

FOR HEALTHCARE LEADERS

HSJ

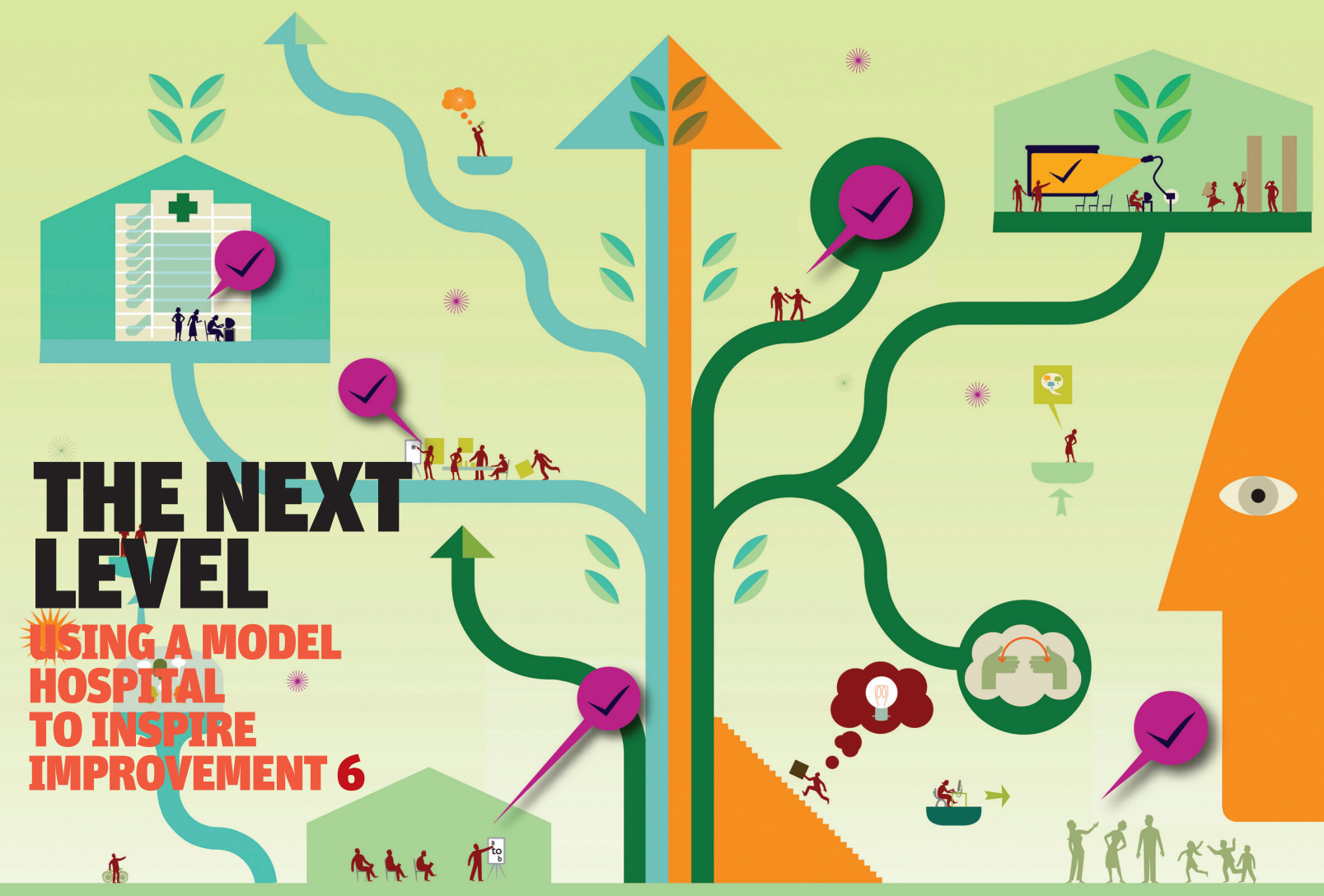
HSJ/NHS CONFEDERATION SUPPLEMENT

AN HSJ SUPPLEMENT/30 MAY 2014



NOBODY KNOWS YOUR NAME

CAN 'PSEUDONYMISED'
RECORDS CALM PUBLIC
FEARS ABOUT CARE.DATA? 2





“ Section 251 is an infamous clause in the Health and Social Care Act 2001, which was re-enacted in the NHS Act of 2006. In summary, section 251 allows the secretary of state for health to make regulations to set aside the common law duty of confidentiality for defined medical purposes.

