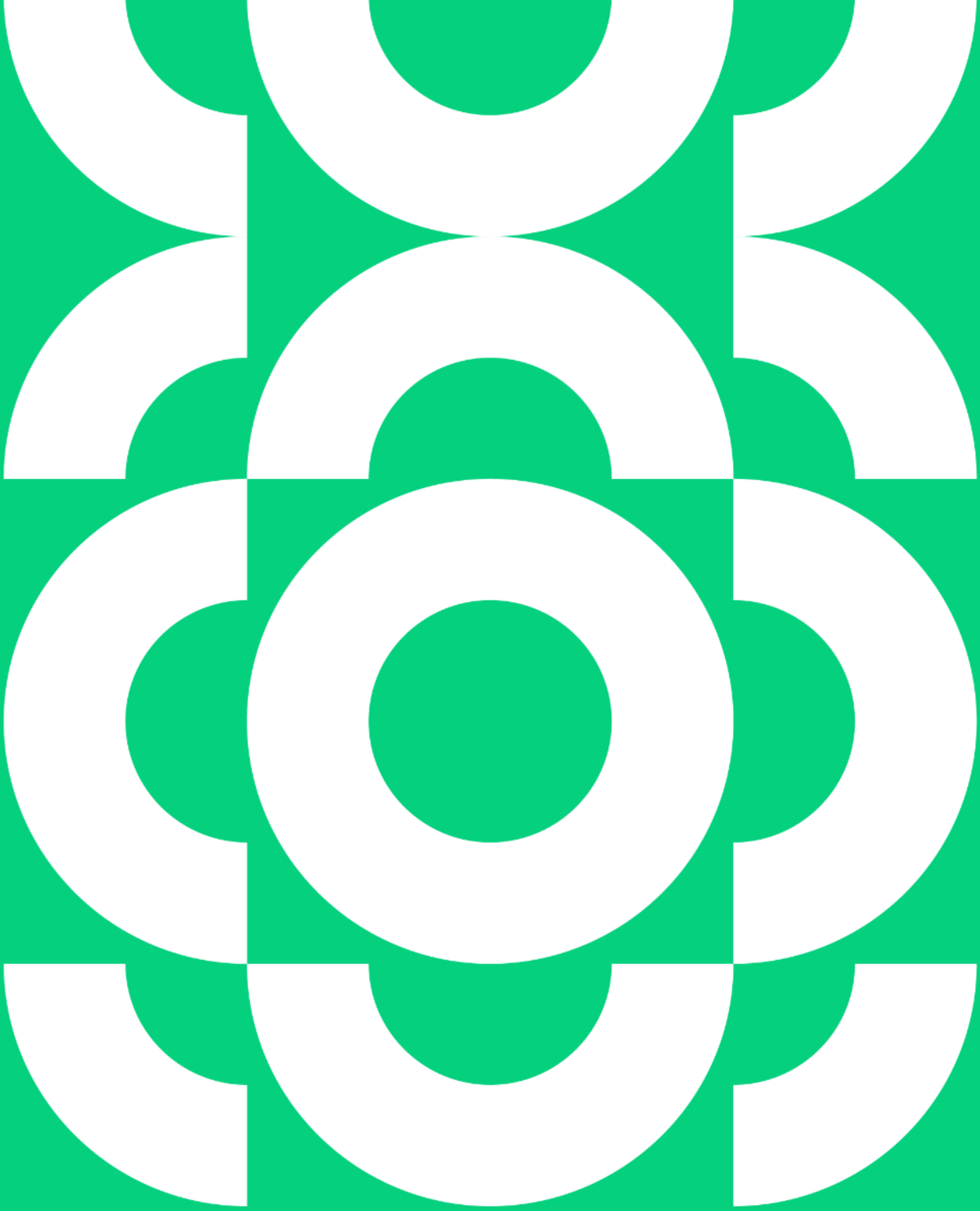

ECHoS
Cancer Mission Hubs

Toolbox for Citizen Participation in Mission Cancer

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1. Introduction

Citizen and patient participation in cancer care is increasingly recognised as a vital component in enhancing the effectiveness and responsiveness of healthcare systems. Participation, as defined by the European Union, involves the active engagement of citizens in decision-making processes, ensuring that their voices contribute to shaping policies, research, and initiatives that directly impact their lives (European Commission, 2022). This approach is not only about empowering individuals but also about improving outcomes in cancer care by aligning services with the real needs and experiences of patients and the public (Brabers *et al*., 2022).

Citizen participation[1] in healthcare, especially in cancer care, is crucial as it can directly influence the success of initiatives such as cancer screening programs (European Commission, 2022; Serrano Sanz *et al*., 2015). Enhanced participation has been shown to improve screening rates for cancers such as breast, colorectal, and cervical cancer. There is also a growing demand to extend these efforts to other cancers, including lung and prostate cancer (European Commission, 2022). Ensuring that these programs are designed to be accessible and relevant to the communities they serve can lead to better outcomes.

