Scientific Contribution

**Privacy Issues in the Japanese Program to Prevent Lifestyle Related Diseases and the Changing Perception of Privacy in Japan**

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Abstract: The Japanese program to prevent lifestyle-related diseases is a health promotion program, which has been in effect since April 2008. It consists of an annual health check to screen for individuals with Metabolic Syndrome and a health guidance, which aims at educating those diagnosed with Metabolic Syndrome about healthy lifestyle habits.

Critics of this program have raised concerns about how the health check data is used by public health care authorities, as well as how the health guidance is conducted and fear interference with patients' privacy rights. In order to learn more about privacy issues in the Japanese program to prevent lifestyle-related diseases, I interviewed several Japanese public health nurses between September 2013 and February 2014 and found that there are various issues concerning privacy in different stages of the program, which also show a change in how Japanese think about privacy.

In this essay, I describe privacy in Japan and in a medical setting in general, before I present the findings of my interviews and discuss them based on the former.

Keywords: privacy, Japan, Metabolic Syndrome, health promotion, public health

1. Introduction

The Japanese program to prevent lifestyle related diseases (hereafter referred to as the program) is a health promotion program, which has been in effect since April 2008. It consists of an annual health check (*tokutei kenshin* 特定健診) to screen for individuals with Metabolic Syndrome (*MetSyn*) and a health guidance (*tokutei hoken shidō* 特定保健指導), which aims at educating those diagnosed with MetSyn (in Japanese *metabo* メタボ) about healthy lifestyle habits. Since MetSyn is said to be a risk factor for so-called lifestyle related diseases such as cardiovascular diseases or diabetes, it is hoped that the program will reduce health care costs attributed to these diseases in the future.
Some critics, however, have raised their voices about ethical issues concerning the program. For example, Tsutsumi Shūzō voiced his concern about the use of patients’ personal information by insurers. While usually intended for the settlement of medical costs only, receipt information may now be used to identify individuals as targets of the health guidance. Japanese public health care authorities claim to have a right to use patients’ information for health promotion purposes, but Tsutsumi argues that they use receipt information without patients’ consent and thus interfere with their privacy.

Other concerns about privacy arise out of the fact that the health guidance often takes place in the home of patients and therefore disproportionately interferes with the private lives of patients. In most cases, the health guidance is conducted by public health nurses (hokenshi 保健師), whose work covers subjects as varied as caring for infants, to child abuse. In order to learn more about the hokenshi's health guidance, I interviewed several hokenshi between September 2013 and February 2014. Based on these interviews, I found that there are indeed issues concerning privacy in the program, which also is evidence of a change in how Japanese think about privacy. In this essay, I shall demonstrate these privacy issues as well as the changed perception of privacy in Japan. However, before I turn to these topics, I want to look at how privacy is discussed in Japan as well as medical privacy in general.

2. Privacy in Japan

Describing Japanese attitudes towards privacy is no easy task, as there exist several and sometimes contradictory concepts of privacy in Japan. Many scholars inside and outside of Japan have claimed that the Japanese were relatively unconcerned with privacy if compared to Western countries. As Adams et al. note, such descriptions date back to at least 1946 when Ruth Benedict wrote:

Because there is little privacy in a Japanese community, too, it is no fantasy that 'the world’ knows practically everything he does and can reject him if it disapproves. Even the construction of the Japanese house – the thin walls that permit the passage of sounds and which are pushed open during the day – makes private life extremely public for those who cannot afford a wall and garden.

Similarly, Masami Itō wrote in 1964: “...in our country [Japan], where a sense of respect for the private life of the individual is lacking, …” Itō wrote this in response to a court decision, which mentioned the term “privacy” for the first time in Japan. The decision dealt with the case of Yukio Mishima’s book “After the Banquet” (utage no ato 宴のあと), which Mishima based on the relationship of a Japanese politician and his ex-wife without the politician’s
permission. “The judgement states that disclosure of private information to the public constitutes an actionable invasion of privacy [...]” 

