



Joint Action on Networks of Expertise

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Toolkit for patient empowerment and engagement in different contexts and for different subjects

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RECIPIENTS OF THIS DOCUMENT

This document is addressed to the whole JANE consortium. It is an official deliverable for the project and shall be delivered to the European Commission and appointed experts.



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Executive summary

This deliverable is the product of the activities in JANE Transversal Taskforce 5, patient involvement. This work culminated in the creation of a patient involvement [toolkit](#). This toolkit aims to support networks of expertise in the maximization of benefits, optimal management of downsides and practical organization of patient involvement initiatives. It was created with a diverse, international, group of patient representatives and patient organizations during interviews and a workshop. The toolkit follows a layered approach, with each layer offering more in-depth information, ending in references to practical examples or theoretical/academic sources.

The toolkit is designed for practical utility. It explains why it is important to adapt patient involvement to specific contexts and how to do it. It includes a list of potential partners to be contacted for patient involvement initiatives. It refers to best practices and concrete examples of previously successful projects.

The report ends with a list of concise recommendations for patient involvement in networks of expertise based on the work done within JANE TTF 5.

Introduction

This report is background information for the JANE TTF 5 patient involvement [toolkit](#). It aims to describe the methods used to build the structure for the toolkit and the collection of experiences from patient representatives and patient organizations.

Since the work to support the networks of expertise in the area of patient involvement was conducted while the networks themselves were being defined, the TTF focused on the general needs of cancer patients and patient representatives as a starting point for the guide. In a later phase, when it became clearer what the networks would look like in practice, this work was translated into a pragmatic toolkit. The report is purposely short as all the content of the TTF 5 work is presented in the toolkit, which is designed to be a standalone feature.

Methodology

This toolkit is the product of a multidisciplinary process of co-creation. The main goal was to enable patients and patient organizations themselves to define what patient involvement should look like in networks of expertise on cancer. To this end, interviews were set up with different patient organizations at European, national and local levels to collect best practices, concrete examples and experiences. A workshop with representatives from 35 patient organizations resulted in the identification of several broadly shared basic values and some remaining areas of tension. The input from patients and patient organizations was complemented by targeted searches of the academic literature on patient involvement and reports about specific patient involvement initiatives.

Interviews with patient organizations

43 patient organizations from 18 countries were contacted. Many organizations responded by sharing documents and experiences, but in the end 14 organizations from 7 countries (Belgium (4), Bulgaria, France (2), Greece (2), Hungary, Italy (2), Europe (2)) proceeded to a full interview. In the interviews, the focus was on the tangible benefits and downsides of patient involvement projects, good and bad experiences with concrete projects, different methods to engage patients and ideas for best practices.

Workshop with patient representatives and organizations

On June 28, 2023, an in-person patient workshop was organized in Brussels with representatives from 35 patient organizations. The content from the interviews was used to determine two main topics for presentations to start the workshop:

1) Legitimacy in patient involvement

If experts or policy makers want to discredit the added value of patient involvement, they often refer to the lack of legitimacy of the patient perspective. Either the patient is ignorant about the medical or scientific reality, or the patient has become a patient-expert to where they can now no longer be considered as a true representative of the patient perspective. This, in combination with questions about the quality of methods used, the practical added value of engagement and the political nature of the topics discussed, leads to a situation where the legitimacy of involving patients or patient organizations is questioned.

2) Funding for patient involvement

Patients and patient organizations are often expected to participate in projects without getting any funding to compensate the time and effort they invest. Moreover, when there is funding, large umbrella organizations tend to have easier access to funding sources, but they may not always be the best equipped organizations to engage 'real' patients.

The workshop proceeded with a moderated interactive discussion in subgroups about two themes: 1) How should patients and patient organizations be engaged in cancer? 2) Which structures exist or should exist to support patient involvement?

During the discussion, moderators were making notes on a Miro board that was shared on a big screen. This allowed participants to verify and adapt the message that was retained after their intervention and different subgroups to interact with discussions that were going on in other groups. After the workshop, the Miro board was shared with all participants to verify the conclusions.

Desk research

The starting point for the toolkit was always input from patients and patient organizations. The desk research merely served to deepen points made by them or to research projects or experiences they mentioned.

Creation of the toolkit

The goal of the toolkit is to give an easily accessible overview of the practice of patient involvement as a whole. The toolkit was created with the professionals in the networks of expertise in mind as a starting point. What if they asked themselves 'I want to engage patients in our activities: what now?'. The toolkit is designed to offer insights in realistic expectations for benefits, barriers to overcome and concrete methods that are tailored to your specific needs.

The structure of the toolkit is based on the input of patients and patient organizations but translated to the needs of networks of expertise. To make the information as accessible as possible, a layered approach was used, focusing first on a clear overview of the core topics, and then adding layers of boxes with short texts to explain the content and detailed sources to help anyone get started with patient involvement.

The toolkit contains a list of potential partners in patient involvement practices at EU and national levels, based on the information gathered during the TTF5 activities.

