

Appendix S1

Examples of Goal Attainment Scales using a stair analogy, in different PRM fields :

- either with all 5 levels/steps precisely described
- or with only the 3 milestones precisely described



Context : ...
General Goal : ...
Specific goal : ...
Target behaviour : ...

Why is this goal important?

...

How can I achieve my goal?

...

Goal (after « x » weeks or months):

Initial level :



Context : 13 year-old boy with Duchenne muscular dystrophy

General goal : to improve health behaviours related to physical activity and diet

Specific goal : to increase physical activity by attending a dance program

Target behaviour : to attend a dance program

Why is this goal important?

Low physical activity can lead to mobility and functional restrictions, osteoporosis, depression, social isolation, and reduced overall health and well-being

How can I achieve my goal?

By following a specific « Solution-Focused Coaching » program, finding a dance club, trying it and subscribing

I am active twice a week (swimming and dance program)

I have registered to attend a dance program

Goal (after 12 weeks): I have attended a dance program to try it out

I have searched for information about a dance program that I could participate in

Initial level : I am active once a week (swimming)



GOAL

Context : 10 year-old boy with spastic diplegia, that likes playing soccer with peers

General goal : to play soccer better

Specific goal : to be able to kick the ball with the right foot

Target behaviour : kicking and aiming the soccer ball into a goal with the right foot, during physiotherapy (PT) sessions

Why is this goal important?

I love playing football and I wish I could score more goals

How can I achieve my goal?

By receiving Botulinum toxin injections, and PT sessions post-toxin 2 to 4 times/week, with goal oriented therapy

I can kick the soccer ball with the right foot into the goal at a distance of at least 18 meters

I can kick the soccer ball with the right foot into the goal at a distance of at least 12 meters

Goal (3 months): I can kick the soccer ball with the right foot into the goal at a distance of at least seven meters

I can kick the soccer ball with the right foot into the goal from a distance of at least three meters

Initial level : I always use the left foot for kicking the ball, I can touch the ball with the right foot but it is difficult to kick and direct it



Context : adult with traumatic brain injury, and Post-traumatic amnesia (PTA)
General goal : improving independence in Instrumental Activities of Daily Living (IADLs)
Specific goal : to prepare a hot drink and a cup of noodles
Target behaviour : preparing a hot drink and a cup of noodles in the rehabilitation centre kitchen, with Occupational Therapy (OT) supervision

Why is this goal important?

Used to take part in meal preparation, that is a social role and will have to do it again, if possible

How can I achieve my goal?

By regular training with my OT, working to learn the different steps and their order

I prepare a hot drink and a cup of noodles independently

I prepare a hot drink and cup of noodles without verbal prompts, but I am helped to initiate this

Goal (2 months): I prepare a hot drink and a cup of noodles with 1 verbal prompt

I prepare a hot drink and a cup of noodles with 2 verbal prompts

Initial level : I prepare a hot drink and a cup of noodles with 3 verbal prompts



Context : 13 year-old child with cerebral palsy

General goal : to increase participation in school activities in relation to posture/mobility

Specific goal : to be on time for lunch while walking with her walker

Target behaviour : walking with her walker between the class and lunchroom (300 ft) – observed during 1 week

Why is this goal important?

If on time in the lunchroom, I will be able to choose where and next to whom I sit

When leaving with my peers, I walk independently using my walker from the class to lunchroom 3 out of 5 days, and arrive as the school lunch line leader.

How can I achieve my goal?

By having school-based physiotherapy therapy

When leaving with my peers, I walk independently using my walker from the class to lunchroom 3 out of 5 days, and arrive at the middle of the school lunch line (between peers)

Goal (6 months): When leaving at the same time as my peers, I walk independently using my walker from the class to lunchroom 3 out of 5 days, and arrive at the back of the school lunch line.

When leaving 2 minutes before class, I walk independently using my walker from the class to lunchroom 3 out of 5 days and arrive at the back of the school lunch line (behind peers)

Initial level : When leaving 5 minutes before the class, I walk independently using my walker from the class to lunchroom, 3 out of 5 days, and arrive at the back of the school lunch line (behind peers)



Context : 4-year old boy with Pitt Hopkins syndrome,
General goal : to improve participation in play activities with other children
Specific goal : to play outside with other children
Target behaviour : frequency of playing outdoors with other children, observed in 2 weeks

Why is this goal important?

