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Facoltà di scienze della comunicazione
Institute of Communication and Health

Sanità 2.0: connessioni o relazioni di cura?

Peter J. Schulz
Institute of Communication & Health
Università della Svizzera italiana

Abitare la responsabilità professionale nella società dei “pazienti per sempre”
SUPSI, Dipartimento economia aziendale, sanità e sociale
Lugano-Canobbio, 10 dicembre 2015

Introduzione

- Le visioni correnti in materia di politica sanitaria riconoscono il consumatore o il paziente come attore attivo e strategico nel processo decisionale relativo a questioni di salute.
- Il programma inglese “expert patient” cerca di migliorare gli esiti sanitari e diminuire i costi legati alla salute educando pazienti cronici alla gestione della propria malattia.
- Internet è considerato come un importante strumento per facilitare la l’autogestione di condizioni mediche da parte dei pazienti.
- Le informazioni presenti online risultano essere di supporto a pazienti e a consumatori nel momento in cui si trovano a dover prendere decisioni di carattere medico?

Cultura della salute (Health Literacy)

… “is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” (Healthy People 2010)

“ Il grado in cui gli individui hanno le capacità di ottenere, elaborare e comprendere informazioni relative alla salute e ai servizi medici per prendere decisioni appropriate in merito”

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Perché la cultura della salute è importante?

Perché la cultura della salute è importante?

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Esiti sanitari/Servizi

- Stato di salute in generale
- Ospedalizzazione e riospedalizzazione
- Utilizzo del pronto soccorso
- Controllo dell'asma
- COPD
- Depressione
- Controllo del diabete*
- Controllo dell'HIV*
- Stadio del cancro alla prostata
- Mammografia*
- Pap test
- Vaccinazione contro lo pneumococco
- Vaccino antinfluenzale
- Screening delle malattie a trasmissione sessuale
- Costi
- Mortalità

Comportamenti

- Abuso di sostanze*
- Allattamento
- Problemi comportamentali
- Aderenza ai trattamenti medici*
- Fumo*
- Consenso informato
- Processo decisionale nel fine vita

Conoscenze

- Controllo delle nascite
- Pap test
- Istruzione presso il Pronto Soccorso
- Asma
- Ipertensione
- Diabete

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Dimensions of patients' empowerment

- Meaningfulness: relevance of managing one's disease
- Competence: sense of competence to manage one's disease
- Self-determination: sense of autonomy to manage one's disease
- Impact: sense of control over the outcome of disease management

(Based on Thomas & Velthouse, 1990; Spreitzer, 1995)

Cultura della salute, empowerment e comportamento del paziente

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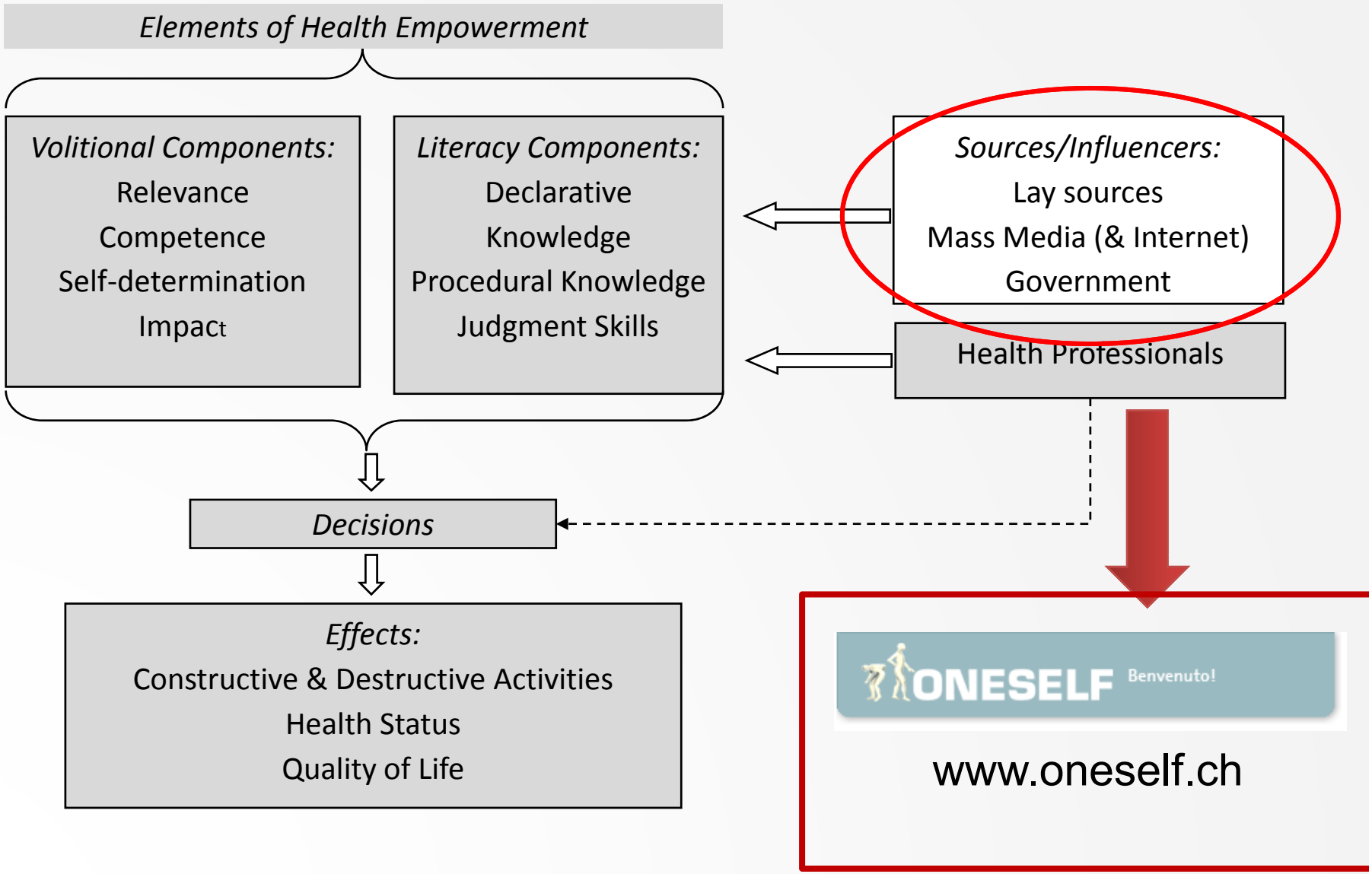
		Psychological Empowerment	
		Low	High
Health Literacy	Low	High-needs Patient	Dangerous Self-manager
	High	Needlessly Dependent Patient	Effective Self-manager

Can web-support increase the level of health literacy and empowerment?

The poor diabetic website, 2011

Theory

Intervention



Esempio opportunità: www.oneself.ch

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HL model implementation

Sections	**Health literacy levels**		
	Declarative knowledge	Procedural knowledge	Integration with existence and goals
Radio	x		
Library	x	x	
Gym		x	
Forum			x
Chat			x
The Specialist Answers			x
Tell-a-Story			x

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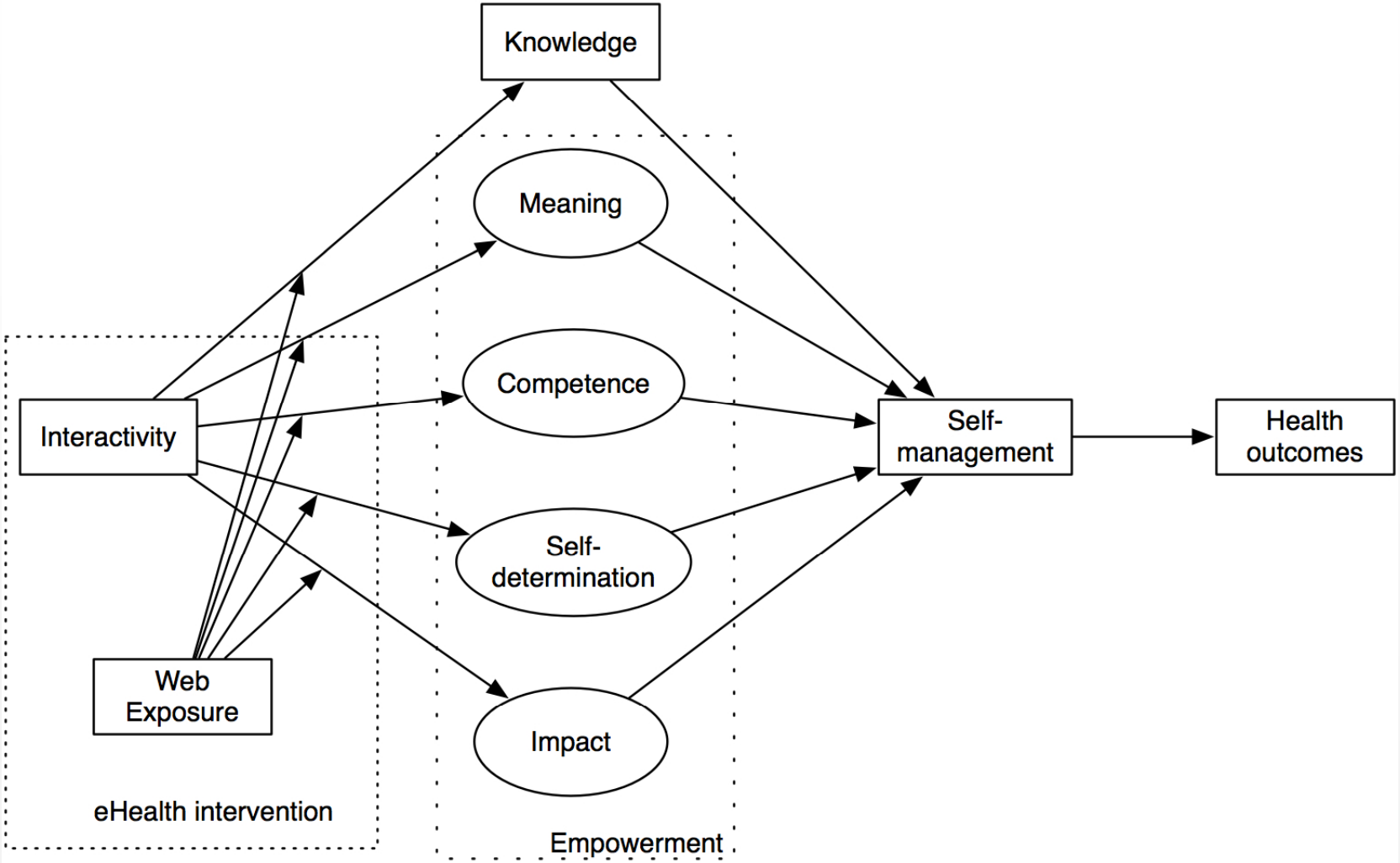
eHealth effects on Health Literacy & Empowerment



