

November 2023**Health and Global Policy Institute (HGPI)****Health Information Project Global Sage Meetings for “Co-creating Health Information Right”
First meeting report (July 21, 2023)****Project background**

While “health information” includes information shared among health institutions, like the disease histories of individuals that are recorded in Personal Health Records (PHRs), it is also a form of knowledge that encompasses information on health in general. The importance of disseminating accurate information about and raising public awareness toward diseases has been emphasized in various Basic Plans for diseases like cancer and cardiovascular diseases (CVDs) formulated in Japan as well as in disease control plans formulated in other countries. We are now transitioning from an era in which health providers seek consent for treatment methods into an era in which health providers and patients will make such decisions together. This means it is now that much more important for each individual to turn their attention toward the topic of health information.

However, the people, organizations, and industries in fields related to healthcare who are expected to communicate accurate health information in Japan are required to operate under various laws and regulations like the Medical Practitioners’ Act and the Pharmaceutical and Medical Device Act. For example, pharmaceutical companies must provide information that includes the individual product names of pharmaceuticals directly to patients. For both chronic disease control and infectious disease control, healthcare is growing more complex and personalized, and there is constant shifting in the latest data and trends. This has resulted in many cases in which the Government has been unable to actively disseminate health information.

In contrast, individuals are extremely mobile in disseminating health information. This is partially due to advances in social networks, video platforms, and other social media, which are now overflowing with a vast amount of information. That includes information that is false or misleading. The field of cancer control has a long history of issues caused by troublesome food advertising or the dissemination of unscientific treatment methods, and in the context of vaccine-related information, problems rooted in false or misleading information were particularly prominent during the Coronavirus Disease 2019 (COVID-19) pandemic. Furthermore, in the current era of “information co-creation,” in which the exchange of information is occurring in a bidirectional manner across various layers, there are cases in which regulations and guidelines have been unable to keep up. A new concept is emerging in which a person’s health is affected by the information they obtain, which is known as “Information as a Determinant of Health.” We now require global discussions that cut across various disciplines to examine how to best provide accurate health information as well as who should be providing it.

In response to these conditions, this project will hold two Global Sage Meetings this fiscal year under the title, “Co-creating Health Information Right.” The first meeting brought together domestic and international healthcare professionals, patients and patient advocate leaders, and experts in fields like philosophy and religion to discuss the issue of the accuracy and reliability of health information from multi-disciplinary perspectives.

The purpose of this meeting was not to reach a conclusion on this issue. Rather, it aimed to merge multiple viewpoints from various perspectives to crystallize discussion points on the nature of health information that we need today and will require in the near future.

Keynote Lecture 1: Co-creating Health Information Right

Takeo Nakayama (Professor, Department of Health Informatics, School of Public Health, Kyoto University)

The common point between medicine and information: Uncertainty

According to William Osler, one of the fathers of modern medicine, “Medicine is a science of uncertainty and an art of probability.” Regarding decision-making, Claude Shannon, the father of information theory, said, “Information reduces uncertainty.” As we can see, “uncertainty” is the common factor among the definitions of “medicine” and “information.”

The importance of literacy in the age of social networks, as reaffirmed by the COVID-19 pandemic

During the COVID-19 pandemic, we saw the rapid spread of misinformation, which is incorrect information, and disinformation, which is fabricated information that is shared deliberately. Dr. Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization (WHO), called this situation an “infodemic.” With society facing such circumstances, the topic of “literacy” among information recipients began to draw attention. Literacy can generally be divided into “information literacy” and “health literacy.” Health literacy can be further divided into “individual health literacy” and “collective health literacy.”

- ✓ **Information literacy:** The ability to utilize information for good decision-making without being influenced by it
- ✓ **Personal health literacy*:** The extent of an individual’s ability to find, understand, and utilize information that is useful for making decisions or taking actions related to their own or someone else’s health
- ✓ **Organizational health literacy*:** The extent to which an organization enables, in an equitable manner, the individual’s ability to find, understand, and utilize information that is useful for making decisions or taking actions related to their own or someone else’s health

*“Personal health literacy” and “Organizational health literacy” were redefined in “Healthy People 2030,” the U.S. equivalent of Japan’s “Health Japan 21.” Rather than referring to the ability to simply read information, as it did in the past, the term is now used to refer to literacy that is more in-depth.

