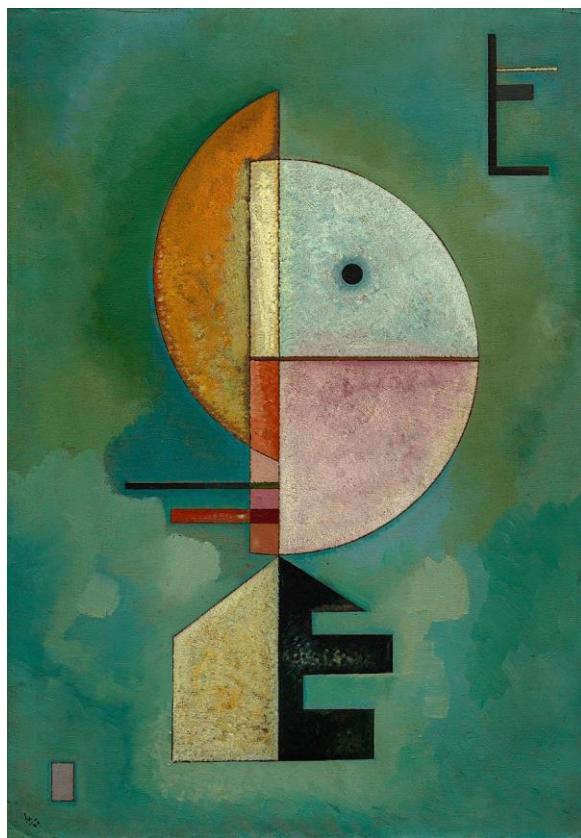


## *Providing Ethics News via an E-mail Newsletter*

*What is it about? How is it done?*

*What would the recipients miss if the newsletter stopped?*



Wassily Kandinski. Upward. (1929).

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## Declaration on the use of artificial intelligence (AI)

During the writing and translation of my text, I have used:

- *DeepL Translator*
- *Google Search*
- *Google Translate*
- *Microsoft Editor*

I have not used Generative Artificial Intelligence (*GenAI*), that type of AI tool that uses large language models (LLMs) to create new content and generate answers to questions asked by their users.

*“The best-known generative AI tools are perhaps ChatGPT, Midjourney and Dall-e, but a trend within this space is the integration of generative AI into narrow-use, user-friendly services, and into familiar services such as Microsoft Office and Grammarly”. (Maunder A, Florén H. 2024).*

*In memory of my friend Cathis Kumlien, a recipient of the Ethics Newsletter from start. She was an incredible dedicated Pediatric Nurse and leader.*

*Thank you to all newsletter recipients for choosing to participate in the exciting “adventure” that the Ethics Newsletter project is! Thank you to those of you who responded to the survey and to those of you who provided valuable feedback on early drafts and on the final version of my text!*

## **A few words to begin with**

The Ethics Newsletter project started in 2016. Many years have passed, about 350 newsletters have been sent, and now it is time to tell the true story about it.

My interest in ethics has been a joyful pursuit for me during a long time. The knowledge and experience I have gained over the years has been of great use in my work as Ethics Coordinator at Karolinska Hospital, where I have trained, guided and supported the hospital's staff, both managers and employees. My duties came to an end when I retired. My knowledge, experience and interest in ethics in practice remained. All this, I thought, should continue to be useful somehow. Although I did not know how it could be done, I had no doubt that I could find a solution, just as it always had been the case when I previously decided to realize some of my other more or less realistic ideas. I had never been short of inspiration or motivation. However, the biggest problem would again be to find someone who would be able and willing to contribute with the necessary resources to implement the project.

When I was employed at the Karolinska Hospital, the managers would usually have a positive attitude towards my proposals, but they would rarely find room in the budget for the extra costs of a new project. I never gave up after the first rejection. If I received a negative decision, I would continue to share my ideas with new people I met, such as other interested parties, experts in the field, senior managers within the organization, or decision makers from outside the organization. Doing this, I often met a large number of knowledgeable and committed people. Unexpected meetings and short conversations could have a big impact and lead to new opportunities.

If I lacked knowledge or skills in a particular area, it never felt like an insurmountable obstacle. I was eager to learn new things each time. Even if the project didn't turn out as planned, it was always worth the effort. Sometimes, in retrospect, there was an unexpected "reward," when someone showed interest in developing something I had started, or when one of my projects was recognized and awarded.

The new project I planned to undertake when I retired would be different from my previous one. It would take place under different working arrangements and conditions than I was used to as an employee.

My idea was to monitor various communication channels and media in order to find, collect and quality assure news about ethics and news relevant to ethics. The aim was to disseminate the most interesting news through an e-mail newsletter to a group of particularly engaged recipients all over Sweden. I wanted to try out an e-mail newsletter to find if this simple digital tool could improve access to information and thus perhaps remedy the lack of quality information on ethics.

I have drafted this report primarily for the recipients of the newsletter, to help them understand what I do, how I do it, and why I do it. The recipients who participated in the survey were able to read the first draft of my text in December 2024. The final report was distributed in Swedish to all the newsletter recipients in March 2025. The final report will be published both in Swedish and in English at the Karolinska Institutet website [Nyhetsbevakning om etik | Karolinska Institutet](#)

This report could be useful in several ways, including as a practical example to utilize as a basis for conversations with people in senior positions to show that an email newsletter can be an effective and appreciated way to communicate qualitative information about ethics.

This report gives me the opportunity to provide a written account of how I have used my affiliation at Karolinska Institutet for more than eight years. Being accepted as an affiliated researcher at the Karolinska Institutet was not given. I am not a PhD researcher due to a number of different circumstances that led me to choose a different path. However, there were two things, both related to my work on practical ethics and to Karolinska Institutet, that may have played a decisive role in my becoming an affiliated researcher. The first was that, as ethics coordinator at Karolinska Hospital, I had a long and fruitful collaboration with Niels Lynøe and Niklas Juth, at a time when both were ethics researchers in the Lime Department at Karolinska Institutet. The second was that I had received the Karolinska Institute Ethics Prize three years earlier.

When no one else was willing to support the project, Karolinska Institutet stepped in and gave me the opportunity to realize my idea. The Karolinska Institutet has provided the same valuable support for more than eight years. This has been a prerequisite for the continuation of the project. I, as the person responsible for the project, and everyone who has benefited from the e-mail newsletter on ethics, are grateful for the Karolinska Institutet's generosity.

**Stockholm, May 2025**

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## Summary

In this three-part report, I present and explain my work with the ethics newsletter for the first time. In part 1, I write about newsletters in general as a phenomenon, about terminology, history, current research and I point out the problem of people not having easily access to qualitative information on ethics. In part 2, I describe the newsletter's focus area, the form and conditions of the work, how I practically work with the ethics newsletter and how I produce and distribute it to the recipients. In part 3, I present the results of a survey from 2024 that was directed at the recipients of the newsletter and whose purpose was to find out what the recipients would miss if the newsletter no longer existed.

### Part 1. About newsletters – a new-old way of conveying information in a time of change

Newsletters in digital form are a relatively new tool. However, newsletters in other forms have been used as a communication channel for several hundred years and can be seen as predecessors to the first printed newspapers. Newsletters are a communication tool that has long demonstrated an ability to adapt to various circumstances, including new technological developments and changes in legislation.

Newsletters, which were once considered almost as an outdated medium, have now become a popular tool for conveying information. Newsletters are a communication channel that is appreciated by many today because it makes it possible to disseminate information in a more personal, direct and targeted way and because it helps to create a confidential contact with readers.

Email newsletters with a special focus on ethics are available in a few countries, mainly in the USA, but not yet in Sweden. The newsletters on ethics that I found during my research looked all different. A literature search did not yield any hits on studies targeting email newsletters on ethics specifically. However, there were studies on email newsletters conveying news (as opposed to newsletters used for marketing). In one of these studies, it was reported that the most important factors making readers choose to use a newsletter were the convenience of the format, the different perspectives that were addressed, the unique content and the tone and personality of the author. In one study, the researchers were looking at the persons behind the newsletter. They find that they could be journalists but increasingly also people without journalism training but who had instead great expertise in a specific subject area such as practical ethics for example.

In many parts of society, perhaps especially in healthcare but also in politics, law and other important areas, there is a lack of targeted and tailored qualitative information on ethics to varying degrees. What seems to be missing is not access to a large amount of scattered information on ethics but instead access to orderly, collected, quality-assured information and, not least, access to reliable, easy-to-use communication channels.

Could an email newsletter created by someone with expertise in the field be a suitable tool to use to convey curated news on ethics?

### Part 2. The ethics email newsletter – a focus on Applied Ethics and a different way of performing work

The ethics email newsletter should focus on applied ethics, which is a part of ethics that touches on many areas and does not have clear boundaries. The information conveyed in the newsletter should be relevant to ethics and, by extension, to practical ethics work. Through the newsletter,

recipients should have access to facts and concrete examples that will help them reflect on the implications of fundamental principles in a variety of areas where ethical considerations arise.

The project with the email newsletter on ethics that started in 2016 is the result of a voluntary non-profit work. Many hours of research, many hours of reading and many hours to complete it are required to produce each newsletter. The person who works non-profit with the newsletter must be committed, motivated, have time and also a secure income from elsewhere. It is the good result that is achieved and the benefit for others that hopefully follows that is the driving force for the person who works non-profit.

Projects cost money. The non-profit work effort would unfortunately not be enough. Some other party must cover the necessary “operating costs” for the project to be implemented. For the newsletter, it is my connection at Karolinska Institutet that has so far covered the costs.

### **Part 3. What would the recipients miss if the Ethics Newsletter were discontinued?**

#### **- Results of the 2024 survey**

The newsletter started as an attempt to address the lack of information about ethics, something that has long been a well-known but difficult-to-solve problem. Indeed, for the recipients of the newsletter, the lack of information had no longer been a problem for many years. How would it be experienced then by those who are now accustomed to regularly receiving information about ethics via email, if the newsletter for some reason had to be discontinued?

I wanted to find this out and decided to investigate what the recipients thought they would miss if my email newsletter had to be discontinued.

In June 2024, I sent a survey via email to 46 recipients. 33 of those who had received the survey (71.7%). responded. This corresponded to 23.4% of the total number of recipients (141) at the time of the survey. It is likely that the survey is the first of its kind to contribute new empirical knowledge in the specific field. This makes it valuable even if it is limited.

A thematic analysis of the data collected through the participants' responses was carried out. Two themes and eight subthemes emerged and illustrated what the participants would miss if the newsletter was discontinued:

Theme 1: The quality and functionality of the service. Subthemes: A unique source of information and knowledge, High-quality compilations, Time savings, A channel that promotes ethical conversation and enables new contacts and collaboration.

Theme 2: Positive experiences and mixed feelings. Sub-themes: Joy, inspiration and other spontaneous positive emotions, Security of being updated, Gratitude to the sender, Concern about losing the newsletter.

### **Conclusion**

The newsletter provided participants with a comprehensive set of quality-assured information that they could not obtain elsewhere and that they would therefore miss if the newsletter were no longer available. In addition to the newsletter's many functional benefits, participants would also miss the positive experiences that the newsletter generated.

