Little needs to be said by us on the conclusion of the present study, carried out on behalf of the 4 Nordic countries by Kompass Kommunikation, between September 2013 and April 2014. A copy of the entire report may be obtained from http://www.prostatacancerforbundet.com/subPage1.asp?nodeid=99829. The initiative was sponsored by Astellas Nordic. The quality of the survey was also assured by the kind co-operation of leading Nordic medical experts for prostate cancer.

The survey involved nearly 7,000 prostate cancer patients living in one of the four participating countries, who were recruited either by on-line website banners, by post or emails, as well as by questionnaires distributed in hospitals and clinics. One notable conclusion which was drawn...
from the survey was the general lack of awareness on the part of the male population of this sly and deadly disease. In fact a notable percentage of patients discovered it quite by chance. This regrettable shortcoming is common in most European countries and will be reported on in the June issue.

The survey also noted the varying reactions to the news to have contracted prostate cancer and the important role then played by partners/wives, families and also by belonging to a Prostate Cancer Association. One of the most common observations was the effect of prostate cancer on their relations to the world around them and, in particular, their partners/wives, especially from a sexual point of view.

We therefore invite you all to take advantage of this possibility to have further insight on this disease which is already second only to cardiovascular disorders for the premature death of the male population, partly due to increasing longevity.

Enjoy your reading.

About the study and the respondents

This study was conducted by Kompas Kommunikation in cooperation with the prostate-patients associations in Denmark (Prostatakæftforeningen PROPA), Finland (Suomen Etarauhasyöpäyhdistys ry), Norway (Prostatakrestforeningen PROFO) and Sweden (Prostatacancerförbundet) together with leading medical experts within prostate-cancer research: Michael Borre (Denmark), Antti Rannikko (Finland), Sophie Fosså (Norway) and Göran Ahlgren (Sweden). The study, completed between September 2013 and April 2014, has been sponsored by Astellas Nordic.

6,916 respondents from Denmark (1,784), Finland (1,106), Norway (1,222) and Sweden (2,804) participated. All respondents were diagnosed with prostate cancer.

The respondents were recruited via online banners on the websites of the Danish, Finnish, Norwegian and Swedish patients associations and via letters and e-mails sent directly to members of the respective patients associations. Further, respondents were recruited via paper-based questionnaires available in hospitals and clinics in the four countries and generally handed out at meetings within the framework of the patients associations. Finally, in Sweden, respondents were also recruited via the online respondent-recruitment network, Smart-response.

With respect to a few of the questions, we observed variations between respondents participating via the online survey and the respondents participating via the paper-based questionnaires. Since the Finnish survey contains a more extensive number of responses via paper-based questionnaires, the results for certain questions should be treated with some reservation as regards variations between Finnish
respondents and the other three nationalities. Thus, in connection with question 2, it appears that – as compared with respondents from the other Nordic countries – the average time that Finnish respondents have been diagnosed with prostate cancer is considerable longer. Also, the mean age of respondents recruited via paper-based questionnaires is higher (72.7 years) than the mean age of respondents using the online option (68 years).

Kompas Kommunikation has adjusted the collected data for the purpose of ensuring the validity of the results. Thus, this adjustment entailed the removal of respondents giving invalid responses; and, likewise, any superfluous responses from respondents participating in the survey more than once were removed. All tables list the number of respondent answers as a total. Not all respondents answered all questions. However, any respondents having answered less than 20% of the survey’s principal questions were removed on the basis of the overall assessment of the data validity.

This report contains the answers from all four Scandinavian countries

41% of respondents are Swedish, 26% are Danish, 18% are Norwegian and 16% are Finnish. Age-wise, 8% of the respondents are below 60 years, 37% are between 60 and 69 years, whereas 55% of the respondents are 70 or older.

The survey comprises respondents who are members of a patients association (PROPA/PROPO/PROFO/Prostatacancerfürbundet/other) (86%) and respondents who are not (14%). A comparison has been made between the responses of the two groups, and there was no noticeable variation.

In tables and graphs, all percentages have been rounded off and listed without decimals, which is the reason why not all tables and graphs state sums at 100 percent.

