

Report of: The Information Management & Technology Service

Report to: The Director of Children's Services

Date: August 2015

Subject: The Leeds Care Record



Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Are there implications for equality and diversity and cohesion and integration?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Is the decision eligible for Call-In?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

Summary of main issues

The Leeds health and social care revenue spend for 2013/14 was approximately £1.83bn (excluding third sector). There are increasing calls to better integrate care across the sector and drive out improvements and efficiencies.

The Leeds Care Record ("the LCR") is a key strategic project for the city of Leeds. It involves systems and essential information being integrated to create a real-time citizen centred view from across Health and Social Care organisations which will help to reduce the silo way of working.

In order to access the LCR, Children's Services needs to sign an Information Sharing Agreement. The Leeds Teaching Hospital NHS Trust (LTHT) hosts the system and therefore acts as a Data Processor to process personal data and sensitive personal data on behalf of the Leeds Health and Social Care Provider Data Controllers.

Children's Services will be piloting the Leeds Care Record in three areas: the residential disability settings; Rainbow House and Acorn Lodge; and with the Care Leavers service. The sharing of information on the LCR for care professionals within Children's Services is supported by our statutory duties around the provision of care and supporting the welfare of children and, as such, consent from those accessing our services to share information will not be sought. However, information will be provided about the LCR and the option to opt out.

Recommendations

The Director of Children's Service's is asked to approve signing the Information Sharing Agreement for the LCR which supports the delivery of integrated care by providing health and

social care professionals with a single point of access to information about a service user, collected from their separate medical and care records.

1 Purpose of this report

1.1 The purpose of this report is to inform the Director of Children's Services of the information governance issues in relation to the Children's Services pilot of the LCR.

2 Background information

2.1 The LCR system is being developed with the intent of enabling organisations providing Health and Social Care Support in Leeds to share relevant information about the people they are working with in order to support the delivery of integrated care.

2.2 The purpose of the LCR is to:

- Improve outcomes and the service provided to the citizens of Leeds
- Provide a core single care view of the citizens of Leeds
- Provide core commonly needed information for care professionals at the point of care to support the need to provide more community based care
- Reduce the need to ask the citizen multiple times for the same information
- Support Integrated Health and Social Care teams and foster an environment of integration and collaboration
- Build on Open Standards and use Open Source technology where possible to standardise the information and share learning with other health and social care organisations

2.3 The LCR is different from the national care record in that it can be adapted and changed locally to meet the requirements of our information systems and the specific needs of our population. 105 out of 107 GP practices in Leeds have already signed up as have the Leeds Teaching Hospital Trust and Leeds Mental Health Trust. Adult Social Care ("ASC") are currently piloting access to the LCR in their Integrated (Health and Social Care) Neighbourhood Teams. At present ASC has read only access to the data and a tab on the LCR for other professionals involved in the care of an individual which contains information on who to contact if they would like to further discuss that service user. ASC are looking to contribute data to the LCR after consultation with those accessing their services about the information they would be comfortable sharing with other professionals involved in their care. It is expected they will be at the stage of contributing data in early 2016.

2.4 The LCR forms part of the Health and Wellbeing Board's 'Leeds Vision' and is commissioned by the Clinical Commissioning Groups in Leeds. It is a web-based portal solution developed by Leeds Teaching Hospitals Trust and Ocean Informatics UK. Ocean Informatics UK Limited are 3rd party processors providing development resources to support the construction of the system. Tactix4 Limited are a sub-contractor of Ocean Informatics UK, and the data will be stored a Tactix4 server used for the development of the Leeds Care Record. The data will be stored securely on the N3 network and will not be transferred outside of the European Economic Area.

