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Soft systems modelling of design artefacts for blockchain-enabled precision healthcare as a service

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ABSTRACT

Precision Healthcare (PHC) is a disruptive innovation in digital health that can support mass customisation. However, despite the potential, recent studies show that PHC is ineffectual due to the lower patient adoption into the system. This paper presents a Blockchain-enabled PHC ecosystem that addresses ongoing issues and challenges regarding low opt-in rates. Soft Systems Methodology was adopted to create and validate UML design artefacts. Research findings report that there is a need for data-driven, secure, transparent, scalable, individualised and precise medicine for the sustainability of healthcare and suggests further research and industry application of explainable AI, data standards for biosensor devices, affordable Blockchain solutions for storage, privacy and security policy, interoperability, and user-centricity.

Keywords: Blockchain, Precision Healthcare, Trust, Sustainability.

INTRODUCTION

PHC can be defined as the integration of emerging technologies that can provide tailored medical treatment for individuals in optimised time and cost, along with navigation, interoperability, and scalability. Its potential is evident with the gradual decrease in genome sequencing prices (Zimmerman, 2013). Furthermore, PHC is potential to improve medication errors (Harvard Business Review, 2018), address ongoing health workforce constraints (Rogers, 2019), and, most importantly, reduce conventional healthcare expenses (Bíró et al., 2018; Hull, 2018). Due to data centrality, PHC's efficacy depends on the volume of health data and applied analytics (Sharma et al., 2019). In contemporary healthcare, PHC initiatives only address chronic diseases (e.g., cancer, tumour, diabetes) (Barker, 2017; Zahid, 2021). Therefore, despite its potential, PHC is currently found to be inefficient in performance due to low adoption by stakeholders.

Empirical evidence shows that people refrain from adopting PHC due to distrust (Sharma et al., 2019). Furthermore, the gradual increase of breach incidents (e.g. cyberattacks) in digital health systems (GDHP, 2019b), the probability of unauthorised health data access and viewing, the possibility of unsatisfactory physician-patient relationships, fear of embarrassment, stigma, and discrimination, and the possibility of disclosure of ethnic information (e.g. race, nationality) are playing the drastic role in compounding this distrust among people. Blockchain, an emerging technology for trust-less platforms, incorporates state-of-the-art characteristics such as decentralisation, encryption, tamper-resistance, traceability, immutability, and transparency; potential to address the issue of an acceptable Trusted Third Party (TTP). Therefore, this paper introduces a Blockchain-enabled PHC ecosystem that addresses the issue of trust in healthcare stakeholders and the resulting low adoption challenges. The research focuses on the design and empirical validation of the ecosystem artefact and sub-artefacts. The designed artefact and sub-artefacts are based on system design principles and rules discussed comprehensively in recent research studies and regulatory guidelines. As empirical evidence shows that the existing digital health infrastructure is incapable of satisfying the current and future health data needs (Svensson, 2019; Zahid et al., 2021), the designed ecosystem artefact and sub-artefacts also incorporate emerging information technologies that have the potential to ensure sustainable health data support, clarity, and trust among the stakeholders and facilitate uptake and adoption.

BACKGROUND REVIEW

The designing of the PHC ecosystem progressed with a comprehensive review of underlying technologies such as IoT, VR, AI and big data. The review outcomes (Zahid et al., 2021; Zahid, 2021) acknowledge these emerging information technologies' potential and suggest inclusion in the ecosystem design. More specifically, an extensive review of scholarly and practice-

oriented literature was conducted to understand the potential design principles and rules to ensure empathic design and trust in the ecosystem. A total of nine design principles and thirty design rules were identified. An iterative enhancement approach has been considered to refine and establish a comprehensive and parsimonious set of design principles which address the "what" question of designing the PHC ecosystem. These principles have spawned the associated design rules that address the "how" question of design artefacts of the ecosystem. These design principles and rules were further presented during the demonstration of the ecosystem to different healthcare industry clients and actors for refinement and validation. Figure 1 depicts the system design principles and rules that are applied for the design of the artefacts of the PHC ecosystem.

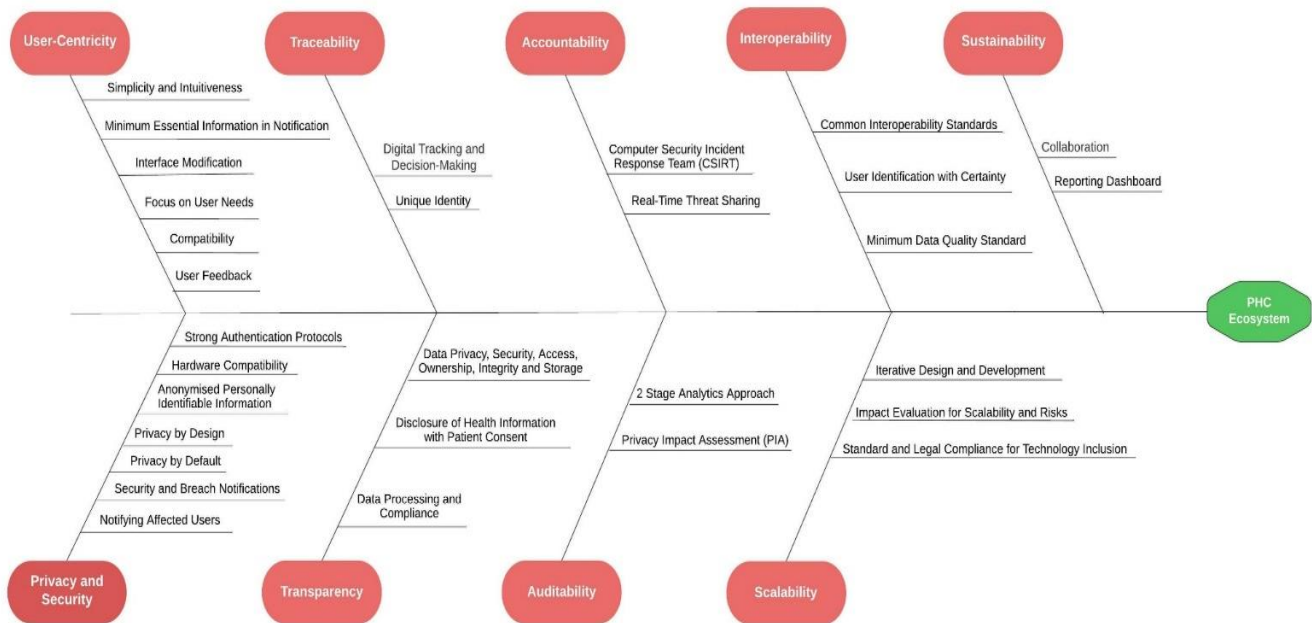


Figure1: Fishbone Diagram of System Design Principles and Rules for PHC Ecosystem.

User-Centricity

For a data-driven healthcare service like PHC, user-centricity is significant for success. Therefore, health policymakers must establish a user-centric system design guideline to ensure active user engagement and success. PHC service should be intuitive and straightforward to ensure user-centricity (Labrique et al., 2018; Nath & Sharp, 2015). It should include various social aspects (traditions, values, translation, environment) while designing services and interventions (Marwaha & Kvedar, 2021). Moreover, it should complement the practical, emotional, and clinical needs of the patient and other healthcare actors (UK Department of Health & Social Care, 2019; Cresswell et al., 2013; Imison et al., 2016; Principles for Digital Development Working Group, 2016d; Stickdorn & Schneider, 2012). Communications between patients and different healthcare actors through PHC service should be succinct, maintaining minimal essential information (Jackson et al., 2018; Phillips et al., 2015). Furthermore, besides computers, PHC service should be compatible with smart gadgets such as notebooks, smartphones, and tablets. It will potentially enrich health equity in remote settings. Lastly, PHC service should incorporate a functional user feedback mechanism to improve further the user-centricity and overall PHC service (Principles for Digital Development Working Group, 2016d).

