ONCOLOGY INFORMATION SYSTEMS

Oncology Information systems

- Outline
  - OIS in general
    - Benefits (POTENTIAL)
    - Barriers (ACTUAL)
    - Overcoming Difficulties (HOW TO MOVE)
  - ARIA specifics

Oncology Information systems

- Benefits
  - in a word – **DATA**
    - what is **evidence-based medicine?**
      - what is **evidence?**
      - where do you get it?
    - any data that can be used to answer questions
      - did I do that letter on Mrs Smith?
      - if a WCC<2.0 on cycle 4, what is risk of FN?
      - this article says supraglottis T3N2M0 has a CSS of 75% with IMRT and 50% with conventional, what are our figures?
      - does a boost make a difference for Stage 1 BRCA?
      - is there an improved outcome for oesophagus treatment?
    - what does the best evidence look like?
      - prospective
      - normal practice
      - complete

the nature of data

- why do we have two data systems?
  - clinical
    - individual oncologist, straight from source, difficult to analyse, manage, store, repetitive, not automation
  - trial
    - support staff, abstracted, easy to analyse, manage, store, single, automation, mutable
    - VERY error prone (25-30% in literature)
    - read these for me!
    - **17/1/07: C50.1, M8500, L+SLND, T1c, G1, CE+, LVI-, PNI-, ER+, PR+, HER2-, N1 (1/25), ECE-, M0, ECOG 1**
    - **18/4/07: 42Gy, ECOG 0, Skin G1, Fatigue G0, Weight 0.2kg, Rx Status G0**
    - **19/8/07: rT0N0M1[OSS], ”Bone Scan”, Pain G1, ”T2-4”, 8Gy, 1Fx, d5cm, 6MV X, 8x8cm**

one OIS to rule them all

- why don't we have one data system?
  - used clinically throughout whole department
  - holds all data relating to clinical work & trials
    - all assessments done as if on trial
    - all major disease categories have a protocol specification
  - functions on strict responsibilities
    - EFT-POD
    - data ownership
- can the OIS do it?
- can **my** OIS do it?

Oncology Information systems

- Benefits
  - in a word – **WORKLOAD**
    - do it once and do it properly
    - stop data repetition, re-use data downstream

	history	diagnosis	staging	intent	prescription	assessment	appointment
Initial Consult	x	x	x	x	x		
Booking Sheet		x	x	x	x		
Prescription		x	x	x	x		
Discharge Summary		x	x	x	x	x	x
Letter	x					x	x

Oncology Information systems

- What is needed to get to this point?
  - software
    - OIS
  - hardware
    - PCs
    - network – must cover all clinical/office areas
  - people
    - LEADER

Oncology Information systems

- Barriers
  - you & me
    - preconceived notions of how it's done
    - short-sighted view of workload
    - excessively high standards of use & safety
    - unfamiliarity & non-learning is not a fault of the software
    - presence of trail blazers
  - software
    - vocabulary, nomenclature & ontology
    - workflow
    - the ERD must reflect reality
      - e.g., disease and operation (OIS v HIS)

entity relationship diagrams

- patient
  - disease
    - stage
      - intent
      - modality
      - operation
      - radiotherapy
      - chemotherapy

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  - disease
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  - radiotherapy
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which accurately record accurately reflects our thought processes? i.e., do oncologists need
a PROBLEM-oriented record or
a DIAGNOSIS-oriented record?

does it matter?

... locally? can I record mastectomy/lumpectomy outcomes for breast cancer?
... nationally? can the NHS get meaningful data if not stored with meaning?

Evaluation of VARiS

- Pattern of DISUSE (this is not complete!)
  - GUI issues
    - mouse dependent — ”b .. r .. e ..” = ”ear” NOT ”breast”
    - redundancy by design — ”malignant, primary”, ”adenocarcinoma”, ”adenocarcinoma, NOS”
    - homage to US market — ICD-O not ICD-10 coding
    - homage to Cancer Registries — ”invasive/metastatic” not ICD10 + TNM
    - preformatted rules poor — RCC of kidney
    - no synopsis for oncologist — revolving door experience in *Click Hell*
    - screen refresh
  - no notes capability — only documents
  - multiple EXE entry — no single start, multiple log in
  - multiple databases — very very slow [P4 3.0MHz]!
  - lots of functionality?
    - extremely RT-centric
    - hidden — few know about it, no trail blazer sites
    - implementation services — cost? ask IT! look at NpfIT!!
  - ERD problems — entry OK, retrieval BAD

Evaluation of VARiS

- BUT, it does ...
  - scheduling
  - activity capture
  - medical documents
  - e-prescribing
    - radiotherapy
    - chemotherapy
  - clinical assessments

Questions

- moving to the future
  - change ... change ... change ... change
    - Notes
      - “Parenthood” reaction
      - oncologists ≠ IT experts
      - oncologists determine content, not format
      - inevitable period of CHAOS and DOUBLE ENTRY
    - can you change the pain?
      - [duration].[severity] = k
      - get professional help
        - who? someone who has re-organised oncologists
        - expensive

Questions

- who is your leader?
  - what do they need?
    - you follow unquestioningly OR get involved
    - if you say “I can't type” ....
  - beware Project Management
    - you don't want a camel, you want a thoroughbred
      - someone has to ride
        - a leader to point directions, cajole, ride, whip ...
      - not democracy, its teamwork
        - needs buy-in, not agreement

Questions

- activities
  - Process Mapping
    - define PROCESS
      - “Registration”, “Consultation”, “Simulation” OR
      - “put the referral form in a folder”
    - the software already does the PROCESSES!
      - map “PROCEDURES” as a checklist for the new organisation
      - don't follow the paper paradigm
      - don't introduce one step until the next step is clear
      - get educated wherever you can find it and DON'T RTW!
  - start with the oncologists

Questions

- will you follow?