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Acne Research

Are We Answering the Right Questions?

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ABSTRACT: Acne is one of the most common dermatological conditions affecting millions of people worldwide. Although often considered a disease of young people, it is increasingly seen in adults, especially adult women. Acne can cause significant physical and psychological suffering, and yet, there is relatively little research into causes and treatments. Increasing importance is being attached to patient and public involvement in healthcare, and this imperative includes providing the opportunity to contribute to the research agenda. This article explains a process in which patients, the public, and healthcare professionals are working collaboratively to identify research priorities in the field of acne.

Key words: Acne, Patient Involvement, Priority Setting, Treatment Uncertainty

PREVALENCE AND IMPACT OF ACNE

Acne vulgaris is a chronic inflammatory disease of pilosebaceous follicles with onset in late childhood/early adolescence. Its major etiological features are end organ hypersensitivity to androgens, hyperproliferation, and abnormal differentiation of follicular keratinocytes and T-cell-driven inflammation. In both genders, rising levels of the androgen, dehydroepiandrosterone sulfate, in the blood during adrenarche trigger the onset of sebum secretion by the large sebaceous glands, which are attached to tiny specialized hair follicles located predominantly on the face and upper trunk (Zouboulis, 2004). Sebum fuels acne via mechanisms that remain poorly understood but result in the formation of microcomedones (comprising sheets of dead skin cells and sebum), which are not visible on the skin surface (Cunliffe, Holland, & Jeremy, 2004). Microcomedones act as the precursors of all other types of lesions, including open and closed comedones (blackheads and whiteheads), papules, and pustules. The resident skin bacterium, *Propionibacterium acnes*, which is harmless in healthy follicles, drives inflammation when trapped inside follicles that are functionally blocked by comedones (Eady & Cove, 2000).

Acne is one of the four most common skin diseases; one estimate is that it affects around 652,000,000 people globally (Vos et al., 2012). Although generally considered to be a disease of adolescence and early adulthood, there is increasing evidence of its persisting into, or appearing in, adulthood (Williams & Layton, 2006). Obtaining accurate prevalence data is difficult for a number of reasons. Both prevalence and presentation of acne differ across races and ethnicities (Perkins et al., 2011). In most developed societies, the availability of effective treatments impacts prevalence to a significant extent (Stathakis, Kilkenny, & Marks, 1997), and many different techniques have been used to measure acne. Methods include semiquantitative and quantitative estimates of the number and type of lesions and adoption of recognized grading systems as well as self-assessment and reporting (Ghodsi, Orawa, & Zouboulis, 2009; Kilkenny, Merlin, Plunkett, & Marks, 1998; Perkins, Cheng, Hildebrand, Miyamoto, & Kimbrall, 2011; Shen et al., 2012; Tasoula et al., 2012). Regardless of the accuracy of prevalence data, many people have acne and that this can cause significant distress is clear.

The literature shows that acne has a detrimental psychological effect on individuals regardless of age, gender, ethnicity, or professionally assessed severity. The ramifications of acne are varied and often include loss of self-confidence/self-esteem (Dunn, O'Neill, & Feldman, 2011; Ritvo, Del Ross, Stillman, & La Riche, 2011); negative body image (relationship difficulties; Hassan, Grogan, Clark-Carter, Richards, & Yates, 2009; Murray & Rhodes, 2005; Ritvo et al., 2011); anxiety (Saitta et al., 2011), and

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The authors declare no conflicts of interest.

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DOI: 10.1097/JDN.0000000000000033

feelings of failure to meet the media portrayal of perfect, flawless skin (Magin, Heading, Adams, & Pond, 2011). Other people's negative reactions trigger or reinforce these negative self-perceptions (Ritvo et al., 2011; Timms, 2013). Given the impact that acne has on individuals, it is particularly important to involve them in planning the research agenda for this condition.

PROCESS OF IDENTIFYING RESEARCH PRIORITIES

In the United Kingdom, it is now widely acknowledged that patients and lay people should have the opportunity to influence the healthcare research agenda. Patient and public involvement can lead to better quality, greater relevance, clearer outcomes, and faster uptake of new evidence by healthcare organizations and the professionals who work within them. The James Lind Alliance (JLA, www.jla.nihr.ac.uk) is a non-profit-making organization established in 2004 to facilitate patients, carers, and clinicians working together to identify and prioritize the top 10 "unanswered questions" about specific heath conditions, which they agree are the most important for research. In April 2013, the JLA became part of the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre, which is a large, multifaceted, and nationally distributed organization with the mission of supporting leading edge research focused on the needs of patients and the public; however, the principles of the JLA remain unchanged. Each group working with the JLA is known as a priority setting partnership (PSP) and agrees to adhere to the procedures laid down in the JLA guidebook.

