

Status of chronic kidney disease prevention programs: International Federation of Kidney Foundation Members 2005/2007

Joanna M. Smith, Susan A. Mott and Wendy E. Hoy, and the Respondents for Member Organizations of the International Federation of Kidney Foundations

The International Federation of Kidney Foundations surveyed its members on chronic kidney disease 'prevention' programs in their regions and countries in 2005 and 2007. A profile was developed, representing 28 countries (56% response). Some form of screening activity was reported in 24 of the 28 countries (85.7%). Two countries (7%) had, or anticipated development of, legislated national screening. Programs were conducted by kidney foundations or research groups, and were variously population based, focused on high risk groups or opportunistic. Tests in 63% of responding programs included weight, height, blood pressure, blood glucose, dipstick urinalysis and serum creatinine. Several programs used the USA's Kidney Early Evaluation Program's and International Society of Nephrology's templates. World Kidney Day activities contributed significantly. Stated needs were for more government recognition, firm policies and approaches, and critically, resources. Repeat responders reported progress in 2007, particularly in government interest and education delivery. Despite difficulties, programs are developing in many regions. Most need more resources and some members need substantial and sustained assistance.

Kidney International (2008) **74**, 1516–1525; doi:10.1038/ki.2008.415; published online 27 August 2008

KEYWORDS: prevention and detection programs for chronic kidney disease; International Federation of Kidney Foundations

A few years ago, the International Federation of Kidney Foundations (IFKF) expanded its focus to include prevention of chronic kidney disease (CKD) and its detection and management. This report summarizes the status of such programs among IFKF member organizations and regions who answered questionnaires in 2005 and 2007.

RESULTS

A total of 50 countries and 69 organizations were surveyed. A total of 36 questionnaires and two letters/summaries were returned from 28 countries (56% response) and 34 organizations (49% response). These constitute the baseline profiles described.

Countries and regions

Table 1 shows the organizations who responded, the country and the year of the responses.

Programs reported

Argentina. Asociacion Solidaria de Insuficientes Renales conducts education and information programs and sporadic screenings of high-risk groups in local areas during educational congresses.

Australia. Kidney Health Australia has appointed a national task force and developed a national chronic kidney disease strategy. It has compiled a national education program, focused on general practitioners but distributed to all health professionals nationwide, a book on *Management of CKD in General Practice*, and developed an accredited practice nurse program. It is also piloting a CKD detection program in 3–4 communities, and has supported the population-based Aboriginal Chronic Disease Outreach Program in six remote health services. It endorses the National Aboriginal Community Controlled Health Organization's *National Guide to a Preventative Health Assessment in Aboriginal & Torres Strait Islander Peoples*, and the Indigenous chronic disease programs supported by Australian government agencies.

Bangladesh. There are local population-based rural and urban programs in Dhaka for screening of diabetes, hypertension, and proteinuria.

Correspondence: Wendy E. Hoy, School of Medicine, Royal Brisbane and Women's Hospital, Centre for Chronic Disease, University of Queensland, Herston, Queensland 4029, Australia. E-mail: w.hoy@uq.edu.au

Received 5 April 2008; revised 18 June 2008; accepted 24 June 2008; published online 27 August 2008

Table 1 | Responding IFKF member organizations, country and response year(s)

Asociacion Solidaria de Insuficientes Renales (ASIR), Argentina 2007
Kidney Health Australia (KHA), Australia 2005/2007
Aboriginal Chronic Disease Outreach Program (ACDOP), Australia 2005
Kidney Foundation (KF), Bangladesh 2007
Bulgaria Renal Association (BRA), Bulgaria 2007
Kidney Foundation of Canada (KFC), Canada 2005/2007
Czech Kidney Foundation (CKF), Czech Republic 2007
National Kidney Foundation Egypt (NKFE), Egypt 2005
Kidney Foundation of Fiji (KFF), The Republic of the Fiji Islands 2005
National Kidney Foundation India (NKFI), India 2005/2007
Tamilnadu Kidney Research Foundation (TANKER), India 2005/2007
Institute of Nova Kidney Foundation (INKF), India 2007
Patient's Kidney Foundation of Iran (PKFI), Iran 2007
Irish Kidney Association (IKA), Ireland 2005
Fondazione Italiana del Rene (FIR), Italy 2007
Renal Child Foundation (RCF), Italy 2007
International Kidney Evaluation Association Japan (IKEAJ), Japan 2007
Kidney Foundation Malaysia (KFM), Malaysia 2005/2007
Fundacion Mexicana del Rinon (FMR), Mexico 2005/2007
Kidney Foundation of Moldova (KFM), Moldova 2007
New Zealand Kidney Foundation (NZKF), New Zealand 2007
Kidney Watch Initiative (KWI), Nigeria 2005
Kidney Consultants International (KCI), Nigeria 2007
Kidney Foundation of Pakistan (KFP), Pakistan 2007
Kidney Foundation of Peru (KFP), Peru 2005/2007
Kidney Foundation of Samoa (KFS), Samoa 2007
National Kidney Foundation (NKF), Singapore 2005
National Kidney Foundation (NKF), South Africa 2005/2007
The Nierstichting/Dutch Kidney Foundation (DKF), The Netherlands 2005/2007
Turkish Kidney Foundation (TKF), Turkey 2005/2007
Anatolia Kidney Foundation (AKF), Turkey 2005/2007
Kidney Wales Foundation (KWF), United Kingdom (UK) 2007
Kidney Research UK (KRUK), UK 2005/2007
National Kidney Federation (NKF), UK 2005/2007
National Kidney Foundation (NKF), United States of America (USA) 2005/2007
National Kidney Foundation of Northeast New York (NKFENY), USA 2005
Northwest Kidney Center (NWK), USA 2007