Due to this apparent lack of a concept of privacy in Japan, it is not surprising that the Japanese word for privacy is taken from English and rendered into the katakana-word puraibashii (プライバシー). Before the introduction of puraibashii, there existed a dichotomy similar to public/private, but not quite the same, which was ōyake/watakushi (公・私). As Makoto Nakada and Takanori Tamura explain, ōyake literally means ‘big house’ referring to the imperial court, the government, society and the nation. It also means to make things open. Watakushi means ‘not ōyake’ or I, but in the rather negative sense of secret or selfish. Consequently, watakushi is not as valued as ‘private’ is in Western societies.

However, Adams et al. claim that the alleged lack of a sense of privacy in Japan is merely a myth and present conceptions of privacy in Japanese culture that existed well before the introduction of the term puraibashii. As Benedict mentioned in the quote above, Japanese houses built in the traditional way, that is, using light wooden structures and paper, did not prevent access to spoken information effectively. In order to still keep things private, the Japanese used the ‘as-if’ tradition, which required “that information that is merely overheard but not explicitly given, is treated as if one did not have it.” Thus, the context in which information is acquired decides how it should be treated.

Context is also crucial in social relationships, which decide what information is given to whom and in what way. The relevant model to describe social relationships in Japan is called uchi/soto (内・外). Adams et al. describe the uchi/soto model as containing different spheres. In general, uchi means ‘inside’ and soto means ‘outside’ but there are several layers in each of these spheres. The uchi or inner sphere consists of the individual self (wataishi 私), close persons like family and friends (miuchi 身内) and other persons considered to be in the same group as the self. The soto or outside sphere consists of people without any direct ties to the self who are regularly encountered, which are soto and those who are rarely or never encountered, which are tanin 他人 (other). Tanin are considered as potentially dangerous but are treated with courtesy and respect. But in contrast to the West, even people who are considered to be “tanin may receive significant private information, due to the lack of continuing contact depriving such relations of their danger.” Additionally, there is a liminal sphere, which consists of people who are sometimes uchi and sometimes soto, depending on the context.

Concerning Japanese attitudes to privacy, this model shows that the inner sphere of self does have a strong need “to keep certain information private from even those closest to it”, as Adams et al. explain:
While the exact nature of the information kept ‘close to the chest’ may differ, the desire [...] for [...] privacy, is just as strong [as in the West]. Similarly, the further away we move from the self, the less information is revealed. To those in the *uchi/soto* liminal zone, [...] less information is revealed than to those always within the *uchi* zone. Of course this static two dimensional representation does not include the dimension of the types of information. Some information is only given to people in a particular circumstance and never to others, even those within the *miuchi* group. This may include privileged groups such as doctors and lawyers, who regularly receive confidences and whose relations with clients/patients are strictly governed by professional ethics, in Japan no less than elsewhere.\(^ {13}\)

So, it would be wrong to deny the Japanese a sense of privacy or talk of privacy as a new and imported concept in Japan. In fact, Japanese have shown great sensibility towards privacy when the Act on the Protection of Personal Information (*kojinjōhō no hogo ni kansuru hōritsu* 個人情報の保護に関する法律, hereafter referred to as the Act) was enacted in 2003 and came into full effect two years later.

The definition of personal information under the Act is very broad, and includes any information specifically identifying a living individual, even information that is not related to what one might normally consider information of a personal or private nature (like medical or financial information) may fall under this definition. Due to this very broad definition, there are several examples for overreactions after the enforcement of the Act. For example, Hiroshi Miyashita names cases:

in which local governments did not release personal information following an earthquake even when this was necessary so that efficient assistance could be given to the elderly and the disabled. Other cases were discussed in which schools stopped distributing student and alumni directories because of data protection concerns.\(^ {14}\)

According to Miyashita, these overreactions happened although the Act allows the use of personal data without consent:

when this can be justified based on (1) provisions of other laws, (2) the protection of life, body, and property of persons, (3) improving public health and promoting the sound growth of children, and (4) cooperating with public institutions.\(^ {15}\)

And he concludes, “that the overreactions resulted from the changing awareness of privacy and data protection among Japanese citizens, most of whom were not familiar with the new concept of data privacy embraced in the Act.”\(^ {16}\)

That the awareness of privacy among Japanese is changing can also be seen in medical settings like the Japanese program to prevent lifestyle related diseases. In order to demonstrate privacy issues in the program, I will look at privacy in medical settings in general first.
3. Privacy in medical settings

Privacy is a crucial value in a medical setting. According to the Stanford Encyclopaedia of Philosophy, there are several aspects of privacy in medical settings, which can be grouped as informational, physical, associational, proprietary and decisional privacy. Since I found informational privacy the most important aspect in the Japanese program to prevent lifestyle related diseases, I shall concentrate on this aspect in this essay.

