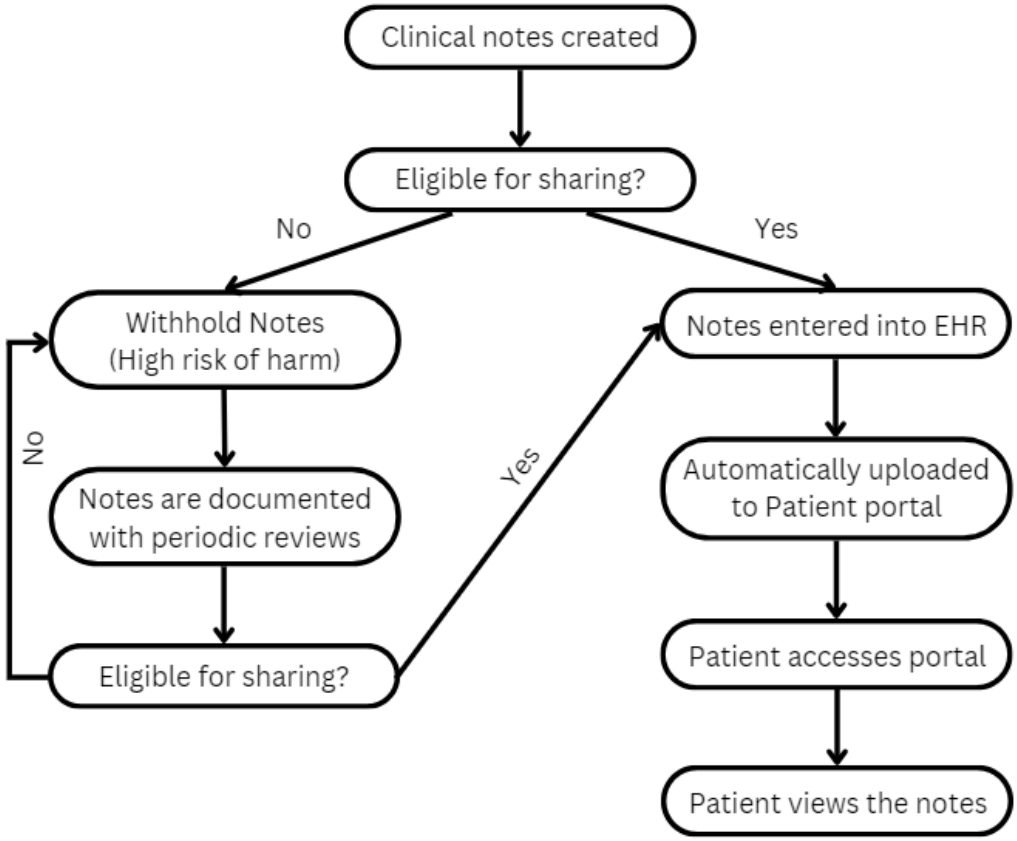
UX Founding Designer Project

Contents

Workflow:



Under the Cures Act, healthcare providers create clinical notes during patient encounters, which are then entered into Electronic Health Records (EHR). These EHR systems, compliant with the Cures Act's interoperability and anti-information-blocking rules, allow patients to access their health data through online portals. This access enables patients to review their medical information, including clinical notes, promoting transparency and better engagement in their healthcare. The process enhances patient-provider communication and care coordination by making health information readily available and understandable, empowering patients to participate more actively in their own health management.

Gaps in the process, the learning about the gap and identifying inefficiencies and potential enhancements:

1) **Patient Portal Transfer:** A significant gap exists in the user experience aspect; patients must acquaint themselves with different patient portals whenever they change healthcare providers. This requirement can lead to confusion and frustration, as each portal may have different interfaces and functionalities.
   Learning about the Gap:

1. **Conduct User Experience Research:** Engage in comprehensive research to identify common issues and preferences among patients regarding different EHR systems and portals.

2. **Utilize Various Feedback Methods:** Employ surveys, focus groups, and usability testing to gather diverse and in-depth feedback.

