The role of the general practitioner during treatment and follow-up of patients with breast cancer
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CHAPTER 7
General discussion
This thesis describes the role of Dutch GPs during the breast cancer treatment phase (defined as the first year since diagnosis) and the follow-up phase (defined as the period starting one year post-diagnosis). Moreover, perspectives of GPs and patients were explored regarding the transfer of breast cancer follow-up to the primary care setting.

**SUMMARY OF THE MAIN FINDINGS**

In the first part of this thesis, results of two longitudinal studies on primary health care use of patients during the breast cancer treatment phase [Chapter 2] and the follow-up phase [Chapter 3] are presented. Increased primary health care use was observed among patients with breast cancer during treatment and follow-up, when compared to women without breast cancer. Reasons for the increased health care use in the first year since diagnosis were, among other problems, related to gastrointestinal problems, psychological problems, skin problems, and to the breast cancer itself. Regarding the follow-up phase, reasons were mainly related to the breast cancer itself. In both phases, patients were prescribed endocrine therapy (hormone antagonists and aromatase inhibitors) by their GP. The main predictors of the observed higher health care use in the first year since diagnosis and the follow-up phase were a higher health care use before diagnosis and a higher age at diagnosis, respectively.

Since September 2008, Dutch GPs have a coordinating role in the long-term follow-up (>5 years) of women aged >60 years who had undergone breast conserving therapy. The second part of this thesis describes the results of a quantitative mail survey exploring GPs’ experiences and perspectives regarding primary care-based follow-up [Chapter 4]. According to 22% of the GPs, at least one patient per year was discharged to them for long-term follow-up. Difficulties to implement this follow-up were related to compliance among breast cancer specialists, communication with these specialists, and the planning of follow-up visits in general practice. Nevertheless, 40% of GPs would accept responsibility for follow-up at an earlier stage (<5 years). The three most perceived barriers were: patients’ preference for specialist follow-up, limited oncology knowledge...
and skills of GPs, and workload pressure. The three most perceived useful tools were: a patient-specific letter from specialists, a refresher course in follow-up, and an updated breast cancer guideline.

In the third part of this thesis, results of a qualitative study exploring patients' views on primary care-based vs. specialist follow-up [Chapter 5] and the aims of follow-up [Chapter 6] are reported. Although the majority of the patients preferred specialist follow-up to other follow-up models, more than half would accept primary care-based follow-up. Prerequisites were: good communication between GPs and specialists, and sufficient knowledge among GPs about follow-up. Perceived benefits of primary care-based follow-up referred to the personal nature of the GP-patient relationship and the easy access to primary care. Perceived barriers to accept primary care-based follow-up were: limited oncology knowledge and skills, time available, and motivation among GPs to provide follow-up care. Another barrier involved patients' confidence with specialist follow-up. Among the patients, detecting recurrent breast cancer and providing reassurance were the most commonly reported aims of follow-up. Less frequently mentioned aims were: providing psychological support, evaluating care, generating hospitals' income, and providing wound care. Younger patients (aged ≤60 years) more often considered reassurance as an aim of follow-up than older patients (aged >60 years). Despite the perceived psychological advantage of receiving reassurance, patients also reported disadvantages in terms of experiencing anxiety and being confronted again with their breast cancer history.

METHODOLOGICAL CONSIDERATIONS

Different study types were used in this thesis, including: two longitudinal studies, a quantitative survey, and a qualitative study.

Primary care database research
Both longitudinal studies on primary health care use [Chapter 2 and 3] were conducted using the primary care database of the Registration Network Groningen [RNG]. This database covers a population of approxi-
mately 30,000 patients in the northern part of the Netherlands. Patients with a diagnostic code for female breast malignancy in their patient record between 1998 and 2007 were identified in this database. Confirmation of the breast cancer diagnosis and additional data concerning breast cancer diagnosis, treatments, and recurrences was obtained in all general practices belonging to the RNG. Patients were individually matched with a reference population from the same database. Rates of face-to-face contacts, drug prescriptions, and referrals as well as percentages of women with any face-to-face contact, drug prescription, and referral were calculated and compared between both groups.

