



# Family support in patients with **Acquired Brain Injury:** the Italian experience



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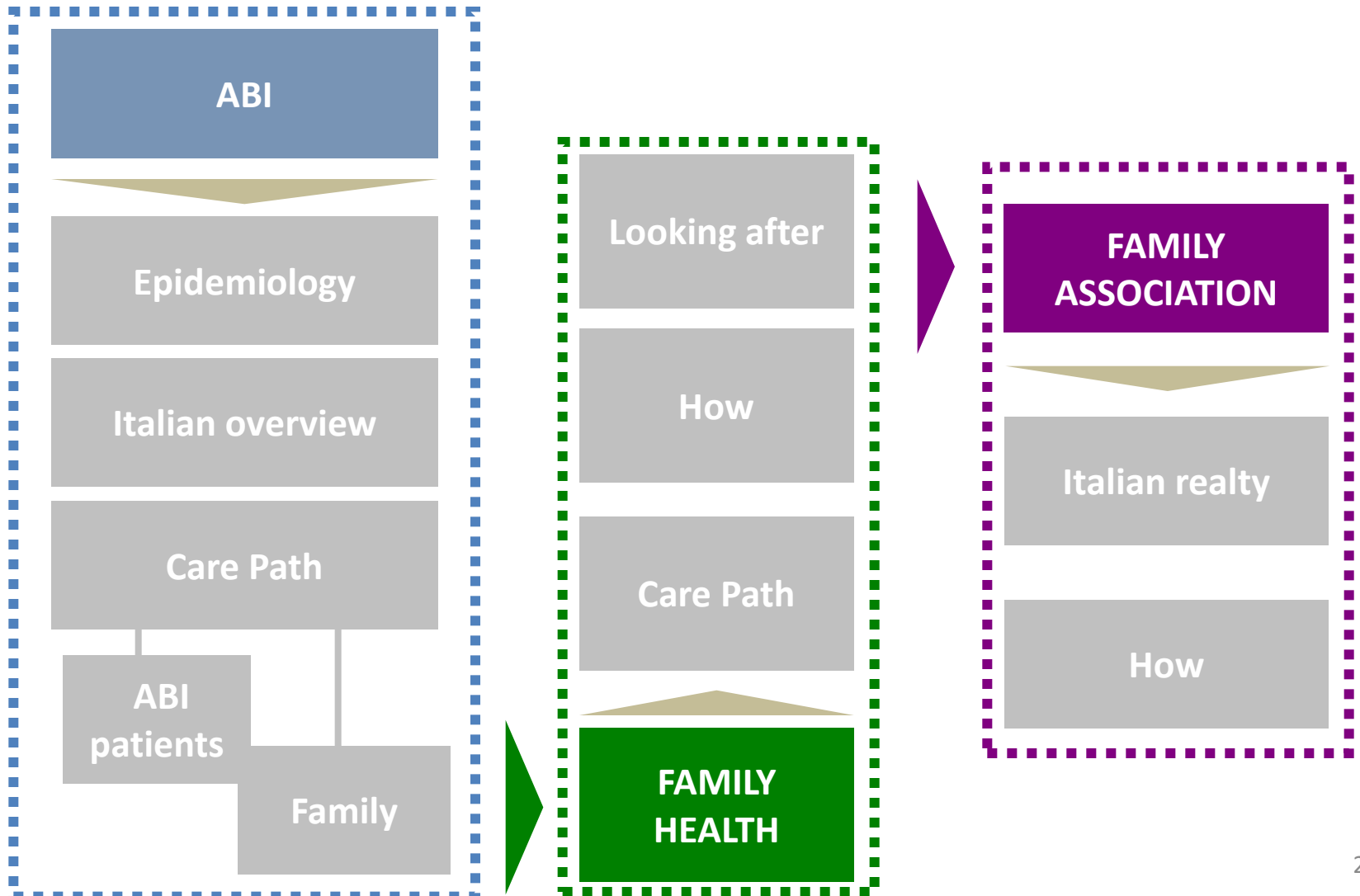
 **SERVIZIO SANITARIO REGIONALE  
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***EUROPEAN EXAMPLES OF FAMILIES SUPPORTS***

