

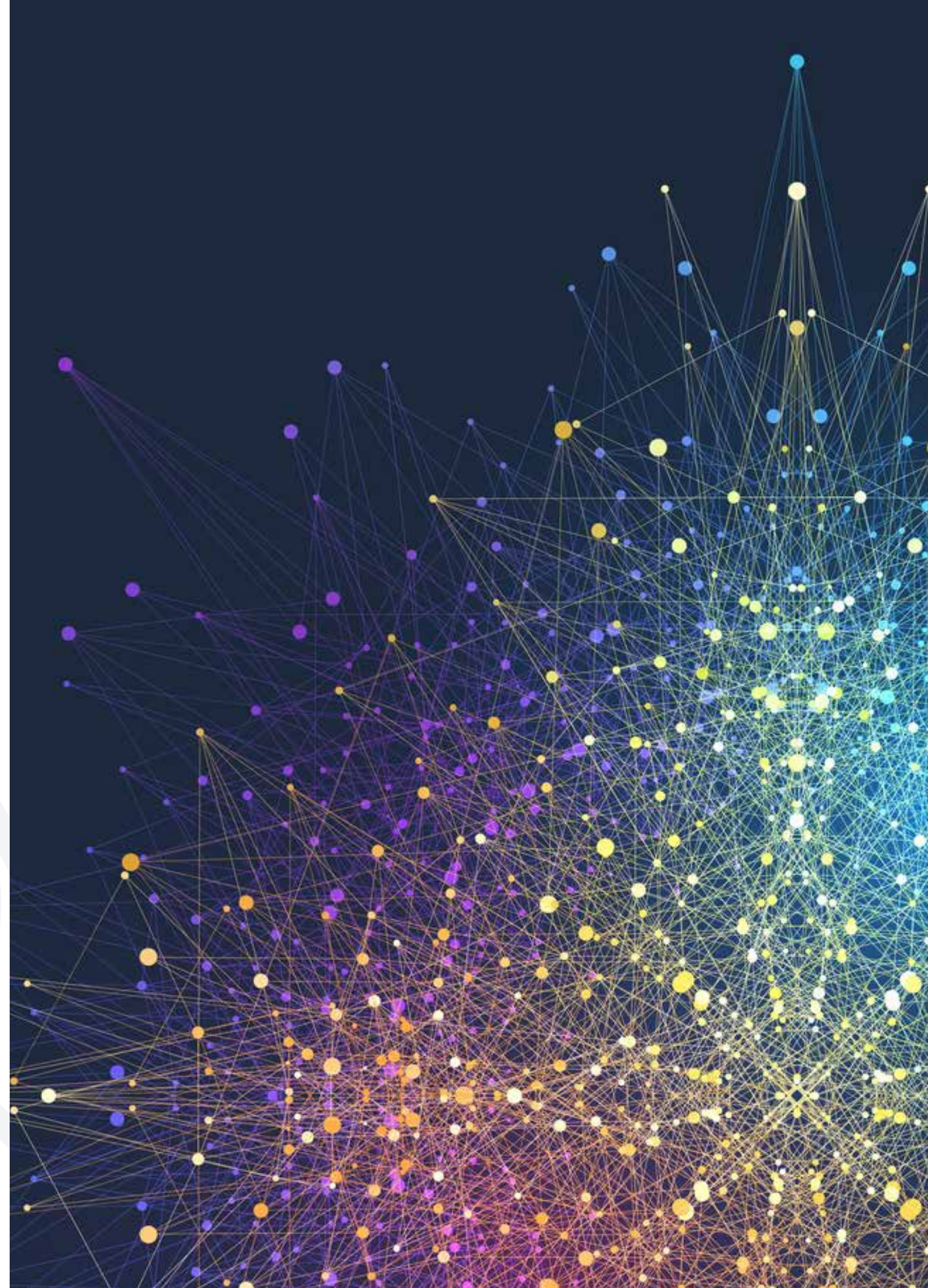
Impact Report

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Introduction

Introduction

A welcome by Andrew George, Chair and Axel Heitmueller, Managing Director

This report showcases the highlights of our work from the last 12 months, a period which saw COVID-19 continue to dominate healthcare both locally and globally.

When the pandemic first took force in March 2020, we refocused most of our efforts and capacity to support efforts in North West London, including operational support to the incident command structure and data modelling and analysis to support rapid decision making. However, over the last 12 months local priorities have shifted to focus on the wider implications from the pandemic. This includes addressing disparities in vaccination roll-out for our diverse population, remote monitoring of patients impacted by Covid-19 and the remodelling of safe, local non-emergency care at a time when face-to-face contact has been extremely limited.

We have continued to adapt our offer to support our members and clients to tackle the crisis as effectively as possible, and our strong expertise in analytics, strategy, project management and communications have continued to be invaluable to their response to the pandemic.

Key achievements include:

- Providing operational and strategic support to enable over 1 million vaccinations to be delivered in North West London
- Supporting the sector to make the best use of volunteers for **vaccination centres** in areas of low uptake, with over 18,000 volunteer tasks completed
- Creating standard operating procedures which supported over 90% of North West London care home residents to get vaccinated
- Led the rapid horizon scanning and deployment of an **innovative vaccination booking system** (before the national system was ready), leading to over 10,000 appointments
- Working with the North West London Integrated Care System (ICS) to set up the **Post-COVID Assessment and Recovery Service**, launching three acute specialist assessment clinics and six community multidisciplinary teams, managed through an integrated pathway
- In partnership with **AstraZeneca and HUMA**, setting up virtual, at-home wards for over 150 patients with Covid-19 and supporting the discharge of thousands of patients from hospital
- Leading the creation of the **North West London Safe Tracheostomy Care Collaborative (NWL STCC)** and the implementation of three vital safety interventions across the relevant settings, ensuring Covid patients received the safest care possible from all staff.



Key to many of these achievements is our continued development of **Discover-NOW, the Health Data Research Hub for Real World Evidence**. The Hub is one of seven pioneering data hubs commissioned by Health Data Research UK (HDRUK), and is a unique partnership bringing together NHS organisations, globally recognised academic, commercial and charity partners as well as patients and the public. It is continuing to revolutionise the way health information is used to treat and prevent disease, and this year we successfully passed our second milestone assessment, with our work being highly commended in all areas.

