Adapting Design Methodology to Enhance Physician Workflow in IBD EHR Systems

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Abstract

Electronic Health Records have the potential to enhance service delivery in the healthcare sector, yet their complexity frequently leads to inefficiencies and user resistance. A major challenge in this context is the identification and interpretation of correlations between diseasespecific parameters, requiring domain expertise. In response to these challenges, a collaborative research effort with domain specialists is underway to develop a Domain Expert-Oriented Design of a User Interface for the registry of Inflammatory Bowel Disease (IBD) patients. This tool aims to be both a database and a basic statistical tool, designed in the physician's natural working environment. The development of this tool is guided by a modified Patient Experience Design framework that is tailored to the specific requirements of healthcare professionals and uses a customized version of the Double Diamond Design model to improve data collection from clinicians and enhance effective interdisciplinary collaboration. This research initiative represents a potentially important contribution to the field of IBD, especially given the absence of existing tools offering comparable functionality.

Keywords: User Experience, Domain Expert Centered Design, Electronic Health Records, Inflammatory Bowel Disease

1 Introduction

User Experience (UX) [3, 11, 13] in healthcare impacts the efficiency and effectiveness of patient care, particularly in managing complex diseases like Inflammatory Bowel Disease (IBD). A well-designed UX is essential for improving diagnostic precision and optimizing clinical workflows, leading to better health outcomes [6]. However, the treatment and management of IBD are often challenged by the limitations of existing Electronic Health Record (EHR) systems, which usually struggle with usability issues due to their complex designs, potentially impacting

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the decision-making processes of healthcare professionals.

This article aims to address these challenges by designing a user interface for the EHR system, specifically tailored for IBD management, involving domain experts during the design process. It focuses on overcoming existing problems by emphasizing explainability, which ensures that the system's data is easily understandable and interpretable by healthcare professionals, thereby facilitating more informed decision-making. The intention behind this methodology centered on domain experts is to enhance the management and understanding of IBD, ensuring an optimal UX for the professionals involved in this domain.

2 Related work

To ensure that the result of our work is effective in delivering a positive user experience, it is important to select an appropriate design methodology. Various approaches, including the one introduced by Sedlmair et al.[14], provide a foundational framework for the development of domainspecific methodologies. In this context, our work aims to explore the integration of a Domain Expert Centered Design methodology, inspired by the principles of Patient Experience Design. Secondly, we need to highlight the importance of data visualization consistency within EHRs. Finally, we analyze the available solutions that have partially attempted to address these issues.

2.1 Patient Experience Design

The standard double diamond approach [2, 1, 10], commonly used in domain-specific areas like medicine, proves insufficient, leading to the development of the Patient Experience Design (PXD). This methodology represents a major change in how healthcare services are designed and delivered, focusing primarily on the needs of the patient. It marks a significant shift from traditional healthcare models, where patient interactions were often secondary to clinical procedures and operational efficiency.

Lisa K. Meloncon defines PXD as a systematic approach aimed at exploring the relationships between technology and human activities in healthcare [12, 9]. As

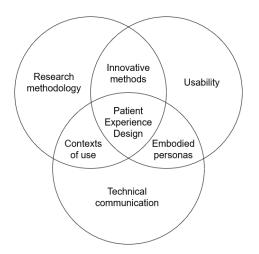


Figure 1: Knowledge domains of PXD with primary concepts [12].

demonstrated by Meloncon in Figure 1, PXD brings together 3 main domains of knowledge: Research methodology, Usability, and Technical communication. The author details them in her study as outlined below [12]. Research methodology refers to the systematic methods and approaches used to collect information and insights that are subsequently applied in the next phases of development. Usability domain emphasizes the need to create patient experiences that are intuitive, efficient, and satisfying. Technical communication encompasses the communication of complex medical information to patients in a way that is easily understandable for them. The author further explains that the overlapping areas are the primary concepts of PXD that are drawn from each domain of knowledge [12]. Understanding the Context of use is important for designing experiences that are relevant and tailored to the patient's needs. Embodied personas emphasizes a more detailed understanding of personas - including the physical and emotional state of the users. Usage of Innovative methods (use of new technologies, unconventional approaches to problem-solving) can affect the resulting experience with the product.

