

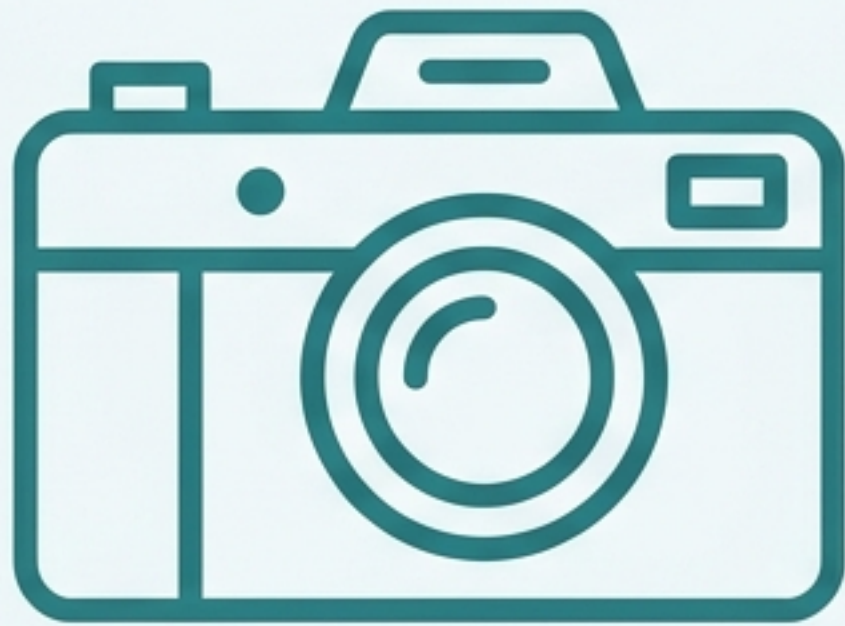
Long-Term Follow-Up in von Willebrand Disease

The Diagnosis Endures, The Patient Does Not Stand Still.



Diagnosis is the Beginning of Longitudinal Care

VWD is inherited, but its clinical expression is not fixed. The task is not simply to preserve or remove a label, but to ask what the accumulated evidence means for the patient today.



The Snapshot

- Isolated laboratory values
- Baseline bleeding history
- Assignment of a VWD subtype



The Motion Picture

- Aging and physiologic stress
- Pregnancies and surgeries
- New medications and comorbidities
- Shifting cardiovascular priorities

Time as a Diagnostic Test

A laboratory value describes one biological state. A longitudinal history records what happened when hemostasis was actually tested.



Childbirth & Pregnancy

Did the postpartum period produce unexpected bleeding?



Dental Extractions & Surgery

Did standard hemostatic plans prevent bleeding?

Life's Hemostatic Challenges



Treatment Exposure

Was the magnitude and duration of desmopressin response adequate?