The Hub has played a vital role in helping to tackle the COVID-10 crisis locally and beyond, providing data and analysis to support the roll-out of remote monitoring, the assessment of vaccine impact and also to understand more about the inequity in vaccine, amongst a range of other projects. Key to this work has been ensuring that the public help shape the programme which is why we have also created a Citizens Advisory Group (CAG) for Discover-NOW.

Indeed, we know that public engagement with how health data is used for research and to develop healthcare services remains absolutely crucial, and demand for our expertise in public deliberation and engagement continues to grow. Last summer we were commissioned, in partnership with Ipsos Mori, to lead a London-wide deliberation on the wider policy implications of Covid-19, with recommendations from this work are now being used to help reconfigure services in London. In partnership with Ipsos MORI and Involve, we also created and ran a public advisory group for the Department of Health and Social Care (DHSC) and NHS Test and Trace, ensuring those who are seldom heard were also able to feed into emerging policies.

To help meet the needs of our members and clients from North West London and beyond, we continue to grow as an organisation, and now have over 60 members of staff from a diverse range of backgrounds and skills areas. Following on from our staff consultation last year, we have developed our internal governance structure, created a new personal development and appraisal process for staff and led focused improvement initiatives in equality, diversity and recruitment. We are immensely grateful to our whole team for taking such an active role in reshaping the organisation and adjusting so well to these changes over the past 12 months.

We have also partnered with **HDRUK on its black internship programme**, offering work opportunities to black data scientists, a group currently under-represented within the health data research community. And, in partnership with **On Purpose**, we also continue to offer ICHP work placements to young professionals looking to work in purpose-driven organisations.

We have continued to work on our many improvement programmes funded by NHS England/ NHS Improvement and other partners, repivoting to focus on Covid-19 where most needed. We consistently receive outstanding feedback from our members and clients, as evidenced by testimonials throughout the report., and other highlights from this year include:

- We continued to lead a £2.35 million project, commissioned by the Greater London Authority (GLA), to support improved access to mental health services for rough sleepers across London. RAMHP services are currently delivered by 4 NHS Mental Health Providers, with teams covering 16 boroughs in North London.
- We supported the launch of the NHS North Thames Genomic Medicine Service Alliance, supported by ourselves and UCL Partners, and one of seven alliances nationally.
- We continued the implementation of the national First Episode Rapid Early Intervention for Eating Disorders (FREED) programme, and successfully engaged our two mental health Trusts in support and spreading the interventions.
- We successfully engaged our two mental health trusts with the national Attention Deficit Hyperactivity Disorder (ADHD) programme, working with them to build an evidence base to spread the programme across all boroughs in North West London.
- We have continued to deliver Rapid Uptake Products, co-ordinating deployment of Placental growth factor (PIGF) based tests in four Trusts across North West London, and supporting five Trust Lipid Clinics to draft Pathway Transformation Fund (PTF) applications to bid for clinician resource to support existing services, to identify and treat more eligible patients.

This is a year where ICHP has continued to deliver for the population of NW London, both in the immediate response to the pandemic but also by fostering innovation in the sector. We can only do this with the support of our partners, both in the NHS and universities, as well as our staff who have adapted and responded to the challenges of the year.

Andrew George
Chair



Axel Heitmueller
Managing Director





About us

About us

Imperial College Health Partners (ICHP) is a partnership organisation bringing together NHS providers of healthcare services, clinical commissioning groups and leading universities across North West London.

We are also the designated Academic Health Science Network (AHSN) for North West London. We were created by the NHS to support innovation and improvement across the sector, with a single, consistent purpose.

Since our inception over seven years ago, ICHP has established a successful track record in delivering complex change across the health and care sector. Through our deep understanding of the NHS, strong connections with industry and a rigorous approach to the generation and analysis of real world evidence, ICHP is in a unique position to create collaborations to address real world problems, to drive real world change.

Our team of diverse and committed experts have the tools, networks and skills to quickly understand and tackle these challenges. We are motivated by our values of creating high quality impact, asking the difficult questions and bringing together the right people to solve a challenge. We are determined to deliver the highest quality of service to help our clients deliver more effective and efficient health and care to their populations.

“To create healthier populations through innovation and collaboration.”

Real World Evidence

Qualitative + Quantitative data and insights to drive and evaluate transformation

Opportunity for greatest impact

‘Supply side’ Partnerships

Strong connections into other industries to support market entry

Local system ‘demand’

Deep understanding of the ICS and its priority issues





Our capabilities

Our capabilities

We effectively help our clients to navigate and deliver complex change throughout the health and care sector through a range of capabilities...

Strategy and planning

We have an experienced team with significant expertise in policy and business strategy development, and a track record of developing politically-sensitive change programmes.

Solution sourcing

We efficiently scout for and find solutions, mapping on to clinical and operational challenges through our extensive international innovation networks, while being agnostic to type and source.

Engagement

Engagement of complex sets of stakeholders such as clinicians, patients and citizens, policy makers and other relevant groups in progressive ways and throughout our work is part of our core DNA.

Data analysis and insight

Grounding all of our thinking and work in robust, actionable insights derived from a variety of data assets including real-world evidence, using one of Europe's largest longitudinal linked-data sources.

Implementing change

Our diverse team and our value-driven business model allow us to support clients beyond problem definition and solution finding, and provide skills, experience and a deep understanding of the NHS, in order to facilitate the implementation of complex change, including whole pathway redesign.

Communications and storytelling

Using creativity and storytelling to inform, inspire and engage as well as amplify our learning.



A low-angle, upward-looking photograph of several modern skyscrapers with glass facades. The perspective creates a sense of height and scale. Overlaid on the image are two large, solid orange geometric shapes: a rectangle on the left and a large, stylized 'Z' or zig-zag shape on the right. The text 'Delivering complex change' is written in white, bold, sans-serif font within the orange rectangle.

**Delivering
complex
change**

Delivering complex change

At ICHP we work in partnership with our members and clients, helping to address the complex challenges they face.

Through our deep understanding of the NHS, strong connections with industry and a rigorous approach to the generation and analysis of real world evidence, we are able to support our members and clients to deliver lasting change. We foster a culture of innovation with our clients to help them adapt and then to adopt innovations. Understandably, over the last year we have focused most of our efforts on supporting North West London on its COVID-19 response. However, we have also continued to deliver other locally and nationally commissioned programmes.

