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# Evaluating impact:

## Developing an assessment framework for online palliative care information

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Flinders University

CareSearch is funded by the Australian Government Department of Health, Disability and Ageing

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*We honour their Elders past, present and emerging.*

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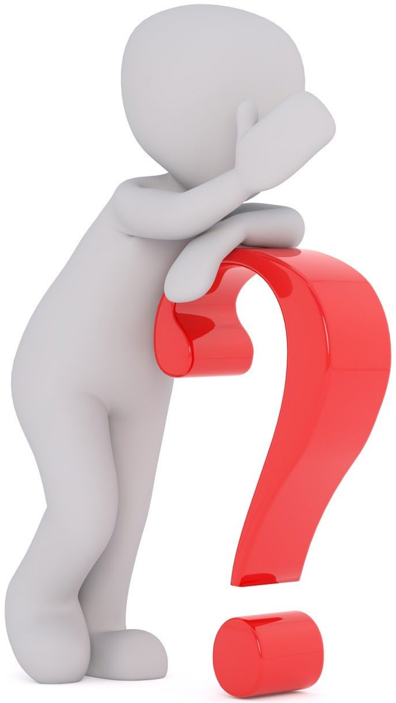
# The CareSearch context

*CareSearch provides nationally available websites to connect health professionals and the general public with trustworthy, evidence-based information and resources in palliative care.*

CareSearch imperatives:

1. Evidence (that is used)
2. Online.

But how do we know if what we do has value and makes a difference?



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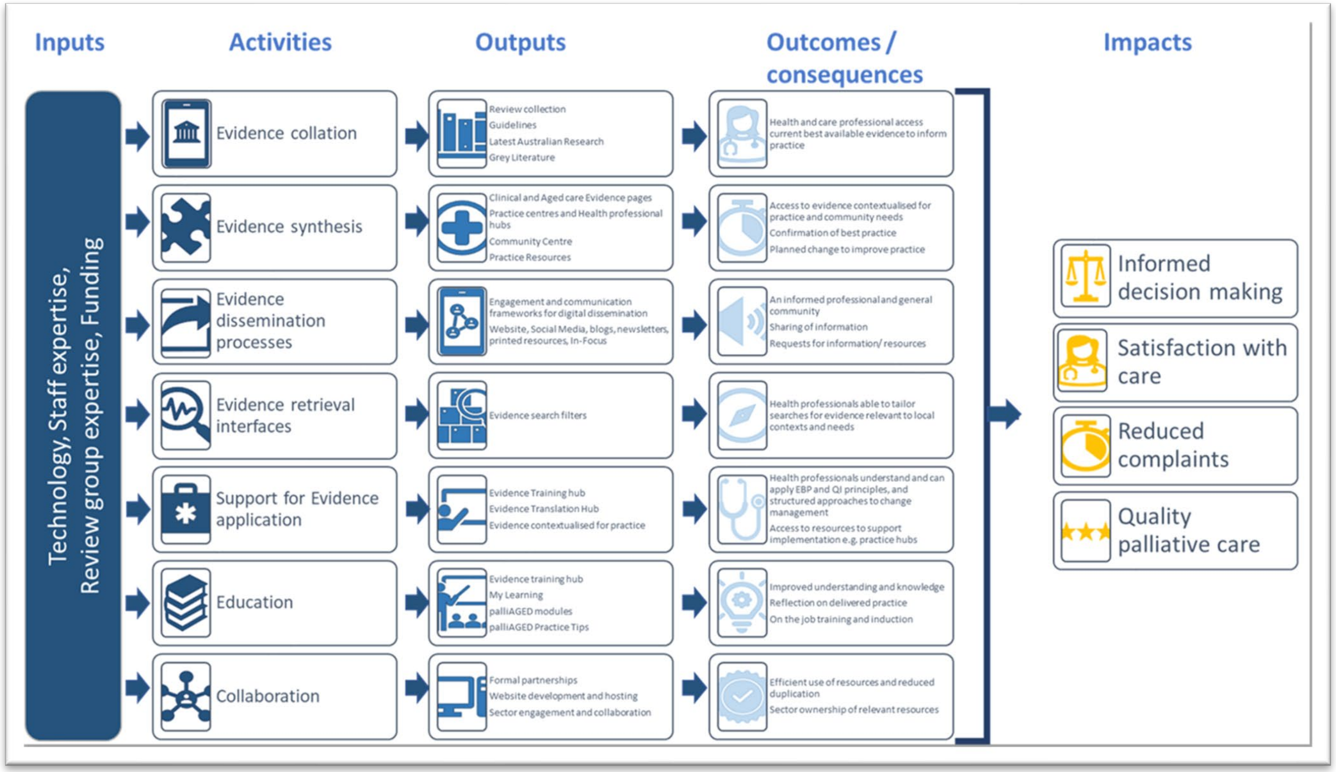
# Need for a framework

Basic: Uses "reach" as a proxy for impact, such as website hits or report downloads

Better: User feedback is used, such as surveys, citations, or mentions in policy.

