Project HealthDesign – Phase II:  
Grantee Technical Architectures and Implementations  

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Introduction

Project HealthDesign is a national program sponsored by the Robert Wood Johnson Foundation designed to promote innovation in the realm of personal health technology. The project focuses on the use of personal health applications and personal health records to improve personal and medical decision-making about health conditions. Now in its second phase, the current group of Project HealthDesign grantee teams is examining how mobile health technology can be used to collect and integrate observations of daily living (ODLs) into personal health decision-making and the clinical workflow.

The projects and project teams participating in phase two of Project HealthDesign are:

- dwellSense – Carnegie Mellon University
- BreathEasy – RTI International and Virginia Commonwealth University
- iN Touch – San Francisco State University
- Crohnology.MD – University of California, Berkeley, Health Communities Foundation, and the University of California, San Francisco
- Estrellita – University of California, Irvine

The grantees are focusing their research on the collection, analysis, and display of a variety of ODL data using technology such as smartphones, in-home sensors, and other commercially available home health devices. A primary goal of all of the grantee projects is to enable patients to share collected information with their healthcare providers so that ODL data may be integrated with the clinical workflow.

Document Purpose

This document describes the technical architectures and implementations of each of the grantee teams. Specifically, this report describes the technologies used by patients to collect ODL data in the course of their daily lives, how the collected data are interpreted by the application, and how the application presents data for review by patients and healthcare providers. The report addresses how the teams met certain requirements of the Project HealthDesign grant, namely integration of ODL data with the clinical workflow, integration of ODL data with third-party data repository platforms (e.g., HealthVault), and mechanisms to prevent or mitigate data loss. Finally, the report presents a summative section that describes patterns and lessons learned across all five projects from their technical implementations.

Grantee Technical Architectures and Implementations

This section describes each of the grantees technical implementations and the architectures of their solutions. The technical implementation of each team is documented in its own subsection. For each grantee team, the report lists the ODLs collected by each project and presents an architectural diagram of their solutions, including the technologies used and the actors involved (please see appendix A for a key to the technical architecture diagrams). Additionally, for each team’s technical implementation, a narrative description of each project is presented, which describes the data collection, data processing,
and the data display solutions implemented. Finally, each team’s description concludes with a discussion of how the project promotes the integration of ODL data into the patient’s life and the clinical workflow.

Carnegie Mellon University – dwellSense
The dwellSense application, developed by Carnegie Mellon University (CMU), focuses on the collection of ODLs using in-home sensor technology from elderly patients who have various chronic conditions and who are at risk for cognitive decline. Data captured by the dwellSense application is intended to help health care providers monitor the patient’s level of cognitive and functional abilities over time. The project seeks to determine whether physicians and other care workers can use the ODL data provided by the application to detect any cognitive declines early enough to make the necessary interventions to prevent, or at least mitigate, further declines.

All data collected by the dwellSense application are collected passively via sensors installed throughout the patient’s apartment, including pillboxes, coffeemakers and telephones. Data are collected to assess when and how the patient interacts with these everyday items. Patients are not required to manually enter any ODL data as part of the project, a clear advantage given the target patient population.

The raw data collected by the sensors are uploaded to a server managed by the CMU project team. The server receives and analyzes the data and makes interpreted ODL data available for review by the patient and the patient’s physician via dashboard applications running on tablet computers.

Figure 1 - dwellSense Technical Architecture Diagram

Data Collection
Each patient involved in the study is offered a sensor-equipped pillbox, coffeemaker, and telephone. Patients are not required to use all three devices to participate in the study (e.g., the coffeemaker is used by approximately half of the subjects). The sensors integrated into these home devices were developed specifically by the CMU project team to collect ODL data automatically for the dwellSense application.

Each device has a number of different sensors to collect information about how exactly the patient interacts with the device. The pillbox sensor device (see Image 1 - left) is able to detect and report when each door is opened, closed, and when the pillbox is inverted. Additional sensors to track medication taking include a scale to track pill sorting and a faucet sensor to detect when the patient gets water to take the medication (not shown). The coffeemaker (see Image 1 - right) contains sensors which detect how much water is added, when the coffee filter is put in place, when the coffee pot put in place, and when the coffeemaker is turned on. To measure phone use, the phone is connected to a modem on a laptop which logs both incoming and outgoing calls. For incoming calls, the laptop detects and records the number of rings before the patient picks up the receiver. For outgoing calls, sensors in the handset detect when the phone is off the hook and the numbers the patient enters to dial a call. In addition to these three sensor-enabled devices, a motion detector is installed in the apartment. The motion sensor provides contextual information about the other recorded ODLs to help the dwellSense team determine when the patient is away from the home (and hence unable to provide ODL data). The CMU project team is currently evaluating whether the captured motion data can be used to help detect cognitive decline.

![Image 1 - dwellSense Pillbox and Coffee Sensor Devices](image1.jpg)

Raw sensor data are transmitted from each device over a Zigbee wireless network, a low-powered network protocol developed specifically for transmitting sensor data. A laptop in the patient’s apartment receives the wireless signal from the sensors and custom software installed on the laptop caches the sensor data until it can be uploaded to the CMU server. Raw data are sent from the laptop to
the CMU server in XML format over HTTPS. Laptops with broadband internet connections send batches of data to the CMU server every 15 minutes. Laptops without broadband data connections use internal modems installed on the laptop to connect to the CMU server over a phone line. ODL data are uploaded over landlines once each day.

The CMU team has implemented a number of policies and tools to prevent data loss during data collection. Battery life of sensors is a significant problem for this project. To prevent data loss due to dead sensor batteries, the CMU team replaces batteries in all sensors weekly. Another potential point of failure is the data collection software running on the laptop in the apartment; if the data collection software stops running for any reason, data cannot be collected from the sensors. To mitigate this problem, the CMU team has developed a “watchdog” service on the server that notifies a project team member if no data has been received from a patient in a 48 hour period. In this event, a project team member can visit the patient’s apartment to troubleshoot the data submission problem. Finally, if the data collection software on the laptop cannot connect to the CMU server, data will be cached on the laptop until a connection can be re-established at which point the collected data will be uploaded to the CMU server.

**Data Processing**

Batch sensor data are received by a web server at CMU which passes the data to a Java application server. The Java application server parses the data, saves the raw data to a MySQL database and processes the data into ODL data that can be interpreted by patients and providers. Raw sensor data for the dwellSense application are processed into derived ODL data (see Table 1 - dwellSense ODLs). This processed data can be stored and made available for display by the patient, physicians, and other caregivers.

