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Identifying acne treatment uncertainties via a James Lind Alliance Priority Setting Partnership

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ABSTRACT

Objectives: The Acne Priority Setting Partnership (PSP) was set up to identify and rank treatment uncertainties by bringing together people with acne and professionals providing care within and beyond the NHS.

Setting: The UK with international participation.

Participants: Teenagers and adults with acne, parents, partners, nurses, clinicians, pharmacists, private practitioners.

Methods: Treatment uncertainties were collected via separate online harvesting surveys, embedded within the PSP website, for patients and professionals. A wide variety of approaches were used to promote the surveys to stakeholder groups with a particular emphasis on teenagers and young adults. Survey submissions were collated using keywords and verified as uncertainties by appraising existing evidence. The 30 most popular themes were ranked via weighted scores from an online vote. At a priority setting workshop, patients and professionals discussed the 18 highest-scoring questions from the vote and reached consensus on the top ten.

Results: In the harvesting survey, 2,310 people including 652 professionals and 1,456 patients (58% aged 24 y or younger) made submissions containing at least one research question. After checking for relevance and rephrasing, a total of 6,255 questions were collated into themes. Valid votes ranking the 30 most common themes were obtained from 2,807 participants. The top ten uncertainties prioritised at the workshop were largely focused on management strategies, optimum use of common prescription medications and the role of non-drug based interventions. More female than male patients took part in the harvesting surveys and vote. A wider range of uncertainties were provided by patients compared to professionals.

Conclusions: Engaging teenagers and young adults in priority setting is achievable using a variety of promotional methods. The top ten uncertainties reveal an extensive knowledge gap about widely used interventions and the relative merits of drug versus non-drug based treatments in acne management.

Box 1. Strengths and limitations of this study
- This study has demonstrated that teenagers and young adults can be engaged in priority setting but considerable resources went into promotional activities which were subsequently found to be ineffective.
- To ensure all views were captured, much effort went into collecting responses from a wide spectrum of people with acne and different types of care professional; despite this, males with acne were under-represented.
- The volume of unsorted questions was so large that grouping into broad themes was the only way of generating manageable numbers to take to the prioritisation stages without overwhelming participants.
- Saturation was reached in that no new uncertainties were contained within the final submissions to the harvesting survey.
- Methods were developed for sorting and sharing large volumes of submissions.

INTRODUCTION

During the last decade, the inclusive methods pioneered and validated by the James Lind Alliance (JLA) for treatment related research priority setting have become well established in the UK (www.jla.nihr.ac.uk). JLA PSPs bring together on a level playing field people with a disease and those who treat them, first to identify, and then to prioritise unanswered questions (uncertainties) about existing treatments. Twenty-six PSPs have been completed to date including this and a further three on diseases of the skin.[1-3] Conditions covered include ones primarily affecting the elderly (e.g. dementia and stroke), infants and young children (cleft lip and palate, eczema) or people at any time of life (Lyme disease, asthma). So far, no PSP has targeted a disease with peak prevalence during adolescence in mainly healthy subjects. Although acne is starting earlier [4] and lasting longer, [5-7] possibly as a result of lifestyle changes, peak prevalence is between the ages of 16 and 20 years.[8, 9] The age range of acne now spans five decades; few teenagers in Westernised societies avoid acne in one form or other.[10] For reasons which remain poorly understood, post-adolescent acne is more common in women than men.[5-7] Acne is one of three skin conditions in the top ten most prevalent diseases worldwide in 2010.[11]. However, the most widely used treatments have changed little in the last thirty years. Systematic reviews have consistently shown a paucity of robust evidence from adequately powered randomised controlled trials.[12, 13] When compared with disease burden as estimated by disability-adjusted life years (DALYs) from the Global Burden of Disease 2010 project, acne is under-represented in the Cochrane Database of Systematic Reviews.[14]

Most clinical trials of new and existing therapies in acne have been conducted by the pharmaceutical industry; few independent trials are conducted anywhere in the world. In consequence, key issues of importance to patients and clinicians remain to be adequately investigated and addressed.

The Acne PSP was formally initiated in November 2012. In order to collect a representative range of opinions, we sought to involve not only NHS patients and staff but also the large numbers of people with acne who never present to a doctor. [15-19] Of importance, we considered that a successful priority setting exercise, by highlighting significant evidence gaps, would stimulate new high quality treatment-related research within and beyond the UK.

METHODS

A steering group to oversee the PSP was established in accordance with JLA guidelines and held its first meeting in January 2013. The steering group, which was chaired by a representative of the JLA, consisted of people with acne, healthcare and allied professionals involved in treatment delivery as well as experts in patient and public involvement in research and information management. At the initial meeting, the protocol and terms of reference for the steering group were formally adopted. The protocol was developed with reference to the JLA guidebook with modifications necessitated by targeting a predominantly adolescent population.

Stage 1: Set-up

Organisations which represent people who treat acne in any setting were contacted and invited to become partners. In the UK, there is no longer a patient group representing people with acne. However, we invited VERITY, the support group for women with polycystic ovarian syndrome to become a partner as persistent acne is often a feature of this condition. Organisations which volunteered to help deliver the priority setting exercise were also invited to become partners. Partner organisations were expected to help promote the PSP to their members or to the public and encourage participation in the harvesting survey and vote. They were required to affiliate to the JLA. Our partners are listed in the Acknowledgements section.

As the target population was expected to comprise mainly teenagers and young adults, it was decided that a dedicated website should be used to collect and disseminate information. The website was launched in April 2013 and included background information about the PSP, partners, steering group members, with a brief summary of acne treatments and ways of obtaining them.

In order to better understand what would motivate people to take part in the harvesting survey, an informal meeting was held in February 2013 in Harrogate to which approximately equal numbers of people with acne and healthcare professionals were invited together with two dermatology patients without acne but with marketing experience. Attendees reviewed and changed the publicity flyer and harvesting survey, which had been drafted to closely match the traditional open JLA layout. To make the harvesting survey form more visually attractive and clearer for young people, two versions were produced. The patient version was more structured, including images and specific questions about each treatment type and contained additional questions to capture details about current and past sources of professional help and treatment. The professional version of the survey adhered to a more conventional layout with a limit of five questions per respondent. Publicity materials were simple in design, carried the banner “Join the fight against acne” to reflect the campaigning dimension requested by meeting participants, and included a QR code linking directly to the survey. To increase participation by teenagers and young adults, a small financial incentive was offered to respondents to the patients’ version. This was £25 or local currency equivalent in vouchers for a global online retailer, awarded to 50 people who submitted at least one uncertainty and whose names were selected at random at the close of the survey. No financial incentive to take part was offered to professionals.

Stage 2: Harvesting uncertainties

Both versions of the survey to collect treatment uncertainties were constructed in Survey Monkey™ and embedded into the PSP website. The survey was open between the 22nd May and 31st August 2013. It was kept open longer than the planned eight weeks after analyses of demographic data showed low levels of participation by some target groups.

A variety of both traditional and novel methods were utilized to publicise the survey. Organisational stakeholders were asked to promote the PSP and survey to members via email, via their own web site or in any other way they wished. Posters and flyers were sent to local and specialist centres within the UK. In addition, a national chain of community pharmacies distributed flyers via their branches. A dedicated Twitter account was set up and at least one original tweet per day was issued until the final workshop had been completed. Steering group members were asked to email colleagues and contacts and/or put adverts in local newsletters. Two national health related organisations, Talk Health and Embarrassing Bodies promoted the survey via a variety of mechanisms including their own web sites. A celebrity agreed to endorse the PSP on the home page of the web site and another generated a promotional video. The local National Institute of Health Research network (North East Yorkshire and North Lincolnshire) took the lead in disseminating information to colleagues in other networks including Primary Care Research Networks and also approached local educational establishments and NHS Trusts.

To complement the harvesting survey, a search of research recommendations within recent, relevant and reliable systematic reviews or treatment guidelines was undertaken with a view to including any novel uncertainties within the prioritization exercise.

Stage 3: Processing the uncertainties

The survey generated very many responses so consideration was required of the most efficient mechanism for analysing the data and distributing workload across the project team. Submissions from Survey Monkey were downloaded into Microsoft Excel to facilitate refining and collating uncertainties. Submitted text was often rephrased for clarity and to separate out individual questions.

To maximise flexibility and to enable the data to be sliced in various ways, controlled vocabulary terms were assigned to the uncertainties. First, uncertainties were collated into themes, many of which were necessarily broad (covering aspects such as adverse effects, long term management and skin care). The themes were supplemented with terms relating to relevant intervention categories (e.g. phototherapy, antibiotics, topical therapies). These controlled lists were defined using the clinical expertise within the Steering Group. The key concepts were then indexed by assigning National Library of Medicine Medical Subject Headings (MeSH), commonly used in searching literature, to each of the included uncertainties. Not all concepts were available in the MeSH vocabulary. To identify controlled terms for these omitted concepts the Excel file was loaded into Google Sheets and parsed with the ISA-TAB Ontomaton tool.[20] As a result the medical subject headings were extended to include terms from other vocabularies such as Clinical Terms Version 3 (Read Codes; National Health Service National Coding and Classification Centre).

Most of the data were validated on input to minimise typographical errors and ensure consistency across the subsets of data; the exception being one of the MeSH descriptor fields that enabled the more obscure concepts to be included. There was no limit to the number of key words that could be assigned to any uncertainty. Therefore each uncertainty could be indexed to a high level of detail if needed, facilitating segmentation of the data and enabling similar submissions to be merged.

In order to manage the above process and the distribution of the data across the project team, the datasets were stored in a central online document repository. Initially based on the National Institute for Health Research (NIHR) SharePoint portal the files were later transferred to a dedicated site on the NIHR Hub when the NIHR moved its infrastructure onto the Google platform. The list of uncertainties generated by this process was reviewed at a meeting of the Steering Group to decide which to take forward to the ranking stage.

The group was provided with information on the number of related submissions so that the shortlist was decided largely by popularity of the uncertainty.

As a final check, the International Clinical Trials Registry (http://apps.who.int/trialsearch/) and the Database of Abstracts of Reviews of Effects (DARE) were searched to ensure that no uncertainty was already being addressed by an ongoing clinical study or had been the subject of an existing or planned high quality systematic review.

Stage 4: voting and ranking

Because large numbers of young people were expected to take part in the vote, the number of questions on the shortlist was limited to thirty. Like the harvesting survey, the voting form was constructed in Survey Monkey and embedded in the PSP web site. Each respondent was asked to choose the three questions they felt were most important and rank them. The order of questions on the voting form was random. The vote was open from 22 December 2013 to 10 February 2014. The same methods used to promote the harvesting survey were used to promote the vote.

A weighted ranking system was used to generate scores from the vote; the first choice question scored three points, second choice two points and third choice one point. Summed scores from patients and professionals were calculated separately; summed scores from professionals were adjusted to take account of the lower number who voted so that ranks could be validly compared from both groups. Votes from respondents who identified themselves as researchers or ‘other’ were excluded. The Steering Group appraised the ranked scores from patients and professionals and selected eighteen uncertainties to take forward to the priority setting workshop based on the highest ranking by both groups.

Stage 5: Priority Setting Workshop

The final stage of the PSP was the workshop. This was held at the London headquarters of the British Association of Dermatologists (BAD) on 04 March 2014. Equal numbers of people with acne and health care professionals working within and outside the NHS were invited to attend. Representatives of partner organisations and Steering Group members not regularly involved in patient care attended as observers. In order to make informed decisions, participants were provided with ranks from the vote and the number of related submissions from the harvesting survey.

Sample size and composition

Sample sizes were available from two previously completed PSPs on eczema and vitiligo; 493 and 461 participants respectively submitted uncertainties to each PSP. Since acne is a more common condition, the protocol for the Acne PSP set an aspiration of 600 respondents for the harvesting survey. Whilst no formal target was set for the vote, numbers and sample composition were closely monitored so that the voting period could be extended if necessary. For both the harvesting survey and the vote, considerable efforts were made to collect responses from representative samples of people with acne and the professionals who care for them. To assist with this, extensive demographic information was collected for the survey and the vote.

Results

Harvesting and collating uncertainties

A total of 4,363 people submitted the harvesting survey form. However, many patients and professionals did so without including a question. Usable submissions containing one or more uncertainties were received from 1,636 patients or family members and 652 professionals. Following rewording and refining, there were 8,276 questions. After removing those which were out of scope (i.e. relating to diagnosis, pathogenesis, genetic predisposition, new drug development or access to treatment), not answerable by research, already answered or not about acne, a total of 6,255 questions remained.

