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REVIEW ARTICLE

Patient and Public Involvement in Dermatology Research: A Review

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Abstract
Patient and public involvement (PPI) in research is defined as research being carried out 'with' or 'by' members of the public, patients, and carers, on both an individual and a group level, rather than simply 'about', or 'for' them. Within dermatology, PPI is increasingly recognised as a vital component of research as it helps to ensure that research remains relevant to the populations we intend to serve. Dermatology scholarship, with its rich psychosocial implications due to the stigma, physical disability, and mental health burdens these conditions may incur, is in a unique position to benefit from PPI to unlock previously inaccessible patient lived experiences or therapeutic consequences. Throughout the rapid growth of PPI, it has been infused throughout the research lifecycle, from design to dissemination and beyond. After first explaining the principles of PPI, we examine the existing evidence base at each research stage to explore whether our specialty has effectively harnessed this approach and to identify any subsequent impact of PPI. Finally, we scrutinise the challenges faced by those implementing PPI in dermatology research.

Key Points

Within dermatology, patient and public involvement (PPI) is increasingly recognised as a vital component of research as it helps to ensure that research remains relevant to the populations we intend to serve.

PPI may be infused throughout the research lifecycle, from design to dissemination and beyond. It is essential to understand the potential for PPI at each research stage to appreciate the wider impact upon our scholarship.

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1 Introduction

Patient and public involvement (commonly referred to as PPI or as PPIE when including 'engagement') in research is defined as research being carried out 'with' or 'by' members of the public, patients, and carers, on both an individual and a group level, rather than simply 'about', or 'for' them [1]. This moral idea that patients should have meaningful influence on interventional research can be argued from the societal perspective of collective responsibility as well as from the ethical principle of autonomy of the individual. The

seeds of PPI were planted in the mid twentieth century [2] and are grown upon the principles that previously untouchable expert researchers warrant scrutiny and that 'lay' input can harness valuable insights, inform debate, and help tackle inequalities associated with underrepresentation [3]. From early patient advocacy during the AIDS crisis [4] leading to meaningful collaboration with the European Medicines Agency to the proactive development of the SECURE-AD patient survey in exploring the impact of the COVID-19 pandemic on those living with atopic dermatitis [5], the field of PPI has transformed in a matter of decades.

Within dermatology, PPI is increasingly recognised as a vital component of research as it helps to ensure that research remains relevant to the populations we intend to serve. This is particularly pertinent for clinical research, but meeting the needs of our patients should be our goal for research from bench to bedside. Dermatology scholarship, with its rich psychosocial implications due to the stigma, physical disability, and mental health burdens commonly involved in these conditions [6], is in a unique position to benefit from PPI to unlock previously inaccessible patient lived experiences or therapeutic consequences. Throughout its rapid growth, PPI has been infused throughout the research lifecycle, from design to dissemination and beyond. Therefore, in this review, we first explain the principles of PPI, then examine the existing evidence base at each research stage to explore whether our specialty has effectively harnessed this approach and to identify any subsequent impact of PPI. Finally, we scrutinise the challenges faced by those implementing PPI in dermatology research.

2 Patient and Public Involvement (PPI) and Its Applications

Three central schools of thought drive PPI. The first argument is that patients have a right to contribute towards research on their condition, and researchers have a moral obligation to reduce any power imbalances that may negatively impact upon research and its therapeutic consequences. This hierarchical shift has taken place as just one small piece of a wider cultural transition from traditional paternalistic principles to more patient-centred care [7–11]. In this context, PPI follows similar principles to 'participatory research' by addressing local needs, priorities, and perspectives. Indeed, the terms have at times been used interchangeably. Second, PPI has been reported to increase the transparency and accountability of research and may be an effective means of attracting resources to support further work [11]. The third and final premise is that the lived experience of patients offers vital alternative perspectives from that of the research team. Such views challenge the historical assumption that the physician knows best and have been furthered in recent decades following clinical scandals and identification of inequalities within research [12].

Since its origins, PPI has been embraced globally, with specific innovation across the UK, USA, and Canada. In these nations, PPI has been openly described as a high priority within academia and is supported by numerous organisations of influence. These include the Patient-Centred Outcomes Research Institute in the USA, INVOLVE in the UK, and Strategy for Patient-Oriented Research in Canada [13–15]. Such groups have developed structured frameworks, tools, guidelines, and values to assess the quality of involvement, break down barriers to patient input, and ultimately strive to promote a stronger research culture [16–18].