Participation can be applied across various areas in the field of cancer. In research, involving patients and citizens can ensure that studies address relevant and pressing issues, leading to more applicable and impactful findings (Serrano Sanz *et al*. 2015). In projects and initiatives, citizen and patient involvement can foster a sense of trust, increasing the likelihood of successful implementation and adoption (Lowndes, Pratchett, and Stoker, 2006). Moreover, engaging these stakeholders in policymaking can lead to more informed and equitable healthcare policies, addressing the specific needs of diverse populations and ensuring inclusivity (European Commission, 2022). Ultimately, participation enhances transparency, accountability, and the overall quality of cancer care, leading to better health outcomes and more sustainable healthcare systems (Brabers *et al*., 2022).

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[1] For the purpose of this report, participation in this field is meant to involve a range of different stakeholders, citizen at large (especially related to prevention), and within that group also patients (especially from the point of diagnosis onwards), as well as healthcare professionals, policy and decision makers and other stakeholders who may be involved or in charge of effectively ensuring participation.

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The EU Mission on Cancer calls for the engagement of a broad range of stakeholders by actively involving patients, survivors, healthcare professionals, civil society and citizens at large, in co-designing policies and initiatives on cancer. This approach aims to ensure that cancer research and cancer care address the needs and perspectives of those affected, fostering collaboration and innovation for more effective cancer prevention and treatment strategies across Europe. Specifically, in its Implementation Plan, the Mission on Cancer aims to engage European citizens at national, regional, and local levels, involving them in cancer-fighting actions. By using activities like focus groups, surveys, and community meetings, the mission will aim to gather feedback and build trust with various groups, such as cancer patients, caregivers, and healthcare providers. As part of the Mission on Cancer Governance structure, connecting European with National Structures and connecting Strategy definition with Operational activities, National Cancer Mission Hubs play a central role in guaranteeing the effective engagement of stakeholders in a variety of activities – by actively doing it and by fostering others to do so.

The "Toolbox for Citizen Participation in Mission Cancer" is developed within Work Package 6 (WP6), Task 6.2 (T6.2) – Citizens' engagement and participation Activities – and designed to showcase a variety of participatory methods, from already established ones to innovative approaches, across all above-mentioned areas. The toolbox is aimed at informing NCMH, as well as all stakeholders and interested parties on good practice of citizen engagement. As mentioned before, it will prioritise content by organisations of non-commercial use and only feature freely available materials and resources.

A landscape analysis on citizen engagement in cancer performed in the framework of WP6, Task 6.2, and published on the website in 2024 (Fröschl *et al.*, 2024, available here) revealed that respondents (ECHoS partners from Member States and Associated countries) identified a prevalence of participation within research projects (n=15, 83%) and consultations (n=15, 83%). More than half of the respondents reported that in their country, community workshops and forums are used (n=13; 72%), as well as online platforms and surveys (n=10, 56%). Fewer than half of the countries mentioned the common use of patient advisory boards (n=8, 44%) or citizens' councils (n=3, 17%). Some countries stood out by reporting recurring use of multiple engagement methods.

Leaning on these results, the toolbox will serve as a comprehensive collection of resources, including links to existing online resources and organisations, that specialise in citizens' participation. A particular focus will be

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dedicated to activities related to cancer and health. These resources have been quality-approved by experts on patient participation or/and participation in public health, including organisations within ECHoS such as the Austrian National Public Health Institute, GÖG (Gesundheit Österreich GmbH) and InoMed, (Center for Innovation Medicine, Romania), as well as in EU wide organisations such as the European Observatory on Health Systems and Policies, EUPATI, EPF, and European Network on Living Labs. This ensures resources relevancy and efficacy. Furthermore, information on how to identify high-quality resources will also be made available. The toolbox will also feature guidelines, checklists, and detailed information on some of the most used participatory methods, offering a foundation for stakeholders looking to engage effectively in cancer-related initiatives. Approaches and broader frameworks to participation, such as the principles of the C.L.E.A.R framework, which emphasizes that participation is most effective when it is Capable, Legitimate, Enabled, Accountable, and Responsive (Brabers *et al*., 2022) will also be featuring in the toolbox.

In sum, the toolbox will be a living online repository seeking to enhance citizens and patients' participation by providing NCMHs and other stakeholders an overview of existing tools and validated good practices. This aligns with the broader goals of EU Mission on Cancer and the Europe's Beating Cancer Plan, which emphasise research, innovation, and citizen engagement as critical components in the fight against cancer (European Commission, 2022).

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2. Methods

Information for the toolbox is gathered via different sources including priorly gathered data, existing research as well as insights from experts collected specifically for the purpose of the toolbox. Sources that have been used so far are listed below. The toolbox will be a "living" repository, meaning that the content can be continuously updated.

2.1. Survey Data

To shed light on "methods and opportunities" for citizen engagement available in ECHoS Member States and Associated Countries (MS/AC), answers to two questions were extracted from the survey on citizen engagement originally conducted for a landscape analysis (MS13) on the methods used across EU countries. An overview of currently used methods and a list of links and resources related to methods and opportunities in different countries will be collected and made available in the quality approved list of resources of the toolbox.

