



2020

HEALTH TECHNOLOGY  
ASSESSMENT REPORT

# HTA

PRE-DIALYSIS EDUCATION  
PROGRAMME

# MaHTAS

Malaysian Health Technology Assessment Section

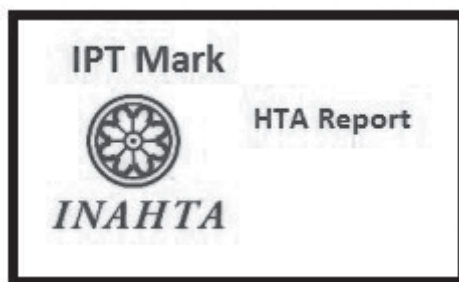
MEDICAL DEVELOPMENT DIVISION  
MINISTRY OF HEALTH



# HEALTH TECHNOLOGY ASSESSMENT REPORT

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## PRE-DIALYSIS EDUCATION PROGRAMME



**MALAYSIAN HEALTH TECHNOLOGY ASSESSMENT SECTION (MaHTAS)  
MEDICAL DEVELOPMENT DIVISION  
MINISTRY OF HEALTH**

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## **DISCLOSURE**

The authors of this report have no competing interest in this subject and the preparation of this report is totally funded by the Ministry of Health, Malaysia.



# EXECUTIVE SUMMARY

## Background

Chronic Kidney Disease (CKD) is a growing public health concern which is responsible for various complications including all-cause and cardiovascular mortality, progression to end-stage renal disease (ESRD), cognitive decline, anaemia, mineral and bone disorders. The Global Burden of Disease 2015 study estimated that, in 2015, about 1.2 million people died from kidney failure, an increase of 32% since 2005. In Malaysia, the prevalence of CKD has increased from 9.1% in the 2011 Malaysian National Health and Morbidity Survey to 15.5% in 2018. The number of patients with CKD is expected to significantly rise in the future largely due to the increasing prevalence of diabetes, hypertension as well as the aging population in Malaysia.

It is known that timely referral to nephrologist is recommended for renal replacement therapy (RRT) in people with progressive CKD. In the Malaysian Clinical Practice Guideline (CPG) for Management of Chronic Kidney Disease (Second Edition) 2018, it is stated in the recommendation that CKD patient with rapidly declining renal function (stage 4 to stage 5) should be referred to a nephrologist/physician. The UK Renal Association recommends that all patients with severe CKD (stage 5 and progressive stage 4), alongside their families and carers, should be offered pre-dialysis education programme (PDEP).

This programme aims at improving knowledge and understanding of the condition, as well as assisting them in making decisions for RRT. However, in most studies, it is reported that about 40% to 60% of patients with CKD start dialysis in an unplanned fashion and/or under urgent circumstances despite regular follow-up by a nephrologist. This is of concern since in unplanned dialysis, patients forego the opportunity to make an informed, shared decision regarding the timing and modality of RRT as options for RRT under urgent conditions are often limited. This highlights the importance of a structured and comprehensive PDEP in preparing advanced-stage CKD patients for RRT.

At present, there is no standard national programme established in Ministry of Health for pre-dialysis education. Pre-dialysis education for advanced CKD patients is often done in different ways across the country. Effectiveness of such methods in delivering pre-dialysis education for advanced CKD patients is largely unknown. Therefore, this health technology assessment (HTA) was requested by Head of Nephrology Services, Ministry of Health, Malaysia to review the available evidence and feasibility of structured PDEP for advanced CKD patients before its adoption into national programme in Malaysia.

## Technical features

Pre-dialysis education programme (PDEP) often described as multidisciplinary education programme, which consists of multiple education sessions where patients are educated by three or more health care professionals such as nephrologist, nurse, dietitian, medical social officer, home-dialysis coordinator, pharmacist, technician, or by other dialysis patients. This programme usually caters CKD patients who are in stage 4 and 5. There are variations in practice, however, PDEP usually includes individualised one-to-one sessions with a member or members of the multidisciplinary team and group discussions, peer counselling as well as problem-solving sessions have been described. The aims of this programme are mainly to provide patients with information on ESRD treatment options, help decision-making between treatments, and encourage self-care to improve quality of life.

## Policy Question

Should a structured PDEP be expanded in all Ministry of Health facilities?

## Objective

- i. To assess the effectiveness and safety of PDEP for advanced CKD patients
- ii. To assess the organisational, ethical, legal and societal implications related to PDEP for advanced CKD patients
- iii. To assess the cost-effectiveness of PDEP for advanced CKD patients
- iv. To assess the most suitable PDEP for Malaysian context

## Research questions

- i. Is PDEP effective and safe for advanced CKD patients?
- ii. What are the organisational, ethical, legal and societal implications of PDEP for advanced CKD patients?
- iii. Is PDEP cost-effective for advanced CKD patients?

## Methods

Studies were identified by searching the electronic database for published literatures pertaining to PDEP for advanced CKD patients. The following electronic databases were searched through the Ovid interface: Ovid MEDLINE® In-process and other Non-indexed citations and Ovid MEDLINE® 1946 to present, EBM Reviews - Health Technology Assessment (4<sup>th</sup> Quarter 2016), EBM Reviews - Cochrane Database of Systematic Review (2005 to Dec 2019), EBM Reviews - Cochrane Central Register of Controlled Trials (Dec 2019), EBM Reviews - Database of Abstracts of Reviews of Effects (1<sup>st</sup> Quarter 2016), EBM Reviews - NHS Economic Evaluation Database (1<sup>st</sup> Quarter 2016). Parallel searches were run in PubMed and INAHTA database. No limits were applied to the search. Detailed search strategy is as in Appendix 3. The last search was performed on 2<sup>nd</sup> December 2019. Additional articles were identified from reviewing the references of retrieved articles.

## Results and conclusions:

### **A. SYSTEMATIC REVIEW OF LITERATURE**

A total of 251 records were found to be potentially relevant and were screened using the inclusion and exclusion criteria. Sixteen out of 75 full text articles comprised of one SR with meta-analysis, one SR, one RCT, three cohort studies, two retrospective cohort studies, two pre- and post- intervention studies, four cross-sectional studies and two qualitative studies were finally included in this review. All studies included were published in English language between 2003 and 2018. Most studies were conducted in Taiwan, United States of America (USA) and Europe. Others were conducted in Brunei, The Netherlands, Turkey, Canada, Philippines and United Kingdom (UK).

### **Effectiveness**

There was limited fair level of retrievable evidence to suggest that participation of advanced CKD patients in PDEP contributed to greater survival probability and higher one-year survival rate compared to those who did not. However, no significant difference reported after two years. Limited fair to good level of retrievable evidence to suggest lower mortality and morbidity rates in patients who had PDEP. Limited evidence demonstrated that patients who had PDEP had longer time to dialysis and better blood profiles compared to those who did not. Significantly lower peritonitis-related mortality rates and lower peritonitis-related morbidity rates were also noted in PD patients.

### **Safety**

There was no retrievable evidence on the safety issues with regards to PDEP for advanced CKD patients.

**Organisational****Hospitalisation / Length of stay**

There was fair to good level of retrievable evidence to suggest that PDEP was associated with significantly lower frequency of temporary catheter use, lower rates of hospitalisation at dialysis initiation and post- dialysis, as well as shorter length of hospital stay.

**Components of programme**

The evidence showed great variation in the components of the programmes described, from the multidisciplinary team members, to the educational process including timing, delivery styles, formats for content, structure, conduct of the programme and materials. However, most evidence reported involvement of multidisciplinary team members almost always comprised of nephrologists, nurses, dietitians and medical social officers, with few had pharmacist, clinical psychologist and patient volunteers. Most studies mentioned multiple individual sessions with few had mixed of individual sessions and group sessions as well as patients' involvement. Majority involved patients with CKD stage 4 and 5 in the programme, with content tailored according to the patients' CKD stage and principally focused on knowledge on nutrition, lifestyle modification, nephrotoxin avoidance, compliance to medications, preparation for RRT and modality choices with few reported hands-on and demonstration. Materials used ranged from video materials, printed materials, and website materials. Frequency of the sessions and follow-up were mostly depended on the CKD stage.

**Guidelines**

Few guidelines from UK, USA, France, Europe and a position statement following an expert meeting in Switzerland have been issued outlining the recommendations on the conduct of PDEP.

**Social / Psychological**

There was fair to good level of retrievable evidence to suggest significant association between PDEP and patient's choice as well as receipt of PD and home dialysis for RRT. Limited evidence also showed higher rates of pre-emptive kidney transplantation rates, higher levels of knowledge of ESRD and RRT options as well as higher levels of adherence, lower depression levels and anxiety levels, and better HRQL were noted in patients who had PDEP.

Limited evidence also showed that patient factors including individualisation, educational factors including tailored education, appropriate time/information, and available resources as well as support systems were the influential factors on patients' decision for RRT. Sub-optimal education, different perspectives between patients and staff, and the influence of patient experience were the three themes identified which related to improving PDEP.

**Cost-effectiveness**

Based on two cost-analyses, significant reduction in medical expenditure after initiation of HD were noted in patients who had PDEP and the cost-saving effect came through the early preparation of vascular access and reduced hospitalisations.

**B. LOCAL SURVEY ON PRE-DIALYSIS EDUCATION PROGRAMME**

A multi-centre cross-sectional questionnaire survey was conducted in January 2020 to identify the essential components of pre-dialysis education programme based on the preferences of patients, carers and healthcare workers. A total of 39 respondents were recruited via purposive sampling from three public hospitals. Based on the survey findings, patients and carers preferred to have a 30-minute single session with multiple educators every three months delivered by a multidisciplinary team consisting of doctor, dietitian, patient representative, medical social officer, psychologist, pharmacist, nurse and medical assistant with a mix of education materials such as hands-on session or demonstration, audio-visual aids, leaflets or pamphlets and information about websites or online videos in the hospital setting. The pre-dialysis education may be given as an individual (one-to-one) or group session depending on the patient's preference. The pre-dialysis education should be initiated approximately six months before starting treatment of choice, allowing patients and carers to have sufficient time to understand about available treatment options. Patients and carers agreed

that being part of a patient support group would be helpful in solving real-life problems and that shared decision-making between doctors and patients is important to them. The healthcare workers expressed different preferences in terms of delivery method, time of initiation, duration, frequency, and venue which may arise from consideration of practical aspects such as daily burden of workload and capacity in delivering the education sessions, which should be taken into consideration when designing the PDEP.

**Recommendation**

Based on the above review, a standardised approach to PDEP should be outlined before its expansion to all Ministry of Health, Malaysia facilities. A multidisciplinary team involving well-trained personnel, and optimally with mixed individual and group sessions as well as using interactive mixed education materials should be established. Comprehensive and more personalised content tailored according to the CKD stage taking account individual needs, emotional support, psychosocial aspects, involvement of family as well as caregivers and additional support from patients' support group are advocated.

# TABLE OF CONTENTS

	Disclaimer	i
	Authors	ii
	Expert committee	iii
	External reviewers	iv
	Acknowledgement and Disclosure	v
	Executive summary	vi
	Abbreviations	xii
1	<b>CHAPTER 1 : INTRODUCTION</b>	1
	1.1 BACKGROUND	1
	1.2 TECHNICAL FEATURES	3
	1.3 POLICY QUESTIONS	3
2	<b>CHAPTER 2: SYSTEMATIC REVIEW</b>	4
	2.1 OBJECTIVES	4
	2.2 RESEARCH QUESTIONS	4
	2.3 METHODS	4
	2.3.1 LITERATURE SEARCH STRATEGY	4
	2.3.2 STUDY SELECTION	4
	2.3.3 QUALITY ASSESSMENT STRATEGY	6
	2.3.4 DATA EXTRACTION STRATEGY	6
	2.3.5 METHODS OF DATA SYNTHESIS	7
	2.4 RESULTS	7
	2.4.1 RESULTS OF THE SEARCH	7
	2.4.2 DESCRIPTION OF THE INCLUDED STUDIES	9
	2.4.3 RISK OF BIAS ASSESSMENT	17
	2.4.4 EFFECTIVENESS	19
	2.4.4.1 PERITONITIS AND PERITONITIS-RELATED DEATH	19
	2.4.4.2 SURVIVAL RATE	20
	2.4.4.3 MORBIDITY AND MORTALITY	20
	2.4.5 SAFETY	22
	2.4.6 ORGANISATIONAL ISSUES	22
	2.4.6.1 HOSPITALISATION AND LENGTH OF STAY	22
	2.4.6.2 COMPONENTS OF PROGRAMME	24
	2.4.6.3 GUIDELINES	27
	2.4.7 SOCIAL IMPLICATION	29
	2.4.7.1 MODALITY CHOICE	29
	2.4.7.2 PATIENTS' SATISFACTION	33
	2.4.7.3 PATIENTS' AND STAFF INSIGHTS	34
	2.4.7.4 PATIENTS' KNOWLEDGE	35
	2.4.7.5 PSYCHOLOGICAL IMPLICATION	36
	2.4.8 COST-EFFECTIVENESS	37
	2.5 DISCUSSION	38

3	CHAPTER 3: LOCAL SURVEY ON PRE-DIALYSIS EDUCATION PROGRAMME 3.1 AIM 3.2 METHODS 3.3 RESULTS 3.4 DISCUSSION AND CONCLUSION 3.5 REFLECTION/CRITICAL PERSPECTIVES	40 40 41 47 48
4	CHAPTER 4: CONCLUSIONS AND RECOMMENDATIONS 4.1 CONCLUSIONS 4.1.1 SYSTEMATIC REVIEW 4.1.2 PATIENT AND PUBLIC INVOLVEMENT IN PRE-DIALYSIS EDUCATION PROGRAMME 4.2 RECOMMENDATIONS	51 51 51 52 52
5	REFERENCES	53
6	APPENDICES Appendix 1- Hierarchy of evidence for effectiveness studies Appendix 2- Health Technology Assessment Protocol Appendix 3- Search strategy Appendix 4- Evidence Table (Included studies) Appendix 5- List of excluded studies Appendix 6- Survey questionnaires Appendix 7- Suggestions to improve Pre-dialysis Education Programme	56 57 63 64 89 92 96

## Abbreviations

<b>AIDET</b>	Acknowledge, Introduce, Duration, Explanation, Thank you
<b>ADL</b>	Activities of Daily Living
<b>CKD</b>	Chronic Kidney Disease
<b>CASP</b>	Critical Appraisal Skills Programme
<b>CI</b>	Confidence Interval
<b>CPE</b>	Comprehensive Pre-dialysis Education
<b>CPG</b>	Clinical Practice Guideline
<b>DVD</b>	Digital Versatile Disc
<b>ESRD</b>	End-Stage Renal Disease
<b>eGFR</b>	Estimated Glomerular Filtration Rate
<b>EU</b>	European Union
<b>FDA</b>	Food Drug Administration
<b>GFR</b>	Glomerular Filtration Rate
<b>GUIDE</b>	Structured Pre-dialysis Education Programme in The Netherlands
<b>GRIPP2-SF</b>	Guidance for Reporting Involvement of Patients and the Public
<b>HCW</b>	Healthcare Workers
<b>HD</b>	Haemodialysis
<b>HTA</b>	Health Technology Assessment
<b>HR</b>	Hazard Ratio
<b>hs-CRP</b>	High-sensitivity C-reactive Protein
<b>INAHTA</b>	International Network of Agencies for Health Technology Assessment
<b>iPTH</b>	intact Parathyroid Hormone
<b>IQR</b>	Interquartile range
<b>KDIGO</b>	Kidney Disease Improving Global Outcomes
<b>MaHTAS</b>	Malaysian Health Technology Assessment Section
<b>MPE</b>	Multidisciplinary Pre-dialysis Education
<b>MDM</b>	Multidisciplinary Meeting
<b>NIH</b>	National Institute of Health
<b>NHI</b>	National Health Insurance
<b>N/A</b>	Not-applicable
<b>OT</b>	Occupational Therapist
<b>OR</b>	Odds Ratio
<b>PD</b>	Peritoneal dialysis
<b>PDEP</b>	Pre-dialysis Education Programme
<b>PPI</b>	Patient and Public Involvement
<b>QoL</b>	Quality of life
<b>rHuEPO</b>	Recombinant Human Erythropoietin
<b>RRTOE</b>	Renal Replacement Therapy Options Education
<b>RRT</b>	Renal Replacement Therapy

<b>RCT</b>	Randomised controlled trial
<b>SR</b>	Systematic Review
<b>USA</b>	United States of America
<b>UK</b>	United Kingdom



# CHAPTER 1: INTRODUCTION

## 1.1 BACKGROUND

Chronic Kidney Disease (CKD) is a growing public health concern which is responsible for various complications including all-cause and cardiovascular mortality, progression to end-stage renal disease (ESRD), cognitive decline, anaemia, mineral and bone disorders.<sup>1</sup> The Global Burden of Disease 2015 study estimated that, in 2015, about 1.2 million people died from kidney failure, an increase of 32% since 2005.<sup>2</sup> In 2010, it was estimated that around 2.3 to 7.1 million people with ESRD died without access to chronic dialysis.<sup>2</sup> However, despite of these growing figures, the awareness remains low among patients and health-care providers.<sup>1</sup>

In Malaysia, the prevalence of CKD has increased from 9.1% in the 2011 Malaysian National Health and Morbidity Survey<sup>3,4</sup> to 15.5% in 2018<sup>5</sup>. Awareness of CKD was hardly improved in seven years from 4% of respondents in 2011<sup>5</sup> to 5% in 2018.<sup>6</sup> In the year of 2011, there were 27,572 patients on renal replacement therapy (RRT) in Malaysia<sup>5</sup> and the figures have grown to a total of 37,183 patients on regular dialysis in 2015, with 7,595 new patients entering dialysis.<sup>3</sup> The number of patients with CKD is expected to significantly rise in the future largely due to the increasing prevalence of diabetes, hypertension as well as the aging population in Malaysia.<sup>3</sup> This will certainly contribute to the major increase in the future needs for RRT and impose a large burden on health care budget.

According to Malaysian Clinical Practice Guideline (CPG) for Management of Chronic Kidney Disease (Second Edition) published in 2018, CKD is defined as an estimated glomerular filtration rate (eGFR) of  $<60$  ml/min/1.73 m<sup>2</sup> that is present for more than three months with or without evidence of kidney damage, or evidence of kidney damage that is present for more than three months with or without eGFR  $<60$  ml/min/1.73 m<sup>2</sup>.<sup>3</sup> Markers for kidney damage includes albuminuria (albumin excretion rate  $\geq 30$  mg/24 hours or albumin-creatinine ratio  $\geq 3$  mg/mmol), urine sediment abnormalities, abnormalities detected by histology, structural abnormalities detected by imaging and history of kidney transplantation.<sup>3</sup> Classification of CKD is currently based on cause, glomerular filtration rate (GFR) category, and albuminuria category and follows Kidney Disease Improving Global Outcomes (KDIGO) 2012 guidelines which has health and prognostic implications.<sup>3,7</sup> The GFR categories mapping to the previous five-stage classification have been retained but with subdivision of the G3 category of 30 to 59 mL/min per 1.73 m<sup>2</sup> into categories G3a (45 to 59 mL/min per 1.73 m<sup>2</sup>) and G3b (30 to 44 mL/min per 1.73 m<sup>2</sup>).<sup>8</sup> This was driven by data supporting different outcomes and risk profiles in these categories.<sup>8</sup> Severity is expressed by level of GFR and albuminuria and is linked to risks for adverse outcomes, including death and kidney outcomes.<sup>8</sup>

**Table 1. Prognosis of CKD by GFR and albuminuria category<sup>3,7</sup>**

				Persistent albuminuria categories		
				Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30 - 300 mg/g 3 - 30 mg/mmol	>300 mg/g >30 mg/mmol
				GFR categories (ml/min/1.73 m <sup>2</sup> ) Description and range	G1	Normal or high
G2	Mildly decreased	60 - 89				
G3a	Mildly to moderately decreased	45 - 59				
G3b	Moderately to severely decreased	30 - 44				
G4	severely decreased	15 - 29				
G5	Renal failure	<15				

Green - low risk, Yellow - moderate risk, Orange - high risk, Red and Deep Red - very high risk

It is known that timely referral to nephrologist is recommended for RRT in people with progressive CKD in whom the risk of kidney failure within one year is 10–20% or higher, as determined by validated risk prediction tools.<sup>7</sup> In the Malaysian CPG for Management of Chronic Kidney Disease (Second Edition) 2018, it is stated in the recommendation that CKD patient with rapidly declining renal function [loss of eGFR >5 ml/min/1.73 m<sup>2</sup> in one year or >10 ml/min/1.73 m<sup>2</sup> within five years] or eGFR <30 ml/min/1.73 m<sup>2</sup> (eGFR categories G4 to G5) should be referred to a nephrologist/physician<sup>3</sup>. UK Renal Association recommends that all patients with severe CKD (stage 5 and progressive stage 4), alongside their families and carers, should be offered pre-dialysis education programme (PDEP).<sup>9</sup>

This programme aims at improving knowledge and understanding of the condition, as well as assisting them in making decisions for RRT.<sup>9</sup> However, in most studies, it was reported that about 40% to 60% of patients with CKD start dialysis in an unplanned fashion and/or under urgent circumstances despite regular follow-up by a nephrologist.<sup>10</sup> This is of concern since in unplanned dialysis, patients forego the opportunity to make an informed, shared decision regarding the timing and modality of RRT as options for RRT under urgent conditions are often limited.<sup>10</sup> Studies reported that advanced age, increased comorbidity burden, late referral to nephrology, and lower GFR at dialysis initiation were the most common independent risk factors for unplanned dialysis.<sup>10,11</sup> In addition, patients who had unplanned dialysis were found much less likely to have received formal pre-dialysis education about the different options for RRT.<sup>10,11</sup> This highlights the importance of a structured and comprehensive PDEP in preparing advanced-stage CKD patients for RRT as unplanned dialysis is known to be associated with increased patient morbidity, mortality, hospitalisations, needs for temporary catheter insertion which subsequently increase the risk of catheter related sepsis and inevitably contribute further to the economic burden of CKD.

At present, there is no standard national programme established in Ministry of Health for pre-dialysis education. Pre-dialysis education for advanced CKD patients is often done in different ways across the country. Several centres in Peninsular Malaysia have specific programme for pre-dialysis education while numerous other centres lack such a programme. Certain hospitals conduct half-day talk monthly which involves sharing experiences by peritoneal

dialysis (PD), haemodialysis (HD) and kidney transplant nurses as well as exploring the funding options by the medical social officer and inputs by dietitian for CKD patients and family members. Effectiveness of such method in delivering pre-dialysis education for advanced CKD patients is largely unknown. Therefore, this health technology assessment (HTA) was requested by Head of Nephrology Services, Ministry of Health, Malaysia to review the available evidence and feasibility of structured PDEP for advanced CKD patients before its adoption into national programme in Malaysia.

## 1.2 TECHNICAL FEATURES

Pre-dialysis education programme (PDEP) often described as multidisciplinary education programme, which consists of multiple education sessions where patients are educated by three or more health care professionals such as nephrologist, nurse, dietitian, medical social officer, home-dialysis coordinator, pharmacist, technician, or by other dialysis patients.<sup>11</sup> This programme usually caters CKD patients who are in stage 4 and 5.<sup>11</sup> There are variations in practice, however, PDEP usually includes individualised one-to-one sessions with a member or members of the multidisciplinary team and group discussions, peer counselling as well as problem-solving sessions have been described wherein patients discuss treatment modalities, as well as barriers, benefits, and troubleshooting of possible problems with other patients.<sup>11</sup> Topics covered in this programme mostly include patients' renal care, nutrition, lifestyle, nephrotoxin avoidance, medications, preparation for RRT and modality choices depending on the CKD stage. Variety of formats have been described in the delivery style of the programme such as group lectures, interactive workshops, open forum sessions as well as written and audio-visual materials to take home.<sup>11,12</sup>

The multidisciplinary team should include or have access to dietary counselling, education and counselling about different RRT modalities including HD, PD, home dialysis, and transplant options, vascular access surgery, as well as ethical, psychological and social care.<sup>8</sup> The aims of this programme are mainly to provide patients with information on end-stage kidney disease treatment options, help decision-making between treatments, and encourage self-care to improve quality of life.<sup>12</sup> A systematic approach with PDEP is thought to assist patients in preparation for RRT and prevent the complications of unplanned dialysis subsequently reduce the complications of ESRD.

## 1.3 POLICY QUESTION

Should a structured PDEP be expanded in all Ministry of Health facilities?

## CHAPTER 2: SYSTEMATIC REVIEW

### 2.1 OBJECTIVE

- 2.1.1 To assess the effectiveness and safety of PDEP for advanced CKD patients
- 2.1.2 To assess the organisational, ethical, legal and societal implications related to PDEP for advanced CKD patients
- 2.1.3 To assess the cost-effectiveness of PDEP for advanced CKD patients
- 2.1.4 To assess the most suitable PDEP for Malaysian context

### 2.2 RESEARCH QUESTIONS

- 2.2.1 Is PDEP effective and safe for advanced CKD patients?
- 2.2.2 What are the organisational, ethical, legal and societal implications of PDEP for advanced CKD patients?
- 2.2.3 Is PDEP cost-effective for advanced CKD patients?

### 2.3 METHODS

#### 2.3.1 Literature search strategy

Studies were identified by searching the electronic database for published literatures pertaining to PDEP for advanced CKD patients. The following electronic databases were searched through the Ovid interface: Ovid MEDLINE® In-process and other Non-indexed citations and Ovid MEDLINE® 1946 to present, EBM Reviews - Health Technology Assessment (4<sup>th</sup> Quarter 2016), EBM Reviews - Cochrane Database of Systematic Review (2005 to Dec 2019), EBM Reviews - Cochrane Central Register of Controlled Trials (Dec 2019), EBM Reviews - Database of Abstracts of Reviews of Effects (1<sup>st</sup> Quarter 2016), EBM Reviews - NHS Economic Evaluation Database (1<sup>st</sup> Quarter 2016). Parallel searches were run in PubMed and INAHTA database. No limits were applied to the search. Detailed search strategy is as in **Appendix 3**. The last search was performed on 2 December 2019. Additional articles were identified from reviewing the references of retrieved articles.

#### 2.3.2 Study selection

Based on the policy questions, the following inclusion and exclusion criteria were used: -

## Inclusion criteria

a.	<b>Population</b>	Adults patients with advanced CKD stage 4, 5
b.	<b>Intervention</b>	<p>Pre-dialysis education programme (PDEP):</p> <ol style="list-style-type: none"> <li>i. Multidisciplinary team comprised of nephrologists/ dietitians/ medical social officers/ pharmacists/ nurses/ psychologists/ HD or PD patient volunteers etc.</li> <li>ii. Multiple sessions</li> <li>iii. Relatively detailed description of the programme, such as sessions frequency, content of sessions, and descriptions of educators</li> </ol>
c.	<b>Comparator</b>	<ol style="list-style-type: none"> <li>i. No PDEP</li> <li>ii. No comparator</li> </ol>
d.	<b>Outcomes</b>	<ol style="list-style-type: none"> <li>i. Effectiveness of PDEP <ul style="list-style-type: none"> <li>- Mortality</li> <li>- Morbidity</li> <li>- Quality of life (QoL)</li> </ul> </li> <li>ii. Safety <ul style="list-style-type: none"> <li>- Complications</li> <li>- Adverse events</li> </ul> </li> <li>iii. Organisational <ul style="list-style-type: none"> <li>- Unplanned dialysis</li> <li>- Hospital admission</li> <li>- Length of hospital stay</li> <li>- Components of pre-dialysis education programme (content, structure, delivery style, timing)</li> <li>- Training</li> <li>- Guidelines</li> </ul> </li> <li>iv. Ethical, legal implications</li> <li>v. Psychological/Societal implications: <ul style="list-style-type: none"> <li>- Compliance</li> <li>- Acceptance</li> <li>- Patient satisfaction</li> <li>- Patient preference/ dialysis modality choice</li> <li>- Mental health issues</li> </ul> </li> <li>vi. Economic impact <ul style="list-style-type: none"> <li>- Cost</li> <li>- Cost analysis</li> <li>- Cost-effectiveness</li> <li>- Economic evaluation</li> </ul> </li> </ol>

e.	<b>Study design</b>	HTA reports, systematic review (SR), SR with meta-analysis, randomised controlled trial (RCT), cohort study, case-control study, cross-sectional study and economic evaluation studies
f.		Full text articles published in English

### Exclusion criteria

- a. Study design: animal study, narrative review, case series, case reports and early stage CKD patients.
- b. Non-English full text article

Based on the above inclusion and exclusion criteria, study selection was carried out independently by two reviewers. Disagreement was resolved by discussion.

### 2.3.3 Quality assessment strategy

The methodological quality of all the relevant full text articles retrieved was assessed using the relevant checklist of Cochrane Collaboration Assessment tools, NIH and Critical Appraisal Skills Programme (CASP) depending on the type of the study design. Assessment of the risk of bias was done by two reviewers and achieved by answering a pre-specified question of criteria assessed and assigning a judgement relating to the risk of bias as either:

+	Indicates YES (low risk of bias)
?	indicates UNKNOWN risk of bias
-	Indicates NO (high risk of bias)

All full text articles were then graded based on guidelines from the U.S./Canadian Preventive Services Task Force (Appendix 1).

### 2.3.4 Data extraction strategy

Data were extracted from the included studies by a reviewer using a pre-designed data extraction form (evidence table as shown in Appendix 4) and checked by another reviewer. Disagreements were resolved by discussion. Details on: (1) methods including study design, (2) study population (3) type of intervention, (4) comparators, (5) outcome measures including effectiveness of PDEP, safety, cost, cost-effectiveness, economic evaluation, organisational and social issues were extracted. Other information on author, journal and publication year, and study objectives were also extracted. The extracted data were presented and discussed with the expert committee.

### 2.3.5 Methods of data synthesis

Data on the effectiveness, safety, cost-effectiveness, organisational and social implication of PDEP for advanced CKD patients were presented in tabulated format with narrative summaries. No meta-analysis was conducted for this review.

## 2.4 RESULTS

### 2.4.1 Search results

An overview of the search is illustrated in **Figure 1**. A total of **332** records were identified through the Ovid interface: MEDLINE, EBM Reviews-Cochrane Database of Systematic Reviews (2005 to December 2019), EBM Reviews-Cochrane Central Register of Controlled Trials (December 2019), EBM Reviews-Health Technology Assessment (4th Quarter 2016), EBM Reviews-DARE, EBM Reviews-NHS Economic Evaluation Database (1st Quarter 2016) and Embase. Searches were also conducted in PubMed, Horizon Scanning database, INAHTA database, and FDA database. The last search was run on 02 December 2019.

Thirty-nine additional records were identified from references of retrieved studies. After removal of 120 duplicates, a total of 251 records were found to be potentially relevant and were screened using the inclusion and exclusion criteria. Of these, 75 relevant abstracts were retrieved in full text. After reading, appraising and applying the inclusion and exclusion criteria to the 75 full text articles, 16 full text articles were included. A total of 59 full text articles were excluded due to irrelevant study design (n = 17), irrelevant intervention (n = 28) and irrelevant population (n = 14). The excluded articles are listed in **Appendix 5**.

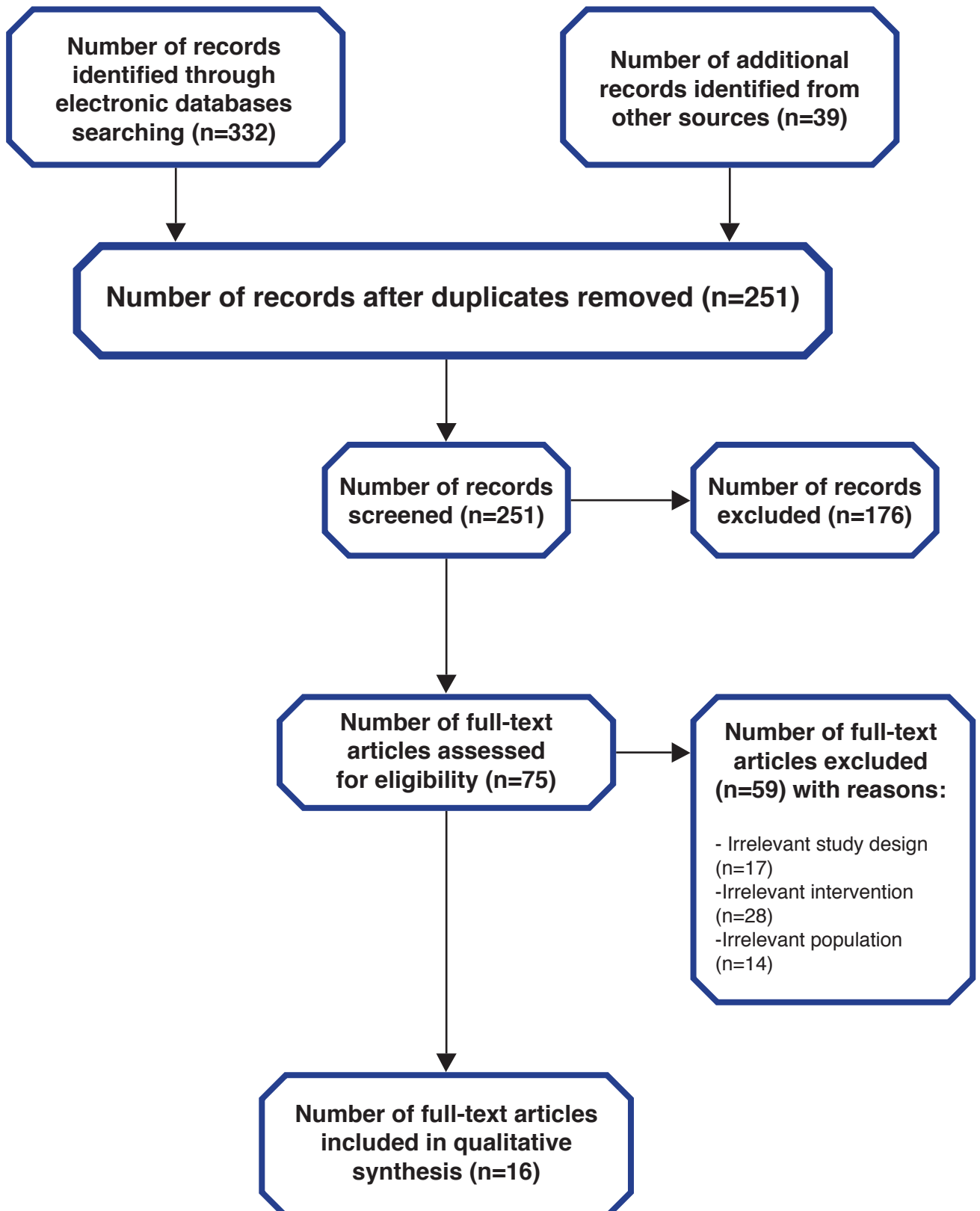


Figure 1: Flow chart of retrieval of articles used in the results



#### 2.4.2 Description of the included studies:

Sixteen full text articles included in this review comprised of one SR with meta-analysis, one SR, one RCT, three cohort studies, two retrospective cohort studies, two pre- and post-intervention studies, four cross-sectional studies and two qualitative studies. All studies included were published in English language between 2003 and 2018. Most studies were conducted in Taiwan, United States of America (USA) and Europe. Others were conducted in Brunei, The Netherlands, Turkey, Canada, Philippines and United Kingdom (UK).

