

Developing learning health systems in the UK: Case studies

No.	Case study	Used to illustrate...
1	Flow Coaching Academy	Full LHS
2	PINCER – a pharmacist-led intervention to reduce medication errors	Full LHS
3	CFHealthHub – a digital learning health system	Full LHS
4	Nightingale bedside learning coordinator	Full LHS
5	The Clinical Effectiveness Group	Full LHS
6	The Children & Young People’s Health Partnership	Full LHS
7	The Secure Anonymised Information Linkage (SAIL) Databank	Data
8	Informatics Consult	Data
9	Towards a national learning health system for asthma in Scotland	Data
10	Reducing the health burden of diabetes with artificial intelligence-powered clinical decision tools (RADAR)	Technology
11	Cambridge University Hospitals’ eHospital programme	Technology
12	Project Breathe – artificial intelligence-driven clinical decision-making tools to manage cystic fibrosis	Technology
13	Thiscovery	Learning community
14	Q Lab UK	Learning community
15	HipQIP – hip fracture quality improvement programme	Improvement
16	Reducing brain injury through improving uptake of magnesium sulphate in preterm deliveries (PReCePT2)	Improvement

These case studies are taken from the report *Developing learning health systems in the UK: Priorities for action*, published by the Health Foundation on 30 September 2022, at: <https://doi.org/10.37829/HF-2022-106>

Case study 1: Flow Coaching Academy

The effective movement of patients between departments and organisations, along pathways of care, and around the wider health and care system, is an essential part of delivering safe, timely and high quality care.¹ Poor flow is a major contributing factor to adverse outcomes, readmissions and higher mortality rates,² whereas good flow can improve outcomes and waiting times, reduce duplication and improve efficiency.³

Set up by Sheffield Teaching Hospitals NHS Foundation Trust in 2016, the Flow Coaching Academy empowers teams to improve flow through a common purpose, language and quality improvement method.⁴ Through open, inclusive and non-hierarchical safe spaces called 'Big Rooms', teams collaboratively identify, develop and test local solutions informed by qualitative and quantitative data.⁵ Critically, each Big Room starts with a patient story to make sure their voice is a central part of the process – whether through a clinician telling a patient story or inviting patients to Big Room meetings.⁶

The Flow Coaching Academy's Roadmap for Improvement and '5Vs Framework' underpin each Big Room, which provides a way for teams to assess a pathway and develop a shared understanding.⁷ Flow coaches, who have undertaken a one-year action-learning programme to develop relational and technical skills, including data analysis and coaching, work with teams to identify and achieve sustainable improvements to care within and across care pathways.

The Flow Coaching Academy has delivered training to nearly 400 coaches from NHS trusts, clinical networks, charitable organisations and health boards across the UK. It has developed a network of local academies and training is currently taking place in Northumbria, Lancashire & South Cumbria and Sheffield.

The Big Room approach shows the importance of creating a learning culture where teams have the tools, opportunity and time to collectively define and implement improvements to service delivery. Part of the success of the Big Room, which emphasises that improvement is '20% technical and 80% relational', is the focus on building multidisciplinary teams and a shared understanding, empowering all members to contribute.

Coaches encourage teams to take ownership of both the learning and improvement process and the data that inform it, which helps to develop better relationships across professional disciplines, including between clinical staff and data analysts. This is essential in building understanding of service performance.

Case study 2: PINCER – a pharmacist-led intervention to reduce medication errors

Medication errors, such as mistakes with prescriptions, preparation or dispensing, occur more than 237 million times a year in England.⁸ While most are minor, in an estimated 1.8 million cases these medication errors could lead to serious patient harm.⁹

Researchers at the Universities of Nottingham, Manchester and Edinburgh developed PINCER, a pharmacist-led intervention that combines clinical audit tools with quality improvement methodology and educational outreach. Through the PINCER online resource centre,¹⁰ pharmacists can download searches to run on GP clinical systems that identify patients at risk of medication error. Pharmacists can compare their data to other practices across the country and then work with practice teams to improve prescribing processes and reduce potential harms.¹¹

PINCER goes beyond simple feedback tools by providing training through action learning sets that give participants the resources and skills needed to drive improvement and embed changes into everyday practice. Pharmacists develop skills in using quality improvement tools and strategies, root cause analysis, action plan development and delivering feedback. The action learning sets model has also provided participants with informal peer networks to support continuing development. More than 2,350 health care professionals have now been trained to deliver PINCER, including 1,785 pharmacists.

