Valuation Studies 12(1) 2025: 143–170

Theme issue contribution

Temporal Layering: How past, future and present intersect in the valuation of pharmaceutical innovation

Anna Brueckner Johansen, Susi Geiger, and Sarah Wadmann

Abstract
We investigate how temporality matters in processes of valuation. Taking our empirical point of departure in the case of a novel gene therapy that has been the centre of a heated pricing debate, we explore how the 'goodness' of such a pharmaceutical good was negotiated by researchers, patients, pharmaceutical companies and regulators, and how these negotiations were shaped by the mobilisation of past experiences and future expectations. Seeking to advance the beginning of an analytical sensitivity to temporality in valuation studies, we develop the notion of 'temporal layering'. We argue that moments of valuation consist of multiple 'temporal layers' where select past experiences and future expectations are rendered visible – or left obscure – depending on how these layers are drawn upon in valuation struggles and by whom. Thus, what is at stake in determining the 'good' in particular moments of valuation is not just a contest over certain qualities or ways to evaluate an object, but also over which (particular layers of) pasts and futures come to count. We suggest that such fine-grained temporal analysis can provide new openings to questions of valuation for a wide-ranging array of economic objects, particularly for those situated in contemporary bioeconomies.

Keywords: temporal layers; gene therapy; pharmaceutical innovation; pricing; temporality; valuation

Anna Brueckner Johansen is a PhD Fellow at VIVE – The Danish Center for Social Science Research and the Department of Public Health, University of Copenhagen.
Susi Geiger is Professor of Markets, Organizations and Society at University College Dublin.
Sarah Wadmann is a senior researcher at VIVE – The Danish Center for Social Science Research and external lecturer at the University of Copenhagen.

https://doi.org/10.3384/VS.2001-5992.2025.12.1.143-170
Hosted by Linköping University Electronic press
http://valuationstudies.liu.se

Introduction

> The documentation of the effect and impact of Luxturna is very uncertain. (…) [Still,] Novartis (…) charges an exorbitant price that is neither connected to value nor development and production costs. A price that made me think of ransom in a hostage drama, though this is not the case in a strictly legal sense. Even with half the price, Novartis will still make a huge profit. What drives the greed behind such prices that bring children and their parents into desperation?
>
> - Prof. Jes Søgaard, December 2019.

The foregoing quote by health economist Jes Søgaard is from a column written during the height of an emotionally heated controversy about patient access to novel gene therapies in Denmark (Søgaard 2019). Søgaard drew on an extreme crisis metaphor, 'a hostage drama' and a morally laden attribute, 'greed', to describe the pricing decisions made by the pharmaceutical company in question. At the centre of the dispute was the gene therapy Luxturna (voretigene neparvovec), licensed by the pharmaceutical company Novartis. Luxturna is the first gene therapy that targets an inherited eye disease causing children and young people to develop blindness. The treatment had been approved for marketing by the European Medicines Agency (EMA) in 2019. Yet, it was rejected as a standard treatment in Denmark due to 'unreasonably high pricing', causing uproar from families affected by the disease. In contrast to the critique raised by the Danish health economist, a co-founder of the American start-up who developed and initially marketed Luxturna expressed concern that 'the promise of gene therapy will never be realised' if pricing becomes 'too much of an issue' because it will divert the attention of researchers and companies away from truly innovative research (Prof. High, pers. comm. 2022).

In line with other authors in this theme issue, we study valuation controversies over one of the manifold objects that are populating 'the good economy' – but we do so with an explicitly temporal tack. Bringing together insights from valuation studies with work on temporality in organisation studies and anthropology, we seek to explore how negotiations about the 'goodness' of Luxturna are shaped through acts of temporal layering, which serve to foreground certain temporalities and obscure others. Marketed as one-time, one-cost treatments, the pricing of gene therapies, like Luxturna, is typically justified with reference to life-long treatment effects and future cost savings to society. Yet, the high upfront costs pose challenges to public healthcare systems facing resource constraints (Wadmann and Hauge 2021). In Denmark, Luxturna was eventually offered to patients in 2020 as part of an outcome-based payment agreement. While the pricing controversy was settled in this case, it raises a more general question about how temporality might shape negotiations over such therapies' 'goodness' when actors draw together the past development

costs with the uncertainties of long-term therapeutic effects, or, conversely, when they emphasise future-oriented hopes and past patient pains. While we argue that temporality always plays into moments of valuation, gene therapies represent a new paradigm in life science that brings distinct valuation dilemmas with it, some of which are intrinsically related to issues of temporality. With Luxturna, temporality was central to everyone's understanding of what a 'good' price ought to entail – but they could not agree 'which' temporal layers mattered.

We suggest that settlements on what is considered 'good' are only temporary stabilisations in ongoing contestations over which past experiences and future expectations come to count. More specifically, we argue for a multilayered conception of time that attends to how past experiences and future expectations are brought into the present and mobilised at particular moments to establish or critique certain ideas of the 'good'. We do so by introducing the notion of temporal layering as the act of selectively choosing, framing and amalgamating specific pasts, presents and futures. Pausing at three particular moments in the 'career' (Çalışkan and Callon 2010: 24) of Luxturna, we explore which understandings of 'the good' are negotiated through such temporal layering in the becoming of the gene therapy. Moments of valuation, from this perspective, are always temporally layered; consequently, valuation studies researchers may benefit from an analytical sensibility towards questions of how temporal layers are brought together and drawn upon in valuation controversies. This analytical move serves to trouble and question taken-for-granted claims about the 'goodness' of current developments in the life science industry as well as other 'biopolitical economies' (or bioeconomies, for short), where different temporalities of life and economy come into tension (Adams et al. 2009).

We start by discussing how the pharmaceutical sector can be understood as one instantiation of the 'good economy'. Next, we outline how valuation studies have started to engage with temporality and discuss how these insights can be further developed through work on temporality in the fields of organisation studies and anthropology. Then, we pause at three moments in the story of Luxturna to illustrate how a temporal layering perspective can help us understand the contingency of any stabilisation of what is considered 'good'. We end with a discussion of how an analytical sensibility to temporality matters for contemporary critique of the good (bio)economy.

Pharma as an instantiation of the 'good economy'

In valuation studies, recent analytical frames have started to consider valuation as a *problem* rather than a *practice* (Board of Editors 2020). In other words, when studying how valuation works,

consideration should centre on the problems, conflicts and political struggles of which practices of valuation are part. In line with this call, analytical attention has been given to shifting normative assumptions undergirding claims about what is 'good' in a given economy, resulting in what Asdal and colleagues (2023) refer to as 'the good economy'. Challenging any unequivocal notion of 'the good' in economic exchange, this concept invites attention to shifts in normative positions over time and the concerns that may be located out of sight when particular versions of the 'good' are promoted by different actors. Accordingly, the scholarly task is to tease out which conceptions of the 'good' are brought forward and by whom, who it can be considered good for, and how dominant conceptions of the 'good' might be challenged.

Because of its position in a contested space where ambitions of doing good for patients and combating disease sometimes clash with concern for market value (Geiger 2021), the pharmaceutical industry can be seen as a peculiar instantiation of 'the good economy'. The pharmaceutical industry moves across different dimensions related to economy, politics and health in what Petryna and Kleinman (2006) have referred to as 'the pharmaceutical nexus'. Scholars have critically examined the normative assumptions underpinning claims towards 'goodness' in this nexus. Mirroring concerns expressed in the opening quote of this article, these prominently include pharmaceutical pricing strategies and patient access to new therapies (Mazzucato and Roy 2019; Bourgeron and Geiger 2022; Kjellberg et al. 2023; Roy 2023; Doganova and Rabeharisoa 2024). Authors have interrogated the economic rationales informing the idea and practice of 'value-based pricing' that increasingly displaces claims about pricing based on research and development (R&D) costs (Mazzucato and Roy 2019; Doganova and Rabeharisoa 2024). Illustrating contestations around 'biofinancialization', Bourgeron and Geiger (2022) show how the economic 'career' of a high-priced medicine for Hepatitis C was laced through with moments of scientific and social contestations of its 'asset condition' obtained through extensive patent protection. Scholars have finally taken the question of what is 'good' in pharmaceutical markets to a global level, noting the inequalities that can arise as some populations bear the risk and costs of pharmaceutical innovation but often cannot partake in its benefits (Petryna 2005; Sunder Rajan 2017).

