

EMPOWERING VOICES: COLLABORATIVE USER BOARDS AS A MODEL FOR INCLUSIVE CANCER PREVENTION

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Summary: Engaging patients, the public, and stakeholders meaningfully is vital for equitable and effective cancer policies. Initiatives like CBIG-SCREEN and ECHoS demonstrate participatory approaches that build trust, legitimacy, and sustainable solutions, particularly for marginalised groups. Barriers to engagement remain including geographic, economic, and institutional constraints, as well as mistrust and power imbalances. Therefore, tailored strategies are essential for addressing these challenges. This article examines how Collaborative User Boards work to overcome contextual challenges and ensure diverse representation within participatory cancer research. It also highlights why overcoming hierarchies is necessary for co-design to work and flourish.

Keywords: Stakeholder Engagement, Participatory Approaches, Marginalised Communities, Health Equity, Cancer Policies

Introduction

Cancer remains a formidable global health challenge, necessitating strategies that effectively prevent and manage its impact on diverse populations. The story of cervical cancer is one of success, initially due to the implementation of population-based screening programmes and, subsequently, through immunisation against the Human Papilloma Viruses that cause it (see Bhatia et al. in this issue).¹ Yet, despite the existence of well-designed screening programmes in many countries,² certain vulnerable groups face persistent barriers,³ including stigma, mistrust, and socio-economic

disadvantage, impeding access to services. Few countries have developed dedicated policies designed to broaden coverage among groups at particularly at high risk.⁴ Addressing these barriers requires a shift in policy and practice, placing community and patient engagement at the forefront.

Community engagement is vital if we are to overcome the persisting systemic inequities in cancer prevention and treatment.⁵ ⁶ Without it, marginalised populations risk exclusion from policies meant to serve them, perpetuating health disparities.⁷ In this paper, we describe the experience of one form of engagement

implemented within a European Union-funded project, CBIG-SCREEN, prioritising public and patient engagement to find sustainable, inclusive solutions for challenges in cancer policy.

CBIG-SCREEN seeks to increase cervical cancer screening among women in vulnerable situations across Europe.¹⁰ A core element is the creation of Collaborative User Boards (CUBs), dynamic, participatory spaces that bring together stakeholders from multiple levels to co-design solutions. CUBs operate as advisory boards, learning environments, and focus groups, facilitating dialogue among local governments, healthcare providers, and communities. Experience with the CUBs illustrates how participatory frameworks can address the many challenges involved in including disadvantaged groups, providing a replicable model for inclusive cancer prevention strategies that align with the objectives of ECHoS and the European Union's Cancer Mission, in particular the need to reduce systemic inequities in access to care.¹¹ They help bridge the gap between grassroots realities and high level policies.

The Policy Imperative for Community Engagement in Cancer Prevention

The EU Cancer Mission, part of Europe's Beating Cancer Plan,¹⁰ underscores the importance of reducing inequities in prevention, diagnosis, and care. In cervical cancer screening, participation gaps are often linked to structural and societal barriers, including language, cultural differences, and economic constraints. These obstacles disproportionately affect ethnic minority women, rural populations, and economically disadvantaged groups, leading to lower screening uptake.¹¹

Community and patient engagement provide an opportunity to challenge these disparities by fostering trust, dismantling stigma, and ensuring culturally appropriate care. Policies informed by meaningful community input can encourage uptake of preventive measures, improve health literacy,¹¹ and enhance the legitimacy of interventions.¹²

Box 1: Efforts to counteract unequal representation: Collaborative User Boards

Collaborative User Boards (CUBs) are currently being implemented as part of HORIZON EUROPE and EU4HEALTH projects across several EU countries, including Portugal, Estonia, Lithuania, Romania, Bulgaria, Poland, France, Denmark, Italy, and Ireland. These boards aim to engage patients, the public, practitioners, and policymakers to share their experiences and perspectives. By doing so, they help identify context-specific solutions to barriers in cancer screening, thereby reducing risks often associated with healthcare interventions' preparation and implementation.

CUBs are an innovative methodology combining elements from advisory boards (for consultancy), learning spaces (to foster mutual learning, intra-group inspiration, and local support), and focus groups (using prompting techniques, interaction, and recorded data for analysis). This approach was developed in 2019 as part of the EU-funded CBIG-SCREEN project, which seeks to improve access to cervical cancer screening for women in vulnerable situations across European countries.