The two relevant survey questions were reference survey footnote:

- What types of opportunities/initiatives/activities for citizen engagement exist in your country that are related to cancer? Please include any type of opportunity and give any information on the level (local, community, regional, national, organisational) and area of cancer (prevention, diagnosis, treatment, survivorship...etc.) that you know of.
- What methods are used for citizen engagement in cancer, in your country? Please chose from the list below and comment where applicable. As the list is not exhaustive, please make sure to add any other relevant methods in the 'other' section:
    - Please choose all that apply and provide a comment:
        - Citizens' Council
        - Consultation
        - Patient Advisory Boards

- Community Workshops and Forums
- Online Platforms and Surveys
- Collaborative Research Projects
- Other

2.2. Expert Interviews

To gather comprehensive insights for the toolbox, expert interviews with leading professionals in the field, were conducted. These interviews aimed to collect detailed information on effective methodologies, best practices, and key quality criteria as identified by the experts. Additionally, exploratory interviews were carried out to focus on innovative approaches, such as Living Labs, to capture insights on these emerging methods and include practical recommendations based on the experts' experiences.

To date the following interviews were completed:

- two interviews specifically on Living Labs, with members of the the European Network of Living Labs as well as an expert from the Centre for Innovation in Medicine (InoMed).
- three general interviews with experts from the following organisations: WHO OBS (European Observatory on Health Systems and Policies), EUPATI (European Patients' Academy on Therapeutic Innovation), MPNEurope (Melanoma Patient Network Europe), Vision Zero Cancer.
- further interviews with experts from additional organisations will be performed and continuously updated on the website.

The toolbox will be continuously updated as further interviews are conducted and additional information is obtained. Interview questions were tailored to align with the interviewees' specific areas of expertise, focusing either on innovative methodologies or broader recommendations, depending on their knowledge and experience.

The interviews are recorded and transcribed. The recordings are only maintained for the necessary duration to complete the analysis and deleted afterwards. The transcripts are used to summarise relevant information for the toolbox (e.g., to add details and info on specific methods, general recommendations that can be used for checklists, resources and links to be shared, among others).

2.3. Workshop with “Community of Practice Participation” at GÖG

The workshop was held on the 21st of August 2024, with eight public health experts from the Austrian National Public Health Institute (GÖG) with ample experience and focus on participatory methods. The workshop aimed to achieve three goals:

- Firstly, collecting information on the most used and effective methods of participation in the experience of the participants including recommendations on Dos and don’ts related to these methods. These included aspects related to inclusivity and accessibility, to reach patients across all population groups.
- Secondly, collecting feedback and recommendations on what to include on the planned toolbox subsite.
- Finally, the workshop included recommendations on quality criteria for resources and links. Amongst other things, aspects on easily understandable language were discussed as well as multilingual materials.

Resources and materials to be shared on the ECHoS Toolbox subpage, include existing online toolkits for participation (e.g., Tool-KIT – Participatory. Tools) which were also shared independently of the website by members of the ”GÖG Community of practice participation”.

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3. Details on toolbox accessibility and content

The Toolbox will be accessible on the ECHoS website via a dedicated subpage. The subpage will be organised into various sections to help users quickly find the relevant information they need. The primary goal of the Toolbox is to provide an easily accessible and a comprehensive overview of existing resources and insights relevant to stakeholders working in the field of cancer, ensuring that duplication of efforts is minimised. Importantly, the toolbox will feature solely resources and content of non-commercial use.

As mentioned, the Toolbox is designed to support stakeholders in the implementation of citizen and patient engagement strategies in cancer care. It will provide a structured knowledge base featuring best practices, methodologies, and resources to enhance meaningful and inclusive participation.

The Toolbox will actively incorporate inclusive and accessible engagement approaches to ensure the participation of underrepresented, underserved, and remote patient communities. This includes tailored materials and guidance on:

- Engaging rural populations, non-native speakers, and individuals with low health literacy.
- Providing best practices for inclusive engagement, such as:
- Utilising community-based participatory approaches to co-develop engagement strategies with affected populations.
- Collaborating with local NGOs, patient advocacy groups, and cultural mediators to build trust and bridge participation gaps.
- Offering multilingual and plain-language materials to facilitate comprehension and accessibility.
- As further explained in the section below, a key component of the Toolbox is a series of expert interviews, each offering insights into different aspects of patient engagement. For example, an interview with two experts from EUPATI explores recommendations for developing educational materials tailored for patient engagement in research and development (R&D). These insights, along with relevant resources and links, will be made available in the resources section of the Toolbox.

Recognising that digital exclusion and digital health literacy remains a challenge for many underserved populations, the Toolbox will feature both digital and non-digital engagement methods. It will also feature resources such as readings on how to best reach/engage these patient groups as well as case studies showcasing successful patient engagement initiatives in underserved communities.

Finally, to further promote the adoption of inclusive engagement practices in both public and patient engagement, the Toolbox will be integrated into workshops and activities organised by ECHoS. These workshops will incorporate elements of accessibility and inclusivity into their exercises, ensuring that engagement strategies reflect the needs of diverse patient populations.

