

# Clinical Informatics and Data Visualisation: Rich Data Interfaces and The Electronic Patient Record

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## From Ambition to Reality with Clinical Informatics

- “There is a seismic shift in the way information can improve the experience, quality and outcomes of health and care services.....
- To achieve this, the health and social care system will need to maximise the use of technology so information can move more freely and securely around the system.
- The information strategy “The Power of Information” sets out a 10-year framework for transforming information for the NHS, public health and social care”.

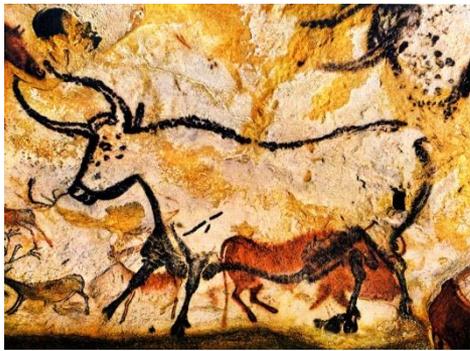
Department of Health: Informatics: The Future (July 2012)

# Realities: The view from the Clinical Coal Face (1)

- An expensive history of unfulfilled ambitions in Health Informatics over 30 years
- Health is a complex & heterogenous “informatics space”
- Interactions between health professionals & patients are infinitely nuanced, non-linear and difficult to capture in IT design
- Individual medical histories involve multiple clinical activities in serial & parallel over many decades
- Limited commercial & institutional effort has been put into clinical user research, needs & engagement

## Realities: The view from the Clinical Coal Face (2)

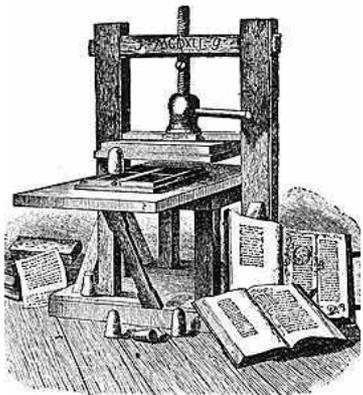
- Clinical Informatics uptake by compulsion (push) rather than user demand (pull)
- = Limited end-user “buy-in” to existing systems
- Huge risk & new forms of inefficiency!
- A recipe for misdirected public sector expenditure & institutional reputational upset



## The Design Challenge to improve the user experience



- The move from paper to electronic formats is as intellectually testing & transformative as from cave paintings -> papyrus -> paper -> printing
- The technical infrastructure now exists for the paperless workplace
- The screen experience for health care users remains primitive
- **The challenge is make the end user experience of clinical informatics both more compelling & more productive than paper**



# Key Public Sector Software System Design Principles (GDS 2010+)

- Start with a clear understanding of End User Needs; interviews, discovery process, hard data: the service provider or purchasing manager is not the end user.
- Do the hard work at the design & implementation stage to make the end user experience as simple & efficient as possible
- Iterate continuously (be Agile): there is always room for improvement
- Fail Early and Fail Fast
- Build Digital Services rather than web sites
- “Make things open - it makes things better”
- The end state is “Digital by Default”: effective & compelling

## The UK Health Sector Challenge

- NHS has yet to adopt GDS Principles
- Reliant upon dominant suppliers with products which have not been rigorously tested to health professional end user needs
- No “sandpits” for testing IT systems on real data & real users in clinical environments
- Badly implemented IT: 10-20% loss of daily staff efficiency?
- Well implemented IT: 10-20% Gain in efficiency on a £100 Billion+ budget?

# My Digital User Need Statement

- As a busy clinician, I need to be able to:
  - obtain a global and/or selective view of any case record
  - at any place and time
  - in the fastest, most efficient & effective manner
  - with linkage to any additional & relevant information systems which I may need to access
- In order to allow me to work as or more effectively, safely and efficiently than with paper records

(and noting that paper is a technology which has evolved over thousands of years to adapt to the human eye-brain-sensory interface)

