Understanding Ultraviolet Protection (UV) in Xeroderma Pigmentosum (XP) Questionnaire

Xeroderma Pigmentosum National Service

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St Thomas' Hospital

Westminster Bridge Road

London SE1 7EH



We are trying to understand more about how having to protect against daylight affects the lives of people who have XP. From the answers we hope to be able to find ways to help patients and their families.

Please answer as many questions as you can. Where you are not sure of an answer, it is fine if you put your best guess.

Remember all the information you give will be treated with the strictest confidence and will be analysed anonymously. The people who look after you in the XP clinic will not see the answers you give.

If you are 12-15 years old and take responsibility for your own UV protection, please look through the questionnaire FIRST to see whether you feel able to complete it on your own. If you do not think you can, or if you are unsure, it is best for your parent or carer to complete one for you instead. They will complete a different version of questionnaire. Please contact our Research Nurse, (**********) if you do not have the version for parents or carers.

Thank you for taking the time to answer this questionnaire. Because XP is rare, every questionnaire that is completed and sent back to us makes a big difference for this research.

Filling out the questionnaire takes about 25 minutes. There are questions on both sides of each page.

The questionnaire is split into different topics:

- XP and your thoughts about it
- What you do to protect yourself from Ultraviolet (UV) in daylight

Some questions ask about what you usually do and others ask about the last few days or weeks. Some questions look the same as others but are actually different, so please can you try to answer as accurately as you can.

- Your views about UV protection
- General things about you and your quality of life

Before we ask about your XP, we'd like to find out a few details about you.

2. Are you: (please tick) Male or Female 3. I am completing the questionnaire because: (please tick one option) I have been diagnosed with XP and I am 16 years or over I have been diagnosed with XP and I am 12 - 15 years old and have chosen to complete the questionnaire myself 4. Do you have any of these qualifications? (Please tick all that apply). If you have no formal qualifications please tick the box below NVQ or equivalent GCE / GCSE / O-level or equivalent A-level or equivalent Undergraduate degree Masters	1.	How old are you now?			Years							
I have been diagnosed with XP and I am 16 years or over I have been diagnosed with XP and I am 12 - 15 years old and have chosen to complete the questionnaire myself 4. Do you have any of these qualifications? (Please tick all that apply). If you have no formal qualifications please tick the box below NVQ or equivalent GCE / GCSE / O-level or equivalent A-level or equivalent Pre-degree foundation course/ diploma / HND or equivalent Undergraduate degree	2.	Are you: (please tick)	Male 🗆	or	Female □							
I have been diagnosed with XP and I am 12 - 15 years old and have chosen to complete the questionnaire myself 4. Do you have any of these qualifications? (Please tick all that apply). If you have no formal qualifications please tick the box below NVQ or equivalent GCE / GCSE / O-level or equivalent A-level or equivalent Pre-degree foundation course/ diploma / HND or equivalent Undergraduate degree	3. I am completing the questionnaire because: (please tick one option)											
4. Do you have any of these qualifications? (Please tick all that apply). If you have no formal qualifications please tick the box below NVQ or equivalent GCE / GCSE / O-level or equivalent A-level or equivalent Pre-degree foundation course/ diploma / HND or equivalent Undergraduate degree	I have been diagnosed with XP and I am 16 years or over											
4. Do you have any of these qualifications? (Please tick all that apply). If you have no formal qualifications please tick the box below NVQ or equivalent GCE / GCSE / O-level or equivalent A-level or equivalent Pre-degree foundation course/ diploma / HND or equivalent Undergraduate degree		I have been diagnosed with XP an	d I am 12	- 15 ·	years old and	l have						
If you have no formal qualifications please tick the box below NVQ or equivalent GCE / GCSE / O-level or equivalent A-level or equivalent Pre-degree foundation course/ diploma / HND or equivalent Undergraduate degree		chosen to complete the question	naire myse	elf								
GCE / GCSE / O-level or equivalent A-level or equivalent Pre-degree foundation course/ diploma / HND or equivalent Undergraduate degree	4.		-									
A-level or equivalent Pre-degree foundation course/ diploma / HND or equivalent Undergraduate degree				N	IVQ or equiva	lent						
Pre-degree foundation course/ diploma / HND or equivalent Undergraduate degree		GO	CE / GCSE ,	/ O-le	evel or equiva	lent						
Undergraduate degree				A	-level or equiva	alent						
		Pre-degree foundation co	ourse/ diplo	oma /	HND or equiva	alent						
Masters				Unc	lergraduate de	gree						
					Ma	sters						

