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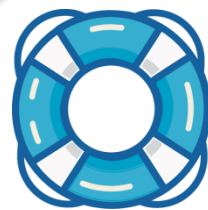
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Eczema Care Online
Self-help toolkit 

What is ECO all about?

Funded by



National Institute for
Health Research

Aims of the Eczema Care Online programme

- To develop interventions to support eczema self-care, and to test their effectiveness compared to standard care
- To provide better evidence to address the safety concerns around the use of topical corticosteroids in eczema
- To explore how to embed interventions for eczema within existing clinical care pathways

Why are we developing Eczema Care Online?

- Eczema causes significant impact on quality of life for many
- Self care for eczema is not easy
 - Regular use of topical treatments is time-consuming and challenging
 - ‘Two treatments used well’, i.e. *regular* emollients plus topical corticosteroids *when required*
 - Concerns and confusion about safe use of topical corticosteroids
 - Additional self-care information needed, e.g. around avoidance of triggers

Eczema Care Online workstreams

- WS 1: Explore support needs and barriers to self-care through reviewing existing evidence and qualitative interviews with people with eczema and their carers
- WS 2: Systematically review evidence on topical corticosteroid safety and create tools to support shared understanding between health professionals and people with eczema
- WS 3: Develop online interventions to help support self-care: one for parents/carers of children with eczema and one for teenagers/young adults with eczema
- WS 4: Determine clinical and cost-effectiveness of online interventions compared to standard care by performing two randomised controlled trials with health economic analyses (feasibility followed by full-scale trials)
- WS 5: Investigate how interventions can be integrated into clinical practice and facilitate their uptake if effective

Eczema Care Online timelines

WS1: Systematic review of qualitative studies around eczema (0-15 months)

Qualitative interviews (0-12 months)

WS2: Systematic reviews of safety of topical corticosteroids (0-15 months)

WS3: Development of two interventions (0-24 months)

WS4: Feasibility RCT of digital interventions (24-33 months)

Two full-scale RCT of digital interventions and within-trial economic evaluations (36-66 months)

WS5: Process evaluation (0 – 66 months)

Implementation and engagement (0 – 66 months)

Eczema Care Online timelines

Phase One 30 months [1 September 2017 to 28 February 2020](#)

Phase Two 36 months [1 March 2020 to 31 August 2023](#) - funding dependent on success of Phase One

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Dermatologists' views of topical steroids

“A major cause of anxiety and barrier to effective compliance is what has been termed ‘corticosteroid phobia’, a phenomenon that causes problems for dermatologists attempting to treat atopic dermatitis with topical corticosteroids...”

GPs' views of topical corticosteroids

“It’s always the stigma of steroid prescriptions which is not helped by my colleagues which still have that unfortunate thing in their head that the steroids are very dangerous and only prescribe hydrocortisone even if the eczema is quite bad.”

“Parents worry about side effects so they go oh, does that mean that they’re going to get- the skin’s going to be thin and they’re going to be prone to infection and is that safe to use on a long-term basis and that sort of conversation.”