In general, informational privacy is concerned with the question of who has access to personal information and under what conditions. Usually, we expect personal information given to doctors, nurses etc. to be kept confidential. Therefore, confidentiality is perhaps the most prominent aspect of privacy in medical settings with a long tradition that can be traced back to the Hippocratic Oath from the 5th century BC and is believed to benefit individual as well as public health. It is argued:

that preventive medicine, early diagnosis and treatment save human lives and money. Individuals will be more inclined to get medical attention if they believe they can do so privately. Policy experts maintain that the cost of health care and insurance would be considerably higher if people avoided routine check-ups and prompt medical attention because confidentiality was not credibly promised.

Moreover, confidentiality promotes the medical autonomy of individuals and enables them to make decisions about their health without interference of third parties. This is especially important in the case of morally controversial treatments, for example, abortion, or stigmatised medical conditions such as infectious diseases like HIV/AIDS, although there is an on-going debate on exceptions to confidentiality. Such exceptions concern the disclosure of an HIV infection to patients’ spouses or of patients’ violent intentions towards potential victims for example.

Another important aspect of informational privacy in medical settings is secrecy. Secrecy works in both directions of the relationships between patients and health care professionals as well as their families and other interested persons. On the one hand, patients may not disclose all information about their health in front of health care professionals or keep their illness secret from family members. Reasons for this may be the embarrassing nature of certain conditions or fear of the consequences. On the other hand, health care professionals and family members may not tell the patient about the true nature of their condition especially if the patient is very old or young and the condition grave. Whether this kind of deception is ethical can be argued and in fact opinions vary greatly among different cultures. Concerning the secrecy of patients towards health care professionals, Anita Allen also points to the possible use of techniques to disclose secrets:
Neuroimaging, brain imagining technologies (BIT) generally, and advanced lie-detection raise critical questions about whether secret thoughts should be available for discernment, and if so under what circumstances. [...] The issue is one of coerced self-disclosure and, potentially, self-incrimination. The right against self-incrimination has been defended by philosophers since the dawn of modernity. Thomas Hobbes named it as one of the few rights a citizen has against his sovereign. [...] 

Needless to say that such an involuntary disclosure of information would compromise patients' autonomy.

A further aspect of informational privacy in a medical setting is data protection and security. Intended to keep health records safe from unauthorized use, data protection and security can include procedural or technical measures. These are especially important in times of an ever-advancing digitalisation of personal information often stored and accessible via web-based services. However, there are exceptions as Allen writes:

Health privacy statutes limit disclosure in the absence of informed consent; but typical statutes recognize numerous exceptions for routine uses, research, public health reporting, and legal process and law enforcement. The policy consensus seems to be that, while medical privacy is important, patients' medical information may be disclosed to third-parties for socially important purposes unrelated to their own care.

When attempting to understand informational privacy and security, anonymity is an important concept. Although anonymity alone may not be enough to protect patients' information, it is commonly used in medical research and practice, for example, in the anonymous testing for certain diseases. Allen remarks that despite the high value placed on confidentiality, it has become more common to speak about personal medical issues openly and show one's accountability as well as being held accountable for one's diseases. Individuals may be expected to report symptoms of disease upon entering a country at the airport or disclose an infectious disease out of consideration not to infect others. However, it is important to note that, “[t]he more disclosures [someone] must make, the wider the circle of confidentiality and the lesser the medical privacy.”

Finally, Allen mentions professional norms as an aspect of informational privacy. Such norms should include an active interest in protecting patients' information. Not only should information be collected, stored and shared securely, but health care professionals should also pay attention not to discuss “client matters on cell phones in public places, such as in office corridors, hospital lobbies and on trains.” This last aspect is especially interesting when we look at privacy issues in the Japanese program to prevent lifestyle related diseases.
4. Privacy issues in the Japanese program to prevent lifestyle related diseases

The following findings are based on interviews with several hokenshi, which I conducted between September 2013 and February 2014 to learn more about ethical issues in the program. Firstly, I interviewed two hokenshi, who enabled me to observe a health guidance consultation at a health center in Nara Prefecture, where I could talk to a further hokenshi, and get in touch with five ‘veteran’ hokenshi, with whom I conducted a group interview. Although these hokenshi were officially retired, they continued working as volunteers in a non-profit organization (NPO), which receives health promotion requests from municipalities all over the Kansai region. Since these hokenshi were already retired, they could look back on decades of working experience and were able to compare their work in former health promotion programs with the current health guidance system.

