Consumer Health Care: Current Trends in Consumer Health Monitoring

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Consumer Healthcare: Current Trends

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Abstract—The term healthcare has a very wide scope that ranges from lifestyle and wellness right up to care for acute conditions. With the availability of digital accessories for monitoring basic biological functions, the potential for obtaining detailed data on life style, habits and behaviour of an individual exists. Such data can enable diagnosis of the causes for a condition with higher accuracy. In the recent past, a large number of devices have become available in the market, that can monitor various aspects of lifestyle and biological functions. Such data provides a feedback to an individual for compliance with “healthy guidelines” as well as contribute information to the healthcare provider for use in diagnosis, in the event of an ailment. In this paper, we identify the various aspects of care that can benefit from consumer grade health monitoring devices and present the overall landscape in the context of self care. We qualify the term “consumer healthcare”, assigning the context to it and identifying the services available in the context.

I. INTRODUCTION

The term consumer healthcare is of recent origin in the industry. Increased health awareness amongst people combined with the consumerism of the Internet has provided the potential for every citizen to be health-conscious. It is the feasibility and affordability of the solutions (devices and applications) emerging in the market that is propelling the advances in healthcare. A fundamental question is whether the end user in healthcare must be termed as a patient or a consumer [1].

“Consumer healthcare” is an industry-coined term which is centered around empowering individuals (consumers) to self-manage their health. This was traditionally achieved through over-the-counter medications and the consumer-health care movement was largely led by the pharmaceutical companies. With the ongoing consumer revolution in healthcare primarily driven by digital disruption and the entry of new players such as electronic device vendors, mobile application developers, mobile operators, there is need to contextualize consumer healthcare for the traditional players within the healthcare sector. Further, what kind of care constitutes healthcare? These are some of the debates in the industry today. Therefore, there is a need to provide a context to defining what consumer healthcare is.

The general difference between the terms patient and consumer, reflects the role of the end user in the care process. Often, the end user is a consumer – assessing cost-benefits for treatment options, choosing a treatment option, and in some contexts, choosing the experts they would want to consult with, in the case of short term ailments and treatment. In case of long term/major ailments or end-of-life (palliative) care the user’s preference is care rather than cost or even making a choice. The user is completely led by the medical expert and may not make choices as in the case of short-term ailments. It is when such continued care is sought, either in a home or a hospital setting that the term “patient” is used [1]. However, from a service standpoint, a patient is always a consumer In contrast to the short and long-term ailment conditions, there are the common ailments that have standard treatment processes that enable self-care; users have the common knowledge available through various means and the medications available as off-the-counter (OTC) drugs. The last type of care is the intensive care as in the event of a surgery or an emergency in a chronic condition [1]. Healthcare, as a function, encompasses these four types of care in the context of adults - acute care, post-acute care, chronic care, and prevention and wellness. Our discussions will address prevention and wellness and chronic care, both of which have their setting outside a hospital.

A. Healthcare, in context

Healthcare is delivered as part of a system. But, is healthcare a system in the traditional sense? [2] compares the healthcare industry and the airline industry to illustrate that the former is not a system in the traditional sense. The difference between the airline industry and healthcare when managing decision-making processes is that the airlines have moved towards a system of production. In contrast, healthcare is a system of craftsmanship where successful outcomes largely depend on the native intelligence and memory capacity of an individual provider, like how an aircraft was piloted years ago. Hundreds of data points coming in real time, provide a continuous feedback to the pilot. They are well-trained on standard, routine methods with a system of checks. These systems provide the confidence that any of the pilots that are part of the system can transport people from point A to point B. In contrast, healthcare systems do not function as deterministically. The outcomes vary with the individuals and are a function of their expertise [2]. IoT can provide the data points of the consumer and the low level support systems that healthcare is lacking, when compared to the traditional systems. The expectation is the healthcare
industry can evolve into an entity closer to a traditional system. Both these aspects play a role in the general healthcare of a consumer.