Here are a few examples of our more recent work:



Supporting Covid-19 vaccine roll-out across North West London

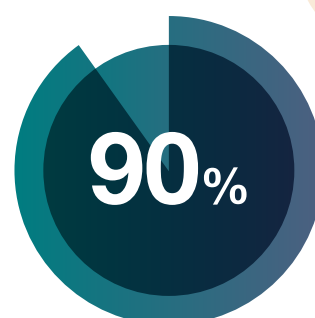
The problem

In North West London, our local sector needed both **strategic and operational support** to roll out its vaccination programme, particularly to its most vulnerable residents including the homeless and elderly care home residents. There was also a huge disparity in vaccine take-up across the region, revealing a **disconnect between the healthcare service and some community groups**. The North West London Collaboration of CCGs needed help with exploring the issues and targeting efforts where they most needed.

10,000 bookings

In less than one week, we created a vaccination booking platform for social care workers (as the national system wasn't ready) with over **10,000 bookings** made.

more than 650 homeless residents have been vaccinated



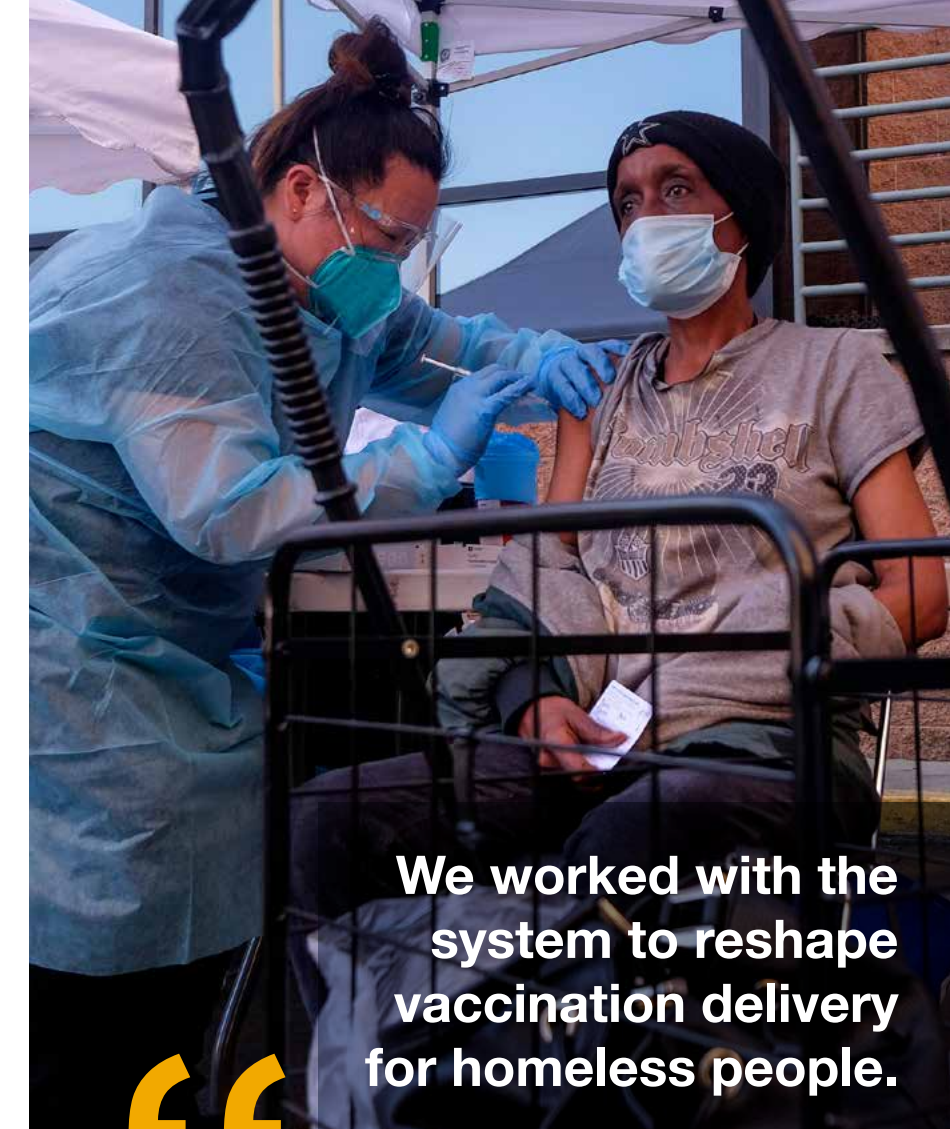
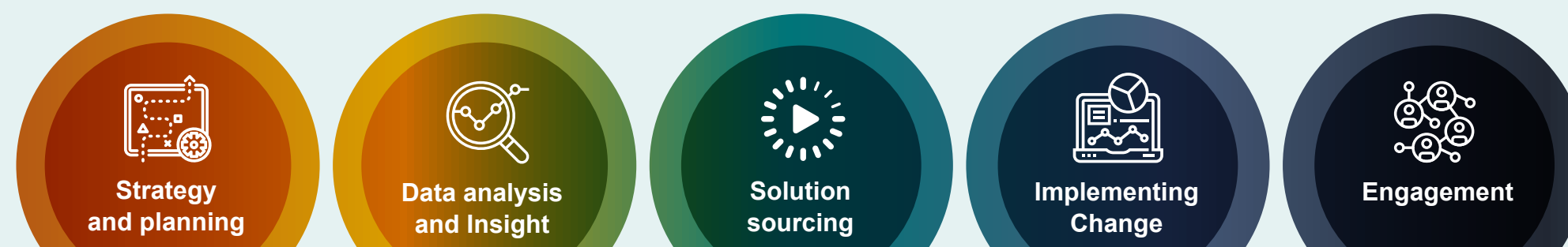
We created a new standard operating procedure for care homes, which led to the sector achieving their **target of 90%** care home residents being vaccinated.

How we helped

We have helped to drive vaccine roll-out across North West London, providing both **operational and strategic support** to the sub-regional Vaccines Operations Centre (S-VOC), **supporting one million vaccinations to be delivered**. We worked with the system to reshape vaccination delivery for homeless people, leading to **651 homeless residents being vaccinated**. We created a new standard operating procedure for care homes, which led to the sector achieving their target of **90% care home residents being vaccinated**. And in less than one week, the team led the rapid horizon scanning and deployment of an innovative vaccination booking system, simplybook, for social care workers, when the national booking system wasn't yet live, with over **10,000 bookings made**.

