

Empowering patient advocacy and cancer prevention

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Panos Bamidis

Conflicts of interest:

1. Co-founder of CAPTAIN Coach (AUTH Spin-off)
2. Co-founder of QODIN, CENEBIT
3. PI of LLM Care, Self-funded initiative at AUTH; business exploitation of LLM Project
4. Some parts of this presentation refer to work produced in projects funded by the European Commission or other National Fundings

President of Hellenic Biomedical Technology Society

President, HL7 Hellas



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iMedphys – AUTH Medical Physics & Digital Innovation Lab

major research and development hub, 10 research groups
(research excellence, experience & funding)

*assistive technologies, applied neuroscience, medical education technologies, affective computing, semantic web, medical robotics, brain computer interfaces, space neuroscience, radiation physics, non-ionizing radiation

- ISO 9001-2015 : software Design, Development & Production / Design & Implementation of Education/Training programmes
- ISO 13485 : Design and development of medical device software for cognitive and physical enhancement and wellbeing of vulnerable groups

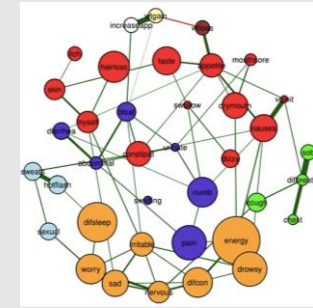
Identification of vulnerable populations



Multi-modal Physical training



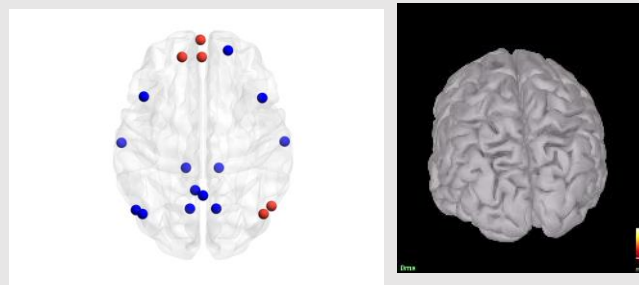
Multi-modal data sources fusion



Big data & deep learning architecture



Brain mapping during exercise



Visual Analytics

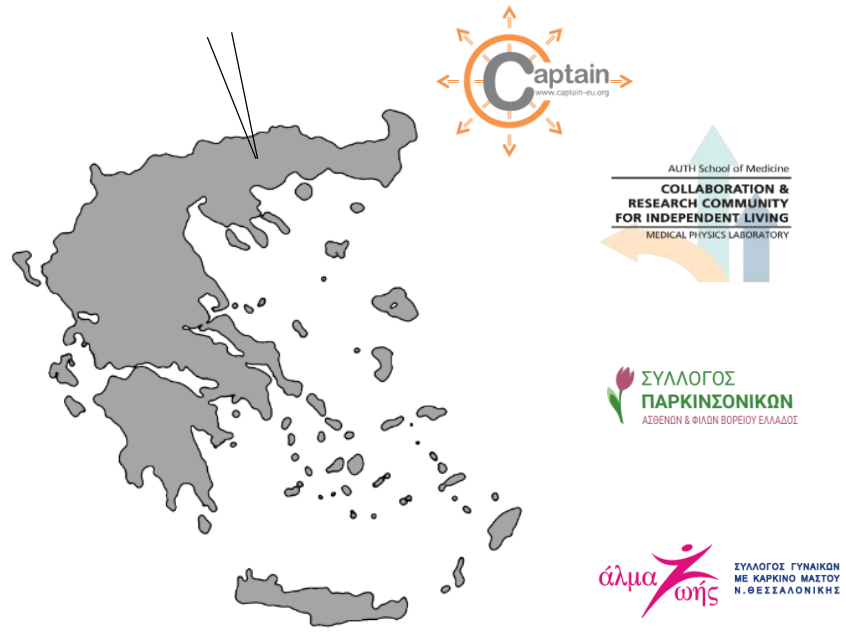


Thessaloniki Action for HeAlth & Wellbeing Living Lab - ThessAHALL

AUTH iMedPhys Infrastructure since 2014



- **AHA domain:** co-creation/co-design of technological solution to improve **QoL** and **Independent Living**
- Inter-connected **hub of multiple actors** (quadruple helix):
 - Academia/research centres
 - Industry (SMEs): CAPTAIN Coach P.C., LLMCare
 - Civil Society (Patients/Professionals' Associations, OKFN Greece)
 - Policymakers (Municipalities, Regional/National Healthcare Authorities -> hospitals, nursing homes, day care centres)



- **European & Regional Partnerships:**
 - ENoLL (effective member) & H&W A European Innovation Partnership on Active and Healthy Ageing EIPonAHA (3* Ref. Site)
 - OTF (leader)
 - Hellenic Inter-Municipal Network of Healthy Cities of the WHO (EDDYPPY)
 - Member HL7 Hellas, Hellenic Society of Biomedical Technology (ELEVIT)

Collaboration & Research community for Independent Living

empowering persons 65+ years old, chronic patients and other vulnerable groups with technical solutions and promoting Active & Healthy Ageing (>100 members)



What is patient and public involvement in research?



Patient and public involvement (PPI) in research refers to the inclusion and engagement of patients or public laypeople as partners in the various stages of the research process, or as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”

INVOLVE the National Institute for Health Research (2019) Briefing notes for researchers. <https://www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle/>.

Patients and the public can contribute in research in three distinct ways:

Involvement – where people are actively involved in research projects and in research organisations.

Participation – where people take part in a research study.

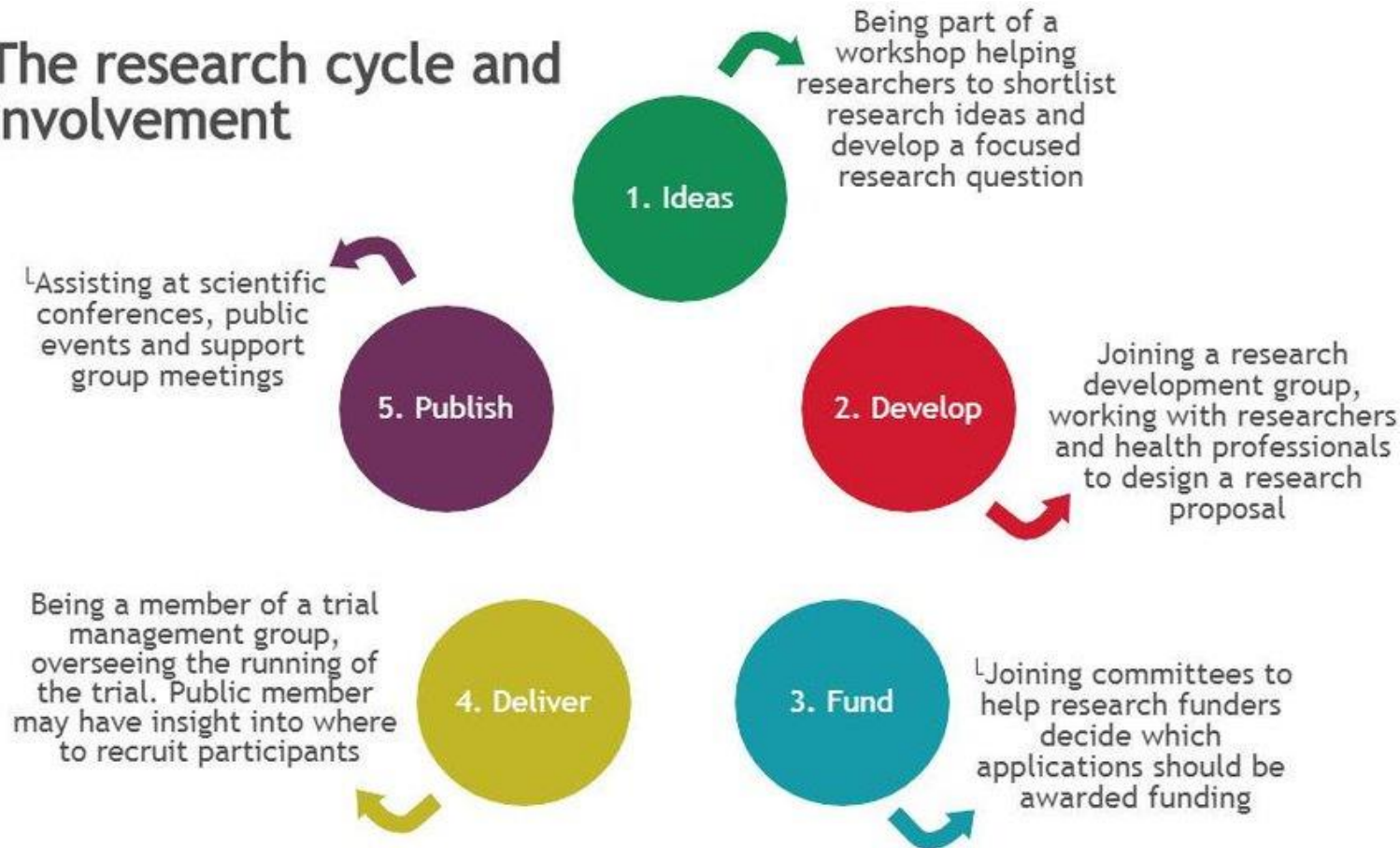
Engagement – where information and knowledge about research is shared with the public.



