



Measuring quality and outcome of person-centred mental health care

- The point of view of the families

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EPA Forum

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EUFAMI

**European Federation of Associations of Families of People with Mental Illness
Europese Federatie van Verenigingen van Familieleden van de Psychisch Zieken
Fédération européenne des Associations de Familles de Malades Psychiques
Europäische Föderation von Organisationen der Angehörigen psychisch Kranker**

Founded in 1992

**Represents circa 25 million families
in Europe**

**35 member organisations in 22
countries**

**EUFAMI's mission is to represent all
family members of persons affected
by severe mental illness at European
level so that their rights and interests
are protected and promoted**





Caring for carers

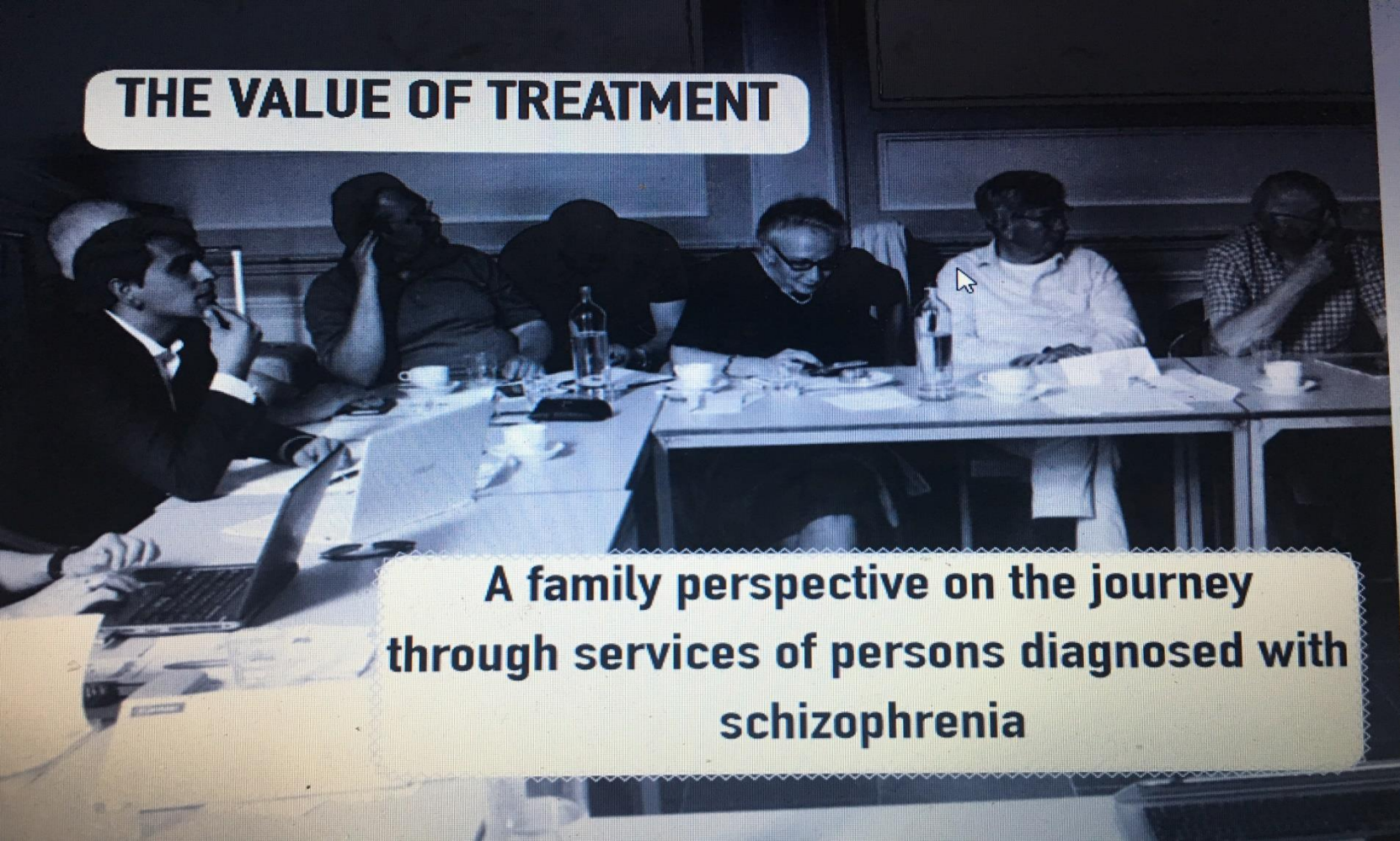


CARING FOR CARERS SURVEY (C4C)

Experiences of family caregivers of persons with severe mental illness: **An international exploration.**

The aim of the Caring for Carers (C4C) survey was to assess the experiences of family caregivers in caring for their relative with severe mental illness from an international perspective, and to highlight the central role they play. The C4C survey was undertaken in 22 countries and received over 1,000 responses, the majority (64%) of which were from those caring for people with schizophrenia/psychosis.

