

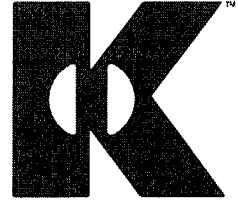
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Standing Committee on Health and Ageing

KIDNEY HEALTH AUSTRALIA

Submission to Enquiry into Health Funding

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Executive Summary

One in three Australians is at increased risk of kidney disease and one in seven has at least one indicator of chronic kidney disease (CKD). At the current rate of progression, the prevalence of patients requiring dialysis will double within a decade, and with an ageing population and increasing rates of diabetes, the rate is set to escalate even further.

There is conclusive evidence that the current practice of health funding is compounding the burden of disease for consumers, carers, professionals and the system as a whole. This submission highlights the following priority areas of concern:

- Reduction of risk of acquiring CKD
- Early detection of established cases of CKD
- Optimal care of people with CKD
- Timely referral of people with CKD
- Choice of mode of dialysis
- Transport
- Forward planning for dialysis
- Organ donation and transplantation
- Family support

Kidney Health Australia is the lead organisation nationally promoting kidney and urinary tract health through research, consumer participation, education and health service excellence. In its 36 year history it has built a significant evidence base to support its current planned expansion into facilitating an evidence based best practice National Chronic Kidney Disease Strategy through a multidisciplinary collaborative methodology designed to deliver significant economic and quality of life outcomes.

In this process, Kidney Health Australia calls for attention to health system funding reforms to reduce the burden of this disease and simultaneously positively influence health outcomes for those with other chronic conditions nationally.

Aims

This submission aims to identify areas in the spectrum of care for people affected by chronic kidney disease (from its earliest asymptomatic form through to established kidney failure) where current systematic funding issues impact adversely on kidney health care delivery.

Background

Chronic disease is a key factor in explaining the increasing demand for health services. In Australia, it is estimated that chronic disease is responsible for approximately 80% of the total burden of disease with an estimated three million Australians suffering from one or more chronic illnesses (1). A retrospective analysis of National Health Priority Areas agreed by Health Ministers as at 1999 (cardiovascular disease, mental disorders, cancer, injuries, diabetes and asthma), demonstrated that these diseases/conditions had accounted for about 40% of total expenditure (\$12.6 billion) in 1993-94 (2). Arthritis and musculoskeletal disorders were later added as a National Health Priority in 2002. Chronic kidney disease (CKD) is not recognized as a Health Priority area, and has received little or no attention by Government in recent times.

CKD is a common, under-recognized, progressive, preventable and treatable condition. Approximately 16% of the adult Australian population has at least one indicator of kidney damage (3), with evidence that kidney disease in the Aboriginal and Torres Strait Islander population is at epidemic proportions in some Australian regions. Moderate or severe CKD is present in 11% of the general population (approximately 1.8 million Australian adults) (3). The majority of these patients are un-diagnosed, primarily because kidney disease may remain relatively asymptomatic until kidney function is severely and irreversibly impaired. The risk of death (especially cardiovascular death) is directly related to the severity of kidney disease (4,5). Once CKD is diagnosed, appropriate therapeutic intervention has been demonstrated in large controlled trials to reduce the rate of progressive deterioration in kidney function by up to 50% (6).

End stage or established kidney failure (ESKF) results in about six new cases starting on Australian dialysis programs each day. The new case rate of kidney failure in Australia has doubled in the last 13 years with a mean annual growth rate of 7% (7). The increase is largely due to increasing numbers of people with diabetic kidney failure and the ageing population. The pool of people on dialysis is expanding due to this increased rate of recruitment exceeding the outflow rate. Exit from dialysis is only by transplantation (Australia has a low transplantation rate compared with international benchmarks) and from death (slightly reducing rate in recent years). These factors have been responsible for a doubling of the pool size (number of people receiving dialysis at any time) in the last decade. The mean annual ongoing increase in the size of the dialysis pool over the last five years is over 7%. This rate of rise is showing no sign of abatement. The experience in Australia is mirrored in most developed countries, and in the United Kingdom the forecast is for no equilibrium to be reached for 25 years (8).

