

# RadPath and Patient Usability

User Experience Research Report

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# Executive Summary

RadPath is a web-based reporting system that integrates pathology and radiology reports, streamlining the cancer diagnostic process. While it has been tested and shown to have high efficacy among clinicians, the report currently is not available for patients to take home or view.

This report aims to understand the patient diagnostic experience—chiefly, whether patients want access to their diagnostic medical records, and if so, how such records could be designed to facilitate comprehension and health literacy. This research objective was addressed through three methods: a stakeholder interview, a data-driven persona, and heuristics-based design recommendations, with the latter two methods involving thorough consultation of medical and user experience design literature. The research showed both a need and a desire for cancer patients to have access to their medical records. Creating a concise, clear one-page PDF version of the RadPath report for patients will increase transparency, trust, and engagement, benefiting patients and physicians alike.

A list of recommended health literacy and user experience design best practices is included, along with a low-fidelity wireframe of the patient report and a persona capturing the patient perspective within the diagnostic experience.

# Introduction

RadPath is a reporting system developed to improve the cancer diagnostic process. Before RadPath, cancer diagnoses required reviewing reports from both pathologists and radiologists. These reports would be sent to downstream physicians without any coordination. Logistically, it could be difficult to track both of these reports down. Diagnostically, when there was discordance between the findings of the two reports, physicians could have trouble reconciling the two reports in order to create a treatment plan, resulting in treatment delays (Arnold et al. 1). RadPath mitigates these issues by integrating pathology and radiology reports and creating a workflow in which radiologists correlate the two findings, noting any discordancies and necessary paths forward (Arnold et al. 5).

Currently, RadPath is directly used by the diagnosing team (radiologists and pathologists) as well as downstream clinicians responsible for the patient's treatment plan (oncologists, pulmonologists, and surgeons). The report has undergone a one-year pilot deployment, with physicians completing over 60 reports. User research has been conducted in the form of a survey consisting of structured responses following a Likert scale and an optional unstructured feedback field. Eight downstream clinicians were sent the survey, with five responding (Arnold et al. 6).

However, while RadPath has been tested to ensure usability amongst clinicians, an important user group remains overlooked—the patients themselves. Currently patients are indirect users of RadPath, as the report critically shapes their treatment plan but they are not given direct access to the system. Dr. Corey Arnold, who is on the development team for RadPath, noted that clinicians will often walk a patient through their RadPath report (Arnold and UCLA UXR 279 class). However, users are not able to take the report home. Arnold said that his team is interested in creating views of RadPath that are more patient-friendly, such as a one-page PDF that could be integrated into the patient's health record (Arnold and UCLA UXR 279 class).

The objective of this research will be to better understand the patient experience with health records and documentation during diagnostic interactions. Do cancer patients want access to their health records? And if so, how can health records, specifically those focused on screening and diagnosis, be designed to facilitate comprehension and health literacy?

These research questions speak directly to concerns already communicated by Arnold. However, developing a patient-friendly version of the RadPath report would require time, labor, and technical investment. Accordingly, this research is especially relevant to the stakeholders that have a hand in deciding how money is invested in RadPath. This could include both Arnold and the agencies and/or entities funding his research. This research could serve as important collateral for advocating either for or against investing in a patient version of RadPath while also guiding potential next steps within that effort.

# Research Methods

I addressed the research question through three methods: a stakeholder interview, a data-driven persona, and heuristics-based design recommendations. The chosen methods complement one another, providing insight into both the needs and the potential solution. The focus on qualitative methods over quantitative methods was both pragmatic and specific to the research objectives. Logistically, I did not have access to the system, so quantitative methods like collecting analytics were out of reach. Conceptually, qualitative methods excel at showing how users are feeling, which is integral to this project's research objectives. (Nunnally and Farkas, "Qualitative Research Methods").

## *Stakeholder interview*

The stakeholder interview with Dr. Arnold was an important starting point, as it was unclear from the article alone why physicians struggle to communicate RadPath findings to patients. Dr. Arnold's expertise and aspirations for the report were helpful for orienting the research questions. The interview was conducted via Zoom on May 8, 2020. I, along with 8 others, were given 25 minutes to ask Dr. Arnold questions. Given the shorter length of the interview and that it was shared with 8 other researchers, I prioritized the most pressing questions. The interview was recorded for future review.

