KING'S College LONDON

Setting and implementing patient-set goals in palliative care

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The Dunhill Medical Trust

OACC

Collaboration for Leadership in Applied Health Research and Care South London (CLAHRC South London)

Cicely Saunders International
Better care at the end of life

Contents

Acknowledgements

This work was supported by:

- The Dunhill Medical Trust [grant number: R423/0515]
- Cicely Saunders International
- CLAHRC South London
- Leonor Marques, who contributed towards the staff consultation on goal setting

Participating Hospices:

Lots of learning within this booklet took place within a research project.
We thank the following hospices that contributed by recruiting participants:

- Hospice in the Weald
- LOROS Hospice
- Marie Curie Hospice Hampstead
- Marie Curie Hospice West Midlands
- Pilgrims Hospice
- Royal Trinity Hospice
- St Andrew's Hospice
- St Christopher's
- St Joseph's Hospice
- St Margaret's Hospice

Introduction

This resource provides guidance on goal setting in the context of palliative care. It is one output from a multi-site study looking at goals within hospice rehabilitation services. We envisage that it may be useful to anyone interested in providing or supporting rehabilitation in palliative care, across all settings.

Goal setting in palliative care

People living with advanced disease want to live well despite their condition and related symptoms. When asked 'what matters?' patients and family members often reply:[1-3]

- Continuing with important life roles and usual routines.
- No longer feeling 'who I once was'.
- Being able to perform daily activities independently.
- Adequate symptom relief and a sense of control.
- Maintaining dignity.
- Maintaining a sense of humour.
- Sharing time with friends and family.
- Not being a burden to others.

The things that matter to people go far beyond the physical impact of their condition. They also highlight the role of rehabilitation, which aims to maximise function, independence and choice. We believe rehabilitation is a key part of expert multidisciplinary palliative care whatever the diagnosis or prognosis.

In rehabilitation practice, goal setting is often used to understand what matters to people receiving care. Goal setting helps make clear what patients want to achieve, so that rehabilitation can be directed in a manner that reflects patient priorities. Goal setting also helps team working, as it underscores how each person, profession or discipline involved in someone's care is working towards the same purpose.[4]

Benefits of using goal setting

Goal setting offers several potential advantages for rehabilitation in palliative care.[5-7] It is often already part of routine clinical practice in rehabilitation or therapy teams. Building on this already established process can help:

- Enhance communication and collaboration between the multi-professional team who are striving towards the same patient-led goal.
- Improve patient involvement - there is evidence that goal setting has positive value in empowering the patients to reach their goals.[6]
- Direct individual patient care towards the most appropriate services and treatments.
- Support reflective learning for both patients and professionals, especially when thinking through the working process of goal setting and achievement.

Goal achievement can also be used to assess meaningful benefit from rehabilitation services in palliative care. Evaluating goal achievement goes beyond, and complements, patient and family ratings of outcomes and experience.[7]

How to set goals

There are several steps in the goal setting process as follows:

Step 1: Introducing goals

When first introducing patient goals, language is very important to sensitively explore what each patient wants to achieve and why. Helpful opening questions include:

- "What matters to you?"
- "What would you like to achieve or work on?" or
- "What would you like to do that you have difficulty doing now?"

It can be useful to probe and find the meaning of a patient's goal. Start by asking questions like "why do you want to do that?" or "why is managing that symptom important to you?". For example, a patient may say they want "to be less breathless", but with some exploration it may become clear that they want to be less breathless so that they can get upstairs, use the toilet, play with their grandchildren, or walk their dog. It might be that returning to an activity is the meaning behind the goal, even though it relates to breathlessness. Rehabilitation goals should be set and owned by patients, and not the clinician. Common goal areas in palliative care involve:

- Social function (e.g. hobbies, social activities, relationships).
- Emotional function (e.g. confidence and anxiety).
- Basic or personal activities of daily living (e.g. toileting, transfers).
- Instrumental or extended activities of daily living (e.g. shopping, food preparation).
- Symptom management (e.g. breathlessness, pain, weakness and fatigue).

We believe it is important to record exactly what the patient wants to achieve word-for-word (i.e. "to dress myself"; "to get to the shop"; "to go out for dinner with friends"; "to pick my children up from school"; "to feel confident climbing the stairs"), as this helps us to remember what is important to them.

