UEMS PRM Section & Board

Clinical Affairs Committee

New accreditation procedure

Programme n° N0006

SAMSAH TC-CL 13: PRM Programme for the long-term accompaniment of patients with acquired brain lesions

ProgN006_SAMSAH20101120.doc

Issue

Version: 1.1
Date of the first version: 26/09/2010
Date of the present version: 20/11/2010

Content:

I. IDENTIFYING DATA 4

II. SUMMARY 5

III. GENERAL FOUNDATIONS OF THE PROGRAMME 6

A. IMPAIRMENT CONSIDERATIONS 6
1. *Aetiology 6*
2. *Natural history and patients' attitude to their impairments 6*
3. *Diagnosis and prognosis 6*
4. *Principles of the treatment prescribed 6*

B. ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS 6
C. SOCIAL AND ECONOMIC CONSEQUENCES 7
1. *Epidemiological data 7*
2. *Social data 7*
3. *Economic data 7*

D. LEGAL FRAMEWORK 8
E. MAIN PRINCIPLES OF YOUR PROGRAMME 8

IV. AIMS AND GOALS OF THE PROGRAMME 9

1. *Inclusion/exclusion criteria 9*
2. *Referral of patients 9*
3. *Stage of recovery 9*

B. GOALS OF THE PROGRAMME 10
1. *In terms of body structure and function 10*
2. *Diagnosis and prognosis 11*
3. *In terms of activity 11*
4. *In terms of participation 12*

V. ENVIRONMENT OF THE PROGRAMME 13

A. CLINICAL SETTING 13
B. CLINICAL PROGRAMME 13

C. CLINICAL APPROACH 14
D. FACILITIES 14

VI. SAFETY AND PATIENT RIGHTS 15

A. SAFETY 15
B. PATIENTS' RIGHTS 15
C. ADVOCACY 16

VII. PRM SPECIALISTS AND TEAM MANAGEMENT 17

A. PRM SPECIALISTS IN THE PROGRAMME 17
B. TEAM MANAGEMENT 17

VIII. DESCRIPTION OF THE PROGRAMME 20

A. TIME FRAME OF THE PROGRAMME 20
1- 2 Phases in the programme and Follow up procedure 20
1. The start-up phase 20
2. Initial assessment phase 20
3. The accompaniment phase 21
4. The end of the period of active assistance and the long-term follow-up 22
B. ASSESSMENT 23
1. Diseases and impairments – the diagnostic approach 23
2. Activities 23
3. Participation - environmental and personal factors 23
C. INTERVENTIONS 23
1. PRM specialists' interventions (other than the usual follow-up and complication management) 23
2. Team interventions 24
3. Complication management 24
D. DISCHARGE PLANNING AND LONG TERM FOLLOW UP 24

IX. INFORMATION MANAGEMENT 25

A. PATIENT RECORDS 25
1. Admission and discharge criteria 25
2. The Treatment Plan 25
3. The final report 26
B. MANAGEMENT INFORMATION 26
1. Organizational data 26
C. PROGRAMME MONITORING AND OUTCOMES 27
1. Continuous assessment of the Programme 27
2. Results 27

X. QUALITY IMPROVEMENT 29

A. WHICH ARE THE MOST POSITIVE POINTS OF YOUR PROGRAMME? 29
1. Meeting the needs 29
2. Networking 29
3. Adapting the Programme to the specific needs of patients with brain lesions in the setting of their homes 29
4. A common language 29
B. WHICH ARE THE WEAKEST POINTS IN YOUR PROGRAMME? 29
1. The increasing numbers of patients with active files (there are more admissions than discharges) 29
2. Patients with severe psychiatric disorders and/or addictions 30
3. Internal communication problems due to participants' temporal and spatial dispersion 30
4. Difficulty in having the funding authorities recognize the needs of patients with "invisible" sequels 30
5. The local needs have not yet been completely covered (our services do not include the Southern sector of Marseille) 30
C. WHAT ACTION PLANS DO YOU INTEND TO IMPLEMENT IN ORDER TO IMPROVE YOUR PROGRAMME?. 30

1. To deal with the increase in the number of active patients' files, the following actions have been planned: ... 30
2. Improving the accompaniment of patients with severe psychiatric disorders and/or addictions 30
3. To reduce the internal communication problems ... 30
A reliable long-distance internal communication software programme has been developed and tested. ... 30
4. To have the needs of patients with "invisible" sequels recognized by the funding authorities 30
5. To complete the coverage of the whole Department ... 31
Steps are being taken to create a new branch of SAMSAH in the Southern sector of Marseille. . 31

XI. REFERENCES ... 32

A. NATIONAL REFERENCES ... 32
B. ATTACHED DOCUMENT ... 32

I. Identifying data

Title	Pr
Family name	DELARQUE
First name	Alain
Position	Scientific director
Phone	+33 6 08 42 65 60
Email	alain.delarque@ap-hm.fr
Year of Board Certification	2000
Name of unit	SAMSAH TC-CL 13
Hospital (facility)	
Address	Le Bel Ormeau Avenue JP Coste
Post code	13 100
City	Aix en Provence
Country	FRANCE

II. Summary

The "SAMSAH TC-CL 13" medico-social unit, specialised in assisting and accompanying adults with acquired brain lesions (TBI, stroke, tumors, etc.) was created in 2005 at the initiative of AFTC 13, an association created by and for the families of patients with traumatic brain injuries.

An internal study conducted in 2006 showed that the healthcare requirements of these patients were far from being met because of the existence of obstacles to long-term medical follow-up, such as patients' cognitive impairments, the burden on their families and lack of medical knowledge about the sequels of brain damage.

An agreement has been signed whereby these patients and their PRM specialist are able to attend the Physical and Rehabilitation (PRM) unit at the La Timone University teaching hospital's ambulatory PRM facility in Marseille. This enables them to benefit from this facility's special PRM programme under the best possible conditions.