Participant study code		Country of residence: U					
		Doctorate/ PhD					
		Professional qualification					
		Other					
	Please write in						
		No Formal qualifications					

ABOUT YOUR XP

Please complete or circle the answer

5. How old were you when you were diagnosed as having XP?	Years
6. Have you ever had a skin cancer?	Yes / No
7. Have you had to see an Eye Specialist doctor because of any problems with the eyes?	Yes / No
8. Has the XP caused problems with your hearing, walking, or speaking?	Yes / No
9. Do you sunburn more easily than other people in your family who do not have XP?	Yes / No
10. Have you ever had sunburn so badly you needed to see a doctor about it?	Yes / No
11. Have you ever had sunburn in the winter in the country where you live?	Yes / No
12. Have you ever had sunburn which took more than 3 days to go away?	Yes / No
13. Do you take special measures to avoid some light bulbs?	Yes / No

14. How would you describe your skin?	
	Fair or light coloured
	Asian
	Light brown
	Afrocaribbean
	Dark brown
15. What colour are your eyes?	
	Blue
	Green
	Brown
	Other
16. Do you know what complementation group of XP you have?	Yes / No
17. If Yes please circle the group	
	A
	В
	С
	D
	E
	F
	G
	V

We are interested in your own personal views of how you see all aspects of your XP.

Please circle the number that best corresponds to your views:

18. How much does your XP affect your life?											
no affect at all	0	1	2	3	4	5	6	7	8	9	10 severely affects my life
19. How long do you think your XP will continue?											
a very short time	0	1	2	3	4	5	6	7	8	9	10 forever
20. How m	nuch cor	ntrol do	you fee	el you l	nave ov	er the v	vay XP a	iffects y	our hea	lth	?
Absolutely no control		1	2	3	4	5	6	7	8	9	10 extreme amount of control
21. How n	nuch do	you thir	nk dayli	ght/U\	/ prote	ction ca	n help y	our skii	n or eye	he	alth?
not at all	0	1	2	3	4	5	6	7	8	9	10 extremely helpful
22. How m		you thir	nk XP tr	eatme	nt in th	e clinic	(e.g. sur	gery, c	reams) (can	help your skin or
not at all	0	1	2	3	4	5	6	7	8	9	10 extremely helpful
23. How m	nuch do	you exp	erience	symp	toms re	elated to	your X	.P?			
no sym at all	0 nptoms	1	2	3	4	5	6	7	8	9	10 many severe symptoms
24. How c	oncerne	d are yo	u abou	ıt your	XP?						
not at all concerned	0	1	2	3	4	5	6	7	8	9	10 extremely concerned

Please circle the number that best corresponds to your views:

25. How well do you feel you understand your XP?										
0 don't understand at all	1	2	3	4	5	6	7	8	9	10 understand very clearly
26. How much does your XP affect you emotionally? (does it make you angry, scared, upset or depressed?)										
0 not at all affected emotionally	1	2	3	4	5	6	7	8		10 emely affected emotionally



ABOUT YOUR PROTECTION FROM ULTRAVIOLET (UV) IN DAYLIGHT

27. What is the date today?			
(day/month/year)		/	/
28. Which is your nearest town?			
If you do not wish to give this information			
please move to the next question.			
These questions focus on the LAS	T 7 DAYS		
29. Over the last 7 days, what is your best gu	<u> </u>		
many days it has been sunny for at least l	half the day?		Days (out of 7)
		•••••	Days (out or 7)
30. Thinking about a typical day in the last 7	days, what is yo	our	
best guess on average for the number of	hours you have	e spent	hours per day
outside in daylight (with or without UV pr	otection)?		
31. We know it can be difficult to protect aga	inst UV all the	time.	Never
Over the last 7 days when you went outsi	de how often d	lid you	rarely
protect yourself against UV?			sometimes
(Please circle the answer)			
			often
			always
32. Do you have UV protective window film o	n home windo	ws?	I have protective film on:
(Please circle the answer)			ALL windows
			SOME windows
			NO windows
			I don't know
			1 don't know
33. Over the last 7 days, when at home to wh	nat extent have	you	Not at all

