



## Using a Limb Lengthening Informed Consent Module for a Paediatric Population to Assist in Pre-operative Education

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## Paediatric Orthopaedics – Why is it so special?

- Not dealing with the patient directly whilst obtaining consent – this task falls to the parent, not the patient
- Must have a full understanding of what consenting to, and implications for everyone, not only self
- Children are not little adults, and respond differently to surgical process

## What about Limb Reconstruction? (LR) – Why is this different?

- Difficult concept to grasp
- High engagement and buy in required – compliance issues
- Long treatment times
- Many complications – from the minor to the potentially catastrophic
- Confronting in appearance for parents, siblings and child
- Multi disciplinary approach – so lots of players
- They are children!



- The education process must be thorough, clear and understandable



- And involve all the relevant parties, including the child

# However.....

- Literature tells us that:
  - 44% of patients are unaware of even the basic nature of the surgery they had recently undergone Byrne, BMJ, 1988
  - 10 – 29 % can't recall the information given to them 6 months later Hutson, JBJS 1991
  - Only 40% of patients read the informed consent before signing it Cassileth NEJM 1980

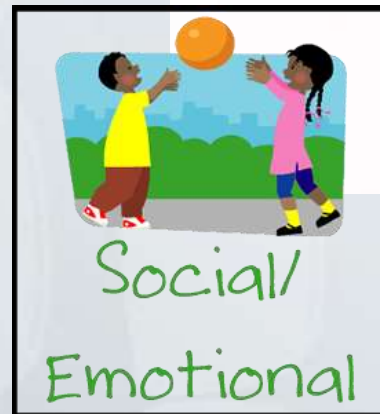
# Learning types

- Visual
- Auditory
- Written
- Kinaesthetic



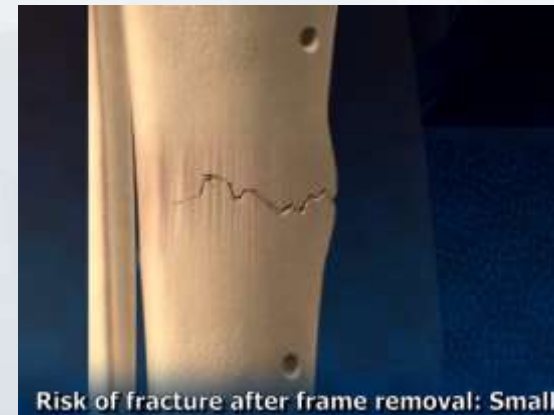
# Ability to learn

- Education
- Culture
- Social
- Literacy
- Trust
- Emotion



# Elements of informed consent

- Nature of the problem
- Aim of the operation
- Limitations of the surgery
- Operative details
- Post operative course
- Expected benefits
- Consequences
- Complications





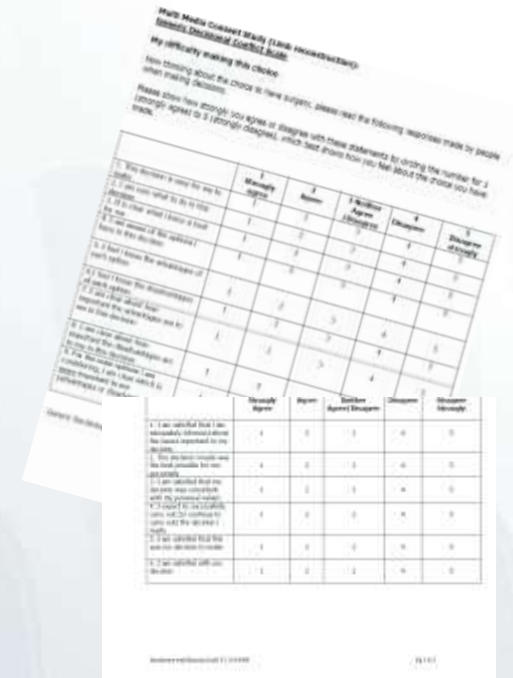
# Use of animation

## Allows

- The complicated to be made more simple
- Incorporate the various learning styles
- Cope with different learning abilities

