# Pocket Karte: Service for Managing Individual Healthcare, Medical, and Welfare Histories

# 1.Introduction

In order for individuals to enjoy optimum medical and healthcare outcomes they must have access to their own detailed medical histories and development records. Yet it is very rare for people to have access to this data, for most of us rely on medical institutions to maintain our medical records. Now, we, the Sustainable Community Center Japan (SCCJ), a Kyoto-based NPO, have come up with a new scheme enabling ordinary citizens to centrally manage and control their own medical records in chronological order that until now have been managed by various medical institutions. This new personal service, called *Pocket Karte*, is now widely available for free throughout Japan, and gives users the ability to manage their own healthcare, medical, and welfare histories. This paper provides an overview of *Pocket Karte*, describing the approach taken and how the system evolved.

#### 2. Project Background and History

A basic key to promoting regional revitalization is environmental enhancement that improves living conditions, especially healthcare and welfare care of people in the community. Yet we are seeing fewer medical institutions all over Japan even as the medical establishment struggles to provide more sophisticated medical procedures to an increasingly diverse and individualized clientele.

There is a wide range of medical institutions throughout Japan-hospitals, clinics, dispensing pharmacies, and so on-but they are operated by different parent organizations, some private (individual and corporate) and others public and state -supported (national, prefectural, municipal, Red Cross, etc.) institutions, and medical histories of patients are kept and managed separately by these various institutions. This means that when someone goes to see a primary care physician then goes in for an appointment with specialist at a hospital, there is virtually no coordination between the pre-exam information collected by the primary care physician (past medical history, family history, allergies, and the like) and the oral consult information given to the specialist. Doctors end up repeating the same advice and tests which is not only a colossal waste of time and medical resources, but also runs the risk of doubling up on prescriptions which could endanger the patient's life. This calls for a better solution, a new framework enabling individuals to centrally manage their own medical and welfare histories in chronological order to make better use of the medical resources that are available including staff, equipment, and facilities.

In order to address this challenge, common throughout the

Yuki Kitaoka

Director Department of Medical Informatics National Hospital Organization Kyoto Medical Center Executive Advisor NPO Sustainable Community Center Japan



country, of too few overburdened medical institutions, the NPO Sustainable Community Center Japan (SCCJ) has developed and deployed the *Pocket Karte* project integrating a *Smart ID Card for Regional Healthcare* for managing one's own personal healthcare, medical, and welfare histories and management of local healthcare resources. The end objective of the project is to create one vast virtual healthcare network that links all regional medical facilities into a vast information infrastructure that delivers highest quality, safe, and secure medical and healthcare services to everyone in the community. Currently, as of March 31, 2016, *Pocket Karte* has over 50,800 registered users, and has contributed significantly to the establishment of a safe secure regional healthcare delivery system.

## 3. Project Details and Service Overview

The project has two basic elements or features. The first key feature is *Pocket Karte* itself. Conceived and developed by the author, *Pocket Karte* is a powerful Personal Health Records (PHR) service administered by SCCJ, that provides anyone in the community with the ability to manage their own healthcare, medical, welfare, nursing care and other medical records throughout their lives and free of charge.

Hospitals, clinics, and pharmacies send the medical records of local citizens to their *Pocket Karte* accounts, where the data can be readily accessed and managed by the individuals themselves, and the data is always available in the event of disaster or emergency situations.

The other key feature of the project is the *Smart ID Card for Regional Healthcare*, also conceived and developed by the author. Essentially this is an IC card where you can register ID numbers for medical facilities and your patient ID numbers at those same facilities for up to 30 different medical institutions. Once you have registered your patient numbers on this one card, you can set up appointments without going through a whole stack of cards issued by all the different hospitals. Eliminating the need to carry around a wallet full of cards is especially beneficial for elderly people who commonly have to see doctors on a regular basis.

*Pocket Karte* is also exceedingly user-friendly. You can access the service by just entering an authentication key, which makes it assessable and easy to use by younger children and older adults who may have trouble operating a computer or smartphone or barcode reader. Cards have been issued to more than 50,000 people in areas around Kyoto and Nagoya, and at the present time (April 28, 2016), some 20,173 cardholders (40% of those issued the card) are using the card to set up their medical visits and doctor's appointments.

