Victorian Framework for Continuing Renal Patient Education

Effectively educating patients with Chronic Kidney Disease, Stage 4 to End of Life:
A guide for health care professionals

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The department also wishes to thank the many organisations and healthcare professionals who contributed their expertise and knowledge to developing this document.
Foreword

This section is yet to be inserted.
1. Setting the scene

Introduction

Purpose of Framework

The Victorian Framework for Continuing Renal Patient Education (the Framework) is a guide for health care professionals to deliver effective education to patients with chronic kidney disease (CKD). The Framework is designed for application across the continuum of care from Stage 4 CKD to end of life.

It is intended that the Framework will be complemented by a toolkit of resources for health care professionals. The toolkit is planned to include a recommended ‘Patient syllabus’ as well as a collection of key resources, tips and tools to assist renal health care professionals in implementing the Framework and delivering effective renal patient education.

Target Audience

The Framework is intended primarily for use by educators and other health care professionals in the Victorian public and private sectors, caring for patients with Stage 4 and 5 CKD and through to end of life, their carers and families.

Contents of Framework

The Framework consists of:

- Key principles that underpin effective renal patient education.
- Key recommendations to guide health care professionals on delivering effective education to patients from Stage 4 CKD until end of life.
- A set of minimum standards to apply the principles and recommendations to everyday practice.

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1 The term ‘patient’ used in this document refers to the particular cohort from Stage 4 CKD until end of life. The use of the term rather than ‘consumer’ is based on the premise that once an individual reaches this point in the progression of their disease, they are usually already known by their renal service and so already a ‘patient’. The terms ‘people’ and ‘person’ are also used interchangeably with ‘patient’, especially in the context of person-centred care. The term ‘consumer’ has not been used but it is acknowledged that this term could also apply to this cohort.
Background

CKD is a progressive condition that can ultimately lead to kidney failure. As the disease progresses, patients have complex decisions to make regarding their treatment options and lifestyle changes.

In order to engage patients and their families in a shared decision-making process regarding their treatment options and ongoing self-management, patients need access to appropriate and tailored information and support. Patient education received prior to treatment commencement may lead to improved outcomes for the patient, such as reduced mortality in late-stage CKD.

Best practice in renal education has been defined in the KHA-CARI guidelines and the NICE guidelines. These guidelines recommend that patient information is timely and tailored appropriately to patient preferences, cultural and social background, CKD disease and cause, stage, risk of progression, associated complications and treatment options. Kidney Health Australia’s (KHA) Kidney Disease Education Pathway Guidelines specify that education is a team responsibility, and is not only required prior to the treatment journey but needs to be revisited throughout the patient’s life.

However, KHA consumer survey data indicated there is variation in patient education practices across Victoria, and Australia. Some inconsistencies were evident regarding: the method and delivery format; time devoted to education; the timing of information delivery; and the provision of information, such as dialysis type and location.

In 2011, the Victorian Renal Clinical Network Leadership group (VRCN-LG) endorsed the introduction of a Key Performance Indicator: Proportion of new, planned patients that have received CKD education before starting dialysis (KPI-1). An audit of this KPI highlighted discrepancies in the provision of education. Of note, data from this KPI does not currently indicate the effectiveness of renal patient education, and education for patients choosing treatments other than dialysis is not captured or measured.

The approach to advancing renal patient education in Victoria has since been informed through:

- the 2014 Victorian Renal Pathways and Model of Care project workshop
- a REAP Investment Logic Map exercise in December 2014 (Appendix A)
- a Victorian Renal Educators Workshop in April 2015

Following these initiatives, the VRCN-LG endorsed funding for the Renal Education Advancement Project (REAP).

The REAP aims to develop and disseminate an effective renal education strategy for Victorians with Stage 4 and 5 CKD. The strategy is intended to guide and assist renal health services adopt best practice in patient education, through a range of activities including the development of this Framework.

