Global Health & Medicine. 2021; 3(5):314-320.
REVIEW
DOI: 10.35772/ghm.2021.01061

Use of information and communication technology in the support of viral hepatitis patients in Japan

Tetsuro Shimakami*, Shuichi Kaneko

Department of Gastroenterology, Kanazawa University Hospital, Ishikawa, Japan.

Abstract: In Ishikawa Prefecture, Japan, the regional core center for hepatitis care coordination (Kanazawa University Hospital, the only regional core center in the prefecture) conducts follow-ups with people who tested positive for viral hepatitis at screenings organized primarily by municipal governments. This program, called the Ishikawa Hepatitis Follow-up Program, has been operating since 2010. The regional core center has conventionally verified the status of program participants using a paper-based system of "examination letters" which specialized institutes mail to the regional core center when a program participant visits a physician there. However, only a low 40% to 50% of examination letters were returned to the regional core center. The program is now using the information and communication technology tool ID-Link to help the regional core center participate in care and provide support through mutual sharing of clinical information with specialized institutes. Currently, 1,632 of the 3,202 people who had tested positive for hepatitis testing since 2002 have consented to participate in the Ishikawa Hepatitis Follow-up Program, and as of the end of March 2021, information about 132 among those 1,632 people is being shared between specialized institutes and the regional core center using ID-link. Sharing of clinical information between the regional core center and specialized institutes enabled by ID-Link provided a more accurate picture of how many people who tested positive for viral hepatitis had visited a specialized institute compared with the previous paper-based system of examination letters, making follow-up more efficient.

***Keywords*:** viral hepatitis, information and communication technology

Introduction

It is estimated that 1.12-1.27 million and 0.98-1.58 million people were persistently infected with hepatitis B virus and hepatitis C virus, respectively, in 2011 in Japan (*1,2*). People with hepatitis B or C are at high risk for developing cirrhosis and liver cancer, which makes it important to test for hepatitis (screening), refer those who test positive to a specialized institute (consultation), and have them start antiviral therapy (treatment). Besides these steps of screening, consultation, and treatment, it is extremely important to conduct follow-ups by tracking which patients have visited a specialized institute and recommending a visit to those who have not.

In Ishikawa Prefecture, Japan, municipal public health staffs have conducted hepatitis screenings as part of the national government's senior health promotion program and later the general health promotion program since 2002, and have been conducting follow-ups with people who tested positive. In 2010, the prefecture also launched the Ishikawa Hepatitis Follow-up Program, in which Kanazawa University Hospital, the only regional core center for hepatitis care in the prefecture, conducts follow-ups with people who tested positive for hepatitis at local screening programs. At the end of 2019, of the 3,202 people who had tested positive for hepatitis testing since 2002, 1,632 had consented to participate in the follow-up program, 525 had declined to participate, and 1,045 did not respond.

The mortality rate due to liver cancer of Ishikawa Prefecture has generally been lower than that of Japan as a whole. It has especially sharply dropped since 2017 (*3*) (Figure 1), suggesting that this follow-up program may be contributing to this decline. The regional core center has conventionally verified the status of program participants by having specialized institutes mail paper examination letters to show that the participant had made their annual visit to that institute. However, only a low 40% to 50% of these letters were returned from the specialized institutes to the regional core center.

The Ishikawa Hepatitis Follow-up Program is now using the information and communication technology (ICT) tool, ID-Link, to share clinical information about program participants between specialized institutes and the regional core center. As of the end of March 2021, information about 132 patients of 18 specialized institutes is being shared between these institutes and the regional core center using ID-link. ID-Link provides

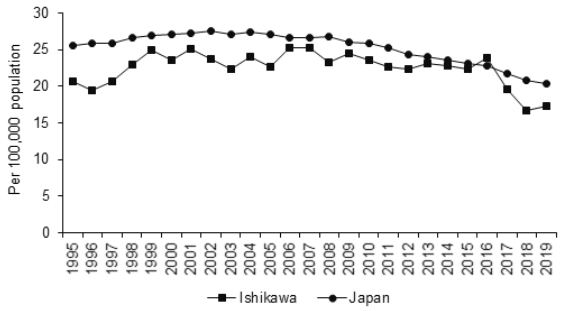

Figure 1. Trend mortality rate cause by liver cancer in Ishikawa Prefecture and Japan. The mortality rate caused by liver cancer in Ishikawa Prefecture and all of Japan is shown. It was calculated per 100,000 population.

