

Development and evaluation of a personalised psychological intervention to improve adherence to photoprotection in adults with Xeroderma Pigmentosum (XP)

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Plain language summary

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Plain language summary

People with xeroderma pigmentosum have a genetic condition that stops their skin repairing damage from ultraviolet radiation, and means they are more likely to develop skin cancers. The only way to reduce this risk is to protect by staying indoors and using items like hats, glasses and sunscreen when outside. People with xeroderma pigmentosum can find it difficult to protect all the time.

We investigated what makes it harder or easier to protect and tested whether an intervention focusing on these things was successful at improving photoprotection. We found that what made protection difficult included doubting the need to protect in different situations (e.g. cloudy weather), concerns about protecting (e.g. looking different) and not having photoprotection routines.

We designed XPAND with our patient and public involvement panel, clinicians and researchers. It involved seven tailored conversations (virtual or live) between a patient and a healthcare professional to identify what motivates them to protect and what makes it harder; we used our studies to create materials (e.g. a magazine describing ways to overcome barriers).

We measured the amount of ultraviolet radiation reaching the face ('dose-to-face') before and after XPAND, compared to a group who did not do the sessions. Our way of measuring was new, using an ultraviolet radiation monitor worn on the wrist and photoprotection recorded in a diary. The XPAND group had lower dose-to-face afterwards than those who did not receive XPAND immediately, suggesting that it could be successful. However, because we were comparing small groups, we cannot be certain that the result was because of XPAND or the group already had a lower dose-to-face. We interviewed participants and they confirmed that XPAND was helpful (photoprotection was more routine and people were more confident). Our assessment of value for money found XPAND patients had lower service costs and similar outcomes to the comparison group.

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This article

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