

# Role of NGOs in the Cancer Mission

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Cancer Prevention Manager

Association of European Cancer Leagues (ECL)

"Conquering cancer – mission possible: coordination of actions in Baltic States"

16 December 2021



## ECLARATIONS



- **X** ECL is independent of any political party or commercial interest.
- ECL's income is primarily through membership contributions, EU-funded projects and joint actions.
- ECL currently receives an Operating Grant from the European Commission under the Third EU Health Programme 2014-2021:

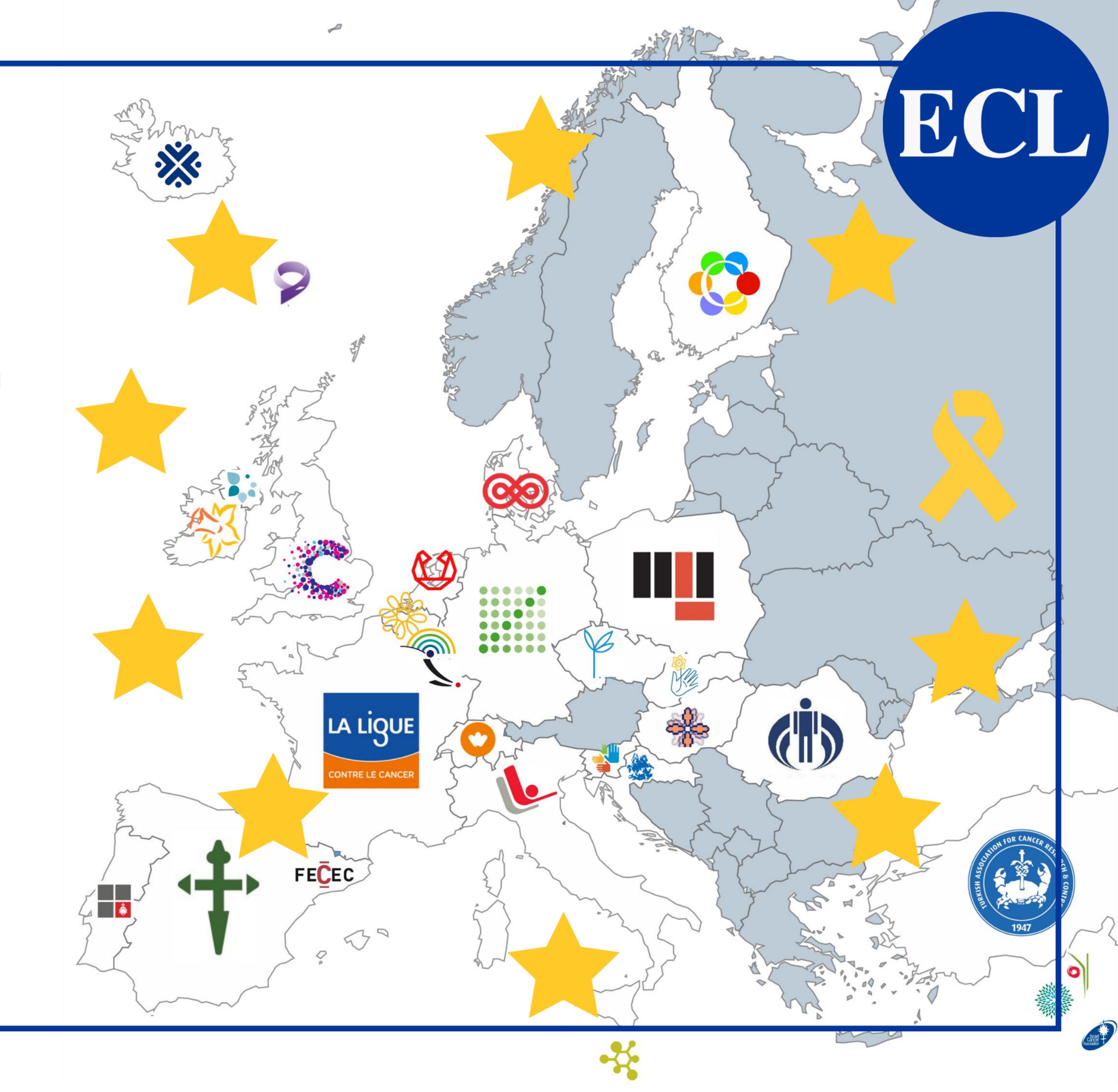


Co-funded by the Health Programme of the European Union

ECL has an unrestricted education grant with L'Oréal Garnier International.



