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Newcastle University Business School

Beyond Medical Data: A personal view from England

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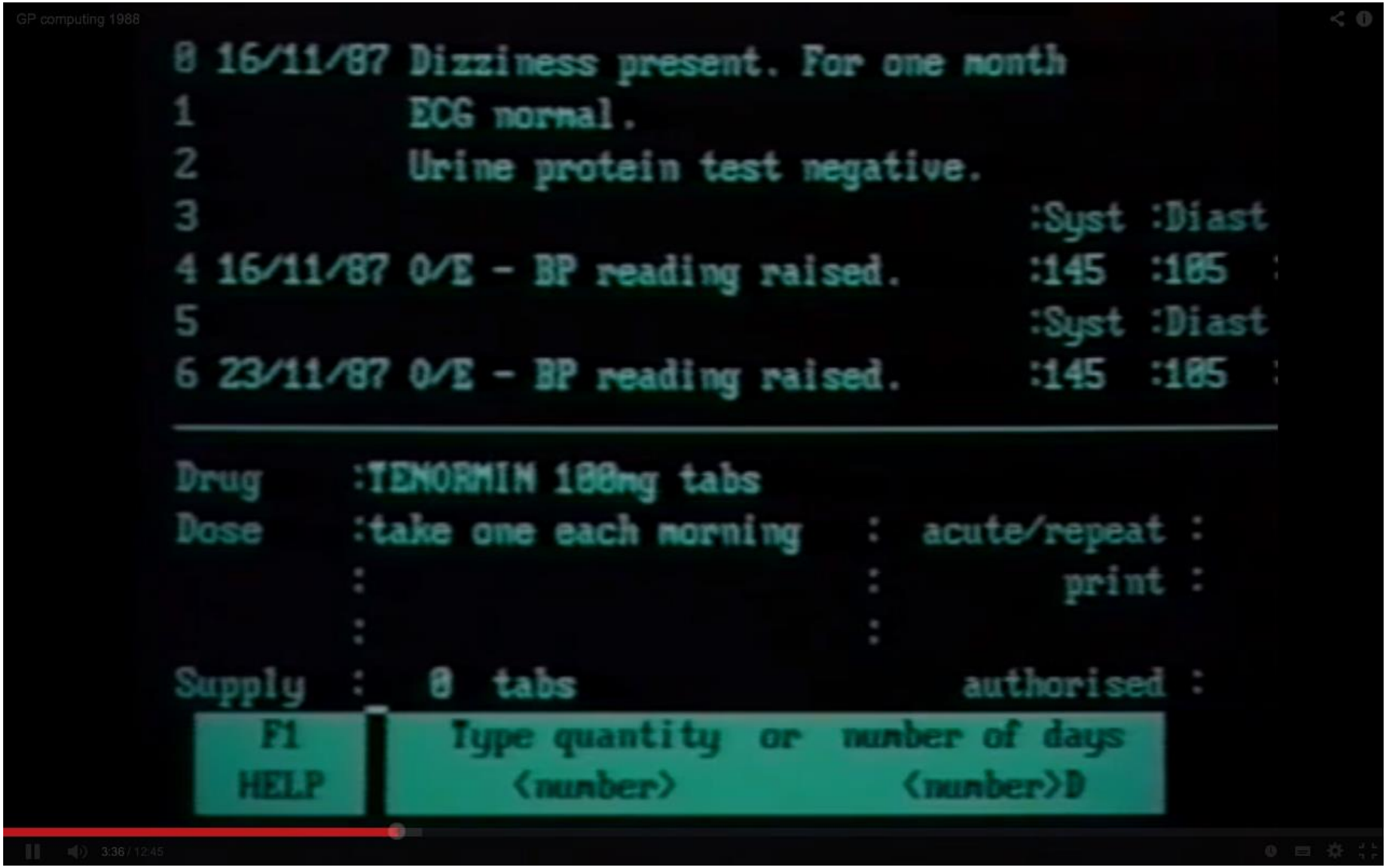
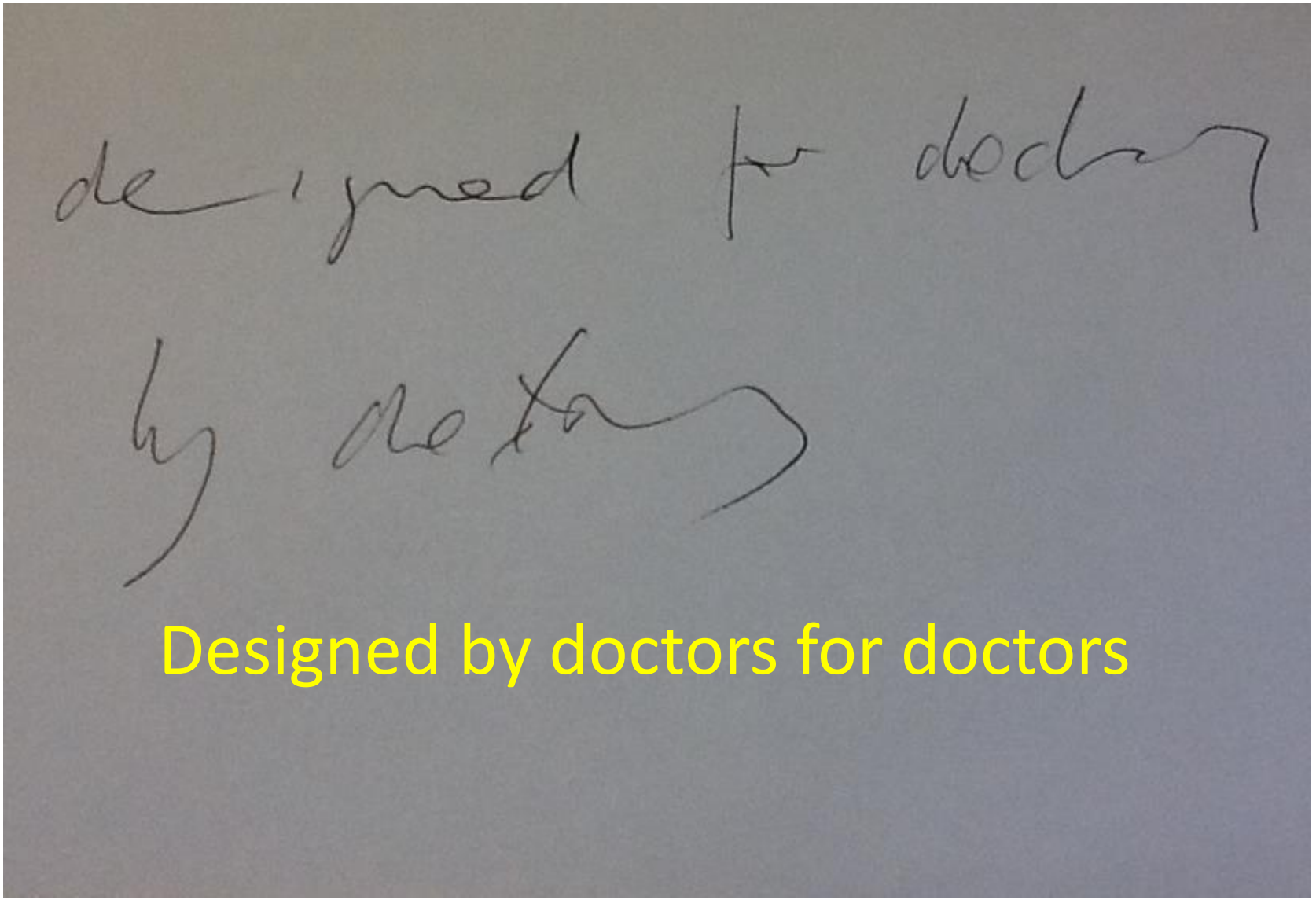
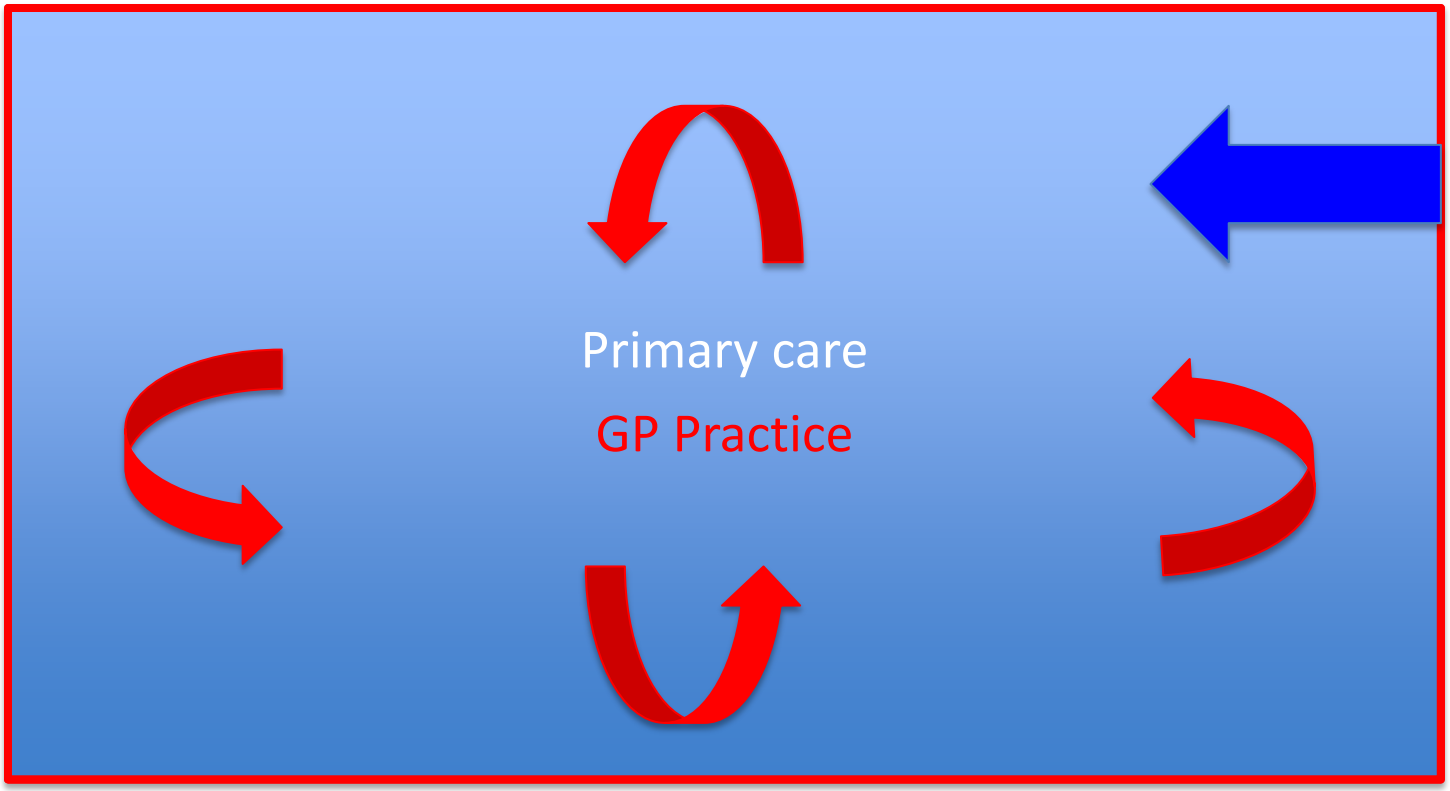
General Practitioner

