Patients

Content Requirements

Display information effectively: cluster information pertaining to the same topic together; apply effective visual hierarchy to enable the identification of priority information quickly; use visual support elements when possible to facilitate communication with patients.

Convey a positive tone: tool should have a warm tone that implies a positive influence on their life.

Clarify actions: support patient compliance by breaking down actions into individual steps with clear sequence.

Reduce complexity: provide definitions for medical terms and keep reading grade level between 5-6.

Align content to user context: reveal content that is relevant to patient.

Provide contextually relevant information and how these factors may effect someone with SCD.

Use common language to describe symptoms, and pair symptoms with recommended actions.

Engage the user: empower patients with ability to set goals and take notes.

Remind the patient: provide patients with option to set reminders to facilitate care.

Allow customization (patient able to customize limited portion of tool): support patient ownership of tool with customizable features.

Content always up to date: create mechanisms for ensuring that the patient-facing tool contains the most up to date medical records, care plans, and pertinent care information and best practices.

User Requirements

Support communication about condition: help patients communicate their healthcare needs and convey concerns related to their disease to their providers.

Focus on lifestyle: educate users on the importance of a healthy lifestyle and assist them in following good practices.

Facilitate planning through self reflection.

Help users identify and avoid pain triggers.

Help users decide when to seek medical help.

Transparent communication and collaboration in care: keep patients informed about their treatment plan and the treatment schedule that the medical staff will follow.

Indicate the context about why some kinds of treatment will be performed.

Secure information: private patient information should be securely stored and sharing is controlled by the user.

Support education and compliance with Hydroxyurea: help patients understand what treatment with HU looks like, including the benefits, risks, and management requirements of using HU to support informed decision making.

Support HU-related responsibilities, including medication adherence, managing lab-related appointments, and pharmacy navigation.

Know how to connect: be able to connect and consult with sickle cell team before going to ED to learn the right pathway and also potentially prevent ED visit.

Structure education: provide information and education for care when it is relevant to the patients needs.

Receive non-medical treatment: get non-medical treatment (e.g. comfort measures like blankets, warm packs, etc.) when SC patient is in ED.

Know when and where to get best care: educate and inform patients on where and when they will be able to receive the best and fastest care for a pain crisis (e.g. the acute care center).

Catalogue pain history: tool allows users to track and monitor their sickle cell symptoms, pain crises, and other health matters, which can be used to start dialog with physicians and community support.

Describe pain: provide patient with way to easily communicate their pain level, location, and type.

Support care compliance: help patients understand how to take their prescriptions, maintain appointments and follow-up visits, and other behaviors required for compliance.

Contextual Requirements

Support understanding and navigation of insurance and benefits: help patients to learn about insurance options and limitations, cost of care, and where their insurance is accepted.

Remind patients to apply for disability (if relevant) or renew insurance to ensure continuity of coverage.

Build community: provide channels for users to connect with other sickle cell patients who have successful experiences managing the disease to learn from each others and discuss their life.

Provide social support: connect patients with support services like social workers who can provide guidance for different life stages.

Help patients learn about available care resources.

Assistance connecting to support services to plan for school and employment.

Support for securing accommodations at school or workplace.

Promote supplemental treatment: empower patients to work toward pain prevention (rather than constantly seeking pain relief).

Learn and adopt alternative treatment options (e.g. mindfulness, various therapies) to potentially reduce need for opioids.

Reduce steps to care: reduce the patient burden to getting care (e.g. getting labs and tests closer to home, easier access to medication).

Providing necessary information and use digital methods to eliminate unnecessary activities and travels.

Adapt to varying levels of resources: consider that some users may not have access to a smart phone or large amounts of data.

Create solutions that can accommodate a range patient situations.

Facilitate flow of information/create common language: tool facilitates communication and interaction between patient and other individuals in care and support network, including medical staff, family, employers, friends, etc.

Team based approach: a team-based approach to care to prevent opioid dependency and addiction as a result of pain treatment.

	Content Requirements	User Requirements	Contextual Requirements
Caregiver	**Align content to user:** reveal content that is necessary for the caregiver to understand disease, provide assistance to patient, and engage with social workers.	**Involve family in care:** create media and tools that will enable caregivers to better understand the disease and assist with care.	**Build community:** provide channels for caregivers to connect with other caregivers who have successful strategies and experiences, and may be able to coach each others. **Team based approach:** a team-based approach to care to prevent opioid dependency and addiction as a result of pain treatment.
ED	**Accommodate existing work style:** care plan should be brief, clear and easy to access when patients come for pain crisis to be compatible with their existing work flow. **Align content to user:** reveal and prioritize content that is enables ED to provide and receive quality information	**Understand the pain:** help to know the location of the pain, quantity of the pain, pain type, differences with previous pain and how to treat it. **Heads up note (patient expect):** heads-up from primary hemotologist about visit history, regimen, labs, initial assessment of the pain, unique circumstances of the patient and reasons why they are sent to ED before patients' arrival. **Validated (and secure) information:** care plan needs to be credible enough for ED to act on; endorsed information comes from sickle cell specialists, branded with institution or primary care hospital, and patients have limited control over the information and data. **Support coordination with SC team:** know primary hospitals and providers of the patients, who should ED call when needed, and how to connect with them during what hours; information about right labs and tests to run based on condition of the patient. **Information for treatment:** an up-to-date consistent personalized care plan includes patients medical history, special conditions need to be noticed, recommended emergency room pain procedures, home pain regimen, and other medical information; updated guidelines for administering medications. **Understand responsibilities:** know the illnesses that the ED provides care for.	**Shareable across hospitals:** medical records (including Sickle Cell Care Plans) need to be more easily shared between different hospitals. **Build community:** provide channels to interact more with patients community to learn about patients' experiences related to the disease and build empathy. **Expedite care process:** assist communication between departments and identify opportunities to transfer patients for care after initial treatment. **Facilitate flow of information/create common language:** timely response from sickle cell center to provide information ED needs instead of asking them to go through all the notes. **Team based approach:** a team-based approach to care to prevent opioid dependency and addiction as a result of pain treatment.
Sickle Cell Team	**Align content to user:** reveal content that is necessary for the Sickle Cell Team to coordinate care with medical system and social workers.	**Heads up:** receive patients' notifications when they have pain crisis and before they come to ED. **Promote and Prescribe Hydroxyurea:** Know the patient's medical history and lifesyle to initiate prescription. Ensure patient understands benefits and side effects, and commitments that patients need to make. **Understand responsibilities:** know the illnesses that the Sickle Cell Team provides care for. **Facilitate flow of information/create common language:** timely medical information from ED to make an assessment of the best treatment plan to make recommendations for the patient in the ED.	**Promote supplemental treatment:** help to create non-medical therapy awareness to help patients understand and take advantage of the benefits of other non-medical therapy. **Assist patient journey:** help patients to establish a regular pattern of primary care for general medicine, rather than regarding the hematology team as their PCPs. **Structured education:** take advantage when patients are in the hospital to educate them step by step to reduce their mental load and resistance. **Team based approach:** a team-based approach to prevent opioid dependency and addiction as a result of pain treatment.

Social Worker

Align content to user: reveal content that is necessary for the Social worker to understand patient needs and interact with medical and social networks.

Involve family with care: identify self-management issues related to struggling relationship with family members and see what services can be provided at home to reduce hospital utilization.

Provide social support: team approach with medical staff to better understand social determinants of health and stressors in patients' life to fully .address needs of sickle cell patients.

Team based approach: a team-based approach to care to prevent opioid dependency and addiction as a result of pain treatment.

| Content Requirements | User Requirements | Contextual Requirements |

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