

DATA SHARING

To: **Health and Wellbeing Board**

Meeting Date: **21 September 2017**

From: **Charlotte Black, Director of Adult Social Care,
Cambridgeshire County Council**

Recommendations: **The Board is asked to:**

- Note the report and comment on future approaches to Data Sharing.

<i>Officer contact:</i>	<i>Member contact:</i>
Name: Geoff Hinkins Post: Transformation Manager Email: Geoff.Hinkins@cambridgeshire.gov.uk Tel: 01223 699679	Names: Councillor Peter Topping Post: Chairman Email: Peter.Topping@cambridgeshire.gov.uk Tel: 01223 706398

1.0 BACKGROUND

1.1 At its meeting in March 2017, the Health and Wellbeing Board considered a paper on Dual Diagnosis of Substance Issues and Mental Health conditions. Highlighted in the report was the fact that difficulties in accessing data held in different services had made the work more complicated. Following discussion at the meeting, the Health and Wellbeing Board requested that an overview of data sharing issues be brought to a future meeting.

1.2 Effective data sharing between services is essential for delivering seamless services that consider how to meet people's needs effectively. Issues surrounding the sharing of people's personal information and data are becoming more complicated as services become more complex. The interconnected nature of health and care services means that people's information is held by a range of different organisations. This has increased significantly in recent years, particularly for three reasons:

- Greater use of digital technology means that more information is being stored in a format that is easily shared;
- More effort is being made to integrate services for people who access services from across health, social care, and the rest of the public sector – and this requires sharing information; and
- Due to some high profile incidents of data loss or inappropriate sharing of information, people want to influence how their data is used by public services and want to know more about their rights.

1.3 Information sharing is a commonly cited barrier in providing more integrated care for people across local organisations; and has been identified as a key challenge across planning of services in Neighbourhood Teams; in making referrals between organisations; and in sharing information about who is known to different services. Professionals are often unsure what information they can and cannot share; and significant changes to legislation will be brought in from May 2018 when a new 'General Data Protection Regulation' comes into force.

2.0 BENEFITS OF INFORMATION SHARING

2.1 Carried out responsibly and with appropriate safeguards in place, information sharing can have significant benefits for patients and citizens. These include:

- Ensuring that the right people are offering the right help to the right people.
- With an emphasis on prevention and well-being paramount in the Care Act (2014), it is vital that services come together to share information in the correct manner, spotting where people can be supported at a 'low level' by a wide range of services before needs escalate.
- Integrated care is seen as increasingly important and this cannot be delivered without effective information sharing.

- Professionals can work together more efficiently
- Giving information only once and sharing appropriately can lead to more efficient use of resources.
- To ensure proper safeguarding.
- Sometimes, failing to share information can have devastating impacts. Concerns about the safety or wellbeing of an individual not shared with others or collectively considered with others who have contact with them has led to several high profile enquiries into deaths through neglect or abuse.
- Time and time again, people who use services talk of having to 'tell their story' multiple times to many different agencies. Often the assumption from the individual is that agencies will 'talk to one another' and share data, when in fact they do not. Information sharing is key to delivering better, more efficient services that can be coordinated around individual needs¹.

3.0 LOCAL AMBITIONS AND PROGRESS

3.1 In 2015, a Cambridgeshire and Peterborough Data Sharing project was established via the Better Care Fund to promote better sharing of information across the health and care system. The project identified a number of common scenarios where effective information sharing could offer patient or strategic benefits that have progressed to various different extents:

3.2 Early help referrals for people who are beginning to become more vulnerable

We want staff across the system to be able to act as 'eyes and ears' – trained to spot indications that someone is becoming more vulnerable, and to refer them to appropriate support. This includes not just clinical or social care staff, but any public or voluntary sector worker who comes into contact with the public. This might include support for staff to enable them to go beyond their core role to provide some low level interventions, where appropriate. Indicators would lead to a planned response to offer support, advice and information. Data to be shared may include the contact information necessary to allow a referral, and a brief description of the nature of the concern identified.

Current status: Some information sharing is in place between individual services – notable examples include the County Council's Adult Early Help service sharing information with voluntary sector organisations where appropriate; and a partnership arrangement between the Cambridgeshire Fire and Rescue Service and local authorities to share information about households that have vulnerable residents. However each instance requires the creation of individual data sharing agreements between organisations, which has limited the speed of development.