Privacy and Security

Due to the recent growth of cyberattacks (GDHP, 2019b) and the possibility of unauthorised access to digital health services (Brothers & Rothstein, 2015), data privacy and security have been significant issues in every healthcare setting worldwide. Therefore, data privacy and security policy for PHC service should explicitly include regulations for data ownership, sovereignty, access and control over data usage and storage. It should be developed in straightforward language (Principles for Digital Development Working Group, 2016a). Personally identifiable information (PII) in the health data should be anonymised for any usage by the PHC service (Ipsos MORI, 2014; Health Data Exploration Project, 2014; Vithiatharan, 2014). In exceptional circumstances, de-anonymisation of PII must be strictly limited. In principle, it should be used for limited purposes, assuring users' data protection, minimisation, and transparency (GDPR, 2018). PHC service must include data security by design and default (GDPR, 2018). PHC service should also incorporate contemporary security techniques such as multi-factor authentication (Borde, 2007; Mikkelsen et al., 2020) besides conventional data privacy and security mechanisms. Furthermore, the PHC service should incorporate effective notification mechanisms to broadcast cyber-incident and breach notifications, security updates, and system updates (Fernandez-Aleman et al., 2015; Mikkelsen et al., 2020). Incorporating these into the data privacy and security policy will assure transparent service operations (GDPR, 2018; Mikkelsen et al., 2020), grow trust among PHC users, and encourage them to active participation and engagement.

Traceability

In today's data-driven environment, PHC service needs to be digital tracking enabled (Agarwal et al., 2018; WHO, 2018; Frøen et al., 2016). It is potential to: a) reduce delays in care delivery and treatment; b) provide assistance to the health practitioners in decision-making at the point of care; c) assist in the personalised healthcare cycle; d) schedule follow-up appointments and other related services (e.g. pathological tests, diagnosis); e) support in organising checklists for care management; and f) decrease cost and time of healthcare delivery at rural settings (WHO, 2019). Digital tracking is significant in a data-driven society to attract users and engage them in digital health services for care management and decision-making (TEFCA, 2018). WHO (WHO, 2019) recommends digital tracking in sharing health status and other related services (e.g. payment, appointment scheduling). Digital tracking should maintain strict data confidentiality. PHC service should incorporate appropriate technological solutions (e.g. Artificial Intelligence, Blockchain) to confirm the users' data privacy and confidentiality. Digital health services should be based on a unique identity management system (Imison et al., 2016; WHO, 2019; Yao et al., 2010). The unique identification management system can assist in the patient search, improve redundant entries in the user registry, and enhance intervention efficiency, quality of treatment, and care delivery (WHO, 2019). Moreover, it is competent to support information exchange (Interoperability) among various healthcare providers (WHO, 2019).

Transparency

Transparency means the predicted outcome from the input in a system cycle (Rouse, 2014b). It is one of the key demands of users in digital health services (Cordina & Greenberg, 2019), such as PHC. Transparency in PHC service can be designed by founding a data flow map. A data flow map can help categorise instances like data processing information (including trace and track of records) and exchanged data types (UK Department of Health & Social Care, 2019). However, a data flow map may cause data misuse (e.g. niche advertising) (Bigelow, 2018; Crawford et al., 2015). PHC service may include appropriate technology (e.g. Artificial Intelligence, Machine Learning, Deep Learning) to set up an informed consent management strategy within their system and service for creating and assuring the best transparency practice for all its users.

Accountability and Auditability

Gradual demand for transparency in digital health services (Cordina & Greenberg, 2019) has made accountability a significant issue in healthcare. Accountability helps to improve a system's auditability. Auditability denotes the ability to evaluate the existing system infrastructure, operations and regulation policies (Rouse, 2014a). Accountability and auditability enhance the traceability and transparency aspects of a digital health service. Therefore, to ensure traceability and information transparency, PHC service should maintain internationally recognised standards for data privacy, security and performance assessment. It may include collaboration initiatives such as a) Computer Incident Response Centre (Ruefle et al., 2013; GDHP, 2019b), b) Real-time threat sharing among various healthcare entities using traffic light protocol (GDHP, 2019b), c) Common Vulnerability Scoring System (CVSS) for all healthcare devices connected with the PHC service (GDPR, 2018; Mell et al., 2007), and d) Privacy Impact Assessment (PIA) (European Commission, 2016; GDPR, 2018). These initiatives assure accountability and auditability of the service as per the regulatory policy and add value to care delivery.

Interoperability

By definition, interoperability means the ability of strategic data access, interchange, integration, and application within health information systems and devices (HIMSS, 2020). Interoperability assures the "standard meaning" of data for all the connected healthcare entities. It enables seamless health data interchange within or beyond the facility and regional boundary. In the current digital health context, it is a pre-condition. Therefore, to achieve interoperability, digital health services such as PHC must confirm user identification with confidence in the system (GDHP, 2019a). It can be achieved by applying standardised identifiers, for instance, the national health index. PHC service must adopt an internationally recognised, common interoperability standard (European Commission, 2014; GDHP, 2019a; Ferranti et al., 2006; Liaw et al., 2014; McMorro, 2014). The PHC service providers may consider open-source platforms such as OpenMRS, CommCare, OpenSRP, and OpenDataKit. They may also consider proprietary interoperability standards such as FHIR. These interoperability standards are flexible to integrate and offer user-friendly features and support. Interoperability has the potential to improve the quality of coordinated care, access equity, and service delivery of PHC (GDHP, 2019a).

Scalability

Scalability is the expansion-ability of the system in proportion to the system's gradual need (Bondi, 2000). It is always demand driven. As the current technology infrastructure of digital health services is becoming ineffectual in supporting the current and future health data needs (Svensson, 2019; Zahid et al., 2021), PHC service must action for the needed system scalability. In compliance with the regulatory guideline, PHC service should be able to incorporate emerging information technologies and Fitness devices into the ecosystem. Moreover, they should strictly monitor minimum data quality standards and maintenance (Principles for Digital Development Working Group, 2016b; GDHP, 2019a). Governing and regulatory entities such as WHO (World Health Organization), IMF (International Monetary Fund), USAID (United States Agency for International Development), and United Nations have already introduced data quality assessment frameworks, strategies, and fundamental principles, which can be applied as reference for such assessments. The PHC service should also include a practical impact evaluation matrix (acknowledging factors such as expertise, priorities, time, and cost) for service scalability and associated risk (Principles for Digital Development Working Group, 2016b; GDHP, 2019a). It may bring effective assessment outcomes for the service scale (Principles for Digital Development Working Group, 2016c). Lastly, PHC service should also consider a

collaborative iteration approach for the service design, development, and improvement to achieve the highest possible service scale.

FIELD RESEARCH METHOD

This research adopts Soft System Methodology (SSM), a wholly consistent variant of Design Science Research (DSR) (Baskerville et al., 2009; Peffers et al., 2007). SSM applies systems thinking to tackle messy, problematic situations (Checkland & Poulter, 2010). SSM includes action-oriented processes for investigating "problematic situations". The researcher acquires knowledge of the situation through exploration and determines the needed action to improve the situation. In SSM, the learning of a researcher commences with a set of organised processes where exploration of a situation is determined through a set of models representing purposeful action, each developed to describe a single worldview. These intellectual tools or devices structure discussion and inform the researcher about the situation and how to improve it (Checkland & Poulter, 2010). Figure 2 depicts the classic 7-step SSM model (Checkland & Scholes, 1999a), including information on this research.

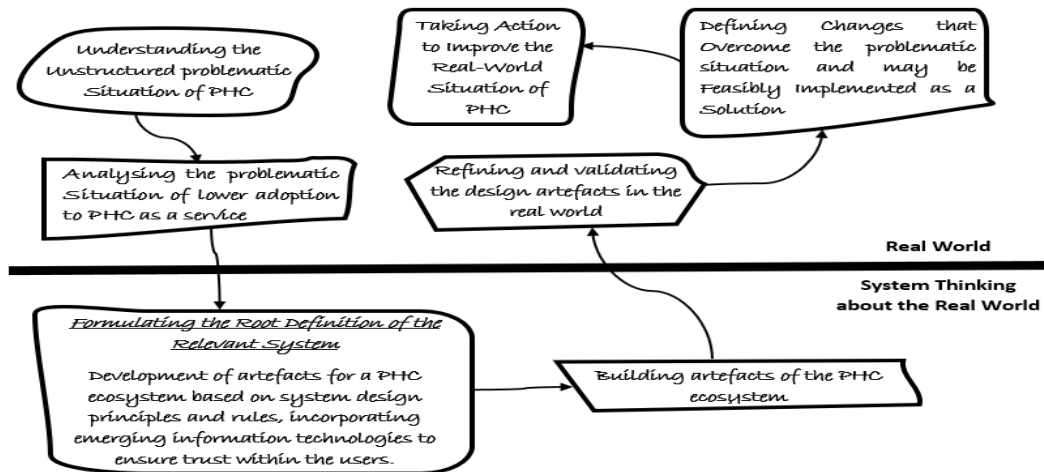


Figure 2: The Adopted Soft System Methodology Approach for the Study.

