Renal Conservative Care

The Victorian Perspective

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Project Officer

Victorian RCC Project

March 2009: Melbourne Health RCC Submission to Department of Health Vic.

Collaborative initiative: Renal, HARP and Palliative Care Services

June 2009: Referred to Renal Health Clinical Network

Unanimous acknowledgement of the need for RCC pathway

July 2009: Allocation of DoH funding to Melbourne Health

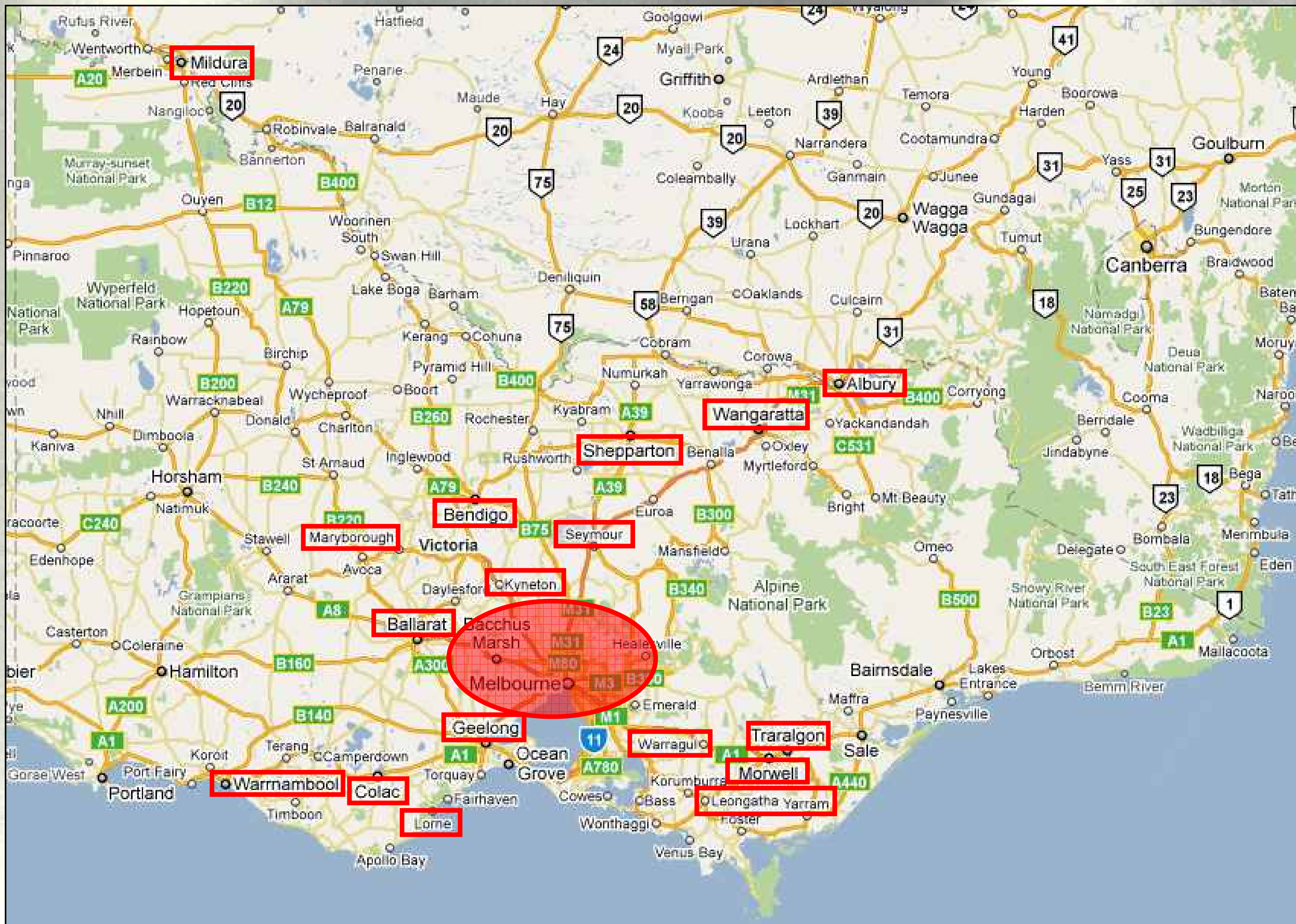
Aug-Oct 09: Scope the project and position (MH & DoH; RHCN endorsed)

Jan 2010: RCC Project Officer: 12 month appointment

Stakeholder Interviews (88)

