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Measuring health-related quality of life in evaluating healthcare

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Health care

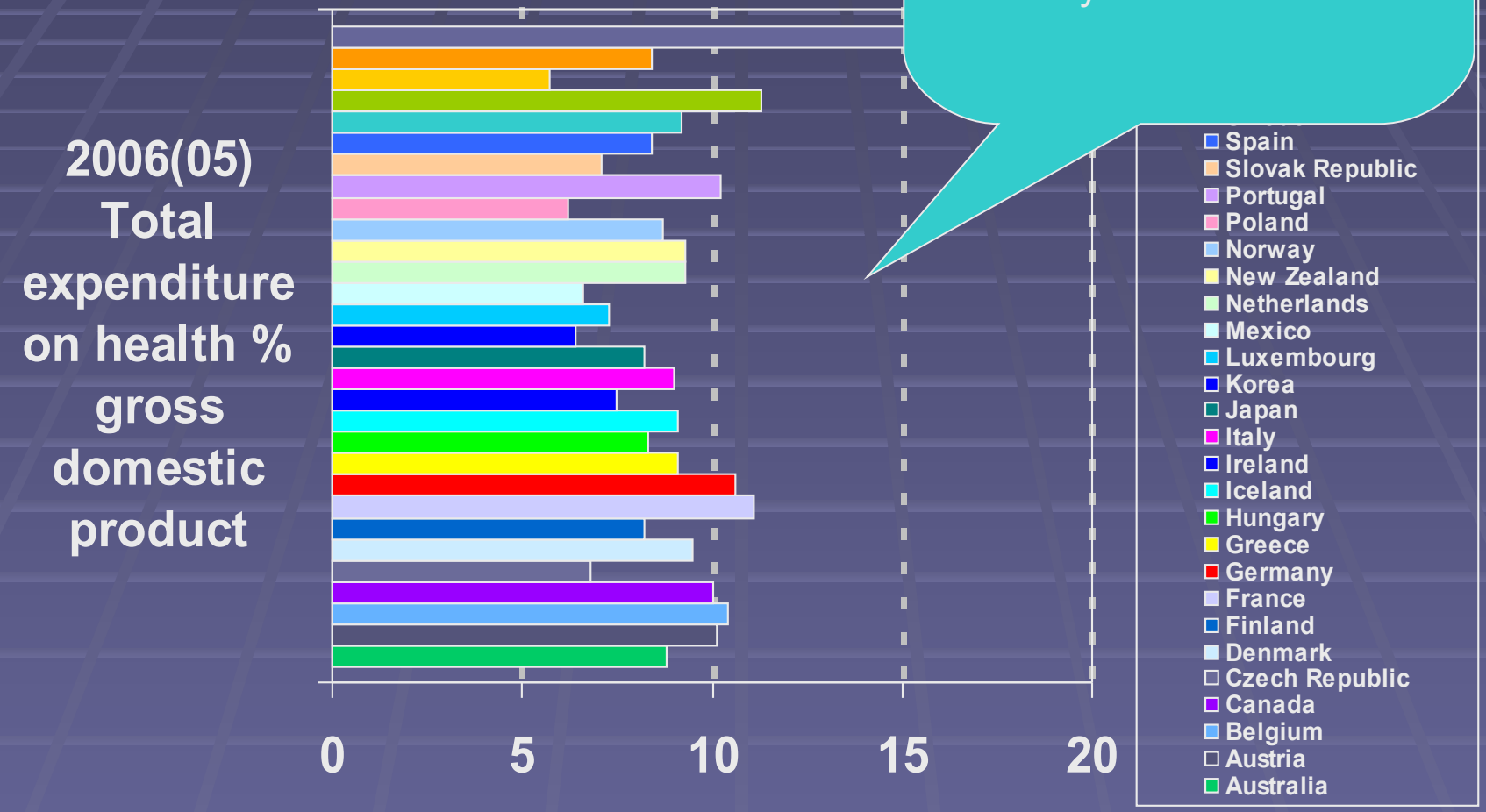
- Health care is an important dimension of daily life for individual citizens and countries
  - Health care reform in the United States
  - Health care spending in the UK
- Health (and consequently health care) is not a major daily concern for individuals until they become ill or need help
- Most people have simplistic ideas about healthcare
  - More is always better
  - “Prevention is better than cure”
  - The doctor always knows (best)

