LA TROBE UNIVERSITY

HEALTHY END OF LIFE PROGRAM

HELP Evaluation Framework

A public health palliative care approach to evaluation based on the Healthy End of Life Program (HELP) Framework

August 2020

About La Trobe University Public Health Palliative Care Unit

The Unit engages in research practice and partnerships that promote healthy dying and invite civic participation. It seeks to build capacity and resilience in communities around dying, death and bereavement.

At the Unit we:

- Focus on the social determinants of healthy living and dying
- Work with community assets to design and implement system and practice change
- Promote inclusive partnerships and sustainable outcomes

We offer:

- Consultancy to and research with community and organisational partners
- Resources to develop community and organisational capacity
- Education through degree coursework and supervision for Higher Degrees

The Healthy End of Life Program (HELP) is a major area of work for the Unit. The Program is led by Andrea Grindrod who is a Council member of Public Health Palliative Care International. This document was produced by HELP team members Emma Sayers, Wendy Dagher and Kelly Gourlay.

For more information visit www.latrobe.edu.au/pcu

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1. Purpose of this document

The purpose of this document is to outline the Healthy End of Life Evaluation Framework (the Framework) – a public health palliative care approach to evaluation based on the Healthy End of Life Program (HELP). The Framework can be applied to any project or initiative that aims to implement a public health approach around end of life matters, including caring, dying, death, grief, and loss. It is complementary to, and can be integrated with, any specific reporting required by organisations or funding bodies.

The Framework is designed to work with common types of project data including data that will be collected as part of standard processes in project delivery. This avoids the collection of data that is only being used for one purpose. It enables the documentation of processes that are central to the projects delivery but are often not formally captured. The design of additional tools to collect specific data on each of the project elements is outside the scope of this Framework. The Framework can be used to inform the development of such tools if required.

After outlining the Framework (section 2), its components are described (section 3). Then, a hypothetical project is used to illustrate the application of a few of the components.

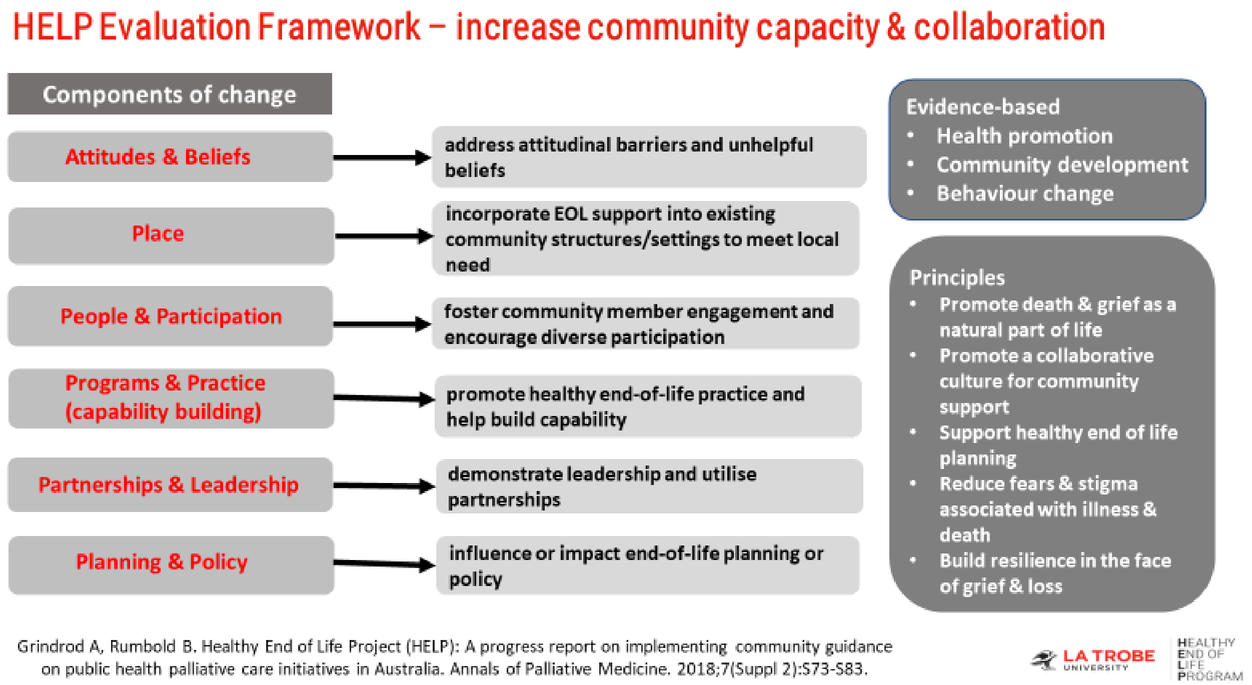
2. HELP – a public health palliative care framework