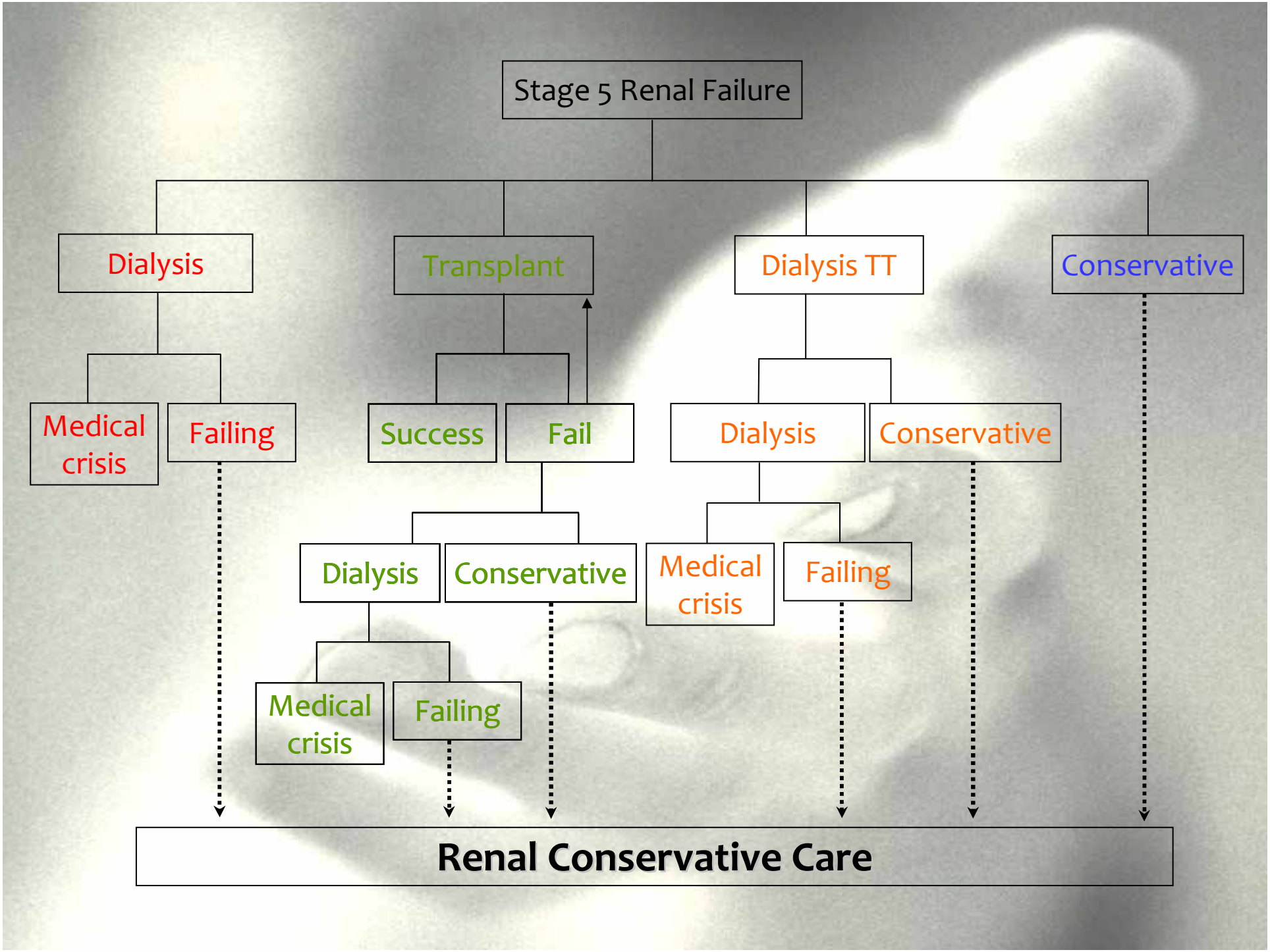
- Dialysis units (27)
- Palliative care services (25)
- Nephrologists (13)
- Patients/carers (5)
- HARP and chronic disease managers (4)
- Residential aged care (3)
- General practitioners (3)
- Aboriginal healthcare (3)
- Geriatricians (2)
- Renal unit managers (2)
- Aged care assessment (1)

