Shared follow-up care for early breast cancer: summary of evidence

This report highlights key findings from Cancer Australia's program of work, undertaken between 2009 and 2015, to develop and evaluate a best practice model of shared follow-up care for early breast cancer*.

The need for new models of follow-up care for breast cancer

Shared follow-up care for early breast cancer is an innovative model of care that supports the provision of holistic follow-up and survivorship care following active treatment.

With high incidence and increasing survivorship following a diagnosis of breast cancer, progressively more people will require follow-up care, placing an increased demand on Australia's health system and resources. Shared care leverages the skills and expertise of the specialist and primary care workforce to support the delivery of high quality, safe and sustainable follow-up and survivorship care.

Breast cancer will affect 1 in 7 people in Australia in their lifetime. It is estimated that 19,535 people will be diagnosed with the disease in Australia in 2019 (19,371 women and 164 men).[1]

Australians experience some of the highest cancer survival rates in the world.[2,3] Breast cancer survival in Australia has improved over the last two decades,[4] with 91% of women surviving at least 5 years after diagnosis.[1] National clinical practice guidelines recommend long-term follow-up care after treatment for early breast cancer.[5] Traditionally, follow-up care has been delivered in tertiary settings, led by a specialist clinician.

As the number of people diagnosed with and surviving breast cancer increases, demand on the health system for follow-up care has grown. The Australian Government Productivity Commission identified a need for new and innovative models of care to alleviate workforce pressures and increase the efficiency and effectiveness of the available health workforce.[6]

Purpose of shared follow-up care for early breast cancer[5]

- Early detection of recurrence
- Screening for a new primary cancer
- Detection and management of treatment-related side effects
- Detection and management of psychosocial distress, anxiety or depression
- Review and updating of family history
- Observation of outcomes of therapy
- Review of treatment including potentially relevant new therapies

Shared care, in which care is shared between specialist and primary care or other health professionals, has been implemented successfully for a range of health conditions, including diabetes, paediatric oncology and obstetric care.[7] Between 2009 and 2015, Cancer Australia undertook an extensive program of work to gather and build the evidence base for shared follow-up care for early breast cancer[a] in Australia.

Aims of Cancer Australia's program of work in shared follow-up care

To better understand:

- the **safety** of shared follow-up care in relation to patient outcomes
- the **effectiveness** of shared follow-up care in delivering patient-centred care
- the **acceptability** of shared follow-up care to specialist clinicians, general practitioners (GPs) and patients
- **adherence to best practice follow-up care** within a shared care model, and factors influencing adherence
- **cost-efficiency** of shared follow-up care compared with specialist-led models of follow-up care
- the **evidence** relating to national and international shared follow-up cancer care.

* Early breast cancer is defined as tumours of not more than five centimetres diameter, with either impalpable or palpable but not fixed lymph nodes and with no evidence of distant metastases.

a Women with DCIS are considered suitable to receive shared follow-up care and were included in Cancer Australia's evidence-gathering activities.

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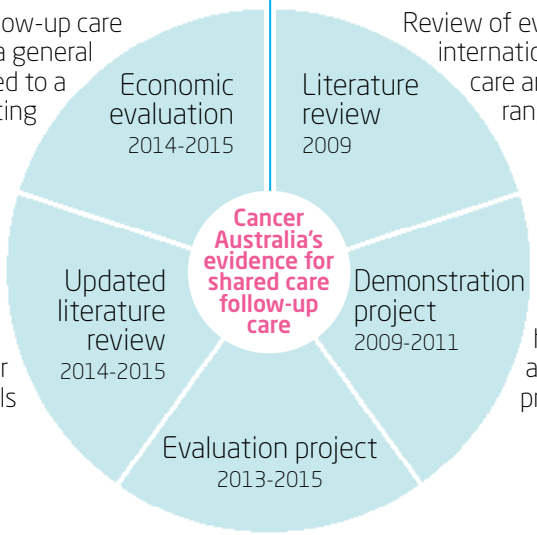
Building the evidence

Cancer Australia's program of work in shared follow-up care for early breast cancer 2009–2015

Principles of shared care
2009

Recommendations for follow-up of women with early breast cancer: a clinical practice guideline
2010



Compared cost of shared follow-up care for early breast cancer in a general practice setting compared to a specialist-led setting

Review of evidence of national and international models of shared follow-up care and current practice across a range of health settings

Follow-up to 2009 review to assess latest evidence about national and international shared follow-up cancer care models

Shared follow-up model implemented across four tertiary sites. Evaluated health professional and patient acceptability and support for best practice follow-up care

Shared follow-up care model implemented across five tertiary sites. Assessed the extent to which the model supports best practice care and qualitatively evaluated patient and GP experiences of shared follow-up care

Foundations for Cancer Australia's work in shared follow-up care

Principles of shared care

Cancer Australia developed the *Principles of shared care* to articulate the key elements that underpin the delivery of shared follow-up care for early breast cancer.

