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セキュリティ HEALTH

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Expectations for the Coming Era of Healthcare DX from People Living with Health Concerns



HGPI Health and Global
Policy Institute

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Introduction

Focusing on everyday life, hopes, and future expectations, Health and Global Policy Institute (HGPI) interviewed nine people living with health conditions or those close to them to investigate how they experience digital technology and the digital transformation (DX) in healthcare. Interview participants included both people directly affected by health conditions as well as their family members, and represented multiple areas including mild cognitive impairment (MCI), cancer, type 1 diabetes, mental health, chronic disease, and pediatric intractable disease.

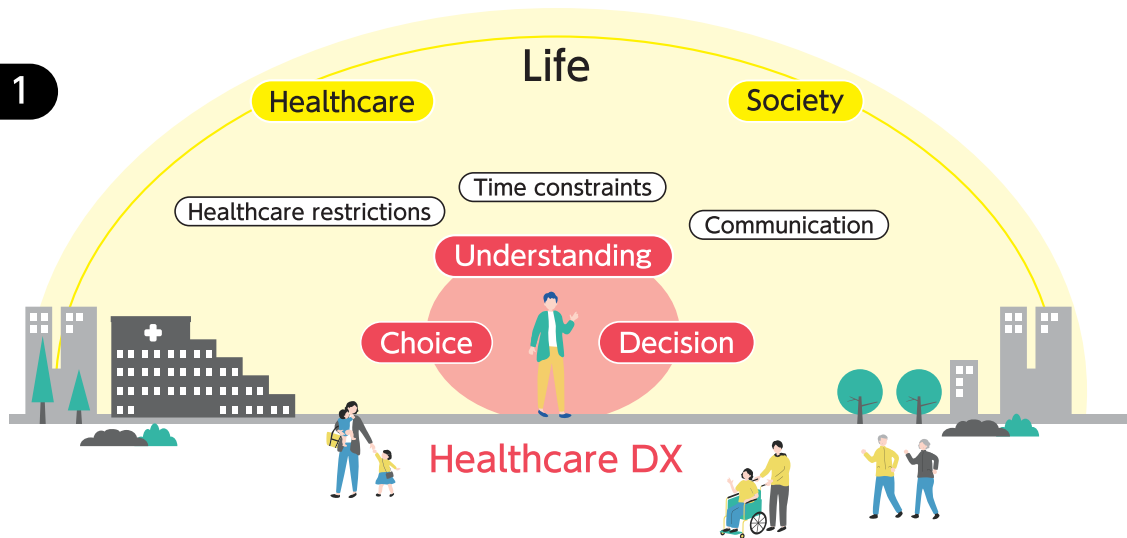
Interviews lasted around one hour and were conducted once per person. The information we gathered has been compiled and arranged in four sections: problems, difficulties, and concerns related to the condition; current solutions; expectations for healthcare DX; and how affected parties feel uneasy about healthcare DX. Focusing on the findings in each category to examine their similarities and differences, we compiled an image of and conceptualized the society in which the affected parties live.

Immediately after the development of the condition or changes that occurred in their families, participants experienced difficulties in self-understanding and self-determination, and felt the need for sufficient knowledge and capacity for independent decision-making regarding treatments or daily living. Furthermore, regardless of treatments or cures for their condition, all participants based their thinking on daily life. This suggests that what will be important in the coming era will be forging connections between the foundation of daily life and healthcare, and transforming the healthcare experience in ways that further facilitate communication and make more efficient use of time. Participants also felt that the development of diseases placed restrictions on their daily lives and they expressed high expectations for healthcare DX to help address such challenges.

It is our sincere hope that this report can serve as a point of reference for all readers regarding each participant’s current daily life and expectations for healthcare DX and that it will promote understanding toward this topic.

Living in Society as an Affected Party and Healthcare DX

Figure 1



Affected parties feel uneasy about healthcare DX

The nine interview participants expressed anxiety toward healthcare DX. In particular, they were concerned that the digitization and sharing of information could have a negative impact on them or their families. For example, advances in technology that lead to the sharing of disease and genetic information may allow people to determine who is susceptible to diseases or who is affected by them. Being identified as someone who visits healthcare facilities relatively often could result in social disadvantages, such as greater difficulties when attempting to enroll in insurance or secure loans. Participants were also concerned about how much information they should share with their family after discovering a health issue through genetic testing.



Participants had the strong impression that the Government is leading the way in healthcare DX. They were also highly conscious of past mistakes related to healthcare DX and were concerned about Government involvement in the data management that accompanies digitalization. Furthermore, we observed that users may be concerned toward DX and the public may be reluctant to participate in it due to a perceived lack of benefits from DX or from the secondary use of data, which is one characteristic of DX.

While remaining fully aware of the worries and concerns that citizens and affected parties feel toward healthcare DX, parties responsible for advancing healthcare DX in Government, the private sector, and academia, as well as us, the authors of this report, must carefully consider the public perception of healthcare DX and proceed through dialogue to avoid letting the digital transformation itself take precedence.

Person living with MCI

Basic information

Mr. D is in his 60s and lives in Nara Prefecture. After graduating university, he began working as an engineer, but voluntarily retired at age 51. He found new employment at a small- to medium-sized manufacturer. In 2015, he underwent a medical examination for abnormal, headache-like floating sensations. He was referred to a neurologist where an MRI revealed brain atrophy and reduced cerebral blood flow. For two years, he continued undergoing regular checkups without a definitive diagnosis. During that time, he was suspected of having a neurological disorder or mild depression. However, ongoing tests showed that his symptoms were progressing, and he was diagnosed with MCI or early Alzheimer's disease. He now operates a community group out of the belief that people living with early-onset dementia and their families need opportunities to hold lighthearted conversations and speak openly about their problems and concerns.

