

Cancer Policy Summit Spring 2012

~ Uniting six voices as one to create better second-generation cancer control programs in every prefecture ~

May 11~13, 2012

Over 3 days from Friday May 11 to Sunday May 13, 2012, Health and Global Policy Institute's Cancer Policy Information Center hosted "Cancer Policy Summit Spring 2012" in Chiyoda-ku, Tokyo.

Coinciding with the planning process of each prefecture's next-stage Cancer Control Program, the Summit was held under the theme of "Uniting six voices as one to create better second-generation cancer control programs in every prefecture". A total of 140 people participated, including 65 current or former patient representative members of Prefectural Cancer Control Promotion Committees (or equivalent) and publicly active patient representatives drawn from 31 prefectures, 24 Prefectural Assembly members from 18 prefectures, 37 officials in charge of cancer control from 26 prefectures, and 14 chairpersons of Prefectural Cancer Control Promotion Committees (or equivalent) and physicians at designated cancer care hospitals in 11 prefectures. Moreover, representatives from industry, academia, media and elsewhere participated as observers.

In a workshop on cancer control planning utilizing data specially collected in advance, there was a passionate exchange of opinions extending well beyond individual standpoints. In addition, a "Special Session: Learning from the National Cancer Plan" was held with the cooperation of the Cancer Control Promotion Council and the Ministry for Health, Labour and Welfare, in which an explanation was given of the new national plan on cancer which the Cabinet is shortly expected to approve, drawing the close attention of participants gathered from across the country.

Learning how to make a plan to take back to each prefecture

At the Summit, participants studied the "how to" of planning for prefectural cancer control by following the 3 steps advocated in the first module of the WHO series on cancer control, "*Planning*": 1) understanding the current situation, 2) developing a plan around clear objectives, and 3) evaluating the plan's implementation.

Session 1, on "Understanding local circumstances", reaffirmed the importance of accurately appraising data, while Session 2 on "Gathering voices from patients, on-site, and locally" discussed effective methods of collecting frank, constructive opinions.

Session 3, "Assembling a plan", focused on use of a logic model in the process of considering the various steps necessary to realize policy objectives and ideal outcomes.

In Session 4, "Drawing up a schedule", a calendar was created of key activities and events in cancer control planning.

Throughout the entire program of sessions, the focus was always on providing and developing knowledge and insight that each participant could take away and put to immediate effective use in the cancer control planning process in their own prefecture.



Special Session "Learning from the National Cancer Plan"

In formulating a prefectural cancer control plan, it is important also to know and understand information on a national level.

Dr. Morito Monden, chair of the national Cancer Control Promotion Council, explained that in the country's 2nd Cancer Control Plan there will be an emphasis on evaluating quality, while Dr. Manabu Sumi of the Ministry of Health, Labour and Welfare's Cancer Control Office said that, although evaluation of the quality of a cancer control program is far from easy, the Ministry is working towards establishing clear indicators to facilitate this process.

Mr. Shinsuke Amano, who represents the patient's standpoint on the national Cancer Control Promotion Council while also serving as its acting chair, asked the other patient representatives at the Summit such motivating questions as "Are we saving all the lives that can be saved? How much could you achieve if you really devoted yourself to it?"

Finally, from Dr. Tomomitsu Hotta, appointed as Chief Director of the National Cancer Center from April 2012, there was an explanation both of the role played by the Center in drawing up the 2nd Cancer Control Plan, and aspirations for putting the seeds developed in the research laboratory to effective practical use in cancer care.



Special Program

Meeting of the National Diet Group of Cancer Patients and Relatives (bipartisan Diet caucus)

After the core issues were outlined by the group's secretary-general, Dr. Satoshi Umemura, there was an exchange of opinions on the theme of developing a regional cancer registry system. Many patient representatives at the Summit voiced the opinion that, together with legislating and arranging data for a regional cancer registry, human resources need to be secured for cancer care and research & development for such a registry to have any practical impact.

The head of the caucus, Mr. Hidehisa Otsuji, stressed that, as any transformation of the law is difficult to achieve, it will require some younger lawmakers to stake their political lives on realizing such a goal for it to happen.



Although a plenary session of the House of Representatives was held the same day, we were still able to welcome 6 members of the House of Councillors, together with 14 Diet members' secretaries. Moreover, the President of the Japanese Association of Medical Sciences, the Chief of the Health Service Bureau in the Ministry of Health, Labour and Welfare, and the chair of the Cancer Control Promotion Council, were all present to hear the opinions raised at the meeting.

Participants' Voices

- The chosen themes were highly relevant. *[patient representative]*
- I could really understand how we patient groups can become involved in and influence prefectural planning. *[patient representative]*
- Right now, these are the same themes that my department is debating daily, so it was very helpful to hear so many opinions offered from different standpoints on these topics. *[government official]*
- I feel that I've found the checkpoints for our prefectural plan (from the National Cancer Plan study session). *[prefectural assembly member]*
- It was good to hear so many patients' opinions first-hand. *[healthcare provider]*
- I think it's a very effective, result-oriented approach to have patients, administrators, lawmakers, healthcare professionals, the private sector and media all sharing a platform and primed to start discussing the issues, and it will lead to an optimal, uniform approach being taken across the country. A lot of learning and emulating of others is being encouraged through the sharing of information and best practices. *[participating observer]*
- It's so valuable to have a place like this to meet and talk in person. I really hope the Summit continues. *[patient representative]*

Patient Representative Session "Moving Ahead with Patient-Centered Cancer Control"

Focusing on patient representatives, an Advocacy Workbook study meeting and "Moving Ahead with Patient-Centered Cancer Control" were held on the third day of the Summit.

The study meeting provided an opportunity for an exchange of ideas and opinions about patient group and advocacy activities. A question from one participant struck a chord with many of those there: "Our time and energy is limited as individuals, so how can we achieve more as leaders?" Invaluable bonds were created and strengthened among patient advocates who usually work in separate locations across the country.

In addition, prominent U.S. advocate, Ms. Paula Kim, gave a presentation on 10 key points for advocacy activity. Moreover, along with sharing details about how patient groups were set up and discussing their activities, all participants were greatly encouraged by the message of "Let's start with what of high priority!" that was conveyed.

In the second half of the session, opinions were exchanged about collaborating with other stakeholders based on the group work conducted earlier at the Summit. Among these, concerns such as "The terminology employed at the Summit is too technical" were heard, but at the same time there were more positive opinions, including "Patients must also make efforts to study and understand what their counterparts are saying," and "We must be able to use administrative terms when speaking with administrators."



The Cancer Policy Summit offers opportunities for encounters, empathy, and encouragement among patient representatives



※ Titles correct at the time of the event. Cancer Policy Summit reports available at <http://ganseisaku.net/>