Involving patients into all steps of research



The research cycle and involvement



LifeChamps: Integrated cancer care for the older cancer champions based on Big-Data and QoL behaviourome: the LifeChamps project

Main Objective:

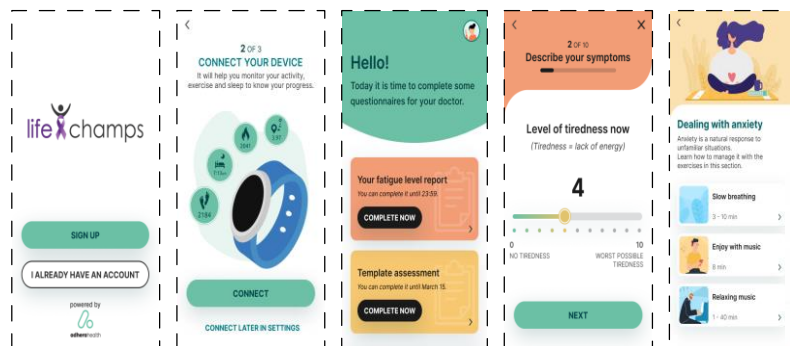
Support **Quality of Life** of **older cancer patients (breast, prostate, melanoma)**, after their **treatment**

The Challenge:

insufficient care and support for older cancer patients & inequitable access to cancer care lead to poorer outcomes & fragmented model of care



Project consortium:



1. Understanding Cancer
2. Moving Forward
3. Living well with Cancer
4. Life after treatment



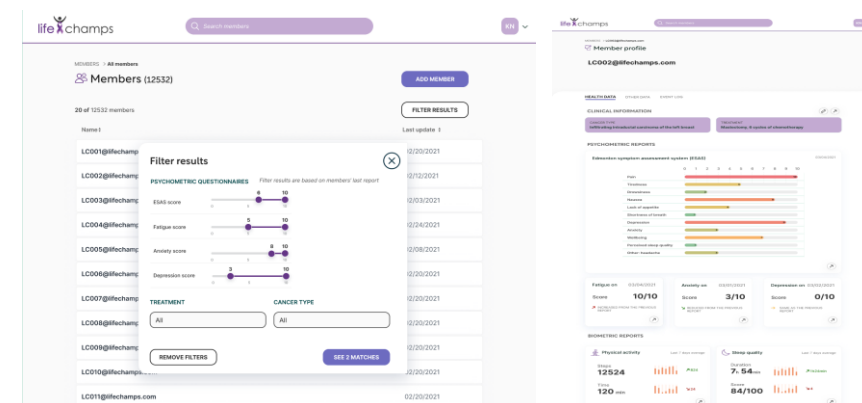
Unobtrusive home monitoring sensors



Smartband

Smart scale

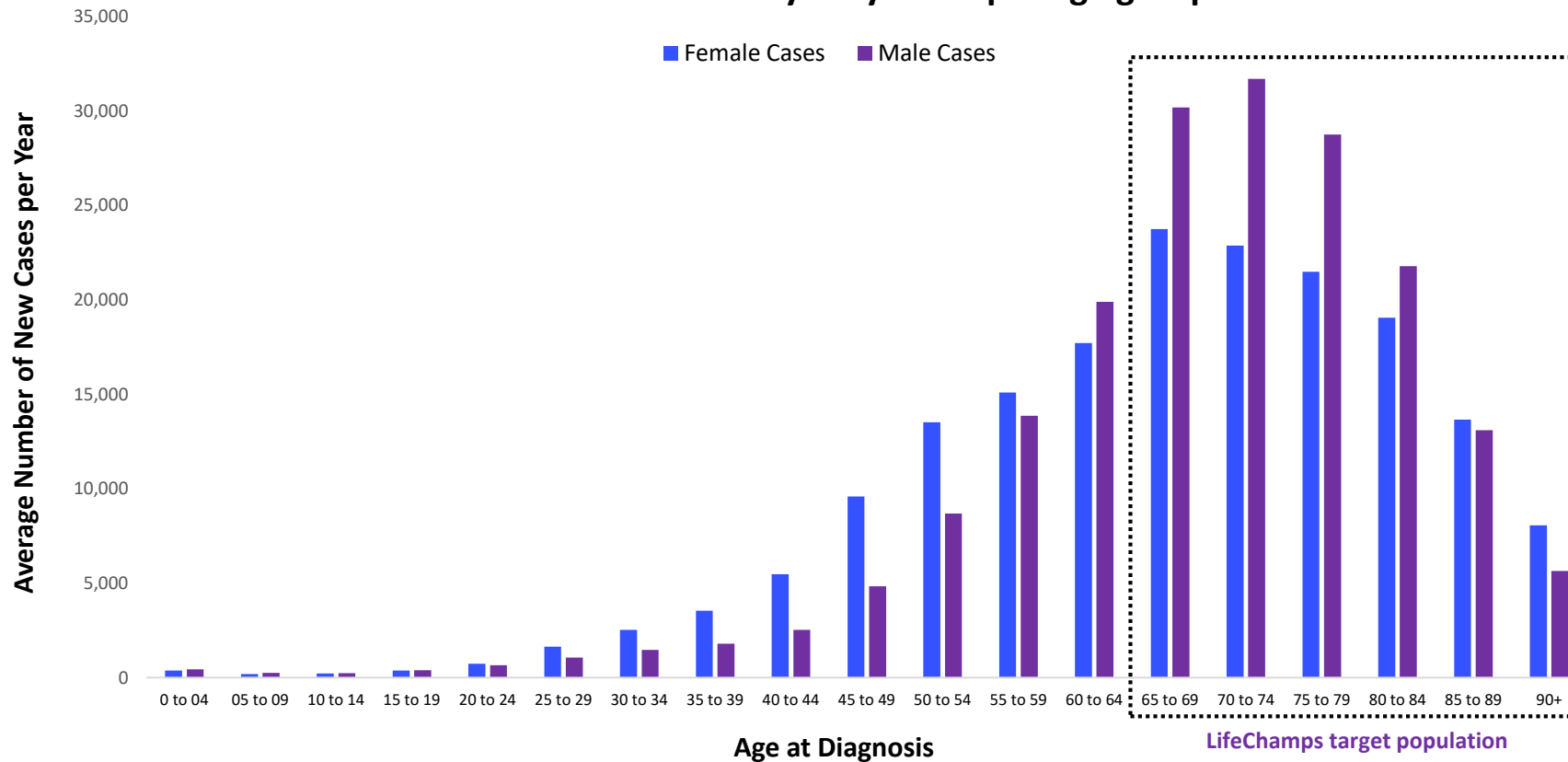
- Contents adapted to breast and prostate cancer
- Integration of wearables and smart devices



- Clinicians' dashboard to monitor cancer patients' data & offer personalized care & advice plan

An increasing life expectancy shows more people developing cancer as older adults