THE VALUE OF TREATMENT

A black and white photograph of a group of people sitting around a long table in a meeting room. They are engaged in discussion, with some looking at laptops and others at each other. The room has a whiteboard in the background.

**A family perspective on the journey
through services of persons diagnosed with
schizophrenia**



Person-centred mental health care?

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- Being person-centred is about focusing care on **the needs of the person** rather than the needs of the service.
 - Most people who need health care these days are not happy just to sit back and let health care staff do what they think is best.
 - Everybody has one's own view on what is best for him and his own priorities in life. Mental health care workers have to be flexible to meet the needs of patients— and to **make our system suit them**, rather than the other way round.



Families in the "journey"

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- Comparing experiences, the first contact of families with services was usually not through **prevention/screening/early interventions** : their journey "started" with a crisis.
 - Family members nowadays are beginning to be involved in treatment and recovery plans by service providers, though **not as much as they should**
 - The reason many journeys starting with crisis was considered to be the **lack of accessibility of services**, in each sense of the word.



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- a person centered care takes **personal environment** in consideration, and most of the time this means his or her family
 - the person has to be the center of a **coordinate partnership** organized around her or him : psychiatrist, psychologist, nurse, social carer AND (family) carers
 - the role of families also includes **warning** the professional team about life events and risks of relapse, or on the impact of treatment and social care on the person's condition : family is part of an **evaluation based treatment** and follow up

Around **9** in **10** want **more opportunities to meet** and share knowledge and experiences with:



Professional carers

93%

As well as with other family members and informal carers

90%

Caregivers **don't feel involved** in **important decisions**

Only **1/3** are satisfied with their involvement in important decisions in treatment and care planning

4 in **10** are dissatisfied with their involvement and ability to influence important decisions



Less than **4** in **10** carers feel that medical and care staff take them seriously

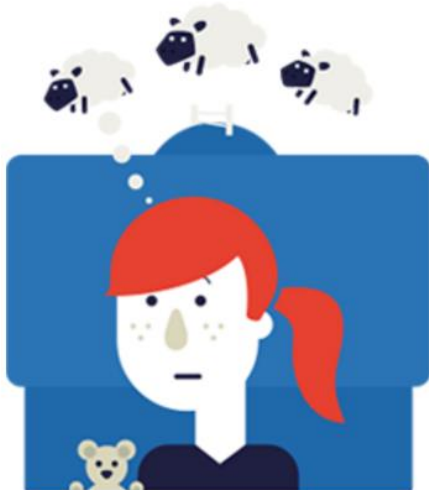
Fewer than **1** in **4** feel communication between healthcare professionals is going well

The **worry** and **stress** means that

1 in **5** feel so exhausted that they cannot function properly

1/3

lack sleep because of the worry
and stress



1/3

feel
depressed



1 in **5**

are unable to find anything
positive in their life





The view of families

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- There was a strong consensus that wide availability of affordable, **mobile services** could prevent many a crisis and involuntary treatment.
 - Primary carers such as GP's, nurses, childcarers, need to be better **educated** in mental health.
 - There is an issue with **access to quality services**, families don't always have the information, knowledge or opportunity to choose a good service provider
 - "One problem in mental health services in general is that the quality of "services is too variable.
 - "Now we have a psychiatrist/psychologist team and the psychologist "is very available, we can call if there's a problem and he answers our "phone calls.



The view of families

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- “It took too much time to find professionals here and there. Mental health needs a multidisciplinary team of professionals working closely together who see the patient and the family as active participants”
 - “It needs to be recognized that family organisations are also part of the service landscape and do give real support to these people who do not know where to go or how to communicate with their family member” Example : UK
 - We need to insert the “family approach” into the very way the services are structured, make it a mandatory box to tick or question to answer in standard questionnaires, put the family aspect in the software that collects that data on mental health, as a case management for each patient.



The "triangle" alliance

- Communication with family members is key, they need to be heard extensively. They can give the family history. They need to be given time to talk about what they have noticed as alarming and strange which a doctor may not ask about but which they know is unusual for this child or relative
- they also need to be given time to talk extensively about their experiences with the child, also because some of what they experience they may not recognize as symptoms while a doctor will.
- **We need a team** instead of individual appointments. It is a complex disease and you get different appointments with different health providers which places a high burden on the patient/ family and each provider sees only its own facet. **Medication alone doesn't cure it.** Psychosocial support is always needed.



