Supplemental File 2: Patients' consent form for Quebec

Consent form
Patients and family caregivers' interview

Version 4, May 23rd, 2017

Title: Assessing care models implemented in primary health care for persons with Alzheimer's disease and related disorders

Investigator
This study is headed by Dr. Isabelle Vedel, from Montreal Jewish General Hospital's Lady Davis Institute. This interview is supervised by Dr. Yves Couturier (Ph.D.), Professor, Health and Social Services Centre — University Institute of Geriatrics of Sherbrooke.

Before you agree to take part in this study, it is important that you read and understand the information in this consent form. Ask as many questions as you need to understand what is expected of you. You have no obligation to participate if you do not want to participate.

Purpose of the study
The Ministry of Health has recently implemented an intervention in the Quebec Family Medicine Groups (FMG). The purpose of this intervention is to improve the quality of care given to patients with cognitive impairments. In this study, we want to see how this intervention was implemented in the FMG and what its effects are on the quality of the care you receive.

This study was sponsored by the Canadian Institutes for Health Research (CIHR).

What is expected of you
If you agree to participate, we will ask you to do an interview, which will last a maximum of 60 minutes. We will ask you about your experience at the FMG and on the care you receive. Specifically, we will ask you about what you enjoy, what you find helpful about your experience, what you do not enjoy, what you do not find helpful, and how your experience could be improved.

Possible risks associated with participation
During the interview, we will ask you about the care you receive, your diagnosis, how it was given to you and your experience in general. Some questions may remind you of painful memories or stressful moments and trigger negative reactions.

Benefits associated with participation and compensation

Participating in this project gives you a chance to talk to a neutral outsider about your experience. It gives you a chance to think back on the good and not-so-good aspects of the care you are given and to take stock.

You will also receive a 20$ gift-card to compensate for the time you have given this project.

Voluntary participation and right to withdraw
You have no obligation to participate. If you refuse, it will not have any consequences on your care and your refusal to participate will be kept confidential. Even if you agree to participate, you can decide not to do so at any time, without consequences or judgment. You do not even have to tell us your reasons. You can also choose not to answer some of the questions during the interview.

Confidentiality and data management

To make sure that your identity will not be discovered by anyone outside our team, we have taken those steps:

- We will give you a personal identification number (PIN) as soon as you will be enrolled. It will be composed of random numbers. That way, your real name will never appear in our reports;
- We will use your PIN for all of our documents. The researcher is the only one who will have access to the list that links your name and your PIN;
- A member of our team will transcribe your interview;
- We will always present results on groups, never on specific individuals;
- The material we will use for the project (recordings, retranscriptions, researcher's notes…) will be kept on the research network of Sherbrooke University's Research Center on Aging, where Dr Couturier works. To get access to the data, we need a computer linked to the server. Every linked computer is protected by a password;
- Our team might participate in another project on the same subject. If so, your data may be re-used, but only the PIN protected data will be used, protecting your identity;
- All paper documents with your name (consent forms, …) will be kept in a locked file cabinet, inside a locked suite, in McGill University's Department of Family Medicine. Only the principal investigators and their assistants will have access to these documents;
- Other paper data will be kept at all time in a locked drawer in room 2444 (which is also locked) in the Research Center on Aging. Only Yves Couturier (researcher in charge of the interviews) and his assistants will have access to it.
- We will present the results of our project in scientific journals and in different conferences, but it will not be possible to identify you specifically or to recognize you. The results will be presented in a general manner, with no link to your FMG or to your identity. We might, however, use a couple of quotes from your interviews. If so, we will use an alias;
- We will send a short summary of our results to interested participants. If you want to receive one, write down your postal or email address in the Signatures section;
- All data will be safely and permanently destroyed by November 2029, at the latest: the paper data will be shredded and we will ask the IT services to permanently delete the data on our computers and our servers. All your personal data will be destroyed;

For surveillance and monitoring purposes, your research file might be consulted by someone mandated by the West-Central Montreal Health's Research Ethics Committee, the establishment, or by someone mandated by authorized public bodies. Each of those persons and bodies are trained to make sure your identity is kept confidential.

For safety purposes, notably to enable us to communicate with you quickly, your name and surname, your contact information and the dates of the beginning and the end of your participation to the study will be kept for a year after the end of the study in a separate repertory maintained by the investigator in charge of the study.

Additional information

If you have any questions about the study or your participation, please contact the principal investigator, Dr. Isabelle Vedel, at: 514-399-9107, or the email address: isabelle.vedel@mcgill.ca.

You can also contact Yves Couturier, who is in charge of the interviews, at: (819) 780-2220 ext. 45143, or email address: yves.couturier@usherbrooke.ca

If you have any complaints or critics about the study, you can contact the Service Quality and Complaints Commissioner of the Montréal West Island IUHSSC at rsteinberg@jgh.mcgill.ca.

If you feel like you need more information and resources on dementia, you can ask your pivot nurse and/or contact the Alzheimer Society at: 514-369-7891, 1-888-636-6473 (41), or by email: info@alzheimerquebec.ca. You can also visit their website: http://www.alzheimer.ca/en/federationquebecoise.

If you feel isolated or if you want to talk about your situation, you can call the helpline Tel-Aînés at: 514-353-2463.

If you are in a situation of abuse, neglect or mistreatment, you can call your clinic's ombudsman and/or call the helpline Ligne Aide Abus Aînés (1-888-489-2287).

Acknowledgments
Your collaboration is precious and will enable us to successfully conduct this study. Thank you for taking the time to participate despite your heavy schedule.

Assessing care models implemented in primary health care for persons with Alzheimer's disease and related disorders

Signatures

I, _____, freely consent to participate in the study named: « Assessing care models implemented in primary health care for persons with Alzheimer's disease and related disorders».

I have read the above information and I have understood the purpose, nature, benefits, risks and discomforts associated with this study. I am satisfied with the explanations and answers the investigator has given me, if needed, regarding my participation in this project.

_____ _____

Participant's signature Date

A small summary of the results will be sent to the participants who will have written the address where they wish the document to be delivered. **The results won't be available until May 2019. If the address were to change before this date, feel free to give the new address to the investigator.**

_____

Address (postal or electronic) where you want the summary to be sent.

I have explained to the participant the nature, benefits, risks and discomforts associated with the project. I have answered to the best of my knowledge the questions asked by the participant and I have made sure that he/she understood.

_____ _____

Investigator's signature Date

Other consent forms are available upon request by contacting the principal investigator (Dr. Isabelle Vedel) directly