

Appendix

Appendix 1 – search strategy for HRQoL tools

A structured review of the literature was performed in November 2017 to identify current HNA, HRQoL tools and PROMs used in clinical practice and research within the burn population. To meet the objectives of the literature review, articles related to HRQoL assessment and articles outlining the original development of the tool were selected.

Search terms

1 Medical Subject Heading (MeSH) Burns – explode all trees.

2 Keyword Burn*.

3 Keyword Thermal Injury*

4 Keyword Holistic Need*s Assessment*.

5 Keyword Prompt list*.

6 MeSH term Survey and Questionnaires explode all trees.

7 MeSH term Health Service Needs – explode all trees.

8 Keyword – unmet need*.

9 OR #4 OR #5 OR #6 OR #7 OR #8

10 #1 OR #2 OR #3.

#11 #9 AND #10

Inclusion Criteria

- The tool must be utilised in an adult, burn population. With an adult defined as greater than 18 years of age, as this is when patients enter the adult health services. As the Burns PCI is intended for adults, paediatric tools were deemed irrelevant.
- Tool is patient reported. The aim of the Burns PCI is to prospectively identify patients' concerns, thus healthcare reported tools are irrelevant.

Exclusion Criteria

- Articles using instruments that were not patient reported (e.g. family member, carer or clinician). As the PCI aims to capture the concerns and issues of patients, tools capturing content from family members, carers or healthcare professionals were deemed irrelevant.
- Articles using generic PROMs that focus on one symptom (e.g. pain). A generic tool being defined as an instrument intended for use in general populations or across a wide range of disease conditions but not specifically to burns patients (Fayers and Machin, 2007). Whilst a number of such tools utilised in adult burn care research (Griffiths et al., 2017), it was believed that such tools mainly focused on assessing the severity of symptoms that were not directly derived from the burn population.
- Articles reporting data/utilising a tool from the paediatric population.
- Articles outlining the cultural validation of HRQoL tools were excluded.
- PROMs and HRQoL tools must have psychometric evidence confirming their reliability, validity and responsiveness; an essential criteria of a HRQoL tool (Aaronson et al., 2002).

Appendix 2 – Interview Questions

Introduction

Explain my experience as patient and doctor.

Explain the rationale behind the study providing an example of the H&N PCI to illustrate the intended purpose

Gain informed consent

Start Recording

Background information

Age:

Occupation:

Region:

Living arrangements:

Date of Injury:

Injury

Can you tell more about your injury?

Were you admitted to the hospital?

What aspects of your injury, either now, in the past or in the future concern you?

What aspects of your treatment, either now, in the past or in the future concern you?

What aspects of your injury or treatment or are important to you, either now, in the past or in the future?

Is this something that you might want to talk to your doctor or other healthcare professional about?

Close

Thank the patient for their time. Explain the next stage of the study – the Delphi and provide PIS. Take email address if patient is willing

Appendix 3 – List of Concerns Extracted from HRQoL tools.

HRQoL Tool	Domains of the Tool	Content Extracted
BSHS-B ²⁵	Simple abilities, heat sensitivity, hand function, treatment regimen, work, body image, affect, interpersonal relationships and sexuality.	Heat sensitivity, skin sensitivity, loneliness, low mood, hand function, work, day to day, sex, family, emotions, appearance, wounds, self-care, daily activities, social interactions, dressings, acceptance, scars and anxiety.
YABOQ ²⁶	Itch, family function, satisfaction with role, family concerns, pain satisfaction with symptoms, appearance, fine motor, social function, social function limited by appearance, sex and religion.	Itch, pain, mobility, hand function, hobbies/interests, appearance, peoples' perceptions, frustration, sex, anger, family, appetite, the future, sleep, work, study, religion, relationships, food, scars, uncertainty and anxiety.
BSPAS ²⁷	N/A – Symptom specific.	Wound healing, anxiety, dressing changes, pain, treatment, coping and surgery.
POSAS ²⁸	N/A Symptom specific.	Scar shape, scar size, scar texture, pain and itch.
SWAP ²⁹	N/A Symptom specific.	Family, people's perception, relationships, appearance, intimacy, friends, acceptance.
ED5Q ³⁰	Mobility, self-care, usual activities, pain/discomfort and anxiety and depression.	Mobility, Self-Care, Day to day activities, hand function, pain, anxiety and depression.
SF36 ³¹	Physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health	Interest/hobbies, mobility, hand function, self-care, energy, fatigue, friends, family, relationships, pain, anxiety, exercise and concentration.

