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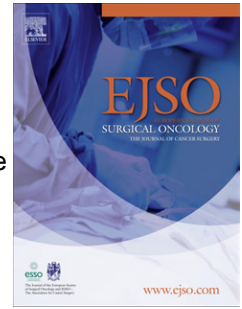
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**Professionals' opinion on follow-up in breast cancer patients; perceived
purpose and influence of patients' risk factors**

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Abstract

Aim: To provide insight into professionals' opinions on breast cancer follow-up to facilitate implementation of new follow-up strategies. The study focuses on current practice, purpose and perceived effects, and preferred frequency and duration of follow-up.

Design: A 29-item questionnaire on professionals' demographics, current practice, opinion on the current guideline, preferences in frequency and duration of tailored follow-up, and the purpose and perceived effects of follow-up was sent to 633 Dutch professionals.

Results: The current national guideline is followed by 81% of respondents. All different specialists are involved in follow-up. Sixty-nine percent of respondents' report nurse practitioners to be involved in follow-up. When asked for tailored follow-up, professionals indicate more factors for increased follow-up (age<40 years, pT3-4 tumour, pN2-3, treatment related morbidity, and psychosocial support), than for reduced schedules (age >70 years and DCIS histology). Alternative forms of follow-up are not endorsed by >90% of respondents. Detection of a new primary tumour of the breast is considered the most important purpose of follow-up (98%), 57% still indicates detecting metastases as a goal.

Conclusions: Professionals tend towards longer and more intensive follow-up than the current guideline for a large group of patients. Limitations and developments in follow-up need to be considered to facilitate alternative follow-up strategies.

Introduction

Although the effectiveness of routine clinical follow-up of breast cancer patients has been debated over the last decades, a routine follow-up schedule is still standard care for most patients. Due to better therapeutic strategies and increasing age of the population, numbers of breast cancer survivors increase over the years. Therefore we need to reconsider the need for routine visits, as they will become a burden for both professionals and patients.

Aims of follow-up are early detection of local recurrence or second malignancy, social support and monitoring treatment effects^{1,2}. Although annual mammograms have shown to improve patient outcome³, no improvement is found for increased frequency or intensity of follow-up⁴⁻⁸. The second aim of follow-up, psychosocial support, has also been questioned. Outpatient visits have been demonstrated to induce anxiety because of the risk of detecting tumour relapse^{9,10}. For assessment of treatment morbidity less frequent outpatient visits or questionnaires may suffice. In two systematic reviews of evidence supporting alternative follow-up schedules, Montgomery et al. and Collins et al. concluded that neither the optimum frequency nor duration has been established.^{11,12} The Dutch national guideline¹³ advises patient history taking and physical examination every 3 months the first year after treatment, every 6 months the second year, and annually thereafter, irrespective of the risk profile or treatment of the patient. An annual mammogram is advised. Duration of follow-up is not specified, although it is advised to consider termination of outpatient visits after 5 years of follow-up in patients over 75 years of age. After the first 5 years, age (<60 vs. >60 years), treatment (breast conserving therapy vs. mastectomy) and the presence of BRCA1/2 gene mutation determine whether annual physical examination is indicated and whether a mammogram is performed annually or biennially.

Research has shown that patients accept alternative follow-up strategies such as decreased frequency, nurse-led follow-up and telephone follow-up, without increased anxiety or decreased patient satisfaction ^{11,14,15}. Few studies report on health care professionals' opinion on follow-up and the role of specialised nurses. Previous reports show that professionals prefer routine follow-up by their own professional group ¹⁶. Donnelly et al. reported that professionals do not always adhere to national guidelines, with 80% continuing follow-up beyond the prescribed duration of follow-up in asymptomatic patients ².

The aim of the present study among Dutch health care professionals was to evaluate their opinion on common clinical practice and the perceived purpose of breast cancer follow-up. Furthermore we surveyed the influence of individual risk factors on preferred follow-up to facilitate the implementation of tailored follow-up.

