Evolution, Survival, Revolution, and Growth

A tale of everyday terminology folk

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Structure of Presentation

- Follow on from Tim Benson's presentation of last year & includes the period 1991 until March 2012
- Read literally hundreds of documents & tidied home and office!!
- Structure of the presentation is on a peculiarly English perspective as set out in my title
- "The function of the historian is neither to love the past nor to emancipate himself from the past, but to master and understand it as the key to the understanding of the present." **E. H. Carr**

History:

1965   Systematised Nomenclature of Pathology (SNOP)

1974   Systematised Nomenclature of Medicine (SNOMED)

1977 Electronic version

1979 SNOMED II

1983   Read Codes

1984   Read 4 character codes (version 0)

1988   Read 5 character codes (version 2)

1990   Read Codes purchased by Crown

1992   Clinical terms version 3 (CTV3)

1993 UMLS Includes SNOMED & SNOMED International

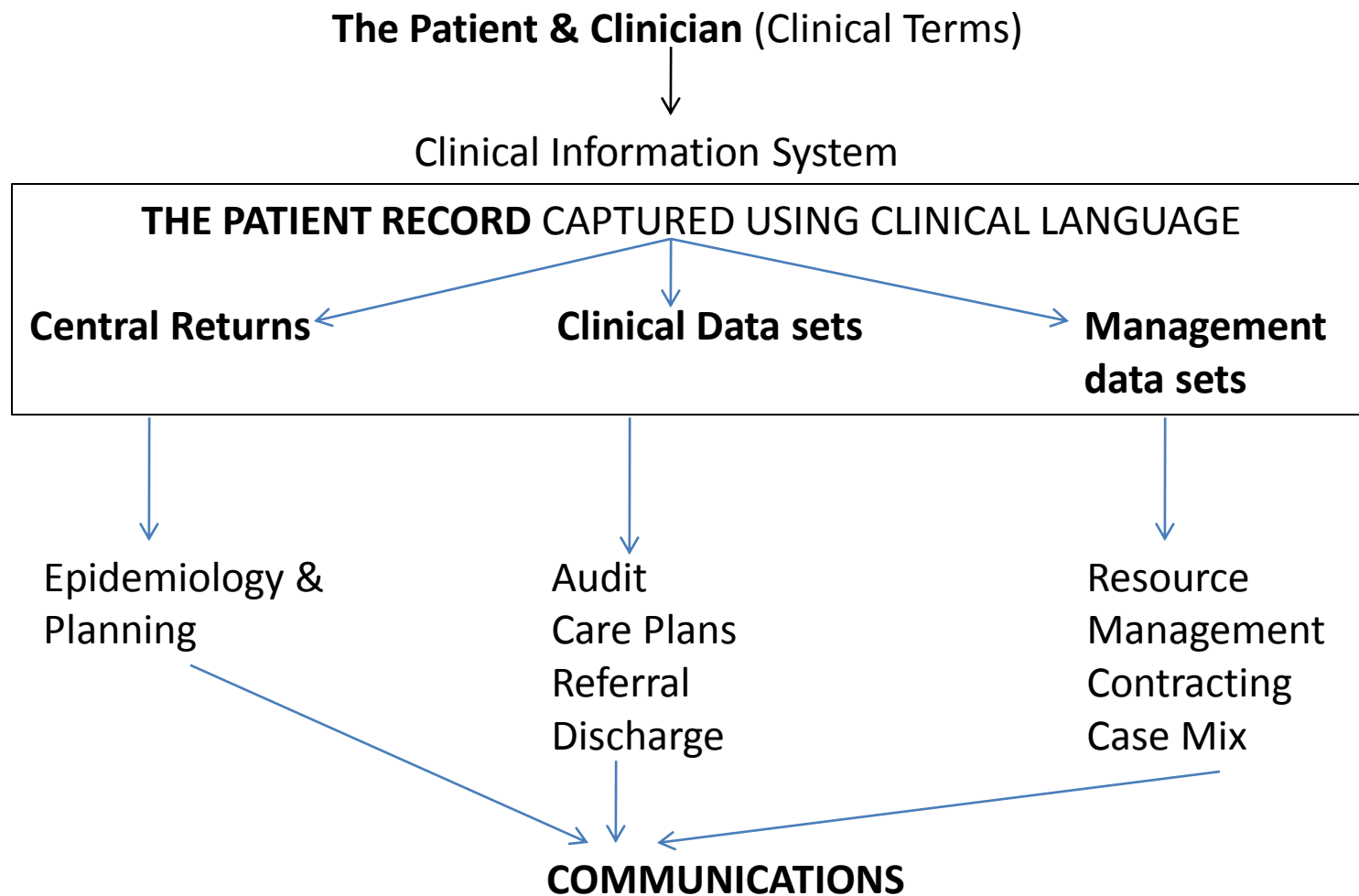2000 SNOMED RT (Reference Terminology)