Key sections will include:

Resources and Links: This section will include a curated area for links to publicly available webinars, workshops, and other key materials referenced elsewhere in the Toolbox. This area will focus on general guides and principles of public/citizen and patient engagement, rather than specific methods. Contents related to

- Training and education materials
- Resources on information and communication materials
- Links to NGOs and non-commercial organisations that can support with matchmaking (e.g., between patients and researchers), recruiting participants, finding target audiences, among others.
- Links on examples of activities with a focus on addressing inequalities in cancer care that included successful collaborations with local NGOs, patient advocacy groups, or cultural mediators (such as living labs). For example, the living lab in 4P-CAN or…
- Curated section on recommended readings (more in-depth, peer reviewed articles on participatory methods and in-depth literature by key organisations etc.). Readings will also include articles on
    - Links/resources on digital tools for patients living in underserved areas

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  - General material that is created in the framework of the toolbox development or continuous update: for instance, a checklist for the planning stage of any engagement activity to ensure meaningful and inclusive engagement, based on (general) recommendations given by experts during the interviews - may be placed or linked to in this section

- This section will also include content related to best practices and recommendations for inclusive engagement. Provide concrete examples or guidelines on how to effectively engage these groups. For example:

  - Handbooks on existing bottom-up or community participatory approaches like the following example:

Example: Community Engagement: A Health Promotion Guide for Universal Health Coverage in the Hands of the People

Published by the World Health Organization (WHO), this guide (link: Voice, agency, empowerment - handbook on social participation for universal health coverage) serves as a resource for implementing community engagement strategies to achieve universal health coverage. It provides practical guidance on involving communities in health promotion activities, which can be adapted to cancer prevention and control efforts. The guide emphasizes the role of community engagement in enhancing health outcomes and ensuring that health services are responsive to the needs of the population. These resources offer valuable insights into participatory approaches that can be applied to cancer care and prevention initiatives.

- Collaborating with local NGOs, patient advocacy groups, or cultural mediators.
- Offering multilingual or easily understandable materials.

Methods Overview: Key information on established and innovative methods that are considered good practices by the community of practice, ECHoS partners, and interviewees will be showcased here (see 7.2 and 7.3 for examples).

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This section will feature a short description of participatory approaches such as bottom-up vs. top down, but also of the IAP2 framework with levels of engagement from information to co-creation etc.

The main aspect of this section will be the list of different methods which can be clicked and will open into a new sub-page each. A collection of engagement methods, each with a dedicated subpage providing:

- A description of the method
- Examples of its application in cancer care
- Key considerations for implementation
- Relevant resources and links,
- Where applicable, key insights from "tested in ECHoS" if the method is tested during a workshop or event

At the end of each, relevant resources and links will be available pertaining to the specific method. A filter function will allow to filter the methods by area or focus. On top of that, methods will contain "tags" to showcase certain key characteristics. In this section, a tag and filter for "inclusive engagement" will be created so that related contents can be easily spotted.

In order to address inclusive engagement, there will be methods that either fully focus on, or include elements pertaining to:

- Reaching patients in underserved areas via digital tools.

- Addressing inclusive and accessible engagement in other relevant ways. This includes Living Labs and other methodologies that incorporate digital solutions, multilingual functionalities, and accessibility features
- Patient Committees and Citizen Juries, to ensure meaningful patient representation

Another dedicated section will feature insights from experts and practitioners with first-hand experience using specific engagement methods. This will include amongst other themes:

- Insights on innovative methods such as Living Labs, which enable patients and citizens to collaborate with researchers in real-world settings (Serrano Sanz et al., 2015).
- Targeted insights on engaging specific populations, such as:

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  - Recommendations for engagement of children and young adults in cancer research (based on a completed interview)
  - Men and cancer, barriers and facilitators to improving accessible engagement in cancer related activities such as screening (a planned interview will explore this topic further)
  - Recommendations on meaningful and accessible educational materials for patients (based on a completed interview)

Interview results section: featuring insights from experts and peers that have experience using specific methods. This section will feature a spotlight on innovative methods, for example, the method of Living Labs, an approach that is emerging as a powerful tool in participatory cancer research. This method — where patients and citizens collaborate closely with researchers in a real-world environment— will be discussed, highlighting both their potential and the challenges they present (Serrano Sanz *et al*., 2015). This section will be enriched by insights from expert interviews, offering practical recommendations, dos and don'ts, and real-world experiences related to the application of living labs. The interviews allow to shed light on how to better reach and engage specific population/patient groups. For example, an interview was performed on the topic of engaging children and young adults in cancer. Another interview is planned to focus on men and cancer – etc.

To enhance the Toolbox's utility, the subpage will also feature a dedicated email address where users can submit additional tools and resources for consideration. All submitted materials will undergo a validation process before being published to ensure their relevance and quality.

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Dissemination/Synergies The dissemination strategy within ECHoS will leverage from existing channels, including the ECHoS website and social networks. Regular updates will be provided to all ECHoS partners through established communication channels, encouraging partners to actively contribute for the Toolbox and promote it within their own networks and platforms. To facilitate this, a ready-made informational infographics or flyer will be drafted for partners to easily incorporate into their communications, making it as simple as possible for them to share the information.