Building on these studies, we start from the vantage point that there is nothing self-evident in the valuation of pharmaceutical goods and that settlements on which forms of 'good' they represent are to be understood as temporary stabilisations, which express themselves, for instance, in the price of a pharmaceutical product or in certain market access agreements. Hence, we use the notion of the 'good' as an overarching term that refers to the multiple types of concerns and

critiques that guide actors in their pursuit to develop, market and access pharmaceutical goods. In line with Dussauge and colleagues (2015: 10), we are interested in 'the production – in practice – of what comes to count as valuable, desirable, or otherwise worth caring for'. Demonstrating the contested nature of these concerns, we seek to tease out how various actors represent and enact the 'goodness' in pharmaceutical markets and how their various conceptions of the good might intersect, collide and be temporarily settled. We take a particular interest in moments of collision and settlements, but rather than seeing these as isolated moments, we argue that paying particular attention to temporality can help our understanding of how actors seek to establish what is 'good'. Contestations over the 'good' in economic exchanges are shaped not only by distinctive past experiences sedimented in certain qualities of the good or in specific tools of valuation; actors may also mobilise different future expectations to establish what is 'good' in the present. Thus, we propose that what is at stake in determining the 'good' in particular moments of valuation is not just a contest over certain qualities or ways to evaluate an object, but also over which particular temporal layers come to count. Attention to these temporalities makes it possible to distinguish how layers of past experiences and future expectations are drawn upon by various actors, unearthing an essential dimension of the normative assumptions that establish the 'good economy'.

Developing an analytical sensibility to temporality in valuation

Combining insights from economics, economic sociology and economic anthropology, Çalışkan and Callon (2009, 2010) outline an ambitious programme for analysing how things acquire economic value through what they call processes of economisation, that is 'the assembly and qualification of actions, devices and analytical/practical descriptions as "economic" by social scientists and market actors' (Çalışkan and Callon 2009: 369). They briefly allude to the importance of temporality for these processes. Drawing on Appadurai (1986), they note that products are goods with a 'career' and argue that 'markets have a history; they also have a future that cannot be reduced simply to an extrapolation of the past' (Çalışkan and Callon 2010: 24). Although this work has been hugely influential, their points about temporality seem to have had limited impact within valuation studies. As Mennicken and Sjögren (2015) highlight, many studies have tended to magnify the 'market moment' without exploring how this moment was shaped by past experiences and future expectations. Only recently has the interplay between valuation and temporality surfaced as an explicit analytical theme in studies such as Hammarfeldt et al.'s (2020) work on narrative trajectories in academic

CVs, in Muniesa and Doganova's (2020) work on future-oriented financial reasoning, or in Doganova and Rabeharisoa's (2024) study on the temporality of pharmaceutical prices.

Engagements with temporality in valuation studies have tended to focus on how future visions are folded into present valuations. Extending an analytical apparatus attuned to exploring how the value of something is configured by the use of particular valuation tools or discursive practices, these studies point to how particular ways of conceiving future value can have important implications in the present (e.g. Beckert 2016; Muniesa and Doganova 2020; Ortiz 2021; Doganova 2024). Some of this work has addressed temporality in a healthcare context. Building on the case of drug development, Doganova (2018, 2024) argues that 'uncertainty' about the future can be enacted in very different ways depending on the specific formulas and practices of discounting that are used. Geiger (2020) suggests that future-rhetorics are powerful devices that shape contemporary capital valuations in health technologies, where the productive power of uncertainty creates visions about open and desirable futures. Costa and Milne (2023) consider the valuation of diagnostic technologies for Alzheimer's through narratives of the inherent 'goodness' of knowing the future. Most recently, Doganova and Rabeharisoa (2024) study the value-based pricing of the gene therapy Zolgensma as a future-oriented technology with political and epistemological consequences. More broadly, a longer-standing tradition in the sociology of health has critically analysed the effects on the present of future imaginaries, expectations and narratives (Brown 2005; Adams et al. 2009).

Where the bulk of this literature has been concerned with future imaginaries and visions, comprehensive literatures on temporality have developed in other areas that can help extend valuation studies' beginning engagement with temporality. In particular, selected works in organisation studies and anthropology can stimulate an analytical sensitivity towards how past, present and future temporalities may be brought together in moments of valuation. It is from this literature that we conceptualise our notion of 'temporal layers' and how 'temporal layering' may be employed to enact these layers.

In organisation studies, seminal work on time highlights the 'immanent' interweaving of pasts, presents and futures in organisational processes (Hernes 2022). Hernes observes that '[organising] implies bringing together strands of a tangled whole within some selected and temporally evolving structures of meaning' (2014: 14). In Hernes's work, this bringing together is expressed through the term 'present-past-future', which signals the potential actualisation of past experiences and future expectations in the present. The ordering of the three words and the hyphens in the term 'present-past-future' emphasise a confluence of the three temporalities, which are all actualised and enacted in the present, no

matter how distant or near these pasts and futures may be (Flaherty and Fine 2001; Hernes and Schultz 2020). Actualising is an organisational process, in the sense that it is aimed at 'creating a meaningful and predictable order out of a tangled world' (Hernes 2014: 14). As with any act of organising, this ordering is not only socially embedded (see Pulk 2022); it is also purposeful.[1] Extrapolating these insights from organisational settings to broader valuation controversies – those happening in various 'good' economies – we take from this literature that what we call temporal layering is a purposeful, organisational act that gives meaning to and simultaneously mobilises certain amalgams of present-past-futures.

A similar move towards understanding the present as a confluence of past, present and future has been made in the newer anthropological literature on temporality. This literature yields additional concepts that point to how actors may go about constructing and deploying a 'multi-layered' present, that is, a present both shaped by past experiences and future 'horizons of expectation' (Bryant and Knight 2019; Elbek 2022).[2] For example, drawing on ethnographic observations from photography, Pinney invites attention to the choices that lead to multiple temporal layers comprising a photograph – which not only 'freezes' a present that is suggestive of a certain past but can also frame future aspirations (2023: 40). Building on Guyer (2007) to explore experimental science as an inherently anticipatory enterprise, Sharp (2014) writes about the normative assumptions embedded in particular 'temporal framings', that is certain ways of conceiving of and representing time, which can serve to legitimise certain actions in the present. We find the photographic metaphors deployed in these studies useful to highlight the selective nature of this temporal ordering: what is chosen to be 'in the frame' is not only a matter of perspective but also one of leaving out that which ought not to be seen.

Taken together, these perspectives invite us to understand temporality as drawn together in multiple layers of past-futures actualised in the present. Further, they bring attention to the compositional and organisational work undertaken by actors as they represent and enact time in certain ways that are themselves imbued

---

[1] Pulk (2022) employs the notion of 'temporal layers' but for her, these are social layers, with some more micro and some more macro ones being brought to bear in the same moments.

[2] These ideas originate from historian Reinhardt Koselleck's work on 'multilayered' history (Koselleck 2018). Although we are inspired by this idea, we do not use his concept of 'Zeitschichten'. Where Koselleck uses the notion of layers to describe three different sediments of time that encapsulate how time progresses with different speeds of change and transformation (2018: 9), we look at temporal layering as a metaphor for how particular present-past-futures are brought into view in valuation processes.

with normativities. While insights from organisation studies allow us to root our notion of temporal layering firmly in discussions on temporality's immanence, the anthropological literature enables us to envisage how past experiences and future expectations may be used to render certain actions in the present 'present'. The way that particular temporal layers are actualised depends on what we refer to as acts of temporal layering that actors employ at any given moment to make certain temporal layers stand out and, consequently (but perhaps not always consciously) to obscure others. We thus highlight the compositional work undertaken by actors to bring certain horizons of expectations and experience to the fore. Temporal layering can be enacted through discursive moves. For example, a 'prophetic' (Sharp 2014) layering may be mobilised by actors in moments of valuation to argue that experimental research's value will materialise in a distant future where young people with inherited eye diseases will no longer go blind. Temporal layering can also be undertaken through the mobilisation of non-human elements. For example, the application of evaluative schemes such as cost-effective analysis relies on a layering of incremental benefit that mobilises a particularly distant horizon of expectation but that by extrapolating costs into this distant future also draws in a layer of the past.