Distribution of new yearly cases per age group



6.7M

New cancer cases worldwide in adults aged 65 years and older

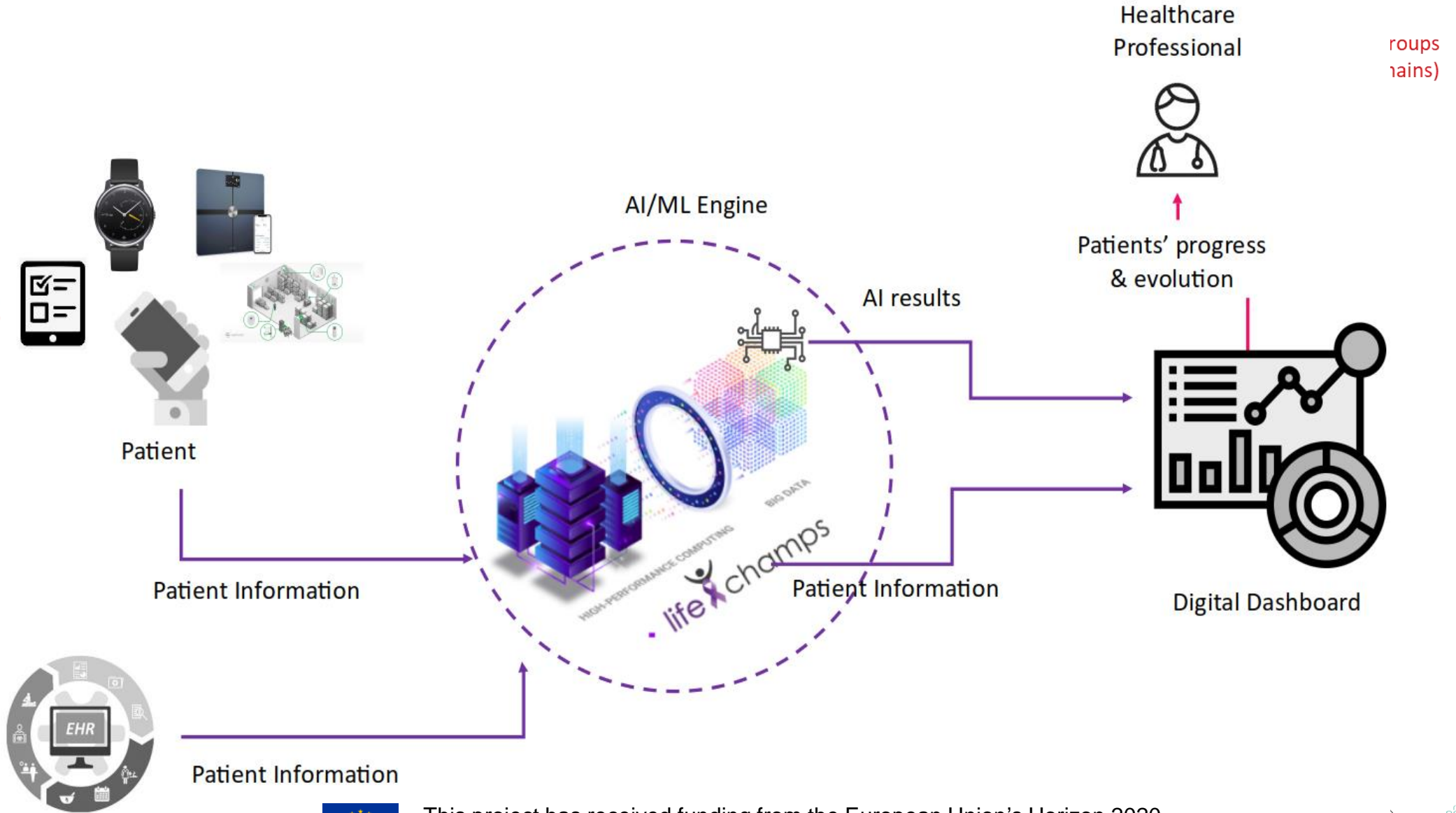
47.5%

Of the total number of new cases worldwide in adults aged 65 years and older

Source: Cruk.org/cancerstats, data referring to 2015-2017

The pain

- Current cancer care practice suffers from signs of **ageism**
 - insufficient care and support for older cancer patients & **inequitable access to cancer care** lead to
 - **Poorer outcomes**
- **Interaction** between **frailty** and a **cancer diagnosis/treatment** in their **combined impact on QOL** of **older cancer patients** is largely unknown
 - ...results to **fragmented model of care**



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No **875329**.



LifeChamps system – Edge sensors, H/W & other data sources



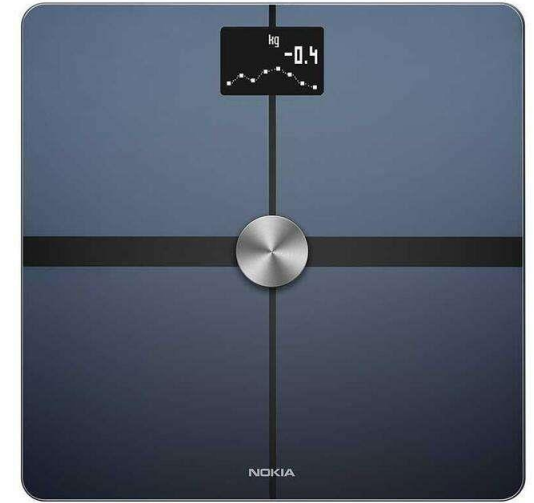
RPi acting as an edge device that validates data and forwards them for storage



Activity tracker for vital signs, exercise and sleep measurements



Smart textile with movesense for measurement of ECG and IMU (accelerometer, Gyroscope, Magnetometer)



Smart scale for measurement of weight, BMI, muscle mass, bone mass, water %



Motion sensors and magnetic contact sensor for presence monitoring and extracting ADL patterns



Power monitoring of appliances for ADL pattern recognition

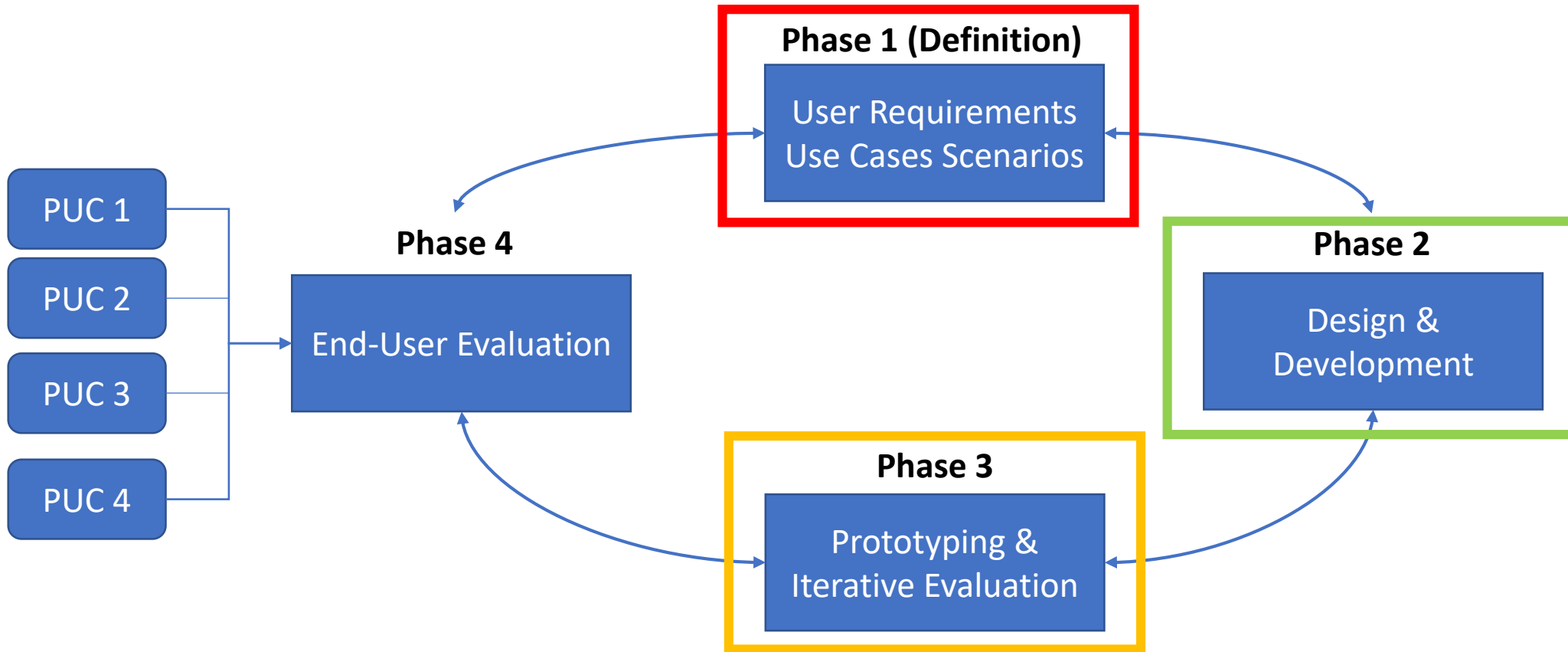


UV Index API for UV exposure measurement and selected questionnaires



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 875329.

