

Follow-up of early stage melanoma: specialist clinician perspectives on the functions of follow-up and implications for extending follow-up intervals

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What's already known about this topic?

Less frequent follow-up than is currently recommended for patients with AJCC stage I or II melanoma has been proposed and a trial is underway in the Netherlands.

What does this study add?

To revise guidelines and successfully implement recommended changes it is important to adequately understand the rationale underpinning existing clinical practice. This study from two Australian specialised centres describes melanoma clinicians' perspectives on the functions of follow-up of patients with early stage melanoma, the psychosocial factors that influence follow-up schedules, and some important considerations for extending intervals.

ABSTRACT

Background

There is limited evidence on the relative effectiveness of different follow-up schedules for patients with AJCC stage I or II melanoma but less frequent follow-up than is currently recommended has been proposed. To revise guidelines and successfully implement future changes it is important to understand the rationale underpinning existing clinical practice.

Objectives

To describe melanoma clinicians' perspectives on the functions of follow-up, factors that influence follow-up intervals, and important considerations for extending intervals.

Method

In-depth qualitative study that comprised semi-structured interviews with 16 clinicians (surgical oncologists, dermatologists, melanoma unit GPs) who conduct post-treatment follow-up at two of Australia's largest specialist centres.

Results

Follow-up in specialist centres is conducted to detect early any recurrences or new primary melanomas, manage patient anxiety, support patient-self care, and as a part of shared care.

Follow-up is also an opportunity to review practice and provide data for research.

Recommended intervals are based on guidelines, but account for each patient's clinical risk profile, level of anxiety, and the visits required to establish rapport and provide patient education. Longer-term considerations are patient preferences and capacity to engage in skin

self-examination, and how clinicians manage suspicious lesions to minimise the possibility of missing a new melanoma.

Conclusions

If evidence supports extended follow-up intervals for early stage melanoma, less frequent visits are more likely to be adopted after the first year when patients are less anxious and sufficiently prepared to conduct self-examination. Clinicians may also retain existing schedules for highly anxious patients or those unable to examine themselves.

INTRODUCTION

There is significant variation between countries in the post-treatment follow-up of patients with AJCC (American Joint Committee on Cancer) stage I/II melanoma¹, with recommended schedules based on patients' yearly risk of melanoma recurrence, patterns of recurrence, patient adherence with schedules, consensus opinion among melanoma experts and historical precedent.^{2,3} There are no completed randomised trials of alternative follow-up schedules, although one is currently under way in the Netherlands.⁴ However, most schedules agree on two principles - more frequent follow-up for higher AJCC stages of melanoma, and reductions in the frequency of visits over time.² Current UK guidelines recommend that patients with stage IA melanoma have 2 to 4 follow-up visits in the first year only, while follow-up for patients with stage IB-IIC is 3-monthly for 3 years, and 6-monthly from 3 to 5 years.⁵ Australian guidelines recommend longer (lifelong) follow-up for all patients with melanoma i.e. 6-monthly (stage I) or 3 to 4-monthly (stage II) for 5 years, and annually thereafter.⁶ As the worldwide prevalence of melanoma continues to increase, post-treatment follow-up poses a significant burden on surgical oncologists, dermatologists and other clinicians.^{3,7-9}

The majority of melanoma recurrences (62%) and most subsequent melanomas (73%) are detected by patients or their partners.^{2,10} It has been proposed that less frequent follow-up for patients with early stage disease could be safe and cost-effective.^{10,11} This is further supported by recent modelling in which reduced frequency of follow-up substantially reduced the number of lifetime visits required, with only a small number of patient diagnoses delayed by more than two months.¹² Extended follow-up intervals may also be appreciated by patients. A recent systematic review identified that while patients value the reassurance of regular skin examinations, many also experience anxiety associated with impending follow-

up visits. Adherence to schedules can be highly variable, with up to half of patients dropping out of recommended follow-up programs in the first five years. Patients also report difficulties with attending hospital-based appointments due to the time and cost of travel, transport and parking difficulties, and long clinic waiting times.¹³

When recommending changes to medical protocols it is important to examine both clinical and psychosocial effects, i.e. emotional, cognitive, social and behavioural outcomes.^{14,15}

Psychosocial considerations impact on both patient wellbeing and clinical practice; for example, melanoma patients attending follow-up report unmet needs for emotional support, and melanoma clinicians may order additional tests (e.g. blood tests or imaging) to reassure patients.¹³ To-date melanoma research has described patients' and general practitioners' experiences of follow-up, but there are no studies reporting the views of melanoma specialists i.e. those responsible for developing and/or implementing follow-up protocols. It is important to understand all of the functions of follow-up, both to inform clinical trials with relevant outcomes, and future revisions of practice guidelines. Melanoma clinicians' can identify important considerations that will need to be addressed if the follow-up schedules that are currently recommended are to be revised and successfully implemented in clinical practice.

