University of Southampton

Faculty of Medicine

School of Primary Care, Population Sciences and Medical Education

Understanding peoples' experiences and views of acne treatments

by

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Abstract

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Acne vulgaris is a common skin condition that predominately affects young people. Topical treatments are first-line but adherence is poor, and many people progress to long courses of oral antibiotics. The aim of this research was to explore people's views and experiences of acne treatments; to develop a behavioural intervention to support self-management of acne; and to provide preliminary evaluation of this intervention in a feasibility trial.

The intervention was developed using a theory, evidence and person-based approach. A systematic review and synthesis of qualitative literature, and a secondary analysis of 25 qualitative interviews of young people with acne were conducted to explore people's perceptions of acne and its treatments. The findings highlighted that the intervention needed to: build on a feeling of 'control'; acknowledge the psychological impact of acne; address concerns around speed of onset of topicals, side effects and management of these; address confusion about different topicals available; and concerns and necessity around other acne treatments. These findings, along with complementary theory-based activities (behavioural analysis and construction of logic model), informed the development of a web-based intervention (built in LifeGuide software), which was refined through think-aloud interviews with 19 young people.

A feasibility randomised trial of the intervention was conducted amongst 53 people aged 14-25 years recruited through primary care practices. The feasibility trial primary outcome (Skindex-16) response rate was 87% at 4 weeks, 6 weeks or both time-points. Intervention usage data showed a high uptake of core intervention content although uptake for other modules were low. The changes observed in the outcome measures showed that the intervention group reported trends in the direction of benefit however, this will need to be explored further due to the feasibility aims of the trial.

This research demonstrated the feasibility of delivering a trial of a web-based intervention to support self-management for young people with acne. However, more work is needed to enhance engagement with the intervention, recruitment and follow-up rates. Recommendations are presented in the discussion chapter and a pilot study is suggested prior to a full trial. The intervention could support people to manage their acne in a way that avoids resorting to oral antibiotics.

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Declaration of Authorship

I, Athena Ip

declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

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I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;

2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;

3. Where I have consulted the published work of others, this is always clearly attributed;

4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;

5. I have acknowledged all main sources of help;

6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

7. Either none of this work has been published before submission, or parts of this work have been published as:

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Signed:

Date:

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Definitions and Abbreviations

HCPs- Health Care Professionals

QoL- Quality of Life

GP- General Practitioner

RCT- Randomised Controlled Trial

PBA- Person-Based Approach

HERG-Health Experiences Research Group

PPI-Public and Patient Involvement

CAM Complementary and Alternative Medicine

ECSM- Extended Common Sense Model

BCT- Behaviour Change Technique

BCTTv1- Behaviour Change Technique Taxonomy version 1

BCW- Behaviour Change Wheel

ISRCTN- International Standard Randomised Controlled Trials Number

NIHR- National Institute for Health Research

Acne-QoL- Acne Quality of Life Questionnaire

PETs- Problematic Experiences of Therapy Scale

PHQ-4- Patient Health Questionnaire

PROMs-Patient Reported Outcome Measures

BMQ-The Beliefs About Medicines Questionnaire

IPQ-Illness Perception Questionnaire

Chapter 1 Introduction

1.1 Chapter overview

In this chapter, I will provide an overview of the current literature about acne vulgaris (henceforth 'acne') including the prevalence, impact and beliefs about acne and current guidelines about the management of acne in primary care. I will then provide an overview of the current literature on non-adherence to acne treatments and describe existing interventions in this area. This introduction will also include my aims, objectives and the overall structure of this thesis.

1.2 Background

1.2.1 Prevalence of acne vulgaris

Acne is a common inflammatory skin condition involving the hair follicles of the skin. Typical features of acne include seborrhoea (production of grease), noninflammatory acne lesions (open and closed comedones), or inflammatory lesions (papules and pustules) [1]. Onset of acne is typically in early teens as this is the stage when they start to produce facial sebum and facial comedones, followed by inflammatory acne lesions [1]. Around 95% of adolescents are affected within Western industrialised countries [2] and approximately 20 to 30% of those affected develop moderate to severe acne [2]. It is considered a chronic condition that can persist into the 20s and 30s for around 64% and 43% of individuals [1]. Mild to moderate acne is usually managed in primary care and accounts for more than 3.5 million visits to general practice every year in the UK [3]. Whether people seek medical help depends on how they perceive their acne in terms of the severity and the impact of their condition [4]. It has been suggested that 60% of people affected usually seek treatment using over the counter products, some of which are not proven to be effective [5].

1.2.2 Causative factors of acne

The role of Propionibacterium acnes (P. acnes; bacteria found in acne lesions) in the causation of acne is unclear as early studies have found a direct link whereas, other research has found this link to be less clear. For example, a review of studies showed the number of P. acnes in the skin of

people with acne and people without were the same, similarly amongst people with severe acne compared to people with mild to moderate acne [6]. The role of genetics as a risk factor or cause of acne is also unclear, although research has found an 80% chance of developing acne if there is a prevalence amongst first degree relatives [1]. People with a family history of acne are more likely to develop acne earlier on and more severely [1]. The role of ethnicity and acne remain unclear and majority of studies have focused on Caucasian and black skin types [1]. Acne is the most common dermatological diagnosis for both African and Caucasian people [1]. However, people with black skin types are more likely to have post-inflammatory hyperpigmentation and keloidal scarring compared to other ethnicities [7]. Despite this, there is currently no difference in terms of guidelines for acne management between ethnicities [7]. There are a number of studies exploring the therapeutic benefits of diet, washing and sunlight for treating acne [8-10]. However, the research in this area is limited and the majority have methodological limitations. A systematic review exploring the role of diet and acne found that studies prior to 2005 had small sample sizes, no controls, and no explicit follow-up duration [11]. More recent studies have addressed these issues and suggest some association between glycaemic index levels, fat and fibre intake and acne [11]. For example, one study found no cases of acne in native non-Westernised people in Papua New Guinea and Paraguay whose main diet consisted of root vegetables, fruit, fish, and coconut [12]. This led the authors to suggest that a diet high in glycaemic load contributed to acne. Further support for this link comes from a RCT which also found a diet low in glycaemic load could improve acne [13]. Additional research is needed to confirm these associations and account for potential confounders. There is insufficient evidence to suggest that chocolate, salt or iodine intake increases risk of acne [11]. There has also been no association found between natural sunlight or poor hygiene and acne severity [1].

1.2.3 Impact of acne

The impact of acne on individuals is substantial, with both physical and psychological manifestations. Physical symptoms include soreness, itching and pain, but the impact of acne is most prominent on quality of life (QoL) [14]. A meta-analysis of 67 studies including 27 skin conditions, found that although the mean effect on QoL for children with these conditions was small, many children with acne (1-5%) experienced a large effect on their QoL [15]. Case-control and cross-sectional studies assessing the impact of acne on psychological health found higher prevalence of depression, anxiety, psychosomatic symptoms, shame, embarrassment, social inhibition, suicidal ideation, and suicidal attempts [16-20]. It has also been highlighted how acne severity and the degree of psychological impairment do not necessarily correspond as some

people with mild acne may experience significant distress whereas others with severe acne can seem less affected [21]. Several cross-sectional studies have suggested that this is dependent on how a person subjectively measures the severity of their condition and these assessments often differ from clinical findings made by a general practitioner (GP) [22-24]. Furthermore, the impact on self-confidence is greater in teenage years, as this is an important time for building confidence and self-esteem [25]. Effective treatment has been shown to alleviate depressive symptoms which subsequently improved acne specific quality of life [26].

1.2.4 Treatments for acne

Treatment for acne differs from person to person, although an effective regimen can be found for most patients [14]. Guidelines for managing acne in primary care suggest that people with comedonal (non-inflammatory) or mild to moderate acne (inflammatory) should be prescribed topical therapies including benzoyl peroxide, retinoids, and topical antibiotics as first and second line treatments [27]. These are effective at improving control and preventing new lesions when used alone or in combination [28]. A randomised controlled trial (RCT) involving 649 community participants found that topical treatments are similarly effective to oral antibiotics [29]. Despite this, most topical treatments can take up to six to eight weeks to show effect [30], and initial side effects including local skin irritation are common [31].

People who are not responding to topical treatments or have moderate acne, are prescribed oral antibiotics, or combined oral contraceptives for women [27]. If an oral antibiotic is prescribed, then a non-antibiotic topical treatment should also be used to minimise risk of antibiotic resistance [27]. However, a recent database study highlighted oral antibiotics are the most commonly prescribed acne related medications in the UK and, in most cases, a non-antibiotic topical was not prescribed alongside [32]. Reducing oral antibiotics is necessary for decreasing the risk of antibiotic resistance in Propionibacterium acnes which could affect acne treatment, reduce their effects for treating other conditions including healthcare associated infections (e.g. MRSA), and cause a selection pressure on non-target bacteria, leading to antibiotic resistant bacteria to survive and flourish [33,34]. Antibiotic use in other conditions are also contributing to a global burden with antibiotic resistance and this has become a priority for the UK government, European Union and the World Health Organisation (WHO) [35-37]. Alternative treatments to antibiotics should be considered to reduce this risk [34].

If the individual is not responding to treatment, has scarring, severe acne, or significant psychological distress the guidelines suggest that they be referred to a dermatologist for

treatment, such as oral isotretinoin [27]. Oral isotretinoin is an effective treatment for acne although it is associated with many side effects including dry skin, possible mood changes, headaches and risk of elevated liver enzymes [38]. In many countries isotretinoin is only prescribed in secondary care including the UK for a number of reasons including teratogenicity and the need for monitoring [39].

1.3 Overview of literature on non-adherence to acne treatments

1.3.1 Overview of quantitative studies

Studies have shown that non-adherence to topical treatments for acne is a major problem [41] and that discontinuing treatment is associated with a rapid increase in microcomedones, resulting in more acne lesions and subsequent treatment failure [42]. A study of 246 secondary care patients with acne, found that adherence to oral treatments (81%) was better than to topical treatments (59%) [43].

Existing quantitative studies which aim to identify factors associated with non-adherence are limited in number of articles and underpowered sample sizes. A systematic review of 15 studies on acne medication adherence between 1978 and 2013, found risk factors for non-adherence in seven studies [44]. The most common associations were side effects and young age [41,45-48], followed by forgetfulness [41,46,47,49]. A review of 29 studies published between 1990 to 2015 on barriers to acne treatment, found lack of knowledge, confusion about usage, weak physician patient relationship, fear of side effects and cost as reasons for 'primary non-adherence' [50]. This was defined as not collecting prescription or initiating use of their medication. They also found factors associated with 'secondary non-adherence', which they defined as early discontinuation or not using treatment sufficiently. These factors included medication not taken as directed, complex regimens, side effects, busy lifestyles, forgetfulness, inconvenience and psychiatric morbidity [50]. The studies included in the review looked at topical and oral treatments, but it is unclear which barriers were specific to which treatments.

1.3.2 Overview of qualitative studies

Both quantitative and qualitative research is needed to rigorously study a phenomenon. Qualitative research adopts a naturalist, interpretive approach to understanding human behaviour which is important to developing a comprehensive understanding of meanings that people attach to phenomena (e.g. beliefs, behaviours) within their natural setting rather than the

identification of cause-effect relationships [51]. There have been some qualitative research exploring non-adherence to acne treatment [52], views of topical treatments [53,54], oral antibiotics [55] and perceptions of oral isotretinoin [56]. However, many of these studies were carried out in other countries [52,53,56], so may not be applicable to a UK population; and others were only exploring barriers to non-adherence briefly, as their primary focus was on QoL [54] or the psychological impact of treatment [56]. Additional qualitative research would be useful for exploring these barriers further and identifying other factors that can influence behaviour.

1.4 Interventions for acne

Interventions are defined as actions that are intended to improve outcomes or change behaviours [57]. In acne, interventions to improve adherence to treatments are limited. The ones that do exist are not informed by theory or developed using robust methods. Public health and health-promotion interventions which are informed by social and behavioural science theories are more effective than those without a theoretical base [58]. Furthermore, many of the trials testing the effectiveness of these have had significant shortcomings. A systematic review including four trials of mobile and electronic health technology on adherence [59] (text message reminders [60], telephone call reminders [61], an internet-based education tool [62] and an internet-based survey [63]) found that an internet-based survey on a weekly basis was more effective than telephone based reminders. Although promising, they had a small sample size of 20 participants and were not powered to detect significance [63]. This study demonstrates the potential for internet interventions as a cost-effective alternative to frequent follow-up visits. Similarly, the other included studies have small sample sizes ranging between 40 to 61 participants and no power calculations, which may have limited their ability to detect statistically significant differences.

A RCT involving 97 primary care acne patients aged 12 years and above, looked at whether patient education could improve adherence to a topical treatment (adapalene/benzoyl peroxide) [64]. Participants were randomised into three group of adapalene/benzoyl peroxide plus: (1) supplementary patient educational materials (video, information card and information online), (2) additional visits to the GP, or (3) standard care. Adherence was measured using a medication event monitoring system and found that participants who were given supplementary educational materials, had improved adherence compared to other groups [64]. However, there was no statistical testing, limited reporting of recruitment, and no reporting of how the training was developed. The benefit of education interventions is also highlighted in a pilot RCT of 17 patients which found that the group randomised to receive a physical demonstration on appropriate

application of a topical treatment (adapalene/benzoyl peroxide), had improved adherence by 15% compared to the control group [65]. Taking into account patient preferences and simplifying routines has also been shown to improve satisfaction with treatment which the authors suggest may subsequently improve adherence [66]. This finding comes from a 15-day open-label study involving 300 participants with acne aged 12 to 35 years. They found that patients preferred using once daily application (evening) of a pump to dispense their topical (adapalene/benzoyl peroxide) instead of a tube because they perceived this to be easier, cleaner and more convenient [66]. Other potential interventions to improve treatment adherence include: enhanced patient consultations [44]; discussing onset of action [50,67]; and informing patients about the varied quality and bias of online information, including some support groups [14]. These are predominately based on expert opinion due to the limited research evidence. It is important that complex behavioural interventions using robust methods are developed to improve uptake and impact behavior change long-term.

1.5 Summary

The literature suggests the need for further qualitative research to inform the development of a novel intervention to improve adherence to acne treatments. Furthermore, this complex behavioural intervention should be developed using robust methods and encompass the evidence base (including simplification, use of technology, and education to improve self-management of acne) informed by the use of theory. Therefore, my doctoral research follows the Person Based Approach (PBA) to develop an intervention to support young people in self-managing their acne. This approach involves carrying out qualitative research (e.g. reviews, qualitative interviews) at every stage to inform and further refine the intervention [68]. The PBA enables the researcher to incorporate the views and perspectives of the intended user whilst addressing the psychological context of users and their views of the behavioural elements of the intervention [68]. More detail about the PBA is provided in chapter 2.

1.6 Aims and objectives of thesis

The overall aim of this thesis is to explore people's views and experiences of acne treatments, to develop a behavioural intervention to support self-management of acne and provide preliminary evaluation of this intervention in a feasibility trial.

Objectives

- To explore the existing qualitative literature of people with acne, their carers and health professionals around the causes of acne, treatments for acne including potential barriers and facilitators to treatment adherence, and impact of acne.

- To explore young people's experiences of acne and its treatments using secondary analysis of 25 interviews carried out by the Health Experiences Research Group (HERG) at the University of Oxford.

- To develop a web-based behavioural intervention to support self-management of acne informed by theory, evidence and the findings from the qualitative research as per the PBA [68].

- To gather user feedback in terms of participants' thoughts and impressions of the web-based behavioural intervention using think-aloud interviews.

- To explore the feasibility of delivering a web-based behavioural intervention to young people with acne in addition to receiving usual care compared with usual care alone.

Outcomes

- To identify potential barriers and facilitators influencing adherence to acne treatments, in particular topical therapies.

    - To develop a behavioural intervention to promote the appropriate use of topical treatments for acne. The intervention will also provide support for other aspects of acne self-management identified as important in the qualitative studies.

    - The behavioural intervention will potentially support people to manage their acne in a way that avoids resorting to oral antibiotics.

1.7 Structure of thesis

This thesis consists of 7 chapters:

- In chapter 1, I will provide an overview of the current literature on acne and the aims of my thesis.

- In chapter 2, I will describe the methodological approach of my thesis in terms of my ontological perspective and the PBA. I will also provide a brief overview of the methods used within each empirical study.
- In chapter 3, I will present a systematic review and synthesis of published qualitative literature on acne. I will include an introduction about existing systematic reviews in the area, a detailed methods section about the use of thematic synthesis with elements of meta-ethnography, a synthesis of studies, discussion and conclusion.
- In chapter 4, I will present a secondary analysis of 25 transcripts of qualitative interviews with young people with acne collected by HERG at the University of Oxford for Healthtalk.org. I will include an introduction about the strengths and limitations of conducting secondary analysis of qualitative data, methods, key themes identified from the transcripts, discussion and conclusion.
- In chapter 5, I will provide an overview of the intervention development process using the PBA. I will describe how findings from the synthesis and secondary analysis were used to inform the intervention content, discuss how the guiding principles were developed and how behaviour change techniques were mapped onto the Behaviour Change Wheel and the Extended Common Sense Model [69]. In this chapter I will also present the think-aloud interviews, which were used to further refine the intervention.
- In chapter 6, I will describe the feasibility RCT of the web-based behavioural intervention. I will include a brief introduction about feasibility trials, methods, results, discussion and conclusion.
- In chapter 7, I will provide a discussion of the overall findings and include a summary of these in relation to previous research. I will also describe the strengths and limitations of the research in this thesis and implications for future research and practice.

Chapter 2 Methodological approach

2.1 Chapter overview

In this chapter I discuss the rationale and theoretical underpinning of my PhD including my ontological and epistemological perspective and the Person Based Approach (PBA). I will briefly describe the methods used for each empirical study, as some of these are described in detail within each chapter.

2.2 Ontological and epistemological perspectives

To address the aims of my PhD, I applied a pragmatic approach using both quantitative and qualitative methods of data collection and analysis (mixed-methods). There is debate on the difficulty of combining these two methods, because of their epistemological differences influencing how a study is designed, conducted and evaluated [70]. Quantitative approaches are primarily associated with positivist or post-positivist epistemologies, as they often take a 'realist' belief that there is one reality that can be observed or measured, and this is reflected in the tools they use (e.g. surveys, statistics). Qualitative approaches, in contrast, are associated with constructionist or interpretive epistemologies, which suggests a 'relativist' belief that people hold different versions of reality depending on local context (e.g. shaped by culture, gender, age, and so on) [71,72].

In recent years, there has been an increase in the use of a pragmatic approach in the design of mixed-methods research. This approach supports the simultaneous use of qualitative and quantitative methods to address different objectives of the study [73]. The priority of the research is not to depict a 'true' version of reality but rather, produce knowledge that reflects the social context in which it was produced [74]. The knowledge produced has the potential to be valuable for health psychology research, for example contributing to improved public health services and individual quality of life for patients with different conditions [75]. It differs from the critical realist approach which assumes that causes and events must be separated. The assumption underlying this research fits with the pragmatic approach in that people's perceptions drive behaviour which has consequences, and that an understanding of people's perceptions can be transferable in developing an intervention.

Within the pragmatic approach there are a number of design typologies that have been developed to enable researchers to use consistent language when explaining their mixed-methods studies [75]. Many of the typologies acknowledge and address the challenges of 'timing' and 'emphasis' of quantitative and qualitative approaches [75]. For example, timing relates to the order at which each component is carried out and includes sequential designs where the researcher carries out one before the other, or concurrent designs when the researcher carries out both components in parallel. Emphasis is related to whether the research is more focused on qualitative, quantitative or is equally weighted.

For my PhD, it was necessary to apply qualitative methods to understand people's perspectives of acne treatments and quantitative methods to assess the feasibility of a web-based behavioural intervention. Therefore, I adopted a sequential exploratory design [76] as qualitative research was used for study 1, study 2 and study 3, whilst quantitative methods were used in study 4 (see Figure 1).

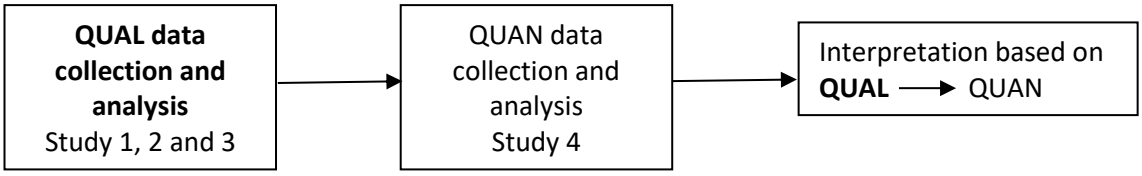


Figure 1: Exploratory sequential design adapted from Creswell and Plano Clark [76]

2.3 Person-based approach

The PBA to intervention development was used to inform my thesis. It is an effective method for developing digital interventions that support people in managing their health and illness [77]. It is referred to as the 'person-based' approach as it incorporates the views and perspectives of the people who will use the intervention [68]. The PBA incorporates traditional approaches including theory-based and evidence-based approaches. Theory-based approaches are useful for providing a framework that can predict and describe factors that are likely to influence behaviour [78] and these can be mapped onto behaviour change techniques [79]. The PBA goes further by addressing the psychological context of users and their views of the behavioural elements of the intervention via detailed iteration to understand practical barriers and issues (e.g. using think-aloud interviews). This approach has been used to create and evaluate a number of interventions for a range of health conditions including asthma [80], emotional distress [81], diabetes [82], dizziness [83], low

back pain [84] and hypertension [85]. Numerous trials of these interventions have been conducted and demonstrate the effectiveness of this approach [86-89].

The PBA consists of two core methods: the first method involves carrying out qualitative research at every stage of the developmental process; the second method involves creating guiding principles (see Figure 2). The qualitative research at the intervention planning stage usually involves a qualitative literature review and supplemented, if needed, by primary interviews with the target population. A complementary theory-based activity that occurred in parallel was selecting a theoretical framework that would best make sense of the experiences and beliefs of the target population. For the current work the most appropriate theoretical framework for understanding the experiences and needs of this population gathered from both the systematic review and synthesis (Chapter 3) and the secondary analysis of qualitative data (Chapter 4) was the Common Sense Model (CSM) [90]. The CSM describes a process through which people respond to and manage health threats via illness representations [91]. Research conducted in a range of conventional medicine settings provides support for the link between coping strategies and beliefs about illness within the theory [92]. Illness representations comprise of cognitive representations including causes (individuals' ideas about cause of illness), identity (the label or symptom given to the condition), consequences (the impact of their condition), time-line (individuals perception about the duration of their illness) and cure/controllability (belief that the condition can be cured or kept under control). Representations of emotion related to illness include anxiety, fear and worry. Peoples' beliefs and representations influence their choice of coping strategy and outcomes (see Figure 2 for a diagram of the CSM that has been adapted by Cameron and Jago [93]). This theory was further developed into an extension that is relevant to the current work; the Extended Common Sense Model of Illness (ECSM). The ECSM incorporates treatment beliefs about necessities and concerns, as research on the predictors of adherence to prescribed medication found that treatment perceptions were more closely related to coping strategies compared to beliefs about illness [69,94].

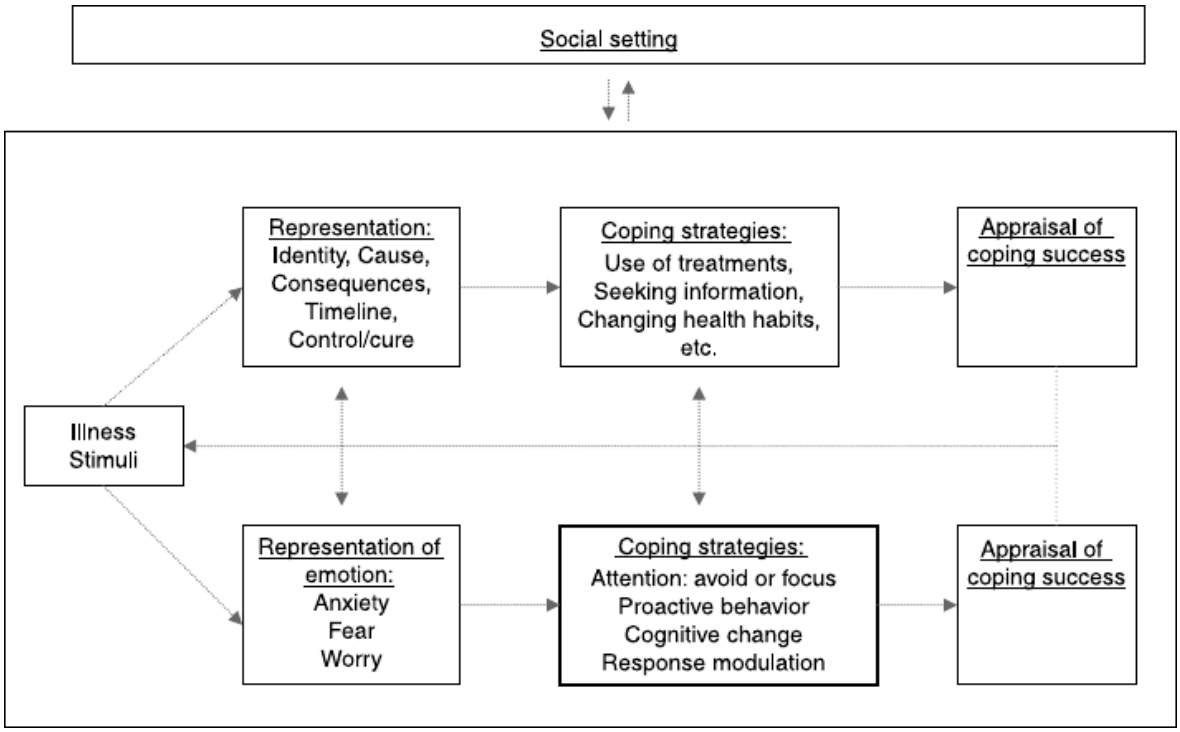


Figure 2: Common sense model of self-regulation from Cameron and Jago [93]

During the intervention optimisation phase, qualitative research is used to evaluate components of the intervention and optimise it from the perspective of the user. This can take the form of think-aloud studies, focus groups, observation, expert panels or interviews. The process evaluation stage involves mixed-methods process analysis to assess the feasibility, acceptability, and effectiveness of the intervention, in addition to identifying further modifications before taking it to a full definitive trial. The guiding principles are created to help researchers inform the intervention development by highlighting the key design objectives and key (distinctive) intervention features intended to address these [68]. The guiding principles are developed in the initial stages using evidence from the literature review and primary interviews and are iteratively developed throughout (see Figure 3).

Theoretical modelling includes creating a logic model and behavioural analysis is carried out alongside the development of the guiding principles. The purpose of the behavioural analysis is to use behaviour change theory to code the intervention content and map it onto the evidence found in the earlier qualitative research [95]. This includes further consideration of theoretical frameworks identified as useful in the qualitative research.

For my thesis, qualitative studies included a systematic review and synthesis of qualitative data, secondary analysis of primary interviews with young people with acne and think-aloud interviews with people using the intervention. I intended to carry out follow-up interviews with participants for the process analysis however, due to time constraints of my PhD I conducted a feasibility trial involving quantitative data analysis only. Guiding principles were developed after the first two qualitative studies and iteratively developed throughout. A behavioural analysis was carried out and is described in chapter 6.

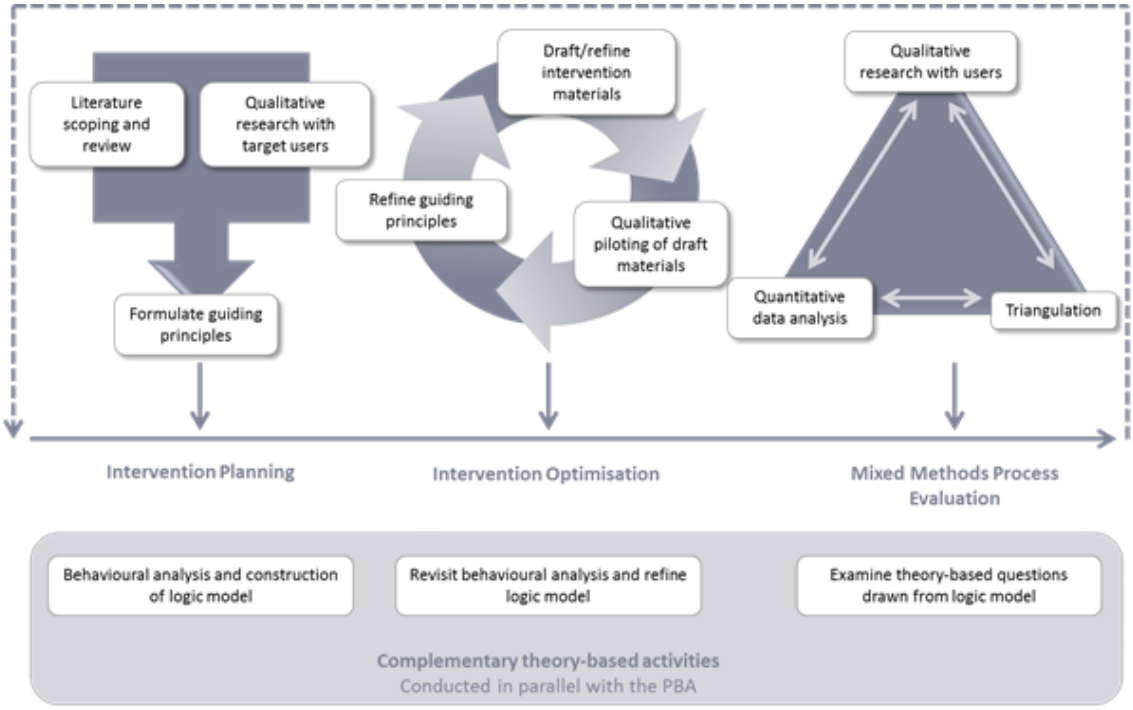


Figure 3: A diagram of the Person-Based Approach from Morrison, et al. [96]

2.4 Method of qualitative data collection in this thesis

2.4.1 Qualitative interviewing

Qualitative interviewing involves one to one communication between the interviewer and the interviewee about their knowledge, experience, perspectives and beliefs regarding a specific topic. Semi-structured interviews are commonly used in qualitative interviewing, and involve the interviewer using a guide which consists of a list of topics and open-ended questions. The questions in the guide can be altered to suit the interviewee in terms of order and phrasing. Qualitative interviews can also be unstructured in-depth interviewing which is the process of conducting intensive individual interviews that are primarily guided by the participant's perspectives [97]. Qualitative interviewing is a method widely used by researchers with different epistemological perspectives, as it is an effective method for understanding and exploring participants' views and experiences of a particular topic.

For my first qualitative study (described in chapter 4), I carried out a secondary analysis of interview data collected by the Health Experiences Research Group (HERG) at the University of Oxford. Although this was a secondary analysis, the transcripts were from semi-structured face-to-face interviews with young people with acne. These interviews enabled me to understand the social and psychological factors which are likely to influence people's non-adherence to acne treatments.

For my second qualitative study (described in chapter 5), I used think-aloud interviews with young people on the SPOTless intervention. This method is often used to evaluate websites as it enables usability experts to see how people are reacting to it [98,99]. It involves the researcher observing the participant using the intervention whilst saying their thoughts aloud. The face-to-face nature of this method enabled me to observe what participants were exploring in terms of the modules chosen and the way they navigated through the intervention. This enabled effective modifications to be made to the intervention from the user perspective.

2.5 Methods of qualitative data analysis in this thesis

There are a number of available methods to analyse qualitative data. Some of the methods can be used by researchers of any epistemological position whilst others are underpinned by specific theoretical or epistemological positions. For example, thematic analysis and framework analysis can be used multifariously depending on the research question and can be used by people with different epistemological perspectives as there are specific steps detailed about the analytical process [100]. Other qualitative approaches including grounded theory [101], discourse analysis [102] and narrative analysis [103] are underpinned by a theoretical framework and therefore, require researchers to have detailed theoretical knowledge about the approach [100].

2.5.1 Thematic analysis

Thematic analysis is used to identify patterns and themes within qualitative data [100]. Braun and Clarke [100], describe two levels of analyses including semantic and latent. Semantic analysis is when the data is described based on the surface level meaning. In contrast, latent analysis involves an in-depth interpretation of the data to look for underlying assumptions and conceptualisations that go beyond the semantic level. Qualitative analysis can also be carried out inductively or deductively. Inductively is when the themes are generated from the data itself whereas, deductively is when a pre-existing framework or theory is applied before-hand.

For my second qualitative study (described in chapter 4), I carried out an inductive thematic analysis using the six step framework outlined by Braun and Clarke [100]. The steps involved familiarisation of the data by repeatedly reading transcripts, generating initial codes via line by line coding of the data, searching for themes, reviewing themes, defining themes and writing-up the findings [100]. I also generated a coding framework to give definitions and labels to my codes using Joffe and Yardley [104] approach to thematic analysis. Further detail about the methods used can be found in chapter 4.

For my third qualitative study (described in chapter 5), I took a deductive approach whereby I had pre-specified codes based on the objectives of the study that I was coding for within each transcript. The purpose of the think-aloud interviews were to aid intervention development because the interview data were, on the majority, 'surface level' making it difficult to generate latent themes. A table of changes was generated to organise the data and make decisions about modifications to the intervention. This was similar to a coding matrix in framework analysis [105] where participants' responses are inputted into the table under the related code. The steps applied are described further in chapter 5.

2.6 Methods of systematic review and synthesis of qualitative research

Qualitative synthesis involves systematically identifying and collating findings from qualitative studies. As a result, common and divergent themes across different studies can be brought together to develop new understandings and provide further interpretation of the data [106]. Some researchers argue that through synthesising qualitative data, there is the possibility that the original context of the studies may be lost [107]. However, by extracting information including aims, methods used, setting and sample, this can help researchers make judgements about whether the studies included are applicable to their own research [108]. The act of synthesising qualitative studies is useful for generating new theories and ensuring that the findings from the primary studies can contribute to greater understanding of a topic, which in turn may be relevant to policy and practice.

Systematic reviews of quantitative data are well established methods whereas methods for synthesising qualitative data are still developing [108]. Current methods for synthesising qualitative papers include: meta-ethnography [109], thematic synthesis [108], critical interpretive synthesis [110] and textual narrative synthesis [111].

For my first empirical study (chapter 3), I carried out a systematic review and synthesis of qualitative research on acne. I used this method as I wanted to ensure that I had fully identified all

relevant pre-existing qualitative research, in order to inform intervention development. I applied a thematic synthesis with elements of meta-ethnography as the included studies were relatively descriptive with little or no second order interpretations. See below for a description of thematic synthesis and meta-ethnography.

2.6.1 Thematic synthesis

Thematic synthesis is a similar approach to thematic analysis, as it involves the systematic coding of data and generating of descriptive and analytical themes [108]. This method has been used to synthesis qualitative studies in different health conditions including: children healthy eating [108], chronic kidney disease [112] impact of stroke [113] and peritoneal dialysis [114].

There are three stages involved with carrying out a thematic synthesis including: free line-by-line coding of findings from primary studies, organising these 'free codes' into related constructs to develop descriptive themes, and generating new analytical themes [108]. The first stage allows for translation of concepts from one study to another. This often involves coding of data within the results section or in some cases the abstract and the discussion of primary studies. The second stage involves comparing and categorising the 'free codes' by noting down similarities and differences to generate descriptive themes. The third stage involves the researcher going beyond the primary studies to develop new analytical themes by applying their own interpretation to the data [108]. Thematic synthesis allows the researcher to either label codes in terms of their own interpretations or remain close to the codes presented by the author of the primary study. This differs from meta-ethnography, as there is less focus on keeping with the context of the original study. Overall, thematic synthesis is a useful method for synthesing studies which are relatively heterogeneous and for organising synthesis data into themes.

2.6.2 Meta-ethnography

Meta-ethnography as described by Noblit and Hare is a type of interpretive qualitative synthesis [109]. This is a common method for synthesising qualitative papers and has been used to understand patients' experiences with being diagnosed with fibromyalgia [115], patients' needs and concerns of breast cancer [116], patients' experiences of diabetes and diabetes care [107], as well as other health conditions. This method outlines seven-steps for reviewing and synthesising qualitative papers including deciding on a research question, identifying and reading relevant studies, assessing the relationships across the studies, translating the studies into one another, synthesising the translations and expressing the synthesis [109].

This method can be understood by first, second and third order constructs. First order constructs are the participant's thoughts and explanations, second order constructs are the author's explanations/theories of the concept, and third order constructs are new, common themes or further interpretations of the second order constructs derived from the original author. The process of synthesising can be conducted via three different approaches: reciprocal translation, which involves translating concepts across the individual studies into one another to develop overarching concepts or metaphors; refutational synthesis, which is used to explain and explore contradictions across the individual studies; and lines of argument synthesis, involves synthesising explanations across the individual studies to offer a fuller account of the phenomenon [109].

For my systematic review and synthesis of qualitative papers on acne (described in chapter 3), I used a thematic synthesis with elements of meta-ethnography where necessary. This was the most appropriate synthesis for my study as after looking at the papers it was apparent that there were some second order interpretations to warrant using elements of meta-ethnography. The papers were also relatively heterogeneous and included similar and contrasting concepts between them.

2.7 Methods of quantitative data collection and analysis in this thesis

For my final empirical study (described in chapter 6) I carried out a feasibility trial of the SPOTless intervention using quantitative methods of data collection and analysis. A feasibility trial is a small study carried out to determine whether a future, definitive randomised controlled trial (RCT) is warranted and practical to conduct [117]. A review of published pilot and feasibility trials between 2000 to 2001, identified seven key objectives of feasibility and pilot trials including: testing the integrity of the study protocol; gaining initial estimates for sample size calculation; testing questionnaires; testing the randomisation procedure; assessing rates of recruitment and consent; determining acceptability and feasibility of intervention; and determining the most appropriate primary outcome measure [118]. Feasibility trials are useful for identifying trends towards effectiveness [119] although, they should not be used to test hypothesis due to small sample sizes limiting their ability to detect significant differences between groups [118,120,121] .

In my study, data on intervention usage was collected via LifeGuide [122](software for researchers to develop interventions). A series of questionnaires and self-reported outcome measures were also used. Data on the number of practices and withdrawals were presented using descriptive statistics. Linear regression was performed to provide estimates of mean scores with key outcome measures between the groups (with their 95% confidence intervals) at follow up. Significance testing was not carried out as this was a feasibility trial to determine recruitment and retention

rates for the target population; assess the feasibility of randomised controlled trial procedures; document uptake and use of the intervention; and describe outcome measures in terms of completion rates and trends. Quantitative methods allowed me to assess the feasibility of the intervention which is a vital step before a full definitive trial [123].

2.8 Public and Patient Involvement

Involvement, as defined by INVOLVE (national advisory group including people with knowledge, experience and insight in public involvement) is research that is conducted 'with' or 'by' the public [124]. The public being the general public, the patients, relatives/carers of patients, potential patients, people who use the health and social care services, and organisations that represent people who use these services [124]. Public and Patient Involvement (PPI) is beneficial for the public and patients as it provides them with the opportunity to influence their own care and treatment. It is also useful for researchers as they can ensure that the research and design is relevant for the target population. PPI was incorporated throughout my PhD as using both PPI and qualitative research has been highlighted as important for developing complex health interventions [125]. However, there is often confusion between qualitative research and PPI and one is usually prioritised over the other. PBA involves qualitative research with participants from the target population enabling a range of views and experiences to be incorporated. Input from research participants offer a fresh perspective as they have not been involved in the intervention development process and are viewing the intervention materials for the first time. On the other hand, PPI are involved at every stage of intervention development including identifying what needs to be prioritised, as well as influencing the design, conduct and eventual dissemination of research (e.g. [126,127]). Their input ensures that the research is relevant and appropriate to the target user which in turn increases its impact. By combining both PPI with the PBA, it can help to create optimally engaging interventions as it incorporates a range of views from participants and PPI contributors that would not have been possible through PPI or qualitative research alone [125].

Table 1 uses the GRIPP2 short form checklist [128] to briefly describe how PPI was incorporated throughout my PhD. More information about their input and how this informed the intervention will be discussed in subsequent chapters.

Table 1. PPI in my PhD using the GRIPP2 short form checklist

Section and topic	Item
1. Aim	To involve people with experience of acne in the development of the SPOTless web-based behavioural intervention to enhance its usability and accessibility for the target population.
2. Methods	Two people with current acne aged 24 and 26 years were recruited onto the PPI panel. One was recruited via an advertisement on the INVOLVE website and the other through word of mouth. Feedback was provided over the phone or via email, and they were paid £25 per hour for their time. They were involved in various activities including: advising on ways to refine the website after think-aloud interviews; commenting on participant facing documents for the feasibility trial (e.g. information sheets); and commenting on choice of primary outcome measure for the feasibility trial.
3. Results	Comments about the website: Both PPI members commented on the draft website after think-aloud interviews. They provided both positive and negative comments on various aspects including the layout, content and appropriateness of the website for the target population. This enabled the intervention to be further refined before the feasibility trial. More detail about specific comments and subsequent changes are described in chapter 5. Choice of primary outcome measure for the feasibility trial: One PPI member commented on their preference between the Acne Quality of Life (Acne QoL) measure and the Skindex-16 questionnaire as a potential primary outcome measure for the main trial. They opted for the Skindex-16 questionnaire as they found the questions more relevant and had reservations about the Acne QoL measure being associated with pharmaceutical company. These reasons are described further in chapter 6. Comments on participant facing documents for the feasibility trial:

	One PPI member commented on the participant facing materials for the feasibility trial. This resulted in changes to the language on the documents making them more appropriate for the target population. More detail about specific changes can be found in chapter 6.
4. Discussion	Overall input from PPI was useful and impacted the design of the website and feasibility trial materials. It was particularly successful in my project as they were involved during a critical stage of website development. However, there were a number of limitations which could have improved PPI input further. For instance, due to the time constraints of my PhD. I required a rapid turnaround for comments regarding some aspects including the choice of primary outcome measure. This resulted in only one patient providing input. There were also difficulties with organising phone calls with PPIs. For these reasons, the participant facing documents were not amended at the start of the feasibility trial which could have potentially resulted in a better response rate. In future, it may be useful to schedule phone calls earlier to allow for more extensive input.
5. Reflection	Key challenges of involving PPI in this research were time constraints and the process of recruiting them. In hindsight I would have wanted to recruit more PPI to ensure that the input was more representative, however, despite advertising on the INVOLVE website, this age group with acne was difficult to recruit. In future, additional platforms may need to be used to reach this group.

2.9 Contribution of others

For my PhD, a number of people contributed to various tasks including double-screening, data collection and trial management. For example, in my systematic review described in chapter 3, after I had screened all titles, abstracts and, where necessary, full text, Dr Duncan Platt independently screened the papers for eligibility. This is a crucial step in systematic reviews to minimise bias and error, thus improving the quality of the study.

For the think-aloud study described in chapter 5, a medical student (Yasmin Bier-Allen) carried out nine interviews with young people with acne on the draft core materials. She recruited

participants via community advertising at the University of Southampton. This enabled me to make modifications to the website before carrying out ten additional interviews on the website as a whole.

The secondary analysis described in chapter 4 involved a re-analysis of interview data collected by Dr Abigail Mcniven from Health Experiences Research Group at the University of Oxford. The data included rich information about perceptions of acne and acne treatments and, subsequent interviews were not needed to supplement these.

Kate Martinson was employed for two days per week as a trial coordinator for six months on the feasibility trial. She was involved with helping to liaise with primary care practices, sending study packs via Docmail and contacting participants if they returned a reply slip in the initial stages. I was responsible for preparing all study documents, seeking relevant approvals and also the day-to-day running of the feasibility trial.

Chapter 3 Systematic review and synthesis of qualitative research on acne

3.1 Aims of chapter

In this chapter, I will present a systematic review and thematic synthesis of the qualitative literature on acne. First, I will present the rationale for adopting a systematic review and qualitative synthesis methodology and detail the aims of the study. Then, I will describe the methods used to synthesise the data, quality assessment and, present the results and discussions of my findings.

3.2 Introduction

To date, systematic reviews in the area of acne have predominately synthesised quantitative data on its epidemiology and aetiology [129], prevention [130], topical treatments [131], systematic treatments [132], and complementary and alternative medicines (CAM) [133]. Reviews on the epidemiology of acne have summarised its prevalence suggesting that there are higher rates of acne in females compared to males and in primary and secondary students between the ages 11 and 16 compared to university students, although this was based on the population in China [134]. They have also found that skin diseases including acne are the fourth leading cause of nonfatal disease burden in the world [129]. Reviews on prevention have mainly explored the therapeutic benefits of diet, hygiene and sunlight [1,11,130,135-138]. For example, a systematic review in 2009 found some evidence of dietary components increasing acne risk, specifically low glycaemic index (GI) diets [11], but more rigorous research needs to be conducted to confirm this. Recent reviews have found a positive relationship between dairy and acne, although these conclusions need to be drawn with caution as the studies were very heterogeneous and included bias [135,136,138]. There has been no association found between natural sunlight or poor hygiene and acne severity [1]. Reviews on topical and systemic treatments for acne have explored their efficacy, safety and adherence e.g. Dressler, et al. [131] explored the efficacy and safety of maintaining use of topical retinoids in five RCTs. They found that there was a significant improvement in acne lesions in three of the trials however, they concluded that due to the limited number of studies more research is needed to explore this further. In regards to systematic treatments such as oral antibiotics, a recent review has highlighted the importance of having consensus guidelines to support dermatologists with prescribing antibiotics appropriately [139]. Finally, a review exploring the efficacy of CAM found

some low quality evidence for the role of tea tree oil and bee venom in reducing acne lesions however, there is lack of evidence to support the use of other CAMs for acne [140].

Although reviews of quantitative data are important (particularly for assessing the effectiveness of treatments and for establishing the causal links), synthesis of qualitative data is necessary to understand people's experiences, beliefs and attitudes towards treatments for acne, causes and impact. Synthesising qualitative data involves systematically identifying and bringing together findings from individual qualitative studies. This enables researchers to bring together common or divergent themes to generate new interpretations and insights into patient and/or organisational needs, preferences and experiences [106].

To my knowledge, there has been no systematic review synthesising qualitative data specifically on acne. A review published in 2016, collated qualitative research on parental, child and adolescent experiences of chronic skin conditions, with the aim of including papers on acne [141]. However, as the review included a number of different skin conditions, their inclusion criteria were more stringent (only included studies where the population was either children or adolescents) and as a result, no papers on acne were included. Enhancing our understanding of the beliefs and experiences of people with acne will enable us to identify behaviour-changing techniques to improve self-management of this condition.

I carried out a systematic review and synthesis to identify the extent of qualitative literature on acne including views and experiences amongst people with acne, their carers' and health professionals around: the causes of acne, treatments for acne including potential barriers and facilitators to treatment adherence, impact of acne, including psychological sequelae.

I undertook a thematic synthesis [108] with elements of meta-ethnography [109] to analyse the data. Thematic synthesis was chosen as it could be used with most types of qualitative data and is not dependent on the presence of second order constructs. This was important as not all of the papers included in this synthesis had an adjacent second order interpretation. Elements of meta-ethnography were therefore only used wherever possible [106].

3.3 Methods

3.3.1 Search strategy and inclusion criteria

I conducted a search of both general and discipline specific databases via Medline (1946 to 2016), EMBASE (1974 to 2016), PubMed (1996 to 2016), PsychINFO (1806 to 2016) and CINAHL (1981 to

2016) on 03/11/16. Although, PubMed includes Medline, PubMed does not allow for the use of specific search terms and the inclusion of both databases is a useful way of double screening for papers. Other resources, including backwards and forwards citations in Google Scholar, searching reference lists in retrieved papers and contacting authors of key papers were also carried out to increase the likelihood of retrieving all relevant studies. I contacted authors of papers when only an abstract was available to obtain a copy of the full-text or to enquire about the status of publication.

Search terms for each database were developed in collaboration with my supervisors and a research librarian. This involved using the Information Specialists' Sub-Group research filter resource to ensure all terms were covered. The terms spanned across two key areas: qualitative research and acne. Appendix A provides the full list of search terms and Boolean operators used for each database.

The title and abstracts of papers identified from the search were screened for relevance by two independent researchers including myself. Some abstracts identified from the database search that appeared relevant could not be obtained because they were in the process of publication or had no intention to publish. Authors were contacted for final drafts of papers before submission but due to the time constraints, the review had to proceed without them. After relevant papers were retained, the full text was reviewed in detail. Studies were included if they were:

- published papers reporting on studies that used qualitative methods of data collection and analysis
- presented qualitative data either stand-alone or distinct part of a mixed-methods study
- research relating to acne vulgaris where participants were either people with acne, health professionals treating acne or carers/parents of children with acne vulgaris
- studies which considered a number of different skin conditions, including acne

Where papers included a variety of skin conditions as well as acne (eczema and psoriasis), I contacted the lead author to attempt to clarify which findings related to acne. There were no date, age or language restrictions to ensure that all papers on acne vulgaris were included. Where papers were of uncertain relevance, I discussed these with my supervisory team.

3.3.2 Quality appraisal and data extraction

There is debate over the value of checklists in appraising qualitative data and which checklists to apply as there is currently no consensus [142-144]. I felt that it was important to assess the quality of the papers in order to inform interpretation of their findings. The quality assessment criteria used in this study was an adapted version of the Critical Appraisal Skills Programme (CASP) tool for

assessing qualitative data [145]. The authors developed this tool after performing a review of existing quality criteria including the CASP checklist. I decided to use this tool as the questions were appropriate for the purpose of my study and it had been successfully used to appraise qualitative studies in a range of systematic reviews, including those using thematic synthesis and meta-ethnography. This tool consisted of 13 questions including the original CASP ones. Example questions were as follows: "Is the sampling method clearly described?", "Is the qualitative approach clearly justified?" and "Is the analysis appropriate for the research question?". My supervisors (MS and AG) and I independently appraised the included studies and where there was any disagreement, a discussion was had and a final decision was made when we reached a consensus. All studies were included in the review, regardless of whether they were poor quality, as the process of quality appraisal was to systematically examine the strengths and weaknesses of the papers and not as a screening process.

I extracted the author(s), country, year of publication, aims of the study, participants (number and sampling method), skin condition(s), method of data collection and analysis, key concepts presented by author and second order interpretations if any. The key concepts and the second order interpretations were usually found within the results and discussion section of the paper. I then entered verbatim all of the results and discussion sections into QSR's NVivo software version 11. I also checked the abstract and conclusions to ensure that I had not omitted any additional results. In some cases, the papers were not available electronically and therefore I retyped these into word and uploaded them onto NVivo.

3.3.3 Synthesis of findings

A thematic synthesis [108] with elements of meta-ethnography [109] was used to synthesise the findings from each qualitative study. As mentioned in chapter 2, meta-ethnography uses the idea of first, second and third order constructs where first order constructs are the participant's own perceptions, second order constructs are the author's interpretations, and third order constructs are common, new themes or going beyond the original researchers' interpretations across the studies. Many of the retrieved papers appeared to be relatively descriptive with little or no second order interpretations. Therefore, I initially decided to carry out a thematic synthesis with a particular emphasis on the stages of line-by-line coding and generation of new themes. However, upon repeatedly re-reading the papers it was clear that within some papers there were sufficient second order constructs to warrant drawing out third order constructs, so elements of meta-

ethnography were included in the analytical process (i.e. Synthesising studies using both reciprocal and refutational translations where necessary).

After line-by-line coding of the data, I then compared the codes produced across each paper to establish similarities and differences between them. This process enabled me to generate new codes or merge existing codes where necessary. I then entered the new or existing codes into a coding manual documenting the code names, code descriptions and example quotations. Through data meetings with my supervisors (M.S., A.G. and P.L.), I was able to group the codes into subsequent themes and subthemes as seen in Table 3. This was essential as there were a range of views from myself and my supervisory team which helped avoid an idiosyncratic collection of themes. In the next stages of analysis, I drew multiple diagrams and had additional data meetings with my supervisors (M.S. and A.G.) to ensure that the final diagram effectively documented the relationships between the concepts. The diagram was useful in helping to develop a 'line of argument' synthesis, or reconceptualisation of the findings, and sought a fresh way to explain all the data. Second order explanations relating to some but not all of the concepts in my synthesis, were identified from each paper. In the early stages, I repeatedly read the second order extracts and it became clear that the explanations were grouped into three main themes. I began synthesising the explanations within each theme using reciprocal and refutational translations where appropriate.

3.4 Results

I identified a total of 2311 papers from the database search and six from other resources: Medline (n=418), EMBASE (n=646), PubMed (n=497), PsychINFO (n=47) and CINAHL (n=703). In total, seven authors were contacted regarding the publication status of nine papers. One out of the nine papers were accepted for publication and the rest of the papers were in the process of publication or had no intention to publish. Full-text articles were excluded where they were either part of a questionnaire development and therefore provided insufficient information on qualitative methods or qualitative findings, had no original data, were a review, were not about acne or not published. 14 papers were included in my synthesis (Figure 4).