Supported by the Health Foundation and all 15 Academic Health Science Networks, the initiative, led by PRIMIS at the University of Nottingham, has now been adopted by more than 40% of GP practices in England through a social franchising model. This model has given individual localities the flexibility to tailor the intervention to their needs, which has been critical to its successful scaling. As a result, more than 220,000 at-risk patients have been identified, and analysis of follow-up data from 1,677 practices has shown a reduction of 32% in the number of patients at risk of hazardous prescribing associated with gastrointestinal bleeding – a common cause of medication-related hospital admissions.

Case study 3: CFHealthHub – a digital learning health system

Around 15 million people in England are living with at least one long-term health condition,¹² accounting for 70% of health and care expenditure.¹³ However, it is estimated that up to half of all medicines prescribed in the UK for long-term conditions are not taken as recommended,¹⁴ with poor adherence to medical treatment having both a personal and an economic impact.³⁷

For the 10,600 people living with cystic fibrosis in the UK, daily inhaled medicines are vital for staying healthy, but only around 36% of people with cystic fibrosis are fully adherent to their complex treatment plans.¹⁵ To address this challenge, CFDigiCare, a collaboration of clinicians and people with cystic fibrosis, developed CFHealthHub – a digital LHS that seeks to optimise cystic fibrosis outcomes by creating a national community of practice that uses data to improve care.¹⁶

Through a digital platform co-designed with users, people with cystic fibrosis can track their progress by accessing real-time medication data captured by their Bluetooth-enabled nebuliser. The CFHealthHub mobile app shows these data through accessible, colour-coded graphs that give feedback on treatment-taking.

Users can also choose to share the data with their clinicians, who then work with them to support behaviour change, identify barriers to effective treatment and talk through evidence-based strategies for overcoming them. A 19-centre randomised control trial showed that CFHealthHub increased adherence to treatment while reducing the burden and effort of self-care.¹⁷

As of May 2022, CFHealthHub is used by 60% of adult cystic fibrosis units in England, creating a learning community of clinicians, managers, pharmacists and allied health professionals who are sharing their learning and best practice. Using the real-time automatic data capture of CFHealthHub, this community of practice is able to understand how well the system is supporting people with cystic fibrosis.

This has led to, and provided the infrastructure for, several linked, systems-optimisation workstreams. For example, the National Efficacy-Effectiveness Modulator Optimisation programme is carrying out a real-time health technology assessment of new medication which can significantly improve lung function,¹⁸ which is able to use data from 1,000 participants. The CFHealthHub has also shown how data gathered by can be built into care, without burdening the patient or clinician, and how they can be used to both support system learning and improve personalised support for people with long-term health conditions.

Case study 4: Nightingale bedside learning coordinator

During the onset of the COVID-19 pandemic, NHS England set up NHS Nightingale Hospital London (the Nightingale) as a temporary facility in an east-London convention centre to cope with the rising number of critical care patients in London. The novel setting, set up quickly with newly formed teams, meant the Nightingale had to manage significant risk and potential human error. In light of the knowledge gap surrounding COVID-19 and the need for rapid implementation of learning about the disease, NHS Nightingale Hospital London was purposefully designed to be an LHS.¹⁹ The LHS approach enabled the Nightingale to rapidly make decisions backed by data and evidence to improve the delivery of care, quickly monitor the impact and make iterative adjustments where necessary.

A key component of the LHS involved gathering staff insights and ideas for improvement. The bedside learning coordinator role was developed as a mechanism to gather these insights rapidly and continuously without creating a burden for staff.²⁰ The role involved:

- capturing staff insights into what was and was not working
- rapidly feeding these insights back to the leadership teams to review and agree how to respond
- implementing agreed changes as appropriate
- enabling robust feedback loops.

Staff from a diverse range of professional backgrounds (both clinical and non-clinical) undertook bedside learning coordinator shifts to give a broad set of perspectives and insights.

Insights captured were triaged into three areas: fix (requiring immediate action), improve (needing suggestions for better ways of doing things) and change (requiring substantial changes). Bedside learning coordinators worked with a central quality and learning team to triangulate insights from the bedside with other data sources, such as incident reports, team debriefs and performance dashboards, as well as external evidence, to inform decision making and implement required actions as appropriate. In addition, as well as external evidence they carried out focused audits to confirm that implemented changes were successful, satisfactory to staff and sustainable. One example of this in action was the identification of mouth care as an area for improvement. Following concerns that staff had raised, a speech and language therapist completed a bedside learning coordinator shift to give specialist insight and recommendations. These were then adopted as standard operating procedure.

