

Summary: An Ethical Approach to Health Journalism in the Netherlands

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- Drug treatments for two rare diseases, Pompe disease and Fabry disease, were threatened with withdrawal of reimbursement in the Netherlands. This would have meant state funding for these expensive treatments (about £400,000 and £200,000 per patient per year respectively) would stop. There were no alternatives available. Both diseases eventually prove fatal.
- Every source approached – patient groups, the government, the pharmaceutical industry – declined to comment, for different reasons.
- The decision was taken to publish after 5 weeks of hearing about the story. The news organisation advised treating doctors to tell their patients the story was about to break but some patients did not hear in time.
- Further stories were published about price differences for these same drugs in different countries. The drug companies declined to comment on why, but removed pricing information from their websites.
- Insurers in the Netherlands decided to continue to pay for the drug treatments and the government continued with reimbursement payments.
- In another case, a GP gave a lethal dose of euthanasia drug to a patient who had withdrawn their explicit consent to assisted dying (legal in the Netherlands in tightly controlled circumstances). This was reported by his assistant and the health inspectorate and police began investigating the doctor. He was admitted to a mental institution but committed suicide on release.
- The story was again reported using off-the-record sources. Most responses from the public were supportive of the doctor, who was acting to alleviate suffering, and suspicious of the government and the health inspectorate.
- An inquiry into this case is still proceeding.
- A clumsy phrase was used in reporting this case, ‘enough morphine to kill an elephant’, provided by an off-the-record doctor. With hindsight, this made matters worse, as did reporting the case as ‘like manslaughter or murder’, and important lessons were learned from this about the need to report sensitively.