Exploring the Future Role of Self-Tracking Data in the Rheumatology Clinic

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About the Authors

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Introduction

• Growing interest from patients and professionals
• Chronic conditions
• Collaborative review of self-tracking data
What do patients and clinicians want from self-tracking data?
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Background & Related Work

What do patients and clinicians want from self-tracking data?
What are the issues?
Co-interpertation of patient self-tracking data

View-Crafting

Knowledge-Sharing
Co-interpretation of patient self-tracking data
… not without its own set of challenges

- Time constraints
- Information overload
- Frequency of appointments
- Conflicting agenda
Research Questions

- What is the typical workflow of a clinical consultation?
- What potential roles can self-tracking data play in the clinic?
- How do we design systems to support co-interpretation activities?
Background

Ankylosing Spondylitis (AS)

- Inflammatory rheumatic disease
- Debilitating and progressive
- Multi-phase healthcare pathway
**Context of Study**

- **Project Nightingale / uMotif application**
  - Symptoms: Pain, fatigue, eyesight etc.
  - Medications: Dosage, adherence etc.
  - Physical activities: Steps, duration, sleep etc.
  - Mental state: Mood, stress etc.
  - Lifestyle: Screen time, caffeine intake etc.

Hi, how are you feeling today?
- **Location** – Royal National Hospital for Rheumatic Diseases (RNHRD)
- **Participants** – 2 rheumatologists, 28 AS patients (Male=17, Female=11, Mean age=29.1 years)
- **Methods** – clinical observation (Mean duration = 17.0 mins), clinician interview (Mean duration = 33.0 mins)
Findings

- Two-phase model
- Existing clinical procedure and data categories
Out-of-Clinic Phase

- Patient onboarding
- Medical examination
- Supplementary examination
- Self-management & intervention
Clinical Check-Up Phase

- 15-20 mins appointment
- Synchronous, co-located patient-clinician interaction
- Six sequential activities
**Preparation (2-3 mins)**

- Review and familiarise with patient’s data
- Summary care records
- Medical examination results
- Clinician-reported outcomes
Evidence Gathering (3-5 mins)

- Data collection for diagnosis and decision-making
- Quick-fire questions
- Patient-reported outcomes
- Clinician-reported outcomes
Physical Examination (2-5 mins)

- Supplementary data collection
- Physical conditions
- Range of movement
**Reasoning Aloud (3-8 mins)**

- Data curation
- Sensemaking and transference of knowledge and data insights
- Leverage disease-specific expertise and own experiences/knowledge
- Holistic view on disease status
**Action Planning** *(3-5 mins)*

- Treatment planning
- Physical exercises
- Medications
- Interventions
**Wrap-Up (2-3 mins)**

- Prescription
- Supplementary medical examinations & appointments
- Patient questionnaire & dictation letter
Role 1: supporting agenda-setting for clinical conversation

- Conflicting agenda
- Self-tracking data as lived experiences
- Features to support highlighting of topics for synchronised discussion

“You have a list of things you need to get to, and patients also have a list of things they’d like to talk about” (CR2)
Role 2: **supplementing existing patient-reported evidence**

- Patient-reported outcomes (PROs) and its collection
- Self-tracking data as supplementary clinical evidence
- Tools to navigate insights & tame data complexity

“*When did the symptoms start to show?”* (CR1)

“*No rashes? …dryness in the mouth? or eyes?”* (CR1)
Role 3: providing a platform for collaborative decision-making

- Establishing consensus through knowledge-sharing
- Lack of tangible evidence
- Leverage self-tracking to support co-decisionmaking

“(Flares) seem to be getting worse since I got off the pills... a lot more frequent” (P23)
Role 4: facilitating realistic target-setting and progress monitoring

- Target-setting and self-management behaviours
- Unrealistic goals
- Self-tracking data enables flexible and realistic target-setting

“Try to make stretches more regular, even 10 minutes a day makes a big difference” (CR1)
• Structured framework for integrating self-tracking data
• Potential roles for self-tracking data in the rheumatology clinic
• Design of tools for exploring and interacting with self-tracking data
• Future directions
  • Personal Informatics for Ankylosing Spondylitis (PIAS)
Thanks for Listening!
### Section 4: Sharing Data with Clinicians

This section is about sharing and using your uMotif data with your AS healthcare professionals.

Your self-tracking data is not only useful for improving your own understanding of the disease, but also that of others. Clinicians may use it to provide better treatment and help you make sense of the data so that you take full advantage of the technology.

<table>
<thead>
<tr>
<th>How comfortable do you feel about sharing the following types of data from uMotif with your health professionals? Please rate from 1 (Not at all comfortable) to 5 (Completely comfortable).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily symptoms (e.g., pain, fatigue)</td>
</tr>
<tr>
<td>Medication and AS-related exercise (e.g., stretching)</td>
</tr>
<tr>
<td>Lifestyle (e.g., sleep, hydration, exercise)</td>
</tr>
<tr>
<td>Mental status (e.g., mood, confidence)</td>
</tr>
<tr>
<td>Any additional data you've made</td>
</tr>
</tbody>
</table>

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25. How do you expect your uMotif data to be used by health professionals? What do you expect them to look for in your data?

- 1) To assist with research and understanding of AS.
- 2) To improve treatment and care for other AS patients.
- 3) To support those suffering from chronic fatigue.

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29. How important is it for your healthcare professionals to review and analyze the uMotif data that you have collected? Please rate from 1 (Not at all important) to 5 (Extremely important).

<table>
<thead>
<tr>
<th>Health professionals</th>
</tr>
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<tbody>
<tr>
<td>Not at all important</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
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<tr>
<td>3</td>
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<td>4</td>
</tr>
</tbody>
</table>
| 5 | Extremely important

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30. How do you expect your uMotif data to be shared with healthcare professionals?

- 1) Not shared with any healthcare professionals.
- 2) Shared with selected healthcare professionals.
- 3) Shared with all healthcare professionals.

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**Thank you for your interest in Project Nightingale**

We’d like to hear about your self-tracking experience with the uMotif application.

Your opinion matters.

Tell us what you think by completing the survey: bathreg.onlinesurveys.ac.uk/umotif

Help yourself, your clinicians and the wider Ankylosing Spondylitis community.

Visit projectnightingale.org to find out more.