The REAP approach complements the Renal Integrated Care Pathway (RICP). The RICP aims to guide renal service providers to deliver services for Victorians with CKD in a consistent, safe and evidenced-based manner that is coordinated, responsive, accessible and sustainable.
The CKD Patient Journey

The journey experienced by people with CKD from early detection and diagnosis, through to treatment and ultimately end-of-life care will vary greatly from one person to another. While Figure 1 presents a linear process for five steps in care, the reality is that the experience is much more complex.[1]

Figure 1: Diagram of key steps in care in the CKD patient journey

![Diagram of key steps in care in the CKD patient journey]


The Victorian Framework for Continuing Renal Patient Education focuses on steps 3, 4 and 5 of the linear diagram shown in Figure 1 above i.e. from Preparation for treatment to Management of end of life care.

The Framework therefore refers to the CKD patient education journey as the patient’s experience from diagnosis of Stage 4 CKD through to end of life.

The initiation of treatment for CKD at Stage 4 or 5 is a well-established patient pathway in renal services.[7] When it is clear that kidney failure is likely, a patient needs to consider life-long treatment.[7] The treatment options generally available to patients at this point are listed in Table 1.
Table 1. Treatment Options for ESKD

<table>
<thead>
<tr>
<th>Transplantation</th>
<th>Live donor kidney transplant (Pre-emptive, before dialysis)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Live donor kidney transplant (after dialysis)</td>
</tr>
<tr>
<td></td>
<td>Deceased Donor kidney transplant (after dialysis)</td>
</tr>
<tr>
<td>Dialysis</td>
<td>Home-based dialysis:</td>
</tr>
<tr>
<td></td>
<td>Peritoneal dialysis</td>
</tr>
<tr>
<td></td>
<td>Haemodialysis</td>
</tr>
<tr>
<td></td>
<td>(Thrice weekly, second daily, extended hour (nocturnal))</td>
</tr>
<tr>
<td></td>
<td>Satellite-based haemodialysis (private or public)</td>
</tr>
<tr>
<td>Supportive Care</td>
<td>Supportive care without dialysis or transplant</td>
</tr>
</tbody>
</table>

Some patients are limited by their co-existing medical conditions, while others have all the options available to them \( ^{14, 15} \). Patients face the difficulty of needing to choose the most suitable treatment option to them. It is at this point of care that effective renal patient education becomes critical.
Patient education

There are multiple factors that can impact the effectiveness of patient education. This Framework hones in on the education relevant to those from Stage 4 CKD through to end of life.

The Framework’s definition of effective renal patient education in this context is:

a process of communication and engagement with patients that enables the exchange of appropriate, timely, current and evidence-based information and support at various key points across the patient journey from Stage 4 CKD to end of life. Throughout this process, the health care professional acts as a patient educator and supporter and works in partnership with the patient, carer and family to facilitate informed and shared decision-making about treatment options and support for ongoing management and self-care.\(^{16}\)

This definition supports that education for patients from Stage 4 through to end of life needs to:

- be responsive and appropriate to the social, demographic, geographic, cognitive, cultural and linguistic needs of the patient,\(^ {1, 17} \)
- build a patient’s understanding of the benefits and risks of all treatments available to them,\(^ {18}\)
- engage patients and their families in a shared decision-making process that achieves informed consent to treatment,\(^ {19, 20} \)
- extend beyond purely making a decision about treatment options,\(^ {6, 7, 21} \)
- support a patient’s understanding, acceptance and self-care of their condition, its prognosis and timing of therapy, and
- include information, support and encouragement to delay disease progression and maintain quality of life.

The role of the educator

The role of the patient educator is usually in the form of a CKD educator (other terms for educator may be coordinator, facilitator, or administrator). Often the educator is a CKD nurse practitioner or a CKD clinical nurse consultant. Transplant and renal supportive care may also have specialty educators.

The Framework defines the patient educator as:

a health care professional whose primary role is to provide information and support to patients with CKD, their carers and families to facilitate an understanding of the patient’s health status, diagnosis and treatment options and ongoing management.

However, there are several roles alongside the primary patient educator role that have an equally important responsibility for educating the patient, on aspects relevant to their role and expertise. This includes any member of the renal health team, such as a nurse, dietitian, pharmacist, social worker, psychologist, nephrologist, registrar and even a peer or peer mentor\(^ {2} \).\(^ {22, 23} \)

Other members that may be involved in the education process include a physiotherapist, occupational therapist, vascular access coordinator, dialysis technician and palliative care staff.