The propagation of social media has driven a transition from an era in which most people were merely information recipients to one in which they can easily become information transmitters, as well. People must be conscious of the fact that transmitting information carries a greater responsibility than receiving it, but as it is currently used, the term “literacy” mainly refers to information recipients. What is being asked now is if all people are transmitting the information they receive reflexively, without properly digesting it, or if everyone understands basic principles like objectivity, transparency, and accountability.

The Original Meaning of “Evidence Based Medicine” (EBM)

While many people understand evidence-based medicine (EBM) to mean “healthcare that emphasizes scientific evidence,” in reality, it has been pointed out that EBM is an integration of the four elements described below (Straus SE, et al. *Evidence-Based Medicine E-Book: How to Practice and Teach EBM* (5th ed.), 2019).

- ✓ Best research evidence: Generalizations gathered using epidemiological methods on human populations

- ✓ Clinical expertise: Proficiencies, techniques, and intuitive judgment abilities that are based on the cumulative experiences of individual healthcare professionals
- ✓ Individual patient values: Patient desires, intentions, and values
- ✓ Circumstances: Patient individuality and diversity combined with the space in which treatment is provided (the clinical setting)

These four elements are sometimes synergetic or reciprocal, so changing how they combine to find which combination best suits the patient is an important duty in EBM.

Professor David L. Sackett, who was upset that only the portion of EBM that emphasizes the use of scientific evidence in healthcare became widespread, pointed out that, “Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett et al. BMJ 1996).

After Professor Sackett pointed out this nuance, Professor Tammy C. Hoffmann followed up with a warning, saying “Without shared decision making (SDM), EBM can turn into evidence tyranny” (Hoffmann TC, et al. JAMA 2014).

Shared Decision Making: A decision-making process in which patients and healthcare professionals communicate as equals

In SDM, conversations are held between patients and healthcare professionals to make healthcare-related decisions together, but SDM can be considered a new form of medical communication for harmonizing the limits of evidence (uncertainty) and diversity in values. Communication is fundamental in the process of setting goals while sharing information, goals, and responsibilities between patients and healthcare professionals. The concept of “patients and healthcare professionals transforming healthcare” is a concept of co-production, co-design, and co-creation, and will be important when thinking about the nature of healthcare in the future.

Keynote Lecture 2: Information is a Determinant of Health

Garth Graham (Head of YouTube Health)

The ways video content can benefit people's health and issues to address in the future

YouTube is a major platform where billions of people log in to view billions of hours of content every month. In Japan alone, videos related to health have amassed over 4 billion views. The advance of YouTube and other social networks has made it possible to provide information in real-time and at a scale that is certainly large enough to have an impact on people's health.

High-quality online information has three elements. It must be accessible (by being free and easy to discover), credible (by being based on the best sources of scientific information that are available), and easy-to-understand (by providing answers to questions that are clear and useful). Social networks are mainly operated by private companies and are superior to other platforms in terms of being accessible. However, it is difficult for social network operators to be involved in ensuring said information is credible and easy-to-understand. Because that information can impact people's health, one issue to address will be ensuring those elements are present.

Healthcare is not only something that exists within hospitals and clinics; it is part of our everyday lives. As individuals, we make decisions regarding various aspects of our lives such as what to eat or drink or when to exercise, and all of these choices impact our health. Operating an information platform to provide video content makes it possible for us to serve as a familiar presence that helps build knowledge and spark inspiration. In doing so, we aim to help people lead the healthiest lives possible and make decisions that are based on information. Highly-reliable, information-based, educational video content provided by healthcare professionals and public health organizations can help encourage people to lead healthier lives. As a platform operator, we think it is necessary to establish a system that allows them to do so in a systematic manner.