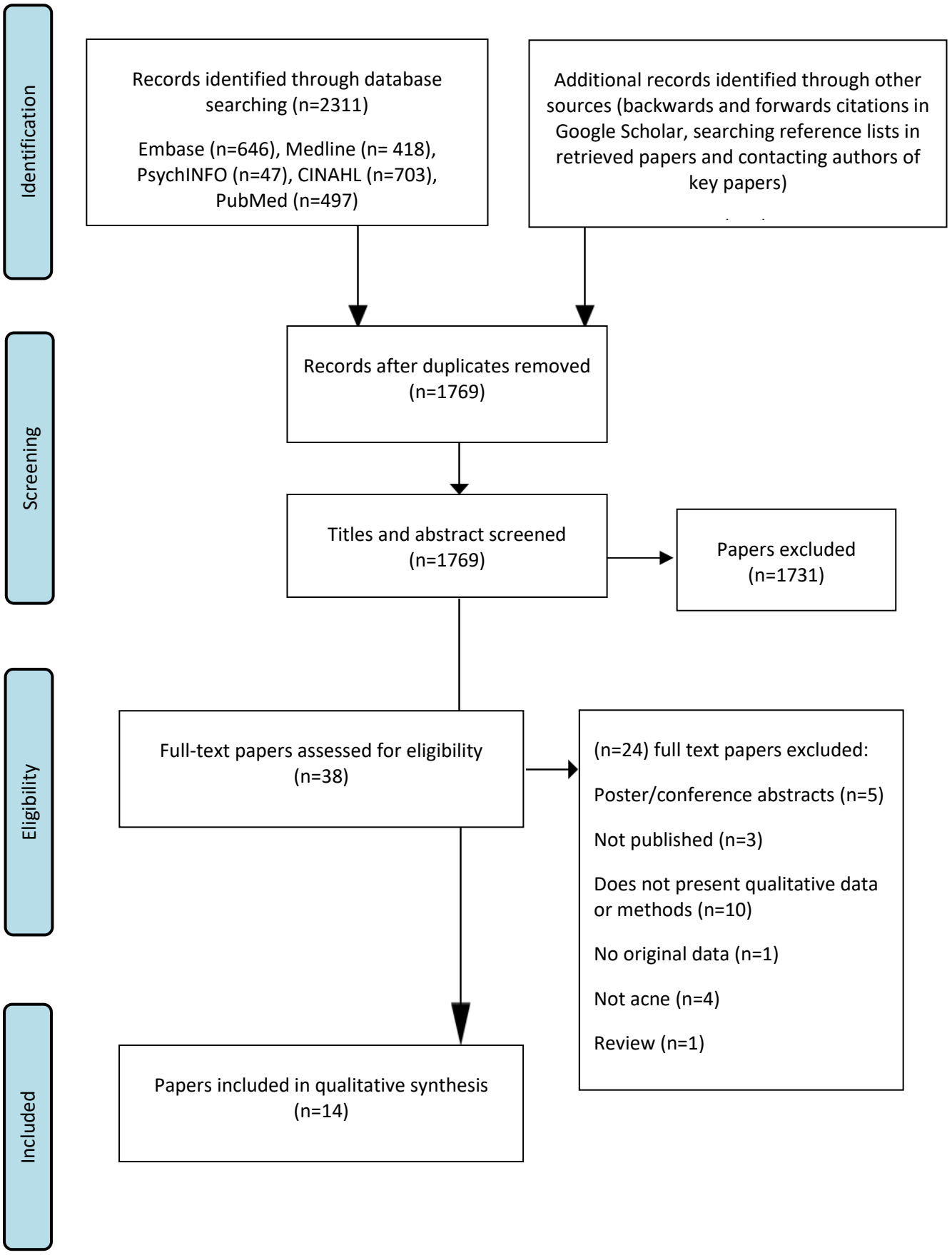


Figure 4: PRISMA flow diagram of the systematic search

3.4.1 Study characteristics

The 14 included papers were relatively heterogeneous in focus. The main topics explored comprised of: perceptions of acne treatments n=2, experiences living with acne n=5, psychological impact of acne n=2, psychosocial impact of acne n=1, CAM n=1, sexual life and acne n=1, patient's relationship with their doctor n=1 and causation of acne n=1. All studies included face-to face interviews with participants apart from Murray and Rhodes [146] who conducted written interview online.

Studies were conducted in various countries including: Australia (n=8), America (n=2), UK (n=3) and India (n=1). It is important to note that eight papers were co-authored by Magin, used participants from the same data set, and five of these included a variety of skin conditions as well as acne (eczema and psoriasis) (see Table 2).

The quality appraisal highlighted several weaknesses that were congruent across the papers. The majority of studies did not report researcher's perspective, disciplinary knowledge and epistemology, qualitative approach or a recognised approach to analysis. This could be attributed to the word count allowed depending on the journal where the papers were published. As the papers varied dramatically in length, the longer articles scored more highly as they provided more information needed for the checklist. A difficulty I encountered was ensuring that the procedure itself was appraised as opposed to the written report, which is a tension reported elsewhere in appraising qualitative studies [147].

Table 2. Characteristics of papers within synthesis

Key: Orange colour coding refers to the papers by the same author

Study (country)	Aims	Participants (sampling)	Skin condition(s)	Data collection and analysis	Key themes presented by author
Skaggs, et al. [53][2] America	To identify key themes and factors that influence the life quality of patients with acne. This study describes patients' personal experiences of acne treatment.	27 young adults with acne (15-21) Single centre (either primary or secondary care)	Acne	Video interviews Not stated	Symptoms; Self-perception; Social placement; and Perception of control.
Magin, et al. [148][3] Australia	To explore the use of complementary and alternative medicine (CAM) therapies in patients with acne, psoriasis, or atopic eczema and the attitudes about CAM therapies.	26 patients with acne, 29 with psoriasis & 7 with atopic eczema (13-73) Primary care, secondary care and community advertising	Acne, psoriasis and atopic eczema	Semi structured interviews Thematic analysis	CAM therapies in acne and CAM therapies for psoriasis and eczema.

Study (country)	Aims	Participants (sampling)	Skin condition(s)	Data collection and analysis	Key themes presented by author
Magin, et al. [149] [4] Australia	To explore the experiences of teasing and bullying in patients with acne, psoriasis and eczema, and the role of appearance-related teasing and bullying as mediators of psychological morbidity in these patients.	26 patients with acne, 29 with psoriasis & 7 with atopic eczema (13-73) Primary care, secondary care and community advertising	Acne, psoriasis and atopic eczema	Semi structured interviews Analytic induction method and modified grounded theory approach	The universally negative nature of teasing; The use of teasing as an instrument of social exclusion; The use of teasing as a means of establishing or enforcing power relationships; Teasing relating to contagion and fear; The emotional and psychological sequelae of teasing; and 'Insensate' teasing.
Prior and Khadaroo [150] [5] UK	To explore the meaning of living with visible acne.	11 young adults with mild-moderate facial acne (18-22) at university Snowball sampling and email to different courses	Facial acne	Interviews Thematic analysis	Coping strategies (Avoidance, avoidance of socialising, avoiding photographs, compensation and concealment); self-perceptions (comparisons to earlier self); and interpersonal relationships (advice and practical support from family).
Murray and Rhodes [146] [6] UK (participants from America, Australia, Britain, Canada, Colombia, Italy & the Pacific Islands)	To detail the salient experiences of adults with severe visible acne, and to set out the implications of these experiences.	11 participants with visible acne (19-33) who visited acne message boards Community advertising (discussion groups and message boards)	Visible acne	Interviews via electronic email Interpretative phenomenological analysis	Powerlessness and the variable nature of acne; comparisons, self-image and identity; the experience of general social interaction; relationships with family and friends; and gender, sexuality; and romantic relationships.

Study (country)	Aims	Participants (sampling)	Skin condition(s)	Data collection and analysis	Key themes presented by author
Magin, et al. [56] [7] Australia	To identify what extent suicide and depression influence patients' decisions to use isotretinoin.	26 participants with acne (13-52) Primary care, secondary care and community advertising	Acne	Semi structured interviews Thematic analysis	Attitudes to 'medical' treatments; Perceptions regarding isotretinoin and adverse effects; Perceptions of psychological effects; and Experiences of psychological sequelae.
Magin, et al. [151] [8] Australia	To explore the experiences of patients with acne, psoriasis or atopic eczema in their relationships with their treating doctors.	26 patients with acne, 29 with psoriasis & 7 with atopic eczema (13-73) Primary care, secondary care and community advertising	Acne, psoriasis and atopic eczema	Semi structured interviews Thematic analysis and modified grounded theory approach	Relationships with GPs and Relationships with dermatologists.
Magin, et al. [152] [9] Australia	To explore the psychological effects of skin disease.	26 patients with acne, 29 with psoriasis & 7 with atopic eczema (13-73) Primary care, secondary care and community advertising	Acne, psoriasis and atopic eczema	Semi structured interviews Thematic analysis	Societal ideal; Role of media; Stigmatization and other psychological sequelae; Appreciation of the falsity of media representations of the ideal; and Male respondents.

Study (country)	Aims	Participants (sampling)	Skin condition(s)	Data collection and analysis	Key themes presented by author
Pruthi and Babu [153] [10] India	To study the physical and psychosocial impact of acne in adult females.	11 female, adult participants with acne (18-25) Primary and secondary care	Acne	semi-structured clinical interview & open-ended questions Not stated	Physical discomfort; Anger; and Intermingling impact of acne.
Magin, et al. [154] [11] Australia	To investigate the psychological sequelae of acne vulgaris.	26 participants with acne (13-52) Primary care, secondary care and community advertising	Acne	Semi structured interviews Grounded theory	Self-perception and social anxiety; central theme: appearance, depression and anxiety; and consequences of the effects of acne.
Magin, et al. [155] [12] Australia	To explore the effects of acne, psoriasis and atopic eczema upon sexual functioning and sexual relationships in the context of a wider exploration of the psychological sequelae of these diseases.	26 patients with acne, 29 with psoriasis & 7 with atopic eczema (13-73) Primary care, secondary care and community advertising	Acne, psoriasis and atopic eczema	Semi structured interviews Thematic analysis and grounded theory approach	<u>Participants with acne</u> The role of appearance and sexual attraction & Gender differences. <u>Participants with psoriasis or atopic eczema</u> The role of appearance and sexual attraction; Effects on body image and self-worth; The unique context of nakedness and intimacy; and Physical aspects of skin lesions.

Study (country)	Aims	Participants (sampling)	Skin condition(s)	Data collection and analysis	Key themes presented by author
Jowett and Ryan [156] [13] UK	To explore how having a skin disease affects occupational, social and emotional functioning.	100 interviewees, 32 had eczema, 38 had psoriasis and 30 had acne (16-79) Secondary care (approached with letter)	Acne, psoriasis and atopic eczema	Semi structured interviews Not stated	Experiences of the disorder (prominent symptoms, the worst aspect? Encountering ignorance and misunderstanding; Employment (Limited opportunities, Functional difficulties. Interpersonal difficulties); Expressive disability (Shame/embarrassment, anxiety, lack of confidence, depression); Interpersonal relationships (family frictions and support, friends, acquaintances and strangers); Daily life and leisure (personal presentation, leisure).
Magin, et al. [157] [14] Australia	To explore beliefs and practice regarding diet, face washing, and sun exposure in patients with acne.	26 participants with acne (13-52) Primary care, secondary care and community advertising	Acne	Semi structured interviews Grounded theory	Beliefs regarding acne causation; Genetic and hormonal influences; Dietary causes of acne; and The role of uncleanliness or dirty. <u>Implications of These Beliefs for Acne Management</u> Dietary manipulation; Face washing as acne therapy; The role of sun and surf; Perceptions of healthy lifestyle; and control.
Koo [158] [15] America	To illustrate the nature of the psychologic distress experienced by patients with acne using verbatim accounts of interviews conducted with these patients.	Not stated	Acne	Interviews Not stated	The psychological effect (decreased self-esteem/self-confidence, problems with body image, embarrassment leading to social withdrawal, depression, anger, preoccupation, confusion/frustration, limitations in lifestyle, difficulty with family members) and Acne and functional status.

3.4.2 Descriptive summary of themes

Four main themes were initially identified from the line by line coding of the papers in NVivo. The themes were derived from first order quotes in the papers and included causes/myths and misconceptions, impact of acne, treatments/coping and demographic differences (Table 3). I will provide an overview of these themes, before going into greater depth regarding the second order interpretations and translating these into third order interpretations.

Causes/myths and misconceptions

The first theme, 'causes/myths and misconceptions', related to the beliefs people held regarding the causation of their acne and included the following subthemes: dirt, diet, stress, myths and misconceptions. Dirt and inadequate washing were spoken about as a causal factor of acne [154,157,158]. Having 'dirty' skin seemed to be viewed as a result of dirty occupations, sweating, oil-based makeup and inadequate washing [157]. These myths and misconceptions regarding acne causation affected relationships as family members were perceived to blame participants for their acne as a result [158]. Myths and misconceptions regarding the contagion of skin disease were spoken about as leading to fears of being judged and stigmatised [154,158]. Unhealthy foods including chocolate, greasy or fatty foods, "fast" or "junk" food, coffee, soft drink, sweet or sugary foods, yeast, fattening foods and alcohol were talked about as potential triggers for acne as people believed that what they put into their body reflected in their skin [157]. Stress was also mentioned as a causal factor for acne, although less common than the role of diet and hygiene [157].

Impact

The second theme, 'impact of acne', included a number of subthemes: physical impact, psychological impact, impact on relationships and avoidance behaviours, perceived control/self-efficacy beliefs, teasing/bullying, feelings of blame, judgment and stigmatisation and perceived impact on personality. The physical impact of acne consisted of itching, decrease in quality of sleep, burning, scaring, redness and pain after popping spots. Many papers referred to the psychological impact of acne in terms of anger regarding its causation, decrease in self-perception and self-esteem, feelings of shame and embarrassment, and an increase in depressive symptoms [53,56,149,154,156,158]. The distress and discomfort led people to withdraw from social gatherings and other aspects of life (employment/school), as well as alter their personality due to fluctuations in their mood [53,146,149,153-156,158]. Psychological impact was further exacerbated by teasing from peers and family members [149,154,157].

People spoke about encountering negative experiences when seeking medical help from their GP or dermatologist. These included feelings of being dismissed and unimportant because of the nature of their skin disease. This reaction left people feeling confused and frustrated about next steps [149,151,158]. Trivialisation of skin disease was also perceived among work colleagues and superiors. Participants said these reactions made them feel as though their condition was not serious enough to warrant time off at work or to see a medical professional [156]. This perceived trivialisation seemed to make participants reluctant to present other problems, including psychological issues to their HCP or people at work.

Treatments/coping

The third theme, 'treatments and coping strategies', referred to: CAM therapies, medical treatments, behaviour and coping, compensation/concealment, advice and practical support from family and comparisons to earlier self and others. CAM therapies were used as a natural treatment for acne and included witch hazel, tea tree oil, aloe vera, zinc and vitamins [56,148,154]. People said they sought CAM therapies in order to gain a sense of control over their acne. They also preferred CAM to orthodox treatments because they were viewed as "natural" as opposed to "chemical" [148]. The use of CAM therapies was usually associated with other healthy lifestyle practices including special diets, face washing and time spent in the sun and sea [154,157]. Some people who used orthodox treatments including topical therapies (adapalene and benzoyl peroxide) said that the treatment made them feel more in control which improved performance at work/school, improved self-perception and reduced feelings of shame and stigmatisation from teasing/bullying regardless of whether their acne had completely cleared or not [53]. These findings should be viewed with caution as the interviewees were participants in a commercial trial testing the effectiveness of this treatment. Trial participants may not be typical in their adherence and engagement with treatments. People who had used oral isotretinoin also said this had improved their mood and confidence, although this was only the case when the treatment was successful, and users also expressed concern about the treatment's side effects, particularly psychological sequelae [56].

Other strategies that studies identified to help cope with acne included altering appearance. This consisted of changing clothing styles to take attention away from acne, growing out hair and putting on make-up to conceal acne [53,148,154]. Support from family members in the form of humour or accompaniment to HCPs was important for people with acne [146,150,156]. Strategies like social or personal comparisons were seen as a double-edged sword used to evaluate people's state of happiness and self-worth. For example, people said that viewing an old photograph where they

had clear skin lowered their mood compared to when they saw a photo where their acne was worse [146,150].

Age and gender differences

Some papers have looked at the role of gender in acne. Specific differences were found in the advice and comments received from friends, control over skincare regimes, comparison to others, romantic relationships and the impact of the media on self-perception [146,150,152,155]. More specifically, females were more likely than males to compare themselves to others [150]. Males in the studies felt that females were more affected by the media and societal ideal of perfect skin [146,152,155]. They also felt that females were fortunate that it was socially acceptable for them to use makeup as a coping mechanism for their acne [146].

None of the papers presented age as an overall theme despite it being referred to in two of the papers [146,158]. One paper found that people felt acne was particularly difficult to manage in their teenage years, as the appearance of acne affected their confidence, contributed to depression and impaired their relationships with the opposite sex. However, as they grew older, they felt better and more secure in themselves [158]. Age was also associated with popular lay health beliefs in that family members felt that participants should have grown out of their acne [146]

Table 3. Contribution of key themes from each study

	Theme Sub-theme	**Summary definition**	**Study reference**
1	**Causes**		
a	Role of dirty skin and hygiene	Dirt or inadequate washing was seen as a causal factor for acne.	14, 11,15
b	Diet	Unhealthy foods were seen as a causal factor for acne (chocolate, greasy or fatty foods, “fast” or “junk” food, coffee, soft drink, sweet or sugary foods, yeast, fattening foods, alcohol).	14,15, 11
c	Myths and misconceptions (sources of information)	Regarding diet, face washing and sun/surf.	14,6, 15
d	Stress	Cause or consequence of acne.	14
2	**Impact**		
a	Physical	Acne physically affected people in terms of quality of sleep, itching, burning, scars, redness and pain after popping.	2,10,11,13
b	Psychological	The psychological impact of acne included feelings of stress, anger, self-perception, shame, embarrassment, self-esteem, depression, anxiety, frustration and self-consciousness.	2 4, 7, 11,13,15

	Theme Sub-theme	**Summary definition**	**Study reference**
c	Relationships and avoidance	Acne affected people's relationships with their family and friends as well as current or potential relationships with the opposite sex.	2,4,6, 10, 11,12,13, 15
d	Perceived control/self-efficacy beliefs	Increased perceived control over acne improved psychological morbidity and was often the reason why people used CAM therapies over medical treatments.	2,3,6,11,14
e	Teasing/bullying	Bullying consisted of other people's perceptions including comments from friends and family as well as antisocial teasing.	4,11,13
f	Employment/school	Acne affected peoples work life in terms of functional difficulties, interpersonal difficulties (insensitive workmates) and career progression (promotions).	13, 15
g	Feelings of blame	People felt blame when the cause of acne was related to diet and hygiene.	5,11, 6
h	Judgment and stigmatisation	People labelled acne as contagious.	4,6,9,11,15
i	Perceived trivialisation by HCPs and others	People felt that GP's and other trivialised their skin condition which made them feel dismissed and unimportant.	4 (eczema and psoriasis), 8, 15, 13

	Theme Sub-theme	**Summary definition**	**Study reference**
j	Role of media (societal ideal)	Perfect skin was often portrayed by the media as the societal ideal which subsequently impacted upon relationships.	9,11, 15
K	Personality	Self-identified as being an 'acne sufferer'. They would alter their personality because of this.	2,6
3	**Treatments/coping**		
a	CAM	CAM therapies were used as a natural treatment for acne (Witch hazel, tea tree, aloe vera, zinc and vitamins).	3,7, 11
b	Medical treatments	Medical therapies were used to treat acne (isotretinioin) but the guidelines and side effects often caused confusion and frustration among users.	2, 3,7
c	Behaviour and coping (face washing/diet/sun/surf)	Face washing and special diets were used as a therapy to keep the acne at bay.	14, 11

	Theme Sub-theme	**Summary definition**	**Study reference**
d	Compensation/concealment	Altering appearance and taking part in activities was used as a coping strategy to keep attention away.	2, 5,11
e	Advice and practical support from family	Support from family helped people cope with their skin condition.	5,6,13
f	Comparisons to earlier self and others	Social comparisons were often used in order to evaluate their current happiness and self-worth.	5,6
4	**Demographic differences**		
a	Gender	Differences between males and females were seen in the advice and comments given from friends, control over skincare regimes, comparison to others, romantic relationships, influence of the media and self-perception.	5,6,9,12
b	Age	Related to myths and misconceptions from family members that people would grow out of it.	6,15

Model in the current synthesis

I developed a model based on the Common Sense Model of illness representation (CSM) [93] as the themes and sub-themes from the synthesis linked closely with the components from the model (See Figure 5). As described in chapter 2, the CSM describes the process in which people respond to and manage health threats via illness representations [90]. The model comprises of illness representations including causes, identity, consequences, time-line and cure/controllability. Representations of emotion related to illness include anxiety, fear and worry about illness. These representations guide coping strategies and subsequent appraisal of these depending on the success or failure of the coping strategies on illness outcome and emotion outcome [90].

Using the CSM provided me with a fresh way to look at the data and understand how people with acne make representations about their illness and emotions, and how these influence their choice of coping strategy.

People's social context and individual differences in terms of gender and age appear to influence their illness representations, which is also linked to their choice of coping strategies. For instance, cognitive illness representations include perceived causes of acne, perceived impact (includes identity) and control (includes timeline). For example, people who believe that their acne is caused by diet or dirt are more likely to engage in behavioural coping strategies such as dietary manipulation or excessive face washing than use medical treatments for their acne. The perceived trivialisation of skin disease by HCPs seemed to influence coping strategies whereby people who felt their GP's to trivialise their skin condition, avoided consulting and used alternative treatments for their skin including CAM/ behavioural strategies. Representations of emotion include worry about side effects from treatments specifically isotretinoin which they coped with through advice and experiences from others who used the treatment.

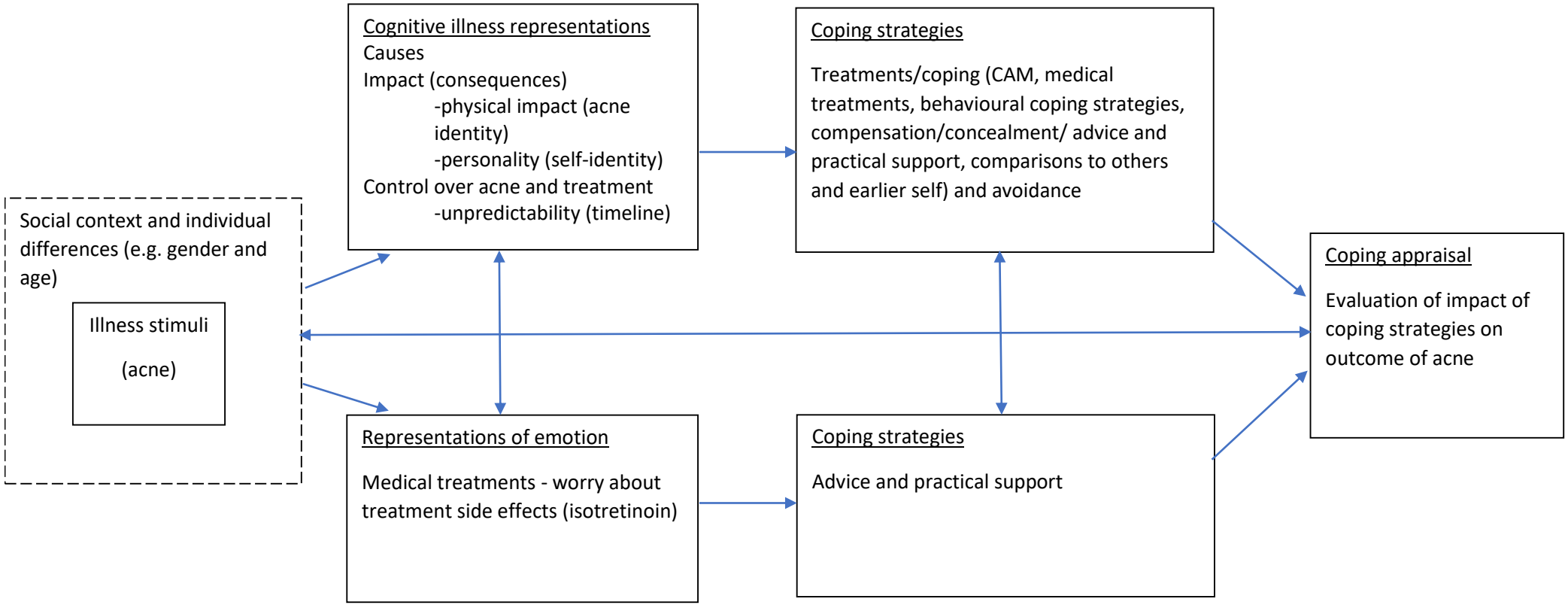


Figure 5: Themes and sub-themes of synthesis data structured to map onto the Common Sense Model [93]

3.4.3 Key themes from second order interpretation

Second order interpretations were identified from the majority of papers apart from Koo [158]. Although many papers contained some second order interpretations, they were generally more descriptive than interpretive and therefore not all of the concepts identified from the line-by-line coding had an adjacent second order interpretation (see appendix B). The second order interpretations are summarised below and can be seen in figure 5.

Feeling of control over treatment (Complementary and Alternative Medicine and medical treatments)

Through reciprocal translation of the studies, it was evident that there were two kinds of perceived control including perception of treatment control and perception of control over acne. The results suggest that even if remedies do not give the latter they can give the former and the psychological sequelae may be less if they have chosen something and it does not work compared to having no control over their treatment and the treatment not working. For example Magin, et al. [148] paper looked at perceptions of CAM therapies in people with acne, eczema or psoriasis and found that people opted for CAM because of the sense of control it gave them over the choice of treatment rather than the control being in someone else's hands (GP) or by chance.

> *The participants with acne used CAM with an expectation of efficacy and a consequent sense of control over their conditions. [148].*

The authors of this paper also found that people who used CAM therapies were more likely to use other self-management techniques including special diets. The relationship between the two were based on the fact that healthy lifestyle and CAM therapies were socially approved, self-performed behaviours that should be rewarded with clear skin. The sense of control or increased self-efficacy experienced when performing these healthy lifestyle practices had the same effect at attenuating psychological morbidity as did CAM therapies [148]. This is congruent with Magin, et al. [154] and Magin, et al. [157] paper which also found an association between control over treatment and CAM/healthy lifestyle practices in attenuating negative psychological sequelae.

Magin, et al. [157] found that although healthy lifestyle practices were based on popular lay health beliefs as opposed to expert knowledge, the sense of internal control afforded by these practices helped people deal with the psychological impact of skin disease.

> *Our study similarly found high levels of belief in myths and misconceptions, but these appear to be associated with an internal locus of control and improved coping with the psychological sequelae of acne. An explanation for these seemingly contradictory findings may be that myths and misconceptions regarding diet, dirt, and sun are based in folk wisdom (independent of educational attainment) rather than in expert knowledge.* [157]

The similarities between these papers could be because they had the same authors and the relationships between the concepts were part of the same schematic model within their paper.

Skaggs, et al. [53] paper provides an additional finding to Magin, et al. [148], Magin, et al. [157] and Magin, et al. [154] papers. In that, regular use of a prescribed topical therapy (adapalene and benzoyl peroxide gel) was also linked with improved mood in addition to improvements in performance at work/school, self-perception and reduced feelings of shame and stigmatisation from teasing/bullying. They postulated that this was because of the increased feeling of control they had over their acne afforded by the medication.

> *The degree to which patients believe their disease or treatment is under their own control can be characterized using a description of internal-external locus of control.* [53]

The differences and similarities between these papers demonstrate the importance of perceived control over treatment and/or control over their condition.

Control over acne

In Murray and Rhodes [146] paper, people spoke about the impact of acne when treatment was not felt to be working. This perceived lack of control over their condition was associated with powerlessness. Participants in this study suffered from severe facial acne and may have construed their illness as being highly symptomatic and therefore having a strong illness identity would have viewed their acne as uncontrollable, chronic and had serious consequences for their lifestyle.

> *The unpredictable fluctuations in the severity of acne over time, and the need to adapt to a constantly changing body-image can, therefore, be seen to cause great uncertainty and disruption in respondents' lives. The lack of control over the trajectory of their health was felt as a form of powerlessness.* [146]

This feeling of 'powerlessness', or loss of control, when treatments were perceived to be ineffective was not explored in face-to-face interviews, possibly partly because this disaffected group may be more difficult to recruit to research studies. Therefore, any possible relationship

between perceived effectiveness of treatments and attitude to treatment adherence or to HCPs remains under-explored.

Avoidance/relationships/personality

Avoidance is mentioned in a number of papers as either a consequence of acne or as a coping strategy. Through reciprocal translation between papers it is clear that avoidance and coping strategies are discussed in a number of ways.

Prior and Khadaroo [150] found that avoidance of socialising was used in conjunction with other strategies including concealment, planning ahead when going out and avoiding photographs. The combination of these strategies appeared to be used differently among participants. Avoidance was rarely used as a coping strategy compared to concealment or planning ahead. The paper mentions that the long term use of these techniques can increase feelings of shame, social anxiety and poor social adjustment. This suggests that social avoidance is inevitable when other coping strategies stop working. The study also highlights an important limitation that it was possible that students who had more severe acne may have dropped out of university due to not coping well. This suggests that people who perceive their acne to be more severe may engage with social withdrawal earlier on than people with mild-moderate acne.

> *Rather, we found that individuals used multiple coping strategies in conjunction with each other (e.g. continuing to socialise, while avoiding photographs and using concealment).* [150]
>
> *While there was some use of avoidance as a coping strategy, more commonly, participants continued to socialise, while using a number of 'subtle safety behaviours' (Thompson, 2005: 66) such as concealment and planning ahead. In the longer term, these safety behaviours are linked to feelings of shame and are typically associated with social anxiety or poor social adjustment (Thompson, 2005). However, in the short term, they enabled the participants to participate in university life while coping with their fluctuating appearance.* [150] (*Note*: Prior and Khadaroo [150] secondary analysis is extending Thompson's secondary analysis)

The point regarding severity of acne and coping strategies is also reflected in Murray and Rhodes [146] paper where they found that concealment was not an effective coping strategy for people with highly visible, severe acne. This was because it was difficult to cover up and therefore led to comments and stigmatisation eventually leading to social withdrawal. This suggests that

concealment may be more feasible for people with mild-moderate acne but it is not an effective coping strategy for individuals with severe acne.

> *However, the highly visible nature of their acne for participants in the present study meant that impression management, at least by attempts to conceal their acne, were largely unworkable.* [146]

The idea of social withdrawal as a consequence of acne is seen in Magin, et al. [149] and Murray and Rhodes [146] paper. Both studies demonstrate the relationship of appearance to avoidance demonstrated in Magin, et al. [154] schematic model of the psychological impact of acne.

As mentioned earlier, how a person views the severity of their condition can influence their perceptions about the consequences of their illness and subsequently affect their choice of coping strategy. Murray and Rhodes [146] found that the identity of an 'acne sufferer' involved doubting self-worth consequently making individuals feel shameful leading to social withdrawal and long-term damage to their self-identity [146].

> *Being an 'acne sufferer' was often the only or most salient identity that could be assumed, and thus social withdrawal was often the result.* [146]

The damage to self-identity is further exacerbated by teasing, bullying and stigmatisation which is a common theme in acne. Magin, et al. [149] found that there were different forms of teasing and bullying that impacted upon relationships with peers. Teasing was used as a way of enforcing social power and as a way of socially excluding people. For example myths about the role of contagion increased stigmatisation amongst people with acne and was used as a legitimate reason to socially exclude individuals [149]. Consequently, the increased damage to their self-identity largely influenced social withdrawal and subsequently their psychological wellbeing.

> *In the schema constructed from this data, the central element in skin diseases producing psychological effects is that of appearance (the physical symptoms, including pruritus, and other aspects of skin disease have little effect). Teasing and taunts have a direct effect on self-image and self-esteem, modifying the effect of appearance (teasing in this study was essentially appearance-based). Embarrassment and self-consciousness (and behavioural avoidance) are consequent effects.* [149]

Myths and misconceptions regarding the causation of acne appeared to lead people to blame themselves for their condition. Some papers described a link that when people believed that the cause of their acne was related to diet or hygiene this would induce feelings of self-blame for not taking control of their skin [150,154]. The feeling of blame appeared not only to be self-inflicted but

came from family and friends who felt that their acne should have subsided with age, and therefore the only explanation for their acne was a lack of hygiene and poor dietary choices [146]. -

> *Young women were more inflexible and disciplined in following elaborate face cleaning routines, which could be linked to feelings of self-blame for the acne and heightened responsibility for a less-than-perfect appearance.* [150]

Sick role and trivialisation of skin disease

When treatments are perceived to be not effective and acne begins to impact upon people's lives, they will seek out expert advice from a HCP. However, these papers suggest that people with skin conditions including acne, eczema and psoriasis usually have a negative experience during consultations which lead them to avoid presenting psychological issues.

For example, both Magin, et al. [151] and Magin, et al. [149] found that people's perception of HCPs including GP's and dermatologists were that they tended to trivialise skin diseases by comparing across illnesses including cancer. As people already perceived HCPs as trivialising skin condition this subsequently led them to avoid presenting any psychological problems due to concerns that these might also be met with stigmatisation and discrimination.

> *The unprofessional behaviour was disturbing but may, in part, reflect the trivialization and lack of sensitivity to the psychological aspects of skin diseases by health professionals noted in previous research.* [149]

> *An unexplored area is how stigmatisation of mental illness might be especially problematic in the setting of skin disease, which is already associated with considerable stigma. This may be accentuated by the perceived trivialisation of skin disease seen in our study and reported elsewhere. Patients with skin disease may be even more reluctant to present psychological symptoms to their GP given these perceptions.* [151]

Koo [158] also found that people had perceived negative experiences with HCPs leaving them feeling discounted and confused about next steps (although first order quote). The perceived lack of sensitivity by HCPs could be influenced by the fact that there is no ideal treatment for acne and therefore people may need to trial a number of treatments before they find the right one. This could potentially make people feel as though their HCP was not caring. Furthermore, the psychological impact of acne is not well known and if individuals are not presenting their symptoms it could lead to misunderstandings.

> *"I felt from the doctors a kind of attitude that there that there really wasn't much they could do for me anyway, and this made me feel very frustrated. I felt sometimes just discounted, or like I am not really being listened to at times." [158] (First order)*

This trivialisation was also perceived to be present among employers and peers. Jowett and Ryan [156] found that the trivialisation of skin disease led to sanctioning work absence and consulting behaviour. People were reluctant to take on the sick role because of ignorance about skin disease from others making them feel shameful and embarrassed. They felt that their condition was not serious enough to seek medical attention or to impede on other areas of their lives.

> *The denial of the 'sick role' to sufferers and subsequent lack of understanding was a problem. [156]*

Because of the trivialisation of skin disease by HCPs, people may resort to CAM therapies or healthy lifestyle practices to avoid seeking further medical help.

3.5 Discussion

3.5.1 Main findings

This study used thematic synthesis with elements of meta-ethnography to synthesise 14 papers reporting on people's experiences with acne and its related treatments. Through thematic synthesis, I identified four main themes including causes/myths and misconceptions, impact, treatments/coping, and age/gender differences. Findings from the second order interpretation showed that increased perceived control over the choice of treatment and/or control over illness may be linked to reduced psychological morbidity for both CAM and conventional treatments, although the role of treatment failure was underexplored. People used various coping strategies that were either effective or not effective depending on their perceived severity of their skin condition. The use of avoidance was both a coping strategy and a consequence of acne especially when the only identity people could assume was being an 'acne sufferer'. Finally, perceived 'trivialisation' of skin disease by work colleagues and HCPs was a common experience, this made people reluctant to present any psychological issues leading to further exacerbation of symptoms.

3.5.2 Findings in context to previous studies

The findings from this synthesis are consistent with a review on the impact of eczema, psoriasis and epidermolysis bullosa that also found that adolescents and children with chronic skin conditions experienced negative social reactions [141]. This negative experience is much like those experienced by people with acne including teasing, bullying, stigmatisation, social isolation,

avoidance, trivialisation and a decrease in self-esteem and wellbeing. Avoidance was also used as a coping strategy which eventually led to further impact as people felt less normal [141]. Furthermore, Williams, et al. [14] supports the findings from this study in that people may not be willing to present psychological problems in consultations due to the nature of their skin disease and the perception that acne can sometimes be dismissed by HCP as a trivial self-limiting condition.

The findings from this synthesis can be understood using the CSM [91] as described earlier. The findings from this synthesis cover all aspects of the model in terms of the domains within cognitive representations (identity, causes, consequences, timeline, control/cure). The findings highlighted a distinction between perceived control over treatment and of illness. This distinction is supported by the development of the revised illness perception questionnaire which provides a quantitative assessment of the components in the CSM [69]. The CSM can also be used to understand how perceived severity of acne can influence how one perceives the consequences of their condition and subsequently their choice of coping strategy. This suggests a novel way of understanding how people's views and experiences of acne can influence their choice of treatments and coping strategies.

The findings from this synthesis also briefly address representations of emotion in terms of how people worry about the side effects of their treatment, specifically isotretinoin. However, emotional representations of anxiety, fear or worry about acne were not represented by the data which could be a reflection of the condition itself (people may not be as worried about their acne compared to other conditions with greater consequences) or be a limitation of secondary analysis in terms of the inability to explore things further. If it reflects the condition this could be because of how common acne is and the perceived risk being small compared to other chronic conditions that may be less common and have more associated risks.

3.5.3 Strength and limitations

This systematic review and synthesis of qualitative studies on acne vulgaris is novel. Due to the heterogeneous nature of the studies, the review provides the opportunity to explore people's experience of acne from social interactions to treatment. I adopted rigorous methods of systematic reviewing following mainly Thomas and Harden [108] step by step guide to carrying out a thematic synthesis as well as employed elements of meta-ethnography from Noblit and Hare [109]. A strength of this review is that two independent researchers including myself screened the title and abstracts to ensure that no relevant papers were omitted. Some papers could not be

retrieved despite contacting authors. The addition of these papers could have provided a different perspective as one of the papers investigated GP's experiences of treating patients. Although this is a potential weakness, attempts to retrieve these papers were exhausted. It should also be acknowledged that with all systematic reviews of qualitative data, there is an element of bias as the findings are based on the author's interpretation. Therefore, the findings from this study is just one interpretation of the data and other researchers could interpret the same findings in a different way. Furthermore, many of the included papers (8) were from one author and therefore shared similar interpretations of what the participants were saying. A further limitation of my review is that eligible papers published after the initial search were not included. We have pragmatically decided not to re-run the search as preliminary scoping of the literature and discussion with subject experts suggests a small number of new papers have since been published which we do not feel will significantly impact the interpretation and themes presented subsequently. We have included the newly available literature in the intervention development and will present an updated search in published work following submission of my thesis.

3.5.4 Implications

Implications for clinical and educational practice

The findings from this synthesis suggest that people with acne may benefit from support to alleviate the psychological impact associated with this skin disease. HCPs could better recognise and manage the psychological burden of skin disease in order to support people with acne in developing an effective treatment regimen. HCPs may also need to ask about and uncover what health beliefs patients have to help guide management. It is essential for HCPs to highlight to patients the importance of taking control of their condition to prevent any long-term damage to self-identity. Finally, clinicians should direct people to reliable sources in order to prevent people mismanaging their acne using methods derived from popular lay health beliefs.

Implications for future research

There were no papers on HCPs or caregivers' experiences of treating acne and therefore, further qualitative research is needed to explore these different perspectives. Only two papers within our synthesis looked at the use of medical treatments for acne however, these papers focused on the psychological aspects around treatment and not treatment adherence in terms of the barriers and facilitators. Previous quantitative research has shown that non-adherence to topical treatments is common and there is relatively little in-depth qualitative information available on this, or on attitudes to treatment in general. Therefore, more studies need to explore people's views of treatment to improve self-management of acne.

Implications for my thesis

The findings from this review highlighted the importance that the intervention should aim to build a feeling of 'control' over acne in a long-term way, providing support or links to support groups for the psychological impact, and providing accurate information about treatments and causation. As the findings linked closely with the CSM, this can also be useful for informing the intervention.

3.6 Conclusion

This is the first qualitative synthesis exploring people's experiences of acne vulgaris and its related treatments. The findings show that control over treatment choice or control over acne are essential for relieving the psychological impact most people face when dealing with acne. The review also found that people use different coping strategies for their acne, which could be dependent on their perceived severity. Finally, perceived trivialisation of skin disease is a common experience for people with acne, further exacerbating any psychological symptoms. There is a need for further acknowledgment and support regarding the psychological impact of acne to enable people to manage their acne more effectively.

Chapter 4 Qualitative interviews with young people with acne

4.1 Chapter overview

In this chapter I will describe my secondary analysis of data from interviews with young people aged 13 to 24 with acne carried out by the Health Experiences Research Group (HERG) at the University of Oxford. I will firstly describe the aims and objectives of both the original and the present study and provide an introduction about secondary analysis of qualitative data. I will then describe the procedure of the original study, my analysis, results, discussion and conclusion.

4.2 Aim and Objectives

The aims of the original study were to explore the information and support needs of young people with four common skin conditions including acne, eczema, psoriasis and alopecia. This was carried out by HERG at the University of Oxford for the website Healthtalk.org in a project funded by the NIHR Research for Patient Benefit (Grant Reference Number: PB-PG-0213-30006). This website is used as a learning and teaching resource for medical students and other health carers but it is primarily intended for patients and the public as a source of information and support on a range of health conditions [159]. Currently one paper on acne has been published using this dataset [160]. McNiven [160] paper focuses on two key differences; firstly, how people perceive that having acne can have a substantial impact on their lives and secondly that people perceive acne as normal and not a legitimate illness even when it bothered them. This secondary analysis of the qualitative interview data also identified similar themes, namely, the impact of acne, causes of acne and identity (the label people give their illness and the symptoms that comes with it). Therefore, I aim to focus more on people's views and concerns about different acne treatments as this is highly relevant to intervention development and requires further research. Where relevant, other issues that may directly impact on the proposed intervention or people's engagement with the proposed intervention will also be explored.

4.3 Secondary analysis of qualitative data

Qualitative interviews are an effective way of gaining an understanding into people's worlds and their experiences and views about a particular health condition. However, the process of carrying out a qualitative study from recruitment to analysis can be time consuming and there is efficiency of fully analysing data provided by research participants wherever possible, rather than seeking further research participant time [161]. This is known as a secondary analysis of qualitative data, which involves analysing existing qualitative data to find answers to specific research questions, which differ from the original study [162]. The strengths of conducting a secondary analysis of qualitative data are as follows: it is efficient; it allows for a focused analysis of the data; it enables analysis of elusive groups of participants that may otherwise be difficult to recruit; it allows for the publication of studies that might not have been published otherwise; and it is effective for informing pilot studies [161]. For these reasons, a secondary analysis of qualitative data is an effective alternative to primary interviews.

Secondary analysis of quantitative research is more common and generally well accepted compared to the reuse of qualitative data [163]. In most cases, people reuse qualitative data for systematic reviews and synthesis of qualitative data. Although, it has been recommended by the Economic and Social Research Council that all publicly funded data should be appropriately archived and shared so that the data can be used in the best possible way [164].

Despite this, there has been an ongoing debate over the reanalysis of qualitative data. Firstly, surrounding the legal and ethical issues and secondly the argument that only the primary researcher present in the interview can fully interpret what the participant is saying [165]. With regard to the legal and ethical issues, these include problems associated with copyright and ownership, the co-construction of data, confidentiality, anonymity, and participant consent over the reuse of data for future studies [165,166]. However, Bishop [167] argues that there are effective ways of overcoming several of these legal and ethical issues. The argument that only the original researcher can understand the context enough to analyse the data also comes from Parry, who argues that the context can only ever be partially recovered [165]. Although, if data is essentially archived, and as much contextual information is included as possible, this could be mitigated against [163].

As mentioned above, one of the major strengths of conducting a secondary analysis is that it is an efficient way of analysing data without seeking further research participant time. In terms of my project, I decided to carry out a secondary analysis due to time constraints of my PhD. I initially

put in an ethics application to conduct five to ten additional interviews to supplement the data provided by HERG but decided against this after reading the transcripts. There was extensive data of high quality and included a lot of information specifically on people's views and experiences of treatments. This allowed more time to focus on the analysis and on the development of the behavioural intervention. I also worked closely with the researcher who carried out the interviews, who has also contributed to the resulting paper as a co-author. This will mitigate against the loss of context in secondary analysis.

4.4 Methods

4.4.1 Participants

A secondary analysis of 25 transcripts on participants' views and experiences of having acne and its treatments was carried out. The transcripts were obtained from HERG at the University of Oxford who conducted a wider study consisting of 97 interviews with young people aged 13-25 years of age between October 2014 and December 2015. In total, 25 of these were with people with acne who were recruited via social media platforms including Facebook and Twitter; patient and public platforms (support groups and online discussion forums); primary care (general practices); secondary care (dermatology departments); and universities, colleges and schools. The researchers used a sampling matrix in order to recruit a sample with a range of demographic factors. This included gender, age, ethnicity and occupation. The interviewer also gathered additional data in the interviews such as duration of condition and perceived severity of condition. Ethical approval for the initial study was obtained by Berkshire NRES Committee South Central and was funded by National Institute for Health Research under its Research for Patient Benefit scheme (Grant Reference Number: PB-PG-0213-30006).

4.4.2 Procedure

Participants who expressed an interest in the study, were contacted by the researcher to arrange an interview. The interviews took place at participant's homes or a mutually agreed location. Consent was sought from participants over 16 years old. Participants under 16 years old gave assent in addition to their parents giving consent. Participants were given the option to be video recorded or audio recorded and asked which format they would like their interviews to be presented on the website (video, audio or written). Semi-structured interviews were carried out following an interview guide. These were later transcribed verbatim ready for analysis.

4.4.3 Data analysis

The 25 transcripts were uploaded onto NVivo 11 software to manage the data. I carried out an inductive thematic analysis, drawing on aspects of Joffe and Yardley's [104] approach in combination with Braun and Clarke's [100]. This involved repeatedly reading the transcripts to familiarise myself with the data. Then carrying out line by line coding on three of the transcripts before developing a coding framework consisting of emerging themes. My supervisor (M.S) also read five of the transcripts to ensure that the themes reflected the data. A coding manual was then used to code the remaining transcripts. This manual was iteratively revised throughout the analysis and after discussions with the full supervisory team.

4.5 Results

The sample consisted of 72% females (18) and 28% males (7), with an age range of 13-24 years (median and mode average age of 20). Participants were majority white British (16) but also consisted of Chinese (4), White Greek (2), White Hungarian (1), White Dutch (1) and White other (1). The time living with the condition ranged from a few months to 13 years and the sample consisted of different severities, which were subjectively measured by the participants (see appendix C).

Three main themes were identified from the secondary analysis including: perceptions about acne (in terms of causes, prognosis, identity and impact); perceptions about treatments (including topical treatments, oral antibiotics, combined contraceptive pill, CAM/DIY treatments and isotretinoin); and information seeking and support (including information and support from general practitioners, pharmacist, friends/family and online). The coding manual, which consists of the themes, subthemes and corresponding quotes, are presented in appendix D. Pseudonyms have been used in place of participant name and unique number (see appendix C).

4.5.1 Perception of acne

Interviewees spoke about their perceptions of acne, particularly in terms of causes, prognosis, identity and impact. I present the findings on prognosis only, because causes, identity and impact have been covered in McNiven's paper using the same dataset [160].

4.5.1.1 Views about acne prognosis

Participant's spoke about diet, weather, hygiene, stress, genetics, and other health conditions such as eczema either causing or exacerbating their condition. However, the most common cause reported appeared to be puberty.

The belief that acne was caused by puberty, seemed to make participants perceive acne as a short-term condition which they expected to grow out of. However, for the young people in this study, their acne often followed a more chronic course. As a result, participants appeared less concerned over their condition further impacting on their engagement with treatment. Alice (aged 21, female) spoke about her confusion around how long she would have acne as the extent of the condition can differ for each person:

> *"So I am not very sure but maybe it will be like, maybe they will do the treatment and you won't have as much acne but oh no I am not really sure about how this works. Yeah. Because I am not sure if acne, it's like really like during puberty or I mean like probably, maybe for some, like for some it can be like for your entire life, something like that." (Alice, female, 21 years)*

There was also an element of self-blame if or when participants had acne into adulthood as they would often wonder what they had done wrong:

> *"But I don't mean like adult spots, I mean like, I don't know, just loads. If you've got loads and loads, like your face is just covered in it when you're an adult, then I'd be a lot more sort of confused and kind of want to get rid of it than if I'm a teenager whose face gets covered in acne." (Adam, male, 15 years)*

4.5.2 Perception of acne treatments

Participants spoke about their perception of acne treatments including concerns and effectiveness of topical treatments, oral antibiotics, combined contraceptive pill, CAM/DIY treatments and isotretinoin. I will present these in turn.

