

Can guidelines and routine screening improve the match between levels of needs and utilisation of palliative care services?

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Outline of presentation

- National policies on specialist palliative care (SPC)
- What do we know about SPC referrals & utilisation in Australia?
- Can we bridge the gap between current and best practice?
- What next?



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National policy on PC

PCA landmark documents provide a framework for needs-based and equitable access to quality end-of-life care:

- *Palliative Care Service Provision in Australia: A Planning Guide (2003)*
- *Standards for Providing Quality Palliative Care for all Australians (2005)*
- *A Guide to Palliative Care Service Development: A population based approach (2005)*

Definition

Palliative care:

- Aims to optimise level of function and comfort for people with life-limiting illness (LLI) and their support network
- Includes physical, psychological, spiritual, cultural, financial, sexual and social domains of care

PCA (2005). A Guide to Palliative Care Service Development: A population based approach.

What do we know about SPC referrals & utilisation in Australia?



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Perceptions about PC

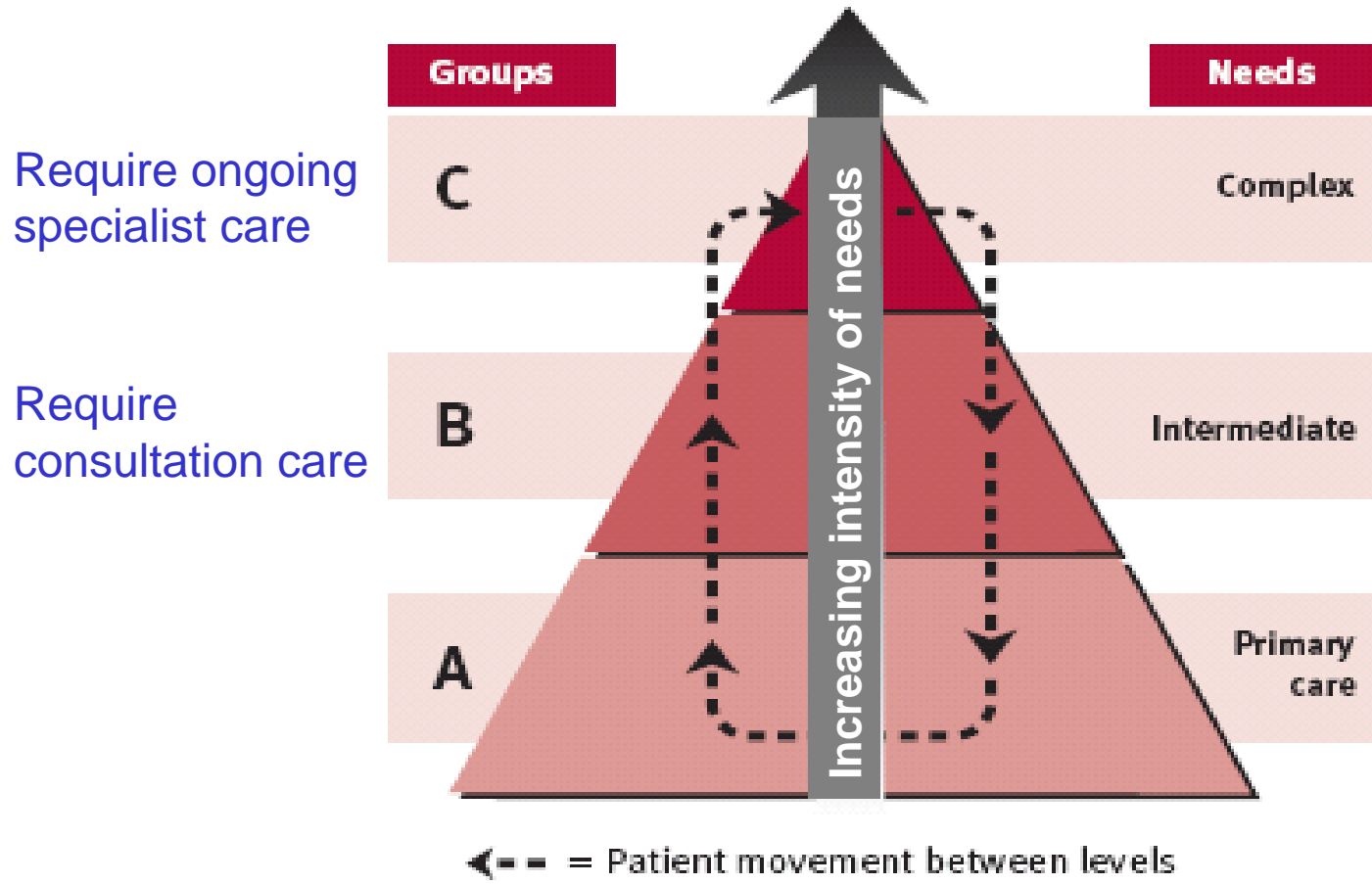
A majority view:

“I think (of palliative care) really as the patient thinks, that I talk about end of life ... I would prefer to retain the term palliative care for what the ordinary punter understands it to be, which is end of life issues”

A minority view:

“I don't believe it's the time at which a referral to palliative care is done, but the critical thing is the nature of the event that precipitates the referral”

Not all who have a LLI will need specialist care - needs-based model



PCA (2005). *A Guide to Palliative Care Service Development: A population based approach.*

But, is there a mismatch between needs and SPC utilisation?

		PLLI who utilise a SPCS		
		Yes	No	
PLLI who would benefit from a palliative care service (need)	Yes	54% (42%-62%)	16% (11%-31%)	70%
	No	2.1% (1.6%-20%)	28% (21-41%)	30%
		56%	44%	100%

Currow et al. Specialist palliative care needs of whole populations: A feasibility study using a novel approach. Pall Med 2004;18(3):239-247

Who misses out on PC?

- The elderly
- People in rural & regional areas
- People of lower SES
- Indigenous Australians
- People whose primary life-limiting illness is not cancer

Eager et al 2004, Good et al 2004, PCA 1999, Hunt et al 1996, McNamara et al 2004, Higginson et al 1999, Sullivan et al 2003

Can we bridge the gap between current and best practice?



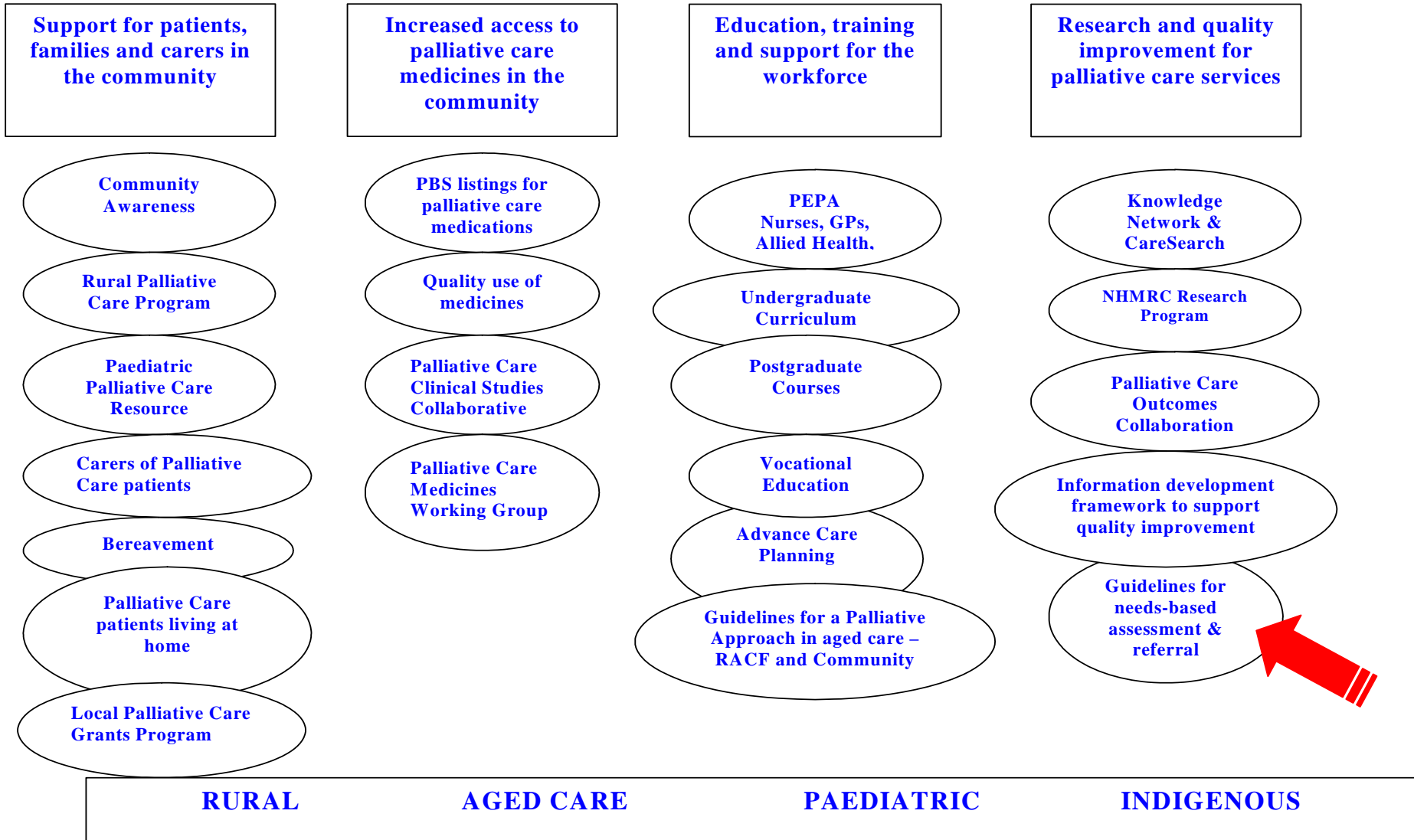