Metodo

Experimental study:

165 FMS patients were randomized in 3 groups/conditions:

Group 1: patients were provided with a static version of ONESELF (baseline)

Group 2: patients were provided with an interactive-only version of ONESELF

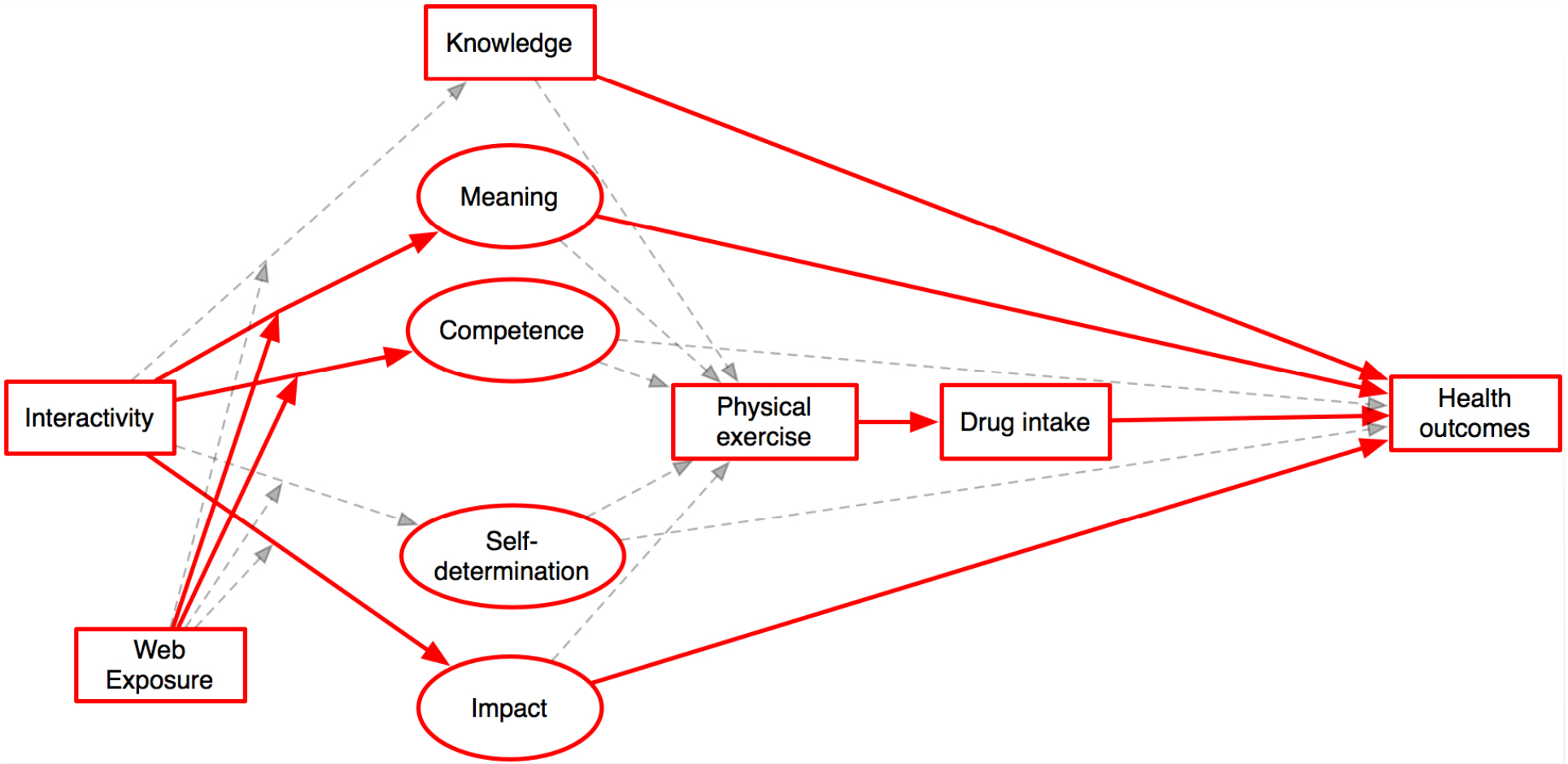
Group 3: patients were provided with the full-fledged version of ONESELF

They completed a pre-test and a post-test after 5 months of navigation.

Cross-sectional study

- 209 patients registered to ONESELF were recruited and asked to complete a cross-sectional survey.
- The cross-sectional study was conducted 5 months after the end of the experiment.

Risultati



Camerini & Schulz, 2012
Journal of Medical Internet Research

Sfide: Informazioni sulla vaccinazione dei bambini

- Content analysis of an online debates on pediatric immunizations on three major forums (alfemminile.com, nostrofiglio.it, and pianetamamma.it)
- Period January 2008 – June 2014
- Posts, N = 6544 mentioning 6223 arguments,
- 1729 participants (98% = women)
- Measures (content categories): posts' main content, users' level of concern, users' request for information, arguments related to the discussed vaccination, recommendation offered, position re vaccination.

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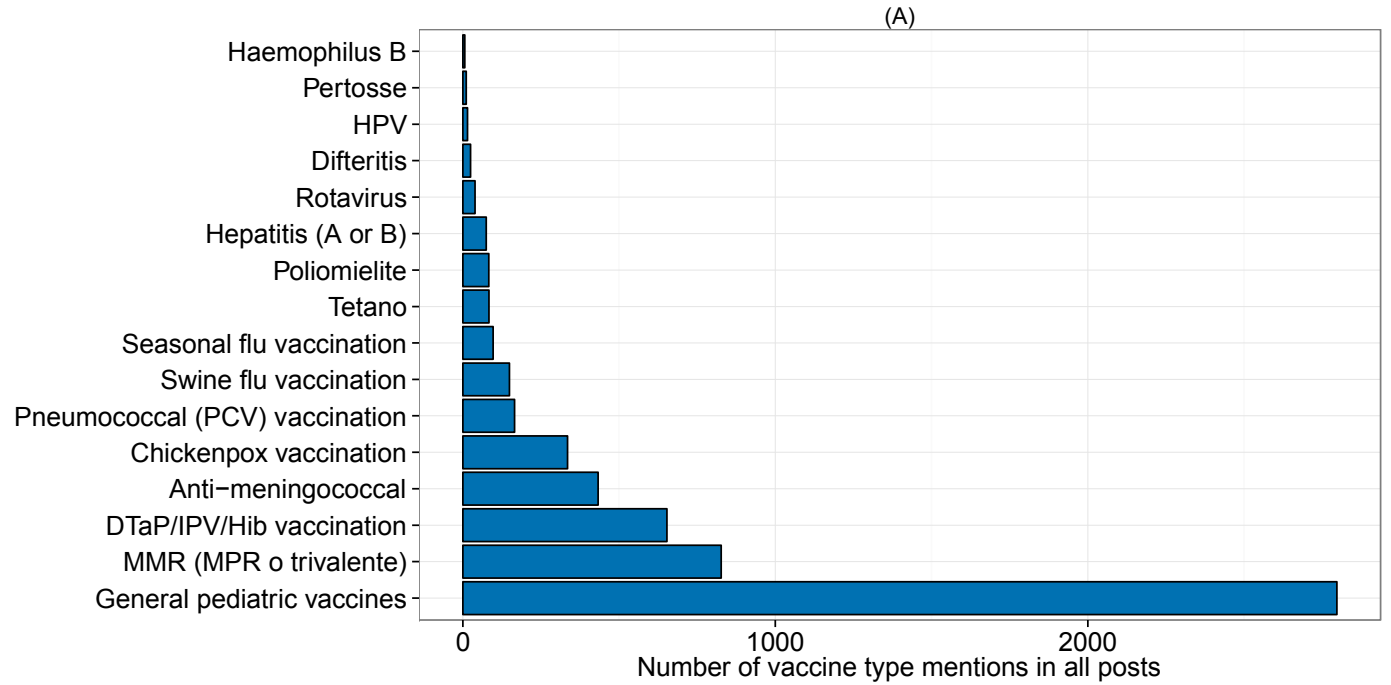