Methods and materials

Questionnaire

A structured web based questionnaire was developed, based on Donnelly's questionnaire on specialists' attitudes² and Stiggelbout's Questionnaire on patients' attitudes towards follow-up¹⁷. The questionnaire was tested on an internal test panel, consisting of surgeons, radiation oncologists, nurse practitioners, an epidemiologist and experts in medical decision making. The questionnaire consisted of 29 questions on 4 themes: 1. professionals' demographics, 2. opinion on the current guideline, 3. opinion on frequency and duration of tailored follow-up, and 4. opinion on the purpose of follow-up; we stated 10 possible reasons for follow-up and asked the respondent to indicate to what extent they agreed (5 point scale). From Stiggelbout's questionnaire¹⁷, we derived 6 additional questions on perceived effect of follow-up (4 point scale).

The anonymous questionnaire was sent as a hyperlink by the Dutch Comprehensive Cancer Centres to all members of the 'breast cancer' and 'oncology nurses' teams of the different regions between March and June 2009. The 633 members consisted of 194 (31%) surgeons, 96 (15%) radiation oncologists, 162 (26%) medical oncologists and 181 (28%) nurse practitioners / breast care nurses, grouped hereafter as 'nurse practitioners' (NP). A single reminder was sent several weeks after the first mailing.

Statistical analysis

Frequencies and percentages were used to display responses to individual questions. Differences between groups were analysed using the Pearson chi-square and students t-test. The statistical package SPSS version 16.0 (SPSS Inc, Chicago, IL) was used to conduct statistical analyses.

Results

Professionals' demographics

One hundred ninety-nine professionals (31%) started the questionnaire (51 surgeons, 44 radiation oncologists, 33 medical oncologists and 71 NPs) of whom 130 (65%) finished the questionnaire. Of the NP's that started the questionnaire, only 45% finished. For other professionals this percentage was higher: 77% of surgeons, 88% of medical oncologists and 68% of radiation oncologists. For information on region and type of hospital of the respondents see table 1.

Current practice

The current national guideline was known by 99%, and was followed by 81% of the professionals. Seventy-three percent was satisfied in general with the frequency of follow-up set by the national guideline. Concerning the number of years of follow-up, 55% was satisfied. The content of the prescribed follow-up (history, physical examination, mammography) was sufficient according to 82% of the professionals, 9% found it insufficient and 7% too extensive.

Patients' opinion on their follow-up schedule was routinely considered in only 12% of respondents' practices. Twenty-one percent of the respondents gave their patients a written follow-up plan, in only 10% of respondents' practices all patients received such a plan.

Frequency and duration of tailored follow-up

When asked about their own preferences regarding follow-up in the years after treatment compared to the current Dutch guideline, professionals agree in general with the recommended frequency and duration. Reasons for at least 40% of professionals to see patients more frequently were the following patient risk factors: age<40 years, pT3-4

tumour, pN2-3, treatment related morbidity, and psychosocial support. Of these factors, age<40 and pN3 status were also arguments for respondents to follow patients longer than the 5 years that the national guideline recommends (fig. 1).

Professionals reported few arguments for less frequent follow-up. More than 25% of respondents indicated the following factors: age >70, N0, DCIS and grade 1 tumour.

Only age >70 years and DCIS histology were considered arguments for shorter follow-up than the guideline in more than 25% (fig 1)

Significant differences between the disciplines in preferred frequency of follow-up were found. Medical oncologists often prefer more frequent follow-up than the guideline, as opposed to radiation oncologists and surgeons who tend to less frequent follow-up (table 2). Medical oncologist name twice as many factors for which more frequent follow-up is needed compared to other professionals (8 vs. 4, $p=0.002$)

The only risk factor for which the opinion on preferred duration of follow-up differed significantly between the disciplines was hormone positive status. Medical oncologists indicated that these patients should be followed longer more often (31%) than surgeons (3%) radiation oncologists (10%) or NPs (6%) ($p=0.005$).