Scheduled social media posts by ECHoS will prompt partners to re-share links to the toolbox, and a unique hashtag (e.g. #CitizenEngagementToolbox) will be created to track engagement and enhance recognition. Furthermore, extended ECHoS Networks working with partner organisations will also be encouraged to mention the Toolbox in their newsletters or social media posts, providing a brief description and a direct link, along with a hashtag.

Efforts will be undertaken to share the Toolbox link among relevant networks in cancer care, research, and advocacy. This will include targeted outreach to key opinion leaders or influencers in the cancer field to amplify the message. The strategy will also capitalise on synergies, with the support of WP4 and WP1 colleagues, by creating links to other resources by EU projects or organisations working on original guidelines, handbooks and relevant materials, to further enhance the toolbox as well as to increase its visibility. In this framework, the creation of new content (short videos or infographics) on the topic of citizen engagement may also be considered in the future.

Planned ECHoS events focused on citizen or stakeholder engagement, such as the future Cancer Mission Fair, the Knowledge Exchange Programme, as well as the National Bilateral Visits with decision-makers and national authorities, will also serve as platforms to disseminate the Toolbox.

Example: **Two workshops at the Cancer Mission Fair in March.** These workshops exemplify one of several ways in which the Toolbox can help to enhance capacity building on citizen and patient engagement across stakeholders. By holding these workshops, where the Toolbox will be used as a **knowledge base repository**, the Cancer Mission Fair will provide an opportunity for students preparing to work in the field of cancer, as well as multidisciplinary professionals, to attend and engage. Participants will gain new skills, insights, and information on patient and citizen engagement. The workshops aim to encourage attendees to apply these insights in their own work, initiating or strengthening citizen engagement within their respective fields.

Two specific Toolbox-related workshops are planned, in which methods featured in the Toolbox will serve as the foundation:

- **Living lab method:** This workshop will focus on how to engage communities in cancer prevention, drawing from the 4P-CAN living lab experience. It will also provide concrete tools for stakeholder engagement, as well as recommendations and resources to ensure inclusivity at every stage of the living lab process.
- **PhotoVoice method:** This workshop will introduce and "test" the PhotoVoice method featured in the Toolbox, one of several participatory approaches included. Additionally, it will present an example of its application in a cancer related project launching in April 2025—ListenIn, which will focus on individuals affected by cancer and experiencing homelessness or precarious living conditions.

4. Next steps

- Meetings with communication officer and web developers to develop the online toolbox have started and more are scheduled for October 2024.
- Further collection of good practices via expert interviews.
- Interim feedback loops with WP6 and ECHoS partners and other participation experts on content for online toolbox.
    - Launch of Toolbox on Website with first contents by Cancer Mission Fair (timing to be established with Web Developers).
    - Testing of living lab method at the Cancer Mission Fair in a dedicated workshop on living labs with focus on cancer prevention – in May 2025

5. Sustainability

The toolbox will be a living repository serving as a steppingstone to create synergies and foster cooperations on the topic of citizen engagement in cancer. Most importantly, the toolbox will offer resources to future NCMHs and their stakeholders.The toolbox serves as a knowledge base that can be leveraged by various pentahelix stakeholders for information sharing and capacity building in the framework of the EU Mission on Cancer. In ECHoS, National NCMH structures can use the toolbox to strengthen patient engagement and, where relevant, broaden public and citizen engagement within their member organisations. It therefore provides practical guidance, examples, and materials that can be further used and adapted for workshops with relevant stakeholders such as the *Cancer Mission Fair Workshops on living labs and Photovoice.*

While the toolbox facilitates the implementation and enhancement of citizen and patient engagement, it does not mandate specific practices. Instead, it offers flexible resources that stakeholders can adapt to their local contexts to support meaningful and sustainable participation.

6. Toolbox Examples

As mentioned above, the Toolbox will be available on the ECHoS website as a subsite. There, it will include three sections: 1) a section featuring “links and resources”, 2) “Method Overview” featuring the main information on participatory any methods included in the toolbox, and 3) another section/type of content titled “Spotlight on innovative methods/ Interview results” featuring interview results to showcase different experiences by experts that have used some of the lesser known or innovative methods, which also may not be common practice yet.

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6.1. Short description of the “Method Overview” section

In the “Methods Overview” Section, different methods and approaches are planned to be visualised at first with clickable boxes with some basic information Including labels and icons to visualise different categories. Upon clicking on the box, the user will get a detailed description. In this list of method, it will be possible to filter for different categories (such as bottom-up approaches, policy related, research related etc.) so that users can easily find what they are looking for.

The unique element of this toolbox will be that every method description will contain **at least one link, resource, example or use case relevant to the field of cancer.** For some methods, if possible, direct examples and strategies for cancer initiatives, research, and others, can be included.

Furthermore, to offer some theoretical context which is important for deciding which method fits best, content could be labelled or linked to a brief explanation of different types of purposes/approaches (e.g., Information the C.L.E.A.R Framework and information on various steps of participation, from information to co-creation).