Living alongside MCI in modern society

Problems, difficulties, and concerns related to the condition

1) The impression given by the name "mild cognitive impairment" does not match its actual symptoms, which confuses both the person affected and those around them when managing the condition

- While people consider forgetfulness to be the main symptom of dementia, the most prominent symptom for Mr. D is fatigue. He has trouble getting other people to understand this feeling.
- It is difficult for Mr. D to express his thoughts in writing. This prevents from working as he intends to, which causes problems at his workplace.
- Mr. D cannot adopt the ideal workstyle that matches the size of his employer, so he is troubled over the need to change his current workstyle.
- During the two years before his diagnosis, Mr. D did not know what he should do and thought he could not be helped.

2) Mr. D has to work to maintain an income for his daily life, but it is difficult for him to do so while facing his symptoms

- Mr. D needs to earn a living to support himself, but he has symptoms that are out of his control.

Current solutions

1) Symptom-based model cases are important

- Mr. D knows a person with higher brain dysfunction who has symptoms that are similar to his own. That person works remotely and gives seminars and lectures during their working hours. This made Mr. D recognize the importance of companies that allow employees to participate in such activities.

2) Establishing an environment that enables social participation, even for people who live with diseases

- People with various conditions can keep working if more worker-friendly environments are established. This may include introducing shorter working hours or allowing people to work remotely.

3) Taking action to improve understanding toward symptoms among other people

- During his lectures, Mr. D tells people about his experiences and that forgetfulness is not the only dementia symptom.

4) Mr. D was saved by receiving a definitive diagnosis and being allowed to openly take time off

- When his doctor recommends a leave of absence from work, Mr. D is saved by having a written diagnosis.



Expectations for healthcare DX

1) Automating data acquisition will improve access to disease-related services

- Many symptoms of dementia make administrative procedures difficult. Mr. D has high expectations that unifying these procedures in the My Number system will simplify various paperwork-based procedures and allow people to receive dementia-related services without having to apply for them.
- Mr. D thinks it will be convenient if data from daily life (such as sleep data or heart rate) can be collected by smart watches and other wearable technology and shared with physicians so that they can provide accurate advice or, when necessary, prescriptions for conditions that people may have difficulty noticing or explaining on their own.
- The ability to collect data continuously will make it possible for healthcare providers to quickly identify changes in patients' conditions.

2) Awareness toward universal design in healthcare DX will advance approaches to dementia

- Mr. D looks forward to seeing forms of DX that improve access to hardware and improve usability for everyone so older adults who are not accustomed to digital technology are not left behind.



Comments from Mr. D

“Keeping a wearable device on you at all times allows you to (objectively) confirm if there is a problem, immediately ... They help me detect problems early and take appropriate countermeasures ... Doctors can also use the data to diagnose people and give them appropriate advice (based on their daily lives) ...Wearable devices can be invaluable tools for daily life and health management.”



Person living with a rare form of cancer

Basic information

Mr. E is in his 40s and lives in Osaka Prefecture. When he was in his 30s, after his wife had a baby, he took an early annual checkup at work where it was discovered that he had a rare type of esophageal cancer that affects only one or two people in 100,000. Looking back on the time of his diagnosis, he experienced few subjective symptoms and can only recall having difficulty swallowing. Around the time of his first surgery, a metastasis was detected in his right lung and he underwent a tumorectomy. However, approximately one year later, multiple metastases were detected in both lungs. In addition to completing standard treatments, Mr. E has undergone tumorectomies and radiofrequency ablation and has taken anticancer medication. While he experiences strong side effects from the medication, he has children and is continuing to work with support from his employer.

Living alongside a rare cancer in modern society

Problems, difficulties, and concerns related to the condition

1) Patients lack support in choosing healthcare providers and treatments, and experience difficulties in accessing care

- Although a lesion was discovered during his health checkup, Mr. E was not told which hospital he should visit and, with no criteria to pick one, he did not know where to go.
- When Mr. E wanted to seek a second opinion after starting treatment, there was little information about his rare cancer, so he had no choice but to search for information on his own.
- Because Mr. E's cancer was rare, even among rare cancers, he felt it was difficult to gather information, select treatments, and look up information on each health institution and specialist. After standard treatment, it was particularly difficult to find information on treatments and clinical trials.

2) There are times when opinions vary among health institutions or physicians

- Partially due to the fact that Mr. E's form of cancer was rare, there were times when recommended treatments varied among physicians. This made it difficult to choose a treatment.
- Rare cancer cases are few in number, so after receiving multiple second opinions, Mr. E felt there was variation in treatment experiences, knowledge, and information among physicians and health institutions.

Current solutions

1) Mr. E makes decisions regarding treatment options and daily life during recuperation based on both physicians' opinions and his own research

- Physicians had various experiences treating cancer, specialties, approaches to treatment, and opinions on prognosis, so Mr. E gathered various perspectives from physicians to make comprehensive decisions.
- Mr. E was guided to the same treatment method no matter where he got a second opinion, which made him understand the need for that treatment. After understanding that, he decided which health institution to use based on their track record and trustworthiness.
- Ultimately, Mr. E feels that whether or not someone can accept their decision is important.

2) Seeking information that can be tailored to one's needs while relying on information from peer support

- While Mr. E was unsure how much trust to place in some of the information from the patient community, there was a great amount of information related to managing symptoms in daily life that was extremely beneficial.
- Even when the advice was the same, hearing it from other affected parties was more agreeable and trustworthy, increasing Mr. E's willingness to try following it.
- Mr. E was also recommended a number of folk remedies from those around him. Even when he did not expect them to be effective, he tried many of them to respect their good intentions as long as the remedies did not have much effect on QOL, including in terms of cost.