The limitations of enhancing literacy at the individual level and the social obligations of information platform operators

Before the internet and social networks existed, people generally obtained information from information providers they already trusted, like their parents or family doctors. However, we can now access information over the internet without knowing who is providing it. When people receive information from someone they cannot meet face-to-face with no assurance that the information is reliable, it is important for them to possess the literacy to choose which information to trust and

which to disregard. However, intersecting factors like education and environment mean that raising information literacy at the individual level to certain standards is not something that can be achieved overnight. As such, the companies who operate social networks must engage relevant and like-minded stakeholders and work to ensure that each item that is shared can be trusted.

The need for initiatives for responsibly assessing and publishing content

We operate our platform with the intent of providing an ecosystem for sharing high-quality healthcare information. We have set rules for information providers with the goal of contributing to better health. For example, content that violates our policy is removed and information is subject to close inspection to ensure it is high quality. In addition to examining content, we also evaluate sources of information. Evaluations on other aspects like accuracy and accessibility are also conducted using fixed criteria.

When assessing information quality, however, reliability of the information source is not the only key indicator; it is also important to consider if the information encourages change toward healthier behaviors. A non-profit organization in the U.S. called the National Quality Forum (NQF) has presented recommendations that call on healthcare institutions to provide high-quality information. In addition to the importance of presenting information that is rooted in fact, they also stress the importance of encouraging people to adopt healthier habits.

From this perspective, after undergoing evaluation using objective criteria, content that is deemed to be high-quality is given a label that lets viewers know at a glance that the video is trustworthy. In Japan, a “Health and Medical Information” panel is displayed on videos and the site has been updated to include a “Health and Medical Information” section. These serve as proof that the party providing the information is trustworthy. For viewers, this provides a way to access information after confirming that it is coming from a reliable source.

Discussion

At this Global Sage meeting, experts from various fields came together to discuss the accuracy and reliability of health information from diverse perspectives that ranged from methodology to fundamental aspects of human thinking and behavior. As such, the following discussion summaries are not intended to present a specific conclusion or to outline an ideal form of accuracy and reliability. Instead, they have been compiled with the intent of presenting a variety of perspectives that will be necessary when considering how to envision health information in the future. Discussion 1 examined four discussion points: challenges, the perspectives of information transmitters, the perspectives of information recipients, and points of view on the co-creation of information by transmitters and recipients. In Discussion 2, we compiled perspectives that might be taken into account when considering items covered in Discussion 1 and the reliability and validity of information.

Discussion 1: Defining “Accuracy” in the Context of Health Information

Discussion Point 1: Issues related to accurate health information that surfaced during the COVID-19 pandemic

1-1. The importance of having a full view of current circumstances when seeing or hearing various facts and events when the situation is constantly shifting during an infectious disease outbreak

- When the COVID-19 pandemic began, the media only reported on the severe circumstances in China, but most of the people being treated for COVID-19 in Japan had minor symptoms. The media only covered a single angle on the situation and did not provide a complete picture of the disease, which was still unfamiliar at the time. Both transmitters and receivers of information needed to know that the situation was uncertain and that the information being presented did not always give a complete picture.

1-2. Different healthcare provision systems gave different impressions of COVID-19

- During the early stages of the COVID-19 pandemic, the public was not told that the longer the time one took to receive treatment after developing symptoms, the greater the risk of severe symptoms. In regions with fragile healthcare provisions systems, people were unable to receive care after the onset of symptoms. This made it appear like COVID-19 was a frightening disease that rapidly caused severe symptoms, which resulted in a commotion. Even when different healthcare provision systems are responding to the same disease, differences in the environment or background surrounding treatment can distort how the disease appears to observers. How to best encompass this fact when transmitting information is a necessary perspective for information accuracy.

1-3. The impact of inaccurate information skillfully disguised as fact in the era of social networks

- Among the various claims and statements that were presented in definitive terms as facts on social networks, some were mixed with personal thoughts and wishes. These statements even confused healthcare professionals, who sometimes went so far as to ask for confirmation. We still do not have an answer as to how we can best confront such situations.

