Patient Registers:
10 Reasons Why You Need One

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Ministry of Health

http://www.crc.gov.my
Contents

- What is patient registry?
  And role of CRC

- Uses of patient registries and why you should have one
What is Patient registry?

A patient registry is an organised information system to collect, process, report and use both clinical service and individual patient level data.

For policy, clinical and research purposes.
What is Patient registry?

- A registry **targets a specific patient population** defined by a particular disease or therapy.

- It employs **survey methods** to collect uniform data on clinical services provided for the target patient population in the country; and **observational study methods** to collect uniform patient level data to evaluate treatment and health outcomes.
The CRC and Patient registries

As part of the MOH, the Clinical Research Centre share MOH’s broad public health mission: “To Improve patients’ health outcomes through ethical and quality clinical research”

In pursuance of our public health research mission, by the year 2010, CRC is committed to:

1. Establish a Patient Register in ALL significant clinical disciplines in Malaysia

2. Establish healthcare surveys, or otherwise secure access to healthcare data, to produce Healthcare statistics critical to MOH’s mission
## Patient registers & Health databases supported by CRC

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<th>#</th>
<th>Patient registries</th>
<th>Health databases</th>
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<td>National Renal Registry</td>
<td>National Suicide Registry</td>
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<td>National Transplant Registry</td>
<td>Nat. CVD (ACS/PCI) Database</td>
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<td>3</td>
<td>National Eye Database</td>
<td>Nat. Dermatology Registry</td>
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<td>4</td>
<td>Malaysian National Neonatal Registry</td>
<td>National Cancer Patient Registry</td>
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<td>Malaysian Liver Registry</td>
<td>Hematological Malignancy Reg.</td>
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<td>National OT Register</td>
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<td>National Trauma Database</td>
<td>Malaysian Registry of Intensive Care</td>
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<td>8</td>
<td>Diabetes Registry of Malaysia</td>
<td>Nat. Inflammatory Arthritis Registry</td>
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<td>9</td>
<td>National Mental Health Registry</td>
<td>Nat. Orthopedic Reg Malaysia</td>
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# Healthcare Statistics projects
Drugs, Med. Technology, Facilities, Healthcare & Workforce

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<th>Healthcare Surveys</th>
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<td>National Medicines Use Survey</td>
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<td>2</td>
<td>National Medical Device Survey</td>
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<tr>
<td>3</td>
<td>National Healthcare Establishment &amp; Workforce Surveys (NHEWS) (NEW)</td>
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<tr>
<td>4</td>
<td>National In-Patient Care survey (incl. Hospital Discharge &amp; Surgical Procedures) (NIPCS)</td>
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<tr>
<td>5</td>
<td>National Ambulatory Medical Care Survey (NAMCS) (NEW)</td>
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Why invest in a registry?

Setting up & operating patient registry is costly (not just monies; but no less expensive in time and efforts required; all are in short supply).

You need to be convinced this is worth the trouble.

Patient registry has three broad purposes:

1. **Policy**: Clinical service planning & development for a population of patients
2. **Clinical**: Clinical care for individual patients
3. **Research**: Leading to publications
Registry as a tool to help you achieve **Clinical Excellence**?

**Clinical care for individual patients**

**Clinical service for a population of patients**

**Performance measure (4Es):**
1. Effectiveness
2. Efficiency
3. Equity
4. Esteeming
Clinical care for individual patients

- Clinical decision making for individual patients
- Natural history of disease
- Health technology assessment
- Clinical & Cost-effectiveness
- Patient safety
- Clinical audit
Clinical service for a population of patients

Planning & development of clinical service:

- Healthcare financing
- Healthcare facilities
- Healthcare workforce
- Medical technology/devices
- Medicines use
Healthcare performance

1. **Effectiveness**: How well does the care & service improve patients’ & population health?

2. **Efficiency**: How well does the care & service improve patients’ & population health given the available resources?

3. **Equity**: How well does the service achieve fairness in the distribution of access to & financing for healthcare?