Collaborative User Boards have the following key features:

- **Eliciting Voices and Perspectives:** The process ensures representation from all stakeholder levels – macro (policy), meso (practitioner), and micro (community) – to identify barriers and propose solutions to healthcare interventions.
- **Promoting Learning and Commitment:** This approach fosters mutual understanding, collaboration, and stakeholder engagement by facilitating discussions within diverse groups.
- **Enabling Cross-Country Comparison:** The methodology collects comparable data across different countries to inform European-level policy recommendations while allowing for local adaptation. An analytical framework supports this cross-national comparison.
- **Stakeholders gather in facilitated sessions to discuss their perspectives, ensuring that all voices are heard and documented. The CUB process is a “consultancy process involving macro, meso, and micro-level stakeholders to identify barriers and solutions to proposed interventions through structured discussions.”**

Due to varying hierarchical structures in participating countries, the implementation of CUBs has differed significantly. In Denmark, where the methodology originated, including stakeholders from all levels in the same discussions was feasible. In other countries, however, practical and contextual constraints meant stakeholder levels were often engaged separately. In most cases, interactions occurred between the meso- and macro-levels or between the meso- and micro-levels. Despite these differences, the approach maintained its core goal of fostering inclusivity and collaboration across contexts.

This flexibility highlights the importance of tailoring engagement processes to fit local realities while maintaining overarching objectives. CUBs represent a promising model for integrating diverse perspectives into healthcare interventions, advancing inclusivity and effectiveness locally and in Europe.

The CUB model recognises that participation must be more than just tokenism. It creates a platform where diverse stakeholders engage as equals, addressing power imbalances often hindering meaningful dialogue (see Box 1). By involving diverse voices

in decision-making, CBIG-SCREEN has fostered a sense of shared ownership and transparency, creating momentum for emerging initiatives.¹³ For instance, CUB-facilitated discussions in Estonia enabled local government representatives

and women from the Russian-speaking minority to address misunderstandings about cervical screening letters, leading to tangible improvements in communication strategies (see Box 2). Meanwhile, in France (see Box 3), they helped overcome resistance to engage with underserved communities. The participatory action research model employed in Ireland (see Box 4) further underscores the value of collaborative design, as initiatives like the Invisible Spectrum Program effectively engaged ethnic minority women using bilingual materials and trusted community ambassadors.

Structure and Operation of CUBs

CUBs have at least three functions. They act as advisory boards, identifying barriers to screening and recommending actionable solutions. They provide learning spaces, encouraging mutual understanding between policymakers, healthcare providers, and communities. And finally, they serve as focus groups, collecting qualitative data to inform tailored interventions. A CUB meeting takes place in-person with attendance by two to four stakeholders from macro (policy), meso

(practitioner) and micro (community) levels. The number of stakeholders on each level is flexible and must consider power imbalances. In this way, it can be better to have two from the macro level and four from the community level than vice versa. The meeting is held in-person and lasts 1.5–2 hours. Like a focus group session, it follows a topic guide (see Box 5)

The CUB meetings can take place several times depending on the topic, thereby functioning, in effect, as advisory boards.

They are designed to align with local structures and contexts, recruiting participants through outreach to community organisations, healthcare institutions, and advocacy groups. Recruitment prioritises the inclusion of marginalised voices, ensuring representation from all levels.

Facilitators play a critical role in setting up CUBs, often engaging trusted community leaders to build credibility and encourage participation. Proactive strategies, including in-person visits and culturally

sensitive communication, address recruitment challenges, such as mistrust or logistical barriers.

Each CUB session is carefully structured to foster mutual learning and collaboration. Facilitators, often with social science or public health backgrounds, employ techniques to ensure all voices are heard. This includes breaking large groups into smaller discussions, using culturally appropriate language, and valuing lived experiences alongside professional expertise. These procedures are discussed further in the Estonia and French examples (see Box 2 and Box 3).

Challenges of implementing CUBs

Implementing Collaborative User Boards (CUBs) has revealed several challenges, highlighting the complexities of fostering inclusive participation. One of the most significant obstacles is the presence of power imbalances within the CUBs. Hierarchies often emerged, with healthcare providers or other authority figures inadvertently dominating discussions, which can marginalise the voices of

Box 2: Collaboration with the CUB in Estonia

Collaboration with CUBs in Estonia played a crucial role in the development of the CBIG-SCREEN intervention, ensuring a community-driven and culturally sensitive approach.

Regular meetings and transparent communication through skilled facilitators were key to designing an effective study and recruiting participants. This approach ensured that stakeholders stayed engaged and informed, enabling meaningful collaboration.

CUBs were pivotal in accessing participants. Their trusted community relationships greatly improved recruitment and engagement. Beyond advocacy, they provided insights into cultural sensitivities and potential biases, helping shape a respectful, inclusive approach tailored to community needs.