“(Palliative care is beneficial) in being sure that all their needs are being met just in terms of having aids for daily living, for which people may be afraid to ask, rails for the toilets ...having foods that are appropriate for them, and other issues such as having their financial and relationship affairs in order”

Johnson 2006 (n=40 doctors from across Australia)

Challenges, eg:

- Misperceptions about PC
- Limited or stretched PC resources
- Changing the balance to needs-based rather than prognosis-based referrals
- Ensuring multiple SPC entry points for those who need it most
- Facilitating exit from, as well as entry to SPC services

Department of Health & Ageing



Palliative Care Program Team

Centre for Health Research & Psycho-oncology (CHeRP) Team:

Afaf Girgis, Claire Johnson, Amy Waller

National Project Team:

David Currow, Linda Kristjanson, Geoff Mitchell, Patsy Yates, Brian Kelly, Martin Tattersall, David Sibbritt, Amanda Neil



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Why another set of Guidelines?

Systematic reviews conclude that Guidelines:

- Improve the process of care
- Improve patient outcomes
- Increase involvement & confidence in decisions
- Are useful training tools

Grimshaw JM, Russell IT, *Lancet* 1993;342(27):1317-1322; 45.

Boon K, Tan H. *Int J Health Care Quality Assurance* 2006;19(2):195-220.

