

ERC Starting Grant 2023 Research Proposal [Part B1]

ETHME: The Ethics of Mortality Measurement

Cover Page:

- Name of the principal investigator (PI): **Carl Tollef Solberg**
- Name of the PI's host institution for the project: **University of Oslo (Norway)**
- Proposal duration in months: **60 months**

There are around 55 million deaths in the world each year. How should we evaluate these deaths?

Diseases and injuries give rise to both morbidity and mortality. Until the 1950s, epidemiologists were concerned with counting the number of deaths. Since then, evaluative measures concerned with the disvalue of death have grown. In parallel, there has been a debate in analytic philosophy since the 1970s that concerns whether death can harm those who die. The philosophers in this latter debate have not focused on deaths at a population level.

In all societies, the demand for health care exceeds the available resources. However, to prioritize scarce resources in a consistent and meaningful manner, we need reliable health measurements to begin with. In society, we use considerable resources to prevent deaths, and the majority of the global disease burden springs from mortality rather than morbidity. Thus, it is remarkable that so few resources are used to provide theoretically robust death measurements. People's attitudes toward death are naturally ambivalent. On the one hand, death is the worst thing that can happen to us. On the other hand, death is nothing to us. Sophisticated methods have been developed to measure morbidity. Such work remains for mortality.

There have been almost no cross-fertilizations between epidemiology and philosophy regarding mortality measurement. Accordingly, ETHME announces the ethics of mortality measurement as a novel and developing field within the philosophy of epidemiology. The core objectives of ETHME are to (a) develop and refine the understanding of the nature of the harm of death, (b) reconcile the evaluation of deaths in summary measures of population health with the most promising accounts of the harm of death, and (c) develop a theoretical grounding for evaluating procreation in future individuals. One work package will be devoted to each objective (WP1–WP3).

ETHME brings together the domains of philosophy and medicine in general and the domains of the badness of death discourse (analytic philosophy) and theoretical debates within epidemiology, in particular. I have been advised to submit ETHME to the panel SH5 (Cultures and Cultural Production) by prof. Jan Helge Solbakk (ERC advanced grant holder ((MORE))). Foundational normative research regarding the nature of harm in death is applied in this project. Thus, the most important thing is that the panel is generally familiar with analytical philosophy. Ideally, the panel should also be familiar with the badness of death debate, which is the main focus of ETHME. There is also considerable focus on summary measures of population health in ETHME. Alternatively, relevant panels could be LS7-15 (Medical Ethics), SH4-13: Philosophy of Science, SH5-12: Ethics, or SH5-11: Metaphysics.

The overarching aim of ETHME is to announce the ethics of mortality measurement as a novel and developing field within the philosophy of epidemiology.

Section a: Extended Synopsis of the Scientific Proposal

Ambition and Expected Results: This project concerns how deaths should be evaluated. To date, there has been little cross-fertilization between philosophy and epidemiology. The project will launch the ethics of mortality measurement as a fundamental research area in the philosophy of epidemiology (1). With **ETHME**, I seek to contribute to the transparency of summary measures of population health. This work also suggests original classificatory models and relevant taxonomy for degrees of how evaluative or descriptive different mortality measures are. A further novel result expected of **ETHME** is simply the development of an ethics of mortality measurement, which includes deliberation on choices and rationales about the scope, construction, and application of specific mortality measures. **ETHME** is also intended to develop sound models for evaluating future individuals through the lens of deliberation about the nature of harm in death and for potentiality regarding models for life years. Moreover, with **ETHME**, I expect to create a Medici effect in the form of a new theoretical innovation where the disciplines and ideas in question undergo friction and interconnect. I expect **ETHME** to have a profound impact on theoretical developments of the philosophical discourse on the nature of the harm of death (WP1) for the reconciliation of philosophical accounts of death and summary measures of population health (WP2) as well as for pioneering the modeling of measures for future individuals (WP3).

State of the Art: Resource scarcity necessitates priority setting in health. Sound priority setting relies on reliable health measurement to identify which interventions should be made first. Deaths are a vital component of health measurements. There are approximately 55 million deaths in the world each year. How should these deaths be evaluated? Historically, epidemiology has been chiefly concerned with mortality in a population determined by descriptive measures such as crude or age-specific death rates (2). The initial descriptive mortality measures are simple, transparent, and inherently universal. Moreover, descriptive mortality measures do not reflect that individuals' deaths are postponed rather than prevented, and they cannot state whether some deaths are worse than others. In the mid-20th century, more nuanced measures such as potential years of life lost (PYLLs) and years of life lost (YLLs) were developed (3). These latter measures are evaluative because they indicate that some deaths are worse than others. These more refined evaluative mortality measures rely on value assumptions such as ideas about a natural life span and are thereby deemed controversial. No mortality measure serves equally well for all purposes, and all mortality measures have their shortcomings.

For monitoring and priority setting, the ability to aggregate morbidity and mortality is necessary, and summary measures respond to this need. Quality-adjusted life years (QALYs) and disability-adjusted life years (DALYs) are the most used summary measures. Both the QALY and the DALY integrate (dis)quality of life and mortality into a single measure (4). Health economists developed QALYs based on expected utility theory, and the QALY measure matured in the late 1970s and early 1980s. Scholars determine the value of different health states by asking a representative sample of people about their own health or the health of others. In the QALY model, full health is worth 1 by convention. Values typically range from 1 to 0 but can also include negative values for health states worse than death (5,6). The numbers of the quality of a state are referred to as utility weights. Methods such as time trade-off (TTO), person trade-off (PTO), and standard gamble (SG) are the benchmarks used to establish these utility weights. QALYs can be used in cost-utility analyses to estimate the cost per QALY per intervention. For instance, the National Institute for Health Care Excellence (NICE) in the United Kingdom has implemented the QALY model in this manner (7). QALYs are also used in Australia and many European countries such as Sweden and the Netherlands.

Disability-adjusted life years (DALYs) were developed in the early 1990s as an integral part of the Global Burden of Disease (GBD) study. GBD scholars constructed the DALY model for two reasons: first, to quantify the burden of disease, and second, to set priorities in health (3). On the DALY scale, 1 represents full disability (equivalent to death), whereas 0 represents no disability (4). One can calculate DALYs as the sum of years of life lost (YLL) relative to some ideal longevity due to mortality in the population and the years lived with disability (YLD) for people living with bad health conditions (3,8,9).

Considerable work has gone into the morbidity component of QALYs and DALYs, including the development of sophisticated methods to establish disability weights for different diseases and injuries to compare these different conditions for monitoring and priority-setting purposes (4–6,10–12). Systematically asking representative samples of the general population which of two bad health conditions they would prefer

is also a way to ascribe some legitimacy to the measures in question. Moreover, the value assumptions behind both the QALY and DALY models, especially their morbidity components, have been debated (e.g., (11–20)). In contrast, there has been much less concern about value assumptions in the mortality component.

In parallel, a specific discourse has evolved within analytic philosophy since the 1970s regarding the badness of death. The main concern with this philosophical debate is to provide an adequate answer to whether death is bad for the individual who dies (21). Death here refers to the incidence of death rather than the process of dying. While any death can be bad for others, such as family, friends, and society, the question here is whether death can be bad for the individual who dies. Epicureanism promotes the view that death cannot be bad for the individual who dies. We cannot experience anything while being dead; nothing can be bad for the nonexistent; and our prenatal nonexistence is not bad for us; thus, death (posthumous nonexistence) should not be bad either (22). A majority of philosophers involved in the debate hold the opposite view, *anti-epicureanism*: that death is, in fact, bad for the one who dies. The leading anti-epicurean view is deprivationism, which is the view that death is bad for the individual who dies because of the loss of the life that a person counterfactually could have had had they not died (21,23–25). Sophisticated accounts have been developed to answer the question of when the worst time to die is (24). Furthermore, deliberations have been held in population ethics over relevant symmetries and asymmetries between the philosophy of the harm of death and the challenges of harm and benefit for future individuals (26,27).

Knowledge Needs: Why is it necessary to enhance the public and academic discourse on the evaluation of deaths? This question was actualized during the COVID-19 pandemic. Should COVID-19 immunization programs seek to measure reductions in deaths or those in life years lost (28,29)? In areas where young COVID-19 deaths are frequent, measuring death count over life years lost could potentially induce a massive difference in the ranking of priority groups for a scarce good.

Several underdeveloped normative issues are met on the path of enchaining the public and academic discourse on the evaluation of deaths. For mortality measures, these complications involve scope, construction, and application. Scope concerns what one chooses to measure and not to measure and what is unintentionally included and neglected due to the nature of the measure, such as the neglect of stillbirths. Construction concerns the value assumptions built into the mortality measures in question, such as using global life tables for DALYs (13–15). Application concerns the reasons for choosing measure *A* instead of *B* for purpose *X*. Together, these three dimensions, along with a set of other dimensions, constitute an ethics of mortality measurement.

Many illustrative examples of the relationship between theory and practice exist within the ethics of mortality measurement. For instance, DALYs and QALYs are almost always assumed to be applicable only from the moment of birth (30,31). Stillbirths are neglected, while neonatal deaths are evaluated as the worst deaths. Moreover, summary measures such as DALYs and QALYs are currently not designed to account for the value of procreation (e.g., in IVF) and harm to future individuals (e.g., in climate crisis; 32). One reason is that these summary measures are simply constructed in relation to currently existing individuals rather than future existing individuals.