The regulations that support the clause are called the Health Service (Control of Patient Information) Regulations 2002. Any references to support or approval given under section 251 actually refer to the approval given under the authority of the regulations.

Section 251 was established because there were certain activities of the NHS (eg: acute resource planning) and medical research that required the use of linked patient information. As patient consent couldn't be obtained, there needed to be a legal basis for providing access. The reasoning behind Section 251 is that there are occasions where it's not possible to use anonymised information but seeking consent isn't practical. Yet I would argue in cases where some key identifiers are being used, the use of strongly pseudonymised data can always be an alternative to section 251.

'Pseudonymised data is always an alternative to section 251'

So how will strong pseudonymisation at source help? This technique takes the patient identifier and creates a new identifier, using a key that can be shared between data providers, so that patient records can be linked together. The new identifier is not reversible; patient identity cannot be accidentally revealed, since actual identity would require work to find the details. This technique alone will not prevent re-identification, but it will go a long way to reassuring those citizens who have been concerned by the recent Care.data debates. The originating organisation would be able to identify patients where patient reidentification is required, using the linkage identifier.

There is also the argument that if, as suggested many times, the use of the NHS number was mandated across all health and care services – including adult social care – section 251 would become redundant, as the unique identifier facilitates full scale pseudonymisation at source using a tool such as OpenPseudonymiser.

As a GP and part of the TPP ResearchOne team, I understand the importance of quality linked data and the benefits it can bring in terms of treating patients and allocating resources. However, as a citizen, I also understand the concern that legislation such as section 251 too easily allows quick access to identifiable data and opens up the potential for dangerous (or unethical) data use.

Dr John Parry is clinical director at TPP.
www.tpp-uk.com

PATIENT RECORDS

THE DATASET WITH NO NAME

Could pseudonymised data at source rescue the beleaguered care.data programme? By Jennifer Trueland

If we have learned anything from recent events it's that people have very strong feelings about sharing patient data – and that there are significant differences of opinion.

While some are horrified that any patient information is seen by anyone apart from, say, the clinician treating them at the time, and have real concerns about what might happen to their records, others believe that sharing data can bring huge benefits both to the NHS and to individual patients.

The Care.data debate is a case in point.

As is well known, in February, NHS England took the decision to postpone the rollout of the Care.data programme, the ambitious initiative to extract data from GP records and share it with the Health and Social Care Information Centre.

The idea is to use the data (linked with hospital episode statistics) to improve patient care, by, for example, identifying disease patterns, monitoring the effects of treatments, or informing NHS planning.

The roll-out was abandoned, however, following concerns raised by the British Medical Association, royal colleges and others. At the time, Tim Kelsey, national director for patients and information with NHS England, said that the message was clear that “patients need more time to learn about the benefits of sharing information and their right to object to their information being shared”.

A six-month awareness raising exercise is now underway – and might even take longer than that.

Although the decision to postpone has been welcomed in some quarters, it has led to raised eyebrows in others, for example, the research community.

Indeed, many believe it would be entirely possible to sidestep the issues raised by Care.data if a different model were applied,

making use of pseudonymisation at source software, and taking the whole question of identification completely out of the picture.

Chris Bates, head of analytics, informatics and research with TPP, and an honorary research fellow at the Institute of Health Sciences at Leeds University, says there are huge benefits in being able to link data from different sources, such as GP information, and hospital episode statistics.

“Care.data has shaken the public's confidence in sharing patient records,” he concedes. “But if we were to take a different approach, and use pseudonymisation at source, then we can allay many of the concerns. If the data simply isn't identifiable, then people's confidentiality isn't at risk.”

