



The Current Status of Patient and Public Involvement (PPI) in Japan and Its Potential in Supportive Care

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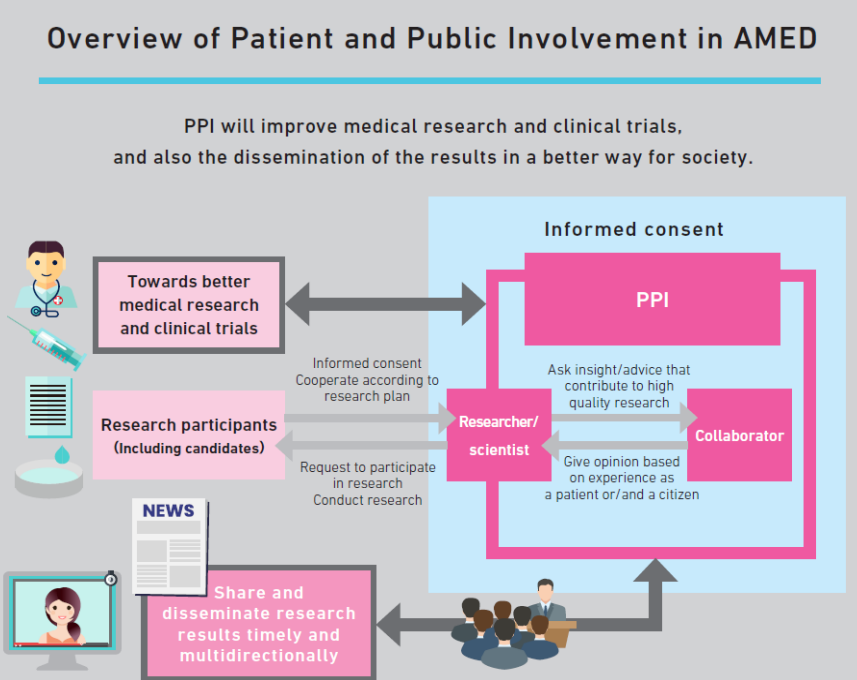


BACKGROUND

The healthcare environment has undergone significant transformations in recent years, marked by a shift in disease profiles towards lifestyle diseases and other chronic conditions. This evolution has normalized living with diseases and disabilities, positioning patients and citizens not merely as healthcare recipients but as active participants in managing their health. Various developments have resulted in initiatives for proactive patient and public involvement in healthcare, including advancements in science and technology, the occurrence of medical accidents, drug lag, and a growing recognition of ethical concerns in health research.

Shared decision-making (SDM) exemplifies this involvement, where healthcare providers and patients collaboratively decide on treatment directions. Patients and citizens are contributing not only as recipients but also on the provider side. Activities such as peer support, where individuals provide counseling based on their own experiences, and participation in external audit committees at advanced treatment hospitals illustrate this shift.

Their involvement is increasingly critical in medical studies, clinical and health guideline formulation, pharmaceutical and medical device development, and health policy. This diverse involvement in medical research is known as Patient and Public Involvement (PPI). "Participation" involves patients and citizens as research subjects, while "involvement" signifies their cooperation as research partners.



Patient and Public Involvement (PPI) in Research PPI Guidebook, Japan Agency for Medical Research and Development

INTRODUCTION/AIM

The involvement of patients in research, particularly in clinical settings, has increased significantly. Patient advocates play varying roles, from limited participation in trial eligibility and feasibility to comprehensive engagement as partners across all research levels. Activities they're involved in include focus groups, grant reviews, and clinical trial protocol review. Since 2009, the Japan Society of Clinical Oncology has initiated an educational program for patient advocate leaders. The 2018 Basic Plan to Promote Cancer Control in Japan advocates for patient and public involvement (PPI) to enhance cancer research, using patient advocates' knowledge to ensure research quality and patient safety. However, a deeper level of involvement is required, especially in supportive and palliative cancer care, aiming to advance PPI in research and practice.

METHODS

As of January 2024, the Japanese Association of Supportive Care in Cancer (JASCC) is establishing a group to increase patient and citizen involvement. The objective is to integrate insights from patients and survivors to augment supportive care research, benefiting both patients and healthcare professionals nationally.

Japanese Society of Clinical Oncology (JSCO)
Patient Advocate Leadership Program (PAL-Program)
JSCO : Committee of Social Network and Patient Advocate Leadership
Mission: To ensure that healthcare providers, together with patients and families, can work together and think on the same level to achieve the best practice in cancer care, participate in conferences to further improve future cancer treatment.

Japanese Society of Medical Oncology (JSMO)
Patient Advocate Program (PAP-Program)
Mission : To provide a platform for patients, families, citizens, and members to share accurate information, identify issues, and engage in discussions. To contribute to the realization of better cancer care.