For the YLL in the DALY, foundational questions, such as whether the youngest deaths should always be counted as the worst ones, remain unanswered. A complete anthology was recently dedicated to the philosophical dimensions of the Global Burden of Disease study (33). However, no chapter was devoted to discussing the value assumptions behind the mortality component of the DALY (Schroeder 2012). The foundational assumption of the DALY is that years lived with disability (YLD) can be aggregated with years of life lost (YLL), meaning that $YLDs + YLLs = DALYs$. Likewise, philosophers in the badness of death discourse have been surprisingly inattentive to the challenge of commensurability between morbidity and mortality. From the perspective of medicine, there is a clear advantage to summarizing morbidity and mortality in a meaningful way. There are many reasons for this need, with the most simple and obvious being that most diseases and injuries give rise to both morbidity and mortality. Therefore, when considering the disease burden or the value of preventing a particular disease or injury, it is usually necessary to simultaneously consider morbidity *and* mortality. It is, therefore, quite surprising that so few attempts have been made to connect the disvalue of the incident of death with the disvalue of disease burden from within life. This is one of the points in which I believe it is possible to advance the philosophical debate by further integrating it with theoretical epidemiology.

These and other knowledge needs require considerably more attention to be resolved. Thus, **ETHME** aims to announce the ethics of mortality measurement as a novel and developing field within the philosophy of epidemiology to answer these knowledge needs. Following this overarching aim, the three core objectives of **ETHME** are specified below.

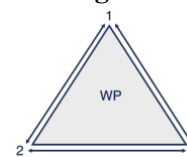
Objective 1: Develop and refine the understanding of the nature of harm in death.

Objective 2: Reconcile the evaluation of deaths in summary measures of population health with the most promising accounts of the harm of death.

Objective 3: Pioneer the development of sound models for evaluating procreation in future individuals.

One work package will be devoted to each of the three core objectives: **WP1**—understanding the nature of the harm in death, **WP2**—building theoretically robust summary measures, and **WP3**—evaluating future individuals. **WP1–WP3** stand in a dialectical relationship (see Figure 1).

Figure 1



Methodology

WP1: Understanding the Nature of Harm in Death

In WP1, the following research questions will be discussed:

- What is the nature of harm in death?
- What is the relationship between the badness of death for those who die and the badness of death for others?
- When is an incident of death bad for those who die (before, under, after, or at some indeterminate stage)?
- How is the badness of death related to age at death?
- Is it possible to coherently numerically measure the harm of death?

Contemporary philosophers have developed valuable insights about the harm of death on the individual level, and similarly, medical doctors and epidemiologists have undertaken substantial work on the disvalue of deaths at the population level. However, philosophers have been surprisingly inattentive to deaths at the population level (34), with a few notable exceptions (25,35). Likewise, foundational philosophical issues around the evaluation of death tend to be disregarded in the literature on population mortality, with a few notable exceptions (11). In **ETHME**, I hypothesize that there is potential for cross-fertilization and mutual exchanges between philosophical work on the individual level and epidemiological work on the population level. Essentially, there are three approaches: one is to scale up philosophical work on the individual level to the population level, another is to scale down epidemiological work on the population level to the individual level (34), and a third is to treat these levels separately.

WP1 seeks to answer several questions about the intersection between the philosophical and epidemiological work on this topic. One such question is whether life years are primarily lost for individuals or their surroundings. If epicureanism is true, morbidity reductions may be prioritized over mortality reductions. Likewise, epicureanism might challenge the commensurability (36) between YLD (morbidity) and YLL (mortality) in the DALY (30). Another such question is when the worst time to die is. According to the received view in both the epidemiological work, this time is right after birth. However, in the philosophical discourse, there are important challenges to this implication, which I will attempt to adjudicate between in this WP. A final question is whether life years lost are in full health or some reduced health state. In WP1, we will work further on these critical issues.

WP2: Building Theoretically Robust Summary Measures

In WP2, the following research questions will be discussed:

- What is the relationship between death at the individual level and deaths at the population level?
- When someone dies, should we account for the loss of only healthy or also unhealthy life years?
- To what degree can and should measures of morbidity and mortality be commensurable?
- Should stillbirths be disvalued in mortality measurements?
- In which contexts should policymakers rely on the number of deaths, and when should they also rely on evaluations of the disvalue of deaths?

Measures of good life years, such as QALYs, and measures of disease burden, such as DALYs, either explicitly (DALYs) or through their actual use (QALYs) depend on the ability to quantify the disvalue of death. This

dependency is highly problematic and remains an issue of widespread debate without consensus or any unifying solution. In **ETHME**, the assumption will not be that a unifying solution exists but instead that death may (morally, economically, and axiologically) mean different things in different contexts and accordingly require several mortality measures. Thus, we need to apply insights from philosophical work on the harm of death for individuals in the appropriate contexts. Expanding on some questions raised in WP1 and WP2, we will adapt and operationalize the most useful and sound insights on the harm of death relating to mortality measurement. These reflections yield the following hypothesis for WP2: improved taxonomy of mortality measures of the disvalue of death will enable policymakers and the public to better understand the values underlying different measures and their strengths and weaknesses. This will contribute to the main aim of **ETHME** by facilitating a better understanding of when inaccurate but efficient measures are the better option and when a comprehensive but costly measure is worth pursuing. Conceivably, several countries might have led an (overall) better pandemic response had they continually reassessed the possibility of substituting maximizing health for minimizing deaths.

WP3: Evaluating Procreation in Future Individuals

In WP3, the following research questions will be discussed:

- What is the theoretical relationship between the prenatal nonexistence (of future individuals) and posthumous nonexistence (death)?
- Does measuring the value of procreation make sense at all?
- Should the value of procreation be considered in a cost-utility analysis of in vitro fertilization?

Priority setting in healthcare requires that we ascertain which interventions are most cost-effective (37). Considerable work has already been conducted on the ethical foundations for determining the value of additional life years with or without disability (38). Nevertheless, it is unclear whether these priority-setting tools are applicable in the case of future individuals who have not yet come into existence (27). These matters are even more pressing given the current trend toward lower fertility rates and higher reliance on medical interventions as nations try to maintain an economically and demographically stable population (39).

At first glance, one might understandably see the inclusion of nonexistent people in summary measures as an abstract thought experiment. However, a cost-effectiveness analysis of fertility treatments might prove otherwise. To complete a cost-effectiveness analysis of *in vitro fertilization* (IVF), for instance, some foundational questions need to be answered, including the following: Is the purpose of IVF to cure biological infertility, to cure unwanted childlessness, or to generate new QALYs? Alternatively, is the purpose some combination of the three? IVF is especially challenging because it is not clear whether the patient is the person being treated or the future individual who is conceived (40). We may get very different CEA results depending on how we answer these two questions. The creation of a new individual determines the success of IVF. Therefore, one could ask whether the QALYs generated through IVF treatment belong to the woman who becomes pregnant, to the child, or both.

Given that the process of IVF entails placing several embryos in the womb, every round of IVF holds the potential of 80 x 2 (or more) life years. If only one of the eggs is brought to term, the IVF is still deemed successful, and approximately 80 life years could be gained. However, if the other embryos are not brought to term, 80 x 1 (or more) potential life years are lost. This scenario demonstrates that the current tools for summary measures of health require closer examination if they are to be applied to future individuals.

Methods of reasoning

ETHME will include reflective equilibrium (41–43). This is arguably the most popular method of moral and political reasoning (44), with some arguing that it is the only ‘defensible’ method (45). It involves seeking coherence between sets of moral judgments (intuitions), moral principles, and background theories by applying them to cases and “the broadest evidence and critical scrutiny” (43). When well-considered judgments and principles are appropriately balanced, they form a reflective equilibrium. This project will employ several types of reasoning. One will be syllogisms, which are logical arguments wherein deductive reasoning is applied to reach conclusions (41–43). I will also use arguments from analogy, which is an inductive type of argument, to explore similarities between two systems to conclude that some further similarity exists (46). While these methods are conventional within ordinary analytic philosophical discourse, their application to analyzing mortality measures in population health is novel. A further method I will employ to study the nature of harm in death is the active use of metaphors. This technique will elicit reflections, creative thinking, and information that cannot be discovered using analogies and formal logic alone (47).

Feasibility of the Scientific Approach

ETHME is a high-risk, high-gain project. The risk is high because this project is strongly theoretically focused on a few selected methods and with death as a foundational theoretical topic with a high degree of complexity. As proof of this field's richness, I have conducted productive research on the harm of death for over 10 years. My MA, PhD, and postdoc can be viewed as precursors of **ETHME**. However, this is not to say that **ETHME** is a continuation of my postdoc. Instead, it involves a selection of the most critical research gaps across knowledge fields that I have identified throughout my research career. These also include challenges that MA and PhD candidates have been able to identify under my supervision. In addition, significant contributions have been made by collaborating colleagues and leading scholars associated with the anthology *Saving People from the Harm of Death* (32). This field has become so rich that it is time to launch **ETHME** as part of the philosophy of epidemiology.