- Terminology
- Decision Support
- Health Architecture
- Consultation Dynamics
- English National Programme for IT
- English Department of Health
- Health and Social Care Information Centre

Cottage Industry Electronic Record




Designed by doctors for doctors


Primary care
GP Practice

The NHS in 1990s

- Paper communication
- Most care delivered by personal GP
- GP record from Cradle to Grave

Durham and Darlington EHR (2001)

- State of hospital EHR
  - Prime purpose fiscal/scheduling/performance/targets
  - Reporting statistics
  - Coding teams culled data from paper records for secondary use
  - Clinical records sparse
  - Based on single episodes
  - Not much interest in history
- Ethnographic study
- First ideas about summaries feeding a derived health record from multiple organisational documents
- And *federation*
- Conviction that EHRs must ***reduce*** work in seeing, recording and reusing information
- And save time!

2003: English National Programme for IT

- 4 super-regions
- Single system?
- National infrastructure
- Regional builds
- Top down integration
- Control clinicians?
- “Toxic Diversity” of the NHS

The degree of success of this programme has been written about extensively

2009: The big clinical issues

- Lack of appropriate user involvement in design
- Poor understanding of clinical content
  - Insufficient coherent business logic across hospital sites
- Flawed implementation of information / technical standards
  - Poor understanding of the nature of medical data
- Coding/ontologies/vocabularies incompatible
  - No coded information being sent to GP systems
  - No need therefore to embrace SNOMED-CT
  - No transformation of collection of hospital data

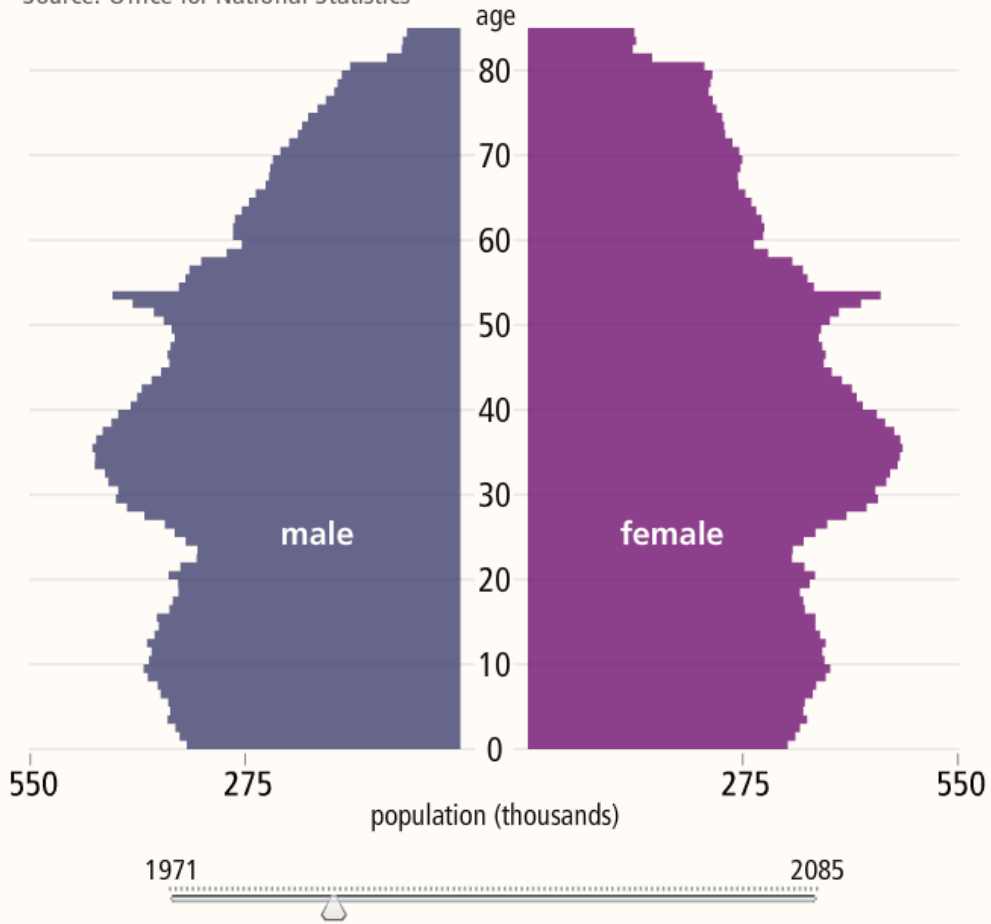
2014: New reality

- Demographic reality of ageing for health and social care
  - Life expectancy is increasing
  - Older people with multiple and complex conditions will be expensive to care for
  - Shift of care closer to home seems inevitable consequence
  - Multiple care professionals from multiple organizations will be involved in care
  - Care will be a mixture of programmed care and unplanned care
  - Self care and co-production

