

News story: Autistic people asked for their views to help transform support

Autistic people, their families and those caring for them are being [asked for their views](#) on how care and support in England can be improved.

The call for evidence is part of the cross-government review of the [national autism strategy](#), which will be refreshed and launched later this year. The strategy will be extended to cover children as well as adults, so services work better for autistic people of all ages.

Autistic people, family members, carers and professionals can all take part in the online survey. The government is asking people to provide their views on:

- how autistic people feel within their local communities and whether members of the public understand their needs
- whether autistic people, their families and carers receive the right support for all their needs at the right time
- how much autistic people are supported to develop their skills and independence
- where progress has been made, and where it still needs to be made
- what the key priorities should be for the future

People now have an opportunity to express their views on what is working and where more needs to be done to transform care and support. This could include:

- in school through support to access the curriculum
- at hospital through timely diagnosis
- within the community through respite care or support to enter the workplace

There will also be face-to-face sessions with groups of autistic people, including children and young people.

Supporting people on the autism spectrum or with learning disabilities is one of the 4 clinical priority areas in the [NHS Long Term Plan](#).

Minister for Care Caroline Dinenage said:

Autistic people must be at the heart of any improvements we make to their care and support. This is an opportunity to make a real difference to hundreds of thousands of lives. We want services from healthcare to education to work better for autistic people of all ages – it's no coincidence that learning disability and autism are one of the clinical priorities in the NHS Long Term Plan.

Please get involved and share your views so we can work harder than

ever to improve care and support for autistic people, their families and carers.

Speech: Building public trust for the use of patient data

I am delighted to be here. As many of you will know, this is an agenda which has personal significance for me.

Although it may feel to us that data ethics and health data sharing are 21st century challenges, it is hardly a new concept that human progress is built on our ability to gather accurate information, share it ethically and, finally, critically analyse it so we can transform raw data into actionable knowledge.

Since before the establishment of the NHS in 1948 we have sought more and better ways to record, share and structure health data for patient benefit.

Indeed, many of the scientific, ethical and regulatory challenges we are debating today in relation to patient data have their heritage in the evolution of clinical trials in which UK researchers have always been world leaders.

From James Lind's famous 1747 scurvy trial, which already contained most elements of a controlled trial.

To the Medical Research Council's (MRC) first double blind trial of patulin (for common cold) in 1943.

To its first randomised control trial of streptomycin in 1946 – which was a landmark trial for its systematic enrolment criteria and data collection compared with the ad hoc nature of other contemporary research.

We should be proud to have led the way in so much groundbreaking medical discovery.

But we must do more than celebrate our successes. We must recognise these highly meticulous and ethical standards that have become deeply ingrained in our medical research and clinical systems is an exceptional national asset.

And they are principles which stand us in good stead to realise the huge potential of patient data to improve health, care and services across the NHS.

Long Term Plan

And that is exactly what the [Long Term Plan](#) recognises. Developed with frontline staff, patients and their families, it calls for targeted investment in health data infrastructure and analysis to help deliver better prevention, earlier diagnosis and more targeted treatment.

But it's easy to forget that a key benefit of using health data more effectively though is safer, more responsive services to enable clinicians to spend less time administrating and more time treating patients. What they were actually trained to do, in other words.

This is why:

- the [Health Secretary's tech vision](#) has laid out a road map for interoperability and better digital standards
- we are investing in the digital infrastructure at different levels in the NHS from Local Health and Care Record Exemplars (LCHREs) to digital pathology and radiology

And why we are building on the great success of the 100,000 Genomes Project – which crucially translates into clinical care with the Genomic Medicine Service – with a National Genomic Strategy to draw together our world-leading strengths from the UK biobank to the commitment to sequence 5 million genomes in 5 years.

Even with all this activity though, we all know we are just at the beginning of this journey and that is why we are so determined to start on firm foundations.

One thing we have learnt through long, hard experience since that first 1747 trial though, that we have heard clearly today, is that the precondition for all medical innovation and clinical care is patient trust.