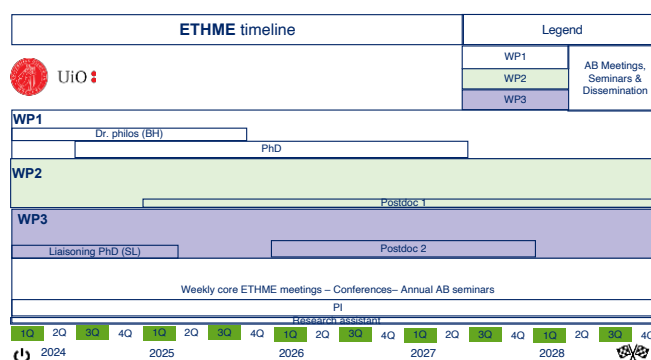
Importantly, **ETHME** is not a project that simply applies philosophical methods to another field (in this case, epidemiology). Instead, the ambition of cross-fertilization between philosophy and epidemiology concerning death is integrative. I believe that the badness of death discourse (1970–) would benefit from confrontation with the challenges with which epidemiology grapples. Such challenges include the need for commensurability across morbidity and mortality, the relationship between death at an individual level and death at a population level, and whether death implies a loss of healthy life years or the loss of life years with suboptimal health. Moreover, across both philosophy and epidemiology, almost no stake has been claimed in how to deal with the harm of death for others. However, it is well known that the loss of a loved one can constitute an existential experience.

Principal Investigator and Project Group

CTS • Carl Tollef Solberg (b. 1988), MA, MD, PhD. As the principal investigator (PI), I (CTS) will lead **ETHME**. The Centre for Medical Ethics (CME) at UoO will be the host institution. The project participants will be organized within two circles.

Circle 1: Core Group: This group will meet biweekly and consist of the following members:

WP1: PhD candidate. 100%, three years (philosopher). **WP2: Postdoc 2.** 50%, four years (MD). **WP3: Postdoc 2.** 100%, two years (philosopher). **WP1–WP3: Research assistant.** 20%, five years. **CTS.** 75%, five years. **PI.** In addition, the following three persons will be affiliated (without additional funding): **BH • Bjørn Hol, MSc, MA. Dr. philos candidate** on WP1; **SL • Sofie Lekve, MA. PhD candidate** on WP3; and **PS • Preben Sørheim, MA, PhD candidate** on WP1 and WP2.



Circle 2: Advisory Board (AB): The AB will meet physically once per year throughout the five-year project period and consist of the following five leading philosophers and researchers: **RD • Professor Rakhi Dandona, PhD IHME (WP2); NE • Professor Nir Eyal, MA, PhD. Rutgers (WP2); JB • Professor John Broome, MA, MSc, PhD. Oxford (all WPs); OFN • Professor Ole F. Norheim, MD, PhD, Harvard (WP2); and JM • Jeff McMahan, PhD, Oxford (WP1 and WP3).**

Key Outputs

- Series of 12 high-quality original journal articles. The following persons will be responsible (first author) for the articles: Postdoc 1 (3), postdoc 2 (3), PI (3), and PhD candidate (3). Research group affiliates and AB members will be encouraged to coauthor articles.
- Monograph by PI launching the ethics of mortality measurement (contract in year one, full version in year four. Publication in year five).
- One edited volume by postdoc 2 and the PI; chapter contributions from the **ETHME** team members, visiting scholars, conference contributors, and the AB members.

Knowledge Transfer/Impact

- Policy briefs for all original articles for the academic community and professional organizations, conference contributions, and creation of a professional network.
- Articles in leading philosophy, medical, and bioethics journals.
- Articles in newspapers and other media engagement, such as radio programs and academic blogs.
- Website for a popular audience and a social media strategy through Twitter, Facebook, et cetera.

3. References

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ERC Starting Grant 2023

Research proposal [Part B2]

ETHME: The Ethics of Mortality Measurement

Section a. State of the art and objectives

Introduction

There are around 55 million deaths in the world each year. How should we evaluate these deaths?

While mortality measurement is a central part of epidemiology, the phenomenon is more complicated than it may initially seem. Some mortality measures report the number of fatalities, while others indicate that some deaths are worse than others. Since the 1950s, a discourse in epidemiology has evolved in which deaths are evaluated (Haenszel 1950); that is, deaths are assessed by different disvalues. For instance, when the global disease burden is estimated, deaths are evaluated based on *disability-adjusted life years* (DALYs). In contrast, the norm during the COVID-19 pandemic has been to count the number of deaths rather than evaluating them through assigning specific disvalues (Feiring and Solberg 2021). Some health measures are constructed to combine morbidity and mortality into a single metric. According to the current practice within global health, neonatal deaths are counted as the worst possible deaths (Murray et al. 2012a), while stillbirths are ignored (Frøen et al. 2016). Considerable and sophisticated work has gone into the methods and challenges of evaluating morbidity. However, according to the DALY model, around 70% of the global disease burden results from premature mortality rather than morbidity. Surprisingly, discussions on how to evaluate deaths have not been very high on the agenda within epidemiology. In summary, the practice of mortality measurement seems to lack a firm theoretical grounding.

In parallel, a philosophical debate on the badness of death has continued since the 1970s (Nagel 1970). This discourse mainly concerns how death can be bad for the individual who dies. The debate revolves around whether death can harm us, even if it involves permanent nonexistence. In response to this issue, two main camps have evolved: an Epicurean camp that holds death cannot be bad for those who die and an anti-Epicurean camp holding that death may be bad for those who die. The majority holds that death can be bad for those who die, but for competing reasons (e.g., gradualism and non-gradualism). Over the years, the badness of death discourse has shown progress in providing different explanations as to why death can be harmful to those who die and the timing of death's badness. However, from an overall perspective, this debate seems quite stagnant. Moreover, almost no attention has been devoted to evaluating deaths in mortality measures, mortality-morbidity commensurability, and the badness of death on a population level.

In my MD–PhD work (2012–2018), I made early attempts to reconcile the philosophical discussion on the individual badness of death with epidemiological mortality measures (Solberg 2013; Gamlund and Solberg 2014; Solberg, Gamlund, and Sørheim 2016; Solberg 2018; 2019). I invited leading philosophers and medical doctors to collaborate and write on this topic, which resulted in the anthology *Saving People from the Harm of Death* (Gamlund and Solberg 2019). In **ETHME**, I continue this work to enhance and refine this discussion on the relationship between the evaluation of deaths and summary measures. I thus aim to achieve cross-cutting interdisciplinarity between philosophy and epidemiology and develop models for the evaluation of future individuals, as well as to pioneer a new academic field: the ethics of mortality measurement.

The overarching aim of ETHME is to announce the ethics of mortality measurement as a novel and developing field within the philosophy of epidemiology.

Ambition: This project involves the evaluation of deaths. With **ETHME**, I seek cross-cutting interdisciplinarity between philosophy and epidemiology. Whereas fields such as health economics and

medical ethics are partly influenced by philosophical theorizing, such is less the case with epidemiology. Until now, there has been little cross-fertilization between philosophy and epidemiology. We may call this interdisciplinary field in which **ETHME** will operate *the philosophy of epidemiology* (Kaplan and Valles 2021). With **ETHME**, I also seek to bring more transparency to value assumptions underlying the mortality component of summary measures of population health, such as *quality-adjusted life years* (QALYs) and DALYs. This work will also suggest original classificatory models and relevant taxonomy for degrees of evaluativeness and descriptiveness of mortality measures. A further novel ambition of mine through **ETHME** is to develop an *ethics of mortality measurement*. Such an ethics involve the ability to deliberate on choices and rationales about the scope, construction, and application of specific mortality measures. **ETHME** is also aimed at developing the theoretical grounding for sound models for evaluating the procreation of future individuals through deliberation on the nature of harm or death and for harnessing the potentiality of models for life years. This ambition might seem like an attempt to solve a pure philosophical puzzle. However, upon closer examination, it is a challenge with implications for medical interventions that affect a number of people, such as those using contraceptives and undergoing in vitro fertilization.

State of the art

In all healthcare systems, the demand for interventions exceeds the available resources. Any imbalance between demand and resources gives rise to scarcity. Thus, priorities must be set to cope with such scarcity. Setting priorities implies ranking interventions in their order of importance to ensure the most important measures are taken first. Public and political awareness of the need to set healthcare priorities has increased during the COVID-19 pandemic. In the long run, we must actively seek sustainability in our healthcare systems to cope with the climate crisis. However, to prioritize resources, we need reliable health measurements. Even if our priority setting is done in an accurate, transparent, and ethically sound manner, we may get our priorities mixed up if our health measures are not reliable, to begin with. Whether we simply seek to monitor health, maximize health, minimize disease burden or distribute health care resources fairly – we will need theoretically robust health measures, to begin with.

Historically, epidemiology has been chiefly concerned with the mortality in a population, and mortality has been measured using descriptive measures such as *crude- or age-specific death rates* (Haenszel 1950). During the 20th century, more nuanced measures, such as *potential years of life lost* (PYLLs) and *years of life lost* (YLLs), were developed (Murray 1994). The latter measures are evaluative rather than descriptive, indicating that some deaths are worse than others. For instance, both the PYLL and YLL measures indicate that early deaths are worse than later deaths, as the former incurs a more considerable loss of future life years than the latter (Haenszel 1950; Murray 1996a). The initial descriptive mortality measures are simple, transparent, and inherently universal. Moreover, descriptive mortality measures do not reflect that individual deaths are postponed rather than prevented and imply that every death has equal disvalue (or that every death is neutral), regardless of—for instance—the age at death. Such disvalue also holds for the literature on the value of statistical lives (VSL), in which value is placed on preventing death. However, for the most part, lives saved are ascribed to the same monetary value (Viscusi and Aldy 2003).

