

Session 2:

Making a Difference: Identifying Best Practices to Measure the Impact of Patient Engagement

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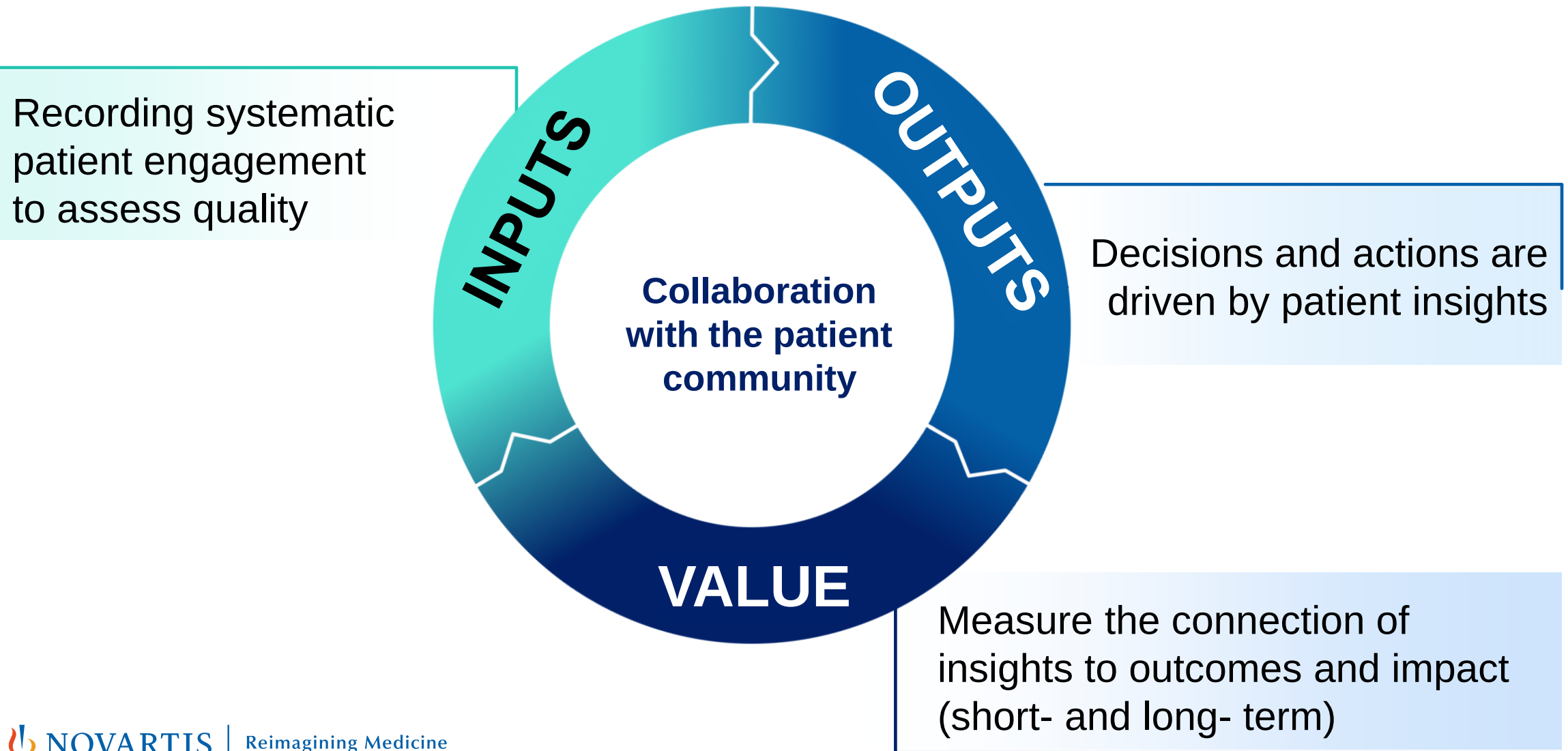
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Disclosures

