

The collaboration between the Nordic National Cancer Societies and cancer patient associations

Collaboration with cancer patient associations

- The Danish Cancer Society: **21 (20)** patient associations
- The Norwegian Cancer Society: **14** patient associations
- The Swedish Cancer Society: **10** patient associations
- The Cancer Society of Finland: **6** patient associations (members of the Cancer Society)
- The Faroese Cancer Society: No independent patient associations – they are a part of the Faroese Cancer Society
- The Icelandic Cancer Society: **2** specific associations, not really patient associations. Most of the diagnosis-specific cancer patient associations are a part of the society

The collaboration

Generally the cancer societies assist the cancer patient associations with:

- Arranging joint meetings /network meetings
- Planning and organizing different activities, meetings, campaigns, conferences etc.
- Providing financial support for activities for patients and relatives
- User involvement: Committees, hospitals, public institutions, research projects
- Workshops and courses
- Presentations from the professionals in the cancer societies
- Providing facilities for their meetings, conferences etc.
- Legal assistance

Collaboration criteria and financial support

- Most of the Nordic Cancer Societies have some collaboration criteria for working with the diagnosis-specific cancer patient associations
- With the exception of the Icelandic Cancer Society, all of the Nordic Cancer Societies provide financial support to the cancer patient associations

Collaboration criteria, Finland

- The associations have to be members of the national cancer society
- The associations have to agree with the mission and constitution of the Cancer Society of Finland.
- They have to be financially independent and self-sufficient
- Support from the pharmaceutical industry can't be the only or most important source of income
- The associations' activities should cover the whole country
- The associations are committed to collaborate with the regional and other member societies of the Cancer Society of Finland
- Collaboration with the tobacco or alcohol industry is not allowed
- Financial support is mainly for counselling, peer support, and cancer prevention

Collaboration criteria

Norway:

- The activities of the associations have to be directed towards patients
- They cannot fundraise in competition with the Norwegian Cancer Society

The Faroe Islands:

- The associations are a part of The Faroese Cancer Society and must therefore comply with the rules of the organization

Collaboration criteria

Iceland:

- No formal criteria for collaboration

Sweden:

- The associations have to work for social change for cancer patients or provide activities for cancer patient and relatives
- The associations have to be democratically built
- The associations cannot have any specific political affiliations
- The associations must have at least 10 members
- Annual fundraising activities have to be below 50 million Swedish crowns
- The associations must have been active for at least two years

Collaboration criteria, Denmark

- The financial support from the pharmaceutical industry must not exceed 5% of the associations' income
- The associations cannot collaborate with or receive funding from the tobacco industry
- The financial support has to be used for activities, events and materials that benefit patients and relatives (eg. network meetings, conferences, pamphlets etc.)
- The associations have to account for the use of the granted money
- The associations' financial assets cannot exceed their annual expenses (based on the previous 2 years)

Termination of a collaboration

Only Norway and Denmark have had to terminate a collaboration with a patient association:

Norway:

- The exact circumstances are not described

Denmark:

- The patient association lacked financial accounting and couldn't account for the use of the granted financial support. This association has been reported to the police because of fraud (however not by the National Cancer Society)
- 2 associations have chosen to leave the collaboration due to the '5% rule'

Financial support from the pharmaceutical industry

Two of the Nordic Cancer Societies have requirements with regard to the size of the financial support from the pharmaceutical industry

The Cancer Society of Finland:

- The support from the pharmaceutical industry can not be the main source of the patient associations' income

The Danish Cancer Society

- The patient associations are allowed a maximum of 5 % of their income from the pharmaceutical industry

User involvement

'Do you use members from these patient associations as representatives in committees etc.?'

- The Danish Cancer Society and the Norwegian Cancer Society both use members from patient associations and patients that are not members/represent a specific organization
- The Icelandic Cancer Society consult members from the patient associations on some matters
- The patient associations in Finland are members of The Cancer Society of Finland:
 - They take part in the election of the Delegation and Board of the Society
 - They are represented in all the committees and working groups
- The Swedish Cancer Society and the Faroese Cancer Society have both answered no to the question

Administrative/secretarial work

To some extent all of the Nordic Cancer Societies assist with administrative or secretarial work. Examples:

- When planning conferences etc.
- Hands-on support: Communication, IT, home pages
- Specific contact persons
- Development of HR policies, financial activities
- Financial accounting, registration of members etc.

Thank you for your help with the answers...

... any further questions or comments?