These principles were informed by evidence and developed in consultation with experts.

Principles of shared care

Patient-centred

The patient and their whole-person care is the focus for all care providers.

Coordination, communication and continuity of care

Care of the patient requires coordination through timely and effective communication, and clarification of the roles and responsibilities of the care providers.

Support for primary care providers

Primary care providers are supported in the delivery of shared follow-up care through early involvement and through the provision of education, resources and protocols.

Support for specialist treatment team

Specialist care providers are supported in the delivery of shared follow-up care through the provision of resources and protocols which improve efficiency and support data collection.

Care is delivered according to best practice standards

Provision of care is in accordance with nationally agreed standards and is outcome focused.

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Model of shared follow-up care for early breast cancer

Shared follow-up cancer care involves joint participation of specialists and GPs in the planned delivery of follow-up care for women with early breast cancer.

Cancer Australia's model of shared follow-up care was used as the basis for the Cancer Australia demonstration project. Follow-up care was delivered in accordance with Cancer Australia's recommended follow-up schedule (Table 1).[5]

Cancer Australia's model for shared follow-up care in early breast cancer

- An initial specialist consultation at the start of follow-up care (3 months after the end of active treatment)
- Follow-up appointments shared between the specialist and GP during the first 5 years after completion of active treatment
- Mammography every 12 months (first mammogram 12 months after diagnosis)
- Transfer of care to the GP 5 years after completion of active treatment, with the GP responsible for all follow-up care and annual mammograms

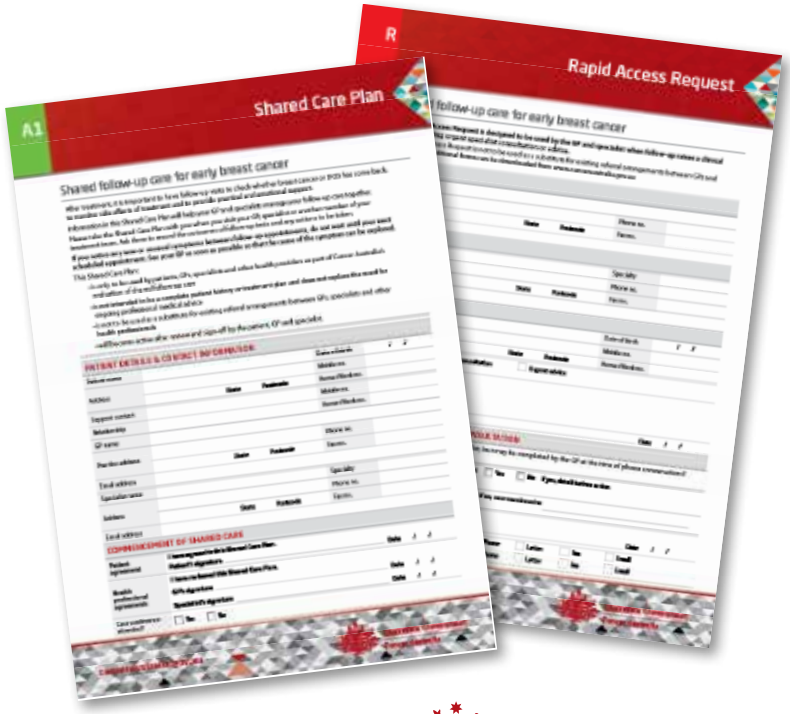
Table 1: Cancer Australia's recommended follow-up schedule for early breast cancer[5]

METHOD	TIME AFTER COMPLETION OF ACTIVE TREATMENT		
	YEARS 1 AND 2	YEARS 3-5	AFTER 5 YEARS
History and clinical examination	Every 3-6 months	Every 6-12 months	Every 12 months
Mammography (and ultrasound if indicated)	Every 12 months*	Every 12 months	Every 12 months
Chest X-ray, bone scan, CT, PET or MRI scans**, full blood count, biochemistry and tumour markers	Only if clinically indicated on suspicion of recurrence		

*First mammogram 12 months post-diagnosis. ŁUse of MRI may be considered in specific high-risk groups.
CT: computed tomography; PET: positron emission tomography; MRI: magnetic resonance imaging

Information was shared between the patient, specialist, GP and other health practitioners via a patient-held **shared care plan**. The shared care plan included information about the patient's diagnostic and treatment history, contact details for the specialist and primary care team, a schedule of follow-up care appointments, and a summary of actions to be taken during follow-up.