The use of a primary care database (PCD) has several advantages. PCDs are rich resources of excellent consultation and prescription data linked to diagnosis and demographic characteristics. It is possible to produce samples of patients with matched controls from the same population on a short notice. Furthermore, data from PCDs are much less prone to recall and non-response bias than self-reported data from quantitative surveys studying primary health care use since the actual presentation of health problems is recorded by GPs contributing to these databases.

The accuracy of our studies depends on the sensitivity [or completeness] and validity of the data. Sensitivity relates to the likelihood that the diagnostic code for female breast malignancy is entered in the patient record, when a patient is diagnosed with breast cancer. For example, research has shown that one in five of patients with cancer was not identified in general practice when a search was conducted using electronic codes for malignancies. The possibility that some women from the reference population in our studies were diagnosed with breast cancer in the past cannot be ruled out. However, this would only underestimate differences in health care utilization rates between patients and women from the reference population. Validity relates to the likelihood that patients with the diagnostic code for female breast malignancy in their patient record truly have a history of breast cancer. In our studies, validity was improved by examining electronic records, electronic specialist letters, and paper records in participating general practices to confirm the breast cancer di-
agnosis. Of all initially identified patients (n=422), 5% had no history of breast cancer and they were therefore excluded from the analyses. The possibility that the diagnostic code for female breast malignancy was wrongly entered in the records of patients included in the analyses would also lead to an underestimation of differences in health care utilization rates.

A common problem when using PCDs is that information about potential confounding variables is often limited. In our studies, patients were matched with three women from the reference population on birth year (±1 year) and GP, to control for age and variation in recording and prescribing among GPs. Confounding might have occurred if factors associated with both a history of breast cancer and primary health care use, were not accounted for in the statistical analyses, leading to overestimation or underestimation of differences in health care utilization rates.

When considering the results of studies from PCDs and deciding their relevance to patients, the generalizability of the data needs to be taken into account. In other words, are the patients included in the RNG database similar to other Dutch patients attending general practice? In the Netherlands, almost all citizens are registered with a GP. This means that the RNG database is population-based and does include patients of all ages. Although the database covers a population of patients in the northern part of the Netherlands, this population is comparable to the overall Dutch population, in terms of age and gender distribution, with a slight overrepresentation of adults aged 25-44 years and women.

Quantitative survey research
GPs’ experiences and perspectives concerning primary care-based follow-up were explored by means of a quantitative mail survey [Chapter 4]. A self-administered questionnaire was sent to GPs in the three northern provinces of the Netherlands (Drenthe, Friesland and Groningen). A modified version of the Dillman method, including three mailing waves, was used to increase response rates. Of the 960 mailed questionnaires, 11 were undeliverable and 502 were returned, giving an adjusted response rate of 53%. The main outcome measure was GPs’ willingness to accept
exclusive responsibility for follow-up earlier than 5 years after completion of active treatment.

Quantitative surveys are conducted at a given point in time\(^\text{155}\) and can be relatively easy, inexpensive, fast, and consistent research tools.\(^\text{156}\) Another advantage is that these surveys are intuitively clear and permit a large number of variables to be examined.\(^\text{155,156}\) However, recall bias may be a problem.\(^\text{156}\) In our study, discharge of patients to primary care in the year before the survey took place might have been over- or underestimated, depending on the ability of GPs to accurately recall relevant cases. Furthermore, social desirability might have influenced the main outcome measured, leading to an overestimation of the percentage of GPs who were willing to take over follow-up at an earlier stage. There is no agreed-upon standard for a minimum acceptable response rate.\(^\text{157}\) Although the response rate of 53% was comparable to that observed in another study among Dutch GPs,\(^\text{119}\) it should be realised that 47% of the invited GPs did not respond. Therefore, the results of our study might be subject to response bias, which means that those with a stronger interest in the topic might have been more likely to respond.\(^\text{86}\) GPs who participated in the study were significantly more often male, older and working in a single-handed practice,\(^\text{121}\) indicating that the results may not be generalizable to the entire GP population in the Netherlands.\(^\text{158}\)

**Qualitative research**

Patients’ views on primary care-based vs. specialist follow-up [Chapter 5] and the aims of follow-up [Chapter 6] were explored by means of a qualitative study. Patients with a confirmed breast cancer diagnosis, registered with a general practice of the RNG at the start of the study [1 January 2009], and able to participate [according to their GP] were eligible for our study. Semi-structured interviews were held with 71 patients, meeting the inclusion criteria, and using an interview guide with predetermined themes.

