

# Issues Paper: Taking Healthcare Home

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# Executive Summary

Potential benefits of the provision of healthcare at the patient's home include improved health outcomes, increased patient and carer satisfaction and reduced costs. This paper focusses on three healthcare in the home services as case studies: hospital in the home (HITH), home dialysis, and home parenteral nutrition. A literature review was conducted into how these services are provided, their effectiveness, and cost effectiveness. Stakeholder interviews were undertaken to explore the barriers and facilitators to the delivery of these services in Queensland.

HITH is the provision of acute, subacute, or post-acute services in the patient's home, where the patient would otherwise require admission to hospital. There is evidence supporting HITH for a range of patient populations, interventions, and modes of care. Better health outcomes have been observed for HITH services that appropriately target patients and where physicians provide significant input into the patient's care. Surveys have found that patients are highly satisfied with HITH services. For the six most common DRG groups HITH is estimated to reduce healthcare cost by 22% compared with in-hospital care.

Home dialysis, an alternative to in-centre and satellite dialysis, is a significant component of the overall market for Renal Replacement Therapy (RRT). Home dialysis has been proven to be cost effective for the majority of chronic kidney disease (CKD) patients. Among the different types of home dialysis, there are: home haemodialysis (HHD), automated peritoneal dialysis (APD), and continuous ambulatory peritoneal dialysis (CAPD). Studies have found many benefits of home dialysis, including dramatically improved survival rates, lower hospitalisation, higher rates of employment, and fewer adverse events. Patients can remain on the machines for longer than if they were at a clinic or hospital, especially if used nocturnally, improving their health outcomes. Home dialysis, while more affordable for the government and health providers, does involve significant costs to the patient.

Patients with long term intestinal failure may require parenteral nutrition for years, making in-hospital provision of parenteral nutrition prohibitively expensive. Home parenteral nutrition (HPN) is the provision of parenteral nutrition at the patient's residence, often administered by the patient themselves or a carer. The Australian Society of Parenteral and Enteral Nutrition (AuSPEN) guidelines found few randomised controlled trials of HPN.

Semi-structured interviews (N=18) were conducted to identify and characterise barriers to healthcare in the home. Factors identified by the interviewees that affect delivery of HITH services include the attitudes and knowledge of health professionals and hospital administration about HITH, administrative burden, financial incentives, fluctuation in demand, geographic distance, and training. The major barriers for Home Dialysis and Parenteral Nutrition were out of pocket costs for patients, geographic distance, patient ability to self-manage care, and feelings of loneliness and social isolation. Facilitating the expansion of healthcare in the home requires supporting the needs of patients, encouraging cultural change among health professionals and ensuring that funding for healthcare in the home adequately compensates providers while avoiding cost shifting between funding systems.

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# Introduction

The objective of this paper is to explore the key public health policy issues around promoting and providing traditional acute and chronic services in the home. Potential benefits of the provision of healthcare at the patient's home include improved health outcomes, increased patient and carer satisfaction, and reduced costs [1-6]. The benefits depend on the disease, the nature of the service, and the model of care. This paper was funded by Baxter Australia and prepared by the Australian Centre for Health Services Innovation to inform the Taking Healthcare Home Ideas Forum to be held in February 2017.

Several factors have contributed to the migration of hospital services to the home, including budget constraints due to an ageing population and increasing costs of medical services, patient preferences for receiving care at home, and growing evidence of the clinical effectiveness, safety, and cost-effectiveness of healthcare in the home [7, 8]. In some cases, healthcare at home has become more feasible due to technological innovations such as highly controlled and programmable intravenous (IV) infusion technologies [9, 10], telemedicine, portable ventilators [11-14], home-based x-rays [8], and handheld ultrasonic devices [15, 16]. Healthcare services traditionally provided in hospitals that are now provided in the home include IV antibiotics, parenteral nutrition, haemodialysis, blood transfusions, and other injections and infusions.

The paper will focus on three services as case studies (1) hospital in the home (HITH), home dialysis, and home parenteral nutrition (HPN). These services will be discussed with regard to how they are delivered in Queensland, their effectiveness, economic considerations, and finally the barriers and facilitators to the delivery of these services in Queensland.

# Review of Published Evidence and Policy Documents

A literature search was conducted using EMBASE to identify relevant published articles regarding the provision, the effectiveness and the cost effectiveness of HITH, home dialysis, and HPN. Policy documents and guidelines regarding HITH, home dialysis, and HPN were also identified and reviewed. The findings from this literature are discussed using a narrative format.

## Hospital in the Home

### Services and the patients

HITH is the provision of acute, subacute, or post-acute services in the patient's home, where the patient would otherwise require admission to hospital [17, 1]. HITH patients are offered coordinated, multidisciplinary care including monitoring, face-to-face clinical care from nurses and physicians, diagnostic testing, and IV medication [18, 19]. Typically, hospital in the home patients are medically stable but may have co-morbidities or otherwise complex needs [20]. HITH is provided by interdisciplinary teams of medical, nursing, and allied health professionals. HITH services have been shown to reduce healthcare expenditure and improve patient recovery and satisfaction [21].

The types of patients who are eligible for HITH differ between services. The most common HITH service in Queensland is IV antibiotics for infectious diseases such as cellulitis, urinary tract infection, and pneumonia. Other HITH services include anticoagulation therapy for deep vein thrombosis and pulmonary embolism, chemotherapy, management of heart failure, and wound management [22]. To be eligible for most programs, the patients are medically stable and do not require high clinical support [20]. Nevertheless, many HITH patients are multi-morbid and have complex needs.

There are a variety of HITH models of care that provide guidance for who retains responsibility of care [1]. The responsibility of care may be retained by the treating inpatient authorised practitioner who consults with the HITH team regarding any changes in the clinical management plan (Inpatient Team Clinical Governance Model). Or, the care may be transferred from the treating hospital inpatient team to an approved HITH authorised practitioner, who takes on the responsibility of the clinical management plan (Authorised Practitioner Governance Mode). Alternatively, responsibility of care may be shared between the inpatient team and the authorised practitioner (Combination Clinical Governance Model). Referral to HITH may be through the patient, GP, Emergency or any ward in the hospital [20].

HITH is a priority commitment of the Queensland Government [1]. HITH was introduced in Queensland to improve patient flow, meet national emergency access targets (NEAT), and to increase capacity within the healthcare system. HITH services in Queensland are provided by private providers such as Silver Chain and Blue Care, or by specialist services provided by hospitals.