4. **Esteeming**: How responsive is the care and service to legitimate expectations of the patients and population?
Clinical care for individual patients

Examples of how registry data can be useful to address the following:

1. Natural history of disease
2. Clinical & Cost-effectiveness
3. Health technology assessment
4. Patient safety
5. Clinical audit
Example: Natural history of disease

Kaplan-Meier survival estimates, by modality

Cumulative survival

Dialysis patient survival by Dialysis modality 1997-2006

CRC
Research that matters to patients
Survival on discharge
Data from the M’sian Neonatal Reg

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<tr>
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<th>VLBW</th>
<th>ELBW</th>
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<tr>
<td>1993</td>
<td>62.6</td>
<td>23.1</td>
</tr>
<tr>
<td>1996</td>
<td>69.3</td>
<td>30.8</td>
</tr>
<tr>
<td>2000</td>
<td>71</td>
<td>40.2</td>
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<tr>
<td>2006</td>
<td>74</td>
<td>48</td>
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MPA VLBW study 1993 & 1996
MOH Modified budgeting system study 2001
M’sian National Neonatal Registry 2006 (MNNR)
Is Dialysis treatment value for money in Malaysia?

Interstudy comparison of dialysis cost/life year saved (all costs in 1996 RM)

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<tr>
<th></th>
<th>MOH</th>
<th>NZ 6</th>
<th>US 7</th>
<th>CANADA 8</th>
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<tbody>
<tr>
<td>Centre HD</td>
<td>21,620</td>
<td>77,231</td>
<td>135,255</td>
<td>182,428</td>
</tr>
<tr>
<td>Home HD</td>
<td>23,375</td>
<td>61,695</td>
<td>139,478</td>
<td>-</td>
</tr>
<tr>
<td>CAPD</td>
<td>30,469</td>
<td>56,691</td>
<td>-</td>
<td>125,115</td>
</tr>
</tbody>
</table>
Example: Health technology assessment

Introduction of Cyclosporine A
(a new & expensive immuno-suppressive drug in the early 1990s) improve graft survival by only about 5% at 1 and 2 years

Kaplan-Meier survival estimates, by Yr
Cumulative survival
Graft survival before and after CsA, 1988-93
duration in months
0 12 24
.5
.75
.9
1
1988-90
1991-93

Graft survival before and after CsA, 1988-93

Research that matters to patients
Example: Clinical Audit

1. **Benchmarking**: Track centres’ performance and benchmark against national standards: league table, Centre report card, NIA/KPI

2. **Clinical performance monitoring/CUSUM**: Track individual clinician’s performance against national standards
Clinical practice variation & opportunity for quality improvement

Huge variation in median prescribed KT/V for HD patients among more than 200 HD centres, *NRR report 2005*
Survival rate of preterm babies BW1-1500 gm by centres 2006
CUSUM charts of Trainee & Consultant Nephrologists’ Renal Biopsy performance

CUSUM charts show the cumulative sum of deviations from a target value over a series of procedures. The graph plots the number of procedures against the cumulative sum (CUSUM) value, illustrating trends and deviations in performance over time.
To achieve excellent performance?

Clinical care for individual patients

Clinical service for a population of patients

Performance measure (4Es):
1. Effectiveness
2. Efficiency
3. Equity
4. Esteeming
Clinical service for a population of patients

Examples of how registry data can be useful to address the following:

1. Healthcare financing
2. Healthcare facilities
3. Healthcare workforce
4. Medical technology/devices
5. Medicines use
• Of the 25 Billion healthcare expenditure in 2006, how much was spent on your clinical service?
• And if you don’t know, how do you justify asking for more?
Level of access (*measured by patients on RRT per million population*) is increasing over time, in fact exceeding Malaysia’s economic growth rate.
Example: Dialysis Financing

Dialysis Patients and Cost

- Dialysis patients
- Dialysis Cost

Cost per year (2005 RM mil.)

N dialysing patients

- 1990
- 1995
- 2000
- 2005

Dialysis patients Dialysis Cost

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Research that matters to patients
International comparison shows that Malaysia attained level of access comparable to rich developed countries, in spite of being much poorer.
Example: Healthcare Workforce

- Categories: Nephrologists, Nurses trained

Graph shows the number of Nephrologists and Nurses trained from 1990 to 2005.
Example: Availability of facilities & workforce matter

Figure 1.3 Relationship between availability of cardiac surgical services and provision of emergency CABG for patients admitted with ACS in 2006

Data source: NCVD-ACS Registry
To achieve excellent performance?