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\(^ {2} \) The terms ‘peer’ and ‘peer mentor’ used in this document refer to a person / patient who has experience in managing their CKD and can share their knowledge and experience to another patient, in a personalised manner. A peer or peer mentor does not offer medical advice but can offer empathy and support, discuss ideas on how to cope and provide a sense of hope. They should be trained to refer patients back to the renal team if medical queries arise. The spectrum of support provided by a peer can extend from their attendance and participation as a speaker at an education session through to a personalised and ongoing mentoring role either in person or via a telehealth program or service.
2. Key principles of effective patient education

The following principles summarise the key concepts in practice that are integral to effective patient education. These principles underpin each of the Framework's recommendations and standards that follow.

1. Equity and access
   Education is provided inclusive of cultural or linguistic background, geographic location, age or gender. Barriers to patient access are assessed and removed as early on as possible.

2. Quality and safety
   Education is based on evidence and delivered by a specialised team in a way that is understandable and enables informed decision-making and action.

3. Person centred and fostering a partnership in care
   Education is achieved by a health professional working in partnership with the patient, carer and family, exchanging information that is tailored to the needs and preferences of the patient.

4. Timely and ongoing through the patient journey
   Education is an ongoing process occurring at appropriate key points across the patient journey. It facilitates and prepares for lifestyle changes that interrelate with mental, social and other areas of the patient's life.

5. Action oriented and supporting positive lifestyle changes
   Education is designed to motivate patients and encourage self-management. It focuses on delivering information in a way that relates to behavioural outcomes and that leads to the patient's improved quality of life.
### 3. Recommendations for renal health care professionals

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Patient education and information that is person and family centred should:</th>
</tr>
</thead>
</table>
| **Recommendation 1** | a) be culturally and linguistically appropriate, tailored to individual needs and enable informed and shared decision making.\[^{6, 24-26}\]  
b) be tailored to the stage of CKD, the associated complications and the risk of progression to kidney failure.\[^{7}\]  
c) include follow-up support that encourages positive lifestyle changes and contributes to improving the patient’s quality of life.\[^{24, 27}\]  
d) be relevant to the patient’s social and psychological needs, and include referral to appropriate professionals or services, as required.\[^{7, 8, 28}\] |
| **Recommendation 2** | Patient education and information should be delivered:  
a) recurrently at appropriate key points along the patient journey until end of life.\[^{7, 8, 24, 28}\]  
b) by healthcare professionals who are committed to developing their skills and experience in facilitating effective communication, adult learning, cultural responsiveness and health literacy.\[^{8, 24, 26}\]  
c) by a multidisciplinary renal team, that can include a range of members as appropriate, such as a nurse, dietitian, pharmacist, social worker, psychologist, nephrologist, registrar and a peer or peer mentor.\[^{8, 26, 28, 29}\]  
d) by a renal service that recognises that CKD education underpins a patient’s right to clear and understandable information about services, treatment and options.\[^{8, 26, 30, 31}\] |
| **Recommendation 3** | The content of patient education and information should:  
a) be of high quality, accurate, consistent with current, evidence-based practice and with the Victorian Renal Clinical Network’s key performance indicator for education.\[^{1, 8, 17, 25, 32}\]  
b) be consistent with health literacy needs and promote self-learning.\[^{1, 8, 17, 25, 32}\]  
c) extend beyond treatment option information and support the patient’s self-management.\[^{7, 8, 16, 18, 19, 24, 28}\] |
| **Recommendation 4** | Education and information about CKD treatment options should:  
a) cover all treatment options, including the risks, benefits and implications of each option in the context of the patient and their carer / family’s lives.\[^{18, 33}\]  
b) be offered to the patient with stage 4 CKD, or to any patient considering switching to another treatment, in sufficient time to process the information and make an informed decision before treatment is required.\[^{8, 7, 8, 31, 33}\]  
c) be provided by healthcare professionals who have specialist knowledge about CKD and its treatment options.\[^{7, 26}\]  
d) include encouragement and support of the patient, their carer and/or family to be actively engaged in the education and decision-making process and to achieve informed consent regarding their selected treatment.\[^{8, 26}\] |
4. Linking the recommendations to standards in every day practice

As shown below, each of the Framework’s recommendations link to a set of agreed **minimum standards**. The standards offer practical steps in every day practice for health professionals to achieve effective and consistent delivery of information and support at appropriate key points in the patient’s journey. The standards can also describe quality measures for renal health services to drive improvement in patient education.

