Sharing health and care records:
Designing IT systems around your local population’s needs

Information and technology for better health and care

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My personal position

• Excellent population health is based to a significant degree on good quality patient care.
• So what sort of sharing is necessary and sufficient to support direct care and meet legislative and common law duties?
• I am going to try and examine this requirement in some depth as a basis for discussion and learning.
Context

• A legitimate relationship between the clinician (A) and the identified individual patient (B) has been created
• The duty of care is being enacted with or without the physical presence of the patient (B)
• A patient record of the activity of clinician A about patient B is created to record the activity
• This is not a shared care or collaborative care scenario
• The clinician requires additional information in order to make a decision
Level 0

• Summary Care Record; a great resource with even greater potential
• Single source of the truth (policy) from GP record
• Relies on sound communication to general practice, timely data transcription and upload from general practice
  – Structured data from clinical services would decrease GP practice workload
  – National Tariff Excluded Drugs (NTEs) need inclusion
• Summary Care Record with additional information
  – 1 in 17 people have a rare disease
• Simpler information governance arrangements
Level 1: Partial record access

- The clinician calls up the Record Locator Service and finds what records the patient possesses.
- Via Articles 6:1(f) and 9:2(h) of GDPR and implied consent to meet their CLDoC the clinician accesses the required provider record.
- The clinician is presented with the last 3 care transition documents [e.g. summary and/or letter on the patient].
- The clinician reads them and ideally can cut and paste the relevant data or copy the document into his/her provider record.
- If this information suffices then the clinician stops record access. If he/she requires any other summary/letter from another provider he/she continues until completion of record access or a decision to proceed to level 2.
Level 1: Partial record access

• Please note:
  – This fulfils the need for an accurate and contemporaneous record by a clinician for good clinical practice
  – It forms a sound artefact for complaint management, legal challenge and professional defence
  – The disseminating provider has an audit trail of the visit of clinician A and the data copied
  – The patient should be notified or have access to the audit trail of access to his/her record
  – The clinical access is proportional to their data protection responsibilities and professional duties
  – Any communication from clinician A should be available to the patient in near real time as a matter of normal practice: Exceptions are based on professional judgement. This is based on professional good practice and DH policy since 2004
Level 2: Full Record Access

- The clinician seeks explicit consent from the patient to access one or more full provider records. This can be done face to face or virtually via phone, email or an alternative digital mechanism.
- The clinician calls up the Record Locator Service and finds the relevant records.
- Via Articles 6 and 9 of GDPR and explicit consent to meet their CLDoC accesses the required provider record.
- The clinician is presented with the patient’s whole record.
- The clinician reads it and ideally can cut and paste the relevant data or copy one or more relevant documents into his/her provider record.
- If this information suffices then the clinician completes record access.
- If record access is followed by a decision the clinician communicates to the patient and relevant clinician(s) and the patient has a copy of that communication. (Please note the clinician may simply progress to a consultation that is wider than purely record access and decision making on that record.)
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Possible Future

- There is a view that clinical care could be improved by the use of artificial intelligence [Big data analytics, algorithms and machine learning] being applied to every record on a given individual such that all health and social care records are:
  - Collected, and linked in a data repository
  - The clinician asks questions of an individual patient’s linked record
  - The technology answers those questions and/or presents the data in answer to those questions

- If such a trial demonstrated better clinical and cost effectiveness with no decrease in patient safety then there would be a case for whole record sharing and mass linkage for each individual citizen and a review of what is currently deemed the minimum necessary information for good quality direct care
What about population health on a national scale?

• For Direct Care there are three questions
  – Should data be shared nationally?
    ▪ My view is “yes”; there are 8 major use cases in favour
  – Are there sufficient safeguards in place?
    ▪ My view is that in combination to the answer to the next question the answer is yes if sound standards are implemented then there are at least 12 organisational and technical constraints in place
  – Should it be whole records or partial records?
    ▪ The supported cases for prospective whole record sharing are: GP to GP record sharing; patient held records; shared or collaborative care and ad hoc scenarios
    ▪ Case against is, it is not recommended by regulators, NICE, professional bodies, ICO, and there may be a down side; medical litigation, speed of decision making. Need for research