2.2 Design and Visualization Techniques in EHR Systems

The usability and effectiveness of EHR systems are heavily dependent on how data is visualized and interacted with by domain experts [8]. Kenichiro Fujita et al. [6] highlight the importance of identifying key attributes in these records for effective processing and management. The most common attributes are patient identifiers, timestamps of interactions within the EHR system, and the specific primary data types relevant to the current system, which are subsequently broken down into more specific elements, as shown in Figure 2. Decomposing complex concepts into smaller, more manageable parts, facilitates a deeper understanding of the data and enhances their visualization.

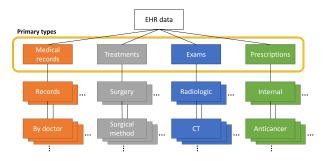


Figure 2: The example tree structure of EHR data types and primary types [6].

Based on the identified attributes, the author proposes the following screen design principles for effectively displaying EHR data: Displaying single patient data in one view, Summarizing data for an overview and providing details on demand, Displaying data in a time-series format, Categorizing data by primary type, and Displaying more data simultaneously when the above principles are met.

By adopting specific principles such as categorization by data type, time-series display, and summarizing data with detailed views on demand, the author further proposes three distinct screen designs, as shown in Figure 3. All of them use color-coding as a visualization technique, categorizing information by EHR primary types. **Design 1** organizes data in a time-series format. Each data point shows a title and expands to reveal details upon interaction. **Design 2** presents data in a matrix layout with two axes - time-series and primary type. This design incorporates all the principles and displays the most data. **Design 3** arranges data in time-series, where selecting a point displays detailed data.

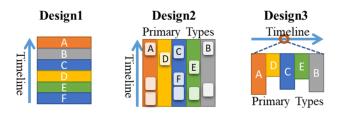


Figure 3: Screen designs using proposed principles [6].

2.3 Research Registries in IBD EHR Systems

Research registries have become essential in advancing medical knowledge, providing comprehensive databases for systematic study. Regarding IBD EHR systems, the only publicly accessible tool is the UR-CARE demo database¹. The UR-CARE database [4], initiated by the European Crohn's and Colitis Organisation (ECCO), aims to enhance patient care and support Inflammatory Bowel Disease (IBD) research, standing out as a dedicated platform in this area. Developed through the collaboration of IBD specialists and contributors from national research database projects throughout Europe, UR-CARE facilitates data collection on IBD symptoms and other key patient data. It covers disease characteristics, diagnostic tests like endoscopy, treatments, and lab results. Additionally, UR-CARE enhances user experience by automatically calculating various indicators, such as the Simple Endoscopic Score for Crohn's Disease, from the data provided.

Aside from the patient's health card management, UR-CARE (demo version) consists of 3 other components: Filters, Statistics, and Inboarding website. In the Filter section, users can create filters using existing patient list or use the already created ones, to aggregate interesting information into different groups according to chosen attributes and set conditions. Subsequently, in the Statistics section, these custom filters are utilized to conduct a deeper analysis of the most important attributes. The statistics can be visually represented using descriptive statistics or one of the three available types of graphs: bar chart, pie chart, and evolution chart. However, the data representation is not focused on usability, which makes it difficult for physicians to make well-informed decisions.

3 Contribution

In this paper, we presented a new approach to the prototyping process called Domain Expert Centered Design, arising from the modified Patient Experience Design [12]. Our year-long case study with medical professionals demonstrated the efficiency of this approach, underscoring the importance of a flexible methodology. An important component of our method was the emphasis on contextualizing information during the communication process, which significantly enhanced the development workflow and led to better feedback from domain experts.

As a contribution, we have created an intuitive user interface for a research-oriented Electronic Health Record (EHR) system, designed with a focus on IBD, using our proposed framework. This system stands out for its straightforward data organization and user-friendly design, which aligns closely with physicians' daily routines, aligning closely with their workflow. While the current system contains only core functionality, its potential for evolution into a comprehensive assistant tool for doctors presents an exciting avenue for future development.

