



From awareness to co-responsibility: engaging citizens and patients

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Personalised prevention requires engagement 2.0



- Patient and citizen engagement build on firm foundations
- Personalised medicine as a new vision requires patient and citizen engagement **even more urgently**
- Why?

Technical innovations (Genomics, Digitalisation, Imaging,...) >>More data
>>More personalisation

Active and informed citizens and patients



PROPHET Roadmap:

“Personalised medicine and prevention, in which genomic information plays an important role, envisions and requires **active and informed patients and citizens** who take an **active role in managing their own health and care**. They need to be well-informed to be **empowered to make decisions regarding their health and prevention** that reflect their personal values, and **be aware of options for contributing to research**, such as via data sharing.”

Patients and citizens are central in personalised prevention



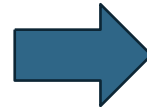
Patients and citizens central in PROPHET project across several Challenges

- #5 Community engagement and trust
- #9 Ethical, Legal, Social Issues
- #10 Changing behaviour

Patients and citizens are central in personalised prevention

Patients and citizens central in PROPHET project across several Challenges

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Collaboration:
Active Citizenship ACN and
European Patient Forum EPF



Engagement across three domains



Check for updates

OPEN ACCESS

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Engagement of patients and the public in personalised prevention in Europe using genomic information: a scoping review

Loes Lindiwe Kreeftenberg^{1,2*}, Lidewij Henneman^{1,2},
Johannes C. F. Ket³, Martina C. Cornel^{1,2} and Carla G. van E^{1,2}

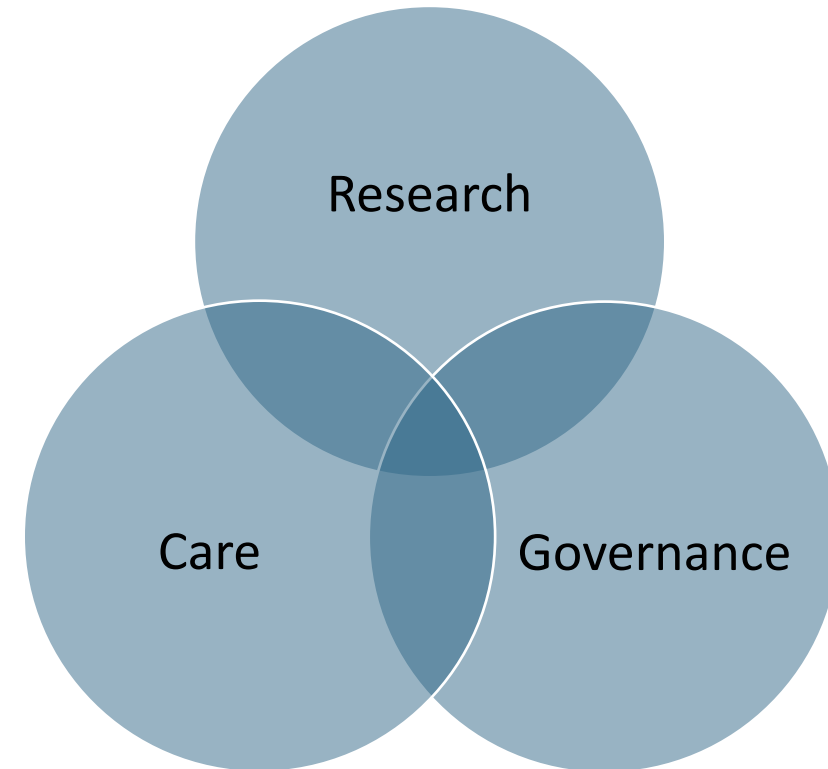
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Systematic Scoping review