***Bordeaux, 20 May 2016***

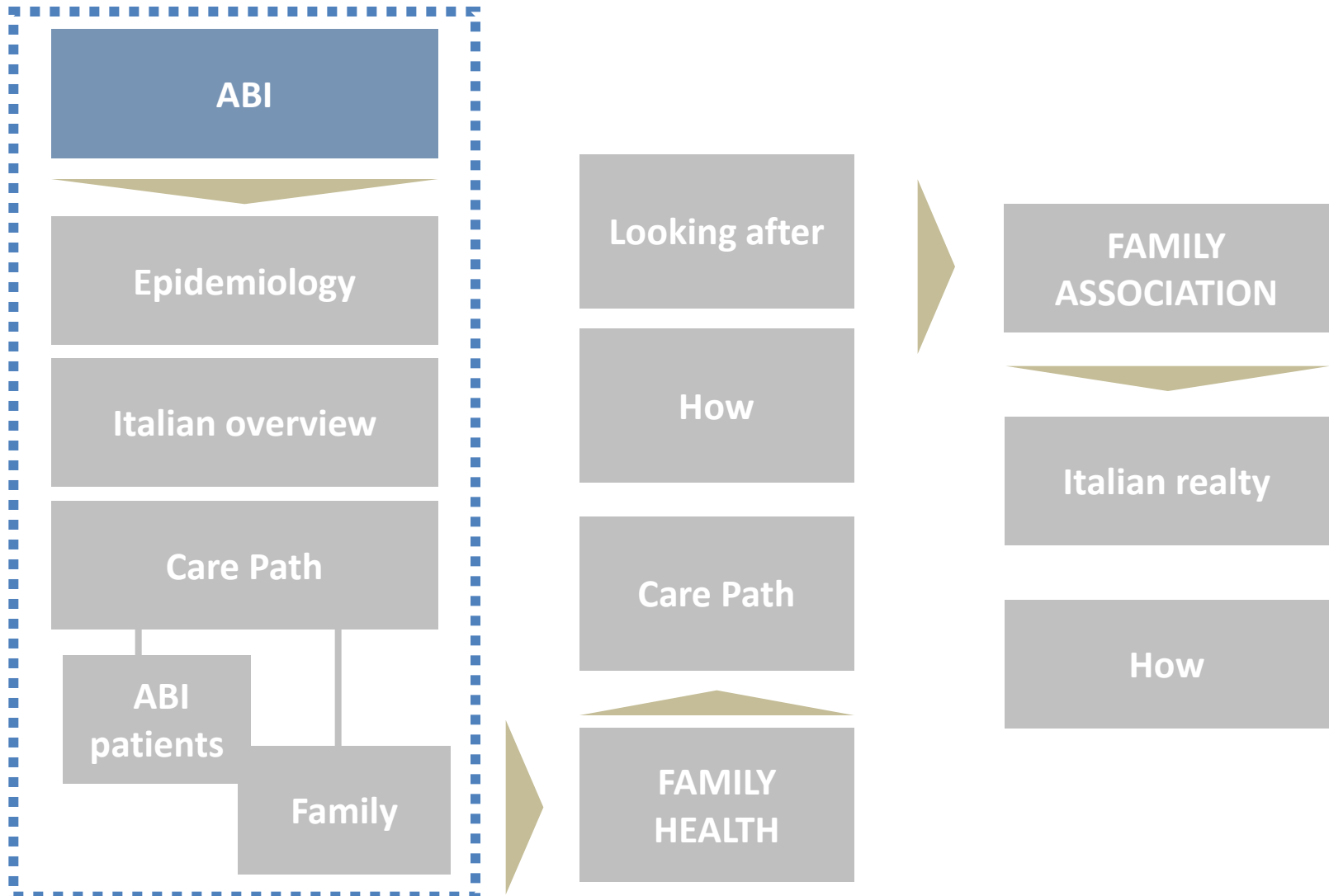
# OUTLINE

## FAMILY support ABI patients

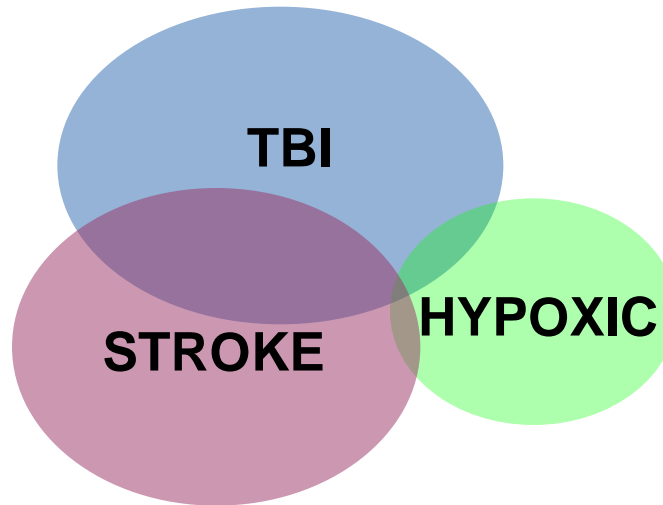


# OUTLINE

## FAMILY support ABI patients



# ABI Incidence



	Europe		Italy
TBI	262 / 10 <sup>5</sup> / yr <i>Peeters W, 2015</i>		314 / 10 <sup>5</sup> / yr <i>Servadei F, 2002</i>
STROKE	113.5 / 10 <sup>5</sup> / yr <i>Béjot, 2009</i>	350 / 10 <sup>5</sup> / yr <i>FHMS, 2008</i>	223 / 10 <sup>5</sup> / yr <i>Corso, 2009</i>
HYPOXIC	250-300 / 10 <sup>5</sup> / yr <i>Reinier, 2011</i>		none

## ITALIAN CONSENSUS CONFERENCES

**2000**

rehabilitation needs,  
assistance **in TBI**  
**acute phase**

service model defined in  
integrated network in  
order to follow the  
patient's stages