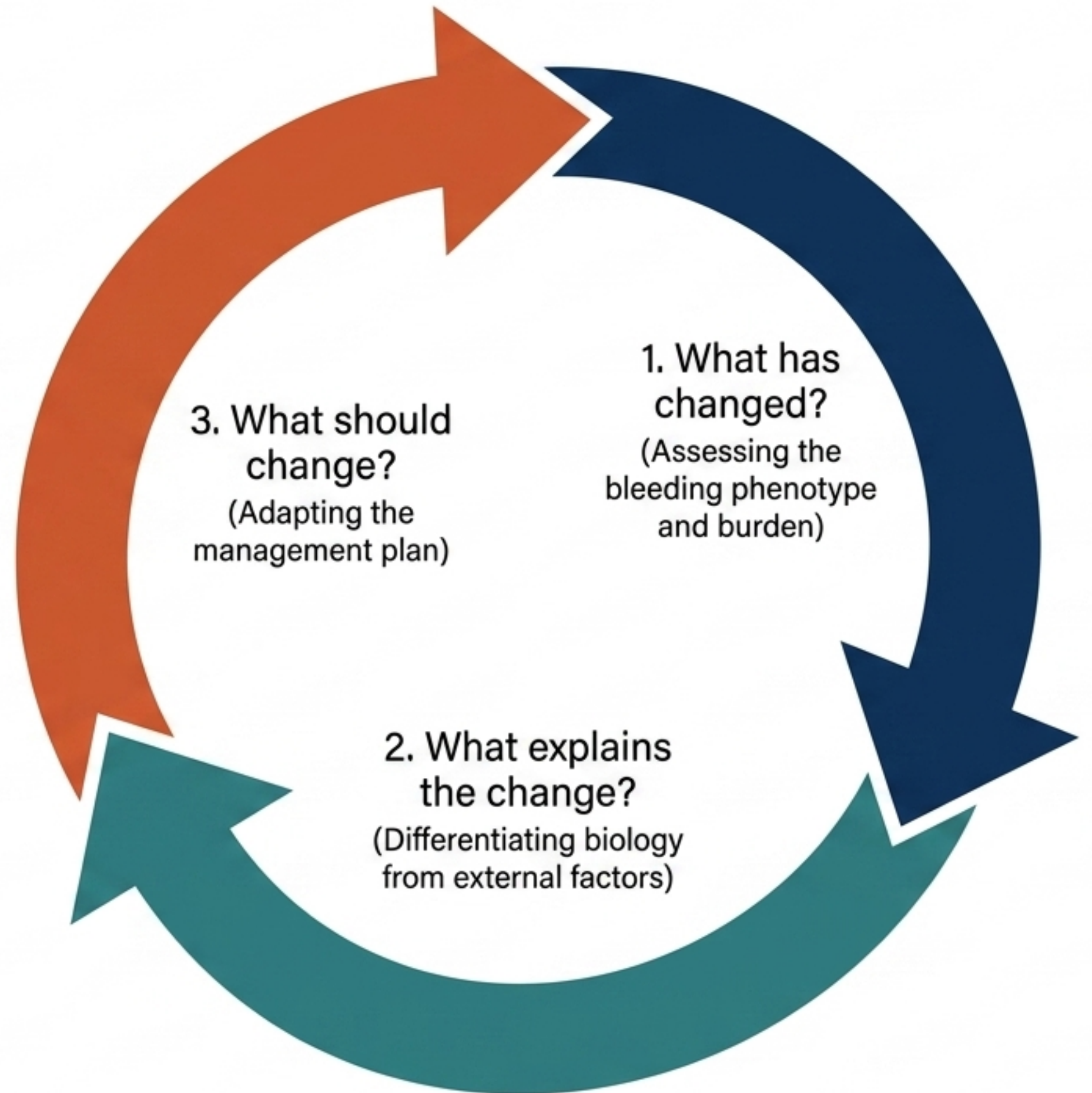


Menstruation

Did heavy bleeding cause recurrent iron deficiency over time?

