QIPP Digital Technology

NHS

Data sharing issues within risk stratification

Key points:

Existing information governance guidance is adequate and there is no requirement to develop any new data sharing agreement templates or guidance.

Be proactive in using communications material to engage with all stakeholders to inform and reassure them of the legitimacy of data sharing and precautions taken to ensure its security and confidentiality.

When starting a data sharing project identify a sponsor. A sponsor has the effect of driving a data sharing project, providing direction, leadership and convincing peers of its value.

Data sharing issues

One of the three key principles of the Quality Innovation Productivity and Prevention (QIPP) Long Term Conditions workstream is the adoption of risk stratification to ensure that commissioners understand the needs of their population and manage those at risk. This will assist in preventing disease progression and will allow for interventions to be targeted and prioritized, contributing to the £20billion of NHS efficiency savings by 2014-15, which will be reinvested in frontline care.

Risk stratification requires the sharing of data between different health care organisations and also between health and social care. This will include patient identifiable data.

One of the barriers to such data sharing is that information governance concerns need to be addressed to ensure the legitimacy of data sharing and that suitable precautions are taken to ensure its security.

A detailed guide is now available from the QIPP Digital Technology team, which provides a recommended approach to handling information governance based on an investigation and interviews with a number of NHS teams who already have an operational Risk Stratification system. The investigation did not identify any deficiencies or gaps in existing information governance standards or guidance for data sharing when applied to risk stratification.

The organisations interviewed identified nine common activity areas within successful data sharing:

- Identify a sponsor
- Establish a project team or stakeholder group
- Map the data flows
- Agree a purpose for sharing data
- Obtain stakeholder agreement
- Draft a data sharing agreement
- Formally sign the agreement
- Management of the agreement
- Produce communications material

Data sharing issues within risk stratification

Who is working with data sharing and what is their experience?

South Central Primary Care Trust Alliance

South Central is using the John Hopkins ACG system to provide; risk stratification, case finding/management, resource management and disease profiling. To date over 205 GP practices across all 9 PCTs covering a population of 1.6 million, have signed up to the use of the ACG system. Each practice gives permission via an overarching information sharing agreement and a Subject Specific Information Sharing Agreement (SSISA) as and when they are ready to participate in the programme. Participation in the ACG programme is purely voluntary.

"It has been hard work designing a technical infrastructure and a set of IG processes that both met available guidance and addressed our stakeholders' concerns. We have communicated regularly with the LMCs whose advice and feedback have been invaluable. We recognise that it is the GP Practices who are the Data Controllers and it is ultimately their decision to share data to support the programme. We make a huge effort to communicate with individual GPs and practices as they express an interest to sign up to the programme both through written material that describes the IG process and through face-to-face meetings. There are very few GPs who once they have seen the safeguards that are in place, do not go on to sign up to the ACG programme". **Alan Bonfield, Programme Manager within the PCT Alliance**.

Key questions

Q: Who should I choose as a sponsor?

A: The sponsor should be a medical professional with both professional and organisational credibility and status. Where the data sharing project will include health and social care data, consider having two joint sponsors one from health care and one from social care.

Q: Who should be in the project team or stakeholder group?

A: Health care representation including representation from any local health care professional bodies. Social care representation if social care data will be shared. Information Governance representation including representation from any cross-organisational or cross-sector local IG groups, forums or committees. ICT representation including representation from any crossorganisational local ICT groups, forums or committees.

Q: Do I need a specific data sharing agreement for risk stratification?

A: Yes. It basically sets out what data it is that you propose to share, the organisations involved in the sharing, the purpose (or reason) for sharing data and the measures taken to ensure data is shared securely and confidentially.

Q: Do all parties have to formally sign the data sharing agreement before their data can be accessed?

A: Yes. The written data sharing agreement is effectively a contract and must be signed by all the parties involved. Publishing it (on-line) is normal practice and meets with fair processing requirements of the Data Protection Act, and disclosure of information under the Freedom of Information Act.

To find out more visit www.connectingforhealth.nhs.uk/qipp
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You can also find us by searching for 'QIPP Digital Technology' on NHS Networks and LinkedIn.