We deploy this analytical framework in the following section as we pause at three moments when Luxturna's 'goodness' opened up to negotiation. While we zoom in on particular moments, we do not see these as isolated events. Rather, we seek to illustrate the specific layers that emerge and linger over time and to trace what this implies for Luxturna's becoming. This framework illuminates that each temporal layer is the outcome of momentarily stabilised struggles. It also opens up possibilities for critique. Instead of naturalising the 'career' of an object, attention to the various temporal layers employed in its valuation makes us aware of the choices made in tracing a particular social biography and of the normativities that render some ideas of the 'good' more visible than others. Combining the literatures above thus chimes with a long-standing tradition in science and technology studies (STS): to explore how things 'could have been otherwise'.

Case presentation and methods

The case of Luxturna is illustrative of current transformations in the pharmaceutical sector and the valuation dilemmas they entail. In 2017, Luxturna was the first gene therapy tackling an inherited disease to be approved for marketing by the US Food and Drug Administration (FDA). Among a small subgroup of young people living with the rare inherited disease called Leber's congenital amaurosis (henceforth LCA), Luxturna represented new therapeutic hope. Orphan drugs, like Luxturna, often fill a gap in existing treatment options for rare disease

patient groups. Yet, they tend to come with unprecedentedly high pricing, and their valuation is often marked by great uncertainty because clinical effectiveness can be difficult to determine due to the small study populations. Randomised controlled trials with as few as nine to 29 patients in each trial, as was the case with Luxturna, are not unusual (Pierce and Bennett 2015). While prices tend to be justified based on the expectation of life-long treatment effects, debates ensue about what constitutes adequate time horizons for estimating the 'added value' of these therapies (Ronco et al. 2021). As horizon scans predict a substantial rise in the number of gene and cell therapies to be marketed from 2020–2030, such challenges of valuation are likely to become more pronounced (Quinn et al. 2019).

We base our study of Luxturna on publicly available documents regarding Luxturna's pricing, access and discussions it raised. These documents include regulatory documents, meeting transcripts, patent applications and news sources. Moreover, we consulted scientific and popular scientific publications about Luxturna's development from 2001–2022 (see Appendix 1 for a complete list of sources used). We conducted a close documentary analysis of all relevant materials, analysing some texts as sites and some as tools written for specific purposes, thus always being conscious of the authorship and purposes of these sources (Asdal and Reinertsen 2022). During the analysis, we attended not only to human actors but also explored the influence of non-human actors, such as laboratory animals or pricing formulas. In addition, we conducted supplementary online interviews with three key actors in the development, manufacturing and pricing of Luxturna in the USA.

We analysed our material through a process of abductive analysis, moving between the empirical material and theoretical abstractions in a dialectic fashion (Tavory and Timmermans 2014). We first gained an overview of the 'career' of Luxturna: taking the pricing debate as our starting point, we sought to trace its origin story. This process soon demonstrated that the story of Luxturna did not evolve as a purely sequential process and that its career could have taken different turns at multiple points in time. From this realisation, we developed an analytical interest in the relationship between temporality and valuation, eventually identifying three key moments of valuation that, according to stakeholders, were incisive for the therapy's becoming. While the three moments are rooted in the empirical material, they are also the product of a particular temporal framing conducted by us, as analysts. Digging more deeply into our data, we realised that these moments were not only crossroads into potentially different careers of Luxturna; they also contained multiple temporal layers as they drew on different and sometimes hypothetical timelines. This insight, in turn, triggered an interest in the actors who mobilised these layers. As we now turn to the analysis, we present the negotiations that occurred

at these three moments to settle the 'goodness' of what eventually became Luxturna and the temporal layers that emerged as a result of these negotiations.

First moment: Entering into clinical trials

We enter the story of Luxturna at a time when genetic research dramatically changed its status in public debate from innovative and hopeful to risky and unethical. In 1999, the tragic death of 18-year-old Jesse Gelsinger, who served as a research participant in a gene therapy trial at the University of Pennsylvania, turned the whole field into a site of heated public debate. While the Gelsinger trial was not targeting inherited eye disease, it nonetheless impacted the research activities that laid the ground for Luxturna.[3] The Gelsinger tragedy appears as a landmark in popular books around genetic research (e.g. Lewis 2012), but it was also emphasised by our informants as a problematic past that made genetic research challenging. According to Professor Jean Bennett, one of the leading genetic scientists behind Luxturna, who worked at the same university, 'it was a very difficult time to continue moving forward'. She elaborated:

> The whole field was rightly criticised, and it came to a screeching halt. Every trial that was started at that point was halted, and money that was being devoted to gene therapy dried up. Companies that had been started to help move gene therapy forward went broke (Prof. Bennett, pers. comm. 2022).

Gelsinger's death made clear that gene therapy research was not universally good. While its scientific potential carried hope, it was also risky – and, according to some, potentially skewed by economic interests or prestige in scientific milieus. Notably, Gelsinger's father described people promoting gene therapy as part of 'a heartless and soulless industry (…); they are doctors so blinded in their quest for recognition that they can't even see the dangers anymore' (Gelsinger 2002). To Bennett and her team, who had developed the techniques with which to assess the expression of recombinant DNA in the retina in the early 1990s and demonstrated the first proof-of-concept of a gene therapy-mediated intervention in a mouse model in 1996 (Bennett 2014), the tragedy shook the ground of their lifework. It also raised serious doubts about the possibility of moving from animal models to human trials. How did researchers succeed in transforming Luxturna from promising animal research to human testing for a non-lethal disease in the shadow of Gelsinger's death? To understand this, we pause at a decisive moment of valuation in the career of Luxturna: an

[3] A few years after the Gelsinger tragedy, five cases of leukaemia occurred in another gene therapy trial, putting an additional damper on the field (Lewis 2012).

assessment undertaken by the National Institute of Health's (NIH) Recombinant DNA Advisory Committee (RAC), which constituted an 'obligatory point of passage' (Callon 1984) for NIH-funded researchers to start genetic research with human subjects.[4]

At the RAC meeting in December 2005, concern about risks for trial subjects rooted in past research experiences was pitted against future prospects of curing blindness. Prof. Bennett recalls:

> The RAC held a public meeting because nobody had ever enrolled children in a gene therapy study for a non-lethal disease. (…) Basically, children are considered vulnerable subjects. They may not necessarily understand all the details of what they're agreeing to and so we had to justify the approach we were using – the dosing, the safety, how we would assent the children and get parental permission, and so forth. We were grilled about this for a whole day (Prof. Bennett, pers. comm. 2022).

With Gelsinger's death lingering large as a problematic past, patient representatives at the meeting shared what Guyer (2007) and Sharp (2014) would call a 'prophetic' framing: their testimonies enacted the hope of a future cure. Eliciting the future social 'good' that this research could convey, some for example argued that 70% of children with blindness end in unemployment. A family told the story of their long-awaited one-year-old child with the LCA-diagnosis to convey the hope that this research represented to them:

> The bicycle I couldn't wait to buy him will be instead a white cane to help him get around. (…) Seeing the pain in our parents' eyes when they come to see their grandchild is devastating (…) This is why I urge you to let those wonderful doctors perform their trial for gene therapy of LCA in children (Transcript, RAC 2004).

In these narratives, the future value of sight is temporally layered with many years of waiting for a healthy child, mobilising particular pasts as a powerful backdrop to the projection of a better future. While it turned out that none of the patients who shared testimonies at the RAC meeting was a candidate for the specific gene therapy, their temporal layering of past pains and future hopes weighed heavily on the day. In the words of a relative at the RAC meeting: 'This study is the first step on the way to the moon in curing blindness. Then people with other forms of Leber's and eventually people with other forms of blindness.' This temporal layering was not unproblematic. For example, a spokesperson for the National Federation of the Blind criticised the framing of these narratives for downplaying blind

[4] The RAC was a public forum with scientific and non-scientific members that reviewed the safety and ethics of experiments involving DNA. Although having no official power, it informed FDA approvals of human trials (Lewis 2012).

people's capacity, stating that high unemployment rates among blind people are rather due to 'society's low expectations for the blind' (Zhang 2017). In any case, these layers of pain and hope alone could not fully convince the RAC; the recent, troubled past made vividly concrete by Jesse Gelsinger's death could not be framed out of their decision. In the end, however, even sceptics were convinced. If not by the explanations offered by scientists and the horizons of hope enacted by patients, then by the playful presence of a photogenic dog.