Stakeholder Interviews

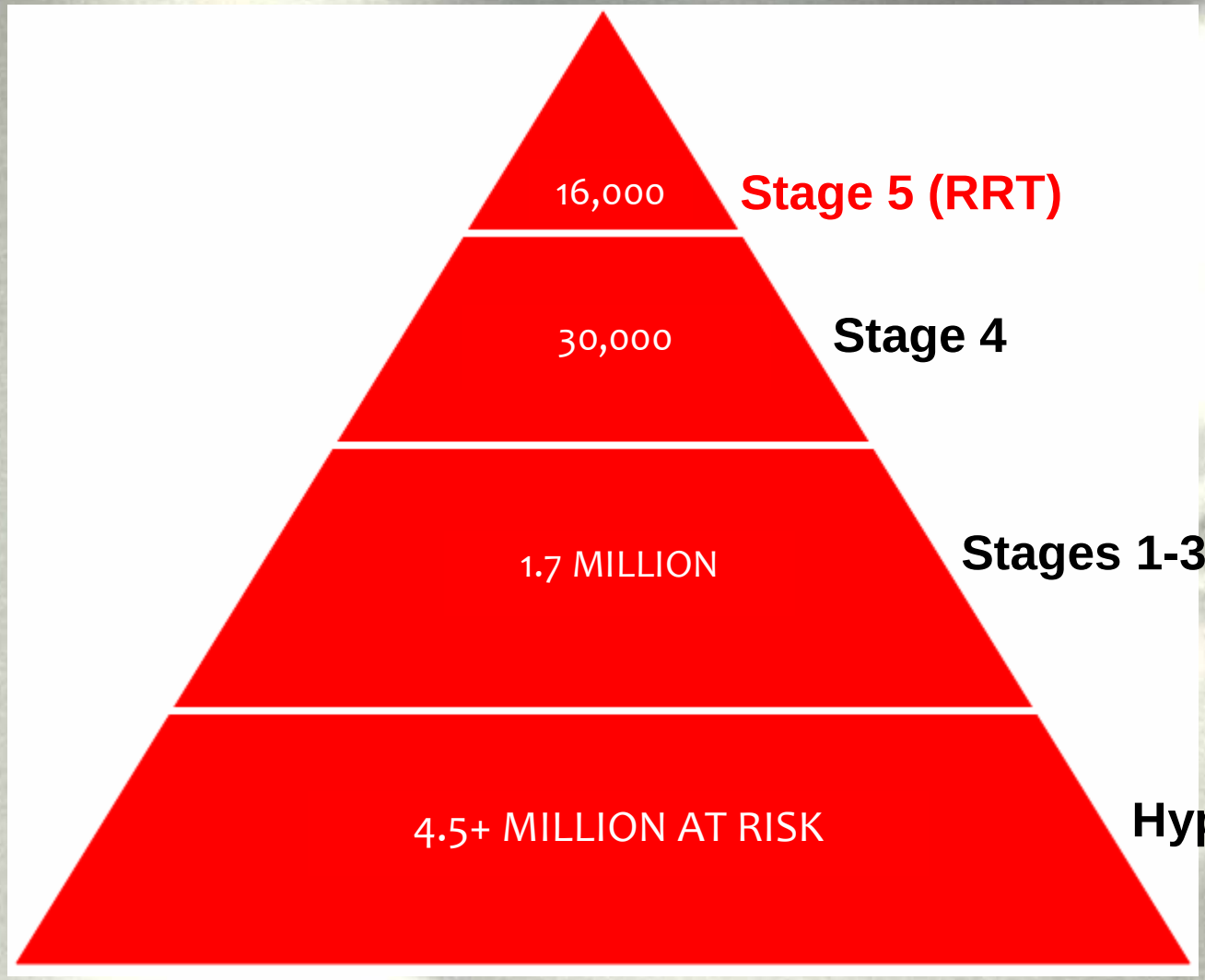


Understanding Conservative Care

- No renal replacement therapy
- Disease management
  - delay progression of renal impairment
  - minimise complications
- Active symptom assessment
- Holistic care
  - psychological, spiritual
- Communication and advance care planning
- Practical support (eg. OT, physiotherapy)
- Family support (education, decisions, bereavement care)
- Coordinated care (community, clinic, hospital)