a more accurate picture of the visit status of people who tested positive for hepatitis and the details of their care compared with the previous paper-based system using examination letters. This review article provides an overview of the Ishikawa Hepatitis Follow-up Program and how it utilizes ICT.

Follow-up of people who tested positive for hepatitis in Ishikawa Prefecture

The Basic Act on Hepatitis Measures was enacted in 2010, and the Basic Guidelines on Hepatitis Measures were published in 2011 to provide guidance on specific measures. These guidelines were revised in 2016. In the 2016 revisions, the Japanese government recommended that local governments coordinate with stakeholders, including local organizations and medical institutions, to conduct follow-ups after hepatitis testing and recommend further care to ensure that people with hepatitis receive appropriate individualized care. In response to these revised guidelines, each prefecture in Japan began efforts to conduct follow-ups with people who test positive for hepatitis (*1,4,5*). However, municipal governments across Ishikawa Prefecture had already been conducting follow-ups with people who tested positive for hepatitis at local screening programs since 2002, before these revised guidelines were issued.

Follow-up of people who tested positive for hepatitis in Ishikawa Prefecture from 2002 to 2009

In Japan, municipal governments have conducted screenings for hepatitis B and C, first as part of a national senior health promotion program from 2002 to 2008, then as part of a general health promotion program from 2008 onward. In Ishikawa Prefecture, 222,029 and 221,967 people had been tested under these programs for hepatitis B virus and hepatitis C virus, respectively. Between 2002 and 2019, 1,956 and 1,655 people were positive for hepatitis B virus and hepatitis C virus, respectively. The positive ratio was 0.88% and 0.75% for hepatitis B virus and hepatitis C

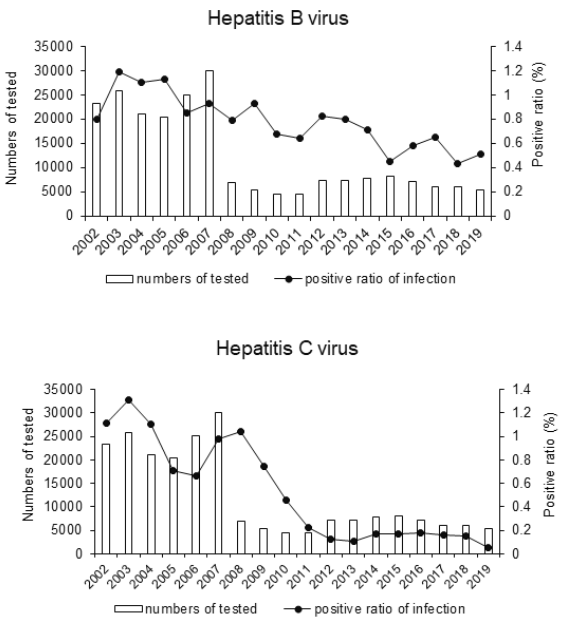

Figure 2. Numbers of people tested for hepatitis B virus and hepatitis C virus infection and positive ratio between 2002 and 2019 in Ishikawa Prefecture.

virus, respectively (Figure 2). In Ishikawa Prefecture, municipal public health staff have conducted follow-ups with people who tested positive for hepatitis at local screening programs since 2002. Municipal public health staff conduct follow-ups every year by making home visits or phone calls to verify which patients have visited a specialized institute and by recommending a visit to those who have not. Kanazawa City, the capital of Ishikawa Prefecture, has a large number of people who tested positive for hepatitis, which made it difficult for public health staff to conduct follow-ups in person. Therefore, the city contracted the Kanazawa Medical Association to conduct follow-ups by contacting medical institutions that conducted hepatitis screenings to confirm whether people who tested positive for viral hepatitis at that institution ever visited a specialized institute. Follow-up data from these municipal governments were anonymized and reported to the Ishikawa Prefecture office for assessing measures against viral hepatitis (Figure 3). However, several problems emerged with this process, including that the increase in people to follow up caused an increase in the workload of municipal public health staff, and that follow-up was not being conducted directly with people who tested positive for viral hepatitis in Kanazawa City due to the larger size of that group.

