Patients’ perspective: Patients with Cancer want early vaccination survey results

ESMO January 8, 2021

Irene Dingemans, MA
Patient representative
Dutch Federation of Cancer Patient Organisations
Nederlandse Federatie van Kankerpatiënten organisaties
Dutch Federation of Cancer Patient Organisations

• National federation of 20 cancer patient organisations / platforms

• 3-5 surveys per year: “Donate your experience”
  [www.doneerjeervaring.nl](http://www.doneerjeervaring.nl)

• In 2020 2 surveys about impact of Corona on cancer patients:
  • March/April: early consequences of corona crisis
  • October/November: Cancer care in “1.5 meters society”
First Survey  March/April 2020

Acute phase corona crisis
> Acute downscaling of regular care
> Quick response of oncology physicians to make cancer care safe

Survey is fast way to collect data on impact on cancer patients:
• what is happening in oncology care
• what is the experience of patients?
4 topics questionnaire

1. Patients’ characteristics
2. Contact with hospital
3. Consequences of Covid-19 pandemic (consultations, treatment and follow-up)
4. Concerns about infection with Corona virus
Methods first survey

- Questionnaire developed by NFK / PO in collaboration with oncology physicians

- Target group: (ex-)cancer patients
  - Direct mail to panel and members patient organisations
  - Social media exposure by NFK/ PO, hospitals and others

- Online data collection: March 29 – April 18, 2020 (Survey Monkey)

- Data-analysis: IBM SPSS statistics, version 25
Fig. 1. Number of patients with a positive test for SARS-CoV-2 in the Netherlands during the three-week period of the survey on (a) March 29th 2020 and (b) April 18th 2020. SARS-CoV-2 = severe acute respiratory syndrome coronavirus 2.
## Characteristics of respondents (n=5,302)

### Patients’ characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>3,413</td>
<td>64</td>
</tr>
<tr>
<td>Men</td>
<td>1,887</td>
<td>36</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;65 years</td>
<td>3,422</td>
<td>65</td>
</tr>
<tr>
<td>≥65 years</td>
<td>1,880</td>
<td>35</td>
</tr>
<tr>
<td><strong>Region in the Netherlands</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Code red according COVID-19</td>
<td>834</td>
<td>16</td>
</tr>
<tr>
<td>Other</td>
<td>4,468</td>
<td>84</td>
</tr>
<tr>
<td><strong>Disease setting</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cured</td>
<td>2,004</td>
<td>38</td>
</tr>
<tr>
<td>Curable disease</td>
<td>793</td>
<td>15</td>
</tr>
<tr>
<td>Incurable disease</td>
<td>1,907</td>
<td>36</td>
</tr>
<tr>
<td>Unknown</td>
<td>598</td>
<td>11</td>
</tr>
<tr>
<td><strong>Treatment setting</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Awaiting treatment</td>
<td>250</td>
<td>5</td>
</tr>
<tr>
<td>Under treatment</td>
<td>2,391</td>
<td>45</td>
</tr>
<tr>
<td>Follow-up</td>
<td>2,661</td>
<td>50</td>
</tr>
</tbody>
</table>

### Cancer diagnosis

<table>
<thead>
<tr>
<th>Cancer diagnosis</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bladder and renal cell cancer</td>
<td>214</td>
<td>4</td>
</tr>
<tr>
<td>Brain tumor</td>
<td>45</td>
<td>1</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>1,187</td>
<td>22</td>
</tr>
<tr>
<td>Colorectal cancer</td>
<td>296</td>
<td>6</td>
</tr>
<tr>
<td>Gastric and oesophageal cancer</td>
<td>92</td>
<td>2</td>
</tr>
<tr>
<td>Gynaecological cancer</td>
<td>177</td>
<td>3</td>
</tr>
<tr>
<td>Head and neck cancer</td>
<td>77</td>
<td>1</td>
</tr>
<tr>
<td>Haematological malignancy</td>
<td>1,660</td>
<td>31</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>622</td>
<td>12</td>
</tr>
<tr>
<td>Melanoma and skin cancer</td>
<td>209</td>
<td>4</td>
</tr>
<tr>
<td>Mesothelioma</td>
<td>34</td>
<td>1</td>
</tr>
<tr>
<td>Pancreatic cancer</td>
<td>55</td>
<td>1</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>160</td>
<td>3</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>56</td>
<td>1</td>
</tr>
<tr>
<td>Testicular cancer</td>
<td>37</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>381</td>
<td>7</td>
</tr>
</tbody>
</table>
Results: concerns about infection with the coronavirus 1/2
Survey cancer patients, March 29 – April 18, 2020, N=5302

To what extend are you worried that you will get infected with the coronavirus?

