By: Helen Buckingham. Director of Whole System Commissioning and Deputy Chief Executive, NHS Kent and Medway

To: Kent Shadow Health and Wellbeing Board

Subject: Information Governance – an update

Classification: Unrestricted

Summary: This report summarises the activity that is being undertaken both nationally and locally on Information Governance.

Executive Summary

The following brief has been written based on the past discussions by the Kent HWBB May and July 2012. It summarises the importance of, and the work carried out till date around the development of Information Governance arrangements for the implementation of the Kent & Medway Long Term Conditions Programme.

To date there has not been a consistent or effective framework for sharing of personal and sensitive patient data between data silos, which sit in different information systems across health and social care organisations. Patient consent for sharing of records is available but in a limited capacity. Blocks also exist around sharing of information (coded data) and the linking of information systems from multiple agencies for the collecting and collating of robust health and social intelligence.

The current LTC programme advocates a whole systems transformational change, particularly breaking down silos caused by commonly perceived barriers due to information governance in two key areas: the linking and sharing of health and social care data for robust population intelligence including risk stratification; and sharing of care of records for effective real time patient care management by the multi-disciplinary health and social care integrated teams.
Over the last few months the K & M Information Governance team has led the design of appropriate protocols to enable the sharing of data and information in these two areas under the auspices of the Kent & Medway Information Sharing Agreement. Work is currently underway to sign them off by the respective agencies and data controllers starting with primary care. Other notable developments include the proposed set up and piloting of a virtual solution for online personalised care planning service in two CCG areas, known as ‘Patients Know Best’.

NB. To ensure consistency, other critical elements and interdependencies (of the LTC programme) such as technical aspects of enabling technologies (for eg. Medical Interoperability Gateway) are not described in detail here but further information can be found in the K&M LTC operational guidance http://www.kent.gov.uk/adult_social_services/social_services_professionals/social_care_events/long_term_conditions_programme.aspx

Background

Major changes to the culture and infrastructure of health and social care are expected over the next 3 to 5 years. Much interest has been re-energised by the input from QIPP (Quality Innovation Productivity Prevention) National team for LTCs in collaboration with consortia leaders in the South East by designing a specific programme of work in this field. The K&M Integrated Plan Board representing all providers and commissioners is committed to encouraging the systematic adoption of the three principles of the LTC model of care approach:

- Population risk stratification to identify patients with the highest risk of crises. These are usually patients with multiple long term conditions requiring a wide range of health and social care agencies for their care management.
- Creating functionally integrated generic care teams at a locality level comprising all relevant health and social agencies to provide joined up and personalised services.
- Empowering patients to maximise self-care, self-management and choice, through access to their medical records, co-production of their care plan leading to delivery of coordinated interventions and targeted care.

It is also important to acknowledge HWBB terms of reference that its mandate for integration and the work being done to develop integrated commissioning and provision which also supports the vision of the QIPP LTC programme being led by Kent & Medway PCT cluster and hopefully by the CCGs after April 2013.

Governance of the LTC Programme

A multi-agency team exists to see through the project locally, at all levels across health and social care organisations from Chair & CEO level through to practitioners delivering services within their organisations. In this time of transition, governance arrangements look to the Health & Wellbeing Board as the future vehicle for oversight and delivery of the programme, linked to the Integrated Strategic Operating Plan (ISOP) as well as the Health and Social Care Integration Programme (HASCIP). Programme support is provided on a “matrix delivery” basis, combining business intelligence, technology support. IT infrastructure support, programme management and so on, which is expected to move to the local Kent & Medway Commissioning Support service and commissioned by CCGs should they wish such support to continue in this form. Additionally, project managers have been recruited for the purpose of supporting (for each CCG) the LTC programme in various workstreams, particularly embedding risk stratification process into routine practice and support the completion of necessary information governance arrangements.

What needs to change?

While the national team have emphasised the 3 key principles for implementation (highlighted in yellow below) in Kent & Medway, at least 17 other key interdependencies and elements have also been identified as critical to the success of the programme, and explained in detail in the LTC operational guidance that was pulled together on behalf of the governance group. In it the fifth element is about developing robust information governance arrangements.