Conversely, the more refined mortality measures rely on value assumptions (Solberg et al. 2020a)—such as ideas about a natural life span—and are thereby deemed controversial. In **ETHME**, I take the stance that no mortality measure serves equally well for all purposes. Both descriptive and evaluative mortality measures can be necessary for informed health policy decisions. To this date, no classificatory system for the different evaluative mortality measures has been proposed.

For monitoring and priority-setting purposes, we must be able to aggregate morbidity and mortality, and summary measures are a response to this need. The QALY and the DALY are the most used measures in this regard. In both measures, (dis)quality of life and mortality are integrated into a single measure (Gold, Stevenson, and Fryback 2002; Robberstad 2009). Health economists developed the QALY based on the expected utility theory, and the measure matured in the late 1970s and early 1980s. Scholars determine the value of different health states by asking a representative sample of people about their own health or the health of others. In the QALY, full health is worth 1 by convention. Values typically range from 1 to 0, but can also be negative for health states worse than death (Robberstad 2009; Weinstein, Torrance, and McGuire 2009). The numbers of the quality of a state are referred to as utility weights. Methods such as *time trade-off* (TTO), *person trade-off* (PTO), and

standard gamble (SG) are the standards used to establish utility weights. The QALY can be used in a cost-utility analysis to estimate the cost per QALY per intervention. For instance, the National Institute for Health Care Excellence (NICE) in the United Kingdom has implemented the QALY model (Ogden 2017). Additionally, QALYs are used in Australia and many European countries, such as Sweden and the Netherlands (Folkhälsomyndigheten 2022; RVZ 2006).

DALYs, whereas, were developed in the early 1990s as an integral part of the Global Burden of Disease study (GBD). The GBD architects constructed the DALY for two reasons: (a) to quantify the burden of disease and (b) to set priorities in health (Murray 1994). On the DALY scale, 1 represents full disability (equivalent to death), whereas 0 represents no disability (Gold, Stevenson, and Fryback 2002). One can calculate DALYs as the sum of YLLs—relative to some ideal longevity—due to mortality in the population and the *years lived with disability* (YLD) for people living with bad health conditions (Murray 1994; Horton 2012; Murray et al. 2012b).

Most diseases and injuries cause both morbidity and mortality. Considerable work has gone into the morbidity component of both the QALY and the DALY. This work includes sophisticated methods for establishing disability weights for different diseases and injuries to compare these conditions for monitoring and priority-setting purposes (Gold, Stevenson, and Fryback 2002; Robberstad 2009; Weinstein, Torrance, and McGuire 2009; Miyamoto et al. 1998; Murray 1996b; Lipman, Reckers-Droog, and Kreimeier 2021). When representative samples of the general population are systematically asked which out of two bad health conditions they would prefer, this is also a way of securing some legitimacy to the measures in question. Moreover, there has been considerable debate about value assumptions behind both the QALY and the DALY—especially their morbidity component. For the mortality component of the DALY, there have also been concerns about the choice of one particular life table over another, whether the selected life table should apply globally or locally, and whether or not life tables should be sex-specific.

In parallel, a specific discourse has evolved within analytic philosophy since the 1970s: the badness of death. The main concern with this philosophical debate is to provide an adequate answer to whether death is bad for the *individual* who dies (Nagel 1970). The debate mainly concerns death at an individual level rather than a population level. “Death” here refers to the incidence of death rather than the process of dying. While any death can be bad for others, such as family, friends, and society, the question is whether death can be bad for the decedent. Recall that to the question of the badness of death for those who die; there are two main camps. Anti-epicureanism is the view that death may, in fact, be bad (or good) for those who die. *Epicureanism* is the view that death cannot be bad for the decedent (Rosenbaum 1986; Taylor 2005; Hetherington 2001). Frequent arguments in favor of epicureanism are that since one cannot experience any sensation (good or bad) while being dead; nothing can be bad for the nonexistent, and a person's prenatal nonexistence is not bad for them; therefore, death (posthumous nonexistence) should not be bad either. However, most philosophers in the debate hold the opposite view is *anti-epicureanism*: that death is, in fact, bad for the one who dies. The leading anti-epicurean view is deprivationism: the view that death is bad for the individual who dies because of the loss of the life that a person counterfactually could have had, had they not died (Nagel 1970; Feldman 1991; McMahan 2002; Broome 2004). Sophisticated accounts have been developed to answer the question of which is the worst time to die (McMahan 2002). Furthermore, within population ethics, deliberations have been held over relevant symmetries and asymmetries between the philosophy of the badness of death and the challenges of burdens and benefits for future individuals (McMahan 2013; Bradley 2013).

The badness-of-death debate can be described as more abstract than applied. The debate has been, and still essentially is, concerned with technical issues surrounding generic deaths. For instance, my survey of recent publications in this discourse shows that fundamental issues, such as the question of when death's badness is incurred, are still a mainstay of the debate (see Meier 2019; Timmerman 2022). However, there are exceptions where attempts are made to apply insights from the debate, such as the anthology I co-edited (Gamlund and Solberg 2019).

Nevertheless, authors of some recent publications have claimed practical limitations to applying insights from this debate. For instance, Bognar (2020) argues that scaling up the badness of death from the individual level to the population level does not make sense. Further, Schramme (2021) argues that central assumptions of deprivationism are dubious in a way that renders the badness of death for individuals immeasurable. If correct, these views spell trouble for applying arguments from the badness-of-death debate to justify summary mortality measures. However, other **ETHME** group members and I

have previously found the badness-of-death debate helpful for such purposes (Solberg and Gamlund 2016; Solberg, Norheim, and Barra 2018; Solberg et al. 2020b; Solberg, Barra, and Robberstad 2020). Thus, I will set out to disprove these recent contributions in WP1. After all, the interdisciplinary research program that **ETHME** launches share some fundamental commonalities. For instance, deprivationists view death from a consequentialist and future-oriented perspective (Kamm 2019), which corresponds with the view of death found in summary measures of population health.

ETHME is broadly situated within the philosophy of epidemiology. While there is a substantial “philosophy of” most scientific disciplines, research on the philosophy of epidemiology is remarkably sparse. The most notable early contribution to the philosophy of epidemiology involves causal inference in epidemiological methods (Broadbent 2013). Another, more recent contribution expands the focus of this subfield to issues of social and racial justice (Valles 2018; 2021). In the introduction to a special issue on the philosophy of epidemiology, the editors ask what is next for this subfield; one suggestion is to make philosophical contributions regarding values and value assumptions in epidemiology (Kaplan and Valles 2021). However, a philosophical debate on summary measures of population health has been ongoing, which the editors have thus overlooked. As a scientific discipline, epidemiology lacks clear boundaries (Frérôt et al. 2018). Moreover, the most accepted definitions of the discipline must include summary measures of population health within it. **ETHME** is thus clearly targeted at expanding the focus of the philosophy of epidemiology to include this aspect of the discipline.

Knowledge gaps

Why does one need to enhance the public and academic discourse on the evaluation of deaths? Allow me first to approach this discussion by way of an anecdotal example. When the first COVID-19 vaccine doses became available in Norway, as elsewhere, their numbers were scarce. Hence, priorities had to be set for who should receive the vaccine doses first. Norway has a long-standing tradition of open priority setting. An external group of experts on ethics and priority setting was established to suggest the overall goals for the Norwegian COVID-19 vaccination program and make overall vaccine prioritizations. I was involved in this group. Discussions on the choice of the proper mortality measure became important. Should COVID-19 vaccination programs seek to measure the reductions in *deaths* or *life years lost*? The committee members were divided on this question, and the literature on this choice was sparse. After having deliberated on this issue, the group chose the *number of deaths* over *life years lost* as a measure. The expert group received criticism for this choice. In a pandemic scenario where young deaths are more frequent than in Norway, the choice of death count over life years lost can potentially influence a massive difference in the ranking of priority groups for the distribution of a scarce good (Feiring and Solberg 2021).

Most diseases and injuries result in both morbidity and mortality. As a society, we use considerable resources to prevent deaths. Nevertheless, people's attitudes toward death (mortality) seem naturally ambivalent. First, there is a sense that death is the worst thing that can happen to us. When we die, we lose everything: our lives, our friends and family, and our “being in the world” for all eternity. However, there is another sense in which death is *nothing to us*. After all, we are not dead when we are alive, and when we are dead, we do not exist (Epicurus). One's view on this matter might affect one's preference of either counting the number of deaths (and thereby treating every death alike) or assigning a specific disvalue to each particular death. One's attitude toward death may also affect the relative weight one places on morbidity reductions versus mortality reductions.

Several underdeveloped normative issues are met on the path of enchaining the public and academic discourse on the evaluation of deaths. For mortality measures, these issues involve *scope*, *construction*, and *application*. *Scope* concerns what one chooses to measure and not to measure and what is unintentionally included and neglected due to the nature of the measure, such as the neglect of stillbirths. *Construction* concerns the value assumptions built into the mortality measures in question, such as the use of global life tables for the DALY (Schroeder 2019; 2016; 2012). *Application* concerns the reasons for choosing measure *A* instead of *B* for purpose *X*, such as the choice made in Norway to count the number of *deaths* instead of *life years lost* when measuring the effects of the Norwegian COVID-19 vaccination program. Together, these three dimensions and a set of other aspects constitute an *ethics of mortality measurement*.

