

**13TH REPORT OF
THE MALAYSIAN DIALYSIS & TRANSPLANT
REGISTRY
2005**

Sponsors:

Malaysian Society of Nephrology
Association of Dialysis Medical Assistants and Nurses

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to this Report*

&

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Abbreviations

CAPD	Continuous Ambulatory Peritoneal Dialysis
CCPD/APD	Continuous cycling peritoneal dialysis/automated peritoneal dialysis
CRA	Clinical Registry Assistant
CRC	Clinical Research Centre
CRM	Clinical Registry Manager
ADMAN	Association of Dialysis Medical Assistant and Nurses
ESRD	End Stage Renal Disease
HD	Haemodialysis
MOH	Ministry of Health
MSN	Malaysian Society of Nephrology
MOSS	Malaysian Organ Sharing System
NRR	National Renal Registry
NGO	Non-governmental organization
pmarp	per million age related population
RRT	Renal replacement therapy
SDP	Source data producer
TX	Transplant

**NRR Advisory Committee Members
2004 to 2006**

MSN Nominees

CHAIRMAN:	Dr. Zaki Morad B Mohd Zaher
MEMBERS:	Dr. Lim Teck Onn
	Dr. Lim Yam Ngo
	Dr. T. Thiruventhiran
	Dr. Tan Hee Wu
	Dr. Wong Hin Seng

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	Norlida Omar
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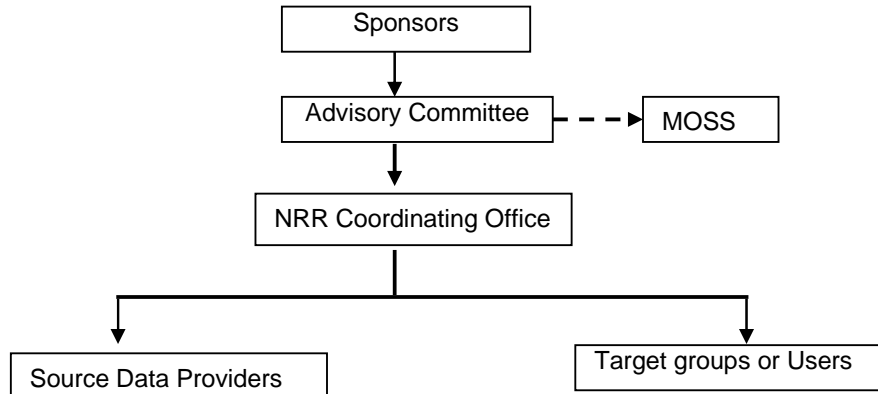
About the National Renal Registry

The National Renal Registry (NRR) has its origin in the Dialysis and Transplant Registry established by the Department of Nephrology in 1992. The sponsors of NRR are the Malaysian Society of Nephrology (MSN) and Association of Dialysis Medical Assistants and Nurses (ADMAN).

The objectives of NRR are to:

1. Determine the disease burden attributable to End Stage Renal Disease (ESRD), and its geographic and temporal trends in Malaysia.
2. Determine the outcomes, and factors influencing outcomes of Renal Replacement Therapy.
3. Evaluate the RRT program.
4. Stimulate and facilitate research on RRT and ESRD.
5. Maintain the national renal transplant waiting list.

The NRR organization is as follows:



Sponsors

The Malaysian Society of Nephrology is the sponsor of the National Renal Registry (NRR) and Malaysian Organ Sharing System (MOSS) and the co-sponsor is the Association of Dialysis Medical Assistants and Nurses.

Advisory Committee

This is the committee established by the sponsors to oversee the operations of the registry and MOSS. Interested parties including source data producers, Renal Registry Unit and target groups or users are represented on this committee.

National Renal Registry Office

The NRR office is the coordinating center that collects and analyses the data. It publishes the annual report of Malaysian Dialysis & Transplant Registry and the Directory of Dialysis Centres in Malaysia. The Clinical Registry Manager (CRM) oversees the daily operation of the NRR. The Clinical Research Centre of Hospital Kuala Lumpur provides the epidemiological, statistical and information technological support to NRR.

Source Data Producers

These are the dialysis centres that collect the required data. It is the most critical and yet difficult element of the system. It has to be systematic and uniform, and producers of source data need to be trained and motivated to ensure high data quality.

Users or Target groups

These are the individuals or institutions to whom the regular registry reports are addressed. It is their need for information to assist in the planning and implementing disease treatment, control and prevention activity that justify the investment in the registry. They include:

1. the renal community
2. the RRT provider
3. the public health practitioner
4. the decision maker in various government and non-government agencies who have responsibilities for any aspects of ESRD treatment, prevention and control
5. the researcher with an interest in ESRD and RRT.
6. the press and the public.

About MOSS

Cadaver organ transplantation activity has noticeably increased in the last decade in Malaysia. A recurring issue of concern was how and to whom cadaver organs are allocated. In 1999, the Malaysian Society of Nephrology (MSN) had established a committee, which was tasked to initiate the development of a national organ-sharing network. The network was referred as the Malaysian Organ Sharing System or MOSS in short, and the committee was thus named MOSS committee

The functions of the MOSS committee thus established then under MSN were to:

1. Make policy decisions concerning MOSS.
2. Secure funding from various sources to support MOSS operation.
3. Designate a place to be the coordinating centre for the operation of MOSS.
4. Canvass the view of nephrologists and other clinical staff involved concerning the policy and operation of MOSS.
5. Oversee the operation of the MOSS.
6. Employ a manager and other necessary support personnel to manage the day-to-day operation of the MOSS.
7. Appoint panel of nephrologists to examine eligibility of potential recipients

The objectives of MOSS in turn as established by the MOSS Committee were:

1. To maintain a list of patients who have voluntarily enrolled as potential recipients in the cadaveric kidney transplantation program
2. To prioritise the waiting list according to an agreed criteria and scoring system
3. To update the waiting lists at periodic intervals according to specified criteria
4. To provide a list of suitably matched potential recipients based on agreed criteria when a cadaver organ is available
5. To prepare an annual report of the status of the cadaveric kidney transplantation program including the waiting list, donor status and outcomes

The National Renal Registry (NRR), which was then sponsor by MSN, was directed to assist in the setting up of MOSS and to make available its database to support MOSS operations. From this database, a transplant waiting list was generated and indeed was in use.

However, the subsequent operations of MOSS such as in entering new patients into the list, maintaining and updating the list, updating patient's information and so on, turned out to be logistically more difficult than had been expected. Over the years, various manual systems and procedures had been tried to coordinate and support the activities of the various parties involved in the transplantation process. In particular:

1. The nephrologist caring for dialysis patients who are potential recipients need to be able to efficiently put their patients on the list, update their patients' data, and take them off the list temporarily or otherwise when necessary.
2. The Transplant Centre performing the transplant surgery obviously need timely access to the recipient wait list that is ranked according to pre-determined criteria, as well as to access their contact information in order to inform patients to come forward for transplant when an organ becomes available. At the same time, the transplant surgeon will want to review the selected patients' clinical information relevant to the transplant surgery.
3. The National Renal Registry is the channel through which nephrologists or dialysis centres notify patients in order to put patients on the wait list.
4. And finally, the MOSS Committee needs to be able to convey its policy and operational decisions to users, such as on assigning patients to nephrologists for the purpose of managing their wait list status, adjudication on patient eligibility for transplant and their ranking on the list, final decision on entry into the SOS list.

In early 2004, the MOSS Committee proposed to MSN council to support the development of a web based system, named eMOSS, to support the operations of MOSS. The nature of MOSS operations, involving multiple parties spread throughout the country was ideally suited for web-based automation. The proposal was accepted and funds allocated for the development. The NRR and the Clinical Research Centre (CRC) were tasked with undertaking this project, and also to help fund it in part.

eMOSS website is allocated in <http://www.msn.org.my> . You may down load a copy of the user manual from the website. This website is reinforced with high security. There are pre-set rules to the access right according to the approved guideline. Access to the patients information is however restricted to authorized and designated user only. To get your password please contact the MOSS coordinator at e-mail: moss@msn.org.my.

