

Patient Registers: **10 Reasons Why You Need One**

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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

#	Patient registries			Health databases
1	National Renal Registry	National Suicide Registry	M'sian Cardio-Thoracic Registry	Healthcare Establishment & Workforce Survey
2	National Transplant Registry	Nat. CVD (ACS/PCI) Database	National Neurology Registry	Health professional registers
3	National Eye Database	Nat. Dermatology Registry	National Chest Registry	National Medicines Use Survey
4	Malaysian National Neonatal Registry	National Cancer Patient Registry	National Urology Registry	National Medical Device Survey
5	Malaysian Liver Registry	Hematological Malignancy Reg.	National ORL Registry	National Medical Care Survey
6	Malaysian GI Registry	National OT Register	National Nuclear Medicine Database	JPN National Death Register
7	National Trauma Database	Malaysian Registry of Intensive Care	National Radiology Registry	Post-Operative Mortality Review
8	Diabetes Registry of Malaysia	Nat. Inflammatory Arthritis Registry	National O&G Patient Registry	Maternal Mortality Register
9	National Mental Health Registry	Nat. Orthopedic Reg Malaysia		National Paediatric Mortality Register

CRC

Research that matters to patients

Statistical Reports from Patient Registries

15th REPORT OF THE MALAYSIAN DIALYSIS TRANSPLANT REGISTRY 2007

NATIONAL TRANSPLANT REGISTRY

3rd REPORT OF THE NATIONAL TRANSPLANT REGISTRY 2007

Editors:
Hooi L.S.
Lela Yasmin Mansor

With contributions by:
Alan Teh K H, Chan L L, Shamala R, Choong Y Y, Michael Lu Mohamed Ezani, David Chew S P, Ashari Yunos, Ganesalingam Lim CB, Tan SS, Gob BL, Surina Sheikh

Report of the Malay National Neonatal Registry 2005

A Study of Critically Ill babies in Neonatal Intensive Care Units

Forensic Medicine Services
Psychiatry and Mental Health Services
Ministry of Health Malaysia

National Suicide Registry Malaysia

PRELIMINARY REPORT: JULY-DECEMBER **2007**

Diabetes in Children and Adolescents Registry (DICARE)

Annual Report of Diabetes in Children and Adolescents Registry (2006-2007)

The First Report of the National Eye Database 2007

The Second Report of the National Eye Database 2008

Includes reports on:
Cataract Surgery Registry 2002, 2003, 2004 and 2007
Diabetic Eye Reg
Contact Lens Reg
Glaucoma Reg
Ophthalmology ?

Edited by:
Goh Pik Pin
Elias Hussein
Mairam Ismail

With:
Zuraidah Mustai, Shamala Reth Chandran
Loh Swee Seng, Roda

NATIONAL TRAUMA DATABASE MAY 2006 TO APRIL 2007 FIRST REPORT

National Trauma Database

National Cardiovascular Disease Database (NCVD)

ANNUAL REPORT OF THE NCVD-ACS REGISTRY 2006

EDITORS:
WAN AZMAR WAN ANWAR, TAN KUI-UIAB

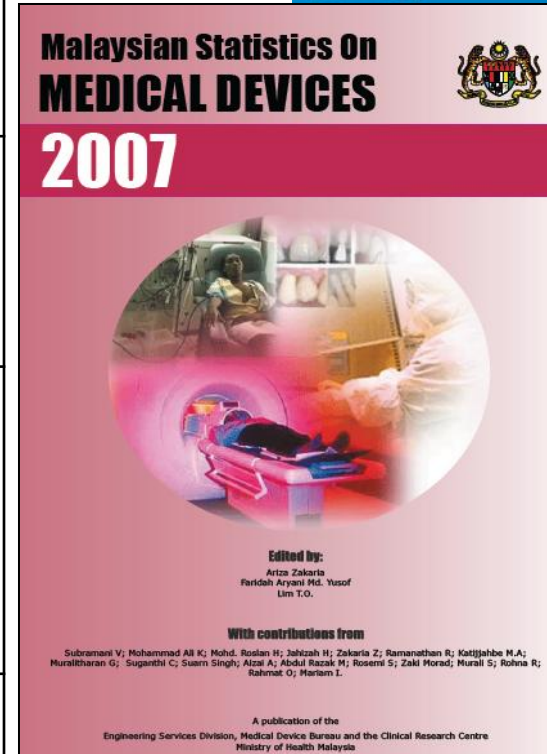
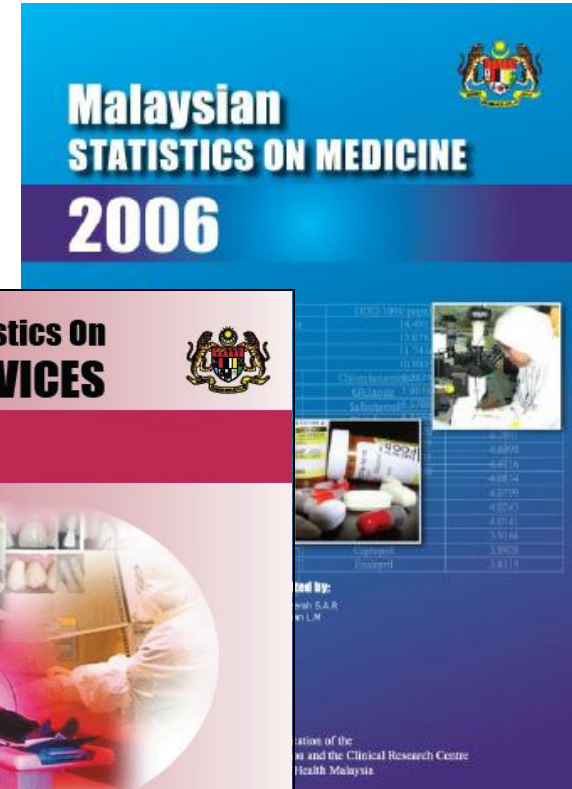
NHAM National Heart Association of Malaysia

CRC Research that matters to patients

Healthcare Statistics projects

Drugs, Med. Technology, Facilities, Healthcare & Workforce

#	Healthcare Surveys
1	National Medicines Use Survey
2	National Medical Device Survey
3	National Healthcare Establishment & Workforce Surveys (NHEWS) (NEW)
4	National In-Patient Care survey (incl. Hospital Discharge & Surgical Procedures) (NIPCS)
5	National Ambulatory Medical Care Survey (NAMCS) (NEW)



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
patient

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?

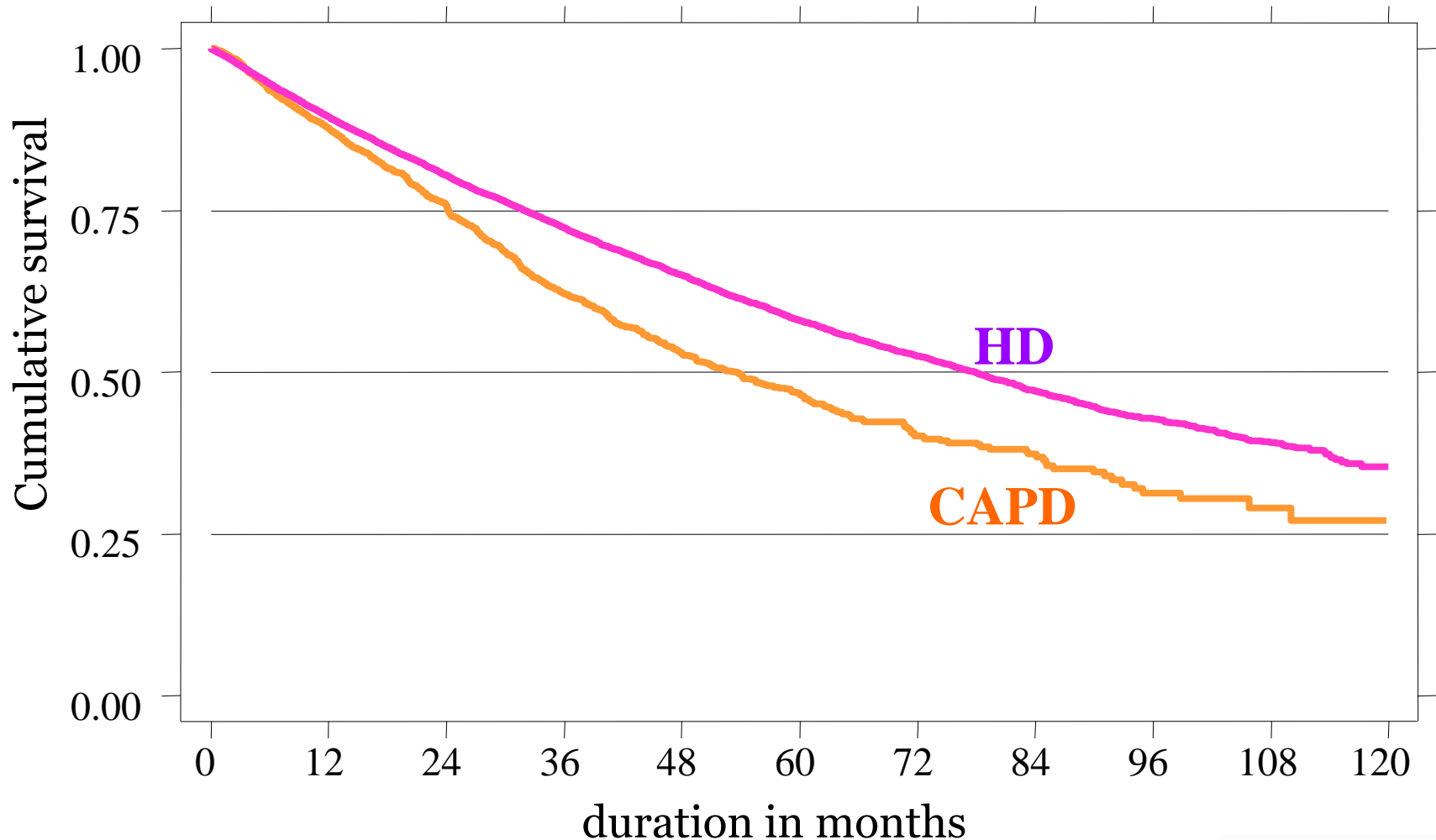
Clinical care for **individual patients**