### Evidence for effectiveness

There is evidence supporting HITH for a range of patient populations, interventions, and modes of care. The definition of HITH is inconsistent between trials [22, 8]—with some trials including services that would typically be considered community care [23]. Some HITH services substitute for the entire hospital admission while other HITH services facilitate early discharge. Some HITH programmes have focussed specifically on certain patient groups, such as children [8].

A meta-analysis by Caplan et al. [21] of 40 randomised controlled trials found that HITH services are safe, effective, and reduce costs compared with care within hospital. HITH is associated with a 20% reduction in mortality and a 25% lower rate of readmission. It is also associated with a reduction in hospital length of stay, but with an increase in total length of care. HITH has been associated with a reduction in adverse events including delirium and geriatric complications involving the urinary tract and the bowel. HITH improves patient and carer satisfaction, although does not have an impact on carer burden.

# Review of Published Evidence and Policy Documents

In contrast, a Cochrane Review <sup>[19]</sup> found that HITH, compared with in-hospital care—had little or no difference on mortality at six months follow-up or readmission to hospital. Similar to Caplan et al., the Cochrane review found that HITH leads to increased patient satisfaction and reduced cost. The review included trials of acute conditions, chronic conditions (COPD, stroke), and trials of mixed conditions.

The inconsistency in the findings between Caplan et al. and the Cochrane systematic review arises from the definition of HITH. Unlike the Cochrane review, the Caplan et al. systematic review only included HITH studies where the HITH substituted for at least 7 days in hospital or replaced at least 25% of control admission duration. The findings of reduced mortality and readmissions were only significant when studies that did not meet criteria were excluded.

There are significant challenges in comparing length of stay between HITH and in-hospital patients <sup>[7, 24]</sup>. Earlier studies have found a longer length of stay for HITH compared with in-hospital care. Ioannides-Demos et al. <sup>[24]</sup> undertook a retrospective analysis of the Victoria In-patient Minimum Dataset (VIMD) and found that this difference in length of stay vanished when the analysis accounted for differences in how the episodes of care were defined in the VIMD for HITH compared with in-hospital care.

Better health outcomes have been observed for HITH services that appropriately target patients and where physicians provide significant input into the patients care <sup>[8]</sup>. Surveys of patient satisfaction have found high positive regard for HITH. The most valued aspect of HITH for patients is the quality of communication and personal care received <sup>[25]</sup>. There is limited evidence regarding the burden on carers; however, the acute nature of HITH naturally places limit on the length of carer burden.

HITH services can also be provided in residential aged care facilities. Such services, sometimes known as hospital in the nursing home <sup>[26]</sup>, have been shown to be safe and effective. A retrospective cohort study found a 10% decrease in mortality of nursing home residents, a decrease in the use of hospital bed-days by 10,000 per year, equivalent to 27 beds every single day of the year <sup>[26]</sup>.

## Evidence for cost effectiveness

The cost of HITH relative to in-hospital care is context dependent, it depends on the nature of the condition and its severity, presence of comorbidities, eligibility criteria for HITH, and hospital-based factors <sup>[17]</sup>. Nevertheless, for the six most common DRG groups, HITH is estimated to reduce healthcare costs by 22% compared with in-hospital care <sup>[27]</sup>. For two Australian studies, HITH was found to reduce cost by more than 50% <sup>[28, 29]</sup>. A meta-analysis of HITH evaluations found that, excluding informal care—healthcare in the home saves money compared with hospitalisation <sup>[19]</sup>.

The primary cost drivers of HITH include staff salary, training for staff and patients, pharmacy costs, pathology costs, and consumables <sup>[30]</sup>. Salary costs may cover nursing, allied health, general practitioner, and specialist care. Home-based therapies require training for staff and in some cases training and competency assessment of the patient or carer <sup>[31]</sup>. The costs of pharmacy, pathology and consumables will be similar to the respective in-hospital costs.

In Queensland, HITH patients are considered inpatients of the hospital facility and may be eligible for Activity Based Funding <sup>[1]</sup>. The Activity Based Funding covers consumables, clinical services, clinical investigators, intervention medications, and equipment. Queensland HITH also receives funding from Department of Veteran Affairs (DVA), third-party insurance, and workers compensation <sup>[1]</sup>.

Table 1 lists the five Diagnosis related groups (DRGs) that are able to be considered HITH for the purpose of activity-based funding in Queensland. For a HITH service to receive activity based funding in Queensland there must be a daily intervention—such as IV infusion—and consultation with a physician.

### Table 1 HITH DRGs

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Deep vein thrombosis  
Pulmonary embolism  
Pneumonia  
Urinary tract infection  
Cellulitis

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DRG, diagnosis related group; HITH, hospital in the home

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# Review of Published Evidence and Policy Documents

## Home Dialysis

### Services and the patients

Home dialysis, an alternative to in-centre and satellite dialysis, is a small but significant component of the overall market for Renal Replacement Therapy (RRT). It is applicable for acute, subacute, and chronically ill patients and has been proven to be cost-effective for a vast majority of Chronic Kidney Disease (CKD) patients.

While transplantation is known to be the most preferable option for patient health, there are still hundreds of patients on dialysis in each state. Many remain on the comparably expensive in-centre or satellite clinic dialysis despite the recommendations of nephrologists and the suitability of their modality of choice compared to home dialysis.

As of 2013, there were 3,401 patients receiving dialysis at home throughout Australia. State level statistics show that there is a roughly stable level of around 500 patients per million on dialysis. This does not include the exception of the Northern Territory, which has over 2,200 patients on dialysis, or around 4.5 times as many as the national average (see Figure 1, below).

While the number of home dialysis patients has increased as prevalence has increased, a majority of patients have selected satellite and in-centre modalities. Home dialysis grew slowly compared to satellite and in-centre modalities and now represents only a third of the market. In 1995, 2,100 out of 4,541 (46%) dialysis patients were receiving home treatments; by 2013, it had become just 3,401 out of 11,774 (29%). The decline in home dialysis rates as a proportion of the total is partly due to the slow growth of peritoneal dialysis <sup>[32]</sup>.