Health is more than the absence of disease and disability. A fundamental requirement for health is a healthy environment. This means strategies for health need to involve much more than providing 'health services' that focus on illness. This invites us to consider the nature of health in the last stage of life, that is, how we might achieve a **h**ealthy **e**nd of **l**ife.

Health promotion seeks to benefit and protect individual people's health and quality of life by addressing and preventing root causes. It recognises that people's choices and behaviour are shaped by social attitudes and context. The evidence from health promotion tells us that if we seek community level change regarding human health-related experiences such as ageing, dying, loss and grief, we must address the social as well as the medical. This means addressing why people behave the way they do, what motivates their behaviour and what social or environmental opportunities enable or restrict their behaviour and choices.

HELP is an evidence-based public health palliative care framework that guides implementation and evaluation (refer to Figure 1). It is based on health promotion principles and a community development approach. It outlines six major components of change that are key to success. They are both individually important and collectively critical to producing sustainable community impact.

The Framework acknowledges that change to human attitudes and behaviours around end of life is complex and takes time. The Framework accommodates multifactorial changes at both the individual and community levels, which cumulatively affect the personal and collective experience of dying, death, and grief. This involves the identification of conditions needed for change including social attitudes and context.



HELP Evaluation Framework – increase community capacity & collaboration

Components of change	
Attitudes & Beliefs	address attitudinal barriers and unhelpful beliefs
Place	incorporate EOL support into existing community structures/settings to meet local need
People & Participation	foster community member engagement and encourage diverse participation
Programs & Practice (capability building)	promote healthy end-of-life practice and help build capability
Partnerships & Leadership	demonstrate leadership and utilise partnerships
Planning & Policy	influence or impact end-of-life planning or policy

Evidence-based
- Health promotion
- Community development
- Behaviour change

Principles
- Promote death & grief as a natural part of life
- Promote a collaborative culture for community support
- Support healthy end of life planning
- Reduce fears & stigma associated with illness & death
- Build resilience in the face of grief & loss

Grindrod A, Rumbold B. Healthy End of Life Project (HELP): A progress report on implementing community guidance on public health palliative care initiatives in Australia. Annals of Palliative Medicine. 2018;7(Suppl 2):S73-S83.

Figure 1: HELP Evaluation Framework

The Framework guides the collection of different types of data from multiple sources which is a way of bolstering the validity of the evaluation findings. It also demonstrates how the same data can be used to tell more than one story of change. To demonstrate change, the Framework recommends where practicable, to collect data pre and post intervention for the purposes of comparison. As noted above, the Framework aims to maximise efficiency in data collection by emphasising the use of data commonly created or collected for project implementation.

A project will not necessarily address all components of the Framework. However, for population impact, working across all these areas is important. Working in one area alone will not produce sustainable change in community beliefs and practices.

3. HELP Components of Change

When applying the HELP Framework to a project, the six components of change each have an associated evaluation question (see Figure 2). These need to be considered across the project as a whole, and against all elements (main activities) of the project. The number and nature of project elements will vary from one project to another. Particular components of change can be emphasised depending on the nature and primary aim of the element. There is flexibility in the framework that allows different choices regarding emphasis depending on the audience and context.

Before considering the specific elements of a project, the intermediate and long term goals need to be articulated. To provide an overview of how the project goals align with the Framework, the goals may be inserted into Figure 2.

The next step is to outline each project element, the relevant evaluation question(s) and the associated types of evidence to collect. Data collection methods are also provided including how/where to source relevant data and recommended time points for collection. An example of this process as it applies to a hypothetical project is provided in section 4.

The remainder of this section is devoted to describing the six components of change.