Through ICHP's access to North West London's Whole Systems Integrated Care (WSIC) integrated data source, we built a **COVID-19 dashboard** which allowed NWL CCGs to see data including first doses administered, second doses administered and refusals, broken down by ethnicity and age. This allowed to better **identify communities with greater hesitancies**, to then engage and build a better picture of the reasons behind these hesitancies and how best to address them.

Capabilities used



We worked with the system to reshape vaccination delivery for homeless people.

ICHP provided a breadth of data on vaccine uptake which allowed us to understand our situation in North West London, identify areas of focus and celebrate improvement. They supported us to link the quantitative data and qualitative insights which helped us better understand the tensions at play and stimulated rich discussions across the group about what we should do next.... ICHP were fundamental to the success of this work and their use of data, specifically WSIC, was invaluable to driving progress in vaccine equity."

Bob Klaber, Director of Strategy, Research & Innovation, Imperial College Healthcare NHS Trust

Supporting patients recovering from the long-term effects of COVID-19

The problem

As the COVID-19 pandemic has progressed it has become increasingly apparent that for many people with COVID-19, **symptoms are lasting much longer than expected**. Post-COVID syndrome, known colloquially as 'long COVID', is diagnosed when symptoms that develop during or after a COVID-19 infection which continue for **more than 12 weeks**. These symptoms can range from breathlessness and fatigue to dizziness and anxiety, meaning that patients can require a variety of services to help treat them. The North West London Integrated Care System (ICS) required **strategic and operational support** to set up a new service for these patients.



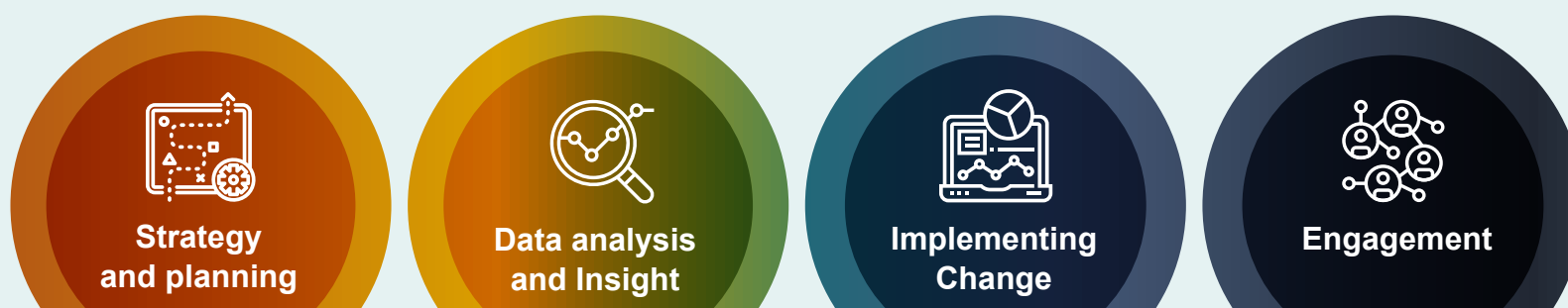
How we helped

We worked with North West London Integrated Care System (ICS) to set up **Post-COVID Assessment and Recovery Services**: brand new services aimed at addressing this new set of emerging patient needs. We combined the use of data with a partnership approach. Our work was split across three areas: compiling evidence to forecast demand, bringing together colleagues to set up the governance needed for pathway design and, thirdly, working with clinical and information experts to challenge and refine assumptions. We also ensured that the **community clinics are collecting data from day one** so that the ICS can monitor patient pathways and numbers of patients, leading to future service provision design.

Our work led to three acute specialist assessment clinics and six community multidisciplinary teams being launched in North West London in March 2021. These services offer patients specialist diagnosis and referral to appropriate care, especially crucial in the case of the multi-symptom, complex needs that post-COVID syndrome often comes with.

Post-COVID syndrome, known colloquially as 'long COVID', is diagnosed when symptoms that develop during or after a COVID-19 infection which continue for more than 12 weeks

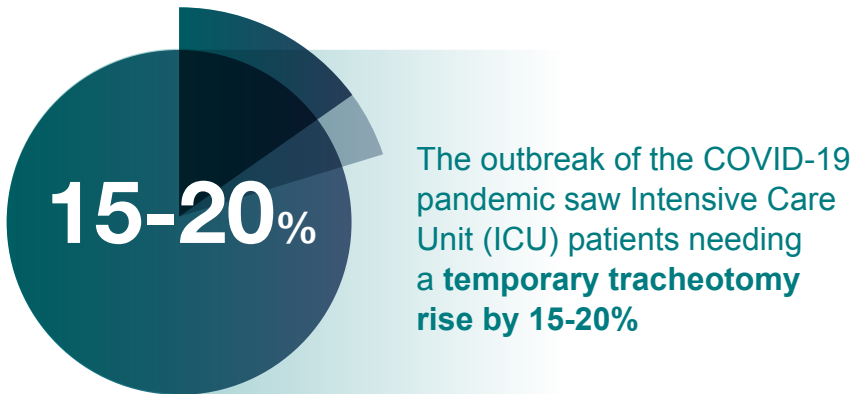
Capabilities used



Providing safe tracheostomy care

The problem

The outbreak of the COVID-19 pandemic saw Intensive Care Unit (ICU) patients needing a **temporary tracheotomy rise by 15-20%**. This increase in demand, coupled with the overall system pressures from the first Covid-19 wave, meant that many of these complex and vulnerable patients would be managed in step-down ICUs or ward areas and cared for by staff who were **not familiar with the key principles** that keep them safe.



How we helped

As part of the national Safe Tracheostomy Care (STC) programme We took a unique approach to **rapidly and effectively increase the adoption of three tracheostomy safety interventions** into all acute-based care settings (bedhead signs, 'bedside' emergency equipment and a daily care bundle). We **secured buy-in and prioritisation** at a regional level via North West London's Critical Care Network and Gold Command and at a local level via Trust Medical Directors. This approach enabled rapid identification and interest from over **40 multidisciplinary clinicians** across **seven Trusts**, to be part of the NWL Safe Tracheostomy Care Collaborative (NWL STCC). We supported colleagues to identify **three main areas of priority**: strengthened collaboration across community and acute teams, multi-disciplinary ward rounds and increased training for staff. We played a key role in helping to establish these new ways of working and steered the development of a series of resources over a **remarkable five month timeframe**.

