



End of Life Directions for Aged Care

ELDAC Tools Forum

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Rydges Sydney Airport

www.eldac.com.au



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Introduction

The need for aged care services is increasing, with the proportion of Australians over the age of 65 continuing to grow. Furthermore, aged care services are a diverse sector. Care in the home is now a genuine option for many older Australians, including those that have palliative care needs. Australians living in residential aged care homes (RACHs) are more likely to have more complex needs and are tending to be older and frailer. For people working in the aged care sector providing high quality care this provides a set of complex challenges.

End of Life Directions for Aged Care (ELDAC) is a project funded by the Australian Government Department of Health to support quality care for older Australians at the end of life. ELDAC aims to connect people working in aged care with palliative care and advance care planning information, resources and services. The five ELDAC toolkits are fundamental in supporting these connections. Importantly, sector engagement was central in developing each toolkit. Toolkits are a collection of information, resources and tools around a particular topic or practice area. They can help users to develop a plan and organise their efforts to follow evidence-based recommendations or practices.

Each of the three clinical ELDAC toolkits provide a pathway for users to access meaningful and practical materials they can use when providing care to older Australians through a specific lens: Home Care, Primary Care and Residential Aged Care. Embedded throughout these are a range of common clinical tools. A recent internal review of these ELDAC common clinical tools raised a number of challenges. These include the:

- Role of clinical tools developed for use within the specialist palliative care sector;
- Role of audit tools, used to measure quality of aged care services; and
- Relationship of these tools to the guidance and resources from the Aged Care Quality Standards and the National Safety and Quality Health Service (NSQHS) Standards.

The **ELDAC Tools Forum** aimed to better understand the need and use of decision-making tools relevant to the delivery of palliative care services within the aged care sector.

Methodology

A focus group was conducted with a range of representatives from Australian peak healthcare organisations (see Appendix 1). Participants were divided into three groups to promote discussion and fed back a summary of their discussions to the larger group. Data were transcribed at each table and collated at the conclusion of the Forum.

There were three prescribed areas of focussed discussion:

1. **Suggested Tools:** To identify and further understand the use and extent of the implementation of clinical/audit tools in both residential aged care and home-based care settings.
2. **Interconnections:** To identify what other considerations around the use of clinical or audit tools in the sector need to be understood.
3. **Moving Forward:** To consider who in the aged care sector would be best placed to take carriage of such a process of discovery.

Themes were subsequently identified using NVivo.

The project was granted ethics approval (Reference: 7947) by the Flinders University Human Research Ethics Committee (HREC).

Results

There were 29 attendees, representing 23 separate national organisations. The quality of discussion and engagement was high for each of the three groups.

We identified three broad themes, from the focus group discussions, including:

- Understanding the Role of Tools Across the Aged Care Sector;
- Challenges of the Multidisciplinary Workforce; and
- Barriers to the Implementation of Tools.

Role of Tools

While organisational and audit tools were discussed, a large share of the focus was in the context of Clinical Tools. Using the ELDAC Common Clinical Tools as the foundation, a number of participants added to this list (see Appendix 2).

Clinical Tools were discussed in context of a number of situations including being used for screening, for making initial assessment and comprehensive assessments of patients and for prognostication. It was identified that the sector needs to better understand the intended utility and scope of any clinical tool.

The suite of ELDAC Common Clinical Tools were described as being primarily symptom specific (medical) and the need for availability of more self-reported assessment (social) tools for the sector was recognised. Specific mention was made regarding the lack of

readily available tools to assess bereavement risk and medication management related issues were acknowledged.

Patient Centeredness

Patient centeredness was a significant focus of the discussion relating to the use of tools in the aged care sector. Given that the patient's goals of care alter as they approach the end of their life, the use of tools need to be interpreted in the context of these shifting goals, including:

- Tools should identify the person's clinical (including psycho-social) needs, without overlooking their strengths;
- How tolerance of risk changes and impacts how results should be interpreted;
- Are more comprehensive tools required to capture the patient complexity and varied care and care provider contexts;
- Are the tools validated in the context of people with palliative needs;
- Does the patient make some contribution to their own assessment; and
- Are there tools to consider the psycho-social impact of illness.

