The New Culture of Data Collection in Orthopaedics

Thursday 13th September 2012
8.30am to 10.00am
Exchange Auditorium

John Timperley
FRCS (Ed)  D.Phil (Oxon)
Major Greenwood. Medical Statistician

“I should like to shame surgeons out of the comic opera performances which they suppose are statistics of operations”
Only 11.3% of studies published in the orthopaedic literature are considered level I.

RCTs in particular constitute approximately 3% of the orthopaedic literature

There is an immense need for improved reporting of orthopaedic RCTs.
The UK problem:

- £15-20 bn shortfall in public finances by 2016
- Cannot be achieved by efficiency savings
ANY PURCHASER OF HEALTHCARE
Sweden for Clinical Research

Report on Sweden’s competitive advantages for clinical development

The report was finalized in December 2009 by author Björn Bergstrand

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.”
# 60 Swedish National Healthcare Quality Registers

<table>
<thead>
<tr>
<th>Respiratory Diseases</th>
<th>Diseases of the Nervous System</th>
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<tbody>
<tr>
<td>Swedovox – Respiratory Failure Register</td>
<td>SMS – Swedish Multiple Sclerosis Register</td>
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<tr>
<td>Swedish Quality Register of Otorhinolaryngology</td>
<td>CPUAP – Quality Register for Children with Cerebral Palsy</td>
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<td>WebRehab Sweden – Quality Register in Rehabilitation Medicine</td>
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<td>SweDem – Swedish Dementia Register</td>
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<td>Childhood and Adolescence</td>
<td>Genitourinary Disorders</td>
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<tr>
<td>BORIS – Childhood Obesity Register in Sweden</td>
<td>GYNOP – National Quality Register for Gynecological Surgery</td>
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<tr>
<td>SWEDADAIDS – The Swedish Childhood Diabetes Register</td>
<td>SRR – Swedish Renal Register</td>
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<td>PNQn – Perinatal Quality Register/Neonatology</td>
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<td>SÖK – National Register of Suspected/Confirmed Sexual Abuse in Children and Adolescents</td>
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<td>Circulatory Diseases</td>
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<td>RiksSvikt – Heart Failure Register</td>
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<td>SGCAA – Swedish Coronary Angiography and Angioplasty Register</td>
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<td>Swedish Heart Surgery Register</td>
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<td>RIKS-HIA – Register on Cardiac Intensive Care</td>
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<td>National Register on Out-of-Hospital Cardiac Arrest</td>
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<td>Riks-Stroke – National Quality Register for Stroke</td>
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<td>Swedvasc – Vascular Register in Sweden</td>
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<td>GUCH – Grown-Up Congenital Heart Disease Register</td>
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<td>SEPHIA – Register on Secondary Prevention in Cardiac Intensive Care</td>
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<td>National Catheter Ablation Register</td>
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<td>Auricula – National Register of Atrial Fibrillation and Anticoagulation</td>
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<td>Endocrine Diseases</td>
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<td>NDR – National Diabetes Register</td>
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<td>Scandinavian Quality Register for Thyroid and Parathyroid Surgery</td>
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<td>SoxReg – Swedish Obesity Surgery Register</td>
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<td>Gastrointestinal Disorders</td>
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<td>Swedish Hernia Register</td>
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<td>GallRiks – Swedish Quality Register for Gallstone Surgery</td>
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<td>Swedish Quality Register for Ventral Hernia</td>
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<tr>
<td>Musculoskeletal Disorders</td>
<td>Other</td>
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<tr>
<td>RIKSHÖFT – National Hip Fracture Register</td>
<td>RIKSAT – National Quality Register for Specialized Treatment for Eating Disorders</td>
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<td>Swedish National Hip Arthroplasty Register</td>
<td>SIR – Swedish Intensive Care Register</td>
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<td>Swedish Knee Arthroplasty Register</td>
<td>PsORReg – Swedish Psoriasis Register</td>
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<td>National Pain Rehabilitation Register</td>
<td>InfCare HIV</td>
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<td>Swedish Rheumatoid Arthritis Register</td>
<td>Swedish Therapeutic Apheresis Register</td>
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<tr>
<td>Followup in Back Surgery</td>
<td>SkaPa – Swedish Quality Register in Caries and Periodontitis</td>
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<tr>
<td>Swedish Shoulder Arthroplasty Register</td>
<td>Swedish National register of Palliative care</td>
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<tr>
<td>Swedish Cruciate Ligament Register – X-base</td>
<td>Senior Alert – National Register on Nutrition, Fall Prevention and Pressure Sores</td>
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<tr>
<td>Swedish National Elbow Arthroplasty Register (SAAR)</td>
<td>Quality Register for Emergent Care</td>
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</tbody>
</table>

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
11 (Potentially 13) UK Orthopaedic Registers

