Edinburgh Research Explorer

Patients, Prescribing & Personalised Pharmacy: Innovations and Opportunities

Patients, Prescribing & Personalised Pharmacy
Innovations & Opportunities

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The Farr Institute
@ Scotland

How might ePharma research impact the patient experience?

- **Data linkage for scaled validation of clinical trial results**
  - Real world intelligence for iterating guidelines & translational R&D
- **Identifying signals of actual and potential ADEs**
  - Early drug withdrawal or reformulation
  - Reduced patient discomfort & risk, better QoL
  - Understanding patient mediators for better stratified prescribing
- **Demonstrating effects of Polypharmacy in natural experiments**
  - Interactions not <u>yet</u> causing harm
  - Serendipidous associations
- **Linking primary care prescribing data with clinical data**
  - Informing personalised & stratified treatments
- **Cost effective analytics**
  - Cost-effective prescribing
  - Value proposition for society

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Detecting Adverse Drug Reactions

- ADRs -> 5-30% of hospital admissions in US, Australia, Europe
- Tip of the iceberg, many go unreported
- RCTs poor detectors. Small samples. Unrealistic controlled settings. Few opportunities to examine behavioral and patient modifiers. Not powered to detect micro effects.
- Scaled clinical data linkage holds great potential, and pharmacovigilance is the most advanced application of these methods so far

- But this is only part of the story…
- Patient reported ADRs hold promise
  - What are the best ways to do this?
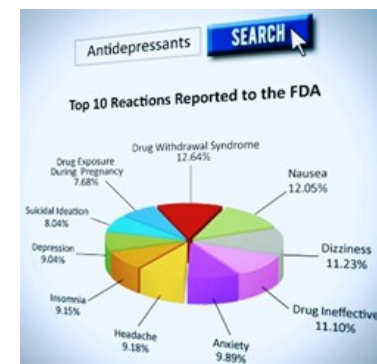
Mobiles & Clinical Trial Coordination

Pharmaceutical industry investing in mobile platforms for trial coordination & data management

Potential to speed translation to innovations for patient care

Companies springing up to fill this gap

Mostly data collection platforms, mobile form submission, updating protocols

Moving towards patient-reported outcomes …

MCT-Congress
24-25 MARCH 2015
EDINBURGH SCOTLAND

Online awareness raising

- 75% of people unaware of clinical studies
- Around half of all trials don't fill their recruitment quotas
- Not just scientists 'pushing' risky trials to patients
- Many patients <u>want and seek</u> engagement
- But risks of suggesting that 'experimental' is better

Dr Claudia Pagliari @EeHRN · Apr 27
Drug companies investing in eHealth to raise trial recruitment. But do they really understand patient motivation?
forbes.com/sites/zinamouk…

TrialReach   About us   Patient stories   Media partners   Pharma

A Clinical Trial For People with Previously Treated Stage IV Non-Small Cell Lung Cancer

Overview   Eligibility   Logistics   Trial drug   Background   Contact

Dr Claudia Pagliari @EeHRN · Mar 25
Why isn't pharma harnessing patients' desire to monitor biomarkers & providing tools for interpretation? #mctcongress
JackWhelan

Direct-to-patient trial recruitment

"After six hours, we have 7,406 people enrolled in our Parkinson's study. Largest one ever before was 1,700 people" (Tweet from Parkinsons app developer, May 2015)

Stanford Uni cardiovascular trial attracted 11,000 volunteers in one day after releasing their 'MyHeart Counts' App in the App Store. It would normally take a year to enroll that many subjects (*Bloomberg Business*, March 2015)

Early days. Sampling challenges (noise, representativeness), but great potential....

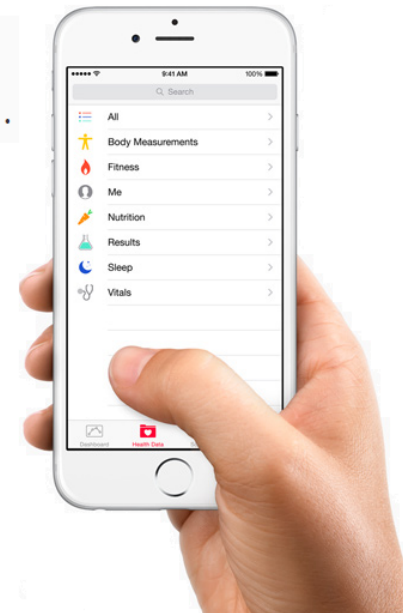## ResearchKit: a clever tool to gather clinical data

The Pharmaceutical Journal | , 7 MAY 2015 | By Dara Mohammadi

New software from Apple makes it easy for iPhone users to contribute to medical research but scientists warn there may be pitfalls.