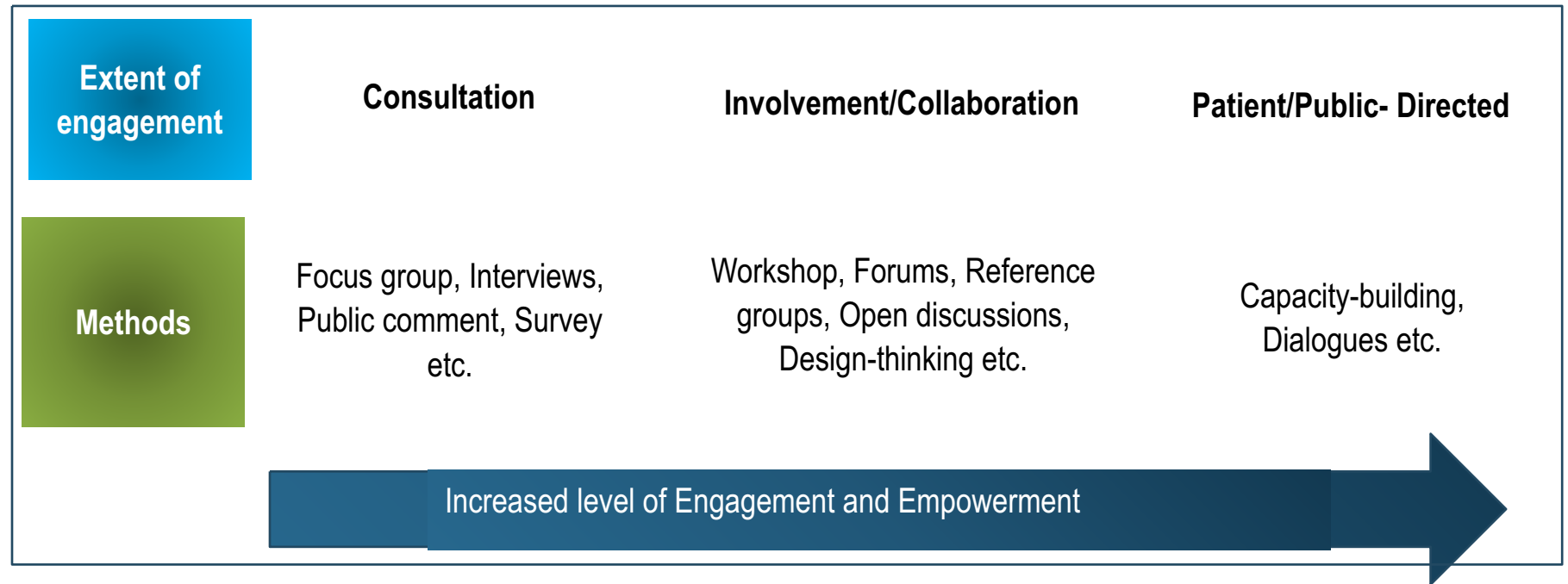
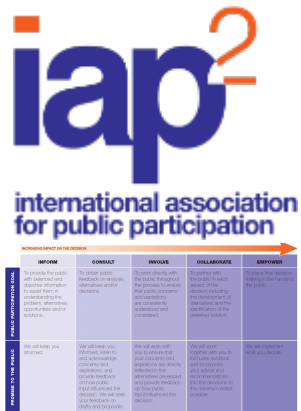
2015 - June 2023

