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HSJ

INNOVATION THROUGH TECHNOLOGY

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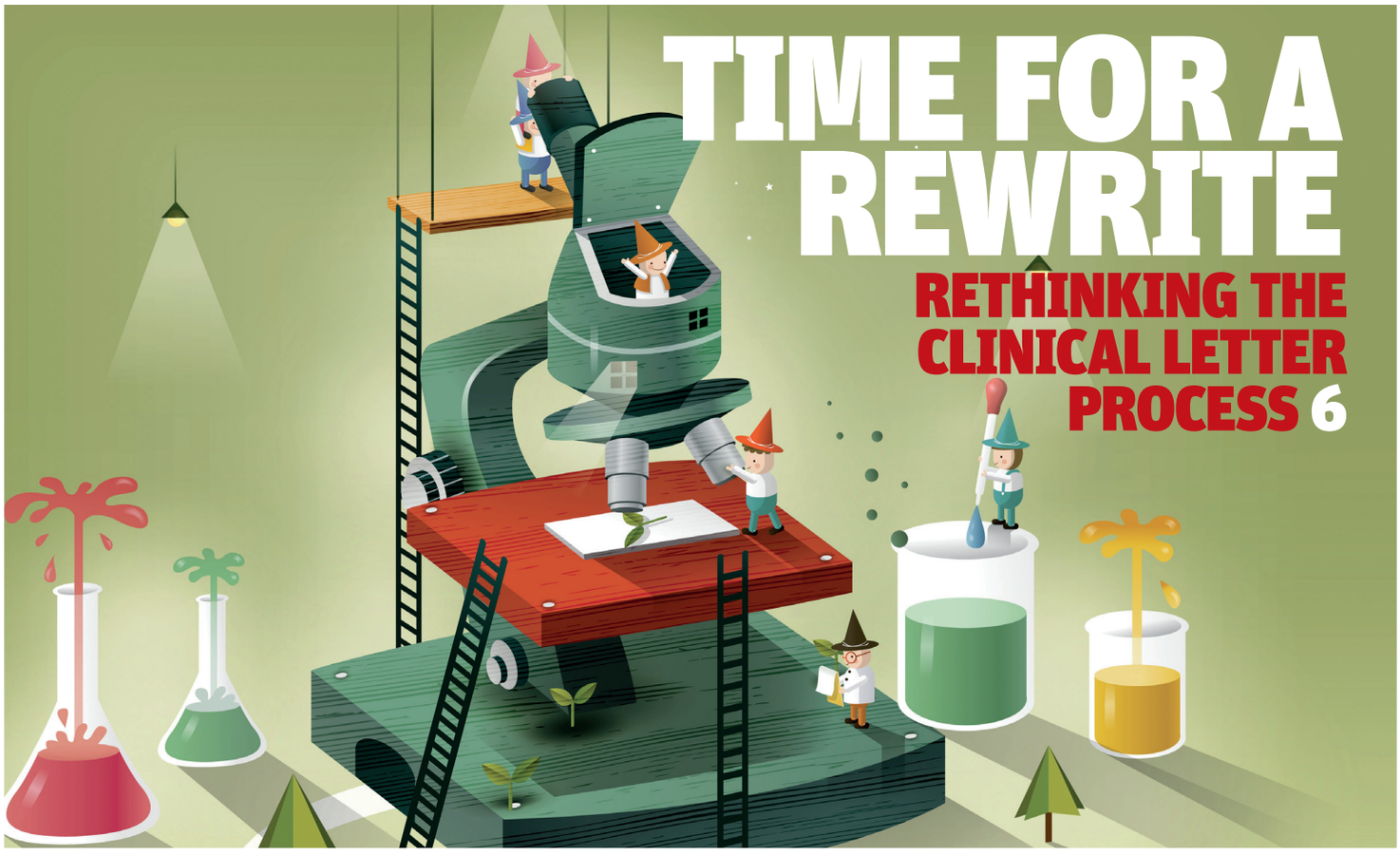

TIME FOR A REWRITE

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BIG AND CLEVER

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RICHARD CORBRIDGE ON RESEARCH SYSTEMS

Ninety nine per cent of NHS trusts are now actively involved in research, but what does "involved" mean? The Clinical Research Network's research league table tells us that research engagement varies widely and that there is still work to be done in engaging trusts in research delivery across a broader range of therapies.

