NOpain:

Automating pain self-management for adolescents and young adults

ECE 1778: Creative Applications for Mobile Devices
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1.0 Introduction

1.1 Need for a Smartphone-based pain self-management intervention. Chronic or persistent pain affects 25-35% of adolescents and young adults (AYA)[1,2] and is now recognized as a disease[3,4]. Pain may be the result of a variety of chronic and life-limiting health conditions (e.g. arthritis, cancer) or its cause may be unknown. If left untreated this pain results in high distress ratings, social and mental health problems, poor academic performance and increased utilization of healthcare services[5]. Despite advancements in the amount and quality of pain management research, persistent pain in adolescents continues to be poorly controlled[6].

Self-management represents a means to improve pain outcomes for AYA. Self-management is defined as an "individual's ability to manage the...consequences and lifestyle changes inherent in living with a chronic condition" (p.178)[7]. The content of self-management interventions typically includes disease-related education, social-support, symptom management education and decision-making support[7]. Importantly however, patient access to pain self-management programming is limited due to difficulties accessing services and cost. Smartphone-based pain self-management represents a means to circumvent these accessibility issues and better manage pain in AYA.

1.2 Project goal. The goal of this project was to design and build a Smartphone-based (Android platform) application to aid AYA in self-managing chronic and persistent pain. In doing so, we developed the NOpain app with the functionalities necessary (based on current scientific evidence[8]) to successfully support AYA in managing pain. The NOPain app is highly applicable to the nursing discipline, which is interested in pain management, and the wider health community (i.e., patients, families, other clinicians).

2.0 Overall Design

Figure 1 shows the overall design of NOpain, and the following subsection offers insight into how the different modules are implemented and how they utilize the phone's capabilities.