Health care – real politique

- Health care resources in any country are always limited
- No healthcare system can provide ***all*** possible treatments for ***all*** patients for ***all*** time
- Demographic change and advances in new medical technologies create increased pressures and make this situation more difficult for policy and decision-makers
- Setting priorities in healthcare is a fact of life

Recent levels of hea

If the US spends 16% of its GDP on healthcare and the UK spends 8% …… Does that mean US citizens are twice as "healthy" as UK citizens ?



Source : OECD.Stat 2008

Health care

- Designed / delivered with the intention of altering the “natural” health status of patients over time
- Relieving pain, suffering
- Prolonging (enabling) life
- Easing process of dying
- Cure (sometimes)

Hippocratic Oath : First, do no harm

- Fundamental question : how do you know if you are helping / harming the patient ?
- As a decision-maker / clinician, you need to know
  - *does treatment CHANGE anything ?*
  - *what is the DIRECTION of change ?*
  - *what is the MAGNITUDE of change ?*

NHS

National Institute for Health and Clinical Excellence

Guide to the methods of technology appraisal

Issue date: June 2008

National Institute for Health and Clinical Excellence (NICE)

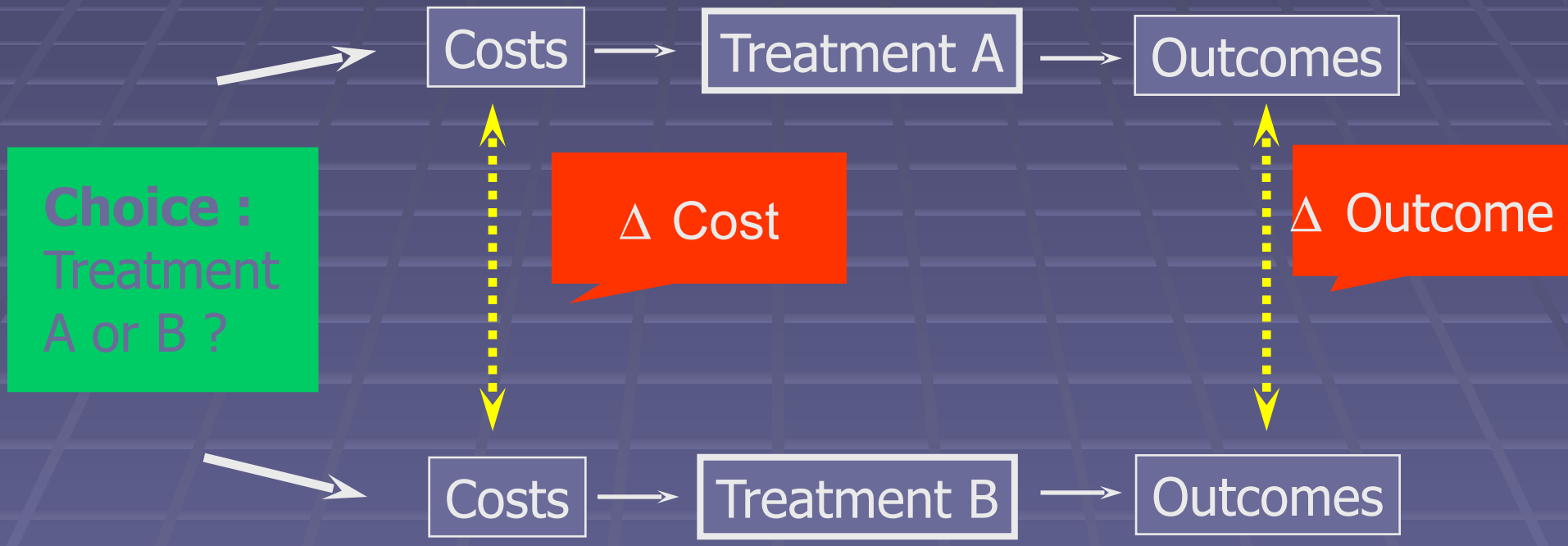
- Undertakes appraisals of new and established technologies, as requested by the UK Department of Health.
- Health technologies referred to NICE include:
  - pharmaceuticals
  - medical devices
  - diagnostic techniques
  - surgical procedures
  - other therapeutic technologies
  - health promotion activities

