Supplementary Document 12: Profiling questionnaire

Participant study code____

IRAS 236877

	XPAND	
Enhancing	Photoprotection Activities - N	New Directions
	Xeroderma Pigmentosum National Ser	vice
	2 nd Floor, South Wing	Ture
KING'S	St Thomas' Hospital	Guy's and St Thomas'
LONDON	Westminster Bridge Road	NHS Foundation Trust
	London SE1 7EH	NH3 FOUNDATION TRUST

Profile tool version 3 12/11/2017

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 U	VR pro	otection	can he	lp your	skin or	eye hea	alth?	
	0 not at all	1	2	3	4	5	6	7	8	9	10 very much
2.	How much	do you	think X	P trea	tment a	t the cli	nic can	help yo	ur skin	or e	ye health?
	0 not at all	1	2	3	4	5	6	7	8	9	10 very much
3.	How well doubtdoors?	o you th	nink yo	ur typi	cal leve	l of prot	ection	protect	s you fr	om	UVR when you're
	0 not at all	1	2	3	4	5	6	7	8	9	10 completely
4.	How much	control	do you	think	you hav	e over	the way	/ XP affe	ects you	ır sk	in or eye health?
	0 no control at all	1	2	3	4	5	6	7	8	9	10 extreme amount of control
5.	How necess	sary do	you thi	nk it is	to prot	ect you	rself fro	om UVR	when		
	it is cloudy?										
	0 not at all	1	2	3	4	5	6	7	8	9	10 essential

it is winter?										
0 not at all	1	2	3	4	5	6	7	8	9	10 essential
How necessary 15 minutes?	y do yo	ou think	it is to	protec	ct yours	elf from	uVR if	you go	outdo	ors for less than

Your experiences of UVR protection...

7.	How impor	tant i	s it comp	ared	to othe	r things	you wa	nt/nee	d to do	?			
	0 not at all	1	2	3	4	5	6	7	8	9	10 very important		
8.													
	0 not at all	1	2	3	4	5	6	7	8	9	10 very much		
9.	How confid	lent a	re you th	iat yo	u can p	rotect a	gainst	JVR eve	en if oth	ner thi	ings get in the way?		
	0 not at all	1	2	3	4	5	6	7	8	9	10 very confident		
10.	How much against UV		u worry	abou	t other	people'	s reacti	ons to t	he thin	gs you	u have to do to protect		
	0 not at all	1	2	3	4	5	6	7	8	9	10 very much		
11.	How much	does	your UVI	R pro	tection	affect y	ou emo	tionally	/}				
	0 not at all	1	2	3	4	5	6	7	8	9	10 very much		

Thinking about your health compared to people without XP

	at do you t son withou		re the cha	ance.	s of a pe	erson w	ith XP g	etting:	skin can	icer cor	mpared to a	
	0 same chances	1	2	3	4	5	6	7	8	9 m	10 nuch more chances	
13. Hov	v much do	believ	e that you	ı wil	l get ski	n cance	er at son	ne poin	it, no m	atter w	hat you do?	
	0 not at all	1	2	3	4	5	6	7	8	9	10 very much	

Thinking about people around you.....

14.	How much (clothes, se							around	you witl	h your	UVR protection	on	
	0 no support at all	1 t	2	3	4	5	6	7	8	9	10 a lot of support		
15.	We know t useful do y								e's need	ls. In yo	our opinion, h	ow	
	0 not at all useful		2	3	4	5	6	7	8	9	10 extremely useful		
16.	16. How open are you about your UVR protection needs with people you know but don't live with (e.g., friends or colleagues)?												
	0 not at all	1	2	3	4	5	6	7	8	9	10 very open		

Thinking about protecting your face from UVR when you go outside tomorrow, How much do you agree with these statements?

17. How motiv	ated ar	e you t	o prot	ect?								
0 not at all	1	2	3	4	5	6	7	8		10 ery motivated		
18. I have made a detailed plan about (when, where and how) I'm going to protect												
0 1 2 3 4 5 6 7 8 9 10 completely totally disagree agree												
19. I have a pla	an for h	ow I'm	going	to pro	tect eve	n if thii	ngs get	in the v	vay			
0 completely disagree	1	2	3	4	5	6	7	8	9	10 totally agree		

Thinking about your UVR protection over the last week

con	.9. 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 strongly disagree	•	2	3	4	5	6	7	8	9	10 strongly agree			
	v often di car) to re		100	40 50		protect	ive iten	ns in key	places	s (e.g.,	sunscreen bottle in			
	0 never	1	2	3	4	5	6	7	8	9	10 all the time			
21. Hov	v often di	d you	use the	e wea	ther as	a way c	f decid	ing wha	t prote	ction y	ou would use?			
	0 never	1	2	3	4	5	6	7	8	9	10 all the time			

THANK YOU VERY MUCH FOR ANSWERING THESE QUESTIONS