Supplementary Document 5: Cross-sectional survey

Participant study code_____ Country of residence: UK

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

Xeroderma Pigmentosum National Service

2nd Floor, South Wing
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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	vour XP.	we'd like to	find out a	few details	about you.

1.	How old are you now?			Years		
2.	Are you: (please tick)	Male 🗆	or	Female 🗆		
3.	I am completing the questionna	ire because	e: (pl	ease tick one op	otion)	
	I have been diagnosed with XP ar	nd I am 16	year	s or over		
	I have been diagnosed with XP are chosen to complete the question			years old and h	ave	
4.	Do you have any of these qualifi If you have no formal qualificat	180			ply).	
			١	NVQ or equivale	nt	
	G	CE / GCSE ,	/ O-I	evel or equivale	nt	
			А	-level or equivale	nt	
	Pre-degree foundation c	ourse/ diplo	oma /	HND or equivale	nt	
			Und	dergraduate degr	ee	
				Maste	ers	

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		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

air or light coloured
Asian
Light brown
Afrocaribbean
Dark brown
Blue
Green
Brown
Other
Yes / No
А
В
С
D
E
F
G
V

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

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Please circle the number that best corresponds to your views:

18. How much does your XP affect your life?										
0 no affect at all	1	2	3	4	5	6	7	8	9	10 severely affects my life
19. How long	do you thi	nk your	XP wil	l conti	nue?					
0 a very short time	1	2	3	4	5	6	7	8	9	10 forever
20. How much	control d	lo you fe	el you	have o	over the	way XI	affect	s your h	ealth	?
0 Absolutely no control	1	2	3	4	5	6	7	8	9	10 extreme amount of control
21. How much	n do you th	nink day	light/l	JV prot	ection	can help	your s	kin or e	ye he	alth?
0 not at all	1	2	3	4	5	6	7	8	9	10 extremely helpful
22. How much eye health		nink XP t	reatm	ent in	the clin	ic (e.g. s	urgery	, creams	s) can	help your skin or
0 not at all	1	2	3	4	5	6	7	8	9	10 extremely helpful
23. How much	n do you e	xperienc	ce sym	ptoms	related	to your	XP?			
0 no sympto at all	1 ms	2	3	4	5	6	7	8	9	10 many severe symptoms
24. How conc	erned are	you abo	ut you	ır XP?						
not at all concerned	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 y	ou fee	l you un	dersta	and you	ır XP?					
0 don't understand at all	1	2	3	4	5	6	7	8	9	10 understand very clearly
26. How much do depressed?)	es you	r XP affe	ect you	ı emot	ionally?	' (does i	t make	you an	gry, sc	ared, upset or
0 not at all affected emotionally	1	2	3	4	5	6	7	8		10 remely affected emotionally



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ABOUT YOUR PROTECTION FROM ULTRAVIOLET (UV) IN DAYLIGHT

Country of residence: UK

			· · · · · · · · · · · · · · · · · · ·
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			
29. Over the last 7 days, what is your best gue			
many days it has been sunny for at least h	nalf the day?		Days (out of 7)
30. Thinking about a typical day in the last 7 of	days, what is yo	our	
best guess on average for the <u>number of</u>		e spent	hours per day
outside in daylight (with or without UV pr	otection)?		
		- Alice	
31. We know it can be difficult to protect aga			Never
Over the last 7 days when you went outsi protect yourself against UV?	de how often d	lid you	rarely
(Please circle the answer)			sometimes
A to commission distancement includes the control of			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
33. Over the last 7 days, when at home to wh	at extent have	you	Not at all

stayed in rooms with UV protection		rarely		
(Please circle the answer)	sometimes			
	often			
		always		
	T-1	5. [6]		
34. Is there UV protective window film on windows at school or work?	ASSESSMENT TO	is film on:		
(Please circle the answer)	ALL windows			
,	SOME windows			
	NO windows			
	I don't know			
	I don't work or go to school			
	outsid	le 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)	sometimes			
	often			
	alway:	S		
36. Do you have UV protective window film on your car's	There	is film on:		
windows?	ALL windows			
(Please circle the answer)	SOME windows			
	STORY STORY OF STORY OF STORY STORY			
	NO windows			
	I don't know			
	I don't have a car			

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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.....