Even though the health guidance is a relatively new public health measure in Japan, the working style of hokenshi remains largely unchanged in that they contact citizens based on the information they gather themselves or receive from insurers. As I mentioned in the introduction, Tsutsumi criticizes the gathering of information without the consent of patients, but according to the first two hokenshi I interviewed, municipalities have a right to know what diseases cause high health care costs and to do so, the combination of receipt data and medical information is necessary. However, only very few hokenshi can access the data and those who do will not conduct the health guidance. The combined data is later anonymized with numbers for statistical use, but statistics are compiled for each municipality only and not gathered by the state as Tsutsumi feared.25

Further, the two hokenshi pointed to the working ethic of hokenshi and other health care professionals, who are required to protect the privacy of clients by law and claimed that hokenshi are even more sensitive about protecting patients’ information since their scope of work is so broad. In fact, they also handle delicate information, such as which individuals abused their children or committed other crimes, are in jail or have relatives who are. Therefore, the handling of medical data such as weight or blood pressure and personal information like work or family life seems rather trivial to the hokenshi. If one were to criticise this information gathering by hokenshi for interfering with patients’ privacy, indeed the whole hokenshi enterprise would be unethical, one of the interviewed hokenshi argued.

The veteran hokenshi argued in a similar way, saying that it is necessary for public health to collect information in different regions in order to describe epidemiologies and decide which lifestyles pose risks to which diseases. But such information will only be
shared among *hokenshi* and never with other members of administration. The veteran *hokenshi* admitted however, that problems could arise in small municipalities, where chances are high that *hokenshi* are also family members or friends of patients and therefore would know the results of their examinations etc. Thus, they argued, it would be advantageous if *hokenshi* from outside the municipality were in charge of the program, just like the veteran *hokenshi* of the NPO.\(^{26}\)

Once the *hokenshi* have collected the necessary data to decide who should participate in the health guidance, they either invite them to come to a health center for the guidance or ask if they allowed a *hokenshi* to visit them and conduct the guidance at their home. According to the first *hokenshi* interviewed, administrations will send a letter to potential participants before a *hokenshi* will call or visit them, because otherwise their privacy would be compromised, but according to the *hokenshi* I talked to at the health center in Nara, sudden visits without prior information took place as well. Also the veteran *hokenshi* reported that they have to carefully explain who they are and what they do if they call or visit, because potential participants have not heard of the health guidance and do not understand why someone they do not know has their health information. It appears that these participants had not received (or not read) a letter to inform them of the health guidance and possible calls or visits. Therefore, actual practices in this respect seem to differ.

Considering home visits, the veteran *hokenshi* compared their experiences from some decades ago and today and mentioned cases in which their visits are met with hostility and suspicion. According to the veteran *hokenshi*, it used to be common sense that everybody in the neighborhood knew when a child was born and nobody would be surprised to be suddenly visited by a *hokenshi* who wants to check if the family needed any help. They say that these visits used to be welcomed by citizens who were pleased to receive assistance, while some citizens nowadays refuse to let the *hokenshi* into their homes. This applies to home visits concerning the health of children as well as the health guidance and shows the changed perception of privacy among Japanese.

With regard to the latter, the veteran *hokenshi* mention lacking knowledge of the program as a reason for hostility, but they also acknowledge societal changes. Traditionally, they say, there is no individualism in Japan and everybody wants to live in harmony (*wakiai*）with society so that it was generally understood that municipalities accessed personal information. But now there is a growing concern of how personal information is used, and some citizens want to know how *hokenshi* got access to personal health information when they are visited.
Despite this growing concern and the lack of knowledge about the program, approximately 50% of the Japanese who should take part in the health guidance actually do participate each year, but privacy issues also occur during the health guidance itself.

