EPICare - Empowering Persons with Disabilities through Participatory Innovation, Co-Creation and Competence Building for Independent Living

Invitation to Join a Horizon Europe Consortium as Specialised Research Partners

Call: Addressing disabilities through the life course to support independent living and inclusion (HORIZON-HLTH-2027-01-STAYHLTH-01)

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Who wer are looking for

We are actively looking for an existing consortium seeking strong partners with expertise in participatory health research, Patient and Public Involvement and Engagement (PPIE), co-design and co-production, qualitative and mixed-methods research, governance of participation, community-based care models, implementation research, interprofessional collaboration, healthcare ethics, epistemic justice, inclusion, disability research, and person-centred care.
Given the size and complexity of this Research and Innovation Action (RIA), we believe that our strongest contribution lies in acting as specialised research partners who can provide complementary expertise in these areas. We would be delighted to explore opportunities to join and strengthen an emerging consortium.

EPICare as a Conceptual Framework and Potential Contribution to a Horizon Europe Consortium

We are seeking opportunities to contribute to an existing or emerging Horizon Europe consortium addressing the topic “Addressing disabilities through the life course to support independent living and inclusion” through our EPICare concept and expertise. EPICare (Empowering Persons with Disabilities through Participatory Innovation, Co-Creation and Competence Building for Independent Living) outlines a complementary perspective that we would be interested in bringing into a broader European consortium. Our primary interest is to join an existing consortium or help create a novel consortium as specialised research partners rather than to coordinate a large-scale Horizon Europe project. Our work focuses on ensuring that persons with disabilities and people with lived experience and disabilities are recognised not only as recipients of services, but as active contributors to research, education, governance, innovation, and healthcare decision-making.

EPICare builds on previous conceptual work developed within the PIONEER alliance between Bern University of Applied Sciences and Laurea University of Applied Sciences. This work explored how participatory competence development and Patient and Public Involvement and Engagement (PPIE) can be strengthened in health professions education and contribute to a broader vision for disability-inclusive, participatory, and community-based health and care systems. Rather than proposing a stand-alone project, EPICare represents a conceptual framework that could strengthen a broader Horizon Europe consortium. It brings together expertise in participatory health research, PPIE, healthcare ethics, epistemic justice, co-design and co-production, community-based care, inclusive governance, and competence development to support disability-inclusive innovation and independent living. Depending on the structure and needs of the consortium, the EPICare concept could contribute as a cross-cutting framework, a dedicated research strand, or the basis for a specific work package.
In addition to questions of access to services, infrastructure, or assistive technologies, EPICare seeks fundamentally asks:

How can healthcare systems, educational institutions, and community services become genuinely participatory and enable persons with physical disabilities to actively shape the services, decisions, and innovations that affect their lives?

Why EPICare?

Across Europe, persons with physical[1] disabilities continue to experience fragmented healthcare pathways, institutional gatekeeping, poorly coordinated services, and inadequate continuity of support. Transitions between hospitals, rehabilitation settings, primary care, and community services frequently expose individuals to avoidable risks. A major reason is that expertise-by-experience often remains insufficiently recognised in clinical and organisational decision-making. Valuable knowledge acquired through living with disability, including self-management strategies, accessibility requirements, community participation practices, support networks, and the conditions necessary for independent living, is frequently overlooked or disregarded. Such failures constitute a particularly concerning form of epistemic injustice, namely testimonial injustice, whereby individuals are not accorded appropriate credibility as reliable knowers of their own lives and health-related needs (Fricker, 2007; Weidmann-Hügle & Monteverde, 2024).

The consequences become especially severe when persons with disabilities require acute hospital care. At precisely the moment when healthcare professionals and organisations should be able to draw upon an individual's extensive experiential knowledge, this expertise is often marginalised, undervalued, ignored, or even actively discarded. Established self-management routines, trusted support networks, accessibility needs, and critical knowledge about everyday living and independent living arrangements may receive insufficient attention during assessment, treatment planning, discharge management, and care coordination.

