THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

Web-based Information Management System for Prostate Cancer Education and Resources for Couples (PERC)

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Abstract

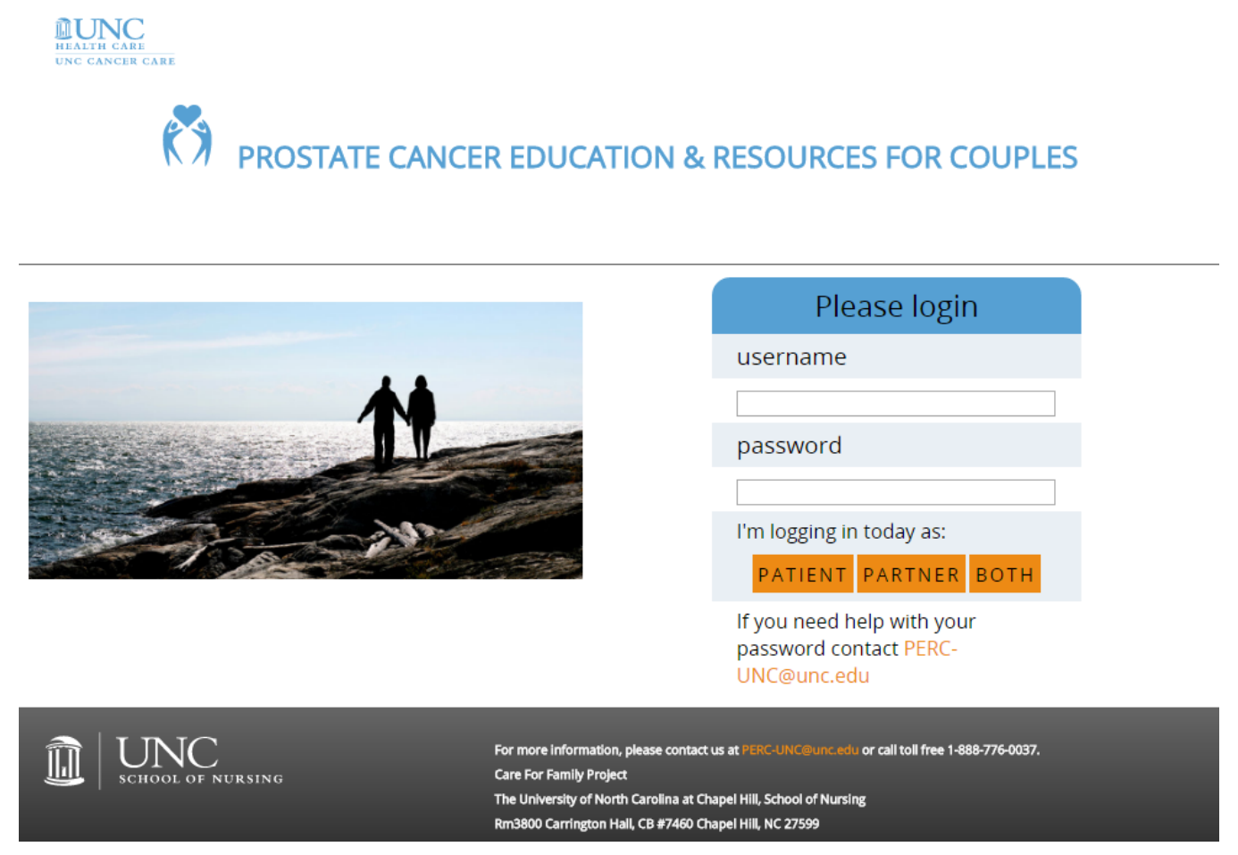
Prostate Cancer Education and Resources for Couples (PERC) is a couple-centered web-based symptom management program. It was developed by nurses, physicians, a psychologist, a media specialist, web designers, and programmers from UNC School of nursing and UNC cancer care. The research involves patient recruitment, target identification, questionnaires, intervention, project management and data analysis. The aim of the project is to develop a supporting web-based information management system to track progresses of the research study, collecting information and processing data for analysis. With the implementation of open source packages, a web-based information management system was designed and coded. By using this platform, researchers successfully collected all the necessary information and used them for their pilot studies.

Introduction

According to the data from CDC, by the year of 2012, there were 20.1 million noninstitutionalized adults (8.5%) who had been diagnosed with different types of cancers in the United States. Therefore, there are huge demands for cancer information from patients, their families and friends, clinicians, policy makers and the whole society. Web is an important source for cancer information. Patients seeking information through web tend to have more knowledge about cancer treatment, survival rates and better cope with cancer.

