Shared records: a literature review

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Aims of the literature review

To inform Connecting for Health / Royal College of General Practitioner guidelines on shared records by:

1. Identifying and mapping topics of importance to health (cf. technical) professionals
2. Distinguishing evidence from other literature
3. Identifying important evidence gaps to guide research
Define scope & key issues

Identify sources, search strategies

Search

Appraise & collate

Map against key issues

Formulate recommendations by issue, consult

Survey, other activities

Appraisal criteria for the type of study

Synthesise by issue & type of evidence
## Results: numbers

<table>
<thead>
<tr>
<th>Stage</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Database search + hard copies + grey literature</td>
<td>936</td>
</tr>
<tr>
<td>Abstracts screened for relevance</td>
<td>587</td>
</tr>
<tr>
<td>After documents on patient sharing removed</td>
<td>527</td>
</tr>
<tr>
<td>Total no. of documents obtained</td>
<td>450</td>
</tr>
<tr>
<td>Included &amp; mapped by key issue</td>
<td>256</td>
</tr>
<tr>
<td>After exclusion of out of scope</td>
<td>202</td>
</tr>
<tr>
<td>Saturation reached (no new issues) after</td>
<td>142</td>
</tr>
</tbody>
</table>

### Exclusions:
- Out of scope (eg. record sharing with patients, technical documents)
- International not UK legislation
- Not eligible after critical appraisal (194 documents)
### No. of documents, by issue & document type

<table>
<thead>
<tr>
<th>Issue Description</th>
<th>Evidence</th>
<th>Theory</th>
<th>Law &amp; regs</th>
<th>Technical</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Data, record sharing benefits</td>
<td>12</td>
<td>18</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2. Preserving privacy while sharing</td>
<td>8</td>
<td>9</td>
<td>9</td>
<td>-</td>
</tr>
<tr>
<td>3. Getting, managing permissions to access data in a shared record</td>
<td>13</td>
<td>16</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>4. Organisation &amp; labelling of data in a shared record (+ Headings, tbc)</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>5. Meaning / interpretation / semantics of data in a shared record</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>7. Responding to significant data in a shared record</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Data or record quality, validity, maintenance</td>
<td>18</td>
<td>13</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>9. Record preservation, deletion</td>
<td>4</td>
<td>10</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td>10. Knowledge &amp; training needs</td>
<td>20</td>
<td>8</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td><strong>Unique documents</strong></td>
<td>49</td>
<td>62</td>
<td>23</td>
<td>8</td>
</tr>
</tbody>
</table>

### Key to cell colours:

- < 5
- 5-10
- 11+
Results of literature review
Benefits of data & record sharing

Weak evidence that sharing:
- Promotes integration, patient focussed care
- Improves quality and cost effectiveness
- Enhances organisational capacity for continuous quality improvement
- Improves accessibility of healthcare to all sectors of public
- Enhances patient safety

Benefits depend on:
- Data quality (completeness and correctness)
- Correct data Interpretation by professionals
- Clear organisation of data within the record
- Minimising unauthorised access
- Ability to respond to new, clinically significant data
- Clear responsibilities for data capture
What does “weak evidence” mean?

Good evidence of a weak effect (eg. tamoxifen increases survival in early breast cancer by 5%)

Weak evidence of an effect (eg. no randomised trial of shared record impact on patient outcomes)

These are not the same !!!

We need more good quality studies on shared records
Shared records as a core infrastructure for clinical systems

Strong evidence for patient benefit from these systems in randomised trials & systematic reviews (Garg, Bates, Walton...)

Doctor  Nurse  AHP  Patient

Shared patient record

Order entry  Alerts  Reminders  ePrescribing
Barriers to data & record sharing
Disruption of workflow

Bedside computers saved nurses 25% of documentation time, but increased physician documentation time by 2-4 times [compared to dictation ?]

Source: systematic review by Poissant et al, JAMIA 2005
Preserving privacy in shared records

- **Shared patient record**
  - Data about urinary tract infection
  - Data about sexually transmitted disease

**Authorisation to view**
- **partial** record
- **entire** record

**Responsible clinician 1**
- Confusion about whether STD history can be mentioned

**Responsible clinician 2**

**Patient**
Organisation of data items in a shared record

Shared patient record

- Data about patient’s UTI
  Responsible clinician 1

- Current infections
  Responsible clinician 2

- No data

- Current problems
  ??
Meaning & semantics

GP environment
- GP training & experience
  - Meaning of “problem”
  - Meaning of “anxiety”

GP

Examines Mrs Smith

Enters “problem = anxiety”

GP record problem field:
Read code for “anxiety”

Real world
- Shared training
  - Guidance on anxiety

Mrs Smith

Read to DSM4 code translator

CPN environment
- CPN training & experience
  - Meaning of “anxiety”
  - Meaning of “problem”

CPN

Decision

Views “problem = anxiety”

CPN record problem field:
DSM4 code for “anxiety”

Shared patient record
Responding to significant data

1. Contact patient’s GP
2. Assess significance of data item
3. Take any actions needed

Lab record
- New data item
  - Add lab data item to shared record

GP records
- Shared records

Shared records
- Lab data
  - GP record
Responding to significant data in shared record