Funding

Funding was considered a key driver for the use of some tools. Concerns were raised around inappropriate use of some tools being used to justify funding. Conversely, participants acknowledged that funding levers were embedded across primary care, home care and residential aged care and may be a valuable means of embedding tools into practice.

There is an opportunity to link the use of tools with specific outcomes that may generate funded activity for the organisation (e.g. case conferences).

Standards

Tools align well with National Safety and Quality Health Service (NSQHS) Standard Five (comprehensive care). This provides an opportunity for the Australian Commission on Safety and Quality in Health Care (the Commission) to be engaged. Participants asked if there is a role for organisations to be accredited against a range of Key Performance Indicators (KPIs) linked with the use of tools.

Multidisciplinary Workforce

The multidisciplinary nature of the aged care workforce was apparent. Health Care Professionals (HCPS) time is costed and there may need to be innovative ways of resource utilisation to ensure patients get best value for money. For example, the use of nurses, pharmacists and other allied health staff to screen and assess patients.

Referral Pathways

Concerns were raised at how HCPs understood what options were available to them once a tool identified a need. Issues raised include:

- Tools should not be used as an end in itself: clear understanding of what a tool score or outcome means and the referral pathways available;
- There are a number of funded resources that HCPs don't take advantage of, such as Medicare Benefits Schedule (MBS) items:
 - How are all HCPs aware of how funding options work together;
 - How do they make the best use of these;
- Lack of publicly funded options such as dentistry and allied health to refer to; and
- Workforce shortages, particularly impacting on how services are delivered in rural and remote areas.

Communication

Patients transition in and out of the acute sector as well as between primary care, home care and residential aged care settings. The consistent use of Tools across all these areas was purported to improve communication between HCPs regardless of their role:

- The use of integrated tools is needed to support better communication between aged care and specialist palliative care;
- Better articulation between the use of Tools and clinical governance in care settings is vital.

Non-professional workforce

In recent years, there have been significant changes in workforce composition, with care workers taking on more responsibilities. Participants acknowledged the role of this large workforce group across the aged care sector, and asked "What tools can/should care workers use?"

Education

Participants acknowledged that HCP education around the role of Tools across the sector would be valuable accounting for the diversity and siloing of disciplines across the aged care sector. Overseas trained HCPs and the non-professional workforce may have specific needs around education.

Barriers to the Implementation of Tools

A number of concerns were discussed about the widespread and consistent uses of tools were identified:

- Multi-morbidity/complexity not being captured by tools which are designed for single issue or general assessment not palliative populations – need specialist tool set. Tools rely on parameters of population characteristics on which they were developed. Changing prevalence can impact accuracy and validity of instruments;
- How to select tools in a crowded space and which version to use;
- Barriers in accessing tools due to cost or registration requirements;
- Information technology (IT systems need to have Tools built in for seamless utilisation;
- There are different levels of health literacy (e.g. between care workers, nurses and prescriber) which can limit:
 - How clinical tools are interpreted; and
 - How information is communicated;
- The diversity of the population (e.g. ATSI, LGBTI, CALD) which impacts of how tools are employed across the aged care sector – issues around sensitivity and specificity;
- HCPs with a lack of confidence in diagnosing people with palliative care needs;
- HCPs with a lack of awareness of people with palliative care needs using their services;
- Multimorbidity complicates the use and interpretation of Clinical Tools.

Moving Forward

Participants agreed on the value of having a common set of tools for clinicians working with people with palliative care needs, in the aged care sector. They were unclear in how to build on the work of ELDAC's common clinical tools. The following opinions were ascertained:

- This is a whole of sector problem;
- CareSearch and palliAGED were highlighted as evidence based national repositories of information;
- Mapping the clinical processes of screening, assessment, comprehensive care etc. could be useful as we are currently assuming how HCPs are using the resources and links offered – are we overwhelming the HCPs;
- Internationally, there may be examples of organisations which have successfully embedded Tools relating to palliative care practice into their aged care sector (e.g. EAPC);
- Conduct a pilot project to gain more evidence, followed by rapid action cycles;
- Use a Delphi process to identify appropriate tools for the sector;
- Start with a pragmatic approach, building on the strengths of success;
- The process needs to be agile and look at things that might come in the future.