A **rapid access request template** allowed GPs to refer patients back to the specialist when required.



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Evidence supporting shared follow-up care in early breast cancer

Safety of shared follow-up care

Published literature shows that shared follow-up care for early breast cancer is safe.

Published literature shows that shared follow-up cancer care undertaken in primary care is safe and does not adversely affect patient well-being, survival, recurrence, recurrence-related serious clinical events, diagnostic delay or patient satisfaction.[8] Most studies included in the literature review reported no difference in quality of life between people whose follow-up was undertaken in primary care compared with a specialist setting.[9-11]

Effectiveness of shared follow-up care in delivering patient-centred care

Published literature and Cancer Australia's demonstration and evaluation projects show that shared follow-up care for early breast cancer is as effective as specialist-led follow-up care in delivering patient-centred care.

Published literature shows that shared follow-up care is as effective as specialist-led follow-up in delivering patient-centred, holistic care.[12] Involvement of a GP in follow-up care for people with cancer has been shown to result in improved physical and psychosocial well-being of patients and continuity of care, especially for people with other health conditions.[13,14]

Cancer Australia's demonstration and evaluation projects[15,16] show that:

- GPs were more likely than specialists to address holistic aspects of care
- shared follow-up care can improve access to care by providing patients with follow-up care closer to home
- shared follow-up care gave patients a sense of receiving 'more care' and a greater sense of control over their health care compared with specialist-led care
- some patients felt that the shared care model was more convenient and cheaper than specialist-led care.

"My GP knows me as a person; the hospital knows me as a number"

Patient, metropolitan

"I feel back in charge of my own health now via my GP"

Patient

"It's good to see the same person, [who knows the] full story of my health [so that there's] no need to repeat myself"

Patient

Acceptability of shared follow-up care

Published literature and Cancer Australia's demonstration and evaluation projects show that shared follow-up care is acceptable to patients, GPs and specialists.

In Cancer Australia's demonstration project:[15]

- 78% (n=1,214) of patients agreed to take part in shared care
- the majority of specialists (84%; n=26) and GPs (68%; n=36) surveyed reported confidence in delivering shared follow-up care
- 92% (n=29) of specialists surveyed were willing to continue delivery of shared follow-up care after the demonstration project.

The patient acceptance rate seen in the demonstration project aligned with the available literature on reported acceptance rates for participation in shared follow-up care for other cancers.[14]

"[Follow-up care] is a core service…that we provide to our patients…From a rural perspective, [it's particularly beneficial] if you can save someone a significant commute"

GP, regional/rural

"[The shared care process] was excellent and very thorough. I presented it to my trainees as the 'ideal model' of follow-up"

Specialist

GPs involved in the Cancer Australia evaluation project[16] also identified non-clinical benefits of being involved in shared follow-up care, including additional professional development opportunities, personal satisfaction and a sense of value in supporting the patient and health system.

Adherence to best practice follow-up care within a shared care model

Published literature and Cancer Australia's evaluation project show that shared follow-up care supports adherence to best practice follow-up care, with GPs as likely as specialists to deliver follow-up care in accordance with best practice.

In Cancer Australia's evaluation project:[16]

- the majority of patients adhered to the recommended schedule of follow-up visits; 73% (n=231) of eligible patients undertook follow-up visits at least as frequently as recommended during the first 5 years after completion of active treatment
- the frequency of mammograms and other key actions was in line with best practice recommendations
  - 73% (n=221) of patients received mammograms at least once every 12 months during the first 5 years after completion of active treatment
  - clinical breast examinations were completed in 93% (n=977) of all documented follow-up visits
- GPs and specialists were equally likely to document completion of clinical breast examination, checks for loco-regional recurrence, symptoms of distant recurrence, and side effects of treatment
- a significantly higher proportion of GP visits (90%; n=402) included documentation of checks for psychosocial issues, compared with specialist visits (81%; n=457) ($p<0.05$)
- a significantly higher proportion of GP visits (90%; n=402) included documentation of other relevant updates/reviews compared with specialist visits, including:
  - family history review/update (82%; n=369 vs 68%; n=381) ($p<0.05$)
  - menopausal status review/update (84%; n=375 vs 70%; n=394) ($p<0.05$)
  - other health conditions review/update (86%; n=388 vs 77%; n=435) ($p<0.05$).