Benefits from PPI may be shared by patients. A King's Fund report identified that patients felt empowered by and confident in research that involved PPI, in addition to developing practical skills and gaining a sense of fulfilment from carrying out a service [17]. PPI may provide opportunities for expressing agency and reconfiguration of the self and identity [19]. From the researcher perspective, PPI has been linked reduced research waste, with patient input via co-applicancy, project management, or as co-researchers associated with increased recognition of wasteful research practices, thereby adding value for money and improving research quality [20]. Practical guidance on patient engagement and embedding patient ambassador groups within research at local health trusts has been established [21].

In the UK, INVOLVE helped to pioneer PPI, and this approach was further harnessed when the National Institute of Health Research (NIHR) was established. Founded in 1996, INVOLVE was one of the few government-funded programmes of its kind in the world. INVOLVE distinguished between different approaches to PPI in research: consultation, collaboration, co-production, and user-controlled research. 'Consultation' refers to asking patients about their views on specific topics chosen by researchers; 'collaboration' or 'co-production' refers to researchers and the public working together, sharing power and decisions; and finally, 'user-controlled research' is where patients actively control, direct, and manage the research with assistance from researchers [22]. A crucial ethos at INVOLVE was that PPI can take place at every stage of the research cycle, which is a helpful example for the wider academic community. Although INVOLVE was merged into the NIHR Centre for Engagement and Dissemination in April 2020, its principles remain a key driver for NIHR PPI work, and it is an exemplar for initiatives in the field [23].

The next section of this review examines each of the major steps of the research cycle and highlights examples of PPI excellence and impact within dermatology academia.

3 PPI as Applied to the Dermatology Research Process

3.1 Research Question and Study Outcome Identification

Involving patients and the public from the outset of dermatology research can be impactful, particularly when considering the identification, refinement, and prioritisation of research questions. This increases the likelihood that the research questions are focused, practical, and patient-driven throughout the research process. In the UK, the James Lind Alliance unites patients, clinicians, and researchers in priority-setting partnerships (PSPs), which conform to a set of principles. Many specialties have adopted the approach of a PSP, with the implicit aim of prioritising a final 'top ten' list of jointly agreed research priorities. Dermatology conditions feature the most frequently in all PSPs conducted. These are included in Table 1. The PSPs are undertaken in three sequential steps: a survey to gather understanding on treatment uncertainties from patients, health professionals, and other stakeholders; a ranking exercise in which patients vote for their favourite topic from a list of most frequently considered uncertainties; and lastly, the facilitation of a workshop where priorities are developed into research questions. Such processes can have direct impacts upon goal setting in research. In a vitiligo PSP [24], five research areas were drawn from the top ten uncertainties and submitted to the NIHR Health Technology Assessment Programme. This body commissioned the HI-Light (Home Interventions and Light therapy for the treatment of vitiligo) trial, a randomised clinical trial of the use of ultraviolet B light combined with topical corticosteroids for the treatment of vitiligo [25]. A similar approach to understanding acne treatment uncertainties identified concerns regarding a paucity of evidence on the relative efficacy and safety of commonly used acne therapies. The process also informed recruitment practice, suggesting some social media and promotional activities were more successful than others [26].

Within dermatology, core outcome sets ensure that clinical trial outcomes are patient-centred and clinically meaningful. The first of these was HOME (Harmonising Outcome Measures for Eczema), a collaborative research group with patients at its heart. HOME recognised the challenge within atopic dermatitis research of non-standardised and inadequately validated outcome measures [27]. They, along with groups such as Cochrane Skin Core Outcome Set Initiative and the International Dermatology Outcome Measures group, support the development of high-quality core outcome sets within the specialty and are driven by patient input [28] into defining what is important to patients. Built upon the principles of collaborative working, these groups may prove transformative for research as systematic reviews frequently identify a lack of consistency around outcome sets. Through consensus, the Acne Core Outcomes Research Network (ACORN) [29] identified core domains for measurement within the context of a clinical study and noted discrepancies between patients and clinicians regarding the impact of acne [30, 31]. ACORN is now developing novel tools where no validated measurements are currently available.

