Navigating Three VITal Interdependent Qualities for Successful Cross-Community Collaboration

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For technology-related research that involves a community, important pre-conditions include a diverse team representing both researchers and community members [Vaughn and Jacquez, 2020], and shared motivation for objectives whose outcomes will span both research value and community impact [Pillai et al 2023]. However, achieving these can be nontrivial. After a team of junior researchers from different disciplines engaged for the first time in a health-oriented collaboration, we reflected on the complex ways that three cross-community collaboration qualities were "**VITal**" to our work:

(1) <u>T</u>rust: The rapport built between researchers and community members (however community is being defined), whether developed in prior relationships or over the course of the collaboration.

(2) <u>Insights</u>: The relevant context, lived experience, and knowledge that community insiders often have and which collaborators might not, including those within the community (e.g. differing perspectives of doctor, nurse and patient).

(3) Aligned <u>Values</u>: The extent to which varying incentives, motivations, and pain points between researchers and community members are reconciled to produce shared objectives.

We realized that intertwinement of these VITal qualities seems to produce a causality dilemma: to increase one quality, another quality must already be present (Figure 1). This can make building a collaboration from the ground-up daunting.

- To build **trust** in the absence of a prior relationship, researchers must demonstrate that they are willing and able to benefit the community. To do this, they need to demonstrate that both parties have shared **values**.
- To align their own **values** with the community's, researchers need **insight** into the community, which they may lack.
- To get these **insights** from the community, researchers need a level of access to gather information. Achieving this access requires **trust**.

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Figure 1: Interdependence of three qualities vital to cross-disciplinary, community-rooted research. An unestablished team faces a causality dilemma, because building each quality requires the others to already be in place.

Case Study: Early-stage HCI researcher / clinician collaboration

Two co-authors experienced this "catch-22" when attempting to collaborate with clinicians as part of a 4-month graduate HCI course design project. Our initial objective, proposed by the health partner, was to integrate a COPD (Chronic Obstructive Pulmonary Disease) clinical prediction model, called ACCEPT [Adibi et al., 2020]; (part of a clinical trial [Michaux et al., 2023]), into clinical workflows. ACCEPT assesses the likelihood of a "severe" COPD exacerbation within the next year, aiming to inform clinicians' (respirologists and family physicians with COPD patients) personalized treatment plans. However, ACCEPT currently requires manual data entry from electronic health records (EHR) into a web app, an infeasible burden on clinicians. Our initial plan was therefore to utilize NLP (natural language processing) methods to automate this step.

Our 4-student team represented epidemiology and health outcomes (co-author AA, an ACCEPT researcher and the proposer of this project), and three non-health disciplines; co-author KM was our instructor, who later joined as a collaborator. It did not include a clinician, our target community. We realized over time that we were limited in what we later identified as the three VITal qualities:

- It was immediately obvious that we lacked *insight* into clinicians' daily workflows, their attitudes toward tools like statistical models, risk scores, or treatment guidelines, and their thoughts on new data entry methods like dictation.
- As we tried to approach clinicians, we realized that our *trust and rapport* with clinicians was limited mostly to AA's pre-existing personal and professional connections.
- At some point, we noticed that the research team's priorities (*values*) differed subtly from the clinicians'. Both sides wanted to save time (for us, by streamlining ACCEPT's integration). However, with ACCEPT's clinical utility unproven, was integration in their interest?

Leveraging Nominal Trust into Insights ...

We conducted interviews with three respirologists, two post-graduate residents and a senior medical student, and shadowed one of the respirologists through four hours of clinical work.

Although small, our existing store of community trust gave a foothold (Figure 2). Clinicians with whom AA had personal relationships or mutual friends provided long, detailed interviews; the most distantly related were most reserved.



Figure 2: Importance of initial trust. Pre-established connections allowed us to engage in interviews and shadowing, putting us on the path towards achieving better insights.

We conducted thematic analysis on our transcripts and observations with an affinity diagram [Holtzblatt & Beyer, 2017]. This produced themes highlighting relevant topics including dictation, the role of risk assessment in COPD, and general attitudes toward existing EHR systems and clinical prediction models.

...Then Realigned Values

Interestingly, this analysis overlooked what became our primary finding: patient data is badly organized in EHRs, a major frustration point for clinicians when using clinical prediction models, but *also* when documenting patient encounters. Several comments relating to this were scattered through our affinity diagram (Figure 3), but we did not initially recognize it as a relevant theme.