Step 1: Understanding the Unstructured Problematic Situation

The problem of this research is the inefficacy of PHC due to the "lower adoption" of users. Empirical evidence shows that people refrain from adopting PHC due to distrust (Sharma et al., 2019). A comprehensive review of PHC was conducted in this research to understand the unstructured problematic situation of PHC in detail. In the review, fear of cyberattack, unauthorised EHR view and access, disclosure of race, ethnicity, or nationality, suffering from stigma, embarrassment, and discrimination, and the unsatisfactory physician-patient relationship is identified as the plausible reasons for lower adoption of PHC service.

Step 2: Analysing the Problematic Situation of Lower Adoption to PHC as a Service

This step involves communicating and validating the problematic situation identified by the researcher. The step is purposed to confirm whether the widespread organisational actors acknowledge the identified problematic situation or not. To acquire this, a researcher can apply different types of tools. Checkland & Scholes (1999) recommends drawing a "rich picture", a detailed, unstructured illustration of the explored problematic situation. Figure 3 depicts the problematic situation of this study as a "rich picture".

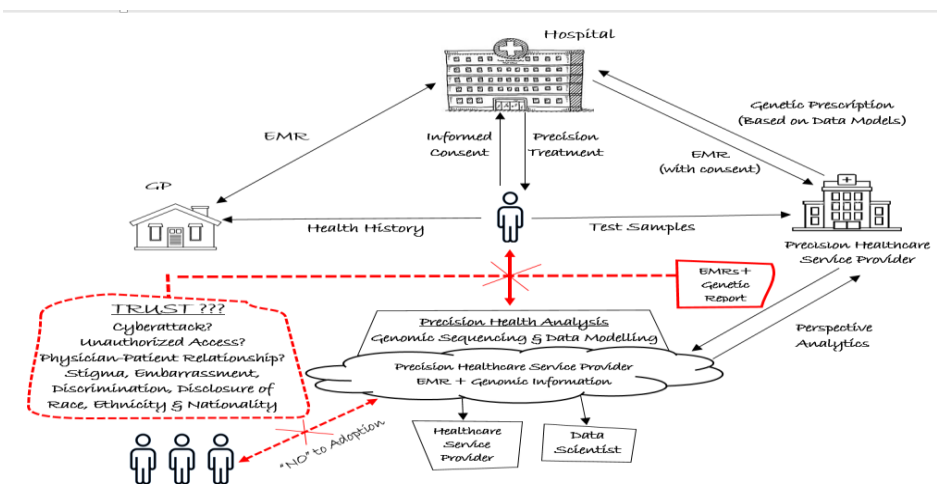


Figure 3: Generalised "Rich Picture" of the Current Problematic Situation of PHC service.

Step 3: Formulating the Root Definition of The Relevant System

This step is the unique step of SSM. The "real" world problem moves into the world of systems through this step. This step is purposed to develop the "Root Definition" of the relevant system. Root Definition means the purpose statement of the human activity system. The definition development progresses with two steps: (i) Clarifying what the system intends to transform or change and (ii) Applying the CATWOE (an acronym; customer/client, actor, transformation process, worldview, owners and environmental constraints) framework to provide the Root Definition for the transformation made. Therefore, as per the description, the Root Definition of this research is:

Development of artefacts for a PHC ecosystem based on system design principles and rules by incorporating Blockchain and emerging information technologies to ensure trust among the users.

The CATWOE framework used to develop the Root Definition is also provided in table 1.

Table 1: CATWOE of Emerging Technology Enabled PHC service.

Clients	<ul style="list-style-type: none"> ▪ Patients
Actors	<ul style="list-style-type: none"> ▪ Patients ▪ Health Practitioners ▪ Providers ▪ Technology Vendors ▪ Payors ▪ Policymakers/Regulators
Transformation	<ul style="list-style-type: none"> ▪ Artefacts for a PHC ecosystem (based on system design principles and rules, incorporating emerging information technologies)
Worldview	<ul style="list-style-type: none"> ▪ Improving practice for growing trust and uptake rates ▪ Enhancing the level of health knowledge of PHC ▪ Eliciting emerging techs for users' uptake ▪ Providing trusted, reliable healthcare monitoring ▪ Enabling precise healthcare with navigation (right time and right location)
Owners	<ul style="list-style-type: none"> ▪ Providers (Government or Non-government)
Environmental Constraints	<ul style="list-style-type: none"> ▪ Data Protection Legislation ▪ Medical Ethics – Genetic Information, Incentive Mechanisms ▪ Emerging Technologies (Currently in development)

Step 4: Building Artefacts of the PHC ecosystem

These artefacts of the PHC ecosystem were designed based on the CATWOE framework, incorporating the design principles and rules discussed in the previous section. Draw.io (A UML designing tool) was used as the diagramming tool to design these artefacts. Besides artefacts, multiple "rich pictures" were also developed to ensure a simple representation of the designed ecosystem during the demonstration. The rich pictures were developed using Microsoft Paint and included different user contexts associated with the PHC ecosystem. Refinement of the artefacts was obtained by using the same tools described to ensure rigour in design, as well as "suggestions and or comments for improvement" given in the design refinement interviews (DRIs) and design validation workshop (DVW). The strategies adopted in the DRIs and DVW are discussed next.

Step 5: Refining and Validating the Design Artefacts in the Real World

The designed PHC ecosystem artefact and sub-artefacts (i.e., dynamic modelling or scenario modelling) of the PHC ecosystem was first presented during the DRIs for informed participation. A total of 18 healthcare actors with different backgrounds (providers, policymakers, payors, technology vendors, researchers, health practitioners, and patients) participated in the DRIs. The participating actors are active professionals working in the health industry of Australia, Bangladesh, Canada, Germany, New Zealand, and the United Kingdom. The number of DRIs was not progressed further due to theoretical saturation. A design refinement instrument (structured in a questionnaire format) addressing the demonstrated artefacts was distributed among the participating healthcare actors during the demonstration. The instrument was developed using guidelines from established design research methodologies (specifically, Checkland & Scholes, 1999b; Hevner et al., 2004; Prat et al., 2015; Vaishnavi & Kuechler, 2015) to assess the efficacy and effectiveness of the designed artefacts and capable of delivering valuable user insights derived from the actors' experience and expertise. Data obtained in the DRIs were further analysed with NVivo (qualitative data analysis tool). After a multi-tier screening of the collected data, 55 comments or suggestions (including repetitive ones) were identified and analysed for further consideration in improving artefacts. The "final versions" of the PHC ecosystem artefact and sub-artefacts were next demonstrated in a DVW, using the New Zealand Healthcare ecosystem as an illustration. A Delphi panel of 20 New Zealand healthcare actors with different backgrounds (providers, policymakers, payors, technology vendors, researchers, health practitioners, and patients) participated in the DVW. The participating actors were active professionals working in Auckland District Health Board (ADHB), Canterbury District Health Board (CDHB), Ministry of Primary Industries, University of Canterbury, and a health-tech organisation in New Zealand. During the demonstration, a structured questionnaire addressing the refined artefacts' technological feasibility, economic viability, and social desirability was sent to the participating actors to obtain their valuable assessments and "comments or suggestions for further improvement" and validation. A guidebook was distributed to all the DRI and DVW participating actors to ensure informed participation. Figure 4 below depicts an example of the demonstrated artefact of the designed ecosystem. The rest of the artefact and sub-artefacts are appended as annexe A.