Further work on outcomes includes the UK STOP GAP multicentre trial of prednisolone versus ciclosporin for the treatment of pyoderma gangrenosum [32]. After initial focus groups and structured interviews with patients, the study design was altered to include greater emphasis on capturing pain as an outcome measure, and details of wound discharge were added to a disease severity assessment tool. This study illustrates the benefits of collective working, particularly in the context of rare diseases. An international research group developed a protocol for understanding stigmatisation and body image impairment in patients with dermatological conditions. The authors conducted a pilot study working with a Norwegian patient society 'the Psoriasis and Eczema Forbundet' to aid in validating research questions and to incorporate patient thoughts about stigmatisation into the study design [33].

Table 1 Priority-setting partnerships in dermatology

Priority-setting partnership name	Year
Pemphigus and pemphigoid	2019–present
Skin cancer surgery	2019–present
Lichen sclerosus	2017–2018
Psoriasis	2017–2018
Cellulitis	2016–2017
Hair loss	2014–2015
Hidradenitis suppurativa	2014
Acne	2012–2014
Eczema	2011–2012
Vitiligo	2010

3.2 PPI and Funding

Funding bodies are increasingly recognising the benefits of involving patients in research and are actively promoting PPI as a criterion in award funding. As a basic standard, the NIHR expects active PPI to be embedded throughout the research that it funds [34]. Additionally, patients have been included on funding committees that decide on award priorities [35]. Through such panels, patients provide feedback to researchers throughout the application process about the value of the research to the public and about how they perceive the design of the research will fare in real-life

healthcare settings. Furthermore, when considering the publication of research, some journals now require a transparent approach that mandates a PPI section at the point of submission. Evidence-based guidelines and checklists exist to help improve the transparency, quality, and consistency of PPI reporting in research [36].

Patient support groups (PSGs), also known as patient advocacy groups, exist to provide resources and emotional support for patients affected by a disease. Dermatology PSGs also directly support skin research activities through funding and supporting patient participation in research. However, compared with other disease areas, the monetary value of such awards is modest. The UK-based charity The Psoriasis Association has awarded over £4 million over the past 40 years and offers two grants: the PhD Studentships and the Cecil King Memorial Award. These small grants may amount to up to £10,000 [37]. In the USA, the National Eczema Association awards grants for patient-oriented eczema research that addresses research priorities such as prevention and alleviating disease burden as well as innovations in clinical practice and care and translational science [38]. Furthermore, the US-based Melanoma Research Foundation has incorporated a patient-centred approach into the grant review process since 2019 to ensure that patient perspectives are incorporated into their funding governance [39]. One challenge that arises by requiring PPI to gain funding for research is that high-quality PPI requires funding in itself. In recognition of this, the NIHR offers grants of up to £1000 to support PPI through its research design services and PPI Small Grants Scheme [40]. These and other such initiatives can enable PPI via support for publicity and covering of travel expenses to make overall PPI budgeting more achievable.

3.3 Study Design

PPI appears to be firmly established in dermatology research following survey methodology, with numerous examples of expert patient contribution to questionnaire item generation through focus groups, interviews, or collaborative working groups [41]. In one mixed-methods study utilising online focus groups to investigate perceptions of 'control' among patients with eczema and parents of children with eczema, question items were revised based upon patient perceptions on facilitating, engagement, and relevant responses during the focus groups. This study was further strengthened by a patient panel from the Centre of Evidence Based Dermatology in Nottingham, which advised on appropriate language when discussing 'long-term control' in advertisements and information about the study, thereby permeating genuine PPI throughout the study design process [42].

Patients and researchers may work together regarding study methods, questionnaire piloting, and input on treatments or interventions planned. This approach has been demonstrated to resolve challenges that may have otherwise inhibited research output. This was demonstrated in a prospective feasibility study across three UK centres recruiting patients with pyoderma gangrenosum or leg ulcers. Researchers aimed to evaluate the suitability of patient-led documentation of wound healing between clinic visits through home photography. The initial approach proved time-consuming and practically difficult for the patient cohort, resulting in poor-quality images and missing data. Discussion with patients led to a change in approach for the methods of documentation [32]. Patient involvement has also been reported in the piloting of cognitive interviews to ensure a user-friendly experience and to provide the interviewer with feedback on the process [43].