4 IBD EHR System Design Proposal

The collaboration between domain experts in IBD, encompassing both clinical and surgical expertise, and IT professionals is essential. Domain experts require analytical skills to uncover hidden patterns and achieve effective data matching for research insights, while IT specialists do not have specific domain knowledge and depend on domain experts to provide it. This collaborative approach led to the creation of a research-oriented IBD EHR system.

4.1 Design Methodology

This system is designed using a Domain Expert Centered Design methodology, integrated with an expanded Double Diamond design process [1], to ensure the system is as intuitive as possible. The main goal is to develop a prototype of the system aimed at assisting doctors in monitoring the state of a patient's disease more effectively, while also enabling the aggregation of patient data for further research of IBD. The topics discussed in Section 2 Related Work primarily focus on Patient Experience Design, yet this approach is almost equally applicable to physicians. It is common for individuals to articulate a full idea more effectively when the information's context is visually represented, as is the case here. Hence, we decided to alter the traditional Double Diamond framework [2, 10, 1]. The main idea is that information gathered during each session would be subsequently analyzed and incorporated into the prototype. This means that the process does not follow a predefined order of phases but instead transitions between them as required. This adjustment not only enhances the development process in terms of quality but also elevates the domain expert experience design.

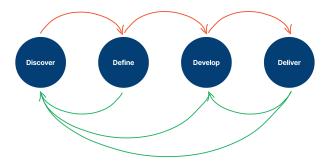


Figure 4: Modified diagram of the Double Diamond. The red color represents the original Double Diamond, and the green color represents extra steps.

During the first phase, **Discover**, the UX team tries to develop a mutual understanding and a shared language between them and medical experts through collaborative interviews and prototype demonstrations [5], which is more challenging than the traditional prototype development, due to the necessary knowledge and expertise in the medical domain. The **Define** phase focuses on information processing. As described before, it's common to find that not

¹Available online, accessed on 10/03/2024: https://perseed.eu/urcare/index.html

all necessary information is available at this stage. As a result, the gathered information is processed, with previously collected data, and any gaps are addressed in the next meeting. During this phase is also created a specific type of persona called an embodied persona [12]. It enables a deeper and more precise identification of the specific needs and objectives related to the problem, as described in Section 2.1. Collaborating with a domain expert requires expertise in a given area that the average person does not have, leading to the creation of a second persona, the IT development team. The UX team then serves as a mediator, facilitating the exchange of information between the domain experts and the IT team. This mediator approach is not typically observed in the traditional development process, highlighting a unique aspect of our methodology. The rest of the second phase remains the same as in the Double Diamond methodology. In the third phase, **Develop**, the goal is to visualize and refine the ideas generated in the previous meetings. Unlike the traditional approach, prototyping does not follow the usual sequence of prototyping. In this specific case, the process begins with basic layout sketches and quickly progresses to more detailed wireframes-mockup hybrid prototypes. The reason for moving directly to hybrids in this phase is to enable doctors to provide effective feedback. Seeing more detailed screens allows them to comment specifically on what aspects of the design align with their workflow, what differs from their current practices, and what elements might be unnecessary or unhelpful. Feedback obtained from the following consultations is systematically integrated into the design revisions, which is the Deliver phase. These changes have to be integrated rapidly, in order to provide better feedback at the next meeting with domain experts. Following multiple iterations of the prototype, when both sides are satisfied, the process progresses to usability testing, which would be conducted according to traditional methodologies.

4.2 IBD EHR System

The collaborative approach described in the previous Section led to the creation of an intuitive user interface for the IBD EHR system. The system proposal incorporates insights gathered from the Section 2 Related Work. The IBD data are systematically categorized as illustrated in Figure 5. Categories arise from the actual process of examination in the IBD domain. Consultations are regular examinations of the patient's overall health, during which physicians may request additional examinations to obtain a current comprehensive overview. Decisions regarding treatment or surgical operation are made during these consultations, hence their inclusion within the consultation category in the tree structure. Examinations like endoscopy or magnetic resonance imaging are also part of the patient's overall condition, but they do not fall under the consultation itself.