Each recommendation and standard is underpinned by the Framework’s principles of effective renal patient education, as defined on page 12:

- Equity and access
- Quality and safety
- Person-centred and fostering a partnership in care
- Timely and ongoing through the patient journey
- Action-oriented and supporting positive lifestyle changes

<table>
<thead>
<tr>
<th>RECOMMENDATIONS (R)</th>
<th>MINIMUM STANDARDS (S)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>R1. Patient education and information that is person and family centred should:</strong></td>
<td><strong>S1. The patient’s education and learning needs were assessed prior to the delivery of education.</strong></td>
</tr>
<tr>
<td>a) be culturally and linguistically appropriate, tailored to individual needs and enable informed and shared decision making.(^8, 24-26)</td>
<td><strong>S2. The education delivery format offered to the patient was selected based on the patient’s identified needs. (Verbal [one-on-one or group], written, audio-visual, web based, and phone based are all valid delivery formats).</strong></td>
</tr>
<tr>
<td>b) be tailored to the stage of CKD, the associated complications and the risk of progression to kidney failure.(^7)</td>
<td><strong>S3. The key education resources offered to the patient were selected based on the patient’s identified needs.</strong></td>
</tr>
<tr>
<td>c) include follow-up support that encourages positive lifestyle changes and contributes to improving the patient’s quality of life.(^24, 27)</td>
<td><strong>S4. The patient was oriented to the individual multidisciplinary renal team members, including their role, contact details and how they can assist the patient.</strong></td>
</tr>
<tr>
<td>d) be relevant to the patient’s social and psychological needs, and include referral to appropriate professionals or services, as required.(^7, 8, 28)</td>
<td></td>
</tr>
</tbody>
</table>
**R2. Patient education and information should be delivered:**

- **a)** recurrently at appropriate key points along the patient journey until end of life.\(^7,8,24,28\)

- **b)** by healthcare professionals who are committed to developing their skills and experience in facilitating effective communication, adult learning, cultural responsiveness and health literacy.\(^8,24,26\)

- **c)** by a multidisciplinary renal team, that can include a range of members as appropriate, such as a nurse, dietitian, pharmacist, social worker, psychologist, nephrologist, registrar and a peer or peer mentor.\(^8,26,28,29\)

- **d)** by a renal service that recognises that CKD education underpins a patient’s right to clear and understandable information about services, treatment and options.\(^9,26,30,31\)

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**Standard 4 also applicable to this section.**

**S5.** Education was offered to the patient at appropriate key points from Stage 4 onwards (12 months pre-treatment, if switching treatments, preparing for treatment commencement, when symptom burden increases and when approaching end of life).

**S6.** Primary educators have ongoing professional development in motivational interviewing, adult learning, cultural responsiveness and health literacy.

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**R3. The content of patient education and information should:**

- **a)** be of high quality, accurate, consistent with current, evidence-based practice and with the Victorian Renal Clinical Network’s key performance indicator for education.

- **b)** be consistent with health literacy needs and promote self-learning.\(^1,8,17,25,32\)

- **c)** extend beyond treatment option information and support the patient’s self-management.\(^7,8,16,18,19,24,28\)

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**S7.** The current Victorian KPI for education was met.

**S8.** Education was offered on medication management, symptom management, mental health, lifestyle factors and lifestyle considerations such as travel and work.