The number of factors that professionals indicated to influence frequency and duration of follow-up corresponded well with the general satisfaction on the current guideline.

Professionals who indicated that follow-up according to the current guideline was too infrequent indicated significantly more arguments for more frequent follow-up than those who indicated that the current guideline recommends too frequent outpatients visits: 17 vs. 4 factors ($p<0.001$).

Specialists involved in follow-up

In current practice, virtually all surgeons (94%) are involved in follow-up, followed by two-thirds of other professionals. Coordination of follow-up is not done by a single

professional in 69% of respondents' practices. When a single coordinator is appointed, this is most often the surgeon (66%), followed by the NP (27%).

When asked who should be involved, even in case of reduced follow-up, the general opinion is that surgeons should 'always' be involved in 44%, followed by the NP according to 39% of the respondents. Only 13% of all respondents indicate that radiation oncologist and medical oncologist should 'always' stay involved. In contrast, 32% of professionals in these two groups think they should 'always' be involved themselves. All professionals agree that the general practitioner (GP) should play a small role in follow-up in the Netherlands; only 8% indicates GP's should 'always' be involved and 24% even thinks they should 'never' be involved in breast cancer follow-up.

Content of follow-up

When asked how follow-up should be performed after the first year, the majority agreed with the national guideline. Essential elements of follow-up according to professionals were to see patients in the hospital to perform a medical history (84%), physical examination (88%) and mammography (92%). Alternative forms of follow-up such as history by telephone, laboratory tests and MRI were not endorsed by 90%, 94% and 96% of respondents respectively. On laboratory tests and medical history taking as part of follow-up opinions differ significantly between disciplines (fig 2).

Purpose and perceived effect of follow-up

Detection of a new primary tumour of the ipsi- or contra lateral breast was indicated by 98% of professionals as a purpose of follow-up. Other purposes were indicated as follows: detecting local recurrence (95%), detecting (late) sequelae of treatment (89%), detecting psychological problems (83%), assessment of quality of life and social integration of patient after treatment (73%), informing about cosmetic operations (73%),

advising on family risk and prevention (72%), organising mammography's (68%) , detecting metastases (57%) and assessing patients' status for research (54%) (fig 3). Concerning the perceived effect, breast self examination and physical examination was thought to aid detection of a new tumour by 22% and 33% of respondents respectively, as opposed to 91% for mammography (fig 3). Seventy-five percent of professionals indicated that early detection of a recurrence or new tumour would increase the chance of cure. Early detection of metastases was indicated to increase this chance by 9% of professionals.

Forty-eight percent of respondents, who agreed that detecting metastases is a purpose of follow-up, think detection will 'not at all' increase the chance on cure.

Only 24% think frequent follow-up visits will significantly improve patients' quality of life (5% 'very much' and 19% 'rather').

Although no significant differences between the different disciplines were reported for the purposes of follow-up, the perceived effect of follow-up significantly differs between the disciplines on two items. Medical oncologist indicate significantly more often than other specialists that physical examination will 'very much' help in detecting a new tumour (24 %, $p=0.05$) and significantly more radiation oncologists indicate that detecting metastases does 'not at all' increase the chance of cure (93%, $p<0.001$).

Discussion

In this large survey among Dutch health care professionals on follow-up of breast cancer patients we managed to get a good overview of the opinion on follow-up in the different professional groups involved. In addition to professionals' views on duration and purpose of follow-up, as reported previously by Donnelly², also their preferred frequency and supposed effect of follow-up were assessed. This is the first study to have included the NPs as a professional group. Their role has been studied separately before^{18,19}, but no reports on professionals' opinion regarding their role in everyday practice have been published.