## The Product: The “UHS Lifelines” Electronic Patient Record Interface

- Research as to available options to meet my user need = None in 2010
- Human Computer Interaction Laboratory (HCIL) University of Maryland Lifelines concept 1996 (For Maryland Dept of Criminal Correction)
- Agile team of three at UHS working pro bono = minimal cost
- To develop & implement a functional, timeline-structured EPR to meet the clinician user need within the legacy UHS Clinical Data Environment
- Achieved in 2011 with Regional NHS Innovations Award 2011
- Goes live in 2016 after rewrite in modern DotNet code with senior institutional buy-in

# The original HCIL Maryland Lifelines Concept 1996-97

In progress version of Lifeline Frame (not for demo purposes - Microsoft Internet Explorer - [Working Offline])

File Edit View Go Favorites Help

Back Links Best of the Web Channel Guide Customize Links Internet Explorer News Internet Start

**Linda Simpson**  
Female 40

Line from input file: %:3-10-1997,3-12-1997,black,p10,Sonogram,images/babysonogr

**Lifeline**

92 93 94 95 96 97

Notes: Tobacco, Depression, Lyme, Arthritis, Obesity, AtrialFlutter, Flu, Pneumonia, KneePain, Fatigue, Diabetes, Diabe, Pregnancy

Hosp.: Appendectomy, Pneumonia, KneeSurgery

Tests: BloodEKG, EKG, Xray, Blood, Blood, Blood, Sonogr

Meds.: Prozac, Heartdrug, Ventolyn, Antib., Advil, Advil, Insulin, Insulin

Others: PhysicalTherapy, LowSaltFatDiet

Immun.: TBtest, Tetanos, Flu

DATE: 5-18-88 PATIENT ID: [REDACTED] 17mm/3.8

**Lifeline Control Panel**

Layout Label

Default

Quick Compact

Slow Compact

Chronologically Ordered

Event Ordered

Apply OK Cancel

Warning: Applet Window



Human-  
Computer  
Interaction Lab

# The Transformative Power of Data Visualisation:



## Ben Shneiderman's design principles:

- Overview (of the entire data set or record)
- Zoom (in on detail of interest)
- Filter (out information which is not of immediate interest)

## Key Principles of the visually rich Lifeline Interface:

- The passage of time is central to all human activities
- The human brain is attuned to visual clues, movement, colour & icons
- Clinical events can be displayed in series or in parallel
- Navigation through the model in three dimensions (X, Y, Zoom)
- Infinitely expandable & adaptable

# UHS Lifelines Jan 2016 iteration: 2 year rolling view of a case history

[Show eDocs History](#)

[Show Results](#)

This patient is not currently registered on the The Southampton Breast Cancer Data System

[Click here to create new breast cancer patient record](#)

or [Click here to select a different patient](#)

## Patient-LifeTrak



# UHS Lifelines: The Key Features

- A “whole of life” descriptive tool for every clinical record
- Real time global electronic information access for every UHS patient
- Immediate reading of the clinical history from the icons & metadata
- Click through functionality to individual documents & reports
  
- A transformative tool for clinical information access
- A testbed for the transition to paperless working
- Highly intuitive for clinical & administrative staff
- An EPR interface with potential for universal application
- For Primary, Secondary (Hospital), Social Care
- With potential for academic & research exploitation



# The Southampton (Breast) Cancer Data System

## Exploitation of UHS Lifelines



- Requirement to develop a scalable & flexible data system for 12,000+ legacy card index & electronic records with continuous case & data accrual
- Exploiting UHS Lifelines & maximising data visualisation tools
- Introducing the UHS LifeTrak as a descriptor of any clinical journey from diagnosis to the present/final outcome
- Maximising data feeds from the UHS Clinical Data Environment
- Allowing a range of reports & data analyses
- Acting a generic test bed for a universal tool to describe the “whole of life”, episode structured course of any chronic disease of child- or adult-hood

