

**Family members' involvement in their relative's kidney disease  
management and treatment choices: a survey using qualitative  
methods.**

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## ABSTRACT

**Background:** Chronic kidney disease (CKD) is a chronic and life-limiting condition with no cure. Family members play a significant, yet often unacknowledged, role in supporting a relative with advanced kidney disease.

**Aim:** This thesis investigates family members' involvement in their relative's kidney disease management and treatment choices. Its objectives are: investigate family members' understanding of CKD and involvement in treatment decisions; identify family members' support needs; explore the emotional impact on family members and how they made sense of their experiences.

**Method:** Cross-sectional survey design employing semi-structured interviews with seven family members of people with advanced kidney disease. Data was analysed using the qualitative framework approach. Participants' narratives were also interpreted using the assimilation model.

**Results:** Four overarching concepts emerged from the findings: 'Uncertainty', 'Maintaining a normal life', 'Developing an understanding' and 'Identifying and meeting needs'. Family members struggled with the uncertainty of their situation. They made sense of their experience at a different pace and oscillated between levels of avoidance and acceptance. Family members attempted to maintain as normal a life as possible but there were often barriers to this. They developed an understanding of CKD and their role within their relative's healthcare decisions and management. Whilst all family members had examples of feeling supported by HCP, most had examples where they felt the support could improve.

**Discussion:** Whilst family members favour treatment and illness management decisions that keep life as normal as possible, their everyday life is impacted by their relative's illness. Family members utilise different strategies to help them cope with the uncertainty of their situation. Using the assimilation model allowed the study to map the process of coming to terms with a problematic experience in a systematic way. Family members support needs could be addressed by family members having time alone with healthcare teams, support groups, and additional resources such as leaflets. Such a support pathway could be co-designed with family members.

**Conclusion:** Family members have support needs that could be addressed with the development of a support pathway within renal services.

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## **CHAPTER 1: INTRODUCTION**

This thesis is about how families are involved in treatment decisions and the impact of chronic kidney disease on families. To provide background information, this chapter will outline kidney disease and the different treatments available to patients. To provide context about family members' support needs and the potential challenges they might face, information regarding how people adjust to living with advanced kidney disease is then presented. While there is little evidence on how family members are impacted by supporting a relative living with advanced kidney disease, the literature on other chronic illnesses is summarised. This chapter will conclude with an overview of the assimilation model, which looks at how people make sense and come to terms with difficult events in their life and maps this process in a structured way. The model will be used to help make sense of this study's data.

### **1.1. Chronic kidney disease (CKD)**

CKD is a long-term condition, without a cure, where a person's kidneys do not work as they should. It is defined as structural kidney damage and / or decline in kidney functioning which has been present for a minimum of 3 months, regardless of cause (Eknoyan & Levin, 2002; Moynihan, Glassock, & Doust, 2013). The term 'chronic kidney disease' was first introduced and its stages classified in 2002 by the United States Kidney Foundation (Eknoyan & Levin, 2002) and later modified in 2012 by the KDIGO (Kidney Disease: Improving Global Outcomes) chronic kidney disease work group (2013). In the UK, the National Institute for Health and Care Excellence (NICE) also adopted this classification system (NICE, 2015). This framework has been largely welcomed as it attempts to introduce both standardised terminology and classification (Moynihan et al., 2013). The five stages of CKD are now fairly conventionally used (Stevens et al., 2007).

Kidney functioning is assessed by estimating a person's glomerular filtration rate (eGFR) and albumin to creatinine ratio (ACR; (Moynihan et al., 2013). A decrease in GFR and increase in ACR means that a person is at an increased risk of kidney disease and kidney damage. For clarity, this study will be defining CKD and its stages in keeping with the KDIGO and NICE guidelines (NICE, 2015). This study is interested in how families are involved in treatment decisions and the impact of chronic conditions on families. This study will therefore be working with family members whose relative has CKD stages 4 or 5. For readability, this will be referred to as CKD or CKD 4 and / or 5 throughout this study. Table 1 illustrates the various stages with the corresponding GFR levels.

**Table 1:** Classification of CKD (adapted from KDIGO chronic kidney disease work group, 2013 and Stevens et al., 2007).

Stage of CKD	Description	GFR categories (ml / min / 1.73m <sup>2</sup> )
Stage 1	Kidney damage with normal or raised kidney function	>90
Stage 2	Kidney damage with mildly reduced kidney function	60 - 89
Stage 3a	Mild to moderate reduction in kidney function	45 - 59
Stage 3b	Moderate to severe reduction in kidney function	30 - 44
Stage 4	Severe reduction in kidney function	15 - 29
Stage 5	Kidney failure	>15

### **1.1.1 Prevalence and co-morbidity**

In the UK, approximately 3 million people are believed to have moderate to severe CKD (Caskey & Dreyer, 2018). People from an ethnic minority background are up to 3-5 times more likely to require dialysis but will also wait longer for a transplant (Caskey & Dreyer, 2018; Roderick, Raleigh, Hallam, & Mallick, 1996). People from lower socioeconomic groups are at higher risk of developing CKD, progressing to a severe stage quicker and dying earlier from CKD (Caskey & Dreyer, 2018; Nicholas, Kalantar-Zadeh, & Norris, 2015; Volkova et al., 2008). Younger people (18-54 years) are less likely to be tested for CKD but have a higher relative risk of worse clinical outcomes from CKD (Caskey & Dreyer, 2018; Hallan et al., 2012). Whilst CKD can occur at any age, it is much more common in older people over 75 year old (Caskey & Dreyer, 2018). This means that many renal patients are living with frailty. Assessing the prevalence of frailty is complex due to the different ways it is assessed (Chowdhury, Peel, Krosch, & Hubbard, 2016) but studies suggest a frailty prevalence of over 60% in people receiving dialysis (Nixon et al., 2018).

Renal patients are also likely to have other medical conditions (Fraser et al., 2015). CKD is often associated with cardiovascular disease (CVD) and type 2 diabetes (Combs & Davison, 2015; De Lusignan et al., 2005; Mucsi, Kovacs, Molnar, & Novak, 2008; Stevens et al., 2007). Type 2 diabetes can cause CKD and CKD, in turn, can cause ventricular complications such as left ventricular hypertrophy or atherosclerosis (Mucsi et al., 2008). People with CKD are at an increased chance of developing cardiovascular problems (Collins et al., 2003; Ritz & McClellan, 2004) and CVD is the main cause of death for CKD patients before they develop stage 5 kidney failure (Coresh, Astor, Greene et al., 2003; De Lusignan et al., 2005; Drey, Roderick, Mullee, & Rogerson, 2003; John, Webb, Young, & Stevens,

2004). CKD poses a significant risk for a person's morbidity and mortality (De Lusignan et al., 2005; Drey, Roderick, Mullee, & Rogerson, 2003; Locatelli, Vecchio, & Pozzoni, 2002).

### **1.1.2 Treatment options**

For people with CKD 4 or 5, there are three treatment pathways. Kidney transplant and dialysis replace some kidney function and are known as renal replacement therapies (RRT). The third treatment option is conservative kidney management (CKM), an individualised package of care which does not compensate for any kidney functioning (Murtagh, Burns, Moranne, Morton, & Saraladevi, 2016; Murtagh et al., 2007). Decrease in kidney functioning presents differently between people making it difficult for clinicians to decide which treatment option to recommend (P. Roderick et al., 2015). Some people can be asymptomatic at diagnosis or have symptoms that are difficult to differentiate from the normal ageing process (Bristowe, Selman, Higginson, & Murtagh, 2019; Brown et al., 2018; Winterbottom, Conner, Mooney, & Bekker, 2007). However, symptom burden increases as the illness progresses and symptoms are used as triggers to decide when to start, adjust and stop treatments (Brown et al., 2018). The National Service Framework for Renal Services (NICE, 2015, 2018) have advocated for the importance of individual choice within kidney treatment. Patients with CKD 4 and 5 should be given advice about the different treatment options available to them in advance, including CKM (Roderick et al., 2015). Whilst national policies and guidelines (e.g. Department of Health, 2005) have emphasised the importance of providing psychological support within renal services, psychological provision is nationally inconsistent (Seekles et al., 2018). However, there is a Clinical Psychology department linked with the local renal clinics used for recruitment in this study.

#### *Kidney transplant*

A kidney transplant is when a donated kidney is surgically placed usually below the existing failing kidneys and functions at about 50% of two healthy kidneys (Bekker et al., 2017).

Patients can receive a kidney donation from friends or family as it is possible to live well with only one healthy kidney, known as a living kidney donation. Close blood relatives are more likely to be a better match for a patient as they are more likely to share tissue type and blood group. This means the patient is less likely to reject the donated kidney. Kidneys can also be donated from people who have recently died, which is called deceased kidney donation (NHS, 2018c).

Finding a donated kidney that is a medical match for a person can take a long time. The current wait in the UK is two and a half to three years for a deceased kidney donation (NHS, 2018c). Children and young adults are given priority when a kidney becomes available as they are most likely to benefit long-term from the transplant. Older patients are allocated a donated kidney depending on their score, which is calculated using factors such as length of time on waiting list and how well matched they are to the donated kidney (NHS, 2018c). The usually long waiting times mean other treatment options such as dialysis are often considered and commenced in the interim period. Following a kidney transplant, the individual will be continually monitored as the transplanted kidney's functioning is likely to decrease over time (NHS, 2016). In addition, the person's own kidneys will continue to deteriorate. Neither transplant nor dialysis can cure kidney disease but can prolong life (Gunda, Thomas, & Smith, 2005).

A transplant is often not suitable for older people living with frailty or people who have co-morbidities. When people are medically unable to receive a kidney transplant, a form of dialysis is usually offered as the next best option.

### *Dialysis*

Dialysis is a treatment where medical equipment does some of the work that kidneys would usually do but does not halt the progression of kidney disease. The equipment filters a person's blood and manages to achieve around 10% of healthy kidneys' function (Bekker et al., 2017). The two main types of dialysis are peritoneal dialysis (PD) and haemodialysis (HD). PD can be done at home and is either administered overnight or up to four times a day for short sessions. HD requires fewer weekly sessions. A patient usually requires around three sessions a week for four hours each time. Sessions can be undertaken at home, but usually occur in hospital due to the size of the machinery required (Bekker et al., 2017; NHS, 2016, 2018a).

Both types of dialysis have advantages and disadvantages and should be discussed and decided with each individual patient and their needs (Ayodele & Olutayo Alebiosu, 2010; Brown et al., 2017, 2009; Eton et al., 2015; Sav et al., 2013, 2015; Song et al., 2011). An advantage of HD is that the person normally has four dialysis-free days. However, due to the bulky equipment HD is usually undertaken at hospital and HD clinics must be located abroad if the patient wishes to travel. HD patients also often have more restrictions on their diet. PD means that the patient avoids weekly hospital visits and, if administered overnight, patients are dialysis-free during the day. They have more flexibility and can travel with the PD equipment. However, PD increases the risk of the patient developing peritonitis, an infection of the thin membrane that lines the abdomen requiring hospitalisation to treat the infection (Brown et al., 2017, 2009) or encapsulating peritoneal sclerosis, a rare but serious complication (Freitas et al., 2008). PD also assumes that someone in the household (patient or relative) will take on responsibly and undertake training in using the dialysis equipment (NHS, 2018b). This may not always be possible, particularly with older patients and families more likely to develop other conditions such as dementia.

The age of people starting renal replacement therapy (RRT) has significantly increased over the last 25 years, especially for people over 75 years old (Feest et al., 2004; Hurst & Figueiredo, 2015; Murtagh et al., 2007; C. Smith et al., 2003; Winterbottom et al., 2018). An increased emphasis on patient-centred care, patient choice and empowerment has meant elderly patients who would have historically been on a CKM pathway are now being offered RRT (Latos, 1996; Malberti et al., 1997; Stringer & Baharani, 2012).

Dialysis may not be beneficial for older people living with frailty (Combs & Davison, 2015). There is uncertainty whether the potential life-prolonging benefits of dialysis outweigh the potential cost to quality of life, especially if patients have multiple comorbidities (Burns & Carson, 2007; Carson, Juszczak, Davenport, & Burns, 2009; Combs & Davison, 2015; Da Silva-Gane et al., 2012; Hussain, Mooney, & Russon, 2013; Murtagh et al., 2007; C. Smith et al., 2003). Research suggests that people over 75 with kidney failure are likely to live longer if they are on dialysis compared to CKM (P. Roderick et al., 2015), but findings are equivocal (Combs & Davison, 2015). However, there is consensus that dialysis is often experienced as a burdensome and invasive treatment (Bristowe, Horsley, Shepherd, Brown, Carey, Matthews, O'Donoghue, et al., 2015; Hurst & Figueiredo, 2015). Dialysis can result in a loss of independence for patients, increased frailty and a loss of functionality (Chandna et al., 2011; Jassal, Chiu, & Hladunewich, 2009; Jassal & Watson, 2008). CKM pathways might therefore be more appropriate for many older renal patients, providing a better quality of life and fewer admissions in to hospital (Combs & Davison, 2015; Da Silva-Gane et al., 2012; Farrington et al., 2017).

#### *Conservative kidney management (CKM).*

There has been some difficulty in defining conservative kidney management (CKM), which is also referred to as comprehensive conservative care or conservative care (Murtagh, Burns,



Moranne, Morton, & Saraladevi, 2016). Conservative kidney management (CKM) will be used in this study as it is a more widely recognised term (P. Roderick et al., 2015). Unlike a transplant or dialysis, CKM does not substitute any kidney functioning and does not halt the progression of the kidney disease (Bekker et al., 2017). CKM been defined as a “planned holistic patient-centred care” (Murtagh et al., 2016, p. 1902) where the CKD is not treated with any form of RRT. It is an individualised package of care where patients are offered active support with symptom management and any treatment to minimize risk of patient complications, psychological support, social and family support, support for making shared decisions, spiritual care, and advance care planning conversations (ACP; for a full description, see section 1.2.5; Davison et al., 2015; Murtagh et al., 2016; Roderick et al., 2015). For some patients, particularly elderly people or those with cardiac disease, the median survival rate on a CKM pathway is reported to be between 6-32 months. This is either similar, or in some studies longer, than the predicted survival rate for these patients on dialysis (Chandna et al., 2011; Ellam, El-Kossi, Prasanth, El-Nahas, & Khwaja, 2009; Joly et al., 2003; Morton et al., 2012; Murtagh et al., 2007).

CKM is perceived and presented differently across different renal services, and there is often unclear or insufficient communication about CKM and its treatment implications (Hussain et al., 2013). People can be on a CKM pathway but be unaware of it (Hussain et al., 2013).

Whilst CKM is recommended to include education to support informed decision-making, assessment and care for CKD and other comorbid symptoms, and ACP conversations (Murtagh et al., 2016) it is often perceived as a passive option (Gunda et al., 2005). It can also be perceived as an option synonymous with palliative and end of life care (Collins, Mclachlan, & Philip, 2017; Murtagh et al., 2016; Roderick et al., 2015). People on a CKM pathway are therefore more likely to have conversations around ACP and end of life

(Davison & Torgunrud, 2007; Holley & Davison, 2015; Janssen et al., 2013). However, people with CKD can die on other treatment pathways (Hussain, Flemming, Murtagh, & Johnson, 2015), highlighting the importance of having ACP conversations with patients and families irrespective of their chosen treatment.