The members of the medico-social team at SAMSAH, who are well informed about each patient's personal history, assess the impairments limiting the activities and restricting the participation of patients with brain lesions in their everyday environment, and the PRM specialist makes interdiscilinary assessments after consulting colleagues in other departments. The two ambulatory PRM programmes in question therefore provide complementary services in terms of diagnosing patients' functional performances and their ability to follow the medical advice received, as well as improving their quality of life.

1 # III. General foundations of the Programme

2 ## A. IMPAIRMENT CONSIDERATIONS

3 ### 1. Aetiology

4 Acquired brain lesions include Traumatic Brain Injury (TBI), Cerebrovascular Accidents
5 (CVAs), brain tumours and non neonatal encephalitis).

6 ### 2. Natural history and patients' attitude to their impairments

7 Structural brain lesions can result in physical, cognitive and behavioural deficits occurring
8 either separately or in various combinations.

9 - Physical deficits: all the physical processes can be either impaired or spared:
10 sensory and pain perception, voice production and speech, the digestive, metabolic
11 and endocrine processes, the genito-urinary and reproductive processes,
12 locomotor abilities and the processes involved in movements of all kinds.

13 - -Cognitive and behavioural deficits: all the main mental functions can be impaired
14 (consciousness, orientation, energy, reflex behaviour, sleep, etc.), and other more
15 specific mental activities such as attention, memory, thought and language can also
16 be affected.

17 Even when one or more of these functions are affected, these patients sometimes show no
18 obvious physical deficits.

19 ### 3. Diagnosis and prognosis

20 The diagnosis and prognosis are based on the specialized assessments to which patients
21 have access thanks to the agreement we have signed with the La Timone University
22 Teaching Hospital in Marseille.

23 ### 4. Principles of the treatment prescribed

24 The patients' treatment is based on the assessments to which patients have access thanks
25 to the agreement we have signed with the PRM unit at the La Timone University Hospital in
26 Marseille.

27 The treatment consists mainly of community based ambulatory follow up and treatment.

28

29 ## B. ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

30 The main limitations involve many activities, such as the following:

31 - Learning and applying knowledge: acquiring skills, focusing attention, problem-
32 solving, decision-making, etc.

33 - General tasks and demands: performing everyday routines, handling stress and
34 meeting other psychological demands.

35 - Communication: receiving spoken messages, producing messages, engaging in
36 conversation, using communication devices and techniques, etc.

37 - Mobility and moving around using public transportation, driving a car, etc.

- Self-care: washing oneself, dressing, attending to one's health.
- Domestic life: acquiring necessities, performing household tasks (preparing meals, doing housework, assisting others, etc.).
- Interpersonal interactions and relationships: maintaining and managing interactions with other people in a contextually and socially appropriate manner (relating to persons in authority, family relationships, etc.)

In terms of restricted social participation, all the main aspects of life can be affected, depending on the nature and the severity of the impairments and their combinations, as well as on the environment and on personal factors such as the patients' situation when the brain lesion occurred, namely:

- Their level of education, especially as regards patients' difficulty or inability to undertake or pursue studies.
- Work and employment: difficulty or inability to train for an occupation, keep a job, complete a task, or carry out unpaid work.
- Economic life: various levels of difficulty in performing basic or complex economic transactions and controlling their own economic resources in order to ensure that their present and future needs will be covered.
- Community, social and civic life: lack of ability or inability to invest in or sustain commitment to or participation in common leisure and associative activities.

Limitations to activity and restrictions to participation affecting patients in their everyday environment because of the motor, cognitive and/or psycho-behavioural deficits resulting from their condition.

These problems can be either serious or completely incapacitating, in which case they result in isolation, social exclusion and loss of health and impose an exhausting burden on the members of the patients' entourage.

C. SOCIAL AND ECONOMIC CONSEQUENCES

1. Epidemiological data

According to data published in 2004 (1), 150 000 persons in France sustain brain lesions every year: the majority (70%) are young men between 15 and 25 years of age. In the official reports on which public policies are based, this problem has been referred to as a social scourge and a real public health issue.

2. Social data

This situation has generated needs for follow-up and assistance at several levels. The needs are being met as follows:

- At the healthcare level: greater awareness of these problems is being promoted, "acute care units" have been created, and greater provision for ambulatory care is being made.
- At the medico-social level: SAMSAH was created by an official decree in 2005 (2). Larger numbers of specialized assesment units and medical nursing homes for patients need to be set up.
- At the social level: road accident prevention campaigns have been launched, and assistance is being provided to patients' own natural helpers (by training family members and helping to give them a break from their tasks, etc.).

3. Economic data

These accidents have considerable economic consequences at personal, family and national levels.

D. LEGAL FRAMEWORK

In 2005, “Services d’Accompagnement Medico Social pour Adultes Handicapés” (SAMSAH) was officially launched (2). On 1 July 2005, this association became a medico-social service, SAMSAH TC – CL 13, the first of its kind to be specialized in the Bouches du Rhône (French Department 13) in providing adults suffering from acquired brain lesions with ambulatory care and assistance.

E. MAIN PRINCIPLES OF YOUR PROGRAMME

This Programme is designed to help patients with brain lesions to become socially reintegrated.

It is carried out in and near the patients’ own homes and places of residence, based on the following two main principles:

- Helping patients to accomplish their projects for the future.
- Adapting patients’ material and human environment in their family and occupational lives.

IV. Aims and goals of the Programme

1. Inclusion/exclusion criteria

a) Inclusion criteria:

- Persons with non-degenerative acquired brain lesions (resulting from cranial trauma, vascular accidents, brain tumours, non neo-natal encephalitis, etc.), however severe the sequels may be.
- aged between 18 and 60 (16-year olds are admitted to the Programme if they have dropped out of school and persons over 60 years of age if they sustained brain lesions before reaching that age) living at home in a specific geographically defined sector.
- Admission to the Programme has to be authorized by the Commission for Human Rights and the Autonomy of Disabled Persons, under the aegis of the French administration responsible for Disabilities. The meetings held by this structure are attended by representatives of disabled persons' associations(3)

b) Non inclusion criteria:

- Persons not fulfilling the criteria in terms of their etiology, age or geographical place of residence are excluded from the Programme**.**

c) Exclusion criteria:

- The main exclusion criteria are those preventing the provision of assistance to the person (refusal to undergo care, failure to comply with the Action Plan drawn up by despite all efforts at mediation).

