

Pasienesia: A Mobile based E-Patient Social Network

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1 Pasienesia: A Mobile based E-Patient Social Network

Promoting Empowerment Among Patients who Experience Similar Diseases

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Abstract— The rising of e-patient has promoted self-awareness and active participation among health consumers and patients to be fully involved in their medical care. One of the embodiments of e-patient movement is the online patient community via social media. More consumers and patients use social media to acquire health information from other consumers and patients who experience similar diseases. Likewise, people become more open to share their personal health condition so that others could take advantage from their experiences. However, the usage of general social media comes with the classical issues of privacy, trustworthiness, and accuracy.

Accordingly, this study aims to build an e-patient social network solution to support the future prospect of social media usage in e-patient and to resolve the classical issues in social media. The proposed system connects patients with similar diseases, facilitates health information sharing and discussion among patients with the assistance of medical professionals. The solution development follows a modified rapid application development methodology consisting of formulating the e-patient social network requirements, designing the mobile-based e-patient system (Pasienesia), and evaluating the implementation. The evaluation with clinicians, consumers, and patients with chronic diseases demonstrates the suitability and the usefulness of the proposed e-patient system solution.

Keywords—e-patient; e-patient social network; pasienesia; mobile; social media (key words)

I. INTRODUCTION

The use of Internet and online sources to support health information is rapidly increasing among non-medical professionals lay people, i.e., consumers and patients [1-2]. More patients actively engage in their medical care as e-patients. They look for health information and medical guidance online both for their own ailments and on behalf of their family members. Recent studies reported the benefit of e-patients, e.g., e-patients find more useful and detail medical information on the Internet than what they obtain from their clinicians [3], they feel more confident when consulting with clinicians [4-5], easier and larger access to medical support group [6], and better understanding when participating in participatory medical decision [5]. On the other hand, e-patients have unique relationships with their clinicians; it could be an enhanced communication or a disrupted relationship. A disruptive relationship may happen when a disagreement

occurs between the clinicians and the patients because the patients stick to inaccurate health information they found online or the clinicians feel their authorities are being challenged.

One of the embodiments of e-patient movement is the use of social media to seek and to share health information, medical advice, and personal health experience. A beneficial implementation of social media utilization is online medical support communities. This support community serves 24/7 to provide health education and health material; to encourage initiative, benevolence, and helpfulness among its members; and to provide emotional support [3, 6-7]. More consumers and patients join support communities to learn and to seek advice from other patients who experience similar diseases and from medical professionals in the community. The experienced members offer useful and detail guidance to those newly diagnosed based on what they experienced in the past, what they had learned from various sources, and what they had been informed by their clinicians [7]. Similarly, medical professionals have acknowledged the benefit of patient online communities. These communities contribute to effective medication management by providing valuable healthcare resources and long-term support for the patient [7-8].

The usage of social media for sharing health information comes with its consequences pertaining to privacy, trustworthiness, and accuracy. There are emergent concerns about protecting personal health record in digital world. Once the data available online, it may disseminate quickly and subject to privacy violation. In addition, since social media depends on user-generated content, all members are able to produce content, including health/medical materials, without proper review and evaluation. Thus, the number of inaccurate health information from untrustworthy resources increases quickly. Inaccurate health information may cause serious impacts to a person's life.

9 Given the current challenges and future prospects of social media for e-patient activities, this paper aims to build a mobile-based e-patient social network system. The proposed social network connects patients with similar diseases, facilitates health information sharing and discussion among patients with the assistance of medical professionals. To support accessibility and mobility and to optimize the benefit, the proposed mobile system is built on Android platform.

