

# Your own Health?

## A position paper on the concept of health ownership: what does it mean and how can it influence our health.

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## 1. Introduction

### 1.1 Defining Health

Over the past decades, the concept of health has shifted from a static, idealized state of complete well-being to a dynamic, realistic, and individualized capacity. In 1946, the World Health Organization's (WHO) defined health as "a state of complete physical, social, and mental well-being and not merely the absence of disease or infirmity". The good thing about this definition is that health is defined from a positive perspective of wellbeing. However, in recent years it faced extensive critique (see Leonardi, 2018 for an overview). The most evident limitation is the idealistic nature of this definition: achieving a state of complete well-being is unattainable for most people, and, at best, only temporary. Moreover, advances in medical diagnostics and the growing prevalence of chronic conditions (61% of Dutch population) make such a state, i.e. complete physical-, social- and mental wellbeing, unrealistic across the lifespan. The definition also lacks practical utility, as health cannot be comprehensively measured against such a standard.

Positive psychology has contributed significantly to addressing these limitations. Seligman (2008) introduced measurable components of health on biological, subjective, and functional levels, emphasizing a multidimensional understanding of well-being. Building on this foundation, Huber et al. (2011, p4163) reframed health in terms of a *dynamic and valued level of resilience* (van Vliet et al, 2024) as "the ability to adapt and self-manage in the face of social, physical, and emotional challenges." This approach highlights a person's capacity to navigate health challenges on three levels: the social level (e.g., adapting social and work life to physical capacities), the bodily level (e.g., resistance to flu viruses), and the mental level (e.g., coping with psychological stress caused by chronic illness).

This dynamic reframing of health, often referred to as *Positive Health (PH)*, places central emphasis on an individual's capacity to actively manage and influence their own health. To further specify the concept of 'health' in a participatory bottom-up research approach, Huber et al. (2016) invited patients, healthcare professionals, and physicians to identify which indicators they use to attain one's health. Their findings produced indicators along six dimensions: bodily functions, mental functions and perception,

spiritual/existential dimension, quality of life, social and societal participation, and daily functioning. These dimensions explicitly broadened the concept of health by shifting away from the sole biomedical perspective, and proved to be of practical relevance for self-reflection, dialogue, and awareness-building around health. The turn in epidemics towards syndemics (e.g. Mendenhall, 2017) reflects a comparable wish to connect contextual factors (e.g. social, economic, environmental, political) to biomedical knowledge to better understand diseases and health conditions worldwide.

Alongside awareness and perceived influence, a crucial feature of PH is its orientation toward a person's health agency: people are not passive recipients of care but active participants in shaping their well-being through adaptation, self-management and lifestyle choices. Moreover, someone's agency towards health is related to life course stages: young children have little agency on their health, and elderly may delegate parts of the health agency. PH emphasizes the individual's ability to adapt and self-manage, thereby framing health as an active process rather than a fixed state. Through its broad set of dimensions, it demonstrates *why* health is significant to people's everyday lives, and these dimensions are increasingly being used as tools for dialogue and reflection about health (van Vliet et al., 2024a). Indeed, in practice the PH-tool has proven valuable as a diagnostic instrument across various health settings to broaden the conversation and shift away from 'what is the matter?' to 'what matters to you?' (van Vliet et al., 2024b)

Despite this holistic and person-centred focus, PH also has its limitations. For instance, coping effectively with a chronic disease does not necessarily mean one is "healthy". Furthermore, it proved to be impossible to design a validated measurement tool for health which incorporated the six PH health dimensions (Prinsen & Terwee, 2019; Van Vliet et al. 2020). Moreover, the focus on the individual's resilience runs the risk of placing excessive responsibility on a person, without sufficiently accounting for contextual influences (e.g. Schermer & van der Horst, 2021). Finally, although the PH concept serves well as health discussion tool for a care-provider and -taker, facilitating empathy and contextual understanding, it doesn't provide the means that are needed to *influence* one's health status. In the present paper we will take a psychological, philosophical and narrative perspective to take a next step from the PH concept towards the theoretical and practical determinants that are expected to facilitate the understanding and influencing of health.

## 1.2 Changing Health by Ownership

A person's capacity to influence one's health takes a central position in the concept of health proposed by PH. Importantly, this capacity is not something that is purely dependent on the capabilities of an individual such as physical functioning, emotional resilience, and health literacy, but also on external conditions, including access to healthcare, social support, economic resources, and institutional arrangements. The philosophical Capability Approach (Nussbaum, 2011; Sen, 1999) adds an important ethical dimension to PH by highlighting that opportunities for health are unequally distributed across individuals and populations and thus, that people differ in the real opportunities available to them to pursue health. From this perspective, health should not be understood solely as an individual achievement or responsibility. The ability to adapt, self-manage, and influence health depends on the interaction between personal capacities and the context in which people live.

Having the possibility to influence health, however, does not yet explain how such influence is realized through action. To influence health, people need to engage in health-related behaviours and decisions. Behavioural science provides a framework for understanding the conditions under which such actions occur. The COM-B model (Michie, van Stralen & West, 2011) proposes that behaviour (B) depends on three interacting conditions: Capability, Opportunity, and Motivation. Capability refers to the psychological and physical capacity to perform a behaviour. Opportunity concerns external conditions that facilitate or constrain behaviour, including physical and social environments. Motivation encompasses the reflective and automatic processes that direct and sustain behaviour. Although COM-B and the Capability Approach originate from different theoretical traditions and use the term 'capability' differently, they provide complementary perspectives for understanding Health Ownership. The Capability Approach addresses whether people have genuine opportunities to influence their

health and provides a normative framework for considering responsibility and justice, whereas COM-B specifies the behavioural conditions through which such influence can be translated into action.

Against this theoretical background, an important conceptual gap in Positive Health remains. Positive Health emphasizes the ability to adapt and self-manage but provides limited theoretical guidance on what enables people to actually influence their health, how this ability is shaped and constrained by context, and how influence over health may be shared with others. The Capability Approach and COM-B help elucidate important aspects of this process, but neither conceptualizes influence over health itself, including how it may change over time and be distributed between individuals and others. In this paper, we introduce and explore Health Ownership as a concept that addresses this gap by describing a person's realistic and changing ability to influence their own or others' health.

