

# **Limits to co-production in philosophy of measurement: Empowerment and the chronically ill**

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## Declaration of Own Work

Hereby I, Steffie Manders, declare and assure that I have composed the present thesis with the title 'Limits to co-production in philosophy of measurement: Empowerment and the chronically ill,' independently, that I did not use any other sources or tools other than indicated and that I marked those parts of the text derived from the literal content or meaning of other works – digital media included – by making them known as such by indicating their source(s). Uden, June 30<sup>th</sup>, 2024.

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## Abstract

Philosophers of science Anna Alexandrova and Mark Fabian (2022) argue for a new strategy for how researchers should define and measure thick concepts, i.e., concepts with a value-laden component such as well-being. Their strategy, co-production, asks stakeholders such as patients to use their lived experience to help researchers define the concept based on their needs and values. While Alexandrova and Fabian argue co-production is essential, I will argue that it does not work in the case of the concept 'empowerment' for chronically ill patients. I will show that the unavoidable power relation between patients and healthcare workers means that the definition of 'empowerment' patients will most likely demand in co-production is not beneficial to research.

# Introduction

Empowerment intervention has become increasingly more popular in different fields of social science, including health care. In the past decades, large influential organisations such as the WHO (2009) have been conducting and publishing research on the topic, as well as various other scientists (i.e. Stepanian et al. 2023; Hood 2010; Schulz and Nakamoto 2013a). But what do they mean when they use the word ‘empowerment’? And is it as beneficial to patients as researchers are making it out to be?

In this thesis I will unpack the complexity behind conceptualising ‘empowerment’ in scientific research. My aim is twofold. First, I will show that while ‘empowerment’ as a concept is on the rise and considered a social good, it is prone to being misused and misunderstood because of the complexities behind the concept. I therefore urge scientists who intend to use the concept to carefully assess their background assumptions on how power works, as well as acknowledge the fact that some definitions of empowerment are not feasible for every patient. One might logically try to resolve the latter issue by involving stakeholders in the process of conceptualising the term, which leads me to my second and main aim.

My second aim is to show concerns and limitations of a new way to conceptualise concepts such as empowerment called ‘co-production.’ Alexandrova and Fabian (2022) argue that their new strategy of co-production is a politically legitimate way of defining so-called thick concepts due to the equal distribution of power and responsibility amongst scholars, service providers and service users. I will argue that this equal distribution of power and responsibility, while certainly avoiding the threat of coercion, does not necessarily result in a politically legitimate process of defining thick concepts, as such a distribution of power and responsibility can be considered unjustified in some cases. By using empowerment for chronically ill persons as an example, I will show that assigning responsibility over defining a complex and demanding concept to stakeholders is unjustifiable. My argument for this bases itself on Heather Douglas’ (2009) famous argument on the responsibility of scientists.

The structure of this thesis will be as follows. First, I will define the meaning of ‘thick concepts’ and show that ‘empowerment’ qualifies as such a concept. Therefore, in order to make the term measurable, scientists must select a strategy fit for defining thick concepts. For the next part, my main focus will be on the framework developed by Alexandrova and Fabian (2022) in which they explicate three strategies for defining thick concepts. While doing so, I

will show the lacunes of these strategies in regard to defining empowerment. I will also explain their method of co-production, which they consider to be part of the third strategy. The third chapter forms the main part of my thesis and focusses on two limitations of co-production. I will discuss the first limitation in chapter 3.1, in which I focus on the limited scope of a concept defined by co-production. The second limitation is discussed in chapter 3.2 and 3.3. There I will argue that the hidden assumptions one has on the workings of power constitute their conception of what ‘empowerment’ means result in more or less problematic conceptualisations of the term. Some of which bring about issues for patients in the sense of not being able to live up to expectations, and some that are outright impossible, such as an equal distribution of power between doctors and patients. Lastly, I will argue that due to the complexities of a term like ‘empowerment’ in the context of healthcare, an equal distribution of power and mainly responsibility among all stakeholders is unjustifiable as the social consequences are exceedingly difficult to oversee.

## Chapter 1: Empowerment as a thick concept

To start out my argument soundly, I must first explain what ‘thick concepts’<sup>1</sup> are in science and show that empowerment is such a concept. Generally speaking, thick concepts are defined as constituting of both a descriptive and evaluative element (i.e. Van der Weele 2021, 1; Alexandrova and Fabian 2022, 2).

Sociologist Gabriel Abend (2019) agrees with this description of thick concepts and elaborates on what differentiates ‘thick’ concept from ‘thin’ concepts. Thin concepts are simply evaluative, meaning they can either be considered positive or negative, and can therefore be applied to anything (Abend 2019, 1). *Beauty*, for example, is a thin concept with a positive connotation. One could state that they think that a musical piece or a building is very beautiful, without facing the risk of being conceptually wrong. They could even state that they think *fountain* by Duchamp is a beautiful artwork. We might question their taste and disagree, but conceptually and semantically, their statement is correct.

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<sup>1</sup> The same term is defined and used in ethics. These definitions, however, I will not include in this thesis, as it is not relevant to my argument.

Thick concepts, like thin concepts, also have either a positive or a negative connotation to them, but as has been stated above, have a descriptive element to them as well. As a result, one cannot apply thick concepts to anything they would like without making a conceptual mistake (Abend 2019, 1). To exemplify this, I will use the concept of ‘well-being.’ This is a positively charged thick concept, by which we could mean descriptively, among other things, that one’s basic needs have been met and they are enjoying life. So, when someone says: ‘these starving people are in an excellent state of well-being,’ we must conclude that they do not understand what ‘well-being’ means and thus made a conceptual mistake.

Philosopher of science Sharon Crasnow agrees that thick concepts are considered to have positive or negative connotations, and adds to this idea (2021). She argues that some thick concepts are considered a good thing in and of itself. Therefore, because this concept is automatically valued as ‘good’ in research, phenomena that do not fit this or contradict it are judged negatively or as less than the concept it is initially measured against (Crasnow 2021, 1218). Van der Weele argues that the same thing happens in the case of ‘independency’ and ‘dependency’, for scientists and politicians consider independency to be a social good, whereas they consider being dependant on something or someone a thing that should be remedied (Van der Weele 2021, 5). However, as philosopher Cora Diamond (1988) in my view correctly identifies, language is not fixed. We learn how to use a term by ‘coming into life with the term,’ (Diamond 1988, 268). As we live and use the term, we redefine it, causing a term that was perhaps considered negative by others to mean something positive. This was the case with ‘dependency’, when Van der Weele (2021) found that severely disabled people who were heavily depended on their caregivers to fulfil their needs would ‘flourish’ with their caregiver’s help (6). ‘Dependence’, in that regard, was not always a negative thing. Thus, the evaluative element is not necessarily always fixed in the sense that it always has either a positive or a negative meaning.