Fundamental principles

- Technologies can be considered clinically effective if, in normal clinical practice, they produce an overall health benefit, taking account of any harmful effects, when compared with relevant alternative treatments
- Technologies can be considered to be cost effective if their health benefits are greater than the opportunity costs measured in terms of the health benefits associated with programmes that may be displaced to fund the new technology

Elements of evaluation

(with apologies to grandmothers everywhere)



Do the **extra** benefits (outcomes) justify the **extra** cost ?

Outcomes

- Life expectancy / survival
- Relief of symptoms (e.g. pain, distress, disability)
- Changed side-effects of treatment
- Convenience / mode of therapy
- Improved functioning (e.g. ability to work)
- Health status
- Health-related quality of life

Outcome indicators

Traditional units of measurement

- Survival rates
- Readmission rates
- Symptom counts
- Employment status
- Days lost through sickness
- Clinical parameters

Measuring health outcomes
mortality

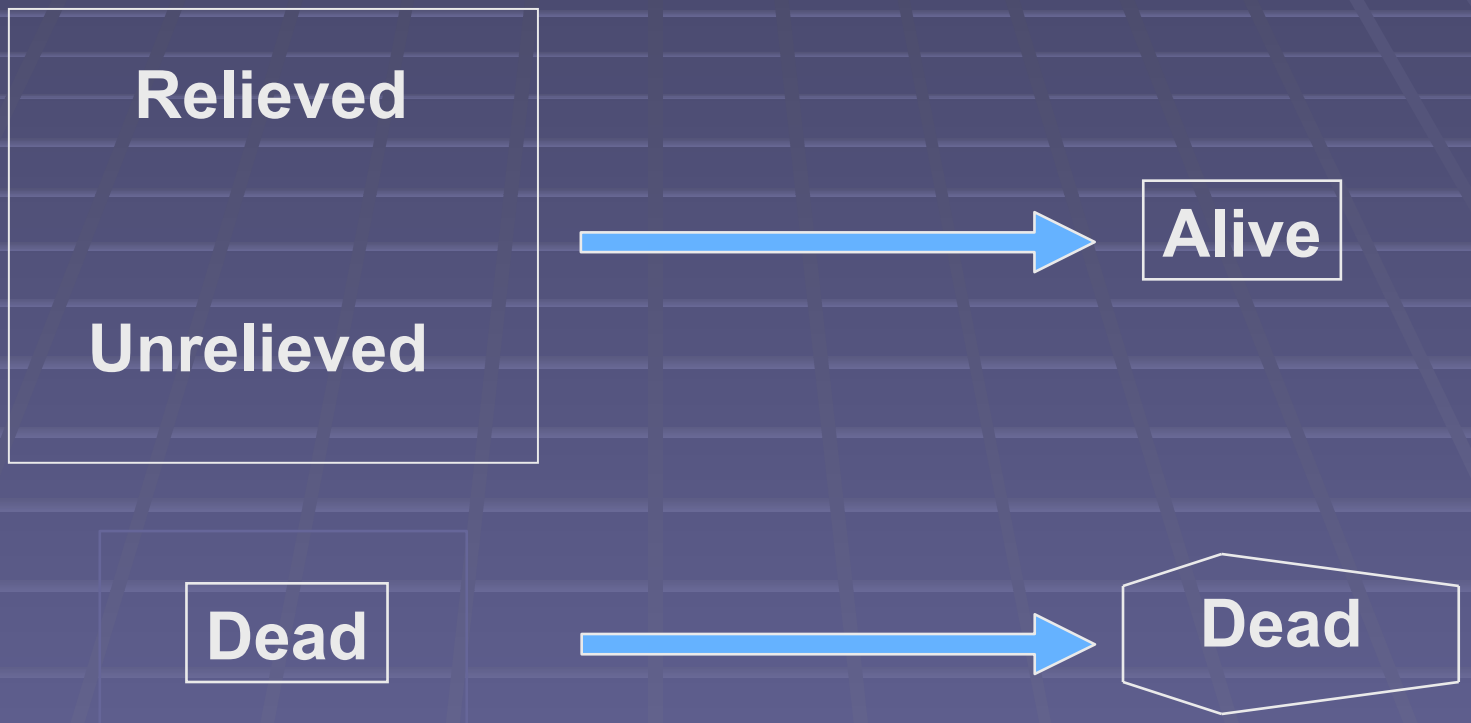
- Population health targets defined in terms of changes to mortality rates
  - Health of the Nation target for heart disease in England
  - “a reduction in death rates .. for people under 65 by at least 40% by the year 2000”
- Implication : life expectancy dominates all other considerations