Patients can also co-design participant information sheets and consent forms, working with researchers to ensure that terminology may be understood by a lay audience. In the DIPSOC study protocol for a case–control diagnostic accuracy study to develop diagnostic criteria for psoriasis in children, patients were involved to ensure the relevance of participant-facing documents. Suggestions from patients regarding participant information sheets were manifold and included altering the format to a leaflet or book; using colours for different sections; emphasizing confidentiality, removing photographs of psoriasis; and providing electronic versions of the information sheets on a website [44]. These are some ways in which patient input can dramatically alter study materials and transform how participants may understand studies they have been recruited to (Fig. 1).

3.4 Recruitment

Poor recruitment and retention of patients in trials are significant sources of research inefficiency as they delay dissemination, inflate costs, and—crucially—can lead to biased findings [45]. A systematic review assessing the impact of PPI on enrolment and retention in clinical trials found that half of the PPI interventions included were associated with significantly higher enrolment rates than were non-PPI interventions. Curiously, however, the meta-analysis did not demonstrate a statistically significant impact of PPI interventions upon participant retention [46]. Practically, researchers may apply for recruitment support through various channels and on various PSG and charity websites, with the psoriasis society website being one prominent example [47].

PPI may facilitate the employment of creative strategies in promoting recruitment. On commencing the UK CLOTHES trial, three patients gave interviews on local and national news channels about the impact of atopic eczema on their lives, ensuring that the research subject was widely distributed and appeared engaging and relevant. As a result, this research team received 492 expressions of interest from