2. Referral of patients

Direct access to the PRM programme	Yes
Referral from general practitioners	Yes
Referral from other specialists	Yes
Referral from specialists in PRM	Yes

3. Stage of recovery

Within two weeks of onset	No
2 weeks to 3 months after onset	No
3 months or longer after onset	Yes

B. GOALS OF THE PROGRAMME

The aim of the Programme is to improve the quality of life of persons with brain injuries in their everyday settings by helping them to define and carry out projects for the future.

SAMSAH improves these patients' acces to care and helps them to set up compensatory strategies, as well as adapting their environment in order to improve their abilities and performances in all fields of life, and thus to enhance their level of social participation.

It carries out interventions of the following kinds:

- Diagnostic procedures (screening patients for neuro-endocrine disorders, for example).
- Assessing deficits, abilities and impairments restricting patients' activities and participation
- Therapeutic procedures (treating epilepsy with the help of a neurologist, for example)
- Assessing and improving the patients' human environment (in their family circle, among their friends and in their working spheres) and their material environment (both at home and at work).
- Improving patients' performances: drawing up compensatory strategies.

1. In terms of body structure and function

ICF code	ICF label
s 110	Brain structure 110
b 1	Mental functions General mental functions 110 114 125 126 130 134 Specific mental functions 140 144 147 152 156 160 164 167 172 180
b 2	Sensory functions and pain Seeing and related functions 210 215 Hearing and vestibular functions 230 235 240 Other sensory functions 250 255 260 Pain perception 280
b 3	Voice and speech functions Voice functions 310 Articulation functions 320 Fluency and rhythm functions 330
b 4	Cardiovascular, haematological, immunological and respiratory functions Blood pressure functions 420 Respiratory functions 440 445 455
b 5	Digestive, metabolic and endocrine functions Functions involving the digestive system 510 525 530 Endocrine glandular functions 555
b 6	Genito-urinary and reproductive functions Urinary functions 620 Sexual functions 640
b7	Neuromusculoskeletal and movement-related functions Joint mobility functions 710 Muscle functions 730 735 Movement functions 750 755 760 765 770

1
2. *Diagnosis and prognosis*

Structural brain injury can result in physical, cognitive and behavioural disorders occurring either separately or in various combinations.

- Physical deficits: all the main physical processes can be either impaired or spared: sensory and pain perception, vocal and speech functions, digestive, metabolic and endocrinian functions, genito-urinary and reproductive functions, locomotor abilities and those associated with movements of all kinds.
- Cognitive and behavioural deficits: all the main mental functions can be impaired (consciousness, orientation, energy, reflex behaviour, sleep, etc.), and more specific mental activities such as attention, memory, thought and language can also be affected.

Even when one or more of these functions are affected, some of these patients show no obvious physical deficits.

3. In terms of activity

ICF code	ICF label
d 1	Learning and applying knowledge Purposeful sensory experiences 110 115 Basic learning 132 155 Applying knowledge 160 163 166 170 172 175 177
d 2	General tasks and demands 210 220 230 240 250
d 3	Communication Communicating –receiving 310 315 325 Communicating - producing 330 335 345 Conversation and use of communication devices and techniques 350 355 360
d 4	Mobility Changing and maintaining body position 410 415 420 Carrying, moving and handling objects 430 Walking and moving 445 450 455 460 465 Moving around using various means of transport 470 475
d 5	Self care 510 520 530 540 550 560 570 571
d 6	Domestic life Acquisition of necesssities 610 620 Household tasks 630 640 Caring for household objects and assisting others 660
d 7	Interpersonal interactions and relationships General interpersonal interactions 710 720 Particular interpersonal relationships 730 740 750 760 770
d 8	Major life areas Education 810 820 825 830 835 Work and employment 840 845 850 855 Economic life 860 865 870
d 9	Community, social and civic life 910 920 930 950

1 The most frequent limitations to activities are:

2 • Learning and applying knowledge: acquiring skills (d155), focusing attention (d160),
3 problem-solving (d175), decision-making (d177),

4 • General tasks and demands: carrying out daily routines (d230), handling stress
5 and meeting other psychological demands (d240),

6 • Communication: receiving and producing spoken messages (d310), engaging in
7 conversation (d350), using communication devices and techniques (d360),

8 • Mobility and moving around in different places (d 460) using means of transport (d
9 470), driving (d475),

10 • Self-care: washing (d510), dressing (d540), attending to one's health (d570),

11 • Domestic life: acquiring necessities (620), performing household tasks (preparing
12 meals (d630), doing housework (d640), assisting others (d 660)),

13 • Interpersonal interactions and relationships: maintaining and managing interactions
14 with other people in a contextually and socially appropriate manner (d720) (relating
15 to persons in authority (d740), family relationships (d760)).

16 **4. In terms of participation**

17 In terms of restricted social participation, all the main fields of activity are affected to some
18 extent, depending on the nature and the severity of the deficits and their combinations, as
19 well as on the environment and personal factors such as the patient's situation at the time
20 of occurrence of the the brain damage, namely:

21 • Education: especially when it is difficult or impossible for patients to undertake or
22 pursue studies (d825).

23 • Work and employment: lack of ability or complete inability to acquire and keep a
24 job or complete a task (d845), or carry out unpaid work (d 855).

25 • Economic life: lack of ability or complete inability to perform basic economic
26 transactions (d 860) or complex economic transactions (d865) or to ensure
27 economic self-sufficiency (d870) or difficulty in controlling their own financial
28 resources so as to avoid economic problems.

29 • - Community, social and civic life: lack of ability or complete inability to invest or
30 continue to invest in normal leisure activities (d920) and associative activities
31 (d910).