Developing the *Palliative Care Needs Assessment Guidelines*

- Extensive literature review & rating of levels of evidence
- National expert review panel (n=66)
 - referrer groups (incl oncologists, physicians, surgeons GPs)
 - palliative care clinicians
 - learned colleges
 - consumer advocates; patients and carers
 - nurses, allied health & supportive care providers
 - health ethicists, clergy, researchers, health economists

Developing the *Palliative Care Needs Assessment Guidelines*

- Extensive literature review & rating of levels of evidence
- National expert review panel
- National consensus meeting (n=66)
- Revision of Guidelines – 9 chapters & summary of key evidence:
 - Background
 - Utilisation of PC services
 - Patient issues – physical, psychosocial, spiritual, cultural and other relevant issues
 - Caregiver and family issues
 - Health professional issues

Palliative Care Needs Assessment Guidelines

Developed by:

Afaf Girgis, Claire Johnson, David Currow
Amy Waller, Linda Kristjanson, Geoff Mitchell
Patsy Yates, Amanda Neil, Brian Kelly
Martin Tattersall, Deborah Bowman

August 2006



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Guidelines will:

- Help health professionals whose primary work is not in PC (GPs, community nurses, specialists, allied health professionals, etc,) to objectively determine whether or not they are currently meeting the needs of individual patients and their families.
- Provide a framework for initial and ongoing assessment of the need for and degree of SPC team involvement in the care of individual patients and their families.

HANG ON...
WHAT SOUNDS
MORE COMMANDING
... "DON'T..." "NEVER..."
OR "THOU SHALT
NOT..."?



Winniet

Facilitating the uptake of the Guidelines

- ✓ Endorsement by key bodies
- **Accompanying screening tools or checklists**
- Appropriate training and dissemination
- Consumer resources

Screening tools and checklists

With appropriate instruction, can:

- Facilitate communication between patients, caregivers and health professionals
- Facilitate tailoring of interventions - prioritise limited resources
- Increase detection of issues
- Increase referrals

The Palliative Care Needs Assessment Tool (PC-NAT)

Principles underpinning the PC-NAT:

- Completed in very short time (~5 minutes)
- Encompasses all needs domains in the Guidelines
- Can be administered by any health professional
- Draws on information that should already be available
- Able to be transferred to electronic data collection tools in the future