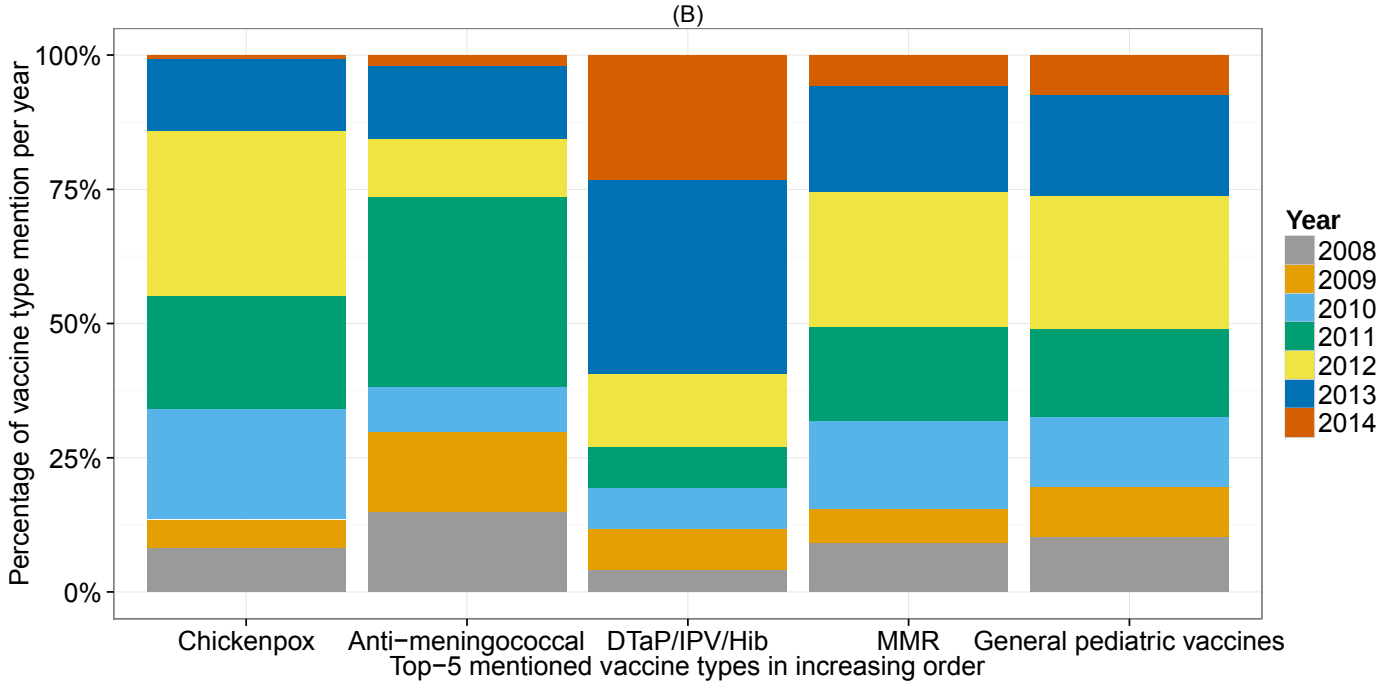

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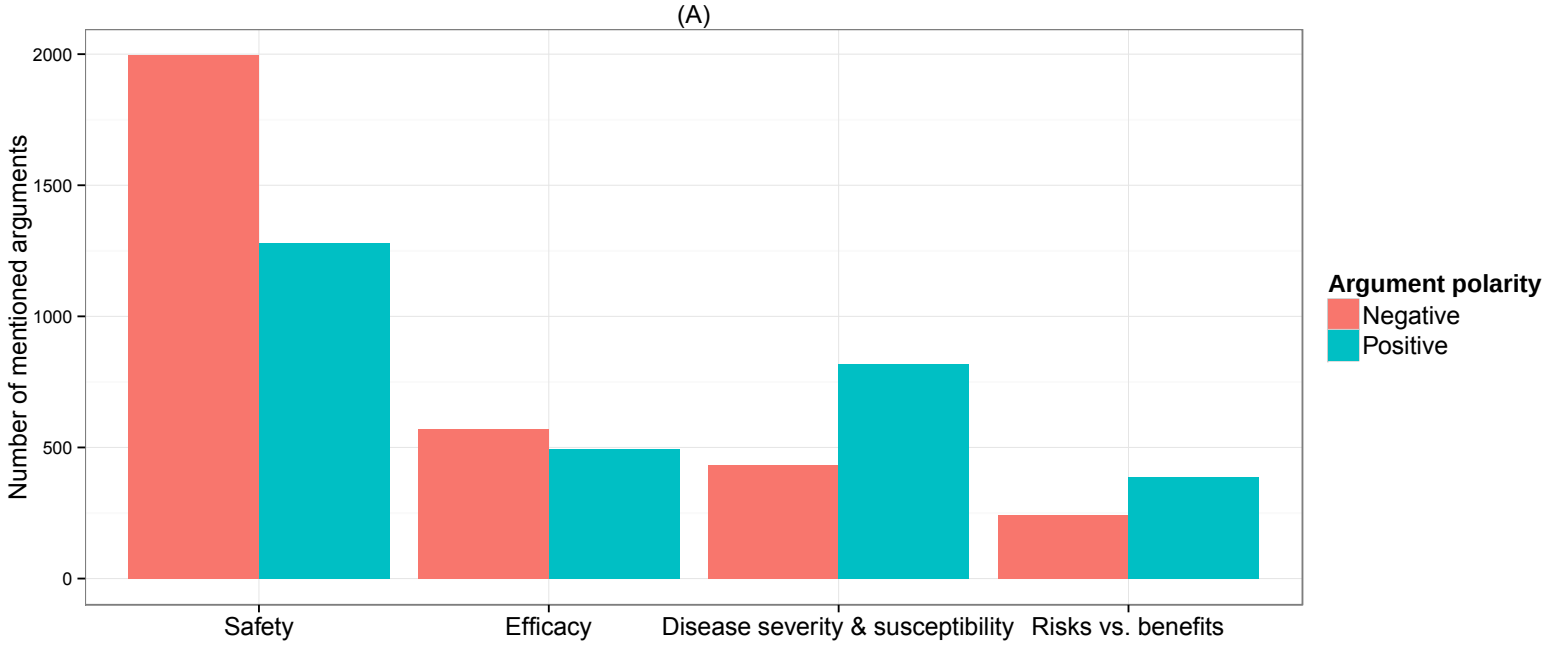

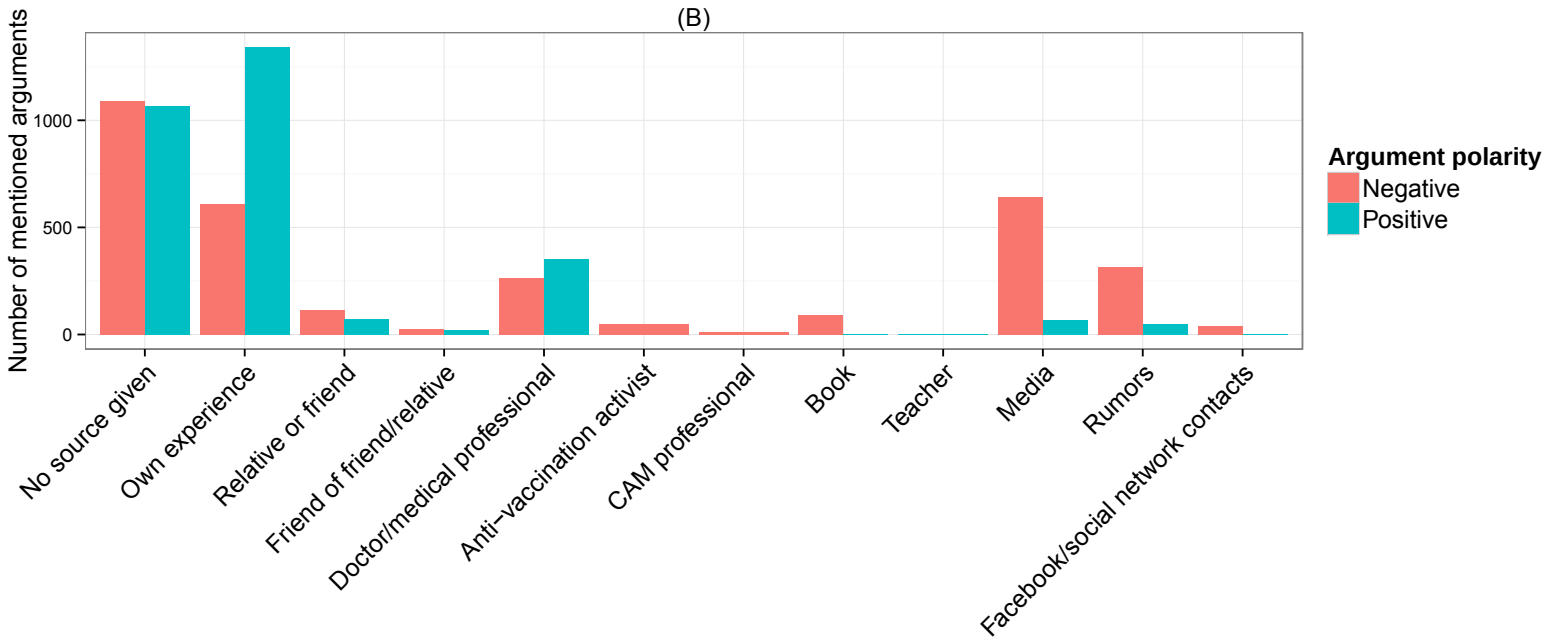

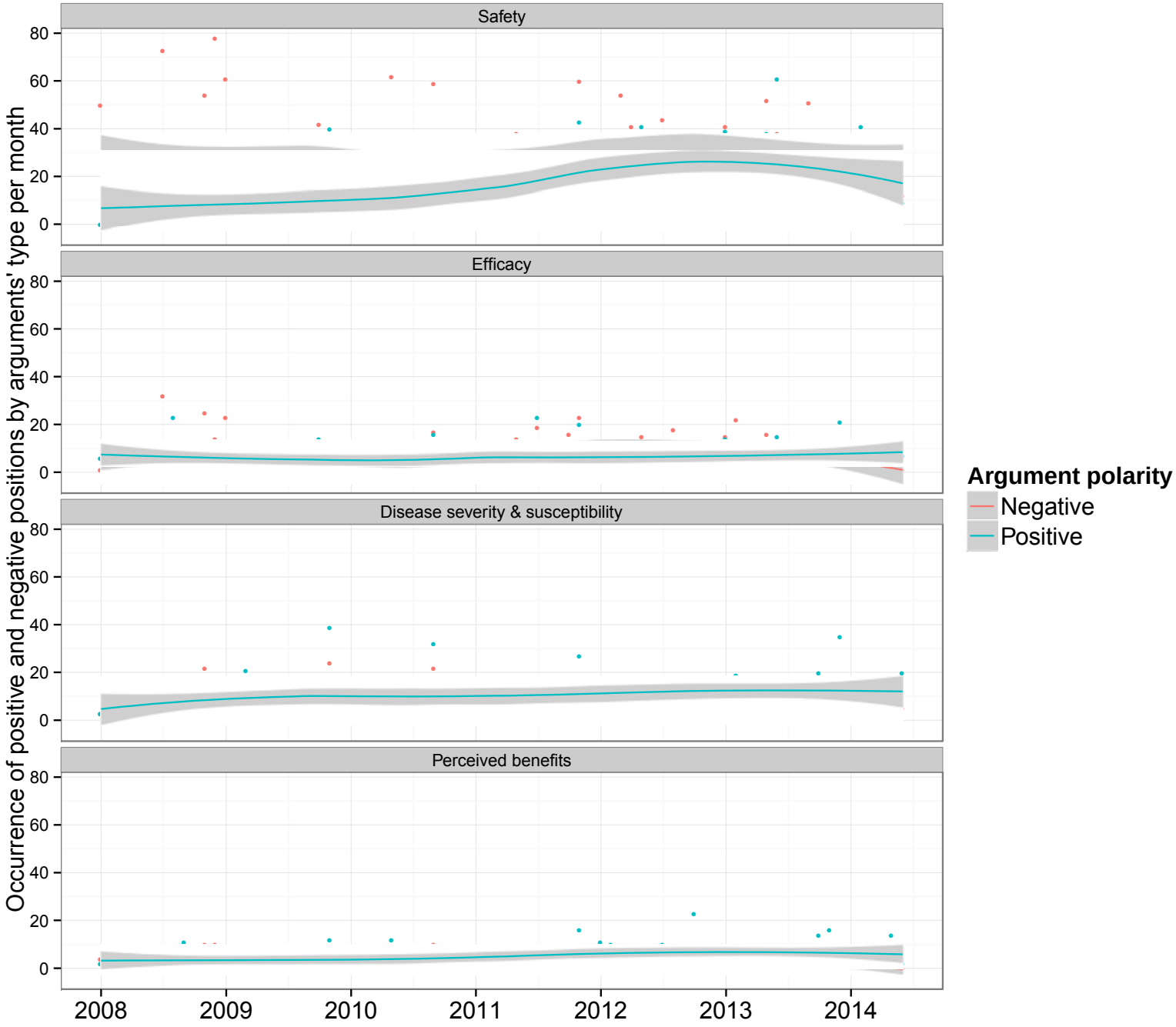
Safety
Efficacy
Disease severity & susceptibility
Perceived benefits
Occurrence of positive and negative positions by arguments' type per month
0
20
40
60
80
2008
2009
2010
2011
2012
2013
2014
Argument polarity
Negative
Positive

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Risultati

- Analysis of online forum discussions among users reveals that anti-vaccination users are active in the online environment and that reliable sources are rarely cited.
- Medical practitioners are among the sources of both pro- and anti-vaccination users, suggesting that vaccination-adverse professionals are gaining attention
- Vaccination promotion initiatives have to focus on vaccination safety and efficacy, the two areas most often addressed by arguments critical of vaccination.
- There is an increasing need for online monitoring systems focusing on detection of false information spread on medical topics to allow for prompt intervention.