The major types or methods used by qualitative researchers are individual or focus group interviews, observation, analysing documents, and analys-
ing speech or behaviour using audio or video tapes. Compared with observation, interviews are relatively economical in terms of time and resources. In health care settings, interviews are the most commonly used qualitative method. Among qualitative researchers, there is lack of consensus about criteria to assess the quality or credibility of their studies, reflecting different underlying philosophical approaches [e.g. positivism, emotionalism, constructionism]. According to Pope and Mays, quality can be assessed with reference to the same broad criteria as quantitative research, although the meaning attributed to these criteria may not be the same and may be assessed differently. In our study, reliability was addressed by pretesting the interview guide, using verbatim transcripts, and using two researchers to code patients’ responses based upon the predetermined themes in the interview guide.

There are various ways of improving the validity of qualitative studies. One of these is reflexivity, meaning sensitivity to the conditions in which the researchers and the research process have shaped the data collection. To ensure reflexivity in our study, personal characteristics of the research team were described, as recommended by the Consolidated criteria for reporting qualitative research (COREQ) checklist. The relationship between the interviewers and the patients was also discussed. Moreover, an account of methods, data collection, and data analysis was provided. Two other ways of improving validity may include respondent validation (or member checking) and triangulation, although their appropriateness to qualitative research has been questioned. Patients in our study were not asked to provide feedback on the preliminary analysis by respondent validation since we considered this to be too time-consuming for them. Triangulation usually refers to combining multiple theories, methods, observers, and empirical materials, to produce a more accurate, comprehensive and objective representation of the object of study. In this thesis, both quantitative and qualitative methods and different data sources [including a PCD, a mail survey, and individual interviews] were used to provide a more complete picture of the role of GPs during treatment and follow-up of patients with breast cancer.
The generalizability of qualitative research can be increased by purposive sampling guided by time and resources and theoretical sampling. The sample should represent the diversity of the topic under study within the target population, but cannot be used for generalisation in a statistical sense. In our study, 71 patients registered with GPs from the RNG and meeting the inclusion criteria were interviewed, covering women from different ages and living one to several years after diagnosis. Nevertheless, the interviewer did not strictly follow the interview guide over time, which resulted in interview transcripts of 70 patients [Chapter 5] and 61 patients [Chapter 6] available for the analyses. Interviewing a large sample of patients might be regarded as less efficient than interviewing a smaller number of patients, recruited on the basis of purposive and theoretical sampling. On the other hand, a large sample makes it possible to count the numbers of responses. In this way, we could conduct descriptive content analysis with qualitative and quantitative elements.

**COMPARISON WITH EXISTING LITERATURE**

*Primary health care use during treatment and follow-up*

In line with our results [Chapter 2 and 3], other studies in Canada, the Netherlands, and the United Kingdom (UK) have reported increased primary health care use in the phases of breast cancer treatment and follow-up. The finding in our study [Chapter 3] that age at diagnosis is the main predictor of a higher primary health care use during the follow-up phase is in accordance with a study among Dutch breast cancer survivors 2 to 5 years after diagnosis, showing that primary care contacts are the highest in older breast cancer survivors and in those with a chronic disease. Just as we did, reasons for increased primary care contacts during the follow-up phase were examined in a study by Heins et al. While in our study reasons were mainly related to the breast cancer itself, the other study found that Dutch breast cancer survivors 2 to 5 years after diagnosis consulted their GP more often for acute symptoms, infections, diabetes, sleep disturbance and depression. These differences in results may be related to differences in sample size [336 vs. 2387 breast cancer survivors]. Unlike the other study, we examined drug prescriptions and...
showed that more patients than women from the reference population were prescribed nervous system drugs (e.g., analgesics and benzodiazepines) until the third year of the follow-up phase. Another finding of our study is that patients were prescribed endocrine therapy by their GP.