4.5.2.1 Topical treatments

Understandings about different topical treatments

Most participants were unsure about which topicals they had used and assumed that they had tried all of the topicals available. They would describe the treatment as "the one from the pharmacy" or "the one my mum bought me". Some seemed to assume that branded products

such as 'Clearasil' were the same as medical treatments prescribed by the general practitioner (GP), leading them to seek medications such as oral antibiotics as a first line treatment. Many participants were confused or appeared to be confused about the different medical names, often mixing them up with one another. This can be seen in the below quote by Melody (aged 20, female) who was unsure about the name of her treatment:

> *"I'm not sure, I've had loads, I've had like benzoyl something, I think I've had. [er] I'm not sure what this one was called actually, I've pretty much been on everything so you can factor it was like one of them. [laughs] [er] so I'm, I'm not sure what it was actually called." (Melody, female, 20 years)*

Alice (aged 21, female) was given an expensive treatment from a private doctor in China but was unsure about what this consisted of and also wanted to find a cheaper alternative. She described how she overcame this by seeking information about the treatment using online resources:

> *"Oh basically I just took their products and then I typed in the components." (Alice, female, 21 years)*

For participants who had some understanding about topicals, this was usually with regard to Benzoyl Peroxide and its associated side effects. This can be seen in the below quote by Cat (aged 21, female) where she goes into detail about the side effects from the drug:

> *"Benzoyl peroxide I think is one and it's basically like bleach, so you just sort of spread it on your skin. And that's actually quite helpful. I still, when I'm getting spots now I tend to use that. [um] It does have a tendency, [um] all my towels have just got like bleach streaks all over them." (Cat, female, 21 years)*

Uncertainty around the efficacy of topical treatments

Many participants felt that topicals were not effective as the treatment was only 'keeping the acne at bay'. However, John (aged 20, male) felt that even though the treatment did not clear his acne completely, the control afforded by his treatment enabled him to feel comfortable in his own skin:

> *"it's something that [um] sort of helped me cope with it a lot better and I kind of just stayed at a, a level where it was bad, but it was kind of I can deal with it type thing. [um] And I'd go through phases of being, having good skin, well, not good skin, but, I'd be able to, I'd feel a lot more comfortable in my skin then" (John, male, 20 years)*

Many participants experienced side effects from topical treatments. Jason (aged 22, male) found topicals to be effective but the side effects led him to stop the treatment early and therefore perceived treatment to be ineffective:

> *"I think I just only remembered the last one I had cos that one had benzoyl peroxide in it. But with that one, I remember the problem was that it tended to make my skin really dry after a while, so you had to stop the treatment. But that was the best one that was working for me. So it really wasn't, so I did it like for a month or two and then my skin got really dry. Then I stopped for a month and then it like came back. So you're just repeating it over and over and over again. You're not really getting a definite cure. So that's, yeah, that's annoying." (Jason, male, 22 years)*

Some participants perceived the side effects to mean that treatment was working and therefore continued application. This was the case for Steph (aged, 20, female):

> *"I didn't for any that I got from the GP. [Er] No. I suppose some of the topical [er] ointments [er] sort of dried out my skin a little bit but I suppose that is what they were designed to do. Yeah." (Steph, female, 20 years)*

Uncertainty around using topical treatments properly

Some participants expressed confusion or misconceptions about how to use topicals appropriately, often applying too much and to sensitive areas causing further irritation. In some cases, the improper use of topicals was influenced by information they had read online about other people's experiences. Cat (aged 21, female) was influenced by someone's testimony online to apply more than the recommended amount of topical which exacerbated side effects:

> *"So I find that, and I, I remember reading somewhere, because I, I read on the sheet, it was like "Spread it on thinly." [um] And it sort of, it kind of worked but it didn't work that well. Then I read online, there was someone saying like, did a testimony to it and they were like, "I absolutely swear by those who just put loads on and it works beautifully." So I, I tried that and I put quite a lot on and it does, it does help, but it does dry your skin out really badly." (Cat, female, 21 years)*

Only Holly (aged 20, female) said that she consulted her GP about uncertainties, and that this helped her to resolve the issue and manage it appropriately:

> *"But then I think my doctor did eventually give me one that was a bit more moisturising. [um] And I also learnt to use like slightly less [laugh]. I think there's always a temptation and most of it is that you use a lot of the product, when actually the recommendation is to*

use like a pea-sized amount and I was probably using like a handful. [laughs] So it was probably exacerbated by that." (Holly, female, 20 years)

Many participants did not report speaking to someone about how to manage side effects, but instead, stopped treatment and progressed to alternative treatments such as oral antibiotics. For Adam (aged 15, male) this was because he perceived tablets to be easier to use than topicals:

"But then over time it just kind of didn't work anymore. And I don't know if I was using it wrong or whatever, but we just decided that it would probably be easier to go for like a tablet, because you can't really do wrong with a tablet." (Adam, male, 15 years)

Some participants described the instructions for applying topicals including branded products as unclear. The number of instructions was perceived by Adam (aged 15, male) to be "stressful" due to the worry of missing a step. He suggested better ways of phrasing these:

"Put it on your face, wash it off, apply moisturiser afterwards." (Adam, male, 15 years)

For others like Tania, they wanted more specific information about how long to use treatment and how to avoid side effects:

"particularly like the topical stuff like should I keep using this should I not [um] how to deal with the sun, that was actually [um] more for stuff, like more stuff for people who have already sought, you know, medical help but it's still not quite, you know, great [um] and how to deal with also like, things like the sun and stuff like that if you've already got medication and stuff like that yeah." (Tania, female, 20 years)

Time-consuming nature of topical treatments

Some participants suggested that applying topicals was time consuming and impractical, partly because of the way it affected other family member's morning routines. Adam (aged 15, male) said that it was unrealistic for a teenager, to wait ten minutes for medication to sink in as they have other priorities:

"But before that it would be a lot more like stressful because it would be a lot more like wash my face with soap and water. Apply cream stuff. Apply moisturiser, Go on with my day and do that at the end of the day. Which made it kind of like less me wanting to do it in a way." (Adam, male, 15 years)

In contrast, John (aged 20, male) appeared to feel empowered when putting on his treatment as he felt that by adhering with the treatment he should be rewarded with clear skin:

> *"So, yeah, it was pretty straightforward and, I mean, when you wake up and you've got spots on your face, it's not like you forget. You're like 'arr', you're more like, I can't wait to put the cream on, hopefully, it's going to do something in the next few hours. So [um] you, it is quite easy to keep on top of it." (John, male, 20 years)*

Time taken for topical treatment to work

As mentioned earlier, some participants viewed acne as a short-term condition, which is potentially why participants expressed how they were looking for a 'quick fix'. It appeared that many participants stopped treatment before onset of action and assumed that this was the treatment not working. Alex (aged 16, male) said that he would rather try a stronger treatment as he perceived these to work quicker:

> *"I decided that I'd rather just go straight back to the stronger [um] medication than have to spend a a long time trying the topical creams which I was pretty sure weren't gonna…I mean maybe they would work but it would just take [er] a lot longer than if I went back to the treatment I was on before that was actually working." (Alex, male, 16 years)*

Tammy (aged 22, female) spoke about how she would try the treatment for a couple of weeks before stopping and trying something else:

> *"I can't really remember the names of them I'm afraid. I think both of us expected results more quickly than they were plausibly going to come and so there was quite a pattern of kind of trying something for a couple of weeks and then just moving on to the next thing." (Tammy, female, 22 years)*

In contrast, Kate (aged 19, female) used the treatment for the recommended amount of time and saw improvements, but wasn't sure if this was attributed to the medication or the unpredictable fluctuations in her acne:

> *"I think it helped a bit but not as much as I expected it, it would be. Like it takes about more than half a month to see a change. And then it's still, it's, it's still very red, but it's kind of better. I'm not sure if it's because of the, the treatment or because the acne just becomes better itself. So, yeah." (Kate, female, 19 years)*

4.5.2.2 Oral antibiotics

Perceived concerns about oral antibiotics

Few participants reported experiencing side effects from oral antibiotics. For those that did, they spoke about how the treatment made them feel 'queasy', discoloured their tongue, have stomach-aches and increased sun sensitivity:

> *"I know I tried Lymecycline, Tetracycline, Erythromycin – I can just remember so many different ones and like, they had horrible side effects as well. So, at one point I had to take like four tablets in a day and like they made me feel so queasy." (Sarah, female, 18 years)*

Izzy (aged 24, female) said that the side effects she experienced were psychological due to the awareness of being on oral antibiotics for a long period:

> *"don't think I had any side effects from the tablets. There was - you know - something in the back of your head saying, 'Oh I'm on antibiotics all the time.' So it was more a sort of mental or social side effect, than an actual physical one." (Izzy, female, 24 years)*

Only two participants explicitly spoke about their concerns regarding antibiotic resistance but many seemed unaware or less concerned of the risks as they did not report this. Tania (aged 20, female) was worried she would become resistant to antibiotics and that it would not work for other illnesses in the future. She also felt that it was the GPs responsibility to advise her of when to stop taking them:

> *"I was becoming more aware of the fact that taking antibiotics you almost feel like you don't really need them when it's your skin [um] and like you kind of want to save it for when you really need it [um] because I mean obviously that's [participant clarification: referring to antibiotic-resistant infections] a growing problem ……I guess it's their responsibility to do that [um] you know but [um] that also kind of, makes it's feel less satisfactory." Tania, female, 20 years)*

Some interviewees had concerns about taking oral medications, as they perceived oral treatments as 'stronger' than topicals. They spoke about how they felt that their acne was not severe enough to warrant the use of oral medications. Sophie (aged 17, female) describes how her skin is external and therefore she doesn't think oral treatments are necessary:

"*Because like when you're taking tablets – you-, I didn't feel at the time that it was necessary. Because I just thought like 'it's j-, it's just on my skin. I can sort it out externally'. And I didn't really want to take medication." (Sophie, female, 17 years)*

Uncertainty around the efficacy of oral antibiotics

The majority of participants felt that oral antibiotics were not an effective treatment in the long term. Ivy (aged 24, female) reported that they helped initially but stopped working after 6 -9 months, which she found frustrating as the loss of control impacted her mental health:

"I guess the real point where I really felt my control completely gone was [um] sort of end of last year when my skin got really bad and the Lymecycline wasn't working which had previously, you know, really worked, and I felt really in control about my skin at that point. [um] So at that point I felt like totally just didn't know what to do and I guess it-, you know, it can have sort of real confidence side-, you know, your confidence completely decreases; you don't feel as attractive anymore and things like that. So, I think [um] it can have real negative consequences for your self-esteem." (Ivy, female, 24 years)

Whereas, Izzy (aged 24, female) felt that antibiotics are the only thing that usually works but she didn't want to add to the *"already prolific antibiotic resistance":*

"I'm not sure, to be honest. Because you don't want to make it all over the counter and have everyone taking everything under the sun, especially when it's the antibiotics that tend to work. You don't want to contribute to the already prolific antibiotic resistance that we've got." (Izzy, female, 24 years)

4.5.2.3 Combined contraceptive pills

Perceived side effects of combined contraceptive pill

Some participants who were prescribed the combined contraceptive pill, experienced side effects including weight gain, mouth ulcers, mood swings and increase in acne lesions. Holly (aged 20, female) found the pill made her gain weight and made her acne worse:

"the pill I didn't really like. [laugh] But I think I just, that kind of made me gain a bit of like water weight, and I think [um] it, it didn't really stop the spots, but it made it-. So as opposed to kind of having a flare-up once a month, it would be like a flare-up twice a month." (Holly, female, 20 years)

Perceived stigma around using combined contraceptive pills

Young people had fears or worry of stigmatisation and embarrassment with using the pill at a young age. Tania (aged 20, female) said that this was because she was not sexually active and people her age were not using contraception:

> *"so I guess both of those I was offered by multiple people but, you know, I, you know the pill when I was too young to be like 'What, no I'd be really embarrassed none of my friends are taking this" (Tania, female 20 years)*

Holly (aged 20, female) was prescribed oral antibiotics instead of the pill when she was aged 15 and assumed this was because she was too young at the time. However, now that she is older she feels that this method of treating acne was more acceptable:

> *"So I took antibiotics for quite a while. I think that's because I was a bit younger, and they didn't want to give me the pill. [um] Because a lot of my friends who [um] have bad skin often get given the pill now and I think that's because, because we're a bit older. [um] And it wouldn't be unusual for like a 20 year old woman to be on the pill, whereas I think if you're 15 it's a bit-. So they started me on antibiotics, I was on them for quite a while." (Holly, female, 20 years)*

Uncertainty around the efficacy of contraceptive pill

The effectiveness of the contraceptive pill varied. Some participants found that it made their acne worse or didn't make much difference, but for many this was after they had been on much stronger treatments such as isotretinoin. Steph (aged 20, female) felt that she needed the treatment as she advocated the cause of her acne to hormones:

> *"Obviously nowadays, my acne only seems to sort of, well, mostly seems to be related to sort of hormones and things so I'm assuming that that sort of is helping. It's certainly a lot better like now, my skin seems a lot better. So, yeah" (Steph, female, 20 years)*

Faye (aged 17, female) did not perceive the pill as necessary as she viewed the primary role of the pill to be for contraception and therefore less superior than medications specifically designed to treat acne:

> *"And also because I wasn't, like I didn't need contraception. And I think that was just, I just found it a bit pointless. I'd rather have done something else specifically for my acne rather than something that might help my acne." (Faye, female, 17 years)*

4.5.2.4 CAM/DIY treatments

Concerns about CAM/DIY treatments

The majority of people who used CAM/DIY treatments did not have any concerns as they viewed them to be 'natural' and therefore expected few side effects. For example, Alice (aged 21, female) reported using natural treatments because she didn't know what "chemicals" were inside conventional acne treatments. Mark (aged 21, male) bought a herbal treatment in another country despite not knowing what it was. He was still willing to use it because he assumed it was 'natural':

> *"It doesn't sound particularly legit……Thinking about it now, but, it was probably, you know, just some, you know, natural stuff, but, yeah." (Mark, male, 21 years)*

Ivy (aged 24, female) preferred CAM/DIY treatments because conventional acne treatments made her feel as though she was medicating herself:

> *"I guess you have more faith that they might not have side effects cos they seem more natural, like natural based, whereas for the [um], for the antibiotics you're always a little bit worried what's in them because they're not as-, I don't know, they don't really feel as natural cos you're taking a pill [um] and you feel like you're sort of medicating yourself." (Ivy, female, 24 years)*

Despite being natural, some participants reported side effects from CAM/DIY treatments (lemon juice, toothpaste, steam machines, Chinese medicines and tea tree oil) including burning, strong smells, bad tastes and bleaching. Holly (aged 20, female) had a negative experience using toothpaste which left her with burn marks:

> *"The toothpaste was probably the worst idea. [laugh] That actually left me with like, like a burn mark across my face. [um] I think most of them are just pretty ineffective." (Holly, female, 20 years)*

Uncertainty around the efficacy of CAM/DIY treatments

Many participants spoke about their uncertainties around the effectiveness of CAM/DIY treatments. However, they were still willing to use them potentially due to their lack of concerns. Charlotte (aged 23, female) carried on using tea tree oil even though she wasn't sure if it was working:

> *"oh, yeah, I was like try the tea tree oil for like years but [uh] I was not so sure about the, it works or not or anything." (Charlotte, female, 23 years)*

Izzy and Cat spoke about how necessary they felt it was to keep trying CAM until something worked:

> *"Yeah, I have - I have a tea tree oil beauty cream that I use day to day, usually at work. [Um] That - I'm not sure if that helps much, but you know, I'm trying." (Izzy, female, 24 years)*
>
> *"But you still try it anyway. [um] So I remember doing all sorts. You make little scrubs out of, you know, honey and oil and sugar and all sorts of bizarre things. And the one that, the one that I'm still not really sure if it works is putting toothpaste on spots." (Cat, female, 21 years)*

4.5.2.5 Isotretinoin

Perceived concerns about isotretinoin

Many participants spoke about experiencing minor side effects from isotretinoin, including dry lips, dry skin and dry throat. Participants were aware of the potential serious side effects but this did not seem to be of great concern as they continued to use their treatment as shown in the below quote by Steph (aged, 20, female):

> *"I knew that there could be much more serious side effects. It can cause anything up to quite serious depression. So that was a quite a worry. But [er] it definitely wasn't enough of a worry to stop me from going on the medication." (Steph, female, 20 years)*

Uncertainty around the efficacy of isotretinoin

Everyone who used isotretinoin found it effective at clearing up their skin. For some, there acne relapsed and a second round of isotretinoin was considered. People often described the treatment as "nuclear", "magic bullet" or the "powerful one". Cat (aged 21, female) was aware that it was a strong treatment that was often used as a last resort:

> *"Is a kind of really powerful one that makes your skin all thin and everything. [um] So I was on that and that worked. [um] Which was good, because I don't think there's anything stronger. [um] So I was on that for maybe six months, a bit longer." (Cat, female, 21 years)*

Sarah (aged 18, female) felt that isotretnioin was the only treatment that completely cleared her skin, but recognised that topical treatments were an effective first line treatment:

> *"So, I guess maybe a combination of both but, personally for me, the only thing that actually got rid of it was the Roaccutane and, that was a tablet so, I guess I might advocate that.*

But [um] maybe some of the creams at the beginning were better than some of the tablets so." (Sarah, female, 18 years)

Perceived inconvenience of isotretinoin

Participants were required to have regular pregnancy tests and blood tests whilst using isotretinoin. Generally, young people did not perceive regular pregnancy tests as necessary, mainly because of their age with some saying that they were not interested in boys.

"I did feel a bit weird doing the, the pregnancy test. Because [um] he like asked me like, "Are, are you sexually active?" And I was like, "No." And then he said, "You just have to do it for like, [um] like document purposes, so they can tell that you're definitely not pregnant. Cos it's really really dangerous for the baby." And [um] I'd never had a blood test before I got that blood f-, well, not that I can remember. But I'd never had one before then. So I was a bit like nervous. But I knew like it, I had to do it to go on the pills. And I didn't really mind." (Faye, female, 17 years)

Furthermore, Sarah (aged 18, female) and Maria (aged 22, female) commented that the process of going back and forth for tests as time consuming, especially as a teenager at University:

"so I was required to take a pregnancy test prior to starting the drug. [um] And I didn't like doing that because it was just, well I knew it wasn't necessary at the time. [um] So, that, I felt that kind of made it even more embarrassing that it had to be. Like, I don't personally like hospitals or anything, and having to be at one and like do that, I felt was like quite annoying and kind of made it harder than it needed, perhaps needed to be." (Sarah, female 18 years)

"I could fit it in but it was quite, yeah [laughs] quite time consuming because I had to get the train back there and then go and everything. [Um] and also because I had to have blood tests and stuff at the GPs so I had to keep making loads of other appointments there [um] so yeah I think, I think that was just quite frustrating." (Maria, female 22 years)

Decision-making about isotretinoin

For many participants, the decision to go on Isotretinoin was a shared one with family and friends. Most often, this was because of worry about the perceived side effects of the drug, which could have the potential to affect other areas of their lives including exams. Therefore, people often had to weigh up the impact of their condition in order to warrant going on such a strong treatment.

Mark (aged 21, male) had discussions with his mum about when was the right time to be on isotretinoin as there was a worry about it affecting his GCSE's:

> *"I mean I suppose my mum was my biggest sort of [um] debate is what I had like the larger sort of debate with my mum about the whole thing so, but other than that not really, I suppose …….Was, you know, do I go on that now and kind of risk jeopardizing my whole kind of, you know, GCSE's and whatnot? But in the end I just went for it, so." (Mark, male, 21 years)*

People's decisions also seemed to be influenced by their age and by information they had read online. For example, Gary (aged 18, male) was put off going on isotretinoin after reading other people's experiences:

> *"They sort of expected it, I suppose, with me being a teenager at the time. [um] They wanted me to go onto the isotretinoin sooner but [um] I just weren't too sure after reading things online about other people that have taken it……. and wanted to commit suicide. So it was, that did sort of put me off." (Gary, male, 18 years)*

4.5.3 Seeking information and support

Interviewees described their experiences seeking information and support from the GP, pharmacist, friends/family and online. These are presented below.

4.5.3.1 Experience of consulting health professionals for acne

Many participants had the perception that the GP couldn't do much for their acne or felt that GPs were 'trivialising' their skin condition. For some participants, this led them to seek alternative treatments or discontinue treatment completely. This was often the case, as participants seemed disappointed by the GPs responses including "try this and come back if it doesn't work". Maria describes how long each stage took from getting an appointment to finding the right treatment:

> *"But it was like each stage took, you know, a while to get an appointment and then a while before, they just kept saying, "Oh, you know, you have to wait and see [um] if it's working." So sometimes, I remember one time [um] I, you know, I was taking, I think it was when I had the three things at once and [um] I, you know, I went back to get more pills after like three months or something and they said, "Oh, it's not working. Okay, well, try another three months," so I went away and I came back and they were like, "Oh it's still not working, oh try another three months". (Maria, female, 22 years)*

Jason (aged 22, male) spoke about his frustration with the process of trial and error as he expected the GP to prescribe him a treatment that would work instantly:

> *"I mean some sickness we just can't cure yet. We can slow it down, you know, what I mean like. In those situations that's a totally different rule, set of rules. But basic things, like acne medicine, acne creams, if it doesn't work, you're the one who's prescribing it for me, and you looked at me. You took your time apparently, apparently to look at it. It's probably not the first case you've seen to be honest. So you should be recommending something that will work." (Jason, male, 22 years)*

However, when Melody was told that treatment may take a while to work and that there was no quick fix, this appeared to help her to feel more at ease and more empowered to take control of her treatment:

> *"So I was never too…and that's always been expressed to me which I think is helpful, is that there are very few medications which are like an overnight [um] cures because I think once you do, you know, get the courage up to go to a doctor and then if you're un-, non-, if you're not aware that it's not gonna be fixed overnight it's probably quite disheartening when, you know, you go maybe a month and you can't see a change. [um] But I mean you really just have to keep at it because I don't know why but the medication doesn't work instantly. [Um] but that's always been stressed to me which has been really helpful." (Melody, female, 20 years)*

Some participants spoke about how their GP gave them a choice of treatment. They would ask participants about their preferences between oral or topicals, which when given the option, majority of participants opted for oral treatments, commonly antibiotics. This was often because they perceived them to be easier, more effective and quicker to take effect. Steph said her GP allowed her to make her own treatment decisions about whether she wanted to stay on her current treatment or try an alternative:

> *"When I was with the GP, they'd sort of give me the choice between more topical treatments [er] which were perhaps stronger or try me on some antibiotics or a combination of both, depending on what I thought was working." (Steph, female, 20 years)*

In terms of the psychological impact of acne a small number of participants perceived their GP to take an interest in their mental health. For those that did, this was a positive experience as they were already embarrassed consulting about their acne. Steph found her experience with her GP positive as they took an interest in her mental health and social life:

> *"The GP was very good about it. [Er] I was prescribed some antibiotics I think at the time. [Er] But I actually remember there was sort of, they were asking me about questions about how it sort of affected and whether people had, you know, been saying things and if it was affecting sort of socialising and things like that. So they were quite understanding which is good, because I was quite nervous about going about it." (Steph, female, 20 years)*

Delay in attending GP

Participants commonly reported a delay in consulting the GP. For most, this was because they did not perceive their acne as severe. As a result, participants tended to use their own remedies or cosmetic treatments until their acne got progressively worse. Steph used over the counter face washes for six months before visiting her GP:

> *"I think I spent a lot of time on these sort of, you know, face washes and all this nonsense like Neutrogena and whatnot and was under the impression that that would help [um] and obviously it didn't really at all. So I don't think I really went to the GP until a few, maybe sort of six months into, you know, having what I thought was quite bad acne." (Steph, female, 20 years)*

Cat was not aware that a dermatology referral was an option so stopped seeing her GP when treatment was perceived as ineffective:

> *"I probably should have then gone back to the, back to the GP and said, "This doesn't work." But you, you sort of like start to lose faith a bit when you've been at it for a couple of years and nothing seems to work. So I sort of stopped going back, tried to do my own thing, [um] then eventually went back and, yeah, they said, "Go to the dermatologist." (Cat, female, 21 years)*

Most participants were encouraged to consult after listening to friends' experiences or family members who saw the extent of the problem. For example, Mary (aged 22, female) self-treated her acne using over the counter products for four years before speaking with her mum who suggested that she go see the GP:

> *"But [um] it continued for, for four years I guess, really severely and then I talked to my mum about it and she notice it, nosed it, noticed everything already [um] so she was like, "Well we can go and see if the doctor can help us a little bit." (Mary, female, 22 years)*

4.5.3.2 Seeking support or information from pharmacist

Very few participants had gone to their pharmacist for advice and support about acne as they were either unaware that it was an option or because they were embarrassed about speaking to somebody. The two participants who did speak to a pharmacist said that they found it helpful. For example, Ivy (aged 24, female) was told by a pharmacist to be careful when using benzoyl peroxide as it could cause bleaching:

> *"They do often at the pharmacist tell me to be careful. [um] I don't necessarily think so, although thinking about it my [um], quite a few of my pyjama tops have bleach all the way round the bottom, [er] sorry, all the way round the rim of where I obviously take my top off, and then it gets on-, must get on the-. So I guess it does bleach my pyjamas, but apart from that. It doesn't, doesn't bleach my like [um] bedding or anything like that." (Ivy, female, 24 years)*

Izzy (aged 24, female) thought that seeing a pharmacist would be useful, however she wasn't sure what they could give her over the counter without a prescription:

> *"Not really, to be honest. [um] I'm not really sure what they'd be able to do. [um] There does seem to be a gap in between what you can buy - not even over the counter, on the shelf, that you don't even have to talk to a pharmacist about. And then the next step is seeing your GP and getting a prescription. So I don't, I'd never have thought of seeing a pharmacist, because I wouldn't expect them to be able to do anything for me. [um] But it would be great if they could." (Izzy, female, 24 years)*

4.5.3.3 Seeking support or information online

Participants used an array of websites for information about acne causation, make up tips, reviews about GPs, medical treatments and CAM/DIY treatments. The websites mentioned were NHS Choices, Google search, Yahoo answers, YouTube, discussion forums, Facebook, Instagram and blogs. Ivy (aged 24, female) said that she knew that the websites were not credible sources but she was particularly interested in and valued other people's experiences. This included people's experiences with different treatments, and their decisions to take or not to take certain medications including isotretinoin and the combined contraceptive pill:

> *"So, and it's interesting cos it doesn't necessarily have to be like a reputable source, it can be a forum of people's experiences." (Ivy, female, 24 years)*

Some participants felt that current websites for acne were not useful for young people and the majority of these were from the US, which was confusing as the names of medications differed to those in the UK:

> *"Well, the NHS ones, they just sort of seem to be a bit generic, they don't, they're not really targeted for a young person, I think. So anybody, it could, the information could apply to anyone." (Gary, Male, 18 years)*

As a young adult, Izzy (aged 24, female) also felt that there was not enough information available for adults with acne:

> *"Which, you know, this is a really long phase, [laugh] if it is. So I think there needs to be a bit more recognition that there are adults with acne out there." (Izzy, female, 24 years)*

Few participants spoke about using internet forums or support groups. Some participants felt that forums could be misleading and that it was difficult to understand a person's whole experience from one comment. For example, Melody (aged 20, female) was investigating people's experiences of using isotretinoin and said, "sometimes it's not quite as comprehensive as you'd like". For others, they were not seen as necessary. Maria (aged 22, female) didn't want to talk about her skin condition to strangers:

> *"I don't really want to talk to nameless faceless people on the Internet" (Maria, female, 22 years)*

A few participants did advocate support groups as they had found ones that were tailored to their specific needs. For example, Gary (aged 18, male) became a volunteer for an anti-bullying charity and said that he would speak with the counsellors on the website to support him when he was feeling "low".

4.5.3.4 Seeking support or information from others

Some participants found it helpful when family members accompanied them to appointments and encouraged them to take their medication:

> *"my parents just say that, "You don't need to do that, like you look as good as you used to be," and [uh] yeah. And they need, they took, they take me to a doctor and they encourage me to take the medicine so, and they reminded me of like every time – so it's much helpful over there, yeah." (Charlotte, female, 23 years)*

People perceived information from family and friends who had acne themselves to be particularly useful. This included information about treatments they had tried, home remedies, as well as treatments for scarring. Whereas, others preferred not to speak about their skin condition, especially at a young age, because they felt that they should have more knowledge and experience about their acne before discussing and providing advice to others:

> *"That's why it's so important, as I said like, finding the right doctors who make you feel welcome and open about this subject 'cos you're not really going to start talking to your friends about these kinds of things during that age. It just makes you feel awkward a little bit and you're embarrassed about it. I mean later on like, I know it's a cliché but when you grow up a little bit more you have more experience, you will know that your friends went through it and it's a little bit easier to talk about it." (Jason, male, 22 years)*

4.6 Discussion

4.6.1 Findings

Young people generally perceived acne as a short-term condition caused by puberty, which seemed to have implications for self-management. Participants often expected instant results from their topical treatment but perceived it as ineffective in the absence of this. Many young people thought that they had tried all the topicals available, but they were confused between cosmetic and pharmaceutical topicals which appeared to prevent engagement with treatment. They also had concerns around how to use their topicals properly and few spoke about consulting their GP or Pharmacist for advice on managing side effects. Few participants mentioned awareness of antibiotic resistance and many opted for oral antibiotics over topical treatments when given the choice. All participants who used isotretinoin, despite experiencing side effects, considered it an effective treatment. Participants found being on isotretinoin inconvenient in terms of regular blood and pregnancy tests but continued treatment nonetheless. Decision-making was often a shared with family members but generally involved research and information from the GP beforehand. Many young people did not view contraceptive pills as a treatment for acne and therefore, there was often self-stigma around taking the pill at a young age. Generally, there was little concern over CAM/DIY treatments as these were considered natural, although, some participants did experience side effects.

Young people often felt frustrated with the trial and error process of trying to find effective treatment for their acne and often felt that health professionals 'trivialised' acne. Furthermore, they felt that the GP did not take an interest in their mental health. Many young people were not

aware that the pharmacist could assist them with their acne but for those that did, they found it helpful. Seeking information and support from family and friends was a positive experience due to the relatable nature of information shared and reassurance that other people had positive experiences with treatments. People also used the internet for this reason, however, there was some hesitation with regards to the credibility of the websites and the perceived lack of information available for young people.

4.6.2 Findings in context of previous studies

Previous research has shown that young people often perceive acne as an insignificant feature of adolescence and therefore, not a reason to seek medical help [160]. My analysis on views about treatments suggests a further link, in that, people's perception of acne as a short-term condition also seemed to influence their approach to self-management and adherence to treatment. Young people's belief that acne should be a short-term condition, may explain why people expected instant results from their topical treatment and were ultimately frustrated when this didn't happen. A recent qualitative study looked at people's preferred attributes regarding topical treatments and found that many people wanted their topical treatments to be fast acting [54]. This present study found that when participants were told by the GP that treatment would not work straight away, this helped them to feel less 'disheartened' at the absence of instant results. This is also supported by recommendations from experts advising GPs to spend time explaining delayed onset of action from treatments [50,67].

Participants felt that they had tried all the topical treatments available but they were often confused between cosmetic treatments from the supermarket, over the counter treatments available from the pharmacist and treatments prescribed by the GP. This perception resulted in young people seeking alternative treatments as first line or not using their topical treatments appropriately. Similarly, a recent cross-sectional study with University students in Saudi Arabia, found that more than half of the sample (58.7 %) did not know the name of their prescribed acne treatment [168]. In this present study, we found that participants were confused about how to use their treatment appropriately including how to manage side effects. This is also supported by Fabrichino et al [54] who found that having no side effects was one of the top preferred attributes for topical treatments. However, it is unclear from their study whether participants were aware of how to manage side effects. My study found that when participants consulted the GP about their concerns, they found this helpful. These findings concur with recommendations from experts who

suggest that GPs should tell patients to expect initial irritation and provide information about how to minimise these [14].

Participants often spoke about how their GP gave them a choice between topicals or orals as first line treatment. A recent study looking at doctors' attitudes to acne management found that doctors had different views around treating patients with topical treatments or antibiotics [169]. More specifically, doctors reported that they didn't have much faith in topical treatments partly because they felt that patients were less compliant with these. When offered a choice of treatment, young people often opted for oral instead of topical. This is a similar finding to previous studies which found that oral antibiotics were commonly prescribed as first line treatment [4,32]. My study suggested that people opted for oral treatments over topicals because they perceived them as being easier, more effective and quicker to take effect. There is also the possibility that participants were more forthcoming with taking oral antibiotics because they reported fewer concerns and many participants seemed unaware or did not report risk of antibiotic resistance. This also appears to be the case for CAM/DIY treatments, as participants were more likely to use them over conventional acne treatments, as they perceived them to be natural with fewer side effects. Although people had more concerns related to isotretinoin, they only reported experiencing minor side effects, which enabled them to continue their treatment and use it appropriately.

In this study, participants felt that the 'trial and error' approach to prescribing as the GP not taking their condition seriously and not coming up with an appropriate treatment plan. This was also found in a previous qualitative study on acne Magin, et al. [151] and in other qualitative studies of skin conditions including vitiligo and psoriasis [170,171]. Participants in this study reported lack of support from their GP regarding their mental health. This is also demonstrated in Magin, et al. [151] study looking at patient's relationships with their GPs and Dermatologists. Although, they also found that participants were reluctant to present these problems in the first place. In contrast, Fildes et al [169] found that there was a general consensus amongst doctors that attention to the psychological impact of acne was an essential part of successful care [169]. This could potentially suggest a difference in expectations amongst doctors and patients regarding consultation. In my study, I found that there was often a delay in consulting, which was possibly due to people's perception about the severity of their acne, and from patients wanting to see whether it could be resolved itself. Again, this could be linked to young people's perception of acne as a cosmetic problem and not a medical condition as explained by McNiven [160].

Participants often sought and were influenced by information they had read online, although some participants did express their hesitation regarding the credibility and reliability of posts they

had read. Santer, et al. [55] highlighted that online discussion forums could increase confusion about acne treatments and the importance of signposting people to correct information. Williams, et al. [14] also recommends that HCPs should inform patients that online acne information, including some support groups, vary in quality and can reflect sponsor bias.

The findings from this study are closely linked with the Extended Common Sense Model of Illness (ECSM) [69]. The theory is an extension of the Common Sense Model of Illness (CSM) with the addition of treatment beliefs (described in chapter 2). In brief, the model includes illness perceptions such as views about timeline (duration of acne), causes, identity and control/curability and treatment perceptions such as beliefs about necessity and concerns regarding medication [69]. This study found that people's perception of the duration of their acne (short-term), and their concerns about treatment ineffectiveness due to side effects and delayed onset of action, seemed to affect young people's adherence to treatment corresponding to the timeline and beliefs about treatment components of the model. Other domains including causes, identity (in terms of whether young people viewed acne as a medical condition or a cosmetic issue) and consequences (impact of acne) were addressed in McNiven [160] study using the same dataset and so were not discussed here. Although the findings drawn from the data show that consequences in terms of perceived trivialisation of acne may influence coping strategies and willingness to disclose any mental health issues. Issues around control were brought up in the data in terms of people wanting control over their choice of treatment. Finally, representations of emotion in terms of worry about treatment side effects including isotretinoin and oral antibiotics (some reference to antibiotic resistance) appeared to make some people avoid or stop treatment. These links suggest that the ECSM could be a useful theory for developing the behavioural intervention to support self-management of acne.

4.6.3 Strengths and limitations

This study provides in depth analysis of young people's perception of acne treatments and its implications for self-management. A strength of this study was that as the sample was recruited using a maximum variation sampling matrix which ensured that a range of views were included. Although, this could also be seen as a limitation as the sample was therefore, relatively heterogeneous and previous literature suggests that demographic factors including age [1], gender [172] and culture [173] may affect people's perceptions about their acne. For example, the majority of participants in the study were female, so the inclusion of more males could have influenced the findings. However, the predominance of females is explained by the fact that females are more

likely to seek help for their acne than males [20]. A further limitation was that, as this was a secondary analysis and not primary interviews, I was unable to prompt participants for further information. However, the transcripts provided a wealth of data for the key areas of interest and allowed for a more focused and time-efficient analysis of the data. I am also confident that data saturation was reached for the main themes of interest. It is worth noting that, as the majority of participants in this study followed a more chronic course of acne, there is a chance that the inclusion of more people with recent onset acne may have provided different findings.

4.6.4 Implications for my thesis

This study highlights the need for better online advice for young people with acne and provides key areas that need to be addressed in the intervention. These include providing people with information about: acne prognosis; treatments for acne and time till onset of action; side effects and the management of these; how to use treatment appropriately; how to talk to GPs and provide psychological support. It also suggests that the intervention should include personal stories from people with acne to improve engagement with the intervention.

4.6.5 Conclusion

In conclusion, my findings showed that the perception of acne as a short-term condition had implications for self-management and treatment adherence. Increased information about treatments need to be provided so that patients can have improved understanding about the different topicals available, how to use treatment appropriately including managing side effects and a realistic idea about the onset of action. Furthermore, better resources are needed to support young people in self-managing their acne.

Chapter 5 Development of a web-based behavioural intervention to support self-management of acne

5.1 Chapter overview

In this chapter, I present the intervention planning and development process for SPOTless, a web-based behavioural intervention to promote self-management of acne in young people. First, I will briefly describe the Person-Based Approach (PBA) to intervention development [68]. I will then describe how the PBA was used to integrate theory and evidence before discussing my findings from the think-aloud interviews which were used to further refine the intervention.

5.2 Introduction

As described in chapter 2, the PBA is an effective method for developing behavioural interventions. It combines user-centred design methods with evidence-based behaviour change methods [68]. This approach involves carrying out qualitative research during intervention development and implementation stages including a qualitative literature review supplemented if needed by primary interviews with the target population. The qualitative data is used to inform the intervention content and design, as well as the usability, engagement and satisfaction with the intervention. Further qualitative work in the form of think-aloud interviews are carried out to further refine the intervention. This provides useful information about every aspect of the intervention to optimise its usability and acceptability within the target population.

Another key part of the PBA is formulating 'guiding principles' [68] by highlighting the key design objectives and key (distinctive) intervention features intended to address these. These are developed in the initial stages using evidence from the literature review and primary interviews and are then further refined throughout the development process.

The PBA complements theory and evidence-based approaches as it suggests the most acceptable and important behaviour change techniques (BCTs) for the target population, it provides guidance on what to avoid or modify in terms of intervention characteristics, how to incorporate the BCTs and it also helps to identify new intervention characteristics which are not already evidence-based [77].

To my knowledge, current interventions have not been developed using robust methods and many of the interventions testing the effectiveness of these have had significant shortcomings. It is therefore, important that this intervention is evidence, theory and person-based to ensure better uptake and engagement with the intervention.

5.3 Theoretical modelling

The web-based intervention was informed by a theoretical framework applied alongside findings from the synthesis of qualitative research described in chapter 3 and the secondary analysis described in chapter 4 as per the PBA. The approaches used as part of intervention planning are outlined below.

5.3.1 Creating guiding principles

Purpose

As part of the PBA [77], guiding principles were developed and modified throughout the intervention development. The purpose of the guiding principles was to highlight the key intervention features that seem important for achieving the intervention objectives [77].

Methods

The first stage of formulating the guiding principles involved stating the key intervention objectives in terms of behaviour change and outcomes informed by the literature and qualitative analysis. Next, I described the characteristics of the intended user of the intervention. I then provided evidence for the key behavioural issues, needs and challenges identified from the synthesis of qualitative research (chapter 3) and the secondary analysis of qualitative data (chapter 4). Based on this information I was able to identify design objectives for the intervention and key intervention features to address these. The guiding principles were iteratively developed throughout the development process as I learnt more about the needs and experiences of the target user.

Results

The guiding principles are presented in Table 4 and are summarised below:

1. To support young people to gain autonomy and competence around acne management.

The secondary analysis of qualitative data highlighted how young people expected their topical treatments to work 'instantly' and judged treatment as ineffective when this did not happen. They were often confused about which topical treatments they had tried resulting in them trying alternative first line treatments or not using their treatment appropriately. They also had difficulty overcoming barriers to topical treatments including managing side effects. Findings from both the qualitative studies (systematic review and synthesis of qualitative data and the secondary analysis of qualitative interviews), highlighted how young people were influenced by myths and misconceptions about acne in terms of causes and treatments.

2. To support and promote autonomy for making treatment choices.

In the systematic review and synthesis of qualitative data, I found that perceived control over treatment choice and control over acne was essential to improve adherence and the psychological impact of acne.

3. To provide support and acknowledge the psychological impact of acne.

This population is likely to be more affected by the psychological impact of acne as the teenage years is an important time for gaining confidence and building self-esteem [14]. The findings from the systematic review and secondary analysis also highlighted the psychological impact experienced by young people with acne and the difficulty associated with presenting and coping with these symptoms.

Table 4: Guiding Principles for the SPOTless intervention

Key: SR= Barriers emerged from systematic review and synthesis of qualitative papers on acne (described in chapter 3); QR= Barriers identified from the secondary analysis of published interview data (described in chapter 4)

			Guiding Principles	
Key intervention objectives	**Patient characteristics**	**Evidence for key behavioural issues**	**Design objectives**	**Key (distinctive) intervention features**
To improve the lives of young people with acne To promote self-management of acne To promote the appropriate use of topical treatments	Young people who have mild-moderate acne vulgaris.	(QR) Little knowledge about acne and its treatments *Young people can be confused with the myths and misconceptions around acne and unaware or unwilling to acknowledge that acne requires on-going treatment.*	To support young people to gain autonomy and competence around acne management	• Offer user choice wherever possible • Minimise disruption to lifestyle • Dispel myths and misconceptions about the causes of acne • Autonomy-supportive language • Ensure they have a complete understanding of acne and the rationale behind their treatment. • To build their self-efficacy for the target behaviours (e.g., 4 week challenge to support patients to formulate a personal goal/action plan, advice on how to minimise
		(QR) Low motivation to engage with long-term treatment *Certain beliefs about the causation of acne may affect people's perceived necessity of treatment.*		
		(QR) Difficulty judging efficacy of topical treatments *Belief that topical treatments do little and are only 'keeping their acne at bay' may result in early abandonment of treatment.*		

		(QR) Difficulty overcoming barriers *Young people can be uncertain about how to manage side effects of treatment, financial constraints, lengthy routines and uncertainties around how to use medication.*		side effects including skin irritation, video with step by step instructions on how and when to apply topical treatments). • Educational information/rationale supported by scientific evidence (topical treatments are equally as effective as antibiotics) • Stories and testimonials to model successful management using topical therapies • Addressing common concerns • Provide list of topical treatments and how they work
		(QR) Confusion between cosmetic and medical treatments for acne *Young people perceive they have tried all the topical treatments available.*		
		(SR) Need for control over treatment choice and disease *Young people want control over their treatment choice as well as their condition as this has been shown to improve adherence and the psychological impact.*	To support and promote autonomy for making treatment choices	• Provide advice on how people can effectively communicate with their GP • Invite, acknowledge and value views/preferences (e.g. CAM therapies) • Provide list of topical treatments and how they work • Offering user choice wherever possible • Autonomy supportive language throughout

		(SR and QR) Difficulty dealing with psychological issues *Young people can be unsure about how to cope with the psychological impact of acne including depressive symptoms, stress, anxiety and embarrassment.*	To provide support and acknowledge the psychological impact of acne	• Acknowledge the psychological impact of acne (e.g. (1) emphasise that everyone with skin disease can be at risk of psychological symptoms, (2) provide patient stories about how they dealt with the impact of acne) • Provide advice on how people can effectively communicate with their GP • Provide advice about different coping strategies
		(SR) Difficulty presenting psychological issues to HCP *Young people may be unwilling to present psychological problems to their HCP.*		

5.3.2 Behavioural analysis

Purpose

To complement the guiding principles, a behavioural analysis was carried out to map the components of the intervention onto the Behaviour Change Wheel (BCW) [78] and elements of the Extended Common Sense Model (ECSM) [69]. The ECSM was chosen as the findings from the systematic review and synthesis of qualitative data (described in chapter 3) and the secondary analysis of interview data (described in chapter 4) linked closely with elements of the model. The components of the intervention were proposed based on the evidence from the systematic review and synthesis of qualitative data, the secondary analysis of qualitative data and evidence from the literature.

Methods

The behavioural analysis involved linking the evidence from the earlier qualitative work and quantitative literature, to intervention components and behaviour change theory. The BCW [78,95] and the Behaviour Change Technique Taxonomy version 1 (BCTTv1) [79] are used to develop complex interventions by identifying which BCTs influence a given behaviour. This is a standardised method of developing interventions as the 93 BCTs allow researchers to use the same terminology when describing which techniques were used in their intervention [79]. The BCW draws on COM-B model, which suggests that behaviour is influenced by a person's capability, opportunity, and motivation to change behaviour [78]. In order to achieve the outcome of improving acne quality of life (QOL), I selected the target behaviour 'appropriate use of topical treatments'. This target behaviour was chosen because evidence suggests that using topicals can effectively improve QoL [47,174]. To address this target behaviour, barriers and facilitators were described along with the intervention component and proposed intervention element. The intervention components were then coded using the BCT and mapped onto the BCW to identify intervention functions and target constructs. Finally, I applied the ECSM to the SPOTless intervention content by seeing where each construct was addressed [69].

Results

The intervention targeted all six target constructs from the COM-B model (physical capability, psychological capability, physical opportunity, social opportunity, automatic motivation and reflective motivation) and used five different BCW intervention functions [78] (persuasion,

education, training, enablement and modelling). It also employed nine different behaviour change techniques which are documented in Table 5. All the constructs from the ECSM were applied to the intervention content. One example is that by providing persuasive and credible information about the side effects of topicals and the safety of them, we are addressing young people's concerns around using topicals and their beliefs about the necessity of treatment.

Table 5: Behavioural analysis of the SPOTless intervention

Key: SR= Barriers emerged from systematic review and synthesis of qualitative papers on acne (described in chapter 3); QR= Barriers identified from the secondary analysis of published interview data (described in chapter 4); QL= Barriers and facilitators emerged from review of literature on acne (including studies testing the effectiveness of interventions to improve adherence to acne treatments).

Target behaviour: Appropriate use of topical treatments						
Barrier/*facilitator* to target behaviour	**Intervention component**	**Spotless module**	**Target construct (BCW)**	**Intervention function (BCW)**	**Behaviour Change Technique (using 93 BCTTv1)**	**Target construct (ECSM)**
Concerns about side effects from topical treatments (e.g. dry skin and bleaching) (QR, SR) (QL) Fabbrocini, et al. [54]- having no side effects was reported as one of the most important attributes of topical treatments	• Provide persuasive and credible information about the side effects of topicals and the safety of them, via scientific evidence and personal stories	Core treatments	Psychological capability; Reflective motivation; Social opportunity	Education; Persuasion; Modelling	5.1 Information about health consequences 6.2 Social comparison 6.3 Information about others' approval 9.1 Credible source	Beliefs about necessity; Concerns over its use
	• Provide advice on how to choose the right topical	Core treatments	Psychological capability	Training; Education	4.1 Instructions on how to perform the behaviour	
Confusion about the different types of topical treatments resulting in difficulty with making own treatment choices (QR, SR)	• Provide advice on how to choose the right topical	Core treatments	Psychological capability	Training; Education	4.1 Instructions on how to perform the behaviour	Curability/ controllability
	• Provide information about different topicals (e.g. most common/least common topicals and how they work)	Core treatments	Psychological capability;	Education	5.1 Information about health consequences	

Belief that topical treatments do little to help as it is only 'keeping their acne at bay' (QR)	• Provide persuasive and credible information about the effectiveness of topicals, via scientific evidence and personal stories • Provide rationale for how topicals control acne • Explain that it can take time for topical treatments to work via personal stories/video	Core treatments	Psychological capability; Reflective motivation; Social opportunity	Education; Persuasion; Modelling	5.1 Information about health consequences 6.2 Social comparison 6.3 Information about others' approval 9.1 Credible source	Beliefs about necessity
	• Provide a chart for them to monitor how their skin is after applying topical treatments each day as part of the 4 week challenge	Core treatments	Reflective motivation	Education; Persuasion	5.1 Information about health consequences 2.3 Self-monitoring of outcomes of behaviour	
Belief that acne is a short-term condition caused by puberty and therefore it will go away on its own (QR) (QL) McNiven [160]- Belief that acne is a cosmetic problem rather than a medical condition	• Provide information on the causes of acne and dispel misconceptions using a myth-busting quiz • Provide persuasive and credible information about how acne can be effectively managed using treatment including	Myth-busting quiz; What are spots or acne; Talking to your GP	Psychological capability; Reflective Motivation; Social opportunity; Physical opportunity	Education; Modelling; Persuasion; Training	4.1 Instructions on how to perform the behaviour 5.1 Information about health consequences 6.2 Social comparison 6.3 Information about others' approval 9.1 Credible source	Cause; Timeline; Identity

	scientific evidence and personal stories • Provide information about what acne is, the importance of treating it early and information about referrals • Provide advice on when to see a HCP about acne • Provide advice on speaking with a HCP about acne					
Lack of skills regarding how to apply topicals and for how long (QR) *(QL) Myhill, et al. [64]- Supplementary patient materials and video about application led to improved adherence;* *(QL) Sandoval, et al. [65]- Education via physical demonstration led to 15% overall higher adherence rates*	• Provide written instructions and an instructional video on how to use topical treatments correctly	Core treatments	Physical capability; Social opportunity; Reflective motivation	Training; Modelling; Persuasion	4.1 Instructions on how to perform the behaviour 6.1 Demonstration of the behaviour 6.2 Social comparison 6.3 Information about others' approval 9.1 Credible source	Concerns over its use
	4 week challenge: • Provide a chart to help people record how their skin is when they have used their topical treatment each day	Core treatments	Reflective motivation	Education; Persuasion	5.1 Information about health consequences 2.3 Self-monitoring of outcomes of behaviour	

Belief that Topicals are time-consuming to apply (QR) *(QL) Rueda [66]- Simplifying regimen and considering patient preference increases adherence*	• Provide information on how to incorporate topicals in everyday life • Reassure people that applying topicals should not be time-consuming • Advise people to plan when they will apply their topical • Suggest applying their topical at the same time in the same context each day	Core treatments	Psychological capability; Automatic motivation	Education; Enablement	1.4 Action planning 4.1 Instructions on how to perform the behaviour 5.3 Information about social and environmental consequences	Concerns over its use
Belief that tablets are easier, stronger and quicker to take effect than topicals (QR) (QL) Santer, et al. [55]- found that some participants preferred oral treatments as they perceived these to be 'stronger' than topicals	• Provide persuasive and credible information about the effectiveness of topicals and antibiotics via scientific evidence and personal stories • Provide information about the consequences of long-term oral antibiotic use	Core treatments; Antibiotics	Psychological capability; Social opportunity; Reflective motivation	Education; Modelling; Persuasion	5.1 Information about health consequences 6.2 Social comparison 6.3 Information about others' approval 9.1 Credible source	Concerns over its use

5.3.3 Logic modelling

Purpose

The purpose of the logic model was to hypothesise how the intervention would work to achieve the desired outcome [175,176].

Methods

The evidence base (earlier qualitative work described in chapter 3, 4 and evidence from the literature) and the behavioural analysis were used to hypothesise how the different intervention components will influence purported mediators and outcomes.

Results

The Logic model included the following components (see figure 6 for the logic model):

1. The problem and intervention targets

The problem is poorly controlled acne in young people which is due to poor adherence to topical treatments. Target behaviour to address this problem was the appropriate use of topical treatments.

2. Intervention techniques and processes

The intervention techniques included a summary of the BCTs from the behavioural analysis and the intervention processes they are hypothesised to affect. These include: knowledge; skills; positive beliefs about consequences of treatments, environmental resources; goals; positive beliefs about capabilities; and social support.

3. Purported mediators and outcomes

The primary outcome of the intervention is QoL. The core behaviour that is most important in determining improved QoL, is regular application of topical treatments to manage acne.

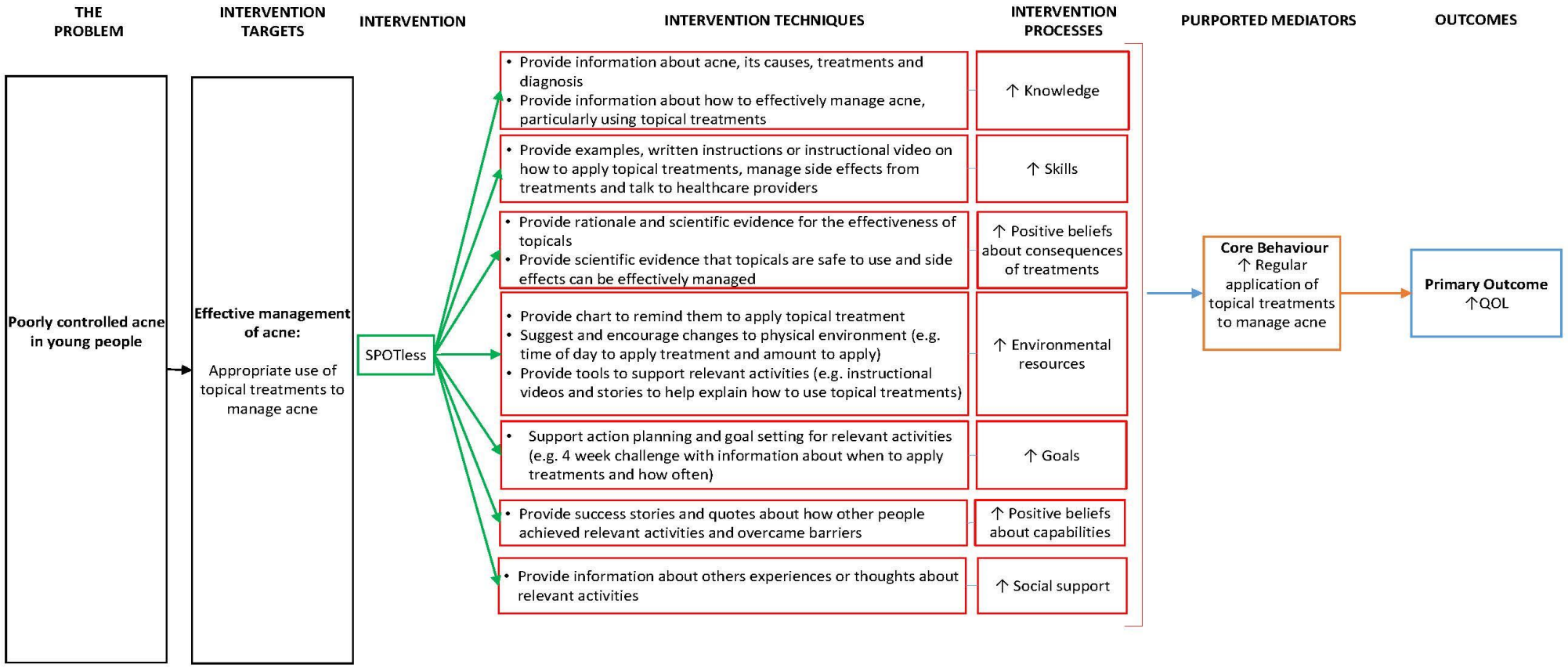


Figure 6: SPOTless intervention logic model

5.4 Intervention

The intervention was developed using the LifeGuide software, which is a tool to help researchers create web-based interventions that do not require computer programming expertise. The process of developing the website involved firstly creating draft pages using a LifeGuide template on word, before incorporating into the LifeGuide platform. This process began in September 2017 and continued until the website was ready to go live for the feasibility trial in September 2018. Input from the supervisory team and patient representatives were consistent throughout the development process. The final intervention was called SPOTless and included seven modules (see Box 1 for visual examples of the intervention):

- **Core treatments** (a compulsory module which provides information about topical treatments for acne, a video about how to use topical treatments appropriately and proposed a 4 week challenge to help motivate participants to adhere to their treatment)

- **What are spots or acne** (optional module which comprises of information about acne including different types, causes and prevalence)

- **Myth-busting quiz** (an optional interactive quiz with the aim of dispelling myths and misconceptions about acne)

- **Oral antibiotics** (optional module which includes information about what oral antibiotics are and its associated risks)

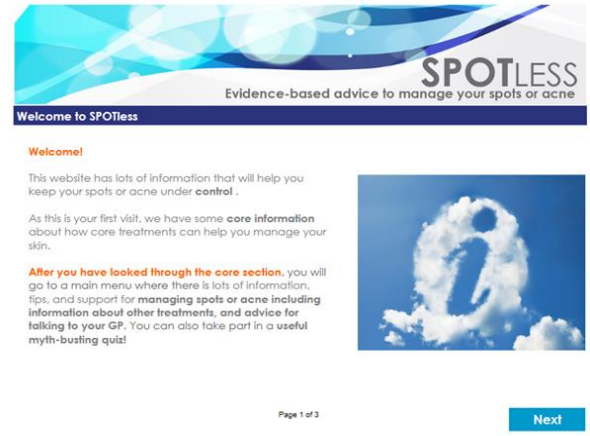
- **Living with spots or acne** (optional module about the psychological impact of acne and different coping strategies)

- **Talking to your GP** (optional module providing advice on how to speak to the GP and the process of referrals)

- **Other treatments** (optional module which includes information about isotretinoin, complementary and alternative treatments for acne and the combined contraceptive pill)

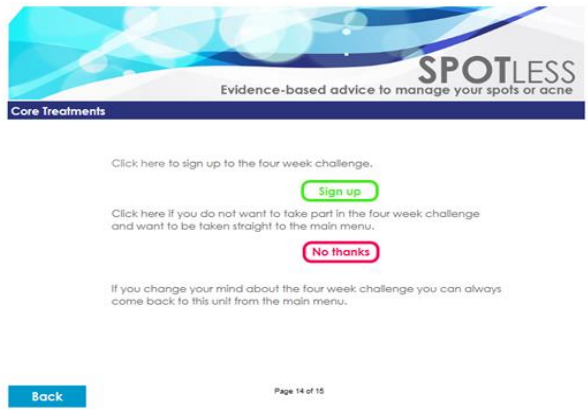
Box 1: Example pages of the SPOTless website.

Welcome Page



Core treatments-list of topicals

Sign up to the 4 week challenge page



Main menu

Example of quiz question page

Example of quiz feedback page

5.5 Think-aloud study

5.5.1 Aims and objectives

The aim of the think-aloud study was to gather user feedback in terms of participants' thoughts, impressions, and experiences using the behavioural intervention. The objectives were to explore participants' views on the following:

- The usability of the intervention
- How engaging the intervention is
- How persuasive they find the intervention
- How relevant they find the content

5.6 Methods

5.6.1 Participants

Invitation for the think-aloud study was via mail-out from five primary care practices in Wessex and opportunistic recruitment. The inclusion criteria were anyone between the ages of 14 and 25 years whose medical records showed that they had acne, or have previously consulted or obtained a prescription for acne in the past year. We asked GPs to ensure that the invitation pack was not sent to patients who they felt were unsuitable for the study. We also displayed posters in hospitals, community pharmacies and at the University of Southampton. The posters included a telephone number and an email address to the study team, which people could phone if interested. Participants aged 16 and over were sent an 'adult study pack' containing a covering letter, information sheet, reply slip and a freepost envelope. Participants under 16 were sent a 'child study pack' which included a covering letter addressed to the parent/carer, information sheet for the parent/carer, information sheet for the young person, reply slip and a freepost envelope (see appendix E for the information sheets and poster). Advertising via social media (Facebook, Twitter etc.) was also used to recruit participants. Ethical approval was obtained from the University of Southampton (ID: 31721) and NHS ethics committee (IRAS ID: 223028) on 31st May 2017.

5.6.2 Procedure

I contacted participants who returned a reply slip to arrange a time and place for an interview. Prior to the interview, participants were asked to fill out a consent form if they were aged 16 years or over. Participants under 16 years were asked to sign an assent form and their parents a consent form. Face to face think-aloud interviews were carried out by myself or by a medical student (Y.B.) who was carrying out supplementary interviews for her student project. People aged under 16 years were given the option to have their parent/carer present during the interview. Interviews were carried out between October 2017 to March 2018 and lasted approximately thirty minutes to an hour and half. The researcher conducting the think-aloud interviews followed a semi-structured interview guide to ensure that all topics were covered while leaving room for the participants to discuss any other concerns they had (see appendix F for the interview guide). The interview guide included open questions to allow the participant to speak more freely about their views and perspectives. Prompts including 'What are your first impressions?' were used throughout to ensure that each page was explored in detail. Finally, post think-aloud questions (e.g., what did you like about the website?) were asked to gain an overall impression of the website. All interviews were digitally recorded to enable transcription. The transcripts were anonymised and I checked these against the recordings to ensure accuracy.

5.6.3 Data analysis

Y.B. created a feedback summary, which included positive and negative comments from participants about the draft core material. This enabled me to further refine the intervention before carrying out additional interviews on the website as a whole. For my analysis, I began by repeatedly reading the transcripts to familiarise myself with the data before coding this using a deductive approach. This involved looking specifically for comments related to the objectives of the study (engagement, persuasiveness and usability). I decided to analyse the data this way because the purpose of the interviews were to pull out positive and negative comments to aid intervention development. Key quotes were inputted into a table of changes which is a similar approach to a coding matrix in framework analysis [105]. The table of changes was used to determine whether a change was necessary based on how important it was, whether it was easy to change, mentioned repeatedly, supported by experts or supported by evidence (see appendix G). Iterations were subsequently made to the website based on comments from participants and discussions with the supervisory team. The themes presented below can be seen in the final column within the table of changes in appendix G.

5.7 Results

Y.B. interviewed nine participants who were recruited opportunistically from the University of Southampton. I later carried out 10 additional interviews with participants via primary care (9) and community advertising (1). The sample consisted of 74% females (14) and 26% males (5), participants were aged between 15 and 21 years (with a mean and median age of 19 years) and they were all students either attending school, college or University.