When kidney function deteriorates to <10%, patients should be supported in making end of life care decisions, regardless of their current treatment option (Winterbottom et al., 2018). Specialist palliative care services provided to patients includes ACP conversations, location care, managing symptoms at end of life, supporting people at home out of hours and supporting admission to a local hospice if needed (Roderick et al., 2015). Research suggests that patients on a CKM pathway are more likely to die at home compared to hospital, with support from palliative services (Chandna et al., 2011; Hussain et al., 2013).

### **1.1.3 Summary**

CKD is a chronic and life-limiting condition (Eknoyan & Levin, 2002; Moynihan, Glasscock, & Doust, 2013). Whilst there is no cure, RRT compensates for some kidney functioning and can prolong life (Bekker et al., 2017). For some people, CKM is considered the best, or only, treatment option (Murtagh et al., 2016). However, CKM is presented and implemented inconsistently across different services and people can be on a CKM pathway without realising it (Hussain et al., 2013). Some services view CKM as synonymous with palliative care and therefore people on this pathway are more likely to have ACP and end of life conversations (Davison & Torgunrud, 2007; Holley & Davison, 2015; Janssen et al., 2013) despite people also dying on other treatment pathways (Hussain et al., 2015).

In the next section a review of people's experiences of having CKD is offered to provide context for what their support needs might be and what challenges they and their family members might face.

## **1.2 Patient experience of CKD.**

Living with a chronic illness is associated with a loss of self, or former self (Bristowe et al., 2019). To be diagnosed with a chronic and life-limiting illness is often such a difficult experience that it requires an adjustment and re-thinking of one's identity, including plans and future expectations (Bristowe et al., 2019; Bury, 1982; Charmaz, 1983).

People with CKD report feeling taken aback about their diagnosis and shocked by the severity of their condition, due to a lack of symptoms early on or the misattribution of symptoms to normal ageing, as well as the routine way in which the illness is often detected (Winterbottom, Conner, Mooney, & Bekker, 2007). They feel unprepared, overwhelmed and unsure about what the future might hold (Schell, Patel, Steinhauer, Ammarell, & Tulskey, 2012).

### **1.2.1 Making treatment decisions**

People with CKD are faced with difficult and complex decisions throughout their treatment journey. As the illness progresses to the later stages, a person's decisions will have significant impact on their day-to-day lives (Jayanti et al., 2015; Tamura, Tan, & O'hare, 2012).

Most people with CKD will choose a RRT as they believe it is their best chance for living longer (Russ, Shim, & Kaufman, 2005, 2007; Song et al., 2013). Others worry that they might be forgotten about by their renal team if they do not choose an active RRT (Moss, 2003). Some people report that the need to survive colours their decision-making and people face fear and existential distress as they become aware of their own mortality (Davison, 2011; Davison & Jhangri, 2010). To alleviate this distress, people with CKD often opt for active RRT compared to a CKM pathway. Despite having received pre-dialysis education, other points for consideration such as side effects, quality of life, the burden of dialysis are often overlooked. This means people with CKD are often unprepared for the reality of dialysis

(Burns & Carson, 2007; Davison, 2010; Davison & Simpson, 2006; Hemmelgarn et al., 2007; Song et al., 2013), expecting it to be “a trivial undertaking” (Stringer & Baharani, 2012, p. 299).

Some people may regret their decision to commence dialysis (Davison, 2010; Song et al., 2013) and will change their mind regarding their treatment “at the 11<sup>th</sup> hour” (Noble et al., 2017; Stringer & Baharani, 2012, p. 300). Deciding to opt for a CKM pathway, or terminate active treatment in favour of CKM, is a multi-faceted and complex decision and people can feel morally conflicted when making this choice (Bostwick & Cohen, 2009).

Research has found that some people consider a ‘trade-off’ between longevity of life and quality of life when making their treatment decisions (Morton et al. 2012). Some people with CKD will opt for CKM, despite the potential life-prolonging benefits of dialysis, as they wished to avoid additional trips to hospital or wanted to be able to travel without restriction. For some people it will be worth trading a shorter life for a life with potentially more autonomy (Morton et al., 2012).

### **1.2.2 Treatment burden**

People living with a chronic illness report high levels of treatment burden (Ayodele & Olutayo Alebiosu, 2010; Eton et al., 2015; Fraser et al., 2015; Sav et al., 2013, 2015). People on dialysis report high levels of fatigue, with many HD patients requiring several hours of rest on both treatment and non-treatment days (Ginieri-Coccosis, Theofilou, Synodinou, Tomaras, & Soldatos, 2008; Song et al., 2011). Despite reporting stable levels of symptom distress and quality of life, patients receiving PD experience a significant negative social impact (Ginieri-Coccosis et al., 2008). Patients on HD report that their quality of life decreases and symptom distress increases over time (Ginieri-Coccosis et al., 2008).

Reported difficulties, such as a lack of appetite, high rates of fatigue, dyspnea (shortness of breath), insomnia, pain, anxiety and depression (Chan et al., 2011; Combs & Davison, 2015; Davison, 2003; Davison, Jhangri, & Johnson, 2006a, 2006b; Davison & Jhangri, 2005; Lopes et al., 2007) are multidimensional challenges with strong psychological and social components. The literature highlights that people with CKD 4 and 5 require a combination of psychological, social as well as medical support, but that these difficulties are underappreciated resulting in a lack of support (Combs & Davison, 2015; Davison et al., 2006b, 2006, 2014).

### **1.2.3 Communication with healthcare professionals (HCP)**

Some people with CKD feel they have the necessary information and support to make treatment decisions (Aasen et al., 2012; Bristowe et al., 2015; Noble et al., 2009). However, research suggests that there is often a lack of communication between HCP and their patients (Combs & Davison, 2015; Fadem et al., 2011; Mehrotra, Marsh, Vonesh, Peters, & Nissenson, 2005; Schell et al., 2012; Song et al., 2013; Wachterman et al., 2013).

People with CKD are often provided with inadequate information (Morton, Tong, Howard, Snelling, & Webster, 2010) and written information supplied by renal teams is often difficult to understand and does not support people to make treatment decisions (Winterbottom et al., 2007). People will therefore often have unrealistic expectations about treatment goals (Combs & Davison, 2015). Research also shows that some physicians do not believe it is feasible or helpful to give their patients too many details regarding dialysis (Iezzoni, Rao, DesRoches, Vogeli, & Campbell, 2012; Stringer & Baharani, 2012). Many people with CKD are unaware that they have a choice regarding their treatment options (Morton et al., 2012; Morton, Tong, Howard, Snelling, & Webster, 2010; Schell, Patel, Steinhauser, Ammarell, & Tulskey, 2012; Song et al., 2013; Song et al., 2011; Stringer & Baharani, 2012; Wachterman et al., 2013).

#### **1.2.4 Prognosis**

A lack of communication and shared understanding between patients and HCP means that people are often unaware that they may only have a few months left to live (Murtagh et al., 2007; Stringer & Baharani, 2012). Older people with CKD, in particular, are unlikely to discuss their prognosis or illness with HCP (Schell et al., 2012). However, this knowledge might influence their decisions regarding treatment (Murtagh et al., 2007; Stringer & Baharani, 2012). The annual mortality rates for CKD are higher than for prostate, breast or colorectal cancer, but many people with CKD are unaware of this (Weisbord et al., 2003) and believe dialysis or a transplant offer a cure (Kane, Vinen, & Murtagh, 2013). The median life expectancy for someone with CKD 5 aged 25 years old is 20 years. This reduces to just five years for people who are 70 years old (Ansell, Castledine, Feehally, Fogarty, & Ford, 2009).

#### **1.2.5 Advance care planning**

Advance care planning (ACP) discussions are conversations between patients, families and HCP. They are a space to discuss things like treatment goals, values, worries, treatment preferences, prognosis and future care options (Bristowe et al., 2015). According to the research, sensitive ACP can improve a person's quality of life, symptom burden and increase hope (Bristowe, Horsley, Shepherd, Brown, Carey, Matthews, O'Donoghue, et al., 2015; Bristowe et al., 2014).

Some patients are unwilling to think or talk about treatment decisions and will avoid these difficult conversations until they are perceived as being unavoidable (Bristowe et al., 2015; Song et al., 2013). Some people would rather delegate the task of choosing their treatment to HCP (Jayanti et al., 2015). However, other people are willing to speak about their treatment, prognosis and end of life (Stringer & Baharani, 2012). Research suggests that most people would like to have these ACP conversations, and at a relatively early stage (Bristowe,

Horsley, Shepherd, Brown, Carey, Matthews, O'Donoghue, et al., 2015; Bristowe et al., 2014).

Many HCP report feeling unprepared and uncomfortable having such conversations (Bristowe, Horsley, Shepherd, Brown, Carey, Matthews, O'Donoghue, et al., 2015; Bristowe et al., 2014). Their anxiety about distressing their patients by having conversations about prognosis, death and end of life (Burns & Carson, 2007; Latos, 1996; Stringer & Baharani, 2012) mean that many patients and their families are not having the opportunity for ACP discussions (Davison & Torgunrud, 2007; Holley & Davison, 2015). Clinicians tend to emphasise the benefits of dialysis because they want to limit their patients' anxieties and want their patients to maintain hope (Davison & Simpson, 2006; Iezzoni, Rao, DesRoches, Vogeli, & Campbell, 2012; Stringer & Baharani, 2012). This is despite the research suggesting that early ACP conversations increase hope for people with CKD (Bristowe, Horsley, Shepherd, Brown, Carey, Matthews, O'Donoghue, et al., 2015; Bristowe et al., 2014).

### **1.2.6 Summary**

People living with a chronic and life-limiting illness such as CKD 4 and 5 will experience the loss of a former sense of self and will be forced to re-think their identity, including their plans and hopes for the future (Bristowe et al., 2019). They face complex treatment decisions (Jayanti et al., 2015; Tamura et al., 2012) and a lack of shared understanding between them and HCP means patients are often unaware of their prognosis (Murtagh et al., 2007; Stringer & Baharani, 2012). People value early ACP discussions but HCP report feeling anxious having these conversations for fear of distressing their patient (Bristowe, Horsley, Shepherd, Brown, Carey, Matthews, O'Donoghue, et al., 2015).

The next section will focus on family members' experiences of supporting a relative with a chronic illness to provide insight into some of the benefits and challenges families of someone with CKD might face. A brief overview of the terminology and rationale for using 'family member' instead of 'carer' is offered, before providing an overview of the impact supporting someone with a chronic illness, including implications for family members' sense of self.

### **1.3. Family members' experiences of supporting a relative with a chronic illness**

#### **1.3.1 A carer or a family member?**

A carer is defined as "anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty... and cannot cope without their support. The care they give is unpaid" (NHS Commissioning, 2018). This definition does not convey the complexity of being a carer (O'Connor, 2007).

Some family members do not wish to adopt the label of 'carer' (Knowles et al., 2016; O'Connor, 2007) believing that to do so would subsume other important identities such as spouse, child, parent (Arksey, 2002; Knowles et al., 2016). Many family members not identifying as carers will nevertheless be engaged in a caring role, whilst others identifying as carers may not always provide as much care to their relative (Henderson, 2001; Kutner, 2001; O'Connor, 2007). Not all family members of people living with CKD 4 and 5 will be classified as carers. Even if they do have a caring role, they may not wish to be seen this way.

Terminology within research is used inconsistently. Whilst some of the research defines the terminology used (e.g. Low et al., 2014; Morton et al., 2010), other research does not (e.g. Belasco, Barbosa, Bettencourt, Diccini, & Sesso, 2006; Belasco & Sesso, 2002; Breckenridge & Locking-Cusolito, 1997; Courts, 2000; Luk, 2002; Noble, Kelly, & Hudson, 2013; Ziegert & Fridlund, 2001) which raises the question of whether these studies are talking about the



same group of people e.g. family members or paid carers. This study will use the term 'family member' to represent people that support their relative with CKD but who are not paid carers and may not identify as a carer.

### **1.3.2 Supporting a relative with a chronic illness**

Supporting a relative with chronic illness can have a significant impact on a person's life, including their psychological well-being (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Broady, 2017; Butow, 2017; de Oliveira et al., 2015; Williams & McCorkle, 2011). The impact can be especially great if they are supporting a relative who is approaching the end of their lives as their relative's needs increase (Ando, Ninosaka, Okamura, & Ishi, 2015; Broady, 2017; Butow, 2017; Shah, Victor, Health, & Cook, 2016; Williams & McCorkle, 2011). Family members will face both practical and emotional challenges (Beng et al., 2013; Broady, 2017; Collins et al., 2016; Funk et al., 2010; Glass, 2016; Lewis, 2015; Stajduhar et al., 2010; Williams & McCorkle, 2011).

Family members also face different forms of loss (Bristowe et al., 2019). These losses include the loss of their previous life, a loss of control, loss of hope, loss of previous values or beliefs and a loss of relationship with the person for whom they are caring as that person's health or cognitive ability declines (Broady, 2017; Butow, 2017; Collins et al., 2016; Kitt-Lewis, Strauss, & Penrod, 2018; Lewis, 2015; Melin-Johansson, Henoeh, Strang, & Browall, 2012; Sand & Strang, 2006; Thomas et al., 2009; Totman et al., 2015). Like their relative, family members' sense of identity may also change. Research suggests that supporting one's relative can become central to a family member's sense of identity (Broady, 2017). This is often described in the research as 'the carer persona' (Beng et al., 2013; Carlander, Sahlberg-Blom, Hellström, & Ternestedt, 2011; Høgsnes, Melin-Johansson, Norbergh, & Danielson, 2014; Lewis, 2015; Totman et al., 2015). Identifying as someone in a caring role can change

the dynamics of a relationship (Knowles et al., 2016; O'connor, 2007) and can lead family members' to prioritise their relative's needs above their own (Beng et al., 2013; Høgsnes et al., 2014; Lewis, 2015; Totman et al., 2015). When their relative passes away, the dissolution of this identity can also feel distressing or disorientating (Broady, 2017; Carlander et al., 2011).

Caring for a relative with a chronic illness can have a positive impact, giving individuals a meaningful and coherent identity, a role which is perceived as both important and fulfilling (Broady, 2017; Griffith & Hastings, 2014; Høgsnes et al., 2014). Some family members report feeling lucky to have the opportunity to care for their relative and that it can lead to a renewed closeness in the relationship (Anderson & White, 2018; Kramer, 1997). The way a person perceives supporting their relative has an impact on experience (Anderson & White, 2018). If an individual has a positive story about supporting their relative, they are likely to have a more positive experience (Anderson & White, 2018; Garlo, O, Van Ness, & Fried, 2010; Rohr & Lang, 2016).

### **1.3.3 Summary**

Supporting a relative with a chronic illness results in both practical and emotional challenges for family members (Beng et al., 2013; Broady, 2017; Collins et al., 2016; Funk et al., 2010; Glass, 2016; Lewis, 2015; Stajduhar et al., 2010; Williams & McCorkle, 2011). Like their relative, family members face a sense of loss for their previous life and hopes and expectations for the future (Broady, 2017; Butow, 2017; Collins et al., 2016; Kitt-Lewis, Strauss, & Penrod, 2018; Lewis, 2015; Melin-Johansson, Henoeh, Strang, & Browall, 2012; Sand & Strang, 2006; Thomas et al., 2009; Totman et al., 2015). The experience of supporting a relative diagnosed with a chronic illness also has implications for the family member's identity and sense of self. Whilst identifying with a caring role can have benefits,

including a sense of purpose and fulfilment (e.g. Anderson & White, 2018; Broady, 2017), it can also mean that family members prioritise their relative's needs above their own (Beng et al., 2013; Høgsnes et al., 2014; Lewis, 2015; Totman et al., 2015).