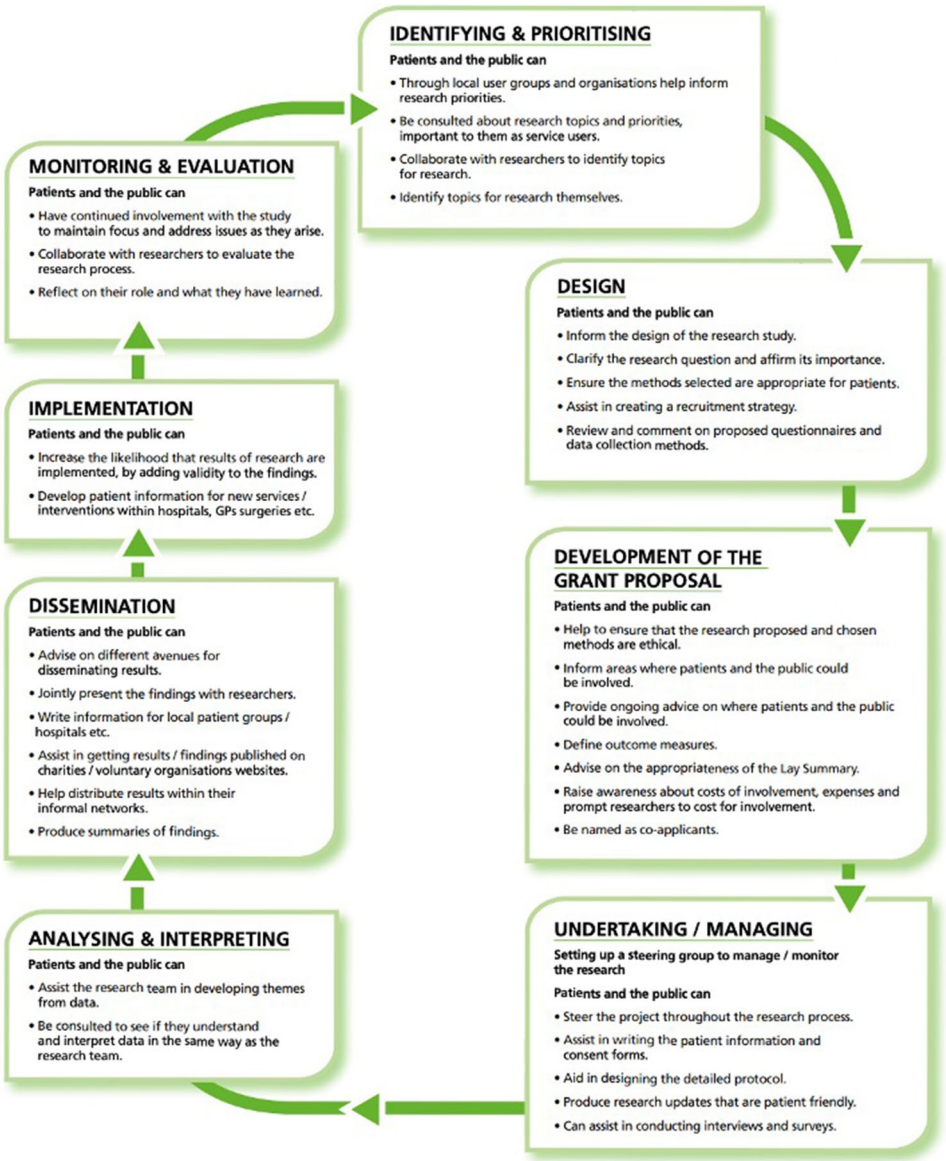

Fig. 1 Patient and public involvement as applied to the research cycle, via National Institute of Health Research INVOLVE [23]

potential participants in 3 months [48]. Figure 2 illustrates this profound impact of media interest.

Patients and the public may also influence the direction of recruitment. The SAFA trial, assessing spironolactone in acne, featured two public contributors with experience of acne to guide recruitment. This led to the integration of social media recruitment during the trial and the removal of an upper age limit of 50 years for inclusion, which was perceived as discriminatory [50].

3.5 Data Analysis

PPI in the data analysis stage has been firmly established in many fields, especially psychiatry, and has indicated that PPI has an important role in qualitative data analysis [50]. However, PPI in data analysis is one of the most challenging, least well-explored aspects of involvement. This means that a valuable perspective in interpreting findings is being lost [51]. In contrast, some researchers who have used PPI in the analysis stage have expressed concerns that they may potentially place too much emphasis on their own experiences rather than analysing the results of the data [52]. A systematic review of collaborative data analysis of qualitative mental health research found that including co-researchers with lived experience produced richer, more in-depth, and alternative understandings of research phenomena [50]. For example, a research study investigating the impact of PPI on the secondary analyses of qualitative transcripts of psychiatric inpatients found that patients coded more questions into the experiences and feelings category, whereas researchers coded more according to procedures and processes around detention [53]. In the UK RECAP qualitative study of atopic

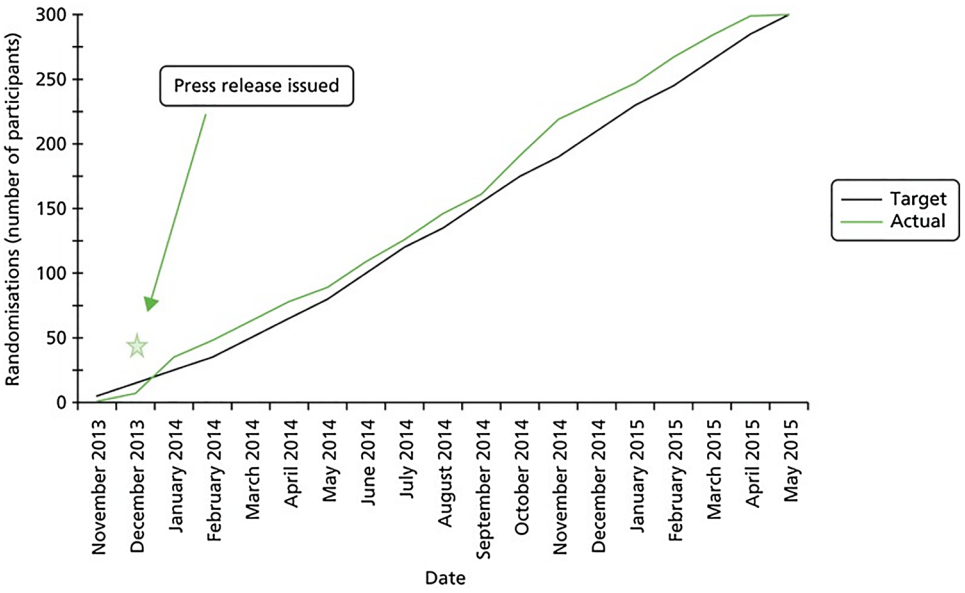

Fig. 2 Recruitment graph for the CLOTHES trial showing the impact of initial media interest. Reproduced from Thomas et al. [48]. Copyright © Queen's Printer and Controller of HMSO 2017

eczema, the expert panel (including patient representatives) were involved in discussions about transcript coding, item scoring and weighting, and deciding on the dependent variable for multivariate regression analysis—'bother caused by the eczema' [43]. Furthermore, in the HI-Light vitiligo trial, people with vitiligo were involved in the analysis of treatment success by blinded assessment of images of study participants in addition to prioritizing the research questions, study design, and oversight [25].