Few respondents submitted questions about specific interventions; the exception was oral isotretinoin. In consequence, the Steering Group decided against generating a long list of specific uncertainties. In order to generate a manageable short-list for voting, questions were sorted into themes which were necessarily broad.

The number of people submitting questions relating to each theme were calculated separately for respondents to each version of the survey and compared. The most common themes are shown in Table 1. Over a quarter of all respondents (27%) and over a third (37%) of respondents to the patient survey asked about the safety and/or efficacy of physical therapies. This was the intervention type about which most questions were asked. Some uncertainties were submitted by similar proportions of patients and professionals, whereas there were marked differences for others.

Table 1. Uncertainties identified by 200 or more respondents to the harvesting survey.

		Number (%) of related submissions from			**In final top ten**
		Patients/family members	**Professionals**	**All respondents**	
1	Which physical therapies including lasers and other light based treatments are safe and effective in treating acne?	573 (35)	34 (5)	607 (27)	YES
2	Are cosmetic remedies for spot prone skin as effective as they claim to be?	439 (27)	8 (1)	447 (20)	NO
3	Which complementary and alternative therapies are safe and effective in treating acne?	356 (22)	7 (1)	363 (16)	NO
4	What is the best treatment for acne scars?	324 (20)	32 (5)	356 (16)	YES
5	What is the best topical product for treating acne?	266 (16)	55 (8)	321 (14)	YES
6	What is the correct way to use antibiotics in acne to achieve the best outcomes with least risk?	159 (10)	121 (19)	285 (12)	YES
7	What dietary advice should be given to people with acne?	255 (16)	14 (2)	269 (12)	YES (merged with 9)
8	What should a consultation for acne involve?	169 (10)	63 (10)	236 (10)	NO
9	Which lifestyle factors influence acne severity the most?	203 (12)	31 (5)	234 (10)	YES (merged with 7)
10	What is the correct way to use oral isotretinoin in acne in order to achieve the best outcomes with least risk?	105 (6)	125 (19)	230 (10)	YES
11	What is the best skin care routine for people with acne?	186 (11)	21 (3)	209 (9)	NO
12	Does diet affect who gets acne or how severe it is?	150 (9)	54 (8)	204 (9)	NO

The 29 most popular themes were taken forward to the vote together with an additional uncertainty about the prevention and management of post-inflammatory pigmentation, which was identified by many people with acne in pigmented skin.   Popularity in the harvesting survey did not predict popularity in the vote or ranking in the top ten (see below).

Characteristics of survey respondents

Extensive demographic information was collected to determine whether a representative sample had been obtained. Interim analyses showed that women were over-represented in the patient sample. Keeping the survey open longer and specifically targeting men via Twitter did not improve participation by males with acne. At the close, the professional sample comprised 64.2% women (Supplementary Table 1), and the patient/family member sample comprised 83.1% women (Supplementary Table 2). Amongst the professionals, most submissions came from doctors, nurses and pharmacists working in primary or secondary care or in the community, but treatment providers working outside the NHS were also represented (Supplementary Table 1).   Among respondents to the patient version were 1,125 individuals with acne at the time of completing the survey, 331 who had acne in the past as well as 132 family members.   The age range was as expected; 40% of respondents to the patient version were aged 16 to 24 (Supplementary Table 2).   The patient sample was predominantly white (80% versus 87% for the UK in 2011 census) but a good spread of minority ethnic groups was represented.   Almost a quarter of the patient sample (23%) lived outside the UK compared with 15% of the professional sample. Within the UK, all but five postcodes were represented in the sample of patients and family members with a large number of responses (33%), as might be expected, from Yorkshire where the PSP management team and the local NIHR research network were based. A majority of professionals (73%) did not disclose their postcodes.

People who had acne at the time that they completed the survey were asked provide information about sources of professional help to ensure that the sample composition included individuals seeking advice and/or treatment from a variety of sources and not just within the NHS. Forty-one percent were not getting any professional help although 88% had sought help in the past (Table 2). The most common source of help was a general practitioner. Interestingly, 26% of respondents had seen a beauty therapist in the past and 34% had sought the advice of a pharmacist. Other sources of professional help not shown in Table 2 included paediatricians, gynaecologists, nurses, health counsellors and the British Association of Skin Camouflage. A minority of respondents said they obtained help from family and friends, the internet and/or social media such as You Tube (an online video sharing website), or became their own expert.

Table 2. Sources of professional help used by respondents (n = 1,125) who had acne when they completed the harvesting survey.

Source of help	**Number (%)[1]**	
	In the past	**When survey completed**
Pharmacist	381 (34)	78 (7)
GP/family doctor	721 (65)	306 (28)
Dermatologist	503 (45)	249 (23)
Complementary or alternative therapist	94 (8)	27 (2)
Beauty therapist	283 (26)	62 (6)
Private practitioner	62 (6)	22 (2)
Not sought any help in the past	138 (12)	n/a
Not getting any help now	n/a	448 (41)
Not disclosed	5 (0.5)	75 (7)
Other	68 (6)	7 (0.6)

[1] Percent of respondents. Total exceeds the number of respondents as many individuals selected more than one option.

The most common source of acne treatment was from a pharmacy with a prescription (Supplementary Table 3). At the time of completing the survey, 40% of people with acne were not using any treatment but 82% had used treatment in the past.

How people heard about the harvesting survey

Respondents were asked to identify how they heard about the survey and the answers are shown in Table 3. The commonest mechanism identified by both patients and professionals was email. Amongst professionals, many (21%) heard about the survey from a colleague. Many patients and family members had heard about the survey via social media (notably Facebook and YouTube) with many specifically mentioning a celebrity video. Methods with negligible impact were the Acne PSP website, Twitter account and the printed word. Three times as many patients heard about the survey from the Embarrassing Bodies or Talk Health web sites than from the PSP's site. There was some evidence of propagation with several people mentioning organisations we had not directly targeted.

Table 3. How respondents heard about the harvesting survey

Mechanism	Number (%)[1]	
	Patient version	Professional version
email	294 (18)	249 (38)
You Tube video	280 (17)	1 (0.2)
Facebook or other networking site	238 (15)	1 (0.2)
Acne PSP web site	55 (3)	n/a
Website of a professional organisation	n/a	79 (12)
Other web site	160 (10)	11 (2)
From a friend or relative	104 (6)	12 (2)
From a doctor/other treatment provider	112 (7)	n/a
From a colleague	n/a	136 (21)
Poster/leaflet	86 (5)	16 (2)
Newsletter	71 (4)	10 (2)

Mechanism	Number (%)[1]	
	Patient version	Professional version
Word of mouth	79 (5)	21 (3)
Twitter	76 (5)	14 (2)
Advert in newspaper or magazine	20 (1)	2 (0.3)
Via a network	6 (0.4)	66 (10)
LinkedIn or other professional networking site	2 (0.1)	60 (9)
Other	66 (4)	16 (2)
Not disclosed	26 (2)	2 (0.3)

n/a = not applicable. [1] Percent of respondents. Total exceeds the number of respondents as some individuals selected more than one option.

Ranking exercise

A total of 3,084 people took part in the online vote. Of these, 277 votes were excluded because the respondent identified themselves as a researcher or 'other'. Valid votes were received from 1,573 people with acne, 237 family members and 1,012 professionals. Again males were under-represented; only 25% of patient voters were male compared to 35% of professionals. A demographic analysis of votes is shown in Table 4; 44% of voters were aged between 16 and 34 years. A large majority of voters (85%) lived in the UK and 81% were white. More than half of patient voters lived in Yorkshire (53.6%). This time, 78% of professionals provided a postcode; of these 21% practiced in Yorkshire. All but seven postcodes were represented in the patient sample and all but 15 in the professional sample. Google Analytics^{TM} showed that most people landed directly on the voting survey without visiting other pages before leaving the PSP web site.

For several uncertainties, there were marked differences in weighted ranks between patients and professionals (Figure 2). For others there was good agreement, especially among the less popular questions. Popular uncertainties with the biggest differences in weighted scores (patients vs professionals) were about use of oral isotretinoin (191 vs 693), ways of preventing acne (1006 vs 461) and the use of antibiotics (282 vs 972).

Table 4. Demographic analysis of the vote.

	Number (% within group)			
	Health Care Professionals	**People with acne***	**Parents, guardians or partners**	**All groups**
n	1012	1573	237	2822
Gender				
Male	356 (35)	400 (25)	58 (24)	814 (29)
Female	647 (64)	1157 (74)	175 (74)	1979 (70)
Not disclosed	9 (0.9)	16 (1)	4 (2)	29 (1)
Age range				
≤15 years	0	72 (5)	1 (0.4)	73 (3)
16 – 24 y	34 (3)	633 (40)	11 (5)	678 (24)
25 – 34 y	164 (16)	443 (28)	7 (3)	614 (22)
35 – 44 y	258 (25)	229 (15)	37 (16)	524 (19)
45 – 54 y	307 (30)	128 (8)	122 (52)	557 (20)
55 – 64 y	198 (20)	51 (3)	42 (18)	291 (10)
65 y and over	39 (4)	16 (1)	11 (5)	66 (2)
Not disclosed	12 (1)	1 (0.1)	6 (3)	19 (0.7)
Location				
UK	846 (84)	1337 (85)	221 (93)	2404 (85)
Overseas	166 (16)	236 (15)	16 (7)	418 (15)
Ethnicity				
Asian Bangladeshi	1	9	0	10
Asian Chinese	16	11	1	28
Asian Indian	58	54	5	117
Asian Pakistani	19	61	16	96
Black African	10	16	2	28
Black Caribbean	7	14	1	22
Hispanic	9	24	2	35
Mixed race	14	53	1	68
White	817 (81)	1268 (81)	204 (86)	2289 (81)
Other	39	40	2	81
Not disclosed	22	23	3	48

* 1162 individuals had acne when they voted; 411 had acne in the past.

The Steering Group used ranked weighted scores to decide which uncertainties to take forward to the final workshop. The distribution of scores

(Figure 1) showed a long tail and, with one exception, uncertainties in the tail were not taken forward. The exception was the uncertainty about the best way to use oral isotretinoin, which ranked fifth amongst professionals but nineteenth amongst patients and family members. This meant a total of eighteen uncertainties were considered at the final workshop.

Final priority setting workshop

A total of 43 people including 13 patients, 12 professionals and 13 observers attended the final workshop. In the first session, three groups comprising equal numbers of patients, professionals and non-participatory observers, each with an independent moderator, were asked to prioritise all 18 uncertainties using a nominal group technique. The results were collated and discussed in one combined afternoon session, moderated by the chairman of the steering group. The final top ten is shown in Box 2. Seven uncertainties were ranked in the top ten without alteration. There were three instances in which two related questions were merged; all three merged questions were also ranked in the top ten. The top ten was announced the following day via the Acne PSP website, Twitter and several partner web sites. Subsequently, thank you postcards promoting the top ten have been disseminated in Harrogate dermatology clinics, at European and Global Alliance acne meetings and through a meeting supported by the British Association of Dermatology. Given the number of more specific questions, work is still ongoing to optimise methods of disseminating these to patients and professionals. In due course, all verified uncertainties will be entered into the UK Database of Uncertainties about the Effects of Treatment (www.library.nhs.uk/duets/).

Box 2. The top ten research priorities for the treatment of acne.

1. What management strategy should be adopted for the treatment of acne in order to optimise short and long-term outcomes?
2. What is the correct way to use antibiotics in acne to achieve the best outcomes with least risk?
3. What is the best treatment for acne scars?
4. What is the best way of preventing acne?
5. What is the correct way to use oral isotretinoin (Roaccutane) in acne in order to achieve the best outcomes with least risk of potentially serious adverse effects?
6. Which lifestyle factors affect acne susceptibility or acne severity the most and could diet be one of them?
7. What is the best way of managing acne in mature women who may/may not have underlying hormonal abnormalities?
8. What is the best topical product for treating acne?
9. Which physical therapies including lasers and other light based treatments are safe and effective in treating acne?
10. How long do acne treatments take to work and which ones are fastest acting?

Discussion

The top ten acne research priorities, reached by consensus between patients and professionals, reveal concern about the paucity of evidence on the relative efficacy and safety of commonly used treatments and their place in both short and long-term management. This evidence gap may reflect the low number of robust, industry-independent trials of acne therapies but also that efficacy within RCTs does not reliably predict effectiveness or patient satisfaction in the real world. In the last five years, no published acne RCTs have been conducted in whole or in part within the UK. Within the Cochrane library, there are only two published Cochrane reviews wholly dedicated to acne therapies although there are six ongoing Cochrane reviews that will provide new insights into some of the uncertainties in the top ten, specifically the efficacy and/or safety of oral isotretinoin, light therapies and topical treatments. Identifying the top ten priorities of patients and healthcare professionals highlights the need for more pragmatic trials which put widely used interventions head-to-head and also more focused research to identify the safest and most effective alternatives to drug based therapies. Whilst awareness of these alternatives among patient responders was high, so was scepticism about paying for such treatments from unregulated practitioners outside the NHS. Several uncertainties which were very frequently identified by respondents to the harvesting survey, including two of the three most asked about intervention types (complementary and alternative medicines [CAM], cosmetic remedies), did not make it into the top ten. Although there was clearly a lot of interest in them amongst people with acne, they did not rank in most voters' top three when presented alongside the other shortlisted questions.