Best: Quantified impact measures, such as on outcomes or money saved.[1]



# Aim of this study

To review digital translation considerations and develop a framework for assessing online health information outcomes and impacts.

Practical intent was to try and identify measures, surrogate markers, or performance indicators that could be used to demonstrate benefits arising from contact with CareSearch.

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# What we did

Internal review of existing operational and agreement documents including CareSearch Quality Processes[2], grant deliverables and KPIs, CareSearch program logic model[3]. Documentation of possible measures from this review.

Scoping review of English-language studies published since 2013 indexed in the Ovid Medline and CINAHL databases to identify and map the methods and measures used to determine the impact of online health information.

Analysis of findings and identification of success indicators from 35 completed CareSearch and palliAGED evaluation projects.

Trial mapping of 2023-2024 CareSearch including palliAGED project activities and outcomes to the Impact Assessment Framework.

CARE SEARCH

CARESEARCH QUALITY PROCESSES

**Ensuring reliability and applicability across diverse stakeholder groups**

**Authors: Erny-Albrecht K & Tieman J**
**September 2022**

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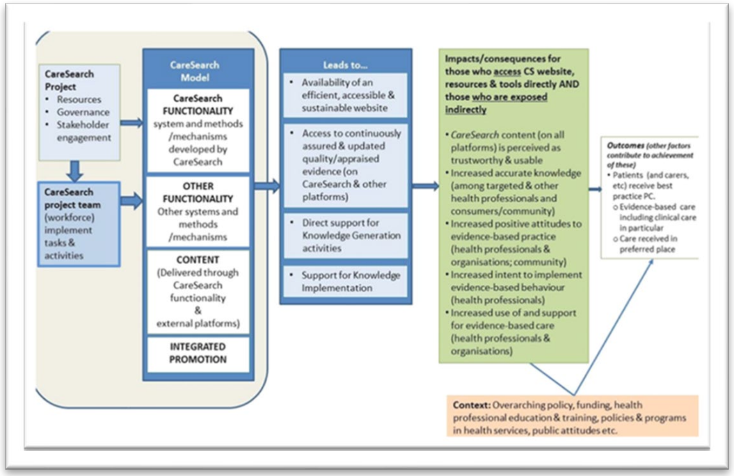


**CareSearch Project**
- Resources
- Governance
- Stakeholder engagement

**CareSearch project team** (workforce) implement tasks & activities

**CareSearch Model**

**CareSearch FUNCTIONALITY**
system and methods /mechanisms developed by CareSearch

**OTHER FUNCTIONALITY**
Other systems and methods /mechanisms

**CONTENT**
(Delivered through CareSearch functionality & external platforms)

**INTEGRATED PROMOTION**

**Leads to...**
- Availability of an efficient, accessible & sustainable website
- Access to continuously assured & updated quality/appraised evidence (on CareSearch & other platforms)
- Direct support for Knowledge Generation activities
- Support for Knowledge Implementation

**Impacts/consequences for those who access CS website, resources & tools directly AND those who are exposed indirectly**
- *CareSearch* content (on all platforms) is perceived as trustworthy & usable
- Increased accurate knowledge (among targeted & other health professionals and consumers/community)
- Increased positive attitudes to evidence-based practice (health professionals & organisations; community)
- Increased intent to implement evidence-based behaviour (health professionals)
- Increased use of and support for evidence-based care (health professionals & organisations)

***Outcomes** (other factors contribute to achievement of these)*
- Patients (and carers, etc) receive best practice PC.
  - Evidence-based care including clinical care in particular
  - Care received in preferred place

**Context:** Overarching policy, funding, health professional education & training, policies & programs in health services, public attitudes etc.