In a letter to the editor [§ 3.1], we commented on the conclusion of Heins et al.\textsuperscript{29} that psychosocial problems were not a major cause for the increase in primary care contacts among breast cancer survivors in their study. As they did not examine drug prescriptions, this may have led to an underestimation of health care use for psychological problems if GPs did not record the psychological problems, but the cancer diagnosis in consultations. After reanalysing their data and in a reply letter,\textsuperscript{163} the authors showed that underestimation of health care use for psychological problems was unlikely because the percentage of GP contacts in which nervous system drugs were prescribed without a psychological diagnosis was not different between the breast cancer survivors and their non-cancer controls.

**Primary care-based follow-up: GPs’ experiences and perspectives**

Specialists in the Netherlands and the UK have reported guideline non-adherence regarding the duration of breast cancer follow-up.\textsuperscript{94,114,143} Patients were followed longer in the hospital than the guidelines prescribed, due to factors such as younger age (<50 years), a higher breast cancer stage, ongoing endocrine therapy, treatment-related morbidity, and a family history of breast cancer.\textsuperscript{94,114} In a qualitative study, specialists in the United States (US) stated that they struggled with discharging breast cancer survivors to primary care due to strong specialist-patient relationships.\textsuperscript{95} Contradictory results have been reported with respect to guideline adherence among primary care physicians responsible for follow-up of (long-term) breast cancer survivors. Two studies in Canada and Spain observed a high compliance with guideline-recommended follow-up frequency in primary care,\textsuperscript{108,164} while other studies in Canada, the UK, and the US showed that breast cancer survivors followed by a primary care physician only were less likely to receive mammograms than those followed by a breast cancer specialist only.\textsuperscript{165-170}
Compared to 19% of GPs in our study [Chapter 4], 51% and 93% of Canadian primary care physicians in two other studies were willing to accept exclusive responsibility for breast cancer follow-up immediately or 1-2 years after treatment completion.\textsuperscript{85,86} In a qualitative study, some US primary care physicians felt that they could assume responsibility for breast cancer follow-up if necessary, but many felt that specialists should continue to see patients.\textsuperscript{95} Differences in the findings between our study and the Canadian studies might be partly explained by the extent to which primary care physicians provide breast cancer follow-up/survivorship care\textsuperscript{85,86,108} and by differences in remunerating primary care physicians between countries [capitation payment vs. fee-for-service basis].\textsuperscript{115,116}

Just as in our study, patient-related as well as physician-related barriers to provide breast cancer follow-up/survivorship care were reported in other studies. In a study among US primary care physicians, the three most perceived barriers to survivorship care were: patients’ inability to pay [or lacking insurance coverage], patients’ refusal/non-adherence to recommended care, and concerns about missed care.\textsuperscript{171} Furthermore, US primary care physicians reported to be concerned about missing a recurrence or new cancer in their patients and to feel not always confident in providing reassurance to them.\textsuperscript{95} In contrast, Canadian primary care physicians providing breast cancer follow-up/survivorship care were most confident in managing surveillance for recurrence. Confidence in this domain improved as the number of survivors in their practices increased.\textsuperscript{108} Limited or delayed communication with specialists was reported by US primary care physicians, when asked about the best approach to breast cancer survivorship care.\textsuperscript{95} Among Canadian primary care physicians, the three most perceived useful tools to assume exclusive responsibility for breast cancer follow-up were: a patient-specific letter from specialists, printed guidelines, and expedited routes of referral.\textsuperscript{86}

\textit{[Primary care-based] follow-up: patients’ perspectives}

Consistent with our results [Chapter 5], other studies in Australia, Canada, the Netherlands, Spain, and the US observed a major preference for specialist follow-up among patients with a history of breast can-
Primary care-based follow-up was acceptable to 57% of patients in our study, compared to 5-39% of patients in three surveys conducted in the Netherlands, Spain, and the UK \cite{87,90,164} and 55 and 67% of patients participating in two randomised clinical trials conducted in the UK and Canada and the UK \cite{52,131}. Patients in our study, similar to patients in an Australian qualitative study \cite{132,133}, considered the GP-patient relationship and the easy access to general practice as advantages of primary care-based follow-up. Psychosocial support was mentioned as a benefit of primary care-based follow-up by Dutch patients in another qualitative study \cite{143}. Poor communication with specialists as well as limited education, knowledge, experience, time, and motivation among GPs were perceived barriers for the patients both in our study and in other studies to accept primary care-based follow-up \cite{91,93,95,132,133,143}. Furthermore, patients' preference for specialist follow-up seems to be related to a strong specialist-patient relationship developed during the active treatment phase \cite{132,133}.