The prospect of losing the newsletter created concern among respondents. It would therefore be important to investigate what alternatives might exist to ensure continued access to comprehensive qualitative information on ethics if the newsletter could no longer be delivered for some reason.

## Part 1

### ***About newsletters***

*- a new-old way of spreading information  
in a time of change*



## 1. Terminology

The report refers to several areas, including journalism and communication, which I am not trained or an expert in. It was therefore particularly important to carefully check what the terms I used in my text stood for and were in relation to each other. In the linguistic world, there are terms that we use when we communicate about concepts, and definitions that describe the concepts. The term is the linguistic expression that can be understood by a specific group. Terms are linguistic expressions for subject-specific concepts. Concepts are defined as perception, notion, idea, defined unit of thought.

**Facts** (plural, from the Latin *factum*): A factual situation that cannot be disputed (NE). Facts represent what is known and proven. When we talk about facts (objective information, phenomena, actions, events) we are talking about something that is true regardless of opinions or beliefs (Karlsson N. 2023). Facts are completely meaningless without knowledge.

In everyday language, evidence is equated with facts that prove that something is true. In scientific contexts, evidence is relative and concerns the scientific evidence that supports a scientific theory. Such evidence is expected to be fact-based and documented in accordance with scientific methods (Swedish National Board of Health and Welfare, 2020)

**Information** is the general term for the meaningful content that is transmitted in communication in various forms. A distinction is often made between information that in principle has a requirement to be factual or objective and subjective information that aims to persuade or influence (NE).

**Knowledge:** Facts, understanding and skills, acquired through study or experience. In a nuance of meaning, knowledge is about the amount of known facts in a certain area (NE). Knowledge is not information. Information only becomes knowledge if we take a position on it, accept or reject it (expose it to criticism) and place it in a context that is understandable to us (Sven-Eric Liedman). You must have knowledge to be able to evaluate facts, and the more facts you get, the more knowledge you can get (Sjöström T. 2018). Knowledge sharpens our skills like reasoning and problem-solving. *“The purpose of knowledge is action not knowledge”* (Aristotle).

**Media monitoring** aims to identify media and journalists who write about a specific topic in relation to the attention and exposure that a person, brand, event or topic receives in different media formats such as print media, web, social media, TV, radio, podcasts, blogs. Locally, regionally, nationally and internationally (Infomedia).

Media monitoring is often part of an organization's external monitoring.

**News.** A published announcement of something significant that was previously unknown: an event, a process, or a condition (NE).

**Newsletter** is defined as an informal publication, often in a simple form, which offers information to a predefined readership (NE). A newsletter is a collection of information, regularly distributed, usually via e-mail, which deals with topics that are of interest to the newsletter subscribers (Lund University). E-mail, e-letter, email, computer mail or electronic mail are systems for sending messages between computer users; the term also refers to the messages themselves (NE).

In this report, the terms “*e-mail newsletter*” and “*Ethics Newsletter*” will be used.

**News reporting.** Collection, evaluation, processing, and distribution of news through some medium. A distinction is made between news reporting and news dissemination, which deals with how news is disseminated to and within the public (NE).

**Business intelligence** encompasses more than just the media and is therefore not synonymous with media monitoring (NE).

## 2. History

The history of news reporting is closely linked to changes in legislation that over time have affected the conditions and forms of news reporting. Our rights to think, say, write and publish basically what we want are (at least at this moment) common democratic rights in Sweden and in many countries. The development of technical means of information and communication has taken place in parallel and has been of great importance (NE).

For several hundred years, newsletters in various forms have been used as a way of conveying information. Newsletters were the predecessors of what later became the first printed newspapers. Early in trade, often between the mother countries and the colonies that were located on another continent, a news report was organized with handwritten information about fabric prices, sunken merchant ships as well as wars and other conflicts. The lack of space meant that the stories had to be kept short and concise. Important information had to fit into a short paragraph, sometimes in a single sentence (Breig J 2003). This way of communicating news played an important role for a long time (Mediekompass. Publicistguiden). Newsletters were eventually replaced by the printed press. However, they continued to be used to convey news to smaller groups within specific areas and were often produced using a stencil device or copying machine.

Since the 1990s, most newsletters have been published in digital form and have been particularly popular in marketing. Newsletters are a valuable, direct and reliable tool, a good alternative to conveying news at a time when journalism is undergoing a major transformation. With the advent of the internet, information has been made available to most people from all conceivable sources. The possibilities and routines for people to orient themselves about what is happening have changed radically, for better or worse. At the same time many traditional media have become obsolete, especially when it comes to digitalization, and have thus lost influence and appeal, especially among young people.

With modern technology in constant change, it has become more difficult to assess which news and which information channel you can trust as a user. The need to obtain information through channels other than search engines or traditional media has increased. The value of a neglected tool like newsletters was rediscovered and interest in independent e-mail newsletters that could convey selected, quality-assured information (curated news) became greater. Well-known journalists from major newspapers as well as people without journalism training began to use e-mail newsletters and through this could also become an opening for a long range of specific topics that previously had difficulty reaching an interested audience. E-mail newsletters are produced and used as a communication channel by journalists in regular media companies who specialize in a specific topic but also by enthusiastic individuals with special expertise in the area. Newsletters prove to be a more effective way to stay in touch with a specialized subject area than, for example, surfing a website (Newman N. 2022). Email newsletters have had the ability to adapt and evolve, and what was once considered an outdated medium has become a valued

effective communication channel that allows journalists and other authors to connect with an audience in a more personal and targeted way (Forbes Communication Council, 2024).

Nowadays there are different types of email newsletters. Newsletters that are intended for marketing have been around for a long time. They are a well-known phenomenon and these newsletters are usually distributed via mass mailings. Although they can help spread knowledge, they are fundamentally used to influence an audience of potential consumers of their services and goods.

### **3. Previous research and other literature on newsletters and news dissemination via e-mail**

There are no more examples of e-mail newsletters on ethics in Sweden (as far as I know). The newsletter on ethics that I am behind seems to be a unique phenomenon in Sweden.

However, e-mail newsletters on ethics do occur in other countries, mainly in the USA. They differ in form and content, in how often they are published, who is behind them, in what their purpose is and whether they are free or not. Most newsletters on ethics are published by larger centers for bioethics research.

My efforts to find academics research studies on e-mail newsletters with a specific focus on ethics yielded no hits. However, there were a number of studies on e-mail newsletters in general within news dissemination. There seems to be a growing interest among researchers in studying the phenomenon from different perspectives now that e-mail newsletters are used to a great extent by both private individuals and large organizations.

In some studies, researchers have described the paradox that in modern times it is so difficult to stay well-informed despite the fact that information is so easily accessible. Some have investigated the consequences of such a problem, how the problem is handled by the various actors and whether an email newsletter could possibly prove to be a better way to convey information.

Today, people have the opportunity to access media content almost all the time and almost everywhere in the world. A simple Google search can result in millions of websites and the searcher is left with the impossible task of sorting through the results (The New York Times 2024). On a smart phone, there are countless news channels, news websites and news sources available. It is easy to feel overwhelmed.

When media users read news via *Google News*, they are using a search engine based on algorithms to find news on the internet. The algorithms that control the selection in Google News then become crucial for what people learn about their contemporaries.

Easily available digital media are not always media that can be trusted. "*Fake news*" flourishes all over. In most cases, people do not have the time or energy to verify each website reliability, check sources and facts, source both texts and images, understand and analyze large amounts of data and understand and manage algorithms to search and verify news articles and various types of sources online (Picha Edwardsson M. 2020).

*"The spread of misinformation is causing a general disbelief attitude in social media users, who tend to stop consuming or accepting information altogether, putting Democracy at risk. Therefore, discussions around misinformation need to include information ethics addressing also information control by social media platforms, as well as social media users' responsibility."* (Troullinou P. 2021)

Overproduction of information, media noise and sterile polemics undermines readers' confidence. (Jean-Jaurès Foundation, 2024). The fatigue of an "information" arises and makes readers turn away from the media. French researchers have looked in detail at what this phenomenon is about. (Boulonne S. 2024).

Some studies have shown that email newsletters can be both accessible and dependable. Therefore, such a communication channel could appear as a valuable alternative for conveying news. However, surveys show that audiences demand that any alternative tools for news delivery should allow news to remain just as easily accessible, preferably at the click of a button. In a world full of digital distractions, email newsletters are easy to find. They are delivered to an inbox, a place that most people visit several times each day (Hendrickx J. 2020). By receiving a newsletter, media users no longer had to rely solely on visiting a website like *Google Search* to find new information. In an email newsletter, the author/sender had already done the searching work.

Email newsletters are available from several media houses and other organizations. Research shows that such a direct channel is appreciated by large media organizations at a time when social media such as Facebook and X (Twitter) are losing trust and users (Seely N. 2021, Internet Foundation, 2025). The New York Times (NYT), a large and well-known American newspaper, has been interested in email newsletters early on. Their first newsletter began to be sent as early as 2001. The NYT publishes several newsletters that have become many readers' first daily interaction with the newspaper's journalism (Newman N. 2022). Another article describes email newsletters as one of the media's new tools to use to continue influencing the media's public/audience in the future (Ahmadi A. 2024).

In a recent survey conducted by the Reuters Institute, the majority of newspaper publishers surveyed (77%) answered they planned to invest more resources in building direct links with their readers via email newsletters and other such channels that they could have more control over (Newman 2024). For the traditional media, it is about being able to maintain the possibility of gaining influence when the digital environment makes the communicative space increasingly narrow due to the large number of new actors and communication channels. One consequence of such a change is that the hierarchy of influences is changing and being greatly modified. This should be considered because it is those who sit at the top of this hierarchy who will ultimately have the power to determine what news is (Solito L. 2023). Journalism is a process in change that needs a restart (Picha Edwardsson M. 2020, Shibsted, 2024).

*"We have seen the traditional media's grip on the public discourse weaken over the past decade, but 2024 saw an explosion of 'decentralized' journalism. Platforms like Substack gave individual journalists the opportunity to bypass corporate gatekeepers and build direct relationships with their audiences. The move of talented writers from newspapers like The New York Times and The Guardian to independent platforms signals a shift from institutional credibility to personal profiling"* (Baydar Y. 2024).

A survey conducted in ten countries (Australia, Belgium, UK, Germany, India, Ireland, Japan, Norway, South Korea, USA) examined the motivations behind the choice to use email newsletters. The researchers found that the most important factors for email newsletter users



were the convenience of the format (65%), the variety of perspectives (30%), the tone and personality of the author (28%) and unique content (24%). The perceived benefits were remarkably similar across the ten countries surveyed. However, the author's voice was valued more in South Korea and India. The characteristics of the most successful email newsletters – convenience, unique perspectives and a personal touch – proved increasingly valuable in a world of information overload. The human aspect was particularly important, as many appreciated the undemanding and rewarding contact with a person who could guide them through the news (Newman N. 2022).