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**R4. Education and information about CKD treatment options should:**

- **a)** cover information on all treatment options, including the risks, benefits and implications of each option in the context of the patient

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**S9.** A patient who commenced any new treatment was aware of all options available to them – transplantation (deceased or living donor), renal supportive care (no dialysis), home dialysis (PD and HD), and centre based dialysis (private and public).
and their carer and/or family’s lives.\textsuperscript{[18, 33]}

b) be offered to the patient with stage 4 CKD, or to any patient switching to another treatment, in sufficient time to process the information and make an informed decision before treatment is required. \textsuperscript{[7, 8, 31, 33]}

c) be offered recurrently at appropriate key points along the patient journey from Stage 4 CKD until end of life.\textsuperscript{[8]}

d) be provided by healthcare professionals who have specialist knowledge about CKD and its treatment options.\textsuperscript{[7]}

e) include encouragement and support of the patient, their carer and/or family to be actively engaged in the education and decision-making process and to achieve informed consent regarding their selected treatment. \textsuperscript{[8]}

S10. The patient was clear about which benefits and risks of each option mattered most to them (measured by decisional conflict tool, \textit{SURE questionnaire}).

S11. Treatment option education occurred within 12 months prior to requiring renal replacement therapy (and initial consultation with nephrologist was more than 3 months prior to requiring renal replacement therapy).

S12. The patient participated in more than one education activity about treatment option education within the 12 month period leading up to the treatment decision (a valid education activity can include a group session or a one-on-one session either in-person, over phone or via an approved telehealth program)*

S13. Those delivering education about CKD treatment options had specialist knowledge and experience about CKD and its treatment options.

S14. The patient’s carer and or family members were invited to participate in the treatment option education.

S15. The patient reported having enough support and advice to make a choice of treatment (measured by decisional conflict tool, \textit{SURE questionnaire}).

S16. The patient was engaged in the decision making regarding the selected treatment, and decision making strategies, tools and aids were employed where possible.

\textit{Note} – A ‘Health Professional’s Toolkit’ will provide a template to help record measures of the patient education experience against some of these standards, OR local recording methods by services could be used.
5. Appendices

Appendix A: REAP Investment Logic Map

A REAP ILM Workshop was facilitated by Mr Patrick Ow, Manager, DHHS Risk and Assurance Services Unit, in December 2014. The stakeholders who attended the ILM workshop were: Ms Jenny Soding, RHCN Manager; Mr Dan Ussher, Renal Consumer; Mr Wayne McGlone, Renal Consumer; Dr Matthew Roberts, Nephrologist; Dr Sarity Dodson, Renal Allied Health Clinician, Ms Penny Patton, Renal Nurse; Dr Gillian Smith, Dialysis Project Officer; Dr Deirdre Fetherstonhaugh, Renal Supportive Care Project Officer; Ms Kirren Grennan, Kidney Health Australia, and Ms Alice Gleeson, Evidence & Evaluation Advisor DHHS.
6. Glossary

**Adult learning principles:** A set of concepts based on those by well-known expert adult educator, M. Knowles. The concepts focus on self-directed and autonomous learning and are based on what is known about the intrinsic ways an adult learns. Educators trained on the principles of adult learning have enhanced their understanding of how to tap into what drives a patient to learn, help a patient identify their readiness to learn, encourage a patient to be responsible for their own decisions, bring experience to learning, employ learning that is task-centred and help the patients to choose options based on their individual needs.

**CKD:** Chronic Kidney Disease.

**CKD patient journey:** The experience for people from diagnosis of Chronic Kidney Disease (CKD), through to management, treatment and end-of-life care. Within the context of the *Victorian Framework for Continuing Renal Patient Education*, CKD patient journey refers to the experience from diagnosis of Stage 4 CKD through to end of life.

**Cultural responsiveness:** The capacity of health services to respond to and be respectful of the cultural and linguistic needs of any individual, family or community. An individual may identify having a particular cultural or linguistic affiliation according to their place of birth, ancestry or origin, religion, or language spoken. Cultural responsiveness requires knowledge, capacity and intervention at a systemic, organisational, professional and individual level.[34]

**Decision making aid:** An intervention or tool designed to help patients make specific choices about different options relevant to their health. Decision aids are generally adjuncts to the patient-health professional interaction, encouraging patients to express their preference in clinical situations when there are different options. Decision-making aids should be unbiased, non-directive and aim to support an informed choice consistent with healthcare values and preferences.[35]

**Decisional conflict tool:** A validated tool used to measure decisional conflict, allowing health care professionals to screen for how comfortable patients are with their decision making.

**Education checklist:** A quick guide for health care professionals prompting minimum education content for decision-making about treatment options.