I conclude from the above that I must do the following in order to see if ‘empowerment’ is indeed a thick concept. First, I must prove that ‘empowerment’ has an evaluative element. Then, I must show that ‘empowerment’ also has a descriptive element and therefore cannot be applied to any sentence we would like.

Completing the first step is quite simple. Firstly, ‘empowerment’ is generally considered to be something positive rather than neutral, which would mean it has an evaluative element. For

example, in a literature review on the economic empowerment of women, the very first sentence is:

‘Economic empowerment of women is increasingly recognized as a critical component of efforts to promote gender equality, reduce poverty, and achieve sustainable development,’ (Reshi and Sudha 2023, 1).

Without looking at the meaning of ‘empowerment’ in this sentence, we can see it is associated with gender equality, reducing poverty and sustainability. Without falling into regression, I trust that we agree that these are positive things. By being considered a ‘critical component’ to attain these things, ‘empowerment’, by extension, becomes something desirable. Or in other words, something we value in a positive way. Thus, ‘empowerment’ has an evaluative element to it. Note that empowerment is generally seen as positive, but that does not have to mean it always is, due to language not being fixed. More specifically, not every definition of empowered should be considered positive if it does not aid its targeted user towards attaining, for example, greater well-being.

Now I must show that ‘empowerment’ also *means* something descriptively. Cambridge Dictionary (n.d.) defines empowerment as: ‘the process of gaining freedom and power to do what you want or to control what happens to you.’ Oxford Learner’s Dictionaries (n.d.) defines the term slightly different from Cambridge, stating that empowerment is ‘the act of giving somebody more control over their own life or the situation they are in.’ A recurring keyword in both definitions is ‘control.’ There seems to be a notion that, when one is empowered, they have gained control over something. This is a descriptive part of the definition of empowerment that cannot be separated from it. So, if I were to state that ‘this prisoner in solitary confinement is empowered’, I would have made a conceptual mistake, for being confined in a room by yourself against your wishes does not stroke with what we take to be the essence of ‘empowerment.’ Thus, ‘empowerment’ as a concept has both a descriptive and an evaluative element, which distinctly makes it a thick concept.

## Chapter 2: Three strategies of defining thick concepts

Now that I have explained what thick concepts are in science and I have shown that empowerment is a thick concept, I will direct our focus towards an exploration of how to measure such concepts. Philosophers Anna Alexandrova and Mark Fabian (2022) identify three different strategies for this goal. The first strategy turns the concepts into technical terms, whereas the second strategy uses in-house value judgements in order to create a definition (Alexandrova and Fabian, 2022). The third strategy, according to Alexandrova and Fabian (2022) aspires to seek political legitimacy. Subsequently, they describe their own method for defining thick concepts called ‘co-production’ as part of the third strategy movement.

### 2.1 The first strategy: Thick concepts as technical terms

According to Alexandrova and Fabian, when scientists use the first strategy, they reduce a thick concept to a technical term. Essentially, they deny the existence of thick concepts altogether, for it would otherwise be impossible to define the concept without its evaluative elements (Alexandrova and Fabian 2022, 3). It might not even matter to these scientists if the concept they created really fits with any common language understanding of the term one would have before the research, as conceptual change is the entire point of the research (Alexandrova and Fabian 2022, 3). Alexandrova and Fabian go on to add that this does not mean that they do not justify their conceptualisation of these terms at all, though. They might justify it in the sense that this particular conceptualisation best fits their tools of measurement or dataset, because it aligns with existing models and definitions or because it’s a theoretically interesting thing to do (Alexandrova and Fabian 2022, 4). They will not, however, make any claims or arguments to recognize or justify any evaluative elements tied to the thick concepts.

Using the first strategy, for example, ‘empowerment’ for people with diabetes could be defined as having ‘the awareness and understanding of what diabetes is and the proficiency to make the right choices and decisions regarding their diabetes self-care,’ (Hood 2010, 77). Such behaviour can be observed and measured through interviews. In this manner, strategy one tries to avoid any evaluation that could be regarded as ‘subjective’, such as whether the

patient has faith in their own future or if the patient feels they are in control of their life and their body.

As explained and exemplified above, scientists who use the first strategy attempt not to generate any moral, political, or social value judgements by leaving out the evaluative part of the definition of a concept, as they believe science should be value-free (Alexandrova and Fabian 2022, 4). Despite their efforts, it appears that these scientists still make value judgements by choosing a particular conceptualisation of a term, as this conceptualisation is never neutral. In the previous example, it was mentioned that empowered patients showed sufficient awareness about their illness and make the ‘right’ decisions based on this awareness. Of course, what is considered ‘right’ would have to be determined through value judgements. The same goes for what scholars define as patients being ‘sufficiently’ aware.

Another argument that shows the value judgements in these seemingly neutral definitions of thick concepts was made by Alexandrova in an earlier work. She states that each chosen definition constrains the range of possible findings (Alexandrova 2018, 435). Philosopher of science Kevin C. Elliott adds to this argument that once we consider the social consequences of choosing one definition over another, any concept becomes value-laden, regardless of the chosen definition’s contents (Elliott 2022, 34).<sup>2</sup> This is also the case in the example I used. Because of the fact that sufficient knowledge and awareness within the patient are required for successful empowerment according to this definition, some patients are being set up for failure. Doctor Gillian Hood, diabetes research manager, states that the journey to empowerment in this case causes issues for patients who struggle with, e.g., a language barrier, cultural differences, psychological difficulties, or cognitive decline (Hood 2010, 77). These issues are difficult to overcome, and in some cases – such as with cognitive decline due to old age – even impossible to resolve. This consequence is one that scientists must accept when choosing the definition mentioned above, thus requiring them to make a value judgement. Not making one explicitly only results in the silent acceptance of it.