The resulting disconnect between professional knowledge and lived expertise can undermine continuity of care, jeopardise independent living arrangements, contribute to preventable deterioration in health status, and restrict opportunities for participation and inclusion in community life. Consequently, persons with disabilities may experience disproportionately poorer health outcomes, avoidable complications, increased yet ineffective healthcare utilisation, and reduced quality of life compared with the general population, reflecting persistent and largely preventable forms of health inequity. These disparities demonstrate that the challenge extends far beyond service coordination and clinical effectiveness. They reflect deeper issues of participation, recognition, the realisation of disability rights, social justice, and the equitable distribution of epistemic authority within healthcare systems. EPICare starts from the premise that sustainable improvements in independent living cannot be achieved through better services alone. They require healthcare systems that systematically recognise persons with disabilities

[1] Our current expertise is centred on fostering participation in the context of physical disabilities. The perspective could be extended to intellectual disabilities where consortium partners contribute the specific expertise required for supported decision-making, assisted autonomy, and inclusive PPIE approaches.

as legitimate knowledge partners whose expertise-by-experience informs healthcare, education, research, and innovation.

EPICare therefore addresses these challenges not merely as organisational and clinical problems, but as ethical, epistemic, educational, and societal concerns. By integrating disability rights, participatory health research, meaningful Patient and Public Involvement and Engagement (PPIE), co-production, service innovation, and participatory competence building, the project seeks to transform the conditions under which persons with disabilities participate in, shape, and benefit from healthcare and community support systems, thereby advancing autonomy, community participation, and independent living.

From Independent Living to Participatory System Transformation

The project is firmly anchored in the principles of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), the European Strategy for the Rights of Persons with Disabilities (European Commission, 2021), and the Guidance on Independent Living and Inclusion in the Community of Persons with Disabilities in the Context of EU Funding (European Commission, 2024).

EPICare understands **independent living** as the ability of persons with disabilities to exercise self-determination and autonomy, make informed choices, participate meaningfully in decisions that affect their lives, access appropriate community-based support, and achieve full inclusion in society.

Participation is not regarded as an optional enhancement of care but as a fundamental requirement of a fair and rights-based healthcare system and a key condition for independent living. EPICare understands participation as a cross-cutting principle operating at multiple levels: not only in individual care and support relationships, but also in the design of services, organisations, educational systems, research processes, governance structures, and policy development.

The Scientific Foundation of EPICare

EPICare brings together three complementary scientific traditions.

1. Ethics, Disability Rights and Epistemic Justice

EPICare understands many barriers faced by persons with disabilities as forms of epistemic injustice. In this line of thinking, the project examines

- recognition of expertise-by-experience
- autonomy and self-determination
- vulnerability,
- shared decision making,
- disability rights,
- ethical conditions of participation.

From this perspective, independent living cannot be reduced to questions of services and accessibility; it equally involves recognition, justice, and the distribution of power, both in material terms and in epistemic terms, addressing the question whose knowledge counts, whose voices are heard, and whose expertise is recognized.

2. Participatory Health Research and PPIE

EPICare treats participation not merely as a method but as a structural principle guiding research, education and innovation. The project draws on:

- Participatory Action Research (PAR)
- Patient and Public Involvement and Engagement (PPIE)
- Caring Communities
- co-production
- co-design

Persons with disabilities will participate as co-researchers, co-designers, co-educators and governance partners throughout the project.

3. Expertise-by-Experience and the Co-Production of Knowledge

EPICare draws on international expertise regarding:

- expertise-by-experience
- participation of vulnerable groups
- inclusive research methodologies
- co-research
- equality, diversity and inclusion

The project will investigate how participation structures can move from consultation towards meaningful and equitable partnership.