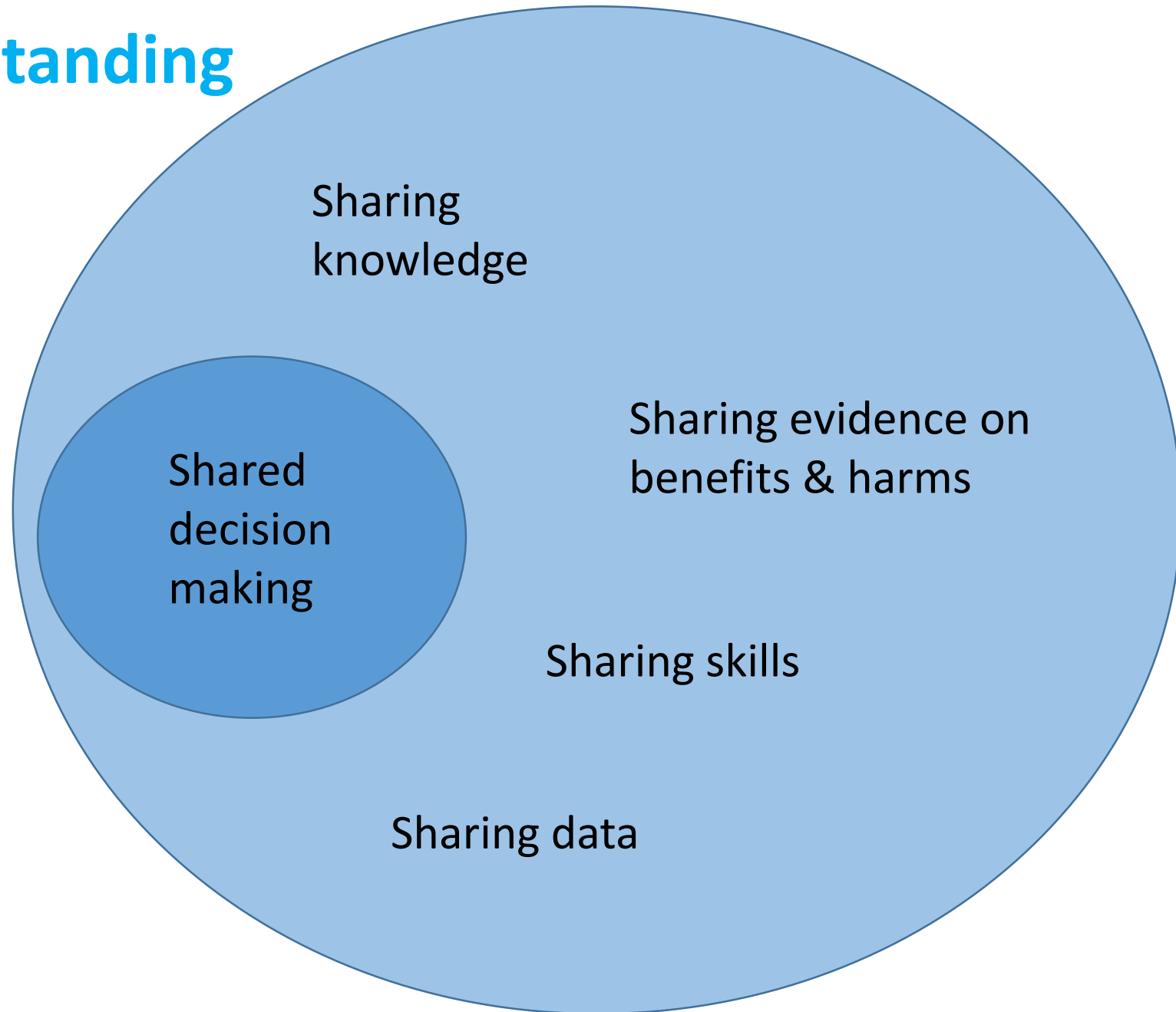
Parents' views of topical corticosteroids

“At one stage, one GP said no, Elocon’s too strong, don’t use that. And then I went back to my other GP because without using it, I couldn’t seem to get to that stage where I could maintain it and that GP was like, no, have the Elocon... It’s hard isn’t it, when you get conflicting advice and then it was even harder when actually I took their advice and then it was not managed well, do you know what I mean? Cause not using the Elocon when it’s bad, just doesn’t work.”

Parents' views of topical corticosteroids

“[Dermatologist] gave me one for the face, cause he has it all round his lips as well, which is not very nice for him and one for his body, but I don't know which one is which; because obviously, I've got so many creams... I haven't got a clue.”

Shared understanding of medicine



‘Shared understanding of medicine’

Actions to deliver real evidence based medicine

- Patients must demand better evidence, better presented, better explained, and applied in a more personalised way
- Clinical training must go beyond searching and critical appraisal to hone expert judgment and shared decision making skills
- Producers of evidence summaries, clinical guidelines, and decision support tools must take account of who will use them, for what purposes, and under what constraints

What does this mean for topical steroids?

