PROPHET
a PeRsOnalized Prevention roadmap
for the future HEalThcare

# PROPHET FOR ALL - FACTSHEET#5

## *ENGAGING THE PUBLIC AND PATIENTS*

Personalised prevention means trying to stop people from getting sick, stop or slow an illness from getting worse, and stop it from coming back. It does this by picking actions that fit each individual person. These actions are based on the person's body and health (for example: family health history, DNA, age or sex, and current health), the places they live and work, their daily habits, and their social and cultural background.

Personalised prevention can only work if the public and patients are really engaged to improve trust and uptake of healthcare interventions. Engagement means being well informed, asked for input, and where possible given a real say in decisions about research, (health)care, and policy/governance. This factsheet explains what personalised prevention looks like in practice, what engagement means, and how the public and patients can be involved in the research, care, and policy domains.

### Why engagement matter ?

Healthcare that fits each person works best when people have clear, easy-to-understand information. People should know what it means to share their health data and feel empowered to make choices that match what matters to them. Being empowered means people can take action, have control over their health, and have the right to join in decisions about their care. Long-term illnesses already affect about one in three adults in the European Union and cause about 900,000 early deaths each year. As prevention increasingly uses DNA and other body information, people should be active partners in deciding how this information is collected and used, not just accept care without having a say.

# THREE DOMAINS OF ENGAGEMENT

Engagement in personalised prevention can be explored in three domains

1. **Research:** involve patients and the public at every step. They can help choose what to study and help share the results.

2. **Care:** help patients and the public take part in care choices that match what they want and need.

3. **Policy/Governance:** involve patients and the public in making rules, guidelines, and big decisions about how health services are run.

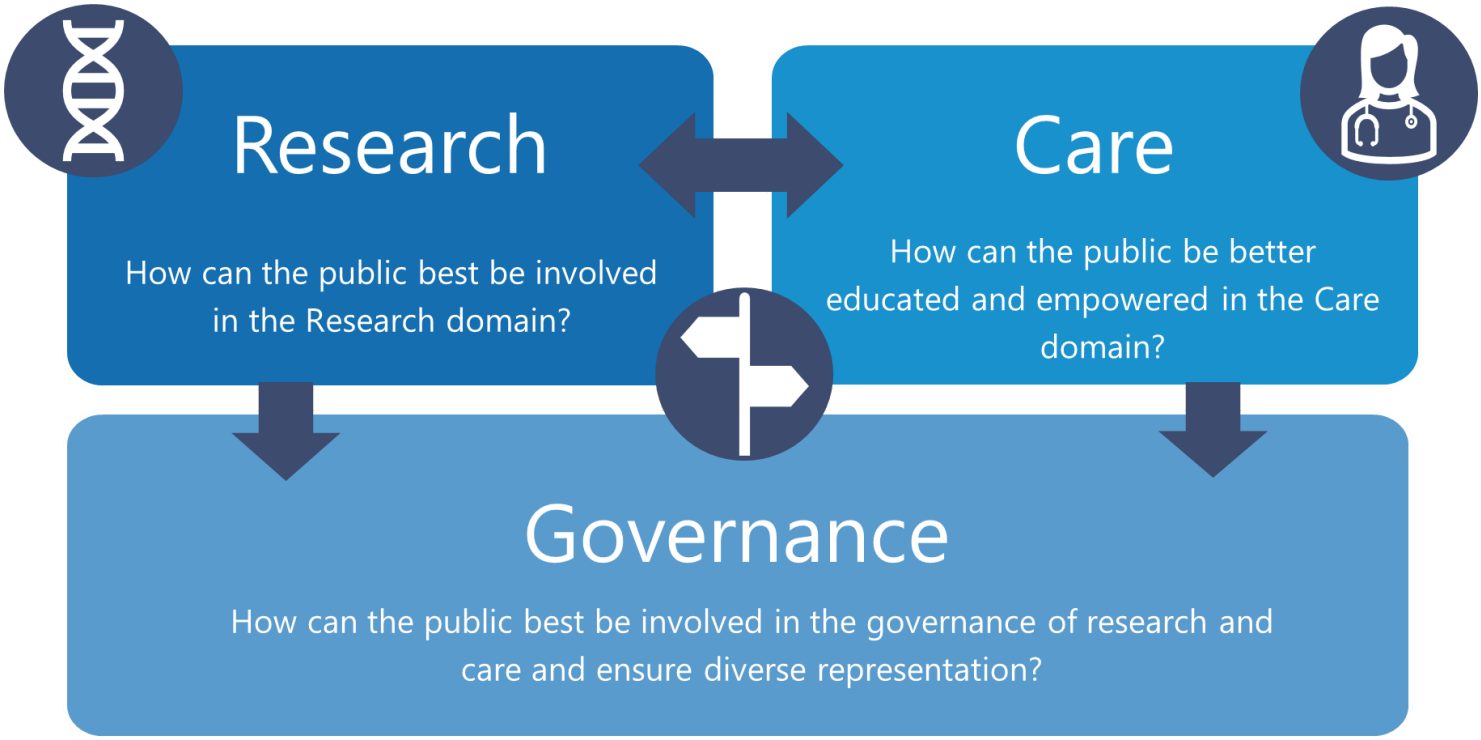


**Fig 1.** Domains of Research, Care and Governance in Personalised Prevention

## LEVELS OF ENGAGEMENT

People can be involved in different ways. There are three levels of how strongly patients and the public are involved, from low to high:

**CONSULTATION**
Low engagement: patients and the public are told information or asked for their opinion only once by researchers or healthcare professionals.

**INVOLVEMENT / COLLABORATION**
Medium engagement: patients and the public work together with healthcare professionals to make decisions.

**PATIENT / PUBLIC DIRECTED**
High engagement: patients and the public have the main say in the decisions.

**Fig 2.** Spectrum of engagement and empowerment of patients and the public. Adapted model based on IAP2 and Shimmin.

In 2024, a European study looked at 23 publications to include people in health programs that try to prevent illness in a way that fits each person. It found that most efforts (78%) only ask people for their input, mostly through surveys or interviews. Very few efforts let people participate in decision-making or lead the work. This means patients and the public are mostly giving input, not taking part in decisions.

## WHAT ENGAGEMENT MEANS IN PRACTICE: EXAMPLES BY DOMAIN

The examples below are drawn from examples in Europe, showing ways the public and patients have been, and can be, involved.

Research domain 

What this means: Patients and the public help choose what to study, how to run the study, and how to share the results.

Examples:

- A patient group joined a cancer research program. They helped plan the work and explain results to the public (involvement/collaboration).
- People helped make an online game to map the DNA of cancer cells. The team used public ideas during design and testing (patient/public-directed).

 **Key takeaway:** Invite patient representatives to research advice groups from the start. Let them help set what matters most to study. Pay them fairly for their time and skills.

Care domain

What this means: Patients help decide their own tests and treatments together with the healthcare professionals. Their experiences guide how care is set up.

Examples:

- Patients with colorectal cancer were interviewed about how information on DNA testing should be given before chemotherapy. Doctors then used this to explain testing to future patients (consultation).
- Women at risk of breast cancer got an online tool and could choose to use the telephone to help them understand their personal risk and screening choices (involvement/collaboration).

 **Key takeaway:** Use many ways (in person, written, online, and phone) to explain risk and DNA testing in plain words, matched to age and reading level.

Policy/ governance domain

What this means: patients and the public help shape rules and policy decisions about how prevention for each person is put in place.

Example:

- A cancer alliance worked with a patient group to share information between patients and research centres (involvement/collaboration).

**Key takeaway:** Set up patient and citizen advice groups at national or regional levels. Give them a clear task, report on what happened, and show how they shaped the choices.

## THE CURRENT PICTURE IN EUROPE

- Many activities focus on patients, while fewer focus on the wider public.
- A large share of examples involve (hereditary) cancers, while other conditions are less often addressed.
- Most activities are found in the care domain, followed by research; policy/governance is least present.
- Evaluation and explaining how feedback is used are often missing, making it difficult to judge whether engagement led to real improvements.

## WHAT PATIENTS AND CITIZEN ADVOCATES WANT

In 2025, a study talked with 29 patients and people from the general public from 16 European countries. They shared how patient and community groups can help people get the health advice and care that best meets their needs.

Their ideas fall into three main areas:

### ① Information and communication

- Health information should be easy to understand, easy to find, and match people's needs and life experience.
- Patients want to join research from the very beginning, not only after decisions are made.
- Messages about DNA test results are often too difficult or don't explain enough.

### ② Representation and inclusivity / Who is included

- Research and health rules should include people from many backgrounds, including people who are often left out.
- Working with local groups and trusted people in the community helps reach those people that regular health services miss.

### ③ Ethical &regulatory considerations / Privacy, pay & rules

- People worry about privacy and how their data about their DNA or health might be used by insurance companies or other private companies.
- People want to be recognised for their time and contribution to the design of research and studies.
- People worry that prevention tailored to each person could be unfair/increase inequalities if the tools and tests cost too much.

## KEY TAKEAWAYS

- Move beyond one-way input toward working together and shared decision-making, wherever possible.
- Use plain language and multiple ways to communicate (written materials, websites, apps, helplines, community meetings), depending on ages, education level, and disease groups.
- Measure how patients/community were involved and how their insights changed decisions, so people can see that their ideas are heard and lead to better care.
- Engage the wider public, not only patients, especially around prevention, data sharing, and policy.
- Make sure engagement is inclusive, and preventive technologies are affordable, so personalised prevention is for everybody.

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