

Knowing the Patient

Developing an ICU-Adapted Humanistic Charting Tool

A qualitative needs assessment of personhood documentation in critical care



The information exists. The infrastructure doesn't.

Who a patient is — baseline function, minimum acceptable quality of life, who truly speaks for them — is collected every day, by physicians, nurses, social workers, and case managers. But it is collected at exorbitant effort, because nothing in the system expects it the way the system expects a basic metabolic panel. So it arrives inconsistently, redundantly — and often only after a palliative care consult finally assembles it.

A lab value — ordered → drawn → resulted → trended. Consistent, expected, automatic: the system does the work.

Who the patient is — asked when someone fights for it → held in one clinician's head → re-asked by every role → lost at handoff. The people do the work.

“I believe anyone living with a chronic, impactful condition deserves what palliative care provides. Most will never get the consult — there aren't enough of you. So the question became: can we extend the reach of what this field does?”

Built with the people who will live with it



Lineage

The Humanistic Charting Tool: a structured home for who the patient is, alongside what they have. ED pilot published in JACEP Open, 2025.



The ICU is different

Patients often cannot speak; surrogates carry the weight; stakes and timelines change. So the adaptation began by asking the ICU workforce itself.



Community-based participatory research

Instruments designed with their users work better than instruments designed for them — and collective ownership is what makes adoption real, not mandated.



The needs assessment is the design process

Every structure you'll see — the questions, the gate, the views — was derived from what informants taught us, not drawn at a whiteboard.


Knowing You · ICU Humanistic Charting Tool · V6

A

A


WE ASK EVERYONE

Help us know **who you are** — beyond the medical picture.

Every patient in this ICU is so much more than the chart. This questionnaire puts the person — their life, their people, their voice — in front of the whole care team, so it is in the room when decisions are made.

One questionnaire, the same for everyone. Every patient and family in this unit receives these exact questions, whatever the diagnosis. Being asked about serious illness here carries no message about anyone's condition — it is simply how we get to know the people we care for.

 **~20 minutes** , pausable
  **Every question skippable**
 **Goes only to the care team**

Some questions touch on sensitive topics, including end-of-life care — the most personal section sits behind its own clearly marked gate, and “not right now” is a fully respected answer. Answer in a word, a name, or a sentence. Your care will be exactly the same whether or not you complete this.

“We ask everyone” — one questionnaire, the same for every patient and family, whatever the diagnosis.

Three aims

1

What is essential

Which personhood information matters in the ICU — and which decisions it informs.

2

What happens now

How that information is currently captured, shared — and lost.

3

What to build

Design requirements for an ICU-adapted Humanistic Charting Tool.

Derived from the workforce, not invented

15

key informants

UCLA RRMC medical ICU

4

role strata

physicians · nursing · social work · case
management (PT/OT pending)

~865 → 50

codes

initial codes distilled to 50 focused codes

8

categories

constant comparison · deviant-case
analysis

Constructivist grounded theory (Charmaz). Purposive sampling across role strata; iterative coding with constant comparison and deviant-case analysis; saturation assessed per stratum — reached in nursing. Everything on the next five slides traces to this corpus.

How it asks

Direct, open-ended, plain language. “What name do they like to be called — and how is it pronounced?” Answers in a word, a name, or a sentence. Every question skippable, never penalized.

“Why we ask,” on the question. Sensitive items carry their own transparent rationale — the answer never changes the care provided.

It catches real things. Emergency contacts vs. the people they’d actually want deciding — a mismatch the tool flags for the team the moment a family notices it.

QUESTION 29

The hospital chart lists emergency contacts for them. Are those the same people you just named — the ones they would want making medical decisions?

▶ WHY WE ASK

☐ Yes — same people

☐ Not sure who is listed

☒ No — the chart should be updated

⚠ Thank you — this matters more than you might think.

We’ve flagged the mismatch for the care team so registration can be corrected and the right people are called. This is one of the most common and most consequential things this questionnaire catches.

QUESTION 30

The surrogate-mismatch catch, live in the worked example.

Who They Are ✓ 6/6

Home & Support ✓ 8/8

Comfort & Ho... ✓ 5/5

Life Before This... ✓ 8/8

Where Things ... ✓ 3/3

What Matters ... ✓ 7/7

Their Voice in ... ✓ 8/8

Prior Experience ✓ 3/3

Treatment Pref... ✓ 5/5

Beliefs, Culture... ✓ 5/5

Planning Ahe... ✓ 12/12

In Their Own W... ✓ 4/4

Review & care sum...

Every question is optional. Blank answers are simply skipped — never penalized.