The Nightingale demonstrates that health care staff often have rich insights and ideas for improvement (including how to improve patient care, workplace efficiency and staff wellbeing), which, when analysed alongside other routine data sources, can support improvement work. The bedside learning coordinator role provides a mechanism to gather these insights, as well as giving staff a greater voice and empowering them to deliver tangible improvements as part of a wider LHS.

Since the initial pilot, several other large NHS organisations have adopted the bedside learning coordinator concept.

Case study 5: The Clinical Effectiveness Group

Data sharing between organisations within health and social care is often disjointed, leading to limited sharing of learning and the duplication of work between providers. As general practice moves to a model where bigger operational units – such as integrated care systems, primary care networks and GP federations – support service users with more integrated care, there is an opportunity to pool learning to support continuous improvement as part of an LHS.

The Clinical Effectiveness Group (CEG) at Queen Mary University of London is an academically supported unit that facilitates data-enabled improvement for 272 north-east London GP practices, serving 2.2 million patients. It brings together people from a range of disciplines, including clinicians, data analysts, informaticians, academic researchers and a team of facilitators who conduct around 300 GP practice visits a year.

The CEG builds standardised data entry templates that GP practices use to enter high quality data into their patient records at the point of care. Its software tools, searches and on-screen prompts then turn these data into actionable insights within the practice, for example to stratify patients by risk or to support self-reported measurements such as home blood pressure recording.

The CEG's cardiovascular disease tools have contributed to improvements in blood pressure control, statin use and the management of other associated long-term conditions in the local population, with pre-pandemic performance among the highest in England. For example, pharmacists in the London Borough of Redbridge, in collaboration with St Bartholomew's Hospital, are using one such tool – APL-CVD (Active Patient Link tool for Cardiovascular Disease) – to improve statin prescribing and identify suitable patients for a new drug that reduces cholesterol.

CEG analysts also create interactive dashboards showing performance across the region, allowing for the identification of areas requiring improvement. The CEG uses this evidence to design and deliver local guidelines and quality improvement programmes to reduce unwarranted variation in outcomes. The most recent is a programme to reduce inequalities in childhood immunisations. The CEG has championed GP recording of self-reported ethnicity to support the identification and reduction of health inequalities. The dashboards similarly reflect information on a range of equity indicators that local authority public health teams use to inform local initiatives.

Evaluation²¹ of the CEG identified key contributors to its success including:

- access to high quality coded GP data from across north-east London
- trust and credibility in its use of data
- engagement with local clinicians and health care providers
- the expertise of its clinical leads.

The CEG's approach has put health data into practice to build an LHS in north-east London. The team is now working with other integrated care systems in London to support this approach in other areas as part of the London Health Data Strategy.

Case study 6: The Children & Young People's Health Partnership

Research shows that some health systems are struggling to keep pace with the changing health needs of young people, and wide inequities in health remain among this group.²² With more than 180,000 children and young people living in the densely populated, diverse and fast-growing London boroughs of Lambeth and Southwark,²³ an integrated approach to the delivery and coordination of care for this rapidly evolving population is essential.²⁴

The Children & Young People's Health Partnership (CYPHP), hosted by Evelina London Children's Hospital and part of King's Health Partners, is a population-level LHS aiming to deliver better health for children and young people.²⁵ Bringing together providers, commissioners, local authorities and universities, the CYPHP collaborates on taking care into the community, uncovering unmet need, and targeting care through technology and data-enabled early identification and intervention.

One of the CYPHP's focuses is asthma.²⁶ Data are gathered from several sources, including biopsychosocial data through a patient portal, routine clinical interaction data, data on wider determinants of health such as poverty and air quality, and data gathered through research that patients can opt into through the patient portal.

The team of clinicians, managers and researchers then translate these data into action by using them to make personalised decisions about patient care, support decisions on triage and inform what packages of care might be needed. The data are also used to inform population health management approaches by identifying which geographic areas have the greatest need, enabling earlier intervention.

The data are also being used for wider quality improvement and research activity. For example, through local test beds, the CYPHP is using a pragmatic but rigorous approach to evaluation by running randomised control trials alongside service evaluations that can quickly provide evidence to clinicians to support continuous improvement.