In this paper, we examine whether the concept of Health Ownership can be used to operationalize the PH resilience-based health definition by specifying a person's realistic ability to influence their own or others' health, drawing on COM-B to examine the behavioural conditions that shape this ability and on the Capability Approach to consider the contextual and normative conditions under which such influence is genuinely possible. The COM-B condition of Capability connects closely to the PH emphasis on the ability to adapt and self-manage challenges. This includes factors such as health literacy and the individual's health status. For example, the question of whether someone is physically and mentally able to comply with a guideline of walking 5,000 steps a day illustrates how capability operates in practice. Opportunity, when understood through health ownership, highlights how external contextual circumstances exert both positive and negative influences on health-related behaviour. These influences may arise from the physical environment, such as the quality of air or the availability of safe walking paths, from cultural traditions and attitudes toward walking, from a person's social environment, and from one's economic environment, including whether someone has the time and resources to take a walk. Finally, motivation in relation to health ownership encompasses processes of reflection, such as recognizing the need for change, decision-making, such as committing to regain fitness and lose weight, by aiming to change habitual patterns, such as late-night snacking. Emotional responses play a large role in motivation since they might facilitate, e.g. enjoying sports and fast-food, and hinder, e.g. dreading to start to sport and cook, one's aimed-for health goal.

Whereas COM-B helps explain the conditions under which influence over health can be exercised, the notion of *ownership* adds another dimension. The theoretical plausibility of connecting ownership to health behaviour is supported by earlier work on the concept of psychological ownership. Pierce et al. (2003) define ownership as the "state in which individuals feel as though the target of ownership is theirs" and they demonstrate that such feelings have strong effects on motivated behaviour, especially when ownership evokes a sense of responsibility to the target of ownership. When the target is another human being's health, such as that of a child or partner, ownership fosters feelings of responsibility for that person's well-being, which often translates into protective, caring, and nurturing behaviours. Extending this reasoning, Mifsud et al. (2019) showed that ownership can be deliberately fostered, for instance by offering patients greater control and participation in their care programs. In their study, feelings of ownership significantly improved adherence to the program, suggesting that the sense of owning one's health—or a health process—can strengthen the motivation to act in health supportive ways.

The association between ownership and responsibility deserves further theoretical attention. Pierce et al. (2003) suggest that ownership is often accompanied by feelings of being responsible for protecting, maintaining, and developing what they perceive as "theirs." In the context of health, this implies that ownership may foster a willingness to influence one's, or others', health by investing effort in health-promoting behaviours, by monitoring and reducing health risks, and by engaging actively in care decisions. However, feeling responsible for one's own health does not necessarily imply that one can reasonably be held responsible for it. This raises a more fundamental question: under what circumstances can individuals reasonably be expected to take ownership of their health? Nussbaum's Capability Approach (2011) offers a normative framework for

addressing this question. Rather than evaluating people according to their achievements or choices, it evaluates whether they possess the Capacities and Opportunities – to pursue lives they have reason to value. Applied to health ownership, this implies that ownership should not be understood as an obligation or personal responsibility only dependent on motivation, but depends on capacities and contextual social, institutional, and economic conditions. Responsibility for health should therefore be considered in proportion to a person's realistic abilities to influence health. Individuals can reasonably be expected to take ownership of their health when they possess sufficient motivation, capabilities and opportunities to do so. However, when health ownership is constrained by illness, disability, poverty, limited health literacy, or social disadvantage, responsibility increasingly may shift towards professional healthcare and institutes acting out of duty of care as well as to informal caregivers acting out of solidarity. Health ownership therefore does not imply that individuals are solely responsible for their health outcomes. Rather, it presupposes a societal responsibility to create the conditions under which meaningful health ownership becomes possible. This perspective follows Nussbaum's view that justice requires supporting people's capabilities.

## 2.0 Method

The definition of Health Ownership was developed through an iterative process of expert discussion and consensus within the transdisciplinary *Your Own Health?* consortium, bringing together expertise from health care, psychology, design, philosophy, ethics, and technology, complemented by the perspectives of artists. This process was informed by Walker and Avant's (2019) concept analysis methodology, which enables a systematic examination of a concept's defining attributes, its consequences, and its empirical referents. In this paper we start our analysis with the identification of the defining attributes of health ownership (2.1), followed by the proposal of a preliminary working definition (2.2). In the next step, we examine the explanatory value of the definition by relating it to three speculative narrative scenarios (section 3), which allows to refine and finalize the definition and its defining attributes. In the discussion (section 4) we present the final definition Health Ownership (4.1), its position to related psychological concepts (4.2), its ethical implications (4.3), its expected effects (4.4) and its limitations and applications (4.4).

### 2.1 Defining Attributes: Temporal and Distributed Health Ownership

The ability to influence one's health is not a fixed or permanent capacity. Rather, it is a dynamic quality that develops and changes throughout the life course. This capacity is shaped both by changes within the individual and by changes in the surrounding context. For example, people can strengthen their ability to influence their health through learning, accumulating health literacy, and gaining experience with self-management and self-experimentation. These processes are informed by the health information available to them and by the outcomes of their own health-related actions. As individuals age, they often become better able to manage and regulate their emotions in ways that support well-being and health (Aldwin, 2011). At the same time, individuals may encounter circumstances that reduce their capacity to influence their health. Older adults, for instance, are more likely to experience adverse life events, such as the onset of chronic illness or the loss of loved ones. Such events can challenge resilience and diminish a person's sense of health ownership. Conversely, favourable contextual conditions, including a healthy neighbourhood, accessible healthcare services, and strong social support, can enhance a person's ability to influence and manage their health. These examples illustrate that health ownership is inherently dynamic. The extent to which individuals can influence their health fluctuates over time as both personal capacities and environmental conditions evolve throughout the life course.

