



**Developing standards for
health and social care records**
**Report of the
Joint Working Group**

Introduction

This report was developed by a Joint Working Group (JWG) convened at the request of the Department of Health Informatics Directorate in England. It was charged with developing a business case, system of governance, constitution, operating framework and legal entity for the establishment of a federated Professional Record Standards Development Body (PRSDB). The PRSDB will have responsibility for overseeing the development of standards for the structure and content of personal records in health and social care, with a particular view to their implementation and use in electronic records.

Endorsements

This report is supported by a wide variety of organisations. The following bodies were represented on the JWG and endorse the contents of his report:

- Academy of Medical Royal Colleges
- Allied Health Professions through the National AHP Informatics Strategic Taskforce (NAHPIST)
- Department of Health Informatics Directorate
- National Voices
- NHS National Services Scotland
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Ophthalmologists
- Royal College of Paediatrics and Child Health
- Royal College of Psychiatry Informatics Committee
- Royal Pharmaceutical Society
- Royal College of Physicians (London)
- Scottish Royal Colleges
- Social Care representative
- University College London Health Informatics

The following organisations have indicated their support for the recommendations contained within the report:

- Academy of Medical Sciences
- Arthritis Research UK
- Cancer Research UK
- College of Occupational Therapists
- Health Quality Improvement Partnership
- Medical Research Council
- National Nursing Informatics Strategy Taskforce (NNIST)
- Research Capability Programme
- Wellcome Trust

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Section 1

Forewords

Jeremy Taylor, CEO at National Voices, the coalition of patient, service and carer organisations working to strengthen the voice of patients

No decision about me without me is a laudable ambition for any government. To be achieved, it must be translated into meaningful tools and experiences for patients.

An especially useful tool for service users will undoubtedly be the patient record. This will put patients in charge of information about them and is likely to become the single most important unit of information in the NHS. It will have significant implications and opportunities for patients – substantially improving the patient experience.

As a coalition of patient, service user and carer organisations, National Voices has been pleased to participate in the Joint Working Group that has produced this proposal to establish a Professional Record Standards Development Body (PRSDB).

If we can, through co-ordinated stakeholder action, get the development of patient records right, the advantages to patients should include:

- Participating in our own care and treatment
- Establishing and maintaining the importance of our preferences and care plans
- Having our care and treatment integrated around our needs

The patient record has the potential to empower patients, putting them more in control of their experiences of health and social services. The record can help to deliver integrated patient care, breaking down geographical, professional and institutional boundaries. This will prevent patients repeating the same information to many professionals – one of the greatest frustrations of service users.

Patient safety can also be improved, building in safeguards to prevent gaps and mistakes in treatment. The ambition is that the information held on the record will include treatment goals and care plans to enable self-management of care for patients recovering from an acute episode or managing long term conditions.

This is already happening in a minority of general practices around England, for example Haughton Thornley Medical Centres¹. Here, patients are now able to access their health records online. Their experience is likely to be extended to hundreds of thousands more patients in coming years, assuming the NHS is able to deliver the government's promise that access to electronic records will become the norm.

These patients speak positively of how access to their record helps to remind them, for example, of what has happened, what was decided in recent consultations, and how to take their medicines. When they have a forthcoming appointment, the records help patients to prepare their side of the consultation, including outstanding questions they want to ask.

The evidence for this approach is clear. Anecdotally patients belonging to these practices are reporting significantly improved satisfaction with their care. High level and systematic research reviews show that access to our records can improve our knowledge and our recall of information, and build a sense of empowerment.²

It is a brave patient who is prepared to voice and stand up for his or her own preferences about the way care and treatment is chosen and delivered. During an acute but not particularly serious episode, I once said to a nurse – the third professional I had seen that day – that I did not want painkillers, since they masked the warnings my body was giving about which way to lie and to move. She looked at me in disgust and said, "If you won't want painkillers, what are you in hospital for?" Such treatment is wholly unacceptable but unfortunately all too common.

Patients do not want to fight often unsympathetic health professionals to get their views across. Records that contain statements of our preferences and, where made, our care plans are an important defence against having our decisions and control removed from us when we pass from one setting to another. National Voices is pleased to note that the record standards already developed and approved by the Academy of Medical Royal Colleges include sections for recording these³.

I, and National Voices, fully support the establishment of a Professional Record Standards Development Body (PRSDB). This group would be charged with making an electronic patient record a reality for all. This is in keeping with the government's policy aims: empowered active patients that are involved in all decisions about their care require good quality information that is easily accessible. We call on the government to set up the PRSDB as a priority. We look forward to playing our part in its future development and operation.

¹ www.htmc.co.uk

² See www.investinengagement.info/choosingtreatmenttop

³ SHORT URL: www.tinyurl.com/clinicians-guides ; FULL URL: <http://www.rcplondon.ac.uk/resources/clinical-resources/standards-medical-record-keeping/structure-and-content-medical-notes/de>

**Charles Gutteridge, National Clinical Director,
Department Health Informatics Directorate (DHID), Clinical Division**

Patients share information about their health with their clinicians and carers throughout their lives. Recording that information and using it to improve people's health is at the core of medicine. We can also advance population health when information is collected to specific standards using computer readable language. As this is such an important part of modern healthcare, the recent White Papers on Health and Social Care commit to the use of clinical data standards to improve the delivery of care to individuals and to tackle some of the inequities of health through the use of aggregated data.

The Clinical Data Standards Assurance (CDSA) Programme in the Department of Health Informatics Directorate is working with a wide range of professional bodies to develop clinical data standards that are fit for use in digital systems. This has included a set of record headings for Admission, Discharge Summary and Handover which has been published by the Royal College of Physicians and endorsed by the Academy of Medical Royal Colleges.

Working across all the disciplines of health and social care, and closely with patients' groups, we have now developed a proposal for continuing the development of clinical data standards through a Professional Records Standards Development Body (PRSDB), which is the subject of this report. This proposed organisation, is supported by the Academy of Medical Royal Colleges for medicine, professional groups for Nursing, Midwifery, Allied Health, and Social Care professions, as well as representation from patient/citizen groups. It will act as a professionally led independent authority which will assure national professional clinical and professional record standards. I believe that the establishment of the Professional Records Standards development body is a vital step towards the creation of digital records that can be used by patients and shared with clinicians for improving health. I look forward to the day when assured standards are used across the community of health and social care professionals for the benefit of patients.

Section 2

Executive Summary

1. This report summarises the deliberations and recommendations of a Joint Working Group established in September 2010 by the Department of Health Informatics Directorate in England. Its remit was to examine matters in relation to the development of Electronic Health Records and recommend how professional requirements and leadership could best support the development of Electronic Health Records (EHRs) in line with national policy.
2. The Group met on six occasions and was chaired by Dr Charles Gutteridge, the National Clinical Director for Informatics. Membership of the JWG included representatives from health (medicine, nursing and AHP) and social care.
3. All 4 nations of the UK are committed to improving services, enabling interoperability of medical records and developing patient access to both records and transactional services.
4. As the volume, complexity and cost of health care increases, so does the need for high quality information to:
 - empower patients
 - inform the general public
 - drive clinical care and research
 - manage scarce resources
5. Health care is awash with information which is:
 - recorded for different purposes and by many different users
 - stored in disparate locations
6. Collating, processing and assuring the quality of the data from such disparate sources is hugely challenging and inefficient and there are enormous information gaps in areas of major public health importance

7. Despite advances in the development and introduction of healthcare information systems, there are major frustrations. Local acquisition of IT systems should lead to better use of resources, but this will only be achieved by the implementation of standards to underpin the structure of records wherever they are created.
8. Health related (clinical) data can be complex, and often only interpretable for a specific and defined context. This sometimes makes the transfer of meaning between electronic record systems, specifically where the data is stored in structured form, particularly challenging. The inclusion of social care data adds a further level of complexity.
9. Technical standards alone do not ensure the ability for information systems to transfer interpretable health data around the NHS so that they can be reliably manipulated and understood. However this problem can be considerably simplified by the clinical/health/social care professions agreeing on standard clinical/professional representations for the content of medical/health/social care records.

Technical standards alone do not ensure the ability for information systems to transfer interpretable health data around the NHS so that they can be reliably manipulated and understood.

10. A vision of common standards for patient focussed health records⁴ was articulated in a widely supported statement⁵ endorsed by the Academy of Medical Royal Colleges (AoMRC)⁶.
11. The first national evidence and consensus based record standards, developed with the leadership of the medical profession, were endorsed as fit for purpose of the whole medical profession by the AoMRC in 2008⁷. There were more than 6,000 contributions from practising hospital doctors in the development of the standards, demonstrating the commitment of the medical profession to this approach. They have been widely welcomed and are now referenced by educational and regulatory bodies⁸.
- 12. The JWG recommends the establishment of a Professional Record Standards Development Body (PDRSB) that would lead the development and professional assurance of clinical record standards across all specialties and clinical disciplines. The standards will provide the foundation upon which to base the collection, storage, communication, aggregation and reuse of structured clinical information across organisational boundaries throughout health and social care.**
- 13. The JWG recommends that an interim body is appointed under the auspices of the Academy of Medical Royal Colleges with the task of establishing the final structure, governance and funding of the PRSDB.**
14. While the major stated policy context refers to England, it has relevance for the four nations of the UK.

