



Supplementary Document 12: Profiling questionnaire

Participant study code _____
 IRAS 236877

Profile tool version 3 12/11/2017

XPAND
Enhancing Photoprotection Activities - New Directions
 Xeroderma Pigmentosum National Service
 2nd Floor, South Wing
 St Thomas' Hospital
 Westminster Bridge Road
 London SE1 7EH

We are interested in your own personal views about XP and ultraviolet (UVR) protection. There are no right or wrong answers.

Answering these questions will help us tailor the XP and programme to your needs.

When we say UVR protection we mean anything you do to protect your face from UVR (e.g. sunscreen, clothing, staying indoors).

It will take about 5 minutes to complete.

Please circle the number that best corresponds to your views:

1. How much do you think UVR protection can help your skin or eye health?	0 1 2 3 4 5 6 7 8 9 10 <i>not at all</i> <i>very much</i>
2. How much do you think XP treatment at the clinic can help your skin or eye health?	0 1 2 3 4 5 6 7 8 9 10 <i>not at all</i> <i>very much</i>
3. How well do you think your typical level of protection protects you from UVR when you're outdoors?	0 1 2 3 4 5 6 7 8 9 10 <i>not at all</i> <i>completely</i>
4. How much control do you think you have over the way XP affects your skin or eye health?	0 1 2 3 4 5 6 7 8 9 10 <i>no control at all</i> <i>extreme amount of control</i>
5. How necessary do you think it is to protect yourself from UVR when..... it is cloudy?	0 1 2 3 4 5 6 7 8 9 10 <i>not at all</i> <i>essential</i>

it is winter?	0	1	2	3	4	5	6	7	8	9	10
	<i>not at all</i>										<i>essential</i>
6. How necessary do you think it is to protect yourself from UVR if you go outdoors for less than 15 minutes?	0	1	2	3	4	5	6	7	8	9	10
	<i>not at all</i>										<i>essential</i>

Your experiences of UVR protection...

7. How important is it compared to other things you want/need to do?	0	1	2	3	4	5	6	7	8	9	10
	<i>not at all</i>										<i>very important</i>
8. How much do you feel that protecting well against UVR disrupts your everyday life?	0	1	2	3	4	5	6	7	8	9	10
	<i>not at all</i>										<i>very much</i>
9. How confident are you that you can protect against UVR even if other things get in the way?	0	1	2	3	4	5	6	7	8	9	10
	<i>not at all</i>										<i>very confident</i>
10. How much do you worry about other people's reactions to the things you have to do to protect against UVR?	0	1	2	3	4	5	6	7	8	9	10
	<i>not at all</i>										<i>very much</i>
11. How much does your UVR protection affect you emotionally?	0	1	2	3	4	5	6	7	8	9	10
	<i>not at all</i>										<i>very much</i>

Thinking about your health compared to people without XP

12. What do you think are the chances of a person with XP getting skin cancer compared to a person without XP?	0	1	2	3	4	5	6	7	8	9	10
	<i>same chances</i>										<i>much more chances</i>
13. How much do believe that you will get skin cancer at some point, no matter what you do?	0	1	2	3	4	5	6	7	8	9	10
	<i>not at all</i>										<i>very much</i>

Thinking about your UVR protection over the last week

19. To do something automatically means that you do it without having to think about it or consciously remind yourself to do it. How much do you agree that UVR protection was something you did automatically?
0 1 2 3 4 5 6 7 8 9 10 <i>strongly disagree</i> <i>strongly agree</i>
20. How often did you purposely put UVR protective items in key places (e.g., sunscreen bottle in the car) to remind you to protect?
0 1 2 3 4 5 6 7 8 9 10 <i>never</i> <i>all the time</i>
21. How often did you use the weather as a way of deciding what protection you would use?
0 1 2 3 4 5 6 7 8 9 10 <i>never</i> <i>all the time</i>

THANK YOU VERY MUCH FOR ANSWERING THESE QUESTIONS