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Standardization of Personal Health Records in the Portable Health Clinic System

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Abstract

A personal health record (PHR) is not only a collection of personal health data but also a personal healthcare and disease management tool for individual patients. Recently, PHRs have been considered indispensable tools for patient engagement in the area of noncommunicable diseases (NCDs) and have gained a special importance. Unfortunately, similar to several other developing countries, Bangladesh remains far behind in establishing a standard PHR system for the country despite the fact that the growth of NCDs is extremely high and accounts for approximately 70% of the total diseases experienced in the country. The Portable Health Clinic system, which has a PHR feature, was established in Bangladesh in 2010. This PHR system requires standardization for each country. The objective of this research is to standardize this PHR system with reference to the PHR system proposed by the Japanese Clinical Societies, which is a pioneer of work in this field in Asia.

Keywords:

Personal Health Record, Electronic Medical Record, Patient Engagement

Introduction

The personal health record (PHR) system has been gaining popularity as an important supportive tool for providing better healthcare services by medical professionals. Currently, there are several applications for smartphones that help manage personal clinical data about noncommunicable diseases (NCDs) treated in clinics and drugs dispensed by pharmacies. This is the simplest form of PHR. However, a standard PHR system is expected to manage information regarding an individual's vital signs, physical exercise, behavior, and location at home or at the office using built-in sensors in the smartphone or using sensor networks based on the internet of things technology. Patients will have access to monitor this personal health/medical data and express personal opinions reflecting the progress of their treatment. This helps the physician to confidently change the policy and intervene when necessary [1]. This type of interaction by patients and their families with the medical staff contributes to ensuring a better treatment outcome. This patient-reported outcome (PRO) is also considered important because the PHR system can function in coordination with PROs for better generation of data with accuracy [2]. The World Health Organization promotes the installation of such patient engagement, particularly for developing countries, and highlights the importance of using PHRs [3].

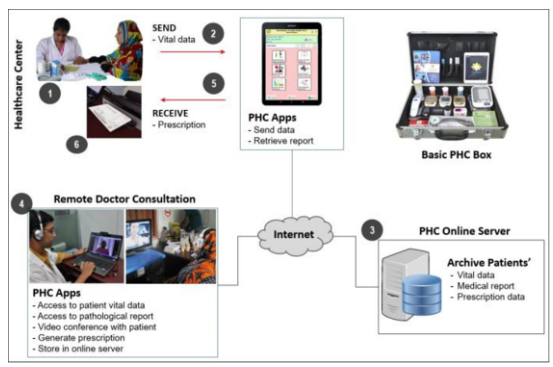

Figure 1- Work Flow of PHC System

Similar to several other developing countries, no public healthcare facilities in Bangladesh even maintain any centralized electronic medical records (EMR) system currently. Some private hospitals that are only accessible to the rich segment of the society have their own EMR system. However, a PHR system is not generally utilized in Bangladesh yet. In this context, when the portable health clinic (PHC) system was designed in 2010 by Grameen Communications, Bangladesh, in a joint collaboration with Kyushu University, Japan, as a telemedicine-based healthcare system [Figure 1], an EMR system existed from the beginning in which patients' vital information was preserved in an electronic format on the online server together with the patients' medical history and feedback [4].

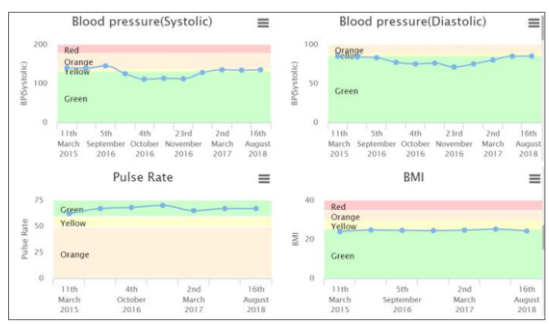

Figure 2- PHR Interface to Patients

A simple PHR service was also added in the PHC system as a personal service for patients. The patients can access their own data on smartphones or other devices to monitor and share their feedback to the system. The concerning physician can access patients' data to provide teleconsultancy with better assessment. The patients can also access their password-protected PHRs anytime anyplace using an online application and share information with the doctors in times of need.