Age Structure of

United Kingdom, 1971-2085

Source: Office for National Statistics



2000

58.9 million people

ANIMATION

play loop

slow fast

ready

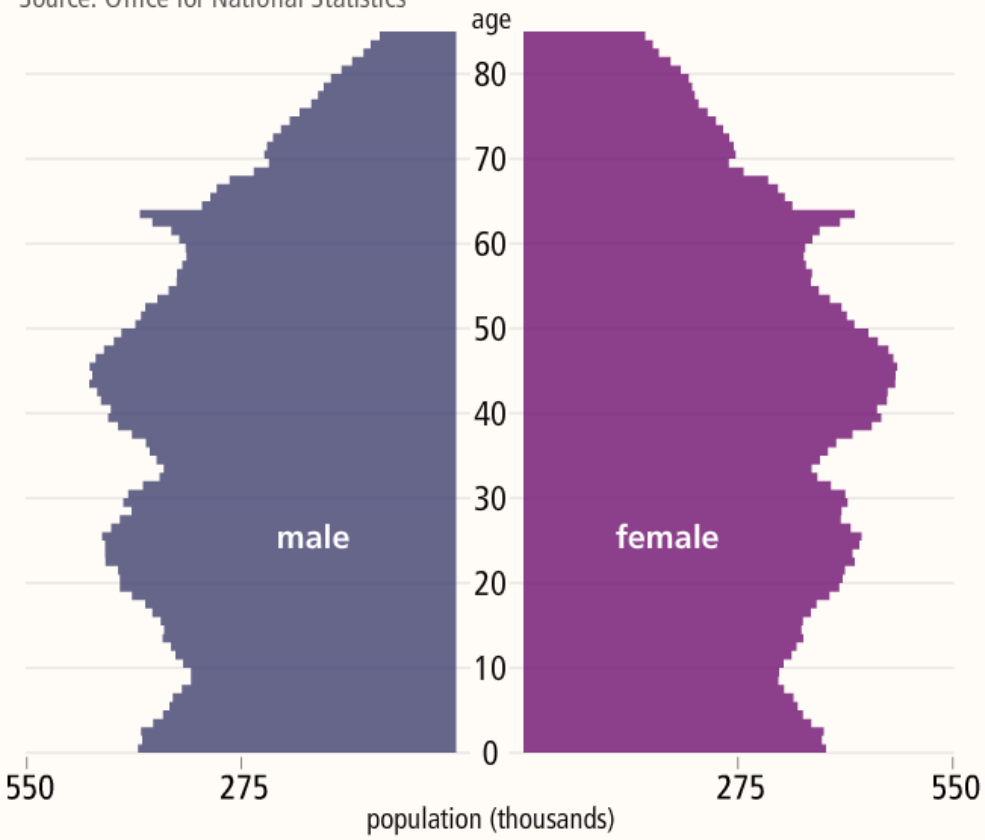
mouseover the graph for individual age band data

graphic by ONS Data Visualisation Centre

Age Structure of

United Kingdom, 1971-2085

Source: Office for National Statistics



2010

62.3 million people

ANIMATION

play

loop

slow

fast

1971

2085

ready

mouseover the graph for individual age band data

graphic by ONS Data Visualisation Centre

Age Structure of

United Kingdom, 1971-2085

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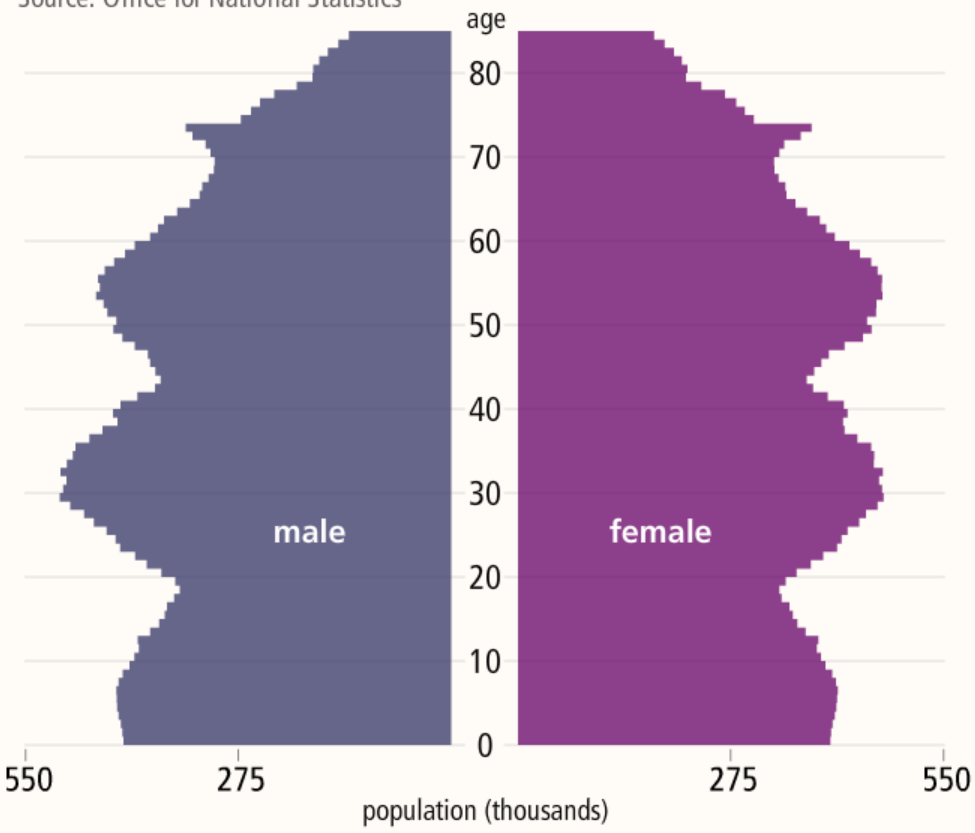