The authors of [3] mention that the healthcare system contributes only about 10% to an individual’s overall health, in her/his lifetime of health. This limitation is due the reactive nature of both the healthcare system as well as the individual. There is a need for the system to explore other components of health status to manage care better, especially in the context of chronic diseases. The authors point out that behavioural patterns (lifestyle, medication adherence, patient engagement, depression, utilization of health services, etc.) represent the largest domain (40%) of an individual’s health status. It is this gap that the healthcare industry is attempting to address in the consumer’s interests.

An increasing concern, over the last decade, is the healthcare for a growing, ageing population (Figure 1). Between 2015 and 2030, the number of people in the world aged 60 years or over is projected to grow by 56 per cent, from 901 million to 1.4 billion, and by 2050, the global population of older persons is projected to more than double its size in 2015, reaching nearly 2.1 billion [4]. It is often assumed that increasing longevity is being accompanied by an extended period of good health, there is little evidence to suggest that older people today are experiencing better health than their parents did at the same age. However, poor health does not need to dominate older age. Most of the health problems that confront older people are associated with chronic conditions, particularly non-communicable diseases. Many of these can be prevented or delayed by engaging in healthy behaviours. Notice, this again points towards behavioural patterns and addresses prevention and wellness.

II. CONSUMER HEALTHCARE

The global healthcare landscape is changing rapidly with the infusion of digital technologies. The primary impact is on the routine delivery of healthcare, the provider-consumer engagement, and a reduction of errors in diagnosis, medication and care. There is a consumer movement of sorts in terms of health awareness and healthy lifestyle adoption. Sensor-based digital accessories are used to monitor lifestyle and make routine decisions about diet, nutrition, hydration, stress levels, etc. Digital technologies are providing new possibilities on all fronts – customer-facing, professionals-facing, and organisation/provider-facing. The challenge is to make them interwork and deliver improved care systems that involve the customer/patient and deliver reliable care with positive outcomes, while remaining cost-effective [5]. In this context, we briefly look at self-care and wellness which are two recent trends in the healthcare landscape that can be impacted substantially and positively by digital technologies.

A. Self-care

People have a key role in protecting their own health, choosing appropriate treatments and managing long-term conditions. Self-management is a term used to include all the actions taken by people to recognise, treat and manage their own health. They may do this independently or in partnership with the healthcare system. During the past decade, increasing number of over-the-counter (OTC) drugs were aimed to ease the pressure on public healthcare, allowing consumers to treat more of their everyday health conditions with no additional cost to the taxpayer, while also enabling healthcare professionals to spend more of their time and attention on patients that require more care. Digital technologies-assisted selfcare can potentially maximise the benefits that the over-the-counter medications are aiming to achieve, in addition to paving the way for innovations within healthcare provisioning. The terms self-care and self-management cannot be used interchangeably due to the distinctions between them. Self-care focuses entirely on treatment. It is defined as the actions that individuals take for themselves, on behalf of and with others, to develop, protect, maintain and improve their health, wellbeing or wellness [6]. Self-care is projected as a continuum, which extends across daily choices of users and lifestyle up to long-term illnesses, with acute conditions out of scope (Figure 2).

The working definition of self-care is the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider. Self-management is used in the context of long-term, chronic health conditions while self-care applies to acute illness or injuries. Self-management is about coping with long-term health conditions, and managing the emotional and practical issues they present. Self-management support can be viewed in two ways: as a portfolio of techniques and tools to help patients choose healthy behaviours; and as a fundamental transformation of the patient-caregiver relationship into a collaborative partnership. The scope of self-management is far higher than that of self-care.

