

## Public questions and answers: Integrated Care Partnership meeting, 22 November 2022

### Questions received from the public with responses from the ICB

<p><b>Question 1</b></p> <p><b>Member of the public</b></p>	<p>Can you list all organisations, including private companies, that have been involved in setting up, helping to manage or analyse, or who otherwise have had and/or currently have access to, what was called our Local Care Record as created in South East London ICS.</p> <p>Please include those companies listed in the Health Services Support Framework.</p> <p>Please also include in the list those organisations and companies who collect and provide data for research and planning purposes, in addition to direct care.</p>
<p><b>Response</b></p>	<p>Participating organisations in the Local Care Record include Guy’s and St Thomas’ NHS Foundation Trust, King’s College Hospital NHS Foundation Trust (including the Princess Royal Hospital), South London and Maudsley NHS Foundation Trust, Lambeth, Southwark and Bromley General Practices, the London Boroughs of Lambeth and Southwark (Social care) and Bromley Healthcare CIC.</p> <p>The Local Care Record was developed in 2013 and at the end of this financial year the Local Care Record will be retired, being replaced with the London Care Record.</p> <p>Integration with primary care involves GP system supplier, Emis, and also uses Healthcare Gateway’s Medical Interoperability Gateway to present GP information to acute users.</p> <p>Since 2020 we have also been developing and creating the London Care Record, which is used to link health and social care data across London and all of the five ICS’s. This is hosted via Lewisham and Greenwich NHS Trust and further details can be found <a href="#">here</a>.</p> <p>In 2021 the service has also been expanded to allow access and data sharing with other ICS in Milton Keynes, Hertfordshire and West Essex.</p>

	<p>The Local Care Record and London Care Record will only be used by health and care professionals involved in delivering your treatments or care. Third parties, companies or individuals not directly involved in your care will not be able to view or access your record. This means that the information cannot be used for purposes such as research which are not direct care. The scope of the Health Systems Support Framework mentioned is limited to non-clinical services and those that do not involve the direct provision of patient care.</p>
<p><b>Question 2</b></p> <p><b>Member of the public</b></p>	<p>ICP Question</p> <p>We note that the Partnership recognises that:</p> <p>The wider pandemic .....has highlighted the challenges our boroughs face around vaccine hesitancy more generally but also the underlying mistrust many of our more deprived populations have with regards to health and care services'</p> <p>We are concerned that people across South East London have not been consulted or told that the ICB is using Discovery to collect and share data for research and planning. We note that Discovery has imported 10 years of detailed primary care data, and secondary data is now being imported , including data on mental health, community and social care.</p> <p>Question</p> <p>What will the ICP do to ensure that we, the people of South East London, are informed that our data is being shared, and with whom, including data on mental health, and social care.</p> <p>This is necessary in addition to the video (<a href="https://www.youtube.com/watch?v=7c6acmpUWW8">https://www.youtube.com/watch?v=7c6acmpUWW8</a>) made about the London Care Record which is for direct care.</p> <p>How will members of the public be informed how to Opt Out if they do not want their data used in this way?</p> <p>What are the current methods of Opt Out for social care service users, and how will the public be told about this?</p>
<p><b>Response</b></p>	<p>For the two key data sharing programmes we operate at an ICP level</p> <p>1. London Care Record (LCR)</p> <p>We have been raising awareness via short films and stills, posters and information leaflets in organisations that are participating in the LCR program.</p>

## 2. Discovery Data Service

In south east London we are developing a data service which is hosted by the North East London Integrated Care Board (ICB). This is called the Discovery Data Service and its use is very carefully managed via the South East London Data Service Data Usage Committee. This committee brings together representative members from all health and care sectors and two members who represent the Healthwatch organisations in South East London

Across London there has been a lot of engagement and involvement work with Londoners, though the [One London programme](#). This includes the large Citizens' engagement project and Summit in early 2020 and further public deliberation work earlier this year (2022).

The use and access to data, via the Discovery Data Service, is underpinned by data sharing agreements, which give details of particular projects as well as the specific policies in respect of people's rights and consent. Some projects will require specific consent and others will be aligned to the national opt-out process. More detail is available on this website [Home \(discoverydataservice.org\)](#)

### Right to Object to processing

In SEL we have focused on two aspects of the right to object to processing of personal data

1. Local Opt-Out - In most cases, each Controller (Health and Social Care organisation) will have a local process in place for their patients/ service users to record their particular wishes about how their information is used and shared more widely by the Controller. In these cases for services such as the Discovery Data Service – these will be the key point of contact to record their wish. For the LCR there is a central form that is held [here](#) and describes the steps to be taken.
2. National Data Opt-Out (NDOO) - From 2018 a national data opt-out has been in place following the recommendations of the National Data Guardian and a register of people's wishes are held by NHS Digital only. This allows the public to register their wish to opt out of the use of their data for secondary purposes (such as research and planning purposes) in a single central point. Where any proposed use of data is made by any organisation, if the NDOO is applicable a search is undertaken by the relevant organisation to ensure that ONLY records that are NOT opted out via the NDOO are used in the agreed projects.

For ease:

- For Discovery Data Services, this is managed by us or by the NHS NEL ICB team who host the service or the SEL ICB for internal projects.
- It is NOT applicable to the London Care Record as this system is ONLY used for Direct Care purposes.

All south east London organisations are required to comply with the opt-out process, and ensure that information about the opt out is on their website. For Social Care please see the following link; [National Data Opt-Out - Digital Social Care](#)

More details of how the public can opt-out if they do not want their data used is available on the national website. [National data opt-out - NHS Digital](#)

In addition to the above you will find information, related to the data and digital work to support care, service and system planning, on the SEL Integrated Care System website. Please see [HERE](#).