A second fundamental attribute of health ownership is its distributed nature. The ability to influence one's health is rarely exercised by individuals alone. Other people often play a direct role in shaping health outcomes, either at a person's request, such as healthcare professionals and informal caregivers, or without explicit

consent, such as parents caring for young children or clinicians making decisions in forensic psychiatric settings. In doing so, these individuals assume a share of the ownership of that person's health by taking/ be given the task and responsibility to influence (a part) of the other's health for a giving period of time. Distributed health ownership can be described through four dimensions: the person who exerts influence, the object of influence (the aspect of health being influenced), the extent of influence (the degree to which influence is exercised), and the duration of influence (the period over which influence is maintained).

Consider, for example, a patient undergoing open-heart surgery. During the procedure, ownership of health is temporarily transferred to the surgeon, who exercises near-complete influence over the patient's cardiac health while the patient is unconscious under general anaesthesia. In this case, the surgeon is the influencing person, cardiac health is the object of influence, the extent of influence is substantial, and the duration of influence is limited to the surgical episode. At the other end of the spectrum, informal caregiving may involve a partner preparing meals for someone who can no longer cook independently. Here, influence is shared rather than transferred entirely. The partner contributes to the person's nutritional and social well-being, exercises a moderate degree of influence, and does so for as long as support is provided. The individual receiving care retains influence over many other aspects of health. These examples illustrate that health ownership is not only *temporal*, varying across different stages and circumstances of life, but also *distributed*, with varying degrees of responsibility and influence shared among multiple actors. The distribution of health ownership may shift over time, becoming more concentrated in others during periods of dependency and more firmly located with the individual when autonomy and capacity increase.

## 2.2 Working Definition of Health Ownership

Based on these theoretical considerations, health ownership can be conceptualized by bringing together insights from health definitions, behavioural science, and the broader notion of ownership. To avoid normative judgments about what constitutes “good” or “bad” health, our perspective emphasizes the degree of influence individuals perceive and enact over their health. Two components guide this conceptualization: temporality (ownership capacities shift over time and across the life course) and distribution (ownership is not exercised in isolation but shaped by social, environmental, and structural contexts). From this perspective, we propose the following working definition:

Health Ownership is *a person's realistic momentary (in)abilities to influence one's own or others' health.*

The extent to which this influence can be exercised depends on an individual's Capability, Opportunity, and Motivation conform the COM-B approach (Miche, vanStralen, West, 2011). Capability provides the knowledge, literacy, and skills that enable ownership. Opportunity encompasses the physical and social conditions that support or constrain ownership. Motivation fosters responsibility and commitment, sustaining ownership over time.

## 3. Scenario-based Method

### 3.1 Scenarios & Attributes of Influence

In our project group, we developed three scenarios in which health ownership plays a central role. These scenarios were designed to explore the practical value of the concept in everyday life, moving beyond a purely theoretical framework. Health ownership is a relatively new concept, and we believe it has significant potential to influence health-related behaviours and shape health communication. By presenting these scenarios, we aim to determine whether the concept can be effectively applied in real-life situations, rather than remaining confined to academic discussion.

Next to this aim, the scenarios serve to refine and expand the definition of health ownership by identifying its specific attributes related to the COM-B model—Capacity, Opportunity, and Motivation—that influence an individual's ability to take charge of their health as well as the ethical dimension through Nussbaum's capability approach (Nussbaum, 2011). Each scenario is constructed as a short narrative, complete with carefully designed characters, settings, and plotlines, all revolving around the theme of health ownership.

After presenting each scenario, we discuss the role of health ownership within the story, highlighting the main attributes as defined in our working framework, such as time and distribution. We then explore the specific elements connected to Capacity, Opportunity, and Motivation, illustrating how these components interact to shape an individual's capacity for health influence.

### 3.2.1 Scenario 1: Diana's Data

Diana is a 28-year-old HR recruiter living an active lifestyle marked by healthy cooking and a commitment to running and fitness apps. She relies heavily on health apps that she syncs to her smartwatch, tracking her heart rate, blood pressure, sleep patterns, and fitness performance. These apps give her a sense of control over her health, and they help her to set and achieve personal goals. Every day she shares her app statistics and achievements such as how much she has run on social media platforms and other fitness apps. Receiving positive reinforcement from friends and followers motivates her to remain conscious of her health and to set higher goals.

Everything changes after Diana receives a diagnosis of an autoimmune disorder. She now must manage a chronic illness that entails substantial lifestyle changes and ongoing medical checkups. Initially, she continues to use the apps to monitor her condition and communicate vital changes to her clinician. However, as the severity of her diagnosis sinks in, she becomes increasingly reluctant to share the data with friends and family, many of whom she has not informed about her condition. Moreover, Diana becomes insecure about the meaning of the data. Fluctuations in her blood pressure cause her distress about her health status and are a source for discussion during her consults at the hospital.

As weeks go by, Diana finds herself grappling with her situation, feeling constantly reminded of her illness through the very apps that once made her feel empowered. She realizes that much of her social network revolved around a shared commitment to health and tracking apps, leaving her feeling isolated since she is no longer actively participating on these platforms. The once helpful data tracking becomes a source of distress, as Diana feels that her illness now controls her life instead of the empowering relationship she once had with her health data. She transitions from viewing data as a tool for empowerment to experiencing it as a reminder of her limitations, leading to feelings of despair and loss regarding her previously vibrant social life. When she discusses her data with her care providers at the hospital, she tries to understand what the data mean and how it will affect her life. To Diana, her health data tool has lost its innocence by turning from a positive social connection tool to a representation of her life as patient.

### 3.2.2 Health Ownership in scenario of Diana

In the scenario of Diana, two distinct periods illustrate how health ownership can vary over time. Before her illness, Diana actively exercises her ability to influence and manage her health, aligning it with her active lifestyle. She uses her health data to monitor and control her well-being, demonstrating a strong sense of health ownership. However, after she is diagnosed with an illness, her position towards her health and her data almost is reversed: she no longer feels to influence and control her health but feels as being controlled by her health. This change highlights that health ownership is not a fixed trait but can change over time and depend on many external factors.