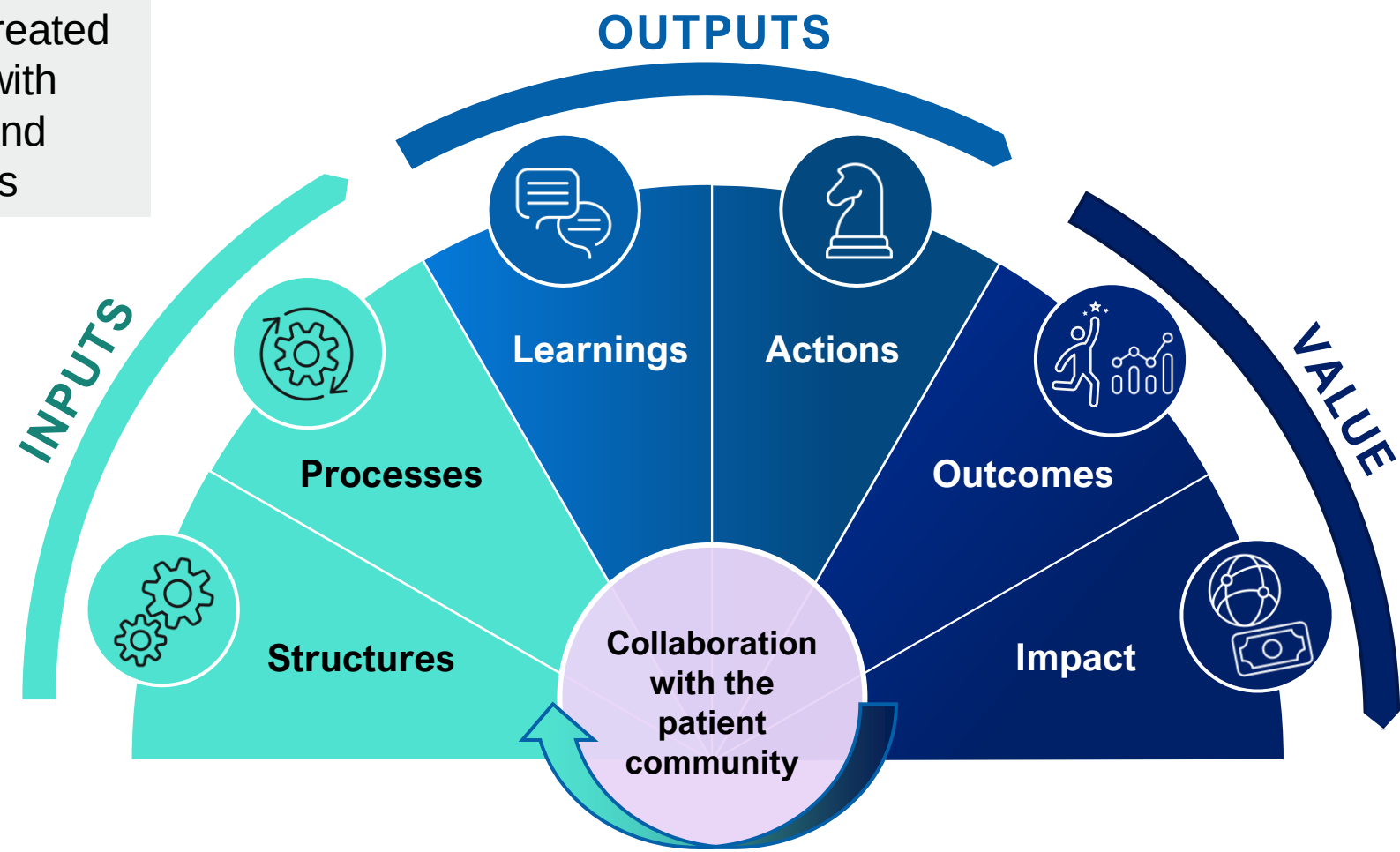
I am an employee and shareholder of Novartis Pharma AG

Quality assessment and improvement is a result of learning what drives valuable outcomes and impact, and how



The outputs of every patient engagement activity may have the potential to affect future activities and decisions through a medicine's lifecycle

Framework co-created in collaboration with expert patients and patient advocates



Quality PE processes to drive impact

- Recording PE is central to quality, impactful PE
- Impact measurement helps patient organizations to direct their resourcing

The good

- ✓ **Connected** systems and processes
- ✓ Patient-centered **mindset**
- ✓ **Systematic** and **consistent** PE
- ✓ **Leverage** existing/new insights across programs
- ✓ **Record** what is done in PE
- ✓ **Memorialize** what is learned from patients
- ✓ **Act** on the insights and record what **is done/ is not done** and **why**
- ✓ Close **feedback** loop with patients – what was done with the insights generated?

The bad

- ✗ Operating in silos
- ✗ Inconsistent and sporadic PE
- ✗ Inefficiency – repeating PED research for each program

The beautiful!

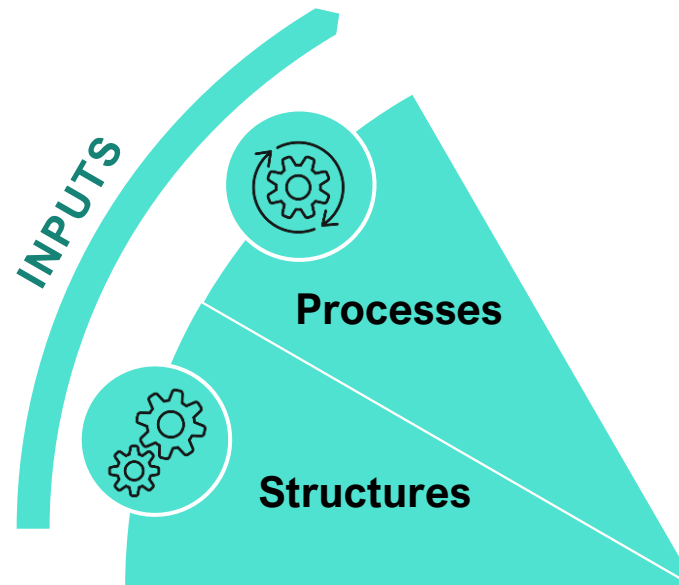
Drive processes that consistently capture what PE is performed, the methodology and the learnings