⁴ SHORT URL: www.tinyurl.com/standards-for-health-records, FULL URL: <http://www.rcplondon.ac.uk/sites/default/files/dev-standards-for-the-structure-and-content-of-health-records-22-oct-2008.pdf>

⁵ SHORT URL: www.tinyurl.com/vision-stakeholder-forum; FULL URL: <http://www.rcplondon.ac.uk/sites/default/files/a-vision-of-a-patient-focused-record-20-oct-2009.pdf>

⁶ SHORT URL: www.tinyurl.com/patient-focus-vision; FULL URL: http://aomrc.org.uk/publications/reports-guidance/doc_download/217-vision-for-patient-focused-records.html

⁷ SHORT URL: www.tinyurl.com/clinicians-guides; FULL URL: <http://www.rcplondon.ac.uk/resources/clinical-resources/standards-medical-record-keeping/structure-and-content-medical-notes/de>

⁸ SHORT URLs: www.tinyurl.com/gmc-tomorrows-doctors, www.tinyurl.com/foundation-curriculum, www.tinyurl.com/consultant-revalidation, www.tinyurl.com/PbR-assurance-2008-2009

FULL URLs: http://www.gmc-uk.org/education/undergraduate/tomorrows_doctors_2009_contents.asp, http://www.foundationprogramme.nhs.uk/download.asp?file=Foundation_Curriculum_2011_WEB.pdf

http://www.aomrc.org.uk/publications/reports-guidance/doc_download/9408-information-on-the-quality-of-medical-note-keeping-to-support-appraisal-for-revalidation.html,

<http://www.audit-commission.gov.uk/nationalstudies/health/pbr/pbrdataassuranceframework200809/Pages/default.aspx>

Section 3

Introduction

As the volume, complexity and cost of health care increases, so does the need for high quality information to inform clinical care, manage health services, inform the general public and empower patients. Health care is awash with information, which is collected and recorded for different purposes by many different information users, and is stored in disparate locations. Collating, processing and assuring the quality of the data is challenging, and presents major problems for service planners, service providers and service users, both the recipients of care and those that deliver it. Furthermore there are enormous information gaps in areas of major public health importance and continuing large regional difference in access and achievement. The picture is of large scale application of effort for less than satisfactory results. It is not efficient.

The objective for the NHS in England, summarised by Health Secretary Andrew Lansley, states a goal common to health services in many countries – *“...to devolve power through the unleashing of meaningful information to citizens. Comparative data about care standards and patient experience will drive up care standards, as the data will influence patient choice. A transparent NHS is a safer NHS”*⁹. The only means for recording and delivering information on this scale is through the use of information systems, systems that have to be appropriately structured to be reliably and efficiently managed.

The record of the dialogue between the clinician and the patient, the decisions made and the actions taken, is the cornerstone of the patient record. Provision of high quality care and consistency in continuity of care, is dependent upon this record, and it is access to this record that will empower patients. It is also information from this record that provides a major component of the data required not just for delivery and management of health care, but also for determining the cost, quality and outcomes of care.

Boundaries and barriers exist within and between primary, secondary, community and social care, and across the health care systems of the United Kingdom. For information from clinical records to be able to underpin safe and effective care, it must be accessible and easily transferable across these boundaries. The information that is recorded should be accessible whatever the setting or context, in the form of free text or of structured data and be transferable between clinical applications, contexts and settings without ambiguity. The successful development of interoperable Electronic Health Records (EHRs) would make the information readily available for clinicians, accessible for patients, and reusable for generating policy, management and research data.

⁹ http://www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_116634

As the proposed record standards assurance will be profession rather than service based, the assurance processes will have a relevance across the four nations of the UK.

Computers require standardisation of data if they are not to create chaos. For EHRs those standards must properly reflect good practice, support rather than hamper the work of clinicians, and enable patients to access their records. The structure and content of the records must reflect the ways that health care is delivered at the interface with the patient if EHRs are to be accepted and implemented by clinicians. Health record standards must be consensus and evidence based if they are to have the support of the clinical professions that will be working with the information systems.

In September 2010, the DH Informatics Directorate in England established a time-limited Joint Working Group (JWG) to consider the issue of professional assurance of clinical record standards. The standards would form a dependable foundation upon which to base the collection, storage, communication, aggregation and reuse of structured clinical information across organisational boundaries throughout the NHS and social care. As the proposed record standards assurance will be profession rather than service based, the assurance processes will have a relevance across the four nations of the UK. In England, for example, the clinical data conforming to the standards will form the basis of the measurement of quality and outcomes of care provision, and a fundamental support of the Choice agenda, Commissioning, and Continuing Professional Development.

This report from the JWG proposes the establishment of a Professional Record Standards Development Body (PRSDB) as a federated, multi-professional body, spanning health and social care, including citizens, with delegated authority to approve clinical and professional record and data standards for use in the NHS. The aim is that it will grow over the next five years, into an authoritative body, led by the health and social care professions, but including input from citizens/service users and other partners. It will set standards of good practice in health informatics and health information science. The PRSDB would advise the NHS (and relevant appointed bodies) on matters relating to Professional Record Standards for electronic clinical and professional records in the NHS.

These professional record and data standards will form the basis of NHS Electronic Health Records of the future, ensuring that information in them is safe, coherent, transferable and retrievable throughout the health service and, where appropriate, across the wider care sectors. Suppliers are able to develop IT systems that can deliver this agenda, but only as long as there are authoritative national professional standards around which to develop those systems.

The JWG considered the financial sustainability of the new professional body, and concluded that independence from government funding is preferable. The favoured model would be for a certification based process of record standard approval and implementation to be adopted and mandated in due course, with the certification income supporting the core functions of the PRSDB. Any professional record standards required by the NHS might also be commissioned through this group.

It is proposed that an interim group is established by the professional colleges and bodies, including representation from social care and patients/citizens, and that this group drafts the long-term PRSDB constitution and modus operandi. The standards declared by the PRSDB will form an important basis for best practice in professional record keeping. The adoption of such standards and good practice will be an important driver for professional creation of patient records, with benefits to the quality and safety of individual patient care, and the quality of aggregate NHS data derived from these records.

The Professional Record Standards Development Body (PRSDB) will also be responsible for the life cycle management of professional record keeping standards. It will negotiate with NHS technical and organisational leads on areas of overlapping and intersecting interest. Once fully established, the body would work alongside and cooperatively with the Information Standards Board in this regard, offering clinical and professional assurance of evolving ISB Standards, and the technical standards community to ensure that clinical records properly formatted can be moved, stored, aggregated and retrieved with reliable safety and retention of meaning.

The adoption of such standards and good practice will be an important driver for professional creation of patient records, with benefits to the quality and safety of individual patient care, and the quality of aggregate NHS data derived from these records.

Background

4.1 Strategic Context

The publication of High Quality For All, Next Stage Review Final report, presented to parliament in June 2008, indicates a change of direction for the NHS in England, with more emphasis on local initiatives to utilise and present existing data in a way that supports clinical objectives. Included in the review is an emphasis on achieving high quality care throughout the NHS.

“For the first time we will systematically measure and publish information about the quality of care from the frontline up. Measures will include citizens’ own views on the success of their treatment and the quality of their experiences. There will also be measures of safety and clinical outcomes. All registered healthcare providers working for, or on behalf of, the NHS will be required by law to publish ‘Quality Accounts’ just as they publish financial accounts.”

The Government’s White Paper, Equity and Excellence: Liberating the NHS set out how the improvement in quality and healthcare outcomes would be established as the primary purpose of all NHS-funded care in England.

The development of national quality metrics is highlighted as important to enable comparisons of quality of services. Many of the proposed quality metrics will require standard supporting guidance material that will need to be assured to a professionally acceptable standard. Coherent professionally set record and data standards will help to ensure that clinical data collected at the point of patient care will be able to contribute to coherent and reproduceable outcome measures across organisational boundaries.

4.2 Why are Professional Record Standards needed?

Health related (clinical) data can be complex, and often only interpretable for a specific and defined context. This sometimes makes the transfer of meaning between electronic record systems, specifically where the data is stored in structured form, problematic without a bilateral agreement about context (*for each pair of systems*) between originating and recipient systems. The inclusion of social care data adds a further level of complexity. However this problem can be considerably simplified by the clinical/health/social care professions agreeing on standard clinical/professional representations for the content of medical/health/social care records.

For example, in the clinical domain, such a clinical representation is known as *the core clinical structure or model*. If this core clinical model is declared as a professionally assured NHS standard, then the electronic records, adherent to this standard, which represent the patient record, can be stored and retrieved throughout the NHS safely with faithful preservation of meaning. Work on the definition and professional agreement of the core clinical model continues. Technical standards are then able to ensure that there is a secure level of interoperability and messages can be sent safely and without loss or change of meaning from one computer to another in the care system, with appropriate security.

Technical standards alone do not ensure the ability for systems to transfer coded health concepts or text around the NHS so that they can be reliably manipulated and understood, safely and coherently, on target (recipient) systems.

The way that clinicians structure medical records so that clinical data can be captured and shared in a national system, requires professional consensus. Work on professionally agreed clinical record standards has been started, and is being further developed, by the Royal College of Physicians (RCP), in close association with the Academy of Royal Medical Colleges (AoMRC) and other professional groups, and citizens, in health and social care.

The first national evidence and consensus based record standards, developed in this programme, were endorsed as fit for purpose of the whole medical profession by the AoMRC in 2008¹⁰. There were more than 6,000 contributions from practising hospital doctors in the development of the standards, demonstrating the commitment of the medical profession to this approach. They have been widely welcomed and are now referenced by educational and regulatory bodies¹¹.

In the year 2010/2011 the National Health Service Litigation Authority paid out £729 million (www.nhs.uk) in clinical negligence claims. The Audit Commission, in their 1995 report "Setting the Record Straight" (<http://www.audit-commission.gov.uk>), showed that as much as 40% of all medical negligence cases are lost due to poor medical record keeping. By reducing errors and assuring standardised quality in documentation, a major cost saving would be achieved in litigation. (NHSLA Risk Management Standards Handbook January 2010).

