Supplementary Online Content


**eAppendix 1.** Selection of study participants

**eAppendix 2.** Questions used in phone interview

**eAppendix 3.** Reasons for missed follow-up visits

**eAppendix 4.** Follow-up experience and self-examination practice

This supplementary material has been provided by the authors to give readers additional information about their work.
eAppendix 1: Selection of study participants

902 people with localised melanoma treated at MIA during 2014

Excluded (n=5); 5 people died before data extraction commenced

897 patients

No diagnosis of recurrence or new melanoma (n=847)

Stage 0/I patients (n=654)

Random selection of stage 0/I patients (n=177)

Stage 0/I patients who participated (n=127)

Potential participants (n=400)

Stage II patients (n=193)

Random selection of stage II patients (n=174)

Stage II patients who participated (n=103)

Actual participants (n=262)

Diagnosis of recurrence or new melanoma (n=50)

Patients with recurrent or new melanoma (n=49)

Patients with recurrent or new melanoma who participated (n=32)

Excluded (n=497); 477 stage 0/I not selected 19 stage II not selected 1 person with new primary not recorded by database at time of selection

Declined to participate (n=138); 121 people without recurrent or new melanoma • 50 stage 0/I • 70 stage II • 1 stage II excluded as index melanoma before 2014 17 people with recurrent or new melanoma
eAppendix 2: Questions used in phone interview

Q1. Starting from after the post-op check following your melanoma being cut out: would you prefer:
   • [For stage 0 patients] 1) A routine clinic visit once in the first year and then no more routine clinic visits. However, you would have increased education and support in examining your skin yourself and would be able to visit a melanoma doctor at short notice if you have any concerns OR 2) Routine clinic visits once a year
   • For Stage IA patients] 1) A routine visit once in the first year and then no more routine visits. However, you would have increased education and support in examining your skin yourself and would be able to visit a melanoma doctor at short notice if you have any concerns; OR 2) Routine clinic visits twice a year
   • [For Stage IB patients] 1) Routine clinic visits twice in the first year, once in the second year, and then no more routine visits. However, you would have increased education and support in examining your skin yourself and would be able to visit a melanoma doctor at short notice if any concerns; OR 2) Routine clinic visits twice a year
   • [For stage IIA patients] 1) Routine clinic visits twice a year for the first 2 years, and then once a year after that. However, you would have increased education and support in examining your skin yourself and would be able to visit a melanoma doctor at short notice if any concerns; OR 2) Routine clinic visits three times a year.
   • [For stage IIB/c patients] 1) Routine clinic visits three times a year for one year, then twice a year for one year, and then once a year from then on. However, you would have increased education and support in examining your skin yourself and would be able to visit a melanoma doctor at short notice if any concerns; OR 2) Routine clinic visits three to four times a year.

   • Have you had other skin cancers in addition to melanoma?
   • How many?
   • Were these [/Was this] diagnosed since the melanoma diagnosis?

Q2. In the LAST YEAR, how many times have you seen ANY doctor for something to do with melanoma or other skin cancers, including routine follow-ups?
   • Were any of these visits for routine melanoma follow-up?
   • How many visits?
   • Were any visits for melanoma urgent or non-routine visits?
   • How many visits?
   • What was the reason for the urgent or non-routine visit(s)?
   • Did you make the appointment yourself?

   • Were any of these visits for 'other' skin cancer?
   • How many visits?
   • Were any of these visits urgent or non-scheduled?
   • How many were urgent or unscheduled?

   • Did you have any other visits to doctors for something to do with melanoma or other skin cancers, that we haven’t covered?
   • How many visits?
   • What was the reason for this visit/these visits?

Q3. In the LAST YEAR did you miss any appointments for routine melanoma follow-ups?
   • Can you tell me what stopped you from going to routine follow-up?

Q4. In the LAST YEAR what was the average time between visits to doctors about melanoma or other skin cancers?

Q5. Have you had a recurrence of your original melanoma, or a new melanoma or other new skin cancer since your original melanoma was cut out?

Q6. How many recurrences of the original melanoma were there in the LAST YEAR? The following questions are about just the first recurrence of melanoma diagnosed in the LAST YEAR
   • Who first detected the recurrence of the melanoma?
• After it was first detected, did you see more than one doctor before the final diagnosis was made and it was treated?
• What was the sequence of doctors you visited before the final diagnosis and treatment?
• How long was it between when the recurrence was first detected and when you had the treatment?
• How was the recurrence treated?
• What is the name of the doctor who treated this?
• Is this doctor a specialist or GP? [GP = General Practitioner, equivalent to Primary Physician]

Q7. How many NEW melanomas were there in the LAST YEAR? The following questions are about just the first NEW melanoma diagnosed in the LAST YEAR
• Who first detected the NEW melanoma?
• After it was first detected, did you see more than one doctor before the final diagnosis was made and it was treated?
• What was the sequence of doctors you visited before the final diagnosis and treatment?
• How long was it between when the new melanoma was first detected and when you had the treatment?
• How was the new melanoma treated?
• What is the name of the doctor who treated this?
• Is this doctor a specialist or GP?