6.2. Example of content within the section "Methods Overview": Power- Interest Matrix

The text below represents an example of content that will appear when users look up different types of methods, as mentioned above, there will be a section with a list of methods that the user can choose from, and each method will be labeled and categorised so that users can filter what they are looking for. This method example would be for users who are looking to find a simple tool used in more hierarchical settings.

Description of the Power/Interest Matrix

A conventional project management tool that can be used if the idea is to understand the level of engagement of different stakeholder groups in a more hierarchical/structural setting (as opposed to bottom-up approaches, which aim to include "low-power, high interest groups" more in decision-taking processes), is the "Power-Interest Matrix". In. Also see: [» Power/Interest Matrix UNaLAB Toolkit (enoll.org)]

The Power/Interest Matrix is structured as follows:

1. **High Power, High Interest (Manage Closely)**:
    - **Stakeholders**: Key patient advocacy groups, influential policymakers, and leading research institutions.
    - **Examples**: Patient organizations and major health policymakers in the EU. These stakeholders have significant influence on the development and implementation of cancer policies and research initiatives. They are deeply invested in outcomes, given their direct impact on patients' lives and healthcare policies.
    - **Engagement Strategy**: Actively involve these stakeholders in decision-making processes for cancer research priorities, screening program designs, and policy formulation. Regular consultations, co-creation of strategies, and ensuring their feedback shapes the final outcomes are crucial. For instance, their input could be vital in the design and implementation of cross-border healthcare access for cancer treatments.

2. **High Power, Low Interest (Keep Satisfied)**:
    - **Stakeholders**: High-level EU officials, large healthcare funders, and private sector partners.
    - **Examples**: EU-level health funders who have the resources to influence large-scale cancer initiatives but may not be as focused on the specific details of every project.
    - **Engagement Strategy**: Keep these stakeholders informed about major developments and outcomes of cancer initiatives, especially how they align with broader EU health strategies or economic goals. Ensure their interests are protected, but without requiring their active participation in every decision.
3. **Low Power, High Interest (Keep Informed)**:
    - **Stakeholders**: Local patient groups, grassroots civil society organizations, and the general public.
    - **Examples**: Local cancer support groups and citizens engaged in advocacy for better healthcare services. While these groups may not have significant political power, they have a strong interest in cancer research and policy due to their direct experience with the disease.
    - **Engagement Strategy**: Provide accessible and regular updates on cancer initiatives, such as the progress of Europe's Beating Cancer Plan. These groups can offer valuable grassroots feedback and support, which can enhance the reach and effectiveness of cancer screening programs and public awareness campaigns. Involvement can be through public consultations, surveys, and educational campaigns.
4. **Low Power, Low Interest (Monitor)**:
    - **Stakeholders**: General public segments not directly affected by cancer or health professionals from unrelated fields.
    - **Examples**: Groups that are not directly engaged with cancer issues, such as the public in areas with low cancer incidence or health professionals focused on non-oncological specialties.

- **Engagement Strategy**: These stakeholders require minimal engagement. However, monitoring their attitudes can be important for understanding broader public health trends and for addressing
- any emerging concerns or misinformation that could affect public support for cancer initiatives. Occasional outreach, particularly in the context of widespread screening programs, can ensure they remain informed and supportive.

6.3. Example: Living lab method

Among the various methods featured in the Toolbox, the living lab method (priorly called "Blueprint for living labs" as of GA) will be presented in greater depth, providing a comprehensive step-by-step blueprint that can be used as is or adapted for different contexts. This section will offer detailed guidance, including elements specifically designed for workshops, along with links to relevant tools and resources.

The living lab section will include:

- A step-by-step blueprint for implementing the method.
- Workshop-ready elements, which can be used to facilitate engagement sessions.
- Links and descriptions of practical tools, such as:
- Stakeholder identification and engagement templates.
- Tools for enhancing inclusivity, accessibility, and equitable participation.
- Examples from cancer-related projects.
- Handbooks and frameworks from other relevant initiatives.

A key feature of this section is its "tested in ECHoS" component. The method has been piloted during the Cancer Mission Fair workshop, allowing for the collection of cancer-specific recommendations and insights directly from participants. These insights will be integrated into the Toolbox, enhancing its practical relevance and applicability for stakeholders.

The Toolbox will enable future NCMH stakeholders to:

- Adapt and implement the living lab method in their national, local, or organisational contexts.
- Use it as a reference for conducting workshops or training sessions.
- Access additional guidance and best practices, even if they are already applying this method.

The unique value of any method featured in the Toolbox lies in its cancer-specific examples and resources. Where applicable, the "tested in ECHoS" insights will further enhance each method by providing evidence-based, context-specific recommendations aligned with the EU Mission on Cancer objectives.

6.4. Example of content within the section "Spotlight on innovative methods/Interview results"

Expert interviews with professionals in the field of cancer who have used living labs were conducted, some key insights are presented below.

But first - what are Living Labs?

A **Living Lab** is a collaborative, user-centred innovation ecosystem that operates in real-life environments, involving multiple stakeholders from the public, private, academic, and civil society sectors (often referred to as the quadruple helix). These labs focus on active user participation, where stakeholders are involved in co-creating, testing, and refining solutions throughout the innovation process. The goal is to ensure that the innovations developed are both relevant and widely accepted by the community.