3. **Analyze Feedback:** Systematically analyze the feedback to determine key areas where EHR systems can be more user-friendly and aligned with patient needs.

Potential Enhancements:

1. Standardization of User Interfaces: Advocate for the standardization of user interfaces across different EHR systems to ease the transition for patients moving between providers.

2. Propose Legislative Amendments: Suggest amendments to the Cures Act or new guidelines that mandate uniformity in patient portal designs to enhance usability.

3. Enhance EHR Vendor Collaboration: Encourage greater collaboration among EHR vendors to adopt common design standards and functionalities, which can help in making system transitions smoother for patients.

2) **Patient meets with an accident abroad:** The Cures Act primarily applies to healthcare systems within the United States and does not cover international jurisdictions or healthcare providers. This presents several challenges in the context of global healthcare and patient data access:
   i) **Jurisdictional Limitations:** The Cures Act mandates access to health information and promotes interoperability within the U.S. healthcare system. However, when a patient is abroad, foreign healthcare providers are not bound by the Cures Act, meaning the act's provisions for data sharing and access do not apply
   ii) **Emergency Access to Health Records:** In emergencies, quick access to a patient's medical history, allergies, and other critical health information is vital. The lack of immediate access to a home country's EHR systems while abroad can impede effective and timely medical treatment.
   iii) **Data Privacy and Security:** Different countries have different laws and standards concerning medical data privacy and security. Navigating these can be complex, and there is a risk that transferring health data across borders could violate privacy laws or lead to data breaches.

Learning about the Gaps:

1**. Global Health Law Research:** Study international health laws and regulations, focusing on how they interact with U.S. laws like the 21st Century Cures Act. This includes learning about the GDPR in Europe, the Personal Information Protection Act in

Japan, and other similar regulations worldwide.
2. **International Healthcare Systems Analysis:** Understand the frameworks of healthcare systems in other popular travel destinations or countries with significant U.S. expatriate populations. This will help in identifying common grounds and barriers in health data management and exchange.
3. **Engagement with International Health Organizations:** Connect with international health organizations like the World Health Organization (WHO) or the International Health Regulations (IHR) to gather insights and recommendations for managing health data for travelers and expatriates.
4. **Case Studies and Incident Analysis:** Review case studies where patients needed emergency medical attention abroad and how issues related to data access were handled. This could provide practical insights into existing protocols and their effectiveness.

Potential Enhancements:

1. **International Health Data Agreements:** Advocate for or participate in the development of bilateral or multilateral agreements focused on health data exchange. These agreements could standardize the process and ensure that critical patient information is accessible regardless of location, adhering to respective privacy laws.
2. **Global Health Data Interoperability Framework:** Develop or support initiatives aimed at creating a global framework for health data interoperability that respects local privacy laws and standards but facilitates necessary data exchange during emergencies.
3. **Education and Awareness Campaigns:** Launch educational and awareness campaigns for travelers on managing their health information while abroad, including how to use international health apps and emergency data access services.
4. **Data Privacy and Security Technology:** Invest in and deploy advanced data privacy and security technologies that ensure the safe transfer of health information across borders without violating any country's privacy laws.

3) **Accessibility for visually impaired:** This presents a notable gap in the Cures Act workflow, particularly in the use of electronic health records (EHRs) and patient portals. Despite the Cures Act's emphasis on broad health information access, many digital health tools fail to accommodate the needs of people with visual impairments. This oversight restricts their ability to independently manage their health data, due to issues like poor screen reader support and inadequate text contrast. Addressing this gap is crucial not only for ADA compliance but also for ensuring equitable access to healthcare for all patients.
Learning about the Gaps:
1. **Disability and Technology Research:** Study current research on the intersection of disability rights, technology, and healthcare. Focus on the challenges and barriers faced by visually impaired individuals in accessing digital health tools.

