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## Patients' expectations of preventive measures of medical institutions during the SARS-CoV-2 pandemic in Germany in women with an increased risk for breast and ovarian cancer

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|-------------------------------|--|
| Journal:                      | <i>BMJ Open</i>  |
| Manuscript ID                 | bmjopen-2021-060038  |
| Article Type:                 | Original research  |
| Date Submitted by the Author: | 14-Dec-2021  |
| Complete List of Authors:     | Schwab, Roxana; Johannes Gutenberg University Hospital Mainz, Department of Obstetrics and Gynecology<br>Droste, Annika; Johannes Gutenberg University Hospital Mainz, Department of Gynecology and Obstetrics<br>Stewen, Kathrin; Johannes Gutenberg University Hospital Mainz, Department of Gynecology and Obstetrics<br>Brenner, Walburgis; Johannes Gutenberg University Hospital Mainz, Department of Gynecology and Obstetrics<br>Schmidt, Marcus; Johannes Gutenberg University Hospital Mainz, Department of Gynecology and Obstetrics<br>Hasenburg, Annette; Johannes Gutenberg University Hospital Mainz, Department of Gynecology and Obstetrics |
| Keywords:                     | COVID-19, Health & safety < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Breast tumours < ONCOLOGY, Gynaecological oncology < ONCOLOGY   |
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## Title

**Patients' expectations of preventive measures of medical institutions during the SARS-CoV-2 pandemic in Germany in women with an increased risk for breast and ovarian cancer**

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## Abstract

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9 34 **Objectives:** To identify patient-approved contingency measures for the protection of  
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12 35 patients and healthcare workers from COVID-19 infection, and to use these findings to  
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15 36 improve the staffs' preparedness to cope with the course of this pandemic or similar  
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18 37 situations.

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21 38 **Methods (design, setting, participants, interventions):** We conducted a cross-  
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24 39 sectional web-based survey of women with an increased risk for breast or ovarian cancer,  
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27 40 regardless of whether they had experienced an active malignant disease during the pandemic.  
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30 41 A self-reported questionnaire, developed for this study, was used to assess expectations and  
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32 42 opinions about preventive measures within medical institutions.

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35 43 **Results:** Sixty-four (71.9%) of the 89 potential participants responded to at least one  
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38 44 question regarding contingency measures within medical institutions. Approximately 37% of  
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41 45 respondents preferred having information about their facility's hygiene protocols before  
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44 46 appointment; 57.8% of respondents endorsed regular SARS-CoV-2 testing of patients prior to  
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47 47 medical appointments and 95.3% endorsed regular testing of HCW. Additionally, 84.4% of  
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50 48 respondents supported HCW's use of surgical masks and 68.8% supported HCW's use of masks  
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53 49 with greater protection. Notably, 75.0% of respondents advocated for the presence of a  
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56 50 significant other during medical consultations; 71.9% approved the use of telemedicine and  
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59 51 93.8% endorsed changes in appointment practices to enable social distancing. No significant  
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52 associations were found between respondents' sociodemographic, disease-specific or  
53 pandemic-specific factors and their opinions on hygiene precautions.

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4 54 **Conclusions:** Patients at high risk for infection or severe course of COVID-19 disease  
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7 55 approve strict contingency measures designed to lower the transmission of COVID-19 in  
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9 56 medical facilities. However, they also value the presence of a significant other during medical  
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12 57 consultations and procedures.  
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### 19 59 **Key words:**

20  
21 60 COVID-19 pandemic, contingency plans, health care facilities, patient care, BRCA 1 & 2  
22  
23

### 24 25 61 **Word number (body text):**

26  
27 62 3261 words  
28  
29

## 30 31 63 **Article Summary**

### 32 33 64 **Strengths and limitations of this study** 34 35 65

- 36  
37 66 • Due to the design of the study (cross-sectional web-based survey), overrepresentation  
38  
39 67 of patients worrying about their health status and the underrepresentation of women  
40  
41 68 without online access are two possible sources of bias.
- 42  
43 69 • As the study was conducted during the first months of 2021, and vaccines against  
44  
45 70 SARS-CoV-2 were inaccessible for a large proportion of the population at that time, we  
46  
47 71 do not know whether the responses accurately depict the current state of the  
48  
49 72 pandemic.
- 50  
51 73 • Our study identified several patient-approved contingency measures for the  
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53 74 protection of patients and healthcare workers from COVID-19 infection, which are  
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3 75 essential in terms to improve the staffs' preparedness to cope with the course of this  
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5 76 pandemic or similar situations.  
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## 15 79 Introduction

16 80  
17 81 By the end of 2019, the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2),  
18 82 which causes coronavirus disease-2019 (COVID-19), was first reported in China before  
19 83 spreading rapidly to other countries by the beginning of 2020. The World Health Organization  
20 84 (WHO) declared the outbreak a "public health emergency of international concern" on  
21 85 January 30, 2020 and a pandemic on March 11, 2020 [1].  
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31 86 Patients with active cancers seem to have a greater risk for acquiring SARS-CoV-2 infection,  
32 87 and severe COVID-19, requiring admission to intensive care units and invasive ventilation.  
33 88 Moreover, patients with pre-existing malignant diseases have a significantly higher risk for  
34 89 fatal outcomes compared to people in the general population without pre-existing medical  
35 90 conditions [2]. In order to protect this vulnerable population from possible infection, it is  
36 91 crucial to implement effective contingency plans in healthcare facilities. As a pandemic is a  
37 92 dynamic process, measures were implemented at various time points by different countries  
38 93 to prevent the spread of infection among the population and to protect persons at high risk  
39 94 for exposure, such as HCW. In Germany, the first widespread social distancing measures were  
40 95 implemented by the government at the end of March 2020 [1], [3]. As a result, healthcare  
41 96 facilities imposed specific safety protocols, general visitation guidelines and outpatient  
42 97 visitation policies in accordance with national and institutional regulations. Subsequently,  
43 98 family members and visitors were temporarily banned from joining ambulatory and  
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3 99 hospitalized patients, with few exceptions, depending on the incidence of SARS-CoV-2  
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6 100 infection.

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9 101 Persons with hereditary cancers, such as women at high risk for breast and ovarian cancer,  
10  
11 102 require regular medical appointments. Women with mutations in breast cancer genes 1 and  
12  
13 103 2 (BRCA 1 & 2) have a cumulative risk of up to 75% by 80 years of age for developing breast  
14  
15  
16 104 cancer and a cumulative risk of up to 44% by the age of 80 for developing ovarian cancer [4].  
17  
18 105 Even if they do not undergo active cancer treatment or follow-up care, this group of patients  
19  
20  
21 106 requires regular medical monitoring and risk-reducing surgical interventions to prevent and  
22  
23 107 detect a malignant disease at early stage [5].

#### 24 25 26 27 108 **Aim of the study**

28  
29 109 We aimed to identify patient-oriented and patient-approved contingency measures for the  
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31 110 protection of patients and HCWs to improve preparedness for future pandemics or similar  
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33 111 situations. Therefore, we assessed the expectations and opinions of women with an increased  
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35 112 risk for hereditary breast and ovarian cancer regarding the preventive healthcare measures of  
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37 113 medical institutions, irrespectively whether women at risk had experienced an active  
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39 114 malignant disease during the pandemic.  
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## 49 116 **Materials and Methods**

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52 117 Recruitment was conducted via a direct link to the survey and an invitation to participate  
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54 118 distributed via the internet platforms of patients support groups for hereditary breast cancer  
55  
56 119 or ovarian cancer. All participants were aged 18 years or older. All participants gave consent  
57  
58  
59 120 to participate in the study. The survey was active from 29<sup>th</sup> January to 22<sup>th</sup> February 2021.



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3 121 The data were collected anonymously, and they included participants' self-reported  
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5 122 sociodemographic and clinical information. The expectations and opinions of the women with  
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8 123 respect to the safety precautions of healthcare facilities and institutions for preventing the  
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10 124 spread of the virus were assessed were assessed using the following questions:

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14 125 1. Would you have liked to be informed about hygiene protocols in advance of your  
15  
16 126 appointment? *(Yes – No – I don't know/does not apply)*

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18  
19 127 2. Would more information about the prevailing hygiene protocols have had a positive  
20  
21 128 influence on your behavior (e.g., meeting appointments)? *Yes – No – I don't know/does not*  
22  
23 129 *apply*

24  
25  
26  
27 130 3. Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory  
28  
29 131 visit/appointment? *Yes – No – I don't know/does not apply*

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31  
32 132 4. Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection  
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34 133 on a regular basis? *Yes – No – I don't know/does not apply*

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38 134 5. Do you think that appointments should be scheduled in such a way to ensure that distancing  
39  
40 135 rules can be strictly observed? *Yes – No – I don't know/does not apply*

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44 136 6. Should a relative or trustworthy person be allowed to accompany patients in the healthcare  
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46 137 setting, despite the COVID-19 pandemic? *Yes – No – I don't know/does not apply*

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49 138 7. Do you think/agree that appointments, which do not require one's physical presence (e.g.,  
50  
51 139 counseling appointments) should be conducted as teleconferences or video conferences  
52  
53 140 during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*

54  
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57 141 8. Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask)  
58  
59 142 during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*

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3 143 9. Do you think that medical personnel should always wear an FFP-2 mask masks during the  
4  
5 144 COVID-19 pandemic to ensure patients' safety? Yes – no – I don't know/does not apply  
6

7 145 A full copy of the questions which were considered for the present evaluation can be found in  
8  
9 146 the supplement file 1 (Supplement\_file\_1).  
10

11 147

### 12 13 148 Patient and public involvement

14  
15 149 No patient involved. Patients support groups for hereditary breast cancer or ovarian cancer  
16  
17 150 supported the survey by distribution of the link via their internet platforms.  
18

19 151

### 20 21 152 Statistics

22  
23 153 For descriptive analyses, missing data consisted of participants who did not answer the  
24  
25 154 survey's questions. Data were analyzed using SPSS 26.0 (SPSS Inc., Chicago, IL, USA).  
26

27 155 Descriptive statistics are expressed as mean, standard deviation (SD), median, interquartile  
28  
29  
30 156 range (IQR) or proportions (%), as appropriate. We used the Mann-Whitney-U-test, the  $\chi^2$ -test  
31  
32 157 and the Fisher exact test to analyze the data for differences between the responders and non-  
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35 158 responders to the survey's questions.  
36

37  
38 159 The Mann-Whitney-U-test,  $\chi^2$ -test or Fisher exact test were used as appropriate, to compare  
39  
40 160 differences of expectations according to demographic, disease-specific and pandemic-specific  
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42  
43 161 variables. The p-values were calculated using a 95% confidence interval. A p-value < 0.05 was  
44  
45 162 considered statistically significant. Because the p-values were not adjusted for multiple  
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47  
48 163 testing, all results should be interpreted as exploratory.  
49

### 50 51 164 Ethics approval

52  
53 165 This study was conducted in accordance with the Declaration of Helsinki, and adhered to the  
54  
55  
56 166 principles of best clinical practices. Prior to the data collection, all patients gave their informed  
57  
58 167 consent, allowing us to collect the data and publish the results. The participants' privacy and  
59  
60  
168 confidentiality were guaranteed following German and European laws and regulations.

169 This survey was approved by the ethical review board of the medical association of Rhineland-  
 170 Palatinate (approval number 15612).

## 171 Results

### 172 Demographic characteristics of the study group

173 Although 89 potential participants accessed the questionnaire (“clicks”), 11% (9/89) did not  
 174 answer any of the questions; 80% (64/80) answered at least one question pertaining to  
 175 hygiene management and expectations for preventive measures, and 20% (16/80) did not  
 176 answer any questions pertaining to preventive measures related to the pandemic. To  
 177 understand the differences between respondents and non-respondents, we analyzed the  
 178 demographic, pandemic-specific and clinical characteristics of both groups (Table 1). No  
 179 significant differences were found between the two groups regarding demographic,  
 180 pandemic-specific or clinical variables, except for a higher educational level of the  
 181 respondents compared to non-respondents.

182 **Table 1: Demographic and clinical characteristics of the total study sample**

|                                     |              | Non-respondents               | Respondents                   | p-value<br>(Non-respondents group vs the Respondents group) |
|-------------------------------------|--------------|-------------------------------|-------------------------------|---|
| <b>Age</b>                          |              |                               |                               |   |
|                                     | Mean (SD)    | 46.64 (2.210)                 | 42,85 (1.363)                 | 0.161 <sup>1</sup>  |
|                                     | Median (IQR) | 47.50 (40.00-54.00)<br>(N=14) | 43.00 (33.75-51.25)<br>(N=62) |   |
| <b>Having a stable relationship</b> |              |                               |                               |   |
| Yes                                 | % of N       | 100 (14/14)                   | 90.6 (58/64)                  | 0.236 <sup>1</sup>  |
| No                                  | % of N       | 0 (0/14)                      | 9.4 (6/64)                    |   |
| <b>Living alone</b>                 |              |                               |                               |   |
| Yes                                 | % of N       | 100 (16/16)                   | 90.6 (58/64)                  | 0.340 <sup>1</sup>  |

|  |          |              |               |                          |
|--|----------|--------------|---------------|--------------------------|
| No   | % of N   | 0 (0/16)     | 9.4 (6/64)    |                          |
| <b>Living with children &lt; 18y</b>                       |          |              |               |                          |
| Yes  | % of n/N | 25.0 (4/16)  | 34.4 (22/64)  | 0.474 <sup>2</sup>       |
| No   | % of N   | 75.0 (12/16) | 65.6 (42/64)  |                          |
| <b>Living with persons &gt;65y</b>                         |          |              |               |                          |
| Yes  | % of N   | 12.5 (2/16)  | 6.2 (4/64)    | 0.399 <sup>1</sup>       |
| No   | % of N   | 87.5 (14/16) | 93.8 (60/64)  |                          |
| <b>Living with a partner</b>                               |          |              |               |                          |
| Yes  | % of N   | 62.5 (10/16) | 60.9 (39/64)  | 0.909 <sup>2</sup>       |
| No   | % of N   | 37.5 (6/16)  | 39.1 (25/64)  |                          |
| <b>Education</b>   |          |              |               |                          |
| Up to secondary level education                            | % of N   | 84.6 (11/13) | 48.4 (31/64)  | <b>0.017<sup>2</sup></b> |
| Tertiary level education                                   | % of N   | 15.4 (2/13)  | 51.6 (33/64)  |                          |
| <b>Did you have COVID-19</b>                               |          |              |               |                          |
| Yes  | % of N   | 0 (0/13)     | 4.7 (3/64)    | 0.429 <sup>1</sup>       |
| No   | % of N   | 100 (13/13)  | 95.3 (61/64)  |                          |
| <b>Someone in your social network has had COVID-19</b>     |          |              |               |                          |
| Yes  | % of N   | 23.1 (3/13)  | 28.6 (18/63)  | 0.687 <sup>2</sup>       |
| No   | % of N   | 76.9 (10/13) | 71.4 (45/63)  |                          |
| <b>Reduction of social network</b>                         |          |              |               |                          |
| Moderate reduction   | % of N   | 15.4 (2/13)  | 15.6 (10/64)  | 0.983 <sup>2</sup>       |
| Large reduction  | % of N   | 84.6 (11/13) | 84.4 (54/64)  |                          |
| <b>Risk profiling for OC and BC</b>                        |          |              |               |                          |
| BRCA 1 & 2   | % of N   | 76.9 (10/13) | 70.3 (45/64)  | 0.895 <sup>3</sup>       |
| Mutations other than BRCA 1 & 2                            | % of N   | 15.4 (2/13)  | 14.10 (9/64)  |                          |
| Positive family history for BC or OC                       | % of N   | 7.7 (1/13)   | 15.6 (10/64)  |                          |
| <b>Having a history of (in situ or invasive) OC and BC</b> |          |              |               |                          |
| Yes  | % of N   | 73.3 (11/15) | 64.1 (41/64)  | 0.496 <sup>2</sup>       |
| No   | % of N   | 26.7 (4/15)  | 35.9 (23/64)  |                          |
| <b>Having a history of invasive BC</b>                     |          |              |               |                          |
| Yes  | % of N   | 60 (9/15)    | 56.20 (36/64) | 0.792 <sup>2</sup>       |

|  |        |              |               |                    |
|--|--------|--------------|---------------|--------------------|
| No                                     | % of N | 40 (6/15)    | 43.80 (28/64) |                    |
| <b>Having a history of invasive OC</b> |        |              |               |                    |
| Yes                                    | % of N | 6.7 (1/15)   | 1.6 (1/64)    | 0.260 <sup>1</sup> |
| No                                     | % of N | 93.3 (14/15) | 98.4 (63/64)  |                    |

183 N = total number of women who answered the question, n = number of respondents to the specific  
 184 answer, SD = standard deviation, y = years, BRCA 1 & 2 = breast cancer genes 1 and 2, BC = breast  
 185 cancer, OC = ovarian cancer; Values in bold indicate statistical significance, as the level of significance  
 186 was set to  $p < 0.05$  (<sup>1</sup> = Mann-Whitney-U-test; <sup>2</sup> =  $\chi^2$ -test, 2-sided; <sup>3</sup> = Fisher exact test, 2-sided).

187

### 188 Opinions about preventive measures

189 Approximately 37.5% of the respondents would have preferred to be informed about their  
 190 facility's specific hygiene protocols prior to their appointment, an equal proportion did not  
 191 care to be informed and a slightly smaller proportion had no opinion on this topic (Table 2).  
 192 Only 20.3% of the respondents indicated that being informed about hygiene protocols would  
 193 have changed their behavior, whereas the majority of respondents either had no opinion or  
 194 denied any possible influence of the information on their behavior (Table 2).