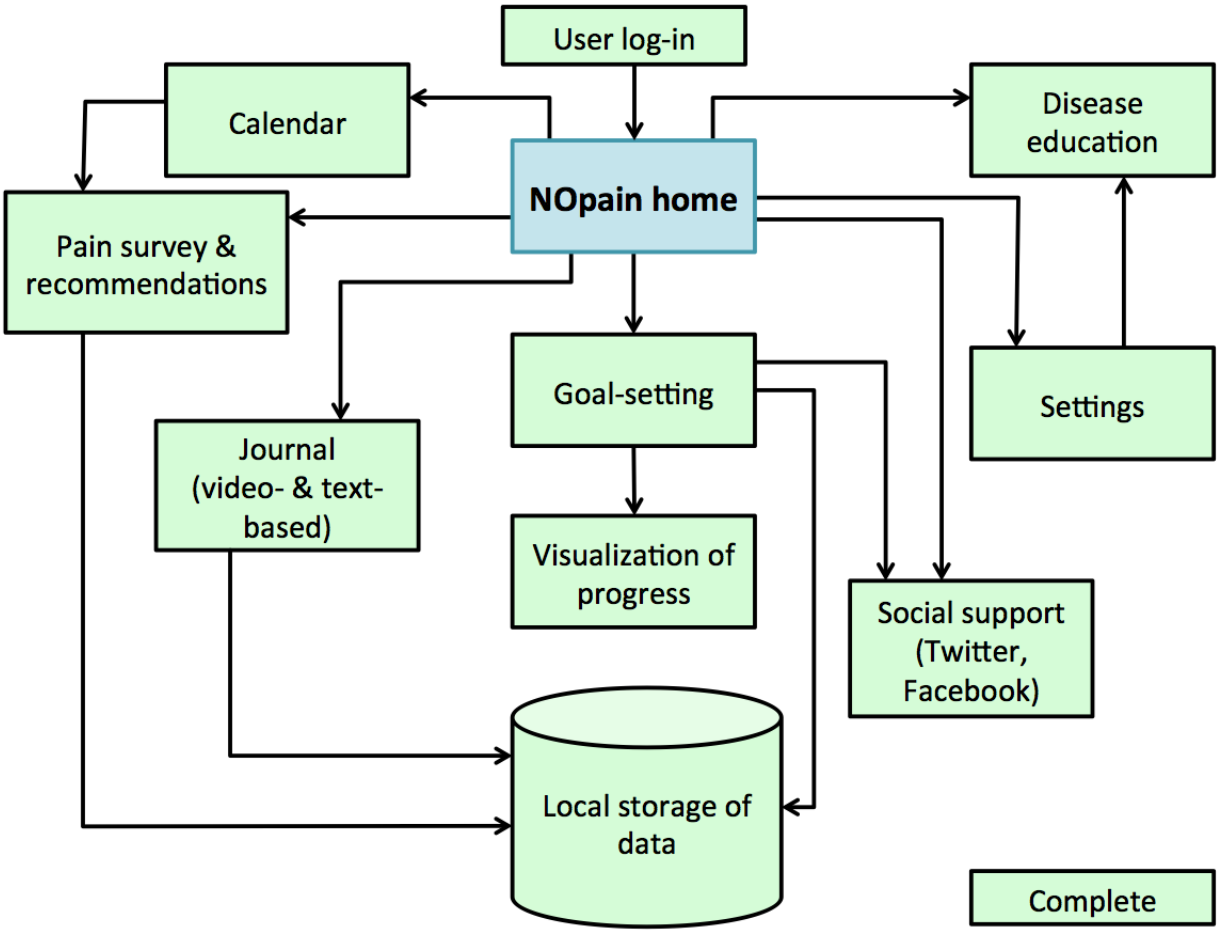


Figure 1: NOPain block diagram.

2.1 Log-in. User-identification and password allows access to NOpain. Users can register new accounts, providing them their own unique settings, calendar and survey storage.

2.2 Home. Provides direct links to NOpain self-managment functionalities. Credits to course, apper, programmers are displayed in placeholder of potential future SickKids branding.

2.3 Pain survey and recommendations. Pain is self-reported via survey. Based on data entered into the survey, tailored pain management recommendations are given. Pain re-assessment occurs post-initial recommendation. All data are stored locally, and in the future can be transferred to external SickKids databases for storage and evaluation by an AYA's healthteam.

2.4 Calendar. The calendar is integrated with the Google Calendar platform to allow tracking of

upcoming pain surveys and clinic visits. The calendar displays recurrent surveys at times specified by the user in settings. All entries displayed in NOpain's calendar event list are visible through the native Calendar app, as NOpain uses the native Calendar Provider libraries. Users may also clear their calendar (i.e., delete all user-set appointments, leaving only twice-daily recurring surveys).

2.5 Goal-setting. Clinical goals (e.g., walk a block every day this week) can be entered by users. Goals can be tracked manually over time and discussed using social media. Historical pain ratings can be graphed for review/reflection by AYA.

2.6 Journal. Thoughts, experiences and progress can be recorded in text and/or video format (both stored locally on external phone memory partition). Functionality for display and playback of video journal entries is also present.

2.7 Social support. Twitter and Facebook can be launched by directly from NOpain to allow communication between AYA (and others) about pain and individual progress.