In another study, the researcher was able to distinguish two broad categories of e-mail newsletters. What made the difference was that the newsletters followed different value models. The first category of newsletters, called "*Functional newsletters*", were information-dense and maintained a distance between sender and recipient. The people involved, especially the newsletter author, were not the central focus. What was important in these newsletters was the content itself. The value lay in the qualities that the newsletter was characterized by and that could concretely help the readers. The second category of newsletters was called "*Relational newsletters*" and referred to newsletters where personality was put to a greater extent in the first place. However, this could contribute to the formation of a close relationship between sender and recipient with the advantage of creating a direct, personal and rewarding contact, but with the risk that the author as a person was exposed more and thus received increased demands of various kinds from the recipients of the newsletter (Andringa P. 2022).

Introducing a more personal tone into the newsletter could though risk revealing the author's bias and polarizing views, consciously or unconsciously. Leonhardt, a well-known journalist at the NYT and author of a newsletter that was heavily criticized for its reporting on covid-19, is an example of this (Newman N. 2022). However, a personal relationship between reader and author is considered by several researchers to be worth cultivating in an era when search engines like Google News and others deliver content generated solely by algorithms (Seely N. 2021).

"*Curator, news curation, curated news*" are terms that recur in English research (and sometimes untranslated in Swedish literature) when describing the process used in digital news distribution. In this case, a curator refers to a person whose task is to select the best information available online with regard to its quality and relevance, sort it, aggregate it and link it to the original news sources. One researcher noted that a "*curator*" did not have to be a journalist but should master many of the skills required of a journalist. Such people could be freelancers or amateurs, or perhaps work for a news organization, sometimes with a great degree of independence and visibility (Guerrini F. 2013).

With newsletters will more "*gatekeepers*" and another level of "*gatekeeping*" occur. The concept of gatekeeper was originally put forward by the social psychologist Kurt Lewin (Burnes B. 2020) and has been used in media and communication science research since the 1950s to describe what controls the selection of news in mass media and other information channels (NE). Gatekeeper refers to a person who controls the flow of communication in a channel (Petersson 2009), a person who "*filters*" through large amounts of information and chooses which parts of that information will reach an audience (Shoemaker PJ. 2009). On its way from the event to the reader, some news must pass many gatekeepers. At each gate, the news is evaluated and compared to other news (NE). In relation to a digital social network, a gatekeeper is defined as a

door opener, a type of person who is considered trustworthy and who is then believed to have the judgment to say which (people/news) are trustworthy (Lalander P. 2011).

The Conversation, a politically neutral, non-profit international news platform on the internet, has been trying since 2015 to make a different voice heard by combining the best of academic expertise with rigorous journalism, and to disseminate independent, free, quality information accessible to everyone via daily email newsletters. The people behind The Conversation were convinced from the beginning that only real expertise can be effective. However, they needed to investigate whether their work, in practice, had a concrete impact on society and social debate. In 2024, a survey was sent to subscribers, which resulted in a report with a number of examples that showed The Conversation's actual impact (Ketchell M. 2024).

### 3. The lack of qualitative information about ethics is problematic

Lack of information means that information about something is missing or that someone has insufficient access to what one needs to know.

The state of being uninformed contains several nuances and could mean being ignorant, unaware, uninitiated, uneducated (Merriam-Webster Dictionary). Having free access to information is considered a prerequisite for participation and for people to have the opportunity to influence. Several circumstances can cause problems for this to happen. The information can be so extensive that it becomes impossible for most people to distinguish what is important from what is irrelevant. It becomes complicated to distinguish information that is true from information that is false and from information that may be intended to harm. It is also common to miss important information completely or partially due to a lack of sufficient knowledge or because certain actors have used a conscious strategy, for example by hiding decision-making processes and preventing transparency in activities.

It has been clear that there has been a lack of qualitative information about ethics in society, and perhaps especially within healthcare. In order to be able to deal with ethical problems, a good knowledge of relevant facts in ethics and several other areas is needed. It is facts and evidence that should be the basis.

Being well informed or at least knowing how to obtain the relevant facts that need to be considered is necessary. A solution needs to be found to improve the situation. Perhaps an email newsletter could prove to be a suitable tool to use to convey information on ethics. It could be worth trying.

*"... One of the great things about having news coming in through email is that you have various viewpoints on what is happening in the world. It saves a lot of time surfing web pages. You can just go through each email and read the content. Newsletters are an incredibly useful tool to keep your audience informed. Curated, tailored newsletters content which is fact checked will go a long way to building up trust".*

Ungapped. Digital platform.

## Part 2

### ***The Ethics Newsletter***

*– focus on Applied Ethics and  
a different way of performing work*



I started the Ethics Newsletter project in June 2016 after leaving my position as ethics coordinator at Karolinska Hospital on 31 May. The target group for the newsletter at that time was the members of the National Ethics Network established in 2004 and initiated by the Karolinska Hospital Ethics Group. I was then given the task being the network contact person for all the members and in general to ensure that the ethics network took shape. In 2016, the National Ethics Network consisted of around fifty committed people working with ethical issues in various organizations across the country.

After the members of the National Ethics Network had been receiving the newsletter for just over a year, I asked them how they perceived and valued my mailings. Their answers showed that they greatly appreciated the service, both its form and its content, and that they wished to continue receiving the newsletter in the future in the same way as before. Once again, I was persuaded by the members to continue my work publishing the newsletter. I ceased the moment to make some improvements. I took the opportunity to open the service to anyone who wished to subscribe to the newsletter, not only members of the National Ethics Network, but also private individuals, authorities and various organizations.

Since then, with the exception for summer breaks, I have been providing a weekly digest of high-quality information on ethics, consisting of carefully selected and checked news items, to a group of particularly interested subscribers. Every one of them has given their consent to receive my mailings.

## 1. Applied ethics

The Ethics Newsletter focuses on applied ethics (practical ethics), which examines practical moral problems and proposes principles and guidelines for solving them using concepts and arguments from ethical theory.

Applied ethics links ethical theory and our moral practice (Stockholm University). Applied ethics is a term that refers to ethical reflection directed towards a particular field (Frey RG. 2005, Lynöe N. 2009).

*“Practical ethics today is concerned with what we should do in any given situation. It reflects on personal, professional, policy, and social choices and structures and holds them up to scrutiny. It may balance or prioritize different values and interests. Good practical ethics relies on an in-depth understanding of the relevant real-world facts and issues and so it is often interdisciplinary”.* (The Uehiro Oxford Institute 2025).

Applied ethics has no clear boundaries and touches many areas such as bioethics, research ethics, medical ethics, healthcare ethics, ethics and politics, ethics and armed conflict, ethics and law, ethics and Artificial Intelligence (AI), press ethics, information ethics, animal ethics, ethics and the environment, business ethics, technology ethics, ethics and migration, ethics and globalization are some examples. The discipline with which the word *ethics* (-ethics) is combined gives rise to its own ethical problems, which require ethical reflection and its own ethical guidelines. Even war is said to require its own war ethics. (Segerdahl P. 2017).

In the newsletter, *Bioethics* holds a special position. *“Bioethics is the multi-disciplinary study of, and response, to moral and ethical questions. Bioethical questions often involve overlapping concerns from diverse fields of study including life sciences, biotechnology, public health, medicine, public policy, law, philosophy and theology. They arise in clinical, research, and political arenas, usually in response to advances in biology, health care, and technology, particularly biotechnology.* (John Hopkins Berman Institute of Bioethics).

The information conveyed via the ethics newsletter should be relevant to bioethics and, by extension, to practical ethics work. It could be about the ethical norms that form the basis for crucial decisions in society, the ethical issues that are topical at the time, the ethical issues in topics that are debated at the moment, about the arguments in favor and against when there is a decision to take and at times when ethics problems appear, about which areas of ethics that are the subject of research and more. The information may also concern how ethical issues are ranked, how ethics are prioritized, how ethics are generally handled in organizations and in society at large.

Recipients of the Ethics Newsletter should have access to facts and concrete examples to help them reflect on the implications of basic ethics principles in a variety of areas where ethical considerations arise. By acquiring such broad knowledge, recipients should be able to view phenomena from different perspectives, identify and distinguish ethical problems, form their own opinions on important ethical issues, and develop and strengthen their own arguments in order to engage in ethical dialogue actively and effectively to consciously deal with ethical problems.

## **2. Voluntary non-profit work**

The fact that non-profit work is unpaid distinguishes it from ordinary paid work. To work non-profit means that someone does something because the person is interested in it and not for making money. The person works for a non-profit goal (NE). Non-profit work is done for the good of someone else. The motivation to work non-profit exists as an internal state that makes people do something, to move in a certain direction and to continue to be involved in an activity (Ormrod J.E. 2016). Non-profit work can fulfill different needs in people and those who work non-profit often benefit from it in some way (Hastö D. 2018).

Challenges in non-profit involvement are lack of time, lack of energy and strength, financial obstacles, emotional challenges, lack of support and too high expectations from others in the organization or from those who benefit from the non-profit work (Volunteer Barometer, 2024).

To work non-profit with the newsletter was a different way of working than what I had previously done when I was assigned to provide conversation support to tortured asylum seekers for three years through the Red Cross. This time my volunteer work would be different in many ways. It would be done on a much larger scale and outside the safe framework that a non-profit organization used to offer. It was also special in the way that my very own non-profit work was the only option left for the newsletter project to become a reality.

A lot of time, expertise and resources were required to make the project works. I was committed, motivated, and had time and opportunity (I had my pension that gave me a secure income). What drove me was only the good result I expected to achieve and the benefit for others who would hopefully follow it.

Working as a volunteer has its advantages, especially because this special way to accomplish my work gives me the opportunity for greater freedom to decide both over my time and over how the work is to be conducted. At the same time, such a form of work offers a number of challenges. It is important to learn to navigate correctly to find your own place when the usual structure that surrounds an employee and that provides protection no longer exists. You might sometimes feel *“different”* and in some ways outside the group of other workers at the workplace. To be able to maintain the motivation it is therefore of great importance for those working as

volunteers that the regular staff is accommodating and willing to show interest for the persons working non-profit and for what they are doing.

### 3. Affiliation with the Karolinska Institutet

All projects require resources to be implemented. If the necessary resources for the “operating costs” were not provided, the newsletter project could not start even if I were working non-profit. It would not be enough. More was needed. With the opportunity to get an affiliation at Karolinska Institutet, the problem could finally be solved. By becoming affiliated, I gained access to a computer, a website, a place to seat and a well-reputed “platform” to start from. Without such a platform, it would have been difficult as a single individual to make my voice heard, to reach my audience and to be taken seriously. Through the Karolinska Institutet Library (KIB), I gained access to a number of scientific journals but it did not include access to daily newspapers, which are an important source of information. I then decided to cover the cost of subscriptions to a number of newspapers myself.

Special conditions must be met in order to be affiliated with the Karolinska Institutet. These conditions were tightened after a number of researchers abused the opportunity. After this, I had to apply for an extension every year and, for my part, explain why the work with the newsletter is so important to Karolinska Institutet that it should be allowed to continue. When the extension of my affiliation is no longer automatic, it is also no longer obvious that I will be able to continue delivering the newsletter year after year. Everything ultimately depends on a decision that the head of the department will make.

*“Being affiliated with KI does not constitute employment, occupation, title or position, but is only an administrative measure to provide access to such resources at KI that are necessary for the purpose of the person’s participation in the activity. Affiliation should only take place in exceptional cases and to the extent that it is specifically justified and necessary for the activity. An affiliation may under no circumstances be used as any form of reward or benefit. An affiliation shall be time-limited and may not exceed 3 years at a time. No special reasons are required to terminate an affiliation.”* (Rules and instructions for affiliation. Karolinska Institutet).