PERC, Prostate Cancer Education & Resources for Couples, is a couple-focused, mHealth tailored symptom self management program. It is an internet-based intervention and guided by an adapted Stress and Coping theoretical framework. The website includes 10 educational modules, forum, other resources and a tool box. It contains a patient portal and a partner portal, and integrates healthy behaviors into couple-focused, tailored mHealth intervention, as well as different social support from various sources.

The pilot studies collected the information on website usage and survey results for analysis. To facilitate the data collection and analysis, an information management system was developed to support the process.



If you need help with your password contact PERC-UNC@unc.edu

For more information, please contact us at PERC-UNC@unc.edu or call toll free 1-888-776-0037.
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Figure 1. Web portal of PERC program

Learning Objectives

1. Applying the knowledge on database, web programming and data management to the project.
2. Developing research and technical skills with clinical related data and following privacy policies.
3. Developing communication skills and coordinating with clinicians, IT personals and statisticians.

Methods

The project contains two parts, patient information management and survey management. The development process includes user needs analysis, timeline and technical stack design, local development and migration to webserver for usage. Additional modifications and updates were performed according to the feedback from users.

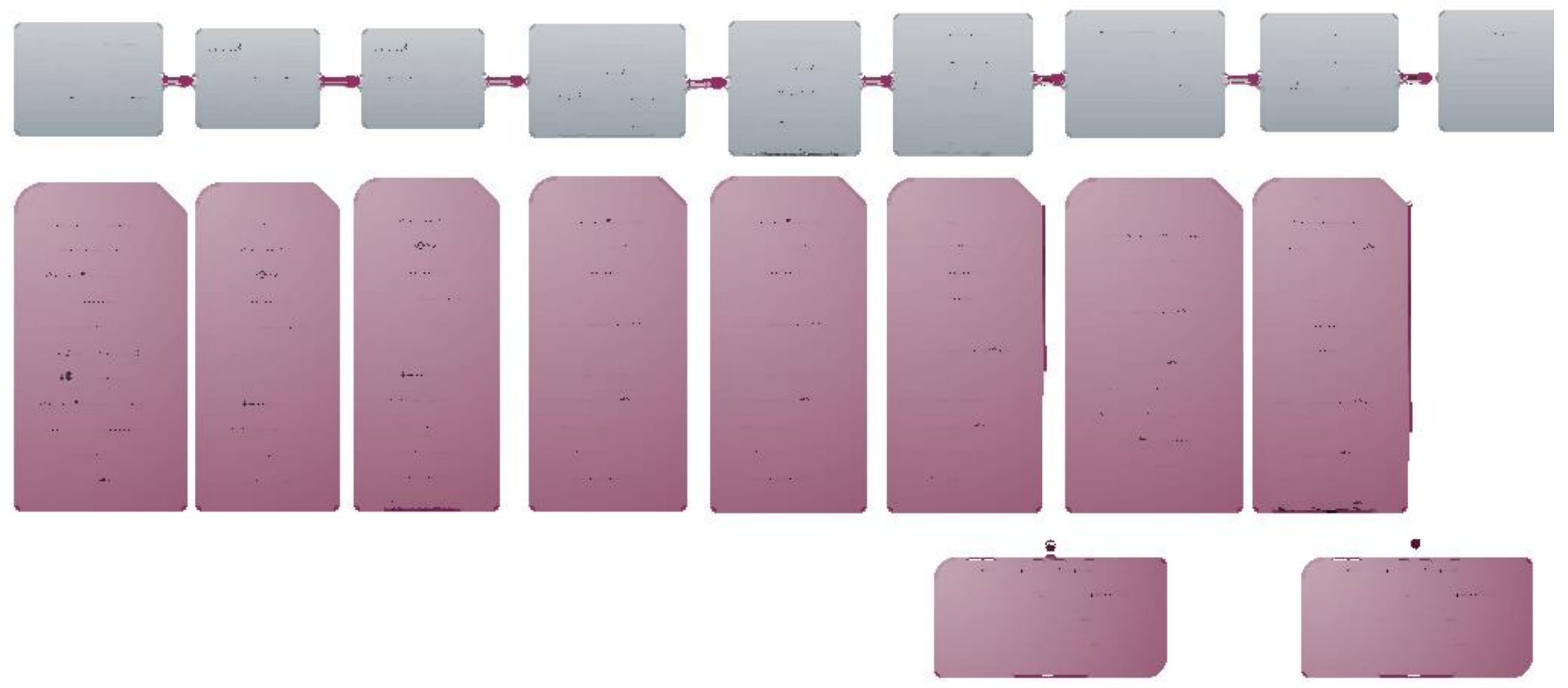


Figure 2. User needs for study process

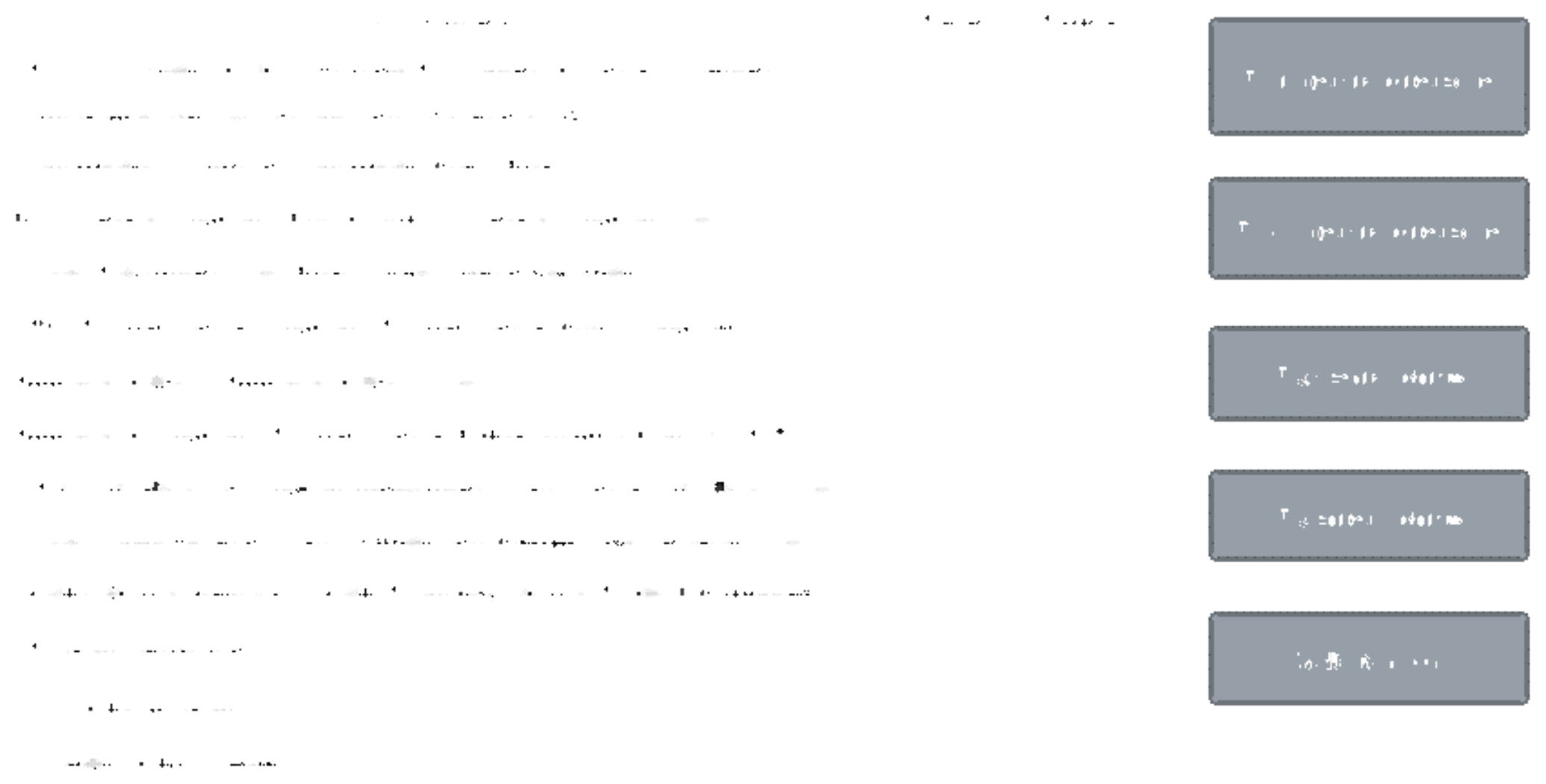


Figure 3. User Needs for Survey development

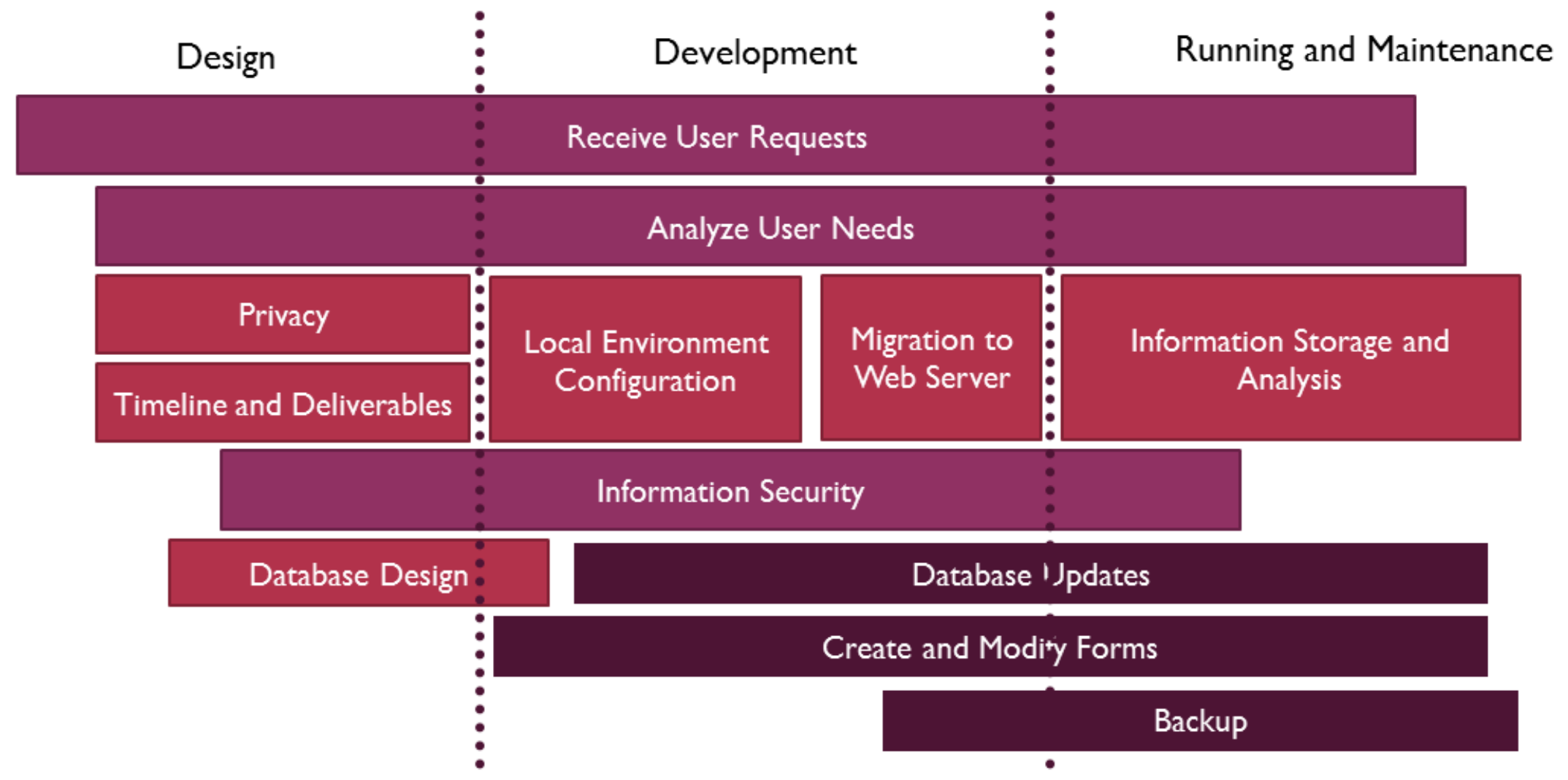
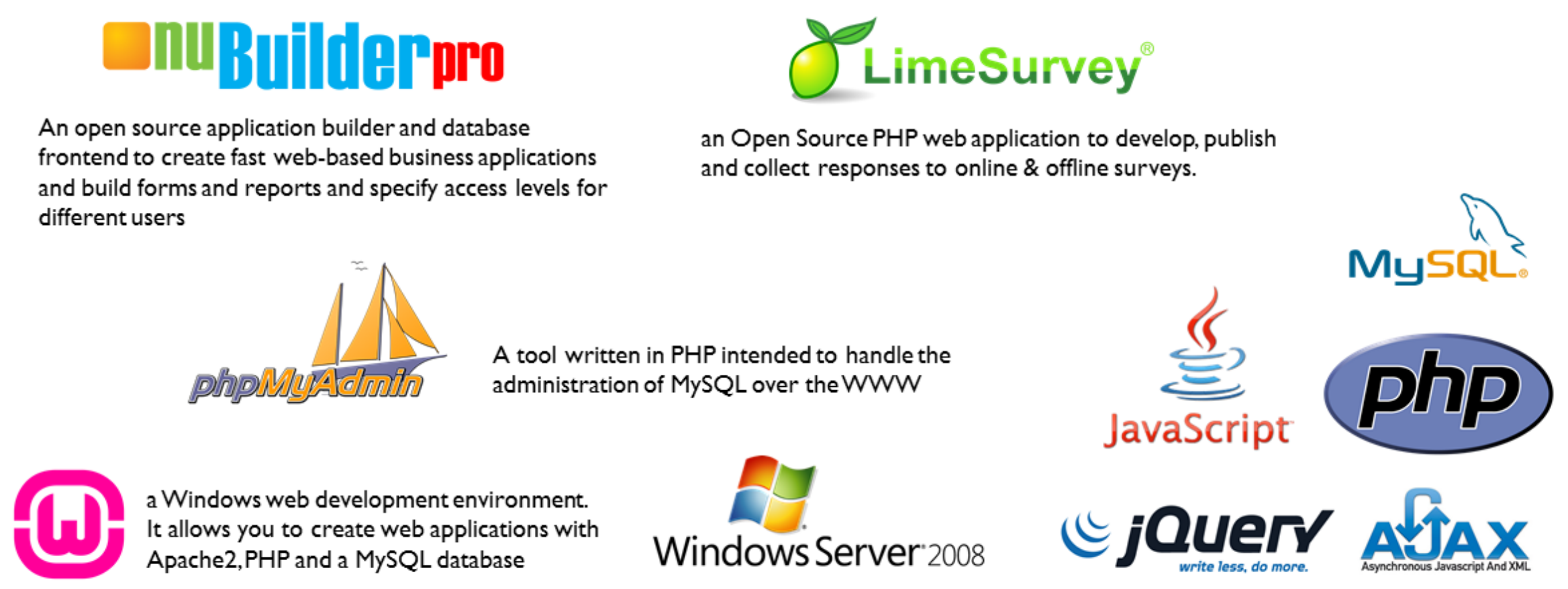