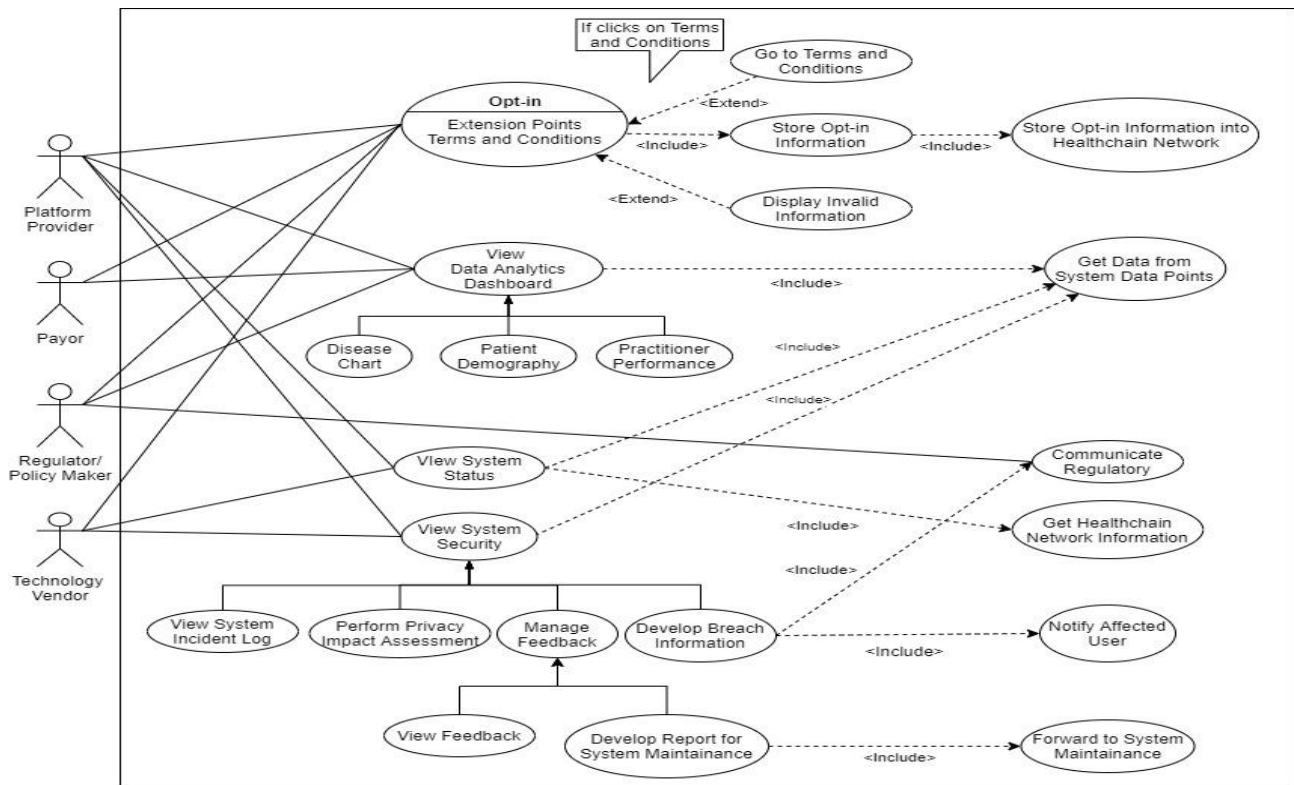


Figure 4: Use Case Diagram - PHC Service Provider, Policy Makers, Regulator, Payor, and Technology Vendor.

Step 6: Defining Changes that Overcome the Problematic Situation and may be Feasibly Implemented as a Solution

The data collected in the DRIs were screened in multiple-tier and evaluated using an assessment matrix, purposed to assess the technological feasibility, economic viability, and social desirability of the designed ecosystem with literature support. The evaluation outcome was further adopted for the artefacts' refinement, either by revisiting the previous steps, through modification or implication on the designed artefacts, or by reserving the evaluation outcome for post-system implementation. After multi-tier iteration for refinement, the designed artefacts were further demonstrated in the DVW, where a Delphi panel of experienced healthcare practitioners (actors) served as validators. Finally, the validated set of designed artefacts is now available for action to improve the current PHC service context.

Step 7: Taking Action to Improve the Real-World Situation of PHC

This step either fulfils the methodological cycle or introduces a new cycle for further research. For the exploratory research undertaken in this thesis, the artefacts of the PHC ecosystem were developed upon rigorous execution of SSM steps, ensuring best-practice system design principles, rules, and trust for its users. It is expected that the real-world implementation of this PHC ecosystem in the current lower adoption context will improve stakeholders' adoption of PHC by ensuring active user participation and engagement with the ecosystem.

FINDINGS AND CONCLUDING REMARKS

To establish an understanding of the perceived viewpoints of the participating healthcare actors and their interpreted, thematic relationship with the adopted system design principles and rules for the PHC ecosystem design, a thematic analysis (Braun & Clarke, 2006) of the data collected was determined. The participating actors with provider backgrounds shared their viewpoints on interoperability, privacy and security, user-centricity, transparency, biosensor device, and practitioner performance monitoring. The actors demand a robust application interface (API) for seamless health data interoperability, regardless of location, service provider, and biosensor device used by the patients. The actors acknowledge the need for security by design and privacy by default in system design, development, and operations. They also suggest regular privacy and security update to reduce data malpractices. For transparency, they support patient-controlled health data usage and suggest digital tracking feature(s) to ensure transparent data flow in the system. Participants also placed the need for practitioners' performance evaluation and demanded such an assessment mechanism in the ecosystem. Regarding user-centricity, the actors recommend simple, intuitive application interfaces that are important to address the patient's needs. Besides, the participating actors also inquired about the potential of contemporary biosensor devices in the designed ecosystem.

Participating researchers shared viewpoints on user-centricity, privacy and security, interoperability, and sustainability. Regarding user-centricity, they suggest simple, user-friendly, modifiable, and ubiquitous access for the users. In addition, they also demand a sentiment analysis mechanism to understand the patient's mental state before visualising sophisticated, emotion-sensitive health data to the patients, which is beyond the scope of this research and needs further research attention. They suggest implementing a multi-factor authentication mechanism for privacy and security to ensure robust security for the

ecosystem and flexible access for the User. Moreover, they acknowledged the use of Blockchain in the ecosystem and inquired about its implementation feasibility (i.e., cost). They suggest a telescopic notification feature comprising the privacy and security details to ensure transparency in privacy and security practices. They also demand a health policy review regarding patients' control over data sharing as it can be a data compromise point (e.g. data breach). In addition, they also demand regulatory concern in reviewing the existing notification distribution mechanism in the digital health settings, as the current practice demonstrates an authoritarian approach by the state-appointed policy advocates and regulators. Regarding interoperability, the actors suggest the usage of a common interoperability standard. On scalability, they suggest collaborative system design and development.

Health practitioner participants shared their viewpoints on privacy and security, user-centricity, and interoperability. They demand patient-controlled data usage to ensure privacy regarding data privacy and security. They desire adequate, uninterrupted data exchange among the stakeholders, which requires the healthcare stakeholders' implementation and usage of common interoperability standards. They also acknowledge the focus on patient needs to ensure user-centric healthcare delivery. The participating actors are firmly aware of the genomic bank, biosensor data, and EHR/EMR, acknowledge the current patient acceptance issues into PHC and demand appropriate action to address the opt-in challenge by improving patient trust. The participating actors also inquired about the competence of the proposed ecosystem in supporting sensitive physical examination (e.g. gyno intervention). From their expression, it is assumed that participating health practitioner actors still have a misconception about "Digital Applications Replacing Doctors"; despite being familiar with its scope, application, capability, and context for years. In the contemporary healthcare setting, where digital transformation is disruptive, it is a challenge to make them understand that the emergence of digital health is to provide data support to health practitioners to ensure efficacy in healthcare services and delivery, not replace them with technology. This vague conception is a challenge for expanding digital health and expect to be improved in the coming days. Nevertheless, the remote intervention of such type (sensitive) is subject to user consent, digital health literacy, overall technology infrastructure, and regulatory guideline (subject to availability). The PHC ecosystem is designed to support remote intervention with video consultation, EHR/EMR, Treatment Plan (periodically executed by the proposed system with patient consultation), clinical taxonomy, genomic profile (subject to availability), and digital twin (based on biosensors data from wearables, can be a generic type or health practitioner advised). The digital intervention of such type (sensitivity) is typically determined with user consent and depends on the health practitioners' competence in treating such. Therefore, the digital intervention of such kind (sensitive) with the demonstrated ecosystem is possible and significantly depends on health practitioners' and patients' experience, technical support and usage (at the user end), user consent (prior intervention), and regulatory approval.

