Adapting a Patient Concerns Inventory (PCI) for parents of children under four with burn injuries

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Background

Paediatric burns are among the most common serious childhood injuries, with the highest incidence in children under four (1).

These children cannot self-report concerns during clinical encounters, so parents act as their voice but frequently struggle to articulate concerns in time-pressured appointments, risking important issues being missed(2,3).

The Adult Burns Patient Concerns Inventory (AB-PCI) already exists to facilitate structured patient-clinician communication in adult burns care, but no equivalent paediatric tool exists, leaving a significant gap in structured parental proxy communication.
(4,5).

Aims

This project employed a two-phase approach to explore and begin development of a Paediatric Burns PCI (PB-PCI).

Phase 1 — Scoping

Exploratory Aims

- Review current literature on unmet needs and concerns in paediatric burns.
- Investigate if prompt sheets and similar tools are used.

Informative Aims

- Determine the most appropriate format(s) for a PB-PCI.
- Identify initial steps toward the design and content of a PB-PCI.

Phase 2 — Survey & Data Collection

Primary Aims

- Assess which items should be retained.
- Identify items for exclusion.
- Highlight items needing modification.
- Collect item suggestions from parents and clinicians for addition.
- Capture suggestions for modifications to existing AB-PCI items.

Secondary Aims

- Collect data on the roles of clinician participants.
- Document demographic details of the children of parental participants.

Methods

Phase 1 — Scoping

A Review of PCI literature

Prompt Sheet Use in Paediatric Burns

Scoping review

Search Returned 48 Papers

5 Included After Screening

Unmet Needs and Concerns in Paediatric Burn Care

Scoping Review

Search Returned 47 Papers

47 Included After Screening

Stakeholder Engagement — Children's Burns Trust (CBT)

CBT ambassadors (parents and their children with burn injuries) met online to provide feedback on the project.
Outcomes
Confirmed parents of under-fours as initial PB-PCI population.
Endorsed facilitated survey delivery with parent and clinician input.
Suggested age-stratification.
Review of previously used Alder Hey prompt sheets to identify overlapping content

Phase 2 — Survey & Data Collection

Parental Survey

Recruited 13 Parents of children under 4
≥8 weeks post-healing
at Alder Hey and by telephone

Facilitated completion in a separate clinic room to reduce bias

Rated each AB-PCI item: Keep, Modify or Remove; suggested additional items

Clinician Survey

Recruited 20 Qualified paediatric burns clinicians, regularly interacting with patients
locally (Alder Hey), regionally and nationally via BBA mailing

Delivered using a Self-administered; pilot tested survey.

Rated each AB-PCI item: Keep, Modify or Remove; suggested additional items

Data Handling & Analysis

Items were classified using the following pre-defined consensus thresholds

- **RI** (Retained Item): ≥70% "Keep" from at least one group
  - **HC** (High Consensus): ≥80% "Keep" from both groups
  - **MC** (Moderate Consensus): ≥70% both groups, one ≥80%
  - **LC** (Low Consensus): ≥70% from one group only
- **EI** (Excluded Item): ≥30% "Remove" from either group
- **MI** (Modified Item): ≥25% "Modify" from either group (not excluded)
- PSIM (participant suggested item modification): Free-text suggestions for MI items
- PSAI (Participant suggested additional item): Free-text suggestions for new items absent from AB-PCI

Draft PB-PCI-PU4 Produced

Ethics: Service evaluation/PROMs development, Alder Hey Children's Hospital clinical governance. NHS REC approval not required. GDPR-compliant throughout.
Responses were stored securely and analysed descriptively.

Results

Scoping Phase

Unmet Needs and concerns: Identified 6 concern domains (physical/functional well-being, psychological/emotional needs, carer-specific burdens).
Evidence of concerns changing with age and widespread parental proxy reporting.

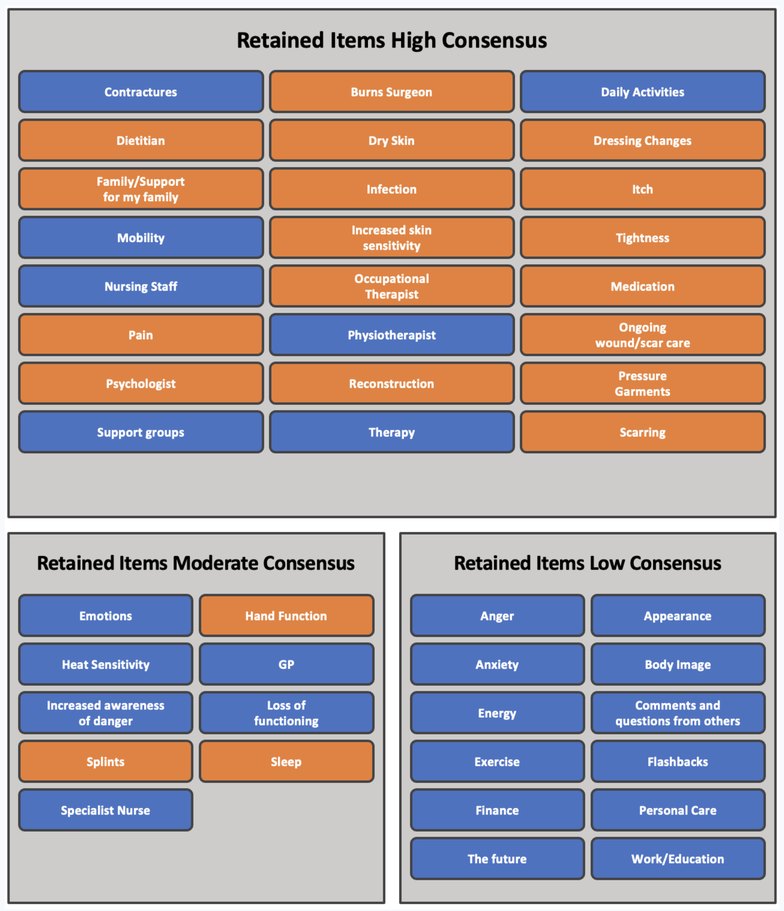
Prompt Sheets: Parental proxy reporting within structured tools was acceptable and reliable. Patient self-reporting preferred where available.