Measuring health outcomes

5-year survival rate

- An individual who lives for 5 years and 1 month is a "success"
- An individual who lives for 4 years and 11 months is a "failure"
- 5 years 1 month of poor quality of life is "better" than 4 years 11 month with good quality of life

The Florence Nightingale Outcome Measurement System



Hospital mortality rates

- Crude mortality rates average around 3% for all patient admissions
- We can be certain about the outcome for around 3 in every 100 patient admissions
- We do not know whether the remaining 97 patients are ‘relieved or ‘unrelieved’

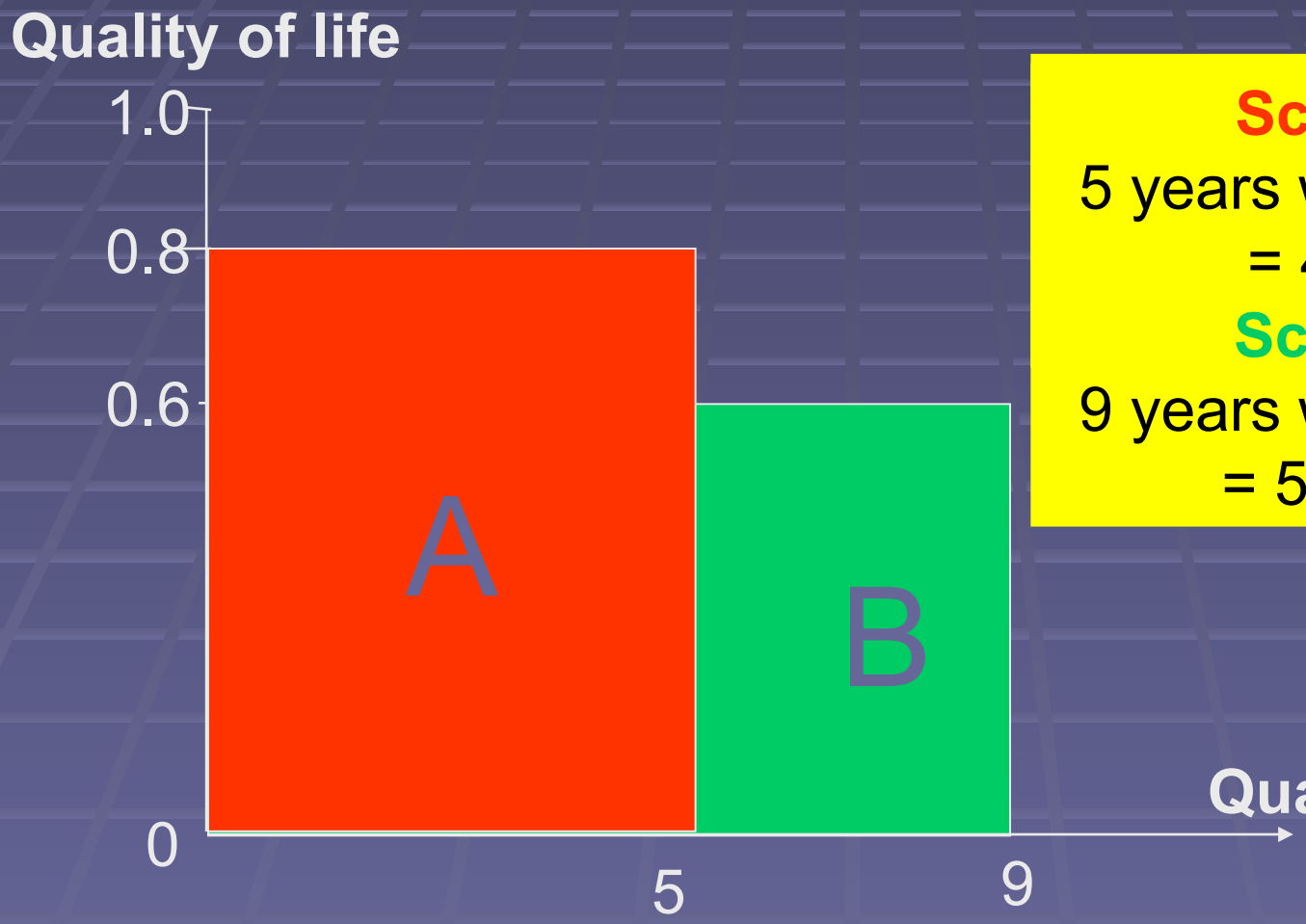
Value

- VALUE forms the foundation of all forms of quantitative measurement
- We may describe an individual's mobility now as "Being able to walk freely" but previously s/he was described as "Needing assistance to walk"
- We know the *direction* of change, but what is its *magnitude* ?
- What units of measurement ?

QALYs

- The QALY is the cornerstone of Cost-Utility Analysis
- It combines information on the quantity and *quality of life*
- Although economists (and others) refer here to *quality of life* the term is incorrectly labelled
  - Health-related quality of life (HrQoL)
- A QALY is a unit of measure defined as one year of life of full quality

Combining information on quality and quantity of life



Scenario A
5 years with QoL of 0.8
= 4 QALYs

Scenario B
9 years with QoL of 0.6
= 5.4 QALYs

Quality-adjustment : desiderata

- HrQoL data must be in a particular format
  - Single index
  - Scale weights on metric where full health = 1 and dead = 0
  - Health states other than full health have weights < 1
  - *Utility weights when combining HrQoL with life expectancy data for QALYs*

Measuring health outcomes

(a) $[\ FEV_1\ ]_{t0} - [\ FEV_1\ ]_{t1}$ → Δ FEV_1

(b) $[\ \text{health}\ ]_{t0} - [\ \text{health}\ ]_{t1}$ → Δ health status

there is a calibrated test procedure for (a)

what do we use for (b) ?

Grading angina severity
New York Heart Association

