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 II-OL-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

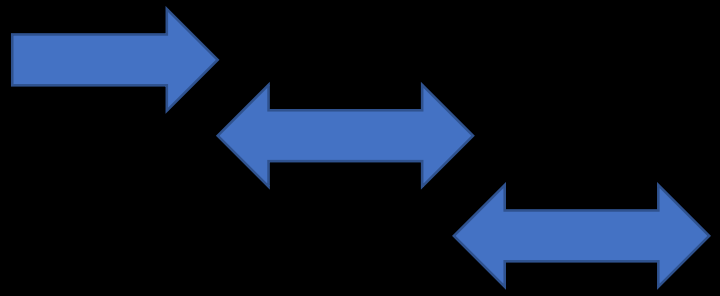
Methodology - Experience Based Co-design

- 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

- Design for Public Good (2013) www.seeplatform.eu

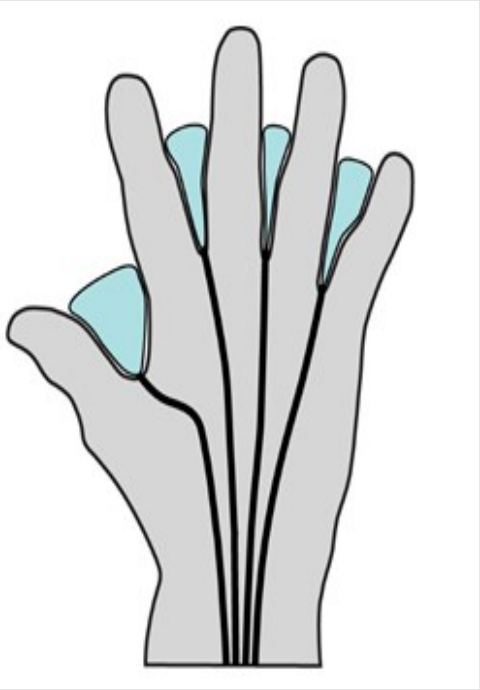



Current fabricated devices to delay deformities:
finger wrapping, scar-management gloves, 'in-house' splints

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

Dressing glove

Skinnies WEB™ web spacer glove

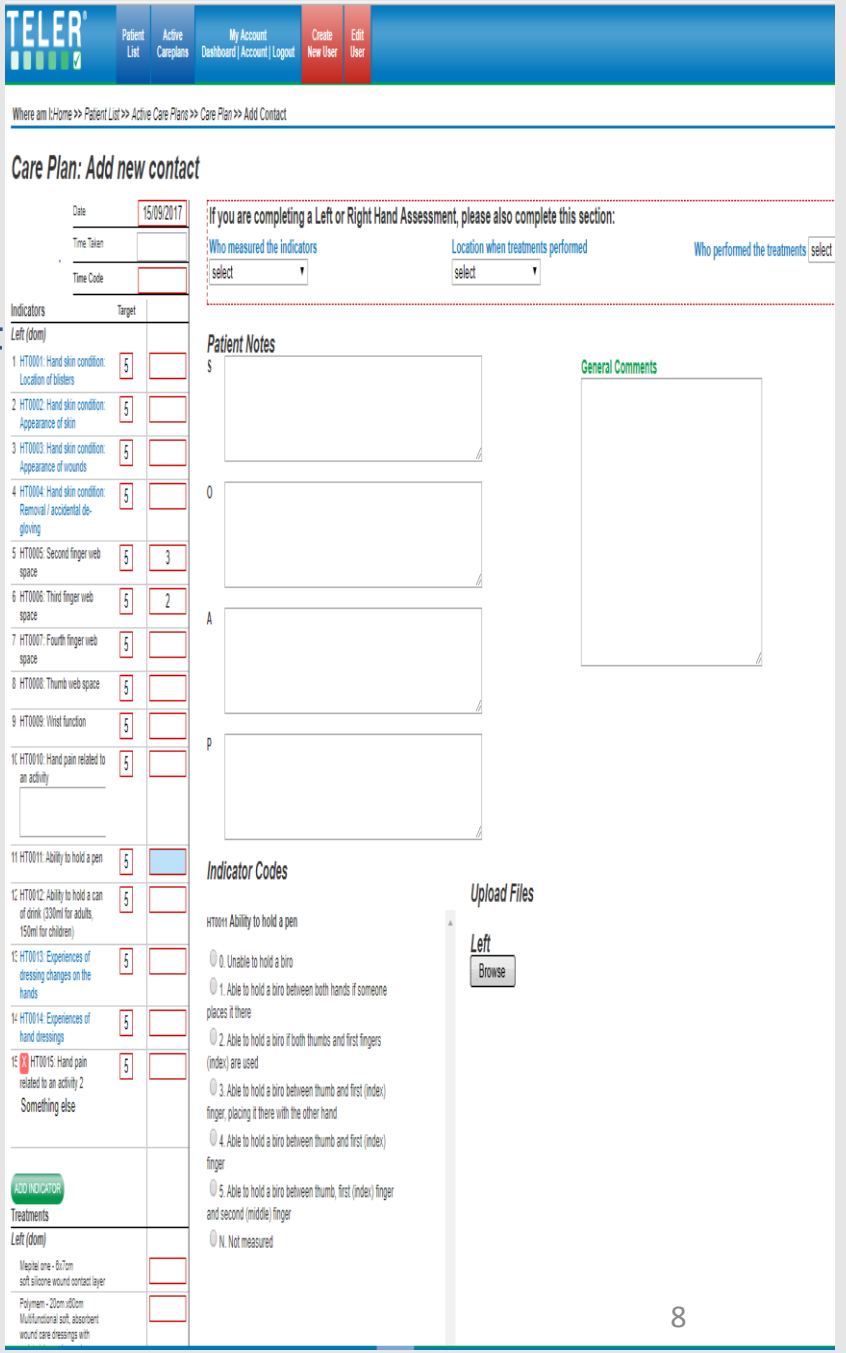


Adjustable Splint Glove: measurement via sensors & individualised pneumatic splinting *built onto the glove, connecting it to the Hand Therapy-Online system*

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



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