The CYPHP has demonstrated impact through a service evaluation, which showed improved health outcomes and quality of care, as well as reductions in emergency department contacts and admissions. Our interviews with the team highlighted that by understanding population need through data, it is possible to deliver care that is proportionate to need and that can therefore help reduce inequalities in access to care among children, alongside reduced associated costs.

Case study 7: The Secure Anonymised Information Linkage (SAIL) Databank

Established in 2007, the Secure Anonymised Information Linkage (SAIL) Databank is a Trusted Research Environment holding anonymised individual-level data for the whole population of Wales. One of the world's first Trusted Research Environments and hosted within Population Data Science at Swansea University, SAIL was set up to use data gathered in health and social care delivery to better inform research, improve services, and inform population health strategy. It includes data that clinical interactions and interactions with social and community services generate, allowing for analysis of links between health outcomes and social factors.

SAIL operates according to a 'privacy-by-design' model, which uses physical, technical and procedural measures to safeguard the data it contains, prohibiting the sharing of data outside the databank without special dispensation. Also, to gain access to data held in the databank, prospective researchers must undertake a two-stage application process, which an independent Information Governance Review Panel assesses.

Population Data Science created the Secure eResearch Platform (SeRP), which powers the SAIL Databank, and allows researchers from across the world to access data linkage services and a wide range of data to answer important questions with the use of analytical tools. By 2020, SAIL had more than 1,200 registered users and has been used to deliver more than 300 research projects, including the development of National Institute for Health and Care Excellence (NICE) clinical guidelines. Strong relationships with many partners – such as Digital Health and Care Wales, the Welsh government and Public Health Wales – underpin the SAIL approach, which has enabled the use of data to inform decisions in policy and practice, notably those made in response to the COVID-19 pandemic through the One Wales collaboration.

From the beginning, the SAIL team recognised that public trust in the handling and sharing of personal data would be critical to the databank's success. This trust relies on several interacting factors such as cultural values, personal preferences and mass media influences. To gain public trust, the SAIL team developed a programme of public involvement and engagement to assess public opinion and gain input into policies and practices, which a consumer panel – including members of the public – oversaw. The consumer panel also advises on routes and methods to engage with the population, recommends how information can be shared with the general public and assists in reviewing proposals from researchers applying to access the databank. Projects that have used SAIL are shared on its website, including a description and a list of outputs, to make sure there is communication and transparency with members of the public and stakeholders.

Case study 8: Informatics Consult

A Health Data Research UK (HDR UK) and Health Foundation Catalyst project

While clinical guidelines play an important role in health care delivery, they are not always backed by a robust evidence base in the form of clinical trials. This is made more challenging as the number of people with comorbidities increases and the health needs of the population become more complex, with there being many situations where a treatment indication and contraindication coexist for one patient, for example patients with both heart failure and kidney failure. Given that treatment for one condition can have an adverse impact on another, and there is limited evidence for some treatment options partly due to randomised control trials frequently excluding patients with several comorbidities, it can be difficult for clinicians to determine the best treatment for their patients.

The growing availability of large datasets and the tools to analyse them provides an opportunity for improving decision making, particularly for patient groups for whom robust evidence does not yet exist. The Informatics Consult platform allows clinicians to select a health condition and order an analysis of large datasets to aid decision making for the specific patient in front of them. The platform employs automated approaches for creating analysis-ready cohorts using the 'DExtER' tool. Within hours, the platform returns easily interpretable clinical information – including on the potential benefits of treatment, prognosis and mortality risk – which can support more personalised treatment plans.

Drawing on population data contained within electronic health records, the platform presents analysis in a way that is understandable for clinicians and can be discussed with their patients. This is not always straightforward, though. For example, many rare conditions do not have specific clinical codes, which leads to challenges incorporating them into the platform.

The project team plans to test the Informatics Consult platform in four NHS trusts to support decision making with patients who have both liver cirrhosis and atrial fibrillation, where the use of anticoagulants can treat the latter while making the former worse. A pilot conducted using Informatics Consult generated new clinical evidence for patients in this group, showing that the initiation of warfarin was common, and may be associated with lower all-cause mortality and may be effective in lowering stroke risk. Surveys of clinicians using the platform showed that 85% found information on prognosis useful and 79% thought they should have access to the platform as a service.²⁷

By providing information on the prevalence of conditions, as well as information on the safety and efficacy of a particular medication, it is hoped that this will stimulate further initiatives to generate new analyses for a wider range of prognostic outcomes. Given the rising trends of multimorbidity, especially in younger people, the Informatics Consult may contribute to the creation of a knowledge base generated from real-world datasets to address the current gaps in randomised control trials (arising from the exclusion of patients with comorbid conditions).

