

Appendix S1

Section 1

The first section of this questionnaire contains some **general background questions** which will be helpful to us in analysing the data. Please tick the appropriate box or write on the dotted line.

1. What is your gender?
 - Male
 - Female

2. How old are you?years.

3. Where were you born?
 - The Netherlands
 - Other:.....

4. What is your present marital status?
 - I have a partner
 - Single

5. What is the highest level of education you have completed?
 - Primary school
 - VMBO
 - HAVO
 - VWO
 - MBO
 - HBO
 - University

6. Do you have any children? If yes, please specify how many:

7. Do you have a history of melanoma(s)?
 - No
 - Yes, 1 melanoma
 - Yes, 2 melanomas
 - Yes, 3 melanomas
 - Yes, 4 melanomas
 - I don't know

If yes, please specify the location of your melanoma(s).....

8. Have you ever had pigmented lesions removed that were not melanoma?
 - Never
 - Once
 - Twice
 - Three times
 - Four times
 - Five or more
 - I don't know

9. Has any of your first degree relatives (parents, siblings, children) or other relatives (grandparents, uncles, aunts, grandchildren) ever had melanoma?
 - No
 - Yes, my.....

Section 2

The second section of the questionnaire contains questions on **skin self-examination**. Please tick the appropriate box or write on the dotted lines.

10. **In the past year**, how often have you carefully examined your skin (head, chest, back, arms, legs, soles of your feet) for new or changed moles? In other words, how often in the past year have you deliberately and purposefully checked the surfaces of your skin?
- Weekly (40 to 52 times)
 Monthly (10 to 12 times)
 Every two months (6 to 10 times)
 Only in the summer months (4 to 5 times)
 Two to three times
 Once
 Never
11. **In the past year**, how often has a physician deliberately and purposefully checked the surfaces of your skin for new or changed moles?
- Weekly (40 to 52 times)
 Monthly (10 to 12 times)
 Every two months (6 to 10 times)
 Only in the summer months (4 to 5 times)
 Two to three times
 Once
 Never
12. Have you ever received instructions on how to perform skin self-examination by a **physician or nurse**?
- Yes
 No
 I don't know
13. Have you ever received a **written instruction** on how to perform skin self-examination?
- Yes (*proceed to question 14*)
 No (*proceed to question 15*)
 I don't know (*proceed to question 15*)
14. The written instruction you received on skin self-examination was clear.
- Strongly disagree
 Disagree
 Neutral
 Agree
 Strongly agree
15. *Please respond to the following statements by circling the number that best reflects how you feel.*

Skin self-examination	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. I always get help from another person when performing skin self-examination. For instance, to help examine the skin on my back.	1	2	3	4	5
b. I always use a (hand)mirror when I examine my own skin.	1	2	3	4	5
c. Performing regular skin self-examination gives me a feeling of control over my own health.	1	2	3	4	5
d. By performing regular skin self-examination I can detect melanoma early.	1	2	3	4	5

e. Performing regular skin self-examination helps prevent advanced melanoma.	1	2	3	4	5
f. I feel confident that I can detect changes in my moles.	1	2	3	4	5
g. I feel confident that I can detect new moles on my skin.	1	2	3	4	5
h. Those people who are close to me will benefit if I examine my skin regularly.	1	2	3	4	5

Skin self-examination	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
i. I do not know exactly what I'm looking for when examining my skin.	1	2	3	4	5
j. Examining my skin makes me nervous because I'm not sure what melanoma looks like.	1	2	3	4	5
k. I believe that the early detection of melanoma leads to better survival.	1	2	3	4	5
l. The thought of finding a new or changed mole makes me nervous.	1	2	3	4	5
m. I do not perform regular skin self-examination, because I get regular clinical skin-examinations.	1	2	3	4	5
n. I do not examine my skin regularly because it does not help prevent melanoma.	1	2	3	4	5
o. I find it difficult to examine my skin.	1	2	3	4	5
p. I am confident that I can recognize skin cancer.	1	2	3	4	5
q. It is nearly impossible to examine my skin because I have a lot of moles and freckles.	1	2	3	4	5
r. Regularly examining my skin provides me with peace of mind about my health.	1	2	3	4	5
s. Asking another person to help me examine my own skin would make me feel embarrassed or uncomfortable.	1	2	3	4	5
t. I do not examine my own skin, because it is too time consuming.	1	2	3	4	5
u. I prefer a physician examining my skin regularly, rather than doing this myself.	1	2	3	4	5

Section 3

This section contains questions regarding the photographs that were taken of your skin and moles. Please tick the appropriate box or write on the dotted lines.