Follow-up of people who tested positive for hepatitis in Ishikawa Prefecture from 2010 onward

In 2010, the regional core center for hepatitis care coordination (Kanazawa University Hospital, the only regional core center in the prefecture) began conducting the follow-up process that was previously

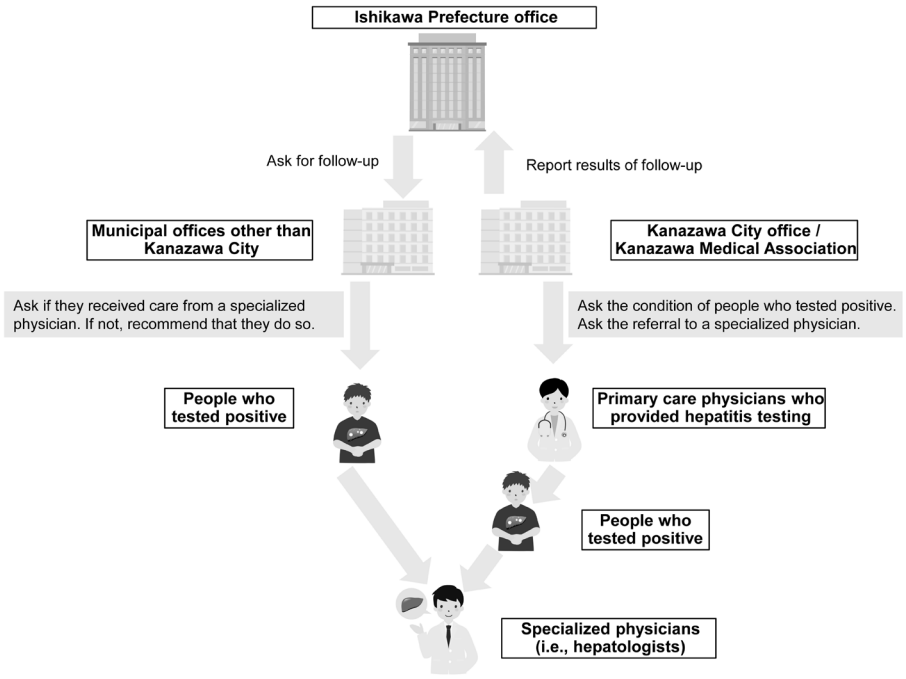

Figure 3. Schematic representation of follow-up for viral hepatitis patients since 2002.

