this is the true intention of the English version of big data then it should be in the leaflet.

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Integration of services or empire building?

Although most general practitioners support integrated care, they are wary of losing their independence as hospital trusts attempt to take over primary care. Gareth Iacobucci looks at how one ambitious trust in Newcastle is trying to win them round.

Integration of services or empire building?

The integrated care bandwagon has been steadily gaining traction in the NHS in recent years. Politicians, clinical leaders, and academics are queuing up to hail the supposed saviour of the UK health service, which is claimed to deliver the holy grail of improved care and long term financial sustainability.1,2

If implemented effectively, it is difficult to argue that collaborative working between primary, secondary, community, and social care will not benefit patients and improve efficiency. But in a health service rife with factionalism, projects are often derailed by disagreements over the definition of integrated care, how it should be delivered, and who should lead it.

In primary care, the term “integration” is often viewed suspiciously as a euphemism for a hostile takeover by large, powerful hospital trusts. Some general practitioners fear that integrated care may lead to the end of their independent contractor status and remove their autonomy by making them employees of hospital trusts.

Clare Gerada, former chair of the Royal College of General Practitioners, argues that GPs must take the lead if integration is to succeed,3 as they have the will to shift more care out of hospitals and into the community. This, after all, is the aim of all major political parties, conscious of an ageing population with more complex and costly health needs requiring treatment closer to their homes.

But hospital trusts such as Newcastle upon Tyne Hospitals NHS Foundation Trust in the north east of England—consistently rated as one of the UK’s top trusts and member of the powerful Shelford group4—believe they are best placed to oversee integration of services.

The trust has already made inroads into primary care—securing three contracts to run general practices in the city and acting as a landlord to other practices after supplying them with new premises.

After also winning the contract to run the city’s community services in 2010, the trust now has its sights set on general practice out of hours care as the next piece of the jigsaw.

But its bid for the out of hours contract has stalled after the incumbent provider, the GP led cooperative Northern Doctors Urgent Care, served local clinical commissioning groups (CCGs) with a legal challenge, claiming that the tendering process was unfair.5

The case is still to be resolved, but it shows the volatility that is threatening to destabilise the system and undermine efforts to improve patient care.

Building bridges

In Newcastle, the push towards integration began to take shape in 2010, when the governors of the trust published a bold and ambitious manifesto for change, entitled Better Together.6 The document set out a vision that included developing new integrated clinical pathways—primarily for common diseases that affect older people—spanning secondary, community, and primary care.

Developed with the support of the local authority and GP clinical advisers appointed by the trust to help foster stronger relations with primary care, Better Together has formed the backbone of the trust’s ambitious plans.

But its description of the process as “vertical integration” proved controversial in primary care, with the trust accused of being predatory.

The trust insists this is not—and never was—the case, and says its proposals are focused on improving care for patients, not on feathering its own nest.

Speaking to the BMJ at the trust’s headquarters at the Freeman Hospital in Newcastle, charismatic chief executive Leonard Fenwick stresses that the perception of a hospital trust “throwing its weight around” is misplaced.

Fenwick believes bringing out of hours under the control of the hospital trust will help manage the “overheating” in the current system that often leads to unnecessary hospital admissions, particularly among frail elderly people.

“A foundation trust is so well placed. I know people will say ‘you’re empire building,’ [but that is] absolute nonsense,” he says firmly.

“Out of hours is where the challenge is for the NHS. That’s when the overheating occurs. There is a lot of risk averse decision making. “We believe with enhanced diagnostics, communication [and] referrals, we can take the pressure off and work more effectively with nursing homes [and] with residential care homes.”

As the longest serving hospital chief executive in the NHS, and head of one of the most powerful foundation trusts in England, Fenwick has been at the sharp end of numerous reshuffles and policy fads.

He says the bid to control out of hours is backed not only by patients but also by the local authority. He views the local authority and the trust as “the two key partners in health delivery” since the Health and Social Care Act gave new powers to local councils.

But Northern Doctors Urgent Care, part of the Vocare Group, which has held the contract to run out of hours care in Newcastle for almost a decade, is putting up a fight. A spokesman confirmed that legal action against the decision was taking place but said he was unable to comment further while the case was ongoing.
Construcive relationships

Despite the legal action, Fenwick insists the trust has a constructive relationship with most GPs in the city, working with them to develop clinical pathways for common diseases affecting older people.

The trust also set up Freeman Clinics in 2008—a standalone provider company 80% owned by the trust and 20% by local GPs—to run general practice contracts under former health minister Ara Darzi’s equitable access to primary care scheme. Freeman Clinics now runs three general practice centres in Newcastle and North Tyneside.

Fenwick believes the polyclinic style of these centres has improved care in deprived parts of the city. “It’s an infrastructure that provides walk-in, diagnostics, some outpatient clinics for hospital based specialists, but it’s primarily general practice. It’s a huge success story,” he says.

Freeman Clinics employs salaried staff at these three centres but also acts as a landlord for other practices that wished to retain their independence, providing new premises in exchange for running some hospital services out of the buildings. One of these is Benfield Park in the east end of Newcastle, described by Fenwick as “a first class general practice,” which approached the trust because its existing surgery was no longer fit for purpose.