A key aspect to further progress is the development of the NHS's research information systems. Although our health system is widely considered one of the most integrated in the world, we are not making the most of the opportunities this integration presents. In order to meet the needs of patients, researchers and the life sciences industry more effectively, we need to transform the way we collect and use research data.

Information strategy needs to support the delivery of defined business benefits and enable solutions to business problems. The NIHR Clinical Research Network has taken this as its mantra for the development of its information strategy. We are creating a world in which NHS research data can be turned into information that provides a catalyst for clinical insight. In turn, this allows "business intelligence" to benefit the whole research economy.

Information systems will be delivered in England before the end of this calendar year

'We are creating a world in which NHS research data can be turned into information that provides a catalyst for clinical insight'

that will increase transparency, reduce complexity and provide an innovative platform for research to be undertaken. These include performance management systems – made available to the NHS, researchers and industry to ensure research is conducted in the right place – and innovative solutions provided by the clinical practice research datalink that the Medicines and Healthcare Products Regulatory Agency and NIHR are delivering together.

But these systems cannot stand alone. They will have an impact because of the NHS's commitment to research and the creation of a joined up attitude to data delivery across the entire healthcare system. With this progressive package in place, we will be able to truly ensure that as much support as possible is in place to enable the research journey to have a significant impact on the health and wealth of the nation.

Richard Corbridge is chief information officer, NIHR Clinical Research Network
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RESEARCH

THE BIG DATA HAYSTACK

Daloni Carlisle on building open and linked systems that can help the NHS lead the world in delivering research

The NHS is perhaps the largest repository of data about people's health in the world. It is also one of only a handful of health systems able to offer a full account of health across care sectors and throughout lives.

In theory, this puts the UK in an unrivalled position to ask the right research questions and identify the right patients and locations to support them. But in reality NHS data often lies in silos, is hard to link and hard to search – hard, in fact, to use.

One of the players addressing this challenge is the National Institute for Health Research Clinical Research Network – the research delivery arm of the NHS. It has research nurses and clinical support staff across the NHS in England, linking patients with appropriate clinical research opportunities, and delivering research to help the research community provide the robust evidence required to improve treatments for NHS patients. In 2012 the Clinical Research Network pledged support to more than 1,300 new research studies, and recruited 595,000 patients into clinical studies.

The Clinical Research Network has just taken a major step in improving the accessibility of research delivery data, by launching the Open Data Platform. The system is partly a response to the government's open data initiative and partly due to a desire to make better use of data that is being recorded about research delivery throughout the NHS.

Richard Corbridge, chief information officer of the NIHR Clinical Research Network likens this platform to "a metal detector for the big data haystack".

He says: "Everyone is talking about Big Data these days. But is big data just more hay on the haystack? What happens when you need to find a specific piece of information that will enable that all important insight? Then you have the proverbial needle in the haystack and you need a metal detector to find it. That's the Open Data Platform."

So right now, Clinical Research Network staff can go to the Open Data Platform and find out, for example, the number of patients being recruited into research studies in a given hospital, or the research being done at that hospital. They can find out which hospitals are best at recruiting patients, how quickly and into what specialist areas. And later this year in phase two of the launch, this information will be made available to the wider clinical research community.

But the ambition is to go beyond this and start linking to other datasets that will help the NHS to make some real business intelligence decisions about how to make research study delivery smarter, faster and more efficient. Cancer registries, HES data and industry data are all being considered for the next steps of the Open Data Platform.