## Patients per million population 2013

Note new RRT also included in dialysis and Transplant

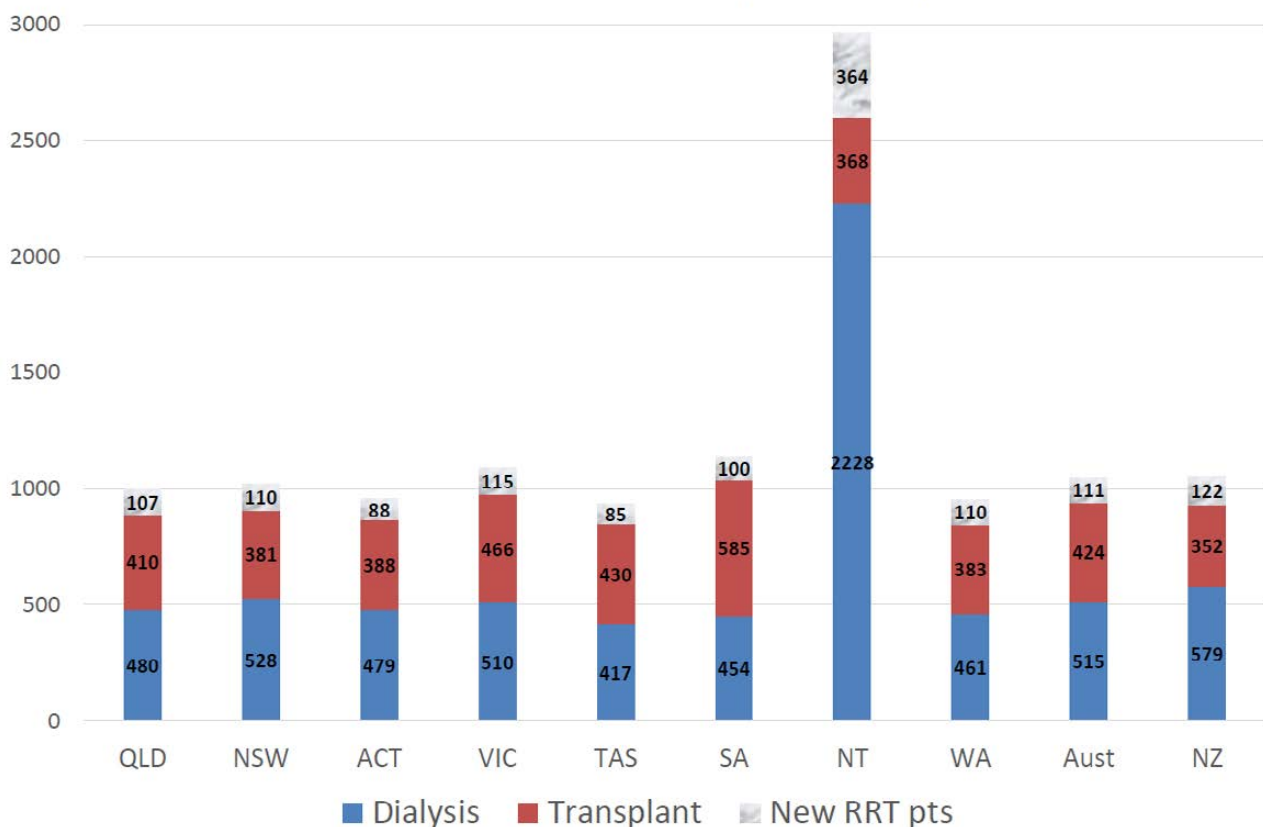


Figure 1 Prevalence of dialysis and transplant patients across Australia and New Zealand <sup>[33]</sup>  
RRT, renal replacement therapy

# Review of Published Evidence and Policy Documents

Queensland has a slightly higher proportion of home dialysis patients at 31.5% than the Australian average of 28.9%. This is marginally lower than the highest rates of home dialysis in New South Wales, at 36.6%, but Australia in

general has only around half the home dialysis rate of New Zealand, which has over 50% of patients on home dialysis <sup>[34]</sup>. This information can be seen in Figure 2, below.