The next section will focus on family members' experiences of supporting a relative with CKD 4 and 5 specifically.

#### **1.4 Family members' experiences of supporting a relative with CKD 4 and 5.**

Family members play a significant, and often unacknowledged, role in supporting a relative with CKD 4 and 5 (Ashby et al., 2005; Lindqvist, Carlsson, & Sjöden, 2000; Low et al., 2014; Luk, 2002; Morton et al., 2010; NHS Kidney Care, 2015; Noble et al., 2013; Ziegert & Fridlund, 2001). Despite this, there has been a paucity of research undertaken with the people supporting these patients with CKD stages 4 and 5 (Noble et al., 2013). There is currently no literature on family members' involvement of supporting their relative with treatment decisions and illness management across all renal treatment pathways.

##### **1.4.1 Treatment decisions and illness understanding**

The current research suggests that, like their relative with CKD, most family members have a lack of knowledge of CKD and renal treatments (Low et al., 2014; Luk, 2002; Noble et al., 2013). Family members can feel unsure regarding the treatment options, what might be in their relative's best interest, and sometimes feel overwhelmed as they try to make sense of their different options (Noble et al., 2013). Some family members whose relatives are on a CKM pathway cannot define CKM, only that it is not an RRT. They can have a lack of understanding about its treatment implications (Low et al., 2014).

There are potential conflicts and tensions between patient, relative and HCP (Low et al., 2014) if families perceive that choosing CKM means their relative is giving up (Low et al.,

2014). Conflict can also occur if families view CKM as a way of treating CKD without the inconvenience of dialysis, instead of as a way of managing symptoms whilst kidney function continues to deteriorate (Low et al., 2014). Some family members may believe their relative should be offered dialysis, as opposed to CKM, because of a perception it would ensure greater life expectancy (Low et al., 2014). Even if their relative is on a CKM pathway, some family members believe that dialysis will be an option if their relative's health deteriorates (Low et al., 2014).

Research suggests that taking charge of the home dialysis machinery can lead family members to become anxious and fatigued, and to a deterioration in the family's relationship (Belasco et al., 2006; Belasco & Sesso, 2002; Brunier & McKeever, 1993; Watson, 1997). Family members describe a pressure to 'get things right' when assisting with their relative's treatment (Ashby et al., 2005; Low et al., 2014) and an increased responsibility of doing the day-to-day tasks at home with no additional support (Luk, 2002; Ziegert & Fridlund, 2001).

#### **1.4.2 Communication with the HCP**

The potential conflicts between family member, relative and the HCP is often due to misunderstanding and a lack of communication between families and HCP (Combs & Davison, 2015; Fadem et al., 2011; Mehrotra, Marsh, Vonesh, Peters, & Nissenson, 2005; Schell et al., 2012; Song et al., 2013; Wachterman et al., 2013). Family members are often confused about the different treatments and unsure why their relative is receiving a particular treatment (Noble et al., 2013). They report feeling under-prepared by HCP for the reality of supporting someone on dialysis (Luk, 2002; Morton et al., 2010) and feel they need more information and knowledge (Low et al., 2014; Luk, 2002; Morton et al., 2010; Noble et al., 2013). If their relative has multiple co-morbidities, family members can feel confused when

trying to understand different symptoms and medications. They can become frustrated when healthcare teams offer different and un co-ordinated advice (Low et al., 2014; Luk, 2002).

Good communication with family members is important as they can influence the treatment decisions that their relative makes (Ashby et al., 2005; Lindqvist, Carlsson, & Sjöden, 2000; Low et al., 2014; Morton et al., 2010; Noble, Kelly, & Hudson, 2013; Ziegert & Fridlund, 2001). Family members might also be able to act as intermediaries between their relative and HCP (Low et al. 2014). Whilst some family members reported that they felt able to contact the renal team whenever they needed to (Luk, 2002), others felt unable to do this despite being told by their renal teams that they could call if needed (Low et al., 2014).

Family members report that having continuity in their relative's care is very important to them. It provides an opportunity to build a good relationship with the HCP (Low et al., 2014; Luk, 2002) and for patients and families to feel as if they are seen as human beings and not just patients (Saeteren, Lindström, & Nåden, 2011).

### **1.4.3 Other sources of support**

The UK health polices recommend that family members supporting a relative with CKD should receive more information, support and needs assessments (Department of Health, 2008; NHS Kidney Care, 2015). In addition, research findings highlight family members should have access to support groups, or additional support / respite services (Low et al., 2014; Luk, 2002; Morton et al., 2010; Noble et al., 2013). However, family members' experiences of receiving information and support is inconsistent (Lindqvist et al., 2000; Low et al., 2014; Luk, 2002; Morton et al., 2010; Noble et al., 2013).

#### **1.4.4 Emotional impact**

Family members report experiencing ongoing anxiety and fears about their relative with CKD deteriorating in the future (Ashby et al., 2005; Low et al., 2014; Noble et al., 2013). Some family members worry that any new symptom is an indicator that the CKD is deteriorating (Noble et al., 2013). Other family members perceive the gradual deterioration in their relative as a part of ageing which can complicate interpreting changes in CKD (Low et al., 2014). Some family members report that they cannot plan for the future (Ziegert & Fridlund, 2001), believing that they must always be available for their relative, limiting their own life and future plans (Ziegert & Fridlund, 2001). Some family members report financial strain, feeling socially isolated, and needing to keep their feelings of loss and anxiety hidden from their relative (Luk, 2002; Ziegert & Fridlund, 2001). Family members feel particularly vulnerable if they are faced with a medical emergency (Low et al., 2014).

#### **1.4.5 Supporting their relative at end of life**

Family members describe finding it difficult not knowing how long their support would be needed as relatives can live for significantly longer than their initial prognosis (Noble et al. 2013) leaving family members unsure about "how terminal is terminal" (Noble et al., 2013, p. 1834). Uncertainty regarding illness trajectory can sometimes lead to families deciding to move their relative to a nursing home. Family members report that this is a complex and difficult decision and is almost always preceded by an event where the family member had not felt able to manage (Noble et al. 2013)

Family members report feeling a lot of pressure to keep caring for their relative at home (Low et al., 2014; Luk, 2002; Noble et al., 2013). However, some family members are resistant to this. Some family members report wanting to protect the rest of the family from the death, whilst others report having a negative experience of someone dying at home in the past.

Some family members are resistant due to the high levels of stress and anxiety it caused (Low et al., 2014).

#### **1.4.6 Conversations around end of life**

Research suggests that family members are reluctant to speak with their relative about end of life even though most have an awareness that their relative's kidneys will continue to deteriorate, eventually leading to death (Low et al., 2014). Some family members attempt to manage this uncertainty by focusing on the present and trying not to worry about the future (Low et al., 2014). Other families are able to speak about the end of life, but tend to focus on more practical, as opposed to emotional needs, such as funeral arrangements (Low et al., 2014).

Other family members will actively avoid having these conversations with their relative (Braithwaite et al., 2011; Low et al., 2014; Noble et al., 2013; Saeteren et al., 2011). There is a fear that talking about death might tempt fate or eliminate their relative's hopes (Low et al., 2014; Noble et al., 2013). However, in Stringer and Baharani (2011)'s study, patients with CKD reported that they would prefer to have discussions about death and end of life with HCP without their family members presents, as they were afraid of causing *them* distress. Patients and their family members can evidently become stuck in a dance of silence where neither party feels able to speak of their troubles for fear of causing upset to others (Coll, Surrey, & Weingarten, 1998; Saeteren et al., 2011; Weingarten, 1997, 2000, 2012; Weingarten & Worthen, 1997) and there is often a "mutual pretence" that the patient is not going to die (Fredman, 1997, p. 1).

Research provides some insight into the experiences of family members supporting a relative with CKD. This research all focuses on a specific patient group, including patients with CKD 5 managed with CKM (Low et al., 2014; Noble et al., 2013) patients who choose to stop

dialysis (Ashby et al., 2005), patients on dialysis (Belasco et al., 2006; Breckenridge & Locking-Cusolito, 1997; Lindqvist et al., 2000) or patients on a specific type of dialysis (Courts, 2000; Luk, 2002; Ziegert & Fridlund, 2001). Currently, there is no research that looks at family members' experiences of being involved in their relative's CKD treatment decisions and illness management across all renal treatment pathways.

#### **1.4.7 Summary**

Family members play a significant, but often unacknowledged role, in supporting their relative with CKD (Ashby et al., 2005; Lindqvist et al., 2000; Low et al., 2014; Luk, 2002; Morton et al., 2010; NHS Kidney Care, 2015; Noble et al., 2013; Ziegert & Fridlund, 2001). Family members value consistency in their relative's care and building a relationship with HCP (Low et al., 2014; Luk, 2002). Family members fear their relative deteriorating in the future (Ashby et al., 2005; Low et al., 2014; Noble et al., 2013) but will avoid speaking to their relative about the end of life, fearing that they will cause distress (Low et al., 2014).

The final section of this chapter will describe the assimilation model, specifically how it proposes people make sense of and come to terms with unwanted life events, and how to map this process of adjustment in a structured way.

#### **1.5 Using the assimilation model to understand how people come to terms with unwanted life events**

The assimilation model is a framework to help understand how people incorporate new experiences and events into their sense of self (Honos-Webb & Stiles, 1998; Honos-Webb, Surko, Stiles, & Greenberg, 1999; Stiles, 1999, 2001; Stiles, Honos-Webb, & Lani, 1999).

This model was first developed as a way to make sense of how clients assimilate an unwanted or problematic experience within psychotherapy (Honos-Webb & Stiles, 1998; Honos-Webb et al., 1999; Stiles, 1999, 2001; Stiles et al., 1999), but can be broadened into a range of



situations (for example, how people and their families assimilate a threatening health diagnosis). Most new experiences are unproblematic and can be easily integrated into an individuals' identity and existing sense of the world (Lishman, Cheston, & Smithson, 2016). However, some experiences are perceived as too traumatic or challenging and their consequences too threatening, to be easily assimilated into an individual's 'sense of being' (Cheston & Jones, 2004).

People will often try to resist the experience by retreating and denying (Lishman et al., 2016). However, even when struggling with or denying an experience, elements of this conflict are often still communicated indirectly, for example, through contradictions in the person's narrative. This suggests that, even when a person is attempting to deny an event or experience, there is a part of that experience that is being processed (Lishman et al., 2016). Coming to terms with an unwanted or problematic life event is often portrayed as a linear process e.g. the five-stage bereavement model (Kübler-Ross, 1970) and it was once thought that a problematic experience would be assimilated in a linear fashion through mapped stages (Stiles, 1999). However, recent research suggests that people oscillate between stages (Cheston, Marshall, Jones, Spreadbury, & Coleman, 2018). This process can be mapped using the markers of the assimilation model, or the problematic experience scale (see Appendix 7; Stiles, 1999; Stiles et al., 1991).

Research using the assimilation model has primarily focused on how therapy clients assimilate unwanted experiences into their sense of self (Newman & Beail, 2002; Varvin & Stiles, 1999). However, it has also been used to explore how people and families adjust to a change in health state, such as dementia (Cheston, Gating, Marshall, Spreadbury, & Coleman, 2017; Cheston et al., 2018; Cheston, Watkins, Cheston, Jones, & Gilliard, 2006; Lishman et al., 2016). This research had clinical implications for dementia care as it

identified opportunities for HCP to have conversations with their patients and families about their diagnosis. In dementia care, greater insight into the condition is associated with decreased care-giver burden (Cheston et al., 2018; Rocca et al., 2010).

Whilst there is no research to suggest that greater insight for either people living with CKD or their families results in less care-giving burden, research on living with and supporting someone with a chronic illness suggests that people face a sense of loss and have to re-evaluate their identities and sense of self as they come to terms with, or assimilate, the diagnosis or their caring role. The assimilation model maps this process in a structured way and could enhance our understanding of how family members of someone with CKD comes to terms with their situation. Research suggests that patients and families would like to have ACP conversations, but that HCP can fear causing distress. Both relatives with CKD and their families can also fear speaking about the illness and prognosis due to concerns about distressing each other. Looking at family members' narratives through an assimilation model lens could identify opportunities for HCP and people with CKD to talk to family members about the diagnosis and prognosis.

## **1.6 Chapter summary**

To summarise, CKD 4 and 5 is a chronic and life-limiting illness (Eknoyan & Levin, 2002; Moynihan et al., 2013) with three treatment pathways – transplant, dialysis and CKM (Bekker et al., 2017). People diagnosed with CKD 4 and 5 face complex treatment decisions (Jayanti et al., 2015). Family members supporting a relative with CKD 4 and 5 play a significant, and often unacknowledged role, in that person's healthcare (e.g. Low et al., 2014; Luk, 2002; Morton et al., 2010; Noble et al., 2013). Family members can feel unprepared for the reality of supporting their relative (Luk, 2002; Morton et al., 2010). The assimilation model could identify opportunities for HCP and people with CKD to speak with their family

members about the diagnosis and prognosis. Whilst there is research into the experience of family members whose relative is on certain renal treatment pathways, (Ashby et al., 2005; Belasco et al., 2006; Breckenridge & Locking-Cusolito, 1997; Courts, 2000; Lindqvist et al., 2000; Low et al., 2014; Luk, 2002; Noble et al., 2013; Ziegert & Fridlund, 2001), no studies explore family members' involvement across all CKD treatment pathways.

### **1.7 Research aim and objectives**

The study aims to explore how family members' experiences of being involved in their relative's CKD treatment decisions and illness management across all CKD treatment pathways. This study has the following objectives:

- Investigate family members' understanding of CKD and their involvement in their relative's treatment decisions
- Identify what support needs family members might have, and what helps or hinders these needs being met
- Explore the emotional impact on family members and how they have made sense of their experiences

## **CHAPTER 2: STUDY DESIGN AND METHODS**

### **2.1. Introduction**

This chapter describes the design and methods used to investigate family members' experiences and impact of involvement in a relative's CKD treatment decisions and illness management. This chapter discusses the rationale for using qualitative methods to address the research question and reflects on the role of the researcher in enhancing and biasing processes that may impact on the validity of the findings.

### **2.2 Study setting**

The two main support networks for people with CKD and their families within the regions of Yorkshire and Humberside are a National Health Service (NHS) acute hospital trust and the Kidney Research Yorkshire (KRY) research group, which includes the Yorkshire Dialysis vs Conservative-management Decision Aid (YoDCA) research group. The NHS trust and KRY / YoDCA supported this study's recruitment. It was decided to recruit from both these settings to maximise recruitment potential.

The care of people with CKD is under the management of specialist kidney professionals in hospital-based clinics. Treatments like dialysis, can take place in people's home or at the hospital. All people with CKD need to take medications and have strict diet, fluid and exercise routines to keep their kidneys as healthy as possible and minimise the impact of kidney failure on their bodies. The role of family members in people's kidney disease management varies. Many will not be aware of kidney services, and / or patient support groups.

### **2.3 Ethical approval**

This study was approved by the Yorkshire & the Humber - South Yorkshire Research Ethics Committee (IRAS number: 258378). Research and Development approval was granted by Leeds Teaching Hospital NHS Trust Wakefield District and by Leeds Teaching Hospitals Trust (Reference number: RL19/125726). See appendices 12 and 13 for letters of confirmation of ethical approval.

## **2.4 Study design**

This study is a cross-sectional survey employing semi-structured interview methods to elicit data from people with a family member who has CKD. Interviews were conducted using face-to-face or telephone conversations. The study will be using qualitative analysis to classify data with reference to a) markers of the assimilation model (Honos-Webb & Stiles, 1998; Honos-Webb et al., 1999) and b) framework analysis, in accordance with framework approach guidance (Smith & Firth, 2011).