Published literature reports contradictory findings in relation to adherence to best practice care within shared care models for follow-up care. Some studies report a higher likelihood of receiving recommended care within a shared care model[17 - 20] while others report no difference.[10,11,21]

Cost-efficiency of shared follow-up care

Cancer Australia's economic evaluation showed that shared follow-up care is more cost-efficient than specialist-led follow-up care from a whole of health system perspective.

Cancer Australia's economic evaluation[22]

The economic evaluation compared the costs of two models of care:

Shared follow-up care

An initial specialist consultation (3 months after end of treatment) with follow-up appointments shared between the specialist and GP for 5 years and mammography every 12 months from the date of diagnosis (all in a public setting).

After 5 years, all care provided by the GP and annual mammography in private imaging centres.

Specialist-led follow-up care

All follow-up care after end of treatment provided by a specialist; mammography every 12 months from the date of diagnosis (all in a public setting).

Cancer Australia's economic evaluation[22] considered costs to the Commonwealth health budget, out-of-pocket expenses for patients and hospital administrative costs. Calculations were based on an estimated 90% uptake rate for shared follow-up care and an annual dropout rate of 3% (based on rates seen in the demonstration and evaluation projects).

Based on these uptake and dropout rates, the economic evaluation found that:

- shared follow-up care is more cost-efficient than specialist-led follow-up care, costing $6.44m–$8.39m less than specialist-led follow-up care over five years
- shared follow-up care is, on average, more cost-efficient per patient than specialist-led follow-up care over a lifetime (20, 25 or 30 years)
- under a shared follow-up care model, specialists are freed up for 10 clinical hours (or 23 visits) per patient over a 20-year follow-up period.

Shared follow-up care in practice

Factors influencing implementation of shared follow-up care

The literature review, demonstration project and evaluation projects identified a range of factors influencing the delivery of shared follow-up care. These included factors related to information technology and workforce management.

Information technology and digital health

The literature highlights clear communication between primary care and secondary care as a crucial element of shared care models.[23] Incompatibility in information technology (IT) platforms is cited as a barrier to timely, effective and secure transfer of information between care settings, creating a significant administrative burden on care providers. E-health programs,[24] compatible IT platforms and accessible electronic health records[9] have been identified as enablers for supporting the delivery of shared follow-up care in Australia. Similarly, the American Society of Clinical Oncology (ASCO) statement for achieving high quality cancer survivorship care notes the need for better integration of treatment plans and summaries into e-health records and for IT solutions to expedite treatment planning and care plan summaries.[25]

The limitations of available digital technology for the development and use of the shared care plan was highlighted in Cancer Australia's demonstration[15] and evaluation[16] projects. Health practitioners noted that the complexity and demands of using paper-based forms created a barrier to shared follow-up care. The literature reinforces this finding, with an Australian study noting that the time required to develop shared care plans is due to the need to tailor the plan for particular users and a lack of IT solutions to support the generation and updating of the plan.[9]

Workforce management

The literature review highlights the workforce challenges and costs associated with initiating and supporting the delivery of shared follow-up care. These included the cost of resources to establish and maintain the model of care as well as potential additions this might add to practitioner workloads.[14,26,27]

A number of studies suggest that targeted workforce education and training may help facilitate this shift, reorienting health professionals from traditional disease-focused follow-up care to integrated approaches to delivery of wellness-focused survivorship care.[9,25]

In Cancer Australia's demonstration[15] and evaluation[16] projects, care coordination was cited as an enabler for sustainable delivery of shared follow-up care, providing patients with a familiar touchpoint to enable continuity of care. Care coordination was shared or delivered individually by a breast care nurse, nurse coordinator or by administrative staff.

Feedback from health practitioners involved in these projects noted that incorporating a care coordination function into the delivery of shared follow-up care could also assist with:

- identification of eligible patients
- explaining the shared care process to patients (and a specialist or registrar, if required)
- GP engagement
- appointment scheduling and reminder support
- facilitating communication between GPs and specialist teams

Factors influencing acceptability of shared follow-up care

Cancer Australia's demonstration and evaluation projects identified a range of enablers and barriers to the acceptability of shared follow-up care.

