

**Mary Shelley's *Frankenstein*
– a metaphor for EuroQol instrument development and use**

Paula Lorgelly¹, Chris Sampson²

1 University of Auckland

2 Office of Health Economics

Abstract

Mary Shelley's 1818 novel *Frankenstein* is considered a literary classic, regarded by some as a romance novel and others as a tragedy. Credited as the first science fiction novel, it is the story of a young scientist who sets out to create a new human life form but instead creates a monster. There have been several editions of the novel, including a substantial revision in 1831. There are over 170 films that draw on *Frankenstein's* monster in one form or another; it was the 1931 film *Frankenstein* that depicted the monster with bolts on its neck.

The concepts and complex scenarios presented in *Frankenstein* have been used extensively in academic literature to stimulate novel thought on ethics, responsibility, critical thinking, and empathy. Metaphors are commonly used in academic discourse to help understand abstract concepts. For example, *Frankenstein's* monster has been used as a metaphor for unregulated markets and modern scientific developments. There is a substantial literature relating the ideas in *Frankenstein* to bioethics, medical ethics, and moral philosophy more broadly.

In this paper, we reflect on recent discussions within the EuroQol Group, offer some points of comparison with Dr Frankenstein, and consider the monster as a metaphor for the EQ-5D. Our metaphor is drawn in relation to the development (i.e. bolt-ons, deep dive, and new instruments) and use of EuroQol instruments for different types of decisions (e.g. clinical, population health) and in different contexts (e.g. infants, indigenous peoples). We use our knowledge of the EuroQol Group's history, EQ instruments, working groups and plans to illustrate our metaphor.

Our metaphorical explication reveals several important learnings from Shelley, which we argue should inform the EuroQol Group's future activities and EuroQol members' priorities and behaviour. These include i) opacity, both textual and philosophical; ii) the dangers of (amoral) scientific pursuit; iii) the limits of understanding; and iv) the role of power and a creator's responsibilities. We also highlight additional insights relating to social roles and norms, the conceptualisation of death, and unintended consequences in general. These learnings are informative to the ongoing ambition for a 'conceptual basis' for EuroQol instruments. In particular, we argue for the need to impose focus, foresight, and transparency in the development and use of EuroQol instruments. In light of EuroQol's vision and mission statements, we hope that this paper encourages some philosophical debate on instrument development and use. These considerations may prove vital in preventing the EQ-5D becoming a monster ("Beware; for I am fearless, and therefore powerful") and the EuroQol Group being a remorseful and powerless creator ("Man, how ignorant art thou in thy pride of wisdom!").

Introduction

Fundamental questions continue to hound the EuroQol Group. Discussions and disagreements about the ‘conceptual basis’ for EuroQol instruments – or the lack thereof – often dominate discussions at Academy and Plenary meetings, without resolve. Reversion to this topic serves to undermine more pragmatic discussions that may help to improve EuroQol instruments or the work of the EuroQol Group in general.

In addition to these internal wranglings, the EuroQol Group – and especially the EQ-5D – faces several existential threats from external sources. The EQ-5D has long faced competition from other instruments and their developers, though these competitors have historically lacked the research foundation of the EQ-5D and systems of support for their use on a grand scale. In recent years, notable efforts have been led by the likes of the International Consortium for Health Outcomes Measurement (ICHOM) [1], the Patient-Reported Outcomes Measurement Information System (PROMIS) [2], and others, that serve to crowd-out the EQ-5D. The importance of the competition becomes greater when the EuroQol Group seeks to maintain instruments for the measurement of health-related quality-of-life ‘from cradle to grave’ and in different decision-making contexts.

More fundamentally, the EuroQol project faces opposition in principle. Most notably, the United States has recently passed legislation that explicitly bans the use of the quality-adjusted life year (QALY) in health care decision-making, thus undermining the role of the EQ-5D in this context, and there is strong opposition to the QALY more broadly [3].

These things considered, a radical assessment of the current status of the EuroQol Group and its work is warranted, and timely. Rather than turning to first principles, or reviewing EuroQol-funded research, in this paper we turn to a much-discussed work of literary fiction that explores the consequences of scientific advancements and their interaction with society. Through our critical theorising, we provide insights and offer recommendations that can inform the future direction of the EuroQol Group.