- Grade I
  - ordinary physical activity does not cause undue fatigue, palpitation or anginal pain
- Grade II
  - comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnoea or anginal pain
- Grade III
  - comfortable at rest. Less than ordinary physical activity causes fatigue, palpitation, dyspnoea or anginal pain
- Grade IV
  - inability to carry on physical activity without discomfort. Symptoms of cardiovascular insufficiency or the anginal syndrome may be present even at rest

Karnofsky Performance Scale

Description	Score
Normal	100
Normal activity ; minor signs / symptoms	90
Subnormal activity ; some signs / symptoms	80
Unable to work or to continue normal activities	70
Requires occasional assistance	60
Requires considerable assistance and frequent care	50
Disabled ; requires special care	40
Severely disabled ; hospitalised	30
Very sick ; hospitalised with active support treatment	20
Moribund	10
Dead	0

FACT-L

	PHYSICAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

Principal generic measures

PROFILE MEASURES

- Sickness Impact Profile (SIP)
- Nottingham Health Profile (NHP)
- SF-community
  - RAND MOS SF-36
  - SF-20 / 12 / 8 / 2
- WHOQOL

INDEX MEASURES

- QWB
- Rosser Kind Index
- 15-D
- HUI cluster
  - HUI II and III
- EQ-5D
- AQLQ
- YHL
- SF-6D

Element of health technology assessment	The NICE Reference case
Measure of health benefits	QALYs
Description of health states for calculation of QALYs	EQ-5D
Method of preference elicitation for health state valuation	TTO
Source of preference data	Representative sample of the general public

EQ-5D

- A generic measure of health status (health-related quality of life) capable of being represented as a single index

- Health is defined in terms of 5 dimensions
  - mobility
  - self care
  - usual activity
  - pain / discomfort
  - anxiety / depression

- Each dimension is divided into 3 levels
  - none
  - some
  - extreme

V vsaki od spodnjih skupin treh trditev označite tisti odgovor ☑, ki najbolj ustrezno opiše Vaše počutje na današnji dan.