Professionals' demographics

Although the response rate was not optimal, it is comparable to prior reported web based surveys to professionals²⁰. Possibly the response to web based surveys is lower than mailed surveys^{2,21}, because of the anonymity. Our respondents well reflect the professionals involved in breast cancer follow-up in the Netherlands, from all regions, all specialties, and different types of hospitals.

Current practice

In contrast to Donnelly's findings² we found good (reported) adherence, with 99% knowing the national guideline, and 81% stating to follow it. The Dutch adherence is higher than in the UK, which might be explained by the fact that the Dutch guideline prescribes follow-up for at least 5 years after treatment, whereas the NICE guidelines propose discharge after only 3 years.

Previous studies show that patient involvement increases perceived quality of life²². We found the patients' role still to be limited, however, as only one in eight professionals indicates that their patients are routinely involved in making the follow-up plan. A written

follow-up plan for patients as recommended in the National Health Council ¹ and Miller et al. ²³ to strengthen care connections and coordination of services, is also rare in everyday practice. With the role of patients in follow-up moving towards 'survivor' as opposed to 'patient', we think involving patients in the considerations and decisions regarding their own follow-up is essential and informing patients should be a priority in follow-up care. In our view NPs could play an important role in this communication.

Frequency and duration of tailored follow-up

In contrast to the tendency to see patients more frequently and longer than guidelines prescribe, almost all respondents indicate that they perceive that frequent follow-up visits do not significantly improve quality of life. Evidence on this subject is conflicting as earlier reports state that anxiety is increased before follow-up visits ^{24,25}, but others found positive attitude towards follow-up visits ²⁶ and reduced rates of cancer worries in patients with guideline follow-up as opposed to reduced follow-up visits ²⁷. Gulliford et al. already reported that less follow-up was acceptable to patients, except for those under the age of 50 ¹⁴.

Our study suggests that professionals, especially medical oncologists, indicate more factors to follow patients more frequently or longer, than factors for less frequent follow-up or earlier discharge than guidelines prescribe. This is in line with previous reports suggesting that professionals tend to see patients too often and have difficulty discharging them ^{2,28}. This might be based on personal clinical experience of detecting a local recurrence which changed outcome for a patient.

More intensive follow-up has never been reported to improve survival and most recurrences are still found in between follow-up visits ²⁹⁻³¹. Ongoing hormonal treatment was a reason for a longer follow-up preference, which may be explained by long term

risks of hormone use, such as decreased bone density and the fact that late local recurrences are seen in ER positive tumours³².

Specialists involved in follow-up

From our results we conclude that the NPs have become part of standard care in current practice, as they are involved in follow-up in two thirds of respondents' practices. Surgeons are in almost all cases involved in the follow-up, medical and radiation oncologists less, but still to a large extent. The coordination of follow-up is, in contrast to national recommendations, most often done by multiple specialists. This might lead to suboptimal scheduling and possibly too many follow-up appointments with different disciplines. If a single coordinator is appointed, this is most often the surgeon, followed by the NP, which again underlines the increasing role of the latter in follow-up care. All specialists agreed that the GP plays only a minor role in follow-up, despite the evidence that in the British and Canadian system quality of life and outcome are similar when follow-up is done by GP after the first year, with annual mammogram³³⁻³⁵. In our view, it is most important that patients receive clear instructions who to contact during follow-up, preferably a dedicated NP.

Content of follow-up

Most professionals in our study agree with the content of the follow-up prescribed by the guideline (physical examination/history taking/mammography). The majority indicate no extra tests are needed, in line with previous reports that show no decrease in morbidity or mortality from extra testing^{6,12}. Like other authors^{36,37}, we found that medical oncologists tend to do more laboratory tests, although this is not effective for detecting recurrent disease. Increased tests may be related to checking blood results during ongoing hormone therapy; we did not specify this question on patient or tumour

characteristics. Alternative forms of follow-up such as medical history by telephone, although effective and acceptable to patients¹⁵, are not preferred by our respondents, possibly as a result of preference for the familiar.

