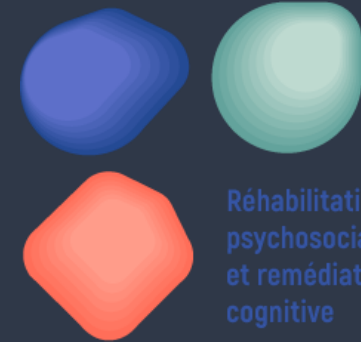




Assistance Publique
Hôpitaux de Marseille



Experimenting Psychiatric Advance Directives in France



CEReSS

Aix Marseille Université

“

■ An **advance directive** in healthcare, also known as a living will, a personal **directive**, a **medical directive** or an **advanced** decision, is a legal document in which a person specifies what actions should be taken for their **health** if they are no longer able to make decisions for themselves because of illness or incapacity.



“

*In some countries, for example the USA,
it has a legally binding status.*

*In France, this is true for end of life living will
instructions, however not for psychiatry.*

*It is legally “persuasive” without being
legally binding. Hence: Directives anticipées
incitatives en psychiatrie*

“

Respect for the individual: two ethical principles

- *People are autonomous agents. We must recognise and value their autonomy.*
- *People with diminished autonomy have the right to be protected. We have to protect them.*



Consent to care versus treatment without consent

Protecting people with diminished autonomy

- Involuntary care
 - Legally defined
 - In constant augmentation in France
 - 2015 : 90 000 people received care without consent of whom 79 000 were hospitalised
 - Up by 15% since 2012 (*Steinert, 2010*)
 - Negative impact on quality of care
 - Ethical dilemmas

 - Half of hospitalisations without consent => Schizophrenia or bipolar disorder (*Coldefy 2015*)

Protecting people's autonomy

■ The recovery approach

- Active participation of the individual
- Self-determination
- Empowerment
- Partnership relationship: we're working through this together

Supporting decision-making

- Taking into account the person's own wishes
 - Advance directives
 - Surrogate decision-making (e.g. a family member, a legally appointed power of attorney)
 - The “best interest” approach: when no one else is available, the deciding clinician must keep the best interests of the patient in central focus
- End of life decisions: Leonetti Law
 - Advance directives, a surrogate decision-maker
- Helping doctors & carers make the right decisions, reducing guilt & doubt
 - The importance of talking about it ahead of time

Psychiatric Advance Directives

- Specificity : fluctuating decision-making capacity
- Instructions about future preferences for mental health treatment if you experience a mental health crisis and have reduced or impaired ability to communicate your wishes during such a crisis.
- A written document, composed at a moment when you are not having a crisis.

Psychiatric Advance Directives



Different models

- Psychiatric Advance Directives (PAD)
- Ulysses Directive
- Joint Crisis Plans
- Wellness & Recovery Action Planning (WRAP)

Qualitative studies

THERAPEUTIC

(Henderson, 2009)

ALLIANCE

(Niçaise, 2012)

Objectives

PREVENTION

(Corrigan, 2002)

(Srebnick, 1999)

AUTONOMY

(William, 1998)

(Widdershoven, 2001)

Quantitative Studies

■ People doing PADs are hospitalised less frequently

- Fewer constraint orders

- Henderson C., Flood C., & Al., 2004

- Swanson JW.,

- Swartz MS., & al., 2008

- Copeland M., 1997

- Papageorgiou A., & al., 2002

■ Conclusion of meta-analysis

- Psychiatric Advance Directives are a promising tool (the more rigorous the PAD, the better it works)
- We need more studies if we are to make serious policy decisions

The DAiP Project in France

- Initiated via a student's thesis on facilitating DAiP using peer support (Magali Pontier)
- A group of users/carers promote the project
- Can we prove it? We need a research project!

The research project

■ Randomised control trial

- Multicentric
- Prospective
- Experimental
- Comparative

■ 2 arms : DAiP vs control

■ 6 months inclusion, 12 months follow-up

■ Principal evaluation criterion: the use of constraint, involuntary hospitalization

The exact title of the study

A multicentric, randomised, comparative, prospective intervention evaluating the impact on care pathways of peer-supported incitative psychiatric advance directives for people with schizophrenia, type 1 bipolar disorder or schizo-affective disorder

With support from...

- French Ministry of Health (DGOS)

- PREPS 2017-0575

- Promoter: Marseille University Hospitals (APHM)

3 sites

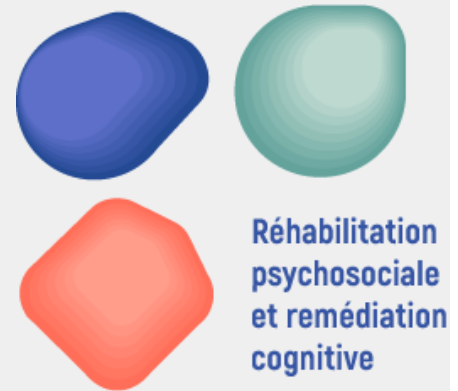
■ Paris

✧ Labo de GHU-Paris (Maison Blanche) – Tim Greacen



■ Lyon

✧ SUR – CL3R – Prof Nicolas Franck



■ Marseille

✧ EA3279 - CEReSS - Aurélie Tinland

✧ CoFoR



400

Subjects to be included

Inclusion criteria



Diagnosis (DSM)