## *Data-driven persona*

Personas are a very clear and digestible way to understand a user (Nunnally and Farkas, "Communicating Insights"). While ideally I would have interviewed cancer patients and create a persona from those findings, I did not have access to such users. Given the time constraints of the project and the complicating factors of COVID-19, I thought it best to get at the user perspective through a literature review. Accordingly, I read articles on the patient diagnostic experience and patient experiences with health records. I then coded the articles on a spreadsheet, and incorporated the sentiments most prevalent across the articles into the persona. Drawing from literature grounds the personas, appealing to stakeholders who respect the authority of peer-reviewed articles while also creating a research artifact that personalizes the patient experience. I conducted the literature review over the course of three sessions, utilizing the PubMed database of scientific journals. Each session was approximately two to three hours.

## *Heuristics-based design recommendations*

Within a health context, users face usability roadblocks not just in design but also in health literacy. Health literacy is the degree to which patients are able obtain, process, and understand health information and services; within the United States, over one third of adults, or 80 million people, have limited health literacy (Hersh 118). Accordingly, when drafting a list of best practices, or heuristics, for designing a patient-centered RadPath report, I pulled from both usability design and health literacy literature, to capture both general usability best practices and the specifics of the health context.

With regard to the medical literature, I referred to peer-reviewed, academic publications concerning health literacy. For the design heuristics, I choose Abby Covert's set of ten heuristic principles, as Covert comes from an information architecture background, especially fitting for RadPath as the report integrates different information sources with different structures into one digestible format (Covert). Over the course of three one-to-two hour sessions, I reviewed the literature, compiled findings in a centralized document, and generated the corresponding wireframe.

# Data Analysis

## *Stakeholder interview*

With regard to data analysis, while best practice would have been to code the interview to identify trends, that approach was less useful since I interviewed one stakeholder (as opposed to several; five would be ideal to get at more representative trends) (Zide). Further, since the interview was shared with eight other researchers, many of Dr. Arnold's responses were not relevant to my research; in all, his answers to two questions were about the patient experience with RadPath. Accordingly, I had a recording and typewritten transcript of the interview, and referred to his answers to shape my research objective and questions.

## *Data-driven persona*

The most extensive data analysis was conducted for the data-driven personas. I aimed to create a persona that would capture the lived realities and concerns of a cancer patient who would have a RadPath report. To accomplish this, I limited my review to peer-reviewed articles that involved cancer patients. Initially I had considered limiting the review to a specific type of cancer; however, I found that the articles with the fullest detail often spanned across different types of cancer. Since RadPath is intended to be used for all types of cancer, I thought it was appropriate to capture commonalities across these perspectives.

In all, I reviewed twelve articles related to the health records and the diagnostic experience for cancer patients. Of these, five were the most relevant to my research objectives and what I ultimately coded. All of the articles used semi-structured interviews to obtain patient observations about their experiences. I lifted patient perspectives from each of the articles, collecting them on a spreadsheet. I then inductively coded each data point within the sentiment, sometimes assigning two or three codes to a single quotation. After completing this first round of coding for all of the articles, I reviewed the codes again, controlling the vocabulary.

I then determined which sentiments from the literature would be incorporated into the persona. I felt it was important to incorporate the most frequent sentiments across all of the articles. Accordingly, I arranged each code from most cited to least. I prioritized sentiments with frequency across articles above sentiments with frequency within the same article. Frequencies for each sentiment ranged from one mention to eight mentions. I aimed to be as comprehensive as possible, and thus included any sentiment with three or more mentions into the persona. As I built out the persona and his personality, I occasionally incorporated additional sentiments as appropriate. Generally, if there were sentiments that were unique to a specific article because the concepts were not covered in other articles (such as patient trust in the security and privacy of an online health record), I did not incorporate that sentiment into the persona. My aim was to capture the biggest trends that cut across all of the articles to highlight the most prevalent issues. See Appendix B for this data analysis.

I generated the demographic information for the persona by reviewing the patient demographics as described in the articles. Three articles were especially detailed, providing the age, gender, marital status, employment status, and type of cancer for the patients they interviewed. The race and age of the patients in the articles skewed overwhelming white and 55+; the gender was more evenly divided, with men slightly more represented. I thus created a 61-year-old, male, lung cancer patient for my persona.

## *Heuristics-based design recommendations*

For the heuristics-based design recommendations, I reviewed Abby Covert's design heuristics as well as four peer-reviewed medical articles. I then collected user experience and health literacy design best practices into a centralized document; in addition to Covert's heuristics, I ultimately featured recommendations from the two most comprehensive medical resources. This document can serve as a helpful reference for the RadPath team when building out their patient solution (see Appendix C).