Purpose and perceived effects of follow-up

When asked for the purpose of follow-up, as expected virtually everyone agrees that detecting new tumour of the breast or local recurrence is important. Also a considerable part of respondents indicated detection and treatment of (late) sequelae to be important, in accordance with Donnelly who reported treatment related toxicity to be the most important consideration for follow-up^{2,38,39}. Unexpectedly, detecting psychological problems is the fourth agreed-on purpose in our study. There is little evidence that routine clinic visits are useful in detecting side effects of treatment or psychological problems^{40,41}. Furthermore, if no other examinations are required, the question should be raised whether the hospital is the best place for this support. Also the organisation of mammograms, a purpose of follow-up visits according to two thirds of respondents, could perhaps be organised outside the outpatient clinic, particularly if a national survey programme exists.

Surprisingly, 6 out of 10 professionals still indicate that detecting metastases is a goal of follow-up, although only one in ten thinks it improves cure, in spite of evidence that detecting distant disease early through intensive follow-up does not improve survival and even decreases quality of life^{5,7,42}. Better education on this subject is needed for professionals to realise the limitations of follow-up and, perhaps more importantly, to be able to communicate this to patients.

Limitations

A limitation of our study is the suboptimal response rate and the length of the questionnaire. As a result of the latter, 30% of the respondents failed to answer the complete list of questions. There is a chance of response bias, as professionals who take the time to fill out our questionnaire might think that follow-up is more important than those who did not. Another limitation is that we only asked for the influence of the different risk factors separately, where in reality a combination of factors will lead to treatment decisions. Finally, we did not directly assess professionals' knowledge of the literature nor the reasons behind the preference for frequency of follow-up. Nevertheless, we are convinced this study gives insight in professionals' daily practice and considerations.

Conclusions

Although the national guideline is well known, many different specialists are involved in follow-up and the coordination is often unclear. When asked about tailored follow-up, professionals, especially medical oncologists, tended to follow-up that is longer and more intensive than the current guideline for a large group of patients, despite the lack of evidence that it improves outcome. Professionals need to be aware of the limitations of and developments in follow-up, so they can communicate these to their patients. Accordingly they could offer alternative ways of follow-up, reduce the number of visits, discharge patients timely and provide a clear written follow-up plan to patients. The nurse practitioners and breast care nurses, who have established their role over the last years, can possibly play an even more prominent role in coordinating and conducting follow-up visits and providing written information to patients.

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Conflict of interest

The authors have declared no conflicts of interest.

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Table 1. Respondents' demographics

| Total (n=130) | N | % of total |
|---|----|------------|
| Discipline | | |
| <i>Surgeon</i> | 39 | 30 |
| <i>Medical oncologist</i> | 29 | 22 |
| <i>Radiation oncologist</i> | 30 | 23 |
| <i>Nurse Practitioners</i> | 32 | 25 |
| Hospital | | |
| <i>University hospital</i> | 32 | 25 |
| <i>District training hospital</i> | 71 | 55 |
| <i>District non-training hospital</i> | 27 | 21 |
| # New patients per hospital/year | | |
| <i>0-100</i> | 25 | 19 |
| <i>100-200</i> | 44 | 34 |
| <i>200-500</i> | 46 | 35 |
| <i>>500</i> | 5 | 4 |
| <i>Unknown</i> | 10 | 8 |
| # Follow-up contacts per week per specialist | | |
| <i>0-5</i> | 23 | 18 |
| <i>5-10</i> | 42 | 14 |
| <i>10-20</i> | 46 | 35 |
| <i>>20</i> | 19 | 15 |

Table 2. Patient and tumour characteristics for which preferred frequency of follow-up differs significantly between disciplines