Agile Methodology

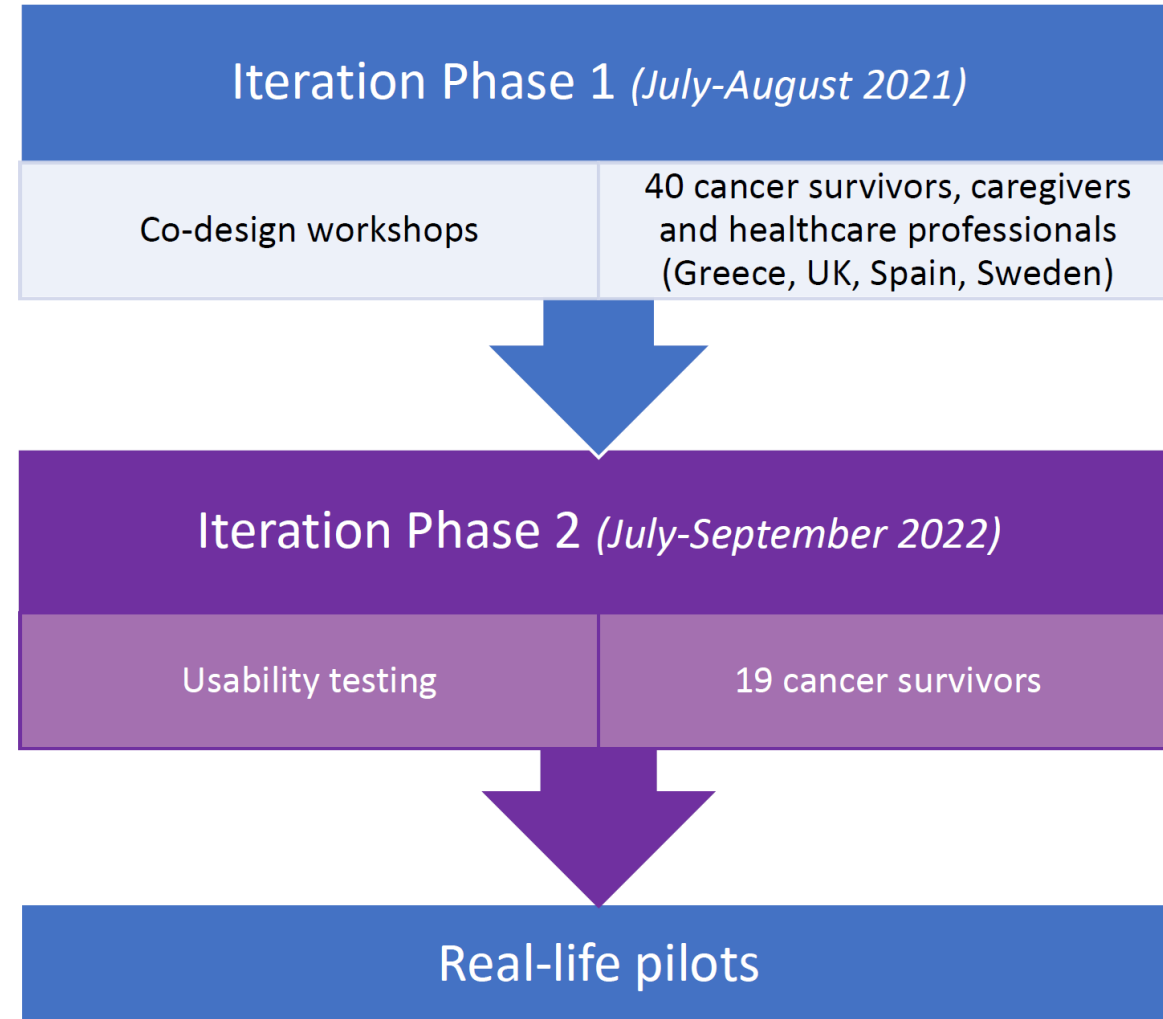


Methodology Overview

Co-validation activities followed the participatory methodology, fostering user engagement, ethical considerations, and structured collaboration.

Both iterations focused on the option of **patient reported outcome measures (PROMs)** self-reporting, **educational** and **motivational content**, and **app navigation**.

Two iterations before the real-life pilot phase



PROMs/PREMs;

Patient-reported outcome measures (PROMs):

- Standardised, valid questionnaires
- Completed by patients
- Perception of health status and sense of well-being as a whole or for a specific condition
- **Patient-reported experience measures (PREMs):**
- Questionnaires
 - Patients' perception of their experience of receiving a treatment/health care
 - ≠outcomes, = impact of procedures on patient experience
 - For example general health status, functional ability, feeling, fatigue or pain.
 - Positive correlation between experience and outcomes

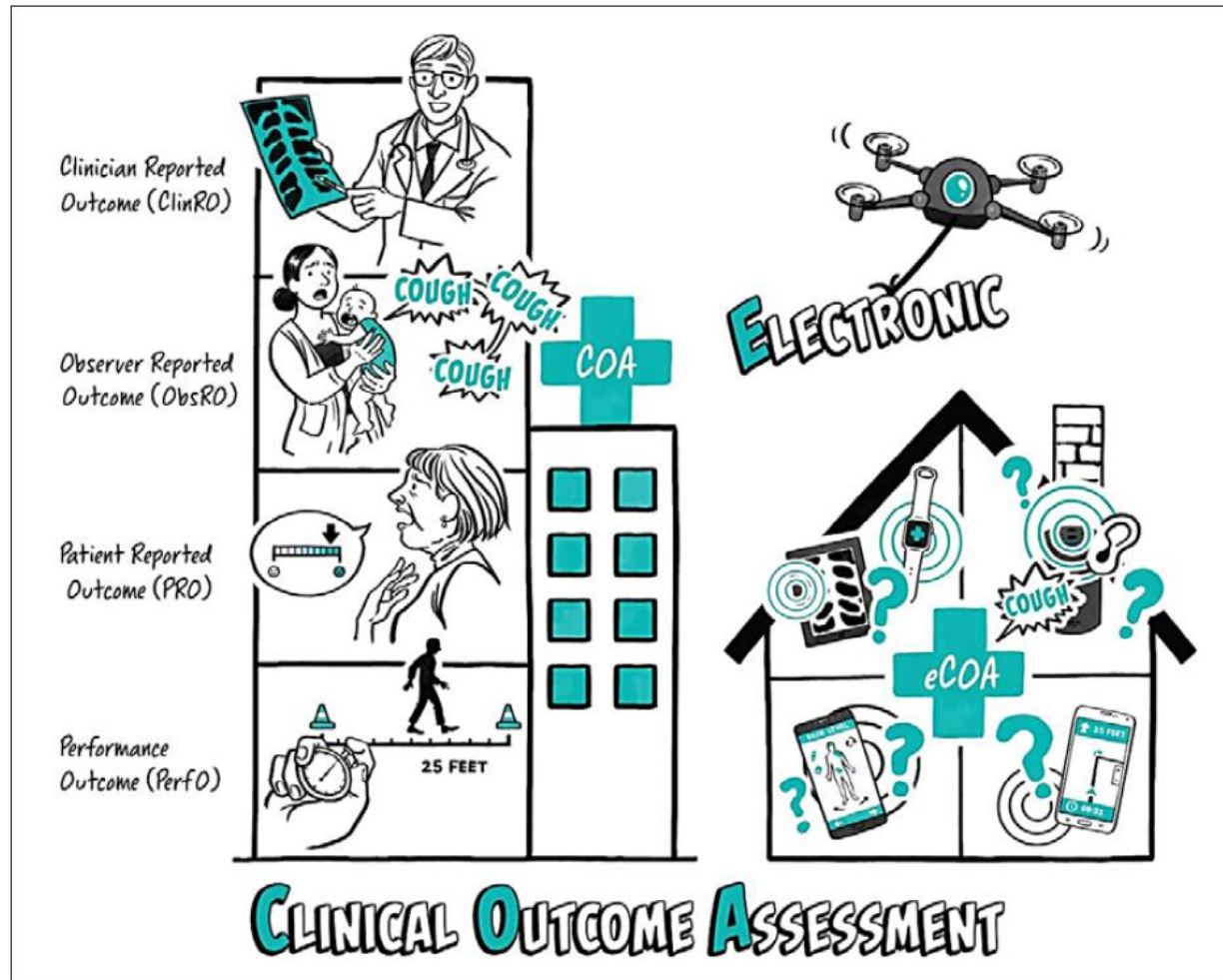


Fig. 8. Clinical outcome assessment. Clinical outcome assessments (COAs) are the instruments used to measure clinical outcomes. The FDA recognizes four types: ClinRO, ObsRO, PRO, and PerfO. If digitized, they are considered electronic clinical outcome assessments (eCOA).

