

# Impact of public exhibition on the perception of birthmarks

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## Abstract

**Background:** The importance of photographs in social media, the steep rise in popularity of tattoos, and the prominence of individuals with visibly different skin in fashion are likely to be changing the landscape of self- and public perception of birthmarks. Study objectives were to assess the impact of a photoshoot and public exhibition on the self-perception of individuals with extensive birthmarks, and to explore the viewing public's reactions.

**Methods:** Thirty individuals with congenital melanocytic nevi (CMN) were recruited internationally. Each had a professional photoshoot portrait with their skin exposed, resulting in a public exhibition in London entitled “How do you C Me Now?” Participants/parents completed pre- and post-questionnaires relating to self-perception and the impact of their birthmarks on behavior. Over 8000 members of the public viewed the exhibition, 464 completing an on-site questionnaire on its effects.

**Results:** All participants/parents rated the experience as positive, valuable and helpful. Scores on self-appreciation and self-confidence were significantly higher after the photo shoot. Members of the general public overwhelmingly reported the exhibition increased their positive feelings towards people with birthmarks. The majority of public respondents also reported that the exhibition made them feel better about their own skin and about their looks in general.

**Conclusion:** This unique exhibition and the associated research has provided a striking new perspective on potential psychological interventions for individuals with birthmarks.

## KEYWORDS

birthmark, congenital melanocytic nevus, exhibition, photographs, self-perception, visible difference

## 1 | INTRODUCTION

Sporadic birthmarks are a common occurrence, usually caused by genetic mutations in a part of the developing embryo or fetus. While much work has been done on the medical aspects of birthmarks in

recent years,<sup>1</sup> far fewer studies have been undertaken to measure the psychological aspects and associated potential therapeutic interventions.

Research on psychological support interventions for self-image and wellbeing in the wider field of body image is much more

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**FIGURE 1** Example images of individuals with CMN from the exhibition (photographs: Brock Elbank), reproduced with written informed consent from the individuals/families and with the permission of Caring Matters Now Charity.

established, with ambitious plans for the future to deliver translational impact.<sup>2</sup> Currently however studies on intervention are often not conclusive,<sup>3</sup> and it has been demonstrated that the problem of psychological impact of visible difference is highly complex and highly variable between individuals.<sup>4</sup> This variability in part is due to the etiology of the visible difference, with skin diseases not necessarily having a negative impact<sup>4</sup>; however other individual, cultural and societal influences are likely to play an important role. Perhaps as a result of this complexity, there is no current consensus on how to measure or address the psychological impact of visible difference on individuals,<sup>4</sup> and specialist provision of psychological support varies even within Europe.<sup>5</sup> Importantly, however, it has recently been shown that implicit attitudes towards those with visible difference may not be negative, and resultant behaviors from the public may result from

uncertainty regarding how to behave, rather than negative perceptions.<sup>6</sup> Public education is therefore likely to be as relevant as psychological support of the individual.

It is commonly believed that large birthmarks would have a substantial adverse psychological effect on affected individuals, and there is evidence that this can be the case.<sup>7,8</sup> The landscape of modern life has, however, changed dramatically in the last decade, which could alter the self- and public- perception of birthmarks in positive and/or negative ways. These changes include the advent of social media promoting the importance of self-image in social interaction,<sup>9,10</sup> the steep rise in the popularity of tattoos in individuals of all ages and particularly in young adults,<sup>11,12</sup> and the recent high profile of several individuals with visibly-different skin (for example, the model Winnie Harlow<sup>13</sup>).