- Founded in 1980
- 30 cancer societies in 25 countries in WHO European region (of which 20 EU MS)
- 8k staff, 300k volunteers, spend €750m a year to fight cancer & represent 570m citizens
- Members = non-profits operating across the whole cancer continuum & patient pathway
- Cancer leagues are the main resource for the public for cancer control information & services
- Vision: 'Europe free of cancers'













WORKING GROUP









## ROLE OF NGOS

## Addressing the gaps



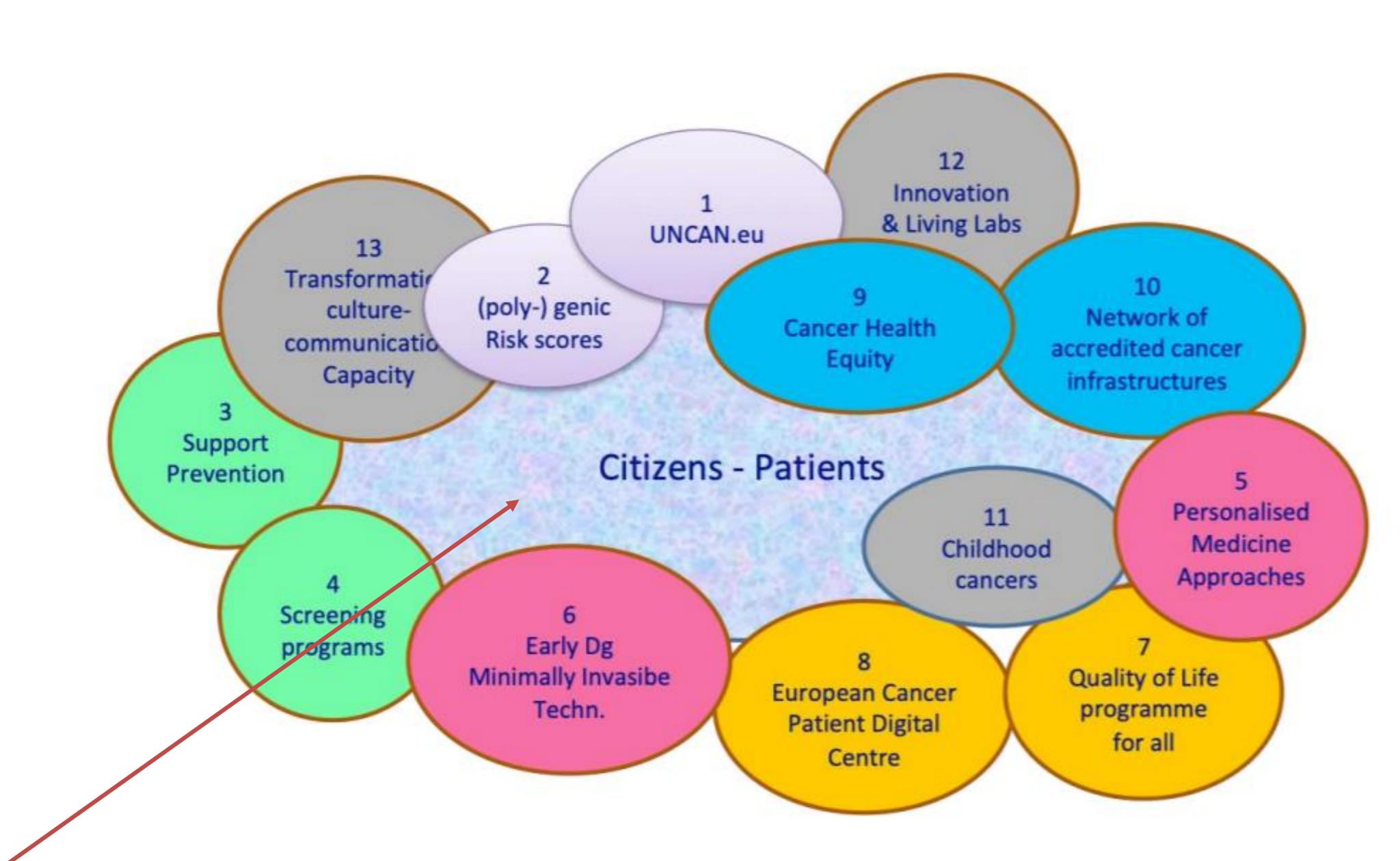








# 13 Citizen- and patient-centred recommendations for actions of the Mission on Cancer





**Objective:** To