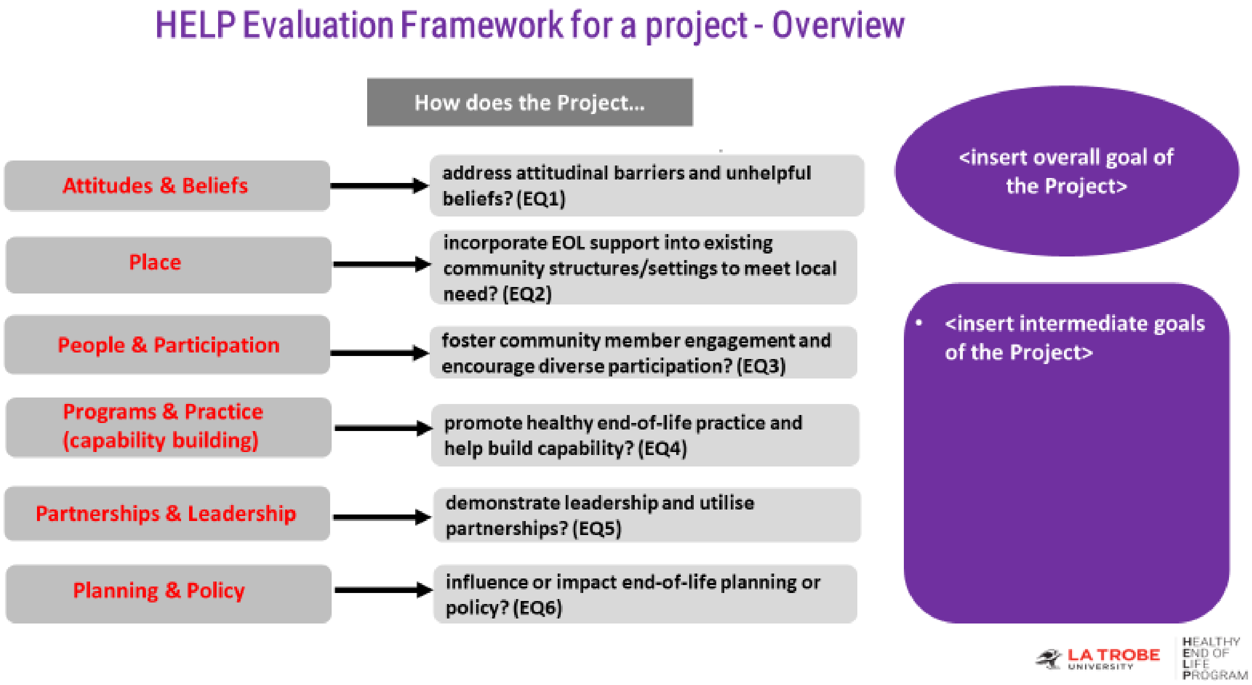


Figure 2: HELP Evaluation Framework with evaluation questions

Attitudes and beliefs

For any project, the Attitudes and Beliefs component will apply across the whole project.

People's choices and behaviour are shaped by social attitudes and context. To change behaviour a project needs to address –

- why people behave the way they do (motivation)
- what social or environmental opportunities enable or restrict their behaviour and choices

The Healthy End of Life Research Program confirmed and highlighted common attitudinal barriers in Australia impacting people with life limiting illness and those involved in their care.

Common attitudinal barriers include:

- Fear and stigma associated with illness and death
- Death and grief are a temporary disruption and life should 'get back to normal'
- Believing that formal services and the person/family are responsible for end-of-life care
    - This is underpinned by the belief that end-of-life care is primarily medical care, and a private concern
- Repositioning people with life limiting illness from patients (passive recipients of care) to community participants (active contributors)
- Reluctance to ask for help or to accept help
- Hoping for the best and not planning for the worst

How does this apply to a project?

Addressing attitudinal barriers and unhelpful beliefs is important to effecting change. Such barriers are likely to surface and potentially impact the effectiveness of all elements of a project. Based on this, the first key question for evaluation is –

Evaluation Question One

How does the Project address attitudinal barriers and unhelpful beliefs?

People and participation

The People aspect of this component is about identifying and engaging local people to connect them to support, as well as involve them in changing social attitudes and providing support to others. Participation is about ensuring that engagement includes all parts of the community, particularly people who are often excluded such as LGBTIQ people, CALD and ATSI people, refugees, people with disability and people experiencing homelessness.

Ideally project planning and design considers the need to create awareness amongst diverse population groups and the potential need to engage partners to guide and assist such as multicultural health experts, Aboriginal Health Liaison, consumer peak bodies and peer-led organisations.