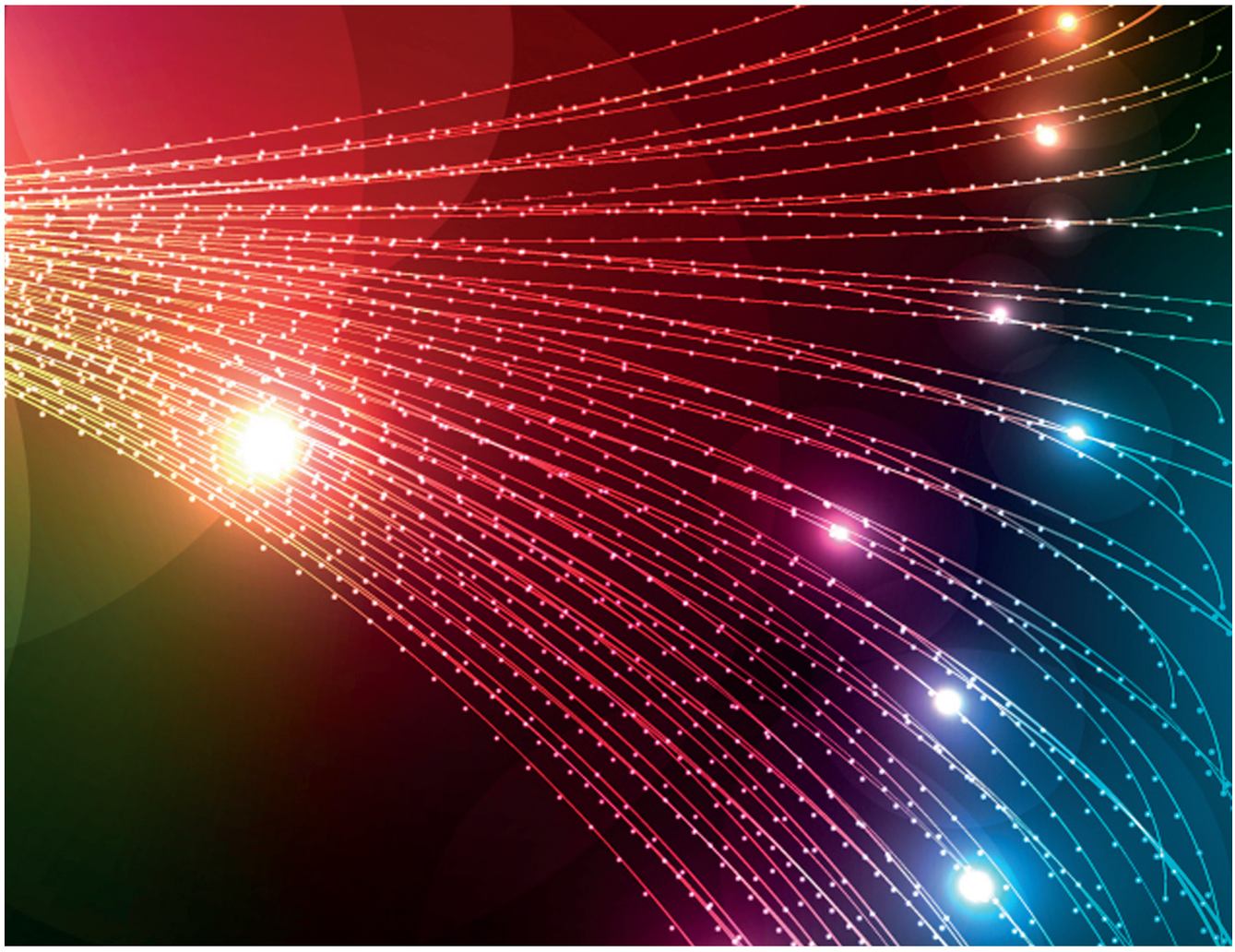
Matt Cooper, assistant director of NIHR's cancer research network, says this approach would ease the burden of research.