II. RESEARCH DESIGN

This paper adopted Rapid Application Development (RAD) methodology to build and to evaluate the e-patient social network system. RAD method reduced development time, encouraged initial reviews and feedback from the users, and enabled extensibility. We expected the proposed system to be extended with new features for the future growth. The method consisted the following four phases:

1. Requirement planning phase,

The first phase was elaborated into two main activities, i.e., requirement elicitation and user requirement analysis. At the elicitation, we interviewed target users, i.e., three consumers (non-medical professionals who seek health information online), four patients with chronic disease, and a clinician (cardiologist). We also conducted literature study synthesis about e-patient, social media, and consumer health informatics. The next activity was analyzing the collected interview data and literature study synthesis result to define the user requirements. This phase produced a list of user requirements, detail features for each requirement.

2. Design phase,

The design phase in this study transformed user requirements into a blueprint of system solution that consisted of scenario modeling and data modeling. The scenario modeling was developed based on use case model and scenario, while the data modeling was constructed using conceptual data model. The output of design phase included use case diagram, use case scenario, conceptual data model, and physical data model.

3. Construction phase,

This phase focused on system development based on defined design. The construction consisted of database development, web service development using Lumen framework, and Android-based client application development.

4. Evaluation phase,

The evaluation phase was elaborated into system testing and system evaluation. The system testing assessed the output of the system against the expected output as defined in the use case scenario. After the system testing, we conducted a User Acceptance Testing (UAT) to evaluate the developed system, whether it has met all user requirements. We recruited all participants from requirements elicitation to evaluate the developed system. Acceptance testing is necessary to verify that the proposed solution works for the users and to ensure user participation in the system development. Lack of user participation is one of the major causes of system and IT management failures [9].

III. PASIENESIA: A MOBILE-BASED E-PATIENT SOCIAL NETWORK SYSTEM

A. User Requirements and Features

Drawing on the interview results and literature study synthesis, the functional requirements of the proposed system composed of:

1. Finding other users who have similar medical profile,

In order to find and to connect user to other patients who have similar disease, each user must complete a medical profile. It includes personal detail, health topics interest, and general medical history. According to Cufoglu (2014), a user profile is necessary to filter and to match recommended users based on specific criteria [10]. After completing the medical profile, user can join any health communities listed in the system. Grouping health communities based on similar medical condition encourages the community's members to talk about their disease and to provide more suitable support for others [7]. Besides join a community, a user should be able to find others who have similar medical profile and send messages to discuss specific ailments in private. To protect user privacy, all users must provide valid identification to register to the system.

2. Participating in a health community,

User participation in a health community occurs in various forms, e.g., creating post(s) in a community page about specific topic, giving response to a post, reporting potentially problematic post and comment, and writing health/medical articles. All participants in the requirement elicitation rate creating post and giving response in the community page as must have. In accordance with the interview result, most of e-patient participants in Hosch and Fergusson study stated that online communities provides more comprehensive health information than their clinicians [7]. In the proposed system, a user can post and comment about personal experience, treatment options, medical self-management, day to day living with diseases, as well as emotional support and health care provider recommendation. Another must have feature is reporting problematic posts/comments to maintain the discussion quality and the accuracy of shared health information in the community page. This feature manages the credibility and trustworthiness of the community page, as suggested by Metzger and Flanagin in their study [11].

The proposed system also provides dedicated features for medical professionals users, i.e., writing health/medical articles, assisting the discussion in a community page, and facilitating private discussion with the patient users. These features are suggested by the clinician in the requirement elicitation. According to studies in [12-13], the clinician presence in online communities is necessary to assist discussion and information sharing among the users. Social media and online communities have grown as one of the key sources for promoting health education. These media extend the capability of medical treatment outside the clinic.

