SALFORD INTEGRATED RECORD
SALFORD CCG

INTRODUCTION

The Salford Integrated Record (SIR) is an IT portal designed to improve care for Salford patients and promote research which benefits the local population.

SIR is a key enabler of the Salford Together partnership's vision for integrated care. The solution currently provides hospital and mental health clinicians with a view of the GP record, and it is being expanded to encompass social care as a priority. Salford's real depth of experience lies in its use of SIR for research purposes, and it has developed communications and governance approaches which support this aim.

AT A GLANCE

SCALE L

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

MATURITY 2

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 THE SALFORD INTEGRATED RECORD IS BEING USED

Individual Patient Care	Care Planning & Coordination	Health & Care System Management	Population Health Management	Research
LIVE	IN FLIGHT	FUTURE	IN FLIGHT	LIVE

> "It was always an aspiration for the Salford Integrated Record to be a resource for research. The Salford Lung Study was the first of its kind and was made possible by access to SIR data."

TIMELINE

2008

2008
SIR first established, building on work done on diabetes care pathways

2009
Initial SIR went live using the Graphnet solution, providing a foundation for integrated care

2016
Salford Lung Study is concluded following an innovative four year drug treatment trial

Plan for 2018+
Add mental health and social care data to SIR and use predictive analytics capabilities

Approx. **900** unique users per month

Approx. **7000** patients involved in Lung Study

Approx. **275k** population

LOCAL CONTEXT

- The Salford Integrated Record grew out of work relating to diabetes care pathways and was first launched in 2008. It was intended to support individual patient care, population health management, and research .
- SIR is seen as a key enabler of two important local care delivery programmes: The Integrated Care Pioneer (Greater Manchester) and one of the Vanguard programmes for Integrated Primary and Acute Care Systems - Salford Together. Both of these exemplify the delivery of integrated care and the potential for technology to join up and enhance services.
- SIR has been developed hand in hand with the Salford Together programme, ensuring the solution's architecture, functionality, scope and implementation model supports the vision of the partnership as a whole – including the city council, commissioners, primary care, acute care providers, and mental health trusts.
- In 2008, NorthWest eHealth (NWEH) was formed between the University of Manchester, Salford Royal NHS Foundation Trust and Salford CCG to enable the use of SIR for research. It has developed a number of innovative tools and techniques to help facilitate research projects and is considered an authority on the delivery of electronic health record enabled randomised controlled trials.
- Use of SIR to support individual patient care is more limited compared to the research component, but it is currently used by hospital and mental health clinicians to gain a view of the GP record, and an expansion to social care is planned next. GPs can also access hospital data, but as its depth is currently limited, this has not been widely adopted yet.
- SIR is currently based on Graphnet's CareCentric product, which uses a SQL-server based central data store to assemble data from the connected systems.
- The overall plan is to combine the local shared care records across the wider region, resulting in an integrated record that covers Greater Manchester.

FOCUS ON: THE CLINICAL PERSPECTIVE

"A few key things spring out regarding the importance of the Salford Integrated Record in advancing the research agenda. First is the breadth and depth of the coded data that's available for the *whole* local population. Before, data was often fragmented or incomplete, so this is really powerful.

Second are some of the tools that have come about as a result of SIR, for example FARSITE which performs feasibility calculations for a proposed research study. This sort of thing could have taken months to determine previously, so it really helps remove those barriers.

Finally, it's enabling new types of research. The Salford Lung Study, for example, represented a shift away from traditional approaches. It was a large scale study using data from patients in their "normal" context, with minimal intrusion into their everyday lives. This is only made possible by interrogating electronic health records."

Dr Owain Thomas, CCIO, Salford CCG

THE SALFORD INTEGRATED RECORD SUPPORTS...

INDIVIDUAL PATIENT CARE

- SIR will ultimately enable clinicians and care givers to work more collaboratively to deliver efficient and safe care. Realising this vision in full is some way off but, in the interim, hospital and mental health clinicians are using SIR to view the GP record to aid decision making, save time and improve the patient experience by avoiding repetition.
- Priorities for extending SIR's usefulness in relation to individual patient care include enhancing the breadth and depth of the datasets available (currently the majority of the data is from GP systems), and bringing social care teams on board, both as viewers and contributors of data. Providing single sign-on access to SIR for GPs will also help embed its use in everyday practice.