ICHP played a key role in helping to establish these new ways of working and steered the development of a series of resources over a **remarkable five month timeframe**.



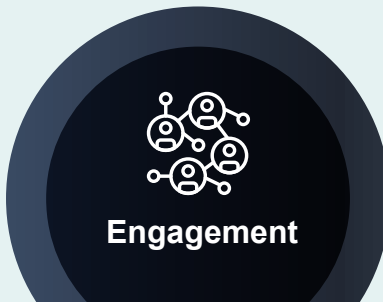
Capabilities used



Strategy
and planning



Implementing
Change



Engagement

40
multidisciplinary
clinicians

This approach enabled rapid identification and interest from over 40 multidisciplinary clinicians across seven Trusts, to be part of the NWL Safe Tracheostomy Care Collaborative (NWL STCC)



Having worked on many multidisciplinary cross trust improvement projects previously I was overwhelmed by the enthusiasm and commitment of this team.

It is an astonishing amount of work to achieve in such a short time and has the potential to have valuable and long-lasting benefits for patients across many trusts.

The difference here from other projects was partly the timely nature of the issue and the obvious clinical need for these resources which resulted in real commitment and dedication from the team, but also the leadership and direction from ICHP was essential and really helped guide and develop the project and led to its success."

Susannah Bloch, Respiratory Consultant,
Imperial College Healthcare NHS
Trust and Chair of NWL STCC

The background is a complex, abstract composition. It features a dense, textured pattern of blue and teal geometric shapes, possibly representing data or a digital environment. A large, stylized teal number '5' is prominently displayed on the right side of the image. On the left, there is a dark teal rectangular area containing the text 'Smart use of data' in white.

Smart use of data

Discover-NOW, the Health Data Research Hub for Real World Evidence, aims to revolutionise the way health data is used responsibly for research into treating and preventing disease.

Led by Imperial College Health Partners, it brings together NHS organisations, globally recognised academic, industry, technology, research and charity partners as well as patients and the public focused on the use of real world health data for research.

Discover-NOW supports access to one of the largest depersonalised linked health data sets in Europe, called Discover, which brings together real-world patient health data, in a safe, secure and Trusted Research Environment (TRE), it is revolutionising the way health data is used for research into treating and preventing disease. This second milestone marks the halfway point of the three-year funding period, through the UK Research and Innovation Industrial Strategy Challenge Fund and delivered through Health Data Research UK— the national institute for health data science.

Through supporting access to one of the largest depersonalised linked health data sets in Europe within a Trusted Research Environment (TRE), it is revolutionising the way health data is used for research into treating and preventing disease. This second milestone marks the halfway point of the three-year funding period, through the UK Research and Innovation Industrial Strategy Challenge Fund and delivered through Health Data Research UK— the national institute for health data science.

Discover-NOW over the last 18 months has demonstrated how it pivoted data improvement efforts to provide more opportunities for all sectors to utilise the power of data in their fight to understand, mitigate and overcome COVID-19.

Key offer



High-performance analytics environment along with methods and expertise



Feasibility and research recruitment tool



Consent to contact register of over **6,000 people.**

We have been using our data to help prevent COVID-19 through:

- Linking COVID-19 testing and pathology data - helping to identify local outbreaks and identify patients at higher risk of contracting COVID-19 to help target risk-reducing interventions.
- Linking COVID-19 vaccination and health data - allowing vaccination breakdown by age, gender, ethnicity, indices of deprivation. This has enabled local healthcare providers to ensure their vaccinate roll-out programme is targeting those areas most in need.

Our data has also helped to manage the impact of COVID-19 through:

- Improvements to admissions and bed use data for COVID-19
- Enabling near patient testing and remote monitoring capability and data
- Improving and curating existing data to generate a shielded patient list
- Improved coding and templates to understand and manage post COVID-19 syndrome

Remote monitoring for COVID-19 patients

The problem

The pandemic placed a **huge pressure on hospital capacity**, resulting in the need for more effective remote monitoring solutions to help keep patients safe at home. Solutions were needed to both **keep patients safe at home**, but also ensure their breathing was being monitored so that they **could be admitted to hospital** if needed.



Technology and implementation appeared inclusive; with the oldest user being 80 years old

In secondary care, the service increased secondary care efficiency by approximately

500%



96% of patients using the service as prescribed

How we helped

Our Discover-NOW team repurposed established work with Hub partner, AstraZeneca, on integrating innovative remote monitoring and near-patient testing into existing pathways for patients with Type 2 Diabetes, to be used to support NWL COVID 'Hot Hubs' – essentially virtual, at-home wards for patients with Covid-19.

Working alongside clinicians, we were able to digitally enhance clinical practice through providing an innovative remote monitoring and near-patient testing service. This remote monitoring setup by Hub partner, HUMA, was fast, flexible, and simple to use, and the data generated from the remote monitoring platform is now linked into the Discover data, which means we can monitor its effectiveness.

Within two weeks from launch, at the peak of COVID-19 in London, the service had:

- Over 150 patients on the virtual ward
- 96% of patients using the service as prescribed
- Technology and implementation appeared inclusive; with the oldest user being 80 years old
- In secondary care, the service increased secondary care efficiency by approximately 500%