PARTICIPATING HAEMODIALYSIS CENTRES

1. 801 Rumah Sakit Angkatan Tentera (Kucing)
2. 819 Rumah Sakit Angkatan Tentera
3. 94 Hospital Angkatan Tentera (Terendak)
4. 96 Hospital Angkatan Tentera (Lumut)
5. Aiman Dialysis Centre
6. Alor Gajah Dialysis Centre
7. Alor Gajah Hospital
8. Alor Setar Hospital
9. AMD Rotary (Penang)
10. Amitabha Centre
11. Amitabha Haemodialysis Centre Johor Bahru
12. Ampang Puteri Specialist Hospital
13. Asia Renal Care (Penang)
14. Assunta Hospital
15. Bakti-NKF Dialysis Centre
16. Balik Pulau Hospital
17. Baling Hospital
18. Bangi Dialysis Centre
19. Banting Hospital
20. Batu Gajah Hospital
21. Batu Pahat Hospital
22. Batu Pahat Rotary
23. Bau Hospital
24. Beaufort Hospital
25. Beluran Hospital
26. Bentong Hospital
27. Berchaam Dialysis Centre
28. Berjaya NKF Dialysis Centre
29. Besut Hospital
30. Betong Hospital
31. Bintulu Hospital
32. BP Renal Care (Batu Pahat)
33. BP Renalcare (Segamat)
34. BP Renalcare (Yong Peng)
35. Buddhist Tzu Chi Dialysis Centre (Butterworth)
36. Buddhist Tzu-Chi Dialysis Centre (Jitra)
37. Buddhist Tzu-Chi Dialysis Centre (Penang)
38. Bukit Mertajam Hospital
39. Bukit Mertajam Specialist Hospital
40. C.S. Loo Kidney & Medical Specialist
41. Changkat Melintang Hospital
42. Charis-NKF Dialysis Centre
43. Che Eng Khor Centre
44. Cheras Dialysis Centre
45. CHKMUS-MAA Medicare Charity
46. Damai Medical & Heart Clinic
47. Damansara Specialist Hospital
48. Duchess of Kent Hospital
49. Dungun Hospital
50. Fatimah Hospital
51. Fo Yi NKF Dialysis Centre
52. Gerik Hospital
53. Gleneagles Medical Centre
54. Gua Musang Hospital
55. Haemo Care
56. Haemodialysis Association Klang
57. Haemodialysis Edina
58. Healthcare Dialysis Centre
59. Hope Haemodialysis Society Ipoh
60. Hospital Pakar Sultanah Fatimah Muar
61. Hospital Raja Perempuan Zainab II
62. Hulu Terengganu Hospital
63. Ipoh Hospital
64. Ipoh Hospital Home Unit
65. Island Hospital
66. JB Lions MAA-Medicare Charity Dialysis Centre (1)
67. JB Lions MAA-Medicare Charity Dialysis Centre (2)
68. Jelebu Hospital
69. Jerantut Hospital
70. Johor Specialist Hospital
71. K K Tan Specialist Specialist (Bukit Mertajam)
72. Kajang Hospital
73. Kampar Hospital
74. Kapit Hospital
75. KAS-Rotary-NKF
76. KB Rotary-MAA Charity Dialysis
77. Kelana Jaya Medical Centre
78. Kemaman Hospital
79. Keningau Hospital
80. Kepala Batas Hospital
81. Kg Baru Medical Centre
82. Kluang Hospital
83. Kota Belud Hospital
84. Kota Kinabatangan Hospital
85. Kota Marudu Hospital
86. Kota Tinggi Hospital
87. Kuala Kangsar Hospital
88. Kuala Krai Hospital
89. Kuala Kubu Bharu Hospital
90. Kuala Lipis Hospital
91. Kuala Lumpur Dialysis Centre
92. Kuala Lumpur Hospital (Home)
93. Kuala Lumpur Hospital (Paed)
94. Kuala Lumpur Hospital (Unit 1)
95. Kuala Lumpur Hospital (Unit 2B)
96. Kuala Lumpur Hospital (Unit 3)
97. Kuala Lumpur Lions Renal Centre
98. Kuala Nerang Hospital
99. Kuala Pilah Hospital
100. Kuala Terengganu Hospital
101. Kuantan Clinical Diagnostic Centre
102. Kudat Hospital
103. Kulim Hospital
104. Labuan Hospital

PARTICIPATING HAEMODIALYSIS CENTRES (continued)

105. Lahad Datu Hospital
106. Lam Wah Ee Hospital
107. Langkawi Hospital
108. Lawas Hospital
109. Lifeline Dialysis Clinic
110. Likas Hospital
111. Limbang Hospital
112. Loh Guan Lye Specialist Centre
113. MAA-Medicare Charity (Butterworth)
114. MAA-Medicare Charity (Cheras)
115. MAA-Medicare Charity (Kajang)
116. MAA-Medicare Charity (Kota Kinabalu)
117. MAA-Medicare Charity (Kuala Lumpur)
118. MAA-Medicare Charity (Mentakab)
119. MAA-Medicare Charity (Teluk Intan)
120. Machang Hospital
121. Mahkota Medical Centre
122. Marudi Hospital
123. Melaka Hospital
124. Mentakab Hospital
125. Mersing Hospital
126. Metro Specialist Hospital
127. Miri Hospital
128. Miri Red Crescent Dialysis Centre
129. Moral Uplifting-NKF Dialysis (Ipoh)
130. Muadzam Shah Hospital
131. Muar Dialysis
132. Muar Lions Renal Centre
133. Mukah Hospital
134. National Kidney Foundation Dialysis Centre (KL)
135. Nephrolife Haemodialysis Centre
136. Nobel Dialysis Centre
137. Normah Medical Specialist Centre
138. Pahang Buddhist Association
139. Pakar Perdana Hospital
140. Pantai Air Keroh Hospital
141. Pantai Indah Hospital
142. Pantai Medical Centre (1)
143. Pantai Medical Centre (2)
144. Pantai Mutiara Hospital
145. Papar Hospital
146. Parit Buntar Hospital
147. Pasir Mas Hospital
148. Pathlab Charity Dialysis Centre
149. Pekan Hospital
150. Penang Adventist Hospital
151. Penang Caring Dialysis Society
152. Penang Hospital
153. Penang Hospital (Home)
154. Persatuan Amal Chin Malaysia Barat
155. Persatuan Buah Pinggang Sabah
156. Persatuan Dialisis Kurnia PJ
157. Persatuan Membaiki Akhlak-Che Luan Khor_NKF
158. Pertubuhan Bakti Fo En Bandar Kulim
159. Pertubuhan Dialisis Rotary-Satu Hati
160. Pertubuhan Hemodialisis Muhibbah Segamat
161. Pertubuhan Hemodialisis Muhibbah Segamat (Labis)
162. Pertubuhan Hemodialisis SPS
163. Pertubuhan Pekhidmatan Haemodialisis AIXIN Kerian
164. PingRong-NKF
165. Poliklinik Komuniti Tanglin
166. Pontian Hospital
167. Pontian Rotary Haemodialysis Centre
168. Port Dickson Hospital
169. Premier Renal Care
170. Province Wellesley Renal Medifund
171. Pusat Darul Iltizam
172. Pusat Dialisis Dr. K K Tan (Kulim)
173. Pusat Dialisis Dr. K K Tan (Sg Petani)
174. Pusat Dialisis Ehsan Perak
175. Pusat Dialisis Emnur Teguh
176. Pusat Dialisis Epic
177. Pusat Dialisis Falah
178. Pusat Dialisis Intan
179. Pusat Dialisis Kuala Kangsar
180. Pusat Dialisis Mesra
181. Pusat Dialisis Nefro Utama (Kota Tinggi)
182. Pusat Dialisis Nefro Utama (Kuala Terengganu)
183. Pusat Dialisis Nefro Utama (Pontian)
184. Pusat Dialisis Nefro Utama (Setapak)
185. Pusat Dialisis Penawar
186. Pusat Dialisis Penawar Permai
187. Pusat Dialisis Perbadanan Islam (Kota Tinggi)
188. Pusat Dialisis Pusat Pungutan Zakat
189. Pusat Dialisis Sijangkang
190. Pusat Dialisis Taiping
191. Pusat Dialisis Taiping (Cawangan Kamunting)
192. Pusat Dialisis Taiping (Cawangan Kuala Kangsar)
193. Pusat Dialisis Trengganu/NKF
194. Pusat Dialisis Tuanku Syed Putra-NKF
195. Pusat Dialisis Waqaf An-nur (Batu Pahat)
196. Pusat Dialisis Waqaf An-nur (Kota Raya)
197. Pusat Dialisis Waqaf An-nur (Pasir Gudang)
198. Pusat Dialisis Mesra (Kapar)
199. Pusat Dialisis Mesra KKB
200. Pusat Dialisis Setia
201. Pusat Haemodialysis St Anne BM
202. Pusat Haemodialysis Suria
203. Pusat HD SJAM Bacang Melaka
204. Pusat Hemodialisis Beng Siew
205. Pusat Hemodialisis Damai
206. Pusat Hemodialisis Darul Iltizam
207. Pusat Hemodialisis Darul Iltizam Tapah
208. Pusat Hemodialisis Darul Takzim
209. Pusat Hemodialisis Dato' Lee Kok Chee
210. Pusat Hemodialisis Fasa
211. Pusat Hemodialisis Harmoni
212. Pusat Hemodialisis Hidayah

PARTICIPATING HAEMODIALYSIS CENTRES (continued)