In the prototype, the data is placed under the "Consul-

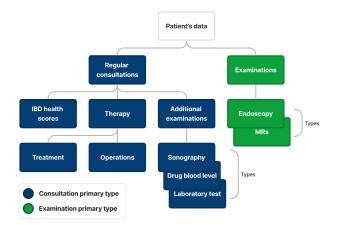


Figure 5: Primary types of IBD data in our work.

tation and examinations" tab. Within this section, data is presented in two ways: a table and a timeline. For domain experts, the timeline view is more important as it provides a visual representation of the patient's overall condition over time. Our design, based on Design 3 [6] (more in Section 2.2) with slight modifications, plots examination points along the time-series axis. These points are coloured based on examination type, helping doctors in visualization. Clicking on a point reveals detailed examination information, organized by primary types using tabs. The interesting feature of our design is that the timeline also incorporates additional sub-levels of IBD data, including current treatment, surgery, and a specific index for Crohn's disease (pCD). This type of extended timeline assists physicians in decision-making and planning further treatment strategies.

Simplifying the process of adding examinations is made more straightforward and user-friendly. In the "Consultation and examinations" section, simply selecting "Add new exam" enables the physician to input essential data without navigating through multiple steps, as in the UR-CARE registry [4]. Notably, our system stores only relevant data to prevent system overload. The research part of the register differs mostly in the study part. Filter creation operates on a similar principle to UR-CARE [4], where doctors specify a parameter and its expected value. In the study part of our IBD registry researchers choose their focus - examining relationships between two variables in a group or comparing a variable across groups. They use an interface for dynamic variable adjustments and a graphical representation, limited to continuous graphs for consistency in study evaluation. In contrast, the UR-CARE system [4] is limited to using just one filter per study, enabling users to choose and graph multiple variables. These are then displayed sequentially, which may affect their readability.



Figure 6: Representation of a patient's IBD data in our work using time-series. The C section represents primary data, coloured by examination type. A Section represents treatment, the B section is for operations and D is the specific index for Crohn's disease. A, B and D sections offer complementary information to the C section.

5 Case Study

The methodologies and design process we proposed were validated through a case study lasting over a year, during which the design process for the research-oriented IBD EHR system was applied to create the user interface design and specifications for iterative agile development.

5.1 Domain-specific Observation

The primary objective of the observation was to gain essential knowledge for the project's development. This included establishing a shared language, identifying the needs and goals of domain experts, and ensuring that before each meeting, the UX team had analyzed information from previous discussions and outlined key points for the upcoming session.

Focus groups with medical practitioners were scheduled twice a month. In the beginning, these sessions primarily focused on doctors' approach to patient examinations, diagnostic processes, and treatment strategies, highlighting the important need for personalized care strategies. The shared language was not immediately clear, it required about 2-3 meetings for the UX team to understand the complexities of the disease and also for domain experts to understand our collaborative approach, including data structuring, providing factual information, staying on topic, etc. The sessions were not strictly moderated to encourage a natural discussion flow. This approach was adopted after realizing that structured moderation limited the number of insights gained from doctors. Allowing the conversations to develop more freely led to more comprehensive feedback from the medical professionals.

These interactions also provided insights into the tools utilized in their practice, specifically the UR-CARE tool and the hospital's primary patient record system. It was identified that exporting data from the system is difficult, and the readability of medical reports is not appropriate. Important information for doctors, such as patient's medical history, treatment details, and screening examinations, are either inadequately presented in the current system. The system currently does not support efficient viewing of screening examination snapshots or adding notes to them. Furthermore, the meeting also highlighted the need for better organization and accessibility of laboratory parameters within the system, as well as the integration of medical reports from various sources.

5.2 Domain-specific Ideation

The domain-specific ideation phase has its goals in defining Personas, Information Architecture, User Scenarios, and User Flows in order to formalize and better understand the knowledge transferred from the domain experts from the observation phase.

Persona

The persona of Dr. Alice was derived from direct interactions with three experienced gastroenterology physicians. These interactions provided insights into the daily operational challenges and technological "pain points" experienced in the field. Unlike common persona creation, a domain-specific approach requires a deeper understanding of the researched field, including technical aspects, specialized tasks, and the specific goals and challenges faced by users within that context.