How does this apply to a project?

The Project targets the population of a suburb in Melbourne, Victoria, Australia. Diverse populations reside in this area including CALD people, LGBTIQ people and refugees. In line with the local council's focus on social determinants and a public health approach, it is important for the Project to encourage diverse participation. Based on this, the third key question for evaluation is -

Evaluation Question Three

How does the Project foster community member engagement and diverse participation?

Programs and practice (capability building)

This component of the HELP framework is about designing programs that meet a locally identified need, engage local community members, and help stimulate public conversations. Programs are then supported and delivered by people who promote healthy end of life practice including emotional, social, and practical support around ageing, illness, loss, and grief. Healthy end of life practice is strengths-based and fosters choice and control through capability building.

Capability is physical and psychological. Physical capability is about physical skill, strength, or stamina. Psychological capability is about knowledge or psychological skills, strength, or stamina. Capability is not just determined by individual capacity associated with inherent personal traits. Capability is enabled or restricted by social and environmental factors and thus can be built by increasing means or reducing barriers. Means include awareness, information, education, and skills training.

To effect change at the individual and community level, it is critical to build capability amongst the different groups involved in the Project, including sector leaders, project partners, health professionals, volunteers, and the broader community. The relationship between capability and capacity is reflexive. The collective outcome of increasing individual capability within communities, organisations, and services, is to increase overall community capacity.

How does this apply to a project?

When designing and delivering initiatives for the Project, it is important to consider how they promote healthy end of life practice and help build capability. Based on this, the fourth key question for evaluation is -

Evaluation Question Four

How does the Project promote healthy end of life practice and help build capability?

Place

Place-based approaches incorporate end-of-life support into existing social and community structures and settings to meet local need (e.g. schools, businesses, sports clubs, local council, libraries, health services). This keeps community members connected to the people, places and possessions that are important to them.

Projects will be located in different environments. Each location varies in its social and structural features, which will influence the specific places and settings the project may choose to focus upon for place-based interventions.

How does this apply to a project?

Harnessing the strengths of a place and its residents is important to effecting change. This is best achieved by integrating support around ageing, dying, loss and grief, within the places that people usually spend their time. Based on this, the second key question for evaluation is -

Evaluation Question Two

How does the Project incorporate end-of-life support into existing social and community structures and settings to meet local need?

Before taking steps to incorporate end-of-life support into existing social and community structures, it is essential to undertake community asset mapping. Assets can be thought of as the ‘capital’ residing in your local area, or what resources you have to work with. The HELP program focuses on two types of assets that relate to local end of life care needs:

1. Existing – currently contributing to end of support in the local area (e.g. local hospice and palliative care services, respite services, funeral services, faith-based groups that support the end of life)
2. Potential – have the potential to incorporate end of life support into their portfolio (e.g. community organisations, businesses, clubs and services that could contribute resources and assistance to the community); creative thinking means existing resources can be used in new or novel ways to generate solutions to local issues

Community asset mapping generates lists or diagrams of assets at a given point in time. Evidence of incorporating end-of-life support into local social and community structures can be obtained from documenting changes in the number and types of assets involved in supporting the community around dying death, loss and grief. Over time, project participants will be able to identify any gaps in services or barriers to access for people in the target area.

Evidence of the identification of existing local services and supports relevant to supporting people around dying, death, loss and grief, can be found in documents and project resources (e.g. outputs of community asset mapping exercises, navigation guides, project databases, and lists generated through searching online directories).

Project participants may engage in signposting with community members. It is important to document evidence of this signposting in project records, including data such as suburb/postcode and any local services or supports suggested.

Partnerships and leadership

Leadership involves building community capacity by using existing resources, engaging partners and ensuring sustainability. Partnership is about developing local solutions through collaborations between health and community sectors. Leaders are in a position to build sector capability in end-of-life care. They have the opportunity to enhance or create relationships within and across sectors to reorient and improve care delivery.

How does this apply to a project?

Identifying and bringing together sector leaders and community champions from the health sector and other sectors in the community creates opportunities for the formation of new partnerships and the enhancement of existing partnerships. Networking and partnerships involving people with influence in the local community are key to successful and sustainable changes in responding to the community's end of life needs. Based on this, the fifth key question for evaluation is -

Evaluation Question Five

How does the Project demonstrate leadership and utilise partnerships?