Among submissions to the harvesting survey, we received many treatment related questions not answerable by research and so not included in the prioritisation exercise. They asked about such things as availability of non-drug based treatments within the NHS and how to identify reliable sources of advice about their safety and efficacy. There were also many questions about affordability and accessibility of treatments not provided by the NHS. These questions reflected valid concerns among people with acne and should be addressed by information providers, policymakers and regulatory bodies.

At the time the Acne PSP was set-up, the JLA process of priority setting through partnership and consensus had already become established. Several PSPs have revised the basic procedures laid down in the JLA guidebook and adopted new strategies to overcome difficulties associated with specific diseases or hard-to-reach groups. For example, the stroke PSP devised a new model for assisted participation and targeted engagement of stroke survivors with communication difficulties.[21] No previous priority setting exercise has been completed for a very common condition that primarily affects teenagers and young adults. We recognised that they might be hard to engage and motivate in an exercise such as this. There are at least three million people with acne in the UK at any one time. A sample of 0.05% would represent a minimum of 1,500 people. Whilst this sounds easily achievable, in the end it was extremely challenging. A huge amount of work by large numbers of people went on behind the scenes to achieve this. Initial discussions with young people suggested that it would be necessary to break with JLA tradition in several ways: a very different layout for the harvesting survey, the use of a small financial inducement and emphasis on the use of social media to promote participation. Whether due to the layout of the harvesting survey or not, we obtained a much broader range of uncertainties from patients than professionals, almost certainly as a consequence of reminding people what treatments are available. Perhaps as a result of opening people's eyes to treatments they were not aware of, we also received many questions from patients about therapies not available within the NHS, most commonly physical treatments as well as CAM. In contrast, two types of drug treatment dominated questions from professionals, antibiotics and oral isotretinoin. Among numerous questions relating to the conduct of a consultation for acne, many asked about doctors' reluctance to engage in conversations about alternatives to commonly used drug-based therapies.

Feedback from respondents showed that some promotional activities were much more successful than others and this information may be of use to those conducting PSPs in future. It was almost certainly not necessary to have a dedicated PSP website or Twitter account and leafleting via a national chain of pharmacies was not as successful as we had hoped. The role of partner organisations was vital in publicising the PSP and encouraging participation. With such a prevalent condition, we felt it was necessary to demonstrate that respondents to the harvesting survey and vote were representative of all people with acne and all professionals who offer care. The demographic information we collected showed a pronounced local concentration of survey respondents in Yorkshire, where both the PSP management team and local NIHR network, which helped to promote the survey, are based. Whilst the effort: reward ratio in terms of respondent numbers to hours spent on promoting the survey might be low, it guaranteed that we achieved a representative sample in terms of age, location and ethnic mix. With patient gender, we were not so successful. Ours is not the first or only PSP to find that only a minority of respondents were male [3, 23, 23] although many PSPs do not report the gender of participants. It is perhaps particularly surprising for acne, as there are fewer treatment options for men. The smaller gender bias among healthcare professionals is not of concern as it simply reflects the 60:40 ratio of females to males within dermatology, pharmacy and general practice in the UK. Weighted ranks show that uncertainties voted for by men and women were broadly similar with the exception of a question about managing acne in mature women (data not shown). This suggests that gender bias in the sample may not have affected the findings of the PSP to a significant extent.

Because of the large number of questions submitted, our approach, like several PSPs before us, was to merge very specific questions on related themes into broad questions that could be voted on. Any PSP has to balance the sample size required to reach saturation (i.e. few or no new uncertainties identified by increasing participation) with the practicalities of processing the large volumes of data generated. The novel use of key words based on MesH descriptors in this PSP was essential to facilitate sorting and grouping. Following the PSP, preliminary discussions have been held with NETSCC about translating the top ten uncertainties into researchable questions which faithfully represent the original submissions. A forthcoming challenge is to capture and disseminate, via UK DUETs and other mechanisms, the insightful more detailed questions which have been lost as a result of merging.

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Contributors All authors made substantive contributions to the conduct of the PSP including promoting the survey and vote to patients and colleagues as well as the collection, analysis and/or interpretation of data. The manuscript was drafted by AE and HW. All authors except HW were members of the Steering Group and all including HW were involved in review and revision and approved the final version. The project was managed by AE and AL with administrative support from Elizabeth Oldham.

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Competing interests None.

Ethical and NHS Governance approval Ethical approval was obtained from West of Scotland REC4 (reference number 13/WS/0015). NHS governance approval was obtained from Harrogate and District NHS Foundation Trust. Both were required in order to embed a research question about outcomes important to patients within the harvesting survey. The findings from that will be published separately.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The anonymised list of unsorted questions will be made available via Dryad. The full list of verified uncertainties will be available in due course from UK DUETS.

Supplementary Table 1. Demographic information for professional respondents.

		Number
	Total respondents	652
Gender	Female	393
	Male	219
	Not disclosed	40
Location	UK	519
	Overseas	96
	Not disclosed	37
Professional group	Pharmacist	137
	GP	139
	Dermatologist	214
	Other physician in secondary care	15
	Cosmetic surgeon/clinical cosmetologist	5
	Nurse	70
	CAM practitioner	4
	Beauty therapist/aesthetician	36
	Private practitioner	25
	Research scientist	20
	Student (pharmacy or medical)	4
	Dietitian	2
	Counsellor/psychologist	2
	Camouflage practitioner	1
	Other	4
	Not disclosed	6

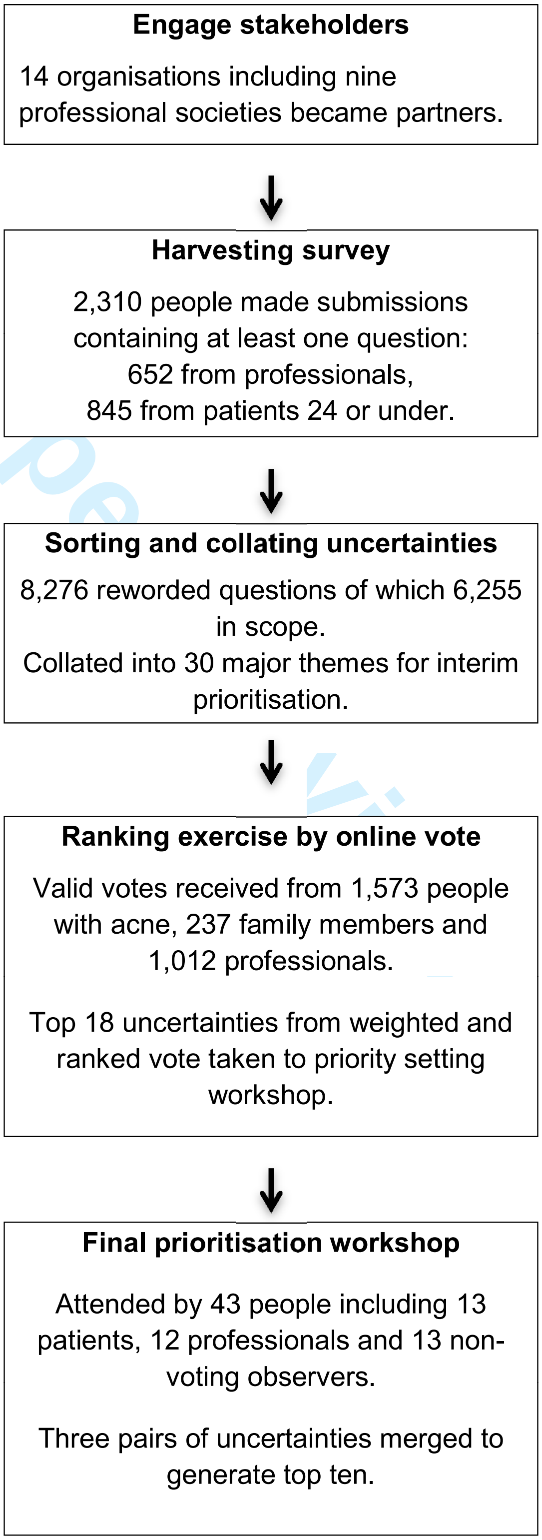
Supplementary Table 2. Demographic information for respondents to the patient version of the harvesting survey

		Number
	Total respondents	1638
Gender	Female	1344
	Male	272
	Not disclosed	22
Age range	15 y and under	161
	16 – 24 y	684
	25 – 34 y	386
	35 – 44 y	169
	45 – 54 y	146
	55 – 64 y	69
	65 y and over	10
	Not disclosed	13
Ethnicity	Asian Bangladeshi	8
	Asian Chinese	28
	Asian Indian	50
	Asian Pakistani	29
	Black African	40
	Black Caribbean	14
	Hispanic	40
	Mixed race	67
	White	1293
	Other	45
	Not disclosed	24
Location	UK	1260
	Overseas	378
Group	Had acne when completed survey	1125
	Had acne in the past	331
	Parent/guardian or partner	132
	Other	50

Supplementary Table 3. Sources of acne treatment used by respondents who had acne when they completed the harvesting survey.

Source of treatment	**Number (%)**	
	In the past	**When survey completed**
From a pharmacy with a prescription	726 (66)	401 (37)
Over-the-counter from a pharmacy without a prescription (something you have to ask for)	359 (33)	86 (8)
From the open shelves in a pharmacy or supermarket	492 (45)	186 (17)
In/from a hospital	127 (12)	46 (4)
From the internet	166 (15)	74 (7)
From a health food shop	142 (13)	33 (3)
From a complementary therapist/alternative practitioner	77 (7)	10 (0.9)
From a private clinic	80 (7)	24 (2)
From a beauty therapist	158 (14)	40 (4)
Not disclosed	2 (0.2)	4 (0.4)
Other	8 (0.7)	9 (0.8)
Number on treatment	903 (82)	650 (59)
Number off treatment	189 (17)	443 (40)
Not disclosed	3 (0.3)	5 (0.5)
Total number of respondents	1095	1098

Figure 1. Flow diagram showing the number of participants and submissions at each stage.



Engage stakeholders

14 organisations including nine professional societies became partners.

Harvesting survey

2,310 people made submissions containing at least one question:
652 from professionals,
845 from patients 24 or under.

Sorting and collating uncertainties

8,276 reworded questions of which 6,255 in scope.
Collated into 30 major themes for interim prioritisation.

Ranking exercise by online vote

Valid votes received from 1,573 people with acne, 237 family members and 1,012 professionals.

Top 18 uncertainties from weighted and ranked vote taken to priority setting workshop.

Final prioritisation workshop

Attended by 43 people including 13 patients, 12 professionals and 13 non-voting observers.

Three pairs of uncertainties merged to generate top ten.

Figure 2. Comparison of summed weighted scores from people with acne versus care professionals.

Summed weighted scores from patients, partners and other family members are shown in blue; summed weighted scores from professionals are shown in orange.

Acne Priority Setting Partnership

STUDY PROTOCOL

Version 1.9 (05 March 2013)

Ethics ref: 13/WS/0015 ***R&D ref:*** R0040 ***UK CRC portfolio ID:*** 119021

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I. Purpose

The purpose of this protocol is to set out the aims, objectives and commitments of the Acne Priority Setting Partnership (PSP) and the basic roles and responsibilities of the partners therein.

Whilst doctors typically consider acne as a skin disorder with a broad spectrum of severity, many people with physiological or mild acne as defined by a doctor will manage their skin condition without medical help and will not consider themself to be a patient. The intention of this PSP is to include everyone with spots of whatever severity. For simplicity, the term acne is used throughout this protocol to include everything from a few spots to severe disease. Similarly, the phrase 'people with acne' is used instead of patients in recognition of the fact that many people with spots do not consult a doctor. Although treatments for acne scars differ to a large extent from treatments for active acne, questions relating to acne scars will almost certainly be submitted and will be included in the prioritisation process.

II. Steering Group

The Acne PSP will be led and managed by a steering group including people with acne, health care and allied professionals involved in treatment delivery as well as facilitators with expertise in relevant research methods.

The Steering Group will agree the resources, including time and expertise that they will be able to contribute to each stage of the process. The JLA will be able to advise on this.