POPULATION HEALTH MANAGEMENT & RESEARCH

- A number of research bodies have used anonymised data from SIR to support their studies.
- The Salford Lung Study was the first major (and high profile) project to do so. It examined the safety and effectiveness of a new drug treatment for asthma and chronic obstructive pulmonary disease (COPD), based on nearly 7,000 consenting patients. This was different to other randomised controlled trials (RCT) as it included a much broader range of patients, and provided a more realistic view of how the drug performed.

- SIR has also resulted in the development of some innovative tools. These typically fall into two categories: 1) tools which aid the research process and make research easier to conduct, and 2) tools developed out of research initiatives which support broader health objectives such as population health management. Examples include:

FARSITE (NorthWest eHealth)

A profiling tool for identifying and contacting patients suitable for research studies, while still preserving their confidentiality. It provides an initial view of the feasibility of a research project. More

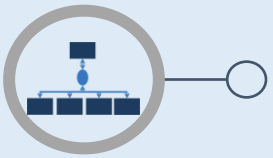
SMASH Dashboard (University of Manchester)

A web application that shows pharmacists and GPs lists of patients that are potentially at risk from the medications they are prescribed. More

PINGR (University of Manchester)

Computer software for GP practices that analyses patient data to suggest what steps could be taken to improve their care. More

TECHNICAL SOLUTION



CENTRAL-REPOSITORY ARCHITECTURE

- Salford Integrated Record uses Graphnet's CareCentric solution, which extracts and integrates data from the underlying clinical systems.
- This provides a centralised summary view of the patient's information, accessible by health care professionals either through a portal or by clicking through from their own system.
- Data is extracted from GP systems every 24 hours.

SOLUTION FEATURES

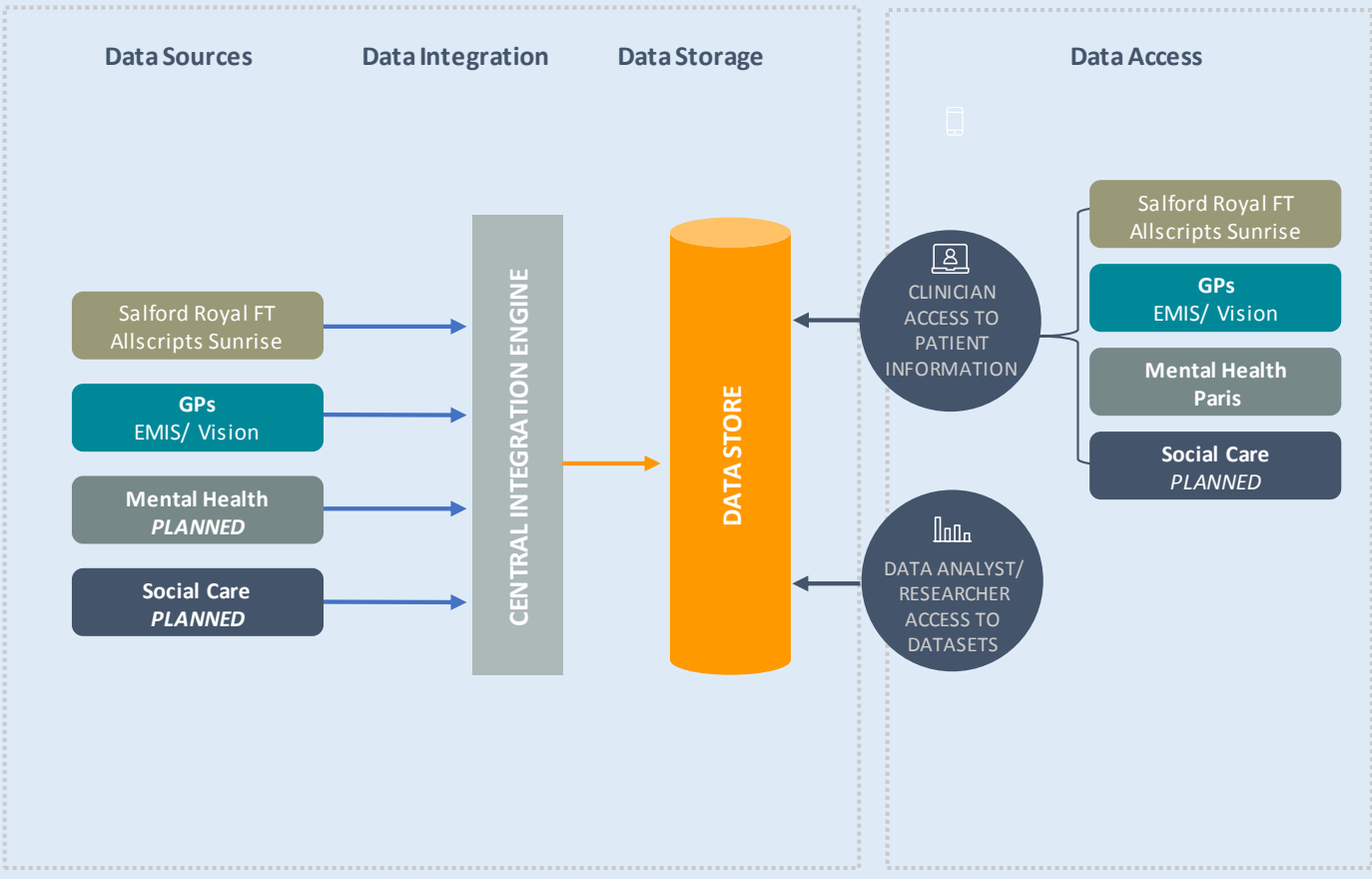
FEATURE	IN USE
Coded data	✔
Free text data	⊘
Bi-directional	⊘
Real time	⊘
Role-based access	✔
Clinical Portal	✔
Analytics	✔
Write access	⊘
Notifications	⊘
Alerts	⊘
Patient Portal	⊘