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

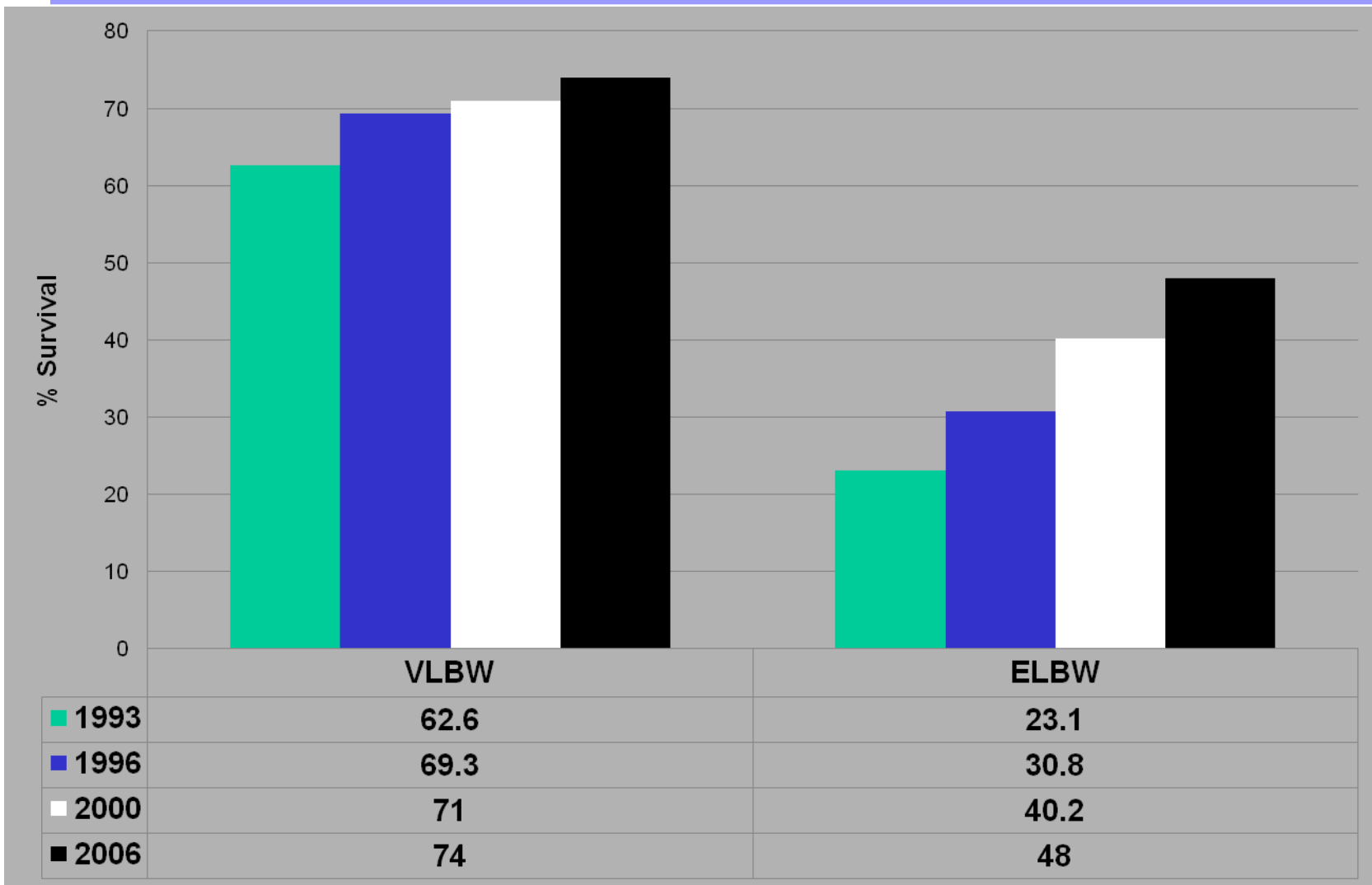
Kaplan-Meier survival estimates, by modality



**Dialysis patient survival by
Dialysis modality 1997-2006**

Survival on discharge

Data from the M'sian Neonatal Reg



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)

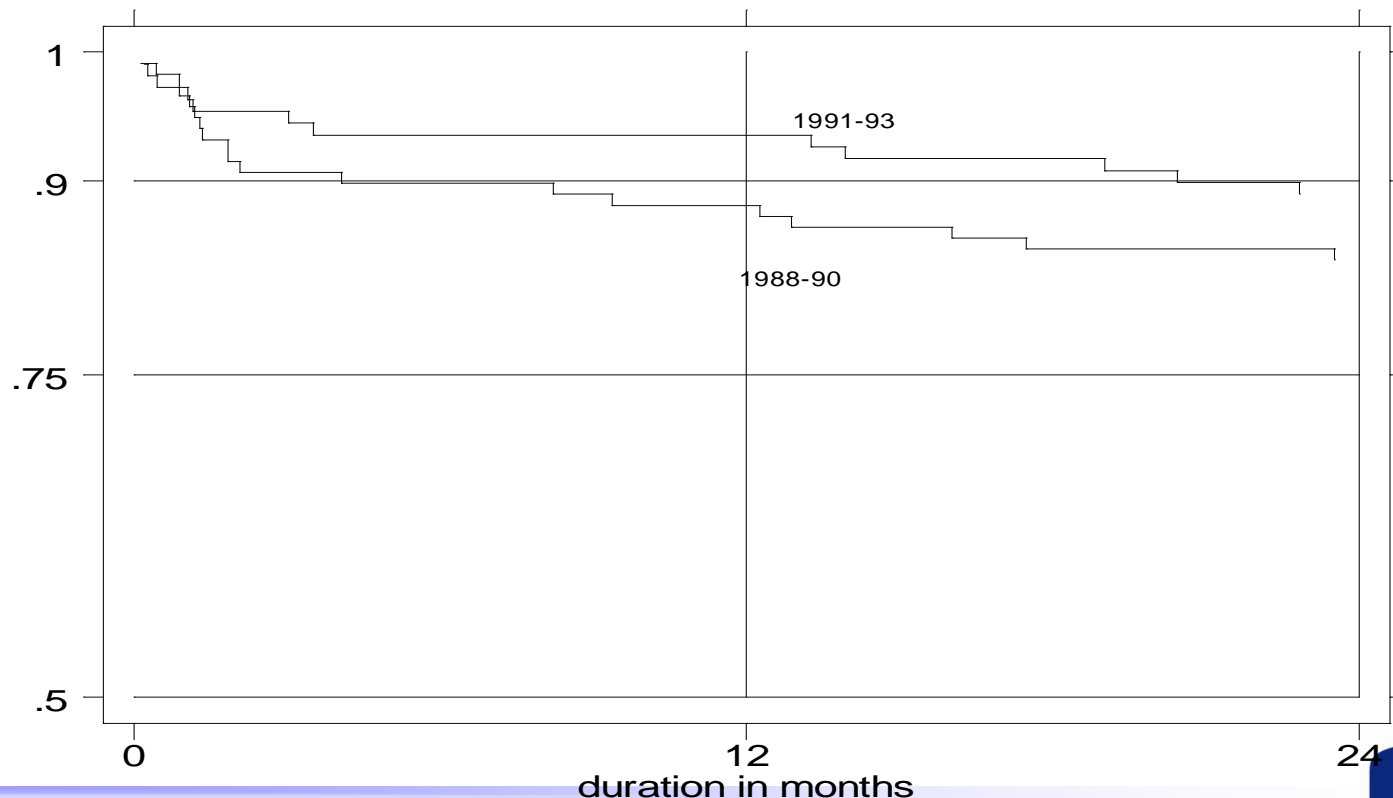
	<i>MOH</i>	<i>NZ</i> ⁶	<i>US</i> ⁷	<i>CANADA</i> ⁸
Centre HD	21,620	77,231	135,255	182,428
Home HD	23,375	61,695	139,478	-
CAPD	30,469	56,691	-	125,115

Example: Health technology assessment

Introduction of Cyclosporine A

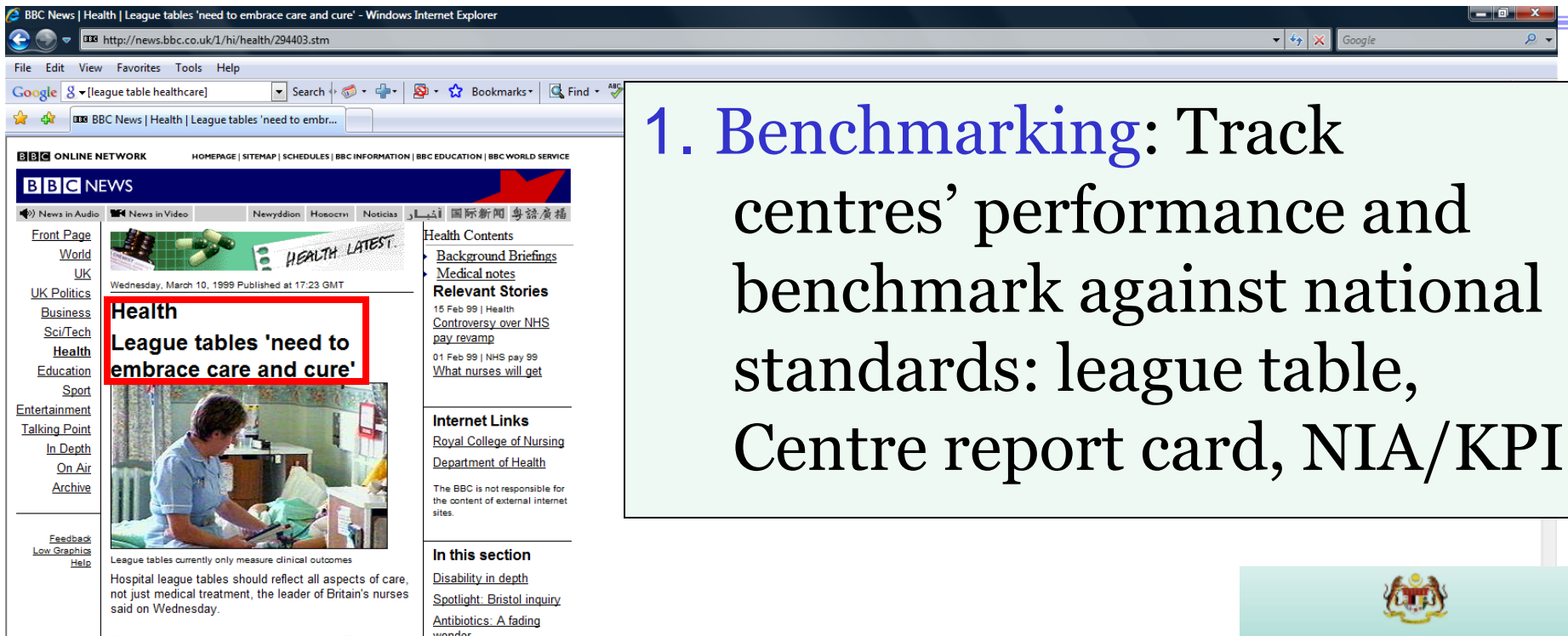
(a new & expensive immuno-suppressive drug in the early 1990s) improve graft survival by only about 5% at 1 and 2 years

