

Digitally supported total skin self-examination at home for people treated for cutaneous melanoma: developing and simulating experience of the ASICA intervention. Murchie et al

APPENDIX 2: Experience lab outcomes

BENEFITS – “WHAT DO I GET FROM THIS?”: Developing motivation to engage with ASICA and TSSE

Patient volunteers perceived the following advantages of the ASICA intervention: reduced travel and time; having your own skin map (an aide memoire and evidence if needed); speed and simplicity of the process; rapid reassurance when concerned; raised awareness of caring for my skin and empowerment; feels like the medical staff care for me; secure and I can trust the NHS with my information.

COMPONENTS – “NUTS AND BOLTS TO MAKE IT WORK”: Action plans to enable TSSE and maintenance of use of ASICA

THE CUE TO ACTION

The email reminder should be sent at the right time – no point sending it on a Friday evening when the patient will be unable to get a response until the following Monday. It seems sensible, therefore, that these would be sent at the beginning of a week. It was also viewed as sensible to send this to another device/using another mechanism to get round the risk that the tablet may be stored in a drawer between skin-checks.

THE INSTRUCTIONAL VIDEO

The video to be embedded within ASICA had the following aims:

- To introduce self-monitoring
- To incentivise a personal skin check
- To provide persuasion from a credible source
- To provide behavioural instruction
- To demonstrate the required behaviour
- To provide information about health consequences

Comments on the existing video were generally negative. It was described as too long and repetitive and in need of “spicing up.” However at least two of the patient volunteers warned that it needed to continue to be comprehensive.

Particular issues for improvement of the video were:

Provide incentive: There was nothing on the video that suggested participants might expect a better outcome by doing a personal skin check. This incentive does not have to be much – it could just be ‘By doing this you will get early attention to any problems which the clinic can then deal with’ You don’t have to say you will save their lives.

Provide Information: Tell us why we are doing this and what we are looking for at each stage. Give us some information about moles (e.g. where are they most likely to be found). Tell us specifically what the things we are worried about look/feel like. Tell us how long the examination will take.

Have an inspiring voice over: The lady on the video was felt to be monotonous.

Make the background less gloomy: The dark background made the video seem oppressive.

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Make the video less repetitive: Basic techniques should be explained once, i.e. examining skin and feeling for lumps.

Tailor the video: Give a video of a man for men and a woman for women.

Idealised body: Participants generally felt that a model with an “ideal” body was preferable to more realistic appearance.

Presence of moles: The model should have some moles. We should see them examining the moles as we would want them to do in the behaviour. We should also see how the patient would record this information within the intervention. This should be re-emphasis in each section of the video (i.e. after “The scalp” “The head” “The back”.)

Use “point of view” perspective: To differentiate parts of the video where you are looking versus feeling. The video should make it clear that “Looking” and “Feeling” are two very different behaviours. This means that the video should emphasise both behaviours. The video should clearly distinguish between “looking” and “feeling.” The video should show what people might see when they “look.” Similarly, they should be shown how to “feel”. This needs to be tailored to parts of the body – i.e. what are the hands doing when the patient is feeling the back of their legs. Video needs to introduce elements of how to feel for lumps, emphasising those that are practically shown at the training day.

Helpers: The EP day made it clear that people are going to be challenged to examine their back and their scalp. It might be good for the video to introduce the idea of “helpers” and a range of whom these might be – e.g. friends, spouse, carers, parents, children, GPs. It would then be good practice to ask the patients to identify an appropriate helper, a person whom they would most like to involve at recruitment. Perhaps a solution needs to be found for those that can’t identify a helper.

Make the video interactive: Split into sections (e.g. head and neck, arms, legs) so that participants can tailor how they do the examination. It will also be important to structure it this way to facilitate a sequence, so that people can tick sections as they go along. The video, therefore, needs to be structured with reference to the check list which will be on the tablet. We should consider having a separate checklist for each part of the body. There is a need, however, to guard against making the system too complicated.

Consequently a new animated video was professionally produced for incorporation onto the tablet.

THE SKIN MAP

What are the technology options for this? Does it need to be broken down or could it be presented as a whole body or video map. It is likely that patients will need to visit Aberdeen for this to be done. Some of Susan’s findings from the interviews suggest that this aspect of the project will need to be handled sensitively, one patient reported that having the skin map formed was a humiliating experience. Patients suggested that they wanted to be able to mark any concerns directly on their skin maps. They wanted to be able to zoom in to see the detail of the skin map and also to be able to move the photo around, i.e. to see the next body part using the touch screen.

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In consequence arrangements were made at Medical Illustration at University of Aberdeen for each patient to have digital skin map images taken. These were subsequently incorporated onto individual Google Tablets for individual patients.

THE REPORT FORM

The report back form should include options for labelling and a free-text box to explain the outcome, e.g. new mole, new spot, lump, no concerns etc. Patients preferred not to have the option to mark the report urgent – felt that this is something for specialists to decide. Previous report backs should be stored within the app for future reference

PROCESSES – “FLOWS OF INFORMATION”

LANGUAGE

Language used throughout should be chosen with care. In particular, when asking people to perform tasks language should be simple. For example, the term “Personal Skin Check” was perceived as more meaningful, understanding and less daunting to an individual than “Total Skin Self-Examination.” Language needs to communicate what they are being asked to do; why they are being asked to do it; how to do it; what might happen when they do it; what the corresponding consequences and further actions of outcomes is.

TRAINING THE USER

Training eventual participants in the pilot exercise will be key.

The issue of engaging participants with the technology is important. The consensus from the plenary was that patients would be more likely to embrace the use of the technology if it was presented in conjunction with the benefits of using technology and the incentives listed about. (e.g. less travel, more control etc). It will also make sense to introduce the technology used as “just something used in healthcare.” Patients can manage many much more complex activities and equipment than are being proposed here, for example nebulisers, home oxygen and glucose monitoring in diabetes.

The training must, however, show people how to do the intervention. As one specialist has pointed out one of the main purposes of follow-up appointments is to detect nodal disease. For this reason the individual participants should be shown how to examine their appropriate lymph node basins (neck, groins or axilla. These are practical skills that need to be demonstrated and can be reiterated on the video

However, it will be important not to make the assumption that people will manage to use the tablet/technology. Appropriate training will, and should be delivered. It will also be important to recognise that younger people may be more easily able to engage with the technology. Nevertheless there is a danger of making assumptions according to age stereotypes. We should aim for a standardised non-ageist way of introducing the technology and training people in the system. We should guard against training which is patronising and offensive to older people and too sketchy for younger patients leaving them less well informed.

REPORTING TO THE SPECIALIST

Several functions of the intervention are encapsulated within this step. In most cases patients will be feeding back negative findings. This will convey a sense of reassurance to them and

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will, in effect, be the reward for performing the behaviour. In other circumstances a new lesion will be found. In this case, a decision on what is to happen will be available within 48 hours, much quicker than under existing systems. It is likely, therefore that both outcomes will reinforce the behaviour.

There were few concerns from patients about communicating information (including body images remotely). They would assume that security was in place. Technology experts offered “scrambling”, “encryption and “cropping images” as further means to ensure security.

FEEDBACK FROM THE SPECIALIST

When the report (no concern) or issue arising is returned participants would want to receive a “report received” receipt. They felt this should be tailored to reflect how long it would take to get a response. It should also provide a phone number which could be contacted if the patient was concerned meantime.