Fadda, Allam & Schulz, 2015
Vaccine

Sfida (2): Tra «cattiva» cultura della salute e navigazione guidata

- Esperimento per studiare l'effetto della qualità di siti internet e di siti internet condizionati
- Oggetto: Fiducia, conoscenze e attitudini verso la vaccinazione (MPR)
- Tre gruppi: (1) Google «non manipolato»; (2) Google manipolato in modo che vengano trovati siti di buona qualità, valutati in base al codice HON; (3) Google manipolato in modo da trovare siti contrari alla vaccinazione
- Pre-post-test con 39 studenti al quale sono stati concessi 12 minuti per trovare delle informazioni sulla vaccinazione
- Misurazioni: fiducia, conoscenze, attitudini, percezione della qualità e dei condizionamenti

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Esperimento I

- Is there something like ‘dangerous literacy’ in connection with searching and using health information on the Internet?

- Hypothesis 1: Users offered high-quality websites by their search engine will gain more knowledge than users offered low-quality websites
  - Pre-post-test design with 39 students; were given 10 minutes to find information about vaccination

- Three experimental groups:

  (1) normal Google (n=12)

  (2) Google configured to find a set of websites that are certified by the Health on the Net (HON) code (n=14)

  (3) an engine configured to search for websites, blogs and forums that discourage vaccination and were run by anti-vaccination activists or movements (n=13)

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Esperimento I

- Pre-test measures:
  - Health status
  - Vaccination knowledge (= vaccination literacy, index of 14 true/false items)
  - Attitude toward vaccination (10 items, 1-7 Likert scale)
  - Perceived side effects and benefists of vaccination (5 items, 1-7 Likert scale)
  - Sources and assessment of health information (7 items, 1-7 Likert scale)
  - Socio-demographics (gender, nationality, age, education, Internet ussage;
- Posttest measure:
  - Vaccination knowledge (as above)
  - Attitude toward vaccination (as above)
  - Trust in information and websites presented (20 items measuring summarily the credibility, satisfaction, trustworthiness and relevance of the information retrieved and the websites visited)
  - Persuasion measure: Categorical items measuring participants' self-perceived persuasion by the sites (12 items)

Risultati

- Knowledge: a significant increase in group 2 (high-quality pro-vaccination sites, $p < .03$), no increase in groups 1 & 3. No pretest knowledge difference. H (2) =4.02, $p = .13$

- Attitude:
  - Group 2: significant increase of importance of vaccination of adults against influenza (z =-2.326, $p < 0.02$) and the effectiveness of vaccination against swine flu (z =-2.230, p <.03).
  - Group 3 (low-quality con-vaccination sites) showed an increase in the concern for side-effects of vaccination on adults (z = -2.582, p <.01) and for believing that vaccination was causing more harm than good (z = -2.200, p <.02).

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Risultati (cont.)

Using one-way ANOVA and Kruskal Wallis test showed no difference between the three groups in terms of

- Trust in the information found ($F(2,36)=1.83$, $p=.17$) ($chi^2=2.54$, $p=.28$),
- Satisfaction with the information found ($F(2,36)=1.84$, $p=.17$) ($chi^2=1.21$, $p=.54$),
- Assessment of its persuasiveness ($F(2,36)=0.99$, $p=.38$) ($chi^2=0.76$, $p=.68$),
- Information relevance ($F(2,36)=2.97$, $p=.06$) ($chi^2=5.44$, $p=.06$)
- Trust in Google ($F(2,36)=3.07$, $p=.06$) ($chi^2=4.20$, $p=.12$).

None of of the measures employed produced any significant differences between the experimental groups

Esperimento I: Risultati

- Gli studenti ai quali il motore di ricerca offriva siti di alta qualità (gruppo 2) hanno acquisito più conoscenze...(Z = -2.088, p = .03)
- … … e valutato in misura maggiore l'importanza della vaccinazione e la sua efficacia contro l'influenza suina rispetto agli altri gruppi (Z = 2.230, p = .03).
- Gli studenti ai quali il motore di ricerca offriva in maniera condizionata siti contro la vaccinazione (gruppo 3) si sono rivelati più preoccupati riguardo agli effetti collaterali e più convinti dei danni legati alla vaccinazione rispetto agli altri gruppi (Z = -2.582, p = .01) .
- Gli effetti positivi dei siti di alta qualità e gli effetti negativi dei siti condizionati si sono verificati indipendente dalla valutazione soggettiva della qualità del sito e dei condizionamenti del sito.