¹⁰ *SHORT URL: www.tinyurl.com/clinicians-guides, FULL URL: <http://www.rcplondon.ac.uk/resources/clinical-resources/standards-medical-record-keeping/structure-and-content-medical-notes/de>*

¹¹ *SHORT URLs: www.tinyurl.com/gmc-tomorrows-doctors, www.tinyurl.com/foundation-curriculum, www.tinyurl.com/consultant-revalidation, www.tinyurl.com/PbR-assurance-2008-2009*

FULL URLs: http://www.gmc-uk.org/education/undergraduate/tomorrows_doctors_2009_contents.asp, http://www.foundationprogramme.nhs.uk/download.asp?file=Foundation_Curriculum_2011_WEB.pdf

http://www.aomrc.org.uk/publications/reports-guidance/doc_download/9408-information-on-the-quality-of-medical-note-keeping-to-support-appraisal-for-revalidation.html,

<http://www.audit-commission.gov.uk/nationalstudies/health/pbr/pbrdataassuranceframework200809/Pages/default.aspx>

4.3 Current Structures

At present, there is in England a Clinical Data Standards Assurance process in place under the aegis of the National Clinical Content and Requirements Board (NCCRB). The primary objective of this board is to commission and advise on development, assurance and maintenance of national clinical record standards (clinical content standards).

Similarly NHS National Service Scotland's Data Recording Advisory Service (DRAS) (www.isdscotland.org/Products-and-Services/Data-Recording-Advisory-Service) has developed a clinical data structure based on 74 sets of clinical data standards previously developed within National Clinical Dataset Development Programme (NCDDP) and supports UK clinical document indexing standards.

To date the majority of England's NCCRB business has been concerned with third party forms, scales and assessments (that is to say instruments which have been designed by a third party organisation, usually the owner of any associated Intellectual Property). These can be used in NHS electronic records, where there is professional agreement that use of such forms represents best clinical practice. Examples would include Glasgow Coma Scale, Waterlow assessment scales for pressure sores, standard assessments of VTE risk. Once nationally professionally assured, the National Clinical Content Service (NCCS) in the clinical division of DH Informatics Directorate can make such forms nationally available through the National Clinical Content Repository (NCCR).

Forms, scales and assessment are not sufficient for the proper tailoring of Electronic Health Records (EHRs) for professional organisational use in the NHS. In order for such systems to achieve maximal clinical functionality, data structures including headings approved for use in records by the Academy of Medical Royal Colleges (AoMRC Headings) and the derived core clinical model, together with agreed coding sets and subsets based on SNOMED-CT, and other standard elements of clinical content, need to be assured, shared and implemented. Using a library of such assured content elements will allow locally based configuration teams, at trust level, to configure EHRs with professionally endorsed standard elements, and enable the collection of nationally comparable clinical data and information.

As presently constituted the NCCRB does not have the constitution to ensure that clinical standards are developed with sufficient professional leadership to enable authoritative endorsement and wide acceptance which is why we propose the establishment of a new Professional Record Standards Development Body (PRSDB). Furthermore, changes in the structure of the NHS and Social Care consequent on new policies, as set out in the NHS and Social Care Bill currently going through parliamentary process, will necessitate a re-constituted NCCRB, which will need to be aligned with:

- National Commissioning Board
- The Information Standards Board for Health and Social Care
- Information Standards organisations currently in DH Informatics Directorate, which may find a new home serving the NCB
- The NHS Information Centre
- National Quality Board and Care Quality Commission
- Monitor
- NICE
- Local Commissioning Groups
- The proposed new professional record standards development body (PRSDB),

As presently constituted, the NCCRB does not have the constitution to ensure that clinical standards are developed with sufficient professional leadership to enable authoritative endorsement and wide acceptance.

Proposals

5.1 The establishment of a Professional Record Standards Development Body (PRSDB)

We propose that a new, professionally based Professional Record Standards Development Body is established. This will develop into a key clinical/professional focus for development of expertise amongst clinicians and care practitioners for the handling of clinical and professional electronic records across the UK (England, Scotland, Wales and Northern Ireland), using a standards based approach.

In due course, responsibility for assurance of professional record and content standards for the UK health services would become the responsibility of PRSDB, which would give professional advice, with appropriate delegated authority, in partnership with NHS Trusts, Commissioners, system suppliers and citizens.

Expertise in the creation of shareable and aggregatable health information, and the design of capable clinical systems, is a limited skill in the professional domain at this moment. PRSDB will become a focus for development of health and social care informatics capability in standards and system design in the future. The PRSDB will promote the professional requirement of clear and precise record keeping which is measurable and easily understood by all readers.

5.2 Proposed Role and Function of the PRSDB

The primary purpose of the PRSDB will be the assurance of record standards for health and social care across the UK in support of best practice, safety and interoperability. These standards supplement relevant regulatory standards, providing additional detail to the record keeping principles.

The PRSDB will derive delegated authority from the professional organisations represented to approve proposed record standards through scrutiny of an assurance process. It will demonstrate adherence to an agreed quality framework and to principles of independence, fitness for purpose, cost effectiveness, fairness, transparency and accountability.

The PRSDB will fulfil this role by:

1. Agreement and regular evaluation of quality criteria for the development, review and maintenance of professional record standards based on editorial principles developed by CDGRS project and other professionally endorsed projects which may report / be adopted, from time to time.
2. Publication and regular evaluation of guidance for those developing or reviewing such standards
3. Prioritisation and coordination of national / UK work to develop / review professional record standards including that commissioned from professional organisations.
4. Approving standards that meet the quality criteria, and publishing them in a suitable repository once approved
5. Receiving and acting on reports on professional record standards, arbitrating on any concerns or challenging issues that are raised.
6. Making recommendations to representative organisations and others on gaps, priorities and other matters related to professional record practice and standards.
7. Monitoring and reviewing membership and ways of working to support continuous improvement.
8. Providing leadership and vision on strategic direction in relation to professional record content standards and their use, particularly their inclusion in professional education, audit and performance review.

5.3 Membership: Who does the PRSDB need to include?

It is proposed that the PRSDB will build on the membership of the Joint Working Group to include wider professional and patient representation, and establish a wider consultative mechanism across all related professional communities and groups in health and social care. The AoMRC will remain a key stakeholder to ensure appropriate representation from the Medical Royal Colleges and associations.

The AoMRC will remain a key stakeholder to ensure appropriate representation from the Medical Royal Colleges and associations.

Professional regulators (GMC, HPC, NMC, GPC) have delegated authority to set regulatory standards which are *rules or orders that establish control through formalised processes*¹². All professional record standards must comply with relevant standards set by professional regulators. This requirement will be central to the assurance criteria set by the new body. The Regulatory bodies should be invited to have representation on the PRSDB.

There are multiple professional organisations that are stakeholders in the assurance and approval of professional record standards and it may be impractical to include them all as members of the new body. Some organisations can represent the interests of a wider professional community, for example, the Academy of Medical Royal Colleges, but it will be important to invite representation from areas that are not able to be represented in this way. Irrespective of the final membership, the assurance criteria for national record standards must include a) identification of the authorities who can 'endorse' a proposed standard and b) all stakeholder groups who must or should be consulted in its development and review.

The non exhaustive list of membership would include:

- Academic Health Informatics
- Allied Health Professions
- Community Practitioners' and Health Visitors' Association
- Intellect Healthcare (<http://www.intellectuk.org/vertical-markets/healthcare>)
- Lab sciences/clinical scientists/radiographers
- Medical Royal Colleges
- National Mental Health Informatics Board
- National Voices
- Professional associations
- Professional Regulatory bodies
- Public Health
- Research organisations
- Royal College of Midwives
- Royal College of Nursing
- Royal Pharmaceutical Society
- Social Care including the Association of Directors of Adult Social Services

¹² *Professional regulatory bodies (Regulators) have the following functions:*

- *setting and promoting standards for admission to the register and for remaining on the register;*
- *keeping a register of those who meet the standards and checking that registrants continue to meet those standards;*
- *administering procedures for dealing with cases where a registrant's right to remain on the register has been called into question; and*
- *ensuring high standards of education for the health professionals that they regulate* (*Trust, Assurance and Safety: The Regulation of Health Professionals, DH 2007*)

5.4 Case Studies

A number of case studies have been developed as examples of how a PRSDB would improve the current situation and challenges being faced in developing clinical record standards.

The Cataract National Data set

Cataract surgery is the most frequently performed surgical procedure in the NHS with over 330,000 operations undertaken in England during 2009-2010. The need for standardised data collection for this high volume procedure was recognised early on and construction of a Cataract National Data set (CND) began in 2002. Tangible benefits for patients and providers have already been demonstrated but the adoption of standards by the Information Standards Board has been slow; one view is that adoption across the NHS requires the CND to align with the data dictionary. Another view might be that a process more in keeping with modern ideas of point of care data collection would indicate the identification and professional assurance of a SNOMED-CT Ophthalmology refset might be the more logical way forward. A decision on the best strategy for clinical purposes requires an authoritative records standard setting body such as the proposed PRSDB to consider the best solution available.

Project Insight: Admission and Discharge Notifications – Information Sharing between Health and Social Care

The Notifications are legal documents sent between NHS Acute/Non-Acute Trusts and Social Care Departments when patients are admitted and when they are medically fit for discharge (when discharges are late, they are often referred to as 'Delayed Transfers of Care'). The documents vary depending on the Borough/County where the patient resides and are in the main, handwritten and faxed. This creates a number of issues around security, timeliness and legibility. The London case study outlines, as an example, how secure email can bring great improvements. It also shows why there is a need for shared standards to enable the transmission of documents between health and social care, but also for the transmission of appropriate information with 3rd parties and, most importantly, patients. It outlines the need for an authoritative body to provide the common standards - the proposed PRSDB.

Mental Health Minimum Data Set

A Mental Health Minimum Dataset has been developed to assist with the commissioning of services. From time to time changes need to be made to the dataset but this has proved difficult, with several disputes involving the Information Centre, Mental Health Informatics Board, National Information Governance Board and the Information Standards Board. The study describes the lack of an authoritative standard setting body and the disconnection between clinical and information standard setting processes which would be bridged by the proposed PRSDB.