- | | |
|--|---|
| 213. Pusat Hemodialisis Islam Makmur | 267. S.P. Menon Dialysis Center (Petaling Jaya) |
| 214. Pusat Hemodialisis Kampar_Yayasan Nayang | 268. S.P. Menon Dialysis Centre (Klang) |
| 215. Pusat Hemodialisis Kau Ong Yah Ampang | 269. Sabah Medical Centre |
| 216. Pusat Hemodialisis Kota Tinggi | 270. Sandakan Kidney Society |
| 217. Pusat Hemodialisis Majlis Perbandaran Kelang | 271. Saratok Hospital |
| 218. Pusat Hemodialisis Manjung | 272. Sarawak General Hospital |
| 219. Pusat Hemodialisis Mawar N. Sembilan (Bahau) | 273. Sarikei Hospital |
| 220. Pusat Hemodialisis Mawar N. Sembilan (Lukut) | 274. Seberang Jaya Hospital |
| 221. Pusat Hemodialisis Mawar N. Sembilan (Rantau) | 275. Segamat Hospital |
| 222. Pusat Hemodialisis Mawar N. Sembilan (Seremban) | 276. Selama Hospital |
| 223. Pusat Hemodialisis Mawar N. Sembilan (Seremban) | 277. Selangor Medical Centre |
| 224. Pusat Hemodialisis Mawar N. Sembilan (Seri Kembangan) | 278. Selayang Hospital |
| 225. Pusat Hemodialisis Mergong | 279. Semporna Hospital |
| 226. Pusat Hemodialisis Nabilah | 280. Serdang Hospital |
| 227. Pusat Hemodialisis Rotary Kulai | 281. Seremban Hospital |
| 228. Pusat Hemodialisis Waz Lian | 282. Seri Manjung Hospital |
| 229. Pusat Hemodialisis Yayasan Felda | 283. Serian Hospital |
| 230. Pusat Hemodialisis Zakat (Balik Pulau) | 284. Sg Siput Hospital |
| 231. Pusat Hemodialisis Zakat (Bukit Mertajam) | 285. Sibu Hospital |
| 232. Pusat Hemodialisis Zakat (Butterworth) | 286. Sibu Kidney Foundation |
| 233. Pusat Hemodialisis Seroja | 287. Sik Hospital |
| 234. Pusat Kesihatan Jitra | 288. Sipitang Hospital |
| 235. Pusat Pakar Tawakal | 289. SJAM-KPS Haemodialysis Centre 1 (Kelang) |
| 236. Pusat Perubatan Premier HUKM | 290. SJAM-KPS Haemodialysis Centre 2 (Kelang) |
| 237. Pusat Perubatan Tentera (Kota Bharu) | 291. SJAM-KPS Haemodialysis Centre 3 (Banting) |
| 238. Pusat Rawatan Dialisis Nefro Utama (Batu Caves) | 292. SJAM-KPS Haemodialysis Centre 5 (Rawang) |
| 239. Pusat Rawatan Dialisis Nefro Utama (Kota Bharu) | 293. SJAM-KPS Haemodialysis Centre 6 (Kuala Selangor) |
| 240. Pusat Rawatan Dialisis Wan Nong Batu Gajah | 294. Smartcare Dialysis Centre (Subang Jaya) |
| 241. Pusat Rawatan Islam (Kuala Lumpur) | 295. Smartcare Dialysis Clinic (Cheras) |
| 242. Pusat Rawatan Islam Ar-Ridzuan | 296. Sri Aman Hospital |
| 243. Pusat Waqaf An -nur (Senawang) | 297. Sri Kota Medical Centre |
| 244. Putra Medical Centre | 298. Strand Specialist Hospital |
| 245. Putrajaya Hospital | 299. Subang Jaya Medical Centre |
| 246. Queen Elizabeth Hospital | 300. Sultan Ismail Pandan Hospital |
| 247. Ranau Hospital | 301. Sultanah Aminah Hospital |
| 248. Raub Hospital | 302. Sultanah Aminah Hospital (Paed) |
| 249. Rawatan Dialisis Amal Lions-NKF | 303. Sungai Bakap |
| 250. Rawatan Dialysis Bukit Tinggi | 304. Sungai Petani Hospital |
| 251. Rawatan Haemodialysis Koswip | 305. Sunway Medical Centre |
| 252. Reddy Clinic | 306. Superkids Trinity-NKF Dialysis Centre |
| 253. Rejang Medical Centre | 307. Systemic Dialysis Centre |
| 254. Renal Associates | 308. Systemic Dialysis Centre (2) |
| 255. Renal Care (Ipoh Specialist) | 309. Syukur Elit Sdn Bhd |
| 256. Renal Care (Kedah) | 310. Taiping Hospital |
| 257. Renal Dialysis Centre | 311. Tambunan Hospital |
| 258. Renal Healthcare | 312. Tampin Hospital |
| 259. Renal Link (Penang) | 313. Tanah Merah Hospital |
| 260. Renal Medicare | 314. Tangkak Hospital |
| 261. Renal-Link (Kelantan) | 315. Tanjung Karang Hospital |
| 262. Renal-Link Sentosa | 316. Tanjung Malim Hospital |
| 263. Rotary Damansara-NKF Dialysis | 317. Tapah Hospital |
| 264. Rotary HD Centre (Johor Bahru) | 318. Tawau Hospital |
| 265. Rotary Tawau Tanjung | 319. Teluk Intan Hospital |
| 266. S.P. Menon Dialysis Center (Kuala Lumpur) | 320. Temenggong Seri Maharaja Tun Ibrahim Hospital |

PARTICIPATING HAEMODIALYSIS CENTRES (continued)

- | | |
|--------------------------------------|---|
| 321. Temerloh Hospital | 336. Tung Shin Hospital |
| 322. Tenang Haemodialysis Centre | 337. Tung Shin Hospital & Yayasan Nanyang Press |
| 323. Tenang Haemodialysis Jasin | 338. Universiti Kebangsaan Malaysia Bangi |
| 324. Tengku Anis Hospital | 339. Universiti Kebangsaan Malaysia Hospital |
| 325. Tenom Hospital | 340. Universiti Sains Malaysia Hospital |
| 326. Tengku Ampuan Afzan Hospital | 341. University Malaya Medical Centre |
| 327. Tengku Ampuan Jemaah Hospital | 342. Victorious Life Centre |
| 328. Tengku Ampuan Rahimah Hospital | 343. Woh Peng Cheang Seah |
| 329. The Kidney Dialysis Centre 1 | 344. Yakin Jaya |
| 330. The Kidney Dialysis Centre 2 | 345. Yan Hospital |
| 331. The Nayang-NKF Dialysis Centre | 346. Yayasan Akhlak-NKF Taiping |
| 332. The Penang Community HD Society | 347. Yayasan Kebajikan SSL |
| 333. Timberland Medical Centre | 348. Yayasan Kebajikan SSL Puchong |
| 334. Tuanku Fauziah Hospital | 349. Yayasan Kebajikan The Southern Melaka |
| 335. Tumpat Hospital | 350. Yayasan Pembangunan Keluarga Johor-NKF |
| | 351. Yayasan Rotary Kluang |

PARTICIPATING PERITONEAL DIALYSIS CENTRES

1. 96 Hospital Angkatan Tentera (Lumut)
2. BP Renal Care
3. Damai Medical & Heart Clinic
4. Hospital Pakar Sultanah Fatimah Muar
5. Hospital Raja Perempuan Zainab II
6. Ipoh Hospital
7. Kuala Lumpur Hospital (Adult)
8. Kuala Lumpur Hospital (Paed)
9. Kuala Terengganu Hospital
10. Melaka Hospital
11. Penang Hospital
12. Queen Elizabeth Hospital , Kota Kinabalu
13. Sarawak General Hospital
14. Selayang Hospital
15. Seremban Hospital
16. Sultanah Aminah Hospital (Adult)
17. Sultanah Aminah Hospital (Paed)
18. Tengku Ampuan Afzan Hospital
19. Tengku Ampuan Rahimah Hospital
20. Universiti Kebangsaan Malaysia Hospital
21. Universiti Sains Malaysia Hospital
22. University Malaya Medical Centre

PARTICIPATING TRANSPLANT FOLLOW-UP CENTRES

1. Alor Setar Hospital
2. Ampang Puteri Specialist Hospital
3. Batu Pahat Hospital
4. Bintulu Hospital
5. Damai Medical & Heart Clinic
6. Duchess of Kent Hospital
7. Hospital Pakar Sultanah Fatimah Muar
8. Hospital Raja Perempuan Zainab II
9. Ipoh Hospital
10. Kemaman Hospital
11. Kluang Hospital
12. Kuala Lumpur Hospital (Paed)
13. Kuala Lumpur Hospital (Adult)
14. Kuala Terengganu Hospital
15. Mahkota Medical Centre
16. Melaka Hospital
17. Mentakab Hospital
18. Miri Hospital
19. Penang Hospital
20. Pontian Hospital
21. Queen Elizabeth Hospital
22. Renal Dialysis Centre Sdn. Bhd, Gleneagles Intan Medical Centre
23. Sabah Medical Centre
24. Sarawak General Hospital
25. Segamat Hospital
26. Selangor Medical Centre
27. Selayang Hospital
28. Seremban Hospital
29. Sibu Hospital
30. Sri Kota Medical Centre
31. Subang Jaya Medical Centre
32. Sultan Ismail Pandan Hospital
33. Sultanah Aminah Hospital (Paed)
34. Sultanah Aminah Hospital (Adult)
35. Sunway Medical Centre
36. Taiping Hospital
37. Tan Medical Renal Clinic
38. Tawau Hospital
39. Tengku Ampuan Afzan Hospital
40. Tengku Ampuan Rahimah Hospital
41. Timberland Medical Centre
42. Universiti Kebangsaan Malaysia Hospital
43. Universiti Sains Malaysia Hospital
44. University Malaya Medical Centre

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FOREWORD

In this and the previous report the treatment rate for dialysis had exceeded the 100 per million-population mark. The continued and consistent growth of the dialysis population over the last two decades let this achievement pass by unnoticed. This figure is significant in a number of ways. For many years the nephrologists in the country have quoted the incidence of end stage renal disease (ESRD) in the country as 100 new cases per million population. Secondly they used this figure as a target of the treatment rate to be achieved and lobbied the government for more treatment facilities. We were of course wrong on the first score. The incidence of ESRD is higher than 100 per million population. A local study had indicated this and figures from neighbouring countries with similar populations showed similar higher incidence. In parts of our country the treatment rate has reached 140 per million. However the “magical” figure of 100 has been useful for nephrologists and the public alike to lobby for more facilities. We were able to garner support from governmental agencies and non-governmental organisations alike to meet this target. This is reflected not just from the varied background of the dialysis providers but also from the funding sources. The combined efforts of all parties led to this achievement. A new target will have to be set. The total number of dialysis patients is expected to increase to about 20,000 by the year 2008 if the current growth rate is maintained. The centre survey done at the end of 2005 indicated that there are almost 13,000 patients on dialysis. The treatment rate for those less than 65 years of age has plateaued while that of those older than sixty-five years continues to rise. This changing demographic is not unexpected and has been noticed for many years. However there is some concern about how prepared and capable some centres are in managing older patients especially those with co-morbidities.