When interpreting these findings, it must be recognized that patients tend to prefer the status quo \cite{173} (specialist follow-up at the time of our study). Therefore, in a study exploring preferences of Australian breast cancer survivors for alternative follow-up models the option of specialist follow-up was removed. This study showed that breast physicians - usually GPs who received specialised training in breast medicine - were the most preferred provider, followed by breast cancer nurses and then GPs \cite{174}. Despite a major preference for specialist follow-up, patients may express high levels of satisfaction with long-term primary care-based follow-up, as observed in the study of Baena-Cañada et al. \cite{164}. Other studies also showed that patients receiving breast cancer follow-up/survivorship care from their primary care physician were satisfied with it \cite{53,93,141}.

Our study (Chapter 6) supports the results from a study by Montgomery et al. \cite{139} that UK patients with breast cancer consider detection of relapse and reassurance as the most important aims of follow-up. In other studies, reassurance was perceived by patients as an important purpose or advantage of breast cancer follow-up \cite{91,92,143,145-147}. However, disadvantages
of follow-up visits were also reported in our study as well as in other studies, in terms of inducing anxiety in patients\textsuperscript{87,91,92,145-147} and bringing breast cancer to the forefront of their life again.\textsuperscript{147} Just as in our study, unrealistic beliefs and expectations regarding surveillance of metastatic disease, additional investigations, and the risk of developing a recurrence during the follow-up programme have been reported in studies among Dutch patients with a history of breast cancer.\textsuperscript{88,90,143} Although patients in our study were already familiar with breast cancer follow-up, results are comparable with those of the study of Montgomery et al. exploring patients’ expectations before starting the follow-up programme.\textsuperscript{139}

**IMPLICATIONS FOR CLINICAL PRACTICE, EDUCATION, AND FUTURE RESEARCH**

**Integration of care in the first year since diagnosis and thereafter**

At the time of starting this PhD project (May, 2008), Dutch GPs were formally involved in early detection of cancer and in symptom control during the palliative/terminal stage, just as GPs in countries like Australia and the UK.\textsuperscript{42,43,57} It was believed that GPs lost touch with their patients during cancer treatment\textsuperscript{58} and that they stayed on the periphery of cancer care until patients reached the palliative stage.\textsuperscript{42} However, the observed increased primary health care use (Chapter 2 and 3) suggests that GPs are already involved in care for female patients with breast cancer in the first year since diagnosis and the follow-up phase, although not in a formal way. Moreover, this increased primary health care use indicates that, from a patient’s point of view, there is a need for input from primary care. Therefore, primary health care delivery during the phases of breast cancer treatment and follow-up should be integrated into the existing delivery of multidisciplinary breast cancer care.\textsuperscript{60} At a time when both the number of women newly diagnosed with breast cancer and the number of women with a history of breast cancer are increasing,\textsuperscript{23} integration of primary and secondary health services in cancer care might have the potential to allow more effective use of health care resources while achieving a higher quality of care.\textsuperscript{175}

In the Netherlands, breast cancer is treated by multidisciplinary teams,
which has been associated with an improved survival of patients.\textsuperscript{32} Core members of these teams are surgeons, radiologists, pathologists, medical oncologists, radiation oncologists, and breast care nurses.\textsuperscript{7,33,34} According to the guidelines of the European Society of Breast Cancer Specialists, these members should guarantee patients continuity of care.\textsuperscript{34} However, it could be argued that continuity of care is further enhanced by including GPs as core members in the multidisciplinary breast cancer teams.\textsuperscript{176} By providing input with respect to the psychosocial context and multi-morbidity of patients, GPs can make an important contribution to treatment decision making.\textsuperscript{177} The Dutch guidelines on breast cancer\textsuperscript{7} and survivorship care\textsuperscript{178} recommend that attention should be given to psychosocial support, especially in the first year since diagnosis. As our results (Chapter 2) suggest that GPs are involved in the management of psychological problems in the first year since diagnosis, psychological support may be either given by breast care nurses or GPs, based on individual patient’s preferences.