Schizophrenia
Type 1 Bipolar Disorder
Schizoaffective Disorder



Forced hospitalisation in 12 preceding months

Les 12 mois précédent l'inclusion



Decisional Capacity

Hopkins Competency Assessment Test (HCAT) >3



No protective measure in place

Not under legal guardianship



Other criteria

Public health insurance
Age > 18
Understands French Language



Agrees

Has received clear information
Has signed the consent form

Evaluating Decisional Capacity

4 elements of decisional capacity	Tick the box
Understanding Understands the information concerning the diagnosis and the treatment, and shows this understanding	
Appreciation Recognises the problem and identifies solutions that will work for him/her self	
Reasoning Able to compare different options, their benefits and risks	
Choice Able to communicate their decision without pressure from others	

Research Participant Pathway

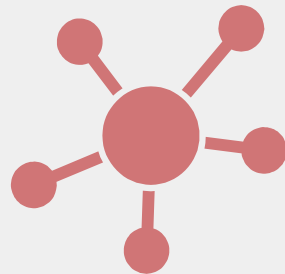
12 month follow-up



The researcher's role

- Meets the candidates
- Informs them about the study
- Collects the data
- Link with peer worke

Facilitation



	Eligibilité Inclusion Eval. Init.	6 mois	12 mois
Consentement éclairé, vérification des critères d'inclusion/de non inclusion : questionnaire d'admissibilité	x		
Caractéristiques socio-démographiques	x		
Données d'anamnèse et antécédents personnels	x		
Données relatives à la santé mentale :			
ICG, rechutes			x
ICG, rechutes	x		
Rétablissement : RAS	x	x	x
Alliance thérapeutique : 4-PAS	x	x	x
Insight : SUMS	x	x	x
Capacité ressentie d'agir: ES, HeiQ	x	x	x
Qualité de vie : S-QOL	x	x	x
Satisfaction CSQ-8	x	x	x
Données relatives au recours au système de soins	x	x	x
Données relatives aux indicateurs de structure et de processus, aux perdus de vue	x	x	x

The role of the peer health worker

- Initial training + ongoing support from central peer team
- A full member of the local research team
- After a subject is included in the study:
 - Informs them about DAiP
 - Helps them write their DAiP
 - Encourages them to share their DAiP with their surrogate decision-maker and their psychiatrist

Peer health workers

- Helps the person write their DAiP
- A different sort of relationship; more trusting
- Importance of experiential knowledge
- A better understanding of what's really in play
- A participative action research role

What's in a DAiP?

The next time I have a crisis:

- Who should be informed?
 - Who can take decisions on my behalf with regard to care (the “surrogate” decision maker)?
 - Who should be contacted to look after my everyday responsibilities: paying the bills, feeding the cat, watering the plants, calling my boss...
- Where would I prefer to be sent for emergency care? Where would I prefer to be hospitalized?
- Which healthcare professionals should be involved? Who should be consulted?
- What sort of treatment would I prefer and why I prefer it.
- If I have any physical healthcare problems, they must not be forgotten about. How should they best be treated?
- Who should be encouraged to visit me? Who should be kept away?
- Facilitate the other factors that are favorable for my recovery process?
- Are there obstacles that should be avoided?

Who should I talk to?

■ Talk it over with the people around you who you can trust

- family
- friends
- your doctor
- your psychiatrist
- your community nurse
- your peer health worker

Identify your advocate, your surrogate decision maker, your « *personne de confiance* ».

- Someone who understands you.
- Someone who understands what you are asking of them. A big responsibility
- Someone who is easily contactable by the psychiatrist if you have a crisis
- Someone who will defend your point of view as expressed in the DAiP
- Someone who may have to make decisions about your care that are not mentioned in the DAiP
- Someone who understands that respecting your DAiP may involve having to override your objections if you are having a crisis.

What should I do with my DAiP?

Make sure several people have a copy or know where they can find it:

- your psychiatrist at the community mental health center
- other key care professionals at the community mental health center
- other care professionals that you are involved with (GP, community nurse...)
- the hospitals that you have used or are likely to use: including emergency services

The role of the research psychiatrist

- Identifies eligible patients
- Makes the link with the researcher
- Fills in the eligibility questionnaire
 - Checks the 7 inclusion criteria
 - ICG, insight
- The person signs the consent form
- Receives the patient's DAiP
- Completes a satisfaction questionnaire at the end of the study
- *Can participate in focus groups in qualitative part of study*

The role of the emergency ward psychiatrist

- Takes into account the person's DAiP and contacts the surrogate
- DAiP not legally binding in France: for example, if a DAiP asks for care that does not follow current care norms, the psychiatrist is not obliged to follow it.
- *Can participate in focus groups in the qualitative part of study: identify obstacles and facilitators for implementing DAiPs and understanding the impact of DAiPs in care pathways*

And where are we up to in June 2019?

- Inclusions slower than planned
 - Mid-June only 190 of the 400
- The system is not accustomed to DAiP
 - Making sure the DAiP figures in the medical records
 - And not only in the psychiatric services but also in the emergency wards
 - Psychiatrists overworked in the current French system. Much turn-over. Make sure the replacement psychiatrists know who has a DAiP...
- But it seems to be settling down: we're optimistic!



Merci !!