

HARG Workshop on wearable medical device data

2018-07-23

The GLOVE Project: Remote data-capture in hand-care, the implications for IT governance of routine-monitoring with patients

Adults, children, parents affected by EB

King's College London

Guy's and St Thomas NHS Foundation Trust

Great Ormond Street Hospital NHS Foundation Trust

Cardiff University

University of Surrey

Longhand Data Limited

Skinwear Limited

SFM Limited



Session Plan

- GLOVE Project Background
- Co-design methodology & iterative validation with NHS clinicians, patients, parents
- Splint Glove Overview
- Hand Therapy-online application
- Evaluation of the Hand Therapy-online in routine practice with a view to implementation
 - NIHR Ready; Steady; Go: Telehealth Implementation Toolkit (<http://clahrc-yh.nihr.ac.uk/industry/ready-steady-go-telehealth-implementation-toolkit>)

IT governance processes
are embedded in the
conduct of the GLOVE
Project

- GLOVE is a research project delivering hand therapy devices and telehealth care system *with* patients, parents, clinicians
- GLOVE follows Health Research Authority Research & Information Governance processes
- Longhand Data Limited operate under Accredited Information Security Management and Quality Management Systems
- GLOVE implementation follows the NIHR Ready; Steady; Go telehealth implementation Toolkit

Background

Generation and evaluation Of hand therapy deVices for Epidermolysis –

GLOVE Project

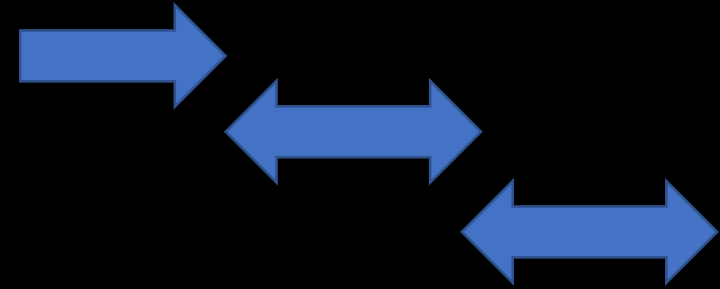
NIHR 11-01-0513-10001

- EB skin blisters and heals with adhesions and scarring
- Re-blistering is the norm
- Deformities include finger webbing, contractures, and loss of function
- Current devices that can delay deformities are not tolerated
- Surgical interventions are short lived – patients are lost to follow-up (range 1 month to 6 years)
- There is no method of systematically & routinely charting deformities, therapies, outcomes or costs

Methodology - Experience Based Co-design

- Participatory approach; values and uses individual experiences to improve medical devices
- Design sciences: use of design principles to 'design-out' limitations of wound care devices and systems with people with EB and the clinicians

Research user need
Visualise Solutions
Prototypes and Refine



- Bate P, Robert G Experience-based design: from redesigning the system around the patient to co-designing services with the patient. Qual Saf Health Care. 2006 October; 15(5): 307-310. doi: [10.1136/qshc.2005.016527](https://doi.org/10.1136/qshc.2005.016527)
- Design for Public Good (2013) www.seeplatform.eu



**Current fabricated devices to delay deformities:
finger wrapping, scar-management gloves, 'in-house' splints**

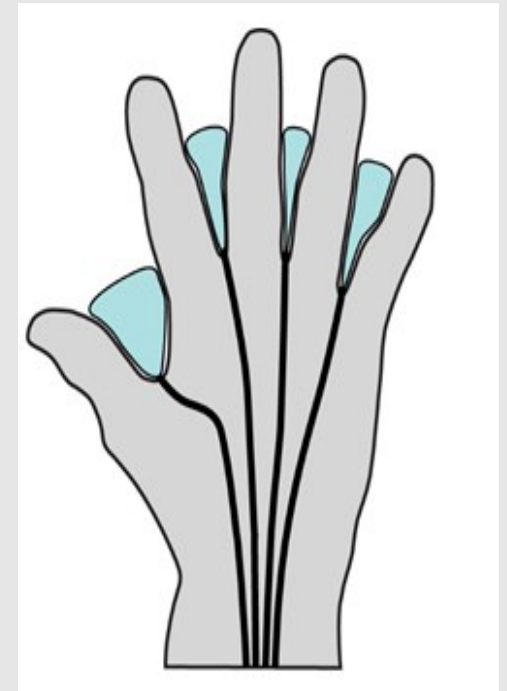
The request: devices to manage blisters and web spaces; a Therapy-Online system *co-designed* with users