Congenital melanocytic nevi (CMN) are moles present at birth (Figure 1). They can be associated with congenital neurological abnormalities and with melanoma, although in most cases these issues do not arise.<sup>14,15</sup> A recent international study of quality of life (QoL), measured via parent-proxy reports, of individuals aged 0–18 years with CMN of all severities has demonstrated that 76% report no or small impact on QoL, with a further 19% rating impact as moderate, despite including individuals with neurological and malignant complications.<sup>16</sup> Parental reports of QoL in children/teens with CMN demonstrated no effect of surgical intervention on psychological health, and that adverse effects of visibility on QoL scores were mediated through perceived stigmatization.<sup>17</sup>

These data are supported by experience in the UK. The CMN patient support group Caring Matters Now ([www.caringmattersnow.org.uk](http://www.caringmattersnow.org.uk)) has spent 25 years advocating “non-hiding” CMN in social situations from birth. This takes the form of not restricting any activities or type of dress as a result of the birthmarks. Anecdotally they have observed that in the immediate postnatal period, individuals and families are exposed to attention and questioning from those around them. However thereafter there appears to be rapid adjustment to and acceptance of the birthmark of those around the child, and good self-perception in childhood and teenage years. This led the support group leaders to hypothesize that as an extension to “non-hiding,” public exhibition of birthmarks might have a beneficial effect on self-perception.

This questionnaire study was designed around a photographic exhibition to assess the baseline self-perception of individuals with extensive and/or highly visible CMN in the current social context, and to measure the impact of taking part. In parallel, data were collected on the impact of the exhibition on how others view individuals with birthmarks, and on the impact of the exhibition on others' own self-image. The exhibition was entitled “How do you C Me Now?”—encouraging the public to look twice, not only at the visible difference, but at the individual.

## 2 | METHODS

In 2016 Caring Matters Now started a partnership with renowned UK-based photographer, Brock Elbank ([www.mrelbank.com](http://www.mrelbank.com)) to create a series of portraits featuring children and adults affected by CMN from around the world. Recruitment was by advertisement on the Caring Matters Now website and social media platforms. Eligibility was defined as having extensive and/or visible CMN.

Potential participants undertook a video call with the photographer. This was to ensure each participant and (where under 18 years of age) their parents understood the aim of the project and the process of being photographed. Following the video call, the participants or parents gave their consent in writing, completing the photographer's Model Release Form and the Caring Matters Now Participation Agreement.

The participants traveled to the photographer's studio in London, accompanied by their parents if under the age of 18 years. The photograph shoot took on average 3 hours, including a first hour focused

on helping the participant to feel at ease. Caring Matters Now then contacted the photographed participants 24 hours after the shoot by email, to check they were comfortable with their experience of being photographed. All participants, or where applicable a parent, were asked to complete a pre- and post-photography questionnaire (Supplementary material). This addressed both the experience of the photoshoot, and the individual's behaviors before and after the event. Each participant received the finally selected photographic image by email, and was asked to consent in writing to inclusion in the exhibition. The participants were invited to a private launch event held 1 day prior to the gallery doors opening to the public.

The 30 portrait images were exhibited at the gallery@oxo, Oxo Tower Wharf, central London, printed at A0 size and mounted onto wooden frames (examples Figure 1). The series of images were exhibited for 10 days in March 2019. A second questionnaire survey was designed to collect data from the members of the general public visiting the exhibition. Visitors were encouraged to complete the online survey after attending the exhibition using iPads situated on the gallery walls. Data are represented as frequencies of individual responses as a percentage of total responses.

Comparison of means for the paired pre- and post-participant survey were analyzed using paired Student *t*-test, with a Bonferroni correction for multiple testing (three tests) applied, which reduced the significance level to  $p < .0167$ .

