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17.09.2020

Tags:

[Norway](#), [Norwegian Cancer Society](#), [Cancer](#), [Oncology](#), [Charity](#), [Research](#)

Ole Alexander Opdalshei introduces the role of the Norwegian Cancer Society within Norwegian cancer research, care services and information dissemination; how medical research charities are able to direct funding towards areas of cancer research missed by the private and public sectors; the burden of cancer within Norway; and the introduction of cutting-edge new treatments into the country's healthcare system.

Can you begin by introducing the Norwegian Cancer Society and its purpose?

We are a non-governmental member organisation working to improve cancer care in Norway. Our three main targets are to reduce the number of cancer cases in Norway, increase cancer survival rates, and increase the quality of care for cancer patients.

There are also three main elements of our work. The first is the financing of cancer research, primarily in Norway but also across the Nordics and Europe. The second is providing cancer care services to cancer patients via meetings, support groups for specific indications, and transportation service to hospitals. The third element is the dissemination of information about cancer through publicity campaigns and via our helpline. We also work at the political level doing advocacy work, ensuring that cancer is kept on the political agenda to get the best possible treatment for patients in

Norway.

The Norwegian Cancer Society is one of Norway's largest contributors to cancer research with around EUR 21 million donated to that field last year. What are your key areas in terms of research funding?

Broadly speaking, there are two areas: one yearly open call which is open to all types of cancer research. This has traditionally been our largest area and has been conducted by the Cancer Society for many years. Any research project relevant to cancer can apply for funding, with applications then evaluated by various panels specialising in basic biological research, translational research, clinical research, epidemiological research, and healthcare services research.

In addition, in recent years we have implemented more thematic areas where we invite people to apply for research funding. For example, we have had clinical research, research in the elderly, and young patients. Moreover, in the last couple of years, we have had a concrete strategy centred around cancer diagnoses that have a bad prognosis. This is modelled on Cancer Research UK's "hard to beat cancer" programme and covers diseases like pancreatic and lung cancer.

We also, as a part of the thematic area, have a pink ribbon campaign relating to breast cancer each year in collaboration with the Norwegian Breast Cancer society.

To what extent does the medical research charity model, as in the UK, help identify unmet needs, represent the patient voice better and fill research gaps left behind by state and industry?

The overarching question is how we, as an NGO, can contribute to cancer research. For example, the open call we have is similar to something that the Norwegian Research Council or the government might do. However, we use these thematic calls to try to better put forward the unmet needs of cancer patients such as in hard to beat cancers. For several years we also had a focus on late effects among cancer patients, which many patients were experiencing and where there was not much research being conducted.

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In addition and this is important I like to stress that our role in research is more than just as a funder. We also work on the political level and in other areas to advocate for more cancer research both in general but especially in areas where we find there are unmet needs.

Norway is a country that has traditionally been an innovator in oil and gas and marine biology. How do you assess the progress and potential of Norwegian health research?

An interesting aspect of health research in Norway is how it is funded. The Ministry of Health, along with the other ministries, gives funding to the Research Council which then administrates research, but also gives a large amount of funding to the four health regions that are responsible for research in their areas. In oncology you also have the Norwegian Cancer Society as a third funding stream.

Across all streams, we are seeing increased levels of funding and interest in healthcare and oncology research.

Being a small country of five million inhabitants, it is not probable that the next global medical breakthrough will come from Norway. On the other hand, we have a lot of good health registries as well as a universal healthcare system and a lot of good researchers that publish at a high level and collaborate with researchers at other international cancer research institutions.

Therefore, the potential for conducting epidemiological research in Norway is high and there is a generally positive vibe about health research in the country. There has been a lot of enthusiasm about Norwegian biotech firms, some of whose ideas have been followed up on by bigger companies. However, clinical studies have been decreasing in number. Reversing this trend is high on the agenda for the industry, clinicians, politicians, and also for the Norwegian Cancer Society. The Ministry of Health has promised to launch a new strategy to increase our clinical studies in December 2020.