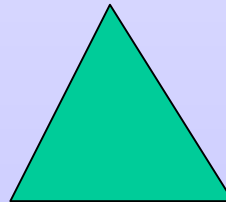
Alliance and team

- People should be able to make informed choices, for quality of life
- As families are the main support to patients, they must be part of brain storming and decision making
- Family members need to be integrated in such care teams. Sharing their day-to-day experiences would bring a different vision to such teams. They should be represented on the teams.
- There also needs to be a contact in the professional team that the family members can **call for assistance**.

the triangle of care :

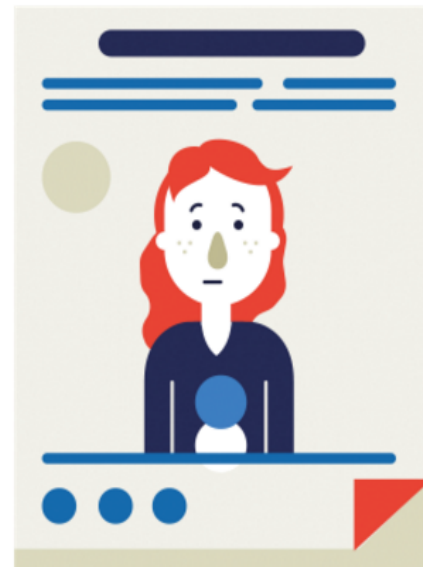
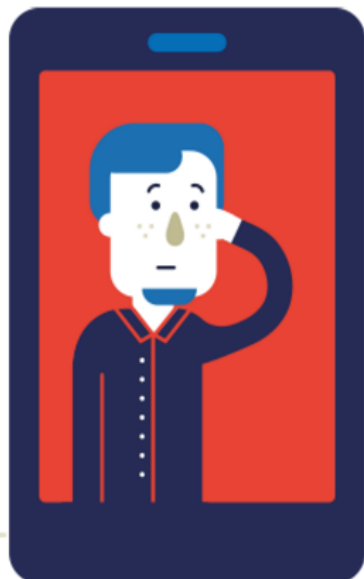
the person

Professionals



Family (or circle)

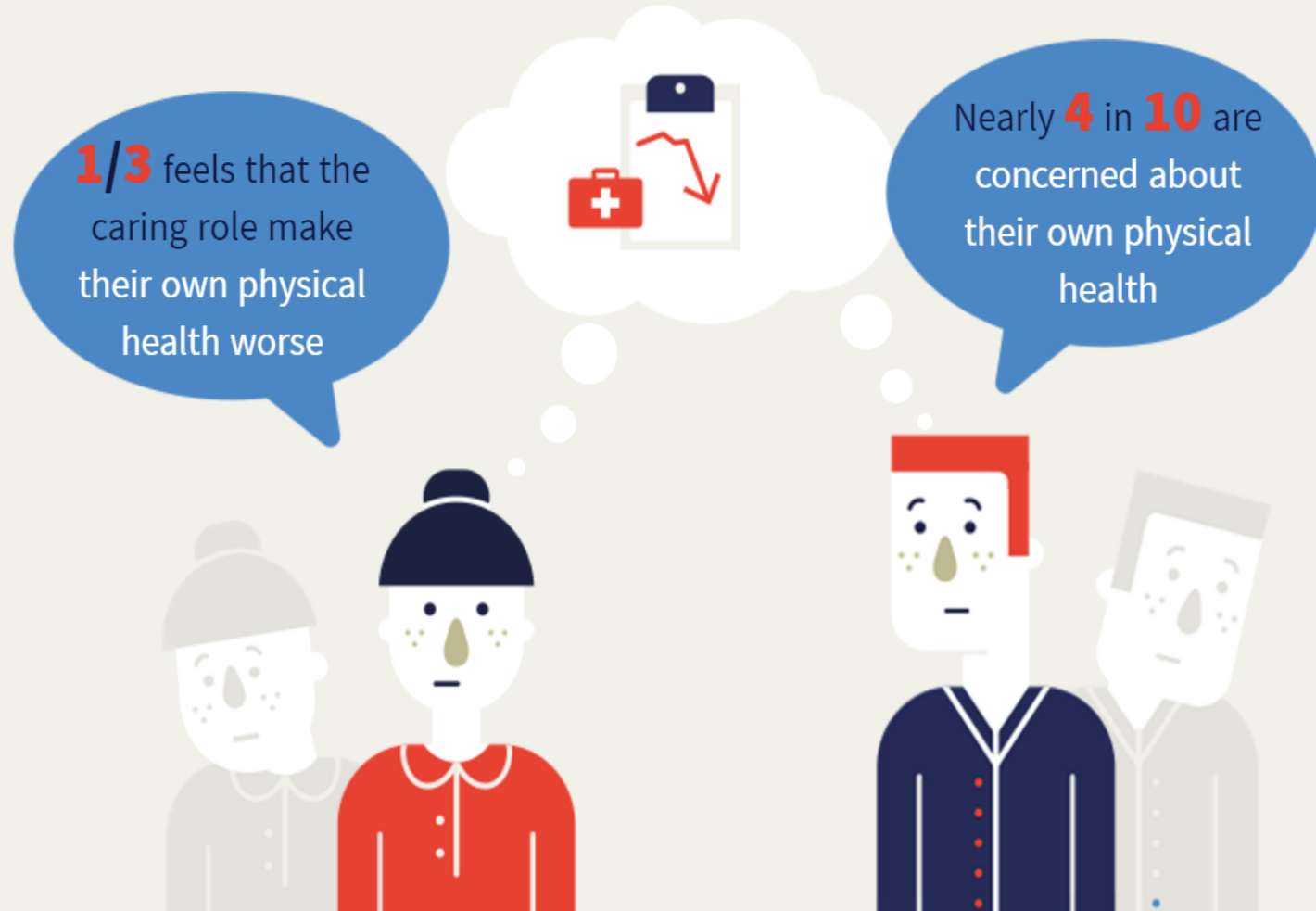
Further **essential information** is critical