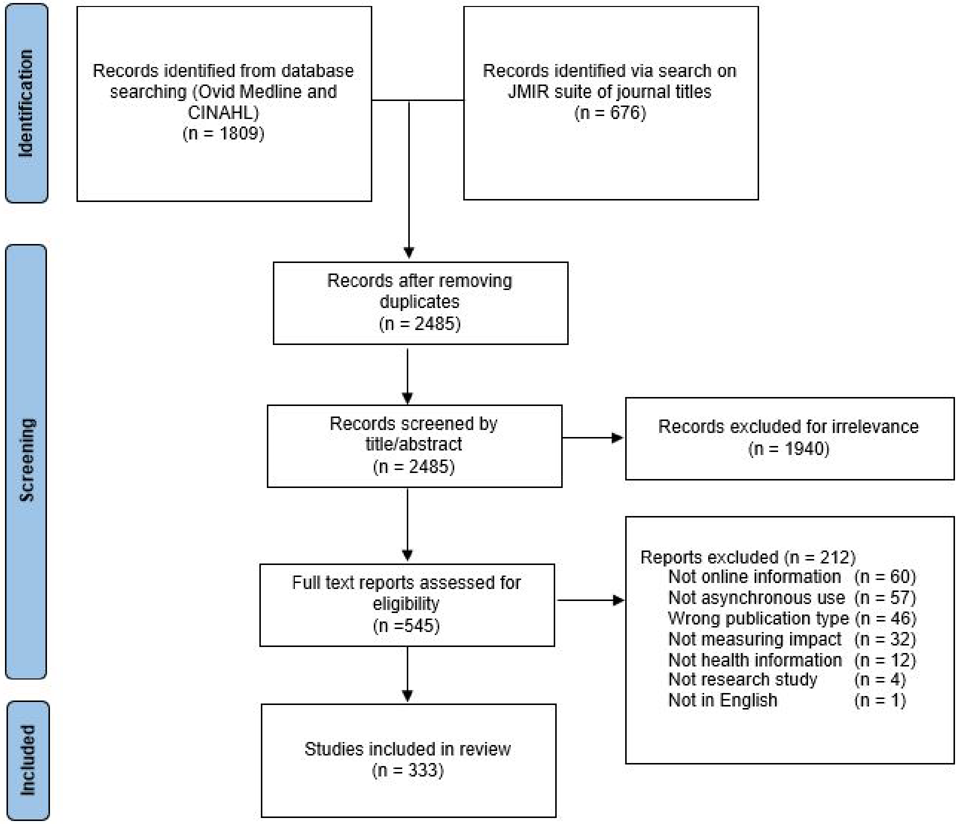
# Scoping review findings[4]

Variability in how impact was defined and conceptualised in studies.

Web metrics were a commonly reported. Still a limited evidence base around the utilisation of system data to explore engagement and outcomes.

Impact was predominately measured on a micro-level focussing on changes in behaviour (33.0%), knowledge (20.1%), attitude (5.1%) or varying combinations of the three.

Missed opportunity to understand how to identify and measure changes at meso (service) and macro (sector or system) levels.



**Identification**

Records identified from database searching (Ovid Medline and CINAHL)
(n = 1809)

Records identified via search on JMIR suite of journal titles
(n = 676)

**Screening**

Records after removing duplicates
(n = 2485)

Records screened by title/abstract
(n = 2485)

Records excluded for irrelevance
(n = 1940)

Full text reports assessed for eligibility
(n =545)

Reports excluded (n = 212)

| | |
|---|---|
| Not online information | (n = 60) |
| Not asynchronous use | (n = 57) |
| Wrong publication type | (n = 46) |
| Not measuring impact | (n = 32) |
| Not health information | (n = 12) |
| Not research study | (n = 4) |
| Not in English | (n = 1) |

**Included**

Studies included in review
(n = 333)

# Analysis of previous evaluation studies

Not all evaluation studies looked at impacts. Some were formative or reported only on activity delivery.

Studies highlighted the diverse nature of intended end users and audiences.

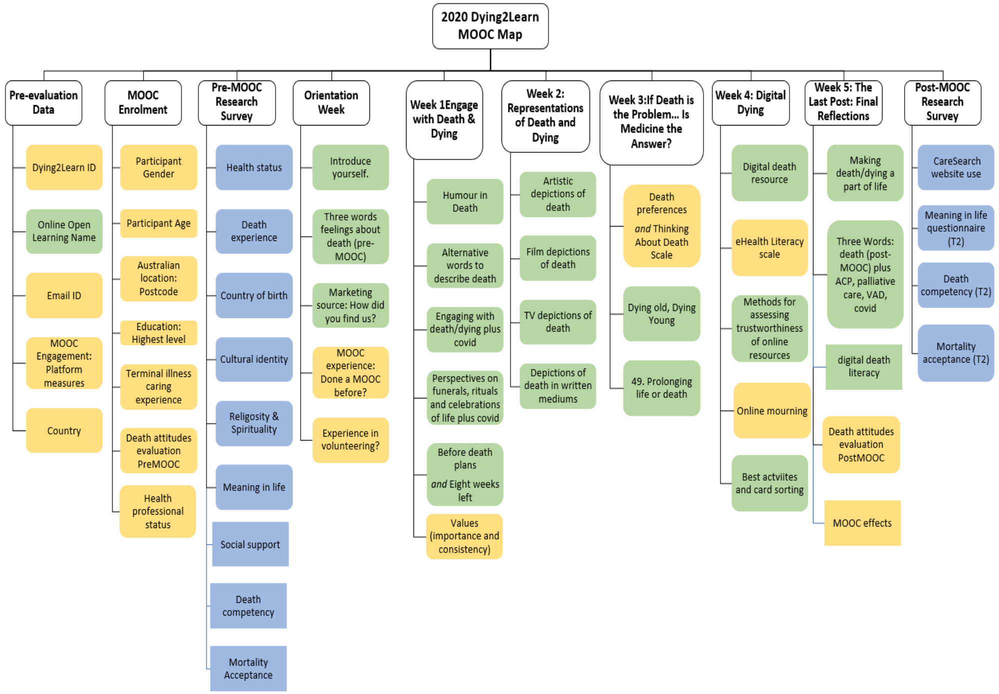
The potential contribution of system metrics to user behaviour analysis was noted.