Evidence based online and in-consultation tools need to include patients/carers in design and user testing.

Aim is to facilitate discussion between clinician and patient that is more than information transfer by changing the dynamics of the consultation

Shared decision making is about more than tools: skills trump tools, but attitudes trump skills

Concerns about steroids are everyone's problem: GPs, pharmacists, Dermatologists and Derm Nurses, as well as parents/carers and patients

Funding acknowledgement

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Department of Health disclaimer

The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.



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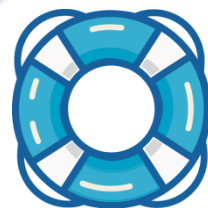
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What is ECO building on?

Funded by

NHS

National Institute for
Health Research

Previous programme grant (Nottingham)

- Setting Priorities and Reducing Uncertainties for the prevention and treatment of Skin Disease (SPRUSD)
- Five work streams:
 - Eczema prevention
 - Eczema treatment
 - Squamous cell carcinoma
 - Vitiligo
 - Pyoderma gangrenosum



SPRUSD
Setting **P**riorities &
Reducing **U**ncertainties
for people with **S**kin
Disease

Eczema prevention

- Overview of systematic reviews of interventions to prevent eczema
 - found very little evidence to support any of the previously tested interventions
 - possible benefit from probiotics given in late pregnancy / during lactation
- BEEP pilot trial – emollients from birth (for 6 months)
 - Preliminary evidence suggesting possible benefit of barrier enhancement
- Led to BEEP main trial (ongoing) – main results due 2019

Relevance to ECO?

- Methodology of overviews of reviews
- Possibly contribute to intervention development (ways of preventing eczema?)

Eczema Treatment

- Priority Setting Partnership
 - Identified top priorities for future research (ECO is now addressing these)
- Scoping review of treatments for eczema
 - 287 RCTs published between 2000 and 2016, covering 92 different treatments
- GREAT Database
 - Online database containing all RCTs and SRs of eczema treatments – updated monthly (814 RCTs and 115 SRs as of 16th August 2017)

Relevance to ECO?

- Overview of current evidence base to inform intervention development
- Topics prioritised as important
- Qualitative understanding of concerns about treatments (from PSP)

Eczema Priority Setting Partnership - ECO

- What is the best and safest way of using topical steroids for eczema: frequency of application, potency, length of time, alternating with other topical treatments, and age limits for treatment?
- What is the long term safety of applying steroids to the skin for eczema?
- Which is more effective in the management of eczema: education programmes, GP care, nurse-led care, dermatologist-led care or multi-disciplinary care?

Other activity relevant to ECO (Nottingham)

- Evidence update alerts
 - monthly updates on the latest systematic reviews
- Annual evidence updates
 - summary of all eczema systematic reviews published in a calendar year (CPD accredited)
- Patient panel
 - active panel with over 30 members with a variety of skin conditions (but mainly eczema)
- Engagement activities
 - Q&A webinar: <https://www.youtube.com/watch?v=aiYuH2kX5XY>
- Harmonising Outcome Measures for Eczema (HOME)
 - Leading development of core outcome set for eczema trials

SPaCE pilot trial (Southampton)

- Funded by NIHR RfPB programme
- Developed an online behavioural intervention for parents of young children with newly diagnosed eczema
- Pilot trial completed
 - 143 patents of children (aged ≤ 5 years) with eczema
 - J Med Internet Res. 2014 March; 16(3): e70. doi: [10.2196/jmir.3035](https://doi.org/10.2196/jmir.3035)
- Results
 - Showed possible benefit, but needs larger study
 - No additional benefit of nurse component

Relevance to ECO?

- External pilot has tested logistics/feasibility of online trial
- Provides template for intervention, which will now be expanded
- Qualitative work to inform intervention development

Eczema epidemiology (Nottingham & London)

- Incidence of eczema
- Eczema triggers
- Co-morbidities and eczema (Wellcome Senior Clinical Fellowship)
- Life course of eczema

Relevance to ECO?