In short, when thick concepts are defined by using the first strategy, scientists attempt to remove the evaluative element of the concept. I have shown that this is never entirely possible due to hidden value judgements in the definitions themselves, as well as the fact that

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<sup>2</sup> The usage of non-epistemic values might also not be the evil that value-free idealists initially make it out to be. In fact, one could argue that we ought to make value judgements to improve on our scientific reasoning. The value-free ideal has been heavily criticized and has become a large debate in philosophy of science. Whilst I will not dive into the matter in this paper, I recommend the following works for further reading on the topic: Douglas (2009); Elliott (2022); Rudner (1953); McMullin (1982); Longino (1990); Betz (2013); Steele (2012).

one needs to accept that their chosen definition will limit their findings to some extent, as well as produce certain social consequences rather than others. The fact that strategy one hides or ignores these value judgements in an effort to be ‘neutral’ is unacceptable in the case of empowerment in healthcare, as fostering beneficial social consequences for chronically ill patients is arguably the entire goal. Strategy one is therefore an unfit method for defining ‘empowerment.’ In the next part, I will look at another possible strategy.

## 2.2 The second strategy: in-house value judgements

The second strategy described by Alexandrova and Fabian relies on in-house value judgements to further define their concepts. Contrary to the first strategy, it recognizes that the chosen conceptualization of a thick concept is a normative choice, and they make this decision on the basis of the scientists’ own norms and moral standards or based on the consensus within their scientific discipline (Alexandrova and Fabian 2022, 4-5). Scientists who use the second strategy, often attempt to defend the implemented definition of the thick concepts (Alexandrova and Fabian 2022, 5).

One might question whether the value judgements made by these scientists are representative of the values that are considered important by i.e. service users, but it is evident by the common usage of this strategy that some scientists may feel that utilizing in-house value judgements, making these judgements explicit in their article and defending them is a legitimate way to cope with thick concepts (Alexandrova and Fabian 2022, 5). I will exemplify this with a recent case study on empowerment intervention research for chronically ill patients.

### 2.2.1 Critique on strategy two: a case study

Stepanian et al. (2023) consider empowerment approaches to be essential for training patients’ capacities to be in control of their own health (1). Upon introducing the research on empowerment intervention, the researchers state that empowerment in healthcare is a ‘patient-centric, collaborative approach that starts with the principle of individuals’ inherent capacity to be in control of one’s life,’ (Stepanian et al. 2023, 2). The experience of empowerment is supposed to encompass personal change that is adequately facilitated by health care workers

(Stepanian et al. 2023, 2). The idea is that while the physical aspect of the patient's life is disturbed – and often social and mental aspects along with it – patients possess over strengths within themselves and from the network around them to help prevent and reduce further deterioration of their condition (Kristjansdottir et al. 2018). The researchers hope to promote health and wellness for patients by utilizing their capabilities. Current research on the topic doesn't provide researchers and health care workers with much clarity however, as empowerment in current health care research has been inconsistently defined and often aimed at patients suffering from one specific disease, rather than chronically ill patients in general (Stepanian et al. 2023, 2-3).

According to Stepanian et al. (2023, 2), the usage of many different definitions of empowerment causes interchangeable use of the concept with other concepts, therefore rendering it near impossible for researchers and policy makers to properly analyse results on a large scale and create a widely applicable empowerment intervention for chronically ill persons. This issue isn't uncommon, and has previously been addressed in philosophy of science by Cartwright and Runhardt (2014) in their article on *Measurement*. By characterising a concept differently each time, it may appear that scholars are researching and measuring the same thing, despite this not being the case at all (Cartwright and Runhardt 2014, 270).

In order to bring an end to this problem in the case of empowerment for chronically ill persons, Stepanian et al. (2023, 2) have come up with their own solution: to conceptualize empowerment according to one general definition the scientists agree on for all future empowerment intervention research for chronically ill patients. The definition they suggest future scientists use is one devised by the World Health Organization. This definition consists of the following four pointers (World Health Organization 2009, 191-192):

1. Patient participation.
2. Patient knowledge.
3. Patient skills, which consists of self-efficacy (the belief that you are capable of setting and reaching a goal) and health literacy (the ability to understand information regarding your health and apply this appropriately).
4. The creation of a facilitating environment.

By defining 'empowerment' through a consensus among the scientists involved, Stepanian et al. (2023) make an in-house value judgement in order to achieve what they think is the right conceptualisation of the term. They justify this by stating it is problematic that there are so

many definitions of empowerment currently in use for different groups of chronically ill people. They further legitimize their definition by stating that all four of these components in some way – though never at the same time – in every piece of literature they reviewed during the study and mentioning the WHO as a kind of authority (Stepanian et al. 2023).

While they might make the process of large-scale empowerment research a bit more convenient for scientists by doing this, they forget to ask themselves some important questions in regard to the people who actually have to *use* the concept, such as healthcare workers and patients. Do the patients *feel* empowered by the aims of the intervention they have to endure? Or do they feel there is something missing in the definition of empowerment? Would offering ‘empowerment’ by this definition be attainable for healthcare workers in their daily encounters with patients? Is each component of the definition realistically attainable for every patient, with any background and chronic disease? Given the fact that 22 out of 35 of the studies they reviewed during the literature review were on patients with diabetes type 2 mellitus, therefore leaving little representation for patients with other chronic conditions, this might be a serious concern.

A logical step to take in order to find answers to such questions, is to involve stakeholders in defining the concept. The third strategy identified by Alexandrova and Fabian (2022) aims to provide exactly that. Their own method, co-production, is part of this cluster, and is an interesting deviation from the in-house value-judgements of strategy two.