- Not worried: 43%
- Slightly worried: 29%
- Worried: 10%
- Very worried: 18%

Note: less than 1% of respondents had had COVID-19 (confirmed by positive test)
### Results: concerns about infection with the coronavirus 2/2

**Survey cancer patients, March 29 – April 18, 2020, N=5302**

<table>
<thead>
<tr>
<th>Patient characteristics</th>
<th>% (very) worried</th>
</tr>
</thead>
<tbody>
<tr>
<td>All respondents</td>
<td>47%</td>
</tr>
<tr>
<td>Resp. under treatment</td>
<td>54%</td>
</tr>
<tr>
<td>Resp. in follow-up phase</td>
<td>40%</td>
</tr>
<tr>
<td>Resp. with incurable disease</td>
<td>55%</td>
</tr>
<tr>
<td>Resp. with curable disease</td>
<td>50%</td>
</tr>
<tr>
<td>Resp. with cured disease</td>
<td>37%</td>
</tr>
<tr>
<td>Resp. in code red regions</td>
<td>51%</td>
</tr>
<tr>
<td>Resp. in other regions</td>
<td>46%</td>
</tr>
</tbody>
</table>
Impact of the coronavirus disease 2019 pandemic on cancer treatment: the patients’ perspective

K. de Joode a,b,3, D.W. Dumoulin c,3, V. Engelen d, H.J. Bloemendal e, M. Verheij f,g, H.W.M. van Laarhoven h, I.H. Dingemans d, A.C. Dingemans c,i,4, A.A.M. van der Veldt a,b,*,4
Second Survey  October/November 2020

Goals

• Gathering information for “the new normal” on e.g. digital oncology care

• Getting insight on willingness for COVID vaccination
Methods second survey

- Target group:
  - (ex-)cancer patients who’ve received cancer care since July 1, 2020
  - Oncology physicians, oncology nurses and nurse practitioners

- Questionnaire developed by NFK / PO in collaboration with society of oncology physicians (SONCOS), oncology nurses and nurse practitioners (V&VN oncology)

- Distribution of questionnaire
  - Direct mail to panel and members patient organisations, to members nursing society and to oncology physicians
  - Social media exposure by NFK, PO, hospitals and others

- Online data collection: October 6 – November 3, 2020

This survey is partially financed by and part of ZONMW project “Impact of COVID-19 outbreak on diagnosis and treatment of cancer patients: lessons for the future (ZonMW: projectnummer 50-56300-98-587)
Response

- 2,412 patients with cancer
- 180 oncology physicians
- 304 oncology nurses and nurse practitioners
Questions

1. Patient characteristics

2. Was the corona crisis of influence on your first contact with you general practitioner when you had your first physical signs/complaints?

3. Which corona measures have been taken by the hospitals and how do they effect the quality of cancer care?

4. How do you experience the hospital appointments on location, by telephone and by videocall and which type of appointment do you prefer for which type of consult?

5. Would you like to get vaccinated against COVID-19 (with priority)?
Results – willingness vaccination
Survey, October 6 – November 3, 2020

Would you, because of your cancer diagnosis, want to receive priority vaccination against corona (COVID-19)?

