

YouApp – “It’s all about YOU”: Finding Patients Like Myself on Facebook

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Abstract. This paper introduces YouApp, a community-building platform integrated into Facebook. It addresses patients with inflammatory bowel disease (IBD; including Crohn’s disease and ulcerative colitis) and their primary caregivers by connecting them on Facebook. YouApp does this in two ways: It shows the user - patient or caregiver - how they fit in, by displaying their social network and how they are embedded in it. Second, it allows users to find and make new friends on Facebook who share similar interests and concerns.

Introduction

The emergence of online social networking is creating unparalleled opportunities to fulfill the basic human needs of connecting to other human beings. Social networking platforms like Facebook and LinkedIn are experiencing unparalleled growth. There is little research about the role of social media and social networking sites such as Facebook in providing support for patients suffering from chronic illness. In a joint project with Cincinnati Children’s Hospital, our team is working to assist in the creation of Collaborative Chronic Care Networks (C3N), communities of patients, families, clinicians, and researchers with the shared purpose of improving the health of IBD patients. It is estimated that more than a million Americans suffer from IBD with that number evenly split between Crohn’s disease and ulcerative colitis. Approximately 30,000 new cases are diagnosed each year. Compared to the US population, it means that 1 of 200 persons suffers from IBD. The incidence of IBD has been steadily growing in the developed world since 1950. According to the "hygiene hypothesis" it is suggested that the lack of exposure to intestinal parasites such as helminthes contributes to the sensitivity to Crohn’s disease.

In earlier work we studied Facebook groups of patients of inflammatory bowel disease (IBD), automatically collecting their profiles and friendship networks, complementing this automatically culled data with netnographic analysis (Kozinets 2002). We identified Facebook groups whose goal it is to improve the lives of Crohn’s patients, or even to find a cure. In a longitudinal analysis we compared the social network metrics of facebook groups on Crohn’s and IBD, The initial social network analysis was performed using the Top 5 IBD Groups on Facebook in the timeframe of 07/2006 – 06/2010 and a total analyzed group network of around 30.000 members. In November 2010, we did an additional analysis of 2.500 members among the five biggest facebook groups on IBD/Crohn’s.

Our surprising finding was the low level of connectivity among the members of these fan pages on Facebook, even considering that we were only able to collect the links of people who made their friends public. There are only little star networks with very short average path length of three to four. When we manually checked a few of them, the person in the center was usually somebody affected with Crohn’s disease, and the people in the periphery where their friends. This does not mean that the people in the center don’t have bridge links through friend-of-friend connections. Rather, this means that the fans of the Crohn’s support pages don’t know each other.

The statistics reveal that 97.5% of our sample in November 2010 were only members of a single group. This result was quite surprising as one might assume that Crohn’s patients are reducing the risk of missed

information by joining multiple groups. Within each group, very few individuals engaged with other members. A few, highly active individuals, not necessarily the administrators, dominated discussion posts. The analysis clearly indicates that interconnectivity within IBD-related groups is very weak. To remedy this situation, we therefore decided to build a “matchmaking” Facebook application to connect IBD patients and their primary caregivers on Facebook, which we call “YouApp”.

Community Survey

To better understand the needs of the users for YouApp, we conducted surveys in the Crohn’s and IBD online communities. The YouApp survey link was posted to several IBD-related Facebook groups’ wall pages, and was also sent directly to a few individuals known to have Crohn’s or ulcerative colitis within the researchers’ personal networks. Over the course of two weeks, 57 responses were collected and analyzed.

Nearly 40% of respondents were between the ages 19-25 and 75% were female. When asked the length of time participants have been diagnosed with IBD, 35% indicated they had been diagnosed for 5-10 years, while 30% said they have been diagnosed for 10+ years. The results indicate that 82% of participants consult their personal physicians for information regarding new treatments, while 67% use websites, 33% seek advice via Facebook, 30% refer to online forums, and 26% use face-to-face support groups.