Step 2: Assessing baseline function

Once a goal area is identified, it is important to recognise the patient's current level of function in relation to their goal. This would generally be done as part of a therapy assessment. Understanding their level of function will form part of further discussions when deciding on a SMART goal together. For example, for a goal "to climb the stairs", you may want to know:

- How are they currently climbing stairs now, if at all or can they do it with help?
- How mobile are they, i.e. bed- or chair-bound, and is this likely to improve?
- What is preventing them from climbing stairs, i.e. weakness, breathlessness, pain, lack of confidence?

Step 3: SMART goal setting

Figure 1 outlines the process of converting a patient stated goal into a SMART (specific, measureable, achievable, relevant, and timed) goal statement. A goal statement will later help you to assess the achievement of the goal in a transparent manner [8]. It moves towards a goal that can be assessed against a standard. This is especially useful where a member of the team, other than yourself, may be reflecting on the goal with the patient.

The SMART goal reflects the intended outcome for each goal within an episode of care, accounting for the patients' current level of function and any negotiation with the patient. During the process of making a SMART goal, it is vital to remember what is important to the patient about the goal. Be careful to keep the meaning in the goal.

Some real examples of patient-set goals converted to SMART goal statements set in hospice services are illustrated in figure 2.

SPECIFIC

What exactly is it that the patient wants to achieve and how?

- Be exact: i.e. “to climb stairs to use the toilet”; “to be less breathless to play with grandchildren in their garden”; “to be confident showering independently”.
- How?: include whether the patient would be independent, need assistance or use of equipment, if they need to use self-management strategies or pacing etc.

MEASURABLE

What is it that you expect to change?

- This is what you expect to change within this episode of care, given the available time and resourses.
- The outcome could be recorded using a standard outcome measure, observation of a task or be patient reported. For example: ‘to improve confidence when climbing the stairs from 4/10 to 6/10 on Visual Aanalouge Scale’, or to self-report being ‘able to catch a bus to the shop once within the next week’.

ATTAINABLE

Is the goal realistic?

- This would involve discussion of the patient’s baseline level of function in relation to the goal and negociation if required, but must be agreed. For example:
  - If a patient with limited mobility of 10m wishes to “run 2 miles in the park in a month” this may become to ‘walk 50m in the park’ or to ‘jog on the spot for 2 minutes in the next 2 weeks’.
  - If a patient’s goal is “to walk better”, but mobility is limited by anxiety and it is unlikely their mobility will improve due to deteriorating health, the goal could be about ‘reducing anxiety when walking’ with less focus on the distance walked.

RELEVANT

Maintain ‘meaning’ within the goal

- It is important not to lose the meaning of the patient-set goal in transition to a SMART goal. For example:
  - If a patient wishes to “walk in the garden” but is fearful of walking outside on their own, the goal could be to ‘walk in the garden accompanied by a family member’.
  - A patient unable to climb stairs wishes to “go to bingo” where there are stairs to climb. The goal should not become ‘to climb stairs when in gym’, but ‘to be able to climb stairs in order to get to bingo’.

TIMED

Set a time-frame by when the goal should be achieved by

- Depending on the goal and the patient’s function, the appropriate time for the goal review will vary patient to patient, and goal to goal. Goals may be set for the next day, the end of the week, or several weeks / months time, or within a certain number of sessions.
- The timeframe of a goal depends on phase of illness, and is generally shorter for inpatients compared to outpatients in palliative care.
- Goals with shorter timeframes may be more achieveable than goals with longer timeframes, as the estimate of intended outcome is often easier to make.