2002 SNOMED CT

Evolution (1)

- Read Codes are owned by the Crown (1990)
- General Practice in England was already extensively using Read Codes in 1991 (~80%)
- Strategic intent to move to electronic records:
  - 'If person-based systems are to capture and share the essence of an individual's clinical record, those systems must be able to record clinical terms meaningfully and their meanings must be common across the NHS'[1]
- Three major national projects to support this strategy: ICWS; Drug & Appliance database and the Clinical Terms Project

1. IM&T Infrastructure Overview. IMG of the NHS Executive, DH. 1992, ISBN 1 858 39021 4

Evolution (2)

- National Working Group on Information Systems
  - Set up in 1991
  - Representatives from:
    - Conference of Medical Royal Colleges
    - Department of Health
    - NHS Management Executive
    - Joint Consultants Committee
- Chaired by Mr Duncan Nicholl CEO NHS
- Proposed:
  - 'Development of a Clinical Language for the National Health Service'
  - Authors were Dr Martin Severs and Dr James Read
  - Simple concept; clinicians share their terms and meanings & terminologists convert these into a machine readable thesaurus

Suggested Scheme of the Priority Building Blocks for information systems in the NHS (1991)

The Patient & Clinician (Clinical Terms)

Clinical Information System

THE PATIENT RECORD CAPTURED USING CLINICAL LANGUAGE

Central Returns

Clinical Data sets

Management data sets

Epidemiology & Planning

Audit
Care Plans
Referral
Discharge

Resource
Management
Contracting
Case Mix

COMMUNICATIONS

Evolution (3)

- Clinical Terms Project
  - Initially 2 year project involving 40 Project Working Groups across medicine and public health and 5 Generic Working Groups (43)
  - Later added Nursing (6 PWGs) and
  - Professions Allied to Medicine [Health Professions] (5 PWGs) and
  - finally social work
- Extended time scale to 3 years and the budget from £2.3m over 2 years to £3.8m over 3years
- Heavily supported by societies and professional bodies

Evolution (4)

- Method
  - 54 PWGs each with a chair and each with a research worker
  - Build comprehensive lists of clinically useful terms from what ever start point they desire but which must include earlier versions of Read
  - Intra & inter PWG consensus processes and iterative working with NHS CCC regarding relationships
  - Piloting exercises

Evolution (5)

- Delivery times were:
  - Medical   01.04.1994
  - PAM   01.04.1994
  - Nursing   01.04.1995
- Outcome was **a single comprehensive thesaurus of clinical terms that were: shared by all health care professions, developed with full consultation, validated by members of professional groups, cross-referenced to national classifications and endorsed by Professional bodies**

Evolution (6)

- This was a massive project [~1000 clinicians some put the figure higher ~2000]
- It was [almost] delivered to time and specification
- Followed by one year of refinement
- Exposed significant but not appreciated vulnerabilities in clinical professions:
  - Strain and sprain
  - Complications
- Placed a massive stress on the NHS CCC