1-4. Hopes for future progress in efforts from public institutions in Japan to transmit accurate information

- For example, users who run a search for “vaccine ingredients” in Japanese will be linked to a Ministry of Health, Labour and Welfare (MHLW) website, but once there, they cannot reach lists of ingredients without spending a significant amount of time searching for them. Running that same search in English leads to the U.S. Center for Diseases Control and

Prevention (CDC) website that provides a detailed list of ingredients and states, “Most vaccines don’t contain any mercury.” It also provides explanations to clear up common misinformation. There are high expectations for public institutions in Japan to follow their lead and be proactive about transmitting the information people want to find.

Discussion Point 2: Successfully transmitting accurate health information: Perspectives from information transmitters

2-1. The desired future direction for the transmission of accurate health information

- While some people have firm standards for decision-making, others want someone else to make decisions for them. Considering this diversity among information recipients, rather than taking a single approach of either promoting public information transmission or curbing the spread of inaccurate information, it will be necessary to do both.

2-2. Potential methods of ensuring information is easy-to-understand, accurate, and detailed

- For information recipients, there can be somewhat of a tradeoff for information being easy-to-understand and accurate. For example, saying “one in six” may be more intuitive than “16.7%,” but some people would say “one in six” is inaccurate. How information is transmitted must be tailored to who is receiving it.
- When expressing percentages, there is room to consider methods of catching the eyes of readers and then working to encourage them to read more by using the phrase, “about one in X people,” which has greater impact. While ease-of-understanding is an important aspect of information, there are times information is presented in great detail to emphasize accuracy, which can make it difficult to understand from consumers’ points of view. One notable example of this is package inserts for pharmaceuticals. Expectations are high for the pharmaceutical industry to play a bigger role in transmitting health information in a manner that takes consumers’ perspectives into account.

2-3. The need to take the characteristics of information that is accurate and information that appeals to the emotions into account

- Information that appeals to the emotions may attract attention, but it is not always accurate. However, it is particularly effective at encouraging changes in attitudes or behaviors among recipients. When providing information, information transmitters must consider the strengths and weaknesses of both and disseminate information that contributes to people’s health.

2-4. The credibility of information that is co-created by information transmitters and recipients

- Expectations are high for major media outlets and other information transmitters to sometimes enforce standards like, “Information even a middle school student can understand,” and work to transmit information that is not only accurate but is easy-to-understand, credible, and useful. After considering the intended recipients, the qualities of information must be tailored accordingly.
- In the current era in which people can access vast amounts of information, both good and bad, it is vital for the transmitter of each bit of information to be clearly indicated so those who receive that information can trust it.
- At times when circumstances are changing every moment, the information provided by healthcare professionals and the media may not always be correct. In one example, a TV program aired a statement saying, “Drinking green tea can reduce the number of COVID-19 viruses.” This was based on an exaggerated interpretation of the antiviral effects of green tea

in a laboratory setting and was a case in which illiteracy on the part of the information provided at the TV station was on full display. Continuous efforts must be made to improve the literacy of information transmitters and update the information they have acquired.

Discussion point 3: Successfully transmitting accurate health information: Perspectives from information recipients

3-1. Preparations that information recipients must make to be able to access accurate information in the future

- In addition to efforts on the part of information transmitters, the transmission of accurate information also requires improved literacy among information recipients. Many people tend to be drawn to dramatic forms of information that tell stories, even when they are searching for information that is accurate. We could consider this problem to be rooted in both human nature as well as insufficient literacy among information recipients. To be prepared for future pandemics, improving literacy related to science and infectious diseases will be an important issue to address.
- On social networks, people display the tendency to try to exclude people who do not agree with their opinions from their communities. In the future, while ensuring information platforms are diverse, it will also be necessary to consider individual criteria that will not be swayed by all sorts of information.

3-2. Forms of social support needed to help patients reach accurate information, from patients' perspectives

- We should keep in mind that when patients pick and choose health information to make decisions, they are doing so under pressure. For example, in the field of oncology, progress in nationwide measures made under the Cancer Control Act have made a vast amount of accurate information available from sources like the National Cancer Center's Cancer Information Service. However, patients cannot become healthy with accurate information alone. Because they want to hear stories about people who recovered and have hope, patients tend to rely on sources of information with narrative elements.
- Sometimes, when they become patients themselves, even some highly literate people or physicians seek medical care with no clear scientific basis. Accurate information will not reach patients and those close to them unless it is provided alongside decision-making and emotional support that addresses the unconscious and intrinsic desire people have to get the information and results they want.
- For patients to reach accurate information, it is important for them not to become isolated. This is where peer support can play a role. If parties like patient advocacy groups and healthcare professionals work together to first provide patients with emotional support in facing their disease, it can become possible for patients to go and get the accurate information they need. Medical and nursing consultation support for patients generally begins with an assessment, but considering the perspectives of patients and other affected parties, it is also important for there to be support provided through peer support and empathy.