KEY SYSTEMS IN SCOPE

SITE	TYPE	VIEW	SHARE	IT SYSTEM
Salford Royal Foundation Trust	Acute	Yes	Yes	Allscripts Sunrise
Greater Manchester Mental Health Trust	MH	Yes	Planned	Paris
16 x GPs (EMIS)	Primary	Yes	Yes	EMIS
29 x GPs (Vision)	Primary	Yes	Yes	Vision
Salford City Council	LA	Planned	Planned	CareFirst

OPEN STANDARDS

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



GOVERNANCE

The Salford Integrated Record Board provides governance to the programme. The Chair and Clinical Lead is a GP. Also represented are the Deputy CCIO, other GPs, secondary care doctors, the LMC, information governance and technology. This gives assurance that the programme is clinically focused and is stewarded correctly – particularly from the point of view of using data for research. Clinical engagement at a senior level is high, perhaps due in part to the research element of the programme, which makes it easy to demonstrate the value of shared data to clinicians.

Applications for access to SIR data go through a rigorous process. Proposals must not only meet IG and clinical criteria but must also demonstrate that they will benefit the local population.

> **We receive a number of requests for access to data to support research and we scrutinise each case individually.**

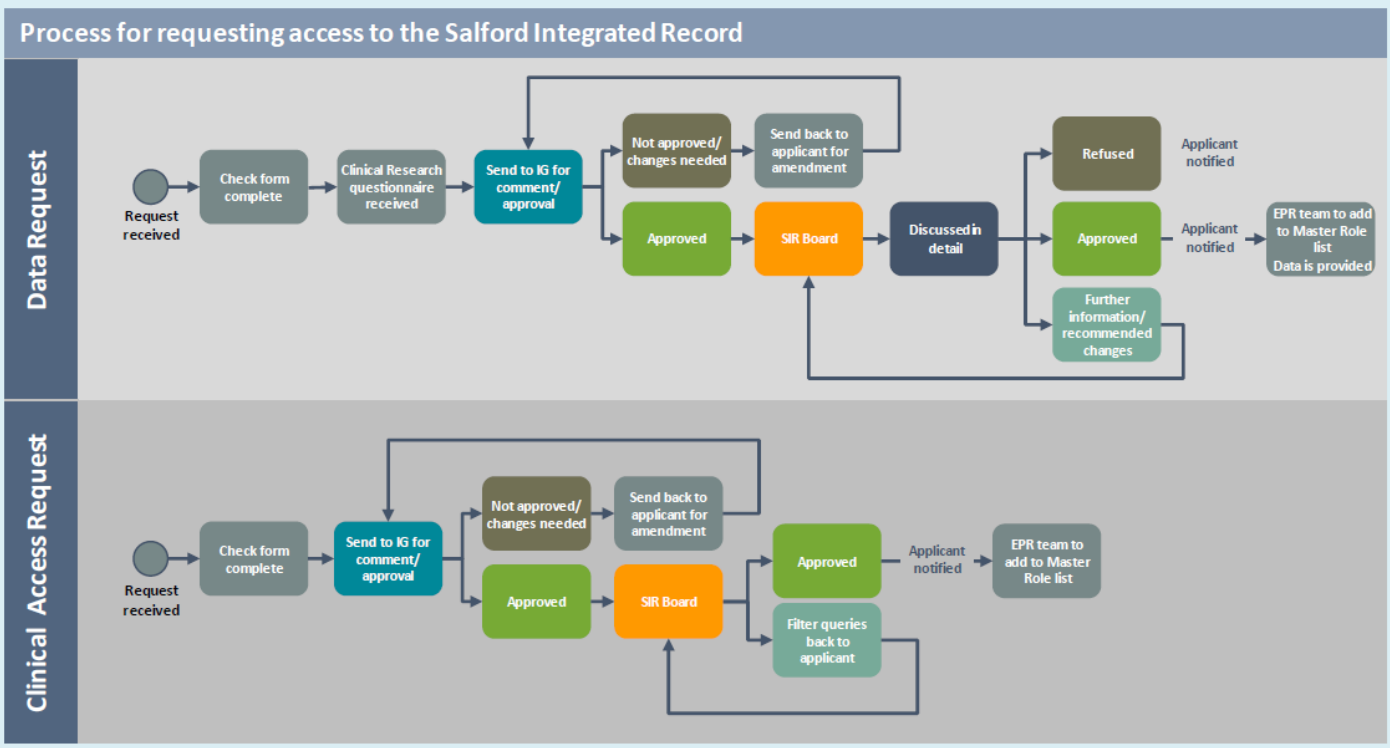
Consent model

All patients were notified when SIR was set up and offered the opportunity to opt out. The intention to use anonymised data for research purposes was clearly stated. Salford has a 1.5% opt out rate which is low in comparison to other areas.

The model is currently such that patients wishing to opt out of their data being used for research are also opted out of information sharing for direct care, and vice versa. Patients who in the past opted out of information sharing initiatives such as Summary Care Record are also automatically opted out of research. The consent model as a whole is being refined to provide more flexible options for patients. The SIR Board is also considering the implications of GDPR.