- Provides evidence to support intervention development:
 - Most eczema starts in first year of life
 - Large proportion of patients continue to experience symptoms into adulthood
 - Triggers for flare (nylon clothing, dust, unfamiliar pets, sweating and shampoos)

Eczema RCTs and GP information needs

- NIHR Fellowship – Written Action Plans, qualitative interviews with GPs to establish information needs
- RCTs in primary care – BEE (best emollients for eczema), COMET, CREAM

Relevance to ECO?

- Provides evidence to support intervention development:
 - Possible module on Written Action Plans
 - Identifying info needs of healthcare professionals to inform process evaluation and implementation planning

Health Economics (University of East Anglia)

- Experience of health economic analyses alongside eczema trials
 - SWET – water softeners for eczema
 - CLOTHES – silk clothing for eczema
 - BATHE – bath emollients for eczema
 - TREAT – systemic treatments for severe eczema
- NIHR Fellowship to explore value of information in prioritising eczema research
 - Developing an economic model for eczema
 - Exploring the best quality of life tools to use in eczema trials

Relevance to ECO?

- Health economic analysis and modelling experience in eczema
- Choice of outcomes in RCTs

What does this mean for ECO?



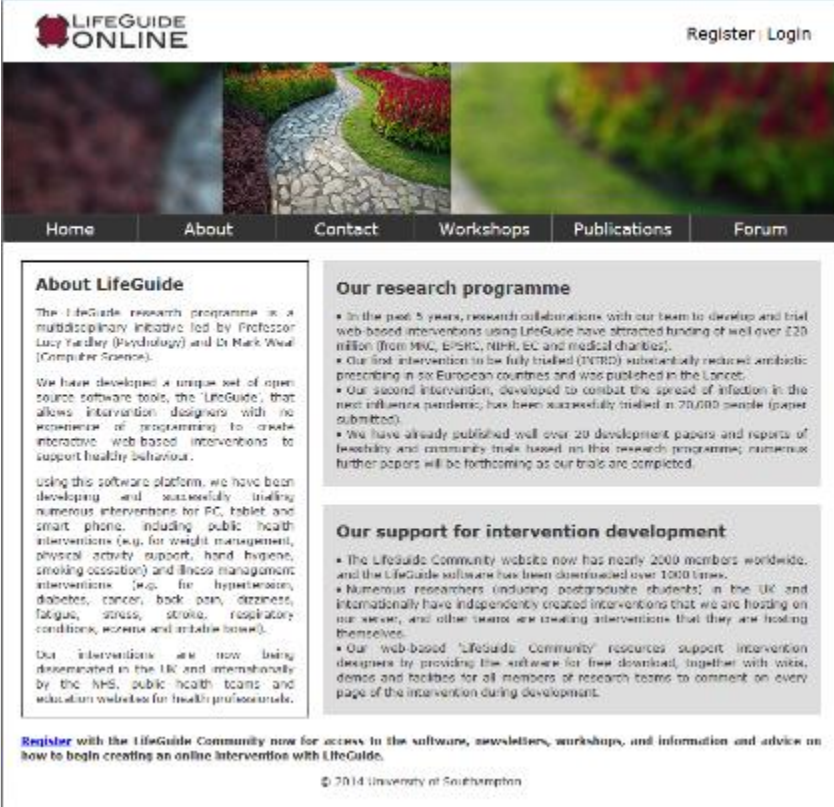
Introducing LifeGuide

Introducing LIFEGUIDE ONLINE

- Suite of software tools for **creating, modifying, disseminating, and evaluating** web-based materials and interventions
- Can be used by anyone – **no programming experience** required!
- Allows you to easily **share** web-based materials with other colleagues or **modify** materials for use in other contexts
- Free and open-source
- For more info: www.lifeguideonline.org

Advantages of LifeGuide

- ✓ **Low cost:** reduces time and effort caused by duplication of programming for individual interventions, provides opportunities for researchers/teams with limited funds
- ✓ **Flexibility:** allows for iterative development and modification to suit varied or changing research needs
- ✓ **Collaboration:** LifeGuide Virtual Research Environment supports joint development by large or dispersed teams, easily share intervention components