Figure 1: Comparison of Pocket Karte project at initial rollout and today



Compared with Electronic Health Records (EHR) and other schemes for sharing medical data between different medical institutions, *Pocket Karte* is unique in a number of respects.

- (1) First, *Pocket Karte* is the only system that give people control over their own medical records all through their lives.
- (2) Second, data stored on *Pocket Karte* is the life-long history or the life log of actual people, and thus provides a way of evaluating the effectiveness of medical procedures and interventions. *Pocket Karte* data is now beginning to be used as a medical research tool in Ministry of Health, Labour and Welfare research studies to assess and improve the quality of medical outcomes.
- (3) Third, once the number of *Pocket Karte* users tops the one million mark, this will open the way for other kinds of studies besides pure medical research to improve the quality of healthcare. *Pocket Karte* could provide invaluable new evidence or a knowledge base for optimizing healthcare costs (healthcare economics), for optimal deployment or training of resources to extend life expectancies (medical staff, equipment, facilities) by analyzing the information as big data stored on *Pocket Karte*.
- (4) And finally, for revitalizing local infrastructure, *Pocket Karte* can provide a more fully developed medical environment. It is not only people and jobs that have been leaving rural areas, the medical environment has also suffered in recent years. The data stored on *Pocket Karte* is critically important to extract the maximum benefit from scarce medical resources, and should provide better telemedicine outcomes by giving access to the full medical history of the individual.

*Pocket Karte* is a kind of *data bank*, where one can store and manage a lifetime of healthcare, medical, welfare, and nursing care historical data at no cost. Likening the service to a bank in the financial sense makes it easier to understand the service. Just as you deposit money in the bank, you deposit healthcare, medical,

welfare, and nursing care historical data (test and lab results, prescriptions, surgeries, hospitalizations, etc.) in *Pocket Karte*. Getting hard-copy medical records from the records department at your local hospital is comparable to withdrawing money from the teller at your local bank. But Internet banking, the basic model for *Pocket Karte*, is more convenient still. Using the *Smart ID Card for Regional Healthcare* to manage your data is comparable to using a cash card to deposit or withdraw money from an ATM machine.

One advantage that *Pocket Karte* has over your bank's ATM machine is that you can peruse your medical data 24 hours a day from the comfort of your own home on your TV set (this only works if you have a cable TV line, as we discuss later). Individual users have access to the *Pocket Karte* service for free, as we have mentioned, but hospitals and other medical facilities pay a modest fee for which they receive some pretty significant benefits. The way it works, *Pocket Karte* continues to operate autonomously and continuously. And by going along with *Pocket Karte*, clinics and hospitals can avoid building and operating their own data systems from scratch and only need to procure the bare minimum of tools.

- Medical facilities: use *Pocket Karte* to share information with patients, and coordinate local healthcare.
- Medical research institutes: use *Pocket Karte* as a database for clinical research and trials.
- Local governments: use *Pocket Karte* to upgrade community services.
- Vendors: use *Pocket Karte* to add value to their services and products.

For implementation and management purposes, a *Pocket Karte Smart ID Card for Regional Healthcare* Committee was set up and meets on the third Thursday of every month (62 meeting have been held so far as of October 8, 2015). The meetings are open to mayors and other government leaders of Kyoto Prefecture, Kyoto City, Uji City, Joyo City, Kumiyama Town, Ikoma in Nara Prefecture, members of the Consortium for Information Society in Kyoto (organized by integrating the former Kyoto Information Infrastructure Council and the former Kyoto Advanced Information Promotion Council), regional medical associations, medical institutions, patient groups, community associations, ICT vendors, and others. Individual members of the SCCJ may also sit in as observers.



## Figure 2: Service vision and system configuration

# 4. Early Setbacks

After a trial version of the service was launched in June 2008, the first official free version of *Pocket Karte* was rolled out a few months later in October 2008. The number of registered users soared to over 100,000 during the first four months, but then the number of new subscribers tapered off. In surveying the users, many complained that "hospitals and pharmacies didn't get the digital data, so I had to enter the data manually one by one, which was a big hassle."