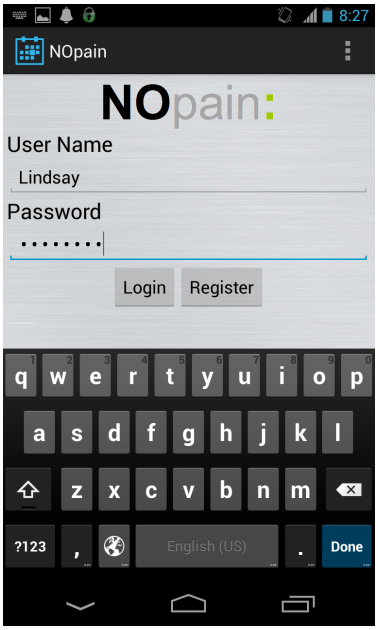
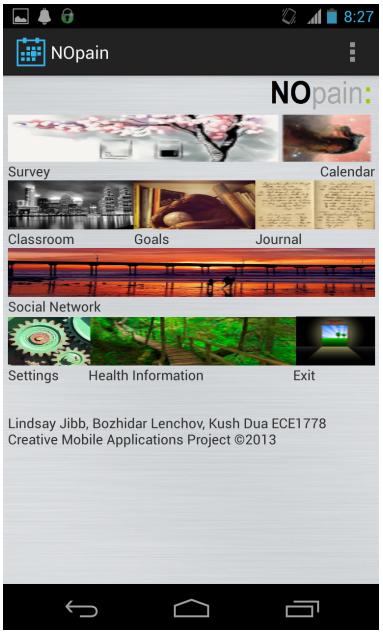
2.8 Disease education. Educational materials about pain and an AYA's painful condition (e.g., cancer) are available for review. The appropriate material is shown based on the underlying pain condition the user indicated in their settings (i.e., General Pain, Cancer, Sickle Cell Disease, Juvenile Idiopathic Arthritis).

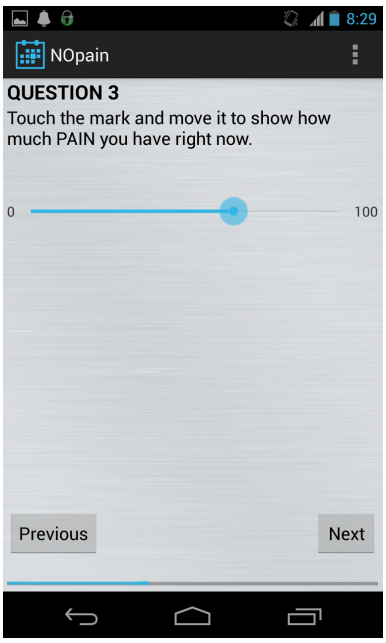
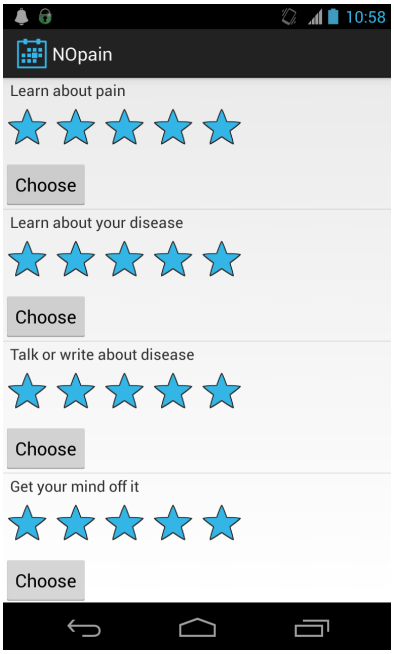
2.9 Settings. AYA can customize/personalize their health condition (used for health education modules) and time of recurring (i.e. daily) surveys in NOpain. All settings are linked to the user account, and stored locally in a database.

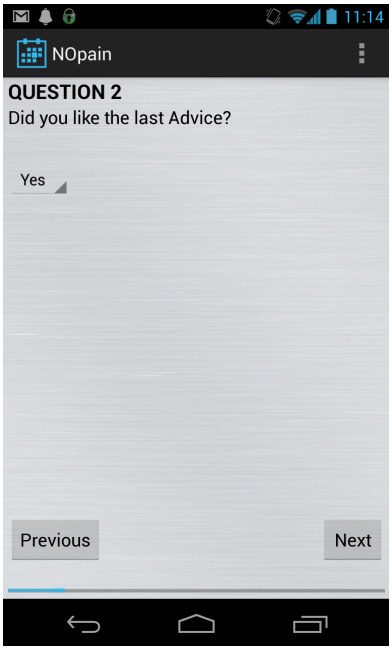
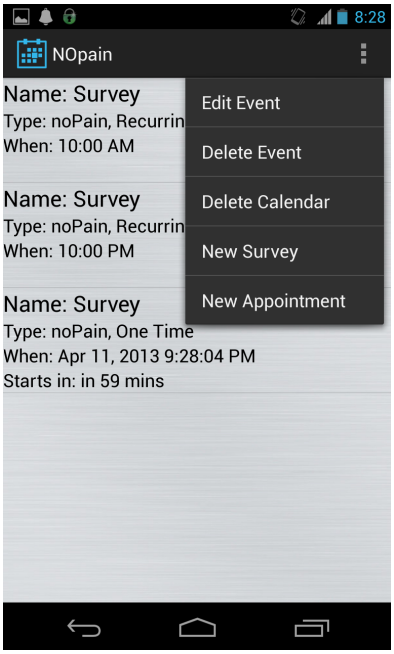
3.0 NOpain functionality