"In breast cancer trials, patients are followed for ten years or more. If you can link their datasets electronically, you do not need to bring them into the clinic for follow up with research nurses." Research is already under way to compare the data quality derived from electronic records with that collected by research nurses – and so far the results show that the quality matches up.

It will also answer some questions about who is taking part in research, he adds. "At the moment, for example, it is difficult to be exact about how many black and ethnic minority patients are taking part in our combined studies because we do not aggregate that information. But with data linkages we could – and find out if there are any populations that are being missed out."

Data linkage is an agenda that Dr Mark Davies, medical director of the Health and

CASE STUDIES OVERLEAF ▶



Social Care Information Centre, certainly supports – and one that fits a wider agenda around research and data.

"I think research is changing in very, very fundamental ways," he says. "It is becoming an integral part of the way we do business and increasingly it is unacceptable for me, as a GP, not to do research."

Dr Paul Wallace, clinical director of the primary care research network, agrees. "It used to be that research was a minority sport for GPs," he says. "Now over 50 per cent are research active and are actively recruiting patients to trials. GP records hold information on 97 per cent of the population's primary care and, increasingly, with electronic discharge summaries, we hold information about their hospital care too. It is a very rich source of data for research."

Dr Davies argues that information systems are beginning to play new roles. "It is taking us to quite an exciting place," he says. "We are beginning to see crowd sourcing of data from websites such as patientslikeme.com where people discuss their medication, or their symptoms and build up pictures of patient experience."

'At the moment, for example, it is difficult to be exact about how many ethnic minority patients are taking part in studies because we do not aggregate that information'

Susan Hamer, organisational workforce development director for NIHR's Clinical Research Network, argues that patient participation and use of patient data is beginning to shape the research agenda. The Michael J Fox Foundation – which funds research into Parkinson's disease, has been at the leading edge of this movement.

"Increasingly patient groups are saying to researchers, 'yes, you may use our data but in return we want you to do some research we think is important in return'," she says.

Then there is "real world" research – what Dr Davies calls the "ugly cousin" of randomised controlled trials (see case study, page 5).

So increasingly, research and making better use of the data held by the NHS on patient's behalf will be crucial to driving better, more efficient care. And the NIHR is set to play its part in making sure that the research community is ready to respond.

"We want to keep research here because it is good for everyone," says Mr Corbridge. "The Open Data Platform is part of making that happen." ●

NHS
National Institute for Health Research
Clinical Research Network

RESEARCH: CASE STUDIES

STUDY FINDING

Developments in managing research include systems that should soon allow potential participants to search online to find trials that interest them

CENTRAL PORTFOLIO MANAGEMENT SYSTEM

One of the hurdles for any research project is recruiting patients to trials and, while the NHS has a good record in many clinical areas, things could always be improved.

So the NIHR Clinical Research Network is developing a Central Portfolio Management System – a database with a web-based front end to manage workflow for clinical research throughout the UK. It goes live this summer.

"It is a massive leap forward for us," says Richard Corbridge, chief information officer of the NIHR Clinical Research Network.

Currently research nurses collect information about the delivery of over 3,700 studies in local portfolio management systems, logging the type of trials, how many patients have been recruited or have yet to be recruited, how many patients have expressed an interest in taking part in research via their GP and so on. This is then pumped out nationally, sometimes through re-keying data and often via a paper based route – so the data is always six to eight weeks out of date.

CPMS will centralise the data collection, which means that the data will be visible as soon as it is inputted within the local system.

"It will show us where people are doing research, where they need to recruit more patients and where those patients are," explains Mr Corbridge. It will not contain patient identifiable data.

Matt Cooper, assistant director of NIHR's cancer research network, says that CPMS will be a valuable resource. Cancer research is an area where the UK has an international reputation – and in which the proportion of patients involved in a trial has risen from 3.5 per cent in 2001 to 23 per cent today – but recruiting patients to clinical trials is an endless task.