INFORMATION AND INVOLVEMENT  
OF THE FAMILY  
AS CENTRAL ELEMENT OF  
GOOD CLINICAL CARE

**2005**

**rehabilitation needs,**  
assistance **in ABI**  
and **families**  
**in late post-hospital phase**

create a profile of  
clinical, social and  
environmental needs



**ABI is a family disease**  
PRIORITY OBJECTIVE OF HEALTH  
SERVICES AND SOCIAL SERVICES  
ALSO IN THE SOCIAL  
REINTEGRATION PHASE

**2010**

Best practice criteria  
**in intensive**  
**rehabilitation phase**  
**in ABI**

more appropriate  
clinical and  
organizational aspects  
reduce differences  
in the approach  
of various centres  
at national level



FOCUS ON  
FAMILY/CAREGIVERS  
AND ASSOCIATION



### ACUTE PHASE



### POST-ACUTE PHASE



### TERRITORIAL REHABILITATION

## MAIN PURPOSE

- SURVIVAL
- LIMITATION CEREBRAL DAMAGE
- PREVENTION COMPLICATION

- CLINICAL STABILITY
- AUTONOMY VITAL FUNCTION
- PREVENTION/TREATMENT IMMOBILITY COMPLICATIONS
- RECOVERY MOTOR, COGNITIVE, BEHAVIORAL
- AUTONOMY ADL
- ENTERING WORK PROGRAMS
- HOME REINTEGRATION
- FACILITATE SOCIAL INTEGRATION
- COMPLETE AUTONOMY PROGRAMS AND RECOVERY ABILITY
- SUPPORT FAMILY

- NETWORK INTEGRATED SERVICES
- ASSESSING REHABILITATION AND ASSISTANCE NEED
- MONITORING, MAINTENANCE, SEARCH GENERAL CONDITIONS (PHYSICAL, PSYCHOLOGICAL)
- SOCIAL AND WORK INTEGRATION
- AUTONOMY
- DEVELOPMENT
- EVALUATION TREATMENT SPECIFIC PROBLEMS

### LONG FOLLOW-UP

### FAMILY CENTERED-CARE

### OUTCOME MONITORING

**1998**

**MINISTERIAL GUIDELINES:  
ADDRESS PLAN FOR  
REHABILITATION**

**2011**

**GUIDELINES TO PROVIDE  
ASSISTANCE FOR PATIENTS  
IN VEGETATIVE STATE AND  
MINIMAL CONSCIOUS STATE**

**INVOLVEMENT PATIENT AND FAMILY**

2001-2003

**GISCAR  
study**

Permanent database  
monitoring  
outcome, destination  
sABI

*Zampolini, 2003*

2004-2016

**GRACER  
network**

Hub and Spoke  
Network,  
Online database  
Emilia Romagna region

*Basaglia, 2016*

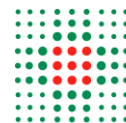
2008-2011

**ITALIAN NATIONAL  
REGISTRY ABI**

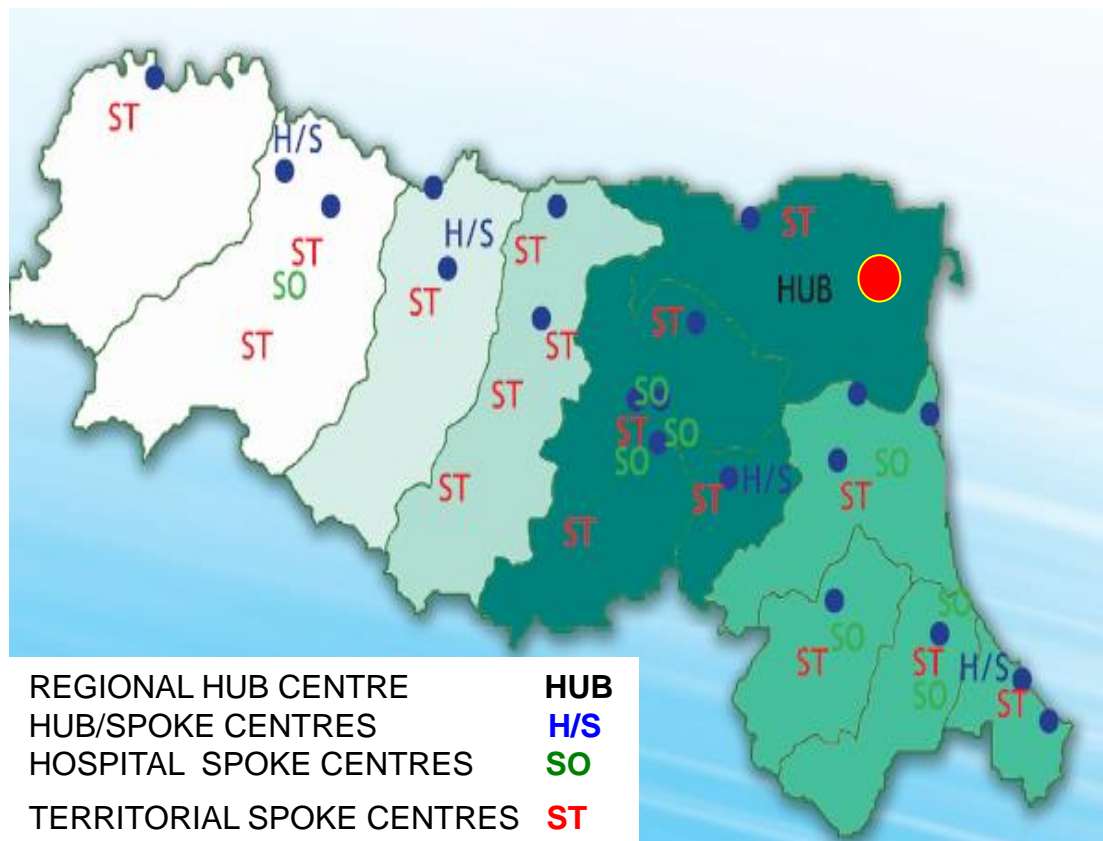
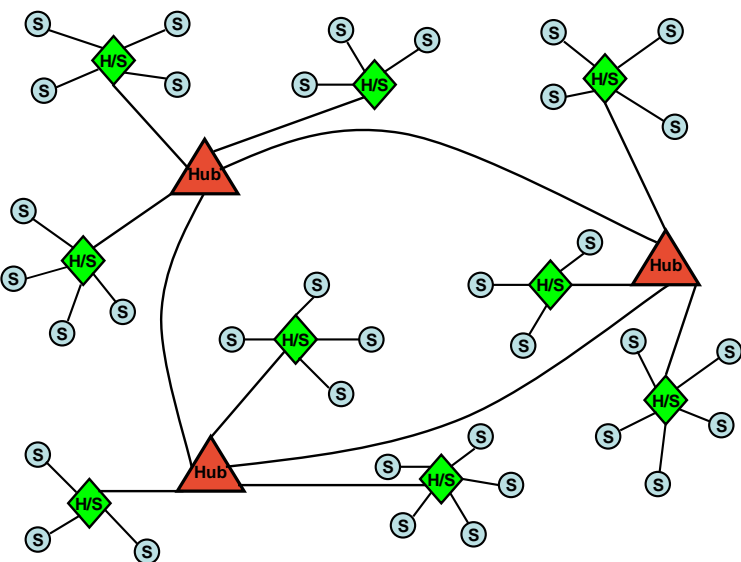
Online network,  
clinical data,  
functional outcome,  
discharge destination