5.7.1 Engagement

Relevance

Most participants enjoyed the myth-busting quiz as they thought it was a good way of testing what they had learnt in prior modules. Some participants felt that the quiz was aimed towards people who were newly diagnosed with acne, as they had previously searched for answers to some of the questions themselves. A few participants reported learning new information and felt that the concept of myth busting was important so that people could manage their acne effectively.

> *I think the, the questions are all actually helpful. They were actual questions that I've had previously and I know other people would have had. So, I think if you - would this website it'd kind of be to go to before going to see your GP or just generally, if it were to… (Participant 12, aged 16, male)*

Participants found the quotes encouraging, for example seeing other people find success using their treatment for 6 weeks made them feel as though they could do it too. This was possibly due to the personal relatable nature the quotes provided making them feel less alone in their condition. Some participants connected less with the quotes in the module 'living with acne' as they reported them as extreme. I therefore, changed the quotes on this module to make them more applicable to the intended user. Another change suggested by participants were to attach names and ages to quotes to make them more relatable.

> *"I think because it's like – stuff that I can relate to, like the thing – like the content of the quotes is something that I've also experienced; so it's like – again – it's about being able to relate to the website and knowing that other people are having similar experiences. And I think it's kind of – nice to see that" (Participant 7, aged 18, female)*

The information about how to manage side effects from topical treatments was perceived as useful, with some expressing how they would have liked this information when they were experiencing it themselves. For some participants, information about sun sensitivity was not applicable in the UK. Others spoke about how their GP had told them that even in cloudy weather sun sensitivity could be a problem and felt that this should be made clearer on the website. For that reason, under sun sensitivity I included a sentence stating that even in cloudy weather sun can be a problem.

> *The sun sensitivity one wouldn't bother me as a person and I don't know if that's because we live somewhere like England or just because we're not outside a lot (Participant 6, aged 21, female)*

Participants were positive about the challenge as they liked the concept and felt that it would be easy to do. They also appreciated being told that treatment would take time to work as from their previous experiences when they were told that treatment would work quickly this was not usually the case. Participants found the chart useful to help them keep track of their progress and stay organised. The 6-week challenge was later changed to 4 weeks based on evidence from a recent study, which suggested that topical treatments could take effect within 1-4 weeks [64].

> *I'm conscious if I'm repeating myself. I think it's nice because, it's, it's, kind of, nice because it gets you thinking, oh, it's like a challenge for myself, so like, like adding it to your routine. 'Cause like a lot of people like having a set routine but like adding new stuff in that will benefit you is actually really useful. If I didn't already like use my, like use this skin stuff religiously, I would like use this to help me. (Participant 17, aged 15, female)*

A number of participants found the module 'Talking to the GP' useful, particularly information about when people should consult. Participants spoke about how they would have liked this information previously as from their own experience they tried numerous over the counter products before seeking medical attention. For some, this was because they viewed acne as a cosmetic or hormonal problem instead of a medical condition. Participants also found the information about dermatologists and tips on how to get the most out of their consultation beneficial.

> *"Because some people don't know when you should actually go to your GP 'cause at first I used to just think it was hormonal, growing-up but like when I realised that I wasn't wearing make-up, I wasn't doing this, I was like, 'Actually, I need to go and speak to my GP, this is not normal.' (Participant 19, aged 18, female)*

Young people were particularly interested in the 'Living with spots or acne' module, as they had or were currently experiencing psychological impact because of their skin. They spoke about how they had used some of the coping strategies themselves which they found helpful. For example speaking to friends and family and applying make-up. One participant suggested putting a link to the NHS website about mental health, however, this change was not implemented as only one participant proposed this and it was not seen as necessary.

> *"Yeah, sometimes you are a bit embarrassed so, yeah, it's kind of good to know that, if you can find a way that helps you, you can kind of just get on with it and eventually solve it." (Participant 11, aged 16, male)*

People thought that the information about antibiotic resistance was very important, as they did not think many people were aware of the risks. Furthermore, they seemed very interested and reported feeling worried by the fact that antibiotics should not be used for longer than 6 months, as for some they had been on the medication for longer.

> *"Yeah, I, I think it's like quite interesting 'cause I, I didn't - I think I've been using one for a lot longer than six months and nothing's been said about that and I didn't actually know that until now and - but, yeah, I think it's like quite important that people know about how it, um, can increase resistance and how that can affect you in later life. [Pause]" (Participant 14, aged 16, male)*

5.7.2 Persuasiveness (levels of trust)

Many participants found the evidence boxes reliable as the statistics were supported by research. One statistic from the 'Oral antibiotics' module about the effectiveness of topical treatments over oral antibiotics, was less convincing. This was possibly because people perceived oral treatments to be 'stronger' and the reference for the statistic was missing. I later included the statistic and clarified that this was referring to people with mild to moderate acne. Furthermore, the 'Meet the team' page received positive feedback as numerous participants reported that they trusted the advice because professionals wrote it.

> *"This is more science [in comparison to other websites], so I like it more and I trust it more, because it's not like – it's not overloading you with stuff, but it's like actual treatments and it's like you can get this from the GP and you can get this from the pharmacy as opposed to Cosmo telling me to put lemon on my face" (Participant 3, aged 20, female)*

A number of participants were confused with the term 'Universal core treatments' as a name for the core module on topical treatments. They assumed that universal treatments meant branded products from the supermarket and expressed concerns that there was a potential commercial element to the website. This appeared to make participants react with distrust as the thought that there was an advertising element made them question the purpose of the website and the financial costs of treatment. After discussions with the team, I changed this module to 'Core treatments'.

> *"I think this idea of universal acne treatment, I wouldn't have called universal acne, the stuff that you get given by the GP; I would have immediately assumed it was like – the branded, like off the shelf kind of stuff. (Participant 2, aged 20, female)*

> *"Universal core treatments sounds quite like you're advertising something. I'm starting to think about my budget". (Participant 5, aged 19, female)*

5.7.3 Usability (includes jargon, clarification and terminology)

Views on terminology

Most participants found the terminology used throughout the website easy to understand. Although, some participants wanted further clarification on the steps for applying topical treatments. This included defining what a thin layer was, clarifying what sensitive areas of the face were, and when the most appropriate time to apply them were (day or night). After discussions with the team, further clarifications were made to all these areas.

> *"Oh yes, yes. I think that – the bit where you could have – clarification is Step 3; try to avoid other areas – because there is a lot of stuff in there like – paperwork that's – avoiding certain bits like eyeballs and stuff, which is fair enough (I: Yes) But – yes, some clarification, I think, would be in areas that you should avoid, if possible." (Participant 8, aged 20, female)*

Some participants were also unsure about the phrasing of 'choose your favourite first line treatment' for the 6-week challenge, because many of them did not have a favourite or did not remember what topical treatments were available. The phrasing of this was later changed and a link to the previous list of treatments was included so that participants had the option to click back.

> *"I like the steps, just apart from the [first one] where it says choose your favourite first-line treatment. So if you're starting out from scratch, how would you know what your favourite one is, if you haven't tried any of them before?" (Participant 4, aged 21, female)*

There were mixed reactions regarding the use of spots or acne on the website content. Some participants preferred acne as it made them feel as though it was legitimising their condition. Whereas, others did not have a preference between the two and expressed how it would be better to be inclusive. We decided to keep both terms as the website is aimed at people with mild to moderate acne who may consider themselves to have spots as opposed to acne.

> *And I think, I think spots or acne, leaving it as it is would be useful. I mean, there's, I think as hard as it would be to read, I don't know if that's the right word, but it would be - I'd personally say go for the spots or acne because it's more inclusive. And you won't necessarily think oh, this is only for a really bad skin problem, or only this is for a really light skin problem. Yeah, I think that's what I'd say. (Participant 12, aged 16, male)*

Structure and layout of website

Young people found the website easy to use, in terms of the layout being easy to follow and navigate. The design of the banner and colour scheme was refined with the help of a graphic designer and participants commented on how professional it looked. Although, some still wanted search bars or dropdown options much like a traditional website. This change was not implemented due to limitations of the LifeGuide software.

> *I don't know maybe things here or like search bars on the top where you could put in like different, do you know what I mean? Like dropdowns at the top or something like (Participant 16, aged 21, female)*

Participants found the page including the list of topical treatments overwhelming in terms of how the information was presented. I therefore, incorporated popup boxes to condense the information and to allow me to be clearer about what brand names were associated with which topical treatments. After making the changes, participants seemed more engaged and positive.

> *"Yes, it was literally just a list of different drugs which I don't think would be that helpful, or maybe if it was set out like the later pages, where you can click on something if you're interested. But other than that, I think the amount of information that you gave and the way that you're given it, is quite well done." (Participant 7, aged 18, female)*

In the early interviews with Y.B., participants wanted to see pictures of treatments as well as before and after photos. I did not include these as in later interviews participants commented on how they preferred the scenic images to pictures of skin. One participant wanted a video about how to use topical treatments appropriately. A short video [177] demonstrating how to use Epiduo was included which participants found useful and informative.

> *"Maybe just like a short video of someone going through the routine of wash your face, dry it, put the cream on; that could be about five seconds and it was like you can see it being done, you can see it doesn't take that long, you can see it's not that hard. You've kind of got no reason not to do it, that's the only thing, I think" (Participant 3, aged 20, female)*

5.7.4 Public and Patient Involvement

PPI members also provided their thoughts on how the draft website could be refined after think-aloud interviews. One member commented on how they felt the pictures were appropriate and made the website more engaging, the text was easy to read and the colour scheme was nice. As for the content, they thought the modules were relevant and the overall website was factual, informative and helpful. They also commented on how the website provided a nice overview and particularly valued the information about treatments as from their own experience, researching about all the available treatments for acne was overwhelming. Overall, they thought the website was appropriate for the target population. A negative comment was that they had concerns around the website header referring to acne or spots as they felt that young people may feel embarrassed if they were looking at the website in public. They suggested 'skin health' although, this was not changed for reasons including that 'skin health' could refer to many skin conditions and participants in the think-aloud interviews did not comment negatively on this aspect.

The other member commented specifically on the layout of the website. They wanted to see more images particularly as the website was targeted towards young people. Additional images were added where necessary. They also spoke about how they did not like the contrasting red colour on the texts which referred to important information. The colour of the text was changed but ensured that the message was not lost.

Both PPI members wanted the layout and navigation of the pages to look like a traditional website with drop down options on one page. This was also mentioned by participants in the think-aloud study but as discussed above, this was not changed due to limitations of the LifeGuide software.

5.8 Discussion

5.8.1 Principal findings

The think-aloud interviews were carried out to see whether the website was engaging, persuasive and acceptable for the intended user. Overall participants found the website engaging, as they commented on how relevant the content was, specifically information about side effects, psychological impact and talking to the GP. They particularly enjoyed the quotes as they found these relatable and encouraging. Most participants were positive about the 4 week challenge and felt that they would be able to complete it. Participants found the website persuasive as professionals wrote it and the evidence was supported by references. Although, some participants had reservations about the module name 'Universal core treatments' as they thought it was advertising something. Generally, participants found the website easy to use and free of jargon but some wanted further clarification in some areas. Main changes made as a result of the interviews included: adding pseudonyms and ages to the quotes to make them more relatable; changing the context of the quotes within the module 'Living with spots or acne' to improve relevancy; clarifications about how to manage sun sensitivity from topicals were made to ensure that people were aware of the potential impact of sun even in cloudy weather; the steps for applying topicals such as the time of day, how much to apply and what sensitive areas are on the face were also defined; the 6 week challenge was changed to 4 weeks based on recent evidence; the module 'Universal core treatments' was changed to 'Core treatments' so that participants would not misinterpret the website as advertising something; and the layout of the intervention in terms of images, banner and colour scheme were modified based on comments from early interviews conducted by Y.B. on the draft content.

5.8.2 Findings in relation to previous research

Similar to previous studies, participants spoke about the delay in seeking medical attention [151] and therefore acknowledged and valued the importance of advice about speaking to a GP. The 4 week challenge was generally well received, similar to a previous study where young people with eczema were given a 2-week challenge to use their emollients [160,178]. Participants in this study were particularly interested in the psychological aspect of the intervention as for many this was a common experience and is in line with the literature suggesting substantial psychological impact of acne [154,169].

Participants also acknowledged how influential side effects of topical treatments had been on their previous adherence and therefore, welcomed the information on how to manage these appropriately as well as feeling motivated to use them. Having this knowledge, possibly helped participants to feel less concerned about their treatment, which could potentially influence adherence to medication as demonstrated by the ECSM [69].

Previous research has also shown how people like receiving 'experiential advice' from other people with the same health condition as them [179] which may be why participants felt encouraged by the quotes in the SPOTless intervention.

In this study, participants trusted the information because they were told who had developed the website and were provided references regarding where the evidence had come from. This contrasts with existing literature exploring views of antibiotic use on online discussion forums as it appeared that people trusted the information regardless of the source [55]. It was clear from this study, that the way participants perceived the motive behind the website influenced whether they were going to take on board the advice. This highlights the importance of stating clear aims of the website and providing accurate sources.

Participants found the website appealing and easy to use, which they emphasised as an important aspect. With the increasing use of the internet to search for information about health conditions [55] it is important that this website is engaging to prevent people from going on unreliable sources where information is not always accurate.

These findings are also consistent with existing literature on interventions for acne. The video received a positive response from participants similar to findings from Myhill et al's RCT (use of supplementary patient educational materials to improve adherence to topicals) [64] as they found increased adherence in the group that received supplementary patient educational materials (including a video) in addition to standard education from their GP. Furthermore, the video includes a demonstration of how to apply topicals and a RCT where participants were given a physical demonstration of how to apply topical treatments found that this improved adherence rates by 15% [65]. In the interviews, most participants reported feeling that they could do the 4 week challenge as it seemed easy to incorporate into their routines which is consistent with findings from a RCT that found simplification of routines increased patient satisfaction [66]. Although, participants wanted the instructions on how to apply topicals to be further simplified in terms of time of day for application, quantity and specific areas to avoid. Participants in this study reported that they had obtained new information from specific modules, similar to a previous

pilot RCT [62] where participants in the intervention group received interactive health education and reported better quality of life despite being limited by sample size. This suggests that people with acne are very keen for information, online interventions and instructional videos to help them use treatment appropriately.

5.8.3 Limitations

There was a potential risk of social desirability bias influencing people's opinions, as participants were aware that I had created the website [180]. However, nine of the interviews were carried out by another researcher who was not involved in the website development. A further limitation was that the sample was all students, with the majority being university students. Therefore, they may have given a less broad range of responses than those from more diverse backgrounds. The majority of participants in Y.B.'s interviews were also medical students who would have had a better understanding about treatments and acne in general. Although, from the data it seemed as though these participants were putting themselves in the position of someone who did not have this knowledge. Changes to the website were made at various time points depending on discussions with the team and therefore, it is difficult to be certain whether these changes had a positive impact on participant's perception of the website. Further qualitative interviews in the form of follow-up interviews after the feasibility trial are needed to continue developing the intervention.

5.9 Conclusion

The findings showed that the intervention was usable, persuasive and engaging. This suggests that online advice could help young people manage their acne more effectively and may have potential in improving adherence to topical treatments.

Chapter 6 Feasibility randomised trial of the web-based behavioural intervention

6.1 Aims of chapter

In this chapter I will present my final empirical study, which is a feasibility randomised trial of the SPOTless intervention to support self-management of acne. First, I will provide my rationale for carrying out a feasibility trial on the web-based behavioural intervention. Then I will describe the methods used in the trial, present my results and discuss my findings.

6.2 Introduction

As described in chapter 2, feasibility trials are small studies designed to assess the feasibility of carrying out a future definitive trial[117]. Furthermore, they are an essential part of complex intervention development [123]. Currently, here are a limited number of interventions developed to improve adherence to acne treatment [60-64,66] and only three of these have been subjected to feasibility or pilot testing [61,62,65]. Research suggests that this is not uncommon and that many studies often skip this vital step before taking their interventions to trial [181]. As a result, these trials have a number of issues with acceptability, delivery, recruitment and retention and are often small in sample size [181]

Few trials in acne have recruited through primary care, instead the majority have recruited through secondary care or have not reported where participants are from. A randomised controlled trial (RCT) investigating the use of supplementary patient educational material on adherence to a topical, recruited 97 participants via primary care clinics in the UK , however there was no statistical rationale for sample size calculation and the decision to recruit 30 participants per group was estimated based on previous research [64]. As there is very little information regarding uptake and retention rates for this group, further feasibility trials are needed to establish this.

I therefore, carried out a feasibility trial of the SPOTless intervention to address these uncertainties and to inform a future trial. In particular, I wanted to determine recruitment and retention rates for this target population; the feasibility of randomised controlled trial

procedures; uptake and use of the intervention; and describe outcome measures in terms of completion rates and trends.

6.3 Methods

6.3.1 Design

I carried out a feasibility trial with two parallel groups randomising participants to either usual care alone or usual care plus access to a web-based behavioural intervention called SPOTless.

6.3.2 Outline of web-based intervention

Development of the SPOTless intervention is described in chapter 5 but I will briefly summarise the content and structure here. The intervention was developed using the LifeGuide software enabling me to evaluate and modify along the way. The final intervention includes a main menu with seven modules identified as key themes from the qualitative studies described in chapter 3 and 4 (Core treatments, What are spots or acne, Myth-busting quiz, Oral antibiotics, Living with spots or acne, Talking to your GP and Other treatments). The module 'Core treatments' is a mandatory module before participants are able to access the other modules on the main menu. As part of this module, participants are asked whether they wish to take part in a 4 week challenge using a topical treatment. This involves picking a topical treatment and using it for 4 weeks as advised by the intervention.

Based on findings from the qualitative research, the Extended Common Sense Model of Illness (ECSM) was used to inform the intervention and specific Behaviour Change Techniques were used to promote the target behaviour 'appropriate use of topical treatments' to improve quality of life. Example behaviour change techniques included: providing simple instruction on how to apply topical treatments, reassuring patients about side effects of topicals and how to overcome these, modelling through people's success stories, helping people understand the misconceptions of acne and the dangers of antibiotic resistance, and providing information about what others think about relevant activities.

6.3.3 Intervention and comparator

Usual care:

Participants in the usual care arm received all treatment as usual including appointments, advice and prescriptions as required from their GPs. If necessary, GPs could refer participants to specialists (e.g. dermatologists) in line with usual care. They were given access to the SPOTless web-based intervention after completion of the 6 week follow-up questionnaires.

Usual care plus SPOTless intervention:

Participants in the SPOTless web-based intervention arm received treatment as usual, in addition to being given access to the SPOTless intervention to help them self-manage their acne.

6.3.4 Study population and inclusion/exclusion criteria

Participants were recruited through a mail out from 20 general practices in the Southwest of England.

Inclusion criteria for GP database searches were included: current acne; received one or more prescriptions for the treatment of acne within the last 6 months; and aged between 14 and 25 years. The participant information sheet highlighted that it was essential to have internet access, an active email address and the ability to read/understand English without assistance, as the intervention was web-based and in English

Exclusion criteria: prior participation in the think-aloud study; acne now clear; and currently on oral isotretinoin for their acne (since the purpose of the intervention was to encourage use of topical treatments, which are not recommended alongside oral isotretinoin due to side effects such as dry skin).

6.3.5 Procedure

Practices sent an ‘adult study pack’ to potential participants aged 16 and over, which included an information sheet with contact details if they wished for further information, a freepost envelope, a covering letter from the GP, a sign-up sheet and an A5 colourful flyer. Participants under 16 received a ‘child study pack’, which was addressed to their parent/carer and included an information sheet and a covering letter for the parent/carer, an information sheet with contact details if they wished further information for the young person, a freepost envelope, a sign-up

sheet and an A5 colourful flyer (see appendix H for the information sheets, sign-up sheets and the A5 flyer). The sign-up sheet included a unique participant identification number and the link to the web-based intervention. Implied parental consent was approved by both the University and NHS ethics committees for participants aged under 16 as invitation letters were sent to the parents, who passed login details to their child inferring consent. The link directed all participants to further information and an online consent procedure. After consenting, participants completed a set of baseline questionnaires before being randomised to one of two groups described above.

6.3.5.1 Randomisation

The randomisation sequence was automatically generated using the LifeGuide software using a, computer-generated algorithm. The intention was to block randomise patients with a 2:1 ratio for intervention to usual care group, but due to a randomisation error on LifeGuide, this was in fact a ratio of 1:1. Participants were randomised after completion of baseline questionnaires and the study team were informed which group they were allocated to via an automated email by the LifeGuide software.

6.3.5.2 Follow-up

Participants received an email at 4 weeks and 6 weeks with a link to complete their follow-up questionnaires. A reminder email was sent to participants a week after their follow-up emails at 5 weeks and 7 weeks if they had not completed these. A further text and phone call were sent following this (see appendix I for wording of emails). Participants were contacted by the study team up to 6 weeks after the 6 week follow-up to complete the questionnaire over the phone.

6.3.6 Outcomes

The primary outcomes for the feasibility trial were as follows:

- Number of practices required to recruit the participant numbers and the rate of recruitment.
- Number of participants withdrawing at 4 weeks and 6 weeks follow-up.
- Intervention usage in terms of number of logins and modules accessed.
- Completion rates of a number of quantitative questionnaires.
- Appropriateness of the Skindex-16 as a potential primary outcome measure for a future full trial.

Secondary outcomes:

- Appropriateness of a range of quantitative outcome measures.

The outcome measures included the following:

The Skindex-16 instrument [182] was included as a skin specific quality of life measure to assess how people feel about their skin. It was chosen as a potential primary outcome measure, as it is a reliable and valid measure for general skin conditions with a Cronbach's alpha between 0.86 and 0.93 [182]. PPI also suggested that they preferred this over the Acne Quality of Life (Acne QoL) measure. They found the questions on the Skindex-16 more relevant and liked how the questionnaire referred to 'skin condition' rather than specifically acne, or acne scars. They had reservations about the Acne QoL measure as this was linked with the pharmaceutical company and felt that this may affect people's trust in the intervention. The Skindex-16 measure includes 16 items with a 6 point Likert Scale ranging from 0 (never bothered) to 6 (always bothered) which I transformed into a 100-point scale as per usual practice. Higher scores indicated lower level of quality of life. As a potential primary outcome for the main trial, Skindex-16 was made compulsory whilst secondary outcome measures were optional. The questionnaire was measured at baseline, 4 weeks and 6 weeks follow-up as a recent study suggested that topicals could take effect within 1-4 weeks and that continuation after the 4 weeks would lead to further improvements [64]. Table 6 shows a list of all the outcome measures and time points at which they were measured.

The EQ-5D-5L [183] was included as a generic measure of quality of life. This measure is shown to have good validity and responsiveness in people with skin disease [184]. The EQ-5D-5L consists of five domains including: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Within each domain there are five levels consisting of: no problems, slight problems, moderate problems, severe problems and extreme problems. Participants were asked to indicate one of the five levels that best described their current health state.

As part of the EQ-5D-5L, a visual analogue scale (EQ VAS) was used to record the patient's self-rated health on a scale ranging from 100 (The best health you can imagine) to 0 (The worst health you can imagine) [183]. This was collected at baseline, 4 weeks and 6 weeks follow-up.

The Problematic Experiences of Therapy scale (PETs) was included as it is a valid and reliable measure of attitudes that predict adherence such as instrumental and affective attitudes, perceived attitudes of others, and perceived control over adherence [185] . It has been shown to have good internal consistency with a Cronbach's alpha between 0.84 to 0.96 [185]. It also uses a patient-centred approach which is useful for identifying where people may need further help to manage their treatment [185]. This was collected at baseline, 4 weeks and 6 weeks follow-up. The scale includes 12 items with 4 subscales including: "problems due to symptoms" (items 1–3), "problems due to uncertainty about therapy" (items 4–5), "problems due to doubts about treatment efficacy" (items 6–8), and "practical problems" (items 9–12). Participants' responses were scored on a scale ranging from 1 (disagree strongly) to 5 (agree strongly), with higher scores indicating fewer barriers to adherence. To score the data, the relevant items were added together and divided by the number of items in that subscale as described in Kirby and colleagues [185]. This method provided an indication of the total number of perceived barriers encountered during therapy.

I also included a treatment monitoring questionnaire which was collected at baseline, 4 weeks and 6 weeks follow-up. This questionnaire consisted of five items asking participants what topical treatments they were using, whether they experienced side effects, how they dealt with these, how often they were using treatment, and any other treatments they were using for their acne. This was included in order to monitor participant's use of treatment throughout the trial.

The Credibility/ Expectancy questionnaire (CEQ) [186] was used to measure a person's belief about their topical therapy and its likely success. This measure was chosen as it is easy to administer and has been shown to have high internal consistency, with a Cronbach's alpha between 0.79 and 0.90 for the expectancy factor, and between 0.81 and 0.86 for the credibility factor [186]. It was collected at baseline only because we were interested in seeing participants' beliefs about their treatment at the beginning and what they expected to happen by the end of the 6 weeks. The CEQ is split into two sets of questions: the first set consists of four questions that assess what a person **thinks** of their therapy and its likely success and the latter, consisting of two questions, assessing how a person **feels**. As the CEQ comprised of two types of rating scales, one from 1 (not at all) to 9 (very much) and another from 0% (not at all) to 100% (very much), the percentage rating scale were therefore, transformed into the 1 to 9 scale to provide an overall score ranging from 3 to 27 for each factor [187].

Anxiety and depression were measured as research has shown that people with acne often experience psychological impairment. This was measured using the Patient Health Questionnaire (PHQ-4) [188] as it is a brief screening tool and has been shown to be reliable and valid for assessing depression and anxiety in young people with a Cronbach's alpha of 0.81 [189]. This was collected at baseline, 4 weeks and 6 weeks follow-up. It consists of four items assessing how bothered a person feels in the last two weeks. The Likert Scale consists of 4 points ranging from 0 (Not at all) to 4 (Nearly every day). To provide a score for anxiety, the first two questions were added together and the last two questions were added together to provide a score for depression. A total score of three or more indicated depression or anxiety.

Table 6: Outcome measures and time points

Name of questionnaire	Time points it will be collected
EQ-5D-5L [183]	Baseline, 4 weeks & 6 weeks
Skindex-16 [182]	Baseline, 4 weeks & 6 weeks
Problematic Experiences of Therapy Scale (PETs) [185]	Baseline, 4 weeks & 6 weeks
Credibility/ expectancy questionnaire [186]	Baseline
Patient Health Questionnaire (PHQ-4) [188]	Baseline, 4 weeks & 6 weeks
Treatment monitoring	Baseline, 4 weeks & 6 weeks

Additional measures:
Demographic data including age, gender, education, age of onset of acne were collected at baseline only. This information was collected in order to adjust for them as potential confounding variables.

6.3.7 Sample size

The target for this trial was to recruit 65 participants, with 25 in the usual care arm and 40 in the web-based intervention arm. We initially wanted the intervention arm to be larger as we wanted more data on intervention usage to see whether the intervention was feasible, but due to the randomisation error participants were randomised equally between groups. This sample size, within a feasibility trial is sufficient to determine the aims and objectives of my study, as guidance

for appropriate sample sizes in feasibility trials range from 12 to 30 plus participants in each arm [190,191].

6.3.8 Data collection

All outcome measures and data regarding intervention usage were collected using automatic data generated from LifeGuide including: number of logins; number of participants signing up to the 4 week challenge (based on whether they entered a start date); number of participants completing the core module; and number of participants visiting other modules.

6.3.9 Analysis

The number of practices recruited and the number of withdrawals were presented in descriptive statistics. The outcome measures were analysed using SPSS version 25 [122]. Estimates of mean scores with key outcome measures between the groups (with 95% confidence intervals) at follow up were made using linear regression (assuming normally distributed residuals), adjusting for baseline scores, age, gender, education and age of acne onset, which were pre-specified as potential confounders. Significance testing was not carried out since the study was not powered to do so and beyond the scope of the feasibility trial purpose. The analysis were carried out on an intention to treat basis including all participants who were randomised, without imputing any missing data.

6.3.10 Ethical approval/Amendments

The feasibility trial was approved by the National Research Ethics Service committee East of England (REC ref: 18/EE/0105) and was registered on ISCRTN registry (ISRCTN number: 78626638) where the protocol can be accessed. As this was a feasibility trial, a number of amendments were made including changes to the sign-up process and participant facing documents. These revisions were critical to assess the feasibility of the study with a population that is challenging to recruit.

On 18th December 2018 I received approval to include a colourful A5 flyer in the study pack (see Appendix H). This was included to improve the response rate to the study.

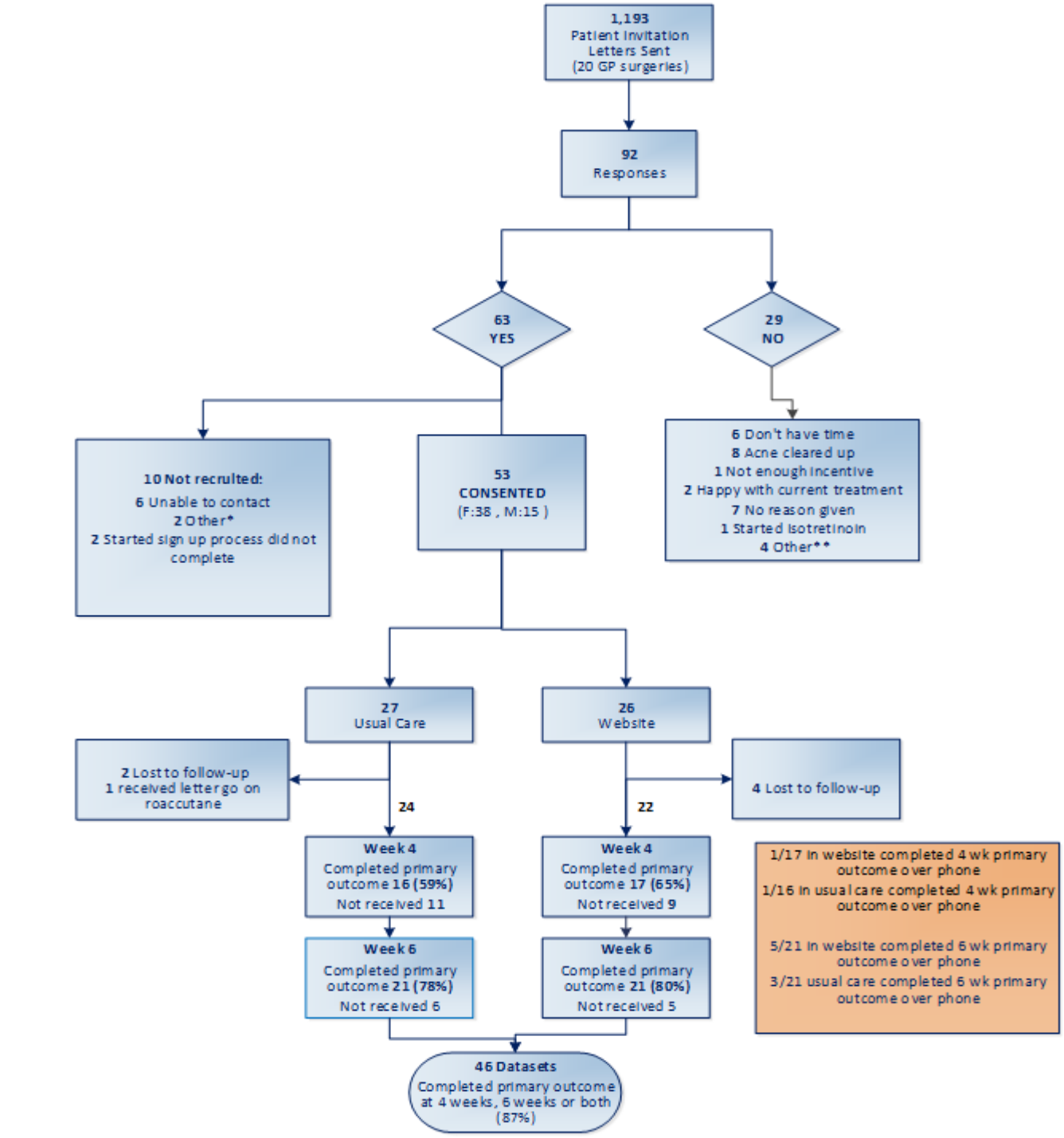
On 30th January 2019 I received approval for an amendment to enable participants to sign up to the study directly, taking out the additional step of first sending back a reply slip before participants were given the web-based intervention URL/ID number. We created a new sign-up sheet to facilitate this change. This was to address the low response rate as well as the large drop-

off between people who posted their reply slip to the study team but then did not complete online registration. We also made the following changes to the language used in the participant facing materials to make it more accessible in line with suggestions from public and patient involvement (PPI). I replaced the words 'intervention' and 'trial' with 'website' and 'study' to make the terminology easier to understand for a lay person, I also replaced the word 'child' with 'son/daughter' in the parent/carer materials to be more appropriate for 14 and 15 year olds.

6.4 Results

6.4.1 Recruitment

A total of 1193 invitation letters were sent out from 20 GP surgeries in the Southwest of England. The recruitment process lasted from September 2018 to April 2019 and the follow-up period ended in June 2019. I received 92 (8%) responses: 63 out of 1193 (5%) participants wished to take part, and 29 (2%) provided reasons why they could not. The main reasons reported were that their acne had cleared up or that they did not have enough time. In total, 53 out of 1193 (4%) participants registered online and were randomised. A total of 46 out of 53 (87%) participants had completed the primary outcome either at 4 weeks, 6 weeks or at both time points and 7 (13%) were lost at follow-up. Specifically, 33 (62%) participants completed 4 weeks follow-up and 42 (79%) participants completed 6 weeks follow-up. Figure 7 shows the flow of participants throughout the trial. In total, five practices were recruited using all the amended documents which resulted in 4.8% of participants signing up compared to 4.5% prior to amendments.



* Problem with LifeGuide randomisation procedures incurred delay and participants did not log back in
**Felt like homework; not planning on using topicals; not interested

Figure 7: SPOTless patient flow diagram

6.4.2 Participant characteristics

Table 7 shows participant characteristics at baseline including those subsequently lost at follow-up. I did not exclude the person who started isotretinoin during the study as they were not taking this when they signed up. The sample included 38 (72%) females and 15 (28%) males aged 14-25 years with a mean age of 19 years. The mean age at onset of acne was 14 years. Of the 53 participants, 74% reported living at home and 83% were in education.

Table 7: Participant characteristics

Participant characteristics	Web-based intervention (n=26)	Usual care (n=27)	Total (n=53)
Gender n (%)			
Female	21 (81)	17 (63)	38 (72)
Male	5 (19)	10 (37)	15 (28)
Age (years), mean (SD)	18.3 (2.6)	18.8 (3.4)	18.6 (3)
Age onset of acne (years), mean (SD)	13.54 (2.1)	13.8 (2.5)	13.7 (2.3)
Living at home, n (%)			
Yes	21 (81)	18 (67)	39 (74)
No	5 (19)	9 (33)	14 (26)
Education, n (%)			
Yes	22 (85)	22 (82)	44 (83)
No	4 (15)	5 (19)	9 (17)

6.4.3 Intervention use

A total of 23 participants out of 26 in the web-based intervention group, completed the core module. Although this module was compulsory, participants were able to click off the web-based intervention freely and go to the main menu when they logged back in. A total of 18 (69%) participants visited the web-based intervention three times or more including baseline sign-up visit. Less than half of the participants (36%) signed up to the 4 week challenge, but this was a little difficult to determine as the 4 week challenge was based on whether participants entered a start date and not if they downloaded the chart or did the challenge without entering a date. There were low uptake of other modules, with 45% looking at the module 'Living with spots or acne' and the least number of people visiting the module 'Talking to your GP' (12%) (see Table 8). Table 9 shows how module choices clustered within person. A total of 15 out of 26 participants in the intervention group visited optional modules. 11 of these visited the 'living with spots and acne module and only 1 participant looked at all of the modules.

Table 8: Intervention use

Measures of intervention use	Web-based intervention (n=26)
Core module completed, n (%)	23 (88)
3 or more visits to intervention, n (%)	18 (69)
Total number of visits to intervention, n (%)	
1	3 (12)
2	5 (19)
3	7 (27)
4	7 (27)
5	2 (8)
6	2 (8)
Signed up to 4 week challenge, n (%)	10 (38)
Visits to other modules, n (%)	
Myth-busting quiz	7 (27)
Living with spots or acne	11 (42)
Oral antibiotics	5 (19)
What are spots or acne	7 (27)
Other treatments	7 (27)
Talking to your GP	3 (12)

Table 9: Module choices within person

Participant	Myth-busting quiz	Living with spots or acne	oral antibiotics	What ae spots or acne	Other treatments	Talking to your GP	Total per person
1	x	x	x	x	x		5
2					x	x	2
3							0
4	x						1
5		x		x			2
6							0
7		x	x	x	x	x	5
8							0
9	x	x		x			3
10							0
11		x		x	x		3
12		x	x		x		3
13				x			1
14		x					1
15	x	x	x	x	x	x	6
16							0
17	x	x	x				3
18	x	x					2
19	x	x					2
20							0
21					x		1
22							0
23							0
24							0
25							0
26							0
Total per module	7	11	5	7	7	3	

6.4.4 Completion rates

At baseline, completion rates of all outcome measures were high, ranging from 92.3% to 100% (see Table 10). EQ-5D-5L self-care and anxiety/pain subscales at baseline were 98.1% completed compared to 100% of the other EQ-5D-5L subscales as there were some missing data. Management of side effects included the proportion of participants that reported experiencing side effects, therefore, this measure appeared relatively low compared to the other measures at all intervals. At 4 weeks and 6 weeks there was a decrease in completion rates, primarily due to the number of people lost to follow-up. Fewer participants completed 4 weeks compared to 6 weeks, potentially due to the short interval between the two time points which resulted in less participants answering the questionnaire over the telephone. In a small number of cases, participants answered the majority of the questionnaire but as they skipped a question, a total score could not be calculated. There was no particular pattern to the items skipped.

Table 10: Completion rates of outcome measures at each interval

Outcome measure	Baseline (53)	4 week	6 week
Overall Skindex-16	100%	71.7%	91.3%
EQ-5D-5L	100%	60.4%	73.6%
EQ VAS	100%	58.5%	64.2%
PHQ-4	100%	58.5%	67.9%
Credibility	100%	n/a	n/a
Expectancy	100%	n/a	n/a
PETs Symptoms (n=26)	100%	65.4%	65.4%
PETs Uncertainty (n=26)	96.2%	65.4%	65.4%
PETs Doubts (n=26)	92.3%	65.4%	65.4%
PETs Practical Problems (n=26)	96.2%	65.4%	65.4%

What topical using	100%	58.5%	67.9%
How often using treatment	100%	58.5%	64.2%
Side effects	96.2%	58.5%	60.4%
Manage side effects (people who reported side effects)	58.5%	35.8%	47.2%
Other treatment	100%	56.6%	69.8%

6.4.5 Potential primary outcome measure

The mean overall Skindex-16 score at baseline was 55.4 (SD=21.8) across the trial arms (see Table 11). When looking at the mean differences in overall Skindex score between groups controlling for baseline and other covariates, the intervention group had a score 5.2 points lower (95% CI -14.58 to 4.09) at 4 weeks and 2.9 points lower (95% CI -13.27 to 7.47) at 6 weeks compared to the usual care group. A reduction in Skindex scores in the intervention group suggests that quality of life had improved with intervention (Table 12).

Individual subscales for Skindex-16:

Symptom subscale: Compared to the usual care group, the intervention group had a score 5.4 points higher (95% CI -8.41 to 19.22) at 4 weeks, and a score 0.9 points lower (95% CI -11.76 to -10.03) at 6 weeks controlling for baseline and covariates (see Table 12).

Emotional subscale: Compared to the usual care group, the intervention group had a score 12.4 points lower (95% CI -24.23 to -0.67) at 4 weeks, and a score 3.9 points lower (95% CI -16.65 to 8.75) at 6 weeks controlling for baseline and covariates (see Table 12).

Functioning subscale: Compared to the usual care group, the intervention group had a score 6.4 points lower (95% CI -20.52 to 7.79) at 4 weeks, and a score 3.4 points lower (95% CI -16.75 to 9.9) at 6 weeks controlling for baseline and covariates (see Table 12).

Table 11: Scores at baseline, 4 week and 6 week follow-up

Outcome measure	Web-based intervention	Usual care	Total
Overall Skindex[a], mean (SD) (n)			
Baseline	55.3 (19.8) (n=26)	55.4 (24) (n=27)	55.4 (21.8) (n=53)
4 week follow-up	45.8 (19.9) (n=17)	54.2 (18.7) (n=16)	49.9 (19.5) (n=33)
6 week follow-up	43.4 (22.2) (n=21)	48.0 (23.8) (n=21)	45.7 (22.8) (n=42)
Skindex Symptom[a], mean (SD) (n)			
Baseline	31.9 (19.8) (n=26)	41.3 (25.5) (n=27)	36.7 (23.2) (n=53)
4 week follow-up	30.6 (24.1) (n=17)	35.5 (21.5) (n=16)	33 (22.6) (n=33)
6 week follow-up	27 (21.5) (n=21)	37.3 (24.3) (n=21)	32.1 (23.3) (n=42)
Skindex Emotional[a], mean (SD) (n)			
Baseline	76.6 (21.1) (n=26)	72.7 (27.5) (n=27)	74.6 (24.5) (n=53)
4 week follow-up	63.7 (22.3) (n=17)	74.2 (23.4) (n=16)	68.8 (23.1) (n=33)
6 week follow-up	62 (24.3) (n=21)	63.6 (28.1) (n=21)	62.8 (25.9) (n=42)
Skindex Functioning[a], mean (SD) (n)			
Baseline	44.1 (27.9) (n=26)	42.6 (28.3) (n=27)	43.3 (27.8) (n=53)
4 week follow-up	31.9 (26.8) (n=17)	41.2 (22.7) (n=16)	36.5 (25) (n=33)
6 week follow-up	30.5 (28.9) (n=21)	34.8 (27.8) (n=21)	32.6 (28.1) (n=42)
PETs Symptoms[b], mean (SD) (n)			
Baseline	3.9 (0.9) (n=26)	3.9 (1) (n=26)	3.9 (0.9) (n=52)
4 week follow-up	4.2 (1.2) (n=17)	4 (1.1) (n=14)	4.2 (1.2) (n=31)
6 week follow-up	4.2 (0.9) (n=17)	4.1 (0.9) (n=17)	4.2 (0.9) (n=34)
PETs Uncertainty[b], mean (SD) (n)			
Baseline	4.4 (1) (n=25)	4.5 (0.9) (n=26)	4.4 (1) (n=51)
4 week follow-up	4.7 (0.6) (n=17)	4.5 (1.2) (n=15)	4.7 (0.6) (n=32)
6 week follow-up	4.9 (0.2) (n=17)	4.2 (1.1) (n=18)	4.9 (0.2) (n=35)
PETs Doubt[b], mean (SD) (n)			
Baseline	3.4 (1.3) (n=24)	3.8 (1) (n=27)	3.4 (1.3) (n=51)
4 week follow-up	4.2 (0.8) (n=17)	3.7 (1.1) (n=15)	4.2 (0.8) (n=32)
6 week follow-up	4.2 (1) (n=17)	3.7 (1.1) (n=18)	4.2 (1) (n=35)
PETS Practical problems[b], mean (SD) (n)			
Baseline	3.8 (1) (n=25)	3.4 (1.3) (n=27)	3.8 (1) (n=52)
4 week follow-up	4 (1.1) (n=17)	3.6 (1.3) (n=15)	4 (1.1) (n=32)
6 week follow-up	4.1 (1.1) (n=17)	3.3 (1.3) (n=18)	4.1 (1.1) (n=35)
Credibility[c], mean (SD) (n)			
Baseline	15.3 (5.1) (n=26)	18.1 (5.7) (n=27)	16.7 (5.6) (n=53)
Expectancy[c], mean (SD) (n)			
Baseline	13.8 (5.6) (n=26)	12.4 (6.1) (n=27)	13.1 (5.8) (n=53)
PHQ-4[d], mean (SD) (n)			
Baseline	4.6 (3.7) (n=26)	4 (3.5) (n=27)	4.3 (3.6) (n=53)
4 week follow-up	2.3 (2.9) (n=15)	3.9 (3.3) (n=16)	3.2 (3.2) (n=31)
6 week follow-up	3.2 (3.7) (n=18)	3.7 (3.3) (n=18)	3.4 (3.5) (n=36)
EQ VAS[e], mean (SD) (n)			
Baseline	80.1 (15.7) (n=26)	74.9 (16.2) (n=27)	77.4 (16) (n=53)

Outcome measure	Web-based intervention	Usual care	Total
4 week follow-up	86.4 (9.1) (n=16)	71.7 (15.2) (n=15)	79.3 (14.3) (n=31)
6 week follow-up	82.3 (18.5) (n=16)	73.5 (18.1) (n=18)	77.6 (18.6) (n=34)

[a]Skindex domain scores and overall score were expressed on a 100-point scale, with higher scores indicating lower level of quality of life.

[b]PETs scores on a scale ranging from 1 (disagree strongly) to 5 (agree strongly), with higher scores indicating less barriers to treatment adherence.

[c]Credibility/expectancy is scored on 1 (not at all) to 9 (very much), with a sum score for each factor ranging from 3 to 27. A higher score indicating that the participant thinks/feels that the treatment will reduce their acne.

[d]PHQ-4 Scores are rated as normal (0-2), mild (3-5), moderate (6-8), and severe (9-12).

[e]EQ VAS expressed on a visual analogue scale ranging from 0-100, with higher scores indicating better health state.

Table 12: Estimates of mean differences in outcomes using linear regression analysis

	Baseline mean (SD)	4 weeks follow-up mean (SD)	Mean difference (95% CI) at 4 week follow-up controlling for baseline and other covariates	6 weeks follow-up mean (SD)	Mean difference (95% CI) at 6 week follow-up controlling for baseline and other covariates
Overall Skindex scores[a]					
Usual care	55.4 (24)	54.2 (18.7)		48 (23.8)	
Web-based intervention	55.3 (19.8)	45.8 (19.9)	-5.2 (-14.58 to 4.09)	43.422.2)	-2.9 (-13.27 to 7.47)
Skindex Symptom[a]					
Usual care	41.3 (25.5)	35.5 (21.5)		37.3 (24.3)	
Web-based intervention	31.9 (19.8)	30.6 (24.1)	5.4 (-8.41 to 19.22)	27 (21.5)	-0.9 (-11.76 to 10.03)
Skindex Emotional[a]					
Usual care	72.7 (27.5)	74.2 (23.4)		63.6 (28.1)	
Web-based intervention	76.6 (21.1)	63.7 (22.3)	-12.4 (-24.23 to -0.67)	62 (24.3)	-3.9 (-16.65 to 8.75)
Skindex Functioning[a]					
Usual care	42.6 (28.3)	41.2 (22.7)		34.8 (27.8)	
Web-based intervention	44.1 (27.9)	31.9 (26.8)	-6.4 (-20.52 to 7.79)	30.5 (28.9)	-3.4 (-16.75 to 9.9)

	Baseline mean (SD)	4 weeks follow-up mean (SD)	Mean difference (95% CI) at 4 week follow-up controlling for baseline and other covariates	6 weeks follow-up mean (SD)	Mean difference (95% CI) at 6 week follow-up controlling for baseline and other covariates
PHQ-4 total[b]					
Usual care	4 (3.5)	3.9 (3.3)		3.7 (3.3)	
Web-based intervention	4.6 (3.7)	2.3 (2.9)	-1.7 (-3.66 to 0.18)	3.2 (3.3)	-0.8 (-2.6 to 0.97)
PETs Symptoms[c]					
Usual care alone	3.9 (1)	4 (1.1)		4.1 (0.9)	
Web-based intervention	3.9 (0.9)	4.2 (1.2)	0.2 (-0.65 to 1.15)	4.2 (0.9)	0.2 (-0.47 to 0.82)
PETs Uncertainty[c]					
Usual care	4.5 (0.9)	4.5 (1.2)		4.2 (1.1)	
Web-based intervention	4.4 (1)	4.7 (0.6)	0.1 (-0.51 to 0.67)	4.9 (0.2)	0.6 (0.19 to 1.08)
PETs Doubt[c]					
Usual care	3.8 (1)	3.7 (1.1)		3.7 (1.1)	
Web-based intervention	3.4 (1.3)	4.2 (0.8)	0.5 (-0.23 to 1.25)	4.2 (1)	0.5 (-0.18 to 1.24)
PETs Practical problems[c]					
Usual care	3.4 (1.3)	3.6 (1.3)		3.3 (1.3)	

	Baseline mean (SD)	4 weeks follow-up mean (SD)	Mean difference (95% CI) at 4 week follow-up controlling for baseline and other covariates	6 weeks follow-up mean (SD)	Mean difference (95% CI) at 6 week follow-up controlling for baseline and other covariates
Web-based intervention	3.8 (1)	4 (1.1)	0.1 (-0.44 to 0.73)	4.1 (1.1)	0.7 (0.02 to 1.3)
EQ VAS[d]					
Usual care	74.9 (16.2)	71.7 (15.2)		73.5 (18.1)	
Web-based intervention	80.1 (15.7)	86.4 (9.1)	9.5 (-0.41 to 19.48)	82.3 (18.5)	3.4 (-7.3 to 14.03)

[a]Skindex domain scores and overall score were expressed on a 100-point scale, with higher scores indicating lower level of quality of life.

[b]PHQ-4 Scores are rated as normal (0-2), mild (3-5), moderate (6-8), and severe (9-12). Total score ≥3 for first 2 questions suggests anxiety.

[c]PETs scores on a scale ranging from 1 (disagree strongly) to 5 (agree strongly), with higher scores indicating less barriers to treatment adherence.

[d]EQ VAS expressed on a visual analogue scale ranging from 0-100, with higher scores indicating better health state.

6.4.6 Secondary outcome measures

Patient Health Questionnaire-4

For PHQ-4 total, baseline levels were in the mild range, with a mean score of 4.3 (SD=3.6) and showed little change. Compared to the usual care group, the intervention group had a PHQ-4 score 1.7 points lower (95% CI -3.66 to 0.18) at 4 weeks and a score 0.8 points lower (95% CI -2.6 to 0.97) at 6 weeks, controlling for baseline and covariates (see Table 12), suggesting slightly greater improvement in the intervention group.

Problematic Experiences of Therapy Scale

PETs symptoms subscale: Compared to the usual care group, the intervention group had a score 0.2 points higher (95% CI -0.65 to 1.15) at 4 weeks, and a score 0.2 points higher (95% CI -0.47 to 0.82) at 6 weeks controlling for baseline and covariates (see Table 12), suggesting similar reported problems related to symptoms around using their topicals in both groups.

PETs uncertainty subscale: Compared to the usual care group, the intervention group had a score 0.1 points higher (95% CI -0.51 to 0.67) at 4 weeks, and a score 0.6 points higher (95% CI 0.19 to 1.08) at 6 weeks controlling for baseline and covariates (see Table 12), suggesting fewer reported problems related to uncertainties around using their topicals in the intervention group.

PETs doubt subscale: Compared to the usual care group, the intervention group had a score 0.5 points higher (95% CI -0.23 to 1.25) at 4 weeks, and a score 0.5 points higher (95% CI -0.18 to 1.24) at 6 weeks controlling for baseline and covariates (see Table 12), suggesting participants in the intervention group had slightly fewer doubts around use of their topical treatment.

PETs practical problem subscale: Compared to the usual care group, the intervention group had a score 0.1 points higher (95% CI -0.44 to 0.73) at 4 weeks, and a score 0.7 points higher (95% CI 0.02 to 1.3) at 6 weeks controlling for baseline and covariates (see Table 12), suggesting fewer reported practical problems using topical treatments in the intervention group.

Credibility/expectancy

At baseline, the mean Credibility score across trial arms was 16.7 (SD=5.6). The intervention group had a lower score (15.3, SD= 5.1) compared to the usual care group (18.1, SD=5.7). This suggested

that people in the intervention group felt that treatment was less credible before randomisation compared to the usual care group (see Table 11).

Mean Expectancy score across trial arms at baseline was 13.8 (SD=5.6). The intervention group (13.8, SD=5.6) and usual care group (12.4, SD=6.1) had similar expectations about their treatment (see Table 11).

EQ-5D-5L

Mean EQ VAS score across trial arms at baseline was 77.4 (SD=16) (see Table 11). At 4 weeks, the intervention group had a score 9.5 points higher (95% CI -0.41 to 19.48) on the EQ5D5L VAS compared to the usual care group. At 6 weeks, the score was 3.4 points higher (95% CI -7.3 to 14.03) (see Table 12). This suggests that the intervention group reported better health state scores compared to the usual care group.

Treatment monitoring:

Type of topical treatment used

At baseline more people in usual care group were using topicals compared to the web-based intervention group. In the intervention group, topical use increased from 61.5% to 88.2% over 6 weeks and in the usual care from 74.1% to 78.9% over 6 weeks (see Figure 8 and Table 13).

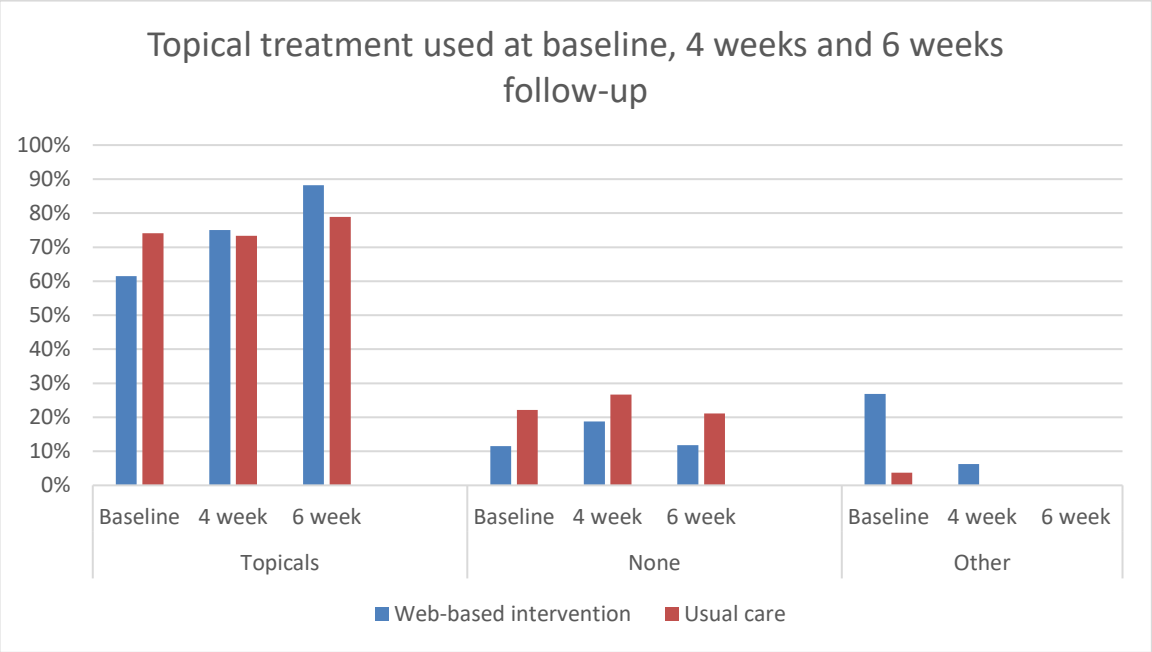


Figure 8: Topical treatment used between groups at each interval

Table 13: Frequency of topical treatment used between groups at each interval

Topical used	Intervention	Usual care
Topicals		
Baseline	16/26 (61.5%)	20/27 (74.1%)
4 week	12/16 (75%)	11/15 (73.3%)
6 week	15/17 (88.2%)	15/19 (78.9%)
None		
Baseline	3/26 (11.5%)	6/27 (22.2%)
4 week	3/16 (18.8%)	4/15 (26.7%)
6 week	2/17 (11.8%)	4/19 (21.1%)
Other		
Baseline	7/26 (26.9%)	1/27 (3.7%)
4 week	1/16 (6.3%)	0/15 (0%)
6 week	0/17 (0%)	0/19 (0%)

Side effects experienced in the past week

The usual care group reported similar side effects at 4 and 6 weeks follow-up compared to the intervention group (see Figure 9 and Table 14).