The recurrent theme in this report is the variation in outcomes of dialysis treatment. This includes mortality as well as other intermediate measures such as blood pressure and dialysis adequacy. This should be studied further. There are differences in case mix but of more concern are differences in structure, processes and expertise. More detailed studies should be done and efforts made to redress this problem. The registry welcomes individuals who are interested in studying this further

The projected increase in the number of dialysis patients has led many to seriously review the strategy in the management of chronic kidney disease (CKD). Although there is awareness on the need to manage CKD effectively, the implementation of prevention of renal failure treatment is far from satisfactory. This is probably because there are many more players in this effort and to implement a cohesive national program can be a major challenge. The role of primary care physicians is crucial and nephrologists in tertiary centres have little contact with them and hence less opportunity to influence their treatment of CKD. Nonetheless a major initiative has to be taken if any success is to be expected. A start would be to look at the prevalence and course of CKD

The National Renal Registry (NRR) has decided that it will assist in this effort by providing data on CKD. The NRR has decided to set up a Glomerulonephritis (GN) Registry that will track the course of biopsy proven GN. Data from such a registry will hopefully help formulate guidelines on the prevention of renal failure in patients with GN. The registry fully appreciates that the major cause of ESRD is Diabetic Nephropathy and any effort on prevention of renal failure will have to deal with this major scourge.

The NRR feels that to develop a Diabetic nephropathy registry will be a major task presently. It hopes that the experience gained with the GN registry will prepare it for the development of a diabetic nephropathy registry

In 2006 the Private Healthcare Facilities and Services Act 1998 will be enforced. A regulation attached to the Act concerns Hemodialysis treatment. Some aspects of the regulation on Hemodialysis have been developed based on prevailing practices as documented in the registry reports. Any regulation on Hemodialysis should take into account evidence based practice. The registry is a repository of much data that can provide evidence to guide practice that can ensure a favourable outcome. It is important that all participants continue to provide timely and accurate data. This will place the registry in a strong position to assist the nephrologists in developing guidelines that are relevant to this country.

Dr. Zaki Morad
Chairman,
National Renal Registry

CONTENTS

	Page
Report Information	i
Acknowledgement	iii
Abbreviations	iv
NRR Advisory Committee Members	v
About the National Renal Registry	vi
About MOSS	viii
Participating Haemodialysis Centres	x
Participating Peritoneal Dialysis Centres	xiv
Participating Transplant Follow-up Centres	xv
Contributing Editors	xvi
Forwards	xvii
CHAPTER 1: ALL RENAL REPLACEMENT THERAPY IN MALAYSIA	1
1.1: Stock and Flow	2
1.2: Treatment Provision Rate	3
CHAPTER 2: DIALYSIS IN MALAYSIA	4
2.1: Provision of Dialysis in Malaysia (Registry report)	5
2.2: Dialysis provision in Malaysia (Centre survey report)	6
2.3: Distribution of Dialysis Treatment	10
2.3.1: Gender distribution	10
2.3.2: Age distribution	11
2.3.3: Method and Location of Dialysis	13
2.3.4: Funding for dialysis treatment	14
2.3.5: Distribution of dialysis patients by sector	15
2.4: Primary Renal Disease	16
CHAPTER 3: DEATH AND SURVIVAL ON DIALYSIS	17
3.1: Death on dialysis	18
3.2: Patient survival on dialysis	20
3.3: Survival of incident patients 2000 – 2005 by centre	24
CHAPTER 4: QUALITY OF LIFE AND REHABILITATION OUTCOMES OF DIALYSIS PATIENTS IN MALAYSIA	25
A: Quality of life on dialysis	26
B: Work related rehabilitation	29
CHAPTER 5: PAEDIATRIC RENAL REPLACEMENT THERAPY	30
A: RRT provision for paediatric patients	31
B: Distribution of paediatric dialysis	33
C: Primary renal disease and	35
D: Types of Renal Transplantation	36
E: Survival analysis	36
CHAPTER 6: MANAGEMENT OF ANAEMIA IN DIALYSIS PATIENTS	38
6.1: Treatment for Anemia in Dialysis	39
6.2: Iron status on Dialysis	43
6.3: Haemoglobin outcomes on Dialysis	51

CHAPTER 7: NUTRITIONAL STATUS ON DIALYSIS	56
7.1: Serum Albumin levels on Dialysis	57
7.2: Body Mass Index (BMI) on Dialysis	61
CHAPTER 8: BLOOD PRESSURE CONTROL AND DYSLIPIDAEMIA	65
8.1: Blood Pressure Control on dialysis	66
8.2: Dyslipidaemia in dialysis patients	74
CHAPTER 9: MANAGEMENT OF RENAL BONE DISEASE IN DIALYSIS PATIENTS	81
9.1: Treatment of renal bone disease	82
9.2: Serum calcium and phosphate control	83
CHAPTER 10: HEPATITIS ON DIALYSIS	93
CHAPTER 11: HAEMODIALYSIS PRACTICES	98
11.1: Vascular access and its complications	99
11.2: HD prescription	101
11.3: Technique survival on dialysis	109
CHAPTER 12: CHRONIC PERITONEAL DIALYSIS PRACTICES	113
12.1: Peritoneal dialysis practices	114
12.2: Achieved solute clearance and peritoneal transport	116
12.3: Technique survival on PD	118
12.4: PD Peritonitis	122
CHAPTER 13: RENAL TRANSPLANTATION	124
13.1: Stock and Flow	125
13.2: Recipients Characteristics	126
13.3: Transplant Practices	127
13.4: Transplant Outcomes	130
13.4.1: Post Transplant Complications	130
13.4.2: Deaths and Graft Losses	130
13.5: Patient and Graft Survival	133
APPENDIX I DATA MANAGEMENT	I
APPENDIX II ANALYSIS SETS, STATISTICAL METHODS AND DEFINITIONS	IV

LIST OF TABLES

	<i>Page</i>	
Table 1.01	Stock and Flow of RRT, Malaysia 1996 – 2005	2
Table 1.02	New Dialysis Acceptance Rate and New Transplant Rate per million population 1996 – 2005	3
Table 1.03	RRT Prevalence Rate per million population 1996 – 2005	3
Table 2.1.1	Stock and flow – Dialysis patients 1996 - 2005	5
Table 2.1.2	Dialysis Treatment Rate per million population 1996 – 2005	5
Table 2.1.3	Dialysis Treatment Rate by State, per million state population 1996-2005	5
Table 2.2.1	Number of dialysis centres, HD machines and treatment capacity by sector, December 2005	6
Table 2.2.2	Number of dialysis centres, number of HD machines and treatment capacity, HD capacity to patient ratio and number of dialysis patients by state in December 2005	7
Table 2.2.3	Growth in HD capacity and HD patients in Private, NGO and MOH sectors, 1980-2005	9
Table 2.3.1(a)	Dialysis Treatment Rate by Gender, per million male or female population 1996 – 2005	10
Table 2.3.1(b)	Gender distribution of Dialysis Patients 1996 -2005	10
Table 2.3.2(a)	Dialysis Treatment Rate by Age Group, per million age group population 1996 – 2005	11
Table 2.3.2(b)	Percentage Age Distribution of Dialysis Patients 1996 – 2005	12
Table 2.3.3	Method and Location of Dialysis 1996 – 2005	13
Table 2.3.4	Funding for Dialysis Treatment 1996 – 2005	14
Table 2.3.5	Distribution of Dialysis Patients by Sector 1996 – 2005	15
Table 2.4.1	Primary Renal Disease 1996– 2005	16
Table 3.1.1	Deaths on Dialysis 1996 – 2005	18
Table 3.1.2	Causes of Death on Dialysis 1996 - 2005	19
Table 3.2.1	Unadjusted patient survival by dialysis modality, 1996 – 2005	20
Table 3.2.2	Unadjusted patient survival by year of entry, 1996 – 2005	21
Table 3.2.3	Unadjusted patient survival by age, 1996 – 2005	22
Table 3.2.4	Unadjusted patient survival by diabetic status, 1996 – 2005	23
Table 4.1	Cumulative distribution of QoL-Index score in relation to dialysis modality, All Dialysis patients 1997-2005	26
Table 4.2	Cumulative distribution of QoL-Index score in relation to Diabetes mellitus, All Dialysis patients 1997-2005	26
Table 4.3	Cumulative distribution of QoL-Index score in relation to Gender, All Dialysis patients 1997-2005	27
Table 4.4	Cumulative distribution of QoL-Index score in relation to Age, All Dialysis patients 1997-2005	27
Table 4.5	Cumulative distribution of QoL-Index score in relation to Year of entry, HD patients 1997-2005	27
Table 4.6	Cumulative distribution of QoL-Index score in relation to Year of entry, CAPD patients 1997-2005	28
Table 4.7	Work related rehabilitation in relation to Modality, Dialysis patients 1997-2005	29
Table 4.8	Work related rehabilitation in relation to Year of Entry, HD patients 1997-2005	29
Table 4.9	Work related rehabilitation in relation to Year of Entry, CAPD patients 1997-2005	29
Table 5.01	Stock and Flow, Paediatric Renal Replacement Therapy 1990-2005	31
Table 5.02	Paediatric Dialysis and Transplant Treatment Rates per million age-group population 1990-2005	32
Table 5.03 a	Dialysis Treatment Rate by State, per million state age group population 1990-2005	33
Table 5.03 b	Dialysis Treatment by State in absolute number; 1990-2005	33
Table 5.08	Primary Renal Disease 1990– 2005	35
Table 5.09	Types of renal transplant 1990-2005	36
Table 5.10	Patient survival by modality of RRT 1990-2005	36