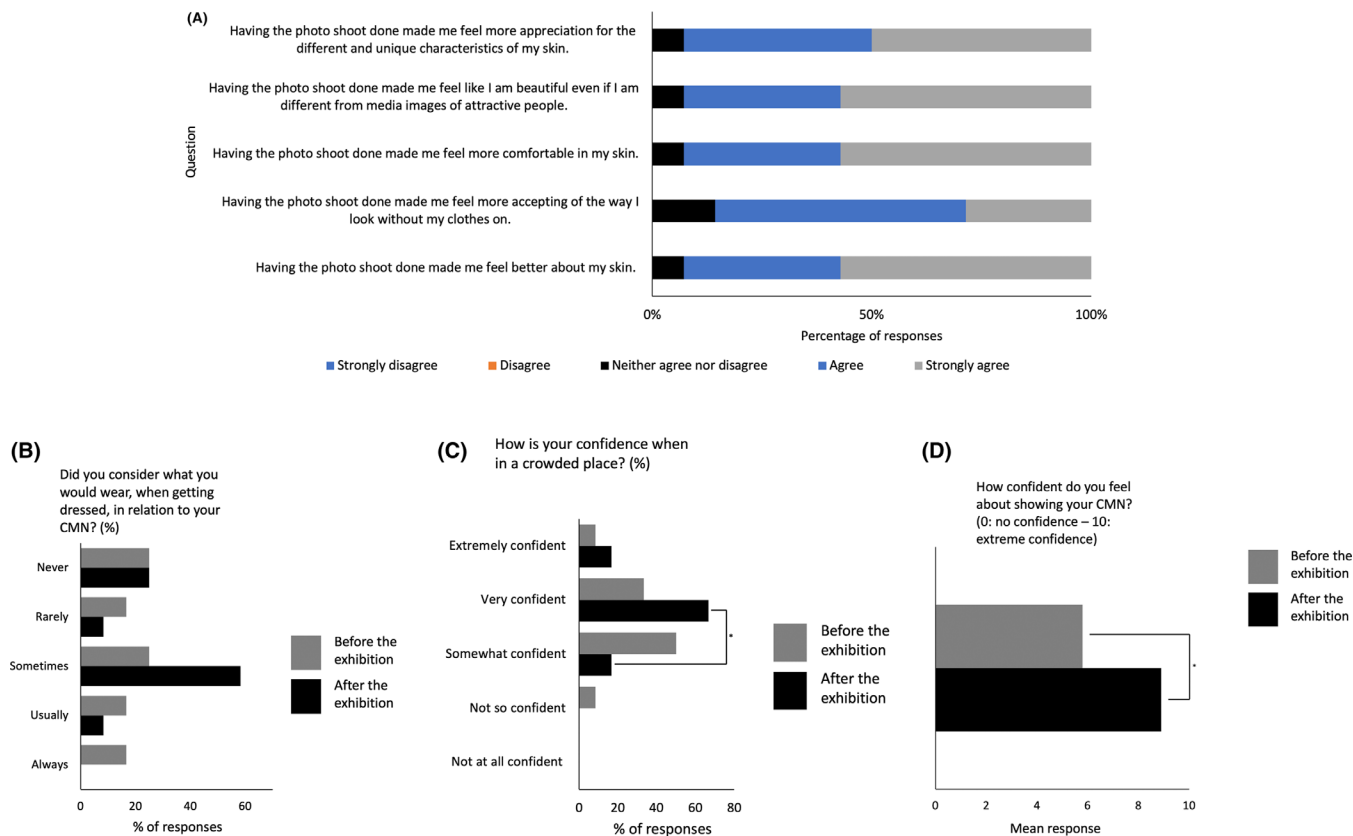
## 3 | RESULTS

### 3.1 | Demographics

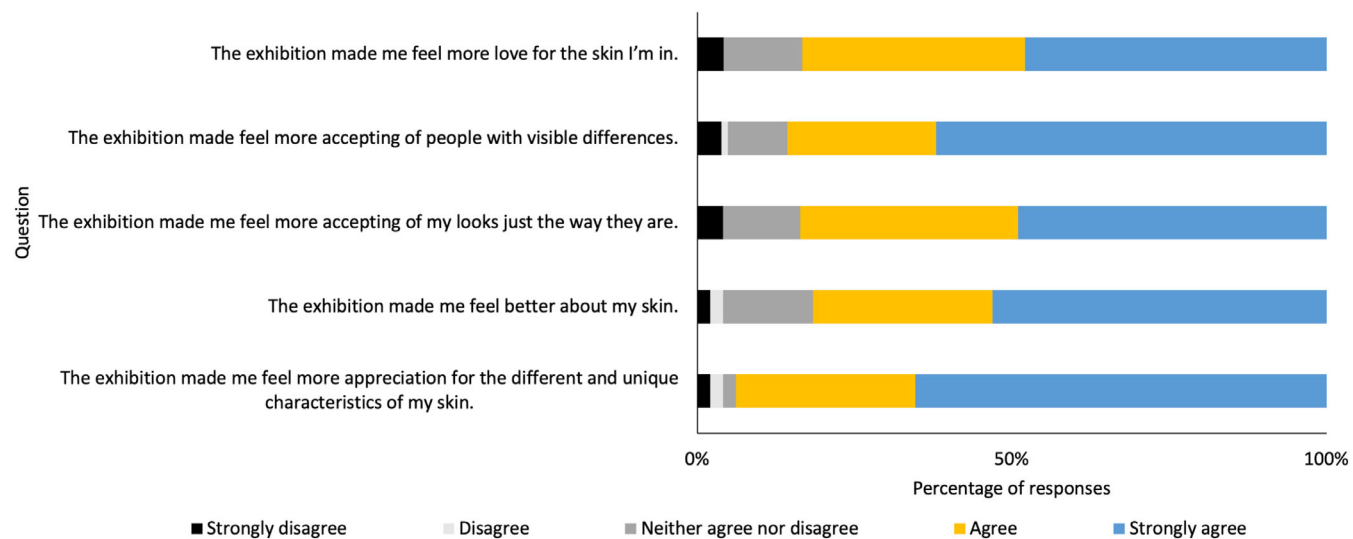
There were 41 initial expressions of interest to participate, 25 females and 16 males. After further information, discussion and consent, 30 individuals with CMN were photographed, 21 females and 9 males, from 13 countries on 5 continents: UK, Italy, Spain, Switzerland, Norway, France, Sweden, Ukraine, Poland, USA, Brazil, Australia and China. The age of the participants ranged from 7 months to 47 years, with 20 of the 30 being 18 years or more. During the 10-day exhibit, over 8000 people visited the gallery, of whom 464 completed the on-site questionnaire.

#### 3.1.1 | Pre- and post-photography shoot participant survey (individuals 18 years plus).

Twenty participants (12 female) in the photo shoot and exhibition completed the participants' questionnaire. More than 90% of participants “agreed” or “strongly agreed” that having the photo shoot made them feel better about their skin, more accepting of their looks without their clothes, more comfortable in their skin, beautiful despite difference and more appreciative of their uniqueness (Figure 2A). In response to three questions: “for me, having the photo shoot done was” (1) “positive,” (2) “helpful,” or (3) “valuable,” 100% of participants agreed or strongly agreed with each of the three statements. (Tables S1–S3).



**FIGURE 2** Experiences of individuals with CMN participating in the photo shoot and exhibition were positive and demonstrated significantly increased confidence (see text for *p* values).



**FIGURE 3** Responses of the general public to viewing the exhibition were largely very positive and appeared to increase not only appreciation of those with visible difference but self-perception.