Pseudonymisation at source involves taking a patient identifier, such as the NHS number, and applying an algorithm to it so that it is no longer identifiable. “You can't routinely reverse it to get the identity of the patient – it can't go backwards,” he says.

“The research community has been doing this for a while, and we see no reason why it shouldn't be adopted more widely.”

Pseudonymisation at source allows different datasets to be linked – such as those from the GP record, hospital episode statistics, cancer registries and cause of death information. Putting them together builds a comprehensive picture with numerous applications – and, the greater the number of datasets, the more synergistic the results.

“From a research point of view we can do it, and we are doing it,” he says.

NHS England has confirmed that the information centre is currently examining the feasibility of pseudonymisation at source, but says it will be challenging to apply it at a large scale because different organisations across the NHS use different information systems.



Dr Bates, however, believes that there is enough consistency to make it valuable – and that 100 per cent coverage isn't necessary as a starting point. "What we would say is that if you can get 50-70 per cent providing pseudonymisation at source, then you can wait for the other 30 per cent.

"The research world has been using this technique very successfully for a number of years – I believe we should be using it in clinical settings too, to allay concerns."

Delays to greater data sharing are regrettable, he believes, but says that restoring public trust is important.

"Care.data has shaken public confidence and people are dropping out," he says. "There's some work to do to reassure the public and to make it clear that it's actually in people's best interests for this to happen. Of course patient confidentiality is vital, but I think we can do this without compromising it."

The information centre is also working to provide further reassurances over the safety of data collected, stored and shared.

The important thing, says NHS England's Tim Kelsey, is to listen, and to get the processes right, for patients and the public. "We are acting on the views of patients, the public, doctors and others, and are making key changes in response," he says. "We want

'The research world has been using this technique for years – we should be using it in clinical settings too, to allay concerns'

to listen carefully rather than setting some artificial deadline for rollout.

"Parliament is also adding important new legal protections to safeguard patient data, while ensuring patients are able to benefit from the quality improvement and breakthrough health advances that this initiative will enable."

The stakes are high on this. Get it right, and Care.data will help maintain standards on clinical safety and effectiveness, and raise the alert if standards drop. If it works as planned, Care.data will mean that the NHS has much more information about what works and what doesn't work, potentially revolutionising outcomes.

But the consequences of getting it wrong – particularly in terms of losing public trust – are also serious. As Dame Fiona Caldicott

recently told BBC Radio 4's *PM* programme, good public information is essential. As chair of the Independent Information Governance Oversight Panel, she believes that the Care.data public information leaflet was not clear enough and did not follow her panel's advice. She also said in the interview that she, personally, did not recall receiving a leaflet, and that NHS England had been in too much of a hurry to roll it out.

NHS England does, however, clearly now understand just how high feelings are running on this issue. This was made obvious in the relatively strong language used in a recent communication sent to the participants of the newly constituted Care.data advisory group (autonomous, but set up by NHS England in March 2014).

Along with draft terms of reference, the letter, which is available on the NHS England website (<http://bit.ly/1jC89Fy>) calls for respect for different views, saying that "people who choose to opt out are not extremist, people who advocate data sharing not cavalier".

The irony, says Dr Bates, is that solutions such as pseudonymisation at source could, potentially, address the concerns of both camps. At the moment, however, there are no concrete signs that the government feels the same way. ●

PATIENT RECORDS: CASE STUDIES

RETURN TO THE SOURCE

How health researchers are already using pseudonymisation of data at source

QRESEARCH DATABASE, NOTTINGHAM UNIVERSITY

As a GP and an academic, Julia Hippisley-Cox has a better idea than most about the value of good patient information – and the more rounded the data the better.

The GP record is valuable, of course, but if you can add hospital episodes, cancer registrations, and even cause of death then you can get a really good picture of what's going on all along the patient pathway.

What you don't need, at least in the vast majority of cases, is information that identifies the patient.

Professor Hippisley-Cox, professor of clinical epidemiology and general practice in the division of primary care at the University of Nottingham, is a pioneer in pseudonymised data.