Kaplan-Meier survival estimates, by Yr



Graft survival before and after CsA, 1988-93

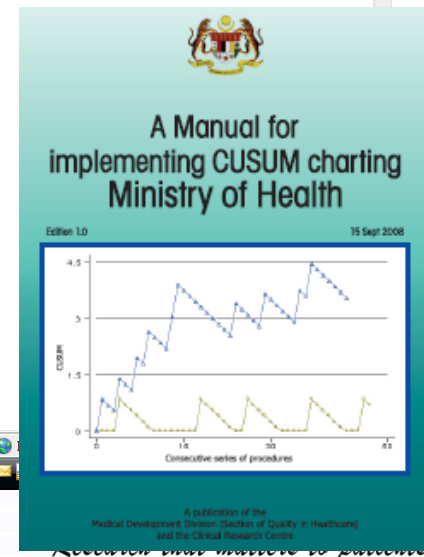
Example: Clinical Audit



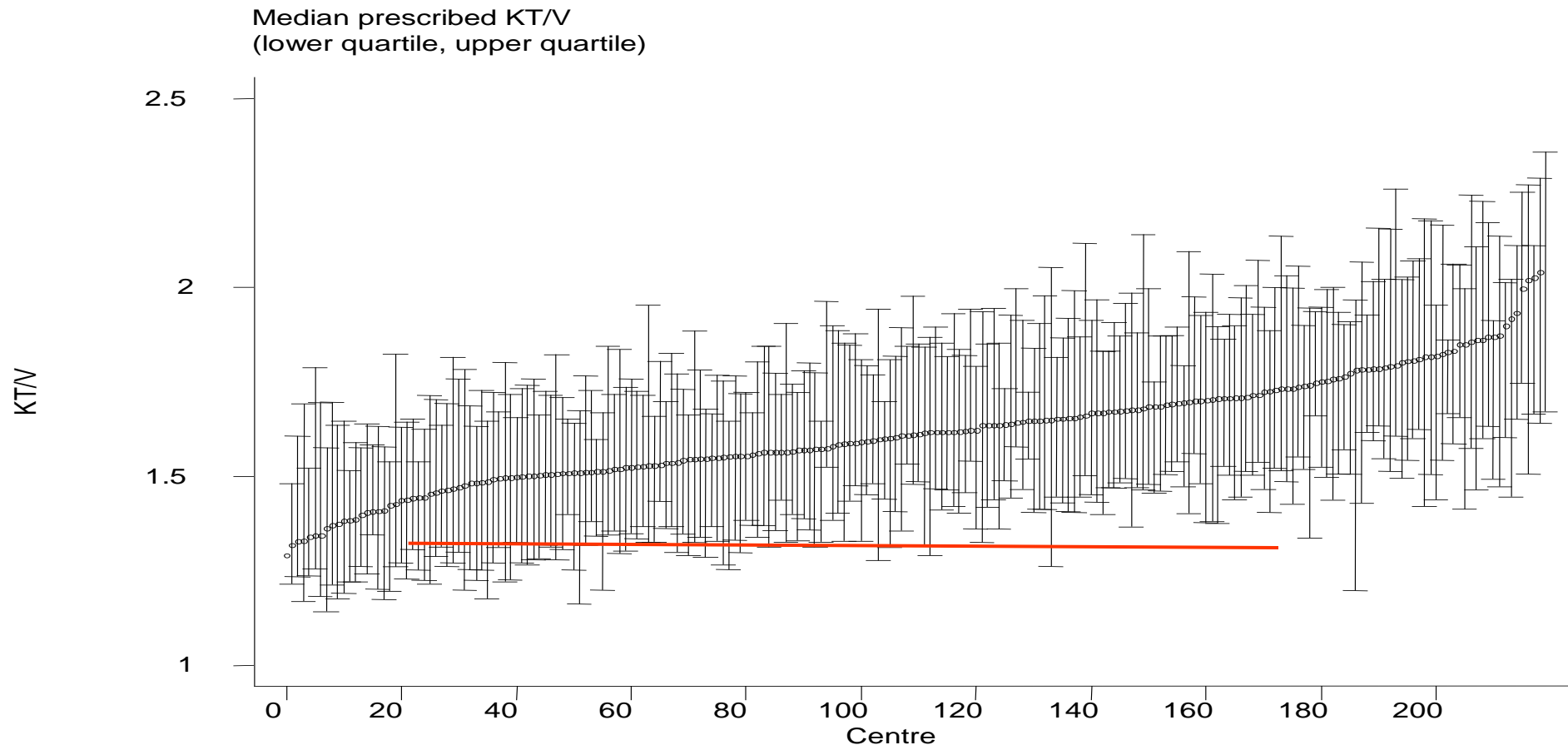
The screenshot shows a web browser window displaying a BBC News article. The article title is "League tables 'need to embrace care and cure'", which is highlighted with a red box. The article is dated Wednesday, March 10, 1999. The main image shows a nurse in a hospital setting. The article text states: "League tables currently only measure clinical outcomes. Hospital league tables should reflect all aspects of care, not just medical treatment, the leader of Britain's nurses said on Wednesday." The page also features a sidebar with "Health Contents" including "Background Briefings", "Medical notes", and "Relevant Stories".

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

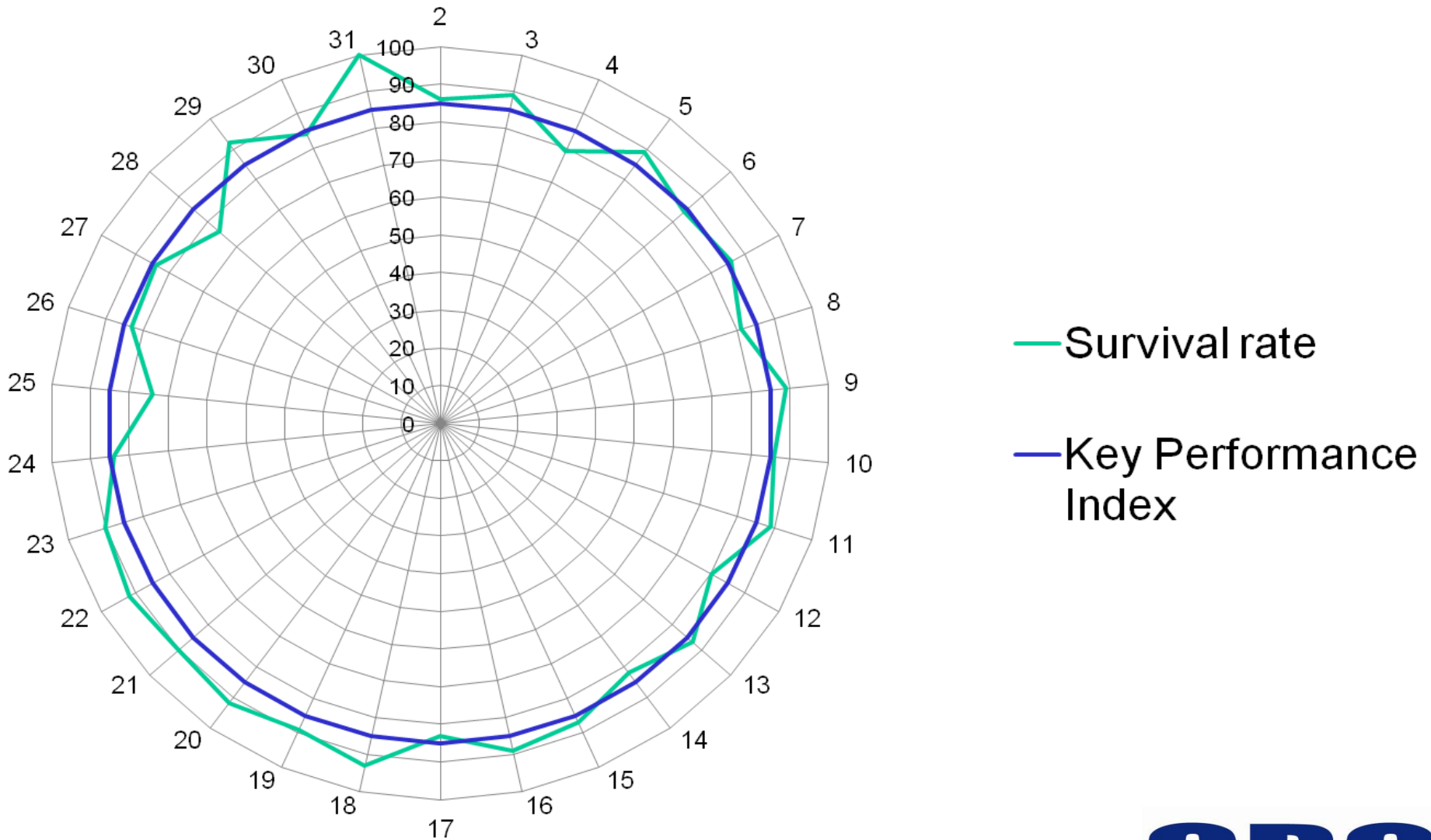


Clinical practice variation & opportunity for quality improvement

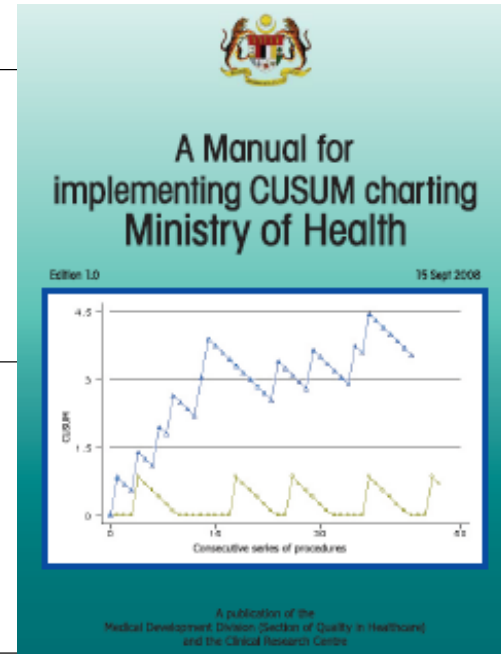
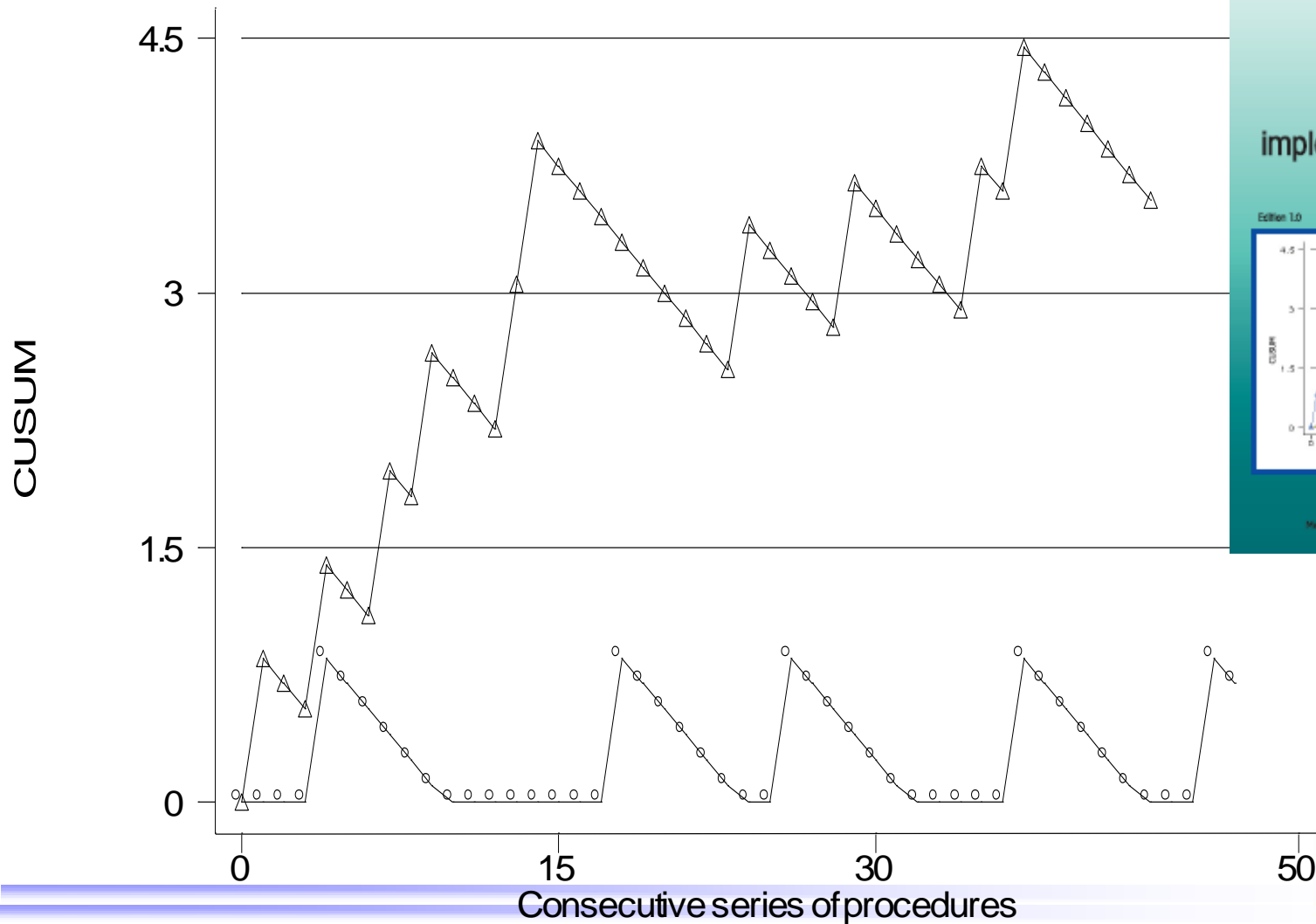


Huge variation in median prescribed KT/V for HD patients among more than 200 HD centres, *NRR report 2005*

Survival rate of preterm babies BW1-1500 gm by centres 2006

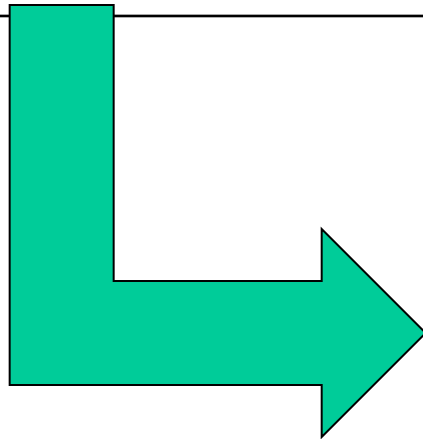


CUSUM charts of Trainee & Consultant Nephrologists' Renal Biopsy performance

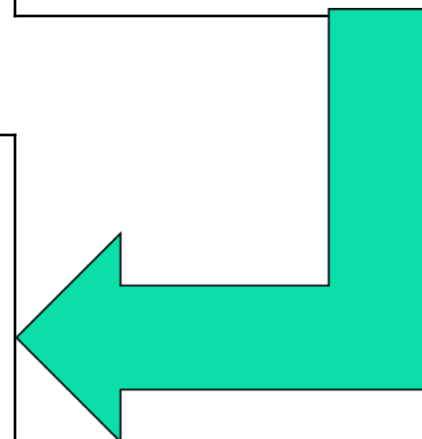


To achieve excellent performance?