Technology vendor actors shared their viewpoints on monitoring practitioner performance, privacy and security, interoperability, and scalability. They demand solutions that will monitor the practitioners' performance while treating patients. Regarding privacy and security, they require privacy by default in the ecosystem and suggest including additional security mechanisms (i.e., Blockchain) besides conventional privacy and security implementations. They acknowledge the data exchange challenge in LMICs (low-middle income countries) as different interoperability standards are in practice. Furthermore, many countries have laws that prohibit storing and sharing identifiable healthcare data offshore. Therefore, they suggest adopting a common interoperability standard for the ecosystem. Regarding scalability, they suggest strategic ecosystem development, including affordability in principle.

Patient participants shared their viewpoints on user-centricity, privacy and security, transparency, and interoperability. They demand simple and user-friendly access focused on patient needs regarding user-centricity. The actors are concerned about the need for data privacy and security and suggest implementing robust privacy and security mechanism (i.e. encryption schemes) in the designed ecosystem. They suggest prior "notification and consent" in practice regarding system and security updates to ensure transparency to every User. Furthermore, the participating actors strongly recommend maintaining minimum data quality standards to support functional data interoperability among the stakeholders.

Participants with policymaker backgrounds shared viewpoints on privacy and security, transparency, biosensor device, data aggregation, and patient engagement in PHC. The actor acknowledges the need for privacy and security in every possible aspect of healthcare data (collection, storage, analysis, and sharing) so that it does not harm the patients. Data should be dealt with patients' prior consent to establish transparency. Expansion of biosensor devices and their usage should be on rollout and context-specific. Strategic imposing of all these mentioned can potentially impact patient engagement in PHC. Furthermore, all these are potential for data aggregation and are significant for healthcare policy development and improvement.

Due to the ongoing COVID-19 pandemic, participating healthcare actors underwent a stressful work cycle in terms of work commitments and workloads. Hence, scheduling DVW on a specific date and time was challenging. In these circumstances, the DVW was conducted in a virtual and asynchronous mode. The demonstration was pre-recorded and distributed among the participants to join at their convenience. A participation link was developed using Google Forms, with consent information, a participant profile, a video overview of the New Zealand PHC service platform, and a design validation instrument [available from the lead author upon request]. The design validation instrument was used to assess (on a 0 to 10 Likert scale) the social desirability, technological feasibility, and economic viability of the set of sub-artefacts developed during the Design Refinement Interviews and submitted in the Annex to this paper. 85% of the participating actors (17 out of 20) rated between 7

to 10 on the social desirability and economic viability of demonstrated PHC ecosystem. Furthermore, 90% of the participating actors (18 out of 20) rate between 7 to 10 on technological feasibility. We may claim face and construct validity.

A few suggestions and comments were also received from the participating actors. Among those, a notable one suggested "multi-tier patient consent" as a requirement during genomic information accessed by the health practitioner. The ecosystem's existing design can support such needs through its notification management without making any design refinement. By design, the system notifies the patients of every activity related to their health data, including consent requests. Therefore, by default, the system will inform the patient about the request made by the health practitioner and ask for consent before approving the genomic information request. It empowers patients' control over their health data usage and motivates active engagement with the ecosystem. The ecosystem visualises genomic information to the patients on request only. It is purposed to optimise the operational and maintenance cost of the ecosystem, as understanding genomic information requires high-level knowledge of medical terms and education and may be counterproductive (e.g. frustrating, demotivating) in patient engagement.

As an agenda for further research, the following are suggested. The artefact and sub-artefacts of the PHC ecosystem are now ready for functional implementation. Therefore, one course of action should be developing a real-world system. Considering the economic viability, implementing the designed ecosystem should be cost-effective in cloud computing infrastructure (Reynoso, 2017). However, due to the sophisticated health data, a such implementation should be conducted with regulatory concern and approval.

Further research on health data privacy and security policy development is also required to accommodate the disruptive information technologies within the digital health domain. The regulators can strategically monitor the operational services and exercise enforcements when needed (Sharma et al., 2019). Furthermore, a significant gap in qualitative research in PHC requires further research attention. A recent study shows that multiple qualitative data repositories are currently under development (Myroniuk et al., 2021), previously known under the domain of quantitative research. These initiatives are significant, but the efficacy of these repositories in qualitative PHC research is yet to be explored. Further PHC research, therefore, should incorporate these data repositories to determine qualitative research focusing on explainable AI, data standards for biosensor devices, and affordable blockchain solutions for storage, privacy, security, interoperability, and user-centricity. It will enable global collaboration for interdisciplinary PHC research and contribute to the targeted sustainability of healthcare and the well-being of humanity.

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ANNEX A: Design Artefact and Sub-Artefacts of the PHC Ecosystem.

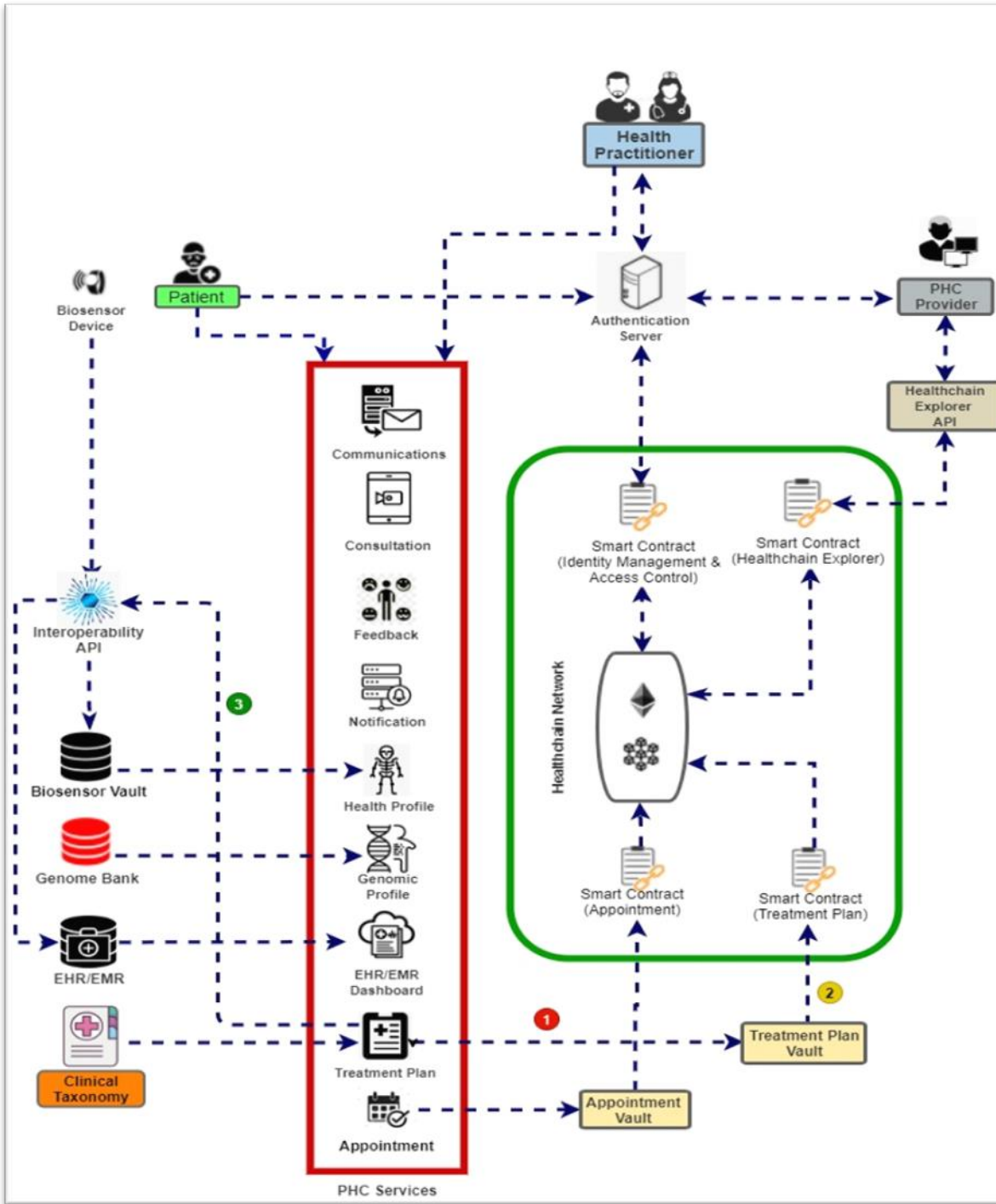


Figure 5: System Architecture of the PHC Ecosystem.