Children's Burns Trust: AB-PCI an appropriate foundation with parental proxy version for under-fours identified as logical starting point. Age-specific versions suggested.

Modified Items

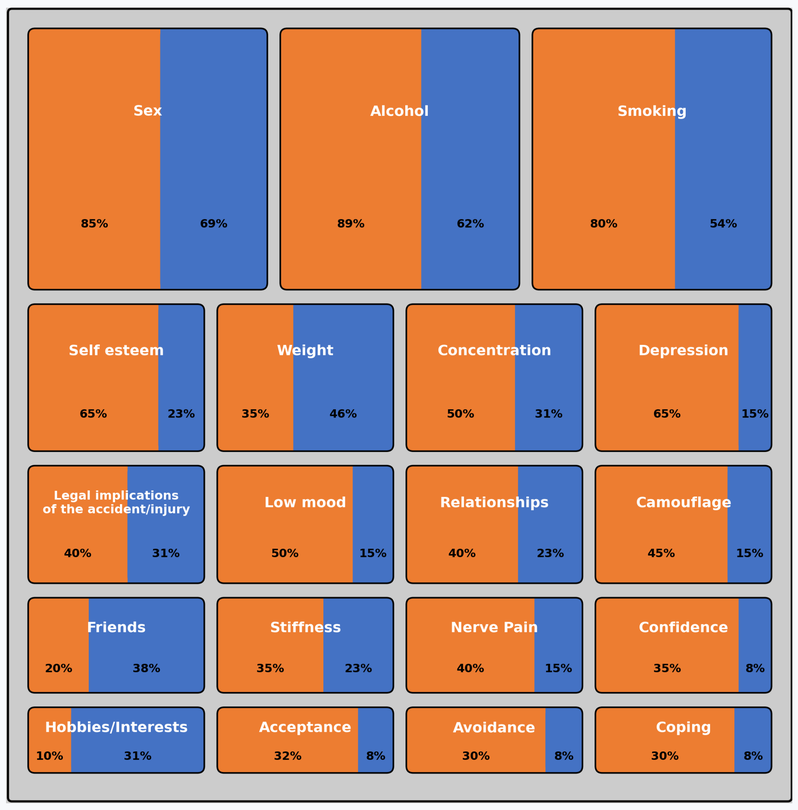
50 items received at least one suggestion for modification.
Age relevance was the most common modification category
All 6 items were clinician-endorsed for modification
Anger (35%)
Flashbacks (40%)
Work/Education (30%)
Anxiety (25%)
Appearance (25%)
Body image (26%)

Figure 1. AB-PCI Retained Items (RI) Grouped by Consensus Level and Primary Endorsing Group



AB-PCI Retained items (RIs) are items endorsed for inclusion in the PB-PCI-PU4. Items are categorised by consensus level: RI-HC (High Consensus, ≥80% "Keep" from both clinicians and parents, n=24); RI-MC (Moderate Consensus, ≥70% "Keep" from both groups with at least one group reaching ≥80%, n=9); RI-LC (Low Consensus, ≥70% "Keep" from at least one group, n=12). Colour coding of the primary endorsing group: orange = clinician-primary (clinician "Keep" % ≥ parent "Keep" %); blue = parent-primary (parent "Keep" % > clinician "Keep" %). No items received equal endorsement from both groups. Items meeting the exclusion threshold (≥30% "Remove" from either group) have been removed prior to classification (n=19 excluded).