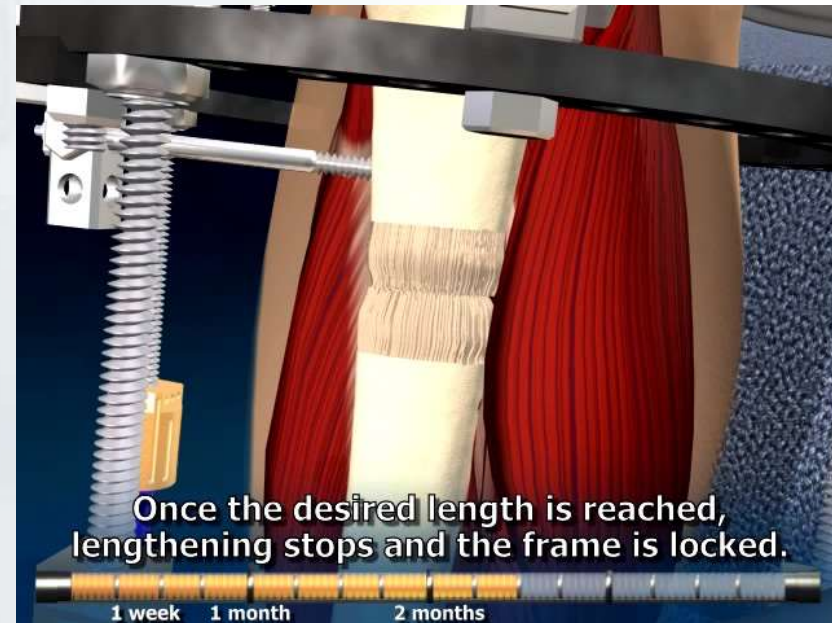
# Developing the module

- Educational objectives set
- Literature Review
- Script
- Story board
- Animation
- Questionnaire development



# Module made use of

- Pictures/Visual
- Words – writing on screen
- Voice / sound – via headphones or speakers



# The project – 2007 to 2012

- Commenced recruitment in 2007
- Study: Prospective, randomized, multi centred, controlled trial
- 68 subjects recruited out of 116 approached
  - Inclusion criteria
    - Significant interest in LR
    - Ability to consent
    - English speaking
    - Over 14 years of age
  - Exclusion criteria
    - Cognitive, visual or hearing impairment

# Further randomisation:

- Previous involvement in Limb Reconstruction
- Over or under 18 years of age

# Module use



- Included as part of the normal preadmission process
- 1 hour information sharing session
- Multi-disciplinary session
- Involves –
  - Seeing/touching a frame, videos, photos, discussion about practical issues, pain management, expectations of appointments, care of the frame, pin site management, LOS, what to look for, what to do, community support, schooling implications – **using all types of learning styles**

# Issues identified

- Eligible for inclusion but
  - Changed mind
  - Could not give the time (young children)
  - Subjective decision on our part not to include
  - Illness
- Made preadmission time very long – staff and family

# Feedback - on the spot

- Module too long – 30 minutes
- Too confronting – didn't want to know
- Wanted to see it again
- Wanted to see at home on internet at leisure
- Would like to show it to others



# Found improvements in

- Satisfaction with the information
- Consistency of information given
- Ease of decision making
- Retention of knowledge over time
- Compliance
- Decreased hospital stay – patients doing better

# So...where to from here?

- Project completed
- Will use the module for all leg lengthening patients (once payment sorted)
- View in own home with a log on
- Module time has been reduced in length
- Cost per view charged to hospital (\$7.00)
- Questionnaires no longer done so decreases time

# Summary

- Paediatric limb reconstruction is a complex area so we need to find better ways to communicate & illustrate this to families
- Long journey but worthwhile
- Looking forward to a bright future with more improvements in changing how we obtain an informed consent from parents & offer them high level & consistent information



# Acknowledgments

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# Thank you



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Excellence in clinical care, research and education