Dressing glove



Skinnies WEB™ web spacer glove



Adjustable Splint Glove:
measurement via sensors &
individualised pneumatic
splinting *built onto the glove,*
connecting it to the Hand
Therapy-Online system

Hand Therapy-online

Application of Longhand Data Limited Digital Data Capture system: Information Management and Quality Management Systems and Accreditation

- Interface with NHS Electronic Patient Record systems for routine charting of hand deformities and clinical outcomes of hand therapy
- Remote data input and access to data: clinicians, patients, parents
- TELER™ patient-recorded outcome measures of observable changes in hand/skin condition; hand function; experiences of hand devices
- Hand measurements recorded by clinicians (face-to-face); digital measurements via the splint glove

The screenshot displays the TELER Hand Therapy online system interface. At the top, there is a navigation bar with the TELER logo and user options: Patient List, Active Careplans, My Account Dashboard | Account | Logout, Create New User, and Edit User. Below the navigation bar, the breadcrumb trail reads: Where am I: Home >> Patient List >> Active Care Plans >> Care Plan >> Add Contact.

Care Plan: Add new contact

Date: 15/09/2017
Time Taken:
Time Code:

If you are completing a Left or Right Hand Assessment, please also complete this section:
Who measured the indicators: Location when treatments performed: Who performed the treatments:

Indicators	Target
1 HT0001: Hand skin condition: Location of blisters	5 <input type="text"/>
2 HT0002: Hand skin condition: Appearance of skin	5 <input type="text"/>
3 HT0003: Hand skin condition: Appearance of wounds	5 <input type="text"/>
4 HT0004: Hand skin condition: Removal / accidental degloving	5 <input type="text"/>
5 HT0005: Second finger web space	5 3 <input type="text"/>
6 HT0006: Third finger web space	5 2 <input type="text"/>
7 HT0007: Fourth finger web space	5 <input type="text"/>
8 HT0008: Thumb web space	5 <input type="text"/>
9 HT0009: Wrist function	5 <input type="text"/>
10 HT0010: Hand pain related to an activity	5 <input type="text"/>
11 HT0011: Ability to hold a pen	5 <input checked="" type="radio"/>
12 HT0012: Ability to hold a can of drink (330ml for adults, 150ml for children)	5 <input type="text"/>
13 HT0013: Experiences of dressing changes on the hands	5 <input type="text"/>
14 HT0014: Experiences of hand dressings	5 <input type="text"/>
15 HT0015: Hand pain related to an activity 2 Something else	5 <input type="text"/>

ADD INDICATOR

Treatments

Left (dom)	Target
Mepitel one - 6x7cm soft silicone wound contact layer	<input type="text"/>
Polymer - 20cm x10cm Multifunctional soft, absorbent wound care dressings with	<input type="text"/>

Patient Notes

S

O

A

P

General Comments

Indicator Codes

HT0011: Ability to hold a pen

- 0. Unable to hold a biro
- 1. Able to hold a biro between both hands if someone places it there
- 2. Able to hold a biro if both thumbs and first fingers (index) are used
- 3. Able to hold a biro between thumb and first (index) finger, placing it there with the other hand
- 4. Able to hold a biro between thumb and first (index) finger
- 5. Able to hold a biro between thumb, first (index) finger and second (middle) finger
- N. Not measured

Upload Files

Left

Conclusions

- The splint glove and the Hand Therapy-online system enable:
 - Evidence informed remote measurement, treatment and management of hand deformities arising from EB
 - Remote and face-to-face routine measurement and charting of hand skin condition, hand function, responses to treatment, experiences of individuals with EB
- The GLOVE Project and current implementation are underpinned by co-design, research and information governance methodology and processes