Regarding the distribution aspect of health ownership, the scenario shows that following her illness, Diana partially transfers control of her health to her clinician, who becomes necessary for interpreting her health data and communicating it to her. As a result, her ability to influence her own health diminishes. In terms of

Capability—which refers to a person’s physical and psychological capacity—Diana’s health status plays a critical role in shaping her potential to influence her health. She must adapt her lifestyle to accommodate her illness, and she can no longer manage it in the proactive way she did before. Alongside the reduction in physical capability, her cognitive and psychological capacity is also affected; she can no longer rely solely on her own health literacy to determine what actions are best for her well-being.

When considering Opportunities, which encompass the external environmental factors that facilitate or constrain her health influence, Diana’s prior ability to manage her health was strongly supported by her *social* network of active friends who shared similar health habits and engaged in a *culture* of health data sharing and praising. Her illness, however, altered this external encouragement, leaving her with fewer environmental supports to influence her health. Motivation, the COM-B category defined as the processes that direct and energize behaviour, is impacted on multiple levels for Diana. Emotionally, her relationship with her health data changes drastically: what once filled her with pride now evokes despair, undermining her energy to manage her health. At the level of agency, her sense of control over her health diminishes; she feels unable to independently care for herself and relies on a medical professional to take control of her health and health data.

In summary, Diana’s scenario illustrates how health ownership, mediated through data, changes in response to changing health conditions. It raises questions about ownership of health data, demonstrating that its significance to an individual shifts over time, influencing when, with whom, and for what purpose it is shared. The scenario emphasizes that health ownership is temporally dynamic, can be distributed among stakeholders, and is shaped by multiple factors—including health status, health literacy, the socio-cultural environment, emotion, and personal agency—that collectively determine a person’s capacity to influence their health.

### 3.2.3 Ethical reflection

Diana’s declining health ownership should not be interpreted as a personal failure to adapt. Rather, her illness alters several central capabilities simultaneously, including bodily health, emotional stability, social functioning, and her ability to give meaning and purpose to her life. While digital health applications provide increasing amounts of health-related information, they do not necessarily enhance an individual’s real capability to influence their health outcomes. This limitation becomes particularly problematic when the perception of control created by these technologies begins to erode. The scenario therefore illustrates that health ownership depends not simply on access to data, but on the preservation of meaningful capabilities that enable individuals to understand, manage, and act upon their health circumstances.

From a justice perspective, Diana’s diagnosis alters the balance of responsibility. Before her illness, substantial health ownership could reasonably be expected because she possessed the capabilities and opportunities to influence her health. After the diagnosis, her capabilities and opportunities (such as the availability of medical instruments) become restricted. Consequently, greater responsibility falls upon healthcare professionals and institutions to support her ability to exercise health ownership. Her reduction of ownership should therefore not be interpreted as a reduction in personal motivation and commitment but because of changing context.

### 3.3.1 Scenario 2: Diederik’s care community

In a small town in the rural area of Limburg, residents decided to become more self-sufficient in terms of caring for their health, driven by rising medical costs and long waiting lists. They formed community care groups where people looked after each other, shared health information, made shared-decisions when to seek medical care, and provided emotional support. This approach initially led to noticeable improvements in social and mental health; people felt less lonely, trust increased, and relationships strengthened.

However, when Diederik, one of the group members, found out he had malignant skin cancer, things changed. What initially seemed like only a small skin lesion, needing no swift referral, turned out to be widespread disease. Diederik was diagnosed too late because the group lacked the medical expertise or equipment to

detect such diseases early. The shock of Diederik's diagnosis created doubt within the group. Many began to question whether they could truly rely on this self-help structure any longer. This led to a fundamental discussion about the limits of what they could provide for each other. The community gathered to discuss which types of care they could and wanted to provide. They acknowledged that while they could offer preventive care and emotional support, complex medical diagnoses and treatments were beyond their capabilities. They decided to establish guidelines for situations where professional medical help was crucial. During these discussions on care for each other some people realized that they didn't want to share everything about their health with the group. For instance, one of the community member Daria felt increasingly gloomy in the past months. When group members asked her if she was OK, she just said she had some stomach problems. Upon which she was giving diet tips.

Members also began to think about how much they wanted to know about medical risks in advance. Some advocated for regular, professional medical check-ups, with costs shared among them if necessary. Others felt more comfortable avoiding the stress associated with extensive medical tests, as long as they had no early symptoms. Some people in the group did not longer want to fully share every concern with the group and fully rely on each other for care. They started to, sometimes secretly, set up connections with private health care specialists which they visited regularly. Not all group members had the financial means to do this. This incident led to a deeper and more realistic understanding of the role of community care and the need to cooperate with official healthcare systems for complex medical problems.

### 3.3.2 Health Ownership in scenario of Diederik

Health ownership in Diederik's care community is clearly distributed among its members, who look after one another and provide as much support as possible. However, the scenario leaves unclear where the boundaries of this shared health ownership lie. This lack of clarity contributes to the crisis that emerges at the end of the story. Had clear agreements been made from the outset regarding when and how professional care could be sought, either collectively or individually, the community might have been better equipped to respond and potential issues like distrust, miscommunication, and late initiation of treatment might have been avoided.

In terms of Capability, the scenario highlights Diederik's illness as a pivotal moment that challenges the community's ability to provide care. Directly linked to this is the community's limited health literacy, which contrasts sharply with the expertise of healthcare professionals and underscores the gap in capability required to manage a life-threatening illness like skin cancer. Regarding Opportunity, the scenario demonstrates how social and cultural norms influence the community members' behaviour, exemplified by Daria's reluctance to share her mental health struggles with the group. In addition, differences in economic resources among community members contribute to decreased cohesion, further affecting their collective capacity to manage health ownership. Motivation is illustrated through Daria's decisions to withhold ownership of her health challenges, driven by emotions such as shame and insecurity. At the same time, the community's collective action to establish guidelines for medical care reflects its exercise of agency, demonstrating that it can adapt and take proactive steps to manage health ownership within the group.

This scenario shows health ownership as a shared, distributed concept within a care community. It raises important questions about the interaction between collective and individual care, illustrating how types of ownership can reinforce one another while also highlighting moments when it becomes necessary to redistribute ownership temporarily to new actors, such as healthcare professionals, to address evolving health needs.