1/3 of family caregivers are dissatisfied with the information on who to contact in case of an emergency

Almost **half** of the family caregivers are dissatisfied with information on how the illness of their relative will develop in the longer term

Caring can often have a **detrimental impact** on the caregiver's **own health**





3. CARER SUPPORT IS LACKING AND THEIR VOICE OFTEN UNHEARD

Caregivers were **equally satisfied** and **dissatisfied** with the **support from healthcare professionals** nevertheless:

4 in **10** are dissatisfied with support from doctors

A **1/3** are dissatisfied with support from nurses

And only **3** in **10** were satisfied with support from their social workers

Half are dissatisfied with the ability to seek help and support from professional staff for their own needs

1 in **4** is dissatisfied with the support they receive from their workspace

Caregivers were more satisfied with the support from patient/caregiver organisations (**6** out of **10**)



1 IN 3 FEELS ISOLATED
AND LONELY BECAUSE OF
THE SITUATION THEY ARE IN.

49% WORRIES ABOUT
THE FINANCIAL SITUATION OF
THE PERSON THEY CARE FOR.



A person-centred mental health care service needs to include the following key dimensions:

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- Each mental health service user needs to be professionally assessed, their personal needs identified and an individual care plan drawn up. In the absence of such an approach, there is loss of dignity and an encroaching sense of loss that all doors are slowly closing.
 - Help in gaining knowledge about one's illness or condition is a must. Linked to this is the responsibility of mental health service providers to invest in information resources that are accessible to users and in their native language.
 - Creation of a range of support interventions enabling users to become self-empowered and seek support, learn, connect with others, find and sustain employment, volunteer, and actively participate in civil society structures and move on with one's lifelong learning journey.
 - Drop-in centres, support groups and clubs for service users are crucial for them to ease out of self-stigma and isolation and to develop friendships.



Such a person-centred approach will contribute to family well-being; anxiety and worries will enable relatives shouldering care responsibilities to stay strong, become more resilient, more knowledgeable about preventing relapse and dealing with crisis situations. Their financial burden will also be lessened; their jobs must not be threatened.

4. CRITICAL SUPPORT FOR CAREGIVERS - WHAT THEY ARE TELLING US THEY NEED

A **staggering 93%** would appreciate some additional support in their role as caregiver



With nearly **half** requesting a significant amount of additional support

Only **7%** need no additional support

8 out of 10 want **individual support** from EUFAMI and family member organisations by providing/offering:



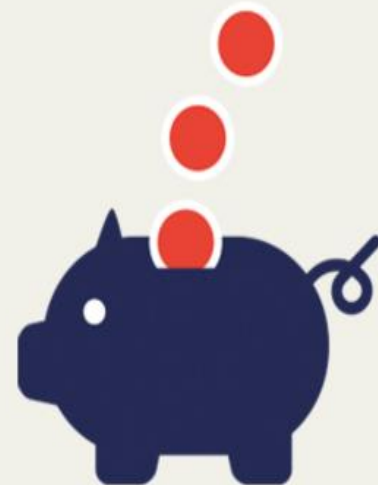
Information
88%



Emotional support
83%



Respite care
78%



Financial support
62%



Outcomes : the view of carers

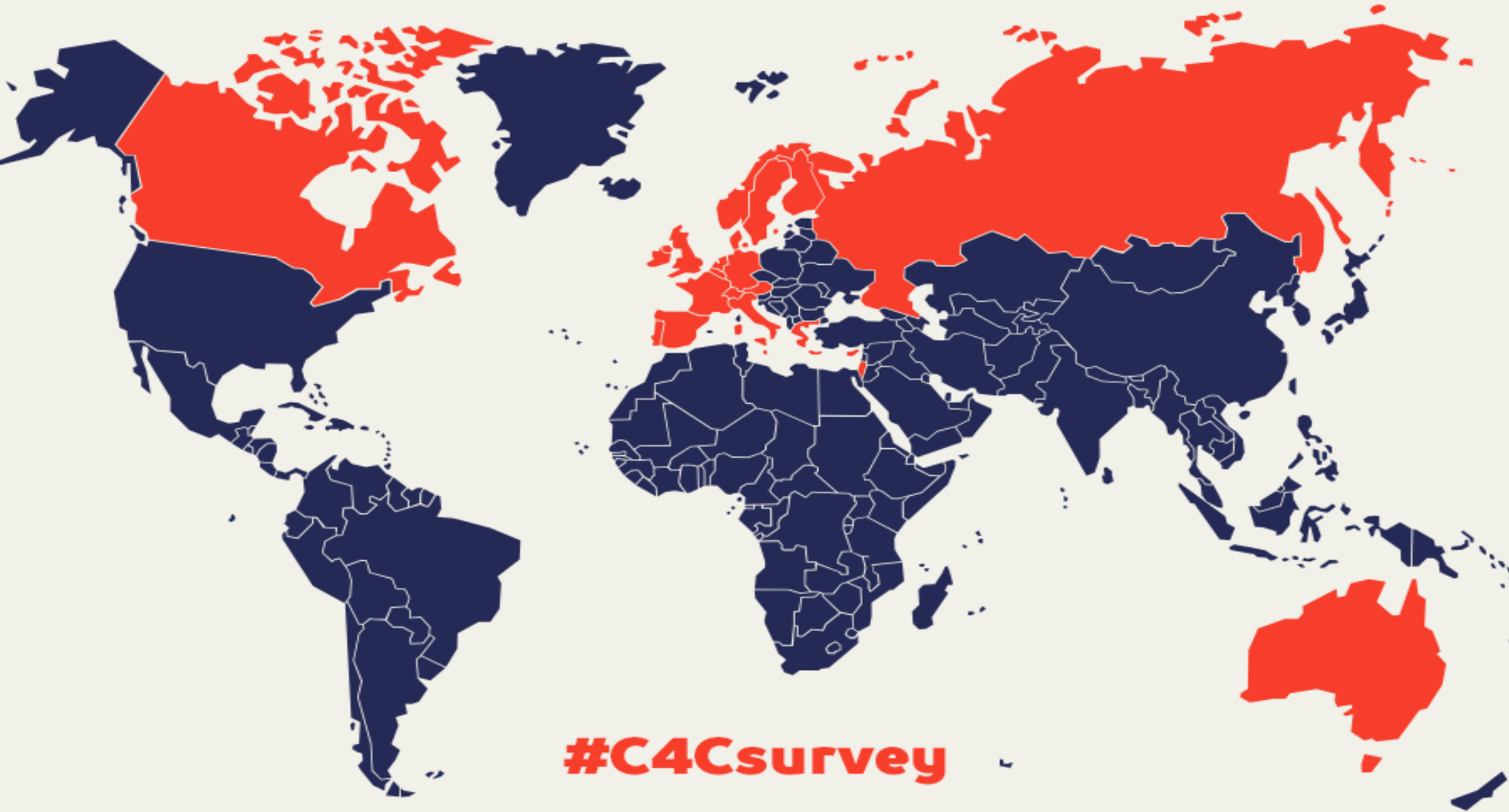
Outcomes in psychiatry are for family carers:

- The patient does not deny his disease anymore
- He or she is compliant on the long term with the medication
- He or she has a regular activity
 - has an independant housing
 - has some happy relationships with some family members and/or friends
 - has no addiction
- Can by himself ask for help **RECOVERY !!**



Thank you

EUFAMI ♥ CARERS



#C4Csurvey