"The plan is for CPMS to have a patient facing aspect, so if you are interested in, say, breast cancer it will show you what trials are open and where. It will potentially enable us to get a greater level of participation. It will allow us to look at studies on a more real time basis."

RECRUITING TO TRIALS

Recruiting patients with dementia to research trials is notoriously difficult – not least because in most cases they are infrequently in contact with the hospital centres where trials are based.

So last year, the prime minister's "dementia challenge" tasked the NIHR's dementias and neurodegenerative diseases research network (DeNDroN) to come up with a solution. The "consent to approach" register is to be launched is this spring.

Piers Kotting, assistant director of DeNDroN, explains: "The biggest issue we have is not that the research is not coming to the UK but that we are unable to recruit as many people as we would like."

So the idea is to find those people who are interested in taking part in research and register them.

"It is a mechanism that would speed up recruitment of people to trials because it would mean researchers can find them quickly and easily," says Mr Kotting. "It will create cohorts of people interested in research and allow researchers to look for people who meet certain criteria.

The idea is that patients attending hospital clinics will be asked about their willingness to take part in research – and that this would be a routine part of their clinical care.

Research shows that a limited dataset of around 40 items provides most value. It will include some demographics, diagnosis, medication and some lifestyle information.

It will be tested in six early adopter trusts and has support from the Alzheimer's Society and Alzheimer's Research UK, who will be publicising the register before rolling it out nationally.

It is not clear yet how many people will sign up. "The ambition is for us to reach 10 per cent of the 350,000 people with a diagnosis of dementia but we do not have a target," says Mr Kotting.

He is keen for trusts to take part – and for managers to encourage this. Registering patients does not mean that, once enrolled in a study, they will receive their care elsewhere. "Patients will still be funnelled back to the trust," he says.

DEVELOPING THE RESEARCH WORKFORCE

NHS patients like taking part in research, says Susan Hamer, organisational workforce development director for NIHR's Clinical Research Network. They like giving something back to the NHS that cared for them, they like the idea of helping the next patient along the line and they enjoy the experience.

"When I talk to patients about their experience they say they really appreciate it,"

she says. "They have a real choice about whether to take part and in particular they really value the experience they are getting with the research nurses.

"It is almost like a community nursing model where they see the same person regularly, often over a period of two years or more."

The NIHR Clinical Research Network provides funding for NHS trusts to employ research nurses throughout England. Their job can include finding patients who fit study criteria, recruiting them and gaining their consent, collecting the data and carrying out follow up. All undergo "good clinical practice" training to ensure they work to the highest professional standards, including data protection and ethics.

But data linkage for research purposes, while widely supported in the health professional community, has not been discussed much among the public. How much do the public understand about how their data is protected?

Dr Hamer is anxious that as much is known as possible about just how seriously the NHS takes this and is now developing open learning material that anyone can use to help gain an understanding of how research in the NHS works. She hopes it will be launched in the autumn.

'Patients attending hospital clinics will be asked about their willingness to take part in research – and this will be a routine part of their clinical care'

REAL WORLD DATA

An innovative use of linked data in clinical research is so-called real world data. This is not an alternative to the gold standard controlled trial but an addition to it.

Broadly, real world data is used in health research to describe data generated in day-to-day situations rather than the artificial setting of a clinical trial. While randomised controlled trials seek to establish the efficacy of a treatment using specialised criteria within controlled environments, real world data looks at the effectiveness of the same treatment in the randomised reality of daily life.

Real world data is based on information collected from anonymised patient records held by GPs and hospitals that are then analysed by researchers. It offers an alternative perspective that helps researchers understand how patients respond to treatment when it is complicated by a range of other factors including conditions, medicines and commitments.

So it helps care providers and commissioners to understand not just the safety of a drug for treating Alzheimer's – but also how someone with both Alzheimer's and diabetes might respond, explains Dr Mark Davies, medical director of the Health and Social Care Information Centre.