### **2.4.1 Justifying a qualitative approach**

Quantitative and qualitative research are often perceived as having contrasting and competing epistemological (what and how is it possible to know about the world) and ontological (our understanding of reality and what we can know about it) positions. Quantitative research is often linked with a positivist epistemological stance and a realist ontology, meaning knowledge about the world is gained objectively and phenomena are systematically studied (Willig, 2001). Qualitative research is linked with an interpretivism stance, meaning that how we (including researchers) interpret and understand our social world impacts on our perspectives and understanding of human experience and therefore cannot be studied objectively (Ritchie & Lewis, 2003, 2014). There are a range of ontological positions within qualitative research methods including critical realism (the belief that there is an external

reality which is knowable only through our socially constructed meanings) and idealism (there is no external reality, only socially constructed meanings) (Ritchie & Lewis, 2003, 2014). However, some researchers believe that these stances are not competing positions but can be considered as complimentary research tools within a toolkit of methods, which will both be appropriate for different research questions and aims (Ritchie & Lewis, 2003, 2014; Sandelowski, 2000; Smith et al., 2011). Philosophical debates regarding epistemology and ontology can detract from the importance of selecting the research method which is best suited for a study's research question (Ritchie & Lewis, 2003, 2014; Sandelowski, 2000; Smith et al., 2011).

Qualitative methods are appropriate to obtain rich and in-depth information about a person's views and experiences which could not be captured by quantitative methods (Mays & Pope, 2000; Pope, Ziebland, & Mays, 2000; Ritchie & Lewis, 2003, 2014). A qualitative research design is appropriate for this project, as it investigates an under-researched area where the participants' views are not known (Braun & Clarke, 2006). The research aims to gain insight into family members' individual perspectives and interpret meaning from their individual accounts (Braun & Clarke, 2013; Smith, Bekker, & Cheater, 2011).

#### **2.4.2 Sample selection strategies**

The sample population are family members of a relative who has, or did have, CKD 4 or CKD 5. Qualitative research collects information rich data. Sample sizes are therefore small in comparison to quantitative research. A balance needs to be achieved between obtaining data of enough depth and breadth and the resources available (Patton, 2015). For the purpose of this study it was anticipated that approximately 5-10 interviews would generate sufficient data and was reasonable within the resources and timeframe (Braun & Clarke, 2006).

However, there was flexibility to increase or decrease the number of interviews until theoretical saturation was satisfied.

#### *Inclusion criteria*

- Adults (over 18 years old) who have, or did have, a relative with kidney disease stages 4 and 5.
- The participants needed to be willing and able to give informed consent.

#### *Exclusion criteria*

- People who do not have / have never had a family member living with CKD.
- People who also have CKD themselves as this will mean they are not only a family member.
- People who have a medical condition which might mean the interviews are not appropriate (e.g. moderate dementia).
- People who the chief investigator knows personally or has worked with therapeutically in the past. Prior knowledge of the person would impact the analyses.
- People who are not fluent in English. In both interviews and analysis meaning and non-verbal communication could be lost / confounded / distorted in the process of interpretation and translation.

### **2.4.3 Data collection methods**

It was decided to use a semi-structured interview format as it provides the flexibility to elaborate or avoid certain topics whilst its structure ensures research aims are also discussed (Barriball & While, 1994). An interview topic guide (see appendix 5) was developed with support from the study's supervisors. The interview schedule was piloted with two participants, who had the opportunity to comment on whether the schedule needed to be

amended. Meetings with supervisors were used to discuss the first transcript from these pilot interviews. The only feedback was for AJ to remember to remain in an interviewer, rather than therapist, role as there was a tendency to focus on people's emotions. However, neither the participants nor supervisors suggested any changes to the schedule. This pilot data was therefore included in the study's analysis.

## **2.5 Materials**

In line with consent and ethics the following materials were designed for this study (see appendices 1 -7):

- Consent form
- Participant Information sheet
- The letter to CKD patients informing them of the study
- Advert for social media
- Interview topic guide
- Coding index
- Assimilation model markers manual

These materials were submitted for ethical approval to the Yorkshire & the Humber - South Yorkshire Research Ethics Committee. Following minor changes, they were approved for use in this study. A coding index was also developed to analyse the data as outlined in the stages for framework approach (see section 2.7.1.).

## **2.6 Procedures**

### **2.6.1 Recruitment procedures**

This study had two recruitment pathways.



1) YoDCA renal clinicians based at St James' Hospital, Leeds (Leeds Teaching Hospital NHS Trust) were contacted. Different renal clinics were attended between October and December 2019. Renal nurses introduced AJ to CKD patients and their family members. If family members appeared interested in taking part in the research, they were given an information pack which included an information sheet and consent form. AJ was also introduced to patients who attended the clinic alone, but where the renal nurses knew that there was at least one family member involved in that person's care. The patient was given a pack which also included a letter to them asking them to give the information to their family member. Interviews were either conducted at the person's home or at St James' Hospital.

2) Kidney Research Yorkshire (KRY) charity advertised the study on their social media page (Twitter and Facebook). The study information included AJ's university email address to enable potential participants to request more information. People who expressed an interest in participating were posted the information sheet and consent form. Interviews were offered at the person's home, or over the phone depending on their geographical location.

### **2.6.2 Interviewing**

Interviews lasted between 48 and 66 minutes. The person with kidney disease was not present for the interviews due to concerns that this might have impacted the family members' responses. Five interviews were undertaken at the participants' home. One interview was undertaken at St James' hospital and one participant was interviewed by telephone interview as they lived a considerable distance from the study location.

### **2.7 Data analysis**

This study had two methods of analysis:

- a) By theme to synthesise findings across the sample to identify family members' needs when supporting a relative with CKD 4 or 5 using the framework approach.
- b) By participant pen portraits to interpret person's response regarding how they came to terms with their situation with reference to assimilation model markers (see 'Results' chapter).

This section will firstly outline the process of selecting the framework approach as its first data analysis method and its stages of analysis. It will then outline the assimilation model analysis and the process of analysis using this model in section **2.7.5**.

Choosing the most appropriate qualitative analysis method can be challenging due to the number of different methods and the similarities between them (Smith et al., 2011).

Qualitative methods that aim to generate new theory, such as grounded theory and qualitative methods which investigate the use and meaning of language, such as discourse or conversational analysis (Smith & Firth, 2011), were not considered. They did not fit with this study's aim to gain an understanding of people's experiences and perspectives. The qualitative approaches that were therefore considered for this study were interpretive phenomenological analysis (IPA), thematic analysis, and the framework approach (Smith et al., 2011).

IPA was considered because the analytic processes aim to uncover what a lived experience means to the individual through a process of in depth reflective inquiry (Larkin & Thompson, 2012). The IPA analysis process is often thought of in terms of a double hermeneutic, whereby the researcher seeks to make sense of the person making sense of their world (Pietkiewicz & Smith, 2014). Data collection in IPA studies focuses on the researcher guiding the discussion in a way that focuses on the lived experience of the phenomena of

interest, with the participant leading the direction of the interview (Biggerstaff & Thompson, 2008). This study's research question does not focus on lived experience or developing a model of experience, but rather addresses a specific question around need. IPA was therefore rejected.

Thematic analysis was also considered because it is theoretically and epistemologically flexible and can provide rich insights into participants accounts (Braun & Clarke, 2013). Thematic analysis can be thought of as the foundational qualitative method, as grouping meanings into themes is one of the few skills required across all qualitative methods (Braun & Clarke, 2006; Holloway & Todres, 2003). However, it has also been criticised for its lack of depth, guidance and structure for analysis and transparency of interpretations (Braun & Clarke, 2013; Smith & Firth, 2011). The 'how' of the analysis is often unclear (Attride-Stirling, 2001). Themes are often described as 'emerging' or 'being discovered', which fails to acknowledge the researcher's active role in identifying and naming themes and subthemes (Braun & Clarke, 2006).

### **2.7.1 Framework approach**

Framework approach was used to analyse and classify data (Smith & Firth, 2011).

Framework approach has an analytical emphasis, where transparency is supported by having clear stages for data analysis (Ritchie & Lewis, 2003, 2014; Smith & Firth, 2011). Having clear, interconnected stages means that the framework approach allows the researcher to constantly review the data, meaning themes are constantly refined and developed while remain close to the data (Ritchie & Lewis, 2003, 2014; Smith & Firth, 2011). The framework approach emphasises the importance of transparency: central to ensure the credibility of qualitative research findings robust is the transparency between the data collected and the researcher's interpretations of the data (Ritchie & Lewis, 2003, 2014; Smith & Firth, 2011).

Having clear stages to follow is helpful for a novice researcher which can help structure the analytical stages (Table 2). The process of each stage of data analysis is clearly described within the framework approach. This makes the journey from initial data collection and immersion to a rich interpretative account of the data feel less overwhelming for the researcher (Ritchie & Lewis, 2003, 2014; Smith & Firth, 2011). A critique of the framework approach is discussed in the 'Discussion' chapter.

**Table 2.** Stages of thematic framework approach (adapted from (Ritchie & Lewis, 2003, 2014).

<u>Phase</u>	<u>Description of the process</u>
1. Familiarising yourself with your data	Transcribing some data, reading and re-reading the data, noting down initial ideas
2. Identify recurring themes or ideas	Identifying different elements of the interviews, including substantive elements (attitudes, behaviours, motivations) and methodological elements (the atmosphere of an interview, the ease with which participants could discuss a topic).
3. Create a conceptual framework	Use both recurring themes and issues introduced into the interviews to create the conceptual framework.
4. Group themes within the framework	Sort and group themes into broader main themes within the framework. Identify links between categories, group these

5. Indexing the data	thematically and sort dependent on generality to create a hierarchical list of themes and subthemes for the framework. Apply the conceptual framework to the raw data.
6. Refining the conceptual framework	Following the indexing process, it is likely that the original framework will need refining.
7. Sort the data by theme or concept	Order the data to enable sections with similar content to be located together, enabling the researcher to focus on each chunk of content in turn.
8. Synthesise the data	Summarise the original data using thematic charts, ensuring original language is preserved.

### **2.7.2 Developing the Coding index**

Initially, the anonymised data was transferred to Microsoft Word, where columns were added alongside the interview data. Initial thoughts were annotated for each line of transcript in an attempt to summarise what the participant was saying. This process also facilitated immersion in the data. Alongside initial thoughts, 'in-vivo' codes were created. These 'in-vivo' codes attempted to stay true to the original data by using the same wording when possible (Smith & Firth, 2011).

**Table 3.** Extract of initial 'in-vivo' codes and initial thoughts

Transcript extract	Description (in-vivo codes)	My initial thoughts
and it gave him the freedom of not being on dialysis you know.	Transplant gave husband 'freedom' compared to dialysis	Benefits of different treatments Importance of normality
Obviously, it started fading at the end and he was struggling a bit but... It still, he never got, you know he struggled with about 20% kidney function but it was fine,	'Struggling a bit' 'it was fine'	Minimising the difficulties, talking around difficulties, a way of coping
he lived his life, his normal everyday life.	'normal everyday life'	Needing things to be normal for her and husband
He was slightly limited as to his energy levels and that but apart from that...	'slightly limited'	Minimising difficulties, a way of coping

The data was then inputted into NVIVO (version 12 plus). NVIVO is a piece of software which supports qualitative researchers to manage large amounts of data and create codes and themes. The remainder of the analysis was done using NVIVO.

The analysis on NVIVO began by using three transcripts which appeared to describe different experiences and reactions. During the progress of analysis, the initial 'in-vivo' codes began to collate into broader codes. As the process continued, similar codes were grouped together to form initial themes. These initial codes and themes formed the coding index, which was then used to analyse the remainder of the data (see table 4). This coding index, and the process of analysis which led to its development, was reviewed by two supervisors who are experienced in qualitative research and the framework approach. The coding index was constantly refined throughout the process of analysing the remaining data as new information led to new ideas

(see appendix 6 for full coding index and appendix 8 for a document detailing the process of refining the coding index).

**Table 4.** Extract of the coding index for two initial themes

Codes	Initial themes
1.1. Taking responsibility for caring 1.2. Beliefs about caring role 1.3. Uncertainty regarding caring role	1. Caring role
2.1. Maintaining normality 2.2. Negotiating treatment decisions 2.3. Weighing up pros and cons 2.4. Importance of having a choice 2.5. Involvement with treatment decisions and management 2.6. Involvement valued by others	2. Treatment decisions

### 2.7.3 Descriptive accounts

To form descriptive accounts of the data, themes and categories are refined through the process of mapping the diversity of the coded data (Ritchie & Lewis, 2003, 2014; Smith & Firth, 2011). When forming descriptive accounts, two key elements of the data for the researcher are the words that participants use (their language) and the content of their account (its assigned meaning). Both elements need to be carefully reviewed in order to capture the different perspectives and descriptions in the data. Smith & Firth (2011) warn that moving from initial codes and themes to more abstract concepts can feel daunting, particularly for a novice researcher. To aid this process, the initial themes and categories were refined until the data was synthesised and a 'bigger picture' developed. By consistently reviewing the original interview data, it was ensured that the themes were grounded in this data and the participants' language and meaning (Smith & Firth, 2011). Following this process, researchers can develop either 'indigenous' or 'analyst constructed' typologies (Patton, 2015), which are "classification systems made up of categories that divide some aspect of the world into parts along a continuum" (Patton, 2002, p. 457). Table 5 illustrates the move from the initial codes

and how these were refined to the final themes and core concepts of 'Uncertainty' (see appendix 9 for a document detailing this process for all core concepts).

**Table 5.** Developing the core concept 'Uncertainty' and its themes from initial codes and themes

Original codes	Final themes	Core concepts
1.1. Taking responsibility for caring 2.5. Involvement with treatment decisions and management	1.1. Attempts to gain control in an uncertain situation	1. Uncertainty
1.2. Beliefs about caring role 1.3. Uncertainty regarding caring role 3.7. Coping strategies e.g. <i>minimising, normalising, comparisons with others, avoidance, focus on positive, focus on present</i> 3.8. Beliefs about coping	1.2. Different ways of coping	
3.6. Adjusting	1.3. Learning to live with uncertainty	
3.1. Impact of caring role on family member 3.2. Impact of caring role on relationship 3.5. Emotional impact	1.4. Emotional toll	

#### 2.7.4 Explanatory accounts

Explanatory accounts are the researcher's attempts to find patterns within the data and explain the reasons behind these patterns (Ritchie & Lewis, 2003, 2014). As recommended by Smith & Firth (2011), the process of developing explanatory accounts began by reflecting on the original interview data and the process of analysis. Four core concepts were developed that appeared to capture the family members' account of their involvement in their relative's CKD treatment decisions and illness management. These four concepts are 'Uncertainty', 'Maintaining normal life', 'Developing an understanding' and 'Identifying and meeting needs'. These will be further discussed in the 'Results' chapter.



### **2.7.5 The assimilation model and pen portraits**

Following the coding index analysis, the assimilation model was used to interpret the participants' narratives (see appendix 7 for the assimilation model manual used). These will be presented in the participants' pen portraits, which also provide context for the study's sample (see the 'Results' chapter). Honos-Webb and Stiles (1998), Honos-Webb, Surko, Stiles, and Greenberg (1999) and Lishman, Cheston, and Smithson (2016) proposed guidelines for analysis using the assimilation model.