III. Background to the Acne PSP

The JLA is a programme initially funded by the National Institute of Health Research with support from the Medical Research Council. Its aim is to provide an infrastructure and process to help patients and the "clinical" provider community work together to agree which are the most important treatment uncertainties affecting their particular interest, in order to influence the prioritisation of future research in that area. The JLA defines an uncertainty as a "known unknown". It is perhaps more helpful to think of an uncertainty as something unknown about an intervention that, if known, could improve or change practice.

The idea for an Acne PSP arose from conversations in spring 2012 between Dr Kim Thomas, Associate Professor in the Centre of Evidence Based Dermatology (CEBD) at the University of Nottingham and Dr Anne Eady, a Research Fellow in Dermatology at Harrogate and District NHS Foundation Trust. Anne was drafting outline proposals (vignettes) for randomised controlled trials in response to the UK Dermatology Clinical Trials Network (UK DCTN) themed call on acne and rosacea when it occurred to her that she had no idea how important these questions were to people with acne or to care professionals outside her own personal networks. It became obvious that an important first step in the process was lacking – a mechanism for identifying unanswered questions that matter most to people with the disorder and those who treat them. The Acne Support Group, a very pro-active advocacy group in the UK, was disbanded in 2007 and has not been replaced. In its absence, there is no obvious point of contact for healthcare researchers wishing to involve people with acne in their decision making. Kim's suggestion was to consider setting up an Acne PSP with support from the CEBD (which has completed two successful PSPs), but based in Harrogate, where the Head of the Dermatology Department, Dr Alison Layton, is a leading international expert on acne.

Systematic reviews and other published articles have repeatedly drawn attention to the shortcomings of the evidence base which underpins acne treatments. Until a decade ago, the UK was a leading global player in acne research. Since then, much expertise has been lost and it has become virtually impossible to obtain public funding for acne research in the UK. It is hoped that the successful completion of this priority setting exercise will put acne firmly back onto the UK research map and unlock funding to address those uncertainties that people with acne and care professionals agree are the most important.

IV. Aims and objectives of the Acne PSP

The aim of the Acne PSP is to identify the unanswered questions about acne treatment from the perspectives of those with the disorder, their parents/guardians/partners and treatment providers and then prioritise those that participants agree are the most important.

The objectives of the Acne PSP are to:

- work with people with acne, their parents/guardians/partners and care professionals to identify uncertainties about the effects of acne treatments
- survey the research literature to identify uncertainties and research recommendations
- identify any ongoing research studies that are in progress addressing submissions and research recommendations.
- agree by consensus a prioritised list of those uncertainties
- translate these prioritised uncertainties into research questions which are amenable to hypothesis testing
- publicise the results of the PSP and the process for obtaining them
- take the results to research commissioning bodies to be considered for funding
- address a number of supplementary research questions which are described in more detail in section XIII

V. Partners

Organisations and individuals will be invited to take part in the PSP, which represent the following groups:

- people who have had or who still suffer from acne of any severity
- parents/guardians of people who have had or still suffer from acne and who are under 16 years of age
- doctors, nurses and allied professionals with experience of managing acne with medical or non-medical interventions

It is important that all organisations which can reach and advocate for these groups should be invited to become involved in the PSP. The JLA will ensure that, by support and challenge to the Project Manager, various stakeholder groups are able to participate equally to the process. A preliminary list of stakeholders for the Acne PSP will be reviewed and modified as necessary by the Steering Group.

Organisations wishing to participate in the PSP will be required to affiliate to the JLA in order to demonstrate their commitment to the aims and values of the organisation. Details on the affiliation procedure can be found at www.lindalliance.org.

VI. Exclusion criteria

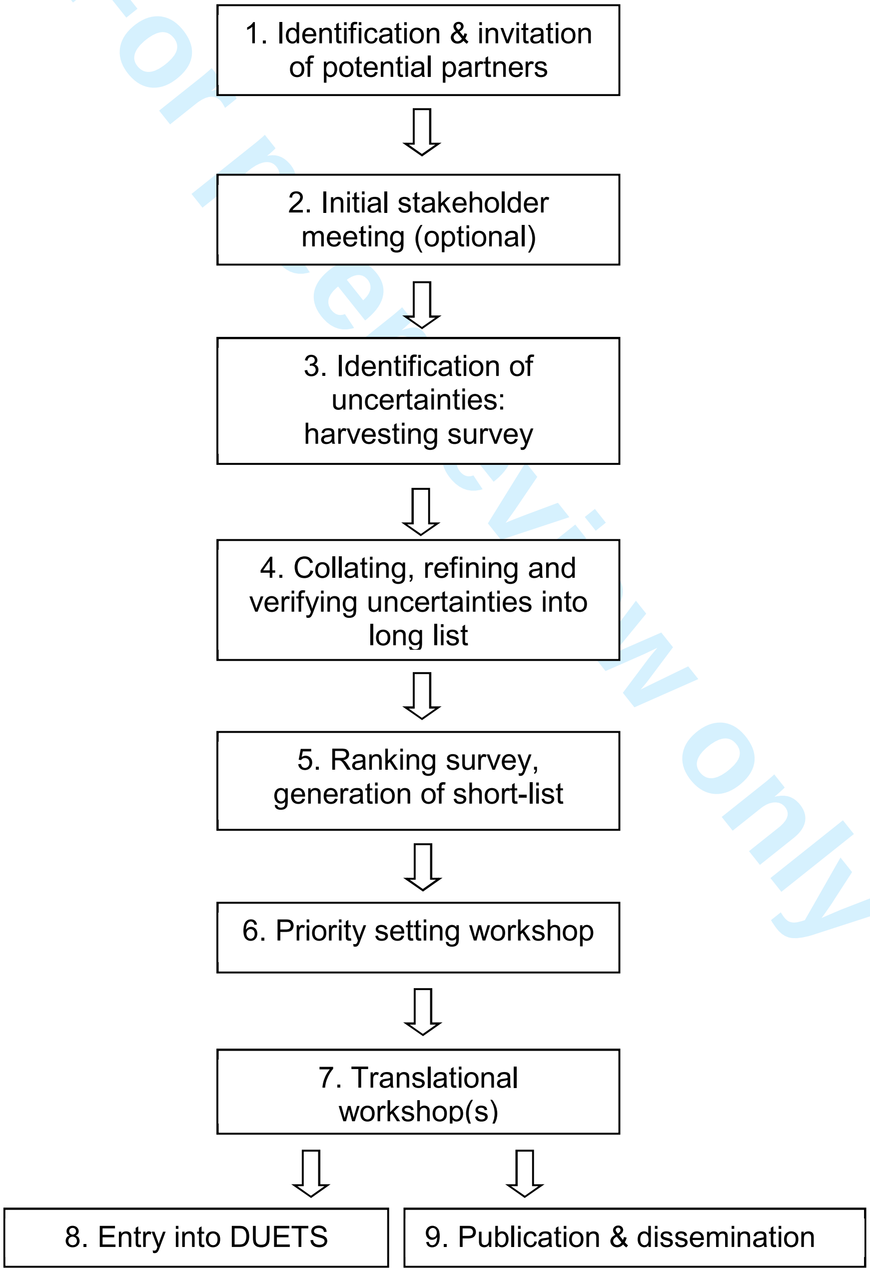
Some organisations may be judged by the JLA or the Steering Group to have conflicts of interest. These may be perceived to adversely affect those organisations' views, causing unacceptable bias. As there is a risk that this could affect the ultimate findings of the PSP, any such organisations will not be invited to participate in the prioritisation process although they can submit uncertainties.

VII. Methods

This section describes a schedule of proposed stages (Figure 1) through which the PSP aims to fulfil its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods adopted in any stage will be agreed through consultation between the partners, guided by the PSP's aims and objectives. More details and examples can be found at www.JLAguidebook.org. The methods will be adapted from the traditional JLA approach to capture learning from previous PSPs in eczema and vitiligo conducted by the CEBD. The main difference is the addition of one or more extra workshops after the identification of the top 10 uncertainties to translate at least some of these into an initial list of mutually agreed research questions.

The prioritisation exercise will take place in the stages shown in Figure 1 and outlined below:

Figure 1. Diagram of the JLA prioritisation process



1. Identification and invitation of potential partners

Potential partner organisations will be identified through a process of peer knowledge and consultation, through the Steering Group members' networks and through the JLA's existing register of affiliates. Potential partners will be contacted and informed of the establishment and aims of the Acne PSP and invited to attend and participate in an initial stakeholder meeting. The JLA will help draft the invitation, which will be mailed out from Harrogate and District NHS Foundation Trust on notepaper with the Trust's logo as well as those of the JLA, the UK Dermatology Clinical Trials Network (UK DCTN) and the Society for Academic Primary Care (SAPC). The UK DCTN and SAPC have provided financial support for this PSP.

2. Initial stakeholder meeting (optional)[1]

Potential partners will be invited to an initial stakeholder meeting which will have several key objectives:

- to welcome and introduce potential members of the Acne PSP
- to present the proposed plan for the PSP
- to initiate discussion, answer questions and address concerns
- to identify those potential partner organisations which will commit to the PSP and identify individuals who will be those organisations' representatives and the PSP's principal contacts
- to establish principles upon which an open, inclusive and transparent mechanism can be based for contributing to, reporting and recording the work and progress of the PSP

The administrative process for convening this meeting will be managed by the Steering Group in co-operation with the JLA.

Following the meeting, organisations which have decided to participate in the PSP will be asked to affiliate to the JLA and complete a declaration of interests, including disclosing any relationships with pharmaceutical or skin care companies.

3. Identification of treatment uncertainties – harvesting survey

A self-completion on-line survey will be used to identify uncertainties from people with acne, parents/guardians/partners, healthcare and other professionals involved in the delivery of medical or non-medical treatments for acne. The survey will also be made available in hard copy for anyone who wishes to complete it off-line.

The format suggested in the JLA guidebook will be used as the starting point for design of the survey and modified following advice from individuals with expertise in this area and by reference to surveys used by previous PSPs available via the JLA web site. Specifically, ways of capturing uncertainties that may lead to the identification of more specific research questions will be explored. The survey will be open for up to eight weeks depending on the response rate and the need to chase under-represented groups; in principle we will continue to collect submissions until no new themes emerge. Because acne is such a common condition, we have set a minimum target of 600 responses to the survey.

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[1] The Steering Group decided at its first meeting that a launch meeting was not necessary.

The methods to be adopted to publicise the survey and encourage participation include but are not necessarily limited to:

- a. Advertisements and links within stakeholder web sites
- b. Identification of champion tweeters, Facebook and/or LinkedIn users with 200 or more followers
- c. PSP members' personal networks
- d. Patient and professional bloggers
- e. Targeted mailshots
- f. Newsletters distributed by stakeholders to members
- g. Leaflets, postcards and posters for display in specialist treatment centres
- h. Utilisation of research networks especially those of the National Institute of Health Research
- i. Use of databases and informatics that can identify potential interested parties, use of texts to contact and encourage respondents

More specifically, we will invite patients in the Harrogate and District NHS Foundation Trust Database who are 16 years of age or above.

Acne is most prevalent during adolescence and early adulthood. Teenagers are a difficult group to motivate to take part in an exercise such as this and the Steering Group will draw on experts to advise how best to promote the exercise to them and encourage participation.

The participant information sheet and survey text will be designed to be easy to understand and provide all the relevant information for self-completion. Submitting the completed survey will be considered consenting to participate in the research and agreement to publication of the uncertainties provided on the UK Database of Uncertainties about the Effects of Treatments (DUETs, see section 10).

4. Collating, refining and verifying uncertainties

The JLA will participate in this process as Chair, to ensure accountability and transparency.

Submissions will be downloaded or manually entered into Excel. Those which are out of scope i.e. relate to delivery of care, are not recognised means of managing acne or are not uncertainties will be excluded from the list of collated indicative questions and kept separately. Similar or duplicate submissions will be combined where appropriate and with agreement from the Steering Group. The remaining raw submissions will be refined via a series of steps into "collated indicative questions" which are clear, addressable by research, understandable by all and suitable for entry into the UK DUETs database. This stage of priority setting is a crucial and demanding one. Rigorous processes will be developed in consultation with the UK DUETs Database Editor to ensure it is accomplished in a logical and efficient manner.

Existing sources of information, in particular systematic reviews, evidence based guidelines and prospective trial registers, will be searched to see to what extent these refined questions have, or have not, been addressed by previous or ongoing research.