Synopsis of the book

Mary Shelley's *Frankenstein, or the Modern Prometheus* [4] explores themes of creation, ambition, and the consequences of playing God. The novel tells the story of Victor Frankenstein, a Swiss scientist who becomes obsessed with the idea of creating life. Driven by ambition and scientific curiosity, Frankenstein assembles a creature (the so called Frankenstein’s monster) from body parts scavenged from graveyards and animates it through a secretive process he has discovered.

The narrative of the novel begins with a series of letters written by Robert Walton, an Arctic explorer, to his sister Margaret Saville. Walton describes encountering Victor Frankenstein in the Arctic, and Frankenstein, in a state of near-death, recounts his tragic story to Walton. Frankenstein narrates how his early fascination with science and alchemy led him to the University of Ingolstadt in Southern Germany, where he began his experiments in reanimation. His success in creating life, however, is immediately overshadowed by horror and regret when he sees the grotesque appearance of his creature. Repulsed by his creation, Frankenstein abandons the creature, who then disappears.

The creature's story is recounted to Saville in Walton's letters, after Walton was told the story by Frankenstein, who recalled it being relayed to him by the creature during an encounter on the glacier of Montanvert in the Alps. Following his creation, the creature was left to fend for himself and experiences a range of human emotions, from loneliness to rage. He learns to speak and read by observing a French family living in a cottage, but his attempts to integrate with human society are met with fear and violence due to his monstrous appearance. The creature confronts Frankenstein and demands that he create a female companion to alleviate his loneliness. Initially agreeing, Frankenstein later destroys the unfinished female creature, fearing the potential consequences of creating another monster.

In retaliation, the creature vows revenge and begins a campaign of terror against Frankenstein, leading to the deaths of several of Frankenstein's loved ones, including his best friend, Henry Clerval, and his fiancé (and adopted cousin), Elizabeth. Devastated by guilt and grief, Frankenstein pursues the creature to the Arctic, where he encounters Walton. The story ends with Frankenstein's death and the creature, mourning his creator, vowing to end his own life by setting himself on fire in the Arctic wastes.

Film depictions of Frankenstein

There are more than 170 films inspired by the *Frankenstein* novel or which feature an interpretation of Frankenstein's monster [5]. Most films are loosely based on the book, and in popular adaptations there are some significant differences between the original novel and the film. These include the complexity of Victor Frankenstein's character – his deep remorse and guilt in creating the creature, abandoning the creature, and the responsibility or guilt for the death and destruction the creature inflicts; Frankenstein is often simplified in the movies, and he is depicted as a mere mad scientist or a tragic (but sometimes handsome James McAvoy) hero. Similarly, the creature is intelligent, articulate, and capable of emotions in the book, educating himself and seeking acceptance and companionship. In movies, he's a brute, with a

lumbering gait, who is sometimes mute. The 1931 classic sees Boris Karloff play him with a rectangular face, a giant forehead, and bolts in his neck. While the 1994 film, which is thought to be more faithful to the novel's plot, has Robert de Niro looking more human, as a reanimated corpse, and is scripted with more emotional depth.

Other differences include how much artistic licence is given to creation and responsibility versus horror and spectacle. The supporting characters in the book, which add gravitas to the guilt and responsibility, often have varying and simplified roles in the movies.

1831 revisions

In 1831 a one-volume revised *Frankenstein* was published. The edition was heavily revised by Mary Shelley, and many believe that this was to make a disturbing book more palatable for conventional readership [6]. Changes included the language being revised to be more formal and polished, character development so Frankenstein's obsession and irresponsibility is more obvious, Frankenstein's wife-to-be being an adopted sister rather than his blood cousin, and the scientific details focusing more on the moral and ethical implications of Frankenstein's experiments than the Romantic period's fascination with electricity.

This paper draws on both the original 1818 version and the 1831 revision, and some film references. The 1831 edition also moves away from atheism and introduces 'don't play God' messaging. Frankenstein's failure to foresee the consequences of his actions and his subsequent refusal to take responsibility highlights the dangers of unchecked ambition and the ethical dilemmas inherent in playing God; this notion is poignant for the discussion that follows.