Terming, Encoding & Grouping

THE PATIENT
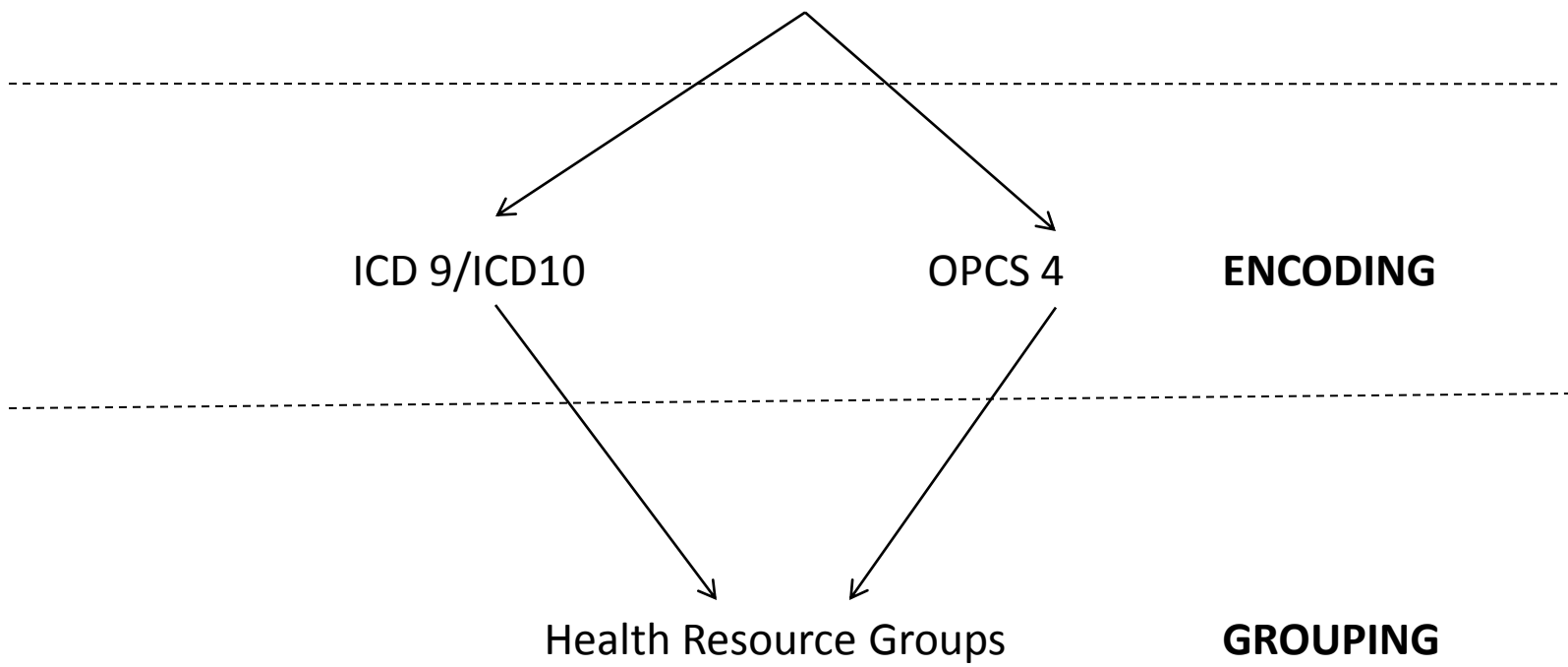
The Read Codes   **TERMING**
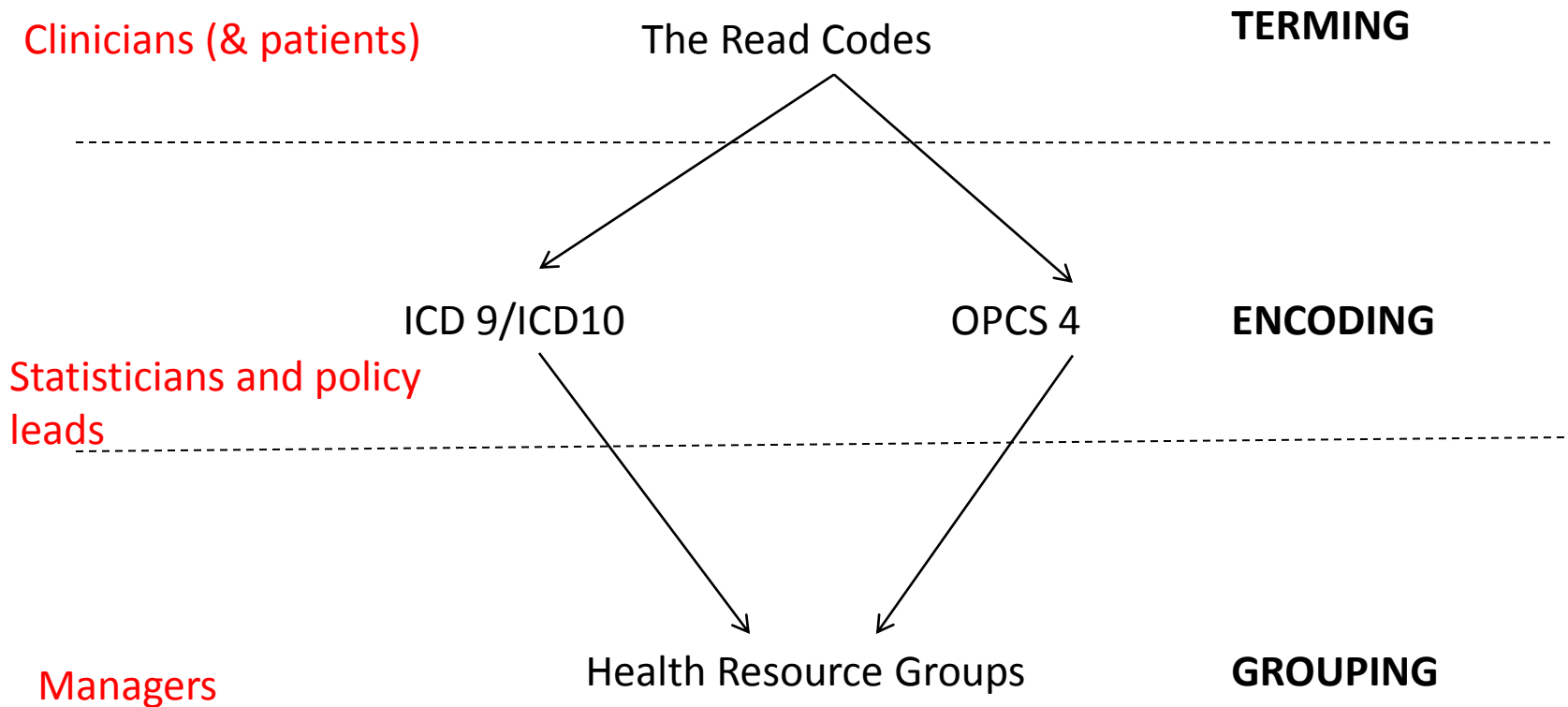
ICD 9/ICD10   OPCS 4   **ENCODING**

