

A Global Partnership on Women's Engagement in Health and Well-being

Draft Founding Document for Co-Creation

WHY?

Women-centric health systems require social participation.

We are launching a global cross-sector partnership, co-led with patient communities, to accelerate effective collective action in implementing women-centric care and R&D.

Discussions with over 15 leaders across sectors have identified the opportunity to bring a collective action framework to federate and accelerate efforts in women-centric care and R&D across sectors and regions in partnership with women, patients and their representative organizations. To reach our vision we need to intentionally defragment efforts, focus and mobilize our collective by bringing a structure, process and outcomes to make necessary changes happen on the ground.

The emerging women's health movement, reflecting more meaningful involvement of women and women patients, offers new momentum for lasting change in women's health and well-being. Ongoing efforts in patient engagement and social participation in health have resulted in many insights, assets and networks to leverage. There is an opportunity to align diverse stakeholders including representatives of women and patients to create and implement a unified framework that can advance women's health on a scale far beyond what individual efforts could achieve in isolation, avoiding duplication and wasted efforts.

Building on over 10 years of experience in incubating collective action programs in partnership with civil society, especially patient organizations, we have sketched the approach, strategic goals, and initial activity areas. We are looking for visionary leaders across sectors and geographies to contribute and co-shape this collective approach with us.

An independent, nonprofit global consortium of individual patients, patient organizations, health companies, healthcare professionals and medical societies, payers, HTA bodies, governments and policymakers, and funders.

WHAT?

We believe that all **women everywhere across the life course deserve the best possible health outcomes and quality of life, because they receive the specific care and therapies that works best for them.**

This Global Partnership on Women's Engagement in Health and Well-being is a global, open, and collaborative multi-stakeholder consortium. We partner with women and other stakeholders to **create a globally replicable women's engagement framework (e.g. tools, guidances and how-tos to put the woman at the center in R&D and**



care...) to practically enable women-centric healthcare and R&D practices on the ground, bringing a community approach to test and apply learnings in different health system, geographical and cultural contexts. It will raise awareness, build advocacy capacity, and establish an active global community of practice. This community will support sharing best practices and facilitate peer-to-peer support for applying proven interventions in women’s health.

This collective action partnership will:

- **Complement existing efforts** by drawing on an **existing, vibrant and knowledgeable patient community**, in line with the recent World Health Assembly Resolution underlining the need for greater social participation in health.
- **Identify and meaningfully connect existing efforts across sectors, stakeholders, and geographic levels** to build intelligence on what works and where.
- **Harness the power of a growing, motivated international community** and enable them to work together with a shared purpose, including the voices of women and patients so that they are not only heard but actively drive the implementation of solutions.
- Take existing best practices at international and local levels, make sense of them, and combine them into **globally replicable insights, practical tools and resources** that will improve women’s lived experiences.
- **Build a structure and capacity for success** to enable different people and sectors to effectively connect and work together, ensuring patient engagement is a foundational element.
- **Enable long term sustainability** by providing a forum to bring together diverse stakeholders, such as government, industry, and philanthropy to explore alternative approaches to fund and support women-centered initiatives.

Draft Strategic Goals and Activity Areas

STRATEGIC GOALS	ACTIVITIES
<p>Goal 1: Connect and Accelerate the Women-Centric Care and Health R&D Ecosystem</p> <p><i>We aim to enable a comprehensive understanding of existing efforts and connectivity across the ecosystem.</i></p>	<p>Map, Synthesize & Connect Ongoing Initiatives and Experts</p> <ul style="list-style-type: none"> ● Conduct a landscape mapping of experts, organizations, and initiatives dedicated to women-centered R&D and care. ● Identify and document areas of overlap, gaps, successes, challenges, and progress. ● Launch a Women’s Health Synapse to provide a dedicated space for this purpose. <hr/> <p>Identify, make replicable, and elevate good practices and resources:</p> <ul style="list-style-type: none"> ● Identify and synthesize existing resources, learnings and best practices.