Of the 16 included studies, one SR, two cohort studies and one retrospective cohort study were included in the effectiveness section of this review. One RCT, two cohort studies and two retrospective cohort studies covered organisational issues related to hospitalisation; one SR with meta-analysis, one SR, and three cross-sectional studies covered organisational issues related to modality choice; one SR and meta-analysis, two qualitative studies and one pre- and post- intervention study covered societal implications related to patients' satisfaction, insights and knowledge; and the other one pre- and post- intervention study covered psychological implications. Studies which covered few different sections were mentioned more than once. Two cost- analysis which were conducted alongside RCT and retrospective cohort study were included in the cost-effectiveness section of this review. No retrievable evidence was found on the safety aspects of pre-dialysis education programme for advanced CKD patients.

Description of 16 full-text articles included in qualitative synthesis are presented in **Table 2**.

**Table 2. Description of the included studies: study design, number of patients, intervention, comparison, components of programme and summary of results.**

Study	Study design	Number of patients	Intervention & Comparison	Components of pre-dialysis education programme	Summary of results
Hsu CK et al. (2018) <sup>13</sup> -Taiwan	Cohort study -f/up 5 years	398 PD patients: 169 PDEP 229 No PDEP before starting PD.	Multidisciplinary pre-dialysis education (PDEP) vs. Customary care (No-PDEP)	<ul style="list-style-type: none"> <li>Education by multiple individual sessions with team members</li> <li>Comprised a nurse of case mx, medical social officers, dietitians, nephrologists, and HD&amp;PD patient volunteers</li> <li>Knowledge on nutrition, lifestyle modification, nephrotoxin avoidance, medications and given acc. to CKD stage</li> <li>Preparation for RRT, modality choices given to late stage CKD</li> </ul>	<p>-PDEP group had significantly:</p> <ul style="list-style-type: none"> <li>less peritonitis</li> <li>lower peritonitis-related death rates</li> <li>longer median time to first peritonitis</li> </ul> <p>-No significant difference in no. of hospitalisation and technique failures</p>
Zukmin K et al. <sup>14</sup> (2017) -Brunei	Retropective cohort study -f/up 2 years	350 new cases of ESRD: 180 PDEP 168 No PDEP -Median eGFR 4.0 mL/min/ 1.73 m <sup>2</sup> ,	PDEP vs. No PDEP	<ul style="list-style-type: none"> <li>Education by multiple individual sessions with team members</li> <li>Team includes nephrologists, trained nurse, dietitians, and medical social officers</li> <li>Strategies to improve compliance, nutritional needs, nephrotoxins avoidance, fast track vascular services for fistula, early RRT</li> <li>Cultural acceptance and religious counselling also covered</li> </ul>	<p>-PDEP group had significantly:</p> <ul style="list-style-type: none"> <li>better survival probability</li> <li>decreased risk of dying</li> <li>higher 1-year survival rate</li> </ul>

Study	Study design	Number of patients	Intervention & Comparison	Components of pre-dialysis education programme	Summary of results
Van den Bosch J et al. (2015) <sup>11</sup>	SR	29 studies: 19 quasi-experimental design 10 narrative reviews  - 19 studies were analysed for effective components of PDEP	PDEP	<p>Descriptions of the educational process varied and included individual and group education, multidisciplinary intervention, and varying duration and frequency of sessions.</p> <ul style="list-style-type: none"> <li>7 articles described PDEP consists of multiple education sessions by 3 or more health care professionals such as nephrologist, nurse, dietitian, medical social officer, home-dialysis coordinator, pharmacist, technician, or by other dialysis patients</li> <li>Education delivery style can either be one-on-one sessions or class room teaching style, but a mix of one-on-one and group sessions is advocated</li> <li>eGFR &lt; 30 mL/min (stage 4 CKD) has been reported as ideal for referral to CKD clinic</li> </ul>	<p>PDEP group:</p> <ul style="list-style-type: none"> <li>8 studies reported better mortality and morbidity rates in PDEP group</li> <li>6/9 studies reported higher proportion of patients selecting home dialysis (PD or another home modality)</li> <li>4/19 quasi-experimental studies reported higher levels of knowledge of ESRF and RRT</li> <li>Two studies reported on lower length of hospital stay</li> </ul>
Wu IW et al. (2009) <sup>15</sup> -Taiwan	Cohort study f/up 1 year	573 CKD patients: -287 PDEP -286 No PDEP CKD Stage 3 (27.4%) Stage 4 (21.5%) Stage 5 (51.1%)	PDEP vs. customary care (No PDEP)	<ul style="list-style-type: none"> <li>Education by multiple individual sessions with team members</li> <li>Comprised a nurse for case mx, medical social officers, dietitians, HD and PD patient volunteers and nephrologists</li> <li>Individual lectures on renal care, nutrition, lifestyle, nephrotoxin avoidance, and medications depending on CKD stage</li> <li>Preparation for RRT, modality choices given to late stage CKD</li> </ul>	<p>PDEP group had significantly:</p> <ul style="list-style-type: none"> <li>longer time to dialysis</li> <li>better blood profiles</li> <li>lower frequency of temporary vascular catheter use</li> <li>greater post-dialysis body weights</li> <li>higher PD intake</li> <li>lower overall mortality</li> <li>higher median survival time</li> <li>lower 1-year hospitalisation rate</li> </ul>

Study	Study design	Number of patients	Intervention & Comparison	Components of pre-dialysis education programme	Summary of results
Yu YJ et al. (2014) <sup>16</sup> -Taiwan	RCT with cost-analysis	445 advanced CKD patients: -232 PDEP -213 No PDEP Mean eGFR 7.49 ± 3.1 (MPE) and 7.87± 3.6 in No PDEP group	PDEP vs. No PDEP	<ul style="list-style-type: none"> <li>Education by multiple individual lecture sessions with team members</li> <li>Comprised a nurse for case mx, medical social officers, dietitians, HD, PD patient volunteers and nephrologists</li> <li>Lectures focused on nutrition, lifestyle, nephrotoxin avoidance, dietary principles, and pharmacological regimens</li> </ul>	<p>PDEP group had significantly:</p> <ul style="list-style-type: none"> <li>fewer and shorter lengths of hospitalisation</li> <li>lower cardiovascular hospitalisation in first 6 months post dialysis</li> <li>fewer vascular access related surgeries</li> <li>lower total medical cost in first 6 months after HD initiation and lower medical cost of inpatient service</li> </ul>
Wei SY et al. (2010) <sup>17</sup> Taiwan	Retrospective cohort study -f/up 6 months before dialysis and at dialysis initiation	140 incident ESRD: 71 PDEP 69 No PDEP	CKD Care Programme (PDEP) vs. Nephrologist Care Group (No PDEP)	<ul style="list-style-type: none"> <li>Education by multiple individual sessions with team members</li> <li>Included nephrologists, renal nurses and dietitians as core members of team</li> <li>Different goals and education contents, according CKD stages and pre-set clinical protocols, delivered approximately 30–45 min at each visit.</li> </ul>	<p>PDEP group had:</p> <ul style="list-style-type: none"> <li>higher creation of vascular access before dialysis</li> <li>Lower hospitalisation for dialysis initiation</li> <li>More frequent outpatient visits during 6 months before dialysis' but lower hospitalisation and shorter length of stay 'at dialysis initiation'</li> </ul>
Yeoh HH et al. (2003) <sup>18</sup> -USA	Retrospective cohort study -f/up 10 days before initiation and 90 days post dialysis	103 patients with CKD: -68 PDEP -35 No PDEP	PDEP vs. No PDEP	<ul style="list-style-type: none"> <li>Education by classes acc. to CKD stages: Kidney Class- mild to moderate CKD Choices Class-moderate to severe CKD or about 3 to 6 months before dialysis</li> <li>After completion of classes, patients were followed up by team members included nurses, nephrologists, dietitians, medical social officers, case managers, and pharmacists</li> </ul>	<p>PDEP group had significantly:</p> <ul style="list-style-type: none"> <li>lower use of temporary catheters</li> <li>lower AV graft placement</li> <li>higher PD catheter placement</li> <li>lower emergency room visits and lower hospital stay</li> </ul>

Study	Study design	Number of patients	Intervention & Comparison	Components of pre-dialysis education programme	Summary of results
Shukla AM et al. (2017) <sup>19</sup> -USA	Retrospective Cohort Study	108 advanced CKD patients - stage 4 and 5 CKD, with occasional patients of stage 3b CKD	Comprehensive Pre-dialysis Education Programme (PDEP) vs. Established patient protocol (No PDEP)	<ul style="list-style-type: none"> <li>Group + individual sessions with team members</li> <li>After group lesson, patients rotated with renal dietitian, medical social officer, trained dialysis nurse including hands-on/demo, and renal physician for patient-specific discussions and detailed on the individual needs and questions</li> </ul>	<ul style="list-style-type: none"> <li>70% of patients in MPE group chose home dialysis, of which, 55% chose PD and 15% chose home HD</li> <li>PDEP resulted in 216% growth in home dialysis census over same period</li> </ul>
de Maar JS et al. (2016) <sup>20</sup> Amsterdam	Cross-sectional study	102 CKD patients -Mean eGFR 12.3 mL/min/1.73 m <sup>2</sup> .	Structured pre-dialysis programme (PDEP)	<ul style="list-style-type: none"> <li>Education starts with home visit, multidisciplinary meeting</li> <li>After meeting, specialised pre-dialysis nurse provides education tailored to patient's profile + training, followed by second meeting and final choice of RRT</li> </ul>	<p>Educational group had:</p> <ul style="list-style-type: none"> <li>increase the number of patients that choose and receive home dialysis (62.8% after programme vs 19% before)</li> </ul>

Study	Study design	Number of patients	Intervention & Comparison	Components of pre-dialysis education programme	Summary of results
Cassidy BP et al. (2018) <sup>21</sup> -Canada	Qualitative study	12 participants -4 patients from each dialysis modality (In-centre HD, PD, Home-PD)	PDEP	<ul style="list-style-type: none"> <li>Education by materials and small group sessions</li> <li>Kidney Foundation of Canada binder, <i>Living with Kidney Disease</i>, 4th edition, 4 multimodal small group classes, patient partners, and a list of trusted CKD online resources</li> </ul>	<p>3 themes influenced modality decision-making process:</p> <ul style="list-style-type: none"> <li>Patient Factors (individualisation, autonomy, and emotions),</li> <li>Educational Factors (tailored education, appropriate time/information, and available resources),</li> <li>and Support Systems (partnership with health care team and family/friends)</li> </ul>
Devoe DJ et al. (2016) <sup>22</sup> - 7 studies from North America, 5 from Europe, 3 from Asia.	SR + Meta-analysis	15 studies included: -7 pre and post intervention studies, -5 cohort studies -2 case-control studies -1 RCT -Mean eGFR ranged from $\leq 15$ to 20.4 ml/min/1.73 m <sup>2</sup>	Pre-dialysis educational interventions (PDEP) vs. Standard care (No PDEP)	Vary greatly between studies <ul style="list-style-type: none"> <li>7 studies included physician as an educator, 10 included a nurse, and 4 included multidisciplinary team</li> <li>8 studies carried out educational interventions in group sessions, 5 had 1 to 1 session only and 2 included both</li> </ul>	<p>Educational group had:</p> <ul style="list-style-type: none"> <li>increase in the odds of choosing PD (2-4x)</li> <li>3-fold increase in odds of receiving PD as the initial treatment modality</li> </ul>

Study	Study design	Number of patients	Intervention & Comparison	Components of pre-dialysis education programme	Summary of results
Prieto-Velasco M et al. (2014) <sup>23</sup> -9 renal units; 6 EU countries -2 units each in UK, Sweden, Spain -3 units in France, Belgium, Italy	Cross-sectional study	4 nurses, 5 nephrologists and 1 clinical psychologist completed questionnaires about their renal unit	Renal replacement therapy option education (PDEP)	<ul style="list-style-type: none"> <li>Few have group education sessions, mostly individual sessions</li> <li>Nurses always involved, with nephrologist, dietitians, psychologists, medical social officers, only 1 has occupational therapy, physio, pharmacist</li> <li>All had background in general or nephrology nursing</li> <li>All includes patients with CKD stage 4 or 5, and family members</li> <li>Key topics such as the 'impact of the disease' were covered by every unit, but only a few units described all dialysis modalities</li> <li>Most have visits to HD, home dialysis</li> </ul>	Same as in components of programme
Danguilan R A et al. (2013) <sup>24</sup> Philippines	Pre- and post-intervention study -f/up 6 months	299 CKD patients: 60% CKD Stage 5 and 19% Stage 4	PDEP	<ul style="list-style-type: none"> <li>Education by multiple individual sessions with team members</li> <li>Trained CKD educators, a nurse and a psychologist, conducted structured educational modules according to CKD stage</li> <li>Take-home materials after each visit</li> </ul>	<p>After PDEP:</p> <ul style="list-style-type: none"> <li>Significant increase in mean overall pre-test scores of CKD knowledge (only 28% patients completed the modules)</li> </ul>

Study	Study design	Number of patients	Intervention & Comparison	Components of pre-dialysis education programme	Summary of results
García-Llana H et al. (2014) <sup>25</sup> Spain	Pre- and post-intervention study -f/up 6 months	42 CKD patients Mean eGFR <20mL/min/1.73 m <sup>2</sup>	PDEP	<ul style="list-style-type: none"> <li>• Education by multiple individual sessions</li> <li>• Patient attended regular appt with nephrologist, nurse and nutritionist</li> <li>• Each patient received 6 individual monthly face-to-face sessions with health psychologist</li> </ul>	<p>After PDEP:</p> <ul style="list-style-type: none"> <li>• significantly higher levels of adherence, lower depression and anxiety levels, and better HRQL (i.e., general health and emotional role domains).</li> </ul>
Cankaya E et al. (2013) <sup>26</sup> Turkey	Cross-sectional study	88 live donor kidney transplant recipients: -61 PDEP -27 no PDEP	Pre-dialysis education programme (PDEP) vs. No PDEP	<ul style="list-style-type: none"> <li>• Education using training kit</li> <li>• Specially prepared kit using visuals and written cards with 6 modules given according to CKD stages</li> </ul>	<p>PDEP group had significantly:</p> <ul style="list-style-type: none"> <li>• Higher pre-emptive kidney transplantation rates compared to no-PDEP group (42.6% vs 18.5%, P&lt;0.001)</li> <li>• Higher donor transplantation rates from spouse, siblings and other relatives</li> </ul>
Combes G et al. (2017) <sup>12</sup> UK	Qualitative study	Semi-structured interviews in 4 hospitals with 96 staff and 93 dialysis patients	PDEP	<ul style="list-style-type: none"> <li>• Education by one to one sessions + group sessions including talks from patients on RRT + written materials/DVDs to take home</li> <li>• Home visits by nurse in several sites</li> </ul>	<ul style="list-style-type: none"> <li>• Most patients reported PDEP overall helpful</li> <li>• 3 themes related to improving PDE identified: -sub-optimal education; -different perspectives between patients and staff; -influence of patient experience</li> </ul>

**Footnote: AV=Arteriovenous, CKD= Chronic Kidney Disease, ESRD=End Stage Renal Disease, eGFR= estimated Glomerular Filtration Rate, HD=Haemodialysis, PD=Peritoneal Dialysis, PDEP=Pre-dialysis Education Programme, RRT=Renal Replacement Therapy, SR= Systematic Review, RCT= Randomised Controlled Trial, HRQL=Health Related Quality of Life**



2.4.3 Risk of bias assessment:

**Assessment for Systematic Review Studies Using Critical Appraisal Skills Programme (CASP) Checklist**

Figure 2 shows the summary of the risk of bias of the two included studies based on the Critical Appraisal Skill Programme (CASP) checklist. Both studies were overall at low risk of bias at all domain assessed. For Devoe DJ et al. (2016), meta-analysis was done on four observational studies on association of pre-dialysis educational interventions with the odds of choosing PD and the odds of receiving PD and reported heterogeneity of  $I^2=76.7%$  and  $I^2=24.9%$ , respectively.<sup>22</sup>

Criteria assessed	Authors look for the right type of papers?	Selection of studies (all relevant studies included?)	Assessment of quality of included studies?	If the results of the review have been combined, is it reasonable to do so (heterogeneity)?
Van den Bosch J et al. (2015) <sup>11</sup>	+	+	+	?
Devoe DJ et al. (2016) <sup>22</sup>	+	+	+	+

+	Indicates low risk of bias
?	indicates unclear risk of bias
-	Indicates high risk of bias

**Figure 2: Assessment of risk of bias of SR**

**Randomised controlled trials**

Cochrane Risk of Bias Assessment tool was used to assess the risk of bias of the RCT included in this review. The summary risk of bias assessment of the RCTs is shown in **Figure 3**.

Criteria assessed	Adequate sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Incomplete outcome data addressed (attrition bias)	Selective reporting (reporting bias)	Free of other bias
Yu YJ et al. (2014) <sup>16</sup>	+	?	?	+	+	+

+	Indicates low risk of bias
?	indicates unclear risk of bias
-	Indicates high risk of bias

**Figure 3: Assessment of risk of bias of RCT**

Yu Y et al. (2014) did not mention the detail of blinding as well as allocation concealment method and thus was classified as unclear risk of bias.<sup>16</sup>

### Assessment Using NIH Quality Assessment Tool For Before-After (Pre-Post) Studies With No Control Group

The risk of bias for Pre-Post studies with no control group was assessed using NIH Quality Assessment Tool. Two studies were included in this assessment. Figure 4. shows the summary of the risk of bias for the studies. Both studies have high risk of bias. Danguilan R A et al. (2013) had two high risk criteria which were loss to follow up more than 20% and the study did not use interrupted time series design.<sup>24</sup> Garcia-Llana H et al. (2014) had three high risk criteria which included small sample size, the study did not use interrupted time series design and did not take individual level data to determine effects at group level.<sup>25</sup>

CRITERIA ASSESSED	Danguilan R A et al. (2013) <sup>24</sup>	García-Llana H et al. (2014) <sup>25</sup>
Question or objective clearly stated?	+	+
Eligibility/selection criteria for study population clearly described?	+	+
Were participants representative for those who would be eligible for the test/ service/ intervention in the population of interest?	+	+
Were all eligible participants that met the pre-specified entry criteria enrolled?	+	+
Sample size sufficiently large to provide confidence in findings?	+	-
Test/service/intervention clearly described and delivered consistently?	+	+
Outcome measures pre-specified, valid, reliable, and assessed consistently?	+	+
People assessing the outcome measures blinded to participants exposure/ interventions?	NA	NA
Loss to follow-up after baseline 20% or less? Loss to follow-up accounted for in the analysis?	-	+
Statistical methods examine changes in outcome measures from before to after intervention? P value?	+	+
Outcome measures taken multiple times before and after intervention? Use interrupted time-series design?	-	-

If intervention conducted at group Level, did statistical analysis take into account of individual Level data to determine effects at group Level?



+	Indicates low risk of bias
?	indicates unclear risk of bias
-	Indicates high risk of bias

**Figure 4: Assessment of risk of bias of (Pre-Post) Studies with No Control Group**

#### 2.4.4 EFFECTIVENESS

Four studies reported on effectiveness of PDEP for advanced CKD patients, of which one was SR, two cohort studies and one retrospective cohort study.

##### 2.4.4.1 Peritonitis and peritonitis-related death

Hsu CK et al. (2018) conducted a cohort study in PD patients in Taiwan to investigate the impact of PDEP on the occurrence of peritonitis, time to first episode of peritonitis and patient outcomes. The study involved 398 patients starting PD at Chang Gung Memorial Hospital, Keelung, Taiwan. Patients were divided into PDEP group (n = 169) and no- PDEP group (n = 229) according to whether the subjects had ever received PDEP before starting RRT. Pre-dialysis education programme (PDEP) recipients were older (63.1±16.2 vs. 58.5±16.4 years old, P = 0.006), were less likely to be man (39.1% vs. 52%, P = 0.01) but had higher prevalence of diabetes (60.4% vs. 43.7%, P < 0.001) compared to the no-PDEP recipients. The PDEP group also had lower baseline educational levels (P < 0.001) and were more likely to use automated PD than patients of no-PDEP group (49.7% vs. 39.7%, P = 0.05). Pre-dialysis education programme (PDEP) was described in the study as education given by a team which comprised of a nurse of case management, medical social officers, dietitians, 10 nephrologists, and HD and PD patient volunteers. The programme included multiple individual sessions on nutrition supplement, lifestyle modification, nephrotoxin avoidance, dietary principles and pharmacological regimens by case-management nurse, according to their CKD stage by National Kidney Foundation Dialysis Outcomes Quality Initiative (NKF/DOQI) guidelines. Monitoring of CKD complications, preparation for timely initiation of RRT, care of vascular or peritoneal access, and registration for inclusion in the renal transplant waiting list were also instructed for late stage CKD patients. Different modality of RRT as well as their benefit, disadvantage and self-care knowledge were explained. Shared decision making was performed for these patients for their choice of renal replacement modality selection. All patients also received dietary counseling biannually from a dietitian. The programme was discontinued once the patients initiate dialysis therapy. Meanwhile, patients in the no-PDEP group received customary care from the same group of nephrologists, who instructed patients regarding the renal function, evaluation of laboratory data and the clinical indicators of renal failure as well as treatment strategies. Writing materials or booklets were given to patients if needed. All patients were subsequently followed up for five years. Incidences of peritonitis and peritonitis-related mortality were compared between the two groups.<sup>13 Level II-2</sup>

The results showed that after five years of follow-up, the PDEP patients had significantly less peritonitis [0.29±0.72 vs. 0.64±1.5 episodes/person-year or median (Interquartile range, IQR): 0 (0.29) vs. 0.11 (0.69) episodes/person-year, P < 0.001] than no-PDEP patients. The PDEP group had lower peritonitis-related death rates compared to no-PDEP group (3.6% vs. 8.7%, P = 0.04). Patients in the PDEP group had longer median time to first episode of

peritonitis compared the no-PDEP group (46.7 months vs. 33.9 months,  $P = 0.003$ ). Cox regression analysis revealed that the educational level below elementary [hazard ratio (HR): 1.925; 95% (CI): 1.257, 2.874,  $P = 0.003$ ] and the use of PDEP (HR: 0.594; 95% CI: 0.434, 0.813,  $P < 0.001$ ) were significant independent predictors for peritonitis-free survival, after adjusting the baseline characteristics of age, gender, diabetes, hypertension and peritoneal modalities. The authors concluded that an efficient standardised PDEP adhered to the NKF/DOQI guidelines may prolong the time to the first episode of peritonitis and reduce peritonitis rate, independent of age, gender, diabetes, hypertension, educational status and PD modality. Subsequently, decreased peritonitis-related death. The findings provided basis for strategic implementation of PDEP as an efficient method to improve dismal outcome of PD patients.<sup>13</sup>

Level II-2

#### 2.4.4.2 Survival rate

Zukmin K et al. (2017) conducted a retrospective cohort study in Brunei to compare survival probability, sociodemographic, and clinical characteristics of multidisciplinary pre-dialysis educated (PDEP) and no-PDEP/crashlander patients. A total of 350 new cases of ESRD from Raja Isteri Pengiran Anak Saleha Hospital and all dialysis centers in Brunei Darussalam were included in the study. Data were extracted from the computerised clinical registry and patients' dialysis records. Data extracted included sociodemographic information, clinical information, survival status, pre-dialysis clinic referral, choice of RRT, and types of vascular access (for HD patients). Patients were divided into PDEP group ( $n = 180$ ) and no-PDEP group ( $n = 168$ ) according to whether the subjects had ever received PDEP before starting RRT. The PDEP groups were more likely to be older ( $P = 0.001$ ), diabetics ( $P = 0.013$ ), and hypertensive ( $P = 0.016$ ), have ischemic heart disease ( $P = 0.014$ ), and to be using arteriovenous fistula ( $P < 0.001$ ). Pre-dialysis education programme (PDEP) was provided in the settings by a multidisciplinary team of professionals which included nephrologists, nurse practitioners, dieticians, and medical social officers. Nurse practitioners comprise specific nurses that specialize in vascular access, HD, PD and transplantation. Geriatricians and palliative care team occasionally involved if patients have pre-emptively decided not to undergo RRT. Clinics were focused on strategies to maintain target blood pressure, improve compliance with medications, nutritional needs, nephrotoxins avoidance, and fast track vascular services for fistula formations and early commencement of RRT. Cultural acceptance and religious counselling were also covered in the clinic to overcome social stigmatisation and improve psychological acceptance. Survival probability, sociodemographic, and clinical characteristics of PDEP and no-PDEP/crashlander patients were compared. The results showed that despite being older and having more comorbidities, PDEP patients have better survival probability ( $P = 0.028$ ) and a 34% decreased risk of dying. The one-year survival rate was higher in the PDEP group compared to no-PDEP group (79.8% vs. 66.2%, respectively). No significant difference reported for survival rates after two years (57.7% and 60.1%, respectively). The authors concluded that PDEP before the initiation of RRT contributed to greater survival probability in near ESRD patients. The survival benefits were evident despite the presence of inherent risks (older age and presence of comorbidities) in the PDEP population in comparison with the no-PDEP group.<sup>14</sup>

Level II-2

#### 2.4.4.3 Morbidity and mortality

A systematic review was conducted by Van den Bosch J et al. (2015) to review evidence on effective components of PDEP as related to modality choice and selected clinical outcomes. Systematic search was performed on PubMed MEDLINE, Cochrane Library, and Ovid (from January 1, 1995 to December 31, 2013) for studies done on pre-dialysis education programme. Literature also reviewed for any information on processes, pathways, and organisation of the pre-dialysis education programme. The review included 29 relevant studies which consisted of 19 quasi-experimental design and 10 narrative reviews. Nineteen studies were analysed for effective components of PDEP. Descriptions of the educational process varied and included individual and group education, multidisciplinary intervention, and varying duration and frequency of sessions. The review found that there were eight

studies reported on mortality and morbidity including biochemical indicators, cardiovascular incidents, infection rates, emotional status (Table 3). All studies reported better rates for the group that received pre-dialysis education.<sup>11 Level I</sup>

**Table 3: Studies which reported on mortality and morbidity**

Studies	Results
Cho et al. (2012)	Less unplanned urgent dialysis (8.7% vs 24.2%), Less cardiac events (2.7% vs 9.4%), less infections (4.0% vs 12.1%)
Klang et al. (1998)	Significant better mood, less mobility problems, less functional disabilities and lower anxiety
Lacson et al. (2011)	Significant better survival rate (adj. HR 0.61)
Levin et al. (1997)	Better biochemical markers: blood pressure, calcium, phosphate, and anemia
Rioux et al. (2011)	35% of all acute starters adopted home dialysis vs 13% before program
Hall G et al (2004)	Less infection rates 18.5 vs. 31.8; (p = 0.00349)
Souqiyeh M Z et al. (2008)	Significantly less dropouts for PD (p < 0.02)

Wu IW et al. (2009) conducted a cohort study in Taiwan to evaluate the impact of PDEP on the incidence of dialysis and outcomes of CKD patients in accordance with the guidelines of the National Kidney Foundation Dialysis Outcomes Quality Initiative (NKF/DOQI). The study involved 573 pre-dialysis CKD patients who visited the nephrology outpatient clinics of the Department of Nephrology at Chang Gung Memorial Hospital in Taipei and Keelung from May 2006 to May 2007. Patients were classified into stages 3, 4 or 5 in accordance with the NKF/DOQI classification system. All patients were divided into two cohorts according to the sites; PDEP group at the Keelung centre (n = 287) and no-PDEP group at Taipei centre (n = 286). Pre-dialysis education programme (PDEP) were described given in multiple individual sessions with team members which comprised of a nurse for case mx, medical social officers, dietitians, HD and PD patient volunteers and 10 nephrologists. Programme consisted of integrated course involving individual lectures on renal health, delivered by case-management nurse that focused on nutrition, lifestyle, nephrotoxin avoidance, dietary principles and pharmacological regimens. Standardised interactive educational sessions were conducted intermittently where all patients were interviewed depending on the CKD stage. For stage 3 CKD patients, programme consisted of lectures on healthy renal function, clinical presentation of uraemia, risk factors and complications associated with renal progression and an introduction to the various RRTs. For stage 4 CKD patients, programme included discussions on the management of complications associated with CKD, indications of RRT and evaluation of vascular or peritoneal access. For stage 5 CKD patients, programme included monitoring for timely initiation of RRT, care of vascular or peritoneal access, dialysis-associated complications and registration for inclusion in the renal transplant waiting list. Patients in Stage 3 or 4 CKD were followed-up three-monthly while patients in stage 5 CKD were followed-up monthly. In contrast, patients in customary care group (no-PDEP) were attended by same group of nephrologists who instructed patients regarding renal function, evaluation of laboratory data and clinical indicators of chronic renal failure as well as strategies for its management and treatment. General principles of HD and PD explained when patients enter stage 4 CKD and patients were provided with written instructions. Patients from both

groups were followed up for 12 months for dialysis initiation or mortality from any cause.<sup>15 Level II-2</sup>

The study showed that dialysis was initiated in 13.9% of patients in the PDEP group and 43% of the patients in the no-PDEP group, ( $P < 0.001$ ). Time to dialysis was significantly longer for PDEP group (11.3 months) compared to no-PDEP group (9.2 months) ( $P < 0.001$ ). Patients in the PDEP group showed better blood profiles [higher serum albumin level ( $3.8 \pm 0.5$  vs.  $3.4 \pm 0.5$  g/dL),  $P = 0.050$ ; lower serum high-sensitive C-reactive protein (hs-CRP) level ( $3.3 \pm 2.8$  vs.  $5.5 \pm 5.6$  mg/L),  $P = 0.032$ ; lower serum ferritin concentration ( $284 \pm 31$  vs.  $532 \pm 59$  ng/mL),  $P = 0.049$ ], higher PD uptake (35% vs. 20.5%,  $P = 0.023$ ), lower frequency of temporary vascular catheter use (25% vs. 50.4%;  $P < 0.05$ ) and greater post-dialysis body weights ( $65 \pm 10$  vs.  $58 \pm 11$  kg,  $P = 0.034$ ) than the no-PDEP patients. Overall mortality was reported lower for the PDEP group than the no-PDEP group (1.7% vs. 10.1%,  $P < 0.001$ ). Patients in the PDEP group had higher median survival time compared to the no-PDEP group (11.9 months vs. 11.2 months,  $P < 0.001$ ). Adjusted hazard ratio (HR) of mortality for PDEP recipients was 0.103 [95% confidential interval (CI) 0.040, 0.265,  $P < 0.001$ ], after adjustment for age, gender, diabetes, hypertension, eGFR, Hb, serum albumin and hs-CRP. Cox regression analysis revealed that diabetes, eGFR, hs-CRP level and PDEP assignment were significant independent predictors for progression to ESRD. Independent prognostic factors for mortality included age, diabetes, eGFR, hs-CRP and PDEP assignment. The authors concluded that efficient standardised PDEP complying with the NKF/DOQI guidelines may decrease the incidence of dialysis and reduce the all-cause mortality and the overall hospitalisation rate in CKD patients. This valuable information confirms the role of PDEP in the care of CKD patients.<sup>15 Level II-2</sup>

#### 2.4.5 SAFETY

There was no retrievable evidence in the scientific databases on the safety of PDEP for advanced CKD patients.

#### 2.4.6 ORGANISATIONAL

##### 2.4.6.1 Hospitalisation and length of stay

There were one SR, one RCT, two cohort studies, and two retrospective cohort studies which reported on hospitalisation and length of stay.

In the cohort study which was conducted by Hsu CK et al. (2018), investigating the impact of PDEP on PD patients in Taiwan, reported that after five years of follow-up, there was no significant difference between patients in PDEP group and no-PDEP group in frequency of hospitalisation [median (IQR), episodes/person-year : 1.36 (2.43) in PDEP group vs. 1.15 (2.04) in no-PDEP group,  $P = 0.66$ ] and the percentage of technique failures requiring shifting of modality to HD [due to either peritonitis; 9.5% in PDEP group vs. 11.8% in no-PDEP group, or poor fluid management; 1.8% in PDEP group vs. 2.2% in no-PDEP group].<sup>13 Level II-2</sup>

The SR by Van den Bosch J et al. (2015) which examined the evidence on the effective components of PDEP, reported that there were two quasi-experimental studies mentioned on length of hospital stay, which was lower for the education groups (6.5 vs. 13.5 total hospital days; 2.2 vs. 5.1 hospital days/patient per year).<sup>11 Level I</sup>

Yu YJ et al. (2014) conducted an RCT in Taiwan involving 445 advanced CKD patients who were randomly assigned to PDEP group ( $n = 232$ ) and no-PDEP group ( $n = 213$ ). Pre-dialysis education programme (PDEP) in this setting consisted of an integrated course involving individual lectures on renal health, delivered by the case-management nurse. The individual lectures focused on nutrition, lifestyle, nephrotoxin avoidance, dietary principles, and pharmacological regimens. The programme team involved a nurse for case management, medical social officers, dietitians, HD and PD patient volunteers and 10 nephrologists.