The screenshot shows the LifeGuide ONLINE website. At the top, there is a navigation bar with the LifeGuide ONLINE logo, a 'Register | Login' link, and a menu with links to Home, About, Contact, Workshops, Publications, and Forum. Below the navigation bar, the main content area is divided into three columns. The left column is titled 'About LifeGuide' and contains text about the multidisciplinary initiative led by Professor Lucy Yardley and Dr Mark Wool. The middle column is titled 'Our research programme' and lists several bullet points about research collaborations, funding, and trials. The right column is titled 'Our support for intervention development' and lists bullet points about the LifeGuide Community website, research support, and intervention development. At the bottom of the page, there is a footer with a registration link and a copyright notice for the University of Southampton.

LifeGuide ONLINE Register | Login

Home About Contact Workshops Publications Forum

About LifeGuide

The LifeGuide research programme is a multidisciplinary initiative led by Professor Lucy Yardley (Psychology) and Dr Mark Wool (Computer Science).

We have developed a unique set of open source software tools, the LifeGuide, that allows intervention designers with no experience of programming to create interactive web based interventions to support healthy behaviour.

Using this software platform, we have been developing and successfully trialling numerous interventions for PC, tablet and smart phone, including public health interventions (e.g. for weight management, physical activity support, hand hygiene, smoking cessation) and illness management interventions (e.g. for hypertension, diabetes, cancer, back pain, dizziness, fatigue, stress, stroke, respiratory conditions, eczema and asthma).

Our interventions are now being disseminated in the UK and internationally by the NHS, public health teams and education websites for health professionals.

Our research programme

- In the past 5 years, research collaborations with our team to develop and trial web-based interventions using LifeGuide have attracted funding of well over £20 million (from MRC, EPSRC, NIHR, EC and medical charities).
- Our first intervention to be fully trialled (ENTRO) substantially reduced antibiotic prescribing in six European countries and was published in the Lancet.
- Our second intervention, developed to combat the spread of infection in the most influenza pandemic, has been successfully trialled in 20,000 people (paper submitted).
- We have already published well over 20 development papers and reports of feasibility and community trials based on this research programme; numerous further papers will be forthcoming as our trials are completed.

Our support for intervention development

- The LifeGuide Community website now has nearly 2000 members worldwide, and the LifeGuide software has been downloaded over 1000 times.
- Numerous researchers (including postgraduate students) in the UK and internationally have independently created interventions that we are hosting on our server, and other teams are creating interventions that they are hosting themselves.
- Our web-based 'LifeGuide Community' resources support intervention designers by providing the software for free download, together with voice, demos and toolkits for all members of research teams to comment on every page of the intervention during development.

Register with the LifeGuide Community now for access to the software, newsletters, workshops, and information and advice on how to begin creating an online intervention with LifeGuide.

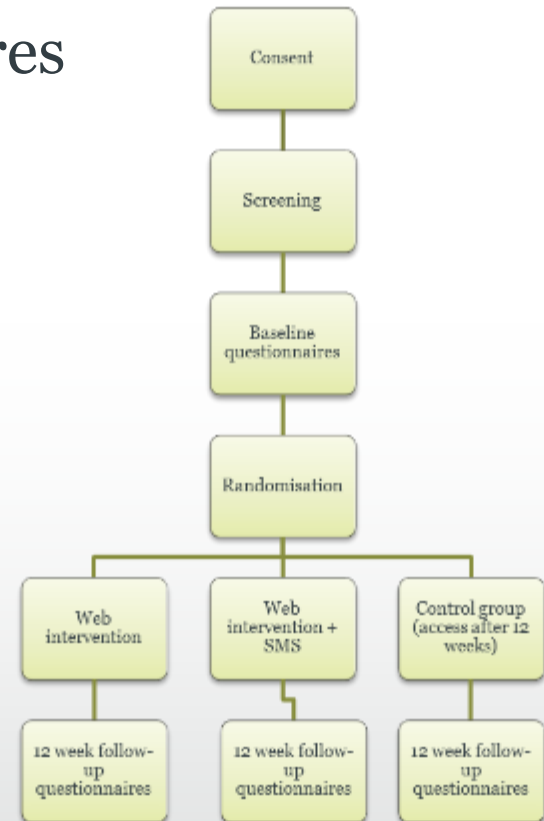
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Data collection / management