Audit of access to clinically significant results following introduction of computer to replace telephone calls about laboratory data to the accident & emergency:

- 45% of urgent results from A&E and 29% from admissions ward never accessed before patient discharged

- In 3% of tests, results that would have led to an immediate change in patient management never seen

Data quality issues in shared records

- Responsible Clinician
- NHS informatics specialist
- Laboratory computer
- Hepatitis serology results
- Rubella serology results
- Shared Patient Record
- Laboratory Results – Viral serology section

Confusion over HBsAg, ARAbS, HbA1C etc.
Guidance on record retention

<table>
<thead>
<tr>
<th>Type of record</th>
<th>Recommended retention period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper maternity records</td>
<td>25 years</td>
</tr>
<tr>
<td>Paper records on children &amp; young people (inc. paediatric, vaccination and</td>
<td>Until pt’s 25th birthday, or 26th if entry made when person was 17; or 10 yrs after death of</td>
</tr>
<tr>
<td>community child health records)</td>
<td>patient, if sooner</td>
</tr>
<tr>
<td>Paper records on persons receiving treatment for mental disorder within</td>
<td>20 years after no further treatment is considered necessary, or 10 years after patient’s</td>
</tr>
<tr>
<td>meaning of Mental Health Act 1983</td>
<td>death if sooner</td>
</tr>
<tr>
<td>Paper records relating to those serving HM Armed Forces</td>
<td>Not to be destroyed</td>
</tr>
<tr>
<td>Paper records relating to those serving a prison sentence</td>
<td>Not to be destroyed</td>
</tr>
<tr>
<td>All other paper personal health records</td>
<td>10 years after conclusion of treatment, death or the date patient permanently left the country</td>
</tr>
<tr>
<td>All electronic records and audit trails of access to these records</td>
<td>Not to be destroyed (RCGP / Information Commissioner advice)</td>
</tr>
</tbody>
</table>

Summary of HSC 1998/217: Preservation, Retention and Destruction of GP General Medical Services records relating to patients
Record retention

General guidance on record retention

Notice of patient demise

“Delete my part of the record”

Data about UTI in 1986

Under control of clinician 1

Data about cancer in 1986

“No, retain the entire record”

Responsible clinician 1

Responsible clinician 2

Guidance on cancer record retention

Shared patient record
Evidence: factors that encourage learning about EPR:

1. Time to learn and adapt to use of shared patient records
2. Amount of data to be managed
3. Standards for data quality required from each professional
4. Willingness to use & share records with other professionals, previous use of clinical systems
5. Financial benefits / penalties to professional and/or organisation

Health Professional 1 → Enters high quality patient data → Shared Patient Record → Correctly interprets data → Improved patient care → Health Professional 2
Barriers to training

Lack of confidence in use of systems

Lack of resources
• A large proportion of practices hardly used the computers present in their practices

Willingness to use systems

Health informatics in the undergraduate curriculum
• Systematic review of primary care computing articles published 1980-97: health professionals viewed training programmes then available as poor

Summary: key issues found

- The benefits of data and record sharing
- The rational and methods for preserving privacy
- Organisation and labelling of data items in records
- Meaning, interpretation and semantics of data across professions and organisations
- Responding to significant data in shared record
- Data or record quality and validity
- Record preservation and deletion
- Knowledge and training needs of professionals
Conclusion

• Appropriate sharing of medical information with colleagues is an important aspect of General Practice
• The potential benefits of sharing information are enormous
• However, without adequate safeguards, so is the potential for misuse, error and mistrust
• Professional guidance & education are key - published on RCGP site 18-8-09:

www.rcgp.org.uk/get_involved/informatics_group/shared_record_professional_guidance.aspx
Knowledge and training needs of professionals

Issues arising from the evidence:

- Varying degrees of competence and IT skills among HCPs
- Need for developing understanding of wider context of data use.
- GPs not fully aware of safety features of computer systems - lack of training
- Healthcare staff had limited awareness of policies in general practice regarding data sharing
- Practices found to be very dependent on external technical support
- IT skills varied highly between general practices – affluent vs. deprived areas
- The majority of NHS professional staff require education and training in almost all Health Informatics topics

1. Delivering 21st Century IT Support for the NHS: Department of Health National Strategic Programme, 2002
Getting and managing permissions to access data

Providing access to health or other professionals to the record based on explicit or implicit consent, according to:

- The professional’s individual or organisational role during a specific time and place
- Their relationship with the patient, length of access rights and the content of the data requested
- Legal or professional recommendations on access to patient data.

Access during emergency situations:
- Emergency override in such situations, safeguarding the subsequent availability of the information after the emergency episode

Problems: Case studies of systems using shared patient records have found that the design of the access control system is complex and not easy to implement or maintain in a real life environment.

Solution: Developing structured access control policies by involving all the users and patient representatives: health professionals, patients and non-clinical staff.
Review process

1. Clarify scope with RCGP group
2. Solicit relevant material from members of project team
3. Search relevant databases
4. Carry out preliminary assessment from abstract
5. Gain overview in shifting from single to shared records
6. Detailed assessment of eligibility by critical appraisal
7. Synthesise under headings: evidence, guidance, legal
8. Summarise main issues under each topic