The graphical analysis of the PHR data in the PHC system makes it extremely easy for patients and doctors to monitor progress. The patients become anxious if there are any irregularities in the data [Figure 2]. This is extremely helpful because patients become more conscious and feel the urgency to communicate with the health workers in a timely manner. Thus, this patient engagement contributes to ensuring better and timely service to prevent further complications.

The PHC system was initially developed for primary healthcare with a special focus on NCDs, including hypertension and diabetes [5]. Later, new modules were added to this system to satisfy patients' demands for serving secondary levels of treatment for eye care and maternal and child health care [6]. Recently, a COVID-19 module has been added. Additional new modules will be added to this system over time as per the requirements of the serving communities. However, this study will focus on the PHR features for hypertension and diabetes only as the main target.

PHR System in PHC

The PHR feature has been developed with the PHC system from the beginning. However, because there was no Bangladeshi national or globally recognized standard for PHRs, we have developed a standard based on the basic healthcare practices in Bangladesh. At this stage, the PHR system contains approximately 20 fields of clinical data and 15 fields of questionnaire-based survey data for understanding patients' medical history, environment, family history, etc., which is important for PHRs. These basic clinical data are collected from health checkups with a special emphasis on NCDs that are responsible for two-thirds of the deaths currently recognized in the country [7]. The data items of this PHR system will also be gradually adjusted with the development of new modules in the PHC system. Therefore, a flexible relational database has been adopted for the PHR data so that it can be modified if necessary.

Standardization of the PHR System

Because the clinical data items of PHR of the PHC system were considered independently based on the local needs for primary care, there are always some issues regarding the use of this PHR data by medical professionals from other organizations at home and abroad in terms of clinical data items and measurement units. The clinical data items in the PHR vary from country to country. The measurement units also vary, leading to interoperability problems. Thus, the PHR system must be standardized for data portability.

The HL7 International® FHIR® (Fast Healthcare Interoperable Resources) is a global solution to the interoperable sharing of data that can be used for standardizing the PHR format [8]. However, there is currently no standard PHR in practice with detailed data items and data units. Therefore, it is difficult to compare the adequacy and compatibility of our PHR system.

Recently, the major Japanese Clinical Societies jointly proposed a standard for PHRs in Japan after years of investigation. This association includes 1) the Japan Association for Medical Informatics, 2) the Japan Diabetes Society, 3) the Japanese Society of Laboratory Medicine, 4) the Japanese Society of Hypertension, 5) the Japanese Society of Nephrology, and 6) the Japan Atherosclerosis Society. This proposal may serve as the basis of a national standard in Japan. This research aims to standardize the PHRs of the PHC system using this Japanese proposal as a standard.

Standard PHR System in Japan

The six Japanese Clinical Societies have jointly recommended a specific clinical data set for the PHR system as a standard primarily for Japan [9]. This is the final outcome of a pioneer work in Japan that started in the 1990s [10]-[12]. This data framework is currently being used in all major healthcare facilities in this country. All major medical vendors in Japan also adopted this framework for developing their PHR systems. Therefore, this could be considered a reference for the standardization of the PHR system of other Asian countries and even as a global standard. They proposed 41 general clinical data items for the PHR with specific units and expressions. The Self-Management Item Sets (SMISs) for diabetes mellitus, hypertension, dyslipidemia, and chronic kidney disease are specified [Figure 3]. This framework has also specified a core data item set (CIS) corresponding to each SMIS that contains the minimum data items necessary. The CIS and SMIS for each disease were standardized in terms of the data item name, granularity, and expression or unit used.

Methods

This study adopts the SMISs recommended by the Japanese Clinical Societies and adjusts all missing items. The item sets of the PHR of the PHC system include most items from the Japanese proposal. Specifically, this study maintains the majority of the clinical data items of the SMISs for diabetes mellitus and hypertension [Figure 4]. Some of the missing items in the PHR system are present in the PHC data structure in the form of medical history, and these will be added to the PHR item sets. The remaining missing items will be newly considered in the PHC system. Because the PHC system is an affordable handy system considering the targeted low economy, the availability of some portable and lightweight medical sensors at a cheap price may currently be a concern. However, similar to many other medical sensors, these will likely be available shortly with further progression in technology development.

The PHR of the PHC system contains other clinical data items based on local disease patterns, including hip–waist ratio, body temperature, oxygenation of blood, arrhythmia, and pulse rate. After introducing the eye-care and maternal and child healthcare modules in the PHC system, additional new clinical data have been added. This combined clinical data set may enable the PHC system to maintain SMISs for additional new diseases in the future. Therefore, these additional items will remain as an extra item set in the PHR structure of the PHC system.