Back in 2002, she co-founded the QResearch database, with pseudonymised data from around 700 GP practices which is a joint not-for-profit partnership between Nottingham University and EMIS. This was linked to cause of death data in 2007, and then to hospital episode statistics and cancer registration data in 2011-12.

Each new dataset linkage added a further dimension to the available information, offering more opportunities for research.

It was the need to find a practical way of linking the data, while retaining patient confidentiality, that gave rise to the pseudonymisation at source software.

Essentially, the process involves taking the NHS number and adding a random password to it. This is then converted using a one way hashing algorithm to create a unique string of 128 characters.

You then apply the same process to each of the data sources. When the data is sent to a third party – in this case, Nottingham

University – there is no way of identifying an individual patient. "It doesn't have real-world meaning," says Professor Hippisley-Cox. "But it allows you to link the datasets together."

The result is a treasure trove of data that can be used for a myriad of research purposes. For example, you could look at patients who have been admitted to hospital for stroke, then check the GP record to see if there had been any signs and symptoms, or if they had been on a particular drug, then you could check the outcome in terms of cause of death.

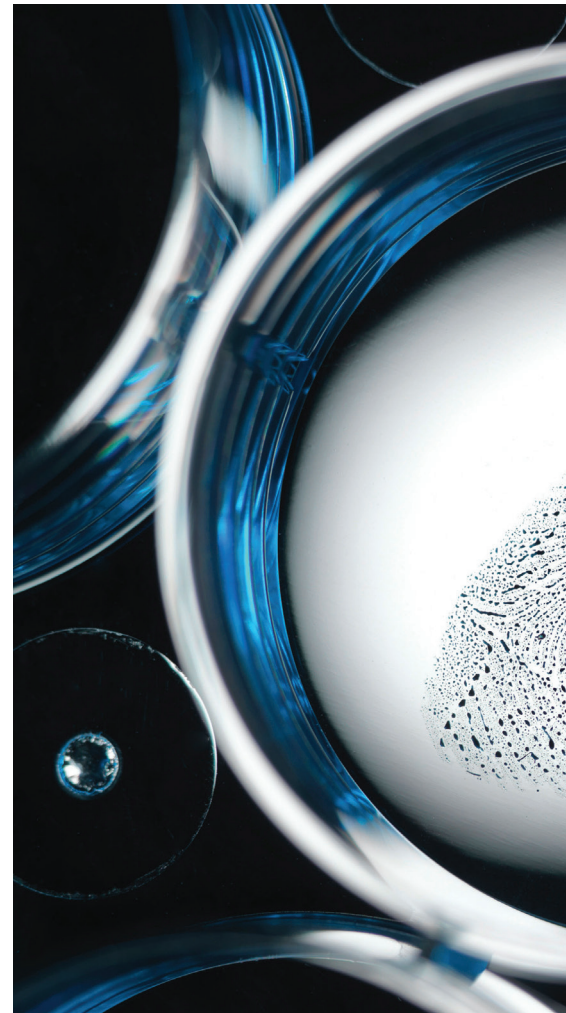
"It allows you to capture events that might only be recorded on one data source," explains Professor Hippisley-Cox. "For example, you could look at patients started on a new tablet, and you can follow them through the system and look for outcomes or side-effects."

Linking data has practical, real world benefits too, she says. She points to QRisk, a system which identifies people at high risk of heart attack, and which is now recommended by NICE as the standard tool.

Pseudonymisation at source was developed when Professor Hippisley-Cox wanted to find a way of scrambling the NHS number, and she spoke to the GP software developer EMIS, which was also keen. "We wanted to get a standard way of doing it so that any legitimate organisations that wanted to link data for patient benefit could get together.

"We held a series of workshops and there was a phenomenal response from other GP software providers, including TPP and In Practice, as well as the Department of Health and all sorts of other organisations. It was quite remarkable."

What people wanted, she explains, was a way of pseudonymising data before it left the system. "If the data is protected and has the right information governance controls, it's



better for patient confidentiality," she adds. "And from the perspective of GPs, as data controllers, this isn't identifiable data, so it doesn't fall under the Data Protection Act."