## Home Dialysis as a % of all Dialysis 2009-2013

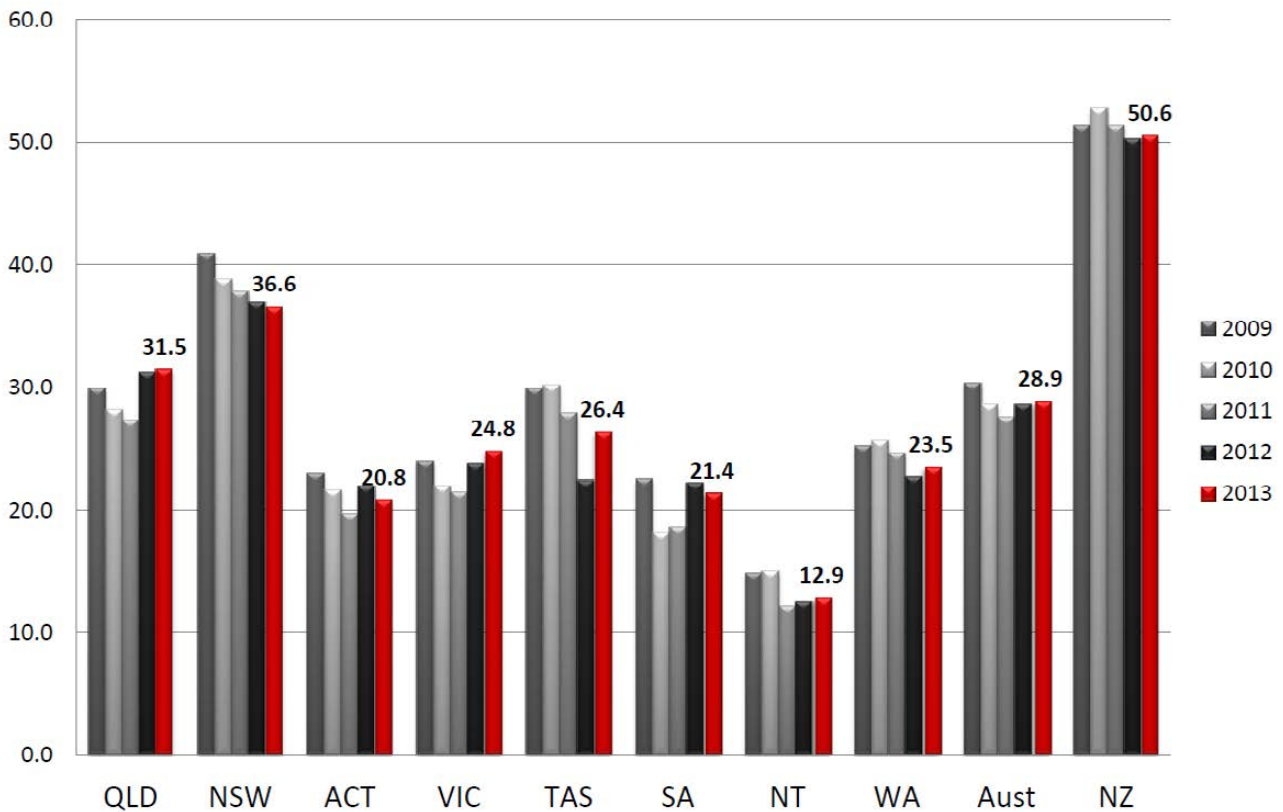


Figure 2 Home dialysis rates in Australia and New Zealand (courtesy of ANZDATA) <sup>[33]</sup>



# Review of Published Evidence and Policy Documents

In 2013, Queensland saw its total dialysis population increase by around 22%, joint third highest with South Australia, behind Western Australia and Victoria. It also saw 12% mortality rate in the dialysis population, which was lower than the Australian average. This can be seen in

Figure 3. This means that while Queensland was taking on a higher than average number of dialysis patients, they were experiencing lower than average mortality rates and thus managing their patient population favourably relative to other states <sup>[32]</sup>.



ANZ Percentage change of dialysis population 2013, (new or deaths) by state

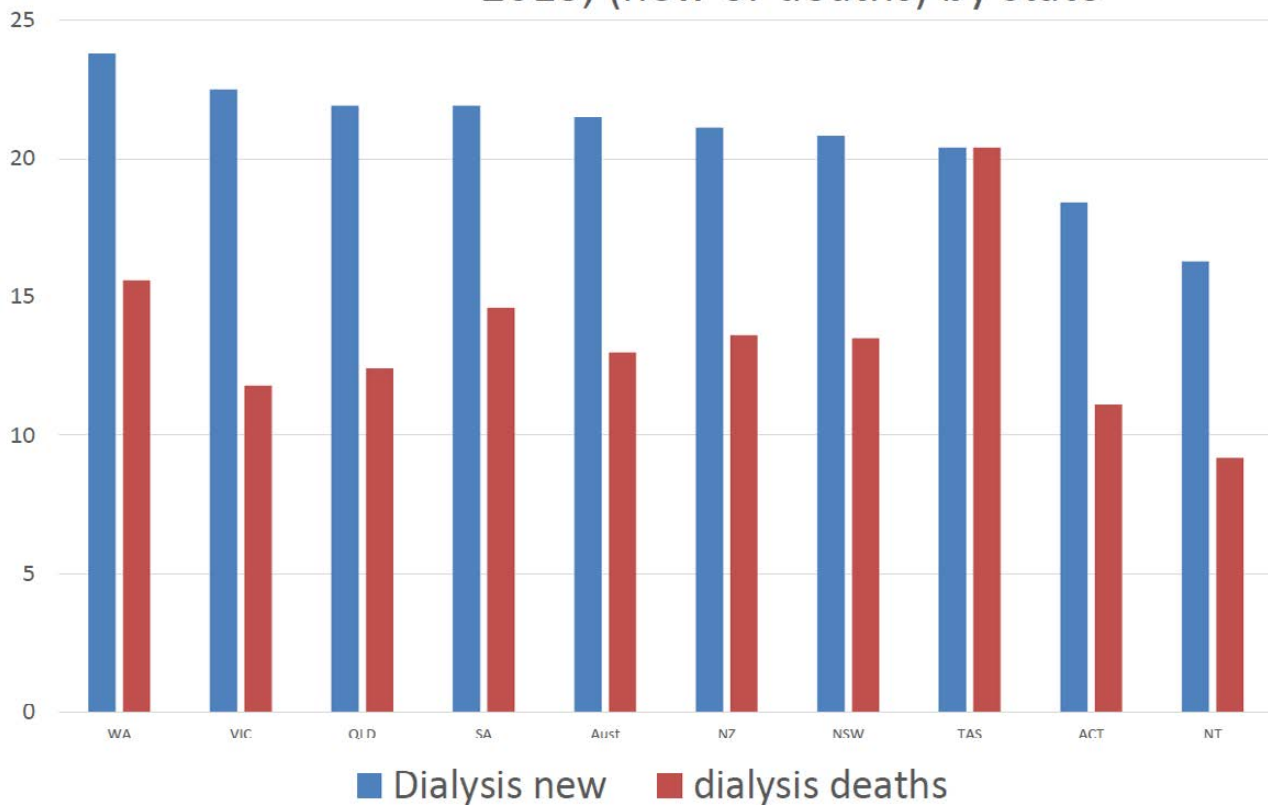


Figure 3 Mortality rates throughout Australia <sup>[32]</sup>

# Review of Published Evidence and Policy Documents

Among the different types of home dialysis, there are: Home Haemodialysis (HHD), Automated Peritoneal Dialysis (APD), which happens overnight using a dialysate solution exchange system, and Continuous Ambulatory Peritoneal Dialysis (CAPD), which uses the solution exchange system four times per day while patients go about their daily lives. There does not seem to be a correlation between the type of home dialysis and mortality rates, only between frequency of dialysis use, though the Northern Territory experiences both the lowest mortality rate and the lowest rate of home dialysis <sup>[32]</sup>. It is crucial not to draw too many conclusions about home dialysis from reported mortality rates, as there are a significant number of supporting factors around each modality that reflect the state of home dialysis in that region rather than its effectiveness as a treatment.

## Models of care

The most comprehensive model of dialysis care in Australia was developed by Kidney Health Australia (KHA) <sup>[34]</sup>. According to the KHA model, patients who are diagnosed with chronic kidney disease (CKD) are educated about their condition and managed according to the specific circumstances of their disease. Based on the modality of choice, including APD, CAPD, HHD, and in-centre haemodialysis (HD), they are then educated and assessed. Those patients suitable for home dialysis treatments, though transplant is also an option, are managed accordingly, with access to in-centre fallbacks if needed and the possibility for more conservative treatment if their condition improves.