Rather than remaining as an abstract and prophetic future, the many hopes and aspirations of patients and researchers materialised in a cob of three blind puppies that Bennett and her team managed to give sight to. As research models, dogs were valued by scientists because of the anatomical similarities between dog and human eyes that made translations potentially viable. Yet, it was the dogs' ability to embody hope in the present even against future risks of experimental research that became their overriding quality. Instead of being euthanised at the end of the experiment, some of the laboratory dogs were adopted by researchers and came to constitute living examples of the potential of gene therapy. One of the dogs, named Lancelot, appeared on popular news media such as Good Morning America (Lewis 2012). Lancelot also became a key actor at the RAC meeting where Bennett and her team showed videos of him and his relatives. Inviting the audience to compare a particular past – the untreated puppy, who 'walks around very tentatively', 'wanting to play' but bumping into other dogs instead – with the presently treated dog who engaged in playful activities, researchers sought to make visible the effectiveness of the treatment. In response to a comment about the risk of testing the treatment in children, a member from the research team responded: 'if this was a study only in adults, Lancelot and the incredible results in the dog model would not be required.' The dog's playful attitude became a compelling manifestation of the 'goodness' of making blind children see, which concretised a hopeful future in the present. With this, the scientific efforts of the researchers coalesced with the hopes of patients and their families into a particular temporal layering that enabled the RAC committee to see the future potential of the experimental therapy. The dogs came to animate painful pasts, future hope and present scientific state of the art at once.

At the beginning of Luxturna's story, concern about questionable research practice and risks to trial subjects grated against the innovative potential of experimental gene therapy and put the research field to a halt. However, against this temporal layering, a horizon of future hope was evoked through the arguments of researchers, testimonies of patients and, most importantly, through a relatively unusual 'valuation device': a freshly sighted dog. Thus, hope came to overshadow a problematic, recent past and enabled the transformation of Luxturna from animal model to experimental human treatment: the

RAC unanimously voted in favour of conducting research with human subjects, and recommended the inclusion of children age eight and above in phase I, if safety could be demonstrated in the initial adult participants.

Second moment: Establishing a start-up

Fast-forward eight years to another negotiation of Luxturna's 'good'. At this moment, the researchers prepared for Luxturna to become a marketable product to benefit more patients. Yet, the future market potential of the therapy grated against concerns about financial conflicts of interest of researchers – concerns that were rooted in problematic experiences of the recent past, particularly Gelsinger's tragic death. To deal with this issue, researchers actively sought to distance market and scientific valuations – and the particular layers of pasts and futures on which they drew – from each other.

Two temporal considerations were central for the research team: speed of market access and patient reach – that is, how quickly the therapy could be made available on the market and how many patients it could reach in the future. Professor Katherine High, who had a central role in this process, recalls:

> Sometimes I was getting pretty discouraged about moving forward with Luxturna. I was thinking: we could just do it forever under an Open IND[5] and never get the product licence. But in the year after Luxturna was approved, we treated more people than in the ten years of clinical development! (Prof. High, pers. comm. 2022).

Until this point, research on Luxturna had been funded through grants from public institutions and charities. However, the research team could not secure sufficient funding through these sources for the expensive phase III trials. Moreover, they were aware that research alone did not ensure that patients would benefit from the therapy. The research team had several offers from large pharmaceutical companies to drive the project further but found it too risky to allow a large company control the testing of the therapy, in case it would shelve the project for some reason – a particular expectation based on past experiences of other biotechnology start-ups. Hence, to realise the scientific and social 'good' of the gene therapy, researchers decided to create a start-up enterprise; a process that required mobilising the therapy's future market value to attract investors. This process inherently draws on specific – but always uncertain – futures, discounted into the present (Doganova 2018, 2024).

---

[5] Open IND: Investigational New Drug Application, where the product is not on the market but is allowed to be used for investigational purposes (FDA 2022).

Spark Therapeutics was established in 2013, but while preparing for Luxturna's market entry, researchers found it necessary to stay clear of 'any taint from the company' on the future scientific project (Prof. Bennett, pers. comm. 2022). One of the problems in the Gelsinger case had been the (suspected) entanglement of economic and scientific interests. Gelsinger's father ended up suing leading actors in the trial to which he lost his son, and his attorney described the field of genetic research as plagued by 'NASDAQ[6] medicine' (Milstein in Kimmelman 2009: 36). Indeed, after Gelsinger's death, the leading researcher of the trial received $US13.5 million in stock for his 30 per cent share in the company that stood to gain from the research (Lewis 2012). To avoid any accusations of economic interests in Luxturna and comply with conflict of interest policies at their university, as well as being able to maintain direct patient contact, Prof. Bennett and her spouse and collaborator, Prof. Maguire, decided to waive any future financial gain from the start-up company (Bennett 2014). They even relinquished economic gain from the patents associated with Luxturna:

> I'm Albert Maguire, the PI for this proposal. (…) In order to eliminate any potential conflict of interest related to my participation in this and other trials, I forfeited any financial benefit related to a pending patent based on this therapy. And likewise, my spouse and collaborator, Dr Bennett has waived any financial interest as well (Transcript, RAC 2004).

Here, the researchers framed their present and future engagement with the company through a clear break with a problematic past. As a result, the potential of future economic gain was distanced from the contemporary scientific practices of researchers – temporal layers in this case were kept well apart.

The establishment of Spark Therapeutics may be considered the 'market moment', the valuation of its scientific results informs the valuation of its market potential. However, rather than a sequential replacement of one mode of valuation with another, the 'market moment' was anticipated earlier in Luxturna's career. For instance, more than ten years before the launch of the start-up, Prof. Bennett had what she describes as the 'Eureka moment', when she saw the potential of their research and thought: 'wow, we can make blind puppies see – we should try to make blind children see!' At this point, the next step for the research team was to write a patent application. She recalls: 'Somebody had mentioned to me that it's really important to get intellectual property on this, because if you end up needing sponsorship from a company, they will want to be able to license the intellectual property.' This patent application, taken out in the early

---

[6] NASDAQ: The National Association of Securities Dealers Automated Quotations Stock Market, an American stock exchange based in New York City (www.nasdaq.com).

days of Luxturna's career, foreshadowed a market future for the gene therapy; a temporal layer that foregrounded an unreleased market potential of a therapy-to-be. The patent application was continuously renewed from 2001 to 2007 when it was finally approved (Acland et al. 2012). The 'market moment' can thus be seen as a continuous process, building up a temporal layer of past market projections. While this market future only crystallised long after the start-up was established, its role in investment valuations was prepared early on in Luxturna's career.

This insight complicates Moreira and Palladino's (2005) juxtaposition of a financialised and future-oriented 'regime of hope' and a scientific and past/present-anchored 'regime of truth'. In our case, both the economic and scientific trajectories were temporally layered 'present-past-futures' that developed in parallel. As Sharp (2014: 154) argued, 'Experimental scientists are focused on the longue durée – a stance that facilitates side-stepping the near future. In contrast, investors inevitably desire "rapid" and "timely" results and profits'. Because of careful efforts to keep these two trajectories apart, it was possible to care for two different, though overlapping, temporal layerings at once – one selectively framing the potential cure and the other its market potential.