2020

67.2 million people

ANIMATION

play loop

slow fast

1971 2085

ready

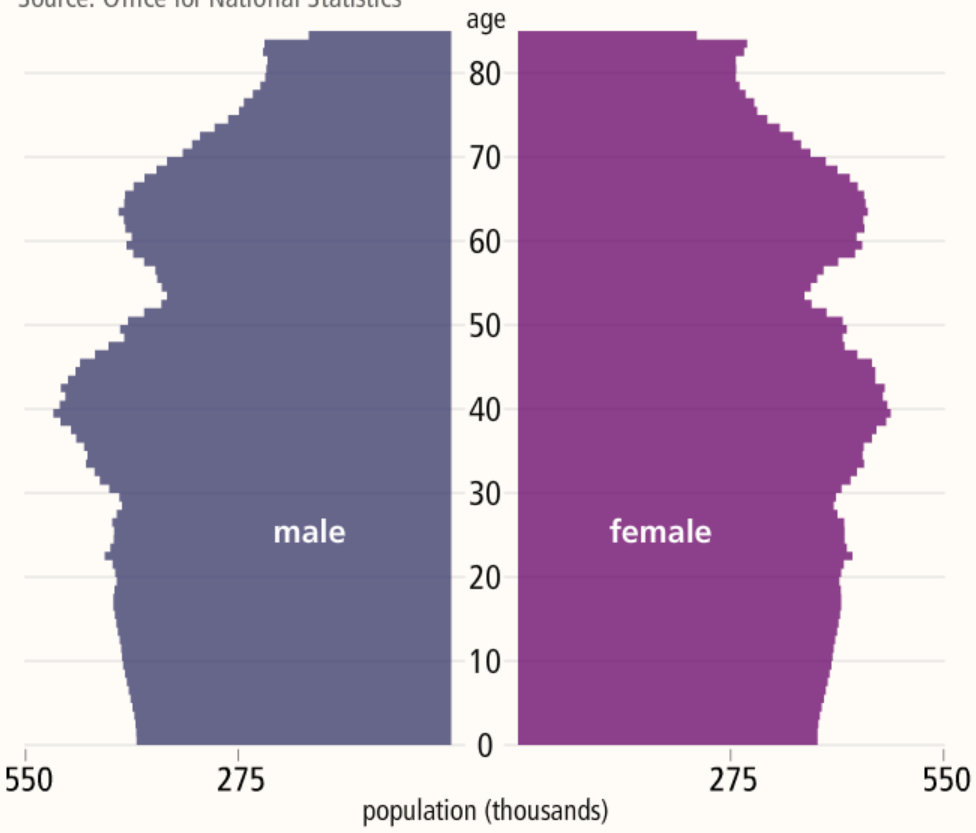
mouseover the graph for individual age band data

graphic by ONS Data Visualisation Centre

Age Structure of

United Kingdom, 1971-2085

Source: Office for National Statistics



2030

71.4 million people

ANIMATION

play loop

slow fast

1971 2085

ready

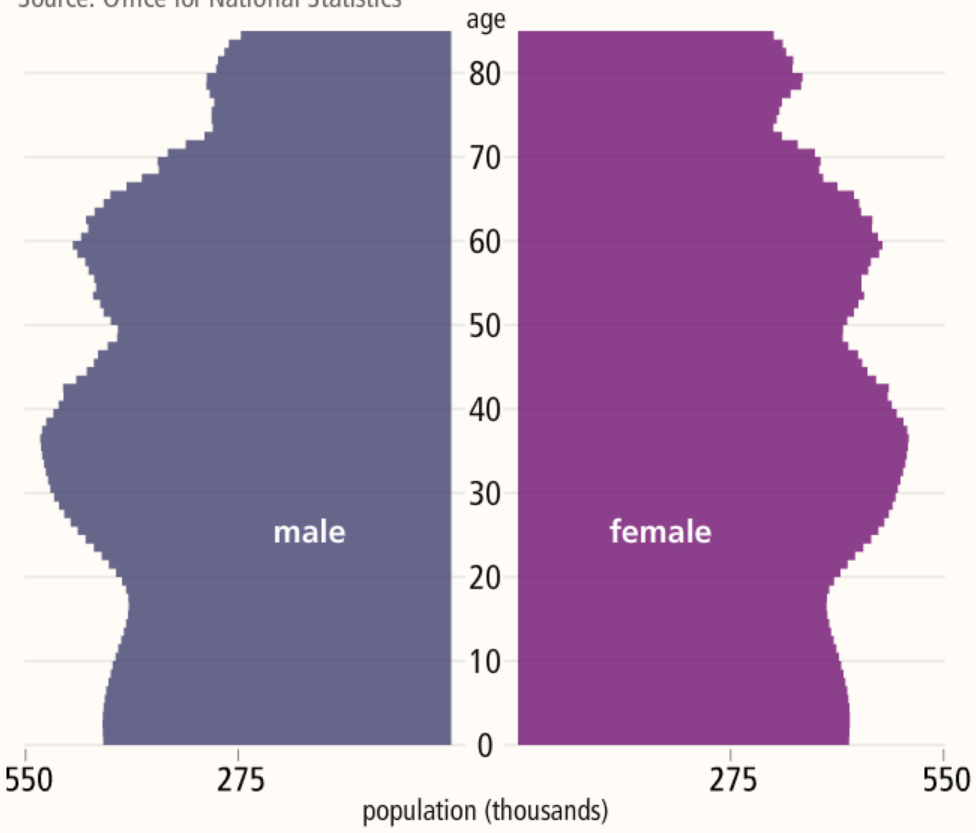
mouseover the graph for individual age band data

