

THE FACE EQUALITY CAMPAIGN – THE EVIDENCE**The incidence and prevalence of disfigurement**

The word “disfigurement” is used to describe the aesthetic effects of a mark, rash, scar or skin graft on a person’s skin or an asymmetry or paralysis to their face or body*. Disfigurement can affect anyone at any time, at any age, from any ethnic group whether from birth, accident, disease or the aftermath of surgery.

There are no official statistics to record the scale of disfigurement, but in 1988 the Disability Survey (conducted by the Office for Population Censuses and Surveys) estimated that there were at least 400,000 people in the UK who had a disfigurement to their face and/or body, defined as “a scar, blemish or deformity which severely affected their ability to lead a normal life”. This figure has, however, little foundation and has been unsatisfactory as a basis for raising public awareness and advocating for better services.

In the autumn of 2007, *Changing Faces* commissioned a thorough search of all existing studies, data and websites to create a better estimate of the incidence and prevalence of disfiguring conditions. This has been conducted by Professor Desmond Julian (retired cardiologist) and Dr James Partridge (MSc (Demography)) supported by the *Changing Faces* Research Council members including Professor Walter Holland (epidemiologist). The survey’s findings will be published in due course in a peer-reviewed journal.

The aim of the survey was to establish a more accurate and sophisticated estimate of the incidence and prevalence** of significant disfigurement, based on reasonable and tough assumptions and differentiated by the medical causes of disfiguring conditions. Significance was taken as having ‘visibility’, ‘extent’ and ‘location’ dimensions.

The research has reached the following conclusions:

- 542,000 (or one in 111) people in the UK have a significant disfigurement to the face.
 - 92,000 have congenital or birth conditions like birthmarks, cleft lips/palates
 - 66,000 have disfigurements from accidents such as burns and facial scars
 - 40,000 have cancer-related disfigurements, from surgery for skin cancer
 - 100,000 have disfigurements from facial paralysis including from stroke
 - 220,000 have disfigurements related to skin conditions like psoriasis, vitiligo and acne
- 1,345,000 (or one in 44) people have significant disfigurement to their face and body.
- 415,500 people are expected to acquire a significant facial disfigurement in the period of a year, some conditions being transient, some life-threatening.

Notes

* It is very difficult to define a ‘disfigurement’ precisely – and some people do not like the thought that they might be counted as having one. Disfigurement is in the eye of the beholder – and the person themselves. It is well-recognised in the psychological research literature that the extent or severity of a disfigurement does not correlate with the amount of distress it causes. What may appear ‘minor’ disfigurements, especially if they appear in the communications triangle on the human face where other people focus their gaze and attention, can be associated with considerable self-esteem and self-confidence problems. Equally, disfigurements that can be hidden by clothing can pose psychological problems.

** *Incidence* is defined as the proportion of new cases of a disorder in a population in a specified time interval and *prevalence* the proportion or number of people who have a given condition in a population at a specified point in time.

APPENDIX: The prevalence and incidence of the main causes are:

	Max number of face and body disfigurement	Disfigurement to the face	Annual cases of facial disfigurement
<u>CONGENITAL CONDITIONS</u>			
Cleft lip and palate	45,000	45,000	750
Craniosynostosis syndromes: Apert's, Crouzon's, Treacher Collins, Moebius, Goldenhar	5,000	5,000	100
Portwine stains and other haemangiomas	160,000	42,000	10,000
<u>ACCIDENTAL CAUSES</u>			
Burns	60,000	12,000	2,000
Scarring and fractures	360,000	54,000	18,000
<u>CANCER TREATMENTS</u>			
Skin	75,000	15,000	37,500
Head and neck	16,000	16,000	8,000
Childhood	9,000	9,000	200
<u>EYE CONDITIONS</u>			
Loss of eye, squint etc – estimated	25,000	25,000	10,000
<u>PARALYSIS</u>			
Bell's Palsy	40,000	40,000	12,000
Stroke	60,000	60,000	140,000
<u>SKIN CONDITIONS</u>			
Acne and eczema	125,000	104,000	125,000
Epidermolysis bullosa and neurofibromatosis	28,000	14,000	2,000
Psoriasis	262,500	78,750	30,000
Vitiligo	75,000	22,500	20,000
TOTALS	1,345,000	542,250	415,550