Frankenstein and (social) science

The novel is a literary masterpiece, not only because of its compelling story (particularly for those who like science fiction) but because the themes lend themselves to analysis from multiple viewpoints. The concepts and complex scenarios presented in *Frankenstein* have been used extensively in academic literature to stimulate novel thought on ethics, responsibility, critical thinking, and empathy [7]. It has been argued that the novel offers a critical vision of the future resulting from technoscientific advances [8], in particular the limits of scientific research and the ethical issues that researchers must consider in their investigations. *Frankenstein* has been used as a warning about scientific controversies – Frankenscience [9] and Frankenfood [10] – although these are often based on moral opinion rather than scientific assertions [11].

A recent literature review reflecting on 200 years of *Frankenstein* [7] explored the usage of the story in the academic literature and how these publications represent science and scientists, including the characterisation of Frankenstein as a scientist, the monster as product of science, the consequences of this creation, and related ethical issues. The authors found that *Frankenstein* may be framed as a science narrative about discovery and creation (Nagy et al [12] suggesting “it is the inherent nature of science to push boundaries, discover new things, and commit overreach”) or about the dangers of science (Hammond [13] argues that “knowledge and expertise, in the wrong hands, and with no structures of social accountability, can be dangerous, and as such present a risk to society”). Frankenstein as a scientist is questioned in the literature that was reviewed, particularly his hubris and arrogance [14]. Some even reflect on Frankenstein being sexist and speciesist [15] (the creature, meanwhile, follows a vegan diet). While a few researchers argue that his ideas and methods aligned with other scientists of the time [16], and it wasn’t that he was evil but incompetent [17].

The literature review found few papers discuss Frankenstein’s creature, or indeed creatures even if the second was dismembered before it was completed [18]. Some papers discuss the description of the monster or its character; Schroll and Greenwood [19] describe the creature as somebody who needs guidelines, education and care, while Mitra [20] argues that it is not a monster but a creature with emerging conscience. Ethical questions and *Frankenstein’s* place in contemporary research have been considered by many papers, although the review’s authors argue that we need to avoid the temptation to consider the science in *Frankenstein* in the light of our times, disagreeing that Victor Frankenstein should need to submit to an ethics committee if the research was to be undertaken today [13]. The review argues that Frankenstein’s major transgression was not creating a creature, but the fact that he fled from it, left it to its own fate, and was unable to control the consequences of his work. The authors conclude that as both literature and cinema invite reflection, Shelley’s *Frankenstein* provides suitable material for educational proposals for the teaching of bioethics and health sciences. This paper follows a similar vein, *Frankenstein* is used to explore the development and use of EQ-5D instrument.

Frankenstein, the EuroQol Group, the EQ-5D, and metaphors

Mary Shelley’s *Frankenstein* – the scientist, the creature(s), the ethics, the science, the power, the hubris, and the responsibility – are used to reflect on recent discussions within the EuroQol Group. The paper considers Victor Frankenstein as a metaphor for the EuroQol Group and its membership, while the monster is a metaphor for the EQ-5D. It is hoped that the paper

offers some reflective (and at times light-hearted) criticism of the EuroQol Group, its instruments and their use.

Our metaphorical analysis is drawn in relation to the development (i.e. bolt-ons, deep dive, and new instruments) and use of EuroQol instruments for different types of decisions (e.g. clinical, population health) and in different contexts (e.g. infants, indigenous peoples). We use our knowledge of the EuroQol Group's history [21,22], EQ instruments, working groups and plans to illustrate our metaphor.

Metaphorical analysis

A metaphor is a figure of speech that compares two different things by saying that one thing *is* the other [23]. Comparisons in metaphors can be stated explicitly “the EQ-5D is a monster” or they may be implicit comparisons “EQ-5D is complex, daunting and overwhelming for those who attempt to navigate its intricacies”, so has qualities of a monster but without explicitly using the word. Comparisons are not meant to be taken literally (nor personally!); they are figurative, creating meaning beyond the literal meaning.

There are two accepted definitions of metaphor: the first is broad, all figures of speech that achieve their effect through association, comparison and resemblance (e.g. antithesis, hyperbole, metonymy and simile); the other is narrow, where a metaphor is concisely compares two things by saying one is the other. This paper applies the broader definition.