Figure 3: Our initial affinity diagram. Initial primary themes are in green. Expanded in the purple rectangle are scattered interview snippets relating to our eventual primary findings.

While the themes we did extract are likely valid insights, they were generated based on ACCEPT-related objectives, and aligned weakly with community values. We uncovered this through empathy achieved while processing our insights (Figure 4).



Figure 4: Insights leading to empathy and value alignment. Deep reflection on our insights eventually helped us align our values with community members.

With more clinician-aligned values, we saw the problem differently. We pivoted from a "better ACCEPT data entry interface" to an NLP tool assisting clinicians in consolidating patient data by automatically summarizing EHR data from patient encounters. This summary could then

be used to assist clinicians in writing letters or notes, addressing their actual pain point. Better-consolidated patient data also helps with integrating ACCEPT; if the NLP tool is able to collect some or all of the data required by ACCEPT, it can also perform the risk assessment and output the prediction as part of its summary.



Figure 5: Conceptual model for final tool workflow. This overview was shared with participants in a pilot study of the interface prototype.

We built a medium-fidelity prototype (Figure 5) with which we conducted an informal suitability evaluation with two medical clerks and one resident. We received positive feedback (a highlight: "*I like that it types the text for me...(laughing) I really like that it types the text for me*"). All three participants were very engaged in providing constructive feedback, suggesting a high level of trust.



Figure 6: Substantiated trust closes the loop. With aligned values, researchers can work towards solutions to community members' actual pain points in a positive feedback loop.

Summary

Finding even a small foothold within just one of the VITal qualities changed our relation to the cycle that was so daunting at first (Figure 6). Once "in", the interdependencies started working to our benefit, carrying us from one to the next. We still had to do the work and observe closely, but this effort now paid off and the cooperation strengthened over time rather than being stalled.

We are interested in how our experiences compare to others, including their generalizability to collaboration with other communities, such as patients, and in areas beyond health.

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Appendix: Alternate Text

Figure 1: The words "trust", "insights", and "aligned values" are written in blue, equidistant from each other. Three blue arrows connect the words in a ring. One arrow points from "trust" to "insights", and is labelled: "facilitates activities that generate". The second arrow points from "insights" to "aligned values" and is labelled: "allows researchers to empathize and achieve". The third arrow points from "aligned values" to "trust" and is labelled: "facilitates closer collaboration, building". Each arrow has a red X drawn through it.

Figure 2: This figure is a copy of Figure 1, with the arrow labels removed, and with everything in gray instead of blue, with the exception of the word "trust" and half of the arrow from "trust" to "insights". A green label is added next to the half-green arrow that says "facilitates high-quality interviews".

Figure 3: An affinity diagram represented by many sticky notes of different colours. There are five distinct clusters of notes, each surrounding a large green sticky note. The large green sticky notes say: "Opinions on Dictation", "Opinions on COPD Risk Assessment", "Trust on Models", "Why do we need models?", and "EHR integration important?" Other sticky notes are hard to read. Seven yellow sticky notes, while illegible, are circled in red, and connected to enlarged versions of themselves in a purple box under the affinity diagram. These enlarged versions contain summarized quotes of clinicians alluding to disorganized information in the EHR and frustration with writing letters and other menial tasks.

Figure 4: This figure is a copy of Figure 2, but now the first and second arrows are fully coloured green, along with all three words: "trust", "insights", and "aligned views". The label on the first green arrow is amended to "facilitates high-quality interviews, amended into". The second green arrow is labelled "enabled us to empathize, leading to".

Figure 5: A tutorial screen from an interface prototype, containing a flowchart representation of a conceptual model. On the left, there are two images: a stack of papers labeled "EHR documents", and a stick figure labeled "User". Arrows connect these images to a big yellow box labelled "Data Summarizer", the arrows say "automatically collected data" and "manually entered data", respectively. Under the big yellow box, an arrow labelled "Model Inputs" connects to a red rectangle that says "ACCEPT (Statistical Risk Model)". Another arrow points back to the big yellow box, saying "Risk Prediction + Tx Recommendation". A third arrow points out of the big yellow box to a single paper on the right of the diagram, which says "Letter/Note Snippet".

Figure 6: This figure is a copy of Figure 6, but now everything is green. An additional label is present next to the arrow between "Aligned Values" and "Trust", saying "helped us produce a well-received prototype, reinforcing".