Can you outline the burden of cancer in Norway and some of its particularities?

According to the most recent statistics, cancer has become the leading cause of death in Norway. This is linked to our ageing population with cases predicted to increase dramatically in the next couple of years. Compared to other countries, the general standard of hospital care for cancer patients in Norway is good.

However, one of the key issues in Norwegian cancer care is the gaps that exist in patients' pathways. When they first come to the hospital, they receive good treatment but then more problems can arise later. These include a lack of follow-up treatment, support for any queries they may have, and the transition between different hospitals and between primary care facilities in their own municipalities. Often, the primary care doctors responsible for following up do not have all the information they need from the hospitals due to IT issues. Although our welfare system is good,

Another issue is inequalities in levels of treatment. In Norway, we are grateful for our strong welfare system, but for some sick people without a lot of resources, it can be difficult to navigate between the different types of service and find the service that is right for them.

Other issues that also need more attention are the implementation of personalized treatment, the introduction of new drugs, and the need for more clinical studies.

What is your take on issues around access and affordability for cutting-edge treatments such as CAR-T?

These therapies represent a great deal of hope and optimism, just as immunotherapies did when they were first introduced a few years ago. The issues of access and pricing have been very high on the political agenda and the debate about prioritisation in Norway has been, and will continue to be, intense.

We are trying to balance the different perspectives and build a bridge between industry and government. We want cancer patients to be able to access treatments that can help them, but we also understand that there has to be a limit on how much the Norwegian healthcare system can pay for them. One option is looking at different payment schemes and models such as pay for

performance. Also, it is fair to say that the industry has to look at its profit model because prices are high and in a universal publicly financed healthcare system such as Norway's it will become impossible to meet these demands.

Another area to touch on is the increasing personalisation of cancer treatment. Many of these new cancer drugs have been very effective for some cancer patients but have had no effect at all on others. We need to do better to get the right medicines to the right patients.

How has COVID-19 impacted your work this year, what kind of hurdles have you had to overcome, and do you see any light at the end of the tunnel?

We had to cancel our largest fundraising campaign which was supposed to start at the beginning of March, losing us around NOK 20 million in making it digital.

In terms of patients, we were very worried about the situation in Norway and were expecting the worst when many European countries went into lockdown but fortunately, our country was not as badly affected as some others in terms of hospital services. We have been following up very closely with the hospitals and for people that were in cancer treatment, things have been moving almost as normal.

One big issue is that the referral for potential cancer cases to the hospitals has been decreasing dramatically because people did not go to their GPs with their diseases. Also, some of the screening programs were stopped or being run at reduced capacity. We are still worried that there is a lag in terms of new cancer cases.

The other issue is that by closing hospitals some relatives have had a hard time trying to follow their loved ones through their cancer treatment. When people were dying, they allowed close family into the hospitals but there were some cases where there were problems. A lot of the following up on treatments that people had before COVID-19 has been disappearing. It might be too early to see what kinds of consequences there are.

On the positive side, the use of digital communication systems has increased dramatically. We made a ten-year leap in progress when it came to digital services. People are getting more used to using digital tools to communicate with doctors and hospitals and becoming more flexible.

The Norwegian Cancer Society got a new secretary general in 2020 after 18 years - what are the goals and aspirations of this new-look organisation?

Internally speaking, we have a new strategy and some areas where we are going to work more systematically. We will work on a new research and innovation strategy this Autumn which will be important to our future work. We will also have an increased focus on the relatives of cancer patients and the services they need. It will also be important to follow up on the Ministry of Health strategy on clinical studies.

Another key aspect is equality. Norway is a very equal country in many respects, but people with higher income and higher education are getting better healthcare services. We want to help those that need it and focus on what can be done to help cancer patients with fewer resources.

A final element will be preventative measures. As in the UK, which has started to prioritise physical exercise, COVID-19 might be showing us the need for more anti-smoking and physical activity

initiatives to help prevent cancer as well as other diseases.

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