



## Caring after stroke

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Fundació **Ictus**

# Disclosure Statement

there are no conflicts of interest to declare

# Summary

- Stroke caregiving
- Data care in Catalonia
- Catalan ABRIC program experience: supporting patients and caregivers
- Ictuscat

# Stroke caregiving

- Responsibility of Caring for Stroke patients: major source of stress for caregivers
- Heavy burden of care + long-term psychosocial stress (sleep disturbances, anxiety and depression)
- Family members or close relatives: the main providers of care (INFORMAL CARE)
- Informal caregivers: unpaid, not always prepared
- Caregiver burden: positive and rewarding but negative impact on caregivers's health, well-being and quality of life
- Participation in leisure, social activities and paid work may be limited
- Burden of informal care: cost overlooked and undervalued



# Data care in Catalonia

## Prospective data 132 caregivers

74,2% women, average age 59,4 ±12,5 years  
56,8% spouses

**Care intensity** mean 24h/week (mild dependence)  
40h/week (severe dependence)

### Higher burden of care if:

- being a woman
- spending more time in care tasks and care receiver need of constant supervision

### Lower caregiver happiness if:

- caregiver burden
- care receiver anxiety or depression

RESEARCH ARTICLE

Care-related quality of life of informal caregivers of stroke survivors: Cross-sectional analysis of a randomized clinical trial

Lorena Villa-García<sup>1,2,3</sup>, Mercè Salvat-Plana<sup>4,5</sup>, John Slof<sup>6</sup>, Natalia Pérez de la Ossa<sup>4,7</sup>, Sònia Abilleira<sup>4,5</sup>, Marc Ribó<sup>8</sup>, Verónica Hidalgo-Benítez<sup>9</sup>, Marco Inzitari<sup>1,10</sup>, Aida Ribera<sup>1,5--</sup>



to develop two types of support interventions for caregivers: **respite and psychosocial support.** (especially for women with high caring burden and/or Caring for persons with high levels of anxiety or depression)



# Fundació Ictus

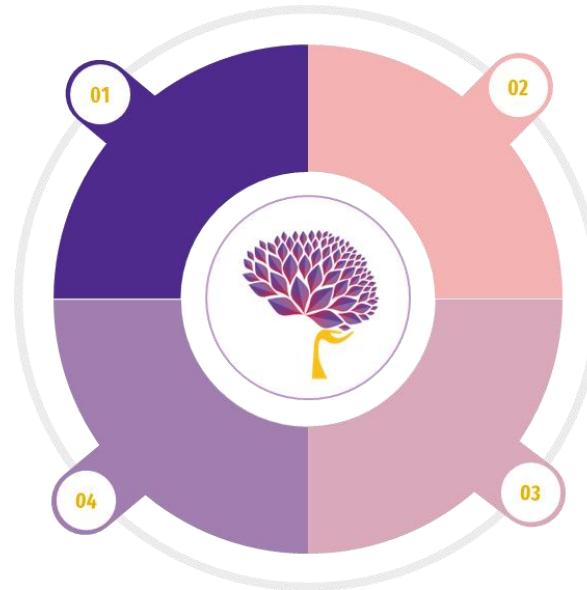
## What do we do?

### Awareness

- Communication campaigns.
- Street actions: What's on your mind?; Take your pulse; Take care of what matters to you.
- Major events: Fast Day; World Stroke Day.
- The hidden face of stroke.
- Leading voice in social networks.

### Knowledge

- Specialized training: Comprehensive Care and Stroke Rehabilitation Course; Nursing Care Course for People Affected by Stroke, etc.
- Training for companies: Take care of what matters to you.



### Support

Abric Program: support, guidance and expert advice for affected people and their families.

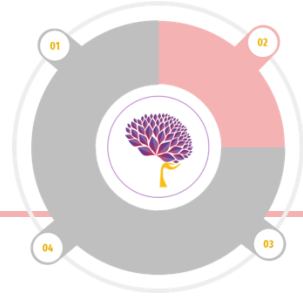
Living after a stroke program: activities and workshops focused on post-stroke rehabilitation and creating spaces for connection between peers.