Q8. How many NEW ‘other’ skin cancers were there in the LAST YEAR? The following questions are about just the first NEW ‘other’ skin cancer diagnosed in the LAST YEAR
• Who first detected the other skin cancer?
• After it was first detected, did you see more than one doctor before the final diagnosis was made and it was treated?
• What was the sequence of doctors you visited before the final diagnosis and treatment?
• How long was it between when the other skin cancer was first detected and when you had the treatment?
• How was the other skin cancer treated?
• What is the name of the doctor who treated this?
• Is this doctor a specialist or GP?

Q9. Do you have any other chronic medical condition for which you regularly attend follow-up?
• Out of these chronic conditions, what is your main health problem at the moment?
• What are the names of doctors you see regularly for all these conditions?
• Is this doctor a specialist or GP? Are these doctors specialists or GPs?
• Where did you see your doctor(s) for follow-up of other medical conditions?

Now I’m going to ask you about self-examination of your skin.
Q10. Do you examine your skin regularly, or do you have a family member examine your skin?
• Do you examine all parts of your body including hard to see areas such as the back of your neck, behind your ears, your back and the soles of the feet?
• How often do you thoroughly examine your skin on average; by ‘thoroughly’ we mean examining all parts of your body?
• Do you have a full length mirror to help you with your skin check?

Q11. How confident are you in your ability to detect any new or recurrent melanoma yourself?
Q12. Do you THOROUGHLY examine your skin on all parts of your body LESS than three monthly because: [READ ITEMS]
Q13. You said you dislike doing a skin check; why is this?

We’re going to finish with some general questions about you
Q14. What is the highest level of education you’ve had?
Q15. What is your current occupation; or previous occupation if not currently working?
Q16. What is your marital status?
Q17. Do you live alone or with others?
Q18. Do you have private health insurance?
Q19. What is your residential postcode?
**eAppendix 3: Reasons for missed follow-up visits**

<table>
<thead>
<tr>
<th>Reasons</th>
<th>AJCC stage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Work/social commitments (n=5)</strong></td>
<td></td>
</tr>
<tr>
<td>“Work commitments”</td>
<td>IIB/C</td>
</tr>
<tr>
<td>“Work”</td>
<td>0</td>
</tr>
<tr>
<td>“Just work commitments – I live a considerable way from the clinic and</td>
<td></td>
</tr>
<tr>
<td>had too much on”</td>
<td>IB</td>
</tr>
<tr>
<td>“I was playing bowls in a tournament”</td>
<td>0</td>
</tr>
<tr>
<td>Death of a family member</td>
<td>IIA</td>
</tr>
<tr>
<td><strong>Organisational issues (n=4)</strong></td>
<td></td>
</tr>
<tr>
<td>Recently moved interstate and is currently trying to find the best</td>
<td>IIB/C</td>
</tr>
<tr>
<td>doctors in their new area</td>
<td></td>
</tr>
<tr>
<td>“I just forgot and it was rescheduled for the next week”</td>
<td>IIB/C</td>
</tr>
<tr>
<td>“The skin cancer clinic near my home closed without notice which</td>
<td>IB</td>
</tr>
<tr>
<td>delayed my skin check”</td>
<td></td>
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<tr>
<td>“I got the dates mixed up”</td>
<td>IIA</td>
</tr>
<tr>
<td><strong>Comorbidities (n=2)</strong></td>
<td></td>
</tr>
<tr>
<td>“I was admitted to hospital and was there for few weeks”</td>
<td>IIB/C</td>
</tr>
<tr>
<td>“Medical condition has made me postpone my appointment”</td>
<td>IIB/C</td>
</tr>
<tr>
<td><strong>Follow-up deemed unnecessary (n=1)</strong></td>
<td></td>
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<tr>
<td>“I just did not worry once I was diagnosed with a clear outcome. After</td>
<td>IB</td>
</tr>
<tr>
<td>the op,”</td>
<td></td>
</tr>
<tr>
<td><strong>Uncertainty regarding follow-up schedule/ possible clinician variation from guidelines (n=9)</strong></td>
<td>IB (n=2) IA (n=3) IIA (n=1) IIB/C (n=2)</td>
</tr>
<tr>
<td>“I thought I only had to go every 12 months”</td>
<td></td>
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<tr>
<td>Eight participants reported not attending any visits in the past year,</td>
<td></td>
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<tr>
<td>but that they had missed no appointments</td>
<td></td>
</tr>
</tbody>
</table>
eAppendix 4: Follow-up experience and self-examination practice

Questions on actual follow-up experience
Participants were asked a series of questions about their follow-up experiences over the last year, including whether they missed any follow-up appointments for melanoma and the reasons for missing these appointments. Participants with a recurrent or new primary melanoma or a non-melanoma skin cancer at time of interview (0.8 to 1.7 years since first primary diagnosis) were asked about how the abnormality was first detected (by themselves, family or friends or a doctor), the process for final diagnosis and the time to, and nature of, definitive treatment. Participants who reported a recurrent or new melanoma in the interview, but who did not have this recorded in the MIA database, were assumed to have non-melanoma skin cancer for the purposes of this report (non-melanoma skin cancer is not captured in the MIA database).

Questions on self-examination practice
Finally, participants were asked questions about how frequently they performed self-examination and the thoroughness of the examination. They were asked about how confident they were in undertaking skin self-examination and reasons why they may do not perform self-examination.