Conducting studies on the Internet and mobile phones

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HUG
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Internet and mobile phone studies

- New industry: health care, marketing
- Health care: data transmission in real time to physicians, compliance
- Surveillance of disease outbreaks by Google searches
- Postmarket drug surveillance: adverse events (rare, late onset events)
- « Infodemiology », « e-epidemiology »
- Very large samples
- Low threshold:
  - some prefer to avoid face-to-face contact
  - rural medical desert
- Once the system is developed, marginal cost = 0 (vs. data collection in person, postal, telephone)
Reach

- Switzerland:
  - 80% of population have access to Internet
  - >90% have a mobile phone
- Mobile phones: high usage even in low-income people / countries
- Low cost for users, once equipped
- Everywhere, even in remote areas (rural medical desert)
- Also for patients with limited access to healthcare (e.g. mothers of young children, old people, handicap)
- Many people do not seek treatment => early detection + treatment (e.g. online screening for alcohol, COPD)
- Translation in several languages for worldwide data collection
Specificity of online/mobile data collection

- Everywhere
- 24 / 7 / 365
- Ecological momentary assessment (EMA)
- Data collection + feedback, advice = mobile, timely, in situation
  - e.g. smoking relapse, pill taking
- Tests + feedback, screening, early detection + treatment:
  - e.g. BMI, depression, alcohol, tobacco dependence, COPD
- Automated programs, with individually-tailored advice, counseling and follow-up (virtual coach, virtual therapist)
- No limit for sample size: dig data for subgroups (e.g. addicted to nic. gum)
- Statistical significance not a guide anymore
Hard-to-reach audiences

- Not online, no smart phone pre-paid cards: limited time online
- Illiteracy, low SES, migrants
- Older people
  (but this may change over time as more and more retired people used Internet professionally)
How to reach the low SES, the illiterate?

- Prevalence of illiteracy in Switzerland = 10-15%
- Involve target audience in the development of study, website, app, questionnaire, data collection system
- Work with specialized social workers + healthcare providers
- Develop specific contents / supports for explanations, informed consent:
  - Video
  - Audio (podcasts)
  - Pictures, comics
  - Interactive features - dialog
- Add TV, radio component to advertise the study
- Financial incentives
Reach: retain participants at follow-up

- Challenges:
- At first assessment:
  - Low participation among those contacted
  - How to maximize completion rates among respondents?
  - Number of pages answered (attrition page after page)
  - Time spent on website / smart phone app
- At follow-up:
  - High attrition rate
  - How to obtain several assessments per visitor, over time?
  - Retain participants over several weeks, months or even years
Determinants of participation

- Re-visit to the data collection site / mobile app depends on:
  - E-mail / phone contact and updates, text messaging
  - Questionnaire: length + difficulty, interesting? easily understood?
  - Familiarity of users with the website, app
  - Trust
  - Counselor contact
  - Advice, feedback received?
  - Interactive services: discussion forums, blogs, chat, newsletter

- Education level
- Involvement with the topic, is the person concerned?
- Perceived interest, perceived benefit from answering
- Enjoyment, positive experience with the websites / app
- Motivation to change behavior
Stop-tabac.ch

Bienvenue sur votre coach pour l’arrêt du tabac.

34 jours sans tabac

+320 CHF
+5 jours de vie

Ça va pas  J'ai envie  J'ai craqué
### Differences Internet vs. general population

<table>
<thead>
<tr>
<th>1996-1998</th>
<th>Internet</th>
<th>Population GE</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>N smokers</td>
<td>1024</td>
<td>211</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>34</td>
<td>39</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Men (%)</td>
<td>57</td>
<td>57</td>
<td>ns</td>
</tr>
<tr>
<td>School years</td>
<td>16</td>
<td>13</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Cig./day</td>
<td>23</td>
<td>17</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Quit attempt in past year (%)</td>
<td>45</td>
<td>30</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Decided to quit in next month</td>
<td>23</td>
<td>4</td>
<td>&lt; 0.001</td>
</tr>
</tbody>
</table>

Int J Epidemiol 2001;30:521-525
Development of scales / questionnaires

- Collection of qualitative data
- Selection of the questions that perform best, our of a large pool of questions
- Test – retest reliability
- Tests of construct validity
  - assess change over time, e.g. withdrawal symptom level changes over time
  - collection of saliva samples by mail (e.g. cotinine x addiction level)
- Tests of predictive validity
  (e.g. addiction / withdrawal predict smoking cessation)

N = 3009 smokers:
A test of proposed new tobacco withdrawal symptoms

- Daily smokers (n = 1126) and former smokers (n = 3239).
- Daily smokers assigned randomly to either continue to smoke for 2 weeks or to stop smoking.
- Answered follow-up surveys 1, 3 and 7 days after their target quit date.
- 31 new symptoms tested.

- Worsening of mood swings
- Abstinence improved sense of smell, sense of taste, sore throat

RCT: impact of messages

- Question:
  Impact of messages recommending the concomitant use of nicotine replacement therapy (NRT) and cigarettes on smokers' intention to quit

- RCT, n = 2027 smokers
- 4 groups, each received a different message by e-mail

- Messages encouraging concomitant use of NRT and cigarettes had either no effect or a positive effect on motivation to quit smoking.

