

Commissioning for rare conditions in England

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National Commissioning Group

Developing, sustaining and ensuring
accessibility
to comprehensive care programmes
for rare conditions

The NHS in England



*National Commissioning Group
for Highly Specialised Services*

- Established 1947
- Budget - c£100bn
- Comprehensive
- 50m people

Planning tiers

- Local < 1m
- Regional 1m – 5m
- National 10m – 50m

Core belief



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Volume drives excellence

- What to expect
- Practical skills
- Full teams

- Procedures
 - Transplant, PTE, SCID
- Disease management
 - LSD, OCD, PNH
- Diagnostics
 - PCD, amyloidosis

Commissioning



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‘Commissioning’ =

- Planning
- Funding
- Monitoring

Planning

- Consensus on ‘highly specialised’
- Develop standards
- Assess against standards

Funding



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- Local and regional commissioning **99.5%**
- National commissioning **0.5%**

Monitoring

- Outcomes
- Access
- Patient opinion
- Benchmarking and peer review

Monitoring outcomes

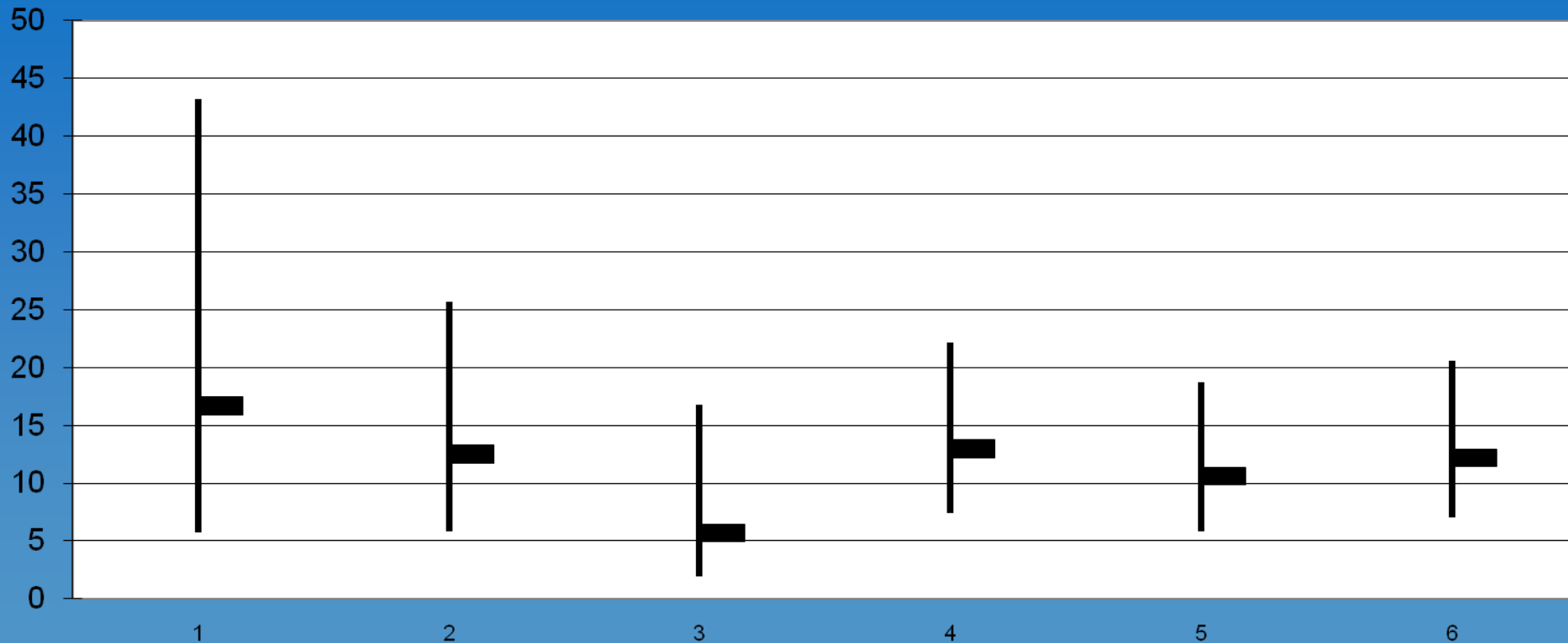


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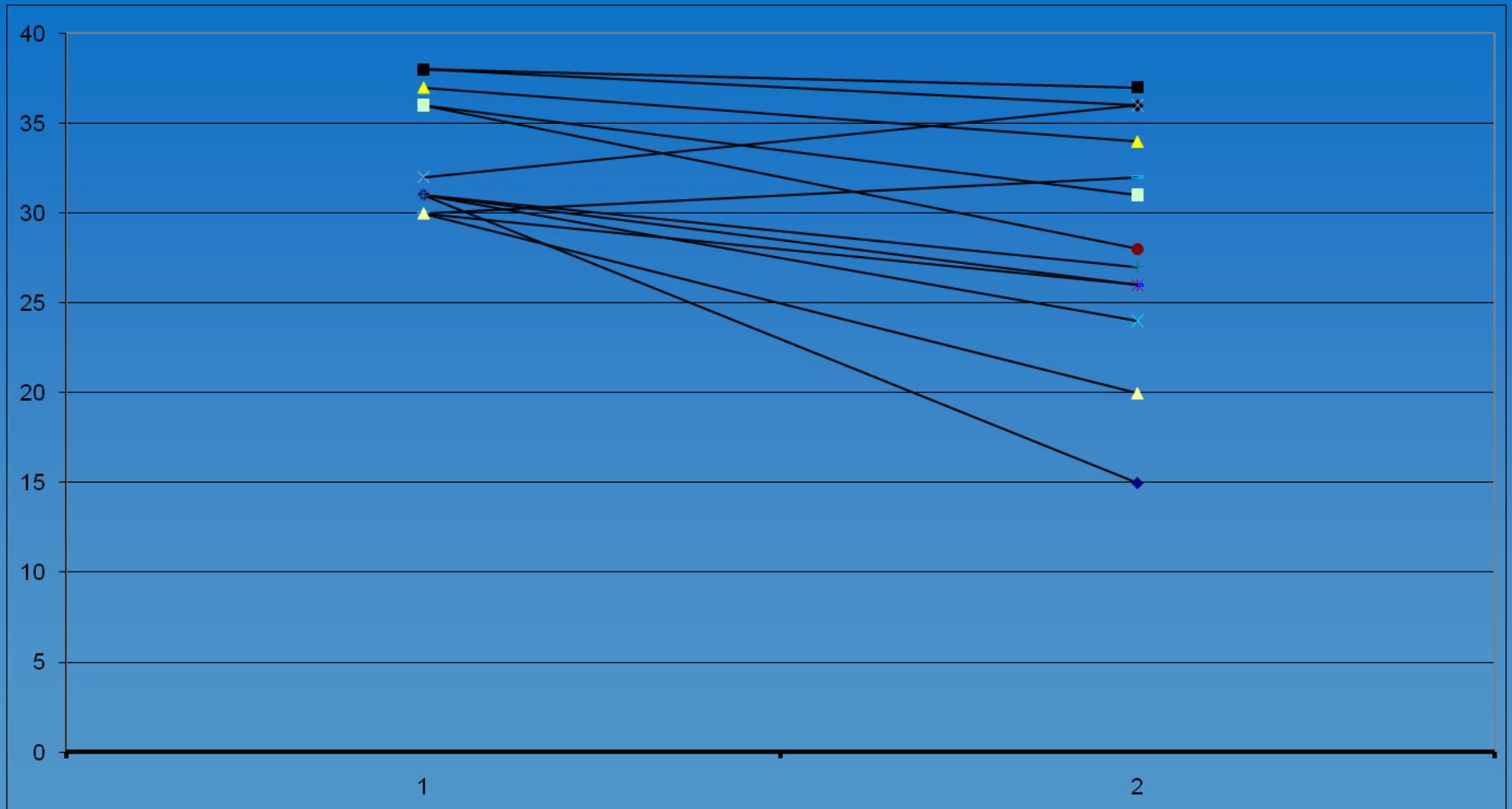
- Mortality
- Symptom scores
- Biochemical
- Quality of life