“We constructed a £3m [€3.7m; $5m] plus modern infrastructure, over which we have a presence in the building from a secondary care perspective—primarily outreach clinics and diagnostics,” he explains.

“We worked with the local authority, the member of parliament, the residents, [and] the patients, and everybody signed up to it. Yes, an NHS foundation trust underpinned it, but the practice is independent; the trust is the landlord. At the end of the day, the population of east Newcastle has benefited.”

The trust has further freehold sites ready for development if the opportunities arise and is already “in dialogue” with GPs, says Fenwick.

Fenwick acknowledges concerns that in this kind of partnership there might be pressure on collaborating practices to refer into the trust but says that patients, who research their options well these days, would ultimately be able to choose where they were referred for treatment.

Since the trust appointed two GP advisers, Mike Scott and Steve Turley, to report to its executive board five years ago, it believes it is more connected with primary care than ever before.

Scott and Turley were involved in establishing the Better Together manifesto and have overseen a range of schemes, including new joint working arrangements for managing patients with conditions such as chronic obstructive pulmonary disease and heart failure. In these instances, nurses are employed and mentored by a acute trust—which gives them access to its expertise while seeing and treating patients in the community.

Both GP advisers practise in the city as well as working at the trust, giving them unique access to senior secondary and tertiary care clinicians. Crucially, the advisers believe that their messages are being received, even when they are challenging.

“I think this trust recognises the pressure on primary care,” says Turley. “It’s in the trust’s interest to help support anything in primary care which actually helps us do our job better and which allows us to care for more people in the community.

“It’s not about one outscoring the other,” he adds. “It’s about recognising that we have a huge role in the success or failure of each other.”

Scott admits that the phrase “vertical integration” has “come to haunt” the trust, but believes breaking down the barriers will reduce territorial quarrels over time.

Concern over independence

Scott and Turley may be enthusiastic cheerleaders for integration, but do other GPs in the city feel the same?

Nicola Weaver, a GP in the west of Newcastle, supports closer working between primary and secondary care but says it is vital that general practitioners retain a separate identity.

“I don’t think you’ll find anybody in primary care who wants the hospital to run their services, but at the same time, we are all in the process of trying to be more integrated,” she says.

“I do think it’s perfectly possible for us to work together and coordinate what we are doing.”

But Weaver says integration must not be achieved at the expense of GPs’ independence.

“One of the things about being independent practitioners is you can challenge in a way that might be difficult if you were employed,” she says.

Turley agrees GPs need to be allowed to challenge their secondary care colleagues. For example, he believes it is important that hospitals are seen to be shifting resources into the community, which he admits poses a challenge to the trust.

“There needs to be a visible transfer of resources from secondary to primary care. It’s not enough just to talk; people have to see real money and real bodies actually moving out there and working collaboratively.”

Fenwick says the decision to invite GPs to the board is proof that the trust is willing to learn from and listen to primary care.

“The two GPs attend the clinical pathway and policy group of a major tertiary trust. They sit at the table with a vote, a shout, and significant influence,” says Fenwick.

“I’ve seen the secondary care clinicians and other practitioners; they are listening. For us it’s been a learning curve because we now understand general practice better than ever,” he adds.

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PRIMARY CARE TEAM OF THE YEAR

Saving money and improving care

The BMJ Primary Care Team of the Year Award recognises primary care teams who have had a substantial effect on the health and wellbeing of the wider community. Judges will be looking for teams who identified a need within a population, created a programme or intervention to meet that need, and can demonstrate that their work produced results that are relevant to UK healthcare. Here are the shortlisted candidates

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Competing interests: none declared.

Winners of The BMJ Awards in association with MDDUS will be announced on 8 May at the Park Plaza, Westminster, London.

To find out more go to http://thebmjawards.bmj.com.

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See the full shortlist and book at table at http://thebmjawards.bmj.com

Norwood Surgery, Stockport
Helping people with diabetes to change their diet

“We found that by removing starch as part of a low carb style diet, type 2 diabetic patients dropped their HbA1c by a surprising 20%. Such diets for diabetics are contentious but our work suggests they should be the subject of further investigation in the UK.”

East Midlands Ambulance Service NHS Trust
Working together to reduce transfer to hospital of “urgent call” patients

General practitioners mostly book urgent calls for ambulances on the basis of a telephone consultation and patients are taken to hospital without retriage by ambulance staff. East Midlands Ambulance Service NHS Trust deployed emergency care practitioners (ECPs) into West Leicestershire Clinical Commissioning Group (CCG) to attend urgent calls to ensure that transportation to hospital was the most appropriate response.

Emergency care practitioners working 9 am to 5 pm on weekdays decided at the scene on the best course of support. If the patient did not require emergency transportation, the practitioner

Tower Hamlets General Practice Networks
General practice networks show value of good neighbours

“Increasing numbers of CCGs are turning to networks to deliver real system change. This is system improvement that translates evidence into patient benefit.”