**Question 3**

**Member of the public**

I have attached a reference from Lambeth Together, where reference is made to concerns about the safety of patient data. In July and again in September I have attached a second reference showing that the Board at Guys and St Thomas Foundation also have real concerns about data security  
Can you please outline the measures the Integrated Care Partnership has in place to address these issues of security of patient data

**Reference One**

<https://lambethtogether.net/wp-content/uploads/2022/07/LTCP-20.07.2022-AGENDA.pdf>

Lambeth Together & Integrated Health and Care Assurance Report **July 2022**

Risk assessment (page 55)

**143** There is a risk that staff may be targeted by internet fraudsters looking to exploit their personal information to gain access to the secure computer servers. This could lead to a major data breach and a potential loss of secure patient data.

And again two months later

<https://lambethtogether.net/wp-content/uploads/2022/07/LTCP-20.07.2022-AGENDA.pdf>

Lambeth Together & Integrated Health and Care Assurance Report **September 2022**

Risk Highlight 5.1 (Page 39)

**143.** There is a risk that staff may be targeted by internet fraudsters looking to exploit their personal information to gain access to the secure computer servers. This could lead to a major data breach and a potential loss of secure patient data.

	<p><b>Reference Two</b> Guys and St Thomas Foundation Trust <b>AUDIT AND RISK COMMITTEE Wednesday 15th June 2022</b> <u>Annual Information Governance and Health Records Report (page 41)</u> 9.1. The Trust was preparing its 2022 annual Data Security and Protection Toolkit (DSPT) return. It was anticipated that the Trust would not, as in 2021, achieve a full ‘standards met’ rating; the reasons for this included the Trust’s overall completion rate of information governance training not meeting the mandatory target of 95%, and the deployment completion date of supported Windows (version 21H2) to enable receipt of security updates (patches). The implications for the Trust in not fully meeting the standards was discussed.</p> <p><b>TRANSFORMATION AND MAJOR PROGRAMMES COMMITTEE Wednesday 27th July 2022,</b> <u>13. Major Programme Updates (page91)</u> 13.2. Committee members’ attention was drawn to the significant challenge of providing comprehensive training to all relevant staff about how to use the new electronic health record system. This was described as critical to a successful implementation.</p>
<p><b>Response</b></p>	<p>The Integrated Care Partnership (ICP) brings together leaders from health and care partner organisations in south east London, including local authorities, NHS hospitals and other providers, Healthwatch and the voluntary, community and social enterprise sector. Organisations in south east London which are Controllers or Processors of patient data must meet the <a href="#">National Data Guardians ten data security</a> standards to keep that data secure.</p> <p>This includes training for all staff about their responsibilities in relation to handling confidential data and security standards, processes that ensure confidential data is only accessible to staff who need it for their current role and access is removed as soon as it is no longer required, logs to ensure all access to personal confidential data on IT systems can be attributed to individuals, strategies for protecting IT systems against security threats, responding to security advice and identifying cyber-attacks, ensuring software is up to date and suppliers are aware of their responsibilities, and continuity plans are in place to respond to threats, data breaches or near misses, and to learn lessons to improve processes.</p> <p>The main way assurance is provided that these measures are in place is the annual submission of the <a href="#">Data Security and Protection Toolkit (DSPT)</a> mentioned in the quote from the Guys and St Thomas’s Trust Audit Committee. Where the organisation identifies any gaps in their standards and action plan is developed and approved to mitigate these gaps and is then shared and agreed with NHS</p>

	<p>Digital as part of the publication of their standards. As your examples show, any risks highlighted by this process are discussed in the governance committees of the organisations so that mitigations can be put in place.</p> <p>Further assurance is provided by the CQC who also review and consider the DSPT when inspecting each organisation.</p>
<p><b>Question 4</b></p> <p><b>Member of the public</b></p>	<p>Have you considered interdisciplinary working to overcome knowledge silos? Overarching frameworks have developed from Marmot's work on social prescribing.</p>
<p><b>Response</b></p>	<p>Responding at the Partnership meeting on 22 November 2022 Dr Jonty Heaversedge welcomed the challenge to think across a broader range of disciplines than had previously been considered. At a recent engagement event the positive impact of care navigators had been discussed, who were able to use their knowledge to connect individual patients with local services which were available. A broader view needed to be taken of the entire workforce available to deliver care include a range of disciplines, and people should be supported to work together in multidisciplinary teams and understand each other's different perspectives for the benefit of residents.</p>
<p><b>Question 5</b></p> <p><b>Member of the public</b></p>	<p>Accepting the strategy is a work in progress and the broad priorities suggested capture the big themes</p> <p>Does the partnership recognise the lack of specific reference to informal/family carers throughout the document or within the priorities?</p> <p>Considering the data both qualitative and quantitative available on carers it is concerning they did not emerge in the current iteration and suggests this may have been missed within the initial scoping?</p>
<p><b>Response</b></p>	<p>We are very conscious of the critical role of carers in supporting our service users and our health and care system. We have now had discussions with carers and representative organisations for carers in a number of forums to help develop our thinking in our strategy and will certainly seek to reflect the critical role carers play in our initial strategy publication. We are currently inviting further views from residents of South East London online and will be working with Healthwatch organisations in South East London to ensure that the perspectives of service users and carers are reflected in the next stages of the work in 2023.</p>