“New” ways of capturing information from clinicians and patients

Kaleb Michaud, PhD
University of Nebraska Medical Center
National Data Bank for Rheumatic Diseases
Real-life Star Trek tricorder nets $10.5M funding
GMA News - 8 hours ago
The tricorder, the handheld all-around medical device used in the hit series “Star Trek,” has just moved closer to reality after a startup that

The Star Trek tricorder just came a little closer to reality
Quartz - Nov 13, 2013
Real-life 'Star Trek' Tricorder receives $10.5 million funding to help ...
Mirror.co.uk - Nov 13, 2013
all 22 news sources »
Web-based forms

- Not “new” (NDB 2001+)
- Reduces data errors
- Allows for easier randomization & testing of items
- CAT (Computerized Adaptive Test) for efficient questionnaire
- How, when, & where entered
# Response - Clinic vs. Home

**NDB & ARCK (N=1439)**

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Clinic</th>
<th></th>
<th>Non-clinic (e.g., at home)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Paper (ref)</td>
<td></td>
<td>Web</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Paper (ref)</td>
<td></td>
<td>Paper</td>
<td></td>
</tr>
<tr>
<td>HAQ-II (0-3)</td>
<td>0.07 (0.06, 0.08)</td>
<td>0.0</td>
<td>0.02 (0.00, 0.04)</td>
<td>0.18 (0.15, 0.21)</td>
</tr>
<tr>
<td>Pain (0-10)</td>
<td>0.98 (0.90, 1.06)</td>
<td>0.0</td>
<td>-0.12 (-0.24, 0.01)</td>
<td>0.71 (0.51, 0.91)</td>
</tr>
<tr>
<td>Global assessment (0-10)</td>
<td>0.55 (0.47, 0.62)</td>
<td>0.0</td>
<td>-0.02 (-0.14, 0.10)</td>
<td>0.00 (-0.19, 0.18)</td>
</tr>
<tr>
<td>Fatigue (0-10)</td>
<td>0.75 (0.67, 0.83)</td>
<td>0.0</td>
<td>-0.02 (-0.15, 0.10)</td>
<td>1.12 (1.01, 1.39)</td>
</tr>
</tbody>
</table>

GEE coefficients adjusted by disease, age, sex, race, education, duration, comorbidity, # of visits

*Inman 2012 ACR Meeting*
Online reports

For patient use or bring to physician
Computers in Clinic?

- High acceptability by patients in clinics
  - highest with tablets (based on non-rheum studies)
- TEST your user-interface! (patients & staff)
- Requires IT support & alternative (paper) backup
- Alternatively, email questions before visit
Non-EMR tablet entry

- Academic research programs (UAB+)
- www.trackmyra.com (Crescendo Bioscience)
MyRA
Track it. Show it. Feel better.
Non-EMR tablet entry

- Academic research programs (UAB+)
- [www.trackmyra.com](http://www.trackmyra.com) (Crescendo Bioscience)
- iRheum.com (eNovation)
iRheum App

The first Rheumatology specific app to integrate labs, outcome measures and biologic prescriptions into a comprehensive workflow efficiency tool.

Features:
Full comprehensive software solution
Automatic tender /swollen joint count
All ACR recommended outcome measures
Labs entry and retroactive entry for outcomes
Full outcomes summary
Tracks biologic dose against DAS28
Full auto-fill of specialty pharmacy form
Save/print/fax/email prescription to pharmacy
Repository for PQRS data
Rheumatology software for ACO’s
Doctor, office and patient portal
Tender 7

Swollen 11

SDAI 35.0

DAS 4.79
Click “Save” and return to receptionist
Non-EMR tablet entry

- Academic research programs (UAB+)
- www.trackmyra.com (Crescendo Bioscience)
- iRheum.com (eNovation)
- Several others! (Spain+)
Tablets in clinic - Next steps

- Pragmatic trials - randomize questionnaire items
- Adding standardized measures for other dx’s
- Connecting with EMRs to reduce redundancies
Using social media

• See my EULAR 2013 talk
Online recruitment - AIR

Arthritis Internet Registry

Help find new ways to treat your arthritis.
AIR - latest

- Enrollment ~4.2K, >800 donated blood
- Difficult to get full participation – expect 50% to continue completing forms, then 50% to donate blood
- GWAS & whole-exome RNA sequence ongoing - DREAM/Sage Bionetworks RA Challenge
- Next steps include longitudinal biomarkers, medical diaries, and recruitment of FDRs
Biometric technology

- fitbit
- Nike+ sportband
- Several other computer linked pedometers
Click on the products below to find the one that's right for you.

**Features**

- **Zip™**
  - Fun, simple tracker for everyone
  - $59.95

- **One™**
  - Advanced activity & sleep tracker
  - $99.95

- **Flex™**
  - Stylish wristband that fits your lifestyle
  - $99.95

- **Force™**
  - Advanced activity & sleep wristband
  - $129.95
Something new
Behavioral metrics - Reality mining technology + smart phones
Behavioral metrics - Reality mining technology + smart phones

Madan 2012 Ginger.io IEEECS
NDB + Ginger.IO pilot project

Pain and Functioning

How much pain have you had because of your illness since yesterday?

Drag the slider until its position best describes how you are doing on a scale of 0-10.

We are interested in learning how your illness has affected your ability to function in daily life since yesterday.

Patient Activity Scale-II

We are interested in learning how your illness has affected your ability to function in daily life over the past week.

Are you able to stand up from a straight chair?

- Without Any Difficulty
- With Some Difficulty
- With Much Difficulty
Future collection

- At-home blood collection
- Remote management of treatments by protocol and tele-health
- Kinect - use to measure gait, 3D modeling of body, deformation, & swollen joints
- Tweets of key words by location/patient
- Adopting best measures over next-gen tools
Thank You!

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**THE SIMPLE ANSWERS**

TO THE QUESTIONS THAT GET ASKED ABOUT EVERY NEW TECHNOLOGY:

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>WILL ______ MAKE US ALL GENIUSES?</td>
<td>NO</td>
</tr>
<tr>
<td>WILL ______ MAKE US ALL MORONS?</td>
<td>NO</td>
</tr>
<tr>
<td>WILL ______ DESTROY WHOLE INDUSTRIES?</td>
<td>YES</td>
</tr>
<tr>
<td>WILL ______ MAKE US MORE EMPATHETIC?</td>
<td>NO</td>
</tr>
<tr>
<td>WILL ______ MAKE US LESS CARING?</td>
<td>NO</td>
</tr>
<tr>
<td>WILL TEENS USE ______ FOR SEX?</td>
<td>YES</td>
</tr>
<tr>
<td>WERE THEY GOING TO HAVE SEX ANYWAY?</td>
<td>YES</td>
</tr>
<tr>
<td>WILL ______ DESTROY MUSIC?</td>
<td>NO</td>
</tr>
<tr>
<td>WILL ______ DESTROY ART?</td>
<td>NO</td>
</tr>
<tr>
<td>BUT CAN'T WE GO BACK TO A TIME WHEN-</td>
<td>NO</td>
</tr>
<tr>
<td>WILL ______ BRING ABOUT WORLD PEACE?</td>
<td>NO</td>
</tr>
<tr>
<td>WILL ______ CAUSE WIDESPREAD ALIENATION BY CREATING A WORLD OF EMPTY EXPERIENCES?</td>
<td>WE WERE ALREADY ALIENATED</td>
</tr>
</tbody>
</table>

xkcd.com