Sometimes, uncertainties are submitted that can be resolved with reference to existing research evidence - ie they are "unrecognised knowns" and not uncertainties. If a question about treatment effects can be answered with existing information but this is not known, it suggests that information is not being communicated effectively to those who need it. A separate record of these 'answerable questions' will be kept. If deemed necessary by the Steering Group, they will be brought to the attention of UK organisations that produce and disseminate acne treatment guidelines/ recommendations.

5. Ranking survey

The refining process will result in a long list of indicative uncertainties, the number of which is hard to predict. This long list will be reduced to a short-list of 20-25 uncertainties by a UK wide process of consultation. If the long list is unduly long, the Steering Group will decide whether they wish to adopt some mechanism for reducing it to a more manageable number (the interim list).

People who respond to the harvesting survey and give contact details will be invited to take part in the ranking exercise. In addition the ranking exercise will be advertised using the same mechanisms that were adopted during the first survey and will be promoted using every possible means to any groups under-represented in the first survey.

Participants in this ranking survey will be invited to choose up to five uncertainties from the long (or interim) list. They will not be asked to prioritise them. The responses obtained will be used to rank the uncertainties by number of votes. The top 20 - 25 or thereabouts will be taken forward into the priority setting workshop.

The priorities of different categories of respondent will be listed separately and compared.

6. Priority setting workshop

The aim of this penultimate stage of the priority setting exercise is to prioritise through consensus the most popular uncertainties relating to the management of acne. This will be carried out by eligible members of the Steering Group and the wider partnership that represents people with acne and care delivery professionals. The process will be facilitated by the JLA to ensure fairness, transparency and accountability. The methods to be used during the workshop will be determined by consultation with partner organisations and with the advice of the JLA.

The intention will be to produce a single top 10 which is agreed by people with acne and care providers. However, it is recognised that differences between the groups may not be reconcilable. If this should occur, the SG will consider how best to address the problem.

The number of participants in the priority setting and translational workshops (see below) will be limited to 40. Attendees who have not already done so, will be asked to complete a declaration of interests, including disclosure of relationships with for-profit organisations.

7. Translation workshop(s) to develop research questions

The Steering Group will convene one or more translation workshops to which acne researchers and representatives of partner organisations will be invited to attend.

Invitations will also be sent to selected care professionals and people with acne who have contributed positively to the Acne PSP and expressed an interest in helping with this final stage.

Participants will be divided into four groups, each with an independent facilitator and including similar numbers of people with acne, care professionals, researchers and representatives of partner organisations. A pro-forma, based on a PICO format (**P**articipants, **I**ntervention, **C**omparator, **O**utcomes), will be used to assist groups in generating research questions in an appropriate way. The procedures to be adopted during the workshops will be decided by the Steering Group in consultation with the JLA.

It is recognised that several workshops may be required in order to generate mutually agreed research questions from all of the prioritised uncertainties. These questions will form the basis of funding applications.

8. Entry into DUETS

Uncertainties in standard format that have not been adequately addressed by previous research will be collated and entered into an acne section within the UK DUETs (www.library.nhs.uk/duets). This is a key component of the JLA process. Entry into DUETs can begin as soon as the Steering Group has agreed the long list of uncertainties.

9. Publication and dissemination

The findings of the Acne PSP will be publicised using a range of mechanisms. As well as a journal article and conference presentation, brief summaries will be included (with permission) in partner web sites and a fuller report will be placed on the Acne Academy site (www.acneacademy.org). The mechanisms put in place to promote the surveys will be adopted to publicise the findings and direct people to the location of information.

The JLA will publicise the top 10 priorities on the JLA web site. Dissemination of the findings will not be held up whilst journal articles are being prepared and submitted. Authorship of articles will be decided by the Steering Group based on two principles: (a) authorship is not an automatic right of Steering Group members and (b) individuals who are not members of the Steering Group may be invited to become co-authors in recognition of a significant contribution to the successful completion of the project.

The priorities identified by the Acne PSP will be reported to funding and research agenda setting organisations such as the NIHR HTA Programme and the MRC, as well as major research funding charities.

A timeline for the Acne PSP can be found in Appendix 1.

VIII. Additional research elements within this protocol

Whilst the basic processes for the conduct of a priority setting exercise are fixed, there is scope and sometimes a need for adaptation and modification to meet the varying challenges that different patient-provider communities present.

It is recognised that a major challenge for this PSP is motivating teenagers whilst not focusing too much effort on them. It is also possible that difficulties engaging professionals may be encountered, as has been found by some other PSPs. Some completed PSPs have reported differences in the priorities of patients and treatment providers. A key question for those who conduct PSPs to address is how well ongoing or recently concluded clinical research studies relate to the uncertainties identified. These aspects provide the basis for additional research elements within the basic procedure of priority setting.

Specifically, the following supplementary analyses will be conducted:

1) comparison of the effectiveness of different mechanisms for promoting the PSP, especially to teenagers
2) comparison of response rates and types of question submitted by different categories of respondent[2], and exploration of the implications of any differences found.
3) comparison of the questions submitted with the topics addressed by acne RCTs and systematic reviews published in the last 5- 10 years or listed as ongoing.

These supplementary analyses will be conducted as time and resources permit. Where sufficiently rigorous, results will be submitted for publication in relevant journals.

Respondents to either survey will be invited to give permission for their demographics and contact details to be placed in a secure NHS database to form an acne registry; this will enable researchers to contact them about any future acne related research studies in which they might wish to participate.

IX. Signed by the Steering Group

The undersigned agree to follow the Acne Priority Setting Protocol.

Names: (1) ANNE EADY (2) ALISON LAYTON

Organisation: Harrogate and District NHS Foundation Trust

Signature 1: *Date:* 05/03/2013

Signature 2: A. M Layton *Date:* 05/03/2013

Name: LESTER FIRKINS

Organisation: James Lind Alliance

Signature: Lester Firkins *Date:* 05/03/2013

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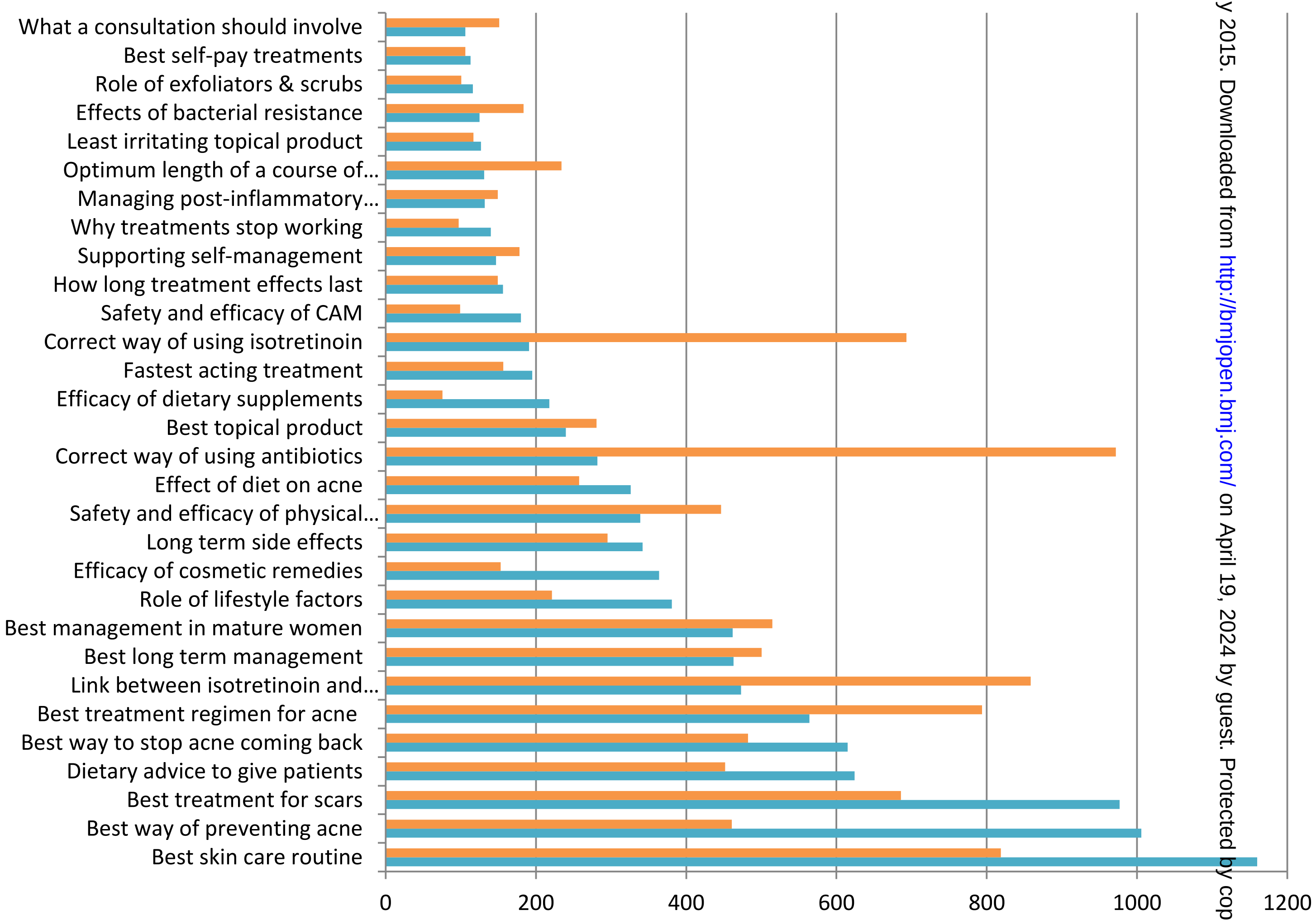
[2] Respondents will be categorised on the basis of the supplementary information provided on a voluntary basis.


What a consultation should involve
Best self-pay treatments
Role of exfoliators & scrubs
Effects of bacterial resistance
Least irritating topical product
Optimum length of a course of...
Managing post-inflammatory...
Why treatments stop working
Supporting self-management
How long treatment effects last
Safety and efficacy of CAM
Correct way of using isotretinoin
Fastest acting treatment
Efficacy of dietary supplements
Best topical product
Correct way of using antibiotics
Effect of diet on acne
Safety and efficacy of physical...
Long term side effects
Efficacy of cosmetic remedies
Role of lifestyle factors
Best management in mature women
Best long term management
Link between isotretinoin and...
Best treatment regimen for acne
Best way to stop acne coming back
Dietary advice to give patients
Best treatment for scars
Best way of preventing acne
Best skin care routine
0
200
400
600
800
1000
1200

BMJ Open

Identifying acne treatment uncertainties via a James Lind Alliance Priority Setting Partnership.

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Primary Subject Heading:	Dermatology
Secondary Subject Heading:	Dermatology
Keywords:	DERMATOLOGY, Acne < DERMATOLOGY, QUALITATIVE RESEARCH

Identifying acne treatment uncertainties via a James Lind Alliance Priority Setting Partnership

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Key words: acne, priority setting, treatment uncertainty, qualitative research

Word count: 4,887 excluding abstract

ABSTRACT

Objectives: The Acne Priority Setting Partnership (PSP) was set up to identify and rank treatment uncertainties by bringing together people with acne and professionals providing care within and beyond the NHS.

Setting: The UK with international participation.

Participants: Teenagers and adults with acne, parents, partners, nurses, clinicians, pharmacists, private practitioners.

Methods: Treatment uncertainties were collected via separate online harvesting surveys, embedded within the PSP website, for patients and professionals. A wide variety of approaches were used to promote the surveys to stakeholder groups with a particular emphasis on teenagers and young adults. Survey submissions were collated using keywords and verified as uncertainties by appraising existing evidence. The 30 most popular themes were ranked via weighted scores from an online vote. At a priority setting workshop, patients and professionals discussed the 18 highest-scoring questions from the vote and reached consensus on the top ten.

Results: In the harvesting survey, 2,310 people including 652 professionals and 1,456 patients (58% aged 24 y or younger) made submissions containing at least one research question. After checking for relevance and rephrasing, a total of 6,255 questions were collated into themes. Valid votes ranking the 30 most common themes were obtained from 2,807 participants. The top ten uncertainties prioritised at the workshop were largely focused on management strategies, optimum use of common prescription medications and the role of non-drug based interventions. More female than male patients took part in the harvesting surveys and vote. A wider range of uncertainties were provided by patients compared to professionals.

Conclusions: Engaging teenagers and young adults in priority setting is achievable using a variety of promotional methods. The top ten uncertainties reveal an extensive knowledge gap about widely used interventions and the relative merits of drug versus non-drug based treatments in acne management.