### 3.3.3 Ethical reflection

The care community illustrates that health ownership is ethically relational rather than purely individual. While the community successfully strengthens capabilities such as affiliation, mutual care, and social support, it lacks the institutional capabilities and opportunities necessary for specialized diagnosis and treatment. Health

ownership therefore requires collaboration between citizens and professional healthcare institutions rather than replacing one with the other.

The scenario also illustrates that responsibilities should be allocated according to capability and opportunity. Community members can reasonably be expected to provide social support, practical assistance, and collective care. However, society, through its duty of care, remains responsible for ensuring access to specialized diagnostics and treatment. Individuals cannot be expected to take ownership of domains in which they lack the necessary capabilities and opportunities. Therefore, while health ownership may be shared, it should not be shifted to individuals beyond the limits of what they can reasonably influence or provide.

### 3.4.1 Scenario 3: Mrs. Rahimi's palliative care hotel

It is the year 2050. Mrs. Rahimi, a 75-year-old woman with metastatic lung cancer, has reached the end of her disease trajectory. After rounds of systemic anticancer treatment, pain management, and oxygen support, the illness now governs her body. While her physical condition deteriorates, her mind remains clear and alert—a dissonance that leaves her feeling trapped. She finds this phase of life deeply disorienting and devoid of meaning, starkly contrasting with the independent, self-reliant person she once was. She lives alone in a high-rise apartment in a dense urban area, her only daughter residing several hours away, in a different part of the country. Her friends are mostly gone, her community fragmented.

Mrs. Rahimi prefers not to burden her daughter or her care team. When asked about dying, she expresses a wish for comfort and deep sleep. She declines euthanasia—not out of fear, but to spare her doctor and daughter the emotional burden. Instead, she opts for palliative sedation: a medically and emotionally considered shared decision. Her pulmonologist informs her that a room is available in a local “Dying Without Suffering” hotel, where if her complaints would become refractory, palliative sedation is carried out safely, painlessly, and according to strict protocol. He expects that in short time she will meet the clinical criteria for sedation. Her daughter accompanies her to the hotel. Though she supports her mother's choice, she is overwhelmed by guilt.

At the hotel, Mrs. Rahimi and her daughter are welcomed by a gentle coordinator. During a brief intake with a nurse, physician, and a counsellor she is asked not only about symptoms but also about her emotional and spiritual needs. Initially hesitant, she quietly asks for someone to sit and pray with her—something that connects her to her youth, her mother, her identity. A caregiver who speaks her native language is called. She softens; she feels seen. Mrs. Rahimi and her daughter sit together, holding hands. They do not say everything—they never have—but what is exchanged in glances, silence, and touch fills the room. Then, Mrs. Rahimi is guided to her bed, where sedation begins.

Her biological values are monitored by a nurse on the ward, who oversees ten patients simultaneously under palliative sedation. The DWS doctor is available for consultation, if needed. After a few hours, Mrs. Rahimi shows slight signs of restlessness, and the nurse administers additional medication. Her daughter receives updates through a sleek and personalized app that is efficient, but sterile. The app updates her on respiratory rate, sedation levels, and estimated time to death—but not on the touch of her mother's skin, or the brief flicker of consciousness that might still be there. She feels helpless, reduced to a passive observer in a process she longs to be part of more intimately.

According to the protocol, if a patient is still alive after 24 hours, the dosage is doubled every four hours. Mrs. Rahimi dies peacefully, 30 hours after sedation begins. Her daughter receives a notification: “Your mother has died at 13:42. We offer our condolences.” The message feels both immediate and surreal. The app now shifts into bereavement mode, offering AI-generated support, digital remembrance options, and suggestions for grief counselling.

### 3.4.2 Health Ownership in scenario of Mrs. Rahimi

This story explores health ownership in the context of the end of life. Taking ownership of one's health can influence not only efforts to extend life, cure diseases, or manage chronic conditions, but also decisions to bring life to a desired conclusion. In this scenario, the temporal dimension of health influence is defined by the moment Mrs. Rahimi chooses palliative sedation until her death. During this period, she actively takes ownership of her health to guide it toward death on her own terms, while gradually distributing more and more control to the palliative care facility she selects. The facility assumes responsibility for managing her health, ensuring her wishes are respected until her passing.

In terms of Capability, Mrs. Rahimi's decision is driven by her health status—her terminal cancer and the unbearable physical suffering it causes—combined with her alert and lively mind. Her ability to exercise health ownership is supported by her contextual opportunities, particularly her economic means, which allow her access to the palliative hotel. The hotel aligns with her social and cultural context, providing care in her native language and accommodating her practices, such as praying with her daughter. This environment enables her to maintain connections to her identity, her youth, and her family, while navigating the final stages of her life.

As to Motivation, Mrs. Rahimi takes agency by exploring her options for her health, ultimately choosing the “Dying Without Suffering” hotel. Her decision is shaped by her emotions, including the distress of her present condition and her protective feelings toward her daughter, which lead her to limit the involvement of both her daughter and her general practitioner in her final care. By entrusting the responsibility for her death to the facility, she achieves her goal of a dignified, controlled end-of-life experience, although this paradoxically results in her daughter losing direct personal contact with her during her final days.

### 3.4.3 Ethical reflection

The scenario of Mrs. Rahimi illustrates that health ownership is not solely about improving medical health or prolonging life. It can also be exercised to enhance quality of life, even when this involves making decisions about the timing and manner of one's death. Mrs. Rahimi exercises ownership by choosing the circumstances under which she wishes to die. However, the scenario also illustrates that health ownership often is relational – it extends beyond the individual. Her daughter's opportunities to participate in the dying process become constrained, raising ethical questions about balancing individual autonomy with relational responsibilities. Health ownership therefore concerns the capabilities of multiple actors simultaneously. This case demonstrates that health ownership involves balancing individual autonomy with relational responsibilities. While Mrs. Rahimi has the capability to shape the circumstances of her dying process, healthcare professionals and family members also carry responsibilities. Justice requires attention not only to the patient's opportunities for self-determination but also to the provided opportunities of significant others to participate meaningfully in care and farewell.