*Avesani, 2013*

# ITALIAN OVERVIEW

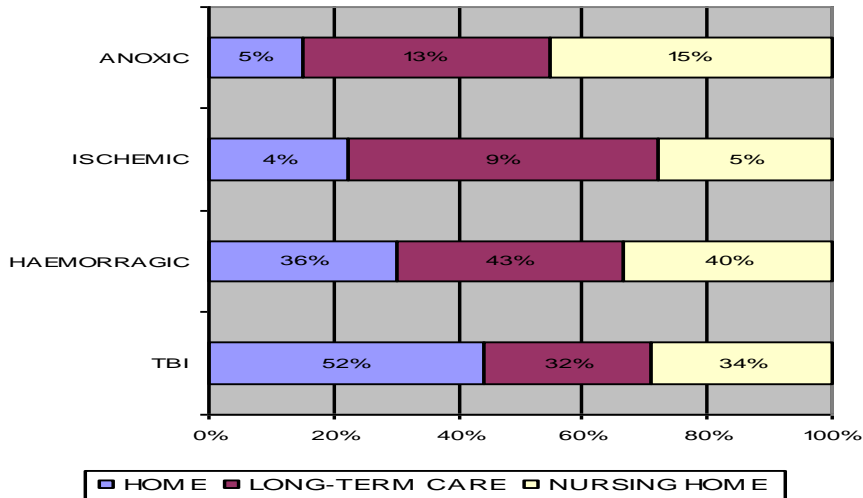


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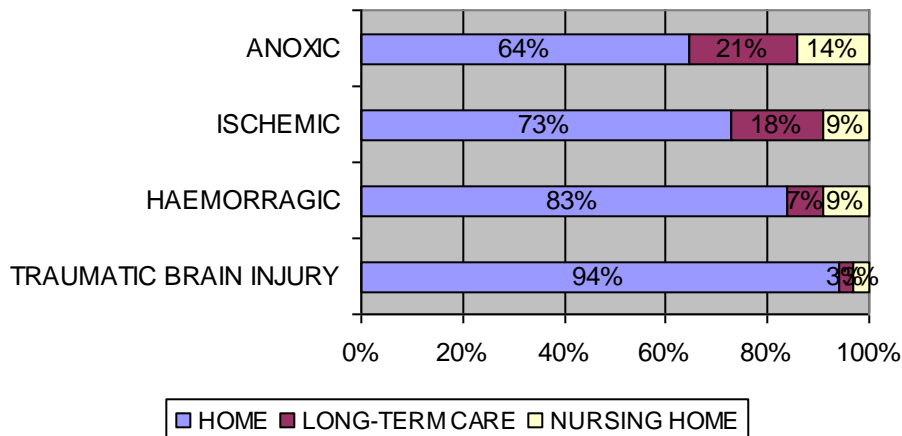
REGIONAL HUB CENTRE **HUB**  
HUB/SPOKE CENTRES **H/S**  
HOSPITAL SPOKE CENTRES **SO**  
TERRITORIAL SPOKE CENTRES **ST**