Bulgaria. Bulgaria Renal Association began a CKD screening program of high-risk groups in 2007.

Canada. Czech Kidney Foundation conducts hypertension and glucose checks at community locations. British Columbia has a CKD screening initiative. The Canadian Society of Nephrology has developed guidelines for health professionals and educational tools. There is e-GFR reporting in Ontario, British Columbia, and Alberta. The Public Policy Council is investigating the feasibility of a national-targeted screening program.

Czech Republic. Czech Kidney Foundation and the Czech Society of Nephrology are preparing a registry of patients with CKD stage 4, and will consider extension to earlier stages of CKD, especially in high-risk groups. There is chronic disease screening in some outpatient nephrology services.

Egypt. No regular screening or education programs were reported in 2005.

Fiji. Education of high-risk groups is occurring. Limited screening is conducted as part of diabetes evaluations.

India. National Kidney Foundation India has rural detection and prevention programs in Chennai and Mysore and has started new education campaigns amongst school children. It also supports the Screening Education Evaluation Kidney Program in Mumbai (2005)—involving 21 centers and 53 community camps at last report. The Tamilnadu Kidney Research Foundation reports improved CKD awareness, is attracting additional sponsors, and has developed an important CKD publication. It also has new localized regular screening programs for company and bank employees and clubs, and camps to serve people in rural areas in Tamilnadu. Institute of Nova Kidney Foundation in Kerala, with other foundations, nongovernmental organizations, and government, has initiated diabetes and hypertension screening in rural and urban areas in all states, targeting adults.

Iran. No regular screening or education programs were reported in 2007.

Ireland. A plan for a national strategy was reported in 2005. It had established within the Health Services' executive a multidisciplinary professional and advocacy National Renal Strategy review group, which would develop a national plan to screen high-risk groups over the next year.

Italy. Fondazione Italiana del Rene has a mobile national screening program for high-risk groups, conducted from trucks and gazebos in city squares or main streets. It had reached 71 cities at the time of reporting.

Japan. Japan has had a legislated population-based CKD screening program since the 1970s, which has included school children and company workers, and since 1983, adults ≥ 40 years. They are offered periodic health checks which include urinalysis, and since 1992, serum creatinine. International Kidney Evaluation Association Japan commenced a version of the USA's National Kidney Foundation (NKF) Kidney Early Evaluation Program (KEEP) in 2006, screening high-risk groups.

Malaysia. Kidney Foundation Malaysia has established a nationwide screening campaign at the 20 Kidney Foundation Malaysia centers, targeting the general population. Screening for high-risk groups is based in hospitals.

Mexico. In 2005, screening of individuals was within diabetes programs only. Fundacion Mexicana del Rinon is to start a version of KEEP in 2008.

Moldova. A screening template was adapted from the International Society of Nephrology's (ISN's) prevention program, with people screened in the general practitioner setting.

New Zealand. Local screening of high-risk groups is encouraged, linked with screening for, and management of, diabetes.

Nigeria. In 2005, Kidney Watch Initiative reported multiple educational initiatives in many cities. Kidney Consultants International reported that there were no sustainable nationwide screening programs but there was improved CKD awareness and follow-up and referral of patients (2007).

Pakistan. There are screening programs for high-risk groups in rural and urban populations.

Peru. The newly formed NGO 'Rurum Wasi' has commenced a health education program in the rural highlands (Chacas and Huaraz).

Samoa. Kidney Foundation of Samoa launched a national population-based screening program, for early detection of noncommunicable chronic diseases.

Singapore. NKF Singapore has well-established programs of population-based health screening at the primary care level and of primary and secondary prevention.