1. LifeGuide **automatically** collects information about **how people use the intervention**
 - Number of log ins, duration of log ins, time/date of log in, time spent on individual pages
2. Data entered by the user
 - Questionnaire responses
 - Other data (e.g. diaries, self-assessments, comments etc.)
3. Interventions can be programmed to collect additional data
 - Time spent on particular sections or parts of the intervention

Automate trial procedures

- LifeGuide can **automate** RCT procedures
 - Patient information sheets and consent
 - Screening, baseline, follow up measures
 - Randomisation/minimisation
 - Receipt/adherence – documents all web usage
- Automated **email updates**
 - To researchers (e.g. trial progress)
 - To participants (e.g. invitations and reminders to complete study measures)



Exa



How will the Breathing Retraining Challenge benefit me?

Scientific studies have shown that people who learn **Breathing Retraining** are able to take part in social activities and do more exercise than people who don't. It is **good for everyone** – not just people with asthma – as you learn to breathe more efficiently.

Breathing retraining may help you:

- Feel less wheezy or short of breath
- Do more or walk further without feeling out of breath
- Feel more relaxed
- Feel more in control of your asthma



It may also help you use your reliever inhaler less often.

Back

Click next to find out more about **Breathing Retraining**. If you want to find out more about other non-medicine ways to stay healthy, click [here](#) to go to your homepage.

Next

Back

The Person-Based Approach to intervention development

The Person-Based Approach

- Approach evolved as learning process developing over 25 interventions for public health and illness management
- Based on >1000 qualitative interviews with users, plus evidence from trials of our intervention effectiveness

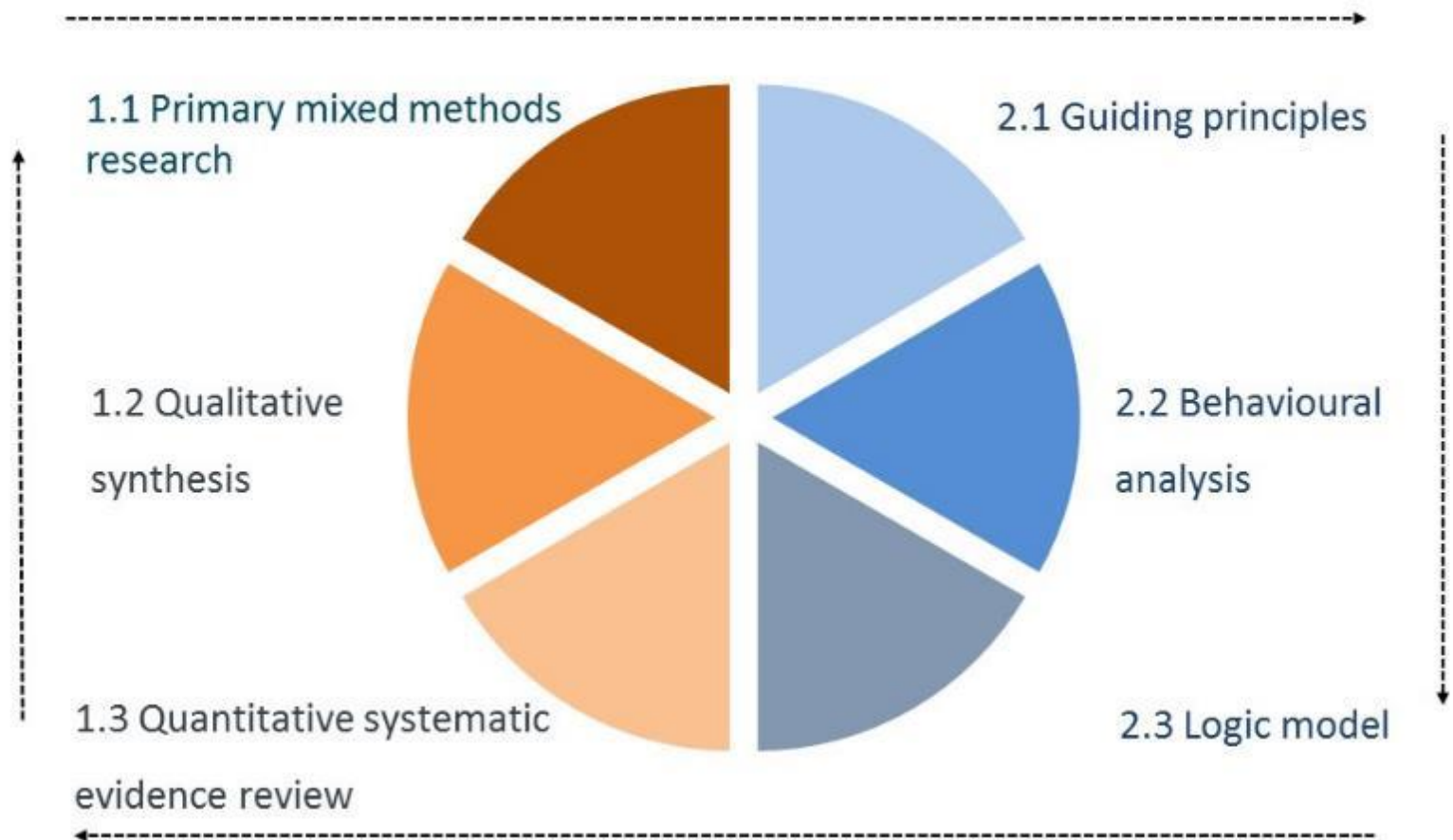
Complements theory-based intervention development by

