

Conducting studies on the Internet and mobile phones

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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



Differences Internet vs. general population

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

Development of scales / questionnaires

- Collection of qualitative data
- Selection of the questions that perform best, out 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:
Etter JF, Le Houezec J, Perneger TV. A self-administered questionnaire to measure dependence on cigarettes: the cigarette dependence scale. *Neuropsychopharmacology*. 2003;28:359-70.

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

- Etter JF, Ussher M, Hughes JR. A test of proposed new tobacco withdrawal symptoms. *Addiction*. 2013;108(1):50-9.

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.
- Etter JF, le Houezec J, Landfeldt B. Impact of messages on concomitant use of nicotine replacement therapy and cigarettes: a randomized trial on the Internet. *Addiction*. 2003;98:941-50.

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.
- Etter JF. Addiction to the nicotine gum in never smokers. *BMC Public Health*. 2007 Jul 17;7:159.
- See also: Postmarket Drug Surveillance Without Trial Costs: Discovery of Adverse Drug Reactions Through Large-Scale Analysis of Web Search Queries. *J Med Internet Res* 2013 <http://www.jmir.org/2013/6/e124/PDF>

Users of electronic cigarettes

- Internet survey of ever-users of e-cigarettes in 2009.
- 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

- Etter JF. Electronic cigarettes: a survey of users. *BMC Public Health*. 2010 May 4;10:231

