

Is Age-based Rationing Evil?

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Novartis now has the the most expensive drug ever after getting US approval

- Swiss pharmaceutical company Novartis on Friday announced it had received US regulatory approval for a gene therapy that treats a rare childhood disorder and has a price tag of \$2.1 million, making it the most expensive drug in history.
- 25 May 2019



Headquarters of Swiss pharmaceutical giant Novartis. Photo: SEBASTIEN BOZ

Outline

- Understanding Health Care Rationing
- Rationing and Human Rights
- Age-based rationing: Ethics & Law
- Conclusions

1. Understanding Health Care Rationing

- Defining Health Care Rationing
- Who decides?
- What criteria?
- Methods

2. Rationing and Human Rights

- Human Rights
- Legitimacy
- Liability

3. (i) Challenging Rationing Decisions: Germany and Switzerland

- New technologies and limited cost-effectiveness:
 - *Nikolausbeschluss* (BVG 6 Dec 2005) German CC:
 - lifesaving (experimental) medicine and Constitutional rights
 - “*spürbare positive Einwirkung*”
 - Elaborated by Fed. Social Crt (BSG) 2006
 - Narrowed in IVIG therapy: life-threatening, critical situation
Off-label use BVG 11 April 2017
 - *Myozyme cases I & II*, Sw. Supreme Crt. 23 Nov 2010; 2015
 - Cost-effectiveness threshold 100.000 CHF QALY
 - “limited cost-effectiveness”

3 (ii). Rationing Litigation in the UK

- General rule: courts will not interfere with the decision about how money is allocated unless that decision is 'frankly irrational'
- Meaning of rationality ?
- *Swindon NHS Primary Care Trust* (Herceptin litigation)

WHO SHOULD
WE TREAT?

Erasmus

3 (iii.) Rationing and the ECtHR: Reduction in night-time care for an elderly lady

- *McDonald v United Kingdom*, No 4241/12, 28 August 2014
- The applicant complained that a reduction in night-time care disproportionately interfered with her right to respect for her private life under Article 8 ECHR.
- ECtHR: State did not exceed the margin of appreciation
- Comment

4. The Controversy: Age-based Rationing

- Excluding elderly patients from *specific* life-extending treatment options for cost constraints
- Age level as a threshold: “fair-innings” argument
- Discriminatory by nature or justified for specific reasons?
- *CESCR General Comment no. 20* Non-discrimination (E/C12/GC/20)

5. Weaknesses

- Arbitrariness
- “Too close to call” cases



Conclusions

- Rationing unavoidable and necessary
- Rationing litigation: Need for public debate on fair rationing: democratic deliberation (L. Fleck) (plea for explicit rationing)
- Incorporating HTA in rationing debate
- Role of the courts: triggering that debate and holding health rights justiciable