graphic by ONS Data Visualisation Centre

Age Structure of

United Kingdom, 1971-2085

Source: Office for National Statistics



2050

78.4 million people

ANIMATION

play | loop

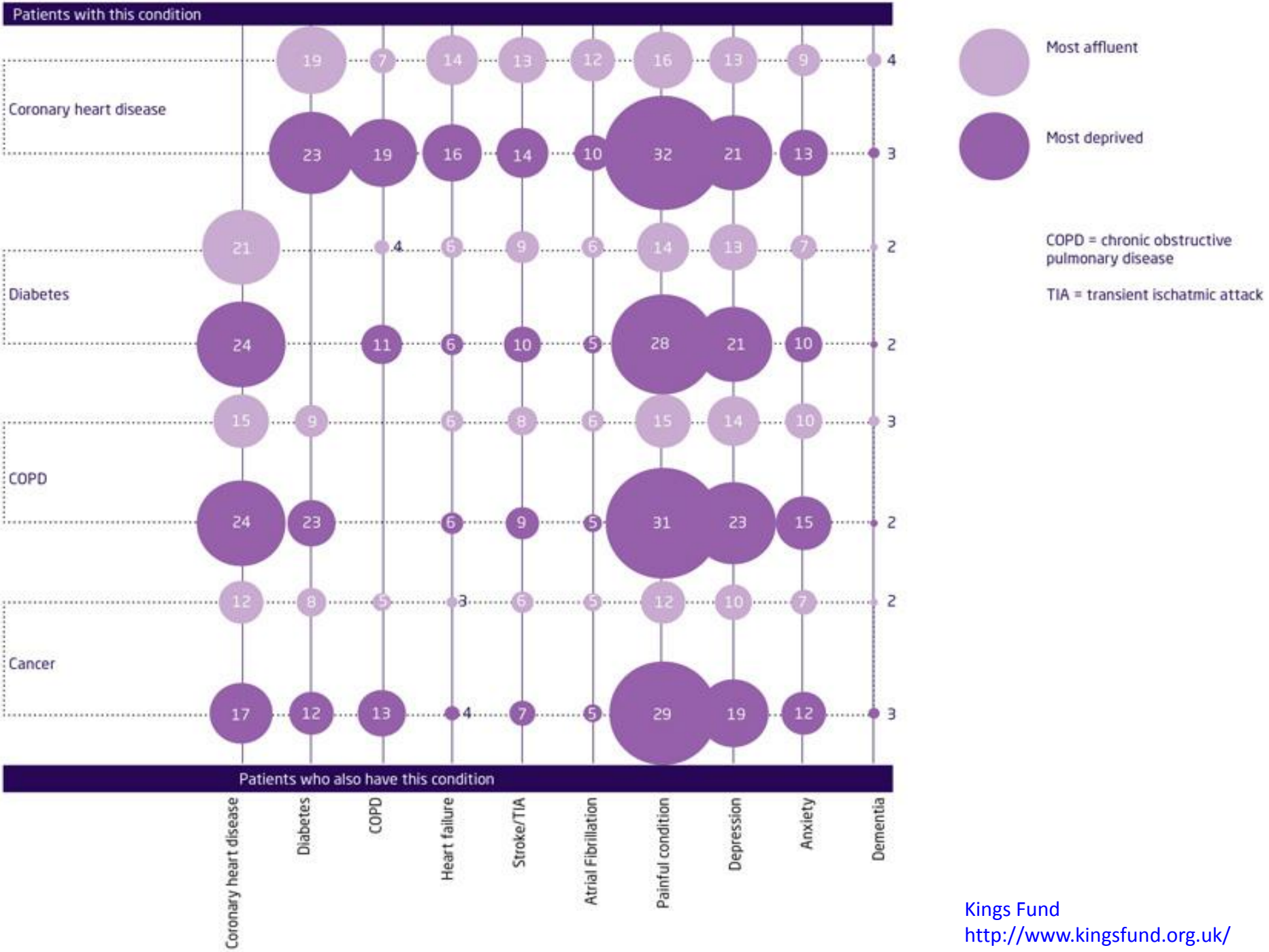
slow fast

1971 2085

ready

mouseover the graph for individual age band data

graphic by ONS Data Visualisation Centre



Kings Fund
http://www.kingsfund.org.uk/

Other certainties of life

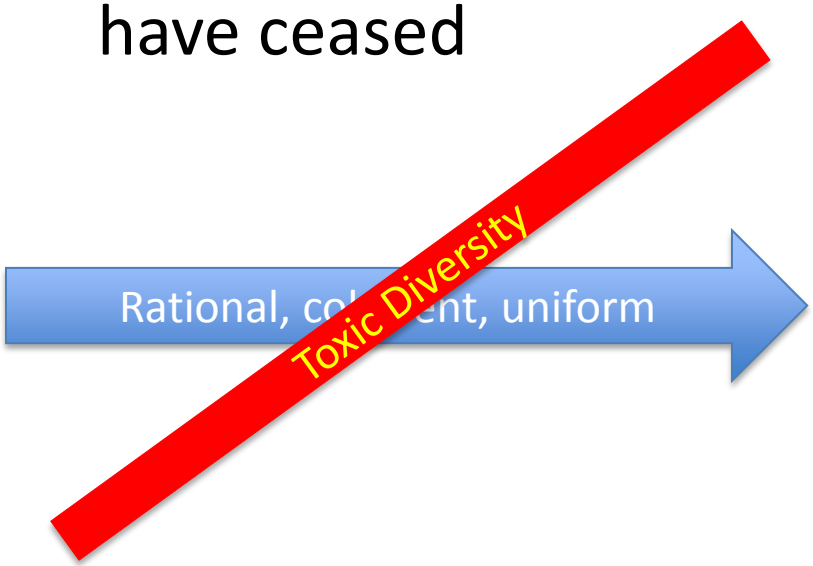
- NHS and Social Care re-organisation will not stop
- Boundaries will shift at least every 5 years
- Experiments in single systems for all did not work

Records must be patient-centred and fed from multiple organisations

  - In Health and Social Care

In other words

- an abandonment of top-down control of design
- national decrees of where lines are drawn have ceased



LOCAL CARE COMMUNITY

Primary care MINE	Secondary care YOURS
Social care THEIRS	Third sector WHO?
Commercial care organizations ????	

And this is the habitat of an elderly patient close to home with multiple conditions

The integrationist view is no more

What other views are there?

- The Universalist view…
  - The web…
  - Joins everyone up


Primary care
MINE
Secondary
Primary care
MINE
Primary care
MINE
Secondary
YOURS
Social care
THEIRS
Third sector
WHO?
Social care
THEIRS
Commercial
EVERYONE CAN SPEAK TO EVERYONE!
hird sector
WHO?
Openness accountability
transparency choice
personal involvement

Universalist view of information sharing

- Public information is public
- Factual information nothing to be ashamed of
- There are huge dividends in analysis of NHS data resources

Is this true of health?

Are most people comfortable with data sharing with universalist governance?

Are most people in H+SC trustworthy?

- Yes – but how many does it take to upset the applecart?

The Third Way
- *Federation*

- Still a place for boundaries and control
- Still a place for web and universalism
- Also a place for federation
  - "My" integration
  - And "your" integration

  …must coordinate
  - ***IN THE INTERESTS OF THE PATIENT***

“Middleware”

- *Aka* Hubs, Enterprise Service Bus, orchestrators…
- Can integrate at an organisational level
- Used extensively in hospital trusts
- Require policies and internal standards
- Shared infrastructure
  - Shared services, single sign on
- Enterprise architecture key to design

“My” + “Your” middleware

- Can become interoperable if we get “new middleware”
- Middleware which makes other middleware interoperable

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Registering Identities and issuing credentials.