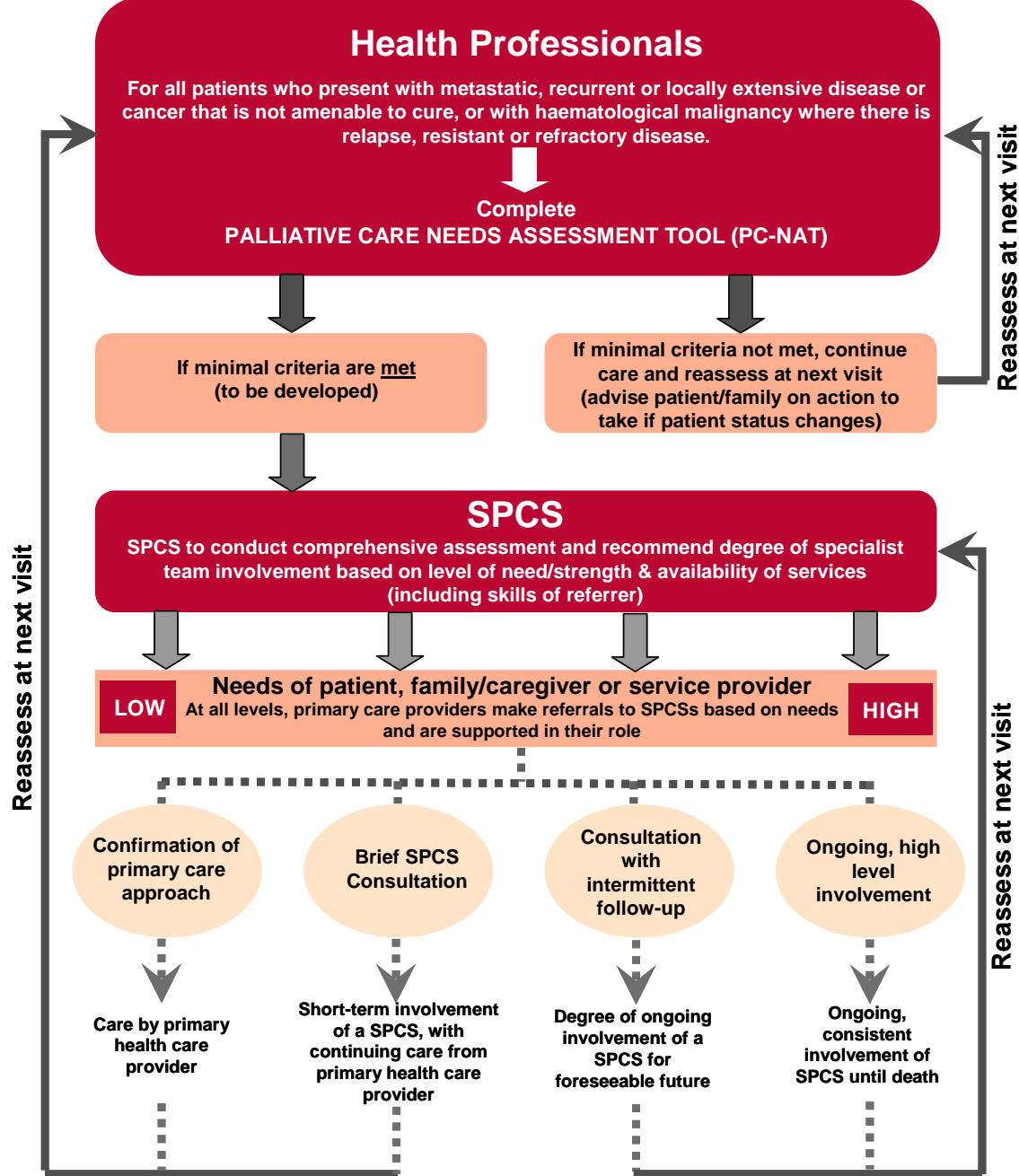


Figure 1: Model for needs-based assessment and triage to appropriate level of palliative care service involvement

Pilot testing of PC-NAT

- Sample (n=103):
 - 18 GPs - Launceston (CME points)
 - 25 Oncologists (radiation, medical, haematology, PC) - Brisbane & Newcastle
 - 39 nurses (community, radiation oncology, palliative care, haematology) - Brisbane
 - 21 allied health workers (social workers, occupational therapists, radiation therapists, speech pathologists, dieticians and pastoral worker) - Brisbane
- Simulated patients & caregivers with GP, oncologist, nurse - DVD plus “referral form”

Pilot testing of PC-NAT

- ✓ High content and face validity
- ✓ Easy & quick to complete
- ✓ Encourages consideration of range of needs
- ✓ Can be completed by any health care provider
- X Low reliability was found for the patient spirituality, information and health beliefs-cultural-social domains; and for the caregiver functional status and bereavement domains

Facilitating the uptake of the Guidelines

- ✓ Endorsement by key bodies
- ✓ Accompanying screening tools or checklists
- **Appropriate training and dissemination**
 - Academic detailing
 - Training resources for future use by PC services and the RACGPs
 - National “Train the Trainer” program in 2009
 - National dissemination plan in 2009
- **Consumer resources**

What next?



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Evaluation of Guidelines and PC-NAT (Aug 2006 – Dec 2008)

Aim:

- To evaluate the degree to which systematic utilisation of the Guidelines and PC-NAT increases the match between the levels of unmet patient and caregiver needs and service utilisation

Training & Dissemination (Jan 2009 – Dec 2009)