It is an idea that is being explored internationally and has the backing of software companies that provide hospital and GP IT systems as well as the pharmaceutical industry.

Kate Peperell, who leads the Association of British Pharmaceutical Industries' work in this area, says: "Real world data is data on what's happening every day in normal clinical practice and therefore reflects what's happening in normal clinical practice outside of a clinical trial. It can include data on treatment pathways, NHS resource use, models of service delivery or real patient or clinical outcomes. It can be captured for a variety of reasons: to improve the evidence base, for technology assessment, to capture early clinical experience, or more formally evaluate NHS joint working projects."

The challenge is to produce data that is robust and reliable and to develop protocols around its use, she adds.

"Real world data has been viewed as too dirty, too difficult to get hold of and requiring too much processing," adds Dr Davies. "But increasingly people in other industries are solving these problems and I think it is a more sustainable way of driving forward knowledge and research."

Susan Hamer, organisational workforce development director for NIHR's Clinical Research Network, agrees. "Increasingly, commissioners are asking drug companies to explain what a new drug means in the real world, not in a trial." ●

CHRIS RODWELL ON BETTER PROCESSES

IN ASSOCIATION WITH WINSCRIBE

winscribe
Let's improve the process

The humble clinic letter is gaining a new profile as commissioners introduce quality payments that reward providers for producing timely, high quality letters for GPs and patients following outpatient clinic appointments.

Technology has its place in streamlining correspondence to help meet these targets, but it is only part of the story. At the core of the process are the people involved. This may seem a strange message from a company best known for providing digital dictation and speech recognition solutions. It is nevertheless our experience.

Producing clinic letters is a process with multiple stakeholders in which creating the dictation is but one step. The key to transformation is streamlining processes – for getting transcribed letters to doctors for signing, for example, or automating the importing of patient or clinic details or test results electronically, eliminating the need for laborious and error-prone manual re-typing. A streamlined process integrated into other hospital systems can automate sending electronic letters to patients or GPs, which in turn can generate savings and benefits.

This is why we think it is time to look at clinical correspondence as a workflow issue that requires transformational leadership with senior level buy-in. This approach, coupled with technological innovation to automate many of the steps in document production, can really start to deliver efficiencies. Where this has been tried, trusts have achieved 48-hour turnaround times. We have seen trusts transform their processes so clinic letters are transcribed and ready for the consultant to sign at the end of the clinic – and for patients to view in a portal before they get home.

'Letters are ready for consultants to sign at the end of the clinic'

Winscribe is the only company currently able to offer an end-to-end document trail to the NHS from clinic to letter distribution, integrating with the hospital's existing systems to populate data. Trusts achieve much more than faster letter production. Safer processes, secure patient data and more accurate documents all improve patient experience.

We have experience of where the bottlenecks are and how they can be streamlined. Our systems, including digital dictation, speech recognition and Epro clinical workflow management, are easy to train on and use. Streamlining clinical correspondence is about more than secretaries and typing. It's about patient satisfaction and safety – an issue we will explore in a forthcoming *HSJ* supplement.

Chris Rodwell is head of healthcare at Winscribe

www.winscribe.com

EFFICIENCY

FIRST PAST THE POST

Trusts racing to speed up clinical letters must radically rethink an often tortuous process. By Daloni Carlisle

Did you hear about the trust where secretaries had to go through ten steps to find the right information to complete standard clinic letters for patients attending an outpatient appointment? Or about the consultants who docked their handheld digital dictation recorders once a day – just before they left for home?

Such scenarios are common and, until now, have largely gone unnoticed because they are just the way things are done. Each of them delays getting that all-important clinic letter to GPs and patients.

But with new pressures on trusts to meet targets for getting letters out in a timely manner – often backed by quality payments – they are now coming under the microscope.

Anna Bayes – a hospital doctor, management IT consultant and director of AB Consulting – says: "A lot of trusts have tried to make quick efficiency gains where they have huge transcription backlogs by using digital dictation or outsourcing their transcription. I hear again and again that this has gone some way to making improvements in timeliness but it has not delivered the savings they expected."