Third moment: pricing a gene therapy

How do you set a price for a therapy if there is no past experience with which to compare it? As the first gene therapy for an inherited disease to be approved by the FDA, this was a key question to the team at Spark in setting the price of Luxturna. While, in the previous valuation moment, researchers had sought to keep the economic and scientific trajectories apart, these were brought together in the health economic evaluations that informed the price in accordance with the idea of 'value-based pricing', as recently examined by Doganova and Rabeharisoa (2024). According to the idea of value-based pricing, the price should reflect the expected economic benefit of the treatment set against the alternative of no treatment and a lifetime of disability. This pricing method involves a peculiar temporal layering that is ostensibly future-oriented but relies on assumptions and costs selectively drawn from the past. This mobilisation was strongly contested by critics who strove instead to bring the past funding streams from patient organisations and public research institutions into view. Accordingly, two conflicting temporal layerings came into tension in the attempts to settle on a 'good' price for Luxturna.

In their price calculations, the start-up company employed an economic model that mobilised particular healthcare costs of the past from which to extrapolate a hypothetical economic future. The pricing and reimbursement team tested different assumptions: indirect cost

(e.g. the cost of educating a blind child), 'quality of life' measures, and direct medical costs over a patient's estimated lifetime. These calculations suggested a price that exceeded US$1 million per patient. This price was then tested against other approaches such as compensation paid out under long-term disability policies in the American insurance industry (anonymous, pers. comm. 2023). Based on these calculations, the final price tag of US$425,000 per eye as a one-time treatment was summarised within the logic that: 'Instead of renting a house, you are buying it' (Green 2019) – a valuation that relied on extrapolating selective past costs into a distant patient future.

Yet, this distant future became a point of contention. Uncertainties remained about the therapy's long-term effects. Luxturna does not cure blindness; rather, it stops the deterioration of the illness, and in many cases it brings substantial improvement to sight, especially in lower light, which is a central problem for patients with LCA (Maguire et al. 2021). Yet, in the phase III clinical trial, only half of the patients (52%) met the FDA's threshold for clinically meaningful improvement (FDA 2017).[7] Further, two patients (5%) experienced permanent vision loss due to the administration of the therapy, and at the time of the price-setting, some uncertainty over the continuation of long-term improvement persisted, based on data from competing trials (Darrow 2019). Demonstrating the contingent nature of the temporal layers informing value-based pricing, different future horizons were mobilised in the cost-effectiveness calculations in different countries: in Sweden, it was assumed that Luxturna's effect would last ten to 15 years (TLV 2019: 40); in Norway, the future horizon was 15 years (Nye Metoder 2020: 25); the American-based Institute for Clinical and Economic Review (ICER) assumed an effect of ten years plus a ten year waning period (ICER 2017), and in England, a lifetime horizon of 85 years was employed (NICE 2019). These temporal orderings inevitably influenced what counted as 'good value'.

As a way of settling the uncertainty related to the one-time treatment's future horizon, Spark Therapeutics decided to deploy a particular version of value-based pricing: outcome-based payment. This implied that payers would not have to pay the full amount for the therapy for patients who did not benefit sufficiently from the treatment. As a valuation device, the payment model also offered an additional temporal layer compared to value-based pricing models. Rather than relying on a projection of selected past costs into a distant future, the payment model served to convert the uncertainty about future costs and benefits into a calculable risk to be discounted into the

[7] The FDA's definition of clinical meaningfulness was improvement by two light levels, but a number of the patients entered the trial already able to pass at the next to lowest light level, which they could only improve by one light level. Thus the test had a "ceiling effect" that may have operated against the trial design (High, personal communication; Russell et al. 2017).

present (Doganova 2024). Furthermore, to the start-up company, the payment agreement came to signal a dedication to innovation that pitted the company's pricing strategy as a 'good' alternative to the conventional practices of 'big pharma'. But it was exactly this break with the past that, according to an expert involved with the pricing, made it difficult to push the new payment model through:

> There is a very big resistance to change in the US and people keep talking about how they want to make change. In reality, there is a lot of people who want to keep the system the same because a lot of people make money from the system in the way that it is (anon., pers. comm. 2023).

Thus, by employing the peculiar temporal layering of outcome-based pricing, Spark Therapeutics cast a historically accumulated layer of economic valuation as an undesirable past. This broke with firmly established industry notions that one-time treatments would not create sustainable sources of continuous income (Lewis 2012; Roy 2020).

The particular temporality of the outcomes-based payment agreement allowed the start-up company to move from a focus on the price per se to negotiations about pricing principles and to distance themselves from 'greedy' pharma pricing practices. Yet, this temporary settlement on what was 'good' was still challenged upon Luxturna's market debut, with a public that kept 'grinding on about the price' (Prof. High, pers. comm. 2022). Rather than being portrayed as a 'good' therapy at a 'good' price, Luxturna was highlighted in some news media as the most expensive medicine being sold in the US at the time (e.g. Feuerstein et al. 2018). Critics argued that a value-based pricing strategy prompts decision makers to ask the wrong questions about the temporalities involved in pharmaceutical innovation:

> We didn't pay for the polio vaccine based on the future cost savings for kids who didn't need to live in iron lungs (…) The question in drug pricing isn't how much is a life worth; it's what makes a fair return on an investment in R&D and an accessible price (Patients for Affordable Drugs 2019).

Here, value-based pricing is challenged on the basis that hypothetical futures should not colonise current market value. In open groups on Facebook, similar critique was voiced, although some patients who had received the treatment pushed back, stating that Spark Therapeutics 'is not some big pharma company' but an alternative who 'laughed, cried and celebrated with us' – mobilising a past layer of shared experience between the company and patients. Arguing that price setting should be informed by R&D investments, Patients for Affordable Drugs also mobilised selective pasts: the actual costs of drug development. Thus, while the temporal framing of value-based pricing highlights the potential savings in the future (based on

selective past costs), the alternative framing made by the patient advocacy group brought forth past and typically long-obscured layers of research investment. These competing temporal valuations underlying rare disease development prolong controversies over a 'good' price.

At the time of writing, the question of whether Luxturna's projected market future has come to pass remains unsettled. The start-up managed to secure more than US$122 million in venture capital funding (Crunchbase 2023) and sold the licence of Luxturna to Novartis for commercial activity outside the US for about US$170 million, before EMA approval of the therapy in 2018 (Sagonowsky 2018). Shortly thereafter, Spark was acquired by Hoffman-La Roche in a US$4.8 billion deal (Morrison 2019).[8] However, according to the expert involved in the pricing of Luxturna, its actual profit is uncertain: 'No one's making a lot of money out of Luxturna, there's not enough patients (…) [Luxturna] was a good proof of concept. It was good to get the first gene therapy approved, but it is not this big money-making machine that is going to keep gene therapy alive' (anon., pers. comm. 2023). Indeed, in 2021 Roche reduced the accounting value of Luxturna, citing 'reduced sales expectations' (Dubnow 2021).

Clearly, in the case of Luxturna, the notion of 'good' entails shifting and multiple temporal layers that bring together selective experienced pasts and possible futures, but that continually come into conflict with alternative temporal layering, making any settlements unstable.

Discussion and conclusion: a temporal lens in valuation studies

The notion of 'the good economy' invites attention to the normativeness enacted in a given economy and how this may shift over time (Asdal et al. 2023). Such attention to historical contingencies makes it clear that 'goodness' depends on efforts to promote and enact particular notions of the 'good'. Building on this perspective, our analysis suggests that the 'goodness' of pharmaceutical innovation and pricing is not merely a story of fairness versus greed, as suggested in the opening quote of this article. Rather, various conceptions of and ways to pursue 'good' converge and clash in the career of novel therapies. We suggest that these conceptions are temporally layered. We argue that moments of valuation consist of multiple such temporal layers of past experiences and future expectations that are rendered visible – or left obscure – depending on how these layers are mobilised by various actors. In our analysis, we showed the different and often

[8] Spark also had other trials underway considered to have high net book value (Roche 2020).

controversial efforts of temporal layering during three particular moments of Luxturna's 'career': in the first, a problematic past was selectively blended out through future prospects of curing blindness conveyed through the present playfulness of a photogenic dog. In the second, distinct layers were kept apart, which made it possible to care for two parallel futures at once – the potential cure and the potential market. And in the third, value-based pricing models established the therapy's future potential as the temporal layer that mattered for the price setting rather than past production costs, which were evoked by contesting actors. Overall, our analysis highlights that a gene therapy's career is not a linear story about how scientific value accumulates and then becomes financialised in biopharmaceutical markets (Chiapello 2015). In contrast to a sequential conception of stages where different forms of valuation replace one another, as suggested by the image of the pipeline, we propose that objects' careers are shaped by valuations where various past and future horizons are brought into play as actors pursue various and often conflicting forms of 'good'.

