

Engagement of patients and the public in personalised prevention using genomic information: Scoping review

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PROPHET Consortium
personalised Prevention ROadmap for the future HEalThcare

Members: 18 Academic & non-Academic
Aim: to develop a Strategic Research and Innovation Agenda (SRIA) for Personalised Prevention

Activities:
 Mapping clinical utility, biomarkers, barriers/facilitators for implementation and patient/professional engagement
 Assessing HTA and HIA analyses of promising applications
 Building educational tools for patients, citizens, health care professionals & policy makers, for effective engagement and implementation

Please join our PROPHET survey to share your views on barriers and facilitators in personalized prevention.

Take our online survey!

Introduction

Aim: To map the current practices of public and patient engagement in personalised prevention in Europe

Vision
 A personalised approach to healthcare envisions and requires the following from the public and patients:
 • aware of the benefits and potential challenges of genomic medicine
 • committed to sharing personal data with trustworthy institutions
 • empowered to orient health decisions towards their personal values

Domains
 Public, Patients and Families are active partners in the planning, delivery and evaluation of
 1) research, 2) clinical care ², 3) education 4) governance

Methods

- Scoping review
 - 2015 - June 2023
- Geographical location: Europe
- Disease focus: common chronic disease
 - Cancers
 - Cardiovascular Diseases
 - Neurodegenerative disorders
- Search hits:
 - 7317 → 23 reports

Results

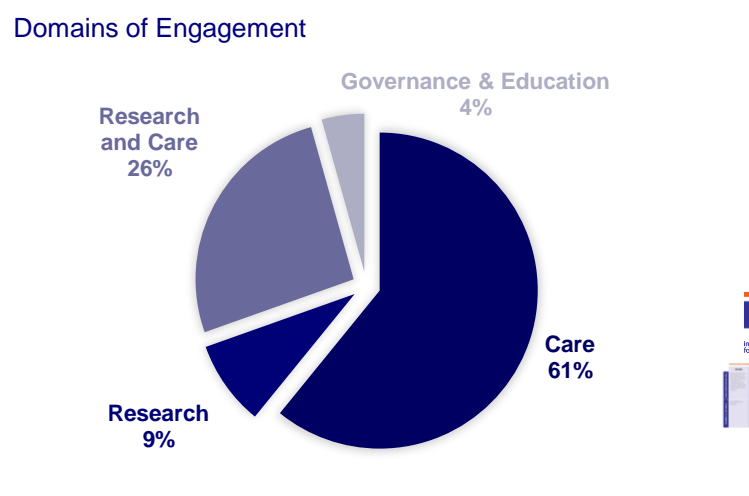
Extent of Engagement

Extent of Engagement	Count
Consultation	18
Collaboration	4
Patient/Public-directed	1

Increased level of Engagement and Empowerment

Extent of engagement	Methods
Consultation	Focus group, Interviews, Public comment, Survey
Collaboration/Involvement	Workshop, Forums, Web 2.0 tools, Reference groups, Open discussions, Design-thinking
Patient/Public-Directed	Capacity-building, Dialogue with governments

Increased level of Engagement and Empowerment



Take-away messages:

- The findings demonstrate the **wide range of approaches and methods to engage** patients and the general public at various levels
 - Mainly one directional engagement methods were used (dissemination, consultation)
 - There is a **need to elaborate practices** that engage public and patients in all the levels
- Lack of evaluation**
 - It is mostly unknown, how these practices impact patients and the public & (health) outcomes
 - **Need to establish evaluation measures**
- Most engagement activities in our review were related to cancer, and none to neurodegenerative diseases.

In order for patients and the public to be empowered, **education, health literacy and knowledge need to be enhanced**