LEEDS CARE RECORD
THE LEEDS TEACHING HOSPITALS NHS TRUST

INTRODUCTION

Leeds Care Record is described locally as a city wide multi-agency integrated record. It contains a rich dataset, supplied by a variety of settings, including mental health and adult and children's social care, and is used exclusively to support direct patient care.

Leeds Care Record is a bespoke solution developed and hosted by The Leeds Teaching Hospitals NHS Trust (LTHT). It is a component of the Leeds PPM+ enterprise platform. A strong focus on engagement, collaboration and understanding what people want has been key to the programme's success.

AT A GLANCE

SCALE **L**

S = < 5 organisations
M = 5-10 organisations
L = 10+ organisations

MATURITY **4**

0 – No planned programme for sharing data
1 – Sharing one data type or planning data sharing
2 – Sharing two data types (inc. GP) at read only
3 – Sharing three or more data types at read only
4 – Sharing three or more data types, with write capability

*for the purpose of comparison the data types are GP, Acute, Community, Mental Health, Adult Social Care, Child Social Care

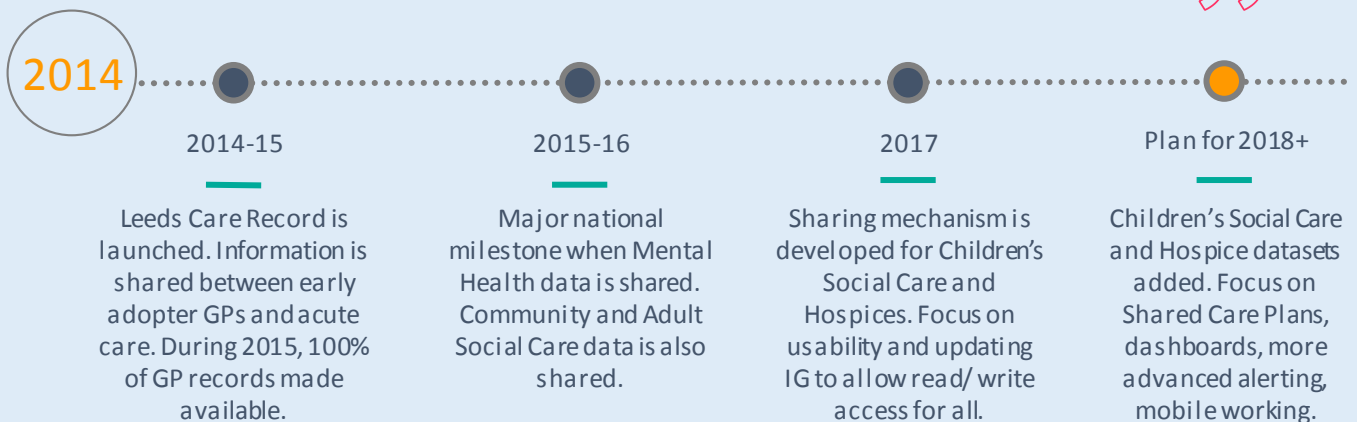### HOW LEEDS CARE RECORD IS BEING USED

Individual Patient Care	Care Planning & Coordination	Health & Care System Management	Population Health Management	Research
LIVE	OUT OF SCOPE	OUT OF SCOPE	OUT OF SCOPE	OUT OF SCOPE

> Leeds Care Record is a rich source of health and social care information which supports the delivery of direct care across the city of Leeds.

TIMELINE

2014

2014-15
Leeds Care Record is launched. Information is shared between early adopter GPs and acute care. During 2015, 100% of GP records made available.

2015-16
Major national milestone when Mental Health data is shared. Community and Adult Social Care data is also shared.

2017
Sharing mechanism is developed for Children's Social Care and Hospices. Focus on usability and updating IG to allow read/ write access for all.

Plan for 2018+
Children's Social Care and Hospice datasets added. Focus on Shared Care Plans, dashboards, more advanced alerting, mobile working.