### 2.3 Co-Production

Alexandrova and Fabian have created quite a detailed account of a method of their own with which they hope to define thick concepts with political legitimacy that they call ‘co-production.’ The definition they give to co-production is a normative one, meant for measuring responsibly, and is as follows:

‘Co-production is an arrangement for sharing power and responsibility in the process of defining thick concepts and developing their measures. This arrangement requires, first, recognising different types of expertise that each group of stakeholders have about these concepts and their measurement and, second, ensuring that the final products meet, to the extent that is possible, the demands stemming from each type of expertise.’ (Alexandrova and Fabian 2022, 12)

By sharing the power and responsibility of the conceptualisation process with stakeholders, it is expected that the social consequences of a definition are better foreseen and accounted for. And even if it somehow goes wrong, the stakeholders themselves bear part of the responsibility for this error, for their input is included in the resulting definition of the concept (Alexandrova and Fabian 2022, 12-13). Alexandrova and Fabian (2022) exemplify this with a case study conducted with Turn2Us, an anti-poverty charity in the UK, who aimed to define the concept of ‘thriving’ via co-production (5-18). In this case, stakeholders were included through questionnaires, interviews, discussions and workshops, until a consensus was reached (Alexandrova and Fabian 2022, 16-17). By doing so, all those involved in the conceptualisation process bear responsibility over the final definition.

When one decides to include stakeholders in research, they must first decide who the stakeholders are. Alexandrova and Fabian (2022, 13-14) discern three general groups, who each have their own expertise:

- The first group includes members of the public, of whom especially users of the service. In this case: chronically ill patients and people close to them. Stakeholders who take on this role, possess lived expertise. Their knowledge about the meaning of a concept supposedly stems from their experiences in navigating daily life within their own circumstances (Park 2020).
- A second group consists of policy makers and service providers. In the case of empowerment for chronically ill patients, this group would consist of policy makers and different types of healthcare workers. According to Alexandrova and Fabian (2022), This group is most aware of how policies get translated into the practical field of institutions and interventions on the work floor (13).
- The third and last group consists of scholarly researchers. They possess mostly technical expertise about concepts, theories and measurement from literature and existing research (Alexandrova and Fabian 2022, 13).

It is important to note that these groups should be seen as ‘roles’, rather than stable categories to which someone belongs (Alexandrova and Fabian 2022, 13). In order to define a concept in a way that makes it usable in a scientific process, we must do three things. First, we must make a characterisation, which means that we must define what the concept is and what its boundaries are – thus deciding which features belong to the concept and which do not (Bradburn, Cartwright and Fuller 2016, 3). Then we must find a representation, which, simply

put, is the way we wish to *represent* the category in our study (Cartwright and Runhardt 2014, 267). Lastly, procedures must be devised that describe exactly what must be done in order to successfully carry out the measurement (Cartwright and Runhardt 2014, 267).

While all stakeholders contribute to the characterisation, representation and procedures tied to the concept, they have different points of focus based on their respective expertise (Alexandrova and Fabian 2022, 14-15). Members of the public, such as service users, focus mostly on characterisation and procedures, whereas scholars focus on characterisation and representation and the policy makers and/or service providers focus on procedures (Alexandrova and Fabian 2022, 15). By distributing the tasks in this manner, the idea is that the process of co-production causes each expertise to be maximised to the best possible extent, while still allowing all stakeholders to participate in each step of the conceptualisation process without overruling one another (Alexandrova and Fabian 2022, 15).

At first glance, the strategy of co-production would seem more fitting to the concept of empowerment for the chronically ill instead, as Stepanian et al. (2023) also insist that we ought to aim for the redivision of power between the doctors, experts and patients. Furthermore, a strategy that involves stakeholders – of which co-production is one such example – is stated to be the most attractive in the case of research close to action (Alexandrova and Fabian 2022, 10). In the next part, I will add some more context to co-production and its unique place in a third strategy of defining thick concepts.

#### 2.4 The third strategy: Political Legitimacy

Broadly speaking, the third strategy is best defined as one that involves stakeholders (Alexandrova and Fabian 2022, 6). Alexandrova's and Fabian's framework of co-production is one way to achieve the goal of involving stakeholders, but other methods that aim to define a thick concept by a legitimate political process, fall into this category as well. With 'legitimacy' is meant that there should be certain constraints on the way in which thick concepts are approached and defined by the scientists involved, as to provide an extra layer of security against unjust – and perhaps even unnoticed – use of power (Alexandrova and Fabian 2022, 6). Instead of only the researchers' judgement of a concept, all methods befitting strategy three require the people whose lives are affected by the research to be involved in the

process of conceptualising in some way, shape or form. From here on out, we will describe this aspect of strategy three ‘democratisation,’ (Alexandrova and Fabian 2022, 6).

In practice, Alexandrova and Fabian distinguish two different kinds of attempts to implement strategy three: one that follows this strategy by the letter, and one that follows it in spirit (Alexandrova and Fabian 2022, 7). When researchers follow the strategy by the letter, they may indicate that some sort of democratic legitimacy is at play, without actually going through a democratic process of legitimization (Alexandrova and Fabian 2022, 7). For example, Alexandrova and Fabian claim that this is the case with the capabilities approach by Martha Nussbaum<sup>3</sup>, when she proposes a list of general capabilities as the best way to honour people’s autonomy. However, as this list is self-generated by Nussbaum, not every stakeholder may agree that the capabilities she defines as indicator of their human dignity indeed do so (Alexandrova and Fabian 2022, 7). In order to effectively live up to the spirit of the third strategy, a different approach ought to be taken. This, however, is not an easy task and highly depends on the context (Alexandrova and Fabian 2022, 7-8). And thus, strategy three, even if followed in spirit, comes with some constraints.

Philosopher of science Kevin Elliott identifies a crucial problem in regard to engagement in research. He states that a specific set of rules applied in the process of engagement, as well as the inclusion of a specific group of stakeholders in research, may produce very different results compared to the utilisation of another set of rules or group of stakeholders (Elliott 2022, 47). This creates doubt around the reliability of the results achieved in a study with stakeholder participation, as there are (too) many variables at play. Thus, procedures are needed to rigidify the process of engagement. Based on Elliott’s concerns, this means that (1) clear rules must apply to the process which can be recovered and if necessary reproduced and (2) a clear outline must be made about which stakeholders ought to be involved in the process and what role they have.