**Table 1 - dwellSense ODLs**

<table>
<thead>
<tr>
<th>ODL</th>
<th>ODL Description/Details</th>
</tr>
</thead>
</table>
| **Medication Taking** | Medication administration “correctness”: Indicates whether the medication was taken; Whether the correct door was opened; ; and whether the pillbox inverted  
                  | Medication administration “timeliness”: When the medication was taken; Whether the medication was taken on-time; How long did the patient took to complete the task  |
| **Coffee Making**   | Coffee making “correctness”: Whether the patient completed all steps; Whether the steps were completed in the correct order  
                      | Coffee making “timeliness”: How long did the patient take to complete the task  |
| **Phone Use**        | Phone use “correctness”: Number of misdialed calls compared to the total number of calls  
                      | Social interaction: The number of phone calls placed and received  |

Derived ODL data provide information about how well or poorly a patient is performing tracked tasks. For the “Coffee Making” ODL, the raw data are processed from the coffeemaker sensors to determine
whether the patient performed the steps in the correct sequence, any steps were missed in the process, and how long the task took to complete. For the “Medication Taking” ODL, the server processes the data to determine whether the correct door was opened on the correct day, whether the patient performed all the expected steps, and the time taken to get the pills out of the pillbox. For the “Phone Use” ODL, the server processes the raw data to determine the number of placed and received calls, misdial attempts, and call durations.

**Data Display**
Processed ODL data are made available to the patient via a patient dashboard app running on an Android 2.3 Samsung Galaxy Tablet computer. The dashboard app presents a simplified view of the patient’s daily tasks to the patient with ODL information indicating how well the patient performed the tasks (see Image 2). Through this view, the patient can get near real-time feedback on how well they are performing everyday tasks. The large type font, color scheme, and simple design make the interface easy to read and understand for elderly patients.

![Image 2 - dwellSense Patient Dashboard](image2.png)

Processed ODL data will also be made available to the patient’s caregivers and physicians to review. The Physician dashboard is currently under development as of this report but the envisioned interface would allow users to view a timeline graph displaying the daily correctness and timeliness scores over a period of time. The timeline interface will be interactive, allowing physicians to drill-down to see the details of a patient’s task performance on a given date.

**Third-Party Platform Integration**
The CMU team has chosen to integrate with Microsoft HealthVault. The CMU project team will create HealthVault accounts for each of the patients enrolled in their study and connect the patient’s dwellSense account to HealthVault account they create for the patient.

The CMU team will utilize HealthVault’s “Custom Data Type” to allow them to upload processed sensor data. However, the team has not yet finalized the set of data that will be uploaded to HealthVault. The team is currently considering uploading all visible information from the patient view. Specifically, the team is planning to upload: the number of successful and unsuccessful calls (and timestamps); the stages of coffee making (success/failure and timestamps); stages of pill taking (success/failure and timestamps);...
timestamps); and the numerical “correctness” and “timeliness” score as applied to each of the three activities.

**ODL Integration with the Patient’s Life**

dwellSense collects all ODL data passively from patients. This approach is a key benefit for the project in light of the fact that the elderly patients will not be required to remember to enter data themselves or rely on their memory of how well they performed their daily tasks. The ODLs selected by the CMU team integrate easily into the patient’s daily life because they comprise tasks that are already part of the patient’s everyday routine and do not require the patients to take any special steps to collect data for the project.

Patients benefit from the availability of the patient dashboard to give them near real-time information about their activities. The dashboard gives them an easy to understand snapshot of how well they are doing cognitively and functionally each day. For example, it provides useful information about medication administration, allowing patients to easily see when they have missed a dose. Patients can then use this information to take steps to compensate for missing a dose if warranted.

**ODL Integration with the Clinical Workflow**

Physicians and health care workers will follow patients’ cognitive and functional ability measures using the physician view of the dashboard. The data collected over time from dwellSense will be correlated with assessments from an occupational therapist as well as monthly measures collected from the patients (e.g., CACMI – Computer Assessment of Mild Cognitive Impairment; SPPB – Short Physical Performance Battery; PASS – Performance Assessment of Self-care Skills). The CMU project team is still in the process of determining the workflow for ODL data review by the patient’s physicians and care team. The current plan is to have physicians review patient ODL data using the Physician Dashboard monthly at a minimum or as need arises for a given patient. Physicians will be able to capture snapshots, static views of the patient’s ODL data, into the patient’s records if desired.
RTI International – BreathEasy

The BreathEasy personal health application was developed by RTI International to help patients with asthma provide a clearer picture of their day-to-day health and asthma management to their clinical teams. BreathEasy supports the tracking of ODLs related to asthma (e.g., symptoms, triggers, and use of asthma medications) as well as anxiety and depression levels, two conditions that are linked with asthma.

The patient enters ODL data related to their asthma, depression level, anxiety level, and level of physical activity into the BreathEasy smartphone app. The ODL data reported by patients is reviewed by clinic staff and the patient receives automated alerts, reminders, and messages via the BreathEasy mobile app to help the patient manage their asthma.

Clinician will use a web-based Dashboard application that displays summary information about the patient’s ODLs over a period of time to track patient ODL values. The dashboard will help clinicians identify trends over time in the patient’s health and asthma management and will give them insight into the patient’s habits and behaviors between visits. The clinicians may use information displayed by the BreathEasy dashboard to provide individualized guidance to patients on how to better manage their asthma.

Figure 2 - BreathEasy Technical Architecture Diagram

Data Collection

Patients involved in the BreathEasy program are given a Samsung Captivate Galaxy S running Android 2.2 OS and enter all ODL data manually into the BreathEasy mobile app. The BreathEasy mobile app mainly collects ODL data from the patient via a daily questionnaire. Table 2 contains a detailed list of all ODL data collected during the daily survey. The BreathEasy mobile app guides patients through the questionnaire and prompts the patient to enter certain ODL information (see Image 3). In addition to
the daily survey, patients may separately enter peak flow rate and use of rescue medication as needed during the day.

![BreathEasy Mobile App Daily Questionnaire](image3.png)

Once the patient completes the daily survey (or enters discrete peak flow or rescue-medication usage), the ODL data are uploaded to the BreathEasy server hosted by RTI for data processing and storage. Incomplete surveys are stored on the phone until the patient completes the survey and uploads the data. Data are uploaded to the RTI server in a proprietary XML format sent over HTTPS.