Many illustrative examples of the relationship between theory and practice exist within such an ethics of mortality measurement. For instance, DALYs and QALYs are almost always assumed to be

applicable only from the moment of birth (Solberg and Gamlund 2016; Solberg et al. 2020a). This assumption neglects stillbirths and evaluates neonatal deaths as the worst ones. Moreover, summary measures such as DALYs and QALYs are not currently designed to account for the value of procreation (e.g., in IVF) and the harms to future individuals (e.g., in climate crisis; Gamlund and Solberg 2019). This is because QALYs and DALYs are simply constructed to be concerned with currently existing individuals. Moreover, given that we want to maximize QALYs or minimize DALYs, any QALY value or DALY disvalue that we add to potential people will imply that some Y amount of future individuals should be prioritized over X number of existing individuals—which may seem problematic.

For the YLL in the DALY, foundational questions—such as whether the youngest deaths should always be counted as the worst ones—remain unanswered. A complete anthology was recently dedicated to the philosophical dimensions of the Global Burden of Disease study (Eyal et al. 2020). However, no chapter was dedicated to discussing the value assumptions behind the mortality component of the DALY (Schroeder 2012). The foundational assumption of the DALY is that YLDs can be aggregated with YLLs, that is to say, $YLDs + YLLs = DALYs$. Philosophers in the badness-of-death discourse have been surprisingly inattentive to the challenge of commensurability between morbidity and mortality. From the perspective of medicine, there is a clear advantage to summarizing morbidity and mortality in a meaningful way. There are many reasons for this need, the most simple and obvious being that most diseases and injuries give rise to both morbidity and mortality. Therefore, we must consider morbidity and mortality when considering the disease burden or the value of preventing a particular disease or injury. It is, therefore, quite surprising that so few attempts have been made to connect the disvalue of the incident of death with the disvalue of disease burden from within life. At this point, I firmly believe we can advance the philosophical debate by further integrating it with theoretical epidemiology.

Both debates—the philosophical and the epidemiological—clearly have one thing in common: They tend to neglect or are at least inattentive to *the badness of death for others*. Let me present this challenge rhetorically: Whom do we cry for at funerals? Do we cry on behalf of the person who died? Or do we cry on our behalf for losing this person? We may, of course, also answer that we cry for both. The badness-of-death discourse was constructed to respond to the question of whether death can be bad for those who die—this is the *raison d'être* of the debate. Naturally, participants of this philosophical debate are inattentive to whether and to what degree deaths can be bad for *others* beyond the deceased. In epidemiology, somewhat greater attention has been paid to this question of the badness of death for others; however, many related questions remain unanswered. Losing someone we love can constitute an existential experience, and grief may change our attitude toward life. Moreover, people express their condolences to the bereaved. Losing a child can be a life-changing experience for a parent. One should thus account for these phenomena in discussions on the nature of harm in death and, by extension, during attempts to measure the harm of death when quantifying disease burden numerically.

To reinforce an earlier point, while sophisticated methods have been developed to consider ordinary people's preferences concerning morbidity, we know much less about ordinary people's attitudes toward the badness of death. Only a few researchers have directly asked people from diverse age groups about their attitudes toward the deaths of individuals. However, several surveys have been conducted on people's preferences for saving lives at different ages. The data from one study suggest that parental grief at a child's death is related to the reproductive value of the child (Crawford, Salter, and Jang 1989). Wright (1995) found similar results: people prioritized good health while raising children. The intuition of favoring the individual with the most reproductive potential seems to make sense in an evolutionary context. However, it does not dictate that reproductive potential is either morally relevant or contributes to the badness of death for an individual (Mogensen 2019). Another problem with using the degree of grief as an indicator of the badness of death is that grief does not differentiate between direct and indirect effects. Grief might as well be an indicator of the badness of death for others (indirect effects) rather than of the badness of death for those who die (direct effects), or it could indicate an inaccurate mixture of the two effects (i.e., indirect and direct effects).

There are lessons to be learned from studies regarding people's attitudes toward the badness of death. First, intuitions about death sometimes play a central role in priority setting. Second, these intuitions do not explicitly differentiate between direct and indirect effects. Third, the authors of these works do not concern themselves with the most well-established accounts of the badness of death in

analytic philosophy. Finally, the intuitions tend to diverge at the earliest phases of life (Denny and Emanuel 2008; Persad, Wertheimer, and Emanuel 2009).

More attention should be given to theoretical developments in mortality measurement from the global-health perspective. When measured through the lens of the DALY, the majority of the total disease burden in the world results from mortality (or premature death) rather than morbidity. Similar effects can be observed when using the QALY model to measure the value of life-saving interventions. Accordingly, one would expect considerably more work to go into the mortality component of these summary measures. Indeed, even slight adjustments to how deaths are evaluated can influence a substantial difference in the total amount of the global disease burden (DALYs) or the utility outcome of life-saving interventions (QALYs; Solberg et al. 2020a).

These and other knowledge needs should be tackled and resolved. Thus, **ETHME** aims to announce the ethics of mortality measurement as a novel and developing field within the philosophy of epidemiology to answer these knowledge needs. Following the overarching aim, the three core objectives of **ETHME** are specified below.

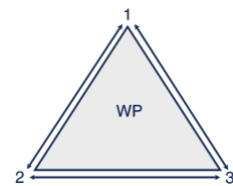
Core objectives

Objective 1: Develop and refine the understanding of the nature of the harm in death.

Objective 2: Reconcile the evaluation of deaths in summary measures of population health with the most promising accounts of the harm of death.

Objective 3: Develop the theoretical ground for sound models to evaluate procreation of future individuals.

One work package will be devoted to each of the three secondary objectives. Directly in line with the three objectives stated above, the three work packages of **ETHME** will be (a) **WP1** – Death; (b) **WP2** – Summary Measures; and (c) **WP3** – Future Individuals. As shown by Figure 1, **WP1–WP3** stand in a dialectical relationship. Theoretical developments and results on the nature of the harm in death (**WP1**) will impact how death should be evaluated within summary measures (**WP2**), as well as how we should think of the current (i.e., prenatal) nonexistence of future individuals who may be harmed or benefited (**WP3**). Likewise, confrontation with the challenges of aggregating morbidity and mortality and enumerating the disvalue of death (**WP2**) might elicit important insights into the counterfactual thinking regarding the harm of death in the philosophical discourse (**WP1**). Summary measures (**WP2**) also challenge our views on whether or not to account for potential individuals in any summary measures of population health (**WP3**).



Section b. Methodology

WP1: Understanding the Nature of the Harm in Death

In WP1, the following research questions will be discussed:

- What is the nature of harm in death?
- What is the relationship between the badness of death for those who die and the badness of death for others?
- When is an incident of death bad for the person who dies (before, under, after, or at some indeterminate stage)?
- How is the badness of death related to age?
- Can we coherently numerically measure the harm of death?

As evidenced by state of the art in the evaluation of deaths, philosophers have done substantial work on the harm of death at an individual level, and medical doctors and epidemiologists have undertaken similar important work on the disvalue of death at a population level. That being said, philosophers have been surprisingly little concerned with deaths at a population level (Bognar 2020), with a few important

exceptions (Broome 2004; n.d.). Likewise, foundational philosophical issues concerning the evaluation of deaths tend to be disregarded in the literature on population mortality (again, with a few important exceptions). In WP1, we will seek answers to the relationship between death at an individual level and deaths at a population level. In this regard, adopting an upscaling strategy would imply that accounts of individual deaths are relevant to population mortality and should thus be scaled up to account for deaths at the population level. Alternatively, a downscaling strategy would imply that accounts of population mortality, being relevant to the individual harm of death, should be scaled down to account for the deaths of individuals. A third option is continuing to treat these two levels (individual and population mortality) separately. Finally, there might be potential for both upscaling and downscaling, and theoretical developments from either strategy can be exchanged. In *ETHME*, I hypothesize there is potential for cross-fertilization and mutual exchanges between the two strategies at both levels. In short, evaluative mortality measures cannot be based on pragmatism alone. However, they must instead indicate whether death implies a loss for the one who dies or for everyone else, as well as at which developmental stage death can be harmful to the individual who dies. Likewise, the debate on the individual harm of death needs to be approached by confronting the challenges of aggregating morbidity and mortality and quantifying the harm of death.

To restate an earlier point, epicureanism implies that deaths *cannot* be bad for those who die, while deprivationism implies that deaths *can* be bad for those who die. However, both views agree that death can be bad for everyone else, such as family, friends, and society. Hence, we are suddenly confronted with whether the lost life years are for individuals or their surroundings. If epicureanism is true, morbidity reductions may be prioritized over mortality reductions. Likewise, epicureanism might challenge the commensurability (Lübbe 2015) between YLD (morbidity) and YLL (mortality) in the DALY (Solberg and Gamlund 2016).

A related question then involves the current dichotomy between birth and pre-birth concerning population mortality, especially the view that deaths right before birth are insignificant. At the same time, deaths right after birth constitute the worst possible tragedies, according to the DALY. This view does not seem to withstand philosophical scrutiny. How, then, might the age or developmental stage of the deceased be related to their individual harm of death? The amount of well-being lost to death, and the decedent's psychological connectedness to that loss are relevant factors when exploring the worst time to die. Relevant competing necessary conditions for the existence of harm in death seem to be sentience, inverted brain death, birth, and personhood. Importantly, these relevant features may appear in degrees instead of as all-or-nothing factors (Solberg 2018; McMahan 2002).