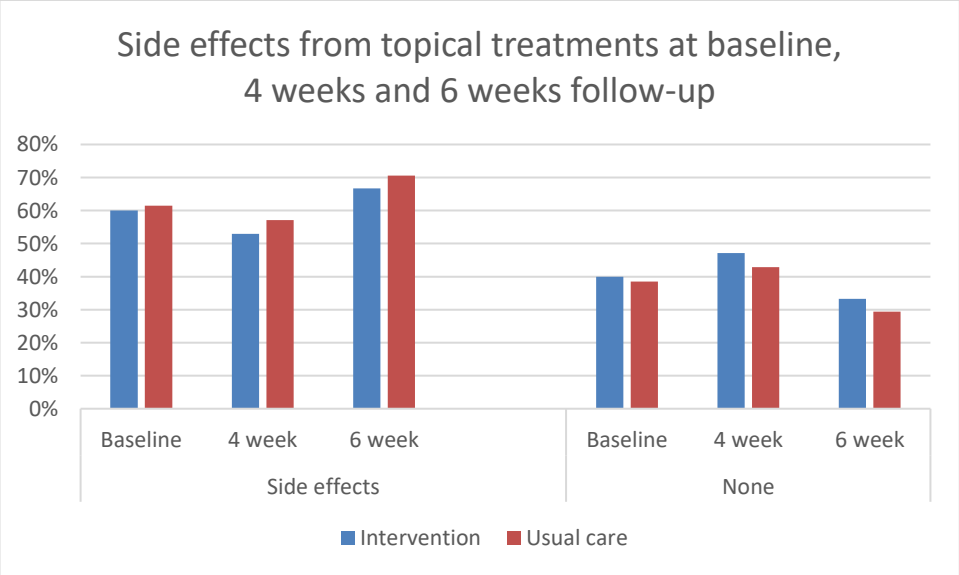


Figure 9: Side effects from topical treatment between groups at each interval

Table 14: Frequency of side effects from topical treatment between groups at each interval

Side effects		Intervention	Usual care
Side effects[1]			
	Baseline	15/25 (60%)	16/26 (61.5.2%)
	4 week	9/17 (52.9%)	8/14 (57.1%)
	6 week	5/15 (66.7%)	12/17 (70.6%)
None			
	Baseline	10/25 (40%)	10/26 (38.5%)
	4 week	8/17 (47.1%)	6/14 (42.9%)
	6 week	5/15 (33.3%)	5/17 (29.4%)

[1]Side effects include dry skin, irritation, bleaching and sun sensitivity.

Management of side effects

At baseline more people in the usual care group reported that they would continue treatment when they experienced side effects compared to the intervention group. However, the number of people who reported that they would continue treatment in the intervention group increased from 64.3% to 72.7% over 6 weeks and decreased in the usual care from 82.4% to 71.4% over 6 weeks (see Figure 10 and Table 15).

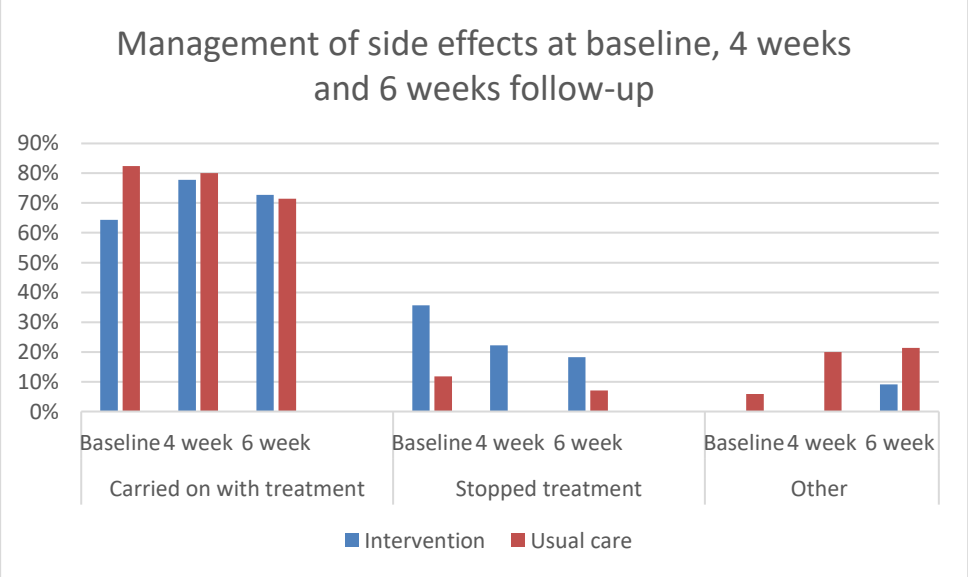


Figure 10: Management of side effects from topical treatment between groups at each interval

Table 15: Frequency of management of side effects from topical treatment between groups at each interval

Management of side effects	Intervention	Usual care
Continued treatment		
Baseline	9/14 (64.3%)	14/17 (82.4%)
4 week	7/9 (77.8%)	8/10 (80%)
6 week	7/11 (72.7%)	10/14 (71.4%)
Stopped treatment		
Baseline	5/14 (35.7%)	2/17 (11.8%)
4 week	2/9 (22.2%)	0/10 (0%)
6 week	2/11 (18.2%)	1/14 (7.1%)
Other		
Baseline	2/14 0 (14.3%)	1/17 (5.9%)
4 week	1/9 0 (11.1%)	2/10 (20%)
6 week	1/11 (9.1%)	3/14 (21.4%)

Application of topical treatment

The most common frequency of application reported at baseline, 4 weeks and 6 weeks for both groups was 'Once/More than once a day/Most days' as opposed to 'Not at all/Once or twice a week'. In the intervention group, the number of participants reporting using their topical 'Once/More than once a day/Most days' increased from 73.1% to 81.2% over 6 weeks and decreased in the usual care from 70.4% to 66.7% over 6 weeks (see Figure 11 and Table 16).

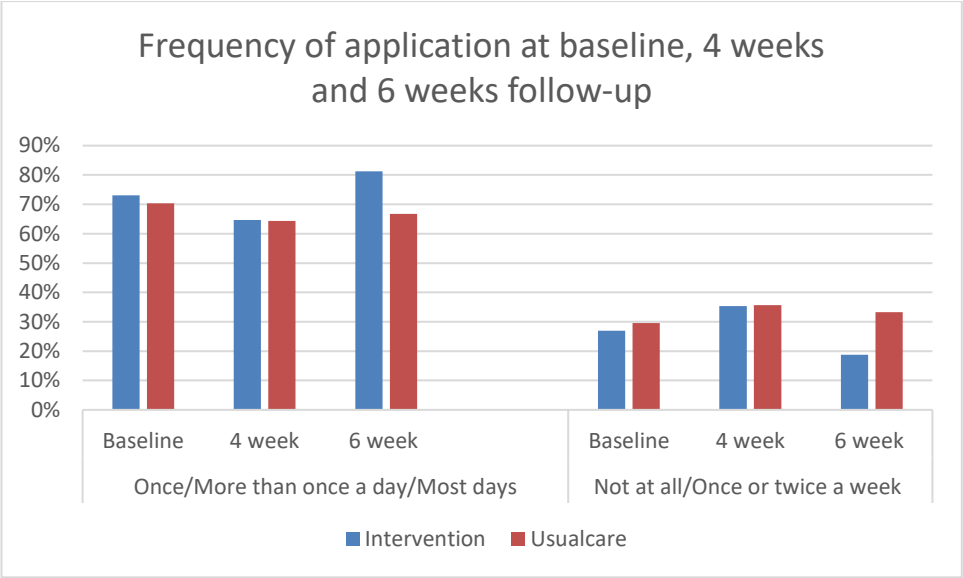


Figure 11: Frequency of application of topical treatment between groups at each interval

Table 16: Frequency of application of topical treatment between groups at each interval

Frequency of application	Intervention	Usual care
Once/More than once a day/Most days		
Baseline	19/26 (73.1%)	19/27 (70.4%)
4 week	11/17 (64.7%)	9/14 (64.3%)
6 week	13/16 (81.2%)	12/18 (66.7%)
Not at all/Once or twice a week		
Baseline	7/26 (26.9%)	8/27 (29.6%)
4 week	6/17 (35.3%)	5/14 (35.7%)
6 week	3/16 (18.8%)	6/18 (33.3%)

Other treatments used

There were no obvious differences between arms at baseline as the most common response in terms of other treatments used were oral antibiotics or none for both groups. This pattern remained at 4 and 6 weeks for the usual care group. For the intervention group, oral antibiotics were still the most commonly reported other treatment at 4 and 6 weeks followed by the combined contraceptive pill (see Figure 12 and Table 17).

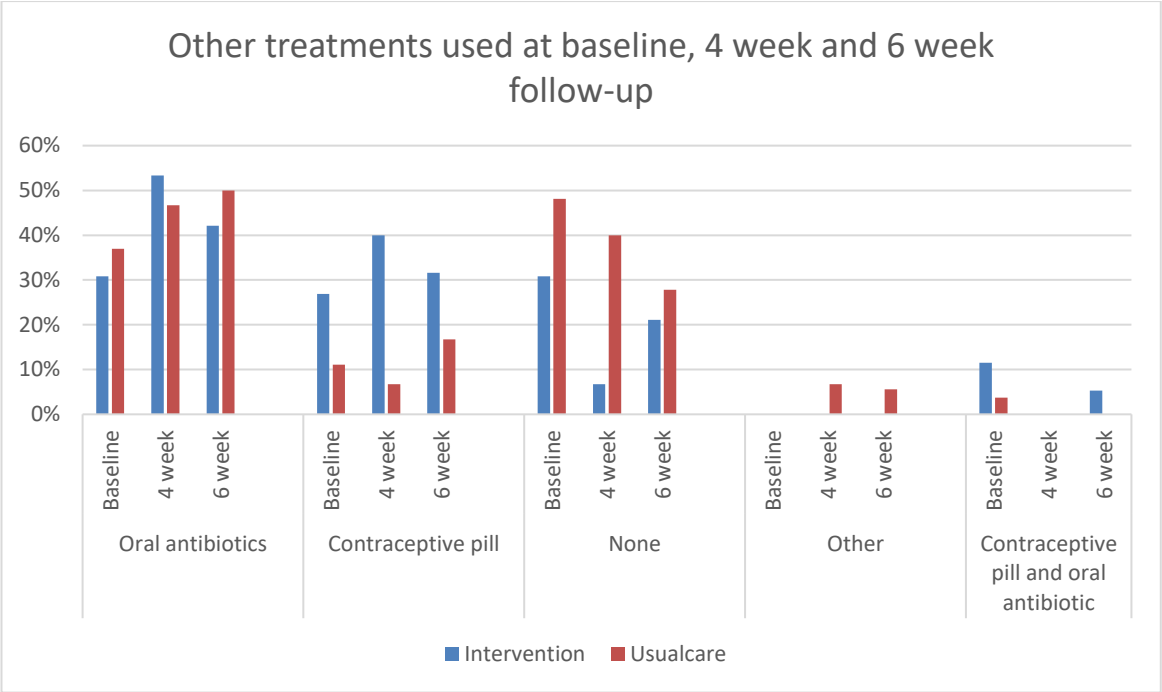


Figure 12: Other treatments used between groups at each interval

Table 17: Other treatments used between groups at each interval

	Intervention	Usual care
Oral antibiotics		
Baseline	8/26 (30.8%)	10/27 (37%)
4 week	8/15 (53.3%)	7/15 (46.7%)
6 week	8/19 (42.1%)	9/18 (50%)
Combined contraceptive pill		
Baseline	7/26 (26.9%)	3/27 (11.1%)
4 week	6/15 (40%)	1/15 (6.7%)
6 week	6/19 (31.6%)	3/18 (16.7%)
None		
Baseline	8/26 (30.8%)	13/27 (48.1%)
4 week	1/15 (6.7%)	6/15 (40%)
6 week	4/19 (21.1%)	5/18 (27.8%)
Other		
Baseline	0/26 (0%)	0/27 (0%)
4 week	0/15 (0%)	1/15 (6.7%)
6 week	0/19 (0%)	1/18 (5.6%)
Contraceptive pill and oral antibiotic		
Baseline	3/26 (11.5%)	1/27 (3.7%)
4 week	0/15 (0%)	0/15 (0%)
6 week	1/19 (5.3%)	0/18 (0%)

6.5 Discussion

6.5.1 Principal findings

This is the first web-based behavioural intervention for young people with acne, that is developed using the Person Based Approach along with theory and evidence [77]. The target number of

participants were not recruited but retention rates for the number of people completing either 4 weeks, 6 weeks or both follow-ups were high. Overall, core module completion was good in the intervention group (88%), although use of some of the other modules were low. Sign up to the 4 week challenge was low, however, this was difficult to interpret as I based this on whether participants entered a start date or not. Completion rates of the questionnaires were relatively high across all intervals with a drop off at 4 weeks and 6 weeks. The changes observed in the primary (Skindex-16) and secondary outcome measures (PHQ-4, EQ5D5L and PETs) were suggestive of a trend to benefit in the intervention group. In terms of treatment monitoring more people in the intervention group reported using topicals compared to the usual care group at 4 and 6 weeks follow-up. In terms of management of side effects, more participants in the intervention group reported continuing treatment at 6 weeks compared to the usual care group. People in the intervention group applied more frequently compared to the usual care group at 4 and 6 weeks follow-up. There was not much difference between groups in terms of other treatments used. The data should be interpreted with caution as due to the feasibility aims of this trial, it was not powered to determine effectiveness. As expected, the confidence intervals were wide due to the small sample size, so a larger sample is needed for a future trial.

6.5.2 Limitations

There were a number of limitations in this study that need to be considered for a future full trial. The mail-out received a low response rate, which suggests that people who took part in the trial may have higher motivation and possibly higher health literacy than other young people with acne and therefore, may be less representative. There is some indication that if changes were made to the protocol sooner, this might have helped with recruitment. One of the main reasons for not participating was the issue of time, suggesting that the participant facing documents need to be clearer about the level of involvement required from participants. Many participants also said that their acne had cleared up which may suggest that the search terms need to be altered to find people who have consulted more recently.

In terms of follow-up rates, these were lower at 4 weeks across both arms partly due to the short interval available for contacting participants before the 6 weeks follow-up. In the main trial, the 4 week follow-up should be monitored more closely and automated emails to the study team sent earlier on. In addition to this, additional email reminders may be beneficial for a larger trial to reduce the percentage of people needing to be contacted via the telephone. The low uptake of optional modules particularly ‘Talking to your GP’ suggests that the intervention may need to be

further refined. These findings highlight that some of the modules may not be perceived as important or necessary at the time for young people with acne. However, this was a key reason for keeping the other modules as optional and not core. More than half of participants visited the optional modules (15) however, 11 did not visit any of these. As with any complex interventions designed to improve health, further iterative development after feasibility trials are necessary [192]. Follow-up interviews with participants who consented in the trial would have been useful in exploring this aspect as well as their experiences and motivations for taking part. However, due to time constraints of my PhD I was not able to carry these out. I also plan to conduct the follow-up interviews after submitting my thesis. The low uptake of the 4 week challenge was difficult to interpret as participants were not monitored throughout, and this was only determined by whether they entered a start date or not. Therefore, data collection for the 4 week challenge will need to be amended to provide accurate numbers of participants signing up.

For many of the outcome measures there were suggestive trends for benefit for the intervention group at both 4 weeks and 6 weeks suggesting that it is feasible to collect data at both time points. However, for several of the measures the change from baseline was bigger at 4 weeks compared to at 6 weeks. This was potentially due to the increased frequency of application and side effects experienced at 6 weeks in addition to the smaller sample size at 6 weeks.

It is important to note that for the symptom subscale in the Skindex-16 measure the change at 4 weeks showed a different direction compared to the change in the overall Skindex score at 4 weeks. This suggests that the overall score difference may have masked apparent changes in different directions in the subscore. Although, the numbers are small as this is a feasibility trial.

The standard deviation for several of the measures were high suggesting variation in the data and the confidence intervals were wide as expected with a small sample size but suggests that we have little knowledge about the effect and further information is needed.

The covariates controlled for in this study were baseline scores, age, gender, age of acne onset and education as these were the covariates thought upfront to be important potential confounders. Although there was a difference between groups at baseline for credibility/expectancy the covariates were not chosen based on their distribution at baseline. This is not the recommend approach due to the possibility that this might introduce bias [193]. In a larger trial I would consider whether these additional covariates should be prespecified in the analysis and consider stratifying on current use of topical treatments or exclude those people regularly using topicals altogether.

The percentage of people using topicals at baseline was high for both groups indicating that people who are not currently using topical treatments or are using them inappropriately may not be represented fully in this study. In a future trial I will consider stratifying on current use of topical treatments or exclude those people regularly using topicals altogether. This will likely involve a mail out by questionnaire to screen for participants who are not currently using topicals.

There was a baseline imbalance between the groups for some demographic and outcome variables, probably due to the small number of participants in each arm. A larger sample size in the main trial would be expected to overcome this. Furthermore, due to a randomisation error which occurred early in the study, I was not aware that the 2:1 ratio had changed to 1:1 and therefore, there was less data for the intervention group.

Although the Skindex-16 showed trends in the direction of benefit, there is currently no published minimal clinically important difference for this measure. Since the feasibility trial, a paper on patient reported outcome measures (PROMs) for acne has been written [194] This paper suggests that the Skindex-16 is equally as acceptable to use compared to the Acne-QoL, and Acne Symptom and Impact Scale. The authors concluded that all of the PROMs were acceptable to use, however as each PROM looked at different domains of quality of life, researchers need to choose the most suitable PROM for their study and a new PROM may need be developed to capture all domains.

6.5.3 Comparison with previous work

Findings are in line with previous trials testing the effectiveness of interventions for acne [61-63,65,66]. A pilot RCT of an interactive health education tool for acne similarly found that the internet intervention group had slightly better quality of life scores than the control group, although the differences were not statistically significant [62]. It is also unclear from their study what treatments participants were using in terms of topicals or oral treatments and therefore comparisons should be made with caution. The PETs scores which were used to measure adherence in the current trial showed a trend in the right direction which is consistent with a previous RCT investigating the effectiveness of supplementary educational materials on a combination topical treatment (adapalene/benzoyl peroxide; A/BPO) [64]. This latter study used an objective measure to assess adherence (medication event monitoring system) as opposed to a subjective measure in this present study. However, there is currently no standardised or fully validated method of measurement for adherence to acne treatments [44].

Follow up rates in this study were high at 6 week follow-up with 79% completing the primary outcome measure (Skindex-16). This is in line with Myhill, et al. [64] study which had a follow-up rate of 84.5% [64] when recruiting through primary care. Yentzer, et al. [63] study (adherence rates using an internet-based survey with young people aged 13-18 years) also found a similar follow-up rate of 75%, although it is not clear where participants were recruited from and the sample size was small consisting of 20 participants. Similar to previous trials on acne, this present study recruited a small sample size. However, the recruitment rates after amendments to the participant facing documents suggested that this may have improved if implemented earlier.

6.5.4 Conclusions

In conclusion, this feasibility study demonstrates that a pilot study prior to a full-scale trial of SPOTless is feasible to further refine the intervention, recruitment, follow-up methods and address the limitations identified in this feasibility study. Subsequent follow-up interviews with participants who consented to be contacted regarding this will need to be carried out to further refine the intervention.

Chapter 7 Discussion and future research

7.1 Chapter overview

This chapter provides a discussion of the overall findings from this thesis. I will first summarise the main findings from each empirical study in terms of how they informed the intervention development, before discussing the novel contributions from this thesis. Then, I will discuss the strengths and limitations, implications of the study for practice and future research, and present my conclusions.

7.2 Key findings

7.2.1 Summary of work undertaken in previous chapters

In chapter 1, I presented an overview of the current research, showing that non-adherence to topical treatments for acne is common and that many patients progress to oral antibiotics. Reviewing the literature also highlighted that few qualitative studies explored people's perceptions of acne treatments. Existing interventions for improving adherence to acne treatments have not been developed using robust methods, such as person or theory-based approaches. Many of the studies testing the effectiveness of these have also included small sample sizes, limiting their ability to detect significant differences. This thesis provides a more in-depth understanding about young people's perceptions of acne treatments through qualitative methods to inform the development of a behavioural intervention to support self-management of acne, developed following the Person-Based Approach (PBA). It also provides preliminary evaluation of this intervention in a feasibility trial. This intervention could potentially improve outcomes in acne and address antimicrobial stewardship.

As discussed in chapter 2, I took a pragmatic approach using a sequential exploratory design to address the aims of this thesis. Therefore, mixed-methods were employed for data collection and analysis including three qualitative studies (a systematic review and synthesis of qualitative data on acne, secondary analysis of qualitative interviews with people with acne, think-aloud interviews to refine the intervention) and one quantitative study to assess the feasibility of the intervention.

In chapter 3, I presented my first qualitative study which was a systematic review and synthesis of published qualitative papers on acne including those exploring peoples' experiences of acne and its related treatments, their carers' experiences and healthcare professionals' experiences treating patients with acne. This was the first qualitative study as part of the PBA. The findings demonstrated the importance of control over treatment choice and control over acne for alleviating the psychological impact. The synthesis also showed how people used different coping strategies, which appeared to be related to the perceived severity of their skin condition. A common experience for people with acne was perceived trivialisation of skin disease, further exacerbating psychological symptoms. These findings highlighted that the intervention needed to build on a feeling of 'control' in terms of better understanding of their condition and choice of treatments, in addition to providing support for the psychological impact of acne including information about coping strategies, and provide accurate information about treatments and causes of acne. The findings from the synthesis were also found to relate to the Extended Common Sense Model of Illness (ECSM) which was useful for informing the behavioural analysis as part of intervention development. The findings highlighted how there was a lack of qualitative research exploring peoples' perceptions of acne treatments and that the role of treatment failure was underexplored. This provided further rationale for conducting the second qualitative study which was a secondary analysis of primary interviews with young people with acne.

In chapter 4, I presented a secondary analysis of qualitative interview data aimed to understand young people's experiences of living with acne and, in particular, their views and concerns about acne treatments. I obtained permission from the Health Experiences Research Group at the University of Oxford to reanalyse data from 25 transcripts of interviews with people with acne. The main findings from this study were that young people often perceived acne as a short-term condition which appeared to influence their uptake and use of treatment. Participants often perceived topical treatments as being ineffective, which seemed to be related to unrealistic expectations around when the treatment would begin to work. Many participants found it difficult to differentiate between prescribed, cosmetic and over the counter topical treatments and therefore, felt they had tried them all. They had concerns around how to use topicals 'properly' and how to avoid side effects often leading to early abandonment of treatments. Some participants had concerns around side effects or necessity of oral antibiotics, though few seemed aware of antibiotic resistance and many opted for oral treatments as they perceived these as stronger, easier and faster to take effect. These findings were useful for identifying barriers and facilitators to treatment adherence as well as for acknowledging other areas that needed to be addressed in the intervention (e.g. speaking to a health care professionals (HCPs), addressing the

psychological impact as a result of acne and information needs regarding other treatments). Similar to the first qualitative study described in chapter 3, the findings could be explained using the ECSM as people's beliefs regarding the duration of acne (short-term), and concerns about treatment ineffectiveness (topicals) appeared to prevent engagement with treatments.

The behavioural analysis presented in chapter 5 enabled me to incorporate the barriers and facilitators identified from the literature, evidence in the systematic review and synthesis of qualitative papers on acne and the secondary analysis of interview data, that were likely to affect the target behaviour 'appropriate use of topical treatments'. Think-aloud interviews on the draft intervention materials were carried out with young people with acne to gather user feedback in terms of participants' thoughts, impressions, and experiences using the behavioural intervention. A table of changes was created to document and make decisions about modifications to the intervention. Overall, the findings highlighted how participants found the website, engaging, persuasive and relevant. The main changes made as a result of the interviews were: clarification of the steps for applying topicals; adding names and ages to quotes to make them more relatable; changing the core module name from 'Universal core treatments' to 'Core treatments' as the word 'universal' made participants trust the website less; the structure and layout of the website were made clearer; and the 6 week challenge was changed to 4 weeks because of evidence from a randomised controlled trial (RCT) showing that topical treatments could take effect within 1-4 weeks [64].

The aim of the feasibility trial in chapter 6 was to assess feasibility of the trial design and delivery of the SPOTless web-based behavioural intervention. This was part of the process analysis stage of the PBA using primarily quantitative methods of data collection and analysis. The findings showed that use of the intervention was feasible as uptake of the core intervention content was high, although uptake of the other modules were low. I was not able to recruit the target number of participants to the study however, it was not powered to detect significance and response rate for the primary outcome (Skindex-16) was 87% at 4 weeks, 6 weeks or both time-points. There were initial challenges with recruitment but follow-up rates were good and overall I feel a pilot study with the changes suggested in the feasibility trial would be beneficial before taking this to a full RCT. The findings from the outcome measures including Skindex-16 and the problematic experiences of therapy scale showed a trend toward quality of life and adherence to topical treatments being greater in the intervention group than in the usual care control although; a future definitive trial is needed to determine effectiveness of this intervention for improving self-management of acne.

7.2.2 Summary of main findings and novel contribution of thesis

Previous research has highlighted a number of risk factors associated with non-adherence to acne treatments which are consistent with findings from the qualitative research in this thesis including side effects, confusion about usage, and onset of action [44,50,67]. The findings from this thesis explore these reasons further as well as provide novel insights into other factors likely to influence treatment adherence.

Previous research that has reported side effects as a barrier did not explore why participants were experiencing side effects, how they were managing these and where they were seeking advice [44,54]. The secondary analysis of qualitative interview data found that some people reported terminating their topical treatments as they were confused about how to use them appropriately (applying too much and to sensitive areas) including how to manage side effects. It is recommended that patients should be told to expect initial irritation and advised about how to minimise this [14]; however, findings from the secondary analysis suggest that participants seek information from the internet over consulting with a health professional. These behaviours could potentially exacerbate confusion as it is unclear what sources of information they use as found in another study which examined views of oral antibiotics in online discussion forums [55]. Furthermore, people often said they had tried all available topical treatments for acne, but seemed confused between cosmetic, pharmaceutical and prescribed topicals, potentially leading them to try alternative treatments such as oral antibiotics as first line.

The secondary analysis also highlighted other novel findings including that people's perception of acne as a short-term condition appeared to influence their expectations around onset of action of treatment and their views about its effectiveness and necessity.

The intervention incorporated evidence from previous research and provides further support for the use of simplification [66], technology [63], and education [64] for improving acne management. The intervention is a novel contribution as it was developed using the robust PBA method helping to ensure better uptake and engagement with the intervention, with a greater likelihood of leading to behaviour change, and hence potentially better healthcare outcomes [68].

The findings from this thesis and challenges encountered also contribute to knowledge around how studies or interventions with young people with acne should be designed. For instance, a high number of telephone call reminders were needed to ensure good follow-up, which would have implications for trial design.

The qualitative studies in this thesis showed how the ECSM was paramount in helping to understand young people's experiences of acne and its treatments. Therefore, measuring psychological variables may be useful to inform theoretical frameworks. Potential measures could include the revised Illness Perception Questionnaire (IPQ) [195] and the Beliefs about Medication Questionnaire (BMQ) [196]. The revised IPQ measures all five domains from the CSM, whilst the BMQ assesses necessity and concerns. Particularly as the questionnaire completion rates were relatively high in the feasibility trial this suggests room for additional measures to be carefully implemented without creating problems with respondent fatigue or response bias.

The findings from the feasibility trial also showed that there was a low response rate for people recruited through primary care, suggesting that other ways of reaching this target population may be more feasible. Recruiting through schools, pharmacies or social media in a pilot study may provide insight into the best way to recruit for a future full trial. Research has highlighted the importance of Public and Patient Involvement (PPI) and qualitative research for developing complex interventions [125]. However, recruiting PPI within this age group with acne was difficult in this PhD. Future research should recruit through other platforms other than INVOLVE as this target population may be better reached through social media including Facebook and Twitter.

As found in the secondary analysis of interview data young people regularly use the internet for information therefore, digital interventions are important for providing this population with evidence-based information. For researchers who are developing digital interventions this PhD demonstrates the strengths of using the LifeGuide software as I was able to iteratively develop the intervention at every stage. I also benefited from the methods that have come out of the LifeGuide programme, namely the Person Based Approach which informed the design of this PhD.

7.3 Strengths and limitations

I will first discuss the overall strengths and limitations of this thesis, before providing the main strengths and limitations from each empirical study, as these have been presented in previous chapters. A strength of this thesis was that I was able to use the PBA to develop a novel intervention. This allowed me to address the target users' experiences of the proposed behaviour change techniques and enhance existing theory and evidence-based approaches to developing interventions. A further strength was that I was able to explore a range of views and experiences

as participants in the studies were recruited through various platforms including: primary care; community advertising at the University of Southampton; social media platforms including Facebook and Twitter; patient and public platforms (support groups and online discussion forums); secondary care (dermatology departments); colleges; and schools. PPI was also incorporated during the crucial stages of intervention development, which is essential for developing complex health interventions [125]. This enabled me to make the intervention more appropriate, usable and engaging for the intended user. As I faced difficulty with recruiting PPI within the target age group, there is a possibility that the input may lack representativeness in terms of obtaining a range of experiences and opinions. People who volunteered may also be more engaged and interested in their health than a typical research participant, however, this is a common limitation of PPI and a further reason for incorporating both PPI and research participants. There is a potential for social desirability bias in the qualitative studies in this thesis, more so in the think-aloud study as participants were aware that I had developed the intervention. However, a medical student (Y.B.) carried out the initial interviews for her student project and the data highlighted a number of positive and negative responses suggesting that this was unlikely to be the case. The sample in all the studies were majority female and males may be underrepresented, which may be important given possibility of gender differences in perceptions of treatments and impact [172,197]. However, this gender imbalance is common since females are more likely to consult with acne despite acne being more prevalent in adolescent males [20].

7.3.1 Main strengths and limitations from each empirical study

A limitation of the systematic review and synthesis (described in chapter 3) was that I was unable to update the review and therefore, some key papers published after the initial search were omitted. However, I have included the additional papers within this thesis, and plan to update the review after submission. A further limitation which is present amongst all systematic reviews and synthesis of qualitative papers, is that I was limited by the extent and any weaknesses of the original literature.

The qualitative interviews with young people with acne (described in chapter 4) was a secondary analysis of primary interviews. Therefore, I was unable to prompt participants for further information. However, the transcripts provided rich data on peoples' experiences of acne and acne treatments.

In the think-aloud study (described in chapter 5), the data was not analysed using a specific qualitative method, although I took a systematic and pragmatic approach to identifying particular

issues to aid intervention development. The interviews did not include in-depth data about people's experiences of acne and its treatments, and this information was already captured in the secondary analysis within chapter 4.

A limitation of the feasibility trial was that I was not able to carry out follow-up interviews, which is a crucial part of the process analysis stage within the PBA. This would have been useful for eliciting some of the findings from the feasibility trial including reasons for low uptake of some of the other modules, further information about the process of the trial and their experiences of the 4 week challenge. Another limitation of the feasibility trial was the small sample size. However, the findings provide us with additional information about recruitment rates, which will be useful to take forward into a pilot study prior to a full trial. The feasibility trial also suggested that it may be useful to recruit slightly differently so that the intervention is targeted towards people who are not currently using topicals or are using them inappropriately. This will probably be achieved using a mail out with a brief survey to screen for participants who are not currently using topical treatments.

7.4 Implications for practice and future research

7.4.1 Implications for practice

This research has provided novel information on young people's perceptions of acne treatments and built on existing evidence. Consequently, the barriers and facilitators identified as important can provide valuable information on what needs to be addressed to improve engagement with effective self-management of acne in primary care. In particular, the importance is clear regarding addressing people's confusion between the different topicals available (including prescribed, cosmetic and pharmaceutical treatments), the potential side effects of topicals and how to manage these, and the speed of onset of action from topicals so that people do not have unrealistic expectations and abandon treatment before it starts to take effect. Another key barrier to self-management identified in the secondary analysis of qualitative data, was misconceptions about the causes of acne which appeared to influence people's perception of the duration of their condition. Clinicians could consider spending time explaining what acne is, causes of acne and how to use treatments to improve management of acne, although there are clearly time constraints, which may make this challenging. Further research may be useful in exploring GPs' behaviours and experiences around managing acne. Findings from the secondary analysis demonstrated how participants regularly use the internet for information about acne and its

related treatments; therefore, it may be useful for HCP's to signpost people to reliable sources. The findings from the systematic review and secondary analysis of interview data showed that young people's behaviours could be understood using the ECSM which suggests potential for GPs and HCPs to use the model in practice to better understand how young people with acne respond to treatment and use various coping strategies based on representations of their illness and treatment. However, as mentioned previously the psychological variables from this model should be implemented into a future trial to further inform this theoretical framework. Furthermore, the feasibility trial showed that majority of participants who took part were already using topical treatments but, as the intervention is intended for people who are not currently using topicals or are using them inappropriately, GPs could help engage patients with interventions of this type.

The SPOTless intervention was developed to support self-management of acne in young people by addressing the barriers and facilitators to appropriate use of topicals. This could potentially be a useful tool for primary care where over 90% of acne is managed in the UK [4]. HCPs could direct patients towards the web-based behavioural intervention to help them answer specific questions and self-manage their acne, potentially improving outcomes and experience of treatment for people with acne. On a wider scale, the intervention could possibly reduce oral antibiotic prescribing by improving adherence to topical treatments and informing people about side effects from other treatments (namely, risk of antibiotic resistance from oral antibiotics). The secondary analysis of qualitative data documented many participants' preference for oral treatments over topicals when given the choice as they perceived these to be easier, more effective and faster acting. Due to people's preference for oral antibiotics, it is important to change their perceptions and address information needs regarding use of antibiotics at a public health policy level. Further development of the SPOTless website before a full definitive trial is needed to determine the effectiveness of the intervention before implementing into practice.

7.4.2 Implications for future research

Whilst this thesis has identified barriers and facilitators to topical treatments, more qualitative research is needed for further exploration. Interviews with HCPs treating patients with acne or parents/carers of people with acne are needed to gain different perspectives. This is particularly the case as both the qualitative studies found perceived trivialisation of skin disease by HCPs as a common experience. Ideally, an intervention for both patients and HCP's would be useful as the research in this thesis also identified other barriers and facilitators that would be better

addressed from both sides (e.g. choice of treatment, acne as a short-term condition and presenting and dealing with the psychological impact of acne).

Further development of the SPOTless intervention is essential prior to a full trial including follow-up interviews with participants who consented in the trial, further think-aloud interviews after modification of the intervention and potentially a pilot study with changes suggested previously. It will also be important to rerun the systematic review and synthesis of qualitative data in future to ensure that it is up to date with the current literature.

7.5 Conclusions

This thesis has provided an in-depth understanding about peoples' perceptions and experiences with acne treatments which was an under researched area. Key barriers were identified as novel risk factors to self-management of acne including: a limited understanding about the different topicals available, their perception of acne as a short-term condition, and lack of understanding about how to use topical treatments appropriately including ways to manage side effects. By exploring these issues, I was able to identify factors likely to influence the target behaviour, endorse appropriate use of topical treatments and develop a novel feasible intervention using the PBA. This thesis also identified areas for further research such as additional developmental research on the intervention including a pilot study prior to a full trial to implement changes and evaluate the effectiveness of the intervention.

Appendices

Appendix A: Systematic review search strategy

Appendix B: Second order interpretations extracted from each paper

Appendix C: Qualitative interview study participant characteristics

Appendix D: Qualitative interview study coding framework

Appendix E: Think-aloud study information sheets and poster

Appendix F: Think-aloud study interview guide

Appendix G: Table of changes

Appendix H: Feasibility trial information sheets, sign-up sheets and flyer

Appendix I: Feasibility trial emails

Appendix A : Systematic review search strategy

MEDLINE

1.	(acne*).ti,ab,af	19,462
2.	exp "ACNE VULGARIS"	10,117
3.	(ethnograph*).ti,ab	7,422
4.	(Qualitative).af	166,594
5.	"QUALITATIVE RESEARCH"	27,398
6.	"FOCUS GROUPS"	19,774
7.	"GROUNDED THEORY"	308
8.	(grounded theor*).ti,ab	9,242
9.	(focus group*).ti,ab	65,019
10.	(thematic analysis).ti,ab	11,241
11.	(content analysis).ti,ab	105,555
12.	"OBSERVATIONAL STUDY"	0
13.	(observation* method*).ti,ab	73,253
14.	(interview*).af	284,428
15.	INTERVIEW	0
16.	(meta-ethnograph*).ti,ab	268
17.	(constant comparative method*).ti,ab	1,956
18.	(field note*).ti,ab	8,927
19.	(participant* observation*).ti,ab	20,121
20.	(narrative*).ti,ab	22,196
21.	(field stud*).ti,ab	229,727
22.	(audio recording*).ti,ab	1,551

23.	"OBSERVATIONAL STUDIES AS TOPIC"	1,603
24.	1 OR 2	19,462
25.	3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23	854,933
26.	24 AND 25	418

PsychINFO

1.	(acne*).af	322
2.	(acne vulgaris).af	64
3.	"QUALITATIVE RESEARCH"	8,494
4.	(qualitative).af	230,008
5.	“GROUNDED THEORY"	3,374
6.	(grounded theor*).ti,ab	16,901
7.	(thematic analysis).ti,ab	9,478
8.	"CONTENT ANALYSIS"	5,240
9.	"DISCOURSE ANALYSIS"	7,462
10.	(observation* method*).ti,ab	31,455
11.	INTERVIEWS	8,169
12.	(interview*).af	400,268
13.	(meta-ethnograph*).ti,ab	162
14.	(constant comparative method*).ti,ab	2,169
15.	(field note*).ti,ab	8,991
16.	(participant* observation*).ti,ab	19,178
17.	NARRATIVES	16,630

18.	(narrative*).ti,ab	49,218
19.	(field stud*).ti,ab	91,684
20.	(audio recording*).ti,ab	1,643
21.	(focus group*).ti,ab	53,715
22.	(ethnograph*).ti,ab	21,516
23.	1 OR 2	324
24.	3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22	684,935
25.	23 AND 24	47

CINAHL

1.	(acne*).af	4,651
2.	exp "ACNE VULGARIS"	1,121
3.	"ETHNOGRAPHIC RESEARCH"	5,129
4.	"GROUNDED THEORY"	10,344
5.	"QUALITATIVE STUDIES"	58,689
6.	(qualitative).af	132,863
7.	(qualitative research*).ti,ab	7,515
8.	(grounded theor*).ti,ab	6,521
9.	"CONSTANT COMPARATIVE METHOD"	5,759
10.	"DISCOURSE ANALYSIS"	2,632
11.	"CONTENT ANALYSIS"	20,676
12.	"THEMATIC ANALYSIS"	34,316
13.	AUDIORECORDING	31,456

14.	NARRATIVES	9,434
15.	INTERVIEWS	93,999
16.	"FOCUS GROUPS"	24,288
17.	"PARTICIPANT OBSERVATION"	4,040
18.	"OBSERVATIONAL METHODS"	10,201
19.	(constant comparative method*).ti,ab	1,025
20.	(audio recording*).ti,ab	396
21.	(narrative*).ti,ab	10,984
22.	(interview*).ti,ab,af	263,698
23.	(focus group*).ti,ab	15,204
24.	(participant* observation*).ti,ab	2,868
25.	(observation* method*).ti,ab	1,265
26.	(ethnograph*).ti,ab	4,807
27.	(qualitative stud*).ti,ab	20,076
28.	(field stud*).ti,ab	2,426
29.	(meta-ethnograph*).ti,ab	136
30.	1 OR 2	4,651
31.	3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29	349,126
32.	30 AND 31	703

EMBASE

1.	(acne*).af	38,845

2.	exp "ACNE VULGARIS"	8,714
3.	(qualitative).af	218,549
4.	"QUALITATIVE STUDIES"	49,193
5.	"QUALITATIVE STUDY"	49,193
6.	"QUALITATIVE RESEARCH"	49,193
7.	"THEMATIC ANALYSIS"	8,120
8.	"CONTENT ANALYSIS"	13,317
9.	"OBSERVATIONAL STUDIES"	122,188
10.	"OBSERVATIONAL STUDY"	122,188
11.	"OBSERVATIONAL METHOD"	1,423
12.	INTERVIEW	203,294
13.	"SEMI STRUCTURED INTERVIEW"	26,942
14.	"STRUCTURED INTERVIEW"	13,637
15.	"TELEPHONE INTERVIEW"	6,701
16.	"UNSTRUCTURED INTERVIEW"	480
17.	INTERVIEWS	203,294
18.	ETHNOGRAPHY	2,640
19.	(ethnograph*).ti,ab	8,226
20.	(meta-ethnograph*).ti,ab	272
21.	(constant comparative method*).ti,ab	1,447
22.	"CONSTANT COMPARATIVE METHOD"	882
23.	(field note*).ti,ab	1,654
24.	"PARTICIPANT OBSERVATION"	6,505
25.	(participant* observation*).ti,ab	3,623
26.	NARRATIVE	15,374
27.	(narrative*).ti,ab	25,541

Appendix A

28.	"FIELD STUDY"	5,921
29.	(field stud*).ti,ab	14,124
30.	"AUDIO RECORDING"	2,069
31.	(audio recording*).ti,ab	1,212
32.	(focus group*).ti,ab	35,957
33.	1 OR 2	38,845
34.	3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32	592,161
35.	33 AND 34	646

PubMed

1.	"ACNE VULGARIS"	10272
2.	(acne*).af	19780
3.	“ANTHROPOLOGY, CULTURAL”	126556
4.	(ethnograph*).ti,ab	7915
5.	“QUALITATIVE RESEARCH”	29015
6.	(Qualitative).af	169942
7.	(focus group*).ti,ab	30718
8.	(grounded theor*).ti,ab	8149
9.	(thematic analysis).ti,ab	8324
10.	(content analysis).ti,ab	17132
11.	(observation* method*).ti,ab	203267
12.	INTERVIEW	48150

13.	(interview*).af	300940
14.	“OBERSVATIONAL STUDIES AS A TOPIC”	1644
15.	(discourse analysis).ti,ab	1285
16.	(meta-ethnograph*).ti,ab	288
17.	(constant comparative method*).ti,ab	1279
18.	(field note*).ti,ab	1467
19.	(participant* observation*).ti,ab	28407
20.	(narrative*).ti,ab	23233
21.	(field stud*).ti,ab	11930
22.	(audio recording*).ti,ab	952
23.	“FOCUS GROUP”	20696
24.	“FOCUS GROUPS”	20696
25.	1 OR 2	19,780
26.	3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24	779,370
27.	25 AND 26	497

Appendix B : Second order interpretations extracted from each paper

Study (country)	Key themes presented by author	Explanation/theory (second order interpretation)
Skaggs, Hix, Huang & Feldman (2017) [2] America	Symptoms; Self-perception; Social placement; and Perception of control.	"The degree to which patients believe their disease or treatment is under their own control can be characterized using a description of internal-external locus of control."
Magin, Adams, Heading, Pond & Smith (2006) [3] Australia	CAM therapies in acne and CAM therapies for psoriasis and eczema.	"The participants with acne used CAM with an expectation of efficacy and a consequent sense of control over their conditions. Respondents with psoriasis and eczema tended to cycle through a much broader assortment of CAM therapies with a marginal expectation of efficacy but a determination to "try anything" and a hope that they might eventually chance upon therapies that would suit their skins. A consequence of these differing cognitions regarding efficacy and control was that the attenuation of psychologic sequelae of acne seen with use of CAM was not apparent with CAM use in psoriasis and eczema" "The differences in uses and impact of CAM between the two groups is based on perceptions of the essential nature of the skin diseases rather than on perceived attributes of CAM." "In respondents with acne there was an expectation that adherence to healthy, socially sanctioned, lifestyle practices would (or should) be rewarded with improvements in acne. CAM therapies, unlike orthodox therapies, were seen by participants to be congruent with this healthy lifestyle approach. "Adherence had inherent attenuating effects on psychologic morbidity above and beyond putative improvements in acne severity. Some of this attenuation of negative psychologic sequelae was contingent upon the sense of control or enhanced self-efficacy afforded by these self-performed or self-accessed health practices"

Appendix B

Study (country)	Key themes presented by author	Explanation/theory (second order interpretation)
Magin, Adams, Heading, Pond & Smith (2008) [4] Australia	The universally negative nature of teasing; The use of teasing as an instrument of social exclusion; The use of teasing as a means of establishing or enforcing power relationships; Teasing relating to contagion and fear; The emotional and psychological sequelae of teasing; and 'Insensate' teasing.	"The first five themes described above can be seen to be inter-related – the universally negative nature of the teasing was inherent in the use of teasing as an instrument of social exclusion and enforcement of social power relationships. Fear of contagion may be postulated to have underlaid the motivation of teasing in some cases, but contagion-related teasing could also be seen to subsequently legitimize social exclusion. The emotional and psychological sequelae of teasing for the individual respondent followed directly from these attributes of the teasing. The theme of 'insensate' teasing was essentially a specific circumstance that, despite its unintentional nature, was still negative in import and capable of producing negative emotional and psychological sequelae." "In the schema constructed from this data, the central element in skin diseases producing psychological effects is that of appearance (the physical symptoms, including pruritus, and other aspects of skin disease have little effect). Teasing and taunts have a direct effect on self-image and self-esteem, modifying the effect of appearance (teasing in this study was essentially appearance-based). Embarrassment and self-consciousness (and behavioural avoidance) are consequent effects. "In our study, however, teasing was invariably socially isolating rather than socially inclusive, and friendly or 'prosocial' teasing and 'off-record' behaviours were notably absent." "Stigmatizing potential of the topic of the teasing of an individual could be a further factor moderating teasing effect in models of teasing." "The unprofessional behaviour was disturbing but may, in part, reflect the trivialization and lack of sensitivity to the psychological aspects of skin diseases by health professionals noted in previous research"
Prior & Khadaroo (2015) [5] UK	Coping strategies (Avoidance, avoidance of socialising, avoiding photographs, compensation and concealment); self-perceptions (comparisons to earlier self); and interpersonal relationships (advice and practical support from family).	"young women were more inflexible and disciplined in following elaborate face cleaning routines, which could be linked to feelings of self-blame for the acne and heightened responsibility for a less-than-perfect appearance." "In balancing out the acne, we are able to see the salience and importance of facial appearance to these young men and women, who nonetheless worked hard to retain some control over their acne and their lives with the considerable help and support of their families." "Rather, we found that individuals used multiple coping strategies in conjunction with each other (e.g. continuing to socialise, while avoiding photographs and using concealment)." "While there was some use of avoidance as a coping strategy, more commonly, participants continued to socialise, while using a number of 'subtle safety behaviours' (Thompson, 2005: 66) such as concealment and planning ahead. In the longer term, these safety behaviours are linked to feelings of shame and are typically associated with social anxiety or poor social adjustment (Thompson, 2005). However, in the short they enabled the participants to participate in university life while coping with their fluctuating appearance."

Study (country)	Key themes presented by author	Explanation/theory (second order interpretation)
Murray & Rhodes (2005) [6] UK (participants from America, Australia, Britain, Canada, Colombia, Italy & the Pacific Islands)	Powerlessness and the variable nature of acne; comparisons, self-image and identity; the experience of general social interaction; relationships with family and friends; and gender, sexuality; and romantic relationships.	"Being an 'acne sufferer' was often the only or most salient identity that could be assumed, and thus social withdrawal was often the result." "The unpredictable fluctuations in the severity of acne over time, and the need to adapt to a constantly changing body-image can, therefore, be seen to cause great uncertainty and disruption in respondents' lives. The lack of control over the trajectory of their health was felt as a form of powerlessness." "unlike for many people with facial disfigurement, the problems for adults with visible acne are 'special' in the sense that their disfigurement is not stable, but continually in flux with good and bad periods. As previously noted then, because of this uncertainty, they are unable to promote, establish and maintain enduring positive self-images." "In the absence of self-protecting identity beliefs of their own, the stigmatized person tends to hold the same beliefs about identity as wider society, and as such, may see him or herself as 'falling short'. Such a response makes the experience of shame likely. Therefore, for people with stigmas, such as facial disfigurement, problems can arise in social interaction with 'normal' or able-bodied persons that have particular and lasting damage for their self-identity." "Because of the fluctuations in acne severity, its uncontrollable nature, and its persistence over time, participants were not able to promote either of the self definitions identified by Levitin (1975). Their acne was neither temporary nor permanent, but paradoxically somewhere in between." "However, the highly visible nature of their acne for participants in the present study meant that impression management, at least by attempts to conceal their acne, were largely unworkable."
Magin, Heading, Pond & Smith (2005) [7] Australia	Attitudes to 'medical' treatments; Perceptions regarding isotretinoin and adverse effects; Perceptions of psychological effects; and Experiences of psychological sequelae.	"Participants, however, were not aware of the weak level of evidence for the association, and tended not to frame the prospect of treatment with isotretinoin in a risk/benefit manner."
Magin, Adams, Heading and Pond (2009) [8] Australia	Relationships with GPs and Relationships with dermatologists.	"An unexplored area is how stigmatisation of mental illness might be especially problematic in the setting of skin disease, which is already associated with considerable stigma. This may be accentuated by the perceived trivialisation of skin disease seen in our study and reported elsewhere. Patients with skin disease may be even more reluctant to present psychological symptoms to their GP given these perceptions."

Appendix B

Study (country)	Key themes presented by author	Explanation/theory (second order interpretation)
Magin, Adams, Heading and Pond (2011) [9] Australia	Societal ideal; Role of media; Stigmatization and other psychological sequelae; Appreciation of the falsity of media representations of the ideal; and Male respondents.	"In our study, participants found their self-image and self-esteem impaired by their failure to live up to the media-generated ideal (and the consequence was psychological morbidity)." "It is possible that female perceptions of male attitudes may also be fashioned by media representations." "From this study it is apparent that the societal ideal of perfect skin has a singular role in the etiology of psychological sequelae of acne, eczema and psoriasis in females. This is despite an appreciation by participants that media portrayals of perfect skin were inherently unrealistic. The perception of participants in this study was that the influence of contemporary mass media on popular culture has led to a pervasive ideal of 'perfect skin'. "
Pruthi & Babu (2011) [10] India	Physical discomfort; Anger; and Intermingling impact of acne.	"The feeling of physical discomfort leads to social withdrawal and in turn decreases the attendance at social gatherings, in a majority of the cases."
Magin, Adams, Heading, Pond & Smith (2006b) [11] Australia	Self-perception and social anxiety; central theme: appearance, depression and anxiety; and consequences of the effects of acne.	"The linear relationship of appearance to self-image and self-esteem, then to embarrassment or self-consciousness, and then to avoidance is shown in Figure 1." "Self-efficacy or an internal locus of control regarding acne attenuated psychological effects. Belief in the efficacy of complementary and alternative therapies (CAM), dietary manipulation, face washing, and exposure to ultraviolet light and salt water were salutary. Regarding diet and washing, this finding could be surprising because believing that lack of cleanliness and poor diet were causative factors in acne might have prompted subjects to blame themselves for the condition. Our findings suggest that the fact that cleanliness and healthy dietary practices were within subjects' control attenuated negative psychological sequelae. Similarly, CAM therapies and sun and surf were easily accessible to participants, more accessible than medical therapies." "The temporal association of acne (or at least the mechanisms of being on show, being scrutinized, and being judged or taunted) and these evanescent emotional reactions is close, unlike the association of mediating mechanisms and pervasive psychiatric conditions, such as depression and anxiety." "Attenuation of negative psychological sequelae came from an internal locus of control or enhanced self-efficacy afforded by subjects' own health practices, such as CAM, dietary manipulation, face washing, and exposure to salt water and sun."