assess the effectiveness and feasibility of personalised breast cancer screening, one that is based on the personal risk of developing breast cancer for each individual woman

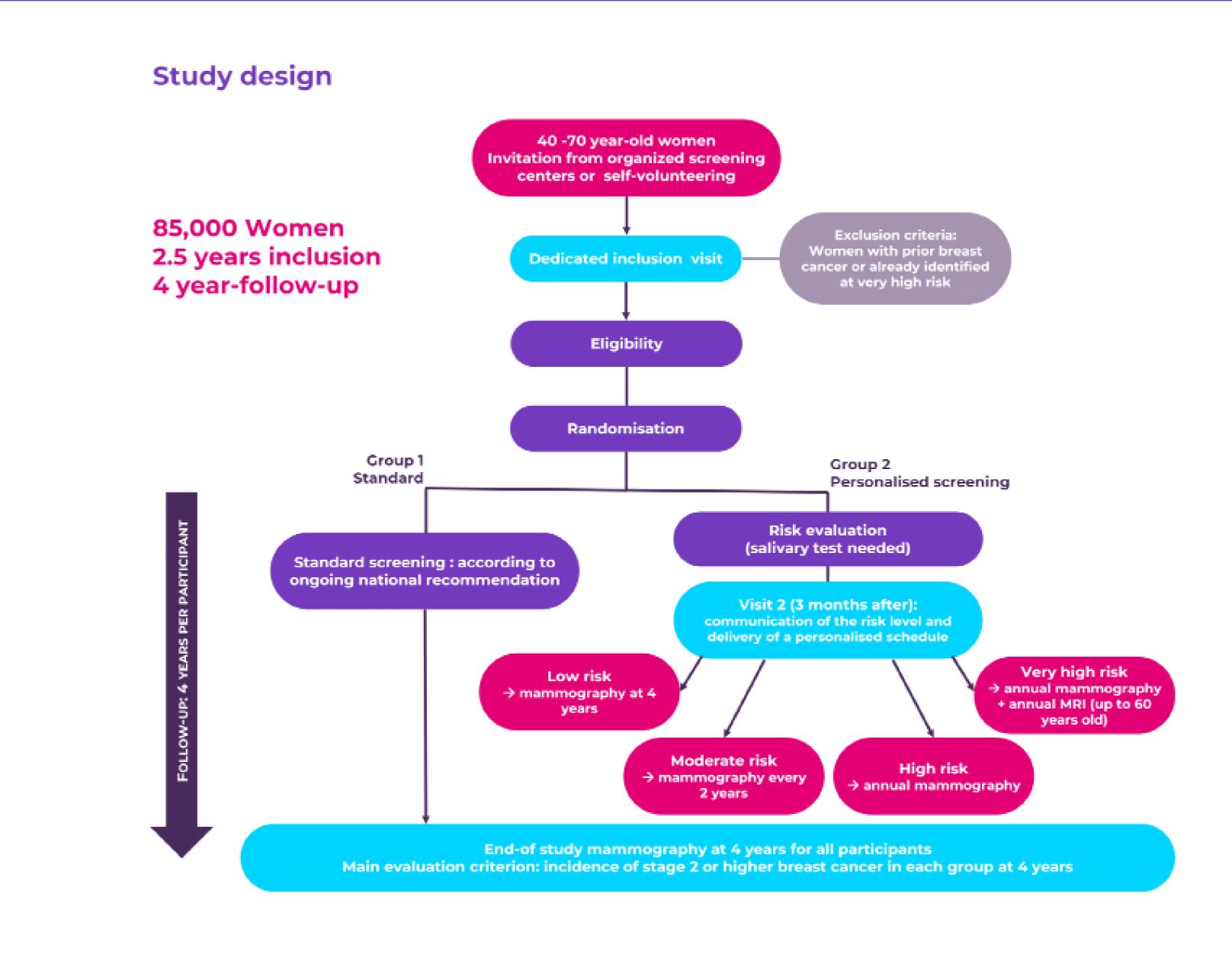
**Overview:** To meet this objective, a multi-centre, international, randomised clinical study will take place, recruiting 85,000 women from Belgium, France, Israel, Italy, the United Kingdom and Spain. This study will compare the current standard breast screening with a personalised strategy, which screens women at higher risk of breast cancer more often, and women at a lower risk of breast cancer less often.