South Africa. The Chronic Disease Outreach Primary Prevention Program at the Dumisane Mzamane African Institute of Kidney Disease has a pilot program in high-risk groups in 20 clinics in Soweto. Progress includes increased awareness and improved management of CKD by nurses, integration of chronic diseases more broadly, database training, and an Internet database. A new local population-based screening program is also beginning.

The Netherlands. DKF commenced its nationwide Niercheck campaign (Kidney Check: testing for proteinuria) in 2006. The University Hospital of Groningen's prevention of renal and vascular endstage disease (PREVEND) research program (1997) has conducted community-based screening. There is some evaluation of high-risk groups in general practice. Screening guidelines are being developed for general practitioners and non-nephrological specialists. An educational program for nurse practitioners and district nurses is about to start. An e-learning program is planned.

Turkey. The Chronic Renal Disease in Turkey Study was started in 2007. This includes screening for prevalence of CKD, hypertension and other kidney diseases in five different regions of Turkey (conducted through the Turkish Society of Nephrology (TSN) and the Turkish Kidney Foundation), and there had been 16,380 participants at time of reporting. TSN and the Universities were soon to commence a screening and follow-up program. Educational programs for health professionals and the general public were increasing (Anatolia Kidney Foundation, Turkish Kidney Foundation). A local pilot screening study was planned in Ufuk (Anatolia Kidney Foundation and Ufuk University). Merging of the social security systems has improved the availability of drugs, treatments, and services.

United Kingdom. A legislated National Service Framework for renal services is being established. The requirement for e-GFR testing at primary care level for at-risk patients started in 2007. A KEEP style program was expected to run as a pilot by late 2007. Identification of CKD has improved. Kidney Wales Foundation was to launch a pilot electronic care pathway for CKD detection and management in early 2008.

United States of America. The US NKF has had KEEP for several years, which screens high-risk groups in the community, at multiple sites, nationwide. It has also developed education materials for primary care providers, clinical practice tools, and public and patient education packages. It is developing a new program for the public-at-large—

Kidney Health Risk Assessment—which identifies CKD risk factors: at-risk individuals are provided educational materials and invited to the next free local KEEP screening. Finally, the NKF conducts and supports advocacy and government relations. The National Institute of Health's National Kidney Disease Education Program continues to evolve. It includes educational components for populations at high risk of CKD and a family reunion outreach program, and is now focused on standardization of serum creatinine measurement for use in e-GFR calculations. The Centers for Disease Control and Prevention designated CKD as a major public health issue in 2006, and has begun to develop a chronic kidney disease screening program, through collaboration with the NKF.

Target groups and settings

Most respondents designated high-risk groups as priorities for screening, such as people with diabetes, cardiovascular disease, hypertension, lipid disorders, obesity, older adults (>40 years in Singapore, older elsewhere), smokers, patients with kidney stone history, people with a family history of kidney disease, and high-risk ethnic or minority groups (Indigenous Peoples, Asian, South Asian, Pacific Islanders, African, Caribbean, and Hispanic origin were specifically cited). School children and youths were also specifically targeted (Argentina, India, Italy, Nigeria, Pakistan, Samoa, Singapore, The Netherlands, Turkey), and in Turkey, especially children with urinary incontinence or abnormal urine color.

There were several models of screening, often more than one existed within an organization or region. Community-wide screening was specified by some respondents (Australia, Bangladesh, Canada, India, Italy, Pakistan, Samoa, Singapore), targeting whole towns and villages, the general public or disadvantaged areas. Some described opportunistic screening (Moldova, Singapore, Turkey), and some conducted workplace screening through corporations, (Australia (pending), Canada, India, Japan, Samoa, Singapore). Pilot studies of community-based prevalence were underway in several target regions in Turkey, and rural house-to-house screening was being carried out in some areas of India and Pakistan.

Health care groups and providers especially targeted for education were: general practitioners, physicians, diabetologists, nurses, healthworkers and dietitians (Argentina, Australia, Bangladesh, India, Ireland, Italy, Mexico, Pakistan, Singapore, The Netherlands, USA), whereas legislators and social and economic policy makers were current or intended targets for education, lobbying and legislative changes.

The physical settings for screening were likewise various. Some were based on hospital outpatients and diabetic clinics (Czech Republic, Fiji, Mexico). Some included primary care or family practice/general practitioner settings (Australia, India, Ireland, Mexico, Moldova, South Africa, The Netherlands) and community health centers in townships and villages (Australia, Bangladesh, India, Pakistan). Community-based screening was conducted at health fairs, community pharmacies, corporate offices, churches, factories and shopping malls (Canada, India, Japan, Singapore). Some

programs used mobile clinics (Italy), or screened village-wide or house-to-house, whereas others had organized screening camps for high-risk groups (Tamilnadu Kidney Research, India). Children were often screened in schools (Japan, Singapore, Turkey).