The Acne PSP consists of people with acne, lay people, healthcare professionals, and people with specific skills such as digital technology expertise. The partnership is funded by the United Kingdom Dermatology Clinical Trials Network and the Society for Academic Primary Care and coordinated by the Department of Dermatology at Harrogate and District NHS Foundation Trust, United Kingdom.

The Acne PSP will work through a series of well-validated steps to gather information from as many people as possible representing all demographics and including people with acne, lay people, clinicians, and allied health professionals.

Step 1: Recruitment of Partner Organizations

We have identified a number of partner organizations that support the aims and objectives of the acne PSP and are able to facilitate its work through promotion of its activities and motivation to participate. A key contact person has been identified in each organization.

Step 2: Survey 1, Identification of Treatment Uncertainties

We have developed two online surveys, one for people with acne and lay people and one for professionals. A panel of patients and healthcare professionals gave robust feedback on the survey design leading to extensive changes before publication. The surveys are worded slightly differently, and both require some demographic detail but more importantly ask participants to identify the research questions that they think are most important to answer. The survey surveys were built in SurveyMonkey and made available via the Acne PSP web site. As acne predominantly affects younger people, particular attention was given to reaching them via social media such as Facebook and Twitter. The survey will be live for at least 8 weeks depending on the response rate and the need to chase underrepresented groups; we are aiming for a minimum of 600 responses but hope to achieve many more.

Step 3: Collating, Refining, and Verifying Uncertainties

All survey responses will be sorted and refined to produce a list of "raw" unanswered questions (indicative uncertainties). A hierarchical taxonomy will be used for this. Any questions that have already been adequately addressed by previous research will be excluded at this stage. This process will be overseen by a representative of the United Kingdom Database of Uncertainties about the Effects of Treatments (UK DUETS, www.library.nhs.uk/duets/) to ensure accountability and transparency as well as to check that the methods adopted are fit for purpose.

Step 4: Survey 2, Ranking Exercise

Step 3 will result in a long list of potential research questions (uncertainties), which will be reduced to a short list of around 30 by the Steering Group. Participants from survey 1 who give their contact details will be invited to take part in the ranking exercise via the advertising mechanisms used for survey 1. Participants will be invited to rank three uncertainties from the short list. The responses obtained will be used to decide which 20 questions to take forward to the priority setting workshop.

Step 5: Priority Setting Workshop

The culmination of the exercise is the final priority setting workshop, which will again involve people with acne, lay people, clinicians, and allied health professionals. It is essential that the Steering Group can confidently defend the shortlist and the process by which it was derived. The format of the workshop will be rigorous but flexible. The process will be facilitated by the JLA to ensure everyone's opinion is taken into account with the aim of reaching consensus through discussion and fair debate. If necessary, the priorities of different categories of participants will be listed separately, but a top 10 agreed by all is the preferred outcome.

Step 6: Translation Workshop(s) to Develop Research Questions

One or more translation workshops will be convened involving people who have contributed to the process; so far, a maximum of 40 people will be involved. In four subgroups chaired by a facilitator, participants will be invited to generating research questions in PICO (patient population, intervention, comparator, outcomes) to ensure each one includes the basic elements required to inform future clinical research studies.

Step 7: Dissemination

All verified uncertainties will be entered into the UK DUETS where they are publicly accessible. The acne top 10 will be disseminated widely using a variety of mechanisms including publication in a peer-reviewed journal, reporting on the JLA and Acne PSP websites, use of social media, and distribution of traditional hard copy summaries.

A successful priority setting exercise should raise public and professional awareness of the most important unanswered questions about acne treatment as well as bring them to the attention of researchers and those organizations that fund their work. It will also have initiated a process in which people with acne are empowered to influence the research agenda. It is hoped that the Acne PSP will ultimately be viewed as the first of many partnership between patients, clinical staff, and researchers, which inform and support individual projects as well as provide long-term oversight of research strategy. Further information about the Acne PSP is available at www.acnepsp.org. ■

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