Pokretnost

- [x] Pri hoji nimam nobenih težav
- [ ] Pri hoji imam nekaj težav
- [ ] Priklenjen-a sem na posteljo

Skrb Zase

- [ ] Zase poskrbim brez težav
- [x] Pri umivanju ali oblačenju imam nekaj težav
- [ ] Ne morem se sam-a umivati ali oblačiti

Vsakdanje Aktivnosti *(npr. delo, študij, gospodinjska dela, družina, prosti čas)*

- [ ] Vsakdanje aktivnosti mi ne povzročajo težav
- [x] Vsakdanje aktivnosti opravljam z nekaj težavami
- [ ] Vsakdanjih aktivnosti nisem zmožen-na opravljati

Bolečina/Neugodje

- [ ] Ne čutim bolečin oz. nimam občutka neugodja
- [x] Pestijo me zmerne bolečine ali občutki neugodja
- [ ] Čutim nevzdržne bolečine ali skrajno neugodje

Tesnoba/Potrtost

- [ ] Nisem tesnoben-na ali potrt-a.
- [ ] Sem zmerno tesnoben-na ali potrt-a.
- [x] Sem skrajno tesnoben-na ali potrt-a.

This state 12223

Logically best state 11111

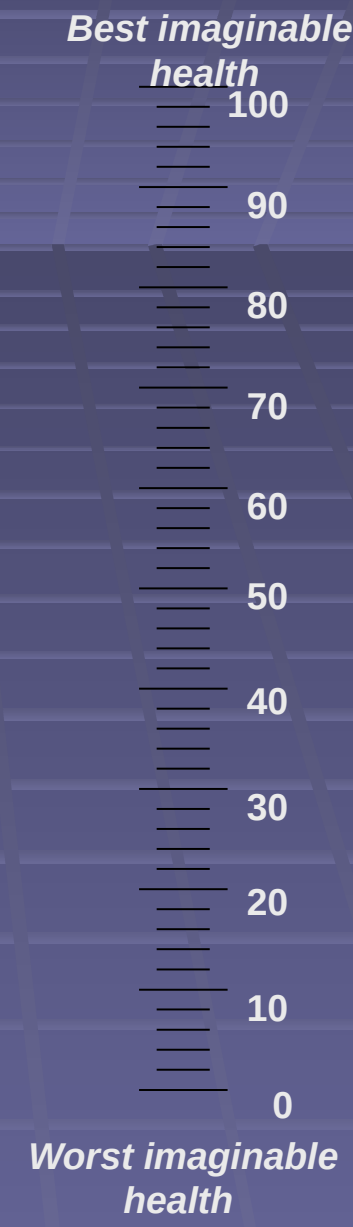
Logically worst state 33333

Think about how good or bad your own health is today.

This scale may help. The best health you can imagine is marked 100 and the worst health you can imagine is marked 0

Please write in the box below, the number between 0 and 100 that you feel best shows how good your health is today