The data units used in our PHR system are those commonly used in Bangladesh. Some of these units vary in other countries including Japan. However, our PHC system maintains an in-built unit conversion process, and units can be easily adjusted based on the service location.

Generally, some of the PHR data are added by the patients at their end based on self-checkup results, and some are added automatically by the sensors in Japan. However, there is always an issue with the reliability and accuracy of the added data in the case of self-reported clinical data. This will be more relevant in a developing country in the case of rural patients with

low literacy and senior citizens with technophobia. For the PHC services, the clinical data are always measured and added by health workers during home delivery service. Thus, the PHR data of the PHC system is expected to be comparatively error-free.

Figure 3 - Standard Items for the PHR Configuration Recommended by Japanese Clinical Societies

ID of SMIS	Item	SMIS for Diabetes Mellitus			SMIS for Hypertension			SMIS for Dyslipidemia			SMIS for CKD		
		from Medical	from Health Check-up	from Home	from Medical	from Health Check-up	from Home	from Medical	from Health Check-up	from Home	from Medical	from Health Check-up	from Home
1	Height	○	○		○	○		○	○		○	○	
2	Weight	○	○		○	○		○	○		○	○	
3	Systolic Blood Pressure	○	○		○	○		○	○		○	○	
4	Diastolic Blood Pressure	○	○		○	○		○	○		○	○	
5	LDL Cholesterol	○	○		○	○		○	○		○	○	
6	HDL Cholesterol	○	○		○	○		○	○		○	○	
7	Smoking	○	○		○	○		○	○		○	○	
8	Serum Creatinine	○			○			○			○		
9	Urine Protein	○	○		○	○		○	○		○	○	
10	Blood Glucose	○	○		○	○		○	○				
11	Age diagnosed as Diabetes Mellitus	○											
12	HbA1c	○	○								○	○	
13	ALT	○	○					○	○				
14	Diabetic Retinopathy	○											
15	Age diagnosed as Hypertension				○								
16	Serum Potassium				○						○		
17	Abnormality on ECG				○								
18	Triglyceride	○	○		○	○		○	○		○	○	
19	Age diagnosed as Dyslipidemia							○					
20	Past History of Coronary Diseases							○					
21	Age diagnosed as CKD										○		
22	Serum Albumin										○	○	
23	Hematuria										○	○	
24	Total Cholesterol	○			○			○			○		
25	Urine Albumin/Creatinine	○											
26	AST	○	○										
27	Waist		○			○			○				
28	Urine Glucose	○	○										
29	γ GTP	○	○										
30	Diabetic neuropathy	○											
31	Regular visit at Dental Clinic	○											
32	Uric Acid				○						○	○	
33	Systolic Blood Pressure at home						○						
34	Diastolic Blood Pressure at home						○						
35	Family History of Renal Failure										○		
36	Urine Protein /Creatinine										○	○	
37	Urine Protein / Day										○	○	
38	Serum Total Protein										○	○	
39	BUN										○		
40	Hemoglobin										○	○	
41	Cystatin C										○		
		CIS for Diabetes Mellitus			CIS for Hypertension			CIS for Dyslipidemia			CIS for CKD		

Results

Of the 41 clinical data items proposed by the Japanese societies, the PHR framework of the PHC system includes 22 items [Figure 4]. Twelve of them, marked as "●", are already present, and another 10, marked as "△", will be easily retrieved from either stored medical history survey data available in the system or additional checkups by the current sensor sets. The remaining 19 items (marked as "Not Available", NA) will be newly added to the PHC system using additional new sensor sets in the PHC system or with the support of the medical facilities.

The SMIS for diabetes mellitus contains 22 clinical data items including 14 CIS from the Japanese proposed standard. Our PHR system contains 12 items, including 8 CIS items. Ten items will be newly added.

The SMIS for hypertension contains 19 clinical data items, including 13 CIS from the Japanese proposed standard. Our PHR system contains 13 items, including 7 CIS items. Six items will be newly added.