B. Wellness

There has been a large increase in products relating to “wellness”. In general, wellness is the state of being in good health, especially as an active pursued goal (Oxford Dict.). The National Wellness Institute has a more detailed definition. They model wellness with six components. There have been significant industry investments due to the market prospects, globally. The Consumer Electronics Show, 2016, (CES 2016) showcased emerging technologies for health and wellness. It is rapidly becoming a forum for consumer health and wellness solutions. The focus in CES 2016 was largely on Internet of Things (IoT). IoT is the enabling technology for wellness and healthcare [7]. The Global Wellness Institute in its Global Wellness Economy report, 2017 estimates a 3.72 trillion USD estimate with a 11% year-on-year growth between 2013–2015 in sectors such as Beauty & Anti-Aging, Healthy Eating, Nutrition & Weight Loss, Wellness Tourism, Fitness & Mind-Body, Preventative & Personalized Medicine and Public Health, Complementary & Alternative Medicine, Wellness Lifestyle Real Estate, Spa Industry, Thermal/Mineral Springs, and Workplace Wellness. At CES 2017, in the wellness segment, sleep related (Sleep apnea, sleep management, etc.) solutions were prominent apart from the focus on wearable devices and virtual reality (VR). There was also ample evidence that healthcare industry has begun to address the self-care segment. Two specific products, a telemedicine station and robotics in rehabilitation care stood out. Figure 3 shows a list of sensor-based devices in the market today and their functional components.

All health-related activities of an individual that are towards the left end of the self-care continuum Figure 2 are enabled by assistive technologies such as sensors and complimented by the availability of computing and storage, be it on a smartphone or in the cloud. A similar capability is applicable to self-care and self-management. It is a combination of the technologies, infrastructure and the services that are delivered to the end user – the consumer – to enable them effectively to track and monitor all aspects of daily life in the context of wellness and care. In the context of care, there is an additional actor – the health care provider, involved. Similar assistive technologies are deployed in “in-hospital” care, but they are part of a larger system such as a telemedicine station demonstrated at CES 2017.

C. Common Terms in use

There are many terms that are used in the context of IoT solutions available in the market. Consumer Internet of Things (CIoT) is used to denote the use of IoT in consumer devices such as smart TVs, wearable health trackers, Internet-enabled home control devices and systems, appliances, virtual reality (VR) headsets, smart glasses, connected cars and so on. They are a class of connected devices that target the consumer market. Another term in use is the Internet of Health/Healthcare Things (IoHT), which deals with devices (ingestible/implantable sensors; refer Figure 3), equipment (smart beds, medication dispensers, bedside dashboards) and IoT-based solutions in the healthcare industry targeted at improving access to health, quality of care, user experience, and operational efficiency. Industrial IoT (IIoT), an orthogonal domain to CIoT in terms of devices and functions that primarily concerns manufacturing and industrial automation, has substantial applications in healthcare infrastructure and operations. Clearly, there are functional overlaps resulting in overlaps across the domains the terms signify.

There are two other terms – personalised care and precision medicine. Personalised care deals with adapting the care to the specific needs of an individual to ensure the support they receive is around their desired outcomes. This need arises from the findings that more than 60% of “health” is based on patient contexts such as behavioural patterns, social circumstances and environmental expo-
sures [9]. Precision medicine is "an emerging approach for disease treatment and prevention that considers individual variability in genes, environment, and lifestyle for each person", according to the National Institutes of Health. Precision medicine is relatively new; the concept, however, has been a part of healthcare for many years. Genomics provides the various data points necessary for the precision of medication and forms the basis of personalised care. The role of IoT-based devices in precision medicine is not entirely evident, yet.

It is in this context that we attempt to define and scope consumer healthcare.

III. CONSUMER HEALTHCARE: LANDSCAPES

Healthcare, in general, encompasses the entire range of wellness, self-care, self-management, and hospitalised care. The healthcare provider has varying roles and involvement across each of the care types. Doctors, surgeons, nurses, carers, etc., are part of the provider eco-system.

We define consumer healthcare as the functional component of the healthcare which:

- Involves activities of consumer concerned with a healthy routine and therefore a healthy lifestyle (wellness)
- Involves the activities a consumer to heal oneself in the event of common ailments (cold, cough, sore throat, etc.)
- Involves activities of a consumer to heal oneself in the event of long term ailments
- Involves activities of a consumer in the event of post-discharge recovery, after hospitalisation

Some or all activities of the consumer, as needed, are monitored with devices and the data is either retained by the consumer (as in the case of wellness) or shared with the healthcare provider. In the case of wellness data, only the anomalies need to be shared.