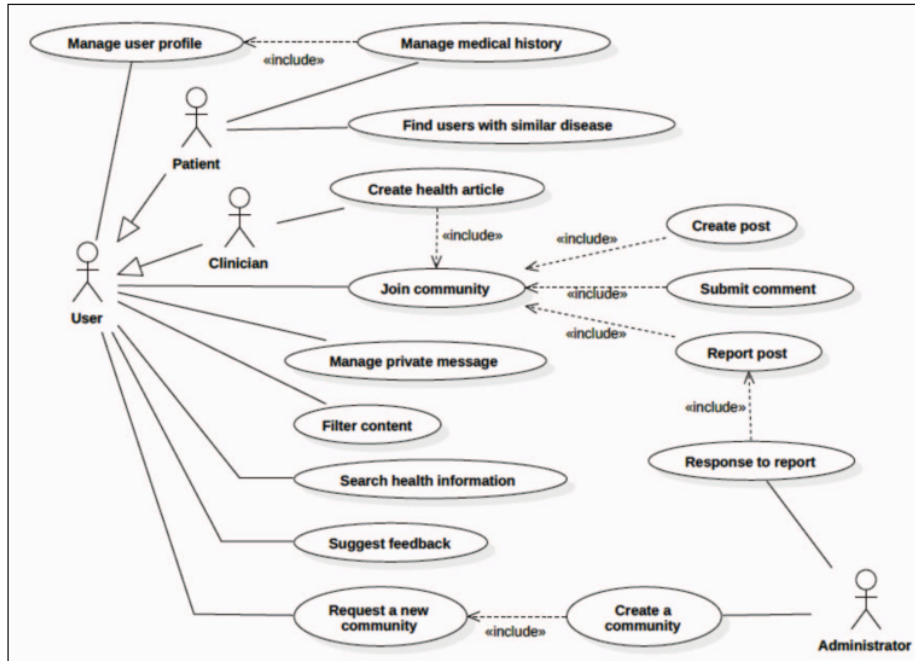


Fig. 1. Use Case Diagram

3. Finding a specific health information,

The next requirement for the proposed system is related to finding relevant health information, i.e., health information search based on user keywords, and content filtering feature. The system provides content filtering based on the interview result with two patients in the requirement elicitation. The filtering system enables personalization based on user needs. User can arrange the displayed content based on selected community and/or post category.

4. Suggesting advice/feedback/recommendation for system improvement,

This purpose of this requirement is to maintain the reliability and the operability of the social network system. The suggested features consist of creating a new community page and suggesting feedback for system improvement.

B. Use Case Model

The use case model for e-patient social network system composed of three actors and twelve use cases as depicted in Fig. 1. The actors represented the system users, i.e., administrator, patient, and medical professional (clinician). The use cases were constructed based on the functional requirements and features as shown in Table 1. The use case model produced 15 use case scenarios.

TABLE I. FUNCTIONAL REQUIREMENT AND FEATURE

No.	Functional Requirement	Feature	
FR-1	Finding other users who have similar medical profile	FR-1-1	Manage user profile
		FR-1-2	Manage medical history
		FR-1-3	Join health communities
		FR-1-4	Find users based on medical profile
		FR-1-5	Send and response private message(s) to other users
FR-2	Participating in a health community	FR-2-1	Create post(s) in a community page
		FR-2-2	Submit comment(s) to a post in a community page
		FR-2-3	Report post(s)
		FR-2-4	Response to user report
		FR-2-5	Create health/medical article(s)
FR-3	Finding a specific health information	FR-3-1	Search health information based on user keywords
		FR-3-2	Filter content based on user preferences
FR-4	Suggesting feedback for system improvement	FR-4-1	Request to create a new health community
		FR-4-2	Suggest feedback for system improvement

C. Data Model

We designed the data model based on the functional requirements using conceptual data modeling. The next step was converting the conceptual data model to physical data model and generating SQL script from physical data model. The data model consisted of non-transactional data and transactional data. The non-transactional data included medical profile, health interest, specialist, and community. The community table listed five prevalent chronic diseases in Indonesia as the initial data, i.e., cardiovascular, stroke, respiratory, cancer, and diabetes. The medical profile and health interest tables listed disease names published by Konsil Kedokteran Indonesia (KKI) in 2012. The specialist table recorded acknowledged specialist categories in Indonesia. The transactional data included post, comment, report, feedback, and user log.