		T .		
stayed in rooms with UV protection		rarely		
(Please circle the answer)		sometimes		
		often		
		always		
34. Is there UV protective window film on windows at school	There	is film on:		
or work?				
(Please circle the answer)		indows		
()	SOME	SOME windows		
	NO wi	NO windows		
	I don'	t know		
	I don't work or go to school			
	outside the home			
35. Over the last 7 days, when at work or school to what	Not at	· all		
•				
extent have you stayed in rooms with UV protection	rarely			
(Please circle the answer)	somet	imes		
	often			
	alway	S		
36. Do you have UV protective window film on your car's	There	is film on:		
windows?	ALL w	indows		
(Please circle the answer)	SOME	windows		
	NO wi	ndows		
	I don'	t know		
	1			

I don't have a car

Appendix 3.

Participant study code_____ Country of residence: UK

We know it can be difficult to protect against UV in daylight all the time.

These items ask how much you agree or disagree with the statements about the different things you could do to protect yourself from UV.

They are very similar statements about each way you could have protected yourself over the <u>PAST 7 DAYS</u>. Please read each question carefully and circle the number that best corresponds to your views. If you did not protect from UV in that way please circle the box "I did not..."

OVER THE LAST 7 DAYS.....

37. "Avoiding go	oing ou	37. "Avoiding going outside during the day was something I did									
automaticall											
							I did not avoid going				
1	2	3	4	5	6	7	outside				
Strongly Disagre	ee					Strongly Agre	e				
38. "Every time I											
something I	did auto	omatic	ally wit	hout th	inking"		I did not wear a face				
	1 2	2 3	4	5	6	7	visor				
Strongly Disagre	ee					Strongly Agr	ee				
39. "Every time I											
something I	did auto	omatic	ally wit	hout th	inking"						
							I did not wear a hat				
1	2	3	4	5	6	7					
Strongly Disagre	ee					Strongly Ag	ree l				
40. "Every time I	got red	ady to	go outs	ide wed	aring gl	asses was					
something I	did auto	omatic	ally wit	hout th	inking"		I did not wear				
1	2	3	4	5	6	7	glasses				
Strongly Disagre	ee					Strongly Ag	ree				
41. "Every time I	got red	dy to	go outs	ide, we	aring su	inscreen was					
something I	did auto	omatic	ally wit	hout th	inking"		I did not wear				
1	2	3	4	5	6	7	sunscreen				
Strongly Disagr	ee					Strongly Agr	ee				

42. "Every time I go	t read	y to go	outsid	e, wea i	ing lip	sunblock was	
something I did	I did not woor lin						
	I did not wear lip sunblock						
1	2	3	4	5	6	7	Sullblock
Strongly Disagree						Strongly Agree	
43. "Every time I go							
buff" was some							
							I did not wear a
1	2	3	4	5	6	7	scarf or "face buff"
Strongly Disagree						Strongly Agree	
44. "Every time I go	t read	y to go	outsid	le, wea i	ing a h	oodie (worn up)	
was something	I did a	utoma	tically (without	thinkin	ng"	I did not wear a
							hoodie (worn-up)
1	2	3	4	5	6	7	noodie (worn-up)
Strongly Disagree						Strongly Agree	
45. "Every time I go							
something I did	autom	aticali	ly with	out thin	king"		I did not wear long
							sleeves
1	2	3	4	5	6	7	
Strongly Disagr						Strongly Agree	
46. "Every time I go	•	_		-		oves was	
something I did	autom	aticali	ly with	out thin	king"		
	•	•		_	_	_	I did not wear
1	2	3	4	5	6	7	gloves
Strongly Disagree						Strongly Agree	
47. "Every time I go	t read	y to go	outsid	le, wea i	ring lon	g trousers or	
thick tights was	some	thing I	did au	tomatic	ally wit	thout thinking"	I did not wear long
_				_	_	_	trousers or thick
1	2	3	4	5	6	7	tights
Strongly Disagree						Strongly Agree	

^{*}sleeves would include coats or jackets

OVER THE LAST 7 DAYS WHEN OUTSIDE.....