32

33 Patients' restricted activities and their limited participation in their social environment as the
34 result of their motor, cognitive and psycho-behvioural deficits constitute an additional
35 handicap.

36 These problems, which can be said to be serious or even completely incapacitating, often
37 lead to isolation and social exclusion, deterioration of the patients' health and the
38 exhaustion of the members of their entourage.

1

V. Environment of the programme

2

A. Clinical setting

3

Individual practice or part of a doctor's group practice	No
Individual practice in a private hospital	No
Part of a local (public) hospital	No
Part of a regional hospital (or rehabilitation centre)	No
Part of a university or national hospital	No

4

5 6 Community based PRM programme of care in partnership with a University teaching hospital

7 • at the patients' homes and the various places they frequent

8 • at the various branches of SAMSAH TC-CL 13 (there exist 5 branches in all),

9 • at the La Timone Hospital's PRM facility (based on a contractual agreement).

10

B. Clinical programme

11

Inpatient beds under PRM responsibility	No
Inpatient beds belonging to other departments	No
Day programme (mostly in outpatient settings, not at home)	No
Outpatient clinic (assessment and/or treatment for up to 3 hours/day)	No
Community based care (in the patient's home or workplace or other relevant community setting such as sports centres)	Yes

12

13 14 Individual and collective ambulatory care in the framesork of patients' individual projects for their future.

15 16 17 18 19 • at the places where patients lead their everyday lives and conduct their usual activities: interviews, observations, role-playing, adaptation, physical accompaniment, consultations, coordination with other professionals working at the hospital Functional Rehabilitation Unit, Home Nursing services, and the UEROS (the Unit for Assessment, Retraining and Social Guidance), etc..

20 21 22 • At the 5 associated centres: interviews, appropriate activities (art therapy, rehabilitative–sport, special events), cognitive remediation workshops, outings, neuropsychological assessments.

23 24 25 • At the PRM centre: special "brain damage" consultations, and ambulatory care involving interdisciplinary assessments with the PRM specialist in collaboration with the Timone Hospital's PRM department.

1
C. CLINICAL APPROACH

2

Uniprofessional	No
Interprofessional	Yes

3

4 The medico-social workers at SAMSAH form a highly complementary team, the members
5 of which work together on a day-to-day basis.

6

7 The SAMSAH unit works in collaboration with the following partners:

8 • the PRM facility at the Timone University Teaching Hospital in Marseille
9 (specialized consultations, ambulatory care);

10 • the associatiion “TCA 13”, which is specialized in providing patients with brain
11 lesions with personal assistance;

12 • the association “Coridys”, which is specialized in assessing services to patients with
13 cognitive disorders;

14 • the association “3A”, which is specialized in organizing recreational activities for
15 disabled people (such as special forms of sport and art therapy).

16
D. FACILITIES

17

Does your programme have a designated space:	
For assessments and consultations?	Yes
For an ambulatory or day care programmes?	No
For inpatient beds?	No
For therapeutic exercises?	No
For therapeutic exercises? **(redondant)**	No
For training in independence and daily living?	Yes
For vocational and/or recreational activities?	Yes

18

19 • central Headquarters where the managerial team work,

20 • five outreach points, where interprofessional groups work with patients and the
21 persons accompanying them.

22 • a consultation room at the Timone Hospital’s PRM unit in Marseille.

1

VI. Safety and patient rights

2

A. Safety

3

4 This is not an inpatient or day hospital programme: all the patients are seen at their homes

5

The safety concerns of persons in the unit where the programme takes place relate to:	
Emergencies (fire, assault, escape)	Yes/No
Medical emergencies	Yes/No
Equipment	Yes/No
Handling of materials	Yes/No
Transport	Yes/No
The safety of persons in the programmes of your unit is provided by:	
Written standards published by National Safety Bodies	Yes/No
Written standards published by National Medical Bodies	Yes/No
Written unit-specific rules	Yes/No
Periodic inspections	
Internal	Yes/No
External	Yes/No

6 This association was duly authorized to conduct its activities by a decree signed by the
7 Prefect and the President of the General Council on 28 December 2004 for a period of 15
8 years, based on the project submitted to a regional commission.

9 It is under the responsibility of the Administrative Department of the Bouches du Rhône, the
10 French Ministry for Social Affairs and the Sickness Insurance Fund, which inspect the
11 budget every year and exercise control over the administrative, financial and functional
12 aspects of the association.

13

14

B. Patients' rights

15

Has your programme adopted a formal policy or statement of patients' rights?	Yes
Does this statement specify the influence that the patient should have in the formulation and implementation of the programme?	Yes
Is the statement known to all patients involved in delivering the programme?	Yes
Is this checked periodically?	Yes
Is the statement made known to and is it available to all persons visiting your unit?	Yes

The rights of patients benefiting from the Programme are subject to the 2002 legislation (4), which stipulates that they must be involved in the decision-making processes and have access to their own files. At admission, patients are given a booklet explaining the charter of users' rights (5). They subsequently sign the Personal Accompaniment Plan (annex 1) presented to them by the members of the SAMSAH team.

Members of the public are informed via a booklet. Accompanied patients are informed by mail about the association's activities and opening hours, and how to contact the professional members of the team. They can also consult the members of the team by phone on weekdays.

C. ADVOCACY

Give at least one example of how your organisation advocates for the people your programme deals with:
This community based programme is linked to an association for TBI patients and their families: AFTC13

VII. PRM Specialists and team management

A. PRM Specialists in the Programme

Does your PRM physician have overall responsibility and direction of the multiprofessionnal team?	Yes
Does your PRM physician have overall responsibility and direction of the rehabilitation programme, not only medical responsibility?	No
Does he/she have a European Board Certification in PRM?	Yes
Does he/she meet National or European CME/CPD Requirements?	Yes
Number of CME or EACCME points earned in the last 3 years:	Reaccreditation2010
The two main functions of the PRM specialist in your Programme are to:	
Treat comorbidity	
Assess patients' potential for rehabilitation	Yes
Analyse & treat impairments	
Coordinate interprofessional teams	Yes

The PRM specialist has to apply the best possible treatment and follow-up procedures, in line with the latest scientific findings in the field of TBI, using all the health and social facilities available in the area and facilitating cooperation between all those involved. This cooperation includes the Timone University hospital and medical school. The scientific director of the programme is an academic Professor of PRM at the Marseille University Hospital: he is responsible for both inpatients' and outpatients' programmes.