There are different types of metaphors: creative, conventional, mixed, extended and absolute. Creative metaphor are those which a writer constructs to express a particular idea or feeling in a particular context which the reader needs to deconstruct or unpack in order to understand what is meant [23]. Creative metaphors are typically new, sometimes referred to as novel metaphor, although they may be based on pre-existing ideas or images. They are often associated with the literature. Conventional metaphors are those which have become a common part of speech, used again and again, for example the “field of health outcomes”, does not refer to a physical field. When a conventional metaphor loses its ability to be metaphoric, it is sometimes referred to as a dead metaphor (“Drop dead” being an example that may be familiar to EuroQol members!)

Frankenstein is rich with metaphors, for example the quote below implies that Frankenstein thinks of himself as a God, bringing light where there is only darkness and creating life where it did not exist before; and he expects that his creations will show him gratitude and worship him without reservation.

“Life and death appeared to me ideal bounds, which I should first break through, and pour a torrent of light into our dark world. A new species would bless me as its creator and source; many happy and excellent natures would owe their being to me. No father could claim the gratitude of his child so completely as I should claim theirs.”

It is important to acknowledge that *Frankenstein* is also abundant in personification, similes and symbolism, and at times this paper may cross the line and use these other types of figurative language, largely because neither author is an English lit major! Given the reference to *Frankenstein* most of the metaphorical analysis uses a creative metaphor lens.

Simple (and obvious) metaphors

An obvious starting point for the metaphorical exploration of *Frankenstein* for our purposes is to consider Victor Frankenstein as the EuroQol Group (or a representative member thereof) and his creation as the EQ-5D (and other instruments).

The EuroQol Group as Victor Frankenstein

An initial point of comparison between the novel and the EuroQol Group is the pan-European setting of the story and the prose. Victor Frankenstein was an Italian born, Swiss scientist (from Geneva so likely spoke French) who also knew Greek and Latin, and studied in a German university. Frankenstein likely also spoke English as he conversed with Walton. The monster taught himself to speak and read French. Although written in English, *Frankenstein* is based firmly in Europe (including taking in France, Ireland, Scotland and England on travels). It has been suggested that Victor Frankenstein was a Euro-modern Promethean seeking assimilation of indigenous people into a Euro-Christian civilization [24]. Walton wrote in his letters his thirst for the undiscovered:

“I shall satiate my ardent curiosity with the sight of a part of the world never before visited, and may tread a land never before imprinted by the foot of man.”

The EuroQol Group is similarly Euro-centric, using English as its lingua franca and headquartered in The Netherlands. More recently, the 2024-2028 Strategic Plan proposed the EuroQol Group increase its international reach and relevance. Similarly, it is later in the novel that Victor Frankenstein speaks of his ambition to travel to England to learn from scholars there. The monster, meanwhile, promises to relocate to South America.

Victor Frankenstein was born to “*one of the most distinguished*” families of the Genevese republic; his ancestors were powerful and influential. An extended metaphor would

be to compare the University of Ingolstadt, at one time Europe's leading institution in anatomy and biology, to Erasmus University Rotterdam (and Erasmus MC), arguably Europe's leading institution in health outcome measurement. Erasmus is named after Desiderius Erasmus Roterodamus, a humanist who is most well-known for writing *The Praise of Folly* which exposes the follies and vices of various social classes, including scholars, monks, and priests, and thereby advocates for humility and self-awareness as ultimately does *Frankenstein*.

New EuroQol Group membership and PhD studentship also have parallels. When Frankenstein attends university in Ingolstadt he is in awe of the intellect and wisdom, not unlike those new to Academy and Plenary meetings [25]. Frankenstein relays to Walton:

“here were books, and here were men who had penetrated deeper and knew more. I took their word for all that they averred, and I became their disciple ... Under the guidance of my new preceptors I entered with the greatest diligence into the search of the philosopher's stone and the elixir of life; but the latter soon obtained my undivided attention. Wealth was an inferior object, but what glory would attend the discovery if I could banish disease from the human frame and render man invulnerable to any but a violent death!”