- suggesting **which** BCTs most important in a particular context
- providing guidance on **how best to implement them**

Combining evidence-, theory- and person-based approaches

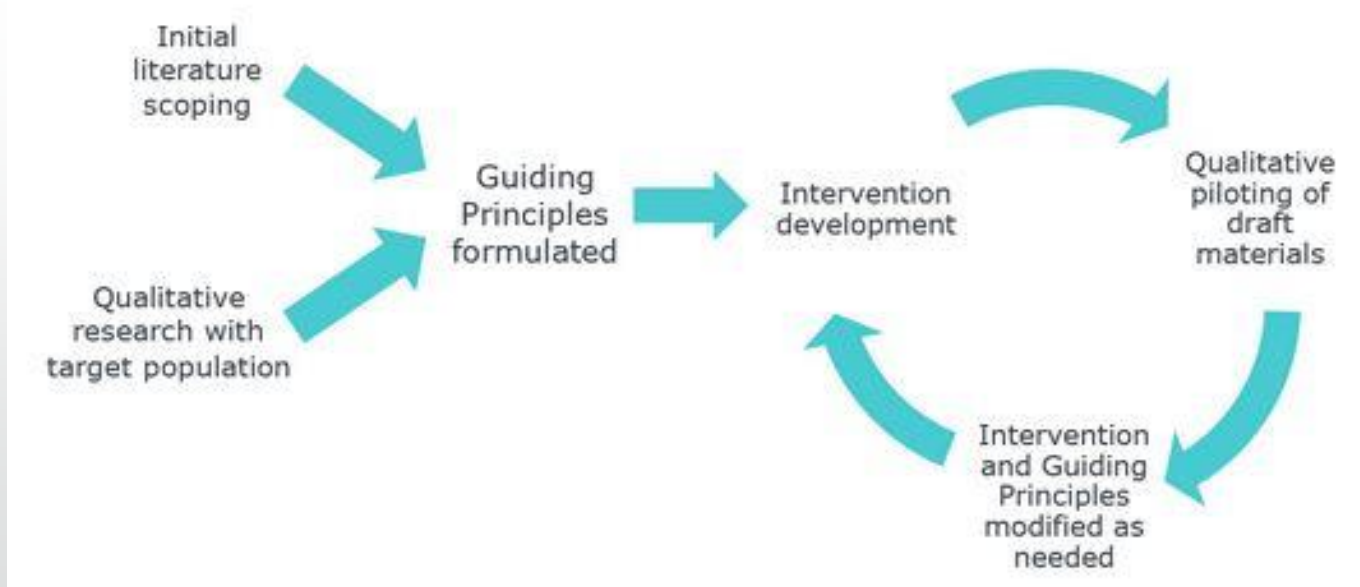
1. Collating and analysing evidence

2. Theoretical modelling



PBA: core methods

- **Iterative qualitative research** with a wide range of people from the target user populations throughout intervention planning, development, and implementation
- Identify 'guiding principles' that can inform intervention development by highlighting key behavioural issues that the intervention must address



Guiding Principles

Qualitative data is used to capture ‘Guiding Principles’ to inform intervention development by highlighting how the intervention will:

- **Identify key intervention design objectives** (based on issues and challenges, and needs identified as crucial to intervention success)
- **Identify key features of the intervention** that can achieve those objectives

Key features could include behaviour change techniques (e.g. goal setting), technology characteristics (e.g. brief modules for mobile phones), implementation setting (e.g. primary care), etc.

Guiding principles common to most interventions

Intervention aim: To promote user autonomy

Key features than can achieve this aim

- offering users choice where possible (e.g. of goals, tools, timing, method of implementation)

Intervention aim: To promote user competence

Key features than can achieve this aim

- providing clear structure and (optional) guidance, examples, stories modelling successfully overcoming barriers, graded goal-setting, minimising conscious effort and lifestyle disruption where possible

Read more ...

- Tutorial paper:
 - “The Person-based approach to intervention development: Application to digital health-related behaviour change”
 - <http://www.jmir.org/2015/1/e30/>

JOURNAL OF MEDICAL INTERNET RESEARCH

Yardley et al

Original Paper

The Person-Based Approach to Intervention Development:
Application to Digital Health-Related Behavior Change
Interventions

Lucy Yardley¹, PhD; Leanne Morrison¹, PhD; Katherine Bradbury¹, PhD; Ingrid Muller^{1,2}, PhD

SPaCE