Strengths and limitations of this study

- This study has demonstrated that teenagers and young adults can be engaged in priority setting but considerable resources went into promotional activities which were subsequently found to be ineffective.
- To ensure all views were captured, much effort went into collecting responses from a wide spectrum of people with acne and different types of care professional; despite this, males with acne were under-represented.
- The volume of unsorted questions was so large that grouping into broad themes was the only way of generating manageable numbers to take to the prioritisation stages without overwhelming participants.
- Saturation was reached in that no new uncertainties were contained within the final submissions to the harvesting survey.
- Methods were developed for sorting and sharing large volumes of submissions.

INTRODUCTION

During the last decade, the inclusive methods pioneered and validated by the James Lind Alliance (JLA) for treatment related research priority setting have become well established in the UK (www.jla.nihr.ac.uk). JLA PSPs bring together on a level playing field people with a disease and those who treat them, first to identify, and then to prioritise unanswered questions (uncertainties) about existing treatments. Twenty-six PSPs have been completed to date including this and a further three on diseases of the skin.[1-3] Conditions covered include ones primarily affecting the elderly (e.g. dementia and stroke), infants and young children (cleft lip and palate, eczema) or people at any time of life (Lyme disease, asthma). So far, no PSP has targeted a disease with peak prevalence during adolescence in mainly healthy subjects. Although acne is starting earlier [4] and lasting longer, [5-7] possibly as a result of lifestyle changes, peak prevalence is between the ages of 16 and 20 years.[8, 9] The age range of acne now spans five decades; few teenagers in Westernised societies avoid acne in one form or other.[10] For reasons which remain poorly understood, post-adolescent acne is more common in women than men.[5-7] Acne is one of three skin conditions in the top ten most prevalent diseases worldwide in 2010.[11]. However, the most widely used treatments have changed little in the last thirty years. Systematic reviews have consistently shown a paucity of robust evidence from adequately powered randomised controlled trials.[12, 13] When compared with disease burden as estimated by disability-adjusted life years (DALYs) from the Global Burden of Disease 2010 project, acne is under-represented in the Cochrane Database of Systematic Reviews.[14]

Most clinical trials of new and existing therapies in acne have been conducted by the pharmaceutical industry; few independent trials are conducted anywhere in the world. In consequence, key issues of importance to patients and clinicians remain to be adequately investigated and addressed.

The Acne PSP was formally initiated in November 2012. In order to collect a representative range of opinions, we sought to involve not only NHS patients and staff but also the large numbers of people with acne who never present to a doctor. [15-19] Of importance, we considered that a successful priority setting exercise, by highlighting significant evidence gaps, would stimulate new high quality treatment-related research within and beyond the UK.

METHODS

A steering group to oversee the PSP was established in accordance with JLA guidelines and held its first meeting in January 2013. The steering group, which was chaired by a representative of the JLA, consisted of people with acne, healthcare and allied professionals involved in treatment delivery as well as experts in patient and public involvement in research and information management. At the initial meeting, the protocol and terms of reference for the steering group were formally adopted. The protocol was developed with reference to the JLA guidebook with modifications necessitated by targeting a predominantly adolescent population.

Stage 1: Set-up

Organisations which represent people who treat acne in any setting were contacted and invited to become partners. In the UK, there is no longer a patient group representing people with acne. However, we invited VERITY, the support group for women with polycystic ovarian syndrome to become a partner as persistent acne is often a feature of this condition. Organisations which volunteered to help deliver the priority setting exercise were also invited to become partners. Partner organisations were expected to help promote the PSP to their members or to the public and encourage participation in the harvesting survey and vote. They were required to affiliate to the JLA. Our partners are listed in the Acknowledgements section.

As the target population was expected to comprise mainly teenagers and young adults, it was decided that a dedicated website should be used to collect and disseminate information. The website was launched in April 2013 and included background information about the PSP, partners, steering group members, with a brief summary of acne treatments and ways of obtaining them.

In order to better understand what would motivate people to take part in the harvesting survey, an informal meeting was held in February 2013 in Harrogate to which approximately equal numbers of people with acne and healthcare professionals were invited together with two dermatology patients without acne but with marketing experience. Attendees reviewed and changed the publicity flyer and harvesting survey, which had been drafted to closely match the traditional open JLA layout. To make the harvesting survey form more visually attractive and clearer for young people, two versions were produced. The patient version was more structured, including images and specific questions about each treatment type and contained additional questions to capture details about current and past sources of professional help and treatment. The professional version of the survey adhered to a more conventional layout with a limit of five questions per respondent. Publicity materials were simple in design, carried the banner “Join the fight against acne” to reflect the campaigning dimension requested by meeting participants, and included a QR code linking directly to the survey. To increase participation by teenagers and young adults, a small financial incentive was offered to respondents to the patients’ version. This was £25 or local currency equivalent in vouchers for a global online retailer, awarded to 50 people who submitted at least one uncertainty and whose names were selected at random at the close of the survey. No financial incentive to take part was offered to professionals.

Stage 2: Harvesting uncertainties

Both versions of the survey to collect treatment uncertainties were constructed in Survey Monkey™ and embedded into the PSP website. The survey was open between the 22nd May and 31st August 2013. It was kept open longer than the planned eight weeks after analyses of demographic data showed low levels of participation by some target groups.

A variety of both traditional and novel methods were utilized to publicise the survey. Organisational stakeholders were asked to promote the PSP and survey to members via email, via their own web site or in any other way they wished. Posters and flyers were sent to local and specialist centres within the UK. In addition, a national chain of community pharmacies distributed flyers via their branches. A dedicated Twitter account was set up and at least one original tweet per day was issued until the final workshop had been completed. Steering group members were asked to email colleagues and contacts and/or put adverts in local newsletters. Two national health related organisations, Talk Health and Embarrassing Bodies promoted the survey via a variety of mechanisms including their own web sites. A celebrity agreed to endorse the PSP on the home page of the web site and another generated a promotional video. The local National Institute of Health Research network (North East Yorkshire and North Lincolnshire) took the lead in disseminating information to colleagues in other networks including Primary Care Research Networks and also approached local educational establishments and NHS Trusts.

To complement the harvesting survey, a search of research recommendations within recent, relevant and reliable systematic reviews or treatment guidelines was undertaken with a view to including any novel uncertainties within the prioritization exercise.

Stage 3: Processing the uncertainties

The survey generated very many responses so consideration was required of the most efficient mechanism for analysing the data and distributing workload across the project team. Submissions from Survey Monkey were downloaded into Microsoft Excel to facilitate refining and collating uncertainties. Submitted text was often rephrased for clarity and to separate out individual questions.

To maximise flexibility and to enable the data to be sliced in various ways, controlled vocabulary terms were assigned to the uncertainties. First, uncertainties were collated into themes, many of which were necessarily broad (covering aspects such as adverse effects, long term management and skin care). The themes were supplemented with terms relating to relevant intervention categories (e.g. phototherapy, antibiotics, topical therapies). These controlled lists were defined using the clinical expertise within the Steering Group. The key concepts were then indexed by assigning National Library of Medicine Medical Subject Headings (MeSH), commonly used in searching literature, to each of the included uncertainties. Not all concepts were available in the MeSH vocabulary. To identify controlled terms for these omitted concepts the Excel file was loaded into Google Sheets and parsed with the ISA-TAB Ontomaton tool.[20] As a result the medical subject headings were extended to include terms from other vocabularies such as Clinical Terms Version 3 (Read Codes; National Health Service National Coding and Classification Centre).

Most of the data were validated on input to minimise typographical errors and ensure consistency across the subsets of data; the exception being one of the MeSH descriptor fields that enabled the more obscure concepts to be included. There was no limit to the number of key words that could be assigned to any uncertainty. Therefore each uncertainty could be indexed to a high level of detail if needed, facilitating segmentation of the data and enabling similar submissions to be merged.

In order to manage the above process and the distribution of the data across the project team, the datasets were stored in a central online document repository. Initially based on the National Institute for Health Research (NIHR) SharePoint portal the files were later transferred to a dedicated site on the NIHR Hub when the NIHR moved its infrastructure onto the Google platform. The list of uncertainties generated by this process was reviewed at a meeting of the Steering Group to decide which to take forward to the ranking stage.

The group was provided with information on the number of related submissions so that the shortlist was decided largely by popularity of the uncertainty.

As a final check, the International Clinical Trials Registry (http://apps.who.int/trialsearch/) and the Database of Abstracts of Reviews of Effects (DARE) were searched to ensure that no uncertainty was already being addressed by an ongoing clinical study or had been the subject of an existing or planned high quality systematic review.

Stage 4: voting and ranking

Because large numbers of young people were expected to take part in the vote, the number of questions on the shortlist was limited to thirty. Like the harvesting survey, the voting form was constructed in Survey Monkey and embedded in the PSP web site. Each respondent was asked to choose the three questions they felt were most important and rank them. The order of questions on the voting form was random. The vote was open from 22 December 2013 to 10 February 2014. The same methods used to promote the harvesting survey were used to promote the vote.

A weighted ranking system was used to generate scores from the vote; the first choice question scored three points, second choice two points and third choice one point. Summed scores from patients and professionals were calculated separately; summed scores from professionals were adjusted to take account of the lower number who voted so that ranks could be validly compared from both groups. Votes from respondents who identified themselves as researchers or 'other' were excluded. The Steering Group appraised the ranked scores from patients and professionals and selected eighteen uncertainties to take forward to the priority setting workshop based on the highest ranking by both groups.

Stage 5: Priority Setting Workshop

The final stage of the PSP was the workshop. This was held at the London headquarters of the British Association of Dermatologists (BAD) on 04 March 2014. Equal numbers of people with acne and health care professionals working within and outside the NHS were invited to attend. Representatives of partner organisations and Steering Group members not regularly involved in patient care attended as observers. In order to make informed decisions, participants were provided with ranks from the vote and the number of related submissions from the harvesting survey.

Sample size and composition

Sample sizes were available from two previously completed PSPs on eczema and vitiligo; 493 and 461 participants respectively submitted uncertainties to each PSP. Since acne is a more common condition, the protocol for the Acne PSP set an aspiration of 600 respondents for the harvesting survey. Whilst no formal target was set for the vote, numbers and sample composition were closely monitored so that the voting period could be extended if necessary. For both the harvesting survey and the vote, considerable efforts were made to collect responses from representative samples of people with acne and the professionals who care for them. To assist with this, extensive demographic information was collected for the survey and the vote.

Results

Harvesting and collating uncertainties

A total of 4,363 people submitted the harvesting survey form. However, many patients and professionals did so without including a question. A majority of patients and parents who didn't ask a question completed other parts of the survey form whereas healthcare professionals and researchers who didn't include a question left the entire form blank. Usable submissions containing one or more uncertainties were received from 1,636 patients or family members and 652 professionals.   Following rewording and refining, there were 8,276 questions.   After removing those which were out of scope (i.e. relating to diagnosis, pathogenesis, genetic predisposition, new drug development or access to treatment), not answerable by research, already answered or not about acne, a total of 6,255 questions remained.

Few respondents submitted questions about specific interventions; the exception was oral isotretinoin. In consequence, the Steering Group decided, at a special face-to-face meeting, not to generate a long list of specific uncertainties.   In order to produce a manageable short-list for voting, it was agreed to sort questions into broad themes with the specific aim of including as many of the original questions as possible within these.   Rigorous efforts were made to avoid bias by collating questions in different ways and counting the number of questions in each set before the final themes were selected. Additionally, members of the Steering Group were asked to review the tentative groupings and could ask for new themes to be evaluated. An example of a broad uncertainty and illustrative questions included within this theme is given in Supplementary Table 1.

The number of people submitting questions relating to each theme were calculated separately for respondents to each version of the survey and compared. The most common themes are shown in Table 1. Over a quarter of all respondents (27%) and over a third (37%) of respondents to the patient survey asked about the safety and/or efficacy of physical therapies. This was the intervention type about which most questions were asked. Some uncertainties were submitted by similar proportions of patients and professionals, whereas there were marked differences for others.

The 29 most popular themes were taken forward to the vote together with an additional uncertainty about the prevention and management of post-inflammatory pigmentation, which was identified by many people with acne in pigmented skin. Together, the top 30 themes encompassed more than 87% of the submitted questions. The question "What are the best ways to support self-management of acne?" was constructed to reflect the large number of submissions, impossible to count accurately using keywords, which reflected people's struggles to manage their acne without professional help. Popularity of a theme in the harvesting survey did not predict popularity in the vote or ranking in the top ten (see below).

Table 1. Uncertainties identified by 200 or more respondents to the harvesting survey.

