Lancement des travaux du Knowledge Management Unit 2 - Capacité mentale et maladie d'Alzheimer

L’objectif de ce KMU2, coordonné par l’UPPA, est d’élaborer et de diffuser des bonnes pratiques à même d’améliorer la capacité de prise de décision des personnes souffrant de troubles cognitifs ainsi que les dispositifs de collecte de leur consentement. L’appel à contributions de tous les partenaires de SIFORAGE, et des membres de leurs réseaux respectifs, a été lancé en Avril 2013, accompagné du planning prévisionnel de réalisation.

What is this KMU objective?

To elaborate and disseminate a “Mental capacity Act” consisting of a “best practices guide” regarding the improvement of:

* the capacity to make decisions for persons with mental health problems, and;
* the collection of the consent.

What will go on?

Each partner is intended to collect information about these best practices and to contact stakeholders who will also give information. 30-40 stakeholders will be selected to participate to annual meetings.

Why a “guide”?

In order to ensure the reality of the aged vulnerable persons’ consents regarding medical acts or participation to specific activities contributing to active ageing.

Who will use this guide?

The guide is dedicated to all professionals working in close relation with aged persons; for instance, they may be professionals of social and health establishments or home services.

What stakeholders are expected to be contacted?

Health establishments (hospitals, medical centers, old people homes, establishments for persons with Alzheimer disease...) civil society organizations, non profit organizations such as ADAPEI, France Alzheimer, CODERPA...), families associations, legal guardians (natural persons such as artificial persons).

What are you going to ask to the stakeholders?

Please use the questionnaires herein enclosed called “questionnaire.xls” for the first contact.
We intend to carry out the KMU in 4 stages.

1st stage – Documentary inventory on the consent of people with cognitive troubles

* State of the art of the partners’ juridical systems regarding the legal capacity of major persons

First of all, we need to know how the local legislations of the partners frame, regulate and control the legal capacity of persons with cognitive problems and protect their consent collection, in particular when the ill person is intended to participate to research activities.

In the French case, the consent system presents a specific formalism for major incapable persons. Indeed, in this case, the consent shall be given by the legal guardian appointed; moreover, the previous agreement of a specific court (the “Juge des tutelles”) or of the “family council” may be compulsory.

* Inventory of the good practices emanating from public authorities

The partners will have to identify and list the existing good practices of their country favouring the improvement of the ill persons’ capacity to make decisions and the collection of such decisions.

Moreover, in a general way as well as concerning the participation of ageing people within the research processes, a main issue is to be sure that the approval by the person is real and effective, and, accordingly that clear and faithful information was previously given.

Consequently, this leads to assess what are the best practices for the consent collection as well as for the person prior information.

We will distinguish between best practices with normative force and best practices relating to ethical issues without any compulsory force.

We will also wonder whether such practices only concern people with mental capacity difficulties or also people mentally healthy; indeed, some good practices identified for healthy people could be of interest, especially in the view of a transposition to people with mental capacity troubles.

* Inventory of the professionals’ good practices

Our objective is to asset good practices implemented by:

Health establishments (hospitals, medical centers, old people homes, establishments for persons with Alzheimer disease...): do such establishments implement practices and advices set by the public institutions and authorities (normative and non normative)? Have such establishments elaborate their own guides of good practices regarding the information delivery and the consent collection? Are there different practices according to the public concerned?
Professionals of home services: how do they deliver the information? How do they collect the consent? Do they respect the advices and practices or their own rules? They may not respect any advice or recommendations?

Persons with cognitive troubles and their families (we intend to contact civil society organizations, non profit organizations such as ADAPEI, France Alzheimer, CODERPA...)

Planning of the 1st stage:

Partners are intended to, before 15th June 2013:

1. Initiate the first contact with their stakeholders; therefore, please:

   Use the template provided by Elena/coordination team in order to formally establish this contact/meeting; you need to complete it and return it to Elena and Nathalie (Nathalie.calatayud@univ-pau.fr, copy to aurelie.launay@univ-pau.fr).

   During the contact/meeting, please use the questionnaires herein enclosed called “questionnaire.xls” and return it completed to Nathalie, copy to Aurélie.

2. Complete themselves the questionnaires herein enclosed with their local rules and practices and return it completed to Nathalie, copy to Aurélie.

UPPA will select 30-40 stakeholders to participate to the KMU’s meetings: 30th June 2013.

UPPA will elaborate a mind map scheme aiming to be diffused (through SIFORAGE Website especially): at the latest 30th June 2013.

Works on the first version of the mind map scheme in the frame of the first meeting with the stakeholders selected: October 2013.

2nd stage – Proposal of a « Mental capacity act »

Study of all returns about the mind map and compilation of all good practices identified for each topic. Dissemination thought the website (December 2013).

Proposal of a « Mental capacity act » consisting of a guide of best practices (February 2014).

Process of remarks/validation by the partners/stakeholders selected (April 2014).

New proposal including the partners/stakeholders selected remarks (June 2014).

Meeting with the stakeholders selected: February 2014 / November 2014

3rd stage - Practical Tests

At this stage, the best practices foreseen by the “Mental capacity act” will be tested in collaboration with the professionals facing persons with cognitive troubles (stakeholders contacted as far as possible). Tests will concern as well professionals themselves as ill persons and their families (March 2015).
Study of the tests results and dissemination, especially bound for the professional stakeholders (June 2015).

Meeting with the stakeholders selected: February 2015 / November 2015

4th stage: Adjustments

Analysis of potential divergences between the original proposal and the needed updating consecutive to the tests results (June 2015).

New proposal of a “mental capacity act” (September 2015).

Process of remarks/validation by the partners (November 2015).

Meeting with the stakeholders selected (January 2016)

Large dissemination though the website (January 2016) and during training sessions addressed to public institutions and authorities, health establishments, civil society organisations, families associations,... (Until the end of the project).