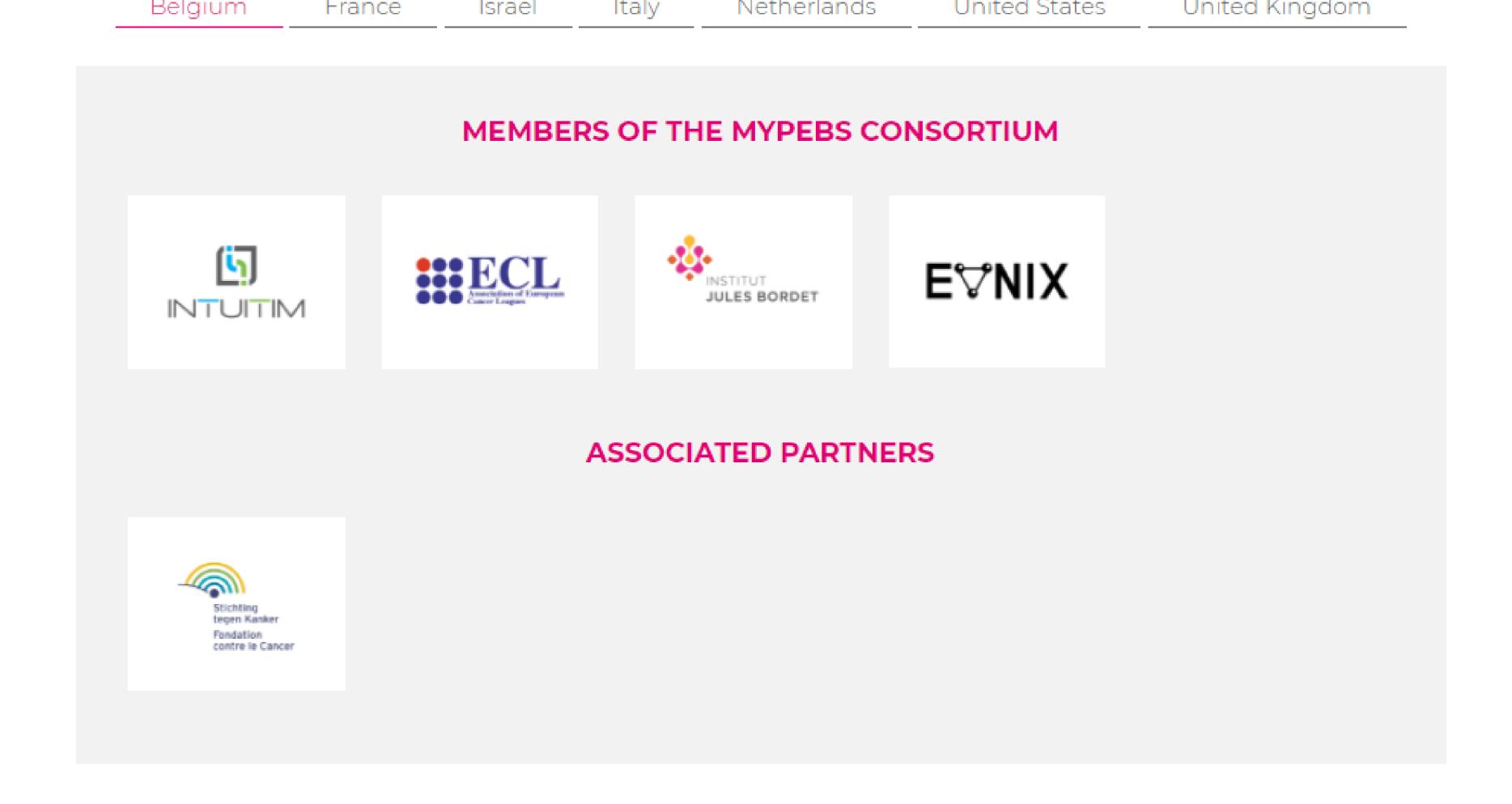
**Partners:** A consortium of 26 partners from 7 different countries, coordinated by Unicancer, including many leading doctors, scientists and researchers, as well as patient representatives and advocates (incl. ECL)