Use a measurement framework to connect this to the value generated

Case study: Patient-Focused Clinical Trial Development in Chronic Myeloid Leukemia (CML)

INPUTS

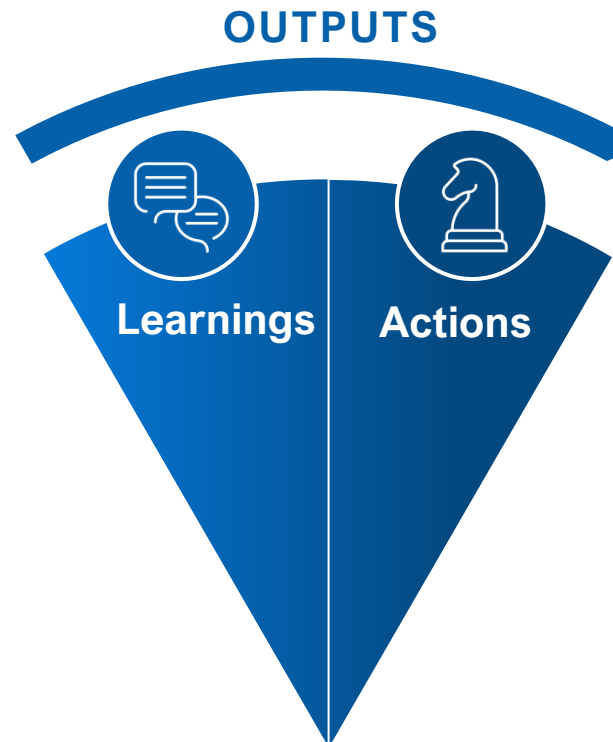
- Advisory board of CML patient advocates
- Reviewed participation and screening criteria for Phase III clinical trials in adults and children



Case study: Patient-Focused Clinical Trial Development in Chronic Myeloid Leukemia (CML)

OUTPUTS (Learnings)

- Recommended removing a bone marrow aspiration test as a requirement to enter the trial
- People living with CML typically already have test results on file
- Confirmatory testing during trial screening was an unnecessary barrier to participation

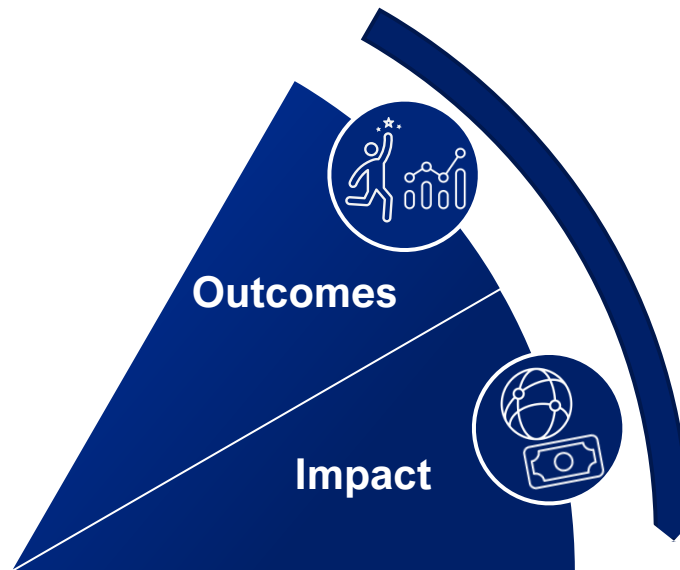


OUTPUT (Action)*

- We removed the requirement for a bone marrow aspiration test from the trial screening process
- Results of patients' previous tests were logged instead

*Based on the learnings from CML patient advocates and following a discussion with regulatory authorities.
CML, chronic myeloid leukemia

Case study: Patient-Focused Clinical Trial Development in Chronic Myeloid Leukemia (CML)



VALUE

- Improved experience for patients and caregivers
- Relatively easier patient recruitment experience (qualitative feedback from investigators)
- Phase III enrolment completed 10 months ahead of schedule

Patient engagement activities are not single isolated moments in time

To measure both short-term and long-term outcomes and impacts of patient engagement, we must track projects:



Across the whole
logic framework
(inputs, outputs, value)



Across functions
and stakeholders
(including patient
organizations)



Over
time

Connectivity

Tracking of long-term value

Q: When is the right time to measure the impact of Patient Engagement?

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Thank you!