Figure 4. Timeline and sub-tasks



An open source application builder and database frontend to create fast web-based business applications and build forms and reports and specify access levels for different users

an Open Source PHP web application to develop, publish and collect responses to online & offline surveys.

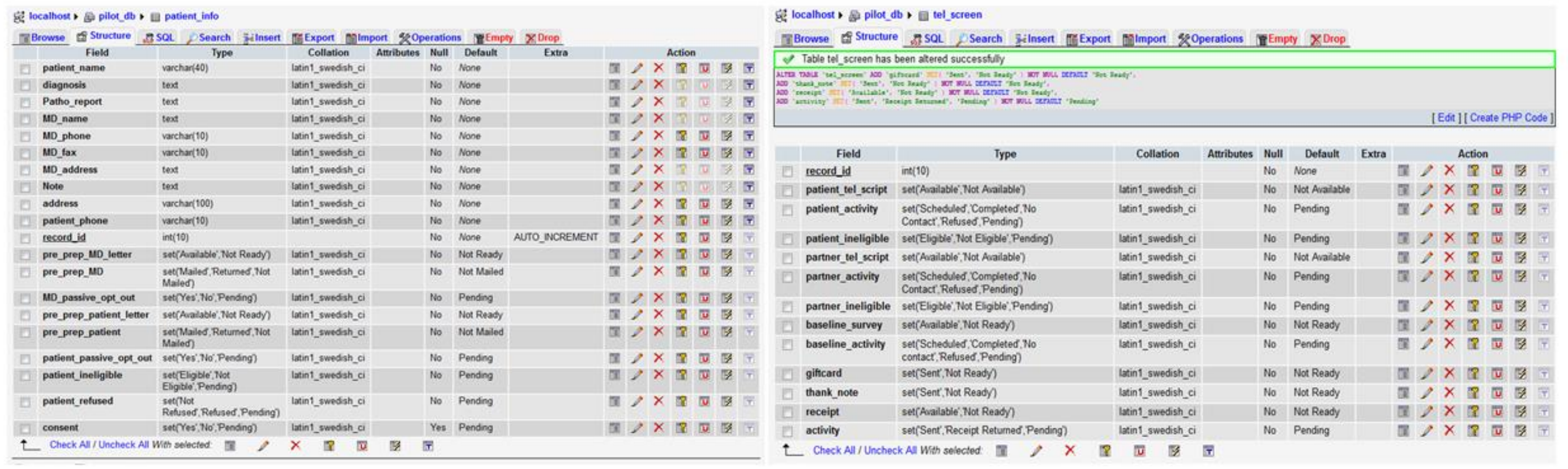
A tool written in PHP intended to handle the administration of MySQL over the WWW

a Windows web development environment. It allows you to create web applications with Apache2, PHP and a MySQL database