The most striking finding indicates that 46% of respondents do not currently use any resource to monitor their illness, but would like to. Responses indicate that 95% of respondents would be willing to share symptoms with other IBD patients, 84% social situation advice, 82% treatment options, and 63% would share physician recommendations. Other responses reveal that almost 50% of respondents feel it is highly important to connect with other IBD patients. Additionally, 84% of respondents selected Facebook as the primary method for connecting with other IBD patients, yet 61% of respondents who are members of IBD-related Facebook groups answered 5 or below when asked “on a scale of 1-10, how active is your participation?” Finally, 81% of respondents indicated they would be interested in Facebook friend recommendations of individuals with similar IBD-related experiences.

A supplemental open-ended question was added to generate a possible list of features potential users of the YouApp would like to see incorporated. Respondents selected symptoms, live weekly chats, live chats with physicians, experience diaries, discussion boards, storytelling platforms, event organization tools, a research center for up-to-date therapies and treatments, diet advice, etc.. Connecting with other patients is very important to survey respondents. It is important to note that this is a selective sample as it was found via Facebook and individual personal networks.

Based on this survey, we concluded that symptoms, treatment options and social situation advice are the key content that patients are looking for. Facebook is what most patients currently use to connect. Most patients however are not currently very active in their respective IBD-related Facebook groups. The biggest incentive for Crohn’s and IBD patients to join IBD-related Facebook groups seems to find like-minded individuals, share ways to cope with the disease, and ultimately to find a cure. Therefore, YouApp is constructed as a tool for belonging and matching, similar to an online dating platform, which matches members dependent on their profile and interests.

YouApp has the potential to give an added community value and community experience. It provides a virtual space for everyday discussions and interactions to occur between Facebook members with similar IBD-related experiences, based on a matching algorithm. Research found that individuals with long-term chronic illness were able to talk about their illness more readily with colleagues than with family members, and that family members prescribed more negative influences on the patient than friends. Additionally, social networks where both friends and family were present fared best in terms of psychological health.

Learnings from Google Health and Goals of YouApp

June 24, 2011 Google announced¹ the abolition of its Health records system Google Health. The prevailing wisdom seems to be that Google Health failed for two main reasons. (1) It was not social and (2) it did not connect with clinical electronic health records (EHRs).

As noted in several online blogs, Google failed to create a personal health record (PHR) experience that allowed users to socialize. Sharing raw and anonymous health information was not enough to attract users to the platform. Besides, simplicity in the data generation is of key importance and should be as automatic as possible. As Google Health demonstrated, it is likely that users are deterred by the burden of data entry. In fact, the platform largely demanded manual data entry².

PHRs and personal health applications (PHAs) that serve as stand-alone data repositories might never succeed. They have to leverage previous user input to provide benefits to the users from the beginning and enable automated data collection. Thus, the industry-wide consensus seems to be that PHRs and PHAs should be set up as extensions of EHRs, as they provide a secure place to store data and offer a wide range of data input.

Thus, a central challenge for applications like the YouApp is to be part of a system that can integrate both clinical (EHR) and personal health information (PHR) in meaningful ways. The goal should be an electronic application (PHA) through which individuals can access and share their health information as well as connect to others, in a private, secure, and confidential environment. The C3N IT platform aims to connect the ICN EHRs with PHRs in a confidential online environment. Thus, the YouApp offers the potential to boost the social component of the platform by providing the algorithms for patients to find others like them.