3) Identifying one's values in life and setting priorities

- With a newfound awareness toward death and the fact that life is finite, Mr. E decided how he wanted to devote his energy and time to things like family, work, and hobbies, and assigned each of them a priority.

4) Having a workplace that is accommodating toward one's disease

- Some of Mr. E's supervisors have experience with cancer, so his supervisor and company expressed understanding toward working while living with cancer.
- Specifically, Mr. E and his employer held repeated discussions during which they discussed Mr. E's wishes and how to create a flexible workplace in which he could perform his best. This included changing his workplace location, his duties, and his working hours. Searching for a way forward together in this manner strongly motivated Mr. E to support himself and has enabled him to continue working.

Expectations for healthcare DX

1) Creating a framework that will allow for patient-centered decision making in the medical process

- Mr. E thinks that well-compiled information on the disease area overall, main treatment methods, and alternative treatments should be provided by a public organization during the initial stages of a disease. He thinks people prefer information from a public source rather than private ones when facing life-threatening situations.

2) Making advances in personalized medicine and care

- In a world filled with a diversity of values, Mr. E hopes that healthcare DX can be used to analyze the various opinions in the world and discover new values to help each person achieve forms of wellbeing that are right for them.
- Mr. E thinks that if AI can be used to analyze the issues faced by individuals with diseases and (to a certain extent) narrow down options while reflecting the diverse needs of individuals, then it will help reduce the number of people who choose the wrong path.

3) Data utilization will drive progress in diagnostic and treatment technologies and communication

- Mr. E thinks that genetic information is a useful form of data and that clarifying the links between genes and certain diseases will help contribute to progress in the field of healthcare. It is his experience with a rare cancer that made Mr. E think we should have systems that allow us to accumulate data.
- Based on the firm premise that steps must be taken to prevent patients and other affected parties from being disadvantaged, Mr. E believes it will also be important for us to be aware of competitive capacity in development and to proceed with a sense of urgency.

Comments from Mr. E

"I think we need healthcare DX to promote digitalization, to streamline healthcare, and to improve accessibility. However, I also believe it will be essential for generating new values from the perspective of defining what happiness means to each stakeholder. To achieve various forms of wellbeing, I think we should make the most of data and continuously move forward with DX."



Person living with type 1 diabetes

Basic information

Mr. H. is in his 50s and lives in Kanagawa Prefecture. During his third year of high school, Mr. H visited a hospital for excessive thirst and frequent urination and was found to have type 1 diabetes. He was hospitalized and started using insulin to control his blood sugar levels. However, he was unable to envision his future because he could not grasp the entire picture of his condition. Combined with the fact that he was at a sensitive age, this made him feel anxious and depressed. During that period, he learned about a patient group for people with type 1 diabetes from somewhere other than his attending physician, which led to the peer support that saved him. He has been involved in the management of peer support groups in Osaka and Yokohama. He also continues to manage a community for type 1 diabetes information online (through a Facebook group). Mr. H has now lived alongside type 1 diabetes for over 30 years and has experienced many advances, such as in blood glucose monitoring technology and insulin administration methods. He is now able to devote time to hobbies and other activities.

Living alongside type 1 diabetes in modern society

Problems, difficulties, and concerns related to the condition

1) Mr. H is more likely to experience physical symptoms when his symptoms are under control, greatly impacting his daily life

- While maintaining control over one's condition in daily life is an essential and unique characteristic of metabolic diseases, many people feel a sense of denial regarding their past selves over the changes in their daily lives and self-image before and after developing their condition. This causes painful feelings in many cases.
- People with diabetes cannot avoid invasive procedures such as finger-prick tests to monitor their condition or injections to administer medications, so there are still many items that inconvenience their daily lives.
- People living with diabetes need to manage their condition to prevent changes in their endocrine system. Inability to do so effectively often results in physical symptoms and can make them susceptible to illness.

2) The process of accepting one's disease is complex, but the lack of set patterns makes acceptance

- Many factors influence disease acceptance and it is difficult for people to find model cases within the disease acceptance process that fit them.
- People develop the idea that the version of themselves without insulin secretion problems was the "correct" one, and self-acceptance after developing diabetes is difficult.

3) There are high barriers to accessing financial assistance from the Government, making it difficult to get

- Treatments that improve QOL tend to be more expensive and the current system does not allow everyone to choose treatments that fit their daily lives.
- The Government's eligibility criteria for subsidies are currently unclear. There are only two possible results for support (pensions for people with disabilities): people either qualify for support, or they do not. It can feel unfair when people with the same disease get different results.

4) The name "diabetes" creates barriers to participating in society

- There is a gap between how society perceives diabetes and how individuals perceive it, and building understanding requires effort and money.

Current solutions

1) As medical technology advances, the number of options for self-monitoring of blood glucose are increasing

- Recent advances have made it possible for people to easily and continuously monitor trends in their blood glucose levels, and tools that perform everything from measuring blood glucose to injecting insulin automatically are now available.



- Methods of measuring blood glucose advanced from glucose urine tests to blood tests and now to transcutaneous monitoring. Each new method has drastically shortened testing times and Mr. H can feel blood glucose monitoring technology advancing day by day.
- While there is currently no cure for type 1 diabetes, technological advances are increasing the number of available methods for controlling it. These make it possible for people living with type 1 diabetes to return to the lifestyles they led before developing the condition.

2) Expanding a patient group nationwide creates a virtuous cycle in information

- Many people share the same problems and patient groups fulfill their needs to share information and interact. This has allowed Mr. H's patient group to spread throughout Japan.
- Patient groups have spread throughout Japan and have created opportunities for people in each region to interact. This has allowed us to capture latent needs and expand peer support.