Standardised interactive educational sessions were periodically conducted wherein all patients were interviewed depending on their CKD stage, determined earlier by using the NKF/DOQI guideline. Stage 3 or 4 CKD patients were followed up every three months, and stage 5 CKD patients were followed up on a monthly basis. For stage 4 CKD patients, the programme included discussions on the management of complications associated with CKD, indications of RRT, and the evaluation of vascular or peritoneal access. For stage 5 CKD, patients were monitored for timely initiation of RRT, the care of vascular or peritoneal access, dialysis-associated complications, and registration for inclusion in the renal transplantation waiting list. All patients received dietary counselling biannually from a dietitian. In addition, case-management nurse often contacted the participants by telephone to encourage them to inform their nephrologists of their symptoms and to reinforce the importance of medical visits. The programme was discontinued once RRTs were initiated. On the other hand, patients in the no-PDEP group were attended by same group of nephrologists who instructed patients regarding renal function, evaluation of laboratory data and clinical indicators of chronic renal failure as well as strategies for its management and treatment. General principles of HD and PD explained when patients enter stage 4 CKD and patients were provided with written instructions.<sup>16 Level II-1</sup>

The study reported that PDEP patients had significantly fewer and shorter lengths of hospitalisation than the no-PDEP patients (median (IQR) 0 (15) vs. 8 (27) days,  $P < 0.001$ ). Eighty-eight (37.9%) patients in the PDEP group had at least one hospitalisation, compared with 127 patients (59.6%) in the no-PDEP group ( $P < 0.001$ ). Cardiovascular disease (including uncontrolled hypertension, coronary artery disease, stroke, heart failure, and peripheral artery occlusive disease) was the main cause of first hospitalisation in all patients. The PDEP patients had lower cardiovascular hospitalisation in the first six months post dialysis (18.53% vs. 29.58%,  $P = 0.007$ ) and fewer vascular access related surgeries during the first admission (15.09% vs. 25.82%,  $P = 0.005$ ) compared to the no-PDEP patients.<sup>16 Level II-1</sup>

Wei SY et al. (2010) conducted a retrospective cohort study involving 140 incident ESRD patients who started HD from August 2004 to July 2005 from the two study hospitals in Taiwan to evaluate the effectiveness of CKD care programme (PDEP) on pre-ESRD care. Patients were divided into two groups; CKD group who received PDEP for at least six months before initiation of HD ( $n = 71$ ) and 'Nephrologist Care Group' (no-PDEP) who were cared for by nephrologists alone for at least six months before initiation of dialysis ( $n = 69$ ). The PDEP included nephrologists, renal nurses and dietitians as the core members of a multidisciplinary team responsible in caring for patients at different CKD stages. Patients were invited to join the care program by the nephrologist and were referred to well-trained renal nurses and dietitians. Different goals and education contents were planned according to stages of CKD and pre-set clinical protocols, and were delivered systematically approximately 30 to 45 minutes at each visit. Every patient received follow-up visits with clinical evaluation, laboratory examinations, nursing and dietary education, which was taken every three months for CKD stages 3 and 4, and every one to two months for stage 5 CKD patients. Main goals of the programme included delaying the deterioration of renal function, early preparations for dialysis, reducing of risk of complications, and ensuring smooth and safe transition to RRT. In contrast, "Nephrologist Care Group" were all treated by nephrologists from the same department, but they did not receive nursing education and dietary counselling by CKD nurses and dietitians. Principle of CKD care, including medications and early preparation of vascular access were routinely delivered to patients by the nephrologists. Patients were followed-up six months before dialysis and at dialysis initiation. Dialysis initiation was the end-point of observation. Quality indicators for evaluation included status of recombinant human erythropoietin (rHuEPO) treatment, vascular access preparation and hospitalisation for initiation of dialysis, were compared between two groups.<sup>17 Level II-2</sup>

The study found that PDEP group had higher creation of vascular access before dialysis. Vascular access had been created before HD in 57.7% of patients in the PDEP Group vs. only 37.7% of the no-PDEP group ( $P=0.017$ ). Percentage of patients who started HD with created vascular access without the insertion of double lumen catheter was 50.7% PDEP, vs. 29.0% in the no-PDEP group ( $P=0.009$ ). Percentage of patients who were not hospitalised for initiation of HD was 40.8% in PDEP group, vs. 18.8% in the no-PDEP group ( $P<0.005$ ). Most patients in no-PDEP group (81.2%) had their first HD through inpatient HD. In terms of frequency of services utilisation, the PDEP group had more frequent outpatient visits during six months before dialysis ( $9.9 \pm 5.5$  vs  $5.5 \pm 5.5$  times/patient,  $P<0.001$ ), but lower percentage of hospitalisation at dialysis initiation (59.2% vs 81.2%,  $P= 0.005$ ), and shorter length of stay ( $6.6\text{days} \pm 16.2$  vs.  $16.2\text{days} \pm 16.2$ ,  $P <0.001$ ) compared to the no-PDEP group.<sup>17 Level II-2</sup>

In another cohort study which was conducted by Wu IW et al. (2009) in Taiwan, reported that the one-year hospitalisation rate was lower in the PDEP patients than in the no-PDEP patients (2.8% vs. 16.4%,  $P=0.034$ ). However, the reason for hospitalisation did not differ significantly between them.<sup>15 Level II-2</sup>

Yeoh HH et al, (2003) conducted a retrospective cohort study in the United States of America (USA), to compare patients who had PDEP with those who did not due to late referral or refusal to participate, in terms of hospitalisations, emergency room visits and dialysis access placement. The charts of 103 CKD patients who were seen in clinic from 1997 to 2000 were retrospectively reviewed. Data on 68 patients who elected to participate in the pre-dialysis classes and 35 patients who decided not to participate in the classes in spite of encouragement to do so or were referred late and required immediate dialysis were reviewed. The PDEP team who were involved in the delivery of education and care of patients consisted of nurses, nephrologists, dietitians, medical social officers, case managers, and pharmacists. The programme comprised of two separate classes given according to the CKD stages; Kidney Class for patients mild to moderate renal impairment and Choices Class for patients with moderate to severe renal disease or about three to six months before dialysis will be needed. The Kidney Class covered general information about kidney disease, causes of renal failure, and its manifestation. The Choices Class covered options in RRT including HD, PD and renal transplantation. Once the patients attended the classes, they were followed-up by all the members of the team regularly. Data from period beginning 10 days before the initiation of dialysis to 90 days after the first dialysis, for a total period of 100 days was obtained. This period captures hospitalisation for initiation of dialysis. Data for each variable were compared for patients who attended the pre-dialysis class and those who did not. The results showed that compared to the group without PDEP, PDEP group had lower percentage of use of temporary catheters (4.4% vs. 37%,  $P < 0.001$ ), lower incidence of AV graft placement (18% vs. 51%,  $P < 0.001$ ) and higher incidence of PD catheter placement (31% vs. 11.4%,  $P = 0.03$ ). Patients in the PDEP group had lower emergency room visits (0.57 vs. 1.1 per patient,  $P = 0.035$ ) and lower average length of hospital stay per patient (1.4 days vs. 9.9 days per patient,  $P < 0.001$ ) than those in no-PDEP group.<sup>18 Level II-2</sup>

#### 2.4.6.2 Components of programme

There was substantial variation noted in various PDEP described in the included studies. Summary of the components of PDEP in each study which was included in this review were tabulated in Table 2.

##### Multidisciplinary team

Most studies [Hsu CK et al. (2018), Zukmin K et al. (2017), Wu IW et al. (2009), Yeoh HH et al. (2003), Yu YJ et al. (2014), Shukla AM et al. (2017), de Maar JS et al. (2016), Cassidy BP et al. (2018)] mentioned the involvement of multidisciplinary team in their PDEP. The team



almost always comprised of nephrologists, nurses, dietitians, and medical social officers. Few had clinical psychologist, pharmacist, and patient volunteers.<sup>13 Level II-2, 14 Level II-2, 15 Level II-2, 16 Level II-1, 17 Level II-2, 19 Level II-2, 20 Level II-3, 21</sup>

A systematic review and meta-analysis was conducted by Devoe DJ et al. (2016) to examine the relationship between patient-targeted educational interventions and choosing and receiving PD. Fifteen studies of educational interventions designed to increase PD selection were included in the review which consisted of: seven pre- and post- intervention studies, five cohort studies, two case-control studies and one RCT. Of 15 studies, two were excluded from meta-analysis due to missing information. Seven studies from North America, five from Europe and three from Asia. Number of participants ranged from 63 to 21,302 for a total of 31,653. Mean eGFR ranged from  $\leq 15$  to 20.4 ml/min/1.73 m<sup>2</sup>. There was great variation of the educational interventions between the studies. Seven studies included physician as an educator, 10 included a nurse, and four included multidisciplinary team. Four studies included family members in educational interventions.<sup>22 Level I</sup>

In the systematic review done by Van den Bosch J et al. (2015), the studies included addressed components of PDEP established. Seven articles retrieved from the scientific literature review described PDEP which consisted of multiple education sessions where patients were educated by three or more health care professionals such as nephrologist, nurse, dietitian, medical social officer, home-dialysis coordinator, pharmacist, technician, or by other dialysis patients.<sup>11 Level I</sup>

Prieto-Velasco M et al. (2014) conducted a cross-sectional study to assess on how is RRT option education being run in European Union (EU) countries. Experts comprised of four nurses, five nephrologists and one clinical psychologist from nine renal units; two units each in UK, Sweden, Spain and three units in France, Belgium, Italy, completed a questionnaire on RRT option education in their unit. The study showed that nurses were almost always responsible for organising the education programme. Seven units also involved nephrologists, five units involved dietitians, four units involved psychologists and three units involved medical social officers. All staff involved had background in general or nephrology nursing.<sup>23 Level II-3</sup>

### Delivery style

Most studies included in this review described PDEP in their settings, which were delivered in multiple individual sessions with mostly multidisciplinary team members as reported in Hsu CK et al. (2018), Zukmin K et al. (2017), Yu YJ et al. (2014), Wu IW et al. (2009), Danguilan R A et al. (2013), García-Llana H et al. (2014), de Maar JS et al. (2016), Cankaya E et al. (2013) and Wei SY et al (2010).<sup>13 Level II-2, 14 Level II-2, 15 Level II-2, 17 Level II-2, 15 Level II-2, 20 Level II-3, 24, 25 Level II-3, 26 Level II-3,</sup>

Mixed of individual sessions and group sessions has been described in Yeoh HH et al. (2003), Shukla AM et al. (2017), Cassidy BP et al. (2018) and Combes G et al. (2017).<sup>18 Level II-2, 19 Level II-2, 21, 27</sup> Few studies including Hsu CK et al. (2018), Wu IW et al. (2009), Yu YJ et al. (2014), Cassidy BP et al. (2018) and Combes G et al. (2017) described patients involvement in their PDEPs such as giving talks and sharing sessions.<sup>12, 13 Level II-2, 15 Level II-2, 16 Level II-1, 21</sup>

A systematic review and meta-analysis which was conducted by Devoe DJ et al. (2016), reported that of 15 studies included in their review, eight studies carried out educational interventions in group sessions, five had one to one session only and two included both.<sup>22 Level I</sup>

Van den Bosch J et al. (2015) reported in their systematic review that education delivery style can either be one-on-one sessions or class room teaching style, but a mix of one-on-one and group sessions were advocated. Educational programmes should contain individualised one-on-one counselling sessions with a member or members of multidisciplinary team. In addition to small group discussions, peer counselling and problem-solving or “brainstorming” sessions

have been described wherein patients discuss treatment modalities, barriers and benefits, and troubleshooting of possible problems with other patients or facilitators. Various formats have been described for group sessions such as group lectures, interactive workshops, or open forum sessions.<sup>11 Level I</sup>

Prieto-Velasco M et al. (2014) reported that most renal units included patients visit to in-centre HD unit (8/9 units) and home-dialysis nurse visit to assess suitability (7/9 units). Half of the renal units have formal meeting with 'expert patient' as part of the education programme. Group education sessions were used in 3/9 units.<sup>23 Level II-3</sup>

### Frequency, follow-up and duration

Most studies included described the frequency of the sessions and follow-up depended on the stages of CKD. Some studies mentioned stage 3 or 4 CKD patients were followed up every three months while stage 5 CKD patients were followed-up on a monthly basis.<sup>15 Level II-2, 16 Level II-1, 17 Level II-2</sup> Devoe DJ et al. (2016), reported that of 15 studies included in their systematic review, eight studies carried out educational interventions two or more days.<sup>22 Level I</sup> Van den Bosch J et al. (2015) reported that number of sessions and duration per session varies by educational program. There were reports of six individual sessions of one hour, four sessions, one night a week for two hours; or at least four to five interviews.<sup>11 Level I</sup>

### Timing

Van den Bosch J et al. (2015) reported that an estimated glomerular filtration rate of less than 30 mL/min (stage 4 CKD) has been reported as ideal for referral to CKD clinic.<sup>11 Level I</sup> Others recommended that patients should be referred as early as possible to renal education (less than six months).<sup>11 Level I</sup> Prieto-Velasco M et al. (2014) reported that education programme for the patient and family began several months before dialysis or according to disease progression and all nine renal units evaluated in their studies have included patients with CKD stage 4 or 5 in the programme.<sup>23 Level II-3</sup>

### Content and structure

There was variation in the content and structure of each pre-dialysis education programme described in the included studies. Most studies reported that the content of the education programme was largely focused on knowledge on nutrition, lifestyle modification, nephrotoxin avoidance, and compliance to medications and tailored according to the patients' CKD stage.<sup>13 Level II-2, 14 Level II-2, 15 Level II-2, 16 Level II-1, 17 Level II-2, 18 Level II-2</sup> Knowledge on preparation for RRT and modality choices as well as fast track vascular services for fistula and early commencement of RRT were given to the patients in advanced CKD stage.<sup>13 Level II-2, 14 Level II-2, 15 Level II-2, 16 Level II-1, 17 Level II-2, 18 Level II-2</sup> Zukmin K et al. (2017) reported that in their PDEP, cultural acceptance and religious counselling were also been covered.<sup>14 Level II-2</sup> Shukla AM et al. (2017) mentioned hands-on or demonstration session by trained dialysis nurse.<sup>19 Level II-2</sup> A systematic review and meta-analysis which was conducted by Devoe DJ et al. (2016), reported that of 15 studies included in their review, five studies included information on diet, six studies used video material, seven used printed materials, and one used website materials.<sup>22 Level I</sup> Cankaya E et al. (2013) used specially prepared training kit using visuals and written cards according to CKD stages for patients in their education programme.<sup>26</sup> Prieto-Velasco M et al. (2014) reported key topics such as the 'impact of the disease' were covered by every unit, but only a few units described all dialysis modalities.<sup>23 Level II-3</sup> Materials used in the nine renal units assessed came in a wide variety of forms and from a wide range of sources.<sup>23 Level II-3</sup> Booklets were used in all units, online materials and DVDs were used in half of units.<sup>23 Level II-3</sup> Cassidy BP et al. (2018) gave a list of trusted CKD online resources<sup>21</sup> while Combes G et al. (2017) and Danguilan RA et al. (2013) mentioned take-home materials for patients after each visit.<sup>12,</sup>

## Training

Most studies did not specify details on training for their multidisciplinary team members in PDEP. Only Prieto-Velasco M et al. (2014) reported that all staff administering the programme had a background in general or nephrology nursing.<sup>23 Level II-3</sup> Other studies included Shukla AM et al. (2017), Danguilan R A et al. (2013), Wei SY et al (2010) and García-Llana H et al. (2014) only mentioned involvement of trained staff but there was no description of the kind of trainings received by them.<sup>19 Level II-2, 24, 17 Level II-2, 25 Level II-3</sup>

### 2.4.6.3 Guidelines

A position statement was compiled by Bagnis C I et al. (2015) following an expert meeting in Zurich, Switzerland in March 2013, involving six nephrologists, eight nurses and one clinical psychologist from a spread of 12 European renal units with established RRT option education programmes. This position statement outlined clear recommendations on important aspects of the programme based on current evidence and in the context of pre-existing guidelines including guidelines from National Collaborating Centre for Chronic Conditions, Royal College of Physicians, UK, The Renal Association, UK, Haute Autorité de santé, France, and Dialysis Advisory Group of the American Society of Nephrology, USA. Overview of the recommendations are as follows<sup>27</sup>:

❖ **Who should be in the team?**

The team consists of a nephrologist and a CKD nurse, at a minimum. Optimally, additional members of the team include a dietitian, a psychologist, a medical social officer, a physical therapist and an expert patient.

❖ **What knowledge, training and experience should the team have?**

Knowledge of CKD and hands-on experience of all treatment modalities are minimum requirements for the team members. Optimally, the team also has training in the principles of adult education, motivational interviewing / communication skills and how to avoid bias when giving information.

❖ **When should the programme begins?**

Starting the programme at least 12 months before the predicted start of dialysis allows time to establish dialysis access, for the patient to accept their situation, and take part in the decision-making. If this is not possible, then the programme begins upon referral for dialysis. Optimally, commencement of the programme is based on the level of disease (CKD Stage 4, progressive) and the rate of disease progression.

❖ **Who should receive?**

The programme is made available to patients in CKD Stage 4 and Stage 5 (planned and unplanned starts), patients expressing an interest in changing modality and all patients upon request. Optimally, family, friends or caregivers of patients also attend the programme.

❖ **Should the programme be individualized? If so, how?**

The programme ends when the patient has sufficient knowledge to make an informed decision regarding treatment modality. A more individualised approach to the programme is warranted if the patient does not have sufficient knowledge.

Optimally, the following are available:

- (i) A key contact person is present to help the patient work through the material in the order and speed of the patient's choosing and help deal with psychological aspects of the disease.
- (ii) There are regular updates on the patient's condition between the education team and the patient's general practitioner (GP).

- (iii) There is regular contact between the patient and the nephrologist/nurse.
- (iv) There is an option for the programme to be delivered in the patients' preferred place (i.e. home or hospital), within time and budget constraints.

❖ **How many sessions are required?**

At least one session is required. Optimally, as many sessions as required to independently reach an informed and balanced decision on modality are held.

❖ **When should finish?**

Programme finishes when the predefined objectives have been met. Optimally, the programme finishes when the patient has chosen a form of RRT, with regular follow-ups being conducted into the treatment phase.

❖ **What topics should be included?**

The minimal topics covered in all programmes are:

- (i) Topics requested by the patient.
- (ii) Unbiased information on CKD and the four treatment options [HD, PD, transplantation and conservative care], and how well they match the patient's beliefs and values.
- (iii) An explanation that it is possible for the patient to change modality if there are no contraindications.
- (iv) Clarification of the patient's right to stop dialysis.
- (v) Ways to delay disease progression.

Optimally, the following topics are also covered:

- (i) Interviews to understand the patient's history, lifestyle, pain levels, comorbidities, physical activity levels, diet, culture, beliefs, wishes and expectations, what the patient knows and wants to know about the disease, patient's social network, how much the patient wants to be involved in the treatment.
- (ii) Implications of CKD upon finances (reduced capacity to work, insurance, treatment costs).
- (iii) Impact of CKD upon QoL.
- (iv) Dealing with emotional stress.
- (v) Practical topics (e.g. transportation to/from treatments, contacting a patient association, and making an advanced healthcare directive).
- (vi) Understanding kidney function test results and blood test results.
- (vii) Timing of placement of dialysis access.
- (viii) Medication required.

❖ **What materials/resources should be used?**

Following materials / resources are used in the programme:

- (i) One-to-one meetings with staff at the unit.
- (ii) Written booklets appropriate to disease stage, level of education and cultural/religious background.
- (iii) Multimedia showing the dialysis modalities in action.

Optimally, the following materials/resources are also used:

- (i) Patient decision aids
- (ii) Tours of dialysis facilities
- (iii) Online material (carefully chosen websites)
- (iv) Meetings with expert patients.
- (v) Videos including interviews with dialysis patients.
- (vi) Group education sessions may be considered.

❖ **How should the programme takes account of language and cultural differences?**

Medical interpreters are necessary and translations of the written material available for key culturally and linguistically diverse populations. Optimally, picture sets are available for sessions with these patients. Religious and cultural perspectives are important with regards to all treatment options. Cultural differences impact the perceived roles of doctor/patient and understanding of health/disease.

❖ **How should the quality of the programme be evaluated?**

A quality evaluation uses one or more of the following indicators:

- (i) The percentage of patients starting treatment with the modality they chose at the end of the programme
- (ii) Proportion of planned initiations with established access/pre-emptive transplantation.
- (iii) Patient satisfaction with modality choice
- (iv) Proportion of patients who have undergone a formal education programme prior to initiation of RRT.
- (v) Patient satisfaction with the level of information they have received.
- (vi) Register of patients with End of Life Care needs.
- (vii) Proportion of those patients identified as having End of Life Care needs who have a workable Advance Care Plan.

Optimally, one or more of the following indicators can be used:

- (i) QoL measurements
- (ii) Measurement of patient involvement
- (iii) Clearly defined: target population; objectives; curriculum; pedagogical tools; criteria for evaluating effectiveness (including clinical, QoL); and sources of finance

This position statement endorses current guidelines, and offers further guidance to ensure patients receive high-quality education aimed at helping them make an informed choice of modality.<sup>27</sup>

The National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (KDOQI) has provided evidence-based guidelines for all stages of CKD and related complications since 1997. The 2015 update of the KDOQI Clinical Practice Guideline for Haemodialysis Adequacy is intended to assist practitioners caring for patients in preparation for and during haemodialysis. In this updated guideline, it is stated that patients who reach CKD stage 4 (GFR <30 mL/min/1.73 m<sup>2</sup>), including those who have imminent need for maintenance dialysis at the time of initial assessment, should receive education about kidney failure and options for its treatment, including kidney transplantation, PD, HD in the home or in-centre, and conservative treatment. Patients' family members and caregivers also should be educated about treatment choices for kidney failure.<sup>28</sup>

#### 2.4.7 SOCIAL IMPLICATION

There were one SR, one SR with meta-analysis, one retrospective cohort study and two cross-sectional studies retrieved on social implications of PDEP with regards to modality choice. Two qualitative studies found which assessed patients' satisfaction as well as patients' and staff insights on PDEP. One SR and one pre- and post- intervention study retrieved examining patients' knowledge related to PDEP.

### 2.4.7.1 Modality choice

Shukla AM et al. (2017) conducted a retrospective cohort study in the USA to report the findings of the initial 22 months of a newly formed comprehensive pre-dialysis education programme (PDEP) clinic for advanced CKD patients and its impact on the rates of home dialysis. The study involved 108 advanced CKD patients with stage 4 and 5 CKD, with occasional patients of stage 3b CKD with rapid renal progression under the care of nephrologists were offered and encouraged transition to the care of PDEP clinic for their routine nephrology care. The PDEP clinic included a renal physician, an advanced nurse practitioner educator, a renal dietitian, and a renal social officer. A pharmacist was added in the PDEP clinic for the latter half of the study period. The PDEP clinic new protocol required patients to attend half-day comprehensive education session. Patients were encouraged to attend with family members, spouse, or caregivers. On arrival, patients were provided with printed material for kidney disease followed by group lesson in classroom format by renal advanced nurse practitioner educator which lasted for a minimum of one hour. After group lesson, patients rotated with renal dietitian, social officer, trained dialysis nurse well versed in all dialysis techniques, and renal physician for patient-specific discussions and detailed on the individual needs and questions. Sessions with dialysis nurse included a 'hands-on' demonstration of home PD, home HD, and in-centre machine as per the needs and requests from patients. Following that, detailed session with the renal physician which started with an interview of the individual's family, social, medical, and occupational needs. All previously provided information was reviewed and specific questions addressed. Patients and their caregivers were encouraged to make 'active choice' for their RRT. Any remaining misconceptions or fears were addressed during this final discussion and final modality choice was recorded in a passive manner. In contrast, patients who were in established patient protocol group had greater freedom to focus on the areas of their choice for counselling and were routinely seen by the renal physician for nephrology care. Patient preferences for RRT were noted at each clinic visit.<sup>19 Level II-2</sup>

The study found that over 22 months of PDEP clinic commenced, 70% of patients in PDEP group chose home dialysis, of which, 55% chose PD and 15% chose home HD. Similar rates of home dialysis choice were noted across spectrum of socio-economic variables. Multivariate analysis showed that the choice of RRT modality was unaffected by the patients' age, gender, race, availability and type of insurance, diabetes status, albumin, or the stage of renal disease. The commencement of PDEP clinic has resulted in a 216% growth in home dialysis census over the same period and resulted in near doubling of home dialysis prevalence to 38% of all dialysis patients within 22 months of initiation.<sup>19 Level II-2</sup>

Devoe DJ et al. (2016) reported in their systematic review and meta-analysis that six studies reported primary outcome of choosing PD, and five provided sufficient data for meta-analysis. In the RCT (N = 70), educational intervention group was associated with more than 4-fold increase in the odds of choosing PD (OR, 4.60; 95% CI, 1.19, 17.74). Meta-analysis results from four observational studies (N = 7,653) showed that patient-targeted educational interventions were associated with a 2-fold increase in the odds of choosing PD (pooled OR, 2.15; 95% CI, 1.07, 4.32;  $I^2 = 76.7\%$ ). For secondary outcome of receiving PD, 10 studies reported secondary outcome, nine had sufficient data for meta-analysis. Meta-analysis results from nine observational studies (N = 8,229) showed that patient-targeted educational intervention was associated with a three-fold increase in the odds of receiving PD as the initial treatment modality (OR, 3.50; 95% CI, 2.82, 4.35;  $I^2 = 24.9\%$ ). The authors concluded that this review demonstrated a strong association between patient-targeted education interventions and the subsequent choice and receipt of PD. The variability in the design of the educational strategies identified and the strength of association across studies highlight the uncertainty about when and how educational interventions should be delivered, as well as likelihood of impact according to baseline PD penetration.<sup>22 Level I</sup>

de Maar JS et al. (2016) conducted a cross-sectional study in Amsterdam, The Netherlands to assess the impact of implementation of a structured PDEP named GUIDE with a home-focused approach on the number of pre-dialysis patients that choose home dialysis, and the number of patients that eventually receive home dialysis. Records of all 102 patients that received a treatment recommendation in the GUIDE programme between September 2013 and December 2014 at Meander Medical Centre were retrospectively reviewed. The structured PDEP process starts when a patient has an eGFR of 15 mL/min/1.73 m<sup>2</sup>. The programme began with home visit from a case manager (social worker) during which first education is given and suitability for home dialysis was assessed. Following that, set of questionnaires were completed by patient, case manager and nephrologist. Patient questionnaire had questions about the patient's social support system, daily activities, level of independence in activities of daily living (ADL), aspects of life that patient values most and preferences and expectations with regards to RRT. Meanwhile, medical questionnaire comprised the categories transplantation, PD and HD, which contained questions about relative and absolute contraindications for each therapy and nephrologist's treatment preference. Case manager's questionnaire covered the suitability of the home, the social environment and the balance between burden and capacity and ended with case manager's judgment of whether or not home dialysis would be suitable. Subsequently, a multidisciplinary meeting (MDM) was held to determine a specific patient profile and treatment recommendation. In MDM, the most suitable treatment for particular patient was chosen. This was then followed by patient education, a second MDM and finally the selection of the treatment by the patient and the nephrologist. After MDM, specialised pre-dialysis nurse provides education tailored to patient's profile. General information related to RRT was given to all patients. Training for patient and family members before the start of home dialysis was discussed. Education was provided in a single session, which was repeated upon request. Written brochures and educational videos were also provided. Meetings with other patients were also offered and arranged if requested by the patient or their family. Patient's response to this educational session was discussed in a second MDM. Following this, patient and nephrologist choose a treatment modality during the next visit to the outpatient clinic.<sup>20 Level II-3</sup>

The results showed that home dialysis was recommended for 62.8% of the patients who were advised to have dialysis treatment. Of patients that opted for dialysis, 34.2% chose PD and 8.2% chose home HD. About 22.9% started home dialysis as their first therapy, compared with 17.6% in the months before implementation of the programme. The study reported that 32.1% of the patients that received dialysis therapy received home dialysis. In the months before PDEP, an average of just 19.5% of patients that received dialysis received home dialysis. The authors concluded that compared with historical data, the standardised and home-focused PDEP, with its home visit, seems to successfully increase the number of patients that choose and receive home dialysis.<sup>20 Level II-3</sup>

Van den Bosch J et al. (2015) reported in their systematic review that six out of nine studies reporting on dialysis modality selection showed a higher proportion of patients selecting home dialysis (PD or another home modality) (Table 4) while three studies found no significant difference in modality choice.<sup>11 Level I</sup>

**Table 4: Studies which reported on preference for home dialysis**

Study	Results
Chanouzas et al. (2012)	20% chose PD 50% choosing PD received PDEP vs 33% of HD patients.
Klang et al. (1998)	Higher number of patients chose PD
Levin et al. (1997)	53% of PDEP group chose PD vs. 42% in control
Manns et al. (2005)	82.1% of PDEP group chose self-care dialysis vs 50% in control
McLaughlin et al. (2008)	PDEP group more likely to choose self-care dialysis
Ribitsch et al. (2013)	54.3% in PDEP group started with PD vs 28% in control

Four pre- and post- intervention studies on PDEP showed higher levels of home dialysis use after the pre-dialysis education intervention.<sup>11 Level I</sup>

Cankaya E et al. (2013) conducted a cross-sectional study in Turkey aimed to investigate the relationship between PDEP for patients and their relatives and pre-emptive renal transplantation. A total of 88 patients who underwent living donor kidney transplantation between May 2004 and August 2012 were divided into two groups; transplantation without PDEP (no-PDEP) (N=27) and transplantation with PDEP (N=61). Pre-dialysis education programme (PDEP) involved specially prepared kit using visuals and written cards given to CKD patients and their relatives with six modules; Module 1 covered general information about kidney disease, Module 2 covered diet, drugs and exercise in CKD, Module 3 covered introduction to treatment of renal failure and general information about RRT, Module 4 on PD, Module 5 on HD and kidney transplantation. Patients with early stage will start with module 1,2,3 while patients with stage 3b and 4, will start with module 1,2,3,4,5,6 and patients with stage 5, modules with RRT chosen by patient will be started. The study found that pre-emptive kidney transplantation rates among PDEP group significantly higher compared with the no-PDEP group (42.6% vs 18.5%,  $P < 0.001$ ). Mothers were the most numerous donors in both groups. In addition, donor transplantation rates from spouse, siblings and other relatives were higher among the PDEP group  $P < 0.001$ ,  $P = 0.001$ , and  $P = 0.002$ , respectively. The authors concluded that PDEP increased the number of pre-emptive renal transplantation among ESRD patients, reducing dialysis-related complications and costs. Dissemination of PDEP in nephrology outpatient clinics appears to be favourable for patient health, quality of life and economics.<sup>26 Level II-3</sup>

Unpublished data from a local audit which was conducted in a cluster hospital in Pahang, Malaysia in 2016 involving 130 patients who were recently started dialysis (crashlanders) and CKD Stage 5, referred from Nephrology clinic for Dialysis Preparatory Clinic (DPC), reported that following the preparatory clinic, almost half of the patients chose PD as their initial preferred option (44.7%) and started PD (48.3%) as their RRT. In a more recent audit in 2018 by the same hospital, it was reported that 68.9% patients chose PD as their preferred option for RRT.<sup>29</sup>



### 2.4.7.2 Patients' satisfaction

Cassidy B P et al. (2018) conducted a qualitative study in Canada to explore participants' satisfaction with the education they received, while identifying educational needs, and the influence of the educational process in their dialysis modality decision making. The study included a sample of 12 participants between August and September 2016 with four patients from each dialysis modality (in-centre HD, PD, home PD). Patients' age ranged from 23 to 77 years old with median age of 62 years old. Highest levels of education attained were high school (33%), college (50%), and postgraduate degree (17%). Pre-dialysis education was provided by multidisciplinary team. Educational supports given included: Kidney Foundation of Canada binder, *Living With Kidney Disease*, 4th edition, four multimodal small group classes, patient partners, and a list of trusted CKD online resources. The four classes covered self-management, living with CKD, stages of change, videos and demonstrations of each dialysis modality, a patient panel, vascular access, and a tour of the dialysis unit. A 30- to 60-minute semi structured interview using the AIDET (Acknowledge, Introduce, Duration, Explanation, Thank You) protocol was conducted with patients along with any family members present to explore on how patients receive information, its influence on their decisions and how the current educational supports could be improved. Demographic survey on patients were also completed. Keywords, phrases, and descriptions were analysed and categorized into themes. Quotes were extracted to best represent the patient voice and were matched to themes through team consensus.<sup>21</sup>

The study found that there were three overarching themes which influenced the modality decision-making process; Patient Factors (individualisation, autonomy, and emotions), Educational Factors (tailored education, appropriate time/information, and available resources), and Support Systems (partnership with health care team and family/friends). For patient factors, individual circumstances including transportation, level of activity, living situation, and support systems were the core of many modality decisions (individualisation). In addition, patients had varying levels of independence, ability and willingness to engage, and preferred different quantities of information (autonomy), and without adequate understanding of their current health state, patients experienced fear, denial, regret, anger, and shock (emotions). For educational factors, the study reported that content and format of education delivered to patients influenced decision making, with individual patient factors had impacts on the effectiveness of the educational support. Patients tended to receive information more effectively, with active engagement and motivation to learn when provided in accordance with their preferred learning styles (tailored education). Demographic and generational variance was apparent factors which influenced certain participants wished to receive information. Patients' requests to improve the current educational support included more face-to-face education from clinicians and patients, videos on dialysis, online educational classes, and written information via pamphlets. It is also reported in the study that providing time and repeated exposure to information enhanced patient-informed decision making (appropriate time/information).<sup>21</sup>

Different patients needed different appropriate amount of time. Patients felt rushed, barraged with information, and overwhelmed when not given enough time. Patients also reported feeling they did not receive balanced information in terms of both the benefits and drawbacks of each modality and desired a more realistic approach. Educational supports had major impact on patients' perception for each modality (available resource). However, not all the resources offered were accessed by the patients. Patients benefited from group learning and the shared patient experiences and perceptions. The HD unit tour helped set expectations, ease fears, and increase comfort levels. The written materials and CKD websites appeared to play a larger role in improving patients' understanding of CKD, the modality options available, and prompting questions to ask the healthcare team. In addition, patients reported consistently referring the healthcare team, family, and friends as an educational resource (support systems).<sup>21</sup>

As for support systems, nephrologists play a significant role in modality education and decision making. When a trusting partnership was established, patients had an enhanced sense of importance, control, and respect. However, the opposite was found when there was not a sense of partnership with healthcare team. Patients were less likely to identify other healthcare team members as crucial to decision making. However, when able, feedback was generally positive. Patients stated the case manager was an important educator, the social worker helped them cope and ease fears, and nurses provided emotional support. Patients also relied on family and friends, and lack of support often influenced the decision for in-centre HD over a home-based therapy. The authors concluded that patient's health literacy, willingness to accept information, pre-dialysis lifestyle, support systems, and values were the influential factors in modality decision making. Patient education requires the flexibility to individualise the delivery of a standardised CKD curriculum in partnership with a patient-health care team, to fulfill the goal of informed and shared decision making.<sup>21</sup>

### 2.4.7.3 Patients' and staff insights

Combes G et al. (2017) conducted a qualitative study in Canada to provide insights into what staff and patients think needs to improve related to pre-dialysis education. Mixed methods were used to look at quantitative changes in home dialysis uptake rates and qualitative case studies to explore barriers and success factors for home dialysis. Four hospital renal units were selected from seven West Midlands units. Formal pre-dialysis education in all four sites included one or more one-to-one sessions with a specialist nurse, a group information session, including talks from patients on RRT and written materials as well as DVDs which patients took home. In several sites, specialist nurses undertook home visits where they discussed treatment options with patients. Doctors also discussed treatment options with patients during out-patient appointments. Semi-structured interviews were conducted with 96 clinical and managerial staff and 93 dialysis patients starting their current treatment within 12 months. For patients, the topic guide in the interview covered were how patients came to be on dialysis, experiences of pre-dialysis and dialysis pathways and suggestions for improvement. For staff, the topic guide covered were current practice, how well the pre-dialysis and dialysis pathways work and how the team had been working to increase uptake of home dialysis. Patients and staff were prompted with an open-ended question about how treatment decisions were made if they did not spontaneously talk about the pre-dialysis period. The semi-structured qualitative telephone interviews were undertaken with 20 to 25 patients and semi-structured qualitative face-to-face interviews were undertaken 20 to 30 staff per site until saturation was achieved. All interviews were audio recorded and were transcribed by a specialist transcription team. The written and audio-visual pre-dialysis education materials used in each site were also reviewed. Data was analysed using thematic framework analysis.<sup>12</sup>

They reported that most staff made favourable comments about pre-dialysis education and valued the role of specialist nursing staff in educating and supporting patients' treatment decisions. Most patients reported finding it was overall helpful. There were three themes identified which related to improving pre-dialysis education; sub-optimal education (restricted range of teaching materials and methods, and bias in the presentation of information and treatment options), different perspectives between patients and staff (importance of informal education, approaches to treatment decision-making), and influence of patient experience (influence from other patients, impact of distress). Patients desired improvements made to the teaching methods and biases eliminated. Patients indicated that restricted range of teaching materials and methods have made them felt that they were unable to use information given because the high volume and complexity of information. Another perspective on teaching materials came from patients who thought that they were not 'real' enough, and struggled to apply the information to their own lives. Seeing different treatments being undertaken by real patients were all suggested as ways of improving the education. On the other hand, from staff perspective, written materials were designed so that patients had information to take

home and consider over time. However, some patients were unable to take advantage of this positive intention. This suggested that patients would benefit from wider range of teaching methods, including interactive methods. Some patients thought that all treatment options were presented fairly and with equal emphasis, others felt not all options had been presented to them and that they had only found out about viable alternatives once they were on dialysis.