State of play and mapping the future

Current situation and main issues identified

The toolkit can be found at the following links:

<https://www.sciensano.be/en/jane-patient-involvement-toolkit>

<https://jane-project.eu/patient-involvement-toolkit/>

All topics are clickable to be explored further.



When a topic is selected, the next level is accompanied by a short explanatory text. The final levels offer more in-depth explanations and further references and sources, including practical examples.



All you need to know about PATIENT INVOLVEMENT



The guide contains a list of potential partners to contact to start up a patient involvement project, structured per region:

Country	Name	Website
Europe	European Patients' Forum (EPF)	European Patients' Forum
	European Cancer Organisation	European Cancer Organisation
	EORTC (European Organisation for Research and Treatment of Cancer)	EORTC
	Youth Cancer Europe	Youth Cancer Europe
	Youth Cancer Survivors	Youth Cancer Survivors
	Cancer Patients Europe	https://cancerpatientseurope.org/
	Childhood Cancer International Europe	https://ccieurope.eu/
	Pancreatic cancer Europe	https://pancreaticcancereurope.eu/
	European Cancer Leagues (ECL)	European Cancer Leagues
Belgium	LUSS	La Luss

	Vlaams Patiëntenplatform (VPP)	Vlaams Patiëntenplatform
	Kickancer	Homepage KickCancer.org
	Kom Op Tegen Kanker	Kom op tegen Kanker
	Sciensano	sciensano.be
	Think Pink	https://www.think-pink.be/en/
	Patient expert center	https://patientexpertcenter.be/
	Fondation contre le cancer	https://cancer.be/
Bulgaria	APO3	АПО3
	Association Lymphoma	Българско Сдружение Лимфом
Croatia	Udruga Nismo same	Nismo Same
Czechia	National Association of Patient Organizations	https://www.eu-patient.eu/Members/The-EPF-Members/Associate-Member/napo---national-association-of-patients-organizations/
	ARCUS	ARCUS - onko centrum, zs
	Mamma Help	Mamma HELP
France	France Assos Santé	France Assos Santé
	Ligue nationale contre le cancer	Ligue contre le cancer
Germany	ILCO	Deutsche ILCO
	BRCA	https://www.brca-netzwerk.de//
Greece	ELLOK	ΕΛΛΟΚ
	Hellenik Cancer Society	https://www.cancerhellas.eu/en/home/
Hungary	Lelek-Zet	Lélekzet Egyesület
	Magyar Rakellenes Liga	Magyar Rákellenes Liga
Italy	FAVO	F.A.V.O.
	AIMaC	Aimac
Lithuania	Teviskes Namai	Dzūkijos savanoriai
	POLA	POLA
Malta	Europa Donna Malta	Europa Donna Malta
	Hospice Malta	For Patients Hospice Malta
Netherlands	Patiëntenfederatie Nederland	https://www.patientenfederatie.nl/
Norway	Norwegian Cancer Society	Front page - Norwegian Cancer Society

	CarciNor	<u>CarciNor</u>
Poland	Rakiety	Fundacja Onkologiczna Rakiety
	PUO	Polska Unia Onkologii
Portugal	Liga Portuguesa contra o cancro	Liga Portuguesa Contra o Cancro
	Viva Mulher	VIVA MULHER VIVA
Romania	FABC	Federatia Asociatiilor Bolnavilor de Cancer
	M.A.M.E Association	Asociatia M.A.M.E.
	Asociatia Redescopera Fericirea. Stop Cancer	Asociatia Redescopera Fericirea organizatie non-guvernament pentru sustinerea persoanelor diagnosticate cu cancer
	Asociația Little People România	https://www.thelittlepeople.ro/en/
Slovenia	Slovensko onkološko društvo (Slovenian Oncology Society)	Institute of Oncology Ljubljana - Home
	DOBS	Društvo onkoloških bolnikov Slovenije
Spain	GEPAC	GEPAC
	Data for patients	https://www.dataforpatients.com/
	AECC	Asociación Española Contra el Cáncer

Changes to be achieved

The guide is meant to support the implementation of patient involvement activities in the networks of expertise on cancer. Several work packages in the JANE2 project refer to patient involvement initiatives. In an ideal world, the experiences from these initiatives will feed the guide over time so it can help increase the effectiveness and impact of patient involvement initiatives across networks of expertise. To this end, all work package and task leaders of the JANE2 consortium can become editors at the backend of the guide.

Recommendations

- 1) There is not one ideal method for patient involvement: a toolkit approach is required, focusing on appropriate adaptation to contextual factors.
- 2) Patient involvement should not be seen as a strategy to sensitize, educate or otherwise manipulate patients. It is an effort to engage in an honest and open dialogue with patients, with the goal of co-creating new solutions.
- 3) Involving patients is an inherent good: patients should be involved because they are involved by definition.
- 4) Patients should be involved as early as possible, ideally from the agenda setting and design phase of a project, to ensure maximal impact and full transparency.
- 5) Networks of expertise should play a leading role in empowering patients through organized, structural patient involvement.
- 6) The JANE patient involvement toolkit offers all participants in networks of expertise a starting point to set up effective patient involvement in diverse projects.