<table>
<thead>
<tr>
<th>ODL</th>
<th>ODL Description/Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peak Flow Rate</td>
<td>Manually entered peak flow rate (a 3-digit number) from the patient’s peak flow meter. The patient may enter peak flow data as part of daily survey or as needed.</td>
</tr>
<tr>
<td>Controller Medication Adherence</td>
<td>The patient indicates whether they adhered to their asthma controller medication regimen (Yes/No) and can provide a free-text explanation for any lack of adherence.</td>
</tr>
<tr>
<td>Rescue Medication Usage</td>
<td>The patient indicates whether they used any asthma rescue medications during the day (Y/N) and the reason(s) for needing to use the rescue medication. Patients may select from a list of reasons (e.g., Wheezing, Coughing, and Shortness of Breath) or may enter a free-text reason. The patient may enter rescue medication usage as part of the daily survey or as needed.</td>
</tr>
<tr>
<td>Asthma Triggers</td>
<td>The patient indicates asthma triggers experienced during the day. The patient may select multiple triggers from among a provided list or may enter a free-text response.</td>
</tr>
<tr>
<td>Asthma Symptoms</td>
<td>The patient indicates asthma symptoms experienced during the day. The patient may select symptoms from a list or may enter a free-text response.</td>
</tr>
<tr>
<td>Physical Activity - General level</td>
<td>The patient indicates how active he or she was during the day (not active; somewhat active; very active).</td>
</tr>
</tbody>
</table>
**ODL**

<table>
<thead>
<tr>
<th>Activity type - Duration - Accelerometer steps</th>
<th>ODL Description/Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient may indicate the type of physical activity he or she engaged in during the day. The patient may select activities from a list or may enter a free-text response. The patient may enter activity duration from a set of duration categories (e.g., &lt;30 minutes, 30-60 minutes, etc.). The patient may optionally enter the number of steps displayed for the day from a pedometer app installed on their smartphone.</td>
<td></td>
</tr>
</tbody>
</table>

**Depression Level**

The patient indicates how happy or depressed they felt during the day. Options include: Happy; Okay; Down; and Depressed. Each emotion has an associated icon to represent the patient’s level of depression.

**Anxiety Level**

The patient indicates how anxious or happy they felt during the day. Options include: Happy; Okay; Anxious; or Worried. Each emotion has an associated icon to represent the patient’s level of anxiety.

**Sleep Patterns**

The patient indicates how they slept in the previous 24 hours. Patients may select from a provided list (e.g., difficulty falling asleep, sleeping too little, and sleeping the right amount).

**Smoking Habits**

The patient indicates if they smoked that day and if so, how many cigarettes, cigars, and pipes were smoked.

The BreathEasy mobile application prevents ODL data loss by caching data on the phone until the data can be submitted to the BreathEasy server (in the event that the phone does not have a network connection). Data are not deleted from the phone until the phone receives a confirmation message from the BreathEasy server that the data has been received and processed correctly. Additionally, data saved to the BreathEasy database is backed up regularly.

**Data Processing**

Data transmitted to the BreathEasy server is received by a web server that passes the data to a C#.NET server-side application that parses the data and saves the ODL data to a SQL Server database.

A messaging server monitors the data stored in the database for all patient accounts and sends messages to the patient’s smartphone based on rules set up by the RTI team. There are three types of messages sent by the messaging server to the BreathEasy mobile app: Compliance reminders; Alerts; and Risk Reduction Notifications.

Compliance reminders are sent to patients to help them remember to enter their daily data. For example, the patient can be sent an automated reminder to enter their daily questionnaire data or provide peak flow data. The messaging server triggers these types of messages when the logic determines that an expected record does not exist for a particular patient. Patients may customize the time that these reminders are sent and may completely disable some, though not all, compliance reminders.

Alert messages are designed to warn patients when provided ODL data are outside of normal parameters or not within the patient’s care regimen. For example, a patient is sent a warning after
submitting multiple peak flow data values that fall in the red-zone or if the patient reports excessive use of rescue medication. Alerts are not configurable and cannot be disabled by the patient.

Risk Reduction Notifications are optional messages designed by the RTI team to provide health promotion information. For example, the system may send a patient prompts about getting more exercise or about tobacco avoidance. The patient may configure when such messages are sent to their smartphone and may disable these types of messages.

**Data Display**

Nurses, physicians, and patients may all view processed and formatted ODL data via the Clinician Dashboard, a web-based data visualization tool. The Clinician Dashboard displays summary patient data to the user (See Image 4 - BreathEasy Clinician Dashboard). Users may select date ranges that display data over one or two weeks at a time. The visualization displays peak flow data with zone information and a list of the other ODL data presented as either being in a “Desired” or “Undesired” state. Users may mouse over individual points in the dashboard to view additional detail (e.g., to get a list of experienced asthma symptoms on a given day). The data displayed in the Clinician Dashboard is read only and clinicians cannot update or add comments to a patient’s BreathEasy account.

Patients may also view their own data within the Clinician Dashboard from their BreathEasy mobile apps on their smartphones. However, the interface was designed with providers in mind and was developed primarily for display on a full browser window.
Third-Party Platform
The BreathEasy personal health application is not currently integrated with any third-party platforms. The RTI project team is in the process of evaluating Microsoft HealthVault as an option for uploading ODL data.

ODL Integration with the Patient’s Life
The patient’s primary interaction with BreathEasy is via the daily patient questionnaire. The patient is sent automatic reminders to help keep them motivated and engaged in entering ODL data. Patients are also sent automatic alerts that make them aware of issues concerning their condition and may prompt them to take action. Other feedback, namely the Clinician Dashboard, is available to the patient; however, this type of feedback has not been designed specifically for use by patients.

ODL Integration with the Clinical Workflow
The BreathEasy Clinician Dashboard is the physician’s primary view into the patient’s ODL data. Nurses and physicians can access the dashboard via any browser (e.g., using a computer in the clinic), which makes it convenient for clinic staff to pull up the patient’s information for the physician to review.

The RTI team is currently developing the protocol to determine when and how often the dashboard is to be reviewed by clinic nurses and physicians and how feedback is to be given to patients (e.g., during visits only, during visits and by email, etc.). The plan is for the clinic physicians to review the dashboard with the patient during a patient visit. As of this report, there are no plans for ODL data from the dashboard to be integrated into the patient’s medical chart nor are there plans to integrate any information from the patient’s chart (e.g., controller and asthma medications) into the patient’s BreathEasy account.
San Francisco State University – iN Touch
The iN Touch program at San Francisco State University (SFSU) was developed to study how collecting ODLs related to diet, exercise, mood, and social interaction can impact the health and daily lives of economically disadvantaged youth struggling with obesity. To collect ODL data from patients, the project uses an existing web-based goal tracking platform, TheCarrot, which has had custom goal “trackers” and reports developed specifically for use by the iN Touch patients.

Patients use an Apple iTouch 3G mobile device running an existing app provided by TheCarrot to enter ODL data (although they may also use TheCarrot website to submit ODL data). Health coaches assigned to the patients regularly track and monitor the patients’ ODL data using TheCarrot website and can provide customized feedback to patients based on the uploaded ODL information. TheCarrot also makes weekly reports available to the patients’ other health care providers (physicians, school nurses, etc.) to view online. iN Touch patients who are also patients of the San Francisco General Hospital (SFGH) teen or pediatric clinics can have reports of their ODL data sent in PDF format from TheCarrot to their SFGH health record.

Figure 3 - iN Touch Technical Architecture Diagram

Data Collection
iN Touch patients are given an Apple 3G iTouch running TheCarrot’s mobile app to enter ODL data and track their own progress. TheCarrot’s mobile app allows patients to manually enter all ODL data (e.g., mood, socializing, food, and exercise) using their standard mobile app interface. The app interface allows patients to associate a photo with any ODL information (e.g., pictures of a patient’s food). The mobile app used by the patients is the same application available to everyone through the Apple app store. The food and exercise ODLs collected for the iN Touch project were already available as standard “trackers” available to all users of TheCarrot. However, the SFSU team worked with TheCarrot to develop and implement mood and socializing trackers for use specifically in the iN Touch study. Table 3 contains a detailed list of all ODL data collected by TheCarrot mobile app.