3 Main issues

- 3.1 Three areas of Children's Services are in scope to pilot the Leeds Care Record: the Children's disability residential settings, Acorn Lodge and Rainbow House; and the Care Leavers service. These Children's Services settings will have consume (read only) access to the LCR. It is likely that Children's Services will utilize the access profile set up for the ASC pilot users, LCC - Direct Care Professional, which was established in consultation between the Information Governance team and the services in scope to determine what information they would need to consume. Care professionals in the pilot areas will only be able to view information that is necessary and relevant to be able to fulfil their role. Going forward it is likely Children's Services will also contribute proportionate information to the LCR to be used for direct care purposes. At this point further consultation will take place with services and service users.
- 3.2 All organisations accessing the LCR are required to sign up to an Information Sharing Agreement, please see background document 7.1. It is designed to support the development of the LCR to enable lawful sharing of care data between the listed partner organisations to support integrated care where it is necessary for the safe, effective care of the individual service user.
- 3.3 The sharing of information on the LCR for care professionals within Children's Services is supported by our statutory duties around the provision of care and supporting the welfare of children. Although consent to share information will not be sought from those accessing our services, Children's Services and its health partners will – as far as is practically possible – communicate to those accessing our services that sensitive personal data will be shared for the purposes of the LCR. Within residential settings information will be provided about the LCR at the point of the young person's arrival. This will ensure that service users and their guardians understand that information will be shared only for direct care purposes and if they wish to opt out of this they are able to do so.
- 3.4 Children's Services do not use the NHS number as a common unique identifier and the NHS number is required to participate in the LCR. Therefore, for the purposes of the pilot a tactical solution will be used to set up a view on the LCR of the Children and Young People who access the services at Rainbow House and Acorn Lodge, as well as the Care Leavers cohort. This will be achieved by Children's Services sending a spreadsheet which details the names, dates of birth, and addresses of our pilot cohort to NHS colleagues in the LCR project team via GCSx (secure) email for them to match individuals to NHS numbers in order to set up the legitimate relationship between NHS systems and the LCR. If the LCR pilot is a success and the system rolled out wider than the pilot services, an automatic process will need to be developed to manage staff access. A second phase of the rollout of the LCR would also investigate the viability of creating an automated process to keep up to date the cohort of Children and Young people whose records care professionals working with them will need access to. It is thought this solution may be a report that is run in Frameworki.

4 Corporate Considerations

4.5 Consultation and Engagement

- 4.5.1 As a city-wide initiative, there has been a range of activities undertaken to raise awareness of the LCR. These have included media coverage in both the Evening Post

and on Look North. Information materials such as posters and leaflets have been produced and are available in venues such as GP surgeries in the city.

- 4.5.2 Consultations for the LCR have previously taken place with Mental Health service users through Leeds Involving People (LIP) who were instructed to ask views of service users around what information they would be comfortable with sharing on the LCR. This consultation formed the basis of what mental health information would be visible on the LCR to other care professionals who are also directly involved in the service users care.
- 4.5.3 Consultation has been undertaken with the services that the LCR will be piloted in initially; Acorn Lodge, Rainbow House, and the Care Leavers service. The feedback from engagement with the services was very positive with both residential settings expressing that access to the LCR would directly improve the outcomes for Children and Young people. In these settings the LCR would mean care professionals would have immediate access to health information which would give additional assurance to their existing process as well as reducing the amount of time spent confirming the information they have been provided is accurate, thus increasing the amount of time they are able to spend with the Children and Young People.

4.6 Equality and Diversity / Cohesion and Integration

- 4.6.1 Equality and Diversity issues have been considered and an Equality Impact Assessment screening form has been completed and is attached.

4.7 Council policies and Best Council Plan

- 4.7.1 The LCR will provide Children's Services in Leeds City Council with accurate and timely information about the Children and Young People in our care by taking a joined up approach with other health and social care providers across Leeds. This is crucial to ensuring as a city we deliver the best possible services to improve outcomes. This is compliant with our ambition to work as a team for Leeds and also to be child friendly city.

4.8 Resources and value for money

- 4.8.1 At present there are no financial implications for the LCR as there are no charges for using the service. However, in the future, likely late 2016, a financial contribution will be required to access the LCR. For this reason we will be conducting a pilot of using the system in order to determine its effectiveness and whether any future cost will constitute spending money wisely.