¹ <http://www.skillsforcare.org.uk/Documents/Topics/Digital-working/Information-sharing-for-social-care-employers.pdf>

3.3 Case finding to identify people that are receiving services from a number of organisations and may benefit from a more co-ordinated approach;

We want to use data from across organisations to identify patients who may benefit from the multi-disciplinary team (MDT) case management process. This data might include medical triggers such as low mood/depression, continence/ frequent Urinary Tract Infections (UTIs), injuries caused by falls, or frequent missed medical appointments. This data will highlight people whose needs are changing over time, to indicate that they might benefit from further support in order to remain independent; and could include identification of patients by care professionals based on their contact with the patient, with a referral into the case finding process. This could be achieved, either through sharing of data from a range of organisations which is then analysed by a single system, in which case data shared would include individual details such as medical conditions and history; or by each organisation analysing their own data and only sharing information on the individuals identified as most at risk. In this case, sharing could potentially be achieved using only a personal identifier (such as an NHS number) and a proxy risk 'score' generated based on an agreed weighted algorithm.

Current status: A 'proof of concept' was developed in 2016 which enabled sharing of data between community health; GP surgeries; acute providers; and local authority social care. This showed that people's identity could be encrypted or 'pseudonymised' and compared across different database to identify individuals at risk. This was followed by a lengthy process of developing information sharing agreements between Cambridgeshire and Peterborough Foundation Trust (CPFT) and all 106 GP practices in Cambridgeshire to allow this work to become mainstream. This was completed in early 2017. However, difficulty in finding capacity has meant that lists of 'at risk' patients are not yet routinely provided to Neighbourhood Teams to inform prioritisation of cases. This process is currently carried out manually, but work is ongoing on a technical solution that would automate the process and make more routine sharing possible.

3.4 Case management, with a lead professional identified for each person and an agreed plan spanning all the services that they receive;

MDT (multi-disciplinary team) proactive case management describes an agreed approach to case management, with a lead professional identified for each person and an agreed plan spanning a range of services in health, social care and wider statutory and voluntary sector organisations. Plans will be personalised and based on the person's needs and choices. Teams will include social care staff who will be aligned to, or 'vertically integrated' with Neighbourhood Teams to ensure the appropriate person is identified as the

lead professional. The benefits of MDT working will be built upon with an assumption that this is a way of working that won't always rely on a set meeting; more a team around the person mode where the relevant professionals come together. To work effectively, professionals across the MDT will need to work in an integrated way, and are likely to therefore have access to a wide range of medical and care information about individuals identified for case management.

Current status: Case management is now well embedded in Neighbourhood Teams. Information is shared between professionals following a request for, and agreement to, consent from each individual patient.

3.5 Secondary use of data to support service planning, research and strategy

Any use of health and care data other than directly providing care to an individual is classed as 'secondary use'. This includes (but is not limited to) healthcare planning, commissioning, public health, clinical audit and governance, benchmarking, performance improvement, medical research and national policy development. Use of data in this way is essential in planning and developing services and improving care for the population. However, precautions need to be taken to ensure that data is used appropriately.

Current status: This is agreed between organisations on a case by case basis. Often this can be done based on data that removes any personal information; where personally identifiable information is required the creation of data sharing agreements is a considerable part of the process.

3.6 Shared care records that bring together information held about individuals into a single system

A stated aim of the Data Sharing Project is for practitioners and professionals to have appropriate access to all relevant data held about a person when making decisions about their care needs.

Currently, data are recorded in a variety of different electronic systems within and across services in health, social care and other organisations. Typically it is not possible for a professional in one part of the system to see information that is held in another - so the GP might not know what the mental health team has written about a patient and vice versa; and hospital staff cannot easily view information held by social care that might be pertinent to the patient's care. Where professionals have permission to view more than one record, this generally requires them to log into more than one system – and this often results in that access being underused.

Current status: As an interim solution, in some areas, selected staff are being offered access to multiple organisations' systems in order to see

information held across organisation boundaries; but it is noted that this approach is sub-optimal and introduces additional risks. A key priority for the future will be to establish a shared record, or single view, so that professionals can access data in other systems in order to make the best possible decisions and recommendations about people's health and care services. This system would require a mechanism that would either:

- Access other systems and pull data across for individual patients at the point of access;
- Pull all data held in various systems into a central system that would offer a single view of the patient's record; or
- Offer a single shared record separate from each organisation's core system that would allow information to be inputted by all services.