16. Has your physician ever used your photographs during your skin examination?
 Once
 Twice
 Three or more times
 Never
 I don't know
17. Did your physician ever decide to excise a mole after comparing your moles to the photographs?
 Once
 Twice
 Three or more times
 Never
 I don't know
18. Did your physician ever decide **not** to excise a mole after comparing your moles to the photographs?
 Once
 Twice
 Three or more times
 Never
 I don't know
19. Did you receive a CD containing your photographs?
 No (proceed to question 22) Yes (proceed to question 20)
20. Have you ever received (written) instruction on how to use the photographs during skin self-examination?
 No Yes
21. *Please respond to the following statements by circling the number that best reflects how you feel.*

Photographs for skin self-examination	Strongly disagree	Disagree	Neutral	Agree	Strongly disagree
a. I find the CD containing my photographs to be useful.	1	2	3	4	5
b. It takes a lot of effort to use the digital photographs during the examination of my skin.	1	2	3	4	5
c. Whenever I think a mole is new or has changed, I use the photographs to confirm my thoughts.	1	2	3	4	5
d. I do not use the photographs because it is too time consuming to use them when I am examining my skin.	1	2	3	4	5
e. I think the photographs are blurry.	1	2	3	4	5
f. Whenever I examine my skin I always use the photographs.	1	2	3	4	5
g. I am more confident that I can recognize new or changed moles since I have the photographs.	1	2	3	4	5
h. The photographs have reassured me once when I thought a mole was new or had changed, because I found that this wasn't true after looking at the photographs.	1	2	3	4	5

i. I examine my skin more often and more deliberately since I have the photographs.	1	2	3	4	5
j. I always examine my skin when I'm under the shower or in the bathroom, where I don't have a computer. Therefore, I never use the photographs.	1	2	3	4	5
k. I'm embarrassed when I see the photographs and I don't want anyone else to see them.	1	2	3	4	5
<i>Proceed to question 24.</i>					

The next 2 questions are only meant for those who have **not** received a CD containing their photographs.

22. Would you like to receive your photographs on a CD so you can use these during the examination of your skin?
 Yes
 No

23. Please respond to the following statements by circling the number that best reflects how you feel.

Photographs for skin self-examination	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. I think that the photographs can be of additional value in skin self-examination.	1	2	3	4	5
b. I don't think I will use the photographs when I examine my skin.	1	2	3	4	5

Section 4

24. How often do you attend the pigmented lesion clinic to have your skin examined by a dermatologist?
 Please tick the appropriate box or write on the dotted line.

- Once every 3 months
 Once every 6 months
 Once every year
 Other:.....

25. Do you benefit from these check-ups? Please tick as many boxes as apply to you.

- Yes, I feel reassured
 Yes, it's a chance to ask questions
 Yes, it's a chance to discuss specific problems or worries
 Yes, it is a chance to check for new disease
 Yes, other reason (please specify):.....

 No, the check-ups are not necessary, I don't have any new or changed lesions
 No, the appointments are too short
 No, the appointments are too frequent
 No, I'm seen by a different doctor each time
 No, other reason (please specify):

26. Do you find it difficult to attend the pigmented lesion clinic?
 Please tick as many boxes as apply to you.

- No

- Yes, because of transport
- Yes, because of expenses
- Yes, because of work
- Yes, because of other commitments
- Yes, there is no one to accompany me
- Yes, other reason (please specify):.....
-

27. I feel nervous or anxious prior to my appointment at the pigmented lesion clinic.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

28. If you have had a melanoma (new or recurrence), was this **found by a doctor or by yourself?** *If you have had multiple melanomas please use the dotted line to specify who found these melanomas.*

- I've never had melanoma
- Found by a general practitioner
- Found by a dermatologist
- Found by myself
- Other:.....
-

29. Would you prefer to have your skin examined by you general practitioner or by a dermatologist?

- I don't mind either way
- I prefer my general practitioner
- I prefer a dermatologist

Section 5

This section of the questionnaire is designed to help us know how you have felt in general over **the past week.**

30. *Please tick the box opposite the response which comes closest to how you have been feeling in the past week. Your immediate reaction to each item will probably be more accurate than a long thought out response.*

