ACP

Consortium for the inclusion of:

Advance Care Planning in the 5th Edition of the RACGP *Standards for general practices*

Submission

May 2015

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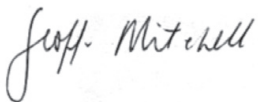

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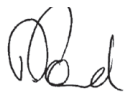

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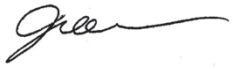

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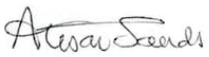

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2. Recommendation

It is recommended that:

Advance care planning (ACP) be included in the 5th edition of the RACGP *Standards for general practices* (the Standards), in that, in accordance with the RACGP's *Position Statement* (2012), ACP should be incorporated into routine general practice.[1]

Our recommendation falls under 'Feedback on the next edition of the RACGP *Standards for general practices*' in the section titled *Content of the Standards in response to the question*:

Is there anything that you think should be included or expanded upon in the next edition of the Standards? If so, please provide details as to why?

3. Why include ACP in the Standards?

3.1 Role of the Standards

In submitting this recommendation, we are mindful of the role of the Standards as described by the RACGP: they are a template for quality care and risk management in Australian general practice and have been developed to help general practice teams deliver better health outcomes for their patients. They have also been designed to keep Australia at the forefront of safe, high quality healthcare delivery.[2]

3.2 What is ACP

3.2.1 Definition of ACP

"Advance care planning is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions." [3]

Practically, ACP assists people to consider, discuss and document:

- their goals, values and preferences regarding future healthcare, including what would be an unacceptable outcome and any treatments they would or would not want.
- their choice of substitute decision maker (SDM) should they become incapable of making decisions about their healthcare

3.2.2 Why is ACP important?

Given that all people die, the processes surrounding dying deserve the same quality improvement considerations as other aspects of healthcare in the Standards. ACP is a key way of improving care at the end of life for the patient, in collaboration with family, caregivers, friends, GPs and other health professionals.[4, 5, 6, 7, 8, 9, 10, 11]

ACP is also valuable for people whose illness has impaired their capacity to make health decisions but from which they are not about to die.

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3.2.3 Evidence of the benefits of ACP

There is evidence that **ACP improves:** [4, 5, 6, 7, 8]

- patient care, including end-of-life care
- the likelihood of a person's end-of-life wishes being known and respected by doctors and families
- patient & family satisfaction with care
- families' perceptions of quality of death
- the likelihood of a person dying in their preferred place
- family preparedness for what to expect during the dying process.

There is also evidence that **ACP reduces:** [4, 5, 6, 9, 10, 11]

- likelihood of unwanted treatment at end of life
- the number of hospital admissions of people who would have preferred to stay at their home/RACF
- stress, anxiety and depression in surviving relatives
- distress amongst healthcare providers
- ineffective or unwanted costly care at end-of-life without increasing mortality

Thus, given the RACGP's *Position Statement* regarding ACP, the evidence of its benefits and the role of the Standards, it is important to incorporate ACP into the Standards to achieve the quality improvement in patient care that ACP facilitates.

As described by Scott et al in the Medical Journal of Australia in 2013[12], "*For ACP to become part of mainstream patient-centred care, accountable clinicians working in primary care, hospitals and nursing homes must effectively educate colleagues and patients about the purpose and mechanics of ACP, mandate ACP for all eligible patients, document ACP in accessible formats that enable patient wishes to accurately guide clinical management, devise methods for reviewing ACP decisions when clinically appropriate, and evaluate congruence between expressed patient wishes and actual care received.*" We interpret "*mandate ACP for all eligible patients*" to mean that ACP should be raised with and/or offered to all eligible/indicated patients, whilst respecting the patient's choice as to whether or not, and to what extent, they wish to consider, discuss and/or document ACP.

3.3 Why is ACP an issue?

The benefits of ACP, when it is done, have been well recognised in the literature and in practice. Implementation of ACP is challenging, according to a recent systematic review by Lund et al (2015). The findings "*underscore both the challenge and the need to find ways to routinely incorporate ACP in clinical settings where multiple and competing demands impact on practice. Interventions most likely to meet with success are those that make elements of ACP workable within complex and time pressured clinical workflows*".[13]

Scott et al (2013) also found that "*although ACP has existed as an idea for decades, acceptance and operationalisation of ACP within routine practice has been slow, despite evidence of its benefits*".[12]

The RACGP, having produced its *Position Statement* - a valuable acknowledgement of the growing recognition of the need for and value of ACP - is now in a position to influence improvement in the quality of patient care by the inclusion of ACP in the Standards.