Health Resource Groups   **GROUPING**

Terming, Encoding & Grouping

THE PATIENT

Clinicians (& patients)   The Read Codes   **TERMING**

ICD 9/ICD10   OPCS 4   **ENCODING**

Statisticians and policy
leads

Managers   Health Resource Groups   **GROUPING**

This is still a wicked issue in 2012!

British Computer Society Award 1994

Evolution (8)

- Beginnings of the perfect storm developing:
  - Implementation ICD 10 1995 [from ICD 9]; why do we need anything else in secondary care?
  - Massive clinical effort; no explicit process for life cycle improvement; What about x gap or y hierarchy?
  - No detailed implementation plan or strategy; Major vulnerability of very senior management
  - Major stresses on NHS CCC and its leadership with consequent effects; leadership and followership issues
  - Information is power and electronic records will shift power from managers and policy leads to clinical front line; lack of senior internal support within the health & social care system
  - Adverse news stories were financial, personal and technical but hit all three media channels and were multi-source
  - No substantive counter agenda to balance detractors; something will have to happen!!!

'IGNORE – REVIEW – DISTANCE – MAKE IT DISAPPEAR' MPS personal comment

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A 1993 authorless paper: Building a US Health Care Vocabulary: Do Read Codes and SNOMED International Offer Complementary Contributions? {'incidental finding!'}

Survival (1)

- Two processes and products which threatened the very survival of terminology in England.

- National Audit Office Report

  - The Purchase of Read Codes and the Management of the NHS Centre for Coding and Classification 12th March 1998

- The Select Committee on Public Accounts

  - Published 6th August 1998

Survival (2)

- The Select Committee examined the purchase of the Read Codes, the arrangements which created a conflict of interest for Dr Read, the failure to organise activities in line with the proper conduct of public business and the state of readiness of Read Codes Version 3.
  - **The need to plan investment in information technology on the basis of sound investment appraisals**
  - **The need to evaluate pilot projects before implementation**

Survival (3)

- **The need to put in place proper governance arrangements for NHS bodies and avoid conflicts of interest.**
- Specific
  - Business case for purchase of Read Codes
  - Arrangements which created a conflict of interest for Dr Read including Computer Aided Medical Systems [CAMS]
  - Weak oversight NHS CCC
  - State of readiness of CTV3 for wide scale implementation
- Points to note:
  - Total cost of NHS CCC 1990 to 1998 was £32m
  - Total cost of 'Version 3 thesaurus were £3.8m over the period 1992-95'
  - Little criticism of CTV3 or the project itself
  - 1998 12 hospitals and community sites implementing CTV3
  - 80% of suppliers anticipated incorporating CTV3 in there systems over the next few years

