

8th Global Patients Congress

24 - 26 May, 2018



International Alliance of
Patients' Organizations
A global voice for patients

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The Novartis Commitment to Patients and Caregivers

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Patients as partners in R&D

- The Novartis Commitment to Patients and Caregivers
- Patients involvement in R&D Novartis
- Patient Research Exchange



The Novartis Commitment to Patients and Caregiver

“Working together, we can improve outcomes for patients and become a trusted partner in changing the practice of medicine”



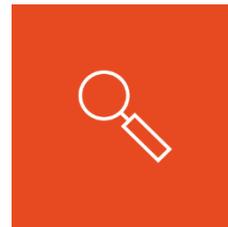
Respecting and understanding the patient community perspective



Expanding access to our medicines

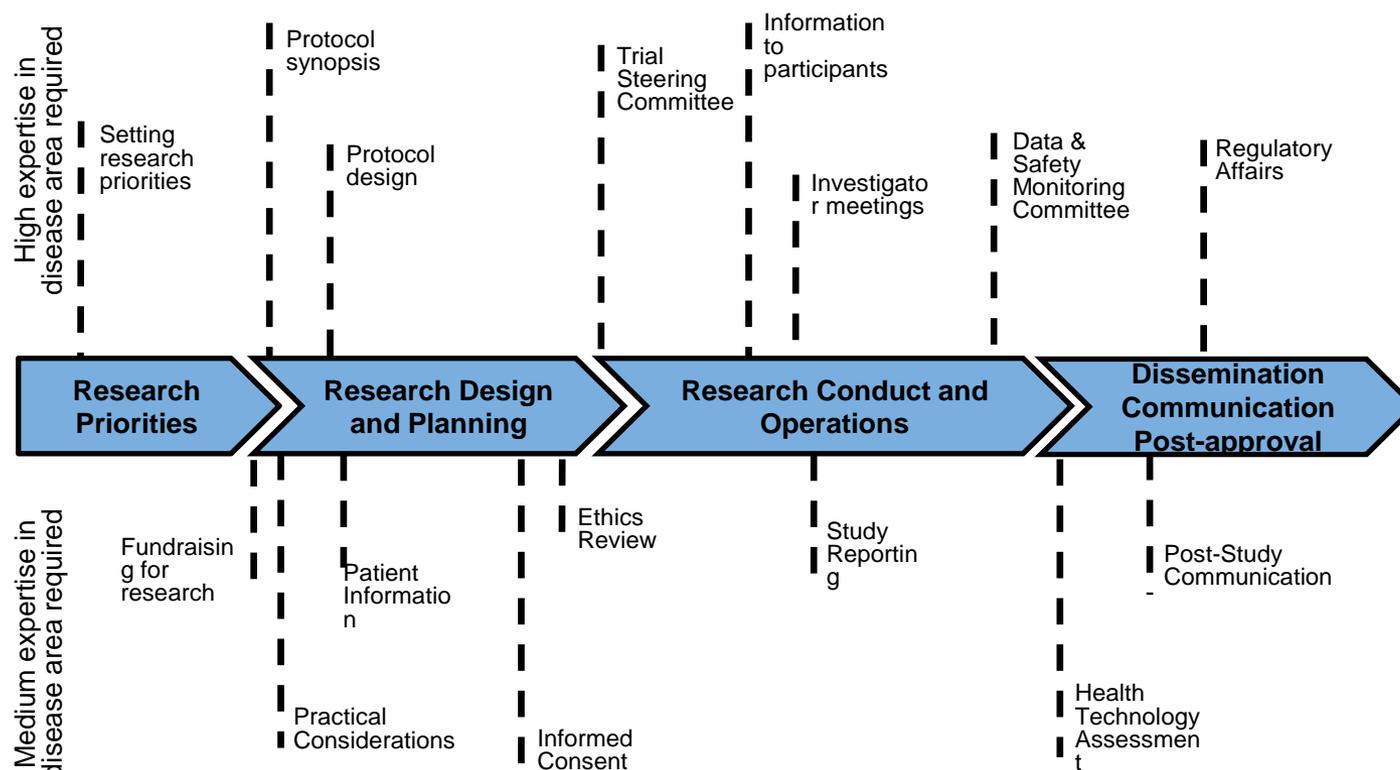


Conducting responsible clinical trials



Recognizing the importance of transparency and reporting

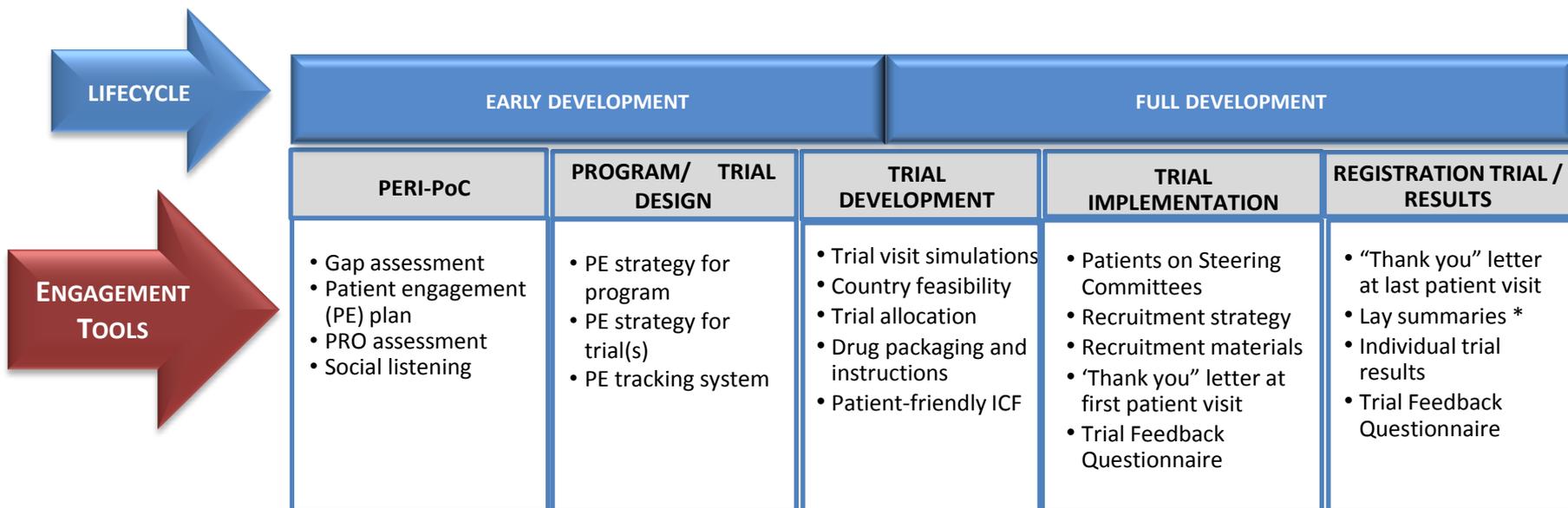
Patient involvement in R&D in industry is a reality today – but not yet systematic



Geissler, Ryll, Leto, Uhlenhopp, Therapeutic Innovation & Regulatory Science (2017), doi: 10.1177/2168479017706405

Communications & Advocacy

Tools & processes are encouraging R&D teams to include the patients perspective



* Starting with Phase 1-3 interventional patient trials with protocols being finalized in 2017, Novartis will provide patient lay summaries to trial investigators to share with their patients and will make these lay summaries publicly available on www.novartisclinicaltrials.com

PRO, patient reported outcome; PE, patient engagement; ICF, informed consent form

Communications & Advocacy

Case studies are powerful to set the scene for more involvement

CML

Recruitment completed ahead of schedule for first NVS global sponsored treatment free remission (TFR) trial due to **patient advocate feedback on ICF and patient Q&A** that explained TFR and study procedures in patient-friendly terms

Sjögren's Syndrome

Interviews with patients and **consultation with patient groups** identified key patient reported outcome measures, which enabled **positive PoC** (Proof of Concept)

Pediatric Heart Failure

Patient insights from **virtual focus groups** allowed clinical team to redesign protocol to **reduce patient burden** and **reformulate the drug**

Psoriasis

Findings from **qualitative patient interviews** and **cognitive tests** were used to create Psoriasis Symptom Diary data that was **accepted by the FDA** and **included in the US label** for itch, pain and scaling

Melanoma

Patient advisory board provided key insights into **protocol process, patient adherence, tolerance to side effects**, and **site level strategies** to support patients with advanced melanoma and their caregivers