Screening tests

Table 2 shows the elements of testing reported. The majority of programs (74%) included weight, height, blood pressure, a measure of blood glucose and a urine dipstick, and most routinely induced a serum creatinine measurement (63%). Some tested lipids and albumin-to-creatinine ratio (ACR) or protein-to-creatinine ratio (PCR) routinely, whereas others

included those tests and serum creatinine only if other conditions were met. At least seven organizations also did liver function tests, at least 'if required'.

Data management

Data management was electronic in most major programs, or was planned (Wales). Fiji and Peru were hoping for computer systems to be implemented and Malaysia had a paper-based system.

Frequently cited needs

- Recognition of CKD by governments as a health priority area.

Table 2 | Screening tests performed

Responding organization, or program, year	Weight	Height	Waist	BP	Urine dipstick	Blood glucose ^a	Tests as required				
							Serum creatinine	Hemoglobin ^b	HbA1c	Lipids	Urine ACR/PCR
Argentina, ASIR 2007	+	+	+	+	+	+	+			+	
Australia, KHA 2007											
Australia, ACDOP 2005	+	+	+	+	+	+/ ^a	+	+	+	+	+
Bangladesh, KF 2007	+	+		+	+	+ ^a	+				+
Bulgaria, BRA 2007	+	+	+	+	+	+ ^a	+	+		+	+
Canada, KFC 2005				+		+					
Czech Rep, CKF 2007	+	+		+	+	+ ^a	+	+	+	+	
Egypt, NKF 2005											
Fiji, KFF 2005											
India, NKFI 2005	+	+		+	+	+	+		+		
India, TANKER 2007	+	+		+	+	+	+				
India, INKF 2007	+	+	+	+	+	+ ^a	+	+ ^b	+	+	+
Iran, PKFI 2007											
Ireland, IKA 2005				+	+		+				
Italy, FIR 2007	+	+	+	+	+						
Italy, RCF 2007	+	+		+	+	+ ^a	+	+ ^b	+	+	
Japan, IKEAJ 2007	+	+	+	+	+	+ ^a	+	+ ^b	+	+	+
Malaysia, KFM 2005					+						
Mexico, FMR 2005				+	+		+				
Moldova, KFM 2007	+	+	+	+		+ ^a	+	+ ^b		+	+
New Zealand, NZKF 2007	+	+		+	+	+ ^a	+	+ ^b	+	+	+
Nigeria, KWI 2005											
Nigeria, KCI 2007											
Pakistan, KFP 2007	+	+	+	+	+	+ ^a	+	+ ^b	+	+	
Peru, KFP 2005											
Samoa, KFS 2007	+	+	+	+	+	+ ^a	+	+ ^b	+	+	+
Singapore, NKF 2005	+	+	+	+	+	+				+	
South Africa, Soweto 2007	+	+	+	+	+	+ ^a	+	+ ^b	+	+	+
The Netherlands, PREVEND, 2005	+	+		+	+	+ ^a				+	
Turkey, TKF 2007					+		+				+
Turkey, AKF 2007	+			+		+				+	
UK, KWF 2007											
UK, KRUK 2005											
UK, NKF 2007											
USA, NKFENY 2005	+	+		+	+	+	+	+		+	
USA, NKF 2005	+	+		+	+	+	+	+		+	
USA, NWKC 2007	+	+		+	+	+ ^a	+			+	+

ASIR, Asociacion Solidaria de Insuficientes Renales; KHA, Kidney Health Australia; ACDOP, Aboriginal Chronic Disease Outreach Program; KF, Kidney Foundation; BRA, Bulgaria Renal Association; KFC, Kidney Foundation of Canada; CKF, Czech Kidney Foundation; NKFE, National Kidney Foundation Egypt; KFF, Kidney Foundation of Fiji; NKFI, National Kidney Foundation India; TANKER, Tamilnadu Kidney Research; INKF, Institute of Nova Kidney Foundation; PKFI, Patient's Kidney Foundation of Iran; IKA, Irish Kidney Association; FIR, Fondazione Italiana del Rene; RCF, Renal Child Foundation; IKEAJ, International Kidney Evaluation Association Japan; KFM, Kidney Foundation Malaysia; FMR, Fundacion Mexicana del Rinon; KFM, Kidney Foundation of Moldova; NZKF, New Zealand Kidney Foundation; KWI, Kidney Watch Initiative; KCI, Kidney Consultants International; KFP, Kidney Foundation of Pakistan; KFP, Kidney Foundation of Peru; KFS, Kidney Foundation of Samoa; NKF, National Kidney Foundation; DKF, Dutch Kidney Foundation; TKF, Turkish Kidney Foundation; AKF, Anatolia Kidney Foundation; KWF, Kidney Wales Foundation; KRUK, Kidney Research UK; NKFENY, National Kidney Foundation of Northeast New York; NWKC, Northwest Kidney Center.

