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An investigation of an online social network for improving asthma management

Submission date
12/07/2013

Recruitment status
No longer recruiting

Registration date
12/09/2013

Overall study status
Completed

Last Edited
15/06/2016

Condition category
Respiratory

[_] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

Plain English summary of protocol

Background and study aims
We are carrying out a study of about 300 asthma patients who manage their asthma with a preventer inhaler (inhalers that control the swelling and inflammation in the airways, stopping them from being so sensitive and reducing the risk of severe attacks). Our goal is to test whether online social networks can improve adherence to asthma preventer medicine and promote feelings of being socially supported. To our knowledge there has yet to be a study to measure the effect of online social networks on medicine adherence, let alone the treatment of asthma. The ease and speed of connection between users holds great promise for spreading new behaviors (such as adherence) and fostering social support.

Who can participate?
Participants who manage their asthma with a preventer inhaler and have access to an internet connection are eligible to participate.

What does the study involve?
Participants will be randomly allocated to the experimental group or the control group. Participants in the experimental group will be asked to track their preventer medication adherence using the online social network AsthmaVillage, posting as they use their inhalers. Participants may also post questions and statuses unrelated to this medication tracking. Participants in the control (AsthmaDiary) group will simply track their preventer use on a simple web-form. Participants in this group will be unaware of the presence of other participants. Participants in both groups are required to post their preventer use at least once each week for 8 weeks. At the start of the study and at follow-up visits all participants will fill out a self-report of preventer adherence. At follow-up participants will also fill out questionnaires on social support and quality of life.

What are the possible benefits and risks of participating?
Participants in both conditions are thought to see an improvement in asthma preventer adherence, with the patients in the experimental group expected to see the largest improvement. All participants who complete the requirements for the study will receive a £20 shopping voucher. One risk is that participants may, through frequent communication with one another, determine the identities of other participants. However, these risks should be

mitigated by full disclosure at the beginning of the study, and guidelines on anonymizing user identities. Group discussions/postings will be monitored, and there will be clear guidelines on participant postings. However, in an open forum like this, topics may come up that are embarrassing to some users. In more extreme cases, users could potentially post hurtful and abusive comments to one another. Abusive and hurtful comments will not be tolerated by the research team. Abusive users will be removed from the study.

Where is the study run from?
This study is run from the University of Leeds, Institute Of Psychological Sciences (UK).

When is the study starting and how long is it expected to run for?
Recruitment began in June 2013. Participants will be enrolled in this study for a period of 8 weeks following the completion of recruitment.

Who is funding the study?
Funding has been provided by the University of Leeds Institute of Psychological Sciences, with the support of a Fulbright Scholarship.

Who is the main contact?
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Contact information

Type(s)
Scientific

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Additional identifiers

Protocol serial number
N/A

Study information

Scientific Title
Can online social networks improve asthma preventer adherence? A randomized controlled trial

Study objectives

Can an online social network for asthma patients improve adherence rates to preventer medicine, and feelings of social support about their asthma, compared to an online asthma diary?

Ethics approval required
Old ethics approval format

Ethics approval(s)
University of Leeds Research Ethics Committee, 29/05/2013, ref: 13-0096

Study design
Randomized controlled trial

Primary study design
Interventional

Study type(s)
Prevention

Health condition(s) or problem(s) studied
Asthma

Interventions
Participants are randomized to either: intervention or active control. Participants belonging to both groups must log in at least once a week for 8 weeks to log their preventer use. Participants are encouraged to log their preventer use daily, after each instance they use their preventer inhalers. For the the intervention arm, there is no limit to the number of postings that can be made.
1. Intervention: AsthmaVillage - Online Social Network Condition
The online social network is very similar to Facebook, with rolling status updates and member groups. Registered participants may log onto AsthmaVillage on a computer, or using the mobile web app site. Participants are asked to track their preventer use in the group "Post Your Daily Preventer Use." Participants are not required to, but may choose to join the group "Hey, I have a question about Asthma!" All postings on the site can be seen by all registered members. AsthmaVillage was developed after a proof-of-concept 4-week pilot study.
2. Active Control: AsthmaDiary - Online Diary Condition
An online diary created using a Google form. Online diary/form asks the question: "How many times did you take your preventer as prescribed?"

Intervention Type
Other

Phase
Not Applicable

Primary outcome(s)
Simple Medication Adherence Questionnaire, an established self-report measure of medication adherence (Knobel et al., 2002). Participants also asked to to estimate their adherence to treatment: "In the past two months, about what percentage of the time did you use your preventer medication as prescribed?" Taken at baseline and follow-up.

Key secondary outcome(s))

1. Mini Asthma Quality of Life Questionnaire (MiniAQLQ). Taken at baseline and follow-up. (Juniper, 1999). Established measure of impact of asthma on quality of life.
2. Theory of Planned Behavior questions on behavioral intentions, attitudes, norms, and perceived behavioral control to take asthma preventer medication as prescribed. Taken at follow-up.
3. The Brief Illness Perception Questionnaire (Broadbent, 2006). Taken at follow-up.
4. A 50 item IPIP Big Five Factor Markers Questionnaire (ipip.org). Taken at follow-up.

Completion date
19/08/2013

Eligibility

Key inclusion criteria
1. Age 18 years or older
2. Managing asthma with a metered dose inhaler (preventer)
3. Able to access a device (laptop, desktop, or smartphone) with an internet connection at least once per week

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 years

Sex
All

Key exclusion criteria
Does not meet inclusion criteria

Date of first enrolment
24/06/2013

Date of final enrolment
19/08/2013

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
University of Leeds
Leeds
United Kingdom
LS2 9JT

Sponsor information

Organisation
University of Leeds (UK)

ROR
https://ror.org/024mrxd33

Funder(s)

Funder type
University/education

Funder Name
Institute of Psychological Sciences, University of Leeds (UK)

Results and Publications

Individual participant data (IPD) sharing plan

IPD sharing plan summary
Not provided at time of registration

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article	results	13/06/2016		Yes	No
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes
Study website	Study website	11/11/2025	11/11/2025	No	Yes