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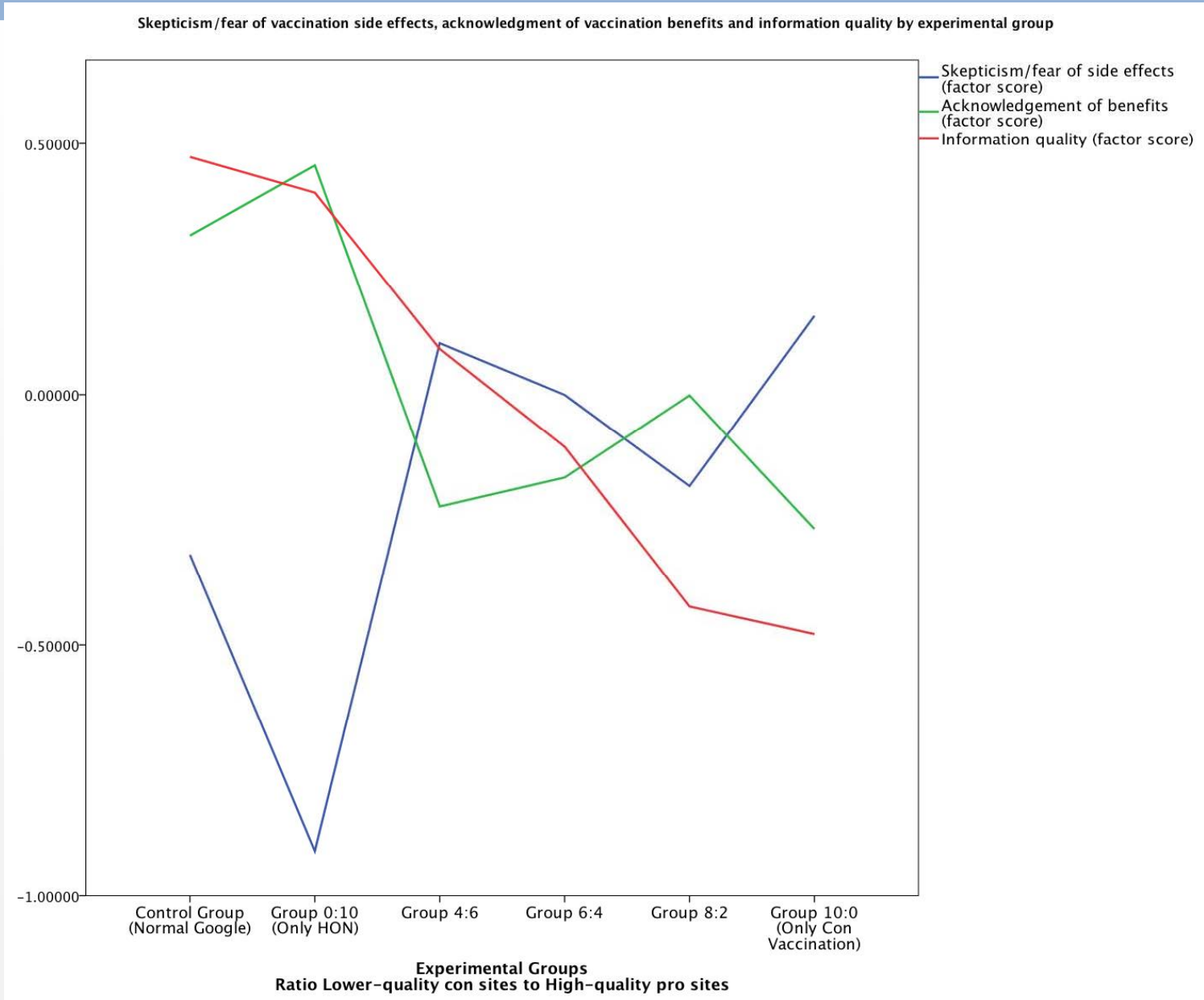
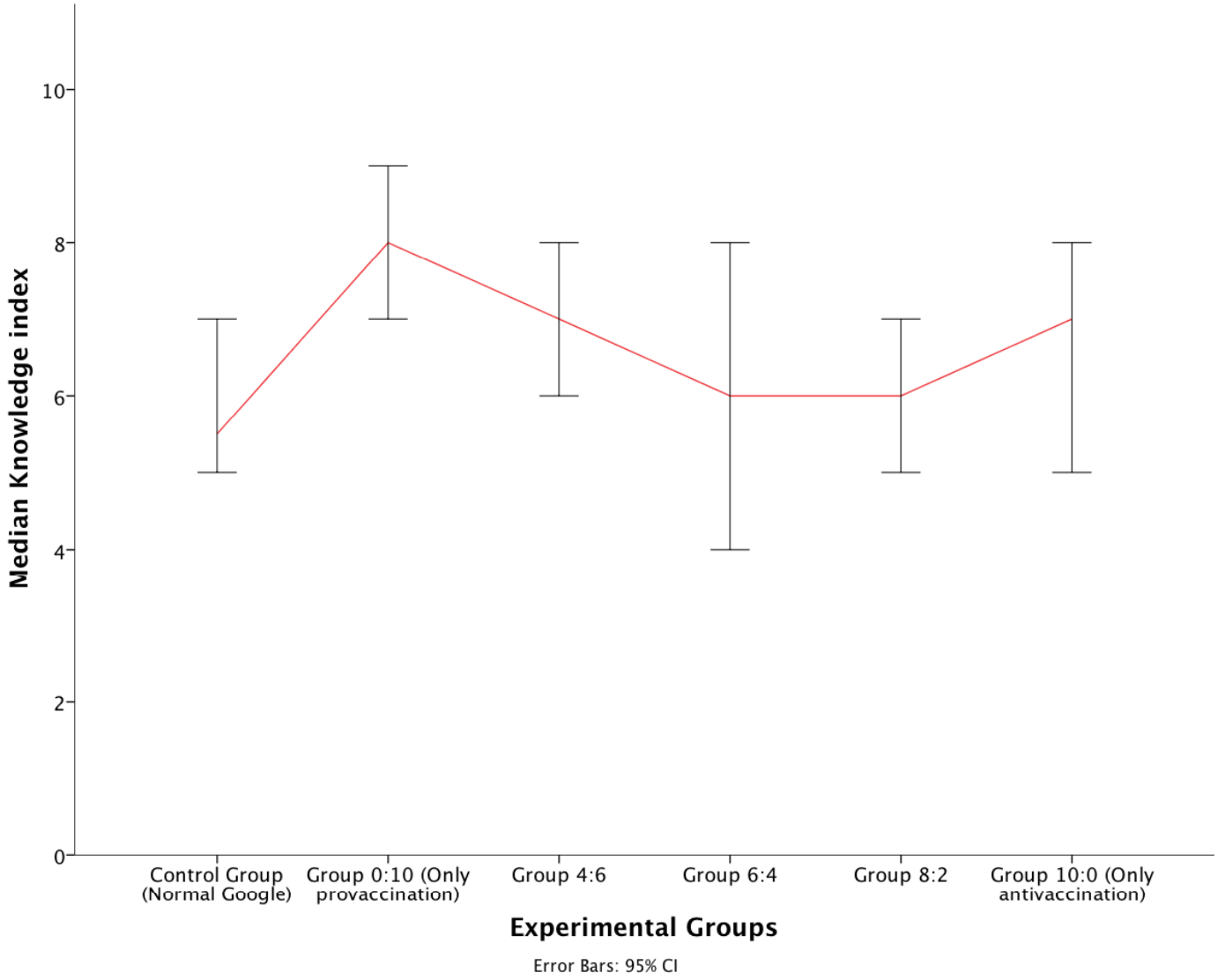
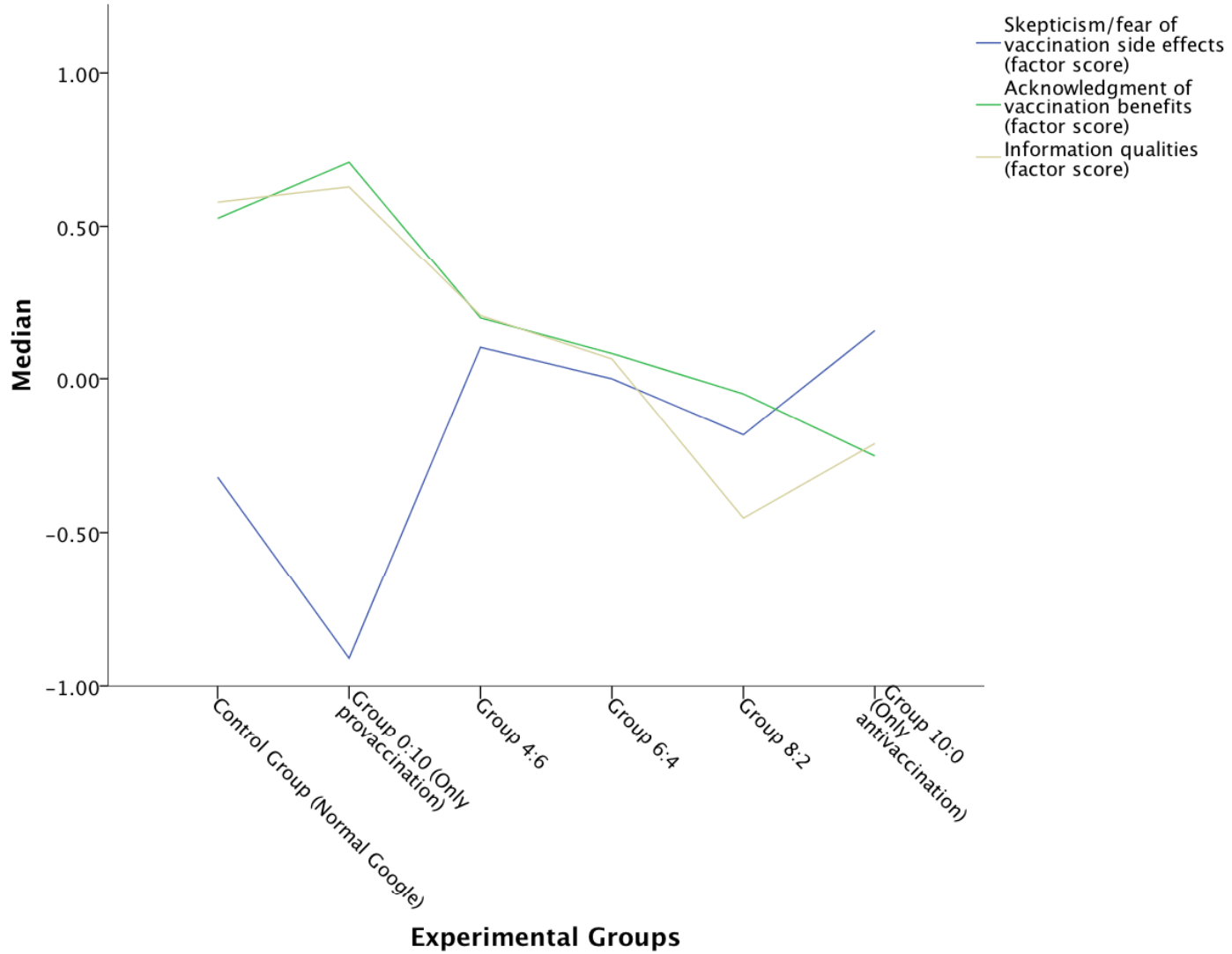
Esperimento II

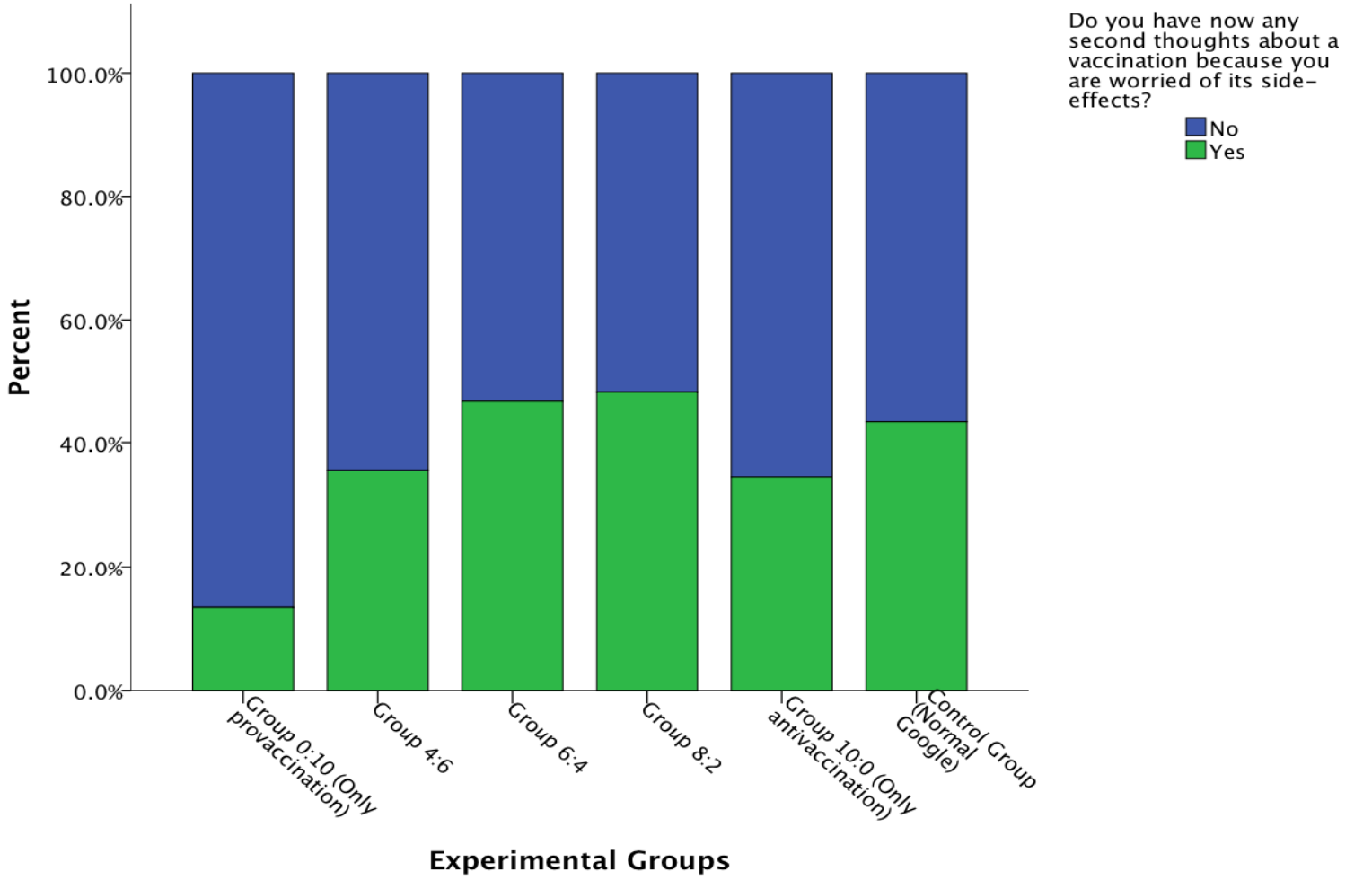
- *Hypothesis*: The higher the share of con-vaccination websites offered by a search engine, the more critical users' attitudes on vaccination will become
- 5 experimental groups + 1 control group. Differences in the ratio of con- versus pro-vaccination sites offered by the customized search engine. (0:10, 4:6, 6:4, 8:2, 10:0)
- Experiment conducted on Mturk, (*n* =197). Age *M*=37.3 (*SD* 11.4).
- Measures: Persuasion measure – 9 items; socio-demographic items (as in Experiment 1).