He becomes a subscriber to the cult (and not just the ‘cult of the self’ as per the Romantic Era). One could even wonder if M. Waldman, Frankenstein's professor and mentor, is a founding EuroQol member offering instructions on what new members and students need to read to be indoctrinated:

“...If your wish is to become really a man of science and not merely a petty experimentalist, I should advise you to apply to every branch of natural philosophy, including mathematics.”

The EQ-5D as Frankenstein's monster

Victor Frankenstein constructs his creation in ways that starkly resemble the development and use of the EQ-5D. The monster and the EQ-5D are both constructions of existing parts with disparate origins unknown.

“I collected bones from charnel houses; and disturbed, with profane fingers, the tremendous secrets of the human frame ... The dissecting room and the slaughter-house furnished many of my materials.”

Shelley provides little detail on the methods for the original construction of the creature, and in the novel Frankenstein is reluctant to divulge details. We do know that the creature is a patchwork creation of a living being from parts of (presumably) once-living beings. Each of

the parts that constituted the construction of the monster may have its own origin and consequential history, the knowledge of which may be informative to the consequences of bringing life to the final creation. Similarly, the EQ-5D was constructed by the integration of elements harvested from existing health outcome and quality of life questionnaires, such as the Nottingham Health Profile [26] and Rosser-Kind index [27], with the original developers of the EQ-5D selecting those elements and techniques that they deemed most suitable to their ends.

The construction of the creature by Frankenstein, though not described in detail, involved the collection of disparate parts with differing purposes, from his “*lustrous black*” hair and “*teeth of a pearly whiteness*”, to his “*yellow skin*” and “*watery eyes*”, which served only to form “*a more horrid contrast*” in the creature’s appearance. Throughout the novel, the creature struggles with incoherence and acceptance of his own appearance, which may be traced back to this disparate construction. The monster also struggles with more practical challenges in the interaction of his parts: “*it was, indeed, a long time before I learned to distinguish between the operations of my various senses*”. The EQ-5D, likewise, is made up of distinct and often contrasting or conflicting dimensions (e.g. anxiety/depression) in the pursuit of a coherent whole for a unified instrument. The interminable challenges of valuation and modelling parallel the creature’s own internal conflicts and Victor Frankenstein’s wavering perceptions of his creation.

The development of bolt-on items for the EQ-5D is, perhaps, the most blatant metaphor linking Frankenstein’s creature and the EuroQol Group’s work, not least because of the creature’s filmic representation with bolts in his neck. The bolt-on metaphor represents an extension of the two points made above about assembly from existing parts (where bolt-on items are derived from or inspired by other instruments) and the integration of diverse components. The EQ-5D was developed as a single measure, intentionally generalisable and not for the purpose of being sensitive to all health problems nor sufficient in any setting. In his early days, the monster does not change according to context: “*my mode of life in my hovel was uniform*”. Over time, the adequacy and completeness of the creation is inevitably questioned, with an unstoppable compulsion to extend capabilities and relevance. The monster observes that his “*mind received every day additional ideas*”. He discovers books and teaches himself to read. He adds cooking to his repertoire of skills. He observes and imitates the De Lacey family – “*endeavouring to discover the motives which influenced their actions*” – in an attempt to make himself acceptable to them, in a fashion that resembles the novel use of the EQ-5D (and new instruments) with populations beyond the original creation’s scope. There are also

parallels here with on-going work within the EuroQol Group relating to ‘deep-dive’ extensions to the EQ-5D, which seek to obtain a deeper and more nuanced understanding of specific dimensions of the existing instrument. In the early part of his life, the creature seeks deeper understanding of other humans and society in general, but does so by focusing narrowly on the residents of one cottage. This narrow focus and singular experience briefly warps the creature’s worldview with destructive consequences.

Metaphorical links may also be drawn between specific activities around the development and use of the EQ-5D. For example, the development of the EQ-5D for use in other languages, through work led by the version management committee (VMC), is comparable to the monster learning language:

“By great application, however, and after having remained during the space of several revolutions of the moon in my hovel, I discovered the names that were given to some of the most familiar objects of discourse; I learned and applied the words, fire, milk, bread, and wood. I learned also the names of the cottagers themselves. The youth and his companion had each of them several names, but the old man had only one, which was father. The girl was called sister or Agatha, and the youth Felix, brother, or son. I cannot describe the delight I felt when I learned the ideas appropriated to each of these sounds and was able to pronounce them. I distinguished several other words without being able as yet to understand or apply them, such as good, dearest, unhappy.”