Although it may not be possible for Dutch GPs - with on average two women with a newly diagnosed breast cancer in their practice per year\textsuperscript{35,56} to attend multidisciplinary meetings in person on a regular basis, they may attend by teleconference or videoconference.\textsuperscript{176} As GPs are involved in care for female patients with breast cancer in the first year since diagnosis, GPs should be kept informed of the team activities and meeting outcomes\textsuperscript{176,177,179,180} in a timely manner and by receiving information about diagnosis, prognosis, treatment options/decisions, and treatment risks/benefits. In this way, GPs are able to discuss the outcomes with their patients and to support their patients in treatment decision-making.\textsuperscript{177} Moreover, they can better adapt primary health care delivery to their patients' needs. To facilitate communication across the primary/secondary interface, criteria for information sharing should be provided in the Dutch breast cancer guidelines regarding the timeliness and minimum content of information as well as the moments of information exchange.\textsuperscript{181}
Survivorship care plans have been recommended to improve communication between healthcare providers and with patients during the transition from active treatment to follow-up. However, a randomised clinical trial found no benefit of using breast cancer survivorship care plans on cancer-related distress at 12 months or other patient-reported outcomes, like quality of life, patient satisfaction, continuity/coordination of care, and health service measures. Moreover, the introduction of survivorship care plans did not lead to a cost-effective use of health care resources. As simple and relatively inexpensive structured information seems to help GPs to have adequate oncology knowledge, to feel confident in managing adverse effects, and to support and counsel patients during the course of their illness, it would be valuable to further study the potential benefits of using standardized templates in the Dutch situation, such as patient-specific discharge letters with a special focus on follow-up.

**Implementation and acceptance of primary care-based follow-up**
Since September 2008, Dutch GPs have a coordinating role in the long-term follow-up (>5 years) of women aged >60 years who had undergone breast conserving therapy. These women cannot be referred to the National Screening programme for biennial mammography, due to positioning and evaluation problems associated with the operated and irradiated breast. Therefore, a discharge to their GP for annual physical examination and biennial mammographic follow-up in the hospital - where the first five years of follow-up took place - is recommended. Although follow-up policy should aim to detect loco-regional or contralateral recurrences as early as possible, the extent to which long-term follow-up would ensure this is unknown. Mammography seems to play a greater role in this early detection than regular physical examination, since the majority of relapses are detected by patients themselves or by mammography. Based on the results of a study evaluating the effectiveness and costs of different follow-up strategies for women with a history of breast cancer in the Netherlands, annual physical examination by the GP seems to be necessary no longer.
In terms of an effective use of health care resources, there is a great gain to be achieved by a successful implementation of the long-term breast cancer follow-up in general practice. Given that 13,987 Dutch women were diagnosed with an invasive breast carcinoma in 2011, that 8977 women were 55-99 years at the time of diagnosis, that 53% of these women underwent breast conserving therapy, and that the 5-year relative survival for these women is 84.5%, about 4000 women aged >60 years and five years after breast conserving therapy may be discharged to their GP in 2016. If, for these women, the annual follow-up visit in the hospital would be replaced by an annual follow-up visit in general practice, savings will be achieved, as observed in the evaluation of long-term follow-up in Spain. Discharging women to their GP after two years of specialist follow-up, lowering the age of discharge from 60 to 50 years, and terminating annual physical examination by the GP may further reduce the costs of follow-up, while maintaining the detection rate of early-stage breast cancer. Moreover, a successful implementation of breast cancer follow-up in general practice may lead to a reduced burden on secondary care.