### DESTINATION AT DISCHARGE



### REGIONAL DATA

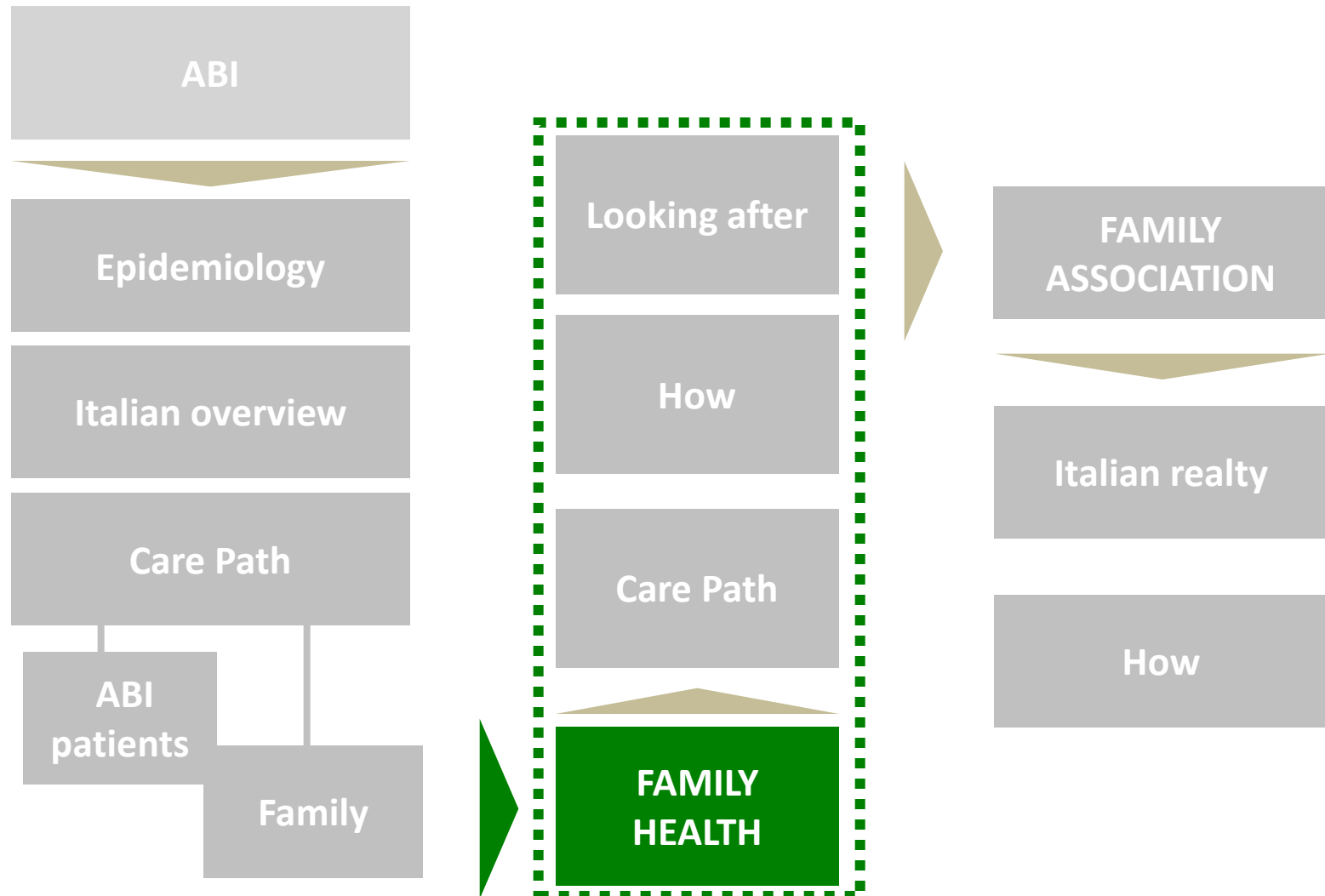
### DESTINATION AT DISCHARGE



### SAN GIORGIO UNIVERSITY HOSPITAL DATA

# OUTLINE

## FAMILY support ABI patients





## ACUTE PHASE



## POST-ACUTE PHASE



## TERRITORIAL REHABILITATION

## MAIN PURPOSE

- ACTIVE INVOLVEMENT AND GUIDED PLANNED
- INFORMATION ON ABI NATURAL HISTORY
- APPROPRIATE [INFORMATION](#)
- PSYCHOLOGICAL SUPPORT

- ANALYSIS OF FAMILY AND ITS [NEEDS](#)
- ACTIVE PRESENCE IN DEPARTMENT OF FAMILY ASSOCIATION
- FINDING MAIN CAREGIVER
- [INFORMATION](#)
- CASE MANAGER AS REFERENCE POINT
- FAMILY [INVOLVEMENT](#) AND SUPPORT
- [EDUCATION](#)
- FLEXIBLE ORGANIZATION
- PSYCHOLOGICAL SUPPORT
- ATTENTION RETURN AT HOME
- [SHARING DISCHARGE PLAN WITH FAMILY AND TERRITORIAL TEAM](#)