The Continuous Reasoning Loop

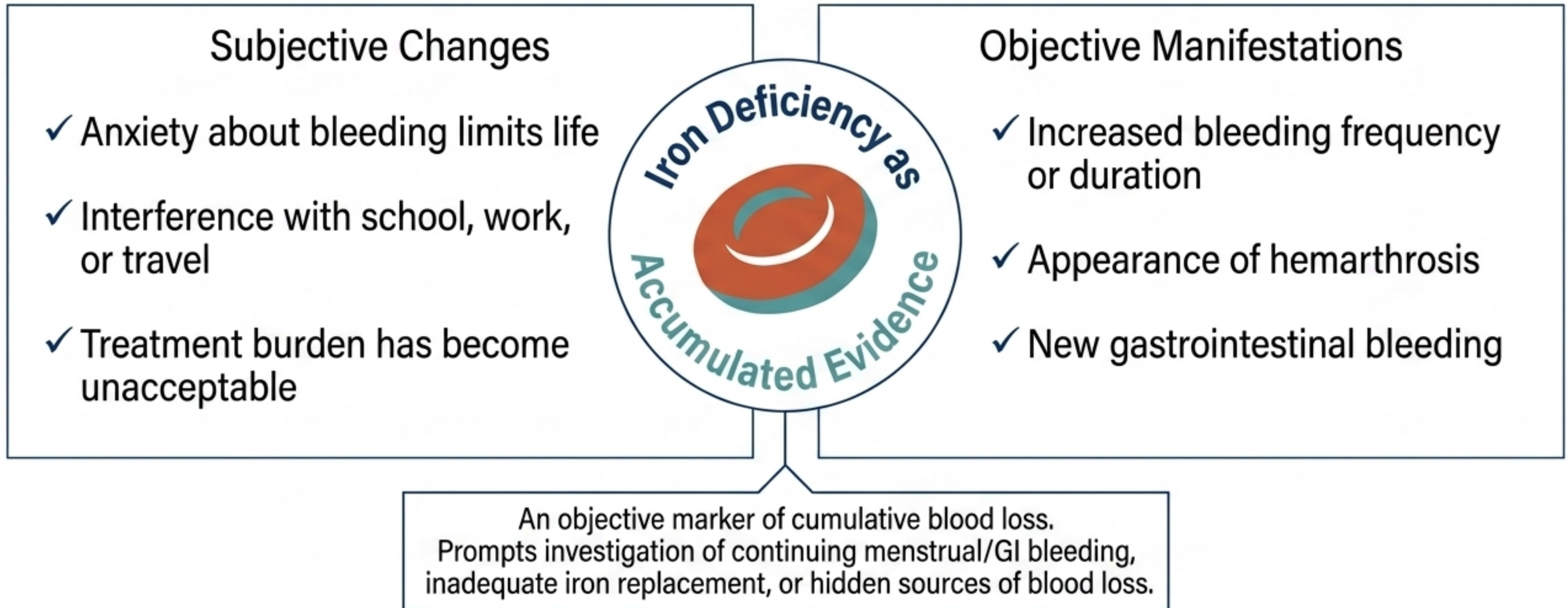
Follow-up is not passive surveillance. It is an active process through which diagnostic and therapeutic certainty increases, decreases, or changes direction.



Loop Q1: What Has Changed in the Phenotype?

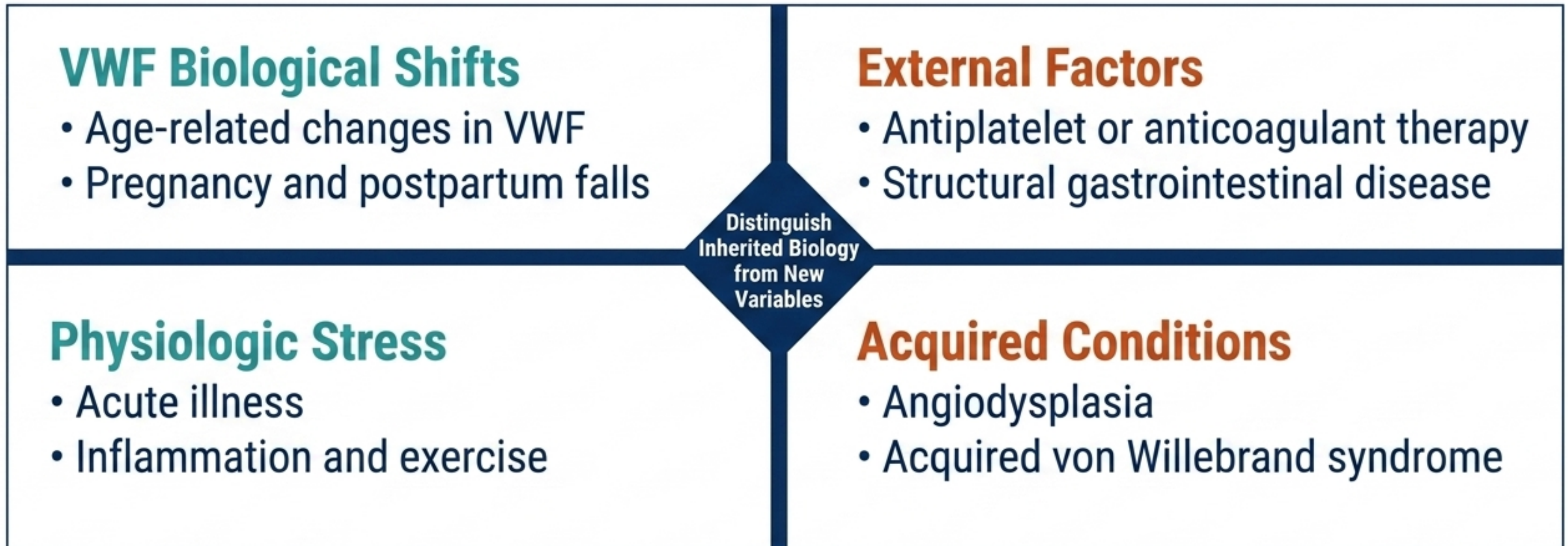
The consequences of bleeding may be more disabling than any single bleeding episode.