- a. I feel tense:
 - Most of the time
 - A lot of the time
 - From time to time, occasionally
 - Not at all
- b. I still enjoy the things I used to enjoy:
 - Definitely as much
 - Not quite so much
 - Only a little
 - Hardly at all
- c. I get a sort of frightened feeling as if something awful is about to happen:
 - Very definitively and quite badly
 - Yes, but not too badly
 - A little, but it doesn't worry me
 - Not at all
- d. I can laugh and see the funny side of things:
 - As much as I always could
 - Not quite so much

- Definitely not so much now
 - Not at all
- e. Worrying thoughts go through my mind:
- A great deal of the time
 - A lot of the time
 - From time to time but not too often
 - Only occasionally
- f. I feel cheerful:
- Not at all
 - Not often
 - Sometimes
 - Most of the time
- g. I can sit at ease and feel relaxed:
- Definitely
 - Usually
 - Not often
 - Not at all
- h. I feel as if I am slowed down:
- Nearly all the time
 - Very often
 - Sometimes
 - Not at all
- i. I get a sort of frightened feeling like butterflies in my stomach:
- Not at all
 - Occasionally
 - Quite often
 - Very often
- j. I have lost interest in my appearance:
- Definitely
 - I don't take so much care as I should
 - I may not take quite as much care
 - I take just as much care as ever
- k. I feel restless as if I have to be on the move:
- Very much indeed
 - Quite a lot
 - Not very much
 - Not at all
- l. I look forward with enjoyment to things:
- As much as I ever did
 - Rather less than I used to
 - Definitely less than I used to
 - Hardly at all
- m. I get sudden feelings of panic:
- Very often indeed
 - Quite often
 - Not very often
 - Not at all
- n. I can enjoy a good book or radio or TV program:
- Often

- Sometimes
- Not often
- Very seldom

Section 6

This section contains questions about **what you think your chances are of developing melanoma sometime in the future**. Please tick the appropriate box or write on the dotted lines.

31. Have you, or has one of your family members, ever been **genetically assessed** for melanoma risk.

- No
- Yes (please specify):.....
- I don't know

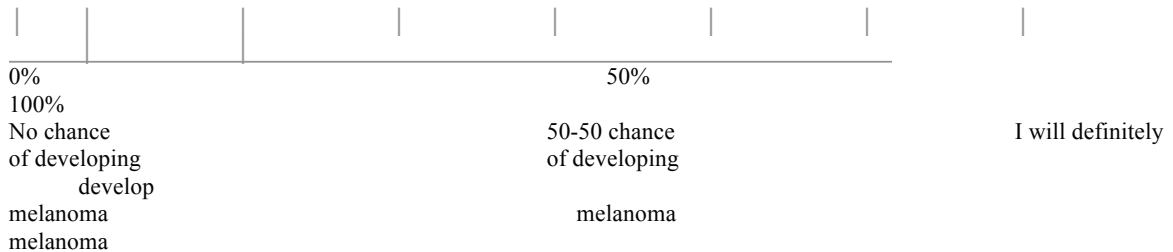
32. Has a **genetic mutation causing increased melanoma risk** ever been found after genetic testing among you or one of your family members?

- No
- Yes (please specify):.....
- I don't know

33. Please rate your chances of having a genetic mutation causing increased melanoma risk.

- 0% chance (you are certain that you do *not* have a genetic mutation)
- 25% chance
- 50% chance
- 75% chance
- 100% chance (you are certain that you *do* have a genetic mutation)

34. Please rate your chances of developing another melanoma sometime in the future. *To do this put a straight line on the scale somewhere between 0% and 100% to indicate what you think your chances of developing another melanoma are.*



35. Do you think you have a higher or lower chance of developing another melanoma sometime in the future compared to someone of your own age and gender?

- Much lower
- Lower
- Same chances
- Higher
- Much higher

36. Do you think you have a higher or lower chance of developing another melanoma sometime in the future compared to someone of your own age and gender **AND** the same family history when it comes to melanoma?

- Much lower
- Lower
- Same chances
- Higher
- Much higher

Section 7

The following statements represents beliefs about melanoma.