1. Ensuring robust CCG governance arrangements for successful implementation of LTC programme
2. Improved understanding of population need using risk stratification to deliver better JSNA and CCG health profiles
3. The importance of a robust minimum dataset from different provider agencies' information systems
4. Achieving financial balance and transforming payment systems by commissioning based on need / risk profiling (based on DH 'Year of Care' model)
5. Setting up robust information governance arrangements
6. A common data repository / warehouse – managed by K&M Health Informatics Service
7. Decision management system – developing a robust dashboard (eg. GPMIS in DGS CCG)
8. Making information accessible and sharing it across organisations *(Medical Interoperability Gateway)*
9. The use of telemedicine and interactive care (technology to enable multi-disciplinary tele and video conferencing)
10. The use of technology for staff to enable agility mobility connectivity (eg. use of ipads and other handheld devices)
11. The use of technology for the patient (rollout of the telehealth and telecare services)
12. Choosing the ideal risk stratification / risk profiling tool
13. Developing and operating integrated health and social care teams
14. Empowering patients to self care and self manage
15. Moving towards a common assessment framework - building on the nationally accredited Functional Assessment in Community Environments (FACE)
16. Applying the LTC model of approach towards the End of Life Care agenda
17. Preventing Long Term Conditions using Audit +
18. Transforming Social Care – developing pooled health and social care budgets to enable the LTC model of care approach
19. Robust evaluation of whole systems change with the help of local academic support
20. Communications and Engagement – to ensure efficient real time cascading and dissemination of best practice across Kent & Medway

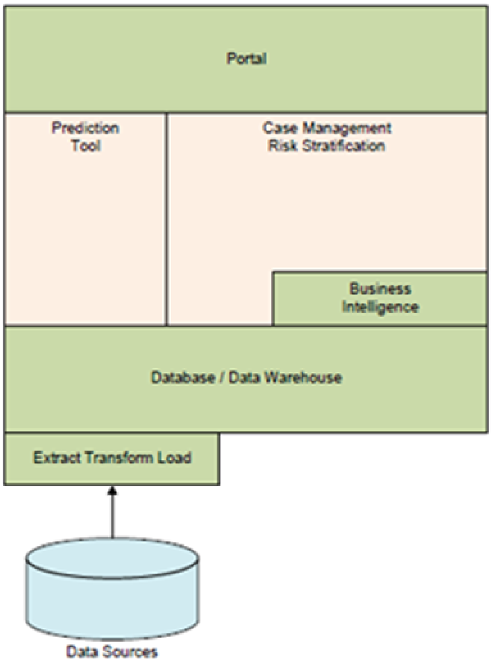
Why information governance is important?

There are two critical areas where robust information governance arrangements are urgently needed:

1. The sharing of health and social care intelligence (coded) data to enable robust population risk stratification and accurately estimate population need.
2. The sharing of care records between the various stakeholders of the individual patient's care, contributing towards a more effective, efficient, prompt and real time development of the patient's care plan.

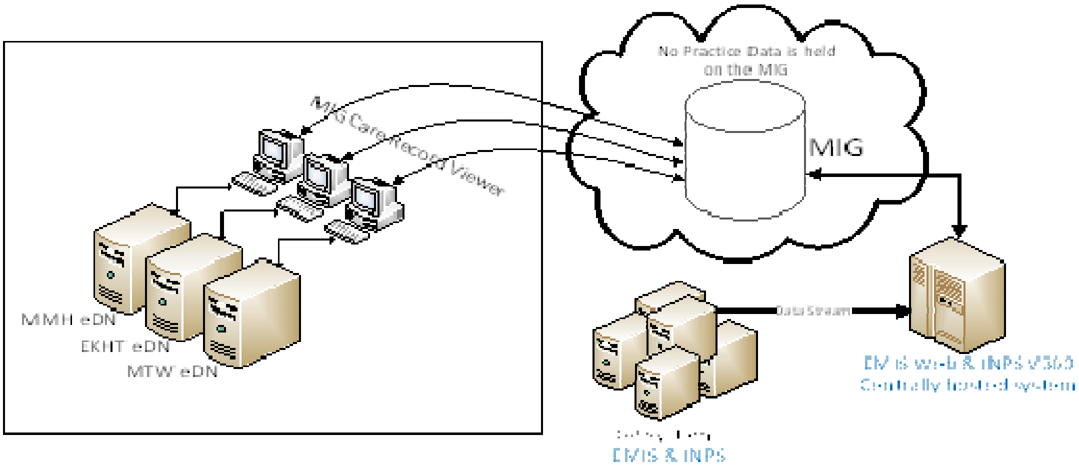
   From the list above, information governance should not be viewed in isolation but is critical and complements the successful development and delivery of almost all the 20 important elements and interdependencies, most notably:

