

Health & Wellbeing Board Notes 17th April 2018

Data and Information Sharing

Presentations from:

Mike Turner – Northern Care Alliance - The Salford ICO journey and lessons learnt from data sharing

slides to be included when received

Jym Bates – Northern Care Alliance - Understanding the GDPR regulations and what this will enable

Gerard Gudgion – Early Help Operational Manager - Sharing health data to improve outcomes for families and children.

Key discussion notes

- Data and information sharing should be an enabler to delivering quality and appropriate care and a better system response to an individual's circumstances
- **It should not be the ultimate end goal**
- Early Help / Fitton Hill example from 2014
 - Both sides identified their markers for identifying those in, or close to crises
 - Shared the qualifying individuals with each other for cross referencing
 - Easy to identify who had been in contact with both services, but the services were not always aware that the other had had contact with the individual
 - If had known, could have developed a very different solution
 - Small data points may seem insignificant but when pieced together across the health / care and wellbeing system then they can paint a very clear picture of a individuals circumstances and how best to approach
 - Consent gained through opt-out process via individualised letters
 - Consent, whilst does enable data sharing, is a very weak footing upon which to build data and information sharing upon as it can be removed at any time by the individual. **The individual also has the “Right to be forgotten”**
 - Exercise, whilst extremely informative, was a highly labour intensive process.
- Risk stratification
 - General consensus that the ability to identify those that are orange (i.e. medium-risk) before they move to red (high-risk) would improve outcomes across the system
 - Capacity – what is the ability and commitment of the system to respond to what the data tells us once we have risk stratified i.e. do we have sufficient early intervention/key worker/MDT/ place based teams type capacity to work with those identified at risk.
 - Not only need data crunchers but we also need the people who can turn the data into intelligence and increase the data's effectiveness

- The more data points and agencies involved, the higher quality and detailed the picture of the individual becomes, but also more difficult it is to categorise
 - How would a stratification matrix to support and deliver this?
- Concerns were raised around how much is “too much data” and could we be at risk at profiling individuals rather than dealing with them as humans, given that health and care is a process of human interaction
 - Data sharing and profiling should only be used as a way of prioritising resource and service interventions to achieve the best outcomes for the individual
- Risk
 - Data and information sharing does involve a level of risk
 - Have to agree as a services, organisations and a system what level of ‘risk’ is acceptable
 - How also use other (Health and Care) statute such as the Care Act and the Health and Social Care Act to share data in a *legally defensible manner* i.e. for the provision of services to support people
 - Do Crime and Disorder statutes allow similar?
 - Historical process have driven people to a point of being risk adverse with sharing data and information
 - GPs have personal responsibility for data (not ‘covered’ by an organisation) and the notes and inputs into their systems are their own work, hence a possible added reluctance to share
 - Need to create a shared, and emotive narrative about why we want to share. Built around the individual and their outcomes
 - Challenge posed about who the data actually belongs to?
 - Is it the GPs / Health Organisations or is it the individuals?
 - Public engagement and co-design how we share data
- GDPR
 - Designed to make sharing easier and is designed to make the individual at the centre of the data sharing process
 - Doesn’t allow for data sharing at population levels
 - GDPR is new and therefore have been few legal precedents set around what can and can’t be done

Summary

Key focus should be on

1. Establish exactly what is wanted
2. Get good, proactive IG people involved early - This is emphasised within the GDPR guidance
3. Work through how to do what want to achieve

Learn from others

- Salford / Northern Care Alliance
- Local – Maternity notes kept by the individuals themselves

- GMCA Digital Strategy
- GMHSCP

Suggestion was that given we already have the ICO work streams and supporting Investment Agreement, should we look to take one theme / condition / service within one of the workstreams and look at in particular:

- The legal framework and the degree to which it enables information sharing to risk stratify, through consent or otherwise. This will help us to properly understand what we can and can't do
- What the implications of GDPR are
- The need to and manner of engaging stakeholders, especially GPs, and develop a new way of doing things together.

This to be discussed and progressed through Joint Leadership

The notes to be shared with the Board and a progress report to be taken to the next HWB meeting on the 26th June.