OVEN	IIIL LA	J /	וחע	<u>J</u>				
37. "Avoid	ing going	outsi	de dur	ing the	day wa	s som	ething I did	
automo	atically wi	I did not avaid noise						
								I did not avoid going
	1	2	3	4	5	6	7	outside
Strongly Disagree Strongly Agree								
38. "Every time I got ready to go outside, wearing a face visor was								
someth	ning I did d	utom	aticall	y with	out think	king"		I did not wear a face
								TO STATE OF THE PROPERTY OF TH
	1	2	3	4	5	6	7	visor
Strongly D	isagree						Strongly Agree	
39. "Every time I got ready to go outside, wearing a hat was								
someth	ning I did d	utom	aticall	y with	out think	king"		
								I did not wear a hat
	1	2	3	4	5	6	7	
Strongly D	isagree						Strongly Agree	
40. "Every	time I got	ready	to go	outsia	le weari i	ng gla	isses was	
someth	ning I did d	utom	aticall	y with	out think	king"		I alial massaam
								I did not wear
	1	2	3	4	5	6	7	glasses
Strongly D	isagree						Strongly Agree	
41. "Every	time I got	ready	to go	outsid	le, wear i	ing su	nscreen was	
someth	ning I did d	utom	aticall	y with	out think	king"		I did not wear
	1	2	3	4	5	6	7	sunscreen
Strongly [Disagree						Strongly Agree	

	y time i go	read	to go	outsid	e, wea i	ing lip	sunblock was	
something I did automatically without thinking"							I did not wear lip	
		_			_		_	sunblock
c	1	2	3	4	5	6	7	
877 (80)	Disagree		5000 • Maria 10194 Pro.		Accompanya and a second	· ·	Strongly Agree	
43. "Every time I got ready to go outside, wearing a scarf or "face buff" was something I did automatically without thinking"								
bujj	was some	ning i	aia au	itomati	cany w.	tnout	ninking	I did wat was a
	1	2	3	4	5	6	7	I did not wear a scarf or "face buff"
Ctus a al	1 Disagree	2	3	4	Э	ь	7	scari of Tace buil
Strongly	Disagree						Strongly Agree	
44. "Evei	ry time I go	t read	to go	outsid	e, wea i	ing a h	noodie (worn up)	
	something l	0.5	-			NO. 100 P. C.		
	· ·							I did not wear a
	1	2	3	4	5	6	7	hoodie (worn-up)
Strongly	Disagree						Strongly Agree	
45. "Every time I got ready to go outside, wearing long sleeves* was								
some	thing I did	autom	aticali	y with	out thin	king"		I did not wear long
								sleeves
	1	2	3	4	5	6	7	Siceves
Strongly Disagree Strongly Agree								
50.01	igiy Disugit	ee					Strongly Agree	
	ry time I go		to go	outsid	e, wea i	ing glo		
46. "Ever		t read;				10000 000		
46. "Ever	ry time I go	t read;				10000 000		l did not wear
46. "Ever some	ry time I go ething I did i	t read;				10000 000		l did not wear gloves
46. "Ever some	ry time I go ething I did	t ready autom	aticali	ly witho	out thin	king"	oves was	KONTONIA SACIARAN SAC
46. "Ever some Strongly	ry time I goo ething I did 1 Disagree	t read; autom 2	aticali 3	ly witho	out thin 5	king" 6	7 Strongly Agree	KOROTOWERS AND REMIET TO RECEIVE AND ADDRESS AND ADDRE
46. "Ever some Strongly 47. "Ever	ry time I got ething I did 1 Disagree	t ready autom 2	3 / to go	y witho	5 e, wea	king" 6 ring lor	7 Strongly Agree	KONTONIA SACIARAN SAC
46. "Ever some Strongly 47. "Ever	ry time I got ething I did 1 Disagree	t ready autom 2	3 / to go	y witho	5 e, wea	king" 6 ring lor	7 Strongly Agree	KONTONIA SACIARAN SAC
46. "Ever some Strongly 47. "Ever	ry time I goo ething I did 1 Disagree ry time I goo etights was	t ready autom 2 t ready some:	3 / to go	y without 4 outsid	5 e, wea tomatic	king" 6 ing lon ally win	7 Strongly Agree og trousers or thout thinking"	gloves
46. "Ever some Strongly 47. "Ever thick	ry time I got ething I did 1 Disagree	t ready autom 2	3 / to go	y witho	5 e, wea	king" 6 ring lor	7 Strongly Agree	gloves I did not wear long

^{*}sleeves would include coats or jackets

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

48. Thinking about all the thin				
past 7 days (e.g., wearing	I did not do			
you think they protected y	anything to protect			
Completely very well	a fair amount	a little	Not at all	myself from UV in the last 7 days

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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 SUNNY.