Evidence of the involvement of sector leaders and community champions can be acquired by collecting stories of change. Participants could be prompted to tell stories about any changes in the nature of their relationships with other network members including experiences of improved communication, knowledge sharing or collaboration, in reference to end of life matters. Stories could also be sought about how network participants influence others within and beyond the network to adopt a public health approach to palliative care.

Other types of relevant evidence pertain to the formation of new partnerships, or the enhancement of existing partnerships. At a minimum, the basic details of the connections should be recorded (who, how many). Also, some information regarding the nature/quality of those relationships can be collected from the members of the network (e.g. asking them to indicate who they work with around end of life issues). This data should be collected pre and post network formation, and again at a later time point to capture sustainability of the relationships. Representing the relationships in the network as a series of diagrams or maps can be helpful for depicting changes throughout the Project.

Planning and Policy

Plans and policies shape the culture and environment of communities and households. They can enable or restrict behaviour, shaping the way supports/services are designed and delivered. At a community level they can – 1) shape language, conversation, attitudes, and behaviour and 2) facilitate or hinder access and participation. At an individual level they can facilitate or impede choice and control.

How does this apply to a project?

Public health approaches to end of life encourage individuals and communities to engage in advocacy for local needs. Such approaches also empower citizens to exercise choice and control over their lives, including making plans around social, medical, emotional, spiritual, and practical needs as they approach end of life. Based on this, the sixth key question for evaluation is –

Evaluation Question Six

How does the Project influence or impact end-of-life planning or policy?

For individuals, the capacity to plan is influenced by personal beliefs like 'I'm hoping for the best and not ready to think about the worst'. People also need planning information and to be supported through the process. Planning is a skill that can be developed.

A project typically needs some time to run before planning/policy barriers or enablers are identified. Also, waiting for the impact of the Project to start to become evident creates more potential leverage in advocating for policy or planning changes.

Try and identify planning or policy opportunities as they emerge. Participants may recount experiences of falling through the cracks by not meeting eligibility criteria for a government support scheme or not being able to access a service that is available in a neighbouring locality. These stories signal opportunities for policy related advocacy (local, State, or national level).

Opportunities extend beyond government policy. It can include influencing policy in settings such as residential aged care or organisations such as Councils. For example, if a Community Centre decides that all staff will participate in the community education program or a Council decides to partner with a health service to deliver free information sessions about end of life planning, that forms evidence of Planning and Policy impact.

Organisations implementing a project may participate in networks in which policy and planning issues are canvassed. We encourage Project leaders and team members to feed relevant, illustrative stories through their Managers, that can in turn be fed through to decision makers.

4. Applying the HELP Evaluation framework to a project - Community Education Program

Description of the Project

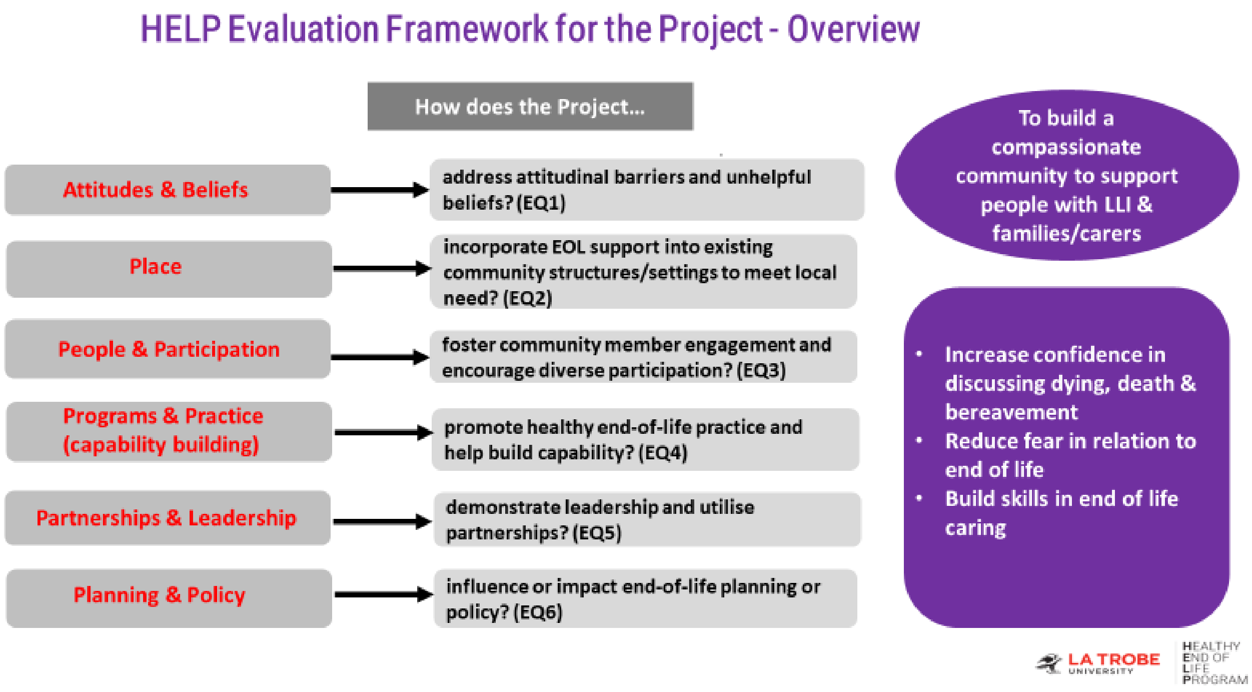
A community house based in a suburb of outer Melbourne wants to set up a compassionate community. As a first step, they have decided to host a Community Education Program (the Project). The Project is aimed at teaching people knowledge and skills about caring for someone who is dying, so they can be involved in supporting family members, friends, neighbours or others in need.