## 4. Discussion

### 4.1 Health Ownership definition and attributes

Health ownership, understood as the *realistic momentary (in)abilities to influence one's own or others' health*, played a central role across all scenarios. Each scenario highlighted different situations in which health ownership played a major part. In Diana's scenario, the changing role of data in her life pushed her to reconsider her position towards her health ownership. For Diederik, the tension between the individual and collective community health ownership necessitated defining guidelines for disturbed health ownership by involving care professionals. In Mrs. Rahimi's scenario, her desire for a death that imposed no social burden on her daughter led her to exercise a strict individual health ownership that ultimately overrode her daughter's relational needs.

The two defining attributes of health ownership, its temporal and distributed nature, proved fundamental across all scenarios. Each scenario demonstrated that health ownership is dynamic, changing both over time and in the individuals who hold or share influence over health. Applying the COM-B framework to these narratives revealed a consistent set of attributes. Capability was shaped by health status, such as the onset of illness and its anticipated effects on daily life, and by health literacy (the knowledge and skills necessary to understand and act upon one's health). Opportunity encompassed the contextual environment that influences health ownership, including social factors (as seen in Diana and Diederik's cases), cultural factors (as evident in the experiences of Mrs. Rahimi and Daria), economic factors (which shaped care-access and -control in the cases of Mrs. Rahimi and Diederik). Opportunity also extended to the physical conditions of the care context including care instruments, itself, whether a hospital (Diana), a community setting (Diederik), or a commercial care enterprise (Mrs. Rahimi). Motivation, the third COM-B category, was expressed through affect and agency. Affect encompassed emotional responses, such as Diana's changed emotional stance to her health data, the social emotional disturbances within Diederik's community, and Mrs. Rahimi's anticipation of burdening her daughter. Agency of health ownership reflected deliberate actions to change control over health, including Mrs. Rahimi's decision to choose for her palliative care hotel, the individual care decisions made within Diederik's community, and the loss of health agency experienced by Diana after her illness.

With respect to the ethical implications, the scenarios demonstrated that changes in health ownership cannot be attributed solely to the actions of an individual. Changes in a person's health status may motivate a redistribution of health ownership to others, such as healthcare professionals, as illustrated in the cases of Diana, Diederik, and Mrs. Rahimi. However, health ownership is not determined by motivation alone. The ability to influence health depends on the interplay of an individual's capabilities, opportunities, and motivations, as well as the capabilities and opportunities available within their environment. Therefore, individuals cannot be held fully accountable for their own health.

This perspective positions health as a fundamentally relational phenomenon. Environmental conditions, social structures, and available resources all contribute to an individual's capacity to influence health and therefore share in the responsibility for health outcomes. Moreover, because health ownership is often distributed across multiple actors, responsibilities may also exist between co-owners of health. Individuals, informal caregivers, healthcare professionals, and others who exercise influence over health may therefore bear shared but differentiated responsibilities that reflect their respective roles, capacities, and opportunities for action. Importantly, distributed health ownership is not merely a distribution of influence but also a relationship between those who share that influence. When health ownership is shared, the individuals involved acquire ethical responsibilities toward one another. Health ownership is therefore not only distributed but also *mutual*: sharing ownership of health requires those involved to ethically relate to one another and to recognize their interdependence in shaping health outcomes. Thus, an important implication of Health Ownership is that responsibility for health is relational and distributed and cannot be attributed to the individual alone.

Taken together, these scenarios lead to the following definition of Health Ownership:

*One's realistic momentary (in)abilities to influence one's own or others' health.*

*These (in)abilities are dependent on 1) one's agency and affect, 2) one's health-status and -literacy and 3) one's social-, cultural-, economic- and care-context.*

## 4.2 Positioning Health Ownership to related psychological concepts

The concept of Health Ownership is rooted in the person-centred and holistic perspective of Positive Health (van Vliet et al, 2024) in which a person's capacity to influence health is considered more important than health status itself. By combining the COM-B model of behaviour change with Nussbaum's Capability Approach, Health Ownership captures the extent to which individuals can realistically and responsibly influence their own health or the health of others. Several established psychological concepts are closely related to Health Ownership. However, none of these concepts fully captures the dynamic, contextual, and distributed nature of health influence that Health Ownership seeks to describe. Examining these relationships clarifies both the theoretical foundation and the distinctive contribution of the concept.

The notion of influence is central to Health Ownership and is closely related to Health Locus of Control (Rotter, 1966). Health locus of control refers to the extent to which people believe that their health is determined by their own actions or by external factors such as chance, fate, or powerful others. Individuals with an internal health locus of control are more likely to believe that they can influence their health themselves, whereas those with an external health locus of control are more likely to attribute influence to healthcare professionals or other external actors. From a Health Ownership perspective, health locus of control primarily influences the motivational component of health influence. Diana's case illustrates how the progression of illness may shift a person's perceived influence from self to specialist care, thereby redistributing Health Ownership. However, whereas health locus of control concerns a person's beliefs about influence, Health Ownership additionally considers whether influence is realistically possible given a person's capabilities and opportunities.

Health Ownership is also related to self-efficacy (Bandura, 2010), defined as people's beliefs in their ability to perform actions that influence events affecting their lives. Individuals with high self-efficacy are generally more willing to influence their health. Self-efficacy develops through knowledge, skills and previous experiences. For example, someone who knows how to treat a minor burn and has done so successfully in the past will typically have greater confidence in managing a similar situation again. In contrast, individuals confronted with a life-changing diagnosis often lack the experience required to feel capable of managing the condition independently. Diederik's diagnosis illustrates how limited self-efficacy may result in transferring influence to healthcare professionals or specialist institutions. While self-efficacy concerns perceived capability, Health Ownership incorporates both perceived and actual capabilities, as well as the opportunities available to act on them.

The motivational dimension of Health Ownership is further connected to Self-Determination Theory (Deci & Ryan, 2008), which proposes that motivation depends on the fulfilment of the psychological needs for autonomy, competence, and relatedness. All three needs can be recognized in the scenarios. Mrs. Rahimi's decisions are strongly shaped by her desire for autonomy. Diana's active engagement in managing her health reflects a need for competence. Relatedness is evident both in the support provided by Diederik's care community and in the involvement of Mrs. Rahimi's daughter. The degree to which these needs are fulfilled influences an individual's willingness to exercise Health Ownership. Nevertheless, Health Ownership extends beyond motivation by acknowledging that even highly motivated individuals may lack the capabilities or opportunities required to influence health effectively.