Reduced mobility limits opportunities for me to explore my social environment. I rarely participate when children play outside.

How can I achieve my goal?

Parents and caregivers will promote social interaction by including me in playground games alongside peers. They will often make initial contact with peers to encourage social interaction with children.

I socialize with other children outdoors for 45-60 minutes, 3 times a week

I socialize with other children for 45-60 minutes outdoors, 2 times a week

Goal (after 12 weeks): I socialize with other children outdoors, for 45-60 minutes once a week

I socialize with other children for 45-60 minutes outdoors, once over a 2 week period

Initial level : I do not socialize with other children outdoors, even not once every 2 weeks



Context : 12-year-old girl with complex regional pain syndrome, that has not been walking for 1 year, difficulties for removal of ambulatory assistive devices

General goal : to improve walking abilities

Specific goal : to be able to walk again without assistive devices

Target behaviour : walking all day long

Why is this goal important?

I do not want to go back to school with assistive devices

How can I achieve my goal?

By training with my physiotherapist and also training at home and outdoors during week-ends

I walk all day without assistive devices

I walk all day with one walking cane

Goal (1 month): I walk all day with two walking canes

I walk all day with a simple walker, without antebrachial support

Initial level : I walk all day long with walker with antebrachial support



Context : 14 year-old boy, acquired brain injury, severe temporo-spatial disorientation
General goal : to improve temporal orientation
Specific goal : to be able to identify today's date
Target behaviour : different caregivers ask him 7 times a day to identify today's date.

Why is this goal important?

Very disturbed by disorientation, I feel reassured when I am able to situate myself in time

How can I achieve my goal?

By getting a watch indicating the date
By training with caregivers several times a day to use my watch so I can get used to it

I manage to find today's date 5 to 7 times on the calendar without my watch

I manage to find the date of the day 5 to 7 times on the calendar by looking at my watch by myself

Goal (after 3 months): I manage to find the date of the day 5 to 7 times on the calendar with prompting to initiate use of the watch. I know how to use the watch

I manage to find the today's date correctly 5 to 7 times on the calendar, with prompting to initiate use of the watch; I need help with the use of the watch

Initial level : I manage to find the correct date 5 to 7 times on the calendar when I am told what the day is



Context : 4 year-old boy, degenerative disease, gaining weight, mainly wheelchair mobility at school, outside of classroom

General goal : to increase energy expenditure

Specific goal : to increase walking time during the day

Target behaviour : walking between classrooms, as reported by school assistant (1 week)

Why is this goal important?

To prevent orthopaedic degradation and maintain my walking abilities

How can I achieve my goal?

By walking as much as I can

I walk between classrooms twice a day, without help, 4 days a week

I walk between classrooms twice a day, without help, 1 to 3 days a week; only done once a day on other days

Goal (after 1 month): I walk between classrooms once a day, without help – school assistant is in charge of my wheelchair; 4 days a week

I walk between classrooms once a day by pushing my wheelchair, 4 days a week

Initial level : I use my wheelchair between classrooms on all 4 school days



Context : 8 year-old girl, with acquired brain injury, severe dyspraxia impacting activities
General goal : to increase capacities in play activities
Specific goal : to be able to make her Barbie a ponytail
Target behaviour : making her Barbie a ponytail.

Why is this goal important?

Because I want to play with my friends

How can I achieve my goal?

By training with my occupational therapist using Cognitive Orientation to daily Occupational Performance (CO-OP) approach



The elastic band is positioned close to the skull. The ponytail is centered on the top of the skull. This result is obtained with any type of elastic band

I put the elastic band around the hair and make a 2nd turn by passing the hair a 2nd time through the elastic. The elastic band is positioned close to the skull. The ponytail is centered on the top of the skull



Goal (after 2 months): I put the elastic band around the hair and make a 2nd turn by passing the hair a 2nd time through the elastic. The elastic band is well positioned close to the skull.