A complete reconsideration of how cancer care should be managed in the Netherlands, especially during the follow-up phase, has been advocated by the Signalling Committee Cancer of the Dutch Cancer Society, in order to deal with the expected increase in the prevalence of cancer survivors. According to this Committee, cancer care should be regarded as a joint responsibility of primary and secondary care providers, whereby specialists should be primarily responsible for diagnostics and treatment and GPs should become responsible for cancer follow-up [unless there is convincing evidence that specialists should play a major part in this follow-up]. However, a successful implementation of the long-term breast cancer follow-up in general practice should be a prerequisite for earlier transfer of this follow-up to the primary care setting. The results described in Chapter 4 suggest that this implementation is not successful yet. Several strategies should be used to overcome the perceived difficulties and barriers among GPs and patients to implement/accept primary care-based follow-up.
To increase compliance and/or familiarity of specialists and GPs with the guideline recommendations on long-term breast cancer follow-up, it is advisable to incorporate these recommendations in local agreements between specialists and GPs on policy regarding follow-up, discharge, and referral of patients with breast cancer. It would be helpful if the NABON breast cancer guideline not only provides scenarios in which specialists coordinate the follow-up (page 192), but also a scenario in which GPs coordinate the long-term follow-up. To improve communication across the primary/secondary interface, criteria for information sharing should be provided in the Dutch breast cancer guidelines and standardized templates may be used (as discussed in the previous section).

To support the organisation of the long-term breast cancer follow-up in general practice, electronic prompt systems may be helpful to remind GPs which patients are overdue for their biennial mammography. In addition, automatic calling systems may remind patients of their next follow-up visit. Such systems have been studied to facilitate population-based breast cancer screening. Further research should investigate if and how these systems can be used for primary care-based follow-up. Patients seem to mainly take the initiative to arrange follow-up visits and mammography appointments (Chapter 4). This may not only be explained by difficulties in the organisation of the long-term follow-up in general practice, but also by a wait-and-see attitude and demand-driven approach of GPs. Despite their recommended coordinating role, Dutch GPs might consider women aged >60 years, five years after breast-conserving therapy, as ‘normal’ primary care patients asking for help when necessary. Nevertheless, it could be questioned whether long-term primary care-based follow-up should be patient-driven or provider-driven or probably both.

In a study examining long-term follow-up of breast cancer survivors in Spain, 45% of follow-up visits in primary care were programmed and 55% were on demand, while guideline-recommended follow-up frequency was high. However, the effect on mammography use among breast cancer survivors was not examined in this study. This needs further study if the long-term primary care-based follow-up remains mainly patient-driven.
Most patients with a history of breast cancer prefer specialist follow-up to primary-care based follow-up (Chapter 5). Their expectations about the benefits of follow-up are sometimes unrealistic. Therefore, they should be educated about the aims and the evidence behind follow-up as well as the advantages and limitations of several follow-up models. Reliable and independent evidence-based information about breast cancer follow-up may be provided on the website thuisarts.nl as well as in leaflets offered to patients at discharge from the hospital. Since patients’ preferences seems to be related to a strong specialist-patient relationship developed during the active treatment phase, formal involvement of GPs in this phase could make it easier for GPs to take responsibility for follow-up and might increase patients’ confidence of primary care-based follow-up. On the other hand, patients may be satisfied with primary care-based follow-up, regardless of their preference for specialist follow-up. Since reassurance is seen as an important aim/advantage of follow-up, especially among younger patients, possible fear of recurrence should be addressed when follow-up is transferred to the primary care setting.

To increase GPs’ and patients’ confidence with primary care-based follow-up, training and education of GPs is important. In a study among Canadian primary care physicians providing breast cancer follow-up/survivorship care, continuing medical education events and online resources were the most commonly reported means to obtain knowledge about breast cancer. Cancer education programmes and e-learning tools (such as the cancer Survivorship E-Learning Series for Primary Care Providers) may be developed by the Dutch College of General Practitioners and Dutch general practice departments and increase GPs’ ability to provide follow-up care for breast cancer survivors. Among others, these programmes and tools should include the guideline recommendations on follow-up, the aims and the evidence behind follow-up, the advantages and limitations of several follow-up models, the value of diagnostic testing, a summary of treatments, assessment and interventions on physical and psychosocial adverse effects of breast cancer and its treatments, comorbidity, and coordination of care across the primary/secondary interface. However, confidence of GPs in their own oncology knowledge and skills
may also increase as the number of patients receiving primary-care based follow-up in their practices increases.\textsuperscript{108}