3) The popularization of the internet makes it easier to acquire information

- Easy access to the internet has increased the number of patients and related parties who are providing information. Information on type 1 diabetes was once only available from health professionals and technical books, but we now have an environment where it can also be obtained online.

4) Enhancing our ability to overwrite negative preconceptions of diseases with positive one

- We are now living in an age when people can try anything, even if they have type 1 diabetes, but strictly speaking, they cannot do everything. However, building up track records that enable people to attempt to do things will certainly make it easier for us to persuade ourselves and those around us.

Expectations for healthcare DX

1) Consolidating identification numbers for enhanced, seamless services

- We should clearly show how linking the My Number system with each identification number will benefit individuals and create a system that lists services to which users will have access once those numbers are linked.
- Mr. H hopes that data centralization will allow people to receive the same quality of healthcare at any hospital by allowing those hospitals to use the same data.

2) Sharing health data in real time will accelerate treatment

- Mr. H hopes that centralizing data in real time and providing feedback based on that data in real time will enable immediate self-management of blood glucose and treatment.

3) Providing relief and support linked to the My Number system after natural disasters

- It is urgent that we establish a disaster support system that automatically sends insulin and other life-sustaining medications to areas that have been affected by earthquakes, tsunamis, and other disasters classified as major disasters that necessitate economic support, without requiring patients to first submit requests for support.

Comments from Mr. H

“For example, if I were out in the city and collapsed due to hypoglycemia, if I have the My Number card, paramedics might be able to use it to quickly refer me to a hospital … My medical information would be provided instantly, providing doctors with details like my history of diabetes treatment that would alert them to the possibility of hypoglycemia. If information is provided in real time, it will become possible to provide accurate diagnoses and treatment, and make streamlined healthcare DX a reality … Integrated platforms must be established so people can be provided with seamless healthcare experiences.”

Person living with a mental health condition

Basic information

Mr. A is in his 40s and lives in Tokyo. Due to immense pressure at work, Mr. A developed panic disorder during his fifth year in the workforce. He first noticed he was unwell about one month before developing the condition, when he had a panic attack on the train during his morning commute. He immediately found a clinic near his home where he was diagnosed with panic disorder. Mr. A took a two-month leave of absence and returned to work while taking medication. Approximately one year later, he experienced feelings of self-loathing after making a mistake at work. He took another leave of absence and was diagnosed with depression at the aforementioned clinic. After recuperating at his own home and sometimes at his parents' home, he recovered and is now operating a service for families of people living with depression.

Living alongside panic disorder in modern society

Problems, difficulties, and concerns related to the condition

1) Standards for healthcare access are based on how Mr. A perceives it during an attack

- After searching for their symptoms and other items that come to mind, it is most realistic for people to choose a hospital near their home and that offers a convenient commute, so it is difficult to go to the hospital that is the most suitable.
- Personal judgment plays a major role in the decision to seek medical care, and it can be a burden to describe one's condition when one's memory is unclear.

2) The procedures needed to maintain a foundation for daily life are difficult to complete

- While Mr. A received notices regarding procedures, in his haste to return to work, he procrastinated on procedures and other items that he was originally supposed to complete during his leave of absence. This led to feelings of psychological resistance.
- Despite the availability of various forms of support including financial support, employment support, and medical support, Mr. A found it difficult to understand everything that was available during the time he was unwell.

3) Economic anxiety exacerbates Mr. A's condition and creates a vicious cycle

- Mental health disorders can occur due to forms of stress like worry and anxiety, but taking a leave of absence from work can increase economic anxiety due to the costs of treatment or living expenses. This leads to a vicious cycle.

Current solutions

1) Having trustworthy supporters is vital

- Staying with his parents eased Mr. A's worries toward living expenses.
- Being around someone caring helped prevent Mr. A from forgetting to take his medicine.

2) Information from community websites and patient groups is helpful

- Mr. A found that it was helpful to hear the voices of other people with the same condition and to share information with them. Doing so allows one to know what information they need, when they need it, as well as what actions they can take.



Expectations for healthcare DX

1) Better communication with healthcare providers will lead to better patient support

- Recording symptoms or problems that are difficult to convey in words or that are only experienced outside of hospitals allows people to accurately describe their condition during medical examinations and helps eliminate communication gaps.
- During the acute stage, it is difficult for people to record or convey information on their own. Mr. A has high expectations for tools that automatically gather health information and share it with healthcare providers.

2) Information from community websites and patient groups is helpful

- Mr. A thinks data will make it easier to sort information and hopes that healthcare providers can use it to alter the information they provide to affected parties and their families, or to organize and provide the right information at the right times along the patient journey.

3) By sharing personal information, burdens placed on patients will be reduced and treatments will become personalized

- Mr. A hopes administrative procedures are simplified to lessen the burdens placed on people experiencing symptoms.
- Mr. A. has high expectations for treatment methods and other services to be personalized by sharing data with health institutions.



Comments from Mr. A

“It is important for patients and physicians to share information and make treatment decisions together to ensure smooth decision-making for patients. However, current circumstances hinder efforts from patients to actively communicate with their physicians and need to be improved. It is still unclear how beneficial digitalization will be for automatically gathering, storing, and sharing data on daily life, but I think it will facilitate communication among patients and physicians.”