#### **1) Familiarisation of the data**

Data immersion and familiarisation of the data had already taken place due to the development of the coding index and analysis using the framework approach.

#### **2) Extracting passages**

Passages of the interview data that contain potential markers were extracted. Markers are identifiable extracts that occur throughout the data which indicate meaningful phenomena.

#### **3) Rating passages**

The passages that were extracted were rated using the manual for rating assimilation (see appendix 7, based on Honos-Webb & Stiles, 1998).

#### **4) Analysis of markers**

Assimilation ratings were made independently by AJ but discussed with supervisors (see appendix 10 for an extract of the assimilation model marker analysis). AJ was trained in interpreting participants' narratives using the assimilation model markers for a previous piece of research (Cheston et al., 2018). Analysis of the markers will be combined with the framework analysis to add to the understanding of the results (see 'Discussion' chapter). This

final analysis of markers stage is akin to the explanatory stage of framework approach where findings are contextualized by exploring their relationship between the final themes.

## **2.8 Reflection on validity of methods**

The following guidelines outlined by Elliott, Fischer, & Rennie (1999) were explicitly used when carrying out this study to enhance the transparency and rigour of the methods (Elliott et al., 1999; Yardley, 2008).

### **1. Owning one's own perspective: The researcher should attempt to describe their values, interests and assumptions and how these could influence their analysis and findings.**

I am training to be a Clinical Psychologist. A requirement of the qualification is to complete a Doctoral thesis. I am interested in this research as I am training to be a healthcare professional myself and have an interest in talking therapies and training others to be therapists. As a Clinical Psychologist in training, I have developed an interest in how people protect themselves from experiences that feel too upsetting or painful. I was involved in some research using the assimilation model (Cheston et al., 2018) and have maintained my interest in this. I have an interest in narratives or stories as a way of understanding other people's viewpoints.

As well as training to be a healthcare professional, I also have experience of being the family member who has relatives who are ill. As a family member, I have had experiences of grief, loss and daily uncertainty and anxiety. I have personal experience of the challenges of coping and adjusting. I have experience of trying to support my family and ill relatives in the way I thought best and trying to work out how and when to speak about the illness and the future. I have had both positive and negative experiences of engaging with different healthcare

systems. I developed an interest in how family members support themselves and their relative who is unwell (see appendix 11 for an extract of a reflective journal kept during the duration of the study).

I informed participants that I was doing this research as part of my training to become a Clinical Psychologist and that I had chosen this research area as I had personal experience of supporting a relative with an illness, though not kidney disease. I believe this knowledge of some shared experiences, alongside my clinical and therapy skills, helped build rapport with participants. By empathising with their experiences and being non-judgemental I tried to create a safe space where participants could talk freely. I was mindful of my questions and responses, particularly when participants seemed agitated or upset. By using my clinical skills, I hoped to both put participants at ease, making it a better experience for them, and capture interview data that was rich and meaningful.

**2. Situating the sample: The researchers should provide key information about participants so that the range of persons and contexts can be understood by the reader.**

Pen portraits of the participants are in the 'Results' chapter. Here I will outline how I familiarised myself with the context for the family members and patient in this illness context in order to enhance the rigour of the study and reduce bias.

By attending and observing different clinics in the renal department, I developed my understanding of kidney disease and how it was managed and talked about in renal appointments. There was always an opportunity to ask questions and families were always seen together. I spent time with the renal nurses who shared with me how they would discuss different treatment options with patients and their families. I attended a dietician's clinic, a

consultant-led conservative management clinic and consultant-led routine renal clinics for patients with CKD 4 and 5.

**3. Grounding in examples: The researcher should use direct quotes to evidence how the data was analysed and to support the final core concepts and themes.**

As someone who has supported relatives with illnesses, there was a danger that I could over-identify with the participants in the study and assume that our experiences would be similar. It was therefore important to ensure that interpretations were informed by the data, and not my own personal experiences. During the interviews, I would check my understanding of the participants' narratives and not assume I had understood their meanings or emotional responses (e.g. *"You just mentioned that your husband had a transplant... Can I just check, was that before he started the dialysis?"*; *"What was that experience like for you?"*). I shared my interpretations and thoughts with supervisors and ensured that I followed the steps outlined for framework analysis (Ritchie & Lewis, 2003, 2014). At the beginning of the analysis process, I attempted to think of concepts and themes before I had refined my coding index and I was encouraged to re-visit the data and the coding index by my supervisors. The assimilation model markers were also discussed with supervisors.

**4. Providing credibility checks: Elliott et al. (1999) recommend several different ways to ensure the study's themes and core concepts are credible including having another researcher review the analysis and themes / concepts.**

The steps I took were sharing the various stages of analysis with my supervisors, including my initial thoughts and ideas, the coding index and final concepts and themes. Due to the COVID-19 outbreak, I was unable to share my workings out and thinking in person but emailed documents detailing how I had analysed the idea as well out quotes to support my

concepts and themes. My supervisors and I had virtual meetings where the concepts and themes were discussed. A first draft of the 'Results' chapter, where core concepts and themes alongside direct quotes are discussed, was also reviewed by my supervisors. Assimilation model marker ratings are completed independently, but my thinking and interpretations were discussed with supervisors.

## **2.9 Ethical considerations**

The development of study information leaflets and consent forms has been described in Section 2.5 'Materials'. This section will outline the ethical issues in relation to ensuring consent was an informed choice, participants were treated respectfully and sensitively, information remained confidential and what would happen if there were disclosures of risk. Ethical approval was granted in line with these considerations.

The ethics panel discussed whether it was ethical to conduct a study if the relative with CKD did not know about the study and that their family member was taking part. However, as the study was focusing on the family members' experiences and needs, it was deemed unethical for an adult with capacity to consent to need to discuss their participation in research with another adult. As well as being unethical, seeking permission from the relative with CKD may have been impossible as the relative might have been too ill to discuss the study or might have died.

### **2.9.1 Informed consent**

Participants were given the information and consent form either at clinic or by email. Interviews were arranged after this initial contact to enable potential participants to process the information, change their minds or contact me with any questions. Consent forms were

signed at the beginning of the interviews. The participants who took part by telephone returned the completed consent form by email.

### **2.9.2 Distress**

This interview was often the first time participants had the opportunity to discuss how they felt about their relative's illness, and the impact its progression and end of life care had on their life and long-term wellbeing. Due to the semi-structured nature of the interviews, participants were able to take the lead in the interviews and were not pressed to discuss subject areas that they wish to avoid. Participants were informed (in the consent form and verbally) that they could stop the interview at any time or decline to answer questions without having to give a reason. If participants had felt that they needed additional support following the interview, they were given the contact details of the renal Clinical Psychologist and permission to consult with them as part of the support offered by Leeds Teaching Hospital Trust for this project.

### **2.9.3 Disclosures of risk**

Participants were informed in the information sheet that their data would be kept confidential, unless the participants disclose that they are at serious risk of harming themselves or others. This would necessitate breaking confidence, in line with UK legal frameworks.

### **2.9.4 Confidentiality and data protection**

Interviews were recorded on an encrypted Dictaphone. The recordings were then securely stored on the university M drive, which is password protected. Other electronic data (e.g. basic demographics) were also stored on the secure M drive. Any identifying features were anonymised when interviews were transcribed. The recordings were transcribed by an independent company which has a data processing agreement with the University of Leeds.

Paper-based data (e.g. consent forms) were securely stored at the University of Leeds. Both the electronic and paper-based data will be destroyed in 3 years, in line with the University Information Protection Policy. All participants' names have been changed to ensure anonymity. Any identifiable information, e.g. relative's name, hospital name, will be omitted from any quotes.

## CHAPTER 3: RESULTS

This chapter presents the study's findings. The four core concepts, 'Uncertainty', 'Maintaining a normal life', 'Developing an understanding' and 'Identifying and meeting needs' are described. The chapter will begin with some information regarding the participants. It will then provide pen portraits, which includes some demographic information, for the study's participants. The pen portraits provide context in line with Elliott et al. (1999)'s recommendation to situate the study's sample. Interview extracts used throughout this chapter will be written in "*italics*" and have been edited for readability by removing repeated words and minor hesitations ('erm', 'hm', 'uh'). The pen portraits will include an analysis of the participants' experiences using the assimilation model markers. Following this, the core concepts and themes will be described alongside extracts from the participants' interviews to evidence that the concepts and themes reflect their experiences.

### 3.1. Participants

Twenty-three potential participants were approached from the renal clinics, with four family members agreeing to participate in the study. One interview did not go ahead as the participant was not at home at the agreed time and did not respond to two emails asking to reschedule. Four participants were recruited from the KRY Twitter and Facebook pages. In total seven people participated in the study. Six of the participants' relatives were alive at the time of the interview and one had died.



**Table 6.** Participant information

Participant pseudonym	Participant age	Relationship to CKD patient	CKD patients' treatments (past and current)
Sharon	65-70	Wife	Transplant and dialysis at home
Geoffrey	70-75	Husband	CKD 4 but no active treatment – monthly appointments
Nicola	40-45	Partner	About to begin dialysis at home
Bryan	40-45	Husband	Haemodialysis at hospital and home
Margaret	70-75	Wife	Overnight dialysis at home
Megan	70-75	Wife	About to begin dialysis at home
Alison	50-55	Daughter	Conservative management

### 3.2. Pen portraits and the assimilation model analysis

The pen portraits for each participant will start with some demographic information and information about the relative's CKD including when they were diagnosed and their treatment options. They will then briefly cover the family members' reported involvement in their relative's care, their reported beliefs about supporting their relative, the emotional toll the experience has had on them and their support preferences. The portraits conclude with the assimilation model analysis, using the assimilation markers.

#### 3.2.1 Pen portrait: Sharon

Sharon is between 65-70 years of age. She is married to and living with her husband, who was diagnosed with CKD 12 years ago. He has had several transplants with periods of home dialysis in between. Sharon's husband became unwell unexpectedly whilst they were abroad. The process of getting the diagnosis was “*scary*” for Sharon. However, she believed that such “*an experience... makes you stronger*”. Sharon described having little prior understanding of CKD and needing to become informed – “*I mean we knew very little about kidney disease and just kidneys in general. I had to find all that stuff out*”.

Sharon was very involved in her husband's care – *“I look after him basically, do everything for him!”* - including decisions around treatments – *“I've always been involved, very much part of the decisions, right from the start”*. She donated one of her own kidneys for her husband and felt *“a bit cheated when it didn't work. I wanted it to be there for him for 20 years, but it didn't work”*. Sharon described herself as *“the strong one of the two of us”* and said she tries to be *“strong for the family”*. Sharon described feeling supported by the renal team and by her friends and family – *“Everyone really just rallied around us”*.

The most frequent assimilation marker for Sharon was 1: Unwanted thoughts. This suggests that Sharon acknowledged experiencing some difficult emotions or events, but that there is evidence of avoidance including minimising the impact of situations. Sharon talked around the CKD and never named it in the interview, calling the illness “it” throughout.

*“There were moments when we'd have some tears together, very few... very, very few”*.

Occasionally, Sharon did reflect on some of the more difficult times she had experienced and described the emotional impact these events had on her (level 3 marker: Clarifying the problem).

*“I'd say that was the worst period we had... I have to admit, that was one time I broke down”*.

Sharon also had some level 0: Warding off markers, where a person states that there is no problem and does express any concerns or show any emotional reaction.

*“I never at any point felt like, ‘oh god this is terrible’, I never felt like that. I felt very positive”*.

### 3.2.2 Pen portrait: Geoffrey

Geoffrey is between 70 – 75 years of age. He is married to and living with his wife, who was diagnosed with CKD four years ago. Geoffrey described how his wife had started to feel poorly and that it was difficult to establish the diagnosis – *“we went to her GP, who, I have to say was quite dismissive about it and principally told us to go away and not make such a fuss, which was a bit upsetting at the time for both of us because we both knew there was something wrong”*. Geoffrey's wife had not yet begun a renal treatment. He knew she would need either dialysis or a transplant in the future, but they were in an uncertain period of 'watch and wait' monthly appointments. He had also decided to donate one of his own kidneys.

Geoffrey described the shock of getting the diagnosis and the process of accepting and trying to understand the diagnosis- *“It was a shock initially and the ‘Why me?’ sort of kicked in... we started off with shock, then coming to terms with it and trying to understand what was happening”*. Geoffrey reported being very involved in his wife's care and support and needing to learn new skills – *“I had to learn a whole new lot of skills: cooking and washing”*

Geoffrey described the impact the illness had on his life – *“You can't do any planning or anything. There's no way that you can control, measure, organise anything”*. He described the emotional impact of having a relative with an illness – *“When you're living with somebody going through that it's tough; it's, you know really tough to, and not being able to do anything to make it better, you know it, it's hard”*. He had worries and concerns about the future but did not feel it was right to share these with his wife – *“...my role, as I see, is to be the support...”*

Geoffrey felt he would benefit from a support group where he could meet people who understood his situation – *“...if we had the opportunity, for example, to go to a discussion*

*group or to meet other people who are going through the same process that, that would be a very positive thing”.*

The most frequent assimilation marker for Geoffrey was 4: Gaining perspective. This suggests that he acknowledged the difficulties he faced, described how this made him feel and how he reacted, but did not get caught up in the emotion. Geoffrey acknowledged the emotional impact the illness had on him but could also talk about how he is trying to cope and carry on. He had a flexible viewpoint, where both positives and negatives could be acknowledged.

*“...it's been three years of crap basically. It's been life-changing... it's possible that today or tomorrow [wife] might be so lacking in energy that even getting dressed, she has to rest. But you've got to remember that other days she can do a bit more. We try and gauge each day according to how she is because even if she's has a bad day one day and has to rest and can't really cope that well, it doesn't mean to say that the next day will be as bad”.*

Occasionally Geoffrey seemed to get stuck in his difficulties, describing his emotional reaction without being able to move forward (3: Clarifying the problem). When Geoffrey spoke about the potential positive impact of a support group, he was thinking of a partial solution to an aspect of his difficulties which is a level 5: Working through marker.

### **3.2.3 Pen portrait: Nicola**

Nicola is between 40-45 years of age and lives with her partner. Nicola's partner had been diagnosed with CKD before they met 10 years ago, and she was unsure precisely when he had received the diagnosis. His *“kidney function's dropped quite rapidly”* a few months prior to the interview. Nicola's partner was about to begin having overnight dialysis at home and hoped to have a transplant in the future. Nicola felt she *“...actually don't know really that*

*much [about CKD]*". However, she reported being involved in his healthcare and attended every renal appointment with her partner and would be attending the training on the overnight dialysis machine. Nicola felt that once the dialysis began at home it would feel more real to her – "*...it's still a little bit unreal. Until you get all set up and I think once he goes in and has his tube that'll sort of make it a bit more, 'Gosh, this is actually happening'*".

Nicola's partner "*suffers from anxiety anyway, so he doesn't cope with things at the best of times, and makes a big too much of things sometimes*" leaving her feeling frustrated – "*I probably lose my patience a bit... I'm pretty hard on him really, you know*". Nicola described that the illness and her role in caring sometimes "*put a bit of pressure on, you know me and the relationship*". However, Nicola was aware of the difficulty of his situation and did worry about him. Like Sharon, Geoffrey and Bryan, Nicola did not share any of her fears with her partner as she believed she needed to be strong to support him – "*I don't share with him my fears, no... I'm there for support*". Nicola reported being supported by her friends – "*I'm really, really lucky that I've got real good friends...*"

The most frequent assimilation markers for Nicola were 1: Unwanted thoughts and 3: Clarifying the problem. She oscillated between both levels suggesting that whilst she could name the difficulties she faced and her reactions and responses, this sometimes felt too difficult and the situation was avoided or minimised. Nicola's narrative had contradictions regarding how she felt about the situation, where she reported the futility of worry whilst also discussing how worried she and her partner were about the situation.