Scope of data

When SIR was first introduced in 2009, over 1000 potentially sensitive diagnoses were excluded from the record. In 2015, the SIR Board took the decision to reduce the number to less than 100, based on a standard list of sensitive codes developed by Graphnet. This demonstrates how attitudes to the subject have changed over time as people's understanding has evolved.



COMMUNICATION

Patient engagement

The Salford Integrated Record team have engaged with patients in multiple ways to ensure they understand how their data is being used. When the project was set up initially there was a widescale communications campaign, sending leaflets to all households. In addition, GPs have had a policy whereby SIR is explained when new patients register at their surgery. Other methods have also been used to capture a wide audience and increase general awareness, for example the Practice Manager Forum, newsletters, videos, and neighbourhood boards.

Explanation is often not enough, however, and Salford Together consulted the public about shared records through its Big Health and Care Conversation. This Salford-wide consultation included a question about patients' willingness to have a shared record. 90% of the nearly 1600 people who answered the question said they would be happy to share information if it helped with health and social care provision.

Messaging to patients about the difference between identifiable data used for direct care and anonymised data used for research has always been clear. The SIR team is now looking to enhance the messaging relating to how SIR is used locally compared with national information sharing initiatives. It feels that this is often where the confusion lies and is keen to provide clarification.

AN INSIGHT INTO RESEARCH APPLICATIONS IN 2016

In 2016, 21 applications for access to SIR data were processed. Of those, 14 were successfully approved.

Seven extracts were being made on a regular basis to support previously approved projects.