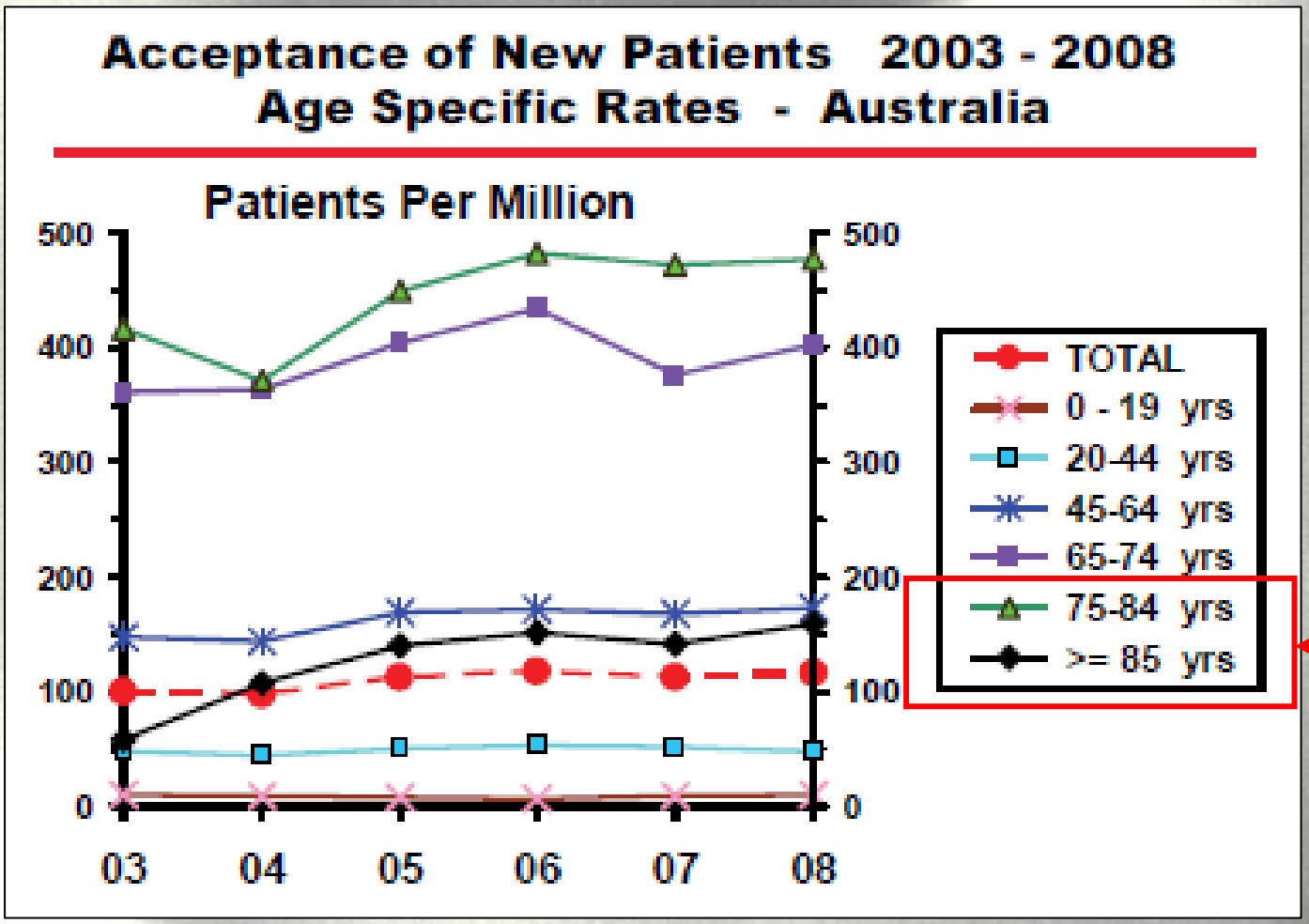

Stage 5 Renal Failure
Dialysis
Transplant
Dialysis TT
Conservative
Medical crisis
Failing
Success
Fail
Dialysis
Conservative
Dialysis
Conservative
Medical crisis
Failing
Medical crisis
Failing
Renal Conservative Care

CKD Population - Australia



AusDiab, 2005

New Dialysis Patients - Australia



ANZDATA, 2009

Renal Patients by State (2008)

National and State Stock and Flow 1-Jan-2008 to 31-Dec-2008

State	New Patients	Transplant Operations *	Deaths		Dialysis Dependent	Functioning Transplants # *	Total
			Dialysis	Transplant			
Queensland	508 (463)	140 (114)	337 (281)	43 (28)	1854 (1804)	1489 (1402)	**3343 (3206)**
New South Wales	792 (755)	223 (168)	464 (458)	46 (69)	3332 (3179)	2135 (2033)	**5467 (5212)**
Aust. Capital Territory	63 (55)	14 (14)	35 (31)	3 (6)	233 (215)	198 (192)	**431 (407)**
Victoria	527 (541)	219 (163)	311 (368)	24 (27)	2465 (2406)	1895 (1765)	**4360 (4171)**
Tasmania	52 (55)	26 (20)	28 (31)	3 (4)	177 (175)	177 (165)	**354 (340)**
South Australia	184 (165)	106 (74)	102 (90)	21 (15)	625 (624)	829 (783)	**1454 (1407)**
Northern Territory	89 (76)	4 (5)	56 (37)	3 (2)	398 (368)	74 (78)	**472 (446)**
Western Australia	261 (256)	81 (56)	149 (163)	24 (17)	978 (930)	744 (702)	**1722 (1632)**
Australia	**2476 (2366)**	**813 (614)**	**1482 (1459)**	**167 (168)**	**10,062 (9701)**	**7541 (7120)**	**17,603 (16,821)**

