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

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

#### 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?

Dr B Hemmelgarn (Public)

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# **Contact information**

#### Type(s)

**Public** 

#### Contact name

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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

#### 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**

#### Kev inclusion criteria

Adults  $\geq$  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
ON N6A 3K7

# Sponsor information

#### Organisation

Interdisciplinary Chronic Disease Collaboration

#### Sponsor details

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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 - Welcome to the Canadian Institutes of Health Research, 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 typeDetailsDate createdDate addedPeer reviewed?Patient-facing?Results articleresults24/08/2016YesNo