

# THE SCAR FREE FOUNDATION

MAKING A WORLD WITHOUT SCARS A REALITY

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## CARe Burn Scales Responsiveness Study:

### Final Report to The Scar Free Foundation July 2020

**Title of grant project:** Detecting changes in patient reported outcomes over time following a burn injury: testing the responsiveness of the CARe Burn Scales.

**Project Acronym:** CARe-R (CARe-Responsiveness)

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## 1. EXECUTIVE SUMMARY

The impact of a burn injury and subsequent scarring on a person's physical, social and psychological well-being can be extensive (Lawrence et al, 2012; Attoe & Pounds-Cornish, 2015). Physical symptoms such as pain, sensitivity and itching of the scar itself are common, together with burden of treatment and psycho-social difficulties such as trauma symptoms, anxiety, depression, sleep disturbance and body image distress (Jones et al, 2017). Unwanted questions and comments about visible scars can be a source of ongoing stress for many (Martin et al, 2017a), and accounts of social avoidance, withdrawal, fear of being negatively judged by others, and negative impacts on self esteem and quality of life (QOL) are common across the lifespan (see, for example, Jones, Buchanan & Harcourt, 2017). Scarring concerns can impact on a child's life at nursery or school, while adults report difficulties in work, and establishing and maintaining romantic and intimate relationships (Lawrence et al, 2012). Whilst some people manage the challenges they face very well and may demonstrate positive outcomes and personal growth following a burn (Martin et al, 2017b), others struggle to make the adjustment and to redefine a sense of normality (Johnson, Taggart & Gullick, 2016).

Furthermore, the well-being of parents/carers supporting a child with a burn has largely been overlooked by research, yet they too can experience significant trauma and psychological difficulties when supporting their child (Griffiths et al, 2015; Heath et al, 2018). Parents can experience difficulties in social situations when others look or stare at their child's scarring and may struggle to know how best to respond and may develop a tendency to avoid future social situations. The parental relationship can also suffer when both parents are coming to terms with the event, changing parental roles and the practical and financial challenges of supporting a child with a burn injury (Griffiths et al, 2016; Phillipps, Fussell & Rumsey, 2007). Research indicates that parental coping predicts how well a child adjusts to their injury (Noronha & Faust, 2007). It is therefore vital for parents' psychological needs to be identified and for specialist psychological support to be provided, to ensure they feel equipped to cope with supporting their child.

Consideration of the wide ranging impact of burn scarring on the lives of patients and their parents/carers is vital in order to effectively assess their post-burn adjustment and identify any support needs, in order to ensure that they receive the most appropriate support and reduce the likelihood and impact of lifelong difficulties. In addition, good burn care provision and practice must be driven by outcome measures that can be reliably implemented and evaluated and include those reported by patients (Hardwicke, 2016).

Patient Reported Outcome Measures (PROMs) are tools to help health professionals identify the needs and therapeutic progress of patients and their family members (Griffiths, 2014). They are standardised and validated health-related questionnaires which patients complete before and after intervention (clinical or research). Injury/condition-specific PROMs tend to have greater face validity than generic measures since they are tailored to the experiences of a specific patient group and are therefore more likely to be sensitive to therapeutic change.

The National Health Service (NHS) Next Stage Review (Department of Health, 2008) highlighted the importance of using PROMs to evaluate healthcare services, inform commissioning and regulatory decision making, and recommended that all NHS Services use PROMs to evaluate outcomes in their service. However, the National Burn Care Review (2001) identified that PROMs were not routinely used in burn care and few burn-specific PROMs existed. This review concluded that the development of new PROMs for this population was a key priority.

In order to address this need, we have conducted a programme of work to develop and validate the CARE Burn Scales – a suite of four age-appropriate burn-specific PROMs (Griffiths, et al, 2019, Griffiths et al, a,b,c). We have followed a recognised, rigorous development and validation process (see Cano et al, 2004) based on the guidelines for the development of health outcome measures (Scientific Advisory Committee of the Medical Outcomes Trust, Aaronson et al, 2002). This involved a step-by-step process for item generation involving literature reviews, qualitative interviews with over 60 patients/parents and 20 health professionals, item reduction (using expert opinion and Rasch analysis) and psychometric evaluation (using psychometric criteria).

Specifically, the suite of CARE Burns Scales consists of the following:

- **Child Form** (for children aged < 8 years, parental proxy measure)
- **Young Person Form** (for young people aged 8 to 17)
- **Adult Form** (for adults aged 18 and over)
- **Parent Form** (for parents of children aged <18)

Previous psychometric testing with 1,302 participants showed construct reliability, internal consistency reliability and validity with other scales (Griffiths et al, 2019, Griffiths et al, a,b,c). However, further psychometric testing is needed before they can be used in the large-scale clinical and psychosocial research that is urgently needed within burn care. Specifically, evidence of their responsiveness (ie. their ability to detect change in patient reported outcomes over time) is needed in order to demonstrate their clinical efficacy and value in longitudinal burn scarring research (Smith et al, 2005). The current study was therefore conducted to develop and strengthen the psychometric evidence to support the use of the CARE Burn Scales in burn care research and clinical practice.

**Aim of the current study:** to test the responsiveness of the CARE Burn Scales to ascertain their ability to identify patient-centred health changes over time.

We conducted a longitudinal study with 15 NHS Burn Services across England, Scotland and Wales, collecting responsiveness data for the four CARE Burn Scales at 3 time points over a 6-month period: T1 (baseline: four weeks post burn); T2 (three months post burn); T3 (six months post burn)).

Participants completed the relevant CARE Burn scale (Child Form, Young Person Form, Adult Form or Parent Form), a number of other QOL PROMs, a set of single anchor health transition questions, and demographic questions. The data was then analysed to identify whether the CARE Burn Scales were able to detect change in patient reported outcomes over time.

During the project, in discussions with specialist burns clinicians/researchers and our study steering committee, it became apparent that producing Minimally Important Difference (MID) values for each subscale was essential in order for them to be as useful and effective as possible. The MID is a patient-centred value for changes on the PROM which reflects a clinically meaningful difference (Revicki, et al, 2008). This would enable clinicians to identify those who require further support, and inform them about treatment effectiveness and long term outcomes after a burn, allow researchers to plan and power studies with a focus on clinical outcomes from the patient perspective, and allow public health decision makers to be better informed. We therefore conducted MID analysis to provide further evidence of responsiveness of the CARE Burn Scales.