While the RACGP's *Position Statement* outlines the reasons why the College believes it should be incorporated into routine general practice[1], this alone is unlikely to change current practice without the leverage and support of the inclusion of ACP in the new Standards for the reasons cited in Lund et al's systematic review, and in Rhee et al's (2012) research on uptake and implementation of ACP in Australia.[13, 14]

We propose that a broad ACP Criterion and achievable Indicators be incorporated into the Standards to make them realistic in the complex time-pressured environment that is general practice to improve the quality of care for patients.

We also note the RACGP's intention to change the structure of the Standards to comprise Core Standards and Modules. Based on the evidence and arguments contained in this submission, we suggest that ACP be included in the Core component of the Standards.

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3.4 ACP: Keeping the Standards current and accommodating key trends

We note in the RACGP Standards *for general practices (4th ed)* (2010) that "*it is important that (the Standards) reflect contemporary general practice and pave the way for quality improvement*". We also note that "*the Standards are designed to accommodate key trends in the general practice environment.*"[2] ACP has been gaining prominence as an important component of good end-of-life care[13] in the context of the evolution from 'cure' to management of chronic and incurable conditions and frailty.[1] The need for advance care planning is growing given Australia's ageing population and the increasing proportion of people who are expected to die from chronic progressive illnesses.[15] It is also well recognised that people are now entering RACFs with higher illness acuity and care needs than previously,[16] and more than 50% are living with dementia which limits their capacity to participate in ACP.[17] Introducing ACP before a patient's condition deteriorates, before they lose capacity, is vital.

In this context, it is crucial for the patient's GP to consider and discuss the person's values and goals, and their preferences regarding future treatment that they would or would not want. The growing recognition of the value of ACP, and the fact that GPs develop ongoing and trusted relationships with their patients, and are well positioned to initiate and promote ACP,[1] are arguments for the inclusion of ACP in the Standards to accommodate these key trends in the general practice population and healthcare environment.

In the RACGP's 2009 Convocation outcomes,[18] the following motion was carried unanimously:

"That the College undertakes to play a leading role in the education and implementation of advance care planning within the profession and wider community."

In addition, the need for a more standardised national approach to ACP is recognised in the Australian Health Ministers Advisory Council's (AHMAC) *National Framework for Advance Care Directives* (2011), (the Framework).[3] The Framework recognises the potential improvements Advance Care Directives (ACDs) may make to care and decision-making during times of impaired capacity, especially towards the end of life. The RACGP is in a position to support these potential improvements by incorporating ACP into the next edition of the Standards.

In recognition of the need for ACP in primary care, the Australian Government has funded the $15 million Decision Assist Program to enhance the delivery of advance care planning and palliative care to older people living in the community and in residential aged care. A key focus of this project is on upskilling GPs through the provision of specialised education as supported by Scott et al (2013). [12, 19]

Further, the *National Safety and Quality Health Service Standards* (NSQHS Standards) developed by the Australian Commission on Safety and Quality in Health Care (ACSQHC), were implemented nationally from 1 January 2013 and are compulsory for the majority of hospitals and day procedure centres across Australia.[20]

ACP is included in the NSQHS Standards as follows:

Within Standard 1: Governance

1.18.1 Patients and carers are partners in the planning for their treatment

1.18.2 Mechanisms are in place to monitor and improve documentation of informed consent

1.18.3 Mechanisms are in place to align the information provided to patients with their capacity to understand

1.18.4 Patients and carers are supported to document clear advance care directives and/ or treatment limiting orders

Within Standard 9: Recognising and Responding to Clinical Deterioration

9.8.1 A system is in place for preparing and/or receiving advance care plans in partnership with patients, families and carers.

9.8.2 Advance Care plans and other treatment-limiting orders are documented in the patient clinical record

The NSQHS Standards provide:

- a quality assurance mechanism that tests whether relevant systems are in place to ensure minimum standards of safety and quality are met
- a quality improvement mechanism that allows health service organisations to realise developmental goals.[21]

Inclusion of ACP in the *Standards for general practices* would also go some way to aligning general practice and the hospital sector on the issue of ACP in that it would be included in both sets of Standards.

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4. How would general practice meet a Standard incorporating ACP?

4.1 Discussion

As described in Section 3.3, implementation of ACP poses significant challenges.[12, 13, 14] Inclusion of ACP in the next edition of the Standards would promote more consistent practice and incorporation of ACP into routine care, as recommended by the RACGP in its *Position Statement*. As evidenced in Rhee's et al's (2013) findings[14], this would contribute to improvements in the quality of patient care.

