Inside the National Diabetes Audit – and beyond

Since 2004, the National Diabetes Audit (NDA) has offered unprecedented insights into the state of diabetes care across England and Wales. Now the NDA is set to markedly increase the breadth and depth of data captured. Meanwhile, increasingly intelligent smartphones offer the prospect of collecting petabytes of data, empowering self-care and supporting clinical consultations. Mark Greener examines whether these advances will help or hinder service improvements.

We live in a world dominated by the analysis of almost incomprehensible amounts of ‘big data’: analysis routinely think in petabytes (quadrillions of bytes). Retailers track millions of purchases – for example, using loyalty cards to understand and target customers. Search engines use big data to improve, for instance, search bar spell checkers. And big data potentially offers novel insights into the risk factors for, and the pathogenesis and management of, numerous diseases from infections to cancer to diabetes.

Indeed, diabetes was – depending on your definition of ‘big’ – arguably one of the first big data initiatives in UK health care. The National Diabetes Audit (NDA), which is one of the world’s largest annual clinical audits, integrates data from millions of patients across primary and secondary care. The 2014–15 NDA, for example, collected data from about 4700 GP practices and 99 specialist services, encompassing 1.9 million people with diabetes. Over the years, the analysis of these data yielded important and unexpected insights.

‘Ten years ago, we had no idea of the extent of the variation in care for people with diabetes across England and Wales. We had no idea of the strength of the association between diabetes and heart failure or the impact on life expectancy. The NDA provided these insights,’ says Peter Knighton, Principal Information Analyst at the Health and Social Care Information Centre (HSCIC). ‘As a statistician I attach all sorts of caveats to the reporting of historical comparisons, such as that we might not directly compare like with like because of changes in definitions and data collection. But it’s clear we’ve seen consistent improvements in the care processes since the first NDA. Sixty percent of people now achieve all eight quality care processes. From a historical perspective, that’s a remarkable achievement.’

Despite the NDA’s high-profile success, the lack of integrated care records across much of the NHS not only wastes resources but also creates data silos that hinder improvements in care. Moreover, the NDA does not yet offer a comprehensive picture: eye disease and mental health are, for example, conspicuous absences from the reported care processes. Meanwhile, a rapidly growing new generation of apps and other – in the tech jargon – ‘mobile health solutions’ raises fears of a digital divide in diabetes care. So, where do we go from here?

Getting to the bottom of IT

The long-heralded, seamlessly integrated patient record that can be used across the NHS by every health practitioner, from a nurse in Newport, to a pharmacist in Penzance, to a diabetologist in Dundee, seems as far away as ever. ‘Patients often expect their consultant to be able to access their primary care records and vice versa,’ says Amy Rylance, Head of Healthcare Professional Liaison, at Diabetes UK. ‘They’re astonished when they can’t.’

Yet, Diabetes UK points out, information sharing, especially of patients’ clinical records, is essential to ensure seamless, integrated, high-quality care. For example, integrated patient records can avoid duplication of measurements of cardiovascular parameters and glycaemic control by both primary and secondary care. Moreover, secondary care clinics often rely on patients’ recall of, for instance, drugs and adherence. ‘Duping assessments is a waste of resources, while having to ask basic questions wastes time in time-pressurised consultations and is often inaccurate,’ Ms Rylance says.

Some areas already use integrated IT clinical record systems across primary and secondary care. Bradford, Ms Rylance notes, has integrated records across the whole health system, including social care. Ipswich has integrated records for diabetes. In most parts of the country, however, there’s one data silo in the community and another in the trust – and never the twain shall meet.

In areas sharing information, users highlight the benefits for patients of being able to offer seamless care based on the integrated record. Implementation across the UK has been inconsistent, however, Ms Rylance adds. ‘For example, local interpretations of regulations around, for example, patient consent and protection of confidentially often hinder uptake.’ Nevertheless, Diabetes UK believes that IT initiatives are best developed locally, rather than waiting for a ‘top down’ infrastructure. ‘These local initiatives have a clear, tangible idea of what they want to achieve,’ Ms Rylance comments. ‘That probably accounts for their success.’

Evolving the NDA

Integrated IT would also facilitate collection of the macro-level data needed to characterise and enhance clinical care at a national and local level. The NDA exemplifies, for example, how big data collections can aid service development. ‘If you don’t measure current performance, you don’t know what to improve,’ points out Bob Young, Consultant Diabetologist, Salford Royal NHS Foundation Trust, and Clinical Lead for the NDA.