Geographical location: Europe

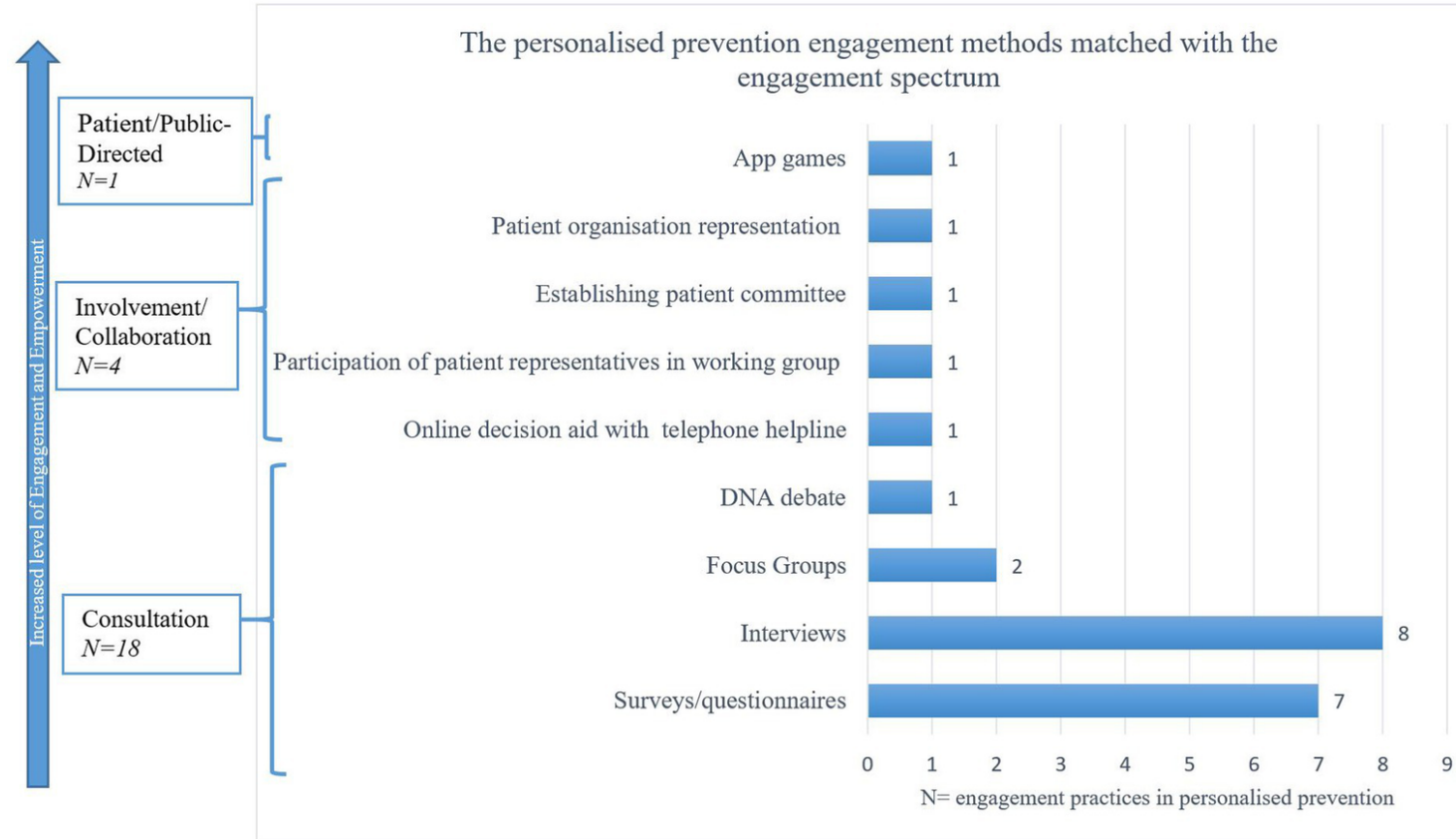
- Disease focus: common chronic disease
 - Cancers
 - Cardiovascular Diseases
 - Neurodegenerative disorders
- Search hits:
 - 7317 → 23 reports



Public engagement as a spectrum



Engagement methods



> *Sociol Health Illn.* 2017 Jan;39(1):143-158. doi: 10.1111/1467-9566.12457. Epub 2016 Jul 27.

Stratified, precision or personalised medicine? Cancer services in the 'real world' of a London hospital

Sophie Day ^{1 2}, R Charles Coombes ³, Louise McGrath-Lone ¹, Claudia Schoenborn ¹, Helen Ward ¹

Affiliations + expand

PMID: 27460935 DOI: 10.1111/1467-9566.12457

Research & Care

Consultation

> *J Transl Med.* 2015 Nov 14;13:360. doi: 10.1186/s12967-015-0711-x.