### 4. The work process

The Ethics Newsletter is expected to maintain a high level of quality and be produced in the most professional way possible. I was not a journalist and had no professional experience in news reporting, but I was interested. I knew what journalism was about and I had a good knowledge of press ethics and the work of the press ombudsman. In addition, through my previous position as ethics coordinator at Karolinska Hospital, I had experience in being responsible for the ethics training of the hospital's managers and employees. I was also tasked with providing information about health and medical ethics, legislation and other matters relevant to ethics.

**Table 1.** The steps in the work process

1. Media monitoring	-----
2. News gathering	7. Evaluation
3. News sorting	8. Follow-up
4. Quality Assurance	
5. Compilation	
6. Dissemination	

When I started the newsletter, there was no guidance, no examples to draw inspiration from, no research to lean on and no one who could provide support. I had to construct my own work

routine with inspiration drawn from journalism. This routine involves monitoring, collecting, sorting, quality-assuring, processing, organizing and distributing news about ethics via email. It also includes follow-up work and evaluation. Several of the steps in the process take place “in parallel” and are repeated every day throughout the week.

Over time, the work routine became a well-functioning process in several steps, and after eight years, I was pleased when, in connection with drafting the report, I discovered that the major American newspaper, the New York Times, had produced guidance that did not differ significantly from my own routine.

**Media watch**

The research I do for the ethics newsletter is about a "*media coverage*" which mainly affects the specific area of practical ethics. My aim with it is to find news about ethics that the recipients need to do a good work. The surveillance covers a large number of media: printed media, internet, social media, TV, radio, podcast, blogs and newsletters. The sources are many. I rarely use search engines like Google News. Instead, I prefer sources that I have chosen myself and which I have considered to be valuable and dependable. I take in new sources as well and can occasionally remove one and the other. Some examples of newsletter that I use and appreciate are reported in Table 2 and the remaining are recorded on the report's page with all references.

**Table 2.** Some examples of ethics newsletters via email

Bergen Centre for Ethics and Priority Setting newsletter (start 12/11 2024). Norge
British Medical Journal (BMJ) Today. Daily news via email.
Ethics Center. Newsletter. Australia.
Ethox Center Oxford. Email newsletter. UK
European Association of Centers of Medical Ethics (EACME). Weekly email newsletter.
Harvard Medical School Center for Bioethics. Email newsletter. US
Hastings Center. Research institute. Email newsletter. US
John Hopkins Berman's Institut of Bioethics. Weekly mail newsletters. US
National University (NUS). Centre for Biomedical Ethics Research. Ethics Bulletin. Singapore.
Nuffield Council on Ethics. Email newsletter. UK

*Bioetiknytt*, which is the Swedish National Council on Medical Ethics (SMER) channel for communicating ethics news is not mentioned in Table 2 as it does not use a newsletter via email. The news is instead published sporadically on the SMER website.

**News collection**

Monitoring the news requires a daily, continuous review. The majority of the research I do at home with the help of my own iPad and iPhone. It can happen at any time of the day.

It is each week's range of news in the media that controls the content of the newsletter. At the collection, my interest is usually aroused first by the title/heading which gives me a first idea of what the news can be about. A quick read of the large headings in the text or of the study's abstract will then be enough for me to decide if I want to save the news for further assessment. I have a long -standing training and I am usually able to decide, through a quick overview, whether the news can be worth keeping. I pass the links on to my email inbox at Karolinska Institutet every time I find interesting news.



### ***News sorting***

I reserve between two and three hours every morning to work with the news sorting. I need a computer but I do not have one on my own at home and therefore this work must at Karolinska Institutet with the computer I am allowed to use at the institution. It is important for me to continuously assess which news may be worth prioritizing. A first sorting takes place directly at the first collection of the news. The amount of links that are collected and then sent to my inbox after each search is always extensive. Therefore, the work on sorting has to be done every day to be manageable. After these first sorting rounds, I transfer the links on the chosen news to a Word document that is filled with news day after day throughout the week.

A link shows little about the content of the news. To clarify what the news is about, I usually add a brief introduction text to each link. That is useful for me, it helps me to sort and will probably also later help the readers to quickly understand what every single piece of news contains.

### ***Quality assurance of the chosen news***

The work to ensure the quality assurance cannot be done at home. It requires that I can have access to several scientific journals in order to be able to read scientific articles, something that I can only get through the Karolinska Institute's library (KIB).

I would go through the content of every article to assess timeliness and relevance. Sources should be identified and validated. The credibility of the source material must be checked and confirmed. When the author of the article is unknown, I control previous publications, institutional affiliation, etc. The quality assurance is also about reviewing the date of the publication to be sure that I do not deliver "old news".

As far as possible I control that there is no hidden advertising to find (maybe not for a product, but for example for a new book, for professional lecturers, for companies that organize paying ethics events etc.). The recipients must trust that I do not make attempts to influence, that I will always stay neutral and do not let my own ideological, political and other personal opinions come up in a way that could feel unwelcome to them.

### ***The compilation of the ethics newsletter***

My choice of news is broad and follows no fixed criteria. The ambition is to achieve a balance in the mixture so that it feels relevant, valuable and also fair because the recipients' areas of interest are many and different. I consider it important to continue to pay attention to the major overall ethical issues in medicine, the "old" ethical issues and all the new ethics issues that arise. I try to follow up on ongoing debate on various important ethical issues by publishing replicas and related articles that highlight several points of view of something that is problematic. I constantly follow new research from both Sweden and the world. I make sure to leave room for news that the recipients themselves tip on both articles and they are author and articles that I missed but which they have noticed and for disseminating information about events that they arrange.

At the time of the compilation, there is usually always too much news left. Priorities become necessary. In the end, several news articles that qualified will not be accommodated. Those who are left over end up on a "residual list" to possibly be included in the next newsletter. It is often difficult to prioritize. Eventually, I usually get a feeling that everything has fallen into place. It will then be a little easier to decide what space and placement in the order the news should get. There should be some logic in the flow of news that is presented in order for the recipient to experience a comfortable and easily accessible reading. A common disposition for the

newsletter is reported in Table 3. On Friday, the newsletter has taken shape. On Saturday and Sunday, it is honed and adjusted. Changes can be made to the very last minute.

**Table 3.** The ethics newsletters disposition

1. A greeting to the recipients with an information or a reflection from the sender
2. A selected article on a large high-current global general issue (war, climate, etc.)
3. New policies from the Swedish government. Reports and other news from authorities and relevant organizations
4. News and debate articles from Swedish newspapers and other media
5. New research from Sverige and the world
6. Articles from foreign newspapers, scientific journals and other media
7. Information on upcoming seminars, courses, conferences from all over the world

***Distribution of the newsletter***

Initially, I didn't attach much importance to what day of the week the mailing took place. It was when I had finished the newsletter. Over the years, as a subscriber to other people's newsletters, I realized that I appreciated knowing what day and time I could expect to receive their email mailing. I thought that this could also play a role for the newsletter recipients. Now I always aim to get the newsletter out every Monday morning, usually before 10:00. Regular mailings also provide a rhythm in my work that makes it easier for me as the sender.

To send the newsletter, I use a mailing list. In connection with the registration, a new subscriber receives general information and is also asked to provide written consent for their name and email address to be on my lists. Collecting addresses that go to individuals means handling personal data and that I have found out what is required by GDPR and personal data legislation. The subscribers' consent and the list of names are saved in Word documents on my computer at KI and in Outlook. The function "BBC. Blind Carbon Copy" (to be able to send e-mail to an entire group without recipients being able to see other people's e-mail addresses) is used for all mailings. The mailing list is updated as soon as messages from recipients about subscriptions or any changes arrive. No automatic function to subscribe and unsubscribe has yet been installed. All conversations need to be conducted via e-mail. Once or twice a year I remind subscribers of how to proceed if they want to cancel their subscription.

I control by myself the entire process from start to finish, including sending (delivery) the newsletters to subscribers. Most organizations don't have the ability to do it themselves, they use a provider, an external service for sending the newsletters. Special newsletter platforms (such as Substack) offer a way to communicate with subscribers and can help create, plan, and send newsletters.

***Evaluation***

There has never been a formal evaluation of the email newsletter on ethics. However, it can be said that a continuous informal evaluation to make the newsletter better is carried out by the recipients by regularly reacting, leaving feedback, sending comments, asking questions and giving tips. Several recipients are well-known experts in the field of ethics. They would not let something I have conveyed pass without comment that obviously contains errors. I regularly encourage the recipients to leave feedback and always consider what they convey to me and correct any errors.

Another type of continuous evaluation is carried out through an automatic function in the Microsoft email system Outlook on my computer. Every week, this function automatically

provides information on how many recipients in percentage have opened the week's newsletter. The figure is usually stable and falls between 60% and 70%. The function also provides the opportunity to see how long it takes for the recipients to open the newsletter after it has been sent. Usually, just over 50% open the newsletter the same morning, i.e. within about 4 hours. The figures show a relatively good result but give no idea of how satisfied the recipients are with the newsletter.

Several recipients forward the newsletter to all or parts of an organization, an ethics group, a workplace, etc. They have voluntarily taken the initiative to act as contact persons. Then it becomes impossible for me to keep track of how many people benefit from the newsletter. Although it may feel a little awkward to lose control of how many people read the newsletter, the important thing is not to be able to show a high number of subscribers. What should always be highly valued is that the information about ethics reaches and is useful to as many people as possible. It is gratifying that there are recipients who are prepared to try to spread the newsletter.

The Ethics Newsletter is not marketed in any other way than by the recipients themselves speaking well of it, telling people about it. According to research, this is likely to prove to be the most effective way of publicity, a way that also costs nothing (Nielsen 2012). The number of subscribers has increased over the years to about 150 people simply because the subscribers themselves speak highly of the newsletter at their workplaces, organizations or with friends. Teachers usually recommend the newsletter about ethics in ethics courses for which they are responsible. The recipients themselves use the newsletter as a communication channel to inform the recipients about their own ethics courses and events of various kinds.

With constant training and acquiring new experiences and knowledge, I have, without thinking about it, developed a higher degree of expertise, a kind of "*fingertip feeling*" that makes my work easier. Even though I have now become an expert, it never really feels like it. I still have a lot to learn and almost after every mailing I tend to wonder if what I am doing is the right thing.

Feedback from the recipients is necessary for me to be able to adjust the content of the newsletter.

Previous studies have investigated why newsletters have failed. It was often because the content did not correspond to what the recipients expected and needed. The newsletters did not deliver what was promised (Social Platform Vero). Therefore, feedback from the recipients of the newsletter is important. The newsletter should be able to meet the expectations of the readers and I need to know if what I do is perceived as relevant and high-quality work. Feedback is also needed on an emotional level, so I feel that what I do is meaningful. The newsletter should meet the readers' expectations in order to continue to exist, but this should always be balanced against what the person behind the newsletter should be able to achieve in order to be able to continue working as a volunteer and get pleasure from doing so.

### ***Follow-up work***

The follow-up work consists, among other things, of providing feedback to recipients who have contacted me with a question, a tip or comments. I respond as quickly as possible and try to help as much as possible.