195 The majority of respondents endorsed regular testing of patients for SARS-CoV-2 prior to visits  
 196 to healthcare facilities. However, a much larger proportion of respondents supported the  
 197 regularly testing of HCW (Table 2).

198 The proportion of respondents that endorsed changes in appointment practices to enable  
 199 social distancing in medical institutions and waiting wards was also quite high. Despite social  
 200 distancing requirements for visitors in medical institutions, the vast majority of respondents  
 201 (75.0%) supported the possibility of being accompanied by a significant other during medical  
 202 consultations, and 71.9% approved the implementation of telemedicine while 21.9%  
 203 disapproved this option (Table 2).

204 With regard to wearing protective gear, a relatively high proportion of respondents (84.4%)  
 205 agreed that HCW should wear surgical masks (not cloth masks) to stop the spread of SARS-  
 206 CoV-2, compared to the much smaller proportions who did not consider surgical masks to be  
 207 necessary or had no opinion on the topic. Fewer respondents (66.8%) agreed that HCW wear  
 208 masks with a higher level of protection (i.e., the FFP-2 mask), while more respondents  
 209 disagreed and others had no opinion (Table 2).

210 **Table 2: Participants' opinions and expectations of hygiene measures during the COVID-19**  
 211 **pandemic**

| Questions  | Yes<br>in % of<br>respondents<br>(n/N) | No<br>in % of<br>respondents<br>(n/N) | I don't<br>know/does<br>not apply<br>in % of<br>respondents<br>(n/N) |
|--|--|---------------------------------------|--|
| Would you have liked to be informed about hygiene protocols in advance of your appointment?  | 37.5%<br>(24/64)                       | 37.5%<br>(24/64)                      | 25.0%<br>(16/64)   |
| Would more information about the prevailing hygiene protocols have had a positive influence on your behavior (e.g., meeting appointments)?   | 20.3%<br>(13/64)                       | 31.3%<br>(20/64)                      | 48.4%<br>(31/64)   |
| Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment?   | 57.8%<br>(37/64)                       | 26.6%<br>(17/64)                      | 15.6%<br>(10/64)   |
| Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis?   | 95.3%<br>(61/64)                       | 1.6%<br>(1/64)                        | 3.1%<br>(2/64)   |
| Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed?   | 93.8%<br>(60/64)                       | 1.6%<br>(1/64)                        | 4.7%<br>(3/64)   |
| Should a relative or trustworthy person be allowed to accompany patients in the healthcare setting, despite the COVID-19 pandemic?   | 75.0%<br>(48/64)                       | 15.6%<br>(10/64)                      | 9.4%<br>(6/64)   |
| Do you think/agree that appointments, which do not require one's physical presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? | 71.9%<br>(46/64)                       | 21.9%<br>(14/64)                      | 6.3%<br>(4/64)   |

|   |                  |                  |                 |
|---|------------------|------------------|-----------------|
| Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic?                | 84.4%<br>(54/64) | 7.8%<br>(5/64)   | 7.8%<br>(5/64)  |
| Do you think that medical personnel should always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients' safety? | 68.8%<br>(44/64) | 18.8%<br>(12/64) | 12.5%<br>(8/64) |

212 N = total number of women who answered the question, n = number of respondents to the specific  
213 answer

### 214 Factors influencing decision making related to hygiene practices during the pandemic

215

216 We examined group differences using the Mann-Whitney-U-test to identify subsets of  
217 patients with similar expectations and assess differences between those who had definite  
218 opinions of the facilities' hygiene management during the pandemic and answered "yes" (vs  
219 "no") to the questions and their counterparts. Missing data included all participants who did  
220 not answer the relevant question or did not have a definite opinion of the topic ("do not  
221 know/does not apply").

222 None of the demographic, pandemic-specific or disease-specific factors were found to have a  
223 significant influence on the respondents' opinions with respect to the hygiene measures  
224 implemented during the pandemic (all p-values > 0.05) (Table 3).

225

226 **Table 3: Influence of demographic, disease-specific and pandemic-specific factors on**  
227 **expectations regarding the prevention of SARS-CoV-2 transmission**

|                                     | 1                  | 2     | 3     | 4     | 5     | 6     | 7     | 8     | 9     |
|-------------------------------------|--------------------|-------|-------|-------|-------|-------|-------|-------|-------|
| Age                                 | 0.441 <sup>1</sup> | 0.373 | 0.316 | 0.100 | 0.102 | 0.487 | 0.263 | 0.729 | 0.821 |
|                                     |                    | 1     | 1     | 1     | 1     | 1     | 1     | 1     | 1     |
| Stable partnership<br>(no vs yes)   | 0.999 <sup>3</sup> | 0.508 | 0.645 | 0.999 | 0.999 | 0.999 | 0.999 | 0.368 | 0.999 |
|                                     |                    | 3     | 3     | 3     | 3     | 3     | 3     | 3     | 3     |
| Living alone (yes vs<br>no)         | 0.348 <sup>3</sup> | 0.508 | 0.999 | 0.999 | 0.999 | 0.577 | 0.133 | 0.999 | 0.567 |
|                                     |                    | 3     | 3     | 3     | 3     | 3     | 3     | 3     | 3     |
| Living with children<br>(yes vs no) | 0.104 <sup>2</sup> | 0.676 | 0.537 | 0.999 | 0.999 | 0.784 | 0.179 | 0.646 | 1.846 |
|                                     |                    | 3     | 2     | 3     | 3     | 2     | 2     | 3     | 2     |

|  |                    |                    |                    |                    |                    |                    |                    |                    |                    |
|--|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|
| Living with an elderly person (yes vs no)  | 0.999 <sup>3</sup> | 0.508 <sub>3</sub> | 0.296 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.541 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> |
| Living with a partner (yes vs no)  | 0.233 <sup>2</sup> | 0.208 <sub>2</sub> | 0.824 <sub>2</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.922 <sub>2</sub> | 0.098 <sub>2</sub> | 0.999 <sub>3</sub> | 0.962 <sub>2</sub> |
| Tertiary level education (yes vs no)   | 0.558 <sup>2</sup> | 0.717 <sub>3</sub> | 0.793 <sub>2</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.542 <sub>2</sub> | 0.999 <sub>3</sub> | 0.244 <sub>2</sub> |
| Having had COVID (yes vs no)   | 0.999 <sup>3</sup> | 0.547 <sub>3</sub> | 0.535 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.556 <sub>3</sub> | 0.999 <sub>3</sub> | 0.522 <sub>3</sub> |
| Someone in their social network having COVID (yes vs no)   | 0.123 <sup>2</sup> | 0.648 <sub>3</sub> | 0.596 <sub>2</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.551 <sub>2</sub> | 0.982 <sub>2</sub> | 0.308 <sub>3</sub> | 0.096 <sub>2</sub> |
| Reduction of social contact (serious and very serious reduction vs low reduction)                            | 0.999 <sup>3</sup> | 0.360 <sub>3</sub> | 0.512 <sub>2</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.800 <sub>2</sub> | 0.442 <sub>2</sub> | 0.577 <sub>3</sub> | 0.622 <sub>2</sub> |
| Risk profiling for OC and BC (-/+ family history but no mutation vs BRCA1 & 2 vs a mutation other than BRCA) | 0.578 <sup>3</sup> | 0.604 <sub>3</sub> | 0.263 <sub>3</sub> | 0.129 <sub>3</sub> | 0.295 <sub>3</sub> | 0.744 <sub>3</sub> | 0.793 <sub>3</sub> | 0.450 <sub>3</sub> | 0.452 <sub>3</sub> |
| Having a history of in situ or invasive BC or OC (yes vs no)   | 0.768 <sup>2</sup> | 0.930 <sub>2</sub> | 0.836 <sub>2</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.163 <sub>2</sub> | 0.179 <sub>2</sub> | 0.999 <sub>3</sub> | 0.185 <sub>2</sub> |
| History of invasive BC (yes vs no)   | 0.999 <sup>3</sup> | 0.353 <sub>2</sub> | 0.887 <sub>2</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.249 <sub>2</sub> | 0.383 <sub>2</sub> | 0.639 <sub>3</sub> | 0.573 <sub>2</sub> |
| History of invasive OC (yes vs no)   | 0.999 <sup>3</sup> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> |

228 1- Would you have liked to be informed about hygiene protocols in advance of your appointment?, 2-  
 229 Would more information about the prevailing hygiene protocols have had a positive influence on your  
 230 behavior (e.g., meeting appointments)?, 3- Do you think that patients should be tested for SARS-CoV-  
 231 2 infection before an ambulatory visit/appointment?, 4- Do you think that medical personnel/physicians  
 232 should be tested for SARS-CoV-2 infection on a regular basis?, 5- Do you think that appointments  
 233 should be scheduled in such a way to ensure that distancing rules can be strictly observed? 6- Should  
 234 a relative or trustworthy person be allowed to accompany patients in the healthcare setting, despite the  
 235 COVID-19 pandemic? 7- Do you think/agree that appointments, which do not require one's physical  
 236 presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences



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3 237 during the COVID-19 pandemic? 8- Do you think that medical personnel should at least wear an FFP-1  
4 238 mask (surgical mask) during the COVID-19 pandemic? 9- Do you think that medical personnel should  
5 239 always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients' safety?; vs =  
6 240 versus, BC = breast cancer, OC = ovarian cancer. The significance level was set at  $p < 0.05$  (<sup>1</sup> = Mann-  
7 241 Whitney-U-test; <sup>2</sup> =  $\chi^2$ -test, 2-sided; <sup>3</sup> = Fisher exact test, 2-sided).  
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## 13 243 Discussion

14 244  
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17 245 Our analysis provides a descriptive analysis of participants' expectations for preventive  
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21 246 healthcare measures in medical institutions during the SARS-CoV-2 pandemic in  
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24 247 Germany. During a pandemic, the implementation of strict contingency plans in medical  
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27 248 institutions is vital. In the beginning of the SARS-CoV-2 pandemic, in January 2020, 41% of the  
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30 249 novel infections seemed to be hospital acquired [6], fueling the spread of the virus among the  
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33 250 wider population. Viral transmission to patients in healthcare facilities will affect the  
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35 251 population with a higher incidence of pre-existing medical conditions, and thus, with a higher  
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37 252 risk for a severe course of the disease [7]. Additionally, infection among HCW could lead to  
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40 253 shortages of qualified personnel to care for the patients, bringing the healthcare system to  
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42 254 the brink of decompensation. Thus, adequate and effective protection of both patients and  
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45 255 HCW are of paramount importance [8].  
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48 256 Persons, including patients with pre-existing medical conditions might be very sensitive to the  
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50 257 proper observance of contingency plans in medical institutions. This is understandable  
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52 258 because the risks for severe and fatal COVID-19 is higher in the aged population and in persons  
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55 259 with comorbidities [7], [9], [10]. One study found that patients with cancer were 10-fold more  
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58 260 susceptible to acquiring nosocomial infections with the SARS-CoV-2 virus than were patients  
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60 261 without cancer [10]. The observed 49% reduction in outpatient appointments for breast-

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3 262 cancer follow-up during the pandemic [11], [12] was either a result of responses to hygiene  
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5 263 plans or protocols within medical institutions or because of patients' worries about becoming  
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8 264 infected with COVID-19 while visiting healthcare facilities. For reassurance, 37.5% of the  
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10 265 participants in this study preferred to be informed of the healthcare facility's hygiene  
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12 266 protocols in advance of medical appointments. More interestingly, over 20% of participants  
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15 267 stated that receiving prior information about safety protocols during the COVID-19 pandemic  
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17 268 would have strengthened their adherence to medical appointments. The dissemination of  
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19 269 information that is valuable, transparent and proactive has been recognized previously by the  
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22 270 WHO as an essential tool to overcome various difficulties or insecurities triggered by the  
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25 271 pandemic [8].

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28 272 The use of physical distancing to limit exposure to potentially infectious aerosols, was widely  
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30 273 recommended [7], [8], [13]. Approximately 93.8% of participants in this study expected  
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32 274 adherence to the recommended physical distancing rules in waiting rooms. The  
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34 275 recommended physical distancing protocol had a decisive influence on the visiting policies of  
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36 276 medical institutions [7]. Al-Shamsi et al. suggested that clinic attendance in outpatient settings  
37  
38 277 should be limited to the patient and one visitor [2]. Nevertheless, one of the pillars of patient-  
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40 278 centered care has proven to be family involvement [14]. One study found that up to 46% of  
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42 279 adult patients were accompanied by family members to routine visits with their physicians  
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44 280 [14]. Family members, friends and caregivers mediate the patient's psychosocial and  
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46 281 emotional support, encouragement and reassurance, thereby improving the communication  
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48 282 processes during medical visits and influencing patients' satisfaction with the physician's care  
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50 283 [2], [14]–[16]. Medical appointments are an anxiety-provoking experience for patients,  
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52 284 especially for those facing a possible or existing malignant diagnosis. The word "distress" is  
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54 285 mentioned by patients with cancer who were denied the option of having a family member or

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3 286 friend with them during medical appointments [17]. Although the respondents in this study  
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6 287 endorsed vigilant sanitary precautions to prevent nosocomial infections, an overwhelming  
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8 288 proportion (75.0%) supported the possibility of being accompanied by a significant other  
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10 289 during medical consultations, irrespective of their demographic, disease-specific or pandemic-  
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13 290 specific characteristics. The company of a trustworthy person seemed to be clearly important  
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15 291 for our study's participants.

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18 292 Other experts have managed to attenuate the detrimental effects of the pandemic on  
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21 293 screening and provide follow-up care for patients with cancer by implementing telemedicine  
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23 294 appointments [7], [11]. The use of telemedicine has been described as a method for patients  
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26 295 and physicians to stay in touch and informed while reducing physical contact [2], [17]–[19].  
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28 296 Notably, 71.9% of the participants in this study approved implementation of telemedicine  
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31 297 whenever possible and reasonable from an oncological viewpoint, in order to reduce face-to-  
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33 298 face contact and minimize potential contact with persons infected with SARS-CoV-2, but  
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36 299 maintain the required standards for treatment. Telemedicine appointments would be  
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38 300 impossible in cases requiring physical examinations or imaging procedures, but it would be a  
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40 301 good choice for offering a second opinion [11].

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43 302 The WHO has stated that regular and widespread testing is crucial to contain the virus and  
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46 303 stop the pandemic [7], [8]. The transmission of nosocomial infections, both patient-to-patient  
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48  
49 304 and patient-to-healthcare-personnel, has been reported previously [6]. These infections  
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51 305 occur, presumably, by transmission from asymptomatic or pre-symptomatic carriers or  
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53 306 persons with mild or atypical symptoms [6], [20]. Precautions are essential, as 17.9% to 33.3%  
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56 307 of patients may have an asymptomatic COVID-19 infection [2]. While pre-operative testing has  
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58 308 been recommended by various medical societies worldwide, and the testing of in-patients  
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60 309 upon their admission to the hospital has been introduced by the vast majority of healthcare

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3 310 facilities [21], regular testing of patients prior to ambulatory appointments to avoid  
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5 311 nosocomial spread among HCWs or other patients, was not. Interestingly, 57.8% of our study's  
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7 312 population indicated they would rather tolerate the inconvenience of repetitive testing before  
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9 313 visiting a healthcare institution, in order to feel safe and avoid exposure to potentially life-  
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11 314 threatening infectious agents.

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16 315 The protection of HCWs from COVID-19 serves both sides: maintaining medical care and  
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18 316 protecting the vulnerable population from a possible fatal nosocomial infection with SARS-  
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20 317 CoV-2 [9]. In Germany, HCWs were tested only if they were symptomatic or were eligible for  
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22 318 the national contact-tracing program (documented contact with an infected person without  
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24 319 adequate personal protective equipment). Nevertheless, data from the United Kingdom  
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26 320 showed that up to 3% of asymptomatic HCWs were infected with SARS-CoV-2 [22]. According  
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28 321 to mathematical models, regular polymerase-chain-reaction(PCR)-based screening of HCWs,  
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30 322 irrespective of whether they are symptomatic or asymptomatic, could reduce their  
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32 323 contribution to transmission by up to 33% [23]. This study showed that 93% of patients  
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34 324 strongly supported the notion of broad screening programs for HCW, irrespective of their  
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36 325 demographic, disease-specific or pandemic-specific factors.