Figure 5. Implementations and technical stacks for development

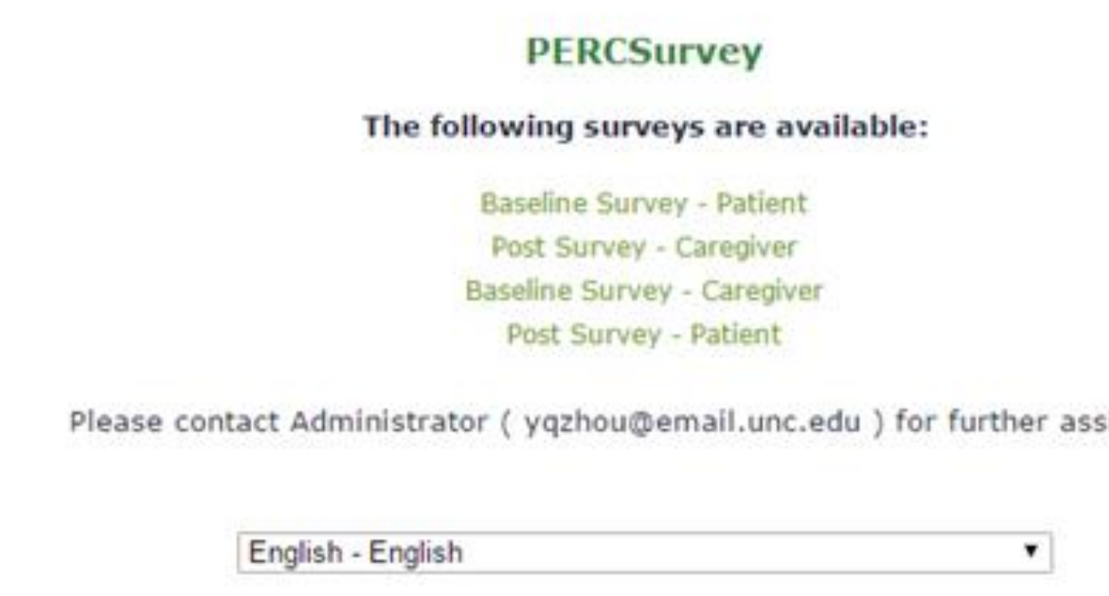
Results

An open source based information and survey management system was developed with user-friendly interfaces. Different user groups have different privileges to create forms, modify databases, backup data or create/modify entries and perform analysis. The system was successfully implemented on a windows server, collected necessary data for research studies.



View from phpMyAdmin Before phone screening After phone screening

Figure 6. Snapshot of Database - backend



PERCSurvey

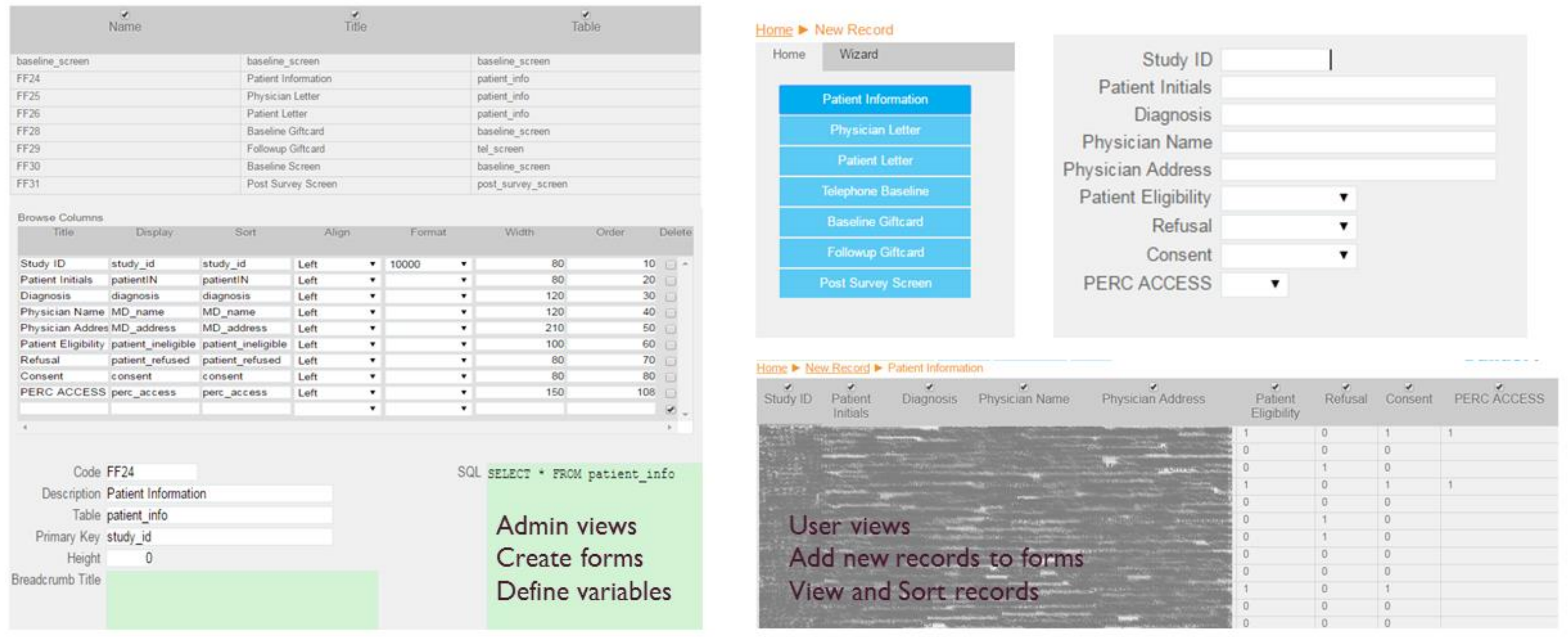
The following surveys are available:

Baseline Survey - Patient
Post Survey - Caregiver
Baseline Survey - Caregiver
Post Survey - Patient

Please contact Administrator (yqzhou@email.unc.edu) for further assistance.

English - English

Figure 8. Web portal of surveys



Name	Title	Table
baseline_screen	baseline_screen	baseline_screen
FF24	Patient Information	patient_info
FF25	Physician Letter	patient_info
FF26	Patient Letter	patient_info
FF28	Baseline Giftcard	baseline_screen
FF29	Followup Giftcard	tel_screen
FF30	Baseline Screen	baseline_screen
FF31	Post Survey Screen	post_survey_screen

Browse Columns

Title	Display	Sort	Align	Format	Width	Order	Delete
Study ID	study_id	study_id	Left	10000	80	10	
Patient Initials	patientIN	patientIN	Left		80	20	
Diagnosis	diagnosis	diagnosis	Left		120	30	
Physician Name	MD_name	MD_name	Left		120	40	
Physician Addres	MD_address	MD_address	Left		210	50	
Patient Eligibility	patient_ineligible	patient_ineligible	Left		100	60	
Refusal	patient_refused	patient_refused	Left		80	70	
Consent	consent	consent	Left		80	80	
PERC ACCESS	perc_access	perc_access	Left		150	108	

Code FF24
Description Patient Information
Table patient_info
Primary Key study_id
Height 0
Breadcrumb Title