2. **Feedback from Visually Impaired Users:** Conduct surveys, interviews, or focus groups with visually impaired individuals to gather direct feedback on their experiences and challenges with current EHR systems and patient portals.
3. **Review of Accessibility Standards:** Examine existing accessibility standards, such as the Web Content Accessibility Guidelines (WCAG), to understand how they are applied in healthcare technologies and where gaps may exist.
4. **Technology Assessment:** Audit current EHR and patient portal systems for accessibility features. This can involve collaboration with accessibility experts and usability testing specifically designed for visually impaired users.

Potential Enhancements:

1. **Enhanced Screen Reader Compatibility:** Ensure that EHR systems and patient portals are fully compatible with leading screen readers. This involves not only technical compatibility but also the layout and navigational ease, which are crucial for usability.
2. **Improved Visual Design:** Adjust text size, contrast, and color schemes to accommodate users with low vision. This includes offering high-contrast modes and the ability to customize visual settings according to individual needs.
3. **Accessible Notifications and Alerts:** Implement systems that provide accessible alerts and notifications. For example, ensuring that all alerts are also conveyed through audio or tactile feedback systems can be crucial for visually impaired users.
4. **Training for Healthcare Providers:** Provide training for healthcare providers on the importance of accessibility and how they can assist visually impaired patients in using digital tools effectively. This could include guidance on how to explain the use of accessible features within the EHR system.
5. **Regulatory Enhancements:** Advocate for stronger regulations or enhancements to existing laws to enforce stricter accessibility standards for healthcare technology developers. This could include revising parts of the Cures Act or related healthcare IT legislation to specifically address the needs of the disabled community.

4) **Patient Understanding:** The issue of patient understanding when accessing clinical notes is significant. Clinical notes are often written in medical jargon that can be difficult for the average person to understand. This gap in comprehension can lead to several potential challenges and considerations:

   i) **Misinterpretation of Information:** Patients might misinterpret medical terminology, leading to unnecessary worry or confusion about their health condition. For example, medical terms that sound alarming might be benign, and without proper context, patients could misunderstand the severity or nature of their condition.
   ii) **Anxiety and Stress:** Misunderstanding medical information can increase anxiety and stress in patients. Reading unfiltered clinical notes that discuss potential

complications or uncertain diagnoses without adequate explanation can lead to heightened worry.

iii) **Ineffective Decision-Making:** Without a clear understanding of their health conditions, patients may be unable to make informed decisions about their treatment options. This lack of understanding can impair their ability to engage actively and meaningfully in their care process.

iv) **Overloading Healthcare Providers:** If patients frequently misunderstand their clinical notes, there may be an increase in communication with healthcare providers to seek clarifications. This can lead to additional workload on healthcare systems already under pressure.

v) **Non-Compliance with Treatment:** Patients who do not fully understand their diagnoses or the reasons behind certain treatments might be less likely to follow their treatment plans accurately.

Learning about the Gaps:

1. **Research on Health Literacy:** Dive into studies and literature that discuss health literacy levels across different demographics. This helps understand the baseline knowledge of the average patient and the specific challenges they face in comprehending medical documents.
2. **Patient Feedback Collection:** Conduct surveys, focus groups, or interviews with patients to gather direct feedback on their experiences with accessing and understanding clinical notes. This would provide insights into common areas of confusion and anxiety.
3. **Professional Insights:** Engage with healthcare professionals to learn about their perspectives on the challenges patients face when reading clinical notes. This could include discussions on how they believe medical communication can be improved.
4. **Analysis of Existing Solutions:** Review existing tools and resources aimed at simplifying medical communication, such as patient education platforms or glossaries of medical terms, to evaluate their effectiveness and identify gaps.

Potential Enhancements:

1. **Simplified Clinical Notes**: Develop guidelines for creating patient-friendly versions of clinical notes. These should use layman's terms and avoid complex jargon, or at least provide clear explanations for medical terminology.
2. **Educational Supplements:** Create supplementary materials that can be automatically attached to specific terms or sections of clinical notes. For example, clickable links in an electronic health record (EHR) that provide definitions, explanations, or even short videos explaining complex terms or procedures.
3. **Training for Healthcare Providers:** Implement training programs for healthcare providers on how to communicate more effectively with patients. This could include best practices for verbal explanations and how to create written content that is accessible to

patients with various levels of health literacy.