Case study 9: Towards a national learning health system for asthma in Scotland

Asthma is a significant cause of ill health and hospitalisation in the UK, costing an estimated £1.1bn and leading to 1,400 deaths every year.²⁸ Around one in every 14 people in Scotland are currently receiving treatment for it²⁹ and 89 in every 100,000 people are hospitalised each year due to exacerbations (increases in severity).³⁰ Timely patient data is key to understanding and preventing exacerbations.

To address this growing challenge, researchers at the University of Edinburgh are working towards developing a national LHS for asthma³¹ that will support clinicians to identify and address modifiable factors that can contribute to exacerbations.³²

By harnessing routinely collected, anonymised data from the Oxford Royal College of General Practitioners Clinical Informatics Digital Hub (ORCHID), the team created an online dashboard for asthma³³ that gives GPs weekly updates on how their practice compares with their network across several indicators.

Information provided includes comparative data on asthma prevalence, vaccination uptake, smoking rates, hospitalisations and body mass index measurements. This enables GPs to see changes in their practice, compare themselves to other practices and rapidly respond to better support people with asthma, prevent exacerbations and potentially prevent avoidable deaths.

In repurposing routine data to generate knowledge that can then be incorporated into clinical practice in real time,³⁴ the LHS for asthma is one of the first applications of LHS approaches at a national level outside the US.³³ The project champions innovative approaches to near real-time data visualisation, allowing health care providers to compare care and service quality to evidence-based standards and drive improvement.

While the impact has so far been limited due to the effects of the COVID-19 pandemic and workforce pressures, the researchers are now seeking further funding to develop complementary behavioural, motivational and organisational interventions that can tackle the barriers to using the data to make improvements. They are also going to develop a learning-based prediction model in order to create a personalised risk assessment tool to further support clinicians to predict asthma attacks and reduce asthma morbidity and mortality.

Case study 10: Reducing the health burden of diabetes with artificial intelligence-powered clinical decision tools (RADAR)

A Health Data Research UK (HDR UK) and Health Foundation Catalyst project

Nearly 5 million people in the UK have diabetes and this is predicted to rise by another 500,000 in the next decade.³⁵ For people living with diabetes, effective management is critical. Uncontrolled diabetes can have serious complications and lead to heart disease, stroke and kidney failure.³⁶ Diabetes costs the NHS £10bn a year, primarily due to complications like amputation and blindness.³⁷ So acting early to prevent complications both improves care and quality of life and avoids complication-associated expenditure.

RADAR (Risk Algorithms for Decision Support and Adverse Outcomes Reduction) was a Better Care Catalyst project, led by North West London Health and Care Partnership, in collaboration with MyWay Digital Health, Imperial College Health Partners, AstraZeneca, the Institute of Global Health Innovation at Imperial College London and Imperial College Healthcare Trust. The aim of the project was to use data and artificial intelligence to improve clinical decision making and self-management for individuals with diabetes.

The project took models that predict the risk of complications in patients with type 2 diabetes, originally developed and validated in Scotland by MyWay Digital Health, and aimed to revalidate them using the longitudinally linked and ethnically diverse Discover dataset of more than 2.5 million people living in north-west London.

The team worked with clinicians and people with type 2 diabetes to understand whether a digital platform embedding predictive models could support self-management and enable clinicians to intervene earlier to prevent complications and hospitalisation.³⁸ Specifically, the platform used algorithms to predict an individual's risk for complications such as loss of sight, amputation and heart disease.

It included a digital interface where clinicians and people with diabetes could see their risk levels, and how they compared to other members of the population. It also allowed users to see how losing weight, increasing activity or stopping smoking could reduce their risk, and work with their clinician to make changes. Users reported feeling empowered by being able to see their data, and by understanding how their actions could influence their long-term health.³⁹

Through workshops with users, the team was able to further develop the platform to make sure that it was easy to navigate and understand. In this way, the project enabled innovators to implement and further validate the risk-prediction algorithms as well as understand how artificial intelligence tools could potentially be delivered across a range of other conditions.⁴⁰

The RADAR project shows how emerging technologies like artificial intelligence and routinely collected data can be embedded into care pathways to support collaborative and personalised decision making. In particular, it highlights the value of having access to safe and secure population-level health data and the importance of user consultation for technological adoption and spread.