3.7 The concept of a 'patient held' record system is being actively explored across the local health and care system. This would allow patients' records from different sources to be stored online with each patient controlling which organisations and professionals they would wish to access their data, granting or withdrawing their consent at any time. This addresses concerns over ensuring consent has been given, enabling greater sharing of information between services. Such systems also offer patients the opportunity to add their own information between appointments with professionals; this could be particularly valuable for managing long term conditions.

4.0 A COMMON APPROACH TO INFORMATION GOVERNANCE

4.1 Despite significant progress highlighted in many areas of ambition for data sharing in Cambridgeshire, embedding data sharing across the health and care system remains challenging. One of the key reasons for this is the perceived complexity of regulations surrounding information governance. What is permissible is influenced by different legislation, including the Data Protection Act 1998, the Health and Social Care Act 2010, and the Care Act 2014, as well as a common law duty to protect confidentiality. A 'General Data Protection Regulation' (GDPR) will come into force from May 2018, and will provide a single framework for information governance. This may ultimately make information sharing easier, but in the short term is likely to lead to further confusion.

4.2 There is a certain degree of subjectivity in how this legislation is interpreted, meaning that different organisations often approach information sharing in different ways. With fifteen organisations currently represented on the Health and Wellbeing Board and a further 106 GP practices, each with different appetites for risk, agreeing a common approach to information sharing is a significant task.

4.3 Recognising the difficulties, the Better Care Fund (BCF) Data Sharing Project brought together information governance professionals to try and agree common approaches to information sharing across the county. The report from that work is attached as Appendix 1 to this report.

- 4.4 The work demonstrated that across local organisations there was a **broad consensus on lawfulness and willingness to share with care providers and other public services**. Our organisations recognise the benefits of sharing information; and agree that with reasonable policies in place and adequate communication, the sharing that we want to carry out is legal. Organisations were committed to working together to ensure that appropriate sharing can take place.
- 4.5 Secondly, the group recognised that there is **no one size fits all approach to sharing data**. The precautions that need to be put in place will vary depending on what is being shared; who is involved; and how much data is being shared. Our approach needs to be proportionate – and importantly we should restrict what we share, **only sharing personal confidential data if it is necessary**.
- 4.6 The group suggested three specific recommendations for data sharing across Cambridgeshire and Peterborough. Collectively our organisations should:
1. Ensure that all organisations are signed up to the Cambridgeshire Information Sharing Framework – and have agreed a common set of clear, transparent principles on consent, information governance and the use of personal information – a common ‘data processing notice’
 2. These principles then need to be widely communicated to staff through ongoing training and awareness raising, and included in inductions for all staff who might have access to patient and service user data. They should be made widely available – displayed prominently on each organisation’s website; displayed in offices, surgeries and care locations; and shared with new patients and service users.
 3. These principles need to form the basis of a marketing campaign, making clear to patients and service users:
 - a. The benefits of information sharing;
 - b. How we will work together to share people’s information; and
 - c. How we will work together to keep people’s information safe.
- 4.7 Whilst there is a willingness amongst partners to resolve these issues and share information, the time needed to address issues of information governance should not be under-estimated. Existing Information Governance professionals in separate organisations have been unable to commit to moving this work forward; the BCF project highlighted the fact that there is insufficient capacity in the system for developmental Information Governance work. This is likely to become a more significant issue as organisations adapt to meet the requirements of the new GDPR.

4.8 It is anticipated that to address this, a strong commitment from leaders in the health and care system to promoting and improving data sharing is required; and that specific Information Governance capacity is needed to work across the system, promoting better sharing and a common understanding of the issues. Partners continue to make the case for this through the Better Care Fund and Sustainability and Transformation Plan (STP) Digital Delivery Group.

5.0 ALIGNMENT WITH THE CAMBRIDGESHIRE HEALTH AND WELLBEING STRATEGY

5.1 This work is relevant to priority 6 of the Health and Wellbeing Strategy: Work together effectively.

6.0 SOURCES

Source Documents	Location
Information Sharing for Social Care Employers	http://www.skillsforcare.org.uk/Documents/Topics/Digital-working/Information-sharing-for-social-care-employers.pdf