4.9 Legal Implications, Access to Information and Call In

- 4.9.1 Under the 1st data protection principle, personal data must be processed fairly and lawfully and in particular must not be processed unless at least one Schedule 2 condition is met, and in the case of sensitive personal data unless at least one Schedule 3 condition is also met. In this particular case, it is considered that condition 5(b) of Schedule 2, and condition 7(1)(b) applies in that this processing is necessary for the exercise of certain statutory functions conferred on the Council. The particular statutory functions are the general power of competence under section 1 of the Localism Act 2011 and powers under section 111 of the Local Government Act 1972. These functions are respectively, the power to do anything individuals generally may do (subject to the limitations set out in the Localism Act 2011), and the power to do anything which is calculated to facilitate, or is conducive or incidental to, the discharge of any of the functions of the Council. In addition the Council will share data in order to comply with

the requirements of the Children Act 2004, in particular section 10, duty to co-operate. This places a duty on the Council to make arrangements to promote co-operation with “relevant partners”, including the NHS and local CCG’s, and such other persons or bodies as the Council considers appropriate, being persons or bodies who exercise functions or are engaged in activities in relation to children in the Council’s area, to improve the well-being of children in the Council’s area including by sharing information appropriately.

- 4.9.2 There is no definition of “fairness” in the 1998 Act, however the Courts have decided that assessing fairness involves a balancing of the interests of the data subject in non-disclosure against the public interest in disclosure. In a similar way, the Courts have said that the word “necessary” as used in the Schedules to the 1998 Act carries with it the connotations of the European Convention on Human Rights, and that those include the proposition that a pressing social need is involved, and that the measure employed is proportionate to the legitimate aim being pursued. Therefore, in order to assess whether processing the data in this way will meet the overall requirement of “fairness”, and whether this processing is “necessary” for the purposes of the Schedule 2 and 3 conditions mentioned above, the interests of the data subjects concerned need to be balanced against the public interest reasons for disclosing this data. In this respect the overriding aim is to be able to support improved outcomes for Children and Young People: by providing a more integrated service; reducing the need for an individual to re-tell their story over and over again; ensuring practitioners know who is working with the individual; have relevant factual information available e.g. appointments and medication. The access to records is based on a practitioner having a legitimate relationship with child or young person and practitioners will only have access to the information necessary to fulfil their role e.g. a Social Worker having access to Care Leaver information but not information about children residing at Acorn Lodge.
- 4.9.3 On balance therefore, and given that the Information Sharing Agreement seeks to minimise the level of intrusion to the data subjects concerned, it is considered there is a pressing social interest in accessing this data for these purposes, and that the proposed access is necessary and proportionate. In addition, for the purposes of the privacy rights recognised in Article 8 of the European Convention on Human Rights, it is considered that the countervailing public interests in Article 8.2, in particular the protection of the rights and freedoms of others, outweigh the rights of the individuals concerned, in these particular circumstances.
- 4.9.4 The legal implications described above sufficiently address the information that would have been contained in a Privacy Impact Assessment (PIA).

4.10 Risk Management

- 4.10.1 Risks associated with the LCR development are being addressed through careful project management.
- 4.10.2 The key risk is around the sharing of personal sensitive information and this is being addressed through careful consideration of the issues from a legal perspective i.e. the legal advice contained in section 4.9 above.

5 Conclusions

- 5.1 The LCR is a key strategic project for the city of Leeds and is a development which is ahead of most other city/ area health and social care economies. It provides significant opportunities to improve outcomes for Children and Young

People through having access to integrated health and social care information as well as delivering efficiencies in the way we work.

6 Recommendations

- 6.1 The Director of Children's Service's is asked to approve signing the Information Sharing Agreement for the LCR which supports the delivery of integrated care by providing health and social care professionals with a single point of access to information about a service user, collected from their separate medical and care records.

7 Background documents¹

- 7.1 Leeds Care Record Information Sharing Agreement.

¹ The background documents listed in this section are available to download from the Council's website, unless they contain confidential or exempt information. The list of background documents does not include published works.