The aims of the Project are:

- To increase confidence in discussing dying, death and bereavement
- To increase knowledge of palliative care
- To reduce fear in relation to end of life
- To build skills in end of life caring (see Figure 3).

The desired long-term community impact of the Project is:

- To build a compassionate community to support people facing life limiting illness (LLI) and their families/carers (see Figure 3).



HELP Evaluation Framework for the Project - Overview

	How does the Project...
Attitudes & Beliefs	address attitudinal barriers and unhelpful beliefs? (EQ1)
Place	incorporate EOL support into existing community structures/settings to meet local need? (EQ2)
People & Participation	foster community member engagement and encourage diverse participation? (EQ3)
Programs & Practice (capability building)	promote healthy end-of-life practice and help build capability? (EQ4)
Partnerships & Leadership	demonstrate leadership and utilise partnerships? (EQ5)
Planning & Policy	influence or impact end-of-life planning or policy? (EQ6)

To build a compassionate community to support people with LLI & families/carers

- Increase confidence in discussing dying, death & bereavement
- Reduce fear in relation to end of life
- Build skills in end of life caring

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Figure 3: HELP Evaluation Framework – Overview of the Project

The contribution of the Project as a public health palliative care intervention is best demonstrated via the components of Attitudes and Beliefs (see Figure 4), as well as People and Participation, and Programs and Practice (see Figure 5).

Attitudes and beliefs

Figure 4 illustrates three types of potential evidence for addressing Question One -

- Messaging
- identification of attitudinal barriers
- Shift in beliefs/attitudes

Messaging can be found in documents (e.g. project descriptions, resources, training content) and promotional material (e.g. social media, advertisements, flyers, media interviews). The messaging should attempt to challenge common attitudinal barriers and unhelpful beliefs. Key message examples could include –

- End-of-life care is medical and social. It's not just the role and responsibility of health services
- Sustainable, high quality end of life care is not possible if one person, family, service, or sector tries to carry the load
- People with life limiting illness remain community participants (active contributors)
- Ask for/accept help without guilt, fear, or a sense of owing
- Offer/provide help for mutual benefit
- Hope for the best but also plan for the worst

Identification of attitudinal barriers can be documented in records (e.g. noted by training facilitators). Listen for comments from participants such as – 'I'm letting my family down' (guilt) and the expression of expectations that begin with 'I should…' ('I should be able to manage', 'I should be coping better').

The use of strategies to shift beliefs/attitudes can also be documented in records. Strategies could include normalising, reframing, or providing information. For example, letting people know that many people refuse help even when they need it, or think they should be able to cope on their own even when they do not expect others to do so. Even the signposting of supports and services itself helps to normalise help seeking and promote the benefits of not waiting for a crisis. In addition, the outcome of these strategies could be demonstrated via pre-post surveys and/or stories of change.