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43 326 HCWs have a significantly high risk for acquiring COVID-19, based on national and  
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45 327 international data [23], [24]. According to some reports, HCWs acquired COVID-19 through  
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47 328 nosocomial transmission in up to 29% of reported cases (China, January 2020) [6]. Thus,  
48  
49 329 effective control of the source of infection is crucial in healthcare facilities. The use of personal  
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51 330 protective equipment by HCW and patients in medical institutions was recommended by their  
52  
53 331 national centers for disease control [2], [8], [13], [21], [25]. A meta-analysis conducted by  
54  
55 332 Iannone et al. found a significant benefit from wearing masks in mitigating the transmission  
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57 333 of SARS-CoV-2 [26]. During an infection outbreak, wearing a N-95 mask or an FFP-2 respirator

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3 334 cuts the risk in half for clinical respiratory infections in HCWs, compared to wearing only a  
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6 335 surgical mask [26], [27]. Furthermore, the protection of HCWs may reduce secondary  
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8 336 transmission of the virus and nosocomial infections. During simulation tests of the spread of  
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10 337 SARS-CoV-2 droplets/aerosols, medical masks and cloth face coverings were 57%–58%  
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12 338 effective in protecting others and 37%–50% effective in protecting the wearer, while the N-  
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14 339 95/FFP-2 masks were more effective in protecting others (effectivity: 86%–90%) as well as the  
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16 340 wearer (effectivity: 96%–99%) [28].  
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## 21 341 Limitations

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23 342 This study has several limitations due to its design (cross-sectional web-based survey). First,  
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25 343 there might be an overrepresentation of patients worrying about their health status because  
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27 344 of their recruitment from support groups and the underrepresentation of women without  
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29 345 online access are two possible sources of bias. Nevertheless, a recent systematic review  
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31 346 showed that Facebook-recruited samples were similarly representative as samples recruited  
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33 347 via traditional methods [29]. Furthermore, as the patients responded directly to the  
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35 348 questionnaire, social desirability bias was greatly limited.  
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41 349 Second, this study was conducted during the first months of 2021. In Germany, the first  
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43 350 vaccine against COVID-19 was approved by emergency use authorization in December 2020  
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45 351 (Comirnaty®, BioNTech Manufacturing, Germany), followed by the emergency authorization  
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47 352 of two other vaccines in January 2021 (COVID-19 Vaccine Moderna, Moderna Biotech, USA  
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49 353 and Vaxzevria, AstraZeneca Life Science, UK) [30]. Due to the strict criteria for prioritizing  
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51 354 eligibility for vaccinations in Germany, the COVID-19 vaccines were inaccessible for a large  
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53 355 proportion of the population during the time we conducted the survey, even for patients at  
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55 356 risk, such as those with active or previous oncological disorders [31], [32]. We did not assess  
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57 357 participants' vaccination status; however, we presumed that most of them were not  
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3 358 vaccinated because of national regulations during the survey period. Thus, we do not know  
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5 359 whether the responses accurately depict the current state of the pandemic, as expectations  
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8 360 may have changed due to the currently available vaccines.  
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## 12 13 14 15 362 **Strengths**

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18 364 The COVID-19 pandemic changed the way patient care is delivered. Strict measures to contain  
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21 365 the virus were implemented swiftly after the onset of the pandemic by experts in infectious  
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23 366 diseases and politicians. Due to the course of the pandemic, there was no possibility to assess  
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26 367 the needs and expectations of patients regarding specific hygiene measures before putting  
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28 368 those in place. Our study identified several patient-approved contingency measures for the  
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31 369 protection of patients and healthcare workers from COVID-19 infection, which are essential in  
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33 370 terms to improve the staffs' preparedness to cope with the course of this pandemic or similar  
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35 371 situations.

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38 372 The high risk and vulnerable groups in our study seemed to approve the most vigilant and  
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41 373 strict contingency programs designed to lower the risk of transmission in medical facilities,  
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43 374 irrespective of demographic, disease-specific or pandemic-specific factors. Additionally, to our  
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46 375 knowledge, this is the first study to assess the wishes of patients with respect to being  
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48 376 accompanied by a person of trust during medical appointments during the pandemic. The  
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51 377 possibility of being accompanied by a trustworthy person seemed to be non-negotiable for  
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53 378 most of the participants in the study. Thus, in addition to the strict visitation policies for  
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56 379 outpatients and rules restricting visitation for hospitalized patients, we also need innovative  
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58 380 strategies to maintain and improve the experiences of patients during the COVID-19  
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60 381 pandemic, such as allowing, that patients are accompanied by a person of trust, provided that

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3 382 they comply with strict precautions measures, for e.g. by providing a current negative SARS-  
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5 383 CoV-2 test result or proof of immunization.  
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9 384 As we assessed participants' needs, fears and expectations, we followed the WHO  
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11 385 recommendation for two-way communication with populations at risk [8]. Our goal is to  
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13 386 improve and optimize the public health measures, which could be implemented during a next  
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15 387 wave of the COVID-19 pandemic or other possible pandemics.  
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## 20 21 22 389 Conclusion

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28 391 In conclusion, we showed that most patients at high risk for infection or severe course of  
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30 392 COVID-19 disease approve strict contingency measures, such as physical distancing rules, the  
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32 393 implementation of telemedicine and the use of highly effective protective masks, designed to  
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34 394 lower the transmission of COVID-19 in medical facilities. However, they also value the  
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36 395 presence of a significant other during medical consultations and procedures.  
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## 42 43 44 45 397 Acknowledgements:

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49 399 We thank

- 50  
51  
52 400 - the support group for persons at high risk for breast and/or ovarian cancer for their  
53 401 engagement in the promotion of this survey.  
54  
55 402 - all participants for participating in our study.  
56 403 Parts of the presented results are part of the doctoral thesis of Ms. Annika Droste.  
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## 405 Author contributions:

406 RS and AD conceptualised the study and planned the data analysis, acquired the data and  
407 drafted the manuscript. KS, WB, MS, and AH, offered intellectual input and provided critical  
408 revision. RS and AD performed the data analysis. All authors contributed to the drafts and  
409 approved the final version of the manuscript for publication.

## 410 Funding:

411 The authors have not declared a specific grant for this research from any funding agency in  
412 the public, commercial or not-for-profit sectors.

## 414 Data availability:

415 Data are available on reasonable request to bona fide researchers.

## 417 Conflicts of interests:

418 RS:

419 Honoraria: Roche Pharma AG, AstraZeneca, Streamedup!GmbH

421 MS: received personal fees from AstraZeneca, BioNTech, Eisai, Lilly, MSD, Novartis, Pantarhei  
422 Bioscience, Pfizer, Roche, and SeaGen. Institutional research funding from AstraZeneca,  
423 BioNTech, Eisai, Genentech, German Breast Group, Novartis, Palleos, Pantarhei Bioscience,  
424 Pierre-Fabre, and Roche. Travel reimbursement from Pfizer and Roche. In addition, M.S. is  
425 named as an inventor on patent EP 2390370 B1 and granted patent EP 2951317 B1.

427 AH:



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3 428 Honoraria: AstraZeneca; Celgen; MedConcept GmbH, Med update GmbH; Medicultus; Pfizer;  
4  
5 429 Promedicis GmbH; Softconsult; Roche Pharma AG; Streamedup! GmbH; Tesaro Bio Germany  
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8 430 GmbH, LEO Pharma  
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10 431 Ad Board: PharmaMar; Promedicis GmbH; Roche Pharma AG; Tesaro Bio Germany GmbH,  
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13 432 AstraZeneca, LEO Pharma, MSD Sharp&Dohme GmbH  
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1  
2  
3 How old are you? [ ] years  
4

5 Do you live in a stable partnership? (Yes – No)  
6

7 How would you describe your home/private environment?  
8

- 9 - *Living alone (Yes – No)*  
10 - *Living with children under 18 years (Yes – No)*  
11 - *Living with older people (over 65 years) (Yes – No)*  
12 - *Living with my spouse/life partner (Yes – No)*  
13 - *others*  
14  
15  
16  
17

18 What is your highest educational qualification?  
19

20 Are/was you infected by the SARS-CoV-2-virus yourself? (Yes – No)  
21

22 Is/was someone in your environment infected with the SARS-CoV-2-virus? (Yes – No)  
23  
24  
25

26 How much, on average, did you reduce your social contact network in the last 12 months  
27 due to the covid-19-pandemic?  
28

29 *Not at all – a little – moderate – significant – very much*  
30  
31  
32

### 33 Questions about your risk of developing breast and/or ovarian cancer 34

35 To which risk group do you belong:  
36

- 37 - I was diagnosed with a mutation in the BRCA1 or BRCA2 gene  
38 - I was diagnosed with a different mutation (except BRCA1 or BRCA2 gene)  
39 - I have an increased risk due to my family history, but I wasn't diagnosed with a gene  
40 mutation (yet)  
41  
42  
43

44 Are/was you already suffering from breast and/or ovarian cancer (benign tumors excluded)  
45

46 *(multiple selection possible)*  
47

- 48 - no, I am not/was not previously diagnosed with invasive breast and/or ovarian  
49 cancer or the respective premalignant lesions (in situ)  
50 - yes, I am/was diagnosed with insitu breast lesions  
51 - yes, I am/was diagnosed with in situ ovarian/tubal lesions  
52 - I am/was diagnosed with invasive breast cancer  
53 - I am/was diagnosed with invasive ovarian cancer  
54  
55  
56  
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58

59 Below we are interested in your opinion on hygiene measures in clinics during the covid-19-  
60 pandemic:

- 1  
2  
3  
4  
5 1. Would you have liked to be informed about hygiene protocols in advance of your  
6  
7 appointment? *(Yes – No – I don't know/does not apply)*  
8  
9
- 10  
11 2. Would more information about the prevailing hygiene protocols have had a positive  
12  
13 influence on your behavior (e.g., meeting appointments)? *Yes – No – I don't know/does not*  
14  
15 *apply*  
16  
17
- 18  
19 3. Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory  
20  
21 visit/appointment? *Yes – No – I don't know/does not apply*  
22  
23
- 24  
25 4. Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection  
26  
27 on a regular basis? *Yes – No – I don't know/does not apply*  
28  
29
- 30  
31 5. Do you think that appointments should be scheduled in such a way to ensure that distancing  
32  
33 rules can be strictly observed? *Yes – No – I don't know/does not apply*  
34  
35
- 36  
37 6. Should a relative or trustworthy person be allowed to accompany patients in the healthcare  
38  
39 setting, despite the COVID-19 pandemic? *Yes – No – I don't know/does not apply*  
40  
41
- 42  
43 7. Do you think/agree that appointments, which do not require one's physical presence (e.g.,  
44  
45 counseling appointments) should be conducted as teleconferences or video conferences  
46  
47 during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*  
48  
49
- 50  
51 8. Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask)  
52  
53 during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*  
54  
55
- 56  
57 9. Do you think that medical personnel should always wear an FFP-2 mask masks during the  
58  
59 COVID-19 pandemic to ensure patients' safety? *Yes – no – I don't know/does not apply*  
60

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

|                              | Item No | Recommendation   | Page No |
|------------------------------|---------|--|---------|
| <b>Title and abstract</b>    | 1       | <b>Patients' expectations of preventive measures of medical institutions during the SARS-CoV-2 pandemic in Germany in women with an increased risk for breast and ovarian cancer</b>   | 1       |
| <b>Introduction</b>          |         |  |         |
| Background/rationale         | 2       | During the COVID-19 pandemic, several strategies were implemented to contain the viral spread within medical institutions, in order to protect persons at higher risk for infection or severe course of the disease, such as patients with active cancers, cancer survivors or healthcare workers (HCW).   | 2       |
| Objectives                   | 3       | To identify patient-approved contingency measures for the protection of patients and healthcare workers from COVID-19 infection, and to use these findings to improve the staffs' preparedness to cope with the course of this pandemic or similar situations.   | 2       |
| <b>Methods</b>               |         |  |         |
| Study design                 | 4       | Cross-sectional web-based survey   |         |
| Setting                      | 5       | Web-based survey delivered by support groups of persons with increased risk for ovarian or breast cancer.<br>89 potential participants accessed the questionnaire. Data were collected anonymously. 80% (64/80) answered at least one question pertaining to hygiene management and expectations for preventive measures, and 20% (16/80) did not answer any questions pertaining to preventive measures related to the pandemic   | 8       |
| Participants                 | 6       | Women at increased risk for ovarian and breast cancer, irrespective if they had experienced an oncological diagnosis at the time point of the survey. All participants were aged 18 years or older. All participants gave consent to participate in the study.   | 5       |
| Variables                    | 7       | Outcomes: expectations regarding different contingency measures with respect to the COVID-19 pandemic  | 6       |
| Data sources/<br>measurement | 8*      |  |         |
| Bias                         | 9       | Web-based survey, patient requirement by support groups. A recent systematic review showed that Facebook-recruited samples were similarly representative as samples recruited via traditional methods.   | 17      |
| Study size                   | 10      | All participants who responded at least one question with respect to contingency measures.   | 8       |
| Quantitative variables       | 11      |  |         |
| Statistical methods          | 12      | (a) Data were analyzed using SPSS 26.0 (SPSS Inc., Chicago, IL, USA). Descriptive statistics are expressed as mean, standard deviation (SD), median, interquartile range (IQR) or proportions (%), as appropriate. We used the Mann-Whitney-U-test, the $\chi^2$ -test and the Fisher exact test to analyze the data for differences between the responders and non-responders to the survey's questions.<br>The Mann-Whitney-U-test, $\chi^2$ -test or Fisher exact test were used as appropriate, to compare differences of expectations according to demographic, disease-specific and pandemic-specific variables. The p-values were calculated using a 95% confidence interval. A p-value < 0.05 was considered statistically significant. Because the p-values were not adjusted for multiple testing, all results should be interpreted as exploratory. | 7       |
|                              |         | (b) The significance level was set at p < 0.05<br>Significance between groups was assessed by.   | 7       |

<sup>1</sup> = Mann-Whitney-U-test; <sup>2</sup> =  $\chi^2$ -test, 2-sided; <sup>3</sup> = Fisher exact test, 2-sided).

(c) For descriptive analyses, missing data consisted of participants who did not answer the survey's questions.

## Results

|              |     |   |   |
|--------------|-----|---|---|
| Participants | 13* | (a) 80% (64/80) answered at least one question pertaining to hygiene management and expectations for preventive measures<br>(b) Give reasons for non-participation at each stage: participants did not answer the questions | 8 |
|--------------|-----|---|---|

| Descriptive data                     | 14*          | (a)  | 8                          |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
|--------------------------------------|--------------|--|----------------------------|--|-----------------|-------------|--|------------|--|--|--|--|--|-----------|---------------|---------------|--------------------|--|--------------|----------------------------|----------------------------|-------------------------------------|--|--|--|--|-----|--------|-------------|--------------|--------------------|----|--------|----------|------------|---------------------|--|--|--|--|-----|--------|-------------|--------------|--------------------|----|--------|----------|------------|--------------------------------------|--|--|--|--|-----|----------|-------------|--------------|--------------------|----|--------|--------------|--------------|------------------------------------|--|--|--|--|-----|--------|-------------|------------|--------------------|----|--------|--------------|--------------|------------------------------|--|--|--|--|-----|--------|--------------|--------------|--------------------|----|--------|-------------|--------------|------------------|--|--|--|--|---------------------------------|--------|--------------|--------------|--------------------------|--------------------------|--------|-------------|--------------|--|
|                                      |              | <table border="1"> <thead> <tr> <th></th> <th></th> <th>Non-respondents</th> <th>Respondents</th> <th>p-value (Non-respondents group vs the Respondents group)</th> </tr> </thead> <tbody> <tr> <td colspan="5" style="text-align: center;"><b>Age</b></td> </tr> <tr> <td></td> <td>Mean (SD)</td> <td>46.64 (2.210)</td> <td>42,85 (1.363)</td> <td rowspan="2">0.161<sup>1</sup></td> </tr> <tr> <td></td> <td>Median (IQR)</td> <td>47.50 (40.00-54.00) (N=14)</td> <td>43.00 (33.75-51.25) (N=62)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Having a stable relationship</b></td> </tr> <tr> <td>Yes</td> <td>% of N</td> <td>100 (14/14)</td> <td>90.6 (58/64)</td> <td rowspan="2">0.236<sup>1</sup></td> </tr> <tr> <td>No</td> <td>% of N</td> <td>0 (0/14)</td> <td>9.4 (6/64)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Living alone</b></td> </tr> <tr> <td>Yes</td> <td>% of N</td> <td>100 (16/16)</td> <td>90.6 (58/64)</td> <td rowspan="2">0.340<sup>1</sup></td> </tr> <tr> <td>No</td> <td>% of N</td> <td>0 (0/16)</td> <td>9.4 (6/64)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Living with children &lt; 18y</b></td> </tr> <tr> <td>Yes</td> <td>% of n/N</td> <td>25.0 (4/16)</td> <td>34.4 (22/64)</td> <td rowspan="2">0.474<sup>2</sup></td> </tr> <tr> <td>No</td> <td>% of N</td> <td>75.0 (12/16)</td> <td>65.6 (42/64)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Living with persons &gt;65y</b></td> </tr> <tr> <td>Yes</td> <td>% of N</td> <td>12.5 (2/16)</td> <td>6.2 (4/64)</td> <td rowspan="2">0.399<sup>1</sup></td> </tr> <tr> <td>No</td> <td>% of N</td> <td>87.5 (14/16)</td> <td>93.8 (60/64)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Living with a partner</b></td> </tr> <tr> <td>Yes</td> <td>% of N</td> <td>62.5 (10/16)</td> <td>60.9 (39/64)</td> <td rowspan="2">0.909<sup>2</sup></td> </tr> <tr> <td>No</td> <td>% of N</td> <td>37.5 (6/16)</td> <td>39.1 (25/64)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Education</b></td> </tr> <tr> <td>Up to secondary level education</td> <td>% of N</td> <td>84.6 (11/13)</td> <td>48.4 (31/64)</td> <td rowspan="2"><b>0.017<sup>2</sup></b></td> </tr> <tr> <td>Tertiary level education</td> <td>% of N</td> <td>15.4 (2/13)</td> <td>51.6 (33/64)</td> </tr> </tbody> </table> |                            |  | Non-respondents | Respondents | p-value (Non-respondents group vs the Respondents group) | <b>Age</b> |  |  |  |  |  | Mean (SD) | 46.64 (2.210) | 42,85 (1.363) | 0.161 <sup>1</sup> |  | Median (IQR) | 47.50 (40.00-54.00) (N=14) | 43.00 (33.75-51.25) (N=62) | <b>Having a stable relationship</b> |  |  |  |  | Yes | % of N | 100 (14/14) | 90.6 (58/64) | 0.236 <sup>1</sup> | No | % of N | 0 (0/14) | 9.4 (6/64) | <b>Living alone</b> |  |  |  |  | Yes | % of N | 100 (16/16) | 90.6 (58/64) | 0.340 <sup>1</sup> | No | % of N | 0 (0/16) | 9.4 (6/64) | <b>Living with children &lt; 18y</b> |  |  |  |  | Yes | % of n/N | 25.0 (4/16) | 34.4 (22/64) | 0.474 <sup>2</sup> | No | % of N | 75.0 (12/16) | 65.6 (42/64) | <b>Living with persons &gt;65y</b> |  |  |  |  | Yes | % of N | 12.5 (2/16) | 6.2 (4/64) | 0.399 <sup>1</sup> | No | % of N | 87.5 (14/16) | 93.8 (60/64) | <b>Living with a partner</b> |  |  |  |  | Yes | % of N | 62.5 (10/16) | 60.9 (39/64) | 0.909 <sup>2</sup> | No | % of N | 37.5 (6/16) | 39.1 (25/64) | <b>Education</b> |  |  |  |  | Up to secondary level education | % of N | 84.6 (11/13) | 48.4 (31/64) | <b>0.017<sup>2</sup></b> | Tertiary level education | % of N | 15.4 (2/13) | 51.6 (33/64) |  |
|                                      |              | Non-respondents  | Respondents                | p-value (Non-respondents group vs the Respondents group) |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Age</b>                           |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
|                                      | Mean (SD)    | 46.64 (2.210)  | 42,85 (1.363)              | 0.161 <sup>1</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
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| <b>Having a stable relationship</b>  |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Yes                                  | % of N       | 100 (14/14)  | 90.6 (58/64)               | 0.236 <sup>1</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| No                                   | % of N       | 0 (0/14)   | 9.4 (6/64)                 |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Living alone</b>                  |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Yes                                  | % of N       | 100 (16/16)  | 90.6 (58/64)               | 0.340 <sup>1</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| No                                   | % of N       | 0 (0/16)   | 9.4 (6/64)                 |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Living with children &lt; 18y</b> |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Yes                                  | % of n/N     | 25.0 (4/16)  | 34.4 (22/64)               | 0.474 <sup>2</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| No                                   | % of N       | 75.0 (12/16)   | 65.6 (42/64)               |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Living with persons &gt;65y</b>   |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Yes                                  | % of N       | 12.5 (2/16)  | 6.2 (4/64)                 | 0.399 <sup>1</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| No                                   | % of N       | 87.5 (14/16)   | 93.8 (60/64)               |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Living with a partner</b>         |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Yes                                  | % of N       | 62.5 (10/16)   | 60.9 (39/64)               | 0.909 <sup>2</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| No                                   | % of N       | 37.5 (6/16)  | 39.1 (25/64)               |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Education</b>                     |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Up to secondary level education      | % of N       | 84.6 (11/13)   | 48.4 (31/64)               | <b>0.017<sup>2</sup></b>                                 |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Tertiary level education             | % of N       | 15.4 (2/13)  | 51.6 (33/64)               |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |



| <b>Did you have COVID-19</b>                               |        |              |               |                    |
|--|--------|--------------|---------------|--------------------|
| Yes  | % of N | 0 (0/13)     | 4.7 (3/64)    | 0.429 <sup>1</sup> |
| No   | % of N | 100 (13/13)  | 95.3 (61/64)  |                    |
| <b>Someone in your social network has had COVID-19</b>     |        |              |               |                    |
| Yes  | % of N | 23.1 (3/13)  | 28.6 (18/63)  | 0.687 <sup>2</sup> |
| No   | % of N | 76.9 (10/13) | 71.4 (45/63)  |                    |
| <b>Reduction of social network</b>                         |        |              |               |                    |
| Moderate reduction   | % of N | 15.4 (2/13)  | 15.6 (10/64)  | 0.983 <sup>2</sup> |
| Large reduction  | % of N | 84.6 (11/13) | 84.4 (54/64)  |                    |
| <b>Risk profiling for OC and BC</b>                        |        |              |               |                    |
| BRCA 1 & 2   | % of N | 76.9 (10/13) | 70.3 (45/64)  | 0.895 <sup>3</sup> |
| Mutations other than BRCA 1 & 2                            | % of N | 15.4 (2/13)  | 14.10 (9/64)  |                    |
| Positive family history for BC or OC                       | % of N | 7.7 (1/13)   | 15.6 (10/64)  |                    |
| <b>Having a history of (in situ or invasive) OC and BC</b> |        |              |               |                    |
| Yes  | % of N | 73.3 (11/15) | 64.1 (41/64)  | 0.496 <sup>2</sup> |
| No   | % of N | 26.7 (4/15)  | 35.9 (23/64)  |                    |
| <b>Having a history of invasive BC</b>                     |        |              |               |                    |
| Yes  | % of N | 60 (9/15)    | 56.20 (36/64) | 0.792 <sup>2</sup> |
| No   | % of N | 40 (6/15)    | 43.80 (28/64) |                    |
| <b>Having a history of invasive OC</b>                     |        |              |               |                    |
| Yes  | % of N | 6.7 (1/15)   | 1.6 (1/64)    | 0.260 <sup>1</sup> |
| No   | % of N | 93.3 (14/15) | 98.4 (63/64)  |                    |

(b)

| <b>Questions</b>  | <b>Yes</b><br>in % of respondents<br>(n/N) | <b>No</b><br>in % of respondents<br>(n/N) | <b>I don't know/does not apply</b><br>in % of respondents<br>(n/N) |
|---|--|---|--|
| Would you have liked to be informed about hygiene protocols in advance of your appointment? | 37.5% (24/64)                              | 37.5% (24/64)                             | 25.0% (16/64)  |
| Would more information about the prevailing hygiene protocols have                          | 20.3% (13/64)                              | 31.3% (20/64)                             | 48.4% (31/64)  |

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|  |                  |                  |                  |
|--|------------------|------------------|------------------|
| had a positive influence on your behavior (e.g., meeting appointments)?  |                  |                  |                  |
| Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment?   | 57.8%<br>(37/64) | 26.6%<br>(17/64) | 15.6%<br>(10/64) |
| Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis?   | 95.3%<br>(61/64) | 1.6%<br>(1/64)   | 3.1%<br>(2/64)   |
| Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed?   | 93.8%<br>(60/64) | 1.6%<br>(1/64)   | 4.7%<br>(3/64)   |
| Should a relative or trustworthy person be allowed to accompany patients in the healthcare setting, despite the COVID-19 pandemic?   | 75.0%<br>(48/64) | 15.6%<br>(10/64) | 9.4%<br>(6/64)   |
| Do you think/agree that appointments, which do not require one's physical presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? | 71.9%<br>(46/64) | 21.9%<br>(14/64) | 6.3%<br>(4/64)   |
| Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic?   | 84.4%<br>(54/64) | 7.8%<br>(5/64)   | 7.8%<br>(5/64)   |
| Do you think that medical personnel should always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients' safety?  | 68.8%<br>(44/64) | 18.8%<br>(12/64) | 12.5%<br>(8/64)  |

Outcome data

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1. Would you have liked to be informed about hygiene protocols in advance of your appointment? (*Yes – No – I don't know/does not apply*)
2. Would more information about the prevailing hygiene protocols have had a positive influence on your behavior (e.g., meeting appointments)? *Yes – No – I don't know/does not apply*
3. Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment? *Yes – No – I don't know/does not apply*
4. Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis? *Yes – No – I don't know/does not apply*
5. Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed? *Yes – No – I don't know/does not apply*

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6. Should a relative or trustworthy person be allowed to accompany patients in the healthcare setting, despite the COVID-19 pandemic? *Yes – No – I don't know/does not apply*
7. Do you think/agree that appointments, which do not require one's physical presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*
8. Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*
9. Do you think that medical personnel should always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients' safety? *Yes – no – I don't know/does not apply*

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|                                      |              | Non-respondents            | Respondents                | p-value (Non-respondents group vs the Respondents group) |
|--------------------------------------|--------------|----------------------------|----------------------------|--|
| <b>Age</b>                           |              |                            |                            |  |
|                                      | Mean (SD)    | 46.64 (2.210)              | 42,85 (1.363)              | 0.161 <sup>1</sup>                                       |
|                                      | Median (IQR) | 47.50 (40.00-54.00) (N=14) | 43.00 (33.75-51.25) (N=62) |  |
| <b>Having a stable relationship</b>  |              |                            |                            |  |
| Yes                                  | % of N       | 100 (14/14)                | 90.6 (58/64)               | 0.236 <sup>1</sup>                                       |
| No                                   | % of N       | 0 (0/14)                   | 9.4 (6/64)                 |  |
| <b>Living alone</b>                  |              |                            |                            |  |
| Yes                                  | % of N       | 100 (16/16)                | 90.6 (58/64)               | 0.340 <sup>1</sup>                                       |
| No                                   | % of N       | 0 (0/16)                   | 9.4 (6/64)                 |  |
| <b>Living with children &lt; 18y</b> |              |                            |                            |  |
| Yes                                  | % of n/N     | 25.0 (4/16)                | 34.4 (22/64)               | 0.474 <sup>2</sup>                                       |
| No                                   | % of N       | 75.0 (12/16)               | 65.6 (42/64)               |  |
| <b>Living with persons &gt;65y</b>   |              |                            |                            |  |
| Yes                                  | % of N       | 12.5 (2/16)                | 6.2 (4/64)                 | 0.399 <sup>1</sup>                                       |
| No                                   | % of N       | 87.5 (14/16)               | 93.8 (60/64)               |  |
| <b>Living with a partner</b>         |              |                            |                            |  |
| Yes                                  | % of N       | 62.5 (10/16)               | 60.9 (39/64)               | 0.909 <sup>2</sup>                                       |
| No                                   | % of N       | 37.5 (6/16)                | 39.1 (25/64)               |  |
| <b>Education</b>                     |              |                            |                            |  |
| Up to secondary level education      | % of N       | 84.6 (11/13)               | 48.4 (31/64)               | <b>0.017<sup>2</sup></b>                                 |

|  |        |              |               |                    |
|--|--------|--------------|---------------|--------------------|
| Tertiary level education                                   | % of N | 15.4 (2/13)  | 51.6 (33/64)  |                    |
| <b>Did you have COVID-19</b>                               |        |              |               |                    |
| Yes  | % of N | 0 (0/13)     | 4.7 (3/64)    | 0.429 <sup>1</sup> |
| No   | % of N | 100 (13/13)  | 95.3 (61/64)  |                    |
| <b>Someone in your social network has had COVID-19</b>     |        |              |               |                    |
| Yes  | % of N | 23.1 (3/13)  | 28.6 (18/63)  | 0.687 <sup>2</sup> |
| No   | % of N | 76.9 (10/13) | 71.4 (45/63)  |                    |
| <b>Reduction of social network</b>                         |        |              |               |                    |
| Moderate reduction   | % of N | 15.4 (2/13)  | 15.6 (10/64)  | 0.983 <sup>2</sup> |
| Large reduction  | % of N | 84.6 (11/13) | 84.4 (54/64)  |                    |
| <b>Risk profiling for OC and BC</b>                        |        |              |               |                    |
| BRCA 1 & 2   | % of N | 76.9 (10/13) | 70.3 (45/64)  | 0.895 <sup>3</sup> |
| Mutations other than BRCA 1 & 2                            | % of N | 15.4 (2/13)  | 14.10 (9/64)  |                    |
| Positive family history for BC or OC                       | % of N | 7.7 (1/13)   | 15.6 (10/64)  |                    |
| <b>Having a history of (in situ or invasive) OC and BC</b> |        |              |               |                    |
| Yes  | % of N | 73.3 (11/15) | 64.1 (41/64)  | 0.496 <sup>2</sup> |
| No   | % of N | 26.7 (4/15)  | 35.9 (23/64)  |                    |
| <b>Having a history of invasive BC</b>                     |        |              |               |                    |
| Yes  | % of N | 60 (9/15)    | 56.20 (36/64) | 0.792 <sup>2</sup> |
| No   | % of N | 40 (6/15)    | 43.80 (28/64) |                    |
| <b>Having a history of invasive OC</b>                     |        |              |               |                    |
| Yes  | % of N | 6.7 (1/15)   | 1.6 (1/64)    | 0.260 <sup>1</sup> |
| No   | % of N | 93.3 (14/15) | 98.4 (63/64)  |                    |

| Questions  | Yes in % of respondents (n/N) | No in % of respondents (n/N) | I don't know/does not apply in % of respondents (n/N) |
|--|-------------------------------|------------------------------|---|
| Would you have liked to be informed about hygiene protocols in | 37.5% (24/64)                 | 37.5% (24/64)                | 25.0% (16/64)   |

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| advance of your appointment?   |                  |                  |                  |
| Would more information about the prevailing hygiene protocols have had a positive influence on your behavior (e.g., meeting appointments)?   | 20.3%<br>(13/64) | 31.3%<br>(20/64) | 48.4%<br>(31/64) |
| Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment?   | 57.8%<br>(37/64) | 26.6%<br>(17/64) | 15.6%<br>(10/64) |
| Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis?   | 95.3%<br>(61/64) | 1.6%<br>(1/64)   | 3.1%<br>(2/64)   |
| Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed?   | 93.8%<br>(60/64) | 1.6%<br>(1/64)   | 4.7%<br>(3/64)   |
| Should a relative or trustworthy person be allowed to accompany patients in the healthcare setting, despite the COVID-19 pandemic?   | 75.0%<br>(48/64) | 15.6%<br>(10/64) | 9.4%<br>(6/64)   |
| Do you think/agree that appointments, which do not require one's physical presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? | 71.9%<br>(46/64) | 21.9%<br>(14/64) | 6.3%<br>(4/64)   |
| Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic?   | 84.4%<br>(54/64) | 7.8%<br>(5/64)   | 7.8%<br>(5/64)   |
| Do you think that medical personnel should always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients' safety?  | 68.8%<br>(44/64) | 18.8%<br>(12/64) | 12.5%<br>(8/64)  |

(b)  
(c)

|                |    |                   |  |
|----------------|----|-------------------|--|
| Other analyses | 17 | No other analyses |  |
|----------------|----|-------------------|--|

|                   |    |   |       |
|-------------------|----|---|-------|
| <b>Discussion</b> |    |   |       |
| Key results       | 18 | 1. 37.5% of the participants in this study preferred to be informed of the healthcare facility's hygiene protocols in advance of medical appointments. More interestingly, over 20% of participants stated that receiving prior information about safety protocols during the | 13-17 |

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COVID-19 pandemic would have strengthened their adherence to medical appointments. The dissemination of information that is valuable, transparent and proactive has been recognized previously by the WHO as an essential tool to overcome various difficulties or insecurities triggered by the pandemic [8].

2. Approximately 93.8% of participants in this study expected adherence to the recommended physical distancing rules in waiting rooms.
3. Notably, 71.9% of the participants in this study approved implementation of telemedicine whenever possible and reasonable from an oncological viewpoint, in order to reduce face-to-face contact and minimize potential contact with persons infected with SARS-CoV-2, but maintain the required standards for treatment.
4. Interestingly, 57.8% of our study's population indicated they would rather tolerate the inconvenience of repetitive testing before visiting a healthcare institution, in order to feel safe and avoid exposure to potentially life-threatening infectious agents.
5. This study showed that 93% of patients strongly supported the notion of broad screening programs for HCW, irrespective of their demographic, disease-specific or pandemic-specific factors.

|                          |    |  |    |
|--------------------------|----|--|----|
| Limitations              | 19 | <p>First, there might be an overrepresentation of patients worrying about their health status because of their recruitment from support groups and the underrepresentation of women without online access are two possible sources of bias. Nevertheless, a recent systematic review showed that Facebook-recruited samples were similarly representative as samples recruited via traditional methods [29]. Furthermore, as the patients responded directly to the questionnaire, social desirability bias was greatly limited.</p> <p>We did not assess participants' vaccination status; however, we presumed that most of them were not vaccinated because of national regulations during the survey period. Thus, we do not know whether the responses accurately depict the current state of the pandemic, as expectations may have changed due to the currently available vaccines.</p> | 17 |
| Interpretation           | 20 | In conclusion, we showed that most patients at high risk for infection or severe course of COVID-19 disease approve strict contingency measures, such as physical distancing rules, the implementation of telemedicine and the use of highly effective protective masks, designed to lower the transmission of COVID-19 in medical facilities. However, they also value the presence of a significant other during medical consultations and procedures.   | 19 |
| Generalisability         | 21 | As we assessed participants' needs, fears and expectations, we followed the WHO recommendation for two-way communication with populations at risk [8]. Our goal is to improve and optimize the public health measures, which could be implemented during a next wave of the COVID-19 pandemic or other possible pandemics.   | 19 |
| <b>Other information</b> |    |  |    |
| Funding                  | 22 | The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.  | 20 |

\*Give information separately for exposed and unexposed groups.

1  
2 **Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and  
3 published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely  
4 available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at  
5 <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is  
6 available at [www.strobe-statement.org](http://www.strobe-statement.org).  
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# BMJ Open

## Patients' expectations of preventive measures of medical institutions during the SARS-CoV-2 pandemic in Germany in women with an increased risk for breast and ovarian cancer: A cross-sectional web-based survey

|                                 |  |
|---------------------------------|--|
| Journal:                        | <i>BMJ Open</i>  |
| Manuscript ID                   | bmjopen-2021-060038.R1   |
| Article Type:                   | Original research  |
| Date Submitted by the Author:   | 13-Apr-2022  |
| Complete List of Authors:       | Schwab, Roxana; Johannes Gutenberg University Hospital Mainz, Department of Obstetrics and Gynecology<br>Droste, Annika; Johannes Gutenberg University Hospital Mainz, Department of Gynecology and Obstetrics<br>Stewen, Kathrin; Johannes Gutenberg University Hospital Mainz, Department of Gynecology and Obstetrics<br>Brenner, Walburgis; Johannes Gutenberg University Hospital Mainz, Department of Gynecology and Obstetrics<br>Schmidt, Marcus; Johannes Gutenberg University Hospital Mainz, Department of Gynecology and Obstetrics<br>Hasenburg, Annette; Johannes Gutenberg University Hospital Mainz, Department of Gynecology and Obstetrics |
| <b>Primary Subject Heading</b>: | Obstetrics and gynaecology   |
| Secondary Subject Heading:      | Health policy, Public health   |
| Keywords:                       | COVID-19, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Breast tumours < ONCOLOGY, Gynaecological oncology < ONCOLOGY  |
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## Title

**Patients' expectations of preventive measures of medical institutions during the SARS-CoV-2 pandemic in Germany in women with an increased risk for breast and ovarian cancer: A cross-sectional web-based survey**

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### Keywords:

COVID-19, Health policy, Organisation of health services, Breast tumors, Gynecologic oncology

### Word number (body text):

4341 words

## Abstract

**Objectives:** To identify patient-approved contingency measures for the protection of patients and healthcare workers from COVID-19 infection, and to use these findings to improve the staffs' preparedness to cope with the course of this pandemic or similar situations.