Table 3 - iN Touch ODLs

<table>
<thead>
<tr>
<th>ODL</th>
<th>ODL Description/Details</th>
</tr>
</thead>
</table>
| Mood   | The patient’s mood, which is composed of the following emotions (all measurements are scored as a 10-point scale with rating language as shown below for each measure):  
- Anger (“None ↔ Extreme”)  
- Happiness (“None ↔ Extreme”)  
- Sadness (“None ↔ Extreme”)  
- Stress (“None ↔ Extreme”) |
| Socializing | The patient’s level of social interaction, which is composed of the following measures (all measurements are scored as a 10-point scale with rating language as shown below for each measure):  
- People influence me (Negatively ↔ Positively)  
- People support me (Not Much ↔ A lot)  
- Social Interaction Level (Not Much ↔ A lot) |
| Food   | The food item consumed for a meal with (optional) calories indicated                    |
| Exercise | The type and duration of exercise.                                                   |

Users enter ODL data by using sliders (e.g., for mood and socializing ODL data) or the on-screen keyboard (for food and exercise data). TheCarrot mobile app provides a database of common food items (with associated calorie counts) and types of exercises that the user may search through and select from. The mobile app also allows users to attach photos and notes to every ODL data item entered. Image 5 below shows examples of TheCarrot’s mobile user interface for entering ODL data. Patients may also upload their ODL data via TheCarrot’s website, but this is far less common as many subjects lack easy and regular access to a computer.

Once data are entered into the mobile app, it is cached on the device until the device is in range of a Wi-Fi network. As soon as the iPod Touch is connected to a network, the data on the device can be synchronized with the data on TheCarrot server. Data are transmitted between the mobile device and the server using TheCarrot’s proprietary XML-based API.

The iN Touch team has enabled the iPod Touch’s default security feature, the 4-digit PIN, to prevent data disclosure. In addition, Apple’s MobileMe service has been activated on each iPod Touch device.
allowing the project team to help locate lost and missing devices or, if necessary, remotely erase data from the device.

Data Processing
All ODL data submitted to TheCarrot, including photos and user notes, are processed and stored for later viewing. TheCarrot is able to pull patient ODL data for both dynamic and static reports (described in the next section).

TheCarrot platform supports email reminders for users, but the iN Touch project team is not making use of this feature for the purposes of their project. Instead, participants may use the built-in calendar functionality of the iPod Touch device to set up their own reminders. Additional reminders and other patient notifications are sent to the participant via text message and phone calls by the SFSU health coaches.

Data Display
The patient may review individual ODL data entries as well as a historical “Journal View” of all data entries submitted using TheCarrot mobile app. The data view is limited on the mobile app and only shows data as it was entered. No special visualizations (e.g., graphs, data comparison, etc.) are available to view within the mobile application.

The patient and health coach may use TheCarrot website to look at different visualizations of the data. The visualization tools provided by TheCarrot website allow users to overlay different data elements and change the time scale of displayed data. In addition to these standard visualization options, the iN Touch team worked with TheCarrot to develop a participant report (see Image 6 below) for patients, health coaches, and clinicians to get a customized view of the ODL data tracked by the project.

The “Participant Report” displays a week’s worth of a patient’s ODL data (left side of the report) as well as a summary of the patient’s data for the last four weeks (middle of the report). The patient’s mood and socializing ODL data are displayed as bubble representations to indicate the degree of the patient’s response (e.g., small circles representing “not much” and large circles representing “a lot”). The report
also provides ratios that compare related ODL data (e.g., the ratio of submitted sad to happy mood scores).

Image 6 - Weekly iN Touch Participant Report

Patients may grant certain users access to their “Participant Report” using TheCarrot’s built-in access-control features. Access-control in TheCarrot is entirely group-based. Users may be assigned to a group and the patient may then grant access to groups so that members of the group may view some or all of the patient’s data. Participants (i.e., patients) cannot be granted access to each other’s information through TheCarrot’s access control mechanisms. Health coaches assigned to the project have been granted full access to all patients’ records by default within TheCarrot. This is a special level of access that allows health coaches to create, edit, and view all data in the patient’s account as if the health coach were the patient. This degree of access cannot typically be granted by users of TheCarrot and was implemented for the purposes of the iN Touch project. The patient may choose to allow members of the SFGH Teen Clinic, Pediatric Clinic, or school nurses at Mission High School Wellness Center to view their “Participant Report” through TheCarrot website. The patient grants report access to any of these groups and users assigned to these groups may then view the patient’s “Participant Report”. These users may not edit or view the patient’s raw data through the website as the health coaches can do.

TheCarrot has the ability to export a PDF copy of the patient’s “Participant Report” and send batches of these PDF reports via sFTP (with username and password authentication) to a server at SFGH. Once transmitted to SFGH, the PDF are loaded into a document management server and associated with the correct patient’s medical record. To associate the PDF with the correct patient record, the patient’s
name, SFGH medical record number (MRN), date of birth, and gender are entered into the patient’s
TheCarrot account profile. TheCarrot automatically generates a PDF report for all patients who have an
SFGH MRN identifier associated with their TheCarrot account. When the PDF is generated, the four
identifiers are written into the PDF report document. The SFGH document manager server parses the
PDF, finds the patient’s MRN and associates the PDF document with the correct electronic medical
record account.

**Third-Party Platform**
TheCarrot serves as both the primary application server and as the third-party platform for the iN Touch
program. Patients are free to use other “trackers” offered by TheCarrot that are not part of the iN Touch
study. The data from these other trackers are not included in the iN Touch reports or provided to the
research team. Patients are also able to grant access to their TheCarrot account to any person they
choose using the platform’s available data access-control features.

**ODL Integration with the Patient’s Life**
Patients manually enter their data into TheCarrot mobile app during the course of their daily lives. In
response to the data they enter, the patient may be contacted by a health coach who oversees the
patient’s progress via TheCarrot website. The health coach provides manual feedback and
encouragement to the patient to help the patient reach his or her goals and to help the patient stay
engaged in the project. The school nurse at Mission High School, the high school attended by many of
the patients enrolled in the program, also has access to TheCarrot and can review data to provide
support to student-patients.

Patients may use TheCarrot website and TheCarrot mobile app as much or as little as they like to track
the ODLs of interest to the iN Touch program. Patients may also track any of the many other ODLs
supported by TheCarrot in addition to the ODLs of interest to the iN Touch team. TheCarrot website and
TheCarrot mobile app fully support data entry for all of the standard “trackers” offered by TheCarrot.