But even with these constraints, one problem as a result of the versatility of a democratic process still remains standing: the results of a conceptualisation process involving stakeholders will likely severely limit the scope of the concept. In the case of empowerment: while the concept of empowerment created by health care workers, patients and researchers may work well for group A who are working with disease X in country C, the very same

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<sup>3</sup> Martha Nussbaum, *Creating capabilities: the human development approach* (Cambridge, MA: The Belknap Press of Harvard University Press, 2011).

definition may not be helpful for group B, who tackle disease Y in country D. This is because there are different variables at play for each group, including but not limited to differences in culture, needs to adjust a lifestyle according to the disease, the structure of the health care system, contact time with the patient, personal capabilities and limitations of both patients and health care workers, et cetera. So while a concept brought forth from strategy three is helpful to one group to accurately describe their experiences and needs, it may overlook some of the needs and experiences another group has, or worse, even harm them. Alexandrova and Fabian (2022, 18-19) address a similar issue themselves, stating that concepts created using strategy three – as well as their own proposal which I shall address in the next paragraph – are aimed at a specific group who are in a specific context, rather than the general public and therefore might not be the right strategy for all research.

In chapter 3.1 I will dive deeper into this issue and show that while some consider this limitation to be a problem, it does not necessarily have to be one – or at least not in all cases. After this, I will show that co-production is a problematic strategy for conceptualising empowerment for the chronically ill for entirely different reasons, thus providing a direct counterexample to Alexandrova and Fabian’s defence of this strategy for thick concepts. In short, I will argue that co-production is unsuitable to define ‘empowerment’ in the case of chronically ill persons, because it is inappropriate to require healthcare workers and chronically ill patients to bear equal power and responsibility to that of scholars in defining the complex term, as conceptual error could not only result in a concept that is ineffective, but also one that causes harm to already vulnerable persons.

## Chapter 3: limits to co-production

### 3.1 Breadth of Scope

While at first glance co-production would seem to be a more fitting strategy for characterising empowerment for chronically ill patients in intervention research due to its involvement of those who should ‘become empowered’ by the intervention and the healthcare workers who are to perform the intervention, it is not a very good strategy for defining a generally applicable concept. Alexandrova and Fabian themselves state this to be a limit of co-production, as I have already discussed in paragraph 2.4 (Alexandrova and Fabian 2022, 18-

19). However, this would mean that the issue presented in the case of the research paper would go unresolved. As shown in chapter 3, Stepanian et al. (2023) are specifically arguing for a broader, more general definition of empowerment to apply to all types of chronically ill persons globally, as to ease the path for further research into empowerment intervention. In order to do this, they use strategy two. But as I have concluded in the previous chapter, a one-size-fits-all definition of empowerment for all chronically ill persons is neither attainable nor desirable.

The logical choice is that we rid ourselves of the idea that empowerment is applicable to every type of chronically ill persons – that is, regardless of illness, age, gender, background, country, or culture – and use a co-production type of method to create more particular conceptualizations of empowerment that apply to certain groups of chronically ill people, but maybe not others. This would mean that I disregard the issue stated by Stepanian et al. (2023) that we need a conceptualization with a broader scope, but this may be justifiable, as scope is arguably just a value with social and political consequences rather than an epistemic requirement. Philosopher of science Helen Longino (1996, 54) argues for such a position, stating that traditional cognitive values – such as simplicity, breadth of scope, consistency and fruitfulness – which we use to choose between theories but also, as I will argue, for developing concepts, are not purely cognitive requirements. Instead, they come with their own social and political consequences that may or may not be justified in a specific context.

For example, a fruitful theory can be understood as one that helps scientists generate new findings or reveals relationships between other theories (Longino 1996, 44). Arguably, the same goes for the defining of (thick) concepts. Upon constructing a definition, a researcher would like for it to be productive as a measure and yield interesting or at least useful results. This seems very logical but is not self-evident or without social consequences. Instead, one might choose to define a concept according to feminist pragmatic virtues, which favour concepts ‘that can be used to improve living conditions in a way that reduces inequalities of power’ (Longino 1996, 53). Upon defining a concept this way, the researcher will end up with a different definition and thus different measures, which then can be used for policy that quite possibly also would have turned out differently as it was based on alternative research.

The case with breadth of scope is very similar to that of fruitfulness. A scientist may want a definition of a concept that can be used for a large amount of data or one that could be applicable to a broad target audience. If one were to see this as a purely cognitive value, they might miss out on alternatives. Such an alternative for ‘empowerment’ could be what Longino (1996, 46-47) defines as ‘ontological heterogeneity’. A concept that is characterized this way, treats different types of entities – for example, different types of chronically ill people, which may be distinguished by their illness, gender, age group, etc. – with an equal amount of importance, instead of postulating one ‘standard’ but ‘widely usable’ entity through which diverse individuals must identify, possibly causing their particular interests to be infringed upon or eliminated entirely. Being different from the standard entity that the chosen definition of a concept is designed for, will then become a failure to meet this standard, rather than simply difference (Longino 1996, 46-47).

Of course, this is not the only possible alternative value to ‘breadth of scope’, but one I simply used to illustrate Longino’s point that these ‘cognitive values’ have political and social consequences in different contexts, and therefore should not be treated as these objectively desirable traits that theories or concepts ought to have (Longino 1996, 54). Thus, the lack of scope produced by co-production may not be the great impediment one might have suspected it to be, but instead a limit one must accept in favour of other more valuable possibilities.

### 3.2 Power and Empowerment

Yet, even whilst believing the limits to the scope of a potential definition of ‘empowerment’ in the ideal of co-production as an acceptable shortcoming in this case, more issues arise. While the term ‘empowerment’ is often used as something with which one hopes to express their good intentions (Rowlands 1997), it must not be forgotten that it is a deeply political and dubious term. Dissimilar from terms such as ‘well-being’, which are goals in and of themselves, ‘empowerment’ is usually considered a tool for achieving greater patient well-being and prosperity (i.e. Stepanian et al. 2023; Kristjansdottir et al. 2018; Haugan 2021). Therefore, there is a gap between ‘being empowered’ and ‘being well.’ As they are not one and the same, the first does not always necessarily lead to the latter, especially if the concept of ‘empowerment’ is defined inadequately for the people it is supposed to foster greater well-being for. I will argue that contrary to thick concepts such as ‘well-being’ and ‘happiness’ of which it goes uncontested that they are a social good, ‘empowerment’ may not be the right

goal for every chronically ill person or their healthcare workers, at least not according to every possible definition of the term. To clarify this point further, I will first dive into some political theory on power. I will do this by explicating three different views on power and how ‘empowerment’ would be defined from each point of view.<sup>4</sup> The views I will discuss include power as a resource, relational power, and power as capacity. This overview will be concise, as it is merely meant to illustrate that one’s background assumptions on the workings of power greatly impact their conception of ‘empowerment.’