- Clinical care for individual patients
- Clinical service for a population of patients

Performance measure (4Es):
1. Effectiveness
2. Efficiency
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4. Esteeming
Example: Clinical effectiveness: 5-year patient survival from 1991 to 2000

Unadjusted 5-year patient survival, 1991-2000

Dialysis program Health Outcomes assessment
Example: Effectiveness

- For life-years saved Rx A = Rx B
- But patients on Rx A had better QOL, hence QALYs for A > B
Example: Efficiency

Affordability can be measured by ratio of Rx cost to household income. A declining ratio (due to BOTH increase income & decreasing Rx cost) demonstrates improving healthcare economic efficiency.
Improving economic efficiency saves lives

Improving healthcare economic efficiency enable more patients to access dialysis for the same expenditure. 13.4% (1786) fewer patients would be on dialysis at 2005 level of expenditure in the absence of efficiency gain.
In healthcare, concern is with **distributive justice** i.e. distribution of benefits or burdens.

“Equals ought to be treated equally and unequals unequally” *Aristotle*

“From each according to ability, to each according to need.” *Marx*

1. The benefit of healthcare should be distributed according to need regardless of income or geography (**Horizontal equity**)
2. The burden of financing for healthcare should be distributed according income; the rich should pay proportionately more than the poor (**Vertical equity**).
Equity of access to dialysis Rx in Malaysia

One way to evaluate this is to investigate the geographic distribution of access to treatment (Geographic equity). Other ways are to examine Rx distribution in relation to income, Socio-economic status, employment sector etc.

Distribution of Dialysis treatment in Malaysia by state, 1997-2004
Measuring healthcare equity

**Concentration curve**: Graph of healthcare vs Income distribution
Area bet. Line of Equality & Curve below X 2 = Concentration Index.
0 is complete equality; +1 complete inequality in favor of the rich

**Y axis**
Cumulative distribution of healthcare in the population

**X axis**
Cumulative distribution of income RM in the population ranked from poorest to richest
Equity of access to dialysis Rx in Malaysia

Geographic equity in access to dialysis in Malaysia has improved over time, from positive in the 1990s to negative from 2000s.
In 2005 (Gini’s coeff = 0.462), the poorest 10% of the population had 3% of income; while the richest 10% had 30%. Half the population had 85% of income.
Vertical equity in dialysis financing

In 2005, public financing proportionate to income distribution but private financing highly regressive; the poor pay disproportionate more for dialysis.
CRC’s framework for evaluating registries
Registry as a tool for **Clinical Excellence**?

- **Clinical care for individual patients**
- **Clinical service for a population of patient**

**Performance measure (4Es):**
1. Effectiveness
2. Efficiency
3. Equity
4. Esteeming
Other uses of patient registry

- Chronic disease management
- Pharmaco-vigilance
- Clinical trial
Patient registries: a central component of the chronic care model

Phil McEvoy, Sylvain Laxade

Phil McEvoy is Service Leader, Primary Care Mental Health Service, Salford PCT and Research Associate, University of Manchester. Sylvain Laxade is Senior Commissioning Manager, Long-Term Conditions, Salford PCT.

The number of individuals with long-term conditions is increasing due to the aging of the population and there is an urgent need to modernize the services that are provided to this group. Information. Registries can support the organization and delivery of care to patients in a variety of different ways. For example, a registry of all the patients with diabetes...
Patient registries provide a mass of evidence on the performance and safety of new drugs in larger and more diverse populations than those covered in clinical trials. Dr Richard E Gliklich and Michelle Bertagna explain why their use looks set to increase as healthcare professionals and providers focus on evidence-based medicine.
PCI or CABG in coronary artery disease?

In *The Lancet* today, Mark Hlatky and colleagues report a pooled analysis of individual data from almost 8000 patients enrolled in ten randomised trials of percutaneous coronary intervention (PCI) and coronary artery bypass grafting (CABG) over the past two decades. They conclude that, while at a median 6 years’ follow-up there was no overall difference in survival, there was a significant survival advantage with CABG in patients with diabetes (hazard ratio already well established that there was no prognostic benefit with CABG. By largely excluding patients with a known survival benefit from CABG (left-main or triple-vessel coronary artery disease, or both, and especially with impaired ventricular function), the trials ignored the prognostic benefit of surgery in more complex coronary artery disease. Nevertheless, inappropriate generalisation of trial results from highly selected populations to most patients with multivessel

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**PCI or CABG for Coronary artery disease?**

- Are trial results generalizable to most real world patients undergoing PCI or CABG?
Thank You