Figure 1: SMART Goal Setting in the context of palliative care

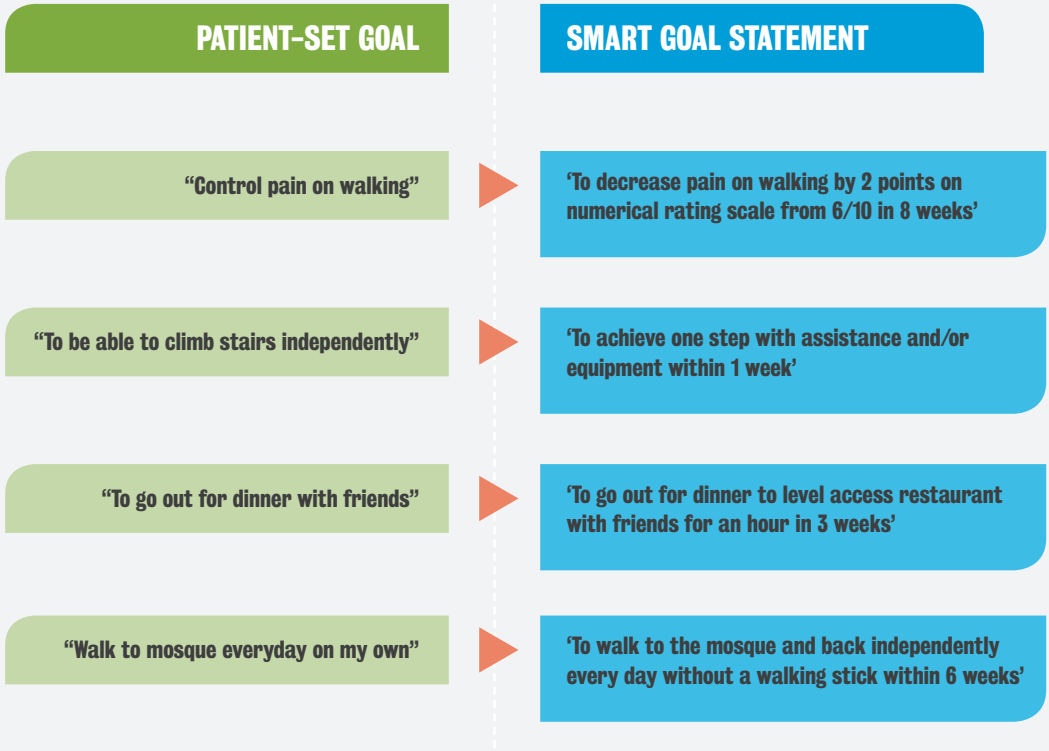

Figure 2: Examples of converting patient-set goals into SMART goal statements

Step 4: Tailored intervention

Once a goal has been set it should help to direct the intervention(s) they receive. Linking the next steps in their care to a goal demonstrates patient priorities have been valued. Care that is aligned with what the patient wants can also help improve patient engagement and satisfaction.[9]

We recommend setting and sharing the goal with the multi-professional team where possible. There may be several steps to achieving the goal, which can be documented in the patient notes. The outcome of interest is the level of achievement of the SMART goal.

"The whole multi-professional team should be involved in goal setting and enabling a person to achieve what is important to them, not just the therapy staff"

Reviewing Goals

What is Goal Attainment Scaling?

People often reflect on goals and simply consider whether they have been achieved, using a 'yes' or 'no' response. This approach is clear, but it misses important progress in people who go some way towards their goal, and does not value people who achieve their goal and continue progressing. The first point is especially important when a patient has an ambitious goal that they want to keep hold of.

Goal Attainment Scaling (GAS) is a system to review goals that:

- Considers baseline function.
- Accounts for goals that are perceived as ambitious or difficult.
- Allows recording of partial achievement and over achievement of goals.

To review goals using GAS, information about baseline function and goal difficulty is recorded alongside the patient-set goal and SMART goal, using a standardised measure, which is illustrated and explained overleaf. It is important that the measure is completed in full, as the information is used to produce a GAS score.

GAS-light is a simple version of GAS that takes less time to complete. It provides a method of scoring the extent to which people achieve their goals, reflecting treatment intent.[4] GAS-light complements standard health outcome measures. It can be used to demonstrate the achievement of important goals, which may otherwise go unrecorded.[10] It avoids some of the problems of global outcome measures, including floor and ceiling effects, and poor sensitivity to change.[6]

To assess goal attainment, GAS-light uses a 6-point verbal rating scale that reflects the way goals are usually recorded in practice.[6] Patients and clinicians review whether the goal was:

- Achieved a lot better than expected.
- Achieved a little better than expected.
- Achieved as expected.
- Partially achieved.
- No change in function relating to goal.
- Worse function relating to the goal.