The NDA now allows users to examine variations at a GP and service level. The 2014–15 NDA found, for example, that the proportion of patients that received all eight care processes ranged from 24.8% to 80.6% across clinical commissioning groups and local health boards, with a median of 58.7%. The proportion of patients that achieved all three treatment targets (glucose, blood
Pressure and cholesterol) varied from 32.7% to 51.7%, with a median of 40.1%.

‘Diabetes UK strongly encourages local commissioning groups to use these data to improve care,’ Ms Rylance remarks. ‘Sometimes there are reasons for inequities in care – such as differences in the ethnic mix between areas. However, this can become an excuse for poor care. So, it is important commissioners use the data to look at comparable areas, which can help them focus on where they can improve care.’

Nevertheless, IT limitations mean that the HSCIC and Diabetes UK cannot, for example, include retinal screening data in the NDA. ‘There are very accurate records for retinopathy screening,’ Dr Young comments. ‘However, these records don’t easily link with our other data systems. We’re changing the way some data is collected over the next 18 months and we expect to be able to collect more robust data about eye care processes going forward.’

Furthermore, the care processes covered by the NDA are likely to expand into other areas. In 2013, for example, the NDA piloted a diabetes patient experience survey and, in the wake of NICE guidance, now includes insulin pumps. ‘We look at the implications of the guidance for the NDA and what we need to do to align,’ Dr Young says. ‘The NDA is in constant evolution and there are plenty of opportunities for development.’

For instance, the Healthcare Quality Improvement Partnership also highlighted the need to improve outcomes and care in people with learning difficulties and diabetes. ‘Provided we get funding, we could expand this to include mental health more widely,’ Dr Young says.

In addition, the NDA will rapidly signal if the NHS Diabetes Prevention Programme (DPP) is helping to reduce the number of type 2 diabetes cases. ‘The DPP has started to collect data on recruitment from the pilot sites,’ remarks Dr Young. ‘This will allow us to have a joined up, robust data set as the DPP rolls out. We expect to begin to see signals, such as on incidence and rates of diagnosis, in the pilot sites within three or four years. So, we’ll have a good idea as to whether the DPP is working. However, it will be longer before we can evaluate fully the DPP’s impact.’

The NDA team also increasingly explores working with other countries, including New Zealand and Sweden. ‘We are considering collaborations with other counties, especially to look at the management of type 1 diabetes,’ says Dr Young. ‘These collaborations allow us to pool data, look for international variations and learn best practice. We’re also looking to integrate the NDA with other registries in England and Wales, such as cardiovascular disease, stroke, renal disease and cancer. We need to establish the mechanisms to collaborate and obtain funding. But it’s likely that in the next five years we will see such collaborations. This could give us a much deeper understanding of the relationships between conditions.’

The future’s already here
In the meantime, mobile health solutions are already a multi-billion dollar industry that is rapidly growing. Analysts expect the market for apps and other ‘health solutions’ for smartphones, tablets and other mobile platforms to grow at about 33% a year, reaching US$59.15 billion by 2020.1

Certainly, people with diabetes can use an increasing number of apps to measure and record blood sugar levels, and track and compare carbohydrate intake, insulin use and physical activity. If patients agree, health care professionals, parents and other carers can access these data. ‘The use of smartphones to aid diabetes management is already happening,’ says Ms Rylance. ‘These can, for example, track glucose levels and insulin use, and can be uploaded to aid consultations, and some people find them very useful.’

Meanwhile, mobile phones are getting smarter. ‘Think how far a smartphone has come,’ says Ali Parsa, Founder and CEO of babylon. ‘In five years, your phone will probably be 50 times more powerful than today. In 10 years, it’ll be 1000 times more powerful.’ Already, babylon allows users to access health care professionals through video consultations, phone calls or text messages. A monitoring system tracks, for example, cholesterol concentrations, blood glucose and sugar levels, and can include an Hba1c test. Babylon’s doctors can analyse the data and suggest preventative measures. Recently, the company also started using artificial intelligence to include genetics, environment, behaviour and biology to increase the system’s power. These will be available in the next generation app, which babylon plans to launch this year.

Dr Parsa compares the change in health that potentially results from these advances to that in the automobile industry several years ago. ‘You used to take your car to the garage when it broke down,’ he explains. ‘Now a car contains numerous sensors that monitor the environment and your behaviour. The car uses sophisticated algorithms to detect that you have to take action – change your oil, for example – to prevent something going wrong. We can already do this with blood glucose monitors. In the not too distant future, we’ll have apps on our smartphones that can diagnose a range of diseases using the non-invasive detection of glucose and other biomarkers in, for example, our breath or tears. The technology is already being developed.