Diagnostic Dashboard



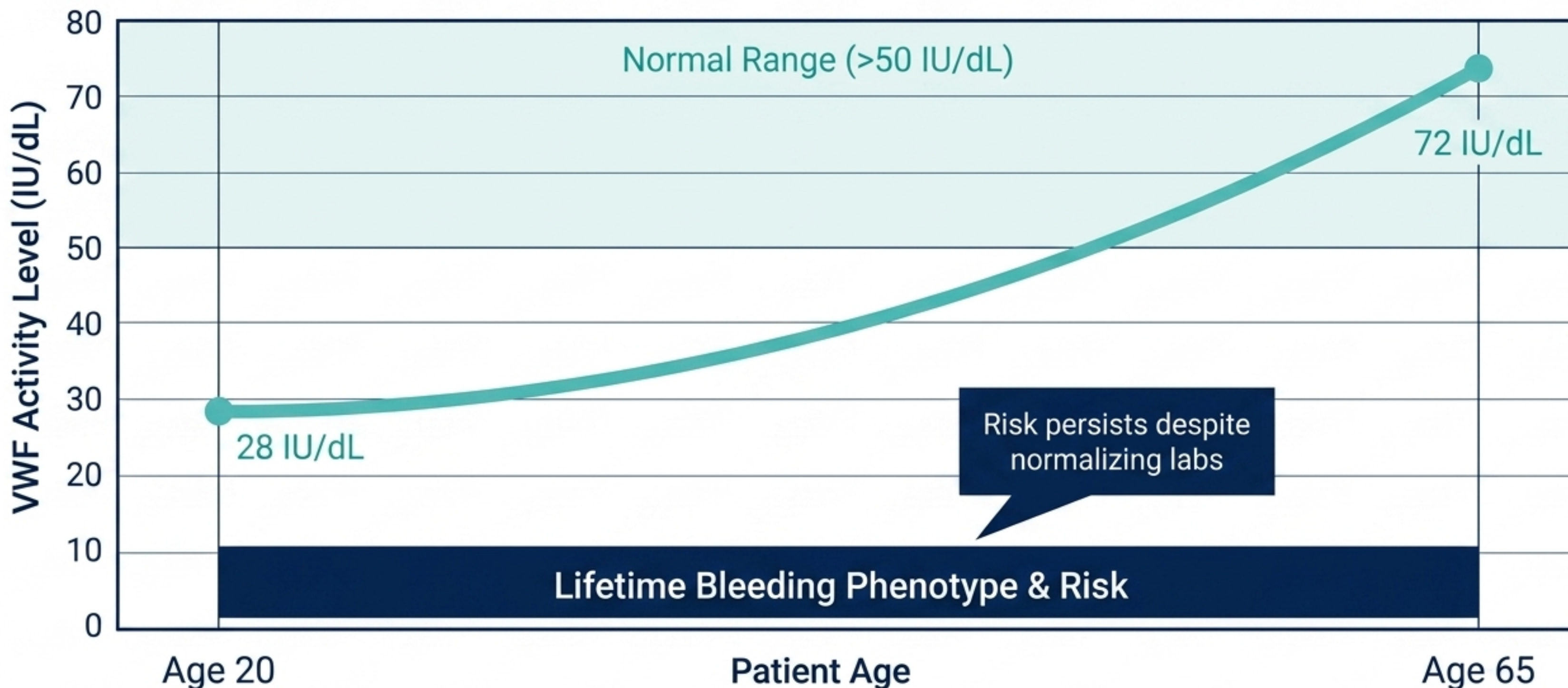
Loop Q2: What Explains the Change?

