Agenda

• Introduction and Objectives - Umbrella and advisory committee for new national orthopaedic Registers? - JT
• Overview of current initiatives in National data collection – JD/AG
• The existing administration structure of the new databases:
  – Registry management structure
  – Data access policy
  – Hospital governance issues
  – Registry Functionality
    • Surveillance/Newsletters/Interrogation/Reports
Agenda 2

- **Update on progress for each Registry - ALL.**
  - An Information Matrix will be distributed and completed pre-meeting as introduction to each Register:
    - Pathways
    - Pre-op scores
    - Diagnosis
    - Op note
    - Complications
    - Other outcome measures.
    - Frequency of collection
    - Surgeon compliance
    - Patient recruitment
  - **Issues:**
    - Consent
    - NHS numbers
    - e-mail addresses
    - Importing historical data

- **For Amplitude customers**
  - Same structure via front page
  - Full operation note
  - Data sharing
  - Co-ordination of data collection
Agenda 3

- **Registry Umbrella**
  - Need for umbrella organisation
    - Possible subcommittee representation: each society, NJR, NHFD, statistician, epidemiologist, governance, PLG
  - If BOA to co-ordinate this role:
    - Higher profile
    - Dedicated sessions at Annual Conference
    - Collaboration with NICE/NJR/NHFD
    - Collaboration with BOA research subcommittee
    - Regular JTO features
    - Funding possibilities
    - Overlap with ideas to change the culture for data collection:
      - Commissioning.
      - Revalidation
      - RCTs

- **Other considerations:**
  - Collaboration with other data collectors e.g. mCO, PROMS2, other
The Data Revolution.

An opportunity and imperative to define a new Culture of Data Collection in Orthopaedics

John Timperley
MB ChB FRCS (Ed) DPhil (Oxon)
Hon. Treasurer
Data, data everywhere!

Problems:
- Accuracy
- Access and Interrogation
- Validity
- Interpretation
- Ownership (Mandate)
Data, data everywhere!

Problems:
- Ownership (Mandate)
- Executive decisions
- Accuracy
- Access and Interrogation
- Validity
- Interpretation

A model for how not to setup a Registry
Data, data everywhere!

(NJR) Problems:

A model for how not to setup a Registry

Expensive

£1m p.a. to Northgate
£0.5m p.a. “extras”

Clinicians

disempowered
overworked
“free”
Patients will get clearer data on surgeons' death rates next year

Patients will be able to compare the death rates of surgeons at every NHS hospital by next year, the national medical director has said, amid criticism that data published so far does not allow the public to make a meaningful choice.

By Laura Donnelly, Health Correspondent
6:36AM BST 02 Jul 2013

Last night, Prof Sir Bruce Keogh, national medical director for NHS England, said changes will be made in future, so that the public could make clear comparisons between doctors.

He said: “The first thing was to get the data out - we had committed to doing this and this is pioneering work. Nowhere else in the world is doing this.”

Prof Sir Bruce said that from next year it will be made mandatory under the NHS Contract for every hospital to publish data listing the mortality rates of their surgeons, adjusted to take account of the risk profiles of the patients being treated.

Prof Keogh said he anticipates that national information will be published at the same time - so that the public can compare the rates of all NHS surgeons, wherever they work - but said an important debate lay ahead.
Out aim:
To drive up the quality of care for our patients

Coincidentally:
“The best way to protect the surgeon is to protect the patient”
Professor Michael E. Porter, Harvard Business School, USA:

“With its strong tradition of quality registries, Sweden is poised to become the world's most advanced nation in measuring the actual outcomes of care across many diseases. This represents a major opportunity for Sweden to lead a global shift toward a new, value-based approach to health care delivery focused on improving patient health outcomes relative to cost.”
# National Healthcare Quality Registers

## Respiratory Diseases
- Swedovox – Respiratory Failure Register
- Swedish Quality Register of Otorhinolaryngology

## Childhood and Adolescence
- BORIS – Childhood Obesity Register in Sweden
- SWEDADKIDS – The Swedish Childhood Diabetes Register
- PNQn – Perinatal Quality Register/Neonatology
- SÖK – National Register of Suspected/Confirmed Sexual Abuse in Children and Adolescents

## Circulatory Diseases
- RiksSikt – Heart Failure Register
- SGCAAR – Swedish Coronary Angiography and Angioplasty Register
- Swedish Heart Surgery Register
- RIKS-HIA – Register on Cardiac Intensive Care
- National Register on Out-of-Hospital Cardiac Arrest
- Riks-Stroke – National Quality Register for Stroke
- Swedvasc – Vascular Register in Sweden
- GUCH – Grown-Up Congenital Heart Disease Register
- SEPHIA – Register on Secondary Prevention in Cardiac Intensive Care
- National Catheter Ablation Register
- Auricula – National Register of Atrial Fibrillation and Anticoagulation