- **National Joint Register (NJR)**
  - Hip arthroplasty
  - Knee arthroplasty
  - Shoulder arthroplasty
- **National Hip Fracture Database (NHFD)**
- **PROMS 2**
- **Non Arthroplasty Hip Register (NAHR)**
- **British Spine Register (BASS)**
- **Knee ligament Register (BASK)**
- **MyClinicalOutcomes (mCO)**
- **Hand surgery (BSSH Audit Website)**
- **Soft tissue shoulder register**
- **Ankle surgery index**
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 UK* could become the world's most advanced nation in measuring the actual outcomes of care
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For each Registry:

Scope of project
History and development
Funding
Future plans
The Non Arthroplasty Hip Register (NAHR)

Launch of the NAHR to all BHS members at Manchester BHS AGM - March 2012

- Register by phoning Bluespier helpdesk: 01905 770505

- NICE guidance on open and arthroscopic femoro-acetabular surgery for Hip Impingement Syndrome states that surgeons should submit details of this surgery to the NAHR (see downloads).

- Surgeons who will be entering data are requested to ensure that their contact details held by the BHS are up to date. Please contact Claire Wilson (c.wilson@boa.ac.uk) to check.

- Surgeons who are not members of the BHS will be able to enter data onto NAHR after September 2012 BOA meeting.

- Draft Policy Documents, Consent Forms etc. are available for comment from BHS members from the "Documents for download" page: [here](#)

User instructions - [Click here](#)

To get started? [Click here](#)

REGISTRY LOGIN PORTAL

(with password from Bluespier Help Desk - see number above)

Updated 28/4/2012
Motivation for setting up Non Arthroplasty Hip Register: Femoro-acetabular impingement (FAI) surgery

• Need to prove the efficacy of this type of surgery in order to get it adequately funded.
• Need for a database of all procedures linked to PROMS and NJR
Arthroscopic femoro–acetabular surgery for hip impingement syndrome

Proof of efficacy
One non-randomised controlled study (75 patients)
Four case series (total 532 patients)

Advice:
Arthroscopic FAI surgery should only be carried out by surgeons with specialist expertise in arthroscopic hip surgery.
The role of the British Hip Society

- At 2011 AGM of the BHS the membership unanimously supported the formation of a national non-arthroplasty register
- The BHS membership funded the NAHR
- At the 2012 BHS meeting it was launched
Scope of the NAHR

• The NAHR was set up by the BHS to collect longitudinal outcome data for any type of hip condition and/or surgery other than arthroplasty.
  – E.g. can be used for DDH, Perthe’s, FAI, peri-acetabular osteotomies, SUFE, trochanteric bursitis

• Single unique pathway per hip from birth to arthroplasty or death

• PROMS and outcome data collected by e-mail and post

• Potential for BHS to lead in understanding hip pathology
Who benefits from the creation of the NAHR?

The Patients.  
Patients will only undergo surgery if it will benefit them.

The Purchasers of Healthcare.  
Funding will be targeted on patients who will benefit from the procedure. Funds will not be used where the outcome clearly does not justify the resource.

Surgeons.  
Potential to understand the natural history of diseases  
Surgeons will be able to define  
which patients will benefit from surgery  
what details of the operative procedure will define a good result.
Practical benefits for surgeon:

- Define what scores you want to collect
- Creates an Operation note for use in clinical record
- Post-op scores can be automatically collected
- Outcomes are graphically displayed for surgeon and patient to see
- Interrogate clinical outcomes of your own set of patients (only!)
- Customise many features to suit your own practice
Welcome To The Non Arthroplasty Hip Register Portal

You may need Acrobat Reader in order to open the following documents.

Data Policy NAHR - download
MDS for NAHR - download
Patient Consent Form - download
NAHR Data Request Form - download
NAHR and FAI surgery - download
NICE guidance on FAI surgery - download
Getting Started - Instructions for users

Downloadable Data Entry Forms:
Assessment Form
EQ-5D-Y
Modified Harris Hip Score
Operation Details
Non Arthritic Hip Score
Hoos Hip Survey
Patient Satisfaction
UCLA Activity Score
iHot 12
Arthroscopic femoro-acetabular surgery for hip impingement syndrome

Guidance:

“Clinicians should submit details of all patients undergoing FAI to the NAHSR”
Summary:

- Whole membership was consulted during its creation
- It’s confidential
- It’s secure
- Unique pathways for all joints
- Tracks PROMS, further surgery, complications, satisfaction
- Ability to upload existing data later this year
- No need for surgical intervention to enter Register
- Generates Op note from data entry
- Choose and display graphically your own outcome scores
BRITISH HIP SOCIETY
The Non Arthroplasty Hip Register (NAHR)
UK Registers

• **Issues:**
  – Ownership
  – Funding
  – Compliance
  – Access to data

• **Dataset:**
  • Unique identifiers
  • Duplication of data acquisition