Participants also reported improvements in confidence after the exhibition, accompanied by reported changes in behavior. The proportion of participants always or usually considering what they would wear in relation to their CMN reduced from 33.3% before the exhibition to 8.3% thereafter (paired Student *t*-test, *p* = .166), and no

participants continued to report that they would always consider what they would wear in regard to their CMN (Figure 2B). Reflecting on their confidence in a crowded place, 41.8% said that they felt “very confident” or “extremely confident” before the exhibition, increasing significantly to 83.3% after the exhibition (paired Student *t*-test, *p* = .012)

(Figure 2C). Overall mean confidence scores rose significantly from 7.1 to 9.0/10 after the exhibition (paired Student *t*-test,  $p = .015$ ) (Figure 2D).

### 3.1.2 | Parents of participant survey (individuals any age)

Parents responding to the participant surveys ( $n = 15$ ) were very supportive of the experience. Analysis of the responses to the open-ended question “In your own words, please list up to three words that you feel best describe the How Do You C Me Now? exhibition” indicated that the participants used the following words only: Inspiring, Valuable, Beautiful, Empowering, Confidence boosting, Exciting, Emotional, Positive, Informative, Brilliant, Proud, Amazing, Wonderful, Grateful. “Inspiring” was the most commonly used term by the parents of the older participants, with 33% of respondents using this adjective. “Beautiful” was the most commonly used term by the parents of younger participants, with 57% of respondents using this term to describe the exhibition. (Tables S4–S8).