	<ul style="list-style-type: none"> ● Filter and validate most relevant and up to date information and outcomes. ● Make these resources more accessible to the community, categorized by specific needs addressed. ● Share insights to inform other activities and initiatives across the ecosystem.
<p>Goal 2: Create the Demand for Women-Centric Care and R&D Through Awareness Raising and Advocacy Efforts</p> <p><i>We aim to unify, complement and extend global awareness and advocacy efforts for women-centric care and R&D by establishing it as essential requirement for healthy societies.</i></p>	<p>Awareness Campaigns:</p> <ul style="list-style-type: none"> ● Conduct multi-channel campaigns (digital platforms, healthcare touchpoints, etc.), leveraging the patient community to highlight patient needs & experiences, the importance of preventive healthcare, and a life course approach with a focus on underserved communities.
	<p>Enhance Capacity for Women-Centric Advocacy:</p> <ul style="list-style-type: none"> ● Strengthen advocacy groups focused on promoting women-centric care and R&D by providing resources, tools, and support to advocate effectively for gender-sensitive health care policies.
	<p>Build and Share Women-Centric Evidence</p> <ul style="list-style-type: none"> ● Aggregate & highlight women’s experiences to support the value case for investing in women, identifying best practices in demonstrating the socioeconomic benefits of women-centered health approaches. ● Leverage emerging learnings in the use of patient experience data (PED) in health decision making to support advocacy.
	<p>Advocate for Legislative Change</p> <ul style="list-style-type: none"> ● Establish dedicated legislative committees dedicated to women-centric care and R&D, leveraging and unifying ongoing efforts. ● Launch a joint call to action that consolidates and communicates these priorities, targeting policymakers and influencers.



	<p>Policy Focus on Pregnancy and Medicine Safety:</p> <ul style="list-style-type: none">● Advocate for policies and incentives specifically addressing the safe use of medicine during pregnancy and breastfeeding, including the need to drive data generation efforts for evidence on pregnancy and lactation safety and promoting collective efforts to address this need. <p>Drive Investment and Funding for Women’s Health:</p> <ul style="list-style-type: none">● Advocate for increased funding from companies and governments, compiling and presenting compelling evidence on the return on investment in women’s health initiatives.● Engage patient communities to help set investment priorities and support organizations representing women’s health interests.
<p>Goal 3: Advance Women-Centric Care and R&D with Scalable Solutions</p> <p><i>We will accelerate practical, scalable solutions that improve outcomes for women at a community level</i></p>	<p>Develop, Pilot and Scale Women-Centric R&D Frameworks and Guidances:</p> <ul style="list-style-type: none">● Identify women-centric drug development unmet needs across all life stages, including neglected health areas that disproportionately affect women.● Adapt and extend existing frameworks for patient engagement across the lifecycle of medicine development (e.g. preclinical, clinical trial recruitment...) to include a women-centered lens, adaptable for diverse geographic and healthcare contexts.● Conduct demonstration pilots in partnership with patient communities to test these frameworks locally and share learnings globally.● Provide industry training in partnership (with organizations like the Healthcare Business Women’s Association), focusing on how to conduct R&D that addresses women’s psychosocial needs and lifecycle stages. <p>Enable Women-Centric Care Delivery:</p> <ul style="list-style-type: none">● Identify and share unmet needs in care delivery, such as primary prevention, safe and early diagnosis, treatment and disease management.● Centralize resources, elevate and pilot successful interventions that enable sex & gender-responsive care practices that consider



	<p>the specific needs of women at different stages of life (e.g. adaptable resources for informed provider-patient communications, reflecting women’s specific needs)</p> <ul style="list-style-type: none">● Collect and analyze real-world data and patient experiences, across life stages, to personalize treatment options and address gaps. Disseminate these insights to improve care pathways and support research.
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Activities to kick off

2024/2025 Project Objectives and Expected Outcomes

We aim to launch the partnership in the next year. Specific outcomes for 2024-2025 include:

- Recognition and validation of a shared concept/approach by leaders in women’s health (e.g. intersectoral leaders from Innovation Equity Forum, IMI ConcePTION, Global Alliance for Women’s Health...)
- Mobilize an active community of practice across country contexts and sectors
- Recognition by the patient engagement community of the need to include a particular focus on women’s health for better patient outcomes, and existing PE frameworks (e.g., guidances for patient engagement in R&D and at care levels) begin to be adapted and validated at fora such as Patient Engagement Open Forum

2024-2025 Project Deliverables to Kick Off

- Public consultation campaign during Safe Motherhood Week to validate and fine tune a shared concept (eg. strategic areas and priority activities) (November).
- Expert consultations across stakeholders at IMI ConcePTION closing event, the Patient Engagement Open Forum and with key opinion leaders (e.g. partners of the Innovation Equity Forum), aiming to extend representation of women and patients.
- Establish incubation working group(s) to refine strategic goals and activity areas, a work plan, and governance structures to get started.
- (Re-)Launch of Women’s Health Synapse with initial mapping and analysis of existing initiatives and best practices.

Participation Benefits

Founding Members are members who join within the first year of the program launch. As a Founding Member, you can actively participate in co-creating the program by contributing your expertise, funding (as sponsors), or providing in-kind support.