### 3.2.1 Power as a resource

Political theorist Moya Lloyd describes the common language definition of power as a resource as ‘something people have that enables them either to do things directly or to get others to do things for them,’ (2013, 113). It is something that individuals held or possessed, that minorities do not. Therefore, power defined in this manner is an unevenly distributed resource (Lloyd 2013, 113).

This view on power is quite common and is still used in research but has received some serious critique from political theorists and philosophers who oppose this outlook on power. Political theorist Iris Young (2012), for example, states that we must make a distinction between resources, such as money or military strength, and power (31). Instead, she argues that power is relational.

When one is to define ‘empowerment’ from the viewpoint of power as a resource, a definition might look like what Haugan and Eriksson, both professors in the Department of Health, describe in their work on health promotion:

‘The aim is to redistribute power from the health care workers to the patients who cope with the challenges of a chronic illness daily,’ (Haugan and Eriksson 2021).

Empowerment according to this definition requires that one (the healthcare worker) gives up some of their own power, to hand it over to another (the patient). But the gifting of one’s own power to someone else is not necessarily the most innovative or desirable way to achieve empowerment. As Jo Rowlands states in her book on empowerment: ‘If power can be

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<sup>4</sup> Of course, more views on power relating to empowerment exist than I mention in this paper. However, I have chosen to limit myself to three of the most common views in both philosophy and science, as the point here is to exemplify the effect an underlying theory on power has on possible definitions of empowerment.

bestowed, it can just as easily be withdrawn; empowerment as a gift does not involve a structural change in power relations,' (Rowlands 1997, 10-11). If we are to believe Rowlands, any power gained in this way might therefore be nothing but a false sense of achievement. Similar to what Iris Young stated earlier, Rowlands seems to think of power as relational; a relationship that must change in order to truly change the workings of power. We will look at this view on power next.

### 3.2.2 Power Over/Relational Power

Relational power is most often described in feminist literature but can be translated to apply to all kinds of minorities. To give a short definition, those who regard power as relational, see oppression as a result of different factors working together in order to 'subordinate' another group or person (Lloyd 2013, 114-115). Power, in this sense, has a very negative connotation to it. Instead of a simple 'redistribution' of power in order to achieve empowerment, we now need to 'overthrow' the current system so we can replace it with a new one (Lloyd 2013, 117). Feminist psychologist Jean Baker Miller provides us with a more neutral definition. She states that relational power usually stems from a structural situation where one group has greater resources and privileges and can therefore control another (Miller 2008).

Medical scientists do not typically conceptualise empowerment in this sense. However, it is useful to look at this conception of power, as it is a common view and definitions of empowerment based on it are deeply problematic. Not only would a concept of 'empowerment' rooted in this view on power require a lot of work in the case of empowerment for chronically ill persons, a revision of the power relations between doctors and patients with the goal of granting both of them equal positions of power is impossible due to the fact that patients inherently depend on doctors for their care. I will return to this later in the chapter.

### 3.2.3 Power as capacity

Power as capacity, also known as 'power to', can be defined as 'the ability to make a change in any situation, large or small, i.e., the ability to move anything from point A to point B without the connotation of restricting or forcing anyone else,' (Miller 2008, 147). This form

of power seems to be one that can, and most likely does, coexist with other forms of power that in fact may force or restrict someone else.

A resulting possible definition of ‘empowerment’ is once again entirely different from the ones we found with the previous conceptions of power. Iris Young (1994) defines ‘empowerment’ from the viewpoint of power as capacity in twofold. One part of her definition has to do with individual empowerment, in which she focusses on autonomy and self-control (Young 1994, 49). The second part has to do with community and collectively working together with people in a similar situation in order to attain shared goals (Young 1994, 48).

Community empowerment in the case of chronically ill patients is currently still very underutilized when it comes to empowerment intervention research. However, doctor Gillian Hood, for example, mentions self-help groups or even religious groups as sources of empowerment for patients outside of the hospital (Hood 2010, 77-78). Instead, definitions of empowerment stemming from power as capacity on the level of the individual patient are more common. An example is as follows: ‘empowerment entails the ability of the patient to make health-enhancing choices deriving from their own knowledge and expertise,’ (Schulz and Nakamoto 2013a, 224). This definition specifically would not cause an issue for the doctor patient relationship directly but is still problematic at other points. For example, not every patient is going to be able to make health-enhancing decisions derived from their own knowledge, due to for example cognitive issues or mental health problems (Hood 2010, 77).

It is important to note that these views on power are only a few of the most common ones, and agreeing with one view does not necessarily lead you to disagree with the others. Different views on power can sometimes coexist, such as ‘power to’ and ‘power over’, but also conflict with each other, as was the case with power as a resource and relational power. It is also possible that there are other, less well-known views one could have on the workings of power. As I have shown above, based on which ideas you have about the mechanism behind power, an entirely different definition of ‘empowerment’ arises. Even more definitions arise when one regards power as a mixture of different views coexisting at the same time. Naturally, some of these definitions are better suited for empowerment intervention in the case of (some) chronically ill patients than others. I will refrain myself from arguing for or against a certain definition however, as this is not my point. The important takeaway here is

that power theory and as a result, a definition of ‘empowerment’, is very complex, even for scholars. Because scientists rarely mention their background ideas on the workings of power and how this affects those who they consider to be in a position of lacking power, social matters of great consequence such as whether empowerment is attainable or desirable for all patients are left undiscussed. It is therefore of great importance that these underlying assumptions are being looked into before defining ‘empowerment’ in this context, as failure to do so has been shown to overlook the most vulnerable chronically ill people.

In the next part, I will reflect on the method of co-production from this angle of power. I will argue that co-production is not a good fit for defining empowerment for the chronically ill, as stakeholders’ assumptions on the workings of power pose a high risk of conceptual error for which they cannot justifiably be held responsible.

### 3.3 Power, Knowledge, and Co-production

Alexandrova and Fabian (2022, 12) state that the starting point of their definition of co-production finds its roots in the moral responsibility of researchers who are to be held accountable for unintended harmful consequences, as they have the power to produce knowledge. For instance, in the case of co-production, this could be the power to produce definitions of thick concepts to be used in science for policy. In equally sharing the power to produce a concept between all stakeholders, the responsibility for potential consequences will be shared equally as well (Alexandrova and Fabian 2022, 12).