Home dialysis patients require both pre-dialysis education and training. Pre-dialysis education is the process of informing the patient of treatment options so that the providers and patients can make an informed decision together to choose and prepare for treatment. After pre-dialysis education, patients who choose home dialysis will require training in order to manage their care. The pre-dialysis education should be conducted by or with the approval of a patient care team. This ensures that patients and care team use the same terminology and are aware of the patient's ability to manage their care.

Healthcare does not exist in a bubble and public policy must reflect the lowest cost, strongest outcome options. The health jurisdiction and provider network for each patient in each region is also important in terms of availability of resources. Patients must be considered on a region by region basis according to provider availability and funding. If there is no financial incentive for a care team and well-educated patients, home dialysis will face an uphill battle despite its benefits.

# Review of Published Evidence and Policy Documents

Queensland Health has come up with a state-wide renal health services plan for 2008-2017. The action plan follows five service delivery guidelines: patient focus, integrated care, responsive to diverse needs, safe/sustainable, and reflective of available resources. Queensland Health plans to see 50% of its patients on home dialysis in the long-term, though this expectation is reduced to 40% in remote locations and delegated to the Northern Area Health Service. This goal requires culturally and regionally specific training programs for health workers in light of labour shortages in the field. The Queensland Health framework plans to use home dialysis as a way to reduce the overall cost and labour burden of end stage renal disease, facilitated by improvements in care integration and with respect to the unique needs and costs of caring for the Queensland population [35].

## Evidence for effectiveness

As there are several modalities for dialysis, there is a significant degree of patient choice when it comes to managing CKD. There are, accordingly, some confounding factors when it comes to dialysis outcomes across the different treatment types. For example, patients choosing home dialysis will generally be more able to manage their own care for a variety of reasons including lower levels of disability, younger patient populations, and less comorbidities such as diabetes mellitus [36]. While all of these factors may affect outcomes, accounting for confounding factors shows that patients on HHD still have better outcomes than in-centre or satellite clinic patients.

Studies have found many benefits, including dramatically improved survival rates, lower hospitalisation rates, higher rates of employment, and fewer adverse events [36, 37].

This is at least in part due to the longer, more intensive treatments permitted by HHD, generally totaling over 12 hours per week compared to satellite or hospital HD, which generally total under 12 hours per week. Patients can remain on the machines for longer than if they were at a clinic or hospital, especially if used nocturnally, improving their health outcomes [38, 39]. Additionally, while high dose HD was technically feasible for in-centre or satellite patients, it was logistically prone to backlogs that are more cost-effective to conduct at home [40].

PD is a suitable alternative to HD, with clinically similar or even superior outcomes [41]. Long-term patient utilities have been shown to be favourable in several cases, with the added benefit of lower costs and thus a better cost per quality adjusted life year (QALY) ratio. It is worth noting that the favourability of PD over HD is generally limited to countries where the supplies for PD, namely dialysate, are readily available. While this may not be a problem in major metropolitan areas, it does add an extra layer of complexity for rural patients who must travel or receive deliveries to have enough solution.

## Evidence for cost effectiveness

Dialysis is estimated to cost Australia \$1 billion per year, and is expected to increase substantially by 2020 [42, 43]. Kidney Health Australia's Economic Impact of End Stage Kidney Disease study found that the annual per patient cost of dialysis varied considerably depending on modality (see Table 2) [30]. The annual costs are the highest with hospital HD, and the lowest with home/self-care HD and PD. Home/self-care HD has a greater initial cost for training and other patient costs compared with home/self-care PD. A literature review conducted on behalf of the Independent Hospital Pricing Authority (IHPA) found roughly comparable results between home-dialysis studies conducted in New South Wales and Queensland with ongoing costs around \$45,000 for both HD and PD and training and set-up costs around \$10,000 for HD and \$5,000 for PD [30].

**Table 2 Annual cost per modality (\$AU 2009) [30]**

Dialysis modality	Hospital HD	Satellite HD	Home/self-care HD	Home/self-care PD
Annual cost per patient	\$85,128	\$70,409	\$53,268	\$56,910
One off costs of training and other patient costs	-	-	\$15,093	\$3,823

HD, haemodialysis; PD, peritoneal dialysis

# Review of Published Evidence and Policy Documents

There is also a significant burden of CKD in terms of patient out of pocket costs. As mentioned above in state frameworks, there have been some allowances for out of pocket expenses in various state governments such as ACT. However, these allowances only apply to patients with machines in the home. For others, costs of transport are significant. KHA estimates that the cost of transport to dialysis centres for both satellite patients and self-managed dialysis patients who use machines away from home to be approaching the \$50 a week mark, disproportionately affecting the low income and rurally located<sup>[43]</sup>. Some patients in the NT must drive up to 200km each way to receive dialysis three times a week, or around 1200km driven per week.

Home dialysis, while more affordable for the government and health providers, does incur significant costs to the patient. Dialysis machines, along with the power and water required to run them, are expensive and may be a significant obstacle for low income patients. The cost of home dialysis varies by state, but KHA has found that current rebates of around \$250 per year are insufficient<sup>[43]</sup>.

Home dialysis solutions tend to have better outcomes than in-hospital and satellite clinic alternatives. In cases where home dialysis is an option, it also tends to be lower cost, though the out-of-pocket costs vary by patient depending on location and ability to afford the utilities costs of HHD and PD<sup>[37]</sup>. Studies examining multiple treatment modalities have recommended the use of home dialysis over other options (except transplant) for cost-effectiveness reasons on a health system level<sup>[38]</sup>. Across a number of studies, findings showed that home dialysis was at worst comparable to in-centre or satellite dialysis in terms of cost and outcomes. At best, home dialysis was a significant improvement in both cost and quality of care, with some studies showing that home dialysis completely dominated other options with both exceptional cost savings and QALY improvements<sup>[38]</sup>.

## Home Parenteral Nutrition

Parenteral nutrition is the IV provision of nutrients and water to prevent undernutrition or dehydration for patients with intestinal failure<sup>[44]</sup>. Patients with long term intestinal failure may require parenteral nutrition for years, making in-hospital provision of parenteral nutrition prohibitively expensive. Home parenteral nutrition (HPN) is the provision of parenteral nutrition at the patient's residence, often administered by the patient themselves or their carer. Approximately 5-7 per million Australians receive HPN. The cost per patient for HPN was estimated in New Zealand to be \$A76,500, but this cost is much less than if the patient required long-term in-hospital parenteral nutrition<sup>[45]</sup>.