Conclusion

Participants of the ELDAC Tools Forum considered the issue of a national set of standardised clinical tools as an important clinical concern requiring addressing. A number of Clinical Tools were identified throughout the forum. In addition, the discussions identified three themes.

The 'Role of Tools' theme recognised: clinical tools need to consider the patient at the centre; linking the use of clinical tools to funding raised concerns; and that tying the use of clinical tools to National accreditation standards made common sense.

The 'Multidisciplinary Workforce' theme revealed: the use of clinical tools requires clear and funded referral pathways to enact the results; needed to recognise the role of the nonprofessional workforce; and required education to ensure the workforce was consistent in its use of the clinical tools.

'Barriers to the Implementation of Tools' were numerous, respecting: the multimorbid nature of this patient cohort; the diversity of the Australian population; and how health literacy can impact on communication of findings.

Future undertakings should aim to address these themes when developing strategies for integrating clinical tools into practice for the management of people with palliative care needs, within the aged care sector.

Appendix 1: ELDAC Tools Forum – organisations represented

Organisation
Aged & Community Services Australia (ACSA)
Australian Aged Care Quality and Safety Commission
Australian Centre for Grief & Bereavement
Australian Dental Association
Australian Healthcare and Hospitals Association (AHHA) – ELDAC
Australian Nursing and Midwifery Federation (ANMF)
Australian Pain Society (APS)
Flinders University - ELDAC
Hammond Care
Leading Age Services Australia (LASA)
Occupational Therapy Australia (OTA)
Palliative Care Australia (PCA) - ELDAC
Palliative Care Nurses Australia (PCNA)
PHN Adelaide
Program of The Experience in The Palliative Approach (PEPA)
Queensland University of Technology (QUT) ELDAC
Resthaven
Royal Australian College of General Practitioners (RACGP)
Speech Pathology Australia
The Advance Project
The Australian & New Zealand Society of Palliative Medicine (ANZSPM)
The Australian Commission on Safety and Quality in Health Care (ACSQHC)
University of Technology Sydney - ELDAC

Appendix 2: List of Tools

Abbey Pain Scale¹

Australia-modified karnofsky Performance scale (AkPs)²

Bereavement support standards for specialist palliative care services

Client Assessment Form recorded on Penelope Case Management System

Client Questionnaire (ISS, ISLES & PG-13 can be downloaded as one document at: <http://bit.ly/acgb-tools-intake>)

Confusion Assessment Method (CAM) - Shortened version*

Cornell Scale for Depression (CSD)*

Edmonton Assessment Scale

Feedback Informed Treatment: Outcome Rating Scale (ORS) and Session Rating Scale (SRS)

Individual Intake Information recorded on Penelope Case Management System

Integration of Stressful Life Experience Scale - short form (ISLES) 8-item self-report questionnaire

International Classification of Functioning, Disability and Health (ICF)

interRAI

Inventory of Social Support (ISS) 5-item self-report questionnaire

IPOS

Kessler Psychological Distress Scale (K10)*

Mini-Nutritional Assessment Short-Form *

Modified Borg Scale (mBORG)*

Modified Resident's Verbal Brief Pain Inventory (M-RVBPI)*

NAT-CC – Needs Assessment Tool for Caregivers*

Numerical Rating Scale for pain (NRS)*

PG-13, 13-item self-report questionnaire/criteria that indicate identified symptoms of Prolonged Grief Disorder (PGD)

Suicide Risk Assessment Form recorded on Penelope Case Management System

Supportive and Palliative Care Indicator Tool (SPICT)*

Symptom Assessment Scale (SAS)*[†]

Verbal Descriptor Scale (Pain Thermometer)*

¹ ELDAC Common Clinical Tools

² Palliative Care Outcomes Collaborative (PCOC) Project suite of tools