Comprehensive costing of the burden of CKD (or indeed even of the ESKF component) in Australia is not available from AIHW, due to a lack of access to costs of out of hospital care and no ability to allocate the spending on high cost drugs used by kidney patients. Crude calculations based on each dialysis patient costing \$60,000/year and each transplant \$15,000/year allow the conclusion that Australia is spending at least \$570 million each year on ESKF and that this is increasing by \$27 million each year. An economic impact study of the full burden of CKD (from its early stages to the end of care) has been commissioned by Kidney Health Australia and will be available by November 2005. It is conservatively estimated that the result of this study will show that the UK estimate of over 2% of the Health budget being spent directly on kidney disease will be confirmed in Australia (9). Additional to this direct cost is the impact on social costs and the quality of life of those affected and their families.

It is achievable to significantly reduce the number of people presenting each year with ESKF. A multi-faceted program aimed at earlier case detection, improved uptake and application of evidence based therapies at the primary care level, and more timely and appropriate referral of patients for end stage care by a multi-disciplinary team have all been demonstrated to be effective (9-13). Whilst there are many different causes of kidney failure, most conditions follow a similar trajectory of progression, and the therapies that have the demonstrated ability to slow or halt the deterioration in kidney function apply to almost all kidney conditions.

United States projections conservatively estimate that appropriate therapeutic interventions for people with moderately severe CKD can result in a 10% reduction in the rate of further deterioration in kidney function (need reference). This translates for Australia into a saving of over \$500 million over the next 10 years. Despite the potential for both direct cost savings and quality of life improvements, there is not one Government program that has been funded to address any of these issues.

Issues in CKD management that are presently under-resourced

The pathway of a person with CKD from its earliest manifestation to the 'end stage' (dialysis or transplantation) or to death at any time is usually one of relentless slow progressive deterioration of kidney function when the condition is undetected and untreated. The problems, costs and impact on the life of those affected and their families are different at each stage along this pathway. This section summarises the opportunities (all requiring new programs or additional resource) for improving health care along this pathway.

Reduction of Risk of Acquiring CKD

Due to the commonality of risk factors, primary prevention measures aimed at reducing the incidence of diabetes, hypertension and cardiovascular disease are likely to significantly diminish the burden of CKD. Thus support for programs aimed at improved nutrition, increased physical activity and cessation of smoking underpin any program aimed at risk reduction and prevention of CKD.

Early Detection of Established Cases of CKD

To ensure that CKD is detected at an early stage the following issues must be addressed:

1. Improved diagnosis through opportunistic screening at primary care contact of high risk groups on an annual basis
2. Focussed community campaigns aimed at increasing CKD awareness and screening of high risk groups
3. Increasing case detection through the automatic reporting of kidney function results any time a chemistry blood test is performed
4. Implementing a cost effective health check in high-risk groups coordinated with other chronic conditions such as diabetes and cardiovascular disease.

Optimal care of people with CKD

Public and professional education campaigns are required to address the discrepancies that currently exist between evidence-based guidelines for the early detection and management of kidney disease and actual clinical practice. Kidney Healthy Australia presently coordinates general practitioner educational workshops and is committed to an expansion of this program including an on-line learning approach, but has limited resources to mount a significant nation-wide campaign. An evidence-based multidisciplinary campaign is essential given the size of the problem and the workforce shortage. In particular, the role of the practice nurse in providing optimal chronic disease care needs to be expanded at the primary care level.

Timely Referral of People with CKD

More than a quarter of people starting dialysis in Australia do not see a nephrologist until less than three months before its commencement. This patient group incurs extra cost, increased morbidity and a 10% increase in mortality over the subsequent 12 months compared to those who are referred earlier. Measures required to reduce this late referral rate include:

1. Improved education of the public and of professionals regarding the asymptomatic nature of CKD, the risk factors for developing CKD, and the implications of CKD for morbidity and mortality
2. Earlier detection of CKD at the primary care level
3. Clarification of referral pathways.

Choice of Mode of Dialysis

There are several different types or modes of dialysis, each with particular advantages and disadvantages, and varying associated costs. In several areas of Australia free informed choice of dialysis modality is not provided to the affected individual – rather a particular type of dialysis is imposed, usually predicated by cost saving and availability. For example, various impediments to home haemodialysis exist in some jurisdictions making it difficult or impossible for patients to choose this option, despite the fact that home haemodialysis is cheaper to deliver, and is associated with a higher rehabilitation rate, improved clinical outcomes (including morbidity and mortality associated with increased dialysis frequency) and enhanced patient satisfaction. The impediments to increased uptake of home haemodialysis include:

1. Shortage of training facilities
2. Lack of resources to buy purpose-designed home haemodialysis machines
3. Negative disincentive for physicians (loss of income)
4. Stress on family members who are required to assist with the dialysis procedure
5. No reimbursement for dialysis helpers (usually family) who are expected to spend 15-20 hours a week in attendance and to take full responsibility for the safety of the procedure (carers pension is denied to these helpers)
6. Costs of haemodialysis machine installation and extra power and water usage

Transport

For those people on haemodialysis travelling to a centre to receive treatment, transport is often difficult to coordinate and finance. Dialysis patients are required to travel to the hospital or satellite centre on three occasions each week, each time for five hours of treatment. For elderly or infirm persons unable to drive themselves for health or other reasons, this means relying on others, and often due to the side-effects of haemodialysis even patients who are otherwise fit to drive are unable to transport themselves home following a treatment session. Multiple schemes currently exist across States in Australia to facilitate this issue, but these options are patchy, often involving considerable costs and significant delays. A specially funded subsidy scheme, equivalent to the Patient Assisted Travel Scheme (PATS) is required.

Forward Planning for Dialysis

The growth rate of the dialysis pool (>7% per year) is such that another doubling in the number of people on dialysis will occur in the next 9-10 years unless in the interim definitive action reduces the input (new case rate) or increases the output from dialysis (more transplants). The estimated cost of dialysis alone in Australia at the end of the next decade will exceed \$1billion (in 2005 dollars). The growth rate of the dialysis pool requires:

- Forward planning or commitment of resource to avoid crisis management
- Substantial effort has been made in two States to address the issue (New South Wales and Victoria) but in only one of these (Victoria) has a commitment been made.

Organ Donation and Transplantation

Kidney transplantation is cost effective and results in significant improvement in rehabilitation and satisfaction for the affected individual and their family. The organ donation rate from deceased donors in Australia is low by international benchmarks. The rate of deceased donation varies significantly between like hospitals in the same city (up to four fold) and between States (South Australia has the double the rate of the next best State). The funding for organ donation agencies in Australian States is a fraction (approximately one-quarter) that of States in the United States where the national deceased donation rate is twice that of Australia. Substantial improvement in the Australian transplantation rate is believed possible if additional resources were available to:

1. Undertake a national audit of organ donor procurement performance in Australian hospitals
2. Utilise a collaborative methodology to establish best-practice organ donation policies and performance in Australian hospitals
3. Remove barriers to live donation, including financial disincentives
4. Undertake an open audit of organ allocation procedures.

Family support

The whole family is substantially affected by the presence of CKD in one member. Income is lost, physical activity reduced, contribution to family life adversely impacted and often there is absence of the affected individual for periods from the home for hospitalisation or for regular dialysis. Issues relating to the provision of adequate psychosocial support of people with CKD and their family/carers include:

- There is a substantial Australia wide shortage of renal social workers, no funds available to initiate support groups, and no programs addressing these needs (other than some ad hoc attempts by volunteers in a few dialysis units)
- The Commonwealth funded Cancer Support Groups Grants program is an example of an appropriate type of support that could greatly advantage many of the CKD patients and their families who are caught up in the net of kidney failure treatment and the associated stresses
- It is a fact that in Australian programs one person in four each year withdraws electively from dialysis (and subsequently dies) due to 'social' reasons. This disturbing statistic reflects in part the total absence of appropriate support programs for those affected and their families.

Conclusion

This submission highlights the major issues existing for CKD in Australia and the shortfalls in present delivery of health care to the area. The first ever report on CKD in Australia is soon to be released by the AIHW, which will add to our knowledge about the burden of kidney disease and its impact on Australians. The dominant facts are:

- The number of people affected by CKD is increasing
- The cost of treating each person with kidney failure is high
- Effective treatments to prevent or slow down progression of CKD are available and yet are poorly applied
- There is little recognition by Government of these issues and there are no programs in place aimed at early detection and appropriate management of CKD.

Detailed action plans addressing these issues are being developed through the CKD Strategy that will be complete within four months. Costs associated with these action plans and the economic impact of their implementation will also be available towards the end of 2005.

The expanding scope of the full burden of CKD, the complexities involved in addressing the clinical load and the high cost of its treatment, merit consideration of CKD as an area of special focus by the Australian Government. A strong case can be made for CKD status as a new National Health Priority area.

Summary Facts

1. In the general Australian community over age 25 there is **evidence of at least one indicator** of chronic kidney disease (proteinuria or reduced kidney function) in about **1 in 7 individuals** (3)

2. **One in 50 Australians has signs of more severe kidney damage** (3) e.g.