We then came up with the idea of having the hospitals, pharmacies, and other medical establishments print a QR code (a type of matrix barcode) on their receipts, so users could enter the data into *Pocket Karte* by simply using their cell phones, PHSs, or smartphone cameras to read to codes. We call the receipts with QR codes *digital receipts*.

In order for drug stores and medical establishments to implement this *digital receipt* system, they had to upgrade their medical accounting systems and POS register systems, which of course involved some investment. We had to give them an incentive which was potentially more valuable than the cost to upgrading to handle *digital receipts*, and for this we offered more users and more patients.

Similarly, we had to incentivize the patients so they would patronize the pharmacies and medical establishments that implemented the *digital receipt* system. For services covered by health insurance, Paragraph (1) Article 4 of the Rules for Health Insurance-covered Dispensing Pharmacies and Pharmacists (Ordinance of the Ministry of Health and Welfare No. 16 of 1957) provides that according to Article 74 of the Health Insurance Act, patients may receive payment of a partial share of the costs, and this amount cannot be reduced or discounted. For this reason, patients are focused on medical expense deductions.

According to statistics published by the Ministry of Internal Affairs and Communications (MIC) in 2007, average annual insurance costs for households of two or more exceed ¥100,000. This fact suggests a 50% probability that households of two or more are receiving medical expense deductions. But at the same time, it also means that 50% of households with two are more are not getting the benefit of medical expense deductions. This is because the procedure for taking the deduction is cumbersome and complicated: you have to gather up all your medical receipts for each member of the family over the course of the year and do some complicated accounting. You also have to submit documentation certifying that you are the person who received the receipts. But starting in 2008, one can claim the deduction electronically using e-Tax, and you no longer need to attach actual receipts. Instead, you are supposed to digitize receipts for all healthcare related expenditures, and we have come up with a convenient service for collecting and managing medical expense receipts for all members of the household by simply snapping a photo of the receipt with your cell phone camera.

With the goal of implementing such a system, we applied to develop "a medical digital receipt platform and value-added service for local residents that works together with healthcare household accounts" as one of the MIC's 2009 "ICT Economic and Regional Revitalization Infrastructure Projects (Ubiquitous Zone Projects)." The proposal was adopted in November 2009, and the official rollout of the new service, again available to ordinary consumers for free, took place in February 2010.

Medical expenses include expenses paid to hospitals and other medical facilities that are covered by insurance as well as expenses for other things that are not covered by insurance, such as adult diapers, taxi fare to the hospital, and so on. Since some things are covered while others are not, the author came up with a "healthcare household accounting" system as part of the service that automates the entire process of assembling information needed to take the medical deduction  $\rightarrow$  perform necessary accounting entries  $\rightarrow$  and automatically format the e-Tax form. I would refer the interested reader to the following YouTube video that illustrates how this service works: http://www.youtube.com/watch?v=IAER0i4ZGBk.

In order to promote widespread adoption of the digital receipt platform, we had to develop a environment capable of converting a user's medical data (data concerning the purchase of goods and services covered by health insurance such as vaccinations, illnesses and diseases, medical exam results, health foods, favorite foods, over-the-counter drugs, back support belts, and so on) into data that can be readily recorded in Pocket Karte. The project to develop a safe secure healthcare, medical, and welfare information infrastructure project by issuing a Smart ID Card for Regional Healthcare recommended by Kyoto City, Uji City, Joyo City, and Kumiyama Town was submitted for funding under the MIC's FY 2010 budget allocation for a broad-based regional partnership utilizing ICT, and was adopted. A Management Council was then organized by all the stakeholders who wanted to be involved in the MIC project-local governments, Kyoto, and a host of experts in different areas-and the project was launched as a demonstration service in January 2011 based at the Kyoto Medical Center (Kyoto, Fushimi Ward) and targeting the geographic area composed of the three cities and one town mentioned above (790,000 households).

