# What Does 'What Does it Mean' Mean?: Suggestions for Contextualizing Lab Results for Pediatric Inpatients and Their Caregivers

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## Abstract

Although patient engagement has been linked to better outcomes, most hospital patient-facing systems lack features to support such engagement. Meanwhile, patients often struggle to interpret information like lab results that are critical components of their care. We interviewed 12 pediatric patients and 3 caregivers in a children's hospital to understand how to improve the presentation of lab results in hospital patient-facing systems. We present several suggestions for improving the presentation of lab results to patients and their caregivers.

## Author Keywords

Health Informatics; Interface Design; User-Centered Design; Patient Portals; Patient Engagement; Hospital; HCI.

## ACM Classification Keywords

J.3 Life and Medical Sciences, Health, Medical Information Systems; H.5.m. Information interfaces and presentation.

## Introduction

Patients in the hospital (inpatients) often face difficulties in getting information about their care (e.g. [8,12]). In the outpatient context, technologies like patient portals grant patients and their caregivers provide information like test results and medical history [6], but these tools are used less commonly in hospitals [[3,7]]. Furthermore, studies on the benefits of patient portals have thus far shown mixed results (e.g. [1,5,11]). Given how many hospitalizations occur each year – more than 34 million in the US in 2014 [2] – finding ways to better meet the information needs of inpatients and their caregivers is an urgent problem.

Although test results are frequently offered through patient portals [6], HCI researchers have not yet fully explored how best to convey information about test results to patients. More work is needed to understand the information needs of patients in interpreting the results of medical tests or procedures they undergo, like x-rays and blood tests, and what design techniques help to convey that information. In this workshop paper, we discuss several suggestions for design recommendations to aid in the interpretation of lab results. These recommendations are drawn from interviews with pediatric patients and caregivers in the hospital with different medical conditions, and could potentially be applied across multiple types of lab or test results. We refer to procedures like blood tests and x-rays rather than the results of major procedures like surgeries.

## Related Work

In recent years, HCI researchers have begun to explore the space of inpatient engagement. Prey et al.'s 2013 review of work to date describes several categories of work in the inpatient space, including design requirements for inpatient technology and generic and patient-centered information delivery [13]. However, most of the work described does not focus on the presentation of medical procedure or lab results to patients. For instance, Vardoulakis et al. offered patients a system which described the purpose of medical tests, but did not show the results of procedures [14]. Similarly, the tablet application offered to inpatients by Vawdrey et al. did not offer patients information about lab or test results [15], nor did the inpatient portal offered by Woollen et al. [17] or the portal offered by Leary et al. [11]. Notably, Woollen et al. reported that patients desired access to their lab results through the application [17].

Two relatively recent studies include insights on the presentation of lab results to patients. Kelly et al. included information about test results in an inpatient portal and found that patients wanted more supplementary content to help them interpret their lab results, including reference ranges and links to educational resources [7]. Wilcox et al.'s paper-based in-room display offered patients a summary of lab results, with information about whether the results were high, low, normal, or if further discussion with the care team was needed. Wilcox et al. thoughtfully discussed the difficulties of reducing the result to a simple 'normal' or 'abnormal' rating, in addition to the complexities providers face in interpreting lab results and difficulties of reducing the result to a simple 'normal' or 'abnormal' rating. However, this discussion was based on the perspective of the clinical care team. The study also revealed that some patients found it helpful to see their lab results, and others did not because they did not understand their results [16].



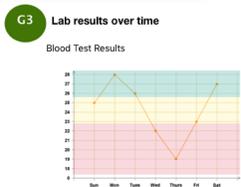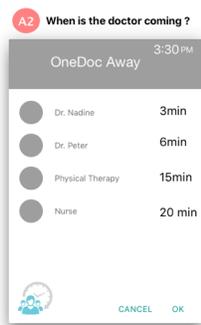Figure 1. Example cards offered to participants

Figure 2. More example cards, including card showing lab results

These findings indicate that more work is needed to identify techniques that help patients interpret their lab results, while still meeting clinician standards for communicating medical information.

Outside of the hospital context, some work has been done to explore new information visualization techniques for patients. For example, AnatOnMe helps clinicians explain to patients their condition [10]. In the realm of chronic disease management, systems like *bant* include visualization components to help users monitor their blood sugar [4]. However, these systems are context-specific and do not offer guidelines that can be applied across the many different types of test results that can be needed in the inpatient context.

## Methods

To understand the information needs of inpatients, we interviewed 12 pediatric inpatients and 3 caregivers in a major pediatric hospital in the northwestern United States. As part of the interview, we offered patients a set of about fifty "feature cards" that depicted different features that could be included in a hypothetical iPad application. We interviewed participants about their responses to different feature cards, and asked them to expand on how they envisioned the feature working, what information would make the feature more useful, and other questions in the same vein. Our goal was to understand how each of these features could fit into their experience in the hospital and uncover their unmet information needs.