This paper reports qualitative research involving melanoma clinicians from two of Australia's leading, tertiary referral, melanoma treatment and diagnostic units. The aims of the study were to: (i) describe the views of melanoma clinicians on the functions of follow-up for patients with AJCC stage I/II melanoma, particularly the psychosocial aspects of care; (ii) identify how melanoma clinicians determine the frequency of follow-up for stage I/II melanoma (i.e. factors that influence follow-up intervals); and (iii) identify important considerations for safely extending intervals in the follow-up of stage I/II melanoma.

METHODS

This study was conducted in collaboration with Melanoma Institute Australia (MIA) and the Sydney Melanoma Diagnostic Centre (SMDC). MIA is one of the largest melanoma treatment units in the world and hosts the clinics of surgical oncologists and dermatologists, as well as melanoma unit general practitioners with who conduct follow-up in some surgeons' practices. The SMDC provides dermatology services and long-term monitoring of patients at high risk of developing primary melanoma, including those with previously treated disease. All clinicians at MIA and SMDC involved in post-treatment follow-up of patients with stage I/II melanoma were invited to participate in an in-depth semi-structured interview. All (n=17) consented but one interview did not eventuate due to logistic difficulties in finding a suitable time, and thus 16 interviews were completed. The specialty and gender of participants are reported in [Box 1](#). The study was approved by the Sydney South West Area Health Service Ethics Review Committee (Protocol No X09-0364).

The interviews, each lasting 30-60 minutes, were conducted face-to-face (n=12) or by telephone (n=4) and all were recorded and transcribed. Clinicians were asked to discuss the psychosocial aspects of follow-up and their views on follow-up intervals. Analysis was conducted as a group process in which 3 researchers (LR, KM and RM) read all transcripts and independently prepared analytical notes^{16,17} on the psychosocial functions of follow-up, and the key relationships between these aspects of care and follow-up schedules. This analysis was discussed in regular meetings where coding of the data was revised and refined, and explanations of observed relationships between categories were explored. Two participating clinicians were invited to provide feedback on the validity of the findings.

Box 1: Specialty and gender of study participants

Clinicians		(Total n= 16)
Specialty	Surgical Oncology	7
	Dermatology	5
	Primary Care, with focus on melanoma follow-up	4
Gender	Male	n= 12
	Female	n= 4

RESULTS

The purpose of follow-up

Clinicians emphasised that the main goal of post-treatment melanoma follow-up was early detection of disease recurrence and/or new primary melanomas, and that routine skin checks should be conducted by an experienced clinician and by the patients themselves - ideally assisted by a family member to examine less accessible parts of the body. The purpose of patients attending follow-up at the specialist centres was reported to comprise a number of core functions (Table 1):

(i) *Direct clinical care*: Clinical examination and skin checks, and providing reassurance and managing patient anxiety. Clinicians developed a comprehensive knowledge of individual patients' health, skin, particular lesions and psychosocial needs. They described two periods of peak anxiety among their patients: (a) in the first stages of follow-up when patients haven't yet had an opportunity to obtain or absorb all the relevant information, and need to spend time with a melanoma specialist to address their concerns; and (b) when they or their clinician identify a potential - and subsequently confirmed - recurrence or new melanoma.

(ii) Facilitation of patient self-care: Patient (and partner) education about melanoma and self-examination, and ongoing review and support of patient self-care. This included monitoring patient adherence with recommended schedules, and assessing their capacity, motivation and conduct of self-examinations. Follow-up enabled clinicians to provide education and counselling as required.

(iii) Coordination of shared care: Follow-up included coordinating or overseeing shared or other follow-up arrangements, and many patients alternated follow-up visits between the melanoma clinic and their local or referring doctor.

(iv) Other functions: Clinicians identified follow-up as an opportunity to review their own clinical practice (e.g. surgical outcomes), and to develop longitudinal clinical experience of melanoma. Data collected during follow-up also contributed towards a patient database for future research purposes, for example AJCC melanoma staging.¹ Follow-up was also described as a significant source of professional satisfaction derived from: the early diagnosis of a recurrence or new primary melanomas, providing reassurance to anxious patients, and the rapport that often develops between clinicians and patients as part of long-term care.