LIST OF TABLES (continued)

Table 5.11	Dialysis technique survival by modality 1990-2005	37
Table 5.12	Graft survival 1990-2005	37
Table 6.1.1	Treatment for Anemia, HD patients 1997-2005	39
Table 6.1.2	Treatment for Anemia, CAPD patients 1997-2005	39
Table 6.1.3	Variation in Erythropoietin utilization among HD centres, 2005	40
Table 6.1.4	Variation in Erythropoietin utilization among CAPD centres, 2005	40
Table 6.1.5	Variation in median weekly Erythropoietin dose among HD centres 2005	41
Table 6.1.6	Variation in median weekly Erythropoietin dose among CAPD centres 2005	41
Table 6.1.7	Variation in use of blood transfusion among HD centres, 2005	42
Table 6.1.8	Variation in use of blood transfusion among CAPD centres, 2005	42
Table 6.2.1	Distribution of Serum Ferritin without Erythropoietin, HD patients 1997 –2005	43
Table 6.2.2	Distribution of Serum Ferritin without Erythropoietin, CAPD patients 1997–2005	43
Table 6.2.3	Distribution of Serum Ferritin on Erythropoietin, HD patients 1997 – 2005	44
Table 6.2.4	Distribution of Serum Ferritin on Erythropoietin, CAPD patients 1997 – 2005	44
Table 6.2.5	Distribution of transferrin saturation without Erythropoietin, HD patients 1997 – 2005	45
Table 6.2.6	Distribution of transferrin saturation without Erythropoietin, CAPD patients 1997– 2005	45
Table 6.2.7	Distribution of transferrin saturation on Erythropoietin, HD patients 1997 – 2005	46
Table 6.2.8	Distribution of transferrin saturation on Erythropoietin, CAPD patients 1997 – 2005	46
Table 6.2.9	Variation in iron status outcomes among HD centres 2005	47
(a)	Median serum ferritin among patients on erythropoietin	47
(b)	Proportion of patients on erythropoietin with serum Ferritin ≥ 100 ng/ml	47
(c)	Median transferrin saturation among patients on erythropoietin	48
(d)	Proportion of patients on erythropoietin with transferrin saturation $\geq 20\%$	48
Table 6.2.10	Variation in Iron status outcome among CAPD centres 2005	49
(a)	Median serum Ferritin among patients on erythropoietin	49
(b)	Proportion of patients on erythropoietin with serum Ferritin ≥ 100 ng/ml	49
(c)	Median transferrin saturation among patients on erythropoietin	50
(d)	Proportion of patients on erythropoietin with transferrin saturation $\geq 20\%$	50
Table 6.3.1	Distribution of Haemoglobin Concentration without Erythropoietin, HD patients 1997 – 2005	51
Table 6.3.2	Distribution of Haemoglobin Concentration without Erythropoietin, CAPD patients 1997– 2005	51
Table 6.3.3	Distribution of Haemoglobin Concentration on Erythropoietin, HD patients 1997 – 2005	52
Table 6.3.4	Distribution of Haemoglobin Concentration on Erythropoietin, CAPD patients 1997 – 2005	52
Table 6.3.5	Variation in Haemoglobin outcomes among HD centres 2005	53
(a)	Median haemoglobin level among patients on erythropoietin	53
(b)	Proportion of patients on erythropoietin with haemoglobin level > 10 g/dL	53
(c)	Proportion of patients on erythropoietin with haemoglobin level > 11 g/dL	54
Table 6.3.6	Variation in Haemoglobin outcomes among CAPD centres 2005	54
(a)	Median haemoglobin level among patients on erythropoietin	54
(b)	Proportion of patients on erythropoietin with haemoglobin Level > 10 g/dL	55
(c)	Proportion of patients on erythropoietin with haemoglobin level > 11 g/dL	55
Table 7.1.1	Distribution of serum Albumin , HD patients 1997-2005	57
Table 7.1.2	Distribution of serum Albumin, CAPD patients 1997-2005	58
Table 7.1.3	Variation in Proportion of patients with serum albumin ≥ 40 g/L among HD centres 2005	59

LIST OF TABLES (continued)

Table 7.1.4	Variation in Proportion of patients with serum albumin ≥ 40 g/L among CAPD centres 2005	60
Table 7.2.1	Distribution of BMI , HD patients 1997-2005	61
Table 7.2.2	Distribution BMI, CAPD patients 1997-2005	62
Table 7.2.3	Variation in Proportion of patients with BMI ≥ 18.5 among HD centres 2005	63
Table 7.2.4	Variation in Proportion of patients with BMI ≥ 18.5 among CAPD centres 2005	64
Table 8.1.1	Distribution of Pre dialysis Systolic Blood Pressure, HD patients 1997-2005	66
Table 8.1.2	Distribution of Pre dialysis Systolic Blood Pressure, CAPD patients 1997-2005	67
Table 8.1.3	Distribution of Pre dialysis Diastolic Blood Pressure, HD patients 1997-2005	68
Table 8.1.4	Distribution of Pre dialysis Diastolic Blood Pressure, CAPD patients 1997-2005	69
Table 8.1.5	Variation in BP control among HD centres 2005	70
(a)	Median Systolic blood pressure among HD patients	70
(b)	Median Diastolic blood pressure among HD patients	71
(c)	Proportion of HD patients with Pre dialysis Blood Pressure $\leq 140/90$ mmHg	71
Table 8.1.6	Variation in BP control among CAPD centres 2005	72
(a)	Median Systolic blood pressure among CAPD patients	72
(b)	Median Diastolic blood pressure among CAPD patients	72
(c)	Proportion of CAPD patients with Pre dialysis Blood Pressure $\leq 140/90$ mmHg	73
Table 8.2.1	Distribution of serum Cholesterol , HD patients 1997-2005	74
Table 8.2.2	Distribution of serum Cholesterol , CAPD patients 1997-2005	75
Table 8.2.3	Distribution of serum Triglyceride , HD patients 1997-2005	75
Table 8.2.4	Distribution of serum Triglyceride , CAPD patients 1997-2005	76
Table 8.2.5	Variation in dyslipidaemias among HD centres 2005	77
(a)	Median serum cholesterol level among HD patients	77
(b)	Proportion of patients with serum cholesterol < 5.3 mmol/L	77
(c)	Median serum triglyceride level among HD patients	78
(d)	Proportion of patients with serum triglyceridel < 2.1 mmol/L	78
Table 8.2.6	Variation in dyslipidaemias among CAPD centres 2005	79
(a)	Median serum cholesterol level among CAPD patients	79
(b)	Proportion of patients with serum cholesterol < 5.3 mmol/L	79
(c)	Median serum triglyceride level among CAPD patients	80
(d)	Proportion of patients with serum triglyceridel < 2.1 mmol/L	80
Table 9.1.1	Treatment of renal bone disease, HD patients 1997-2005	82
Table 9.1.2	Treatment of renal bone disease, CAPD patients 1997-2005	82
Table 9.2.1	Distribution of corrected serum calcium, HD patients 1997-2005	83
Table 9.2.2	Distribution of corrected serum calcium, CAPD patients 1997-2005	83
Table 9.2.3	Distribution of Serum Phosphate, HD patients, 1997- 2005	84
Table 9.2.4	Distribution of Serum Phosphate, CAPD patients 1997-2005	84
Table 9.2.5	Distribution of corrected calcium x phosphate product, HD patients 1997-2005	85
Table 9.2.6	Distribution of corrected calcium x phosphate product, CAPD patients 1997-2005	85
Table 9.2.7	Variation in corrected serum calcium levels among HD centres 2005	86
(a)	Median serum calcium level among HD patients	86
(b)	Proportion of patients with serum calcium 2.2 to 2.6 mmol/L	86
Table 9.2.8	Variation in corrected serum calcium levels among CAPD centres 2005	87
(a)	Median serum calcium level among CAPD patients	87
(b)	Proportion of patients with serum calcium 2.2 to 2.6 mmol/L	87
Table 9.2.9	Variation in serum phosphate levels among HD centres 2005	88
(a)	Median serum phosphate level among HD patients	88
(b)	Proportion of patients with serum phosphate ≤ 1.6 mmol/L	88
Table 9.2.10	Variation in serum phosphate levels among CAPD centres 2005	89
(a)	Median serum phosphate level among CAPD patients	89
(b)	Proportion of patients with serum phosphate ≤ 1.6 mmol/L	89

LIST OF TABLES (continued)