A. The Wellness Landscape

Wellness is a term used to denote the broader context of healthy (practices that ensure very low susceptibility to diseases, especially chronic) living. It is used as a means of disease prevention. Wellness practices have been encouraged for adoption in different ways across age groups. Older adults (senior citizens) are typically guided by the healthcare system or via the community. Employed adults benefit from employer sponsored wellness activities. Younger adults are generally on their own seeking an active lifestyle while in schools and colleges. There is a relatively high focus on wellness of middle-aged and older adults. Typical wellness activities range from visiting fitness centres, spas and beauty salons, going on activity holidays, and taking silent retreats. Tools such as sensor-based consumer health devices (currently with features covering the areas of cardiovascular, overall fitness and development, pulmonary medicine, endocrinology neurology, and ophthalmological wellness) that provide consumer-generated data, help to increase medication adherence and allow better management of their own health. Such preventive measures will ultimately reduce the overall costs of healthcare in the future, while increasing the quality of life for the consumer.

The key transformative component in healthcare is consumer-generated healthcare data (CGHD), defined as health-related data created, recorded, gathered, or inferred by the consumers (Table I) or their apps to address a health concern [11]. All wellness data is completely stored and owned by the consumer and used personal decision-making. Being outside a clinical setting, an interface with the healthcare system is conspicuously absent. The accessibility and clinical utility of such data for diagnosis or research is currently limited. Accuracy of CGHD, its characteristics (sampling rate, precision, etc.), security, and the lack an API for the healthcare system’s health/medical record database contribute to the limitations. Unification of the data from a diverse device ecosystem is pioneered by initiatives such as Aqua.io, Human API, “Here is my Data” and Vivametrica that provide APIs for developers to use the data. There is no effort towards integrating such data into the healthcare systems. The challenge here is the usability (accuracy, precision, etc.) of the data since the consumer devices are not yet approved as “medical” grade devices. A recent draft guidance document from The Center for Devices and Radiological Health (CDRH) at the U.S Food and Drug Administration (FDA) defines a wellness device or product as one that is only intended for general health and wellness and which also presents a very low risk to the user.

The Industry however, has responded with integrated application development frameworks such as the Apple HealthKit, Microsoft HealthVault and Google Fit offer options for wellness data gathering. HealthKit and ResearchKit help to develop applications that can interact with various consumer devices and sensors, specifically the Apple smartphone. The Google Fit SDK, in contrast, is focused on fitness apps and enables consumers control their fitness data as well as enable developers and manufacturers create a variety of smart apps and consumer devices embedded in routinely used accessories.

<table>
<thead>
<tr>
<th>Monitored Attributes</th>
<th>Units</th>
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<tbody>
<tr>
<td>Accelerometry</td>
<td>Activity intensity</td>
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<td>Blood Pressure</td>
<td>mmHg</td>
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<td>Blood Levels</td>
<td>Glucose, Medication</td>
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<tr>
<td>Environment</td>
<td>Exposure-dependent</td>
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<tr>
<td>Fall</td>
<td>Times fallen</td>
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<tr>
<td>Geo-location</td>
<td>Geo-coordinates</td>
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<tr>
<td>Heart rate</td>
<td>Beats per minute</td>
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<tr>
<td>Pedometry</td>
<td>Steps</td>
</tr>
<tr>
<td>Sleep</td>
<td>Duration, interruptions, latency</td>
</tr>
<tr>
<td>Temperature</td>
<td>Centigrade/Fahrenheit</td>
</tr>
<tr>
<td>Weight</td>
<td>Stones, pounds, kilograms</td>
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Typical consumer attributes that constitute CGHD [10]
Microsoft’s HealthVault is a platform that is geared to provide the infrastructure that is both patient-facing as well as provider-facing to integrate the medical record information from the provider with the CGHD from the consumer. The objective is to provide the consumer (and the provider) a holistic view of the status of the consumer’s health. The status includes information about the consumer’s behavioural events and patterns.

On similar lines as the industry’s application development frameworks, there are open source efforts. Openhumans.org provides a means of sharing members’ wellness data through an API for purposes of research. SHimmer provides a simple API which serves clinically-valid data in the Open mHealth format. Physionet provides MIMIC, an openly available dataset comprising anonymised health data associated with 40,000 critical care patients. It includes demographics, vital signs, laboratory tests, medications, etc. Kaggle provides data mining and analysis tools for large data sets. Between them, these platforms provide the databases, the APIs for their access as well as the tools for processing them. They are intended primarily for research but evolving to be platforms for limited public use, for now.