Enablers for acceptability of shared follow-up care

The demonstration[15] and evaluation[16] projects, together with the literature review, identified a number of enablers that could help address receptivity of shared follow-up care. These include:

- early provision of information to patients
- a gradual transition of patients to shared follow-up care
- established GP and patient relationships
- early and continued engagement of GPs by specialists
- prior GP experience in delivering shared care
- assurance of rapid access to specialist consultation
- high-quality supporting resources, including clinical practice guidelines
- strong clinical leadership in the specialist setting
- assurance that participating patients are low risk.

> *"I really liked the guidelines for primary care teams and felt clear and confident about what I had to do"*
>
> ***GP***
>
> *"The rapid access is a good idea. Patients feel more comfortable that they still have a connection with their specialist"*
>
> ***Specialist***

Barriers to acceptability of shared follow-up care

The demonstration[15] and evaluation[16] projects identified that:

- not all patients are confident in their GP's ability to deliver follow-up care
- some specialists are uncertain about GPs' abilities to deliver shared follow-up care and are resistant to changing how follow-up care is traditionally delivered
- some GPs have limited confidence and availability to deliver shared follow-up care
- some patients perceive that a shared model of follow-up care raises the risk of communication errors between specialists and GPs
- some patients perceive that shared follow-up care would be more expensive than traditional follow-up care, in particular due to costs associated with visiting a GP who does not bulk bill, as well as the cost of mammography outside the public hospital setting.

Factors influencing adherence to best practice

Cancer Australia's demonstration and evaluation projects identified a number of enablers and barriers influencing adherence to best practice follow-up care within a shared care model.

Enablers of adherence to best-practice follow-up care

Enablers of adherence to best practice follow-up care identified in the demonstration[15] and evaluation[16] projects included provision of well-organised and informative resources and tools, health literacy and GP education.

The majority of GPs (68%; n=36) and specialists (94%; n=29) surveyed agreed that resources used in the demonstration project were useful in supporting best practice follow-up care. The shared care plan was identified as a key supporting resource for facilitating communication and defining responsibilities between the GP and specialist. Participants also noted that good health literacy in patients enabled patients to understand and navigate the shared follow-up care process.

These findings are supported by studies identified through the literature review, which found that the use of shared care plans improved communication between specialists and GPs.[14,28] Shared care plans are also encouraged in the majority of survivorship care guidelines examined.[25,29-33] An Australian literature review recommends greater emphasis should be given to the development and implementation of shared care plans to reduce the burden on specialists, increase primary care professional confidence in providing follow-up care and to optimise the continuity and quality of patient care.[34]

More broadly, well-organised transition, treatment summaries, shared care plans, GP education, and guidelines have been identified as necessary components of successful follow-up.[23,28]

The literature also supports patient engagement as an enabler of adherence, particularly in the primary care setting.[34] Some studies have placed particular emphasis on expanding the knowledge of primary care professionals on ways to engage patients in different population groups, noting that further research is needed to develop awareness by primary care professionals of factors that may help and hinder some patient groups from engaging with cancer care.[34]

GPs in Cancer Australia's demonstration[15] and evaluation[16] projects acknowledged the importance of education and training in developing practitioners' skills and familiarity in best practice follow-up care. This is supported by the literature review, which highlighted the ability of education and training to enhance primary care professional engagement in models of survivorship care.[8,9,34] ASCO and the Institute of Medicine highlight the importance of developing and implementing a survivorship curriculum to ensure that providers have access to the tools, resources and knowledge to care for cancer survivors in the community.[25,35]

Breast cancer online learning modules:

Cancer Australia developed a suite of evidence-based online education modules to support health professionals in providing best-practice care for breast cancer.

The module *'Breast cancer treatment is over – what's next?'* relates to follow-up care including lifestyle and psychosocial aspects of survivorship.

Barriers to adherence to best practice follow-up care

Anecdotal feedback from participants in the demonstration[15] and evaluation[16] projects revealed variation in how the recommended follow-up schedule guideline was interpreted. This poses the risk of diluting adherence to recommended best practice.

Challenges around patient adherence to best practice guidance were identified in the evaluation project.[16] For example, one site reported issues around patients booking and attending GP follow-up visits, and patients forgetting their hand-held shared care plans when attending appointments.

Conclusion

Cancer Australia's body of work has found that follow-up care for early breast cancer shared between a specialist and a GP:

- is safe
- is as effective, if not more effective, than specialist-led care in delivering patient-centred care
- is acceptable to patients and health care providers
- supports cancer care being delivered in accordance with evidence-based best practice
- optimises the use of the specialist workforce
- is cost efficient.

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