Survival (4)

- SNOMED Collaboration {30th April 1998}
  - Joint meeting 11.11.1997 NHSCCC and CAP 'concluded that a desirable outcome would be a single joint international vocabulary that can be tailored to meet national requirements'
  - Objectives
    - Jointly developed and maintained
    - Tailored to local eg national requirements
    - Incorporates both works
    - Stable and internationally accepted
    - Underpins electronic patient records and decision support

Survival (5)

- Benefits
  - Information sharing across professional, organisational and national boundaries
  - Supports for clinically accurate data to underpin decision making about individuals and populations
  - Single vocabulary with clear and explicit links to other vocabularies and classifications
  - Lower cost to developers and users including less need for local terminology development*
  - Overcoming (perceived) political and national boundaries*

Survival (6)

- Issues
  - Copyright
  - Licensing
  - Financial sustainability {costs, price and Royalties}*
  - Distribution
  - Mappings and Linkages
  - Market acceptability and uptake
    - USA and UK
    - Rest of world

* Was still a view that local costs & financial risk can be minimised through license fee income

Survival (7)

- CAP – NHS Agreement 1ˢᵗ April 1999
  - Calls for the development of a 'New Work' that combines SNOMED RT and Clinical Terms Version 3 (the Read Codes)
  - NHS grant CAP a non-exclusive in perpetuity, royalty free license to copy and other wise use the Read codes*
  - NHS will deliver £1.8 million/annum authoring expertise to CAP to deliver New Work at the end of 2001.
  - Commitment to work with clinicians, system suppliers government agencies and end users

* Could not give CAP the ownership of NHS data from past or have UK totally reliant

Survival (8)

– SNOMED International Authority will assume overall authority for the strategy and operations of New Work [NHS 20% = 3 places]*

– SNOMED International Editorial Board will provide editorial standards, guidelines for external input, field testing and will oversee the quality and quality assurance of the product [NHS 50%]

– Anglo-American Design Group & UK Transition Group

– CAP will own the copyright and all other IP in New Work and all derivative works throughout the world

– Revenue sharing scheme from License fees**

– Formal announcements 12 -14th April 1999

Issues associated with both * and ** will become more important over time

Survival (9)

- New Work {SNOMED CT}
- SNOMED International Authority
- Relationship issues surprise
- High pressure on budgetary spend
- Mapping priority

- SNOMED RT {finish and launch}
- CAP Board of Governors
- External relationship issues
- Pace of work was running behind budget
- Mapping less of priority

RK on my first meeting 'Beat, Eat or Meet' CAP's approach to Read decided on 'meet' 1st October 1999

Survival (10)

- Spring 2000 structure of SNOMED CT agreed, work plan agreed with beta testing planned December 2001, first 'clinical partner agreement'
- CAP Launch SNOMED RT May 9th 2000
  - Really good material, very well presented; some of the more interesting aspects of content:
    - All the material is referenced from and aimed at USA market
    - 'Backed by more than 35 years of pioneering research coupled with a nimble organisation'
    - 'People have on average 11.2 medical records' John Neff Chair SIA
    - CAP......and has committed more than $17 million to the SNOMED work
- USA Government through National Library of Medicine [NLM] sole source contract call and negotiation for terminology products and services
  - Still got my handwritten notes from the meeting!
- External relationship management continues to take up substantive SIA time [3 activities]

Survival (11)

- Participated in General Practice Coding Jury RFI from Australia
- National Programme for IT begins in 2001
- SNOMED CT work progressing well
  - Alpha test of SNOMED CT in 42 sites in 6 countries took place
  - First Release of SNOMED CT is planned January 2002
  - Mapping to national classifications planned 2002/03
- NLM negotiations promote some deep thinking about terminologies and their governance and sustainability:
  - Benign monopoly, fair shares, control, public ownership, citizen data, risk management at national level with proprietary standards.