CUB members also contributed to study documents, ensuring consent forms, information sheets, and questionnaires were accessible, clear, and jargon-free. They participated in pilot testing, identifying issues with comprehension, wording, and sensitivity, which improved the materials' effectiveness.

Throughout the process, CUBs were active and responsive to challenges and opportunities. Macro and meso-level members openly shared perspectives, while micro-level challenges

included encouraging participation, addressing hesitancy in smaller towns, and raising awareness about cervical cancer in areas with low screening rates.

The intervention which was then created, in part through this process, aims to improve participation in cervical cancer screening by sending an opt-out self-sampling kit along with the screening invitation letter. The package also includes a questionnaire, a leaflet explaining HPV test result interpretation, and information on the cervical cancer screening pathway. The study population consisted of women living with HIV in a low-participation county. To ensure the materials were appropriate and accessible, representatives from this population were involved in developing and refining the study materials and wording.

Co-creation was essential to the study's success. Incorporating diverse perspectives fostered trust and made the intervention relevant to the target population. Reflecting community input increased acceptance and enhanced the likelihood of developing an effective, culturally appropriate intervention aligned with community needs.

Box 3: CUBs in France

France is a highly centralised country where public health policy, including the organisation of screening programmes, is decided at national level by the General Directorate of Health. The regional structures, which are responsible for operational management, have no power to decide on the adaptation of organised screening programmes. In addition, the organisation, management and monitoring of screening programmes involve several national actors in different roles: the French National Health Authority, the French National Cancer Institute and Santé Publique France.

Time constraints limited recruitment to the Paris area and reduced the intended participant diversity. Although potential stakeholders were identified through the WP2 survey, engagement varied significantly. Macro-level stakeholders were particularly reluctant, often declining participation and citing concerns about impartiality.

Recruiting micro-level stakeholders, through NGOs working with underserved populations, was time-intensive. Many were

unresponsive to emails and calls, necessitating repeated phone calls and in-person visits to secure responses. In contrast, meso-level participants were more receptive due to established relationships, which helped balance the recruitment process.

The facilitators, with social science and public health backgrounds, worked effectively together to create a safe space for women to share openly. They clarified roles and anticipated challenges in advance, using humour to ease discussions and limiting their involvement to timekeeping. However, hybrid participation during the second session was challenging, reducing the involvement of some online NGO representatives.

Micro-level stakeholders responded positively, expressing a sense of duty to help improve access to cervical cancer screening for vulnerable women. Macro-level responses were less favourable. While the CUB did not alter the project since France is not an intervention country, it inspired meso- and micro-level discussions on collaboration and influenced meso-level stakeholders to reconsider projects on cervical cancer and care access.

Box 4: Ireland experience of participatory action research to improve access

The Invisible Spectrum programme is an annual engagement initiative designed to improve healthcare accessibility and research participation among ethnic minority communities in Ireland, particularly those of Bangladeshi origin. This programme was developed in response to the traditionally low levels of engagement with healthcare services observed within these communities, aiming to empower them in their healthcare decision-making. Aims of the programme include raising awareness of cancer symptoms, encouraging uptake of cancer screening, improving communication between attendees and the medical/scientific communities and promoting research participation among the attendees.

The programme employs a participatory action research design, which involves community members, activists, and

scholars in co-creating knowledge and social change. This approach ensures that the programme is tailored to the specific needs and cultural contexts of the community. A significant aspect of the programme is its reliance on oral communication networks, recognising the importance of “word of mouth” in minority communities. Over four years, the Invisible Spectrum programme has evolved based on feedback from attendees, with each iteration focusing on different thematic areas. The programme includes bilingual materials and live translation to overcome language barriers, and it involves community leaders as ambassadors to build trust and facilitate participation. The programme’s success is attributed to its collaborative structure and co-design process, which have strengthened ties with the community and increased engagement. The Invisible Spectrum serves as a model for similar initiatives aiming to enhance minority inclusion in cancer healthcare and research.

Source: ¹⁴

community participants. In France, for example, CUBs faced initial resistance from macro-level stakeholders, such as policymakers, who feared impartiality issues. However, persistent engagement led to productive dialogues with meso-level stakeholders, such as NGOs, resulting in targeted outreach to underserved women (see Box 3). Facilitators addressed this by actively encouraging quieter members to share their views and emphasising the unique value of lived experiences to the overall discussion. In Estonia,

CUB members provided critical input on consent forms and information sheets, ensuring materials were clear and respectful of cultural sensitivities.