Clinical care
for
individual
patients



Clinical service
for a population
of patient



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:

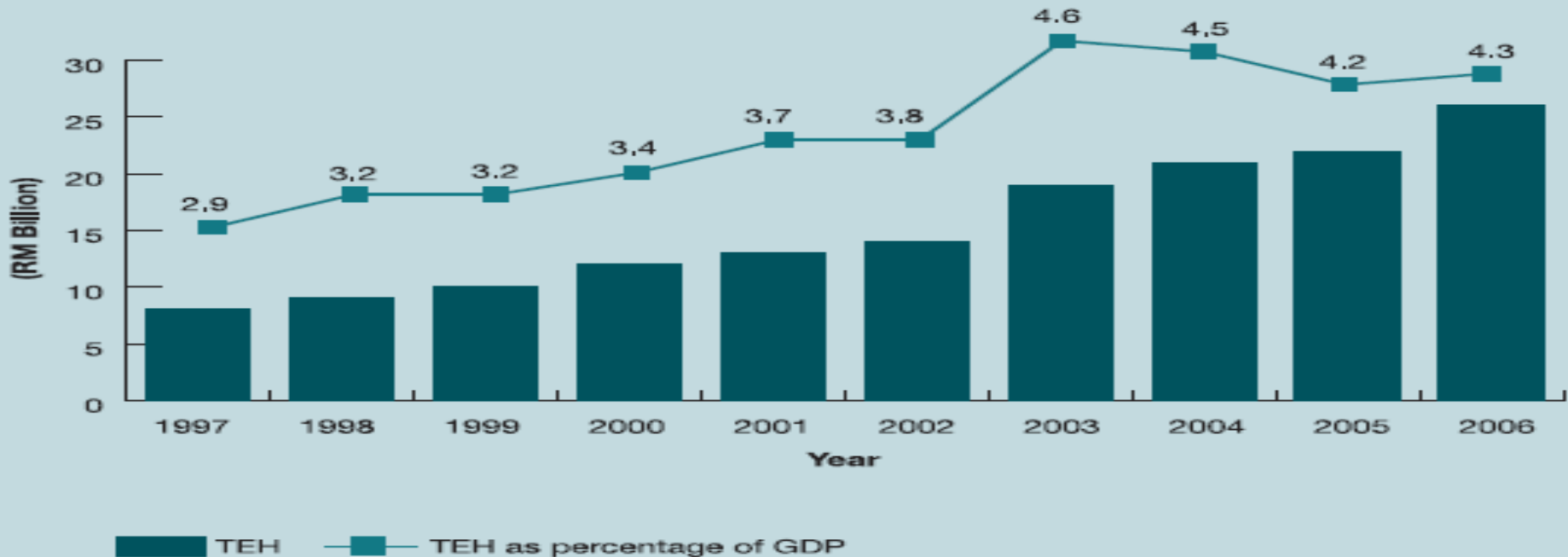
1. Healthcare financing
2. Healthcare facilities
3. Healthcare workforce
4. Medical technology/devices
5. Medicines use

Example: Healthcare Financing

Malaysia Healthcare Expenditure

Source: Malaysia National Health Account 1997-2006

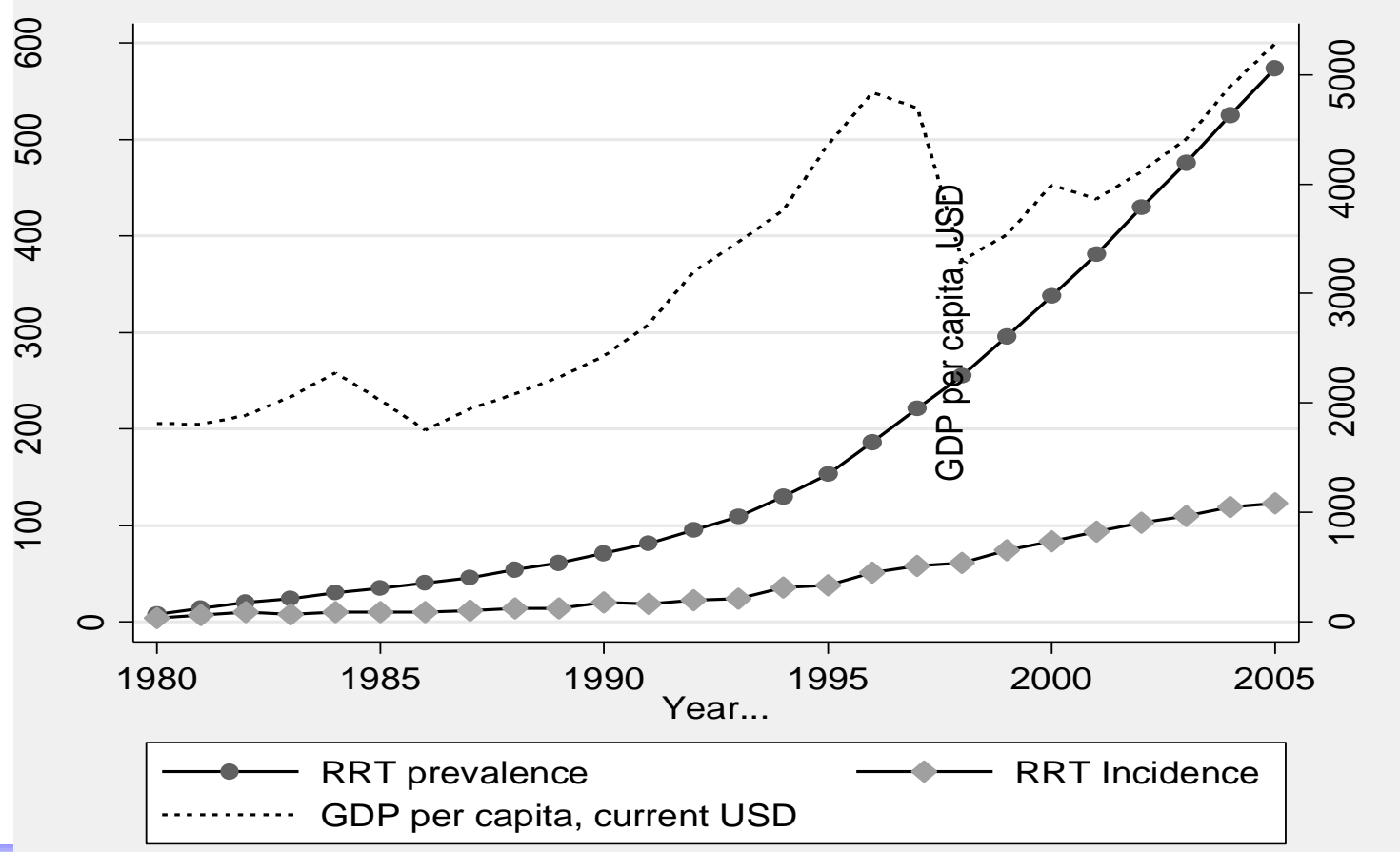
Trend for Total Expenditure on Health, 1997-2006 (RM, Nominal Value)



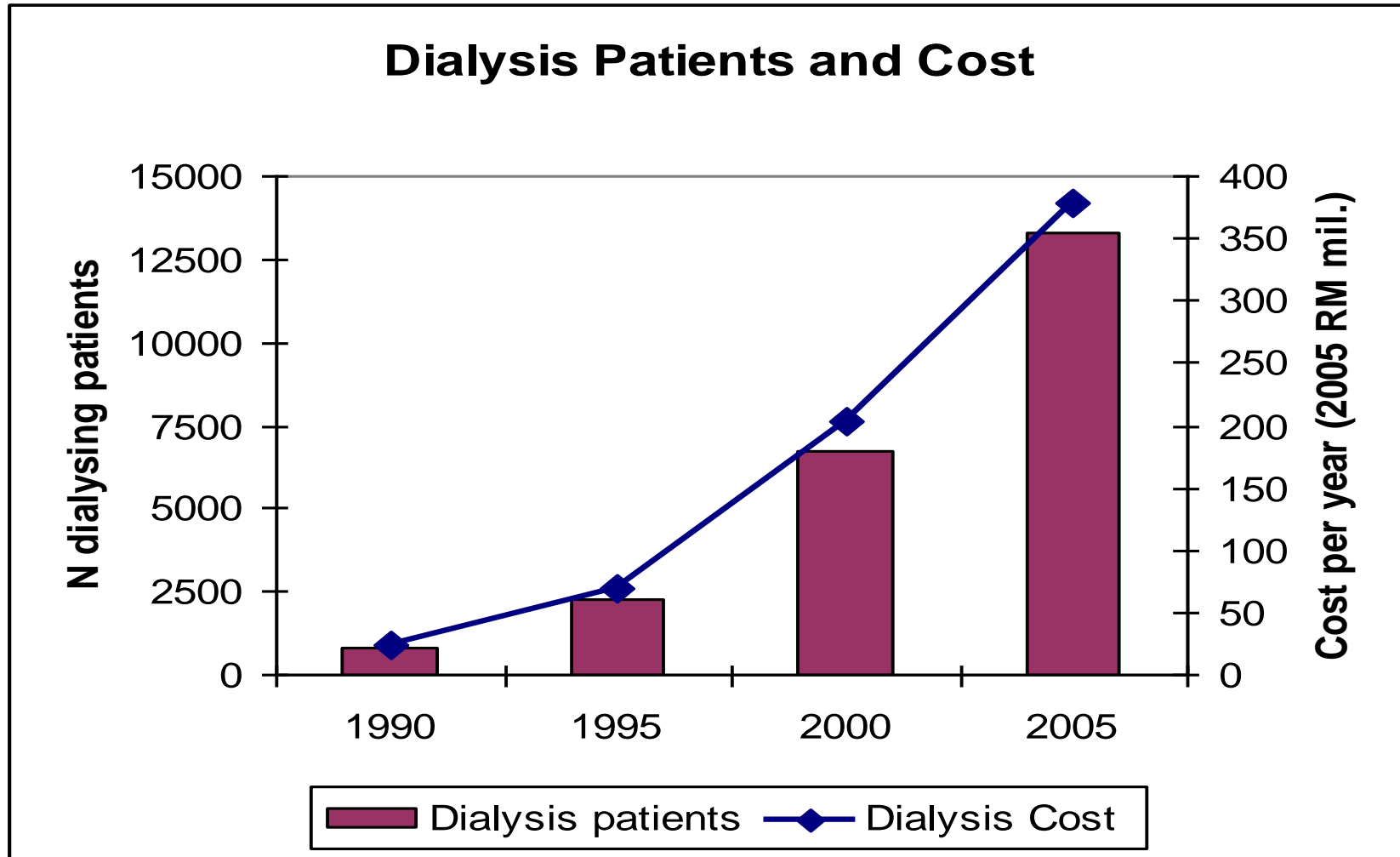
- Of the 25 Billion healthcare expenditure in 2006, how much was spent on your clinical service?
- And if you don't know, how do you justify asking for more?