48. Thinking about all the things you did to protect yourself over the		
past 7 days (e.g., wearing sunscreen, wearing a hat), how well do	I did not do	
you think they protected you from UV? (Please circle).	anything to protect	
Completely very well a fair amount a little Not at all	myself from UV in the last 7 days	

Appendix 3.

Participant study code_____ Country of residence: UK

We know that people adapt their UV protection to fit in with everyday life.

These questions are about what you <u>USUALLY</u> do throughout the year to protect yourself from UV in daylight when it is <u>CLOUDY AND</u> then what you do on days when it is <u>SUNNY</u>.

Please circle how often you do the different things on the days when it is <u>CLOUDY</u> and then on the days when it is <u>SUNNY</u>, throughout the year.

Cloudy days	Sunny days
Never	Never
rarely	rarely
sometimes	sometimes
often	often
always	always
	Never rarely sometimes often

WHEN YOU GO OUTSIDE... (Please circle the answer)

	Cloudy days	Sunny days
Thinking about your FACE		
50. How often do you wear a face visor?	Never	Never
	rarely	rarely
	sometimes	sometimes
	often	often
	always	always
51. How often do you wear a hat?	Never	Never
	rarely	rarely
	sometimes	sometimes
	often	often
	always	always
52. How often do you wear glasses?	Never	Never
	rarely	rarely
	sometimes	sometimes
	often	often
	always	always

When you go outside (Please circle the answer)	Cloudy days	Sunny days
53. How often do you use sunscreen on	Never	Never
your face?	rarely	rarely
	sometimes	sometimes
	often	often
	always	always
54. If you use sunscreen on your face, what sun protection factor does it have? (or circle I do not)	SPF number	SPF number
	I do not wear su	nscreen on my face
55. How often do you reapply the sunscreen on your face during the day? (or circle I do not)	x/day	x/day
	I do not wear su	nscreen on my face
56. How often do you put on lip sunblock?	Never	Never
	rarely	rarely
	sometimes	sometimes
	often	often
	always	always
57. How often do you wear a scarf or "face	Never	Never
buff"?	rarely	rarely
	sometimes	sometimes
	often	often
	always	always

When you go outside (Please circle the answer)	Cloudy days	Sunny days
58. How often do you wear a hoodie (worn	Never	Never
-up)?	rarely	rarely
	sometimes	sometimes
	often	often
	always	always
Thinking about your ARMS OR HANDS	5	
59. How often do you wear long sleeves?	Never	Never
	rarely	rarely
	sometimes	sometimes
	often	often
	always	always
60. How often do you use sunscreen on	Never	Never
your arms or hands?	rarely	rarely
	sometimes	sometimes
	often	often
	always	always
61. How often do you wear gloves?	Never	Never
	rarely	rarely
	sometimes	sometimes
	often	often
	always	always
Thinking about your LEGS		
62. How often do you wear long trousers or	Never	Never
thick tights?	rarely	rarely
	sometimes	sometimes
	often	often
	always	always

When you go outside	Cloudy days	Sunny days		
(Please circle the answer)		, ,		
63. How often do you use sunscreen on	Never	Never		
your legs?	rarely	Rarely		
	sometimes	sometimes		
	often	often		
	always	always		
Thinking about using sunscreen on your OR LEGS	ur BODY (NOT FAC	CE), ARMS, HANDS		
64. If you use sunscreen on any of these areas (body, arms, hands or legs) what sun protection factor does it have? (or circle I do not)	SPF number SPF number			
		reen on my body, arms, ls or legs		
65. How often do you reapply the sunscreen to any of these areas (body, arms, hands or legs) during the day? (or circle I do not)	x/day	x/day		
		reen on my body, arms, ls or legs		

YOU'RE OVER HALF OF THE WAY THROUGH NOT MUCH MORE TO GO..

Appendix 3.

