1	Public views are needed for skin colour scales
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3 4 5	Stephanie J. Lax, ¹ Amanda Roberts, ^{1,2,3} Eleanor Cliffe, ¹ Grishma Ramesh, ¹ Dija Ayodele, ⁴ Hywel C. Williams, ¹ Sharon Belmo ⁵ and Paul Leighton ¹ on behalf of the Centre of Evidence Based Dermatology Patient Panel
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7 8	¹ Centre of Evidence Based Dermatology (CEBD), School of Medicine, University of Nottingham, UK.
9	² CEBD Patient Panel
10	³ Nottingham Support Group for Carers of Children with Eczema, Nottingham, UK
11	⁴ Black Skin Directory, London, UK
12	⁵ Dr Sharon Belmo Dermatology, London, UK
13	
14	Corresponding author: Paul Leighton
15 16	Email: paul.leighton@nottingham.ac.uk
17	ORCiD: SJL - 0000-0002-7000-9364
18	HCW - 0000-0002-5646-3093
19	SB - 0000-0003-1314-9587
20	PL - 0000-0001-5208-0274
21	
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- 26 Data availability: The data underlying this article will be shared on reasonable request to the
 27 corresponding author.
- **Ethics statement:** This public engagement exercise was exempt from IRB approval as the survey did not
- 29 require any personally identifiable information, or information that might be used to link to individuals
- 30 in other sources which would reveal their identity.

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- 5 Dear Editor, In dermatology a concern for health inequalities casts an obvious and necessary focus upon skin of
- 6 colour. The misuse of The Fitzpatrick Scale (originally a guide for UV therapy) as a shorthand for skin colour/ethnicity
- 7 in medicine has been criticised,^{1,2} and, the absence of skin of colour in medical education and medical images has
- 8 been rightly recognised.^{3,4} The development of new promising skin colour scales is a positive advance,^{5,6} yet the
- 9 public voice seems to have been mainly lacking from these efforts and discussions.
- 10 To address the apparent absence of a patient and public perspective on these matters, the Centre of Evidence Based
- 11 Dermatology Patient Panel instigated an online, social media-delivered public survey about the language of skin
- 12 colour. Respondents were asked three things: (i) to position their skin tone on a pictorial version of the Fitzpatrick
- 13 Scale; (ii) to select the most appropriate text descriptor from the Fitzpatrick Scale; and (iii) to report in their own words
- 14 their skin tone (and their skin tone when irritated).
- 15 The survey generated 1,296 anonymous responses. Self-ascribed ethnicity included Asian/Asian British (14%),
- Black/African/Caribbean/Black British (12%), White (63%), Mixed (6%) and Other (4%). The majority were aged 25-54
 (67%) and most were female (78%).
- 18 Responses demonstrated that neither the pictorial nor textual descriptor versions of the Fitzpatrick Scale adequately
- 19 represent how individuals consider their own skin. Most respondents did not align their skin tone with Fitzpatrick
- 20 images or descriptors: for the pictorial version more than 50% (759/1296) positioned their skin between or outside of
- 21 six skin tone images, 12% (150/1296) considered their skin tone lighter than the lightest shade, and only 44% of
- 22 Black/Black British considered their skin tone to be included in the scale. For the textual descriptors confidence in use
- was greater, but again more than 50% (717/1296) positioned themselves between or outside of the six descriptors.
- 24 Correlations between image and textual descriptors were also not consistent. Only 17% (8/46) of those who selected
- 25 textual descriptor VI ("skin does not burn") also selected point VI on the image scale (darkest skin tone). Five of the six
- 26 Fitzpatrick image categories were selected by this "skin does not burn" group. For Descriptor I ("skin burns very easily)
- 27 89% (77/86) selected the palest skin tones on the image scale, although again responses spanned four of the six
- 28 image categories.
- 29 The top ten most frequently used 'own word' descriptors for skin colour reflect that most respondents self-identified
- 30 as White: pale (407 mentions), brown (333), white (294), light (198), tan (171), fair (126), olive (121), freckles (110), pink
- 31 (94), and yellow (93). For irritated skin variations on red and pink dominated: red (1021 mentions), pink (291), dark
- 32 (119), brown (88), blotchy (80), angry (62), sore (43), dry (34), purple (33), and bright (31). The breadth of language
- 33 non-white respondents used to describe their skin tone is shown in Figure 1. Some respondents offered comment
- 34 that their choice of words reflected social convention more than actual skin colour: "red, but only because white
- 35 doctors have described it as such" (self-ascribing as Asian/Asian British); "it's hard to choose my 'own' words because we
- 36 *live in a context where white skin is the norm*" (self-ascribing as Black/African/Caribbean/Black British). These
- comments illustrate the persistence of structured and embedded inequalities in healthcare, where cultural languageconventions override lived experience.
- 39 It should be acknowledged that our online survey reached a relatively small number of respondents, the sample is
- 40 largely drawn from the UK (85%), and many respondents will have been reached via patient and disease-specific
- 41 networks (more than 50% had experienced eczema).
- 42 Our findings suggest that skin colour scales need to be more sensitive to the lived experience of skin colour. They
- 43 should reflect greater variation in skin tone (especially for darker skin) and include descriptors that are meaningful to
- 44 members of the public, and which are decoupled from race. The involvement of members of the public in the

- 1 development of skin colour scales (irrespective of their purpose or scope) will result in tools that are more
- 2 comprehensive, inclusive, and widely understood by health care professionals and the patients that they serve.
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18 Figure legends

- 19 Figure 1 (a) Words and phrases used by non-white respondents to describe their skin tone when under
- 20 normal conditions (i.e., not inflamed); (b) Words and phrases used by non-white respondents to
- 21 describe their skin tone when inflamed.
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