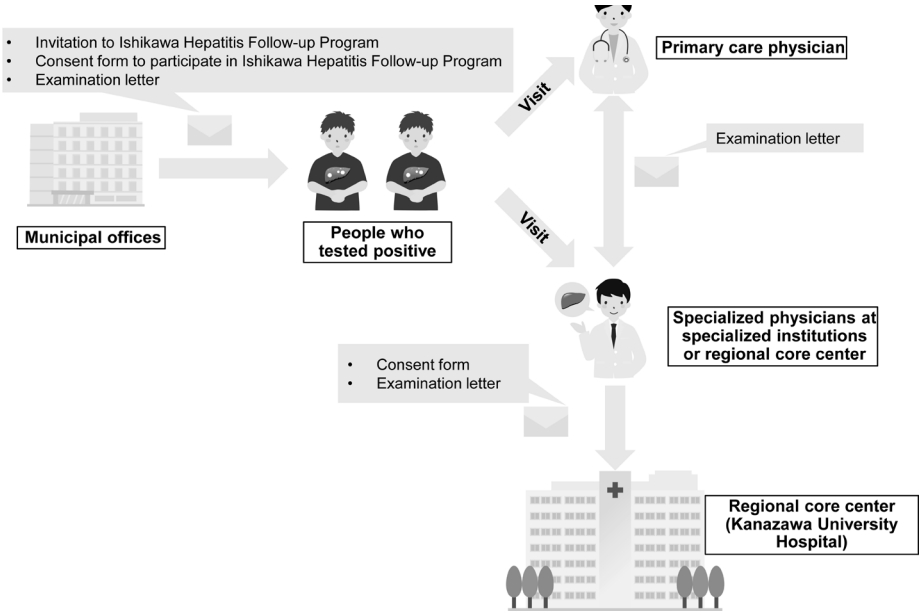

Figure 4. Schematic representation of the approval process for participation in the Ishikawa Hepatitis Follow-up Program.

the responsibility of municipal public health staff. The program, called the Ishikawa Hepatitis Follow-up Program, is run jointly by Ishikawa Prefecture, municipal governments, and the Ishikawa Medical Association. Program staff recommend that participants visit a specialized institute for hepatitis care selected by Ishikawa Prefecture (21 institutes as of April 2021) to be examined by a hepatologist and undergo liver imaging at least once a year. When this follow-up program was launched, municipal staff could not directly transfer personal information such as the names and addresses of people who tested positive for hepatitis to the regional core center due to policies about protecting personal information. However, municipal staff solved this problem by mailing people who tested positive for hepatitis a consent form to participate in the follow-up program and have their personal information shared between the regional core center and municipal government. This enabled the regional core center to send mail directly to people who tested positive for hepatitis and consented to participate in the program (Figure 4).

Every year in July, the regional core center directly mails the program participants a leaflet recommending

that they visit a specialized institute as well as an examination letter for their physician to complete with the details of their visit. The participant brings this letter with them to the specialized institute for the hepatologist they visited to record on the letter, the date of examination, diagnosis, the liver imaging tests performed, the recommendations for further testing and treatment, and the next appointment (Figure S1, *https://www.globalhealthmedicine.com/site/supplementaldata.html?ID=28*). If the participant initially visited a primary care physician (*i.e.*, not a hepatologist), they can use the examination letter as a referral form to visit a specialized institute. The letter is completed in triplicate, and copies are sent to the primary care physician and the regional core center. The examination letter is used to provide details of the examination at the specialized institute for the primary care physician's reference. In addition, the regional core center uses returned examination letters to confirm whether each participant visited a specialized institute, and enters data such as treatment and condition details into a database (Figure 5). After the first round of examination letters are mailed, participants whose examination letters have not been returned to the regional core center by November of that year are once again sent a leaflet recommending they visit a specialized institute along with an examination letter around December.

Initially, participation in the Ishikawa Hepatitis Follow-up Program was restricted to people who tested positive for hepatitis at local screening programs conducted as part of a national senior health promotion program or a general health promotion program. However, the program has now been extended to anyone who tests positive for hepatitis at any kind of screening, such as the specified infectious diseases screening program, a prenatal checkup, a workplace health checkup, or preoperative testing.

Current state of the Ishikawa Hepatitis Follow-up Program and issues to be resolved

At the end of 2019, 1,632 (51%) of the 3,202 people who had tested positive for hepatitis since 2002 had consented to participate in the follow-up program, 525 (16.3%) had declined to participate, and 1,045 (32.7%) did not respond. Program staffs continue to send these 1,045 people who did not respond, a leaflet encouraging their participation along with a consent form. Those who declined or did not respond are still followed annually by municipal public health staff, as they have done since 2002, and follow-up data from these municipal governments were anonymized and reported to the Ishikawa Prefecture office for assessing measures against viral hepatitis.

Only 40% to 50% of examination letters are returned to the regional core center in an average year, suggesting that only 40% to 50% of participants are making their recommended annual visit to a specialized institute. Consequently, efforts must be made to increase this percentage.