The controversies along Luxturna's career are not unique. Indeed, similar discussions are regularly brought up in relation to pharmaceutical innovation (Bourgeron and Geiger 2022). Still, current development and marketing of gene therapies make a temporal analysis of such debates particularly pertinent as these therapies are often expected to be one-time treatments with potentially lifelong effects whose pricing is justified based on such, necessarily uncertain, future 'horizons of expectations' (Bryant and Knight 2019). Lifetime cures are longed for by patients with rare diseases and could radically change individual futures. Yet, in resource-constrained healthcare systems, the expected increase in advanced, high-cost therapies inevitably raises questions about how to balance patient access in the present with the promissory horizons of a cure for a few (Green et al. 2023). In the pharmaceutical sector, such discussions are likely to become more prevalent as advanced one-time therapies will continue to present prophetic potential without much past precedent, leading, as we showed, to highly contestable temporal layerings. Clearly, these different configurations of 'the good' will remain open to critique and contestation as long as actors draw on differing pasts and futures. While our case demonstrated a few such mobilisations of temporal layers, we could have pointed to others, by other actors or in other places.

A temporally sensitive analysis thus produces new openings for critique as it points to the contingency of existing practices in these markets and may allow the excavation of those that had been 'layered over'. For instance, it is not a given that the best possible outcome of a start-up is to be acquired by bigger pharmaceutical companies. If the future beyond the typical three-to-four-year payback horizon for venture capital was made more visible, it would render present

economic valuations vastly different (Doganova 2024). It is not a given that drug prices are increasingly tethered to speculative stock market expectations (Roy 2023), or that the main economic incentive structure of pharmaceutical innovation consists of 20-year patent monopolies (Geiger and Bourgeron 2023). If in these and other cases the temporal layering built into certain models of innovation are made explicit, they can be challenged more easily. For example, past public R&D investments, which are often obscured in price negotiations, could serve to strengthen public bodies' negotiating power. Alternatively, the peculiar economic temporality imposed by patents could be replaced with nearer-term innovation prices or R&D vouchers that would compensate firms for actual innovation efforts rather than future market returns (Mazzucato and Roy 2019).

Overall, our analysis demonstrates how temporal layers are mobilised and come to count in the valuing of objects, often against alternative layerings. We propose this analytical sensitivity as one way to advance critique of economies that claim to be 'good'. While Asdal and colleagues developed their concept of the 'good economy' mainly in relation to environmental concerns espoused through the 'bioeconomy', this article focuses attention on how the 'goodness' of medical goods is promoted and contested in the pharmaceutical sector – as another 'bioeconomy' (Birch and Tyfield 2012; Mittra and Zoukas 2020). In both fields, the juxtaposition of 'bio' and 'economy' already hints at the temporal controversies that may arise when questions of 'bios', of life, spanning (sometimes multiple) lifetimes, are brought into the vicinity of economic calculations, with their concerns firmly rooted in the present and (often near-term) futures (Adams et al. 2009). Indeed, at the core of this amalgamation is a 'desire to generate new types of value from the monetisation of … biological processes and technologies' (Mittra and Zoukas 2020: 3), a desire that at its core is promissory but is also sourced from creating certain continuities and breaks with the past. We maintain that a fine-grained temporal analysis can provide new openings to questions of valuation in these bioeconomies. These range from exploring explicit contestations over temporal horizons of 'bios', such as in Kinsella's (2020) case of nuclear waste, to those where temporalities directly feed into actors' economic valuation processes, as in Kragh-Furbo et al.'s (2023) case of 'temporal prospectors' in electricity aggregation. Attention to temporalities may also help explain how the promissory politics surrounding bioeconomies may hide present assetisation processes (Birch 2017). How do normativities in the form of past experiences and visions for the future shape what temporal layers are rendered visible in such contestations of 'the good'? How is value established in the present when actors draw on incompatible temporal layers, all claiming to be concerned about these economies' (and their objects') 'goodness'? And most

importantly perhaps, how can those temporal layers that lie obscured be unearthed through critique?

Attention to the temporal orderings made locally by different actors to determine what is 'good' cannot be seen in isolation from broader political and economic conjunctures. Newer contributions within valuation studies have started to 'politicise' the field (Helgesson et al. 2017). Our article demonstrates that these contributions can be enriched through a temporal sensitivity, which not only shows how 'things could have been otherwise', but which additionally draws attention to the fact that 'things can still be (layered) otherwise' by bringing different horizons of experience and expectations into view.

Acknowledgments

The authors wish to thank our research participants for the information and views that they generously shared with us. We also wish to thank the two anonymous reviewers and the theme issue editors at *Valuation Studies*, as well as the participants at the workshop organized as part of this theme issue, whose extremely valuable feedback and discussions helped to strengthen our article and argument, especially our discussant Philipp Golka. Special thanks are due to Laura Emdal Navne and Amalie Martinus Hauge for their helpful feedback during the early stages of this paper.

Funding sources

The work of Anna Brueckner Johansen and Sarah Wadmann was supported by The Independent Research Fund Denmark [grant no. 1055-00010B]. The work of Susi Geiger was supported by the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant agreement No 771217).

Ethical statements

The research protocol that forms the basis of this work has been reviewed and approved by the Institutional Review Board of VIVE – the Danish Center for Social Science Research.

Declaration of competing interest

As part of her employment at VIVE – the Danish Center for Social Science Research, Sarah Wadmann has conducted contract research for public authorities in Denmark and pharmaceutical companies. She has received no personal remuneration.

References

Acland, Gregory M., Gustavo D. Aguirre, Jean Bennett, William W. Hauswirth, Samuel G. Jacobson, and Albert M. Maguire. 2012. *Method of Treating or Retarding the Development of Blindness*. US8147823B2, filed 8 July 2010, issued 3 April 2012.

Adams, Vincanne, Michelle Murphy, and Adele E. Clarke. 2009. "Anticipation: Technoscience, Life, Affect, Temporality." Subjectivity 28: 246–265.

Appadurai, Arjun. 1986. *The Social Life of Things: Commodities in Cultural Perspective*. Cambridge: Cambridge University Press.

Asdal, Kristin, and Hilde Reinertsen. 2022. *Doing Document Analysis: A Practice-Oriented Method*. London: Sage.

Asdal, Kristin, Béatrice Cointe, Bård Hobæk, Hilde Reinertsen, Tone Huse, Silje R. Morsman, and Tommas Måløy. 2023. "'The Good Economy': A Conceptual and Empirical Move for Investigating How Economies and Versions of the Good Are Entangled." *BioSocieties* 18: 1–24.

Beckert, Jens. 2016. *Imagined Futures: Fictional Expectations and Capitalist Dynamics*. Cambridge, MA: Harvard University Press.

Bennett, Jean. 2014. "My Career Path for Developing Gene Therapy for Blinding Diseases: The Importance of Mentors, Collaborators, and Opportunities." *Human Gene Therapy* 25(8): 663–670.

Birch, Kean. 2017. "Rethinking Value in the Bio-economy." *Science, Technology, & Human Values* 42(3): 460–490.

Birch, Kean, and David Tyfield. 2012. "Theorizing the bioeconomy: biovalue, biocapital, bioeconomics or … what?." *Science, Technology, & Human Values* 38(3): 299–327.

Board of Editors. 2020. "Towards a Reformulation." *Valuation Studies* 7(1): 1.

Bourgeron, Théo, and Susi Geiger. 2022. "(De-)Assetizing Pharmaceutical Patents: Patent Contestations behind a Blockbuster Drug." *Economy and Society* 51(1): 23–45.

Brown, Nik. 2005. "Shifting Tenses: Reconnecting Regimes of Truth and Hope." *Configurations* 13(3): 331–355.

Bryant, Rebecca, and Daniel M. Knight. 2019. *The Anthropology of the Future. New Departures in Anthropology*. Cambridge: Cambridge University Press.