We recommend the Criterion, and Indicators proposed in Sections 4.2 and 4.3, to maintain consistency with the RACGP's *Position Statement* and support its uptake and translation into practice, based on evidence of improved quality of care when ACP is undertaken. We consider that the proposed broad Criterion and Indicators are realistic and achievable for general practices. See Section 4.4.2 for guidance for practices on how to meet the ACP Indicators, and Section 4.4.3 for resources to support practices.

In consideration of the introduction of a Criterion and Indicators on ACP, the Consortium would be willing to assist the RACGP in any refinement, including *Explanation* and related content, and guidance and support for practices.

We are aware that, at times, new Criteria and Indicators are unflagged and therefore not mandatory upon initial inclusion in the Standards. We are also aware that '*working towards*' meeting new Criterion and Indicator(s) may be implemented by the RACGP as a first step. Our position, for the reasons cited above as to why ACP is important, and in line with the RACGP's goal of keeping the Standards current and accommodating key trends in healthcare, is that that the proposed Indicators be flagged, and not limited to '*working towards*' for the 5th edition of the Standards, due for release in October 2017.

To wait for a 6th or 7th edition of the Standards before the ACP Criterion and Indicators become flagged would not support improved quality care for the identified patient cohorts, and is also likely to have adverse consequences for these patients as cited in Section 5. Given the timeframe for iterations of the Standards, these adverse consequences could continue for many years.

4.2 Proposed Criterion: Advance Care Planning

Our practice incorporates advance care planning (ACP) into routine patient care for patients for whom ACP is indicated.

4.3 Proposed Indicators for ACP:

- A. Our practice team can describe its system for incorporating advance care planning (ACP) into routine care for patients for whom ACP is indicated.*
- B. Our practice has policies and procedures in place to support ACP
- C. Our doctors and nurses have ready access to patient, health professional and legal information about ACP
- D. Our practice provides information about ACP to patients and their families or carers
- E. ACP is undertaken by staff trained in ACP#
- F. Our practice records and stores outcomes of ACP discussions and/or documentation
- G. Our practice reviews Advance Care Plans/Advance Care Directives periodically and as required
- H. Our practice has a system in place to transfer ACP information across health settings

**Refer 4.4.2 in Explanation section for guidance on patients for whom ACP is indicated.*

#Training may be through RACGP or other online training and/or education sessions/workshops

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4.4 Explanation

4.4.1 Proposed Key Points

To include definition, value and benefits to patients (See 3.2)

4.4.2 Guidance for practices on how to meet the ACP Indicators

A patient for whom ACP is indicated includes a person who meets one or more of the following criteria: [1, 12, 22, 23, 24, 25, 26, 27]

- Raises ACP with a member of the general practice team
- Has an advanced chronic illness (e.g. COPD, heart failure) or a life limiting illness (e.g. dementia or advanced cancer)
- Is aged 75 years or older, or 55 years or older if they are an Aboriginal and/or Torres Strait Islander person
- Is a resident of, or is about to enter, an aged care facility
- Is at risk of losing competence (e.g. has early dementia)
- Has a new significant diagnosis (e.g. metatastic disease, transient ischemic attack)
- Is at a key point in their illness trajectory (e.g. recent or repeated hospitalisation, commenced on home oxygen or dialysis)
- Does not have anyone (e.g. family, caregiver, friend) who could act as substitute decision maker
- May anticipate decision-making conflict about their future healthcare (e.g. within family [or caregivers or friends], between family and patient, and/or between family and doctor)

4.4.3 Resources

National websites:

> RACGP http://www.racgp.org.au/your-practice/business/tools/support/acp/

> Advance Care Planning Australia (ACPA) http://advancecareplanning.org.au/

> Decision Assist www.decisionassist.org.au

> CareSearch http://www.caresearch.com.au/caresearch/tabid/450/Default.aspx

State and territory websites:

> ACT: http://www.health.act.gov.au/our-services/chronic-disease-management/chronic-disease-services/advance-care-planning

> NSW: http://www.health.nsw.gov.au/patients/acp/pages/default.aspx

> NT: http://www.nt.gov.au/justice/pubtrust/app/index.shtml

> QLD: http://apps.health.qld.gov.au/acp/Public_Section/What_Is_ACP/whatIsACP1.aspx

> SA: http://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Clinical+resources/Advance+care+directive