Surveys as common form of data capture but also interviews to unpack post contact effects. Some bibliometric analysis were found.

Where possible information on practice change or service use had been considered and captured.

Investigations into registered users and partner projects provided indications of ongoing relationships - a possible measure of engagement or partnership.

Some studies enabled more complex evaluations of activity, outcome, and effects (eg Dying2Learn).



**2020 Dying2Learn MOOC Map**

- **Pre-evaluation Data**
  - Dying2Learn ID
  - Online Open Learning Name
  - Email ID
  - MOOC Engagement: Platform measures
  - Country
- **MOOC Enrolment**
  - Participant Gender
  - Participant Age
  - Australian location: Postcode
  - Education: Highest level
  - Terminal illness caring experience
  - Death attitudes evaluation PreMOOC
  - Health professional status
- **Pre-MOOC Research Survey**
  - Health status
  - Death experience
  - Country of birth
  - Cultural identity
  - Religosity & Spirituality
  - Meaning in life
  - Social support
  - Death competency
  - Mortality Acceptance
- **Orientation Week**
  - Introduce yourself.
  - Three words feelings about death (pre-MOOC)
  - Marketing source: How did you find us?
  - MOOC experience: Done a MOOC before?
  - Experience in volunteering?
- **Week 1Engage with Death & Dying**
  - Humour in Death
  - Alternative words to describe death
  - Engaging with death/dying plus covid
  - Perspectives on funerals, rituals and celebrations of life plus covid
  - Before death plans *and* Eight weeks left
  - Values (importance and consistency)
- **Week 2: Representations of Death and Dying**
  - Artistic depictions of death
  - Film depictions of death
  - TV depictions of death
  - Depictions of death in written mediums
- **Week 3:If Death is the Problem… Is Medicine the Answer?**
  - Death preferences *and* Thinking About Death Scale
  - Dying old, Dying Young
  - 49. Prolonging life or death
- **Week 4: Digital Dying**
  - Digital death resource
  - eHealth Literacy scale
  - Methods for assessing trustworthiness of online resources
  - Online mourning
  - Best actviites and card sorting
- **Week 5: The Last Post: Final Reflections**
  - Making death/dying a part of life
  - Three Words: death (post-MOOC) plus ACP, palliative care, VAD, covid
  - digital death literacy
  - Death attitudes evaluation PostMOOC
  - MOOC effects
- **Post-MOOC Research Survey**
  - CareSearch website use
  - Meaning in life questionnaire (T2)
  - Death competency (T2)
  - Mortality acceptance (T2)