^aFasting blood glucose level performed as well as random blood glucose level.

^bFull blood count also performed.

- Assistance with program design, including program structure and administration.
- Information from the experience of other programs, invited speakers and exchange programs; educational and promotional materials; information and opportunities for training, development of clinical skills, and assistance with technology and information management and transfer.
- Assistance with database development, data analysis and data reporting in several countries that were generating data (Argentina, Czech Republic, New Zealand, Nigeria, Pakistan, Samoa, National Kidney Foundation India, Tamilnadu Kidney Research, India (reporting only), Malaysia, South Africa). Some organizations had adequate capabilities and resources (Bangladesh, Bulgaria, Iran, Italy, Mexico, Moldova, The Netherlands, Turkey, UK, USA).
- Funding and resources (any or more) in most settings, with the notable exception of Singapore, where programs were adequately resourced.
- Collaborative influence and clout from the IFKF and other bodies for advocacy with local authorities, both in countries with existing programs and those who wanted them.
- A more active role of the IFKF website as a repository of information, for referral, to expose current successes, and in promoting World Kidney Day (WKD). It was also suggested that the IFKF host more international meetings, help strengthen and expand partnerships with other organizations, corporations and government agencies, and facilitate links with big international organizations like the World Health Organization. Finally, it was suggested that IFKF link up with other CKD and chronic disease efforts on a global basis.

Impact of World Kidney Day

At the IFKF meeting in Dublin 2005, it was resolved to support the ISN's initiative of WKD, rather than create a separate platform for raising consciousness. Incidentally, Dr Joel Kopple, who founded the IFKF, was also the prime instigator of WKD. Respondents in 2007 were very positive about the impact of WKD, although some needed more time to assess. Respondents cited WKD's ability to rally awareness of the media, families, the general public, health care generalists and specialists, entire countries and the global community. It improved knowledge of the prevalence and risk factors for CKD, the need for early detection, and its potential for modification by good management. It prompted educational opportunities (Argentina, Australia, Canada, Czech Republic, National Kidney Foundation India, Tamilnadu Kidney Research, India, Italy, Nigeria, Peru, Turkey, UK, USA), targeted activities like walkathons, health fairs, exhibitions, art competitions, screening activities, national conferences and award ceremonies. It provided the occasion for petitions, delegations and presentations to government (India Institute of Nova Kidney Foundation, Malaysia, South Africa, USA National Kidney Foundation of Northeast New

York, USA Northwest Kidney Center) and for the official launch of the National Service Framework for renal disease in the UK and several other UK CKD programs. WKD coincided with the initiation of Niercheck in the Netherlands. It was suggested (by Italy) that the IFKF's website give more exposure to WKD and to the related activities and successes in responding organizations.

Progress 2005–2007

Organizations in Australia, Canada, India, Malaysia, Mexico, Nigeria, Peru, South Africa, The Netherlands, Turkey, United Kingdom and USA provided follow-up data. All reported some progress. Most cited growth in CKD awareness and improved management and program planning, and many cited additional education and prevention programs. Among them, only Nigeria and Peru still had no existing or imminent screening programs.

CONCLUSION

There are many limitations in this report. First, half the organizations did not respond. Lack of personnel, organizational stability, funding, morale and e-mail access undoubtedly contributed, so that the survey is heavily weighted in favor of organizations with something positive to report. Second, the questionnaires were not designed as research tools, most questions were open ended, answers were supplied in free form and the baseline and follow-up questionnaires were not worded in precisely the same way. Third, the necessary paraphrasing, grouping, and compression of answers limit accuracy and potential for discernment. Fourth, the answers are already outdated for all respondents, even those who replied in 2007, and they are seriously outdated for those whose most recent response was in 2005.

Nonetheless, the report shows considerable activity in CKD detection and prevention activities in some of the regions that the IFKF membership represents. The larger organizations and those in affluent countries with stable governments report progress. The best prospects for strong and sustained programs are likely to be those that can be embedded in national health care policy and practice. However, the productivity of KEEP in the USA shows what affluence and the support of major academic/scientific organizations can achieve.