1) Observations: In terms of building solutions for consumer use, several generic hardware and software platforms for IoT are available. They increase the potential for the wide-spread generation of CGHD [12]. Integrating CGHD with existing health data into electronic medical records (EMR), or personal health records (PHRs) along with other biological and genetic data could provide information to assess patients’ progression from health to sub-clinical disease to a clinically significant pathological state [13]. While this is the future one anticipates, the need for accurate data from the devices is a primary requirement. A few consumer devices that were calibrated were not sufficiently accurate. Personal fitness tracker–derived heart rates were slightly lower than those derived from cECG monitoring in real-world testing and not as accurate as pulse oximetry (SpO2, R-derived) measured heart rates [14]. [15] estimated accuracy of heart rate and energy expenditure monitoring of three consumer devices the Apple Watch, Fitbit Charge HR and Garmin Forerunner 225 and reports that Apple Watch had the lowest mean absolute percentage error across three different levels of exercise for both heart rate and energy expenditure, with Fitbit Charge and Garmin Forerunner 225 being second and third in terms of the mean absolute percentage error.

Several fitness devices (Jawbone UP, Fitbit Ultra, Fitbit One; Zip, Jawbone UP, Miift Shine, Nike Fuelband, Sensewear Armband Mini, Striiv Smart Pedometer, and Withings Pulse) have been tested for functional accuracy. Measuring steps for walking, running, elliptical exercises and agility drills and estimates of energy expenditure are two basic functions that have been verified for accuracy and consistency and their results compared with those from similar research grade devices [16]. Therefore, there is evidence that fitness devices are evolving to be reliable in recording functional information. Transparency of algorithms used to calculate activity levels would be useful in making appropriate evaluations for accuracy as well as for product comparisons.

[8] also reports a somewhat unsatisfactory overall experience with the use of devices by consumers with inconsistent results; they do not report the expected outcomes. Reports of negative outcomes exist, though the reasons are yet to be established. Despite these findings, the overall utility of wearable devices and their use is positively articulated in [17]. The use of technologies such as fitness trackers and smartphone apps, demonstrate a large potential for measuring and encouraging physical activity. There is evidence of impact of the use of “consumer” technologies to effect substantial changes in lifestyle across age groups, to achieve wellness. Older adults benefit by having healthy lifestyles and preventing disease, younger adults adopt healthy lifestyles. The consumer devices, when combined with behavioral strategies, show evidence of achieving objectives.

B. The Self-care Landscape

Self-care is a set of activities that a consumer performs on her/his own as part of self-management of a health condition that is:

- as part of a recovery process after a period of post-acute care in a hospital
- as part of a continued treatment for a chronic condition, with assistance from a provider that is responsible for continuous monitoring of the condition of the consumer

Self-care is typically in a home (outside of a hospital) setting, where the consumer has complete autonomy. Studies have shown that consumers discharged from hospitals after acute care have often had a re-occurrence of an emergency due to lack of adherence to the recommended medication plan as well as lifestyle. Monitoring such consumers for their routine activities and adherence to medication can help fine-tune the medication as well as ensure that their body condition (weight, sleep and rest, activity, heart rate, oxygen levels, etc.) is on par with guidelines and the risk of re-occurrence of an emergency condition is low.

The chronic care model (CCM), specifically lists self-management support as one of its components and describes it as a means to help consumers acquire skills and confidence to self-manage [18].

Typically, in the case of chronic illnesses, post-hospitalization, or long-term ailments the consumers of care are passive in the course of the treatment. Currently, their engagement in the care process is encouraged and partnerships between healthcare professionals (HCP) and the consumer are yielding better healing and a reduction in healthcare costs.