- People and roles
- Physical Resources
- Documents.

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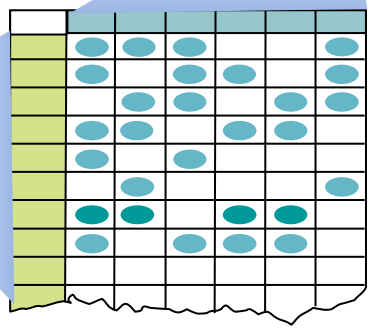
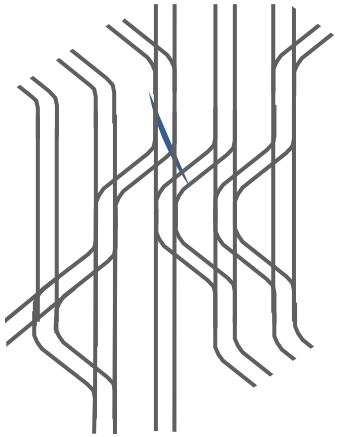
Service Identifiers

User Identifiers



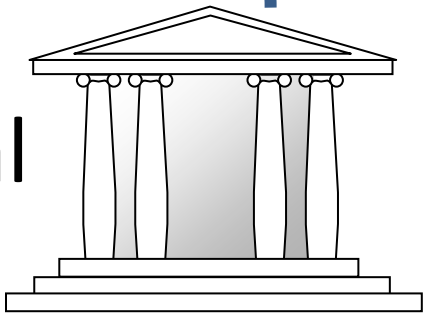
Registering and correlating relationships .

Hub



Switch

Portal



Marshalling and dispatching: Getting things to the right place, on time and in the right order.

Communicating, Publishing, Syndicating, Searching & Discovering.

A federated view of joining up systems

- Acts of summarization already happen when patients pass from one provider organisation to another
- Systems in hospitals and other provider organizations will have their own information models and “standard interfaces” for the foreseeable future
- Documents may become the currency for summarization and communication
- Interoperability of documents can be achieved:
  - Local health community
  - Groups of local health communities
  - Sub-region or region
  - More widely…

Logical Structure of Federated Health and Social Care

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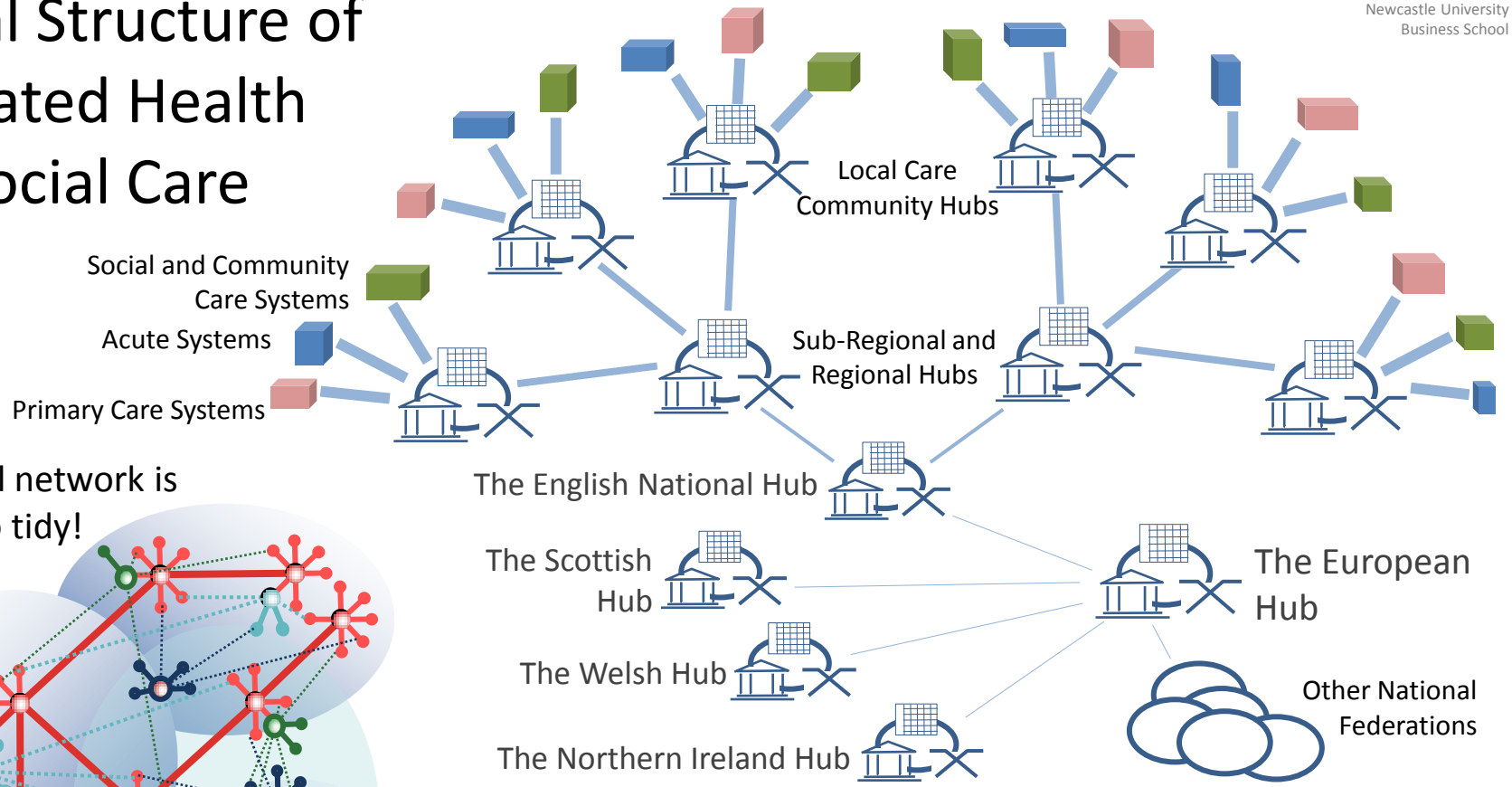
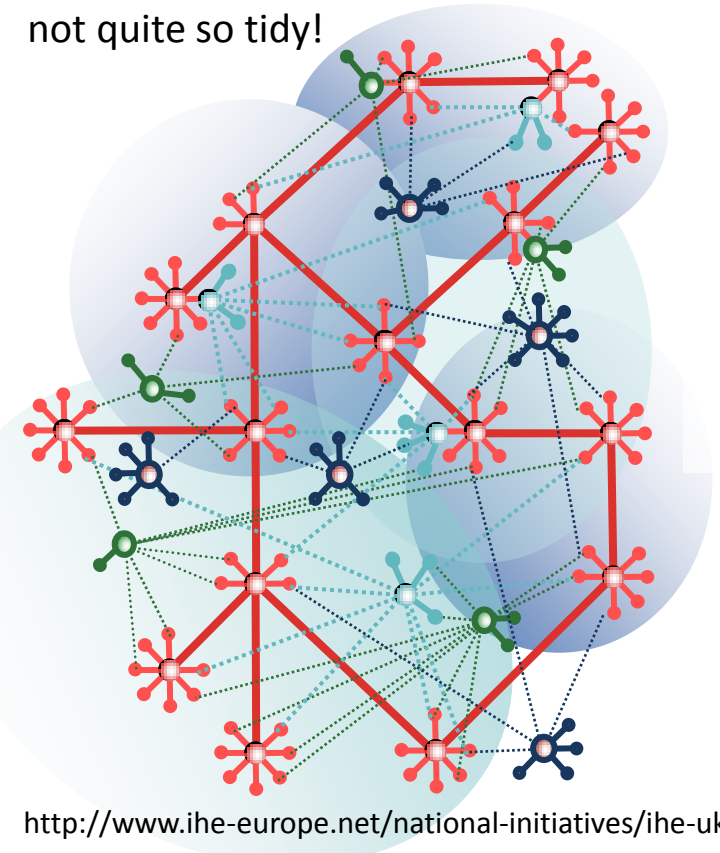


