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# A participatory platform to foster science - society dialogue and inform research priorities in cancer research

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## INTRODUCTION & OBJECTIVES

In health democracy, participatory research approaches – such as public and patient involvement (PPI) and community-based research– recognize the experiential knowledge of people with lived experience of cancer as complementary to scientific knowledge.
(Demange et al., 2012, Godrie et al. 2022; Olivier et al. 2024).

These approaches

- ✓ ensure that advancements in cancer research on prevention, diagnosis, treatment, and care are in tune with the real needs and priorities of the growing community affected by cancer (Pii et al., 2019).
- ✓ ensure the research is relevant (defining priorities), assure that the research tools are appropriate, assure that the research is acceptable (defining objectives, revising methods), feasible, to assure actionability (Colomer-Lahiguera et al., 2023).
- ✓ mostly enfold with small numbers of participants and focus on single types of cancer or aspects of care (Colomer-Lahiguera et al., 2023; Nygaard et al., 2019).

→ However, there is a **need for testing and developing large scale initiatives in the cancer field based on participatory approaches, such as public consultation**.

### PLATFORM OBJECTIVES

Create **a space where the public can ask questions on cancer** they would like answers researchers to provide answers to.

- ❑ Open up dialogue between researchers and the public and better inform the latter about research advances and challenges
- ❑ Enrich and inspire future calls for projects and research projects with the questions and identified

## METHODS & ANALYSIS

Collect questions from participants in 2024 (France)

***"What questions on cancer would you like researchers to provide answers to?"***

**Survey**: up to 6 open-ended questions gradually brought the participants to raise questions, after having shared their thoughts about cancer research and themes of research they thought cancer research focused on. The survey also integrated short informative sections – meant to accompany the participants in their thought process – about the different types of cancer research, risk factors, screening and diagnosis, treatments and side effects, after cancer, cancer at different stages of life.

**Worshops**: in person or online, moderated by Seintinelles or self-moderated thanks to a moderating guide provided by Seintinelles.

Participants were recruited through Seintinelles, through partners and patient organisations. Anybody living in France and who is 18 years-old or older can participate.

Seintinelles is a French collaborative platform facilitating the participation of the public in cancer research, in order to build a direct, reciprocal and lasting relationship between the public and researchers, and facilitate collaboration through communication tools, most of which are digital. Seintinelles aims at making research more efficient, more relevant and have a greater scientific and social impact.

### ANALYSIS

- Multi-stage, iterative thematic analysis of the questions : AI assisted (Bluenove) and multiple in-person checks and analysis (Excell and Maxqda) > 76 sub-themes & 10 themes (2 753 mentions) (Braun and Clark, 2023).
- A clustering analysis using R software (logistic regressions) analysed the quantitative data (particularly socio-demographic data) to identify profiles of participants who had engaged with the 10 themes of questions covered.

## RESULTS

Between September and December 2024

**1 084 participants (total)** → **718 participants shared 2 442 questions**

51 years old (mean age)

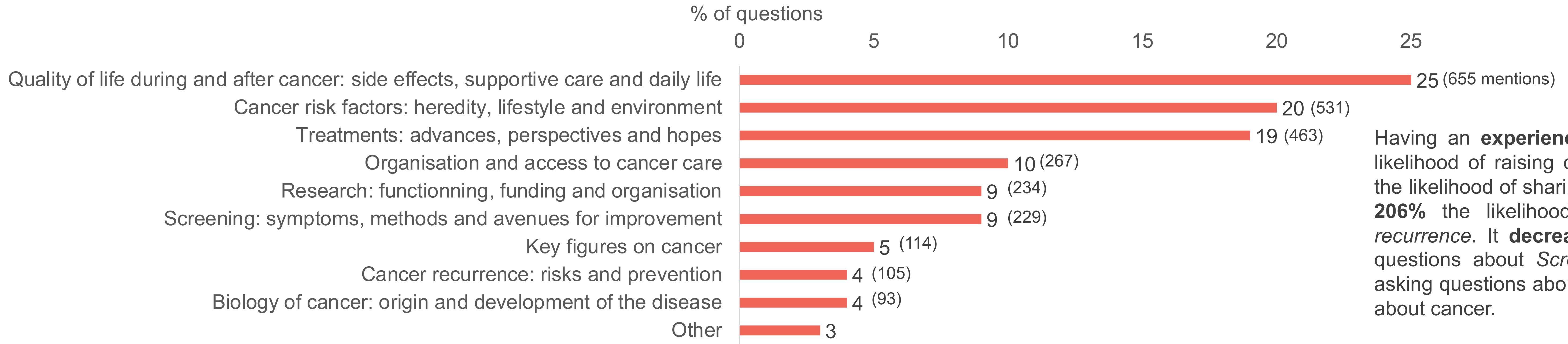
91% women

41% masters degree or higher

63% intermediate or high socio-professional categories

53% experience of cancer

53% careers



- ❖ The participants mostly asked about **(1) quality of life during and after cancer**, **(2) cancer risk factors**, **(3) treatments**.
- ❖ Most questions are rather short sentences, and rather general questions concerning one specific topic or aspect of cancer (more limited number of questions were more complex or technical).
- ❖ Many of the questions were **information requests** (about **existing results**).
- ❖ There is a genuine **curiosity about research**, and a need to **better understand** how research on cancer works.
- ❖ Difficulty of sharing questions : **only 66% of the participants asked questions**.

Having an **experience of cancer increased** by 170% the likelihood of raising questions about *Quality of life,* by **64%** the likelihood of sharing questions about *Cancer care, and* by **206%** the likelihood of asking questions about *Cancer recurrence*. It **decreased** by **53%** the likelihood of sharing questions about *Screening,* and by **45%** the likelihood of asking questions about *Key statistics and general information* about cancer.

**Being a career increased by 69%** the likelihood of asking questions about *Quality of life*, and decreased by **38%** the likelihood of asking question about *Screening.*

The **older the participants** were, the **less likely** they were to share questions about *Cancer risk factors,* and about *Research*.

Being a **man increased by 229%** the likelihood of sharing questions about *Treatments*, and by **96%** of likelihood of raising questions related to *Research*.

Participants with an education **lower than a master's degree were 47%** less likely of asking about *Cancer care*.

## CONCLUSION

- Novel results as they provide an **overview of the overall information needs of the public** (in France), although the participants are mostly of rather **high socio-economic position** and most of them are **women,** and mostly **recruited through Seintinelles.**
- Results suggest a need for **more and better support for the public in participatory research processes** (especially with large scale initiatives).
- The questions therefore reflect both **information needs** (what participants want to understand) and **articulation abilities** (what participants know how to express and consider legitimate to ask), thus reflecting participants' interactive and critical level of health literacy (Nutbeam, 2000).
- Health literacy as a requirement for participating in large-scale participatory research approaches (?), and difficulty of large scale participatory or consultation approaches (need for significant accompaniment of the public).

## *WHAT'S NEXT ?*

- Ongoing survey: 566 participants in 2025 > analyse future results.
- Share questions with researchers to enrich their projects.
- Inform participants about existing results and about cancer research organisation.

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