Esperimento II: Risultati




Median Knowledge index
10
8
6
4
2
0
Control Group (Normal Google)
Group 0:10 (Only provaccination)
Group 4:6
Group 6:4
Group 8:2
Group 10:0 (Only antivaccination)
Experimental Groups
Error Bars: 95% CI


Skepticism/fear of vaccination side effects (factor score)
Acknowledgment of vaccination benefits (factor score)
Information qualities (factor score)
Median
1.00
0.50
0.00
-0.50
-1.00
Control Group (Normal Google)
Group 0:10 (Only provaccination)
Group 4:6
Group 6:4
Group 8:2
Group 10:0 (Only antivaccination)
Experimental Groups


Do you have now any second thoughts about a vaccination because you are worried of its side-effects?
No
Yes
Percent
100.0%
80.0%
60.0%
40.0%
20.0%
0.0%
Group 0:10 (Only provaccination)
Group 4:6
Group 6:4
Group 8:2
Group 10:0 (Only antivaccination)
Control Group (Normal Google)
Experimental Groups

Riassunto 2 esperimenti

- Internet Users are flying blind on the Internet

- One explanation for that is that users are not systematically elaborating on the search and its results; instead they are guided by heuristic principles

- Is there any way for debiasing, to manipulate people in a beneficially way?

Allam, Schulz & Nakamoto, 2014, *JMIR*

Sviluppare strategie di “debiasing”

- Two strategies to overcome biases / heuristics
  - technological approach
  - benevolent manipulation

- How to make the user aware about possible biases?
  - the strategy of inoculation;

Strategie di Debiasing

3 x 2 factorial between subject design, availability of information as first factor, the warning of the presence of false information as the second;

CrowdFlower Platform, N = 279

All participants were asked to conduct a 10-minute search on vaccination-related topics and started their search on the manipulated version of Google

Strategie di Debiasing: esempio

Vaccination

Field of study

Immunization is the process whereby a person is made immune or resistant to an infectious disease, typically by the administration of a vaccine. Vaccines stimulate the body's own immune system to protect the person against subsequent infection or disease.
World Health Organization
See also: Myths and facts about vaccination

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Risultati

- Users exposed to the comprehensible version of the info gained higher post-search knowledge levels and a more favorable attitude towards vaccination;
- While the combination of warning and information coming from Wikipedia steers users away from vaccination.
- The addition of the warning as implemented in this study did not provide an indication to any position toward the searched health topic;
- Further research is needed to identify ways how to avoid blind flying on the Internet.

Ludolph, Allam & Schulz, 2016, *forthcoming*

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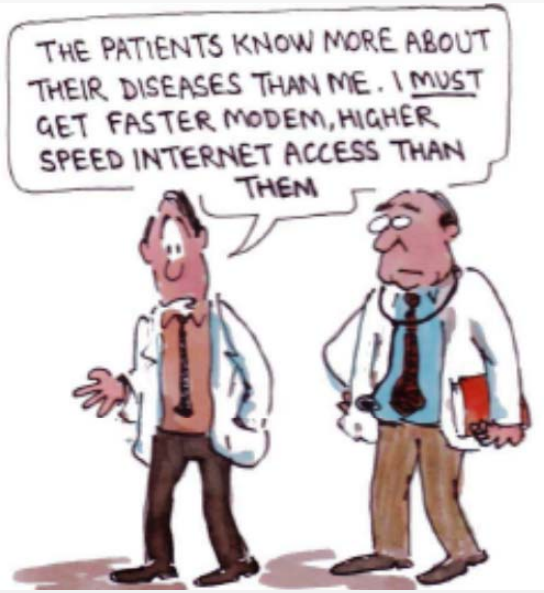
E che ruolo giocano gli apps?

BMJ

How Web 2.0 is changing medicine

Dean Giustini

BMJ 2006;333;1283-1284
doi:10.1136/bmj.39062.555405.80



E che ruolo giocano gli apps?

Corriere della Sera Domenica 19 Aprile 2015

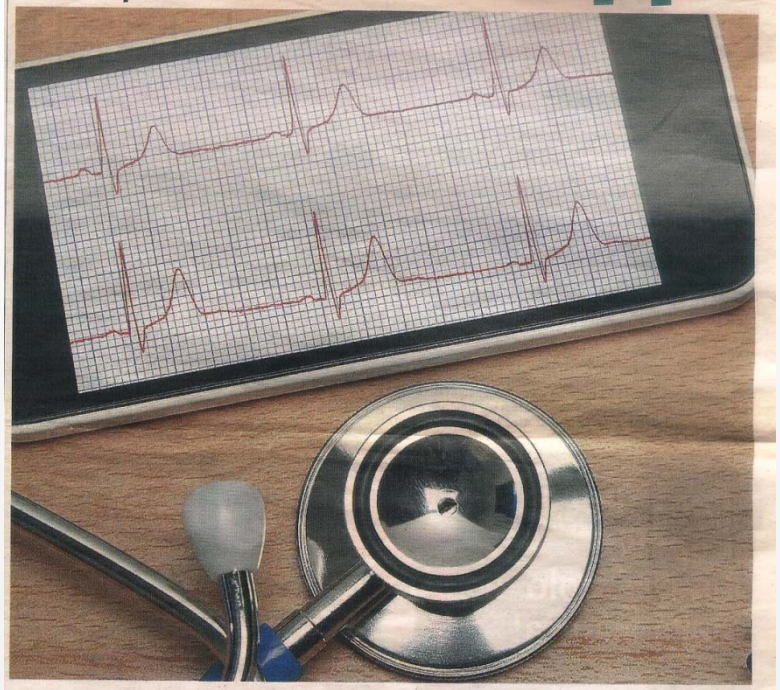
CorriereSalute

Le pagine del vivere bene
www.corriere.it/salute

Procedono velocemente l'offerta e l'utilizzo di software di carattere medico scaricabili su smartphone e tablet. È invece solo ai primi passi l'elaborazione di regole e strumenti di verifica perché siano garantite ai fruitori qualità e sicurezza

Possiamo affidare la salute al telefonino?

La nuova medicina è quella delle app



La tecnologia «mobile» offre opportunità enormi nel campo della salute, sia nella gestione del benessere personale, sia nel rapporto con il medico e con i servizi sanitari. Ma adesso deve passare il vaglio delle verifiche in tema di attendibilità, rispetto della privacy e sicurezza

E che ruolo giocano gli apps?

Un documento politico…

EUROPEAN COMMISSION

Brussels, 10.4.2014
COM(2014) 219 final

GREEN PAPER

on mobile Health ("mHealth")

1. INTRODUCTION

Mobile health (hereafter "mHealth") covers "*medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices*"[1].

1 World Health Organisation *"mHealth – New horizons for health through mobile technologies, Global Observatory for eHealth series – Volume 3"*, page 6

2 Lifestyle and wellbeing apps primarily include apps intended to directly or indirectly maintain or improve healthy behaviours, quality of life and wellbeing of individuals.

2. POTENTIAL OF MHEALTH

2.1. Potential for healthcare

The healthcare systems in Europe are facing new challenges such as the ageing of the population, and increased budgetary pressure. In this context, mHealth could be one of the tools to tackle these challenges by contributing to a more patient-focused healthcare, and supporting the shift towards prevention while at the same time improving the efficiency of the system.

Attention to prevention has the potential to improve people's quality of life and even extend life expectancy and could be accelerated by finding novel ways of promoting "healthy behaviours". In this respect, motivation and user engagement remain key and a fruitful area of research for behavioural economics.

2.2. Market potential

2.2.1. mHealth market

In recent years mHealth has emerged as a complementary way of delivering healthcare building on the ubiquitous connectivity of mobile networks and the proliferation of smartphones and tablets.

The growth in wireless subscriptions, which has reached over 6 billion wireless subscribers in the world, has favoured the uptake of the mobile health and wellbeing market[5].

2.2.2. mHealth app market

The market for mobile apps has developed very rapidly in recent years to become a key driver of mHealth deployment facilitated by smartphone penetration. Interestingly, this market is dominated by individuals or small companies, with 30% of mobile app developer companies are individuals and 34.3% are small companies (defined as having 2-9 employees)[10].

In 2013, the top 20 free sports, fitness and health apps already accounted for a total number of 231 million installations worldwide, as per a recent IHS report.[11]

According to Juniper *"a burgeoning market for healthcare peripherals and increasing smartphone processing power will result in the number of patients monitored by mobile networks to rise to 3 million by 2016."*

It is also foreseen that by 2017 3.4 billion people worldwide will own a smartphone and half of them will be using mHealth apps[12].

According to recent estimations[13] 97,000 mHealth apps are currently available across multiple platforms on the global market. Approximately 70% of mHealth apps target the consumer wellness and fitness segments. 30% of apps target health professionals, easing access to patient data, patient consultation and monitoring, diagnostic imaging, pharmaceuticals information etc[14].