Study (country)	Key themes presented by author	Explanation/theory (second order interpretation)
Magin, Adams, Heading and Pond (2010) [12] Australia	Participants with acne The role of appearance and sexual attraction & Gender differences. Participants with psoriasis or atopic eczema The role of appearance and sexual attraction; Effects on body image and self-worth; The unique context of nakedness and intimacy; and Physical aspects of skin lesions.	"more common than direct genital effects was a pervasive effect on sexual self-image and an inhibition of sexuality based on the appearance and texture of non-genital skin and the resultant avoidance of disclosure or exposure of affected skin."
Jowett & Ryan (1985) [13] UK	Experiences of the disorder (prominent symptoms, the worst aspect? Encountering ignorance and misunderstanding; Employment (Limited opportunities, Functional difficulties. Interpersonal difficulties); Expressive disability (Shame/embarrassment, anxiety, lack of confidence, depression); Interpersonal relationships (family frictions and support, friends, acquaintances and strangers); Daily life and leisure (personal presentation, leisure).	"The denial of the 'sick role' to sufferers and subsequent lack of understanding was a problem
Magin, Adams, Heading, Pond & Smith (2006a) [14] Australia	Beliefs regarding acne causation; Genetic and hormonal influences; Dietary causes of acne; and The role of uncleanliness or dirty. Implications of These Beliefs for Acne Management Dietary manipulation; Face washing as acne therapy; The role of sun and surf; Perceptions of healthy lifestyle; and control.	"The association with perceptions of healthy living (and thus with socially approved behaviors) resulted in adherence to diet, washing, or surf regimens producing positive psychologic effects distinguishable from that attributable to any putative objective improvement in acne." "It was further apparent that this perceived control had an attenuating effect on respondents' otherwise problematic psychological responses to acne." "Our study similarly found high levels of belief in myths and misconceptions, but these appear to be associated with an internal locus of control and improved coping with the psychological sequelae of acne. An explanation for these seemingly contradictory findings may be that myths and misconceptions regarding diet, dirt, and sun are based in folk wisdom (independent of educational attainment) rather than in expert knowledge."
Koo (1995) [15] America	The psychological effect (decreased self-esteem/self-confidence, problems with body image, embarrassment leading to social withdrawal, depression, anger, preoccupation, confusion/frustration, limitations in lifestyle, difficulty with family members) and Acne and functional status.	n/a

Appendix C : Qualitative interview study participant characteristics

		Sex	**Age at interview**	**Time with condition**	**Ethnicity**	**Occupation**
Adam	SKI01	Male	15yrs	2-3yrs	White British	Secondary school student
Alice	SKI03	Female	21 yrs	6-7yrs	Chinese	University undergrad student
Sarah	SKI04	Female	18 yrs	3-4yrs	White British	University undergrad student
John	SKI08	Male	20 yrs	4yrs	White British	University undergrad student
Cat	SKI09	Female	21 yrs	7 yrs (no longer active)	White British	University undergrad student
Steph	SKI017	Female	20 yrs	10yrs	White British	Student
Mark	SKI019	Male	21 yrs	3yrs	White British	University undergrad student
Jason	SKI020	Male	22yrs	7-8yrs	White (Hungarian)	Shop manager
Tammy	SKI021	Female	22yrs	6yrs	White British	House Parent
Gary	SKI028	Male	18 yrs	5yrs	White British	Student
Kate	SKI032	Female	19 yrs	2yrs	Chinese	Student

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Maria	SKI038	Female	22 yrs	on & off 13 yrs	White British	Student
Alex	SKI045	Male	16 yrs	3yrs	White British	Student
Mary	SKI048	Female	22 yrs	13yrs	White Dutch	Student
Charlotte	SKI049	Female	23 yrs	3yrs	Chinese	Student
Melody	SKI050	Female	20 yrs	9yrs	White British	Student
Sherry	SKI051	Female	20 yrs	11yrs (2 w/ ecz age 6-8)	Chinese	Student
Ivy	SKI058	Female	24 yrs	5yrs (all life with ecz)	White British	Postgrad student
Faye	SKI066	Female	17 yrs	3yrs	White British	Student
Sophie	SKI071	Female	17 yrs	teen with acne, now gone	White British	Student/Healthwatch ambassador
Izzy	SKI072	Female	24 yrs	12yrs	White British	MA student & research fellow
Tania	SKI073	Female	20 yrs	8yrs	White Other	Student
Jen	SKI074	Female	13 yrs	>1 yr	White Eu	School student
Sam	SKI075	Male	14 yrs	>1 yr	White Eu	School student
Holly	SKI094	Female	20 yrs	5yrs	White British	Student

Appendix D : Qualitative interview study coding framework

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
1	**PERCEPTION OF ACNE**	**Beliefs about the causation, duration, consequences and control of their acne**	
A	**Perceived causes**	Beliefs/understandings about what does or does not cause acne	
	A1) Stress	Belief that acne is or is not caused or exacerbated by stress	*I think stress probably doesn't help, is what I've heard. I don't know exactly because I don't really make that connection myself. But I know people who say that their spots get worse with stress, or like I know people who say that their spots get better in summer and stuff like that. And I don't know if it's just [um] something to do with the summer or it's something to do with them, or if it's just something they feel but might not actually be true. I don't know. But for me personally I just kinda go by it day by day. So I don't really make those sort of connections. I, I would just sort of, I don't know. I do think they get worse with stress though. SKI01*
	A2) Diet	Beliefs that acne is or is not caused by diet	*And I personally think they get worse if I eat rubbish food the night, the day before. If I've had a whole pizza the night before and then forgot to wash my face, when I wake up I'd probably be more spotty than if I ate. But that could, apparently that's not actually a thing according to my doctor. But I don't know, different people.SKI01* *For me, [um] like I, I think just eating like junk food, like, you know, like, like the take away pizzas. [um] Things like that kind of, like, put a, I think, well I might be so, it might be just me thinking, "Oh I flared up today, that's probably because of the pizza I had last week". [um] But, yeah, I mean, that, I, I always try to kind of eat, eat fairly healthily. [um] But, yeah, no, I didn't, didn't really have like that much knowledge of what I was eating in my diet was causing SKI08* *t's something we've consistently, well, and when I say we, I mean my mum has consistently raised with my doctors and my doctors have consistently denied that there has been a link.SKI021*

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	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
	A3) Hygiene/makeup	Belief that acne is or is not caused by dirt/oily skin and makeup: -Includes the role of makeup in trying to conceal and face washing as an acne therapy	*I'll just still have it, even if I put [on medicated] creams and stuff because I put foundation [on] so it won't stop anything.SKI074* *I've had spots regardless of whether I've worn make-up or not. And I think that's sort of-, it's interesting because make-up has become such a safety net for me, of being able to have more confidence when you have spots. But on the other hand people then assume that, you know, make-up's actually the cause of spots rather than something that's helped to mask it. So, I guess it's that sort of people maybe judging why you have spots or trying to put reasoning as to why you have spots.SKI058*
	A4) Puberty/hormones	Belief that acne is or is not caused by puberty and hormones	*So, I'd say all in all I thought it was just [uh] something you experience when you're in your early teens SKI08* *No, I, it, it was really weird. [um] I wasn't really, it just cleared up by itself I think. [um] Again, like acne's so hormonal, it can, you know, you can have like, your hormones can change like, over the course of several months. [um] [coughs] So, I think [um] yeah, clear, it just, it just cleared itself up. [um] I wasn't on any particular strong drug or anything like that and I was actually off prescription medication for a good while [uh] while it was clear. SKI08*
	A5) Genetics	Belief that acne is or is not influenced by genetics • includes instances about the inevitability of acne	*From my understanding when I was a kid – I, you know, I just had acne and that was, you know, that was tough like, people get it, you know, that's just life kind of thing. Some people do, some people don't, I didn't really think of it as a cause and effect kind of… SKI019*
	A6) Weather	Belief that acne is or is not caused by the weather	*Yeah, so, [er] I think that's the sunshine helped a little bit. Getting some sun on it and my dermatologist actually, she said it was one of the few people she'd suggest going out and getting some sun tan [laughs]. Getting some sun on it. So, in the summer it always improved a little bit compared to the, compared to the winter. So I always sort of looked forward to the summer a little bit [laughs] yeah. It was a limited amount of times that I, particularly the acne on my chest, that I'd have showing like at home I didn't mind having it on show and getting some light on it. But [um] if I was out and about in summer otherwise I would always try and cover up [laughs]. SKI017* *It's always better in the summer which makes sense. [um] But no I've not really noticed much of a connection in terms of what I'm eating.SKI021*

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
			Yeah, when it's sunny I tend to find that I'm sweating more. [um] So I sort of tend to stay in like the cooler areas. [um] But also with the isotretinoin, they sort of, the doctors did say to avoid direct sunlight [um] and they sort of said to keep away from it really.SKI028
	A7) General perceptions	Beliefs about the causes of acne (e.g. no cause and effect) • includes beliefs about previous illness causing acne (e.g. eczema)	*Oh, I don't know. Not sure. I don't, I don't think so. Again, not that I was really aware of. [um] [sighs] Yeah, no, I, I don't think so. I didn't really, as I say, I didn't really kind of have that cause and effect kind of thing, I wasn't aware that oh yeah, this makes it bad or whatever.SKI019* *but there was nothing really that seemed to be making it worse either, it was just like always there. [Um] so yeah I mean, I, nothing that I know of really triggered, I mean it just seemed to be bad all the time [laughs] but yeah. I mean like if I'd known I would have done anything to stop that but there was nothing I was aware of.SKI038*
B	**Timeline (acute/chronic)**	Belief around the timeline of acne • included whether people talk about it as an acute or chronic condition • includes all references to possible recurrence	*Not really but I guess at the end it's more of a pro because like your skin will look better. Yeah but I'm not sure, I am not sure if like acne it's like a long term effect. I mean like even after it's done what happens if it, like done the treatment or a bit like a few thousand dollars for it and then what if it has another reaction and then you're like, yeah. So I am not very sure but maybe it will be like, maybe they will do the treatment and you won't have as much acne but oh no I am not really sure about how this works. Yeah. Because I am not sure if acne, it's like really like during puberty or I mean like probably, maybe for some, like for some it can be like for your entire life, something like that.SKI03* *I think I started having my first treatment when I was thirteen I think, and that, and that was when it started to get sort of... It was, it was getting worse basically, and that didn't really help and I just had that for quite a long time, longer probably than I should've done. [um] From when I, when I was thirteen to probably when I was about fourteen, and then I just…over when I was fourteen to fifteen, I tried loads of different treatments.SKI045* *I mean I'd known it from my elder brother having it [um] but he hadn't actually used medication and he'd had it quite severely but it had been like for a short period of time. So I was kind of like 'that would be the same for me' like, I based my experience on that and I was like 'maybe I'm just gonna have it for a short period of time'.SKI050* *I thought, I thought it was like a teenage thing. And everyone says that when you reach, when you reach a certain, a certain age – the acne will go away. But like, looking at my friends who have serious acne [erm] from teenagehood that's just not true. Like you actually do have to take something to like help it go away.SKI051*

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			My skin was just as-, just got bad again and I was, you know, I'd turned 24 and I was just really stressed out about it because I thought [um], you know, I'm 24, this is the sort of thing that typically you associate with teenagers, with adolescence, and I, I guess it just got me down quite a lot. [um] So that wasn't really that fun.SKI058 *So I've had acne, I worked out, more than half my life now. Started to flare up probably in Year 8 at school. Really quite badly, to begin with. [Um] But at that point I was thinking 'Oh well this is great, I'll get it out the way now, and I'll have beautiful skin by the time I'm, I'm going to sixth form.' And here I am at 25, still [points to jaw line] having it flare up and be part of, part of my daily life. [Um] I have been to various doctors about it.SKI072* *Yeah, I think I got a bit frustrated because after a year or so it was like 'surely it has to clear up at some point?'SKI094*
C	**Impact of acne (consequences)**	Experiences or lack of experiences regarding the impact of acne	
	C1) Physical impact of having acne	Concerns or lack of concerns expressed about the physical impact of acne: • includes the pain and discomfort experienced with acne, • includes references to scars left behind as a result of acne • includes any changes to appearance because of acne (growing hair longer and wearing specific clothes to hide acne) • includes impact on other health conditions	*Yeah, so [er] because my scarring is in this sort of area [points to chest] [er] I've got a high neck thing on now, but I didn't buy any clothes that could possibly show it for quite a long time. Because I didn't want anybody to see the sort of the scarring and the scabs and things.SKI017* *And I was like, for me, like every time I look in the mirror I can just see it because it's sort of… I had like… for me it was quite like it came out from my skin so, and it was really painful and red as opposed… yeah so it was really painful. SKI04* *Mhm. Yeah, so the, I remember that often you'd, it wasn't that painful usually, but then sometimes you'd get sort of the big kind of nodal acne where you'd have these big lumps under your skin and that would be painful. You'd like, they'd sort of throb during the day and if you touched them they'd be painful. [um] So that was a kind of uncomfortable pain.SKI09*

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
	C2) Social impact of having acne	Concerns or lack of concerns expressed about the social impact of acne: • includes social gatherings such as sleepovers and parties • includes impact on relationships (family, friends & romantic) • includes impact on physical activities (e.g. swimming and football) • impact on work and education	*I wondered when I say this kind of thing if I am protesting too much and actually it is terribly important to me and I'm just not allowing myself to acknowledge it but I, I, it's just not really something that I've noticed myself worrying about that much. I don't feel like it's affected my friendships or my social life or my relationships. And obviously, given the choice, I would rather not have acne but [pause 4 secs.] given that this is the situation I am in, I'd rather just get on with my life and not worry about it that much.SKI021* *There were also talk, calling me fat, ugly, different things like that as well. [um] But a lot of the bullying was around the acne and the other operation that I'd had that which I'm not gonna sort of go into.SKI028* *And another thing is that I don't really want to make new friends because I don't want them to see me, [um] the most ugly m-, like to see the most ugly me, yeah. So it kind of hold me back to, yeah, communicate with others. And [um] sometimes I feel quite [um] lonely.SKI032*
	C3) Psychological/emotional impact of having acne	Concerns or lack of concerns expressed about the emotional impact of acne: • includes emotional impact of talking about their acne • includes emotional impact of worsening of acne	*I think I've become like [uh] depressed about myself, is some effect with the acne. [uh] And [3 secs] and sometimes I just feel hopeless about my face at that time, as I try. So I was like avoid seeing people and like I can only see my fr-, like close friends and family at times. SKI049* *And of course like you end up like trying to pick it, trying to like, do anything you can about it and it's like, kind of like a downward spiral. And then, sort of the weeks goes on and you sort of go [uh] often it's like you have good weeks, you have bad weeks, but when you do have bad weeks, it's, it's sort of I don't know just a bit depressing really.SKI08* *And I think, and when it started to get worse it was a bit more frustrating because I think with the cystic lumps they can be quite painful. [um] But then I think then other people started to get spots so I didn't feel as bad. [laugh] But [um] yeah, I just remember being really self-conscious. I, I think it, it-. I got quite depressed about it because I-SKI094*
	C4) Location of acne	Experiences and beliefs about acne on different parts of the body: • includes impact and implications for treatment (back acne harder to apply treatment)	*I remember my housemate last year, she had had acne and had taken a course of I think it was a steroid cream that had cleared it up. [um] And kind of going on and on about how she had 'bacne' and how much she hated it. I think that kind of created a bit of a stigma about back acne that for some reason I don't feel about face acne.SKI021* *But yeah, they'll just tell you to, they'll examine like your back and, well I, I suppose if your male it's more likely to be on your back, so, they got me to take me shirt off, have a look at my back [um] which luckily hasn't been affected at all. SKI08*

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
			I think, yeah, I'm, I'm obviously like the, with your back [um] it's not on display a lot. So, in that sense, it's, it, you know, a lot of people might say, "Oh yeah, I prefer it on my back to my face". [um] But then obviously your back's a bigger area, so, like, [um] I suppose in terms of like scarring, you can end up with more scars, but [um] like I said they're not seeable. So I suppose I mean if I had a choice, I don't, I suppose I'd, I'd rather have it on my back I guess, but I can't really sort of say that definitely because I've never had it on my back. SKI08
	C5) Gender	Perceptions about the impact of acne in males and females • Includes attitudes towards wearing makeup	*Oh okay, yeah, I guess, the being female [er] was a sort of issue when I was in secondary school. Partly because the girls seemed to get acne a lot less than the boys. But also because they were looking at make-up and you've got all these sort of magazines with like perfect skin in them. Whereas, for guys, it seemed less important that they had this perfect skin and they didn't really care so much about it. For girls, I think we're sort of expected to like, you know, wear lots of make-up and look pretty and I couldn't at that point. [Er] and so, I think that sort of did have an impact.SKI017* *Well, in my opinion I think acne is easier on boys. [Um] we do tend to hit puberty and the teenage age in a quick rate and then leave it even quicker, girls seem to gradually grow and that would mean a girl with acne could last for some years. A boy it will usually leave after a year or two and stop because that's how his growth spurt finished, I'd suppose.SKI075* *Yeah, I can imagine as a, as a female I think it would've been probably a lot worse and I think they would have taken it a lot worse, you know, female, you know, idealised, you know, notions of beauty or whatever. I think, I think it would have impacted on, on, you know, girls a lot more than it would have impacted on me. I think I, I think men are supposed to take that in stride sort of thing in terms of body image and stuff maybe. So I think possibly the gender aspect would be a lot more severe for kind of women possibly, but obviously I don't know, I'm, you know, I'm not part of that, that's how kind of I would imagine that to be.SKI019*
	C6) Age	Perceptions about the impact of acne at different ages (young person compared to adult)	*like you go into sort of late 20s, 30s, you look a bit rugged anyway. So, a few little scars aren't going to really make me feel self-conscious at all.SKI08* *I didn't have anything [spots] up until then really, so I guess it frustrated me a little bit because I thought I had passed that; that I'd been lucky to not have any spots really. I guess I was frustrated because I felt like I'm not supposed to have it. I'm not-, it's when-, you have spots when you're a teenager.SKI058* *Just mostly it's your image within teenage society I'd say, having acne and [um] also the constant [um] care or attention you need to give to your face, not to scar it, not to scratch because they can lead to further issues in the future.SKI075*

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
	C7) financial		*I don't know. I've, I don't buy it myself. My parents buy it, so I've no idea. I don't think they're too expensive. And also I think the one at the moment cos I'm under 16 is free. And then the rest is just soap, water and moisturiser. And water's kinda free. Moisturiser I doubt is expensive. And a bar of soap I hope isn't expensive. SKI01* *I don't think so. I mean, I presume I got Roaccutane on the NHS? But I'm not sure? I'm asking you a question.(SKI019)* *Yeah, [um] my antibiotics and all those I do pay for. It's not a huge amount. I've seen worse. I mean, but it's still on some level, you're paying for your wellbeing, so. I don't really see why am I paying for my NIN, life insurance and all of that kind of stuff if I still have to pay on top of that. If it's like that then to be honest, I don't think I should be paying for it, you know what I mean, like. If it's going to be like how I'm paying a hundred pounds or something every month towards my general, my GP and stuff like that then….. (SKI020)* *My mum's been great. She has paid for everything and continues to pay for good skincare products and good make-up. (SKI021)* *It's purely just for me getting into [city name][um] where, where the GP, where the dermatology is. (SKI028)*
E	**Identity**	How people interpret and label their condition and the symptoms associated with it: Includes excerpts from diagnosis and interpretation of the severity of acne e.g. not a serious condition	*It's annoying admitting that you've like got an actual condition or a problem. The word 'acne' just sounds a bit harsh […] I felt a bit like-, I guess disappointed in myself. But, I know it wasn't my fault exactly, I know that everyone has bad skin as a teenager but getting told you've got severe or moderate acne-, yeah, I felt a bit annoyed and a bit insecure about it. (SKI04)* *I remember actually when I went to the dermatologist the most recent time and he said, you know, 'This is a disease and we're going to treat it,' and I just remember that being such a turning point because […] it had always just been like 'bad skin, a teenage thing' and then suddenly it was someone who was really taking it seriously as a disease that was treatable. I think the way people talked about it did really have an impact and I didn't really realise that until suddenly this dermatologist was saying-, speaking about it in that way. That made me feel like so much better in some ways because, even though it was like 'oh my God, I've got a disease', it made me feel like I was justified in being as upset as I was and that this was a serious problem – but someone was taking it seriously and was going to fix it for me. (SKI038)* *I always found it very difficult when other people told me I had severe acne because implicit in that was [pause] them telling me that I had a problem. And [pause] that made me feel [hm] [pause 5 secs]. It made me feel a bit out of my hands. [um] I think a lot of this is down to the fact that it was not me driving a lot of these meetings. [um] I think there's a danger, acne is a condition I inherited from my mother and I think there's, I think it is very easy for parents to want to cure their children because they found it traumatic themselves when, when they were children.SKI021*

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			Some, yes, it's not good for a, a long-term use but it's just for some control of the very serious, serious condition. (SKI032) *R: [um] It was just, well, spots really, I suppose just on my face, it was largely just on my face, nowhere else really. [um] So yeah, it was quite visible, like acne I suppose. (SKI019)* *And it's a very teenage-associated thing. As an adult with acne, it makes me feel like I should have grown out, out of this by now. (SKI072)* *Because at one side of the spectrum I want to take control, I want to take ownership of it, I want it to be something that I don't let impact my life as much as it could. But at the other end, I don't - I don't like the, a large amount of medical intervention, cos it's not - it's not an illness, it's not a sickness, it's not something that you need to declare on health forms or things like that, so. I do sometimes struggle with that. [um] And again, that's something that I am still working on.(SKI072)* *I suppose I felt quite uncomfortable at the beginning talking about spots, I suppose not as serious as other conditions that people could talk to a doctor about.(SKI075)* *I guess if I was talking to myself when I was younger, which is really the only sort of reference point I've got, the key advice would be to not let it define you. That it's a part of you but it's not the most important part. It's not the bit that everyone sees, it's just a small part of you. So you shouldn't let it consume what you think you are. And that there is help out there, go and have a look, go and talk to your doctor, Google it, find other people to talk to about it. You're not on your own with this, but that doesn't mean you have to live with it. Which I think is the trap that I fell into, thinking 'Oh well, it's just something people get, and you just deal with it'. No, there are loads of things out there that you can do to help. I'm still discovering some of them, so they're definitely out there a lot, and I would urge people to find them.SKI072*
2	**PERCEPTION OF ACNE TREATMENTS**	**Beliefs about the barriers/facilitators and the necessity of treatment**	
B	**Topical**	Perceptions about topical treatments: includes any treatments prescribed by a HCP, pharmacist and any shop bought topicals.	

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
	B1) Perceived necessity	Perception about the necessity of treatment based on its effectiveness or ineffectiveness (e.g. that treatment work/don't work or work to some extent (partially/initially) only keeping it at bay.)	*"Then I stopped for a month and then it like came back. So you're just repeating it over and over and over again. You're not really getting a definite cure. So that's, yeah, that's annoying." SKI020* *Yeah, so they were kind of things like they'd be tablets and sort of one cream after another, and, you know, that's, you'd think, you'd think they were doing things like they kind of kept it at bay, but they didn't get rid of it. It was kind of just sort of a keeping it at a certain level as opposed to absolutely like clearing your whole skin and making it sort of a lot better [uh] what you wanted it, basically. SKI08* *but, it's something that [um] sort of helped me cope with it a lot better and I kind of just stayed at a, a level where it was bad, but it was kind of I can deal with it type thing. [um] And I'd go through phases of being, having good skin, well, not good skin, but, I'd be able to, I'd feel a lot more comfortable in my skin then SKI08* *But my feeling with a lot of the creams has been like it doesn't do that much. Like it's kind of stabilised it at times but then I, I'd still be prone to like break outs and like since I haven't so I haven't been on any creams for probably like two months at the moment, it's quite bad at the moment but that is with the understanding that I would like to go on something stronger in the next few months.SKI050* *I guess once I sort of started noticing that certain products were working; so, as soon as I went on the benzi-, benzoyl peroxide, for example, I noticed it worked straight away. You know, even after a couple of days it-, you know, and, and it, the side effects weren't really there for example with the other creams that I'd been on.SKI058* *I think I just only remembered the last one I had cos that one had benzoyl peroxide in it. But with that one, I remember the problem was that it tended to make my skin really dry after a while, so you had to stop the treatment. But that was the best one that was working for me. So it really wasn't, so I did it like for a month or two and then my skin got really dry. Then I stopped for a month and then it like came back. So you're just repeating it over and over and over again. You're not really getting a definite cure. So that's, yeah, that's annoying.SKI020* *I think it's a difficult one because I think the tablets I tried at first did nothing and, also the creams I also feel didn't get to the root of the problem. So, I guess maybe a combination of both but, personally for me, the only thing that actually got rid of it was the Roaccutane and, that was a tablet so, I guess I might advocate that. But [um] maybe some of the creams at the beginning were better than some of the tablets so.SKI04*

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
			Yeah I sort of did but they didn't really help [er] too much. I mean I'm sure my skin was clean and soft and stuff, but I don't think it really helped. I mean maybe that's just me because p-, pretty much any sort of actual acne cream I used didn't work, [um] but I, I don't think it helped me specifically anyway.SKI045 *They were, did well in the short term, but [erm] they didn't have, but the effect wasn't sustained, like maybe [erm] the day after they were reduced, but after that they would just come back [hiccups] oops, yeah.SKI051* *Yeah [um] so the cream I put on every night, I keep it overnight. So the morning it like dries them off a bit so then I take it off and well, I see a difference every day. [Um] and then the soap, it just like cleans them up so they're not like dirty anymore, and that helps a lot. And yeah SKI074*
	B2) Perceived side effects	Concerns or lack of concern about side effects: • includes how people perceive side effects (treatment working or not) • includes any ref to how people manage side effects (e.g. short or infrequent application or applying moisturiser)	after applying creams my face is really dry and it does irritate for at least an hour so yes it does affect me trying to fall asleep. And in the night if I pick by mistake it could actually wake me up. So in that sort of sense yes, it does affect sometimes.SKI05 Yeah. So, [um] with the creams it was just - I think they're very aggressive. And different ones [um] would be worse than others. So I think with a lot of the gel or the lotion, [um] they dry my skin out really badly and I'd have like sort of cracked skin around my mouth. And [um] obviously you couldn't really get them like near sensitive areas but if you accidentally did, and I'd have like kind of almost eczema-like sort of bits on the sensitive eye areas and around the mouth in particular. [um] And that, and so that's not that pleasant. But then I think my doctor did eventually give me one that was a bit more moisturising. [um] And I also learnt to use like slightly less [laugh]. I think there's always a temptation and most of it is that you use a lot of the product, when actually the recommendation is to use like a pea-sized amount and I was probably using like a handful. [laughs] So it was probably exacerbated by that. [um]SKI094 Oh one of the topical ones he offered me, I didn't take it. Apparently if you put it on your face you can't go outside in the sunlight at certain points or something. Which is, I, I decided I didn't want that, because that kind of scared me. I didn't really want to risk that. But [um] none, none I have taken, no. SKI01 Yeah, the one from the pharmacy made my like skin quite dry down here [points to chin/lower face] and sort of here [points to beneath eyes] and kind of here [points to forehead], just because that's where I was getting it the most, like here and here. And that was really annoying because I didn't know whether I could moisturise [laughs] again. So I didn't know whether I should moisturise and that sort of thing. And then the other ones were, I don't think I had anything with the other ones. I just think that they probably weren't working that well and that's probably why I moved on. So I used the whole bottle or like packet of it, and then I kind of just decided whether I wanted to keep using it if it was working, yeah.SKI01

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			So I had lots of that. [um] Really powerful stuff, I remember staining, like, my towel, because when I washed my hands I didn't wash them, I just wiped my hands, so my towel was just bleached with white stuff.SKI019 Yeah, it's not that it made it worse. It just like, for example, dried my skin to such a level that literally it started cracking. So to me, that is worse.SKI020 Well, I, with the cream it was [um] I could sort of reach some places but obviously I didn't want anybody else doing it for me, I'd rather me do it myself. But [um] one of the problems that I've found with the creams that sort of put me off from using them on my back anyway was the fact that they'd bleach most of my clothes. So it was just, I'd put them on my face or wherever it wouldn't touch any clothing anyway. [um] Because a lot of my clothing'd come out of the wash and they'd be pink. [laughs]SKI028 It makes my skin really dry so in any case I mean like the skin gets flakey easily so like the scars can be like peeled out.SKI03 Sometimes I feel that my skin is too dry and too [um] tense and it doesn't feel very well.SKI032 But that was… I felt like that wasn't as great either; it was quite, it was just very sticky and like it was quite sore and made my skin burn yeh SKI04 Well, no, not really. Like the cream I used in the beginning, like, i-in the complete beginning that just dried out the skin [um] It dried out the skin to such an extent maybe that the skin kind of broke sometimes, you know, that you could s-, you'd peel off your own skin. That's how bad it dried it in. And [um] it didn't really make my skin look that much better, I guess. It just gave me white spots on one side and then, if you use it on the other side they looked a little bit less, then the other one you would see the difference in skin tone.SKI048 And [3 secs] [uh] I recently like [uh] got for a, I don't know what you call it, like a tube of something, [uh] it's a gel form and like for all faces [uh] and it makes the acne back-, better now. But I'm still like struggling with this situation like [uh] good or bad, like it irritates a lot. SKI049 What creams I had. OK, this only goes back-, oh no 2010. 2010. I think it could have been the adapalene, and I also had one [er] [pause 3 seconds] I can't remember now. So, I went on the adapelene cream [um] and I didn't really feel like it worked very much. [um] It made my skin really dry. SKI058

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			And you sort of pour one into the other and you've got, then you shake it and then you like sort of like spread it. It's kind of like a Pritt Stick, you just sort of spread it over your face at night. [um] And that, it burns [um] but, you're like, "Oh, it burns, so it must be working." [laughs] [um] And I know one of my friends, she uses that now and it, it works for her.SKI09
	B3) Time consuming	Concerns or lack of concern expressed about the time spent applying topicals	I had wake up at bizarre times to take them. [Er] for the bathroom, I still have quite a long skin care routine 'cos I still have like topical treatments for it and I am very careful about what I put on my skin. My brother would always moan that I spent ages in the bathroom [laughs] and I always felt justified [laughs] for doing so.SKI017 I used to have like a, a skincare routine. So like I would cleanse, then tone, then moisturise, then do the, the whole treatment thing. So that kind of took longer in the evening and in the morning like I'd have to put like time out to do it. But I usually just did it in my room. So it wasn't a big deal for like my, annoying my brothers in the bathrooms or something. So that was okay. SKI066 And then do - spend ten minutes doing nothing while it sank in. So that was quite impractical, just for my morning routine, as well. Because if you're a teenager you don't have ten minutes to sit and do nothing while your acne meds sink in. [um] I don't think I had any side effects from the tablets.SKI072 So, yeah, it was pretty straightforward and, I mean, when you wake up and you've got spots on your face, it's not like you forget. You're like 'arr', you're more like, I can't wait to put the cream on, hopefully, it's going to do something in the next few hours. So [um] you, it is quite easy to keep on top of it.SKI08 But before that it would be a lot more like stressful because it would be a lot more like wash my face with soap and water. Apply cream stuff. Apply moisturiser, Go on with my day and do that at the end of the day. Which made it kind of like less me wanting to do it in a way. Because at least with the pill it's really quick and easy. Because I just take that and I'm, hopefully that gets to work hopefully. But unlike the topical where it's a lot more, like you get, if you miss it and you get into bed you're a lot more like, "Oh, I don't really want to get up." Because that takes a good five, ten minutes to do all that.SKI01 No not really. I mean people put makeup for one hour or one and a half hours. Yeah I don't do one hour in one and a half hour of makeup so. [uh huh]SKI03 Yeah, yeah definitely. [Um] I will always [um] in the mornings [um] like I have a lot of, I feel [um] quite unsettled if I don't [um] wash my face before I go out, if I don't obviously put my like topical stuff on [um] and also I have to like sometimes [um] make sure that like… is that okay? Is it alright? SKI073

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			[um] It can be. I mean most of the time I, I keep it quite simple, so I don't tend to do a lot. But when, when I feel, yeah, when I feel the spots coming, then I, I take, I take the time, yeah.SKI09
	B4) understandings of the different topicals available	Description of all types of topicals including High Street (Tea Tree Oil) or CAM (herbal remedies) OTC, Pharmacist or from GP or when they express uncertainty about what type of topical they are using	*Yeah, the one from the pharmacy SKI01* *Yeah [um] there, yeah so there was definitely a cream [laughs] and then, I mean I don't know all the medical names [um] and then there was a kind of like gel thing which I had again later on when they were trying to, you know, find something else. [Um] I can't remember what that was called [laughs].SKI038* No it was just from, yeah just from a, like I think it's from pharmacies SKI03 Yeah, so I got a bit of topical cream. I got benzoyl… hydroxide?.....Something like that? I'm not sure.SKI019 Other than that I mean I've ended up trying a range of over the counter non-medicated topical creams. [um] Some of which I bought as a teenager, the kind of [brand name]. Those are the ones that always appealed to me, the ones that looked kind of relatively clinical and approved. [ah] The ones that always appealed to my mum are the ones that looked kind of healthy and natural. [um] I can't really remember the names of them I'm afraid.SKI021 I tried some products that, [um] yeah, that my, [um] [um] I'm not sure how to describe that, some products. And I didn't eat medicine, [um] take medicines. I just put on more like treatments on my skin. I: Okay. Like creams and gels? R: Creams, yes. SKI032 I did have, yeah I've forgotten what it was called. I think it's called zinc oxide or zinc … it had zinc in it, that's all I know.SKI04 I'm not so sure about the name, but it's [uh] like [uh] similar to like A.H.A., something like that.SKI049 Yeah so I don't necessarily know all the, the names of them because there've been quite a few……. I'm not sure, I've had loads, I've had like benzoyl something, I think I've had. [er] I'm not sure what this one was called actually, I've pretty much been on everything so you can factor it was like one of them. [laughs] [er] so I'm, I'm not sure what it was actually called. SKI050 Yeah, when I, [um] I think it was with one of the creams I had. I can't remember what it was called.SKI066

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
			I can't remember what it was. [um] But it was like a cream that I, I would put on my face [um] to basically dry out [um] like the spots and stuff.SKI071 one of the creams we've been just finding in [pharmacy name] but one of them was suggested by a GP during my summer holidays in Greece, that suggested I should apply this.SKI075 but I can't, I can't really [um] remember them, off the top of my head.SKI08 a Yeah, [um] I don't, I should have looked up the names of things really. [um] I had, I think the first one he gave me, I'm not sure what it's called, but it was like a little pot and you get it and it's got a powder in. And then you've got another one with a liquid in. And you sort of pour one into the other and you've got, then you shake it and then you like sort of like spread it. It's kind of like a Pritt Stick, you just sort of spread it over your face at night.SKI09 Tried a lot of different topical things, so. Can't remember exactly. I think basically most of them that the NHS offers. [um] So like gels and creams and lotions, and [um] probably changed, changed to different ones quite often.SKI094
	B5) Time for treatment to work	Views and experiences expressed about time waiting for the treatment to work	*I think when my acne started to get worse after the strong treatment, [um] I was offered to s-, be on different topical stuff cos I started taking the antibiotics and then also extra topical stuff and they offered for basically more topical stuff and just keep going. But because I'd already been down that route and just kept trying different topical creams; I decided that I'd rather just go straight back to the stronger [um] medication than have to spend a a long time trying the topical creams which I was pretty sure weren't gonna…I mean maybe they would work but it would just take [er] a lot longer than if I went back to the treatment I was on before that was actually working. SKI045* *I think it helped a bit but not as much as I expected it, it would be. Like it takes about more than half a month to see a change. And then it's still, it's, it's still very red, but it's kind of better. I'm not sure if it's because of the, the treatment or because the acne just becomes better itself. So, yeah. SKI032* *I've, for some reason topical creams never came up while I was an undergraduate. Somebody did actually prescribe me a topical cream while I was at [university city 2], a GP. And I ended up not using it because it's not recommended for use in patients with ulcerative colitis. [um] Other than that I mean I've ended up trying a range of over the counter non-medicated topical creams. [um] Some of which I bought as a teenager, the kind of [brand name]. Those are the ones that always appealed to me, the ones that looked kind of relatively clinical and approved. [ah] The ones that always appealed to my mum are the ones that looked kind of healthy and natural. [um] I can't really remember the names of them I'm afraid. I think both of us expected results more quickly than they were plausibly going to come and*

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			so there was quite a pattern of kind of trying something for a couple of weeks and then just moving on to the next thing. SKIO21
	B6) How to use topicals	Concerns or lack of concerns about the appropriate use of topicals and suggestions for improving this	
	B6.1) Not sure if using properly	Concerns or lack of concerns about how to use topicals: • includes any details of how they use topicals (e.g. just on individual spots or on whole affected area)	*Oh, that's, there's, that's most of the creams that I've used. There's always stuff like, so like, I don't know, the branded ones will always be like, "Put it in your hand, rub it, a thin layer round your face, wash it off with hot water and then pat dry." Which is really stressful. And then the other one was sort of like, "Rub it in until it disappears." But the problem with those ones is I don't know whether I'm supposed to moisturise before or after, or whether I'm supposed to wash my face at all before that. I probably am but like, whether I'm supposed to wash my face before or after in case it comes off. So like you kind of have to work out. So like I stopped using moisturiser when I used the one that you just rub in, because I figured that you wouldn't like, and [sister's name] was like, "You probably shouldn't do both." But then again that didn't help because I wasn't moisturising. So that left like dry skin and stuff. So it was kinda, it wasn't very well explained on the back basically.SKI01* So I find that, and I, I remember reading somewhere, because I, I read on the sheet, it was like "Spread it on thinly." [um] And it sort of, it kind of worked but it didn't work that well. Then I read online, there was someone saying like, did a testimony to it and they were like, "I absolutely swear by those who just put loads on and it works beautifully." So I, I tried that and I put quite a lot on and it does, it does help, but it does dry your skin out really badly. SK1008
	B6.2) Information needs regarding instructions	Includes any information about the instructions people would like to receive about the use of topicals	*It would be nice if they were like, "Put it on your face, wash it off, apply moisturiser afterwards." Because then at least it's just all there and then you know what you need to do and you don't have to worry about, "Should I be doing this? Should I be doing that?" Which is quite annoying. Because it's already stressful enough having spots without having to worry about what sort of treatment you have to do and how you have to do the treatment, yeah. SKI01* *I even tried putting toothpaste on my spots because my friend told me that [laughs] so like go on [um] yeah I think or like places if you feel like it's not really being addressed properly even with the help of medication or like how do you know the medication is helping you [um] you know, particularly like the topical stuff like should I keep using this should I not SK1073*
C	**Antibiotics**	Perceptions about antibiotics	

Appendix D

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
	C1) Perceived side effects	Concerns or lack of concern about side effects: • includes how people perceive side effects • includes any ref to how people manage side effects	*But, I mean I don't know if that was just me or…but [um]. And then, so yeah I was going on, like and I kept trying loads of different things like, I tried so many different antibiotics. I tried like…I know I tried Lymecycline, Tetracycline, Erythromycin – I can just remember so many different ones and like, they had horrible side effects as well. So, at one point I had to take like four tablets in a day and like they made me feel so queasy. And so, I just felt it was quite hopeless because the medication that was supposed to help the acne, I feel like was just making things so much worse. SKI04* *with the antibiotics they make you really sensitive to the sun [um] which is, it's kind of annoying because [um] you know, I've always found the sun, I mean like not, you know, it's like a small thing but like sun cream gives you worse spots you don't want to put it on and you have to put a bit more on and like it restricts how much you go outside which is not great when you're young and [um] quite active SK1073* *he pills have side effects, but I haven't got any of them. Like they can turn your tongue sort of white, not white as in the whole colour but like the top bit gets like a white thing on it. And I think there's something else but I don't really know.SKI01* *Hmm, not the initial tablets or benzoyl peroxide, no.SKI019* *Yeah I thought those were, those were fine, no no problems with that.SKI045* *And then I think it was tablets. But it wasn't Accutane that gave me stomach aches. But I can't remember what the tablets were.SKI066* *I don't think I had any side effects from the tablets. There was - you know - something in the back of your head saying, 'Oh I'm on antibiotics all the time.' So it was more a sort of mental or social side effect, than an actual physical one.SKI072* *But [um], yeah. And then I switched to the pill, cos the antibiotics weren't really working. Also the- I think after, because it was so long term, I think it started to affect my sort of, my tummy quite a bit. And [um], yeah, I wasn't very happy. It kind of gave me like almost IBS-like symptoms. [um] And my Mum was like, "Maybe it's a good idea to get off antibiotics, because you've actually been on them for two and a half years," [laugh] which isn't, isn't [um] good. SKI094*

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
	C2) Perceived necessity	Perceived necessity based on people's perceptions regarding the effectiveness of antibiotics	*I just pretended it didn't exist [laughs], yeah, [er] my mum tried some creams with me, but it didn't work, so she brought me to the doctor and we did antibiotics, but I didn't take the antibiotics very seriously, so then, it didn't, it didn't work like and got more resistant and so we had to use Roaccutane, yeah.SK1051* *They put me on some pills, some acne pills, [er] but [sigh], so my acne problems basically were really carried on for a long, long time until I got to maybe two years ago where they stuck me on [um] maybe, I think they stuck me on Lymecycline, maybe that's a year and a half-, about a year and a half ago they stuck me on Lymecycline and that worked really, really well. [Video tape 1: 03:41] [um] And I [um], like all my spots went [um] and I had real faith in it and it worked really, really well, so I was on that about, for about six to nine months I think…… and so then I went back to the doctors and they put me on Lymecycline again. [um] I think that's around Christmas time and it just didn't work [um] so I was a bit frustrated about that because it had once worked really, really well. SK1058* *I spent quite a few years taking different [um] antibiotics like oral tablets [um] I took about think about three different ones of those [um] and finally when I went to see a dermatologist when I was like 16 I found the one that actually helped a bit but not, you know, didn't completely go away [um] and I stopped taking that last year because it was quite a strong antibiotic and, you know, I just, it was a lot, it was better SK1073* *I felt like that didn't too much really. I mean I think it had a bit of an after taste as well, but apart from that I just think it looked like a bit of a waste of time personally but, for some people, it might work; I think it's different for everyone. SKI04*
	C3) Perceived concerns	Perceived concerns of taking antibiotics (e.g. view that will be less able to fight infection in the future if they take long-term antibiotics, external vs internal and the sick role)	*Because like when you're taking tablets – you-, I didn't feel at the time that it was necessary. Because I just thought like 'it's j-, it's just on my skin. I can sort it out externally'. And I didn't really want to take medication.SKI071* *But that also made me feel kind of rubbish because [um] I was becoming more aware of the fact that taking antibiotics you almost feel like you don't really need them when it's your skin [um] and like you kind of want to save it for when you really need it [um] because I mean obviously that's [participant clarification: referring to antibiotic-resistant infections] a growing problem and actually like whenever I went to the GP or anyone that had a list of the medication I was on, it's the first thing they would comment on like 'Do you really need that like your skin looks alright' but was my skin looking, you know, I mean like alright, alright or a bit worse than it is now [um] you know, was it okay because I was taking medication, I don't know. But [um] and I guess it's their responsibility to do that [um] you know but [um] that also kind of, makes it's feel less satisfactory. SKI073*

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
			But there've been like antibiotic medications, which the only reason I have been wary about taking them is that like I don't necessarily feel like the doctors I've seen there's not much like [er], …like any check-up has been initiated by me and so I kind of felt uncomfortable with being on antibiotics cos it's, obviously it's a long term thing in my case, I didn't necessarily want to be on antibiotics for that long period of time without feeling that like I was, had doctor who was kind of continually aware of it and since, yes since I was initiating the check-ups that didn't really feel like that, that way to me and I kind of feel a bit more comfortable about creams than [um] pill medication .SKI050 *And there's something in your mind frame about 'Oh, if I'm on pills for something then I must be sick'. And I really don't like that notion. I'd rather have worse skin, but not feel like an invalid for it. [Um] Which is probably my mental mindset, and not - not how I should be interacting with the treatments. SKI072* *And then I was on antibiotics about two and a half years, which is [um] not ideal. [laugh] But, to be on it so long term, I think. SKI094* *I am quite nervous about going off it because every time for the past two years when I've gone off it, it's come back. So, I guess that's where I'm at at the moment really, is sort of [um] – and I've got my sister's wedding coming up, and I, I really- cos they were asking whether I wanted to, after a few months, whether I wanted to go off it and see how it is, or keep on going for about six months. And I said, "Well, [laughs] I've got my sister's wedding and I want to be spot-free," [laughs] so then I said that I wanted to have it for six months and then see where I am. So, that's where I am at the moment.SKI058*
D	**Contraceptives**	Perceptions about taking contraceptives as acne treatment *(excludes instances when used for isotretinoin)*	
	D1) Perceived side effects	Concerns or lack of concern about side effects	*Well so the pill, as I said, got rid of the rash and it didn't come back. And it significantly helped the acne. [um] However it gave me really bad mood swings and that wasn't really worth it……. [um] Well it definitely made me quite volatile emotionally. [um] I've been on a number of different pills. [um] All of them have made me quite volatile. The first one I was on which was Dianette, which was kind of prescribed particularly because of the high oestrogen levels [um] in the hope that that would help my acne. That gave me really bad mouth ulcers which is not listed as a side effect of Dianette but they stopped the minute I stopped taking it and I can't think of anything else that would have caused that to happen. [um] I think all of them also made me gain weight which, I mean, I'm aware that this is very silly because I could stand to gain a bit of weight but I did not like it. [um] And in general I just found that I was*

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
			happier off them than on them, in spite of the impact they had on my skin, and without fail every contraceptive pill I've been on has improved my skin.SK1021 *I don't think I've had any like mental health side effects or anything from, from, from the pills or, or on Yasmin or anything like that SK1058* *the pill I didn't really like. [laugh] But I think I just, that kind of made me gain a bit of like water weight, and I think [um] it, it didn't really stop the spots, but it made it-. So as opposed to kind of having a flare-up once a month, it would be like a flare-up twice a month. [laugh]SK1094*
	D2) Perceived concerns	Concerns or lack of concern around the stigma and embarrassment related to taking contraceptives at young age	*Yep, that one, yeah, I had that. [Um] yeah cos the first time I had that was when I was 12 [laughs] and that was also really weird [um] and just cos I was so young and like I was sort of taking this contraceptive pill and it was really strange.SKI038* *yeah so I guess both of those I was offered by multiple people but, you know, I, you know the pill when I was too young to be like 'What, no I'd be really embarrassed none of my friends are taking this'SK1073* *So I took antibiotics for quite a while. I think that's because I was a bit younger, and they didn't want to give me the pill. [um] Because a lot of my friends who [um] have bad skin often get given the pill now and I think that's because, because we're a bit older. [um] And it wouldn't be unusual for like a 20 year old woman to be on the pill, whereas I think if you're 15 it's a bit-. So they started me on antibiotics, I was on them for quite a whileSK1094* *So I think when like I first started going to the GP then they didn't even mention that. And I think it was when I was around 15 that they were like, "Oh, yeah, the Pill would work." And I knew one of my friends had gone on the Pill for [um] acne like purposes. And [um] like she, me and her are quite like sporty and she told me that with going on the Pill she'd put on weight. So I didn't really want to go on it because I didn't really wanna put on weight. If that sounds kind of bad. But that was one of the main reasons I didn't really wanna go on it. And also because I wasn't, like I didn't need contraception. And I think that was just, I just found it a bit pointless. I'd rather have done something else specifically for my acne rather than something that might help my acne.SKI066*
	D3) Perceived effectiveness	Perceived necessity based on people's perceptions regarding the effectiveness of combined contraceptive pills	*And it wasn't until I sort of finished my course of Roaccutane and they were sort of thinking about [er] the future beyond going to the dermatologist. They suggested that going on a sort of hormonal contraceptive pill, certain ones of those might help improve my skin. I didn't have a prescription from them then but they sort of suggested that might be an option to talk about to the GP in the future, which I did, so, yeah……. Yeah, as far as I am aware [er] it seems to have helped. Obviously nowadays, my acne only seems to sort of, well, mostly seems to be related to sort of hormones*

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			and things so I'm assuming that that sort of is helping. It's certainly a lot better like now, my skin seems a lot better. So, yeah SK1017 *So I started using the pill to see if that works. It didn't really work for my skin to be honest, not, I didn't want to go into a heavier pill or something but [um] it didn't really work for my skin to get really better, I guess.SK1048* *And I did feel that that really worked actually [um] cos I had a lot of pimples on my forehead, and they completely disappeared when I-, like a few months after I'd started Yasmin. [um] And alongside it I had other creams but I didn't feel like they worked very much SK1058* *Yeah, absolutely. They do, [um] they do get a little better when I'm on the pill. [um] And sometimes I'm just on the pill just because it does mediate my skin a bit better. [um] Rather than I'm needing them for contraception. So I definitely do prefer to be on the pill because it, it helps my skin. [Um] Doesn't make it go away entirely, and I still get a monthly fluctuation in my skin. But it's less noticeable. [Um] I do try and have a, a couple of months off every, every year or so when I'm on the pill. And I can definitely notice then my skin get considerably worse. [Um] I haven't noticed a difference between them, though. Like I've tried quite a few different pills, and I don't, I haven't found one that's miraculously cured everything. [Um] So just sort of pick them on the other side of things, rather than acne being my main, main prioritisation. [um] I don't think there's any other medication that's impacted them that much though.SKI072* *Obviously nowadays, my acne only seems to sort of, well, mostly seems to be related to sort of hormones and things so I'm assuming that that sort of is helping. It's certainly a lot better like now, my skin seems a lot better. So, yeah SKI017*
E	**CAM & DIY treatments**	Perceptions about using CAM/DIY treatments for acne	
	E1) Perceived concerns about CAM	Percieved concerns or lack of concerns of CAM: • includes beliefs about how natural CAM is compared to medical treatments	*Oh, oh, oh yeah. Yeah maybe if, yeah maybe like home products or something like that. Like more of an organic solution rather than like, yeah I don't know what chemicals and stuff but yeah, may be quite interested in.SK1003* *It doesn't sound particularly legit……Thinking about it now, but, it was probably, you know, just some, you know, natural stuff, but, yeah.SK1019* *And I just thought I'll give it a go because at that point-. I think when you have acne [um] you are literally willing to give absolutely everything a go. For example, I put, for quite a while [laughs[I put asp-, I got a pestle and mortar and*

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
			put [um], got aspirin tablets and then made it into like a paste and then stuck it on my spots, and stuff like that. SK1058
	E2) Perceived necessity	Perceived necessity based on people's perceptions regarding the effectiveness of CAM	*I remember trying things like, it's all the, it's all the weird ones that don't work but you think maybe they will. Like tomato skins, you're meant to put them on your face and then let them dry. Or I once read the in-, sort of the inside of, the lining of an eggshell, you're meant to put that on and that's meant to work. [um] Just all, all the sort of weird home remedy type ones that people are, "I absolutely swear by putting bananas on my face" and then you try it and you're just like, "This isn't working" [laughs] [um] yeah. But most, mostly it was quite helpful. Everything I read I took with a pinch of salt I think, [um] just because you have to cos you don't know the full story. [um] But generally speaking it worked.SKIO09* *Yes. Like [uh] mainly like tablets or skin care things like [uh], oh, yeah, I was like try the tea tree oil for like years but [uh] I was not so sure about the, it works or not or anything.SKI049* *It was also through a friend. [um] He, he just said he used it for his skin and [um] he was at my-, I was at his house one time and [er] basically he put-, he like made a paste for me, I stuck it on my skin for about two hours or something, and like I felt like the redness had gone down, and the next day I did it again and-. I mean I don't [laughs], I don't know how useful it is but I did feel like the redness went down……..[um] So, I did that for about maybe like a couple of weeks after [laughs], after that and then I sort of forgot about it. But, yeah, it's interesting how you're willing to definitely improvise SKI058* *it's kind of like a cleanser thing like with tea tree. That's a big, [laugh] a big acne preventer. And I just like put it on my face and then I wash it off in the morning. And then [um] in the evening I kind of like where you put it on like a cotton pad and cleanse it. And then [um] I moisturise it as well. And, [um] but I noticed like when I was on the Accutane I didn't do any of that. Because he said, my dermatologist said you didn't have to. And [um] I don't think my skin really, it doesn't make that much of a difference I don't think. I just do it like kind of out of habit now rather than because I think it might prevent my acne or something, yeah.SKI066* *Yeah, I have - I have a tea tree oil beauty cream that I use day to day, usually at work. [Um] That - I'm not sure if that helps much, but you know, I'm trying.SKI072*
	E3) Perceived side effects	Concerns or lack of concern about side effects	*Tea tree oil. Which, it does that thing where it kind of, you put it on and it burns a bit so you think it's working. [um] And that kind of helped, but obviously it's really strong smelling. [um] The same with TCP, that had the sort of drying thing, but it just, the smell just stays on your face for the next two days. So I try not to use it any more, [um] yeah.SKI09*

Appendix D

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
			But like, a lot, there's a lot of also things like cures I've heard about that I've, like lemon juice is one. But then I read a lot that you shouldn't use it because it is just bleaching your skin [um] and also like yeah it burns so that's why I stopped using it. I think that's always a good indication that it's probably not the right medication [laughter]…… Yeah I also like, so like there's stuff like toothpaste and lemon juice I've heard but in my experience they do both burn. [er] And like, like the advice I've always had with cream is like if it burns take it off, like so I kind of didn't do them [um].SKIO50 *at their best, a lot of them are just pretty useless. [um] The toothpaste was probably the worst idea. [laugh] That actually left me with like, like a burn mark across my face. [um] I think most of them are just pretty ineffectiveSKIO94*
F	**Isotretinoin**	Perceptions about going on Isotretinoin	
	F1) Perceived side effects	Concerns or lack of concerns about side effects	*And the, yeah, the side effects of that were horrible [um] I don't know if we're talking about that later on or whatever, but [um] my skin just dried up to like a prune – it was, I had really bad lips especially like in the corners of my mouth was really, really bad.SKIO19* *well every time I had it I started on a lower dose, I think you start with like half the quantity and then after like a month or two you move up to the full dose. [Um] and so I think that kind of like eased it in without like too many side effects straight away but like, yeah just like horribly dry skin [laughs] [um] and like your lips just peeling all over the place [laughs]. [Um] and, I mean I don't, I mean they do say that like it can affect your mood, but I mean I think I was quite upset about the whole process anyway so I don't think it was necessarily the pills that were making it worse. SK1038* *And it has like quite bad side effects. And unfortunately I got like quite a lot of the side effects. At the beginning was quite bad, cos it kind of, it gets worse before it gets better. So I had loads of side effects and it got worse. And it was, it was not very nice. But then [um] eventually I kind of like, my body got used to it and it started getting better. And then he upped the dose. And so I had two capsules a day. And even though I still had the side effects, it got, my skin got so much better. It was so good. And then the side effects started to go.SK1066* *I guess really with the muscle aches and things like that, I just didn't think about it too much. The chapped lips, I had a massive stash of Vaseline pots and [laughs] I was just putting it on like all the time in class. But I, I didn't mind the side effects at all because of the improvement to my skin. [Er] and, yeah, I also remember at the time [er] like it made my*