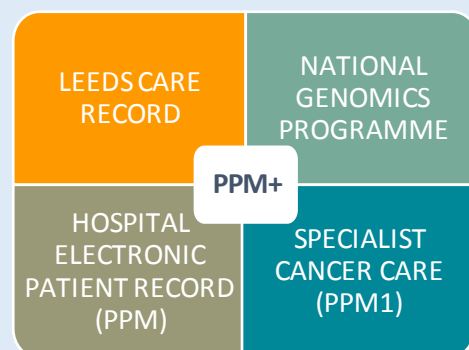Approx. **115,000** clicks on Leeds Care Record per month

5500+ active users

Approx. **780k** population

LOCAL CONTEXT

- Leeds Care Record is a secure web based solution that shares real time data between care providers, enabling joined up health and social care for over 800,000 people.

- Every health and social care organisation in Leeds has a different set of records held in over 300 clinical systems. Leeds Care Record pulls key data about people from many of these systems and displays it in one combined record, which is organised through a set of views or "tabs".

- Leeds Care Record covers primary care, acute care, adult social care, children's social care, mental health, hospice and community.

- Users of Leeds Care Record can access the record from within their own clinical system, for example a GP can launch Leeds Care Record by clicking on the relevant link from within a patient record in SystmOne or EMIS. Usability has always been a key aim, so the technical team was tasked with ensuring users only had to make three clicks or less to get into Leeds Care Record.

- Leeds Care Record is part of a number of digital initiatives in the Leeds region, and one of four programmes that use Leeds' bespoke PPM +enterprise platform to deliver its functionality.

The PPM+ Platform...

- supports the delivery of cancer services within the Leeds Cancer Centre, and across the Yorkshire network of cancer units (known as PPM1).

- delivers The Leeds Teaching Hospital's trust-wide electronic health record (PPM), which was developed with academic and commercial partners.

- powers Leeds Care Record, which connects care givers across the city, specifically for the purpose of delivering direct care.

- supports the 100,000 Genomes Programme across Yorkshire by capturing data relating to rare diseases.

LEEDS CARE RECORD	NATIONAL GENOMICS PROGRAMME
	PPM+
HOSPITAL ELECTRONIC PATIENT RECORD (PPM)	SPECIALIST CANCER CARE (PPM1)

FOCUS ON: BUILDING RELATIONSHIPS TO DELIVER OUTCOMES

"Leeds Care Record continues to join the dots in our pursuit of more integrated and collaborative care. To do this effectively, forming strong and trusted relationships is a big priority. We use different strategies to achieve this – for example pro-active citywide workshops with patient, clinical, technical and information governance representatives enable us to generate support which is central to our success.

The solution is 'home grown' (powered by the in-house hospital platform) allowing us to drive digital innovation from its core. We are proud to be seen as pioneers for integrated care records nationally.

Leeds Care Record is part of the Leeds Health and Wellbeing Strategy and helps us deliver some of the City's key priorities and outcomes."

Julia Millman, Programme Manager at The Leeds Teaching Hospitals NHS Trust

LEEDS CARE RECORD SUPPORTS…

INDIVIDUAL PATIENT CARE

- Leeds Care Record includes the following to support the delivery of care:

  - details of contacts, appointments or clinic visits
  - notes and reports about health, treatment and care
  - results of images, scans and laboratory tests

  - relevant information about those involved in care
  - alerts and/or notifications to support decision making for example high risk medicines.

- A series of tabs is used to organise the record's rich dataset, including "Hospital", "General Practice", "Community", "Adult Social Care", "Children's Social Care", "Mental Health", and "Hospice"

- GP staff also have access to a "virtual ward" view which shows the status of people who are registered to their practice and are currently in hospital. This ensures that GPs do not lose touch with a patient if they go into hospital and can see their progress during their stay, while Community nurses don't waste time on visits to people who are not at home because they have been admitted. Similarly, there is a discharge view which provides key information relating to people who have recently been discharged, e.g. medicines administered. GPs use this to manage people's ongoing care more proactively.

- The Leeds Care Record team is in the process of working with partner organisations to develop a more advanced set of alerts that will be displayed when Leeds Care Record is accessed. There is great demand for this functionality but all stakeholders are aware that it must be well thought out, as alerts drive clinical behaviours. The aim is for alerts to persist throughout the user journey, including on mobile devices and eWhiteboard views.

## Communications and Engagement

A significant emphasis has been placed on developing the Leeds Care Record brand to foster a positive response from the public and staff. A dedicated patient group has helped with the development of communications and fair processing information.

The aim has been to produce a set of resources which is easily accessible and informative. The Leeds Care Record website is a good example of this. It provides information, materials, links and news relating to the record, allowing people to see which of the services they use is involved and how it might impact them. The "What are people saying?" section features testimonials from a wide range of staff, providing a first hand insight into what Leeds Care Record means and how it benefits care.