## Endocrine Diseases
- NDR – National Diabetes Register
- Scandinavian Quality Register for Thyroid and Parathyroid Surgery
- SOReg – Swedish Obesity Surgery Register

## Gastrointestinal Disorders
- Swedish Hernia Register
- GallRiks – Swedish Quality Register for Gallstone Surgery
- Swedish Quality Register for Ventral Hernia

## Musculoskeletal Disorders
- RIKSHÖFT – National Hip Fracture Register
- Swedish National Hip Arthroplasty Register
- Swedish Knee Arthroplasty Register
- National Pain Rehabilitation Register
- Swedish Rheumatoid Arthritis Register
- Followup in Back Surgery
- Swedish Shoulder Arthroplasty Register
- Swedish Cruciate Ligament Register – X-base
- Swedish National Elbow Arthroplasty Register (SAAR)

## Diseases of the Nervous System
- SMS – Swedish Multiple Sclerosis Register
- CUPP – Quality Register for Children with Cerebral Palsy
- WebRehab Sweden – Quality Register in Rehabilitation Medicine
- SweDem – Swedish Dementia Register

## Genitourinary Disorders
- GYNOP – National Quality Register for Gynecological Surgery
- SRR – Swedish Renal Register

## Cancer
- National Prostate Cancer Register
- National Breast Cancer Register
- National Quality Register for Esophageal and Stomach Cancer (NREV)
- Swedish Rectal Cancer Register
- Swedish Gyn-Oncology Register
- Swedish Colon Cancer Register

## Eye Disorders
- Swedish National Cataract Register
- Swedish Corneal Transplant Register
- Macula Register

## Other
- RIKSÄT – National Quality Register for Specialized Treatment for Eating Disorders
- SIR – Swedish Intensive Care Register
- PsOsReg – Swedish Psoriasis Register
- InfCare HIV
- Swedish Therapeutic Apheresis Register
- SkaPa – Swedish Quality Register in Caries and Periodontitis
- Swedish National Register of Palliative Care
- Senior Alert – National Register on Nutrition, Fall Prevention and Pressure Sores
- Quality Register for Emergency Care

Source: "National Healthcare Quality Registries in Sweden 2007", Swedish Association of Local Authorities and Regions
8 Swedish Orthopaedic National Healthcare Quality Registers

RIKSHÖFT – National Hip Fracture Register
Swedish National Hip Arthroplasty Register
Swedish Knee Arthroplasty Register
National Pain Rehabilitation Register
Swedish Rheumatoid Arthritis Register
Followup in Back Surgery
Swedish Shoulder Arthroplasty Register
Swedish Cruciate Ligament Register – X-base
A peer in health care system quality

European health care quality
Results index, 18 indicators*

A lower index indicates better outcomes

World's largest per capita producers of medical publications
Publications per year and million inhabitants

Source: "Clinical Research in Finland and Sweden", Academy of Finland and Swedish Research Council, 2009
Expanding UK Orthopaedic Registers

- National Joint Register (NJR)
  - Hip arthroplasty
  - Knee arthroplasty
  - Shoulder/elbow arthroplasty
- National Hip Fracture Database (NHFD)
- Trauma Audit and Research Network (TARN)
- PROMS 2
- Non Arthroplasty Hip Register (NAHR)
- British Spine Register (BASS)
- Knee ligament Register (BASK)
- Paediatric Register (BSCOS)
- MyClinicalOutcomes (mCO)
- Hand surgery (BSSH Audit Website)
- Soft tissue shoulder register
- Ankle surgery index
A vision for the future in UK orthopaedics

- It could become the normal culture that *all* orthopaedic procedures are automatically entered onto a Registry
- There could be collaboration between Registries
- They can be a vehicle for multi-centre RCTs
- The BOA could co-ordinate between Specialist Societies and Registries
Goals of the day:

- **Registry Umbrella**
  - Is there support for umbrella organisation?
    - Subcommittee representation:
      - each society
      - statistician, epidemiologist, governance, PLG, IT expert
      - (?NJR, TARN, NHFD)
  - Function of umbrella organisation
    - Strategic planning
    - Database structure and overlap
    - Functionality
    - Policy (e.g. data access)
    - Governance
  - Funding
    - What is required?