Table 5. Clinical outcome assessment examples

Clinical outcome assessment (COA)	Example
<p>Clinician-reported outcome (ClinRO) – ClinROs are those COAs requiring clinical expertise</p>	<p>“Readings” are clearly defined results that are observed and reported in a dichotomous manner on the basis of clinicians’ judgment like the presence or absence of clinician-identified radiographic vertebral fractures [109]</p> <p>“Ratings” are categorical (either ordered or not) or continuous measures like those in Part III of the Unified Parkinson’s Disease Rating Scale or the Brief Psychiatric Rating Scale in mental disorders [109]</p> <p>“Clinician Global Assessments” (CGAs) are assessments based on a clinician’s overall judgment like the “clinician global impression” (CGI) or “clinician global impression of change” [109]</p>
<p>Observer-reported outcome (ObsRO) – ObsROs are assessments of how patients feel or function in their daily lives made by a non-expert third party (spouse, caregiver, parent, sibling, etc.)</p> <p>ObsROs are useful when the patient themselves may struggle to reliably assess their own symptoms and experiences (i.e. children or cognitively impaired patients)</p>	<p>A parent’s report of a child’s vomiting episodes</p> <p>A caregiver reporting a patient wincing through pain during activities when they cannot report this themselves</p>
<p>Patient-reported outcome (PRO) – PROs are assessments about how patients feel or function in their daily lives where the information is reported by the patient themselves, without interpretation or modification by someone else</p>	<p>Gastrointestinal Quality of Life instrument (GQLI)</p> <p>European Organization for Research and Treatment of Cancer QLQ-C30 (EORTC QLQ-C30) is a questionnaire that assesses the quality of life of patients with cancer</p> <p>The Impact of Weight on Quality of Life (IWQOL-Lite) assesses obesity-specific quality of life measures</p>
<p>Performance outcome (PerfO) – PerfOs are assessments of a task(s) performed by a patient following instructions given by a healthcare professional; performance outcomes require patient cooperation and motivation</p>	<p>Timed 25 foot walk test as a measure of gait speed</p> <p>Severe Impairment Battery as a measure of cognitive function</p>

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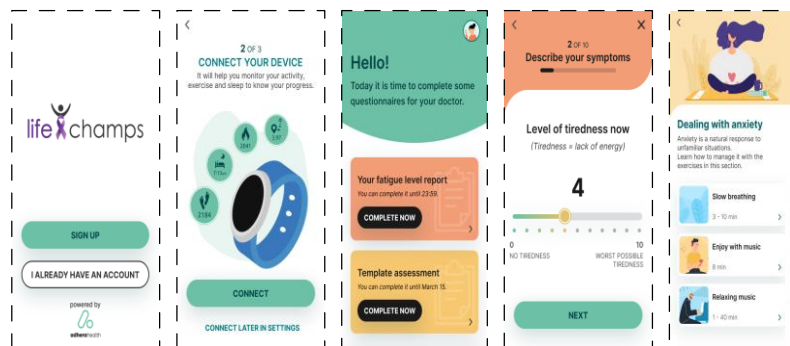
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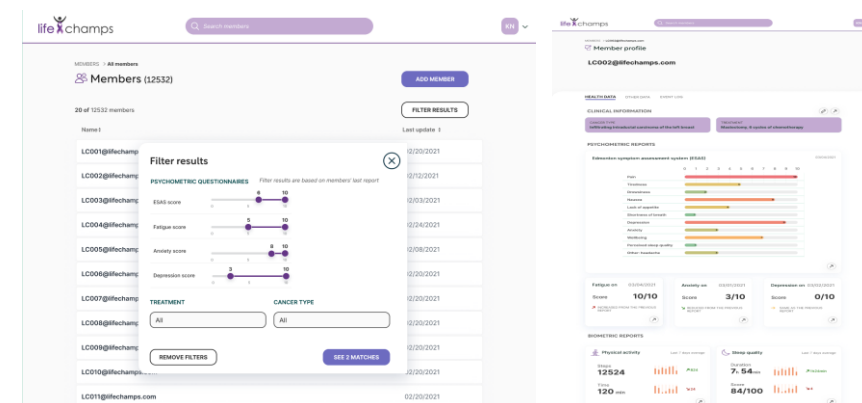
Unobtrusive home monitoring sensors



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Smart scale

- Contents adapted to breast and prostate cancer
- Integration of wearables and smart devices



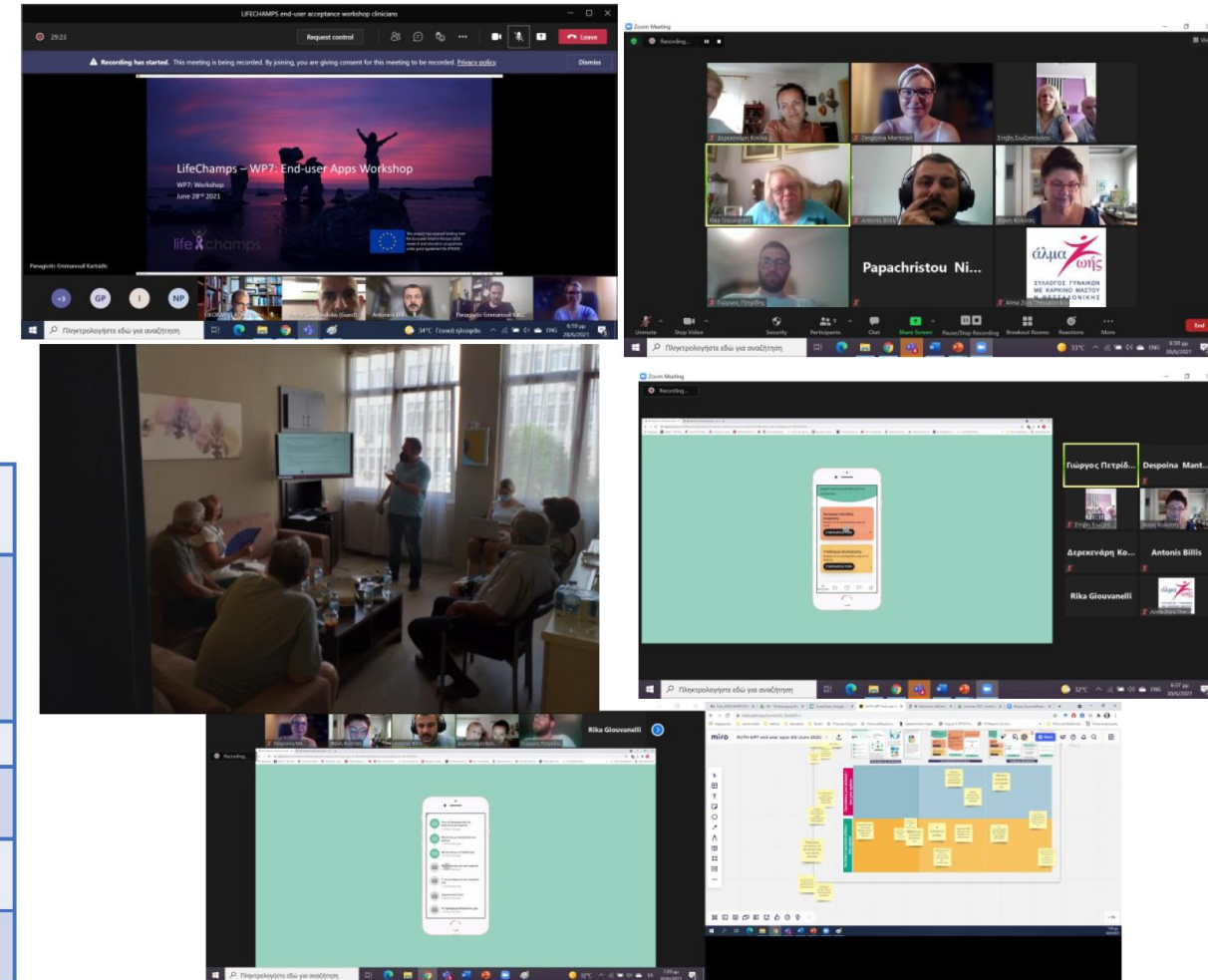
- Clinicians' dashboard to monitor cancer patients' data & offer personalized care & advice plan

Iteration Phase I - Methods



- **9 co-design workshops** (online and/or physically)
- **Mock-up screens** of the app's functionalities
- **Feedback** (collected via group discussion) categorized into **"Need to change/Dislikes"** and **"New ideas/Updates/Additions"**

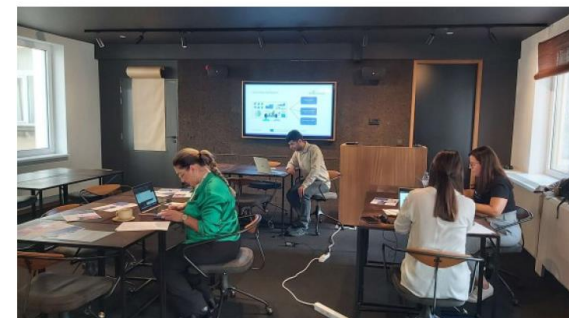
Pilot site	Nr. of participants (total = 40)	
	Patients and/or Caregivers (total = 21 participants)	Healthcare professionals (total = 19 participants)
Sweden (APC)	3 participants	4 participants
Greece (AUTH)	11 participants	6 participants
Spain (HULAFE)	-	3 participants
Scotland (UoG)	7 participants	6 participants



Iteration Phase II - Methods



- **Usability testing - 19 participants**
- Patients interacted with the **app prototype**, providing feedback (via user interviews / workshop), on **functionalities**, **educational/motivational modules**, also identifying areas for improvement.