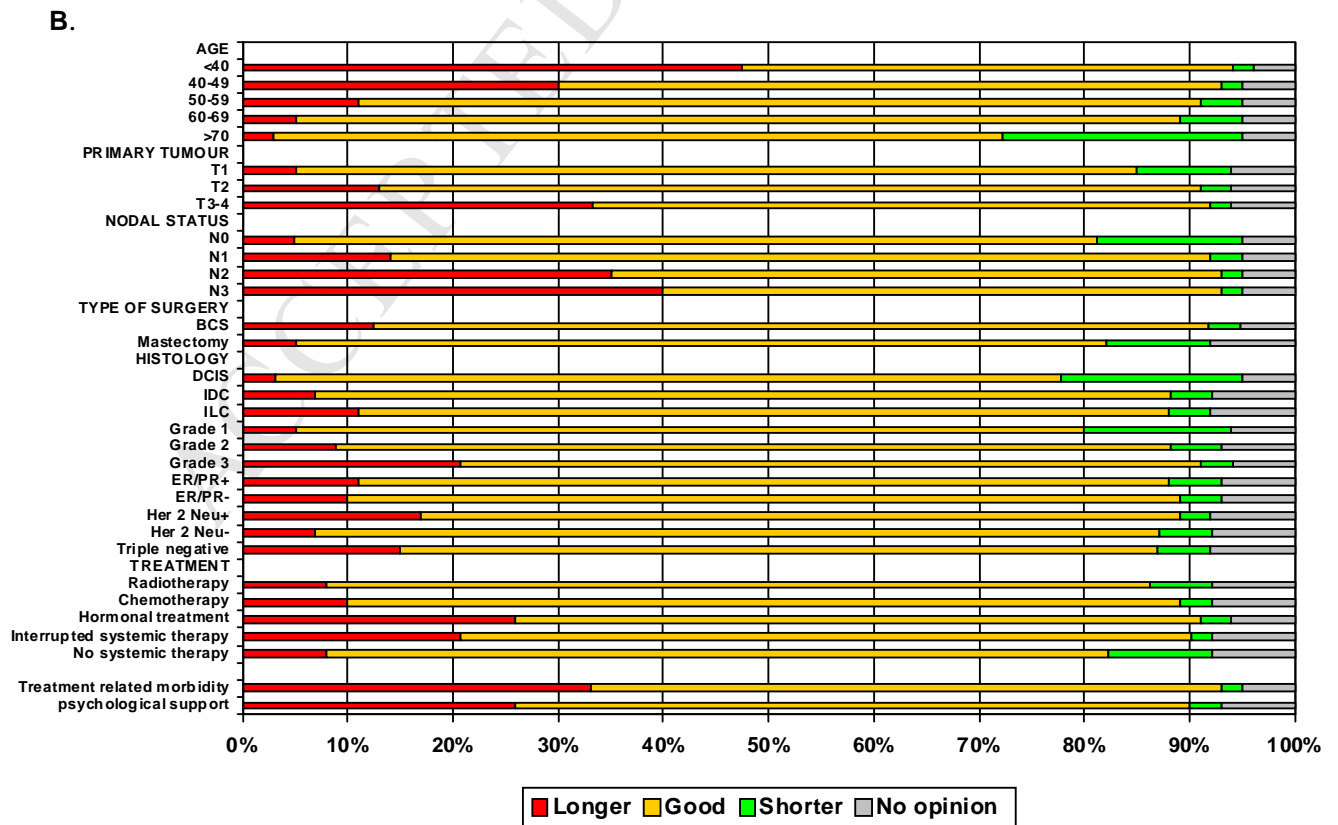
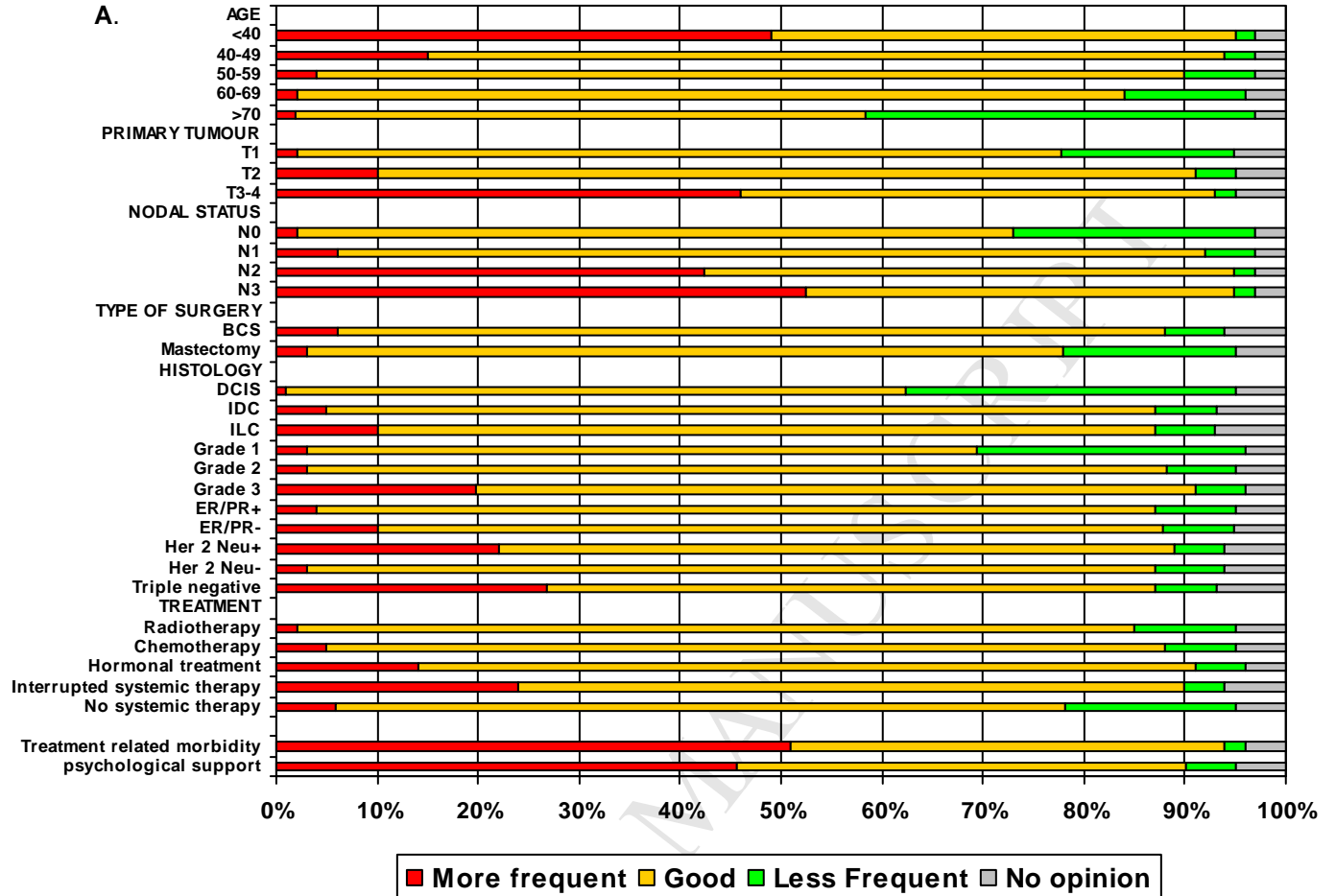
| Risk factor | Preferred frequency of follow-up ^c | Surgeons (%) | Radiation Oncologists (%) | Medical Oncologists (%) | Nurse Practitioners (%) | P (pearson chi-square) |
|------------------------------|---|--------------|---------------------------|-------------------------|-------------------------|------------------------|
| < 40 yr | More ^a | 40 | 43 | 76 | 42 | 0.02 |
| | Less ^b | 0 | 7 | 0 | 0 | |
| 50-60 yr | More | 0 | 3 | 14 | 0 | 0.03 |
| | Less | 5 | 13 | 7 | 3 | |
| 60-69 yr | More | 0 | 0 | 10 | 0 | 0.01 |
| | Less | 18 | 20 | 7 | 3 | |
| T1 | More | 0 | 0 | 10 | 0 | 0.04 |
| | Less | 18 | 30 | 10 | 12 | |
| Mastectomy | More | 3 | 0 | 10 | 0 | 0.01 |
| | Less | 18 | 33 | 7 | 9 | |
| Grade 1 | More | 0 | 0 | 14 | 0 | 0.001 |
| | Less | 38 | 40 | 7 | 18 | |
| ER/PR+ | More | 0 | 0 | 17 | 0 | 0.001 |
| | Less | 8 | 20 | 3 | 3 | |
| Hormonal treatment (ongoing) | More | 5 | 10 | 35 | 9 | 0.04 |
| | Less | 5 | 10 | 3 | 3 | |

