Improving care and outcomes in adolescent arthritis through patient input, telemonitoring, and personalised feedback

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Juvenile Idiopathic Arthritis

Independence

Sexuality

Body Image

Peer Relationships
Juvenile Idiopathic Arthritis

• < 16 years of age
• 1 in 1,000 children in the UK
• Symptoms
Treating JIA

• Monitoring & medications
• 20-25% of missed appointments
• Low physical activity
• Improve self-management
centre for adolescent rheumatology

Health Care Apps
Phase I

- 5 JIA patients 10-14 years old (2 females)
- 5 JIA patients 17-24 years old (2 females)
- 7 parents

2 FGs with 19 HCPs
Phase 2

- 7 JIA patients 10-14 years old (4 females)
- 6 JIA patients 16-23 years old (5 females)

2 FGs with 15 HCPs
Results

• **Theme 1:** Monitoring

• **Theme 2:** Reminders

• **Theme 3:** Education & support

• **Theme 4:** Motivation

• **Theme 5:** Design
Theme 1: Symptoms
Theme 1: Health Assessment

DRESSING and GROOMING

Are you able to:

- Dress yourself, including tying shoelaces and doing buttons?

- Without ANY Difficulty
- With SOME Difficulty
- With MUCH Difficulty
- UNABLE to do
- Not Applicable

Please check any disturbances which may have been caused by the medication you are taking:

- None
- Vomiting
- Weight gain
- Weight loss
- Fever
- Headache
- Skin rash

How many days of school did you miss IN THE PAST WEEK?

- 0
- 1
- 2
- 3
- 4
- 5
Theme 1: Monitoring Mood

Indicate how much you felt these emotions:

- Angry
- Anxious
- Sad
- Neutral
- Energetic

Do you feel stressed?

- I didn't feel any stress at all
- I felt a little stress
- I clearly felt stress
- I felt too much stress
- I felt a lot of stress
- I felt the worst stress I can think of

Have you had any problems relating to the following?

- parents or siblings
- getting made fun of/bullied
- getting into trouble
- academic deadlines
- health
- friends
- girl/boyfriend
Theme 1: Monitoring Exercise

**HIP ABDUCTORS**
- Lying on your side with both legs straight and pointing slightly backwards. Lift your upper leg up to the side and backwards. Do not twist your back (keep your hip leaning forward). Return leg to the starting position slowly.

**Sets:** [3]
**Repetitions:** [4]

**HIP EXTENSORS**
- Lying face down. Lift your leg towards the ceiling.

**Date:** 08/10/2015
**Sport:** Surfing

**Duration (HH:MM):** 01:03:00

- Reset
- Save
Theme 2: Reminders
Theme 3: Education & Support

As you grow up, it is normal to occasionally feel sad or be annoyed at your arthritis. However, there are things you can do to help you manage your stress and anxieties.

Occasionally, young people may experience bullying at school. It is important to let a parent or teacher know about this.

For emotional and practical support and information for anyone affected by arthritis, visit: Arthritis Care helpline.

Offers help for young people with any worries or distress, visit: Childline.

mark as read (collect points in 7 sec.)
Theme 4: Motivation
Theme 4: Motivation
Theme 5: Design

- HAQ
- Symptoms
- Mood
Evaluation

“...The app itself is already beneficial to the users, but the images as rewards is actually pretty nice and simple. I like it.”

“I think this app is very good, especially for doctors to use for assessment.”

“Especially when you’re first diagnosed, doctors should tell you about this.”

“The app is a good way to keep track of my symptoms.”
• Despina Eleftheriou
• Alice Cai
• Hema Chaplin
• Stephen Hailes
• Linda Suffield
• Lucy Wedderburn
• John Ioannou
• Debajit Sen
• Brenda Bell
• Patients, Families, and HCPs