Case study 11: Cambridge University Hospitals' eHospital programme

The eHospital programme provides a single integrated electronic patient record system for most inpatient and outpatient service information in Cambridge University Hospitals NHS Foundation Trust. Launched in 2014, the platform is accessible to trust staff, primary care colleagues and other hospitals in the region. It highlights some of the benefits that health care providers in the UK can achieve through using electronic record systems. The system is linked to the national GP Connect service, enabling clinicians to share and view primary care information.

With more than 95,000 people registered with the platform through the MyChart app, service users also benefit from greater access to health information, such as diagnoses, test results and medication history. Service users can view correspondence with clinicians, report their own data and self book appointments.

The team report that the eHospital programme has increased service user activation and empowerment and reduced the administrative and logistical burden on staff. The system also enables a range of digital services such as outpatient kiosk self-check-in, automated coding of outpatient procedures and automated letter generation, reducing the burden on administrative resources. Other significant impacts include improvements in medication safety and organisation-wide cost savings. The team has estimated that 124 nursing whole-time-equivalents are saved each year through direct recording of observations and medication administration at the bedside.

The system also supports service learning and improvement through the generation of usable real-time insights. For example, Cambridge University Hospitals NHS Foundation Trust has used insights from record data to develop alerts to support the early identification and treatment of possible sepsis. The eHospital programme shows the importance of staff engagement and change management for successful implementation. The programme team worked with more than 1,000 hospital staff to make sure the system was configured to their needs. This included pre-launch sessions to illustrate new system workflows and gather feedback, as well as roleplaying and simulations to understand how the system might interact with other processes. Patients played a critical role in configuration and deployment decisions for the MyChart platform, and the team has continuously gathered feedback, allowing for iterative improvement.

Learning from the programme highlights the need for staff education and training. For example, staff digital literacy was identified as a potential barrier to implementation, so intensive training was delivered to more than 12,000 staff before the launch. The eHospital team has also recognised the importance of building data analytics capability within the organisation, through recruiting data analysts and upskilling clinical teams in analytical methods. The team has also invested time in raising awareness about data quality and supporting staff with best practice approaches to recording information, which has led to a reduction in the need for data 'cleaning'.

Case study 12: Project Breathe – artificial intelligence-driven clinical decision-making tools to manage cystic fibrosis

A Health Data Research UK (HDR UK) and Health Foundation Catalyst project

Cystic fibrosis, an inherited disorder affecting one in every 2,500 babies born in the UK,⁴¹ can cause severe damage to the lungs, digestive system and other organs.⁴² As a degenerative condition, it will get worse over a person's lifetime and requires lifelong management. People with cystic fibrosis can also experience pulmonary exacerbations,⁴³ which must be diagnosed and managed early and effectively to minimise any negative effect on their quality of life and survival.⁴⁴

In 2019, Project Breathe, a Better Care Catalyst project, tested whether self-reported data and data generated by home-monitoring devices could track health and wellbeing, reduce unnecessary clinic visits, better inform clinicians and improve quality of life for people living with cystic fibrosis.⁴⁵ Collaborators from the Cambridge Centre for AI in Medicine at the University of Cambridge, Microsoft Research and social enterprise Magic Bullet (funded by the Cystic Fibrosis Trust, the National Institute for Health and Care Research and LifeArc) used these patient-owned data to develop adaptive artificial intelligence that could analyse and learn from the data in order to identify the early signs of exacerbations.

120 adults were given devices to self-monitor their lung function, activity, heart rate, oxygen saturation and weight. The pseudonymised data were stored in a secure, online system and provided to participants in real time via the Breathe app. Their clinicians also used the data to monitor early changes to health, detect signs of exacerbation and make informed decisions about when to see patients face to face and where changes to treatment might be needed. The project has shown some early signs of impact. As a result of integrating the technology into their self-care routines, participants reported that they had developed a better understanding of their health and were able to adjust their plans or lifestyle to make sure they stayed well for longer.⁴⁶ Almost all patients using the app have also been able to avoid unnecessary clinic attendance by remotely reviewing the data with their clinician.⁴⁷

The artificial intelligence analysis of the data has also predicted symptom flare-ups up to 10 days earlier than when antibiotics would typically have been given, meaning treatment can be given earlier and preventable hospitalisations and negative outcomes potentially avoided. The project has now recruited hundreds more participants from both the UK and Canada to better refine the algorithm and deepen learning.