TECHNICAL SOLUTION
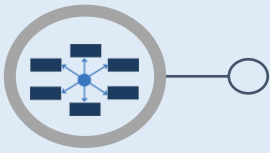
FEDERATED RECORD LOCATOR MODEL

- Leeds Care Record is part of the PPM+ platform which was developed by The Leeds Teaching Hospitals Trust.
- It utilises MIG2 to provide a view of data from GP systems. GP Connect is being piloted to provide a much richer dataset. FHIR messaging is also used.
- Data is pulled from underlying systems on request and displayed. No data is persisted.
- The solution now supports write access.
- It is launched in less than three clicks from the user's own clinical system.

SOLUTION FEATURES

FEATURE	IN USE
Coded data	✔
Free text data	✔
Bi-directional	✔
Real time	✔
Role-based access	✔
Mobile	Planned
Write access	✔
Notifications	✔
Alerts	✔
Patient Portal	Planned

SYSTEMS IN SCOPE

ORGANISATION	TYPE	VIEW	SHARE	IT SYSTEM
The Leeds Teaching Hospital	Acute	Yes	Yes	PPM
Leeds Community Healthcare	Comm	Yes	Yes	Rio/SystmOne
Leeds City Council - Adults	LA	Yes	Yes	CIS
Leeds City Council - Child	LA	Yes	Planned	Mosaic
Leeds and York Partnership	MH	Yes	Yes	Paris
103 GP Practices	GP	Yes	Yes	SystmOne/EMIS
St. Gemma's Hospice	Hospice	Yes	Early	SystmOne
Wheatfields Hospice	Hospice	Yes	Early	SystmOne
HM Prisons Leeds	Prison	Yes	No	SystmOne
Local Care Direct	Urgent	Yes	No	SystmOne

OPEN STANDARDS

STATUS	SNOMED	Read	dm+d	HTML	ITK	HL7	HL7 FHIR
IN USE	✔	✔	✔	✔	✔	✔	✔
NOT IN USE							
PLANNED							FHIR+

HIGH LEVEL TECHNICAL ARCHITECTURE

Data Sources

- GP SystmOne/EMIS
- Community (LCH) RiO/SystmOne
- Mental Health (LYPFT) Paris
- Social Care (Adults) CIS
- Social Care (Child) Mosaic *PLANNED*
- St Gemma's Hospice SystmOne *PLANNED*
- Wheatfields Hospice SystmOne *PLANNED*

Data Integration

- MIG
- GP Connect
- Data Warehouse
- Data Warehouse
- Data Warehouse
- Acute (LTHT) PPM

LEEDS CARE RECORD PORTAL

CLINICIAN ACCESS TO PATIENT INFORMATION

Data Access

- GP
- Acute (LTHT)
- Community (LCH)
- Mental Health (LYPFT)
- Social Care (Adults)
- Social Care (Child)
- Hospices
- HM Prisons Leeds
- Local Care Direct

IMPLEMENTATION

Leeds Care Record is developed and implemented by a core team at The Leeds Teaching Hospital Trust. The agile delivery approach relies on clinical input, and has a mechanism for continuous improvement, based on feedback from staff and the public.

The solution is run, maintained and managed through a service management agreement which is outsourced to a third party service provider.
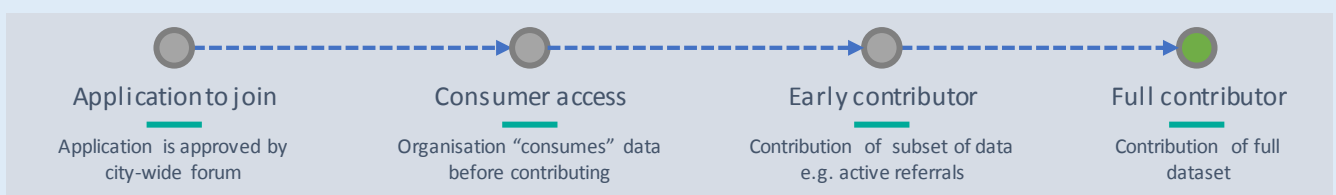