Another part of the follow-up work involves collecting the month's newsletters, usually four, in a PDF file each month, which is then published on the department's website. Since the start in 2016, approximately 350 newsletters have been distributed. All newsletters have been saved so

that anyone who wishes can read them. Newsletters from 2016-2018 are archived on my computer. Newsletters from 2019-2024 are published on my website Karolinska Institutet, Department Lime. [Nyhetsbevakning om etik | Karolinska Institutet](#)

Such a collection of information about ethics is unique and can be good to have access to if, for example, you want to investigate which ethical issues have received more or less attention or how the debate on a specific ethical issue has developed over a period of time. For example, recipients should be able to search for and go back to information they haven't saved but now need. New subscribers should be able to use the collection to get an idea of what the newsletter is about. Finally, this collection can help me gain perspective on how my work with the newsletter has changed over time, if what I'm doing is going in the right direction.

***What topics have previously been covered in the email newsletter on ethics?*** - An example from a six-month period January-June 2018. (Table 4)

**Table 4.** Most common topics in the newsletter during January-June 2018

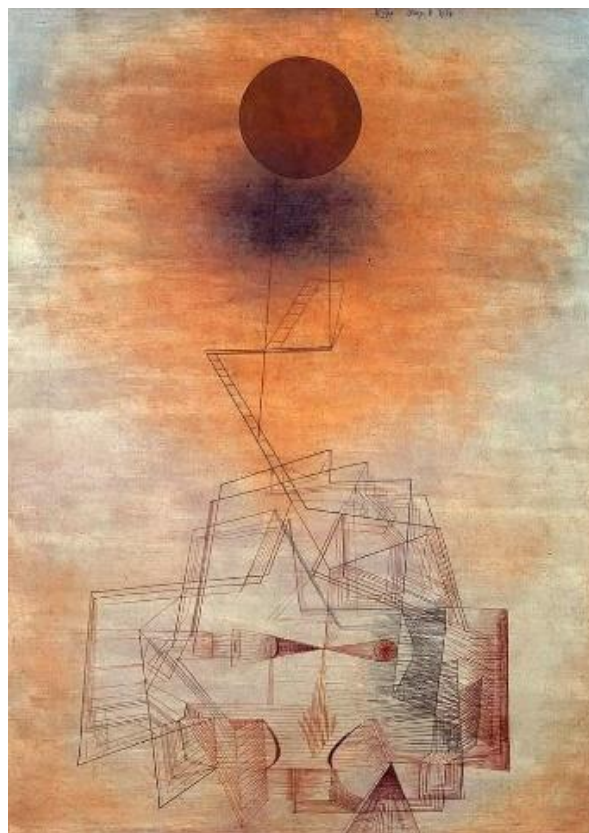
Artificiell intelligens (AI)	Life-determining care decisions at the end of life
Care for people without a permit	Late abortions
Centralization of highly specialized care	Mental illness
Children and other relatives who interpret	Medical age assessments in the asylum process
Child marriage	
Compulsory care, Compulsory vaccination	
Decision-making capacity	New legislation.
Digitalization. Digital care.	New reports and surveys
Discrimination	New research
Expensive drugs	Organ donation
Ethical review of research	Private healthcare companies
Experimental treatment	Screening for prostate cancer
Equal care. Priorities. Cost-effectiveness principal.	Shaking baby syndrome
Fetal diagnostics	Use of consultants and temporary staff
Genetic	Waiting time for cancer patients
Governance and management of healthcare	Work environment. Threats and violence

If we were to compare the results from 2018 with the same period in 2024, we would be able to see differences in which topics were relevant but also many similarities. The content of the newsletter changes based on what is happening nationally and internationally. The collected newsletters thus provide a picture of how society and values are changing.

## Part 3

### *What would the recipients miss if the Ethics Newsletter were discontinued?*

*- results of the 2024 survey*



Paul Klee. Bounds of the intellect. (1927).

*"In a world where hate and threats are becoming more and more normalized, especially when you have a different opinion, it is especially important to have an inner compass that guides you to the right decisions and the right attitude. This can only be achieved with training. The articles in the newsletter Marie sends are exactly that. A training for a correct ethical attitude."*

C.S.M., participant in the 2024 survey.



## Abstract

**Background.** The e-mail newsletter on ethics is the result of non-profit work. It started in 2016 in an attempt to address the lack of information on ethics that had long been a well-known but persisting problem despite the fact that access to such information is essential. After eight years and approximately three hundred and fifty newsletters, the recipients had become accustomed to regularly receiving up-to-date information on ethics via e-mail. The lack of information on ethics for this group of people was not a problem anymore. How would it feel then for the recipients of the newsletter if it had to be stopped for some reason? Would they miss it?

**Aim:** Investigate what the subscribers would miss if the e-mail newsletter on ethics were discontinued

**Method.** Qualitative study. A survey with a single open-ended question was sent via email in June 2024. Of the 46 selected recipients, 33 (71.7%) responded. This corresponded to 23.4% of the total number of recipients of the newsletter (141) at the time. A thematic analysis was conducted.

**Results.** Two themes and eight sub-themes emerged that illustrated what the participants would miss if the email newsletter were discontinued: **Theme 1:** *The quality and functionality of the service.* Four sub-themes: *A unique source of information and knowledge, Compilations with high quality, The time saving and A channel that promotes the ethics conversation and enables new contacts and collaboration.* **Theme 2:** *Positive experiences and mixed emotions.* Four sub-themes: *Joy, inspiration and other spontaneous positive emotions, Security of being updated, Gratitude to the sender and Worry about losing the newsletter.*

**Conclusion.** There are no examples of similar newsletters on ethics in Sweden. The literature search gave no such results and the participants did not know of any other ethics newsletters. It is likely that the survey is the first of its kind to contribute empirical knowledge in this specific field. The newsletter provided participants with aggregated information that they could not obtain elsewhere. In addition to the newsletter's functional benefits, participants would miss the positive experiences that the newsletter generated. The prospect of losing the newsletter made many of them worried. It would therefore be important to start investigating what alternatives might exist to ensure continued access to information about ethics, both for the newsletter's recipients and others.

**Keywords:** E-mail newsletter, news coverage, news reporting, digital information, ethics, non-profit work

## 1. Background

Our society is based on a number of ethical values. These values have been defined, established and ethical principles have been ranked in an ethical platform. It constitutes the guideline for the laws that regulate various areas of society, including the field of health and medical care.

Information about ethics is therefore information that should be considered important and in many cases necessary to know. Many are aware of this and regret that information about ethics is not made more accessible and understandable.

We all have a responsibility to stay informed, but for some people in society, such as politicians, lawyers, doctors, nurses, it is a moral duty to stay informed at least within their specific areas in order to be able to make decisions based on facts and evidence. Someone who is uninformed lacks knowledge about (and thus also understanding of) a specific area, a specific issue and that could lead to limited awareness of available alternatives and of the possible consequences of a decision. Furthermore, it could lead to an inability to be involved and then to be able to influence what is going to happen.

Concrete measures are needed to address this frustrating lack of information that is having negative consequences and that affects stakeholders on a daily basis.

Lack of access to information and thus lack of knowledge about ethics has been a well-known problem in some circles in society, but, apart from the occasions when something serious has happened, the question has never received sufficient attention.

As a registered nurse and especially through my background as an ethics coordinator, I was very aware that a new, simple, qualitative and adapted way of conveying information about ethics was needed. When the time of my retirement came I had just started using newsletters via email as a communications channel, although only sporadically, to convey ethics news. My newsletters were

sent to the ethics representatives at Karolinska Hospital and to the members of the National Ethics Network, a network that I had initiated and of which I had been chairman for many years. In 2016, I had the opportunity to test a newsletter as a communication channel, this time on a larger scale and with Karolinska Institutet as my new platform.

In 2024, the ethics newsletter had existed for eight years. Approximately three hundred and fifty newsletters had been sent. The newsletters recipients had become accustomed to receiving weekly information on ethics and other areas such as law and politics, as these are highly relevant to ethics. The lack of information on ethics for this group had not been a problem for a long time.

I wondered now how the recipients would feel if they could not continue to have access to the email newsletter on ethics, if for some reason it had to be discontinued?

### **Aim of the study**

The purpose of the study is to find out what the recipients would miss if the email newsletter on ethics were discontinued.

## **2. Method**

### ***Design***

Qualitative method. The survey had one (single) open-ended question: “*What would you miss (if anything) if my weekly newsletter with news about ethics was no longer available?*”.

### ***Participants***

The survey was aimed at the newsletter’s recipients. The names of the participants were taken from the mailing list that I used for sending the newsletter.

46 recipients were invited to participate in the survey. The selection was made based on two criteria: 1. A geographical spread should be achieved

2. A combination of new participants and of participants who had received the newsletter for a longer time should be achieved

### ***Data collection***

At the end of June 2024, I sent an information letter and a request via email to 46 newsletter recipients (attachment). 33 recipients sent an answer to my question.

The response rate was 71.7%. This corresponded to 23.4% of the total number of subscribers, which was 141 at the time.

### ***Data analysis:***

Participants' responses were received via email. The responses contained valuable information that showed that the participants were engaged and that the issue was felt to be important.

The responses were copied from the email to a Word document as they went along. The data collected was analyzed using a thematic analysis (Braun and Clarke 2022, Byrne 2022).

The three main goals of the thematic analysis were to:

1. Identify important themes from the data,
2. Understand how they relate to each other,
3. Find how the themes appeared in the data so I then would be able to use them to describe the phenomenon that this study was looking at.



**Respondents' background data**

- **Gender:**

Women:	(n 20)	60.7%
Men:	(n 13)	39.3%
- **Participants' professions:** Nurse (9), doctor/physician (8), philosopher (6), physiotherapist (2), dentist (1), sociologist (1), psychologist (1), journalist (1), hospital chaplain (1), administrator
- **Geographical distribution:** Dalarna, Gävleborg, Halland, Kronoberg, Linköping, London, Norrbotten, Skåne, Stockholm, Västmanland, Västerbotten, Västra Götaland, Uppsala, Örebro.
- **Participants' workplaces**

**Table 1.** Participants' workplaces

<b>University/College:</b> Gävle University of Applied Sciences. Karolinska Institute (KI). Royal Institute of Technology (KTH). Linköping University. Lund University. School of Health and Psychological Sciences, City University of London. Stockholm University. Umeå University. Uppsala University. Örebro University.
<b>Hospital:</b> Astrid Lindgren's Children's Hospital. Växjö Central Hospital. Halland Hospital. Karolinska University Hospital. Sahlgrenska University Hospital. Södersjukhuset. Örebro University Hospital.
<b>Health center, Psychiatry, Public dental care:</b> Halland Region. Dalarna Region. Norrbotten Region. Gothenburg City. Örebro Region.
<b>Other:</b> Swedish Red Cross in Stockholm.

Many survey respondents took place as members in ethics groups within various healthcare organizations, in professional associations, in pensioners' councils, in non-profit aid organizations, etc. (Table 2).