As with the VMC, the monster is cautious at first:

“although I eagerly longed to discover myself to the cottagers, I ought not to make the attempt until I had first become master of their language; which knowledge might enable me to make them overlook the deformity of my figure”

The metaphor explicitly carries, also, to the creation of new instruments. The monster demands that Frankenstein construct “a female” version of himself. Frankenstein initially refuses, before relenting, but later destroying his creation. Parallels lie here with instruments such as the EQ-HWB that is intended to complement the EQ-5D. The creation demands new creations.

It is also possible to draw a metaphor around naming conventions, or indeed the lack of names. It is well known that the EuroQol instrument, the EQ-5D, is often (incorrectly) thought to be an abbreviation, and there has been a plea for the correct use of the nomenclature [28]. In *Frankenstein* the monster is referred to as a creature, a fiend, a dæmon, and an ogre. Frankenstein did not give it a name, and the name is not ‘monster’. Confusingly people think

that Frankenstein is the name of the monster, and the movie *Bride of Frankenstein* does not help with this confusion.

Plenary metaphors

We may also entertain a metaphor for plenary paper writing, where the monster shares with Frankenstein of his time developing after he was abandoned:

“The moon had disappeared from the night, and again, with a lessened form, showed itself, while I still remained in the forest. My sensations had by this time become distinct, and my mind received every day additional ideas. My eyes became accustomed to the light and to perceive objects in their right forms; I distinguished the insect from the herb, and by degrees, one herb from another. I found that the sparrow uttered none but harsh notes, whilst those of the blackbird and thrush were sweet and enticing.”

And for the plenary discussant, where the monster reflects on the gifts of the human mind and its ability to create and destroy:

“One day, when I was oppressed by cold, I found a fire which had been left by some wandering beggars, and was overcome with delight at the warmth I experienced from it. In my joy I thrust my hand into the live embers, but quickly drew it out again with a cry of pain. How strange, I thought, that the same cause should produce such opposite effects!”

Deeper Learnings

(The trouble with) Opacity

The novel is characterised by opacity that leaves it open to diverse interpretations and critical – and perhaps misguided – analyses. The narrative structure is – seemingly intentionally – obtuse, with much of the story being told fourth-hand (in letters to Saville, sent by Walton, telling the monster’s story as relayed by Frankenstein). This narrative complexity, with layers of perspective, make it unclear whose opinion and whose framing of events we are really observing. This links to the obscured historical routes of the EQ-5D: how did we come to have the EQ-5D as we know it today?

A related feature of complexity within the novel is the use of intertextual references. The creature learns French from found books – Milton’s *Paradise Lost*, portions of Plutarch’s *Parallel Lives*, and Goethe’s *The Sorrows of Young Werther* – and draws ethical insights from their contents. Other reference points include *The Rime of the Ancient Mariner* and the

Prometheus myth. The EQ-5D and the EuroQol Group, likewise, drew heavily on existing sources in their creation, but these are not clearly recorded.

The EuroQol Group should strive for narrative transparency. This may be difficult, as it was for the monster. The roots are lost and where they are not their meaning is obscured.

*“It is with considerable difficulty that I remember the original æra of my being:
all the events of that period appear confused and indistinct.”*

The novel is also ambiguous about its morality, which is only reinforced by inconsistencies between versions. This reflects the moral foundations of the EQ-5D, and the morality of its use today, which are largely unspecified.

Frankenstein tells us about the risks associated with opacity. Frankenstein conducts his experiments in isolation, withholding information not only from the reader, but also from his family and friends. This opacity prevents opportunities for input and oversight and – most significantly – ethical guidance, and allows Frankenstein to pursue his science without considering the broader implications of his work and potential ethical blind spots. In part, this ambiguity and opacity in the characters of the novel arises through failures in communication. The intentions of the monster himself are also obscured by his appearance, stature, and limited skills in communication, and the misunderstanding of the monster that arises from this obscurity of intent is what leads to social rejection and tragic outcomes.