Factors that influence frequency of follow-up (intervals)

Routine follow-up was based on Australian guidelines⁶, with adaptations to accommodate the clinical and psychosocial needs of individual patients and each clinician's own preferred practice. For example, clinicians invited patients to return earlier if they wanted to monitor more closely a new lesion or other skin changes. Sometimes they also adjusted follow-up schedules to address non-melanoma skin cancers; e.g. if a patient required more regular treatment for other skin cancers a full body skin examination for melanoma was conducted at the same time. Many patients' schedules were determined by their participation in clinical trials, with follow-up determined by the particular study protocol. The individual patient and

clinician-related factors that influenced the schedules adopted in the follow-up of stage I/II melanoma are summarised in Figure 1. They also included: clinical risk profile, patient preferences for follow-up; time required to establish trust with a patient and provide the relevant education; patient capacity and willingness to engage in routine self skin examination; the clinician's own preferred practice - particularly in relation to minimizing the possibility of missing a melanoma, monitoring suspicious lesions, and dealing with patients unable to undertake self-examination; and whether or not follow-up was shared with other doctors. We outline below how the psychosocial factors in particular influenced follow-up schedules; reflecting clinicians' views on the potential benefits of extending follow-up intervals, as well as some their concerns.

Patients' needs and preferences

Clinicians described significant variation in how patients presented at follow-up. Many appeared anxious until clinical examination indicated there was no recurrence or new primary melanoma. The majority of patients readily accepted their clinician's recommendation on the required frequency of follow-up. A few, however, would request more frequent follow-up than would usually be advised on clinical indications alone. Clinicians also noted that some patients were reluctant to decrease their frequency of follow-up once a schedule had been established, e.g. patients who asked to retain existing schedules at the end of a clinical trial or after recurrence-free periods of 5 years or more. Some patients wanted more frequent reassurance because a family member or friend had died as a result of melanoma. Melanoma prevention television advertisements¹⁸, while valuable for increasing public awareness, also added to the anxiety of existing patients by graphically illustrating an undetected spread of melanoma. Where possible, clinicians tried to reassure and/or accommodate patients who felt anxious about extending follow-up intervals. Clinicians also noted that patient demand for

frequent follow-up may be influenced by skin-cancer clinics in their neighbourhood offering routine 3-monthly monitoring for anyone with a history of melanoma.

Other patients were reported to be pleased when advised that they could reduce the frequency of clinical surveillance, both because they associated this with lessened risk, and because of the time and cost burden of attending for follow-up. Clinicians widely agreed that if there was good evidence for extending intervals in long-term follow-up with no adverse effects on patient outcomes (e.g. extending intervals from 3 to 6 months, or 6 to 12 months) they would be willing to make the changes, and that many of their patients would feel relieved to attend less often. It was also noted that less intensive monitoring may improve adherence to recommended follow-up, and that extended intervals may encourage patients to return more quickly if they found a suspicious lesion rather than waiting for their next scheduled appointment.

Establishing rapport and trust, and providing education to support patient self-care

All clinicians emphasised the importance of gaining the trust of patients and establishing good doctor-patient rapport as essential ingredients for effective patient education and a prerequisite for supporting patient self-care. Clinicians described the regular visits in the first 1-2 years post-diagnosis as important for getting to know their patients. Patients also needed multiple visits to absorb new information, to consider and discuss the implications of what they had learnt, and to ask questions and discuss concerns. Thus when considerations of a reduction in the frequency of follow-up were discussed, it was usually with the proviso of retaining 2-4 visits within the first year to support patient self-care. Clinicians also reported that good doctor-patient rapport helped patients to feel more able to make unscheduled return

visits – particularly if they were concerned that the clinician may have missed something at the last appointment.

Patients' capacity for self-examination

A patient's apparent willingness and capacity to engage in skin self-examination was also identified as an important consideration in determining how often that patient was advised to return for clinical follow-up. More frequent schedules were adopted for those less able to examine themselves because they were older, had poor eyesight, no partner to assist with self-examination, or seemed otherwise unable or unwilling to conduct self-surveillance. The clinician's assessment of a patient's level of engagement and self-responsibility also influenced their approach in dealing with suspicious lesions. For example, if it was perceived that a patient was unlikely to notice changes in skin lesions, or if they had a history of non-adherence to recommended schedules, clinicians were more inclined to remove a suspicious lesion at that visit than to ask the patient to monitor it themselves and return for reassessment a few months later.

Preferred practice

Several clinicians noted the absence of trial evidence on the relative effectiveness of alternative follow-up schedules; thus recommended follow-up was thus based on differential rates of disease risk in melanoma patient populations, and also influenced by historical practice. To consider extending intervals beyond current guidelines, clinicians primarily wanted to know the likely effects on disease detection rates, and on the stage of disease at detection. Many clinicians noted that some melanomas can be very difficult to identify and that there was always a chance that a difficult lesion could be missed during clinical examination. Several clinicians reported that this caused them some concern and anxiety, and

that regular examinations were one way to reduce the clinical impact of a once missed melanoma. For this reason some said the current guidelines of 6-monthly (stage I) and 3-4-monthly (stage II) examinations provided a good safety net for routine follow-up. Such schedules were also often shared with other providers e.g. alternating visits between a melanoma unit clinician and local general practitioner, dermatologist, or skin cancer clinic. Some melanoma clinicians worried that if they detected recurrences or new melanomas at an earlier stage than those detected by other clinicians or patients themselves, less frequent visits to a specialist unit may result in later diagnoses. Concerns were also expressed whether extended follow-up intervals would result in more frequent or earlier removal of suspicious moles and other lesions, and/or more ordering of additional (non-recommended) diagnostic tests as a backup for clinical assessments.