Another challenge lies in the recruitment of vulnerable populations. Engaging these groups required extensive effort, as many were initially distrustful of institutions or unaware of the programme. Persistent outreach, including personalised communication and collaborations with

trusted local leaders, proved crucial in overcoming these barriers. Additionally, resource limitations posed difficulties, particularly in hybrid sessions where technological disparities made it challenging for some participants to engage effectively. Bridging these gaps remains a priority for the programme.

Successes of CUBs

Despite these challenges, CUB implementation has achieved significant success. Campaigns co-designed with input from CUB members successfully reduced the stigma around Pap smears, particularly in rural communities, where misconceptions about the procedure had previously hindered participation.

Establishing trust between community members and stakeholders also emerged as a key achievement. Transparent communication and visible action on CUB recommendations fostered a sense of shared ownership, encouraging sustained engagement. Furthermore, insights generated through the CUBs influenced local and national policies, demonstrating the transformative potential of participatory approaches in shaping effective cancer prevention strategies.

Multilevel Engagement: Macro, Meso, and Micro Perspectives

The CUB framework illustrates how engagement can operate effectively across macro, meso, and micro levels. At the macro level, policymakers used insights from CUB discussions to develop broader health policies and allocate resources more effectively. At the meso level, healthcare providers adapted their practices based on direct community feedback, leading to improved service delivery. At the micro level, community members actively designed and implemented interventions, ensuring that these measures were culturally relevant and accessible.

CUBs have facilitated a deeper understanding of the barriers to cervical cancer screening, yielding several critical insights. Open discussions about cervical cancer within these boards helped to destigmatise the topic, empowering women to prioritise their health. The co-creation of culturally tailored materials and outreach strategies ensured that the initiatives resonated with diverse communities, significantly improving their effectiveness. Participants often became advocates within their own networks, amplifying the programme's impact and extending its reach. In this way, CUBs

Box 5: Excerpt from a CUB topic guide

- What specific aspects of the (topic) are you particularly **interested in or concerned about?** Why?
- What are your **expectations** for the outcomes of the (topic)?
- What potential **challenges** do you foresee in the implementation of the (topic)? Why?
- How would you prefer to **give/receive information** about the (topic)?
- How can we ensure a **positive experience for patients** in relation to the (topic)?
- Are there considerations or strategies to enhance accessibility for **diverse populations** (vulnerable populations, ethnic minorities, transgender people)?
- How can we best **collaborate** to ensure the success of the (topic)?
- What **coordination** mechanisms do you think would enhance the effectiveness of the implementation?
- What specific **resources** (financial, human, technological) do you believe are crucial for the (topic)?
- How can we ensure effective engagement with the **community** during the implementation of the (topic)?
- What strategies do you think would be most effective in **reaching and involving** community members?
- How would you prefer to provide feedback on the ongoing implementation?
- What do you think should be considered for the **long-term sustainability** of the (topic)?
- How can we plan for **continuous** improvement and adaptation based on evolving needs?

extend beyond traditional meeting spaces, creating dynamic and impactful learning environments

Another powerful example of multilevel engagement comes from Ireland, whose “Invisible Spectrum” programme leveraged a multilevel engagement framework to engage Bangladeshi women, addressing cultural barriers through bilingual materials and live translation services. This multilevel approach enhanced the program's relevance and ensured broader acceptance and participation among the target population (see Box 4).

Conclusion

The success of CUBs underscores their potential as a cornerstone of cancer prevention strategies. By fostering inclusive, participatory spaces, CUBs address the systemic inequities that hinder cervical cancer screening. Their integration into National Cancer Mission Hubs can promote community engagement as a standard practice, amplifying the voices of people, communities, and civil society in cancer prevention and care. To achieve sustainable change, cancer policies must embrace the principles demonstrated by CUBs. Prioritising patient and community engagement ensures that interventions are not only effective but also equitable, paving the way for a future where no one is left behind in the fight against cancer.

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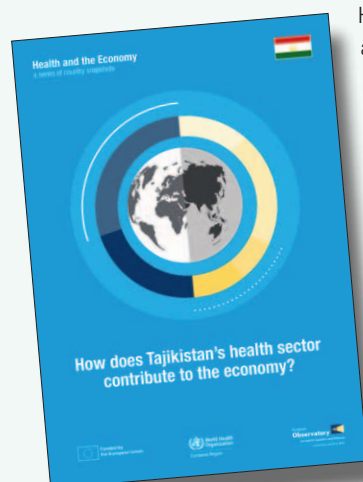
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