RCT: efficacy of Internet-based smoking cessation programs

- Interactive “coach”
- First RCT of Internet-delivered smoking cessation program published in a peer-reviewed journal
- 2 versions, developed 3 years apart
- N= 11’969 current smokers (74%) and former smokers (26%)
- Follow-up survey after 3 months, answered by 4237 people (35%)

Etter JF. Comparing the efficacy of two Internet-based, computer-tailored smoking cessation programs: a randomized trial. J Med Internet Res. 2005 8;7:e2.
Addiction to the nicotine gum in never smokers

- Internet questionnaire in 2004-2006 in a self-selected sample of 434 daily users of nicotine gum
- Five never smokers used the nicotine gum daily.
- They had been using the nicotine gum for longer than the 429 ever smokers (median = 6 years vs 0.8 years, p = 0.004), and they had higher NDSS-gum Tolerance scores (median = 0.73 vs = -1.0, p = 0.03), a difference of 1.5 standard deviation units.
- Two never smokers had never used smokeless tobacco, both answered "extremely true" to: "I use nicotine gums because I am addicted to them"
- First report of addiction to nicotine gum in never users of tobacco.

Users of electronic cigarettes

- Data collected in Sept-Oct 2009, article submitted in Oct 2009
- First survey of “vapers” published in a peer-reviewed journal
- 81 users, 77% men
- 63% ex-smokers, 37% current smokers
- Duration of e-cig use: 100 days (median)
- 175 puffs / day on e-cig (median)
- Most said they used e-cigs to quit smoking
- Side effects: dry mouth, dry throat

Cotinine in e-cigarette users

<table>
<thead>
<tr>
<th>N</th>
<th>30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily users of e-cig</td>
<td>97%</td>
</tr>
<tr>
<td>Used tobacco or NRT in past 48h</td>
<td>0</td>
</tr>
<tr>
<td>Puffs per day on e-cig (median)</td>
<td>200</td>
</tr>
<tr>
<td>Cotinine in saliva, median 25th et 75th percentiles</td>
<td>322 ng/ml 138 / 546 ng/ml</td>
</tr>
</tbody>
</table>

*In the literature: in EX-smokers who use NRT:* 100-250 ng/ml

Etter JF, Bullen C. *Eur Respir J.* 2011 Nov.
### E-cigarette use, in daily users

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Puffs / day</td>
<td>120</td>
</tr>
<tr>
<td>Refills / cartridges per day</td>
<td>5</td>
</tr>
<tr>
<td>Duration of current episode of use</td>
<td>3 months (5 months)</td>
</tr>
<tr>
<td>(in former smokers)</td>
<td></td>
</tr>
<tr>
<td>Have been using e-cig for ≥1 year</td>
<td>15%</td>
</tr>
<tr>
<td>Use nicotine-containing e-cig</td>
<td>97%</td>
</tr>
<tr>
<td>E-liquid: nicotine concentration (same for all brands)</td>
<td>18 ng/ml</td>
</tr>
<tr>
<td>Buy their e-cig on the Internet</td>
<td>96%</td>
</tr>
<tr>
<td>Monthly spending for e-cig</td>
<td>33 USD</td>
</tr>
<tr>
<td>Use e-cig to inhale other substances, not in commercial e-liquids: vitamins, flavors, cannabis (n=5), alcohol (n=1)</td>
<td>0.9%</td>
</tr>
</tbody>
</table>
Most used models (sold under various brand names)

- 510: 40%
- eGo: 29%
- KR808: 9%
- 901: 11%
- Tornado: 6%
- Other: 5%
Reasons for use

Unable to stop it: 4%
Reduce tob: 28%
Avoid go outside 2 smoke: 34%
Smokefree places: 39%
Avoid bother others: 44%
Cheaper than tob: 57%
Deal w withdr symp: 67%
Quit smoking: 77%
Deal w craving: 79%
Less toxic than Tob: 84%
Ongoing studies

- **E-cigarettes:**
  - follow-up after 1, 3, 6 and 12 months
  - already 1200 participants
  - addiction to e-cigs
  - impact on smoking cessation + reduction

- **Financial incentives study, n=800**
  - enrollment
  - follow-up after 3, 6 and 18 months
  - response rate 95%
Mobile phone app

- “Coach” = embarked system: questionnaire then feedback, counseling
  - age, sex, smoking status, motivation to quit, dependence level
  - monitoring of participation
  - data used for further developments

- Satisfaction survey on app
  - 5400 participants

- Planned RCT in n=6000
- Real app vs. placebo app
Questions

- For which type of studies is online / mobile data collection best suited?
- What do they allow us to explore, that cannot be explored otherwise?
- Pros & Cons of web / mobile phone studies vs. traditional methods?
- Participant’s characteristics that predict participation?
  (age, sex, education, motivation, severity of disease, comorbidity)
- Moderators / mediators of these effects?
- Generalizability of results?
- Who runs this new industry, for the benefit of whom?
- Who should pay for this new business?
- Electronic tattoo, data protection
Conclusions

- High reach
- New frontier
- Explore things that cannot be explored otherwise
- Complementary to traditional data collection methods
- Online screening => early detection + medical care sought earlier
- Potential for development:
  - integration in traditional studies
  - develop data collection with comprehensive reach (low SES, elderly)
  - translate + export to low-income countries