The PRM specialist disseminates information about this Programme in Marseille at the medical school and at the other health and social teching establishments involved.

The PRM specialist disseminates information about this Programme to all the professional workers involved.

B. Team management

Which rehabilitation professionals work on a regular basis (at least once per week) in your Programme? (give the number)	
Physiotherapists	0
Occupational therapists	2
Psychologists	5
Speech & Language therapists	1
Social workers	5

Vocational specialists	0
Nurses	0
Orthotists/prosthetists’ assistant technicians/engineers	0
Other (please specify)	Educateurs 3 Sport & Art therapists 11

The SAMSAH is a specialised deparmental pluridisciplinary organization intended to provide each patient with comprehensive individual coordinated assistance with their personal projects for their future. One of the aims of the outreach services provided by this association is to improve patients’ environment .

In 2009, the mobile team of professionals consisted of 20.85 Full Time Equivalents (FTEs), 9.875 of whom were funded by the national Sickness Insurance Fund (as part of the health budget).

- The outreach team includes social workers responsible for social rehabilitation and collective activities. It is headed by a coordinator who is a qualified psychologist and neuropsychologist. In 2009, three teams of students in the field of social work were recruited for at least one year.
- In addition, there are 11 part-time professionals specialised in specific activities, who run workshops for accompanied patients (sport, cognitive remediation, art therapy, musicotherapy, etc.). These professionals are not included in the list of permanent staff.
- The healthcare team includes a speech therapist, two occupational therapists and two PRM physicians (1 FTE in 2010), one of whom acts as the coordinating physician. Application has been made to create two positions for nurses in 2010.
- The steering committee consists of administrative staff (a medical secretary, a secretary, and an accountant) under the responsibility of a managerial head of department. It also includes the manageress responsible for all the professionals at the unit, who answers to the funding authorities and the Board of Administation as regards the smooth running of the association and the quality of the services it provides.
- Professor Alain Delarque, the PRM Professor in charge of the MPR facilities at the La Timone Medical Faculty, is responsible for the scientific basis of the services provided.

The professionals involved in the patients’ family association (a social worker and a secretary) complete the SAMSAH team.

All the association’s salaried employees (apart from the secretaries) have undergone University training courses on the medical and social aspects of traumatic brain injuries or have acquired experience in the field of brain lesions.

1

How often do members of your staff undergo formal continuing vocational education at present?	
In team rehabilitation work:	Every year
In their own profession:	Every year
Do team activities in your rehabilitation programme include the following?	
Is the patient at the centre of a multiprofessional approach?	Yes
Do you always give informed choices of treatment?	Yes
Do you regularly promote family involvement?	Yes
Does your approach to multiprofessional teamworking include:	
Holding regular team meetings with patients' records (more than 2 members)	Yes
Holding regular team meetings (more than 2 members) in the presence of the patients themselves	Yes
Joint assessment of the patient or joint interventions	Yes
Regular exchanges of information between team members	Yes

2

VIII. Description of the programme

A. Time frame of the programme

1- 2 Phases in the programme and Follow up procedure

The Programme consists of three phases: the start-up phase, the initial assessment phase, and the accompaniment and follow-up phase

1. The start-up phase

a) Content

- Listening and Understanding
- Informing and Guiding

b) Interventions

- Two or more interviews with the coordinating psychologist/neuropsychologist
- Providing documents about brain trauma
- The PRM physician gives an opinion and possibly sees the patient
- Contacts woth other professionals and services
- Team meetings to examine whether the inclusion criteria are met

c) Follow-up

After the start-up phase, patients join the programme.

d) Duration

The duration of this phase depends on the requirements and the situation (patient leaving the Functional Rehabilitation Centre, the history of the lesion, family members exhausted, patient expelled from rented accommodation)

2. Initial assessment phase

a) Content

- Helping to draw up and formulate individual projects for the future,
- An ecological assessment (Measuring the patient's performances),
- Measuring the patient's abilities
- Drawing up a Personal Accompaniment Plan

b) Interventions

- Observating real-life situations and individual and collective role-playing.
- Consulatations at the hospital PRM unit, interviews at the SAMSAH centre or in the patient's home if necessary.

- The PRM physician may decide to have the patient admitted for ambulatory care at the hospital PRM unit to undergo assessments and specialized consultations and if necessary, to have neuropsychological assessments made by a specialized partner in consultation with the SAMSAH's psychologis/neuropsychologist.

- Assessing the patient's social situation.

- Assistance with the various procedures designed to quickly improve the patient's situation when there exist serious problems (such as a threat of expulsion from rented accommodation, infringement of patients' social rights, family violence) or when changes occur (such as leaving the rehabilitation centre).

- Identifying any facilitating elements and any obstacles in the patients' material environment (occupational therapy) and their human environment (via an interprofessional team).

c) Follow-up:

At the end of this phase, the patient's Personal Plan is drawn up: this plan outlining the patient's projects for the future, the goals and reasons why assistance is required and the actions it is proposed to carry out is presented to the patient and discussed before being signed by the patient and the SAMSAH.

d) Duration:

The mean duration of this phase is 6 months, but it can be longer if necessary.

3. The accompaniment phase

a) Content

- Determining the sequels in real-life situations, helping patients to accept their handicap, facilitating access to care.

- Furthering patients' readaptation and integration into everyday social and relational life and activities, including occupational activities.

- Educational and psychological follow-up.