Çalişkan, Koray, and Michel Callon. 2009. "Economization, Part 1: Shifting Attention from the Economy towards Processes of Economization." *Economy and Society* 38(3): 369–398.

Çalişkan, Koray, and Michel Callon. 2010. "Economization, Part 2: A Research Programme for the Study of Markets." *Economy and Society* 39(1): 1–32.

Callon, Michel. 1984. "Some Elements of a Sociology of Translation: Domestication of the Scallops and the Fishermen of St Brieuc Bay." *The Sociological Review* 32: 196–233.

Chiapello, Eve. 2015. "Financialisation of Valuation." *Human Studies* 38(1): 13–35.

Costa, Alessia, and Richard Milne. 2023. "Detecting Value(s): Digital Biomarkers for Alzheimer's Disease and the Valuation of New Diagnostic Technologies." *Sociology of Health & Illness* 46(S1): 261–278.

Crunchbase. 2023. "Spark Therapeutics – Funding, Financials, Valuation & Investors." https://www.crunchbase.com/organization/spark-therapeutics/company_financials, accessed 21 March 2023.

Darrow, Jonathan J. 2019. "Luxturna: FDA Documents Reveal the Value of a Costly Gene Therapy." *Drug Discovery Today* 24(4): 949–954.

Doganova, Liliana. 2018. "Discounting and the Making of the Future: On Uncertainty in Forest Management and Drug Development" In *Uncertain Futures: Imaginaries, Narratives, and Calculation in the Economy*, edited by Jens Beckert and Richard Bronk, 278–297. Oxford: Oxford University Press.

Doganova, Liliana. 2024. *Discounting the Future: The Ascendancy of a Political Technology.* New York: Zone Books.

Doganova, Liliana, and Vololona Rabeharisoa. 2024. "The Temporalities of Prices: 'Value-Based Pricing' in Pharmaceutical Markets." *Economy and Society* 53(2): 183–204.

Dubnow, Shoshana 2021. "Years Later, a First-of-Its-Kind Treatment Shows the Power, and Limits, of Gene Therapy." *BioPharma Dive*, November 15, 2021. https://www.biopharmadive.com/news/luxturna-gene-therapy-eye-leber-lca/609832/.

Dussauge, Isabelle, Claes-Fredrik Helgesson, and Francis Lee (Eds.). 2015. *Value Practices in the Life Sciences and Medicine*. Oxford: Oxford University Press.

Elbek, Laust Lund. 2022. "Rupture, Reproduction, and the State: The Arab Spring on Lampedusa as 'Layered Event'." *History and Anthropology* 33(5): 652–669.

FDA (Food and Drugs Administration). 2017. "Clinical Review for Voretigene Neparvovec (Luxturna) (BLA 125610)." https://www.fda.gov/files/vaccines%2C%20blood%20%26%20biologics/published/Clinical-Review--December-16--2017---LUXTURNA.pdf, accessed 24 May 2024.

FDA (Food and Drugs Administration). 2022. "Investigational New Drug (IND) Application." *FDA*. July 20, 2022. https://www.fda.gov/drugs/types-applications/investigational-new-drug-ind-application, accessed 24 May 2024.

Feuerstein, Adam, Damian Garde, and STAT 2018. "The Most Expensive U.S. Medicine Now Has an Official Sticker Price." *Scientific American*,

January 3, 2018. https://www.scientificamerican.com/article/the-most-expensive-u-s-medicine-now-has-an-official-sticker-price/.
Flaherty, Michael G., and Gary Alan Fine. 2001. "Present, Past, and Future." *Time & Society* 10(2–3): 147–161.
Geiger, Susi. 2020. "Silicon Valley, Disruption, and the End of Uncertainty." Journal of Cultural Economy 13(2): 169–184.
Geiger, Susi. 2021. *Healthcare Activism: Markets, Morals, and the Collective Good*. Oxford: Oxford University Press USA.
Geiger, Susi, and Théo Bourgeron. 2023. "In the Name of Transparency: Organizing European Pharmaceutical Markets through Struggles over Transparency Devices." *Organization Studies* 44(11): 1751–1773.
Gelsinger, Paul. 2002. "Jesse's Intent." In *Guinea Pig Zero: An Anthology of the Journal for Human Research Subjects*, edited by Robert Helms. New Orleans, LA: Garrett County Press.
Green, Adam. 2019. "Biotech Companies Defend Prices of One-off Gene Therapy." *Financial Times,* February 15, 2019. https://www.ft.com/content/edd639fc-9755-11e9-98b9-e38c177b152f.
Green, Sara, Barbara Prainsack, and Maya Sabatello. 2023. "Precision Medicine and the Problem of Structural Injustice." *Medicine, Health Care, and Philosophy* 26(3): 433–450.
Guyer, Jane I. 2007. "Prophecy and the Near Future: Thoughts on Macroeconomic, Evangelical, and Punctuated Time." *American Ethnologist* 34(3): 409–421.
Hammarfelt, Björn, Alexander D. Rushforth, and Sarah de Rijcke. 2020. "Temporality in Academic Evaluation: 'Trajectoral Thinking' in the Assessment of Biomedical Researchers." *Valuation Studies* 7(1): 33.
Helgesson, Claes-Fredrik, Monika Krause, and Fabian Muniesa. 2017. "Attempting to Bring Valuation and Politics Together: The Politics of Valuation Studies at a Series of Sessions in Copenhagen." *Valuation Studies* 5(1): 1–6.
Hernes, Tor. 2014. *A Process Theory of Organization*. Oxford: Oxford University Press.
Hernes, Tor. 2022. *Organization and Time*. Oxford: Oxford University Press.
Hernes, Tor, and Majken Schultz. 2020. "Translating the Distant into the Present: How to Address Distant Past and Future Events through Situated Activity." *Organization Theory* 1(1): 1–20.
ICER (Institute for Clinical and Economic Review). 2017. "Voretigene Neparvovec for Biallelic RPE65-Mediated Retinal Disease: Effectiveness and Value." https://icer.org/assessment/inherited-retinal-disease-2018/#overview, accessed 24 May 2024.
Kimmelman, Jonathan. 2009. *Gene Transfer and the Ethics of First-In-Human Research: Lost in Translation*. Cambridge: Cambridge University Press.
Kinsella, William J. 2020. "Extracting Uranium's Futures: Nuclear Wastes, Toxic Temporalities, and Uncertain Decisions." *The Extractive Industries and Society* 7(2): 524–534.

Kjellberg, Hans, Ebba Sjögren, and Linus Johansson Krafve. 2023. "The Functions of Known to Be Inaccurate Prices in Markets: A Cross-Country Comparison of Pharmaceutical List Pricing." *Journal of Business Research* 167 (November): 114193.

Koselleck, Reinhart. 2018. "Sediments of Time: On Possible Histories." In *Sediments of Time*. Stanford, CA: Stanford University Press.

Kragh-Furbo, Mette, Gordon Walker, and Mitchell Curtis. 2023. "The Production of Infrastructural Value and the Extension of the Electricity Grid: Demand-Side Response and Aggregators as Temporal Prospectors." *Science & Technology Studies* 36(3): 43–59.

Lewis, Ricki. 2012. *The Forever Fix: Gene Therapy and the Boy Who Saved It*. New York: St. Martin's Publishing Group.

Maguire, Albert M., Jean Bennett, Elena M. Aleman, Bart P. Leroy, and Tomas S. Aleman. 2021. "Clinical Perspective: Treating RPE65-Associated Retinal Dystrophy." *Molecular Therapy* 29(2): 442–463.

Mazzucato, Mariana, and Victor Roy. 2019. "Rethinking Value in Health Innovation: From Mystifications towards Prescriptions." *Journal of Economic Policy Reform* 22(2): 101–119.

Mennicken, Andrea, and Ebba Sjögren. 2015. "Valuation and Calculation at the Margins." *Valuation Studies* 3(1): 1–7.

Mittra, James, and Giorgos Zoukas. 2020. "Unpacking the Concept of Bioeconomy: Problems of Definition, Measurement, and Value." *Science & Technology Studies* 33(1): 2–21.