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.

49. To what extent do you try to avoid	Cloudy days	Sunny days
going outside during the day?	Never	Never
	rarely	rarely
	sometimes	sometimes
	often	often
	always	always

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
	l 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

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When you go outside	Cloudy days	Sunny days
(Please circle the answer)	Cloudy days	Sumy 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	S	
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 yo 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, s 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, s or legs

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

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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 hear	Ith depends on pro	tecting ag	gainst UV"			
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree	
67. "Having i	to protect against	UV worrie	rs me"			
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree	
68. "My life	would be impossibl	le without	protecting ag	ainst UV"		
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree	
69. "If I did n	ot protect against	UV I woul	ld be very ill"			
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree	
70. "I someti	mes worry about o	ther peop	ole's reactions	to the things	I have to do to protect against	
UV (e.g.,	wearing a visor, us	sing sunsc	reen, wearing	a hat)"		
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree	
71. "I someti	71. "I sometimes worry about long-term effects of having to protect against UV"					
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree	

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
73. "My he	ealth in the future	will depen	d on protectin	g against UV	n
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
74. "Havin	ng to protect again.	st UV disru	ıpts my life"		
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
75. "Prote	cting against UV st	ops my he	ealth getting w	orse"	
	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
W. 1977	-	W- 990	1995 200	er ploons er e	
76. "I som	netimes worry abou	it the imp	act on family o	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 <u>YOU THINK</u>.

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.

7. Over the next 7 days I <u>intend</u> to pr	rotect n	nyself b	y avoid	ing goir	ng outside during the daytime
1 2	3	4	5	6	7
Strongly Disagree					Strongly Agree
Strongly Disagree					Strongly Agr

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When I am outside in the NEXT 7 DAYS	<u>.</u>					
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 vis	or					

78. I <u>intend</u> to protect r	nyself by	/ wearii	ng a fa	ice viso	r				
	1	2	3	4	5	6	7		
Strongly D	isagree						Strongly Agree		
79. I <u>intend</u> to protect r	nyself by	/ wearii	ng a h	at					
	1	2	3	4	5	6	7		
Strongly Disagree							Strongly Agree		
80. I <u>intend</u> to protect r	80. I <u>intend</u> to protect myself by wearing glasses								
	1	2	3	4	5	6	7		
Strongly Disagree							Strongly Agree		
81. I i <u>ntend</u> to protect r	nyself by	/ puttin	g on :	sunscre	en				
	1	2	3	4	5	6	7		
Strongly Disagree							Strongly Agree		

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

82. I <u>intend</u> to protect	82. I <u>intend</u> to protect myself by putting on lip sunblock							
	1	2	3	4	5	6	7	
Strongly Disagree							Strongly Agree	
83. I <u>intend</u> to protect	mysel	f by we a	aring a	a scarf	or "face	buff"		
	1	2	3	4	5	6	7	
Strongly Disagree							Strongly Agree	
84. I <u>intend</u> to protect	mysel	f by we a	aring a	a hoodi	e (worı	ո-up)		
	1	2	3	4	5	6	7	
Strongly Disagree							Strongly Agree	
85. I <u>intend</u> to protect myself by wearing long sleeves								
	1	2	3	4	5	6	7	
Strongly Disagree							Strongly Agree	
86. I <u>intend</u> to protect	mysel	f by we a	aring g	gloves				
	1	2	3	4	5	6	7	
Strongly Disagree							Strongly Agree	
87. I intend to protect	mysel	f by we a	aring I	ong tro	ousers c	r thick	tights	
	9200	9200		1942			6501	
	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 <u>confident</u> I could avoid going outside during the daytime								
	1	2	3	4	5	6	7	
Strongly Disa	gree						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.)

VII You are mor misen	u 6 co	50 04:0.	we		te / wwy	o picas	c skip to question 55.)	
89. I am <u>confiden</u> t I could wear a face visor								
	1	2	3	4	5	6	7	
Strongly Disagree Strong					Strongly Agree			
90. I am <u>confident</u> I could wear a hat								
	1	2	3	4	5	6	7	
Strongly Disagree							Strongly Agree	
91. I am <u>confident</u> I	could w e	ear glass	ses					
	1	2	3	4	5	6	7	
Strongly Disagre	ee						Strongly Agree	