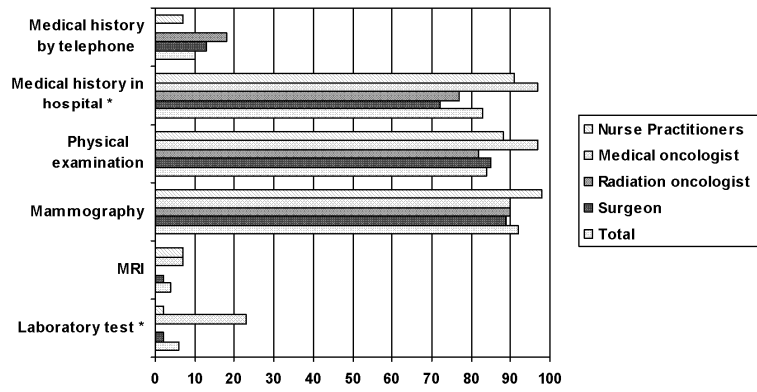
^a 'more' refers to the percentage of respondents who indicated a preference for more frequent follow-up visits than the current Dutch guideline prescribes.

The guideline prescribes follow-up every 3 months the first year after treatment, every 6 months the second year, and annually thereafter [13]

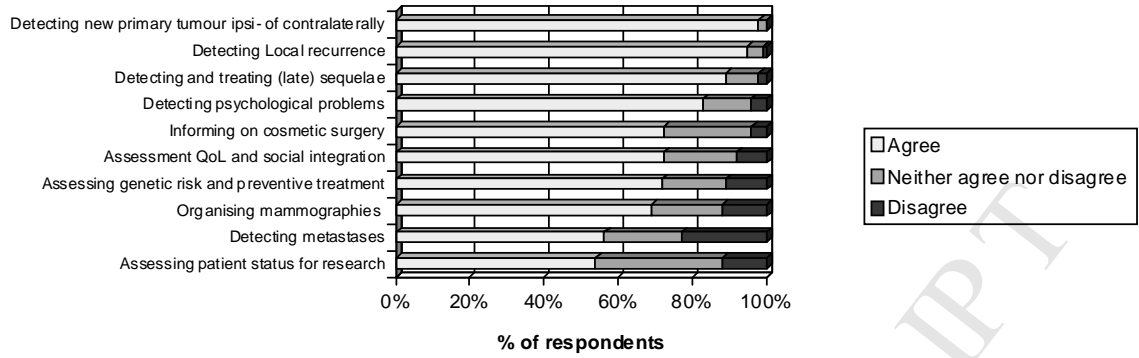
^b 'less' refers to the percentage of respondents that indicated a preference for less frequent follow-up visits than the current Dutch guideline.

^c The remainder of the respondents, not explicitly shown in the table, indicated to prefer the frequency according to the Dutch guideline.





A.



B.