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			hair, 'cos it stops you producing oil to a certain extent. And I always got quite dry hair which is really strange [laughs] as a sort of teenager. [laughs] yeah, so, but.SKI017 *I didn't like the idea of the dry skin because this is a problem that I have had. [um] I didn't much like the idea of having to go on the pill to be on Roaccutane, having just come off the pill, not having enjoyed it very much. [um] I know the birth defects obviously are only a side effect if you're pregnant. I think I was just quite freaked out and this doesn't sound, this obviously is not particularly rational. I was just a bit freaked out to think that if it was powerful enough to cause those birth defects then what might it do to me which, which I know is not particularly rational. [um] But it was just anything that causes those kinds of birth defects I don't want to be putting it in my body I think was the feeling I had.SKI021* *See, recently with the isotretinoin I've noticed that I've been, my temperature, well, my temperature's normal but I feel a lot warmer and I start sweating a lot more as well. So that's one of the things that the doctor was looking at. [um] Of, by, [uh] looking at how I can sort of control the sweating, because otherwise, that is one thing that people notice, is the, that they see you sweating and you sort of start thinking, "Oh, people are going to see it", and it makes you sweat more or something.SKI028* *[um] So, obviously that, that's one of the biggest side effects. [um] Another side effect was, it was [um] like headaches and toothache as well. [um] I had a lot of bleeding gums, my gums were bleeding quite a bit while I were on the steroids for the isotretinoin [um] and, again, that was another side effect, so I've sort of had quite a few of the [uh] side effects that are listed that you're expected to get as well. SKI028* *although isotretinoin [um] that was…makes you more sensitive to the sun, so I got pretty much straight away, I got a sun-tan [um] which wasn't too bad. And but I, I get really flaky lips and really dry lips and I still…you know at the moment I've still got quite dry lips, [um] but that's totally manageable. [um] And I th-, I think as, as it goes I've actually had quite bad side effects but you know they're completely manageable. It's just like dry lips and my skin's a bit dry [um] but apart from that, yeah not too bad.SKI045* *Yeah, yeah, yeah. Definitely quite a few years. [um] And yeah, my, my only regret, like I said, is that I didn't go on it sooner [um] the Roaccutane, because [um] yeah, I mean, it cleared up straight away and I had no sort of feeling, I mean, you get dry lips and sort of dry skin, but apart from that, you don't, I, I myself didn't experience any sort of bad, bad symptoms at all really.SKI08*
	F2) Perceived effectiveness	Perceived necessity of isotretinoin based on people's perceptions about the effectiveness or ineffectiveness	*And I was put on, I can't remember what it's called. Is it Roaccutane? Is a kind of really powerful one that makes your skin all thin and everything. [um] So I was on that and that worked. [um] Which was good, because I don't think there's anything stronger. [um] So I was on that for maybe six months, a bit longer.SKI09*

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
			The fact that, you know, it is, it does really sort you out. Well it sorted me out, I don't know about other people, but like it worked wonders for me, but obviously it comes with some quite [um] severe side effects, so I suppose he was trying to get across like more of a balanced point of view.SKI019 *And then I, in about six months of being on it I'd pretty much got clear skin. And this was around I think January time when it, I'd finished. And I went back and he said, "It's worked really well. You don't have to go on any more."SKI066*
	F3) Perceived inconvenience	Perceived inconvenience including: • blood tests • contraception and regular pregnancy tests	*Yeah so they, so I was required to take a pregnancy test prior to starting the drug. [um] And I didn't like doing that because it was just, well I knew it wasn't necessary at the time. [um] So, that, I felt that kind of made it even more embarrassing that it had to be. Like, I don't personally like hospitals or anything, and having to be at one and like do that, I felt was like quite annoying and kind of made it harder than it needed, perhaps needed to be.SKI04* *They had, they said I had to have a pregnancy test because I think it was sort of everyone over 16 or so had to have a pregnancy test. And [um] it's because I think it, it did like a similar thing to Thalidomide with babies. It makes them deformed or something. [um] And, yeah, but it, he, he was really apologetic about having to make me do it because I, he was like, "Obviously you'd know if there was a possibility of you being pregnant." And, [um] but, yeah, I had to, I had to do it anyway. But they were, they were very nice about it, [um] yeah.SKI09* *I was being seen in [home city] but I was at university here [um] that was quite [um] inconvenient because I had to [um] I had to go home for the, for like 24 hours and I mean luckily because of my degree I don't have a lot of like contact time [um] so I could fit it in but it was quite, yeah [laughs] quite time consuming because I had to get the train back there and then go and everything. [Um] and also because I had to have blood tests and stuff at the GP's so I had to keep making loads of other appointments there [um] so yeah I think, I think that was just quite frustrating.SKI038*
	F4) Information received about isotretinoin	Any information received about isotretinoin (from HCP): • includes information on how to take the medication • side effects • how to manage side effects either in consultation or through leaflets provided by HCP	*Yeah, I mean, as I say, the, that sort of information came from the dermatologist mainly and honestly the GP was, you know, fairly well versed in those sort of effects, but, you know, the real kind of specifics came from the dermatologist so in terms of those emotional side effects, yeah.SKI019* *It was sort of pretty straight forward when I went to see them because I'd already been given three trees' worth of information about the different things cos the doctor gave me a pack about stuff and then they gave me another pack. SKI028* *I got leaflets on Roaccutane and on [um] contraception as well cos that's sort of related. [um] I don't think I got that many on all the different options or, I didn't get anything on other people's experiences of acne, so I did feel a bit like I*

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			didn't really know; cos I didn't know anyone else that had been on it at all. [um] And none of my friends had really had any skin problems, so I did feel a bit [um] slightly uninformed but they were really helpful so yeh.SKI04
	F5) Decision making/support about going on isotretinoin	Experiences making the decision to go on isotretinoin: • includes conversations with family and friends • support from friends and family	*So it was more kind of like oh, you know, "I'm thinking about it" kind of thing. Less, you know, "What are your thoughts, etcetera"? I mean I suppose my mum was my biggest sort of [um] debate is what I had like the larger sort of debate with my mum about the whole thing so, but other than that not really, I suppose……Was, you know, do I go on that now and kind of risk jeopardizing my whole kind of, you know, GCSE's and whatnot? But in the end I just went for it, so.SKI019* *Yes. [um] Well I, I spoke to my mum. My mum had been in both consultations where Roaccutane was recommended and the first thing she said when we went out was, "Gosh, you're not going to go on Roaccutane, are you?" [um] And I think after that there wasn't really a need for a discussion with, with anyone else.SKI021* *They sort of expected it, I suppose, with me being a teenager at the time. [um] They wanted me to go onto the isotretinoin sooner but [um] I just weren't too sure after reading things online about other people that have taken it……. and wanted to commit suicide. So it was, that did sort of put me off. SKI028*
G	**Other Treatment for acne and scarring**	Treatments for acne and scarring including steroid injections, steroid cream and laser therapies: • includes whether it's necessary • concerns or lack of concern about safety and side effects • includes people's experiences at skin clinics	*Nah unless it's really bad but yeah I think it is ok for now. I can deal with this. SKI03 (Laser therapy)* *But they said that one of the side effect is that your face is going to be more sensitive. And you have to [um] continuously like apply something on your face and, yeah, pay more attention to it. Yeah. I'm not sure. I hope that in the future there, there will be a very safe [um] treatment for me to, yeah. SKI032* *Yeah. I had a couple of different treatments. I think there was something, I'm not sure what it was but it was something to do with like a red light. [Er] Yeah, because unfortunately I had keloid scarring. And so they wanted to try and flatten them out because I was quite conscious, self conscious of them. I didn't wear anything low cut for quite a few years. [Er] so, yeah. SKI017*
4	**SEEKING INFORMATION AND SUPPORT**	**Views and experiences regarding information and support received about acne**	

Appendix D

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
A	**Experiences of consulting HCP's**	Experiences of consulting HCPs to include: • perceptions of whether the impact of acne was acknowledged • frustrations with delays in treatment effect and referral • experience of making treatment decisions with HCP • experience of info sharing from HCP (including how informed they felt about the treatment they had received) • awareness of GP and dermatologists and attitudes towards them (e.g. comparisons) • questions people asked the HCP	*I think it would be better for them to communicate more with the GP rather than expecting the young person know the names of the medication. [um] Because, I mean, when I spoke to my GP about that first dermatologist, they provided me with a list of all of the medication that I'd been on, even if it hadn't been related to the medication, even if it had not been related to the acne – they still provided that list of everything, so that the G-, the dermatologist could look through it.SKI028* *My advice to GPs for young people that have got acne is to [um] listen to them and to actually understand that it's, it might affect [um] who they are and their self-confidence. And to give them some self-reassurance. Because I know for me it was quite daunting, just going and speaking to my GP.SKI071* *"I mean some sickness we just can't cure yet. We can slow it down, you know, what I mean like. In those situations that's a totally different rule, set of rules. But basic things, like acne medicine, acne creams, if it doesn't work, you're the one who's prescribing it for me, and you looked at me. You took your time apparently, apparently to look at it. It's probably not the first case you've seen to be honest. So you should be recommending something that will work." SKI020* *I don't know. Be like my doctor was. Just don't be any like. Just, I think if they don't question, because obviously my brother said you had to make it a lot worse than it was, even though my doctor didn't make me make it a lot worse. I feel like if they've come already to the doctor's, you might as well give them something, because it's obvious that they don't like it. And even if it doesn't look bad or even if it's not the baddest, if they don't like it, then it should be treated. Cos it's like it's just something. So I guess don't be like "oh you should try this" which you know isn't the best thing. Or, "Have you tried this?" and they're like, "Yes" and you're like, "Well, keep trying it" sort of thing. Just make sure you give them something that will actually work. SKI01* *But it was like each stage took, you know, a while to get an appointment and then a while before, they just kept saying, "Oh, you know, you have to wait and see [um] if it's working." So sometimes, I remember one time [um] I, you know, I was taking, I think it was when I had the three things at once and [um] I, you know, I went back to get more pills after like three months or something and they said, "Oh, it's not working. Okay, well, try another three months," so I went away and I came back and they were like, "Oh it's still not working, oh try another three months".SKI038* *I only really remember being asked like, "Do you prefer like tablets or would you prefer to put something on your skin?" I think that's the main one. But, I think I usually preferred like tablets I think. And, also they're like, "Do you prefer like a thin or a thick cream," as well so, that's the main input really but, yeh.SKI04*

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			The GP was very good about it. [Er] I was prescribed some antibiotics I think at the time. [Er] But I actually remember there was sort of, they were asking me about questions about how it sort of affected and whether people had, you know, been saying things and if it was affecting sort of socialising and things like that. So they were quite understanding which is good, because I was quite nervous about going about it.SKI017 *particularly when, when I had the implant and then that made it worse [um] and like that let me up a lot because I felt like it was my fault. Because I felt like I'd been kind of talked into having it and I'd kind of been, I felt a bit misled because obviously they'd said, "Oh, like don't worry, like if it's a problem we'll just take it out and it will go back to normal." [Um] but I felt like I should have said, "No," that it wasn't worth the risk [um] and so I, yeah that was particularly kind of [um] yeah, frustrating for me because I felt responsible.SKI038*
B	**Delay in attending the GP/a medical concern?**	Beliefs and concerns about attending the GP	*But [um] it continued for, for four years I guess, really severely and then I talked to my mum about it and she notice it, nosed it, noticed everything already [um] so she was like, "Well we can go and see if the doctor can help us a little bit". SKI048* *I think I spent a lot of time on these sort of, you know, face washes and all this nonsense like Neutrogena and whatnot and was under the impression that that would help [um] and obviously it didn't really at all. So I don't think I really went to the GP until a few, maybe sort of six months into, you know, having what I thought was quite bad acne.SKI017* *I guess I had been-, spent like quite a few years [um] trying to sort my own remedies out, and then sort of when I maybe reached the end of my tether and I thought, 'well, these aren't working' and [um], then I guess I decided to go to the GP and ask. I often find, with various things, when I go to the GP SKI058* *Yeah, I spoke to like most people in my family because all, most of my brothers and sisters have had it. And they would tell me what they thought that you should do. Friends would say what they've done. And then my mum and dad would tell me what they thought I should do as well. 'Cos I think we saw the doctors as like not necessarily like the thing we should do first, because we figured we should try all the other stuff first. So yeah. SKI01* *I think I spent a lot of time on these sort of, you know, face washes and all this nonsense like Neutrogena and whatnot and was under the impression that that would help [um] and obviously it didn't really at all. So I don't think I really went to the GP until a few, maybe sort of six months into, you know, having what I thought was quite bad acne.SKI019* *Yeah, I did try several ones, like I did try the ones that would work for my mom for example. But because she has a different skin tone, for me, some it just made it worse. So then I was just like, "Yeah, I give up, let's just go to the doctor and get it checked out. It's a lot easier."SKI020*

Appendix D

	CODE NAME	**DESCRIPTION**	**EXAMPLE TEXT**
			For both the rash and the acne. [um] Going to the doctors was, so we, for quite a while I think I tried to deal with it, you know, just by putting on creams and whatever [um] with my mum's help. And eventually we went to the doctor and got referred to a dermatologist who tried to treat both conditions but [pause] what happened?SKI021 *When I first getting a spot I didn't see a doctor because it's, my, my mum thinks, thinks, thinks, thinks that it's normal. So, yeah. [um] And it's because I think [um] for young people, [um] their skin kind of become very oily and some, sometimes com-, [um] combined skin s-, condition. So it's, yeah. SKI032* *I didn't really do anything to be honest for a couple of years which I suppose wasn't…was probably the w-, a bad thing to do because it made, made my acne get worse; I mean so much so that [er] that the sort of creams and stuff when I finally got around to getting it treated didn't really do too much. SKI045* *so I've had acne since I was probably about eleven but like to varying levels so like when I was eleven it probably wouldn't have been that bad and then like gradually as I got into my teens, I'm 20 now [uh] so that's like nine years [um]. And I didn't go to the doctor's for a few years, I think when I, I probably went to the doctor's when I was like 14 or 15 [uh] because my mum wasn't very keen on me [uh] like medicating for it [um] and then since I went to the doctor's I was put on like a number of like [er] creams and [er] pills and medications [um] which like a l-, I think a lot of them take like a long period of time like that's kind of the idea I think.SKI050* *So when I was about 13 I started getting like spots on my face. And it wasn't that, like that bad at first. So I didn't really mind. But then it started getting really bad. It was mostly on my forehead and like I get the T-zone bit. And [um] I started to get like more self-conscious about it. So we went to the GP and he gave me, it was like a dabber like with some, it was more like an alcohol kind of thing that you'd put on your face like twice a day.SKI066* *But it wasn't until I was probably in my twenties that I thought about going to the doctor for it. [Um] While I was a teenager, I just sort of considered it was something that was happening to me, that I didn't have any control over. Which probably isn't the best mind frame. [Um] Maybe if, if more people - maybe if I knew that I could go to the doctor about it, and there were things, medical interventions, that you could have to help, then maybe it wouldn't have bothered me as much because I would have been getting the help earlier.SKI072* *and I started getting, you know, spots on my face and stuff [um] and then it sort of gradually got worse and [um] like yeah I think I had like probably my mum took me to the GP, you know, when I was around that time and then, you know, I've, don't really think I've found like much successful [um] particularly successful stuff. SKI073*

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
			I haven't yet and probably the reason is because I've just accepted that acne is an issue that you just have to be patient about but I don't know if there's any radical solutions on to helping acne leaving or destroying it, but I'm not sure. SKI075
C	**Seeking information from pharmacist**	Experience seeking information from pharmacist	*I'm not sure, to be honest. Because you don't want to make it all over the counter and have everyone taking everything under the sun, especially when it's the antibiotics that tend to work. You don't want to contribute to the already prolific antibiotic resistance that we've got. [um] But maybe if you could see a pharmacist instead?SK1072* *That one was over the counter. Because in the summer I'd asked mum about the doctor's and she said, "I'll go to the pharmacy first and ask what they recommend." And we tried that and it did work a bit to start with.SKI01* *Yeah, just the pharmacist, you know like in [pharmacy name] or something like that. So, I mean, which is kind of weird because the people at the pharmacy care more about you than your own doctor. So they're actually nice about it. So when you go there they are actually nice and welcoming. So that's a little bit weird.SKI020* *Not particularly, but that's probably, probably a good idea; I think it'd probably will maybe now cos that'd be quite helpful in sort of, you know what to do and what not to do.SKI045* *No I think was still quite embarrassed by that stage so I probably wouldn't have gone like to speak to somebody. [um] Like I spoke to my brothers probably about what they were doing and like you do see a lot of advertising and stuff. [um] But I didn't actually; I didn't speak to anybody [er] who worked in a pharmacy [er] or yeah.SKI050* *They do often at the pharmacist tell me to be careful. [um] I don't necessarily think so, although thinking about it my [um], quite a few of my pyjama tops have bleach all the way round the bottom, [er] sorry, all the way round the rim of where I obviously take my top off, and then it gets on-, must get on the-. So I guess it does bleach my pyjamas, but apart from that. It doesn't, doesn't bleach my like [um] bedding or anything like that.SKI058*
D	**Seeking acne information online**	Experience seeking online information for acne including: • sources • credibility • commercial influence	*Yeah, it's just like, [um] you know, you kind of just Google stuff like tips to [um] tips to avoid getting spots or, [uh] just things like that really. And, or YouTube, sort of videos might come up and like there'd be someone with immaculate skin saying, "Yeah, it's all about hydration, or". [um] And things like that. So. .....Well, I mean, there might be sort of NHS kind of advice type stuff that you could, that I could look into. But all in all, it's just sort of a case of spending sort of 10 minutes or so, just, I mean, I look see if there's anything new that I haven't been doing.SKI08* *I would go to the NHS website first, [um] first and foremost. If, if it's something like a lot more [um] medical based then I'd definitely go to the NHS. If it's something, for example about [um] food-, cutting out food, like, you know, the*

	CODE NAME	DESCRIPTION	EXAMPLE TEXT
		• any comment about how sources of info were identified • suggestions about the type of support they would like to see	*dairy thing, I, I would be more happy with the people's experiences because often I guess they're more like [um] different-, less medical remedies you think might help SKI058* *And even just the sort of stuff people put on [um] online. Like homemade treatments and stuff like that, like we used a lot of those. And I think I've tried some really odd things. Like we tried [um] like aloe vera juice. Like some, someone online was like, "This works really well for skin." So I remember my Mum buying like from a health [um], a website online just like this jug of aloe vera juice, and it was really grim. But [um] we used to have this like syrup, and did like the typical kind of washing in salt water. Tried toothpaste, which actually burnt my skin really badly. So that was [um], I would not recommend that. [um] And I tried like Sudocrem, which actually works quite well.SKI094*
E	**Seeking information from others**	Experience seeking information from family and friends: • includes advice about washing • includes advice about consulting • others experiences of acne	*well when I [um] I think, yeah so initially I went with my mum when I was like really young [um] and then [um] and yeah she came with me to the dermatologist like the first time round and then the second time round, she came for the first appointment and then was like, "Oh, well you don't need me," and I was like a bit upset about that because I felt like I did, but never mind. [Um] and then [um] this time in [university city], my boyfriend came with me [um] and he's a medical student so that was just kind of reassuring as well because [um] you know, he was there but. SKI038* *The main ones. Just sort of, like, you know, [um] so before they'll sort of, sort of, you know, they'll agree with what you're thinking type thing [um] so you feel more assured [um] and then they'll kind of give you compliments when it's clearing up and, yeah, you kind of, it makes you feel a lot better really SKI08* *Like [uh] when I tried cover up my acne with any like foundation, concealer, everything like – my parents just say that, "You don't need to do that, like you look as good as you used to be," and [uh] yeah. And they need, they took, they take me to a doctor and they encourage me to take the medicine so, and they reminded me of like every time – so it's much helpful over there, yeah.SKI049*

Appendix E : Think-aloud study information sheets and poster

Information sheet for participants aged 16 or over

UNIVERSITY OF Southampton

Participant Information Sheet

Experiences of acne vulgaris and its related treatments: a qualitative interview study followed by think aloud user testing

Thank you for your interest in this study. This leaflet explains why the research is being done and what it would involve for you.

What is the study about?
The aim of this study is to find out your views and impressions about our new online advice for people with mild and moderate acne (spots). This will help us to improve the feasibility and usability of the website.

Why have I been invited?
You have been invited to take part in this study as we are looking for people aged between 14 and 25 who have acne or have previously had acne. We want to interview 30 people with acne to find out their views about the website.

Do I have to take part?
You do not have to take part in this study. Your GP will not be told whether you decide to take part in the study or not. Your current or future care will not be affected in any way whether you choose to participate or not.

What will be involved in taking part?
A member of the research team will interview (face to face) you about your thoughts and impressions of the website at home or at the University of Southampton. The interview will last 30 to 60 minutes, during which you will click through the website as you would normally do if you were alone and say your thoughts out loud. The interview will be audio recorded to allow the data to be typed up. You will be given a £10 gift voucher for your time.

Will my taking part be kept confidential?
Yes. All of the information you provide during the study will be kept confidential and only shared amongst members of the research team. However, if it appears that someone is a danger to themselves or others the information may be shared outside of the study. If you agree to have your interview recorded, what you say will be typed up and any names mentioned will be removed or replaced to ensure anonymity. Your contact details will be stored in a secure file on the University computer or locked in a filing cabinet with authorised access only for the researchers working on the project. After the study is finished these details will be destroyed and at no point will identifiable information be removed from University premises. Anonymised data (names and contact details removed) may be shared with other researchers.

Information sheet for participants aged 16 or over

What will happen to the results of the study?

Once the data has been analysed it may be published in academic journals and reports. We will use quotes from the interviews and any identifiable information will be removed from the report. We can send you a copy of the final report.

Who is organising and funding this research?

This study is organised by researchers at the University of Southampton, and it is funded by the National Institute of Health Research through the School of Primary Care Research.

What will happen if I don't want to carry on with the study?

If you no longer want to take part in the study, you can withdraw without giving a reason. If you decide during the interview, you can stop at any time and any data gathered up to that point will be deleted.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and approved by xx Research Ethics Committee. This study is sponsored by the University of Southampton and has been given approval by the University of Southampton ethics committee.

What if there is a problem?

If you have any concerns about any aspect of the study, please contact the researcher Miss Athena Ip on 023 8024 1086. You may also contact the Research Governance manager at the University of Southampton (email rgoinfo@soton.ac.uk or telephone 023 8059 5058.)

What next?

Please fill in the reply slip to let us know if you would be happy for us to contact you to arrange a time and date for the interview. If you would like any more information, please contact the researcher using the details below.

Further information and contact details

If you have any further questions or queries, please contact:
Athena Ip
Primary Care and Population Sciences, University of Southampton
Southampton, SO17 1BJ
Tel: 023 8024 1086
Email: A.Ip@soton.ac.uk

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

UNIVERSITY OF Southampton

Parent Information Sheet

Experiences of acne vulgaris and its related treatments: a qualitative interview study followed by think aloud user testing

Thank you for your interest in this study. This leaflet explains why the research is being done and what it would involve for your son/daughter.

What is the study about?
The aim of this study is to find out your son/daughters views and impressions about our new online advice for people with mild and moderate acne (spots). This will help us to improve the feasibility and usability of the website.

Why have they been invited?
They have been invited to take part in this study as we are looking for people aged between 14 and 25 who have acne or have previously had acne. We want to interview 30 people with acne to find out their views about the website.

Do they have to take part?
They do not have to take part in this study. Their GP will not be told whether they decide to take part in the study or not. Their current or future care will not be affected in any way whether they choose to participate or not.

What will be involved in taking part?
A member of the research team will interview (face to face) them about their thoughts and impressions of the materials at home or at the university. The interview will last 30 to 60 minutes, during which they will click through the website as they would normally do if they were alone and say their thoughts out loud. The interview will be audio recorded to allow the data to be collected and typed up. They will be given £10 gift voucher for their time.

Will their taking part be kept confidential?
Yes. All of the information they provide during the study will be kept confidential and only shared amongst members of the research team. However, if it appears that someone is a danger to themselves or others the information may be shared outside of the study. If they agree to have their interview recorded, what they say will be typed up and any names mentioned will be removed or replaced to ensure anonymity. Their contact details will be stored in a secure file on a University computer or locked in a filing cabinet with authorised access only for the researchers working on the project. After the study is finished these details will be destroyed and at no point will identifiable information be removed from University premises. Anonymised data (names and contact details removed) may be shared with other researchers.

What will happen to the results of the study?

Once the data has been analysed it may be published in academic journals and reports. We will use quotes from the interviews and any identifiable information will be removed from the report. We can send you or your son/daughter a copy of the final report.

Who is organising and funding this research?

This study is organised by researchers at the University of Southampton, and it is funded by the National Institute of Health Research through the School of Primary Care Research.

What will happen if your or your son/daughter don't want to carry on with the study?

If they no longer want to take part in the study, they can withdraw without giving a reason. If they decide during the interview, they can stop at any time and any data gathered up to that point will be deleted.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and approved by xx Research Ethics Committee. This study is sponsored by the University of Southampton and has been given approval by the University of Southampton ethics committee.

What if there is a problem?

If you or your son/daughter have any concerns about any aspect of the study, please contact the researcher Miss Athena Ip on 023 8024 1086. They may also contact the Research Governance manager at the University of Southampton (email rgoinfo@soton.ac.uk or telephone 023 8059 5058.)

What next?

Please fill in the reply slip to let us know if you would be happy for us to contact you and your son/daughter to arrange a time and date for the interview. If you would like any further information, then please contact the researcher using the details below.

Further information and contact details

If you or your son/daughter have any further questions or queries, please contact:
Athena Ip
Primary Care and Population Sciences, University of Southampton
Southampton, SO17 1BJ
Tel: 023 8024 1086
Email: A.Ip@soton.ac.uk

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

UNIVERSITY OF Southampton

Information Sheet for Young People

Experiences of acne vulgaris and its related treatments: a qualitative interview study followed by think aloud user testing

SUMMARY

We want to know about your views and impressions about our new online advice for people with acne (spots).

What is the study about and what will it involve for me?

A member of the study team will chat to you in person about your views and impressions of our new online advice for people with acne (spots). This will take between 30 minutes and an hour, during which you will click through the website and talk about what you like or dislike about it.

Why is the study being done?

This study is being done because we want to give people better advice on how to manage their acne (spots) and develop support tools to help them do this.

Where will the study take place, will I need to take time off school?

You won't need to take time off school/college as the interviews will take place at a convenient time for you. You can choose to have the interview either at home or at the University of Southampton.

What are the risk and benefits?

There are no risks to taking part and you may find the study interesting. We can also offer you a £10 voucher for your help.

Who will lead the study?

Miss Athena Ip from the University of Southampton:
Tel: 023 8024 1086
Email: A.Ip@soton.ac.uk

UNIVERSITY OF Southampton

PARTICIPANTS NEEDED

Website to support people with acne: think-aloud study.

Researchers at the University of Southampton are looking for people to participate in an interview during October - November 2017. The aim of this study is to find out your views and impressions about our new online advice for people with mild to moderate spots or acne.

We are looking for English-language speakers, aged between 14 and 25 who have spots or acne.

This study will enable us to improve our online advice, making the website more appropriate for people with mild to moderate spots or acne.

All participants will receive a £10 voucher as a thank you for their time (approximately 30-60 minutes).

Interviews will be carried out at a time to suit you, either at the university, hospital or your home.

If you are interested or would like more information about the study, please contact us using the details below.

If you would like to take part in the study or have any questions, please contact us on:

Tel: 02380 241086 or email us: A.Ip@soton.ac.uk

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Poster for community advertising Phase 2_v1 22.02.17_ Acne interview study IRAS ref: 223028

Appendix F : Think-aloud study interview guide

Think-aloud Interview Guide

We are interested in your views about our new online advice for people with mild and moderate acne (spots). Please use the website as you would normally if you were alone and say your thoughts out loud.

To help you think aloud you may find it useful to read aloud or tell me what you are clicking on and why. You may find at times I will say aloud what you have clicked on or what page you are looking at – this is so that when I listen to your views again, I know what part of the website you are talking about.

This is not a test and you are not being judged. There are no right or wrong answers, so please say any thoughts which spring to mind, even if you think they might not be important. I just want you to say out loud any thoughts which are running through your mind.

Please do say any negative thoughts you may have about the advice as these will be really useful in helping us improve it. Your views are really important, the more you can tell us, the better.

After you have finished looking at the website, I would like to have a chat with you about your experiences with your overall views of the materials.

(Note: wording may change)

Prompts about the advice

What are your first impressions?

What are you thinking now?

Why did you choose that option?

What do you think about [this activity; this information; this video]?

What do you think about following this advice?

Neutral prompts

That's interesting, could you say a bit more about that?

What makes you say that?

Could you tell me more about that?

Why do you think that?

What do you think about that?

Post Think-aloud questions

Can you tell me about your first thoughts when you saw the website?

How did you find the website overall?

What did you like about the website?

What did you dislike about the website?

How do you feel about the advice in the website?

Were there any parts of the website you found particularly helpful / unhelpful?

Were there any parts of the website you found particularly encouraging / demotivating?

Have you come across websites like this before? If so, how does this one compare?

Which bits of the website did you find easiest/hardest to use?

Which bits of the website kept your attention?

Were any parts of the website too complicated? If so, can you tell me about these?

Is there anything in the website you didn't understand? If so can you tell me about it?

What did you think of the [specific section] of the website?

Is there anything you would like to have seen that wasn't in the website?

Appendix G : Table of changes

Coding framework		
Code	**Stands for**	**Means**
IMP	Important	This is an important change. For example, a participant has highlighted a problem with the intervention and it is important to address this problem before continuing. Please specify why it is important. Also use this category to highlight big changes that warrant discussion.
EAS	Easy	An easy and feasible change that doesn't involve any major design changes. For example, a participant was unsure of a technical term, so you add a definition.
REP	Repeatedly	This was said repeatedly, by more than one participant.
EXP	Expert	Experts (e.g. clinicians on your team) agree that this would be an appropriate change.
EV	Evidence	This is supported by evidence. Please specify what evidence.
NC	Not changed	It was decided not to make this change. Please explain why (e.g. it would not be feasible; or only one person said this).

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Core treatments					
	I think this idea of universal acne treatment, I wouldn't have called universal acne, the stuff that you get given by the GP; I would have immediately assumed it was like – the branded, like off the shelf kind of stuff. (Participant 2)	Change 'universal core treatments' to 'core treatments'	Change 'universal core treatments' to 'core treatments'	REP EAS	*Persuasiveness (levels of trust)*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
	I'm not quite sure what it means by universal, core treatments, but I guess – is that just if I went to the doctor and had acne, they'd be like – here's something and that's it? I think that's what it means by universal, core treatment (Participant 3) *universal core treatments sounds quite like you're advertising something. I'm starting to think about my budget (Participant 5)* *I don't really understand why it's needed, as in ... I'm a bit confused as to why – the beginning bit is like telling you about the core treatments and [some people] don't use the treatments, but this is for everyone; like if it's for everyone, you don't need to split us into two groups straightaway, as people who have had treatment and people who haven't – or it hasn't worked. Do you know what I mean? (Participant 6)* *For example, when they - that the, what universal core treatments are, like, are they trying to say what, for example, the creams and gels being used? Like, how well*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
	some of the creams or gels work? But obviously, they're different. Some - it depends what kinda brand or what things you're using and what skin type you are, as well. (Participant 10)				
I like how you've got a page like actually say how they work. (Participant 14) *There, they're useful. Just, and not necessarily needed for other, in conjunction with other treatments. Yeah, definitely. That's definitely true. That's really useful, because not many people know that you can go to the GP, or anything to have anything that, you can only buy what's on the counter, which doesn't necessarily work at all. [Pause for reading 0:03:27.6]. Mm, yeah, that's useful to know what's in it. (Participant 12)* *Okay so that's the top one (I: mhm), is the only one you can buy without a prescription (I: mmm). Yeah. I didn't know that. I didn't know there were any that you could buy without a*	*Yes, it was literally just a list of different drugs which I don't think would be that helpful, or maybe if it was set out like the later pages, where you can click on something if you're interested. But other than that, I think the amount of information that you gave and the way that you're given it, is quite well done. (Participant 7)* *So I think – well being a medical student, I think it's – as my – I think – it's probably more interesting for me and more comprehensive and understandable for me. I think initially I was a bit – felt it was quite a lot of words that I wouldn't – that I wouldn't initially be familiar with if I wasn't a medical student. And if I was someone who hadn't already come across these things, because I haven't used them – yes – it would be quite – overwhelming, I think. (Participant 4)*	Use popup boxes to make the list look less busy and be clearer on what are brand names and what are the different types of treatments	Add in popup boxes	REP EAS	<u>*Structure and layout of website*</u> <u>*Relevance*</u>

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
prescription, I thought you needed a prescription for all of them (I: okay). I have no idea which is the one that I had. (Participant 1) Yes, yes. I wouldn't know what they are, so it's set out quite well. [Reading from screen] ... So click these? (I: Yes) ... So I got given antibiotics before I was given – actual – like – treatment, (I: Okay), which they did work for a while, but it says not be used as first-line treatment (Participant 2) *Yes, it seems good. I mean I'm imagining they're going to explain it in more detail later, but, yes. It's nice that they've specified the different types xxx a bit clearer. (participant 5)* *Yeah, yeah. Yeah, it's kind of helpful where you, you can know that you can still go to someone and they can give you something different and there's more options…….. Erm, I think that is good to know what, what they kind of have inside and that, there it*	*Okay – this is good; it's got some information. So if you don't know – if you've just got acne and you're a young teenager and have no idea what to do, this is quite good; it's like a first step. This is showing what the first step can be. ... [Reading from screen] ... Okay. ... I feel like if I was going to – it's nice to have this but if I was going to go to my GP, I wouldn't bring this list and be like – can I have xxx like I'd expect them to know. So maybe, for the common creams, you could just be like – you can have these topical ones or you can have antibiotics. I don't think all the names – but then if someone is particularly interested, the names might be useful. (Participant 6)* *a lot of names I don't understand. Yeah. All right. No, it, it would be useful to know which form they come in because… (participant 13)* *Yeah, I mean, maybe, maybe if instead of like a list it was like benzoyl peroxide and then you spoke about all the fit stuff to do*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
says that they can be brought at a pharmacy, in this case you're kind of wondering where you can go to get them (Participant 11) *I think it's good because people will know there's more stuff out there that they haven't tried. Maybe they've tried some of it and they haven't tried all of it, 'cause like there's always, they're always going to bring out more stuff, so, unless they just discontinue it, which is like the saddest thing ever. (Participant 17)* Yeah. I think just knowing that there's more than one treatment available and there are lots to choose and try out, it's again useful to know. (Participant 12) That's interesting to know how different ones do different things. And to prove that they're not all the same, just trying to re, rebranded. Mm hmm. (Participant 12) *To be honest, I've, I've never heard about any of these treatments. It's just,*	*with benzoyl peroxide and then topical retinoids later, just like that seems like quite a big and overwhelming list. (Participant 15)* *I think if I was, um, okay, if I was at home now looking at this I would be a bit like, 'cause you're naming them out it, like it doesn't really many anything to me, I'm just like - like these are just big words. It's - it's still good that you've put them in, um, that's good, but, yeah, if I was at home I'd be like 'I don't know what', like I'd be like, 'These are just big words to me', okay, but still good, yeah…… I don't know, like maybe 'cause - just because I'm doing the nursing or something I'm like, 'Okay, I recognise that one, I don't recognise that one', but I don't know, if I was just like, oh, just searching up acne at home or something, again, it's just like - like all the, you know, these kind of words, like I don't know. (participant 16)*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
erm, I used to use antibiotics but these were like, tablets, but as soon as I stopped, it comes again. Like, the spots. So, it didn't really work well for me. (Participant 10) *The information here is quite good because you don't want to try something super extreme and I think potentially if people are looking this up they might be fed up with spot creams and stuff, because they're over-the-counter and in theory if you have a spot you'll buy some of that and try that. So the fact that they're saying that that was the right thing to do is reassuring. Sometimes I felt I was wasting my money on them, but it's nice to know obviously that there are less side effects and I think it's going to go on obviously because it's part one, to give me more information about them which is really interesting. (Participant 18)* *Oh, great okay. That's probably quite interesting then because I think where*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
some of the branded ones would contain some of the active ingredients, this is a better way to go about it and then I guess you might have more faith in it actually working, because they have ones that smell nice and stuff and there's just a lot of other things in there I suppose. I think the image that you've got is good obviously without the watermark, because it is ones that you'd be prescribed, not like, 'Try Neutrogena's face wash' and stuff like that. Perfect, so the creams and gels are more important than antibiotics and things like that. I wouldn't have expected that actually. That's quite interesting. I'd potentially bold those statistics though. This is the one you can get over-the-counter isn't it the benzoyl? (Participant 18)					
Good to have illusion of choice whether day or night	*I think I just put mine on – like – in the morning and left it during the day. It probably doesn't actually matter, but I think because – if I've read – in the morning, then wash off, I'll be like – okay, I need to do it at night. (Participant 3)*	Specify put cream at night in 'steps for creams' page	Specify put cream at night in 'steps for creams' page	REP EXP	<u>*Views on terminology*</u>

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
	because it just says choose whether you'd like to, but it doesn't really explain if that's an important factor or not. (I: Okay) So I think maybe saying – it's up to personal preference or something like that, would be quite helpful, in case someone's like concerned about applying it at the right time of day. (I: Which one?) Yes, or like if applying it, at night is better, because it can sit on your skin more, or something, you know. (Participant 7) *I don't find it hugely clear, because I tend to wash my face in the morning, so it's saying in the morning again; it could be more clear. (Participant 5)* 'Choose whether you would like to apply the cream', mm, er, okay. I think, I don't know, I think maybe the doctor would suggest whether to - you apply it, um, yeah, he - he will tell you whether to - to do that, so, um, 'Speak to your doctor about whether it's better to apply in the morning or the night.' (Participant 16) *Oh, okay cool, 'cause you say in the morning there, but then it doesn't say*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
	before bed at the beginning. (Participant 18)				
Yeah, I think like it's fairly easy like to, to follow but it's like, for example, I wouldn't do things as dry it with a towel but if this page and it like it links back again to the like professors and people who have actually made it like you know it's professional advice, so you're more likely to take it. (Participant 14) *Yeah, that's, that's useful, that's really useful, because not many - because you generally just think put the cream straight on. But then washing it with, in, with, it makes sense, but you wouldn't realise to do it at first. (Participant 12)* *Yeah. I mean, I did for the first couple of weeks and there was just no, no difference. But then I saw a big difference in the next few weeks. Yeah, a big difference (Participant 12)*	*Oh yes, yes. I think that – the bit where you could have – clarification is Step 3; try to avoid other areas – because there is a lot of stuff in there like – paperwork that's – avoiding certain bits like eyeballs and stuff, which is fair enough (I: Yes) But – yes, some clarification, I think, would be in areas that you should avoid, if possible. (Participant 8)* *I'd probably tell you to avoid the sensitive parts, like lips and around the eyes, but I'd probably tell you that if you start having dry skin, to stop and to moisturise. (Participant 4)* *To be honest, I did exactly the same steps and especially when they say like, they say as well when they see redness or something, you, like, you have to, er, put warm water on it. Like, I used to take, for example, er, hot showers regularly a day because - but it still didn't reduce any redness, sometimes it became even bigger and worse, so. (Participant 10)*	Specify what the sensitive areas to avoid are (eyeballs, nose and lips)	Specify what the sensitive areas to avoid are (eyeballs, nose and lips)	EAS	*Views on terminology*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
It's, it's lay-, it's kind of laid-out, pretty simple I think. It's easy to follow, yeah. (Participant 11) *Um, I really liked that it had the step by step guide and how you have to be diligent with your routine and all that sort of stuff I really liked about it.(Participant 15)* *I'd follow it, and it would have been useful when I used the gel because I would have known I had to wash it off in the morning, or cream off, because I've never act-, I've never been told that before. …….. Yes step 4 would have been good to know in advance (I: okay), and to try and avoid using it in other areas because that can cause dryness (I: okay), because that was something I did because I get, I get spots everywhere on my face, or like it just went everywhere on my face, whereas if I'd known to only apply it to like, maybe just the really bad areas, and use it as a treatment rather than*	*I think they're like the step by step's really good, but I think it would also be worth, I don't know, maybe mentioning like, um, some of the things in like, just like the soaps and the cleansers and that sort of thing like, the stuff that we haven't already talked about. Things to look for in those products and like what products to avoid like perfume ones and what brands are better than others maybe. (Participant 15)*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
like a preventative method, then it would have been better. (Participant 1) *The steps of the face washing and stuff, yeah I didn't think about it. I tend to…in theory yeah, I apply it before I go to bed, but I don't always think about necessarily washing my face first. But yeah, it seems simple once it's there as sort of…but yeah, I think it's nice to have it simplified though because you just get a lot of conflicting information to be like it's genuinely the simple way to deal with things that's sometimes better. The side effects are interesting. They're not too bad but then, yeah I think that I've had those before, maybe the dry skin and stuff because I think you're literally drying out your skin to get rid of spots sometimes, so it kind of makes sense. (Participant 18)*					
	. Like I had a gel and I can't remember which one it is (I: mhm), and the guy didn't say how to use it correctly, he said something about like, putting on a thin layer, but like how much is a thin layer (I:	Clarify what a thin layer is	The video on how to apply topicals was incorporated and specifies a pea sized amount for entire face	EAS	<u>*Views on terminology*</u>

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
	okay), that's not, it wasn't really helpful. (Participant 1) *I've often felt that when I've missed a few days, I felt like the thicker the layer, the more quicker it will work. (I: Okay) So maybe a little comment about thin is good and this is not - doesn't make a difference or won't help, would be useful. (Participant 4)*				
'How can you manage the side effects?', see this was what would have been good to know (I: laughs). 'Here are some tips on what you can do about any side effects, click on the'. Okay so we'll start off with the dry skin, because this is the one I should have known about. 'You can use oil free, fragrance free emollient moisturisers alongside treatment. These can be bought over the counter from the pharmacy or you can ask your GP if they could prescribe them'. Okay so I just used, err, what-it-me-called, erm, not clearer skin but clerasil or something, clearo-something, one of those, of the like, ones you buy in	*Sun sensitivity I want to know what that is, so. 'Make your skin sensitive to the sun', okay self explanatory (I: okay, laughs). I use sun cream, avoid strong sun, that's okay in England (Participant 1)* *Sun sensitivity [Reading from screen] See, I've never experienced sun sensitivity, but then I guess it's because we don't live somewhere where we have strong sun all the time. [Reading] Yes, I think that's probably because of where we live; it's not an issue.(Participant 2)* *The sun sensitivity one wouldn't bother me as a person and I don't know if that's because we live somewhere like England or*	Side effects page- under sun sensitivity suggest that even in cloudy weather sun can be a problem -Bold the line "side effects are a sign of treatment working"	Suggest that even in cloudy weather sun can be a problem -Bold the line "side effects are a sign of treatment working	EAS REP	<u>*Views on terminology*</u> <u>*Relevance*</u>

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Sainsburys (I: mhm) type moisturises which was oil free because I know not to add oils to my face if I can avoid it (I: mhm), but I guess if its one that you have to have from the pharmacy or your GP then its probably, better, so if I'd known I could have gone to the GP and asked for something and then used that with the gel I probably would have been, okay, (I: okay), that would have been useful to know, again (I: mhm), because they didn't say anything on the packaging, and the packaging just spoke in lots of chemical languages that I don't know, so (I: okay), that would have been useful. Sun sensitivity I want to know what that is, so. 'Make your skin sensitive to the sun', okay self explanatory (I: okay, laughs). I use sun cream, avoid strong sun, that's okay in England, apply treatments in, ahhhh! Okay. (Participant 1) *I was always told, as well, to put sun cream on on a cloudy day; cloudy days can make you burn too. (Participant 4)*	*just because we're not outside a lot (Participant 6)* *I didn't experience this as well because I have, I have - like, we hardly see sun, so it's not really that, you know, it's not affecting. (Participant 10)*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
I think maybe – mentioning here like avoid strong sun, but then also – I know I was told that even if it was overcast and really cloudy, I'd still have to be careful. So I think maybe saying – like avoid strong sun gives off the wrong impression because it seems as though – as long as it's not a really, really bright day, you can get away without wearing sunscreen. (Participant 7) *Yeah, sun sensitivity. But yeah, I don't, like, personally haven't. [Pause for reading 0:10:23.6]. Yeah, definitely. Definitely agree with that statement there. (Participant 10)* *'Some people get these side effects early [?this is a sign 0:11:45:4] the treatment is not working', yeah, that's really - I'd even put that in bold, because back in the day like I used to be like if I start getting like really red again, I'd be like, 'Oh, it's my skin, um, reacting and that it's not working.' I*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
think you could put that in bold definitely. (Participant 16) *As I was saying, quite useful, because sometimes people do get the side effects and that's kind of the solution there, even if they do get them, they know how to get rid of them which is, is a good thing to have. (Participant 11)* *I think sometimes when I put on the creams, it, it used to dry-out my skin a lot. Erm, yeah, so that, that's kind of helpful for me to know as well (Participant 11)* *I think that's true to an extent because when I had to have cream for my back it got itchy and noticed it was improving. But sometimes if the product is too strong, sometimes it can go red and blotchy and then you have to like go back to where you got it from and just like do their tests and stuff. But it's just nice to know that like some stuff can make it better, so like these couple things might be working,*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
showing that it's working, but others won't, won't. (Participant 17) *And I think, as well, like mentioning that getting the side effects doesn't mean that it's necessarily an ineffective treatment, is very good as well. ... Yes, and like this little box here – I wasn't fully aware of that, that sometimes it doesn't work, just because you give up on it, because I know, for me, I would quite often use the treatment for like a week maybe and then if I didn't see any results or if I thought it made it worse, I would stop, because I was afraid of making it even worse, later on. (Participant 7)* *I think that's reassuring, actually, that it's not because you get side effects because it's not working, it's because it is working, and that's quite reassuring. (Participant 4)* *Yeah, I used to do it like, every day and in a day, I used to do it twice as well, so I think I did too much, maybe that's the*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
reason why it caused redness and dry skin. [Pause] To be honest, dry skin - I use more oils because I think dry skin oils helps it more, so yeah (Participant 10) *Yeah, especially, I think putting it on, putting the cream on and then going straight to bed, I think there's a rather bleached pillowcase…..Oh yeah, that's like, yeah, it is, um, nice to know that it's not gonna affect you really badly or... [Pause] I like how you've got the little link down at the bottom to show it was a real experiment rather than just saying it happened because like it's secondary data or something. So like it shows that you've actually gone out and done research yourself. [Pause] I think this is good 'cause if, if people have got - had specific side effects and now they are quite worried about it, instead of having to go to the doctors and do it there, they can just go here and it's got it explained. (Participant 14)*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Yeah, I like how it's got, um, advice on how to deal with it 'cause I, I don't think I would have thought to use it a bit less at a time if your doctor's saying to use it every day, then - but if it's saying that it's safe to do so, um, I think that's good. I think maybe here you could put some examples of like things that you could buy over the counter 'cause like you've got lots of examples of the actual treatments that you can use for acne but, yeah. (Particpnt 14) *I-, I liked the, the bleaching one especially. Um, I was just told to use white towels [laughs] when I had it so, yeah, no, I really like that, um, for all of them actually. Yeah, no, I, I rea-, I really like that they have like how to avoid them and how to make them not quite as bad. (Participant 15)* *so common percentages and then I think that's the over-the-counter one that you've talked about before, but it's interesting to see, like you might*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
assume if you've got quite damaged skin which might mean your skin is quite sensitive that you need something that's like as strong as ten per cent, but to say that they're similar is quite reassuring. You can use oil and fragrance-free moisturisers. Okay, yeah it's just simple things I suppose, but it's quite nice. It just seems simple and logical, because I think obviously this whole kind of area is just plagued with so much sort of information. Using sunscreen, yeah, okay and there's more research evidence which is quite good. Oh and it's the one about the 2.5 per cent and the ten per cent ones, okay. Yeah, I think everybody wants a quick fix (Participant 18)					
Well, personally, I get dry skin with my one, so that's why I've clicked on to the dry skin one to see what the tip was, which is actually quite good [chuckling] as well 'cause I get told use, um, moisturisers alongside it. (Participant 19)	*I like the steps, just apart from the [first one] where it says choose your favourite first-line treatment. So if you're starting out from scratch, how would you know what your favourite one is, if you haven't tried any of them before? (Participant 4)* *... Okay ... Asking me to choose my favourite first-line treatment and then*	Take out favourite first-line treatment and incorporate list of treatments with reference to GP.	Changed to "Choose a cream or gel treatment- click here to see the page on treatments to help you decide. Don't worry if you can't pick one, you can always go to your GP or	REP	<u>*Views on terminology*</u>

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
	saying – don't worry if you haven't got a favourite – is a bit like – if I haven't got a favourite ... You're asking me to do something and then you're saying, don't worry if you can't do it; do you know I mean? Maybe not ... maybe don't use the word – favourite first-line of treatment, just choose a first line of treatment, like together with your GP, working out what's best for you, not your favourite one. (Participant 6) *Yes, it's quite weird to me that it's like – choose your favourite; I don't know, that seems quite – like I know, for me, it was just my GP was – this is the most effective for you. (Participant 7)* *But – choose your favourite first-line treatment. That's like I would never follow that advice. (I: Okay) I would – yes – I would just go to a GP; that sounds like much better advice to me. (Participant 8)* *'Use the chart to de, de, de, choose your favourite first-line treatment', mm, I don't know, 'Choose your favourite', I'm trying to*		pharmacist and find one that is right for you."		

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
	think of how to say that better. Um, 'Choose your favourite', wait, do you mean like, oh, go and get, you know, um, you know those little ones you can buy just in the supermarket, like the Clean & Clear? Is that what you mean kind of by then or do you mean like..... 'Choose your favourite first-line treatment', you could say, um, I don't know, maybe, 'Speak to your doctor about the first-line treatment', or something like that, um, but yeah, and, 'Find one that's right for you', yeah. 'Participant 16)				
I think it's a good idea (I: mhm), it's just like, obviously, some people have brilliant willpower and they'd stick to it, but I don't have brilliant willpower and wouldn't stick to it. I'd try. I'd give it my best shot, it is only six weeks actually so I'd probably end up doing it (I: okay) so that would be good. Yeah (I: okay). But it would be a fault with me, not the plan if I didn't stick to it wouldn't it, so. Carry on (Participant 1) *Well I think it definitely makes sense – that I can definitely sympathise why*	*Yes, the phrasing of the bit in bold: you need to continue treatment six weeks before deciding if it's working for you or not ... might not be – I don't know – it seems a bit like – if they – explained that the treatments do take time for seeing whether they are working and seeing their effects, instead of just saying – you need to continue with it. (Participant 8)* *Yeah, that's exactly like, I was - like, what I said, erm, like, nobody has the patience, like, has time to wait or people get lazy as well. Like, I used to do it regularly but then,*	Changed 6 week challenge to 4 week challenge with an explanation that the treatment may take up 6-8 weeks for the best results	6 week challenge changed to 4 weeks: Phrasing changed to "You should start to see some improvement in 4 weeks. Acne is a long term condition and could last for months or years so make sure you stick with your treatment and you should continue to see further	REP EV: Myhill et al., (2017)	<u>*Relevance*</u>

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
you would give up too soon and especially if you're a teenager; if you're 11, 13, 15, six weeks – doing this every day for six weeks feels like forever. But that's a good, motivating statement. (Participant 4) *I think it's a good thing; it is really useful to know that. Yes, it would encourage me to not just decide that it's not working very well and swap to something else before it ends. (Participant 5)* *That's really good as well, saying that you need to continue it for six weeks, because I think – like – I think a lot of people tend to be very impatient, especially if you do see like some kind of side effects, like redness; I think that's something that would immediately, to most people, seem like a red flag and at that point you might stop. So I think emphasising that you can't immediately judge whether it's working until you've waited a while, is really – like that's a really important*	*by the time, I just - or sometimes, I don't have time to even do it. So, it's better if we get it like, obviously, get rid of it quick but I know it's not gonna be, for example, it's not gonna be possible because this is skin and everything takes time 'til it gets like, 'til it's treated. [Pause] Six weeks. As I said, some people would start with the challenge but then give up too soon because they're not strong enough to wait all that time. To be honest, for me personally, I wouldn't give it a try…… To be honest, I would try it on some part - obviously, not the face, but like, other parts that are more hidden because, as I said, I don't need to apply anything on it, so it's more easier to follow but as I said, morning - well, like, mornings or at night, so it doesn't have to be twice. It can just be once and then it's done. So, yeah, that should work (Participant 10)* *I don't know, I kind of get - I kind of get from this that it's saying like, 'Oh, go out to the pharmacy and just pick up something and try for four weeks', um, which is good, which is, yeah, it's okay. ……*		improvement over the coming months."		