While the goal of the application from a user perspective is to increase connectivity and “we-feeling” among IBD patients on Facebook, the research goals of YouApp are twofold: The first goal is to better understand the social networking structure and behavior of communities of patients of chronic diseases as measured in terms of social network analysis such as centrality metrics of individuals and Crohn’s Facebook group networks. The second research goal is to increase the demographic understanding of the sub-community of Crohn’s patients active on Facebook, by analyzing the Facebook walls of the groups and their aggregated “likes” and “interests”. YouApp therefore combines three goals: “connect”, “community”, and “collect”. Towards the first goal, “connect”, YouApp provides a system for linking the disparate members of the dozens of Crohn’s and IBD related Facebook communities. At last count, these members numbered over 100,000 with the largest communities having well over 10,000 members. According to our analysis, however, these community members are individually isolated. This is where YouApp comes in, suggesting to Facebook users new friends based on their profile, preferences, and membership in existing Crohn’s communities. To address the second goal, “community”, YouApp actively engages users in a dialogue, nurturing their participation by providing a quiz-like user interface where users can specify new questions, capturing what matters for them, and answering questions that others have entered before. Towards the third goal, “collect”, YouApp enables researchers to collect lifestyle related patient data from the Facebook communities. This will permit researchers to get aggregated patient data on a large scale. It will also allow patients to compare their own lifestyle related health data with the anonymized aggregated data of the entire patient community.

System Description

YouApp is implemented in Java as a Java EE (Enterprise Edition) application. Its architecture can be divided roughly into three layers: the Client tier, the Middle tier, and the Database tier. The client tier is responsible for the client-side presentation. It includes the HTML and Javascript code, which is displayed or executed inside the client’s browser. The YouApp relies on technologies such as HTML, CSS and Javascript. The middle tier contains the business code and the code that is necessary for rendering HTML. It can be divided into three parts: First the server-side presentation consisting of JSPs (JavaServer Pages) and Java Servlets, representing the view templates that are dynamically filled with the YouApp’s content.

¹ http://news.cnet.com/8301-27083_3-20074134-247/google-euthanizes-google-health-unplugs-powermeter/

² See http://projecthealthdesign.typepad.com/project_health_design/2011/08/in-the-wake-of-google-health.html

Second the server-side business logic, which directs the processing of the user input as well as the retrieval, computation and storing of information. Third the server-side data access layer, which retrieves and stores the data, therefore being responsible for the initialization of transactions and the communication with the database. The middle tier heavily relies on the Spring framework (<http://www.springsource.org/>) and runs inside a Tomcat servlet container (Brittain 2003).

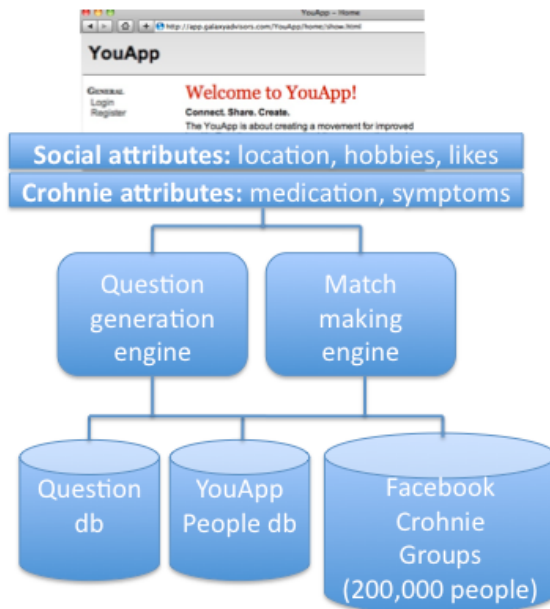


Figure 1. System Architecture of YouApp

The database tier is the place where the actual data is stored. For the YouApp, a MySQL database is used. The database stores the user and application data. The user data includes information about the user which can either be public and therefore visible to other users (i.e. job description, location, medication etc.) or private which means it's primarily used for the computation of new friend matches (i.e. friendships and connections to other users, certain likes or answers to questions etc.). The user data is mainly retrieved from Facebook but can be extended with IBD-specific data like medication or symptoms. In addition the YouApp maintains a pool of questions, which can be answered by users. The replies to these questions contribute to the matching algorithm and therefore partially determine the matching algorithm's output. In addition there are tables that temporarily store the output of the matching algorithm and track which friendship propositions have been made. Also the database has to save data for forms like countries, states, cities or languages.