The devices used in such consumer care are referred to as “point-of-care technologies” (POCT). Figure 4 illus-
Figure 4. Wearable POCT devices ([19])

trates the use of implantable devices for highly sensitive point-of-care diagnostics. POCT has been prevalent in the context of blood glucose testing and monitoring of anti-coagulation in warfarin-treated individuals (thrombotic problems). With IoT, the scope of POCT has increased immensely and they can assist in monitoring adherence to the carer’s/provider’s recommendation (currently, poor), medication compliance, and adherence to recommended pharmacological therapy. IoT-based technologies have enabled Wi-Fi–connected pill bottle caps and internet-connected sealable blister packs, inhalers, or injectables to provide monitoring of patient medication compliance.

The use of devices for remote symptom monitoring for older adults susceptible to heart failure have shown to improve outcomes. In the results reported in [20], studies on the use of information and communication technologies (ICT) to provide person-centered care to consumers with chronic conditions (cancer, cardiovascular, diabetes, respiratory and stroke), 64% of the studies reported a positive outcome and 12.9% reported a negative or no impact. The use of ICT, termed as Internet intervention, included monitoring devices and corresponding apps, in addition to the use of web-based tools and apps providing access to medical records.

[21] studied patients in a hospital that required continuous predictive monitoring during their post-surgery stabilisation and recovery period, on the ward. Wearable devices such as mobile pulse oximeters and mobile ECG sensors were used for continuous data acquisition after which machine learning methods were applied. The goal was to provide early warning of serious physiological occurrence, such that predictive care may be provided. The study highlights the difficulties of implementation, while also illustrating that such predictive monitoring is feasible and practical.

There is substantial evidence that engaging a consumer/patient in her/his care of a chronic condition improves the outcomes [22]. The consumer benefits from various means of engagement with the provider, with information exchange both ways; the consumer reporting done using CGHD and the provider by way of verifying adherence, revising activity regimes contextually, and fine-tuning medication, all of which leads to a higher mortality and a better quality-of-life to the consumer. In summary, consumers with chronic diseases have benefited from the “disease-state” monitoring (CGHD), to receive fine-tuned care and increased life-spans [23].

IV. State-of-the-Art

The feasibility of use of consumer health devices for wellness monitoring and prevention is now well established. The consumer-facing infrastructure for wellness monitoring has evolved significantly to provide a stable monitoring infrastructure for wellness parameters. There are well defined interfaces between the consumer devices and apps/apps providers. The accuracy of the devices are currently acceptable. The CGHD from the devices are mostly stored within the apps. The apps set activity goals on a per-day basis and provide notifications to the consumers to remind them to meet the goals, in addition to projecting the trends of the various monitored wellness parameters on a dashboard. The consumer data is further backed up to storage provided by the device/app provider.

While the utility of IoT devices and apps in the context of care is well established, there are limitations in its widespread use and integration into the main stream of healthcare. Two primary problems are apparent:

- the evolution of device technologies is still underway. Improvements in accuracy and consistency are expected along with refinement of algorithms to include the right parameters for energy expenditure estimation
- the integration of CGHD into the mainstream healthcare data (often owned by the government) remains to be done.

In the meantime, app vendors have begun to provide apps that can store health records and CGHD, within the app itself. One such app that mentioned in literature is myFitnessCompanion. It can upload and download health data from various servers, such as Microsoft HealthVault, Google Fit, Jawbone, Fitbit, and many more.

Healthcare apps developed using HealthKit can now request medical records that conform to Health Level 7 (HL7). The HL7 Version 3 Clinical Document Architecture (CDA) is a document markup standard that specifies the structure and semantics of “clinical documents” for the purpose of exchange between healthcare providers and patients. Similar developments are available with HealthVault. It is obvious that these providers are enabling users to store their health data, both existing data as well as the data they generate from their consumer healthcare devices in a single consolidated medical record. Consequently, such medical records will have the complete long-term data of
the consumer in significant detail due to the availability of lifestyle and medication adherence information.

The introduction of health monitoring and telemedicine devices approved by the FDA provide real-time and remote health monitoring of patients with chronic conditions for rapid monitoring of blood glucose levels or other variables. While a subset of these data are currently available to the care provider, a systematic way to integrate these data during the “disease window” of the patient with data from his or her prior healthy state is currently limited.