Agile Delivery Approach
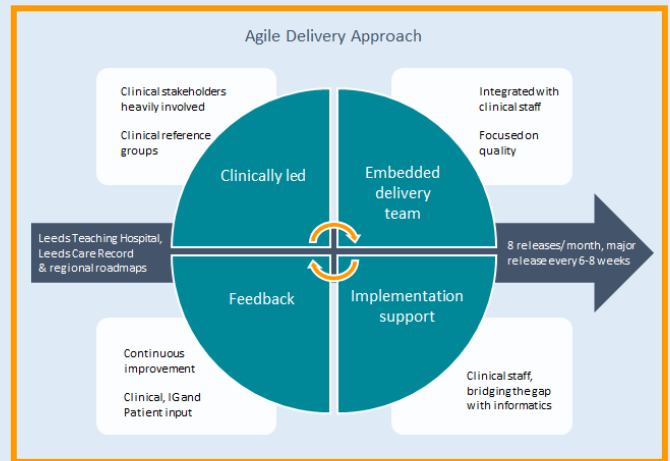
GOVERNANCE

The Leeds Care Record Project Board and the Health & Wellbeing Board are the main points of governance for the programme. The Leeds Information Governance Steering Group also provides support. The Leeds Care Record partners have developed a standard suite of information governance documentation, including a communications toolkit which provides information for organisations and the public.

An Information Sharing Agreement (ISA) was developed early and made publicly available on the Leeds Care Record website. The ISA is regularly discussed and updated.

Process for joining Leeds Care Record

Organisations wishing to join Leeds Care Record to contribute data submit an application to a city-wide forum detailing their case for membership and the dataset they would like to share. They present at a workshop attended by key clinical and operational stakeholders, leaders, and IG specialists. The organisation's membership request is debated, with a focus on benefits to care, and the details of the dataset are discussed and refined. If membership is approved, the dataset is developed. A phased process is then initiated to bring the organisation on board.

Application to join	Consumer access	Early contributor	Full contributor
Application is approved by city-wide forum	Organisation "consumes" data before contributing	Contribution of subset of data e.g. active referrals	Contribution of full dataset

Applications from organisations wishing to access Leeds Care Record in a "consumer" capacity only are referred to the Leeds Information Governance Steering Group. Recent applications from HM Prisons Leeds and Local Care Direct were approved on the basis that by having access to Leeds Care Record, these organisations could improve the direct patient care they provide.

Legitimate relationships

Access to Leeds Care Record is based on a fair processing model for direct care purposes only. Users can only access information relevant to their patient group and role. User roles are determined by a role-based access control (RBAC) framework. Users can access information in an emergency according to a strict protocol. All access is fully auditable.

Members of the public can object to their participation in Leeds Care Record by contacting the Access to Health Records team. Where possible, the team take the time to have a conversation with objectors about the purpose and value of Leeds Care Record. It has been found that this approach often clarifies misconceptions. In total only 3% of people have opted out.

BENEFITS

In 2016 the Leeds Care Record team conducted an evaluation to identify direct and indirect benefits. This helped quantify some of the benefits that had long been recognised through anecdotal evidence from clinicians and managers with access to Leeds Care Record.

The evaluation analysed detailed usage reports and web analytics, combined with local benchmarks, such as costs of phone calls. Total annual savings as a result of Leeds Care Record were estimated as **£826,750**.

This took into account the following tangible and intangible benefits:

1. Reduction in non GP users contacting practices (due to instead accessing the GP tab)
2. Reduction in contacts with acute (due to users accessing the Leeds Teaching Hospitals tab)
3. Preventing duplicate tests and inappropriate treatments
4. Getting it right first time, and thus minimising wasted resources
5. An improved patient experience which means people are more reassured and less resistant

WHAT END USERS SAY…

PRIMARY CARE

"I have found Leeds Care Record an invaluable aid to my clinical practice. It gives me a window into the hospital. I can see when my patients have appointments, which of my patients are in hospital and it allows me to view letters and results that may have not yet arrived at the practice."

Dr Adrian Rees, GP Partner, Yeadon Tarn Medical Practice

COMMUNITY & SOCIAL CARE

"Leeds Care Record gives us a holistic picture of our complex patients, enabling us to follow their journey across care settings."

Julie Summerscale, District Nurse, Yeadon

"Leeds Care Record has really sped up the assessment process of patients. The adult social care information has been a really useful improvement, it allows me to easily see who is involved in my patients' care."

