

Supplementary Document 2: Adult interview topic guide

Topic guide for qualitative interviews

Introduction

We are having this conversation to find out what it is like living with XP. We are interested in your views and understanding XP from your perspective. There are no right or wrong answers.

The interview is confidential and when we write up the study any quotations that we use will be anonymous and will not be linked to your name. The staff at the XP clinic will not hear your interview and will not know what you have said.

Taking part in the interview is voluntary - you can stop at any time. If you want to stop just let me know. If you want to take a break, just let me know. You can take your time to think about what you want to say – there is no rush.

In the information leaflet we explained that we would like to record the conversation. Is this still OK with you? This is to help us with the analysis.

1. Participants personal story of their/family members XP (Brief)

When did you first become aware of having a skin problem?

When was this first formally diagnosed as XP and how did the diagnosis occur?

How long have you been going to St Thomas' for your XP?

How helpful have you found going to the XP clinic/in what way? (*emotional/clinical management of XP/role of clinic*)

What sorts of treatment have you had at the XP clinic? (e.g., Aldara Cream/surgery)

Do you also see anyone locally about XP? Have they consulted any other types of healers (who/why?) or tried any other remedies – what are these?

2. Psychosocial meanings of XP

Nature of the burden

It will be really helpful to understand what are the main ways it affects your activities, such as work/school/leisure activities/relationships? Have you found ways to reduce this impact over time?

I'm wondering if the impact is always negative? How? (*adaptation & acceptance*)

What changes, if any, have you had to make to your life because of XP? (practical things e.g., working at home)

Do other people understand/support you – in what ways?

How involved are others in helping you cope with XP?

Meanings and emotions

Going back to when XP was diagnosed – what was your understanding of XP at that time? How did you feel about having this condition? How do you feel about it now? Has the way you think about XP changed since you were diagnosed? (*emotions related to XP/change in meaning of XP*)

How does XP effect how you see yourself more generally, if at all? Do you see yourself in a different way because of your XP compared to yourself if you didn't have XP?) (*negative impact on self esteem*) Has this changed at all over time? (*adaptation & acceptance*)

I'm wondering if you feel different to other people who don't have XP or not? How? (*perception of negative difference*) Has this changed at all over time? (*adaptation & acceptance*)

What are your biggest worries about having XP? (*range of emotions*)

(restrictions on activities, feeling different, fears about reactions of others, experience of social isolation/exclusion, fear of cancer, uncertainty about the future?)

Do you worry about what others think about you because of your XP? (family, friends strangers) Have you had any experiences that have made you feel this way or not? (*enacted stigma*)

What things do you do when you feel this way? (*coping*)

We've spoken about how XP affects you- How does XP affect your family and friends, if at all?

3. Photoprotection practices- How are people protecting themselves? (*Normalise non-adherence*).

PROTECTION OUTSIDE

Suncream – how important for you? How regularly use and do you go out without using? Where use on body – mainly face/face and hands? What are the problems with it?

Visors – who made it? Do you wear it going out? Is it comfortable? What are problems with it? How important to use? If doesn't ever use visor: Have you ever worn one? Why did you stop?

Clothing to cover up – do you make special efforts to wear clothing including gloves, long sleeves, long trousers and hats that covers? Glasses? Is this easy or problems? Special UV protection clothing.

Not going out in daylight – whether avoid going out when sunny, how restricts life, problems (for non-burners) of not knowing if daylight having harmful effect?

PROTECTION INSIDE

Do you do any UV protection when inside?

UV light metre – how do you use this? When? What is a safe reading?

Adapting environment – do you have UV filter films on windows of home? Are they also on windows at home/school/ work? Have you tried to get these put on? Do you avoid UV light inside buildings in other ways? How important do you think this is?

CLINIC

Just so I'm clear, are these all things that people at **the clinic have told you to do?** (*probe exactly what they have been asked to do*) Do you do anything else?

TRIGGERS/ PRACTICAL STRATEGIES

Triggers to protect

I'm wondering if there is anything that draws your attention to needing to protect throughout the day? (e.g. weather, heat, eyes streaming/ burning etc.)

Have you worked out systems that work for you? (plans/lists/asking family to help) Do you have any problems in remembering what you should do?

SOCIAL BARRIERS

How do other people react to the things you do to protect against UV? (*enacted stigma*) Can you tell me about your experiences? Are there reasons why you might not do your UV protection? (*anticipated stigma*)

Do you find it easier or harder to protect in different situations? (at work/family/out with friends/ crowded places)

Social support + photoprotection

We know from talking to other people with XP that friends and family can help with photoprotection – do they help you or not?

How do they help? What do they do? Is there anything that they do that you don't find helpful?

What sort of help do you get? Is it directly related to XP or more general support?

Is it enough to know that support is there if you need it?

Do different people give different sorts of support? (*explore sources of support, family, friends, work colleagues*)

Negative social interaction

Do you find the same support always helpful? Are there times when you don't ? why? (*explore change over time*)(*explore conflicting views of XP and photoprotection between patient and family*)

Do you feel supported? (*explore the nature of deficits in support*)

Are there times when friends or family don't help and make photoprotection more difficult? (e.g., *suggesting taking more UV risks*)

Do you talk to others about XP? If not why not? What do you tell them? Do you tell different people different things? What stops you telling them? (*explore disclosure*)

Are there days when it is different? What gets in the way of your UV protection?

Have there been times in the past when UV protection has been harder/easier? Have you changed the different types of things you do over time?

EFFICACY

How effective do you think these things are at protecting you against UV damage?

4. Perception of risk - Why do you think it is important to protect ?
(susceptibility to skin cancer, other skin changes e.g. freckling, other symptoms)

How risky is every day light for you? Are there riskier times of day? Is it the same at different times of year? (clocks going forward) Riskier weather conditions? How important is it to protect in the context of the demands of everyday life? How much do you need to do to have enough protection? Do you think this amount of protection is realistic for you and your life?

Have you had changes to skin because of XP?

Burners: can you tell me about what it is like when you do burn?

Earlier we talked about the treatment you had for skin changes at the clinic, could we talk about this treatment in bit more detail? (perception of efficacy of clinic treatment compared to UV protection)

I'm wondering whether these skin changes (e.g., skin cancer/ burning) effect how you think about UV protection and what you do? How? How long do these changes last? (self/treatment control over XP)

How do you feel about your routine clinic checks? (Are they useful? How do you feel before/ after? Does it change the way you feel about your UV protection after the appointment?)

Close

Before we end is there anything else that you'd like to add that is important for me to understand what it is like living with XP?

Useful phrases for prompting

That is interesting can you tell me more about that?

I'm wondering if..

Let me make sure I have it right..

You mentioned earlier that... can I ask about...

Risk Management

"You have said something that makes be concerned for your safety I need to let someone else know what you've said. I'm going to discuss with Lesley Foster and then speak to your GP and I'll let you know what they advise"

"I notice that you're feeling quite upset, would you like to take a break? We don't want to start again if you don't want to.. Would you like me to contact the clinic on your behalf to see if they can organize some extra support for you?

You can also get in touch with your GP to see what support is available in your local area."