*"you've got to try and make the most and get on, take each day as it comes, don't you. Not just sort lay down and think 'Oh, woe is me'!"*

*“I feel quite frightened and daunted by it because I can't imagine and I think, ‘Gosh, I can't imagine... If I feel like that, what must it be like for him?’ you know it must be really, really scary for him”.*

### **3.2.4 Pen portrait: Bryan**

Bryan is between 40-45 years of age. He is married to and living with his wife, who was diagnosed with CKD 16 years ago. Bryan's wife had been diagnosed with CKD whilst pregnant with their first child and had haemodialysis in hospital. She had become extremely unwell and the baby died - *“It was awful, what we'd been through, me almost losing her that week it was, you know, ‘What next?’”* Bryan's wife refused dialysis during her second pregnancy. Since then she has received haemodialysis at home. For health reasons, she cannot have a transplant or PD dialysis.

Bryan reported that he has *“always tried to, to be involved and find out what the doctor said and try and get an understanding of what the doctor said”*. Bryan described the impact this has had on his life – *“Whereas a couple that haven't got any health issues... you know a mate rings up, ‘Do you want to come out?’ ‘Yeah, no problem.’ Whereas somebody can ring us up, and say, ‘Do you fancy going out tomorrow?’ ‘Well I can come but [wife] can't cause she's got to dialysise and they go, ‘Oh okay, we'll sort out another night,’ and it kind of gets forgotten”* - and how they have had to adjust to a *“new normal”* life. Like Sharon, Geoffrey and Nicola, Bryan felt he needed *“to be strong for [wife] in hospital but also having to deal with being absolutely petrified myself”*.

Bryan said he would like to attend support groups and meet people whose relatives had CKD as he reported that some of friends and family lacked understanding around CKD. He did not

feel that he or his wife had been adequately prepared by the renal team for the reality of life with CKD and life on haemodialysis.

The most frequent assimilation markers for Bryan were 4: Gaining perspective and 5: Working through. This suggested that Bryan had gained some emotional distance from the events he experienced and could describe their impact on him and how he responded. He was able to offer a balanced view of events. Bryan also recognised some aspects of his situation could be changed and worked on. He described recently starting to actively plan his life around dialysis and thought that a support group and some additional guides would be helpful for people in his situation. He wondered whether he could start a group in his local area or contribute to writing a lived experience guide.

*“In a week or so, we’ll start talking about dialysis over Christmas and work out where to stick in a two-night break so she’s not on dialysis on Christmas eve and Christmas day”.*

*“I’ve been involved in a support group for losing your child... and I think a support group... for people who’ve got spouses or close family members on dialysis to sort of to talk to, to share experiences – what I’m thinking, what’s particularly annoying me... Maybe I should start something... I’d be more than happy to work with any guides that’d be useful to people...”*

### **3.2.5 Pen portrait: Margaret**

Margaret is between 70-75 years of age. She is married to and living with her husband, who was diagnosed with CKD approximately 10 years ago. Margaret was “stunned” when they were told he would need dialysis – “*I just thought it’d go on forever at the clinic. I never thought for a minute he’d end up on dialysis really*”. They decided to have an overnight dialysis machine at home.

Margaret reported that she is very involved in her husband's care and treatment. Margaret took responsibility for the machine and clearing up afterwards. It was extremely important for her to care for her husband and keep his life as normal as possible – *“And what I do as well for [partner] because he's the one that poorly, I disconnect him and then I take everything away for him”*. Margaret said that, not only had caring for her husband given her some purpose and routine – *“If it [CKD] wasn't there, as [husband] said to me the other day, if it wasn't there what would you do with yourself?”* – but that she enjoyed it and found learning about the dialysis machine pleasurable – *“I loved it!... It's not a problem for me at all. I do like it. I'm happy doing it... I enjoy doing it”*.

Margaret described CKD as having very little impact on her life. She reported that the illness did sometimes impact her mood but that this soon passed – *“Sometimes I feel a bit down... But then that soon goes”*.

Margaret reported feeling very supported by the renal team – *“I must say that when we went to the PD unit, the treatment is amazing. You know the staff are so specialised, they know exactly what they're doing and they know exactly what treatment you need... They're so reliable and so good”*.

The most frequent assimilation marker for Margaret were 0: Warding off and 1: Unwanted thoughts, suggesting that Margaret oscillated between stating that there were no problems for her and acknowledging that she experienced some difficulties but avoided or minimised the impact of events.

*“I don't have any worries or concerns”*.

*“You do have that little bit of impact on your life”*



There were also some level 2 markers: Vague awareness, which suggests the person is in distress and that this distress originates from conflicting emotions regarding an experience.

Margaret appeared irritated when she reported that her husband was not a candidate for transplant.

*“We were disappointed he couldn't have a transplant, but it's not for him, it's not suitable so that's it, that's it. Forgotten.”*

Occasionally Margaret did describe her initial reaction to the diagnosis, how she felt and her response, which is a level 3: Clarifying the problem marker.

*“I thought that's it; that's our life finished; we won't be able to go anywhere; it'll just be a gradual decline in health, and I thought 'oh this is going to be horrible. Our lives will be culled. It'll be so restrictive'”*

### **3.2.6 Pen portrait: Megan**

Megan is between 70-75 years of age. She is married to and living with her husband, who was diagnosed with CKD approximately 2 years ago. Her husband was diagnosed with CKD as the result of health checks for other physical conditions. Megan described that they only recently realised that the CKD was “*actually quite serious*”. They were both hoping that he would be able to have PD dialysis at home as she believed this would keep her husband's life as normal as possible – “[*husband*] *has loads of hobbies, home hobbies, and his, his days are planned as to what he's going to do and he's really interested in those*”. Megan's husband was not considered for a transplant due to age and health concerns.

Megan reported that she has always been involved in her husband's care and treatment decisions, and that the HCP have always made her feel involved – “*The doctors and nurses have always involved me in those conversations, yes. They always ask [husband] if he's got*

*any questions and then they also ask me.... and I've got my list". Megan reported that her and her husband felt able to discuss painful topics, such as whether her husband would want a 'do not resuscitate' - "I think just knowing one another really well and loving the life we've had helps with these conversations".*

Megan talked of being grateful for every day – *"every day is a bonus"*. She said she tended to worry about things before they had happened and had lots of creative and present-focussed hobbies to help her cope. She enjoyed walking and talked of *"bringing life back to him [husband]"* by telling him of her walks. Megan was very organised and liked to have control in any aspect of the illness that she could – *"I like to know really what's coming and it prepares you"*.

Megan reported that she was supported by both the renal team and her *"brilliant family. Our daughter, and my granddaughter and our son-in-law, they're very, very supportive"*. Her granddaughter is a medical professional herself and Megan felt reassured that she could call her for advice and support.

The most frequent assimilation markers for Megan were 4: Gaining perspective and 5: Working through. Level 4 markers indicate Megan acknowledged her husband's illness and its emotional impact on her in a flexible and balanced way and that she had gained some emotional distance from emotive topics.

*"With there being a 14-year age gap, something is more likely to happen to him isn't it. I mean, I keep saying it could be me because I've had health problems. But the percentages – it would happen to [husband] first with him being well in his 80's... a few weeks ago when he was rushed in, it's the immediate thing that comes into your head, you worry about losing him"*.

Level 5 markers indicate Megan had thought of potential solutions to difficulties she and her families might face, such as having a 'do not resuscitate' conversation and a family discussion about this so that everyone is on the same page. Megan and her husband had received training on the dialysis machine, but then also trained her daughter in case something happened to her.

*"I told her [daughter] we had some difficult things to talk about and I said we'll talk it through together [end of life decisions]... I think it's important we all know now rather than something happen and then you're uncertain".*

### **3.2.7 Pen portrait: Alison**

Alison is between 50-55 years of age. She lived a five-minute drive away from her father, who was diagnosed with CKD approximately 4 years ago. Her father had died from kidney failure a few weeks prior to the interview. Her father was diagnosed with CKD as the result of health checks for other physical conditions. When Alison's father was first diagnosed a few years ago, he attended the renal appointments alone. Alison was unsure whether he was aware of the seriousness of CKD or whether he kept this from his family. Alison was not aware of the seriousness of the condition for a few years – *"Kidney failure, I don't know, didn't register as being as bad"*.

Alison described having *"conflicting messages"* regarding the severity of her father's CKD and the treatment options available to them. They had a visit from a renal nurse to discuss different types of dialysis. The next week, when Alison insisted the renal consultant speak with her alone, *"she kind of explained to me that my dad wouldn't be able to have dialysis; he wasn't well enough. So it was like complete contrast to what we'd been told the week before"*.

Alison reported that she became involved in her father's care and support after approximately two years. She reported feeling that her needs as her father's main support were not taken into consideration – *“I really wanted to have a conversation with her by myself. My dad was obviously there and listening to everything and... if you spoke about things in front of my dad, my dad would immediately think ‘that’s it I’m dying next week’”*. Alison did not feel she had been made aware of how little time she had left with her father, as the staff *“were always giving us hope”*. She felt that staff had protected her with hope rather than be honest with her, and she had some regrets about not doing things together before he died – *“There was just one little thing that he wanted to do... he wanted to go to the seaside”*. She wished she had been given more honest and transparent information and support – *“You’re left in a wilderness to find out and do what you can”*.

The most frequent assimilation marker for Alison was 4: Gaining perspective, suggesting Alison could discuss her difficult experiences with clarity, emotional distance and perspective.

*“He was an ok age, which is why I think I’m alright. I just think if I got to his age, I’d be alright. Obviously, you want them [parents] to live forever but that’s not what life is about.*

*Life circles, we don’t live forever”*.

Alison makes several suggestions about how she feels she could have been better supported by HCP, including more consistent and transparent communication, conversations about the future and end of life and more involvement of the wider family. As these are retrospective suggestions, these have not been interpreted as level 5: Working through (partial solutions to a current problem) markers.

### 3.2.8 Summary

The assimilation model analysis illustrates how participants vary in how they come to terms with their situation, with identified markers ranging from level 0: warded off to level 5: working through. The analysis also shows that participants did not remain within one level and oscillated between levels of assimilation. Both the theoretical and clinical implications of this analysis will be explored in the 'Discussion' chapter.

### 3.3. Core concepts and themes from framework analysis

Four overarching concepts were elicited from the from the systematic application of the framework approach used to analyse the interview data, described in the 'Methods chapter'. The four concepts, 'Uncertainty', 'Maintaining normal life', 'Developing an understanding' and 'Identifying and meeting needs', and their associated themes are presented in table 7.

**Table 7.** Core concepts and associated themes

Core concepts	Themes
Uncertainty	Different ways of coping Attempts to gain control in uncertain times Learning to live with uncertainty Emotional toll on family member
Maintaining normal life	Making treatment and illness management decisions that keep life as normal as possible Barriers to a normal life Adjusting to a new normal
Developing an understanding	Making sense of CKD Sources of information Family members developing an understanding of their role
Identifying and meeting needs	How Healthcare Professionals (HCP) can effectively support family members Facilitators and barriers to family members feeling supported

### 3.3.1 Core concept 1: Uncertainty

Associated themes are highlighted in **bold**.

Uncertainty emerged as a dominant feature of participants' accounts of being a relative of someone with CKD. Participants had developed **different ways of coping** with the uncertainty they faced. Participants felt they took responsibility for their relative's care and **attempted to gain a sense control in uncertain times** by becoming involved in treatment decisions and illness management. Some participants attempted to actively help their relative by donating their own kidneys. Participants openly spoke about the difficulties of **learning to live with uncertainty** and not being able to plan or organise their lives. The uncertain nature of the illness, its trajectory and its impact on everyday life took an **emotional toll** upon participants.

#### *Theme 1: Different ways of coping*

Participants utilised different ways of coping with the uncertainty of their situation. Some participants were aware of their anxieties and used external strategies e.g. present-focussed hobbies to help alleviate worry. Other strategies used by participants included normalising, minimising, favourably comparing their situation to others' and avoidance.

*I'm sure it'll be fine; lots of people do it [have home dialysis], don't they – Nicola*

*(normalising)*

*I can't say my life has changed a great deal – Margaret (minimising)*

*And it's nowhere near as bad as like when you see other people, with cancer and things you know – Sharon (favourable comparisons with others)*

*I think again, because it's one of those things you want to put at the back of your mind, it's not something we've researched. You know out of sight, out of mind, isn't it; if you don't think about it, it's not really happening – Nicola (avoidance)*

Participants had beliefs about the best ways of coping with a difficult situation and how a family member in their position should behave and feel. Participants reported that they needed to stay strong and positive for their relative.

*I want to be strong for the family, especially my daughter and son and grandchildren and that. This sounds awful, but I think I coped really well, up to a point. I'm the strong one of the two of us... I think it's important for you to say positive and that helps other people stay positive too – Sharon*

*You can't dwell on it, love. You've got to be positive. You've got to have a positive attitude otherwise where would you be. You'd be living in sadness all your time, wouldn't you and that's no good to anybody – Margaret*

Participants spoke about having fears and concerns about the illness and the future but believed that they should or could not share these with their relative. They believed their role was to protect their relative and not be a burden to them. They believed that sharing their own anxieties would cause their relative additional stress and worry.

*I don't know but my view on it at the moment is, without being too masculine: my role, as I see, is to be, is to be the support; to be the person that, no matter what happens, physically or mentally, ups and downs, I've got to be able to support, deal with it and move on – Geoffrey*  
*I don't share with him my fears, because I think he's scared enough on his own. I'm there for support... I can't go to pieces cause sometimes he does so I just think well I can't... he's got*

*enough of his own concerns and I know that he'll know that I'm concerned, but I think he'd worry more if he thought how concerned or worried I was – Nicola*

***Theme 2: Attempts to gain some control in an uncertain situation***

Participants described how becoming more informed and involved with their relative's care gave them a sense of feeling more in control when the reality of their situation is so uncertain. Participants described being involved in their relative's treatment decision making and illness management. They spoke about attending the appointments and making lists of questions to ask the Healthcare Professionals (HCP). Family members whose relatives were receiving dialysis took charge of operating the dialysis machine.

*I think sometimes that makes me controlling, because I know that I always need to know about everything, but feeling in control, it just helps - Sharon*

*I like to be in control as much as we possibly can with any situation... I think having some control with the machine will make me feel better. It means I'm actually helping, you know? I'm not just saying I don't know what to do or what happens if this happens... I like to know really what's coming and it prepares you. If you've got an idea of what's in front of you then you can prepare. It's that control, isn't it - yeah. More control; more in charge, more certain*  
*– Megan.*

Participants had a sense of taking responsibility for their relative's care, for example, by operating the machine and cleaning up afterwards.

*What I like to do is get rid of everything [all the dialysis equipment] as quickly as possible so he doesn't have to look at it all and be reminded - Margaret*

Some participants had, or were in the process of, donating their own kidneys. Doing so made



them feel that they were actively helping their relative, which is a way of coping with the uncertainty of their situation.

*When you're living with somebody going through that it's tough; it's, you know really tough to, and not being able to do anything to make it better, you know it, it's hard. So... it just struck me that, you know if this is the way of getting back some quality of life sooner rather than later... Being honest I was probably being selfish saying, 'Right, I'll give you one of mine!', felt like I was doing something – Geoffrey*

### **Theme 3: Learning to live with uncertainty**

Participants spoke about how the illness' uncertain trajectory meant they could not look ahead or make any plans.