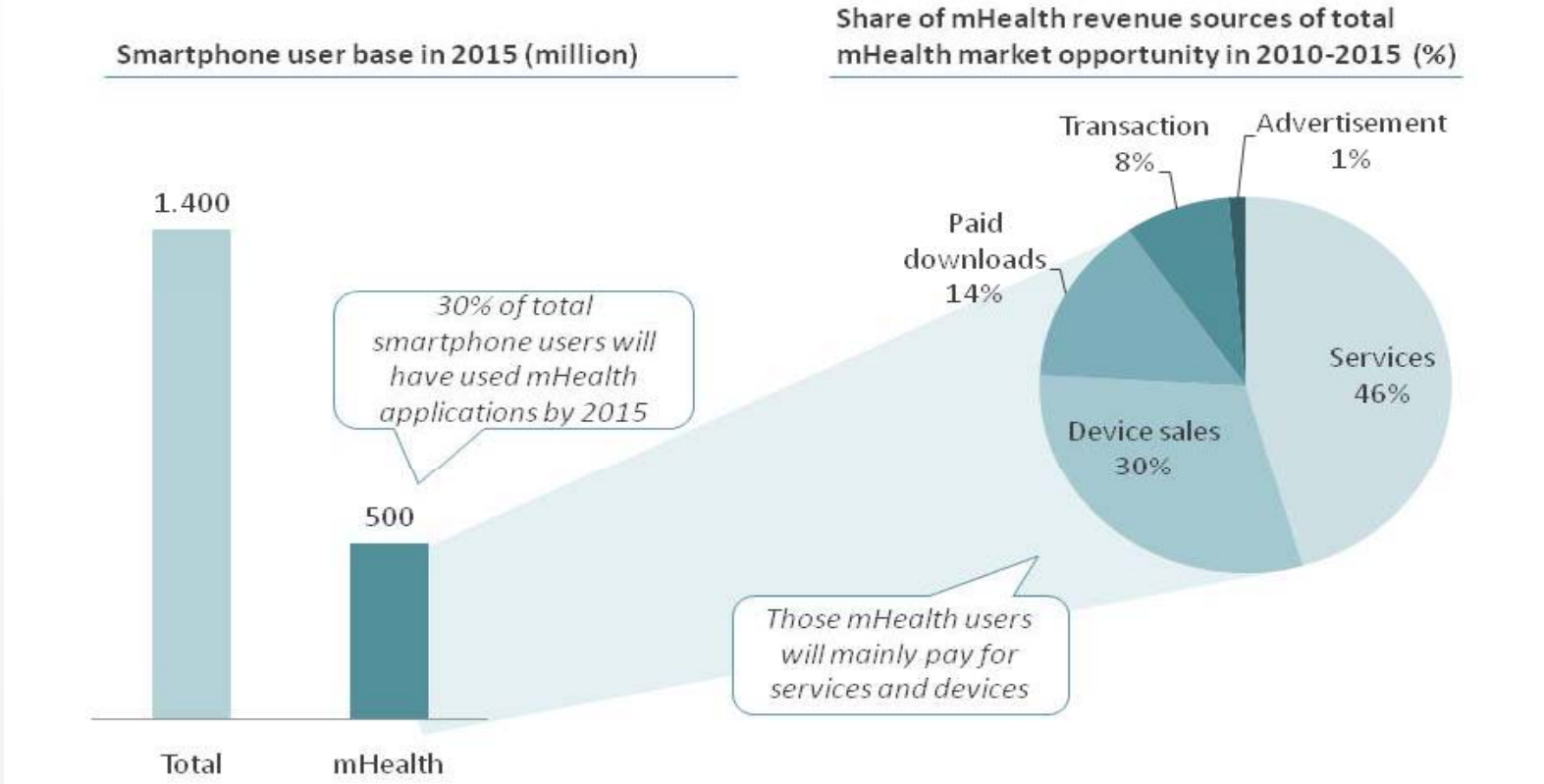
3.9. Research and innovation in mHealth

Diet, exercise and other wellness apps are wildly popular with consumers, but it is questionable whether most of them do more than provide information[54].

There is a need to invest more in research and innovation in the field to support the development of more advanced and innovative mHealth solutions while ensuring a high degree of efficacy and reliability as well as secure processing.

mHealth mercato in Europa

mHealth market 2015: 500m people will be using healthcare smartphone applications

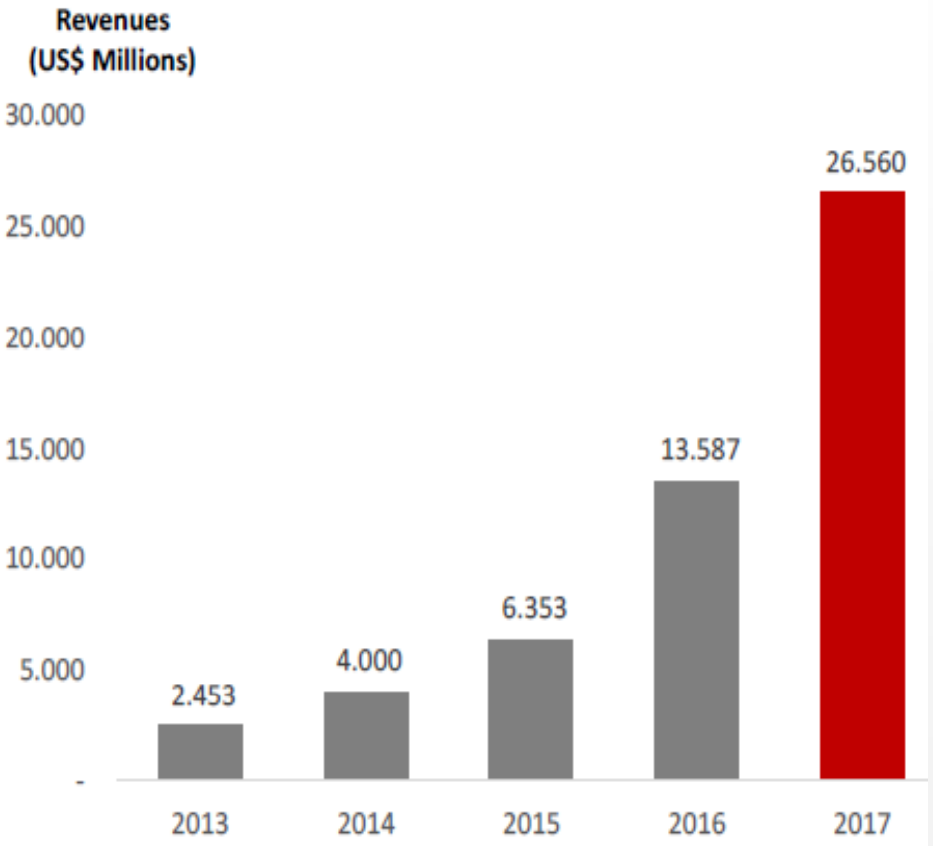


Smartphone applications will become the killer applications for mobile health solutions.

research2guidance
the mobile research specialists

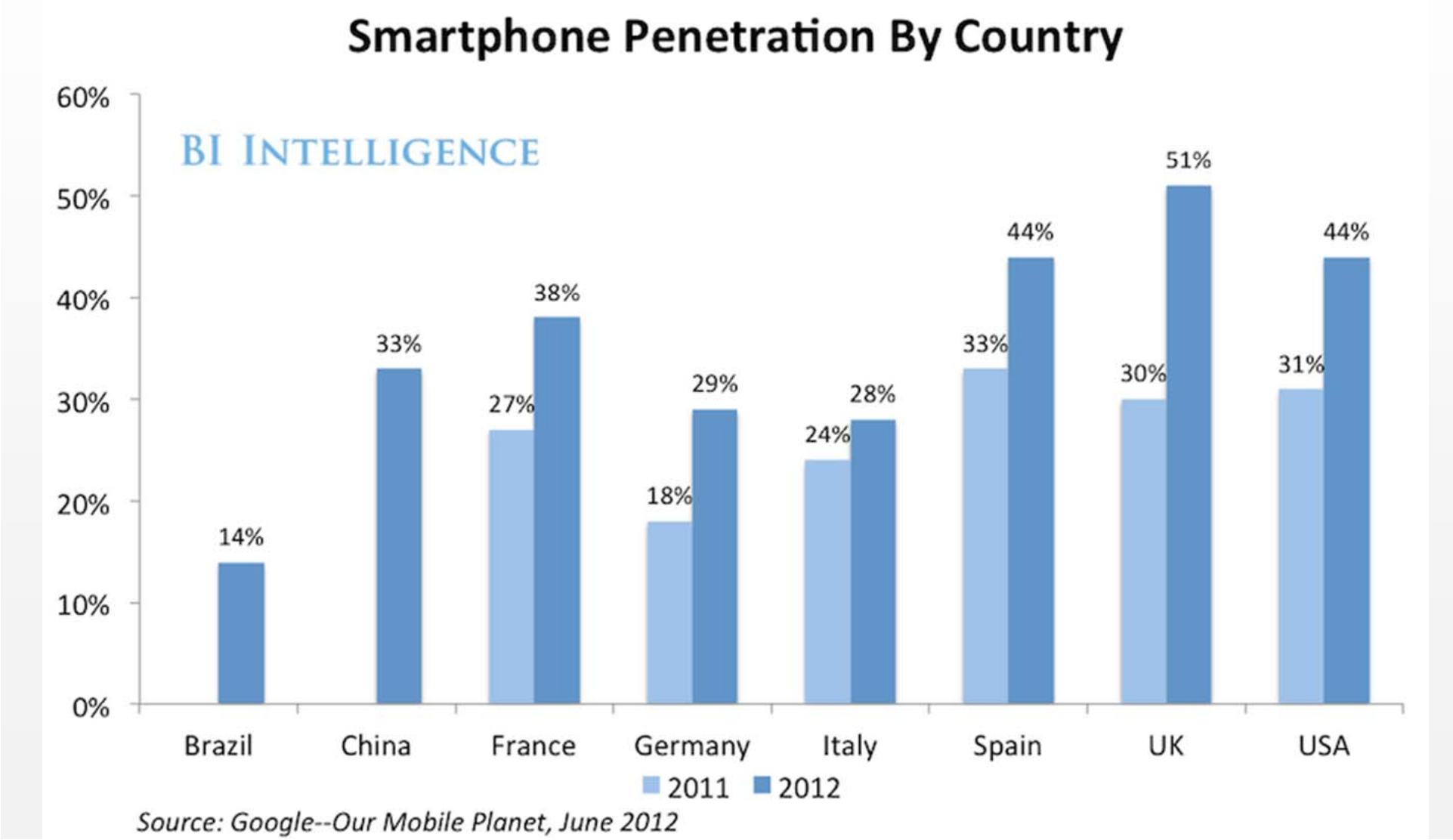
mHealth mercato

Global mHealth market revenue in USD (2013-2017)



Source: research2guidance, mHealth App Market Report 2013-2017

mHealth


Smartphone Penetration By Country
BI INTELLIGENCE
60%
50%
40%
30%
20%
10%
0%
14%
33%
27%
38%
18%
29%
24%
28%
33%
44%
30%
51%
31%
44%
Brazil
China
France
Germany
Italy
Spain
UK
USA
2011
2012
Source: Google--Our Mobile Planet, June 2012

Tipi di Health Apps

Types of Health Apps

% of health app users who use apps to track...

All health app users (n=254)	
Exercise, fitness, pedometer or heart rate monitoring	38%
Diet, food, calorie counter	31
Weight	12
Period or menstrual cycle	7
Blood pressure	5
WebMD	4
Pregnancy	3
Blood sugar or diabetes	2
Medication management (tracking, alerts, etc)	2
Mood	*
Sleep	*
Other	14

Source: Pew Internet/CHCF Health Survey, August 7-September 6, 2012. N=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 7 percentage points for results based on health app users.