### Research




Participation in research projects: Harmonics, REVASCAT, RACECAT, HIC-Cat, HSA-Cat.

Promotion of own research and innovation projects: Ictuscat.


# Support





## Objectives

-  Provide free guidance and advice to people who have experienced a stroke, as well as their families, caregivers and people around them
-  Offer expert advice in nursing, rehabilitation, social work and neuropsychology.
-  Offer resources available in the territory through collaboration agreements with other entities.


## Target

- 
-  People who have experienced a stroke.
-  Relatives and informal caregivers.
-  Patient associations in Catalonia.

## Abric Program

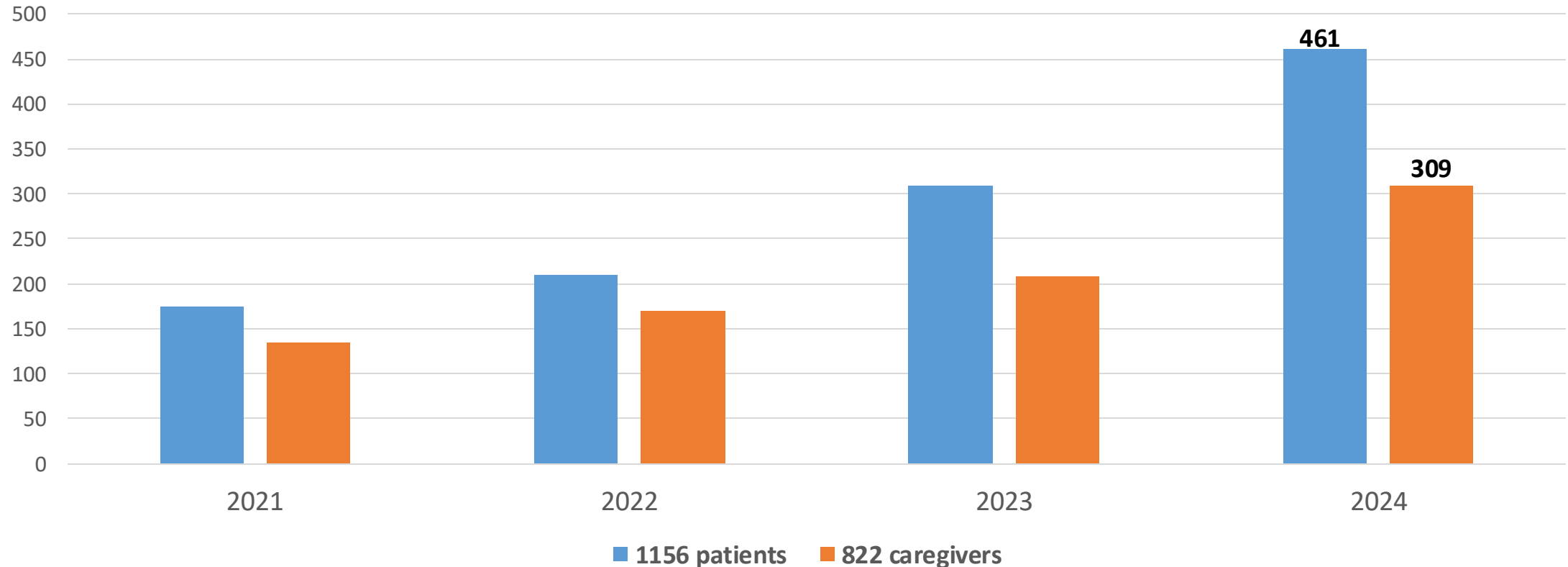
-  Space for support and guidance.
-  Made up of professionals in nursing, rehabilitation, social work and neuropsychology.

## Living after a Stroke Program

-  In collaboration with local patient associations, we offer activities to improve the rehabilitation of affected people.