Participation is a key element in Living Labs, emphasising the co-creation of value by all stakeholders involved. This participatory approach allows for real-time feedback and adaptation, leading to more effective and socially sustainable outcomes. Living Labs are widely used in various domains, including urban development, healthcare, and public sector innovation, to address complex societal challenges through collaborative efforts.

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This approach is recognised by organisations like the OECD (Organisation for Economic Co-operation and Development) and the European Network of Living Labs (ENoLL), which emphasise the importance of user-driven innovation and the integration of diverse perspectives to enhance the impact and relevance of new technologies and policies.

For more detailed information, you can refer to resources from the European Network of Living Labs and the OECD Observatory of Public Sector Innovation.

A relevant resource by the European Network of Living labs is to be found on the Toolkit for building sustainable living labs

Read about leading Experts experiences and recommendations when using Living Labs:

The interviewees highlight the Living Labs method as a valuable approach in cancer research, emphasising stakeholder involvement, real-life experimentation, inclusiveness, and trust. While there are challenges in implementation, especially in varying local contexts, the method offers significant benefits in enhancing engagement and co-creation of solutions in cancer care. The approach requires adaptability and a focus on building trust to be effective across different regions and demographics.

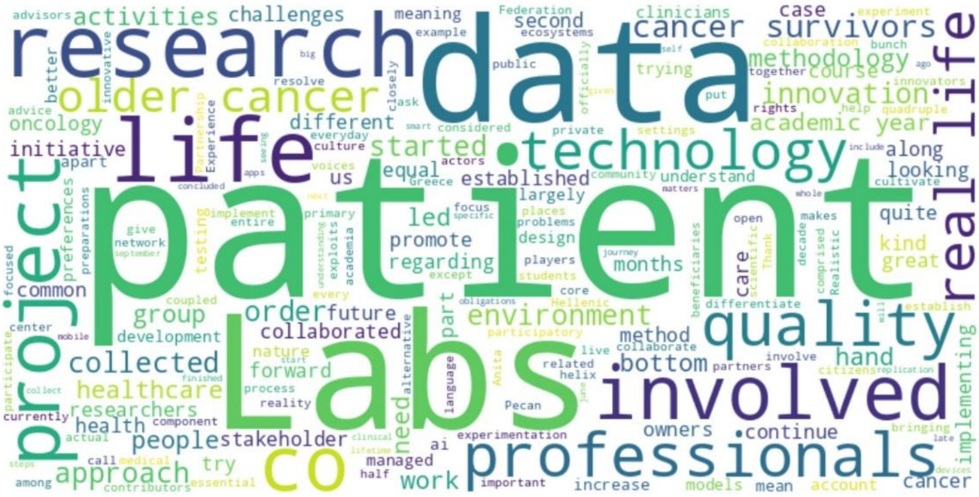

Figure 1. Wordcloud of living lab interview

Example of wordcloud to go with each interview, in this case words most mentioned by experts, on interviews on living labs:

Key Points from Interview with experts from the European Living Lab Network:

Definition and Key Characteristics of Living Labs

1. **Open Innovation Ecosystems**:
   - Living Labs are described as open innovation ecosystems that involve stakeholders in every part of the research and innovation process.
   - These ecosystems differentiate themselves by incorporating real-life experimentation and research in real-life settings with actual participants.

1. Stakeholder Involvement:

- A significant characteristic of Living Labs is the involvement of stakeholders, not just as advisors, but as equal partners in the research and innovation activities.
- This includes a wide range of participants such as citizens, public and private sectors, and academia, reflecting the Pentahelix Model in line with the EU Mission on Cancer

2. **Bottom-Up Approach**:
   - The Living Labs methodology promotes a bottom-up approach, emphasising the active participation and engagement of the primary beneficiaries of the research.

Examples of Living Labs in Cancer Research (see USE CASES below for more details)

1. **Partnership Experience in Cancer (PECAN)**:
   - This initiative established the first oncology-focused Living Lab in Greece, which is patient-led.
   - It involved patients, healthcare professionals, medical students, and researchers working together for an entire academic year to address

  - problems and challenges related to the everyday living and quality of life of cancer patients.
  - The goal was to cultivate a common language and culture among all stakeholder groups and to establish a patient-led Living Lab.

2. **LifeChamps Project**:
   - This project focused on the development of AI models and big data to improve the quality of life of older cancer survivors.
   - It involved collecting data through smart devices, mobile apps, and self-reports to understand what quality of life means for older cancer survivors.
   - The project emphasised the importance of involving patients from the beginning, including in the testing and adoption of technology in their own environments.
   - Collaboration with healthcare professionals was also crucial to co-create solutions that consider both patient and clinician preferences, enhancing communication and understanding of patient-generated data.