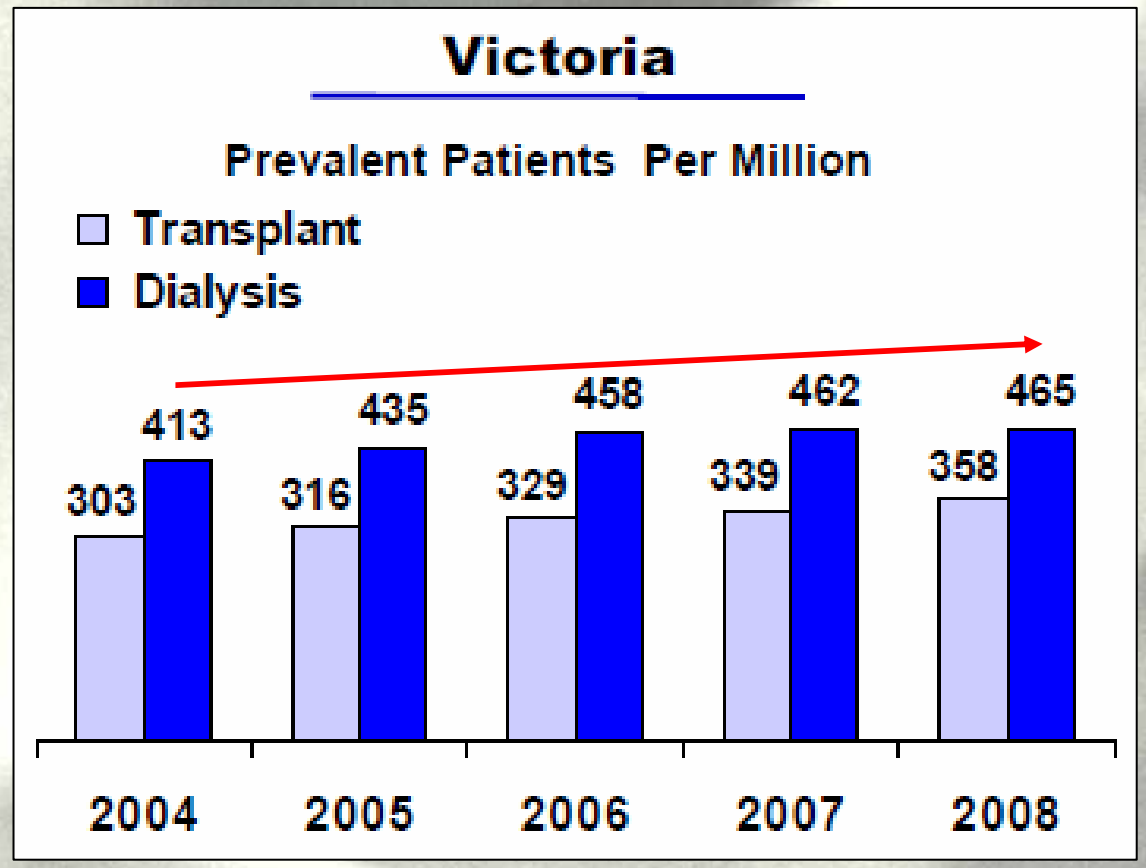
ANZDATA, 2009

Dialysis Patients by State

Dialysis	2004	2005	2006	2007	2008
Queensland	1443 (372)	1604 (405)	1705 (417)	1804 (431)	1854 (433)
New South Wales *	2556 (391)	2764 (421)	3024 (458)	3179 (476)	3332 (493)
Aust. Capital Territory *	185 (353)	192 (362)	205 (381)	215 (391)	233 (419)
Victoria	2055 (413)	2187 (435)	2348 (458)	2406 (462)	2465 (465)
Tasmania	147 (305)	156 (321)	163 (333)	175 (355)	177 (355)
South Australia	512 (334)	569 (369)	604 (385)	624 (394)	625 (390)
Northern Territory	279 (1396)	316 (1558)	334 (1585)	368 (1712)	398 (1810)
Western Australia	830 (419)	849 (422)	876 (425)	930 (442)	978 (452)
Australia	**8007 (398)**	**8637 (425)**	**9259 (447)**	**9701 (462)**	**10,062 (471)**

