

Supplementary file 1: Search Strategy development process

One known relevant systematic review (Sampogna *et al* 2017) was used as a starting point to identify records within databases. A draft search strategy was developed by using candidate search terms that were identified in the titles, abstracts and subject indexing of that systematic review.

Table 1: Preliminary keywords/search terms identified:

<p>Psychosocial or psycho-social or psychodermat* or social or cognit* or emotion* or well-being or psychological* or adjust* disorder or depress* or anxiety or anxious or coping or stress or mental health or guilt or embarrassment</p> <p>disease specific or dermatolog* specific or disease burden or burden of disease or scale or needs assessment or psychosocial assessment or index or tool or interview or quality of life or validat* or QoL or measure or impact or screen* or wellbeing or well being or questionnaire or health related quality of life or health profile or inventory or intervention or evaluation or schedule or survey or audit or neuropsychological assessment or activities of daily living or dermatolog* specific health instrument or psychosocial impact or psycho social impact</p> <p>Caregiver* or family or 'family caregiver' or 'family care giver*' or parent or homecare* or home care* or adult or adults* or grownup* or grown up or families or relative or relation* or mother* or father* or family nurs* or primary care provider* or informal caregiver* or carer* or 'greater patient concept' or homecare</p> <p>Child or children or infant* or toddler* or baby or babies or youngster* or young pers* or preschool* or teenage* or adolescen* or prematur* or pediatri*</p> <p>Skin* or skin condition* or skin disorder* or scaliness or keratos* or cornificat* or rare skin dermatology* or chronic disease or chronic condition or long-term condition or chronic illness or incurable or disability or life limiting or long term care or life threatening or palliative or assistive technology or continu* of care or chronic car* or Ichthyos* or continuing car* or impact of chronic skin disease</p> <p>Skindex or measuring the family impact of dermatological conditions or the family impact of skin diseases</p>
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Additional search terms were then identified from the results of that strategy, from the reference list of the systematic review, from systematic searching of each relevant electronic database for relevant “MeSH” terms (included in each search strategy below) and from checking using the PubMed PubReMiner word frequency analysis tool. This strategy was tailored to the specifications of each of the databases searched and developed in collaboration with a subject-specific librarian (J.A.) and expert group. We did not include a specific definition of psychosocial because, given a lack of consensus in the literature on the

use of this term, we wanted to include a diverse range of tools (cognitive, social and emotional) to answer the research question.

Pre-planned keyword searches were limited to titles and abstracts, with MeSH terms being exploded, where available. Each of the keywords above were individually mapped to appropriate subject headings (MeSH) in each database, where available, to ensure a broad and thorough search. Each concept was taken individually and OR MeSH with the keyword(s). This process was repeated with all five concepts and were AND together at the end. The Cochrane RCT filter (reported in the Cochrane Handbook v5.2) was used in the development of the MEDLINE strategy. Independent peer review, by both first and second author, involved proofreading the overall structure, spelling and syntax. The search strategy was validated in MEDLINE when it successfully identified the one known systematic review and three of five further studies (Finlay, 1997; Ashcroft *et al* 1998; De Korte *et al* 2002; Bennett *et al* 2003; Haywood *et al* 2005; Nemeth, 2006) identified as part of the strategy development process.

As per eligibility criteria, the original search strategy was limited to English language studies and from studies published between 01 January 2000 to 01 April 2020. We searched in MEDLINE, PsycINFO and EMBASE using the OVID interface. CINAHL EBSCO (Cumulative Index to Nursing and Allied Health Literature) was additionally searched.

Updated searches were conducted on the 5th October 2021 for 01 April 2020 to 5th October 2021 (using original search strategies). The PRISMA flow diagram accounts for this updated search and has been included with this submission (Figure 1).