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
thing to point out to people. (Participant 7) *Yeah, that's useful because it's kind of reminding you that you have to keep at it, if you actually want to see a change. (Participant 11)* *I'm conscious if I'm repeating myself. I think it's nice because, it's, it's, kind of, nice because it gets you thinking, oh, it's like a challenge for myself, so like, like adding it to your routine. 'Cause like a lot of people like having a set routine but like adding new stuff in that will benefit you is actually really useful. If I didn't already like use my, like use this skin stuff religiously, I would like use this to help me. (Participant 17)* *No, not that I can think of. I think the six week challenge was really - I haven't seen that one anywhere, that anyway. Yeah, I think all of it was really useful and I can't actually, I can't think of anything else, but (Participant 12)*	*Um, it's just like I love the colours, everything, but it's just too - wait, let me just have a look back again because, um, there's just some parts that seem a bit too like airy-fairy sort of thing 'cause like, um, I would like it be a bit more like serious. Um, okay, so scrap - scrap the four-week challenge (Participant 16)*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
. It's got a name which is good, the six-week challenge. [Laughter] Okay, so a chart as well. That's, that's, good……It's definitely a good idea to get into a routine because it's kind of like brushing your teeth, I guess. If you get, if you get into the habit of it then you'll just do it without thinking. Okay. That's useful to have that, common questions, I imagine people might be worried about. (Participant 13) *Yeah, I think, yeah, that especially like step 1, finding the one that's right for you and like it makes it just seem a bit more, don't know, like user-friendly, er, I guess. I think like having a chart like it, it's good 'cause it - like it will remind you that you need to do it if you've forgotten or... And I think that, sorry, having the PDF of the chart there like so people can see what it's like, I, I think that's... [Pause] These, these are good but 'cause they like if you do have a concern, a specific concern like it tells you about why other people might have that concern but also like gives*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
advice on how to deal with that and how you can get over the worry or problem. (Participant 14) *Um, yeah, I think it would be really helpful, um, especially because when I had my acne I was quite little and very unorganised [laughs] so yeah, no, I - and like I don't know, calling it a challenge I think is probably helpful as well. (Pasrticipant 15)* *Yeah, this is true because obviously, every skin type is different, so it might take like, a while 'til you find your right treatment but it's worth it, then that's it. Yeah. (Participant 10)* *R1: I think it's quite useful 'cause, actually, giving it a chance to actually happen because it's not gonna, you're not gonna wake up overnight and have nothing 'cause it would be gone because… And it has a tag inside to be able to even get any process and one treatment's not going to change that. (Participant 19)*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Okay, so it's sort of, it's kind of an interesting perspective because it's saying that what you're doing is probably a good idea. You just need to do it properly, so with the regime that you've like recommended and you've got to be like persistent with it because sometimes you'll see a spot and you're like I want that to go like within four hours and a lot of, and some like spot creams will advertise that. Like I've seen quite a few of them that say your spots will be reduced in like two or three hours or something, but like to do it properly is to do it like this, which is good to know. Oh, it's as long as four to six weeks, okay. (Participant 18) *That yeah, it just seems like, almost like a text box type thing to look at, but, yeah, no, the steps and stuff are really clear and the actual challenge itself seems, seems really good and doable and the only option I had you've already done so (Participant 18)*					
Yes. [Reading from screen] ... I think that's very useful because you probably	*'Choose a time of day where you can fit an extra fifteen minutes into your routine'*			NC Only 1 participant	

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
underestimate how long it takes you to actually apply the creams and the gels and waiting for them to dry; so actually warning people and saying this will take 15 minutes of your day – is actually really handy. (Participant 4) *It's pretty manageable, although it probably wouldn't actually take me 15 minutes, but if I wash my face anyway it's going to take me like two minutes to put the cream on. I feel like 15 minutes might be an overestimate but I guess if you've got it all over your back and you've got to cleanse your back and then dry and then put – that might actually take 15 minutes.(Participant 3)*	*okay. Fifteen minutes is a big ask for someone who's a bit lazy but- (Participant 1)*			commented on this	
I like that there's help to like make sure that people stay on track as well. (Participant 15) *It's really good, organised. So, for example, you don't get confused when you write, erm, the daily report. (Participant 10)* *That's quite good the, um, the chart because most people just like forget*	I thought it would be a bit more jazzier. It - it's - it's fine, like it - it's fairly basic which is grand. Um, I don't know [laughs], I - I, um, would like it may be a bit more jazzier, a bit of colour, like maybe - maybe like a graph or something like that, um, but it's okay, it's okay. It - it, kind of, it - it just looks like something you - I could make at home myself, which - which is fine again, yeah, it's okay. Um, so yeah, (Participant 16)			NC Only 1 participant commented on this	*Structure and layout of website*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
about it sometimes and… Like I, the amount of times I've forgotten to take my tablets because I was just like, 'Mum, did I take it this morning?' Um, no I didn't and taken it late at night. So with the other chart you can go, 'Oh I had it this morning, I don't need to do it.' (Participant 19)					
Quotes					
It's quite good having the, the quote from someone there…….Yeah. It, it means there's someone who has actually gone, 'Actually I did do it regularly, and it did help.' (Participant 13) *It's nice to see a person's response to like - like there's, you see like different transformations for people that have had like really bad acne and what they've used to like get rid of it. (Participant 17)* *Also quotes made, gave, they were much more, felt much more relevant and personal than just reading a*	*because it has no – name after, which, I guess, is fair enough, but ... something like –….So like – a small – non-identifying piece of information, like – I don't know ... like a ... I don't know, like an age and how long they had been suffering with acne or something. (Participant 8)* *Just some things were a bit unclear. So I think with the quotes and some of the statements, it is a bit – very ambiguous as to what kind of severity of acne it's referring to and I think it could be misleading, in terms of if adolescents were to read that, I think that xxx – I mean you could have two sat right by each other, one with a few spots, one with very severe acne and xxx one gets the benefits, the*	Include pseudonyms and ages on speech bubbles	Include pseudonyms and ages in speech bubbles	REP EAS	<u>*Relevance*</u>

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
paragraph about what a doctor said. Yeah.(Participant 12) *Yeah. It, it means there's someone who has actually gone, 'Actually I did do it regularly, and it did help.' (Participant 13)* *As that statement is saying, like, that person tried to give up on chocolate and cheese, as they said, it can be a reason, but she didn't see a difference. That's exactly like me. Even they say, drink a lot of water. I used to drink up to four litres a day and I didn't - I don't know if I saw a difference or not because sometimes, my skin is good and sometimes, it's not and I don't know the reason. So, you just go back to the normal like, lifestyle, how you used to eat and drink. (Participant 10)* *Oh, yeah it is, it was always reassuring to know that other people have it so like it is one thing to - this is quite a handy quote, 'cause obviously if you read a quote about other people*	*other one doesn't. Maybe with the quotes, there could be – I don't know – more details as to how bad their acne was before [their statement] (Participant 4)* *I like how this like encouragement to like tell people that they're not, not just the only person that's gonna be going through... [Pause] I like how the - this is like a click the boxes format 'cause it's a bit different to how the other ones are structured or some of the other pages are structured. Yeah, again, here, maybe add a, a name or, yeah, just to make it more like realistic. (Participant 14)*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
having it that's something and then you find out that they realise that their friends had it in…yeah, that's all good to know. (Participant 18) *So that, so that's a good quote as well 'cause it kind of, she has the six-weeks as well where it says that they used it for six weeks and that it helped them and that they're still using it and it's, it's going away completely. (Participant 11)*					
Things people wanted to see					
	Maybe also pictures of the products, because I wouldn't be able to walk into a shop and know what the oxides – all these different things are; I wouldn't know what they looked like.(Participnat 2) *I think some pictures would kind of spruce it up a bit, just make it a bit more interesting. Like I said, it was good having the quotes that humanise it; maybe some pictures of people with glowing, clear skin or whatever, pictures of the treatments so that you can kind of think, oh, that's what*	Add in more images as this was with the draft intervention on word	Add in relevant images	REP EAS	*Structure and layout of website*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
	it looks like, that sort of thing – would help, yes. (Participant 3) *Probably, as well – as pictures, especially, I guess, of – what the medication looks like, like the creams and the gels and which ones are tablets, which ones are bottles; that would have been helpful.(Participant 4)* *And I think if there was something visual there, then it would be a bit easier; it helps you to identify which ones are cream and which ones are gel and they can know what they're looking for. (Participant 5)* *With images – images of like – don't put gross images on there, basically. That would be off-putting. [Slight laughter from both] (I: Yes) Yes, images of universal core treatments, in this instance, would be better than – images of acne. (Participant 8)*				
	Just some pictures, because that gives you something else to look at. Also pictures	Before and after pictures		NC	

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
	help in terms of knowing what acne – whether this is applicable to your acne, because I mean – acne varies in its appearance; so someone with really severe acne might, from the onset, feel this isn't applicable. Maybe a video of some people – some kind of – obviously it's hard to do, but like before and afters are helpful, like this is my acne before the six week challenge; this is my acne afterwards, this is my acne before using a certain medication, this is my acne after; that's always helpful. (Participant 4) *I think the before and after pictures. (I: Okay) I know sometimes people don't believe the pictures that are put online and stuff but I think having an example of like – this is someone's face before they used it and here's their face after they've done these four steps with this product and the six weeks. (Participant 2)*				
	Maybe just like a short video of someone going through the routine of wash your face, dry it, put the cream on; that could be about five seconds and it was like you can see it being done, you can see it	Include video of how to use cream/gel	A video about how to use Epiduo was incorporated into the intervention [177].	EAS	

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
	doesn't take that long, you can see it's not that hard. You've kind of got no reason not to do it, that's the only thing, I think (Participant 3)				
Layout					
I quite like it 'cause it's different 'cause like with most websites, you just get an information page with the search bar or something like different pages you can go to across the top but like it's quite nice how it, it's different in its structure rather than just the same as all the other pages. Yeah, I like how you can go back as well like if you think - so, what, you didn't read something right, yeah, it gives you a chance to go back. (Participant 14) *It seems very like welcoming, like simple. It's got nothing too fancy, 'cause usually when you go on websites they're all like posh. They're all like, nothing, not really appealing to a younger generation. Oh, this reminds me of this book that I have. It's like, it goes through like all the pages of like how spots are normal and everything's*	*Maybe a little bit more colourful, because it's quite plain and I feel like if you're pitching this to people who have a lot of acne are like teenagers xxx, not that you necessarily need to have colour, but I think sometimes a nicer website people will go to for it – if they are like typing in on Google or whatever, they will pick one that looks good, compared to one that looks quite like – done simply, even though it's simple and it's good, I think maybe making it look a bit more presentable would be a good thing for people to go to. (Participant 2)* *Overall – again I'd say it was quite plain, the graphics, I don't know if that hasn't been done yet but (I: Useful, yes), so I would probably try and add a bit more colour, ever so slightly more [slight*	Edit banner and layout	Redesign banner and layout	REP IMP- to make the website engaging for the intended user	*<u>Structure and layout of website</u>*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
normal and it gives you like advice on how to like get rid of them, so I found this like really, like it looked really good. (Participant 17) *It's good it's divided. There's like bold bits and there's different colour bits. You know, having the first sentence being, having spots or acne's common. It's very, very good. (Participant 13)* *Really easy to read, short bits of texts and there was no, like, massive paragraphs that you had to go through. And, I mean, it had the images as well, which that's easier on the eyes, so you didn't just have like a block of text to try and trawl through.(Participant 12)* *It's not too in your face, like, and it's brief. There's not loads of different information, so, like most websites there'll be a hundred different things on it like, I can't be bothered to read them. (Participant 19)*	*laughter from both] but I think the format and everything was good. (Participant 5)* *Er, I don't know, it just needs a little bit of jazz or something like that. Um, okay, it's like the colours are really good and stuff like that, but it just looks a bit, um, hm, I don't know what the word is. I'm trying to think of what to put in. Um, [makes clicking noise with tongue] I don't know maybe things here or like search bars on the top where you could put in like different, do you know what I mean? Like dropdowns at the top or something like (Participant 16)* *Um, just that it was a bit like, I don't know, it's a bit odd that it's like a PowerPoint presentation rather than a normal website where you've got the bars up at the top. (Participant 15)*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
So the colour scheme is quite nice. It's quite clear and crisp. (Participant 18) *I like the images of water more than having maybe somebody with totally perfect skin. I don't know. I think with acne and spots and stuff you danger [sic] into looking like a lot of the adverts that don't really mean anything. So, yes I think that what you have got is really nice. (Participant 18)*					
	The red – kind of – makes it a bit aggressive and like – stop – they shouldn't be used, but you're also trying to promote using them as something that would help. And I get that it's important to mention that they shouldn't be used as a first line treatment, but the red is a bit like – I don't know (Participant 6) *I'm not, mm, I don't know, but I don't know [laughs]. I'm not sure if I - like this is just too much in, but like you want the truth, so the orange and the red, I don't know, I'm not mad on that myself, um, but still that's good. (Participant 16)*	Change the colour red to a dark blue or grey	Change the colour red to a dark blue or grey	EAS	
Main menu					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Um, I really like the main menu page (Participant 15) *Oh, sorry yeah I'll go back to that in a second then. I think like I said before it does seem kind of more central and it doesn't like fill the page, but I do think the sort of blue is a really nice kind of…I don't know, it's like one of those psychological things isn't it? It's quite like a calm website and 'cause everything you're saying is quite reassuring, it all kind of goes together nicely. I think I'd potentially have, where this is like, this is like kind of fine 'cause it fills the space on the main page, but have like a contents thing down the side or at the top just so if I was on core treatments I could go straight to oral antibiotics or, rather than having the middle man of the main menu. Or maybe have some pictures on it or something, but yeah, they wouldn't have to be anything major. Like you've got ones that are like quite scenic and stuff or bring back some of the ones from the other things, like the ones with the person washing*	*It seems very like professional and like it looks a, kind of, like it would have good information on it, 'cause like usually you see like these ones from like the doctors and they're just like straight words. Or like if you want to know something, I don't know like myth-busting queries or like living with spots, you just click on it and it tells you. I think it would probably tell you everything about it. It's like you wouldn't really want to have to scroll through heaps and heaps and heaps of like information, but if it's just right in front of you it's so much easier.* *Yeah, it's quite, it's quite, it's quite good. It's a bit, it's a bit plain looking, but apart from that, yeah, apart from that it's all right. (Participant 13)* *Yeah, um, it's, um, it's a little bit plain. Um, but I like how it's quite spread out and it's not all bunched together (Participant 14)*	Edit the main menu page	Redesign to include more images	EAS	*Structure and layout of website*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
their face or something like that, just to grab your attention, or maybe have ones that were relevant to each specific thing. So, like the tubes and things for the core treatments and creams or the picture of like a GP or something like that. Okay, yeah so that's the, the chart, great. The chart I think only has one week on it though doesn't it? (Participant 18)					
Other treatments					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
I just think, just if, it's just the option of if nothing is working then it be prescribed, that, just to know there is actually something. Because there's a massive range of treatments that you can use and they're all, they're definitely, there's almost definitely something that you can do to help. It's not worth giving up on the first treatment that you try. If it doesn't work then don't just give up, you can actually go back and ask for more (Participant 12)	*Yeah, that - that's a bit, yeah. Um, [pause whilst reading] no, that looks like just, um, like I wouldn't know what any of that means or, um, so not too mad on that, but yeah, that's okay, that's okay, that's a cool pic, yeah (Participant 16- contraceptive pill names)* *Okay, and saying maybe underneath and having - er, instead of having skin-friendly like as the link, say, um, click here for some examples of, um, contraceptive pills that are or aren't skin-friendly. [Pause] Yeah, I like how you've got examples of things there, so if people aren't sure on what to do or on what, um, medication it is making it worse, they've got examples there. [Pause] (Participant 14)* *Well, I think, er, for example, nowadays, the, the doctors did not really do much research about them, because they're thinking more about how to invest or create more chemical stuff. (Participant 10)*			NC – only 2 people said it	
Living with acne					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Yeah, sometimes you are a bit embarrassed so, yeah, it's kind of good to know that, if you can find a way that helps you, you can kind of just get on with it and eventually solve it. (Participant 11) *Um, I, I like that - yeah, I, I liked that it was talking about not just acne but like the whole thing that comes with acne, um, and stuff. (Participant 15)* *Yeah, I definitely, like, I can definitely see with people with acne like might feel that and stuff like that. Um, like I was going to say even if you popped in a few suggestions, like things like mindfulness, meditation, all that, but again, you know, that's not for everybody, so I think kind of probably the safest thing is the thing about the GP, um, or you could do, like you could throw that in about that, but I definitely, like I definitely think that that's three common, um, emotions, you know, associated with acne, so that is good (Participant 16)*	*Mm. I mean I did like the other two as well, but I think that maybe if they were in there with like some other stories that maybe weren't so extreme.(Participant 15)* *I've never heard of anybody being that bad, but I guess if it is that bad and you're that self-conscious, I can understand where that would come from. And, and then again it's finding the, finding the right treatment and sticking with it, and it will eventually get better. (Participant 12)* *I don't know if - I know that you mentioned I think in one of the things that you work with the NHS. I don't know if you'd want to include links to their maybe sections on anxiety and stress and depression 'cause they'd be more…if somebody is actually concerned that they've got them, they might want more information. 'Cause obviously it's quite nice and succinct to just have a couple of sentences, but if someone was like, 'Oh that might actually be me' and then have a look. I don't know if you'd want to interlink them or not. (Participant 18)*	Quotes on the living with acne page make them less extreme	Change quotes to make more relatable	REP	<u>*Relevance*</u>

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Yeah, for example, it just reminded me of my sister when she gets one spot - obviously, not a small one, a big one, she's like, oh, I'm not going to uni today, I'm gonna stay home! So, I think some people obviously have that as well and like, yeah. But especially, for us girls, it might be more easier because we have make-up. Some days, we think make-up hides it, but it doesn't really, but it, it gives us more confidence, and yeah. (Participant 10) *I think definitely most people do get stressed or anxious over their acne. I haven't too much. No, I haven't really to be honest. But it's understandable why they would. And it's interesting to see how it's, it's about how much control you have over the treatment as opposed to actually how bad they are. That's interesting to know. As I say, if you have a, I guess if you had a, absolutely, absolute control over your treatment you'd feel better, even if it were bad. (Participant 12)*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
(make-up) I'm not really interested in it, but… No, that doesn't really concern me, but… Yeah, that's a good one. Yeah, because I didn't, I didn't talk to my family at all, and then when I finally did I discovered my dad also had acne when he was my age, so he knew exactly what it was like. Wow, that's really good, useful to have because I never thought about going to the GP until, until a lot later. (participant 13) *Yeah, like this is, this is what I did and I think people should, yeah, know about how it - how finding a way to cope with it can really help, so I think this is good. (Participant 14)* *And quite useful, like how do I know like the difference between some of them because just, like just having some negative thoughts, like some people don't know like the difference between anxiety, depression like or in fact they just think they all come under one thing. So knowing, like to have*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
something to say the difference is kind of quite useful because luckily, luckily, I never got any of them, but I do feel very anxious when I'm out the house and that because I went to an all-girl's school so everyone's judgemental there (participant 19) *I think that will be really reassuring for some people to have that and it's good that they acknowledge that it's sort of a short-term fix, but you're not saying don't use makeup. Like you're saying it's a perfectly acceptable way to like deal with it, but it needs to be sort of with other things. (Participant 19)*					
Meet the team					
Yeah, I think it's quite nice 'cause it shows that the, the whole website is actually built by people who know what they're doing and they've actually got professional - um, yeah, they've got the degrees and stuff and they know what they're actually doing compared to people who just make a website because... [Pause] (Participant 14)	*Because, I think like if… 'Cause obviously it says about like what they're like, like Paul* for example is a GP and Professor. No one's gonna really care about what their career is, like maybe like they said like they're interested but not explaining their like back history 'cause no one's really gonna… They're gonna read the first*			NC- mostly positive comments	*Persuasiveness (levels of trust)*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Erm, yeah, it's good. You get to know the people and what they do. Yeah, it's a bit of extra information, yeah so, it's fine. (Participant 11) *Well, it's nice to know what experts are saying 'cause usually you're just like watching YouTube and they're saying, 'You can get this. Don't look back' and usually it doesn't really work. Like apparently drinking tonnes of water is supposed to help so… (Participant 17)* *Well, obviously, it gives you more like, you can see that there are people supporting and help- willing to help and, yeah. (Participant 10)* *Oh, so every knows [sic], everybody knows what they're doing obviously. That's, that's always good to know. (Participant 12)* *I really like that just because there's so much online about like just from like beauticians and people that don't really know what they're talking about,*	*sentence and be like, like, 'I don't really care about that. (Participant 19)*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
s-, so it's quite nice that this, you know, seems more factual. (Participant 15) *The meet the team page originally obviously there was quite a lot of text per person, but it's quite interesting to see, because I imagine everybody is going to come from a slightly different background and you've previously said meeting the experts and stuff, so that's good. I like that you have photos because that just makes it clearer. You might want to have just the name on a separate line maybe because it's just like a big block of text. So you've got 'psychology, researchers, the GP, postgrad [sic], the psychologist within medicine,' which is quite interesting for psychologists actually, because it's like a different perspective and another GP. So it reinforces the thing it was saying earlier based on experts, because a lot of things say it's based on scientific research and experts and even those click up ads at the bottom say that, but because you've got the meet the team it justifies it. (Participant 18)*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Statistics and evidence boxes					
Oh yeah, that's like, yeah, it is, um, nice to know that it's not gonna affect you really badly or... [Pause] I like how you've got the little link down at the bottom to show it was a real experiment rather than just saying it happened because like it's secondary data or something. So like it shows that you've actually gone out and done research yourself. [Pause] I think this is good 'cause if, if people have got - had specific side effects and now they are quite worried about it, instead of having to go to the doctors and do it there, they can just go here and it's got it explained. (Participant 14) *Yeah, it kind of helps you understand that, you're not alone and obviously, again, this is the research evidence that's kind of there to show the facts and support, erm, you and help you. (Participant 11)* *Okay, it's nice to have it because when you've got references like that it does*				NC- no negative comments	*Persuasiveness (levels of trust)*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
make it seem sort of like actual research, 'cause everybody - like I said before - uses the term 'based on scientific research' or like…and they're not necessarily lying, but it's sort of so commonly said that it's quite reassuring to be like, 'Oh here actually is the research' and it just says, 'Click here if you want to see it.' So you don't have to scroll through loads of research to get there, so I think that's really good. Oh yeah, this is talking about the moisturiser that's quite good. I like that you've got sort of the names of things that aren't brands to be fair because if you go to the pharmacy you can be like, 'I need this type of moisturiser' because you probably don't want to recommend brands anyway 'cause that might be an issue. Oh, okay so you've done it per side effect which is quite good. (Participant 18)					
Well that's interesting (I: mhm). So I wanted to go on the, was it the oral antibiotics are the pills right? (I: mhm) I wanted to go on them because I didn't see much of a difference when I used	*I find it a very low – a very low percentage. (I: Okay) [Reading from screen] That's a really random number as well. Actually if you were going to be actually using antibiotics, you'd want them to actually be*	Clarify this statistic is about people with mild-moderate acne Provide reference to this statistic	Add in reference and clarify that the statistic is about people with mild-moderate acne		<u>*Persuasiveness (levels of trust)*</u>

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
the gel (I: okay). But it says that other people did see a better difference with the gel. Interesting, what was I doing wrong? (Participant 1) *So how xxx does it work? [Reading from screen] [19%], that's not too bad compared to antibiotics. ... That's good (Participant 5)* *I think it's quite surprising actually, because I suppose – for me obviously when I was trying acne creams and stuff, they weren't prescribed by the GP. So the ones I was trying didn't really do much for me; they were just kind of – either exacerbated it or there was no change whatsoever. So I wouldn't expect to see that actually it is something that's so helpful.(Participant 7)* *It, it's useful to know that creams and gels are, are better than acne, better for treating acne than antibiotics. Yeah, that's, that, that, that's quite good to know because if people are, if people*	*a bit more higher than 16% success rate, wouldn't you. The same with – no treatment, I guess, that's – you can understand that. I feel like all antibiotics xxx so they don't work as well. (Participant 2)* *So – 19% fewer acne spots; I don't really know how you can determine or quantify that. [Reading] ... Really? [Laughter from both] Because, again, from personal experience, and from what it said earlier in the website, it was like – that topical treatments are used first and if not then you go on to a combination treatment. So surely – if oral antibiotics are second line, then the first line treatment with the topical treatment, hasn't been as effective, or is this in combination with? Is this oral antibiotics, just oral antibiotics or is this oral antibiotics in combination with topical treatments?(Participant 4)* *I don't know. I just – it just seems weird. ... Maybe it's just like my ignorance surrounding acne, but how – do you just like count the spots one week – and then*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
are worried about taking oral antibiotics then it means they're actually all right by just doing the creams. Oh, okay. (Participant 13) *And I also liked that, sorry, on that last page there, um, they've got a percentage so it's not, you know, no one's promising to cure like completely any acne, just so that people's expectations are managed and stuff. And I like this quote thing. (Participant 15)* *Yeah, er, I think it's like quite interesting 'cause it shows how like different methods are working for different people, so that, that you're more likely to, er, get fewer spots if you use the gel compared to the tablets 'cause you just think of it as, well, they're both gonna help but you've actually got, well, facts here to show you how they help and how much they help. Yeah, I, I like this like how it like kind of explains. (Participant 14)*	*like count them the next week? (Participant 8)* *If I – was – if I was thinking about – if I had mild acne and was thinking about getting a topical cream, it could have side effects as well, 19% fewer spots would – probably not be very thrilling, may put me off getting treatment if I knew that that's how much I'd expect it to go down by. (Participant 6)* *The statistics are good but they are not necessarily very high statistics. You can look at it and think, only 19%, that's what I think, anyway. (I: Okay) But I suppose it depends how – like – how severe your acne is. So if you have mild acne, 19% may not be that much, whereas if you had moderate acne, it's quite a lot. But I guess this is an average? (I: Yes) ... And maybe it needs to say – like – how many people were – in the survey, I guess. (I: Yes) So you know, because if it's out of five people, it's not actually that significant, as opposed to if it was like out of 1000 people. (Participant 9)*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
In case people wanted to, to try out the cream, it's good information so they're just as better as the antibiotics. (Participant 11) *Again, comparing the antibiotics with gel, so they say this- they- the studies have found out that gel works, like, works better for most of the people than antibiotics…..Well, obviously, it's making me like, concerned about antibiotics. But I don't know really about gels because I didn't try that many gels, so I think I should give it a try. (Participant 10)* *That's, yeah, it's good quality, you have your sources in, um, you have your little fun fact boxes, um, yeah, I like this page, this is a good page. Yeah, I love that, yeah, the World Health Organisation, yeah, they're good 'cause I think a lot of people like will have heard about them, so they'll be like, 'Oh, okay, okay'. Okay, (Participant 16)*	*People had fewer acne spots. Well, like, what are they trying to say? Was it…? What do they mean by oral antibiotics? (Participant 10)* *: I don't, um, I don't really agree with the cream and gel, the treatment, because I know quite a few people who have acne, um, and some of them being my very close friends and they tried cream and they had no difference and then now they're on tablets, they're see-, er, seeing slightly more difference from when they had with cream so to me that shocks me to be honest, the fact that creams work actually better than… 'Cause when you get Aracytine [sic] it's tablets so it's just kind of shocking the fact that they actually work, though 'cause the one that works most, on most people is a tablet [laughter]. (Participant 19)*				
Myth-busting quiz					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Yeah, um, it's, um, it's a little bit plain. Um, but I like how it's quite spread out and it's not all bunched together and... [Pause] Okay, got the like you can click there for the answer if you're not sure and I like how you've got when you do answer it right or wrong, I don't know if it comes up for both but, um, adv- advice on how that can help or what you can do as well as that to help. (14) *Yeah, it was all right. I think it was like kind of a, a recap on what had been said during the main part of the website, so just like little like refresher to make it more memorable. I think this is quite important I think. (14)* *I think the, the questions are all actually helpful. They were actual questions that I've had previously and I know other people would have had. So, I think if you - would this website it'd kind of be to go to before going to see your GP or just generally, if it were to… (Participant 12)*	*Okay, I like the quiz, um, photo on your right, okay, I like the photos. I don't know if I like the boxes in that, but again, I know this is going into way too much, but, um, yeah, I don't know, maybe if there was a different way to put in the quiz. Um, do, do, do. Definitely the use of colour, like those little photos, they're very good. (Participant 16)* *I think maybe at the end of the quiz like maybe have a little, little summary. (Participant 14)* *: It is a bit easy but then obviously I know, but then from where I had it very long, I've had it from feeling I know more about it than someone who just got it. So they might find it different than someone who's had it for many years compared to someone who's just found out they have acne, um, but it's actually quite useful to know. It actually, like makes you question like, like the one with washing your face 'cause I didn't know that, touching one spot and moving it to the other I would keep thinking, 'Oh I haven't washed my*			NC	*<u>Relevance</u>*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
. It's nice to have like a little quiz 'cause some people would be like, oh, this would totally work, and then they find out, oh, wait, it doesn't work so I'm going to have to like… This is kind of like, that should be like a maybe question 'cause like most of the stuff is like so [?expensive 00:25:30]. Especially if you're an adult and you have acne, it's just like, go to the GP. Wait, that's like £10 for a moisturiser or like cream or whatever. I wish it was like cheaper, like because it's only doing your spots. It's not like it's getting… (Participant 17) *I think the idea of myth busting is quite a good idea because I've tried a lot of treatments before that can slightly burn your skin and things, so I think it's probably a really good idea to have the myth busting things. (Participant 18)*	*face enough, it's clearly getting it, trying to tell me,' sort of thing. (Participant 19)*				
Summary pages					
Er, not really, no, I don't think so but if, if it is relevant to other people then... I think these are good like how this section will look at because you know				NC	*Structure and layout of website*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
what, what's gonna be included in it and if it's gonna be relevant to you or not. So you can quickly have a look at it and if it's not, not interesting you, then you can like go on to another bit but if it is, then you've just got a brief bit tell you what it's gonna look at and you can go on from there. (Partcipant 14)					
Talking with GP					
And to have specific questions ready 'cause if people like were gonna have a G-, a meeting with the GP and they didn't - they weren't told to have questions ready and they just had a basic idea of what they wanted to say and then if they forgot that or something, then they're less likely to get that outcome that they want. So I think that's like good to have on there.(Participant 14) *Yeah, that's good information, like I wouldn't have thought to - to put in like, 'How to get the most of your consultation', so that could definitely separate you from other, um, acne pages, so yeah, I like that. 'Don't be*				NC	*Relevance*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
discouraged', yeah, that's good, 'Don't be discouraged, de, de, de, keeping positive', that's good, that's good. (Participant 16) *Yeah, yeah. Yeah, it's kind of helpful where you, you can know that you can still go to someone and they can give you something different and there's more options. (Participant 11)* *Because some people don't know when you should actually go to your GP 'cause at first I used to just think it was hormonal, growing-up but like when I realised that I wasn't wearing make-up, I wasn't doing this, I was like, 'Actually, I need to go and speak to my GP, this is not normal.' 'Cause, like, I see people who wear make-up and I know acne on their face is caused by make-up 'cause they're getting one spot, touching it with the brush and it's spreading. But I was doing everything to keep myself, skin clear and then I realised, 'This isn't normal.' So, knowing when you need to go and see your GP 'cause if you, if*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
you're doing the right things then you, you raise your questions like, 'Why is this happening?' (Participant 19) *: They're making sure that you need to get… If you're unhappy, if you feel that you need to speak to your doctor about it, um, and the tip, like the tip is helpful get-, getting someone to go to the appointment with you 'cause I know I used to get emotional talking about it 'cause I was like, 'It's controlling me.' So having someone to like just talk when you can't, it was kind of like… 'Cause I was in my m-, I was like… My mum was the one that got me to go so my mum knew how it was affecting me. So when I couldn't ex-, like, well I wasn't getting seriously 'cause I was a teenage girl covered in spots. Having my mum there to back me up was kind of like useful 'cause they're like, 'Actually we'll do something.' 'Cause you always seem more, like doctors kind of , er, when it's a teenage girl walking in they're like, 'Well…' And she's clearly wearing make-up 'cause… Er, so if you have your mum there*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
they're like, 'No, actually she doesn't,' it kind of [unclear words 0:19:21] yours 'cause the amount of teenage girls saying, 'They don't wear make-up' and they probably do. (Participant 19) *Talking to your GP…that's quite interesting. Skin specialist - that's probably quite good actually because you always hear about dermatologists on TV but you're not really sure if you're ever going to get recommended to one or what will happen. (Participant 18)*					
Antibiotics					
Yeah, that's again good for people to know, because I don't think many would realise how dangerous it could be with bacteria becoming resistant to all antibiotics. Participant 12 *problems in your stomach, I didn't know about that. [Unclear words - reading 0:21:06.9]. That's, I wasn't told about that either, if the antibiotics haven't worked after three months*	*Um. I mean, I didn't get any of them. I think it would be worth mentioning how common they are, um. I don't know, I think sometimes when I see the word side effects it's something that will happen rather than something that may happen, um. (Participant 15)* *Hopefully. You can never have everything. Not sure if I want to know more about*			NC	<u>Relevance</u>

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
then they're probably not going to be helpful for you. I wasn't told about that. (Participant 12) *Um, like it's, I think it's, it's helpful and it would be, I don't know, making people aware before they go to their GP so that they don't go in with any kind of expectations and that sort of thing, um…….. And also the awareness of that and just making sure that people know.(Participant 15)* *Well, it sounds like it's not a good treatment, as they say it, but it doesn't make sense as well because doctors tell you to take it for some period, like a long time, and at the same time, it says it's not good. So, I don't really understand the sense behind that. [Pause] That statement down there is, is making sense because, for example, if that person, like, she took antibiotics already because of acne and then later on, she might need to take it again so that, she's trying to say that it wouldn't work for her or it might do like, any*	*antibiotic resistance (I: okay). Because that's scary (Participant 1)* *those common types of antibiotic, tetrazine for...', okay, 'Tetrazine, cycline, mm, like the most common types of anti de, de, de, de, are from the tetrazine [?cycle 0:41:21:1].' You do maybe, um, some little box that maybe explains that, that word. (Participant 16)*				

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
risks. Hmm. [Pause] Hmm, well, it's true because my mum always used to tell me some bac- like, we - everyone obviously has bacteria, because some bacteria helps us as well, so if - until you take antibiotics for a long time, that means you're clearing everything out so nothing will be left and then, it's just bad for you. At the same time as me, I take antibiotics at the same - like, at the moment and I have to take it for like, three months. So, if it doesn't work after three months, I have to stop, so. (Participant 10) *It's worrying, that's for sure. [Laughter] Yeah, antibiotic resistance is quite a serious thing, so, yeah. It's a good idea to put it there, and in, and in red, so, they're definitely able to, you'll definitely see it (Participant 13)* *Yeah, I, I think it's like quite interesting 'cause I, I didn't - I think I've been using one for a lot longer than six months and nothing's been said about that and I didn't actually know that until now*					

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
and - but, yeah, I think it's like quite important that people know about how it, um, can increase resistance and how that can affect you in later life. [Pause] (Participant 14) *I think it's actually like quite useful to know because, like, I don't ever sit there reading the leaflets that come with the medications, obviously, having it in smaller print that it just gets to the point that you don't go, 'cause it's like if I went and got my medication right now I'd be like, 'This could happen but this could happen or this and this and this.' And there's like 101 different things then it's only like the slightest chance that it could happen compared to like the ones that are usually long-term that you could actually have side effects of compared to like, you could in the slightest chance have this? (Participant 19)*					
What is acne module					
Yeah, that's true. They say about the genes as well, but when I look at my parents, I see that, they look like	*I'm not sure, again, maybe click down or - it just - no, I'm not too mad on that, um, but yeah, it's - the content is good though.*	Space out the writing on the page	Spaced out the writing on the page	EAS	*Structure and layout of website*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
they've never really had any because my mum's face is clear, she doesn't have any spots or nothing, and my dad as well, no. So, I don't think like, for - to me, it's not something with genes or something that's got to do with the family, it's just… Sometimes as well, because they say when you touch your face too much, dirt like, because your hands are dirty, that's how you get acne or spots and yeah, make-up is one reason as well because obviously, you're letting the dirt, like, the dirty things and bacteria go into your pores and you don't clean properly, so that's how spots, yeah, develop. (Participant 10) *Yeah, I think that's just another thing that's thrown around (diet) (Participant 12)* *Er, the explanation of what are spots or acne, I like that bit 'cause it was quite interesting with the science behind it like how the, the skin - dead skin gets in the pores and stuff. (Participant 14)*	*De, de, de. Okay, this is a good picture, good colour. 'So, what's acne [pause whilst reading] different type', yeah, that's good. Er, I think here either space it out, space it out, it just looks, um, too much. (participant 16)*				*Relevance*

Positive Comments	Negative Comments	Possible Change	Agreed change	Reason for change	Theme in chapter
Oh, I've never heard of this before. Oh, okay so it is saying that oh right, okay so if you have a diet low in glycaemic load is that saying it is good for your acne or…oh it helps to improve your spots and acne, okay. I think the pictures are good as well. You've got like diversity and stuff as well. It's quite probably quite nice to know for somebody that's older that they're not like alone in it as well, 'cause you do associate it with being younger, but… (Participant 18)					

Appendix H : Feasibility trial information sheets, sign-up sheets and flyer

Information sheet for participants aged 16 or over

UNIVERSITY OF Southampton

Participant Information Sheet

A website to support self-management of acne or spots: a feasibility randomised study

Thank you for your interest in this study. This leaflet explains why the research is being done and what it would involve for you.

What is the study about?
The aim of this study is to see how well a website (SPOTless) can support young people to help manage their acne or spots. This website has been developed in partnership with people with acne or spots, and has been improved with several rounds of their feedback. The website is now ready for further testing, which will help shape research to improve care and support for people to look after their skin.

Why have I been invited?
You have been invited to take part in this study because your GP records show that you have received treatment for acne in the last 6 months. We are hoping for 65 people aged 14-25 with acne to take part in the study. If your acne has cleared up or you are currently on isotretinoin (Roaccutane) you will not be able to take part in this study.

Do I have to take part?
You do not have to take part in this study. Your GP will not be told whether you decide to take part in the study or not. Your current or future care will not be affected in any way whether you choose to participate or not.

What will be involved in taking part?
Everyone will get access to the SPOTless website, but for some people this will be delayed so that we can see if the website actually does help. Everyone also has access to usual care from their GP or specialists. The study is online so you will need access to the internet. If you are interested in taking part, please follow the instructions on the included 'How to Take Part' sheet. You will then be asked to fill in an online consent form and questions at the beginning of the study, and again after 4 weeks, and after 6 weeks. After completion, you will be automatically randomised to one of two groups (40 in group 1 and 25 in group 2):

Group 1	OR	Group 2
Complete online questionnaires + Usual treatment from GP or specialist + Access to the SPOTless website throughout the study		Complete online questionnaires + Usual treatment from GP or specialist + Access to the SPOTless website after 6 weeks

Additional interviews:
You will be given the option of whether or not you would like to take part in an interview at the end of the study. If you selected yes to being contacted, a member of the study team will contact you to arrange a time, date and place that is convenient for you. You can choose to have the interview either face to face (at home or at the University of Southampton), or if you prefer, we could do a telephone interview. The interview will be approximately 30-60 minutes long and will explore your thoughts and experiences taking part in the trial and using the website. Whether or not you decide to take part in the interviews will not affect your participation in the trial. People who take part in the interview will be given a £10 gift voucher for their time.

Will my taking part be kept confidential?
Yes. All of the information you provide during the study will be kept confidential and only shared amongst members of the research team. However, if it appears that someone is a danger to themselves or others the information may be shared outside of the study. If you agree to be interviewed and recorded, what you say will be typed up and any names mentioned will be removed or replaced to ensure anonymity. Digital recordings will be destroyed after transcription and anonymised data will be stored for 10 years at an offsite storage facility which will have agreed to the terms and conditions laid out by the sponsor following the Standard Operating Procedure for archiving at the end of the study. Your contact details will be stored in a secure file on the University computer or locked in a filing cabinet with authorised access only for the researchers working on the project. After the study is finished these details will be destroyed and at no point will identifiable information be removed from University premises. Anonymised data (names and contact details removed) may be shared with other researchers.

What will happen to the results of the study?
Once the data has been analysed it may be published in academic journals and reports. We will use anonymised quotes from the interviews and any identifiable information will be removed from the report. We can send you a copy of the final report.

Who is organising and funding this research?
This study is organised by researchers at the University of Southampton, and it is funded by the National Institute of Health Research through the School of Primary Care Research. The NIHR funds health and care research to encourage the development of products, treatments, devices and procedures to improve health. This study is part of a PhD from the department of Primary Care and Population Sciences.

What will happen if I don't want to carry on with the study?
If you no longer want to take part in the study, you can withdraw without giving a reason. If you decide during the interview, you can stop at any time and any data gathered up to that point may still be used unless you tell us otherwise.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and approved by Essex Research Ethics Committee.

Information sheet for participants aged 16 or over

This study is sponsored by the University of Southampton and has been given approval by the University of Southampton ethics committee.

What if there is a problem?

If you have any concerns about any aspect of the study, please contact the researcher Miss Athena Ip on 023 8059 1779. You may also contact the Research Governance manager at the University of Southampton (email: rgoinfo@soton.ac.uk or telephone: 023 8059 5058).

What next?

Please fill in the reply slip to let us know if you would be happy for us to contact you. If you would like any more information, please contact the researcher using the details below.

Further information and contact details

If you have any further questions or queries, please contact:
Athena Ip
Primary Care and Population Sciences, University of Southampton
Southampton, SO17 1BJ
Tel: 023 8059 1779
Email: A.Ip@soton.ac.uk

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

UNIVERSITY OF Southampton

Parent Information Sheet

Experiences of acne vulgaris and its related treatments: a qualitative interview study followed by think aloud user testing

Thank you for your interest in this study. This leaflet explains why the research is being done and what it would involve for your son/daughter.

What is the study about?
The aim of this study is to find out your son/daughters views and impressions about our new online advice for people with mild and moderate acne (spots). This will help us to improve the feasibility and usability of the website.

Why have they been invited?
They have been invited to take part in this study as we are looking for people aged between 14 and 25 who have acne or have previously had acne. We want to interview 30 people with acne to find out their views about the website.

Do they have to take part?
They do not have to take part in this study. Their GP will not be told whether they decide to take part in the study or not. Their current or future care will not be affected in any way whether they choose to participate or not.

What will be involved in taking part?
A member of the research team will interview (face to face) them about their thoughts and impressions of the materials at home or at the university. The interview will last 30 to 60 minutes, during which they will click through the website as they would normally do if they were alone and say their thoughts out loud. The interview will be audio recorded to allow the data to be collected and typed up. They will be given £10 gift voucher for their time.

Will their taking part be kept confidential?
Yes. All of the information they provide during the study will be kept confidential and only shared amongst members of the research team. However, if it appears that someone is a danger to themselves or others the information may be shared outside of the study. If they agree to have their interview recorded, what they say will be typed up and any names mentioned will be removed or replaced to ensure anonymity. Their contact details will be stored in a secure file on a University computer or locked in a filing cabinet with authorised access only for the researchers working on the project. After the study is finished these details will be destroyed and at no point will identifiable information be removed from University premises. Anonymised data (names and contact details removed) may be shared with other researchers.

Information sheet for parent/carer

What will happen to the results of the study?

Once the data has been analysed it may be published in academic journals and reports. We will use quotes from the interviews and any identifiable information will be removed from the report. We can send you or your son/daughter a copy of the final report.

Who is organising and funding this research?

This study is organised by researchers at the University of Southampton, and it is funded by the National Institute of Health Research through the School of Primary Care Research.

What will happen if your or your son/daughter don't want to carry on with the study?

If they no longer want to take part in the study, they can withdraw without giving a reason. If they decide during the interview, they can stop at any time and any data gathered up to that point will be deleted.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and approved by xx Research Ethics Committee. This study is sponsored by the University of Southampton and has been given approval by the University of Southampton ethics committee.

What if there is a problem?

If you or your son/daughter have any concerns about any aspect of the study, please contact the researcher Miss Athena Ip on 023 8024 1086. They may also contact the Research Governance manager at the University of Southampton (email rgoinfo@soton.ac.uk or telephone 023 8059 5058.)

What next?

Please fill in the reply slip to let us know if you would be happy for us to contact you and your son/daughter to arrange a time and date for the interview. If you would like any further information, then please contact the researcher using the details below.

Further information and contact details

If you or your son/daughter have any further questions or queries, please contact:
Athena Ip
Primary Care and Population Sciences, University of Southampton
Southampton, SO17 1BJ
Tel: 023 8024 1086
Email: A.Ip@soton.ac.uk

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

UNIVERSITY OF Southampton

Information Sheet for Young People

A website to support self-management of acne or spots: feasibility randomised study

We want to see whether our new website is helpful for young people in managing their acne or spots.

What is the study about and what will it involve for me?

This study is part a PhD at the University of Southampton, department of Primary Care and Population Sciences. The aim of this study is to see how a website (SPOTless) can help young people to manage their acne or spots. You will be asked to fill in questions about yourself and your skin at the beginning of the study, and again after 4 weeks, and after 6 weeks. You will be randomly put into one of two groups (40 in group 1 and 25 in group 2):

Group 1	OR	Group 2
Complete online questionnaires + Usual treatment from GP or specialist + Access to the SPOTless website throughout the study		Complete online questionnaires + Usual treatment from GP or specialist + Access to the SPOTless website after 6 weeks

You will also have the option to take part in an interview at the end of the study. If you decide to take part in the interview a member of the study team will chat to you about your thoughts and experiences of the study and how you found the website. This will take between 30 to 60 minutes. You can choose whether you want your parent in the room with you.

Why is the study being done?

This study is being done because we want to give people better advice on how to manage their acne or spots and provide them with support tools to help them do this. If your acne has cleared up or you are currently taking oral isotretinoin (Roaccutane) you will not be able to take part.

Where will the study take place? Will I need to take time off school?

You won't need to take time off school/college as the study will take place at home on your computer. If you decide to take part in the interview this will take place at a convenient time for you. You can choose to have the interview either face to face (at home or at the University of Southampton), or if you prefer, we could do a telephone interview.

What are the risk and benefits?

There are no risks to taking part and you may find the study interesting. We can also offer you a £10 voucher if you take part in the interview.

Will my taking part be kept confidential?

Yes. All of the information you provide during the study will be kept confidential and only shared amongst members of the research team. However, if it appears that someone is a danger to themselves or others the information may be shared outside of the study. If you agree to be interviewed and recorded, what you say will be typed up and any names mentioned will be removed or replaced to ensure anonymity. Digital recordings will be destroyed after transcription and anonymised data will be stored for 10 years at an offsite storage facility which will have agreed to the terms and conditions laid out by the sponsor following the Standard Operating Procedure for archiving at the end of the study. Your contact details will be stored in a secure file on the University computer or locked in a filing cabinet with access only for the researchers working on the project. After the study is finished these details will be destroyed and at no point will your information be removed from University. Anonymised data (names and contact details removed) may be shared with other researchers.

What will happen to the results of the study?

Once the data has been analysed it may be published in academic journals and reports. We will use anonymised quotes from the interviews and any identifiable information will be removed from the report. We can send you a copy of the final report.

Who is organising and funding this research?

This study is organised by researchers at the University of Southampton, and it is funded by the National Institute of Health Research (NIHR) through the School of Primary Care Research.

What will happen if I don't want to carry on with the study?

If you no longer want to take part in the study, you can withdraw without giving a reason. If you decide during the interview, you can stop at any time and any data gathered up to that point may still be used unless you tell us otherwise.

What if there is a problem?

If you have any concerns about any part of the study, please contact the researcher Miss Athena Ip on 023 8059 1779. You may also contact the Research Governance manager at the University of Southampton (email: rgoinfo@soton.ac.uk or telephone: 023 8059 5058).

Who will lead the study?

Miss Athena Ip from the University of Southampton:
Tel: 023 8059 1779
Email: A.Ip@soton.ac.uk

UNIVERSITY OF Southampton

Acne website study: SPOTless

HOW TO TAKE PART

Before you begin, please make sure that you are not currently taking oral isotretinoin (Roaccutane) and that you are aged between 14 and 25.

- **STEP 1: SIGN UP**

  If you would like to take part, you can sign up on the study website: https://spotless.lifeguidewebsites.org using your study ID: **<<PID>>**.

  Allow yourself 15-20 minutes to read the information carefully and to answer the questions.

  Please phone or email using the contact details below if you have any questions.

  When you sign up, you will be given the chance to take part in an interview about your experience of using the website after the 6 weeks. You will receive a £10 gift voucher as a thank-you for taking part in the interview study. The interview is optional, so if you do not wish to be contacted about this please choose "I want to take part in the study only".

- **STEP 2: RANDOMISATION**

  After you have signed up and completed the questionnaire, the website will put you in one of two groups:

  (1) Use of the SPOTless website straightaway

  (2) Use of the SPOTless website after 6 weeks

  If you are put in Group 1, please explore the SPOTless website and see if there are any changes you can make to the way you look after your skin. It has been designed by healthcare professionals and patients and contains the most up-to-date information about how to manage acne.

- **STEP 3: FOLLOW-UP**

  In 4 weeks' time you will be asked to answer a second questionnaire. We will send you an email to let you know when to do this. We will also send you a link to the final set of questions 2 weeks after that.

If you have any questions about the study please contact Athena Ip: Email: a.ip@soton.ac.uk
Tel: 023 8059 1779

If you have any problems with the website please contact Kate Martinson: km3@soton.ac.uk

THANK YOU!

****

Website URL: https://spotless.lifeguidewebsites.org

Your Study ID: <<PID>>

****

Acne website study: SPOTless
HOW TO HELP YOUR CHILD TAKE PART IN THE STUDY

Before you begin, please make sure that your son/daughter is not currently taking oral isotretinoin (Roaccutane) and is aged 14 or over.

- **STEP 1: SIGN UP**

  If you would like to take part, you can sign up on the study website: https://spotless.lifeguidewebsites.org your study ID: **<<PID>>**.

  Allow 15-20 minutes for your son/daughter to read the information carefully and to answer the questions.

  Please phone or email using the contact details below if you or your son/daughter have any questions.

  When your son/daughter signs up, they will be given the chance to take part in an interview about their experience of using the website after the 6 weeks. They will receive a £10 gift voucher as a thank-you for taking part in the interview study. The interview is optional, so if they do not wish to be contacted about this they should choose "I want to take part in the study only".

- **STEP 2: RANDOMISATION**

  After your child has signed up and completed the questionnaire, the website will put them to one of two groups:

  (1) Use of the SPOTless website straightaway

  (2) Use of the SPOTless website after 6 weeks

  If your son/daughter is put in Group 1, please encourage them to explore the SPOTless website and see if there are any changes that could be made to the way they look after their skin. It has been designed by healthcare professionals and patients and contains the most up-to-date information about how to treat acne.

- **STEP 3: FOLLOW-UP**

  In 4 weeks' time your son/daughter will be asked to answer a second questionnaire. We will send an email to let them know when to do this. We will also send a link to the final set of questions 2 weeks after that.

If you have any questions about the study please contact Athena Ip: Email: a.ip@soton.ac.uk
Tel: 023 8059 1779

If you have any problems with the website contact Kate Martinson: km3@soton.ac.uk

THANK YOU!

****

Website URL: **https://spotless.lifeguidewebsites.org**

Your Study ID: **<<PID>>**

****

SPOTLESS

Evidence-based advice to manage your spots or acne

Do you need help with your acne or spots?

You could take part if:

- You have acne or spots ✓
- You're not using isotretinoin (Roaccutane) ✓
- You are aged between 14 and 25 ✓
- You have access to the internet ✓

We are looking for people with spots or acne to take part in our research study!

What is involved?

- Online study
- No appointments!

Read on for more information.....

Appendix I : Feasibility trial emails

Who?	Description of email	Subject heading of email	Email content	When the message is sent
Participants in usual care group	Informing participants which group they are in and next steps	SPOTless - You have been randomised	Thank you very much for registering for the SPOTless study and for filling in the study questionnaires. You will be asked to fill in these questions again after 4 weeks. You have been randomly selected to be in the usual care group. This means you should continue using your usual health services as you normally do. You will be able to use the website, if you want to, in six weeks' time. Your taking part in the study is really important and will help us to see if people benefit from using the website or not. If you are having problems using the SPOTless website please get in touch with a member of the SPOTless team at spotless@soton.ac.uk. With best wishes from the SPOTless team."	After randomisation

Who?	Description of email	Subject heading of email	Email content	When the message is sent
Participants in intervention group	Informing participants which group they are in and next steps	SPOTless - You have been randomised	"Thank you very much for registering for the SPOTless study and for filling in the study questionnaires. You will be asked to fill in these questions again after 4 weeks. You have been randomly selected to be in the website group. You can login and use the website by clicking on this link: https://www.lifeguideonline.org/player/play/spotless Thank you for taking part in this important research. If you are having problems using the SPOTless website please get in touch with a member of the SPOTless team at spotless@soton.ac.uk. With best wishes from the SPOTless team."	After randomisation
Participants in both groups	Informing participants that there follow up questionnaires are ready	Your next set of SPOTless questionnaires are ready	"Your next set of SPOTless questionnaires are now ready for you to complete. Please take the time to fill these out, your data is very important to the study. You can access the questionnaires by clicking this link: https://www.lifeguideonline.org/player/play/spotless Please do not hesitate to get in touch if you are having technical difficulties, or if you have any other queries at spotless@soton.ac.uk. With best wishes from the SPOTless team."	4 weeks

Who?	Description of email	Subject heading of email	Email content	When the message is sent
Participants in both groups	Reminder email about the follow up questionnaires	Your next set of SPOTless questionnaires are waiting	"Please login as soon as possible to complete your SPOTless questionnaires. It is very important that everybody participating in the study answers these questions. To access these questionnaires please use the following link: https://www.lifeguideonline.org/player/play/spotless Please do not hesitate to get in touch if you are having technical difficulties, or if you have any other queries at spotless@soton.ac.uk. With best wishes from the SPOTless team."	5 weeks
Participants in both groups	Informing participants that there second follow up questionnaires are ready	Your next set of SPOTless questionnaires are ready	"Your next set of SPOTless questionnaires are now ready for you to complete. Please take the time to fill these out, your data is very important to the study. You can access the questionnaires by clicking this link: https://www.lifeguideonline.org/player/play/spotless Please do not hesitate to get in touch if you are having technical difficulties, or if you have any other queries at spotless@soton.ac.uk. With best wishes from the SPOTless team."	6 weeks
Participants in both groups	Reminder email about the second follow up questionnaires	Your next set of SPOTless questionnaires are waiting	"Please login as soon as possible to complete your SPOTless questionnaires. It is very important that everybody participating in the study answers these questions. To access these questionnaires please use the following link: https://www.lifeguideonline.org/player/play/spotless Please do not hesitate to get in touch if you are having technical difficulties, or if you have any other queries at spotless@soton.ac.uk. With best wishes from the SPOTless team."	7 weeks

Who?	Description of email	Subject heading of email	Email content	When the message is sent
Participants in usual care group	Thank you email to participants in the usual care group letting them know that a link will be sent to them so that they can use the website	Thank you from The SPOTless Team	"Thank you for participating in the SPOTless study and completing the questionnaires. We will email you the link to the website shortly. If you would like to contact us for any reason please email us at spotless@soton.ac.uk Thank you again, The SPOTless Team."	Once participant has completed the final questionnaires
Participants in intervention group	Thank you email to participants in the intervention group	Thank you from The SPOTless Team	Thank you for participating in the SPOTless study. We will email you the link to the website shortly. If you would like to contact us for any reason please email us at spotless@soton.ac.uk Thank you again, The SPOTless Team."	Once participant has completed the final questionnaires
SPOTless team		Participant A0001 has completed the baseline questionnaires	Study ID: XXXXX Username: XXXX@XXX.ac.uk has completed baseline questionnaires	Once participant has completed the baseline questionnaires

Who?	Description of email	Subject heading of email	Email content	When the message is sent
SPOTless team		Participant has not completed baseline questionnaire	Username: XXXX@XXX.ac.uk has received a reminder email but has still not completed the baseline questionnaire. Contact participant. Study id and username	If it has been 1 week since they signed up to the study
SPOTless team		Participant B0001 has completed the randomisation process	Study ID: XXXXX Username:XXXX@XXX.ac.uk has been randomised to Usual Care/intervention participant has been randomised.	As soon as they are randomised after baseline questionnaires
SPOTless team		Participant A0001 has completed FU1	Study ID: XXXXX Username: XXXX@XXX.ac.uk has completed the 4 week / FU1 questionnaire.	Once participant has completed the follow-up questionnaires at 4 weeks
SPOTless team		Participant , loadvalue(username, "studyid"), " has not completed FU1"	Username:XXXX@XXX.ac.uk has received a reminder email but has still not completed the 4 week / FU1 questionnaire. Contact participant. Study id and username	5 weeks and 3 days
SPOTless team		Participant A0001 has completed FU2	Study ID: XXXXX Username: XXXX@XXX.ac.uk has completed the 6 week / FU2 questionnaire.	Once participant has completed the follow-up questionnaires at 6 weeks

Who?	Description of email	Subject heading of email	Email content	When the message is sent
SPOTless team		Participant , loadvalue(username, "studyid"), " has not completed FU2"	Username: XXXX@XXX.ac.uk has received a reminder email but has still not completed the 6 week / FU2 questionnaire. Contact participant. Study id and username	7 weeks and 3 days

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