Example: National wealth & Healthcare

Level of access (*measured by patients on RRT per million population*) is increasing over time, in fact exceeding Malaysia's economic growth rate

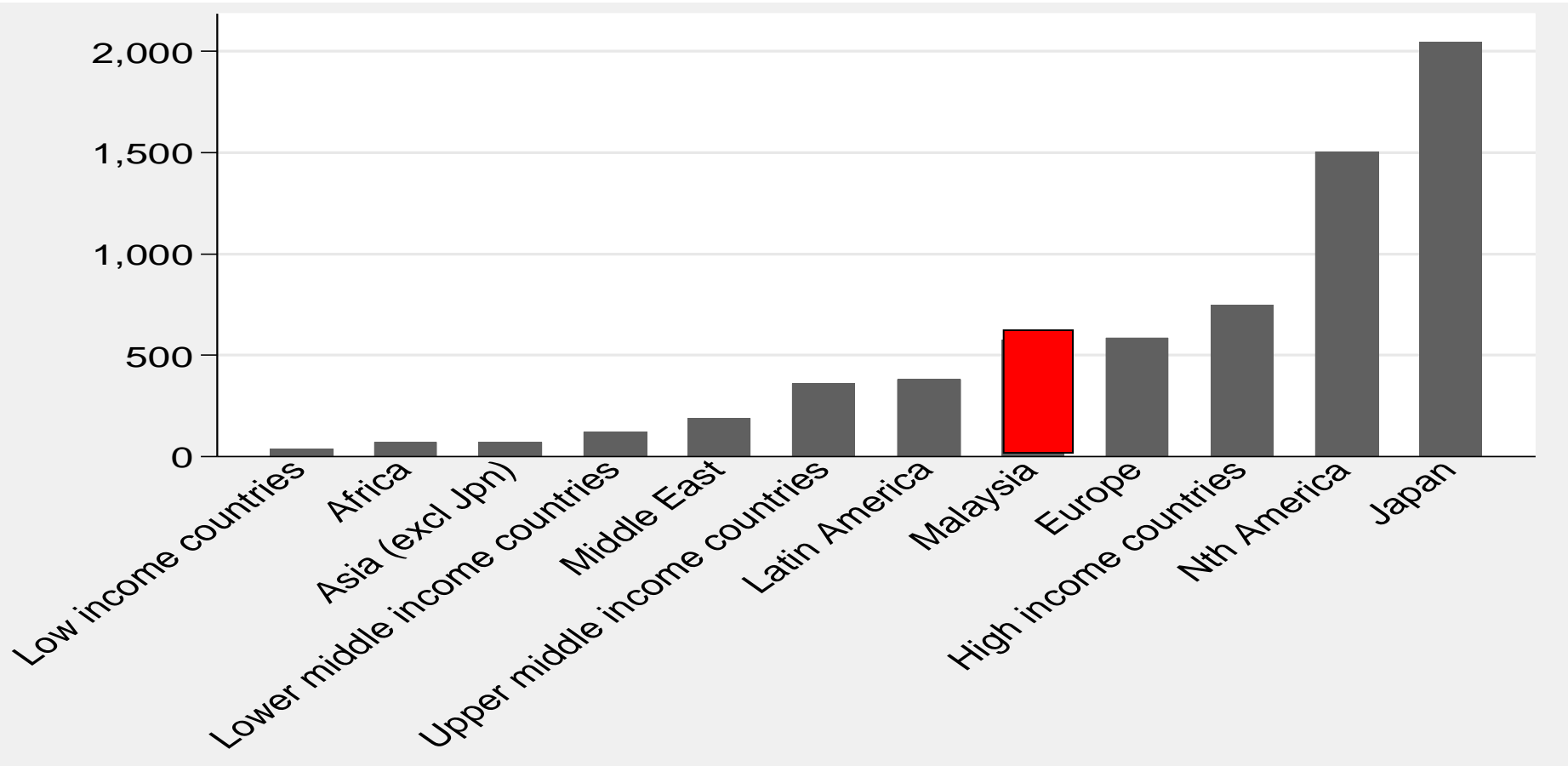


Example: Dialysis Financing

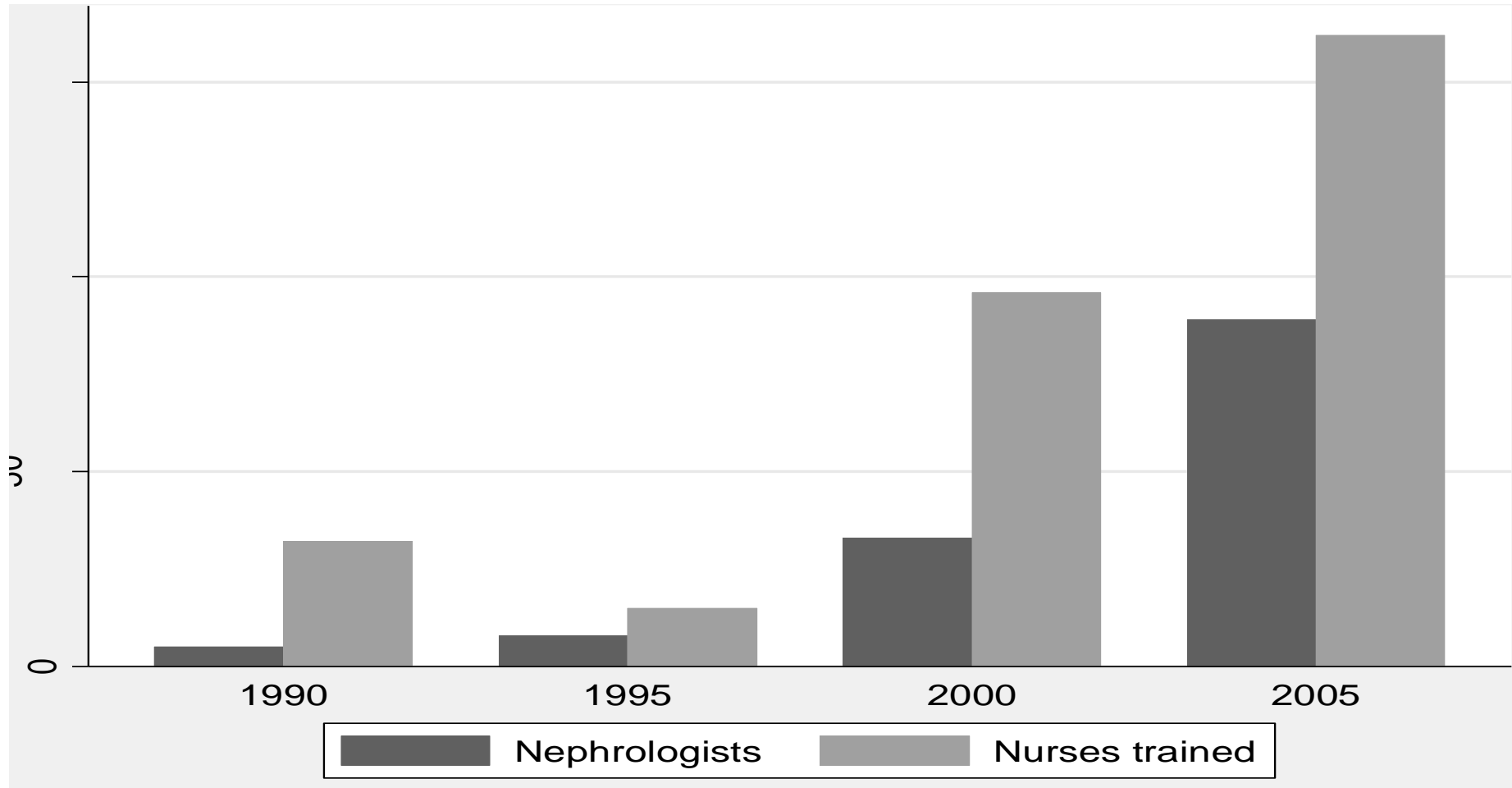


International comparison of access to Dialysis

International comparison shows that Malaysia attained level of access comparable to rich developed countries, in spite of being much poorer

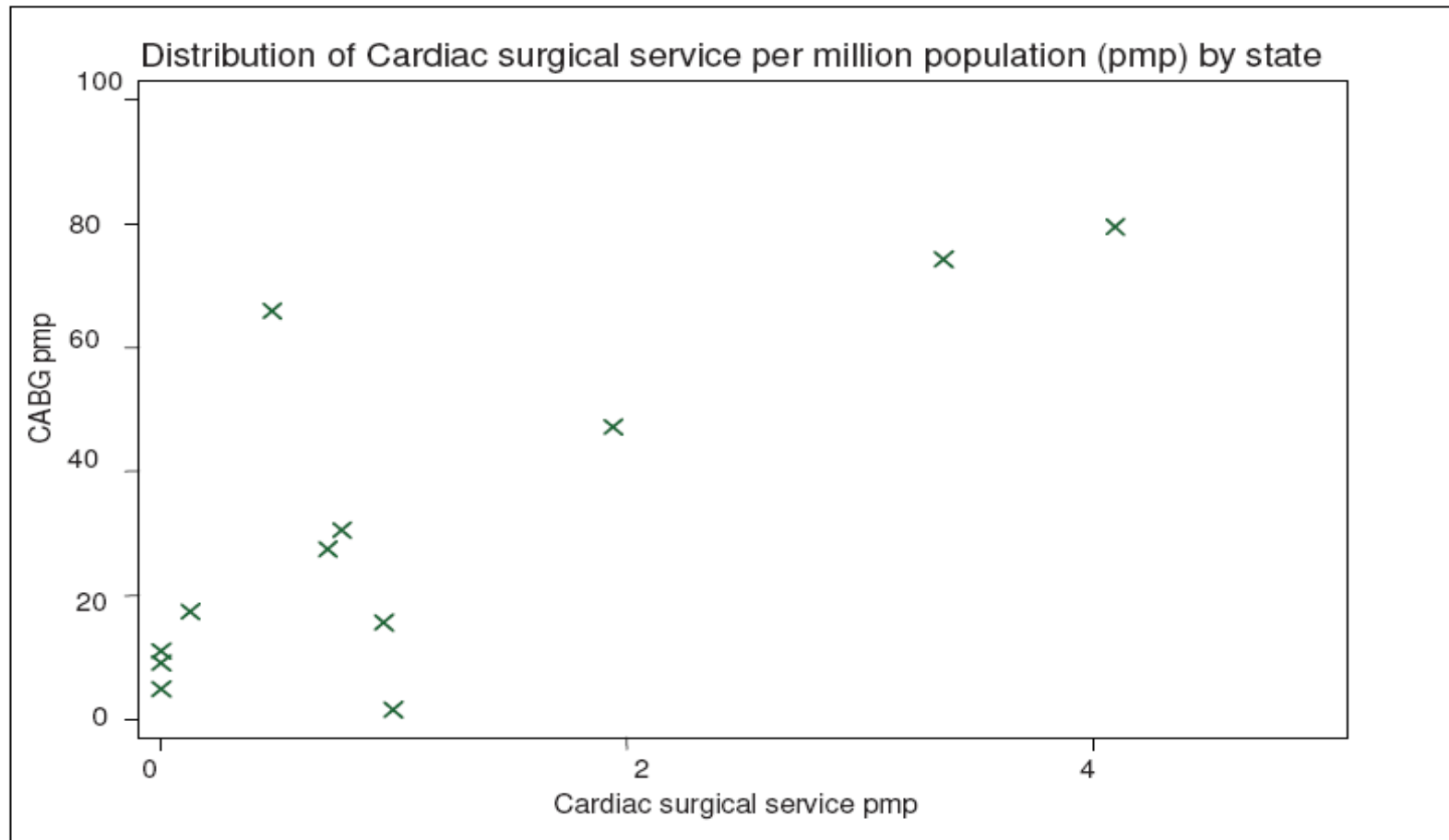


Example: Healthcare Workforce



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?