### Methods (design, setting, participants, interventions):

We conducted a cross-sectional web-based survey of women with an increased risk for breast or ovarian cancer, regardless of whether they had experienced an active malignant disease during the pandemic. A self-reported questionnaire, developed for this study, was used to assess expectations and opinions about preventive measures within medical institutions.

**Results:** Sixty-four (71.9%) of the 89 potential participants responded to at least one question regarding contingency measures within medical institutions. Approximately 37% of respondents preferred having information about their facility's hygiene protocols before appointment; 57.8% of respondents endorsed regular SARS-CoV-2 testing of patients prior to medical appointments and 95.3% endorsed regular testing of healthcare workers (HCW). Additionally, 84.4% of respondents supported HCW's use of surgical masks and 68.8%

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3 54 supported HCW's use of masks with greater protection. Notably, 75.0% of respondents  
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5 55 advocated for the presence of a significant other during medical consultations; 71.9%  
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8 56 approved the use of telemedicine and 93.8% endorsed changes in appointment practices to  
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10 57 enable social distancing. No significant associations were found between respondents'  
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13 58 sociodemographic, disease-specific or pandemic-specific factors and their opinions on hygiene  
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15 59 precautions.

## 18 19 60 Conclusions:

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23 61 Patients at high risk for infection or severe course of COVID-19 disease approve strict  
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25 62 contingency measures designed to lower the transmission of COVID-19 in medical facilities.  
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28 63 Moreover, vulnerable groups may profit from contingency plans in healthcare facilities in  
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30 64 order to follow preventive measures, avoid diagnostic delay or avoid worsening of preexisting  
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33 65 conditions. However, they also value the presence of a significant other during medical  
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35 66 consultations and procedures.

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## 41 42 68 Article Summary

### 43 44 69 Strengths and limitations of this study

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49 71 • Due to the design of the study (cross-sectional web-based survey), overrepresentation  
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51 72 of patients worrying about their health status and the underrepresentation of women  
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53 73 without online access are two possible sources of bias.
- 54  
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56 74 • As the study was conducted during the first months of 2021, and vaccines against  
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58 75 SARS-CoV-2 were inaccessible for a large proportion of the population at that time, we  
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3 76 do not know whether the responses accurately depict the current state of the  
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5 77 pandemic.

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8 78 • Our study identified several patient-approved contingency measures for the  
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10 79 protection of patients and healthcare workers from COVID-19 infection, which are  
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12 80 essential in terms to improve the staffs' preparedness to cope with the course of this  
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14 81 pandemic or similar situations.  
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## 25 84 Introduction

26 85  
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28 86 By the end of 2019, the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2),  
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30 87 which causes coronavirus disease-2019 (COVID-19), was first reported in China before  
31  
32 88 spreading rapidly to other countries by the beginning of 2020. The World Health Organization  
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34 89 (WHO) declared the outbreak a "public health emergency of international concern" on  
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36 90 January 30, 2020 and a pandemic on March 11, 2020 [1].  
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41 91 Vulnerable groups, such as the aged population or patients with active cancers seem to have  
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43 92 a greater risk for acquiring SARS-CoV-2 infection, and severe COVID-19, requiring admission  
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45 93 to intensive care units and invasive ventilation. Moreover, older persons and patients with  
46  
47 94 pre-existing malignant diseases have a significantly higher risk for fatal outcomes compared  
48  
49 95 to people in the general population without pre-existing medical conditions [2]. In order to  
50  
51 96 protect this vulnerable population from possible infection, it is crucial to implement effective  
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53 97 contingency plans in healthcare facilities, such as in ambulatory healthcare services, hospitals  
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55 98 or nursing homes [3]. As a pandemic is a dynamic process, measures were implemented at  
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3 99 various time points by different countries to prevent the spread of infection among the  
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6 100 population and to protect persons at high risk for exposure, such as HCW. In Germany, the  
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8 101 first widespread social distancing measures were implemented by the government at the end  
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10 102 of March 2020 [1], [4]. As a result, healthcare facilities imposed specific safety protocols,  
11  
12 103 general visitation guidelines and outpatient visitation policies in accordance with national and  
13  
14 104 institutional regulations [3]. Subsequently, family members and visitors were temporarily  
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16 105 banned from joining ambulatory and hospitalized patients, with few exceptions, depending  
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18 106 on the incidence of SARS-CoV-2 infection.  
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23 107 Persons with hereditary cancers, such as women at high risk for breast and ovarian cancer,  
24  
25 108 require regular medical appointments. Women with mutations in breast cancer genes 1 and  
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27 109 2 (BRCA 1 & 2) have a cumulative risk of up to 75% by 80 years of age for developing breast  
28  
29 110 cancer and a cumulative risk of up to 44% by the age of 80 for developing ovarian cancer [5].  
30  
31 111 Even if they do not undergo active cancer treatment or follow-up care, this group of patients  
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33 112 requires regular medical monitoring and risk-reducing surgical interventions to prevent and  
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35 113 detect a malignant disease at early stage [6].  
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#### 41 114 [Aim of the study](#)

42  
43 115 Vulnerable groups are on one hand dependent on a reliable and functioning health-care  
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45 116 system, and on the other they are at increased risk for adverse medical outcomes related to a  
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47 117 SARS-CoV-2 infection. To our knowledge, this is the first study to assess and identify patient-  
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49 118 oriented and patient-approved contingency measures in persons at an increased risk for  
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51 119 breast and ovarian cancer. Additionally, to improve preparedness for future pandemics or  
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53 120 similar situations, it is crucial to identify if specific demographic or disease-specific factors  
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55 121 influence the decision-making process regarding the prevention of SARS-CoV-2 transmission.  
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## 122 Materials and Methods

### 123 Study participants

124 The target population was made up of approximately 1300 German-speaking persons at  
125 increased risk for breast and ovarian cancer being subscribed (actively or passively) at an  
126 internet platform of patients support groups for hereditary breast cancer or ovarian cancer  
127 during the period of recruitment. Recruitment was conducted via a direct link to the survey  
128 and an online invitation to participate distributed via the internet platforms of patients  
129 support groups. The survey was limited to individuals visiting the website who were aged 18  
130 years or older and who gave electronic informed consent to participate in the study. The  
131 survey was completely anonymous to encourage honest and unbiased responses. Participants  
132 received no incentives for completion of the survey. Due to the recruitment method used in  
133 this study it was not possible to calculate response rates, nevertheless we expected for this  
134 descriptive survey approximately 100 participants. Power analyses were conducted using  
135 PROC POWER, SAS Version 9.4 for estimation of confidence interval (power >99.9%;  
136 proportions 0.65-0.90; half-width confidence interval 0.10).

### 137 Data collection and measures

138 The survey was active from 29<sup>th</sup> January to 22<sup>th</sup> February 2021. A questionnaire targeting the  
139 expectations and needs of persons with respect to hygiene measures related to the COVID-19  
140 pandemic was developed based on a review of relevant literature [7], [8], [9], [10], [11], [12],  
141 [13], [14], [15], [16] [17]. The data was collected anonymously, and they included participants'  
142 self-reported sociodemographic and clinical information. The expectations and opinions of the  
143 women with respect to the safety precautions of healthcare facilities and institutions for  
144 preventing the spread of the virus were assessed were assessed using the following questions:

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2  
3 145 1. Would you have liked to be informed about hygiene protocols in advance of your  
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6 146 appointment? *(Yes – No – I don't know/does not apply)*  
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9 147 2. Would more information about the prevailing hygiene protocols have had a positive  
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11 148 influence on your behavior (e.g., meeting appointments)? *Yes – No – I don't know/does not*  
12  
13 149 *apply*  
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15  
16 150 3. Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory  
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18 151 visit/appointment? *Yes – No – I don't know/does not apply*  
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22 152 4. Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection  
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24 153 on a regular basis? *Yes – No – I don't know/does not apply*  
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28 154 5. Do you think that appointments should be scheduled in such a way to ensure that distancing  
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30 155 rules can be strictly observed? *Yes – No – I don't know/does not apply*  
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33 156 6. Should a relative or a close person be allowed to accompany patients in the healthcare  
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35 157 setting, despite the COVID-19 pandemic? *Yes – No – I don't know/does not apply*  
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39 158 7. Do you think/agree that appointments, which do not require one's physical presence (e.g.,  
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41 159 counseling appointments) should be conducted as teleconferences or video conferences  
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43 160 during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*  
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47 161 8. Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask)  
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49 162 during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*  
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53 163 9. Do you think that medical personnel should always wear an FFP-2 mask masks during the  
54 164 COVID-19 pandemic to ensure patients' safety? *Yes – no – I don't know/does not apply*  
55  
56 165 A full copy of the questions which were considered for the present evaluation can be found in  
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58 166 the supplement file 1 (Supplement\_file\_1).  
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60 167

### 178 Patient and public involvement

179 No patient involved. Patients support groups for hereditary breast cancer or ovarian cancer  
180 supported the survey by distribution of the link via their internet platforms.

181

### 182 Statistics

183 For descriptive analyses, missing data consisted of participants who did not answer the  
184 survey's questions. Data were analyzed using SPSS 26.0 (SPSS Inc., Chicago, IL, USA).

185 Descriptive statistics are expressed as mean, standard deviation (SD), median, interquartile  
186 range (IQR) or proportions (%), as appropriate. We used the Mann-Whitney-U-test, the  $\chi^2$ -test  
187 and the Fisher exact test to analyze the data for differences between the responders and non-  
188 responders to the survey's questions [18].

189 The Mann-Whitney-U-test (used for continuous variables),  $\chi^2$ -test (used for categorical  
190 variables) or Fisher exact test (used for categorical variables) were used as appropriate, to  
191 compare differences of expectations according to demographic, disease-specific and  
192 pandemic-specific variables [18]. The p-values were calculated using a 95% confidence  
193 interval. A p-value < 0.05 was considered statistically significant. Because the p-values were  
194 not adjusted for multiple testing, all results should be interpreted as exploratory.

### 195 Ethics approval

196 This study was conducted in accordance with the Declaration of Helsinki, and adhered to the  
197 principles of best clinical practices. Prior to the data collection, all patients gave their informed  
198 consent, allowing us to collect the data and publish the results. The participants' privacy and  
199 confidentiality were guaranteed following German and European laws and regulations.

200 This survey was approved by the ethical review board of the medical association of Rhineland-  
201 Palatinate (approval number 15612).



## 192 Results

### 193 Demographic characteristics of the study group

194 Although 89 potential participants accessed the questionnaire (“clicks”), 11% (9/89) did not  
 195 answer any of the questions; 80% (64/80) answered at least one question pertaining to  
 196 hygiene management and expectations for preventive measures, and 20% (16/80) did not  
 197 answer any questions pertaining to preventive measures related to the pandemic. To  
 198 understand the differences between respondents and non-respondents, we analyzed the  
 199 demographic, pandemic-specific and clinical characteristics of both groups (Table 1). No  
 200 significant differences were found between the two groups regarding demographic,  
 201 pandemic-specific or clinical variables, except for a higher educational level of the  
 202 respondents compared to non-respondents.

203 **Table 1: Demographic and clinical characteristics of the total study sample**

|                                      |              | Non-respondents               | Respondents                   | p-value<br>(Non-respondents group vs the Respondents group) |
|--------------------------------------|--------------|-------------------------------|-------------------------------|---|
| <b>Age</b>                           |              |                               |                               |   |
|                                      | Mean (SD)    | 46.64 (2.210)                 | 42,85 (1.363)                 | 0.161 <sup>1</sup>  |
|                                      | Median (IQR) | 47.50 (40.00-54.00)<br>(N=14) | 43.00 (33.75-51.25)<br>(N=62) |   |
| <b>Having a stable relationship</b>  |              |                               |                               |   |
| Yes                                  | % of N       | 100 (14/14)                   | 90.6 (58/64)                  | 0.236 <sup>1</sup>  |
| No                                   | % of N       | 0 (0/14)                      | 9.4 (6/64)                    |   |
| <b>Living alone</b>                  |              |                               |                               |   |
| Yes                                  | % of N       | 100 (16/16)                   | 90.6 (58/64)                  | 0.340 <sup>1</sup>  |
| No                                   | % of N       | 0 (0/16)                      | 9.4 (6/64)                    |   |
| <b>Living with children &lt; 18y</b> |              |                               |                               |   |
| Yes                                  | % of n/N     | 25.0 (4/16)                   | 34.4 (22/64)                  | 0.474 <sup>2</sup>  |

|  |        |              |               |                          |
|--|--------|--------------|---------------|--------------------------|
| No   | % of N | 75.0 (12/16) | 65.6 (42/64)  |                          |
| <b>Living with persons &gt;65y</b>                         |        |              |               |                          |
| Yes  | % of N | 12.5 (2/16)  | 6.2 (4/64)    | 0.399 <sup>1</sup>       |
| No   | % of N | 87.5 (14/16) | 93.8 (60/64)  |                          |
| <b>Living with a partner</b>                               |        |              |               |                          |
| Yes  | % of N | 62.5 (10/16) | 60.9 (39/64)  | 0.909 <sup>2</sup>       |
| No   | % of N | 37.5 (6/16)  | 39.1 (25/64)  |                          |
| <b>Education</b>   |        |              |               |                          |
| Up to secondary level education                            | % of N | 84.6 (11/13) | 48.4 (31/64)  | <b>0.017<sup>2</sup></b> |
| Tertiary level education                                   | % of N | 15.4 (2/13)  | 51.6 (33/64)  |                          |
| <b>Did you have COVID-19</b>                               |        |              |               |                          |
| Yes  | % of N | 0 (0/13)     | 4.7 (3/64)    | 0.429 <sup>1</sup>       |
| No   | % of N | 100 (13/13)  | 95.3 (61/64)  |                          |
| <b>Someone in your social network has had COVID-19</b>     |        |              |               |                          |
| Yes  | % of N | 23.1 (3/13)  | 28.6 (18/63)  | 0.687 <sup>2</sup>       |
| No   | % of N | 76.9 (10/13) | 71.4 (45/63)  |                          |
| <b>Reduction of social network</b>                         |        |              |               |                          |
| Moderate reduction   | % of N | 15.4 (2/13)  | 15.6 (10/64)  | 0.983 <sup>2</sup>       |
| Large reduction  | % of N | 84.6 (11/13) | 84.4 (54/64)  |                          |
| <b>Risk profiling for OC and BC</b>                        |        |              |               |                          |
| BRCA 1 & 2   | % of N | 76.9 (10/13) | 70.3 (45/64)  | 0.895 <sup>3</sup>       |
| Mutations other than BRCA 1 & 2                            | % of N | 15.4 (2/13)  | 14.10 (9/64)  |                          |
| Positive family history for BC or OC                       | % of N | 7.7 (1/13)   | 15.6 (10/64)  |                          |
| <b>Having a history of (in situ or invasive) OC and BC</b> |        |              |               |                          |
| Yes  | % of N | 73.3 (11/15) | 64.1 (41/64)  | 0.496 <sup>2</sup>       |
| No   | % of N | 26.7 (4/15)  | 35.9 (23/64)  |                          |
| <b>Having a history of invasive BC</b>                     |        |              |               |                          |
| Yes  | % of N | 60 (9/15)    | 56.20 (36/64) | 0.792 <sup>2</sup>       |
| No   | % of N | 40 (6/15)    | 43.80 (28/64) |                          |
| <b>Having a history of invasive OC</b>                     |        |              |               |                          |
| Yes  | % of N | 6.7 (1/15)   | 1.6 (1/64)    | 0.260 <sup>1</sup>       |
| No   | % of N | 93.3 (14/15) | 98.4 (63/64)  |                          |

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|--|--|--|--|--|
|  |  |  |  |  |
|--|--|--|--|--|

204 N = total number of women who answered the question, n = number of respondents to the specific  
 205 answer, SD = standard deviation, y = years, BRCA 1 & 2 = breast cancer genes 1 and 2, BC = breast  
 206 cancer, OC = ovarian cancer; Values in bold indicate statistical significance, as the level of significance  
 207 was set to  $p < 0.05$  (<sup>1</sup> = Mann-Whitney-U-test; <sup>2</sup> =  $\chi^2$ -test, 2-sided; <sup>3</sup> = Fisher exact test, 2-sided).

208

## 209 Opinions about preventive measures

210 Approximately 37.5% of the respondents would have preferred to be informed about their  
 211 facility's specific hygiene protocols prior to their appointment, an equal proportion did not  
 212 care to be informed and a slightly smaller proportion had no opinion on this topic (Table 2).  
 213 Only 20.3% of the respondents indicated that being informed about hygiene protocols would  
 214 have changed their behavior, whereas the majority of respondents either had no opinion or  
 215 denied any possible influence of the information on their behavior (Table 2).

216 The majority of respondents endorsed regular testing of patients for SARS-CoV-2 prior to visits  
 217 to healthcare facilities. However, a much larger proportion of respondents supported the  
 218 regularly testing of HCW (Table 2).