About the study and the respondents

<table>
<thead>
<tr>
<th>Country-code</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>1,724*</td>
<td>26%</td>
</tr>
<tr>
<td>Finland</td>
<td>1,195*</td>
<td>14%</td>
</tr>
<tr>
<td>Norway</td>
<td>1,022*</td>
<td>18%</td>
</tr>
<tr>
<td>Sweden</td>
<td>1,614*</td>
<td>26%</td>
</tr>
<tr>
<td>Total</td>
<td>6,556*</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Basic: All respondents having answered.

**Conclusion**

This section comprises the most significant conclusions drawn from the Nordic survey among prostate-cancer patients performed in Denmark, Norway, Sweden and Finland from the autumn 2013 to the spring of 2014.

**Diagnosis**

A significant number of the Nordic prostate-cancer patients are not familiar with the typical symptoms of prostate cancer. Many are not aware that back pain (55%), blood in the semen (44%), blood in the urine (39%), incontinence (32%) and difficulty in passing urine (16%) may be symptoms of the disease. Differences among the countries can, however, be detected. Thus, 27% of the Finnish respondents are not aware that blood in the urine is a symptom of prostate cancer, whereas it is almost half of the Swedes (47%) who are not aware of this. On the other hand, more than 4 out of 10 (44%) of the Finnish respondents know about back pain as a symptom of the disease, while this is only the case for every fifth (22%) of the Danish respondents.
Frequently, prostate cancer is detected by pure chance. Half the patients (49%) detected their prostate cancer by chance in connection with a visit to their General Practitioner (GP) for other reasons; whereas slightly fewer (41%) detected the disease because they experienced symptoms which made them seek medical advice. Most Finnish respondents detected the disease by pure chance (57%); and, similarly; the Finns rank highest when it comes to detect symptoms and seek subsequent medical assistance (49%).

More than 4 out of 10 (44%) of the patients are not aware that prostate cancer may be hereditary. Most Swedish respondents are aware of this (61%) and fewer Norwegian (47%). Collectively, 3 out of 10 (29%) have experienced previous cases of prostate cancer in their family, while an equal number (29%) have no knowledge as to whether there have been previous cases of prostate cancer in their family. In this connection, the variation among the four countries is only minor.

The diagnosed prostate cancer is received with mixed feelings. For half the Nordic respondents (48%), the initial reaction was a determination to fight and conquer the disease. However, many (32%) reacted by becoming sad, and a large number (38%) feared the subsequent proceedings. There are, however, a number of variations among the countries. Thus, 4 out of 10 (42%) of the Danish respondents reacted by becoming sad, whereas this only applied to every fifth (21%) of the Finnish respondents.

**Treatment**

In general, the Nordic prostate-cancer patients feel well-informed about their disease. 3 out of 4 (77%) state that, when diagnosed, the explanation they received about prostate cancer and its treatment from their doctor/the healthcare professionals was satisfactory. A similar number (76%) feel well-informed about the disease.

However, 4 out of 10 (36%) have not received information about new research and new therapeutic options from their doctor/the healthcare professionals. This is especially the case for the Swedish respondents (39%) and to the least extent for the Finns (23%). At the same time, many of the Nordic respondents (68%) would like to have further information about the disease. In Sweden, the interest in additional disease information is quite large (80%), whereas, for Denmark, it is somewhat lower (56%).

The Nordic patients like to be involved and have a say in connection with their therapy. By far the most (88%) prefer to discuss therapeutic options with their doctor and, subsequently, make a joint decision concerning their therapy. In this respect, there are only quite slight variations among the countries.

Collectively, every fourth patient (23%) experiences the fact of having met many different medical practitioners in the course of their disease, as problematic. This is especially the case for the Danish respondents (33%), whereas this issue is significantly less important in Sweden (15%).

7 out of 10 (71%) of the Nordic respondents are aware that they are entitled to hear another doctor's opinion about their treatment options, whereas every fifth (18%) are not aware of this option. The highest number of patients (75%), aware of this option, are Swedes; whereas the lowest number is constituted by Danes (64%). Collectively, 30% received a second doctor's opinion concerning their treatment options; and, in this respect, the variation among the countries only amounts to a few percent.