Smaller organizations or those in resource-poor regions are struggling and some have not been able to develop programs at all. Some felt discouraged and isolated, and uncertain about available assistance and how to access it. These especially, and other programs to various degrees, need robust and committed support. The current models of assistance, which include visiting speakers, small short-term grants, exchange scholarships and gratis help from other organizations, need to be supplemented by strong and sustained help and funding mechanisms. Each country or region should be supported in conducting limited prevalence studies of disease and risk factors, and then in persuading governments to support policies of prevention, early

detection, and treatment. The argument would be based on humane grounds, as well as on cost effectiveness, estimates of which should factor in delay of disability and death in the most economically productive members of society. Major grants for multinational programs should be pursued, with potential sponsors identified like the Bill Gates Foundation, the Wellcome Trust, World Health Organization, and the World Bank. Such agencies would be more attracted if initiatives were linked to chronic disease more broadly; a concept, which the broad menu of tests for CKD, proffered by the respondents in this study, already accommodates.

METHODS

In early 2005 questionnaires were sent by e-mail and post to IFKF members, using the executive's contact list. A compilation of replies was presented at the Dublin IFKF meeting in May 2005, and sent out by e-mail in September 2005. In 2007, organizations that responded in 2005 were sent a follow-up questionnaire, whereas the 13 new members of IFKF, and those who had not previously responded, were sent the original questionnaire.

The nature of, or opportunities for, 'prevention' programs, regionally or nationally, were queried, together with the setting of such activities, groups targeted for screening and education, screening tests performed and data management methods and requirements. They were also asked for their impression of program prospects, challenges and obstacles, and the extent of government and nongovernment support or collaborations. These questionnaires are shown in the appendix.

DISCLOSURE

All the authors declared no competing interests.

ACKNOWLEDGMENTS

Respondents

Argentina 2007

Mrs Maria Eugenia Vivado Duran, Asociacion Solidaria de Insuficientes Renales, Buenos Aires, Argentina

Australia 2005

Dr Marie Ludlow, Kidney Check Australia Taskforce, Kidney Health Australia, North Adelaide, SA, Australia

Australia 2007 FU

Mrs Anne Wilson, Dr Marie Ludlow, Kidney Health Australia, Melbourne, Victoria, Australia

Bangladesh 2007

Dr Harun ur Rashid, Kidney Foundation, Dhaka, Bangladesh

Bulgaria 2007

Professor Dr Zdravko Kraev, Professor Dimitre Nenov, Bulgaria Renal Association, Sofia, Bulgaria

Canada 2005

Mr Gavin Turley, Ms Beryl Ferguson, Kidney Foundation of Canada, Montreal, Quebec, Canada

Canada 2007 FU

Mrs Marlene Shoucair, Kidney Foundation of Canada, Montreal, Quebec, Canada

Czech Republic 2007

Professor Vladimir Tesar, Czech Kidney Foundation, Prague, Czech Republic

Egypt 2005

Professor Adel Afifi, National Kidney Foundation Egypt, Cairo, Egypt

Fiji 2005

Mr Hector Hatch, Dr Joji Malani, Kidney Foundation of Fiji, Suva, The Republic of the Fiji Islands

India 2005

Dr VN Acharya, Colonel Satnam Singh, National Kidney Foundation India, Mumbai, India

India 2005

Dr Suresh Sankarasubbaiyan, Dr Georgi Abraham, Tamilnadu Kidney Research Foundation, Chennai, India

India 2007 FU

Mrs Latha Kumaraswami, Tamilnadu Kidney Research Foundation, Chennai, India

India 2007 FU

Dr VN Acharya, National Kidney Foundation India, Mumbai, India

India 2007

Dr Karunan Kannampoyilil, Institute of Nova Kidney Foundation, Kerala, India

Iran 2007

Dr Mitra Mahdavi-Mazdeh, Patient's Kidney Foundation of Iran, Iran

Ireland 2005

Mr Mark Murphy, Ms Ashling Hand, Irish Kidney Association, West Dublin, Ireland

Italy 2007

Professor Vittorio E. Andreucci, Fondazione Italiana del Rene, Naples, Italy

Italy 2007

Professor Rosanna Gusmano, Renal Child Foundation, Genova, Italy

Japan 2007

Dr Susumu Takahashi, International Kidney Evaluation Association Japan, Gobancyo, Chiyoda-ku, Tokyo

Malaysia 2005–2007 FU

Mr Goh Sen Chuan, Kidney Foundation Malaysia, Petaling Jaya, Selangor, Malaysia

Mexico 2005

Dr Alejandro Trevino Becerra, Fundacion Mexicana del Rinon, Mexico DF, Mexico

Mexico 2007 FU

Mr Leopold Garvey, Fundacion Mexicana del Rinon, Mexico DF, Mexico

Moldova 2007

Dr Igor Codreanu, Fundatia Renala Moldova, Chisinau MD, Republic of Moldova

New Zealand 2007

Professor Kelvin Lynne, New Zealand Kidney Foundation, Christchurch, New Zealand

Nigeria 2005

Mr Uche Okpa-Iroha, Kidney Watch Initiative, Lagos, Nigeria

Nigeria 2007 FU

Mr Adebayo Sokunbi, Kidney Consultants International, Lagos, Nigeria, West Africa