If GPs would assume a more active role in breast cancer care and if follow-up is shifted to the primary care setting, attention should be given to increased workload pressure, due to increased primary health care use among patients, attendance of multidisciplinary meetings, and education in the field of cancer care.\textsuperscript{175,177} Solutions for this problem may be expanding the capacity of GP training programmes, introducing oncology nurses in primary care, and referral of patients to other primary care professionals for non-medical elements of survivorship care.\textsuperscript{60,94,175,177,194} In addition, attention should be given to adequate financial remuneration for GPs when providing follow-up to their patients with a history of breast cancer.\textsuperscript{175,177}

**GENERAL CONCLUSIONS**

The increased primary health care use observed in this thesis suggests that Dutch GPs are already involved in care for female patients with breast cancer during the first year since diagnosis and the follow-up phase, although not in a formal way. Since the number of patients in the two longitudinal studies presented in this thesis were relatively small, further studies on primary health care use should involve larger samples of women with and without breast cancer. However, other results presented in these thesis indicate that the implementation of the long-term breast cancer follow-up in Dutch general practice is not successful yet. Several strategies have been described in this chapter to overcome the perceived difficulties and barriers among GPs and patients to implement/accept primary care-based follow-up. Recommendations for clinical practice, education, and research have been provided (Box 1). More research is needed to define which strategy (or a combination) is most effective for a successful implementation of breast cancer follow-up in general practice. In this thesis, the issue of primary care-based follow-up was explored from the perspectives of Dutch GPs and patients. Future studies should provide a better understanding of Dutch specialists’ perspectives on primary care-based follow-up.
Box 1. Summary of recommendations

Clinical practice

- Primary health care delivery during the phases of breast cancer treatment and follow-up should be integrated into the existing delivery of multidisciplinary breast cancer care
- GPs should be kept informed of the multidisciplinary team activities and meeting outcomes in a timely manner and by receiving information about diagnosis, prognosis, treatment options/decisions, and treatment risks/benefits
- To facilitate communication across the primary/secondary interface, criteria for information sharing should be provided in the Dutch breast cancer guidelines regarding the timeliness and minimum content of information as well as the moments of information exchange
- It is advisable to incorporate the guideline recommendations on long-term breast cancer follow-up in local agreements between specialists and GPs on policy regarding follow-up, discharge, and (re-)referral of patients with breast cancer
- It would be helpful if the NABON breast cancer guideline not only provides scenarios in which specialists coordinate the follow-up, but also a scenario in which GPs coordinate the long-term follow-up
- Reliable and independent evidence-based information about follow-up may be provided on the website thuisarts.nl as well as in leaflets offered to patients at discharge from the hospital
- Since reassurance is seen as an important aim/advantage of follow-up, especially among younger patients, possible fear of recurrence should be addressed when follow-up is transferred to the primary care setting
- If GPs would assume a more active role in breast cancer care and if follow-up is shifted to the primary care setting (at an earlier stage), attention should be given to increased workload pressure of and adequate financial remuneration for GPs

Education

- Cancer education programmes and e-learning tools developed by the Dutch College of General Practitioners and Dutch general practice departments should increase GPs ability to provide follow-up care for breast cancer survivors
- These programmes and tools should include the guideline recommendations on follow-up, the aims and the evidence behind follow-up, the advantages and limitations of several follow-up models, the value of diagnostic testing, a summary of treatments, assessment and interventions on physical and psychosocial adverse effects of breast cancer and its treatments, comorbidity, and coordination of care across the primary/secondary interface
Research

- Further studies on primary health care use should involve larger samples of women with and without breast cancer.
- It would be valuable to further study the potential benefits of using standardized templates across the primary/secondary interface, such as patient-specific discharge letters with a special focus on follow-up.
- Further research should investigate if and how electronic prompt systems can be used to support the organisation of the long-term follow-up in general practice.
- The effect of primary care-based follow-up on mammography use among breast cancer survivors needs further investigation.
- More research is needed to define which strategies described in this thesis are most effective for a successful implementation of breast cancer follow-up in general practice.
- Future studies should provide a better understanding of Dutch specialists’ perspectives on primary care-based follow-up.