Discussion point 4: Building a Better Society of Information Co-Creation in the Future: Perspectives Needed for Bridging the Gaps Among Transmitters and Recipients

4-1. How to best transmit information to bring people who feel uncertain and undecided closer to accurate information, centered on the perspective of wellbeing

- When an information recipient selects information, their choices are changed by differences

in the scientific expertise of information transmitters and their personal criteria (or, the presence or absence of such criteria). For people who are on shaky ground because they cannot determine what information is correct due to mismatches with their personal criteria, we should think about how to best transmit information from the perspective of bridging those gaps to further improve their wellbeing.

4-2. The potential for real-world evidence to be utilized in information co-creation

- Providing daily updates of the nationwide estimated number of positive tests for COVID-19 and seasonal influenza by region improves public health and helps prevent the spread of infections.
- In a recent survey of approximately 1,000 physicians and 3,000 members of the general public, 59.0% of physicians and 44.4% of citizens said they would like for their data to be actively utilized. When asked their reason why, the most popular response was, “To improve my own health or treatment.” Other respondents selected, “To create new and improved treatments” and “To confirm the effects of a medicine or the results of a treatment.” The survey also found that many respondents felt that “Having data from Japan rather than from other countries will help build trust and a sense of security.”
- In Japan, vaccination records and health information are not linked and establishing real-world evidence on a scale as large as in the U.K. and the U.S. will take time. However, if this can be achieved, it will be useful to both individuals and to society.
- Vaccine side effects or COVID-19 symptom severity can vary, even among family members. Utilizing and studying such events as forms of real-world evidence may help lead to future progress in personalized medicine.

4-3. The need to promote fact-checking practices that meet global standards

- In addition to transmitting accurate information and improving information literacy, it will also be necessary to fact check information that is transmitted. Japan did not have an organization that is certified by the International Fact-Checking Network (IFCN) until 2023. Looking at the number of items that are fact-checked, Japan only has a few hundred. This is far fewer than other countries such as Indonesia, where approximately 10,000 items were fact-checked. Moving forward, Japan must catch up to global standards.
- Japan should also add literacy education to public education programs. To popularize both fact-checking and literacy education together, Japan should actively participate in international conferences and similar events where parties like journalists, fact-checking and literacy educators, researchers, activists, and policymakers hold cross-disciplinary discussions to share best practices so we can acquire knowledge from around the world.

Discussion 2: How We Should Consider Information Reliability and Validity

How individuals and society should perceive and approach health information reliability and validity

- The root of the issue is understanding that there is no such thing as one right answer. Even if a piece of information is evidence-based, that evidence only represents what is currently visible, and nobody can say if it will still be correct in a few years or decades. This is especially true in healthcare. That is the world we live in, and we are trying our best to seek the truth given that fact. There is a Buddhist line of thought in which one begins by saying, “I am wrong,” or “We know nothing.” First, we should adopt this perspective as a society, because it might help foster information literacy.
- There is a concept called agnotology, which is the study of deliberate ignorance. Ignorance

can be harmful or it can be virtuous. The former is harmful in that people with limited access to information are harmed by not knowing they are ignorant. The latter refers to ignorance when it is more useful not to become informed, or a state of ignorance that precedes the acquisition of new knowledge. Society and individuals must reaffirm the value of “virtuous ignorance.”

- To begin with, in addition to scientific literacy, information recipients and society itself must also pay attention to physical and mental health as well as spirituality. Both health information and healthcare itself are parts of people’s everyday lives and are parts of human history, which makes it difficult to discuss healthcare as an isolated topic. Humanity has been dealing with the inevitable parts of life– namely, birth, aging, sickness, and death – since before the advent of modern medicine. Healthcare is related to all of these in the modern era, but none of them are complete with healthcare, nor can their narratives be contained within it.