The health guidance at the health center in Nara was performed in one big room, where participants sat at a table in the middle of the room until it was their turn, while at the side of the room two participants at a time talked to one hokenshi each. It was therefore possible for participants to overhear the health guidance given to others. This is not an unusual scenario compared to other medical environments in Japan, as I know from my own experience with medical clinics in Japan. Apparently, it is expected to respect the aforementioned as-if tradition in these settings, if one hears information told to somebody else, but this would be in stark contrast to all hokenshi's claims to protect patients' information.

This contrast also becomes visible when looking at the health guidance taking place at participants' homes. Although the hokenshi claimed not to share patient information with family members, family members may in fact be present at when health guidance is given. One reason is that it used to be common sense in Japan that family members attend medical consultations or even replace patients who might not be told the true nature of their disease. Hokenshi take advantage of this and sometimes use family members as a source of information. For example, one veteran hokenshi reported a case in which the wife of a patient brought tea into the room where the health guidance took place and stayed afterwards to give information completely different from what the patient himself had told the hokenshi. In this particular case, it turned out that he had made his daily alcohol consumption smaller than it was in actuality.

However, one has to ask whether this kind of information gathering is ethical. On the one hand, information gained through family members may be more reliable for the hokenshi than that given by the patient and they argue that counselling only makes sense if the whole family is involved, especially since in most cases wives are responsible for preparing meals and need information on healthy cooking. On the other hand, the veteran hokenshi say that there are patients who do not want their wives to know they are metabo precisely because they fear they will not be able to eat what they like anymore. So the question remains why the patient did not offer correct information by himself and whether he approved of the action of his wife. The hokenshi admit that they could not ask family members about patients' habits in the first place, but they do not refuse their interference either. Therefore, secrecy as described by Allen above is clearly not given in this case.

Sometimes family members also listen to the guidance in secret and disregard the as-if tradition completely, while in other cases family members cannot help but hear the
conversation between patient and hokenshi, due to a lack of space and thin walls. This problem is common in small apartments, where not only family members but also neighbors may be able to overhear conversations. Therefore, the hokenshi sometimes conduct the guidance consultation outside of the home, e.g. in a café, but of course this is not free of conflict either.

Indeed, this practice contradicts the professional norms Allen described above. Even worse than discussing medical information on a cell phone in public where the patient cannot be seen, here, it is discussed together with the patient in the same place so that not only the discussion is audible but the individual whose health is discussed is visible too. To conduct a health guidance consultation in a public place can hardly provide enough security to talk about health issues and it is questionable whether reliable information can be obtained in such a place. On the other hand, the as-if tradition seems to apply in these cases and some Japanese prefer to make their personal information audible for total strangers (tanin) instead of family members. In fact, there are other private matters for Japanese that are apparently unproblematic to discuss surrounded by tanin such as their insurances. More than once did I notice talks between an insurance agent and his or her client while sitting in a café. Thus, although some Japanese have become more critical of how their private data is used by authorities, complete strangers are often still considered harmless and therefore all right to hear very personal information.

5. Conclusion

As we have seen, there are different privacy issues in the Japanese program to prevent lifestyle related diseases occurring in each of its phases.

Firstly, the collection, access and storage of patients' information pose questions of confidentiality, data protection and security, as well as anonymity. While concerns about possible interferences with patients' privacy exist in this respect, the hokenshi I interviewed were well aware of the importance of protecting personal information and explained that confidentiality was provided because data access is limited and separated both from hokenshi who conduct the health guidance and municipal governments that can only use anonymous data for statistical use. Since the Act on the Protection of Personal Information allows the use of personal data without consent in order to improve public health, this kind of usage is acceptable and reasonable, given that security measures are sufficiently implemented.

However, some Japanese citizens show mistrust about how their data is used. This became clear in the second phase of the program, when hokenshi try to make contact with
potential health guidance participants. As I learned from my interviews, more Japanese question approaches by *hokenshi* than before and do not understand how their data is used by authorities. Compared to some decades ago, they are more critical of possibly illegitimate use of their personal information and demand explanation. Authorities as well as *hokenshi* cannot rely on the often heard Japanese wish for harmony as a guarantee for unquestioned data use anymore and may have to make it more transparent in consideration of the changed attitude towards privacy among Japanese citizens.