The philosophical debate on the individual harm of death straddles counterfactual statements, and one may even question whether these can be deemed true or false (Bennett 2003). Moreover, one can also question whether the badness of death for an individual is by itself measurable (Schramme 2021). However, both philosophers and epidemiologists commonly hold that death incurs a loss of life years for those who die. Given this, does death incur the loss of healthy or unhealthy life years? The answer is not obvious.

On the one hand, death represents the negation of every possible morbidity condition; thus, it implies the loss of healthy life years. This view is the orthodoxy within evaluative summary measures such as the DALY, where every year of life lost to premature mortality is assumed would have been one in full health (Murray 1996b). On the other hand, there are reasons to suspect that the life that one would have had, had one not died, would bear similarities to the life that one lived, which implies a loss of unhealthy life years instead. The latter view is frequent within philosophy (Bradley 2009). Some of this tension might be resolved with enhanced terminology, but there are also reasons to suspect that this tension goes beyond the terminology itself. In WP1, we will work further on this critical issue.

WP2: Building Theoretically Robust Summary Measures

In WP2, the following research questions will be discussed:

- What is the relationship between death at the individual level and deaths at the population level?
- Should we account for the loss of only healthy or unhealthy life years when someone dies?
- To what degree can and should measures of morbidity and mortality be commensurable?
- Should stillbirths be disvalued in mortality measurements?

- When should policymakers count the number of deaths, and when should they also evaluate the disvalue of these deaths?

In its foundations, utility theory—upon which the current models for health benefits are constructed—relies on a notion of a player and their “preferences.” In utility theory, one is “locating all ‘events’ in which we are interested at the same, standardized moment, preferably in the immediate future” (Von Neumann and Morgenstern 2007; section 3.3.3). WP2 will be based on the hypothesis that scrutiny of the original assumptions behind utility theory and their current adaption to health measurement will reveal that many of these original assumptions are not satisfied. Furthermore, many of these assumptions implicitly exclude deaths from being consistently treated within the current adaption of utility theory to health measurement.

Measures of good life years (e.g., the QALY) and measures of disease burden (e.g., the DALY) either explicitly (the DALY) or through their actual use (the QALY) depend on an ability to quantify the disvalue of death. This dependency is highly problematic and remains an issue of widespread debate without consensus or any unifying solution. In **ETHME**, I will not assume that a unifying solution exists but instead work under the assumption that “death” may (morally, economically, and axiologically) mean different things in different contexts and, accordingly, require several mortality measures.

Stillbirths and neonatal mortality straddle the moment of birth. The standard view within global health is that the disease burden is generated only from the moment individuals are born (Gamlund and Solberg 2019). For instance, in the current Global Burden of Disease (GBD) study, 2.7M annual neonatal deaths are counted. However, there are around 2.6M annual stillbirths, and these deaths do not contribute to the DALY count (Lawn et al. 2011; due to the lack of counting in many countries, the stillbirth death toll may be considerably higher). Stillbirths have recently been estimated and monitored (GBD 2015; Frøen et al. 2016) but have not generated any YLLs to date (Phillips and Millum 2015). Hence, a moral dichotomy is played out between developed fetuses and neonates. Different accounts of sentience and personhood, alongside purely pragmatic concerns, seem to confront current public health measures directly. Moreover, medical concerns do not resonate with a pre-birth–post-birth dichotomy. Nevertheless, we can resolve many such technical controversies by being explicit in our moral assumptions, thus moving the debate away from technical details and toward ethical deliberation.

The above discussion implies the following hypothesis for WP2: An improved overview of the value assumptions inherent in mortality measures will enable policymakers and the public to better understand the strengths and weaknesses of these mortality measures. Such a taxonomy should include information about how *efficient* the different measures are: How fast and at what cost can a given level of accuracy be obtained? During the ongoing pandemic, public health administration has largely been guided by descriptive measures, such as crude death rates, rather than overall well-being. There may be good reasons for this, but recent experiences show that the public's acceptance of imposed restrictions has been heterogeneous. In WP2, we will contribute to the main aim of **ETHME** by facilitating a better understanding of when inaccurate-but-efficient measures are the better option and when a comprehensive-but-costly measure is worthwhile to pursue. Conceivably, several countries might have led an (overall) better pandemic response had they continually reassessed the possibility of substituting “maximizing health” for “minimizing deaths.”

WP3: Evaluating Procreation in Future Individuals

WP1 and 2 are the main WPs of **ETHME**. With regard to the devoted time, WP3 constitutes a slightly smaller WP compared to WP1–2. Hence, there is also only three research questions in WP3. In WP3, the following research questions will be discussed:

- What is the theoretical relationship between prenatal nonexistence (of future individuals) and posthumous nonexistence (death)?
- Does measuring the value of procreation make sense at all?
- Should the value of procreation be considered in a cost-utility analysis of in vitro fertilization?

How should we compare *never coming into existence* with *death* (Parfit 1984; Benatar 2008)? Never coming into existence is a non-comparativist evaluation because either an individual comes into

existence or not. Death, however, is a comparativist evaluation (see, e.g., McMahan 2013), because death can only be bad compared to what one could have had, had one not died (Gamlund and Solberg 2019). If there is a trade-off between non-comparativist and comparativist evaluations, how should we measure it? Priority setting in healthcare requires that we ascertain which interventions are the most cost-effective and consider factors such as reasonableness, fairness, and legitimacy (Kamm 2015). Considerable work has already been conducted on the ethical foundations for determining the value of human life and the value of additional life years, with or without disability (Eyal et al. 2013). Nevertheless, whether these tools are applicable in the case of future individuals who have not yet come into existence is not clear (Bradley 2013).

Nevertheless, it is increasingly evident that ethical consideration of future generations is necessary. For instance, those who work on climate change must grapple with the challenge of ethics for the currently nonexistent. Nevertheless, similar considerations concerning healthcare priority setting remain undertheorized. Thus, in WP3, I aim to address this deficit and develop tools for evaluating, measuring, and, ultimately, including existence and identity questions concerning future generations and healthcare priorities. The fact that our current summary measures seemingly cannot account for future individuals poses a problem not solely for nonexistent people. At the core of these measurements is the concept of potentiality, which cannot be interchanged with probability in this context. The exclusion of nonexistent people from our summary measures of health might uncover some core problematic aspects of such measures.

At first glance, one might understandably see the inclusion of nonexistent people in summary measures as an abstract thought experiment. However, a cost-effectiveness analysis of fertility treatments proves otherwise. To complete a cost-effectiveness analysis of procreative interventions like IVF, some foundational questions need to be answered: Is the purpose of IVF to cure biological infertility, to cure unwanted childlessness, or to generate new QALYs? Alternatively, is it some combination of the three? IVF is especially challenging since it is unclear who the patient is: Is it the person being treated or the future individual who is conceived (Smajdor 2014)? Depending on how we answer these two questions, we may get very different resulting degrees of cost-effectiveness for the intervention of IVF. The creation of a new individual determines the success of IVF. Therefore, one could ask whether the health benefits generated through IVF treatment belong to the woman who becomes pregnant, to the child, or both.

Given that the process of IVF entails placing several embryos in the womb, every round of IVF holds the potential of 80×2 (or more) life years. If only one of the eggs is brought to term, the IVF will still be deemed successful, and approximately 80 life years could have been gained. However, if the other embryos are not brought to term, 80×1 (or more) potential life years will be lost. This scenario demonstrates that the current tools for summary health measures need closer examination if we apply them to future individuals. These matters are even more pressing given the current trend toward lower fertility rates and higher reliance on medical interventions as nations try to maintain an economically and demographically stable population (Baldwin 2019).

Methods of reasoning

ETHME will be based on what has proven the most resilient and valuable method of moral and political reasoning: the wide *reflective equilibrium* (Rawls [1971] 1999; Daniels 1979; 1996). This method attempts to produce coherence between sets of moral judgments (intuitions), sets of moral principles, and sets of relevant background theories. These sets are applied to cases, and subjected to “the broadest evidence and critical scrutiny” (Daniels 1996). When well-considered intuitions and principles are appropriately balanced, they form what one may call a reflective equilibrium. The reflective equilibrium is arguably the most popular method in moral and political philosophy (Sinnott-Armstrong, Young, and Cushman 2010), with some suggesting that it is the only ‘defensible’ one (Scanlon 2014).

A distinction is commonly drawn between a narrow and wide reflective equilibrium. A narrow reflective equilibrium denotes a process wherein one's considered second-order principles balance well-considered intuitions about ethical issues. This process leads to the discovery of well-considered intuitions that do not necessarily fit with the relevant principles. If there is an imbalance between well-considered intuitions and principles, one must revise either the relevant intuition or the principle (Rawls [1971] 1999; Daniels 1979; 1996).