3.6 Dissemination

Results from clinical research published in scientific and medical journals often do not reach the public because access to such resources is not equitable. Additionally, some patients have difficulty interpreting research outcomes and implications. The role of PPI within this domain is to facilitate the dissemination of results and conclusions through provision of advice on how, when, and where research may be published. This can be undertaken through collaboration in drafting reports, writing comprehensible summaries of findings, and consultation on distribution and presentation of conclusions so that they may be accessible to all age ranges and hard-to-reach groups. This latter approach has recently been adapted in the digital space through podcasts [54], mobile applications [55], and YouTube video material [56]. Moreover, the use of relevant PSG websites and social networking websites has become incredibly important to advocate research in patient communities to disseminate study results to patients, carers, and the public [57].

The rise of online 'virtual communities' for patient conditions has made it easier to rapidly disseminate electronic surveys to potential research subjects, which has been commonplace within online spaces relating to treatment practices across a number of dermatological conditions [58]. Social media platforms such as Facebook play a critical role in the dissemination of information pertinent to dermatology research to the public, with one study identifying significant engagement rates relating to academic journal articles and educational posts [59]. Creative examples of patient involvement in academic discourse include the development of dermatology Twitter journal clubs [60]. Although social media journal clubs themselves are not particularly novel, the stated involvement of patients in such discussions is.

Furthermore, there is evidence to support the idea that dissemination featuring PPI may provide access to a wider audience than traditional academic circles [61]. This tends to manifest as translation of findings into meaningful everyday messages and improved relevance to patients. PPI may facilitate the development of more creative methods of dissemination than the researchers alone would have, further empowering patients [62], or may provide access to groups and forums that the researcher is not aware of [63]. Through dissemination of PPI, patients may assume the identity of advocates. The peak of this academic advocacy may take the form of patient editors of dermatology journals. Of the top ten worldwide dermatology journals ranked by impact factor, only the *British Journal of Dermatology* features a publicly facing dedicated 'patient associate editor' [64]. This editor has innovated with independent, patient-led organisations such as the Dutch Association for People with Atopic Dermatitis [65].

Crucially, work in PPI has established that dissemination must not be uniform or via one single medium. The acne PSP suggested that preferred outcomes should be disseminated through a variety of mechanisms, combining traditional

methods such as publication in peer-reviewed journals and reporting on official web pages with a strategic approach to social media and distribution of traditional hard copy summaries [26]. Learning from 'negative' results related to PPI may be just as informative as successes. Despite a surge in the use of social media dissemination in PPI more generally, the acne PSP found dissemination via a dedicated Twitter account to be 'unnecessary' and unsuccessful at achieving the stated aims. In a rapidly growing social media field that is becoming increasingly commercial via 'influencers', caution and careful thought to strategy is perhaps warranted with digital dissemination using PPI [66].

3.7 Role of PPI in Implementation Activities

It has been recognised that panels involved in the development of clinical practice guidelines should include public stakeholders such as patients or patient representatives and public interest or public health groups [67].

Despite this, a review of the quality of recently published acne treatment guidelines using a number of guideline appraisal tools identified that stakeholder representation on guideline development groups was universally poor [68]. Moreover, a scoping review of the global production of dermatology clinical practice guidelines showed wide variation in geographical representation, article accessibility, and reporting of funding [69]. This review was undertaken by the GUIDEMAP collaborative and involved patients. Greater integration of PPI within guideline development is underway with the work of such organisations and must be a priority for clinical bodies developing guidelines.