While both the health literacy and design heuristics were helpful, it is important to note that the design heuristics were created for interfaces, with potential applications across different channels (i.e. laptops, mobile, tablet, print). Since the RadPath one-pager would only exist as a PDF document, there were a number of elements within the design heuristics that were less relevant to this project. Accordingly, I focused on evaluating and incorporating the heuristics that would apply to a PDF one-pager.

After reviewing these best practices, I incorporated the recommendations into a low-fidelity wireframe for a potential design of a patient-centered RadPath report. The wireframe focuses on the basic design over content, as Dr. Arnold has the medical expertise to know best what information needs to be included. Accordingly, the design is intended to offer guidelines, from both a design and health literacy perspective, of what a PDF one-pager could look like (see Appendix D).

## *Limitations*

The biggest limitation faced within this research project was the lack of access to the RadPath system and its users. This prevented potentially fruitful research methods, such as analytics, contextual inquiry, interviews, or surveys. The stakeholder interview also involved some limitations, as the 25-minute session had to be shared with eight other researchers with different research objectives. Despite this, the data-driven persona and heuristics-based design recommendations were effective solutions to get at the issue by turning to the professional literature of both medicine and user experience design.

# Research Findings

Clinicians have responded positively to RadPath, noting that the reporting system improves the diagnostic workflow and reduces time spent searching for information (Arnold et al. 7). However, while RadPath may work well for clinicians, each research method yielded findings that advocate for the need for a patient version of the RadPath report as well.

The literature review and resultant persona overwhelmingly identified that access to medical records benefits patients (see Appendix A and B). Importantly, access to medical records increased patients' understanding of their diagnosis, as records served as a resource that they could refer back to. Often patients found in-person appointments to be overwhelming; having access to their medical record was a useful memory aid they could use to ensure they recalled and understood everything their clinician said. Psychically, having access to medical records made patients' feel more in control, reducing uncertainty and anxiety. Patients also felt that the records made their treatment plan more transparent, increasing their trust in clinicians and improving both communication and their relationship with their clinician. Nearly every article reviewed showed that access to medical records increased patient engagement with their treatment. While many patients were confused by some of the medical jargon within the records, patients still appreciated and benefitted from having access to these records. These findings have been incorporated into the "wants, needs motivations, and concerns" section of the persona, to provide a digestible, clear portrait of how access to patient records can affect the patient's diagnostic experience (see Appendix A and B).

From the stakeholder perspective, Arnold expressed a desire for creating a report for patients to access and incorporate into their health record, but acknowledged that currently the language used in RadPath is "not at all accessible" to patients (Arnold and UCLA UXR 279 class). The confusion with medical jargon, then, is not only supported by the professional literature but is also acknowledged within the context of RadPath by a chief stakeholder.

In addition to identifying a need for a cancer diagnostic medical record that patients can access, the research also indicates that many patients—over one third of adults in the United States, to be specific—have limited health literacy (Hersh 118). Clearly explaining medical concepts and crafting straightforward, clear documentation is critical, then, to facilitating patient comprehension. In order to facilitate comprehension and have the greatest impact, ideally a patient version of the RadPath report should incorporate specific design and language best practices. See Appendix C and D for a full list of such practices, as well as a wireframe of what a patient RadPath one-pager could look like.

# Recommendations

RadPath is currently a web-based platform that only clinicians have access to. The report is highly detailed and technical, with multiple views into the diagnosis. While this excels at facilitating medical care, the report would need to be streamlined, in both content and design, to facilitate patient clarity and comprehension. Dr. Arnold's suggestion of a PDF one-pager for patients is very much in line with these parameters, with the added bonus of preventing issues with technical literacy as a PDF can be both digital and printed.

To accomplish this, the one pager should follow the heuristic guidelines outlined in Appendix C. A low-fidelity sketch incorporating said guidelines can be found in Appendix D. In all, the health literacy heuristics encourage clear, concise, and accessible content while the design heuristics call for intuitive materials where users can find necessary, desirable, and valuable information, and are able to recall said information after.

An important balancing act that Arnold identified during the stakeholder interview is that a potential drawback of opening RadPath to patients is that some physicians may begin to start writing reports in a different way that is less for conducting medicine and is more for explaining concepts to patients (Arnold and UCLA UXR 279 class). This is a significant risk to consider, as a medically sound treatment plan is of primary concern to all involved.