Person who has experienced an aortic dissection and stroke

Basic information

Mr. B. is in his 60s and lives in Tokyo. He works for a medical device manufacturer. At a health checkup in his 30s, he was diagnosed with essential hypertension and has been on medication for the condition. While this did not cause him stress at work, there were many times he drank alcohol late into the night. Having little time to spare also meant he was unable to take care of his health regularly. When he was in his 50s, he experienced an acute aortic dissection and underwent multiple cardiovascular surgeries. These included blood vessel prosthesis implantation and surgeries for valvular disease and coronary artery stenosis. One year after his first blood vessel prosthesis implantation, he had a stroke, and he now experiences difficulty moving and speaking. He makes regular visits to an outpatient clinic as part of his daily life.

Living alongside aortic dissection and stroke in modern society

Problems, difficulties, and concerns related to the condition

1) Mr. B is dominated by a fear of serious disease

- During the acute stage of Mr. B's aortic dissection, he was preoccupied with the blood vessel prosthesis implantation. During an explanation after the procedure, he learned for the first time that he had been given a mechanical valve. Had been able to choose, he probably would not have selected a mechanical valve.
- Mr. B feels that he lacked knowledge before developing his condition, and that people should have opportunities to learn about diseases and treatments.

2) The environment is ill-equipped to help Mr. B live alongside his condition

- After Mr. B was discharged, he lost access to health professionals that were easy to communicate with, such as nurses and pharmacists, so he had nobody to consult on smaller matters.
- There are no highly specialized cardiac rehabilitation facilities near Mr. B's home.

3) Life changes after the onset of the condition are difficult to cope with

- Even though Mr. B could not even walk ten meters, he had to complete grueling rehabilitation at home.
- After returning to work, Mr. B's employer was accommodating and assigned him a job with fewer burdens. However, he felt less needed at his workplace, which was painful.

Current solutions

1) People who can help one through daily life and provide emotional support are crucial

- Mr. B had been unable to tell his doctor about the procedure he wished to undergo, but he was able to arrange such a meeting through a nurse. This allowed him to undergo his preferred procedure.
- Mr. B had lost a relative to the same disease, so he chose to prioritize his physical health over work.
- Mr. B's family helped him manage his diet after his surgery.
- While he had to make an effort to get exercise at first, he joined friends for nature restoration activities that allow him to get exercise naturally.

2) Rearranging life priorities to prioritize physical health

- When Mr. B had a stroke at 55, he realized his health was more important than his job, and he retired.
- Mr. B chose to retire early so he could be more careful about eating a healthy diet, exercising regularly, and avoiding stress.



Expectations for healthcare DX

1) Remote medical examinations and support will improve healthcare access and create seamless links between daily life and healthcare

- Heart disease requires urgent care, and Mr. B. has high expectations for telemedicine to speed up treatment and improve access.
- Conducting regular outpatient visits and monitoring remotely will reduce physical burdens and allow people to make more effective use of time.
- Treatments provided at hospitals and care provided to people over the course of daily life are both healthcare. Mr. B thinks that healthcare DX must be expanded to consider how these areas are connected.

2) Changing citizens' health behaviors and communication with health professionals, and helping disseminate knowledge

- Using apps and remote technology to teach children about CVDs at school will help children be aware of these diseases early on. Taking those lessons back home with them will create opportunities for them to discuss CVDs with their families so they can reexamine their health choices.
- Sharing firsthand experiences in patient groups or online will make daily habits for many people and communication between healthcare providers and patients more significant.

3) Secondary data use will help identify the underlying causes of diseases

- The underlying causes of CKDs are complex, but identifying them may lead to advances in areas like targeted lifestyle guidance or new drug development.

4) Selecting services that suit one's condition based on comprehensive data

- There are currently many services offered through apps and other resources, but the only one that Mr. B uses is one that lets him submit prescriptions electronically. In the future, if Mr. B is provided with a list of services that lets him find ones that suit him, he would like to try using other services, as well.

Comments from Mr. B

"I think healthcare is a very broad topic. After all, receiving treatment in a hospital and receiving treatment over the course of daily life are both healthcare. I do not see daily life and healthcare as separate; rather, I think they are closely related. This is because once someone completes treatment at a hospital, they then return to their daily lives at home. I think we need continuity, so we must not think of them as separate. I think the gaps between the two will narrow if digitalization advances, even a little. They may even become seamless."



Person living with lung cancer

Basic information

Mr. C is in his 50s and lives in Kanagawa Prefecture. He was working as a freelancer when, in 2010, he attended a medical examination for swelling in his neck after experiencing a cough for about two weeks. He was diagnosed with stage 4 lung cancer and was given approximately one year to live. For about two years, Mr. C underwent various treatments including chemotherapy, radiation therapy, and surgery. However, he had a recurrence three years later. The cancer later metastasized, but there has been no progression to date. Over the treatment process, Mr. C became aware that reality and theory are different, so to hear the opinions of various people, he visited multiple hospitals for second opinions. He is also providing peer support to others with the same disease.

Living alongside lung cancer in modern society

Problems, difficulties, and concerns related to the condition

1) Treatment prevents Mr. C from working and he does not expect to receive social support

- Although he is nearing the end of his life, Mr. C has no insurance and cannot leave an inheritance for his wife and children.
- Mr. C's health is deteriorating, which prevents him from working. Because he was a freelancer, he did not think he could receive social support.

2) A lack of knowledge about lung cancer and its treatment makes it difficult for Mr. C to make his own deci-

- Mr. C did not know who to turn to for advice when considering cancer treatments.
- Mr. C felt that he lacked the necessary knowledge to weigh the pros and cons of treatments, which prevented him from making decisions on his own. He also did not have sufficient knowledge or guidance on treatment options or methods of consulting doctors about treatment strategies.