Here is an example that directly relates to **ETHME** (WP1): How is age at death related to the badness of death for the individual who dies? Some people may start with the intuition that death is bad irrespective of age: We will all die, we only die once, and death is the common denominator for all of us. Others may hold that death cannot be bad for those who die, and according to this intuition, age is less relevant to the harm of death. Yet, others may believe death is generally worse for younger people than for older people. To balance these different intuitions, we would need to work back and forth on each intuition's rightness (or wrongness) and the reasons offered for that judgment. In this process, a common trait of philosophical work will also become important: a *conceptual analysis*. For instance, we need to clarify what we mean by "age," which is not straightforward (see Räsänen 2021). Age has different implicit dimensions. It informs us of precisely how many life years a person has lived (past), which may, in turn, serve as a proxy for the total amount of well-being that person has received. Age also tells us about potential future years of life that a person will be biologically capable of having. After all, the standard view is that a young person will lose more life years by dying than an older person. Third, age indicates the developmental stage of an individual, such as whether the individual in question is a fetus, a neonate, a child, or an adult person. To those who believe death is always bad irrespective of age, one can ask whether this intuition holds for all three dimensions of age: past life years, past well-being, and developmental age. Likewise, with conceptual clarification, we can quickly see a distinction between *the badness of death for those who die* and *the badness of death for others*. Even if one believes that death is bad for those who die, death can still be bad for others (those who have lost a loved one).

In **ETHME**, we will, of course, employ several types of reasoning (Williamson 2018). As a starting point, ETHME will be concerned with "good thinking". Virtues that we will strive for in ETHME are analytical rigor, a clear and accessible language (even if the discussed topics are of high complexity), and compliance with the rules of logic. Moreover, we will seek to avoid circular reasoning and tautologies, ad hominid arguments, and polemics.

One type of argument this is central to the badness of death debate are syllogisms, which are logical arguments in which deductive reasoning is applied to reach conclusions. This method can be traced back to Aristotle. There are many such syllogism to be found in the badness of death discourse. One example is *the experience argument*, which is an argument in favor of epicureanism: P₁. For something to be bad for us, we must experience it. P₂. When we are dead, we cannot experience. C. Therefore, death cannot be bad for us. P₁ is, in this case, the major premise, which is disputed among philosophers in the debate, while P₂ is a premise that is presumed to be true (and in this sense a minor premise). This argument is valid, which is to say its conclusion follows by logic.

We will also use another prominent type of reasoning: arguments from analogy, an inductive type of argumentation for exploring similarities between two systems to conclude that some further similarity exists (Bartha, n.d.). Analogies are frequently used within the badness of death discourse. For instance, it is common for anti-epicureans to provide analogies between harms (or benefits) within life that might be analogically similar to the harm of death. Examples of such analogies are medical preventions, unfaithfulness etc. That is, such phenomena are used to provide that there exist things that can be good or bad for us, even if we do not experience them – and that death – by analogy – is one such phenomenon. (Of course, there will be counterarguments to such analogies). In ETHME we will strive for a coherent system in the use of analogies and disanalogies.

A further method that will be employed within **ETHME** to study the nature of harm in death is metaphors. This is a method that is seldom used within the conventional badness of death discourse. The technique of metaphors will not be used to provide explanations or as a central feature in reasoning but rather at early creative phases to elicit reflections, inventive thinking, and information that cannot be discovered using analogies and formal logic alone (Peres 1998). Such a use of metaphors will be especially central for the study of epicureanism in WP1, which will be employed by both dr. philos candidate Bjørn Hol and the ETHME-PhD-candidate. Moreover, to a larger degree than in ordinary philosophy, **ETHME** will rely on updated empirical evidence whenever the same is relevant to the issues discussed and when statements are empirical rather than normative in nature. A wide range of methodologies is used in this regard by philosophers and bioethicists (Ives and Draper 2009; Davies, Ives, and Dunn 2015). However, in **ETHME**, it should be sufficient to rely on a smaller range of standardized methods of using empirical evidence (Ives et al. 2018), as the interaction between empirical data from summary measures of population health and philosophical reasoning, in general, is already well-established (Wikler and Brock, n.d.).

While most of the above-mentioned methods of reasoning are conventional within ordinary analytic philosophical discourse, their application in the refining and construction of mortality measures in population health will be novel.

Feasibility of the Scientific Approach

ETHME is a high-risk, high-gain project. The risk is high, as this project will be strongly based on theory, with a few selection methods, and since the foundational theoretical topic of death carries a high degree of complexity. Questions regarding the harm of death are highly complex, and one may question whether there exist final answers to the nature of harm in death. To this challenge, I respond that my ambition with **ETHME** is not to provide final answers to foundational normative questions but instead to provide *better* answers. There is a need to bring the philosophical literature on the badness of death into greater contact with the meta-epidemiological literature on how to quantify the harms caused by premature death. There is also a high potential for *betterment* in developing new methodologies for evaluating and quantifying the disvalue of deaths at a population level.

As proof of this field's richness, I have conducted research on the harm of death for almost 10 years. My MA, PhD, and postdoc can be seen as precursors of **ETHME**. However, this is not to say that **ETHME** is a direct continuation of my PhD or postdoc. Instead, the **ETHME** project involves a selection of the most critical research gaps across knowledge fields which I have identified throughout my research career. These also include challenges that MA and PhD candidates under my supervision have identified. In addition, significant contributions have been made by collaborating colleagues and leading scholars associated with the *Saving People from the Harm of Death* anthology (2019). The field has become so rich that it is time to launch **ETHME** as part of the philosophy of epidemiology.

Importantly, **ETHME** will not be one of those projects in which philosophy is simply applied to a new discipline (in this case, epidemiology). The ambition of **ETHME** is more integrative than that. With this **ETHME**, I do believe in general cross-fertilizations between the badness of death debate, summary measures of population health, and the application of issues on population ethics. For instance, I believe that the badness-of-death debate (1970–) would improve even further if its scholars were more confronted with the challenges theoretical epidemiology grapples with, such as that of commensurability across morbidity and mortality, the relationship between death at an individual level and death at a population level and whether death implies a loss of healthy life years or the loss of life years with suboptimal health. My experience is also that attempts to provide a numerical value of the disvalue for death highlight challenges that are not visible through the conventional philosophical discourse of the badness of death. Moreover, across both philosophy and epidemiology, no stake has been claimed on how to deal with the harm of death for others, although we know that the loss of a loved one can constitute an existential experience.

Principal investigator and project group

CTS • Carl Tollef Solberg (b. 1988), MA, MD, PhD. I (CTS) will lead **ETHME** as the principal investigator (PI). The Centre for Medical Ethics at UoO will be the host institution. I will devote 75% of my time to **ETHME** over five years. The **ETHME** research group will consist of one postdoc for two years in a 100% position, a PhD candidate for three years in a 100% position, a research assistant for five years in 20 %, and another postdoc for four years in a 50% position. In addition, Bjørn Hol, Sofie Lekve, and Preben Sørheim will be affiliated with the **ETHME** research group.

The project participants in **ETHME** will be organized within two circles. Circle 1 will constitute the core research group, and circle 2 will comprise the advisory board.

Circle 1: Core group

Four core individuals will be conducting research on this grant. This core group of **ETHME** will consist of a **PhD candidate** in WP1, **Postdoc 1** in WP2, and **Postdoc 2** in WP3, and myself as a **PI** (WP1–3). In addition, a research assistant (RA) will be recruited in a 20 % position for five years across all three WPs (WP1–3). Moreover, **Bjørn Hol** (WP1), **Preben Sørheim** (WP1–2), and **Sofie Lekve** (WP3) will be affiliated with the research group. I will lead this group, and we will have a weekly one-hour meeting to ensure the progress of **ETHME**, update each other, provide feedback, and exchange ideas.

WP1: This **PhD candidate** will be recruited through international calls for three years in a 100 % position. The PhD candidate sought should be a scholar in analytic philosophy. Knowledge of

medicine and epidemiology will be an advantage. I will be seeking a philosopher for this position – but there will be an advantage with other education or knowledge in addition, such as in health economics, medicine, or psychology. This position will be announced broadly in national and international channels, and we will encourage women to apply. This PhD candidate will have the primary responsibility (first author) of three philosophy articles within WP1. These three articles should relate to some of the five research questions stated in WP1. I (CTS) will be the principal supervisor of this PhD-candidate. In addition, Bjørn Hol will be affiliated with this group. BH is an experienced economist and a philosopher and is, among other things, the former director of the Faculty of Medicine at UiO. He wrote his MA thesis on the epicurean view of death and will continue to refine this work within the realms of BH is aiming for a dr. philos degree, which implies that there will be no need for funding for this doctoral work except for costs such as travel expenses, access to relevant books, etc. BH will be affiliated with the CME, UoO, and I (the PI) will supervise him throughout his doctoral work. The plan is that BH will submit his dr. philos degree in late 2015, and so, BH will work on ETHME in Y1–2.

WP2: This **postdoc 1** will work in a 50 % position for four years in WP2. The working period will be years 2–5 of ETHME. **Postdoc 1** will play an essential role in translating work and finding other **ETHME** collaborators in the work of mortality measures. For this postdoc position, I will ideally seek an MD working part-time as an academic and part-time within societal medicine or something similar. This postdoc should be interested and know philosophy, but philosophy education is no requirement. Other educations that are sought for this position are psychology and health economics. The PI (CTS) will mentor this postdoc. In addition, philosopher and PhD candidate Preben Sørheim will be affiliated with this WP. Sørheim wrote his MA on the badness of death. Sørheim is currently finishing a PhD on the value of longevity under the supervision of the PI. By the beginning of **ETHME** in 2024, Sørheim will likely have finished his PhD. Through being affiliated with **ETHME** and WP2, **PS** will apply for additional funding through open postdoctoral calls.