You're already carrying a powerful medical research tool.

ResearchKit

Clinical Trials & Data Quality

Patient Recruitment
Expense & inconvenience limit numbers & generalizability.
Recruiting via apps could open up a population of potential
trial participants. 700 million iPhone users

Data Objectivity
Trial data can be subjective (e.g. symptom ratings) &
clinical data can be flawed. ICT can generate quantifiable
metrics e.g. exercise (actigraphy), biomonitoring
(embedded sensors & linked peripherals), self-report tools
etc. May reduce false reporting by patients

Data Frequency
80% - 90% of iPhone users keep them within arm's length
27/7. *"We're trying to change the scale of the data that we
can collect, from data collected every three months, to
every second."*   Apple Executive, quoted in *Forbes
Business,* March 9th

MEDICAL RESEARCH
Volunteers Needed!

Data quality – *"Many Carbon
Monoxide poisonings may have
been intentional rather than
accidental, raising questions for
national reporting (Miller, Pagliari
et al, IoM, 2011)*

Download Our Cancer
Clinical Trials App Today

Search for trials by disease, phase,
physician, or location on your Apple
or Android device.

The new wearables

Linked to HealthKit, the Apple Watch can track blood glucose, heart rate, blood pressure, exercise and much more. Being portrayed as everything from a personal lifestyle checker to a cure for cancer.

"Google X is building a wearable health sensor for cardiac and activity tracking, but it isn't a Fitbit or Apple Watch competitor: Google's device is a clinical-grade sensor designed for investigational use" MobiHealthNews, June 23rd
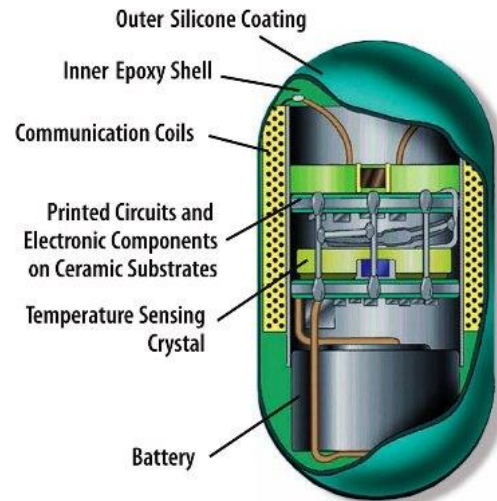
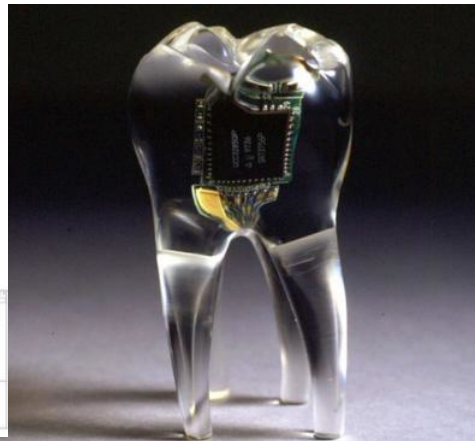# Home-based telemonitoring is gaining traction but mHealth is the future

Coming soon

Proteus Ingestible Sensor for Tracking Medication Intake Receives FDA Clearance
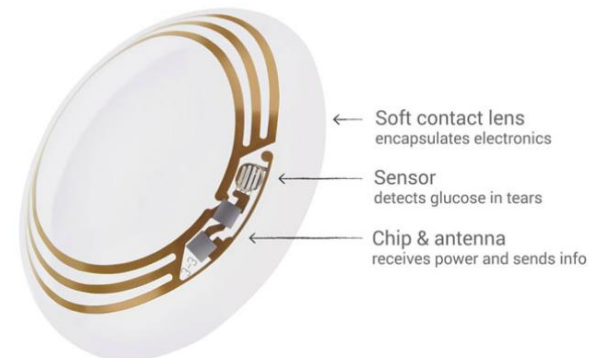by WOUTER STOMP on Jul 31, 2012 · 1:42 pm