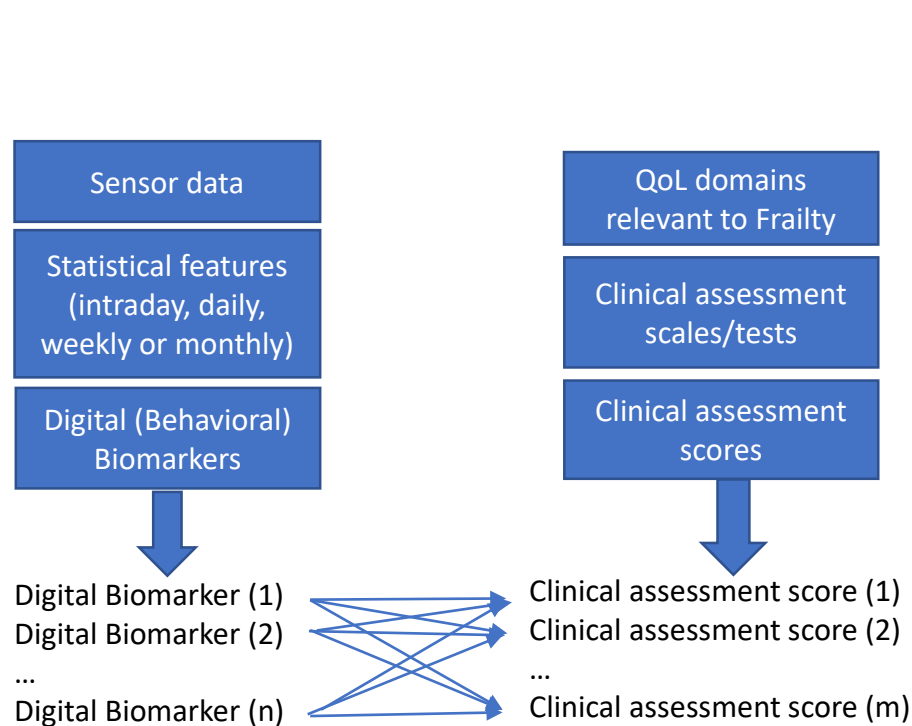
	Patients (cancer survivors) 19 participants
Greece (AUTH): interviews	12
Scotland (UoG): interviews	2
EU-wide (ECPC): workshop	5



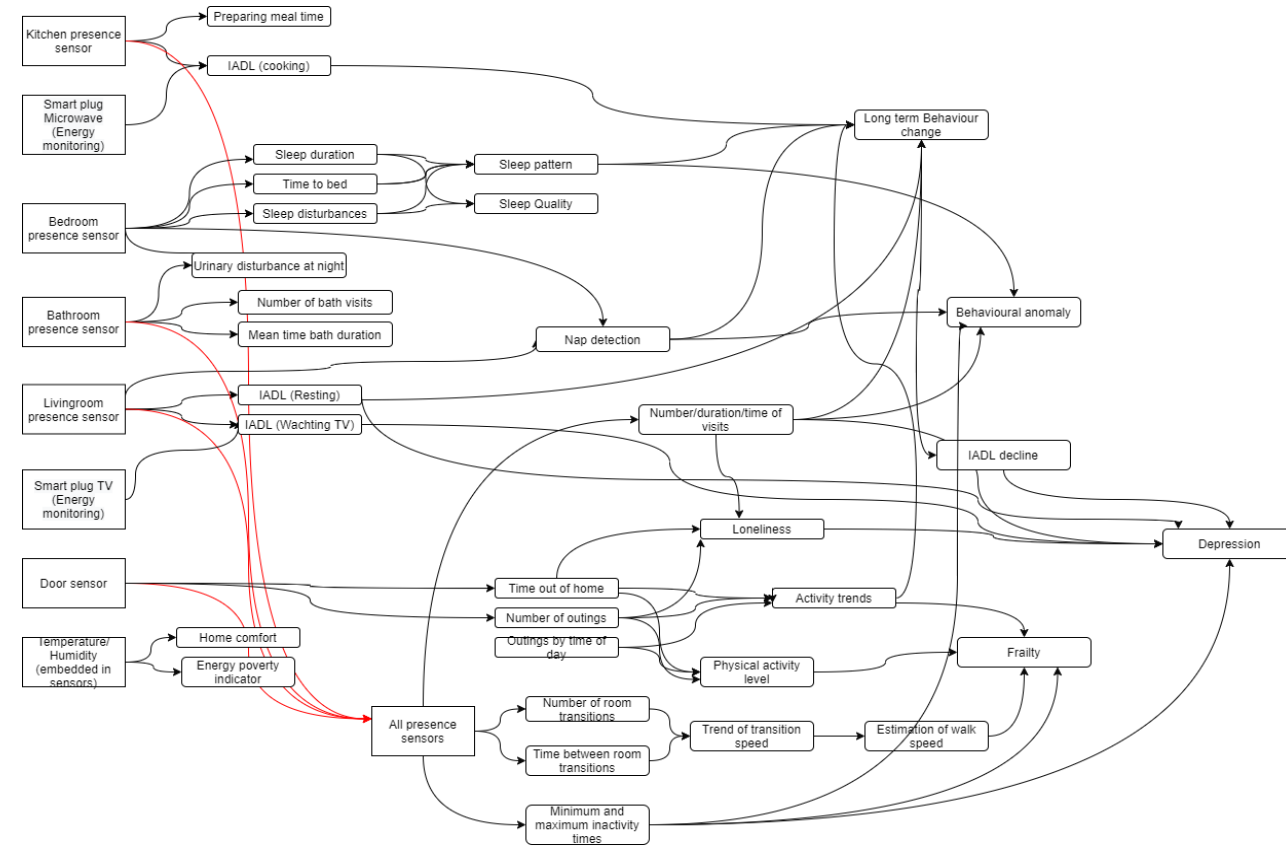
LifeChamps system – Digital Biomarkers QoL model



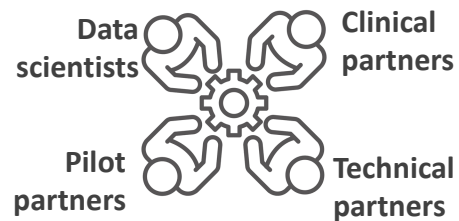
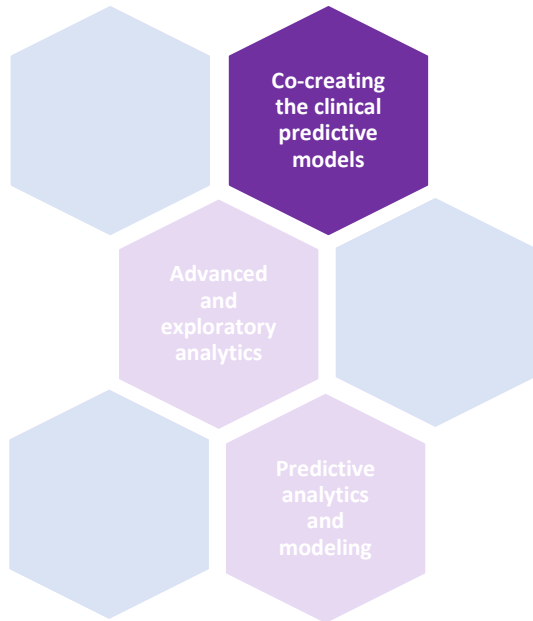
Quality of Life Monitoring and Modelling using sensor data as proxies