**ODL Integration with the Clinical Workflow**
The health coach is the person primarily responsible for overseeing the weekly data submitted by each
patient. If any ODL values are of significant concern, the health coach will contact the patient to discuss
the situation or may notify the patient’s physician or nurse if warranted.

iN Touch participant reports are uploaded to the patient’s SFGH EHR as described above and become a
part of the patient’s medical record. Physicians at SFGH pediatric and teen clinics may view the
uploaded PDF reports within the patient’s record. Physicians and school nurses may view patient ODL
data by logging in to TheCarrot website if the patient has granted them access to their account. The
clinicians and patient may discuss the information presented in the report during medical appointments.

**University of California, Berkeley – Crohnology.MD**
Crohnology.MD is personal health application for patients with Crohn’s disease developed by the
University of California, Berkeley (UC-B) in partnership with Healthy Communities Foundation and the
University of California, San Francisco (UCSF). Crohnology.MD helps patients create visual narratives of
their condition by allowing patients to enter ODL data comprising symptoms, vital measurements, and
responses to treatment and by allowing the patient to customize how the information is displayed. Patients can then share these visual narratives with their providers to determine the course of their treatment.

Patients are able to enter ODL data manually via an iPhone application running on an iPhone or iPad. Some patients may also elect to submit ODL data via text messaging, i.e. by responding in a specified way to text messages sent by the Crohnology.MD application. In addition to manual data entry, some ODL data (e.g. weight, physical activity, and sleep) can be collected passively, using wireless personal health devices.

ODL data are uploaded to the Crohnology.MD server and processed for display via a separate iPad visualization application that allows the patient to design data reports that help the patient present a picture of his or her health. The patient can share these “visual narratives” with physicians and review them during medical appointments.

**Data Collection**
Patients enter most ODL data tracked for the project (Table 4) manually via the Crohnology.MD mobile app running on an Apple iPhone or iPad device. Patients enter ODL data such as abdominal pain, energy level, and medications into the mobile app using sliders, numeric, and text entry interfaces (see Image 7 below). All ODL data entered into the mobile application can have photos and word tags attached (tags...
allow a patient to associate related ODLs based on a common keyword. Data are synchronized between the Crohnology.MD server and mobile app using a proprietary XML-based format. The logic that ensures the mobile device is synchronized with the server data was developed by the project team using code written for Apple’s x-Code application framework. Data are cached on the phone if no network connection is available and synchronized with the server once a network connection is reestablished.

Image 7 - Crohnology.MD iPhone & iPad App Interface

In addition to using the Crohnology.MD mobile application to enter data, patients may elect to enter ODL data via text message using any SMS compatible cell phone. Patients enter data by responding to text message prompts from the server in a specified way. For example, in response to a text message prompt to enter abdominal pain, the patient responds with a number from one to ten. The text messaging service is hosted by Twilio, a third-party service that provides text message interfaces for applications. Twilio handles the sending of the scheduled prompt messages and the receipt of the patient’s responses. The Crohnology.MD server then pulls the ODL data from Twilio to update the patient’s record.

Table 4 - Crohnology.MD ODLs

<table>
<thead>
<tr>
<th>ODL</th>
<th>ODL Description/Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdominal Pain</td>
<td>The level of abdominal pain the patient experienced during the day. Reported as a 10-point scale. Abdominal pain scores are manually entered by the patient.</td>
</tr>
<tr>
<td>Energy Level</td>
<td>The patient’s level of energy each day. Reported as a 10-point scale. Energy level scores are manually entered by the patient.</td>
</tr>
<tr>
<td>Journal</td>
<td>Free-text journal entry the patient may use to describe events related to their condition.</td>
</tr>
<tr>
<td>Appointments</td>
<td>Appointments the patient has scheduled. The patient may associate reminders. Appointments are manually entered and managed by the patient.</td>
</tr>
<tr>
<td>Medications</td>
<td>Medications the patient is taking. The patient may associate medication reminders.</td>
</tr>
<tr>
<td>ODL</td>
<td>ODL Description/Details</td>
</tr>
<tr>
<td>-----</td>
<td>------------------------</td>
</tr>
<tr>
<td>Medications</td>
<td>Manually entered and managed by the patient.</td>
</tr>
<tr>
<td>Weight</td>
<td>The patient’s daily weight. Weight ODL data are automatically captured via a Withings Wi-Fi-enabled scale (<a href="http://www.withings.com">www.withings.com</a>).</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>The patient’s activity level measured in number of steps (measured), distance travelled (calculated), and calories burned (calculated). Physical activity ODL data are automatically captured via a FitBit Bluetooth device (<a href="http://www.fitbit.com">www.fitbit.com</a>).</td>
</tr>
<tr>
<td>Sleep</td>
<td>The patient’s sleep duration (start time and end time) and level of activity. Sleep data are automatically collected via a FitBit Bluetooth device.</td>
</tr>
</tbody>
</table>

The Crohnology.MD application supports the passive collection of patient weight using the Withings home body scale. The Withings scale is a Wi-Fi enabled device that connects to the patient’s home network. Weight data are uploaded automatically to the patient’s Withings account (set up and managed by the patient) as long as an Internet connection is available. The Withings scale supports a store-and-forward capability if no network connection is available and cached weight data are uploaded once a connection is reestablished. The patient associates his or her Withings account with their Crohnology.MD account by entering their Withings account credentials (email and password) into their Crohnology.MD account settings. Once associated, the Crohnology.MD server uses a REST-based web-services API provided by Withings to pull the patient’s weight data from the Withings server over HTTPS. Data is pulled from the Withings server on demand (i.e., whenever a patient interacts with the mobile device to access their account). When a user accesses the mobile app, the Chronology.MD server checks to see if new data is available on the Withings server. If so, data is then pulled from the Withings server to the Chronology.MD server and synched with the user’s mobile device. The Withings REST-based API uses the OAuth protocol for authentication, a token-based authentication standard commonly used in web services.

The patient’s physical activity and sleep patterns are also collected passively using the FitBit accelerometer device. Patients wear the FitBit device during the day to track their level of physical activity. The device tracks and reports the number of steps taken, the calculated distance, and the calculated number of calories burned each day. Patients may also wear the FitBit device at night to track their sleeping patterns. While in “sleep mode”, the device tracks the patient’s sleep duration, time to fall asleep, and the number of wake-ups. The FitBit device is Bluetooth enabled and uploads data wirelessly to a base station connected to a home computer every 15 minutes while the device is connected to the base station. The data are saved on the home computer and uploaded to the patient’s FitBit server as long as an Internet connection is available. Data are stored on the patient’s home computer if an Internet connection is not available. Patients associate their FitBit account with their Crohnology.MD account as they do for the Withings weight scale. Once a patient’s accounts are linked, the Crohnology.MD server pulls the patient’s physical activity and sleep data over into the patient’s account using an API provided by FitBit. As with the Withings interface, the Chronology.MD interface with FitBit uses a REST-based API with OAuth authentication policies to transmit data on demand from the FitBit to the Chronology.MD server.