37. Please respond to the following statements by circling the number that best reflects how you feel.

Statement on beliefs and experience	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
believe that clinical skin examinations (by a doctor) help in detecting melanoma early.	1	2	3	4	5
believe that sunprotection is effective in preventing melanoma.	1	2	3	4	5
believe that melanoma is fatal, even if it is detected in an early stage.	1	2	3	4	5
believe that even if someone has melanoma it is never too late to do something about it.	1	2	3	4	5
worry about getting melanoma sometime in the future.	1	2	3	4	5

Statements on melanoma	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
f. When I think about getting melanoma sometime in the future this triggers other unpleasant thoughts (such as death, suffering and the consequences for my family) .	1	2	3	4	5
g. I think it is normal to be worried about the possibility of developing melanoma.	1	2	3	4	5
h. I worry about my children getting melanoma sometime in the future.	1	2	3	4	5
i. I feel guilty about possibly passing on a genetic mutation responsible for an increased melanoma risk to my children.	1	2	3	4	5
j. I think I worry too much about the possibility of developing another melanoma sometime in the future.	1	2	3	4	5
k. Others think I worry too much about the possibility of developing another melanoma sometime in the future.	1	2	3	4	5
l. My experiences with melanoma (in my family) have had a negative impact on my life.	1	2	3	4	5

38. The following questions aim to better understand the experience of worries about developing melanoma. Please respond to the following statements by circling the number that best reflects how you feel.

Situations that make me think about the possibility of developing melanoma:	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. Watching television shows or reading newspaper articles about melanoma, cancer or illness.	1	2	3	4	5
b. An appointment with my dermatologist or general practitioner.	1	2	3	4	5
c. Conversations about cancer or illness in general.	1	2	3	4	5

d. Hearing about someone in my surroundings who's ill.	1	2	3	4	5
Situations that make me think about the possibility of developing melanoma:					
e. Going to a funeral or reading the obituary section of the newspaper.	1	2	3	4	5
f. When I feel sick.	1	2	3	4	5
g. I try to avoid situations that make me think about the possibility of developing melanoma.	1	2	3	4	5

39. How often do you think about the possibility of developing melanoma? *Please tick the appropriate box.*

- Never
- A few times a month
- A few times a week
- A few times a day
- Several times a day

40. How much time every day do you spend thinking about the possibility of developing melanoma?

- I don't think about it
- A few seconds
- A few minutes
- About half an hour
- An hour
- Several hours

41. *Please respond to the following statements by circling the number that best reflects how you feel.*

When I think about the possibility of developing melanoma, I feel:	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. Worry, fear or anxiety.	1	2	3	4	5
b. Sadness, disencouragement or disappointment.	1	2	3	4	5
c. Frustration or anger.	1	2	3	4	5
d. Helplessness.	1	2	3	4	5

42. *Please respond to the following statements by circling the number that best reflects how you feel.*

My thoughts or fears about developing melanoma disrupt:	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. My social activities (e.g. sports, travels, outings).	1	2	3	4	5
b. My work and everyday activities	1	2	3	4	5
c. My relationship with those close to me.	1	2	3	4	5

d. My mood.	1	2	3	4	5
e. My quality of life in general.	1	2	3	4	5

43. Please respond to the following statements by circling the number that best reflects how you feel.

When I think about the possibility of developing melanoma, these are the strategies I use to reassure myself:	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. I call my general practitioner or dermatologist.	1	2	3	4	5
b. I make an appointment with my dermatologist for a thorough skin examination.	1	2	3	4	5
c. I try to distract myself.	1	2	3	4	5
d. I try to get the thought out of my head, to not think about it.	1	2	3	4	5
e. I pray, meditate or do relaxation exercises.	1	2	3	4	5
f. I try to convince myself that everything will be fine.	1	2	3	4	5
g. I talk to someone about it.	1	2	3	4	5
h. I try to replace this thought with a more pleasant one.	1	2	3	4	5
i. I tell myself to stop thinking about it.	1	2	3	4	5
j. Do you feel reassured when you use one of these strategies?	1	2	3	4	5

Section 8

This is the last section of the questionnaire. It contains some **general questions** which will be helpful to us in analysing the data. Please tick the appropriate box or write on the dotted lines.

44. What is the color of your eyes?
- Pale blue, pale green or light grey
- Blue, green or grey
- Light brown
- Dark brown
- Brown to black
45. What was your natural hair color at the age of 18?
- Red or reddish blonde
- Blonde
- Dark blonde
- Brown/dark brown
- Black