However, another method of confirming participant status besides examination letters may also be needed, given that some participants had made their visit but the specialized institute did not return their examination letter to the regional core center. In addition, the regional core center enters data from returned examination letters such as treatment and condition details into a database but can only collect limited data through these letters. As the age of this group of hepatitis patients increases, they may develop comorbidities such as dementia and

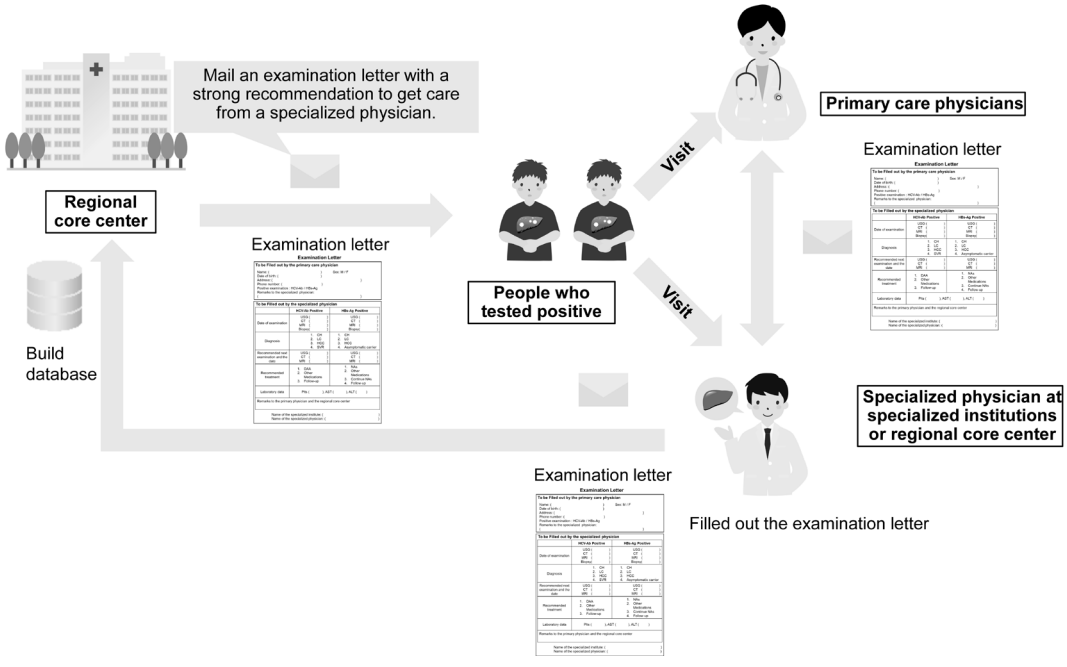

Figure 5. Schematic representation of the Ishikawa Hepatitis Follow-up Program.

cancers other than liver cancer, become more limited in their activities of daily living, or move into an elder care facility. It is important to conduct follow-up with these patients in a way that suits their individual circumstances, and this requires accurate knowledge of their health status. In addition, a review of examination letters revealed that some patients had made the effort to visit a specialized institute but had seen a physician other than a hepatologist or had not undergone annual liver imaging tests. This illustrated a problem with the system: regional core center staff had no means of notifying the physician at the specialized institute if they had suggestions regarding the participant's treatment at that institute based on the content of the examination letter.

Utilization of ICT in the Ishikawa Hepatitis Follow-up Program

Ishikawa Prefecture has been actively promoting the use of the Ishikawa Clinical Information Sharing Network, which uses ID-Link, in order to realize collaborative care by sharing clinical information among medical institutions in the prefecture. A plan was made to utilize this system in the Ishikawa Hepatitis Follow-up Program based on the idea that it might help to solve the various problems with hepatitis follow-up that had been uncovered.