Alliance Against Cancer, the network of Italian cancer centers bridging research and care

Paolo De Paoli ¹, Gennaro Ciliberto ², Manlio Ferrarini ³, PierGiuseppe Pelicci ⁴, Paolo Dellabona ⁵,
Francesco De Lorenzo ⁶, Alberto Mantovani ⁷, Pellegrino Musto ⁸, Giuseppe Opocher ⁹,
Piero Picci ¹⁰, Walter Ricciardi ¹¹, Ruggero De Maria ¹²

Affiliations + expand

PMID: 26578263 PMCID: PMC4650281 DOI: 10.1186/s12967-015-0711-x

Governance & Education

Collaboration

Editorial > *FEBS Lett.* 2022 Apr;596(7):845-848. doi: 10.1002/1873-3468.14331.

Epub 2022 Mar 29.

GENIGMA: an app to map the 3D genome of cancer cell lines through extreme citizen science

Daniela Ruffell ¹

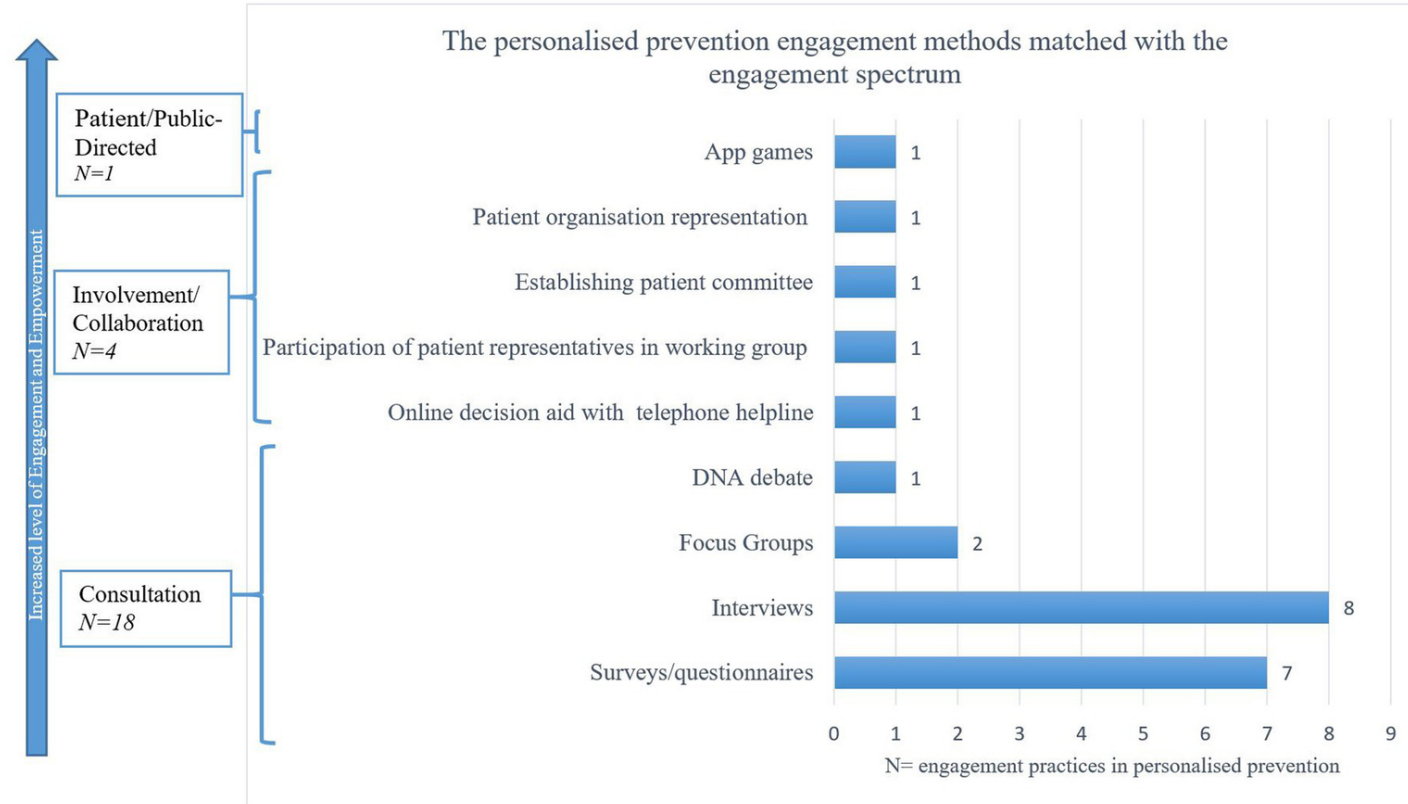
Affiliations + expand

PMID: 35349172 DOI: 10.1002/1873-3468.14331

a PeRsOnalized Prevention roadmap
for the future HEAlThcare

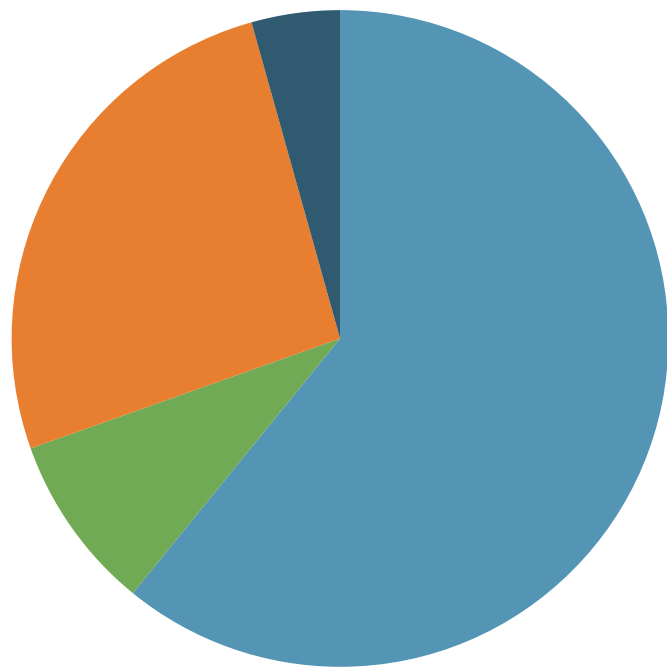
Research

Public-directed



Domains of Engagement

■ Care ■ Research ■ Research and Care ■ Governance & Education

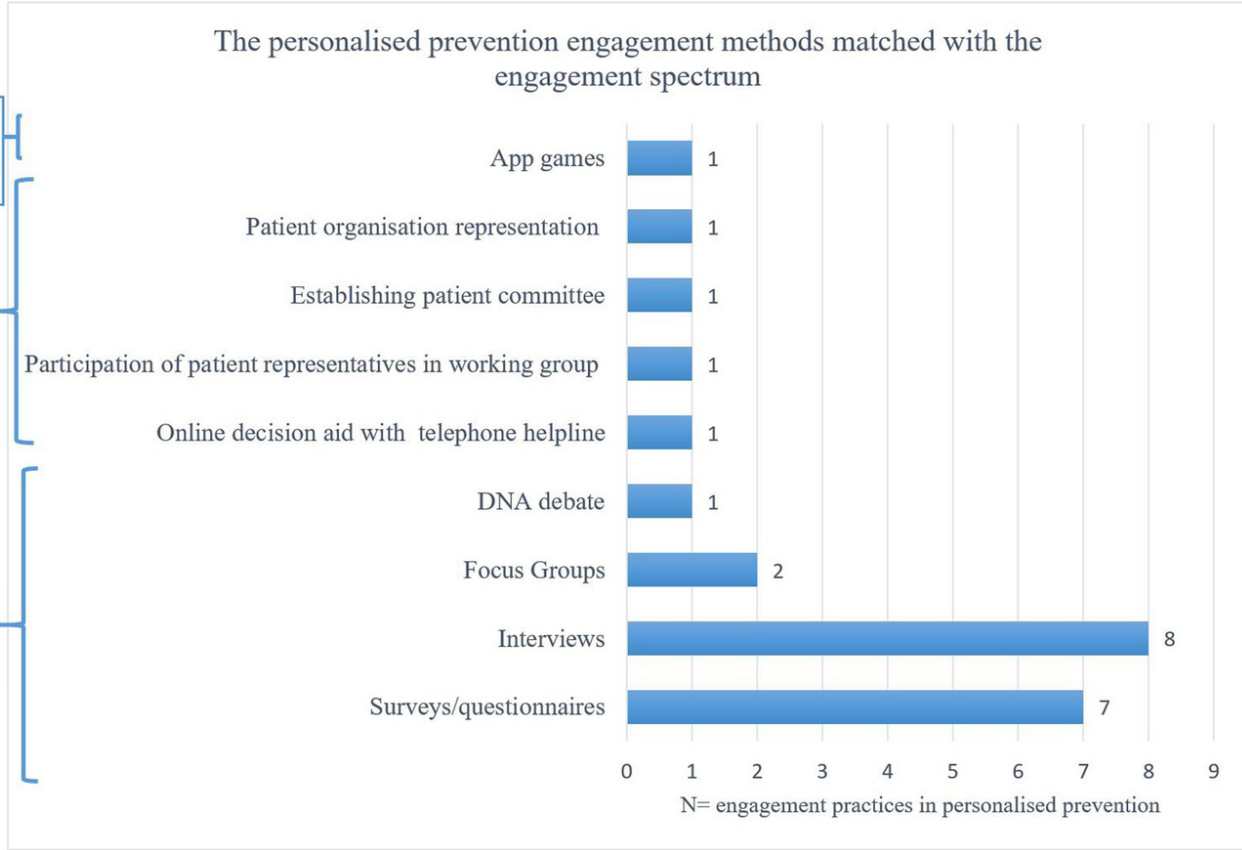


Increased level of Engagement and Empowerment

Patient/Public-Directed
N=1

Involvement/Collaboration