The management of undernutrition with parenteral nutrition is associated with a reduction in adverse events, retention of muscle, improved wound healing, and reduction in length of hospital stay<sup>[46, 47]</sup>. There are risks with long-term parenteral nutrition, including HPN, such as catheter related infection, liver disease, and metabolic bone disease<sup>[48]</sup>.

Clinical practice guidelines have been developed to improve practice and reduce adverse events. The Australasian Society of Parenteral and Enteral Nutrition (AuSPEN) have developed clinical practice guidelines for HPN<sup>[44]</sup>. HPN guidelines have also been produced in the US<sup>[49, 50]</sup>, UK<sup>[51]</sup> and Europe<sup>[52-54]</sup>. The guidelines evaluated the HPN clinical literature and provided clinical practice and policy recommendations. There were few randomised controlled trials of HPN to inform the guidelines, nevertheless the guidelines provide graded recommendations for how HPN patients should be selected, how HPN should be provided and monitored, how complications should be managed, and how HPN should be funded in Australia.

# Review of Published Evidence and Policy Documents

The decision of whether a patient requires parenteral nutrition is clinically based, and is similar across states in Australia and internationally <sup>[55]</sup>. Further assessment is required to determine the appropriateness of transferring the patient to HPN. When determining the eligibility of a patient for HPN the AusPEN guidelines recommend considering the physical and emotion ability of the patient or carer to undertake HPN training and to co-operate with therapy. The guidelines recommend an assessment of the patient's residence to determine factors that may have a negative impact on HPN. The patient should have a landline telephone, be able to live independently or have adequate assistance, the home environment should be sufficiently clean and have enough space for HPN delivery with a dedicated fridge for HPN solution storage.

The AusPEN guidelines found no published trials of models of training patients in HPN management, although the guidelines recommend that the patient should be trained in management of HPN as an inpatient before going home—a process that can take several days or weeks depending on the needs of the patient. At the end of the training process the patient should be able to demonstrate an understanding of asepsis and safe delivery of HPN. The patient is trained to recognise specific problems and how to respond appropriately.

AusPEN guidelines recommend HPN patients should receive the assistance of a multidisciplinary nutrition support team (NST). This is consistent with recommendations from international guidelines, which have all suggested similar roles for the NST, including <sup>[48]</sup>:

- Preparing management protocols to facilitate education
- Making individualised care plans with overall aims
- Follow-up care of patients
- Providing physiological and emotional support
- Providing contact details of people with a significant role in the patients' care

Most hospitals that provide HPN services have fewer than 20 patients enrolled at any time <sup>[55]</sup>. Few hospitals have dedicated teams that manage HPN patients. The hospitals with dedicated teams are multidisciplinary, involving medical staff (typically gastroenterology), nursing staff, dieticians, and pharmacy staff. There are several modes of nutrient delivery in Australia including direct pickup by the patient (or carer) from the hospital or local pharmacy, or alternatively through direct delivery by the supplier.

The AusPEN guidelines recommend periodic monitoring of patient quality of life, nutritional status, and liver function <sup>[44]</sup>. Unlike the UK, home visits for HPN patients by nursing or allied health staff is rare <sup>[55]</sup>. Most monitoring of HPN patients in Australia is through telephone consultations.

# Interviews with Healthcare in the Home Stakeholders

Semi-structured interviews were conducted to identify and characterise barriers to healthcare in the home, specifically HITH, home dialysis, and HPN. Interviews were conducted with 18 stakeholders, using an interview protocol. The interviews were audio recorded and themes were identified. Interview subjects included providers of HITH services (a director of a private HITH provider, director of nursing, two nurse unit managers, and two clinical nurses), three consultant physicians with experience of the HITH referral process, a Director of Department, two dietitians with experience with HPN, a patient representative from Parenteral Nutrition Down Under (PNDU), a nephrologist, and two nurses with home dialysis experience. The findings were also informed by published literature on the barriers and facilitators to delivery of healthcare in the home.

## Barriers and Facilitators to Delivery of HITH Services in Queensland

Physicians who believe that HITH services are less safe or an unnecessary burden on the patient will not readily refer patients to HITH. There needs to be a level of familiarity with the providers of the HITH services. The perception that HITH is a cost saving measure at the cost to the patient's welfare leads to physician resistance to referral of patients to HITH. Low HITH rates for tertiary hospitals and for surgical wards in particular was seen by some of the interviewees as being due to the attitude that the patients are more severe or complex than in other settings and physicians in these settings are less likely to feel comfortable handing over care of their patient to another team. One interviewee identified factors that drive a positive attitude to HITH amongst physicians, including cost consciousness, patient preferences, equal if not better effectiveness, patient satisfaction, and business case.

In general, there is low awareness of HITH. HITH is not part of medical curriculum or part of registrar rounds, and HITH is mostly unknown in the community <sup>[22]</sup>. Interviews and focus groups conducted by De Vliegher et al. <sup>[36]</sup> found that healthcare workers had limited awareness of the knowledge, competences, and experiences of home nurses. Several interviewees noted the existence of a "that isn't done here" attitude to HITH. This attitude led to competitiveness between the healthcare settings and the HITH settings exacerbated by the lack of communication between disciplines, lack of time for multidisciplinary meetings, and financial systems that did not support collaboration. Greater awareness of HITH by health professionals and the community could result wider adaption of HITH.

Several interviewees had found that physicians would not refer patients to HITH if there was a perception of administrative burden. The physicians need to understand which patients are appropriate for HITH and the process required to refer a patient to HITH.

Also discussed, was the importance of having staff—whether a senior medical officer or a clinical nurse consultant—at the hospital to facilitate referral to HITH. The role of these dedicated members of staff is to build relationships with referring services, understand the HITH process and the paperwork involved, engage with clinical groups, provide education, and advocate for more HITH.



# Interviews with Healthcare in the Home Stakeholders

The distinct funding mechanisms for hospitals and community care leave HITH susceptible to cost shifting. Queensland maintains a limited range of conditions that are eligible for HITH. These conditions were chosen because they could be appropriately provided in the patient's home but also because the conditions were unambiguously HITH rather than community care. Private health insurers are only required to pay for within hospital care at public hospitals and are not required to reimburse hospitals for HITH services [Private Health Insurance (Benefit Requirements) Rules 2011, Schedule 2, Paragraph 1(b)].