Although it falls outside the provisions of the act, there is still a need to ensure that patients know about it and have a chance to opt out, she adds – but this is a matter of good practice rather than law.

The workshops were oversubscribed, she says, and the pseudonymisation at source software is free to use. "We wanted to remove barriers to using it," she says, adding that it will work on any platform.

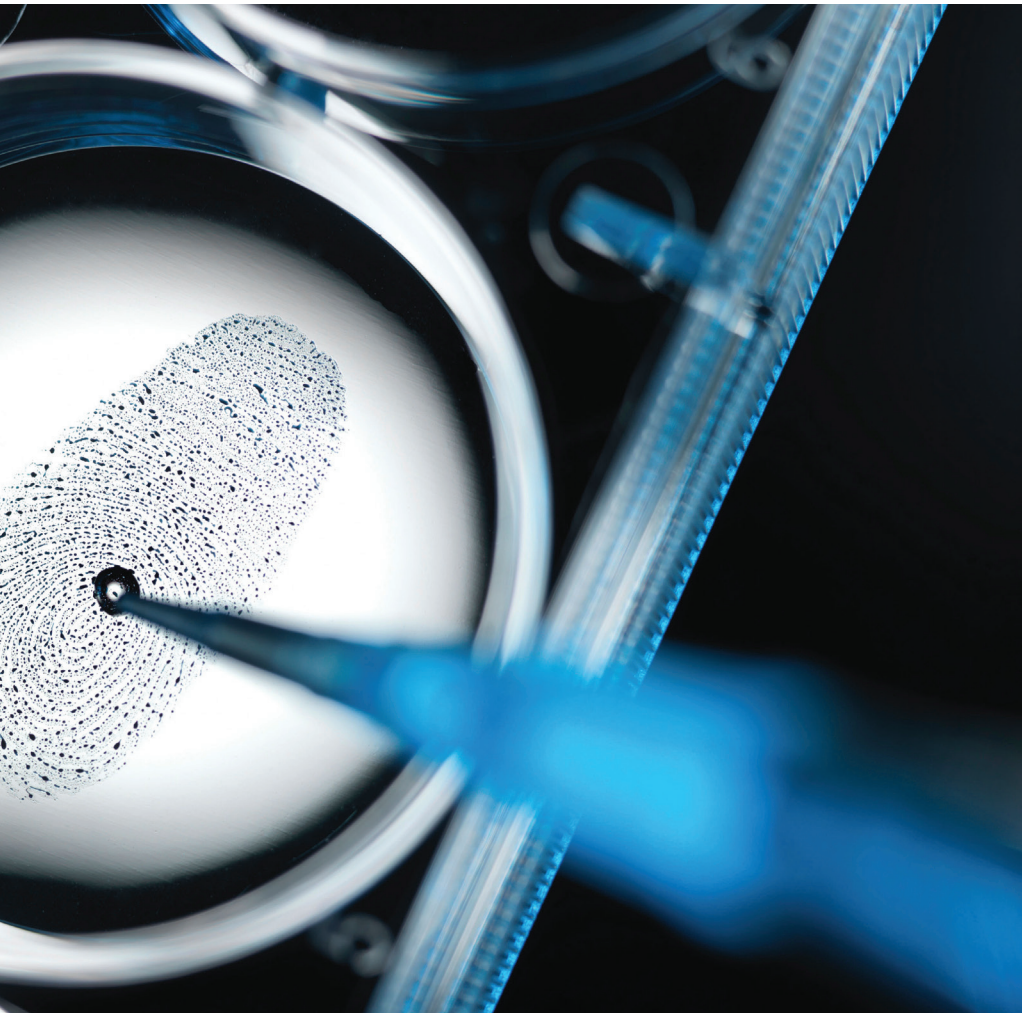
It was for her work on this project that Professor Hippisley-Cox won the John Perry prize last year – an award set up to recognise outstanding contributions to primary care computing.

So is she pleased with the achievement? Up to a point.

"I'm pleased with the project but we need to people to get over the idea that they need patient identifiers."

She feels that the software would answer many of the concerns that led to the postponement of Care.data. "I'm a bit frustrated at the moment," she says.