ID-Link

ID-Link is a nationally standardized cloud service developed by NEC Corporation that aggregates clinical information dispersed throughout a region. It connects participating regional medical institutions over an internet connection, enabling institutions to reference each other's clinical information and to closely coordinate care. The Ishikawa Clinical Information Sharing Network is run primarily by the Ishikawa Medical Association. The institutions participating in the Ishikawa Clinical Information Sharing Network are broadly classified into "information-sharing hospitals" (with 32 institutions as of May 2021) and "information-viewing institutions" such as primary care physicians, pharmacies, home nursing stations, and dentists' offices (with 566 institutions as of May 2021). The "sharing" institutions have servers allowing them to share clinical information specified by each institution such as images, blood test results, and prescriptions. The "viewing" institutions are authorized to view information only for the purpose of providing care.

All 21 specialized institutes in Ishikawa Prefecture participate in the Ishikawa Clinical Information Sharing Network and are classified as information-sharing hospitals authorized to share clinical information with other hospitals. To participate in the Ishikawa Clinical Information Sharing Network, the patients must submit the names of the institutions with which they wish to share clinical information and the ID numbers of each institution and then sign the designated consent form. The service is free for patients and the system allows the sharing of clinical information only for patients who have ID numbers at both institutions between which clinical information will be shared (in this case, the regional core center and a specialized institute). In other words, they must have previously visited both the regional core center and a specialized institute (Figure 6). At the end of 2017, only 312 of the 1,358 participants in the Ishikawa Hepatitis Follow-up Program had an ID at both the regional core center

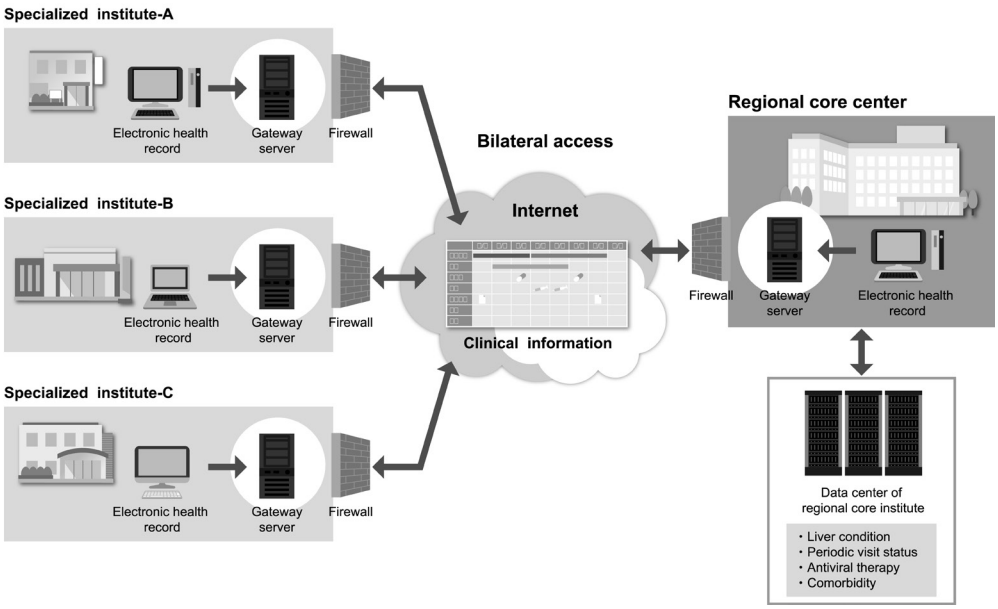

Figure 6. Schematic representation of the use of ID-Link in the Ishikawa Hepatitis Follow-up Program.

and any of the 21 specialized institutes. These 312 people were asked for their consent to participate in the Ishikawa Clinical Information Sharing Network. When the decision was made to use ID-Link for the Ishikawa Hepatitis Follow-up Program, agreements were reached and the implementation process was coordinated in advance between stakeholders, including the prefectural government, the Ishikawa Medical Association, and specialized institutes.

Current sharing of clinical information through ID-Link

In November 2018, the Ishikawa Hepatitis Follow-up Program began obtaining consent from program participants to participate in the Ishikawa Clinical Information Sharing Network to enable sharing of clinical information between specialized institutes and the regional core center. As of the end of March 2021, information about 132 patients of 18 specialized institutes is being shared between these institutes and the regional core center.