**Data Processing**

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Data are collected by the patient’s Crohnology.MD account from the supported data sources (i.e., mobile app, Twilio, Withings, and FitBit). Data are parsed and saved to a MySQL database. The Crohnology.MD servers are hosted on Amazon’s EC2 Cloud Hosting service which handles full data backups and server redundancy for the program.

**Data Display**

Patients are able to use the iPhone application to view data basic data entries and see some historical data, though the data reviewing features are somewhat limited on the Chronology.MD mobile application. Full data visualization of data will be provided by a separate iPad-specific app that will allow patients to view and display data in a variety of ways. This application is currently under development by the Crohnology.MD team; *as such, descriptions and images of the app are subject to change*.

Using the Chronology.MD visualization app, patients will create what are referred to as “Filter Sets”, (i.e., custom views of their ODL data). These views allow the patient to overlay certain of their ODLs so that the patient may create a visual narrative about their condition. The filter sets can be saved by the patient to their Crohnology.MD account and these views may be shared with the patient’s physician so that the physician may view the custom data view from the physician’s own iPad tablet.

![Image 8 - Mockup of Crohnology.MD ODL Visualization App](image)

Physicians and patients can review ODL data together using the iPad visualization app. The interface will allow users to zoom in and out to see short or longer timeframes and to drill-down into specific data entries to see the underlying information. Photos and tags associated with ODLs can also be viewed within the visualization app.
Third-Party Platform
The Crohnology.MD team intended to send patient ODL data to Google Health using Google’s custom CCR format and API. Under this plan, all ODL data was to be uploaded as CCR “Result” data elements in order to fit with the CCR data model. However, when Google announced the termination of their Google Health service, the UC-B team was left without a third-party platform solution.

The team is currently evaluating other options for third-party platform integration. One option being considered is to upload data in CCR format to HealthVault. Since HealthVault supports the CCR format as an allowed data type, the team could reuse the CCR file generation logic already developed to send data to HealthVault. Another option under consideration is to simply support the export of ODL data in CCR and to send CCR formatted data to other external applications (e.g., EHRs and PHRs) as requested. While supporting export of ODL data in CCR format by itself doesn’t constitute integration with a third-party platform, it would enable the sharing of ODL data with other applications.

ODL Integration with the Patient’s Life
Patients enrolled in the Crohnology.MD study have a number of ways to submit ODL data, both manually and passively. Home health devices passively collect data automatically for the patient, which removes the need for the patient to remember to enter these ODL data. Automated reminders generated by the application are designed to help the patient remember to enter ODL data regularly.

During physician visits, the patient meets with his or her provider to review the visual narratives prepared to describe the patient’s response to treatments for their condition. The physician and patient use this information to make decisions about future courses of treatment.

ODL Integration with the Clinical Workflow
The Crohnology.MD plan to integrate ODL data into the clinical workflow is to have the three UCSF physicians involved in the study review data with enrolled patients during the course of the intervention. A clinic nurse will prepare the patient’s filter sets for review on the physician’s iPad prior to a patient visit. During the visit, the patient and physician will review the ODL data, discuss the ODLs in the context of the patient’s treatment and decide if any changes are needed in the patient’s treatment. The physician may also recommend that the patient begin collecting other ODLs through the Crohnology.MD application.

Currently, there is no incorporation of data from the Crohnology.MD application into the patient’s medical record (e.g., a snapshot of the patient view). The UCSF practice involved in the study is in the process of rolling out an Epic EMR implementation and there is not time or budget to integrate ODL data.
University of California, Irvine – Estrellita

The Estrellita (Spanish for “little star”) personal health application, developed by the University of California, Irvine team (UC-I), collects ODL information from caregivers of high-risk infants. Caregivers (usually the infant’s mother) provide ODL data about the infant (e.g., the baby’s weight and dirty diaper counts) and about themselves (e.g., their mood and stress levels). The goal of the program is to provide tools that improve provider-caregiver communication to ensure the best possible care for the infant.

Caregivers enter ODL data manually into a smartphone app or via the Estrellita website. Data are uploaded to the UC-I server where data are processed and saved to the database.

The Early Developmental Assessment Center (EDAC) case managers at the Children’s Hospital of Orange County (CHOC) monitor the infant’s progress daily using the Estrellita website to view the infant’s ODL data. Based on the ODL information provided, the EDAC case manager can contact the infant’s caregiver to provide recommendations for infant care. Patients may use ODL information displayed on their smartphone to share information about their infant with other healthcare providers outside of CHOC.

Data Collection

Caregivers enter all ODL data manually via the Estrellita mobile application running on a T-Mobile G2 smartphone with Android 2.2 OS. See Table 5 for a detailed list of the ODLs collected via the Estrellita mobile app. The Estrellita mobile app provides a variety of interfaces for entering ODL data customized for the type of data entered. For example, the baby “Fussy-o-Meter” uses a dial interface to allow the
caregiver to indicate how fussy the baby is and the caregiver “Mood Map” uses a two-dimensional map interface to allow the caregiver to indicate how they themselves are feeling (see Image 9). Each ODL may be entered separately as needed by the caregiver.

Image 9 - Estrellita Mobile App Interfaces

The baby’s weight and diaper change ODLs may have pictures associated with the entered data. For the baby’s weight, the caregiver may take a picture of the baby on the scale. For diaper changes, the caregiver may take a picture of the dirty diaper with no additional data entry for later processing by the server and review by the EDAC case manager (see below).

Table 5 - Estrellita ODLs

<table>
<thead>
<tr>
<th>ODL</th>
<th>ODL Description/Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant’s ODLs</td>
<td></td>
</tr>
<tr>
<td>Weight</td>
<td>Caregivers use a digital scale (Salter 914 Electronic Baby &amp; Toddler Scale) to weigh their baby. Caregiver manually enters baby’s weight (pounds and ounces) into Estrellita app. Caregiver may also attach a photo of the weighing. Caregivers are asked to submit the weight ODL weekly.</td>
</tr>
<tr>
<td>Diaper Changes</td>
<td>Caregivers manually enter number of wet, dirty, and wet &amp; dirty diapers into mobile app. Caregiver may also attach a photo of dirty diapers. Caregivers are asked to submit diaper change ODLs daily.</td>
</tr>
</tbody>
</table>
| Appointments | Caregivers may manually enter infant appointment information. The app allows caregivers to enter details about the appointment including:  
- The doctor’s contact information (name, specialty, address, phone);  
- The appointment date and time;  
- Notes to discuss during appointment or follow-up notes;  
- Whether or not they went to the appointment |
| Bonding    | Caregivers specify any of five bonding activities they engage in with their infant each day. Bonding activities that are tracked via the Estrellita app are:                           |
## ODL Description/Details