The physical network is not quite so tidy!



http://www.ihe-europe.net/national-initiatives/ihe-uk

This is *not* a hierarchy of control but a Federation Infrastructure operating under the principle of subsidiarity.

IHE Virtual Structures

Overlapping *Integrated Health Enterprise* Domains, such as Oncology Networks, Pharmacy and Laboratory support and Research Networks, etc. These are hosted across the physical network supported by the logical federation structures. *Hub, Spoke and Axle Architecture !*

Architecture for health and social care

- Care closer to home demands regional and sub-regional inter-operabilty across disparate organisational boundaries
- No structure for ownership at this level currently exists
  - *Answer will not come from the centre*
- Community needs to define and design the infrastructure
  - which platform services?
  - fully configurable permissions for sharing
    - By the patient or citizen?
  - …

My requirements for Long term care close to home

- Vendor agnostic infrastructure
- Regional or subregional coverage
- Federable to other regions/nationally/Europe wide
- Multiple organizations
- Suitable for needs of health care professionals
- Always shareable openly with patients
- Underpinned by patient or citizen consent
- Fed by documents created in any organisation (act of summarization)
  - Common core content
  - Professionally assured

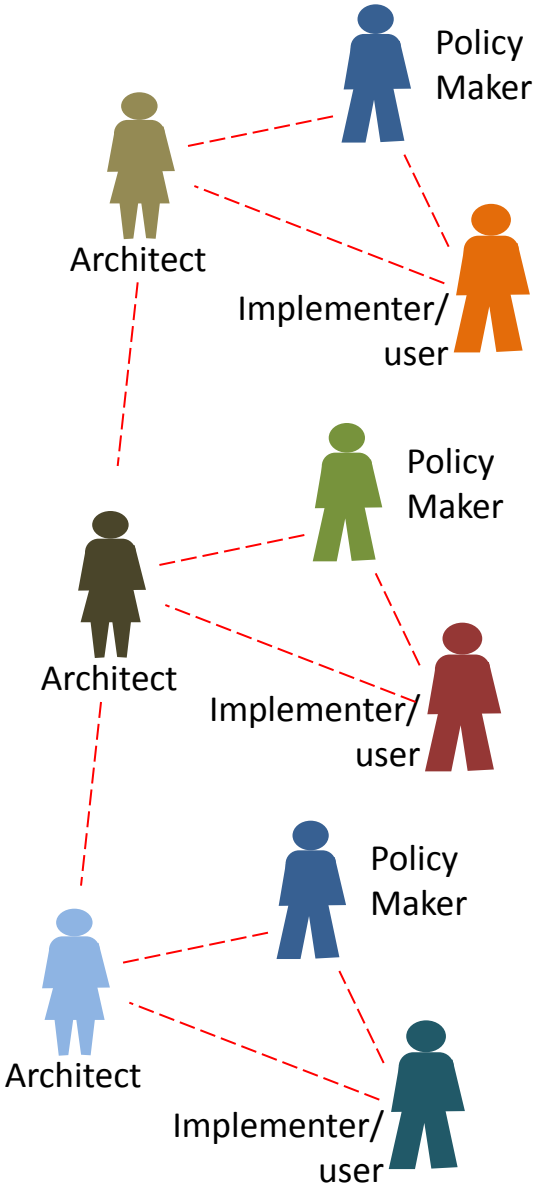
And finally we need better discourse

- Between clinicians and architects
  - In a more sophisticated working environment…

Care pathways

Clinical Information

Technical systems



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