Survival (12)

- CAP and NHS have undertaken reciprocal financial audits
- 2nd release of SNOMED CT July 2002 & 3rd release Jan2003
- Emergence of 'costs' as a problem = vendors; academics especially UK
- April 17th 2003
  - Summary and Analysis of Terminology Questionnaires submitted by developers of candidate terminologies for PMRI Standards: A draft Report to NCVS subcommittee on Standards and Security
  - SNOMED CT scored highest by a long way over rival terminologies when licensing/IP issues were excluded (20/20) but not when licensing/IP scores were added ?/26. [Note 6 points for licensing and IP]
- 1st July 2003
  - College of American Pathologists and National Library of Medicine sign a $32.4 million 5 year sole source contract to license to English and Spanish editions of SNOMED CT starting in January 2004 access will be through UMLS or SNOMED International
  - Free to all USA users*.

(Quiet) Revolution (1)

- The experience from multiple sources including the NLM negotiation brought into sharp focus the need for an 'open' terminology model. This grew over 3-4 years
  - The most advanced thinking and articulation was done by an ever increasing community but principles and ideas from Colin Price, Anthony Nolan, Peter Drury, Keith Campbell, Kent Spackman, Kevin Donnelly & Betsy Humphreys were the key building blocks
  - This was done in dialogue with CAP {although uncomfortable, credit should be given}

(Quiet) Revolution (2)

- The sparks that ignited the creation of the IHTSDO were:
  - Richard Granger
  - Richard Alvarez, David Brailer, Ian Reinecke
  - European Union colleagues
- Partially stimulated by high implementation costs
  - 2004 Kaiser Permanente to spend $1.8 billion to automate its patient files for its 8.4 million members[1]
- Combined with:
  - Change in context; global vs local; do once & not duplicate; sharing risk; good governance; need to reduce costs over time
  - Financial pressures; inside and outside of CAP
  - Willingness of CAP BOG to enter the dialogue {day trip to Phoenix; Nov 2004}

1. Rhonda L Rundle Big HMO Plans to Put Medical records Online. WSS 2nd April 2004

(Quiet) Revolution (3)

- Making it happen: Step 1 2005: Establishing a compelling business case
  - NHS = Richard Granger: Richard England, Sarah Bagshaw & Martin Severs AND
  - CAP = Mary Cass/Thomas Sodeman: Kevin Donnelly, Cheryl Chelfond, Steven Castanien
    - Principles [purpose, integrity, financial sustainability] and values at core plus detail worked down to 2 levels
      - Governance of a 'monopoly supplier'
      - Explicitly face and manage risks associated with implementation
      - Local adaptation is essential
      - Protection of the integrity of the product by mutuality
      - Membership and contributorship financial model

(Quiet) Revolution (4)

- Step 2: 2005- 2006: Confirming a viable entity
  - Same teams gaining 'charter members' from around world via a joint letter of invitation
  - Development Proposal, FAQs and in person Presentations Washington D.C., Hong Kong, Sydney, London, Brussels
    - Standard class travel; completed in just over a week
    - Issues: WHO role; (some) cultural views
- Created a grouping of Charter Members and met with CAP 26 -28th June 2006

(Quiet) Revolution (5)

- Stage 3: Negotiation, registration and contractual execution
- Nearly a year of work culminating weekly calls and hard negotiation with 29 closing documents
  - Australia, Canada, Denmark, Lithuania, Netherlands, New Zealand, Sweden, United Kingdom and United States of America
  - Registration March 2007
  - Acquisition of Intellectual Property and activation of contracts including service contract with CAP April 2007.

Registration

Yes; I did lose my shirt!

Growth (1)

- 2007 -2012
  - Mostly delivered to time & specification: Made mistakes; yes but only ONCE!*
  - Rigorously conformed to the Articles of Association [unless the GA wanted to change them]
  - Grown in Membership: 9 -19 countries
  - Stuck to principles and values; even when it causes pain: talking the talk is easier than walking the walk!
  - Clear strategy and vision
  - Management is held accountable by our Members in public; It is very painful (personal reflection)

Growth (2)

- Improvement through change is the norm
- People trust the IHTSDO and it has benefitted from some great acts of generosity Kaisar Permanente for example*
- Relationships are hard work but well worth it eg, WHO and GMDN Agency 'Together we are stronger' is true
- Officers are crucial and IHTSDO has some of the best! Look after them

Growth (3)

GROWTH IS ABOUT THE PEOPLE AND THE IHTSDO HAS SOME OF THE BEST THANK YOU

Dr James Read

its costs, and to improve the quality of service delivered to patients.