Data Privacy Compliance: Legal requirements and DH policy

Health Information is confidential by law
"…the law is clear that personal health information is confidential and that the duty of confidence is owed by the treating clinical care team. To reiterate, in order to use information for secondary uses, there must either be:
• a statutory basis for disclosure (which includes powers under S60) OR
• the data must be anonymised prior to disclosure OR
• valid consent for its use in identifiable form sought OR
• Exceptionally, there may be an over-riding public interest justification"
Patient Information Advisory Group (PIAG) Response: Report of the Care Record Development Board Working Group on the Secondary Uses of Patient Information, p. 7

If data is not being used for what the patient originally intended, consent must be obtained or the data must be de-identified
"The key principle of the duty of confidence is that information confided should not be used or disclosed further in an identifiable form, except as originally understood by the confider, or with his or her subsequent permission. NHS organisations should have, or be putting in place, procedures for reviewing the appropriateness and necessity of using confidential patient information to support specific purposes. They should also be developing staff codes of practice and putting in place information sharing protocols to govern working across organisational boundaries."
Confidentiality: NHS Code of Practice, p. 34, section 27

Clinical data re-purposed for Commissioning and other "Secondary Uses" must be de-identified
· "Many current uses of confidential patient information do not contribute to or support the healthcare that a patient receives. Very often, these other uses are extremely important and provide benefits to society – e.g. medical research, protecting the health of the public, health service management and financial audit. However, they are not directly associated with the healthcare that patients receive and we cannot assume that patients who seek healthcare are content for their information to be used in these ways."
*Confidentiality: NHS Code of Practice, p. 8, section 13*
· NHS organisations should have, or should be putting in place, systems and processes that will, over time, restrict the use and disclosure of confidential patient information to those activities that are directly concerned with or support patient healthcare.
Confidentiality: NHS Code of Practice, p. 29-30, section 6

DH Guidelines on Secondary Uses of Patient Information
· "The expectation should be that data for secondary uses are provided in unidentifiable (aggregated or anonymised) form except where specific justification can be made and approvals provided. Thus the default is the use of data which cannot be linked back to individuals. Where there is a need to

SAPIOR

ENABLING ETHICAL DATA SHARING
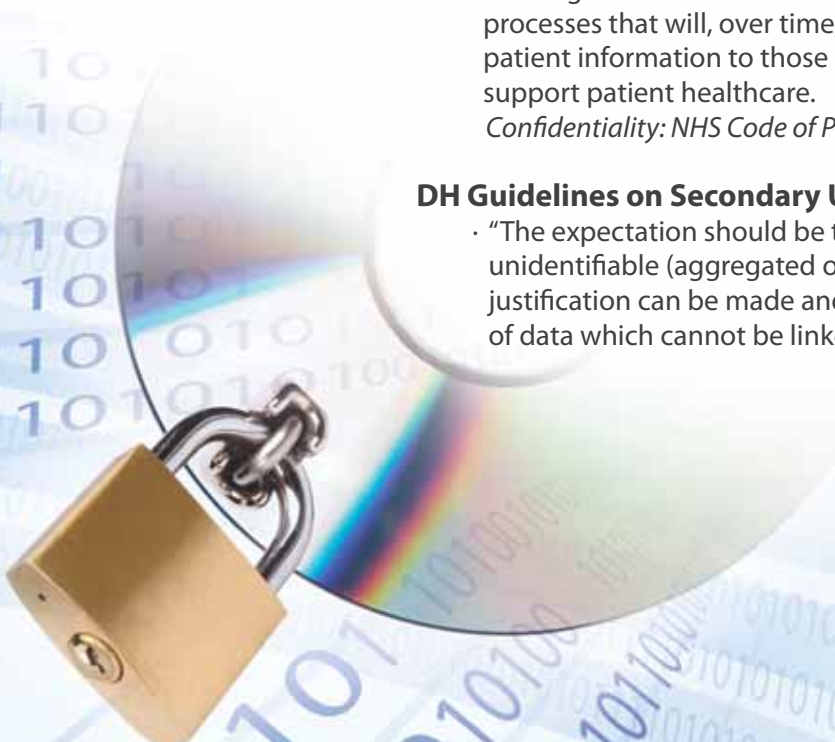
Examples of Secondary Uses of Data

Checking quality of care
· Testing the safety and effectiveness of new treatments and comparing the cost effectiveness and quality of treatments in use
· Comparative performance analysis across clinical networks
· Ensuring the needs of patients within special groups are being met
   - e.g. Children at risk, chronically sick, frail and elderly

Managing NHS spending
· Data for Payment by Results
· Data for practice-based commissioning
· Data for payment of GPs through Quality Management Analysis Service (QMAS) – based around the aggregated Quality and Outcome Frame work (QOF) indicators

Managing the health service
· Capacity and demand planning
· Commissioning
· Data for Standards and Performance Monitoring
· Measuring and monitoring waiting times, in support of the 18 week target
· Agenda for Change
· Benchmarking
Report of the Care Record Development Board Working Group on the Secondary Uses of Patient Information, p. 6, fig. 1

link data from different data sets or over time, linked pseudonymised data should be used with the key to re-establishing identity not available to the researchers/users."
Care Record Development Board Working Group Report on the Secondary Uses of Patient Information, p.11-12

What is De-Identified data?
· "Effective anonymisation generally requires more than just the removal of name and address. Full postcode can identify individuals. NHS Number can be a strong identifier and other information, e.g. date of birth, can also serve as an identifier, particularly if looked at in combination with other data items."
Confidentiality: NHS Code of Practice, p. 29, footnote 12

P-Day is April 2009 – What should you do?
· "Prepare your organisation to set up a project for the local implementation of pseudonymisation. Outline guidance for the overall implementation of pseudonymisation is expected to be available towards the end of the first quarter of 2008, and will include the need for a local project."
DH, SUS IG Awareness Workshop Delegate Summary, p. 1

· A Pseudonymisation service is needed for potentially all secondary uses, including SUS, Local Service Providers and other NHS secondary use databases. The target date for Pseudonymisation implementation is April 2009."
DH, SUS IG Awareness Workshop Delegate Summary, p. 2

BIBLIOGRAPHY and ADDITIONAL READING
1. Confidentiality: NHS Code of Practice
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAnd
Guidance/DH_4069253

2. Care Record Guarantee
http://www.connectingforhealth.nhs.uk/nigb/crsguarantee/crs_guarantee.pdf

3. Care Record Development Board Working Group Report on the Secondary Uses of Patient Information
http://www.connectingforhealth.nhs.uk/crdb/workstreams/secusesreport.pdf

4. Patient Information Advisory Group (PIAG) Response: Report of the Care Record Development Board Working Group on the Secondary Uses of Patient Information
http://www.advisorybodies.doh.gov.uk/piag/piagresponse-CRDB-SUS.pdf

5. Use and Disclosure of Health Data, Information Commissioner's Office
http://www.ico.gov.uk/upload/documents/library/data_protection/practical_application/health
data-_use_and_disclosure001.pdf

6. SUS IG Awareness Workshop Delegate Summary
http://www.connectingforhealth.nhs.uk/systemsandservices/sus/SUS-IG.pdf