- NETWORK INTEGRATED SERVICES
- SUPPORT AND [INFORMATION](#) FAMILY
- ASSESSING ASSISTANCE [NEED](#): CLINICAL FACTORS, PERSONAL, AND ENVIRONMENTAL AND EVALUATE MODIFICATIONS IN TIME
- MONITORING, MAINTENANCE AUTONOMY, INCLUSION IN FAMILY AND SOCIETY
- SOCIAL, SCHOOL, WORK [INTEGRATION](#)

## LONG FOLLOW-UP

## FAMILY CENTERED-CARE

## OUTCOME MONITORING

**FAMILY HEALTH**

**CARE PATH**

# CONSENSUS CONFERENCE

Family burden after severe brain injury:  
the Italian experience with families and volunteer  
Associations. **Mosconi et al**, 2011



**FAMILY  
HEALTH**

**FAMILY BURDEN**

**EFFICACY  
FAMILY  
COPING**

**INFORMATION AND INVOLVEMENT  
BY ALL TEAM MEMBERS**

**SPECIFIC TRAINING OF HEALTH WORKERS  
ABOUT COMMUNICATION AND INFORMATION**

**VERIFY  
INFORMATIVE MODALITY**

## INPATIENT REHABILITATION



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✓ Informative paper material (Guidebook ABI, Alert Organism Book)



✓ information / formation meeting



✓ Family training



✓ Family reunions



✓ Counselling



✓ Self-help group



✓ Domiciliation test



## AT DISCHARGE

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✓ **Multidisciplinary equipe**

✓ **Follow-up**

✓ **Re-hospital admission**

✓ **Self-help group**

✓ **Counseling**

✓ **Integrated home care**



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✓ **Care and support cheque**