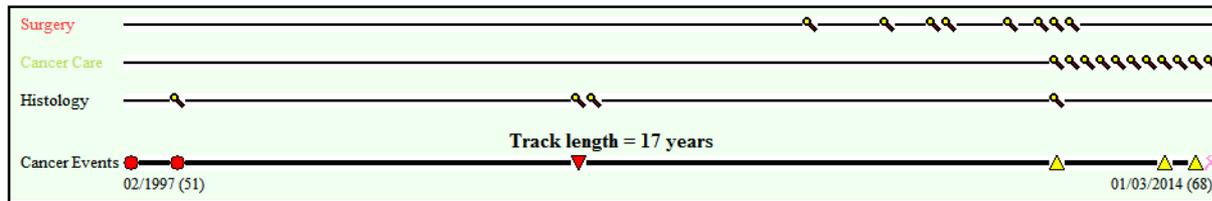
# Southampton Breast Cancer Data System: Individual Patient Record Screen

The Southampton Breast Cancer Data System Data Entry - Total Records = 16734  
Welcome Cara Campbell you have Read-only access

Hospital number	NHS number
Name	Address
Date of birth	Date of death
Registered GP	GP practice

(1) Demographic

## Cancer-Lifetrak



2.) Timeline

[Show eDocs History](#) [Show Results](#) **Cancer Record Exists** referral source not recorded [x-GTR\\_DB](#) Record Status

3.) Administrative and Cause of Death

Notes of Special Interest  Known DOD

Patient death confirmed  Get notes  Notes checked  Referral Type

Likelihood of breast cancer as COD  [Info](#)