		Number (%) of related submissions from			In final top ten
		Patients/family members	Professionals	All respondents	
1	Which physical therapies including lasers and other light based treatments are safe and effective in treating acne?	573 (35)	34 (5)	607 (27)	YES
2	Are cosmetic remedies for spot prone skin as effective as they claim to be?	439 (27)	8 (1)	447 (20)	NO
3	Which complementary and alternative therapies are safe and effective in treating acne?	356 (22)	7 (1)	363 (16)	NO
4	What is the best treatment for acne scars?	324 (20)	32 (5)	356 (16)	YES
5	What is the best topical product for treating acne?	266 (16)	55 (8)	321 (14)	YES
6	What is the correct way to use antibiotics in acne to achieve the best outcomes with least risk?	159 (10)	121 (19)	285 (12)	YES
7	What dietary advice should be given to people with acne?	255 (16)	14 (2)	269 (12)	YES (merged with 9)
8	What should a consultation for acne involve?	169 (10)	63 (10)	236 (10)	NO
9	Which lifestyle factors influence acne severity the most?	203 (12)	31 (5)	234 (10)	YES (merged with 7)
10	What is the correct way to use oral isotretinoin in acne in order to achieve the best outcomes with least risk?	105 (6)	125 (19)	230 (10)	YES
11	What is the best skin care routine for people with acne?	186 (11)	21 (3)	209 (9)	NO
12	Does diet affect who gets acne or how severe it is?	150 (9)	54 (8)	204 (9)	NO

Characteristics of survey respondents

Extensive demographic information was collected to determine whether a representative sample had been obtained. Interim analyses showed that women were over-represented in the patient sample. Keeping the survey open longer and specifically targeting men via Twitter did not improve participation by males with acne. At the close, the professional sample comprised 64.2% women (Supplementary Table 2), and the patient/family member sample comprised 83.1% women (Supplementary Table 3). Amongst the professionals, most submissions came from doctors, nurses and pharmacists working in primary or secondary care or in the community, but treatment providers working outside the NHS were also represented (Supplementary Table 2). Among respondents to the patient version were 1,125 individuals with acne at the time of completing the survey, 331 who had acne in the past as well as 132 family members. The age range was as expected; 40% of respondents to the patient version were aged 16 to 24 (Supplementary Table 3). The patient sample was predominantly white (80% versus 87% for the UK in 2011 census) but a good spread of minority ethnic groups was represented. Almost a quarter of the patient sample (23%) lived outside the UK compared with 15% of the professional sample. Within the UK, all but five postcodes were represented in the sample of patients and family members with a large number of responses (33%), as might be expected, from Yorkshire where the PSP management team and the local NIHR research network were based. A majority of professionals (73%) did not disclose their postcodes.

People who had acne at the time that they completed the survey were asked provide information about sources of professional help to ensure that the sample composition included individuals seeking advice and/or treatment from a variety of sources and not just within the NHS. Forty-one percent were not getting any professional help although 88% had sought help in the past (Table 2). The most common source of help was a general practitioner. Interestingly, 26% of respondents had seen a beauty therapist in the past and 34% had sought the advice of a pharmacist. Other sources of professional help not shown in Table 2 included paediatricians, gynaecologists, nurses, health counsellors and the British Association of Skin Camouflage. A minority of respondents said they obtained help from family and friends, the internet and/or social media such as You Tube (an online video sharing website), or became their own expert.

Table 2. Sources of professional help used by respondents (n = 1,125) who had acne when they completed the harvesting survey.

	Number (%)[1]	
Source of help	**In the past**	**When survey completed**
Pharmacist	381 (34)	78 (7)
GP/family doctor	721 (65)	306 (28)
Dermatologist	503 (45)	249 (23)
Complementary or alternative therapist	94 (8)	27 (2)
Beauty therapist	283 (26)	62 (6)
Private practitioner	62 (6)	22 (2)
Not sought any help in the past	138 (12)	n/a
Not getting any help now	n/a	448 (41)
Not disclosed	5 (0.5)	75 (7)
Other	68 (6)	7 (0.6)

[1] Percent of respondents. Total exceeds the number of respondents as many individuals selected more than one option.

The most common source of acne treatment was from a pharmacy with a prescription (Supplementary Table 4). At the time of completing the survey, 40% of people with acne were not using any treatment but 82% had used treatment in the past.

How people heard about the harvesting survey

Respondents were asked to identify how they heard about the survey and the answers are shown in Table 3. The commonest mechanism identified by both patients and professionals was email. Amongst professionals, many (21%) heard about the survey from a colleague. Many patients and family members had heard about the survey via social media (notably Facebook and YouTube) with many specifically mentioning a celebrity video. Methods with negligible impact were the Acne PSP website, Twitter account and the printed word. Three times as many patients heard about the survey from the Embarrassing Bodies or Talk Health web sites than from the PSP's site. There was some evidence of propagation with several people mentioning organisations we had not directly targeted.

Table 3. How respondents heard about the harvesting survey

Mechanism	Number (%)[1]	
	Patient version	Professional version
email	294 (18)	249 (38)
You Tube video	280 (17)	1 (0.2)
Facebook or other networking site	238 (15)	1 (0.2)
Acne PSP web site	55 (3)	n/a
Website of a professional organisation	n/a	79 (12)
Other web site	160 (10)	11 (2)
From a friend or relative	104 (6)	12 (2)
From a doctor/other treatment provider	112 (7)	n/a
From a colleague	n/a	136 (21)
Poster/leaflet	86 (5)	16 (2)
Newsletter	71 (4)	10 (2)

Mechanism	**Number (%)[1]**	
	Patient version	**Professional version**
Word of mouth	79 (5)	21 (3)
Twitter	76 (5)	14 (2)
Advert in newspaper or magazine	20 (1)	2 (0.3)
Via a network	6 (0.4)	66 (10)
LinkedIn or other professional networking site	2 (0.1)	60 (9)
Other	66 (4)	16 (2)
Not disclosed	26 (2)	2 (0.3)

n/a = not applicable. [1] Percent of respondents. Total exceeds the number of respondents as some individuals selected more than one option.

Ranking exercise

A total of 3,084 people took part in the online vote. Of these, 277 votes were excluded because the respondent identified themselves as a researcher or 'other'. Valid votes were received from 1,573 people with acne, 237 family members and 1,012 professionals. Again males were under-represented; only 25% of patient voters were male compared to 35% of professionals. A demographic analysis of votes is shown in Table 4; 44% of voters were aged between 16 and 34 years. A large majority of voters (85%) lived in the UK and 81% were white. More than half of patient voters lived in Yorkshire (53.6%). This time, 78% of professionals provided a postcode; of these 21% practiced in Yorkshire. All but seven postcodes were represented in the patient sample and all but 15 in the professional sample. Google Analytics™ showed that most people landed directly on the voting survey without visiting other pages before leaving the PSP web site.

For several uncertainties, there were marked differences in weighted ranks between patients and professionals (Figure 2). For others there was good agreement, especially among the less popular questions. Popular uncertainties with the biggest differences in weighted scores (patients vs professionals) were about use of oral isotretinoin (191 vs 693), ways of preventing acne (1006 vs 461) and the use of antibiotics (282 vs 972).

Table 4. Demographic analysis of the vote.

	Number (% within group)			
	Health Care Professionals	**People with acne***	**Parents, guardians or partners**	**All groups**
n	1012	1573	237	2822
Gender				
Male	356 (35)	400 (25)	58 (24)	814 (29)
Female	647 (64)	1157 (74)	175 (74)	1979 (70)
Not disclosed	9 (0.9)	16 (1)	4 (2)	29 (1)
Age range				
≤15 years	0	72 (5)	1 (0.4)	73 (3)
16 – 24 y	34 (3)	633 (40)	11 (5)	678 (24)
25 – 34 y	164 (16)	443 (28)	7 (3)	614 (22)
35 – 44 y	258 (25)	229 (15)	37 (16)	524 (19)
45 – 54 y	307 (30)	128 (8)	122 (52)	557 (20)
55 – 64 y	198 (20)	51 (3)	42 (18)	291 (10)
65 y and over	39 (4)	16 (1)	11 (5)	66 (2)
Not disclosed	12 (1)	1 (0.1)	6 (3)	19 (0.7)
Location				
UK	846 (84)	1337 (85)	221 (93)	2404 (85)
Overseas	166 (16)	236 (15)	16 (7)	418 (15)
Ethnicity				
Asian Bangladeshi	1	9	0	10
Asian Chinese	16	11	1	28
Asian Indian	58	54	5	117
Asian Pakistani	19	61	16	96
Black African	10	16	2	28
Black Caribbean	7	14	1	22
Hispanic	9	24	2	35
Mixed race	14	53	1	68
White	817 (81)	1268 (81)	204 (86)	2289 (81)
Other	39	40	2	81
Not disclosed	22	23	3	48

* 1162 individuals had acne when they voted; 411 had acne in the past.

The Steering Group used ranked weighted scores to decide which uncertainties to take forward to the final workshop. The distribution of scores

(Figure 1) showed a long tail and, with one exception, uncertainties in the tail were not taken forward. The exception was the uncertainty about the best way to use oral isotretinoin, which ranked fifth amongst professionals but nineteenth amongst patients and family members. This meant a total of eighteen uncertainties were considered at the final workshop.

Final priority setting workshop

A total of 43 people including 13 patients, 12 professionals and 13 observers attended the final workshop. In the first session, three groups comprising equal numbers of patients, professionals and non-participatory observers, each with an independent moderator, were asked to prioritise all 18 uncertainties using a nominal group technique. The results were collated and discussed in one combined afternoon session, moderated by the chairman of the steering group. The final top ten is shown in Box 1. Seven uncertainties were ranked in the top ten without alteration. There were three instances in which two related questions were merged; all three merged questions were also ranked in the top ten. The top ten was announced the following day via the Acne PSP website, Twitter and several partner web sites. Subsequently, thank you postcards promoting the top ten have been disseminated in Harrogate dermatology clinics, at European and Global Alliance acne meetings and through a meeting supported by the British Association of Dermatology. Given the number of more specific questions, work is still ongoing to optimise methods of disseminating these to patients and professionals. In due course, all verified uncertainties will be entered into the UK Database of Uncertainties about the Effects of Treatment (www.library.nhs.uk/duets/).

Box 1. The top ten research priorities for the treatment of acne.

1. What management strategy should be adopted for the treatment of acne in order to optimise short and long-term outcomes?
2. What is the correct way to use antibiotics in acne to achieve the best outcomes with least risk?
3. What is the best treatment for acne scars?
4. What is the best way of preventing acne?
5. What is the correct way to use oral isotretinoin (Roaccutane) in acne in order to achieve the best outcomes with least risk of potentially serious adverse effects?
6. Which lifestyle factors affect acne susceptibility or acne severity the most and could diet be one of them?
7. What is the best way of managing acne in mature women who may/may not have underlying hormonal abnormalities?
8. What is the best topical product for treating acne?
9. Which physical therapies including lasers and other light based treatments are safe and effective in treating acne?
10. How long do acne treatments take to work and which ones are fastest acting?

Discussion

The top ten acne research priorities, reached by consensus between patients and professionals, reveal concern about the paucity of evidence on the relative efficacy and safety of commonly used treatments and their place in both short and long-term management. This evidence gap may reflect the low number of robust, industry-independent trials of acne therapies but also that efficacy within RCTs does not reliably predict effectiveness or patient satisfaction in the real world. In the last five years, no published acne RCTs have been conducted in whole or in part within the UK. Within the Cochrane library, there are only two published Cochrane reviews wholly dedicated to acne therapies although there are six ongoing Cochrane reviews that will provide new insights into some of the uncertainties in the top ten, specifically the efficacy and/or safety of oral isotretinoin, light therapies and topical treatments. Identifying the top ten priorities of patients and healthcare professionals highlights the need for more pragmatic trials which put widely used interventions head-to-head and also more focused research to identify the safest and most effective alternatives to drug based therapies. Whilst awareness of these alternatives among patient responders was high, so was scepticism about paying for such treatments from unregulated practitioners outside the NHS. Several uncertainties which were very frequently identified by respondents to the harvesting survey, including two of the three most asked about intervention types (complementary and alternative medicines [CAM], cosmetic remedies), did not make it into the top ten. Although there was clearly a lot of interest in them amongst people with acne, they did not rank in most voters' top three when presented alongside the other shortlisted questions.

Among submissions to the harvesting survey, we received many treatment related questions not answerable by research and so not included in the prioritisation exercise. They asked about such things as availability of non-drug based treatments within the NHS and how to identify reliable sources of advice about their safety and efficacy. There were also many questions about affordability and accessibility of treatments not provided by the NHS. These questions reflected valid concerns among people with acne and should be addressed by information providers, policymakers and regulatory bodies.