There is, perhaps, a deeper learning here. That the opacity of the novel, its themes, and its characters vacillations, reflect a fundamental truth about the impossibility of resolving moral and philosophical ambiguities. The EQ-5D and the EuroQol Group may, therefore, be destined always to struggle and, ultimately, to perish in extreme circumstances.

We recommend that the EuroQol Group:

1. Be transparent about the history of the Group and the original construction of the EQ-5D. This may require additional work to understand the parts of other instruments that the EQ-5D borrowed, adapted, or was otherwise inspired by.
2. Be transparent about the meaning of the various elements of the EQ-5D (and other instruments and extensions) and their moral significance.
3. Maintain transparency in research and in processes associated with the EuroQol Group’s activity.

The dangers of (amoral) scientific pursuit

The novel provides a warning about the dangers of scientific pursuit. The subtitle for *Frankenstein* is *The Modern Prometheus*, and the Greek mythology of Prometheus is influential throughout the novel. The name Prometheus is generally interpreted as meaning ‘forethought’ or ‘forethinker’ (pro=before, manthano=learn), and the myth is often used as an allegory of the unintended consequences of scientific pursuit. Frankenstein was driven by ambition and hubris and, ultimately, a desire to play God. In particular, Frankenstein’s pursuit is framed as lacking any moral foundation, and it is this feature that ensures regret and isolation result. Frankenstein treats his activities as a wholly scientific challenge rather than a profound undertaking with moral implications. Frankenstein objectifies his creation, initially denying it any human or emotional significance, and consequently ignoring the inherent complexities of life.

Consequently, Frankenstein failed to foresee the ramifications of his experiment, which is characterised by unintended consequences. His achievement became something other than what he expected, and this caused pain. Guilt, regret, and a general unhappiness follow Frankenstein throughout the novel:

“dreams that had been my food and pleasant rest for so long a space, were now become a hell to me; and the change was so rapid, the overthrow so complete!”

Cowardice and shame act as facilitators for bad consequences in the novel:

“when I perceived that the popular voice, and the countenances of the judges, had already condemned my unhappy victim, I rushed out of the court in agony.”

More significantly than its impact on Frankenstein’s emotions, his creation resulted in death and destruction, and was in general a catastrophe, creating extensive collateral damage.

The EuroQol Group must ensure that the development of the EQ-5D and related tools is guided by strong ethical principles. In practice, the Group must actively seek to anticipate future developments and address potential unintended consequences of instrument development and use. This may include the ways in which instruments (and research) influence health policies, resource allocation, and patient care.

We recommend that the EuroQol Group:

1. Establish a moral foundation for all pursuits, especially new instruments and extensions and adaptations, but also for research and Group activities in general.
2. Consider the potential harm that may reasonably be expected to arise from the use of EuroQol instruments.

3. Assess the potential for unintended consequences.

The limits of understanding

The novel speaks to the complexity of human experience. Frankenstein fails to understand the needs (and emotions) of his creation, despite having been the one who created it. The EuroQol Group cannot expect to ever fully understand the EQ-5D and other instruments. Likewise, the EuroQol Group cannot expect to ever fully understand the human condition.

More generally, the novel challenges a narrow focus on scientific methods, of which the EuroQol Group is surely guilty. The novel warns of the risks of relying solely on scientific input and the idea that we can understand and predict all consequences. There is also a signal that the work of scientists can be unscientific: *“The mere presence of the idea was an irresistible proof of the fact.”*

Early in the novel, Frankenstein appears to acknowledge some of the considerations. He expresses the need to be modest: *“Young men should be diffident of themselves, you know, M. Clerval; I was myself when young: but that wears out in a very short time.”* Arguably, Frankenstein was also not oblivious to the personal risks of scientific pursuit described above. In relation to science in general, he states:

“how dangerous is the acquirement of knowledge, and how much happier that man is who believes his native town to be the world, than he who aspires to become greater than his nature will allow”

However, it seems clear that Frankenstein’s understanding of these dynamics was limited, resulting in the guilt and regret that dominates his life following the creation.