DISCUSSION

This study drew on the strengths of qualitative research¹⁷ to provide an in-depth examination of melanoma unit clinicians' rationale for routine follow-up of patients with early stage melanoma. It documented the clinicians' perspectives on the functions of post-treatment follow-up, and described how they determined and adapted follow-up schedules. The participants in this study were from tertiary referral melanoma treatment and diagnostic units, and it is important to acknowledge that their perspectives as described in this paper may therefore differ to those of other clinicians conducting melanoma follow-up in other units, or in community-based practice. We believe, however, that the implications of the findings for any considerations of extended follow-up intervals may be readily generalised to other settings.

Implications for extending intervals in melanoma follow-up

Several potential benefits of extending existing intervals in the follow-up of AJCC stage I/II melanoma have been proposed.^{4,10-12} Clinicians in this study also reported that many of their patients would feel relieved if less frequent follow-up was recommended by their melanoma specialist – a view supported by patients themselves.¹⁹ The important considerations for extending intervals in the follow-up of AJCC stage I/II melanoma that are derived from the study findings are as follows. Primarily, there is a requirement for evidence that extended intervals have no adverse impact on patient outcomes. This would mean no deleterious effects on early detection of recurrences or new primary melanomas, the stage of disease at the time of detection, the severity of treatment, or patient prognosis. Ideally, such evidence would be from controlled clinical trials of alternative follow-up protocols. A trial in the Netherlands is currently evaluating the effects of a 33% reduction in the number of follow-up visits for melanoma stage IB or II. Outcomes include patients' well-being, expressed in health related quality of life, level of anxiety, satisfaction with the follow-up schedule, and sufficiency to detect recurrences and second primary melanomas.⁴

It is important to retain provisions for several visits with an experienced melanoma clinician in the first year of follow-up in order to provide patients with relevant information, to meet their psychosocial needs, and enable development of good doctor-patient trust and rapport to support longer-term patient self-care. It is also essential to retain capacity for high quality patient education – particularly in first few follow-up visits – which should be conducted either by melanoma specialists or other clinicians with melanoma follow-up expertise.

Patients need to feel able to return to their melanoma specialist within 1-2 weeks if they, or another clinical provider, identify a suspicious lesion that could be a recurrence or new primary disease. Revised protocols should also retain flexibility for those patients who require more frequent follow-up than indicated by their melanoma risk profile alone. Finally,

the rationale for any changes to established follow-up schedules must be clearly understood by the patients affected. This will rely on adequate opportunity to discuss revised schedules with a melanoma clinician to allay patients' anxiety, and to avoid patients misinterpreting what the new schedules indicate about their own progressive level of risk for recurrent or new disease. These requirements for extending intervals in the follow-up of patients with AJCC stage I/II melanoma are summarised in Text Box 1.

Text Box 1: Melanoma clinicians' requirements for extending intervals in melanoma follow-up

- Sufficient evidence that extended intervals have no adverse impact on patient outcomes.
- Retain provision of several visits with experienced melanoma clinician in the first year of follow-up.
- Retain capacity for high quality patient education in early stages of follow-up.
- Ensure patients are able to return to a melanoma specialist at relatively short notice.
- Allow flexibility for those patients who require more frequent follow-up than indicated by melanoma risk profile alone.
- Ensure the rationale for changes to established schedules are understood and accepted by the patients affected.

In conclusion, if clinical trials and/or other research support extended intervals for the follow-up of early stage melanoma, and recommended schedules are to be revised, the requirements for extending intervals identified in this study should be addressed in clinical practice guidelines. This will ensure guidelines consider the important psychosocial functions of follow-up. It will also enhance the acceptability of revised follow-up schedules among the melanoma clinicians who are responsible for their implementation. Further research may be

needed to examine alternative schedules in the first year of follow-up to address the psychosocial aspects of care e.g. comparing existing schedules to less frequent but longer appointments that place particular emphasis on establishing rapport and trust, patient education, and providing additional emotional support when required. There also is significant scope to incorporate into clinical trials the provision of some of the identified functions of follow-up by other providers, such as physician assistants or nurse practitioners.

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