The study describes the lack of an authoritative standard setting body and the disconnection between clinical and information standard setting processes

Recording for Safeguarding children

Despite extensive guidance and ongoing educational efforts, many health and social care staff are unclear about what should be recorded and shared when there are concerns about a child, even when a child protection plan is in place. The Royal College Paediatrics and Child Health (RCPCH), Royal College of Nursing and Association of Emergency Care are working with relevant government departments to specify a record content standard to address this issue. However, this needs to apply to all health and social care professionals and therefore needs to be approved by an authoritative joint professional group – the proposed PRSDB would be this authority.

The Electronic 24-hour discharge summary toolkit

The DH Clinical Data Standards Assurance programme has delivered a ‘gold standard’ national, clinically-assured electronic Discharge Summary (DS)¹³, which focuses on the DS which is sent from an acute medical/surgical team to the GP within 24 hours of the patient being discharged.

The basis of this work is the published Academy of Medical Royal College (AoMRC) DS headings. Using this and working with the Royal College of Physicians (RCP) and the Royal College of General Practitioners (RCGP), this project focussed specifically on meeting the DS needs of the GP and patient.

The output of the work, the toolkit, was produced to enable trusts to implement this work locally in a consistent manner, learning from the experiences of the trusts who worked on the project.

In doing this, trusts will take a step towards achieving their Commissioning for Quality and Innovation¹⁴ (CQUIN) targets and will ensure that patients and GPs are better informed about their care and any after care needed.

In the long term, this will improve the information provided to patients and create a better way of patients and GPs working together in an informed manner, and in turn could result in a reduction of readmissions.

Despite extensive guidance and ongoing educational efforts, many health and social care staff are unclear about what should be recorded and shared when there are concerns about a child

¹³ *LONG URL:* <http://www.connectingforhealth.nhs.uk/systemsandservices/clinrecords/24hour>.
SHORT URL: www.tinyurl.com/e-discharge-summary

¹⁴ http://www.institute.nhs.uk/commissioning/pct_portal/cquin.html

5.5 Why does the PRSDB need to be professionally independent?

Providing a multi-agency assured set of standards for record keeping and professional records will provide consistency for the different disciplines within the health service, leading to reduced duplication of recording and testing, and improvement in clinical safety. It will also allow for aggregation and comparison of clinical indicators and the assessment of care quality and outcomes in both relative and absolute terms. Healthcare professional representative bodies, in their role as a 'responsible body of opinion', will take the responsibility for defining their 'clinical best practice' for the Electronic Patient Record. It is their oversight that will reduce the risk that poor or outdated practice will be designed into new applications, resulting in increased patient risk, lack of credibility from patients and clinicians, additional costs for rework and a failure to achieve the benefits of Health ICT.

NHS Connecting for Health funded the multi-professional development and assurance of the Professional Standard for Generic Medical Record Keeping led by the Royal College of Physicians and approved by the Academy of Medical Royal Colleges (AoMRC)¹⁵. This record keeping standard has been recommended for use by the Care Quality Commission¹⁶ and the NHS Litigation Authority¹⁷.

This work demonstrated the value that can be gained from the professional development and approval of clinical record and data standards. Going forward, there is a need for a formalised process for multi-professional, collaborative approval of further work to build on these standards, which includes the wider clinical professions working closely with service user groups and other interested parties. This approach has been endorsed by the Chair of the Information Standards Board and also the National Quality Board Report "Information on the Quality of Services"¹⁸

- Professionally led and owned record standards development will ensure acceptability across health and social care professions and will lead to standards being adopted and used.
- Professional coordination and ownership of record standards will reduce wasted time in repeating work already undertaken.
- Record standards would be professionally owned with accepted governance and roles and relationships to be regarded as the right place for the DH/NHS/System suppliers and other related organisations to go for standards related advice on how to collect data for various clinical and care related purposes in the NHS. It would also be best placed to represent assured expertise in the design and configuration of Electronic Health and Social Care Records from a clinical/professional perspective.
- Proper use of Professional Care record standards will become the accepted standard behaviour acceptable and recommended by Royal Colleges and other professional bodies with devolved responsibility from the regulators. As such they will become incorporated in main stream education, and in appraisal and revalidation processes, ensuring widespread adoption and resulting in improved record quality.

¹⁵ <http://www.rcplondon.ac.uk/resources/clinical-resources/standards-medical-record-keeping-hospital-admission-handover-and-disc-1>

¹⁶ http://www.cqc.org.uk/dbl/documents/Info_governance_FINAL_PDF.pdf

¹⁷ *NHSLA Risk Management Standards Handbook January 2010* <http://www.nhs.uk>

¹⁸ *NQB(10)(03)(02)(A)Information on the quality of services* <http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Healthcare/Highqualitycareforall/NationalQualityBoard/index.htm>

5.6 Governance and accountability of the PRSDB

The final structure, accountability, governance and funding of the PRSDB will need to take into account:

- Devolved responsibility for professional standards from regulators and parent colleges
- Accountability of representatives to AoMRC and other professional bodies
- Transparent consultative processes with relevant professional societies and associations in health and social care
- Appropriate patient representation
- Relationships to organisations such as the NCB and Information Standards Board and appropriate links with NHS Scotland, Wales and Northern Ireland
- An appropriate funding model.

Next Steps – a Transitional body

The next step is authorising the establishment of the transitional body with a requirement to report to the AoMRC, the nursing, midwifery and allied health professional organisations and agreed national NHS and policy bodies with progress reports at six months and one year. The transitional body would necessarily develop itself on the basis of the JWG report, with the responsibility and authority to move forwards on the basis of consensus of the stakeholder based membership. The transitional body would aim to establish the PRSDB as a legal entity one year from its establishment.

Appendix I - Glossary and Acronym list

| Term | Definition / explanation |
|----------------------------------|---|
| Regulatory standard / regulation | Rule or order made by government or a regulatory body that establishes control through formalised processes |
| Professional standard | <p>Document approved by a regulatory or professional body that specifies rules, guidelines or characteristics for activities or their results with the overall aim of ensuring safe effective care and treatment through consistent, quality performance in a given context. (based on ISO definition)</p> <p>NOTE 1: Professional standards may identify requirements for performance by which a practitioner will be held accountable.</p> <p>NOTE 2: Professional standards are generally based on evidence but may be established by consensus.</p> |
| Record standard | <p>A regulatory or other professional standard related to:</p> <ul style="list-style-type: none"> i. Record content, structure and semantics, e.g. how to represent allergies in a discharge summary ii. Record keeping practice, e.g. all record entries must be dated iii. Records management, e.g. maternity records must be kept for x years. <p>NOTE: this document refers mainly to i) above.</p> |
| Assurance Criterion | <p>Specified element against which a judgment is made.</p> <p>For example:</p> <p>Fit for practice - attribute of an individual or object; judgement based on evidence that the person / object meets stated performance or safety criteria related to clinical practice.</p> <p>Fit for purpose - attribute of a product, service or initiative; judgement based on evidence that a product, service or initiative achieves its stated objectives or outcomes.</p> |

Appendix II – Role of The Joint Working Group

Role of the Joint Working Group

The Joint Working Group, which was created in September 2010, has multidisciplinary membership from Professional Bodies and Associations. It has been sponsored by NHS Connecting for Health, and the Clinical Division of the DH Informatics Directorate. The JWG was commissioned, as a time-limited project with the specific purpose of considering the setting up of a permanent professional body to be responsible for professional record standards for health and social care, by the DH Informatics Directorate Clinical Division.

The Academy of Medical Royal Colleges (AoMRC) had previously been asked to consider the importance of suitable clinical foundations which will support technical standards, and in so doing be able to collaborate, with other clinical professional organisations, in the clinical assurance of NHS systems in a single high level clinical governance body. The development of clinical informatics skills within professional organisations is still an early stage in the main, but there was no doubt that such skills should eventually underpin all clinical assurance. However, such professional organisations need help to develop their own expertise in this new area. The AoMRC and other professional were duly asked in mid 2010 to support this endeavour.

In particular the AoMRC were asked to: nominate five representatives from the AoMRC to take part in a Joint Working Group to develop a business case for a federated, multi-professional body with delegated authority to approve Clinical Record and data Standards for use in the NHS to support designers, users and system suppliers.

Other organisations outside of the medical group represented by AoMRC were also invited to participate in the Joint Working Group.

This group comprised: *(A - accepted; D - declined)*

Royal College of Nursing (A)

Royal Pharmaceutical Society (A)

Social Care (A)

Patient Representatives through National Voices (A)

Nursing E-Health (A)

Royal College of Psychiatry Informatics Committee (A)

Federation for Healthcare Science (D)

The Joint Working Group held its first meeting in October 2010. Terms of Reference were agreed (Appendix V) and a series of monthly formal meetings scheduled. In addition a JWG listserver was established to enable additional information sharing and discussion .

Objectives of the JWG

The objective of setting up the Joint Working Group project was to deliver a proposal for the establishment of a federated, multi-professional body with delegated authority to approve Clinical Information Standards for use in the NHS to support designers, users and system suppliers.

The timescales for deliver of the proposal was March 2011, however as the JWG matured, it became apparent that the task was more complex and challenging than first considered. Therefore the decision was made to submit a formal Change Control Note for extension to June 2011 to enable further research and consultation.

Appendix III – Membership of The Joint Working Group

Membership of the Joint Working Group

Membership of the JWG is representative of a number of clinical professions with each member agreeing responsibility for wider representation. Patient representation was agreed with National Voices and National Patient/Public Lead.