Throughout the novel, the creature struggles to connect with humans, in part because he lacks understanding of their fears and motivations. In other instances, he cites the limits of his understanding that his creator would have done well to acknowledge:

“I wished sometimes to shake off all thought and feeling; but I learned that there was but one means to overcome the sensation of pain, and that was death – a state which I feared yet did not understand.”

Frankenstein is filled with misunderstandings and commentaries on the consequences of not recognising the limits of science and (human) understanding. These effects are exacerbated by the isolation and opacity described above, which prevents the input of contrasting ideas.

We recommend that the EuroQol Group:

1. Identifies its own limitations in terms of knowledge generation and capacity for realising its ambitions.
2. Ensures that others' perspectives are considered in all development and use of instruments. This includes considering the perspectives of end-users, but also implies the need for interdisciplinary work.

Power and responsibility

Responsibility is a dominant theme in the novel, and Frankenstein's neglect of his creature serves as a cautionary tale. The EuroQol Group has a duty to not only guide and oversee the EQ-5D and its ongoing development, but also to support those who come into contact with it, ensuring that it is not harmful to them.

This is, perhaps, one area in which the EuroQol Group excels, with close oversight of the development and use of the EQ-5D, and clear sets of procedures that dictate responsibility. Nevertheless, there are learnings to be drawn from the novel.

The novel speaks to the power of creation. In creating the monster, Frankenstein created a power that he could not control. Though Frankenstein creates the monster, the monster later exercises his superior power in order to manipulate Frankenstein. The monster does not start out evil, and his intentions are not consistently good or bad. There is a significant 'nature vs nurture' theme throughout the novel, as the monster's intentions wax and wane:

"This was then the reward of my benevolence! I had saved a human being from destruction, and, as a recompence, I now writhed under the miserable pain of a wound, which shattered the flesh and bone. The feelings of kindness and gentleness, which I had entertained but a few moments before, gave place to hellish rage and gnashing of teeth. Inflamed by pain, I vowed eternal hatred and vengeance to all mankind. But the agony of my wound overcame me; my pulses paused, and I fainted."

A creation may be both good and evil, and the balance will be determined by both the mechanics of creation and contextual influences.

The preceding sections describe a scientist at work without any social accountability that may serve to enforce the responsibilities of a creator. Consequently, Frankenstein is able to neglect his creation resulting in plight for the creation, the creator, and many others. There is no consideration for how society may judge the creation, and the creature is ultimately rejected by society. This is not before the monster is – briefly – perceived as "good spirit,

wonderful” in his effect by the cottagers before they observe him directly. Similarly, the EQ-5D may face rejection by those in society who lack understanding of it.

Ultimately, Victor cannot escape responsibility, and the form of the beast he created, even in the wilderness: “*I perceived, as the shape came nearer, (sight tremendous and abhorred!) that it was the wretch whom I had created.*”

We recommend that the EuroQol Group:

1. Explicitly recognise its duty to consider the consequences of using the EQ-5D (and other instruments) and maintain mechanisms of social accountability
2. Acknowledge that the EQ-5D is more powerful than the Group, and not entirely within the Group’s control.
3. Adopt responsibility for education relating to EuroQol instruments.

Concluding thoughts

The EuroQol Group was born with “*bright visions of extensive usefulness*”, but is now dominated by “*gloomy and narrow reflections upon self*”. In drawing parallels between Mary Shelley’s *Frankenstein* and the development and use of EuroQol instruments, we have identified learnings that can help turn the group away from this trajectory.

The metaphor of Frankenstein and the EuroQol Group and the EQ-5D as his creation serves as a reminder of the responsibilities inherent in scientific pursuit for the creation of tools that will be used in society. It is the EuroQol Group’s duty to ensure that the use of these tools does not cause undue harm or result in unintended consequences.

Insights from the novel emphasise the importance of transparency, ethical considerations and moral clarity, and the limitations of scientific methods and understanding in general. These themes should resonate strongly with ongoing activities within the EuroQol Group, and we have set out broad recommendations relating to these themes. We need to prevent the EQ-5D becoming a monster “*Beware; for I am fearless, and therefore powerful*”, and the EuroQol Group being a remorseful and powerless creator “*Man, how ignorant art thou in thy pride of wisdom!*”.

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