Pakistan 2007

Mr Jaffa Naqvi, Kidney Foundation, Pakistan

Peru 2005

Dr Abdias Hurtado, Kidney Foundation of Peru, San Isidro, Lima, Peru

Peru 2007 FU

Dr Abdias Hurtado, Dr Elizabeth Escudero, Kidney Foundation of Peru, San Isidro, Lima, Peru

Samoa 2007

Dr KS Prabhakar, Kidney Foundation of Samoa, Motootua, Apia, Samoa

South Africa 2005–2007 FU

Professor Ivor Katz, Dumisane Mzamane African Institute of Kidney Diseases, Chris Hani Baragwanath Hospital, Soweto, Johannesburg, South Africa

Singapore 2005

Dr KS Prabhakar, National Kidney Foundation, Singapore

Singapore 2005

Dr Jeremy Lim, for TT Duraii, National Kidney Foundation, Singapore

The Netherlands 2005–2007 FU

Dr Elisabeth W. Boeschoten, Naarden, The Netherlands

The Netherlands 2005–2007 FU

Dr Paul E. De Jong, Groningen, The Netherlands

Turkey 2005–2007 FU

Professor Dr Ayla San, Anatolia Kidney Foundation, Ankara, Turkey

Turkey 2005–2007 FU

Mr Timur Erk, Turkish Kidney Foundation, Istanbul, Turkey

United Kingdom 2007

Professor John Williams, Mr Roy Thomas, Kidney Wales Foundation, Cardiff, Wales, UK

United Kingdom 2005

Mr Nick Turketine, Mr Charles Kernahan, Kidney Research UK, Priestgate, Peterborough, UK

United Kingdom 2007 FU

Mr Charles Kernahan, Kidney Research UK, Priestgate, Peterborough, UK

United Kingdom 2007 FU

Mr Timothy F. Statham, National Kidney Federation, Workshop, Nottinghamshire, UK

United States of America 2005

Mrs Geraldine Biddle, for the National Kidney Foundation of Northeast New York, New York, USA

United States of America 2005

Ms Monica Gannon, Mr John Davies, National Kidney Foundation, New York, USA

United States of America 2007 FU

Ms Lesley Pratt Dyer, National Kidney Foundation, New York, USA

United States of America 2007

Dr Leanna Tyshler, Ms Joyce F Jackson, Northwest Kidney Centers, Seattle, USA

Concept and development support

Dr Tim Mathew, Kidney Health Australia, North Adelaide, SA, Australia

Mrs Geraldine Biddle, World Foundation for Renal Care, Albany, USA

Project support

The Presidents and Executive 2005 and 2007, International Federation of Kidney Foundations: Mr Paul Beerkens, Mrs Anne Wilson, Professor Sudhir Shah, Prof Miguel Riella, Dr Vittorio Andreucci, Dr Allan Collins, Mr Knud Erben, Mr Timur Erk, Professor Joel Kopple, Mr Warwick Prime, Marianne Vennegoor

APPENDIX: DATA COLLECTION INSTRUMENTS**1. IFKF 2005 Initial CKD Questionnaire****IFKF 2005 Initial CKD QUESTIONNAIRE**

Name:

Country or Area being represented:

Address:

Phone:

Email:

1. What is actually happening with prevention and detection?
2. What would you like to see happening?
3. What are the target education and screening groups?
4. In what settings would you test?

5. What do (or would you) test for?
6. What would you test with?
7. How would you follow the data and outcomes?
8. What information systems do you have?
9. What are the prospects for the programs spreading further?
10. What are the prospects for sustainability?
11. In what ways do you work with other organisations, in public health, primary care, diabetes, cardiovascular disease, hypertension, lung associations, etc?
12. What are your links to government and other powerful groups?
13. What is the level of your country's commitment?
14. What are your unmet needs?
15. How could you be helped?

**IFKF
2007 Initial CKD QUESTIONNAIRE**

Kidney Disease, Prevention and Detection
(and related chronic diseases e.g. diabetes, hypertension, cardiovascular disease)

Name:

Country or Area being represented:

Address:

Phone:

Email:

Please Read Attached Letter

1. What is actually happening in your country concerning the early detection and prevention of kidney disease (and related chronic diseases e.g. diabetes, hypertension)?
Consider your organization, as well as others who may also screen for CKD.
2. What would you like to see happening? Within your foundation? In your area?
Country wide?

3. What are your target groups for CKD education?
4. Do you have strategies for public and individual education?
 Public (Yes, No)....Describe

 Individual (Yes, No)....Describe

5. What are your target groups for screening (or would be, if you were planning it or could do it)?
 Currently screening? (Yes, No)
 Current target groups.....