Figure 2. Excluded Items (EI) from the AB-PCI Ranked by Combined Removal Endorsement Rate with Clinician and Parent Contribution



AB-PCI items exceeding the 30% exclusion threshold (≥30% "Remove" endorsement from either parent or clinician respondents) were excluded from the draft PB-PCI-PU4 (n=19). Items are ranked by combined exclusion endorsement rate (clinician + parent); box area reflects total combined endorsement. Colour split indicates the proportion attributable to each group: orange = clinician "Remove" %; blue = parent "Remove" %. Items with the highest combined endorsement included alcohol (89% clinician, 62% parent), sex (85%, 69%), and smoking (80%, 54%). Notable divergence was observed for depression (65% clinician, 15% parent) and self-esteem (65%, 23%). Three items were primarily parent-endorsed for exclusion: hobbies/interests (10% clinician, 31% parent), friends (20%, 38%), and weight (35%, 46%). n=20 clinicians, n=13 parents.

Discussion

This is the first project to adapt the Adult Burns PCI for use in paediatric care, producing a structured tool to help parents of children with burn injuries communicate their concerns during clinic appointments.

Of 70 AB-PCI items reviewed, 45 were retained across three levels of consensus, covering physical, treatment-related and psychosocial concerns. In total 19 items were excluded for clear adult-orientation.

Notably, parents' and clinicians' opinions sometimes diverged, for example on depression and self-esteem, highlighting the importance of capturing both perspectives.

Strengths: Evidence-based approach; input from both parents and clinicians; systematic item-by-item evaluation.

Limitations: Small parental sample from a single centre; requires formal validation before clinical use.
This work demonstrates that developing a paediatric burns concerns checklist is not only feasible but needed. The project acts as a foundation for further validation and age-specific versions that could transform how families and clinicians communicate across all stages of childhood.

Future Directions

Clinical piloting in outpatient burns clinics to assess usability and consultation impact.

Formal validation across multiple UK burns services.

Item refinement through formal focus groups and interviews to confirm items modifications and any additional items prior to finalisation.

Age-appropriate versions for older children and adolescents, including self-reported formats.

Translation into other languages to support non-English-speaking families.

Figure 3. Draft PB-PCI-PU4 Adapted from the AB-PCI

Insert tailored branding for PCI users/Burns services here.

Paediatric Burn Patient Concerns Inventory [PCI] for Parents of Children Under 4

Please choose from the list of issues you would specifically like to talk about in your child's consultation in clinic today.
You can choose more than one option (tick boxes).

Physical and functional well-being:
- ☐ Contractures
- ☐ Daily Activities
- ☐ Dry Skin
- ☐ Energy
- ☐ Exercise
- ☐ Hand Function
- ☐ Heat Sensitivity
- ☐ Increased skin sensitivity
- ☐ Itch
- ☐ Loss of functioning
- ☐ Mobility
- ☐ **Nerve Pain**
- ☐ Pain
- ☐ Scarring
- ☐ Sleep
- ☐ **Stiffness**
- ☐ Tightness
- ☐ **Weight**

Social Care and Social well-being:
- ☐ Family/Support for my family
- ☐ Finance
- ☐ **Friends**
- ☐ **Hobbies/Interests**
- ☐ **Legal implications of the accident/injury**
- ☐ Personal Care
- ☐ ***Work/Education***

Psychological, emotional and spiritual well-being:
- ☐ **Acceptance**
- ☐ **Alcohol**
- ☐ ***Anger***
- ☐ ***Anxiety***
- ☐ ***Appearance***
- ☐ ***Body image***
- ☐ **Avoidance**
- ☐ Comments and questions from others
- ☐ **Concentration**
- ☐ **Confidence**
- ☐ **Coping**
- ☐ **Depression**
- ☐ Emotions
- ☐ ***Flashbacks***
- ☐ Increased awareness of danger
- ☐ **Low mood**
- ☐ Psychological Trauma
- ☐ **Relationships**
- ☐ **Self esteem**
- ☐ **Sex**
- ☐ **Smoking**
- ☐ The future

Treatment related concerns:
- ☐ **Camouflage**
- ☐ Dressing changes
- ☐ Infection
- ☐ GP
- ☐ Medication
- ☐ Ongoing wound/scar care
- ☐ Pressure Garments
- ☐ Reconstruction
- ☐ Splints
- ☐ Support groups
- ☐ Therapy

Suggested Additions
- *Play*
- *Play Therapist*
- *Burn Club/Camp*
- *Starting School*
- *Development*
- *Siblings*
- *Guilt*
- *Future Treatment*

Name:

Affix label here

The Draft PB-PCI-PU4 adapted the AB-PCI (4) to show items retained (Black), excluded (Red), and modified (Orange Italics). Domains were unaltered to demonstrate areas of exclusion and modification, e.g., the psychological, emotional and spiritual well-being domain. Frequently suggested additional items from the data were also included.

Insert tailored branding for PCI users/Burns services here.

The following page gives you the opportunity to highlight people you may wish to talk to. Are there any people you would specifically like to talk with either in clinic or by referral?

- ☐ Burns Surgeon
- ☐ Nursing Staff
- ☐ Specialist Nurse
- ☐ Psychologist
- ☐ Dietician
- ☐ Occupational Therapist
- ☐ Physiotherapist
- ☐ Other: .....

Thank you for your time. All information is confidential. We found PCI has helped patients express issues in their clinic. Please hand this is to clinic staff.

© Acknowledgements regarding the creation of the PB-PCI

Affix label here

Name:

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