**Duration:** 8 years (2018-2025)

**Funding:** €12.5 million euros from the Horizon 2020 research and innovation programme (H2020-EU.3.1.3. - Treating and managing disease)

https://www.mypebs.eu/





# MyPeBS

results

set up

### Clinical trial

WP1 – Sponsorship & CT data flow

WP2 - CT Investigation

WP3 - methodology and data analysis

Non inferiority then superiority of personalised screening strategy

WP4 - Economical evaluation

WP5 - Sociological, ethical and psychological assessments

WP6 - Communication and dissemination

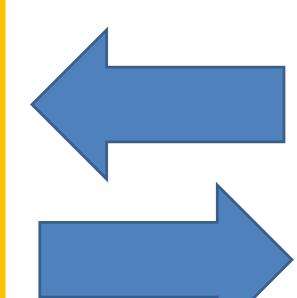
Association of European Cancer Leagues

Cost effectiveness

Adherence, attendance and universalism

Inclusion
Dissemination

Exchange results, tools



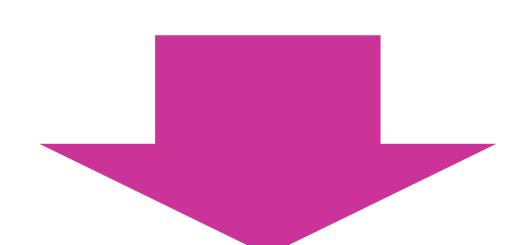
WP7 - Recommendations



# MyPeBS' expected outcomes

Planned outcomes





Strong evidence to sustain (or not) the implementation of risk-based screening in the general population

(future EU recommendations)

Efficacy and risk/benefits

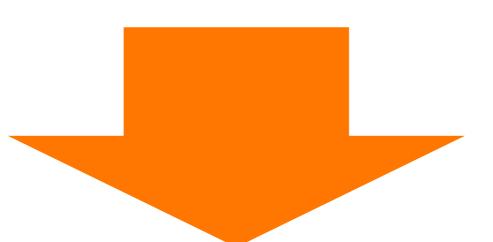
Target populations

Cost

Psycho-social impact

Tools ready for implementation

Preparation of stakeholders



### From images and biobank:

New risk models and softwares New cancer risk genes and SNPs New Prevention biomarkers



Substudies
Imaging
Prevention
Early detection



Prevention New economical models



### MyPeBS: 27 consortium partners



Gustave Roussy – stats & study PI France

Statlife – risk calculation, imaging (breast density)

CNGE (GPs association) - material for investigators training

Paris 13 University— ethics and psycho-sociology

University Lyon1 - psycho-socio

**ARC Foundation** – communication & dissemination

Santé Publique France – access to social security data

**CNRGH/CEA** – Genotyping

**CEPH-Fondation Jean Dausset** – DNA extraction from saliva

Associated partners: NCI (INCa), screening structures, patients associations, gynecologists, radiologists



Assuta Medical Centers: study PI Israel and investigation

Maccabi Healthcare Services: investigation

**ERASMUS University –** medico-economics



Hospital del Mar Barcelona – study PI, investigation and psycho socio





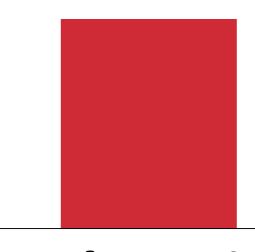
University of Cambridge – study PI and genetics

University of Manchester - investigation + psycho-socio + risk calculation (TC)

