

Research Priorities and Identification of a Health Service Delivery Model for Psoriasis from the UK Psoriasis Priority Setting Partnership

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For which topic were research priorities identified?

psoriasis

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Psoriasis impacts the health and psychosocial functioning of patients, conferring a significant economic burden on healthcare systems. There remain unmet needs in psoriasis care, which if addressed by research, could improve clinical outcomes.

What was the objective?

to identify unmet needs and prioritize the order these should be addressed by research

What was the outcome?

a ranking list of 20 research questions

How long did the research prioritization take?

July 2017 - November 2018

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: identification and invitation of potential partners, establishing steering group. Step 2: collecting research questions: via survey, 2133 questions submitted. Step 3: data processing: check against evidence, 55 indicative questions formulated. Step 4: interim ranking: via survey, participants were asked to vote for up to 10 questions from the list of indicative questions, resulting in shortlist of 20 questions based on highest ranked priorities including top ten questions ranked by patients/carers and top ten questions ranked by healthcare professionals. Step 5: final prioritization: workshop: small group discussions and small group rankings, followed by plenary session to achieve consensus

Which stakeholders took part?

Those with lived-experience of psoriasis and healthcare professionals. Survey: 805 participants: 71% patients and 22% HCPS. Interim ranking: 1154 participants: 66% patients and 25% HCPS. Workshop: 26 participants: 46% patients, 42% healthcare professionals, 12% Psoriasis Association.

How were stakeholders recruited?

For survey 1, participants were recruited via the Psoriasis Association website and via outreach through the partner organizations and the individual efforts of SG members via their networks. The PsPSP was also promoted to the British Society for Investigative Dermatology, British Society of Rheumatology, Royal College of General Practitioners, Royal College of Nursing, School Nurses Forum, Community Practitioners and Health Visitors Association, and the Cochrane skin group. Also, the project team engaged with the Cross-Party Group on Skin at the Welsh Assembly and Skincare Cymru and advertised the PSP in schools, community centres and approached several parenting and men's health websites. For the workshop, SG, representatives from partner organizations, patient representatives and healthcare professionals were invited to participate (n=26; 42% HCPs; 46% patients and 12% Psoriasis Association).

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 7 patient representatives and 7 healthcare professionals with experience of managing psoriasis in primary, secondary and tertiary care and representing medicine, nursing and psychology. The members oversaw the whole process.