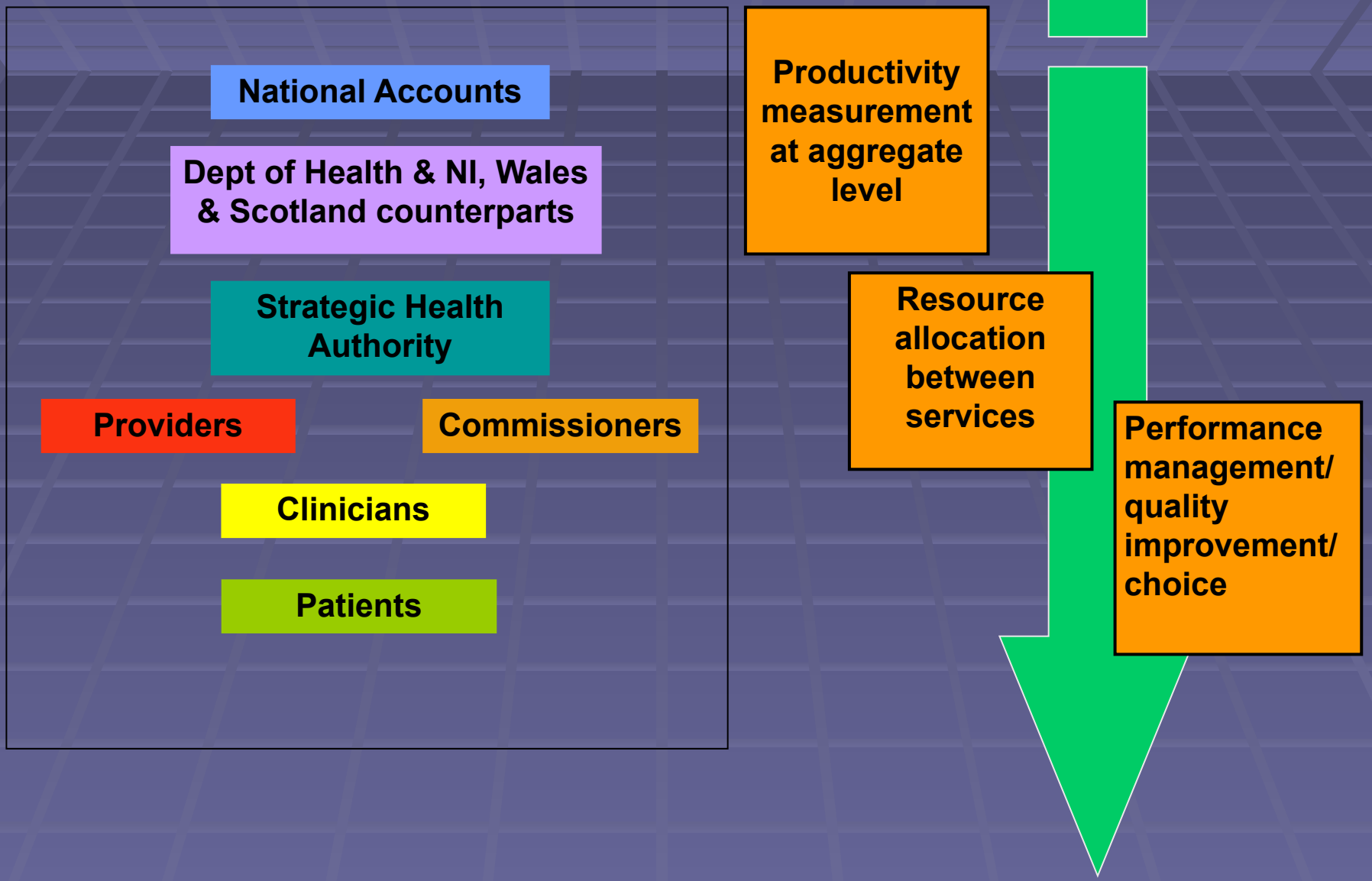
Your own health today



Measuring outcomes in the NHS

- From April 2009 health outcomes has been measured routinely in 4 elective surgical procedures
  - Hip / knee replacement
  - Hernia repair
  - Varicose veins
- Health status measure pre- and post-operatively using EQ-5D
- Extend this to most other areas of NHS healthcare during 2010

Outcomes data are generally useful



Summary

- Health care is designed to influence health status of individuals and communities
- Interventions impact on either/both QUANTITY / QUALITY of life
- Focussing on single clinical parameters may lead to incorrect estimates of (dis)benefit
- Holistic measures that capture multidimensional aspects of health-related quality of life are needed
- Such measures are increasingly used in economic and clinical decision-making

THANK YOU

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