*Less than 1% of respondents

Apps nel campo della salute

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Apps nel campo della promozione della salute

- A disposizione di tutta la popolazione
- Integrabili nella "vita quotidiana"
- Strumenti efficienti nell'autovalutazione e nella generazione di feed-back in tempo reale
- Presenti nel momento in cui possono servire
- Personalizzabili rispetto ai bisogni di chi li utilizza
- Gratuite o a basso costo

Apps nel campo della salute

BMJ 2015;350:h1887 doi: 10.1136/bmj.h1887 (Published 14 April 2015)

HEAD TO HEAD

HEAD TO HEAD

Can healthy people benefit from health apps?

Some apps have the potential to encourage healthier habits and are accessible to most people, writes **Iltifat Husain**, but **Des Spence** notes the lack of any evidence of effectiveness and the potential for encouraging unnecessary anxiety

Iltifat Husain *editor, iMedicalApps.com, and assistant professor of emergency medicine, Wake Forest School of Medicine, North Carolina, USA*, Des Spence *general practitioner, Glasgow, UK*

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mHealth

JOURNAL OF MEDICAL INTERNET RESEARCH

Review *(J Med Internet Res 2013;15(5):e95)* doi:10.2196/jmir.2430

Mapping mHealth Research: A Decade of Evolution

Maddalena Fiordelli, PhD; Nicola Diviani, PhD; Peter J Schulz, PhD

Institute of Communication and Health, Faculty of Communication Sciences, University of Lugano, Lugano, Switzerland

Corresponding Author:
Maddalena Fiordelli, PhD
Institute of Communication and Health
Faculty of Communication Sciences
University of Lugano
Via G. Buffi, 13
Lugano, 6900
Switzerland
Phone: 41 586664757
Fax: 41 586664647
Email: maddalena.fiordelli@usi.ch

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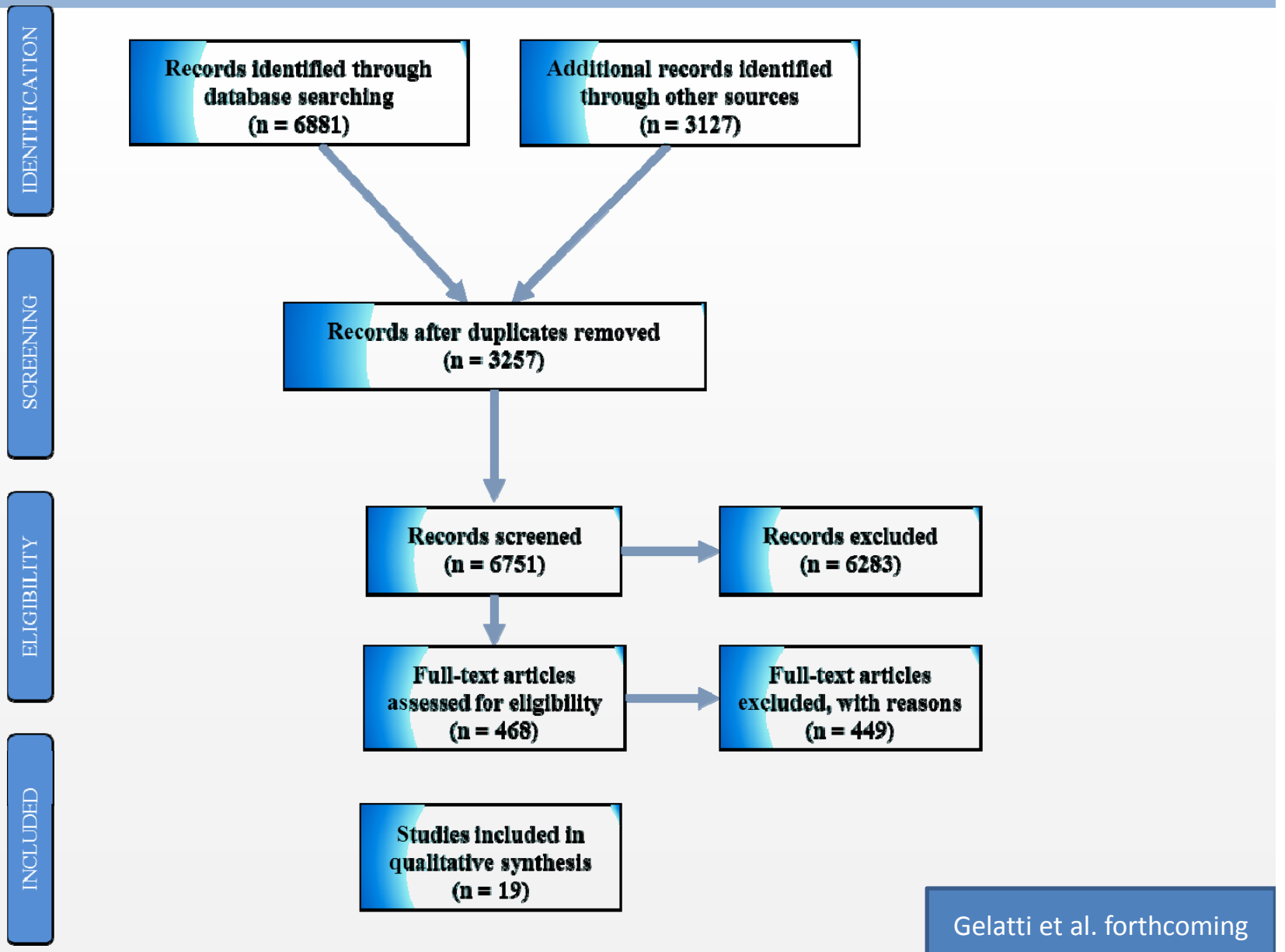
mHealth – una revisione della letteratura



Gelatti et al. forthcoming

mHealth – una revisione della letteratura

Alcune considerazioni…

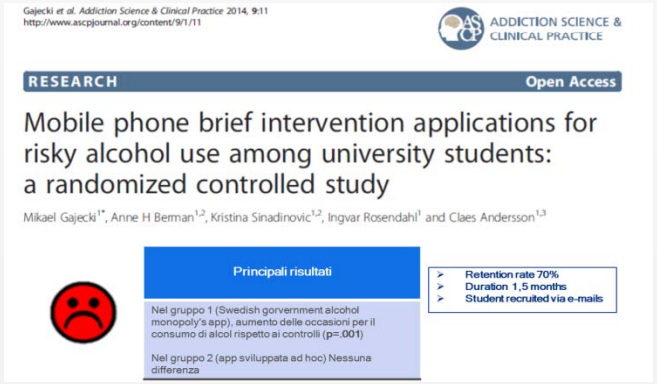
- **Basso numero di RCT (19)**
- **Breve durata temporale**
- **Numerosità del campione incluso nello studio molto variabile**

Journal of Cardiovascular Nursing
Vol. 30, No. 1, pp 35-43 | Copyright © 2015 Wolters Kluwer Health | Lippincott Williams & Wilkins

The Use of mHealth to Deliver Tailored Messages Reduces Reported Energy and Fat Intake

Erica J. Ambeba, PhD; Lei Ye, BMed; Susan M. Sereika, PhD; Mindi A. Styn, PhD; Sushama D. Acharya, PhD; Mary Ann Sevick, ScD; Linda J. Ewing, PhD; Molly B. Conroy, MD, MPH; Karen Glanz, PhD, MPH; Yaguang Zheng, MSN; Rachel W. Goode, MSW; Meghan Mattos, MSN; Lora E. Burke, PhD, MPH

- IG/CG 70/140 Retention rate 86%
- Obese adults only



Gajecki et al. Addiction Science & Clinical Practice 2014, 9:11
http://www.ascpjournal.org/content/9/1/11

ADDICTION SCIENCE & CLINICAL PRACTICE

RESEARCH Open Access

Mobile phone brief intervention applications for risky alcohol use among university students: a randomized controlled study

Mikael Gajecki[1*], Anne H Berman[1,2], Kristina Sinadinovic[1,2], Ingvar Rosendahl[1] and Claes Andersson[1,3]

Principali risultati

Nel gruppo 1 (Swedish gorvernment alcohol monopoly's app), aumento delle occasioni per il consumo di alcol rispetto ai controlli (p=.001)

Nel gruppo 2 (app sviluppata ad hoc) Nessuna differenza

- Retention rate 70%
- Duration 1,5 months
- Student recruited via e-mails

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Conclusioni: Internet e i limiti della culture della salute

- Le informazioni disponibili su internet risultano essere di supporto a pazienti e a consumatori nel momento in cui si trovano a dover prendere decisioni di carattere medico.
- Anche qualora le informazioni siano qualitativamente buone, non risultano essere né universali (p.es. alcuni effetti collaterali sono rari), né adeguate per tutti i pazienti.
- I medicamenti non sono sempre adatti a tipologie diverse di pazienti e anche qualora lo fossero, possono non essere efficaci in maniera unilaterale.
- P.es. Le probabilità di efficacia (di un medicamento) possono differire tra pazienti con caratteristiche diverse tra loro.

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Competenze dei pazienti e internet

- Le competenze di un singolo paziente sono legate alle specifiche caratteristiche dei suoi sintomi, delle sue esperienze e dei suoi obiettivi di salute.
- Si è di fronte ad una situazione problematica quando un paziente riceve delle informazioni che non è grado di valutare adeguatamente.
- Internet non è propriamente costituito come strumento di supporto nei processi decisionali del paziente: la flessibilità che lo contraddistingue lo rende, per alcuni versi, potenzialmente dannoso.
- Le preferenze, i desideri e le predilezioni del paziente condizionano il processo di ricerca di informazioni: ciò potrebbe portare il paziente a costruire una struttura conoscitiva orientata sui propri desideri invece che su informazioni oggettive.

Internet ed empowerment

- Bisogni: Strumenti di ricerca e siti web che, invece di simulare un supporto a decisioni di carattere medico, si riferiscano a criteri oggettivi da prendere in considerazione.
- P.es.: Descrizione di medicamenti: Le informazioni dovrebbero include i seguenti dettagli:
  (1) La decisione di trattare una patologia con un medicamento o con altre misure (alimentazione equilibrata, esercizio fisico, ecc.)
  (2) La decisione di prescrivere un particolare tipo di medicamento
  (3) La decisione di sceglire un medicamento in particolare.
- Evitare scelte facile ma al contempo potenzialmente dannose

Grazie per la vostra attenzione!


I'VE LOOKED UP MY SYMPTOM ON THE INTERNET AND I THINK I'VE GOT ALL THESE LIFE THREATENING ILLNESSES
WILL ATTRACT WORRIED WELL
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