Founding Members benefit from the unique opportunity to help shape the foundation of the Program. This includes defining the governance structure, strategic focus and priorities, identity, and content, as well as guiding early



activities such as stakeholder engagement. Founding Members are also invited to participate in multi-stakeholder working groups, discussions, and roundtables to directly shape the future of women-centric care and research.

Membership Benefits

Shape the Program Strategy and Outputs

- Play a key role in defining the strategic direction and objectives of the partnership, ensuring women’s voices and needs are at the core of healthcare and R&D efforts.
- Directly influence the creation of a global framework that aims to transform women’s health outcomes across regions and healthcare systems.
- Your contributions will help establish key initiatives. Leveraging your expertise, you will design targeted solutions that address women’s needs at various life stages, from early prevention to advanced treatment.

Lead the Co-Creation of Real-World Solutions

- Take a leadership role in shaping co-creation sessions, where you will collaborate closely with patient communities, healthcare leaders, and diverse stakeholders to develop scalable, women-centered solutions.
- Be at the forefront of demonstration pilots, testing innovative approaches to women’s healthcare, with the objective of replicating these successful models globally.
- Help identify unmet needs and propose practical solutions that address gaps in today’s healthcare and research landscapes.

Develop Your Influence and Network

- Collaborate with a diverse range of partners, from patient advocates to policymakers, exchanging insights that enhance your ability to drive meaningful change in women’s health.
- Expand your reach and influence by building relationships with global thought leaders in women’s healthcare, positioning your organization as a key player in this movement.
- Engage with influential stakeholders across sectors and geographies to ensure that the solutions and frameworks developed are inclusive, sustainable, and impactful for women everywhere.

Exclusive Access and Tools

- As a Founding Member, you will have access to curated program resources and premium tools to support your organization’s role in advancing women-centric healthcare and research.

Participation Levels

Yearly Benefits	Supporting Community Practice (Non-Members)	of Leading Member €50k - €100k*	Premier Founding Member €50k - €300k*
Co-creation Working Groups	+	+	+
Stakeholder Engagement Surveys & Consultations	+	+	+



Contribute to and benefit from a globally active network to share learnings and best practices.	+	+	+
Connect with experts and important actors in sustainable health and well-being face-to-face	+	+	+
Access program deliverables (open access)	+	+	+
Participation at Events and Roundtables		+	+
Participate in pilot programs		+	+
Partner logo on “corporate” collateral (website, brochures, ...)		+	+
Eligibility for Board Membership		+	+
Eligibility for Executive Committee		+	+
Shape the Program’s strategic focus areas and priorities			+
Define the governance and membership structure			+
Define the Program’s branding and identity			+

*Annual membership fees and governance structures will be decided by the Board

Annex 1: Ongoing consultations

Consulted:

- ALINE CLAUSS, Head of Communications, Mibelle Group
- ALISSA GOODALE, Project Lead for Advancing Inclusive Research & Women's Health, Genentech (USA)
- ALISSA PEREIRA, LMIC Hub Commercial Lead at Roche
- DR. ELEANOR NWADINOB, International President, Medical Women's International Association (MWIA) | Member of the Partnership Subcommittee of the Innovation Equity Forum (Nigeria)
- JAMIE WHITE, Women’s Health Advocate and former Co-Chair, Innovation Equity Forum and Health Science Strategy & Relations Lead at NIH (USA)
- HON. JULIETA KAVETUNA, Member of Parliament, National Assembly of Namibia, Mental Health Specialist (Namibia)