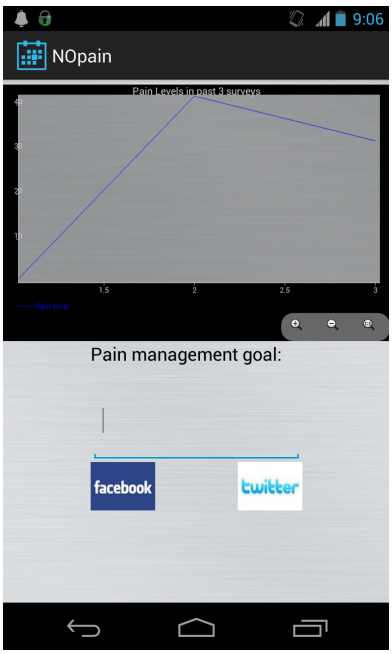
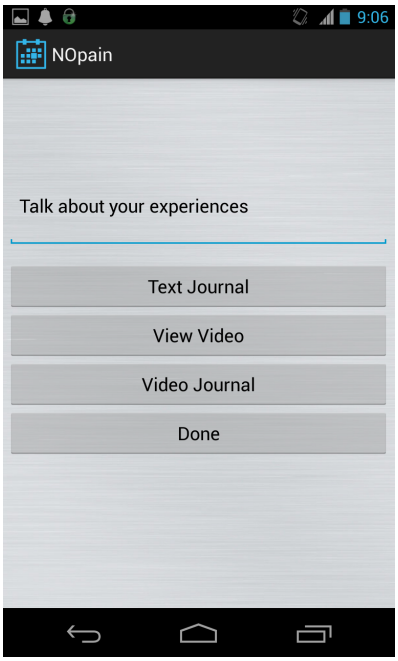
A statement of NOpain functionality appears in **Table 1**.

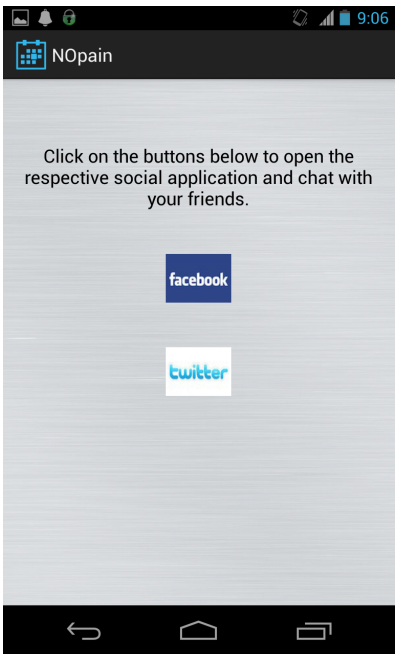
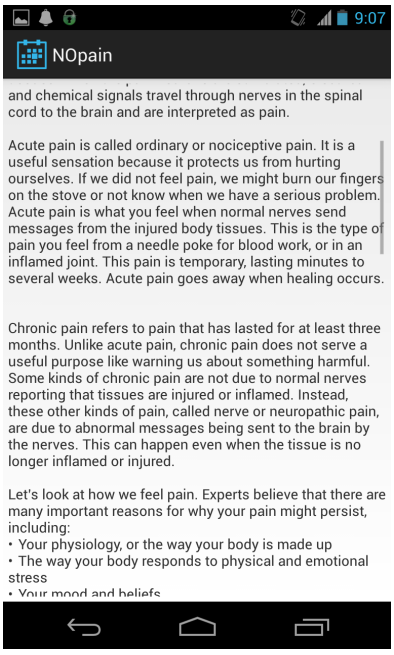
Table 1. Description of NOpain functionality