- Defining and implementing compensatory strategies correponsding to patients' projects for their future.

b) Interventions

- Setting up and coordinating the medical follow-up: PRM consultations, coordination between physicians and paramedicals, preparing medical files and summaries and healthcare information, providing appropriate nursing care and rehabilitation, checking any special fittings. (under the responsibility of PRM physicians)

- Organizational efforts facilitating access to care (correcting cognitive problems): planning and preparing for appointments, organizing means of transport, accompanying patients to consultations, reading assessments, ensuring that the physicians' recommendations are put into practice, helping to apply medical advice (these tasks are carried out by the members of the team, based on the Programme).

- Helping to understand sequels by promoting awareness and acceptance.

- Mobilizing a network of professional workers: identifying the means of assistance required, helping to organize interventions (by defining the requirements and setting up appropriate actions), organizing meetings and the collaboration of professionals (possibly after giving them the requisite vocational training), providing information about invisible handicaps (under the responsibility of the coordinating psychologists/neuropsychologists in charge of the various SAMSAH branches).

1 - Social assistance: providing help with individual procedures and with the organization of
2 patients' activities and their relationships with their entourage (under the reponsibility of the
3 social workers in charge of patients' social rehabilitation.

4 - Collective activities: workshops (sport, art therapy, cognitive remediation, music therapy,
5 etc.), occasional collective activities, looking for other suitable non-paying leisure activities
6 (under the responsibility of the social workers in charge of collective actions).

7 - Adaptation of patients' environment: *in situ* assessments, tests and retraining, providing
8 suitable assistance (under the responsibility of occupational therapists).

9 - Helping patients' entourage: lending an ear, counseling, explaining the sequels (under the
10 responsibility of a multiprofessional team).

11 **c) Follow-up**

12 This phase involves drawing up a Personal Action Plan for each individual patient (k)
13 defining the priorities to be targeted by professionals working with the SAMSAH and
14 specifying all the relevant actions to be undertaken. This document is drawn up collectively
15 by the team and gradually reassessed as required by the patients' situation.

16 The situation is reviewed at least every 12 to 18 months.

17 **d) Duration**

18 The duration of this phase varies from one patient to another. It can sometimes last for
19 several years.

20 Funding is provided by the "Maison Departementale des Personnes Handicapés" (the
21 French administration responsible for disabled persons) for a period of 1 to 5 years: this
22 period can be extended by application.
23

24 **4. The end of the period of active assistance and the long-term follow-up**

25 The administrative agreement as to the coverage of patients' follow-up is delivered initially
26 by the "Maison Départementale des Personnes Handicapées", which decides whether to
27 refer the patient to SAMSAH. Six months before this orientation phase comes to an end,
28 the team at SAMSAH TC – CL 13 holds a meeting to decide whether or not the patients'
29 accompaniment should be continued. In this case, a new application for patients to renew
30 their contract with SAMSAH TC-CL 13 is submitted to the MDPH. The number of renewals
31 possible is not restricted. Patients can therefore be accompanied throughout their lives if
32 necessary, as explained in the circular sent to patients with brain lesions.

33 The objectives of the accompaniment are decided at a "patient review meeting" at which
34 the patients' case history is reviewed.

35 These meetings are held whenever the professional members of the SAMSAH TC-CL 13
36 team report that:

37 - a patient has become more self-sufficient, the Personal Action Plan has been completed,
38 the accompaniment provided by SAMSAH TC-CL 13 is no longer necessary and the
39 patient would like to fend for himself unassisted;

40 - a recurrent obstacle has been encountered which prevents the services provided by
41 SAMSAH from being efficiently carried out (when members of the patient's entourage
42 prevent professionals from intervening, for example).

43 In cases of this kind, SAMSAH proposes to end the contract by applying for this purpose to
44 the MDPH and the patient's GP. Other suitable structures (services providing social
45 assistance, healthcare professionals working at private practices, etc.) are contacted. If
46 necessary, the patient can subsequently be re-admitted to SAMSAH.

B. ASSESSMENT

1. Diseases and impairments – the diagnostic approach

- Diagnostic procedures (such as scanning for neuro – endocrine disorders located distally from the initial lesion, apnea during sleep, etc.),
- Assessing patients' deficits and abilities (clinical tests, blood tests, etc.),

2. Activities

- Analyzing the limitations to patients' activity detected by the members of the SAMSAH team,

3. Participation - environmental and personal factors

- Analyzing the restrictions to patients' participation detected by the SAMSAH team,

C. INTERVENTIONS

1. PRM specialists' interventions (other than the usual follow-up and complication management)

a) Responsibilities:

- The PRM physicians confirm the justification for referring patients to SAMSAH.

- They are responsible for ensuring the safety and comfort of patients and their entourage (by relieving them of the formalities involved in obtaining human and material assistance, for example)

- They must act as advisers and make sure that any invisible sequels are fully understood by patients' families and by the professionals and healthcare workers to whom they are entrusted (by providing these people within formation and vocational training if necessary).

- They must check that the improvements acquired are long-lasting and follow the patients' evolution.

- They have a preventive role to play: prescribing screen tests, detecting sequels, and applying for legal protection if necessary. They must make sure the advice given by professionals and the treatments prescribed are carried out (and coordinate the work of the various therapists treating the medical problems resulting from the lesion and any associated problems)

-Their therapeutic interventions include, for example, prescribing special **orthotic devices** for use in the patients' homes and promoting contacts between the various professionals attending to patients at home,

b) Interventions :

- With populations and families:

- Giving special "brain lesion" consultations with patients' families.

- As a team:

- Multiprofessional assessments and analyses of patients' situations,

- Interventions focusing on patients and their entourage, depending on the requirements, at least once per year,
- centralizing medical and follow-up data,
- summarizing patients' medical data,
- drawing up personal plans for patients' access to care.