I put the elastic band around the hair and make a 2nd turn by passing the hair a 2nd time through the elastic (the elastic can be placed anywhere)

Initial level : I put the elastic band around the hair



Context : 57 year-old woman, stroke / severe hemiplegia, very poor upper-limb function
General goal : to increase independence in self care
Specific goal : to cut the nails of the hemiplegic hand more easily
Target behaviour : cutting nails at home.

Why is this goal important?

The tasks currently requires a family member and can be painful if not done

How can I achieve my goal?

By receiving Botulinum toxin injections, stretching my spastic muscles, training my goal

I cut my nails alone, in less than 5 minutes

I cut my nails alone, the task remains difficult but takes less time (between 5 and 10 minutes)

Goal (after 4 months): I cut my nails alone, but the task is difficult and long (more than 10 minutes)

I get my nails cut by my sister, the task becomes easier (passive extension of fingers is easier)

Initial level : I get my nails cut by my sister, the task is difficult (the hand and fingers are closed)



Context : 28 year-old-woman, spinal muscular atrophy type 2. Uses a computer and performs keyboard typing with the right hand (index or middle finger). Needs to take frequent breaks while typing
General goal : to improve upper-limb function
Specific goal : to improve endurance when using her computer keyboard
Target behaviour : number of words typed without a break, computer placed at a suitable height

Why is this goal important?

Because I use of my computer at home and at work daily

How can I achieve my goal?

By following a treatment by Nusinersen during 6 months

Typing on my laptop, at home, with correct typing posture, I am able to type **at least 55 words without a pause.**

Typing on my laptop, at home, with correct typing posture, I am able to type **46 to 54 words without a pause .**

Goal (after 6 months): typing on my laptop, at home, with correct typing posture, I am able to type **36 to 45 words without a pause.**

Typing on my laptop, at home, with correct typing posture, I am able to type **20 to 35 words without a pause.**

Initial level : typing on my laptop, at home, with correct typing posture, I am able to type **<20 words without a pause.**



GOAL

Context : 55 year-old-woman, spinal muscular atrophy type 3.

General goal : to improve walking and balance abilities

Specific goal : to climb the step more easily to reach her balcony

Target behaviour : climbing the step to the balcony

Why is this goal important?

I used to go to the balcony of my apartment to relax after work daily, and I enjoyed it. To reach my balcony, I have to climb a short step approximately 10cm high.

How can I achieve my goal?

By following a treatment by Nusinersen during 6 months

I climb the step to the balcony in one step, **without holding myself**

I use one hand to hold onto the edge of the window frame to climb the step. I climb the step to the balcony **in one step**.

Goal (after 6 months): I **use one hand** to hold onto the edge of the window frame to climb the step. I climb the step to the balcony in two steps

I use both hands to hold onto the edges of the window frame to climb the step. I climb the step to the balcony in two steps.

Initial level : I am unable to climb the step to the balcony.



Context : school-aged child, acquired brain lesion, decreased mobility and lack of initiative
General goal : to follow his peers during the school day
Specific goal : to walk faster and be on time in class
Target behaviour : walking between resource room and classroom

Why is this goal important ?

Because I am always late to class and would love to walk without my school assistant

How can I achieve my goal?

By receiving physiotherapy services to train mobility and by walking as often and as fast as I can

I walk with my walker from the resource room to classroom in less than 6 minutes, **independently (no supervision / verbal cueing)**

I walk with my walker from the resource room to classroom in less than 6 minutes with supervision and **no verbal cueing**

Goal (after 3 months): I walk with my walker from the resource room to classroom in **less than 6 minutes**, with supervision and verbal cueing

I walk with my walker from the resource room to classroom **in 6 to 8.4 minutes**, with supervision and verbal cueing

Initial level : I walk with my walker from the resource room to classroom in 8.5 minutes, with supervision and verbal cueing



Context : 15-year-old girl, with persistent headaches that began 4 years ago.
General goal : to manage pain and perform daily activities
Specific goal : to use active pain control tools and identify triggers
Target behaviour : self-report of pain management, using active pain control tools

Why is this goal important?

Headaches are extremely disabling and prevent me from doing the activities I want to do

How can I achieve my goal ?