3) Gathering second opinions takes time, so Mr. C felt growing anxiety that his disease would progress

- While Mr. C was told he only had a short amount of time left, there were many things he had to decide before proceeding with treatment, which took time.
- In addition to costing money, getting a second opinion took one month on average. Mr. C was very concerned that his condition would progress while waiting for results.

Current solutions

1) Sharing information about treatments and daily life with a patient group

- Mr. C's patient group encourages dialogue and information sharing among patients, provides a forum to ask questions and share concerns, and serves as an information resource with open lectures for the general public.
- Information handled by Mr. C's patient group is mostly based on information from academic societies and provides insight on the specialist discussions that lead to the formulation of guidelines.

2) Seeking out second opinions at key turning points before making decisions

- Mr. C wanted to know how his body was changing after undergoing various treatments. By receiving second opinions, he was able to feel the effects of those treatments and accept the choices he had made.
- Mr. C received multiple second opinions whenever he had to undergo a new treatment, such as during diagnosis or when selecting treatments.

3) Considering the future in terms of income and household expenses

- Friends donated money to Mr. C and his family.
- After confirming his pension and calculating household finances, Mr. C and his family determined they could get by even if his wife worked part-time.

Expectations for healthcare DX

1) Providing patients with decision-making support

- Mr. C believes that there will be no need for patients to improve their literacy if digital technology can provide them with the right information at the right times throughout the treatment process and give advice that anticipates their concerns.
- In the context that patients have been informed of their remaining time, Mr. C hopes digital technology can provide the type of support that helps them find happiness in daily life and see the signs that they are alive.
- Health data accumulated daily using apps and other tools can be utilized to achieve deeper communication with healthcare professionals, who can in turn provide appropriate examinations while focusing on daily life. This will make patients feel more reassured that someone is watching over them.

2) Helping cancer patients overcome their worries and concerns

- If healthcare DX could reduce the time it takes for patients to get second opinions, such as by the next day, then patients would have more time to consider the future.
- Mr. C would be very happy to have his data used if it is with a good vision of the future.



Comments from Mr. C

“I think the best direction to set for healthcare DX is to try to create a recommendation system that accurately provides the information people need, when they need it. I think it would be good if it could predict where I (or another patient) might get lost and provide advice ahead of time. While some say patient literacy must be improved, I think there may be no need for them to do so if it becomes possible to provide precise support through healthcare DX. As data accumulates, it could lead to a world in which people can use healthcare even if they do not improve their literacy.”



Person living with chronic obstructive pulmonary disease (COPD)

Basic information

Mr. F is in his 60s and lives in Tokyo. Around 2016, Mr. F was diagnosed with chronic obstructive pulmonary disease (COPD) following a health checkup, but he did not undergo any particular treatment. About five years later, he was taken to the emergency room with pneumonia and was hospitalized for two weeks. He then began home oxygen therapy for COPD. His attending physician told him to take thorough measures to prevent getting an infectious disease when he was discharged, so he did not leave his home during the COVID-19 pandemic. This caused him to feel socially isolated and depressed, so he is now more proactive about going out and exercising. He needs to bring oxygen with him during outings. Since he feels that portable oxygen tanks are inconvenient, he also uses a rechargeable portable oxygen concentrator. Because of his underlying condition, he had experience working remotely by the time of the COVID-19 pandemic, and he still does most of his work remotely.

Living alongside COPD in modern society

Problems, difficulties, and concerns related to the condition

1) Life with an oxygen tube is inconvenient

- It is essential for Mr. F to wear an oxygen tube daily, and moving around while always attached to a heavy oxygen tank is inconvenient.

2) Changes in one's body image and the psychological burdens caused by physical restraints

- Mr. F had often seen people walking around with oxygen tanks, but he never thought that one day it could be him.
- Mr. F had to prepare himself to live alongside COPD for the rest of his life, and attaching an oxygen tube felt like shouldering a heavy cross.
- The weight of having a tube physically attached for the rest of his life makes Mr. F feel that he is also restrained in his mind.

3) Securing oxygen for outings requires cumbersome preparations

- When traveling for business or on vacation, Mr. F must arrange oxygen to use at his destination. The procedure requires a visit to his attending physician and is very cumbersome.

Current solutions

1) Incorporating self-care into daily life

- Mr. F is proactive about going out and interacting with others as a form of self-care when he is feeling discouraged.
- To avoid becoming too accustomed to the remote lifestyle, Mr. F is devoted to maintaining and restoring real connections with others.
- To maintain exercise habits and his physical fitness, Mr. F has incorporated exercise into his daily routine. For example, he added walking to his workday commute.

2) Planning activities carefully

- Mr. F is careful to select a form of home oxygen therapy (rechargeable portable oxygen concentrator, portable oxygen tank, etc.) according to the time, place, and occasion.
- Mr. F plans his trips around managing his oxygen, such as by selecting transportation methods that allow him to recharge his rechargeable portable oxygen concentrator or that stay within the range of its battery life.

3) Partially due to circumstances in society, there is an environment that allows Mr. F to stay in the workforce while living with a chronic disease

- Remote work became common around the world during the COVID-19 pandemic, so Mr. F has been able to continue working from home as he did during that period.

