

Web-based Assessments:

The Internet is an Emerging
Modality in Patient Reported
Outcomes

Brian Tiplady



PRO Consulting[®]

23rd Annual
EuroMeeting
28-30 March 2011
Geneva, Switzerland



www.diahome.org

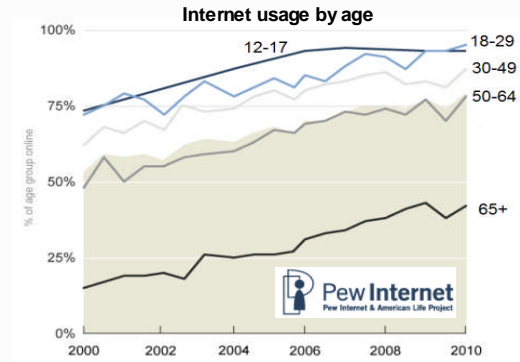
Disclaimer

The views and opinions expressed in the following PowerPoint slides are those of the individual presenter and should not be attributed to Drug Information Association, Inc. (“DIA”), its directors, officers, employees, volunteers, members, chapters, councils, Special Interest Area Communities or affiliates, or any organization with which the presenter is employed or affiliated.

These PowerPoint slides are the intellectual property of the individual presenter and are protected under the copyright laws of the United States of America and other countries. Used by permission. All rights reserved. Drug Information Association, DIA and DIA logo are registered trademarks or trademarks of Drug Information Association Inc. All other trademarks are the property of their respective owners.

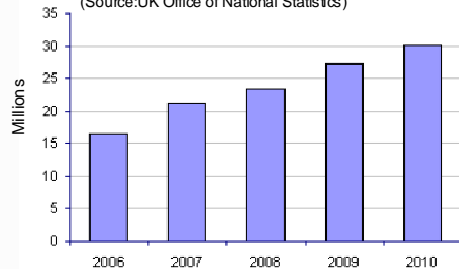
The Internet: It ain't slowing down (much)

USA

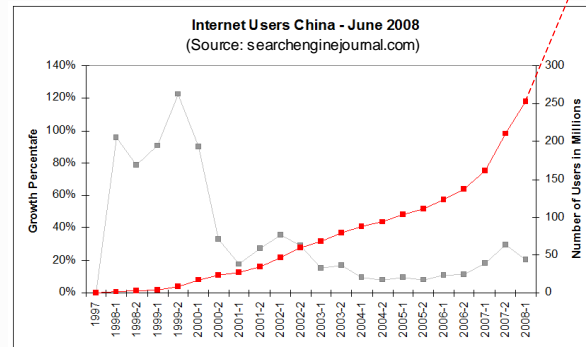


UK

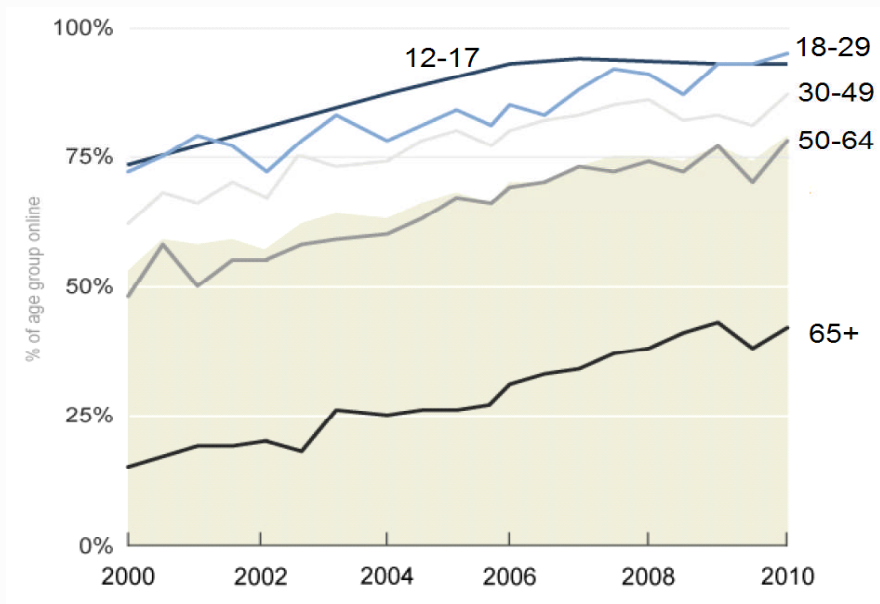
Adults using the internet everyday (UK)
(Source: UK Office of National Statistics)