Table 9.2.11	Variation in corrected calcium x phosphate product among HD centres 2005	90
(a)	Median corrected calcium x phosphate product among HD patients	90
(b)	Proportion of patients with corrected calcium x phosphate product < 4.5 mmol ² /L ²	90
Table 9.2.12	Variation in corrected calcium x phosphate product among CAPD centres 2005	91
(a)	Median corrected calcium x phosphate product among CAPD patients	91
(b)	Proportion of patients with corrected calcium x phosphate product < 4.5 mmol ² /L ²	91
Table 10.1	Prevalence of positive HBsAg and positive Anti-HCV at annual survey, HD patients 1997-2005	94
Table 10.2	Prevalence of positive HBsAg and positive Anti-HCV at annual survey, CAPD patients 1997-2005	94
Table 10.3	Variation in Proportion of patients with positive HBsAg among HD centres, 2005	94
Table 10.4	Variation in Proportion of patients with positive HBsAg by CAPD centre, 2005	95
Table 10.5	Variation in Proportion of patients with positive anti-HCV among HD centres, 2005	96
Table 10.6	Variation in Proportion of patients with positive anti-HCV among CAPD centres 2005	97
Table 11.1.1	Vascular Access on Haemodialysis, 1997-2005	99
Table 11.1.2	Difficulties reported with Vascular Access, 1997-2005	99
Table 11.1.3	Complications reported with Vascular Access, 1997-2005	100
Table 11.2.1	Blood Flow Rates in HD Units, 1997– 2005	101
Table 11.2.2	Number of HD Sessions per week, 1997 – 2005	102
Table 11.2.3	Duration of HD, 1997 – 2005	102
Table 11.2.4	Dialyser membrane types in HD Units, 1997 – 2005	103
Table 11.2.5	Dialyser Reuse Frequency in HD Units, 1997- 2005	104
Table 11.2.6	Dialysate Buffer used in HD Units, 1997 – 2005	105
Table 11.2.7	Distribution of prescribed Kt/V, HD patients 1997-2005	105
Table 11.2.8	Variation in HD prescription among HD centres 2005	106
(a)	Variation in Median blood flow rates among HD patients	106
(b)	Variation in Proportion of patients with blood flow rates above 250 ml/min	106
(c)	Variation in Median 3 HD sessions per week	107
(d)	Variation in Median prescribed Kt/V among HD patients	108
(e)	Variation in Proportion of patients with prescribed Kt/V ≥ 1.3	108
Table 11.3.1	Unadjusted technique survival by dialysis modality, 1996 – 2005	109
Table 11.3.2	Unadjusted technique survival by year of entry, 1996 – 2005	110
Table 11.3.3	Unadjusted technique survival by age, 1996 – 2005	111
Table 11.3.4	Unadjusted technique survival by diabetic status, 1996 – 2005	112
Table 12.1.1	Chronic Peritoneal Dialysis Regimes, 1997-2005	114
Table 12.1.2	CAPD Connectology, 1997-2005	114
Table 12.1.3	CAPD Number of Exchanges per day, 1997-2005	115
Table 12.1.4	CAPD Volume per Exchange, 1997– 2005	115
Table 12.2.1	Distribution of delivered Kt/V by centre, CAPD patients 2003-2005	116
Table 12.2.2	Variation in Proportion of patients with Kt/V ≥ 2.0 per week among CAPD centres 2005	116
Table 12.2.3	Peritoneal transport status by PET D/P creatinine at 4 hours, New PD patients 2003-2005	117
Table 12.2.4	Peritoneal transport status by PET D/P creatinine at 4 hours, prevalent PD patients 2003-2005	117
Table 12.3.1	Unadjusted technique survival by dialysis modality, 1996 – 2005	118
Table 12.3.2	Unadjusted technique survival by year of entry, 1996 – 2005	119
Table 12.3.3	Unadjusted technique survival by age, 1996 – 2005	120
Table 12.3.4	Unadjusted technique survival by diabetic status, 1996 – 2005	121

LIST OF TABLES (continued)

Table 12.3.5	Unadjusted technique survival by gender 1996 - 2005	121
Table 12.4.1	PD Peritonitis rate by centre, 2003-2005	122
Table 12.4.2	Causative organism in PD peritonitis, 2000-2005	123
Table 12.4.3	Factors influencing peritonitis rate, 2000-2005	123
Table 13.1.1	Stock and Flow of Renal Transplantation, 1996-2005	125
Table 13.1.2	New transplant rate per million population, 1996-2005	125
Table 13.1.3	Transplant prevalence rate per million population, 1996-2005	126
Table 13.2.1	Renal Transplant Recipients' Characteristics, 1996-2005	126
Table 13.2.2	Primary causes of end stage renal failure, 1996-2005	127
Table 13.3.1	Type of Renal Transplantation, 1996-2005	127
Table 13.3.2	Biochemical data, 2004-2005	128
Table 13.3.3	Medication data, 2004-2005	129
Table 13.4.1	Post transplant complications, 2004-2005	130
Table 13.4.2	Transplant Patients Death Rate and Graft Loss, 1996-2005	130
Table 13.4.3	Causes of Death in Transplant Recipients, 1996-2005	132
Table 13.4.4	Causes of Graft Failure, 1996-2005	132
Table 13.5.1	Patient survival, 1993-2005	133
Table 13.5.2	Graft survival, 1993-2005	133
Table 13.5.3	Patient survival by type of transplant, 1993-2005	134
Table 13.5.4	Graft survival by type of transplant, 1993-2005	134
Table 13.5.5	Patient survival by year of transplant (Living related transplant, 1993-2005)	135
Table 13.5.6	Graft survival by year of transplant (Living related transplant, 1993-2005)	135
Table 13.5.7	Patient survival by year of transplant (Commercial cadaver transplant, 1993-2005)	136
Table 13.5.8	Graft survival by year of transplant (Commercial cadaver transplant, 1993-2005)	136

LIST OF FIGURES

	Page
Figure 1.01	2
(a)	2
(b)	3
Figure 1.02	3
Figure 1.03	3
Figure 2.2.1(a)	6
Figure 2.2.1(b)	6
Figure 2.2.1(c)	7
Figure 2.2.1(d)	7
Figure 2.2.2(a)	8
Figure 2.2.2(b)	8
Figure 2.2.2(c)	8
Figure 2.2.2(d)	8
Figure 2.2.3	9
Figure 2.3.1(a)	10
Figure 2.3.1(b)	10
Figure 2.3.2(a)	11
Figure 2.3.2(b)	12
Figure 2.3.3	13
Figure 2.3.4	14
Figure 2.3.5	15
Figure 2.4.1	16
Figure 3.1.1	18
Figure 3.2.1	20
Figure 3.2.2	21
Figure 3.2.3	23
Figure 3.2.4	23
Figure 3.3.1(a)	24
Figure 3.3.1(b)	24
Figure 3.3.2(a)	24
Figure 3.3.2(b)	24
Figure 4.1	26
Figure 4.2	26
Figure 4.3	27
Figure 4.4	27
Figure 4.5	28
Figure 4.6	28
Figure 5.01(a)	31
Figure 5.01(b)	31
Figure 5.02	32
Figure 5.04	34

LIST OF FIGURES (continue)

Figure 5.05	Dialysis and Transplant Treatment Rate by Age group 1990-2005	34
Figure 5.06	New Dialysis by treatment modality 1990-2005	34
Figure 5.07	New Dialysis by sector 1990-2005	35
Figure 5.10	Patient Survival by Modality of RRT, 1990-2005	36
Figure 5.11	Dialysis Technique Survival by Modality, 1990-2005	37
Figure 5.12	Transplant Graft Survival 1990-2005	37
Figure 6.1.3	Variation in Erythropoietin utilization among HD centres, 2005	40
Figure 6.1.4	Variation in Erythropoietin utilization among CAPD centres, 2005	40
Figure 6.1.5	Variation in median weekly Erythropoietin dose among HD centres 2005	41
Figure 6.1.6	Variation in median weekly Erythropoietin dose among CAPD centres 2005	41
Figure 6.1.7	Variation in use of blood transfusion among HD centres, 2005	42
Figure 6.1.8	Variation in use of blood transfusion among CAPD centres, 2005	42
Figure 6.2.1	Cumulative distribution of Serum Ferritin without Erythropoietin, HD patients 1997-2005	43
Figure 6.2.2	Cumulative distribution of Serum Ferritin without Erythropoietin, CAPD patients 1997-2005	43
Figure 6.2.3	Cumulative distribution of Serum Ferritin on Erythropoietin, HD patients 1997-2005	44
Figure 6.2.4	Cumulative distribution of Serum Ferritin on Erythropoietin, CAPD patients 1997-2005	44
Figure 6.2.5	Cumulative distribution of transferrin saturation without Erythropoietin, HD patients 1997-2005	45
Figure 6.2.6	Cumulative distribution of transferrin saturation without Erythropoietin, CAPD patients 1997-2005	45
Figure 6.2.7	Cumulative distribution of transferrin saturation on Erythropoietin, HD patients 1997-2005	46
Figure 6.2.8	Cumulative distribution of transferrin saturation on Erythropoietin, CAPD patients 1997-2005	46
Figure 6.2.9(a)	Variation in median serum ferritin among patients on erythropoietin, HD centres 2005	47
Figure 6.2.9(b)	Variation in proportion of patients on erythropoietin with serum ferritin ≥ 100 ng/ml, HD centres 2005	47
Figure 6.2.9(c)	Variation in median transferrin saturation among patients on erythropoietin, HD centres 2005)	48
Figure 6.2.9(d)	Variation in proportion of patients on erythropoietin with transferrin saturation $\geq 20\%$, HD centres 2005	48
Figure 6.2.10(a)	Variation in median serum ferritin among patients on erythropoietin, CAPD centres 2005	49
Figure 6.2.10(b)	Variation in proportion of patients on erythropoietin with serum ferritin ≥ 100 ng/ml, CAPD centres 2005	49
Figure 6.2.10(c)	Variation in median transferrin saturation among patients on erythropoietin, CAPD centres 2005)	50
Figure 6.2.10(d)	Variation in proportion of patients on erythropoietin with transferrin saturation $\geq 20\%$, CAPD centres 2005	50
Figure 6.3.1	Cumulative distribution of haemoglobin Concentration without Erythropoietin, HD patients 1997-2005	51
Figure 6.3.2	Cumulative distribution of haemoglobin concentration without Erythropoietin, CAPD patients 1997-2005	51
Figure 6.3.3	Cumulative distribution of Haemoglobin Concentration on Erythropoietin, HD patients 1997-2005	52
Figure 6.3.4	Cumulative distribution of Haemoglobin Concentration on Erythropoietin, CAPD patients 1997-2005	52
Figure 6.3.5 (a)	Variation in median haemoglobin level among patients on Erythropoietin, HD centres 2005	53