Outcomes

90-day graft loss

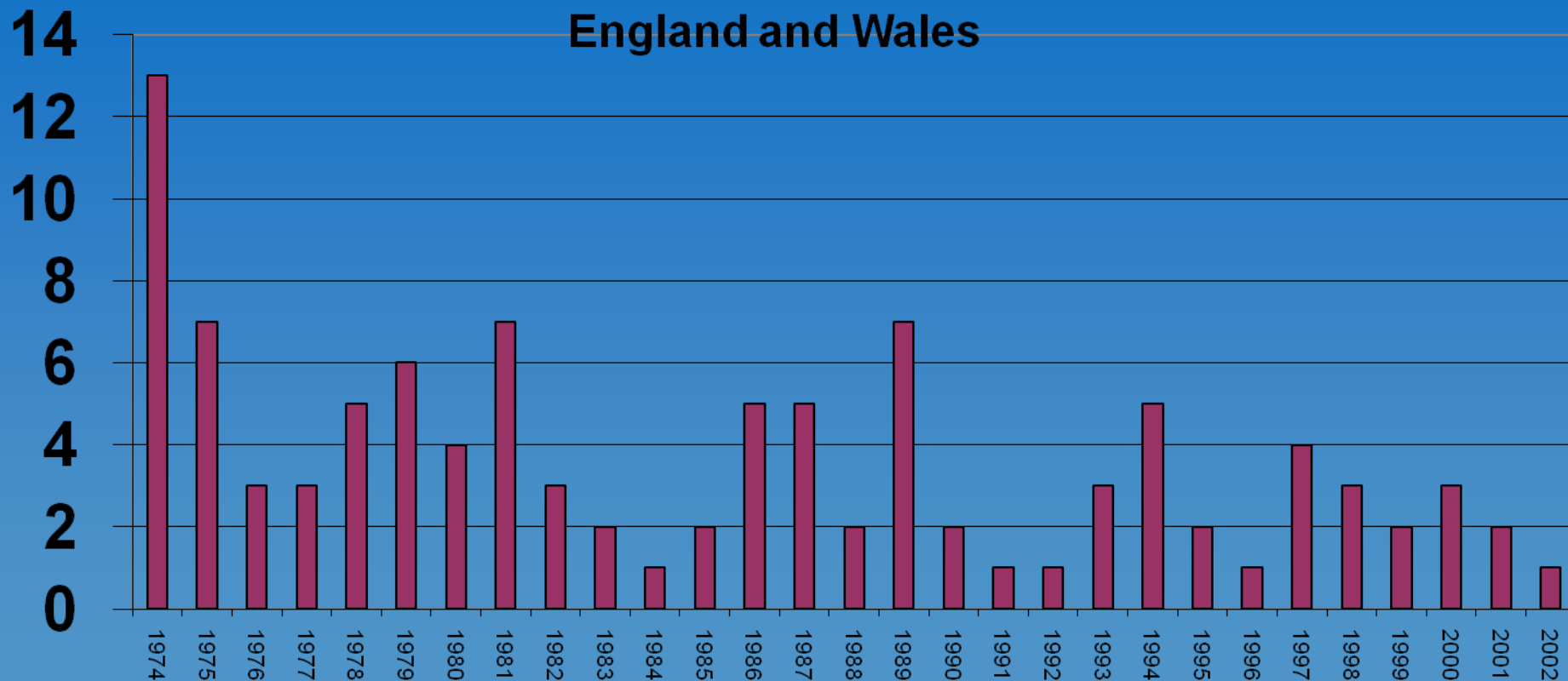


Outcomes



Outcomes

Placental tumour deaths England and Wales



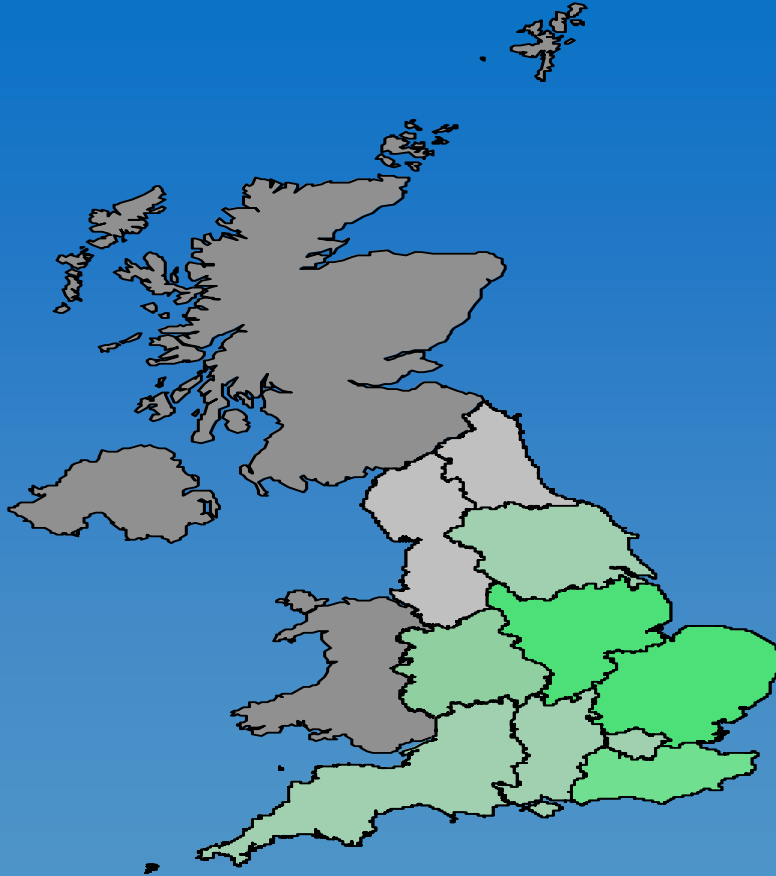
Monitoring

- Outcomes
- **Access**
- Patient opinion
- Benchmarking and peer review

Analysis of Geographical Equity of Access for the Amyloidosis service - 2007/08

Amyloidosis confirmed cases per million head of population by English SHA (new configuration)

- 5.47 to 6.23 (2)
- 4.72 to 5.47 (1)
- 3.97 to 4.72 (1)
- 3.22 to 3.97 (4)
- 2.47 to 3.22 (2)