- At the hospital PRM unit:
  - special interprofessional consultations for patients with brain damage (with podo-orthesists, orthoprosthesists, suppliers of special equipment, occupational therapists, etc.),
  - requesting the hospital PRM unit to perform check-ups and assessments (urodynamic tests, screening and treating osteoporosis, assessing and treating the untoward effects of spasticity, performing balance and locomotor tests, psychological tests, speech tests and social fitness tests.
  - Coordinating the work of hospital specialists and obtaining expert advice on problems such as swallowing disorders, sleep disorders, epilepsy, endocrine disorders, etc..
- Coordinating the work of the SAMSAH team with external professionals:
  - Healthcare professionals: GPs, PRM physicians working at clinics and hospitals and other medical specialists (ear, nose and throat specialists, endocrinologists, neurologists, psychiatrists, occupational physicians, etc.), with paramedicals working at private practices and healthcare establishments (physiotherapists, nurses, speech therapists, etc.), and other healthcare professionals (occupational therapists, podo-orthesists, orthoprosthesistes, suppliers of medical equipment) and social workers (social assistants).
  - Professions working with patients' entourage (home care workers).
  - Other professionals in the fields of Law, occupational issues, the environment, leisure activities, etc. Ensuring coordination between GPs and specialists (doctors with private practices and hospital doctors)

- Teaching and research activities
  - Giving lectures about the Programme to students at the Medical School
  - Organizing special sessions on this theme at national PRM congresses in 2010

2. Team interventions

These have been described above in Section VIII A

3. Complication management

No complications (?) observed

D. DISCHARGE PLANNING AND LONG TERM FOLLOW UP

See above in Chapter VIII A 4

IX. Information management

A. Patient records

Do the rehabilitation records have a designated space within the medical files?	Yes
Do you have written criteria for:	
• Admission	Yes
• Discharge	Yes
Do your rehabilitation plans include written information about aims and goals, time frames and identification of responsible team members?	Yes
Do you produce a formal discharge report (summary) about each patient?	Yes

1. Admission and discharge criteria

The inclusion criteria used at SAMSAH are social criteria (age, place of residence, administrative situation) et medical criteria.

From the medical point of view:

All patients with non degenerative acquired brain lesions, however long the history of the lesion and however severe the sequels may be, including patients undergoing hospital care at their homes.

Patients whose brain lesions are associated with psychiatric disorders should preferably also be treated at a psychiatric department.

Patients are referred by PRM physicians working at functional rehabilitation centres and hospital PRM units and by GPs and other specialists, the “Maison Départementale des Personnes Handicapées” (MDPH), social services and associations. All the patients are seen by the coordinator in charge (who is a psychologist and neuropsychologist) and applications for their admission to SAMSAH TC-CL 13 are submitted to the MDPH (the administration responsible for disabled patients).

Exclusion criteria:

These criteria are mainly the existence of obstacles to working with the patient (refusal of care making it impossible to set up an Action Plan, repeated lack of compliance with the patient’s Action Plan despite several efforts at mediation).

Discharge criteria:

- if the Personal Action Plan has been completed,
- if the patient and/or the family does not wish to benefit from the assistance provided by SAMSAH.

2. The Treatment Plan

Patients’ own GPs are responsible for their treatment.

The personal accompaniment plan is drawn up by the SAMSAH team and signed by the patients or their legal representatives.

1
3. The final report

2 3 4 5
At the end of the period of accompaniment, a final summary is drawn up and sent to the patient, the GP and the “Maison Départementale des Personnes Handicapées” (MDPH), the administration which initially authorized the patient’s admission.

6
B. MANAGEMENT INFORMATION

7

Does your programme show evidence of sustainability?	
• Established part of public service:	No
• Has existed for more than 3 years:	Yes
• Has received national accreditation (where available):	Yes
How many new patients (registered for the first time) are treated in your programme each year:	**35**
In your day care or inpatient programme:	
• What is the mean duration spent in therapy by patients on this programme	> 3 years
• How many hours a day do the patients spend in therapy.	NS
Give the mean duration of stay spent in the programme:	>3 years

8

9
1. Organizational data

10

11 12
SAMSAH was created on 1 July, 2005. Its capacity, and hence the number of patients accompanied, has been increasing steadily since then.

Year	Capacity	Active files	Number of entries	Number of discharges
2005	31	49	49	0
2006	45	70	25	4
2007	45	78	21	13
2008	65	100	29	7
2009	73	144	52	11

13

14 15 16
The mean duration of the assistance authorized by the Commission for Disabled Patients’ Rights and Autonomy was 2.5 years in 2008. Patients’ admission can be renewed at the request of the SAMSAH team.

17 18 19
Although the mean period of accompaniment cannot be calculated exactly, it is longer than the mean period authorized, since 21 of the 49 patients enrolled since July 2005 were still present at the end of 2008, 3.5 years after their admission.

20

C. PROGRAMME MONITORING AND OUTCOMES

Does your programme have an overall monitoring system in addition to patient's records?	Yes
Are the long term outcomes of patients who have completed your programme regularly monitored?	
• Impairment (medical) outcomes:	Yes
• Activity/Participation (ICF) outcomes:	Yes
• Duration of follow up of the outcomes:	longer
Do you use your outcome data to bring about regular improvements in the quality of your programme's performance?	Yes
Do you make the long term overall outcomes of your programme available to your patients or to the public?	Yes

1. Continuous assessment of the Programme

a) Organization of assessments

Continuous assessment of the Programme is based on an annual satisfaction survey and statistical studies on the beneficiaries and the activities of SAMSAH. An annual report is submitted to the supervisory administrations.

An annual satisfaction survey (as from 2006) is conducted at the beginning of each year, based on an anonymous written questionnaire which is sent to all the patients who benefited from the services of SAMSAH during the previous year (including those whose period of accompaniment has come to an end) and their entourage. This questionnaire is sometimes preceded by qualitative interviews carried out by an external expert. The results of this survey are presented in SAMSAH's annual activity report.

Continuous statistical studies are being carried out, since SAMSAH is equipped with a databank in which information about the patients' situation and the interventions performed by the various professionals working for the association are automatically collected. During the first term of each year, statistical data are collected on patients, their profiles, their social situation and SAMSAH's activities. The results are presented in the annual activitiy report, along with an article on a relevant theme, such as "Coordination between the various professionals dealing with patients" (in 2007) or "The interdisciplinary services provided" (in 2008).