ANZDATA, 2009

Victorian RRT Population



ANZDATA, 2009

Current RCC in Victoria

- No State-wide care guidelines for non-RRT patients
  - some independent initiatives
- Victorian hospital staffing
  - conservative care = ???
- Ad hoc management, minimal data on patient numbers, symptoms, quality of life, longevity
- Without these data and comprehensive guidelines, conservative care can not confidently be offered

What We Need to Know

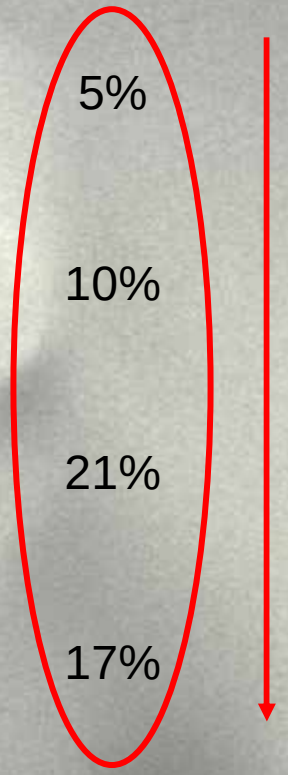
- Number of conservative care patients
  - not seen by primary care provider
  - not seen by nephrologist
  - another (primary) co-morbidity
- Length of patient involvement
- Professionals and services utilised and needed
- Patients' and professionals' healthcare goals

Melbourne Health Data

- Royal Melbourne Hospital (RMH)
- “No to dialysis” data (2004 – 2010)
- Social workers and dialysis coordinator
- Initial decision only
  - Subsequent outcome may be different

Saying “No” to Dialysis

Year	Registered patients	Said “no” to Dx	Percentage
2004 – 2005*	432	21	5%
2005 – 2006*	450	47	10%
2006 - 2007	337	70	21%
2007 - 2008	390	67	17%



** 2004 – 2006 data includes Western Hospital*

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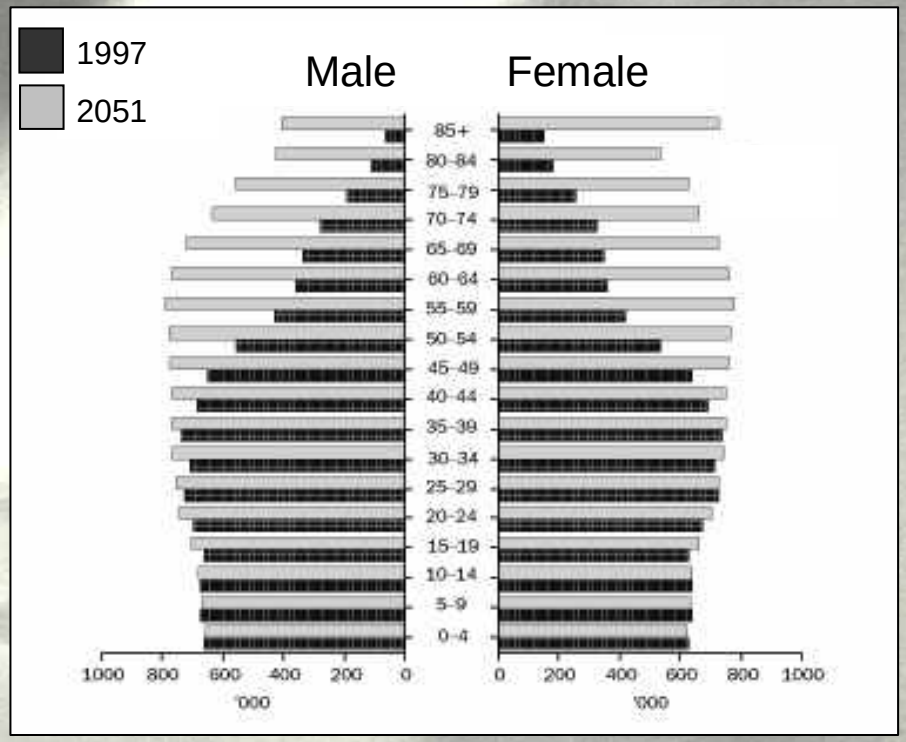
Anecdotal “No” Factors

- Ageing population
- Recognition
  - Medical issues
  - Autonomy
- Confidence
  - Experience
  - Research evidence