> **"GAS makes goal setting more quantifiable and can make it easier sometimes to demonstrate or measure outcomes across various domains (e.g. function, symptom management, quality-of-life, etc.)"**

"I found reviewing goals regularly very important as people's conditions fluctuated and often disease progressed"

The GAS-light measure

GAS light measure

Patient stated goal	Baseline function *(Describe current level of function in relation to patient stated goal – use this information to negotiate the SMART goal with the patient)*	SMART goal *(specific, measurable, attainable, relevant, timed)* AND Difficulty achieving SMART goal *(professionals perception)*
	☐ Some function ☐ None *(as bad as can be)*	Date Set: …… ☐ Not difficult ☐ Minor difficulty ☐ Moderate difficulty ☐ Extreme difficulty

Explanatory notes

This is exactly what the patient says	This is the patient's current function in relation to the goal	Record SMART Goal statement and level of goal difficulty as perceived by clinician
For example: • "To have a shower". • "To pick children up from school". • "To use toilet on my own". • "Walk to shop".	For example: • For a goal about "walking better" this would relate to the person's mobility. • For a goal about "being able to feed independently" this would refer to the person's upper limb function and ability to feed themselves. Tick 'some' or 'none' function in relation to the goal. For example if the goal is "to walk to the park" or "climb the stairs": • Tick 'some' function if they are currently walking outside or if they can climb at least one step. • Tick 'none' function if they are not currently walking outside or not managing any steps, even if they are mobile indoors or on the flat.	• This is the agreed goal following negotiation with the patient, which has been made SMART (see SMART goal setting). • It is important these remain patient-set goals and should not be changed to suit the clinicians expectations if the patient does not wish to compromise. • Depending on the person's current level of function, rate the goal as 'none', 'minor', moderate' or 'extremely' difficult. • This comes in useful when a patient does not agree to adapt their goal according to their baseline level of function. • For example: 'To climb a flight of stairs' may be 'extremely' difficult for a bed bound person in the deteriorating phase of illness, but of 'minor' difficultly for someone who is independently mobile with slight breathlessness and in the stable phase of illness.

Outcome measure *(state outcome measure tool or alternative used (i.e. observation) and record outcome at goal setting (pre) and goal attainment review (post))*	**Achieved** *As expected = achieves goal as expected, partially achieved = some improvement but goal not achieved, same as baseline = no change, a little better = achieved more than the goal, much better = over achieved goal)*	**Variance** *(Describe achievement if differs from expected and give reasons)*
Tool: (Pre/post score)	☐ Yes: ☐ Much better ☐ A little better ☐ As expected ☐ No: ☐ Partially achieved ☐ Same as baseline ☐ Worse	Date: .....
This is the method of measurement used to review the goal	**Record level of goal achievement via tick boxes**	**This is an explanation of why the goal was not achieved as expected or overachieved**
• For the tool, it is optional to fill in this section, but helps with the formation of the SMART goal • A standard outcome measure (for example a walking test or symptom questionnaire) may be appropriate to use • Observation of a person or a rating using a numerical rating scale or visual analogue scale may also be useful • The pre score referes to a person's baseline level of ability and the post score refers to their level of ability or score at goal review	• Tick 'yes' or 'no' to whether they have achieved their goal. • Tick 'worse' if they are worse than before, deteriorating or have died (unless they achieved their goal before they deteriorated/ died). • Tick 'same as baseline' if there has been no change. • Tick ' partially achieved' if they have not achieved the goal but are better than before. • Tick 'as expected' if the goal has been achieved exactly as it was written in the SMART goal. • Tick 'a little better' if they achieved the goal slightly better than expected (i.e. if the goal was 'to manage stairs with assistance', but they can do them independently). • Tick 'much better' than expected if they achieved the goal above and beyond what was expected (i.e. if a goal was 'to walk to the next room once in one week' but they manage to walk to the local shop several times).	Explain why the person has over- or under-achieved on the set SMART goal. Include: • what they are able to do now. • whether they have deteriorated, died, or improved unexpectedly. • if they have got any new symptoms. • if they did not attend or declined rehabilitation.

"The goal setting process was helpful and I found it beneficial for staff and patients"

Goal Attainment Scoring

The information collected in the standardised GAS-light measure can be transformed numerically using a free online calculator to produce a GAS t-score (see Resource section). The verbal rating scale is converted onto 5-point numerical scale (-2 to +2), depending on their baseline rating as shown in figure 3.

One or several goals can be registered for each patient. The calculator will produce a t-score (ranging from 0 to 100) that takes into account the characteristics and level of attainment for each goal.[5]

As a reminder, GAS-light is conceptually different from standardised outcome measures – it does not measure a change in health status, but the achievement of patient goals.[6] The goal itself is the most important determinant of attainment.