WP3: For **postdoc 2**, I will seek a philosopher. This philosopher will be recruited through international channels. This philosopher should be familiar with population ethics, the badness of death discourse, or, ideally, both. The work conducted by this philosopher will be of high theoretical complexity. In addition, PhD-candidate Sofie Lekve (SL) will be liaising under this WP. SL is a young philosopher with some training in economics. She wrote her MA thesis on population ethics. The supervisors of SL are the PI (CTS) and prof. Anna Smajdor. With CTS's help, SL could secure (01.09.21–09.09.25) a competitive open PhD grant at the Department of Philosophy, University of Oslo. SL's PhD proposal, "What is the value of a future life? A challenge for summary measures of population health," has been written within the realms of WP3. Thus, throughout the rest of her funded research period, SL will be affiliated with WP3. Through this affiliation, SL will apply for additional funding for a postdoctoral position under WP3.

WP1–3: A **research assistant** (RA) in a 20% position will be recruited for five years and tasked with organizing the research meetings, seminars, and AB meetings. The RA will also have primary responsibility for the SoMe activities of **ETHME**, with help from the **PhD candidate**. Moreover, the RA will assist the team with scoping literature reviews. The RA will also be provided with the opportunity to write a scientific article with hands-on supervision from the **ETHME** research group members. **ETHME** will finance the necessary travel expenses and access to essential literature for circle 1 collaborators. The RA will be recruited among master students in either philosophy, medicine, health economics or psychology. At the RA role goes along for five years, then I should not take for granted that the same person will continue in the RA-role for five years. I expect that at least two different persons might have the role of RA through the period of five years. '

As the **PI**, I will hold the main responsibility of **ETHME**, provide leadership to all **ETHME**-members, and ensure that **ETHME** implements its methodology and delivers on its promises. I will supervise the PhD student, and mentor the two postdocs. I will of course also provide supervision to the current PhD-candidates mentioned, which will be involved in **ETHME**. I will conduct a considerable part of the **ETHME** research and will especially be contributing to WP1 and WP2. My research profile as well as my interdisciplinary background as both a medical doctor and a philosopher – will come at hand when seeking to provide cross-fertilization between WP1 and WP2. Recall that I will devote 75% of my time to **ETHME** over five years. This 75 % will remain stable throughout the **ETHME** research period. My 75 % in the first year will allow me to set up the project and hire the necessary staff. Next, I will start working on a proper book proposal for a monograph launching the *ethics of mortality*

measurement. I will submit this book proposal to Oxford University Press late in 2024. I will visit Oxford for one week at the time in Y1,2 and 4, to reestablish my network there – and to be able to present and revise the main content of **ETHME**. In year three, I will start working on an anthology together with PD2 – in which the key personnel in **ETHME**, in addition to senior international scholars, will be invited to contribute. The research questions present starting points of several of the planned original articles. I will take first authorship and main responsibility of three of these articles. In addition, I will provide co-authorship on articles written by the PhD and the PDs.

Circle 2: Advisory board

Circle 2 will entail the advisory board (AB) and comprise top-level senior academic researchers. All five AB members are at the international forefront of their respective fields of expertise. Moreover, each of them complements—from different angles—the ambitions of **ETHME**. The AB (circle 2) will meet the core **ETHME** group (circle 1) once a year. Three AB members (RD, OFN, and NE) will also participate in the co-writing of selected articles. Moreover, the AB members will help facilitate potential guest research ships at their respective institutions for members of circles 1 and 2. Next, a presentation of each of these five AB members and their intended roles will follow.

RD • Rakhi Dandona, PhD, is a Professor of Health Metrics Sciences at the Institute for Health Metrics and Evaluation (IHME) at the University of Washington and a Professor at the Public Health Foundation of India, New Delhi, India. She is a leading scholar in evidence development for disease burden in developing countries. She is interested in helping build evidence for decision-making to maximize population health and health equity. RD will serve as a senior advisor of **ETHME**'s more *applied* concerns. She will be especially concerned with WP2 and will advise and challenge **ETHME** members on the usefulness of their results for the SDGs, developing countries, and stillbirth advocacy. Moreover, **RD** and CTS will write an article for a leading medical journal that explores the most central arguments for evaluating stillbirths in the Global Burden of Disease study.

OFN • Ole F. Norheim, MD, PhD, is a Professor of Medical Ethics at the Department of Global Public Health and Primary Care, Director of BECEPS (partner institution of **ETHME**), University of Bergen, and Adjunct Professor of Global Health at Harvard TH Chan School of Public Health. OFN is an internationally leading scholar on healthcare priority setting, focusing on health inequality. He will mentor the overall direction of **ETHME**, suggest further collaborating partners if necessary, and seek to bridge gaps between theory and practice. OFN will serve as a senior advisor on **ETHME**'s *hybrid* concerns (i.e., applied and theoretical) and will provide counsel across all work packages. Moreover, he will be involved in the co-writing of selected articles in WP2.

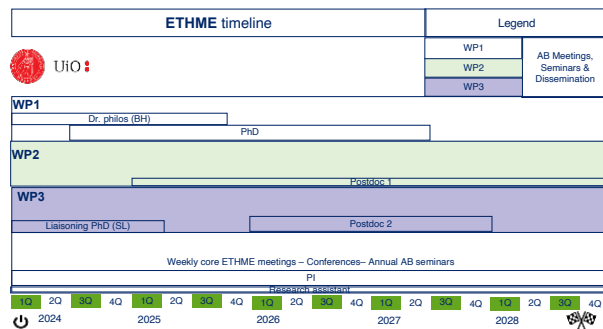
NE • Nir Eyal, MA, PhD, is a Henry Rutgers Professor of Bioethics and Director of the Center for Population-Level Bioethics (CPLB) at Rutgers University, USA. NE's advice will be important for **ETHME**'s ambition of establishing a pioneering philosophy of epidemiology. His expertise will be critical in WP2, where NE will also be invited to co-write articles.

JB • John Broome, MA, MSc, PhD, is an Emeritus White's Professor of Moral Philosophy at the University of Oxford, UK, and Adjunct Professor at Australian National University. JB is one of the leading philosophers within moral philosophy and the philosophy of economics and has contributed to the theoretical foundation of many priority-setting discourses, the harm of death, and population ethics. JB will serve as a senior advisor on **ETHME**'s theoretical and hybrid concerns across all three work packages.

JM • Jeff McMahan, PhD, is a White's Professor of Philosophy at the University of Oxford. He is one of the leading current moral philosophers. The main proponent of gradualism, JM has provided some of the most important contributions to the relationship between death (posthumous nonexistence) and future individuals (prenatal nonexistence). He will serve as a senior advisor involved in **ETHME**'s theoretical concerns, and the JM will also play a crucial role in the cross-fertilization between **WP1** and **WP3**.

Project organization and management

The ETHME timeline is described in detail above. CTS will hold the overall responsibility of project management, including administration, dissemination, supervision of the PhD candidates, and oversight



of interactions among different members of **ETHME**. SME, UiO, will be the main hub of **ETHME**. The research assistant will ensure that people are invited, rooms are booked, and Zoom links for meetings are sent to members. Circle 1—the core group—will meet physically or on Zoom biweekly. Once yearly, the core **ETHME** group will meet the AB. The AB will review and give us inputs on the project's progression every year. Moreover, all PhDs and postdocs involved in **ETHME** will have the opportunity to apply for guest

research stays at one or more of the excellent home institutions of the AB members (*please see Budget description for details on institutions). Lastly and most importantly, in **ETHME**, we will do our best to create a constructive and meaningful work environment that will allow some of the most innovative ideas to flourish.

Key outputs and knowledge transfer

*Please see the extended essay for key outputs and knowledge transfer. This information will not be repeated in the B2.

Potential for impact

Through engaging with the continuous dialectics among WP1 (death), WP2 (summary measures), and WP3 (future individuals), we expect to create a Medici effect in the form of new theoretical innovations when the disciplines and ideas in question undergo friction and interconnect. In this way, we expect **ETHME** to have profound implications for theoretical developments in the philosophical discourse on the nature of harm in death (WP1), for the reconciliation of philosophical accounts of death and summary measures of population health, and the modeling of measures for future individuals. Sophisticated use of analogous reasoning will allow us to move ideas between these different research fields.

Measures for communication and exploitation

Dissemination of **ETHME** will primarily, but not exclusively, involve the following:

- The **ETHME** research group will aim for the Publication of scientific articles in leading journals in medical ethics (e.g., *Journal of Medical Ethics* and *American Journal of Bioethics*), philosophy (e.g., *Utilitas* and *Philosophical Studies*), and health policy (e.g., *Health Services Research* and *Health Policy*). For the most critical policy-related work, we will also aim to publish commentaries and editorials in some leading medical journals (e.g., *The Lancet* and *JAMA*).
- The core group shall attend relevant national and international events (i.e., seminars, workshops, and conferences), allowing us to present the preliminary work of **ETHME** and exchange ideas with the most influential researchers on this topic. These interactions will also open up new opportunities for collaboration.
- Through **ETHME**, I will also work on a monograph for Oxford University Press.

To help **ETHME** reach the general audience, the following communication plan is contemplated:

- Public understanding of the research field will be actively promoted. For relevant scientific publications, policy briefs for each Publication will be created and disseminated broadly. Some of the scientific work will be broadcasted through population presentations (e.g., for students, through radio programs/podcasts).
- The research assistant will be responsible for overseeing the SoMe activities of **ETHME**. The media for disseminating these population presentations will include Twitter, ResearchGate, Academia, and a dedicated **ETHME** blog. All **ETHME** participants will be encouraged to contribute to the communication activities.

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