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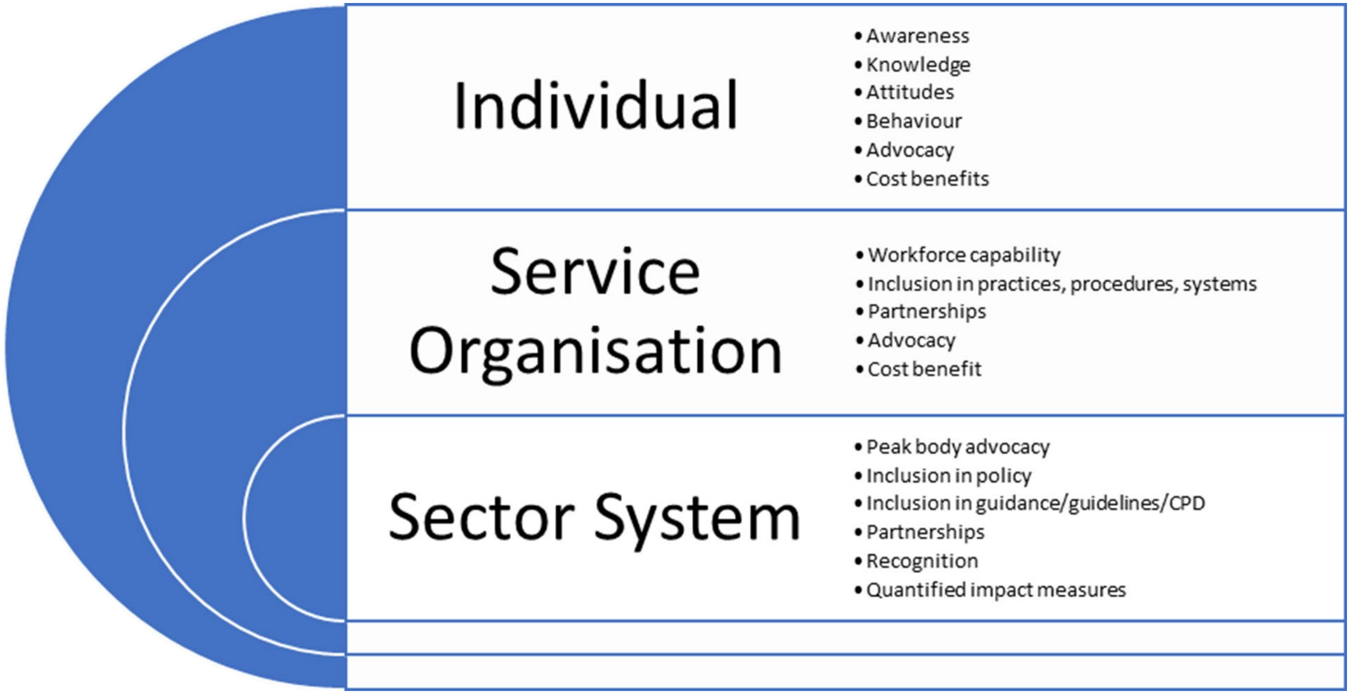
# Developing the framework

Results from the two studies and findings from the review of operational and quality processes were compared.

Several key constructs emerged:

1. Impacts were experienced at the individual, service and sector level
2. Assessment of impact may be missed if follow up studies are not undertaken
3. Identifying benefits is important
4. Significant number of potentially meaningful impacts
5. Measures of impact may be indirect (eg guideline inclusion implying practice change)
6. Few quantified measures found.



**Individual**

- Awareness
- Knowledge
- Attitudes
- Behaviour
- Advocacy
- Cost benefits

**Service Organisation**

- Workforce capability
- Inclusion in practices, procedures, systems
- Partnerships
- Advocacy
- Cost benefit

**Sector System**

- Peak body advocacy
- Inclusion in policy
- Inclusion in guidance/guidelines/CPD
- Partnerships
- Recognition
- Quantified impact measures

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# Creating a data matrix

- We determined to create a data matrix to enable comprehensive data capture and representation.
- Identified benefits were created as reporting cells.
- Benefits were allocated at the individual, service/organisation or system/sector level.
- Types of measures used in identifying or capturing benefits were also noted.
- We developed and described hypothetical KPI exemplars that could apply to each impact/realised benefit.
- We included items even if CareSearch had not yet been able to report against them.
- The matrix was conceived as a summative device that could capture and frame diverse impacts.