Membership:

| | |
|-----------------------------|---|
| Charles Gutteridge (Chair) | National Clinical Director for Informatics, DH Informatics Directorate |
| Nick Booth | Director for Clinical Data Standards, Clinical Division, DH Informatics Directorate |
| Helen Hood | Senior Programme Manger, Clinical Division, DH Informatics Directorate |
| Oz Eryeler | Secretariat, Clinical Division, DH Informatics Directorate |
| Susan Hamer/Aidan Mullen | Nursing e-Health/Midwifery |
| Joe McDonald | Royal College of Psychiatry Informatics Committee |
| India Hardy | Royal Pharmaceutical Society |
| Bill Aylward | Royal College of Ophthalmologists |
| Ian Carpenter/John Williams | Royal College of Physicians (London) |
| George Youngson | Scottish Royal Colleges |
| Libby Morris/Robert Milne | Royal College of General Practitioners |
| Yvonne Pettigrew | Allied Health Professions |
| David Ingram | Professor of Health Informatics, UCL |
| Keith Strahan/Penny Hill | Social Care |
| Anne Casey | Royal College of Nursing |
| Roz Meek, Patient | National Voices |
| David Shortland/David Low | Royal College of Paediatrics and Child Health |
| Liz Mitchell | NHS National Services Scotland |

Appendix IV – List of Academy of Medical Royal Colleges Member Organisations

Academy of Medical Royal Colleges Member Organisations

College of Emergency Medicine

Faculty of Dental Surgery

Faculty of Occupational Medicine

Faculty of Pharmaceutical Medicine

Faculty of Public Health

Royal College of Anaesthetists

Royal College of General Practitioners

Royal College of Obstetrics and Gynaecology

Royal College of Ophthalmologists

Royal College of Paediatrics and Child Health

Royal College of Pathologists

Royal College of Physicians and Surgeons of Glasgow

Royal College of Physicians of Edinburgh

Royal College of Physicians of Ireland

Royal College of Physicians of London

Royal College of Psychiatrists

Royal College of Radiologists

Royal College of Surgeons of Edinburgh

Royal College of Surgeons of England

Royal College of Surgeons of Ireland

Appendix V – Terms of Reference for Joint Working Group

Terms of Reference

1 Purpose

This document describes the membership and role of the Joint Working Group (JWG) for the development of a proposal for the establishment of a Professional Record Standards Development Body (PRSDB).

2 Accountability

The Project Board will be managerially accountable to the Senior Leadership Team within NHS Connecting for Health.

Members will be responsible for representing and communicating the interests of the community which they have been nominated to represent.

3 Scope

The Joint Working Group is charged with developing a business case, system of governance, constitution, operating framework and legal entity for the establishment of a federated Professional Record Standards Development Body.

4 Responsibilities

- 4.1 Operational
- Approve JWG Terms of Reference
- Define roles and responsibilities of JWG members
- Agree objectives and key tasks
- Agree timescales
- Identify and monitor Risks and Issues
- Consider ways of working to ensure that the interests of all communities are represented together with methods of information sharing and gathering.

4.2 Delivery

- Development of a robust Business Case for the PRSDB
 - Recommended membership
 - Operating framework
 - System of governance
 - Legal Entity
 - Terms of Reference
 - Purpose
 - Outputs

5 Membership of the JWG

Chair

An agreed number of nominated representatives from the Academy of Medical Royal Colleges (AoMRC)

Nominated representative from Nursing and Midwifery

Allied Health Professional representative nominated by AHP Federation

Pharmaceutical professional representative nominated by Royal Pharmaceutical Society

Clinical Scientist representative and/or RCPATH nominated representative

Representative from the Academic Community

Mental Health Informatics Networks

Patient Representative/s

Representation from Social Care

Secretariat/Project Delivery

Nominated deputies will enable wider representation within communities. Members will be responsible for maintaining continuity.

6 Quorum

Quorum is agreed if a minimum of five nominated members are in attendance. This excludes the Chair and members of the Secretariat./Project Delivery team.

7 Communication Methods

Communication between members of the Joint Working Group will be primarily through electronic media including email but also through regular face-to-face meetings and teleconferences.. Members will ensure that effective communications are established and maintained with all stakeholders and professional groups relevant to the Joint Working Group Scope. An agreed Communications Strategy will be produced with the support of NHS CfH Corporate Communications Team

8 Frequency of Meetings/Ways of Working

For the first six months the JWG will conduct face-to-face meetings each month, with additional meetings at the decision of the Chair. Tele/video conferencing facilities may be used when appropriate to maximise member input

Members will respond in a timely manner to requests from the Chair for input to decisions that are required between meetings

Members will ensure that all allocated tasks are completed in a timely manner between meetings and where appropriate, circulated in advance of next meeting for review.

9 Deliverables

A document which sets out the business case for the establishment of a Professional Record Standards Development Body.

Any supporting documentation

Risk and issue log maintained for the duration of the project

Communications materials for publicising the aims and progress of the JWG

Communications log which demonstrates the engagement undertaken by JWG members

A powerpoint presentation which summarises the business case.

Communications Strategy - agreed method and timescales for dissemination of information

Register of professional sign-off of business case

Evidence base to support key decisions

Appendix VI – Detailed Case Studies

1. **The Cataract National Data Set**
2. **Making Amendments to Mental Health Minimum Data Set (MHMDS)**
3. **Admission and Discharge Notifications – Information Sharing between Health and Social Care**
4. **Recording for Safeguarding Children**
5. **Ensuring the safe transfer of information about medicines when patients move care settings**

1. The Cataract National Data set

John Sparrow

3 May 2011

Cataract surgery is the most frequently performed surgical procedure in the NHS with over 330,000 operations undertaken in England during 2009-2010. The need for standardised data collection for this high volume procedure was recognised early on and construction of a Cataract National Data set (CND) began in 2002. This was an iterative process which built the data set from scratch, incorporating feedback from stakeholder review groups. Initially development took place within the Royal College of Ophthalmologists and subsequently through Connecting for Health (CFH). The 2006 CFH Do Once and Share (DOAS) cataract project supported an important phase of data set specification development, gaining partial NHS Information Standards Board (ISB) approval (first of three stages) by the time the project funding ran out. Following his appointment the CFH National Clinical Lead (NCL) for Ophthalmology (JS) initiated a further round of peer reviewing and updating in preparation for a CFH sponsored functionality gap analysis (against the supplier Outline Base Specification) completed in early 2009. At this point the partial ISB approval achieved by the DOAS project had expired and a fresh approach to approval was adopted by the CFH NCL for Ophthalmology. Working with the ISB a simplified one step approval process suitable for 'in use' or 'inherited' data sets was developed. The cataract data set formed a test case for demonstrating the fitness for purpose of the simplified ISB approval process, and the Cataract National Data set finally received ISB approval as an Inherited Data set in 2010 (submission and data set specification available at <http://www.isb.nhs.uk/documents/isb-0085/amd-156-2010>).

At this relatively advanced stage of the development of the data set a couple of further pieces of work still remain outstanding. The data set and NHS Data Dictionary (DD) are as yet not fully aligned, there remain specialty and topic specific data items (e.g. visual acuity) still to be included in the data dictionary. Once the data set has been fully aligned with the DD it will be possible for it to be mandated for use in the NHS. In order to facilitate and underpin interoperability between and within systems and across institutional and geographical boundaries, the clinical terms within the data set must be coded, SNOMED-CT being the terminology of choice for the NHS.

The primary purpose of the data set is to standardise data collection for people undergoing cataract surgery. The data set is structured around the patient pathway and from the point of view of system developers and suppliers an approved data standard supplies 'stable clinical content' against which they can demonstrate compliance. Specialist electronic patient care record systems of varying degrees of CND compliance and sophistication already exist for cataract surgery and have been in use in the NHS for up to a decade. As such cataract surgery is 'ahead of the curve' with significant clinical benefits already having been realised as a by product of routine electronic collection of detailed and standardised clinical data. As part of the DOAS cataract project a multi-centre data extraction was undertaken with the original purpose of demonstrating fitness for purpose of the CND. In this exercise data on 55,567 cataract operations were extracted from 12 participating NHS Trusts. Analyses of these data have provided the ophthalmological community with a range of updates for purposes of benchmarking and audit. On the basis of these and other analyses of electronically collected cataract care data 11 peer reviewed outputs have been published. These include demographics, medications, vision, (eye) health, lens implant biometry, surgical and anaesthetic complications, visual acuity outcomes and case mix adjustment of surgeon's results for cataract surgery. The most striking result so far relates to an analysis of risk indicators for the benchmark surgical complication, posterior capsule rupture (PCR) in which it has been found that the predicted probability of a complication arising during a given operation varies by as much as 100 fold depending on the risk profile of individual patients and eyes. The ability to quantify a personalised predicted probability of a complication from routinely collected preoperative data has allowed more accurate consenting of patients and can be used to ensure that higher risk operations are performed by the most highly skilled surgeons. The risk calculator uses routinely collected data to estimate the likelihood of a surgical complication and a 'calculator' has been included in the most widely used electronic care record system. In at least one deanery the surgical trainers are now using this calculator preoperatively to select cases suitable for trainees, with impressively low complication rates being achieved by the most junior surgeons, thus minimising the adverse impact of training on recipients of NHS cataract surgery. On the basis of the complications risk model the Academy of Medical Royal Colleges supported a revalidation project to develop case mix adjustment for high volume surgical procedures using cataract surgery as a 'worked example'.

Further data extractions are currently being undertaken within a fresh initiative named the National Ophthalmology Database (NOD) project. This work intends to extend our current approach to other areas of ophthalmological practice as well as updating the published risk model for cataract surgery. To date over 175,000 cataract operations have been extracted from 20 participating trusts with more trusts expected to sign up to participation in the near future. As part of this project contributing surgeons will have access to a website which provides them with their own results in the context of those of their anonymised peers. Future refinement will incorporate case mix adjustment of the presented results which will ease the data collection burden and facilitate revalidation for participating surgeons.

The Cataract National Data set has to date not only produced a standardisation of cataract surgical data but has also provided a focus and opportunity for updating audit, benchmarking, and risk analysis. This in turn has delivered payback in terms of benefits to patients through improved understanding of how better to manage cataract surgical risk. In addition this work is expected to provide a template for other fields of surgical and medical activity and with wider adoption this approach should bring benefits to many.