Some of these patients thought that opportunities to talk to patients already on treatment might have helped to give them a more balanced view of what life on dialysis might be like. Staff were also aware of the potential for bias in the presentation of information and treatment options, however, all staff groups thought that the first conversation with doctors about treatment options is crucial in influencing patients' treatment choice. Staff were less aware than patients of how informal staff-patient conversations can influence patients' treatment decision-making. Many staff felt ill equipped to talk about all treatment options in a balanced and unbiased way due to lack of training or lacked experience of the full range of treatment options. It was seemed that some patients continued to consider treatment options well after they had started dialysis, and continued gathering information and views about treatment options, some with intention to switch treatment. This highlighted the importance of all staff, irrespective of their role, being able to present all options neutrally and answer basic questions about all types of treatment.<sup>12</sup>

As for approaches to treatment decision-making, patient decision-making was found to be complex and patients' abilities to make treatment decisions were adversely affected in the pre-dialysis period by emotional distress. Nearly all staff described a rational fact-based approach to treatment decision-making while most patients talked about a more personalised approach of thinking about their own lives and how different treatment options might work for them. With regards to the influence of other patients on decision-making, some patients valued having opportunities to talk to other patients, particularly those who were already on dialysis, because they were able to portray what treatment is really like and some patients thought this helped to balance any biases from staff. Some staff also recognised that pre-dialysis patients can find it beneficial to converse with patients on RRT however, other staff were more cautious and actively discouraged patient contact, because some patients may have atypical experiences or be biased against certain treatments. The impact of distress on decision-making emerged as a strong theme across all patient groups and sites. Patients described at length, the traumatic and frightening nature of the transition to end-stage renal failure. It seemed likely that distress was a major factor contributed to the difficulties of making treatment decision including for patients who had known for years they would need RRT and who might therefore be expected to be well prepared for treatment decision-making. However, very few staff appeared to appreciate the potential adverse impact of psychological distress on patients' ability to make treatment decisions.<sup>12</sup>

#### 2.4.7.4 Patients' knowledge

One SR and one pre- and post- intervention study were found reporting on patients' knowledge.

Van den Bosch J et al. (2015) reported in their SR that four of 19 quasi-experimental studies found higher levels of knowledge of end-stage renal disease and of different treatment options for patients receiving pre-dialysis education compared to those who did not receive.<sup>11 Level I</sup>

Danguillan R A et al. (2013) conducted a pre- and post- intervention study in Philippines to review the efficacy of PDEP and counselling programme in improving CKD knowledge. The study involved 299 CKD patients not yet on RRT from June 2009 to February 2010 and consisted of; 60% CKD Stage 5, 19% Stage 4, 10% Stage 3, 1% Stage 2 and 2% Stage 1. An evaluation tool was administered before and after the education modules to determine its efficacy in improving CKD knowledge. Pre-dialysis education programme (PDEP) involved a team comprised of trained CKD educators, a nurse and a psychologist, who conducted

structured educational modules according to CKD stage. After each module, patients were instructed to return after every out-patient follow-up for completion of the education modules and further counselling. Patients were given take-home materials after each visit and were instructed about the recommended completion times for the modules: within three to four months for CKD stages 1 to 3, within one to two months for CKD stage 4 and within one month for CKD stage 5. Evaluation tools consisted of four self-administered questionnaires; a 30-item tool (22 items on general CKD knowledge and eight items on RRT), three 10-item tools covering lessons learned from each of the three CKD Clinic visits, an eight-item tool on patients' health-care seeking behaviour prior to consultation at hospital, and a four-item questionnaire on perceived CKD knowledge. The 30-item tool evaluated patients' baseline or actual knowledge (overall pre-test) and again after the patient completed all the education modules (overall post-test). The 10-item tools were administered after each visit to reinforce the lessons learned. Patients were followed-up for six months and overall pre- and post-test scores were compared to determine if there was improvement in the patient's CKD knowledge.<sup>24</sup>

The study found that only 28% patients completed the modules within six-month follow-up period. Most patients who did not complete the programme (83%), no longer presented for follow-up after three months due to various reasons; poor compliance due to financial, came only for diagnosis, too ill to return for follow-up, lack of understanding, and low priority given. For perceived CKD knowledge, majority (34%) had no knowledge about CKD, 30% had little, 28% some, and 8% claimed a great deal of knowledge. Most were unaware of RRT options; 70%, 64.2%, and 54.2% had no knowledge of PD, HD, and transplantation, respectively. No significant association between CKD stage and knowledge of RRT. About 90% scored < 60% on general knowledge of CKD and 90% scored < 50% on the actual knowledge of ESRD treatment options. Among patients who claimed that they had extensive CKD knowledge, all scored < 60% in the actual knowledge questionnaire. For efficacy of education modules, there was significant increase in mean overall pre-test scores of CKD knowledge from  $7.0 \pm 5.11$  (maximum score 30) to  $23.0 \pm 4.5$  (maximum score 30) points in the overall post-test, with 69% scoring  $\geq 75\%$  ( $P < 0.00001$ ). There was an increase in number of patients (58%) who gained knowledge on the different aspects of CKD after completing the educational modules except for the topic on signs and symptoms of CKD. Patients aged < 50 years had significantly higher pre- and post- test results compared to older age groups ( $P = 0.007$ ). The authors concluded that the CKD education and counselling programmes were effective in improving patients' knowledge of their disease. Elderly and non-high-school graduates of a financially disadvantaged population may need specially designed education modules to improve their comprehension.<sup>24</sup>

#### 2.4.7.5 Psychological Implication

García-Llana H et al. (2014) conducted pre- and post- intervention study to determine the effectiveness of an individual, pre-dialysis intervention programme in terms of adherence, emotional state and health related quality of life (HRQL) in pre-dialysis patients with advanced CKD. All 52 adult patients with advanced CKD under pre-dialysis treatment with eGFR of  $\leq 20$  ml/min or less were included in the study. The programme involved a six-month individual programme with every patient entering the study attended their regular appointments with nephrologist, the nurse and nutritionist and each patient received six individual monthly face-to-face sessions about 90-minutes duration each time with health psychologist. Every session had two distinct aims; first 45 minutes of sessions provided training in skills that facilitated the patient's adaptation to the advanced CKD and its treatments, and last 45 minutes helped improve adherence to medication through motivational interviewing. Assessments were administered prior to the intervention and after the intervention. Patients were followed-up for six months and evaluated for adherence, depression, anxiety and HRQL with standardised self-report questionnaires. Biochemical markers were also registered.<sup>25</sup> Level II-3

The study found that after the intervention, patients reported significantly higher levels of adherence [Mean score (SD) range; pre-test 27.12 (2.74), 22–33 vs. post-test 31.45 (2.05), 26–33 ( $P < 0.001$ )], lower depression levels [(M = 10.92) pre- vs. post- (M = 8.86) intervention] and anxiety levels [(M = 18.22) pre- vs. post- (M = 14.41)]. Health-related quality of life (HRQL) scores on the General Health subscale increased significantly (from M = 37.19 to M = 45.97), as did scores on the Emotional Role subscale (from M = 71.82 to M = 77.57). No effects were found in other domains of HRQL (physical function, physical role, bodily pain, vitality, social function, mental health). Biochemical parameters were found significantly better controlled after the intervention, except for iPTH. The authors concluded that the findings highlighted the potential benefit of applying individual psycho-educational intervention programmes based on motivational interviewing and using the stages of change model to promote adherence and wellbeing in advanced CKD patients.<sup>25</sup> Level II-3

#### 2.4.8 COST / COST - EFFECTIVENESS

Yu YJ et al. (2014) conducted RCT with cost-analysis in Taiwan to analyse the medical expenditure and utilisation incurred during the first six months of dialysis initiation in 445 incident HD patients who were randomised into PDEP and no-PDEP groups before reaching ESRD. Medical expenditure and utilisation in the first six months of initiation of haemodialysis in these patients were accurately recorded and compared between PDEP and no-PDEP patients. Medical service utilisation was calculated as the frequency of outpatient visits and the frequency and length of hospitalisation. Medical service expenditures included outpatient expenditures (all costs including physicians' and nursing fees, examinations, surgery, and medication) and inpatient expenditures (all costs including laboratory testing, imaging testing, medications, surgery and consulting, ward and administrative, nasogastric tube feeding, and haemodialysis fees). The expenditures for each participant were totalled to compute the sum of ambulatory and inpatient medical service utilization costs and expenditures. Analysis of costs only included those medical costs for which our hospitals made reimbursement claims to the NHI. The salaries, overheads, and administrative costs of the care team were not included in the analysis. The results showed that PDEP patients had lower total medical cost in the first six months after HD initiation ( $9147.6 \pm 0.1$  USD/patient vs.  $11190.6 \pm 0.1$  USD/patient,  $p = 0.003$ ) compared to the no-PDEP patients. Medical cost of inpatient service was significantly lower in MPE patients (mean  $2261.8 \pm 5635.8$  USD/patient in PDEP patients vs. mean  $3698.8 \pm 5540.9$  USD/patient in no-PDEP patients,  $p < 0.001$ ), principally due to reduced cardiovascular hospitalisation and vascular access-related surgeries. The decreased inpatient and total medical cost associated with PDEP were independent of patients' demographic characteristics, concomitant disease, baseline biochemistry and use of double-lumen catheter at initiation of haemodialysis. The authors concluded that participation of multidisciplinary education in pre-dialysis period was independently associated with reduction in the inpatient and total medical expenditures of the first six months after dialysis owing to decreased inpatient service utilisation secondary to cardiovascular causes and vascular access-related surgeries.<sup>16</sup> Level II-2

Wei SY et al. (2010) conducted a retrospective cohort study with cost-analysis in Taiwan involving 140 incident ESRD patients who started dialysis and divided into two groups; PDEP group who received care and education from multidisciplinary team and Nephrologist Care Group (no-PDEP) who received standard care from nephrologist only. Medical services utilisation and costs were analysed from six months before initiation of dialysis to the time of the first HD, and the time periods were divided into 'six months before dialysis', 'at dialysis initiation', and the sum of the two periods as the 'total period of observation'. Outcome measures for service utilisation included average outpatient visits before dialysis, frequency of hospitalisation before dialysis, percentage of patient hospitalisation at dialysis initiation, and average length of stay. Measurement of costs only included direct medical costs for which the study hospitals made claims for reimbursement. Salaries, overheads and indirect costs of the care team were not included in the analysis. The results showed

that PDEP group had higher costs during the six months before dialysis (US\$1428 +/- 2049 vs US\$675 +/- 962/patient,  $P < 0.001$ ), but was significantly associated with lower medical costs at dialysis initiation (US\$942 +/- 1941 vs US\$2410 +/- 2481/patient,  $P < 0.001$ ) and for the total period of observation (US\$2674 +/- 2780 vs US\$3872 +/- 3270/patient,  $P = 0.009$ ). The cost-saving effect resulted from the early preparation of vascular access and the lack of hospitalisation at dialysis initiation. The authors concluded that PDEP had successfully helped pre-ESRD patients to proceed into dialysis initiation with better preparedness, which reduced the probability of emergency dialysis through hospitalisation and saves money.<sup>17</sup> Level II-2

## 2.5 DISCUSSION

Our systematic review included 16 studies comprised of one SR with meta-analysis, one SR, one RCT, three cohort studies, two retrospective cohort studies, two pre- and post- intervention studies, four cross-sectional studies and two qualitative studies on pre-dialysis education programme for advanced CKD patients. There was no HTA report retrieved. The evidence was gathered according to the outcomes for effectiveness, safety, organisational, social implications and cost-effectiveness. The findings showed that with regards to effectiveness, participation of CKD patients in structured PDEP was associated with significantly better survival probability, mortality and morbidity rates. The one-year survival rate for HD patients who received structured PDEP were found to be higher despite of them being older and having more comorbidities. Peritoneal dialysis (PD) patients who had structured PDEP beforehand also found to have significantly lower peritonitis-related mortality rates and lower peritonitis-related morbidity rates compared to those who did not. These findings highlight that structured PDEP contributed to improved outcomes in advanced CKD patients. Meanwhile, PDEP in MOH facilities in Malaysia vary greatly across the country and have yet to be standardised. Future works are seriously needed to further strengthen PDEP in MOH, Malaysia facilities through standardisation to ensure effective outcomes for advanced CKD patients.

We did not find any retrievable evidence on the safety issues related to the programme. Frequency of temporary catheter use, rates of hospitalisation at dialysis initiation and post-dialysis, as well as length of hospital stay were also found to be significantly lowered in CKD patients who had PDEP. Significantly more patients who participated in the programme had their vascular access created before the initiation of HD. Cost-analyses included in this review, highlighted that medical expenditure after HD initiation significantly reduced in patients who had PDEP and achieved cost-savings principally due to reduced cardiovascular hospitalisation and vascular access-related surgeries.

In terms of modality choice, our findings demonstrated substantial association between PDEP and the subsequent choice and receipt of PD. An increase in rates of home dialysis and pre-emptive kidney transplantation rates were likewise noted. Similarly, the results from the local audits in Malaysia on advanced CKD patients who attended PDEP clinics also showed a higher preference for PD as their option for RRT and these findings are in line with findings from this SR. Higher PD uptake has been shown to have significant impacts on ESRD patients notably in superior social and patient experience compared to HD. In particular, patients treated with PD reported better quality of life,<sup>30-34</sup> greater independence<sup>34</sup>, more flexible lifestyle<sup>34</sup> and improved job opportunities.<sup>34</sup> Better cognitive functions and lower dementia risk have also been reported in patients treated with PD.<sup>35</sup> In addition, most studies suggest that PD is less costly with comparable or better health outcomes than HD.<sup>36</sup>

In terms of patient's knowledge and psychological implications, higher levels of ESRD knowledge and of different treatment options, as well as higher levels of adherence, lower depression and anxiety levels, and better HRQL were reported for patients in PDEP. Two qualitative studies in this review explored patients' satisfaction and insights towards the programme and reported that modality selection is a complex process requiring an

individualised approach for each patient. Patients' decisions on RRT were influenced by their own preferences and values, the education delivered to them, and the support systems available to them. Emotional distress was a strong theme described by patients in the transition to end-stage renal failure which then affected their abilities to make treatment decisions. However, the impact of psychological distress on patients was found mostly underappreciated by the healthcare staff.

In general, our results indicated that PDEP had favourable outcomes on advanced CKD patients. However, there was wide variation between the components of programmes outlined in all the included studies in this review. These findings are in line with previous systematic reviews done by Devoe DJ et al. (2016) and Van den Bosch J et al. (2015) which highlighted such a great variation between different components of the programmes.<sup>11 Level I, 22 Level I</sup> Both SRs reported that the nature of educational interventions varied greatly between studies.<sup>11 Level I, 22 Level I</sup> Our review detailed similar findings that most studies described varying educational components and processes. Multidisciplinary team members were almost always comprised of nephrologist, nurses, dietitians, and medical social workers with few programmes had clinical psychologist, pharmacist, and patient volunteers. Delivery style ranged from multiple individual sessions with multidisciplinary team members to mixed of individual sessions and group sessions as well as patients' involvement particularly in peer sharing sessions. Variety of formats for content, structure, frequency of sessions, follow-up and duration of sessions have been described. Materials used came in a wide variety of forms and sources included printed materials, video and website materials. Timing for PDEP were mentioned at stage 4 and 5 CKD or few months before dialysis commencement. Training for the staff administering the programme was not specified in most included studies.

These findings emphasised on the lack of standardisation in the conduct of PDEP which could hinder advanced CKD patients from getting optimal quality educational interventions to ensure effective outcomes for RRT and the subsequent improvement in quality of life. A more standardised approach to PDEP is needed to further establish its effectiveness for advanced CKD patients. Since most of the studies included in our review had follow-up duration of between three months to two years with exception of one study on PD patients that had follow-up duration of five years, more studies with longer follow-up period are needed in the future to demonstrate the long-term effects of PDEP for advanced CKD patients.

## Limitations

This systematic review has several limitations and these should be considered when interpreting the results. Although there was no restriction in language during the search, only the full text articles in English published in peer-reviewed journals were included in the review, which may have excluded some relevant articles and further limited the study numbers. Firstly, one of the important limitations was the methodological quality of the included reviews and the limitations of the primary studies themselves. The SRs in this review have included mostly quasi-experimental studies and often without control groups or pre- and post- intervention measures. Some studies presented data in comparison to other reports or to previous findings instead of in comparison to control groups. We did not conduct a rigorous assessment of the concordance of the data reported in the SR with those stated in the primary studies. It is presumed that each review generally included the full available and eligible evidence that data extraction was accurate, and that analyses were scientifically sound. Secondly, the huge variation between the PDEP conducted in the included studies would be an important aspect that should be considered when interpreting the results. Most of the included studies in this review were conducted in Taiwan, USA and other parts of Europe which could potentially raise some questions on the applicability of the results to Malaysian population.

## CHAPTER 3: PATIENT AND PUBLIC INVOLVEMENT IN PRE-DIALYSIS EDUCATION PROGRAM

Over the years, Malaysian Health Technology Assessment Section (MaHTAS) has continuously ensured patient involvement in the development of HTA and CPG. Patients or their representatives are often involved as committee members for HTA and CPG. This is the first patient and public involvement (PPI) initiative by the authors to obtain perspectives from patients, carers and HCWs via a questionnaire survey as part of the HTA on PDEP. The short form of Guidance for Reporting Involvement of Patients and the Public (GRIPP2-SF) checklist is used for the reporting of this survey which includes five sections: aim, methods, study results, discussion and conclusion, and reflection/critical perspective.<sup>37</sup>

### 3.1 AIM

Pre-dialysis education has been offered to CKD patients in several major and minor specialist centres in Malaysia. However, a structured and user-centric PDEP is yet to be established in public health facilities. As each treatment option has its own advantages and disadvantages, sufficient information should be provided for better informed decision-making by the patients and carers. The aim of this survey is to identify the essential components of PDEP based on the preferences of patients, carers and HCWs to inform the development of a structured PDEP in Malaysia.

### 3.2 METHODS

The survey instrument was developed in English language based on findings from previous studies<sup>37-40</sup>, informal interview with a 30-year-old Malaysian female CKD patient with 12 months' dialysis experience, and questions of feasibility and acceptability that the survey was designed to answer. The survey items were revised via professional judgement on relevance to pre-dialysis education in Malaysian public health facilities and appropriateness in terms of simplicity, ambiguity, validity, and sentence structure.

The survey consisted of 20 partial close-ended questions divided in three sections (Appendix 6): (i) socio-demographics (age, sex and level of education); (ii) background/treatment experience (type of respondents, place of treatment/workplace, and experience of dialysis and pre-dialysis education); and (iii) preferences of PDEP (preferred patient educators, types of information needed, delivery method, education materials, time of initiation, duration, frequency, preferred venue, and importance of patient support group and shared decision-making). Respondents were allowed to choose more than one answer for some of the questions.

The multicentre cross-sectional survey was conducted in January 2020 by a team of four researchers at the nephrology clinic or dialysis centre of three selected public hospitals under the Ministry of Health Malaysia (MOH):

- 1) Hospital Kuala Lumpur (HKL)
- 2) Hospital Tengku Ampuan Rahimah Klang (HTAR)
- 3) Hospital Ampang

Inclusion criteria were age  $\geq 18$  years old, Malaysian citizens and CKD patients, carers of CKD patients or HCWs involved in the care of CKD patients. Those who were experiencing medical conditions deemed unfit to participate were excluded from the survey. Target sample size was a minimum 30 respondents (10 participants from each study site). Respondents were recruited via purposive sampling by nephrologists or HCWs in charge of the nephrology



clinic at selected public hospitals. The survey was answered by respondents themselves (self-administered) or administered by researchers if respondents were unable to read the English language. Informed consent was obtained prior to administration of the survey. An additional short interview session was carried out following the survey for participating HCWs to obtain in-depth information on the existing pre-dialysis education being offered to CKD patients at selected public hospitals. Data tabulation and descriptive analysis were performed using Microsoft Excel® version 2016 (Microsoft Corporation, Redmond, WA, USA) software.

### 3.3 RESULTS

A total of 39 respondents consisting of patients, carers and HCWs were recruited from selected public hospitals. About two-third of the respondents were younger than 50 years of age (64.1%) (Table 5). Approximately half of the respondents were female (53.8%) and had completed education up to secondary school (56.4%). Time to complete the survey ranged from 10 to 30 minutes.

Majority of respondents were CKD patients (69.2%) and from HKL (43.6%) (Table 6). Most of the patients and carers of CKD patients (N=31) had received pre-dialysis education prior to initiation of dialysis (67.7%); about 18 of them (58.1%) had been initiated on dialysis with duration of dialysis ranging from less than six months to more than 18 months.

**Table 5: Socio-demographics of respondents.**

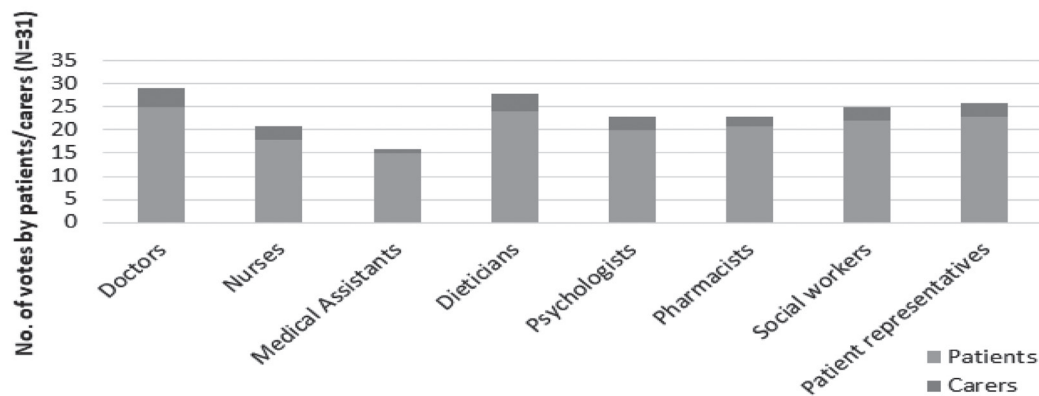
Characteristics (N=39)	Frequency, n (%)
<b>Age</b>	
18-30	4 (10.3)
31-40	8 (20.5)
41-50	13 (33.3)
51-60	9 (23.1)
61-70	5 (12.8)
<b>Gender</b>	
Male	18 (46.2)
Female	21 (53.8)
<b>Level of education</b>	
Primary	3 (7.7)
Secondary	22 (56.4)
Tertiary	14 (35.9)

**Table 6: Respondents' background/treatment experience.**

Background/treatment information	Frequency, n (%)
<b>Type of respondent (N=39)</b>	
Patient	27 (69.2)
Carer	4 (10.3)
HCW	8 (20.5)

<b>Hospital/workplace (N=39)</b>	
HKL	17 (43.6)
HTAR	12 (30.8)
Hospital Ampang	10 (25.6)
<b>Received pre-dialysis education (patients/ carers, N=31)</b>	
Yes	21 (67.7)
No	10 (32.3)
<b>Initiation of dialysis (patients/carers, N=31)</b>	
Yes	18 (58.1)
No	13 (41.9)
<b>Duration of dialysis for those on dialysis (N=18)</b>	
<6 months	4 (22.2)
6-12 months	0
12-18 months	2 (11.1)
>18 months	12 (66.7)

In terms of preferred educators, the preference of patients and carers (N=31) in decreasing order was doctor (94%), dietitian (90%), patient representative (84%), medical social officer (81%), psychologist (74%), pharmacist (74%), nurse (68%) and medical assistant (52%) as shown in Figure 5.



**Figure 5: Preferred patient educators.**

For the type of information needed prior to initiation of dialysis as illustrated in Figure 6, majority of patients/carers (N=31) agreed that it is important to be given the information on dietary advice (100%), advantages and disadvantages of treatment options (97%), medications and supplements associated with each treatment (97%), side effects of dialysis (97%), how dialysis was performed (97%), costs associated with treatment options (87%) and the effects of dialysis to daily lives (87%). However, information on how to dress for dialysis was less required by the patients/carers (39%).

As for the delivery method, patients and carers (N=31) had a slightly higher preference for individual (one-to-one) sessions (39%), followed by group sessions of 2-5 people (29%) and group sessions of 5-10 people (29%); one respondent voted for group sessions of 15-20 people. The majority of HCWs (N=8) also showed preference for individual (one-to-one) sessions (63%) instead of group sessions of 2-5 people (25%) and group sessions of 5-10 people (12%). A slightly higher proportion of patients and carers (N=31) preferred one single session with multiple educators (32%) compared to multiple sessions by appointment (26%), multiple sessions upon request only (26%) and one single session with a single educator (16%). Meanwhile, half of the HCWs (N=8) voted for multiple education sessions by appointment (50%), followed by one single session with multiple educators (25%) and one single session with a single educator (25%).

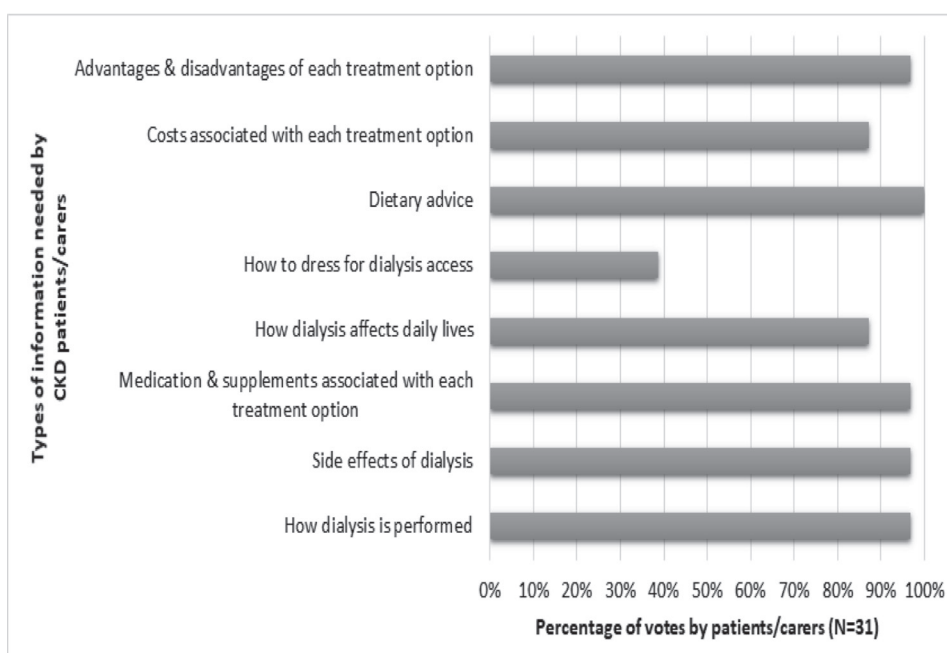


Figure 6: Types of information needed by patients/carers prior to initiation of dialysis.

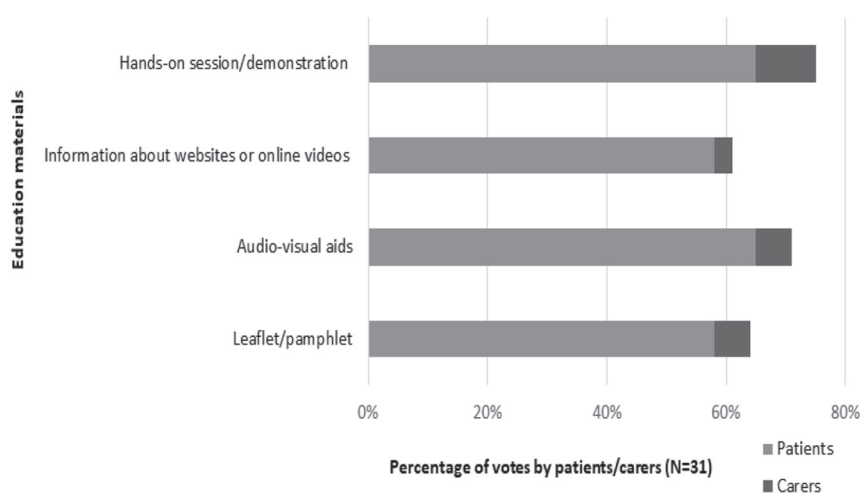


Figure 7: Education materials.

In terms of education materials, preference of patients and carers (N=31) in decreasing order was hand-on session/demonstration (74%), audio-visual aids (71%), leaflet/pamphlet (64%) and information about websites or online videos (61%), suggesting that a mix of different education materials may be suitable for PDEP.

With regards to the time of initiation, patients and carers (N=31) had the highest preference for pre-dialysis education to be given six months before initiation of dialysis (39%). However, half of HCWs (N=8) voted for pre-dialysis education to be given one month before initiation of dialysis (50%).

For the duration of each session, patients and carers (N=31) preferred a shorter session of 15-30 minutes per session (52%) followed by 30-45 minutes (32%), 45-60 minutes (10%) and >60 minutes (6%). Majority of HCWs (N=8) voted for a longer session of 30-45 minutes for each session (63%).

In terms of frequency, patients and carers (N=31) had the highest preference for pre-dialysis education to be held once every three months (36%), followed by once every two months (29%), once every month (26%) and once a year (7%); one respondent preferred for on an as-needed basis. Similarly, HCWs showed the highest preference for once every three months (50%), followed by once every six months (37%) and once every month (13%).

Majority of patients and carers (N=31) voted for hospitals (65%) as the preferred venue for PDEP, followed by dialysis centres (39%). However, 75% of HCW voted for community clinics. Some of the HCWs commented that PDEP should be expanded to primary care or community level; however, issues on commitment, sustainability and continuity of the programme need to be considered.

Almost all patients and carers (N=31) agreed that being part of a patient support group would be helpful to discuss solving problems faced in real life (96.8%) and that doctor-patient shared decision-making on initiation of dialysis is important (96.8%).

Some of the respondents provided suggestions to improve PDEP (Appendix 7) which were grouped into four themes: individualised, support system, training and comprehensiveness (Table 7).

Based on the information provided by the participating HCWs, the three selected public hospitals had provided pre-dialysis education to their patients with some differences in programme content, structure and component (Table 8). All three programmes involved a multidisciplinary team of HCWs such as doctors, nurses, pharmacists and dietitians.

**Table 7: Summary of suggestions to improve PDEP**

No.	Themes			
	Individualised	Support system	Training	Comprehensiveness
1.	Programme must be well-organised as scheduled and should accommodate the patient's personal schedule.	Family members/ partners/ friends should be included throughout the patient's CKD journey.	Educators must be well-qualified, knowledgeable, and experienced to be able to advise and answer patients' questions correctly.	Contents of the module should be comprehensive and hands-on demonstration should be included.
2.	Educators must provide more human touch and be sensitive towards patients' needs and emotions as they may be very fragile during the pre-dialysis stage.	Consistent attendance from the same family member/ partner/ friend should be encouraged.	Educators must be well-trained in providing adequate emotional support to patients.	Patients and carers should be educated on CKD and its progression, signs and symptoms of ESRD and preventive measures to delay ESRD.
3.	Weekend sessions are preferred to minimise interference with daily work.	Carers should be well-educated about CKD, end-stage renal disease (ESRD) and dialysis to provide sufficient support and help patients make informed decisions.	HCWs should know how to communicate effectively with patients to ensure accuracy of information before starting each dialysis such as body weight, dry weight and dietary intake.	Counselling by a psychologist can be given by appointment for patients who need it.