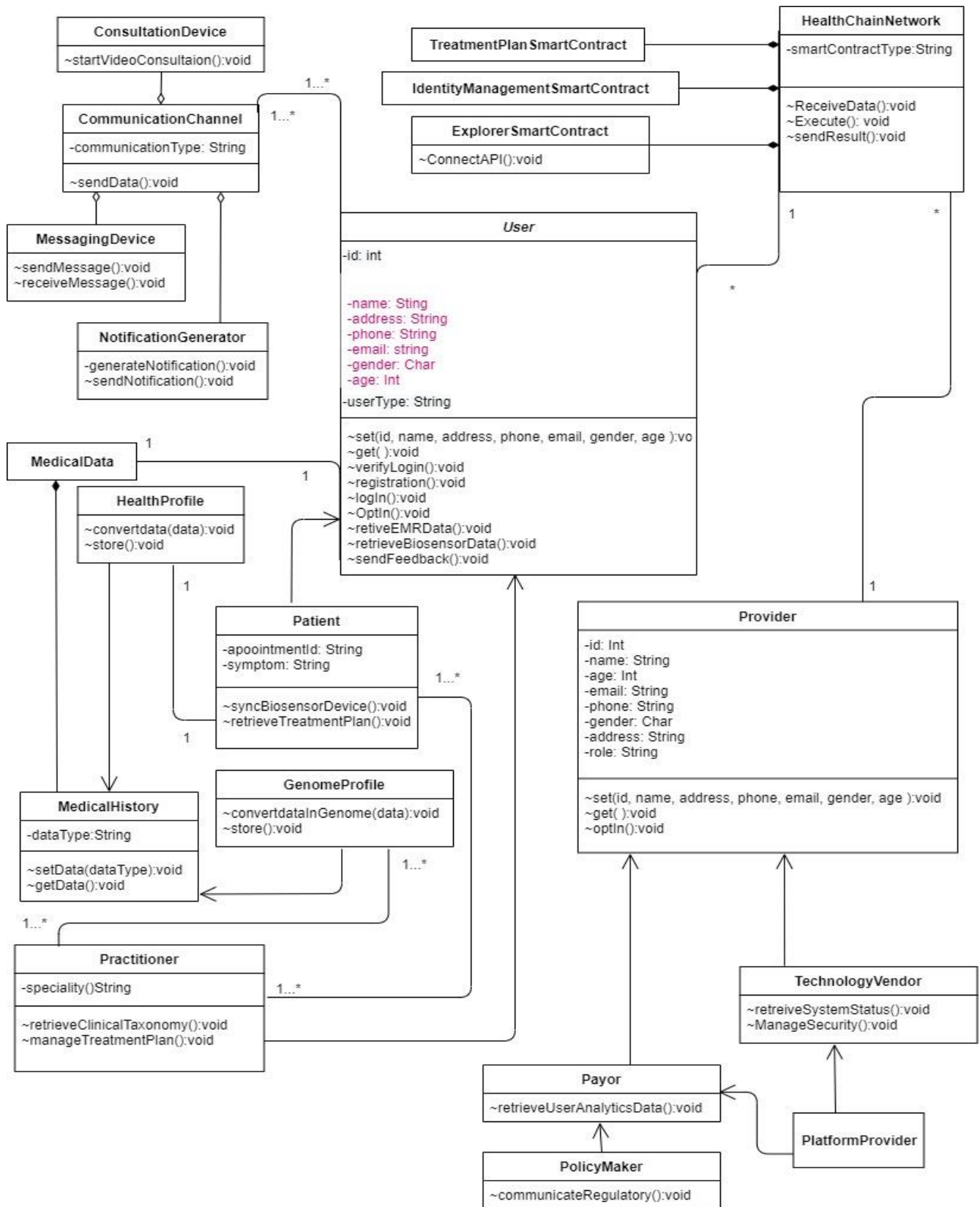


Figure 6: Class Diagram of New Zealand PHC Ecosystem.

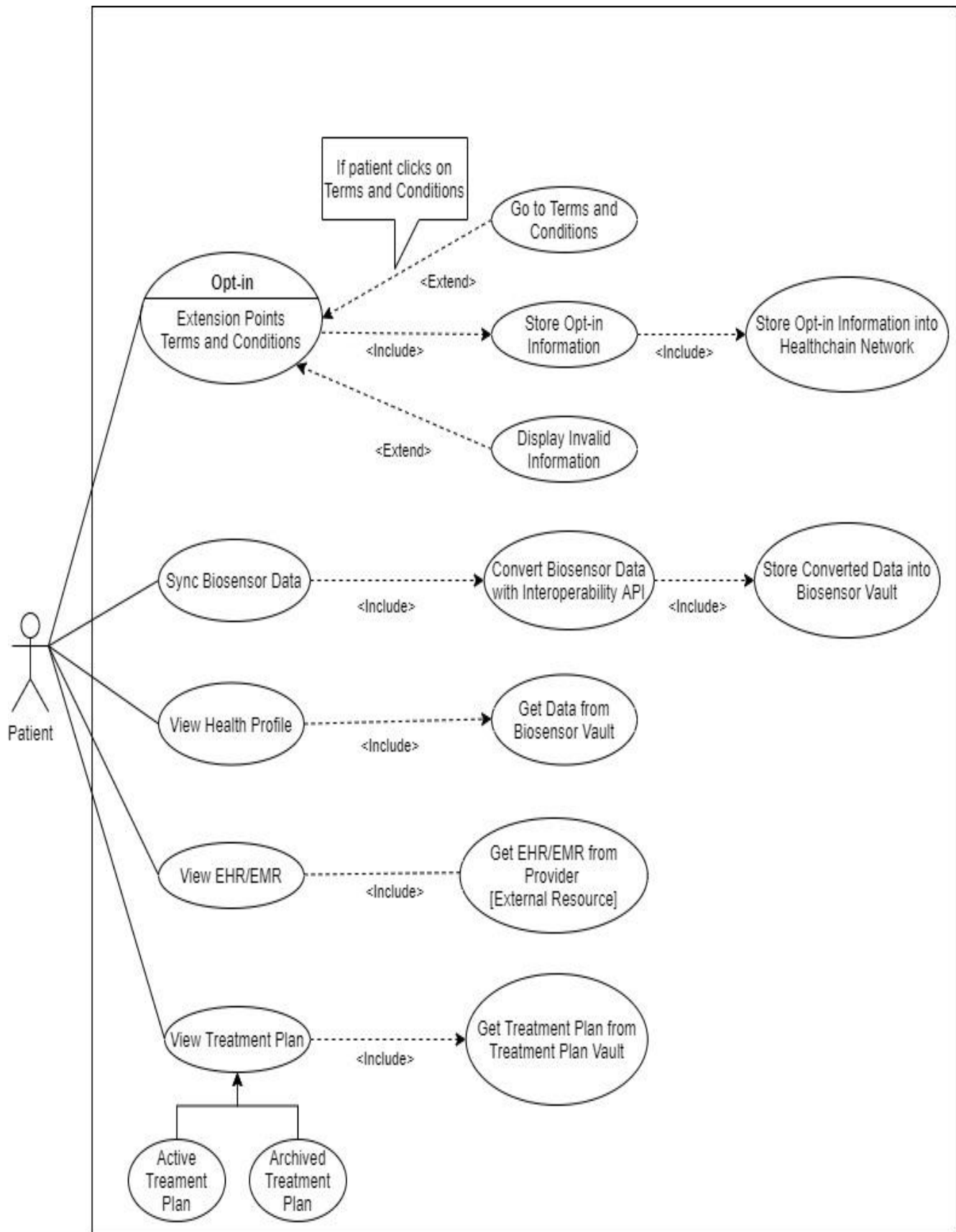


Figure 7: Use Case Diagram - Patient.