**University of Nottingham – radiology QC** 

Queen Mary University of London - Recommandations

ICPV (independant cancer patients' voice)- patients advocacy



**Azienda Unità Sanitaria Locale Reggio Emilia-**(AUSL-RE) – study Pl Italy and tomosynthesis

- investigation + communication

Istituto ScientifiAzienda Ospedaliera Città della Salute e della Scienza di Torino (CPO-

AOU) Romagnolo per lo Studio e la Cura dei Tumori (IRST-IRCCS) - investigation Institute for Study and Cancer Prevention (ISPO)- investigation

Im3D- imaging (breast density)

Associated partners: Screening centres from Este-monselice and Lombardy regions



# WP6: general communication (general public, stakeholders) + dissemination of results/findings

Institut Jules Bordet: Study PI Belgium, investigation

**European Cancer League : communication** 

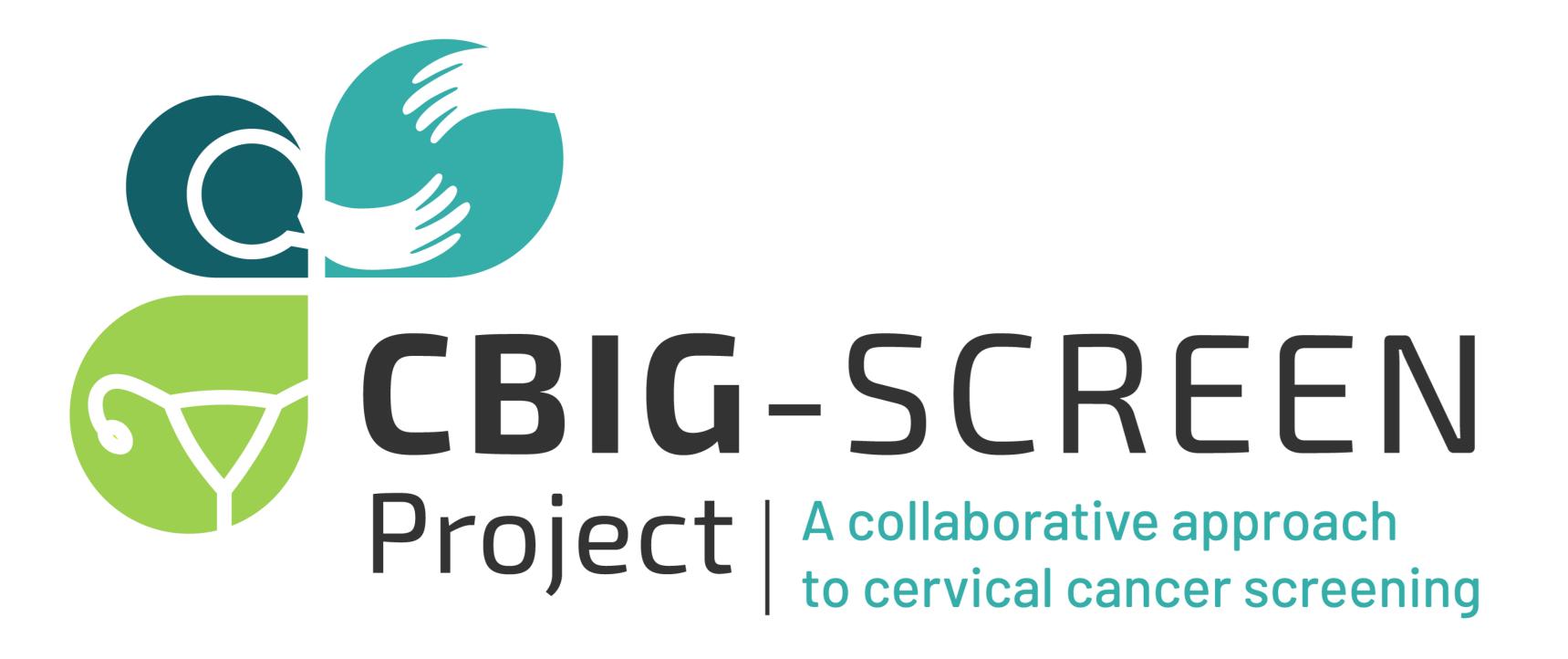
EONIX: webplatform development

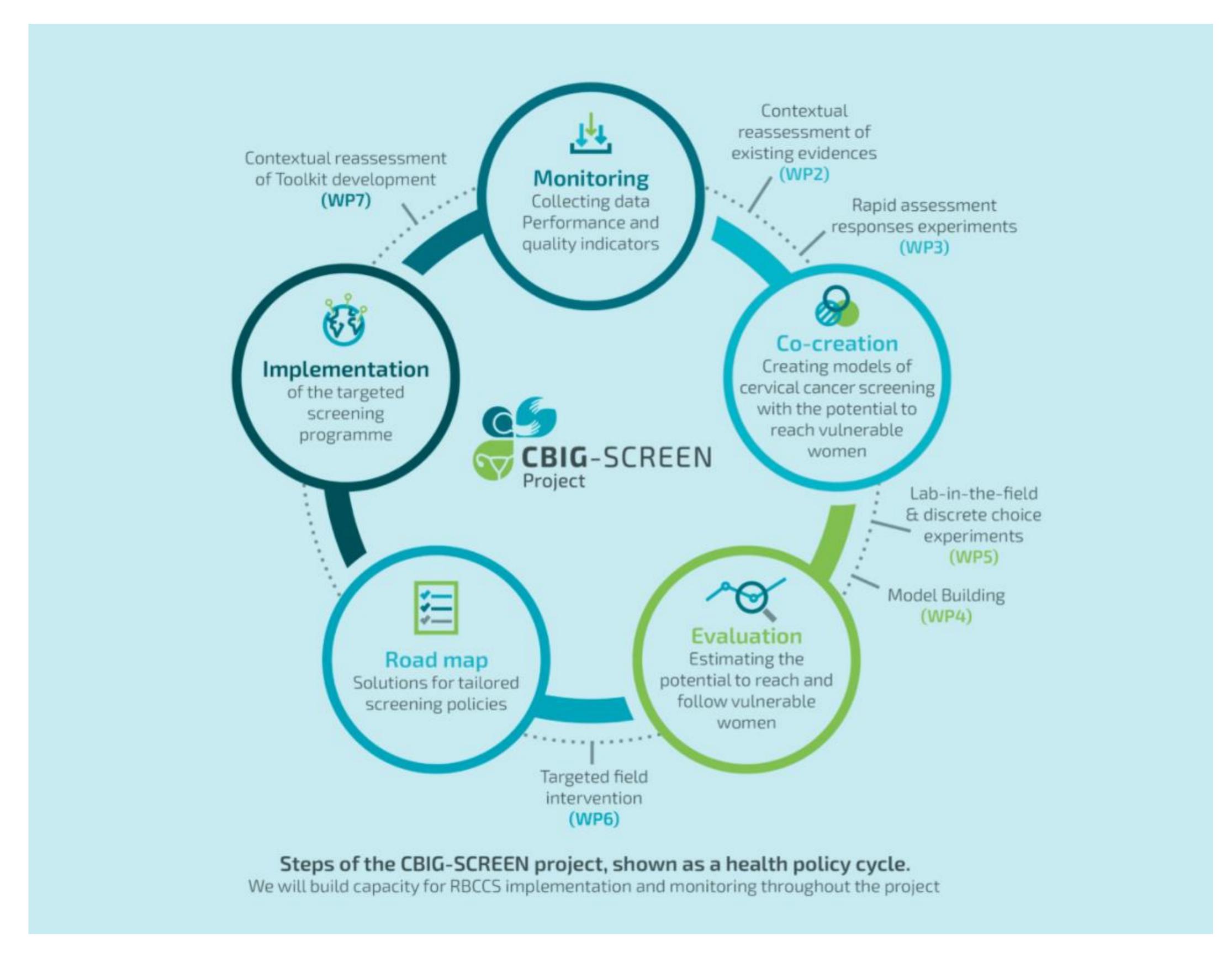
Intuitim: trusted third party – data host

Associated partners: Screening centres from Flandres, Wallonie and Brussels regions;