User Scenarios

Correct application of the proposed methodology in the Observation phase required identifying user scenarios that match the experiences of the doctors we spoke with. This section enumerates only the most important scenarios through motivators that have been identified, covering



Dr. Alice

- Research-oriented Gastroenterology doctor.
 EHR systems (AMBIS) are confusing and intricate.
 The UR-CARE app is unnecessarily overloaded with
- The UR-CARE app is unnecessarily overloaded with information that is not essential for research.

Cannot always identify disease in its initial stage.

Apps

AMBIS: ambulatory system UR-CARE: online international registry capturing IBD patients' records

Figure 7: Persona of Dr. Alice.

all aspects of the proposed application.

- 1. Dr. Alice has examined the patient and needs to record the examination results in the patient's record.
- 2. Dr. Alice has to add new test results to a patient's record for further examinations.
- 3. Dr. Alice wants to review and analyze a patient's health trends for better medical assessment.
- 4. Dr. Alice needs to create a filtered group of patients that meets her specific criteria for a more targeted analysis in her research.
- 5. Dr. Alice wants to visually analyze the relationship between different health parameters (using a chart) for a specific patient group in her IBD study.
- 6. Dr. Alice needs to use the data for further analysis outside the IBD research system. She wants to be able to work with all relevant data from her study, including charts, patient lists, and other related information in an external statistic tool.

Information Architecture

The design of Information Architecture (IA) was inspired by the UR-CARE registry (for consistency), enhanced using insights gained from the observation phase. Our proposed system consists of 3 main sections - User management, Electronic Health Records, and the Statistics section. The core part of the IA is the IBD EHR system itself, which can be seen in Figure 8. The User management part of the IBD EHR system is not included, as it is out of the scope of our research.

Since the doctors were already familiar with the UR-CARE application, we tried to keep this structure in the new one and modify it according to our needs. The statistic part has the same structure as UR-CARE, it is divided into 2 sections: one for filtering a group of patients and another for descriptive statistics of studies. This division is based on the insights from the Observation phase, where a domain expert's initial step in new research involves defining the study group. Within the registry, the patient management section is preserved, while the method of adding patient examinations and other medical records differs in many aspects. Based on the insights from observation, we

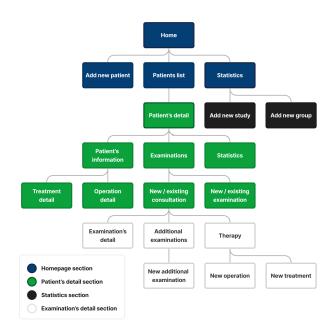


Figure 8: Information Architecture of research-oriented IBD EHR system. Colors in the legend represent different subsections of the Information Architecture.

organized the data and discovered that the entire data input procedure revolves around patient examinations. For their research, it's important to attach a timestamp to each piece of data, enabling them to efficiently filter and explore additional correlations. Consequently, the primary tier is the examination, which is then subdivided into specifics, subsequent related examinations, and the patient's therapy.

User Flows

After the scenarios were specified, the next step involved defining User Flows to ensure precision in the subsequent prototyping stage. These flows were based on already created User scenarios, requiring minimal additional specifications. Within the EHR part, beyond managing patient information, understanding the complex process of patient examinations was essential to ensure the system matches the real patient examination process. During the development of User Flows for the Statistics module, it was also important to consider findings obtained from user research conducted in the Observation phase. They indicated that doctors prefer initially to define a patient group for their studies, followed by the need to monitor specific data in the selected group. These insights were subsequently converted into User Flows.

5.3 Prototyping

As outlined in Subsection 4.2 IBD EHR System Design Proposal, the prototyping phase started with low fidelity prototypes. They were not drawn on paper, but using an online collaborative whiteboard. The primary purpose of these low fidelity prototypes was to define the layout of the application and to illustrate the flow of information within the proposed system.