Access



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Monitoring

- Outcomes
- Access
- Patient opinion
- Benchmarking and peer review

Monitoring

- Outcomes
- Access
- Patient opinion
- Benchmarking and peer review

Issues

- Burden of travel
- Shared care

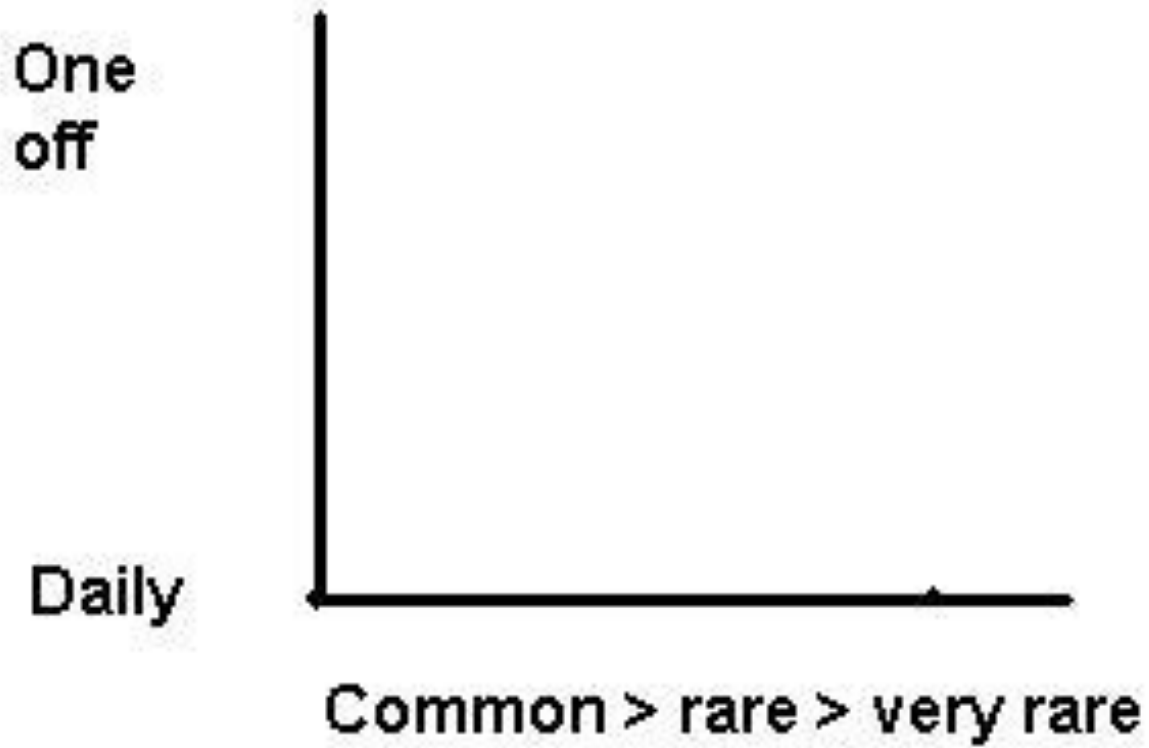
- ‘Commissionable unit’



Travel

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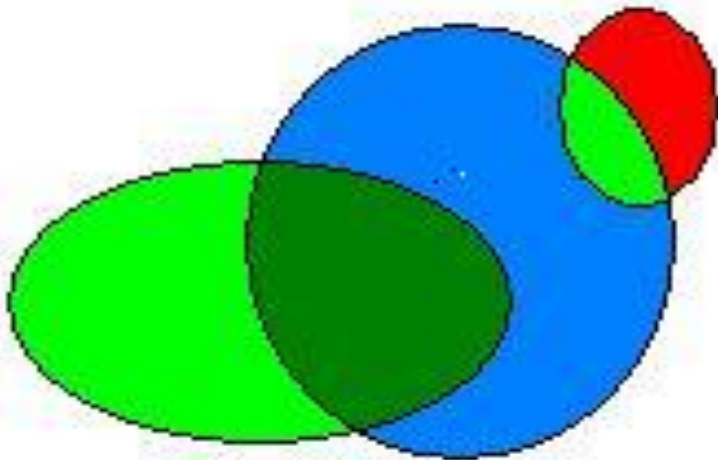