Published outputs to date

Johnston RL, Sparrow JM, Canning C, Tole D, Price NC, UK Cataract EPR users group. Pilot National Electronic Cataract Surgery Survey: I. method, descriptive and process features. *Eye* 2005;19:788-794.

Sparrow JM. Editorial. Cataract Surgery: Benchmarks for established and trainee Surgeons. *Eye* 2008; 22, 1371–1372.

Jaycock P, Johnston RL, Taylor H, Adams M, Tole DM, Galloway P, Canning C, Sparrow JM and the UK EPR user group. The Cataract National Dataset Electronic Multi-centre Audit of 55,567 Operations: Updating Benchmark Standards of Care in the UK and Internationally. *Eye* 2009;23:38-49.

Narendran N, Jaycock P, Johnston RL, Taylor H, Adams M, Tole DM, Asaria RH, Galloway P, Sparrow JM and the UK EPR user group. The Cataract National Dataset Electronic Multi-centre Audit of 55,567 Operations: Risk stratification for posterior capsule rupture and vitreous loss. *Eye* 2009;23:31-37.

El-Hindy N, Johnston RL, Jaycock P, Eke T, Braga AJ, Tole DM, Galloway P, Sparrow JM and the UK EPR user group. The Cataract National Dataset Electronic Multi-centre Audit of 55,567 Operations: Anaesthetic techniques and complications. *Eye* 2009;23:50-55.

Benzimra JD, Johnston RL, Jaycock P, Galloway P, Lambert G, Chung A, Eke T, Sparrow JM and the UK EPR user group. The Cataract National Dataset Electronic Multi-centre Audit of 55,567 Operations: Antiplatelet & Anticoagulant Medication. *Eye* 2009;23:10-16.

Johnston RL, Taylor H, Smith R, Sparrow JM. The Cataract National Dataset Electronic Multi-centre Audit of 55,567 Operations: variation in posterior capsule rupture (PCR) rates between surgeons. *Eye* 2010;24:888-93.

Knox Cartwright N, Johnston RL, Jaycock PD, Tole DM, Sparrow JM. The Cataract National Dataset electronic multicentre audit of 55,567 operations: When should IOL Master biometric measurements be rechecked? *Eye* 2010;24:894-900.

Aristodemou P, Knox Cartwright N, Sparrow JM, Johnston RL. Intraocular lens formula constant optimization and partial coherence interferometry biometry: Refractive outcomes in 8108 eyes after cataract surgery. *Journal of Cataract & Refractive Surgery* 2011;37:50-62.

Aristodemou P, Knox Cartwright N, Sparrow JM, Johnston RL. Formula choice: Hoffer Q, Holladay 1, or SRK/T and refractive outcomes in 8108 eyes after cataract surgery with biometry by partial coherence interferometry. *Journal Cataract & Refract Surgery* 2011;37:63-71.

Sparrow JM, Taylor H, Qureshi K, Smith R, Johnston RL. The Cataract National Dataset Electronic Multi-centre Audit of 55,567 Operations: Case Mix Adjusted Surgeon's Outcomes for Posterior Capsule Rupture. *Eye*, Advanced Online Publication, May 2011.

2. Making Amendments to Mental Health Minimum Data Set (MHMDS)

Making necessary changes to MHMDS has proved very difficult. A number of organisations are involved in approving the changes particularly, ISB and NIGB both of whom lack expertise in the Mental Health Field and need the advice of a body of experts to advise them. In the hope of easing the process of standardising information sources within Mental Health an infrastructure for Mental Health Informatics was formalised at a meeting 2 years ago of the then newly formed National Mental Health Informatics Network. At that meeting A Mental Health Informatics Board was set up within DH to provide oversight to all matters concerning Mental Health Informatics including proposed amendments to MHMDS.

The board meets bimonthly and its work is supported by the broader Mental Health Informatics Task Force drawn from the wider National Mental Health Informatics Network which meets annually.

The lack of an authoritative source to draw together the needs of clinicians, the DH and the Royal Colleges had previously left something of a vacuum in terms of deciding what should and should not be included in MHMDS which is now the source which will be used to support the introduction of payment based on outcomes for patients (Payment by Results) in mental health next year.

However we have encountered a number of problems in our interaction between the infrastructure we created and other existing infrastructures:

ISB:

1. They have no Mental Health expertise among their appraisers which meant that even existing processes had to be explained, leading to delay.
2. Their lack of expertise was especially problematic because we also changed the version of the data set which ISB approved.

For some reason, they had previously approved the version of the MHMDS which was created by the MHMDS Assembler which is not the data items which Providers had to collect so, for example, it included age at various points but not date of birth. However, ISB had no sight of the data collected by Trusts, which didn't change much, but v4 looks very different to ISB compared to what they had previously approved. If they'd had an appraiser who worked in MH, then they would have understood.

We told them and took lots of evidence from Trusts to this effect but it was very difficult to persuade ISB without any internal reassurance.

- We had a carefully crafted set of changes to meet various needs but they "suggested" that we split it into two - one to include the Care Clusters and Clustering Tool and one for everything else. In retrospect this was a mistake as ISB then got it in their head that all that was needed for PbR was the Clusters and Clustering Tool when actually some of the other changes were needed to make better sense of the data, also to support PbR.

- Maybe we tried to put too much into one release (given all of the above) but we did lots of tidying up e.g. instead of breaking community contacts into nursing and other professionals, we have one set of contact details, which we thought went logically together. We now have a better product so it was worth the pain.
- ISB changed the rules as we went along: first they said we could use old documentation, then we had to use new, we were getting official comments from the domain lead and appraisers and then more comments from the ISB Director which sometimes contradicted what the domain lead said. There were also numerous changes of personnel along the way which didn't help but couldn't have been avoided.

NIGB:

- Inconsistency - had MHMDS flowed via SUS, then commissioners would have had access to patient identifiable data since 2006 (if SUS had worked) so we assumed that asking for this, just not from SUS, would not be a problem. We were wrong.
- NIGB have a belief that mental health data is more sensitive than other health data and should be subject to more restrictive rules, like sexual health, and operated according to this belief.
- Having requested identifiable data and made a case for it, eventually we had to back down because it was all we could do to get approval quickly. So, the current position is that commissioners still won't get identifiable data for mental health.

Conclusion:

Current arrangements for setting information gathering standards are not sufficiently nimble for the large task in hand.

3. Admission and Discharge Notifications between Health and Social Care

Focus on Secure email and Standards to share Admission and Discharge Notifications between Hospitals and Social Care Departments

Overview

NHS London is working with London Social Care Departments and Hospitals to enable them to share legal documents called Admission (Section 2) and Discharge (Section 5) Notifications more securely and efficiently using secure email.

The explicit consent model should always be used for information sharing between Health and Social Care.

The process

The Admission and Discharge Notification process is a good example of cross-boundary working.

When a patient is admitted to hospital and is likely to require social care support on discharge, an Admission (Section 2) Notification is issued to the Social Care Department where that patient is resident. This alerts the Social Care Department to start preparing a support package. This is a prime example of cross boundary flow of information.

Once the patient is medically fit and a date for discharge is proposed, a Discharge (Section 5) Notification is issued to the same Social Care Department. With the Section 5, there is a two-way flow of information between the hospital and the Social Care Department. The Social Care Department will send back confirmation of the support package and confirm whether they are able to meet the discharge date. If the support package is not available, it is called a Delayed Transfer of Care.

The project

Admission and Discharge Notifications have been primarily faxed across London between Hospitals and Social Care Departments. This creates a number of issues around security, timeliness and legibility.

NHS London are promoting the use of secure email to support this workflow through the implementation of a generic NHSmail email account within Hospital and a corresponding generic GCSX email account within Social Care Departments. This enables Hospitals and Social Care Department to share patient identifiable information more efficiently and securely and at minimal cost.

Background

The project was piloted within Ealing Hospital and Ealing Social Care Department who went live with secure email to support their Admissions and Discharge Notifications workflow in January 2011. NHS London ran process mapping sessions to identify the current process of sending the admissions and discharge information between the hospital and social care. This was followed up with a subsequent session to identify how future processes could operate if secure email was used to replace the fax.

As the project progressed, it emerged that the neighbouring West Middlesex University Hospital and Hounslow Social Care Department were already sending information securely between their hospital (using NHSmail) and Hounslow Social Care Department (using GCSX). So in January 2011, West Middlesex University Hospital also started sending notifications to Ealing Social Care Department for patients who were resident in Ealing. Ealing Hospital subsequently sent notifications through to Hounslow Social Care Department and a domino effect took place across London.

Since starting the project with Ealing, NHS London has so far engaged with 60% of London Boroughs and (50%) of London NHS Trusts who have now started similar projects. Other patient workflows being addressed are: Continuing Care (where often 80 pages of paper per patient assessment are being faxed), End of Life, Long Term Conditions (with GP involvement) and Child Protection.

Another part of the project, with support from the NHSmail Team, is to extend the NHSmail Directory to hold Local Authority contact information, making these available across NHS and Local Authority sites. The infrastructure is already in place, so relatively easy to set up and replicable.

Timescales

Within Ealing, the project took 4 months between initial kick-off and go-live. However, timescales for other similar projects will vary depending upon the amount of change required to introduce secure email. It is important to note that Trusts are not expected to have to fully “migrate” to NHSmail to participate.

Benefits and Efficiencies

The key benefits and efficiencies and from introducing secure email to support the admissions and discharge workflow:

- More efficient use of administrative resource within the Social Care Department
- More efficient use of administrative resource within the Hospital
- Reduced time to clarify data
- Reduced risk to patient safety
- Reduced time taken to communicate Section 2s and Section 5s between the Hospital and Social Care
- Less time required for staff to follow up on whether a form has been received
- Provides an improved electronic audit trail
- Reduces the amount of paper

- Fewer instances where information is sent to the wrong address / fax number
- Pan London standardisation of Documentation has now been agreed..
- Third party encryption technology now being investigated to send appropriate discharge information to Third Parties, and most importantly, patients themselves.