Reasons for "No" Decision

Primary reason	Cease Dx (*n=52*)	Not for Dx (*n=49*)	Trial Dx (*n=13*)	Yes to Dx (*n=5*)
Medical futility	23 *(44%)*	4 *(8%)*	3 *(23%)*	
Co-morbidities	13 *(25%)*	28 *(57%)*	1 *(8%)*	
Quality of life	3 *(6%)*	12 *(24%)*	2 *(15%)*	1 *(20%)*
Accepting of death	5 *(10%)*	4 *(8%)*		
Desire to live			6 *(46%)*	4 *(80%)*
Accept Dx if needed			1 *(8%)*	
Vascular access	3 *(6%)*	1 *(2%)*		
Social reasons	1 *(2%)*			
Improved function	1 *(2%)*			
Malignancy	1 *(2%)*			
Education/other	1 *(2%)*			
No reason recorded	1 *(2%)*			

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Key People in Decision Making

Primary decision maker	Cease Dx (*n=52*)	Not for Dx (*n=49*)	Trial Dx (*n=13*)	Yes to Dx (*n=5*)
Physician	18 *(35%)*	3 *(6%)*	1 *(8%)*	1 *(20%)*
Patient	21 *(40%)*	21 *(43%)*	6 *(46%)*	3 *(60%)*
Patient/Physician	7 *(13%)*	10 *(20%)*	2 *(15%)*	
Patient/Team	1 *(2%)*	9 *(18%)*		
Physician/Family	5 *(10%)*		2 *(15%)*	
Patient/Family		2 *(4%)*	1 *(8%)*	1 *(20%)*
Team		1 *(2%)*	1 *(8%)*	
Family/Carer		1 *(2%)*		
Physician/Team		1 *(2%)*		
Physician/POA		1 *(2%)*		

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Where “No” is Decided

Decision venue	Cease Dx (*n=52*)	Not for Dx (*n=49*)	Trial Dx (*n=13*)	Yes to Dx (*n=5*)
Ward review	30 *(58%)*	7 *(14%)*	7 *(54%)*	1 *(20%)*
Clinic	3 *(6%)*	28 *(57%)*	2 *(15%)*	2 *(40%)*
Long term Dx	13 *(25%)*			
Start Dx	1 *(2%)*		1 *(8%)*	1 *(20%)*
Acute start Dx	4 *(8%)*		2 *(16%)*	
Private rooms	1 *(2%)*	12 *(24%)*	1 *(8%)*	*1* *(20%)*
Fail Tx (clinic)		2 *(4%)*		

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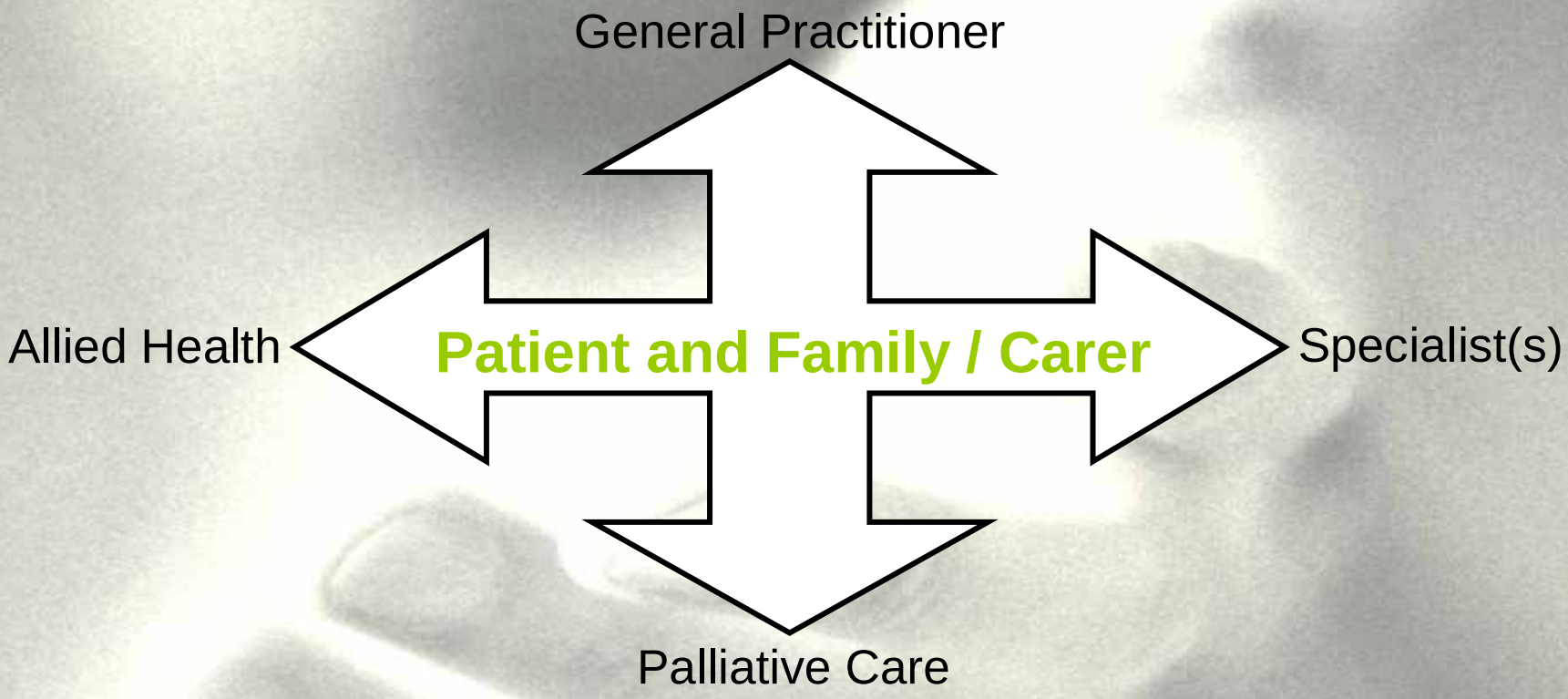
Interviews – 5 General Themes