<table>
<thead>
<tr>
<th>ODL</th>
<th>Description/Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking to the infant, Taking a walk with the infant, Singing to the infant, Reading to the infant, Spending “Tummy Time” with the infant</td>
<td>Caregivers are asked to submit bonding ODLs daily.</td>
</tr>
<tr>
<td>Fussy-o-Meter</td>
<td>Caregivers manually enter how fussy the infant is using a 9-point Likert scale (displayed as a meter).</td>
</tr>
<tr>
<td>Mood Map</td>
<td>Caregivers tap an area of the map that best represents their emotional state. The map measures emotion on the x-axis (negative to positive) and energy level on the y-axis (low-energy to high energy). Data are submitted as a Cartesian coordinate pair (e.g., [5, -2]). Caregivers submit the Mood Map ODL as needed. Caregivers may attach personal notes to mood map entries.</td>
</tr>
<tr>
<td>Stress Scale</td>
<td>“Perceived Stress Scale” is a 10 item survey answered on a 5-point Likert scale. Caregivers are asked to submit a stress scale survey monthly.</td>
</tr>
<tr>
<td>Post-Partum Depression Score</td>
<td>Edinburgh Postnatal Depression (PPD) Scale is a 10-item survey that measures post-partum depression. Caregivers are asked to submit a PPD survey monthly.</td>
</tr>
</tbody>
</table>

Data are synchronized with the server regularly to ensure that data on the phone are consistent with the data on the Estrellita server. Data are transmitted between the smartphone and Estrellita server in JSON format. If the phone is lost or damaged, data can be downloaded from the server onto a new phone. If the phone cannot upload data because a wireless network is unavailable, data will be cached on the phone until it can connect.

### Data Processing

The UC-I web server handles inbound JSON data sent over HTTPS and passes the data along to a C#.NET application server. The application server processes the data and saves it to a MySQL database. Dirty diaper and baby weight images are saved to the server’s file system and then processed. Images of diapers are processed by the server to produce a color histogram analysis, which is intended to help EDAC case managers evaluate the baby’s digestive health. The server breaks the image of the soiled diaper down into a color gradient with numerical values that indicate the percentage amounts of each color (See Image 10). These percentages are then stored in the patient’s record and the histograms are made available for viewing on the Estrellita website by EDAC case managers. Images of babies on scales are currently saved for later viewing by the EDAC case manager. The UC-I team is evaluating the feasibility of processing the images to automatically determine whether the baby was placed on the scale correctly for weighing to help gauge the accuracy of the baby’s weight.

The Estrellita mobile app is programmed to provide the caregiver with regular alerts and reminders to help the caregiver remember to enter infant ODL data. For example, the caregiver is reminded nightly to enter bonding ODL information for the day. The Estrellita server also has a “Virtual Coach” feature that gives feedback to the caregiver based on the ODL data entered. For example, in response to the...
Caregiver entering bonding information, the Virtual Coach will send a message to the caregiver’s phone such as, "Good job bonding with your baby!"

![Image 10 - Estrellita Diaper Color Histogram (Percentage of Color)](image)

Case managers also receive alerts from the Estrellita server which are generated based on ODL data submitted by caregivers. These alerts notify case managers when there are trends in infant data that require attention. For example, the server sends alerts to the case manager when the server detects there has been no increase or there has been a decrease in infant weight over the previous two-week period. Any case manager who logs into the Estrellita website will see these alerts and case managers can be notified by email for certain alerts.

One special alert is sent to both the caregiver and case manager in response to a submitted post-partum depression score that meets a defined threshold. This alert is the only caregiver-specific alert supported by the application and the caregiver receives the alert via the mobile app user interface. The Estrellita project has instituted a procedure and put a referral process in place to provide caregivers with assistance in addressing issues with post-partum depression. The case managers receive alerts through the Estrellita website (which is checked daily) to notify them if and when a caregiver has an alarming PPD score reported. In response to the alert, the case manager will contact the caregiver and provide recommendations for treatment of PPD.

**Data Display**

All data collected from the caregiver is made available for display on the Estrellita mobile app. Patients are able to view historical ODL data in the form of graphs and summary information (see Image 11). Caregivers may use the data views available in the Estrellita mobile app to share their infant’s ODL information with healthcare providers at CHOC and physicians outside of the EDAC program. This method of sharing ODL data are expected to be the most common modality for study participants.
The other method for reviewing infant ODL data is via the Estrellita website (see Error! Reference source not found.). EDAC case managers are the primary clinical users of the website, though patients and other physicians at CHOC may access the site as well. Case managers use the data displayed through the site to examine the baby’s daily progress and address problems and questions posed by caregivers. The website primarily supports the display of diaper usage, appointment and weight information. Because the infants are the subjects of the study and because of sensitivity to caregiver privacy, the Estrellita website does not display the caregiver ODL information to the EDAC case managers. In addition to displaying ODL information, the website provides communication tools to allow the case workers to send messages to caregivers and one another.
Third-Party Platform
The Estrellita personal health application is integrated with Microsoft HealthVault. The project team creates HealthVault accounts for each caregiver enrolled in the program and associates the caregiver’s HealthVault and Estrellita accounts. Standard ODL data (e.g., infant weight) are stored in the corresponding HealthVault data elements. However, the majority of ODL data (e.g., diaper changes and mood) are stored as a custom report uploaded using the HealthVault custom data element. For example, the “Diaper Change” ODL is uploaded as a series of name-value pairs that indicate the number of wet, dry, and dirty diapers and numerical scores from the histogram color analysis of the diaper image.

Caregivers may grant access to their HealthVault account to other health care providers who can then view these uploaded custom reports using the basic HealthVault data display interface.

ODL Integration with the Patient’s Life
The Estrellita mobile app allows caregivers to easily enter data about their high-risk infants as needed during the day. Automated alerts and reminders, in addition to the manual alerts and notifications from the EDAC case managers, help caregivers maintain data entry during the course of the study.

The Estrellita team believes that the caregivers will use the mobile app as a tool to communicate the health status of their infants with the infant’s pediatrician and other members of the care team. The mobile app provides useful views of the data that can be shared with health care providers to provide information about both infant and the caregiver.

ODL Integration with the Clinical Workflow
The Estrellita application provides case managers with information and insight into whether the infant’s ODLs are normal or not. The case manager’s main job is to get caregivers the resources they need to best care for their infants. The Estrellita website is a tool that EDAC case managers can use to better understand the needs of both infant and caregiver.

When ODLs are not normal, case managers can take a number of steps depending on the type of ODL that are outside of the expected values. For instance, if the care giver indicates via an Appointment ODL that she is going to miss an EDAC appointment, the case manager can contact the caregiver to understand why the caregiver cannot make the appointment and, if possible, provide resources and assistance to help the caregiver attend the appointment. In other cases, if the infant’s weight is down or if the number of diapers used over a period of time is concerning, the case manager can alert the caregiver to contact the infant’s pediatrician. Finally, if the caregiver’s post-partum depression score is of concern, the case manager can provide physician referrals and encourage the caregiver to seek help.
Common Experiences and Lessons Learned
This section describes patterns and lessons learned across all five projects from their implementations during phase two of Project HealthDesign.