We will measure and report our progress internally and externally



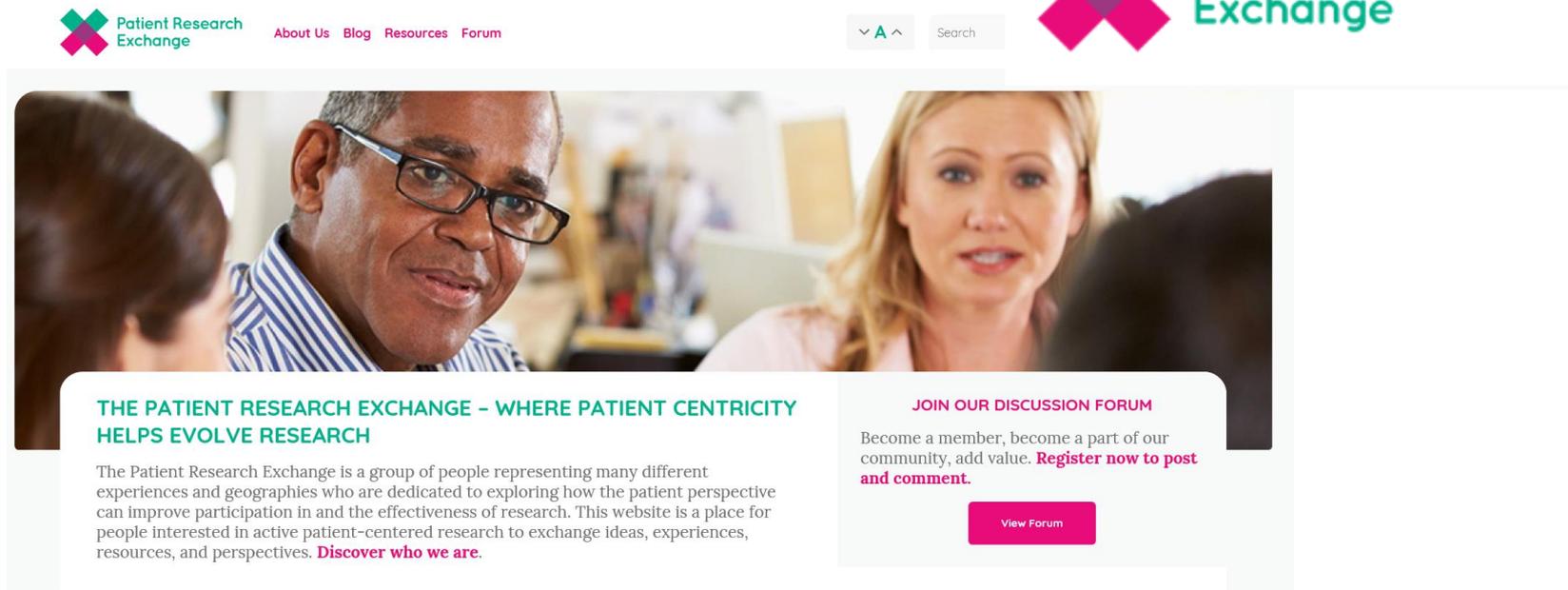
We will start with baseline measurements of engagement and build a more comprehensive framework over time

At the beginning we will focus on:

- # of simplified summaries of Phase 1-3 clinical studies that are sent to investigators and posted on [novartisclinicaltrials.com](https://www.novartis.com/clinical-trials)
- # of clinical development plans for new compounds with a patient engagement component
- # of patients reached through managed access programs¹

Performance indicators on select Novartis access approaches are published in the Annual Report² and the Corporate Responsibility Performance Report³

How the patient perspective can improve participation in and the effectiveness of research ?



The screenshot shows the Patient Research Exchange website. At the top left is the logo, a stylized 'X' made of four colored squares (green, purple, pink, teal), followed by the text 'Patient Research Exchange'. To the right are navigation links: 'About Us', 'Blog', 'Resources', and 'Forum'. Further right is a search bar with a magnifying glass icon and the text 'Search'. On the far right is a larger version of the logo and the text 'Patient Research Exchange'. Below the navigation is a large photograph of three people in a meeting: a man with glasses, a woman with blonde hair, and another person partially visible. Below the photo are two text boxes. The left box has the heading 'THE PATIENT RESEARCH EXCHANGE - WHERE PATIENT CENTRICITY HELPS EVOLVE RESEARCH' and a paragraph of text. The right box has the heading 'JOIN OUR DISCUSSION FORUM' and a paragraph of text with a 'View Forum' button.

THE PATIENT RESEARCH EXCHANGE - WHERE PATIENT CENTRICITY HELPS EVOLVE RESEARCH

The Patient Research Exchange is a group of people representing many different experiences and geographies who are dedicated to exploring how the patient perspective can improve participation in and the effectiveness of research. This website is a place for people interested in active patient-centered research to exchange ideas, experiences, resources, and perspectives. **Discover who we are.**

JOIN OUR DISCUSSION FORUM

Become a member, become a part of our community, add value. **Register now to post and comment.**

[View Forum](#)

<https://www.patientresearchexchange.org/>

Patient Research Exchange is owned and managed by IAPO with support of Novartis Pharma AG.
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Conclusion

By working together can we improve outcomes for patients and become a trusted partner in changing the practice of medicine



Contact us

Please visit our website to find out more:

<https://www.novartis.com/our-focus/patients-caregivers>

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Thank you!