In addition to last year's deliverable—the scheme for transmitting data to *Pocket Karte* using the *digital receipts* platform and the monetary data (receipts and statements) for determining medical expense deductions—the MIC projects has been

#### Table: Model of Pocket Karte Usage

1. Electronic drug notebook

More than 2,000 pharmacies supported nationwide (as of March 31, 2016).

- 2. Electronic dialysis notebook
  - Developed novel electronic dialysis notebook in February 2014 in collaboration with Department of Nephrology, Kyoto University Hospital.
  - Began providing services to 15,000 dialysis patients through Kyoto Association of Kidney Disease Patients, Osaka Association of Kidney Disease Patients, Hyogo Prefecture Association of Kidney Disease Patients, and Shiga Prefecture Association of Kidney Disease Patients.

3. Electronic healthcare notebook

- Developed electronic healthcare notebook in April 2014 in collaboration with Japanese Red Cross Kashiwabara Hospital (Tamba, Hyogo Prefecture). Currently, 12,276 people are using the services (of which 37% are community health exam subjects).
- 4. Electronic NICU Discharge Notebook
  - Developed electronic NICU discharge notebook in April 2014 in collaboration with Osaka Medical Center and Research Institute for Maternal and Child Health (Izumi City, Osaka)
  - On April 1, 2015, began using the discharge notebook to register medical records for all children discharged from NICU as a tool for long-term follow up of these patients.
  - Committee approved to oversee use of *Pocket Karte* and other tools as monitoring platform for intractable diseases of children by the Japan Pediatric Society, and study expanded nationwide.

5. Cable TV Pocket Karte

- Rolled out Cable TV *Pocket Karte* service tailored for elderly and rural citizens who are unfamiliar with computer, cell phones, smartphones, etc.
  - (1) In October, 2013 launched trial on J:COM Kyoto-miyavision.
  - (2) In September 2014, expanded nationwide to include all J:COM group companies (31 companies).
  - (3) From March 2015, began rolling out services among cable TV operators in Japan Cable Television Federation.
- 6. Pocket Karte iOS application (medical notebook, medical exam results, medical expense report, medical facility receipts)
  - (1) Built-in bar code reader makes it easy to read in clinical data
    - (2) App is capable of reading both *Pocket Karte* QR codes as wells as Japan Pharmaceutical Association recommended QR code data

broadened to include (1) prescriptions, (2) screening data and results, (3) treatment data, and more. Our solution for dealing with (1) prescriptions is the electronic drug notebook service. This service has been especially well received for its fully automatic recording method that eliminates all the problems associated with conventional paper-based drug notebooks: affixing seals, handwritten transcription, and so on.

Finally, we would note that the use of *Pocket Karte* requires some familiarity with data terminals in the form of cameraequipped cell phones, PHSs, smartphones, bar code readers, or computers. Unfortunately, not all patients or consumers who have doctor's appointments or visit a pharmacy are smartphone or computer savvy. This was the main reason that we brought out the *Smart ID Card for Regional Healthcare* to provide services to those who may be technically challenged. We would refer the interested reader to the following YouTube video that shows an overview of how the *Pocket Karte* was received in the initial service area which includes five hospitals and the Kumiyama town office: http://www.youtube.com/watch?v=w-ISKTvmSvA.

### 5. Future Developments

The Sustainable Community Center Japan has a saying that "those with money contribute money, those with brains contribute wisdom, and those with neither brains nor money contribute sweat equity!" The idea is that everyone in the community can get involved in projects and help establish the kind of ecorecycling sustainable society that SCCJ and the rest of us desire. Through this project we hope to achieve ongoing and autonomous operations without relying on public funding, to come up with an innovative new business model through expansion of *Pocket Karte*, and to create a virtuous cycle of business expansion (see Table).

The introduction and maintenance costs for this project vary greatly depending on the region, the facilities available, and project specifics. For more detailed information about this project, please contact us at the numbers shown below.

For further information, contact:

Specified NPO Sustainable Community Center Japan (SCCJ) Telephone: 0120-988-617 (weekdays, 9:00 AM to 5:00 PM) E-mail: pocketkarte\_support@dokokaru.net