By identifying pain control tools and using them appropriately :

- watch TV
- read (book, magazine)
- snack
- break from current activity
- exercise, go for a walk
- relaxation tape + imagery
- medication (+ something else)
- figure out what caused headache + resolve it

I actively identify and modify triggers.

I use strategies straight from the beginning of a headache, but I can't solve the "triggers" of the headaches.

Goal (after 2 months): I use one of the tools from the list of active pain control strategies as soon as the headache starts

I know strategies to control my pain but I use these inappropriately (for example too late, or not the best strategy)

Initial level : I have no strategies and do nothing to control my pain



Context : 46-year-old factory worker, on disability for 18 months experiencing low back pain, immobility and severe chest pains.

General goal : to tolerate pain and engage in more positive thinking

Specific goal : to avoid sick role behaviours and engage in well-behaviors

Target behaviour : reported engaged behaviours, from the lists below

Why is this goal important?

...

How can I achieve my goal ?

By identifying behaviours and choosing the right ones when appropriate:

- Sick role behaviours : leaving house only for medical appointments, wearing slippers outside the house, not buying own cigarettes or newspapers, not getting dressed, not preparing breakfast or lunch though able to
- Well-behaviours : completing all self-care within capabilities, exploring interests and retraining programs offered to me...

I engage in more than 3 stated well-behaviours and no sick role behaviours

I engage in 2-3 stated well-behaviors

Goal (after 2 months): I engage in fewer than stated sick role behaviors and at least one stated well-behavior

I engage only in sick role behaviours that are stated in the list

Initial level : I engage in more sick role behaviors than the behaviors stated in the list



Context : ...
General goal : ...
Specific goal : ...
Target behavior : ...

Why is this goal important?

...

How can I achieve my goal?

...

Goal (after ... months):

Initial level :



Context : 30 year-old man with traumatic brain injury, not able to estimate how much time he needs to get ready, late for rehabilitation appointments if not stimulated

General goal : to be on time for appointments

Specific goal : to learn using Smartphone alarms to prompt getting ready for appointments

Target behaviour : setting adequate alarms on his smartphone

Why is this goal important?

I do not feel comfortable being late, nor do I feel comfortable always being prompted by my caregivers to avoid being late

How can I achieve my goal?

By learning how to use Smartphone alarms

I have set realistic alarms for all rehabilitation appointments (12 out of 12 appointments scheduled per week).

Goal (after 6 months): I have set realistic alarms (for example, alarms with sufficient time ahead of target time which allows to getting ready and time for travel) for half of the rehabilitation appointments (5-7 out of 12 appointments scheduled per week)

Initial level :

I am always late for rehabilitation appointments, I do not anticipate the time needed to get ready and time needed to arrive to the rehabilitation room



Context : 7-year-old girl with spastic quadriplegia
General goal : to improve independance in selfcare
Specific goal : to go to the toilet
Target behavior : sitting on the toilet and wiping

Why is this goal important?

I woud like to be able to go to the toilets at school, with the help of my school assistant

How can I achieve my goal?

By receiving Botulinum toxin injections in the hip adductors, stretching my spastic muscles, using grab bars and wearing adapted clothes

I need help to transfer but can manage the toilet alone. I have sufficient hip abduction to avoid wetting my clothes and to wipe myself.

Goal (after 4 months):

I can be left alone on the toilet, but require an adult to maintain sufficient hip abduction in order to be able to wipe myself

Initial level :

I cannot be left alone on the toilet. I require an adult to maintain sufficient hip abduction, so the urine does not wet my clothes.



Context : 9-year old girl with spastic quadriplegia

General goal : to be part of leisure activities with her schoolfriends

Specific goal : to ride a horse

Target behavior : horseback riding with her educators, once a week.

Why is this goal important?

This activity is meaningful for me, I would be very happy if I could be part of it with my schoolfriends

How can I achieve my goal?

By receiving Botulinum toxin injections, stretching my spastic muscles, training my goal

I can ride a horse with normal-positionned stirrups and sit comfortably on the horse's back.

Goal (after 4 months): I can ride a horse but the stirrups have to be placed higher to allow the important knee flexion accompanying the hip abduction

Initial level : I cannot ride a horse because of hip adduction and hamstrings spasticity that do not allow sufficient leg opening (too painful even with stirrup adaptations).