N=4

Consultation
N=18



Towards better practices

RESEARCH

Open Access



Personalised prevention: what patients and citizen advocates want for better engagement – a qualitative study

Loes Lindiwe Kreeftenberg^{1,2*}, Lidewij Henneman^{1,2}, Claudia Louati³, Yasemin Zeisl³, Estefanía Callejas de Luca³, Daniela Quaggia⁴, Martina C. Cornel^{1,2} and Carla G. van El^{1,2}

Across all three domains: Research, care and Governance - Points to consider

- CARE
 - clear information, also on genetic testing
 - non-specialist mentors (patient organisations)
 - access to medical records
- RESEARCH
 - involvement in various stages of research process
 - include diverse groups/populations in research
 - fair compensation of patients' time in engagement
- GOVERNANCE
 - representation of diverse groups
 - data: quality, transparency and protection
 - better use of patient-generated data



Welcome to PROPHET TOOLBOX

In this Toolbox the PROPHET project shares the results of our research and engagement on personalised prevention. The Toolbox offers an insightful overview of information to be used for education and capacity building. For each stakeholder group of healthcare professionals, public and patients, and policymakers, you will find fact sheets, reports, videos and useful links highlighting promising examples and challenges for personalized prevention and its integration into healthcare systems.



Discover the PROPHET Toolbox! 

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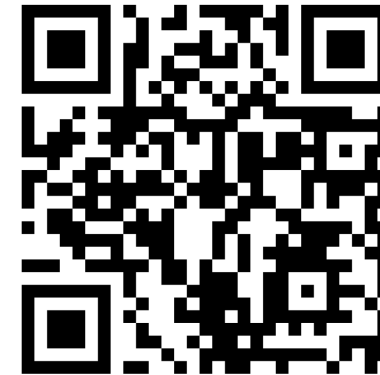
Policy makers

[Learn more →](#)



Citizens and patients

[Learn more →](#)



Toolbox PROPHET: <https://prophetproject.eu/prophet-toolbox/>

Further take aways from PROPHET for citizen and patients engagement

- Structural funding
- Evaluation of engagement – explicit goals!
- Improvement of information sharing in affected families : cascade testing
- More research into behaviour change - acceptability and effectiveness of health advice
- Increase health literacy and digital literacy

For effective implementation of personalised prevention we need meaningful patient and citizen engagement as a co-responsibility of all stakeholders!



UNIVERSITÀ
CATTOLICA
del Sacro Cuore

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