> TAS: http://www.dhhs.tas.gov.au/palliativecare/advance_care_planning_for_healthy_dying

> VIC: http://www.health.vic.gov.au/acp/

> WA: http://www.health.wa.gov.au/advancecareplanning/home/

The laws of ACP:

> ACPA http://advancecareplanning.org.au/advance-care-planning/for-professionals/the-law-of-advance-care-planning/ Includes information for all Australian States and Territories

Having the ACP conversation:

> The 'Next Steps' *Training Resources for Doctors* Videos; Department of Health (Vic) http://health.vic.gov.au/chi/training-videos.htm

> ACP discussion checklist (in development)

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MBS Item Number resources:

> MBS resources (in development) may be used for general practice to support ACP, providing the requirements of the MBS Item Numbers are met. These will include guides, and case studies demonstrating how ACP can be supported through the MBS. These resources will be available on the Decision Assist website.

> MBS Online http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Home

Education:

> Online education (free)
>
> - RACGP *via gplearning* http://gplearning.racgp.org.au/Account/Login?ReturnUrl=%2f
> - ACPA: e-Learning course http://www.rpctraining.com.au/

Resources for population groups:

Aboriginal & Torres Strait Islander peoples:

> ACPA. Take Control of your Journey booklet
> http://advancecareplanning.org.au/library/uploads/documents/act/141331_ACP_Booklet_LOWRES.pdf

> SA Health (2006) Advance care yarning
> http://192.185.24.77/~rpccom/images/stories/Advance_Care_Yarning_ATSI_SA.pdf

People with dementia:

> Alzheimer's Australia
> https://fightdementia.org.au/support-and-services/families-and-friends/advance-care-planning

> Start2talk http://www.start2talk.org.au/

Culturally and linguistically diverse communities:

> ACPA http://advancecareplanning.org.au/language-services

> Decision Assist: http://www.caresearch.com.au/caresearch/tabid/3372/Default.aspx

> Centre for Culture, Ethnicity and Health http://www.ceh.org.au/resources/publications#CCtipsheets
>
> See Tip Sheets including:
> - Cultural considerations in health assessment
> - Speaking with clients who have low English proficiency
> - Assessing the need for an interpreter
> - Communicating via an interpreter

> Clark, K., & Phillips, J. (2010). *End of life care: the importance of culture and ethnicity. Australian family physician, 39*(4), 210. http://www.racgp.org.au/afp/2010/april/end-of-life-care-%E2%80%93-the-importance-of-culture-and-ethnicity/

LGBTI people:

> National LGBTI Health Alliance http://lgbtihealth.org.au/# *Silver rainbow project;* Funded by the Australian Government Department of Social Services

> National Council for Palliative Care and the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations *Open to all? Meeting the needs of lesbian, gay, bisexual and transgender people nearing the end of life.* (DVD and booklet). UK

> Cartwright C, Lienert T, Beck K. (2010) *Knowledge about and Attitudes towards End of Life Care for Gay, Lesbian, Bisexual and Transgender People. Phase 2, Stage 1: State-wide Survey.* Report to Law and Justice Foundation

Older people:

> RACGP (2006) Silver Book (4th ed): *Medical care of older person in residential aged care facilities*
> http://www.racgp.org.au/your-practice/guidelines/silverbook/

5. What would be the consequences of not meeting a proposed ACP Standard / Criterion / Indicators?

The benefits of ACP cited in Sections 3.2.1, 3.2.2 and 3.2.3 lead to the conclusion that, if ACP is not done, the quality of patient care will be adversely impacted. The evidence is that it is unlikely to be done unless it is incorporated into routine care, and this can best be achieved by its inclusion in the Standards.

If ACP is not done, there is a greater likelihood of unwanted treatment at end-of-life; a higher number of hospital admissions for people who would have preferred to die at home or in their RACF; unwanted and/or ineffective costly care at end-of-life; increased post-traumatic stress, anxiety and depression in surviving relatives and distress amongst healthcare providers. [4, 5, 6, 7, 8, 9, 10, 11]

The RACGP's P*osition Statement* cites the risks that, if people lose the ability to make decisions about their care, the healthcare system will prolong their suffering by keeping them alive in a condition they would not wish to be in, and fail to attend to their wishes. [1] To avoid such consequences, and to ensure that a patient's expressed wishes remain at the forefront of decisions in relation to their care, we strongly recommend that ACP be included in the 5th edition of the Standards in the manner described in our submission, to optimise the incorporation of ACP into routine general practice.

References

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