Almost half the people who submitted the harvesting survey did not include a question, although most patients and parents did provide demographic information and contact details. This may reflect the offer of a small financial inducement even though the survey form clearly specified that inclusion in the prize draw was dependent on submitting at least one question. Feedback from local patients indicated that they were definitely interested in the survey (sufficient to want to open it) and curious about its content. The issue was that they had nothing specific they wanted to ask or did not know how to frame a research question. It remains unclear why 302 professionals and 30 researchers did not submit a question.

At the time the Acne PSP was set-up, the JLA process of priority setting through partnership and consensus had already become established. Several PSPs have revised the basic procedures laid down in the JLA guidebook and adopted new strategies to overcome difficulties associated with specific diseases or hard-to-reach groups. For example, the stroke PSP devised a new model for assisted participation and targeted engagement of stroke survivors with communication difficulties.[21] No previous priority setting exercise has been completed for a very common condition that primarily affects teenagers and young adults. We recognised that they might be hard to engage and motivate in an exercise such as this. There are at least three million people with acne in the UK at any one time. A sample of 0.05% would represent a minimum of 1,500 people. Whilst this sounds easily achievable, in the end it was extremely challenging. A huge amount of work by large numbers of people went on behind the scenes to achieve this. Initial discussions with young people suggested that it would be necessary to break with JLA tradition in several ways: a very different layout for the harvesting survey, the use of a small financial inducement and emphasis on the use of social media to promote participation. Whether due to the layout of the harvesting survey or not, we obtained a much broader range of uncertainties from patients than professionals, almost certainly as a consequence of reminding people what treatments are available. Perhaps as a result of opening people's eyes to treatments they were not aware of, we also received many questions from patients about therapies not available within the NHS, most commonly physical treatments as well as CAM. In contrast, two types of drug treatment dominated questions from professionals, antibiotics and oral isotretinoin. Among numerous questions relating to the conduct of a consultation for acne, many asked about doctors' reluctance to engage in conversations about alternatives to commonly used drug-based therapies.

Feedback from respondents showed that some promotional activities were much more successful than others and this information may be of use to those conducting PSPs in future. It was almost certainly not necessary to have a dedicated PSP website or Twitter account and leafleting via a national chain of pharmacies was not as successful as we had hoped. The role of partner organisations was vital in publicising the PSP and encouraging participation. With such a prevalent condition, we felt it was necessary to demonstrate that respondents to the harvesting survey and vote were representative of all people with acne and all professionals who offer care. The demographic information we collected showed a pronounced local concentration of survey respondents in Yorkshire, where both the PSP management team and local NIHR network, which helped to promote the survey, are based. Whilst the effort: reward ratio in terms of respondent numbers to hours spent on promoting the survey might be low, it guaranteed that we achieved a representative sample in terms of age, location and ethnic mix. With patient gender, we were not so successful. Ours is not the first or only PSP to find that only a minority of respondents were male [3, 22, 23] although many PSPs do not report the gender of participants. It is perhaps particularly surprising for acne, as there are fewer treatment options for men. The smaller gender bias among healthcare professionals is not of concern as it simply reflects the 60:40 ratio of females to males within dermatology, pharmacy and general practice in the UK. Weighted ranks show that uncertainties voted for by men and women were broadly similar with the exception of a question about managing acne in mature women (data not shown). This suggests that gender bias in the sample may not have affected the findings of the PSP to a significant extent. However, we perhaps could have made greater attempts to target males, for example, via sports clubs, magazines, men's lifestyle websites or schools for boys.

Because of the large number of questions submitted, our approach, like several PSPs before us, was to merge very specific questions on related themes into broad questions that could be voted on. Any PSP has to balance the sample size required to reach saturation (i.e. few or no new uncertainties identified by increasing participation) with the practicalities of processing the large volumes of data generated. The novel use of key words based on MesH descriptors in this PSP was essential to facilitate sorting and grouping. Following the PSP, preliminary discussions have been held with NETSCC about translating the top ten uncertainties into researchable questions which faithfully represent the original submissions. A forthcoming challenge is to capture and disseminate, via UK DUETs and other mechanisms, the insightful more detailed questions which have been lost as a result of merging.

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Contributors All authors made substantive contributions to the conduct of the PSP including promoting the survey and vote to patients and colleagues as well as the collection, analysis and/or interpretation of data. The manuscript was drafted by AE and HW. All authors except HW were members of the Steering Group and all including HW were involved in review and revision and approved the final version. The project was managed by AE and AL with administrative support from Elizabeth Oldham.

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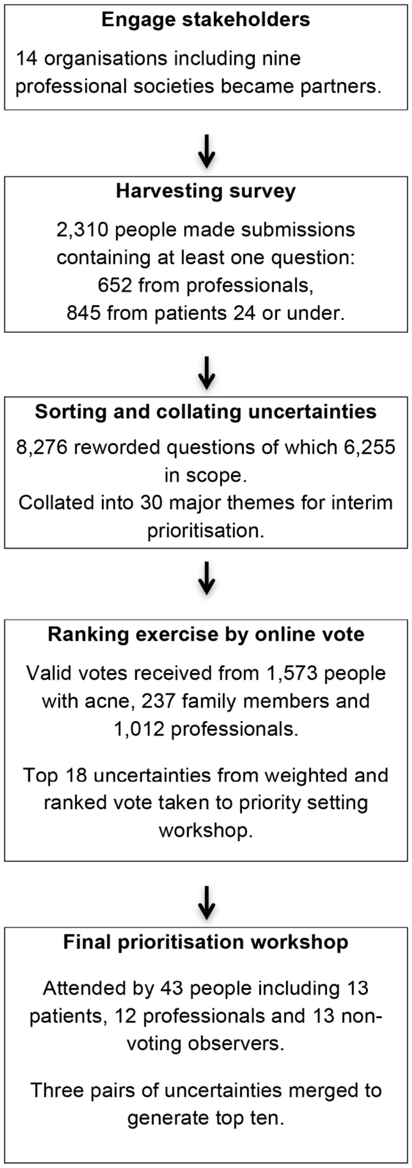
Ethical and NHS Governance approval Ethical approval was obtained from West of Scotland REC4 (reference number 13/WS/0015). NHS governance approval was obtained from Harrogate and District NHS Foundation Trust. Both were required in order to embed a research question about outcomes important to patients within the harvesting survey. The findings from that will be published separately.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The anonymised list of unsorted questions will be made available via Dryad. The full list of verified uncertainties will be available in due course from UK DUETS.



Engage stakeholders

14 organisations including nine professional societies became partners.

Harvesting survey

2,310 people made submissions containing at least one question:
652 from professionals,
845 from patients 24 or under.

Sorting and collating uncertainties

8,276 reworded questions of which 6,255 in scope.
Collated into 30 major themes for interim prioritisation.

Ranking exercise by online vote

Valid votes received from 1,573 people with acne, 237 family members and 1,012 professionals.

Top 18 uncertainties from weighted and ranked vote taken to priority setting workshop.

Final prioritisation workshop

Attended by 43 people including 13 patients, 12 professionals and 13 non-voting observers.

Three pairs of uncertainties merged to generate top ten.

Flow diagram showing the number of participants and submissions at each stage.

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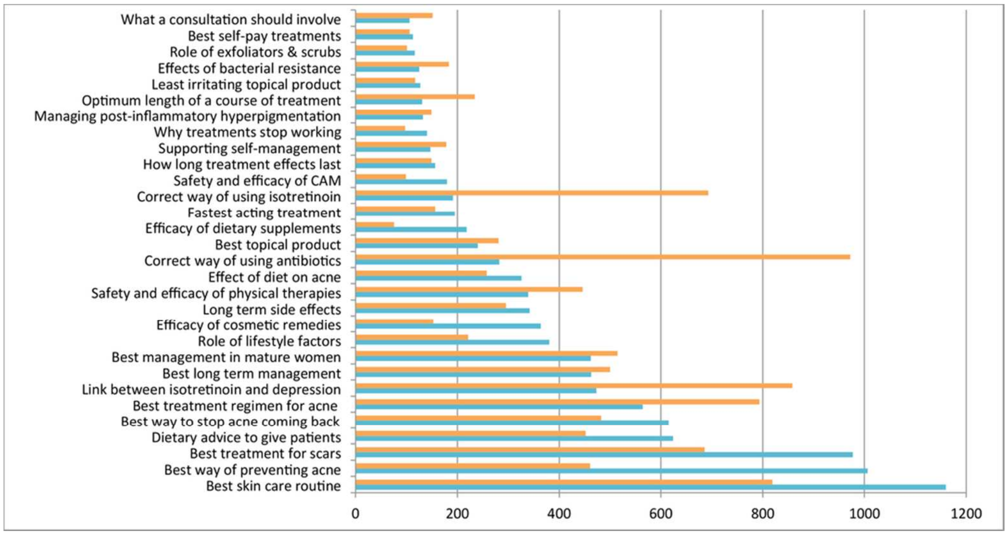

Comparison of summed weighted scores from people with acne versus care professionals.

Summed weighted scores from patients, partners and other family members are shown in blue; summed weighted scores from professionals are shown in orange.

91x48mm (300 x 300 DPI)

Supplementary Table 1: Example of an uncertainty based on a broad theme and illustrative specific questions included within it.

Verified Uncertainty
What is the best skin care routine for people with acne?
Questions included within this uncertainty[1]
Is there any evidence that how often you wash your skin and what products you use to do so have any effect on acne severity?
What should we tell patients about frequency of cleansing and what moisturisers should we recommend?
Does cleansing regime make any difference to acne?
Is it best to use a cleanser before applying the spot cream or just use warm water?
Do scrubs help all acne types or do they just irritate the skin further causing it to break out?
Which facial washes are good to use to get rid of back acne and face acne?
Is it bad to use multiple types of products at the same time such as cleansers and scrubs?
Is there any basis to the necessity of the cleanse-tone-moisturize ritual, or does that differ from person to person?
What are good ingredients a scrub/cleanser should contain to help my acne improve?
If you cleanse too much does it make acne worse?
Are expensive spot-specific face washes more effective than regular soap & water?
What are the best products to recommend patients use to wash with e.g. soap, medicated cleansers, face wipes, etc?
Can good skincare from an early age help to prevent the onset of acne?
Do I need to use any other skin care products with my prescriptions?

[1] These are examples only and not an exhaustive list.

Supplementary Table 2. Demographic information for professional respondents.

		Number
	Total respondents	652
Gender	Female	393
	Male	219
	Not disclosed	40
Location	UK	519
	Overseas	96
	Not disclosed	37
Professional group	Pharmacist	137
	GP	139
	Dermatologist	214
	Other physician in secondary care	15
	Cosmetic surgeon/clinical cosmetologist	5
	Nurse	70
	CAM practitioner	4
	Beauty therapist/aesthetician	36
	Private practitioner	25
	Research scientist	20
	Student (pharmacy or medical)	4
	Dietitian	2
	Counsellor/psychologist	2
	Camouflage practitioner	1
	Other	4
	Not disclosed	6

Supplementary Table 3. Demographic information for respondents to the patient version of the harvesting survey

		Number
	Total respondents	1638
Gender	Female	1344
	Male	272
	Not disclosed	22
Age range	15 y and under	161
	16 – 24 y	684
	25 – 34 y	386
	35 – 44 y	169
	45 – 54 y	146
	55 – 64 y	69
	65 y and over	10
	Not disclosed	13
Ethnicity	Asian Bangladeshi	8
	Asian Chinese	28
	Asian Indian	50
	Asian Pakistani	29
	Black African	40
	Black Caribbean	14
	Hispanic	40
	Mixed race	67
	White	1293
	Other	45
	Not disclosed	24
Location	UK	1260
	Overseas	378
Group	Had acne when completed survey	1125
	Had acne in the past	331
	Parent/guardian or partner	132
	Other	50

Supplementary Table 4. Sources of acne treatment used by respondents who had acne when they completed the harvesting survey.

Source of treatment	Number (%)	
	In the past	When survey completed
From a pharmacy with a prescription	726 (66)	401 (37)
Over-the-counter from a pharmacy without a prescription (something you have to ask for)	359 (33)	86 (8)
From the open shelves in a pharmacy or supermarket	492 (45)	186 (17)
In/from a hospital	127 (12)	46 (4)
From the internet	166 (15)	74 (7)
From a health food shop	142 (13)	33 (3)
From a complementary therapist/alternative practitioner	77 (7)	10 (0.9)
From a private clinic	80 (7)	24 (2)
From a beauty therapist	158 (14)	40 (4)
Not disclosed	2 (0.2)	4 (0.4)
Other	8 (0.7)	9 (0.8)
Number on treatment	903 (82)	650 (59)
Number off treatment	189 (17)	443 (40)
Not disclosed	3 (0.3)	5 (0.5)
Total number of respondents	1095	1098