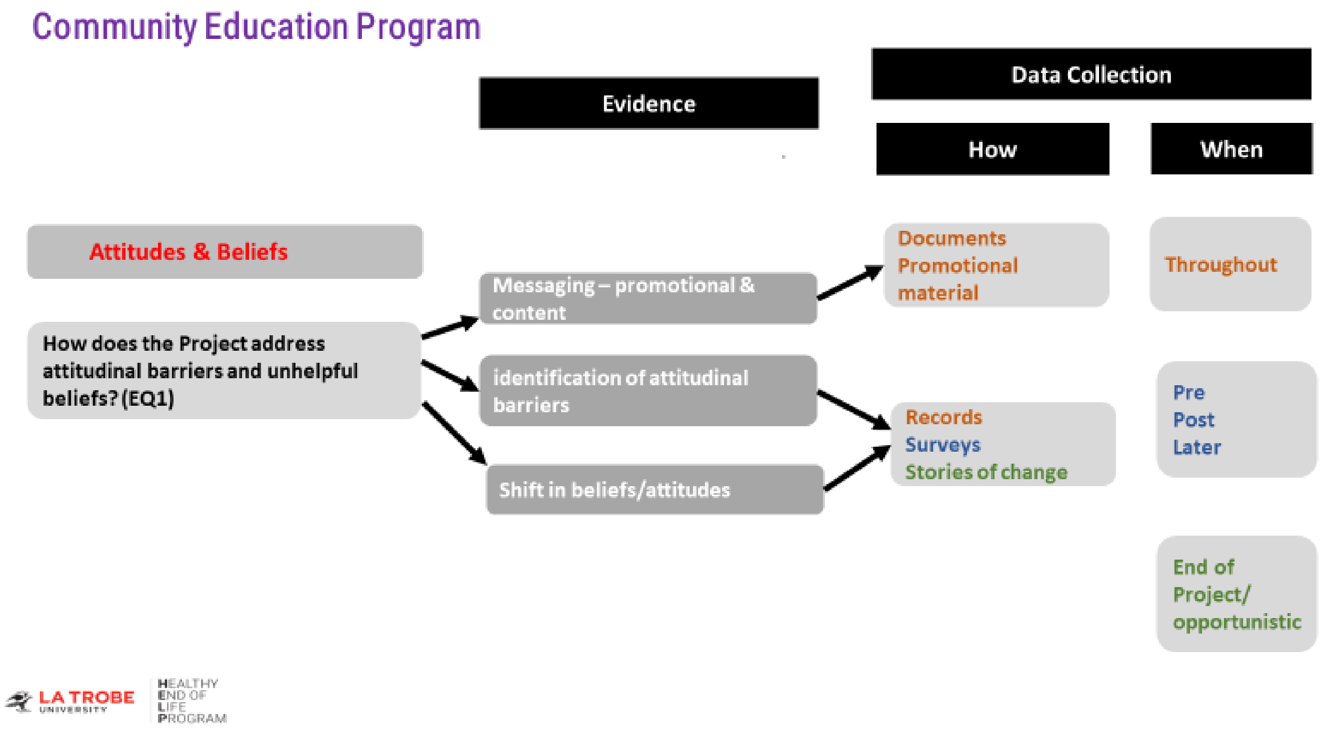

Figure 4: HELP framework – evidence and data collection relevant to all elements of the Project: Attitude and Beliefs (evaluation question 1).

People and participation

Figure 5 illustrates two types of potential evidence for addressing Question Three – inclusivity and diversity.

Evidence of inclusivity for the community education program element of the Project could be found in documents (e.g. project descriptions, resources, training content) and promotional material (e.g. social media, advertisements, flyers, media interviews).

Evidence of diversity relating the community education program could be documented in project records (participant demographics such as age range, gender, country of birth, Aboriginal & Torres Strait Islander, language spoken at home). If the assistance of a cultural advisor or translator is needed this should also be noted.