Outer Silicone Coating

Inner Epoxy Shell

Communication Coils

Printed Circuits and Electronic Components on Ceramic Substrates

Temperature Sensing Crystal

Battery

Google-Novartis Diabetes Monitoring Contact Lens Patented Jan 2015. Others following e.g. Medella Health

The MDM Sensor (for measuring movement)

The Recording and Feedback Device

The MDE Sensor and Electrode (for measuring muscle activity)

LIVE software

Radboud umc

„Insideables"

Soft contact lens encapsulates electronics

Sensor detects glucose in tears

Chip & antenna receives power and sends info

Digital Phenotype

The data captured as we interact with digital technologies and services, have potential to provide a phenotypic footprint, useful for research, diagnostics, prognostics and personalised medicine

Multiple channels:

- Web searches
- Social media
- Mobile apps
- Wearables
- Smart homes
- Internet of Things
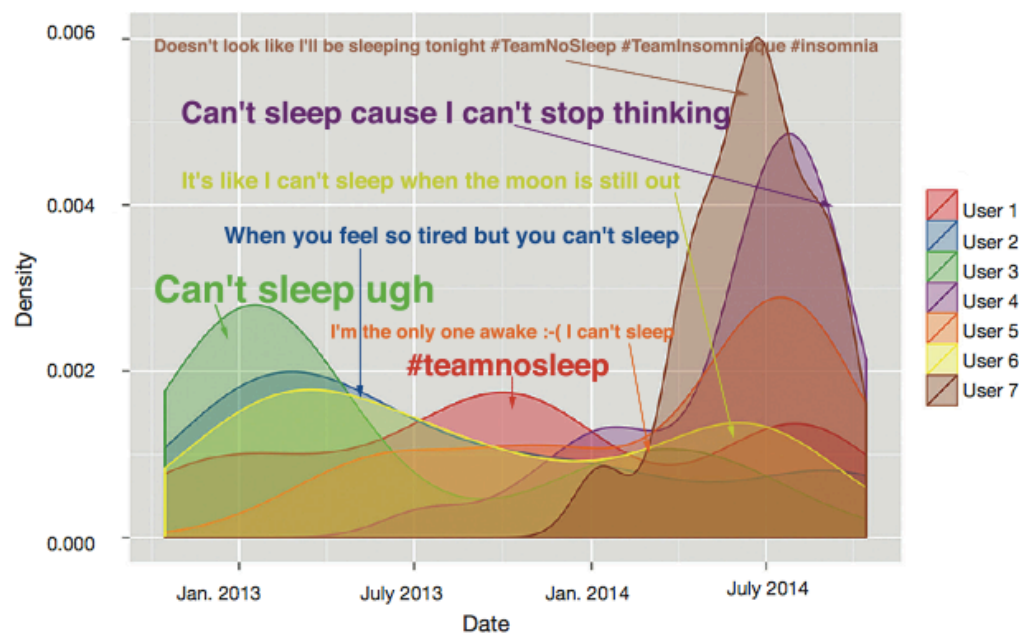- TV habits, Shopping etc.

Figure 1 Timeline of insomnia-related tweets from representative individuals. Density distributions (probability density functions) are shown for seven individual users over a two-year period. Density on the *y* axis highlights periods of relative activity for each user. A representative tweet from each user is shown as an example.

Jain et al May 2015. *Nature Innovation*

Taylor, Pagliari, Osborne (2013). How Gestational Diabetes is Discussed on Twitter

Stanford | MEDICINE X
THE INTERSECTION OF MEDICINE AND EMERGING TECHNOLOGIES

Using Society's Data Trails

New Responsibilites for Govt & Pharma?

Adverse Events: Does Social Media Trigger Reporting?

- Nielsen BuzzMetrics' analysis of 500 messages shows that just 1 message meets meet all four reporting criteria.

