

Project Name: Building an online portal for patient symptom tracking

Project Period: 24/08/2020 to 17/11/2020

Sponsor(s) or Client: Susanna Park

Organisation: Brain and Mind Centre

Project Supervisor: Waheeb Faiz Mohammad (Tutor)

Background: <i>The context for this project</i>	<p>Chemotherapy-induced nerve damage or peripheral neuropathy (CIPN) is a major side effect of the treatment of cancer, leading to early cessation of treatment and long-lasting disability. Despite successful treatment and long-term survival prospects, up to 40% of cancer survivors may be left with long-term functional disability and reduced quality of life due to CIPN. There are a number of patient-reported outcome measure questionnaires to facilitate collection of patient-relevant symptom data. However, these are largely paper-based and not useful for patients to track their symptoms over time or for clinicians to access information about patient symptoms.</p>
Aim Purpose of the project.	<p>To enable CIPN patients to record symptom information, track the progress of their symptoms over time, and provide their clinicians easy access to this information.</p>
Objectives (SMART): <i>Goals of the project.</i>	<ol style="list-style-type: none"> 1. Patient-focused goal: To streamline the process of symptom tracking for CIPN patients by creating a single space to record and view symptoms. Patients should report an increased ease of symptom recording and an increased understanding of symptoms and their progression over time after using the portal for more than a month. 2. Clinician-focused goal: To allow clinicians to directly access summarised patient symptom information and mitigate the under-reporting of symptom frequency and severity. Discrepancies between patients' survey reporting and clinician reporting should be reduced through the use of the portal. 3. Researcher-focused goal: To enable researchers to utilise aggregated and anonymised symptom tracking data for their research. The data should be used in relevant CIPN studies after the portal has been used by CIPN patients for more than 6 months.
Success Criteria: <i>What does success look like for the sponsor and how can it be measured.</i>	<ul style="list-style-type: none"> ● Patients, clinicians and researchers report positive experiences interacting with the portal. ● The portal is used by a significant number of patients regularly, measured by the number of weekly users and the number of daily users 6 months after the portal is deployed. ● Patients report satisfaction with the symptom tracking process and a greater understanding of their own symptoms and their progression over time. ● Clinicians report a more in-depth understanding of their patients' symptoms. ● Researchers use the symptom tracking data in their research.
Deliverables <i>List the outputs that will be produced as part of the project including the final product or service.</i>	<ul style="list-style-type: none"> ● Final product: online portal for patient symptom tracking ● Final project report ● Final project demo and presentation ● Scope statement ● User stories ● User guide ● Other project documentation completed throughout the course of the project