1. Communication	C
2. Assessment	A
3. Recognition	R
4. Education	E
5. Planning	PLAN

1. Communication



1. Communication

Gene[illegible]Practiti[illegible]

Allied He[illegible]

Renal Conservative Care Nurse
Renal Conservative Care Case Manager

[illegible]Specialist(s)

[illegible]alliati[illegible]Care

1. Communication

- Discharge reports, clinic reports, GP consultations, pathology…
- End of life
  - Better use of PEPA program
  - Rotations
  - Other forms of education
- Patient support
  - Support groups
  - Needs of isolated patients

2. Assessment

- Patient medical assessment
- Patient goals assessment
- Personal situation
- Sound knowledge of literature
  - KPS and independence
  - Co-morbidity burden and risks
  - Survival variables and considerations

2. Assessment - Medical

- Symptoms
  - POS/1
  - Edmonton
- Quality of life
  - SF-36
  - Kidney Disease Quality of Life
  - WHO Quality of Life
- Quality of dying
  - Dialysis Quality of Dying APGAR
  - Palliative Outcomes Scale
- Cognitively impaired patients
  - DOLOPLUS2, PACSLAC
- Mental Health
  - K10
  - Beck depression inventory

- When
- Who
- Scoring
- Recording
- Monitoring

3. Recognition - Medical

Symptom	Overall prevalence (%)	Renal dialysis	End-stage COPD, CHF	Advanced cancer
Fatigue	76	71	84	73
Pruritus	74	55	26	27
Dyspnoea	61	37	86	23
Pain	53	47	49	63
Muscle cramps	50	46	-	-

Murtagh *et al* (2007); Murtagh *et al* (2007a); Tranmer *et al* (2003); Portenoy *et al* (1994)

3. Recognition - Medical

Symptom	Overall prevalence (%)	Renal dialysis	End-stage COPD, CHF	Advanced cancer
Restless legs	48	30	-	-
Lack appetite	47	49	43	44
Insomnia	41	44	64	53
Constipation	35	53	30	34
Nausea	26	33	28	45

Murtagh *et al* (2007); Murtagh *et al* (2007a); Tranmer *et al* (2003); Portenoy *et al* (1994)

3. Recognition – Other

- Patient wishes (ED)
- Sexual difficulties
- Family dynamics
- Mental health
- Talk of death and dying

4. Education - Professional

- Students and junior doctors
  - Palliative approach
- Medical staff
  - GPs in community and hospital staff
  - Rotations, PEPA
- Role/scope of palliative care
- Publication of guidelines
  - Australian Family Physician Journal
  - Annual review/guideline reminders
- Aged care facilities

4. Education - Patient and Carer

- Role/scope of palliative care
- Literature
- DVD
  - Reality of options
- Other resources
- Advance care planning

5. Planning

- Advance care planning
- Early referral
  - Nephrologist
  - Palliative care
- Symptom management
  - Pain and non-pain symptoms
  - Pharmacological and non-pharm approaches
- Life goals
  - The “bucket list”

Level 1 Recommendations

- Patient literature
- Assessment tools
  - use, record and monitor
- Advance care planning
- RCC clinic (PC consultant)
- RCC nurse/coordinator

Level 2 Recommendations

- Data collection
- Development of guidelines
- “Cardio card” equivalent
- Improve access to services
- Support for patients and family
- Further RCC clinic development

Level 3 Recommendations

- Research and evaluation
- Easier non-PBS medications access
- Medicare items
  - ACP
  - Chronic diseases planning
- Chronic diseases clinics
- Professional, undergraduate education