Context : 16 year-old girl, acquired paraplegia, lives with her parents
General goal : to increase independence in personal care
Specific goal : to be able to go alone to the toilet
Target behaviour : to move from wheelchair to toilet and back

Why is this goal important?

I used to visit and sleep at my friends quite often, I want to be independent (and the toilet may be higher than my wheelchair)

How can I achieve my goal?

By training my balance, and strengthening my upper-limbs.

I move alone from wheelchair to toilet even if there is up to 20 cm difference between the two seats

Goal (after 2 months): I move alone from wheelchair to toilet if there is no difference of height between the two seats

Initial level : I need a transfer board, and physical assistance for legs to move from wheelchair to toilet.



Context : 45 year-old man, traumatic brain injury, lives alone
General goal : to improve financial management independence
Specific goal : to improve management of administrative documents
Target behaviour : contact with social worker and management of administrative documents

Why is this goal important?

To maintain an income pension, avoid late payment penalties, purchase of a new home, additional resources etc...

How can I achieve my goal?

By attending appointments with social worker; preparing documents prior to appointment; managing independently what is possible; seeking appointment in case of difficulty

I manage administrative documents alone and am up to date with payments.

Goal (after 6 months): I regularly go to the social worker's office to systematically review my administrative difficulties.

Initial level : I do not manage administrative documents (unpaid invoices, health appointments...)

Appendix S2

Variability in implementation of GAS methodology

This document is non exhaustive. It presents examples of variants relating to different aspects of GAS methodology.

Due to the high heterogeneity of GAS use, research protocols could use the following chapters to clearly state which methodology is used and keep the GAS methodology uniform across the trial.

- Person setting goals :

- Therapists independently (1, 2);
- Therapist – patient informed (context of post-traumatic amnesia)(3);
- Therapist in collaboration with Patient (4–20);
- Therapist in collaboration with children and family (21–27);
- Patient set goals, therapist formulate achievement levels (28);
- Patient (29–32);
- Children alone (33);
- Parents independently (33);
- Parents with therapists or day caregivers (34, 35);
- Caregivers together with patients (6);
- Rehabilitation team (31, 32, 36, 37);
- Community-based volunteers with patient and use of eHealth app (38);

→ *Literature recommends to involve the patient and/or caregivers whenever possible in the process of setting goals*

- Types of goals set and choice of target behaviors :

- ICF Participation level (1, 4, 23, 39, 40);
- ICF Activity level (23);
- Any type of goal, with reference to ICF domains, including BSF (14, 17, 25);
- Physical activities (31, 39);
- Physical and functional goals (26, 28, 32, 41, 42);
- Skill or impairment level (19, 40);
- Life and health (activity level) goals (29, 31, 38);
- Specific domains, as for examples:
 - Challenging behavior goals (aggression, inappropriate behaviors) (20);
 - Teachers' classroom management (43);
 - Posture/Mobility, Recreation/Fitness, Self-care, Academic goals (44);
 - Activities based on bimanual hand use (24, 45);
 - Upper-limb tasks involving somatosensory cues (27);
 - Social and interpersonal skills (including communication, refusal skills, assertiveness, and empathy) (46);
 - Cognitive skills (including decision-making, critical thinking, and self-evaluation) (46);
 - Emotional coping skills (including stress management and increasing an internal locus of control) (46);
 - Maintaining caregiver's own health (47);
 - Work activities (31).

→ Literature tends to promote the use of GAS for activity and participation ICF levels, not for body structure and function level, for which other more validated measures exist. GAS are encouraged to be a functional measure of daily life, not an impairment measure.

- Number of goals set:

- Just one goal (22, 31, 48–50);
- One or several goals (3, 10, 23, 35, 42, 44, 51);
- More than one goal (7, 8, 11, 12, 34, 52);
- 2 goals (16, 18, 20, 30);
- Up to 3 goals (17, 25, 29);
- 3 goals (15, 21, 22, 26, 31–33, 53);
- 3 goals, description of only one goal (24);
- 4 goals (39);
- 3 to 5 goals (4, 5, 14, 43);
- Maximum of 4 goals (1, 19);
- 5 goals (28, 39);
- Between 1 to 7 goals (54).

