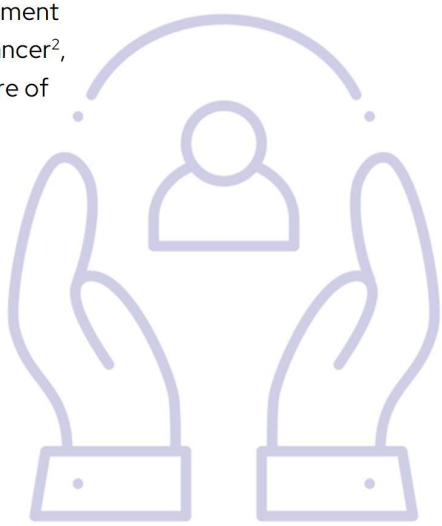
POLICY BRIEF

Structural patient and citizen engagement as a catalyst for better care, research and policy making in cancer

This policy brief outlines the need for more structural patient engagement in Belgian healthcare and research. It highlights the limited capacity and funding of Belgian patient organisations compared to neighbouring countries. The brief argues that stronger patient involvement can improve healthcare outcomes and policymaking.

In Belgium, the most relevant reports on the need for greater patient engagement were produced by the King Baudouin Foundation[1], the Foundation Against Cancer[2], the Belgian Association of Hospital Directors[3] and the Think Tank on the Future of Healthcare[4], and have served as a basis of the analysis in this brief. All these reports have been the result of multistakeholder engagement, including specialists, hospitals, industries, policymakers, sick funds and patient organisations. The government agreement[5] also emphasises the importance of patient organisations and the need to recognise them formally and to set up a structural funding mechanism (p. 110). At the European level, the JANE patient involvement toolkit[6] was developed to provide methodological support.



In Belgium, structural patient engagement is slowly on the rise, for example through patient advisory boards in Brussels[7], Ghent[8] and Antwerp[9] or the allocation of research funds at Kom op tegen kanker[10]. However, our neighboring countries go a lot further. : For example, in the UK, in the field of genomics and health, the Health and Care Act 2022 makes structured public and patient involvement obligatory for research projects seeking funding. In the Netherlands[13] researchers must justify why they would not involve patients.

Patient engagement can help individual patients, but also help organise our healthcare system to become much more effective and efficient. Only patients can properly testify whether the healthcare system has successfully transformed their needs into outcomes. Yet today, many cancer patient organisations lack the capacity and financing to survey their members about their collective experiences and needs, and even when they do, there is no formal process in the healthcare system to systematically share the data. The absence of this much-needed feedback from the end-users of our healthcare is possibly the biggest blind spot in the system.

Patient organisations should be able to work in a more professional format than today. According to a recent report[14], 54% of Belgian patient organisations have an annual revenue of less than 10,000 euro. This limits the potential value of patient organisations to be the consistent advocacy organisations and patient support organisations that they represent in other EU countries. In the Netherlands, every patient organisation can

apply for structural funding of approximately 50,000 euro per year[15], with additional project money for valuable initiatives[16]. The Dutch equivalent[17] of the Patient Expert Center which trains patients for professional interaction with stakeholders, has a government supported budget of 5.5 million euro. In Belgium, funding for patient organisations is centralized in umbrella organisations (VPP and LUSS) who are able to do important policy work regarding the role of the patient in the Belgian healthcare system, but provide limited or no disease specific support and advocacy.

KEYWORDS
Ethics
Participation
Co-design

GAPS & RECOMMENDATIONS

Leveraging patient organizations

In Belgium, the healthcare system does not sufficiently leverage patient organisations as a structured source of information and expertise, which limits the identification of key issues in cancer care and hinders the systematic improvement of care quality.

No formal and systematic structure to report and remediate issues experienced by patients, causing many of these issues to remain under the radar of the healthcare system (e.g. misdiagnosis, the time between first symptoms and a correct diagnosis, lack of information, sub-optimal treatment leading to complications and consequences, inadequate consideration of co-morbidities, etc.).

The lack of patient-relevant data. Other issues are never questioned because the question about getting the patient-relevant data is never asked (e.g. Belgium lacks data on mortality linked to malnutrition or sepsis in cancer patients, despite international evidence showing their relevance). If we do not have the relevant data, there will never be anyone looking for a solution. Because patients experience the issues, they can ask to investigate certain aspects so that all patients with the disease can benefit. Patient organisations are always on the look-out for existing data and benchmarks to identify where the best care outcomes are being generated.

RECOMMENDATIONS

- **Leveraging patient organizations to provide services for better cancer care** by
  - Disseminating information
  - Acting as patient navigators
  - Providing peer support
  - Involving patient experts

- **Work towards formal recognition[18] of patient organizations as potential service providers in the healthcare system, including clear quality criteria :**
  - Recognition of patient expert and patient navigator as secondary occupation in the context of association work (art 17 of Social Security resolution of 28 Nov 1969). This may help to make social work more attractive and help cover the current workforce problems in healthcare.
  - Having cancer patient volunteers requires education, training, coordination and a dispatching system. This could significantly help the shortage of staff in some areas of cancer care.
  - Necessary support (financial and logistical) so that patient organisations can work in an independent and transparent way. LUCAS is working on a scientific study about effective financing for patient support groups.

- **Formal collaboration models and instruments between hospitals and recognized patient organizations**. The Patient Expert Center has already co-designed some of these collaboration models with hospitals who volunteered to participate. Yet much more can be done, allowing to add quality services and reduce the burden for hospitals (by developing shared services, decision-aids, checklists, information kits, and by taking over some of the information and navigation tasks).

Patient contributions

A major gap remains in the lack of structured and meaningful patient involvement in cancer research and healthcare decision-making. Patient expertise is still insufficiently integrated into research prioritization, funding, and professional training.

The lack of structured and meaningful patient involvement in cancer research and healthcare decision-making.

RECOMMENDATIONS

- Maximizing patient contributions to cancer research **by supporting co-design, structured recruitment efforts and involvement in the allocation of research funding.**
- **Structural patient involvement :**
  - Patients should play a role in the allocation of research prioritisation and funding.
  - The role of patient advisory boards within hospitals should be clarified and be made more disease-specific.
  - Proportional funding for contributions to health care, policymaking and research by patients and patient organizations.
  - Involve patient experts in the training of health professionals and researchers.

Policy making with patients

Patient organizations remain underrepresented in policymaking due to limited capacity, funding, and formal support. Stronger structural collaboration is needed to integrate patients' lived experiences into cancer policies.

In general, most patient organisations do not have the knowledge or capacity to participate in all policy working groups (in contrast to industry, sick funds, pharmacists, doctors, researchers, ...). The patient representatives are not properly remunerated for their participation, and very often there is no consideration that they have to take a half day off to participate in working groups during work hours. As a consequence, patients are generally under-represented in policy working groups of government agencies.

RECOMMENDATIONS

- **Co-design with specialists and experts a plan for each type of cancer** with a list of Key Performance Indicators from prevention to end of treatment, to be annually discussed and course-corrected if needed
- **A formal policy contact** point where cancer patients could share their positions and improvement points with government agencies
- **Proportional and appropriate funding of patient organisations,** in line with other healthcare stakeholders, would allow to fully and qualitatively integrate the collective 'lived experience' of cancer patients in policy making at all levels

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