LIST OF FIGURES (continue)

Figure 6.3.5 (b)	Variation in proportion of patients on erythropoietin with haemoglobin level > 10 g/dL, HD centres 2005	53
Figure 6.3.5 (c)	Variation in proportion of patients on erythropoietin with haemoglobin level > 11 g/dL, HD centres 2005	54
Figure 6.3.6 (a)	Variation in median haemoglobin level among patients on Erythropoietin, CAPD centres 2005	54
Figure 6.3.6 (b)	Variation in proportion of patients on erythropoietin with haemoglobin level > 10 g/dL, CAPD centres 2005	55
Figure 6.3.6 (c)	Variation in proportion of patients on erythropoietin with haemoglobin level > 11 g/dL, CAPD centres 2005	55
Figure 7.1.1	Cumulative distribution of Albumin, HD patients 1997-2005	57
Figure 7.1.2	Cumulative distribution of Albumin, CAPD patients 1997-2005	58
Figure 7.1.3	Variation in Proportion of patients with serum albumin \geq 40g/L, HD Centres 2005	59
Figure 7.1.4	Variation in Proportion of patients with serum albumin \geq 40g/L, CAPD centres 2005	60
Figure 7.2.1	Cumulative distribution of BMI, HD patients 1997-2005	61
Figure 7.2.2	Cumulative distribution of BMI, CAPD patients 1997-2005	62
Figure 7.2.3	Variation in Proportion of patients with BMI \geq 18.5, HD centres 2005	63
Figure 7.2.4	Variation in Proportion of patients with BMI \geq 18.5, CAPD centres 2005	64
Figure 8.1.1	Cumulative distribution of Pre dialysis Systolic Blood Pressure, HD patients 1997-2005	66
Figure 8.1.2	Cumulative distribution of Pre dialysis Systolic Blood Pressure, CAPD patients 1997-2005	67
Figure 8.1.3	Cumulative distribution of Pre dialysis Diastolic Blood Pressure, HD patients 1997-2005	68
Figure 8.1.4	Cumulative distribution of Pre dialysis Diastolic Blood Pressure, CAPD patients 1997-2005	69
Figure 8.1.5(a)	Variation in median systolic blood pressure among HD patients, HD centres 2005	70
Figure 8.1.5(b)	Variation in median diastolic blood pressure among HD patients, HD centres 2005	71
Figure 8.1.5(c)	Variation in proportion of HD patients with pre dialysis blood pressure \leq 140/90 mmHg, HD centres 2005	71
Figure 8.1.6(a)	Variation in median systolic blood pressure among CAPD patients, CAPD centres 2005	72
Figure 8.1.6(b)	Variation in median diastolic blood pressure among CAPD patients, CAPD centres 2005	72
Figure 8.1.6(c)	Variation in proportion of CAPD patients with pre dialysis blood pressure \leq 140/90 mmHg, CAPD centres 2005	73
Figure 8.2.1	Cumulative distribution of Cholesterol, HD patients 1997-2005	74
Figure 8.2.2	Cumulative distribution of Cholesterol, CAPD patients 1997-2005	75
Figure 8.2.3	Cumulative distribution of serum Triglyceride, HD patients 1997-2005	75
Figure 8.2.4	Cumulative distribution of serum Triglyceride, CAPD patients 1997-2005	76
Figure 8.2.5(a)	Variation in median serum cholesterol level among HD patients, HD centres 2005	77
Figure 8.2.5(b)	Variation in proportion of patients with serum cholesterol < 5.3 mmol/L, HD centres 2005	77
Figure 8.2.5(c)	Variation in median serum triglyceride level among HD patients, HD centres 2005	78
Figure 8.2.5(d)	Variation in proportion of patients with serum triglyceride < 2.1 mmol/L, HD centres 2005	78
Figure 8.2.6(a)	Variation in median serum cholesterol level among CAPD patients, CAPD centres 2005	79

LIST OF FIGURES (continue)

Figure 8.2.6(b)	Variation in proportion of patients with serum cholesterol < 5.3 mmol/L, CAPD centres 2005	79
Figure 8.2.6(c)	Variation in median serum triglyceride level among HD patients, HD centres 2005	80
Figure 8.2.6(d)	Variation in proportion of patients with serum triglyceride < 2.1 mmol/L, CAPD centres 2005	80
Figure 9.2.1	Cumulative distribution of corrected Serum Calcium, HD patients 1997-2005	83
Figure 9.2.2	Cumulative distribution of corrected Serum Calcium, CAPD patients 1997-2005	83
Figure 9.2.3	Cumulative distribution of Serum Phosphate, HD patients 1997-2005	84
Figure 9.2.4	Cumulative distribution of Serum Phosphate, CAPD patients 1997-2005	84
Figure 9.2.5	Cumulative distribution of corrected Calcium x Phosphate product, HD patients 1997-2005	85
Figure 9.2.6	Cumulative distribution of corrected Calcium x Phosphate product, CAPD patients 1997-2005	85
Figure 9.2.7(a)	Variation in median serum calcium level among HD patients, HD centres 2005	86
Figure 9.2.7(b)	Variation in proportion of patients with serum calcium 2.2 to 2.6 mmol/L, HD centres 2005	86
Figure 9.2.8(a)	Variation in median serum calcium level among CAPD patients, CAPD centres 2005	87
Figure 9.2.8(b)	Variation in proportion of patients with serum calcium 2.2 to 2.6 mmol/L, CAPD centres 2005	87
Figure 9.2.9(a)	Variation in median serum phosphate level among HD patients, HD centres 2005	88
Figure 9.2.9(b)	Variation in proportion of patients with serum phosphate ≤ 1.6 mmol/L, HD centres 2005	88
Figure 9.2.10(a)	Variation in median serum phosphate level among CAPD patients, CAPD centres 2005	89
Figure 9.2.10(b)	Variation in proportion of patients with serum phosphate ≤ 1.6 mmol/L, CAPD centres 2005	89
Figure 9.2.11(a)	Variation in median corrected calcium x phosphate product among HD patients, HD centres 2005	90
Figure 9.2.11(b)	Variation in proportion of patients with corrected calcium x phosphate product < 4.5 mmol ² /L ² 2005	90
Figure 9.2.12(a)	Variation in median corrected calcium x phosphate product among CAPD patients, CAPD centres 2005	91
Figure 9.2.12(b)	Variation in proportion of patients with corrected calcium x phosphate product < 4.5 mmol ² /L ² , CAPD centres 2005	91
Figure 10.3	Variation in Proportion of patients with positive HBsAg among HD centres, 2005	94
Figure 10.4	Variation in Proportion of patients with positive HBsAg by CAPD centre, 2005	95
Figure 10.5	Variation in Proportion of patients with positive anti-HCV among HD centres, 2005	96
Figure 10.6	Variation in Proportion of patients with positive anti-HCV among CAPD centres 2005	97
Figure 11.2.1	Blood Flow Rates in HD Units, 1997–2005	101
Figure 11.2.4	Dialyser membrane types in HD Units, 1997 – 2005	103
Figure 11.2.7	Cumulative distribution of prescribed KT/V, HD patients 1997-2005	105
Figure 11.2.8(a)	Variation in median blood flow rates in HD patients among HD centres 2005	106
Figure 11.2.8(b)	Variation in Proportion of patients with blood flow rates > 250 ml/min among HD centres 2005	107
Figure 11.2.8(c)	Variation in proportion of patients with 3 HD sessions per week among HD centres 2005	107
Figure 11.2.8(d)	Variation in median prescribed KT/V in HD patients among HD centres 2005	108
Figure 11.2.8(e)	Variation in proportion of patients with prescribed KT/V ≥ 1.3 among HD centres 2005	108
Figure 11.3.1	Unadjusted technique survival by Dialysis modality, 1996-2005	109
Figure 11.3.2	Unadjusted technique survival by year of entry, 1996-2005	110

LIST OF FIGURES (continue)