219 The proportion of respondents that endorsed changes in appointment practices to enable  
 220 social distancing in medical institutions and waiting wards was also quite high. Despite social  
 221 distancing requirements for visitors in medical institutions, the vast majority of respondents  
 222 (75.0%) supported the possibility of being accompanied by a significant other during medical  
 223 consultations, and 71.9% approved the implementation of telemedicine while 21.9%  
 224 disapproved this option (Table 2).

225 With regard to wearing protective gear, a relatively high proportion of respondents (84.4%)  
 226 agreed that HCW should wear surgical masks (not cloth masks) to stop the spread of SARS-  
 227 CoV-2, compared to the much smaller proportions who did not consider surgical masks to be  
 228 necessary or had no opinion on the topic. Fewer respondents (66.8%) agreed that HCW wear

229 masks with a higher level of protection (i.e., the FFP-2 mask), while more respondents  
 230 disagreed and others had no opinion (Table 2).

231 **Table 2: Participants' opinions and expectations of hygiene measures during the COVID-19**  
 232 **pandemic**

| Questions  | Yes<br>in % of<br>respondents<br>(n/N) | No<br>in % of<br>respondents<br>(n/N) | I don't<br>know/does<br>not apply<br>in % of<br>respondents<br>(n/N) |
|--|--|---------------------------------------|--|
| Would you have liked to be informed about hygiene protocols in advance of your appointment?  | 37.5%<br>(24/64)                       | 37.5%<br>(24/64)                      | 25.0%<br>(16/64)   |
| Would more information about the prevailing hygiene protocols have had a positive influence on your behavior (e.g., meeting appointments)?   | 20.3%<br>(13/64)                       | 31.3%<br>(20/64)                      | 48.4%<br>(31/64)   |
| Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment?   | 57.8%<br>(37/64)                       | 26.6%<br>(17/64)                      | 15.6%<br>(10/64)   |
| Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis?   | 95.3%<br>(61/64)                       | 1.6%<br>(1/64)                        | 3.1%<br>(2/64)   |
| Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed?   | 93.8%<br>(60/64)                       | 1.6%<br>(1/64)                        | 4.7%<br>(3/64)   |
| Should a relative or a close person be allowed to accompany patients in the healthcare setting, despite the COVID-19 pandemic?   | 75.0%<br>(48/64)                       | 15.6%<br>(10/64)                      | 9.4%<br>(6/64)   |
| Do you think/agree that appointments, which do not require one's physical presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? | 71.9%<br>(46/64)                       | 21.9%<br>(14/64)                      | 6.3%<br>(4/64)   |
| Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic?   | 84.4%<br>(54/64)                       | 7.8%<br>(5/64)                        | 7.8%<br>(5/64)   |
| Do you think that medical personnel should always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients' safety?  | 68.8%<br>(44/64)                       | 18.8%<br>(12/64)                      | 12.5%<br>(8/64)  |

233 N = total number of women who answered the question, n = number of respondents to the specific  
234 answer

### 235 Factors influencing decision making related to hygiene practices during the pandemic

236

237 We examined group differences using the Mann-Whitney-U-test to identify subsets of  
238 patients with similar expectations and assess differences between those who had definite  
239 opinions of the facilities' hygiene management during the pandemic and answered "yes" (vs  
240 "no") to the questions and their counterparts. Missing data included all participants who did  
241 not answer the relevant question or did not have a definite opinion of the topic ("do not  
242 know/does not apply").

243 None of the demographic, pandemic-specific or disease-specific factors were found to have a  
244 significant influence on the respondents' opinions with respect to the hygiene measures  
245 implemented during the pandemic (all p-values > 0.05) (Table 3).

246

247 **Table 3: Influence of demographic, disease-specific and pandemic-specific factors on**  
248 **expectations regarding the prevention of SARS-CoV-2 transmission**

|  | 1                  | 2          | 3          | 4          | 5          | 6          | 7          | 8          | 9          |
|--|--------------------|------------|------------|------------|------------|------------|------------|------------|------------|
| Age  | 0.441 <sup>1</sup> | 0.373<br>1 | 0.316<br>1 | 0.100<br>1 | 0.102<br>1 | 0.487<br>1 | 0.263<br>1 | 0.729<br>1 | 0.821<br>1 |
| Stable partnership<br>(no vs yes)            | 0.999 <sup>3</sup> | 0.508<br>3 | 0.645<br>3 | 0.999<br>3 | 0.999<br>3 | 0.999<br>3 | 0.999<br>3 | 0.368<br>3 | 0.999<br>3 |
| Living alone (yes vs<br>no)                  | 0.348 <sup>3</sup> | 0.508<br>3 | 0.999<br>3 | 0.999<br>3 | 0.999<br>3 | 0.577<br>3 | 0.133<br>3 | 0.999<br>3 | 0.567<br>3 |
| Living with children<br>(yes vs no)          | 0.104 <sup>2</sup> | 0.676<br>3 | 0.537<br>2 | 0.999<br>3 | 0.999<br>3 | 0.784<br>2 | 0.179<br>2 | 0.646<br>3 | 1.846<br>2 |
| Living with an elderly<br>person (yes vs no) | 0.999 <sup>3</sup> | 0.508<br>3 | 0.296<br>3 | 0.999<br>3 | 0.999<br>3 | 0.541<br>3 | 0.999<br>3 | 0.999<br>3 | 0.999<br>3 |
| Living with a partner<br>(yes vs no)         | 0.233 <sup>2</sup> | 0.208<br>2 | 0.824<br>2 | 0.999<br>3 | 0.999<br>3 | 0.922<br>2 | 0.098<br>2 | 0.999<br>3 | 0.962<br>2 |
| Tertiary level<br>education (yes vs<br>no)   | 0.558 <sup>2</sup> | 0.717<br>3 | 0.793<br>2 | 0.999<br>3 | 0.999<br>3 | 0.999<br>3 | 0.542<br>2 | 0.999<br>3 | 0.244<br>2 |

|  |                    |                    |                    |                    |                    |                    |                    |                    |                    |
|--|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|
| Having had COVID (yes vs no)   | 0.999 <sup>3</sup> | 0.547 <sub>3</sub> | 0.535 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.556 <sub>3</sub> | 0.999 <sub>3</sub> | 0.522 <sub>3</sub> |
| Someone in their social network having COVID (yes vs no)   | 0.123 <sup>2</sup> | 0.648 <sub>3</sub> | 0.596 <sub>2</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.551 <sub>2</sub> | 0.982 <sub>2</sub> | 0.308 <sub>3</sub> | 0.096 <sub>2</sub> |
| Reduction of social contact (serious and very serious reduction vs low reduction)                            | 0.999 <sup>3</sup> | 0.360 <sub>3</sub> | 0.512 <sub>2</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.800 <sub>2</sub> | 0.442 <sub>2</sub> | 0.577 <sub>3</sub> | 0.622 <sub>2</sub> |
| Risk profiling for OC and BC (-/+ family history but no mutation vs BRCA1 & 2 vs a mutation other than BRCA) | 0.578 <sup>3</sup> | 0.604 <sub>3</sub> | 0.263 <sub>3</sub> | 0.129 <sub>3</sub> | 0.295 <sub>3</sub> | 0.744 <sub>3</sub> | 0.793 <sub>3</sub> | 0.450 <sub>3</sub> | 0.452 <sub>3</sub> |
| Having a history of in situ or invasive BC or OC (yes vs no)   | 0.768 <sup>2</sup> | 0.930 <sub>2</sub> | 0.836 <sub>2</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.163 <sub>2</sub> | 0.179 <sub>2</sub> | 0.999 <sub>3</sub> | 0.185 <sub>2</sub> |
| History of invasive BC (yes vs no)   | 0.999 <sup>3</sup> | 0.353 <sub>2</sub> | 0.887 <sub>2</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.249 <sub>2</sub> | 0.383 <sub>2</sub> | 0.639 <sub>3</sub> | 0.573 <sub>2</sub> |
| History of invasive OC (yes vs no)   | 0.999 <sup>3</sup> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> | 0.999 <sub>3</sub> |

249 1- Would you have liked to be informed about hygiene protocols in advance of your appointment?, 2-  
 250 Would more information about the prevailing hygiene protocols have had a positive influence on your  
 251 behavior (e.g., meeting appointments)?, 3- Do you think that patients should be tested for SARS-CoV-  
 252 2 infection before an ambulatory visit/appointment?, 4- Do you think that medical personnel/physicians  
 253 should be tested for SARS-CoV-2 infection on a regular basis?, 5- Do you think that appointments  
 254 should be scheduled in such a way to ensure that distancing rules can be strictly observed? 6- Should  
 255 a relative or a close person be allowed to accompany patients in the healthcare setting, despite the  
 256 COVID-19 pandemic? 7- Do you think/agree that appointments, which do not require one's physical  
 257 presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences  
 258 during the COVID-19 pandemic? 8- Do you think that medical personnel should at least wear an FFP-1  
 259 mask (surgical mask) during the COVID-19 pandemic? 9- Do you think that medical personnel should  
 260 always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients' safety?; vs =  
 261 versus, BC = breast cancer, OC = ovarian cancer. The significance level was set at  $p < 0.05$  (<sup>1</sup> = Mann-  
 262 Whitney-U-test; <sup>2</sup> =  $\chi^2$ -test, 2-sided; <sup>3</sup> = Fisher exact test, 2-sided).

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## Discussion

Our analysis provides a descriptive analysis of participants' expectations for preventive healthcare measures in medical institutions during the SARS-CoV-2 pandemic in Germany. During a pandemic, the implementation of strict contingency plans in medical institutions is vital. In the beginning of the SARS-CoV-2 pandemic, in January 2020, 41% of the novel infections seemed to be hospital acquired [19], fueling the spread of the virus among the wider population. Viral transmission to patients in healthcare facilities will affect the population with a higher incidence of pre-existing medical conditions, and thus, with a higher risk for a severe course of the disease [20]. Additionally, infection among HCW could lead to shortages of qualified personnel to care for the patients, bringing the healthcare system to the brink of decompensation. Thus, adequate and effective protection of both patients and HCW are of paramount importance [21].

Persons, including patients with pre-existing medical conditions might be very sensitive to the proper adherence to contingency plans in medical institutions. This is understandable because the risks for severe and fatal COVID-19 is higher in the aged population and in persons with comorbidities [7], [20], [22]. One study found that patients with cancer were 10-fold more susceptible to acquiring nosocomial infections with the SARS-CoV-2 virus than were patients without cancer [7]. The observed 49% reduction in outpatient appointments for breast-cancer follow-up during the pandemic [11], [12] was either a result of responses to hygiene plans or protocols within medical institutions or because of patients' worries about becoming infected with COVID-19 while visiting healthcare facilities. Nevertheless, the implementation of appropriate contingency measures may reinforce vulnerable groups to attend necessary

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3 287 medical consultations, e.g. during medical emergencies, as well as mandatory diagnostic  
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6 288 procedures in order to act in an appropriate and timely manner to avoid possible harm or  
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8 289 excess deaths due to the pandemic [23], [24]. Accordingly, a study assessing medical outcomes  
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10 290 during the COVID-19 pandemic in rural Japanese nursing homes did not observe an increased  
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13 291 risk of emergencies by implementing appropriate contingency measures [3].  
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16 292 For reassurance, 37.5% of the participants in this study preferred to be informed of the  
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18 293 healthcare facility's hygiene protocols in advance of medical appointments. More  
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20 294 interestingly, over 20% of participants stated that receiving prior information about safety  
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23 295 protocols during the COVID-19 pandemic would have strengthened their adherence to  
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25 296 medical appointments. The dissemination of information that is valuable, transparent and  
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28 297 proactive has been recognized previously by the WHO as an essential tool to overcome various  
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30 298 difficulties or insecurities triggered by the pandemic [21].  
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33  
34 299 The use of physical distancing to limit exposure to potentially infectious aerosols, was widely  
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36 300 recommended [13], [20], [21]. Approximately 93.8% of participants in this study expected  
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38 301 adherence to the recommended physical distancing rules in waiting rooms. The  
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40 302 recommended physical distancing protocol had a decisive influence on the visiting policies of  
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43 303 medical institutions [20]. Al-Shamsi et al. suggested that clinic attendance in outpatient  
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45 304 settings should be limited to the patient and one visitor [2]. Nevertheless, one of the pillars of  
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48 305 patient-centered care has proven to be family involvement [14]. One study found that up to  
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50 306 46% of adult patients were accompanied by family members to routine visits with their  
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53 307 physicians [14]. Family members, friends and caregivers mediate the patient's psychosocial  
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55 308 and emotional support, encouragement and reassurance, thereby improving the  
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58 309 communication processes during medical visits and influencing patients' satisfaction with the  
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60 310 physician's care [2], [14], [25], [26]. Medical appointments are an anxiety-provoking



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3 311 experience for patients, especially for those facing a possible or existing malignant diagnosis  
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6 312 [27]. The word “distress” is mentioned by patients with cancer who were denied the option  
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8 313 of having a family member or friend with them during medical appointments [15]. Although  
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10 314 the respondents in this study endorsed vigilant sanitary precautions to prevent nosocomial  
11  
12 315 infections, an overwhelming proportion (75.0%) supported the possibility of being  
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14 316 accompanied by a significant other during medical consultations, irrespective of their  
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16 317 demographic, disease-specific or pandemic-specific characteristics. The company of a  
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18 318 trustworthy person seemed to be clearly important for our study’s participants.

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23 319 Other experts have managed to attenuate the detrimental effects of the pandemic on  
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25 320 screening and provide follow-up care for patients with cancer by implementing telemedicine  
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27 321 appointments [11], [20]. The use of telemedicine has been described as a method for patients  
28  
29 322 and physicians to stay in touch and informed while reducing physical contact [2], [15], [28],  
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31 323 [29]. Notably, 71.9% of the participants in this study approved implementation of  
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33 324 telemedicine whenever possible and reasonable from an oncological viewpoint, in order to  
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35 325 reduce face-to-face contact and minimize potential contact with persons infected with SARS-  
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37 326 CoV-2, but maintain the required standards for treatment. Telemedicine appointments would  
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39 327 be impossible in cases requiring physical examinations or imaging procedures, but it would be  
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41 328 a good choice for offering a second opinion [11].

42  
43 329 The WHO has stated that regular and widespread testing is crucial to contain the virus and  
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45 330 stop the pandemic [20], [21]. The transmission of nosocomial infections, both patient-to-  
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47 331 patient and patient-to-healthcare-personnel, has been reported previously [19]. These  
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49 332 infections occur, presumably, by transmission from asymptomatic or pre-symptomatic  
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51 333 carriers or persons with mild or atypical symptoms [19], [30]. Precautions are essential, as  
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53 334 17.9% to 33.3% of patients may have an asymptomatic COVID-19 infection [2]. While pre-

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3 335 operative testing has been recommended by various medical societies worldwide, and the  
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6 336 testing of in-patients upon their admission to the hospital has been introduced by the vast  
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8 337 majority of healthcare facilities [31], regular testing of patients prior to ambulatory  
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10 338 appointments to avoid nosocomial spread among HCWs or other patients, was not.  
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13 339 Interestingly, 57.8% of our study's population indicated they would rather tolerate the  
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15 340 inconvenience of repetitive testing before visiting a healthcare institution, in order to feel safe  
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18 341 and avoid exposure to potentially life-threatening infectious agents.

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21 342 The protection of HCWs from COVID-19 serves both sides: maintaining medical care and  
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23 343 protecting the vulnerable population from a possible fatal nosocomial infection with SARS-  
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25 344 CoV-2 [22]. In Germany, HCWs were tested only if they were symptomatic or were eligible for  
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27  
28 345 the national contact-tracing program (documented contact with an infected person without  
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30 346 adequate personal protective equipment). Nevertheless, data from the United Kingdom  
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33 347 showed that up to 3% of asymptomatic HCWs were infected with SARS-CoV-2 [16]. According  
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35 348 to mathematical models, regular polymerase-chain-reaction(PCR)-based screening of HCWs,  
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38 349 irrespective of whether they are symptomatic or asymptomatic, could reduce their  
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40 350 contribution to transmission by up to 33% [17]. This study showed that 93% of patients  
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43 351 strongly supported the notion of broad screening programs for HCW, irrespective of their  
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45 352 demographic, disease-specific or pandemic-specific factors.