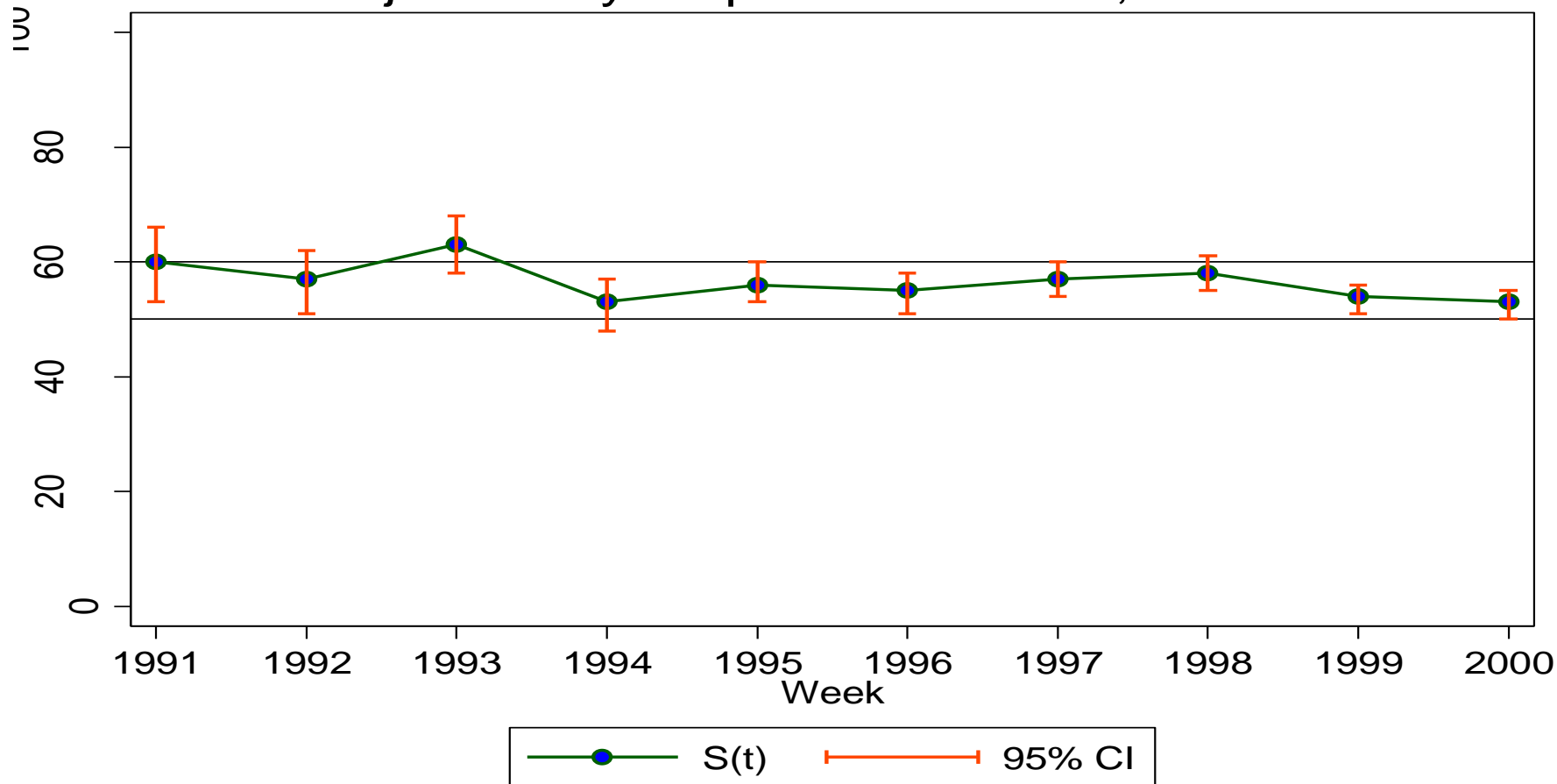
Clinical care
for individual
patients

Clinical service
for a population
of patient

**Performance
measure (4Es):**
1.Effectiveness
2.Efficiency
3.Equity
4.Esteeming

Example: Clinical effectiveness: 5-year patient survival from 1991 to 2000

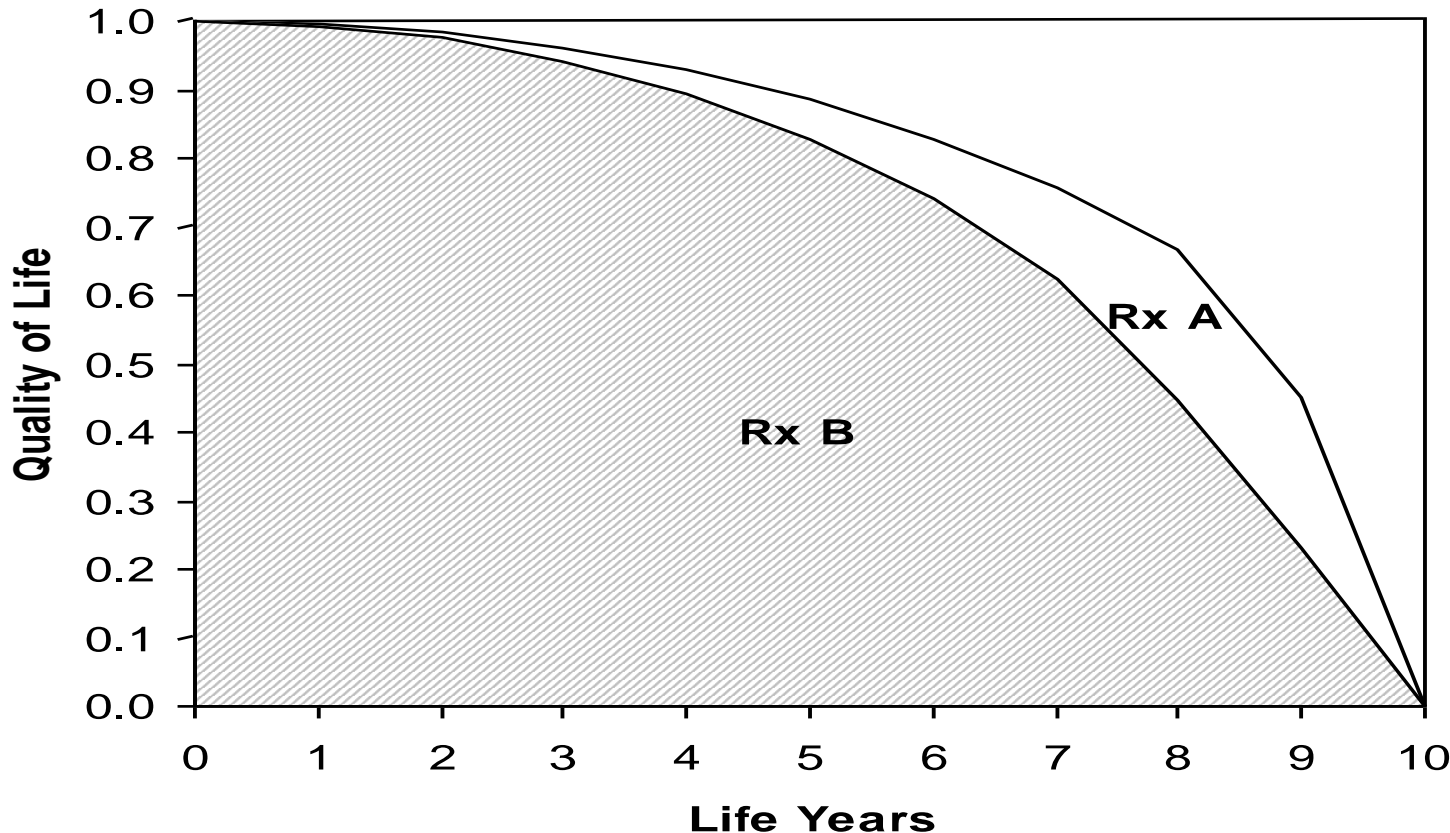
Unadjusted 5-year patient survival , 1991-2000