In order to retrieve user data from Facebook, users have to establish their identity with their Facebook credentials. The Facebook Platform uses the OAuth 2.0 protocol (ietf 2010) for authentication and authorization. When using YouApp for the first time, the user gets prompted for the authorization of the application. After this step, the YouApp has access to the user's data.

The Facebook data is used in several situations. Upon registration parts of the registration form are prefilled with available user information. In order to prevent proposing already existing Facebook-friendships, a user's friendship connections are stored, too. Likes and certain interests in groups or pages (music, books, movies etc.) are stored as well because this data describes a user's interests and is therefore an important source of information for the matching algorithm. In case that a friendship between two YouApp users is created, this information has to be forwarded to the Facebook API. This is the only situation where the YouApp leads to the creation of new information inside Facebook. For the communication with Facebook, the Java library called "RestFB" (restfb.com/) is used.

User Interface

A new YouApp user first creates a new YouApp profile. For this purpose, the YouApp asks the user to log in via Facebook. After the user has provided his/her Facebook credentials, the YouApp displays a registration form, which has to be filled out by the user (figure 2). Thanks to the Facebook user data retrieved after the authentication, the registration form is prefilled with the basic user data. If the user enters invalid input data, the YouApp asks him/her to correct the mistakes. After the user has submitted all the necessary information, the YouApp displays the user's profile information. Users can always see their profile under the menu item "My Profile".

The screenshot shows the 'YouApp' registration interface. On the left, a navigation menu includes 'GENERAL', 'Login', and 'Register'. The main content area is titled 'Registration' and contains the following fields:

- General Information:**
 - First name: Jane
 - Last name: Doe
 - Nick name: [empty]
 - Gender: Male, Female
 - Birthday: 1986/10/14 (format: yyyy/mm/dd)
- Location:**
 - Country: Switzerland
 - State: Aargau
 - City: Baden
- Symptoms:**
 - Dropdown 1: -- Please Select (open menu shows: Nausea, Vomiting, Pain, Diarrhea, Partial / Complete Obstructions, Fecal Occult Blood, Other, 6-MP / Imuran)
 - Dropdown 2: -- Please Select
 - Buttons: Add, Clear All

A 'Submit' button is located at the bottom of the form.

Figure 2. User interface for registering new users and their attributes

Homophily – Finding “People Like Yourself”

A key component for gaining a demographic understanding of the “Crohnies” on Facebook is a gamedating-like match-making Facebook Application, which permits users to define questions and answers for a quiz to be taken by Facebook friends with whom they would like to connect. Assume a user defines a question “What do you like better, chocolate or cheese?” with possible answers “cheese”, “chocolate”, “none,” or “both”. Let’s say the user likes cheese better. By applying a match-making algorithm to the answers given by other users, the original user will be able to find other cheese lovers. By aggregating the different answers of many users to this question, the researcher will then know (a) that the distinction between cheese and chocolate matters for Crohn’s patients, and (b) whether the majority of Crohn’s patients likes cheese or chocolate better.