<p>Scope <i>The work that needs to be accomplished in order to deliver/complete the project.</i></p>	<p>The in-scope requirements are flexible to changing client needs, changing understandings of implementation techniques, and changing time and resource estimations. The scope is expressed in terms of functional and non-functional requirements and divided according to patient, clinician and researcher requirements.</p> <p>Functional requirements:</p> <p>(1) General functional requirements</p> <ul style="list-style-type: none"> ● Ability to create an account of type: clinician, patient, or researcher (admin) ● Ability to recover account password with email or SMS if forgotten <p>(2) Patient functional requirements</p> <ul style="list-style-type: none"> ● Ability for patients to provide their email, password, name, gender, age, mobile number and treatment type on signup ● Ability for patients to approve the anonymous use of their symptom data ● Ability for patients to grant their clinician access to their profile via the clinician's email ● Ability for patients to view and edit their profile information ● Ability for patients to record individual symptoms at any time, with severity on a five-point scale, entry date, and a morning/afternoon/night tag <ul style="list-style-type: none"> ○ Ability for patients to record historic symptoms ○ Ability for patients to edit and delete symptom records ○ Ability for patients to add qualitative descriptions to symptom records ○ Ability for patients to add specific activities that were difficult to complete to symptom records. ○ Ability for patients to configure the frequency of (or toggle on/off) email notifications that remind them to record their symptoms. ● Ability for patients to complete a standardised weekly symptom survey ● Ability for patients to toggle on/off the <i>default</i> weekly email notification reminding them to complete the standardised weekly symptom survey ● Ability to view past symptom records and surveys ● Ability to view symptom trends over time in a graphical format <ul style="list-style-type: none"> ○ Ability to filter by symptom ○ Ability to change the viewed time range ● Ability to export symptom data as (a) raw CSV data or (b) a PDF report, via (a) email or (b) direct download, specifying period of data coverage <p>(3) Clinician functional requirements</p> <ul style="list-style-type: none"> ● Ability for clinicians to provide their email, password and name on signup ● Ability for clinicians to view a detailed or summarised version of each of their patients' symptom data <ul style="list-style-type: none"> ○ Ability to view all past surveys completed by their patients ○ Ability to view symptom trends over time in a graphical format <ul style="list-style-type: none"> ■ Ability to filter by symptom ■ Ability to change the viewed time range ○ Ability to export symptom data as (a) raw CSV data or (b) a PDF report, via (a) email or (b) direct download, specifying period of data coverage
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	<p>(4) Researcher functional requirements</p> <ul style="list-style-type: none"> • Ability for admin researcher account to authorise other researcher accounts • Ability for researchers to provide their email and password on signup • Ability for researchers to view aggregated, anonymised symptom data in a graphical format <ul style="list-style-type: none"> ○ Ability to filter by age, gender or treatment type ○ Ability to filter by symptom ○ Ability to select time range ○ Ability to export symptom data as (a) raw CSV data or (b) a PDF report, via (a) email or (b) direct download, specifying period of data coverage • Ability to modify weekly survey questions <p>Non-functional requirements</p> <p>Accessibility</p> <ul style="list-style-type: none"> • Compatibility with larger and smaller screens • Ensure that the size, spacing and manipulability of buttons are suitable for patients with CIPN, particularly for mobile display • Minimise the use of drop down menus and drag and drop features <p>Privacy: Patient data must be anonymous and be approved for use by patients</p> <p>Security</p> <ul style="list-style-type: none"> • Login must be secure with user authentication • Permissions and restrictions for patients: cannot view other patients' profiles • Permissions and restrictions for clinicians: can only view profiles of patients who have approved them as their clinician by adding their clinician's email to their profile • Permissions and restrictions for researchers: <ul style="list-style-type: none"> ○ Can edit surveys viewed by all patients ○ Can view aggregated and anonymised data
<p>Out Scope <i>Work you are not required to deliver as part of your project</i></p>	<p>Taking an agile scoping approach, the out of scope items may be moved in scope if the team decides that we have the time and resources to complete them. Deciding which features to include, if any, will be a group decision involving a weighting of each features' value and size.</p> <p>Out of scope requirements</p> <ul style="list-style-type: none"> • Symptom severity rating scale is accompanied by a range of facial expressions for more intuitive symptom recording • Ability for patients to fill in a guided notes section to record notable trends in their symptoms (for example, is there anything which makes the symptoms better or worse?) • Ability for patients to select part of an interactive graphic of the body in symptom recording • Ability for patients to upload images to a symptom record • Ability for patients to create a medication schedule with reminders • Ability for patients to record sleep periods and exercise

	<ul style="list-style-type: none"> • Ability for patients to post to a forum to share information and ask questions about symptoms with other CIPN patients • Ability for patients to write journal entries • Ability for patients to access a CIPN information and FAQ page with links to information about the condition • Ability for clinicians to leave notes on their patients' records • Ability for clinicians to edit individual patients' weekly symptom survey to fit their patients' personal situations • Ability for researchers to deep dive specific symptom trends with data analysis techniques and statistical information • Ability for researchers to create new surveys • Ability for researchers to modify the list of recordable symptoms • Dark theme • SMS notifications
Milestones <i>Key checkpoints with the client e.g. client deployment, approval deadlines</i>	Weekly: Client meeting to update on project progress 03/09/2020: First client meeting and project introduction 11/09/2020: Project scope approval 29/09/2020: First project demo and presentation 16/09/2020: First client deployment 17/11/2020: Final project demo and presentation 20/22/2020: Final client deployment
Human Resources: <i>Are there other specialist staff or subject matter experts that will participate?</i>	<ul style="list-style-type: none"> • Researchers at the USYD Brain and Mind Centre • The USYD Brain and Mind Centres's clinician contacts
Other Resources: <i>Are there other resources to be utilized in the project? Data? Equipment?</i>	<ul style="list-style-type: none"> • Web application host for online portal
Reporting/ Meeting Frequency: <i>With what regularity will the team meet with the client and report to the client.</i>	<ul style="list-style-type: none"> • Team will meet with the client once a week, at a minimum • Additional meetings will be scheduled as needed • Team will provide an update on the project progress as well as any issues, risks, or changes to scope or schedule.