The Unique Selling Proposition (USP) of EPICare

For addressing the needs of persons with disability, many European projects develop rehabilitation models, care pathways, assistive technologies, community-based services, and targeted healthcare interventions. EPICare goes one step further: the project investigates how healthcare systems can become capable of sustainably creating the conditions that enable persons with disabilities not only to thrive, but also to continuously shape healthcare logics and community support through meaningful participation and co-production.

What distinguishes EPICare is its focus on transforming the conditions through which persons with disabilities can participate in shaping the services they use, the organisations that provide them, and the systems that govern them. This perspective draws on expertise in participatory health research, Patient and Public Involvement and Engagement (PPIE), co-design and co-production, healthcare ethics, epistemic justice, inclusive governance, community-based care, and participatory competence development.

Together, these elements position EPICare at the intersection of disability rights, participatory health research, service innovation, and health professions education, creating a unique platform for advancing independent living, community participation, and disability-inclusive systems transformation.

Participatory Competence Building: The Educational Innovation

One of the most innovative aspects of EPICare is its educational pillar. While many projects focus on service innovation, EPICare additionally investigates how future healthcare professionals can be prepared for meaningful participation and co-production. Undergraduate nursing education serves as the primary educational testbed because nurses play key roles across acute care, rehabilitation, primary care, home care, community healthcare and long-term care. At the core of this educational pillar is the participatory co-development and validation of a European EPICare Competence Framework designed to prepare future healthcare professionals for disability-inclusive, participatory, and community-based practice. Consistent with the project's commitment to disability rights, epistemic justice, PPIE, and co-production, the framework will be developed ***with*** **persons with disabilities rather than** ***for*** **persons with disabilities**. Through meaningful involvement and partnership, persons with disabilities will actively contribute to defining the competence domains, learning outcomes, educational approaches, assessment strategies, and implementation processes. The framework addresses four interrelated competence domains:

Ethical Competence

- disability rights
- autonomy
- self-determination
- epistemic justice
- equitable care

Participatory Competence

- effective PPIE
- co-production of knowledge
- partnership working
- shared decision-making

Inclusive Competence

- accessibility of services and barrier reduction
- equity of resource allocation
- inclusivity of services and products

Co-Creative Competence

- co-design of processes
- collaboration within living labs
- participatory innovation
- collaborative problem-solving

A distinguishing feature of the framework will be the active involvement of persons with disabilities throughout the entire development, implementation, and evaluation process as:

- co-teachers
- co-assessors
- curriculum co-designers
- mentors

By embedding participation and co-production in both the content and the development of the framework itself, EPICare seeks to prepare future healthcare professionals to work in genuine partnership with persons with disabilities and to contribute to more participatory, inclusive, and rights-based healthcare systems.

Central Research Hypothesis / Theory of Change

EPICare hypothesises that fragmented and insufficiently participatory healthcare and support systems contribute to poorer health outcomes, ineffective use of health resources, restricted autonomy, limited community participation, and the under-recognition of the expertise-by-experience of persons with disabilities.

EPICare further hypothesises that more ethical, participatory, inclusive and co-creative healthcare and support systems can address these challenges. This requires strengthening the competencies of future healthcare professionals, systematically involving persons with disabilities as equal partners in research, education and service innovation, and promoting more participatory governance, policy and funding arrangements. Together, these changes will lead to:

- improved recognition of the expertise-by-experience of persons with disabilities
- more responsive and coordinated services
- stronger participation of persons with disabilities in healthcare decisions and in decision-making across care
- more inclusive governance and funding structures that foster genuine choice regarding place of living and care
- increased autonomy and self-determination
- greater community participation
- enhanced opportunities for independent living
- sustainable integration of participation within health, social care and educational systems.