Benefits of Using Living Labs

- **Increased Stakeholder Engagement**: By involving stakeholders as equal partners, Living Labs foster greater engagement and ownership among participants.
- **Real-Life Context**: Experimentation and research in real-life settings provide more relevant and applicable insights.
- **Enhanced Communication**: The method improves communication and understanding between patients and healthcare providers, leading to better co-created solutions.
- **Inclusiveness**: Living Labs can engage vulnerable populations and ensure their voices are heard, promoting inclusiveness in research and innovation.

Challenges and Considerations

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- **Complexity of Cancer Research**: Cancer is seen as a sensitive issue, often associated only with clinical research. The broader scope of cancer research, including prevention and quality of life, can benefit from the Living Labs approach.
- **Resource and Contextual Factors**: The maturity of implementing Living Labs varies across countries, influenced by local contexts and available resources. There is a need for adaptable methods to fit different local contexts.

- **Inclusiveness in Practice**:
    - Engaging vulnerable populations, such as older adults and those in rural areas, remains a challenge.
    - Living Labs must develop methods to include these groups effectively.
    - **Example**: In the LifeChamps project, involving older cancer survivors and ensuring their participation in technology adoption was key.
    - **Example**: In PECAN, involving cancer patients directly in the research process to address their specific needs and challenges.

Trust and Its Importance in Living Labs

- Trust between citizens and clinicians or researchers is crucial for the success of Living Labs.
- In regions with high trust in clinicians, such as Greece, leveraging this trust can facilitate greater patient engagement.
- **Example**: In Greece, patients tend to trust their clinicians, which aids in engaging them in Living Lab projects.
- **Building Trust**: Personal communication, regular engagement, and acknowledging participant contributions help build and maintain trust.
- **Sustainable Engagement**: Creating a sense of community and belonging among participants can lead to long-term engagement and participation.

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Recommendations for Future Use

- **Adaptability**: Different tools and methods should be used to engage various stakeholder groups, ensuring information is accessible and understandable for all.
- **Dedicated Roles**: Having dedicated roles, such as a panel manager, can help maintain engagement and communication with participants.
- **Sustainable Engagement**: Building a sense of community and belonging among participants can lead to long-term engagement and participation. This can be done for example, by inviting participants, the community, citizens, to dedicated events or reunions (without any work involved) regularly to say thank you and spend time together and build a connection.
- **Practical Implementation**: Researchers who aim to use this method can join the annual conference on living labs, where hands-on experience and real-life applications are explored to fully understand and utilise the Living Labs methodology. Learning focus on by doing is also a recommended approach by the interviewees.
- **Inclusiveness**: Ensure to leverage all possible tools and resources to achieve inclusivity of all demographics (to the most possible extent), including those often marginalised, such as older adults, rural populations, and those of lower socioeconomic status.

Key Insights on Inclusiveness

- **Inclusiveness in Practice**:
    - Engaging diverse populations, such as older adults and those in rural areas, was a significant focus.
    - Methods were adapted to include these groups effectively, ensuring their voices were heard.
    - **PECAN**: Direct involvement of cancer patients in research processes addressed their specific needs and challenges.
    - **LifeChamps**: Older cancer survivors' data and feedback were crucial in developing and refining AI models and technologies.

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Conclusion

The experiences shared in the interview highlight the effectiveness of the Living Labs methodology in cancer research. By involving stakeholders as equal partners and focusing on real-life contexts, Living Labs can address practical challenges and enhance the quality of life for cancer patients. The method's emphasis on inclusiveness and trust-building is crucial for its successful implementation and sustainability.

USE CASES

1. Partnership Experience in Cancer (PECAN)

- **Objective**: Establish the first oncology-focused Living Lab in Greece, which is patient-led.
- **Participants**:
    - Cancer patients
    - Healthcare professionals
    - Medical students
    - Researchers
- **Activities**:
    - An alternative research group was formed, comprising various stakeholders, to address everyday living and quality of life issues for cancer patients.
    - The group worked together for an academic year to identify and resolve problems and challenges faced by cancer patients.
    - Emphasis was placed on cultivating a common language and culture among all stakeholders involved.
    - Patients were not only participants but co-owners of the research process, having both rights and responsibilities.

- **Outcomes**:
    - Creation of a patient-led Living Lab infrastructure.
    - Development of a research agenda with needs and solutions raised by patients, intended to be used as an advocacy tool with policymakers.
    - This approach highlighted the innovative aspect of involving patients deeply in the research and decision-making processes.

2. LifeChamps Project

- **Objective**: Improve the quality of life of older cancer survivors using AI models and big data.
- **Participants**:
    - Older cancer survivors
    - Healthcare professionals
- **Activities**:
    - Data was collected through smart devices, mobile apps, and self-reports, focusing on what quality of life means to older cancer survivors.
    - Patients were involved from the beginning, including in the testing and adoption of technology in their own environments.
    - Healthcare professionals collaborated closely to co-create solutions, considering both patient and clinician preferences.

- **Outcomes**:
    - Technology was tested in real-life environments (patients' homes) for three months, providing valuable insights into challenges and barriers to technology adoption for older cancer survivors.
    - Enhanced communication between healthcare professionals and patients, with professionals better understanding patient-generated data.

- The project emphasised the importance of real-life context and inclusiveness in the research process.

7.References

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