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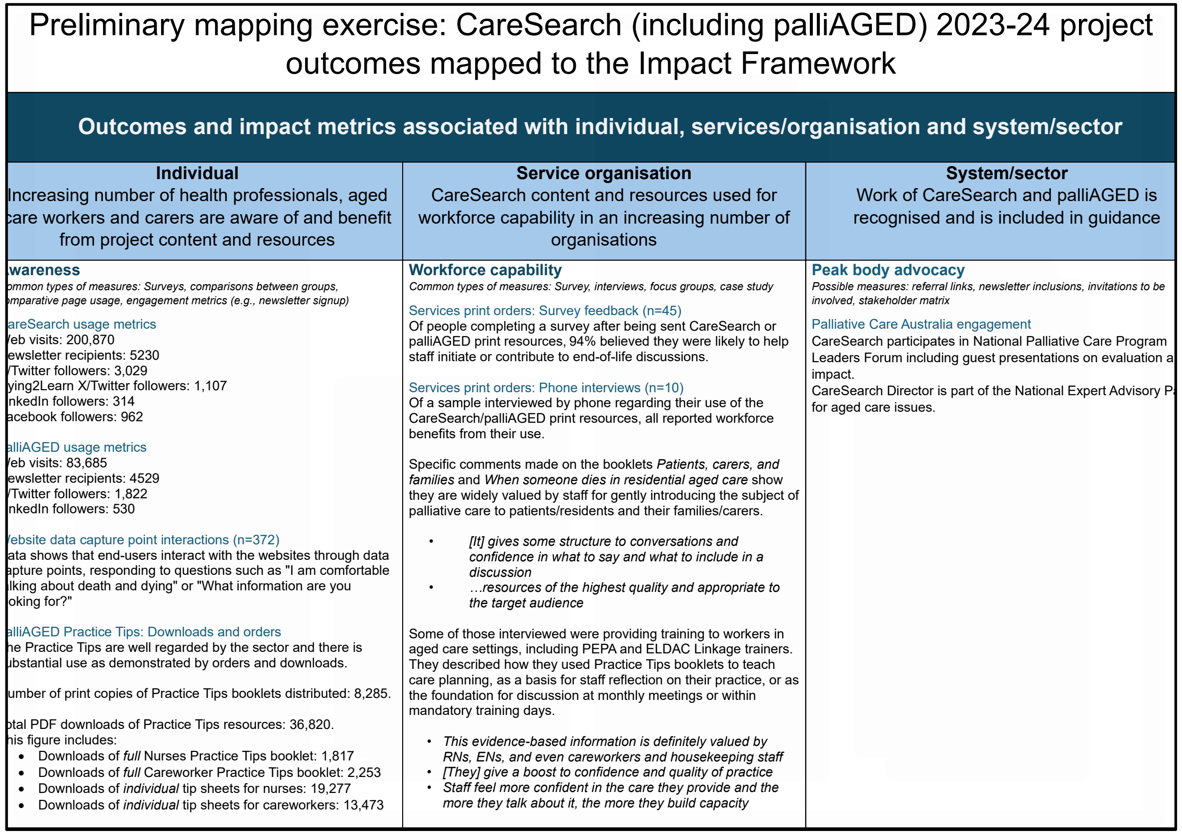
**Table 1: Outcomes and Impact Metrics associated with Individual, Services/Organisation and System/Sector**

| **Individual**<br>Increasing number of Health Professionals, aged care workers and carers are aware of and benefit from project content and resources | **Service Organisation**<br>CareSearch content and resources used for workforce capability in an increasing number of organisations | **System/Sector**<br>Work of CareSearch and palliAGED is recognised and is included in guidance |
|---|---|---|
| **Awareness**<br>Common types of measures: Surveys, comparisons between groups, comparative page usage, engagement metrics (eg newsletter signup)<br>***Exemplar KPIs***<br>> 5% of individuals registering for newsletters identify as GPs | **Workforce Capability**<br>Common types of measures: Survey, interviews, focus groups, case study<br>***Exemplar KPIs***<br>Resource orders/downloads from 5% of aged care services | **Peak body advocacy**<br>Possible measures: referral links, newsletter inclusions, invitations to be involved, stakeholder matrix<br>***Exemplar KPIs***<br>100% PC state and national bodies include CS/pA links |
| **Knowledge Change**<br>Common types of measures: Survey (pre-post, post only), Interviews, Responses to knowledge questions within activities. Reported new understandings, Follow up knowledge activities<br>***Exemplar KPIs***<br>>70% self-report increased knowledge on ACP at end of module | **Inclusion in practice/systems**<br>Common types of measures: Survey, interviews, focus groups, case study, system data such as orders, referral linkages, organisational training programs<br>***Exemplar KPIs***<br>#agreements to use resources<br>Examples of training schedules provided | **Partnerships**<br>Types of measures: network analysis, engagement matrix, rates and quality of participation<br>***Exemplar KPIs**:*<br># stakeholders involved in project activities<br>Recognised with Health Direct accreditation |
| **Attitudinal Change**<br>Common types of measures: Survey (pre-post, post only) Interviews, Self-reported attitude change<br>***Exemplar KPIs***<br>>50% self-report increased confidence in managing difficult conversations at end of module | **Partnerships**<br>Types of measures: Network analysis, Engagement matrix, Partnership registry, Representation registry, Participation rates (eg working groups), Dissemination activities<br>***Exemplar KPIs***<br>#invitations to present | **Inclusion in guidance/CPD**<br>Possible types of measures: Environmental scan, citation analysis,<br>***Exemplar KPIs***<br># palliative care guidance documents referencing CareSearch<br>#educational CareSearch/palliAGED activities/proportion of sector |
| **Behaviour/Practice Change**<br>Types of measures: Survey (pre-post, post only, self-report/supervisor/trainer, follow-up)<br>Interviews, objective measures (eg clinical indices), Intent to change reports, System metrics (eg app usage patterns), Reported descriptions of benefit and use<br>***Exemplar KPIs***<br>>50% report/describe change in behaviour<br>>repeat usage rates of resources | **Advocacy**<br>Types of measures: Organisations promoting value of CareSearch to members, Endorsements from groups or organisations<br>***Exemplar KPIs***<br>#stories or items encouraging use of CareSearch | **Inclusion in policy**<br>Possible types of measures: Environmental scan, citation analysis<br>***Exemplar KPIs***<br># policy documents referencing CareSearch or palliAGED |
| **Advocacy**<br>Types of measures: Feedback survey, Participation in review groups, meetings; Social media monitoring; event participation; case study, contact analysis<br>***Exemplar KPIs***<br>>5% of LinkedIn followers share item or provide a comment | **Cost benefits**<br>Types of measures: Avoided costs in resource development, imputed savings in treatment choices<br>***Exemplar KPIs***<br>Value of cost sharing of a platform<br>Avoided cost of training package development<br>#services projects including CareSearch content or resources | **Recognition**<br>Types of measures: Awards, media monitoring, environmental scanning, conference, and scientific meetings<br>***Exemplar KPIs***<br># media stories<br>#success rates conference abstracts<br>#invited speaker |
| **Cost Benefits**<br>Types of measures: Value of volunteer contribution to project<br>***Exemplar KPIs***<br>>500 hours volunteer contribution | | **Quantified impact measures**<br>Types of measures: Societal outcomes (eg gains in QALYs, avoided hospitalisations); money saved (eg costs avoided); new knowledge or processes<br>***Exemplar KPIs***<br>0.5% of RACF transfers avoided |