Japanese Cancer Association (JCA)
Survivor Scientist Program (SSP Program)
Aim : By deepening the understanding of cancer research, 'research advocates' from the standpoint of cancer patients and their families can be nurtured to participate in cancer research. The collaboration between cancer researchers aims to promote cancer research and contribute to the improvement of cancer care.

Japanese Society for Palliative Medicine (JSPM)
Patient Advocate Lounge (PAL)
Aim : To acquire knowledge and the latest information on palliative care both domestically and internationally, deepen communication with participants, and apply to activities that promote, educate, and improve palliative care, as well as support patients, families, and bereaved ones.

Table 1. Patient Partnership Program in Japanese Societies on Cancer Care

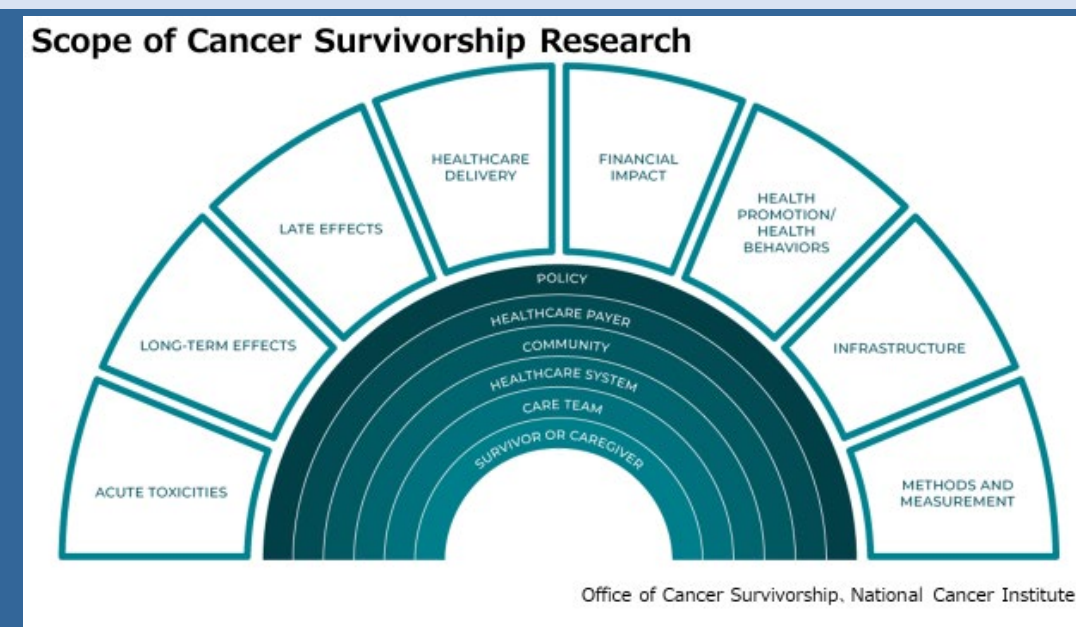
JASCC-PPI Working Group

Member : 4 Patient advocates, 2 doctors, one pharmacist

Aim : Promoting patient and citizen participation in supportive care research and practice

#1. To broadly incorporate the knowledge of patients and survivors in the planning, implementation, and dissemination of supportive care research

#2. To make cancer supportive care research effective and beneficial for patients and citizens, and to widely return the results to the public



RESULTS

While JASCC offers associate memberships, opportunities for patients and survivors to interact with medical professionals are limited. The JASCC-PPI working group intends to investigate the engagement of patients, survivors, and the public in supportive care, addressing their expectations and challenges. Starting in 2024, a training program will be launched to foster patient and public collaboration in cancer research. The involvement is particularly crucial in areas like improving quality of life, mitigating side effects, and addressing financial and social challenges in supportive care and survivorship research.

Action Plan of JASCC-PPI WG

#1. Short-term Goals :

Preparation and Promotion for the 9th Annual Meeting (#JASCC24)

#2. Mid-term Goals :

Cooperation with #JASCC committees, WGs

Research planning, implementation, evaluation, dissemination, etc.

Proposal to move from "associate member" to "partner member": co-work, collaborate, co-creation

Proposal for linkage with the education and training system (JASCC certification system, education program for advocates)

Survey targeting departments, WGs, and committees Current status of PPI, needs and challenges regarding collaboration and cooperation

Collaboration with MASCC PPI WG (unit of patient organizations / corporate collaboration and policy proposals, etc.)

CONCLUSIONS

Incorporating patient perspectives in research, practice, and information dissemination leads to improved and safer care. The JASCC PPI-working group, inspired by MASCC's approach, aims to work with various stakeholders, including patients and the public, to meet the unmet needs in cancer survivorship.

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