Third-party Platform Integration
One of the original requirements of both phases of Project HealthDesign was for grantees to integrate their solutions with a third-party data repository system, such as HealthVault and Google Health. During the course of the project implementations, it has become apparent that integrating with third-party platform systems is somewhat harder than a few of the current teams expected. Two of the five teams have not integrated with a third-party system and do not have plans to do so at the present time. A third team does plan to move ahead with integration but has not decided on what ODL data to upload. The SFSU team on the other hand has had great success using TheCarrot as a third-party data repository. The experiences of the current grantees raise some questions about the costs and benefits of integrating with such systems.

One problem the grantees faced is the limited number of options for integrating with a third-party for offloading ODL data. In June 2011, Google announced that they would be discontinuing support of the Google Health solution; this move removes a major player from the health data repository options. HealthVault is continuing to provide service, as is TheCarrot, Indivo X/Dossia, and the Project HealthDesign “Common Platform.” However, of these, only HealthVault and TheCarrot were viable options for the current teams based on the teams’ architectures and technologies used.

HealthVault was selected by several current teams. A major reason the teams gave for selecting HealthVault was the fact that the medical groups and hospitals the projects are associated with had previously announced plans to integrate with HealthVault at some point. This meant that the teams could work towards integrating ODL data with the clinical workflow by sending data to HealthVault, which was already integrated with the health care organization.

Unfortunately, the HealthVault integrations did not develop as hoped. Over the course of the project, none of these interfaces between HealthVault and any of the associated health care organizations were completed. Further, the integration plans of the health care organizations focused more on the export of patient data from the organization to HealthVault and less of the transfer of patient data from HealthVault to the patient’s medical record. This approach undercuts the value of HealthVault integration from the perspective of the current teams since even if the health care organizations integrate with HealthVault, data would not flow from the current teams’ systems into the patient’s clinical record.

Another problem the grantees faced was the lack of support by the third-party platforms for their ODL data types. The groups that selected HealthVault as their third-party platform were required to upload a majority of their data using the Custom Data Element feature provided by HealthVault. Because Project HealthDesign teams developed unique and innovative ways to collect data, the ODLs they collect do not easily fit into HealthVault’s predefined data model. The HealthVault data model is fairly rigid and
Microsoft is unable to support additions to their core data model to support individual requests. As a result, teams are forced to upload data using customized data models specific to their projects.

Uploading ODL data to repositories using custom defined data types has a couple of downsides for current teams. First, it increases the overall complexity of the interface with the third-party system. Teams must first define their custom data model and understand the mechanism for uploading custom data elements before they can integrate with the third party system. Second, using custom data elements limits the value of the uploaded data for other systems integrated with the third-party platform. Specifically, other applications cannot automatically make use of data stored in custom formats. To make the data usable by others, teams must publish or share their custom data model so that other developers interested in using the data may program their systems to parse the custom ODL data.

Finally, teams have struggled to balance the cost of third-party platform integration with the benefits provided. In general, teams implemented their systems such that data from their selected mobile devices were first sent to servers managed by the project team and all processing and visualization logic is performed on local copies of data stored on servers operated by their projects (the one exception being the iN Touch team). This design approach was predicated by the fact that the APIs for the available platforms are either not supported by the mobile application development tools or are overly cumbersome to implement. Since the ODL data was already present on the servers managed by the project teams, the teams cited the performance benefits of using local copies of data for processing and visualization to explain why it did not make sense to run these processes off of data stored in third-party repositories.

In the end, most project teams ended up integrating with third-party platforms mainly to provide a means of making ODL data available to outside systems (and to meet the requirements of the project), not for use by their own projects.

**Integration of ODLs with Clinical Systems**

Another goal of phase two of Project HealthDesign was to enable patients to share ODL information with members of their clinical care team in a way that can be integrated into the clinical workflow. One of the desired outcomes of the project was for ODL data to be incorporated into clinical systems such as EHRs. Although the projects did develop technical solutions that allow clinical teams to review ODL data in a variety of ways, patient-generated data has not been integrated into clinical systems for the most part. The notable exception is the iN Touch team, which was able to get a PDF report of patient ODL data into the patient’s medical record as a stored document.

There are a number of reasons for the lack of raw ODL data integration. As mentioned above regarding third-party platform integration, the planned integration between clinical systems and platforms such as HealthVault did not move ahead appreciably during the course of the current teams’ studies. In addition, the teams report that the medical groups and hospitals they are working in association with are in the midst of implementing new electronic health record systems. As a result, the health care organizations and their IT teams have neither the time nor the budget to develop custom interfaces to
support integration with project teams. The current teams did not report any integration issues related to security concerns on the part of health care organizations’ IT staffs as a reason for the lack of ODL integration with certain clinical systems. This may be because none of the teams’ clinical system integration plans moved forward to the stage of discussions that would have prompted this sort of feedback their respective health care organizations.

**Battery Life**
The duration of battery life was an issue for several of the current teams. Smartphones that have Bluetooth, GPS, and other sensors enabled have limited battery lives that often do not last a full day. This makes using these devices inconvenient for patients and can negatively impact compliance. The limited battery life mobile sensor devices also can be an issue for patients and projects. These devices must be able to last all day and continue transmitting data so as to not lose data.

Given these limitations, projects must evaluate the impact on their patient’s daily life and on their projects when considering the use of mobile devices. The dwellSense team addressed the problem by using a low powered wireless protocol (Zigbee) to help extend battery life and by scheduling weekly battery changes to ensure that sensors do not run out of power. Other projects, such as BreathEasy, had to reevaluate the use of sensor devices to collect data passively because they determined that battery life was going to have too large of an impact on the patient’s life.

**Data Caching on Mobile Devices**
In the original call for proposals, the prospective Project HealthDesign grantees were asked to implement solutions that included redundancies and fail-safes to prevent or mitigate the loss of ODL data. Each project team implemented a similar set of solutions to address this requirement. While the mobile devices had a network connection available, ODL data was typically uploaded as soon as the patient completed the data entry. Uploading data immediately to the server (as opposed to waiting and sending a batched upload once a day) reduces the chance of data loss if the device is lost, damaged, or stolen. Some exceptions to this general approach were the BreathEasy daily survey and the dwellSense sensor data. In the case of the BreathEasy daily survey, the application caches a patient’s incomplete survey for later submission if the patient does not complete all the survey questions. For the dwellSense application, the laptop collecting the sensor data in the patient’s home sends batch data every 15 minutes (when a broadband internet connection is available) or daily (for those apartments with dial-up).

Every team implemented the ability for smartphones to cache data when an Internet connection is not available. Once a network connection is reestablished, data on the phone is synchronized with data on the server. If devices are ever lost or stolen, ODL data can be synchronized with a new device once the patient’s credentials are entered into the mobile app on the new device. On the server side, every project team implemented a database backup policy to ensure that ODL data was protected from loss or corruption.
Appendix A – Architectural Diagram Key
The following diagram provides a key for the grantee architectural diagrams presented in this document.

![Diagram]

Figure 6 - Grantee Architectural Diagram Key