Biology and bleeding do not always move together. The established diagnosis is a starting point, not an automatic explanation.



The Aging Paradox: Reconsidering $\neq$ Erasing

The laboratory value has changed. The lifetime bleeding history has not.



Loop Q3: What Should Change in Management?

A treatment that once worked is not automatically the treatment that should always be used.

State Transformation

Desmopressin



Becomes less suitable as cardiovascular disease or hyponatremia risks emerge.

Episodic Control



VWF concentrate may now be required for major procedures, even if minor bleeds were previously managed without it.

On-Demand Therapy

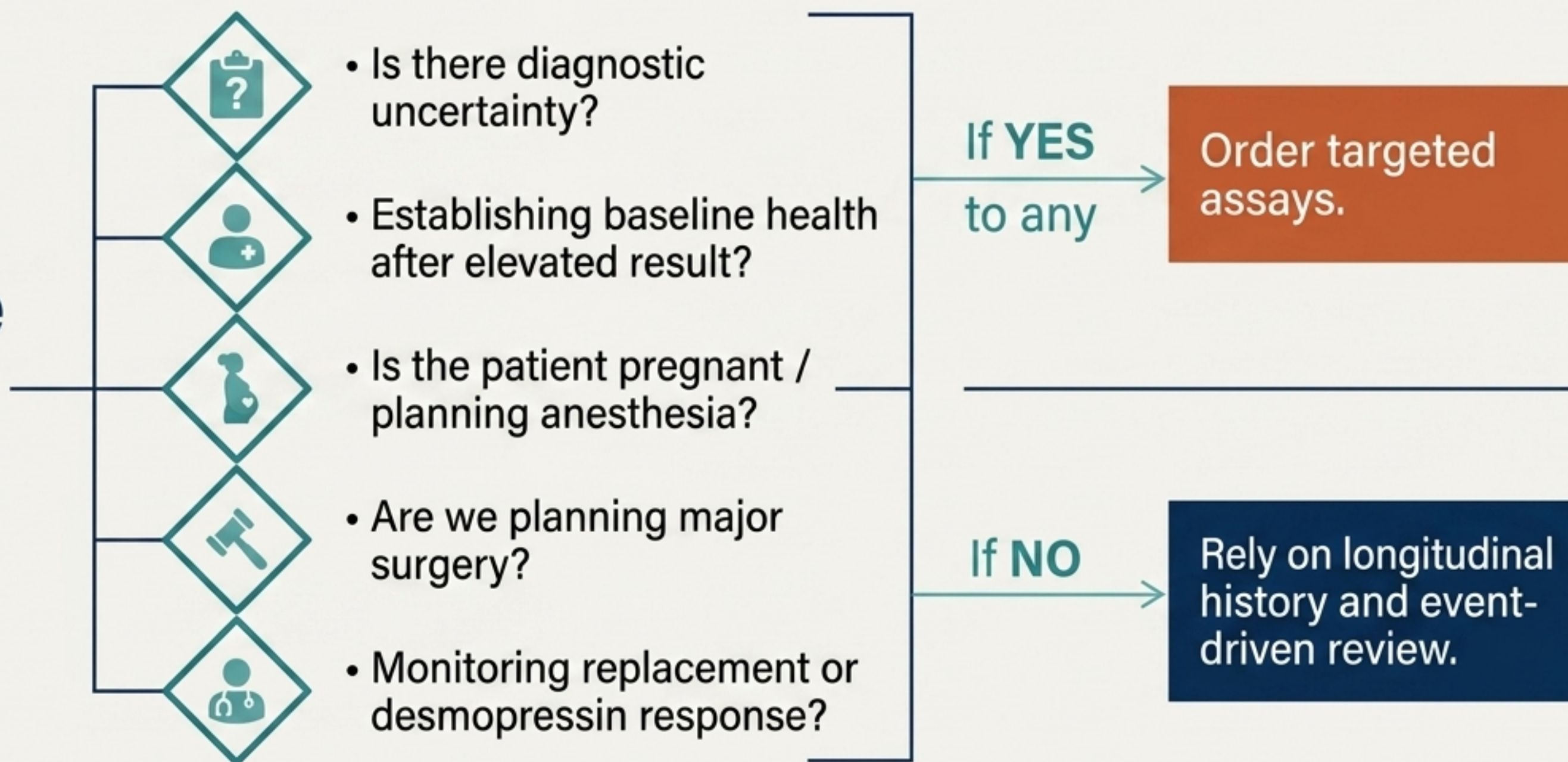


Shift to prophylaxis if recurrent severe bleeding demonstrates that on-demand treatment is failing.

Purposeful Laboratory Testing

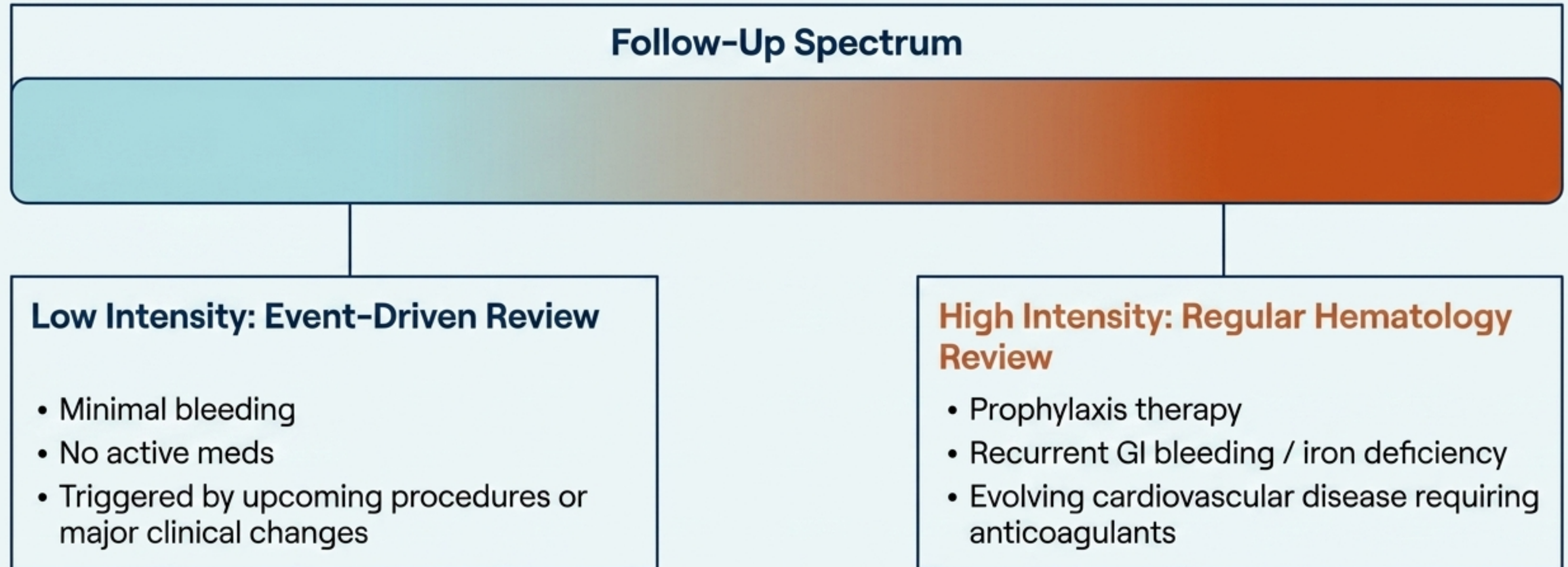
The purpose of testing is not simply to determine whether a number has changed, but whether the new number should alter interpretation or care.