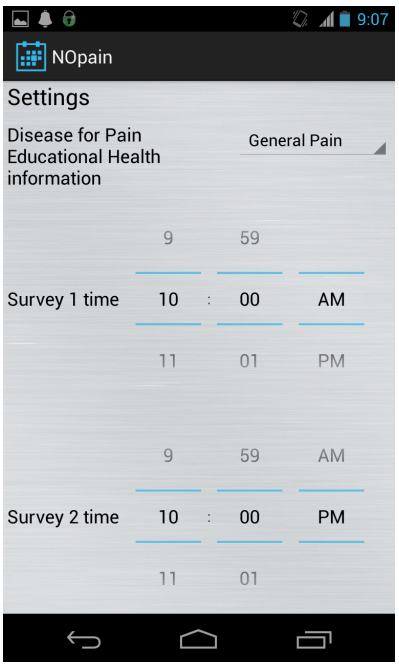
Functionality screenshot	Functionality description and reason for implementation	Functionality-related issue?
	***User-login.*** When accessing NOpain, users are prompted to enter a user-name and password. This help protect the privacy of user information and allows multiple users to use the same application to manage their pain (while guarding their individuality and privacy appropriately).	No.
	***Homescreen.*** This is a library of all pain self-management functionalities allowing one-step access to management solutions to improve app effectiveness and the user experience.	No.

	***Pain survey.*** Users are prompted (using audible alerts) every 12 hours to complete a pain survey. Reporting 'yes' to pain 'now' or in the previous 12 hours triggers the initiation of 7 follow-up questions (**Appendix A**). Users may also complete an *ad hoc* survey when in pain. Data are stored locally in a database. *Note: Questions determined by pain expert opinion.*	No.
	***Pain management recommendations.*** User-logged pain data drives NOPain's provision of several user-selectable pain management recommendations. The generated list is determined by a pain management algorithm (**Appendix B**). This decision-support is meant to aid AYA managing their pain. *Note: Because of the importance of providing clinically-sound advice, this algorithm was created in consultation with pain clinicians.* User-ratings of recommendation likability are translated into a 5-point "star-rating". When future pain management advice is given to users, most-liked recommendations are offered first.	No.

	***Pain re-assessment.*** When pain is re-assessed at next survey, users disclose if the previous management recommendation was used and liked. The combination of their pain report and use and likeability of the recommendation are fed back into the algorithm and a new pain recommendation is made (if pain is reported on re-assessment). *Note: the system recognizes 'pain emergencies' (e.g., sustained severe pain based on historically saved survey records) and recommends emergency action.*	No.
	***Calendar.*** Upcoming pain surveys are stored in a Google-synced calendar to allow for planning of activities (important for self-management). Other appointments (e.g., clinic visits) and self-scheduled survey reminders may also be stored.	No.

	***Goal-setting.*** Individualized pain control goals can be set by users. Users can track progress towards their goal over time, promoting both activity-planning and feelings of self-efficacy. Self-rated pain over time can be graphed (up to last 10 records).	All basic functionality present. For future, the graph may be annotated with management recommendations that were used and goals that were achieved.
	***Journaling.*** Users can track their thoughts, progress etc. using text- or video-journals allowing for reflection on progress and the changing of management strategies as needed. These can also be reviewed by users and shared with clinicians if desired.	No.