- Development of a common data warehouse - Patient level activity real time data from our main health and social care organisations will need to be pooled and collated in one place, namely the data warehouse run by the Kent and Medway Health Informatics Service, of which the Business Intelligence wing will have operational supervision. Data that is sent to the warehouse will be clear format, undergo pseudonymisation process before undergoing risk stratification. The data will then be sent back to GP practices in a clear format for case management. Another extract of pseudonymised data can be made available to organisations such as Public Health for the purpose of population health intelligence (see diagram below).



Source: K&M LTC Operational Guidance 2012

- Development and operation of CCG Clinical Dashboards / Decision Management Systems - A single, consolidated review of organisational performance from a wide range of existing, disparate data sources, which will enable senior managers to see what is going on in parts of the system they would not normally have sight of, by enabling disparate information within existing systems to be consolidated and presented in a single, graphical, easy-to-understand dashboard view as shown in the diagram above.
- Development and operation of the Medical Interoperability Gateway – Based on the NHS Connecting for Health Interoperability Toolkit, its purpose is to share care records between multiple organisations such that it will not alter the way the care record is managed as shown in the diagram below.
- Patient care management by the integrated care teams - A locally delivered online personalised care planning service that will allow patients to be active partners in their care, working together with their care professionals (health and social care). Information will flow between the care records and the personalised care plan, which can be developed by the patient, and enables the digital delivery of targeted information and learning material based around the plan.



Source: K&M Operational Guidance 2012

What is the current situation on Information Governance?

To date there has not been a consistent or effective framework for sharing of personal and sensitive patient data between data silos. In this context data silos sit at various points within the local health economy, on GP Patient Administrative Systems, on mental health provider systems, acute systems and Social Services records etc.

Interoperability between electronic systems and inconsistency of record keeping has proved problematic to resolve. This has been further compounded by a lack of a clear and understandable patient data sharing consent model that has the capacity to establish patient trust that records will be shared appropriately and shared and stored securely.

Nationally the NHS has a poor record for data breaches and inappropriately shared or lost records form regular news stories which undermine patient trust. In addition to this, the Information Commissioner's Office (ICO) has recently begun to exercise their powers to fine organisations for data breaches and recent months have seen the first fines levied against NHS bodies.

Historically, there has been an implied consent model for the use of personal data by the NHS. This was refined by the Summary Care Record project which established informed consent but only against a basic dataset. Recent developments in clinical provision, including more proactive approaches such as LTC, envisage scenarios for cross service working to provide improved care. However, the patient consent model for sharing information in this way has not been present or at least has not been explicitly communicated to patients.

Blocks also exist around sharing of information and the linking (and compatibility) of information systems (using coded data) from multiple agencies for the collecting and collating health and social intelligence. This has become of paramount importance because of the growing cohort of people with multiple morbidities who are most commonly the frail elderly who are at the top of the population pyramid of need in terms of requiring services from a wide range of health and social care agencies as mentioned earlier. This implies an urgent shift and emphasis towards a more robust approach to accurately quantifying and estimating population need using risk stratification.

A national review is under way to look at the Caldicott Guardian principles.

The vision for the future: What does national policy say?