And that's because producing a letter is a process: the clinician dictates the letter, possibly having to wait for test results to complete it; the secretary transcribes it and adds in details such as patient demographics and the GP details; the doctor reviews and approves it; and then out the letter goes. Possibly by post.

And at each stage of this process there are potential bottlenecks. Some are human; some can be solved with technology.

"The first bottleneck is the dictation," says Dr Bayes. "Some clinicians do it as they go; some do it at the end of the clinic; some do it later. Yes, there might be clinics where they need to wait for test results, but many clinicians believe it should be done at the point of care when their memory about that patient is fresh."

Next comes transcription. Here there are two more bottlenecks – first the speed with which audio files reach the secretaries and second the speed and accuracy with which secretaries can complete letters, for example by adding patient names and addresses, checking the GP details and importing test results. Templates really help too.

Speeding up this part of the process is part human – getting clinicians to send audio files in a timely manner – and part automation. "Digital dictation and speech recognition systems need to integrate with and communicate with other hospital systems such as the PAS and National GP Database," explains Chris Rodwell, head of healthcare for Winscribe.

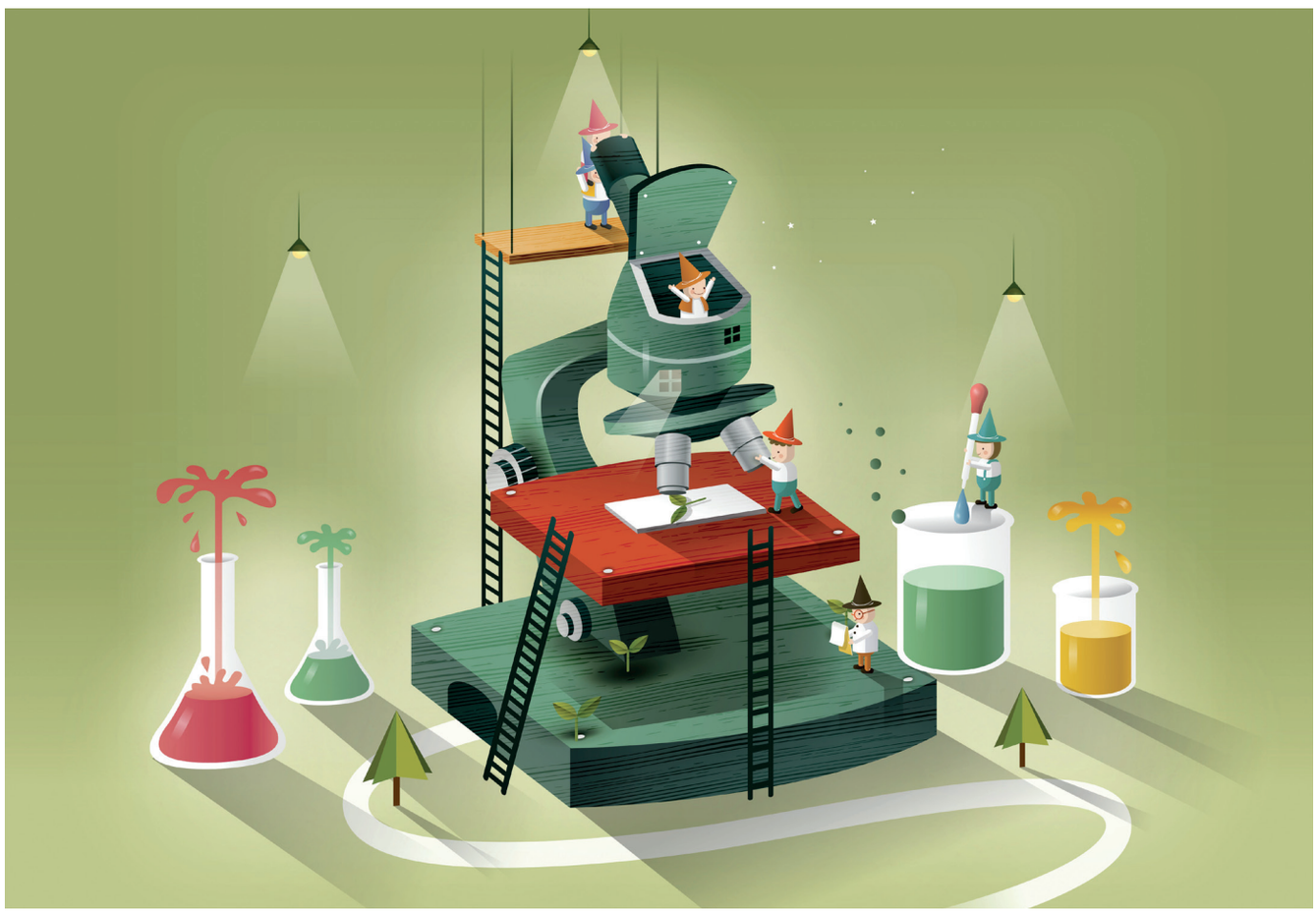
Then there is review and approval. Again clinicians vary in how they like to do things. Some want every iteration printed, says Dr Bayes. "But the more IT savvy are happy to review and correct on screen themselves rather than instructing secretarial staff to make corrections. Some even use electronic signatures."