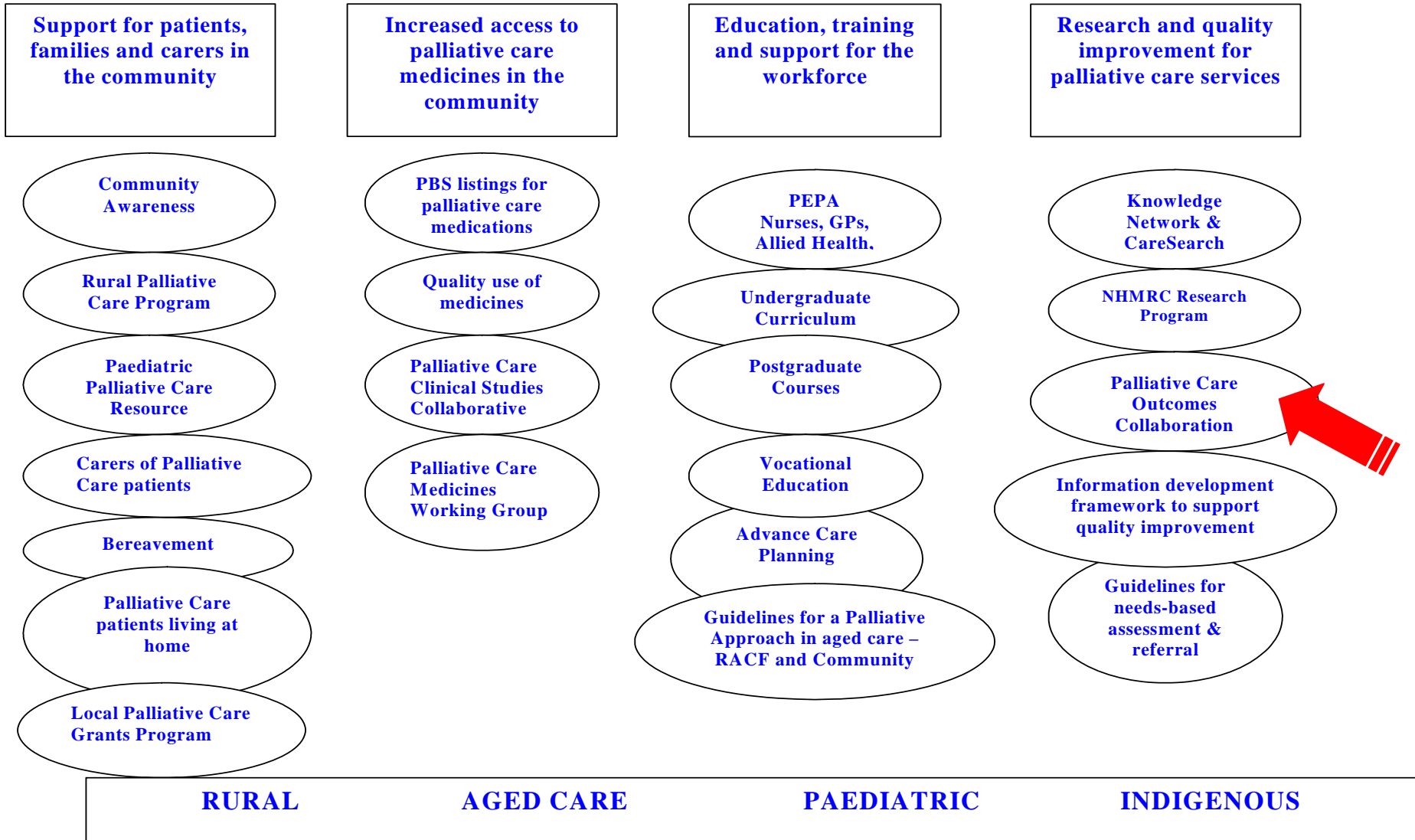
Phase 5:

- Develop national dissemination plan
- Deliver “Train the Trainer” program nationally
- Develop training resources for future use by PC services and the RACGPs

Phase 6:

- Guidelines and Tool generalised and pilot tested with one non-malignant palliative group

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Acknowledgements

Funding:

- Australian Government Department of Health & Ageing
- The University of Newcastle RCG Grant & PhD scholarship for A Waller
- Effective Healthcare Australia
- Cancer Trials NSW supported



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