The argument on the moral responsibility of researchers used by Alexandrova and Fabian (2022) is based in large part on Heather Douglas’ (2009) philosophical argument on the moral responsibility of scientists (Alexandrova and Fabian 2022, 12-13). In the fourth chapter of her book *Science, Policy and the Value-Free Ideal*, Douglas famously argues that scientists in their role of scientists are responsible for assessing the potential negative social consequences of their actions during research (2009). There is a general consensus among philosophers that this argument describes the minimal responsibilities of scientists (i.e. Elliott 2013; Alexandrova and Fabian 2022). In what follows, I will take a closer look at Douglas’ full argument, to spell out my concerns about co-production in the case of empowerment of chronically ill persons. The overall structure of Douglas’ argument is as follows:

First, Douglas states that moral agents bear responsibility over their actions if and only if the following statements are true:

- a. They are competent at making decisions and assessing risks (Douglas 2009, 67);
- b. They are free of the influence of coercion (Douglas 2009, 67);
- c. There exists a relevant causal relation between the action and the consequence – a relevant causation being one for which a person may receive praise or blame. This includes situations in which either intent or unjustified risk in the form of negligence or recklessness play a role (Douglas 2009, 67-69).

Douglas then states that scientists should not be exempt from the responsibilities of a moral agent, as statements a, b, and c are at least as true and applicable to scientists as they are to the general moral agent (Douglas 2009, 70-71).

Moreover, scientists are likely more competent than others for the task of assessing consequences due to their knowledge and expertise on their research topic (Douglas 2009, 73-74). Preventing them from assessing risks might even prove harmful, as constant third-party moral oversight is unrealistic and such a third party might miss part of the risks due to them being less knowledgeable on the topic than the scientists themselves are (Douglas 2009, 74). Thus, she concludes, scientists should be held accountable for the claims they make and therefore bear moral responsibility [indexed to the scientific community] (Douglas 2009, 83).

As mentioned before, in co-production, the responsibility of scientists is shared equally among all stakeholders involved in the process of defining a concept, as they also share equal power. In the case of empowerment for the chronically ill, an important question arises in premise 1a: Are those involved, including patients and healthcare workers, sufficiently aware of the workings of power and therefore of all the potential forms empowerment could take in order to define it in a way in which it yields the best – or at the very least positive – results for them?

An example of a potential but realistic issue is that patients might demand considerably more power over health decision making, despite not having enough health literacy and medical expertise to make these choices properly and safely. Some at-risk populations might already have trouble with comprehensive reading and numeracy due to limited education, language barriers or simply age, but even those who do possess these basic

skills need to be capable of more (Schulz and Nakamoto 2013a, 224). Supplementary necessary skills might include declarative knowledge, e.g., knowledge about medicine, and procedural knowledge, e.g., knowledge about rules that ought to guide us to a suitable course of action (Schulz and Nakamoto 2013b, 6). To grant patients more power and in extension responsibility over health decisions whilst lacking these skills because they feel that is what ‘empowerment’ means to them, seems unreasonable.

Another potential issue is that patients, along with their healthcare workers, might set very high standards for themselves regarding the amount of control, independence and emotional regulation they are to exhibit in order to be a ‘good, empowered patient’, despite this not contributing positively to their own well-being. For example, when patients are asked what they consider to be important when becoming ‘empowered’, they might find it important to part-take in medical decisions, learn about their illness and set goals for their appointments. In reality though, these things may be very difficult to attain depending on the individual’s capabilities (Keizer, Tiemeijer, and Bovens 2019) and whether they are able to accept their illness or experience ambiguous loss.<sup>5</sup> To let them force themselves to train their literacy skills will then only add to their stress-levels. After all, it is often not the patients asking to become empowered, but rather the scholars who feel that it is good for patients<sup>6</sup> – and as I have shown in chapter 3.2, the scholars themselves seem to have enough trouble acknowledging what influence different conceptions of power have on their idea of empowerment. Patients might be motivated to gain the required skills such as health literacy (which includes gathering and applying information), planning ahead and identifying goals (Keizer, Tiemeijer, and Bovens 2019, 5; 17) but we must not forget that they each suffer from an illness which reduces the amount of energy they have to actually learn them. Being ill is also in many ways a very vulnerable experience. One might be able to take on more physical and mental load than the other, and it might even fluctuate over time. A demanding definition of empowerment, no matter how well-intended, will then cause additional stress to those who ‘fall behind’ and are (temporarily) incapable of displaying the sort of ‘empowerment’ they set out to achieve. Such stress can lead to temporarily reduced self-control and performance,

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<sup>5</sup> Ambiguous loss is a phenomenon often seen in people with an incurable (chronic) illness. This feeling of loss can be as debilitating as the illness itself (Boss and Couden 2002, 1352). They may become immobilized, depressed and preoccupied with the management of their illness, whilst forgoing many other activities because of it (Boss and Couden 2002, 1351-1352).

<sup>6</sup> One could argue that co-production could potentially result in a definition that is more respectful of patients’ boundaries. While it is potentially the case that some patients advocate their boundaries, there is also a sizeable risk that they will not due to their ideals of what they want to be capable of not matching with the reality, in which case my point still stands.

which in turn leads to more poor decisions, which causes even more stress, and the patient lands in a vicious cycle (Keizer, Tiemeijer, and Bovens 2019, 111). Thus, one small moment of falling behind on the ideal can lead to issues that are very difficult to resolve for patients by themselves (Keizer, Tiemeijer, and Bovens 2019, 111).

Furthermore, not even all physicians show awareness of the power they have over their patients and what this would mean for a potential conceptualization of ‘empowerment,’ (Nimmon and Stenfors-Hayes 2016). Some state that their power over patients has long since been diminished by patients who ‘bully’ them into agreeing to other plans and others seem to believe that the power relation between doctor and patient is dissolved by conversation tactics driven by kindness and the ideal that ‘the other is their equal’ (Nimmon and Stenfors-Hayes 2016, 5). This belief is false however, as patients are dependent on healthcare workers to get the help they need (Bending 2015, 195), regardless of how much the healthcare worker ‘sees the patient as their equal’. For it is the healthcare workers who possess over the knowledge and expertise that patients depend on for their health and safety. It would take a world in which patients no longer need doctors to dissolve this power imbalance. In that case, patients would no longer be patients at all. It is therefore not a question of idealism whether a doctor’s heightened position in the balance of power is legitimate or not; It is simply the case out of necessity. As a result, any characterization of empowerment for chronically ill people that depends on transferring power from the physician to a patient in order to even out the power imbalance is by definition unfeasible. If it is the healthcare worker’s power over their patients we are worried about, research regarding the legitimate use of power that inherently comes with the role seems more fruitful.