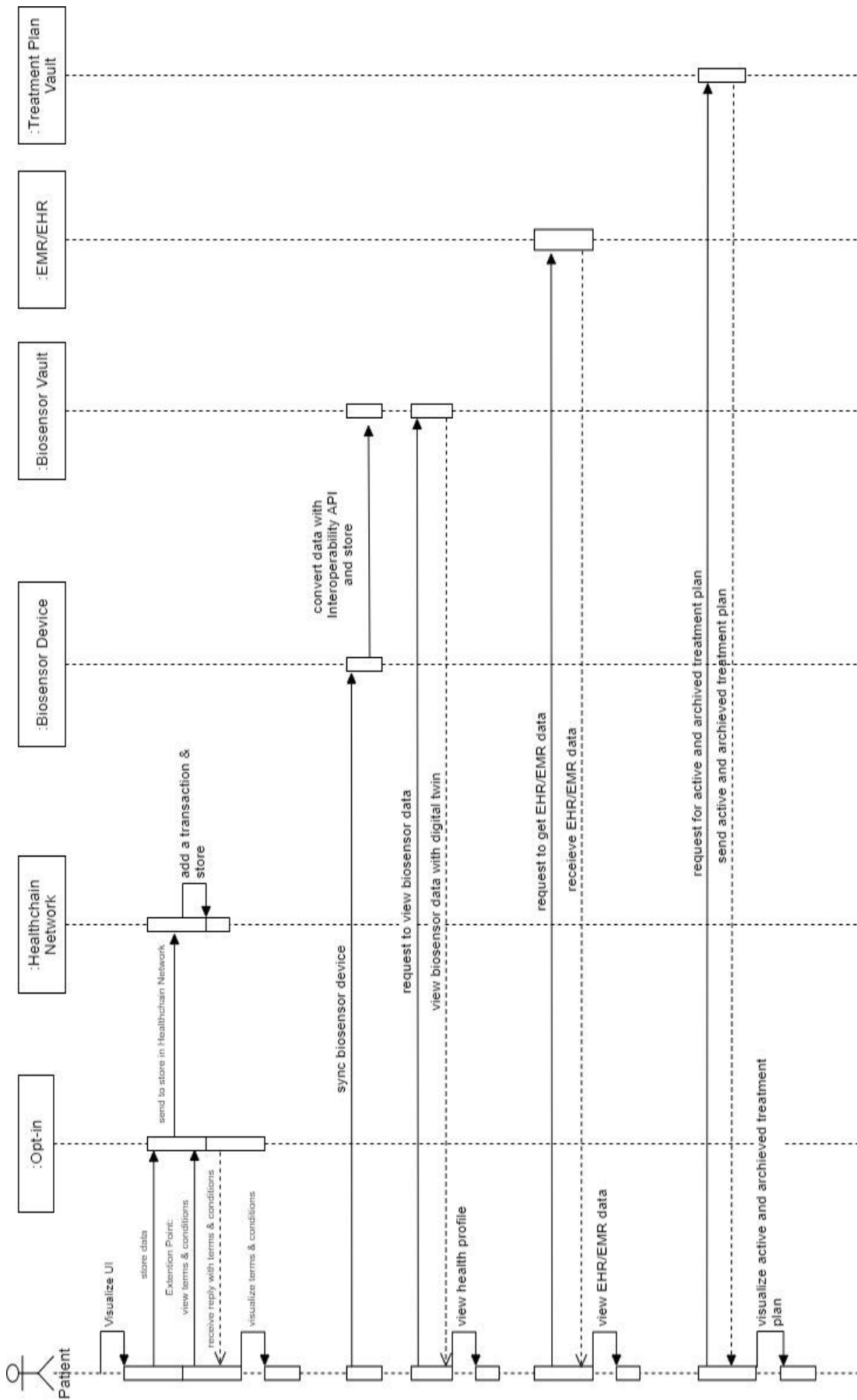


Figure 8: Sequence Diagram - Patient.

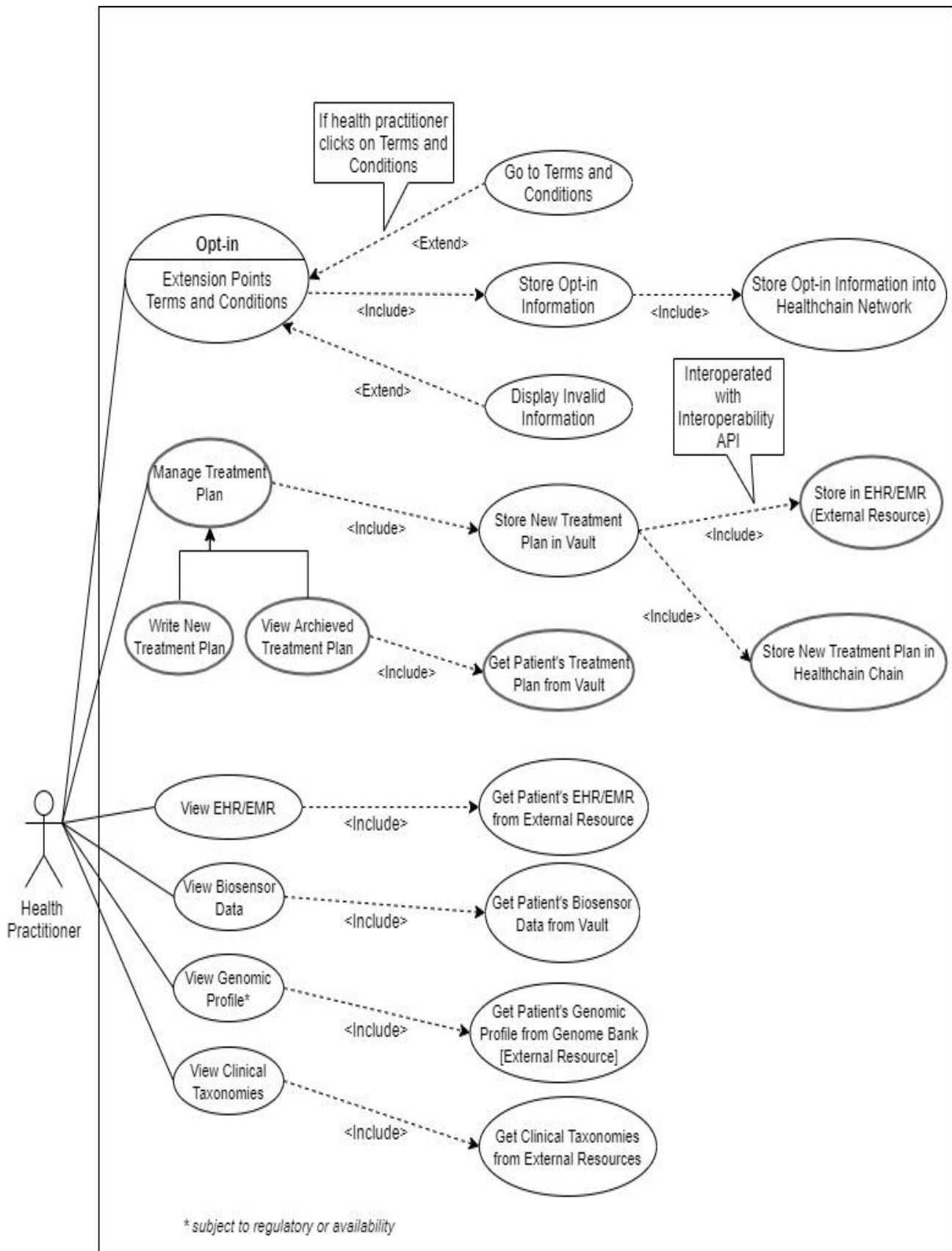


Figure 9: Use Case Diagram – Health Practitioner.