The feature cards themselves were drawn from data gathered in previous studies (e.g. [8,9]). The cards covered a broad range of features, including information about medications, safety checklists, a graph representing generic "lab results" grouped by medical problem and shown over time, and features that supported interactions with the care team (see Figures 1 and 2 for examples of cards). In this paper, we focus on interview findings that relate to the presentation of lab results.

## Suggestions for contextualizing test results

Participants overall reacted very favorably to the idea of a feature that would tell them what their result meant. Participants described a variety of data types that would increase their comprehension of medical information generally. Below we describe how some of the data they wanted could be incorporated into the medical record to increase its comprehensibility.

*Contextualization with personal histories*

Several participants suggested that it would be useful to be able to view their lab results over time. For example, P08 (age 11) wanted to see lab results over time to "know if I'm getting better or getting worse." Some participants already kept their own personal records, like P06's caregiver, who liked to keep a copy of all the patient's blood cell count results and "just keep flipping through". Additionally, participants described other ways of tracking progress over time that were not linked to specific lab results. P06 (age 10) and his caregiver also took pictures of P06's surgical scars to document the healing progress over time. P04 (age 17) had taken similar pictures in the past, and wanted to "keep it archived in the app and go back and look at it and then like the doctor [can] have access to it through their computers…"

Based on these results, we suggest two possibilities for the design of an inpatient tool to incorporate patients'

and caregivers' desire for viewing lab results over time. The first is using summary statistics of the patient's personal history, useful when the same test has been administered more than once. Summary statistics of the patient's personal history like past highs, lows, and averages could be added to the tabular or graphical presentation of lab results to help patients contextualize their progress and reduce the cognitive burden of keeping everything in memory.

A second possibility for displaying historical information is to allow patients and caregivers to enrich the medical record with their own documentation. Although the patient-captured data described by our participants, like photographs of surgical scars, were not linked to particular lab results, our participants' actions show a desire to contribute to the medical record. We suggest that lab results also support this need by allowing for patient and caregiver annotations. These annotations could potentially be used as a communication tool between patient and clinician, as described by P04.

*Contextualization with reference ranges*
Our feature cards contained colors representing reference ranges (see Fig. 2). One caregiver, P14, commented explicitly about how they liked this feature: "So it's fine if you have charts but normal ranges and things like that should be included in a readout of the lab result." Another participant, P06's caregiver, added that they would find it useful to have other people's lab results as a comparison point to P06's.

This finding echoes Kelly et al.'s results [7]. However, as discussed earlier, Wilcox et al. point out that generic reference ranges may not be appropriate in all cases [16]. There are many possibilities for resolving these

contradicting needs. One technique that could be explored is to provide reference ranges that can be turned on and off by clinicians as appropriate for individual patients. Another is to use design techniques to indicate that the reference range may or may not apply to the patient, for instance by an explicit comment or a visual indicator that the reference range may not apply to the patient, or an indicator of confidence in the reference range. However, future research is needed to understand the best way for communicating this information.

*Contextualization with future projections*
Several participants wanted to understand medical information in the context of what it meant for their future, specifically what care they would need to undergo and what they could expect to happen to their bodies. One participant connected this desire explicitly to lab results. P06's caregiver wanted lab results to show "at what points you're going to need the transfusion so you can see oh, I'm getting close to like the red line ... critical values so that you know they're going to have to do something about it".

Another participant, P13 (a caregiver), stressed the importance of seeing future projections with regard to medications and procedures, wishing she had the power of "…just knowing at what point could a medication be weaned or adjusted or things like that…[and] any new up and coming changes to surgical procedures…."

How to incorporate future projections into the presentation of medical information will depend on the type of medical information being presented and the future projection being requested. For lab results, a

representation could include "critical values" that mark when next steps need to be taken, as suggested by P06's caregiver. One can also imagine graphical representations showing different trajectories of illness or recovery, with annotation about the projected plan of care in each contingency. These projected plans should include information about medication changes or alterations to procedures to meet the needs of users like P13. Future work should explore additional ways to contextualize medical information with future projections.

### Limitations and future work

Our recommendations so far are drawn from a small sample of pediatric inpatients and caregivers across services, from a single hospital site. Future work will examine the needs of adult patients and additional caregivers to form a more inclusive sample. In addition, our suggestions for improving the design of inpatient-facing systems have not yet been validated. Further work is needed to create concrete design options from these suggestions and to empirically evaluate them with feedback from inpatients and their caregivers.

### Conclusion

Design has the potential to make lab results more comprehensible to patients and caregivers. In this paper we suggest three design techniques that can be used to improve the legibility of lab results: contextualization with personal histories, contextualization with reference ranges, and contextualization with future projections. Researchers should explore these design techniques to evaluate their efficacy in increasing patient understanding of lab results and to further our knowledge of patient and caregiver information needs.

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