*But it was still, in some ways, living appointment to appointment – Bryan*

*So we had to learn to live with the uncertainty of well this is going to happen next month; is it going to be next year, in ten years' time, you know nobody could tell us basically because it doesn't work like that, different people react in different ways – Geoffrey*

### **Theme 4: Emotional toll on family members**

Participants spoke of how the uncertainty of their situation and the impact of supporting their relative had an emotional impact on them. Whilst some participants denied having any concerns or worries regarding their relative's illness early in the interviews, they were able to discuss times where they had felt upset and concerned.

*But now I can just see myself now walking down the road and getting the results down the phone and crying my eyes out. Yes, yes it was scary – Sharon*

*Because oh, the illness, looking after him, it gets me down sometimes... Sometimes I do need to just escape, you know. It sounds awful but I do feel awful sometimes it's like he's dragging me down. Like, what's it gonna be like today? – Nicola*

*It's just so hard to watch your loved one failing away, cause the kidney's failing and you don't know; I didn't know what was happening. No idea what was happening - Alison*

### **3.3.2 Core concept 2: Maintaining normal life**

Participants were in favour of **treatments or illness management decisions that kept life as normal as possible**. Some faced disappointment when their preferred treatment was not an option for their relative due to health reasons. Even when they and their relative had chosen the least invasive treatment method option available to them, participants reported that they still faced **barriers to a normal life**. Participants spoke about having to **adjust to a new normal**. They described trying to find a way of maintaining as much of their old normal as possible whilst embedding CKD and its treatments into their daily routine.

#### ***Theme 1: Making treatment and illness management decisions that keep life as normal as possible***

Participants all spoke about how they had personally weighed up the pros and cons of the different treatment decisions. Participants favoured a transplant, if this was medically possible, or dialysis at home, even though this treatment is administered more frequently. Participants and their relatives felt that hospital dialysis was the least favourable option as it was most disruptive to normal life. When an RRT was not possible, it became important to make illness management decisions that kept their relative's life as normal and valued as possible.

*From what I know about it [dialysis at home], it's a lot more flexible, although you need to do it everyday – but it would be more flexible not having to rely on hospital – Geoffrey*

*I guess more for inconvenience really of having to go to the hospital to get it [dialysis] three times a week, cause, you know it's like a whole day thing, isn't it; by the time you get there: four hours there, get it. it's three days a week of your life gone – Nicola*

*Things can happen having a transplant but at the same time hoping it will be like a new lease of life – Bryan*

*...my dad... did eat things that he shouldn't eat... And she [HCP] said, 'Oh, he shouldn't have this and he shouldn't have this.' And his kidney function had gone by that time down to I think it were 10 or 11. And I said to her 'you're saying that the things he couldn't have are things that he liked'. I kinda kept thinking but if this is all he's got left... it's a fine line isn't it, between my dad being a little bit happy and having that normality... in the end I did let him have them – Alison*

Whilst some participants were grateful for a choice of treatments, other participants' relative's health limited their options. They reported feeling constricted and that their control and choices had been taken away from them.

*I was so happy that there was a choice – Sharon*

*There's no choice in that. They [HCP] just choose what's gonna happen, they just said they're not going to treat his kidneys anymore... - Alison*

*...there wasn't many options, the treatment options they were very limited and they weren't really any choices - Bryan*

## **Theme 2: Barriers to a normal life**

Despite participants and their relatives making treatment and illness management decisions that tried to keep life as normal as possible, participants faced barriers to living their normal lives. Participants spoke about how the illness and treatment prevented them from travelling abroad. Some participants technically could travel abroad as their relative was either on dialysis or had lived with their transplant for longer than a year. However, they spoke about the difficulties of arranging dialysis abroad, health insurance and the general worry of their relative becoming unwell whilst away kept them from making these trips.

*...we haven't gone on a proper holiday once in that last 15 years... we just don't go on holiday because of the difficulties in trying to arrange dialysis; so wherever you go on holiday, you have to book it all in and I believe you have to cover the cost of it because depending on where you're gonna be whether the EHC card'll cover it.... if you're going outside the EU... - Bryan*

Participants described how CKD and / or the treatments had impacted on their daily life. It had impacted valued activities and interests such as having pets, belonging to walking groups, volunteering, and diet. Dialysis treatment was also reported to negatively impact sex drive and the intimacy of relationships. Participants described feeling that they were constantly in touch with the hospital or GP surgery, either in person or over the phone.

*All our married live, we've had one or more dogs, and we lost a dog about 18 months ago... We were tempted to get another one. The reason we haven't got another one or two dogs is that risk that to home dialysis – Geoffrey*

*I was going to volunteer... volunteering is something important to me, but I need some more information first before I can commit because, well really, we've had quite the year! - Sharon*

*The only other thing that I can think of, sort of a very personal thing, would be how to deal with intimacy with it. Because with the treatment for men and women with kidney failure, it affects drives and things like that - Bryan*

*The hospital is our second home! We're always there – Nicola*

### **Theme 3: Adjusting to a new normal**

Participants described having to adjust to a new way of life. Some participants reported that, although they had found this process difficult in the beginning, they had managed to fall into a new pattern without much difficulty. Others described a more difficult transition where they were continually learning about what this new life with CKD looked like and how they had only recently started to plan the treatment around their life as opposed to planning their life around the treatment.

*You know I was absolutely stunned but now we're living with it it's not half as bad as what I first feared it might be, we've gotten used to it... It's [CKD] part of our lives now – Margaret*

*It's possible that today, or yesterday or tomorrow, [wife] might be so lacking in energy that even getting dressed, she has to rest... You've got to deal with that, and literally be prepared for what the new day provides... 'Okay, we won't do what we used to do in some ways. We'll deal with it.' So it's all a sort of learning curve, learning to deal with it - Geoffrey*

*I think we went a long time where we've planned our life round dialysis whereas probably in the last year-ish we've tried to plan dialysis more round our life and to try make a change that way... it takes a lot of planning but we have tried to start doing things differently – Bryan*

They reported having to adjust to a 'new normal' and accepting that their normal might look different to other people's idea of a normal life

*So normal looks a bit different for us... it's almost like we won't have a chance to have what a lot of people would call a normal married life, you know it's a different normal for us, we've had to get used to a new normal, but it's not the normal that other married couples are going through – Bryan*

### **3.3.3 Core concept 3: Developing an understanding**

Participants described a process of **making sense of CKD**. This included establishing the diagnosis and developing an understanding of the diagnosis and treatments. Participants made sense of the illness timeline and, if their relatives had any comorbidities, how these interacted with the CKD. Participants described having very little prior knowledge of CKD and using a variety of **sources of information** to develop their understanding. As well as developing an understanding of the illness and treatments, participants also described **developing an understanding of their role** in supporting their relative.

#### ***Theme 1: Making sense of CKD.***

Participants described the process of establishing a diagnosis to be an uncertain and scary time where their relative had either become unwell without knowing the cause or had received the diagnosis unexpectedly after routine check-ups.

*About five weeks ago he'd had a week where he was getting more and more breathless and so I got him an appointment at the doctors and he examined him and he said I'm sending for an emergency ambulance straightaway – Megan*

Participants had little to no knowledge around CKD before their relative received this diagnosis. Whilst some had assumed the worst upon hearing the diagnosis, others had not realised the severity of the diagnosis. Participants described feeling unsure about what the diagnosis meant and needing to find out more about it.

*I thought that's it; that's our life finished; we won't be able to go anywhere, it'll just be a gradual decline in health and I thought oh this is going to be horrible. We're just gonna be, you know our lives will be culled. It'll be so restrictive - Margaret*

*Leukaemia you think cancer, so you're scared aren't you. Kidneys, I don't think it sank in with any of us... I didn't realise the seriousness of it, but kidney failure, that's one of the things ultimately you die from it, don't you. Yeah, I didn't realise – Alison*

Participants had developed their own understanding of both the cause and maintenance factors behind CKD, as well as the symptoms of the illness and its treatment options.

*Kidney failure is due to hardening of the arteries. The kidneys themselves are in good working order, it's just that the blood hasn't been able to get through... his kidney was slowly shrinking because of the blood that couldn't get through – Margaret*

*One of the functions of the kidney is cleaning the blood and sorting it out; that has an effect on the brain, and the emotional side of things – Geoffrey*

*I might have thought of a transplant more of a cure to start with... but it's definitely a treatment, rather than a cure but it still is a cure in the sense that you can live a normal life - Sharon*

Some of the participants' relatives only had other co-morbidities, including heart and breathing problems. They reported learning how these co-morbidities impacted their relative's treatment options and how the different illnesses interacted.

*He couldn't have dialysis because of his heart... There was tablets they had to give him for his kidney, well they affected his heart, and obviously if your heart's not working then you're not here anyway – Alison*

### ***Theme 2: Sources of information***

Participants had received information from Healthcare professionals (HCP) during hospital appointments and home visits, as well as leaflets and booklets from the renal team. They also described other sources of information, including online kidney groups, T.V. programmes about kidney transplants, YouTube videos and family or friends who were either Doctors themselves or who also had CKD. Researching online was a popular source of information for participants, though they had a sense of how misleading internet information could be and said they mainly used NHS websites. There was a sense of being judged at having looked online for information.

*I only looked on the internet once, that's all – Sharon*

*If I needed to at a pinch, I would do what most doctors really want you to do - Google it!*

*Because then I go in and say, 'I saw this on online' I think they get annoyed – 'Oh yeah, you're a Google doctor, are you?' but what else are you meant to do? – Bryan*

### ***Theme 3: Family members developing an understanding of their role***

Participants described how they had developed an understanding of their role in supporting their relative. This included understanding how to be in their relative's appointments and negotiating who would ask what questions and when. There was an understanding amongst participants that they might want different information, or information at different times, to their partner.

*...there's lots of questions that I wanted to ask towards the end but you don't have long enough. And, you know, they're directing it all at my dad and my dad hated any fuss. So he'd be like, 'It's all right, it's all right.' But actually there were things I wanted to know but maybe he didn't – Alison*



Some participants reported that they would know how their relative would feel, and when it was okay to ask more difficult questions.

*...if it was really bad news I know [husband] would maybe shy back a bit from it. He would want to know but it would probably be me that would say 'Can you give us a timespan,' or whatever. I think in some respects [husband], he would want to know but he wouldn't want to ask it – Megan*

Participants also spoke about how they had developed an understanding of their role in their relative's treatment decision making process. Participants had strong opinions about what the most appropriate treatment decisions was for their relative, but often reported that it was not their decision to make. They spoke of wanting to support their relative in their decision making and were pleased when their decisions were the same. However, some were more vocal in the decision-making process, telling their partner what decision they thought was best for them.

*It was his choice, I didn't tell him 'you must have this dialysis at home'. No [husband], when he heard about it, he wanted to have it at home - Sharon*

*I came to the conclusion the automated, overnight dialysis would be best for us... I knew what would be best for him... I said, 'I think the overnight dialysis would be best, what do you think?' And he said 'well listening to all the options, yes, I would agree' - Nicola*

Participants reported feeling unsure about the parameters of their role when supporting their relative, and whether they were getting it right. They spoke about feeling unprepared for responding to and supporting their relative and the difficulty of making decisions regarding end of life and feeling unsure whether they were the right decisions.

*Once, she said to me... 'No, that's it. I'm not doing it anymore' .... it'd be nice to be better prepared or be able to give a better reaction, give a perfect reaction to, to the person on dialysis - Bryan*

*I don't know. I think that it shouldn't have been left as long as it was for him to go to that hospice. I don't know what the right thing was... there is no easy answer, is there – Alison*

### **3.3.4 Core concept 4: Identifying and meeting needs**

Participants described **how Healthcare professionals (HCP) could effectively support them as family members**. They gave examples of times where they had both felt supported and unsupported by HCPs. Some participants described feeling let down by HCPs.

Participants also spoke about how there were both **facilitators and barriers to them feeling supported**.

#### ***Theme 1: How HCP can effectively support family members***

Participants felt that their relative had received examples of good care and support from the HCP. They reported feeling reassured and supported by being able to speak to the HCPs at their relative's renal appointments.

*I actually feel better at the hospital. When you do come home you do feel a bit isolated again cause it's just [partner] then again; but as I say, when you go, it does you good in that clinic. Seeing all the professionals, it helps... they're [HCP] always really reassuring to him, well us... - Nicola*

They described feeling reassured that the renal team were available to them over the phone. However, this number was not available to all participants and they felt its loss.

*... we've now got a number that I can ring if there's anything I'm worried about which is brilliant, you know you've got somebody that you can get in touch with. That makes, and that makes life a lot easier. I think it's peace of mind - Megan*

*I just know that when with the [other health department] I could ask anybody in that department, there were a card and I could ring up. But with the kidneys, there was just nobody - Alison*

Most participants reported valuing HCP transparency. Whilst some participants felt that the HCP were transparent with them by providing information irrelevant of whether it was good or bad news, others were unsure about HCP transparency. They wondered whether the lack of transparency was the HCP's way of protecting families. However, there was also a belief that HCP were not always transparent, but that this was best and family members would be told what they needed to know only, meaning they could stay hopeful for longer.

*They were very willing to share information. Even if it was bad news, or bad information if you know what I mean, they never hid anything, they always told us how it was... - Sharon*

*I don't think it would be any good knowing about kidneys and how serious it can all be... I wouldn't have liked to know how serious it was earlier because we all live in hope – Margaret*

*And she [hospice nurse] didn't say it was end of life; they were talking about him going in there for respite. Did they think he'd never come back? Because they never ever said that - they talked about him going there for respite, so whether they believed that, I don't know... I don't know whether they didn't want to upset me or whether they might, I think they did have a little bit of hope... I don't know if people are trying to be kind, but honesty is just the way. And, you know whether they're doing it to protect you, to protect the patient... - Alison*

Some participants felt afraid to ask certain questions and felt that the HCP could have started these conversations.

*I was terrified of asking the question that I wanted to and needed to know the answer to. It took me a few months to get the courage to ask that question to how long has she got to live.*

*But they [HCP] never brought it up, it was always me... - Bryan*

Participants spoke of the importance of having a relationship with the HCP. They gave examples of when HCPs had done something to make them feel important and valued and more than a patient.

*When we were in clinic she [renal nurse] came to see us and she said 'they actually rang me while I was holiday to tell me about your transplant' and I said 'they didn't call you to tell you?!' and she said 'well, they only do it for special patients'. That was lovely - Sharon*

*...the consultant was walking down and she greeted me... she was actually going to see her dad in the opposite ward to my dad but then she went to see my dad. My dad said, 'I think, I think that lady came to see me.' I said, 'She did!'. I knew, she told me she was gonna but I thought she might be busy so I didn't tell him and get his hopes up, but my dad said 'she did' and he said, 'She gave me a hug.' - Alison*

Most participants felt their role in supporting their relative was valued by HCP. They felt that the HCP involved them in the decisions and appointments and felt included in any discussions around treatments or illness management.

*My opinion was asked, and I've been involved with it right from the beginning. The doctors and nurses have always involved me in those conversations. They always ask [husband] if*

*he's got any questions and then they also ask me – Megan*

Whilst most participants' described their interactions with HCP as supportive and reassuring, there were also examples where they felt they could have been better supported. Suggestions included HCP preparing them for when a difficult conversation such as a 'do not resuscitate' was going to be discussed, being more transparent, being more informative around how CKD was going to impact their lives and having more conversations about the future. Other suggestions were around HCP involving family members who do not live with the patient by sending them information, asking the patient if they would like them to speak to them on the phone. Participants wanted HCP to ask family members more about how they, not just their relative, are coping.