At no point is it recommended that clinicians change the way they write their own reports, as successful medical care is the overriding priority. While ideally the patient report would be drafted separately from the clinician report, with sufficient editing and care taken to follow design best practices, it is possible that some clinicians may not have time for this, and instead would copy and paste sections of the clinician report into the patient report, without editing for patient readability. While not ideal, this is still preferred to altering the way clinicians draft the initial report, used for diagnosis. While medical jargon prevents comprehension, one study found that patients took this confusion more or less in stride. Within the study, when patients were confused by portions of the medical record or found what they regarded to be mistakes, they consulted the Internet, asked relatives and friends, or waited until their next doctor visit to consult with their doctor (Rexhapi 122). Importantly, no patient attempted additional contact with physicians, showing that even when medical jargon is involved, patients do not present an additional strain on clinician time, or react destructively.

Further, there are strategies to clarify medical jargon, even if it is left within the report. Physicians could provide supplemental materials alongside RadPath, defining medical jargon and terminology that is likely to be included in the report. For the digital PDF, such terminology could even be hyperlinked to the correct section of the corresponding documentation. Such supplemental documentation would be a cost- and time-effective approach to the issue.

Further areas of research include conducting user testing with the developed materials, to ensure comprehension. Cancer is a significant and often overwhelming diagnosis. Equipping patients with information can help them better understand their diagnosis and be more engaged in their treatment plan. A patient-centered version of RadPath could thus improve the diagnostic and treatment experience for patients and doctors alike.



# References

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# Appendix

A: Data-Driven Persona

B: Data Analysis for the Persona

C: Health Literacy Heuristics and Design Heuristics

D: Patient-Centered RadPath Wireframe

# Greg Thompson



*"What can I do to get better?"*

**Moment in time:** Diagnosis  
**Age:** 61  
**Location:** Pasadena, CA  
**Illness:** Lung cancer  
**Family:** Married, newly a grandfather  
**Occupation:** Retired pilot

## Bio

Greg Thompson is a retired pilot and new grandfather looking forward to spending more time with his family. He has just received the news that he has lung cancer, and is concerned about what that means. He spends a lot of time reading about lung cancer online, and is unsure of how this information applies to him. Greg wants to understand his diagnosis better and do whatever he can to help his health.

## Wants

- To improve his health
- To feel more in control of his life and his health
- To trust his doctor and the treatment he's recommending
- To feel more prepared for future doctor visits

## Needs

- To better understand his disease and what he can do
- To be engaged and committed to his treatment plan
- To reduce his anxiety and improve his mental health
- Information to be repeated or available for later review

## Concerns

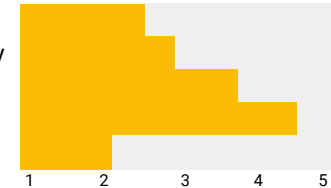
- The severity of the disease and his prognosis
- Remembering all of the information his doctor tells him
- Confused by "medical speak" and what terms really mean
- Not sure that his doctor always understands him

## Motivations

- Improving his health in the short and long term
- Building a good relationship with his doctor
- Feeling less anxious and overwhelmed
- Reassuring his family about his condition and his treatment plan

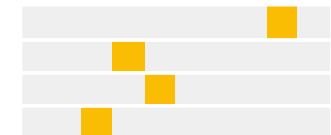
## Behaviors

- Health literacy
- Technology literacy
- Asks questions
- Self-confidence
- Self-questioning



## Personality

- Introvert
- Thinking
- Sensing
- Skeptical



- Extrovert
- Feeling
- Intuition
- Trusting

## Questions

- What is my diagnosis, and what does it mean?
- How can I get better?
- How do I refer back to this information later?
- What do these medical terms mean?
- Is everything on my chart accurate?
- How do I know what the best treatment is for me?
- What can I tell my family?

code	Kayastha	Odai	Rexhapi	Fisher	Mossanen
increases understanding	■		■	■	■
increases engagement	■	■	■		■
wants communication/relationship with physician	■	■	■		
increases trust in clinicians	■			■	
increases control	■		■	■	
overwhelming in-person	■	■	■		
memory aid	■		■		
confused by medical jargon	■	■			■
improves communication			■	■	■
reduces anxiety	■		■	■	
reduces uncertainty	■			■	
increases transparency	■			■	
better prepared for doctor visits			■	■	
less fear	■			■	
accessed records when/if they wanted				■	
too much repetition in records	■				
track progress of their cancer			■		
regret reading	■				
patients need information repeated		■			
patients need more information		■	■		
allows choice to hear results in person or privately			■		
better able to plan for the future				■	
better compliance with treatment plan					■
moral right to the information				■	
faster access to laboratory results			■		