D. System Construction: Pasienesia

The construction of the proposed e-patient social network, Pasienesia, comprised of mobile-based client application development, web service development, and database construction. Fig. 2. illustrates Pasienesia system architecture.

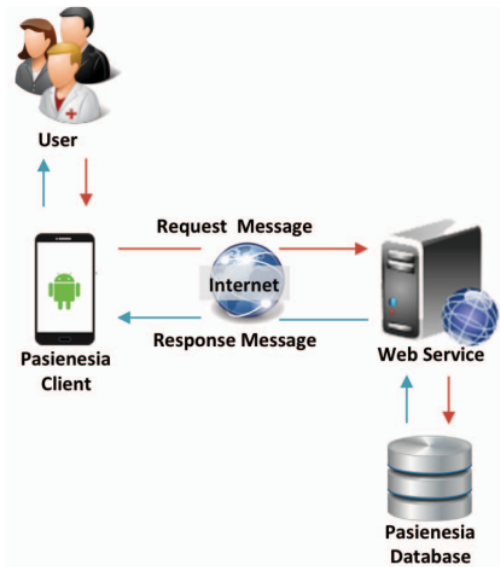


Fig. 2 Pasienesia System Architecture

We developed the web service using Lumen framework [14]. The web service connected mobile-based client (Android application) and Pasienesia database in MySQL. The bridge connection was required because Android-based client could not communicate directly with MySQL. The connection between client and web service was built using library Retrofit 2 [15]. Retrofit performed HTTP Request by translating the API into Java interfaces. This feature enabled data access and manipulation between client and database via web service.

We developed the mobile-based client as an Android application to support accessibility and mobility. Recent survey in 2016 reported that mobile devices accounted for 51.3% of Internet usage worldwide [16] and Android apps generated more than 80.7% of mobile data traffic in 4Q 2016 [17]. Android-based client development composed of initiating Retrofit to the application project and constructing the program code for each feature in the use case model.

The feature implementation included main user menu, join health communities, submit comment(s) to a post in a community page, and find other users who have similar disease as shown in Fig. 3, Fig. 4, Fig. 5, and Fig. 6 respectively.