**Health literacy:** An individual's ability to obtain, understand and use health information to make appropriate health decisions and follow instructions for treatment.[17] Clinicians have a key role in health literacy by collaborating with consumers, avoiding using medical jargon and framing conversations in terms that consumers and families understand. This includes providing clear explanations of next steps and checking that key information has been properly understood.

**Health Professionals’ Toolkit:** An online collection of resources for health care professionals designed to complement *the Framework*. It is anticipated that the toolkit will include a ‘patient syllabus’, a recommended ‘patient education pathway’ and ‘education checklist’, a shortlist of patient resources and a number of local resources, tips and tools that can assist renal health care professionals in implementing *the Framework* recommendations and standards.

**Informed consent:** A patient’s agreement to commence treatment; an agreement which results from a health professional / clinician ensuring the patient understands all the available options and the expected outcomes, such as the success rates and/or side effects for each option.[25]

**Informed decision-making:** A process of communication that results in a patient’s agreement to treatment. Throughout this process, the health professional /clinician should ensure the patient understands all the available options and the expected outcomes.[25]

**Investment Logic Map (ILM):** A simple single-page depiction of the logic that underpins an investment. The map is developed in a facilitated workshop during which investors and key stakeholders identify the drivers, objectives and benefits justifying an investment, and the business changes and enablers that are required for the benefits to be achieved.

**KPI:** Key Performance Indicators (KPIs) are measures of performance that are used to measure how well a service is performing against targets or expectations. The Victorian Renal Clinical Network (VRCN) established a Renal KPI working group who are responsible for analysing KPI data and ensuring that the indicators remain accurate, meaningful and relevant. Each of the renal hub services participate
in the bench-marking program by entering their data via an on line website at the end of each month. The
department is responsible for overseeing data entry and collating reports every quarter.\textsuperscript{[36]}

Motivational interviewing: A non-confrontational, patient-centred, goal-focussed counselling strategy
aimed at encouraging a person to change their behaviour. It is consistent with Knowle’s principles of
adult learning (see adult learning).

Multidisciplinary renal team: A team composed of members from various healthcare professions with
specialised skills and expertise. The members collaborate with each other and the patient to make
treatment recommendations that facilitate quality patient care.\textsuperscript{[37]} Members can include a nurse,
dietitian, pharmacist, social worker, psychologist, nephrologist, registrar, physiotherapist, occupational
therapist, vascular access coordinator, dialysis technician, palliative care staff, peer mentors and others.

Patient: A person with Stage 4 or 5 CKD. In this context, the term ‘patient’ is synonymous with the term
‘consumer’ however for the purposes of clarity and consistency, the term ‘patient’ has predominantly
been used in this document. ‘Person / people with CKD’ has also been used interchangeably with
‘patient’.

Patient education pathway: A template to plan and monitor an individual patient’s education experience
from stage 4 onwards, including prompts for milestones at recommended times and using recommended
processes.

Patient education syllabus: A detailed list of topics for education about treatment options and ongoing
self care.

Patient educator: A health care professional whose primary role is to provide information and support to
patients with CKD, their carers and families to facilitate an understanding of the patient’s health status,
diagnosis and treatment options and ongoing management. The role of the patient educator is usually in
the form of a CKD educator (other terms for educator may be coordinator, facilitator, or administrator).
Often the educator is a CKD nurse practitioner or a CKD clinical nurse consultant. Transplant and renal
supportive care may also have specialty educators.

Peer mentor: A person / patient who has experience in managing their CKD and can share their
knowledge and experience to another patient, in a personalised manner. Like an untrained peer, they do
not offer medical advice but can offer empathy and support, discuss ideas on how to cope and provide a
sense of hope. A peer mentor should be trained to refer patients back to the renal team if medical
queries arise. The spectrum of support provided by a peer mentor can extend from attendance and
participation as a speaker at an education session through to a personalised and ongoing mentoring role
either in person or via a telehealth program or service.

Person centred: In the context of the Victorian Framework for Continuing Renal Patient Education,
education that is person-centred is that which is responsive to the needs and preferences of the patient,
their carer and/or family. Person-centred education and care is vital to safety and quality.\textsuperscript{[38]}

Principles: Fundamental concepts in practice integral to effective patient education. The principles
underpin the Framework recommendations and standards.