2016 Applications

STATUS	NUMBER
Research approved with changes/ caveats	8
Research approved	6
Ongoing	2
Staff member access request	1
Application withdrawn	1
Research (requested follow up none received)	1
Research (no outcome recorded)	1
Research not approved	1
Total	**21**

2016 Regular Extracts

NAME
Salford Lung Study SIR Feed
FARSITE
End Of Life -Carefirst Extract
Risk Stratification
SMASH Dashboard
Diabetes Patient View
Salford Royal End Of Life Care

SUCCESS FACTORS

EFFICIENCY

PROCESS

- The process for granting access to data has become slicker over time as better ways of doing things have emerged.
- Through regular iterations, the governance model has become more efficient and robust.
- Involving the right stakeholders has also been key. Processes need to be clinically focused but they also need the perspective of non-clinicians who are specialists in their field, for example IG, Research & Development or technology.

VISION

CLEAR OBJECTIVES

- When SIR was first established, its potential for research was understood, and measures were built into the programme early to allow it to be used for this purpose.
- This clear objective meant communications could be open about the use of data from the start, which has fostered public support.
- The criteria that research projects must fulfil have also been well defined. Projects using SIR data must some local benefit. This stipulation is rigorously adhered to, as evidenced by the fact that applications have been refused if they cannot demonstrate this.

COLLABORATION

ESTABLISHMENT OF NORTHWEST eHEALTH

- The creation of NorthWest eHealth as a partnership between the University of Manchester, Salford Royal and Salford CCG, to manage engagement with research organisations and lead the way in developing new research approaches has been highly successful.
- NorthWest eHealth acts as a useful bridge for academic researchers, helping them find their way and ask the right questions to ensure a quality outcome.

FUTURE AMBITIONS

The next phase of the Salford Integrated Record programme will focus on:

- Using SIR for planning purposes at CCG level.
- Promoting the record for direct care, which in turn will see its usefulness for research purposes increase.
- Making the record more useful to GPs for direct care, so that they can become consumers of the data rather than simply contributors.
- Expanding the scope of the record by adding mental health and social care.
- Potentially combining the Salford record with neighbouring Manchester, Stockport, Bolton and HMRs CCGs to give a better service to the Greater Manchester public.
- Developing further population health management initiatives.

LESSONS LEARNED

RESEARCH SCOPE

Challenge: Careful consideration needs to be given to the scope and set up of research projects because of the IG implications. Research questions need to be clear, otherwise the IG impact cannot be properly assessed. The SIR team have had instances of projects wishing to change scope but this has not been possible – even if the scope change would have led to a more beneficial piece of research – because the original consent obtained did not cover it.

Lesson Learned: It is not possible to go back and change the scope of a project once it has been agreed and consent has been sought. Projects need to be clear about what the data will be used for (both initially and potentially in the future) from the outset.

CLOSING THE LOOP

Challenge: While the SIR team have developed a robust process for vetting proposals for access to SIR data, they have placed less focus on following up the research projects that were approved to find out how they have progressed.

Lesson Learned: Ensure processes include steps to "close the loop" as a matter of course.

DATA QUALITY

Challenge: The data available is not always suitable for research. What (and how) clinicians record data in a patient's record for the purpose of direct care often differs from the data that is needed to carry out meaningful research. For example, the number of encounters a patient has had with their GP is not always easy to determine because of the way GP records are structured. There can also be inconsistency in the clinical codes used (they have found this with Read codes), and general data quality and completeness can vary between organisations.

Lesson Learned: The team has found that improving data quality is about changing behaviours. Implementation of the Salford Standard has helped. This is a set KPIs, with associated financial incentives, for General Practice. The Standard articulates the level of care that all Salford patients should expect. It reduces variation in the care itself and how care is recorded.

There a ways of "reading" the data to make it meaningful. The SIR team is working with NorthWest eHealth to come up with solutions. For example, they have developed a tool to infer how many times a patient has visited their GP when this is not clear from the data.

FURTHER INFORMATION

INFORMATION CORRECT AS OF 27/04/2018

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LINKS

Salford Integrated Record
Salford Together
New Care Models
Salford Lung Study
NorthWest eHealth

Produced in collaboration with NECS and Accenture