

**Submitted Questions for the 15 Dec 2011 Webex
QIPP LTC Workstream: Predictive Modelling: busting the myths on choosing,
populating and testing**

Q1 - What is the process for procuring a risk stratification tool?
Need to look at your overall information strategy for the health care organisation for example do you want an in house or out-sourced solution, do you already have a data warehouse in place that has a sub-set of the data and could be extended to provide the core of the data required. Guidance in the Nuffield and AQUA documents on what tools and providers exist. Not aware that there are any specific framework agreements e.g. through Buying Solutions that cover this area. [Jim Lewis]
Dependent on type of product or service there may be a requirement for formal tender. [Colin Styles]
Q2 - What steps have been taken by the pilot sites to inform their populations that risk profiling is being undertaken and how an individual can find out about what information regarding their risk is being held by whom and for what purpose?
There is PIAG guidance on this saying patients do not need to be individually informed, although there is a need to ensure 'fair processing notices' are displayed. Organisations we have worked with have put leaflets/posters in GP surgeries and on websites. See http://www.dh.gov.uk/ab/Archive/PIAG/index.htm [Colin Styles]
Q3 - In addition how they might find out what their personal risk score is and what the implications of this are?
The risk score should be available to the health care organisation (e.g. GP practice) who can reveal this to the patient as part of a subject access request, however note that not all tools explain how the risk score was derived. The implications depends how you are using the results in your organisation, usually this is to inform clinical decision making, alongside other data. Note that if you are making decisions purely on the risk score alone then you need to register this fact under 'automated decision tools' in your data protection registration. However organisations I have spoken to aren't using it alone but alongside other clinical data/facts. [Colin Styles]
Q4 - Also, if a cut off at say the top 5% risk is used to determine which individuals are going to be reviewed and actions considered to alter the nature of the care provided to that individual how is the risk score communicated to that individual to inform them that this is why their care package is being reviewed?
That is up to the organisation, but my understanding is that clinicians would usually explain to the patient they have been identified as being at high risk, and not be explicit about the risk tool/score unless asked. [Colin Styles]
Q5 - If it is determined that an individual's care package cannot be altered is this then communicated to that individual along with their risk score?
That is up to the organisation as for Q4. [Mike Kelly]
Q6 - How is the IG risk that someone whose risk score is say just outside the top 5% but who ends up getting admitted and say has an adverse event during that admission

being managed? If we hold a risk score, have not individually contacted that individual to make them aware of that risk score and discussed with them how that risk could be reduced and they suffer an adverse outcome during an admission during the 12 months after the risk profiling had been undertaken.
The tool is being used to inform clinical decision making as for Q4. [Colin Styles]
Q7 - What social care criteria can be used in risk profiling individuals?
The Nuffield Trust have demonstrated that models can be developed to identify which individuals are most at risk of starting intensive social care in the next year. These new models are thought to be the first of their type in the world. See http://www.nuffieldtrust.org.uk/ for more detailed information. [Mike Kelly]
Q8 - What evidence is there that this helps to identify and target the right resources to such individuals?
There is some debate about the actual utility of risk profiling due to a limited current evidence base. However the Nuffield Trust provides several publications that give references to the extant evidence base. [Mike Kelly]
The LTC Members Guide documentation available on their NHS Networks site provides details of the evidence base as well. [Jim Lewis]
Q9 - What evidence is there that this tool can help to save time and money for social care services?
See answer to Q7. [Mike Kelly]
Q10 - How wide have others allowed access rights – community, secondary care, social care?
My current understanding from discussions with a number of localities is that the risk scores at a patient identifiable level have only been made available to the relevant GP Practice this may include wider staff such as community nurses who have honorary contracts in place with specific GP Practices to access patient data. [Jim Lewis]
Q11 - Can we integrate social care data?
See answer to Q7. [Mike Kelly]
Q12 - What does cost effective look like?
Some information provided in the LTC Members Guide. [Jim Lewis]
Q13 - How do we overcome the data sharing issues?
At the moment this is a bottom up approach; individual organisations have to put in place specific data sharing agreements with other organisations. This is a wider IG issue across health and social care and is not specific to predictive modelling. [Mike Kelly]
Information Governance needs to be considered very early in the life-cycle. The key data sharing agreements will be with the GP Practices for provision of the primary care data to feed the model. Sample data sharing agreements should be available from those teams that have already done this but it still requires each practice to sign-up. It should not be underestimated the effectiveness of strong clinical leadership e.g. a lead GP for the locality who can talk at LMC and with individual practices to explain the reasons for the data being shared. [Jim Lewis]
Q14 - Is there a simple easy to use system out there?
There a number of different tools and systems available. As above links are provided to

sources that list these. Talking with suppliers and localities that have already implemented risk stratification is recommended as is having a good idea of how you plan to use the tool within your locality. [Jim Lewis]

Q15 - How have others implemented the data sharing agreements?

See answer to Q13. [Mike Kelly]

Q16 - There are tools/models that provide retrospective modelling high risk based on people already known to the system (system = health, MH, social care). Geraint has cautioned that this type of approach (e.g. Evercare) needs to account for 'regression to the mean'. Other tools are predictive and many high risk people have been previously unknown to the system. What is the guidance/advice re using either or both in tandem?

It is desirable to use all data sources e.g. primary care, secondary care and social care in tandem to define a model. See the Nuffield Trust for a detailed discussion. [Mike Kelly]

Q17 - What databases are you going to use to support the development of the model?

See answer to Q16. [Colin Styles]