4. **Interactive Patient Portals:** Enhance patient portals with features that allow patients to easily ask questions about their clinical notes directly within the portal. This could be facilitated through a secure messaging system or a feature that allows patients to highlight text and request clarification.

5. **Feedback Mechanisms:** Introduce mechanisms where patients can provide feedback on the clarity of their clinical notes. This data can be used to continuously improve the readability and patient-centeredness of the information provided.

6. **Health Literacy Campaigns:** Conduct campaigns to improve general health literacy, which would help patients better understand their clinical notes. These could include workshops, informational resources distributed in clinics, or online educational materials.

5) **Language Barriers:** In the United States, a nation characterized by its diverse population where many individuals do not speak English as their first language, language barriers pose a significant gap in the implementf Sta i

healthcare systems that have successfully overcome language barriers.
4. **Legal and Ethical Standards Review:** Review legal requirements and ethical standards related to language access in healthcare, such as those outlined in the Civil Rights Act and guidelines from healthcare accreditation organizations.

Potential Enhancements:

1. **Multilingual Access to EHRs:** Ensure that electronic health records (EHR) systems and patient portals offer multilingual support. This involves not only translating the interface but also ensuring that patient-specific information, like clinical notes, is available in the patient's preferred language.
2. **Translation Services:** Implement robust translation services, both in-person and through technology such as real-time translation apps or services. These services should be readily available across all points of care.
3. **Training Healthcare Providers:** Train healthcare providers in cultural competence and the importance of language access. This includes using interpreters effectively and understanding the cultural context that influences how patients interact with healthcare systems.
4. **Community Outreach Programs:** Launch outreach programs in communities with high non-English speaking populations to educate them about available language resources and how to access health information in their preferred language.
5. **Feedback and Continuous Improvement:** Establish mechanisms for ongoing feedback from non-English-speaking patients to continuously improve language services. This could involve regular surveys, community engagement sessions, and feedback incorporated into system updates.

6) **Patient Access Issues:** All patients might not have easy access to the patient portal, which might be the case due to factors like technology limitations, lack of internet access, or low digital literacy. Alternative methods for accessing notes might be necessary to ensure equity.

Learning about the Gaps:

1. **Technology Access Research:** Study the extent of technology and internet access across different demographics and regions in the U.S. This helps identify which populations are most affected by access issues.
2. **Patient Surveys and Feedback:** Conduct surveys or focus groups with patients who have reported difficulties or who are likely to face barriers in accessing digital health tools. This feedback is crucial for understanding their specific challenges and needs.
3. **Digital Literacy Studies:** Examine studies on digital literacy levels across various populations to better understand the skills gap that may prevent effective use of health information technology.
4. **Review of Alternative Access Methods:** Look into current alternative methods for

accessing health information that do not rely on direct internet access or advanced technology use, such as telephone-based information systems or mailed paper copies.

Potential Enhancements:

1. **Multiple Access Channels:** Provide multiple ways for patients to access their health information. Besides online patient portals, consider options like phone-based systems where patients can receive information through voice prompts, and secure mail services for receiving physical copies of health records.
2. **Community Health Access Points:** Establish community access points in libraries, community centers, and clinics where patients can use computers with internet access to log into their health portals. Staff or volunteers could assist patients in navigating the systems.
3. **Enhanced Support for Digital Literacy:** Offer digital literacy programs tailored to help patients navigate EHR systems. These could be set up as part of community education programs or provided through healthcare providers.
4. **Offline EHR Access Solutions:** Develop and provide offline solutions that allow patients to access their health records without needing continuous internet connectivity. This might involve secure apps that sync information when internet access is available but can be accessed offline.
5. **Mobile Optimization and Low-Tech Solutions:** Ensure that patient portals and EHR access tools are optimized for mobile devices, which might be more widely accessible than computers. Additionally, consider simpler, low-tech versions of these tools that can operate on basic mobile phones or through SMS-based interfaces.