	***Social-networking.*** As a pain management strategy, users can communicate with peers about their self-management experience and progress via Twitter and Facebook (direct links available from NOpain).	No.
	***Health education.*** Information specific to painful health conditions (written by a healthcare professional [Lindsay]) is accessible. Trusted educational material will empower users in self-management and in communication with clinicians.	No.

	***Settings.*** Several NOpain customizable options are available. The time of day of surveys, frequency of survey reminders and AYA health condition can all be user-specified. This is intended to improve the user experience and use of NOpain.	No.

4.0 Key Learning

4.1 Methods for pain care algorithm development. At the onset of this project we faced two major hurdles: (1) a unified algorithm for managing pain in AYA did not exist and (2) there is no standardized protocol to develop such an algorithm. A decision to use a systematic pain management literature review followed by a consensus conference with experts in pediatric pain to build the algorithm was eventually made. Once preliminary algorithms were drafted, they were vetted by pain experts and revised accordingly.

4.2 Android native calendar functionality. Due to the internal calendar design, using the native Google Calendar platform through the Calendar Provider (CalendarContract classes) was of particular challenge. For example, there is a unique database table for: different calendars, events, reminders. This meant a lot of exposed functionality to track in order to achieve our custom calendar/reminder system functionality. This all gives rise to an important lesson - evaluating different alternatives prior to choosing a developmental path. Using a third party open source calendar platform, if available, might have been a better way forward as it might have been simpler and allowed us to spend more time on other functionalities or on polishing NOpain. In the end, Calendar integration worked successfully and the unneeded functionality (if we were using a third party solution in comparison) is kept to a minimum.

4.3 Functionality first, polish second. The importance of establishing the fundamental functionality of each NOpain component before polishing it (e.g. agile principles) was an important lesson learned. With NOpain, each system component (e.g., pain survey and recommendations) was essentially discussed, designed, coded for and refined fully before development of the next component was initiated. Even when several components were worked on in parallel by the same programmer, polishing the UI and thoroughly testing corner cases took up unnecessary amounts of time. This was problematic in terms of time-management. In retrospect, we would simultaneously begin development on all components and establish their basic functionality before each was completely polished.

5.0 Contribution by Group Members

5.1 Lindsay Jibb. Lindsay built the pain algorithm piece of NOpain. She conducted a literature review and consensus meeting with experts in pediatric pain to decide how to best manage AYA pain. Lindsay researched and developed pain- and disease-specific education, which will be administered via NOpain and developed the NOpain design theme (information gleaned from class lecture by Konrad Group). Finally, she liased with Kush and Bozhidar on all pain-related functionalities of the app (e.g. timing of pain assessments, emergency alerts) to create an app that has the best chance of being clinically effective in managing pain in AYA.

5.2 Kush Dua. Kush implemented the NOpain algorithm that Lindsay designed. The algorithm gives users a set of advice and lets them choose the recommendation they would like to do. The next time the survey is taken, users can rate the previous recommendation and, based on this, the rating for the recommendation goes up or down and the position of the recommendation in the list of suggested ones changes accordingly (the highest rated recommendation is most likely to appear on top). This way the algorithm tailors to user preference over time. The second functionality that he worked on is the journaling module where users can enter their feedback in text and video format and review that at a later point in the future. The last component is the education module where information about different diseases can be found for user-reference.

5.3 Bozhidar Lenchov. Bozhidar implemented the initial survey layout as well as the social and home screens for Spiral 2. For Spiral 4 Bozhidar investigated calendar implementations and initiated database integration into the different modules (not demo'd at that time due to incompleteness). He also collaborated with Kush on the design and testing of the other

screens (journalling, survey and recommendation). For Spiral 6, Bozhidar fully completed the Calendar integration allowing users to save one-time surveys and appointments (to more effectively manage their pain and upcoming schedule) and change recurring ones (e.g. recurring pain survey twice a day at user-specified times). Additionally, Bozhidar finalized the settings screen, health information screen (with educational text content provided by Lindsay) and goals screen (allowing users to visualize their progress by showing them their recorded pain level in recent surveys and share their goals with friends on Facebook and Twitter). Both the settings and goals screens integrate fully with the local database and the data stored in it. He also offered feedback on the general flow of NOpain, and addressed bugs and crashes as they were found throughout the app development.