"To me it's a no-brainer. There's so much



Fingerprints removed: the NHS is being told to use systems that make it hard to identify patients

“For a lot of the research we do we have full section 251/relevant ethical approvals to hold identifiable data but to minimise risks we would carry out analyses on anonymised/pseudonymised versions of the data,” she says.

“A lot of the time we have data where the identifiers (for example, date of birth, postcode, NHS number) have been replaced with an ID number. This number can be related back to the original data by the database analysts who performed the original linkage.

The team’s work has been well received, she says, and certainly the results are impressive and potentially useful.

“The analysis of the linked data has allowed us to look at a wide variety of topics such as variations in post-operative mortality across trusts, factors associated with early mortality after cancer diagnosis, management and treatment of the elderly. We are also looking at extending the use of the data, for example linking patient reported outcomes data with treatment and survival data.”

Although she is using the data for research, Dr Downing’s work has real life NHS applications. For example, much of her activity has focused on breast cancer, bringing together information about care and outcomes, with a particular emphasis on applying novel methodologies to lead to a better understanding of what is often complex data.

Since 2011, she has been funded by a Cancer Research UK grant looking at national colorectal cancer intelligence. Again, the idea is to find appropriate statistical methods of looking in detail at the care and outcomes of people with this disease.

Recently the department has also completed a piece of work which involved analysing the results of a survey of colorectal cancer survivors about their quality of life after treatment.

This has allowed the researchers to feed back “toolkits” to trusts so that they can use the information to improve the patient experience – or to build on good practice.

Dr Downing has no doubt that the sharing of data, and the linking of different datasets, is a positive development, but says she understands the fears of people who are concerned about the confidentiality of their patient information and health records.

“People read media reports about patient information being sold to private companies and are concerned about that, which is a shame.

“Sharing patient information has the potential to do so much good, and our work shows that it doesn’t have to be identifiable patient information. That’s a message that we really need to get across.” ●

benefit to be had from using patient information. If [NHS England] had started working on this earlier then we could have seen some progress by now.”

CANCER EPIDEMIOLOGY GROUP, LEEDS UNIVERSITY

Without access to linked patient datasets, Amy Downing’s job simply wouldn’t be possible. And that would be a shame, both for the NHS and for the population as a whole.

Dr Downing is a research fellow in cancer epidemiology at the Leeds University Institute of Cancer and Pathology. Her research focuses on the analysis of linked datasets, such as cancer registry and hospital admissions data, to follow patient pathways and relate these to outcomes.

The work of her department means that, for example, trusts have a better idea of the factors that might lead to good – or bad – outcomes, and give them a change to adapt the pathway accordingly.

Essentially, the more information about what happens to each patient, at each stage, the better. Crucially, however, she never needs to know the patient’s name.

Even where her group has permission to

‘It’s a no-brainer. If NHS England had started working on this earlier then we could have seen some progress by now’

hold identifiable data, they do not actually use it in this way, choosing to use data which is pseudonymised at source. This is mainly to minimise risks, but is also possible because identifying the patient wouldn’t necessarily add anything to the research.

“Our work in the cancer epidemiology group at Leeds University consists primarily of the analysis of linked datasets,” she explains.

The more information sources the better, in many ways. “It helps us get a more rounded picture. Some of the data isn’t very good, and the more sources we have, the truer a picture we can get.”

As researchers, the group are given extracts of data, which are processed and stored according to the ethical approvals for the specific project.



MARTIN JOHNSON ON CONTINUOUS IMPROVEMENT

IN ASSOCIATION WITH BMI HEALTHCARE



“ At BMI Healthcare we believe a culture of continuous improvement can benefit patients in terms of both high quality clinical outcomes and their experience.

We introduced “lean” thinking into BMI Healthcare as we believe it is one of the simplest but also the most powerful and consistent ways of engaging and equipping our people to continuously improve what they do and how they do it. Together, we embarked on a journey to nurture excellence and share best practice through what we call “the BMI Way”. It encompasses a defined way of working based on a philosophy of continuous improvement, where we review results and ask ourselves the question: “How could I do this better today?”