There is another dimension in a changing NHS. "More and more we are seeing outpatient clinics taking place in community settings," adds Mr Rodwell. "If the clinician comes once a week to a clinic, ideally you want the letters ready for review and approval by the end of that clinic."

Finally comes dispatch. Increasingly this is done electronically, using NHSmail or other information exchanges.

"Ideally what you want is for the patient to see the letter too, via a web portal," adds Mr Rodwell. "This is all part of improving the patient experience and empowering patients."

All of this is technically achievable with Winscribe and its clinical workflow Epro modules that can manage letter production



from end to end. But it is not easy and requires not just the IT but also time and motion studies to understand existing processes, where these might need to change and how technology can fit in.

Sheffield Teaching Hospitals Foundation Trust has recently begun to explore this dynamic in a pilot project with Winscribe. The trust already uses digital dictation–– and is now keen to explore wider benefits.

The four-month pilot will look at workflow in three clinical areas picked to represent a good sample of the type of work carried out by the trust and which are at various stages in terms of meeting document turnaround time targets using a range of different processes.

"We want to understand where the variance comes from and identify improvements," says Alan Smith, the trust's project manager. "We know there may need to be some difference in processes between departments but as much as possible we want standard processes."

The project has senior buy in – it is one of a series of transformation projects that reports to the chief executive. Mr Smith reports via the director of HR while the project sponsor is the deputy medical director.

The pilot will involve looking at how and when clinicians make their dictations, how quickly they can be transcribed and approved, how they get to GPs and patients – and how this can be streamlined to improve patient experience. It will also introduce speech recognition.

'The burning platform for clinicians is patient safety. When patient letters get delayed or lost, you risk drug errors or the inability to follow treatment plans'

Only once these workflow processes have been thoroughly understood – along with any potential benefits and drawbacks of new technology – will the trust make any decisions about future investment or move forward with a formal tendering process.

It is an approach endorsed by Winscribe, where Mr Rodwell is interested in going beyond selling the technology to helping trusts get the most from it.

Yes, there is scope for trusts to make significant savings. He has seen trusts slash their bills for paper, printing and postage as well as reduce the number of porters pushing trolleys of notes between clinics and records.

But ultimately the major benefits should be in patient experience and patient safety. As Dr Bayes says: "The burning platform for clinicians is patient safety. When patient letters get delayed or lost, you risk drug errors or the inability to follow treatment plans. That's why commissioners are getting feisty about this – and why hospital doctors and senior managers must get engaged." ●

ALAMY