

You said, we did: How have we started to fulfil the commitment made to Londoners?

3 March 2021



One year after the Citizens' Summit, Luke Readman - Director of Digital Transformation for the NHS in London and Chief Officer for OneLondon - describes how public recommendations are being used to shape policy for the join-up and use of health and care data.

1 March 2021 marked one year since the conclusion of the OneLondon Citizens' Summit, where 100 Londoners - reflective of the city's diverse population - deliberated over two weekends to form recommendations for how health and care data should be joined-up and used across London to support individual care, planning, improvement, and research.

At that time, the first cases of COVID-19 infections were starting to be reported. Since then, we have all felt the profound impact of coronavirus across our communities.

Despite ongoing challenges, the coronavirus vaccine offers hope for a return to some normality in the coming year. We remain incredibly grateful for the commitment of our health and care staff and key workers.

Responding to COVID-19

COVID-19 has highlighted, more than ever, the need to join-up health and care data to provide the real-time information that supports individual care, public health, and protects the lives of Londoners. But we must do so in a way that is legitimate and trustworthy.

Thanks to the recommendations set out by participants involved in the Citizens' Summit, for the first time we have clear instruction from the public to policymakers and health and care leaders as to how we should be using health and care data in a way that builds trust and confidence. This also offers clarity and direction to our frontline health and care staff, and data controllers.

It has meant that where the join-up of information across London has been accelerated over the last 12 months in response to COVID-19, we can be confident that this is what citizens expect. As a result, we have been able to better manage COVID-19 incidence across London, and support and protect the lives of some of our most vulnerable citizens. For example:

- The join-up of local authority and GP data in north central London identified and prioritised support for vulnerable patients with poorly controlled long-term conditions

- A dataset drawn from GP, hospital, and community data sources in north east and north west London identified vulnerable patients who required immediate intervention, and flagged those at high risk
- Research using de-personalised (non-identifiable) data about inner city residents from two south London hospitals found that people from Black, South Asian and minority ethnic groups were more likely to get COVID-19 and were at greater risk of worse outcomes

You said, we did

In the 12 months since the Citizens' Summit, the OneLondon collaborative - made up of London's five health and care partnerships, the Greater London Authority, and the London Ambulance Service - has taken significant steps towards developing a consistent set of policies for the use of health and care data, shaped by Londoners' recommendations.

This is contributing to the wider vision of transforming London's health and care services by joining up information to support faster, safer, more effective care.

So what does this mean in practice?

ACCESS AND CONTROL IN HEALTH AND CARE DATA

You said:

We expect health and care professionals to access and use information relevant to their roles.

We did:

We have implemented the London Care Record - a single shared record that provides an accurate, complete picture of a person's health and care from over time and across organisations to provide faster, safer, more effective care.

This means that, for the first time, GPs, hospitals, the London Ambulance Service, NHS 111, community care services and care homes across London can access a joined-up picture of a person's health and care information, available at the point of care.

Impact:

The London Care Record currently covers a population of 7.5 million Londoners, with the aim to include the full population of 9 million citizens by the end of March. Here's how it's supporting more effective care:

"By accessing the London Care Record I could see patient's full MRI results. This information changed my management plan of the patient who needed urgent assistance due to the severe pain."

Clinician, London Ambulance Service Clinical Hub

"One of the quick wins of using the shared record has been fast-tracking two-week wait referrals for suspected cancer patients."

GP, London

"When patients are transferred to our stroke unit, our stroke team can immediately see what investigations have already been carried out and can access the results."

Consultant Geriatrician

"The benefit is that we have up-to-date information about the customer. This supports assessment and evidence for care provision, which also supports the carer."

Social Worker, Newham

You said:

We expect that a senior person or group should authorise the level of data a staff member can access.

We did:

We are looking to implement a model of Roles-Based Access Control (RBAC) in London. This ensures that users are suitably authorised to access appropriate information.

Impact:

“Hospital Pharmacists can click through and see on the shared care record what medication the patient is currently taking. That’s a massive benefit.”

Chief Clinical Information Officer

“It helps me to quickly find out which hospital or ward a customer is in, how many times they have been admitted and why, as well as their discharge summary. This helps ensure all health partners are working together to complete a safe discharge.”

Hospital Discharge Officer, Hospital Social Work Team

You said:

We expect safeguarding of information and accountability.

We did:

We have developed a data sharing framework for London to support consistent safeguarding of information and accountability.

This data sharing framework summarises the legal principles and good practice guidelines placed on providers across London’s five health and care partnerships for wider data sharing for the purposes of individual care, planning and improvement, and research. The framework is underpinned by data protection legislation and the Common Law Duty of Confidentiality.

The framework has been developed and agreed by information governance leads across London’s five health and care partnerships. We are now consulting with data controllers, information governance and data protection experts, health and care professionals, the National Data Guardian and the Information Commissioner’s Office, to ensure that it is fit for purpose.

USING DE-PERSONALISED (NON-IDENTIFIABLE) DATA FOR HEALTH AND CARE PLANNING, IMPROVEMENT AND RESEARCH

You said:

We expect that de-personalised health and care data must be shared and used to plan and improve services and benefit health in London.

We expect all health and care organisations in London to join-up de-personalised information, as part of a population dataset, to support proactive care, planning and research and development.

We expect a fair and productive partnership to meet conditions around benefits, charging and transparency.

We did:

We have developed the following to underpin and enable the consistent use of de-personalised data for health and care planning, improvement, and research:

- A data sharing framework for London: sets out the principles for safe and secure join-up of data for multiple purposes to ensure a consistent approach
- A health data strategy for London: single strategy that links the capabilities of the NHS and academia to support data driven innovation and improve the health of Londoners

This includes consistent processes for sharing the data (consistent with the National Data Opt Out) and access in an environment that is secure, accredited, monitored, and prevents unauthorised use.

GOVERNANCE AND OVERSIGHT

You said:

“We expect the public to be involved in ongoing policy development.”

We did:

Following Londoners’ recommendation that there should be a diverse citizens’ advisory group, we have secured support from NHS England (London Region) for a wider public involvement and engagement mechanism.

This would enable Londoners’ to hold the system to account and influence policy in practice as to health and care data use. We will share further updates as this develops.

Over the past 12 months we have seen some great momentum across London’s health and care system as we work collaboratively to fulfil the commitment made to Londoners at the OneLondon Citizens’ Summit.

This journey will continue at pace in the coming year and we are looking forward to sharing more stories and examples of how this join-up and use of data is making a real impact to health outcomes and improving the lives of Londoners.

For more information visit www.OneLondon.online or follow [@OneLondon4](https://twitter.com/OneLondon4) on Twitter