**Table 8: Comparison of existing PDEPs in three public hospitals.**

	HKL	HTAR	Hospital Ampang
<b>Time</b>	Monday afternoon (2.30pm – 5.30pm)	Wednesday morning (10.00am)	Monday/ Wednesday
<b>Frequency</b>	Twice a month (Week 1 & 3)	Once a week	Twice a week
<b>Venue</b>	Seminar room HKL	Nephrology Clinic (lobby)	Haemodialysis unit (HDU)/ CAPD unit
<b>Session</b>	Approximately 30 minutes for each speaker	<ul style="list-style-type: none"> <li>One hour (10.00am – 11.00am)</li> <li>Counselling by doctor during clinic visit</li> </ul>	<ul style="list-style-type: none"> <li>Morning session by referral from clinic</li> <li>Counselling by doctor during clinic visit</li> </ul>
<b>Speaker</b>	<ul style="list-style-type: none"> <li>Doctor, medical social officer, dietitian, CAPD &amp; HDU representatives</li> <li>No pharmacist/ psychologist involvement during education session</li> </ul>	<ul style="list-style-type: none"> <li>Doctor/ medical assistant/ sister/ staff nurse on rotation basis</li> <li>MTAC pharmacist reviews patient in clinic separately</li> </ul>	<ul style="list-style-type: none"> <li>Doctor/ medical assistant</li> <li>Referral-based dietitian services</li> <li>Pharmacist stationed at nephrology clinic</li> </ul>
<b>Participant</b>	<ul style="list-style-type: none"> <li>Patient and family/ relatives (compulsory attendance)</li> <li>Between 10-30 participants/ session</li> </ul>	<ul style="list-style-type: none"> <li>Large group of patients attending pre-dialysis clinic</li> </ul>	<ul style="list-style-type: none"> <li>1-5 patients/ session</li> </ul>
<b>Content</b>	<ul style="list-style-type: none"> <li>Physiology of the disease</li> <li>How to take care of CKD patient (e.g. blood pressure measurement for patient with fistula/ self-hygiene)</li> <li>More detailed explanation will be given by CAPD/ HDU once the patient decides on the type of treatment</li> <li>Dietary requirement</li> <li>Financial aid (SOCISO/ <i>Lembaga Zakat</i>)</li> </ul>	<ul style="list-style-type: none"> <li>Dietary requirement by medical assistant/ sister/ staff nurse</li> <li>Disease and treatment by doctor (approximately 45 minutes)</li> <li>More detailed explanation will be given by CAPD/HDU once the patient decides on the type of treatment</li> <li>First CAPD training 4 times a day, subsequent training via home visit</li> </ul>	<ul style="list-style-type: none"> <li>Disease and treatment by doctor (approximately 45 minutes)</li> <li>More detailed explanation will be given by CAPD/HDU once the patient decides on the type of treatment</li> <li>Dietary requirement by medical assistant/</li> <li>First CAPD training 4 times a day</li> <li>Financial aid information/ documentation by HDU staff; application process is facilitated by medical social officers</li> </ul>
<b>Education materials</b>	<ul style="list-style-type: none"> <li>Video/ slide presentation/ leaflet: dietary restriction, (occasionally general leaflet on CKD)</li> <li>No hands-on demonstration; details will be covered by respective units</li> <li>Existing patient support group program by CAPD/ HDU</li> </ul>	<ul style="list-style-type: none"> <li>Slide presentation</li> <li>Educational Talk</li> </ul>	<ul style="list-style-type: none"> <li>Booklet</li> <li>Video show</li> <li>Educational talk</li> <li>Education corner (dietary intake)</li> <li>Practical session in HDU/ CAPD Unit</li> </ul>

### 3.4 DISCUSSION

The PPI initiative has revealed essential preferences of patients, carers and HCWs for pre-dialysis education which are valuable information for the development of a national, structured and patient-centred PDEP in Malaysia. Engagement of patients and stakeholders not only increases its relevance to users by answering questions of importance to patients and carers, but also empowers them to play a more active role; supports democracy and accountability; improves acceptability of research findings; and accelerates adoption into practice.<sup>41</sup> A number of suggestions for improvement has also emerged, highlighting the importance of an individualised approach, strong support system, adequate staff training, and comprehensiveness of the programme. Our findings resonate with results from previous qualitative study where a much more individualised approach is required, taking into account the wide variation of patients' motivation and interest in making treatment choices, which would demand a higher level of skill and training for staff involved in PDEP.<sup>38</sup>

Emotional distress in CKD may impede patients' and carers' understanding of information. In addition to effective communication skills, HCWs need to be well-informed about all treatment options as well as complexities and difficulties patients and carers face when considering treatment options so that they are able to provide adequate assistance and emotional support. Combes et al. (2017) observed that staff and patients may not conceptualise pre-dialysis education in the same way; patients appeared to place additional value on more informal education, arising from conversations with staff and other patients whilst staff tended to focus on formal pre-dialysis education sessions and discussions during outpatient appointments.<sup>38</sup> Hence, HCWs need to be aware of how informal staff-patient conversations can influence patients' treatment decision-making and be sufficiently trained in providing informal education in an unbiased way.

It is noteworthy that in this survey, patients and carers expressed different preferences in terms of delivery method, time of initiation, duration, frequency and venue compared with HCWs' preferences. Such differences may arise from varying past experiences of patients and carers. Individual sessions may provide more comfort to those who are emotionally overwhelmed and assistance to those with low health literacy who find it difficult to process and apply health information to their own lives. Some may prefer group sessions which encourage interaction among participants, improving education efficiency, knowledge perception and self-management behaviours.<sup>42</sup> Therefore, method of delivery in terms of individual or group sessions should consider patients' needs and suitability prior to enrolment in PDEP.

Different preferences may also arise from HCWs' consideration of practical aspects in implementing the programme. For example, in this survey, HCWs voted for pre-dialysis education to be given one month before initiation of dialysis in contrast to patients' and carers' preference of six months before initiation of dialysis. This coincides with findings by Morton et al. (2010) where patients and families conveyed the need for more time to absorb information and to adjust to the approaching treatment regardless of the treatment options they were contemplating; however, nephrologists tend to provide information in increasing detail closer to the initiation of renal replacement therapy which would reduce the time available for patients to make decisions, possibly coinciding with patients being symptomatic or cognitively impaired.<sup>39</sup> Therefore, the timing of pre-dialysis education should allow sufficient time for patients and carers to understand about treatment options before making treatment decisions. Nevertheless, HCWs may have different perspectives due to the daily burden of workload and capacity in delivering the education sessions, which should be taken into consideration when designing the PDEP.

Another important aspect to be considered is that different healthcare facilities may have varying capacities and needs influencing the delivery of PDEP, which was evident from the comparison of existing PDEPs at the three selected public hospitals in this survey. The lack of standardization of education programmes is acknowledged by professionals in the field of pre-dialysis education.<sup>40</sup> The delivery of current PDEP in Malaysia is highly dependent on the availability of human resources, staff competencies, appropriateness of facilities, number of patients and content of the programme. Different structure, components and methods of delivery in these facilities suggests the need for standardisation in the design and implementation of PDEP among the MOH hospitals to ensure effective and standardised educational methods.

The strength of this survey was the experiential knowledge obtained from different categories of respondents (patients, carers and HCWs) which provided unique perspectives to promote more useful evidence that is relevant and responsive to patients' and stakeholders' needs. There was variation in the duration of dialysis, ranging from less than six months to more than 18 months which gave a broad perception of PDEP based on the patients' experience with dialysis. The limitation of this survey is that some respondents required researchers' help in administering the questionnaire where translation of English language to other languages such as Malay and Mandarin was required, during which translated items may not retain the same meaning as original items. The survey is also limited by a small number of respondents due to a short study period which may not fully represent each category (patients, carers and HCWs). The inclusion of all three study sites in Klang Valley implied limited respondent demography and results may not be generalizable to suburban or rural populations due to limited respondent demography. Nevertheless, this survey provided valuable insights of CKD patients' and carers' experiences and preferences which helped stakeholders identify the key areas for the development of a national structured patient-centred PDEP.

Based on the survey findings, the preferences of patients and carers for the PDEP could be concluded as below:

- 1) **Educators:** A multidisciplinary team consisting of:
  - a) Doctor
  - b) Dietitian
  - c) Patient representative
  - d) Medical Social officer
  - e) Psychologist
  - f) Pharmacist
  - g) Nurse
  - h) Medical assistant
- 2) **Delivery style:** According to the patient's preference; single individual (one-to-one) session or group session with multiple educators every three months
- 3) **Education materials:** A mix of materials such as:
  - a) Hands-on session/demonstration
  - b) Audio-visual aids
  - c) Leaflet/pamphlet
  - d) Information about website/online video
- 4) **Time of initiation:** Sufficient time to understand about treatment options; approximately six months before initiation of treatment
- 5) **Duration:** Approximately 30 minutes for each session
- 6) **Preferred venue:** Hospital

### 3.5 REFLECTION / CRITICAL PERSPECTIVES

The comparison of existing PDEPs in three public hospitals showed different interdisciplinary approaches in which the extent of involving healthcare professionals from different disciplines differed among the hospitals. Based on the survey findings, respondents preferred pre-



dialysis education to be delivered by a multidisciplinary team consisting of doctor, dietitian, patient representative, medical social officer, psychologist, pharmacist, nurse and medical assistant. Respondents expressed that they had different needs throughout their CKD journey which ought to be addressed by healthcare professionals from different disciplines. A retrospective cohort study reported that recipients of a multidisciplinary PDEP, including nephrologists, dialysis nurses, pharmacists, dietitians, and medical social officers experienced reduced unplanned urgent dialysis, hospital stays, cardiovascular events, and infections as well as improved metabolic status on dialysis initiation compared with non-recipients.<sup>43</sup> Interdisciplinary care models that emphasise shared responsibility for CKD education among multiple professionals should be promoted as it may improve patient outcomes and create efficiencies in education delivery.<sup>42</sup>

In this survey, respondents had emphasised on the inclusion of family members or other carers during pre-dialysis education sessions as they too need to be well informed in order to provide the support and advice that patients need. In addition, carers reported feeling unprepared, having insufficient knowledge and receiving inadequate support from healthcare professionals. For patients with CKD, family members and other carers not only provide important support to them, but also have the potential to help overcome socio-cultural barriers and institutional/medical mistrust which is prevalent among hard-to-reach groups who carry the highest burden of CKD. Support from family and other social groups has also been shown to be a key factor in changing diet patterns (e.g. sodium reduction) and increasing physical activity. Therefore, including family and other carers in pre-dialysis education may better equip them to support the patients who they care for and ultimately yield improved patient outcomes.<sup>42</sup>

Majority of respondents agreed that being a part of a patient support group would be helpful for CKD patients. Some respondents expressed that they were more comfortable to hear from those with experiential knowledge and were more open to discuss their concerns with them. Indirect involvement of motivated dialysis patients in the PDEP can offer support to other patients through experience-sharing. In a research by Salter et al. (2015), participants acknowledged that other fellow dialysis patients provided emotional support beyond what they were receiving from their friends and family. Many participants described how dialysis patients encouraged one another to keep a positive attitude and formed close bonds, which they considered as social support from their “dialysis family”.<sup>44</sup> Having the opportunity to talk to those already on renal replacement therapy could help patients envisage what life on dialysis is really like.<sup>38</sup> Hence, sharing sessions by experienced dialysis patients, either by volunteering or through incentive methods, may be incorporated in the PDEP for a more comprehensive programme. However, this may need to be implemented with care as patients’ stories may have more influence than clinical advice on other patients’ treatment choice.<sup>38,39</sup>

The respondents also agreed that shared decision-making between doctors and patients is important. Shared decision-making, a collaborative process that allows patients and their providers to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient’s values and preferences, is recognized as a central component of patient-centred care and self-management support.<sup>35</sup> Decision-making in ESRD is complex and dynamic, evolving over time and toward death. Patients, families and healthcare professionals should make joint decisions about starting or stopping dialysis treatment to ensure that decisions are informed and consistent with the patient’s preferences. However, factors that affect patients and healthcare professionals in making such decisions must be understood. A systematic review found that for the initiation of dialysis, patients based their choice on “gut instinct”, as well as weighing over the effect of treatment on quality of life and survival. Healthcare professionals, on the other hand, focused on biomedical factors and were led by an instinct to prolong life. Both patients and healthcare professionals described feeling powerless from different aspects of disease management.<sup>45</sup> Hence, patients’ input in decision-making is valuable for the healthcare professionals to design an acceptable and

feasible PDEP. By taking into account the differences in values perceived, the feeling of powerlessness for both the patients and healthcare providers can be addressed mutually.

How patients coped with emotions was also an important aspect to be considered. In handling ESRD, two coping mechanisms were highlighted by the patients, which are problem controlling and emotion controlling. The effect of emotions on choice is well described, and it is suggested that an emotional reaction to a stimulus is the most important factor to guide decisions.<sup>45</sup> During the survey, some respondents expressed that they were having problems in accepting the fact that they need dialysis and this may not be well-addressed in the current PDEP. As a result, patients faced difficulties in making decisions for dialysis options and hence, kept on delaying in initiating treatments. In the qualitative study by Combes et al. (2017), patients described in detail, the traumatic and frightening nature of the transition to end-stage renal failure; however very few staff appeared to appreciate the potential adverse impact of psychological distress on patients' ability to make treatment decisions.<sup>38</sup> Therefore, the presence of a counsellor or psychologist in the PDEP team to offer counselling sessions regularly or by request would be crucial to specifically address the patient's emotional needs.

Questionnaire survey was the preferred method used to gather information from patients and stakeholders in this PPI initiative given the short timeframe. Moving forward, other complementary methods such as focus group discussion may be conducted to consolidate the survey findings. Qualitative data from focus group discussion may provide new insights on factors influencing patients' decision-making on treatment choice. In a focus group study by Salter et al. (2015) among patients with ESRD undergoing haemodialysis, participants disclosed their perceptions of being treated poorly by medical professionals, lacking information about renal disease and treatment options, as well as desiring more knowledge about treatment options.<sup>37</sup> Focus group discussion may also reveal potential explanations on findings from other quantitative studies, for example, the reasons behind why certain groups of patients were less interested in suggested interventions by the treating doctors. Recommendations for best practice in focus group discussion include clear rationale for the choice of this method, skills and techniques of the moderator or facilitator, methods and results should be reported explicitly, cautious towards biases affecting group discussion, and ensure a clear pathway between the data obtained, coding and subsequent analysis of data.<sup>46</sup>

During the survey, some patients and HCWs appeared to be facing language barrier in receiving and providing pre-dialysis education, respectively, which was expected as Malaysia is a multicultural and multilingual country. Education materials and sessions may need to be provided in Malay the national language as well as English the second language, both widely spoken in Malaysia. For non-Malay and non-English speaking patients, language barrier may impede their ability to understand with sufficient depth about CKD and treatment options, resulting in their needs being inadequately addressed. In a qualitative study exploring the experience of healthcare decision-making among culturally and linguistically diverse adults receiving in-centre haemodialysis for advanced CKD, patients expressed that while different cultural backgrounds did not influence their communication with healthcare providers, it was much easier understanding their providers and expressing their concerns and questions in language-concordant consultations.<sup>47</sup> In the circumstances of language discordance between patient and provider, family member/partner/friend of diverse linguistic background or interpreter may be required to accompany the patient for pre-dialysis education session. The linguistically diverse population in Malaysia further emphasises the importance of an individualised approach in providing pre-dialysis education.

## CHAPTER 4: CONCLUSIONS AND RECOMMENDATIONS

### 4.1 CONCLUSION

#### 4.1.1 SYSTEMATIC REVIEW

##### **Effectiveness**

There was limited fair level of retrievable evidence to suggest that participation of advanced CKD patients in PDEP contributed to greater survival probability and higher one-year survival rate compared to those who did not. However, no significant difference reported after two years. Limited fair to good level of retrievable evidence to suggest lower mortality and morbidity rates in patients who had PDEP. Limited evidence demonstrated that patients who had PDEP had longer time to dialysis and better blood profiles compared to those who did not. Significantly lower peritonitis-related mortality rates and lower peritonitis-related morbidity rates were also noted in PD patients.

##### **Safety**

There was no retrievable evidence on the safety issues with regards to PDEP for advanced CKD patients.

##### **Organisational**

##### **Hospitalisation / Length of stay**

There was fair to good level of retrievable evidence to suggest that PDEP was associated with significantly lower frequency of temporary catheter use, lower rates of hospitalisation at dialysis initiation and post- dialysis, as well as shorter length of hospital stay.

##### **Components of programme**

The evidence showed great variation in the components of the programmes described, from the multidisciplinary team members, to the educational process including timing, delivery styles, formats for content, structure, conduct of the programme and materials. However, most evidence reported involvement of multidisciplinary team members almost always comprised of nephrologists, nurses, dietitians and medical social officers, with few had pharmacist, clinical psychologist and patient volunteers. Most studies mentioned multiple individual sessions with few had mixed of individual sessions and group sessions as well as patients' involvement. Majority involved patients with CKD stage 4 and 5 in the programme, with content tailored according to the patients' CKD stage and principally focused on knowledge on nutrition, lifestyle modification, nephrotoxin avoidance, compliance to medications, preparation for RRT and modality choices with few reported hands-on and demonstration. Materials used ranged from video materials, printed materials, and website materials. Frequency of the sessions and follow-up were mostly depended on the CKD stage.

##### **Guidelines**

Few guidelines from UK, USA, France, Europe and a position statement following an expert meeting in Switzerland have been issued outlining the recommendations on the conduct of PDEP.

##### **Social/Psychological**

There was fair to good level of retrievable evidence to suggest significant association between PDEP and patient's choice as well as receipt of PD and home dialysis for RRT. Limited evidence also showed higher rates of pre-emptive kidney transplantation rates, higher levels of knowledge of end-stage renal disease and RRT options as well as higher levels of adherence, lower depression levels and anxiety levels, and better HRQL were noted in patients who had PDEP.

Limited evidence also showed that patient factors including individualisation, educational factors including tailored education, appropriate time/information, and available resources as well as support systems were the influential factors on patients' decision for RRT. Sub-optimal education, different perspectives between patients and staff, and the influence of patient experience were the three themes identified which related to improving PDEP.

### **Cost-effectiveness**

Based on two cost-analyses, significant reduction in medical expenditure after initiation of HD were noted in patients who had PDEP and the cost-saving effect came through the early preparation of vascular access and reduced hospitalisations.

## **4.1.2 PATIENT AND PUBLIC INVOLVEMENT IN PRE-DIALYSIS EDUCATION PROGRAMME**

Based on the survey findings, patients and carers preferred to have a 30-minute single session with multiple educators every three months delivered by a multidisciplinary team consisting of doctor, dietitian, patient representative, medical social officer, psychologist, pharmacist, nurse and medical assistant with a mix of education materials such as hands-on session or demonstration, audio-visual aids, leaflets or pamphlets and information about websites or online videos in the hospital setting. The pre-dialysis education may be given as an individual (one-to-one) or group session depending on the patient's preference. The pre-dialysis education should be initiated approximately six months before starting treatment of choice, allowing patients and carers to have sufficient time to understand about available treatment options. Patients and carers agreed that being part of a patient support group would be helpful in solving real-life problems and that shared decision-making between doctors and patients is important to them. The healthcare workers expressed different preferences in terms of delivery method, time of initiation, duration, frequency, and venue which may arise from consideration of practical aspects such as daily burden of workload and capacity in delivering the education sessions, which should be taken into consideration when designing the PDEP.

## **4.2 RECOMMENDATIONS**

Based on the above review, a standardised approach to PDEP should be outlined before its expansion to all Ministry of Health, Malaysia facilities. A multidisciplinary team involving well-trained personnel, and optimally with mixed individual and group sessions as well as using interactive mixed education materials should be established. Comprehensive and more personalised content tailored according to the CKD stage taking account individual needs, emotional support, psychosocial aspects, involvement of family as well as caregivers and additional support from patients' support group are advocated.

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## 6.0 APPENDICES

### Appendix 1

#### HIERARCHY OF EVIDENCE FOR EFFECTIVENESS STUDIES

##### DESIGNATION OF LEVELS OF EVIDENCE

- I Evidence obtained from at least one properly designed randomized controlled trial.
- II-1 Evidence obtained from well-designed controlled trials without randomization.
- II-2 Evidence obtained from well-designed cohort or case-control analytic studies, preferably from more than one centre or research group.
- II-3 Evidence obtained from multiple time series with or without the intervention. Dramatic results in uncontrolled experiments (such as the results of the introduction of penicillin treatment in the 1940s) could also be regarded as this type of evidence.
- III Opinions or respected authorities, based on clinical experience; descriptive studies and case reports; or reports of expert committees.

**SOURCE:** *US/CANADIAN PREVENTIVE SERVICES TASK FORCE (Harris 2001)*



## HEALTH TECHNOLOGY ASSESSMENT (HTA) PROTOCOL PRE-DIALYSIS EDUCATION PROGRAMME

### 1.0 BACKGROUND INFORMATION

Chronic Kidney Disease (CKD) is a growing public health concern which is responsible for various complications including all-cause and cardiovascular mortality, kidney-disease progression to end-stage kidney disease, cognitive decline, anaemia, mineral and bone disorders.<sup>1</sup> The Global Burden of Disease (GBD) 2015 study estimated that, in 2015, about 1.2 million people died from kidney failure, an increase of 32% since 2005.<sup>2</sup> In 2010, it is estimated that around 2.3 to 7.1 million people with end-stage kidney disease died without access to chronic dialysis.<sup>2</sup> However, despite of these growing figures, the awareness remains low among patients and health-care providers.<sup>1</sup> In Malaysia, the prevalence of CKD has increased from 9.1% in the 2011 Malaysian National Health and Morbidity Survey<sup>3</sup> to 15.5% in 2018<sup>5</sup>. Awareness of CKD was hardly improved in seven years from 4% of respondents in 2011<sup>5</sup> to 5% in 2018.<sup>6</sup> In the year of 2011, there were 27,572 patients on renal replacement therapy (RRT) in Malaysia<sup>5</sup> and the figures have grown to a total of 37,183 patients on regular dialysis in 2015, with 7,595 new patients entering dialysis.<sup>3</sup> The number of patients with CKD is expected to significantly rise in the future largely due to the increasing prevalence of diabetes, hypertension as well as the aging population in Malaysia.<sup>3</sup> This will certainly contribute to the major increase in the future needs for RRT and impose a large burden on health care budget.

According to Malaysian Clinical Practice Guideline for Management of Chronic Kidney Disease (Second Edition) published in 2018, CKD is defined as an estimated glomerular filtration rate (eGFR) of  $<60$  ml/min/1.73 m<sup>2</sup> that is present for more than three months with or without evidence of kidney damage, or evidence of kidney damage that is present for more than three months with or without eGFR  $<60$  ml/min/1.73 m<sup>2</sup>.<sup>3</sup> Markers for kidney damage includes albuminuria (albumin excretion rate  $\geq 30$  mg/24 hours or albumin-creatinine ratio  $\geq 3$  mg/mmol), urine sediment abnormalities, abnormalities detected by histology, structural abnormalities detected by imaging and history of kidney transplantation.<sup>3</sup> Classification of CKD is currently based on cause, GFR category, and albuminuria category (CGA) and follows Kidney Disease Improving Global Outcomes (KDIGO) 2012 guidelines which has health and prognostic implications.<sup>3,7</sup> The GFR categories mapping to the previous five-stage classification have been retained but with subdivision of the G3 category of 30 to 59 mL/min per 1.73 m<sup>2</sup> into categories G3a (45 to 59 mL/min per 1.73 m<sup>2</sup>) and G3b (30 to 44 mL/min per 1.73 m<sup>2</sup>).<sup>8</sup> This was driven by data supporting different outcomes and risk profiles in these categories.<sup>8</sup> Severity is expressed by level of GFR and albuminuria and is linked to risks for adverse outcomes, including death and kidney outcomes.<sup>8</sup>

**Table 1. Prognosis of CKD by GFR and albuminuria category<sup>3,7</sup>**

				Persistent albuminuria categories		
				Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30 - 300 mg/g 3 - 30 mg/mmol	>300 mg/g >30 mg/mmol
				GFR categories (ml/min/1.73 m <sup>2</sup> ) Description and range	G1	Normal or high
G2	Mildly decreased	60 - 89				
G3a	Mildly to moderately decreased	45 - 59				
G3b	Moderately to severely decreased	30 - 44				
G4	severely decreased	15 - 29				
G5	Renal failure	<15				

Green - low risk, Yellow - moderate risk, Orange - high risk, Red and Deep Red - very high risk

It is known that timely referral to nephrologist is recommended for RRT in people with progressive CKD in whom the risk of kidney failure within one year is 10–20% or higher, as determined by validated risk prediction tools.<sup>7</sup> In the Malaysian Clinical Practice Guideline for Management of Chronic Kidney Disease (Second Edition) 2018, it is stated in the recommendation that CKD patient with rapidly declining renal function [loss of eGFR >5 ml/min/1.73 m<sup>2</sup> in one year or >10 ml/min/1.73 m<sup>2</sup> within five years] or eGFR <30 ml/min/1.73 m<sup>2</sup> (eGFR categories G4 to G5) should be referred to a nephrologist/physician<sup>3</sup>. UK Renal Association recommends that all patients with severe CKD (stage 5 and progressive stage 4), alongside their families and carers, should be offered pre-dialysis education programme.<sup>9</sup> This programme aims at improving knowledge and understanding of the condition, as well as assisting them in making decisions for RRT.<sup>9</sup> However, in most studies, it is reported that about 40% to 60% of patients with CKD start dialysis in an unplanned fashion and/or under urgent circumstances despite regular follow-up by a nephrologist.<sup>10</sup> This is of concern since in unplanned dialysis, patients forego the opportunity to make an informed, shared decision regarding the timing and modality of RRT as options for RRT under urgent conditions are often limited.<sup>10</sup> Studies reported that advanced age, increased comorbidity burden, late referral to nephrology, and lower GFR at dialysis initiation were the most common independent risk factors for unplanned dialysis.<sup>10,11</sup> In addition, patients who had unplanned dialysis were found much less likely to have received formal pre-dialysis education about the different options for RRT.<sup>10,11</sup> This highlights the importance of a structured and comprehensive pre-dialysis education programme in preparing advanced-stage CKD patients for RRT as unplanned dialysis is known to be associated with increased patient morbidity, mortality, hospitalisations, needs for catheter insertion for haemodialysis which subsequently increase the risk of catheter related sepsis as well as central vein stenosis, and further, inevitably contribute to the economic burden of CKD.

Pre-dialysis education programme often described as multidisciplinary education programme, which consists of multiple education sessions where patients are educated by three or more health care professionals such as nephrologist, nurse, dietitian, medical social officer, home-dialysis coordinator, pharmacist, technician, or by other dialysis patients.<sup>11</sup> There are variations in practice, however, pre-dialysis education programme usually includes individualised one-to-one sessions with a member or members of the multidisciplinary team and group discussions, peer counselling as well as problem-solving sessions have been described wherein patients discuss treatment modalities, as well as barriers, benefits, and troubleshooting of possible problems with other patients.<sup>11</sup> Variety of formats have been described in the delivery style of the programme such as group lectures, interactive workshops, open forum sessions as well as written and audio-visual materials to take home.<sup>11,12</sup> In its Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease, KDIGO

recommended that patients with progressive CKD should be managed in a multidisciplinary care setting.<sup>8</sup> The multidisciplinary team should include or have access to dietary counselling, education and counselling about different RRT modalities, transplant options, vascular access surgery, and ethical, psychological, and social care.<sup>8</sup> The aims for this programme are mainly to provide patients with information on end-stage kidney disease treatment options, helps decision-making between treatments, and encourages self-care to improve quality of life.<sup>12</sup> A systematic approach with a pre-dialysis education programme is thought to assist patients in preparation for RRT and prevent the complications of unplanned dialysis subsequently reduce the complications of end-stage renal disease.

At present, there is no standard national programme established in Ministry of Health for pre-dialysis education. Pre-dialysis education for advanced CKD patients is often done in different ways across the country. Several centres in Peninsular Malaysia have specific programme for pre-dialysis education while numerous other centres lack such a programme. Certain hospitals conduct half-day talk monthly which involves sharing experiences by peritoneal dialysis, haemodialysis and kidney transplant nurses as well as exploring the funding options by the medical social officer and inputs by dietitian for CKD patients and family members. Effectiveness of such method in delivering pre-dialysis education for advanced CKD patients is largely unknown. Therefore, this health technology assessment was requested by Head of Nephrology Services, Ministry of Health, Malaysia to review the available evidence and feasibility of structured pre-dialysis education programme for advanced CKD patients before its adoption into national programme in Malaysia.

## 2.0 POLICY QUESTION

Should a structured pre-dialysis education programme be expanded in all Ministry of Health facilities?

## 3.0 OBJECTIVES

- 3.1 To assess the effectiveness and safety of pre-dialysis education programme for advanced CKD patients
- 3.2 To assess the organisational, ethical, legal and societal implications related to pre-dialysis education programme for advanced CKD patients
- 3.3 To assess the cost-effectiveness of pre-dialysis education programme for advanced CKD patients
- 3.4 To assess the most suitable pre-dialysis education programme for Malaysian context

### Research Questions

- i) Is pre-dialysis education programme effective and safe for advanced CKD patients?
- ii) What are the organisational, ethical, legal and societal implications of pre-dialysis education programme for advanced CKD patients?
- iii) Is pre-dialysis education programme cost-effective for advanced CKD patients?

## 4.0 METHODS

- 4.1. Search Strategy
  - 4.1.1 Electronic databases will be searched for published literatures pertaining to pre-dialysis education programme for advanced CKD patients. The databases are MEDLINE, PubMed, and EBM Reviews-Cochrane Database of Systematic Review, EBM-Reviews-Cochrane Central Register of Controlled Trials, EBM Reviews-Health Technology Assessment, EBM Reviews-Cochrane Methodology Register, EBM Reviews-NHS Economic Evaluation Database, Database of Abstracts of Reviews of Effects (DARE), Horizon Scanning, INAHTA database, and HTA database.
  - 4.1.2 Additional literatures will be identified from the references of the related articles.
  - 4.1.3 General search engine will also be used to get additional web-based information.
  - 4.1.4 There will be no limitation applied in the search such as year and language.
  - 4.1.5 The search strategy will be included in the appendix.

## 4.2 Inclusion and Exclusion Criteria

### 4.2.1 Inclusion Criteria

- a. Population :Adults patients with advanced CKD stage 4,5
- b. Intervention:Pre-dialysis education programme;
  - i. Multidisciplinary team comprised of nephrologists/ dieticians/ social workers/ pharmacists/ nurses/ psychologists/ HD or PD patient volunteers etc.
  - ii. Multiple sessions
  - iii. Relatively detailed description of the programme, such as sessions frequency, content of sessions, and descriptions of educators
- c. Comparators :
  - i. No pre-dialysis education programme
  - ii. No comparator
- d. Outcome :
  - i. Effectiveness
    - Mortality
    - Morbidity
    - Quality of life
  - ii. Safety
    - adverse events
    - complications
  - iii. Organisational issues
    - Unplanned dialysis
    - Hospital admission
    - Length of hospital stay
    - Components of pre-dialysis education programme (content, structure, delivery style, timing)
    - Training
    - Guidelines
  - iv. Ethical, legal implications
  - v. Psychological/Societal implications
    - Compliance
    - Acceptance
    - Patient satisfaction
    - Patient preference/ dialysis modality choice
    - Mental health issues
  - vi. Cost-effectiveness, economic evaluation, cost-analysis
- e. Study design :Health technology assessment (HTA) reports, systematic reviews (SRs), randomised controlled trials (RCTs), non-randomised controlled trials (NRCTs), cohort study, case-control study, pre- and post- intervention, cross-sectional study and economic evaluation studies.
- f. English full text articles

### 4.2.2 Exclusion Criteria

- a. Study design : Animal study, laboratory study, narrative review, case-series, case study, early stage CKD patients
- b. Non English full text articles

Based on the above inclusion and exclusion criteria, study selection will be carried out independently by two reviewers. Disagreement will be resolved by discussion.

### 4.3 Critical Appraisal of Literature

The risk of bias (methodology quality) of all retrieved literatures will be assessed using the relevant checklist of Cochrane Collaboration Assessment tools, Critical Appraisal Skill Programme (CASP) by two reviewers depending on the type of the study design.

### 4.4 Analysis and Synthesis of Evidence

#### 4.4.1 Data extraction strategy

The following data will be extracted:

- i. Details of methods and study population characteristics
- ii. Detail of intervention and comparators
- iii. Details on outcomes for effectiveness, safety and cost associated with pre-dialysis education programme for advanced CKD
- iv. Details on organisational, ethical, legal and societal issues related to the practice

Data will be extracted from selected studies by a reviewer using a pre-designed data extraction form and checked by another reviewer. Disagreements will be resolved by discussion.

#### 4.4.2 Methods of data synthesis

Data on the efficacy/effectiveness, safety and cost-effectiveness of pre-dialysis education programme will be presented in tabulated format with narrative summaries. Meta-analysis maybe conducted for this Health Technology Assessment.

### 4.5 Local economic evaluation

Published scientific evidence related to economic evaluation on pre-dialysis education programme will be examined first and if appropriate local data is available, local economic evaluation will be conducted for this HTA.

### 4.6 Patient involvement

As the target population for pre-dialysis education programme are advanced CKD patients, patients' acceptance is deemed vital. Thus, patient engagement has been proposed to be included in this HTA. The mechanism of patient engagement will be scrutinised and conducted together in collaboration with nephrologists from Hospital Kuala Lumpur, Hospital Ampang and Hospital Tengku Ampuan Rahimah, Klang.