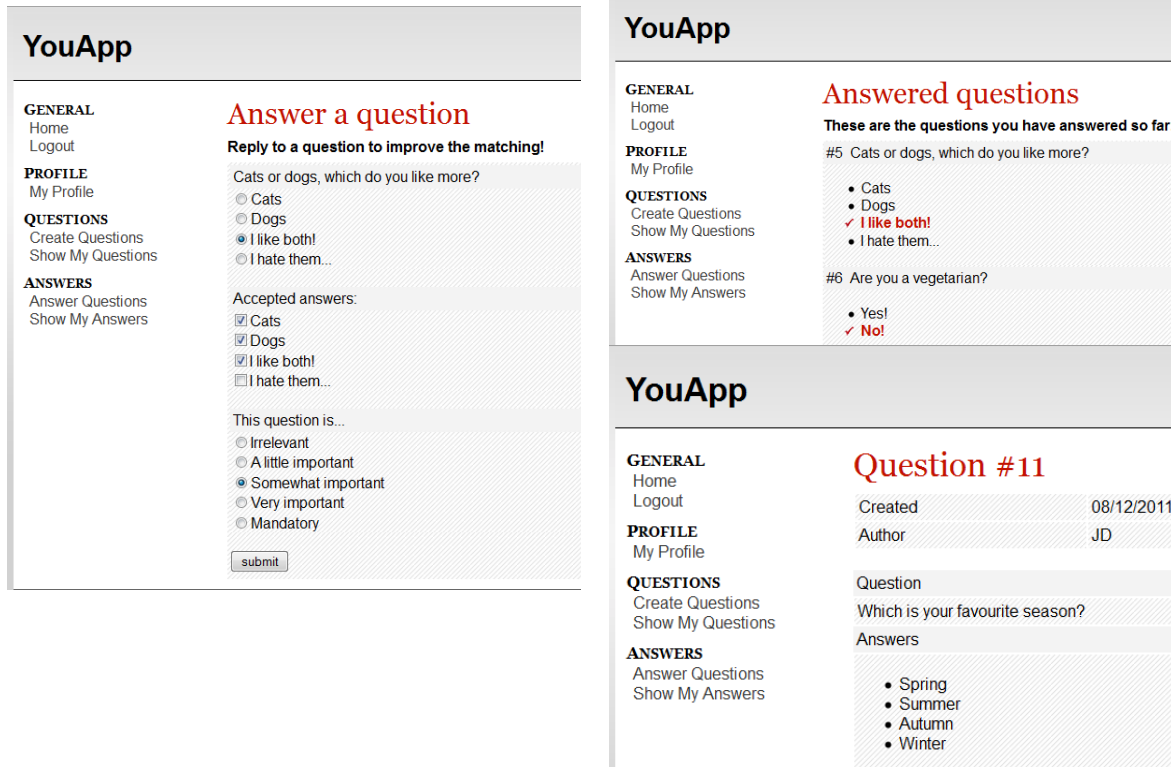


Figure 3. User interface for answering, and creating new matchmaking questions

The YouApp currently allows users to create their own questions under “Create Questions” (figure 3.). These questions can then be answered by the creator or by other users. Based on the replies to these questions, the matching algorithm calculates the matching between the YouApp users. Users can always look at their created questions by selecting the menu item “Show My Questions”. By clicking on “Answer Questions” the YouApp suggests the user a question to be answered. Currently, the YouApp simply shows a user the next not yet answered question available from the database.

Outlook

For the future, many additional features are planned. For example, besides the basic user data, a user’s friendship connections should be stored too. This is necessary to avoid duplicate friendship recommendations. Furthermore, a user’s likes, groups and pages should be stored because they represent a user’s interests and can therefore be useful for the matching algorithm. It should also be possible to add more data to a user profile like job description, sign, languages, education, religion, pets etc. The friendship network will also be shown as a social network map.

It should also be made certain that only non-redundant matchmaking question will be added to the questions database. Before creating a new question to the database, the question is compared with all the existing questions. If there is a similar question, the user has to confirm the creation. This process should avoid duplicate questions. We also anticipate need for community-appointed administrators to check on the appropriateness of the questions.

A sophisticated matching algorithm, which can generate new friendship recommendations based on a user’s interests and characteristics should be implemented. As soon as the matching algorithm is working, friendship recommendation should be displayed. A more powerful search should allow user to search for friends based on certain criteria like distance, interests or matching percentage.

We envision building a multifunctional testbed to further evaluate the usefulness of online social networking for patients of chronic diseases. While this pilot focuses on Crohn's disease-related communities, we anticipate easy transfer and scalability of the same concepts and software to any other chronic disease-related online communities.

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