Benefits of sharing of clinical information through ID-Link

There were 57 examination letters returned to the regional core center by the end of November 2020 from the 131 patients who consented to participate in the Ishikawa Clinical Information Sharing Network using ID-Link up to June 2020 (a 43.5% response rate). When the statuses of the 74 individuals whose examination letters had not been returned were checked using ID-Link, it was found that 62 had indeed visited a specialized institute after April 2020. These results show that a total of 119 participants (90.8%), comprising the 57 whose status was verified by their examination letter and the 62 whose status was verified by ID-Link, had visited a specialized institute (Figure 7). In addition, 5 of these 62 patients had visited a specialized institute but did not see a hepatologist.

By referencing both ID-Link and examination letters, it was determined that 119 of 131, or about 90% of patients, had visited a specialized institute in 2020. Although there were still 12 patients who had not visited a specialized institute, this number is much smaller than the 62 counted from examination letters alone. Referencing both ID-Link and examination letters enabled a more accurate counting of patients who had not visited a specialized institute, which should facilitate more focused and efficient efforts to encourage visits.

Challenges and future outlook of sharing clinical information through ID-Link

At present, only patients who have ID numbers at both the regional core center and a specialized institute can use this system. However, about 75% of participants in the Ishikawa Hepatitis Follow-up Program do not have an ID at the regional core center, so their clinical information cannot be shared with the regional core center. Going forward, a strategy must be devised to ensure that the clinical information of patients who do not have an ID at the regional core center can be shared

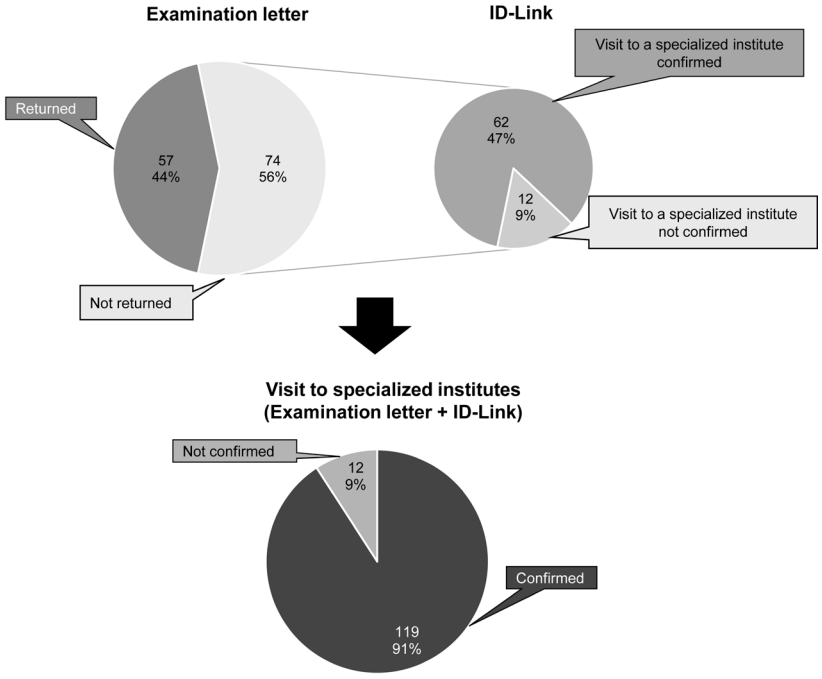

Figure 7. Comparison of data collection by examination letter and ID-Link.

with the regional core center.

When patient status was verified by ID-Link, it was discovered that some patients had not been seen by a hepatologist or gastroenterologist, even though they visited a specialized institute. Efforts must be made to allow regional core center staff to provide feedback on information sent by specialized institutes and request coordination between departments at the specialized institute.

The program is currently using ID-Link to share clinical information only between specialized institutes and the regional core center, but many primary care physicians also have information-viewing authorization on ID-Link. Going forward, the program will work to promote the use of ID-Link by not only the regional core center and specialized institutes but also by primary care physicians.