National Data Guardian

That is why I am so pleased to be here today to mark the role of the [National Data Guardian](#) being placed on a statutory footing.

This is an enormous achievement. It was a longstanding government commitment, but there were some challenges along the way to getting here and we would not be here without all of you – so I want to thank every one of you who played a role in getting us passed the finish line.

Placing the National Data Guardian on a statutory footing strengthens the role as an independent and authoritative voice for the patient on how their data is used across the health and care system. It is right that patients are confident they have a strong champion, not only to advise them, but also to challenge the system and ensure that confidential information is safeguarded and used appropriately.

In establishing this role, Dame Fiona has firmly rooted the National Data

Guardian within the health and care system as an essential building block for building public trust for the use of patient data.

Public trust

As Dame Fiona says, the 10 principles have been a key step in moving us forward in public and clinician trust for health data sharing.

We remain absolutely committed to ensuring that the public have trust in how their data is used, that it is used effectively to support better health and care outcomes, and they understand there are robust safeguards in place to ensure it is used for purposes which they recognise as appropriate.

Patients should have a clear explanation of how their data may be used for purposes beyond their individual care and of the security and legislative controls that are in place to protect their data.

People want to know their privacy and rights are safeguarded and to understand how and when data about them is shared, as well as how and when they can make an informed choice about whether to share their data.

We must continue the conversation we have started with the public, to build and maintain trust and confidence, recognising that there is no 'one' public and also that people's views on patient data will naturally evolve depending on their personal experience and of course the advances in technology.

That is exactly why the role and independence of the National Data Guardian is so vital.

Cybersecurity

But of course, our ability to unlock the benefits of using data relies not only on the public having confidence in the health and care system's appropriate and effective use of data but also in their confidence that their data is held securely.

Cyber threats to patient data are constantly evolving and always present. Health and care organisations must remain prepared and ready to respond.

This isn't just about protecting patients' confidentiality by making sure that their data is secure, though of course that's essential. It's also about making sure the systems on which patients' data is held can't be disrupted or corrupted, because we want the right data to be available at the right time.

For this reason we've worked with our arm's length bodies to provide a range of specialist services that help organisations manage cyber risk and, if the worst happens, respond quickly in the event of an incident.

Since the 2017 WannaCry attack we've invested over £60 million to make significant improvements in the cyber resilience of local infrastructure and we have a stronger regulatory framework to impose harsh penalties on organisations that allow data breaches to occur.

We can never be complacent when it comes to ensuring the cyber security of our hospitals, ambulance services, or any of the many organisations that handle patient care and data, and there is still work to do.

But this work to toughen up the cyber protection of the NHS is an essential enabler of better care, to ensure that data can be available where it's needed, and that the public can trust that their data is secure.

Role of NHS staff

But as Dame Fiona so clearly laid out, we all know this isn't only about trust. The role of NHS staff is critical.

Unsurprisingly, we've found that the public are most likely to listen to information about the benefits of, and their choices around the use of their data if it comes from frontline NHS staff.

Medical researchers and secondary care clinicians are obviously on board with health data sharing, but the wider picture is more mixed. The Your Data Matters work highlighted that certain groups of NHS staff were less positive than the public about the benefits of data sharing. Others are unclear on how the rules apply to them. It goes without saying that if we are to realise the full potential of health data sharing – for patients, for our health system, indeed for those very NHS clinicians – this must change.

Patients like me with complex illnesses and co-morbidities are crying out for a health system that shares our data better so we don't have to explain our medical history at every appointment.

Patients like me with rare diseases, who have battled through a decades-long diagnostic odyssey, are desperate for advances in data science to be applied to our anonymised health data so that others don't have to suffer as we did and can be diagnosed and treated earlier.

Patients like me want to have more control over our health data so we can manage our own long-term conditions more effectively and reduce unplanned GP and A&E visits, not to mention improve our quality of life.

We are looking to the whole health and care system – including clinicians – to help us do this.