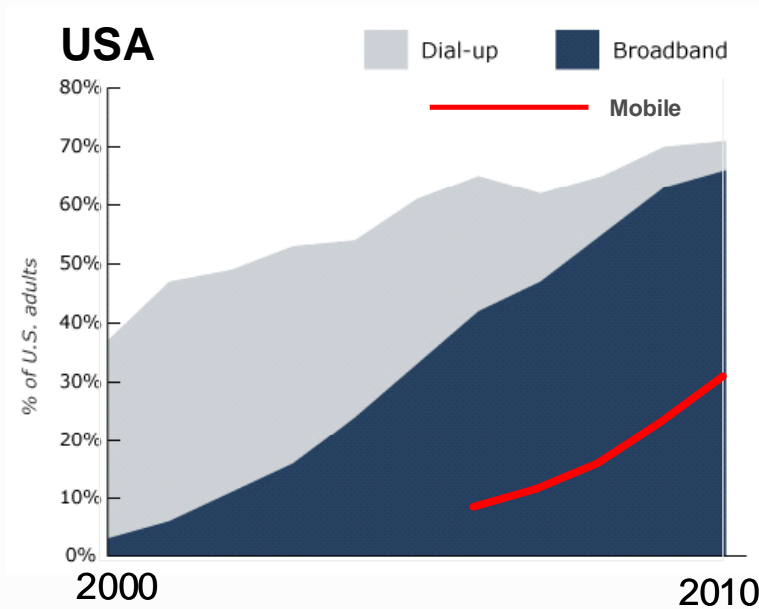
China



Internet Usage by Age

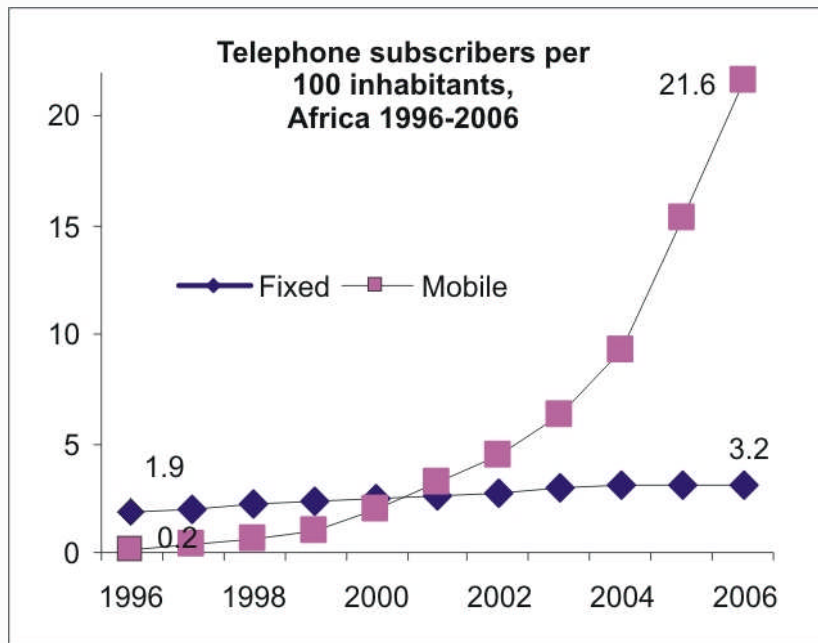


Internet: Mode of Connection



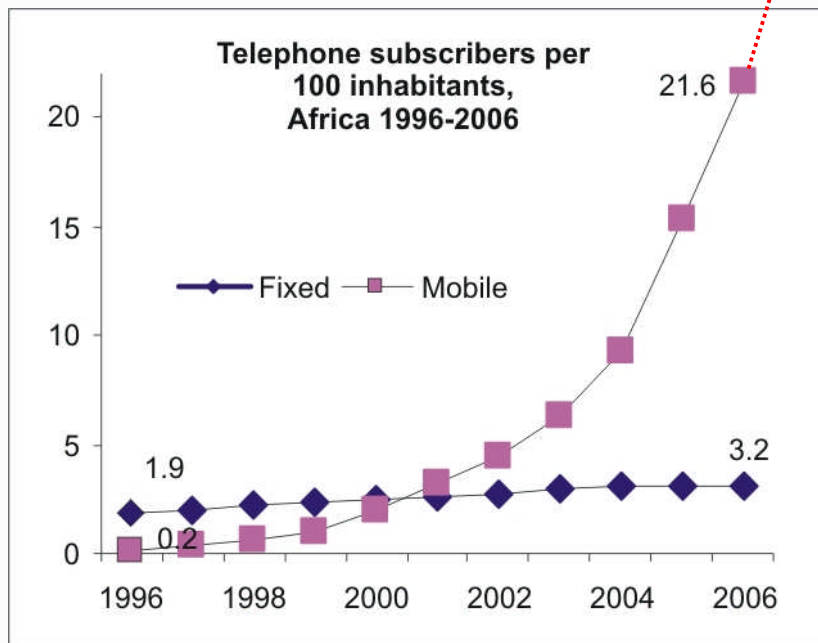
Sources: CircleID &  Pew Internet
Pew Internet & American Life Project

Mobile Phones in Africa



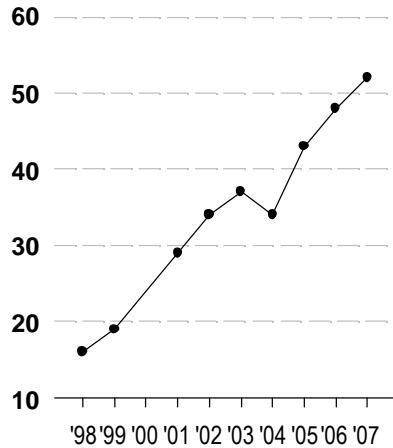
Mobile Phones in Africa

2010:
Now
around
50%



The Internet for Healthcare

% of adults looking for health information online, 1998-2007



Source: Harris Interactive

- Information Search
- Support Groups
- Surveys
- Personal Monitoring
- Therapy

Support Groups

- Help in finding relevant information
- Sharing experiences
 - What will it be like?
 - What aren't they telling me?
 - They're telling me too much! What is most important?
- Social support
 - Reduce feelings of isolation and uncertainty
 - Beneficial effects on stress and mood

Support Groups and Research

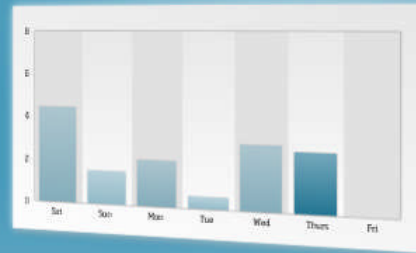
- “What’s it like”
 - Qualitative methods can be used to analyse experience of symptoms and the impact of disease
 - Informing therapeutic research (is your sample representative?)