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

92. I am confident 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 93. I am confident I could put on lip sunblock 1 2 3 4 5 6 7	
93. I am <u>confident</u> I could put on lip sunblock 1 2 3 4 5 6 7	
1 2 3 4 5 6 7	
Channels Discours	
Strongly Disagree Strongly Agree	
94. I am confident I could wear a scarf or "face buff"	
1 2 3 4 5 6 7	
Strongly Disagree Strongly Agree	
95. I am <u>confident</u> I could wear a hoodie (worn-up)	
1 2 3 4 5 6 7	
Strongly Disagree Strongly Agree	

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96. I am <u>confident</u> I could w e	ar long	sleev	es			
1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree
97. I am <u>confident</u> I could w o	ar glov	es				
1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree
98. I am <u>confident</u> I could ea	sily wea	ar long	trouse	ers or th	nick tigh	nts
1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree
Overall in the NEXT 7 [99. I am confident I can do t			nt to d	o to pro	tost m	volf from LIV
1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
About your XP and the						- IV
						around you with your UV protectio
No support hardly any	suppor	t So	ome su	pport	lots o	f support comprehensive support
101. How satisfied are you	ı with th	ne sup	port or	help th	at you	have to help you with your UV
protection?						
Very dissatisfied	fairly di	ssatisf	ied	uncert	ain j	fairly satisfied very satisfied
		<		~		~
Y	OU'RE YO			HE FINA OST FI		

Appendix 3.

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:

102.	"Thinking about the futur	e is pleaso	ant to	me"				
	1	2	3	4	5			
	Very true of me				Very untrue of me			
103.	"When I want to achieve .	something	g, I set	goals	and consider specific means of			
re	aching those goals"							
	1	2	3	4	5			
	Very true of me	-	3	87.0	Very untrue of me			
104.		adlines an	d doin	a othe	r necessary work comes before			
	night's play"			9				
	1	2	3	4	5			
	Very true of me				Very untrue of me			
105.	"It seems to me that my f	uture plar	ıs are	pretty	well laid out"			
	1	2	3	4	5			
	Very true of me				Very untrue of me			
106. "I think that it seems useless to plan too far ahead because things hardly ever								
come out the way you planned anyway"								
			~		_			
	1	2	3	4	5			
	Very true of me		2000au 270a	00000 NI -10000	Very untrue of me			
107.	"If I do not get done on ti	me, I do n	ot wo	rry abc	out it"			
	1	2	3	4	5			
	Very true of me				Very untrue of me			
108.	"I try to live one day at a	time"						
	1	2	3	4	5			
	Very true of me	2	3	-	Very untrue of me			
109.	<u> </u>	ortant to e	enjov v	what v	ou are doing than to get the work			
do	one on time"		• •		5			
				121				
	1	2	3	4	5			
10/10/100	Very true of me				Very untrue of me			
110.	"I do not do things that a	re good fo	r me i	f they	do not feel good now"			
	1	2	3	4	5			
	Very true of me				Very untrue of me			

			_	_		:	2
н	D	D	е	n	а	ix	3

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 been feeling	g optimisti	c about the future"						
1	None of the time	Rarely	Some of the time	Often	All of the time				
440	/// 1 2 5 C 1'	C 111							
112.	"I've been feeling	g useful"							
No	one of the time	Rarely	Some of the time	Often	All of the time				
113.	"I've been feeling	g relaxed"							
No	one of the time	Rarely	Some of the time	Often	All of the time				
114.	114. "I've been dealing with problems well"								
No	one of the time	Rarely	Some of the time	Often	All of the time				
115.	"I've been thinki	ng clearly"	,						
j	None of the time	Rarely	Some of the time	Often	All of the time				
116.	"I've been feelin	g close to d	other people"						
ı	None of the time	Rarely	Some of the time	Often	All of the time				
117.	"I've been able t	o make up	my own mind about	things"					
N	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.

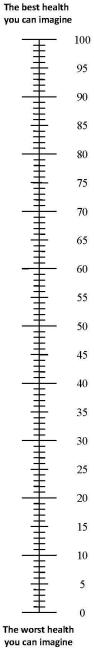
Under each heading, please tick the ONE box that best describes your health
TODAY.

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

We would like to know how good or bad your health is TODAY.
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.
Now, please write the number you marked on the scale in the box below.

123. YOUR HEALTH TODAY =



Appendix 3. Participant study code	 -	Country of 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 please write in		African		
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				
	thts or	comments please can you write	them I	here:

THANK YOU VERY MUCH FOR COMPLETING OUR QUESTIONNAIRE.