- Adverse experiences are uncommon in CGM discussion, occurring in just 1% of messages.

99% of messages mention an identifiable patient

11% of messages mention an identifiable reporter

Overlap: Specific medication + identifiable reporter = 3% of all messages

21% of messages mention a specific medication; all but 4 include an identifiable patient

1% of messages mention an adverse experience; all include identifiable patient and specific medication; 1 message also includes an identifiable reporter

Among 500 messages scored, 1 message incorporates all four reporting criteria

The MHRA has announced that it is to lead European medicines regulators, academics and pharma in a three-year project to develop new ways of gathering drug safety information.

Known as 'WEB-RADR', the project is in response to the rise in the use of smartphones, apps, and social media for discussing issues with medicines and health, says the MHRA.

the
PHARMACEUTICAL JOURNAL
A Royal Pharmaceutical Society publication

Searching social networks to detect adverse reactions

The Pharmaceutical Journal, 22 JAN 2015 | By Elizabeth Sukkar

Looking to communities for innovative research
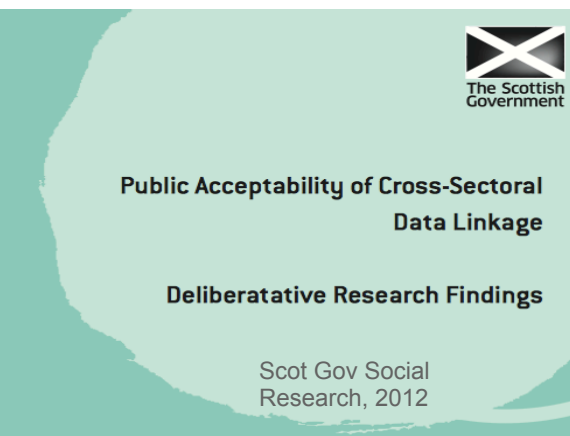

May 9, 2015
"The first patient-driven campaign to find and fund critical research for high-risk multiple myeloma patients"
http://mcri.myelomacrowd.org.

Ethics

- Making the most of data from research repositories, clinical records and patients requires a new understanding of concepts like 'science', 'personalised', 'ownership' & 'privacy'

- Managing the tense intersection between academic & commercial research remains a barrier, and the dividing line is often blurred

- Our social & policy research is seeking to establish the boundaries of the social contract and inform the wider data science agenda for the UK and beyond

The Scottish Government

Public Acceptability of Cross-Sectoral Data Linkage

Deliberatative Research Findings

Scot Gov Social Research, 2012

Administrative Data Research Centre
Scotland

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The Farr Institute
@Scotland

Claudia Pagliari
Programme Director, MSc in Global eHealth at The University of Edinburgh

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Privacy, data science and personalised medicine. Time for a balanced discussion

Mar 26, 2015   👁 189   👍 16   💬 4

Patient Record Access & Trust

Enabling patients to access and question their data may help to build trust in research, identify errors, and support trial recruitment

*Pharmacists asked us to identify controls, so I put the call out…I have 3000 patients with access to their records. When they know what they're sharing they have more trust. **It only took 6 hours to find the 80 or so patients that were needed!...**"The key was that patients had been carefully consented. If people know what they're signing up for and what the risks are, they won't be as inclined to fear it later" (Amir Hannan)*

HARRIS

Harris Healthcare UK @HarrisHealthUK · Feb 26
Dr Claudia Pagliari #ehealthscotland says #patient portals key innovation to enable patient access to their records

Bringing patients and their records together: rights, benefits and the digital society

Contents lists available at ScienceDirect

Computers in Biology and Medicine

journal homepage: www.elsevier.com/locate/cbm

ELSEVIER

Editorial

Understanding the evolving role of the Personal Health Record

Claudia Pagliari
Programme Director, MSc in Global eHealth at The University of Edinburgh

Edit post   View stats

Value of Personal Health Records for Patients, Citizens & Science

Apr 19, 2015 | 👁 171 | 👍 12 | 💬 7 | in f g+ 🐦

Pinciroli & Pagliari (2015)

Building capacity

- eHealth is multidisciplinary, multi-platform, cross-sectoral & global
- Rounded eHealth professionals are vital for future research, policy & practice

Thank you

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