Of course there are challenges. But that is the case with every medical innovation in history. The 'challenges' didn't stop Lind's scurvy trial or the MRC's streptomycin trial or the 100,000 Genomes Project.

All those achievements involved overcoming great odds and discovering new clinical standards, new protocols and effectively disseminating them – setting up new ways of working right across the whole health and care system.

No health system in the world is better at this than us. We are more than equipped to respond to the challenges that health data sharing creates.

And I know that because of all of you and the work you have already done.

Conclusion

Today I have referred to a few examples of clinical trial success, but the Understanding Patient Data website is awash with case studies of outstanding practice from across the country. Clinicians, industry, researchers, charities and government working together – all in accordance with the rules set out by the National Data Guardian – to improve patient care, patient safety and NHS services.

To all of you Health Data Leaders here today – I want to offer my personal thanks. I look forward to working with all of you.

I look forward to working with the National Data Guardian. Not only to ensure we keep building trust. But also that data saves more lives.

[News story: Female representation in the City is rising thanks to Treasury Charter](#)

Over 800,000 employees in the UK are now covered by the [Women in Finance Charter](#), as more than 30 new companies sign up to the government's plan to tackle gender inequality in financial services.

Vitality, Skipton Building Society, and Commerzbank AG are just some of the new firms signed up to the Charter, taking the total number of businesses signed up to over 330.

Today's announcement also marks the launch of the [second Women in Finance Charter Annual Review](#), which shows that female representation in senior management at firms who have signed up to the charter is rising, with 86% of signatories having either increased or maintained the proportion of women in the top jobs. The Review also shows that the Charter is holding firms to their promise, with 87% of signatories on track or already having met their ambitious targets.

John Glen, Economic Secretary to the Treasury said:

Gender equality is not just a moral imperative, it's also better for employees and better for business. Which is why it's vital that we see conversations on gender diversity taking place across the financial sector. "Without the committed women and men championing the gender agenda at every level in their firms, we would not have

seen the fantastic progress that we have today. But, we will only see long-lasting change with consistent action, so we'll continue to monitor the progress of the sector closely to ensure it keeps up the momentum. If progress slows, we can and will take further action.

Jayne Anne-Gadhia, the government's Women in Finance Champion said:

HM Treasury's Women in Finance Charter continues to play a leading role in improving the gender balance across the UK's financial services sector

We know that there is more to be done and I am pleased to see the progress made by Charter signatories so far, and that a further 36 financial services firms have made a public commitment to develop a more diverse and inclusive workforce by signing the Charter.

HM Treasury's Women in Finance Charter asks financial services firms to commit to four industry actions to prepare their female talent for leadership positions.

Further Information:

Over 330 firms have now signed the Women in Finance Charter. The 36 new firms that have signed the Charter are:

- Addidi Wealth Limited
- Uinsure Ltd
- Glenhawk
- Sapphire Capital Partners LLP
- St Mary's Private Wealth
- IPTF (Income Protection Task Force)
- Bridging Finance Solutions Group
- TFA (Tom French & Associates Limited)
- Hope Capital
- Vitality
- Vanilla Thinking Limited (ACQ5)
- FLA (The Finance & Leasing Association)
- AMP Capital Investors UK
- Castle Trust
- Ark Wealth Ltd
- Bibby Financial Services Ltd
- Crowe U.K. LLP
- Also Communications
- ABN AMRO UK
- Crito Capital LLP
- Skipton Building Society
- Bluestone Leasing Limited
- Triodos Bank
- AMC Executive Search

- BMW Financial Services (GB)
 - AEGON UK
 - Amundi London
 - Commerzbank AG
 - Everyday Loans Group
 - Cameron Hume Limited
 - ISDA (International Swaps & Derivatives Association)
 - Stifel Nicolaus Europe Limited
 - CDC Group
 - Provident Financial plc
 - Pays Services UK Limited (Paysafe)
 - HW Global Talent Partner
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News story: Animal medicines improvement notice: Meditech UK, Trade Stand Doncaster National Spring Pigeon show

This notice was issued to Meditech UK Trade Stand.