Expectations for healthcare DX

1) Improving QOL for people living with chronic illnesses and relieving the feeling of being physically

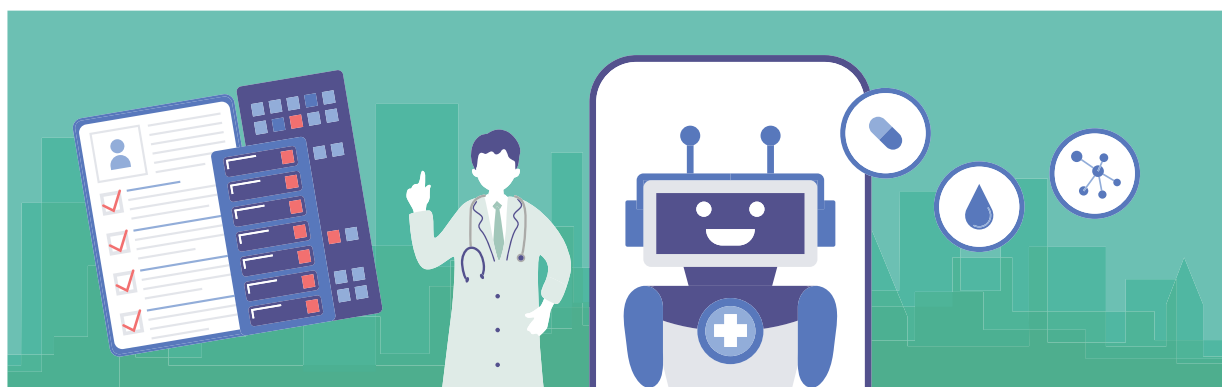
- Mr. F has high expectations for rechargeable portable oxygen concentrators to become more compact or to be improved in other ways so people can move around without worrying about their oxygen.
- Mr. F would like to see the introduction of multiple systems for supplying oxygen so that people do not have to rely on devices that are charged using onboard power supplies, such as during emergencies. For example, this could include allowing them to use electricity from EV vehicles.
- Mr. F looks forward to further technological developments that improve QOL, such as by introducing wireless oxygen supply equipment and power supplies to eliminate the need to use cords and tubes while on the move.

2) Making health services more customizable to fit individual needs

- As the data that is gathered through digitalization is becoming enormous, Mr. F thinks many would benefit if it were used to design services that people can customize to suit their own needs.

3) Care provided by machines and by people will be efficiently integrated

- As seen with the introduction of long-term care robots, Mr. F would like to see care from machines effectively integrated so people can focus on the care that can only be provided by people. This will have effects both in terms of personnel shortages among providers as well as respecting the dignity of care recipients.



Comments from Mr. F

"I feel many restrictions on my activities if I am hospitalized. ... I have to attach a cable every time I use a new machine, such as when I am being tested ... We can now charge smartphones wirelessly by simply setting them on a table. If some medical devices also become wireless ... daily life would be much more convenient. I mean for the system itself, as well, and I think that is what healthcare DX means."



Person living with chronic kidney disease (CKD)

Basic information

Ms. G. is in her 50s and lives in Fukuoka Prefecture. In her 30s, she visited a local doctor for headache, fatigue, and nausea. It was discovered that her creatinine level was high, and she was referred to a general hospital. A more thorough examination resulted in a diagnosis of rapidly progressive glomerulonephritis caused by anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitis. After a one-month hospitalization and treatment, she has been managing her symptoms with immunosuppressive drugs. Since her discharge from the hospital, she has been avoiding stress in her daily life and has been following a kidney-friendly diet. Effects of her disease led her to start visiting a gynecologist, and she continues working while managing her kidney disease and gynecological symptoms.

Living alongside CKD in modern society

Problems, difficulties, and concerns related to the condition

1) Changes in daily life and troubles due to a mysterious physical condition for which even Ms. G did not know the cause

- There were many times when results of the tests that Ms. G underwent every week were unrelated to her physical condition. Because the test results were unusable as indicators of her physical condition, it made it difficult to control her daily life.
- Ms. G cannot grasp which behaviors would be too much for her body or disease, so she is now taking care not to place too much strain on herself in her daily life.

2) Experiencing feelings of despair toward the diet aspect of treatment and the need to alter one's lifestyle

- Instead of eating what she enjoys, as she used to, Ms. G now follows dietary reference intakes (DRIs) and must refer to lists of ingredients while planning her diet as part of her treatment.
- Worried that she could never have the food she loved ever again, Ms. G experienced feelings of hopelessness.
- She also experienced malnutrition due to excessive dietary restrictions introduced in the name of treatment.

3) Detachment between understanding toward kidney disease among the people around Ms. G and her own

- Because she does not fully understand her poor physical condition herself, Ms. G cannot find the right words to explain her condition to those around her.
- Because her symptoms are difficult to understand, those around Ms. G have poor understanding of her disease and there are times when she must strain herself at work.

4) Peer support is difficult to access due to differences in underlying causes

- Because CKD has few subjective symptoms and there are various underlying conditions that cause it, experiences with successful treatments may be incompatible with others' conditions, so carelessly sharing one's stories with others may end up putting them at risk.

Current solutions

1) Ms. G reassessed her current lifestyle while referring to her test data

- The only way for Ms. G to manage her health is to review her lifestyle based on blood tests she takes every few weeks and revise her daily habits until the next test.
- By introducing simplified tests she can perform at home, Ms. G is doing her best to lead her life based on her recent condition to the greatest extent possible.

2) Ms. G is adjusting and changing her own daily habits in accordance with her treatment, which requires

- Ms. G discussed dietary restrictions with her doctor to establish periodic rewards for herself, such as setting days she can eat at restaurants. This helps her follow dietary restrictions over the long term.
- While exploring looser restrictions and keeping a close eye on her own physical condition, Ms. G is able to follow her diet without straining herself.

Expectations for healthcare DX

1) Simplifying testing and speeding up access to test results

- The lack of subjective symptoms means that people living with CKD may have to structure their life around test results. Ms. G hopes to see faster test results in the future.
- Because her condition requires repetitive testing, Ms. G hopes to see less invasive, highly-accurate tests in the future.