Finally, Health Ownership relates to the Common-Sense Model of Self-Regulation (Leventhal, Phillips, & Burns, 2016), which explains how individuals perceive, interpret, and respond to health threats and illness. People's subjective understanding of a health condition strongly influences how they cope with it and what actions they undertake. The ability to recognize a health problem, evaluate its significance, and determine an appropriate response depends on these illness representations. Diederik's case demonstrates how different interpretations of skin cancer diagnosis can result in different coping strategies and patterns of support. The Common-Sense

Model helps explain how individuals understand health changes, whereas Health Ownership focuses on the broader question of whether individuals and others can influence the resulting health trajectory.

Taken together, these theories illuminate complementary aspects of Health Ownership. Health locus of control helps explain how individuals perceive the sources of influence over their health, self-efficacy captures confidence in exercising that influence, Self-Determination Theory clarifies the motivational processes that drive health-related action, and the Common-Sense Model explains how individuals interpret and respond to changes in health. Combined, these concepts help explain why people differ in their willingness and ability to influence health, as well as why health ownership may change across situations and over time. Health Ownership brings these perspectives together within a broader framework that considers not only beliefs, motivations, and perceptions, but also a person's health status, health literacy, capabilities, opportunities, and social context. In doing so, it provides an integrative understanding of the realistic and momentary capacity to influence health, whether exercised individually or shared with others.

### 4.3 Ethical implications of Health Ownership

From a capability perspective, several ethical implications follow for how Health Ownership should be understood and applied. These implications concern justice, responsibility, relationality, and the obligations of healthcare systems.

#### *Health Ownership and justice*

From a capability perspective, Health Ownership should be evaluated according to the real opportunities individuals possess to influence their health rather than according to health outcomes alone. People living with poverty, disability, discrimination, or chronic illness may possess substantially fewer opportunities for health ownership despite equal motivation.

#### *Health Ownership is not health responsibility*

Health ownership should not be interpreted as transferring responsibility for health from healthcare systems to individual citizens. Such an interpretation risks blaming people for circumstances largely beyond their control. Instead, ownership describes the capability to influence health, a capability that healthcare systems and society have an ethical obligation to support.

#### *Distributed ownership as shared responsibility*

The distributed nature of health ownership reflects the fundamentally relational character of human life. Throughout the life course, individuals live in relationships of mutual dependence and solidarity, relying on others to develop, maintain, and restore their capabilities. Consequently, health ownership should be understood as a shared responsibility to create the conditions for a dignified human life. This responsibility is distributed across individuals, communities, healthcare professionals, and public institutions, each contributing according to their capabilities and opportunities, rather than being reduced to a matter of isolated autonomy.

#### *Proportional responsibility*

A central ethical challenge of Health Ownership concerns the distribution of responsibility between individuals and society. If ownership is interpreted as a purely individual responsibility, it risks reinforcing victim-blaming and overlooking structural determinants of health. Conversely, if ownership is attributed entirely to healthcare systems or governments, individual agency may be neglected, potentially discouraging people from taking an active role in maintaining and improving their health and placing avoidable pressure on healthcare services. We therefore propose a principle of proportional responsibility. The degree of responsibility that can reasonably be expected from individuals should be proportional to their capabilities and opportunities to influence health, including their capability to develop new competencies over time. Where individuals possess sufficient health literacy, resources, social support, and physical capabilities, active engagement in health management may reasonably be expected. This may include efforts to strengthen their own capabilities, for example by learning

how to care for themselves and others more effectively. Where such opportunities are restricted by illness, disability, poverty, discrimination, or other structural disadvantages, responsibilities increasingly shift towards healthcare organizations, communities, and public institutions. Health ownership should therefore not be understood as a fixed allocation of irresponsibility but as a dynamic distribution of responsibilities that change across situations and across the life course.

#### *Responsibilities of healthcare systems*

If health ownership is considered a capability, healthcare organizations have an ethical obligation to create environments that expand people's opportunities to exercise influence over their health. This includes improving health literacy, supporting shared decision-making, reducing socioeconomic barriers, and recognizing relational forms of care.

### 4.4 Expected effects of Health Ownership

The potential value of Health Ownership lies not in maximizing individual ownership, but in achieving an appropriate alignment between a person's realistic, including future, possibilities to influence health and the distribution of influence, action, and shared responsibility. Importantly, Health Ownership should not be equated with maximizing health. A person who chooses to go to the gym and a person who knowingly chooses to smoke may both display Health Ownership, provided these choices genuinely reflect their own agency and are not primarily the result of manipulation, addiction, or other limiting influences. The concept therefore concerns ownership over health-related influence and decision-making, not the moral or medical desirability of the choices themselves.

Depending on the situation, increasing Health Ownership may involve strengthening an individual's possibilities to influence health, sharing influence with others, or shifting action towards healthcare professionals, organizations, communities, or wider societal systems. When individuals have sufficient capability, opportunity, and motivation to influence their health, Health Ownership may support the translation of these possibilities into health-related action. Depending on a person's health situation and goals, this may include managing health conditions, engaging in health-promoting behaviours, such as physical activity or healthy eating, a positive attitude and adherence to treatment and participating actively in health decisions.

Conversely, when capability or opportunity is constrained, increasing motivation alone is unlikely to result in sustainable health-related action. In such situations, Health Ownership may help identify what needs to change to increase a person's realistic possibilities for influence, for example, through improving health literacy or skills, providing social or professional support, or modifying environmental or institutional conditions. Where important determinants of health lie partly or entirely outside the individual's sphere of influence, meaningful action is required from supporting actors, including informal and formal caregivers. Thus, Health Ownership may contribute to a better alignment between the locus of influence and the locus of action and responsibility. Rather than assuming that health-related action is primarily an individual responsibility, the concept directs attention to where meaningful possibilities for change actually reside. This may support more appropriately targeted interventions, ranging from individual behaviour change and self-management support to changes in healthcare systems.