The power of narrative in health information transmission

- In both clinical research and in citizen science, in which members of the general public participate in scientific research, narratives are a vital element that help researchers decide how to contextualize their research in explanations provided to collaborators. The value of narrative-based medicine, which uses a holistic approach that encompasses the entire daily lives of patients and families while keeping their backgrounds in mind, has been recognized for many years. Similarly, when transmitting health information, in addition to communicating accurate information that is based on scientific evidence, it is also important to determine how to tell a story that fits within a context that suits the recipient. There are high expectations for health information to be transmitted in a manner that keeps this narrative-based approach in mind.

Remarks on management provided by the Government or by health institutions during pandemics

- Michel Foucault coined the terms “biopower” and “biopolitics” in the 1970s. In short, these concepts argue that nation states once regulated their subjects through punishments or imprisonment, but now imposes health on them or forces them to live in biomedical health instead.
- During the COVID-19 pandemic, information regarding the right actions for citizens to take was transmitted through the media and other information resources by the Government and by healthcare institutions, and citizens listened. We also saw anger among the public during the pandemic, even in developed countries. Before we can determine if healthcare-related information was received accurately, we must first recognize the tension between individuals and the state and other institutions with authority to serve as a premise for considering the transmission of health information.
- A contemporary Italian philosopher named Giorgio Agamben uses two terms to refer to life: bios and zoe. To put it simply, bios refers to the vivid manner in which humans live their lives, while zoe refers to an animalistic way of living. He also refers to people with only zoe as “Homo Sacer.” Homo Sacer are people who exist outside of the protection of the law and can be killed without it being considered a sin, but cannot be used as a sacrifice to the gods during religious ceremonies.
- When healthcare professionals managed patients or society during the COVID-19 pandemic, were patients drained of their bios? Did it result in modern Homo Sacer who were only allowed to keep living?
- When people in Japan observed behavioral guidelines such as masking, it was not because

they were forced to do so by law, but because doing so became the social norm. While certain aspects of this could be considered good examples, it may also be safe to call it a state in which citizens were observing only their biomedical health. Expectations are high for experiences from the COVID-19 pandemic to serve as opportunities for each citizen to reconsider the question, “What is the purpose of living?” and gain perspectives on both bios and zoe.

The education, lifestyles, and perspectives necessary to build literacy and acquire critical thinking

- People have an innate desire to hang onto or grasp something, and one aspect of Buddhist thought considers “faith” to be “a mind without doubt.” This is a similar sentiment to being open-minded and listening to the voices of others rather than clinging to any specific piece of information. To avoid being misled by conspiracy theories and similar narratives, people must keep an open mind without holding a rigid belief in any particular opinion, and religious studies, philosophy, and liberal arts are useful for attaining that.
- Having faith that is based on having an open mind is to have a perspective that is similar to critical thinking. If someone trusts in something with a closed mind, they may begin to distrust other information. This may make them vulnerable to conspiracy theories that doubt every bit of information provided from sources like the mass media with statements like, “The Government must be connected behind the scenes” or “Everything they say is wrong.”
- The foundation of critical thinking is a healthy lifestyle. Finding small forms of happiness in our everyday lives over the course of activities like cleaning up, greeting each other in the morning, reciting sutras, and sharing meals forms the foundation for critical thinking and allows us to open up our minds and say, “No matter what happens, life is good.” Rather than only using one’s head, critical thinking should combine both mental and physical cultivation. It is important to foster physical health, mental health, and critical thinking from early on in life, accompanied by physical and mental nurturing, and we should look forward to building a world in which we can feel wellbeing based on this.
- In the future, introducing mental health education at schools may help children learn about systems of the mind, emotions, and feelings to help them grow and enjoy better mental health. Knowing the mind means knowing what one is feeling in the moment, and it means knowing oneself. It is important to decide which actions to take based on this knowledge. Furthermore, having the mental ability to set criteria that allow us to make decisions for ourselves is the foundation for receiving information.