SQL `SELECT * FROM patient_info`

Home ▶ New Record

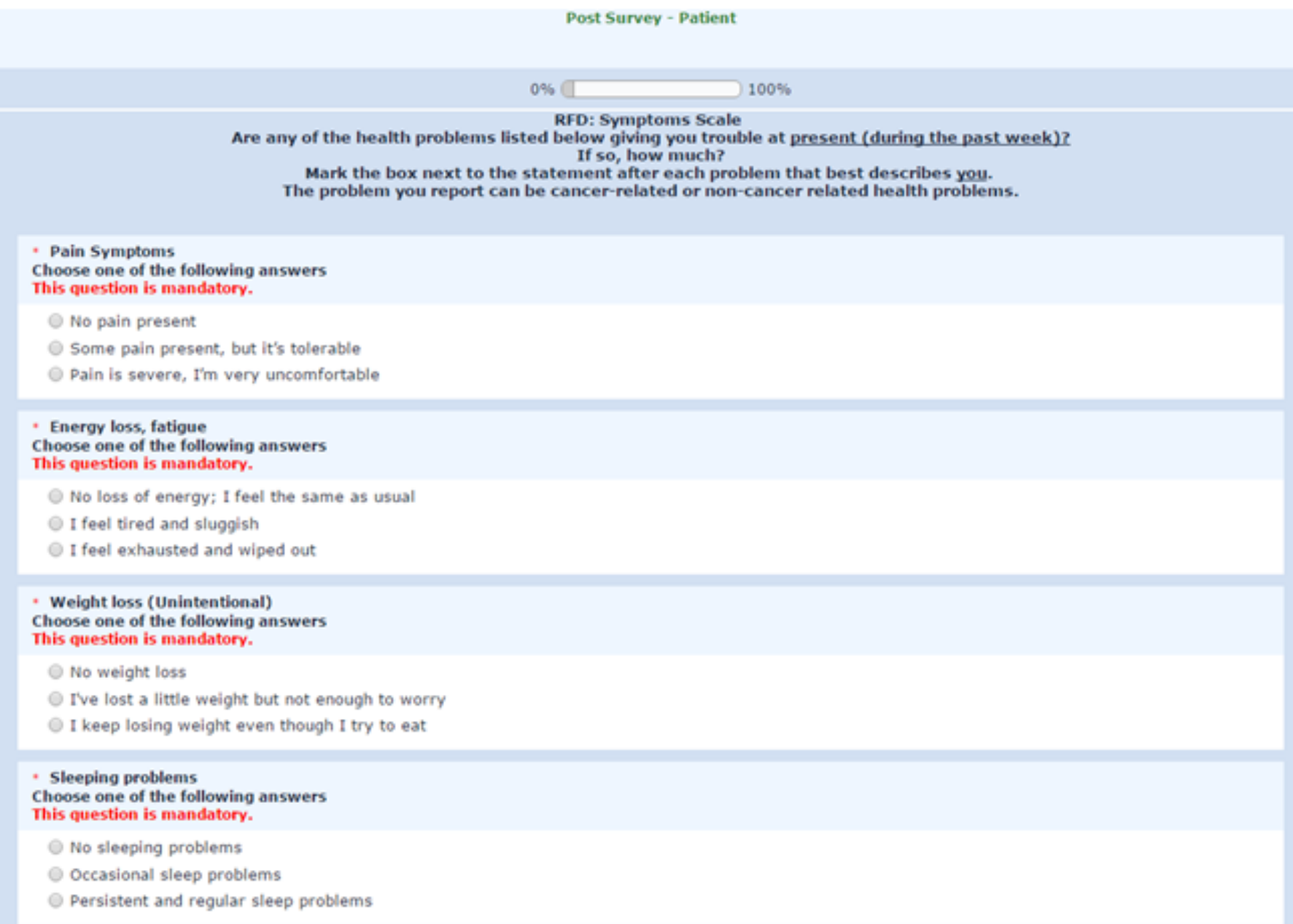
Home Wizard

Patient Information
Physician Letter
Patient Letter
Telephone Baseline
Baseline Giftcard
Followup Giftcard
Post Survey Screen

Study ID
Patient Initials
Diagnosis
Physician Name
Physician Address
Patient Eligibility
Refusal
Consent
PERC ACCESS

Home ▶ New Record ▶ Patient Information

Figure 7. Forms and variables, administrator's view (L), User's view (R)



Post Survey - Patient

0% 100%

RFD: Symptoms Scale
Are any of the health problems listed below giving you trouble at present (during the past week)?
If so, how much?
Mark the box next to the statement after each problem that best describes you.
The problem you report can be cancer-related or non-cancer related health problems.

* Pain Symptoms
Choose one of the following answers
This question is mandatory.
○ No pain present
○ Some pain present, but it's tolerable
○ Pain is severe, I'm very uncomfortable

* Energy loss, fatigue
Choose one of the following answers
This question is mandatory.
○ No loss of energy; I feel the same as usual
○ I feel tired and sluggish
○ I feel exhausted and wiped out

* Weight loss (Unintentional)
Choose one of the following answers
This question is mandatory.
○ No weight loss
○ I've lost a little weight but not enough to worry
○ I keep losing weight even though I try to eat

* Sleeping problems
Choose one of the following answers
This question is mandatory.
○ No sleeping problems
○ Occasional sleep problems
○ Persistent and regular sleep problems

Figure 9. Snapshot of a survey

Conclusion

The researchers conducted their pilot behavior studies with prostate patients and their partners regarding on the mHealth intervention by PERC program.

In summary, the pilot study lasted ~ 7 months in total. The initial patient screen lasted for 3 months. There were 266 patients initially after being referred. For surveys, the initial baseline survey received 23 complete and 3 partial responses from patients and 22 responses from caregivers. After the intervention, there were 13 responses from the patients and 12 responses from the caregivers. The information management systems had one administrator and more than 3 active users recording and tracking data through this system.

Future Directions

1. Increase accessibility

Currently the system is restricted to local accessibility (IP address specified) due to security restriction by using university's web server. In the large scale study, patients and partners should be able to access to the surveys for convenient data collection.

2. Allow scalability

The pilot study was small scale and the analysts manually input the patients' information to the system. However, it may be not very practical when involving a few thousands of patients. The system should be compatible with database import to accommodate large scale information.

3. The system needs to support advanced queries for analysis.

4. Set up automatic alerts. For example, the system is able to set up reminders during study process for information collection and survey completions.

5. Optimize the design and content of the system by users' requests.

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