Participant study code Country of residence: UK

We would like to ask your personal views about protecting against UV in daylight. This means whatever you do to protect yourself, including:

- avoiding going outside during the day
- putting on sunscreen and lip sunblock
- wearing glasses
- wearing protective clothes (e.g., hat, scarf or face-buff, gloves, long sleeves, long trousers/thick tights)
- or wearing a face visor

These are statements other people have made about their UV protection.

Please indicate the extent to which you agree or disagree with what they have said by circling the answer that best corresponds to your views.

There are no right or wrong answers. We are interested in **YOUR PERSONAL VIEWS**.

66. "My health depends on protecting against UV"											
Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree							
67. "Having to protect against UV worries me"											
Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree							
68. "My life would be impossible without protecting against UV"											
Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree							
69. "If I did not protect against UV I would be very ill"											
Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree							
70. "I sometimes worry about other people's reactions to the things I have to do to protect against											
UV (e.g., wearing a visor, u	sing sunso	creen, wearing	a hat)"								
Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree							
71. "I sometimes worry about long-term effects of having to protect against UV"											
Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree							

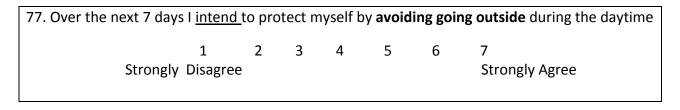
72. "I don't really understand why I need to protect against UV"

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree				
73. "My h	nealth in the future	will depen	d on protectin	g against UV	"				
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree				
74. "Havi	ng to protect again.	st UV disru	ıpts my life"						
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree				
75. "Protecting against UV stops my health getting worse"									
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree				
76. "I sometimes worry about the impact on family and friends of having to protect against UV"									
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree				

We are now asking about the NEXT 7 DAYS.

These questions are about the different things you might do to protect yourself from UV. We know that people want to do some things more than others, and they find some things easier to do than others. We want to find out what YOU THINK.

These statements are very similar to each other about the ways you might protect yourself over the next 7 days. Please read each question carefully and think about each way in turn.



Appendix 3.	qΑ	pen	dix	3.
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Participant study code_____ Country of residence: UK

When I am outside in the **NEXT 7 DAYS....**

(If you are not intending to go outside in the next 7 days please skip to question 88.)

78. I <u>intend</u> to protect myself by wearing a face visor									
	1	2	3	4	5	6	7		
Strongly D	isagree						Strongly Agree		
79. I <u>intend</u> to protect myself by wearing a hat									
	1	2	3	4	5	6	7		
Strongly Disagree							Strongly Agree		
80. I <u>intend</u> to protect myself by wearing glasses									
	1	2	2	4	F	6	7		
Strongly Disagree	1	2	3	4	5	б	Strongly Agree		
81. I intend to protect myself by putting on sunscreen									
	1	2	3	4	5	6	7		
Strongly Disagree							Strongly Agree		

When I am outside in the NEXT 7 DAYS....

when I am outside		112/		77 11 0	<u></u>					
82. I <u>intend</u> to protect myself by putting on lip sunblock										
	1	2	3	4	5	6	7			
Strongly Disagree	1	2	,	7	3	U	Strongly Agree			
83. I intend to protect myself by wearing a scarf or "face buff"										
	1	2	3	4	5	6	7			
Strongly Disagree							Strongly Agree			
84. I <u>intend</u> to protect	mvself k	ov we a	aring a	hood	ie (worn	-up)	0, 0			
15 p. 00000	,	.,			- (~ [-7				
	1	2	3	4	5	6	7			
Strongly Disagree							Strongly Agree			
85. I <u>intend</u> to protect	myself k	y we a	aring l	ong sle	eeves					
	1	2	3	4	5	6	7			
Strongly Disagree							Strongly Agree			
86. I <u>intend</u> to protect	myself k	y we a	aring g	loves						
	1	2	3	4	5	6	7			
Strongly Disagree							Strongly Agree			
87. I intend to protect	myself k	oy we a	aring l	ong tro	ousers o	r thick	tights			
	•	-	_	_			-			
	1	2	3	4	5	6	7			
Strongly Disagree							Strongly Agree			

"We know these questions are repetitive...thank you for keeping going"

Over the **NEXT 7 DAYS.....**

88. I am confident I could avoid going outside during the daytime									
	1	2	3	4	5	6	7		
Strongly Disagree Strongly Agree									

When I am outside in the **NEXT 7 DAYS....**

(If you are not intending to go outside in the next 7 days please skip to question 99.)