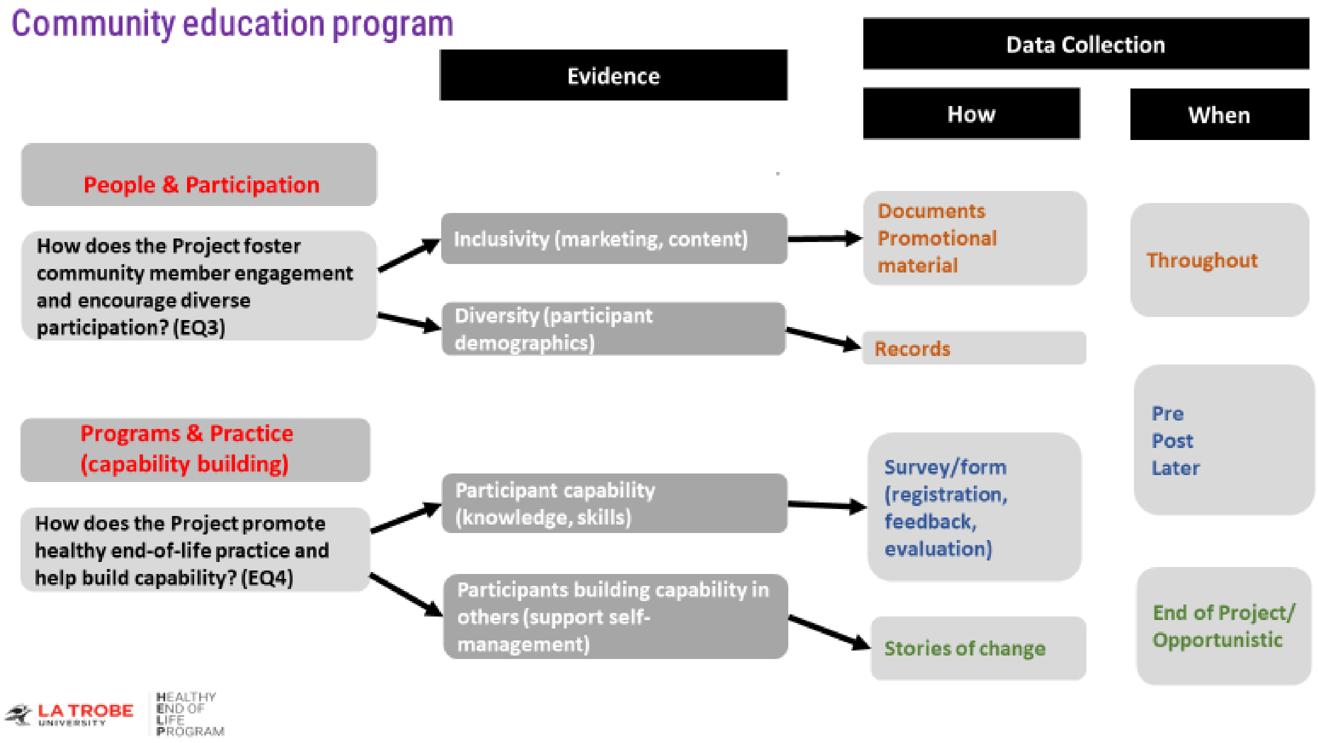

Figure 5: HELP framework applied to Community education element of the Project – evidence and data collection relevant to People and Participation (evaluation question 3), and Programs and Practice (evaluation question 4).

Programs and Practice (capability building)

Figure 5 illustrates two types of potential evidence for addressing Question Four –

- participant capability (knowledge, skills)
- participants building capability in others (support self-management).

Participant capability refers to the knowledge and skills developed by community members and volunteers who undertake the community education program. Evidence of capability building could be obtained via surveys or data collected in course registration or evaluation forms. To demonstrate change in capability, this data should be collected pre and post training, and at a later time point to measure sustainability of any changes.

It is expected that participants who complete the community education program will use their increased capability (knowledge and skills around end of life) to facilitate capability building in the community (e.g. with families, friends, neighbours, colleagues, and others). Evidence of capability being built in others could be collected via stories of change, which may include people's experiences of increased awareness or knowledge, and improved self-management.

5. Conclusion

The decision to apply an evidence based public health framework to implementation and evaluation positions any project to act as a model for others. HELP provides a comprehensive framework that maximises the capacity to tell persuasive stories of change, backed up by evidence. A reminder that community level change is complex and takes time. This framework allows the tracking of change at different levels and in different stages. Remember in public health, the process is part of the outcome.

The strength of a public health approach is its capacity to both illuminate individual experience and uncover structural inequity and systemic barriers. Organisations are encouraged to use their project evaluation findings in varied and creative ways to advocate for needed changes in their communities, and to stimulate broader discussions about public health approaches to end of life.

6. References

The ideas and recommendations outlined in this document draw on definitions/concepts and evidence provided in the following references -

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