There are gaps in the Medicare Benefits Schedule (MBS) for the services that GPs and Specialists provide for HITH patients<sup>[20]</sup>. Several interviewees discussed the uncertainty surrounding HITH in Queensland with the public-private contract ending 30th June 2017.

The successful delivery of HITH requires a multidisciplinary team working together to provide care to the patient. An interviewee recommended that healthcare at home services should be integrated into planning from the point the patient enters the hospital. The multidisciplinary team needs to be able to provide out of hours care.

Fluctuations in demand for HITH services increase the complexity of maintaining adequate staffing. HITH in Queensland requires a daily visit with a nurse as a minimum, which limits the ability to deliver HITH services in rural and remote areas. Services that require twice daily interventions (such as anticoagulation therapy) may be provided in some regions but not in others because of the challenges with travel. HITH nurses require training for adapting practices to the home and technologies associated with HITH; training may also be required for the patient or the carer. There were hospital HITH programs that had limited capacity for nurses to deliver HITH. However, one interviewee discussed the need to prove demand for HITH to justify an increase in staff.

Telemedicine—the delivery of medical services with the aid of telecommunications—has facilitated the delivery of HITH in some cases. Telemedicine increases the number of patients who can receive consultations and allows for consultations where distance would otherwise be prohibitive. Clinical outcomes appear equivalent between telemedicine and the equivalent in-person services, with a reduction in cost.

## Barriers and Facilitators to the Delivery of Home Dialysis Services in Queensland

The most significant obstacle for many Australians with regards to home dialysis is cost. Both HHD and PD have significant utility costs, including power costs for HHD and power and water for PD. Nocturnal home dialysis methods may show improved clinical outcomes due to longer sessions, but also entail greater costs of more frequent use. In many cases, this can be prohibitively expensive; even rebates of \$250 annually were found to be insufficient in covering the utilities costs for CKD patients<sup>[43]</sup>. Given that rebates are ostensibly the entirety of the home dialysis plan for SA and ACT, it may be worth considering a cost-effectiveness analysis on the relative worth of complete cost defrayment of up to thousands of dollars per patient for home dialysis patients compared to satellite or hospital based alternatives.

In addition to cost concerns, geographic distance is also a consideration for CKD patients. While home modalities may reduce travel times for treatment in most cases, making them an advantage, rural PD patients still require regular refills of dialysate, and both HHD and PD patients require visits with their clinical care team, and the option of fast repair should their machines fail.

Many rural CKD patients end up moving to accommodate their illness. This means that despite the ability to self-treat at home, HHD and PD sometimes fail to change the treatment dynamic for a number of reasons, such as if the patient has been on satellite dialysis and is reluctant to change. Many patients begin dialysis in either hospitals or satellite clinics and have already adapted to these modalities. In many cases, patients are unaware or unenthusiastic of the option to treat at home, and despite nephrologist preferences for home PD and HD, patients typically remain on in-centre HD<sup>[56]</sup>.

# Interviews with Healthcare in the Home Stakeholders

Even when patients are aware of the home treatment options, they often remain skeptical about the ability to self-manage care. If patients require visits from health professionals, more frequent training, and other support systems, these are difficult to access in cases of geographic isolation. An additional concern regarding support systems for rural CKD patients is loneliness or social isolation. KHA states that feelings of abandonment are common in home dialysis patients, which can be exacerbated when they are further from urban centres with a large carer labour force <sup>[34]</sup>. Carer burnout also comes into play in cases where home dialysis patients require significant amounts assistance. The stress and workload of caring for a disabled or frail CKD patient may create shortages or gaps in care, which can affect the viability of long term home modalities.

Patient disability and age can affect self-management and thus clinical outcomes. The frail elderly and physically or cognitively impaired may not be able to operate the machine, reliably prevent infection, or remember to undergo treatment. Given that cultural and language differences can also represent barriers to care, preventing training or self-management, there are a variety of reasons why home dialysis might be unsuitable and it is important to recognise these cases as they appear. Infection, while possible in all modalities for RRT, may be a particular worry for patients who cannulate more frequently, such as patients who choose nocturnal HD or either type of PD. Infections may turn serious very quickly given the possibility for sepsis, and as with the barriers listed above, patient self-management and the distance from health providers can be significant deterrents despite literature that found the highest mortality rate from infection was in facility HD patients <sup>[34]</sup>.

The chief facilitators to home modalities are the advantages in cost, quality of life, and patient satisfaction. Health spending in Australia is increasing annually and there is continuous pressure on state and national governments to achieve the Triple Aim of lower costs, improved outcomes, and improved access. It is evident from a review of the literature on dialysis modalities that the home options achieve the triple aim when compared to in-centre dialysis and in some cases compared to satellite dialysis as well.

In addition to clinical outcomes, the ease of use and reduced burden on CKD patients' lives is a clear benefit. Given that a majority of nephrologists from around the world prefer home modalities to the current practice, professional recommendation and patient education should be sufficient to warm patients to the idea <sup>[56]</sup>. KHA notes the following improvements to patient lifestyles over satellite or in-centre dialysis <sup>[34]</sup>:

- Patient autonomy and flexibility with respect to treatment regimes
- Improved patient moods, interaction, cognition, and sex drive
- Less need to relocate
- Facilitation of travel and holiday due to HHD and PD machine mobility
- Reduced travel times to treatment centres
- Improved dietary and fluid allowances
- Less medication use
- Greater ability to return to work
- Lower rates of depression, improved sleep, lower rates of restless leg syndrome
- Improved morbidity and mortality due to extended HHD hours, lower rate of hospitalisation and complications from inter-dialytic wait times between thrice-weekly treatments, and reduced hospital acquired infections

There are several options to incentivise home dialysis from a funding and structural perspective. The most effective would be to only reimburse in-centre dialysis if home modalities are contraindicated. While forced home dialysis likely carries legal issues and may be politically charged, it has proven effective on Hong Kong where PD is the prevailing dialysis choice <sup>[57]</sup>. It represents a heavy-handed approach, but only highlights that there are top-down options for state and national governments to pursue. Funding models typically vary by state in Australia, including private health insurance, Commonwealth grants, and personal costs, but there is potential for each state to tailor its approach to the population and make home dialysis the financially easy choice for patients and providers. As most patients are evaluated for reimbursement by Diagnostic Related Group (DRG) and Activity Based Funding (ABF), changes that affect renal health will not interfere with other diseases.