## Breast Cancer Treatment Episodes

Treatment episode sequence 1st

Month/year of diagnosis   (MM / YYYY) Main location of treatment

Disease presentation  Responsible consultant

Treatment episode sequence 2nd

Month/year of diagnosis   (MM / YYYY) Main location of treatment

Disease presentation  Responsible consultant

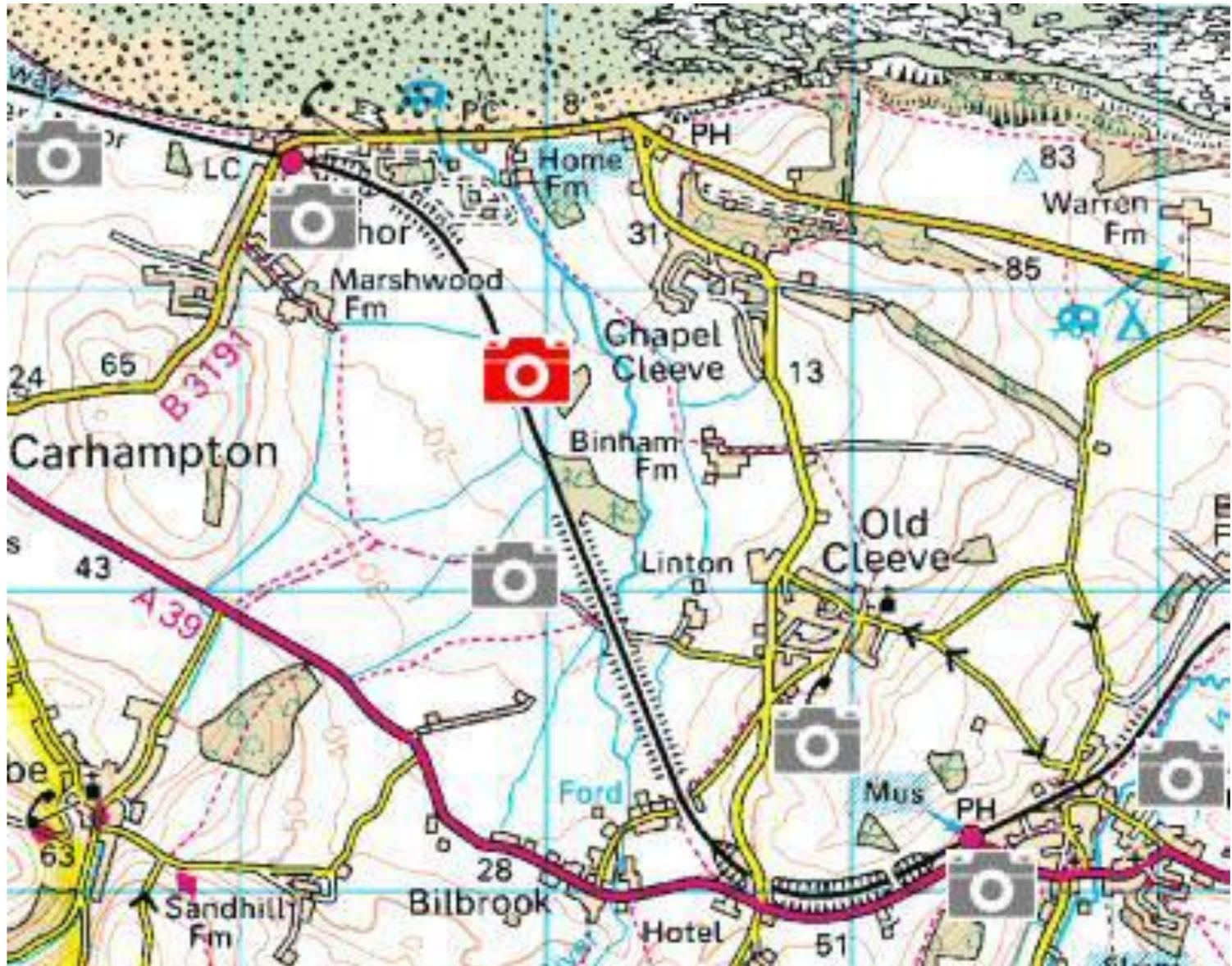
Treatment episode sequence 3rd

Month/year of diagnosis   (MM / YYYY) Main location of treatment

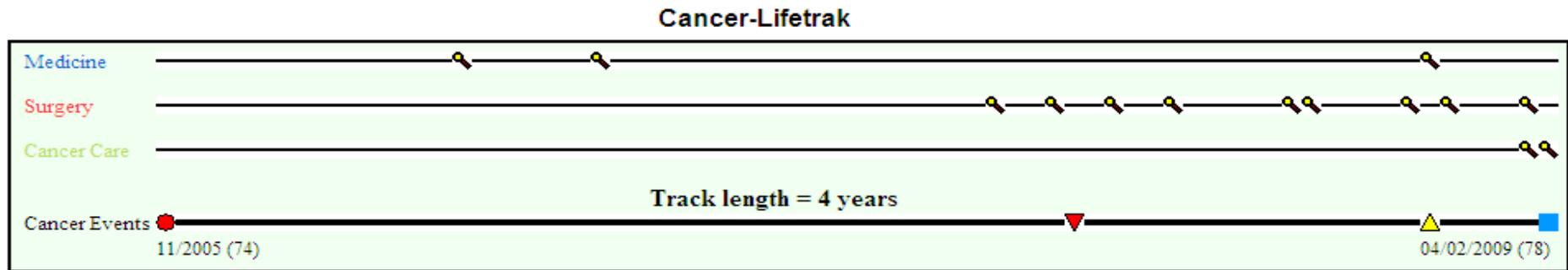
Disease presentation  Responsible consultant

4.) Data Entry

# UK Ordnance Survey maps, railway tracks, stations and the UHS LifeTrak



# UHS Lifelines and the master LifeTrak



- Episodes = stations: primary diagnosis, local recurrence, metastases
- Graphic is automatically populated for each & every patient in real time
- The timeline is continuously recalibrated
- Selected lifeline documents & reports run in parallel
- Items immediately expanded into a window by clicking on microscope icons
- Evidence base Integral to the dataset
- “Patient Journey” can be read instantaneously
- Information retrieval (eg in outpatient clinics) is faster than paper records
- Individual patient record updating is manual but quick and easy

# UHS Breast Cancer Data System exemplar: Selection of a cohort of “primary chemotherapy” patients

Southampton Breast Cancer Database Mining ([Back to reports](#) [Home Page](#))

Select your required criteria including diagnosis year(s) or age or both (Only patients initially diagnosed/treated at UHS are selected)

Diagnosis from start of  To end of

Age at Diagnosis  Age +/-  Years

Status at Follow-up after  Yrs

Cancer Type of

Maximum Invasive Size

Maximum Tumour Grade

ER Status

HER2 Status

With subsequent diagnosis of  **N.B. The subsequent diagnosis and treatments selections affects the Lifetrak graphic only and NOT the listing to browser/Excel**

Treatments

Diagnostic biopsy OR  Wide local excision OR  Simple mastectomy OR  No surgery **AND**