Systems involved: NHSmail, GCSX

Organisations/ Groups involved: Department of Health, NHS London SHA, NHS Connecting for Health, London Social Care Departments, National and London Social Care Information Management Groups

Key Contacts: Keith Strahan, NHS London Keith.Strahan@nhs.net Mobile: 07799-340001

4. Recording for Safeguarding children

Despite extensive guidance and ongoing educational efforts, many health and social care staff are unclear about what should be recorded and shared when there are concerns about a child, even when a child protection plan is in place. Children are significant users of A&E and Out of Hours services – clinicians in these settings cannot practice safely if they are not informed of known safeguarding issues. Record keeping in this area is known to be poor, for example, multiple different codes are used for safeguarding data in primary care systems, information is frequently out of date and the fact that a child is subject to a child protection plan is not communicated to clinicians who need to know.

The Royal College Paediatrics and Child Health (RCPCH), Royal College of Nursing and Association of Emergency Care plan to work with relevant government departments to specify a record content standard to address this issue. However, this needs to apply to all health and social care professionals and therefore needs to be approved by an authoritative joint professional group – the proposed PRSDB would be this authority.

5. Ensuring the safe transfer of information about medicines when patients move care settings

5.1 The Context

It is widely accepted that when patients move care settings the risk of miscommunication and unintended changes to medications is a significant problem. Some studies have reported that up to 70% of patients can have either an error or an unintentional change to their medication when their care is transferred. In some cases the impact on the patient is minimal however in other cases the results can be devastating.

In 2006, the then Royal Pharmaceutical Society of Great Britain (RPSGB) published guidance on discharge and transfer planning called *Moving Patients, Moving Medicines, Moving Safely*. The guidance outlined in detail the risks to patient safety from medicines errors when patients transfer from one care setting to another and gave examples of local approaches to improve discharge and transfer planning.

Since 2006, several national organisations have been involved in initiatives to reduce the risk of error and improve the quality of information about medicines on admission to hospital through the promotion of medicines reconciliation¹. In 2009 a Care Quality Commission report further scrutinised the management of medicines when patients were discharged from hospital and made a range of recommendations for improvements.

As the NHS enters a new phase of re-structuring, with GP Consortia commissioning services for the NHS and new providers of care encouraged to tender for NHS services, there is an opportunity, and a need, to re-emphasise the importance of ensuring that information about medicines is effectively transferred when care moves from one provider to another.

Currently, around four to five percent of hospital admissions are due to preventable problems with medicines. Improving the transfer of information about medicines across all care settings should reduce incidents of avoidable harm to patients by improving patient safety, and therefore contribute to a reduction in avoidable medicines related admissions and readmissions to hospital. This provides a clear link to the Quality, Innovation, Productivity and Prevention (QIPP) programme and the NHS outcomes framework. With this in mind, the two National Clinical Directors for Pharmacy have asked the Royal Pharmaceutical Society (RPS) to lead on an initiative to improve the transfer of information about medicines.

5.2 The initiative

As already highlighted, whenever a patient transfers care settings there is a risk that information about their medicines is not transferred, or inaccurately transferred. There are a wide range of potential transfer points for patients, the most obvious being home to hospital and back. However others include, but are not limited to; home to care home, hospital to care home, offender institution to home, home to respite care and back (adult and children), home to hospice or hospice to hospital.

¹ *These organisations, include the National Patient Safety Agency, the National Institute for health and Clinical Excellence and the National Prescribing Centre.*

In addition, there are instances where the patient's care is being managed simultaneously by multiple healthcare professionals and medicines may be started or stopped by any one of them. For example, GPs may have patients who are under their care but who are seen as outpatients in specialist hospital clinics; or present for unscheduled care to an out-of-hours service; or are seen in community clinics by specialist nurse prescribers; or routinely visit a community pharmacist.

At all these transfer points and interfaces there is a risk to patient's safety when information about their medicines is transferred inaccurately or not at all.

The Royal Pharmaceutical Society has, therefore, developed, in conjunction with patients, patient groups, health and social care professionals, professional bodies and national agencies, core principles to underpin the safe transfer of information about medicines whenever the patient transfers care providers, at any point in the care pathway.

In addition to the core principles, minimum standards have been developed for the information about medicines that should always be transferred when patients move from one care provider to another. Information contained in the minimum standards should, and may already be, incorporated into communication between healthcare professionals and patients.

The development process for the principles and standards is illustrated in Appendix 1.

Taken together the core principles and minimum standards give health and social care professionals, and commissioner and provider organisations a common framework and clear expectations about good practice around transfer of information about medicines.

The principles and standards will also give patients and patient support groups clarity about the steps that we all need to take to ensure the safe use of medicines as patients move through the health and social care system. They will also provide the basis for the development of patient focused support resources and initiatives to improve the quality of information transfer.

We envisage that the principles and minimum standards will be used and potentially further developed and refined by the following groups:

1. Professional bodies to promote good practice amongst their members

- Question 1: How can professional bodies use the principles and minimum standards?
- Question 2: How could RPS best partner / link with professional bodies?

2. Providers to help design safe services

- Question 3: How would provider services put the principles and minimum standards into practice locally?
- Question 4: Do you know of a provider service that may be interested in acting as an early adopter site for the principles and minimum data set?

3. Commissioners to incorporate within service specifications;

- Question 5: Would the principles and minimum standards need further development before being incorporated into contracts?
- Question 6: What outcome measures could assist commissioners in measuring /monitoring providers against the principles and / or standards?

4. Patients and patient groups to help actively involve patients in managing their medicines when they transfer care settings.

- Question 7: How best could we work with patients and groups to raise awareness about the importance of understanding the what, why and when of their medicines?

- **5.3 The core principles**

The core principles have been developed to underpin the safe transfer of information about medicines whenever the patient transfers care providers, at any point in the care pathway.

- The principles are for use by patients, all health and social care professionals, and organisations to develop a culture that encourages the safe and effective transfer of information about patients' medicines.
- Processes put in place to improve information transfer about medicines should be consistent with these core principles.
- The principles should be embedded in national and local commissioning frameworks and professional good practice guidance.

5.3.1 THE PRINCIPLES (Involve the patient, take responsibility, follow up and learn)

1. Patients, parents, carers or advocates should be actively engaged and supported in the communication of information about their medicines when they move settings.
2. Where possible, patients (or their parents, carers or advocates) moving care settings, should know in plain terms what medicines they are taking, why they are taking them, how long for and why any changes have been made.

3. Information about patients' medicines should be communicated in a way which is timely, clear, unambiguous and legible; ideally printed or transferred electronically.
4. The health care professional transferring a patient's care to a different care setting and the healthcare professional taking over the care of the patient both have a responsibility to ensure that all necessary information about the patient's medicines has been accurately transferred.
5. Organisations must support healthcare professionals by having processes, with pharmacist input where possible, to ensure that information about medicines is accurately transferred and is seen as a priority.
6. Processes which are developed to improve the timely transfer of information should focus on improving patient safety and patient outcomes, not the delivery of the process itself.
7. Organisations and healthcare professionals should audit how accurately and effectively they have been in ensuring the transfer of information when patients move care settings.
8. Where information about medicines is transferred well, good practice should be shared and disseminated, similarly if things go wrong, incidents should be reported and learning shared.
 - Question 8: Would any of these principles be better removed and included in the introductory bullet points?
 - Question 9: Have you got any general or specific comments on the core principles?

5.4 The Minimum standard

To reduce the risk of errors and harm to patients, the minimum standards outlined in box 1 represent the information that should be transferred with patients when they move care settings.

The minimum standards focus on what information about medicines it is CRITICAL that the healthcare professional taking over responsibility for the patient's care has access to when the patient arrives in their care setting.

The minimum standards for information about medicines apply whenever a patient is transferred from one care setting to another. It is likely that these minimum standards would form part of more detailed transfer records which are tailored specifically to each transfer setting.

However, in the absence of a detailed record, or where there are doubts about the timely transfer of the record, it is expected that the organisation and healthcare professional transferring the patient would ensure that, as a minimum, information outlined in these standards is supplied.

Box 1: Minimum standards for information about medicines to be transferred with patients when they move settings

- Patient details
- Surname, forename, known as, date of birth, gender, NHS number, patient address, patient telephone number
- Conditions (if known and/or appropriate)
- Current Medications (complete list, prescribed, OTC, herbal, dressings, devices etc)
 - Name
 - Dose
 - Frequency
 - Formulation (tablets, drops, liquid, Special preparation etc)
 - Route of administration
 - Storage where relevant
- Medication changes
- Medication started – why, for how long, who reviews and when
- Medication stopped – why
- Allergies, adverse reactions or contraindications
- Additional relevant information/special instructions
- Additional information supplied to the patient e.g. how long a new medicine may take to work
- Additional information about specific medicines e.g. preservative free required, brand names where bioavailability issues
- Adherence support required (e.g. compliance aids, prompts, packaging etc)
- Information should be signed and dated by the healthcare professional transferring details of the medication.
- Contact details of a named individual should be available to the healthcare professional receiving the patient.

Question 10: Have you got any general or specific comments on the minimum standards?

