



## Lifelong health records - who needs them?

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## Issues with health records

- Patient identity?
- Complete? Correct? Accessible? Trustworthy?
- Information overload?
- No common structure
- Information Technologies evolve
- No universal language or terminology
- Medical knowledge expands
- Professional accountability

Delegates at The British Medical Association's Local Medical Committees' conference (June 2005) decided that patient care would **NOT** "benefit from the safe sharing of electronic information across the NHS"

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## Why?

- A politically motivated statement?
- Genuine concerns about patient safety?
- Patient Records are a clinician's "working notes" more than their "published paper"?
- Focus only on information useful and relevant for their main task - diagnose and treat?

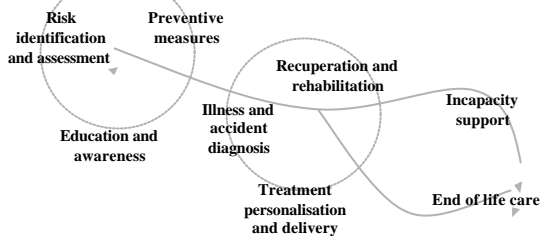
"It's a bit like having a full service history for a car. Nice to have if you're buying the car ... but it doesn't prove anything about the current health of the car. And if I have a flat tyre, I can see I have a flat tyre and I need it fixed ..."

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## The continuum of welfare and healthcare



Before the event

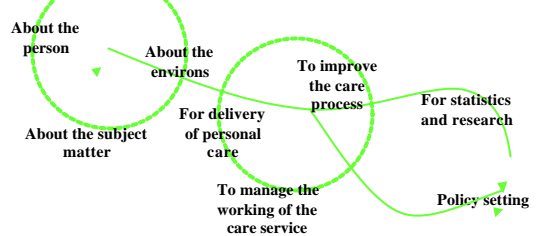
After the event

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## The continuum of information



Knowledge capture

Tactical use

Strategic use

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## The core issue?

- A typical patient record often omits:
  - links to causal factors - especially psycho-social
  - unreported, undiagnosed and unrecognised conditions
  - diagnosis accuracy assessment
  - rationale for treatment regime decision
  - treatment compliance
  - treatment regime outcomes
  - treatment effectiveness assessment
  - links to social care follow-up

“A person-centric lifelong electronic ‘daybook’ that only records encounters with welfare and healthcare professional neither hold all the information needed to manage the patient’s wellbeing nor that needed to make significant contribution to the nation’s.”

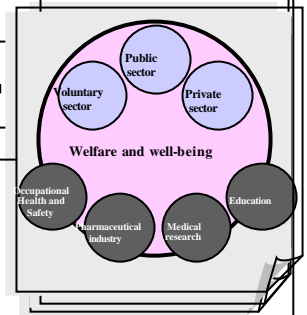
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## What do we need?

- Better data capture
- Better collation and consolidation of available data
- Knowledge sharing
- Recognition that person-centric healthcare and welfare data are a vital part of the whole, but not THE whole.



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## Vision or reality?

- Actual UK progress in coordinated Health and Social care Services
  - Welsh Assembly Government
  - Medway Unitary Authority
  - Northern Ireland
- Government “white paper” designed to deliver integrated health and social care systems announced by Care Services Minister, Liam Byrne
- Commitment from UK Government “to set up a ‘virtual’ social care information initiative to look at information sources and ensure that it can be readily available to support policy development, practice improvement and performance management.”

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## Summary

- Knowledge sharing not information blizzard
  - across the whole stakeholder community
  - the gain must exceed the pain at every granularity
- Legal, moral and ethical issues
  - are changes necessary?
- Education, awareness and training
  - rights and obligations
  - using technology
  - interpreting information
- Think big, but start small
- Cross-service and cross-discipline

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