## 5.0 Report writing

## 6.0 References

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**Search strategy:****Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present**

- 1 Kidney Failure, Chronic/
- 2 (chronic adj2 (kidney failure or renal failure)).tw.
- 3 esrd.tw.
- 4 (end stage adj2 (kidney disease or renal disease)).tw.
- 5 (end-stage adj2 (kidney disease or renal disease or renal failure)).tw.
- 6 Renal Insufficiency, Chronic/
- 7 (chronic adj2 (kidney disease\* or renal disease\*)).tw.
- 8 (chronic adj2 (renal insufficienc\* or kidney insufficienc\*)).tw.
- 9 esrf.tw.
- 10 Advanced ckd.tw
- 11 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
- 12 HEALTH EDUCATION/
- 13 community health education.tw.
- 14 health education.tw.
- 15 Pre-dialysis.tw.
- 16 Predialysis.tw.
- 17 Pre-dialysis education.tw.
- 18 Predialysis education.tw.
- 19 Pre-dialysis education program\*.tw.
- 20 Predialysis education program\*.tw.
- 21 Multidisciplinary pre-dialysis education.tw.
- 22 Multidisciplinary predialysis education.tw.
- 23 12 or 13 or 14 or 17 or 18 or 19 or 20 or 21 or 22
- 24 11 and 23

**PubMed**

Search (((((((((((KidneyFailure, Chronic/[MeSH Terms]) OR ((chronic adj2 (kidney failure[Title/Abstract] OR renal failure))[Title/Abstract])) OR esrd[Title/Abstract]) OR ((end stage adj2 (kidney disease[Title/Abstract] OR renal disease)).[Title/Abstract])) OR ((end-stage adj2 (kidney disease[Title/Abstract] OR renal disease[Title/Abstract] OR renal failure))[Title/Abstract])) OR Renal Insufficiency, Chronic/[MeSH Terms]) OR ((chronic adj2 (kidney disease\*[Title/Abstract] OR renal disease\*)) [Title/Abstract])) OR ((chronic adj2 (renal insufficienc\*[Title/Abstract] OR kidney insufficienc\*)) [Title/Abstract])) OR esrf[Title/Abstract]) OR Advanced ckd[Title/Abstract])) AND (((((((((((HEALTH EDUCATION/[MeSH Terms]) OR community health education[Title/Abstract]) OR health education[Title/Abstract]) OR Pre-dialysis[Title/Abstract]) OR Predialysis[Title/Abstract]) OR Pre-dialysis education[Title/Abstract]) OR Predialysis education[Title/Abstract]) OR Pre-dialysis education program\*[Title/Abstract]) OR Predialysis education program\*[Title/Abstract]) OR Multidisciplinary pre-dialysis education[Title/Abstract]) OR Multidisciplinary predialysis education[Title/Abstract])

## Appendix 4

Evidence Table : Effectiveness  
Question : How effective is Pre-dialysis Education Programme for advanced CKD patients?

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristics	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
1. Hsu CK, Lee CC, Chen YT et al. Multidisciplinary pre-dialysis education (MPE) reduces incidence of peritonitis and subsequent death in peritoneal dialysis patients: 5-year cohort study. PLoS One. 2018;13(8):e0202781. Taiwan	<p>Cohort study</p> <p><b>Objective</b> To investigate impact of MPE on the occurrence of peritonitis, time to first episode of peritonitis and patient outcomes of PD patients who receive this educational program</p> <p><b>Method</b> -All patients starting PD at Department of Nephrology, Chang Gung Memorial Hospital, Keelung, from July 1, 2007 to December 31, 2016 were enrolled and follow-up for 5 years from PD initiation. -Patients were divided into MPE group and non-MPE group according to whether the subjects had ever received MPE before starting renal replacement therapy. -Incidence of peritonitis and peritonitis-related mortality were compared between MPE recipients and non-recipients. -Content of the MPE was standardized in accordance with the NKF/DOQI guidelines. -Kaplan-Meier analysis and Cox proportional hazards model were applied to identify the prognostic factors associated with peritonitis-free survival. -Study endpoints: ❖ Episodes of peritonitis ❖ Outcomes after peritonitis (including hospitalisation, technique failure, switching of modality into hemodialysis or death)</p>	II-2	<p>398 PD patients: 169 MPE 229 No MPE before starting PD.</p> <p>-MPE recipients older (63.1±16.2 vs. 58.5±16.4 years old, P=0.006), had higher prevalence of diabetes (60.4% vs 43.7%, P&lt;0.001) -MPE group had lower baseline educational levels (P&lt;0.001) -No differences in initial laboratory findings, baseline peritoneal (PET) and PD adequacy between two groups -Patients dropped out: MPE group (switch to HD 27, death 20) 20% vs Non-MPE group (switch to HD 16, death 6) 13%.</p>	<p>Multidisciplinary pre-dialysis education (MPE)</p> <p>-Comprised a nurse of case mx, social workers, dietitians, 10 nephrologists, and HD&amp;PD patient volunteers. -Delivery of knowledge on nutrition supp, lifestyle modification, nephrotoxin avoidance, dietary principles and pharmacological regimens by nurse acc. to CKD stage -Monitoring of CKD complications, preparation for timely initiation of RRT, care of vascular or peritoneal access, and registration for inclusion in the renal transplant waiting list were CKP patients.</p>	<p>Customary care (Non-MPE)</p> <p>-Same group of nephrologist who instructed pts reg. renal function, evaluation of laboratory data and the clinical indicators of renal failure as well as treatment strategies. -Writing materials or booklets given to patients if verbal instructions are difficult and without help of case-mx nurse</p>	5 years after PD starts	<p><b>Results:</b> After a 5-years of follow-up (mean follow-up duration: 29.4 months; 30.1 months in MPE group vs. 28.5 months);</p> <p><b>Peritonitis.</b> -MPE patients had <b>significantly less peritonitis</b> [0.29±0.72 vs. 0.64±1.5 episodes/person-year or median (IQR): 0 (0.29) vs. 0.11 (0.69) episodes/person-year, P&lt;0.001] than non-MPE patients.</p> <p><b>Peritonitis-related death rates</b> -MPE group had <b>lower peritonitis-related death rates</b> compared to non-MPE group (3.6% versus 8.7%, P=0.04).</p> <p><b>Time to first episode of peritonitis</b> -Median time to the first episode of peritonitis in the non-MPE and MPE groups was 33.9 months and 46.7 months, respectively (Cox-Mantel log rank test, P = 0.003). -Cox regression analysis revealed that the educational level below elementary [hazard ratio (HR): 1.925; 95% (CI): 1.257, 2.874, P= 0.003] and the use of MPE (HR: 0.594; 95% CI: 0.434, 0.813, P&lt; 0.001) were significant independent predictors for peritonitis-free survival, after adjusting the baseline characteristics of age, gender, diabetes, hypertension and peritoneal modalities</p> <p><b>Authors conclusion</b> In conclusion, an efficient standardized MPE program adhered to the NFK/DOQI</p>	<p>-Single centre study -education by team, multiple individual sessions</p>



**Evidence Table : Effectiveness**  
**Question : How effective is Pre-dialysis Education Programme for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristics	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
2. Zukmin K, Ahmad I, Wynn AK et al. A comparative study to evaluate factors that influence survival in multidisciplinary pre-dialysis educated patients and "Crashlanders". Saudi J Kidney Dis Transpl. 2017;28(4):743-750.	<p><b>Retrospective cohort study</b></p> <p><b>Objective:</b> To compare survival probability, sociodemographic, and clinical characteristics of multidisciplinary pre-dialysis educated (MPE) and non-MPE/crashlander patients</p> <p><b>Methods:</b> - All new ESRD patients who started first hemodialysis (HD) from January 2013 to December 2014 from Raja Isteri Pengiran Anak Saleha Hospital and all dialysis centers in Brunei Darussalam were enrolled -Data extracted from clinical registry and dialysis records. -Data included sociodemographic information, clinical information, comorbidities, survival status, pre-dialysis clinic referral, choice of RRT, and types of vascular access (for HD patients). -Survival probability, sociodemographic, and clinical characteristics of multidisciplinary pre-dialysis educated (MPE) and non-MPE/crashlander patients were compared.</p>	II-2	<p>Total 350 new cases of ESRD</p> <ul style="list-style-type: none"> <li>-Median age 56.0 years.</li> <li>-Slightly more males</li> <li>-Malays (86.6%) non-Malays (13.4%)</li> <li>-Median estimated GFR 4.0 mL/min/1.73 m<sup>2</sup>.</li> <li>-119 patients (34.6%) were deceased at the end of study period.</li> <li>-MPE groups older (P=0.001), diabetics (P=0.013), and HTN (P=0.016), IHD (P=0.014), and using arteriovenous fistula (P &lt;0.001).</li> </ul>	<p>Multidisciplinary pre-dialysis education (MPE) (n=180)</p> <ul style="list-style-type: none"> <li>-Multidisciplinary team includes nephrologists, nurse practitioners, dietitians, and medical social workers</li> <li>-Nurse comprise specific nurses that specialize in vascular access, HD, PD, and transplantation</li> <li>-Geriatricians and palliative care team occasionally involved if patients have pre-emptively decided not to undergo RRT</li> <li>-Clinic focuses on strategies to maintain target BP, improve compliance with medications, nutritional needs, nephrotoxins avoidance, and fast track vascular services for fistula formations and early commencement of RRT</li> <li>-Cultural acceptance and religious counselling also covered in this clinic to overcome social stigmatization and improve psychological acceptance</li> </ul>	No MPE (n=168)	2 years	<p><b>Results:</b> <u>Survival</u></p> <p>Survival status All patients MPE (%) Non MPE (%)</p> <p>Alive/censored 225 (65.4%) 127 (56.7%) 97 (43.3%)</p> <p>Deceased 119 (34.6%) 52 (44.1%) 66 (55.9%)</p> <p>-Despite being older and having more comorbidities, MPE patients have <b>better survival probability</b> (P = 0.028) and a 34% decreased risk of dying</p> <p>1 year (%) 2 years (%)</p> <p>MPE 79.8% 57.7%</p> <p>Non-MPE 66.2% 60.1%</p> <ul style="list-style-type: none"> <li>- The <b>1-year survival rate was higher</b> in MPE group compared to non-MPE (79.8% versus 66.2%).</li> <li>- No significant difference after two years (57.7% and 60.1%)</li> <li>- Older age (P = 0.001), high serum creatinine level (P &lt;0.001), lower estimated GFR (P &lt;0.001), and lower hemoglobin level (P = 0.017) were associated with the reduction in the survival probability.</li> </ul> <p><b>Authors conclusion:</b> Multidisciplinary pre-dialysis education (MPE) before the initiation of RRT contributed to greater survival probability in near ESRD patients. The survival benefits were evident despite the presence of inherent risks (older age and presence of comorbidities) in the MPE population in comparison with the non-MPE cohort.</p>	<p>Multi-centre study</p> <p>Education by team, multiple individual sessions</p>

**Evidence Table : Effectiveness**  
**Question : How effective is Pre-dialysis Education Programme for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
3. Van den Bosch J, Warren DS, Rutherford PA. Review of predialysis education programs: a need for standardization. PatientPreference Adherence. 2015;9:1279-1291.	<p><b>Systematic review</b></p> <p><b>Objective:</b> To review evidence on effective components of pre-dialysis education programmes as related to modality choice and selected clinical outcomes.</p> <p><b>Method:</b> -Systematic search was performed on PubMed MEDLINE, Cochrane Library, and Ovid (from January 1, 1995 to December 31, 2013) -Inclusion criteria applied: ❖ Adults only ❖ Pre-dialysis education for CKD stage III, IV, and V ❖ Planned start patients, unplanned start patients, and patients on dialysis, ie, incident and prevalent patients. ❖ Detailed description of programme ❖ Multiple sessions ❖ Multidisciplinary programme involving physicians, nurses, dietitians, etc.</p> <p>-Outcomes included: ❖ Dialysis modality choice and the numbers of patients choosing each modality ❖ Any clinical outcome associated with pre-dialysis education ❖ Health-related quality of life ❖ Measures associated with patient choice ❖ Financial impact of patients choosing more home therapies ❖ Patient satisfaction</p> <p>-Literature also reviewed for any information on processes, pathways, and organization of the pre-dialysis education programme</p>	I	<p>29 relevant studies: 19 quasi-experimental design 10 narrative reviews</p> <p>-19 studies were analysed for effective components of pre-dialysis education programme</p> <p>-Descriptions of the educational process varied and included individual and group education, multidisciplinary intervention, and varying duration and frequency of sessions.</p>	Pre-dialysis education programmes			<p><b>Results:</b> <b>Mortality and morbidity</b> -8 studies reported on mortality and morbidity (including biochemical indicators, cardiovascular incidents, infection rates, emotional status). -All studies reported <b>better rates</b> for the treatment group.</p> <p>Cho et al. (2012) Less unplanned urgent dialysis (8.7% vs 24.2%), less cardiac events (2.7% vs 9.4%), less infections (4.0% vs 12.1%)</p> <p>Kiang et al. (1998) Significant better mood, less mobility problems, less functional disabilities and lower anxiety</p> <p>Lacson et al. (2011) Significant better survival rate (adj. HR 0.61)</p> <p>Levin et al. (1997) Better biochemical markers: blood pressure, calcium, phosphate, and anemia</p> <p>Rioux et al. (2011) 35% of all acute starters adopted home dialysis vs 13% before program</p> <p>Hall G et al (2004) Less infection rates 18.5 vs. 31.8; p = 0.00349</p> <p>Souqjyyeh M Z et al. (2008) significantly less dropouts for PD (p&lt;0.02)</p> <p><b>Authors conclusion:</b> There is a need for a standardised approach built on best evidence from CKD and also from other clinical conditions and existing knowledge on the evaluation of complex interventions to ensure formal evaluation of predialysis education programmes, and their effects on clinical outcomes and modality choice.</p>	Most without control groups

## Evidence Table : Effectiveness

## Question : How effective is Pre-dialysis Education Programme for advanced CKD patients?

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
4. Wu IW, Wang SY, Hsu KH et al. Multidisciplinary predialysis education decreases the incidence of dialysis and reduces mortality—a controlled cohort study based on the NKF/DOQI guidelines. Nephrol Dial Transplant. 2009;24(11):3426-3433. Taiwan	<p>Cohort study</p> <p><b>Objective:</b> To evaluate the impact of multidisciplinary pre-dialysis education (MPE) on the incidence of dialysis and outcomes of CKD patients in accordance with the guidelines of the National Kidney Foundation Dialysis Outcomes Quality Initiative (NKF/DOQI).</p> <p><b>Methods:</b> -All study participants were pre-dialysis CKD patients who visited the nephrology outpatient clinics of the Department of Nephrology at Chang Gung Memorial Hospital in Taipei and Keelung from May 2006 to May 2007. -Patients were classified into stages III, IV or V in accordance with the NKF/DOQI classification system -Information was collected for further analyses, including demographic variables, causes of primary renal disease, initial status of renal function, obvious uraemic.</p> <p>-All participants were divided into two cohorts according to the sites: ❖ MPE group at the Keelung centre ❖ Non-MPE group at Taipei centre.</p> <p>-Patients were attended by same group of nephrologists under same follow-up schema, and were followed up for 12 months for dialysis initiation or mortality from any cause.</p>	II-2	<p>Study involved 573 CKD patients: ❖ 287 received MPE ❖ 286 Non MPE</p> <p>-317 (55.3%) were males and 256 (44.7%) females; -Average age was 63.4±14.8 years. -Mean eGFR : 23.8 ±20.1 mL/min/1.73 -Stage III 157 (27.4%) -Stage IV 123 (21.5%) -Stage V 293 (51.1%) - MPE recipients older (65.5±13.9 vs 61.2±14.8 years old, P=0.048) with much lower prevalence of hypertension (5.2% vs 22%, P &lt; 0.001).</p>	<p>Multidisciplinary pre-dialysis education (MPE)</p> <p>-Comprised a nurse for case mx, social workers, dietitians, HD and PD patient volunteers and 10 nephrologists -Programme consisted of integrated course involving individual lectures on renal health, delivered by case-mx nurse -Lectures focused on nutrition, lifestyle, nephrotoxin avoidance, dietary principles and pharmacological regimens -Standardized interactive educational sessions were periodically conducted where all patients were interviewed depending on CKD stage -Stage III or IV CKD patients: f/up 3monthly, stage V: f/up monthly</p> <p><b>-Stage III patients:</b> programme consisted of lectures on healthy renal function, clinical presentation of uraemia, risk factors and complications associated with renal progression and an introduction to the various RRTs</p> <p><b>-Stage IV patients:</b> programme included discussions on the mx of complications associated with CKD, indications of RRT and evaluation of vascular or peritoneal access.</p> <p><b>-Stage V patients:</b> monitored for timely initiation of RRT, care of vascular or peritoneal access, dialysis-associated complications and registration for inclusion in the renal transplant waiting list</p>	<p>Customary care</p> <p>-Same group of nephrologist instructed participants regarding renal function, evaluation of lab data and clinical indicators of chronic renal failure as well as strategies for mx &amp; tx -General principles of HD and PD explained when patients enter stage IV -All patients provided with written instructions. -Comorbidity factors evaluated before referral to nurse specializing in HD or PD. -Nursing staff provided instructions for daily living and explained criteria for HD and PD selection and the difference between modalities.</p>	12 Months  -Mean follow-up period was 11.7±0.9 months.	<p><b>Results:</b> -Incidence of dialysis and non-MPE groups, respectively (P &lt; 0.001) -Time to dialysis was significantly longer for MPE group (11.3 months) vs Non-MPE group (9.2 months) (P&lt;0.001) -MPE recipients showed: ❖ a higher serum albumin level (3.8 ± 0.5 versus 3.4 ± 0.5 g/dL, P = 0.050), ❖ lower serum hs-CRP level (3.3±2.8 versus 5.5±5.6 mg/L, P=0.032), ❖ lower serum ferritin concentration (284 ± 31 versus 532 ± 59 ng/mL, P = 0.049), ❖ higher PD uptake (35% versus 20.5%, P = 0.023), ❖ lower frequency of temporary vascular catheter use (25% versus 50.4%; P &lt; 0.05) ❖ and greater post-dialysis body weights (65±10 versus 58±11 kg, P=0.034) than the non-MPE patients.</p> <p><b>Mortality</b> -Overall mortality was 1.7% and 10.1% in the MPE and non-MPE groups, respectively (P &lt; 0.001). -Median survival time in the non-MPE and MPE groups was 11.2 and 11.9 months, respectively (Cox–Mantel log rank test, P&lt;0.001) -Adjusted hazard ratio of mortality for MPE recipients was 0.103 [95% confidential interval (CI) 0.040, 0.265, P &lt; 0.001], after adjustment for age, gender, diabetes, hypertension, eGFR, Hb, serum albumin, hs-CRP</p> <p>-Cox regression analysis revealed that diabetes, estimated glomerular filtration rate (eGFR), high-sensitive C-reactive protein (hs-CRP) and MPE assignment were significant independent predictors for progression to ESRD. -Independent prognostic factors for mortality included age, diabetes, eGFR, hs-CRP and MPE assignment</p> <p><b>Authors conclusion:</b> An efficient standardized MPE programme complying with the NKF/DOQI guidelines may decrease the incidence of dialysis and reduce the all-cause mortality and the overall hospitalisation rate in CKD patients. This valuable information confirms the role of MPE in the care of CKD patients</p>	Multiple individual sessions with team members + patients + volunteers

## Evidence Table : Organisational (HOSPITALISATION)

Question : What are the organisational issues with regards to Pre-dialysis Education Programme for advanced CKD patients?

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
1. Hsu CK, Lee CC, Chen YT et al. Multidisciplinary pre-dialysis education (MPE) reduces incidence of peritonitis and subsequent death in peritoneal dialysis patients: 5-year cohort study. PLoS One. 2018;13(8):e0202781.	<p>Cohort study</p> <p><b>Objective</b> To investigate impact of MPE on the occurrence of peritonitis, time to first episode of peritonitis and patient outcomes of PD patients who receive this educational program</p> <p><b>Method</b> -All patients starting PD at Department of Nephrology, Chang Gung Memorial Hospital, Keelung, from July 1, 2007 to December 31, 2016 were enrolled and prospectively follow-up for 5 years from PD initiation. -Patients were divided into MPE group and non-MPE group according to whether the subjects had ever received MPE before starting renal replacement therapy. -Incidence of peritonitis and peritonitis-related mortality were compared between MPE recipients and non-recipients. -Content of the MPE was standardized in accordance with the NKF/DOQI guidelines. -Kaplan-Meier analysis and Cox proportional hazards model were applied to identify the prognostic factors associated with peritonitis-free survival.</p> <p>-Study endpoints: ❖ Episodes of peritonitis ❖ Outcomes after peritonitis (including hospitalisation, technique failure, switching of modality into hemodialysis or death)</p> <p>-Patients who drop-out from PD (death, renal transplant, switch to hemodialysis) before development of first peritonitis were censored.</p>	II-2	<p>398 PD patients: 169 MPE 229 No MPE before starting PD.</p> <p>-MPE recipients older (63.1±16.2 vs. 58.5±16.4 years old, P=0.006), had higher prevalence of diabetes (60.4% vs 43.7%, P&lt; 0.001) -MPE group had lower baseline educational levels (P&lt; 0.001) -No differences in initial laboratory findings, baseline peritoneal equilibration test (PET) and PD adequacy between two groups -Patients dropped out: MPE group (switch to HD 27, death 20) 20% vs Non-MPE group (switch to HD 16, death 6) 13%.</p>	<p>Multidisciplinary pre-dialysis education (MPE)</p> <p>-Comprised a nurse of case mx, social workers, dietitians, 10 nephrologists, and HD&amp;PD patient volunteers. -Delivery of knowledge on nutrition supp, lifestyle modification, nephrotoxin avoidance, dietary principles and pharmacological regimens by nurse acc. to CKD stage -Monitoring of CKD complications, preparation for timely initiation of RRT, care of vascular or peritoneal access, and registration for inclusion in the renal transplant waiting list were also instructed for late stage CKD patients. -Shared decision making was done for these patients for their choice of RRT. -Benefit, disadvantage and self-care for different modality was explained. -All patients also received dietary counselling biannually from a dietitian. -MPE program discontinued once the patients initiate dialysis therapy</p>	<p>Customary care (Non-MPE)</p> <p>-Same nephrologist who instructed epis reg. renal function, evaluation of laboratory data and the clinical indicators of renal failure as well as treatment strategies. -Writing materials or booklets given to patients if verbal instructions is difficult and without help of case-mx nurse</p>	5 years after PD starts	<p><b>Results:</b> After a 5-years of follow-up (mean follow-up duration: 29.4 months; 30.1 months in MPE group vs. 28.5 months; Hospitalisation and technique failures -No significant difference between two groups in frequency of hospitalization (median (IQR), episodes/person-year : 1.36 (2.43) in MPE group vs 1.15 (2.04) in non-MPE group, P=0.66 and the percentage of technique failures requiring shifting of modality to HD (due to either peritonitis; 9.5% in MPE vs. 11.8% in non-MPE, or poor fluid management; 1.8% in MPE vs. 2.2% in non-MPE)</p>	<p>Single centre study</p> <p>-education by team, multiple individual sessions</p>

## Evidence Table : Organisational (HOSPITALISATION)

Question : What are the organisational issues with regards to Pre-dialysis Education Programme for advanced CKD patients?

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/ Effect Size	General Comments
2. Van den Bosch J, Warren DS, Rutherford PA. Review of predialysis education programs: a need for standardization. Patient Prefer Adherence. 2015;9:1279-1291.	<p><b>Systematic review</b></p> <p><b>Objective:</b> To review evidence on effective components of pre-dialysis education programmes as related to modality choice and selected clinical outcomes.</p> <p><b>Method:</b> -Systematic search was performed on PubMed MEDLINE, Cochrane Library, and Ovid (from January 1, 1995 to December 31, 2013) -Inclusion criteria applied: ❖ Adults only ❖ Pre-dialysis education for CKD patients stage III, IV, and V ❖ Planned start patients, unplanned start patients, and patients on dialysis, ie, incident and prevalent patients. ❖ Detailed description of programme ❖ Multiple sessions ❖ Multidisciplinary programme involving physicians, nurses, dieticians, etc.</p> <p>-Outcomes included: ❖ Dialysis modality choice and the numbers of patients choosing each modality ❖ Any clinical outcome associated with pre-dialysis education ❖ Health-related quality of life ❖ Measures associated with patient choice ❖ Financial impact of patients choosing more home therapies ❖ Patient satisfaction</p> <p>-Literature also reviewed for any information on processes, pathways, and organization of the pre-dialysis education programmes</p>	I	29 relevant studies: 19 quasi-experimental design 10 narrative reviews  -19 studies were analysed for effective components of pre-dialysis education programme  -Descriptions of the educational process varied and included individual and group education, multidisciplinary intervention, and varying duration and frequency of sessions.	Pre-dialysis education programmes			<p><b>Results</b> <b>Hospitalisation</b> Two studies reported on length of hospital stay, which was lower for the education groups (6.5 versus 13.5 total hospital days; 2.2 versus 5.1 hospital days/patient per year).</p>	Mostly without control group

**Evidence Table : Organisational (HOSPITALISATION)  
Question : What are the organisational issues with regards to Pre-dialysis Education Programme for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/ Effect Size	General Comments
3. Wu IW, Wang SY, Hsu KH et al. Multidisciplinary predialysis education decreases the incidence of dialysis and dialysis and reduces mortality--a controlled cohort study based on the NKF/DOQI guidelines. Nephrol Dial Transplant. 2009;24(11):3426-3433.	Cohort study <b>Objective:</b> To evaluate the impact of multidisciplinary pre-dialysis education (MPE) on the incidence of dialysis and outcomes of CKD patients in accordance with the guidelines of the National Kidney Foundation Dialysis Outcomes Quality Initiative (NKF/DOQI). <b>Methods:</b> -All study participants were pre-dialysis CKD patients who visited the nephrology outpatient clinics of the Department of Nephrology at Chang Gung Memorial Hospital in Taipei and Keelung from May 2006 to May 2007. -Patients were classified into stages III, IV or V in accordance with the NKF/DOQI classification system -Information was collected for further analyses, including demographic variables, causes of primary renal disease, initial status of renal function, obvious uraemic -All participants were divided into two cohorts according to the sites: ❖ MPE group at the Keelung centre ❖ Non-MPE group at Taipei centre. -Patients were attended by same group of nephrologists under same follow-up schema, and were followed up for 12 months for dialysis initiation or mortality from any cause.	II-2	Study involved 573 CKD patients: ❖ 287 received MPE ❖ 286 Non MPE  -317 (55.3%) were males and 256 (44.7%) females; -Average age was 63.4±14.8 years. -Mean eGFR : 23.8 ±20.1 mL/min/1.73 -Stage III 157 (27.4%) Stage IV 123 (21.5%) Stage V 293 (51.1%) - MPE recipients older (65.5±13.9 vs 61.2±14.8 years old, P=0.048) with much lower prevalence of hypertension (5.2% vs 22%, P < 0.001).	Multidisciplinary predialysis education (MPE) -Comprised a nurse for case mx, social workers, dietitians, HD and PD patient volunteers and 10 nephrologists -Programme consisted of integrated course involving individual lectures on renal health, delivered by case-mx nurse -Lectures focused on nutrition, lifestyle, nephrotoxin avoidance, dietary principles and pharmacological regimens -Standardized interactive educational sessions were periodically conducted where all patients were interviewed depending on CKD stage -Stage III or IV CKD patients: f/up 3monthly, stage V: f/up monthly - <b>Stage III patients:</b> programme consisted of lectures on healthy renal function, clinical presentation of uraemia, risk factors and complications associated with renal progression and an introduction to the various RRTs - <b>Stage IV patients:</b> programme included discussions on the mx of complications associated with CKD, indications of RRT and evaluation of vascular or peritoneal access. - <b>Stage V patients:</b> monitored for timely initiation of RRT, care of vascular or peritoneal access, dialysis-associated complications and registration for inclusion in the renal transplant waiting list	Customary care -Same group of nephrologist instructed participants regarding renal function, evaluation of lab data and clinical indicators of chronic renal failure as well as strategies for mx & tx -General principles of HD and PD explained when patients enter stage IV -All patients provided with written instructions. -Comorbidity factors evaluated before referral to nurse specializing in HD or PD. -Nursing staff provided instructions for daily living and explained criteria for HD and PD selection and the difference between modalities.	12 Months -Mean follow-up period was 11.7±0.9 months.	<b>Results:</b> <u>Hospitalisation</u> - The 1-year hospitalisation rate was lower in the MPE patients (2.8%) than in the non-MPE patients (16.4%, P = 0.034). -However, the reason for hospitalisation did not differ significantly between them.	Multiple individual sessions with team members + patients + volunteers

Evidence Table: Organisational (HOSPITALISATION)  
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Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
4. Yeoh HH, Tiquia HS, Abcar AC et al. Impact of predialysis care on clinical outcomes. Hemodial Int. 2003;7(4):338-341.  USA	Retrospective cohort study <b>Objective:</b> To compare patients who had pre-dialysis education programme with those who did not due to late referral or refusal to participate, in terms of hospitalisations, emergency room visits and dialysis access placement. <b>Methods:</b> -Charts of 103 patients seen in clinic from 1997 to 2000 were reviewed -All 103 patients with CKD were encouraged to attend the educational classes. -Data on 68 patients who elected to participate in the pre-dialysis classes and 35 patients who decided not to participate in the classes in spite of encouragement to do so or were referred late and required immediate dialysis were reviewed -Data from period beginning 10 days before the initiation of dialysis to 90 days after the first dialysis, for a total period of 100 days was obtained. -This period captures hospitalisation for initiation of dialysis. -Data for each variable were compared for patients who attended the pre-dialysis class and those who did not	II-2	68 patients participated in pre-dialysis education programme and 35 patients who did not  Mean age for intervention group: 60.3 years old  Mean age for control group: 54.9 years old (P=0.098)	Pre-dialysis education programme -Team involved in education and care of patients consists of nurses, nephrologists, dietitians, social workers, case managers, and pharmacists -Educational program comprised of 2 separate classes -Kidney Class for patients mild to moderate renal impairment -and Choices Class: pre-dialysis education for patients with moderate to severe renal disease or about 3 to 6 months before dialysis will be needed. <b>-Kidney Class:</b> general information about kidney disease, causes of renal failure, and its manifestation <b>-Choices Class:</b> to familiarise patient with options in RRT including HD, PD and renal transplantation -Once the patients attended the classes, they were followed by all the members of the MDT in a coordinated manner.	No pre-dialysis education programme	10 days before initiation and 90 days post dialysis	<b>Results:</b> Dialysis access placement <b>-Necessity for use of temporary catheters</b> was seen in 13 of 35 patients (37.0%) in the group without pre-dialysis education vs. 3 of 68 (4.4%) in the patients who attended education classes (p<0.001) <b>-Incidence of AV graft placement was higher</b> in patients without pre-dialysis education (51% vs. 18%, p<0.001) -AV fistula placement rate was lower in patients without pre-dialysis education (34% vs. 51%); but was not statistically significant. -Incidence of PD catheter placement was higher in the educated group (31% vs. 11.4%, p=0.03). Hospitalisations and emergency room visits <b>-Twice as many emergency room visits</b> for patients without education as for those with education (1.11 vs. 0.57) per patient (P=0.035) -Causes of hospitalization for both groups included: ❖ fluid overload, ❖ problems related to vascular access, ❖ gastrointestinal bleeding, ❖ infections ❖ and metabolic causes.  -Average length of hospital stay per patient for patients with no pre-dialysis education was over seven times higher (9.9 vs. 1.4 days per patient) (P<0.001) <b>Authors conclusion:</b> Patients who participated in a multidisciplinary pre-dialysis education programme had fewer complications, ER visits, and hospitalizations. They also had fewer temporary catheter placements, shorter hospital stays, and reduced costs associated with initial dialysis.	Education by classes

## Evidence Table : Organisational (HOSPITALISATION)

Question : What are the organisational issues with regards to Pre-dialysis Education Programme for advanced CKD patients?

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
5. Yu YJ, Wu IW, Huang CY et al. Multidisciplinary pre-dialysis education reduced the inpatient and total medical costs of the first 6 months of dialysis in incident hemodialysis patients. PLOS One. 2014;9(11):e112820. Taiwan	<p>Randomised controlled trial with cost-analysis</p> <p><b>Objective:</b> To analyse the medical expenditure and utilisation incurred during the first 6 months of dialysis initiation in 425 incident haemodialysis patients who were randomised into multidisciplinary pre-dialysis education (MPE) and non-MPE groups before reaching ESRD.</p> <p><b>Methods:</b> -A total of 2280 patients were enrolled in the study and were randomly divided into the MPE group and the non-MPE group by using a random table at study entry. -445 patients reached ESRD needing haemodialysis after a mean follow-up of 33±2.6 months. -232 patients in the MPE group -213 patients in the non-MPE group -Program consisted of an integrated course involving individual lectures on renal health, delivered by the case-management nurse -Lectures focused on nutrition, lifestyle, nephrotoxin avoidance, dietary principles, and pharmacological regimens. -Case-management nurse contacted the patients to ensure timely follow-up -For stage IV CKD patients, the program included discussions on the management of complications associated with CKD, indications of renal replacement therapy, and the evaluation of vascular or peritoneal access. -For stage V CKD were monitored for timely initiation of renal replacement therapies, the care of vascular or peritoneal access, dialysis-associated complications, and registration for inclusion in the renal transplantation waiting list. -All patients received dietary counselling biannually from a dietitian. -In addition, case-management nurse often contacted the participants by telephone to encourage them to inform their nephrologists of their symptoms and to reinforce the importance of medical visits. -The MPE program was discontinued once renal replacement therapies were initiate</p>	II-1	<p>445 advanced CKD patients: ❖ 232 patients in MPE group ❖ 213 patients in non-MPE group</p> <p>-Mean age of patients was 63.8±13.2 years, and 221 (49.7%) of them were men -Mean eGFR 7.49 ± 3.1 MPE group and mean eGFR 7.87 ± 3.6 in the non-MPE group</p>	<p>Multidisciplinary pre-dialysis education (MPE)</p> <p>-MPE program comprised a nurse for case management, social workers, dietitians, haemodialysis, peritoneal dialysis patient volunteers and 10 nephrologists</p>	<p>Non-MPE nephrologists instructed patients about renal function, evaluation of laboratory data, and clinical indicators of chronic renal failure, and strategies for its mx and tx</p> <p>-General HD and PD explained when patients at Stage 4 CKD</p>	6 months of dialysis initiation	<p><b>Results:</b> Hospitalisation and vascular access related surgeries -MPE patients had significantly <b>fewer and shorter lengths of hospitalisation</b> (median (IQR) 0 (15) vs. 8 (27) days, p&lt;0.001] than non-MPE patients). -Cardiovascular disease (including uncontrolled hypertension, coronary artery disease, stroke, heart failure, and peripheral artery occlusive disease) was the main cause of first hospitalization in all patients. -Eighty-eight (37.9%) patients in the MPE group had at least one hospitalisation, compared with 127 patients (59.6%) in the non-MPE group (p&lt;0.001). -Participation in MPE program <b>reduced cardiovascular hospitalisation in first 6 months</b> post dialysis (18.53% vs. 29.58%, p=0.007). -MPE group were more likely to have <b>fewer vascular access related surgeries</b> during the first admission [35 patients (15.09%) vs. 55 (25.82%), p=0.005]. <b>Authors conclusion:</b> Participation of multidisciplinary education in pre-dialysis period was independently associated with reduction in the inpatient and total medical expenditures of the first 6 months post-dialysis owing to decreased inpatient service utilization secondary to cardiovascular causes and vascular access-related surgeries.</p>	<p>Single-centre study</p> <p>Education by individual sessions with team</p>



## Evidence Table : Organisational (HOSPITALISATION)

### Question : What are the organisational issues with regards to Pre-dialysis Education Programme for advanced CKD patients?