6.0 Contribution of Project to Apper Field.

Chronic and recurrent pain due to chronic and life-limited diseases or due to unknown causes is a major and common health problem for AYA. Despite advancements in pain management research and clinical practice, pain continues to be problematic for this group. Self-management has shown to be successful in managing other health conditions and has been proposed a means to improve AYA pain-related health outcomes.

Despite this knowledge, major barriers to accessing pain-related self-management programming for AYA exist. These barriers include: limited number of available self-management programs, limited number of trained self-management professionals and the cost of attending programs. Given the scope of this problem, personal suffering involved and limited research that has been undertaken in this population; there is a need for accessible and effective interventions to assist young people in better managing chronic and recurrent pain. Smartphone technologies offer an innovative approach to meet this need.

The NOpain Smartphone app developed through this course therefore represents a first step towards an important improvement in healthcare for AYA with chronic or recurrent pain. In building this app we have drawn on the empirical and theoretical literature to include self-management modalities (e.g., decision-support) that are known to most often result in positive health outcomes. In the future, I will seek to refine this app and rigorously test its effectiveness on pain-related outcomes (e.g., pain intensity, pain duration, pain interference) through a randomized controlled trial. NOpain has the potential to improve pain management for AYA in everyday environments (i.e., out of the hospital), minimize barriers to optimal symptom treatment and enhance interaction with healthcare providers to ultimately improve AYA health-related quality of life.

If found effective, NOpain represents not only a means to manage chronic and

recurrent pain in AYA, but also can act as a model for how healthcare delivery in general may be improved in the future. The rising numbers of people living with chronic health conditions and the movement of healthcare from the hospital to the home, means novel mechanisms to aid in managing health are increasingly needed. Smartphone self-management apps such as NOpain may represent one such mechanism.

In addition, as the apper for this project, I have conducted a systematic literature review of pain management studies. I will seek to disseminate this information to researchers and clinicians through publication. I have also held a consensus conference with experts in pediatric pain to build and vet the algorithms that drive the pain management advice given by NOpain. Once completed and tested, I will also seek to publish this algorithm and the methods I used to build it.

7.0 Future Work

7.1. Polish user-interface. Some undesirable features of the interface should be refined (e.g., spacing of selectable pain management recommendations). To improve the user experience, the interface and functionality (corner cases) should be polished/refined.

7.2 User-centred usability testing. User-centred testing is necessary to develop an app that is well-used. Conducting usability testing with AYA would allow us to: (1) change functionalities, (2) refine the design and interface, (3) ensure NOpain is understandable and (4) reveal and address NOpain technical issues.

7.3 Effectiveness testing. To be adopted by patients and clinicians on a wide-scale, rigorous testing (i.e., a randomized control trial) is necessary to establish NOpain's clinical effectiveness.

7.4 Integration with hospital databases. Ideally, data generated through the use of NOpain would be integrated with an AYA's electronic medical record to streamline care and communication across healthteams. However, this poses several changes including better securing of data stored on the phone, as well as potential security audits and verifications.

8.0 Marketing/Entrepreneurship Next Steps

We support the idea of having a business class taking up marketing of apps developed in

ECE1778.

9.0 App Development Resources Utilized

The Google Calendar Provider page was of particular usefulness (http://developer.android.com/guide/topics/providers/calendar-provider.html).

AChart's API examples available at https://code.google.com/p/achartengine/source/browse/#svn%2Ftrunk%2Fachartengine%2Fdemo%2Forg%2Fachartengine%2Fchartdemo%2Fdemo%2Fchart%253Fstate%253Dclosed were also useful in getting the charting functionality up and running.

10.0 References

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