The latest DH paper entitled “The power of information: Putting all of us in control of the health and care information we need”, sets out the following ambitions for information governance:

- Information used to drive integrated care across the entire health and social care sector, both within and between organisations
- Information regarded as a health and care service in its own right for us all – with appropriate support in using information available for those who need it, so that information benefits everyone and helps reduce inequalities
- A change in culture and mindset, in which our health and care professionals, organisations and systems recognise that information in our own care records is fundamentally about us – so that it becomes normal for us to access our own records easily
- Information recorded once, at our first contact with professional staff, and shared securely between those providing our care – supported by consistent use of information standards that enable data to flow (interoperability) between systems whilst keeping our confidential information safe and secure
- Our electronic care records progressively become the source for core information used to improve our care, improve services and to inform research, etc. – reducing bureaucratic data collections and enabling us to measure quality
- A culture of transparency, where access to high-quality, evidence-based information about services and the quality of care held by Government and health and care services is openly and easily available to us all
- An information-led culture where all health and care professionals – and local bodies whose policies influence our health, such as local councils – take responsibility for recording, sharing and using information to improve our care

The progress so far in Kent & Medway

Stakeholder Consultation - The first Kent & Medway workshop in May 2012 led by the cluster Information Governance team discussed in detail the set up and proposed features of how the Medical Interoperability Gateway will function and the importance of designing an explicit patient consent model to enable different stakeholders to access different care records. A follow up workshop is to be planned later this year / early next year to describe progress so far.

Kent & Medway Information Sharing Agreement (KMISA) - This agreement has been developed to provide a framework for embedding best practice with regard to the exchanging of information proactively. All key health and social care organisations across Kent & Medway have signed into this agreement. It sets out a legal gateway making reference to key legislation such as the Data Protection Act 1998. It also contains the standard operating procedures (SOP) for which the signatory partners have agreed in detail how and what information they are to share with each other, while ensuring compliance with legal and regulatory responsibilities. These SOPs are expected to be reviewed on an annual basis. A sample template is shown in Appendix 1. Details of those developed in connection with the LTC programme are outlined in the next section.

Completing Privacy Impact Assessments leading to design and development of SOPs - A Privacy Impact Assessment is usually completed when there is a need to explore in detail the privacy risks before the commencement of a new project or piece of work and to determine whether less privacy invasive options can be used. The PIA describes in detail the generation, transmission, storage and use of data in two stages: Data processing and data protection. Signing off the PIA will lead to the design and development of the SOPs to be incorporated in the KMISA.

Between July to September 2012, the K & M Information Governance team along with KCC colleagues led the completion of the necessary PIAs and SOPs (involving weekly teleconferences) in the following key areas:

- Acute trust and Community Health to view access to GP records using explicit patient consent.
- The sharing and linking (with SUS or hospital data) of <u>pseudonymised</u> primary care data for the purpose of risk stratification and population health intelligence with permission of data controller but explicit patient consent not required.
- The sharing of care records by the Multi-Disciplinary / Integrated Care Team. This has been drafted primarily for the use of sharing of data between KCC and KCHT. Other agencies will be incorporated once the scope of the MIG has been widened to include them.
- *The sharing and linking (with SUS or hospital data) of pseudononymised social care data for the purpose of risk is on hold whilst clarification from NIGB/ICO is being sought on merging Health and Social Care data without consent. This is further described in a later section.*

Agreement signing off by data controllers - GP practices in the East Kent Federation have been selected first to arrange necessary sign off of SOPs by their data controllers which should be completed by September / October 2012. It is expected that all 265 practices across K&M will have signed their agreements by the March 2013 along with consecutive roll out of the risk stratification tool. The LTC project managers have been specially delegated to ensure task completion. Parallel discussions are also taking place with respective Local Medical Committees to explore how they could facilitate this process.

Caldicott Information Governance Review - KCC is coordinating a response back to the national review of Caldicott requirements (mentioned earlier) in terms of an evidence gathering exercise, summarising the information sharing process across adult social care in Kent and how this will be altered as we move to closer integration with health providers. This will hopefully contribute to the review of Information Governance at a national level and bring about a change in legislation so that our vision of integration can be achieved.