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48 353 HCWs have a significantly high risk for acquiring COVID-19, based on national and  
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50 354 international data [17], [32]. According to some reports, HCWs acquired COVID-19 through  
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52  
53 355 nosocomial transmission in up to 29% of reported cases (China, January 2020) [19]. Thus,  
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55 356 effective control of the source of infection is crucial in healthcare facilities. The use of personal  
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58 357 protective equipment by HCW and patients in medical institutions was recommended by their  
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60 358 national centers for disease control [2], [13], [21], [31], [33]. A meta-analysis conducted by

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3 359 Iannone et al. found a significant benefit from wearing masks in mitigating the transmission  
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6 360 of SARS-CoV-2 [8]. During an infection outbreak, wearing a N-95 mask or an FFP-2 respirator  
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8 361 cuts the risk in half for clinical respiratory infections in HCWs, compared to wearing only a  
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11 362 surgical mask [8], [9]. Furthermore, the protection of HCWs may reduce secondary  
12  
13 363 transmission of the virus and nosocomial infections. During simulation tests of the spread of  
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15 364 SARS-CoV-2 droplets/aerosols, medical masks and cloth face coverings were 57%–58%  
16  
17 365 effective in protecting others and 37%–50% effective in protecting the wearer, while the N-  
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19 366 95/FFP-2 masks were more effective in protecting others (effectivity: 86%–90%) as well as the  
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22 367 wearer (effectivity: 96%–99%) [10].  
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25

## 26 368 Limitations

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28 369 This study has several limitations due to its design (cross-sectional web-based survey). First,  
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30 370 there might be an overrepresentation of patients worrying about their health status because  
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33 371 of their recruitment from support groups and the underrepresentation of women without  
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35 372 online access are two possible sources of bias. Nevertheless, a recent systematic review  
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38 373 showed that Facebook-recruited samples were similarly representative as samples recruited  
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40 374 via traditional methods [34], [35]. Furthermore, as the patients responded directly to the  
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43 375 questionnaire, social desirability bias was greatly limited. Moreover, as we did not reach the  
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45 376 expected number of participants, we potentially may have underestimated the importance of  
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47  
48 377 some specific demographic, disease-specific and pandemic-specific factors on expectations  
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50 378 regarding the prevention of SARS-CoV-2 transmission, although this is unlikely.  
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53 379 Next, this study was conducted during the first months of 2021. In Germany, the first vaccine  
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55 380 against COVID-19 was approved by emergency use authorization in December 2020  
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58 381 (Comirnaty®, BioNTech Manufacturing, Germany), followed by the emergency authorization  
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60 382 of two other vaccines in January 2021 (COVID-19 Vaccine Moderna, Moderna Biotech, USA

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2  
3 383 and Vaxzevria, AstraZeneca Life Science, UK) [36]. Due to the strict criteria for prioritizing  
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5 384 eligibility for vaccinations in Germany, the COVID-19 vaccines were inaccessible for a large  
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8 385 proportion of the population during the time we conducted the survey, even for patients at  
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11 386 risk, such as those with active or previous oncological disorders [37], [38]. We did not assess  
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13 387 participants' vaccination status; however, we presumed that most of them were not  
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15 388 vaccinated because of national regulations during the survey period. Thus, we do not know  
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18 389 whether the responses accurately depict the current state of the pandemic, as expectations  
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20 390 may have changed due to the currently available vaccines.  
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23 391 Finally, the obtained results reflected the needs and expectations of women who were at  
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25 392 increased risk for BC and OC during the COVID-19 pandemic, and the results are not  
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28 393 necessarily generalizable to other vulnerable groups or to other life adversities.  
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### 31 394 **Strengths**

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35 396 The COVID-19 pandemic changed the way patient care is delivered. Strict measures to contain  
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38 397 the virus were implemented swiftly after the onset of the pandemic by experts in infectious  
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40 398 diseases and politicians. Due to the course of the pandemic, there was no possibility to assess  
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43 399 the needs and expectations of patients regarding specific hygiene measures before putting  
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45 400 those in place. Our study identified several patient-approved contingency measures for the  
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48 401 protection of patients and healthcare workers from COVID-19 infection, which are essential in  
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50 402 terms to improve the staffs' preparedness to cope with the course of this pandemic or similar  
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52 403 situations.  
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56 404 The high risk and vulnerable groups in our study seemed to approve the most vigilant and  
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58 405 strict contingency programs designed to lower the risk of transmission in medical facilities,  
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60 406 irrespective of demographic, disease-specific or pandemic-specific factors. Additionally, to our

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3 407 knowledge, this is the first study to assess the wishes of patients with respect to being  
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5 408 accompanied by a person of trust during medical appointments during the pandemic. The  
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8 409 possibility of being accompanied by a close person seemed to be non-negotiable for most of  
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10 410 the participants in the study. Thus, in addition to the strict visitation policies for outpatients  
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12 411 and rules restricting visitation for hospitalized patients, we also need innovative strategies to  
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14 412 maintain and improve the experiences of patients during the COVID-19 pandemic, such as  
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16 413 allowing, that patients are accompanied by a person of trust, provided that they comply with  
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18 414 strict precautions measures, for e.g. by providing a current negative SARS-CoV-2 test result or  
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20 415 proof of immunization.  
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26 416 As we assessed participants' needs, fears and expectations, we followed the WHO  
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28 417 recommendation for two-way communication with populations at risk [21]. Our goal is to  
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30 418 improve and optimize the public health measures, which could be implemented during a next  
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32 419 wave of the COVID-19 pandemic or other possible pandemics.  
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## 39 421 Conclusion

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45 423 In conclusion, we showed that most patients at high risk for infection or severe course of  
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47 424 COVID-19 disease approve strict contingency measures, such as physical distancing rules, the  
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49 425 implementation of telemedicine and the use of highly effective protective masks, designed to  
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51 426 lower the transmission of COVID-19 in medical facilities. However, they also value the  
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53 427 presence of a significant other during medical consultations and procedures.  
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## Acknowledgements:

430

431 We thank

432 - the support group for persons at high risk for breast and/or ovarian cancer for their  
433 engagement in the promotion of this survey.

434 - all participants for participating in our study.

435 Parts of the presented results are part of the doctoral thesis of Ms. Annika Droste.

436

## Author contributions:

438 RS and AD conceptualized the study and planned the data analysis, acquired the data,  
439 performed data analysis and drafted the manuscript. KS, WB, MS, and AH, offered  
440 substantially intellectual input to analysis and interpretation of data. All authors contributed  
441 to the manuscript drafts and approved the final version of the manuscript for publication.

## Funding:

443 The authors have not declared a specific grant for this research from any funding agency in  
444 the public, commercial or not-for-profit sectors.

445

## Data availability:

447 Data are available on reasonable request to bona fide researchers.

448

## Conflicts of interests:

450 RS:

451 Honoraria: Roche Pharma AG, AstraZeneca, Streamedup!GmbH

452

453 MS: received personal fees from AstraZeneca, BioNTech, Eisai, Lilly, MSD, Novartis, Pantarhei

454 Bioscience, Pfizer, Roche, and SeaGen. Institutional research funding from AstraZeneca,

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2  
3 455 BioNTech, Eisai, Genentech, German Breast Group, Novartis, Palleos, Pantarhei Bioscience,  
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5  
6 456 Pierre-Fabre, and Roche. Travel reimbursement from Pfizer and Roche. In addition, M.S. is  
7  
8 457 named as an inventor on patent EP 2390370 B1 and granted patent EP 2951317 B1.  
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13 459 AH:

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15 460 Honoraria: AstraZeneca; Celgen; MedConcept GmbH, Med update GmbH; Medicultus; Pfizer;

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17 461 Promedicis GmbH; Softconsult; Roche Pharma AG; Streamedup! GmbH; Tesaro Bio Germany

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19  
20 462 GmbH, LEO Pharma

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22 463 Ad Board: PharmaMar; Promedicis GmbH; Roche Pharma AG; Tesaro Bio Germany GmbH,

23  
24 464 AstraZeneca, LEO Pharma, MSD Sharp&Dohme GmbH

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For peer review only

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3 How old are you? [ ] years  
4

5 Do you live in a stable partnership? (Yes – No)  
6

7 How would you describe your home/private environment?  
8

- 9 - *Living alone (Yes – No)*  
10 - *Living with children under 18 years (Yes – No)*  
11 - *Living with older people (over 65 years) (Yes – No)*  
12 - *Living with my spouse/life partner (Yes – No)*  
13 - *others*  
14  
15  
16  
17

18 What is your highest educational qualification?  
19

20 Are/was you infected by the SARS-CoV-2-virus yourself? (Yes – No)  
21

22 Is/was someone in your environment infected with the SARS-CoV-2-virus? (Yes – No)  
23  
24  
25

26 How much, on average, did you reduce your social contact network in the last 12 months  
27 due to the covid-19-pandemic?  
28

29 *Not at all – a little – moderate – significant – very much*  
30  
31  
32

### 33 Questions about your risk of developing breast and/or ovarian cancer 34

35 To which risk group do you belong:  
36

- 37 - I was diagnosed with a mutation in the BRCA1 or BRCA2 gene  
38 - I was diagnosed with a different mutation (except BRCA1 or BRCA2 gene)  
39 - I have an increased risk due to my family history, but I wasn't diagnosed with a gene  
40 mutation (yet)  
41  
42  
43

44 Are/was you already suffering from breast and/or ovarian cancer (benign tumors excluded)  
45

46 *(multiple selection possible)*  
47

- 48 - no, I am not/was not previously diagnosed with invasive breast and/or ovarian  
49 cancer or the respective premalignant lesions (in situ)  
50 - yes, I am/was diagnosed with insitu breast lesions  
51 - yes, I am/was diagnosed with in situ ovarian/tubal lesions  
52 - I am/was diagnosed with invasive breast cancer  
53 - I am/was diagnosed with invasive ovarian cancer  
54  
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58

59 Below we are interested in your opinion on hygiene measures in clinics during the covid-19-  
60 pandemic:

- 1  
2  
3  
4  
5 1. Would you have liked to be informed about hygiene protocols in advance of your  
6  
7 appointment? *(Yes – No – I don't know/does not apply)*  
8  
9
- 10  
11 2. Would more information about the prevailing hygiene protocols have had a positive  
12  
13 influence on your behavior (e.g., meeting appointments)? *Yes – No – I don't know/does not*  
14  
15 *apply*  
16  
17
- 18  
19 3. Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory  
20  
21 visit/appointment? *Yes – No – I don't know/does not apply*  
22  
23
- 24  
25 4. Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection  
26  
27 on a regular basis? *Yes – No – I don't know/does not apply*  
28  
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- 30  
31 5. Do you think that appointments should be scheduled in such a way to ensure that distancing  
32  
33 rules can be strictly observed? *Yes – No – I don't know/does not apply*  
34  
35
- 36  
37 6. Should a relative or a close person be allowed to accompany patients in the healthcare  
38  
39 setting, despite the COVID-19 pandemic? *Yes – No – I don't know/does not apply*  
40  
41
- 42  
43 7. Do you think/agree that appointments, which do not require one's physical presence (e.g.,  
44  
45 counseling appointments) should be conducted as teleconferences or video conferences  
46  
47 during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*  
48  
49
- 50  
51 8. Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask)  
52  
53 during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*  
54  
55
- 56  
57 9. Do you think that medical personnel should always wear an FFP-2 mask masks during the  
58  
59 COVID-19 pandemic to ensure patients' safety? *Yes – no – I don't know/does not apply*  
60

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

|                              | Item No | Recommendation   | Page No |
|------------------------------|---------|--|---------|
| <b>Title and abstract</b>    | 1       | <b>Patients' expectations of preventive measures of medical institutions during the SARS-CoV-2 pandemic in Germany in women with an increased risk for breast and ovarian cancer</b>   | 1       |
| <b>Introduction</b>          |         |  |         |
| Background/rationale         | 2       | During the COVID-19 pandemic, several strategies were implemented to contain the viral spread within medical institutions, in order to protect persons at higher risk for infection or severe course of the disease, such as patients with active cancers, cancer survivors or healthcare workers (HCW).   | 2       |
| Objectives                   | 3       | To identify patient-approved contingency measures for the protection of patients and healthcare workers from COVID-19 infection, and to use these findings to improve the staffs' preparedness to cope with the course of this pandemic or similar situations.   | 2       |
| <b>Methods</b>               |         |  |         |
| Study design                 | 4       | Cross-sectional web-based survey   |         |
| Setting                      | 5       | Web-based survey delivered by support groups of persons with increased risk for ovarian or breast cancer.<br>89 potential participants accessed the questionnaire. Data were collected anonymously. 80% (64/80) answered at least one question pertaining to hygiene management and expectations for preventive measures, and 20% (16/80) did not answer any questions pertaining to preventive measures related to the pandemic   | 8       |
| Participants                 | 6       | Women at increased risk for ovarian and breast cancer, irrespective if they had experienced an oncological diagnosis at the time point of the survey. All participants were aged 18 years or older. All participants gave consent to participate in the study.   | 5       |
| Variables                    | 7       | Outcomes: expectations regarding different contingency measures with respect to the COVID-19 pandemic  | 6       |
| Data sources/<br>measurement | 8*      |  |         |
| Bias                         | 9       | Web-based survey, patient requirement by support groups. A recent systematic review showed that Facebook-recruited samples were similarly representative as samples recruited via traditional methods.   | 17      |
| Study size                   | 10      | All participants who responded at least one question with respect to contingency measures.   | 8       |
| Quantitative variables       | 11      |  |         |
| Statistical methods          | 12      | (a) Data were analyzed using SPSS 26.0 (SPSS Inc., Chicago, IL, USA). Descriptive statistics are expressed as mean, standard deviation (SD), median, interquartile range (IQR) or proportions (%), as appropriate. We used the Mann-Whitney-U-test, the $\chi^2$ -test and the Fisher exact test to analyze the data for differences between the responders and non-responders to the survey's questions.<br>The Mann-Whitney-U-test, $\chi^2$ -test or Fisher exact test were used as appropriate, to compare differences of expectations according to demographic, disease-specific and pandemic-specific variables. The p-values were calculated using a 95% confidence interval. A p-value < 0.05 was considered statistically significant. Because the p-values were not adjusted for multiple testing, all results should be interpreted as exploratory. | 7       |
|                              |         | (b) The significance level was set at p < 0.05<br>Significance between groups was assessed by.   | 7       |

<sup>1</sup> = Mann-Whitney-U-test; <sup>2</sup> =  $\chi^2$ -test, 2-sided; <sup>3</sup> = Fisher exact test, 2-sided).

(c) For descriptive analyses, missing data consisted of participants who did not answer the survey's questions.

## Results

|              |     |   |   |
|--------------|-----|---|---|
| Participants | 13* | (a) 80% (64/80) answered at least one question pertaining to hygiene management and expectations for preventive measures<br>(b) Give reasons for non-participation at each stage: participants did not answer the questions | 8 |
|--------------|-----|---|---|

| Descriptive data                     | 14*          | (a)  | 8                          |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
|--------------------------------------|--------------|--|----------------------------|--|-----------------|-------------|--|------------|--|--|--|--|--|-----------|---------------|---------------|--------------------|--|--------------|----------------------------|----------------------------|-------------------------------------|--|--|--|--|-----|--------|-------------|--------------|--------------------|----|--------|----------|------------|---------------------|--|--|--|--|-----|--------|-------------|--------------|--------------------|----|--------|----------|------------|--------------------------------------|--|--|--|--|-----|----------|-------------|--------------|--------------------|----|--------|--------------|--------------|------------------------------------|--|--|--|--|-----|--------|-------------|------------|--------------------|----|--------|--------------|--------------|------------------------------|--|--|--|--|-----|--------|--------------|--------------|--------------------|----|--------|-------------|--------------|------------------|--|--|--|--|---------------------------------|--------|--------------|--------------|--------------------------|--------------------------|--------|-------------|--------------|--|
|                                      |              | <table border="1"> <thead> <tr> <th></th> <th></th> <th>Non-respondents</th> <th>Respondents</th> <th>p-value (Non-respondents group vs the Respondents group)</th> </tr> </thead> <tbody> <tr> <td colspan="5" style="text-align: center;"><b>Age</b></td> </tr> <tr> <td></td> <td>Mean (SD)</td> <td>46.64 (2.210)</td> <td>42,85 (1.363)</td> <td rowspan="2">0.161<sup>1</sup></td> </tr> <tr> <td></td> <td>Median (IQR)</td> <td>47.50 (40.00-54.00) (N=14)</td> <td>43.00 (33.75-51.25) (N=62)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Having a stable relationship</b></td> </tr> <tr> <td>Yes</td> <td>% of N</td> <td>100 (14/14)</td> <td>90.6 (58/64)</td> <td rowspan="2">0.236<sup>1</sup></td> </tr> <tr> <td>No</td> <td>% of N</td> <td>0 (0/14)</td> <td>9.4 (6/64)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Living alone</b></td> </tr> <tr> <td>Yes</td> <td>% of N</td> <td>100 (16/16)</td> <td>90.6 (58/64)</td> <td rowspan="2">0.340<sup>1</sup></td> </tr> <tr> <td>No</td> <td>% of N</td> <td>0 (0/16)</td> <td>9.4 (6/64)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Living with children &lt; 18y</b></td> </tr> <tr> <td>Yes</td> <td>% of n/N</td> <td>25.0 (4/16)</td> <td>34.4 (22/64)</td> <td rowspan="2">0.474<sup>2</sup></td> </tr> <tr> <td>No</td> <td>% of N</td> <td>75.0 (12/16)</td> <td>65.6 (42/64)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Living with persons &gt;65y</b></td> </tr> <tr> <td>Yes</td> <td>% of N</td> <td>12.5 (2/16)</td> <td>6.2 (4/64)</td> <td rowspan="2">0.399<sup>1</sup></td> </tr> <tr> <td>No</td> <td>% of N</td> <td>87.5 (14/16)</td> <td>93.8 (60/64)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Living with a partner</b></td> </tr> <tr> <td>Yes</td> <td>% of N</td> <td>62.5 (10/16)</td> <td>60.9 (39/64)</td> <td rowspan="2">0.909<sup>2</sup></td> </tr> <tr> <td>No</td> <td>% of N</td> <td>37.5 (6/16)</td> <td>39.1 (25/64)</td> </tr> <tr> <td colspan="5" style="text-align: center;"><b>Education</b></td> </tr> <tr> <td>Up to secondary level education</td> <td>% of N</td> <td>84.6 (11/13)</td> <td>48.4 (31/64)</td> <td rowspan="2"><b>0.017<sup>2</sup></b></td> </tr> <tr> <td>Tertiary level education</td> <td>% of N</td> <td>15.4 (2/13)</td> <td>51.6 (33/64)</td> </tr> </tbody> </table> |                            |  | Non-respondents | Respondents | p-value (Non-respondents group vs the Respondents group) | <b>Age</b> |  |  |  |  |  | Mean (SD) | 46.64 (2.210) | 42,85 (1.363) | 0.161 <sup>1</sup> |  | Median (IQR) | 47.50 (40.00-54.00) (N=14) | 43.00 (33.75-51.25) (N=62) | <b>Having a stable relationship</b> |  |  |  |  | Yes | % of N | 100 (14/14) | 90.6 (58/64) | 0.236 <sup>1</sup> | No | % of N | 0 (0/14) | 9.4 (6/64) | <b>Living alone</b> |  |  |  |  | Yes | % of N | 100 (16/16) | 90.6 (58/64) | 0.340 <sup>1</sup> | No | % of N | 0 (0/16) | 9.4 (6/64) | <b>Living with children &lt; 18y</b> |  |  |  |  | Yes | % of n/N | 25.0 (4/16) | 34.4 (22/64) | 0.474 <sup>2</sup> | No | % of N | 75.0 (12/16) | 65.6 (42/64) | <b>Living with persons &gt;65y</b> |  |  |  |  | Yes | % of N | 12.5 (2/16) | 6.2 (4/64) | 0.399 <sup>1</sup> | No | % of N | 87.5 (14/16) | 93.8 (60/64) | <b>Living with a partner</b> |  |  |  |  | Yes | % of N | 62.5 (10/16) | 60.9 (39/64) | 0.909 <sup>2</sup> | No | % of N | 37.5 (6/16) | 39.1 (25/64) | <b>Education</b> |  |  |  |  | Up to secondary level education | % of N | 84.6 (11/13) | 48.4 (31/64) | <b>0.017<sup>2</sup></b> | Tertiary level education | % of N | 15.4 (2/13) | 51.6 (33/64) |  |
|                                      |              | Non-respondents  | Respondents                | p-value (Non-respondents group vs the Respondents group) |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Age</b>                           |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
|                                      | Mean (SD)    | 46.64 (2.210)  | 42,85 (1.363)              | 0.161 <sup>1</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
|                                      | Median (IQR) | 47.50 (40.00-54.00) (N=14)   | 43.00 (33.75-51.25) (N=62) |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Having a stable relationship</b>  |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Yes                                  | % of N       | 100 (14/14)  | 90.6 (58/64)               | 0.236 <sup>1</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| No                                   | % of N       | 0 (0/14)   | 9.4 (6/64)                 |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Living alone</b>                  |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Yes                                  | % of N       | 100 (16/16)  | 90.6 (58/64)               | 0.340 <sup>1</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| No                                   | % of N       | 0 (0/16)   | 9.4 (6/64)                 |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Living with children &lt; 18y</b> |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Yes                                  | % of n/N     | 25.0 (4/16)  | 34.4 (22/64)               | 0.474 <sup>2</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| No                                   | % of N       | 75.0 (12/16)   | 65.6 (42/64)               |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Living with persons &gt;65y</b>   |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Yes                                  | % of N       | 12.5 (2/16)  | 6.2 (4/64)                 | 0.399 <sup>1</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| No                                   | % of N       | 87.5 (14/16)   | 93.8 (60/64)               |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Living with a partner</b>         |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Yes                                  | % of N       | 62.5 (10/16)   | 60.9 (39/64)               | 0.909 <sup>2</sup>                                       |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| No                                   | % of N       | 37.5 (6/16)  | 39.1 (25/64)               |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| <b>Education</b>                     |              |  |                            |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Up to secondary level education      | % of N       | 84.6 (11/13)   | 48.4 (31/64)               | <b>0.017<sup>2</sup></b>                                 |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |
| Tertiary level education             | % of N       | 15.4 (2/13)  | 51.6 (33/64)               |  |                 |             |  |            |  |  |  |  |  |           |               |               |                    |  |              |                            |                            |                                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                     |  |  |  |  |     |        |             |              |                    |    |        |          |            |                                      |  |  |  |  |     |          |             |              |                    |    |        |              |              |                                    |  |  |  |  |     |        |             |            |                    |    |        |              |              |                              |  |  |  |  |     |        |              |              |                    |    |        |             |              |                  |  |  |  |  |                                 |        |              |              |                          |                          |        |             |              |  |