This may call for a discussion on accountability as well. The *hokenshi* claim that municipalities have a right to collect data for epidemiological research, which is backed by the Act. But since the program uses patients’ data also to target certain individuals, they are in fact being held accountable for their health and expected to change their lifestyle if necessary. Whether this is acceptable for Japanese society or not should be a subject of public debate, especially since it was reported in October 2014 that the Japanese Ministry for Health, Labor and Welfare (MHLW) considers lowering health insurance fees for those who succeed in losing weight.29

Finally, privacy issues occurring during the health guidance concern secrecy and professional norms. When looking at privacy in Japan in general, the indifference towards *tanin* who could gain access to personal information is striking compared to other countries. It is generally expected that *tanin* overhearing conversations they are not involved in will follow the *as-if* tradition and treat any information gained like this as if they did not hear it. In return, *tanin* are treated as if they do not exist, because it is expected that they will not be met again, adding another dimension to the *as-if* tradition. Therefore, it is no problem for Japanese to discuss personal issues in public spaces.

However, when *hokenshi* approach potential participants in the health guidance, conflicts are possible as the *hokenshi*’s experience demonstrates. In approaching citizens, *hokenshi* are perceived as *tanin* until they establish a relationship with them and are given the privileged status of someone, whom it is acceptable to share personal information with, even if rarely encountered. But in contrast to other privileged persons like doctors or lawyers, *hokenshi* are not approached by citizens who seek their assistance. They approach citizens themselves without being asked to do so; thus citizens encounter *hokenshi* *tanin* who possess information, which was not directly given to them and is not treated like the *as-if* tradition would demand. This may not have been a problem some decades ago when Japanese were generally uncritical towards the use of their personal information by authorities but bears the potential for conflict in times of heightened sensibility for data protection.
Hokenshi have understood the changed perception of privacy in Japan and bear in mind that how and what information is shared with family members varies for each individual. Some Japanese still like family members to attend medical consultations while others prefer to talk to hokenshi alone, even if that means that they are surrounded by strangers. Therefore, hokenshi consider the place of the health guidance and conduct it outside of the home if necessary, although they might not always do so consequently, as could be seen in cases in which family members were used as a source of information.

To address the privacy issues involved in this practice, the professional norms of hokenshi should be discussed. Also hokenshi need to be aware of their contradicting position as tanin who do not follow the as-il tradition. Their role in a society whose expectations towards privacy are changing should also be considered for discussion.

Notes

1 The term 'Metabolic Syndrome' is used to describe a cluster of several risk factors for disease, especially cardiovascular disease and diabetes. There are currently seven definitions of MetSyn in use that vary in detail but in general describe a combination of overweight, high blood pressure, high triglyceride or LDL-cholesterol levels, low HDL-cholesterol levels and insulin resistance (Kassi, E. et al.: Metabolic syndrome: definitions and controversies. BMC Medicine 2011: 9: 48). In Japan, obesity is the necessary criterion for MetSyn since there is no ‘overweight’ category. It is determined either by waist circumference (WC), which should be lower than 85 cm for men and lower than 90 cm for women, or by body mass index (BMI). If someone is not obese by WC but has a BMI of 25 or more he or she will count as obese. Further criteria are high blood pressure (higher than 130 over 85), high blood sugar levels (higher than 100 mg/dl) and high triglyceride levels (higher than 150 mg/dl). However, since the program’s reform in 2013, individuals fulfilling criteria for MetSyn other than obesity will also be considered targets of the program. (MHLW: Hyōjuntekina kenshin/hokenshidō purōguramu (kaiteiban). Apr 2013).


3 Ibid.


Ibid.: 332-333.

Ibid.


Latanya Sweeney, for example, demonstrated the possibility of re-identifying anonymous medical information by linking it to publicly available data such as voter registration lists and proposes a model for better privacy protection. (Sweeney, Latanya: k-anonymity: a model for protecting privacy. In: *International Journal on Uncertainty, Fuzziness and Knowledge-based Systems* No. 10 (2002): 557-570.

Actually, the veteran hokenshi explained the reason for why municipalities use hokenshi from outside is to save money, because it would be more expensive to employ younger hokenshi than to put retired hokenshi receiving pensions voluntarily in charge of the program.