Supporting Parents and Carers of Children with Eczema





Welcome to SPaCE



Welcome!

This website has lots of information that should answer your questions about eczema and **help you to keep your child's skin healthy**.

As this is your first visit we have collected **core information** about what eczema is and how emollient moisturisers can help your child's skin.

This is **essential knowledge** for anyone looking after a child with eczema. You may find you know lots of this already but we recommend you look through and check.

[Back](#)

[Next](#)



Emollient moisturisers

"The first cream we tried used to sting her and it was a nightmare getting it on her, but we have a different one now that she doesn't mind. Actually sometimes she even asks for it."

Does my child need to use a moisturiser?

Emollients help to:

- Moisturise and soften the skin
- Form a barrier against infection
- Help control itching
- Prevent flare-ups of eczema and damp down the eczema process

Every child is different, but most children with eczema need emollients **at least twice a day**.

Many children will find the emollient soothing, **so it's very important to find one that they like**.



Two week challenge

Two week challenge

The best way for you to find out how much emollient moisturisers can help your child is to try putting them on as much as possible on daily basis.

The two week try-out is **a way you can test this yourself** by choosing an emollient and using it regularly for two weeks to see how much difference it makes to your child's skin.



[Back](#)

Click concerns if you have any worries about the two week try-out

[concerns](#)

Click next to find out more about our two week try-out

[Next](#)



Main menu

Diet and allergy

Topical steroids



Emollient
moisturiser

Talking to your
GP

Starting school

Managing
scratching

Sleep problems

Involving your child

Bath time

Click on any of the units you
would like to read about



You marked this unit as a favourite



You've completed this unit

Avoiding stress for
parents

Washing clothes

Going on holiday

Swimming

Eczema in summer

Eczema in winter

[Click here](#) to meet the SPaCE team

Pictures

Videos

Print sheets