### 3.1.3 | Post-exhibition public survey

A total of 464 responses were recorded (313 female, 109 male, 9 undisclosed) (Tables S9–S11). As respondents were able to skip questions the total number of responses to each question varied. 51% of the general public had heard of CMN prior to the exhibition; 11% of exhibition attendees had CMN themselves. More than 85% of respondents agreed or strongly agreed that the exhibition made them feel more appreciation for their skin uniqueness, made them feel better about their skin and more accepting of their looks, more loving towards their own skin, and more accepting of people with visible difference (Figure 3), and 74% rated the experience as very helpful (Figure 3). Of the attendees who had CMN and answered this block of questions ( $n = 42$ ), 74% rated the experience as “very helpful.”

## 4 | DISCUSSION

The staging of a professional photoshoot and a public exhibition for individuals with extensive and/or visible birthmarks was conceived by a patient support group with many years of experience observing the beneficial effects of non-hiding of visible difference. While the participants could be argued to already have robust self-perception to put themselves forward for such an experience, the clear demonstration here of measurable beneficial psychological impact afterwards compared to before is a radical proof of concept. Furthermore, in the era of social media, where the negative psychological effects of posting self-photographs are frequently reported, the positive effect of this exhibition on the views of the general public is a perhaps surprising demonstration of the power of this novel approach. In particular, the general public not only looked more

positively on the participants with visible difference, but felt better regarding their own appearance.

Traditionally, photographs of birthmarks have been medical images in textbooks or online, where the focus is on the birthmark rather than the individual. In addition, these photographs often demonstrate medically concerning areas, and are presented for healthcare professionals as important diagnoses not to be missed. As recently as 25 years ago, it was common practice in the UK for children with extensive birthmarks to be advised to hide their birthmarks as much as possible, with separate changing areas made available for them at school, and routine avoidance of sports such as swimming or dancing that might lead to a birthmark being seen. Although well-meant, the message was essentially that there was something “wrong” with the child, and that it was something shameful to be hidden. It is not surprising in this societal context that birthmarks could lead to psychological distress.

Since the exhibition, the patient support group has been inundated with applications from individuals with CMN to be photographed. Clearly it is not financially feasible for the support group to continue to offer professional photoshoots, however some individuals have since organized their own version, for example a photoshoot plus home exhibition. In parallel, the support group has published an exhibition book (<https://www.caringmattersnow.co.uk/product/how-do-you-c-me-now-book/>). This can be used in homes and also in clinics by professionals. The impact of this as a tool has yet to be evaluated.

In conclusion, a professional photoshoot with a public exhibition has shown beneficial effects on self-perception and confidence in participants, and on members of the viewing public. These data support the impression of the UK support group Caring Matters Now Charity, that non-hiding of visible difference on the skin can have beneficial psychological effects. Further studies will be required to assess whether this approach works in the context of other forms of visible difference, and whether the effects can be replicated using the exhibition book.

## 5 | LIMITATIONS

The self-selective nature of both the participants of the photo shoot, and those in the general public who attended most likely resulted in collections of data from samples reflective of the most motivated individuals. This may therefore reduce the generalizability of the findings. In addition, in order to optimize questionnaire completion, personal demographic data other than gender were not gathered from the general public. This meant that the analysis could not identify predictors of differing experiences of the public exhibition.

### ACKNOWLEDGMENTS

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photography and use of the images in Figure 1 to Brock Elbank and Caring Matters Now respectively.

### CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

### DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

### CONSENT STATEMENT

Images of individuals with CMN were obtained after written consent and have been used in this publication with specific further written consent. Consent from the self-selective voluntary sample was handled by Caring Matters Now patient support group and the photographer.

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### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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