**Table 2.** Participants' participation in ethics groups, associations, networks

<b>Central ethics groups:</b> Preparation group for research applications to the European Research Council (ERC), Media Ethics Board, Swedish Medical Ethics Council, Swedish Medical Association Delegation for Medical Ethics (DME), Swedish Nursing Ethics Council, National Board of Health and Welfare's Ethics Council.
<b>Local ethics committees:</b> Karolinska University Hospital, Ethics Council for the Dalarna Region, Ethics Council for the Halland Region, Ethics Council for the Norrbotten Region, Sahlgrenska University Hospital, Södersjukhuset, Västmanland Region.
<b>Associations, councils, networks:</b> The Health and Medical Services Board's Pensioners' Council, the Municipal Executive Board's Pensioners' Council, the Rosengrenska Non-Profit Medical Network, the Swedish Association for Narrative Medicine, the Swedish Red Cross.

**Ethical aspects**

Participation in the survey was voluntary. Participants were informed about the purpose of the study. The participants' names do not appear in the report. All data is stored on my computer at KI and only I have access to the participants' original responses.

Participants were given a first draft of the report to read and were asked to provide feedback before further distribution to other subscribers and further publication on the Karolinska Institutet website would take place.

### 3. Results

Through the thematic analysis, two main themes and eight sub-sub-themes emerged that describe and represent the different specific views of the participants' responses and illustrate what the participants thought they would miss if the newsletter were no longer available and what they feel in the face of this eventuality.

**Table 3.** Thematic analysis. *What would the participants miss?*

<b>Theme 1: Quality and functionality of the service</b>
High-quality compilations
Time savings
A unique source of information and knowledge
A channel that promotes ethical conversation and enables new contacts and collaboration
<b>Theme 2: Positive experiences and some mixed emotions</b>
Joy, inspiration and other spontaneous positive emotions
Feeling secure being updated
Gratitude to the sender
Worries about losing the newsletter

#### Theme 1. Service quality and functionality

*"I would miss the overview of what is happening in the field of research and medical ethics. The newsletter is a very simple and effective way to stay up to date, but it is not just about saving me time – I would not have been able to find evidence from such a wide range of sources, even if I had been able to find the time. So the newsletter is very valuable. I often forward things I have noticed through the newsletter to colleagues, and I include it in our own monitoring of the world. I hope that you want to and will have the opportunity to continue with the newsletter!".* Sent by a university administrator and researcher.

All participants would miss the newsletter in some way. Many considered the newsletter to be very important, some thought the newsletter was indispensable, others answered that the newsletter *"made a difference"* to them. Many participants felt the newsletter was important and had great value for them. The majority of the respondents would simply miss everything the newsletter brought to them.

*"What are the current issues that are being discussed within Ethics in Sweden and sometimes from other countries? I would largely miss this, or not be aware of it, if the weekly newsletter did not exist."...*

*"What I would miss if the newsletter no longer existed is that it would be missing!"...*

*"It's easy to answer that question: I would miss everything"...*

*"The answer is very simple: if there is one email correspondence that I would miss if it were to stop tomorrow, it would actually be your emails newsletters"...*

*"I would really miss the weekly newsletters - for me they make a difference!"...*

*"The newsletter are absolutely indispensable for me" ...*

#### ***A unique source of information and knowledge***

The "uniqueness" of the work that was done with ethics newsletter was addressed by the participants: *"Marie does a unique job by compiling articles and links related to ethics"*.

The newsletter gave the participants valuable information that they could not get from any other source and they did not know any other similar source of information about ethics to go to that would work for them if the newsletter was discontinued.

*“Your weekly newsletter is the only summary/ compilation in ethics that I know of.” ...*  
*“If Marie’s newsletter were missing, there would be no one to contribute this knowledge”...*  
*“If the newsletter did not exist, I would not have the knowledge that I need to be able to do what I do”...*

The list of what kind of information and news the participants appreciated and would miss if the newsletter did not exist got long. (Table 4).

**Table 4.** Specific information/topics that participants valued most in the newsletter

<ul style="list-style-type: none"><li>• Articles that are relevant based on the reality we live in here and now and with different perspectives and in more contexts</li><li>• Articles in the field of research- and medical ethics</li><li>• Current news articles, referrals, scientific literature</li><li>• Current ethical issues discussed in ethics in Sweden and from other countries</li><li>• Current issues that broadly fall within the areas of healthcare ethics and medical ethics</li><li>• Current issues with broader societal connections and ethical elements</li><li>• Current ethical issues in Health/Human Rights/ethics/migration</li><li>• "Deeper" reading on issues related to Ethics in Health and Medical Care</li><li>• Information about conferences, courses, dissertations, upcoming events, about when various ethics gatherings will take place.</li><li>• International news which gives a picture of what the debate looks like outside Sweden's borders</li><li>• News about what is happening in the field with a focus on Swedish conditions</li><li>• News about politics (government and agency investigations, bills, etc.)</li><li>• News about different types of ethical initiatives in healthcare</li><li>• News from international UN bodies, the EU and other important authorities and organizations that write about ethics in original articles</li><li>• Ongoing investigations, new reports, debate articles and scientific articles</li><li>• Popular science articles in magazines and newspapers</li></ul>
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**High-quality compilations**

The participants agreed that the compilation/summary of the news was of high quality, very useful, very important for them and that they could not be without it. They described several qualities in the newsletter that they would badly miss if it were discontinued (Table 5).

*“The scope and expertise of the selection is admirable”...*  
*“Your newsletters are incredibly important and valuable”...*  
*“Your weekly newsletter is so packed with essentials and I wouldn’t want to be without any of your research.”*

The newsletter's wide range of news relevant to ethics made the participants aware of news that, according to them, they would not have been able to find anywhere else. The newsletter gave them access to a big amount of information that they did not usually "scan" themselves and that they could therefore have missed completely. This included articles that contained different perspectives on ethical questions or problems. It could also be information about events from around the world which were in some way relevant to ethics:

*“what I would miss most is the breadth of the news and topics you highlight – some I have come across before, but usually only a fraction”...*  
*“I can see that each newsletter always contains at least one – often more – links (texts etc) that I did not know about and that have been of interest and useful to me in my job.” ...*

*“The newsletter broadens “my ethical field of vision” as topics come up that I probably would not always think of searching for myself”*  
*“I would miss not being able to devote myself to “deeper” reading about issues related to Ethics in Health and Medical Care and also issues with broader societal connections and ethical elements”...*  
*“I had never found the summer school at Venice International University (theme 2023 - ethics & organ donation), which was a fantastic experience last summer”.*

A participant who is a medical ethicist, appreciated the way the newsletter was structured: *“I really appreciate that the letter is so well balanced. It is rich in content but still easy to understand (there are too many newsletters that are not).”*

Another participant appreciated that the newsletter was sent frequently and regularly: *“What I would miss if the weekly newsletter no longer existed is the frequent and regular updates”...*

**Table 5.** *“Qualities”* in the newsletter compilations

<ul style="list-style-type: none"><li>• Balance in the mix</li><li>• Breadth</li><li>• Competence in the selection</li><li>• Completeness</li><li>• Frequent, regular updates</li><li>• Great usability. Easy to use in practice</li><li>• High standard achieved every time</li><li>• Information tailored to the recipients</li><li>• Selected and quality-assured content</li><li>• The scope</li></ul>
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***A time saver***

The word time in relation to lack of time appeared in many responses. Participants experienced lack of time as a major obstacle to being able to obtain the information about ethics they needed. The respondents would not have the energy to search for new information themselves either if the newsletter did not exist.

*“The weekly newsletter gives me the world monitoring that I myself have neither the opportunity nor the time to do on my own” ....*  
*“I don’t have time to look for the information I need”...*  
*“I wouldn’t have time to look up everything you find for us readers” ...*  
*“Collecting the information would be too time-consuming for me, so I would simply be less well-informed about what’s happening in the areas”...*  
*“If your weekly newsletter didn’t exist, I would have to search for articles on the subject myself, which would happen much less”...*

Several respondents reported that the time saved thanks to the newsletter made it possible instead to do work on integrating ethics into daily work in various ways. The newsletter was also great source of inspiration and brought every week lots of material that respondents could use locally in their own ethics work.

*“I can quickly absorb the essentials without reading through extensive material”...*

*"The newsletter saves me a lot of time that I can instead use for more direct work with ethics in practice"...*

*"I don't have time to follow all the media, so the newsletter gives me a picture of what the ethical discussion looks like in Sweden. It helps me relate my work to this ethical discussion when I write and or make presentations in Sweden."*

### ***The newsletter: a channel that promoted the ethics conversation and enabled collaboration***

A large number of respondents would miss the newsletter because it achieved an important function in making the conversation about ethics possible, making it happen more often and more easily with a bigger number of people.

*"I usually give my own small ethics group here biannual summaries of what is going on in ethics-Sweden"...*

*"I forward the articles I consider to be particularly interesting to my colleagues. This opens up discussions within ethics among us that, otherwise, would not happen as often"...*

*"Your weekly letters are very valuable in my work (which is a constant endeavor!) in raising and maintaining the ethical perspectives in my work with quality and patient safety"*

*"Your newsletters are incredibly important and valuable even now in my assignment as chairman of the municipal board's pensioners' council. We handle several matters from the municipal board, especially elderly issues. I also sit on the health and medical care board's pensioners' council. There are lots of ethical aspects in both of these councils"*

A respondent would miss the opportunity that the newsletter created to make new contacts and new collaborations, as well as the feeling of being part of a community:

*"To feel like part of a larger community by receiving emails from an expert and at the same time make new contacts and collaborations that the newsletter often leads to."*

Another respondent described how the information delivered through the newsletter could have an influence in increasing awareness of ethics in his own workplace:

*"Ethics is more important than many people think and are aware of. It is rarely discussed at the health center, which is my workplace. Yet everyone works with ethical issues and makes ethical decisions without being really aware of it. So I would really miss the weekly letters - for me they make a difference!"*

The newsletter was considered to be an important and effective channel for receiving information but also for distributing the recipient's own information throughout the country. For example, to advise on new articles that one's own institution had published or to advise on various ethics events that were organized locally throughout Sweden.

*"The weekly newsletter serves an important function for the conversation about ethics in Sweden. It is also important for disseminating information"...*

*"Our association has benefited greatly from the mailing. Both for gaining knowledge and for disseminating information about our activities, which have a clear ethical focus"...*

*"The newsletter is an effective channel for giving tips about various ethics events, such as Smer's seminar days and SLS's ethics days"...*

*"We got some students to the evening course thanks to the announcement on the weekly newsletter"...*

Several respondents had the habit of forwarding the entire or selected parts of the newsletter to others within their own ethics council, their own organization, but also outside.

*"I am the leader for a Councils ethics group and I forward your letter to the other members of the ethics group every week" ...*

**Table 6:** Examples of how participants used the newsletter in practice

<ul style="list-style-type: none"> <li>• On a daily basis directly in the organization</li> <li>• To disseminate information about courses on ethics, coming events and new publications</li> <li>• To incorporate information about ethics from the newsletter into my own organization external monitoring</li> <li>• To initiate discussion and reflection on ethics at the workplace</li> <li>• To highlight and maintain the ethical perspectives of the work with quality and patient safety</li> <li>• To provide the ethics group with semi-annual summaries of what is going on in ethics-Sweden</li> <li>• To forward information to colleagues, departments and people in different parts of the organization</li> <li>• To forward information to various ethics groups, to the ethics councils' members, the ethics representative, etc.</li> <li>• In discussions within the Swedish Pensioners' council (PRO), NGO etc.</li> </ul>
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## Theme 2. Positive experiences and mixed emotions

The participants' experiences and feelings generated by the newsletter were put in focus in Theme 2 (table 7).