Dialysis program Health Outcomes assessment

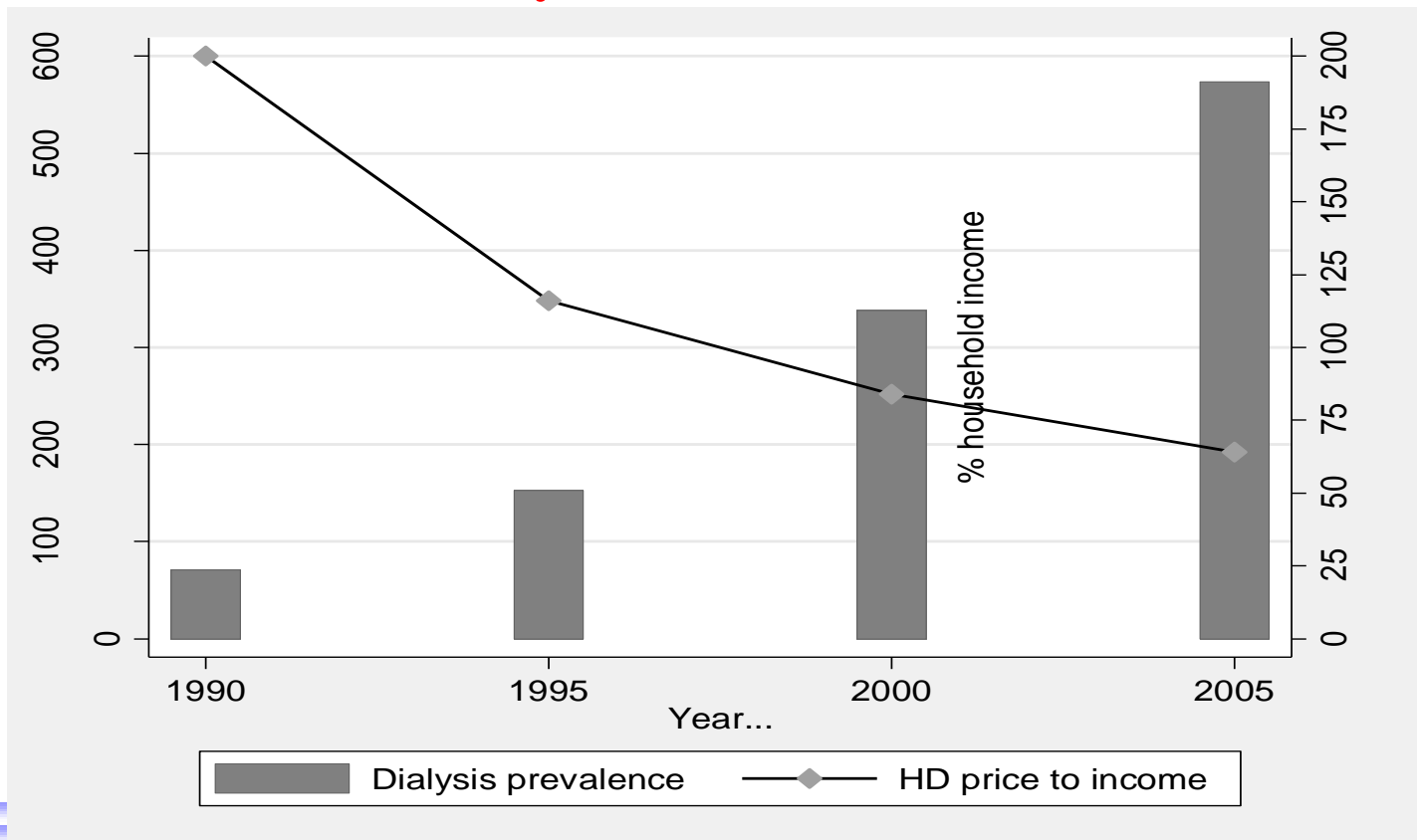
Example: Effectiveness

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



Example: Efficiency

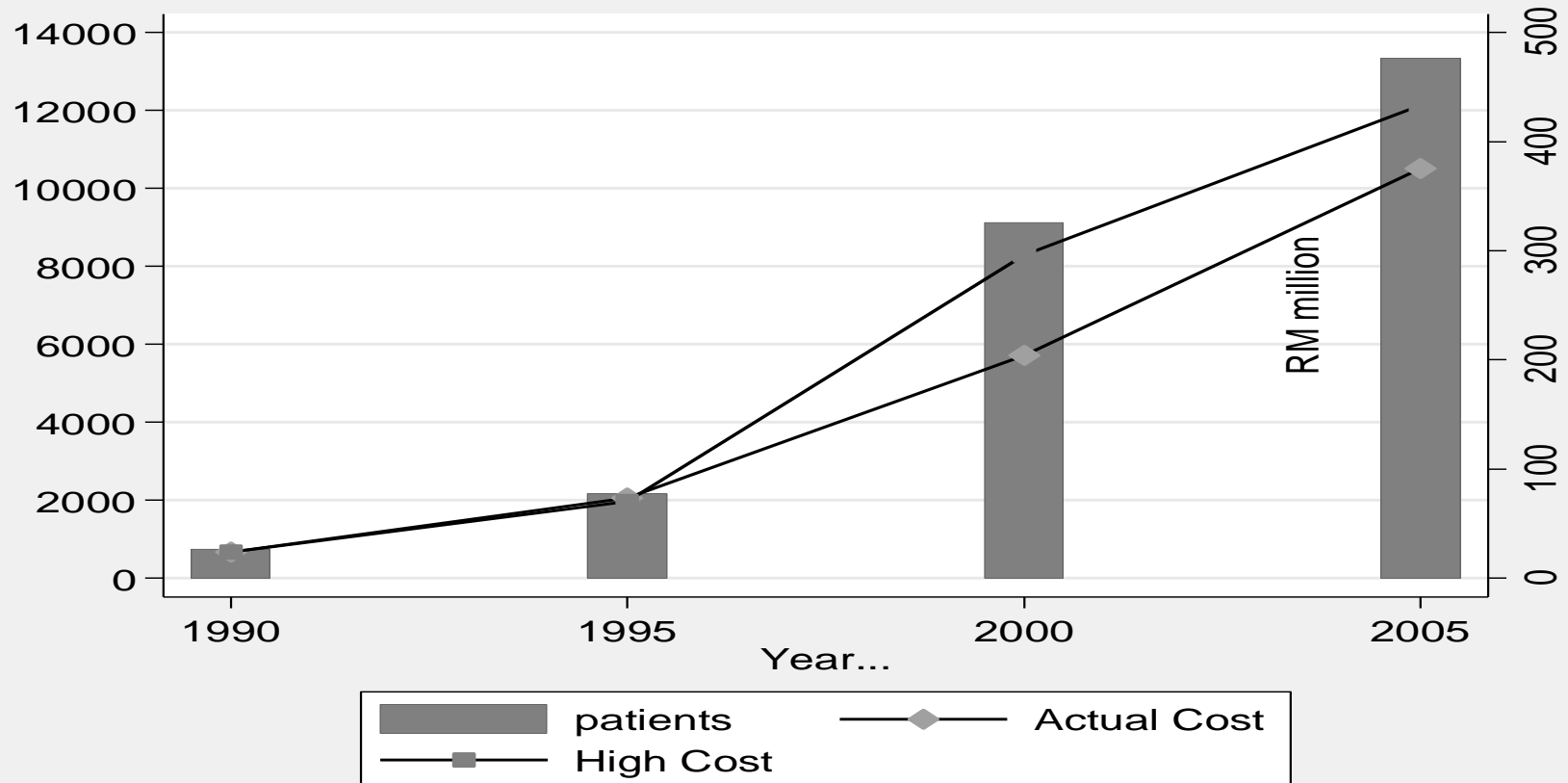
Affordability can be measured by ratio of Rx cost to household income. A declining ratio (due to BOTH increase income & decreasing Rx cost) demonstrates improving **healthcare economic efficiency**



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



Example: Equity or Justice in Healthcare

In healthcare, concern is with **distributive justice** i.e. distribution of benefits or burdens

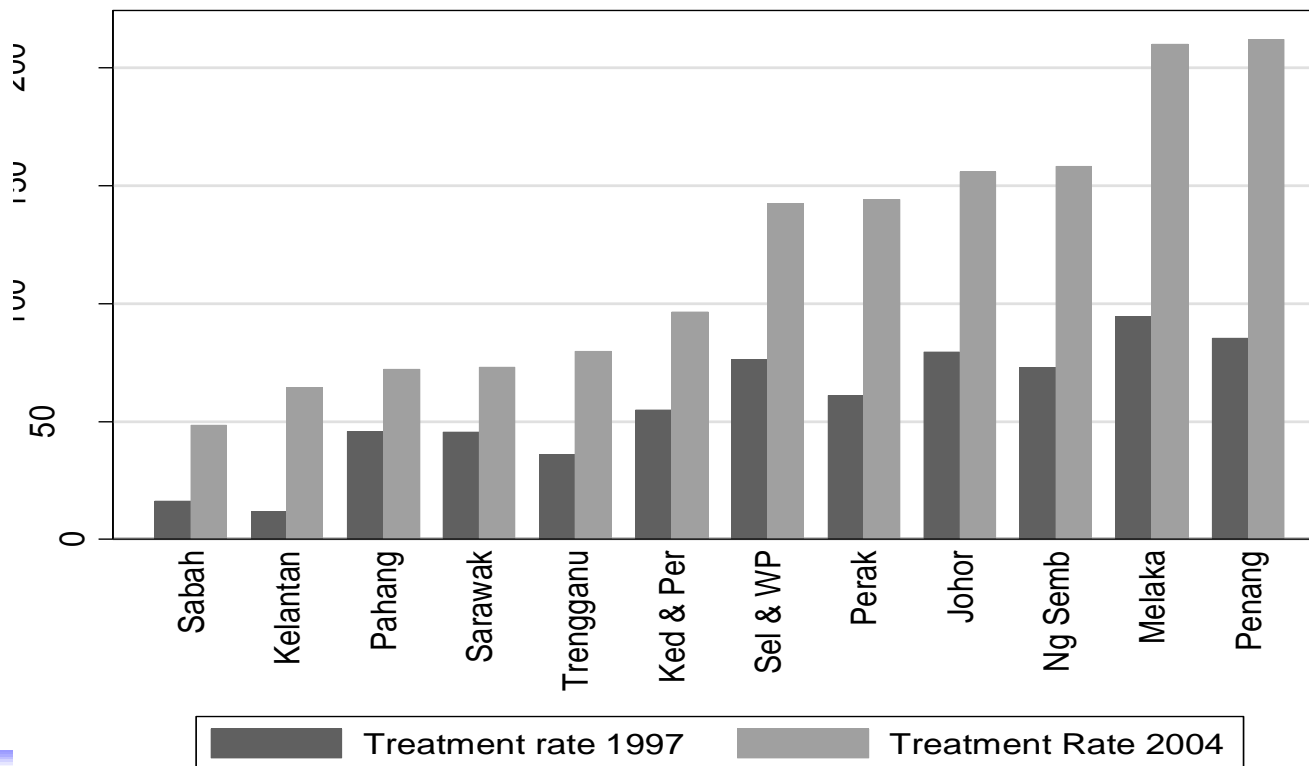
“Equals ought to be treated equally and unequals unequally” *Aristotle*