**Should we
run new
labs?**



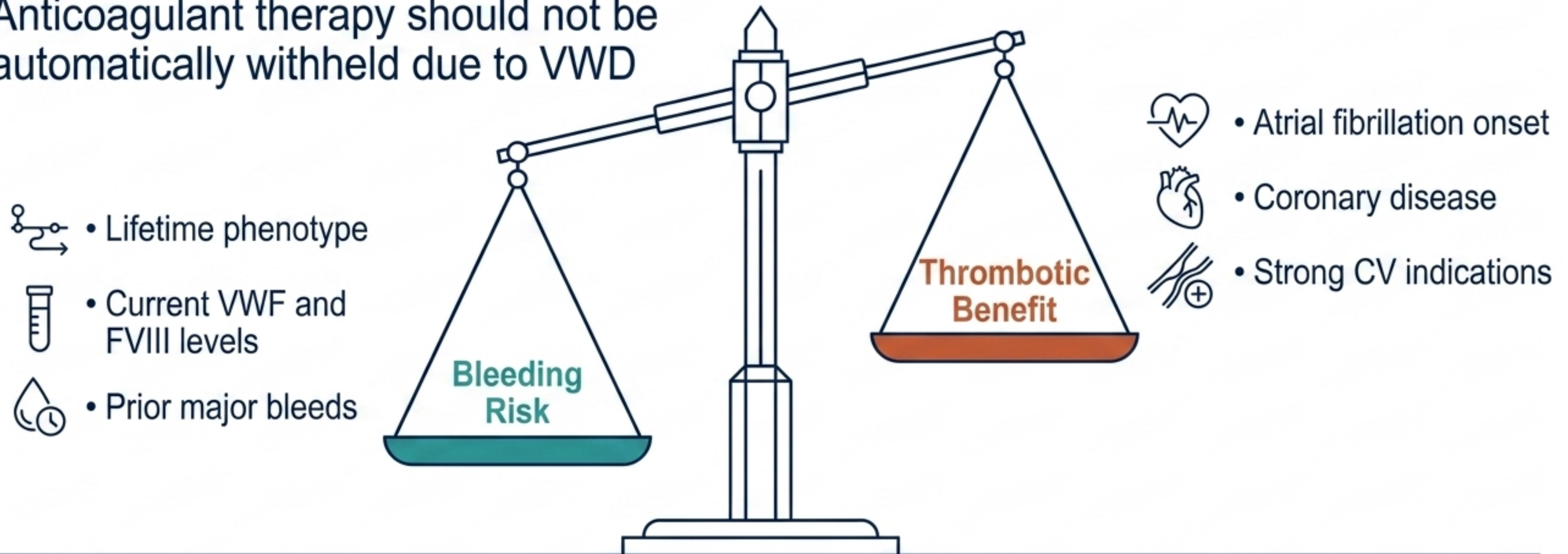
Tailoring Follow-Up Intensity

No universal schedule exists. Ensure clinically important change is recognized before it becomes a crisis.