Axillary lymph node biopsy OR  Axillary clearance OR  Axillary sampling OR  Sentinel node biopsy OR  No axillary surgery **AND**

Adjuvant chemotherapy OR  Adjuvant radiotherapy OR  Primary chemotherapy OR  Oophorectomy (lap or open) OR  Hormone OR  Plastic procedure OR  Herceptin OR  No treatment

Statistical Analysis for patients aged between 15 and 75 at diagnosis where the initial diagnosis was between 1990 and 2014

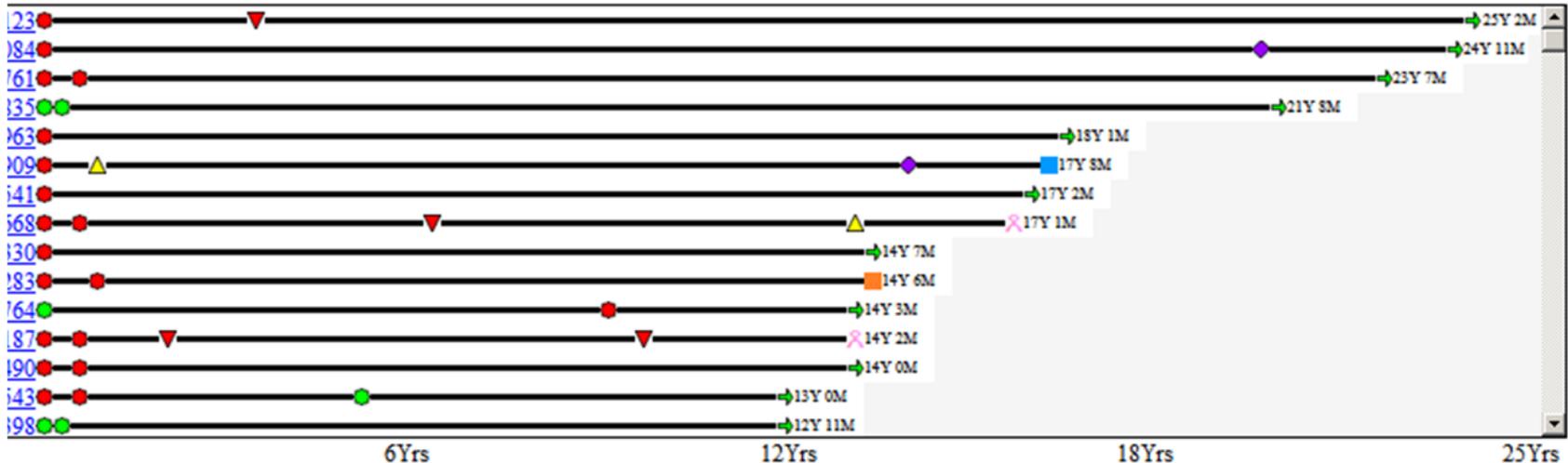
	Alive	Deceased
Patients Selected	126 ( 50.6%)	123 ( 49.4%)
With subsequent recurrence	4 ( 1.6%)	11 ( 4.4%)
With subsequent metastases	10 ( 4%)	109 ( 43.8%)
Average survival from date of diagnosis to now/death	6.1 years	3.2 years
Assigned cause of death	N/A	Breast Cancer : 115 ( 93.5%) Other Cancer : 1 ( 0.8%) Cardiac Disease/Failure : 2 ( 1.6%) Unknown cause : 5 ( 4.1%)

Note:

Use as a powerful research tool

Use as a decision assistance tool for individual treatment

## UHS LifeTrak display of defined cohort of records in the Southampton Breast Cancer Data System



- Scrollable
- Easily read
- A rapid tool for record validation
- Link back to the individual records
- Scope for further development: eg automatic calculation of episode intervals

## Summary: Lessons learned from the UHS Lifelines Project

- Healthcare informatics is a complex challenge
- A small & agile team can produce powerful outputs in health informatics at modest cost
- Ground-upwards iteration can be more effective than top down enforcement of “Grand Designs”
- Timeline structured EPR interfaces are likely to prove to be a powerful methodology for the paperless health economy

## UHS Lifelines: The work continues!