- GFR <30 ml/min (severe reduction)
- At least 2 of proteinuria, diabetes or hypertension (equates with an increased risk of progression)
- Already in end stage kidney failure

3. At the end of March 2004, **7,728 patients were alive on Australian dialysis programs** and 6,013 were alive with a functioning kidney transplant (7)

4. The contribution of kidney failure to mortality in Australia has been seriously underestimated due to historical reliance on a single coded cause of death. Poor concordance is evident between death certificates and ANZDATA Registry records. A conservative estimate is that **kidney failure causes or contributes to at least 9.5% of all deaths in Australia** (14)

5. The **death rate** (age standardised per 100,000) from kidney failure (underestimated as it is) **has risen 20% in the last 15 years in contrast to a fall in deaths from stroke (43%), chronic lung disease (42%), lung cancer (28%), coronary heart disease (60%) and asthma (50%)** and many other conditions over the same time interval (AIHW)

6. The rate of acceptance (population adjusted) onto Australian **dialysis programs** increased from 62 new cases/per million population (pmp) in 1992 to 98 new cases/pmp in 2003. This represents a mean **growth in actual numbers of patients of 7% year** over the last decade.

In contrast, the latest international figures available (2002) show that the new case rate for the USA was 336/pmp, Taiwan 365/pmp, Japan 254/pmp, Greece 165/pmp, Turkey 122/pmp and New Zealand 115 cases/pmp. There is no evidence to support the unlikely possibility that there is less CKD occurring in Australia, and thus it appears likely **we are delivering insufficient care for end stage kidney failure** (7,15).

7. Despite the comparatively low rate of entry of new cases to Australian dialysis programs the **prevalence of dialysis patients has continued to grow** in the last decade from 4,098 patients on dialysis at Dec 1994 to 7,728 patients at March 2004 representing a mean annual growth rate of 9% year. At the current rate of growth the **numbers on dialysis will double again in the next 10 years**. Factors driving this increased prevalence of dialysis patients (other than increased new patient entry) include:

- Patients leave dialysis only by dying or receiving a transplant
- The overall death rate for all dialysis patients (deaths per 100 patient years) has improved only marginally in the last decade (15.6 in 1993 versus 14.9 in 2002) (7)
- The number of transplant operations has increased only marginally in recent years (a 5 year mean of 463 operations/year from 1993-97 versus a 5 year mean of 529 from 1999-02), and only due to an increase in live kidney donation that has compensated incompletely for the low deceased donor rate (9)
- The number of transplants performed falls far short of demand as evidenced by a lengthening waiting time for transplantation and by the fact that only 5.8% of dialysed patients received a transplant in 2003 (7)

8. The new patient entry to dialysis programs is predicted to **grow further** for the following reasons:

- The incidence of kidney failure rises sharply with age and the **Australian population** is ageing
- The mean age of entry to Australian programs has risen steadily from 52.1 years in 1992 to 59.4 in 2002
- The age specific entry rate for those 75 years and over in Australia in year 2001 was 280/pmp compared with the USA entry rate of 1542 (Greece 620, Canada 410) indicating the likely presence of restrictions on the entry to dialysis programs in Australia for this age group at this time (15)
- **Diabetes** as a diagnosis of new patients entering dialysis programs **has increased** from 8.8 new cases/pmp in 1992 to 25 new cases/pmp in 2003. Diabetes is predicted in the next year to become the most frequent single cause of dialysis dependency (as is already the case in most European countries and in Nth America). Further growth in the number of diabetics presenting for dialysis is certain to occur

9. Whilst community screening for early kidney disease has not been shown to be cost-effective, **targeting groups at high risk for chronic kidney disease such as diabetes and hypertension, and those who smoke, are over age 50 and are from indigenous backgrounds increases the yield and appears to be worthwhile** (10).

10. Once CKD is diagnosed, appropriate therapeutic intervention has been demonstrated in large controlled trials **to reduce the rate of progressive deterioration in kidney function by up to 50%** (6, 11)

11. Surveys in Australia have shown there is a considerable deficiency in delivering this **evidence of prevention of progression and an unacceptably high rate of late referral to specialist care** of those with advanced kidney failure

- GP workshop pre-evaluations reveal a high level of uncertainty concerning management of kidney patients (16)
- Late referral (<3 months before first dialysis treatment) for specialist care occurs in 26% of patients at the current time (7)
- Late referral has been shown to increase the mortality, morbidity and cost of treatment of patients with end stage kidney failure (13)

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