→ Most authors limit GAS use to 3 to 5 goals, to keep the person involved in each of them, even if more GAS scales can be written for subgoals.

- Pre-intervention (or initial) level:

- Always -1 (4, 19, 20, 34, 38, 39, 50);
- Always -2 (1, 5, 10, 14, 16, 23, 25, 26, 31, 32, 36, 42, 44, 55, 56, 57);
- Always -3 (31, 32, 36);
- Initial level depending on the possibility of aggravation : -1 if aggravation is possible or -2 if aggravation is not (11, 21, 51, 58, 59);
- -1 if the goal is to improve a current state and 0 is the goal is to maintain the current state (47);
- Any level (28).

→ If GAS is used in a group study, GAS score interpretation seems easier if all patients start from the same level to ensure they have the same number of possible ordinal categories for progression, and that groups are comparable on GAS pre-intervention score. If patients may start from -1 or -2, group comparability regarding their GAS before intervention should be provided. If T-scores are not used, Steenbeek's method of starting always from -2 and scoring worsening as -3 seems the best option.

- Assessment methods:

- Objective performance on pre-identified target behavior measured by therapist (55, 60–63);
- Objective performance on pre-identified target behavior measured by caregivers or proxies (64);
- Objective performance on pre-identified target behavior measured by technology devices
- Subjective perception of therapist regarding patient's performance (based on interviews) (65);
- GAS as a patient reported outcome measure, based on self-measured behaviors (measured for ex. by apps, diaries...)
- GAS as a patient reported outcome measure, based on patient/family's subjective perception of goal attainment (identified during interviews) (25, 47, 54, 66).

→ GAS based on objective measures makes it a more reliable outcome measure (67). If goal attainment cannot be measured objectively, self-measures of performance can be used, rather than retrospective perceptions collected through interviews.

- Number of GAS levels described :

- Only 2 levels described, Turner-Stokes GAS-light approach(68)
- 3 levels described (54);
- Full description of all 5 GAS levels (29, 65, 69);
- Full description of all 6-level scale (with -3 in case of deterioration) (55, 63, 70).

→ The number of levels described may impact intra- and inter-reliability. Studies exploring the reliability of the different methods are necessary.

- GAS scoring methods :

- T-score[31];
- Mean GAS score (75);
- Median GAS score (61, 61, 70);
- Raw scores i.e. GAS levels treated as ordinal categories (16, 24, 27, 34, 44, 50, 54, 63, 66, 76);
- Scored as number of ordinal categories improvement: 0 = no change; + = 1 scale improvement; ++ = 2 scale improvement; +++ = 3 scale improvement (77).

→ Statistical analysis must take into account that GAS are ordinal data, and equidistance of levels cannot be totally obtained. The proposition of calibrating GAS by Rasch analysis is to our knowledge not currently used, because authors promote GAS as a highly personalized measure

- Person scoring GAS :

- Treating therapist (3, 14, 16, 26, 27, 31, 35, 74);
- Independent rater (24, 30, 32, 33, 51, 78);
- Patient alone (29, 36, 49, 66);
- Patient and parent in collaboration with an independent rater (22);
- Therapist from family reports (23);
- Patient and therapist/physician (6, 52, 65);
- Different raters (and scores) for each goal (79, 80).

→ In research, an independent blinded rater is recommended; in clinical practice, scoring GAS in collaboration with therapist and patient/family allows a broader view on how goal attainment is perceived (especially if the GAS is not based on an objective measure).