 - Establishing content validity of PRO instruments (e.g. Wicks et al., 2011)
- Patients description of outcomes
 - Evidence for treatment efficacy and adverse events
 - Useful supplement to Phase IV research (e.g. Frost et. al., 2011)

Individual Monitoring

- Regular input of data by user
 - Exercise
 - Diet
 - Alcohol consumption
 - Medication adherence
- Feedback from site to user
 - Performance compared to targets
 - Change over time
 - Patterns and associations within data

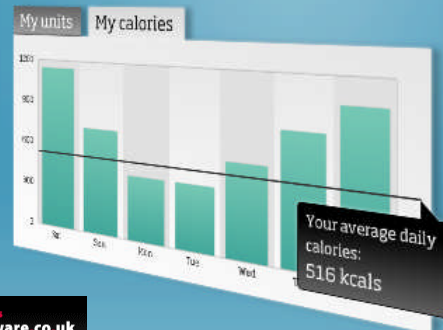
Track your drinking over time

Find out how many units are in your favourite drinks. Add them to your diary and see the running total.



Get personal feedback

See how the units and calories are adding up over days and weeks.



 **MyDrinkaware** for the facts
drinkaware.co.uk

23rd Annual EuroMeeting


www.diahome.org

Exercise Monitoring



Track Progress

Update your progress through web, email, or phone.



See Results

Get feedback about your progress and learn what influences your behavior.



Get Encouraged

Receive encouragement from your friends or others with the same

goal!