**Liam Sanders, Lead Nurse, Leeds Community Healthcare**

More

"I've been using IT solutions for 20+ years and Leeds Care Record is the best solution I've ever worked with for joining up care settings."

Julie Bootle, Head of Service, Adult Social Care, Leeds City Council

KNOWLEDGE SHARING

- Being one of the more mature local shared care record areas, the Leeds Care Record team receives multiple requests for information. They are keen to share their experience with others and so have developed a process to manage these requests. They share case studies and key documents on a request basis, and attend events.

- Leeds is a member of the "Connected Health Cities" programme which aims to improve health and social care in the North of England through linking data.

SUCCESS FACTORS
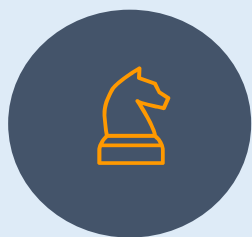
STRATEGY

CLEAR SHARED VISION

- Leeds Care Record has adopted a philosophy of one team, one system and one care record across the partnership
- In addition, the purpose of Leeds Care Record is for direct care only, something they have been clear about from the start, which has enabled the team to shape communications and governance accordingly
- This clearly defined vision has helped senior leadership across the region buy into the programme
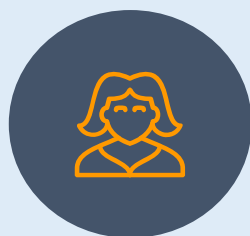
PUBLIC INVOLVEMENT

INVOLVING THE PUBLIC

- Members of the public were actively involved in the co-production and co-design of information sharing messages and materials
- Several agencies have been involved in engaging with the public and Leeds Care Record has a dedicated Patient Focus Group which comes together to consider points of interest and gauge opinion.
- Indeed the public have been involved in the Leeds Care Record initiative as a whole, for example decisions relating to what data to share and the direction of travel, such as the move to write access.

CLINICAL ENGAGEMENT

CLINICAL USE CASES

- Clinicians have been involved in the development of Leeds Care Record from the start to ensure its practical use is always at the centre.
- It was found that having a rich data source was very important to uptake and therefore the local authority was engaged from the beginning to get social care data into the record
- Partner organisations have a clinical sponsor with additional "interested people" who encourage and promote Leeds Care Record

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FUTURE AMBITIONS

As part of the future development of Leeds Care Record, there are specific plans to:

- Create Shared Care Plans to enable further care coordination
- Add an agreed set of alerts into the record
- Add legal status and other important alerts / indicators to the record e.g. power of attorney, and do not resuscitate (DNR)
- Add ambulance service datasets to the record to make it even richer
- Give access to Leeds Care Record on mobile devices
- Create condition specific summary views

LESSONS LEARNED

GUIDING PRINCIPLES

Challenge: As Leeds Care Record was one of the early local integrated care records it was passed to clinicians in the hope that it would simply add value, with a more formally identified set of benefits being understood and realised over time. For this reason its use has developed organically and as such it is used in very different ways across the health and care economy in Leeds.

Lesson Learned: The programme team is now actively developing guiding principles to help ensure that the record is used consistently where possible across the City. This work will continue to mature over time in order to ensure Leeds Care Record is used to its full potential.

TRAINING

Challenge: While training has been enthusiastically received across the City, it has proven difficult to provide face to face training to so many people. Low levels of IT literacy among some user groups have also impacted the effectiveness of a one-off training programme.

Lesson Learned: To combat this, eLearning options needed to be developed to support organisations whose employees couldn't always be available for face to face training sessions. A Leeds Care Record champion scheme to support users on a day to day basis has also been established. A combination of all these strategies has ensured that users now become active users more readily.

HOLISTIC APPROACH

Challenge: Historically organisations within Leeds made IT strategy decisions in isolation especially around commissioning new clinical systems. These decisions have had significant knock-on effects for system interoperability.

Lesson Learned: Strategic IT decisions are now being discussed at a city level. The creation of CIO and CCIO roles has helped create holistic conversations on the region-wide digital footprint and the need for interoperability and open standards principles where possible.

FURTHER INFORMATION   **INFORMATION CORRECT AS OF 27/04/2018**

CONTACT   LINKS
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LEEDS TEACHING HOSPITALS NHS TRUST   Leeds Local Digital Roadmap
julia.millman@nhs.net   National Data Guardian Review

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