4 Challenges Facing PPI

A historical criticism of PPI is that patients lack the relevant knowledge or understanding to contribute to appropriate stages of the research cycle [3]. As only 12% of US-based adults are described as having proficient health literacy skills [70], it has been argued that involvement may lead to patients feeling intimidated and doubting their ability to add value to a study. However, this is a relatively superficial approach to this phenomenon. A more holistic view would acknowledge that patients have inherent knowledge of the lived experiences associated with their illness and can add priceless perspectives, which can only enhance the rigour of research. This should not require patients to become experts in the wider research processes. Although work to change the culture of research is ongoing, some resistance from professionals is evident. Therefore, it is essential to encourage investigators to take the time to educate and train stakeholders in our methods, while learning in turn from patient perspectives. Basic considerate approaches may include using accessible language, avoiding unhelpful jargon, and valuing patient input, which in turn will impact on patient-oriented research [71]. Moreover, the availability of participants varies and tends to fall outside of the typical working hours for a research team, which may require flexibility from both patients and investigators. It is important that expectations of both researchers and stakeholders are managed, particularly regarding the relatively slow pace of the research cycle and the inability to guarantee a direct impact on clinical care [72].

The research community can sometimes find it difficult to know where to start. We recommend budding and experienced researchers alike maintain close links with local, regional, and national PPI-centred initiatives such as the UK Clinical Trial Network. Such bodies can facilitate contact with expert patients and important stakeholders and flag relevant patient agendas. It is important to remember that it can take time for researchers to build relationships and trust with patient representatives, but this is a key factor for successful PPI [73].

Research must represent the populations it serves. The generations of historical injustices and inequalities mean that patients from underrepresented communities may mistrust medical and scientific communities, and extra effort may be required to create an environment of inclusivity and to establish trust [73]. Although we have demonstrated that PPI continues to grow in importance within dermatology scholarship, the demographic behind this PPI is unknown and likely subject to the social inequalities pervasive within our specialty. Dermatology has been criticised as the second least diverse of US medical specialties, and race is reported in only 11% of dermatology clinical trials [74, 75]. It is therefore likely to be insufficient to simply improve PPI across dermatology research in terms of numbers—efforts must be made to appropriately engage with communities identifying as underrepresented in medicine to correct such disparities.

Despite the establishment of PPI within a diverse range of methodological approaches, there remains a surprising lack of patient input into the research question design of qualitative research in dermatology. As this approach gains momentum in qualitative research outside of dermatology, including in dementia [76] and emergency medicine [77], it is possible that an influx of PPI into dermatology qualitative scholarship is imminent; however, this will likely require close collaboration between patients and the qualitative dermatology research community [78].

Careful thought is required when considering the use of social media for PPI in research dissemination. Despite the perceived significance of social media in this area, academic institutions and journals have been relatively slow to adapt. A 2012 study revealed that less than 15% of the 102 dermatology journals identified maintained a presence

on either Facebook or Twitter [79], although this footprint had improved among the most impactful dermatology publications by 2021 [80]. However, it should be recognised that social media platforms vary wildly in terms of popularity across demographics such as age and nationality, and some of the fastest growing platforms, such as TikTok, feature a lack of authoritative dermatology scholarship presence [81]. Newer social media may prove to be the next great battleground against misinformation, as—even within dermatology—it has been demonstrated that misleading videos may gather more 'likes' and inspire more comments than higher-quality, 'official' social media posts [82, 83]. Recognition of the importance of such challenges has become so marked that efforts have been made to use artificial intelligence to combat misinformation and provide patients with accurate research materials [85]. The appetite or capacity for dermatology academic leaders, institutions, or journals to take on this information fight, hand in hand with patients, remains to be seen.

5 Conclusions

PPI is an emerging force in dermatology research. PPI may be infused across the research cycle and, although evidence of such practice may be in its infancy, examples of excellence in practice exist. Rather than appearing to be tokenistic, patient input should be seen by dermatology researchers as an exciting opportunity for patients to enhance studies by bringing their lived experience and providing previously unseen perspectives. Support for innovation with PPI is available from international patient-led bodies, academic institutions, and virtual communities of practice. Our profession stands to benefit from building the wealth of the evidence base in PPI, while bearing in mind the important challenges associated with inclusivity, representation, and misinformation that impact the field more widely.

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Ethics approval As a review article, this work involved no human subjects, so no ethical approval was sought.

Consent to participate Not applicable.

Consent to publish Not applicable.

Availability of data and material Not applicable.

Code availability Not applicable.

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