- A typical GAS t-score after treatment is 50. This shows goals were generally realistic but challenging enough.
- If the score is much higher than 50, this might mean the goals are either too easy or the patients function has improved unexpectedly.
- If the score is lower than 50, this means that the goal is either too challenging, or the patient has deteriorated unexpectedly. It may also mean they did not attend for rehabilitation for whatever reason.

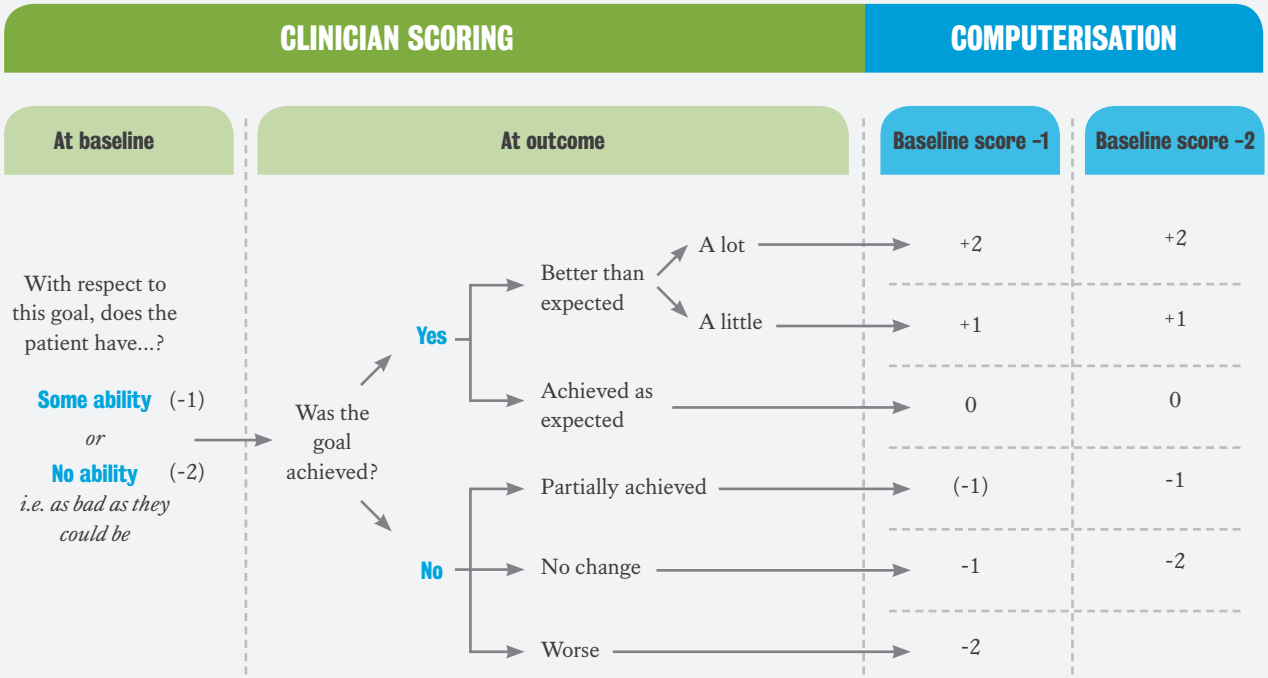

Figure 3: Algorithm for converting verbal ratings into a 5-point goal attainment score

Implementation

Who can use it?

Any member of the multi-professional team can use GAS. Specific training focussed on communication, SMART goal setting and goal negotiation is recommended.

Negotiating goals is especially challenging in deteriorating patients or patients with an uncertain prognosis. It is also sometimes challenging, due to:

- Clinical inexperience (e.g. limited insight into what may be appropriate or achievable).
- Patients' lack of insight or acceptance of their condition.
- Patients lack of understanding of goals or what is proposed to them.

If a goal requires rehabilitation, this should be delivered or guided by the rehabilitation team.

How long does it take to use?

Goal setting is often part of the initial therapy assessment, where discussing and negotiating goals is common practice [11]. Formalising the usual goal setting process using GAS-light should only take an additional 5 to 20 minutes of staff time. The measure itself does not need to be completed with the patient but the information needs to be gathered within the initial assessment. In our experience this is time well spent and is offset against gains that the person gets from the service.

When to use it?

Goal setting and GAS can be used when a patient has an identified rehabilitation goal.