Section 3 of 12100% · answers stay saved while this page is open · pause anytime

Worked example — Rosa Maldonado (fictional). Completed by family (Maria — daughter). Every answer is editable — browse the sections to see how each screen looks filled in.

Clear example & start your own

SECTION 3

Comfort & How They Like Things Done

The small things are not small. How they take their pills, what plays in the room, how they like their hair — these are what make care feel like their care. Everything here goes straight to the nurses at the bedside.

QUESTION 63

What name do they like to be called — and how is it pronounced?

e.g. Bob, never Robert; Doña Rosa — ROH-sah

Rosa — the family says Doña Rosa; ROH-sah

QUESTION 64

How do they like the small things done — medications one at a time or all together? Water with or without ice? A favorite drink?

whatever makes the everyday feel right — this goes to the nurses

Medications one at a time, with juice — never all at once; water without ice; she loves her cafecito with a little milk

In the patient's corner — by design

No new burden on the workforce. Completion sits with patients and families — in the waiting hours ICU families have in abundance. The team engages with the output, not the intake.

Entirely optional. If they want to fill it out, they can. If they don't, they don't — and care is exactly the same.

The most personal section is a genuine choice. Planning Ahead sits behind its own gate: now, later, or not at all.

Deferral is data, never a blank. “Come back later” is recorded as deferred; “skip” as declined by choice. Readiness has its own timeline — the record respects it.



Before the next section — a genuine choice

This last main section is about planning documents — Advance Directives, POLST forms, and organ donation.

We ask every patient and family these questions. They are part of this questionnaire for everyone, no matter their condition. They are also the most personal questions we ask.

You can complete them now, come back to them later, or skip them entirely — all three are completely fine, and your care will be exactly the same.

Continue now

I'm ready to answer these.

Come back later

Skip for now — remind me at the end. Recorded as “deferred,” never as missing.

Skip this section

A respected answer. The care team sees “declined by choice” — not a blank.

The Planning Ahead gate — three answers, all respected, all recorded.

How it maps: story in, structure out

Open answers on the surface, AI mapping underneath. Free-text stories about daily life are mapped onto validated instruments — Clinical Frailty Scale, Katz, Barthel, Lawton, ECOG approximations.

Drivers stay visible. Every derived score shows exactly which answers produced it — and is labeled an approximation, not a substitute for clinical assessment.

Nobody fills out a Barthel. The Barthel emerges from the story. Narrative and quasi-objective structure from a single capture — you don’t choose between them.

Consistent like a panel. Fixed sections, fixed order, fixed summary strip — clinicians find the surrogate the way they find a potassium.

Physician

Nursing

Social work

Case management

Full narrative

My answers

Optimized for the thirty-second read between rounds. Fixed field order, every note — where POLST lives never changes; where the surrogate lives never changes. The coverage-state line shows which goals-of-care ground has been walked and what remains.

⚠ **ADVISORY — CONFIRM CURRENT POLST / CODE STATUS.** The preferences below were captured from the patient or family via the ICU-HCT and have NOT been reconciled against existing code-status orders or any formal POLST on file. Before using them for clinical decision-making or copying them into the medical record, confirm current code-status orders and any existing POLST. If the answers diverge from current orders, reconciliation through a goals-of-care conversation and formal POLST update is required.

KNOWING YOU · SUMMARY STRIP

Rosa Maldonado · completed by family (Maria — daughter) · 8/9/2026

Coverage state	Sections answered: 11 of 11 core sections · Planning Ahead: completed (12/12 items) · FAST module: not triggered
PRE-MORBID FUNCTION	
Clinical Frailty Scale	5 — mildly frail. Driven by: slowing trajectory; medication reminders; cane; help with bathing/transfers/dressing (approximation — not a substitute for clinical assessment)
Katz ADL	4/6 — moderate dependence. Driven by: transfers, dressing
Barthel approximation	80/100 at baseline — Baseline approximation — cross-timepoint ruler for post-ICU clinic.
Lawton IADL (approx.)	7/8. Driven by: medication reminders
ECOG	1 — most things, tired more easily
Pre-ICU trajectory	Slowing down (Ferrante flag)

One capture, many readers

Role-distributed views. Physician, nursing, social work, case management — the same capture, pre-arranged for each reader’s thirty seconds.

Dosed, not dumped. The physician view opens at a one-line read; depth is on demand. Informants were precise about how much personhood data a clinician can absorb — the tool doses it.

Guard-railed. Preferences are never chart-ready orders: a standing advisory requires reconciliation against current code status and POLST.

“The ‘About Me’ field — finally with something in it.”