Piloting of 'Patients Know Best' - Patients Know Best is an national award winning approach towards virtual online solution for sharing the patient care plan where the patient is the 'asset control manager'. It is currently the only product on the market that currently offers the following set of critical and unique functionalities:

- Enabling patients to decide and authorise access to all or parts of their records on the system (including healthcare professionals, carers and others).
- Enables patients to decide and withdraw access to all or parts of their records on the system (including healthcare professionals, carers and others).
- Should allow patients to add or annotate their records, without changing the original record on the system.
- Provide full audit trails for access to all or parts of the patients' record.
- Allow secure messaging between patients and health professionals.
- Ability to integrate and synchronise with health records held by various health providers and carers.
- Use encryption for all traffic.
- A agreement has made to pilot the use of Patients Know Best approach towards sharing of care records in the Swale and South Kent Coast CCG areas. This is expected to commence in October and will be mainly used for patients identified through risk stratification. Evaluation of patient experience will be one of the main outcome measures. If successful, the Patients Know Best will be adapted to provide an explicit patient consent model, built into the Medical Interoperability Gateway once it is up and running, to facilitate the sharing of care records between different agencies.

Key challenges

Most of the national and local debate on designing effective IG arrangements has been so far around sharing of care records by the integrated team through the MIG, but not enough around the linking and sharing of data for combined health and social care intelligence and risk stratification. Latest guidance from the National Information Governance Board on risk stratification was developed to clarify its position and explain the necessary IG arrangements for the same. However, it suggests using the explicit patient consent approach (as in the case of sharing of care records) for the purpose of linking health and social care data which is deemed not practical to obtain for the whole K&M population of 1.7 million. A solution is currently being looked at by KCC FSC leads on this. In addition, it is hoped that this will be clarified in the national review.

As this is a Kent & Medway programme it is imperative that our partner organisations in Medway, particularly Medway Council are involved in the necessary discussions to progress the equivalent workstreams over there as well.

Conclusion

The national policy clearly states that the sharing of information is the first critical step and milestone towards system and service integration. A considerable multi agency effort has been made so far to achieve the progress till date. But further work is still required to complete any remaining SOPs for the sharing of information through all possible methods from the various agencies. The Kent HWBB can help facilitate this by raising awareness and promoting the importance of this workstream as part of the whole systems change in the context of the LTC programme, particularly to CCGs and its constituent GP practices. It can also establish appropriate links with the Medway HWBB ensure a common consistent approach towards implementation across Kent & Medway.

APPENDIX 1

STANDARD OPERATING PROCEDURE TEMPLATE

This Template provides advice (in red) and the standard format and words (in black) to assist staff preparing a Standard Operating Procedure (SOP) document. (See live examples in Appendix C)

Type of Agreement

This SOP is to be read in conjunction with the Kent & Medway Information Sharing Agreement and Method XX (Description to be inserted). There is the option to include more than one Method.

Personnel involved in the information sharing process must be fully aware of the requirements of Agreement Method XX.

Parties to this Agreement and contact number to identify Primary Designated Officer (PDO)

List the parties to the specific agreement and contact numbers as indicated above. The details are to include the job roles as well of the names of the individuals currently holding those positions.

A list of regular PDO and Designated Officer (DO) contacts is to be maintained for easy reference and is to be attached to this document (electronic and paper version). If there is any doubt about the contact or the information requested check with your supervisor before disclosing information.

Purpose

List the purpose and the reason for considering the disclosure of information e.g. targeting/investigating crime and disorder incidents, notices seeking possession or eviction, child curfew notices or noise abatement investigations and notices.

Administration/Process

List specific administration/processes that are relevant to the particular SOP, such as the response times. There is always a need to specify how each partner will keep a record of decisions and the reasons, whether it is to share or not (see Golden Rules item 5, above). Apart from this requirement, there may not be a need to add more text if the standard wording provided in the Information Sharing Agreement (ISA) is sufficient. For example, the requirement for PDOs, a standard information sharing form and the need to keep records are all specified in the ISA, but if there is a need to identify other roles, vetting levels if required, or be specific about the format of a meeting/minutes additional information will need to be inserted here.

Information Disclosure Types (Examples)

Disclosure for the following relevant areas for each partner will be considered. Specific exclusions are also listed.

List information for which disclosure will be considered for each partner. Specific exclusions are also to be listed, if required (e.g. evidence in council led court cases will not be disclosed until the conclusion of the hearing).

Signatory partners recognise that any data shared must be justified on the merits of each case.