# Interviews with Healthcare in the Home Stakeholders

While there is a cost saving in moving a patient from another modality to home dialysis, it should be taken into consideration that increasing prevalence will cause dialysis spending to increase regardless of incentives. Accordingly, future evaluations on the effectiveness of any home dialysis program should take into account the expected 6% per annum due to increasing prevalence. KHA also estimates around 10% per annum growth in renal health expenditures<sup>[34]</sup>. It is important that budgets, expectations, and political discourse reflect the fact that not all changes to cost will be due to the recommended modality.

In addition to DRG related reimbursements, patient level cost concerns are important to reduce the burden of disease on CKD patients. Improved subsidies over the current standard in some states will be required to incentivise home care, not only for utilities, carer costs (if necessary) but also for the dialysis machine and requisite supplies as well. A voucher for CKD patients can be cost-effective up to thousands of dollars given the cost template in Table 1 before it becomes equivalent to satellite HD. These patient cost concerns can also include a transportation service, such as the subsidy provided by Queensland Health for patients travelling long distances<sup>[58]</sup>. This can include carer-assisted transport for the infirm.

Reimbursement for home dialysis also needs to address the support services for CKD patients. Home support services can include phone or email check-ups, clinic visits for training and health assessment, home visits, and telehealth evaluations. On the flipside, patients must be able to contact their health provider or other allied health professionals including social workers and psychologists in order to feel confident and safe in their choice of home dialysis. Provision of support services should be reflective of the specifics of the patient population, including Aboriginal or Torres Strait Islander status and language barriers.

Kidney Health Australia have identified issues relating to the provision of dialysis to privately insured patients<sup>[59]</sup>. Some private health funds have had a limit on the number of their customers that they will provide coverage for dialysis, in which case the patient must either return to the public system, pay the 'gap' to the private provider, or try to switch health funds. Kidney Health Australia found a disconnect between funding rates for dialysis paid by government compared with the private sector—with the government paying a higher rate to adequately cover the cost of treatment.

Pre-dialysis education requires buy-in from a variety of stakeholders including government, health professionals, and health insurance companies. Physicians generally have very little time set aside for patient education, but nurses and other healthcare providers can be suitable as a more cost-effective and engaged alternative. According to KHA, good pre-dialysis education and training includes referral to current best practices, advanced knowledge of the benefits and drawbacks of each modality, coordination with renal care teams, culturally and rurally specific attention to detail, and good communication skills<sup>[34]</sup>.

While these traits are all necessary for a good pre-dialysis education, they are crucial for those health professionals that train patients how to use their machines, how to be more aware of their own health and clinical indicators, and how to liaise with health professionals to maintain good renal health. KHA believes this education should begin up to a year before commencing dialysis, which is supported by international recommendations<sup>[34]</sup>. This does not preclude late referrals from home dialysis, but at least two sessions, either as one-on-one sessions or workshops or both, and comprehensive written instructions are required for any patient beginning home dialysis. As patients tend to become attached to one modality, training and pre-dialysis education should reflect this attachment when outlining the reasons why they should switch to home dialysis. Treating in-centre and satellite modalities as a stop-gap may be an effective psychological tool for home eligible patients.

Training CKD patients requires adequate support from clinical providers across all relevant health structures, including dietitians, nurses, data analysts, and specialists. Ideally, data collection could be conducted both on a quantitative and qualitative basis. Qualitative data can be gathered in the form of informal phone or in-person interviews and conversations with home dialysis patients. These serve a dual purpose in both identifying any immediate flaws or misgivings as well as providing a platform for further research on the burden of their disease and modality. Quantitative data can include not only feedback from the dialysis machine itself, but also patient self-testing of risk factors such as blood pressure or HbA1C.

# Interviews with Healthcare in the Home Stakeholders

Minimisation of risk factors is a key component of both home dialysis continuation and of reducing mortality and morbidity overall. Some risk factors such as a failure to correctly use the dialysis machines can be assessed and rectified by teleconference or nurse call-outs and further training, while others such as infection should be monitored more regularly by patient self-testing. Data collection on patient vitals, moods, and adherence are crucial for improving outcomes, reducing costs, and making home dialysis a more comfortable patient experience.

## Barriers and Facilitators to the Delivery of HPN Services in Queensland

Several clinical practice guidelines<sup>[51, 60]</sup>, including the AuSPEN guidelines<sup>[44]</sup>, have recommended that HPN patients should be referred early to receive support from an expert centre with a multidisciplinary team, based on observational evidence that patients who receive such support have better health outcomes than if the support is not available<sup>[61-63]</sup>. The AuSPEN guidelines recommend that HPN patients should be regularly monitored by the multidisciplinary team. A review of the implementation of HPN clinical practice guidelines internationally found that most guidelines are being implemented in practice, with the exception that there was little evidence that HPN patients had been supported and monitored by a multidisciplinary team<sup>[64]</sup>.

Interviewees found that there was often insufficient support for HPN patients in the transition to home or the ongoing management of care. Some patients are not able to break the nutrition bag or otherwise cannot self-administer, which can result in carer burden or an increased risk of adverse events.

Funding for HPN in Queensland is allocated as part of the budget for the relevant clinical service unit. There is no Activity Based Funding for HPN in Queensland and HPN is not eligible for provision as a HITH service. Some private health funds provide funding for short term PN if it is directly related an event for which the patient has been hospitalised; however if long-term care is required the patient usually becomes the responsibility of a public hospital<sup>[44]</sup>.

There is also a lack of routinely collected data for HPN. ASPEN managed a registry of HPN patients; however, the registry has subsequently been aborted. The lack of routinely collected data limits the management and monitoring of HPN services.

## Summary and Recommendations

In many cases it is better for the patient and more cost effective to receive healthcare in the home that would otherwise be provided in-hospital. The needs of the patient must be paramount. The patient needs to be adequately supported in the transition to the home which may require training, evaluating the appropriateness of the residence and ensuring adequate support for carers. Out of pocket costs for the patients should be factored in. Cultural change in the health profession is required for further expansion of healthcare in the home. Healthcare in the home providers need to work with health professionals in hospitals to overcome uncertainty about the quality and safety of the at-home service. Finally, funding for healthcare in the home must ensure that healthcare in the home providers are appropriately compensated while avoiding cost shifting between state and national health funding systems.

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