Other studies are occasionally carried out, such as that conducted in 2009 by experts in the field of ergonomics on the workload of the professionals employed by SAMSAH.

b) Informing the public

The annual activity report is submitted to the funding organizations and members of the Board of Administrators, as well as to all the professionals and bodies who have requested to be sent copies. It is presented at the Association's Annual General Assembly, which all SAMSAH's patients are invited to attend. A summary is distributed at these meetings to the participants and members of the Association.

2. Results

The following main observable results have been obtained since SAMSAH was created in 2005:

1 - The sources from which patients have been referred have been diversified.
2 - The number of patients admitted has increased.
3 - Patients' situation has stabilized and projects for their future have been set up.
4 - A very high level of satisfaction has been achieved among patients and their families.
5 - Patients have had access to specialist care and benefit from specialized medical follow-
6 up.
7 - Patients have been given access to new forms of assistance (that provided by home care
8 workers, in particular).
9 - SAMSAH's expertise has been recognized:
10 ▪ Papers have been presented at national and international congresses,
11 ▪ **Specialized SAMSAH project-holders** have been given expert advice
12 ▪ An MDPH assessment has been applied for
13 ▪ SAMSAH has contributed to the initial vocational training of doctors, social
14 workers and psychologists.

X. Quality improvement

A. WHICH ARE THE MOST POSITIVE POINTS OF YOUR PROGRAMME?

1. Meeting the needs

- We have responded to national recommendations whereby patients with brain injuries should be given long-term follow-up.

- The needs identified at local level are being met.

2. Networking

- Partnership agreements have been signed with the structures helping to deal with the patients. One of these structures, the University teaching hospital PRM unit at the University of the Mediterranean in Marseille, has developed a programme for accompanied patients **with brain lesions**, which has been accredited at European level.

- Coordination between independent and hospital physicians.

- Serving as a hub for this innovative project for improving the quality of life of patients with cranial trauma and brain lesions in their normal everyday settings (by introducing a system of shared accommodation between patients and specialized home care workers, for example).

3. Adapting the Programme to the specific needs of patients with brain lesions in the setting of their homes

- Obtaining the services of specialized mobile staff

- Making these services available throughout the region

- Using a comprehensive interdisciplinary approach based on the work of a permanent team focusing on all the aspects of patients' lives (their everyday lives and their social, family and emotional lives, their accommodation, activities and healthcare, etc.).

- Personalizing and regularly updating the Programme in keeping with patient's everyday lives and their everyday environment.

- Providing long-term accompaniment when necessary

- Working with members of the family entourage.

4. A common language

- The WHO International Classification of Functioning, Disability and Health (the ICF)

B. WHICH ARE THE WEAKEST POINTS IN YOUR PROGRAMME?

1. The increasing numbers of patients with active files (there are more admissions than discharges)

- We cover a large population (based on the national and local epidemiological **statistics**)

- There exist few suitable **relay** structures facilitating patients' discharge, such as special meeting places and centres running activities for disabled persons.

2. Patients with severe psychiatric disorders and/or addictions

3. Internal communication problems due to participants' temporal and spatial dispersion

4. Difficulty in having the funding authorities recognize the needs of patients with "invisible" sequels

5. The local needs have not yet been completely covered (our services do not include the Southern sector of Marseille)

C. WHAT ACTION PLANS DO YOU INTEND TO IMPLEMENT IN ORDER TO IMPROVE YOUR PROGRAMME?

1. To deal with the increase in the number of active patients' files, the following actions have been planned:

a) Enlarging the teams

- Recruiting healthcare professionals, especially nurses
- Increasing the working hours of the professionals forming outreach teams

b) Signing new partnerships

- Developing contacts with all the social services.
- Finding structures with which to share the accompaniment of patients with co-morbidities.
- Launching a project to create a cooperative social and medico-social network focusing on cognitive impairments.

c) Developing novel responses

- Proposing new solutions to accommodation and home care problems
- Providing family helpers with occupational solutions and moments of respite.
- Providing patients' families with special means of support

2. Improving the accompaniment of patients with severe psychiatric disorders and/or addictions

We have started working together with local psychiatric and hospital facilities (at University teaching hopitals and elsewhere) in the Bouches du Rhône Department (Department no.13).

3. To reduce the internal communication problems

A reliable long-distance internal communication software programme has been developed and tested.

4. To have the needs of patients with "invisible" sequels recognized by the funding authorities

1 Special reports on this topic have been submitted to these authorities as well as being
2 presented at scientific congresses and meetings.

3 5. To complete the coverage of the whole Department

4 Steps are being taken to create a new branch of SAMSAH in the Southern sector of
5 Marseille.

XI. References

A. NATIONAL REFERENCES

1. REPUBLIQUE FRANCAISE MINISTERE DE LA SANTE ET DE LA PROTECTION SOCIALE - SECRETARIAT D'ETAT AUX PERSONNES HANDICAPEES DHOS/SDO/01/DGS/SD5D/DGAS/PHAN/3B/280 du 18 juin 2004 relative à la filière de prise en charge sanitaire, medico-sociale et sociale des traumatises crânio-cerebraux et des traumatises medullaires

2. REPUBLIQUE FRANCAISE MINISTÈRE DES SOLIDARITES, DE LA SANTE ET DE LA FAMILLE
Decret no 2005-223 du 11 mars 2005 relatif aux conditions d'organisation et de fonctionnement des services d'accompagnement à la vie sociale et des services d'accompagnement medico-social pour adultes handicapes

3. Loi n° 2005-102 du 11 fevrier 2005 J.O n° 36 du 12 fevrier 2005 page 2353
Representation personnes handicapees dans les instances

4. Loi 2002-2 de renovation de l'action sociale et medico-sociale (JO du 3 janvier 2002)

5. Loi 2002 References de la Charte des droits des usagers : Arrête du 8 septembre 2009 (JO du 9 octobre 2003)

B. ATTACHED DOCUMENT

The Personnal Accompaniment Plan