- NNEKA NWOKOLO, Co-Founder and Specialist, NewWoman Health, and Head of Global Patient Affairs at ViiV Healthcare
- SUSAN MCCLURE, Individual Patient and CEO, Genome Creative
- KATJA WINTER, Healthcare Businesswomen's Association (HBA) Regional Chair Western Europe
- LAURA MINQUINI, Founder, AthenaDAO
- DR. MAIKE SHARP, Deputy Director, Strategy at Bill & Melinda Gates Foundation and Co-Chair, Innovation Equity Forum (USA)
- MARIAM JASHI, CEO Global Sepsis Alliance, Secretary General MWIA, Global Board Member UNITE Parliamentarian Network (Georgia)
- MARJOLEIN WILLEMEN, Medical Policy & External Collaborations Lead, Novartis Pharma AG | Project Lead for IMI ConcePTION (Switzerland)
- DR. METIN GULMEZOGLU, Executive Director, Concept Foundation (Switzerland / Turkey)
- DR. PAULA WRAY, Senior Manager NIHR ARC Oxford and Thames Valley (UK)
- REBECCA VERMEULEN, VP Global Patient Networks, Product Development Medical Affairs, Roche (USA)
- DR. RISHMA DHILLON PAI, Senior Gynaecology Consultant, Lilavati Hospital (India)
- DR. RU-FONG CHENG, Director, Women's Health Innovations | Gender Equality Division, Bill & Melinda Gates Foundation (USA)
- STEPHANIE SASSMAN, Portfolio Leader, Women's Health, Genentech (USA)
- DR. SUSAN NICHOLSON, Former VP, Women's Health, at Johnson & Johnson
- AMIRA GHOUAIBI, Head, Global Alliance for Women's Health, World Economic Forum and EMILY FITZGERALD, Global Alliance for Women's Health, World Economic Forum
- JOANA PEREZ, and GONCALO PINTO MENDES, UNITE Global Parliamentarians Network
- AKIKO OTANI, Senior Director, Public Private Partnerships & Global Science Policy at Takeda
- PEGGY MAGUIRE and REBECCA MOORE, European Institute of Women's Health
- Mirjam Kaijer, Voices for Women Foundation
- Roundtable participants from the [2023](#) & [2024](#) PEOF Session

Annex 2: Shared Vision

Women everywhere across the life course have the best possible health outcomes and quality of life, because they receive the specific care and therapies that works best for them.

Women everywhere and across the life course are able to live to their full potential because when the lives of individual women improve, the communities around them improve. They have the best possible health outcomes and quality of life, with equitable access to prevention and treatment approaches tailored to their needs so that they receive the specific care & therapies that work best for them. Equitable inclusion, participation, and funding of women across the R&D continuum, including embedding sex and gender considerations at all stages, exist. A thriving private sector ecosystem for women's health innovations and investments in women-centered care approaches demonstrate high return on investment potential, including financial and economic returns and health and social benefits.

(Co-developed at Patient Engagement Open Forum 2024)



Annex 3: About The Synergist

THE SYNERGIST

[The Synergist](#) is a non-profit dedicated to solving complex societal issues through collective action. By bringing together individuals, organizations, and initiatives, The Synergist creates conditions for collaboration and builds systems that deliver sustainable outcomes. Its focus areas include patient engagement, precision medicine, maternal health, and environmental impact.

Programs brought to fruition by the Synergist:

- **The Motherhood Collective Impact Program (MCIP)**
[MCIP](#) is a partnership focused on addressing key challenges in maternal health using a systems-based approach. By uniting diverse stakeholders, including mothers, it aims to improve maternal and neonatal care and ensure all women have access to high-quality maternal care before, during, and after pregnancy.
- **From Testing to Targeted Treatments (FT3)**
[FT3](#) is a global, open, and collaborative multi-stakeholder program that aims to build synergies and accelerate pragmatic efforts to make PM an accessible reality for all those who could benefit from it, starting with cancer and testing. We build with patients for patients. Using a co-creation approach, we directly involve patients, healthcare professionals, and other stakeholder groups in problem-solving and decision-making at every step and in an ethically responsible way. The aim is to accelerate the benefits of Personalized Medicine and Precision Medicine (PM) by generating better evidence, creating awareness, and building the conditions for better access to targeted medicine in oncology and beyond.
- **Patient Focused Medicines Development (PFMD)**
[PFMD](#) is a not-for-profit collaborative initiative benefiting patients and health stakeholders by designing a patient-centered healthcare system WITH patients and all stakeholders. The aim is to improve global health by co-designing healthcare WITH patients. Its mission is to bring together initiatives and best practices that integrate the voice of the patient, thereby speeding up the creation and implementation of an effective, globally standardized framework. This framework, designed in collaboration with patients as valued partners, will be complemented by essential tools, services, and support systems, fostering widespread adoption among diverse stakeholders. Check out the [PFMD PEM Suite](#); a global hub for practical tools to plan, assess, and execute any patient engagement initiative.

Other programs where The Synergist leads efforts in fostering inclusive, patient-centered engagement and coordinating multi-stakeholder collaboration:

- **GUIDE.MRD**
[GUIDE.MRD](#) focuses on advancing precision oncology through the use of circulating tumor DNA (ctDNA) to detect minimal residual disease (MRD) in patients with solid tumors, enabling more targeted treatment decisions. The project aims to benchmark ctDNA assays, validate their clinical utility, and develop guidelines to integrate these diagnostics into healthcare systems. The Synergist plays a central role in facilitating



stakeholder engagement, coordinating the Patient Advisory Board, and ensuring a patient-centered approach.