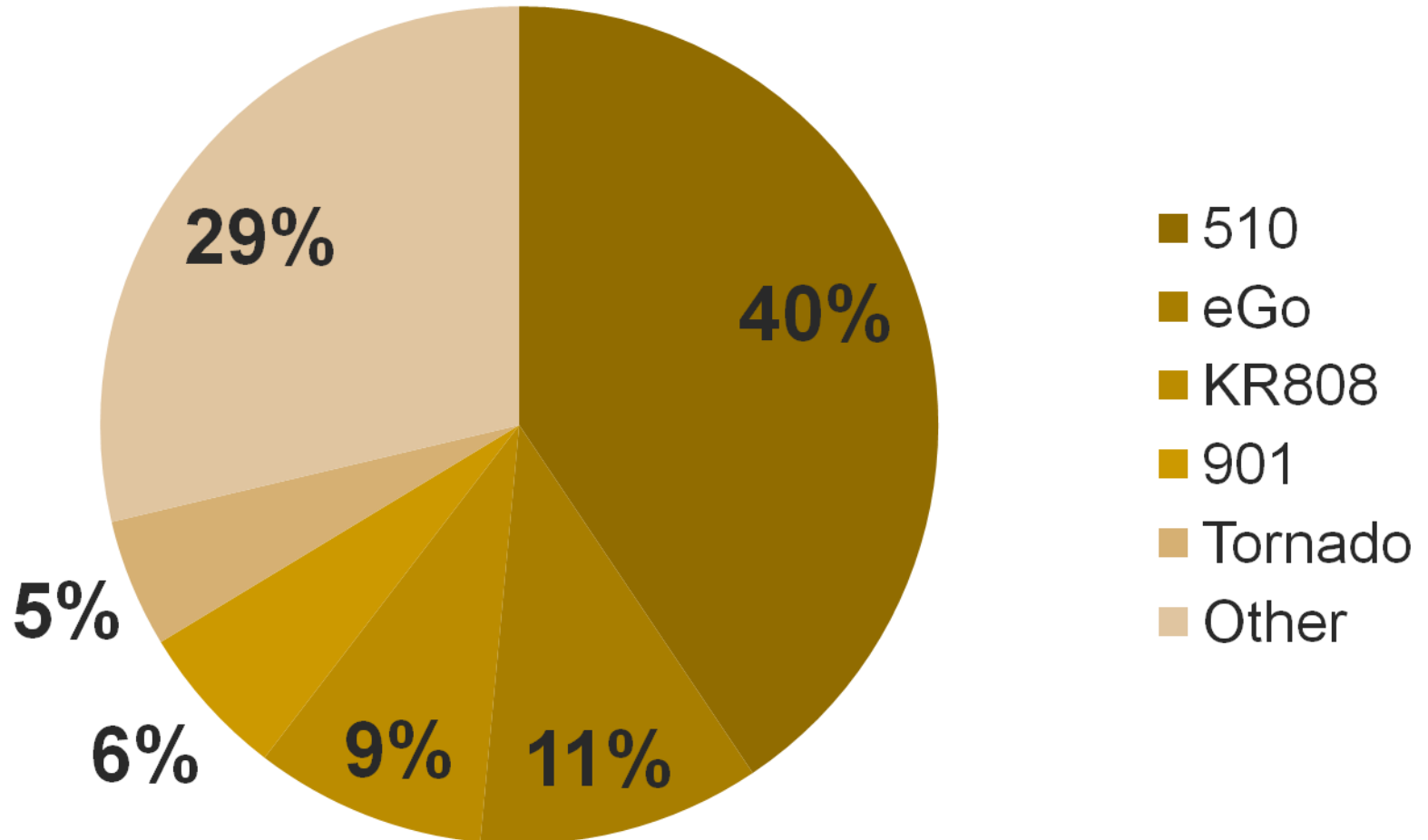
Cotinine in e-cigarette users

N	30
Daily users of e-cig	97%
Used tobacco or NRT in past 48h	0
Puffs per day on e-cig (median)	200
Cotinine in saliva, median 25 th et 75 th percentiles	322 ng/ml 138 / 546 ng/ml
<i>In the literature: in EX-smokers who use NRT:</i>	<i>100-250 ng/ml</i>

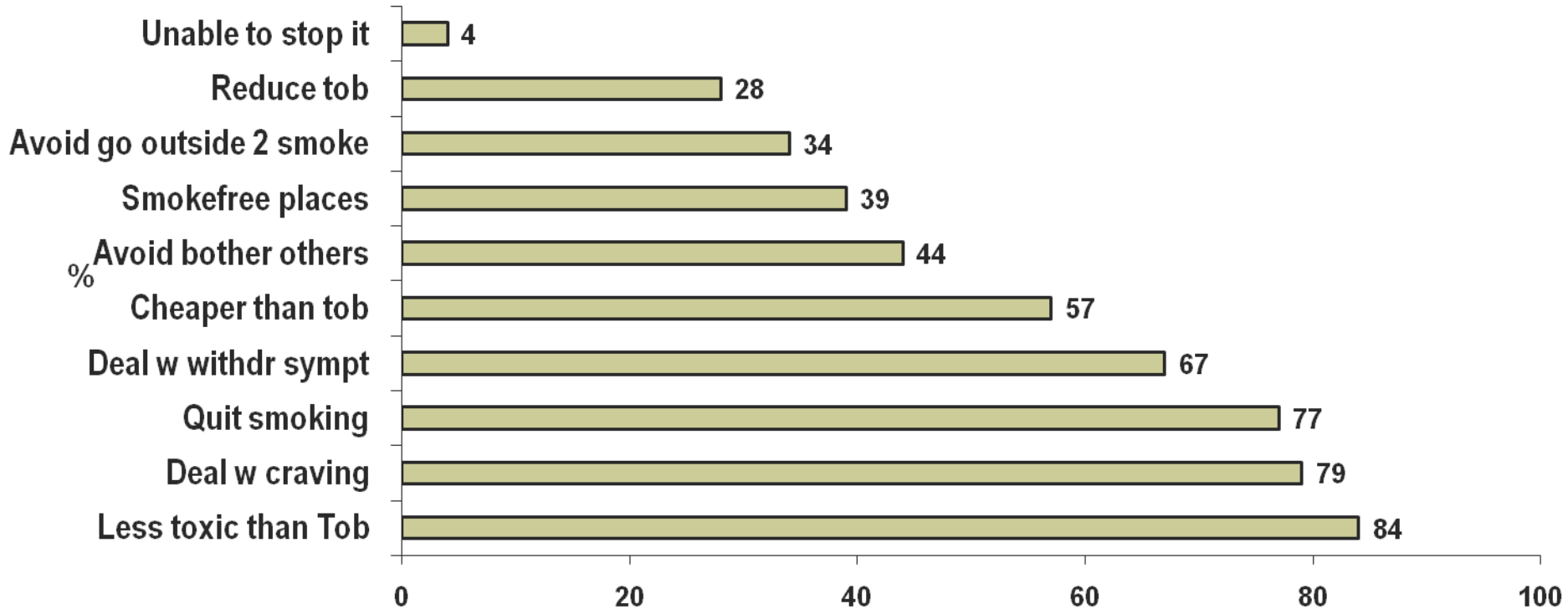
E-cigarette use, in daily users

Daily e-cig users (Etter & Bullen, <i>Addiction</i> 2011)	N=2896
Puffs / day	120
Refills / cartridges per day	5
Duration of current episode of use (in former smokers)	3 months (5 months)
Have been using e-cig for ≥ 1 year	15%
Use nicotine-containing e-cig	97%
E-liquid: nicotine concentration (same for all brands)	18 ng/ml
Buy their e-cig on the Internet	96%
Monthly spending for e-cig	33 USD
Use e-cig to inhale other substances, not in commercial e-liquids: vitamins, flavors, cannabis (n=5), alcohol (n=1)	0.9%

Most used models (sold under various brand names)



Reasons for use



■ Agree %

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