TrackVille

Key Features of the Health Internet

- Broadly-based content and participation
 - Web2.0 emphasises user-generated content rather than access to centrally generated material
 - Multiway communication among users and sites
 - An active and autonomous community
- Population often not well-defined
 - Sites are in general open and anonymous
 - Cannot document actual diagnosis or demographics
- Large numbers of patients available

Telehealth

- Older model, rapidly developing
 - Specialist care of known patients
 - Originally used point-to-point communications, e.g. transmission of ecg data to specialist unit
- Uses a variety of technologies
 - Physiological monitoring
 - Teleconferencing
 - Mobile communications
 - Web-based collection and review of information

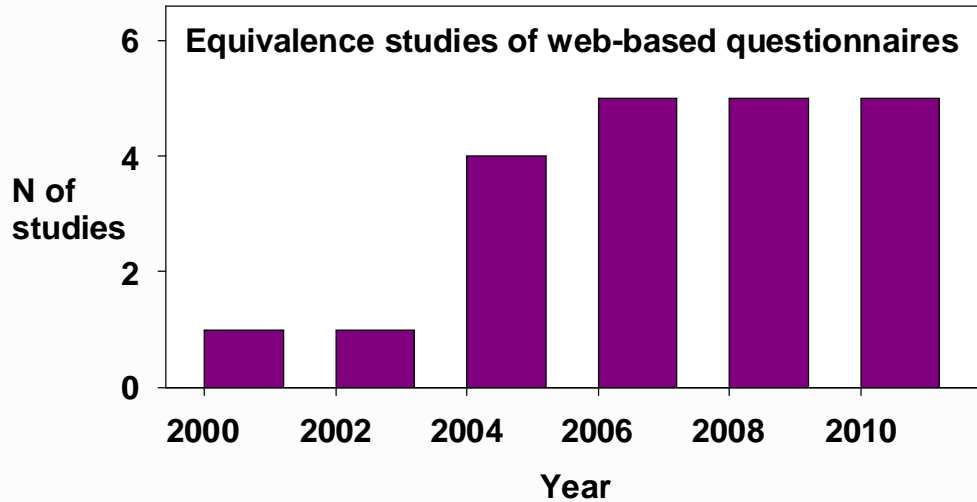
Potential of the Internet in Clinical Research

- Characterising populations
 - Surveys
 - Content analysis of support sites and blogs
- Instrument development
 - Ensuring content validity of measures
 - Large-scale testing
- Data collection
 - PRO instruments deployed on the web
 - Parallel development of web and other modalities
- Recruitment

Instrument Development: An example in multiple sclerosis

- Content analysis of PatientsLikeMe.com online community used to develop survey of treatment adherence (MS-TAQ)
- Cognitive interviewing of small face-to-face sample
- Sample recruited from PatientsLikeMe completed survey online
 - 431 complete from 1209 invited
 - Patients had similar sex ratio to those in previous conventional sample, but were slightly younger (47 vs 51), and had disease for slightly shorter time (11 vs 9 yrs)
 - Significant correlations between compliance and “Barriers” (0.50) and “Coping” (-0.30) subscales, supporting scale validity

Source: Wicks et al. (2011)



- Less data available than for device-based ePRO (PC or handheld)
- Good support for mode-equivalence
- No published reports of use in clinical trials

WHOQOL Equivalence study

- 80 subject randomised crossover, web vs paper
- 1016 subject web validation sample
- No significant differences in scores web vs paper
- ICC in range 0.71-0.85 for scale domain scores
- Cronbach's alpha 0.60-0.83
- Missing data on paper, none from web
- Results similar to those seen from ePRO validation meta-analysis

Sources: Chen et al. (2009), Gwaltney et al. (2008)

Equivalence Studies on the Web

- Web delivery of in-clinic solutions
 - Supervised setting
 - Equipment specification can be standardised
 - Issues are very similar to conventional ePRO
- Everyday Life Assessment
 - Unsupervised setting
 - Limited information about devices
 - Need to address implications of greater variability



Safety Monitoring

- iGuard.org is established monitoring site
- Patients enrolled in online survey
- Survey is similar to PRO instruments
- Results published on several CNS medications
- Most adverse events were not reported to patient's doctor

See, e.g. Cascade et al (2010)

Conclusions

- Web methods clearly applicable to clinical research
- Issues of selection bias need to be considered
 - Web recruitment
 - Availability of internet to all patients?
- Benefits are various
 - Cost, especially when existing infrastructure is used
 - Versatility
 - Ease of distribution
 - Methods familiar to many patients and investigators

Contact

Brian Tiplady

[Btiplady@patient
reported.com](mailto:Btiplady@patientreported.com)

+44 (0)7760 263283