CCG Miriam Primary Care Group, Wirral
Minor injuries and illness services make the most of general practices

Miriam Primary Care Group's nurse led minor injury and illness service on the Wirral has stabilised emergency attendances against the national trend of rising rates, boosted patient choice, and produced savings.

With local research showing that people were content to have minor conditions treated in primary care settings, Wirral CCG established a block contract for a nurse led service with GP support based in existing practices. The service was initially based in two practices, one of which is part of the Miriam Primary Care Group that won the contract. It has now been extended to four. The service is available to any patient, even if not registered at the practice.

AT Medics Group
Waving goodbye to paper—the paper light environment project

It was really powerful to use improvement methodology such as Lean and to see your staff writing each step in the referral process on paper on the floor and recognising how complex it was. Redesigning that process from the ground up was a beautiful sight.”

Headline and Primary Care Team Sponsor

MDDUS
UK-wide support and indemnity

See the full shortlist and book at table at http://thebmjawards.bmj.com
This project seeks to tackle the rise in the numbers of people with impaired glucose tolerance and type 2 diabetes by making dietary treatment a reality for this group. David Unwin and colleagues at Norwood Surgery in Southport sought to educate and support 18 patients with impaired glucose tolerance or diabetes as they tested a low carbohydrate, higher fat diet that international studies have suggested could benefit them. Little research has been done in the UK.

A lot of the work was done in groups with patients’ families, which staff say was scary at first but became great fun. Several members of staff also joined the patients on the diet. By using group work and a diet emphasising food with healthier fats, vegetables, and protein, the team hoped that the process would be enjoyable for participants. Around half of the 18 met as a group for reviews of progress while the remainder had individual meetings with a GP or practice nurse.

Over nine months there were clinically and statistically significant improvements in weight, waist circumference, glycated haemoglobin, and γ-glutamyl transferase results. Mean weight fell from 100.2 kg to 91 kg and glycated haemoglobin levels fell steadily. There has been no evidence of cholesterol concentrations rising. Six patients were able to stop taking hypoglycaemic drugs, antihypertensive drugs, or antacids.

General practices and commissioners in Tower Hamlets, an area with high levels of deprivation and ethnic diversity, saw local networks as a way of tackling both the enormous health challenges and the apparent underperformance by primary care. Among the problems facing the area were the fourth highest premature cardiovascular death rates in England and chronic obstructive pulmonary disease and diabetes levels among the highest in England, together with high hospital admission rates for these diseases. In 2008, a children’s MMR vaccination rate of 80% resulted in the area having the highest rates of confirmed measles cases in England.

From 2009, the former primary care trust invested an extra £10m in four care packages to be delivered by eight networks comprising four to five neighbouring practices. The packages covered cardiovascular disease, diabetes, chronic obstructive pulmonary disease, and childhood immunisation. Each network had a manager and other administrative support. Guidelines and educational support from the clinical effectiveness group at Queen Mary University of London were reinforced by network based multidisciplinary meetings and other educational support. The Queen Mary group also provided data entry templates for practices and performance dashboards for use at practice, network, and primary care trust (now CCG) level.

The funding increase and this network model led to significant improvements across all four care areas. Tower Hamlets moved from the lowest quintile of national Quality and Outcomes Framework performance to one of the top CCGs in both London and England within four years. For childhood MMR vaccination, the CCG was the top in London.

The numbers treated have risen from 2500 across two locations in its first year (2010–11) to over 20,000 patients in 2013–14 across four locations. Nursing capacity and opening hours were increased after an evaluation of activity in 2011–12. Some 61% of patients are seen and discharged after the first attendance, with less than 4% referred to emergency departments or walk-in centres.

The CCG estimates that the service saves over £650,000 a year by diverting patients from emergency departments and by using general practice premises and infrastructure rather than incurring the costs of a traditional standalone walk-in centre.

The prime motivation behind the decision of one practice in the AT Medics group to move to paperless processes was concern about the safety implications of delays in sharing information, hospital letters going astray, and lost prescriptions.

However the paper-free initiative has also spawned savings, as well as making the practice greener. Annual spending on paper and toner fell by E10,000.

It has now been rolled out across the company’s 16 practices based in seven London CCG areas and implementation is nearly complete. A major step was removing paper prescription forms from all clinical rooms, resulting in 99% of prescriptions being issued electronically.

Measures include:
- Online registration and repeat prescription requests
- Text messages to inform patients of appointments and test results
- Most incoming secondary care data received through electronic data transfer
- Electronic mailing system for communication between clinicians
- Patients booking hospital appointments before leaving the practice.

The move was carefully thought through before initiation, with clinical and non-clinical staff meeting to consider how paper could be eliminated from their work. Patient representatives were asked for their views. The measures have not only improved clinical safety but also given patients more control over their prescriptions and appointments without their need to speak to reception staff, while streamlining processes such as referrals.

The paperless approach has also been a key factor in a reduction of almost half in attendances at emergency departments by the practice’s patients while the list size went up. This is largely because the practice now screens patient attendance at emergency departments with improved and faster data sharing hours.