Fondation contre le Cancer

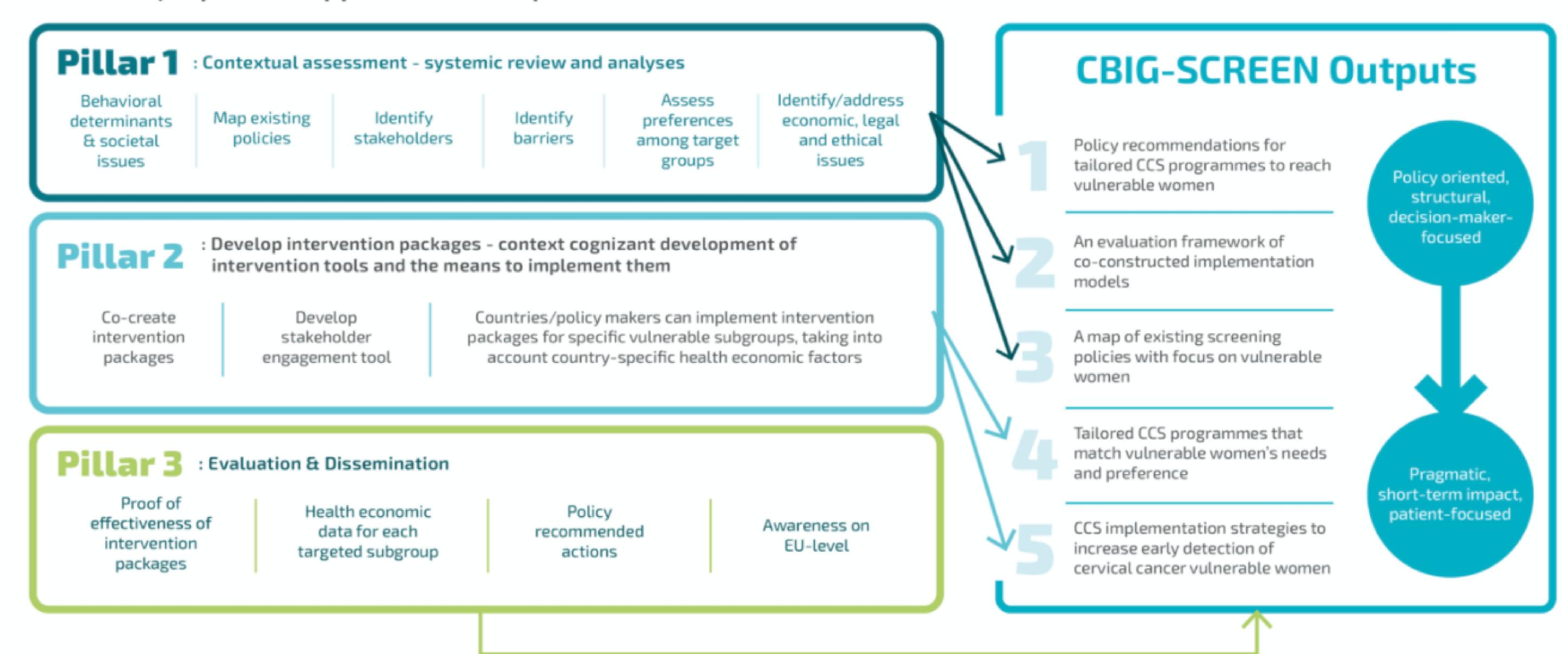






#### > THE CONCEPT

#### Three major pillars support the concept of CBIG-SCREEN



## **Co-creating the offer of cervical screening** with vulnerable groups for vulnerable groups

5 Years 2021-2026 14
Partners
in the project

10 European countries €3.6

Million funding from Horizon 2020





### THE CONSORTIUM



France Denmark United Kingdom Italy Portugal Estonia Romania

Ireland Bulgaria Belgium



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CBIG-SCREEN, a 5-year collaborative research project, has received funding from the EU Horlzon 2020 Research and Innovation Programme under Grant Agreement No 964049. Official starting date: 01. March 2021

# THANK YOU!



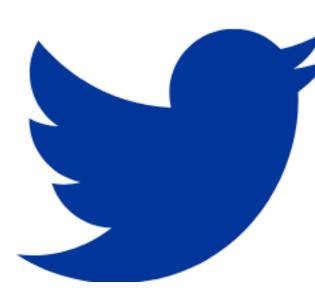
### ANY QUESTIONS?

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### LINKEDIN

ECL Association of European Cancer Leagues