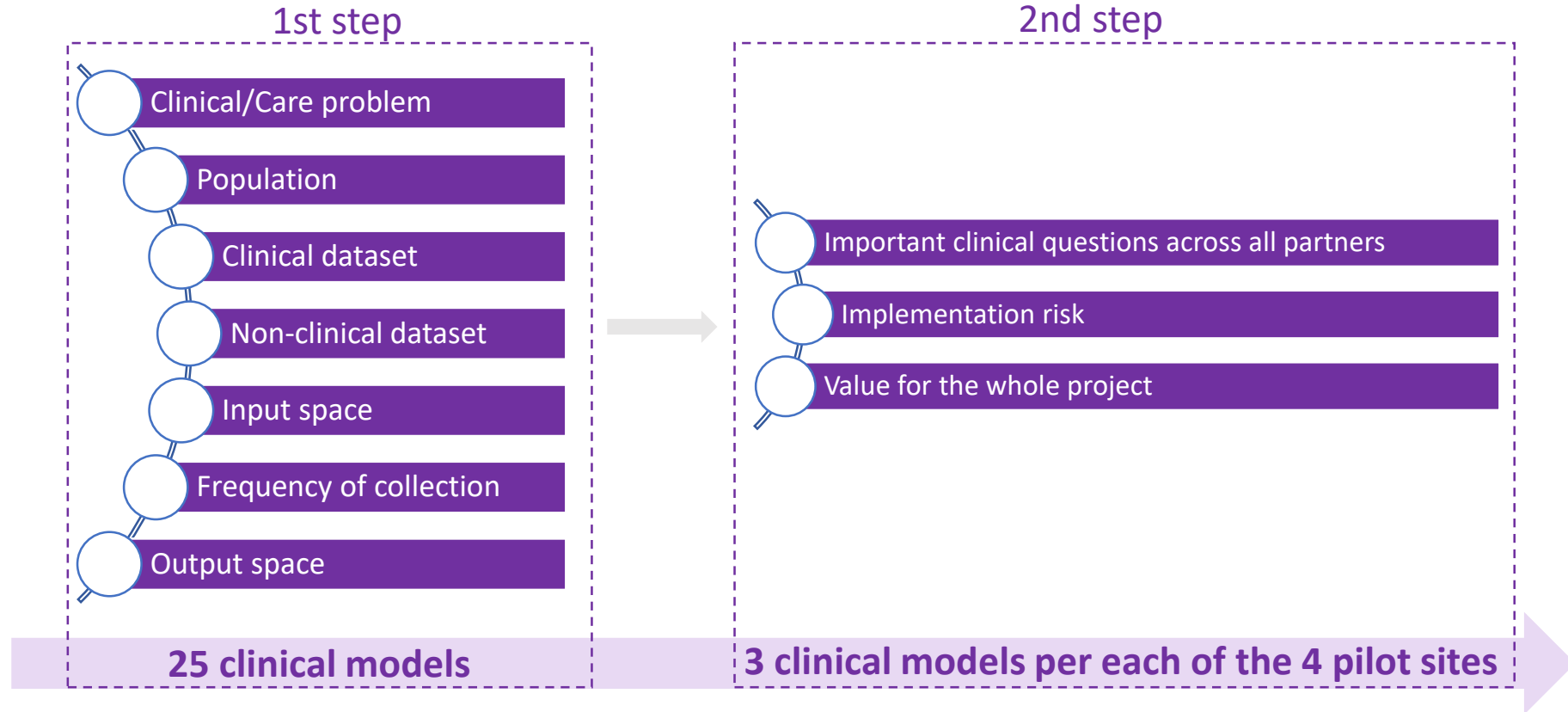
Correlations - Regression models



Co-creating the clinical predictive models



[LifeChamps.eu](https://www.lifechamps.eu)



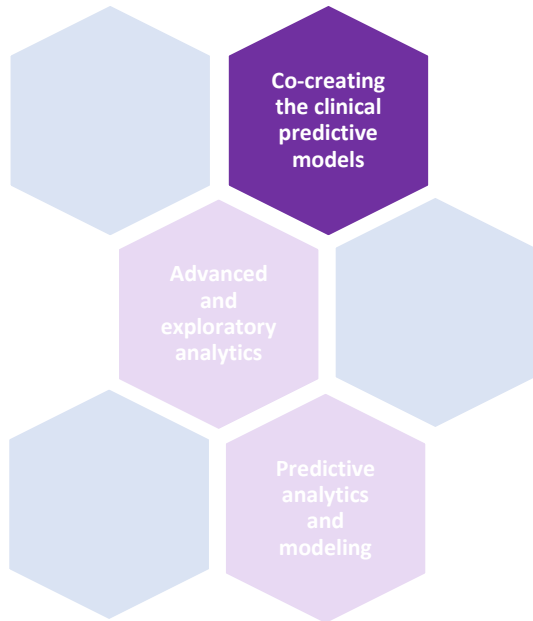
Adaptation of the Transparent Reporting of a multivariate prediction model for Individual Prognosis or Diagnosis (TRIPOD) Statement. [Collins et al. 2015]

Adaptation of the health research priority setting framework. [Viergever et al 2010]

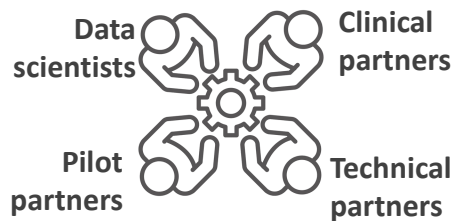


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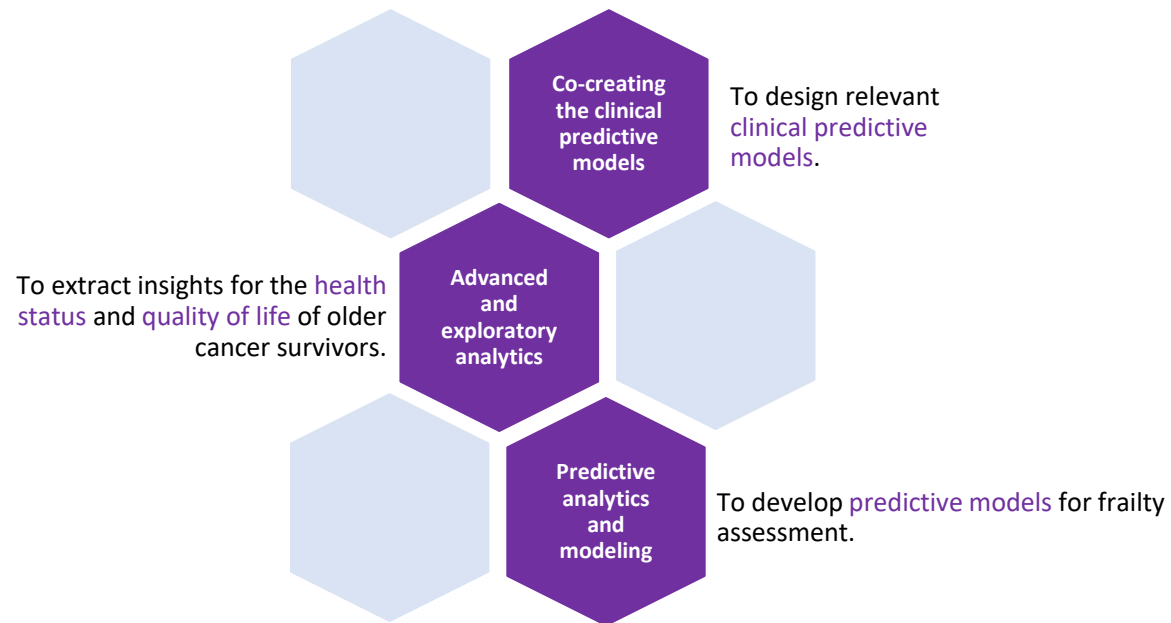
Co-creating the clinical predictive models



- ➔ **Predicting the risk for *frailty*.** (3 pilot sites)
Patients with prostate, breast and skin (melanoma) cancer
- ➔ **Predicting the risk for *depression and anxiety*.**
Patients with prostate and skin (melanoma) cancer.
- ➔ **Monitoring *erectile dysfunction*.**
Patients with prostate cancer.

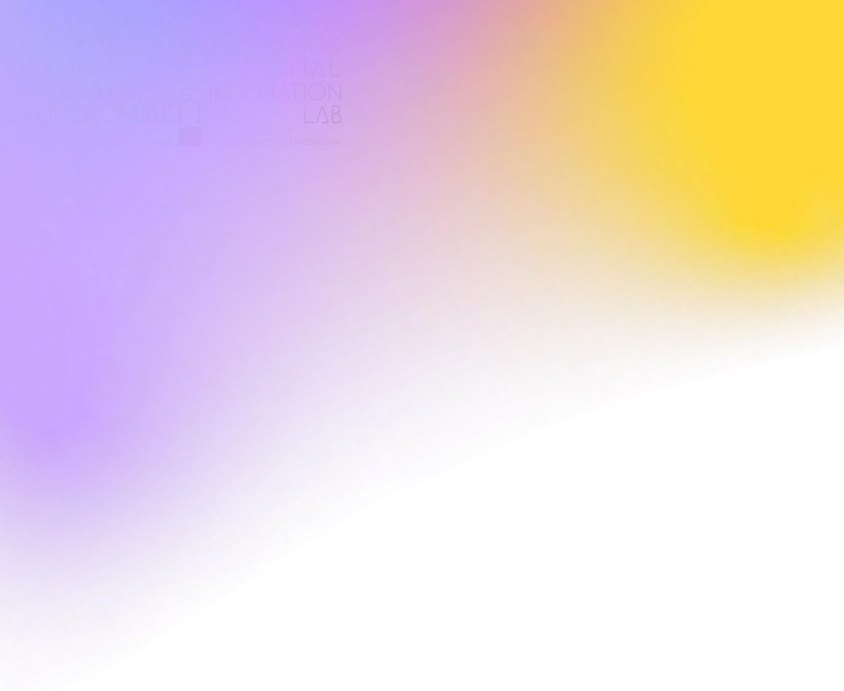


Journey overview



- ✓ Importance of **robust** model development process
- ✓ Identifying and monitoring **frailty** in older cancer patients
- ✓ Guiding **personalized** interventions and treatment plans
- ✓ **Improving** patient outcomes and quality of life
- ✓ **Enhancing** healthcare **decision-making** in cancer care