## Health Literacy Heuristics

### Writing style

- Limit medical jargon, and define terms when necessary
- Use short, simple sentences
- Avoid words of more than two syllables
- Materials should be written at or below a fifth- to sixth-grade reading level

### Visual design

- Group information into clearly marked sections, organizing information in the way patients would use it
- When possible, use bulleted lists over blocks of text
- Bold keywords
- Use simple headers that are close to the text
- Balance white space with content
- Text should always use both uppercase and lowercase letters.
- Font style and size should be easy to read (at least 12-point)

### Content

- Visual aids and images should:
  - Avoid unnecessary details
  - Include captions
  - When appropriate, include cues (i.e. circles or arrows) to point out key information
- Limit content to the most significant and relevant information, avoiding details
- Break down information into small, concrete concepts

### Implementation

- Before release, test initial draft with patients, checking for comprehension of language and visuals
- During the in-person appointment, the clinician should review the report with the patient, underlining or circling key points and assessing for comprehension by:
  - Using plain, nonmedical language
  - Speaking clearly and at a slower pace
  - Limiting the content reviewed to 3 key points
  - Repeating these key points
  - Checking verbal and nonverbal communication to confirm patient understanding of the report

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### References

- Hersh, Lauren, et al. "Health Literacy in Primary Care Practice." *American Family Physician*, vol. 92, no. 2, July 2015, pp. 118–24.
- National Cancer Institute (NIH). *Developing Effective Print Materials for Low-Literate Readers*. U.S. Department of Health and Human Services, 1994.

### Additional resources

- "Plain Language in Healthcare." *Plainlanguage.gov*, <https://plainlanguage.gov/resources/content-types/healthcare/>.
- "Toolkit for Making Written Material Clear and Effective." *Centers for Medicare & Medicaid Services*, <https://www.cms.gov/Outreach-and-Education/Outreach/WrittenMaterialsToolkit/index?redirect=/WrittenMaterialsToolkit/>.
- "Automatic Readability Checker." *Readability Formulas*, <https://readabilityformulas.com/free-readability-formula-tests.php>.

# Design Heuristics

## Findable

- Can users easily locate that which they are seeking?

## Accessible

- Does it meet the levels of accessibility compliance to be considerate of those users with disabilities?

## Clear

- Is it easy to understand?
- Is the target demographics' grade and reading level being considered?
- Would a user find it easy to describe?

## Communicative

- How is messaging used throughout? Is messaging effective for the tasks and contexts being supported?
- Does the messaging help establish a sense of place that is consistent and orienting across content?

## Useful

- Is it usable? Are users able to complete the tasks that they set out to without massive frustration or abandon?

## Credible

- Is the design appropriate to the context of use and audience?
- Do you have help/support content where it is needed?

## Controllable

- Is information a user would reasonably want available?

## Valuable

- Is it desirable to the target user?
- Can a user easily describe the value?

## Learnable

- Can it be grasped quickly?
- What is offered to ease the more complicated processes?
- Is it memorable?
- Is it easy to recount?
- Does it behave consistently enough to be predictable?

## Delightful

- What are your differentiators from other similar experiences or competitors?
- How are user expectations not just met but exceeded?

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## References

Covert, Abby. *Does It Have Legs? Information Architecture Heuristics for Interaction Designers*. <https://www.slideshare.net/AbbyCovert/information-architecture-heuristics>. Interaction 12.

## Patient-Centered RadPath Wireframe

Below is a wireframe of what a patient RadPath PDF one-page report could look like. All of the health literacy and design heuristics were considered and incorporated into its creation. A few notable characteristics are noted below.

# RadPath Diagnostic Report

Patient: John Doe  
 Treating clinician: Jane Smith  
 Report date: 05 / 15 / 2020 

## Summary

Summary of correlation and diagnosis. Two to three sentences max.

## Pathology

- finding 1
- finding 2
- finding 3




Image caption

## Radiology

- finding 1
- finding 2
- finding 3




Image caption

- Group information into clearly marked sections

- Balance white space with content

- Use short, simple sentences

- Can it be grasped quickly?

- Limit to the most significant information

- Can users easily locate that which they are seeking?

- Bold keywords

- Is information a user would reasonably want available?

- When possible, use bulleted lists

- Include captions

- Is it easy to recount?

- Use simple headers close to the text

HLH = Health literacy heuristics

DH = Design heuristics