User Testing and Feedback:

Stakeholders:

1**. Patients**

- Diverse Demographics: Include patients of various ages, backgrounds, languages, and health conditions to ensure the solutions are inclusive and address the needs of a diverse population.

- Special Needs Groups: Specifically include patients with accessibility needs, such as those who are visually impaired or have other disabilities, to test the usability of accessibility features.

2. **Healthcare Providers**

- Doctors and Nurses: Engage medical professionals who use EHR systems daily. Their insights on usability and functionality are vital for practical improvements.

- Administrative Staff: Include receptionists, medical record clerks, and other administrative personnel who interact with EHR systems, as they often handle patient data transfers and need efficient workflows.

3. **Healthcare IT Professionals**

- System Developers and Engineers: The technical team that develops and maintains the EHR systems can provide insights into what is technically feasible and help troubleshoot issues during testing.

- Data Security Experts: Involve cybersecurity experts to ensure that any changes or new features maintain or enhance the security and privacy of patient data.

4. **User Experience (UX) Designers and Researchers**

- UX Designers: The primary designers who will be iterating on the system based on feedback and testing results.

- Human Factors Engineers: Specialists in designing systems that accommodate human usability and limitations, crucial for making systems intuitive and user-friendly.

5. **Regulatory and Compliance Experts**

- Legal Advisors: To ensure all modifications comply with relevant health information laws, such as HIPAA in the U.S.

- Standards Compliance Officers: These stakeholders ensure that the systems meet national and international standards for health data interoperability and accessibility.

Plan for testing prototype with each type of stakeholder:

1. **Patients**

Plan:

- Objective: Test usability, accessibility, and patient engagement features.

- Participants: Diverse demographics and special needs groups.

- Scenarios:

- Accessing Medical Records: Evaluate ease of accessing and understanding personal health information.

- Communication with Providers: Test features for messaging and telehealth consultations.

- Accessibility Features: Specifically test for visually impaired patients using screen readers and other assistive technologies.

Execution:

- Method: Individual testing sessions.

- Tools: Screen recording, usability testing software, feedback forms.

- Facilitators: UX designers and researchers.

- Duration: 0.5-1 hour per session.

Follow-up:

- Collect Feedback: Immediate verbal feedback and detailed feedback forms.

- Analyze Data: Identify common usability issues and areas for improvement.

- Iterate: Make necessary changes based on feedback and retest.

2. Healthcare Providers

Plan:

- Objective: Test usability, functionality, and efficiency of workflows.

- Participants: Doctors, nurses, and administrative staff.

- Scenarios:

  - Patient Check-in/Check-out: Test the efficiency of administrative tasks.

  - Electronic Health Records (EHR) Navigation: Assess ease of entering, updating, and retrieving patient information.

  - Order Entry and Management: Evaluate the process for ordering tests, prescriptions, and referrals.

  - Clinical Decision Support: Test the effectiveness of decision support tools integrated into the system.

Execution:

- Method: Group and individual testing sessions.

- Tools: Screen recording, usability testing software, workflow simulations.

- Facilitators: UX designers and researchers.

- Duration: 1-2 hours per session.

Follow-up:

- Collect Feedback: Immediate verbal feedback and detailed feedback forms.

- Analyze Data: Identify workflow bottlenecks and usability issues.

- Iterate: Make necessary changes based on feedback and retest.

3. IT Professionals

Plan:

- Objective: Test technical feasibility, system performance, and data security.

- Participants: System developers, engineers, and data security experts.

- Scenarios:

 - System Integration: Test integration with existing systems and data interoperability.

 - Performance Testing: Evaluate system performance under various load conditions.

 - Data Security: Test security features, including data encryption, access controls, and breach detection mechanisms.

Execution:

- Method: Technical testing sessions.

- Tools: Performance testing tools, security testing tools, integration testing tools.

- Facilitators: Lead engineers and security experts.