The Ultimate Balancing Act: Bleeding vs. Thrombosis

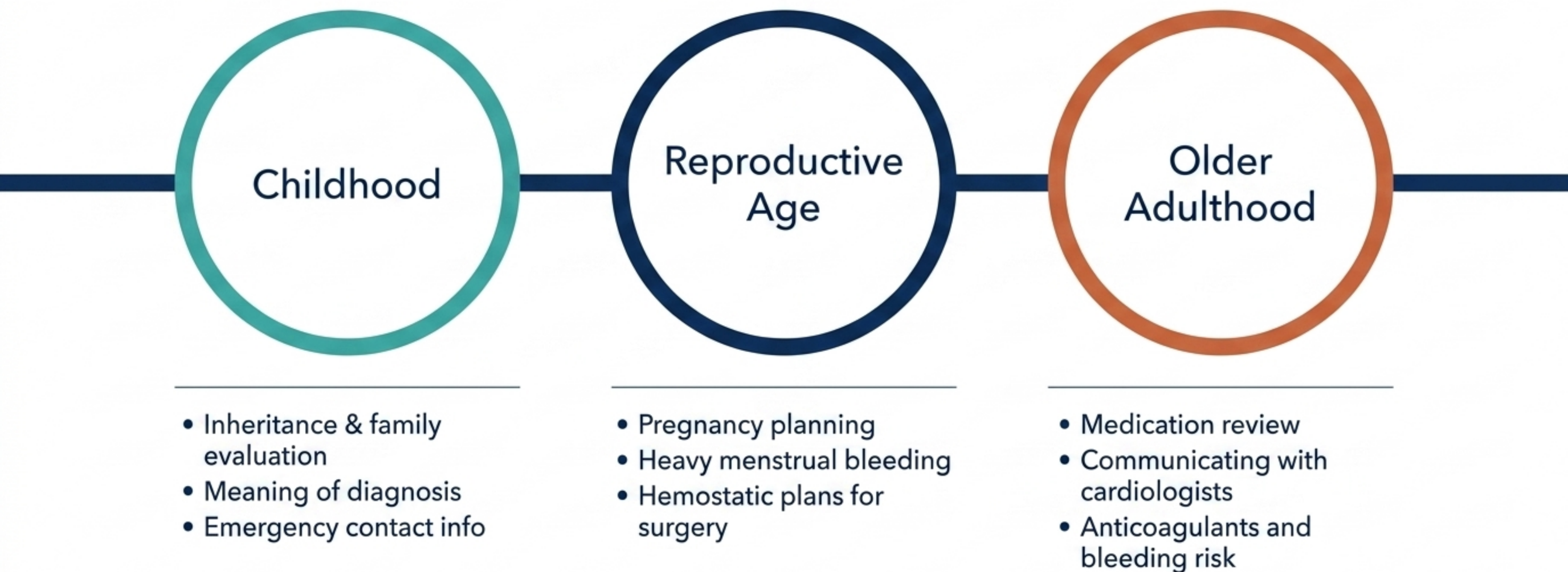
Anticoagulant therapy should not be automatically withheld due to VWD



The goal is the best achievable balance, not zero bleeding risk.

The Evolution of Patient Education

Education is not a one-time event delivered at diagnosis. Information irrelevant in childhood becomes critical decades later.



The Evidence Anchor: Data Behind Longitudinal Care

What the Data Shows	Clinical Implication	Evidence Limitation
Age-dependent trajectories (30% move to 30-50 IU/dL range, 23% normalize).	Normalization does not erase previous phenotype.	Observational cohort data.
Treated future bleeding doesn't differ significantly between historical low vs normalized VWF levels.	Longitudinal risk must incorporate presenting phenotype, not just borderline lab differences.	Retrospective, tertiary-center cohort.
2021 guidelines suggest reconsidering rather than removing type 1 VWD diagnosis when VWF normalizes.	Reassessment should integrate original diagnosis accuracy, lifetime history, and current labs.	Conditional recommendation based on very-low-certainty evidence.

Reflect & Apply: The Clinical Synthesis

Age 19

VWF Activity: 28 IU/dL



Years of epistaxis, heavy menstrual bleeding, iron deficiency.

What diagnosis best explains this patient?

Age 62

VWF Activity: 74 IU/dL (Normal)



No longer menstruating, atrial fibrillation requiring anticoagulation, recurrent GI bleeding.

What have the years taught us?

Synthesis: Re-evaluating structural GI disease and anticoagulant effect without erasing the historical type 1 VWD phenotype. Managing thromboembolism while mitigating bleeding.

Guideline Takeaways: Reassessment is Targeted, Not Formulaic

- 1. The first assessment establishes a working diagnosis; longitudinal care tests and refines it.**
- 2. A laboratory value describes one state; a longitudinal history records actual hemostasis.**
- 3. Repeat testing and treatment revision must serve a defined clinical purpose, not occur automatically.**
- 4. At every follow-up, ask: What has changed? What explains it? What should change?**