| <b>Did you have COVID-19</b>                               |        |              |               |                    |
|--|--------|--------------|---------------|--------------------|
| Yes  | % of N | 0 (0/13)     | 4.7 (3/64)    | 0.429 <sup>1</sup> |
| No   | % of N | 100 (13/13)  | 95.3 (61/64)  |                    |
| <b>Someone in your social network has had COVID-19</b>     |        |              |               |                    |
| Yes  | % of N | 23.1 (3/13)  | 28.6 (18/63)  | 0.687 <sup>2</sup> |
| No   | % of N | 76.9 (10/13) | 71.4 (45/63)  |                    |
| <b>Reduction of social network</b>                         |        |              |               |                    |
| Moderate reduction   | % of N | 15.4 (2/13)  | 15.6 (10/64)  | 0.983 <sup>2</sup> |
| Large reduction  | % of N | 84.6 (11/13) | 84.4 (54/64)  |                    |
| <b>Risk profiling for OC and BC</b>                        |        |              |               |                    |
| BRCA 1 & 2   | % of N | 76.9 (10/13) | 70.3 (45/64)  | 0.895 <sup>3</sup> |
| Mutations other than BRCA 1 & 2                            | % of N | 15.4 (2/13)  | 14.10 (9/64)  |                    |
| Positive family history for BC or OC                       | % of N | 7.7 (1/13)   | 15.6 (10/64)  |                    |
| <b>Having a history of (in situ or invasive) OC and BC</b> |        |              |               |                    |
| Yes  | % of N | 73.3 (11/15) | 64.1 (41/64)  | 0.496 <sup>2</sup> |
| No   | % of N | 26.7 (4/15)  | 35.9 (23/64)  |                    |
| <b>Having a history of invasive BC</b>                     |        |              |               |                    |
| Yes  | % of N | 60 (9/15)    | 56.20 (36/64) | 0.792 <sup>2</sup> |
| No   | % of N | 40 (6/15)    | 43.80 (28/64) |                    |
| <b>Having a history of invasive OC</b>                     |        |              |               |                    |
| Yes  | % of N | 6.7 (1/15)   | 1.6 (1/64)    | 0.260 <sup>1</sup> |
| No   | % of N | 93.3 (14/15) | 98.4 (63/64)  |                    |

(b)

| <b>Questions</b>  | <b>Yes</b><br>in % of respondents<br>(n/N) | <b>No</b><br>in % of respondents<br>(n/N) | <b>I don't know/does not apply</b><br>in % of respondents<br>(n/N) |
|---|--|---|--|
| Would you have liked to be informed about hygiene protocols in advance of your appointment? | 37.5% (24/64)                              | 37.5% (24/64)                             | 25.0% (16/64)  |
| Would more information about the prevailing hygiene protocols have                          | 20.3% (13/64)                              | 31.3% (20/64)                             | 48.4% (31/64)  |

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|  |                  |                  |                  |
|--|------------------|------------------|------------------|
| had a positive influence on your behavior (e.g., meeting appointments)?  |                  |                  |                  |
| Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment?   | 57.8%<br>(37/64) | 26.6%<br>(17/64) | 15.6%<br>(10/64) |
| Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis?   | 95.3%<br>(61/64) | 1.6%<br>(1/64)   | 3.1%<br>(2/64)   |
| Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed?   | 93.8%<br>(60/64) | 1.6%<br>(1/64)   | 4.7%<br>(3/64)   |
| Should a relative or a close person be allowed to accompany patients in the healthcare setting, despite the COVID-19 pandemic?   | 75.0%<br>(48/64) | 15.6%<br>(10/64) | 9.4%<br>(6/64)   |
| Do you think/agree that appointments, which do not require one's physical presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? | 71.9%<br>(46/64) | 21.9%<br>(14/64) | 6.3%<br>(4/64)   |
| Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic?   | 84.4%<br>(54/64) | 7.8%<br>(5/64)   | 7.8%<br>(5/64)   |
| Do you think that medical personnel should always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients' safety?  | 68.8%<br>(44/64) | 18.8%<br>(12/64) | 12.5%<br>(8/64)  |

Outcome data

15\*

1. Would you have liked to be informed about hygiene protocols in advance of your appointment? (*Yes – No – I don't know/does not apply*)
2. Would more information about the prevailing hygiene protocols have had a positive influence on your behavior (e.g., meeting appointments)? *Yes – No – I don't know/does not apply*
3. Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment? *Yes – No – I don't know/does not apply*
4. Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis? *Yes – No – I don't know/does not apply*
5. Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed? *Yes – No – I don't know/does not apply*

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6. Should a relative or a close person be allowed to accompany patients in the healthcare setting, despite the COVID-19 pandemic? *Yes – No – I don't know/does not apply*
7. Do you think/agree that appointments, which do not require one's physical presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*
8. Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic? *Yes – No – I don't know/does not apply*
9. Do you think that medical personnel should always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients' safety? *Yes – no – I don't know/does not apply*

Main results 16 (a) 8, 11

|                                      |              | Non-respondents            | Respondents                | p-value (Non-respondents group vs the Respondents group) |
|--------------------------------------|--------------|----------------------------|----------------------------|--|
| <b>Age</b>                           |              |                            |                            |  |
|                                      | Mean (SD)    | 46.64 (2.210)              | 42,85 (1.363)              | 0.161 <sup>1</sup>                                       |
|                                      | Median (IQR) | 47.50 (40.00-54.00) (N=14) | 43.00 (33.75-51.25) (N=62) |  |
| <b>Having a stable relationship</b>  |              |                            |                            |  |
| Yes                                  | % of N       | 100 (14/14)                | 90.6 (58/64)               | 0.236 <sup>1</sup>                                       |
| No                                   | % of N       | 0 (0/14)                   | 9.4 (6/64)                 |  |
| <b>Living alone</b>                  |              |                            |                            |  |
| Yes                                  | % of N       | 100 (16/16)                | 90.6 (58/64)               | 0.340 <sup>1</sup>                                       |
| No                                   | % of N       | 0 (0/16)                   | 9.4 (6/64)                 |  |
| <b>Living with children &lt; 18y</b> |              |                            |                            |  |
| Yes                                  | % of n/N     | 25.0 (4/16)                | 34.4 (22/64)               | 0.474 <sup>2</sup>                                       |
| No                                   | % of N       | 75.0 (12/16)               | 65.6 (42/64)               |  |
| <b>Living with persons &gt;65y</b>   |              |                            |                            |  |
| Yes                                  | % of N       | 12.5 (2/16)                | 6.2 (4/64)                 | 0.399 <sup>1</sup>                                       |
| No                                   | % of N       | 87.5 (14/16)               | 93.8 (60/64)               |  |
| <b>Living with a partner</b>         |              |                            |                            |  |
| Yes                                  | % of N       | 62.5 (10/16)               | 60.9 (39/64)               | 0.909 <sup>2</sup>                                       |
| No                                   | % of N       | 37.5 (6/16)                | 39.1 (25/64)               |  |
| <b>Education</b>                     |              |                            |                            |  |
| Up to secondary level education      | % of N       | 84.6 (11/13)               | 48.4 (31/64)               | <b>0.017<sup>2</sup></b>                                 |

|  |        |              |               |                    |
|--|--------|--------------|---------------|--------------------|
| Tertiary level education                                   | % of N | 15.4 (2/13)  | 51.6 (33/64)  |                    |
| <b>Did you have COVID-19</b>                               |        |              |               |                    |
| Yes  | % of N | 0 (0/13)     | 4.7 (3/64)    | 0.429 <sup>1</sup> |
| No   | % of N | 100 (13/13)  | 95.3 (61/64)  |                    |
| <b>Someone in your social network has had COVID-19</b>     |        |              |               |                    |
| Yes  | % of N | 23.1 (3/13)  | 28.6 (18/63)  | 0.687 <sup>2</sup> |
| No   | % of N | 76.9 (10/13) | 71.4 (45/63)  |                    |
| <b>Reduction of social network</b>                         |        |              |               |                    |
| Moderate reduction   | % of N | 15.4 (2/13)  | 15.6 (10/64)  | 0.983 <sup>2</sup> |
| Large reduction  | % of N | 84.6 (11/13) | 84.4 (54/64)  |                    |
| <b>Risk profiling for OC and BC</b>                        |        |              |               |                    |
| BRCA 1 & 2   | % of N | 76.9 (10/13) | 70.3 (45/64)  | 0.895 <sup>3</sup> |
| Mutations other than BRCA 1 & 2                            | % of N | 15.4 (2/13)  | 14.10 (9/64)  |                    |
| Positive family history for BC or OC                       | % of N | 7.7 (1/13)   | 15.6 (10/64)  |                    |
| <b>Having a history of (in situ or invasive) OC and BC</b> |        |              |               |                    |
| Yes  | % of N | 73.3 (11/15) | 64.1 (41/64)  | 0.496 <sup>2</sup> |
| No   | % of N | 26.7 (4/15)  | 35.9 (23/64)  |                    |
| <b>Having a history of invasive BC</b>                     |        |              |               |                    |
| Yes  | % of N | 60 (9/15)    | 56.20 (36/64) | 0.792 <sup>2</sup> |
| No   | % of N | 40 (6/15)    | 43.80 (28/64) |                    |
| <b>Having a history of invasive OC</b>                     |        |              |               |                    |
| Yes  | % of N | 6.7 (1/15)   | 1.6 (1/64)    | 0.260 <sup>1</sup> |
| No   | % of N | 93.3 (14/15) | 98.4 (63/64)  |                    |

| Questions  | Yes in % of respondents (n/N) | No in % of respondents (n/N) | I don't know/does not apply in % of respondents (n/N) |
|--|-------------------------------|------------------------------|---|
| Would you have liked to be informed about hygiene protocols in | 37.5% (24/64)                 | 37.5% (24/64)                | 25.0% (16/64)   |

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| advance of your appointment?   |                  |                  |                  |
| Would more information about the prevailing hygiene protocols have had a positive influence on your behavior (e.g., meeting appointments)?   | 20.3%<br>(13/64) | 31.3%<br>(20/64) | 48.4%<br>(31/64) |
| Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment?   | 57.8%<br>(37/64) | 26.6%<br>(17/64) | 15.6%<br>(10/64) |
| Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis?   | 95.3%<br>(61/64) | 1.6%<br>(1/64)   | 3.1%<br>(2/64)   |
| Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed?   | 93.8%<br>(60/64) | 1.6%<br>(1/64)   | 4.7%<br>(3/64)   |
| Should a relative or a close person be allowed to accompany patients in the healthcare setting, despite the COVID-19 pandemic?   | 75.0%<br>(48/64) | 15.6%<br>(10/64) | 9.4%<br>(6/64)   |
| Do you think/agree that appointments, which do not require one's physical presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? | 71.9%<br>(46/64) | 21.9%<br>(14/64) | 6.3%<br>(4/64)   |
| Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic?   | 84.4%<br>(54/64) | 7.8%<br>(5/64)   | 7.8%<br>(5/64)   |
| Do you think that medical personnel should always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients' safety?  | 68.8%<br>(44/64) | 18.8%<br>(12/64) | 12.5%<br>(8/64)  |

(b)  
(c)

|                |    |                   |  |
|----------------|----|-------------------|--|
| Other analyses | 17 | No other analyses |  |
|----------------|----|-------------------|--|

|                   |    |   |       |
|-------------------|----|---|-------|
| <b>Discussion</b> |    |   |       |
| Key results       | 18 | 1. 37.5% of the participants in this study preferred to be informed of the healthcare facility's hygiene protocols in advance of medical appointments. More interestingly, over 20% of participants stated that receiving prior information about safety protocols during the | 13-17 |

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COVID-19 pandemic would have strengthened their adherence to medical appointments. The dissemination of information that is valuable, transparent and proactive has been recognized previously by the WHO as an essential tool to overcome various difficulties or insecurities triggered by the pandemic [8].

2. Approximately 93.8% of participants in this study expected adherence to the recommended physical distancing rules in waiting rooms.
3. Notably, 71.9% of the participants in this study approved implementation of telemedicine whenever possible and reasonable from an oncological viewpoint, in order to reduce face-to-face contact and minimize potential contact with persons infected with SARS-CoV-2, but maintain the required standards for treatment.
4. Interestingly, 57.8% of our study's population indicated they would rather tolerate the inconvenience of repetitive testing before visiting a healthcare institution, in order to feel safe and avoid exposure to potentially life-threatening infectious agents.
5. This study showed that 93% of patients strongly supported the notion of broad screening programs for HCW, irrespective of their demographic, disease-specific or pandemic-specific factors.

|                          |    |  |    |
|--------------------------|----|--|----|
| Limitations              | 19 | <p>First, there might be an overrepresentation of patients worrying about their health status because of their recruitment from support groups and the underrepresentation of women without online access are two possible sources of bias. Nevertheless, a recent systematic review showed that Facebook-recruited samples were similarly representative as samples recruited via traditional methods [29]. Furthermore, as the patients responded directly to the questionnaire, social desirability bias was greatly limited.</p> <p>We did not assess participants' vaccination status; however, we presumed that most of them were not vaccinated because of national regulations during the survey period. Thus, we do not know whether the responses accurately depict the current state of the pandemic, as expectations may have changed due to the currently available vaccines.</p> | 17 |
| Interpretation           | 20 | In conclusion, we showed that most patients at high risk for infection or severe course of COVID-19 disease approve strict contingency measures, such as physical distancing rules, the implementation of telemedicine and the use of highly effective protective masks, designed to lower the transmission of COVID-19 in medical facilities. However, they also value the presence of a significant other during medical consultations and procedures.   | 19 |
| Generalisability         | 21 | As we assessed participants' needs, fears and expectations, we followed the WHO recommendation for two-way communication with populations at risk [8]. Our goal is to improve and optimize the public health measures, which could be implemented during a next wave of the COVID-19 pandemic or other possible pandemics.   | 19 |
| <b>Other information</b> |    |  |    |
| Funding                  | 22 | The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.  | 20 |

\*Give information separately for exposed and unexposed groups.

1  
2 **Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and  
3 published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely  
4 available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at  
5 <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is  
6 available at [www.strobe-statement.org](http://www.strobe-statement.org).  
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