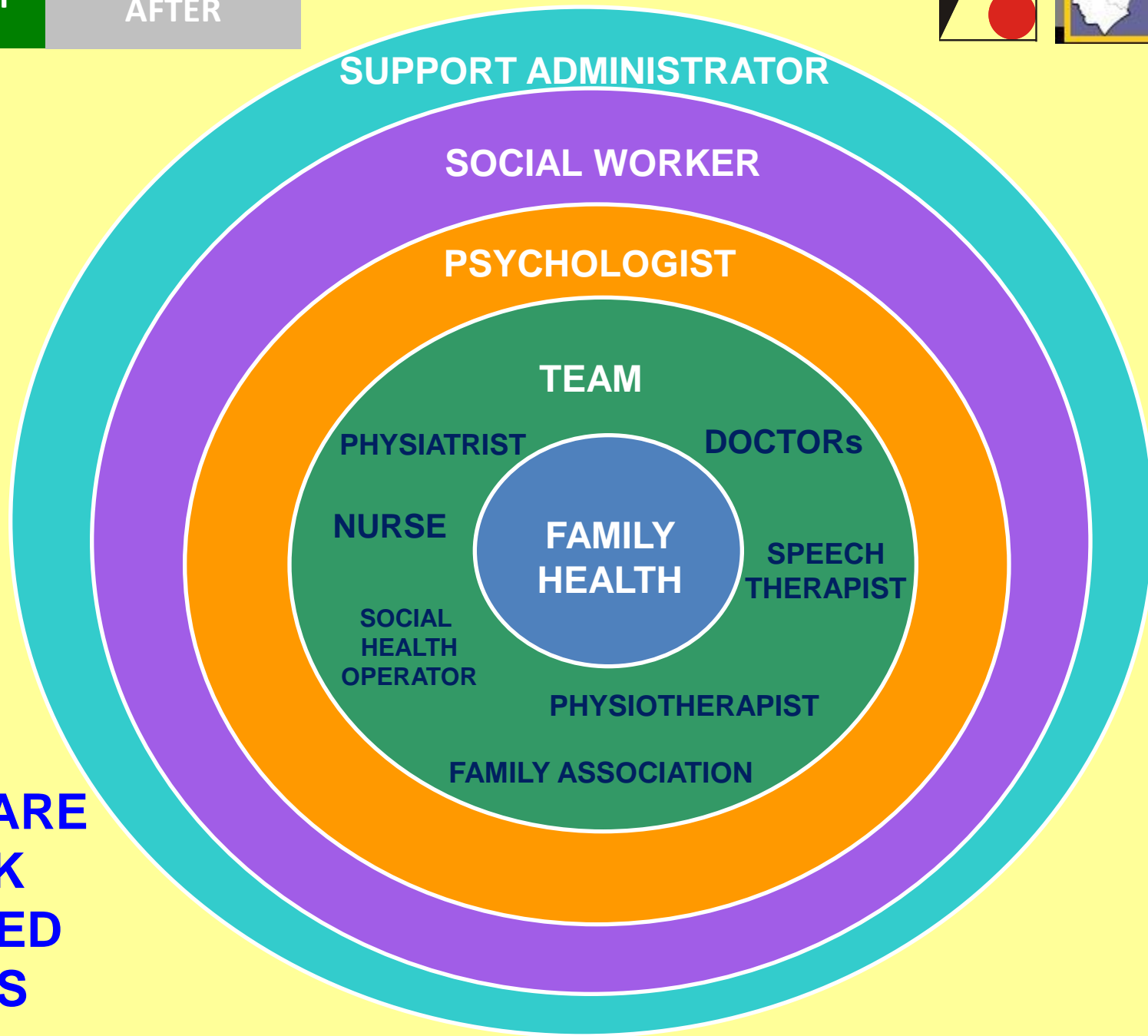
✓ **Prosthesis Assistance**

✓ **Measures adapting  
domestic environment**

✓ **Administrative support  
DGR 2068**

✓ **Residential solutions**

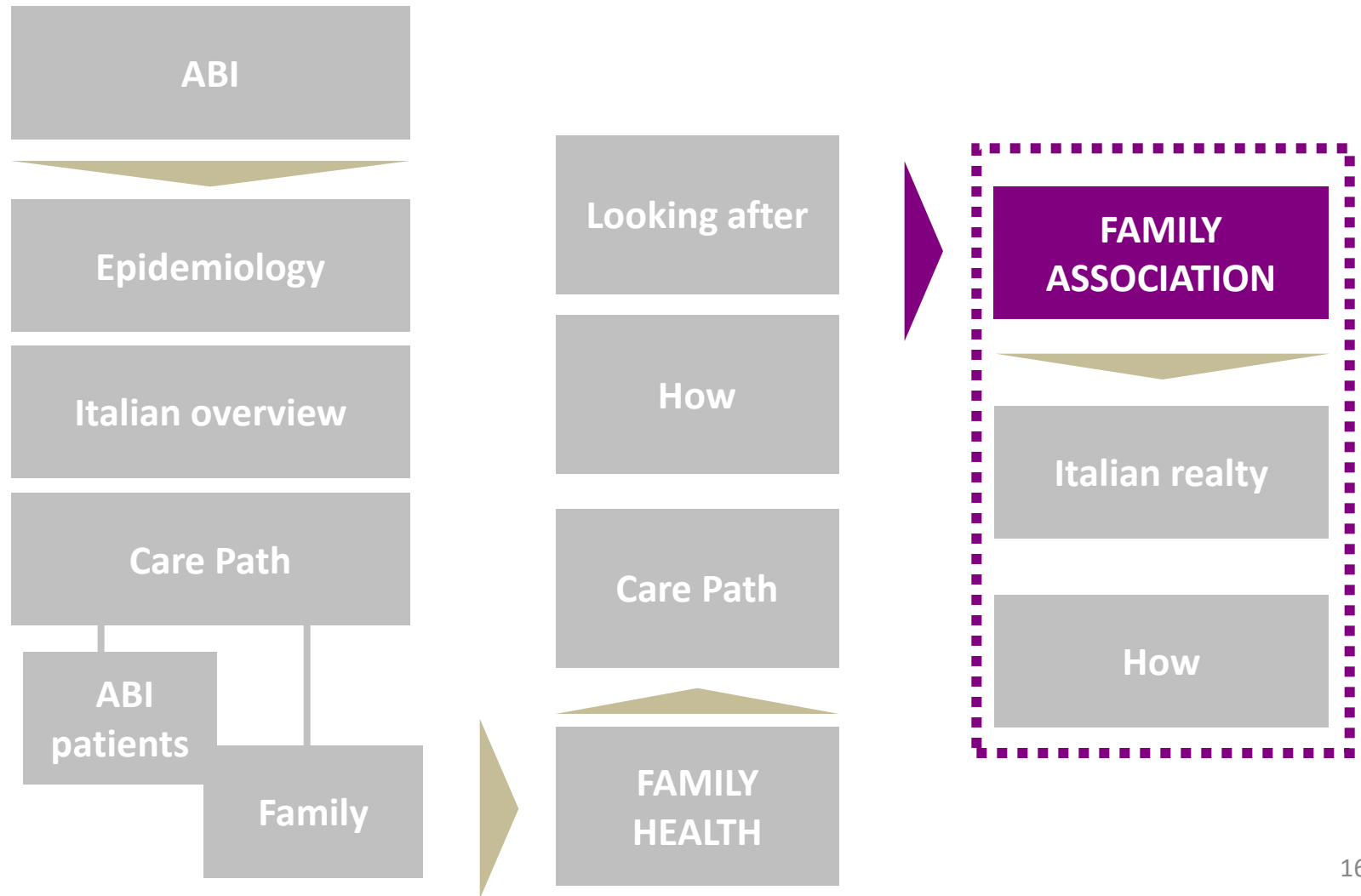
✓ **Occupational vocational  
facilities/services**



**CLINICAL/CARE  
NETWORK  
INTEGRATED  
SERVICES**

# OUTLINE

## FAMILY support ABI patients



**Constitution of the  
Italian Republic**  
**Art . 2**

The Republic recognizes and guarantees the **inviolable rights of man, as an individual and in social groups** where he expresses his personality, and demands the fulfillment of the mandatory duties of political solidarity, economic and social.