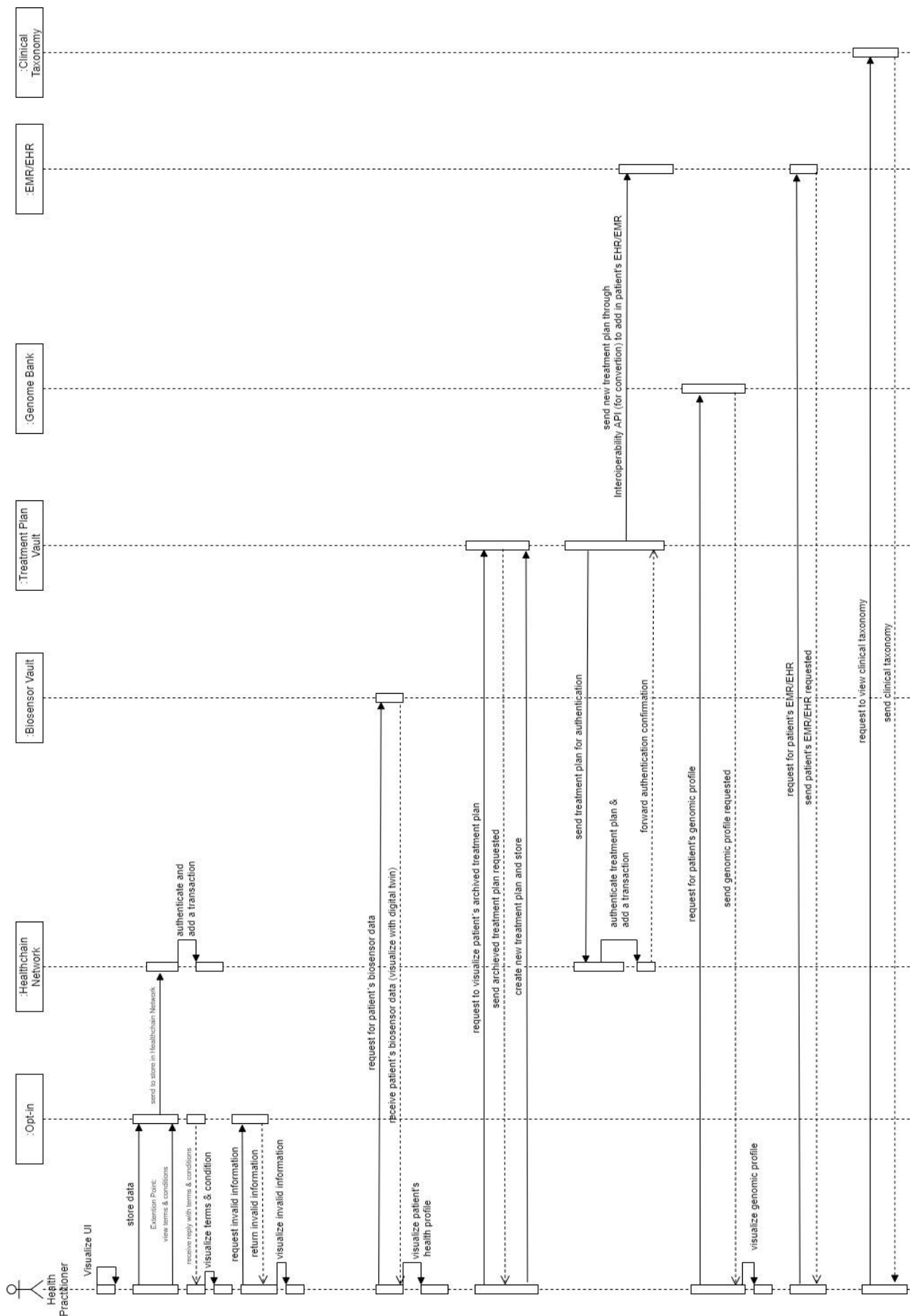


Figure 10: Sequence Diagram – Health Practitioner.

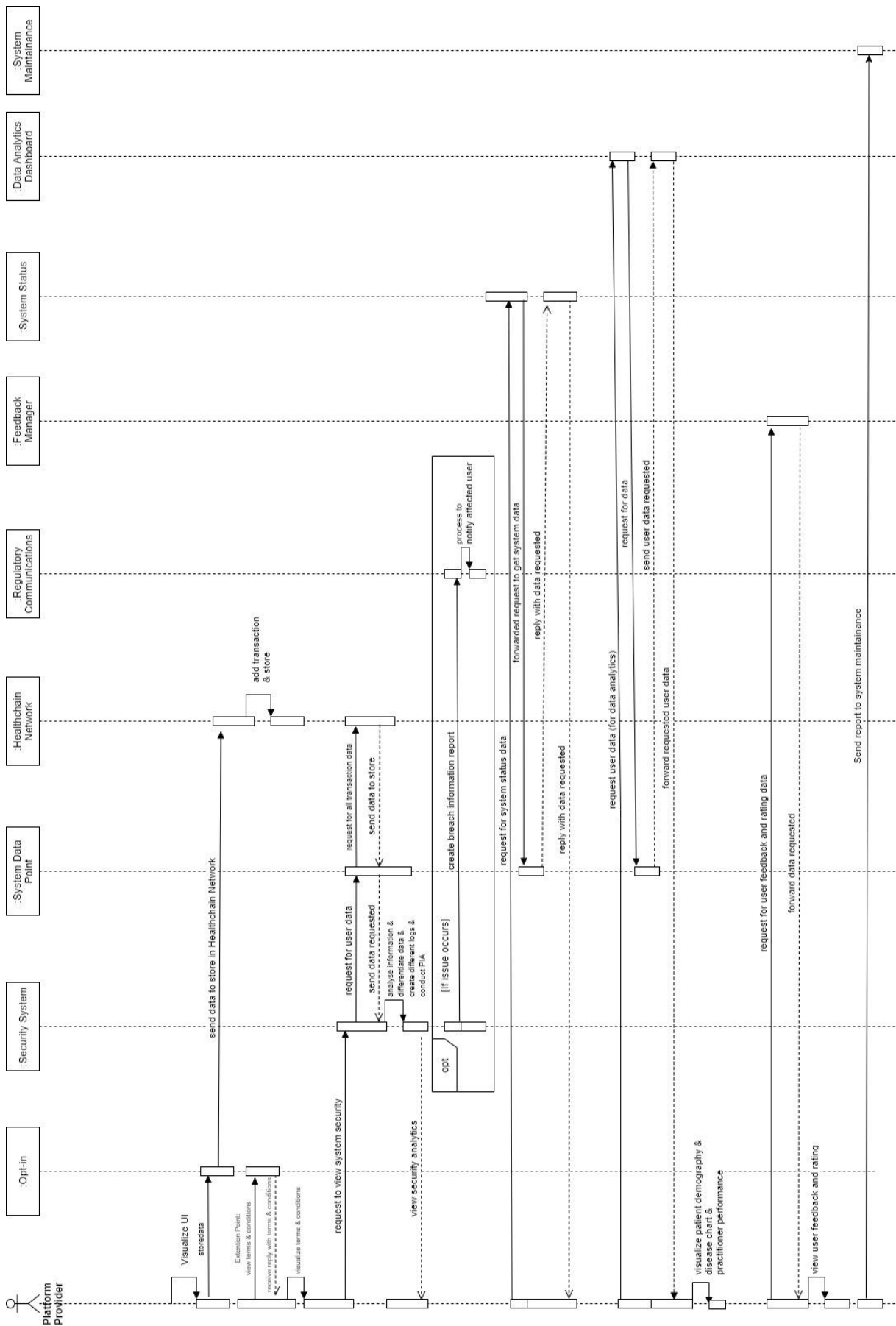


Figure 11: Sequence Diagram – PHC Service Provider.