‘Further studies need to determine the biomarkers’ accuracy, but we’re on the verge of being able to perform real-time diagnosis of diseases such as diabetes, although regulation hasn’t kept pace,’ Dr Parsa predicts. ‘We have the technology to allow you to call your car and it self-drives to your door in the morning. But we can’t implement it because of insurance and regulatory hurdles. It’s similar in health. Politicians need to transform the regulatory environment so the UK – which is currently a world leader in e-health – can retain its position.’

Dr Parsa denies that such high-tech systems will predominantly appeal to already motivated patients or the ‘worried well’ rather than those who most need support. ‘There is a lot of talk of a digital divide. But there are always early adopters of any technology, who are in the vanguard and who act as...
advocates. The alternative is to do nothing,’ he says. ‘Furthermore, terms such as “worried well” are patronising comments by the health intelligentsia. The worried well are people who are doing what health care professionals are supposed to want. They are measuring their benefit of society.’

A consensus
Clearly, mobile health solutions will generate petabytes of patient-level data. However, while such apps may aid individual consultations, it’s unlikely to make much difference to commissioners, policy makers or the NDA. ‘Apps provide operational data about day-to-day lives. They can give useful information to help patients self-manage their diabetes. However, the NDA takes a more strategic view covering total care provision. It’s difficult to see how data collected by apps would help,’ Dr Young says. ‘Nevertheless, we’re hoping to develop a “my diabetes” tool that allows users to compare themselves to other people in the local area.’

Even Dr Parsa – and you don’t need to speak to him for long to realise his almost evangelical passion for technology – doesn’t feel that big data used to empower individual patients will be much help to commissioners and policy makers. And he doesn’t feel that IT solutions imposed ‘top down’ – for example, by government – aimed at the patient-physician interaction will deliver better care. ‘Health care professionals aim to fix one health problem in one patient at a time. Government and the NHS create the most optimal environment to allow professionals to work,’ he says. ‘They go hand-in-hand, and big data and technology can support both sides. But God help us if government ever tries to write an app. And God help us if app developers ever write policy.’

Book review
The hands-on guide to diabetes care in hospital

By David Levy
Published December 2015 by Wiley-Blackwell
176 pages
Paperback £21.99
ISBN: 978-1118973493
Website: www.wiley.com

This book offers a practical and precise guide for the management of a person with diabetes during a hospital admission. The book is easy to navigate and, in its six chapters, concentrates on basics, acute diabetes problems, clinical cases complicated by diabetes, glucose management, and glucose-lowering medication in general. This provides a one-stop basic guide on what a practitioner needs to know about diabetes care.

Dr Levy acknowledges the importance of evidence-based care and the use of policies and protocols, but also cleverly integrates experience and opinions into the text (which he describes as “tricks of the specialty”). He uses humour when appropriate to engage the reader and thus avoid the laborious read which so many text books offer. However, it may be useful for the reader to check on local policies/protocols in areas where references have not been cited.

Checklists, top tips, key points, tables and diagrams are used to clearly impart information regarding practical issues and care; a further strength is the guidance on which member of the diabetes team to contact when there are specific problems or when advice is needed.

An important feature is discharge planning and the focus on holistic patient care rather than just the health problem requiring admission. This is a strength of the book which ensures care does not finish as the patient leaves the hospital building.

As we all know, diabetes is a complex and challenging disease to manage and, for junior or inexperienced medical and nursing staff in diabetes, important aspects of care could be overlooked. This book offers a straight-to-the-point and concise resource to ensure the physiological, psychological and social aspects of an individual’s care are provided.

Another recommendation from Dr Levy which is worthy of note is to communicate with patients to gain an understanding of diabetes, and use the information alongside the clinical guides within this book.

Jacqui Charlton, Lecturer/Specialist Nurse in Diabetes, Edinburgh Napier University/NHS Lothian, UK

Over the next few years, health care professionals, commissioners and registries such as the NDA will help us gain a much clearer idea of when and where big data will help improve care. But some trends seem clear. A growing number of areas will develop integrated IT systems to reap the benefits some parts of the country already realise. The NDA will continue to inform service improvements, while increasing the care processes it encompasses. And for the foreseeable future at least, apps will aid consultations and help some patients at least self-manage their diabetes rather than aid service development. It seems that in diabetes knowledge – and that increasingly means big data – is power.

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