# Testing the framework (Whole of project)

A trial mapping of possible impacts that occurred in the 2023-2024 reporting period was undertaken. Using the matrix, data from project sources and from other sources (eg citation data, engagement activities) was accumulated.

Data was entered into relevant cells to display the spread of impacts and intensity of impact data.



Preliminary mapping exercise: CareSearch (including palliAGED) 2023-24 project outcomes mapped to the Impact Framework

**Outcomes and impact metrics associated with individual, services/organisation and system/sector**

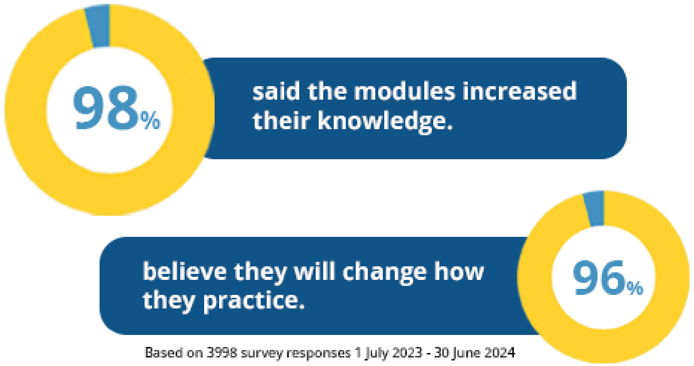
| **Individual**<br>Increasing number of health professionals, aged care workers and carers are aware of and benefit from project content and resources | **Service organisation**<br>CareSearch content and resources used for workforce capability in an increasing number of organisations | **System/sector**<br>Work of CareSearch and palliAGED is recognised and is included in guidance |
|---|---|---|
| **wareness**<br>*ommon types of measures: Surveys, comparisons between groups, mparative page usage, engagement metrics (e.g., newsletter signup)*<br>areSearch usage metrics<br>/eb visits: 200,870<br>ewsletter recipients: 5230<br>/Twitter followers: 3,029<br>ying2Learn X/Twitter followers: 1,107<br>nkedIn followers: 314<br>acebook followers: 962<br>alliAGED usage metrics<br>/eb visits: 83,685<br>ewsletter recipients: 4529<br>/Twitter followers: 1,822<br>nkedIn followers: 530<br>/ebsite data capture point interactions (n=372)<br>ata shows that end-users interact with the websites through data apture points, responding to questions such as "I am comfortable lking about death and dying" or "What information are you oking for?"<br>alliAGED Practice Tips: Downloads and orders<br>he Practice Tips are well regarded by the sector and there is ubstantial use as demonstrated by orders and downloads.<br>umber of print copies of Practice Tips booklets distributed: 8,285.<br>otal PDF downloads of Practice Tips resources: 36,820.<br>his figure includes:<br>• Downloads of *full* Nurses Practice Tips booklet: 1,817<br>• Downloads of *full* Careworker Practice Tips booklet: 2,253<br>• Downloads of *individual* tip sheets for nurses: 19,277<br>• Downloads of *individual* tip sheets for careworkers: 13,473 | **Workforce capability**<br>*Common types of measures: Survey, interviews, focus groups, case study*<br>Services print orders: Survey feedback (n=45)<br>Of people completing a survey after being sent CareSearch or palliAGED print resources, 94% believed they were likely to help staff initiate or contribute to end-of-life discussions.<br>Services print orders: Phone interviews (n=10)<br>Of a sample interviewed by phone regarding their use of the CareSearch/palliAGED print resources, all reported workforce benefits from their use.<br>Specific comments made on the booklets *Patients, carers, and families* and *When someone dies in residential aged care* show they are widely valued by staff for gently introducing the subject of palliative care to patients/residents and their families/carers.<br>• *[It] gives some structure to conversations and confidence in what to say and what to include in a discussion*<br>• *…resources of the highest quality and appropriate to the target audience*<br>Some of those interviewed were providing training to workers in aged care settings, including PEPA and ELDAC Linkage trainers. They described how they used Practice Tips booklets to teach care planning, as a basis for staff reflection on their practice, or as the foundation for discussion at monthly meetings or within mandatory training days.<br>• *This evidence-based information is definitely valued by RNs, ENs, and even careworkers and housekeeping staff*<br>• *[They] give a boost to confidence and quality of practice*<br>• *Staff feel more confident in the care they provide and the more they talk about it, the more they build capacity* | **Peak body advocacy**<br>*Possible measures: referral links, newsletter inclusions, invitations to be involved, stakeholder matrix*<br>Palliative Care Australia engagement<br>CareSearch participates in National Palliative Care Program Leaders Forum including guest presentations on evaluation a impact.<br>CareSearch Director is part of the National Expert Advisory P for aged care issues. |