<table>
<thead>
<tr>
<th>Category</th>
<th>I would like vaccination with priority</th>
<th>I would like vaccination, but no priority</th>
<th>I don’t want vaccination</th>
<th>I don’t know yet whether I want vaccination</th>
<th>I prefer not to say</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer patients</td>
<td>37</td>
<td>29</td>
<td>6</td>
<td>28</td>
<td>1</td>
</tr>
<tr>
<td>Oncology physicians</td>
<td>39</td>
<td>38</td>
<td>3</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td>Oncology nurses and nurse practitioners</td>
<td>13</td>
<td>31</td>
<td>8</td>
<td>47</td>
<td>1</td>
</tr>
</tbody>
</table>

FIGURE 1. WILLINGNESS VACCINATION
Results – willingness vaccination patients – treatment setting
Survey cancer patients, October 6 – November 3, 2020, N=2412

Would you, because of your cancer diagnosis, want to receive priority vaccination against corona (COVID-19)?

- Treatment yet to be started: 21% would like vaccination with priority, 37% would like vaccination, but no priority, 6% don't want vaccination, 35% I don't know yet whether I want vaccination, 2% I prefer not to say.
- Currently in treatment: 43% would like vaccination with priority, 25% would like vaccination, but no priority, 5% don't want vaccination, 26% I don't know yet whether I want vaccination, 1% I prefer not to say.
- Wait and see policy / active surveillance: 35% would like vaccination with priority, 31% would like vaccination, but no priority, 4% don't want vaccination, 31% I don't know yet whether I want vaccination, 0% I prefer not to say.
- Treatment completed: 34% would like vaccination with priority, 31% would like vaccination, but no priority, 7% don't want vaccination, 28% I don't know yet whether I want vaccination, 1% I prefer not to say.

FIGURE 3. TREATMENT SETTING
Results – willingness vaccination patients – disease setting  
Survey cancer patients, October 6 – November 3, 2020, N=2412

Would you, because of your cancer diagnosis, want to receive priority vaccination against corona (COVID-19)?

- I am (probably) cured: 28% would like vaccination with priority, 34% would like vaccination, but no priority, 7% don’t want vaccination, 31% don’t know yet whether I want vaccination
- I will (probably) be cured: 38% would like vaccination with priority, 27% would like vaccination, but no priority, 7% don’t want vaccination, 27% don’t know yet whether I want vaccination
- I will (probably) not be cured / chronic cancer: 46% would like vaccination with priority, 25% would like vaccination, but no priority, 4% don’t want vaccination, 25% don’t know yet whether I want vaccination

FIGURE 2. DISEASE SETTING
Context: timing of survey

Survey: October 6 till November 3, 2020

Break through on vaccine: November 9, 2020
Willingness for COVID vaccination – Dutch Population 2020-2021

To which extent are you willing to get vaccinated if a good vaccine against corona is available?

- **November**
  - Zeker wel: 37%
  - Waarschijnlijk wel: 29%
  - Waarschijnlijk niet: 10%
  - Zeker niet: 11%
  - Weet ik niet: 13%

- **December**
  - Zeker wel: 44%
  - Waarschijnlijk wel: 25%
  - Waarschijnlijk niet: 10%
  - Zeker niet: 10%
  - Weet ik niet: 11%

- **Januari**
  - Zeker wel: 51%
  - Waarschijnlijk wel: 24%
  - Waarschijnlijk niet: 7%
  - Zeker niet: 8%
  - Weet ik niet: 10%

**Vaccinatiebereidheid**
- November (20-23 november): 66%
- December (18-20 december): 69%
- Januari (30 december-4 januari): 75%

*Basis: Nederlanders (191), nationaal representatieve steekproeven, 20-23 november (n=1.048), 18-20 december (n=1.060), 30 december-4 januari 2021 (n=1.007).*
October 4, 2020: survey results in the news and Dutch public offers vaccine to cancer patients
Conclusion

COVID-19 has high impact on cancer patients
   concerns for infection with the virus
   people live in isolation with very few social contacts

Urgency for early vaccination is strong, especially amongst
   those who are receiving treatment and
   those with incurable disease

>> appeal to Dutch government to give cancer patients a priority position in the national vaccination programme
Thank you for your attention

Irene Dingemans, MA
Dr. Vivian Engelen

Patient representative resp. researcher surveys
Dutch Federation of Cancer patient organisations

i.dingemans@nfk.nl
www.nfk.nl
www.doneerjeervaring.nl