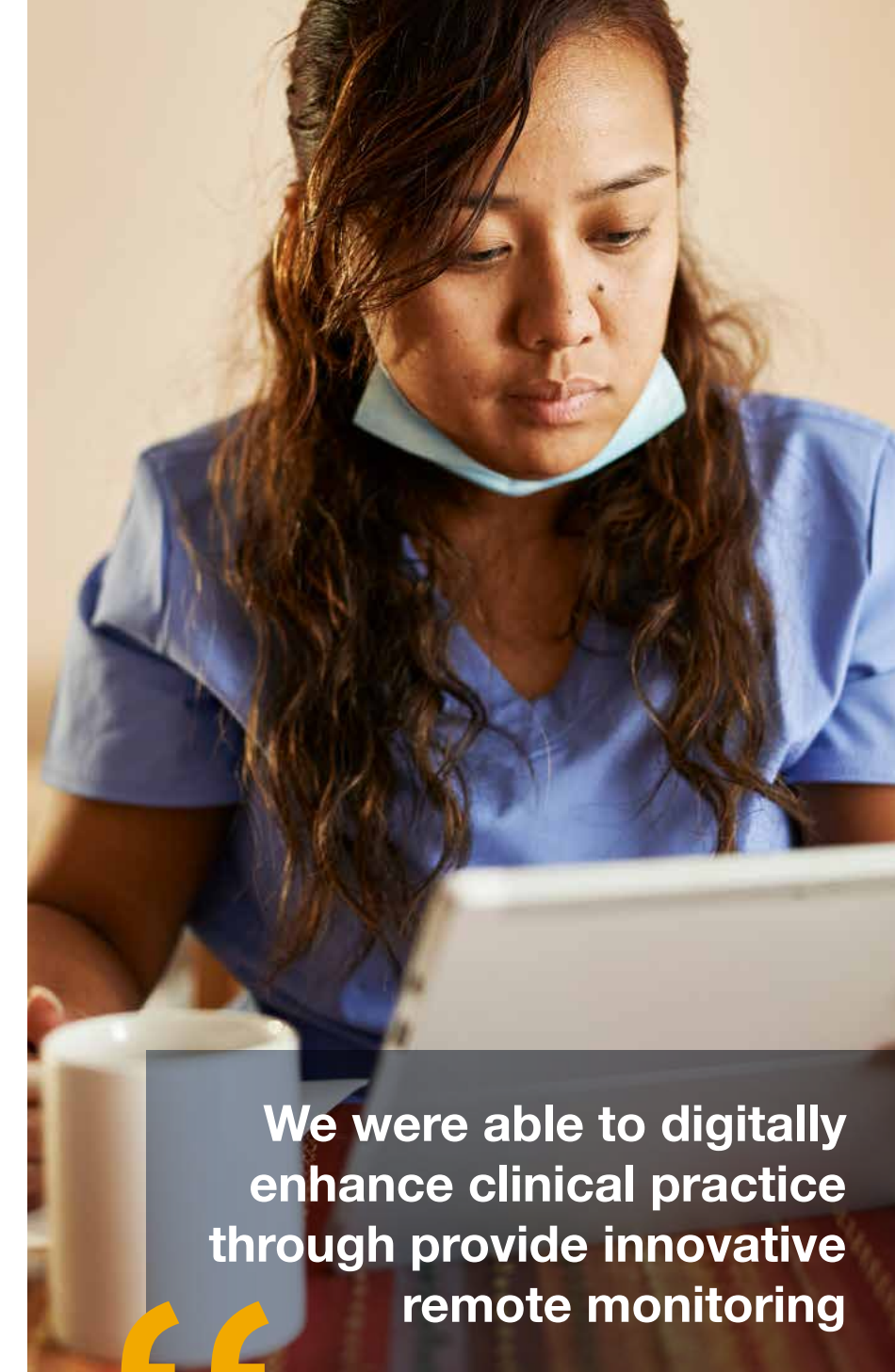
This is understood to be the fastest ever implementation of a digital service in the NHS; start to go-live in under four weeks. Several thousand patients have to date have been discharged from the pathway. **Channel 4 reported on the service.**

We were able to digitally enhance clinical practice through provide innovative remote monitoring



The Hub's role as a facilitator between the NHS, academia and industry partners to provide a level playing field and a safe environment to experiment is critical to the success of innovative and transformational work."

Ross Stone, Global Programme Director, Healthcare, AstraZeneca



Understanding the impact of bariatric surgery on patients with severe mental health illness

The problem

Bariatric surgery has been shown to be one of the most **cost-effective and efficacious treatments** currently available for obesity. However, a subset of patients struggle with significant psychological distress and increased care needs after bariatric surgery, including emergency hospital admissions, chronic pain, alcohol use disorder and increased psychological disorder. There was a **common perception** that pre-existing psychiatric disorder plays a role in post-operative outcomes, but no studies had been carried out in the UK to examine whether this is the case. A review was needed to **examine the procedure's effects on those with a psychiatric diagnosis**, to help better allocate resources for people undergoing this surgery.



“In the first year after surgery the **serious mental illness group** had higher healthcare usage post operatively in comparison with the other two groups.”

How we helped

West London NHS Trust commissioned ICHP to undertake this review, and we used the **Discover depersonalised longitudinally linked data set** to carry out a retrospective study of patients undergoing bariatric surgery and examine the procedures effects on those with a **psychiatric diagnosis**.

Using a **five-year data period** we split patients in North West London who had undergone Bariatric Surgery during the study period into three groups for comparison; no psychological diagnosis, common mental illness, and serious mental illness.

In the **first year after surgery** the serious mental illness group had higher healthcare usage post operatively in comparison with the other two groups. Following surgery **up to two years post operation**, the serious mental illness and common mental illness groups had a reduction, or no significant increase in:

- A&E usage
- Non elective admissions
- Outpatient appointments
- Mental health outpatients
- Community contacts

West London NHS Trust were able to use our data to better plan pre and post-operative support for those patients with a **serious mental illness**.