It actively empowers and enables everybody at BMI Healthcare to make a difference and helps them to focus on what really matters, our patients. Our people join a 10 minute daily session called a “communication cell” to discuss yesterday’s performance, the learning from yesterday that will be incorporated into today’s activity, and to plan ahead over the coming weeks. The aim is that a problem today is fixed so that it is not a problem tomorrow. Everyone has a voice at these sessions, stimulating an environment where concerns are dealt with in a timely manner and innovation is accelerated, all of which promotes our ethos of “serious about health, passionate about care”.

The BMI Way captures best practice in each of our hospitals and knits it into a way of working

‘98pc would recommend their BMI hospital to friends and family’

that is systematically shared and adopted so that we can achieve even higher levels of care: 98 per cent of our patients said that they were extremely likely or likely to recommend their BMI hospital to their friends and family if they needed similar care or treatment.*

Our staff have been delighted with the ways of working we have created together and the Care Quality Commission gave us positive feedback on our culture and approach when they inspected sites operating the BMI Way.

Our aim is to embed the BMI Way in all our hospitals and our offices. The scale of change and the positive impact is heart warming. We believe that this is the best and most complete example of lean healthcare in hospital delivery anywhere in the UK at the moment and we want to make it better still.

Martin Johnson is managing director for commercial, business improvement, infrastructure and technology at BMI Healthcare. www.bmihealthcare.co.uk

*Based on a sample of 35,624 patients completing a questionnaire during the period April-December 2013. Questionnaires analysed by Quality Health, an independent survey provider.

SERVICE IMPROVEMENT

THE EXEMPLAR HOSPITAL

How an independent hospital group built a model that the rest of its organisations could learn from

How do you bring in significant change in an organisation as complex as a group of hospitals, spread across the country and with their own ways of doing things? One answer is with the help of an exemplar hospital where changes have been piloted and refined.

The 65 BMI hospitals are moving towards adopting “the BMI way” – an approach which incorporates “lean” thinking but has enhanced communication with staff at its heart. The aim is to improve patient care, says John Coulston, process improvement director for BMI Healthcare.

Mr Coulston says improving staff engagement has been a key aim of the project. “What we are trying to do is really make our clinical peoples’ lives’ easier,” he says. “We are asking our staff to do a lot of things that might have made sense five years ago but today are a waste of time.” Changing this could increase their capacity to care for patients, he says, and the aim is also to empower them to solve more problems at source as staff are the experts.

One of the key ways of driving forward change is through communication cells. These are a succession of short meetings, starting with each shift at ward level and working up through the organisation, where problems can be raised. This can be as simple as a member of staff having phoned in sick: using the pyramid system of meetings this can either be dealt with at a lower level (for example, by transferring staff between wards) or can be escalated up to director level within a short period of time. Ultimately issues raised can be cascaded through to the hospital’s leadership team and right up to the chief executive.

Communication notice boards allow anyone to add a concern at any point with an expectation that it will be discussed and acted on. The whiteboards also allow for

performance indicators to be recorded and for information to be passed down through the organisation just as quickly.

“We have always had a major emphasis on improving communication to ensure that we escalate risks and concerns to people who can do something about them,” says Mr Coulston. “It is about helping the leadership team recognise their primary focus is supporting frontline staff in delivering great care.”

‘When we had staffing problems, everyone was in their own world and not always supporting people on other wards’

The pilot site for these changes has been the Alexandra Hospital in Manchester. “At the Alex, the whole hospital is working in this way and we are now cascading it to other hospitals in the group,” he says. “We have created a growing number of standard solutions but we appreciate every hospital is different so we have tried to see these standard solutions as guidelines.”

The aim is to encourage a sense of ownership in the solutions – rather than people being told what to do too explicitly – and make them more sustainable with a tailored solution for the local circumstances.

Karen Higginbotham, associate director of nursing at the Alexandra Hospital, says: “The experience here has been very positive and I think now people are beginning to see the benefits.” Introduction was not without challenges, she says, and there was some resistance. However, the more open communication has paid off. “Before, when