Appendix 4 Content generated from the MDT.

Professional	Number	Items Added
Consultant Burns Surgeon	3	Camouflagability Guilt Blame Stigma weight
Consultant Anaesthetist	2	Toileting Chronic pain Neuropathic pain
Consultant Clinical Psychologist	3	Drug and alcohol use Flashbacks Withdrawal from usual activities /Isolating self Staring Function generally Pain generally Nightmares Intrusive thoughts or images Guilt Embarrassment Avoidance of reminders of accident/injury Comments and questions from others Contractures Frustration Hypervigilance – increased awareness of danger Inability to do certain tasks Loss of functioning
Physiotherapist	3	Function Normality Therapy Touch Confidence Ownership Responsibility Time Enjoyment Fear Future Confusion
Occupational Therapist	2	Compliance
Staff Nurse	4	Reconstruction Exclusion Future – what does it hold? Future – fear Isolation Why me?

		Family's response Family support Friend's response Guilt Further surgery What now? Dry skin I'm ugly They're ugly (scars) This is me now
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Appendix 5- List of the total number of items identified

HRQoL tools	Patients	Staff
Acceptance	Acceptance	Avoidance of reminders of accident/injury
Anger	Alcohol	blame
Anxiety	Anger	Camouflagability
Appearance	Anxiety	Chronic pain
Appetite	Appetite	Comments and questions from others
Concentration	Avoidance	Compliance
Coping	Body image	Confidence
Daily activities	Bullying	Confusion
Day to day activities	Burning pain	Contractures
Depression	Camouflage	Dry skin
Dressings	Chronic pain	emotion
Emotions	Coping	Enjoyment
Energy	Creams	Exclusion
Exercise	Daily living	Exercise
Family	Depression	Family's response
Family	Dressing changes	flashbacks
Fatigue	Driving	Friend's response
Food	Family	Frustration
Friends	Family Support	Function
Frustration	Fatigue	Further surgery
Hand function	Fear	Future – fear
Heat sensitivity	Finance	Future – what does it hold?
Hobbies/interests	Flashbacks	GP
Interest/hobbies	Guilt	Guilt
Intimacy	Hair	Hyperalgesia/increased sensitivity to pain
Itch	Hand function	Hypervigilance – increased awareness of danger
Loneliness	Heat sensitivity	I'm ugly
Low mood	Hobbies	Inability to do certain tasks
Mobility	Infection	information
Pain	Information	Isolation
Peoples' perceptions	Intimacy	Loss of functioning
Relationships	Itch	Neuropathic pain
Religion	Legal Implications	Normal

Scar Shape	Low mood	Normality
Scar size	Medication	Online information
Scar texture	Mobility	Ownership
Scars	Nerve pain	personality
Self care	Pain	Reconstruction
Sex	People's perception	Responsibility
Skin sensitivity	Personal care	splints
Sleep	Pregnancy	Stigma
Social interactions	Pressure Garment	stress
Study	Psychological Trauma	Support groups
Support for my family	Relationships	Therapy
Surgery	Scarring	They're ugly (scars)
The future	Self-Esteem	This is me now
Uncertainty	Skin sensitivity	Time
Work	Skin strength	To be touched
Wound healing	Sleep	Toileting
Wounds	Smoking	Touch
	Splint	weight
	Tightness	What now?
	Travel	Why me?
	Treatment	
	Weight	
	Work and education	
	Wound care	