(ii you are not intending	g to go	outsia	C 111 C	ic lickt	, augs	Jicasc	skip to question ss.j			
89. I am <u>confiden</u> t I could wear a face visor										
	1	2	3	4	5	6	7			
Strongly Disagree	9						Strongly Agree			
90. I am confident I could wear a hat										
:	1	2	3	4	5	6	7			
Strongly Disagree							Strongly Agree			
91. I am confident I could wear glasses										
	1	2	3	4	5	6	7			
Strongly Disagree							Strongly Agree			

When I am outside in the **NEXT 7 DAYS....**

92. I am <u>confident</u> I could put on sunscreen								
	1	2	3	4	5	6	7	
Strongly Disagree	!						Strongly Agree	
93. I am confident I could put on lip sunblock								
	1	2	3	4	5	6	7	
Strongly Disagree	!						Strongly Agree	
94. I am <u>confident</u> I co	ould w e	ear a sca	arf or '	face b	uff"			
	1	2	3	4	5	6	7	
Strongly Disagree	!						Strongly Agree	
95. I am <u>confident</u> I co	ould we	ear a ho	odie (worn-น	ıp)			
	1	2	3	4	5	6	7	
Strongly Disagree	!						Strongly Agree	

Appendix 3.

Participant study code_____ Country of residence: UK

96. I am <u>confident</u> I could wear long sleeves							
	1	2	3	4	5	6	7
Strongly Disag	ree						Strongly Agree
97. I am confident I could wear gloves							
	1	2	3	4	5	6	7
Strongly Disagre	e						Strongly Agree
98. I am <u>confident</u> I co	ould eas	sily wea	r long	trouse	ers or th	nick tigh	ts
	1	2	3	4	5	6	7
Strongly Disag	ree						Strongly Agree

Overall in the NEXT 7 DAYS......

99. I am confident I can do the things I want to do to protect myself from UV								
Strongly Disagre	1 ee	2	3	4	5	6	7 Strongly Agree	

About your XP and the people around you.....

100. How much support or help do you have from the people around you with your UV protection?

No support hardly any support Some support lots of support comprehensive support

101. How satisfied are you with the support or help that you have to help you with your UV protection?

Very dissatisfied fairly dissatisfied uncertain fairly satisfied very satisfied

YOU'RE NOW IN THE FINAL SECTION YOU'VE ALMOST FINISHED!

ABOUT YOU AND YOUR QUALITY OF LIFE

These questions are about you, your thoughts about the present and future, your emotions and your quality of life.

Please circle the number that best corresponds to your views:

				•	<u>, </u>		
102.	D2. "Thinking about the future is pleasant to me"						
	1	2	3	4	5		
	Very true of me				Very untrue of me		
103.	"When I want to achieve s	omething,	, I set	goals	and consider specific means of		
re	aching those goals"						
	1	2	3	4	5		
	Very true of me				Very untrue of me		
104.	•	dlines and	doing	g other	r necessary work comes before		
to	night's play"				,		
	4	2	2		-		
	1	2	3	4	5		
405	Very true of me				Very untrue of me		
105.	"It seems to me that my fu	iture pians	s are p	oretty	well laid out"		
	1	2	3	4	5		
	Very true of me				Very untrue of me		
106.	"I think that it seems usele	ess to plan	too f	ar ahe	ad because things hardly ever		
со	me out the way you planned	d anyway'	,				
	1	2	3	4	5		
	Very true of me				Very untrue of me		
107.	"If I do not get done on tin	ne, I do no	t wor	ry abo	ut it"		
	1	2	3	4	5		
	Very true of me	2	3	4	Very untrue of me		
108.	"I try to live one day at a ti	ime"			very untitue of the		
100.	Tity to live one day at a ti	iiiic					
	1	2	3	4	5		
	Very true of me				Very untrue of me		
109.	"I feel that it is more impo	rtant to e	njoy w	vhat yo	ou are doing than to get the work		
do	ne on time"						
	1	2	3	4	5		
	Very true of me				Very untrue of me		
110.	"I do not do things that are	e good for	me ij	f they o	•		
	1	2	3	1	5		
		2	3	4			
	Very true of me				Very untrue of me		

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Participant study code_____ Country of residence: UK

Below are some statements about feelings and thoughts.