 Desired target groups.....

6. In what settings do (or would you) test?
 Current settings.....

 Desired settings.....

7. What do (or would you) test for?
Currently test for.....
 Weight Yes, No; Height Yes, No; Waist Yes, No;

 BP Yes, No; Blood Glucose Yes, No; Haemoglobin
 Yes, No; Dipstick Urine Protein Yes, No; ACR Yes, No;
 PCR Yes, No;

Where indicated:
 Fasting Blood Glucose Yes, No; HbA1c Yes, No; Lipids Yes, No;
 Full Blood Exam Yes, No; Liver Function tests Yes, No; Urea/Elects/Creat
 Yes, No;
 Other.....
- Desired to test for.....
8. What do (or would you) test with?
Currently test with:
 Finger prick - Glucose Meter Yes, No; Haemacue (Hb) Yes, No; DCA2000 (HbA1c)
 Yes, No; Pathology Laboratory Yes, No;. Other.....
- Desire to test with:.....

9. Do you collect and manage data from screening programs?.....
 What screening "outcomes" do you follow?
10. In what form is your screening information stored? (On computer? Paper copy only?)
 If computers are used, what software is being used?
11. What are the prospects for initiation/expansion of screening programs in your area?
 (Locally, Regionally, Nationally?), Don't know,
12. What are the prospects for long term sustainability? Explain:
 Excellent.....

 Good.....

 Poor.....

 Don't know.....

13. Do you work with other health related organizations on CKD screen and education programs? (public health systems; primary care systems; diabetes; cardiovascular disease; hypertension; lung associations; etc?)
 Yes...
 No...List/Explain:.....

14. What are your links to government and other influential groups?
15. Does your Government's Health Portfolio have formal policies about Chronic Disease early detection and treatment programs? (Yes, No, Don't know)
 What is the level of their commitment?
16. Does your Government's Health Care System have formal policies about Chronic Disease early detection and treatment programs? (Yes, No, Don't know)
 What is the level of their commitment?
17. Has the announcement of World Kidney Day made an impact in your setting?
18. What are your unmet needs as they relate to CKD early detection and treatment programs?
19. Do you need help with data analysis and reporting? Yes, No, Explain..
20. In what other manner can the IFKF be of help to your foundation?

We thank you enormously for your time and input to complete this questionnaire.

Wendy Hoy Email: w.hoy@uq.edu.au and Jo Smith Email: j.smith@uq.edu.au

IFKF
FOLLOW UP QUESTIONNAIRE 2007
Kidney Disease, Prevention and Detection
(and related chronic diseases - Diabetes, Hypertension, Cardiovascular Disease)

*What changes, progress, challenges have happened in your
 Chronic Kidney Disease (CKD) Program since the 2005 IFKF Conference?*

*Have any new CKD programs commenced in your country?
 Your previously completed Questionnaire is attached to assist you.*

Please Read Attached Letter

Name:

Country or Area being represented:

Address:

Phone:

Email:

Since the May 2005 IFKF Conference:

1. What positive changes have happened in your CKD early detection and prevention program?
2. Have any new CKD early detection and prevention programs begun in your country?
3. What further challenges or difficulties have you experienced in your program; or in trying to set up a program?
4. Have any of the responses you gave in 2005 for the question "What would you like to see happen" become a reality for you? (See previous response attached)
5. What are your target groups for CKD education now?

 Do you have strategies for public or individual education?
 Public (Yes, No)....Describe
 Individual (Yes, No)....Describe
6. Does your Government Health Portfolio have formal policies about Chronic Disease early detection and treatment programs? (Yes, No, Don't know)
 What is the level of their commitment?
7. Does your Government's Health Care System have formal policies about Chronic Disease early detection and treatment programs? (Yes, No, Don't know)
 What is the level of their commitment?
8. What are your target groups for screening now (or would be, if you were planning it, or could do it?)
 Currently screening? (Yes, No)
 Current target groups

 Desired target groups
9. In what form is your screening information stored? (On computer? Paper copy only?) If computers are used, what software is being used?
10. Do you need help with data analysis and reporting? Yes, No, Explain..
11. What practical, helpful support have you received in the past 2 years in your program; or in trying to set up a program?.
12. In what way has the announcement of World Kidney Day made an impact in your setting?
13. Do you have any suggestions or experiences to offer to organizations starting new programs?
14. In what other manner can the IFKF be of help to your foundation?
15. Any other Comments welcomed

We thank you enormously for your time and input to complete this questionnaire.

Wendy Hoy Email: w.hoy@uq.edu.au and Jo Smith Email: j.smith@uq.edu.au