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Comparison of two methods to determine research priorities for patients with chronic kidney disease

Submission date 19/04/2015	**Recruitment status** No longer recruiting	[X] Prospectively registered
		[_] Protocol
Registration date 21/04/2015	**Overall study status** Completed	[_] Statistical analysis plan
		[X] Results
Last Edited 25/08/2016	**Condition category** Urological and Genital Diseases	[_] Individual participant data

Plain English summary of protocol

Background and study aims

The importance of involving patients, clinicians and health policy makers in decision-making processes surrounding the focus of scientific research is well known. But not many studies have looked at how the research focus is decided in the chronic kidney disease (CKD) population. The James Lind Alliance (JLA) is a non-profit organisation that brings patients, carers and clinicians together in workshops to discuss what they feel are the top 10 most important unanswered questions about the medical treatments relevant to them. People that attend the JLA workshop create a list of treatment areas they believe should be top priority in scientific research using a method called the nominal group technique (NGT). The NGT is a way of helping groups of people work together to identify a problem, create a solution and decide on the best way to go about it. The downside of the JLA/NGT workshop method is that it involves a lot of resources. It also requires participants to attend a workshop which might not always be convenient. Also, travel may be difficult for patients with chronic illness, and this may affect their ability to participate in such an event. An online wiki-based NGT may be a more cost-effective way of running workshops. A ‘wiki’ is a website that anybody can contribute to, so it may help involve a broader group of participants in online workshops. The aim of this study is to compare how well a new NGT-wiki website helps create a top 10 list of CKD-related research questions compared to the traditional, in-person NGT-workshop approach. The top 10 research priorities lists resulting from each process will be used to see whether the online method works as well as the in-person workshop method.

Who can participate?

Adults who are either CKD patients, CKD-patient caregivers, CKD clinicians or CKD-related health policy makers.

What does the study involve?

Participants are randomly allocated into one of two groups. Those in group 1 (intervention group) attend an in-person workshop. Those in group 2 (intervention group) have access to an online wiki-based website.

What are the possible benefits and risks of participating?
There are no risks or benefits to participants.

Where is the study run from?
1. University of Calgary (Canada)
2. The University of British Columbia (Canada)
3. University of Alberta (Canada)
4. University of Manitoba (Canada)
5. University of Toronto (Canada)
6. Memorial University (Canada)
7. University of Western Ontario (Canada)

When is the study starting and how long is it expected to run for?
September 2014 to June 2015

Who is funding the study?
1. The Interdisciplinary Chronic Disease Collaboration (Canada)
2. Canadian Institutes of Health Research (Canada)
3. Alberta Innovates - Health Solutions (Canada)

Who is the main contact?
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Contact information

Type(s)
Public

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Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers
N/A

Study information

Scientific Title
A comparison of an in-person nominal group technique and an online wiki-based nominal group technique in chronic kidney disease research prioritization: a randomized controlled trial

Study objectives
Among groups of patients with chronic kidney disease (CKD), informal caregivers', policy makers' and clinicians' use of an online wiki-based platform and nominal group technique will achieve similar CKD research priorities to an in-person nominal group technique (reference standard) as determined through comparison of the top 10 ranked research priorities lists resulting from each process.

Ethics approval required
Old ethics approval format

Ethics approval(s)
Conjoint Health Research Ethics Committee, University of Calgary, 05/03/2015, ref: REB15-0252

Study design
Randomized controlled parallel trial

Primary study design
Interventional

Secondary study design
Randomised parallel trial

Study setting(s)
Other

Study type(s)
Other

Participant information sheet
Not available in web format, please use contact details to request a participant information sheet.

Health condition(s) or problem(s) studied
Chronic kidney disease

Interventions
Participants will be randomized into one of two groups:
1. In-person workshop
2. Online Wiki-based platform

Intervention Type

Behavioural

Primary outcome measure
The top 10 CKD-related research uncertainties analyzed by pairwise agreements between the two groups' priorities (provided as ranks).

Secondary outcome measures
1. Perceived engagement of participants in the prioritization process
2. Participant satisfaction with the process
3. Time requirements to complete the prioritization process
4. Costs associated with each process

Overall study start date
01/09/2014

Completion date
25/06/2015

Eligibility

Key inclusion criteria
Adults ≥ 18 years that belong to one of the following groups:
1. Patients with CKD (eGFR < 45 mL/min/1.73 m2, not on dialysis or with a prior transplant)
2. Informal caregivers of persons with CKD
3. Clinicians (physicians, nurses, and allied health professionals) who care for patients with CKD
4. Health policy makers (those who determine policies and practices related to health care delivery for CKD)
5. Eligible participants will have high health literacy and access to a computer and internet

Participant type(s)
All

Age group
Adult

Lower age limit
18 Years

Sex
Both

Target number of participants
37 assigned to each intervention.

Key exclusion criteria
1. Patients with eGFR <15 mL/min/1.73 m2 and/or receiving dialysis
2. Patients who have received a kidney transplant
3. Persons with an underlying diagnosis of dementia or cognitive impairment
4. Patients admitted to hospital or deemed unfit to travel
5. Non-English speaking individuals

Date of first enrolment
30/04/2015

Date of final enrolment
31/05/2015

Locations

Countries of recruitment
Canada

Study participating centre
University of Calgary
Calgary
Canada
AB T2N 1N4

Study participating centre
The University of British Columbia
Vancouver
Canada
BC V6T 1Z4

Study participating centre
University of Alberta
Edmonton
Canada
AB T6G 2R3

Study participating centre
University of Manitoba
Winnipeg
Canada
MB R3T 2N2

Study participating centre
University of Toronto
Toronto
Canada
ON M5S

Study participating centre
Memorial University
St John's
Canada
NL A1B 3X9

Study participating centre
University of Western Ontario
London
Canada
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Sponsor information

Organisation
Interdisciplinary Chronic Disease Collaboration

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Sponsor type
University/education

Funder(s)

Funder type
Research organisation

Funder Name
Interdisciplinary Chronic Disease Collaboration

Funder Name
Canadian Institutes of Health Research

Alternative Name(s)
Instituts de Recherche en Santé du Canada, Canadian Institutes of Health Research (CIHR), CIHR_IRSC, Canadian Institutes of Health Research | Ottawa ON, CIHR, IRSC

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
Canada

Funder Name
Alberta Innovates - Health Solutions

Alternative Name(s)
AIHS

Funding Body Type
Private sector organisation

Funding Body Subtype
For-profit companies (industry)

Location
Canada

Results and Publications

Publication and dissemination plan

We intend to publish the results in a nephrology journal, and aim to have this submitted by fall 2015. We will also present at conferences, including the Canadian Society of Nephrology (spring 2016) and American Society of Nephrology (fall 2016).

Intention to publish date

01/01/2016

Individual participant data (IPD) sharing plan

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?

Results article	results	24/08/2016	Yes	No