Please circle the answer that best describes your experience of each over the <u>LAST 2 WEEKS</u>

111. "I've beer	111. "I've been feeling optimistic about the future"							
None of the	e time Rarely	Some of the time	Often	All of the time				
112. "I've beer	n feeling useful"							
None of the t	time Rarely	Some of the time	Often	All of the time				
113. "I've beer	n feeling relaxed"	,						
None of the t	time Rarely	Some of the time	Often	All of the time				
114. "I've beer	n dealing with pro	oblems well"						
None of the t	time Rarely	Some of the time	Often	All of the time				
115. "I've beer	n thinking clearly	"						
None of the	e time Rarely	Some of the time	Often	All of the time				
116. "I've beer	n feeling close to	other people"						
None of the	time Rarely	Some of the time	Often	All of the time				
117. "I've beer	n able to make up	my own mind about	things"					
None of the	time Rarely	Some of the time	Often	All of the time				

These questions are about how your quality of life is affected by the XP.

Under each heading, please tick the ONE box that best describes your health

TODAY.

118. MOBILITY	
I have no problems in walking about	
I have slight problems in walking about	
I have moderate problems in walking about	
I have severe problems in walking about	
I am unable to walk about	
119. SELF-CARE	
I have no problems washing or dressing myself	
I have slight problems washing or dressing myself	
I have moderate problems washing or dressing myself	
I have severe problems washing or dressing myself	
I am unable to wash or dress myself	
120. USUAL ACTIVITIES (e.g. work, study, housework,	
family or leisure activities)	
I have no problems doing my usual activities	
I have slight problems doing my usual activities	
I have moderate problems doing my usual activities	
I have severe problems doing my usual activities	
I am unable to do my usual activities	
121. PAIN / DISCOMFORT	
I have no pain or discomfort	
I have slight pain or discomfort	
I have moderate pain or discomfort	
I have severe pain or discomfort	
I have extreme pain or discomfort	_

Appendix 3. Participant study code	Country of residence: UK
122. ANXIETY / DEPRESSION	
I am not anxious or depressed	
I am slightly anxious or depressed	
I am moderately anxious or depressed	
I am severely anxious or depressed	
I am extremely anxious or depressed	П

The best health you can imagine

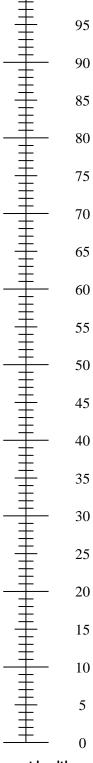
100

- This scale is numbered from 0 to 100.
- This scale is numbered from 0 to 100
- 100 means the <u>best</u> health you can imagine.
 0 means the <u>worst</u> health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.

We would like to know how good or bad your health is TODAY.

• Now, please write the number you marked on the scale in the box below.

123. YOUR HEALTH TODAY =



The worst health you can imagine

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Participant study	v code	Country	of residence: UK
Participant Study	/ code	Country	or residence: UK

ONE MORE QUESTION ABOUT YOU...

This is an extra question, some people may not want to fill it out. If you don't want to do this question, just leave it blank.

124. Which of the following **best** describes your **ethnicity?** Please tick **one** of the following options.

White	Black or Black British	
British	Caribbean	
Any other White background	African	
please write in		
Mixed	Any other Black background,	
White and Black Caribbean	please write in	
White and Black African		
White and Asian	Chinese or other ethnic group	
Any other Mixed background	Chinese	
please write in	Any other	
	Please write in	
Asian or Asian British		
Indian		
Pakistani		
Bangladeshi		
Any other Asian background		
please write in		

If you have any additional thoughts or comments please can you write them here:

THANK YOU VERY MUCH FOR COMPLETING OUR QUESTIONNAIRE.