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
6. Wei SY, Chang Y.Y, Mau LW et al. Chronic kidney disease care program improves quality of pre-end-stage renal disease care and reduces medical costs. Nephrology (Carlton). 2010;15(1):108-115.  Taiwan	Retrospective cohort study with cost-analysis <b>Objective:</b> To evaluate the effectiveness of CKD care programme on pre-end-stage renal disease (ESRD) care <b>Method:</b> -Total of 140 incident ESRD patients, who started HD in the period from August 2004 to July 2005 from the two study hospitals were retrospectively reviewed -Study subjects divided into: ❖ <b>'CKD Care Group'</b> (71 incident HD patients who received the CKD care programme intervention for at least 6 months before initiation of HD), ❖ <b>'Nephrologist Care Group'</b> (69 incident HD patients who were cared for by nephrologists alone for at least 6 months before initiation of dialysis)	II-2	140 incident ESRD patients who started dialysis and divided into: -CKD Care Group (71 patients) -Nephrologist Care Group (69 patients)  -Mean eGFR, mL/min per 1.73 m <sup>2</sup> 3.8 ± 1.3 in CKD Care Group, 3.7 ± 1.5 in Nephrologist care group	CKD care programme (n=71)	Nephrologist Care Group (n=69)	6 months before dialysis and at dialysis initiation	<b>Results:</b> Quality of pre-ESRD care <b>Preparation at dialysis initiation: EPO treatment</b> -No significant difference on percentages of patients who received rHuEPO treatment at initiation of HD and the average monthly dosage of rHuEPO <b>Preparations at dialysis initiation: Vascular access</b> -Vascular access had been created before HD in 57.7% of patients in the CKD Care Group vs. only 37.7% of the Nephrologist Care Group (P = 0.017). -Percentage of patients who started HD with created vascular access without the insertion of double lumen catheter was 50.7% in the CKD Care Group, vs. 29.0% in the Nephrologist Care Group (P = 0.009) <b>Preparations at dialysis initiation: Hospitalisation</b> -Percentage of patients who were not hospitalised for initiation of HD was 40.8% in CKD Care Group, vs. 18.8% in the Nephrologist Care Group (P < 0.005). -Most patients in Nephrologist Care Group (81.2%) had their first HD through inpatient HD. <b>Frequency of services utilisation</b> <b>Period of 6 months before dialysis'</b> -More frequent outpatient visits in CKD Care Group (9.9 ± 5.5 vs 5.5 ± 5.5 P<0.001), but the frequency of hospitalisation and length of stay had no difference with Nephrologist Care Group. <b>Period of at dialysis initiation'</b> -Lower percentage of hospitalisation for initiation of dialysis in the CKD Care Group (59.2% vs 81.2%, P= 0.005). -Length of stay in hospital much shorter for CKD Care Group. (6.6days ± 16.2 vs. 16.2days ± 16.2, P <0.001) <b>Authors conclusion:</b> CKD care programme successfully helps pre-ESRD patients to proceed into dialysis initiation with better preparedness, which reduces the probability of emergency dialysis through hospitalisation and saves health dollars from CKD to ESRD	Education by multiple individual sessions

**Evidence Table : Organisational (COMPONENTS OF PROGRAMME)  
Question : What are the components of Pre-dialysis Education Programme for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
1. Van den Bosch J, Warren DS, Rutherford PA. Review of predialysis education programs: a need for standardization. Patient Prefer Adherence. 2015;9:1279-1291.	<p><b>Systematic review</b></p> <p><b>Objective:</b> To review evidence on effective components of pre-dialysis education programs as related to modality choice and selected clinical outcomes.</p> <p><b>Method:</b> -Systematic search was performed on PubMed MEDLINE, Cochrane Library, and Ovid (from January 1, 1995 to December 31, 2013) -Inclusion criteria applied:  <ul style="list-style-type: none"> <li>❖ Adults only</li> <li>❖ Pre-dialysis education for CKD patients stage III, IV, and V</li> <li>❖ Planned start patients, unplanned start patients, and patients on dialysis, ie, incident and prevalent patients.</li> <li>❖ Detailed description of programme</li> <li>❖ Multiple sessions</li> <li>❖ Multidisciplinary programme involving physicians, nurses, dietitians, etc.</li> </ul> </p> <p>-Outcomes included:  <ul style="list-style-type: none"> <li>❖ Dialysis modality choice and the numbers of patients choosing each modality</li> <li>❖ Any clinical outcome associated with pre-dialysis education</li> <li>❖ Health-related quality of life</li> <li>❖ Measures associated with patient choice</li> <li>❖ Financial impact of patients choosing more home therapies</li> <li>❖ Patient satisfaction</li> </ul> </p> <p>-Literature also reviewed for any information on processes, pathways, and organization of the pre-dialysis education programmes</p>	I	<p>29 relevant studies: 19 quasi-experimental design 10 narrative reviews</p> <p>-19 studies were analysed for effective components of pre-dialysis education programme</p> <p>-Descriptions of the educational process varied and included individual and group education, multidisciplinary intervention, and varying duration and frequency of sessions.</p>	Pre-dialysis education programmes			<p><b>Results:</b> Components of pre-dialysis education programmes</p> <p><b>Multidisciplinary education</b></p> <ul style="list-style-type: none"> <li>-Pre-dialysis care is delivered by a multidisciplinary team including a nephrologist, a nurse, a dietitian, and a social worker.</li> <li>- The team can also include: <ul style="list-style-type: none"> <li>❖ a pharmacist who explains information on medicines needs</li> <li>❖ a psychologist expert, which could be a specialised nurse for emotional support when needed;</li> <li>❖ a case manager;</li> <li>❖ representatives from the local patient kidney support group;</li> <li>❖ and other patients established on maintenance dialysis</li> </ul> </li> </ul> <p>-7 articles retrieved from the scientific literature review described multidisciplinary education program which consists of multiple education sessions where patients were educated by three or more health care professionals such as nephrologist, nurse, dietitian, social worker, home-dialysis coordinator, pharmacist, technician, or by other dialysis patients</p> <p><b>Delivery style</b></p> <ul style="list-style-type: none"> <li>-Education delivery style can either be one-on-one sessions or class room teaching style, but a mix of one-on-one and group sessions were advocated</li> <li>-Educational programs should contain individualised one-on-one counselling sessions with a member/member of multidisciplinary team.</li> <li>-This can be a physician, nephrologist, nurse, dietitian, social worker, etc.</li> <li>-In addition to small group discussions, peer counselling and problem-solving or "brainstorming" sessions have been described wherein patients discuss treatment modalities, barriers and benefits, and troubleshooting of possible problems with other patients (or facilitators).</li> <li>-Group sessions can have a variety of formats such as group lectures, interactive workshops, or open forum sessions.</li> </ul> <p><b>Frequency and duration.</b></p> <ul style="list-style-type: none"> <li>-Number of sessions and duration per session varies by educational program.</li> <li>-There were reports of 6 individual sessions of 1 hour, 4 sessions, 1 night a week for 2 hours; or at least 4 to 5 interviews</li> </ul> <p><b>Timing</b></p> <ul style="list-style-type: none"> <li>-An estimated glomerular filtration rate of less than 30 mL/min (stage IV CKD) has been reported as ideal for referral to CKD clinic.</li> <li>-Others recommend that patients should be referred as early as possible to renal education (&gt;6 months).</li> </ul> <p><b>Authors conclusion:</b> There is a need for a standardized approach built on best evidence from CKD and also from other clinical conditions and existing knowledge on the evaluation of complex interventions to ensure formal evaluation of pre-dialysis education programs, and their effects on clinical outcomes and modality choice.</p>	Most studies without control group

**Evidence Table : Organisational (COMPONENTS OF PROGRAMME)  
Question : What are the organisational issues with regards to Pre-dialysis Education Programme for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
2. Prieto-Velasco M, Isnard Bagnis C, Dean J et al. Pre-dialysis education in practice: a questionnaire survey of centres with established programmes. BMC Res Notes. 2014;7:730.	Cross-sectional study <b>Objective:</b> To help address knowledge gap: replacement therapy option education (RRTOE) being run? <b>Methods:</b> -An expert meeting was held in March 2013 to formulate a position statement on optimal ways to run RRTOE. -Experts were selected from units that had extensive experience in RRTOE or were performing research in this field. -Before the meeting, experts completed a pilot questionnaire on RRTOE in their own units.	II-3	Four nurses, 5 nephrologists and 1 clinical psychologist (9 renal units; 6 EU countries) participated. -2 units each in UK, Sweden, Spain -3 units in France, Belgium, Italy	Renal replacement therapy option education (RRTOE)			<b>Results:</b> Staff involved -Nurses were almost always responsible for organising RRTOE. (8/9 units) -Nephrologists spent 7.5% (median) of their time on RRTOE ❖ Nephrologists also involved in RRTOE programme (7 units), dieticians (5 units) ❖ psychologists (4 units), social workers (3 units), physiotherapist (1 unit) ❖ occupational therapist (1 unit) ❖ pharmacist (1 unit)  -All staff administering the programme had background in general or nephrology nursing  Starting RRTOE -Education for the patient and family began several months before dialysis or according to disease progression -RRTOE participants included: ❖ patients with CKD stage IV or V (9 units), ❖ patients requiring a change in RRT treatment (8 units), ❖ family members of patients (9 units)  Content and structure -Key topics such as the 'impact of the disease' were covered by every unit, but only a few units described all dialysis modalities. -Most RRT patients visit in centre HD unit (8/9 units), patients visit home dialysis nurse to assess suitability (7/9 units) -Half of units have formal meeting with 'expert patient' as part of RRTOE programme -Group education sessions were used in 3/9 units.  Decision-making -Most have formal decision-making process with written support materials in place (7/9 units) with both nurses and nephrologists  Materials -Materials came in a wide variety of forms and from a wide range of sources -Booklets were used in all units, online materials and DVDs were used in half of units  Quality assurance measures -Most widely used (6/9 units): ❖ patient satisfaction, ❖ number of patients completing the programme, ❖ linking attendance/completion of programme to clinical follow up, ❖ and regularly updating materials  -Most widely agreed upon factors perceived to be important were national/local guidelines mandating RRTOE programme and the clinical leadership in the renal unit (each 6 units)  <b>Authors conclusion:</b> There were substantial variations in how RRTOE is run between the units.	

**Evidence Table : Societal implications (MODALITY CHOICE)**  
**Question : What are the societal implications of Pre-dialysis Education Programme for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
1. Shukla AM, Easom A, Singh M et al. Effects of a Comprehensive Predialysis Education (CPE) Program on the Home Dialysis Therapies: A Retrospective Cohort Study, Perit Dial Int. 2017;37(5):542-547.  USA	Retrospective Cohort Study  <b>Objective:</b> To report the findings of a retrospective analysis of the initial 22 months of newly formed CPE clinic for advanced CKD subjects, and its impact on the rates of home dialysis (HoD)  <b>Methods:</b> -All patients with stage 4 and 5 CKD, with occasional patients of stage 3b CKD with rapid renal progression under the care of nephrologists were offered and encouraged transition to the care of CPE clinic under a single nephrologist for their routine nephrology care. -CPE clinic included: ❖ a renal physician, ❖ an advanced nurse practitioner (ANP) educator, ❖ a renal dietitian, ❖ and a renal social worker.  -A pharmacist was inducted in the CPE clinic for the latter half of the study period. -All patients admitted to clinic for first time were seen on new patient protocol, and returning patients were seen on established patient protocol -Analysis 22 months of CPE clinic were done	II-2	108 advanced CKD patients  -with average eGFR of 18.34 ± 6.5 mL/min were seen in the first 22 months of the CPE clinic -Majority of patients were referred to the CPE clinic late with late stage 4 (eGFR 16 – 22 mL/min) and stage 5 comprising 74% of the total CPE population.	Comprehensive Pre-dialysis Education Programme (CPE):  -New protocol required patients to attend half-day comprehensive education session. -Pts encouraged to attend with family members, spouse, or caregivers. -On arrival, patients provided with printed material for kidney disease followed by group lesson in classroom format by renal ANP educator, which lasted for a min. of 1 hour. -After group lesson, patients rotated with renal dietitian, social worker, trained dialysis nurse well versed in all dialysis techniques, and renal physician for patient-specific discussions and detailed on the individual needs and questions. -Sessions with dialysis nurse included a 'hands-on' demonstration of home peritoneal dialysis (PD), home hemodialysis (HD), and in-center machine as per the needs and desires of pts. -Visit ended with detailed session with the renal physician. -Provider sessions started with an interview of the individual's family, social, medical, and occupational needs. -All previously provided information was reviewed and specific questions addressed. -Patients and their caregivers encouraged to make 'active choice' for their RRT. -Any remaining misconceptions or fears were addressed during this final discussion. -The last member of the clinic team recorded final modality choice in a passive manner.	Established patient protocol  -Greater freedom for patients to focus on the areas of their choice with all clinic members available for counselling. -Seen by the renal physician for their routine nephrology care. -Patient preferences for RRT were noted at each clinic visit	22 months	<b>Results:</b> Over 22 months CPE clinic:  Rates of home dialysis (HoD) ❖ 70% of patients in CPE group chose HoD. ❖ Of which, 55% chose peritoneal dialysis (PD) and 15% chose home hemodialysis (HHD).  -Rates of HoD choice were similar across spectrum of socio-economic variables. -54.6% of those choosing to return for more than 1 session, 25.3%, changed their modality preference after the first education session, and nearly all reached a final modality selection by the end of third visit. -Multivariate analysis showed that the choice of RRT modality was unaffected by the patients' age, gender, race, availability and type of insurance, diabetes status, albumin, or the stage of renal disease (p > 0.05). -Initiation of the CPE program resulted in a 216% growth in HoD census over the same period and resulted in near doubling of HoD prevalence to 38% of all dialysis patients within 22 months of initiation.  <b>Authors conclusion</b> Comprehensive patient education improves the choice and prevalence of HoD therapies. We further find that 3 sessions of CPE may provide needed resources for the large majority of subjects for adequate decision-making	Group+ individual sessions with team members

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Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristics	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
2. Devoe DJ, Wong B, James MT et al. Patient Education and Peritoneal Dialysis Modality Selection: A Systematic Review and Meta-analysis. Am J Kidney Dis. 2016;68(3):422-433.	<p>Systematic review and meta-analysis</p> <p><b>Objective:</b> To characterise the relationship between patient-targeted educational interventions and choosing and receiving PD.</p> <p><b>Methods:</b> -Systematic search were done in MEDLINE, EMBASE, CINAHL and EBMR &amp; included controlled observational studies and randomized trials of educational interventions designed to increase PD selection in the review -Abstracts from annual meeting of the American Society of Nephrology for 2009-2014 were reviewed -Relevant articles also hand searched from reference list -Two reviewers reviewed the titles and full text for inclusion according to criteria: ❖ adults with CKD ❖ reported patient-targeted education strategies about available dialysis modalities ❖ reported relevant outcomes (choosing PD or receiving PD only or choosing PD or receiving PD with home HD) ❖ and incorporated standard care as control group</p> <p>-Risk of bias assessment was done -Primary outcome was choosing PD, defined as intention to use PD regardless of whether PD was ever used. -Secondary outcome, receiving PD, was defined as an individual receiving PD as his or her treatment. -Meta-analysis were done, studies estimates were pooled</p>	I	<p>Of 3,540 citations, 15 studies were included: -7 pre and post intervention studies, -5 cohort studies -2 case-control studies -1 randomised controlled trial (RCT)</p> <p>-Of 15 studies, 2 were excluded from meta-analysis due to missing information -7 studies from North America, 5 from Europe, 3 from Asia. -Number of participants ranged from 63 to 21,302 for total of 31,653. -Mean age ranged from 58 to 70.8 years old -Percentage of men ranged from 45% to 64.3% -Mean eGFR ranged from <math>\leq 15</math> to 20.4 ml/min/1.73 m<sup>2</sup> -Two studies included only stage 5 or ESRD</p>	<p>Pre-dialysis educational interventions.</p> <p>-Educational interventions vary greatly between studies -7 studies included physician as an educator, 10 included a nurse, and 4 included multidisciplinary team -8 studies carried out educational interventions in group sessions, 5 had 1 to 1 session only and 2 included both material, 7 used printed materials, and 1 used website materials -4 studies included family members in educational interventions</p>	<p>Standard care</p> <p>-6 out of 15 studies reported control intervention -of the 6 studies, 2 included standard education from nephrologist and 2 had standard education given by multidisciplinary team</p>	<p>-Duration of follow up ranged from 12 to 144 months</p>	<p><b>Results:</b> <b>Primary outcome-choosing PD</b> 6 studies reported primary outcome, and 5 provided sufficient data for meta-analysis:  -In the RCT (N=70), educational intervention group was associated with a more than 4-fold increase in the odds of choosing PD (OR, 4.60; 95% CI, 1.19,17.74). -Based on results from 4 observational studies (N=7,653), patient-targeted educational interventions were associated with a 2-fold increase in the odds of choosing PD (pooled OR, 2.15; 95% CI, 1.07,4.32; I<sup>2</sup>=76.7%).  <b>Secondary outcome-receiving PD</b> 10 studies reported secondary outcome, only 9 had sufficient data for meta-analysis:  -Based on results from 9 observational studies (N=8,229), patient-targeted educational intervention was associated with a 3-fold increase in the odds of receiving PD as the initial treatment modality (OR, 3.50; 95% CI, 2.82, 4.35; I<sup>2</sup>=24.9%).  <b>Authors conclusion:</b> This systematic review demonstrates a strong association between patient-targeted education interventions and the subsequent choice and receipt of PD. The variability in the design of the educational strategies identified and the strength of association across studies highlight the uncertainty about when and how educational interventions should be delivered, as well as likelihood of impact according to baseline PD penetration.</p>	

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 Question : What are the societal implications of Pre-dialysis Education Programme for advanced CKD patients?

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
3. de Maar JS, de Groot MA, Luik PT et al. GUIDE, a structured pre-dialysis programme that increases the use of home dialysis. Clin Kidney J. 2016;9(6):826-832.	Cross-sectional study <b>Objective:</b> To answer the following question: Does the implementation of a structured pre-dialysis programme with a home-focused approach increase the number of pre-dialysis patients that choose home dialysis, and the number of patients that eventually receive home dialysis? <b>Methods</b> -Records of all 102 patients that received a treatment recommendation in the GUIDE programme between 12 September 2013 and 18 December 2014 at Meander Medical Centre were retrospectively reviewed. -The structured pre-dialysis programme (GUIDE) process starts when a patient has an eGFR of 15 mL/min/1.73 m <sup>2</sup> . -Begins with home visit from a case manager (social worker) during which first education is given and suitability for home dialysis is assessed. -Next, questionnaires were completed by patient, case manager and nephrologist. -Patient questionnaire contains: <ul style="list-style-type: none"> <li>❖ questions about the patient's social support system,</li> <li>❖ daily activities,</li> <li>❖ level of independence in activities of daily living (ADL),</li> <li>❖ aspects of life that patient values most</li> <li>❖ and preferences and expectations with regard to RRT.</li> </ul> -Medical questionnaire comprises the categories Transplantation, PD and HD, which contain questions about relative and absolute contraindications for each therapy and nephrologist's treatment preference. -Case manager's questionnaire covers the suitability of the home, the social environment and the balance between burden and capacity and ends with case manager's judgment of whether or not home dialysis would be suitable. -A multidisciplinary meeting (MDM) is held to determine a specific patient profile (treatment recommendation). -In MDM, most suitable treatment for particular patient is chosen, while taking into account the sequence of programme's treatment preference. -This sequence implies transplantation is recommended when possible over dialysis and home dialysis over in-centre dialysis. -An automated GUIDE dashboard, which generates a profile using an algorithm based on answers to the questionnaires -This is followed by patient education, a second MDM and finally the selection of the treatment by the patient and the nephrologist.	II-3	102 patients were included who started the process at a mean eGFR of 12.3 mL/min/1.73 m <sup>2</sup> . -Mean age was 68.6 years and 44.1% were female	GUIDE (structured pre-dialysis programme) -After MDM, specialised pre-dialysis nurse provides education tailored to patient's profile. -All patients receive general RRT information -Training that patient and family members receives before the start of home dialysis is discussed. -If there are no family members who are willing or able to contribute, passive HHD (or passive PD) with the help of home care is discussed. -If the profile only includes CHD, no information is provided on other modalities -Education is provided in a single session, which is repeated if the patient wishes. -Written brochures and educational videos are also provided. -Meetings with other patients are offered and arranged if requested by the patient or their family. -Patient's response to this educational session is discussed in a second MDM. -Following this, patient and nephrologist choose a treatment modality during the next visit to the outpatient clinic.			<b>Results:</b> <ul style="list-style-type: none"> <li>❖ Home dialysis was recommended for 62.8% of the patients who were advised to have dialysis treatment.</li> <li>❖ Of patients that opted for dialysis, 34.2% chose PD and 8.2% chose HHD; 22.9% started home dialysis as their first therapy, compared with 17.6% in the months before implementation of GUIDE.</li> <li>❖ 32.1% of the patients that received dialysis therapy received home dialysis.</li> <li>❖ In the months before GUIDE, an average of just 19.5% of patients received dialysis received home dialysis.</li> </ul> <b>Authors conclusion:</b> Compared with historical data, the standardised and home-focused pre dialysis programme GUIDE, with its home visit, seems to successfully increase the number of patients that choose and receive home dialysis	Education starts with home visit, MDM meeting, and education+ training, second MDM and final choice of RRT

**Evidence Table : Societal implications (MODALITY CHOICE)**  
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4. Van den Bosch J, Warren DS, Rutherford PA. Review of predialysis education programs: a need for standardization. Patient Prefer Adherence. 2015;9:1279-1291.	<p><b>Systematic review</b></p> <p><b>Objective:</b> To review evidence on effective components of pre-dialysis education programmes as related to modality choice and selected clinical outcomes.</p> <p><b>Method:</b> -Systematic search was performed on PubMed MEDLINE, Cochrane Library, and Ovid (from January 1, 1995 to December 31, 2013) -Inclusion criteria applied: ❖ Adults only ❖ Pre-dialysis education for CKD patients stage III, IV, and V ❖ Planned start patients, unplanned start patients, and patients on dialysis, ie, incident and prevalent patients. ❖ Detailed description of programme ❖ Multiple sessions ❖ Multidisciplinary programme involving physicians, nurses, dieticians, etc.</p> <p>-Outcomes included: ❖ Dialysis modality choice and the numbers of patients choosing each modality ❖ Any clinical outcome associated with pre-dialysis education ❖ Health-related quality of life ❖ Measures associated with patient choice ❖ Financial impact of patients choosing more home therapies ❖ Patient satisfaction</p> <p>-Literature also reviewed for any information on processes, pathways, and organization of the pre-dialysis education programmes</p>	I	<p>29 relevant studies: 19 quasi-experimental design 10 narrative reviews</p> <p>-19 studies were analysed for effective components of pre-dialysis education programme</p> <p>-Descriptions of the educational process varied and included individual and group education, multidisciplinary intervention, and varying duration and frequency of sessions.</p>	Pre-dialysis education programmes			<p><b>Results</b></p> <p>Modality selection -6 out of 9 studies reporting on dialysis modality selection noted a higher proportion of patients selecting home dialysis (PD or another home modality)</p> <p>Chanouzas et al. (2012) 20% chose PD. 50% choosing PD received PDEP vs 33% of HD patients.</p> <p>Kiang et al. (1998) Higher patients chose PD</p> <p>Levin et al. (1997) 53% of PDEP group chose PD vs. 42% in control</p> <p>Manns et al. (2005) 82.1% of PDEP group chose self-care dialysis vs 50% in control</p> <p>McLaughlin et al. (2008) PDEP group more likely to choose self-care dialysis</p> <p>Ribitsch et al. (2013) 54.3% in PDEP group started with PD vs 28% in control</p> <p>-3 studies found no significant difference in modality choice -4 studies with pre- and post- intervention (pre-dialysis education) measurements showed higher levels of home dialysis use after the pre-dialysis education intervention</p>	Mostly without control group

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
	<p>If patients/ staff did not spontaneously talk about the pre-dialysis period, they were prompted with an open-ended question about how treatment decisions were made</p> <ul style="list-style-type: none"> <li>-Semi-structured qualitative telephone interviews were undertaken with 20–25 patients per site until saturation was achieved.</li> <li>-Staff population was clinical staff working with CKD stage 5 patients and managerial staff.</li> <li>-Semi-structured qualitative face-to-face interviews were undertaken on-site with 20–30 staff per site until saturation was achieved.</li> <li>-Interviews lasted for 30–60 min and were undertaken in private with only the interviewer and interviewee present</li> <li>-All interviews were audio recorded and were transcribed verbatim by a specialist transcription team.</li> <li>-Transcripts were checked by researchers but not participants</li> <li>-The written and audio-visual PDE materials used in each site were also reviewed</li> <li>-Data was analysed using thematic framework analysis.</li> </ul>						<p><b>The impact of distress</b></p> <ul style="list-style-type: none"> <li>❖ a strong theme across all patient groups and sites</li> <li>❖ Patients described at length, the traumatic and frightening nature of the transition to end-stage renal failure</li> <li>❖ Patients' abilities to make treatment decisions were adversely affected in the pre-dialysis period by emotional distress</li> <li>❖ Very few staff appeared to appreciate the potential adverse impact of psychological distress on patients' ability to make treatment decisions.</li> <li>❖ Authors conclusion: <ul style="list-style-type: none"> <li>-Suggested improvements to teaching methods and educational materials are in line with previous studies and current clinical guidelines.</li> <li>-All staff, irrespective of their role, need to be trained about all treatment options so that informal conversations with patients are not biased.</li> <li>-The study argues for a more individualised approach to PDE which is more like counselling than education and would demand a higher level of skill and training for specialist PDE staff.</li> <li>-The study concludes that even if these improvements are made to PDE, not all patients will benefit, because some find decision-making in the pre-dialysis period too complex or are unable to engage with education due to illness or emotional distress. -It is therefore recommended that pre-dialysis treatment decisions are temporary, and that PDE is replaced with on-going RRT education which provides opportunities for personalised education and on-going review of patients' treatment choices.</li> <li>-Emotional support to help overcome the distress of the transition to end-stage renal disease will also be essential to ensure all patients can benefit from RRT education.</li> </ul> </li> </ul>	



Evidence Table : Societal implications (MODALITY CHOICE)

Question : What are the societal implications of Pre-dialysis Education Programme for advanced CKD patients?

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
5. Cankaya E, Cetinkaya R, Keles M et al. Does a predialysis education program increase the number of pre-emptive renal transplantations? Transplant Proc. 2013;45(3):887-889.  Turkey	Cross-sectional study  <b>Objective:</b> To investigate relationship between pre-dialysis education programme (PDEP) for patients and their relatives and pre-emptive RT  <b>Method:</b> -Patients who underwent living donor kidney transplantation between May 2004 and August 2012 were enrolled in the study -Patients were divided into two groups: ❖ transplantation without pre-dialysis education program (Non-PDEP) ❖ transplantation with PDEP  -Pre-emptive transplantations rates were compared between two groups	II-3	88 live donor kidney transplant recipients into 2 groups:  -Transplantation without education (non-PDEP;n=27), and education before transplantation (PDEP;n = 61).  -Mean eGFR non-PDEP 10.2 ±2.1 (stage 5). -Mean eGFR PDEP 12.2 ± 1.7 (stage 5)	Pre-dialysis education programme (PDEP)  -Specially prepared kit using visuals and written cards with 6 modules. -This kit educates CKD patients and their relatives -Summary of modules:  <b>Module 1</b> -Info about kidney disease <b>Module 2</b> -Diet, drugs and exercise in CKD <b>Module 3</b> -Info to tx of renal failure and general info about RRT <b>Module4</b> -PD <b>Module5</b> -HD -Kidney transplantation  -a file was opened for each patient, determining social, cultural, economic, physical and psychological profiles. -During each visit to outpatient clinics, patient complains, physical examination findings and lab results were recorded and eGFR calculated. -Patients with early stage will start with module 1,2,3 -Patients with stage 3b n 4, will start with 1,2,3,4,5,6 -Patients with stage 5, modules with RRT chosen by patient will be started	No pre-dialysis education programme (Non-PDEP)		<b>Results:</b> -Pre-emptive kidney transplantation rates among PDEP group significantly higher compared with the non-PDEP group (42.6% vs 18.5%, P<0.001) -Mothers were the most numerous donors in both groups -Donor transplantation rates from spouse, siblings and other relatives were higher among the PDEP group P<0.001, P=0.001, and P=0.002, respectively.  <b>Authors conclusion:</b> Pre-dialysis education programme increased the number of pre-emptive renal transplantation among ESRD patients, reducing dialysis-related complications and costs. Dissemination of PDEP in nephrology outpatient clinics appears to be favourable for patient health, quality of life and economics.	Education using training kit

**Evidence Table : Societal implications (PATIENTS' SATISFACTION)  
Question : What are the societal implications of Pre-dialysis Education Programme for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
1. Brendan P. Cassidy, Lori Harwood, Leah E et al. Educational Support Around Dialysis Modality Decision Making in Patients With Chronic Kidney Disease: Qualitative Study Can J Kidney Health Dis. 2018; 5: 2054358116803323  Canada	<p><b>Qualitative study.</b></p> <p><b>Objective</b> To explore participants' satisfaction with the education they received, while identifying educational needs, and the influence of the educational process in their dialysis modality decision making</p> <p><b>Methods</b> -A qualitative descriptive study was conducted with a sample of 12 participants between August-September 2016 -Eligible participants were patients with CKD on either:  <ul style="list-style-type: none"> <li>❖ in-centre hemodialysis (IC-HD),</li> <li>❖ PD,</li> <li>❖ Home-HD</li> </ul> </p> <p>who started dialysis within 6 months of the study and were &gt;18 years of age, fluent in English, and able to participate in an open-ended interview. -CKD education was provided by multidisciplinary team. -4 patients from each dialysis modality were interviewed, along with any family members present -Patients also completed demographic survey -A 30- to 60-minute semi structured interview using the AIDET (Acknowledge, Introduce, Duration, Explanation, Thank You) protocol was conducted with patients/family members -Interviews were done exploring:  <ul style="list-style-type: none"> <li>a. how patients receive information,</li> <li>b. its influence on their decisions,</li> <li>c. how the current educational supports could be improved.</li> </ul> </p> <p>-Keywords, phrases, and descriptions were analysed and categorized into themes. -Quotes were extracted to best represent the patient voice and were matched to themes through team consensus.</p>	12 participants  -4 patients from each dialysis modality (IC-HD, PD, Home-PD) -7 male: 5 female -Age range of 23 to 77 years, median age 62 years old. -Highest levels of education attained -High school (33%), college (50%), and postgraduate degree (17%).	<p>Multidisciplinary pre-dialysis education</p> <p>Educational supports included: -Kidney Foundation of Canada binder, <i>Living With Kidney Disease</i>, 4th edition, -4 multimodal small group classes, -patient partners, and a list of trusted CKD online resources</p> <p>The 4 classes covered: -self-management, living with CKD, -stages of change, -videos and demonstrations of each dialysis modality, -a patient panel, -vascular access, and a tour of the dialysis unit</p>			<p><b>Results:</b> 3 overarching themes influenced the modality decision-making process:  <ul style="list-style-type: none"> <li>❖ <b>Patient Factors</b> (individualisation, autonomy, and emotions),</li> <li>❖ <b>Educational Factors</b> (tailored education, appropriate time/information, and available resources),</li> <li>❖ <b>and Support Systems</b> (partnership with health care team (HCT) and family/friends).</li> </ul> </p> <p><b>Patient Factors</b>  <ul style="list-style-type: none"> <li>a. <b>Individualisation</b> -Individual circumstances including transportation, level of activity, living situation, and support systems</li> <li>b. <b>Autonomy</b> -Varying levels of patient's independence, ability and willingness to engage, and preferred different quantities of information.</li> <li>c. <b>Emotions</b> -without adequate understanding of their current health state, patients experienced fear, denial, regret, anger, and shock.</li> </ul> </p> <p><b>Educational Factors</b>  <ul style="list-style-type: none"> <li>a. <b>Tailored education</b> -Patients tended to receive information more effectively, with active engagement and motivation to learn when provided in accordance with their preferred learning styles.</li> <li>-<b>Demographic and generational variance</b> was apparent in the way certain participants wished to receive information.</li> <li>-Patients' requests to improve the current educational support included <b>more face-to-face education from clinicians and patients</b>, videos on dialysis, online educational classes, and written information via pamphlets.</li> </ul> </p> <p>b. <b>Appropriate time and information</b>  <ul style="list-style-type: none"> <li>-Providing time and repeated exposure to information enhanced patient-informed decision making</li> <li>-Appropriate amount of time differs among patients. When not given enough time, patients felt rushed, barraged with information, and overwhelmed</li> <li>-Patients also reported <b>feeling they did not receive balanced information</b> in terms of both benefits and drawbacks of each modality and desired a more pragmatic approach</li> <li>-One patient had 2 clinicians providing information, one presenting options in a hopeful manner, while the other was more realistic about life on dialysis. The patient preferred the latter approach</li> </ul> </p> <p>c. <b>Available resources</b>  <ul style="list-style-type: none"> <li>-Educational supports utilised by patients had a significant impact on their perception of each modality. However, not all resources were accessed, even when offered</li> <li>-The multidisciplinary teams were influential in supporting patients through the pre-dialysis period and in dialysis modality choice. <b>Patients benefited from group learning and shared patient experiences and perceptions.</b></li> <li>-The <b>haemodialysis unit tour</b> helped set expectations, ease fears, and increase comfort levels. The KFOC binder and CKD websites appeared to play a larger role in improving patients' understanding of CKD, the modality options available, and prompting questions to ask the HCT, rather than directly impacting their modality decision.</li> </ul> </p> <p><b>Support systems</b>  <ul style="list-style-type: none"> <li>a. <b>Partnership with HCT.</b> -Nephrologists play a significant role in modality education and decision making -When a trusting partnership was established, patients had an enhanced sense of importance, control, and respect.</li> <li>b. <b>Family and friends.</b> -Patients relied on family and friends, and lack of support often influenced the decision for IC-HD over a home-based therapy. -Some patients relied on family members to educate them</li> </ul> </p> <p><b>Authors conclusion:</b> Modality selection is a complex process requiring an individualized approach for each patient. Patients' decisions on renal replacement therapy are influenced through their own preferences and values, the education delivered to them, and the support systems available to them. Patient education can be improved through the standardisation of a CKD curriculum and the establishment of a patient-HCT partnership. Consideration of each patient's unique situation and values will allow educational challenges to be identified and overcome, achieving informed, shared decision making.</p>	Education by team, materials and small group sessions	