This may also be particularly relevant to shared care and shared decision-making. Explicitly discussing and learning to act according to Health Ownership may help patients, informal caregivers, and healthcare professionals clarify expectations about who are able to influence which aspects of health, what can reasonably be expected from each actor, where support is needed, and how roles and responsibilities should be distributed. This may facilitate expectation management in both formal and informal care. When individuals have sufficient possibilities for influence, this may support autonomy and active participation in care.

Conversely, recognizing constrained Health Ownership may facilitate the timely sharing or redistribution of influence towards informal caregivers, healthcare professionals, or other actors. Ultimately, because Health Ownership is dynamic, the appropriate locus of influence, action, and responsibility may change over time as a person's capabilities, opportunities, motivation, health status, and context change. Health Ownership may thus help align what is expected from individuals and others with what they can realistically influence at a given point in time.

#### 4.5 Applications, Limitations and Future research

Health Ownership may provide a useful framework for reflecting on how influence over health is distributed in practice. Rather than focusing exclusively on what individuals should do to manage their health, it encourages people, patients, informal caregivers, healthcare professionals, organizations, and policymakers to consider who can realistically influence which aspects of health, under what conditions, and at what point in time. This perspective may be particularly relevant when expectations regarding self-management, informal care, and professional support need to be negotiated or reconsidered.

Closely related to responsibility is the concept of trust. Individuals are more likely to assume responsibility for their health when they trust their own capabilities, the information available to them, and the healthcare professionals and institutions that support them. Conversely, healthcare professionals may be more willing to share decision-making and transfer aspects of health ownership to patients when they trust patients' capacities for self-management. Ownership may therefore strengthen responsibility through trust, while trust simultaneously facilitates the process that develops through interaction between individuals, communities, and healthcare systems. Future research could further explore how ownership, responsibility, and trust mutually reinforce one another, how they can be aligned across various actors involved in health journeys and care pathways, and how such alignment can contribute to sustainable health behaviour and effective healthcare.

A strength of the present work is that the concept of Health Ownership emerged from an iterative process of expert discussion and consensus within the interdisciplinary '*Your Own Health?*' consortium. The consortium brings together expertise from psychology, medicine, design, philosophy and ethics, and technology, complemented by the perspectives and methods of artists. This interdisciplinary approach enabled Health Ownership to be examined from behavioural, clinical, ethical, technological, and experiential perspectives. The development and refinement of the concept therefore reflect a collaborative process integrating multiple disciplinary perspectives rather than being grounded in a single theoretical or professional tradition. Such an interdisciplinary approach is particularly relevant to a concept such as Health Ownership, which concerns not only individual behaviour and health, but also relationships, healthcare practices, technological developments, ethical considerations, and the broader social and structural conditions that shape people's possibilities to influence health.

At the same time, several limitations should be considered. Health Ownership is a newly proposed concept, and its definition, attributes, and expected effects have not yet been empirically validated. The speculative scenarios used in this paper were developed to explore, illustrate, and refine the concept across different health contexts; they cannot establish whether Health Ownership predicts health-related behaviour, treatment adherence, self-management, participation in healthcare decisions, or other outcomes. Moreover, although the scenarios were deliberately constructed to represent different contexts and distributions of Health Ownership, they cannot capture the full diversity of health conditions, social circumstances, cultures, and healthcare systems in which Health Ownership may operate. Further conceptual and empirical work is also needed to establish how Health Ownership can be distinguished from related constructs and whether it provides explanatory or practical value beyond these existing concepts.

Future research should examine the conceptual and empirical validity of Health Ownership, including whether its temporal and distributed nature can be observed and assessed in practice. Studies across different health and care contexts are needed to explore how Health Ownership develops and changes over time, how it is negotiated between different actors, and whether it contributes to health-related action, expectation management, and the appropriate distribution of roles and responsibilities. Importantly, future research should focus not on maximizing Health Ownership, but on understanding what constitutes appropriate Health Ownership in different situations, including when Health Ownership should be strengthened, shared, or transferred.

Moreover, future research should investigate how the concept of Health Ownership can be translated into practice, particularly through the design and evaluation of interventions and tools that support appropriate Health Ownership in different contexts. This includes examining how products, services and environments can be designed to strengthen Health Ownership where appropriate. For example, research could explore how social media can be designed to support Health Ownership (cf. Daria's scenario), how care communities can be organized to facilitate a realistic distribution of Health Ownership among different actors (cf. Diederik's scenario), and how discussions about Health Ownership can be incorporated into palliative care to align emotional relationships (cf. Mrs Rahimi's scenario). Similar questions arise in the design of care products and therapies: can these be designed in ways that support a patient's Health Ownership? Health Ownership could also be investigated as a tool to improve shared decision-making processes by making explicit who can take ownership of which aspects of health and for what period of time. Finally, future research could examine how children, adults, caregivers, and health professionals can be supported in understanding and applying Health Ownership, both in relation to their own health and in supporting the Health Ownership of others.

## 5. Conclusion

Positive Health has shifted thinking about health from the absence of disease towards people's ability to adapt and self-manage. However, this person-centred perspective provides limited guidance on what people can realistically influence in relation to their health, how these possibilities are shaped by individual and contextual conditions, and how influence over health may be shared with others. In this paper, we introduced Health Ownership to address this gap, defined as one's realistic, momentary (in)abilities to influence one's own or others' health. Drawing on the Capability Approach and COM-B, and exploring the concept through three speculative scenarios, we propose that Health Ownership is inherently dynamic and distributed: possibilities for influencing health may change over time and may reside with individuals, informal caregivers, healthcare professionals, communities, organizations, or wider societal systems.

Health Ownership therefore does not imply that individuals should have greater control over their health or bear greater responsibility for it. Rather, its value lies in clarifying when health can realistically be influenced, by whom, and under which conditions. This provides a basis for considering what constitutes appropriate Health Ownership in a given situation, including when influence should be strengthened, shared, or transferred. Ultimately, Health Ownership highlights that the ability to influence health is fundamentally relational: our realistic possibilities to influence our own or others' health are shaped by context and shared with others.

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