“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

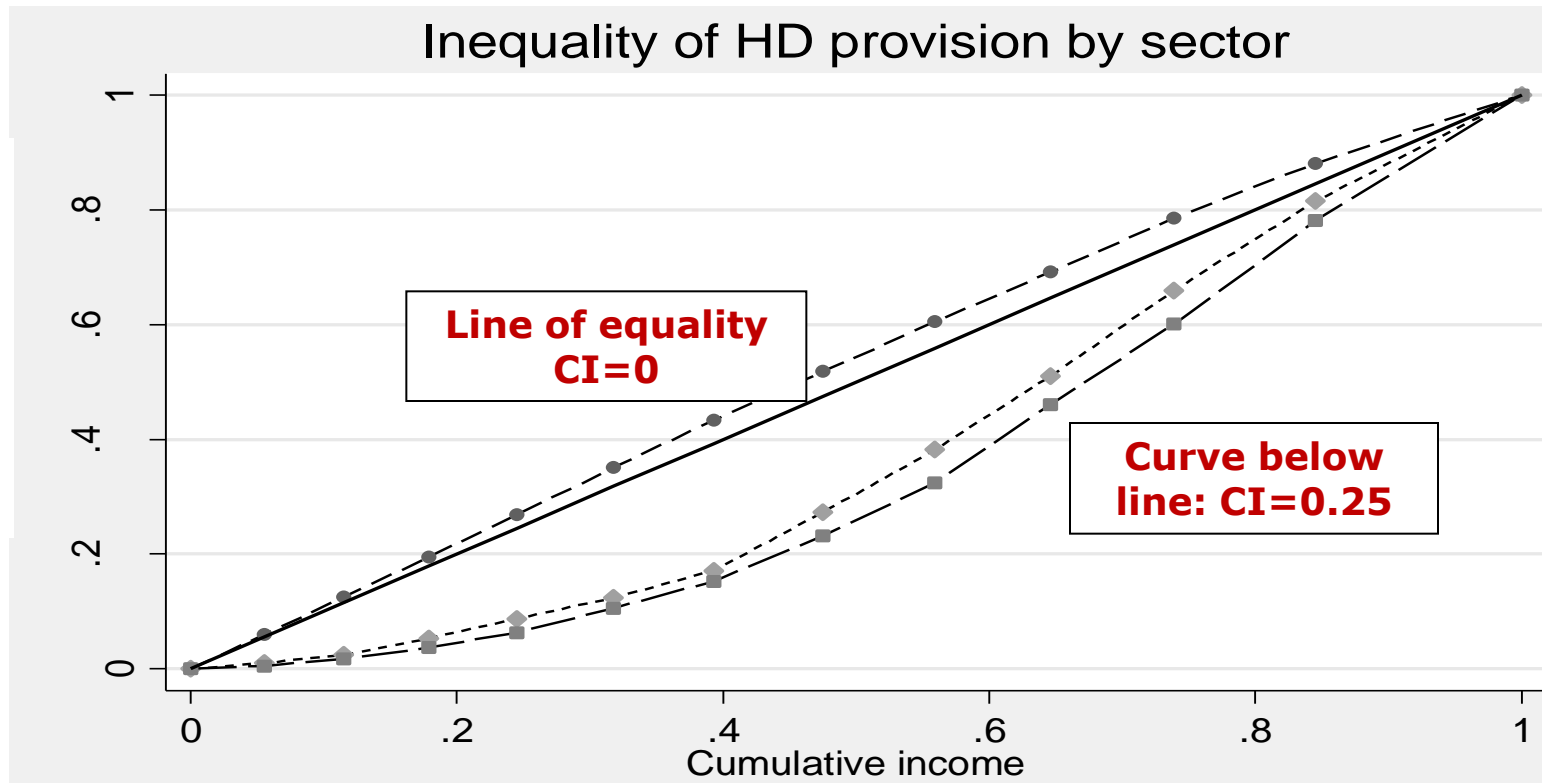


Distribution of
Dialysis treatment
in Malaysia by state,
1997-2004

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

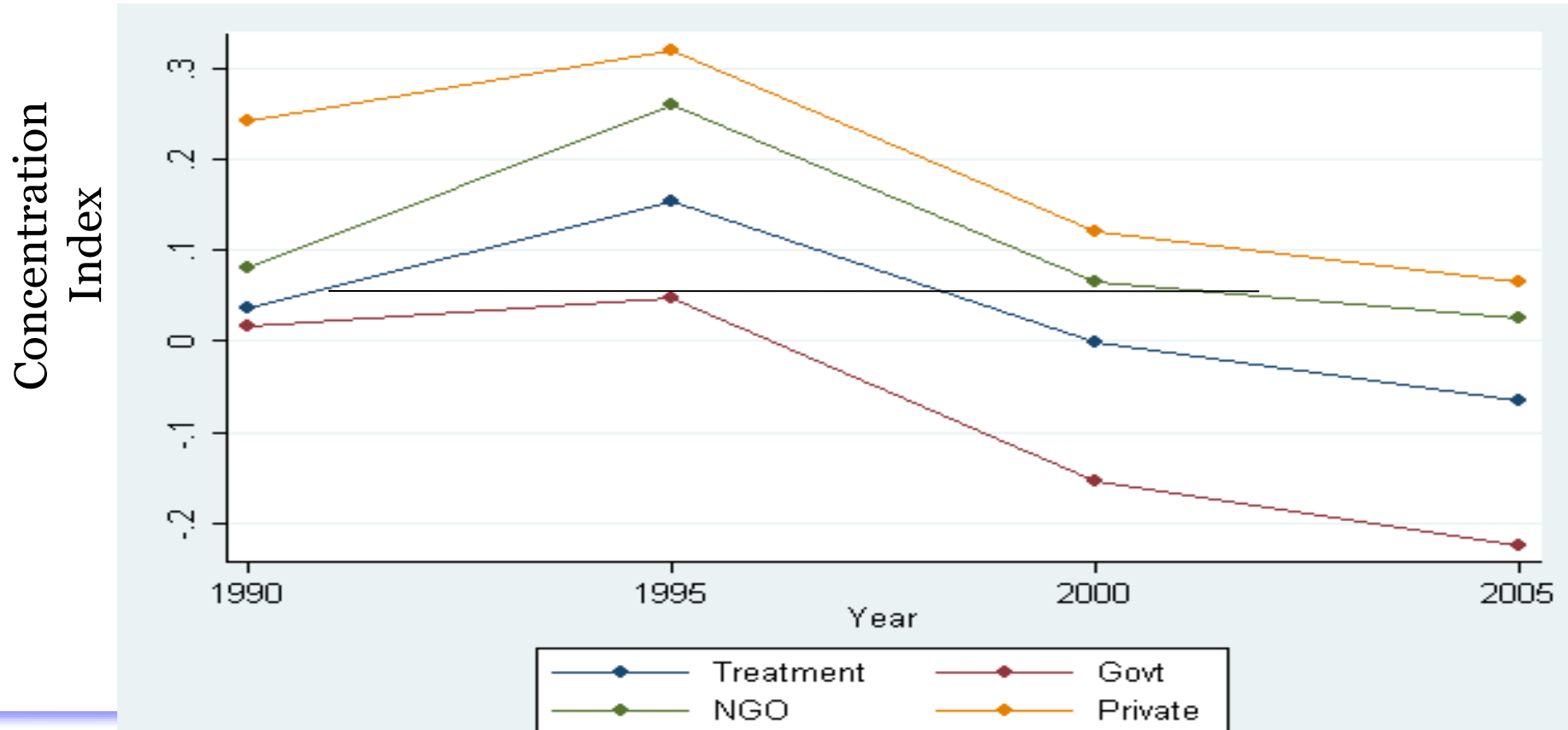
Y axis
Cumulative
distribution
of
healthcare
in the
population



X axis **Cumulative distribution of**
income RM in the population
ranked from poorest to richest

Equity of access to dialysis Rx in Malaysia

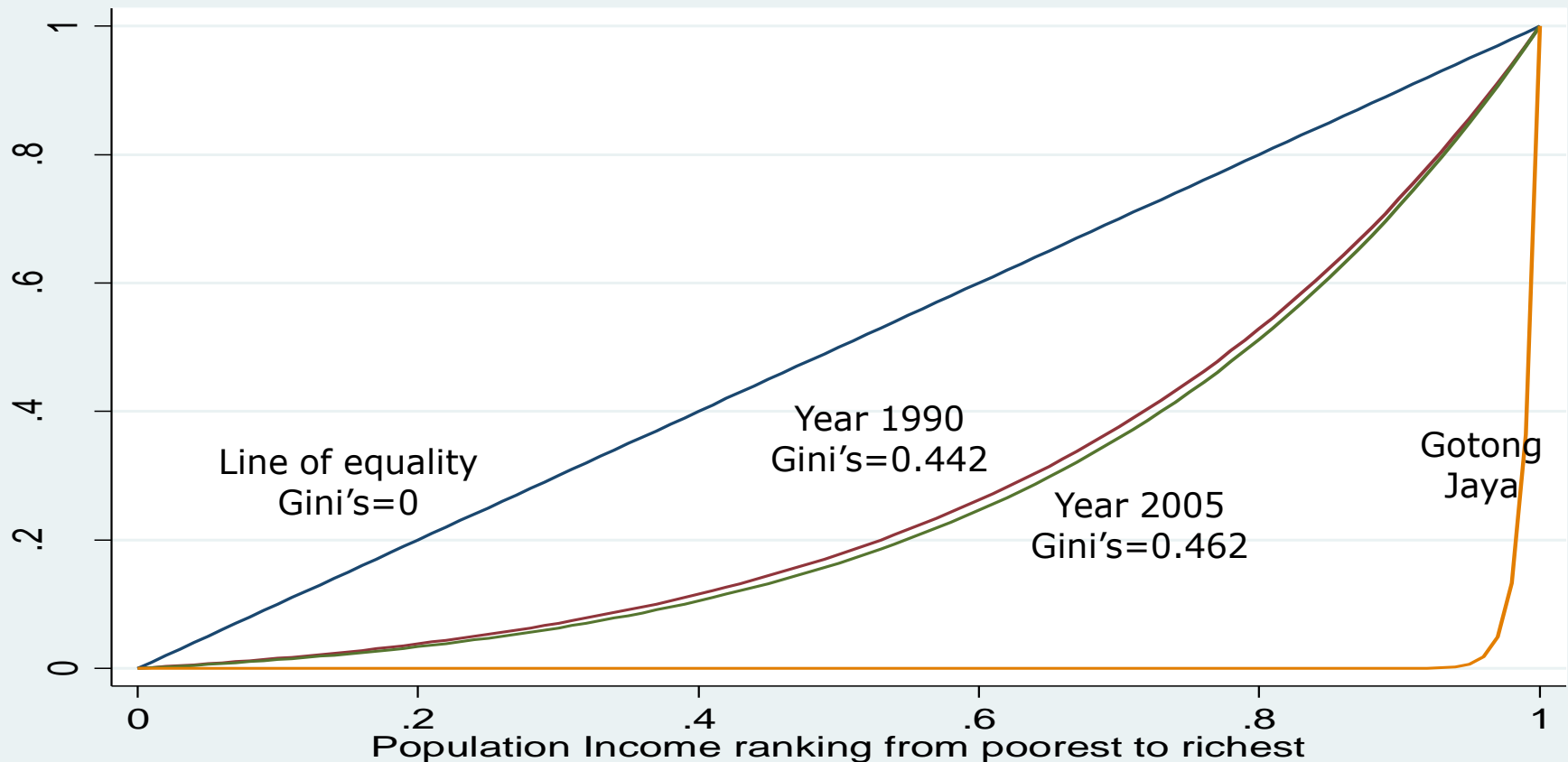
Geographic equity in access to dialysis in Malaysia has improved over time, from positive in the 1990s to negative from 2000s



Income distribution:

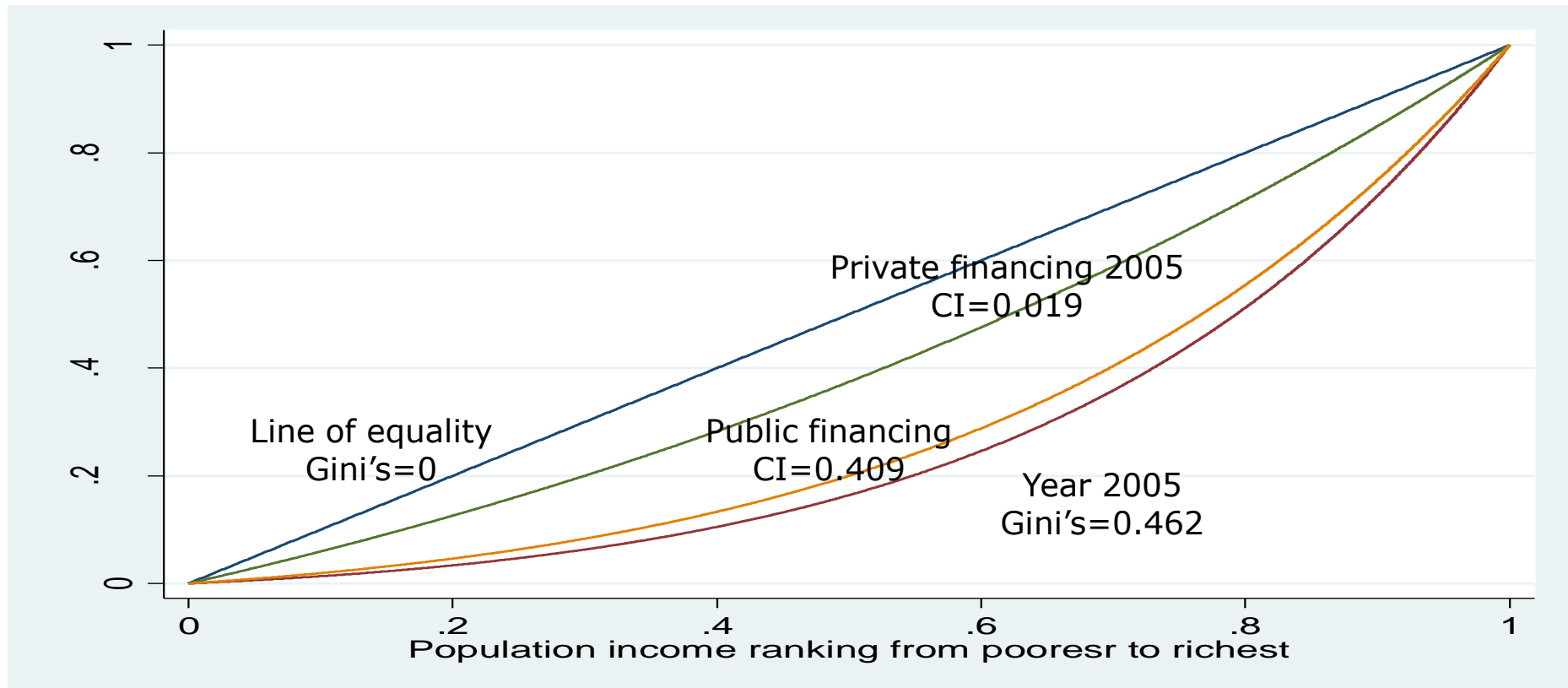
How rich are the rich in Malaysia?

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):

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Other uses of patient registry

- Chronic disease management
- Pharmaco-vigilance
- Clinical trial

Chronic care & Patient registry

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

Email: phil.mcevoy@salford-pct.nhs.uk

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 they are provided to this ...


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

...

British J Community Nursing 13(3);127

Pharmacovigilance & Patient registry



The emerging role of the patient registry

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

GCPj 2006

Clinical trial & Registry

PCI or CABG in coronary artery disease?

Published Online

March 20, 2009

DOI:10.1016/S0140-

6736(09)60574-2

See [Articles](#) page 1190

In *The Lancet* today, Mark Hlatky and colleagues¹ 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.⁴ 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 function⁴), 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

PCI or CABG for Coronary artery disease?

- Are trial results generalizable to most real world patients undergoing PCI or CABG?
- SYNTAX Trial: incorporates a registry arm for patients excluded from randomization *Serruys PW et al. N Engl J Med 2009; 360: 961–72.*

Thank You

www.crc.gov.my

HELPING THEM GET RESULTS;

The Collaborative Research Experience