The existing Outcome Assessment and Complexity Collaborative (OACC) core outcome measures can be used to identify these points:[13]

- Phase of Illness: patients in the stable (or stabilised from another phase) or deteriorating phase (unstable symptoms usually need to be addressed prior to goal setting).[14]
- Australian-Modified Karnofsky Performance Status: score of between 20% - 80% or a reduction in score, which is limiting participation in activities of daily living, work, social life or society.[15]
- Integrated Palliative Care Outcome Scale (IPOS) symptoms:[16] patients affected by the following symptoms which is limiting their function:
  - Pain.
  - Breathlessness.
  - Weakness or lack of energy.
  - Poor mobility.
  - Low mood.
- Integrated Palliative Care Outcome Scale (IPOS) main concern: patient identifies a concern such as problems with mobility or a functional activity, (e.g. to shower independently, be less of a burden on family, wish to go home, walk the dog etc.), which may be possible to address with rehabilitation.

> **"The increase in time and documentation is worth it to have a robust, individualised outcome to demonstrate value and impact"**

Figure 4: The where, when, and how of goal setting in palliative care

More information on the OACC suite of outcome measures and the Palliative Care Outcome Scale can be found in accompanying resources.

Other factors to take into consideration are that patients should be able to engage in the goal setting process and should not be in a very distressed or emotional state. Remember that goal setting involves thinking and talking about the future.

A review of the SMART goal statement will take place at an agreed time point, which will differ case-by-case. New goals may be set if the patient enters a different rehabilitation service (new episode of care) or there is a change in the core OACC measures.

Where and with whom to use it?

Goal setting and GAS can be successfully used in all palliative care settings. Based on our experience, Figure 4 illustrates how the population, goal area and timeframe, and therapy intervention and delivery, may vary between the inpatient, outpatient and community settings.

In all settings, goal attainment can be affected by other factors outside of your control, for example:

- Other patient priorities or commitments, e.g. hospital appointments, family events.
- Speed of deterioration or change of Phase of Illness.
- Family and carer support.
- Staff time.
- Availability of external services, e.g. equipment provision.

Some settings have specific challenges, which are important to consider prior to implementing SMART goal setting or using GAS.

In the inpatient setting, it is important to engage the wider multi-professional team to help identify and work towards patient-set goals. Therefore, education and training for the wider multi-professional team prior to using GAS helps to get everyone on board to increase chances of success.

In outpatients and the community, long service delivery times mean the goal timeframe and intended outcome may be some way into the future. It is important to remain focused on the patient-set goal, and not make the SMART goal more challenging to fit reviewing the goal with usual service delivery. For example, if the patient has joined a 10-week course, but you feel their goal can be achieved in a few weeks, then try to review it at this point. If reviewing goals / patients in person more regularly is not feasible, consider using self-reported progress by phone.

> **"I can see huge benefits of introducing the concept of goals beyond therapy services"**

Resources

If you are interested in learning more about goal setting and GAS, the resources below and the reference list are good places to start. GAS is just one approach to setting and reviewing goals. Other approaches may be equally or more useful to your practice.[7]

- Rehabilitation Goal Setting: Theory, Practice and Evidence:[12] Seminal text book on goal setting intended to help every team member in their day-to-day work.
- The Cicely Saunders Institute website: https://www.kcl.ac.uk/nursing/departments/cicelysaunders/index.aspx Under 'Resources' search for
  - GAS: Information and links to published papers on GAS and GAS-light, including the GAS-calculator and information on training.
  - OACC: Information and links to the Outcome Assessment and Complexity Collaborative (OACC) Suite of Outcome Measures.
- The Palliative Care Outcome Scale (POS) website is a resource for palliative care practice, teaching, and research: https://pos-pal.org

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Registering with OACC

The OACC project team collaborates closely with clinical teams enrolled in OACC to achieve and monitor the implementation of outcome measures into routine clinical care. It is important that they are chosen, implemented and used in an evidence-based way. OACC therefore draws on existing psychometric study of outcome measures in palliative care, and believes that strong academic and clinical partnerships help provide solutions to many challenges faced in implementing outcome measures. Launched in 2013 and led by the Cicely Saunders Institute and Hospice UK, we welcome you to contact us if you would like to become an OACC-registered service or if you would like further information about what we offer and how we can work with you to achieve better outcomes for patients and families.

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