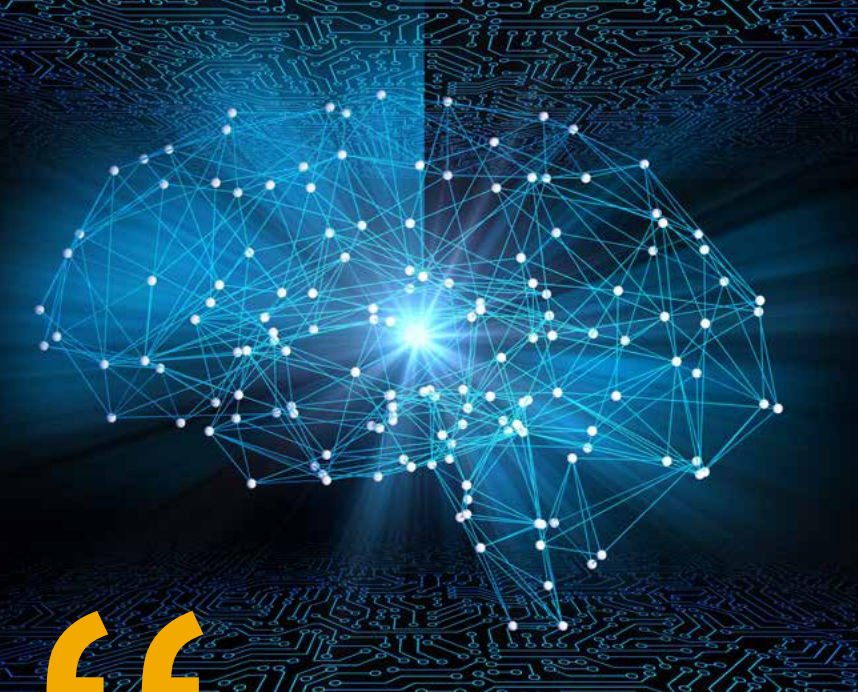
This study allows us to better understand the care needs of people with serious mental health difficulties presenting for bariatric surgery.

People living with obesity and serious mental illness face premature mortality and stigmatising attitudes from the public and healthcare professionals.

This dataset allows us to objectively analyse long term healthcare usage in a number of settings, not only hospital, but also community care and GP appointments, before and after bariatric surgery so that we can objectively assess the benefits to our patients, thereby reducing the stigmatising attitudes they may face when presenting for bariatric surgery.

By understanding the higher healthcare needs after surgery in this group we are also better able to plan their pre-surgery and aftercare with them and plan services accordingly.”

Dr Samantha Scholtz, Consultant Psychiatrist
- Bariatric surgery, St. Mary's Hospital
Research and Development Director



Heart failure dashboard

The problem

Around **920,000 people in the UK** have been diagnosed with heart failure, a complex clinical syndrome where the heart does not pump blood around the body as effectively as it should. Heart failure commonly develops over time, but signs and symptoms can appear suddenly, with patients often experiencing several acute episodes leading to **unplanned emergency hospital admissions**, that can lead to further deterioration in health.

Although there is no cure for heart failure, there are several proven treatments that when combined with **lifestyle changes** and **holistic support**, can allow many patients with heart failure to live well for longer. While, around **8 out of 10 heart failure diagnoses** in England are made in hospital, studies show that around half of these patients experience symptoms that **should have been picked up by an earlier assessment**, indicating the importance of early diagnosis.

138,000
undiagnosed

Working in partnership with Novartis, we created a new tool which could help healthcare professionals find more than 138,000 undiagnosed heart failure patients in England

How we helped

Working in partnership with Novartis, we created a new tool which could help healthcare professionals find more than **138,000 undiagnosed heart failure patients in England**. The Heart Failure Dashboard uses real world data to help identify gaps in heart failure diagnosis, broken down by geographical region in England. The dashboard provides health professionals with **data and insights for their local health systems**, providing the real-world evidence they need to introduce changes that will have a **positive impact on patients' lives**.

The Heart Failure Dashboard uses Quality Outcome Framework (QOF), HES and ePACT data to **highlight opportunity gaps**, allowing healthcare professionals to see the following stats for their CCG:

- Number of patients potentially undiagnosed with heart failure
- Number of patients not diagnosed according to guidelines
- Number of patients not receiving adequate treatment

Once these gaps have been identified, the dashboard allows clinicians to model the effect on both mortality and cost of applying high impact interventions in their local area, **building the data evidence** needed to create an impactful detection, diagnosis and treatment plan.

The Heart Failure Dashboard uses real world data to help identify gaps in heart failure diagnosis



Public deliberation

Public deliberation on the COVID-19 pandemic

Public deliberation continues to be a priority area of focus for ICHP, working in collaboration with our delivery partner Ipsos MORI. As a result of our collaboration with OneLondon for the Citizen summit on public expectations of the use of health and care data, we were commissioned by NHS England and Improvement to explore with Londoners the dilemmas relating to emergency policy proposals in light of the Covid-19 pandemic, to help inform future decision making.

Two virtual dialogue workshops were conducted in June, and a further four virtual deliberative workshops: all six with the same 59 Londoners. Alongside the main workshops, we also conducted interviews and a sense-check workshop with advocates of vulnerable groups, and interviews with individuals experiencing barriers to accessing and using NHS services. A number of key themes emerged:

- **Participants were generally accepting of the need for change** and the reduction of choice some of the measures discussed might result in.
- However, they raised **a number of concerns around the practicalities** of how the different measures discussed during the workshops would be implemented.
- Key among these was how **changes to services would affect different groups of people**, particularly those considered more vulnerable. They wanted the NHS to show some flexibility and adaptability towards patients in vulnerable circumstances to avoid further exacerbating any existing inequalities.
- Participants felt **safety and reassurance should be at the core of every communication** with the public. Linked to this, they thought the public need to understand the rationale behind each policy change

The recommendations were used to help shape policy and, following from the success of the London Covid-19 deliberation, in March 2020 we won a tender (in partnership with Ipsos Mori and Involve) to create and run a new Public Advisory Group for the Department of Health and Social Care (DHSC) and NHS Test and Trace. In addition, we are continuing to support public and staff engagement within regional priorities, such as the Community Diagnostic Hub programme.



We were commissioned by NHS England and Improvement to explore with Londoners the dilemmas relating to emergency policy proposals in light of the Covid-19 pandemic, to help inform future decision making

Public deliberation on the use of health data for research

We recruited 40 citizens to a Citizens Advisory Group (CAG), reflecting the diverse North West London population, to take part in a series of deliberations to set clear expectations about how the value of using health data for research is realised and distributed. The deliberations were held to inform the next steps for Discover-NOW, our Health Data Research Hub for Real World Evidence and one of the UK's seven Health Data Research Hubs. The CAG has been formed as part of the Hub's commitment to engaging patients and the public in a meaningful and authentic way to ensure trusted use of data as part of the recommendations from OneLondon's Citizen Summit on 'Public deliberation in the use of health and care data'.

The deliberations were split into two themes across four virtual workshops:

"What conditions need to be in place for non-NHS partners (universities, industry, charities) to have access to health and care data in a trusted research environment?"

"How should the value of Discover-NOW's health and care data for research be realised and distributed?"