Figure 11.3.3	Unadjusted technique survival by age, 1996-2005	111
Figure 11.3.4	Unadjusted technique survival by Diabetes status, 1996-2005	112
Figure 12.2.1	Cumulative distribution of delivered KT/V, CAPD patients 2003-2005	116
Figure 12.2.2	Variation in proportion of patients with KT/V \geq 2.0 per week among CAPD centres 2005	116
Figure 12.3.1	Unadjusted technique survival by Dialysis modality, 1996-2005	118
Figure 12.3.2	Unadjusted technique survival by year of entry, 1996-2005	120
Figure 12.3.3	Unadjusted technique survival by age, 1996-2005	120
Figure 12.3.4	Unadjusted technique survival by Diabetes status, 1996-2005	121
Figure 12.3.5	Unadjusted technique survival by Gender, 1996-2005	121
Figure 12.4.1	Variation in peritonitis rate (pt-month/ epi) among CAPD centres 2005	122
Figure 13.1.1	Stock and Flow of Renal Transplantation, 1975-2005	125
Figure 13.1.2	New transplant rate, 1975-2005	125
Figure 13.1.3	Transplant prevalence rate, 1975-2005	126
Figure 13.4.2(a)	Transplant Recipient Death Rate, 1975-2005	131
Figure 13.4.2(b)	Transplant Recipient Graft Loss Rate, 1975-2005	131
Figure 13.5.1	Patient survival, 1993-2005	133
Figure 13.5.2	Graft survival, 1993-2005	133
Figure 13.5.3	Patient survival by type of transplant, 1993-2005	134
Figure 13.5.4	Graft survival by type of transplant, 1993-2005	134
Figure 13.5.5	Patient survival by year of transplant (Living related transplant, 1993-2005)	135
Figure 13.5.6	Graft survival by year of transplant (Living related transplant, 1993-2005)	135
Figure 13.5.7	Patient survival by year of transplant (Commercial cadaver transplant, 1993-2005)	136
Figure 13.5.8	Graft survival by year of transplant (Commercial cadaver transplant, 1993-2005)	136

REPORT SUMMARY

- Intake of new dialysis patients showed a linear increase over the years -from 952 in 1996 to 2774 in 2004 with corresponding treatment rates of 45 and 108 per million population respectively.
- Prevalent dialysis patients increased from 2922 (138 per million) in 1996 to 11767 (460 per million) at year end 2004.
- The number of new transplant patients increased from just above 151 in 1996 to 185 in 2004 but transplant rates remain about 5-7 per million. Patients with functioning renal transplants increased from 1024 (48 per million) to 1582 (62 per million) over the same period.
- Dialysis treatment rates varied from about 48-80 per million state population in the economically underdeveloped states to >140 per million in the more economically advantaged states in 2004.
- From the centre survey carried out at the end of 2005, there were a total of 12974 dialysis patients, 34% in the Ministry of Health hospitals, 32% in non-governmental organization (NGO) centres and about 31% in the private sector. The gap between HD capacity and patient intake was widening for all 3 sectors but was widest for the NGO sector.
- The treatment gap between men and women has remained consistent over the years.
- Dialysis treatment rates for those < 65 years of age had plateaued while those >65 years continue to register rapid increase. 52% of new dialysis patients were at least 55 years old
- At least 88% of new patients were accepted into centre haemodialysis
- The government continued to fund about 50% of dialysis treatment, NGO funding decreased to 12% in 2004, and self funding had decreased to 23%.
- Diabetes mellitus continued to be the commonest cause of ESRD accounting for 52% in 2005, followed by hypertension at 7%.
- The annual death rate for those on CAPD remained relatively unchanged while there was an upward trend in the annual death rate for those on haemodialysis.
- Cardiovascular disease and death at home remained the commonest cause of death in 2005; sepsis was next at 12%.
- The unadjusted 5 and 10 year patient survival on dialysis were 59% and 37% respectively. HD patient survival was superior to that on CAPD. HD patient survival varied widely between centres. Adjusted patient survival varied widely between CAPD centres at 5-years but not at 1-year.
- Older and diabetic patients had poorer survival on dialysis.
- Median QoL index scores were satisfactory. Patients on HD, diabetics and older patients reported lower QoL scores.
- Employment among HD and CAPD patients increased with increasing years on dialysis.
- In 2005, 80% of HD and 72% of CAPD patients were on erythropoietin (EPO). Blood transfusion rate in dialysis patients remained at 10 -15%. There was decreasing use of oral iron supplements; use of IV Iron has increased. Variations were seen in the use of EPO, blood transfusion rates and measures of iron stores in HD and CAPD centres

REPORT SUMMARY

- Serum albumin levels remained at mean and median of 40g/L for HD but showed a decreasing trend in CAPD patients. There were wide variations in the proportion of patients with serum albumin >40g/L in both HD and CAPD centres.
- BMI for both HD and CAPD patients improved. There was some variation in proportion of patients with BMI ≥ 18.5 in both HD and PD centres.
- In 2005, the mean and median predialysis systolic BP was 149 mm Hg in HD and 140 mmHg in CAPD patients, while the diastolic BP was about 80 mmHg for both HD and CAPD patients. The variation noted among the various HD and PD centres in median systolic or diastolic BP was not wide but there was wide variation in the proportion of patients achieving BP of <140/90 mmHg.
- Improving cholesterol levels were seen in both HD and CAPD patients with lower levels seen in HD patients. Serum triglyceride levels did not show much change over the years and was lower in HD patients. There was not much variation in lipid control between dialysis centres.
- In 2005 calcium carbonate remained the major phosphate binder in both HD and CAPD patients. Phosphate control was better in CAPD patients. The target of calcium phosphate product of less than $4.5 \text{ mmol}^2/\text{L}^2$ was achieved more by CAPD patients than HD. There was variation in serum calcium, phosphate and calcium phosphate product among both hemodialysis and CAPD centres.
- The prevalence of Hepatitis B infection has remained unchanged over the years, and was quite similar between HD and CAPD patients. HCV prevalence showed a declining trend of about 9% since 2001. The proportion of HCV infected patients varied widely between HD centers.
- Haemodialysis practices have changed since 1997 to 2005. There was increased use of brachiocephalic fistulae, higher blood flow rates, increased usage of synthetic membranes, increased number of reuse and almost universal use of bicarbonate buffer. Median prescribed KT/V plateaued over the last few years at 1.6. There was wide variation in the proportion of patients with blood flow rates of >250 ml/min, and KT/V of ≥ 1.3 among HD centres. Technique survival was better in HD compared to PD, in the younger age groups and the non-diabetics but was not related to the year of starting dialysis.
- Chronic PD - In 2005, CAPD remained the commonest mode of PD at 93% but APD use increased to 4%. The Baxter disconnect system was the commonest connectology used. Ninety-four percent of patients performed 4 exchanges a day, 90% used a fill volume of 2 L. The median delivered weekly Kt/V was 2.1, 61% achieved target of 2.0 with a 8-fold variation between the highest- and the lowest-performing centres. 78% of prevalent patients had low-average or high-average PET status. High PET status was more common among prevalent patients. Technique survival was better for younger patients and non-diabetics but was not related to the year of starting dialysis or gender.
- In 2005, median peritonitis rate was 35 patient-months but varied between 23 and 65 patient-months/episode among centres. Gram positive and Gram negative organisms each accounted for 35% and 32% of peritonitis episodes.

REPORT SUMMARY

Chapter 13 Renal Transplantation

- There were 151 new renal transplant recipients in 2004 and 1657 with functioning transplants.
- Mean age of new transplant patients in 2005 was 39 years; 71% were male, 21% diabetic, 4% HbsAg positive and 3% anti-HCV positive at the time of transplantation.
- Commonest known primary renal disease was chronic glomerulonephritis followed by hypertension.
- In 2005, commercial transplants from China constituted 69% of all new renal transplantation, live donor transplantation 26% and local cadaveric transplants contributed only 3%.
- 78% of renal transplant recipients were on cyclosporine, 97% on prednisolone, and 14% were on tacrolimus. 41% were on MMF and 40% on azathioprine
- 13% of the prevalent renal transplant recipients had diabetes mellitus before transplantation, another 8% developed diabetes mellitus post transplantation
- In 2004, 37 (2%) of transplant recipients died and 44 (3%) lost their grafts. Infection, cardiovascular disease and cancer were the commonest causes of death for the last decade accounting for 25%, 10% and 18% in 2004. Renal allograft rejection accounted for 50-60% of graft loss.
- The overall transplant patient survival rate from 1993 to 2005 was 95%, 92%, 88% and 81% at 1 year, 3 years, 5 years and 10 years respectively, while the overall graft survival rate was 92%, 85%, 79% and 63% respectively.

Chapter 5: Paediatric Renal replacement therapy

- Intake of new paediatric dialysis patients increased from 12 in 1990 to 75 in 2005 giving a dialysis acceptance rate of 1 per million age related population (pmarp) to 7 pmarp respectively.
- New renal transplant rate at only 1 pmarp over the last 15 years.
- At the end of 2005 there were a total of 429 patients under 20 on dialysis giving a dialysis prevalence rate 39 pmarp.
- The number of patients with functioning transplants in 2004 was 120 giving a prevalence rate of 11 pmarp.
- Dialysis treatment rates were higher in the economically advantaged states of Malaysia.
- The number of 0-4 year olds provided RRT remained very low.
- Chronic PD was the preferred mode of initial dialysis modality; 20% of which was APD.
- More than 90% received dialysis in government centres.
- Glomerulonephritis accounted for 28% of ESRD, focal segmental glomerulosclerosis 11%, and SLE 7%. 34% of patients had unknown primary renal disease.
- Patient survival on HD was 94% for 1 year, 85% for 5 years and 78% for 10 years. CAPD patient survival was 95% at 1 year, 81% at 5 years
- CAPD had worse technique survival compared to HD 2 years after the start of dialysis.
- Patient survival for renal transplantation was 97% for 1 year, 94% at 5 years and 94% at 10 years post transplant; graft survival was 90% at 1 year, 79% at 5 years and 67% at 10 years.