# Catalan ABRIC program experience: supporting patients and caregivers

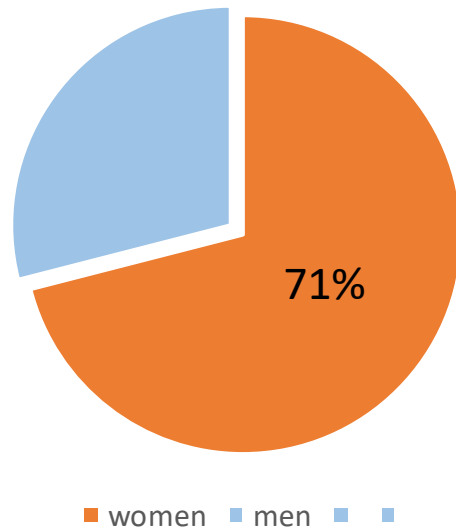
Nº people attended



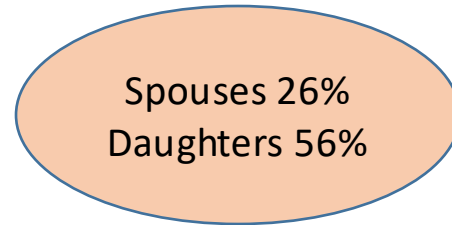


# Catalan ABRIC program experience: supporting patients and caregivers

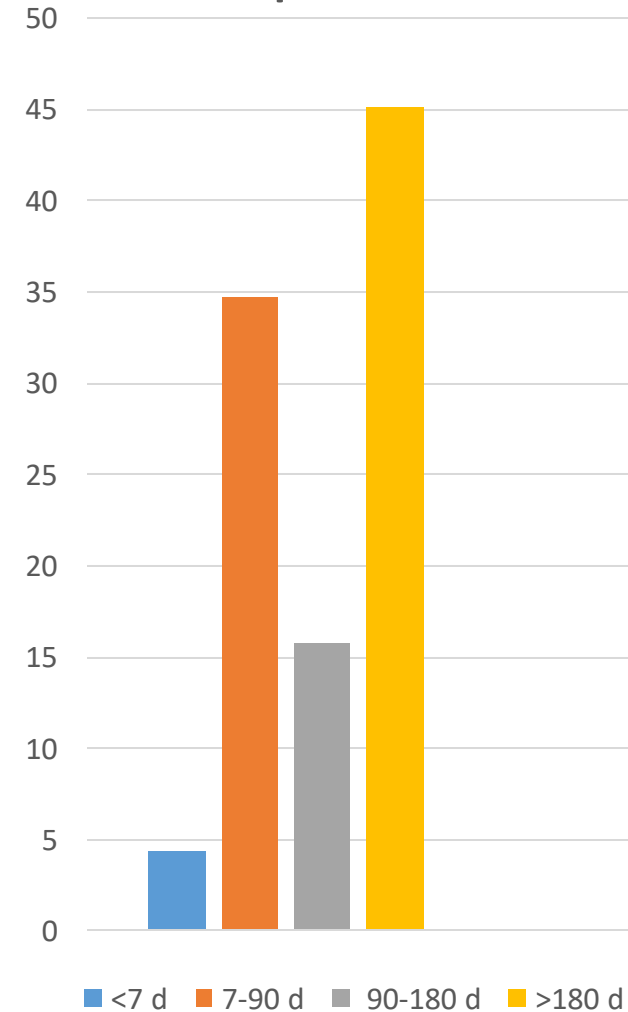
Sex of caregivers



Women caregivers 82%



Time post stroke



# Catalan ABRIC program experience: supporting patients and caregivers

## interventions

### neuropsychology interviews 50%

rehabilitation interviews	19%
family counseling	13%
nurse interviews	9%



information (books, podcasts, website...)	243
home adaptation services	221
patient associations	147
psychological support	106
Rehabilitation services	75
procedure for dependency aid	65
Cognitive therapy	63
Speech therapy	63
job/legal reintegration	15
Caregiver services	42
Driving	19
Others	41

**Satisfaction** with the ABRIC program was excellent in 78% of cases

## Next steps

- follow up
- telerehabilitation to prevent functional deterioration in the chronic phase (NPS, FT, SLT)

# Ictuscat

mobile application that allows the health, social and cultural care continuum to be implemented for all actors involved in the stroke care