More than half the Nordic prostate-cancer patients experience their therapy to exert a negative influence on their quality of life only to a lesser degree (46%) or not at all (9%), while 38% experience the negative influence to a high (30%) or very high degree (8%). Collectively, the least affected patients are the Finns, where only 30% feels that their therapy has had a negative influence on their quality of life; whereas the Norwegians are the most affected (48%).

The Nordic patients do, however, experience considerable side effects in connection with their prostate-cancer therapy. Erectile dysfunction is the most frequently experienced side effect (80%). This is followed by incontinence (38%),
fatigue (31%), and hot flushes (29%). Every fifth (22%) has experienced the development of breasts or impaired muscular strength (21%) as a result of the therapy; whereas a little lower number of respondents have experienced weight gains (16%), insomnia (14%), depression (13%) or faecal incontinence (11%). As to side effects from the therapy, there are only slight variations among the countries.

Life with prostate cancer
After being diagnosed with prostate cancer, a significant number of the Nordic prostate-cancer patients have developed a more positive outlook on life. Thus, 2 out of 3 (67%) think more about living in the moment and enjoy life while they can still do so. This applies to most Finnish respondents (73%), and to fewer Norwegians (56%). Collectively, a little less than half the respondents (46%) think more about acting out their dreams; and for 4 out of 10 (40%) every single extra day counts.

However, some respondents think more about death (33%) and about what will happen to their family when they are no longer there (36%). Most Danes (40%) think about what will happen to their family, whereas the Finns seem to be the least worried in this respect (28%).

In general, the Nordic patients feel well equipped. As many as 9 out of 10 (87%) believe that they handle their disease well; and 7 out of 10 (72%) feel prepared to live with prostate cancer for the rest of their lives.

But the disease afflicts virility in all countries. Collectively, 6 out of 10 (63%) feel that they have lost part of their virility after being diagnosed with prostate cancer.

Family and relatives play an important role for the Nordic patients. Almost 9 out of 10 (85%) receive emotional support from their family, while 7 out of 10 (71%) find support from their friends. At the same time, half the respondents (51%) feel that their relationship with their partner/wife has grown closer after being diagnosed with prostate cancer. This applies to most Danish respondents (56%) and to the fewest in Norway (46%).

Collectively, almost 9 out of 10 (85%) mainly discuss their disease with their partner/wife – apart from their doctor; and, likewise, their children also play an important role as conversation partners (48%). Other than these parties, however, there is considerable variation as to with whom the patients in the different countries mainly prefer to discuss their disease. Thus, half (50%) of the Finnish respondents mainly discuss their disease with other prostate-cancer patients, while this only applies to every fourth (23%) of the Danish respondents.

Sex life
Prostate-cancer therapy afflicts the sex life of the patients. 6 out of 10 (60%) of the Nordic prostate-cancer patients are dissatisfied with their sex life; and 9 out of 10 (87%) have experienced problems with the ability to get an erection after having received prostate-cancer therapy. Similarly, many have experienced problems with respect to functioning sexually (79%) and getting an orgasm (71%).

At the same time, a large number (33-39%) consider the loss of sexual desire to be frustrating or to constitute a major problem; or they are worried that this also frustrates their partner/wife.

As to the questions focused on sex life, there are only slight variations among the countries.

Information and counselling
68% of the Nordic patients get information from their patients association. Most probably, this is attributable to the fact that most of the survey respondents (86%) are members of a patients association. Furthermore, 48% get information from a urologist, 40% from the internet and 34% from a hospital doctor. A considerable number, however, also obtain information from their GP (29%), from information leaflets (27%) or from other prostate-cancer patients (25%).

However, the sources of information vary considerably from country to country. Thus, 6 out of 10 (57%) of the Swedish respondents get information from a urologist; whereas this only applies to one third (33%) of the Danish respondents. On the other hand, half the Danish get information from a hospital doctor, while it is only 1 out of 6 (17%) of the Finnish respondents.
Instead, 6 out of 10 (60%) of the Finns get information from their GP – in contrast to only 3 out of 10 (28%) of the Danish respondents.

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