The following contravened the Veterinary Medicines Regulation (VMR) 2013:

- Failure to keep records of POM-VPS supplies contrary to regulation 23 (Records of the receipt or supply of prescription products) of the VMR
- Trade stand has no evidence of a valid registration contrary to schedule 3, paragraph 10 (Supply by a pharmacist) as a pharmacist was supplying POM-VPS products.

The improvements required are:

- Evidence of recording of POM-VPS supplies to be provided, including a procedure for all staff outlining who can supply
 - Evidence of General Pharmaceutical Council (GPHC) registration to be provided
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Press release: Report 01/2019: Runaway

of a road-rail vehicle at Bradford Interchange

PDF, 10.8MB, 47 pages

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Summary

At about 01:40 hrs on Friday 8 June 2018, a road-rail vehicle (RRV) ran away while being on-tracked at a road-rail access point south of Bradford Interchange station. The RRV ran downhill for approximately 340 metres, before coming to a stop as the track levelled out in the station. The RRV's machine operator and machine controller were able to run along with it and warned a member of track maintenance staff, who was able to move clear in time.

The RRV ran away because its rail wheels were, incorrectly, partially deployed and because the rail wheel braking system had not been correctly maintained.

Partial deployment of the rail wheels was a result of the machine operator not following the standard industry procedure for on- and off-tracking. He had routinely been on- and off-tracking in this manner and this had not been detected by his employer, Readypower.

The braking system on the rail wheels had not been correctly maintained because fitters were not following the original equipment manufacturer's instructions and Readypower had not detected this.

An underlying factor was that the industry's competence management system for machine operators focuses on the renewal of qualifications, rather than demonstrating ongoing competence.

Recommendations

The RAIB has made three recommendations. The first one seeks to improve the industry's competence management system for all machine operators who work on Network Rail's infrastructure. The second, addressed to Readypower, is intended to improve the management of competence of its staff. The last recommendation aims to improve the quality of the maintenance instructions and training provided to Readypower's fitters.

Simon French, Chief Inspector of Rail Accidents said:

“Getting road-rail plant safely on and off the track ought to be a straightforward business. Unfortunately, over the years RAIB has had to investigate too many incidents in which this operation has gone wrong, and the machine involved has run away downhill, often for quite long distances. Too often the people in charge have not known what to do to stop the runaway. In this case, the machine operator’s actions were not in line with what he had been trained to do, and no-one had checked on him. Of greater concern, however, is that the machine’s brakes did not hold it stationary on the 1 in 46 gradient. This was because they were badly maintained, a state of affairs that can be traced back to poor instructions and inadequate supervision of the plant hire company’s maintenance staff.

“The management of safety in the rail plant industry is something that RAIB has expressed concern about before. In the past, one of the important issues has been the competence of machine operators and maintainers. In this case, the problems were not only at the plant hire company. The project to convert many road-rail vehicles to direct rail wheel braking also lacked important elements of safety assurance, such as provision for proper information about the machines being converted, and adequate arrangements for training the people who would have to maintain the new braking systems.

“This incident provides an opportunity for the industry to learn major lessons from a relatively minor event. Our recommendations are directed to Network Rail and one other company, but I hope that people in all areas of the rail plant sector will take note of the learning points in this report, and make sure that their company safety management systems are comprehensive and fully implemented.”

Notes to editors

1. The sole purpose of RAIB investigations is to prevent future accidents and incidents and improve railway safety. RAIB does not establish blame, liability or carry out prosecutions.
2. RAIB operates, as far as possible, in an open and transparent manner. While our investigations are completely independent of the railway industry, we do maintain close liaison with railway companies and if we discover matters that may affect the safety of the railway, we make sure that information about them is circulated to the right people as soon as possible, and certainly long before publication of our final report.
3. For media enquiries, please call 01932 440015.

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