Commissionable unit

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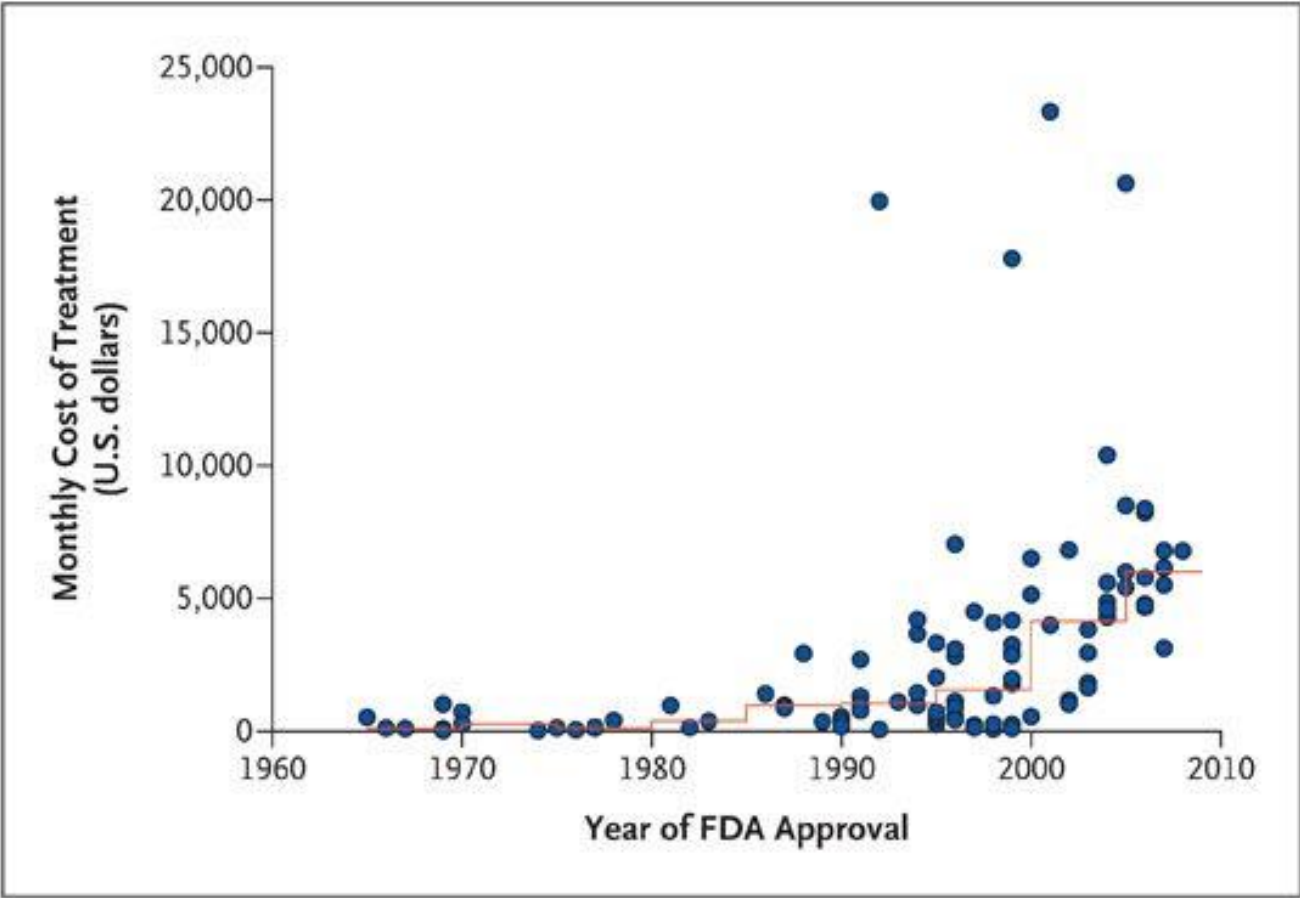
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Drugs



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Bach P. N Engl J Med 2009;360:626-633

'Ultra orphan' drugs

- Naglazyme £310 000
- Aldurazyme £185 000
- Elaprase £310 000

- Eculizumab £250 000

NICE



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NICE –

National Institute for Health and Clinical
Excellence

Guidelines

Technology appraisal

Appraisals



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- Drugs
- Procedures
- Uniform availability

Economics

- How much does it cost?
- What does it do?

- compared to alternative - incremental

Temozolamide for glioblastoma multiforme

- Effect – 6 weeks increased survival
- Cost - £1000
- ~ £200 per extra week of life
- i.e. ~ £10 000 per life-year gained

Exjade - SMC advice



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“In patients with β -thalassaemia the cost per QALY was around £20000, in patients with sickle cell disease (SCD) it was around £30000, and in patients with MDS it was over £38000 per QALY.

All of these figures are in comparison with desferrioxamine.

On this basis the cost-effectiveness of deferasirox was acceptable in patients with β -thalassaemia and with SCD but the case has not been demonstrated in patients with MDS”

NICE and costs per QALY



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- No absolute threshold
- Empirically - £30 000 per QALY
- Social value judgements
- End of life care

'Ultra orphan' drugs

Cost per patient or total cost?

Political judgement – rFVIII

Any upper limit?

The NHS Act 2006



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*“The Secretary of State must continue the promotion
in England of a comprehensive health service
designed to secure improvement—*

*(a) in the physical and mental health of the people of
England, and*

*(b) in the prevention, diagnosis and treatment of
illness...”*



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