Thessaloniki Action for Health & Wellbeing Living Lab



ΕΙΔΙΚΗ ΜΟΝΑΔΑ ΒΙΟΙΑΤΡΙΚΗΣ
ΕΡΕΥΝΑΣ ΚΑΙ ΕΚΠΑΙΔΕΥΣΗΣ
BIOMEDICAL RESEARCH AND
EDUCATION SPECIAL UNIT



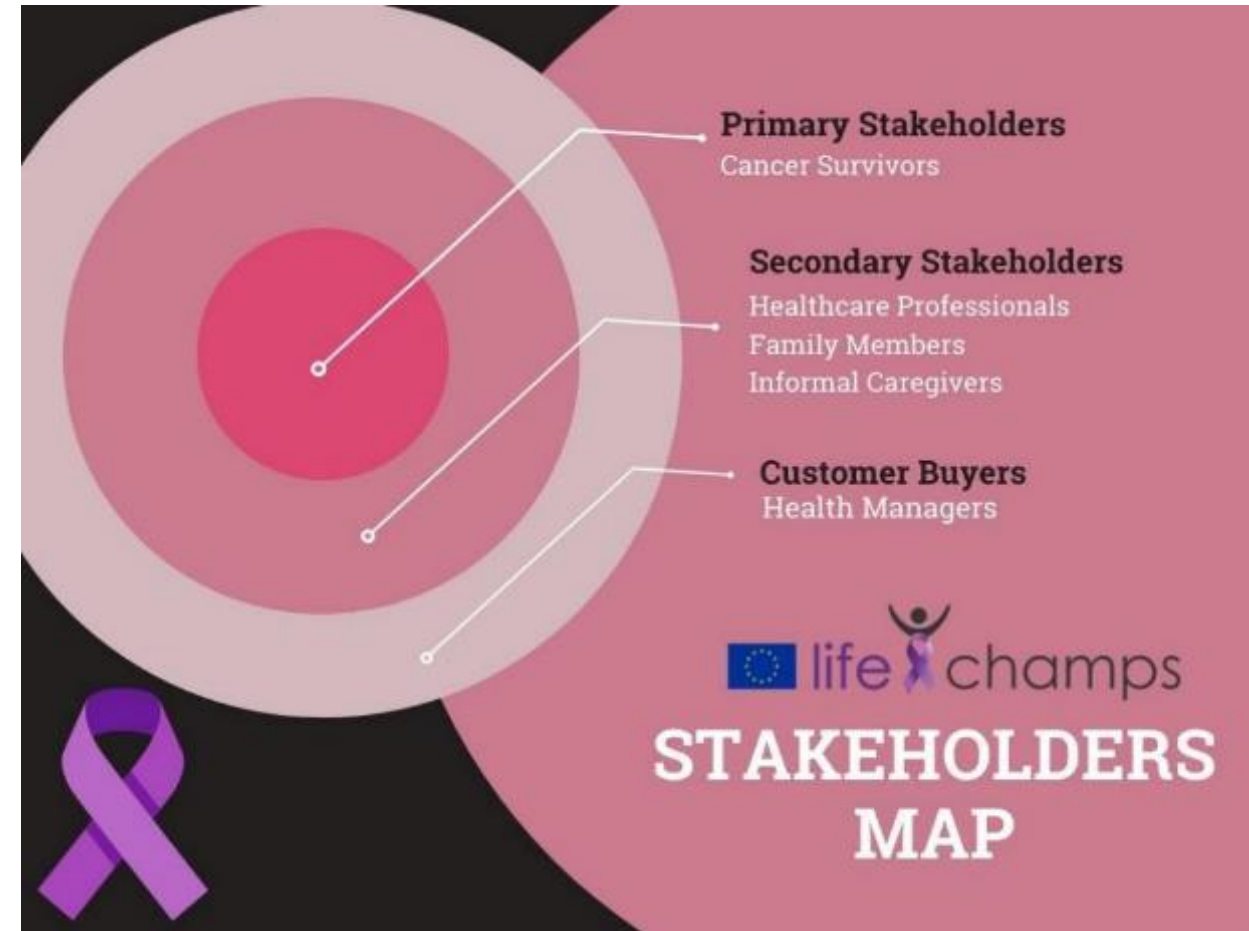
We do not work alone...against all odds...



>150 stakeholders

EU wide launch of

- Online workshops
- Delphi study
- Online surveys
- Phone interviews



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...and what's next?



Networking:



Cancer-related LL activities:



EU Mobile App for Cancer Prevention



European Partnerships:

- **ENoLL** (effective member) & **H&W Task Force** (leader)
- **EU CSI “Mental Health”** (Co-Ordinator/Lead city: Thessaloniki)
- **Vitalise H2020**: Harmonization of H&W LLs
- **Cancer Survivorship – AI for Wellbeing Cluster**

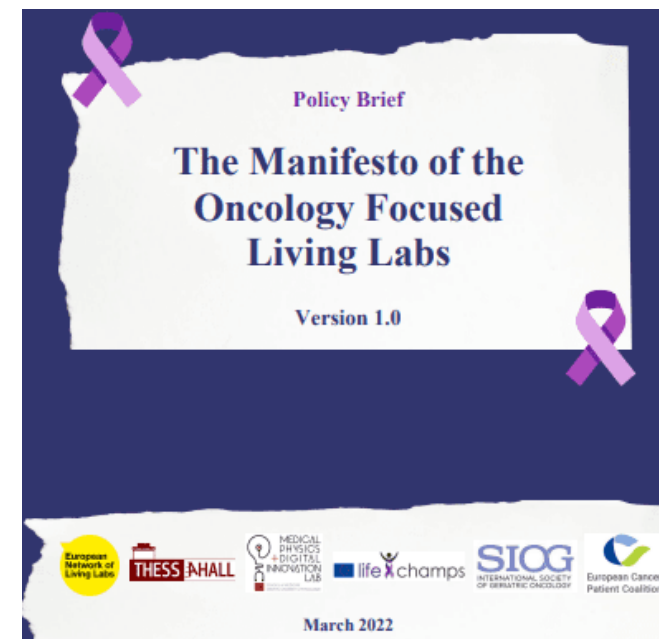
Infrastructures:

- eHome -Transitions Care LL (Hospital)- Human Centrifuge – ULL-Museums/Library etc.
- **Oncology-Focused LL (funded by Pfizer)**

[LifeChamps.eu](https://lifechamps.eu)



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Oncology-Focused Living Labs

A new challenge or opportunity to transform the cancer clinical practice & care?



Our Vision...



"We envision not another test-bed, but open innovation & research, mutual collaboration & real-life experimentation ecosystems to foster the digital transformation of the clinical practice & make innovative health & care services equally accessible & inclusive to ALL cancer patients".





PECAN

Partners of Experience in Cancer

Lifelong researchers for cancer

Supported by an independent education grant from Pfizer



Lifelong researchers for cancer



Creation of the first Living Lab as a result of close collaboration between cancer patients and medical students

What is a living lab?



A living laboratory is a user-centred open innovation ecosystem, often operating in a thematic context (e.g. city, rural area, medical community), integrating research and innovation processes in a public-private, society and science partnership.

RESEARCH PROGRESS

- **Interactive role playing: patients, researchers, health professionals, local and national government**
- **Contact with patients: discussion, needs analysis, persona creation**
- **Literature search**
- **Recording ideas - creating a guide**



Educational activities: Staff training & education and alignment with existing practice

e-Training programme:



Patient/staff empowerment



Digital skills



Patients' rights & safety



Communication training

'EU Mobile App for Cancer Prevention' (HaDEA)

Our Vision: Provide the means for minimizing the existing adoption gap of best practices and guidelines regarding cancer prevention in general public, through a citizen-centred approach where no citizen is left behind.

Project Duration: 24 Months (Nov 2022 – Oct 2024)

The proposed solution focuses on:

- Personalization ensuring that the app is always adapted to current user status.
- Conveying concrete actions for citizens through tailored motivational messages.
- Hands-on practice through interactive learning scenarios and gamified quizzes to stay engaged.
- Enhanced Accessibility both in terms of physical impairments, limited literacy and cognitive impairments.
- Enhanced adaptability through tailored educational content and motivational messages/recommendations.
- Social learning to transform the learning experience of individuals into a more collective one.



Figure 8: Key Design Principles



THANK YOU THANK YOU



@AUTH Medical Physics & Digital Innovation Lab



ΕΡΓΑΣΤΗΡΙΟ
ΙΑΤΡΙΚΗΣ
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ΨΗΦΙΑΚΗΣ
ΚΛΙΝΟΤΟΜΙΑΣ
ΤΜΗΜΑ ΙΑΤΡΙΚΗΣ
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+ DIGITAL
INNOVATION
LAB

SCHOOL of MEDICINE
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REFERENCE SITE
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CERTIFIED
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