Proposed Objectives

The project aims to:

1. Investigate barriers and facilitators of independent living and community participation across Europe.
2. Analyse how healthcare systems recognise and use expertise-by-experience.
3. Develop a rights-based framework for meaningful PPIE and co-production across care, organisational, educational, governance, and education-policy settings.
4. Establish European Disability Participation Living Labs.
5. Co-design innovative community-based solutions supporting independent living.
6. Develop and validate the EPICare Competence Framework.
7. Generate evidence for healthcare transformation, policy development and health professions education.
8. Analyse organisational, governance, and funding structures that facilitate or hinder meaningful participation and independent living.

Proposed Work Package Structure

WP1 – Governance, Disability Leadership and PPIE

- project governance
- disability leadership council
- ethics and rights monitoring
- participation quality assurance
- international scientific review panel
- governance and policy stakeholder platform

WP2 – Independent Living and Service Pathways

- service mapping
- care transitions
- continuity of care
- healthcare utilisation
- expertise-by-experience

WP3 – Rights, Participation and Epistemic Justice

- disability rights implementation
- participation structures
- policy and organisational analysis
- ethical conditions of participation
- governance and funding conditions for participation and independent living
- epistemic justice in healthcare, education and policymaking

WP4 – Participatory Development of the EPICare Framework

- competence framework development
- curriculum design
- learning outcomes
- assessment strategies
- organisational and governance competencies for participation

WP5 – Disability Participation Living Labs

- participatory innovation
- co-design
- local solution development
- stakeholder engagement

WP6 – Participatory Competence Building

- co-teaching
- undergraduate nursing education
- train-the-trainer activities
- faculty development
- leadership and governance capacity building in PPIE
- participation competencies for healthcare organisations

WP7 – Co-Produced Service Innovation

- care coordination
- community navigation
- transition support
- disability-inclusive service pathways
- co-produced organisational innovation

WP8 – Evaluation and Impact

- autonomy
- independent living
- participation
- quality of life

- service outcomes
- competence outcomes
- organisational outcomes
- governance outcomes
- participation quality indicators

WP9 – Policy Translation and Scale-Up

- implementation science
- sustainability
- policy recommendations
- European dissemination
- governance recommendations
- institutionalisation of participation
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Consortiums and Partners We Would Like to Connect With

We are particularly interested in joining multidisciplinary Horizon Europe consortia that are seeking expertise in participatory health research, Patient and Public Involvement and Engagement (PPIE), co-design and co-production, healthcare ethics, epistemic justice, governance of participation, qualitative research, implementation science, community-based care models, and interprofessional collaboration. Potential collaborators include:

- disability organisations;
- organisations led by persons with disabilities;
- nursing and health professions schools and educators
- rehabilitation providers;
- hospitals;
- primary care providers;
- municipalities;
- community organisations;
- disability rights scholars;
- ethicists;
- participatory health researchers;
- implementation scientists;
- public health researchers;
- policymakers;
- assistive technology and digital health organisations

Expected Impact

EPICare aims to contribute directly to the Horizon Europe ambition of enabling persons with disabilities to live independently, participate fully in society and access responsive community-based health and support systems.
The project seeks to transform:

Individuals

through greater autonomy, participation and independent living.

Services

through disability-inclusive and co-produced innovation.

Healthcare Education

through participatory competence building of future professionals.

Systems

through sustainable governance models that embed meaningful participation and expertise-by-experience into healthcare, policy and education.

Organisations and Governance

through the integration of participation, co-production, and expertise-by-experience into organisational decision-making, leadership, funding structures, and policy development.

Ultimately, EPICare aims to create a European community of practice capable of advancing independent living through disability rights, participatory innovation, co-production, education, and competence building. The project further seeks to strengthen the capacity of healthcare, social care, educational, and policy systems to recognise people with disabilities as active partners in governance, education, research, innovation, and service development.

We would be pleased to connect with coordinators and consortium teams interested in strengthening their proposals through expertise in participatory health research, PPIE, healthcare ethics, epistemic justice, qualitative research, governance of participation, implementation research, and community-based approaches to independent living and inclusion. We welcome opportunities to discuss potential collaboration within an existing or emerging Horizon Europe consortium.

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