Recommendation: In the context of the Victorian Framework for Continuing Renal Patient Education, a
recommendation is a guiding statement based on current and evidence-based information that aims to
assist health care professionals on how to plan and deliver effective education.

Renal health care professional: A health professional in the public or private sector, whose role is to
care for those with chronic kidney disease. The term renal health care professional used in the
Framework specifically refers to those caring for patients with Stage 4 and 5 CKD and through to end of
life, their carers and families.

Renal patient education: A process of communication and engagement with patients that enables the
exchange of appropriate, timely, current and evidence-based information and support at various key
points across the patient journey from Stage 4 CKD to end of life. Throughout this process, the health
care professional acts as a patient educator and supporter and works in partnership with the patient,
carer and family to facilitate informed and shared decision-making about treatment options and support
for ongoing management and self-care.\textsuperscript{[16]}
Self-management: Self-management refers to “engaging in activities that promote health, build physiologic reserve, and prevent adverse sequelae; interacting with health care providers and adhering to recommended treatment protocols; monitoring physical and emotional status and making appropriate management decisions on the basis of the results of self-monitoring; and managing the effects of illness on the patient’s ability to function in important roles and on emotions, self-esteem, and relationships with others.”[32]

Shared decision making: Shared decision-making is a consultation process where a clinician and patient jointly participate in making a health care decision, having discussed the options and their benefits and harms, and having considered the patient’s values, preferences and circumstances”[39] In both shared and informed decision-making, a patient receives information about treatment in order to make a final decision about treatment. However shared decision-making takes informed decision-making or informed consent to another level, by giving the patient more responsibility.

A structured process for shared decision-making should be followed such as; deliberation (acknowledging a decision to be made), options talk (identifying options), choices talk (exploring options and weighing up consequences), and finally decision-making.[8]

Stage 4 CKD: People with CKD with an eGFR of 15-30mL/min/1.73m2 on 2 occasions 3 months apart. This is also a key point in the patient journey as it should trigger decision-making and planning for treatment.

Stage 5 CKD: People with CKD with an eGFR < 15mL/min/1.73m2 on 2 occasions 3 months apart, or dialysis.

Standards: The standards provide a number of measures and / or practical steps for health professionals to employ in everyday practice in order to achieve the recommendations and can be used to report against to drive improvement.

SURE questionnaire: The SURE questionnaire is a 4-item screening test used to check for decisional conflict, allowing health care professionals to screen for how comfortable patients are with their decision making.

Telehealth program: The use of telecommunication techniques for the purpose of providing medical or health information and education over a distance.

The Framework: The Victorian Framework for Continuing Renal Patient Education, also known as the Framework, is a part of a larger strategy that is intended to guide and assist renal health services adopt best practices in patient education. Endorsed by the department’s Victorian Renal Clinical Network, the Framework presents an agreed approach for creating an effective renal education strategy for Victorians with stage 4 and 5 CKD. The Framework is the first of its kind in Australia.

Treatment options: When it is clear that kidney failure is likely, a patient needs to consider life-long treatment.[7] Some patients are limited by their co-existing medical conditions, while others may have all the treatment options available to them.[14, 15] Patients face the difficulty of needing to choose the most suitable treatment option for them. It is at this point of care that effective renal patient education becomes critical. The treatment options available to a patient to keep the kidney functioning include:

<table>
<thead>
<tr>
<th>Transplantation</th>
<th>Live donor kidney transplant (Pre-emptive, before dialysis)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Live donor kidney transplant (after dialysis)</td>
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<tr>
<td></td>
<td>Deceased Donor kidney transplant (after dialysis)</td>
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<tr>
<td>Dialysis</td>
<td>Home-based dialysis:</td>
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<td></td>
<td>Peritoneal dialysis</td>
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<tr>
<td></td>
<td>Haemodialysis</td>
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<tr>
<td></td>
<td>(Thrice weekly, second daily, extended hour (nocturnal))</td>
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<tr>
<td></td>
<td>Satellite-based haemodialysis (private or public)</td>
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<tr>
<td>Supportive Care</td>
<td>Supportive care without dialysis or transplant</td>
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</tbody>
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7. References