Moreira, Tiago, and Paolo Palladino. 2005. "Between Truth and Hope: On Parkinson's Disease, Neurotransplantation and the Production of the 'Self'." *History of the Human Sciences* 18(3): 55–82.

Morrison, Chris. 2019. "Spark's Meteoric Rise from Hospital-Funded Spinout to $4.8 Billion Deal." *Nature Biotechnology* 37(5): 492–493.

Muniesa, Fabian, and Liliana Doganova. 2020. "The Time That Money Requires: Use of the Future and Critique of the Present in Financial Valuation." *Finance and Society* 6(2): 95–113.

NICE (National Institute for Health and Care Excellence). 2019. "Voretigene Neparvovec for Treating Inherited Retinal Dystrophies Caused by RPE65 Gene Mutations. Highly Specialised Technologies Guidance." https://www.nice.org.uk/guidance/hst11/evidence, accessed 24 May 2024.

Nye Metoder. 2020. "Beslutningsforum for Nye Metoder: Innkalling og saksdokumenter." Stjørdal, Norge: *Nye Metoder.* https://nyemetoder.no/Documents/Beslutninger/Saksdokumenter%20samlefil%20offentlig%20utgave%2030MARS2020.pdf, accessed 24 May 2024.

Ortiz, Horacio. 2021. "Political Imaginaries of the Weighted Average Cost of Capital: A Conceptual Analysis." Valuation Studies 8(2): 5–36.

Patients for Affordable Drugs. 2019. "$2.1 Million Drug Marks Troubling Trend in Drug Pricing." *Patients for Affordable Drugs*. May 24, 2019. https://patientsforaffordabledrugs.org/2019/05/24/zolgensma/.

Petryna, Adriana. 2005. "Ethical Variability: Drug Development and Globalizing Clinical Trials." *American Ethnologist* 32(2): 183–197.

Petryna, Adriana, and Arthur Kleinman. 2006. "The Pharmaceutical Nexus." In *Global Pharmaceuticals*, edited by Adriana Petryna, Andrew Lakoff, and Arthur Kleinman, 1–32. Durham, NC: Duke University Press.

Pierce, Eric A., and Jean Bennett. 2015. "The Status of RPE65 Gene Therapy Trials: Safety and Efficacy." *Cold Spring Harbor Perspectives in Medicine* 5(9).

Pinney, Christopher. 2023. "What Time Is the Visual? Photography and the History of the Future." *Visual Anthropology Review* 39(1): 24–56.

Pulk, Kätlin 2022. T*ime and Temporality in Organisations: Theory and Development*. London: Palgrave Macmillan.

Quinn, Casey, Colin Young, Jonathan Thomas, Mark Trusheim, and MIT NEWDIGS FoCUS Writing Group. 2019. "Estimating the Clinical Pipeline of Cell and Gene Therapies and Their Potential Economic Impact on the US Healthcare System." *Value in Health: The Journal of the International Society for Pharmacoeconomics and Outcomes Research* 22(6): 621–626.

Roche. 2020. "Finance Report 2020". Basel, Switzerland: F. Hoffman-La Roche. https://assets.cwp.roche.com/f/126832/x/db9d31e8a7/fb20e.pdf, accessed 21 March 2023.

Ronco, Virginia, Myriam Dilecce, Elena Lanati, Pier Luigi Canonico, and Claudio Jommi. 2021. "Price and Reimbursement of Advanced Therapeutic Medicinal Products in Europe: Are Assessment and Appraisal Diverging from Expert Recommendations?" *Journal of Pharmaceutical Policy and Practice* 14(1): 30.

Roy, Victor. 2020. "A Crisis for Cures? Tracing Assetization and Value in Biomedical Innovation." In *Assetization: Turning Things into Assets in Technoscientific Capitalism,* edited by Kean Birch and Fabian Muniesa, 97–124. Cambridge, MA: MIT Press.

Roy, Victor. 2023. *Capitalizing a Cure*. Oakland, CA: University of California Press.

Russell, Stephen, Jean Bennett, Jennifer A Wellman, Daniel C Chung, Zi-Fan Yu, Amy Tillman, Janet Wittes et al. 2017. "Efficacy and Safety of Voretigene Neparvovec (AAV2-hRPE65v2) in Patients with RPE65-Mediated Inherited Retinal Dystrophy: A Randomised, Controlled, Open-Label, Phase 3 Trial." *The Lancet* 390(10097): 849–860.

Sagonowsky, Eric. 2018. "Spark, Novartis Tie up in Gene Therapy Licensing Deal Worth up to $170M." *Fierce Pharma*. 25 January, 2018. https://www.fiercepharma.com/pharma/spark-novartis-tie-up-gene-therapy-licensing-deal-worth-up-to-170m.

Sharp, Lesley A. 2014. *The Transplant Imaginary: Mechanical Hearts, Animal Parts, and Moral Thinking in Highly Experimental Science,* 1st edn. Berkeley, CA: University of California Press.

Sunder Rajan, Kaushik. 2017. *Pharmocracy: Value, Politics, and Knowledge in Global Biomedicine*. Durham, NC: Duke University Press.

Søgaard, Jes. 2019. "Medicinalindustriens prispolitik gør patienter og deres familier utrygge." *Altinget Sundhed,* December 19, 2019. https://

www.altinget.dk/sundhed/artikel/jes-soegaard-medicinalindustriens-prispolitik-goer-patienter-og-deres-familier-utrygge.
Tavory, Iddo, and Stefan Timmermans. 2014. Abductive Analysis: Theorizing Qualitative Research. Chicago, CA: University of Chicago Press.
TLV (Tandvårds- & läkemedelsförmånsverket). 2019. "Hälsoekonomisk Bedömning Av Luxturna (Voretigen Neparvovek)." Tandvårds- och läkemedelsförmånsverket. Dnr 2697/2018. Underlag För Beslut i Regionerna. https://www.tlv.se/download/18.2e325bfb16afd0e62b5285d1/1559141988196/bes190506_underlag_luxturna.pdf, accessed 24 May 2024.
Wadmann, Sarah, and Amalie Martinus Hauge. 2021. "Strategies of Stratification: Regulating Market Access in the Era of Personalized Medicine." *Social Studies of Science* 51(4): 628–653.
Zhang, Sarah. 2017. "Is a 'Cure' for Blindness Worth $1 Million?" *The Atlantic,* December 27, 2017. https://www.theatlantic.com/science/archive/2017/12/gene-therapy-blindness-luxturna/549059/.

Anna Brueckner Johansen is a PhD Fellow at VIVE – The Danish Center for Social Science Research and the Department of Public Health, University of Copenhagen. She is part of the research project PRIME – Priority Setting in Personalised Medicine (https://www.vive.dk/en/themes/prime/). Her research investigates how techno-scientific developments in medicine create new ethical and economic dilemmas in the context of the welfare state. She has a background in medical anthropology from the University of Copenhagen.

Susi Geiger is Professor of Markets, Organizations and Society at University College Dublin and the principal investigator of the ERC Consolidator Project MISFIRES (grant no. 771217). Her research investigates how markets are organized and contested in the context of social justice concerns, particularly in healthcare. She has published numerous journal articles on these issues, including in *Organization Studies*, *Research Policy*, *Journal of Business Ethics*, J*ournal of Cultural Economy*, *Economy and Society*, and *Business & Society*, and edited the volumes *Concerned Markets* (Elgar, 2014) and *Healthcare Activism: Markets, Morals, and the Collective Good* (Oxford University Press, 2021).

Sarah Wadmann is a Senior Researcher at VIVE – The Danish Center for Social Science Research and external lecturer at the University of Copenhagen. She is the principal investigator of the Sapere Aude project PRIME (grant no. 1055-00010B) and is also heading a cross-disciplinary research project on the conceptualization and operationalization of priority setting criteria in healthcare. Her research focuses on the introduction of new technologies in healthcare and its ethical, social and regulatory implications. She is an editorial board member of SSM – Qualitative Research in Health. Recent work appears in *Social Studies of Science, Social Science & Medicine*, *Sociology of Health & Illness*, *Economy and Society* and *BioSocieties*.