So while it’s seemingly honourable at first glance that stakeholders are involved in the process of conceptualising by giving them power and responsibility for both potential success and error, this is unjustifiable in the specific case of empowerment for chronically ill persons. The question I mean to unpack is this one: Are the stakeholders involved justifiably responsible for error if they are unaware and uneducated on topics of major importance to the concept (i.e. power theory)? In order to answer this question, let us return to the argument on responsibility by Heather Douglas.

In the first premise of her argument, Douglas (2009) names three criteria that need to be met in order to attribute justified moral responsibility to someone over their (lack of) actions.

The first criterium requires the absence of coercion. On this topic specifically, Alexandrova and Fabian write the following in their case study on defining ‘wellbeing’ via coproduction: ‘To ensure healthy power dynamics in the working group, the chair compiled a coproduction social contract that enforced norms of respect and forestalled dominating behaviour by any members of the group,’ (Alexandrova and Fabian 2022, 17). While such a social contract would not be possible during an actual empowerment intervention for chronically ill patients due to their inherent dependence on their healthcare workers, this issue is not necessarily at play during the conceptualization process. A social contract might therefore very well prevent risks of coercion between all participants. Thus, the first criterium is met.

For the second criterium, all participants of the conceptualization process need to be considered competent at making decisions about a definition of ‘empowerment’, as well as at assessing the risks of an ill-suited definition of empowerment. This is where it gets trickier. As I’ve shown in 3.2, our ideas on what ‘empowerment’ means, depend on our underlying conception of ‘power’ and how we believe it functions. I have also shown that this is a highly complex matter and that resulting definitions of ‘empowerment’, even those contrived by trained scholars, vary greatly because of it. Some of these definitions might put undue pressure on already vulnerable patients or even be impossible to bring into practice given the nature of a patient-doctor relationship, as I have argued to be the case for definitions that require an equal distribution of power between the two. Medical professionals, too, have been shown to bear misconceptions on the power they have over their patients (Nimmon and Stenfors-Hayes 2016).

And finally, patients have been argued to require both declarative and procedural knowledge on top of other basic literacy skills in order to give them a reasonable chance at being successful at making their own health decisions alongside their doctors (Schulz and Nakamoto 2013b). Depending on a patient’s disposition and personal circumstances, training these skills may be exceedingly difficult (Keizer, Tiemeijer, and Bovens 2019, 111). In addition to this, if a definition requires too much self-reliance from patients in the short term, chances are they are less self-reliant in the long term due to having asked too much of themselves (Keizer, Tiemeijer, and Bovens 2019, 112). These findings, I argue, make it unreasonable to expect scholars, healthcare workers and patients in equal positions of power to contrive a fair definition of ‘empowerment’ as they do not clearly oversee the risks of flaws in their definition.

As a result, the third criterium, which is based on whether one can reasonably receive praise or blame for their actions, cannot be met either. It would be unfair to blame someone for not overseeing consequences that were unforeseeable for them in the first place.

Therefore, I argue that we cannot blame healthcare workers and patients for contriving a definition of ‘empowerment’ that does not contribute positively to the patients’ well-being – or worse, impedes on it – when they are not sufficiently aware of the workings of power. Of course, the same goes the other way around. Even if they were to contrive a sufficient definition of empowerment despite being unaware of the complexities, I would attribute this to luck rather than praise them for their expertise on the topic.

In conclusion, due to the fact that not all three criteria have been met, moral responsibility cannot be attributed to the stakeholders involved in a coproduction definition of ‘empowerment’ as by its current design, for the stakeholders are not justifiably responsible for error if they are unaware and uneducated on topics of major importance to the concept of empowerment. This poses an issue for the strategy of coproduction, as the equal distribution of responsibility over the concept defined lays at its very foundation. Thus, coproduction, too, is an inappropriate strategy for defining empowerment for chronically ill patients.

## Conclusion

‘Empowerment’ is a deeply complex thick concept that is gaining popularity among scientists as a beneficial concept to aid minorities in gaining a better social status. This is also the case for healthcare related studies, as different researchers and organizations have called for empowering chronically ill patients (i.e. Stepanian et al. 2023; Haugan 2021). Many current definitions of the term that are devised by either reducing it to a technical term or by scientists making in-house value judgements have appeared to be problematic, due to misunderstandings about the workings of power and/or poor considerations of patients’ capabilities. More research on both these issues is needed in order to pursue appropriate definitions of ‘empowerment’ in healthcare.

Another strategy scientists could use is the method of co-production, designed by philosophers Anna Alexandrova and Mark Fabian. They propose a new way for defining thick concepts by involving scholars, professionals, and service users. While each of these groups

has their own expertise – such as theoretical knowledge and lived experience – all contribute to the concept in full while holding an equal amount of power *and* responsibility over the final result.

However, as stated above, the complexity of empowerment is often overlooked. The lack of knowledge of healthcare workers and patients – and, it appears, even some scholars – on the matter is a serious cause for worry as they each hold equal power over the resulting concept. Consequently, depending on the definition, ‘empowerment’ may prove unproductive, or worse, a burden on healthcare workers and chronically ill patients and thereby impeding on their well-being. The process of defining empowerment is therefore a delicate and risky one, making it unjustifiable to expect stakeholders to bear equal responsibility for the efficacy of the definition, as the method of co-production requires. Thus, I argue the ambiguity and complexity of ‘empowerment’ in healthcare makes it a thick concept unfit to be defined by stakeholders such as patients and doctors.

It is important to note that I do not state that co-production, as a method, is bad or should not be used for defining thick concepts in general. What I do mean to say is that one ought to be careful when selecting a thick concept to define when using this strategy, as the equal distribution of power and responsibility does not always result in a politically just conceptualisation process, such as when the responsibility is undue.

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