# Testing the framework (Specific study)

Two specific evaluation studies are being completed and written up. As well as providing necessary research level data on effect of activities, they provide an opportunity to assess how the framework applies to individual studies.

The specific studies examining use and value are:

- palliAGED resources evaluation
- Clinical Evidence Summaries studies.



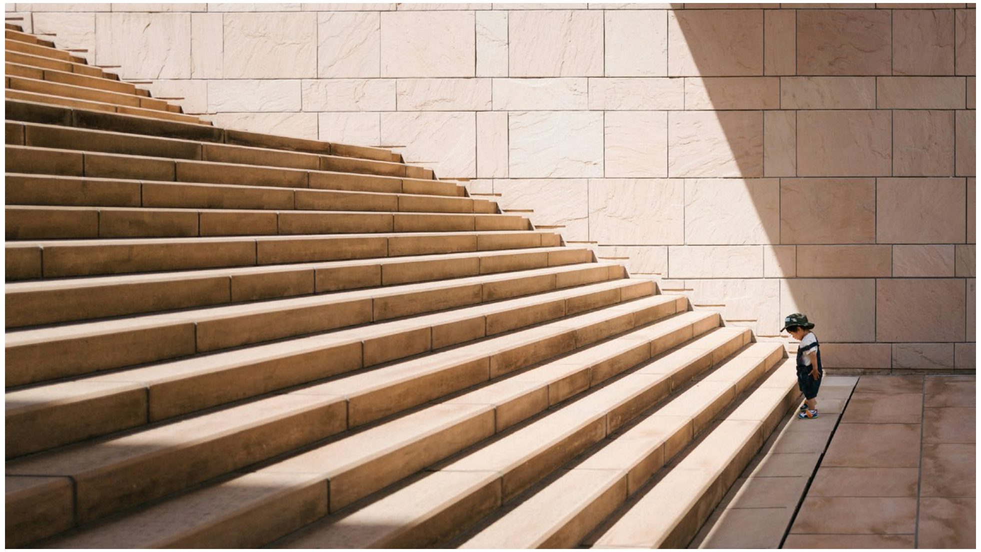
said the modules increased their knowledge.

believe they will change how they practice.

Based on 3998 survey responses 1 July 2023 - 30 June 2024

# Challenges and directions

- Anonymity of being an online provider – how do we follow up unknown users?
- There is a non-linear pathway from activity to impact. Dosage of activity is at discretion of the user.
- Impact measures are still ambiguous in terms of value against purpose (funder versus individual).
- Ability to collect meaningful data without disrupting the ability to deliver the work program efficiently.
- Addressing the issue of diversity and impacts. Universal or targeted impacts.
- Reality of collecting and analysing data eg ethics, time commitment, expertise?



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# Embedding impact assessment

Recognise that demonstrating value and identifying benefits is a core responsibility in research, projects and grant funded activity.

Extend thinking from how to deliver project activities to what could/should happen because this activity has been delivered.

Use of an impact assessment framework provides a focus for considering impacts and also for reporting benefits associated with the work.

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