CARE SUMMARY

Rosa Maldonado — as a person, on one page

One capture, three readers: the physician's thirty-second read, the nurse's bedside personhood card, and the social work assessment — pre-answered. Choose a view; copy or print it for the chart.

Daily Check-In — two questions, under a minute • 1 saved

Physician

Nursing

Social work

Case management

Full narrative

My answers

Physician

Nursing

Social work

Case management

Full narrative

My answers

The bedside personhood card — the “About Me” field, finally with something in it — beside the communication preferences that shape every interaction.

⚠ COMMUNICATION — read before you speak to them: Hearing aid in her left ear — please make sure it is in before you speak to her; reading glasses on the tray

AT THE BEDSIDE	WHAT THEY TOLD US
Call them	Rosa — the family says Doña Rosa; ROH-sah
Who they are	The person who raised five kids on a grocery store cashier's salary and still had dinner on the table every night. She takes care of everyone.
They love	Her garden — more plants than she has room for, roses especially
Everyday joy	Her morning cafecito in the garden and the 6 pm call from her granddaughter Lucia
Proud of	Getting her citizenship in 1998 and buying her own house three years later

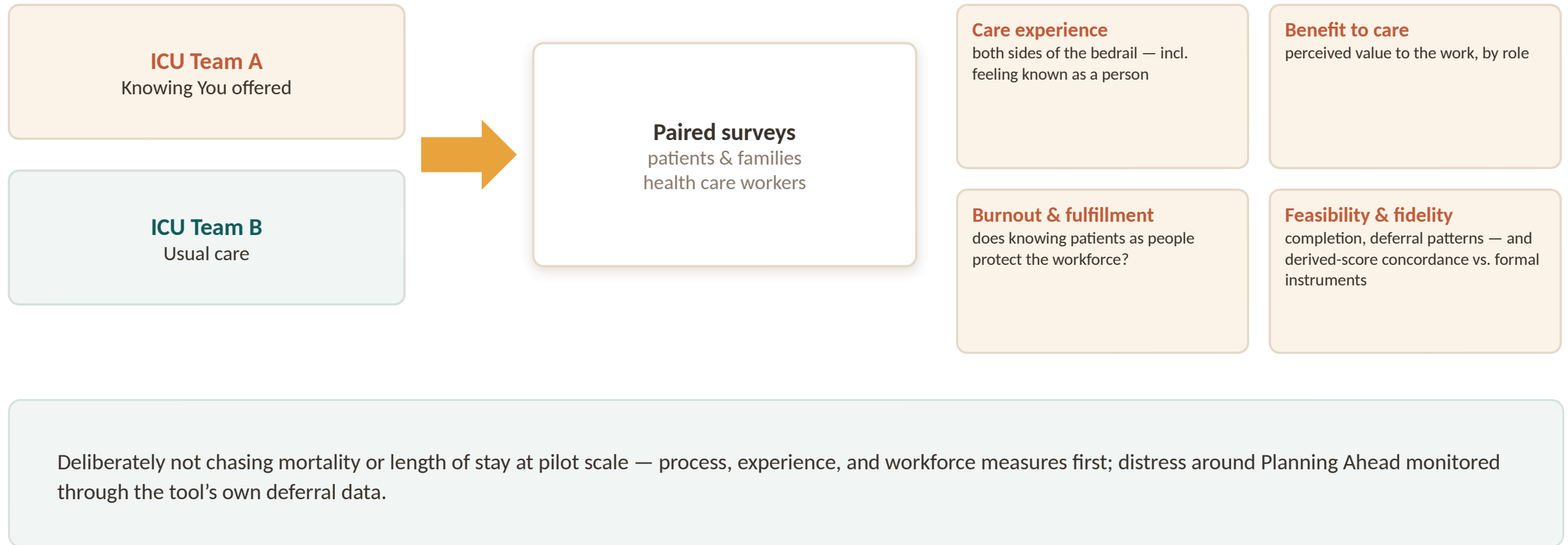
WHAT THIS IS — AND ISN'T

It does not replace the conversation. It extends its reach.

- **For the patients who never get the consult** — most people living with serious illness.
- **For the days before the consult arrives** — so the specialist starts from a populated picture, not a blank one, and the first twenty minutes aren't inventory.
- **For the handoffs where beautiful information dies** — captured once, structured where it can be, narrative where it must be, present at decisions.

Built out of admiration for what those conversations produce — and impatience that so few patients ever get one.

The pilot: does knowing the patient change care?



The needs assessment told us what to build. The pilot asks whether it changes care. *What else should it measure? — that's my question for this room.*