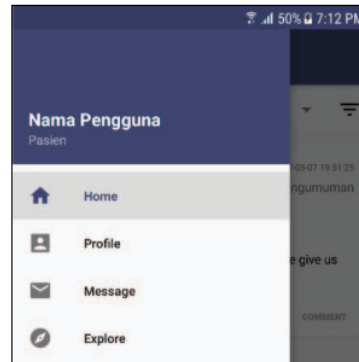


Fig. 3. Main Menu Interface

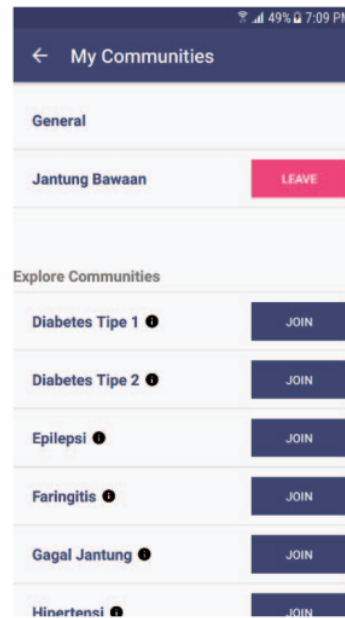


Fig. 4. Join Health Communities Interface

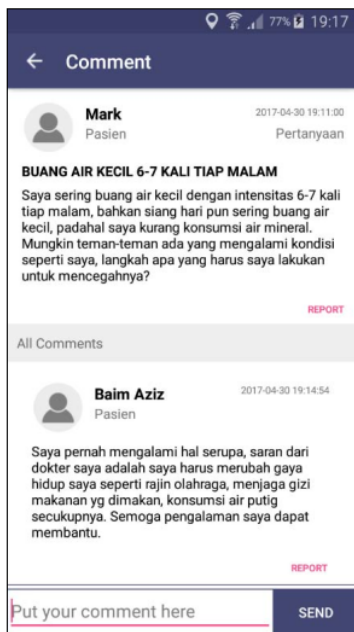


Fig. 5. Submit a Comment to a Post Interface

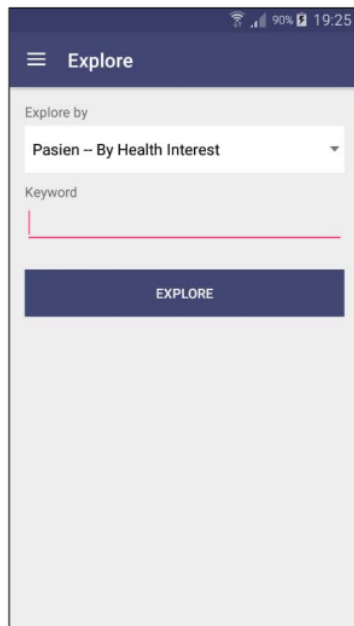


Fig. 6. Find other users who have similar disease

E. System Evaluation

We conducted functional testing and user acceptance testing to evaluate the correctness and the completeness of the requirements implementation and the system usability.

1. Functional testing,

The first evaluation examined the functionality of the system based on the specifications using equivalence partitioning method. We partitioned the test cases based on the use case model. We tested one condition from each test case. The functional testing showed that all test cases were passed, thus all specifications had been implemented in the developed system.

2. User acceptance testing,

User acceptance testing validated the system functional compliance with the user requirements. The testers incorporated all participants in the requirement elicitation, i.e., three consumers, four patients with chronic disease, and a clinician (cardiologist). The clinician tester assessed 100% for functional correctness and completeness and 100% for usability. Equivalently, patient and consumer testers also rated the system as having 100% functional correctness and completion. All features, i.e., manage user profile, manage medical history, find users with similar diseases, create health article, join community, manage private message, filter content, search health information, suggest feedback, create health community, and request health community, operated properly. For the usability testing, all participants agreed that the developed system had implemented basic usability guideline for mobile applications.

IV. DISCUSSION

This paper proposes Pasienesia, a mobile-based e-patient social network system. The system requirements come from the target users, i.e., the consumers and patients with chronic diseases, and clinician. We incorporate clinician (as the representative of medical professionals) to the e-patient system. The presence of medical professional is required to ensure the trustworthiness and accuracy of health information being shared. Besides, medical professionals can use the system to educate the patient, to extend the social responsibility pertaining to health and medical issues, and to gain new perceptions from other users. In the future, the e-patient system may serve as more promising health care resources. The responsibilities of health care are shared between patients and medical professionals. As stated in [7], a technology-based networked team management connecting patients, caregivers, and medical professionals is the future of health care innovation.

Based on the evaluation result, all participants acknowledge the system requirements formulation and the willingness of using the developed system. Although the result of the system development corresponds to the goal of this study, a more comprehensive evaluation is required. The next evaluation should involve larger participants from patients, consumers, clinician, and caregivers. The e-patient social network should be updated and improved regularly to accommodate the

progressive development of healthcare management in the future. We also obtained suggestions from the participants, such as increasing the number of system participants, providing notification feature, and adding activity dashboard page for each user.

V. CONCLUSION

This study addresses the future prospect of utilizing social media for e-patients as well as the solution to resolve the privacy, accuracy, and trustworthiness issues. The results of this study support two main contributions, i.e., the essential user requirements and the mobile-based e-patient social network system. Patients can use the system to find other patients who have similar diseases, by accessing patient exploration feature and joining available health communities, and to acquire reliable health information. The developed system also incorporates medical professionals to contribute to the e-patient system.

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