**Table 7.** Experiences and emotions generated by the newsletter

Positive	Positive (forts.)	Negative (if the newsletter was discontinued)
Joy, Expectation, Curiosity, Wonder, Aha! experience, Positive energy, Inspiration, Motivation, Thought, Reflection, Depth	Sense of participation, Community, Security Gratitude --- Gives a golden edge to life Makes a difference Feels like a gift	Concerns about losing something unique and important.  Feeling of loss, hollowness, boredom if it happened

The participants said that the newsletter generated a wide range of positive feelings like joy, curiosity and inspiration. Being able to stay constantly updated gave the recipients a sense of security. They participants expressed gratefulness to be able to receive the newsletter. They valued that the newsletter came from a committed and engaged sender they knew and could easily communicate with.

At the same time though, the participants' answers expressed a clear concern knowing now that the service could someday no longer exist.

### ***Joy, curiosity, inspiration and other positive emotions***

The participants were in many ways touched, sometimes deeply, by being offered the opportunity to get the newsletter and all the good it was bringing to them:

*"I am so happy and grateful every time a newsletter from you drops by"...*

*"I read your newsletter with joy and curiosity"...*

*"With curiosity and wonder, I am captured by everything that is going on"...*

*"There have been many times during this time that I have had an Aha! experience when I read your mailings"...*

*"It is a personal, ongoing education to read other people's thoughts, research, deep knowledge..."*

A respondent who was active member of several ethics' councils described in detail the experience of receiving the newsletter every week and how much she would miss it:

*"I would miss not being able to look forward to receiving the Weekly Newsletter on Ethics, as I often read it on the weekend when I am free, it then becomes a time for thought and reflection. It gives depth with an ethical dimension to various issues in our time. It feels like a bit of a "golden edge", a "silver lining" in life to be able to read the weekly newsletter, even though there can be difficult things that are discussed."*

### ***Security of feeling updated***

Keeping up to date in order to find out the facts is crucial in every person's life. The participants were aware of this and many felt that the information provided by the newsletter was an important factor in keeping them up to date with what was happening in the field of ethics.

*"If I hadn't had your weekly letter, I would have been much less updated on current ethical issues and that would have been both boring on a personal level and bad for my professional role."...*

*"Having the opportunity to stay updated through the newsletter gave the participants a sense of calm and security." ...*

*"I feel more at ease that I'm not bringing old news that is no longer relevant." ...*

*"The newsletters compilation makes me feel safer and more secure that I "have control." ...*

*"It is important for me to keep up with what is being discussed in ethics, since I am a member of an Ethics Group in my own Region." ...*

### ***Gratitude to the sender***

Several participants wrote that it meant something to them that it was someone they knew who happened to be the sender of the newsletter. *"It is a great joy that it is you who is the sender, someone I know unlike anonymous sites."*

Some valued that I was doing my work in a different way: One participant appreciated the fact that the newsletter struck a good balance between the personal and the professional: *"I like that the newsletter has a personal touch, without making it any less professional."*

Many participants expressed gratitude for the work being done by the sender:

*"I am always very grateful and impressed by your compilations"...*

*"I always think about how lucky we are to have you there to do this for the rest of us!" ...*

*"I am grateful that you offer us this great service, completely free of charge and always spiced up with nice pictures, which I appreciate very much and which makes me happy!" ...*

*"I am so grateful that I can get a dose of selected articles and topics to think about and discuss further"...*

*"First of all, I want to say that your weekly newsletter and the work you do is fantastic"...*

### **Concerns about losing the newsletter**

There was a general concern among the participants that the newsletter could disappear and with it the possibility having access to comprehensive, up-to-date and curated information on ethics. The respondents had difficulty imagining what would happen if the newsletter were discontinued. Many thought they would feel sadness and emptiness:

*"I can't imagine what it would be like if you stopped"...*

*"It would be very sad if the newsletter stopped"...*

*"It would be an empty hole that I myself cannot fill"...*

*"I would miss the inspiration and motivation that the newsletter provides"...*

Respondents did not have any suggestions of their own on how the future of the newsletter could be secured. However, they had a strong desire and hope that the sender would be able and willing to continue delivering the service:

*"I hope you will continue for a long time to come!"... "I hope you continue as long as you can"...*

### **Other findings**

Two respondents reacted to the fact that the newsletter was based on non-profit work: A chief physician at a university hospital wrote that one could not expect a non-profit to continue for a long time. *"A non-profit work cannot last forever, of course"*.

A chairman of an ethics council questioned whether it was right to use non-profit work as a form of work, whether it could be unethical to do so and whether this risked sending the wrong signals about the value of ethical work: *"Ideally, it shouldn't have to be, I think, unethical if nothing else. If ethical work is to be based on non-profit work, it sends the wrong signals about the value"*.

## **4. Conclusion**

The ethics newsletter has created an opportunity to focus on the topic of *"practical ethics/applied ethics"* and subscribers have, through the newsletter, been given the chance to be part of a network with other people who are particularly interested in practical ethics in a broad sense. Research has shown that the use of email newsletters as a communication channel can help *"niche specific"* topics that have previously had difficulty reaching an interested audience to come to light (Newman 2022). Such a positive effect is also described in the responses to the survey and is consistent with what the researchers have observed in other studies.

The current survey is the first of its kind to contribute to empirical knowledge in the specific field of *"email newsletters on ethics"*. This makes it valuable even if the survey is limited.

The fact that I did not send the survey to all subscribers was due to a calculation I made about how much work the survey would require of me and how much I thought I could handle. I decided that it was better to conduct a small study than to do no study at all.

Even if the survey participants represented a fifth of the total number of subscribers their answers could still give a fair picture of how things were in the larger group of subscribers regarding professions, workplaces, institutional affiliation, and geographical distribution.



The participants' answers showed that they were committed and knowledgeable people, often with great expertise in the field of ethics. The collected data contained valuable material that met my expectations. I was not surprised by the results. I already knew that the recipients of the newsletter generally had a great interest in the subject and that many were involved in the development of ethics in theory and practice. The expertise, the accumulated experiences, and the commitment that the recipients of the newsletter possess should be seen as an important resource for the organizations they belong to and for society at large. The question is whether they themselves felt that they were given the opportunities to contribute to the same extent that would be needed and as they wished.

The recipients of the newsletter who participated in the survey came from different organizations and were struggling with different ethical challenges. It is conceivable that they were primarily interested in the specific ethical issues they needed to deal with on a day-to-day basis. However, their answers showed that they were unexpectedly very satisfied with receiving a large and mixed amount of information, even from outside their specific field.

The fact that the newsletter's mixed content had the ability to trigger curiosity and wonder was something that the participants appreciated, something that gave them a recurring pleasant "*Aha experiences*".

Many mentioned the breadth of the compilations as something very positive. Through the great mix that the newsletter offered, they were able to find both the specific information that they needed and at the same time allow themselves to be tempted to take part in information from other areas that they would not have spontaneously searched for. The participants did not express any wishes to receive more or any other information than the one that was delivered in the newsletter.

Based on this observation, one could consider whether it would be worthwhile, when teaching ethics or providing general information about ethics, to venture beyond the usual ethical issues to a greater extent than today. It would perhaps be valuable to aim for a greater breadth, a greater mix by including highly topical ethical issues from many different directions, as I do in the newsletter. In that case, the content of the newsletter could be a help/resource for teachers. In the time of change we live in, when everything is moving so fast, it has become necessary to be in step with what is happening in the world, with how people discuss and handle ethical issues and ethical challenges they face. By broadening the ethical perspective, one could reduce the risk of remaining stuck in old patterns. The discussion, conversation and reflection on ethics could then possibly become more dynamic, interesting, and useful.

The participants described the newsletter as something unique and necessary that they could not get anywhere else. It was the only way for them to access a comprehensive, quality-assured, up-to-date information on ethics. They mentioned everything they would miss if the newsletter no longer existed. It built a long list that exposed a number of existing shortcomings that the participants encountered in their daily lives in their respective organizations. These shortcomings had usually been known for a long time but had almost never been addressed.

The respondents referred to the lack of information on ethics and the lack of time in general for ethics. They said that there was a lack of time to acquire the information they needed, but also a

lack of opportunities to initiate spontaneous ethics discussions when necessary or to arrange regular times to discuss current local ethics issues together in depth.

The survey results provided a range of examples illustrating how the newsletter could facilitate ethics work and how the participants used it in practice for themselves and with others within their organization, in ethics group or in other groups. The continuous delivery of news addressing ethical issues from all over the world provided participants with a variety of material to practice for example identifying and analyzing ethical problems. The news provided support that helped readers to take the initiative to invite others for a moment of ethical dialogue or reflection. Some respondents noted that, thanks to the support provided by the newsletter, better organized professional ethics conversations might have taken place more often.

In addition to the functional benefits of the newsletter, respondents would miss the personal positive impressions that the newsletter generated. For most of them the newsletter was particularly valuable, something able to give rise to a number of positive experiences, including feelings of joy when the week's newsletter arrived and a sense of being secure when the participants could be sure that they were constantly properly updated on everything that was happening in the ethics and other relevant areas. One respondent wrote that the newsletter felt like receiving a gift every Monday, another wrote the ethics newsletter added a *golden edge*, a *silver lining* to everyday life. Experiencing such positive feelings felt like something special.

Several participants expressed gratitude that it was a person, a human being, not a robot who was the sender. They appreciated that the newsletter came from someone they knew and could trust, a person they could interact with and receive support from.

The fact that it was important for many participants that the newsletter was sent by a committed person with expertise in the subject area was something that had been observed in previous research and is therefore consistent with the results of the survey.

Some participants who read the first draft of my text noted that it was only by reading my report that they became aware of how much time I had to spend and how much work I had to put in to produce a newsletter each week. This new insight made them appreciate the newsletter and my commitment even more.

The survey showed that it is possible to address the lack of information about ethics by using an email newsletter as a communication channel. The recipients had quickly become accustomed to receiving regular information about ethics via email and for this group the lack of information was no longer a problem. The participants' answers showed that my work with the newsletter, which I do with all my heart, had the potential to increase their knowledge and to change their situation for the better.

By participating in the survey, however, the recipients became aware that the newsletter might have to be discontinued at some point and that it could happen even if I did not want it to be so. This was probably something that few recipients had reflected on before. This new insight prompted a concern about losing something valuable.

This concern was clearly expressed in many participants' responses. Their strong reactions did not leave me unmoved and that made me feel an even greater responsibility to safeguard the existence of the newsletter and to try even harder to be worthy the task I had taken on.

The newsletter is mainly the result of my non-profit work. I can understand that it might be seen as problematic that the newsletter project is dependent on my non-profit work and on my affiliation with Karolinska Institutet, which is needed to cover the operating costs. It is also true that these circumstances are the reason why the newsletter has an inevitable *inherent fragility* which in the long run might make its continued existence more uncertain than one would wish it were. I had actually already thought that could be a problem even before the project started. However, I decided that it was worth giving the project a chance.