**ASSOCIATION**



**Federazione Nazionale  
Associazioni Trauma Cranico**

<http://www.associazionitraumi.it>

**21 Associations, 13 regions**

**Promote activities ABI patients**

**Promote research**

**Prevention campaigns**

**Sharing with Health Care Providers**

**Training courses**

**Family information/participation**

**20 Federation Regional Associations**

**Solicit Specialized Centers**

**Protect Right's Patient**

**Spread information about stroke**

**Create a link**



**A.L.I.Ce. Italia Onlus**

**Associazione per la Lotta  
all'Ictus Cerebrale**

<http://www.aliceitalia.org/>

**ONLY 14% OF FAMILIES ATTEND  
GROUPS OR ASSOCIATIONS**

✓ fail to effectively represent the subject

✓ lack of visibility to the public

✓ lack of synergy between the associations



**INHOMOGENEOUS FAMILY ASSOCIATION**

✓ territorial distribution

✓ number of volunteers

✓ type and complexity of organization

✓ relations with Institutions and the scientific community

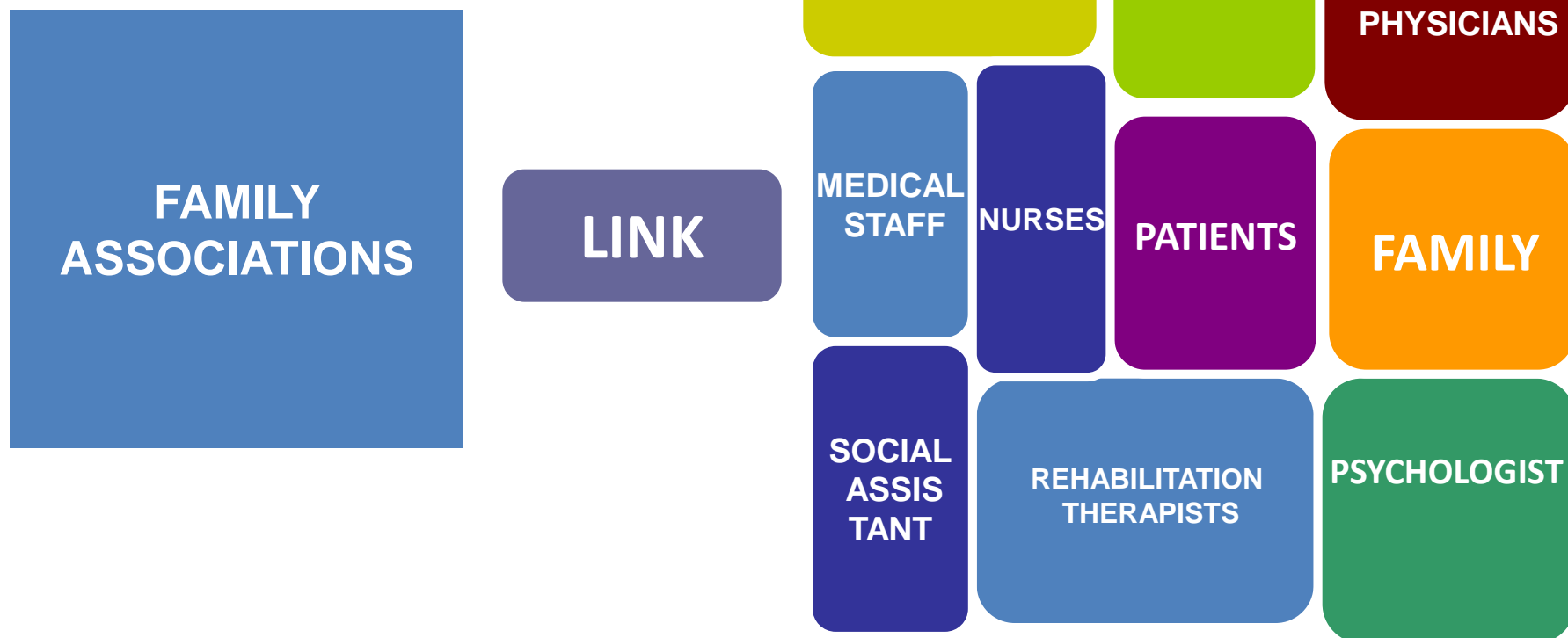


**LOW INFORMATION FROM TEAM**

✓ inpatient rehabilitation

✓ post-hospital phase

Survey on Family and Family Association  
**CONSENSUS CONFERENCE 2010**



**TO LISTEN FAMILY AND PATIENT NEED  
TO PROVIDE ANSWERS  
THROUGH:**

- **INFORMATION DESK ABOUT FAMILY ASSOCIATION**
- **GUIDEBOOK FOR CAREERS**

# CONCLUSIONS

## MORE **NEEDS** FOR

TEAM INFORMATIONS  
TO MAKE CAREERS  
CONSCIOUSLY INVOLVED  
IN PROCESS OF CARE

MANAGEMENT  
PROGRAMS IN THE  
COMMUNITY  
TO SUPPORTS PATIENTS  
AND FAMILY CAREERS  
OF ABI

ADEGUATE SOCIAL  
SUPPORT, INCLUDING  
VOLUNTEER  
ASSOCIATIONS IN THE  
PRE AND POST-HOSPITAL  
PERIOD

**Considering family impact on rehabilitation outcomes**

**Sander et al, 2002  
Tramonti et al, 2015**

## Traumatic Brain Injury: Diagnosis, Acute Management and Rehabilitation

>> MARCH 2007



The only word not translated into the English language is  
the Maori word for family  
**WHĀNAU**

**Merci Beaucoup  
pour votre attention !**