2) Helping to expand treatment options and driving innovation

- Ms. G has high expectations for the development of new medicines and medical devices for the treatment of kidney disease.
- Ms. G would also like to see the development of treatment methods that can be provided early and without impacting patients' lifestyles (like dialysis) and without harming others (like transplants).

3) Increasing the overall quality of all experiences related to self-management of health

- Ms. G thinks that sharing data stored in electronic medical records will help health providers smoothly link medical histories to the treatments and prescriptions patients currently need, even if patients visit different physicians or departments.
- Ms. G hopes that healthcare DX will make healthcare more convenient by removing the need to physically handle paperwork for procedures in and out of hospitals by allowing the information to be shared as data instead. She also hopes such changes reduce unnecessary costs for items like document issuance fees patients must pay to access assistance.



Comments from Ms. G

“For example, if test results could be taken daily using digital tools that ... only require placing a sensor on your hand to get a reading, decision-making criteria (for daily life) would gradually take form. It would be nice if testing could be performed in a day or two rather than being something two months in the future, during which the patient might strain themselves the entire time or overlook something they should have kept in mind. If that were to happen, it might help me be able to explain things I cannot put into words now, such as my feelings of fatigue. I think that determining the standards (for healthy behavior in daily life, such as for diet or exercise) for today using the ones from yesterday—or having the ability to do so—is extremely important.”

Person raising a child who lives with an intractable disease

Basic information

Mr. I. is in his 50s, lives in Saitama Prefecture and has a child with congenital spinal muscular atrophy. While his child requires help on a daily basis, even to turn over in bed, they do not require medical care. They usually use an electric wheelchair and sometimes go out to play with friends. His second child developed temporal lobe epilepsy during their first year of high school. They chose to undergo surgery and take medication to prevent seizures. When his first child was born, he felt it was difficult to gather sufficient information. He then met other parents whose children had the same condition, which led to the formation of a parent's group. Based on his belief that social support for people with intractable diseases at places like schools and workplaces is insufficient, Mr. I has acquired relevant certifications and serves on government-related committees and other bodies to actively participate in developing and creating a supportive environment.

Living alongside their child's condition in modern society

Problems, difficulties, and concerns related to the condition

1) Daily life requires human support as well as giving many things up

- When children go out into society, such as to school or to work, daily life is difficult if they do not have support from caregivers and similar parties.
- There are many things children cannot do without help, and Mr. I thinks this is something they can grow accustomed to, and that can make them become complacent. Thinking of this makes Mr. I lost as to what parents can do.

2) Service systems that are dependent on society or other people are unavoidable

- Mr. I is concerned that support may vary depending on how local government leaders or school principals think about how children with disabilities should live in their communities, which may lead to disparities.
- Mr. I feels that support for travel and other events is insufficient, and that systems and the social environment do not currently help children with disabilities become independent.

Current solutions

1) Working actively to create a support system for children

- The internet was not widely available when Mr. I's child was born and most information was medical in nature. In response, Mr. I started a parents' group so members could share information on daily life.
- As Mr. I gathered more and more information, his focus shifted from curing the condition to living alongside it, and he started concentrating on support for daily life.
- Mr. I began studying social welfare on his own, earned a certification, and launched a support project in his community.
- Mr. I studied the healthcare system, the welfare system, and related topics to be able to participate in discussions at the local government and other agencies on even footing.
- Aiming to improve current support systems and the social environment, Mr. I has also approached the government himself.

2) Making full use of support programs from a municipal government that is willing to assist

- The local government in Mr. I's community has its own proactive support system that his family made full use of to assist daily life in society.



Expectations for healthcare DX

1) Further simplifying procedures and improving service efficiency

- Mr. I has high expectations that sharing data through healthcare DX will make it easier to prepare paperwork for administrative procedures or to complete procedures at the counter.
- He hopes data will be linked with other fields like welfare and education in addition to healthcare to make the experiences of everyday life more convenient.
- Mr. I hopes healthcare DX benefits support providers by reducing human error and by simplifying manual data entry for the various forms of paperwork that must be filled out.

2) Better communication between citizens and the national Government or administration

- Healthcare DX should be used to provide systems that allow people to feel benefits in everyday life, even if they are only slight.
- A system should be established to deliver the opinions of citizens to the Government.
- Healthcare DX should be used to visualize the process of changing systems so people can feel the benefits of healthcare DX more directly.

3) Promoting innovation

- The vast amount of personal information that is collected should be used in a way that encourages the development of new medicines that give people living with disease hope for a cure.



Comments from Mr. I

“In places like real-world healthcare settings, people often have to undergo various examinations or procedures. When a person with a disability needs to have a document written or collect a document to submit to a government office, they have to go out of their way to visit a hospital for an examination for that document. On top of that, they have to pay the document fee out-of-pocket and submit it on their own. (As healthcare DX is said to be connected to many things) it would be good if healthcare DX could improve on aspects like that.”

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Health and Global Policy Institute (HGPI) is a non-profit, independent, non-partisan health policy think tank established in 2004. In its capacity as a neutral think-tank, HGPI involves stakeholders from wide-ranging fields of expertise to provide policy options to the public to successfully create citizen-focused healthcare policies. Looking to the future, HGPI produces novel ideas and values from a standpoint that offers a wide perspective. It aims to realize a healthy and fair society while holding fast to its independence to avoid being bound to the specific interests of political parties and other organizations. HGPI intends for its policy options to be effective not only in Japan, but also in the wider world, and in this vein the institute will continue to be very active in creating policies for resolving global health challenges. HGPI's activities have received global recognition. It was ranked second in the "Domestic Health Policy Think Tanks" category and third in the "Global Health Policy Think Tanks" category in the Global Go To Think Tank Index Report presented by the University of Pennsylvania (as of January 2021, the most recent report).



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