- Duration: Multiple sessions over a week.

Follow-up:

- Collect Feedback: Detailed technical reports.

- Analyze Data: Identify technical issues and areas for improvement.

- Iterate: Make necessary changes based on feedback and retest.

4. User Experience (UX) Designers and Researchers

Plan:

- Objective: Test user interface (UI) design and overall user experience.

- Participants: UX designers, human factors engineers.

- Scenarios:

 - Usability Testing: Conduct comprehensive usability tests covering all major user interactions.

 - A/B Testing: Compare different design variations to determine the most effective UI elements.

- User Satisfaction: Measure overall user satisfaction and identify pain points.

Execution:

- Method: Lab-based testing and remote usability testing.

- Tools: Usability testing software, eye-tracking tools, satisfaction surveys.

- Facilitators: Lead engineers and security experts.

- Duration: Ongoing testing throughout the prototype development.

Follow-up:

- Collect Feedback: Usability test results, user satisfaction scores.

- Analyze Data: Identify UI design issues and areas for improvement.

- Iterate: Make necessary changes based on feedback and retest.

5. Regulatory and Compliance Experts

Plan:

- Objective: Ensure compliance with relevant health information laws and standards.

- Participants: Legal advisors, standards compliance officers.

- Scenarios:

  - Legal Compliance: Review features for compliance with HIPAA and other relevant regulations.

  - Standards Compliance: Test the system against national and international health data standards.

Execution:

- Method: Documentation review and compliance testing.

- Tools: Compliance checklists, legal review documents.

- Facilitators: UX Designers, Lead engineers and security experts.

- Duration: Several review sessions.

Follow-up:

- Collect Feedback: Compliance review reports.

- Analyze Data: Identify compliance issues and areas for improvement.

- Iterate: Make necessary changes based on feedback and retest.

Methods for collecting and integrating user feedback into continuous improvement cycles

1. Feedback Collection

- Structured Surveys and Questionnaires: Develop detailed surveys tailored to each stakeholder group to capture both quantitative and qualitative feedback. Questions should be specific to the features tested and the roles of the respondents (e.g., usability for healthcare providers, compliance issues for legal advisors).

- In-depth Interviews: Conduct one-on-one interviews to gather more nuanced insights, especially from stakeholders who have complex or critical feedback that might require elaboration.

- Focus Groups: Organize focus group sessions with stakeholders to facilitate a discussion about the prototype, encouraging interaction that can yield deeper insights into user experience and functionality.

2. Data Analysis

- Thematic Analysis: For qualitative data, perform thematic analysis to identify common themes or issues across different stakeholder feedback. This helps in understanding broader usability or functionality problems.

- Statistical Analysis: Use statistical tools to analyze quantitative data from surveys, providing a measurable understanding of issues like system performance metrics or user satisfaction ratings.

3. Prioritization and Planning

- Urgency-Importance Matrix: Use an impact-urgency matrix to prioritize feedback based on the severity of the issue and the impact of its resolution on the user experience. This helps in addressing the most critical issues first.

- Roadmap Integration: Integrate the prioritized changes into the development roadmap. Plan sprints or phases in which these changes will be developed and tested, ensuring resources are allocated efficiently.

4. Implementation and Iteration

- Development Sprints: Implement the prioritized feedback in development sprints, using agile methodologies to quickly adapt and evolve the prototype.

- Prototype Re-testing: After modifications, re-test the prototype with the same stakeholders to ensure that the changes have addressed the initial concerns. This iterative testing cycle is crucial for continuous improvement.

5. Stakeholder Communication and Engagement

- Feedback Loop Closure: Communicate back to the stakeholders how their feedback has been implemented. This transparency builds trust and encourages continuous engagement.

- Ongoing Engagement: Establish regular check-ins or updates with stakeholders to keep them informed about progress and to continue gathering ongoing feedback as more features are developed or refined.

6. Documentation and Compliance

- Change Log and Documentation: Maintain detailed documentation of all feedback, changes made, and the rationale behind these decisions. This is important for future reference and for compliance with regulatory standards.