One should perhaps ask why it had to be this way. Many people know or have experienced for themselves that it is usually difficult if not impossible to find people in leading positions in various organizations to invest money in organized ethics work and to allow ethics to take place as a natural part of the work. Such an attitude might possibly be rooted in a misunderstanding of what ethics actually is or in a difficulty in imagining what benefits there might be when investing resources in integrating ethics into the organization.

It is not a good thing when ethics does not get prioritized as highly as other areas in an organization. Without doubt this lack of interest for ethics could bring negative consequences. Ethics should be allowed to cost money. I completely agree. But when you, despite extensive efforts, fail to get resources and when there are no other options, then sometimes the choice to work as a non-profit may still be the only (emergency) solution for those who really want to try to bring about change.

I and many others have spent lots of time working on ethics without being paid for it. I chose to do so on a larger scale and for a large number of years because I have always been convinced that it is really important to care about ethics in the organization. I constantly wanted to find simple ways to arouse interest in ethics in practice, for that kind of ethics that everyone could adopt, could learn to use and could directly benefit from in their daily work and furthermore in their daily lives.

Deep down inside me, has my hope always been that if the non-profit ethics work could yield good results, this would make visible all the positive things that can come from working with ethics in practice. The concrete good results could then possibly lead to the subsequent provision of the resources needed to continue the ethics work that had already been started and already been proven. This happened to me 1997 when the hospital management at Karolinska Hospital established a new and first position as ethics coordinator after I had worked for several years as a volunteer organizing ethics work at the hospital. It happened then and can happen again.

When I now work on the ethics newsletter as a volunteer, it is not with the hope that what I do will lead to paid work – for myself. However, I would be happy if my work could lead to other people committed to ethics, preferably those who are currently recipients of my newsletter, somewhere in the country being given the task of in turn conveying information about ethics via email locally at the workplace or centrally within the respective organization. For example, as part of a service they already have.



## Closing words and final thoughts

In the introductory text of the report, I wrote about how enjoyable and meaningful it has always felt for me to work with ethics. But the newsletters' project was special because I knew that it would be my last project. It has been fantastic to work with it and now it has been exciting to write about it.

I enjoy writing about what I do and what happens to me in general although the exercise of writing can be full of challenges. Neither Swedish nor English are my native language and it makes it more difficult for me to achieve the right balance and to catch the right feeling in my text as well as to succeed with the correct grammar. In a number of cases, however, I will usually remain unaware of whether I have made such mistakes.

The report gave me the opportunity to familiarize myself with new areas such as journalism, news reporting, communication and even to learn a few more Swedish and English words. It took me time but I have persistently searched for the right word. Furthermore, I have tried to completely *own* my text, to let it sink into me in order to be able to shape it so that the reader would not only learn things but even have a pleasant reading experience. By authoring the report, I eventually found myself able to gain a better perspective on what working with the ethics newsletter entails as well as to acquire a better self-understanding of what I am doing.

Ethics should not be kept only for the few. The vast majority of people have the capacity to think, reflect, analyze and act ethically. Educating people in the subject of ethics once in their lives during their professional educational training so that they can have a foundation to stand on is good and necessary. However, such a short period of training won't be enough for a systematic ethical thinking to be integrated into everyday life, both at work and in life. A lot more training opportunities should be offered and researched. In order to deal with ethical problems and the many ethical challenges one constantly faces, not only regular training would be needed but also learning to use tools of various kinds. Developing tools to have at hand for ethics work has been an important part of my work as ethics coordinator at Karolinska University Hospital. I would want to try out everything I could think of to promote ethics in practice.

In 2005, almost exactly 20 years ago, The Karolinska University Hospital published a small notebook on ethics with the title "*Ethics and the art of being a fellow human being*". Every employee at the hospital received one exemplar. The notebook format was so small that it could fit in the breast pocket of the work shirt (so that you could always have it with you).

The hospital management together with the hospital ethics group were the initiators. I was one among several other co-authors. The notebook describes several *ethical tools* that humans have inside themselves and that are ready to use to deal with ethical problems to which they are confronted. The ethics notebook is still available on the hospital's website after all these years.

The ethics newsletter can be seen as another tool that could take place in an *ethics toolbox*. A simple tool that provides continuous support and that makes ethics feel closer, more accessible and useful. Having some well-functioning tools and having a supportive person to turn to can often be what is needed, what is effective for ethics to work in practice.

A participant in the survey wrote me the following thoughtful words: *“THANK YOU for what you do! I hope it brings you a lot of positive energy and joy!”*. The fact is that for me working with the ethics newsletter does not feel difficult or tiring. Using my expertise and my time to make it easier to convey information about ethics news gives me a strong feeling that I am doing what I have to do for others and for me. Simply, it makes me feel good. I am happy to still have something to give, happy to once again have the opportunity to engage other people, happy to be able to start a new project and make it work for a long period and happy to get the chance to become better at what I love to do. My greatest joy, however, is when the recipients show appreciation for my work both by giving me continuous feedback and by remaining subscribers year after year.

My ambition for the future is no more than to continue in the same way as I have done so far, this means continuing to inform the recipients about what is highly topical in the fields of practical ethics. In the troubled times we live in, there will inevitably be a lot to report on in the future. In such a context, it seems to me unnecessary right now to list a number of areas that should be prioritized. I can only promise to try to refine the news coverage so that nothing important will be missed. I hope that the recipients of my newsletter will continue to contribute by sending tips and giving feedback. All of that to make our ethics newsletter even better, together.

Finally, one might ask whether Artificial Intelligence (AI) would soon be able to take over the work I do producing the ethics newsletter. The question cannot be answered yet. AI is developing at such a pace that it is difficult for us to imagine what will or will not be possible in the near future. Though, recently, I read in The Guardian that it might be more difficult for AI to deal with information about news that is highly topical. More than half of the AI-generated answers in these matters were found to have *“significant issues”*:

*“Leading artificial intelligence assistants create distortions, factual inaccuracies and misleading content in response to questions about news and current affairs, research has found. More than half of the AI-generated answers provided by ChatGPT, Copilot, Gemini and Perplexity were judged to have “significant issues”, according to the study by the BBC. The findings prompted the BBC’s chief executive for news, Deborah Turness, to warn that “Gen AI tools are playing with fire” and threaten to undermine the public’s “fragile faith in facts” (Weaver M. 2025).*

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Dagens Nyheter (own newspaper subscription):

The Guardian (own newspaper subscription):

Le Figaro (own newspaper subscription):

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Altinget. Daily

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Centre for Biomedical Ethics Research Ethics Bulletin. National University Singapore (NUS)

Civil Rights Defenders

Ethox Center Oxford

Etikprövningsmyndigheten

EU AI Act Newsletter

EU. Publications Office Newsletter. Weekly

Europaparlamentets kontor i Sverige.

European Association of Centres of Medical Ethics (EACME). Weekly

Folkhälsomyndigheten

Forska!Sverige

Harvard Medical School Center for Bioethics

IAEA. Weekly

Institutet för Framtidsstudier

John Hopkins Berman Institute: Weekly newsletter Bioethics in the Academic Literature +

Berman Institute Bioethics Bulletin + Ethics & Emerging Biotechnologies newsletter + Global

Food Ethics

Karolinska Institutets omvärldsrappport via epost. Bimonthly

Läkare utan Gränser

Myndigheten för vård- och omsorgsanalys

Myndigheten för psykologiskt försvar

Nationellt kompetenscentrum anhöriga NKA

New England Journal of Medicine

Nuffield Council on Ethics

Palliativ utveckling centrum i Lund

Region Stockholm

Regionalt Cancer Centrum Stockholm Gotland

Regeringens och Regeringskansliets. Daily continuous email reports

Riksrevisionen

Röda Korset

SBU. Statens beredning för medicinsk och social utvärdering

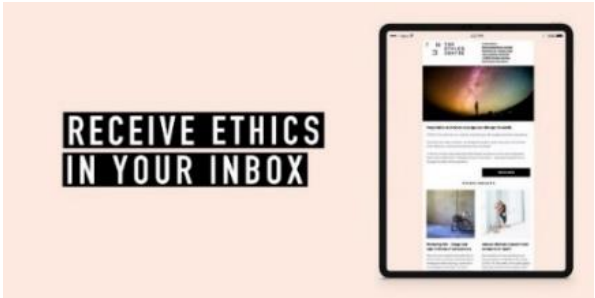
Scientific American

SST. Myndigheten för stöd till trossamfund

Socialstyrelsen  
Stockholms universitet  
Sveriges Tidskrifter nyhetsbrev. Branschorganisation i medievärlden.  
Tidskriften Sjukhusläkaren  
Time Magazine  
The British Medical Journal (BMJ) Today. Daily news via email.  
The Conversation. Daily email newsletter. Global edition  
The Economist  
The Hastings Center (research institute Bioethics)  
The Journal of Medicine and Philosophy, Oxford Academic  
Tidningen Curie  
Universitetsläraren

***Social platform X***

Aftonbladet Ledare + Debatt  
AMA Journal of Bioethics. US  
Bergen Centre for Ethics and Priority Setting  
Centre for Research Ethics and Bioethics Uppsala University Nyheter + Etikbloggen  
Dagens Medicin  
DN Debatt  
Expressens Ledare + Debatt  
Institute for Ethics in AI. Oxford University. Philosophy Faculty.  
Institute of Medical Ethics (IME). UK.  
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JAMA Pediatrics  
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Läkarförbundet  
Läkartidningen  
Ministère de la Santé et de l'Accès aux soins. France  
Nuffield Council on Bioethics. UK  
Ordre des Médecins. France  
Röda Korsets Högskola  
Stanford Medicine. US  
Stockholm War Ethics  
The American Journal of Bioethics. US  
The Ethics Center. Australia  
The Hastings Center. US  
The Lancet  
Svenska Läkaresällskapet  
Cambridge University. UK  
UKCEN. UK Clinical Ethics Network.  
UN Human Rights  
University of Oxford. UK  
Université Paris 1 Sorbonne. France  
Venice International University. Italy



## Appendix

### Information letter to participants. June 2024.

Hello! Today I have a question for you. If you have the opportunity to answer, that's great, but I can understand if you don't have time. I am aware that the period just before the summer is not the best choice of time to get answers to questions.

My question: ***What would you miss (if anything) if my weekly newsletter with news about ethics was no longer available?***

Your and others' answers will be used as part of a report that I plan to write during the summer. In the report, I will tell you about how I once came up with the idea of a project to use a newsletter and why I decided to work as a volunteer with a newsletter about ethics, how I carry out the news coverage (which sources I use, etc.), how I choose the news and compile the weekly letter, what feedback the recipients give me and how they interact with me, how the weekly letter and my way of working have developed since 2016. The report is primarily intended for the recipients of the weekly letter and could also be useful to have on hand when someone asks about what I actually do here at Karolinska Institutet.

If I get the chance, I will gladly continue with my non-profit work at Karolinska Institutet. However, I am aware that nothing lasts forever and therefore it feels meaningful to take the time to tell you about what I do now that I have the opportunity.

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