In the subsequent phase, we started creating wireframemockup hybrids, which was based on insights from meetings with physicians and brainstorming sessions inside the UX team. The prototype presentation revealed significant gaps in our initial designs (mainly for domain knowledge misalignments), leading to the rejection of approximately 60% of the very first design decisions. However, this process was also valuable, because of providing important insights from practitioners who highlighted the differences between our proposed designs and their real-world practice, guiding necessary refinements. Design validation sessions with doctors became more frequent, and all changes were consulted continuously. Each session systematically progressed through the defined user scenarios using visualized interactive high-fidelity prototypes for feedback gathering, which was rapidly incorporated into the next iteration of the prototype.

Through a series of meetings and iterative revisions, we developed our first workable mockups, containing mainly the application's core features. Scenarios that were successfully validated, were transferred to the IT team for development, including functional specifications, to ensure delivery of the research-oriented IBD EHR system to the domain experts in a reasonable amount of time. Meanwhile, the UX team continued to work on designing the interface for the remaining user scenarios.

6 Discussion

Considering our methodology, it becomes evident that our approach differs from the traditional double-diamond model [2, 10, 1]. From the very beginning, we were overwhelmed with plenty of information that required immediate and ongoing processing, which continued to grow and evolve throughout subsequent meetings. Moreover, our process incorporated prototyping at a much earlier stage than what is typically observed in the classical doublediamond model [2, 10, 1]. This unique approach to our project is illustrated in Figure 4, which illustrates how we navigated back and forth between different phases as the situation demanded.

To bridge the language gap between domain experts and the UX team, we established a shared language [12]. This common language allowed the UX team to act as a mediator between domain experts and the IT team, facilitating effective communication and collaboration across disciplines. An additional aspect related to this was the necessity of validating the prototype through in-person meetings rather than remotely. This approach allowed the UX team to more accurately interpret feedback to the IT development team, leveraging their understanding of the established common language.

Another interesting aspect observed during the case study is that in the traditional Double Diamond design ap-

proach [2, 10, 1], there's a large accumulation of information during the Discover phase. This information is then processed to what is essential in the Define phase. Typically, in the Development phase, there is a second, smaller peak in information volume as the design becomes more concrete. In our case, as we can see in Figure 9, the reduction and refinement of information in our case did not occur during the first two phases, but rather during the prototyping stage. It was exactly as described in Section 5 Case Study, because, at this point, the doctors were able to visually interact with our concepts of their daily workflows and processes and provide us with concrete feedback, pointing out what aspects were incorrect or beneficial.

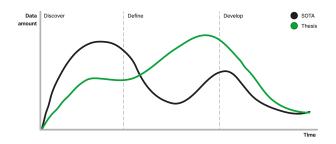


Figure 9: Figure illustrates the volume of data collected over time during prototype development. The black line represents the traditional Double Diamond approach, while the green line shows our domain expert-centered approach.²

7 Conclusion

In this paper, we present outcomes from a year-long collaboration with three specialists in IBD treatment research, focusing on creating a user interface for an IBD EHR system designed around their specific needs and workflows. Using a modified double diamond design approach, we emphasized the importance of incorporating domain experts throughout the design cycle. A key aspect of the development process involved showing the context of the information being communicated at any given time. Once this concept was applied to the defined design process, the development process smoothed out, resulting in improved quality of feedback. The structure of the proposed EHR system is more straightforward and user-friendly for physicians than the state-of-the-art IBD EHR system, which was also confirmed by the physician: "Finally, managing my patient health records will become much easier and less error-prone with the system being aligned with my typical workflow. Also, I'll no longer need to manually extract the patients' data from the system and use

²Graphical representation of the Double Diamond process, emphasizing the relationship between data volume and time, sourced from IDEO Tools, https://www.ideo.org/tools. The black line represents the State-of-the-art development of data amount (retrieved from the article) and the green line represents the author's.

various complex tools for my IBD-related research studies". The statistical section has been refined to remove unnecessary details and simplify operations, making it more suitable to the specific research practices of our domain experts.

While the system is not yet fully developed, with numerous potential enhancements remaining, one of the most beneficial additions would be transforming the system into an assistant tool for doctors. This would not only speed up their daily tasks but also assist in diagnosing and identifying disease parameter correlations. Plans also include conducting usability testing on fully functional prototypes. Additionally, we intend to extend the proposed system integrating explainability support to reveal hidden trends in the IBD EHR database without directly incorporating AI algorithms[7].

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