V. Security in Healthcare

There are many challenges that are associated with integrating the digital technologies into the existing health care fabric. Within the Self-care and wellness landscape, one of the main challenge is the interoperability between the heterogeneous self-care and Wellness technologies, the Personal Health Records(PHRs) and the centralised Electronic Health Records (EHRs), which is being addressed by many researchers. Interoperability is crucial for recording health information, developing common interfaces, agreeing on common data sets, and defining quality standards. Interoperability necessitates development of data platforms in an international, comparable context and thus requires common principles.

While the open challenges relating to information exchange between health information systems and heterogeneous set of medical devices including the wearables are being addressed by the research community, a major roadblock on the road to large scale digitization of health care is security concerns. In particular, the safety and security of individual patient records in a digital world and the security threats emerging out of self-care and wellness devices connected to the Internet [24]. Balancing patient privacy protections with advancing systems interoperability and enabling more data-driven analytics is an ongoing challenge for many healthcare organizations.

The security challenges relating to the health care can be broadly classified as data-centric and device-centric. Data-centric concerns are ethical in nature and address data confidentiality, privacy and data ownership. Device-centric challenges are technical in nature, particularly caused by the devices and wearables due to the need for their availability and constant connectivity for access to services. Disruptions affect the device data streams. Attacks impact the service delivery, severely. The impact is not restricted to reputation, financial loss and customer dissatisfaction, but can affect patient safety making this a safety-critical issue. Finally, authentication and identity management of the devices to ensure encryption of data in transit is an existing challenge [25]

A. Confidentiality

Confidentiality of personal information gathered by self-care and wellness technologies entirely relies on trust, given the fact that users are unaware internal working of self-care/wellness devices and applications or the services they connect to. The pre-requisite is a trust relationship between the consumers and the service providers and application developers ensuring compliance with privacy regulation and security-best practices [26] and that the regulations and standards are in place to safeguard consumer interests. While the patient privacy dictates that the consumers have the right to control how their information is collected and used, in practice the patient information is at risk in a number of ways. Medical information stored on devices that are lost or stolen may be accessed by malicious users, particularly if information is not secured using encryption. Information may be shared unexpectedly because privacy practices and settings are confusing or poorly described. Some apps may offer free services in return for access to personal information, an arrangement to which users can only give informed consent if fully disclosed. When physical, technical or organizational confidentiality arrangements are inadequate, information transmitted online may be at risk of interception or disclosure and could potentially have drastic personal consequences such as on health insurance and employment contracts etc. [26]

B. Data Reliability

Data reliability is a concern in large-scale implementation and integration of self-care and wellness technologies into the existing systems. Both the consumers and health care providers require the data generated by self-care and wellness technologies to be reliable and accurate, particularly when some systems rely on manual entry of health data (PHRs) that may be prone to error and bias from human entry. Data validity is another concern. Monitoring devices would require calibration to ensure that the sensed data is accurate and to estimate the error margins. There may be a need to calibrate periodically. One of the largest concerns for CGHD is in regards to data provenance, or the process of tracing and recording the source of the data as it enters the system and moves across databases. The ability to capture and record contextual and source information ensures CGHD is useful, as these details impact the provider’s understanding of the information and enhances their trust in the data. This is a policy-related issue as much as it is a technical one, as standards are yet to be developed.

VI. Conclusions

The availability of consumer devices, essentially IoT-based, for purposes of monitoring daily activities or elements of biological function of an individual has opened up a wide range of possibilities from maintaining wellness to disease prevention. There is a range of devices available in the market that address wellness and lifestyle and some elements of self care. Their accuracy levels have evolved substantially enough for consistent use but not to be imported into medical records. Integration of
such CGHD into medical records is facilitated by a few providers by storing them in HL7v3 CDA, making it available for integration with data with the healthcare providers. Security and privacy of CGHD are concerns being addressed, as are data validity and reliability. Our ongoing work addresses some questions on type of care vs., their requirements and devices, such as How does self-care apparatus change in terms of monitoring devices? What are the medical requirements of a continuous monitored data stream (sample rate, missed samples and data drop patterns, permissible, velocity, etc.), standards for the monitoring devices, the certifying bodies and their recommendations.

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