**Evidence Table : Societal implications (PATIENTS AND STAFF INSIGHTS)**  
**Question : What are the societal implications of Pre-dialysis Education Programme for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments							
1. Combes G, Sein K, Allen K. How does pre-dialysis education need to change? Findings from a qualitative study with staff and patients. <i>BMC Nephrol.</i> 2017;18(1):334.	<p><b>Qualitative study</b></p> <p><b>Objective</b> To report findings relevant to PDE from a larger mixed methods study, providing insights into what staff and patients think needs to improve.</p> <p><b>Methods</b> -Mixed methods was used to look at quantitative changes in home dialysis uptake rates and qualitative case studies to explore barriers and success factors for home dialysis -Four hospital renal units, selected from seven West Midlands units -Patient population was dialysis patients aged 18+ starting their current treatment within 12 months, -Semi structured one-to-one interviews were undertaken with dialysis patients and clinical and managerial staff</p> <p>-For patients, the topic guide covered:  <ul style="list-style-type: none"> <li>❖ how patients came to be on dialysis;</li> <li>❖ experiences of pre-dialysis and dialysis pathways;</li> <li>❖ suggestions for improvement.</li> </ul> </p> <p>-For staff, the topic guide covered:  <ul style="list-style-type: none"> <li>❖ current practice,</li> <li>❖ how well the pre-dialysis and dialysis pathways work;</li> <li>❖ how the team had been working to increase uptake of home dialysis;</li> <li>❖ suggestions for improvement</li> </ul> </p> <p>- If patients/ staff did not spontaneously talk about the pre-dialysis period, they were prompted with an open-ended question about how treatment decisions were made</p> <p>-Semi-structured qualitative telephone interviews were undertaken with 20-25 patients per site until saturation was achieved.</p> <p>-Staff population was clinical staff working with CKD stage 5 patients and managerial staff.</p> <p>-Semi-structured qualitative face-to-face interviews were undertaken on-site with 20-30 staff per site until saturation was achieved.</p> <p>-Interviews lasted for 30-60 min and were undertaken in private with only the interviewer and interviewee present</p> <p>-All interviews were audio recorded and were transcribed verbatim by a specialist transcription team.</p> <p>-Transcripts were checked by researchers but not participants</p> <p>-The written and audio-visual PDE materials used in each site were also reviewed</p> <p>-Data was analysed using thematic framework analysis.</p>		Semi-structured interviews in four hospitals with 96 clinical and managerial staff and 93 dialysis patients	Pre-dialysis education (PDE)  Formal PDE in all four sites included:  -one or more one-to-one sessions with a specialist nurse;  -a group information session, including talks from patients on RRT; -and written materials/ DVDs which patients took home.  -In several sites, specialist nurses undertook home visits where they discussed treatment options with patients. -Doctors also discussed treatment options with patients during out-patient appointments.			<p><b>Results:</b></p> <ul style="list-style-type: none"> <li>❖ -Most staff made favourable comments about PDE and valued the role of specialist nursing staff in educating and supporting patients' treatment decisions.</li> <li>❖ -Most patients recalled taking up part or all of the formal PDE on offer and reported finding it helpful overall.</li> <li>❖ -3 themes related to improving PDE identified:  <ul style="list-style-type: none"> <li>❖ <b>sub-optimal education;</b></li> <li>❖ <b>different perspectives between patients and staff;</b></li> <li>❖ <b>influence of patient experience</b></li> </ul> </li> </ul>	Education one to one sessions + group sessions + written materials							
UK							<p><b>Table 4 Themes and sub-themes</b></p> <table border="1"> <thead> <tr> <th>Themes</th> <th>Sub-themes</th> </tr> </thead> <tbody> <tr> <td>Sub-optimal education</td> <td>Restricted range of teaching methods and materials Bias in the presentation of information and treatment options</td> </tr> <tr> <td>Different perspectives between patients and staff</td> <td>The importance of informal education Approaches to treatment decision-making</td> </tr> <tr> <td>The influence of patient experience</td> <td>How other patients can influence decision-making The impact of distress</td> </tr> </tbody> </table> <p><b>a. Sub-optimal education</b></p> <ul style="list-style-type: none"> <li>❖ In making treatment decisions, some patients felt they unable to use information given because the <b>high volume and complexity of information meant</b></li> <li>❖ From staff perspective, written materials were designed so that patients had information to take home and consider over time.</li> <li>❖ However, it seemed that some patients were unable to take advantage of this positive intention</li> <li>❖ Another perspective on teaching materials came from patients who thought that they <b>were not 'real enough'</b>, and struggled to apply the information to their own lives.</li> <li>❖ Seeing different treatments being undertaken by real patients were all suggested as ways of improving the education</li> </ul> <p>-This suggests that patients would benefit from the use of a wider range of teaching methods, including interactive methods.</p> <p><b>Bias in the presentation of information and treatment options</b></p> <ul style="list-style-type: none"> <li>❖ Some patients thought that all treatment options were presented fairly and with equal emphasis, others <b>felt not all options had been presented to them</b> and that they had only found out about viable alternatives once they were on dialysis.</li> <li>❖ Some of these patients thought that <b>opportunities to talk to patients already on treatment</b> might have helped to give them a more balanced view of what life on dialysis might be like.</li> <li>❖ Staff were also aware of the potential for bias</li> <li>❖ However, all staff groups thought that the first conversation that doctors have with patients about treatment options is crucial in influencing treatment choice</li> </ul> <p><b>b. Different perspectives between patients and staff</b></p> <p><b>The importance of informal education</b></p> <ul style="list-style-type: none"> <li>❖ Staff were less aware than patients of how informal staff-patient conversations can influence patients' treatment decision-making.</li> <li>❖ Some patients may have atypical experiences or be biased against certain treatments</li> </ul>	Themes	Sub-themes	Sub-optimal education	Restricted range of teaching methods and materials Bias in the presentation of information and treatment options	Different perspectives between patients and staff	The importance of informal education Approaches to treatment decision-making	The influence of patient experience	How other patients can influence decision-making The impact of distress
Themes	Sub-themes														
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**Evidence Table : Effectiveness**  
**Question : How effective is Pre-dialysis Education Programme for advanced CKD patients?**

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**Evidence Table : Psychological/Societal implications (PATIENTS' KNOWLEDGE)**  
**Question : What are the psychological/societal implications of Pre-dialysis Education Programme for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
2. Dangulian R A, Cabanayan-Casasola C B, Evangelista N N et al. An education and counseling program for chronic kidney disease: knowledge. Kidney International Supplements.2013;3(2):215-218. Philippines	<p>Pre- and post-intervention study</p> <p><b>Objective:</b> To review the efficacy of pre-dialysis education programme and counselling program in improving chronic kidney disease (CKD) knowledge</p> <p><b>Methods:</b> -Incident CKD patients not yet on RRT from June 2009 to February 2010 answered questionnaires developed to determine health-seeking behaviour, perceived, and actual CKD knowledge. -An evaluation tool was administered before and after the education modules to determine its efficacy in improving CKD knowledge -Trained CKD educators, a nurse and a psychologist, conducted structured educational modules according to CKD stage -After each module patients were instructed to return after every out-patient follow-up for completion of the education modules and further counselling -Patients were given take-home materials after each visit and were instructed about the recommended completion times for the modules:  <ul style="list-style-type: none"> <li>❖ within 3–4 months for CKD stages 1–3,</li> <li>❖ within 1–2 months for CKD stage 4,</li> <li>❖ and within 1 month for CKD stage 5,</li> </ul> in order to improve the retention of the information provided for this group  -Evaluation tools consisted of four self-administered questionnaires:  <ul style="list-style-type: none"> <li>❖ a 30-item tool: 22 items on general CKD knowledge and 8 items on RRT;</li> <li>❖ three 10-item tools covering lessons learned from each of the three CKD Clinic visits,</li> <li>❖ an 8-item tool on patients' health-care seeking behaviour prior to consultation at our hospital;</li> <li>❖ and a 4-item questionnaire on perceived CKD knowledge.</li> </ul> -The 30-item tool evaluated patients' baseline or actual knowledge (overall pre-test) and again after the patient completed all the education modules (overall post-test).  -The 10-item tools were administered after each visit to reinforce the lessons learned.  -Overall pre- and post-test scores were compared to determine if there was improvement in the patient's CKD knowledge.</p>	II-3	<p>299 CKD patients: -60% males, -mean age 49 years, -and 37% were high-school graduates. -60% CKD Stage 5 and 19% Stage 4. -Only a few were from earlier stages: 10% Stage 3, 1% Stage 2, and 2% Stage 1.</p>	<p>Pre-dialysis education programme</p> <p>Structured educational modules according to CKD stage:  <b>Visit 1</b> – modules 1–5 on renal anatomy and function, types of kidney failure, CKD aetiology, and stages, signs and symptoms, nutrition, and medications prescribed to CKD patients.  <b>Visit 2</b> – modules 6–8 on laboratory tests in CKD, metabolic effects of CKD such as anaemia, bone disease, and other complications, preservation of kidney function.  <b>Visit 3</b> – modules 9–13 on RRT options and treatment cost.  <b>-CKD stages 4 and 5:</b>  <b>Visit 1</b> – modules 1–5 and 9–13. These were discussed simultaneously to give the patients time to make an informed decision about the treatment options for their illness, since at this late stage the requirement for RRT was imminent.  <b>Visit 2</b> – modules 6–8.</p>		6 months	<p><b>Results:</b>  <b>Perceived CKD knowledge</b>  <ul style="list-style-type: none"> <li>❖ Majority (94%) had no knowledge about CKD, 30% had little, 28% some, and 8% claimed a great deal of knowledge.</li> <li>❖ Most were unaware of RRT options; 70%, 64.2%, and 54.2% had no knowledge of peritoneal dialysis, haemodialysis, and transplantation, respectively.</li> <li>❖ No significant association between CKD stage and knowledge of RRT.</li> </ul> <b>Actual CKD knowledge</b>  <ul style="list-style-type: none"> <li>❖ 90% scored &lt;60% on general knowledge of CKD treatment options.</li> <li>❖ Among patients who claimed that they had extensive CKD knowledge, all scored &lt;60% in the actual knowledge questionnaire.</li> </ul> <b>Efficacy of education modules</b>  <ul style="list-style-type: none"> <li>❖ Only 83 out of 299 patients (28%) completed the modules within 6-month follow-up period.</li> <li>❖ Most patient who did not complete the program (83%), no longer presented for f/up after 3 months (poor compliance due to financial, came only for diagnosis, too ill to return for f/up, lack of understanding, low priority given)</li> <li>❖ <b>Significant increase in mean overall pre-test scores of CKD knowledge</b> from 7.0±5.11 (maximum score 30) to 23.0±4.5 (maximum score 30) points in the overall post-test, with 69% (57 out of 83 patients) scoring ≥75% (P&lt;0.00001).</li> <li>❖ An increase in number of patients (58%) who gained knowledge on the different aspects of CKD after completing the educational modules except for the topic on signs and symptoms of CKD.</li> <li>❖ Patients aged &lt;50 years had significantly higher pre- and post-test results compared to older age groups (P=0.007).</li> <li>❖ Pre-test scores were significantly higher in at least high school graduates (P&lt;0.03)</li> <li>❖ Sex and CKD stage were not associated with better test scores.</li> </ul> <p><b>Authors conclusion:</b>  The CKD education and counselling program was effective in improving patients' knowledge of their disease. Elderly and non-high-school graduates of a financially disadvantaged population may need specially designed education modules to improve their comprehension</p> </p>	<p>72% (215 pts) did not complete the modules</p> <p>Education by multiple individualised sessions</p>

**Evidence Table : Psychological implications (ADHERENCE, DEPRESSION AND ANXIETY LEVEL)  
Question : What are the psychological implications of Pre-dialysis Education Programme for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
1. Garcia-Ulana H, Remor E, del Peso G et al. Motivational interviewing promotes adherence and improves wellbeing in pre-dialysis patients with advanced chronic kidney disease. J Clin Psychol Med Settings. 2014;21(1):103-15.	Pre- and post- intervention study <b>Objective:</b> To determine the effectiveness of an individual, pre-dialysis intervention program in terms of adherence, emotional state and health related quality of life (HRQL) in pre-dialysis patients with advanced chronic kidney disease <b>Method:</b> -All 52 patients in the study sample met the following eligibility criteria: ❖ older than 18 years; ❖ diagnosis of advanced CKD under pre-dialysis treatment; ❖ GFR of 20 ml/min or less; ❖ no DSM IV psychiatric diagnoses; ❖ able to read and speak Spanish; ❖ and had accepted and signed an informed consent form to participate in the program	II-3	42 patients advanced chronic kidney disease included  -Average age 68years old -Most were men (60%), married (59%), unemployed (69%)	Pre-dialysis intervention program  -6-month individual program was managed by a trained health psychologist. -Every patient entering the study attended their regular appointments with nephrologist, the nurse and nutritionist -Each patient received 6 individual monthly face-to-face sessions (90-min duration) with health psychologist -Every session had two distinct aims: a. first 45 min of sessions provided training in skills that facilitated the patient's adaptation to the ACKD and its treatments, b. last 45 min helped improve adherence to motivational interviewing		6 months	<b>Results:</b> After the intervention, patients reported significantly higher levels of adherence, lower depression and anxiety levels, and better HRQL (i.e., general health and emotional role domains).  <b>Adherence level</b> ❖ Patients reported <b>better adherence to treatments</b> after the individual session program as measured by the adherence to treatment survey (Higher score indicates greater degree of treatment adherence)  Mean score (SD) range: Pre-test 27.12 (2.74), 22-33 vs Post-test 31.45 (2.05), 26-33 (P<0.001) and by the Morisky-Green-Lewine Test (p<0.001). ❖ Rates of non-adherence to oral medication, as measured by the Morisky-Green-Lewine Test, decreased significantly from before the intervention (29 %) to after the intervention (16%).  <b>Depression and anxiety level</b> ❖ Depression levels <b>significantly decreased</b> from before (M = 10.92) to after (M = 8.86) the intervention, ❖ as did anxiety levels (from M = 18.22 to M = 14.41)  <b>Health-related quality of life (HRQL)</b> ❖ Health-related quality of life (HRQL) scores on the General Health subscale <b>increased significantly</b> (from M = 37.19 to M = 45.97), as did scores on the Emotional Role subscale (from M = 71.82 to M = 77.57). ❖ No effects were found in other domains of HRQL (physical function, physical role, bodily pain, vitality, social function, mental health)  Clinical markers of advanced CKD patients in pre-dialysis before and after the program ❖ Biochemical parameters were controlled significantly better after the intervention, except for iPTH.  <b>Authors conclusion:</b> These findings highlight the potential benefit of applying individual psycho-educational intervention programs based on motivational interviewing and using the stages of change model to promote adherence and wellbeing in advanced CKD patients.	Small sample size, Education by multiple individual sessions

**Evidence Table : Cost-effectiveness**  
**Question : Is Pre-dialysis education programme cost-effective for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristics	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
1. Yu YJ, Wu IW, Huang CY et al. Multidisciplinary pre-dialysis education reduced the inpatient and total medical costs of the first 6 months of dialysis in incident haemodialysis patients. PLOS One. 2014;9(11):e112820. Taiwan	<p>Randomised controlled trial with cost-analysis</p> <p><b>Objective:</b> To analyse the medical expenditure and utilisation incurred during the first 6 months of dialysis initiation in 425 incident haemodialysis patients who were randomised into multidisciplinary pre-dialysis education (MPE) and non-MPE groups before reaching ESRD.</p> <p><b>Methods:</b> -A total of 2280 patients were enrolled in the study and were randomly divided into the MPE group and the non-MPE group by using a random table at study entry. -445 patients reached ESRD needing haemodialysis after a mean follow-up of 33±2.6 months:  <ul style="list-style-type: none"> <li>❖ 232 patients in the MPE group</li> <li>❖ 213 patients in the non-MPE group</li> </ul> </p> <p>--Program consisted of an integrated course involving individual lectures on renal health, delivered by the case-management nurse            -Lectures focused on nutrition, lifestyle, nephrotoxin avoidance, dietary principles, and pharmacological regimens.            -Case-management nurse contacted the patients to ensure timely follow-up            -For Stage IV CKD patients; the program included  <ul style="list-style-type: none"> <li>❖ discussions on the management of complications associated with CKD,</li> <li>❖ indications of renal replacement therapy,</li> <li>❖ and evaluation of vascular or peritoneal access.</li> </ul> </p> <p>-For Stage V CKD:  <ul style="list-style-type: none"> <li>❖ monitor for timely initiation of renal replacement therapies, the care of vascular or peritoneal access,</li> <li>❖ dialysis-associated complications,</li> <li>❖ and registration for inclusion in the renal transplantation waiting list.</li> </ul> </p> <p>-All patients received dietary counselling biannually from a dietitian.            -Case-management nurse often contacted the participants by telephone to encourage them to inform their nephrologists of their symptoms and to reinforce the importance of medical visits.            -The MPE program was discontinued once renal replacement therapies were initiate            -Medical expenditure and utilization in the first 6 months of initiation of haemodialysis in these 445 patients were accurately recorded and compared between MPE and non-MPE patients            -Medical service utilisation was calculated as the frequency of outpatient visits and the frequency and length of hospitalization.            -Medical service expenditures included outpatient expenditures (all costs including physicians and nursing fees, examinations, surgery, and medication) and inpatient expenditures (all costs including laboratory testing, imaging testing, medications, surgery and consulting, ward and administrative, nasogastric tube feeding, and haemodialysis fees)            -The expenditures for each participant were totalled to compute the sum of ambulatory and inpatient medical service utilization costs and expenditures.            -Analysis of costs only included those medical costs for which our hospitals made reimbursement claims to the NHI.            -The salaries, overheads, and administrative costs of the care team were not included.</p>	II-2	<p>445 advanced CKD patients:  <ul style="list-style-type: none"> <li>❖ 232 patients in MPE group</li> <li>❖ 213 patients in non-MPE group</li> </ul> </p> <p>-Mean age of patients was 63.8±13.2 years, and 221 (49.7%) of them were men            -Mean eGFR 7.49 ± 3.1 MPE group and mean eGFR 7.87 ± 3.6 in the non-MPE group</p>	<p>Multidisciplinary pre-dialysis education (MPE)            -MPE program comprised a nurse for case management, social workers, dietitians, haemodialysis, peritoneal dialysis patient volunteers and 10 nephrologists</p>	<p>Non-MPE            -Same group of nephrologists instructed patients about renal function, evaluation of laboratory data, and clinical indicators of chronic renal failure, and strategies for its mx and tx            -General principles of HD and PD explained when patients at Stage 4 CKD</p>	6 months of dialysis initiation	<p><b>Results:</b>            Hospitalisation and vascular access related surgeries  <ul style="list-style-type: none"> <li>❖ MPE patients had significantly fewer and shorter lengths of hospitalisation (median (IQR) 0 (15) vs. 8 (27) days, p&lt;0.001) than non-MPE patients.</li> <li>❖ Eighty-eight (37.9%) patients in the MPE group had at least one hospitalisation, compared with 127 patients (59.6%) in the non-MPE group (p&lt;0.001).</li> <li>❖ Participation in MPE program reduced cardiovascular hospitalisation in first 6 months post dialysis (18.53% vs. 29.58%, p=0.007).</li> <li>❖ MPE group were more likely to have fewer vascular access related surgeries during the first admission [35 patients (15.09%) vs. 55 (25.82%), p=0.005].</li> </ul> </p> <p><b>Medical Cost</b>  <ul style="list-style-type: none"> <li>❖ MPE patients tended to have lower total medical cost in the first 6 months after haemodialysis initiation (9147.6 ± 0.1 USD/patient vs. 11190.6 ± 0.1 USD/patient, p=0.003)</li> <li>❖ medical cost of inpatient service was significantly lower in MPE patients</li> </ul> </p> <p>mean 2261.8 ± 5635.8 USD/patient in MPE patients vs. mean 3698.8 ± 5540.9 USD/patient in non-MPE patients, respectively, p&lt;0.001, owing to reduced cardiovascular hospitalisation and vascular access-related surgeries.            The decreased inpatient and total medical cost associated with MPE were independent of patients' demographic characteristics, concomitant disease, baseline biochemistry and use of double-lumen catheter at initiation of hemodialysis.</p> <p><b>Authors conclusion:</b>            Participation of multidisciplinary education in pre-dialysis period was independently associated with reduction in the inpatient and total medical expenditures of the first 6 months post-dialysis owing to decreased inpatient service utilization secondary to cardiovascular causes and vascular access-related surgeries.</p>	<p>Education by individual sessions with team</p>

**Evidence Table : Cost-effectiveness**  
**Question : Is Pre-dialysis education programme cost-effective for advanced CKD patients?**

Bibliographic Citation	Study Type/Methods	LE	Number of Patients & Patient Characteristic	Intervention	Comparison	Length of Follow Up	Outcome Measures/Effect Size	General Comments
2. Wei SY, Chang YY, Mau LW et al. Chronic kidney disease care program improves quality of pre-end-stage renal disease care and reduces medical costs. Nephrology (Carlton). 2010;15(1):108-115. Taiwan	<p>Retrospective cohort study with cost-analysis</p> <p><b>Objective:</b> To evaluate the effectiveness of CKD care program on pre-end-stage renal disease (ESRD) care</p> <p><b>Method:</b> -Total of 140 incident ESRD patients, who started HD in the period from August 2004 to July 2005 from the two study hospitals were retrospectively reviewed -Study subjects divided into: ❖ <b>'CKD Care Group'</b> (71 incident HD patients who received the CKD care program intervention for at least 6 months before initiation of HD), ❖ <b>'Nephrologist Care Group'</b> (69 incident HD patients who were cared for by nephrologists alone for at least 6 months before initiation of dialysis)</p> <p>-CKD Care Program included nephrologists, renal nurses and dieticians as the core members of a multidisciplinary team responsible for caring for patients at different CKD stages. -CKD patients, invited to join the care program by the nephrologist, were referred to well-trained renal nurses and dieticians. -Different goals and education contents, according to stages of CKD and pre-set clinical protocols, were planned and delivered systematically approximately 30–45 min at each visit. -Every patient received follow-up visits with clinical evaluation, laboratory examinations, nursing and dietary education, which was taken every 3 months for CKD stages 3 and 4, and every 1–2 months for stage 5 patients. -Primary goals included: ❖ slowing down the deterioration of renal function, ❖ early preparations for dialysis, ❖ reducing of risk of complications, ❖ and ensuring the process of entering dialysis smoothly and safely.</p> <p>-Nephrologist Care Group were all treated by nephrologists from the same department, but they did not receive nursing education and dietary counselling by CKD nurses and dieticians. -Principle of CKD care, including medications and early preparation of vascular access, were routinely delivered to patients by the nephrologists -End-point of observation was dialysis initiation. -Quality indicators for evaluation included: ❖ Status of recombinant human erythropoietin (rHuEPO) treatment, ❖ Vascular access preparation ❖ Hospitalisation for initiation of dialysis</p> <p>which were compared between two groups -Medical services utilisation and costs were analysed from 6 months before initiation of dialysis to the time of the first HD, and the time periods were divided into '6 months before dialysis', 'at dialysis initiation', and the sum of the two periods as the 'total period of observation'. -Indicators of service utilisation included: ❖ Average outpatient visits before dialysis, ❖ Frequency of hospitalisation before dialysis, ❖ Percentage of patient hospitalisation at dialysis initiation, ❖ Average length of stay (LOS)</p> <p>- Measurement of costs in this study only included direct medical costs for which the study hospitals made claims to the NHI for reimbursement -Salaries, overheads and indirect costs of the care team were not included</p>	II-2	<p>140 incident ESRD patients who started dialysis and divided into: -CKD Care Group (71 patients) -Nephrologist Care Group (69 patients) -Mean eGFR, 1.73 mL/min per 1.73 m<sup>2</sup>, 3.8 ± 1.3 in CKD Care Group, 3.7 ± 1.5 in Nephrologist care group</p>	CKD care program	Nephrologist Care Group	6 months before dialysis	<p><b>Results:</b> Quality of pre-ESRD care <b>Preparation at dialysis initiation: EPO treatment</b> -No significant difference on percentages of patients who received rHuEPO treatment at initiation of HD and the average monthly dosage of rHuEPO <b>Preparations at dialysis initiation: vascular access</b> -Vascular access had been created before HD in 57.7% of patients in the CKD Care Group vs. only 37.7% of the Nephrologist Care Group (P = 0.017). -Percentage of patients who started HD with created vascular access without the insertion of double lumen catheter was 50.7% in the CKD Care Group, vs. 29.0% in the Nephrologist Care Group (P = 0.009) <b>Preparations at dialysis initiation: hospitalisation</b> -Percentage of patients who were not hospitalised for initiation of HD was 40.8% in CKD Care Group, vs. 18.8% in the Nephrologist Care Group (P &lt; 0.005). -Most patients in Nephrologist Care Group (81.2%) had their first HD through inpatient HD. <b>Frequency of services utilisation</b> <b>Period of 6 months before dialysis'</b> -More frequent outpatient visits in CKD Care Group (9.9 ± 5.5 vs 5.5 ± 5.5 P&lt;0.001), but the frequency of hospitalisation and length of stay had no difference with Nephrologist Care Group. <b>Period of 'at dialysis initiation'</b> -Lower percentage of hospitalisation for initiation of dialysis in the CKD Care Group (59.2% vs 81.2%, P= 0.005). -Length of stay in hospital much shorter for CKD Care Group. (6.6days ± 16.2 vs. 16.2days ± 16.2, P &lt;0.001) <b>Medical costs</b> ❖ Participation in CKD care program, though with higher costs during the 6 months before dialysis (\$US1428 +/- 2049 vs US\$675 +/- 962/patient, P &lt; 0.001). ❖ was significantly associated with lower medical costs at dialysis initiation (\$US942 +/- 1941 vs \$US2410 +/- 2481/patient, P &lt; 0.001) ❖ and for the total period of observation (\$US2674 +/- 2780 vs \$US3872 +/- 3270/patient, P = 0.009) -The cost-saving effect came through the early preparation of vascular access and the lack of hospitalization at dialysis initiation. <b>Authors conclusion:</b> CKD care program successfully helps pre-ESRD patients to proceed into dialysis initiation with better preparedness, which reduces the probability of emergency dialysis through hospitalization and saves health dollars from CKD to ESRD</p>	Education by multiple individual sessions



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**SURVEY QUESTIONNAIRE**

**Title of Survey: Pre-dialysis Education Programme for Chronic Kidney Disease (CKD) Patients: How would you like it to be?**

Available at: <https://tinyurl.com/predialysissurvey>

**Purpose of survey**

The purpose of this survey is to understand the preferences of patients, carers and healthcare staff for pre-dialysis education so that we can develop a programme that better meet their needs. This survey would take no more than 10 minutes.

**Informed consent**

Your participation in this survey is voluntary. You may choose not to participate. If you decide to participate in this survey, you may withdraw at any time. If you decide not to participate in this survey or if you withdraw from participating at any time, you will not be penalized. Your responses in this survey will be anonymous and confidential.

I have read the above information and I voluntarily agree to be part of this survey and to provide necessary information to the doctor, nurse, or other staff members, as requested.

- Yes  
 No

Kindly fill in your name.

.....

**Section 1 of 3: Socio-demographics**

1. How old are you?

.....

2. What is your gender?

- Male  
 Female

Other: .....

3. What is your level of education?

- Primary school  
 Secondary school  
 Tertiary education (college, university)  
 None

### Section 2 of 3: Patients' or carers' treatment experience

4. Are you currently a patient diagnosed with chronic kidney disease (CKD); a carer of family member/ partner/ child diagnosed with CKD or a part of healthcare team for CKD patients?

- Patient
- Carer
- Healthcare staff (skip question 6 and 7)

5. (If patient or carer) Which hospital are you (or the patient you are caring for) currently under follow-up?

(If healthcare staff) Where do you work?

- Hospital Kuala Lumpur
- Hospital Ampang
- Hospital Tengku Ampuan Rahimah, Klang

6. Did you (or the patient you are caring for) receive pre-dialysis education prior to initiation of dialysis?

- Yes
- No

7. How long have you (or the patient you are caring for) been on dialysis?

- < 6 months
- 6-12 months
- 12-18 months
- > 18 months
- Not on dialysis

### Section 3 of 3: Patients' or carers' preferences

8. Who do you think should be the one to provide pre-dialysis education to CKD patients? (You may select one or more)

- Doctor
- Nurse
- Medical assistant
- Other: .....

9. Do you think CKD patients would also benefit from receiving counselling or advice from the following healthcare professionals? (You may select one or more)

- Dietician
- Psychologist
- Pharmacist
- Social worker
- Patient representative
- Other: .....

10. What type of information do you think is important for CKD patients to know prior to starting dialysis? (You may select one or more)

- How dialysis is performed
- Advantages and disadvantages of each treatment option (dialysis, kidney transplantation, conservative care without dialysis)
- Side effects of dialysis
- Costs associated with each treatment option (dialysis, kidney transplantation, conservative care without dialysis)
- Dietary advice (e.g. what to eat before, during and after dialysis)
- How to dress for dialysis access
- How dialysis may affect daily life (family, work, school, or leisure activities)
- Medications & supplements associated with each treatment option (dialysis, kidney transplantation, conservative care without dialysis)
- Other: .....

11. How do you think pre-dialysis education should be conducted?

- Individually (one-to-one)
- GroupSD session (2-5 people)
- Group session (5-10 people)
- Other: .....

12. Should it be conducted in a single session or multiple sessions?

- One single session with one **single educator** (for example: doctor or nurse)
- One single session with **multiple educators** (for example: doctor, nurse, pharmacist, dietician and psychologist)
- Multiple sessions with each educator **by appointment** (for example: doctor, nurse, pharmacist, dietician and psychologist)
- Multiple sessions with each educator **upon request only** (for example: doctor, nurse, pharmacist, dietician and psychologist)
- Other: .....

13. What education material(s) should be included in the pre-dialysis education? (You may select one or more)

- Leaflet / Pamphlet
- Audio-visual tools such as videos or slide presentations
- Information about useful online websites or videos to refer at your own free time
- Hands-on session to show how each dialysis option works
- Other: .....

14. How soon do you think CKD patients should start receiving pre-dialysis education prior to dialysis?

- 1 month before
- 2 months before
- 3 months before
- 5 months before
- 6 months before
- Not sure

15. How long should each pre-dialysis education session be?

- < 15 minutes
- 15-30 minutes
- 30-45 minutes
- 45-60 minutes
- > 60 minutes

16. How frequent do you think pre-dialysis education should be given?

- Once a month
- Once every 2 months
- Once every 3 months
- Once every 6 months
- Once a year
- Other: .....

17. Which of the venue below would be suitable for pre-dialysis education? (You may select one or more)

- Hospital
- Community clinic
- One-stop centre
- Dialysis centre
- Other: .....

18. Do you think it would be helpful to be part of a patient support group to discuss about solving problems faced in real life?

- Yes
- No
- Maybe

19. Do you have any other comments/suggestions to improve pre-dialysis education?

.....

.....

.....

20. Following pre-dialysis education, do you think it is important that the doctor shares the decision-making about starting dialysis with the patient?

- Yes
- No
- Maybe

**That's the end of our survey.**  
**Thank you for taking the time to complete this survey.**  
**Your contribution is much appreciated!**

## SUGGESTIONS TO IMPROVE PRE-DIALYSIS EDUCATION PROGRAMME

1. Programme must be well-organised according to planned schedule and should accommodate the patient's schedule so that the patient's own time is not affected.
2. Emotional and spiritual information or support should be provided.
3. Educators must be sensitive and provide more human touch to address patients' needs and emotions as CKD patients may be fragile and depressed during the pre-dialysis stage.
4. Weekend sessions are preferred to minimise interference with daily work.
5. Family members should attend pre-dialysis education session with patients to improve understanding of the disease and treatment. Family members are very important for patients throughout the CKD journey.
6. There should be consistent attendance from the same family member/partner or friend.
7. Carers need to know how to help the patient make decisions.
8. Education should be extended to carers as they should know about symptoms of kidney failure.
9. Education to carers should be provided.
10. Educators must be qualified and knowledgeable to teach and answer questions correctly.
11. Nurses must have sufficient experience before educating patients.
12. Good communication between healthcare staff and patients especially before starting each dialysis is important to ensure accuracy of information such as body weight, dry weight and dietary intake.
13. Prevention of CKD should be included in the module.
14. There should be early education on disease progression and preventive measures to avoid ESRD.
15. Counselling by a psychologist can be given by appointment for patients who need it.
16. Contents of the module should be comprehensive and include demonstration.
17. Pre-dialysis education is very important as it can help patients feel more comfortable to start dialysis.
18. PDEP can be organised with any campaign in other clinics.







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