Each workshop lasted three hours and included a combination of informative expert presentations and moderated group discussions in which smaller groups of around six participants reviewed stimulus materials and deliberated their views, experiences and expectations.

The work of the CAG is already directly influencing how data is used and accessed for research purposes in North West London. The reports from both deliberation themes and recommendations have been shared and supported by the Discover-NOW Board to be embedded and align to the recommendations.

Specifically:

Refining **the criteria for data access requests to ensure** that data access requests reflect what is important to the CAG.

Reviewing **the membership of the NWL region's existing data access committee to ensure** it reflects the recommendations of the CAG.

Steering the development of its new **Trusted Research Environment and how this could be used safely** with other datasets.

Using the findings to informing **Discover-NOW's future commercial policy**.

This work is viewed as a huge step forward in influencing and shaping how non-NHS organisations will access depersonalised data in a trusted way. As such, these findings are also being shared on a larger scale across our networks in North West London and all the other Health Data Research Hubs nationally.



I firmly believe in health data being used responsibly for research into treating and preventing disease, but this is only possible if we have the support, confidence and trust of our communities. Through examples of involvement like Discover-NOW's CAG we have clear recommendations and expectations from the public, only possible through engaging in meaningful and trustful ways."

John Norton, CAG member

We recruited 40 citizens to a Citizens Advisory Group (CAG), reflecting the diverse North West London population, to take part in a series of deliberations to set clear expectations about how the value of using health data for research is realised and distributed





Looking ahead
to 2022 and
beyond

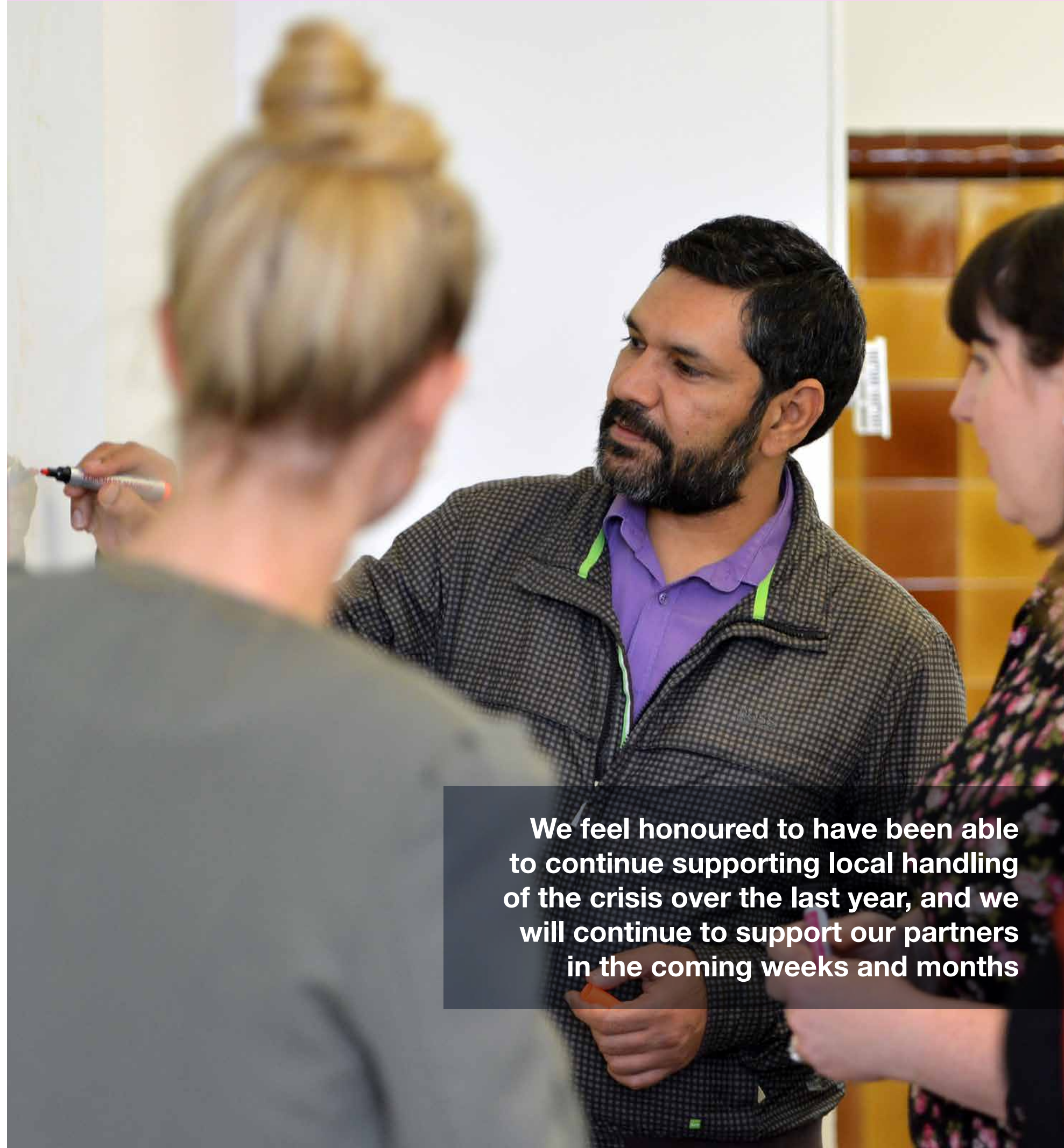
Looking ahead to 2022 and beyond

We're enormously thankful to our hardworking team, and the dedication and enthusiasm they have shown in supporting North West London's response to the pandemic, through what has proved to be another difficult year for all of us. We feel honoured to have been able to continue supporting local handling of the crisis over the last year, and we will continue to support our partners in the coming weeks and months.

Looking ahead, we know the pandemic has already started to bring both transformative change and difficult challenges for North West London and beyond. Over the next year we will continue to:

- Provide transformation capacity and expertise for the sector to address areas of real challenge;
- Invest on behalf of the sector in vital data infrastructure;
- Provide connections into the wider innovation ecosystem nationally and internationally.

We will also continue to evolve as an organisation, developing both our service offer and our team members, and we look forward to continuing to support our colleagues, members and stakeholders.



We feel honoured to have been able to continue supporting local handling of the crisis over the last year, and we will continue to support our partners in the coming weeks and months



Find out more

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