Project Breathe is showing that, for long-term conditions such as cystic fibrosis, being able to collect and analyse up-to-date information and integrate this into decisions about care can be an effective way to empower people and support decision making.⁴⁸ It has also shown that doing so does not necessarily increase the burden on health care professionals and can simultaneously make it easier for them to monitor and manage their patients and intervene where necessary.

Case study 13: Thiscovery

Many challenges facing health care could benefit from bringing together multiple forms of expertise to design solutions at scale. Thiscovery, an online research platform developed and hosted by The Healthcare Improvement Studies Institute (THIS Institute), helps to address this need. Founded on the principle of co-creation, it brings people who have questions about how to improve care together with people who can help build the evidence for answers – including, most importantly, patients and staff. The platform can enable a range of research, evaluation and consultation processes, including consensus-building, iterative development and the evaluation of solutions. Since April 2020, Thiscovery has been used to deliver more than 30 discrete research tasks and has more than 6,000 registered participants who can take part remotely and at different times.

One of its first projects arose in response to a problem that surfaced as the COVID-19 pandemic took hold: how to adapt clinical processes for COVID-19 scenarios. The obstetric emergency known as post-partum haemorrhage (heavy bleeding after birth) was one important case where new processes were needed to keep people safe and still deliver high quality care and experience. Having separate units devising processes in silos is time-consuming and wasteful, but it also wasn't going to be possible to use the in-person meetings characteristic of pre-pandemic collaborative approaches.

A novel approach was required to enable rapid iterative learning at scale while minimising participant time and effort. Thiscovery enabled this with more than 100 experts in maternity care taking part through a novel consensus-building methodology to generate recommendations, with participants given rapid feedback via interactive charts. The project produced rapid consensus on 16 practical, actionable recommendations to adapt usual care for COVID-19. Major professional bodies and NHS services endorsed the results, including a video showing the adapted processes. The project continues to contribute to education, with more than 130,000 views of the online video, and the approach used has been codified into a formal methodology, which is already being used as the basis of other projects.

Recent projects show how Thiscovery can support learning communities and play a key role in LHSs by offering a mechanism to understand problems, co-create visions and evaluate solutions. The co-design approach is especially important in making sure that solutions can be developed and tested at scale in ways that allow diverse priorities, views and ideas to be respected, while the quality of engagement, ownership and endorsement increases the chance of impact.

Case study 14: Q Lab UK

Q is a community of thousands of people across the UK and Ireland, collaborating to improve the safety and quality of health and care. Members share their knowledge and support each other to tackle challenges, enabling faster progress in improving health and care

Q supports a network of labs across the UK and Ireland. The network currently includes Q Lab UK and Q Lab Cymru. Q Lab UK uses creative and collaborative approaches to work on a single complex challenge and brings together organisations and individuals from across the UK and Ireland to pool knowledge about the topic. They then uncover insights and develop, test and scale ideas. The Lab also draws on approaches and tools from quality improvement, and disciplines such as social innovation and design.

Since 2017, Q Lab UK has explored themes such as the importance of peer support and improving care for people living with both mental health problems and persistent back and neck pain. The Lab is currently working in partnership with NHS England on how to build staff and patient trust and confidence in technology-enabled remote monitoring, so that it can be scaled across the health and care system.

To explore an issue, the Lab works with a broad group of people with relevant interest and expertise, from a range of backgrounds both within and outside of the health and care sectors. The Lab instigates collaborative research activities, such as surveys, workshops and interviews, to generate initial intelligence. The Lab then invites leaders within health care organisations to apply to become 'test teams'. These teams are given tailored coaching and support to work together to identify potential solutions, and test and scale them over time.

The test teams, along with a range of contributors from the Q community, convene regularly through participatory workshops, where they learn and apply methods for design thinking and collaborative working. The learning and insights collected from the Lab community are shared widely and used to support improvement efforts in their own work and beyond.

A recent evaluation of Q Lab UK shows that teams appreciate the ways of thinking and working used in the Lab, particularly around participation and collaboration. People also value the opportunity and encouragement to be curious, to slow down and to ask bold questions. They also find the process a good opportunity to be exposed to methods that help better understand service users' needs and to have the space to practise creative facilitation skills.

It is through Q Lab UK's convening infrastructure and processes that participants develop new ideas, skills and capabilities. Importantly, they also work together as a learning community to build shared purpose, supportive relationships and collective energy, which helps to create the context and conditions for scaled impact in health and care.