- For everyone, free!
- Easy to use for all actors in the stroke world
- Patient and family-centered with professional consensus
- Coverage of the entire territory – without limits (equity)
- Breaks the gaps between healthcare levels
- Proactive for professionals
- Support and healthcare continuum in chronicity
- Obtain post-stroke data in Catalonia



Finançat per:



# the team

## PROMOTERS

- STROKE FOUNDATION
- EURECAT

## OBSERVERS

- Stroke /Socio-health care / Primary Care Programs
- Agència d'integració social i sanitària
- Agència de salut pública
- Stroke scientific and professional societies

## COLLABORATORS

- Patient associations of Catalonia
- ABRIC collaborating entities

Finançat per:



Next Generation  
Catalunya



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# PR23-0261 ICTUSCAT

Solució tecnològica

## Solució tecnològica (LL0 + LL1 + LL2)

### APP Smartphones

Home → Com et sents? → Estat anímic + físic + On Ets?

Home → Suport



Home



Estat anímic + físic



On ets ?  
(Circuit: Hospita, Centres SS,  
Casa, RIB...)



Suport



Suport: FAQs



Suport: Form contacte

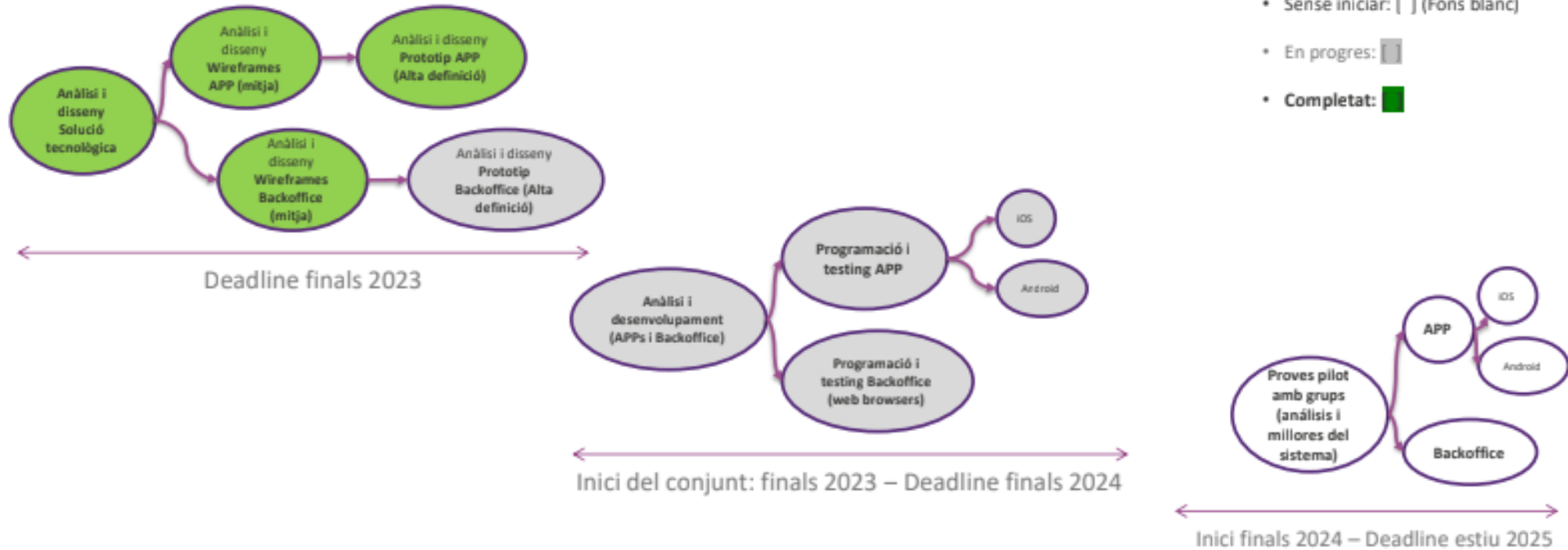


Suport: Chatbot

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## Roadmap



Finançat per:



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