- Regulatory Review: Ensure that changes made based on stakeholder feedback are reviewed for compliance with relevant healthcare regulations, such as HIPAA in the U.S., to avoid legal issues.

Pain-points within the Cures Act and how they can be improved.

Patient:

1. Understanding Medical Information

- Pain Point: Clinical notes and other medical records often contain complex medical jargon that is difficult for the average patient to understand.

- Solution: Implement tools within EHR systems that automatically simplify or provide explanations for medical terminology. Offer supplementary educational content such as videos or diagrams to help patients better understand their conditions and treatments.

2. Interoperability and Data Portability

- Pain Point: Patients may struggle with transferring their health information between different healthcare providers, leading to incomplete or inaccurate health records.

- Solution: Advocate for and develop standards that ensure interoperability between different EHR systems. Provide patients with a centralized digital health record that they can control and share with any provider seamlessly.

3. Accessibility Issues

- Pain Point: Patients with disabilities, including visual impairments, often find EHR systems difficult to navigate.

- **Solution:** Design EHR interfaces that are fully accessible, incorporating features like screen reader compatibility, high contrast modes, and audio descriptions. Conduct regular accessibility audits to ensure compliance with ADA guidelines.

4. Data Privacy Concerns

- **Pain Point:** Patients may have concerns about the privacy and security of their medical information, especially when it is accessible online or shared across platforms.

- **Solution:** Strengthen data protection measures by implementing end-to-end encryption, robust authentication mechanisms, and clear patient consent protocols. Regularly educate patients on how their data is protected.

5. Language Barriers

- **Pain Point:** Non-English speaking patients or those with limited English proficiency may find it challenging to access and understand their health information.

- **Solution:** Offer multilingual support within EHR systems, including translation services for clinical notes and other medical documents. Employ multilingual staff and interpreters to assist in communication.

6. User-Friendly Interface

- **Pain Point:** EHR systems can be difficult to navigate, especially for older adults or those not familiar with digital tools.

- **Solution:** Design intuitive, user-friendly interfaces that cater to a broad demographic. Include tutorials and in-person help options to guide patients through the process of accessing and understanding their health information.

7. Overwhelm with Information

- **Pain Point**: Patients can feel overwhelmed by the volume of information made available to them, especially when receiving new diagnoses or treatment plans.

- **Solution:** Offer personalized dashboards that prioritize critical health information and alerts. Provide options for patients to customize the dashboards show only the information they deem most important, such as upcoming appointments, medication schedules etc.

Healthcare workers:

1. Time-Consuming Data Entry

- **Pain Point:** The requirement to input detailed data into EHR systems can be time-consuming, reducing the time available for direct patient care.

- **Solution:** Implement more efficient data entry methods such as voice-to-text transcription, and simplified user interfaces that reduce the number of steps to enter or retrieve data.

2. Interoperability Between Systems

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7. Regulatory Compliance

- **Pain Point:** Navigating the complexities of healthcare regulations, including those related to the Cures Act, can be challenging and time-consuming.

- **Solution:** Provide clear, concise, and regularly updated guidelines on regulatory requirements. Offer legal and compliance support to help practitioners understand their obligations and ensure compliance without excessive burden.

Conclusion

This comprehensive analysis of the 21st Century Cures Act underlines the critical importance of continuously improving healthcare technology to better meet the needs of all stakeholders involved. By addressing gaps in patient portal transfers, international access to health records, accessibility for the visually impaired, language barriers, and other critical areas, the project aims to enhance the functionality and user-friendliness of EHR systems. The emphasis on rigorous user testing and feedback integration across diverse demographic groups ensures that the solutions not only comply with the Cures Act but also advance patient engagement and healthcare delivery. As we move forward, it is essential to maintain this momentum of innovation and collaboration, ensuring that healthcare technology evolves in tandem with the needs of patients and healthcare providers, ultimately leading to a more efficient, inclusive, and patient-centered healthcare system.