Appendix 1: Outline development process

The process used to develop the core principles and minimum standards is illustrated below:

SCOPING

- Literature review
- Working group scoping meeting
- Interviews and follow-up

DRAFT AND DEVELOP

- Principles and standards drafted
- Drafts refined and developed through multidisciplinary user groups
- Patient group to test drafts

CONSULTATION

- Wide circulation to commissioners, providers, professional bodies and patient groups for comment

USER TESTING/PILOTING

- Multidisciplinary user group testing
- Early adopter sites identified

SIGN-OFF, PUBLICATION AND LAUNCH

- Working group and steering group agree final drafts
- Published on RPS website
- Multidisciplinary and patient launch events/publications

Appendix 2: Acknowledgements

STEERING GROUP

- Howard Duff Royal Pharmaceutical Society
- Jonathan Mason Department of Health
- Catherine Picton Royal Pharmaceutical Society (commissioned)
- Martin Stephens Department of Health
- Heidi Wright Royal Pharmaceutical Society

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Carol Lange Prison pharmacist
Maria Rice Patient with Parkinson's Disease
Pearl Hughes Carer
Bert Osbourne Patient
Jo Cummings Patient with Arthritis
David Josephs Person with a son who has severe epilepsy
Melvin Sandler's Carers Forum
Daiga Heisters Parkinson's UK
Peter Twist Terrence Higgins Foundation
Bohdan Solomka Royal College of Psychiatrists
Andrena Mcelvanney The Royal College of Ophthalmologists

APPENDIX 3: SUMMARY OF QUESTIONS

- Question 1: How can professional bodies use the principles and minimum standards?
- Question 2: How could RPS best partner / link with professional bodies?
- Question 3: How would provider services put the principles and minimum standards into practice locally?
- Question 4: Do you know of a provider service that may be interested in acting as an early adopter site for the principles and minimum data set?
- Question 5: Would the principles and minimum standards need further development before being incorporated into contracts?
- Question 6: What outcome measures could assist commissioners in measuring / monitoring providers against the principles and / or standards?
- Question 7: How best could we work with patients and groups to raise awareness about the importance of understanding the what, why and when of their medicines?
- Question 8: Would any of these principles be better removed and included in the introductory bullet points?
- Question 9: Have you got any general or specific comments on the core principles?
- Question 10: Have you got any general or specific comments on the minimum standards?

Appendix VII – Future Transition into a financially independent organisation

1 Future transition into financially independent organisations

1.1 A target to move towards

CCHIT (the Certification Commission for Health Information Technology¹) in the US seems to be a logical model to target when considering a direction of travel from the JWG towards the PRSDB. The goals for the PRSDB may not be identical to those of CCHIT, but there is sufficient commonality of purpose for it to provide at least a target to move towards.

CCHIT is a not for profit organization, established as a legal entity, with the public mission of accelerating the adoption of health IT. It was founded in 2004, and established the first comprehensive, practical definition of what capabilities were needed in electronic health record (EHR) systems. It started certifying EHRs in 2006 on the basis of certification criteria developed through a voluntary, consensus-based process engaging diverse stakeholders. It is officially recognized by the federal government as a certifying body.

Uptake by the health IT industry was rapid, with more than 200 EHR products certified by mid-2009, representing over 75% of the marketplace. Provider organizations endorsed the work as well. Based on this broad acceptance, healthcare funders and purchasers in the government and private sectors began offering incentives to providers for adopting certified EHR technology. In February 2009, Congress acknowledged the value of certification and enacted incentive payments to providers and hospitals for the meaningful use of certified EHR technology.

1.2 Who would be involved

The objective of an established operational PRSDB will not happen in a single leap as there is currently insufficient breadth and depth of understanding within the NHS and professional organisations. There are however now well established relationships with the health professional organisations of all the health care disciplines and health informatics in the on going work of the CDGRS (Clinical Documentation and Generic Record Standards) programme funded by Connecting for Health and currently led by the Health Informatics Unit of the Royal College of Physicians, London. This project is developing evidence and consensus based professional structure and content standards for EHRs that reflect day to day best practice. All the Medical Royal Colleges and Specialist Societies have nominated representatives to participate in the project, as have the nursing, midwifery and allied health professional organisations. In addition, a large number of NHS Trusts have made nominations for Trust representatives who are also participating in the workshops and consultations of the current work programme.

This project and the network of engaged health professionals provides both a task focus and representative group that could form the basis of a transitional body in the steps towards establishing a PDRSB as a legal entity.

¹ <http://www.cchit.org/about>

1.3 How a transitional body would be established

The transitional body would initially need to be formed under the auspices of an established entity. The Academy of Medical Royal Colleges would be a natural starting point on the basis of 'with the blessing of, but no resource commitment from' the Academy.

A first step would be informing all the nominated representatives taking part in the CDGRS programme of the establishment and goals of the PRSDB. This would be by email with an introductory paper on the purpose and nature of the proposed body. The email would invite comments and suggestions. The initial consultation would be followed by a stakeholder meeting such as those hosted by the RCP HIU². These meetings were enormously successful with wide stakeholder engagement and participation. This initial stakeholder meeting would formulate membership and structure of the transitional body which would have the task of defining and establishing the PRSDB on the basis of consensus of the full stakeholder body. The structure may for example take the form of a council and membership formed from the stakeholders.

1.4 Where could funding come from

Evidence from the industry supplier community suggests that the development of professionally endorsed standards for structuring health records is almost a golden key to opening the development and more steady implementation of EHRs. The standards provide standardisation on the basis of professionally endorsed best practice with the associated benefit of reducing the overwhelming task of attempting to customise products for every different care provider. The likelihood is that were the PRSDB established as a coherent group, industry may be prepared to support it on the same basis as the CCHIT.

Initial requirements would be a small secretariat and clinical leadership with committed time to develop the infrastructure documents, establish initial meeting, relationships with stakeholders, identify funders and establish a recognisable entity and brand. Funding from CFH would clearly be the surest option were it available, but would likely need to be on the basis of fixed start up costs with a target of securing external funding within the first one or two years.

1.5 Next Step

The next step would be authorising the establishment of the transitional body with a requirement to report to the AoMRC, the nursing, midwifery and allied health professional organisations at six months and one year. The transitional body would necessarily need to develop itself on the basis of the JWG report, with the responsibility and authority to move forwards on the basis of consensus of the stakeholder based membership. While it is not possible to state how long the transition process would last, a reasonable goal may be to establish the PRSDB as a legal entity one year from establishing the transitional body .

² <http://www.rcplondon.ac.uk/resources/stakeholder-meetings>

Appendix VIII – Options for a transitional body before financial independence including options appraisal

Options for a transitional body before financial independence

A number of models in other organisations have been previously identified which support the assurance and/or development of best practice/ 'standards' in care.

One such model develops content using a panel including stakeholders representing a range of professional groups, experience and other constituents. This approach was used by other models such as NICE, the NHS Quality Improvement Scotland (NHS QIS), and the Council for Healthcare Regulatory Excellence.

The RCP Generic Record Keeping Standards gained significant credibility through their assurance by the Academy of Medical Royal Colleges, but this body is only appropriate for assurance of 'medical' activity.

Currently, most HCP representative bodies are not set up to fulfil this need and would need funding to undertake this work. The NHS CFH National Clinical Leads have been influential in engaging with HCPs and at a senior level in the Department of Health in this area. A number of potential Responsible Bodies of Opinion are now either in place or being set up, for example, the eCare subgroup of the Nursing and Midwifery Advisory Group.

The Professional Record Standards Development Body will be required to own and manage the development, assurance and maintenance of Record Standards. The membership of the PRSDB will take into consideration previous and current models used and identify a robust mechanism for integrating all professional groups in the approved operating model.

Options

An options appraisal exercise carried out by the JWG examined the following options for the development of governance and funding models for the PRSDB :-

- 1) Sole Proprietor
- 2) Partnership
- 3) Co-op
- 4) PLC
- 5) Quango
- 6) Hosted by another organisation
- 7) Social Enterprise
- 8) Statutory Body
- 9) Registered Charity

The JWG discussions concluded that a not for profit Social Enterprise or a statutory body could fulfill the governance and funding needs of the PRSDB. It would be a task for the Interim Group to work up a detailed business plan for the chosen model.

Appendix IX– Case for Change

The Case for Change

Difficulties encountered:

- The existing framework agreements available for procurement do not include responsible bodies of opinion, such as HCP representative bodies
- Very few procurements have been undertaken of this nature, resulting in little experience on which to build
- Limitation on procurement support, resulting in increased timescales for development and approval of Output Specification for procurement
- The scale of activity, including, potentially, development assurance and maintenance of content requires a procurement using the Official Journal of the European Union process that takes 4-6 months
- Currently only a few of the HCP representative bodies are resourced in such a way to bid for OJEU contracts
- In addition, few of the HCP representative bodies have structures in place to support wide consultation of their members (e.g. mailing lists, web surveys)
- The potential for the HCP representative body to ‘mark its own homework’ if it is developing and assuring the professional standard
- Economies of scale
- Recurrent procurement activities and associated time lapse from beginning of activity to assured product
- Ensuring that the most appropriate professional bodies are involved
- Ensuring that the products have true multi-professional input and assurance
- Need to include all professional bodies whatever their Informatics organisation and resourcing
- Role of professional bodies as developers and approvers of standards and the associated conflicts of interest that may arise
- Top down and bottom up approaches and the associated processes and procedures
- End to End processes where technical and data standards would be part of the assurance process with the incorporation of the Information Standards Board for Health and Social Care (ISB HaSC) procedures.

NHS Connecting for Health (NHS CFH) has piloted the development of professional Clinical Record Keeping Standards, by providing funding for the multi-professional development and assurance of the Professional Standard for Record Keeping led by the Royal College of Physicians (the RCP) and approved by the Academy of Medical College. The pilot has demonstrated the value of such work, but also the significant costs associated with the development of such Clinical Standards – the pilot cost of £250,000 covered the development of the assurance methodology and the development and assurance of three Record Keeping Standards.

The number and complexity of the record standards will be difficult to predict,. To this end there is a need to identify an appropriate model for Development, Assurance, and Maintenance of Professional and Clinical Standards.

Investment Objectives

The model for Development, Assurance, and Maintenance of Record Standards needs to be professionally owned, fit-for-purpose by working clinicians and contributing to adding value to everyday clinical care,.

In this way the development and implementation of record standards will be maximised; cross boundary care will be implemented rather than organisational care based around application modules, national debate on clinical risk issues facilitated and clinical risk minimised by facilitating the adoption of agreed standards of care.