The data units used by the Japanese societies are almost similar to those used in our PHR configuration, which follows Bangladesh's common practice. The few exceptions include blood glucose and body temperature, for which Japan uses mg/dL and Celsius, respectively, and the PHR configuration uses mmol/dL and Fahrenheit, respectively. Some of the items also vary in other countries where the PHC system is being used. This includes Cambodia, China, India, Indonesia, Malaysia, and Pakistan. Because this is a part of the local culture, our PHR configuration does not change these items; instead, it maintains an inbuilt unit conversion feature, and units can be easily adjusted based on the service location.

Figure 4- Comparison of PHR Items of the PHC System with the Proposed Japanese Standard

ID of SMIS	Item	PHC's PHR Item Set			SMIS for Diabetes Mellitus			SMIS for Hypertension		
		from Health Check-up	from History Survey	to be newly added	from Medical	from Health Check-up	from Home	from Medical	from Health Check-up	from Home
1	Height	●			●	●		●	●	
2	Weight	●			●	●		●	●	
3	Systolic Blood Pressure	●			●	●		●	●	
4	Diastolic Blood Pressure	●			●	●		●	●	
5	LDL Cholesterol			NA	●	●		●	●	
6	HDL Cholesterol			NA	●	●		●	●	
7	Smoking	●			●	●		●	●	
8	Serum Creatinine			NA	●			●	●	
9	Urine Protein	●			●	●		●	●	
10	Blood Glucose	●			●	●		●	●	
11	Age diagnosed as Diabetes Mellitus		△		●					
12	HbA1c			NA	●	●				
13	ALT			NA	●	●				
14	Diabetic Retinopathy			NA	●					
15	Age diagnosed as Hypertension		△					●		
16	Serum Potassium			NA				●		
17	Abnormality on ECG			NA				●		
18	Triglyceride			NA	○	○		○	○	
19	Age diagnosed as Dyslipidemia		△							
20	Past History of Coronary Diseases		△							
21	Age diagnosed as CKD		△							
22	Serum Albumin			NA						
23	Hematuria			NA						
24	Total Cholesterol	●			○			○		
25	Urine Albumin/Creatinine			NA	○					
26	AST			NA	○	○				
27	Waist	●				○			○	
28	Urine Glucose	●			○	○				
29	γ GTP			NA	○	○				
30	Diabetic neuropathy		△		○					
31	Regular visit at Dental Clinic		△		○					
32	Uric Acid	●						○		
33	Systolic Blood Pressure at home		△							○
34	Diastolic Blood Pressure at home		△							○
35	Family History of Renal Failure		△							
36	Urine Protein /Creatinine			NA						
37	Urine Protein / Day			NA						
38	Serum Total Protein			NA						
39	BUN			NA						
40	Hemoglobin	●								
41	Cystatin C			NA						
x01	Hip-Waist Ratio	●								
x02	Body Temperature	●								
x03	Oxygenation of Blood	●								
x04	Arrhythmia	●								
x05	Pulse Rate	●								

Discussion

The PHR system is currently considered an extremely important tool for obtaining better treatment in any country. Furthermore, medical service over the geographical border, also called "medical tourism," is a very common and important service at this time and will continue to grow in the future.

In most cases, people from a developing country go to another developing country or a developed country for better treatment. However, when they see a medical professional, they must undergo all basic investigations again because the patients cannot share previous health history or reliable medical data. This takes extra time and increases costs for foreign patients.

Therefore, a standard PHR system is extremely needed in every country to preserve patient's health information and medical data sufficiently, accurately, and in an appropriate format. This will enable patients to share their detailed personal health history and medical data with the new overseas doctor with ease.

Finally, this will reduce the huge burden of performing the same tests and investigations by the overseas doctor and reduce the costs. Of course, regulations for medical data transferring will be required for this purpose, but that is a different concern and not within the scope of this study. From a medical service point of view, the development of the PHR system and its standardization is extremely desired for a wider scope of healthcare services. This work demonstrating PHR standardization of the PHC system is a step forward in this direction from the perspective of Bangladesh.

Conclusions

PHC activities are currently expanding in different parts across the globe and have thus far expanded to 10 Asian countries. Owing to its low cost and easy operation system, PHC activities will continue to expand in other parts of the world. Therefore, it is high time to standardize this system for better compatibility and interoperability of clinical data. This is important both from the patient treatment point of view and data analysis for research purposes. Therefore, implementing this study is extremely important. Moreover, it is crucial because it proposes a standard PHR system for Bangladesh.

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