Case study 15: HipQIP – hip fracture quality improvement programme

Hip fracture is the most common serious injury in older people and costs the NHS and social care more than £1bn a year. Nearly a third of people who fracture their hip will die within a year and a fifth of patients will not return to their own home. Northumbria Healthcare NHS Foundation Trust leads the hip fracture quality improvement programme (HipQIP), which aims to improve care and outcomes for people presenting to hospital with a fragility hip fracture (one that results from minimal trauma, such as a slip or fall). Initially this was developed for use within Northumbria but it has been scaled successfully to five acute hospital trusts – four in England and one in Scotland.⁴⁹

The programme focuses on prioritising additional nutrition for patients with hip fractures; implementing a surgical care bundle, pain block in A&E and surgery within 36 hours; and carrying out root cause analysis of any deaths; all while gathering outcome data and learning from different sites on their approaches to improve care.

Independent peer reviews of each department allowed for accurate and replicable baselines before interventions. Teams then attended learning events to review evidence and share ideas about improvement solutions. They tested and implemented iterative changes in their local settings and collected data to measure the impact of the work. This approach helped to build a strong 'breakthrough collaborative' – a learning community across the five different trusts that offered a safe space for both raising concerns and sharing learning between individuals and organisations.

The four English hospitals recorded 119 fewer deaths than expected if mortality had remained at the baseline and 77 fewer deaths than deaths at the hospitals used as controls during the same period. 30-day mortality rates in patients in hospitals within the collaborative reduced from 9.2% to 5.8%. Furthermore, 100 extra patients returned home instead of going to a nursing or residential home, and length of hospital stay was reduced by 2 days compared with the baseline.⁵⁰

In successfully scaling to five additional trusts, HipQIP shows the importance of working with peers to share learning and spread good practice, which can facilitate more robust improvement. Independent peer evaluations provided the necessary baseline to help trusts objectively understand where they started from and where to focus their improvement efforts. The programme also shows the importance of evidence-based quality improvement methodology, such as the Institute for Healthcare Improvement's Collaborative Model,¹⁶¹ which enabled providers to confidently identify areas of good practice and areas requiring further iterative improvement.

Case study 16: Reducing brain injury through improving the uptake of magnesium sulphate in preterm deliveries (PReCePT2)

Around 60,000 babies are born prematurely in the UK each year.⁵¹ These preterm babies are at greater risk of brain injury and conditions such as cerebral palsy⁵², which affects 500 premature babies a year.⁵³ Evidence shows that mothers at risk of premature delivery who take magnesium sulphate during preterm labour and before birth can reduce the risk of their babies developing cerebral palsy by a third.⁵⁴ The cost of a dose is less than £1⁵⁵, but less than half of eligible mothers were receiving the treatment in 2016.⁵⁶

From 2014 to 2015, the PReCePT1 project was implemented in five West of England maternity units. During the project, maternity units and mothers co-developed a Quality Improvement (QI) Toolkit,⁵⁷ which provided practical tools and training to increase knowledge and awareness of using magnesium sulphate to protect against preterm brain injury. As a result, the number of women receiving the preventative treatment in these units increased by an average of 25%.⁵⁶

Following this success, the project was supported to scale up nationally, called PReCePT2. From 2017 to 2020, 13 maternity units received an enhanced quality improvement intervention in addition to the standard model of implementation, including bespoke one-to-one and team coaching and access to learning events.⁵⁸ 'Snapshot' tools, such as communication and implementation plans and embedding tools,⁵⁹ were developed so that staff could understand how much progress they had made, alongside tools to plan how changes would be sustained.

The project shows how using data to evidence the need for improvement and sharing service users' stories to highlight impact can be effective ways of gaining buy-in. PReCePT2 uses performance data to stimulate action, including data on the number of people not getting magnesium sulphate, cases that could be avoided and the cost comparison between the intervention and cases of cerebral palsy.

PReCePT2 also highlights the importance of bringing together all professionals involved in a care pathway to collaborate on improvement, and of planning for long-term sustainability at the outset.⁶⁰ PReCePT has now been adopted by all 152 maternity units in England and magnesium sulphate uptake has increased to more than 85% for eligible mothers. As a result, it is estimated that 48 cases of cerebral palsy were prevented between 2018 and 2021, saving £38.4m in lifetime health and social care costs.⁶¹

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