Recently, the Extension for Community Healthcare Outcomes (ECHO) Model was developed by the University of New Mexico Health Sciences Center as a platform to deliver complex specialty medical care to underserved populations through an innovative educational model of team-based interdisciplinary development. By using state-of-the-art multipoint telehealth technology and clinical management tools, ECHO trains and supports primary care providers to develop knowledge and self-efficacy on a variety of diseases. Now, the ECHO model is reported to enhance the competency of community-based based physicians to deliver optimal care to patients with HCV infection (*6*-*8*). While we have been using ID-Link mainly for collecting accurate clinical information of the participants and confirming the participants' periodic visit to specialized institutes, we would like to use ID-Link for encouraging introduction of anti-HCV therapy and continuous care after HCV elimination.

Conclusion

The use of ICT provided a more accurate picture of which participants had visited a specialized institute compared with the previous paper-based method involving examination letters. Sharing clinical information via ICT should improve the efficiency of follow-ups with hepatitis patients and allow for multiple physicians to collaborate in these patients' care. Going forward, individual regions will likely adopt various forms of ICT to promote coordination between hospitals. When doing so, they should actively consider using ICT to support viral hepatitis patients as well.

Funding: This work was supported by the Ministry of Health, Labour and Welfare Policy Research for Hepatitis Measures Program (grant numbers JPMH18HC1001 and JPMH21HC1001).

Conflict of Interest: The authors have no conflicts of interest to disclose.

References

1. Tanaka J, Akita T, Ko K, Miura Y, Satake M; Epidemiological Research Group on Viral Hepatitis and its Long-term Course, Ministry of Health, Labour and Welfare of Japan. Countermeasures against viral hepatitis B and C in Japan: An epidemiological point of view. Hepatol Res. 2019; 49:990-1002.
2. Tanaka J, Akita T, Ohisa M, Sakamune K, Ko K, Uchida S, Satake M. Trends in the total numbers of HBV and HCV carriers in Japan from 2000 to 2011. J Viral Hepat. 2018; 25:363-372.
3. Cancer Statistics. Cancer Information Service, National Cancer Center, Japan (Vital Statistics of Japan, Ministry of Health, Labour and Welfare). *https://gdb.ganjoho.jp/graph_db/gdb1* (accessed June 24, 2021)
4. Oza N, Isoda H, Ono T, Kanto T. Current activities and future directions of comprehensive hepatitis control measures in Japan: The supportive role of the Hepatitis Information Center in building a solid foundation. Hepatol Res. 2017; 47:487-496.
5. Kanto T, Yoshio S. Hepatitis action plan and changing trend of liver disease in Japan: viral hepatitis and nonalcoholic fatty liver disease. Euroasian J Hepatogastroenterol. 2017; 7:60-64
6. Arora S, Kalishman S, Thornton K, *et al.* Expanding access to hepatitis C virus treatment – Extension for Community Healthcare Outcomes (ECHO) project: disruptive innovation in specialty care. Hepatology. 2010; 52:1124-1133.
7. Arora S, Thornton K, Murata G, Deming P, Kalishman S, Dion D, Parish B, Burke T, Pak W, Dunkelberg J, Kistin M, Brown J, Jenkusky S, Komaromy M, Qualls C. Outcomes of treatment for hepatitis C virus infection by primary care providers. N Engl J Med. 2011; 364:2199-2207.
8. Ni Cheallaigh C, O'Leary A, Keating S, Singleton A, Heffernan S, Keenan E, Robson L, Sears J, Moloney J, Arora S, Bergin C, Norris S; Irish Hepatitis C Outcomes Research Network. Telementoring with project ECHO: a pilot study in Europe. BMJ Innov. 2017; 3:144-151.

Received May 28, 2021; Revised June 27, 2021; Accepted July 27, 2021.

Released online in J-STAGE as advance publication September 5, 2021.

**Address correspondence to*:
Tetsuro Shimakami, Department of Gastroenterology, Kanazawa University Graduate School of Medicine, 13-1 Takara-machi, Kanazawa, Ishikawa 920-8641, Japan.
E-mail: shimakami@m-kanazawa.jp