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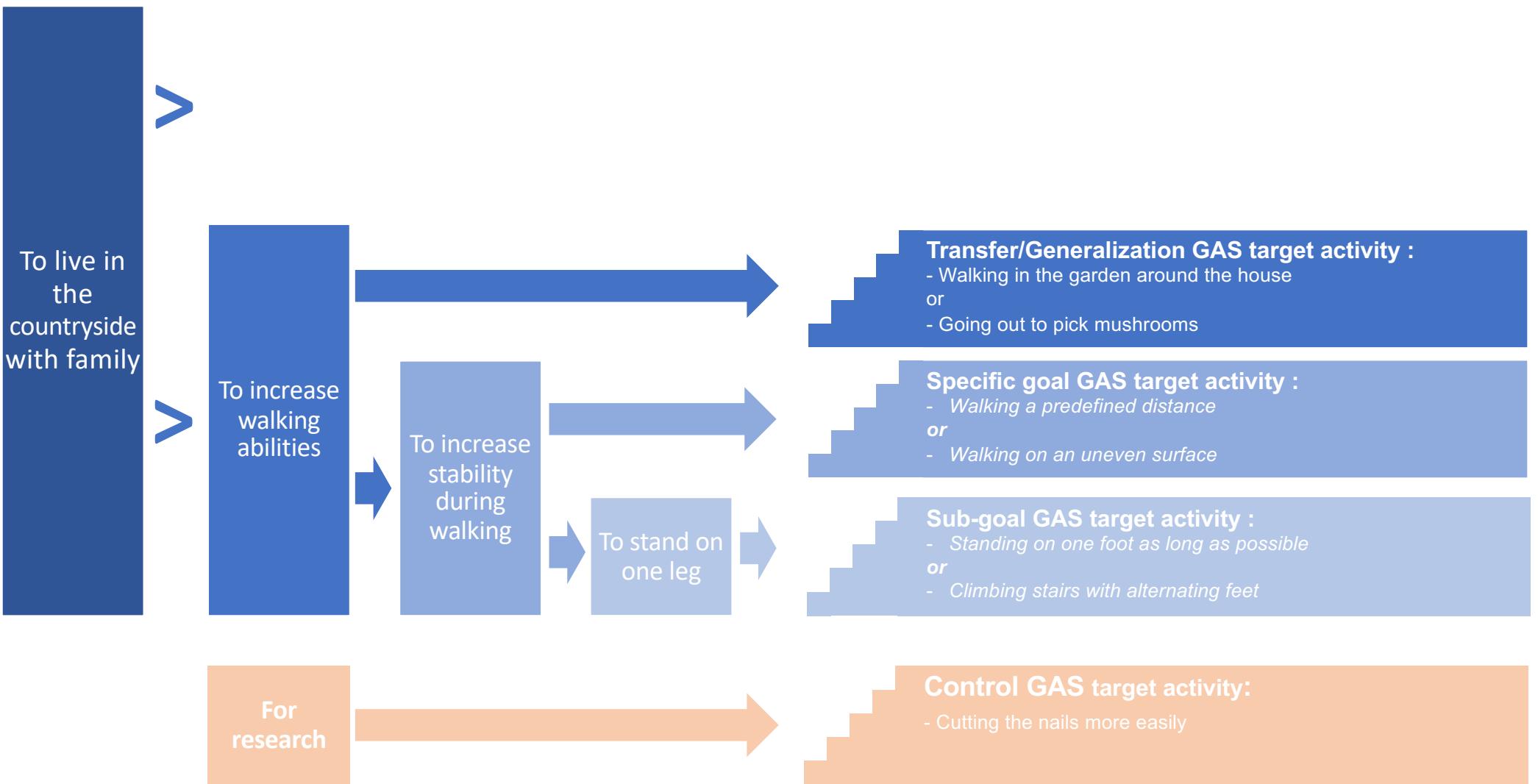
Appendix S3

Different types of goal attainment scales can be set for one general goal for one patient.

Figure 3 presents a conceptual framework for the different types of goals, that could be (or not) declined in a goal attainment scale. A life goal can not be defined and measured with a time-limited scale, but main goals should be in line with the life goal. Main goals can sometimes be directly declined into scales, or may need to be specified before being defined into a scale, or even may sometimes need to be divided in subgoals.

Control GAS are specific for the research context.

Here are examples of application of this conceptual framework.



To be able
to manage
my daily
life
independ-
ently



To improve
the manage-
ment of my
daily
schedule



To improve
the manage-
ment of
appointments
at the
rehabilitation
centre



To use aids
(alarms...)



Transfer/Generalization GAS target activity :

- Managing appointments with friends, meetings at school, or medical appointments alone

Specific goal GAS target activity :

- Attending appointments at the Rehabilitation Centre

Sub-goal GAS target activity :

- Systematically recording appointments in an agenda
or
- Using smartphone alarms

For
research



Control GAS target activity:

- Synthesizing a text