*I think it would be quite nice actually, if the doctors and nurses did check with the family how they were coping. They haven't ever asked me how I'm doing. I think it would be quite nice –*

*Nicola*

Some described feeling let down by the HCP, giving examples of miscommunication within the healthcare teams and between the teams and families. It was reported that it was very difficult to have open conversations with HCP as no time was afforded to family members alone. When family members were able to be seen alone, it was reported that they were given different information regarding treatment options. Participants reported feeling confused and isolated. There were reportedly no conversations regarding end of life care options and participants remained unaware of their relative's prognosis.

*I were just really cross and I said, 'But I've taken a day off work for this appointment... and I need to see somebody cause we don't know what's going on.' She said 'No' and I got really upset, so then she said 'just wait a minute'. Anyway, to cut a very long story short, I did end up seeing them, they did end up agreeing to see me... She's called an End of Life doctor, I think... But I saw her anyway she kind of explained to me that my dad wouldn't be able to*

*have dialysis; he wasn't well enough. So it was like complete contrast to what we'd been told  
the week before....*

*I'd said, 'I don't want you to tell my dad now cause obviously he's just had another heart  
attack. I don't think he needs to know this right now'; but they did come... I'd just got there  
not long after he'd left and my dad says 'Ohh, they've been to see me, and I can't have  
dialysis.' And I were shocked. I said, 'Okay'. He said, 'I think this is the end'. I went, I said,  
'Don't be silly.' I said, 'What they're trying to say to you is that you can't have dialysis  
because you're not well enough with everything else but it's not the end.' But he went, 'I  
think they've just said that I, I can't have anything.' – Alison*

## ***Theme 2: Facilitators and barriers to family members feeling supported***

Participants described various sources of support and having different support needs and preferences. Participant support included their relative, their friends and family and friends and family with a medical background and friends who also had CKD. Some wished that there were more support groups that they could attend to meet people in similar circumstances to them, but participants acknowledged that this group support would not suit everyone.

*One of the questions we asked him [doctor] ... was are there any support groups or anything?  
It would've been very helpful, then and now, if there were people that were contactable to be  
able to talk to about your experience – Geoffrey*

*“Talking to other people, it's not something I would do” - Margaret*

A barrier to participants feeling supported was the general lack of knowledge and understanding around CKD. Whilst friends and family could provide support, some friends' lack of knowledge left participants feeling frustrated.

*...if she'd had cancer, I know I keep using that, but if she'd had cancer I think our friends would've been, found it easier to relate to the situation, but now when they see her, you know apart from having to walk with a stick, there's essentially not much wrong with her – on the face of it and that's hard – Geoffrey*

*...a lot of people, especially friends, in the early days when it was getting round our friends [wife] had kidney failure, it was the assumption because she used to drink a lot. And you go, 'No. No, no. that's got f\*\*k all to do with it, that's your liver, a completely different organ! – Bryan*

### **3.4 Summary**

All participants struggled with the uncertainty of their situation. They used a variety of both coping strategies to help them manage their anxieties and the powerful emotions they experienced. Whilst participants attempted to maintain a normal life as much as possible, there were often barriers to this, and they had to adjust to a new way of living. Participants needed to develop an understanding of CKD, its associated treatments and their role within their relative's healthcare decisions and management. Participants gave examples of how they could be effectively supported by HCP. Whilst all participants had examples of feeling supported by HCP, most had examples where they felt the support could improve. All participants had experiences of feeling supported by others, but also faced barriers such as the general lack of knowledge around CKD.

In the 'Discussion' chapter, the findings of this study will be discussed in relation to the previous research and its clinical implications will be explored.

## **CHAPTER 4: DISCUSSION**

### **4.1 Introduction**

The aim of this study was to explore family members' experiences of being involved in their relative's CKD treatment decisions and illness management across all CKD treatment pathways. Seven family members of people with CKD were interviewed and this data analysed using the framework approach and pen portrait analysis informed by the assimilation model. The results from these analyses are discussed in relation to the relevant literature to answer the study's three research objectives. This chapter examined the strengths and limitations of this study, and implications for, people with kidney disease and their families, and clinical psychology theory and practice.

### **4.2 Research objective one – Investigate family members' understanding of CKD and their involvement in their relative's treatment decisions**

Previous research suggested that most family members have a lack of knowledge of CKD and renal treatments (Low et al., 2014; Luk, 2002; Noble et al., 2013) and that they feel overwhelmed as they try to make sense of their different options (Noble et al., 2013). The research suggested that if their relative has multiple co-morbidities, family members can feel confused when making sense of the different symptoms and medications (Low et al., 2014; Luk, 2002). Family members in this study had a similar lack of prior knowledge of CKD before their relative received their diagnosis, with some not realising the severity of the diagnosis. However, this study demonstrated that family members will use a variety of sources to seek knowledge and develop their own understanding of CKD, its symptoms, renal treatments, and the impact of co-morbidities. As well as reading the information supplied to them by HCP, they did their own research into CKD by going online, watching TV



programmes, or speaking with family or friends who were either HCP themselves or who also had CKD.

This study found participants developed a strong opinion about the most appropriate treatment options for their relative. Family members in this study tended to favour the treatment options that kept life as normal as possible. Whilst other research reports that family members can influence the treatment decisions their relative makes (Ashby et al., 2005; Lindqvist, Carlsson, & Sjöden, 2000; Low et al., 2014; Morton et al., 2010; Noble, Kelly, & Hudson, 2013; Ziegert & Fridlund, 2001), this study reported family members keeping their opinions to themselves as they felt it was not their decision to make. Instead, they reported wanting to support their relative to make their own decision. Unlike other research (Low et al., 2014), family members in this study did not describe any conflict or tension between themselves and their relative regarding treatment decisions. In this study, family members also described developing an understanding of their role in supporting their relative. This included developing an understanding of how to be in their relative's appointments and negotiating what questions were asked. Family members were aware that they may want different information, or information at a different time to their relative.

#### **4.3 Research objective two – Identify what support needs family members might have, and what helps or hinders these needs being met**

This study found that family members do have support needs, and that some of these are not currently being met. This study identified that a barrier to family members feeling supported was a general lack of knowledge and understanding by the public regarding CKD. Family members described how some of their friends and families' misconceptions around CKD left them feeling frustrated. They believed that if their relative had a more well-known condition, their family would receive more empathy and understanding.

This study's findings echoed the previous research. Family members identified that another barrier to feeling supported was needing more information and better communication with HCP (Combs & Davison, 2015; Fadem et al., 2011; Luk, 2002; Mehrotra et al., 2005; Morton et al., 2010; Schell et al., 2012; Song et al., 2013; Wachterman et al., 2013). Family members' experiences of receiving information and support was inconsistent (Lindqvist et al., 2000; Low et al., 2014; Luk, 2002; Morton et al., 2010; Noble et al., 2013). Family members described feeling let down by HCP and feeling upset and confused by different and uncoordinated information regarding treatment options (Low et al., 2014; Luk, 2002). Family members in this study were not aware when their relative was on a CKM and had a lack of understanding about this treatment pathway (Low et al., 2014). Similar to other studies, family members felt unprepared by HCP for the reality of supporting someone with CKD (Luk, 2002; Morton et al., 2010) and were unsure about the illness trajectory (Noble et al., 2013). In this study family members reported that they felt HCPs' lack of transparency was their way of protecting families and helping them maintain hope. However, most family members reported valuing transparency and being given clear messages regarding prognosis. Family members provided suggestions around how their support needs could be met by HCP including: having time alone with HCP so that they could have discussions around topics such as prognosis that their relative may not wish to hear; resources to help them discuss difficult topics with the person with CKD; having more information about how their relative having CKD would impact their lives and what would become a part of their 'new normal'. For example, they described being told that HD allowed them and their relative to travel abroad but then not being prepared for the difficulties of arranging dialysis abroad and the health insurance cost. There appeared to be a need for HCP to involve family members who do not live with the person with CKD by offering to speak with them on the phone and

suggesting support groups that could help them cope. These suggestions are in line with UK health policies which recommend family members should receive more information, support, needs assessment and have access to support groups and additional support / respite services (Department of Health, 2008; Low et al., 2014; Luk, 2002; Morton et al., 2010; NHS Kidney Care, 2015; Noble et al., 2013).

The study did identify that some of the family members' needs were being met. Family members described feeling supported by their relative with CKD, and their wider friends and family. Some of the family members' needs were also being met by HCP. Some family members felt reassured and supported by being able to speak with HCPs at their relative's renal appointments. Some family members felt their role was valued by HCP and that HCP involved them during any consultation appointments. Similar to other research, some family members felt reassured by being provided with the renal teams' direct contact telephone number (Luk, 2002). Unlike other research, all who were given this number felt able to call if needed (Low et al., 2014), but this number was not available to all family members.

Family members spoke of the importance of continuity on their relative's care, as it gave them the opportunity to build a relationship with the renal team (Low et al., 2014; Luk, 2002). Family members gave examples of when HCP had done something to make them feel like valued human beings and not just patients (Saeteren et al., 2011).

#### **4.4 Research objective three – Explore the emotional impact on family members and how they made sense of their experiences**

This study had some similar findings to other research when exploring the emotional impact on family members. Family members reported that the uncertainty of their situation caused fear and anxiety (Ashby et al., 2005; Low et al., 2014; Noble et al., 2013). Family members felt that they needed to keep their fears and concerns about the future to themselves as they

believed their role was to protect their relative and not be a burden to them by causing additional stress or worry (Luk, 2002; Ziegert & Fridlund, 2001). This is similar to the general literature on caring (not CKD specific), which describes how family members will prioritise their relative's needs above their own (Beng et al., 2013; Høgsnes et al., 2014; Lewis, 2015; Totman et al., 2015). This study provided additional information about family members' beliefs about how someone in their situation should feel and behave. Family members reported they believed their role was to be strong and positive for their relative.

Similar to the findings of other studies, the illness' uncertain trajectory meant that family members' everyday life was impacted and that they could not make future plans (Ziegert & Fridlund, 2001). Family members believed that they should be available for their relative meaning that valued activities were restricted, and family members felt they were constantly in touch with, or visiting the hospital or GP surgery (Ziegert & Fridlund, 2001). Family members in this study also reported feeling an increased responsibility to complete day-to-day tasks at home with no additional support (Luk, 2002; Ziegert & Fridlund, 2001).

Previous research has suggested that taking charge of home dialysis machinery can lead family members to feel more anxious, and to a deterioration in the family's relationship (Belasco et al., 2006; Belasco & Sesso, 2002; Brunier & McKeever, 1993; Watson, 1997). However, this study's results suggested that taking responsibility for aspects of their relative's care was a way for family members to cope with their situation. By becoming more informed and involved in their relative's care by, for example, donating a kidney, taking charge of dialysis machines, making lists of questions for appointments, family members gained a sense of control which helped them cope in an uncertain time. This study demonstrated other strategies that family members used to cope with the uncertainty of their situation. Some family members reported using external strategies such as present-focused

hobbies. Other strategies used by family members included normalising, minimising, favourably comparing their situation to others' and avoidance.

Family members differed in whether they had discussions around prognosis with their relative, echoing previous findings (Braithwaite et al., 2011; Low et al., 2014; Noble et al., 2013; Saeteren et al., 2011). Some family members in this study had open discussions about end of life. Others were aware that their relative was approaching end of life but did not feel able to discuss this with their relative for fears of distressing them or eliminating their relative's hopes (Low et al., 2014; Noble et al., 2013). Stringer and Baharani (2011)'s study reported that patients with CKD also avoided these discussions with family members for fear of causing *them* distress. This study therefore supports the idea that families collude in the pretence that the patient is not going to die and become stuck in a dance of silence, where both parties feel unable to voice their fears due to fears of upsetting others (Coll et al., 1998; Fredman, 1997; Saeteren et al., 2011; Weingarten, 1997, 2000, 2012; Weingarten & Worthen, 1997). Other family members denied having any concerns or worries regarding their relative's illness and actively avoided conversations around prognosis (Braithwaite et al., 2011; Low et al., 2014; Noble et al., 2013; Saeteren et al., 2011).

This study supported the more general literature into how family members are emotionally impacted by supporting a relative with a chronic illness. Family members faced a change in their sense of identity, with some family members feeling fulfilled by their new role (Broady, 2017; Griffith & Hastings, 2014; Høgsnes et al., 2014). Other family members struggle with this new identity, and experience loss for their previous identity and life, a loss of hope, and a loss of control (Broady, 2017; Butow, 2017; Collins et al., 2016; Kitt-Lewis, Strauss, & Penrod, 2018; Lewis, 2015; Melin-Johansson, Henoeh, Strang, & Browall, 2012; Sand & Strang, 2006; Thomas et al., 2009; Totman et al., 2015).

This study explored how family members assimilate an unwanted and problematic event (their relative being diagnosed with a chronic and life-limiting illness) into their sense of self, and how they made sense of this experience. There were differences between family members. Whilst some family members were often unable to discuss how their relative's illness had impacted them, others were able to both discuss how it affected their everyday life and their attempts to ameliorate its impact. However, this study also demonstrated differences within participants. It showed that coming to terms with an experience and assimilating an unwanted experience into one's identity is an ongoing process and family members oscillated between levels of avoidance and acceptance. Family members should therefore not be seen as fixed in either a state of avoidance or acceptance.

#### **4.5 Strengths and limitations**

##### **4.5.1 Strengths**

This study was conducted robustly and steps were taken to ensure the study's validity (Elliott et al., 1999). Qualitative methods are appropriate for gaining rich and in-depth information about people's experiences in an under-researched area where views are not known (Braun & Clarke, 2006; Mays & Pope, 2000; Pope et al., 2000; Ritchie & Lewis, 2003, 2014) The framework approach has clear and transparent stages of analysis (Ritchie & Lewis, 2003, 2014; J. Smith & Firth, 2011) and concepts and themes are not described as simply 'emerging' from the data (J. Smith & Firth, 2011). The study's concepts and themes are supported by direct quotes and there is evidence to show how the data was analysed (see appendix 9). Regular supervision to discuss the coding index, themes, concepts, and assimilation model interpretations mean that the study's findings are both credible and grounded in the interview data. Semi-structured interviews provided the flexibility to elaborate or avoid certain topics and areas whilst ensuring research aims were met (Barriball

& While, 1994). The values, interests and assumptions of AJ were outlined in the 'Methods' chapter, and an extract of a reflective journal can be found in appendix 11. Key demographic information has been provided for participants.

#### **4.5.2 Limitations**

Qualitative research is appropriate for gaining in-depth and rich information (Mays & Pope, 2000; Pope et al., 2000; Ritchie & Lewis, 2003, 2014), and the findings from this study resonate with research from other studies suggesting some validity. However, the small sample size means there may be other factors of important to people with different experiences. Whilst this study's sample was heterogeneous in some aspects (gender, relationship to person with CKD, age and treatment / illness journey), the sample could have been diverse (more children of people with CKD, siblings, more family members whose relative has died). The sample was also homogeneous in terms of ethnicity and culture (all participants were White British). Future research in this area might consider further investigation of this study's findings by recruiting a bigger and more heterogeneous sample and conducting a quantitative research project using different methods, such as questionnaires.

The framework approach can be appealing for researchers trained in quantitative approaches due to its systematic stages and matrix format. It can tempt researchers without an understanding of qualitative research to attempt to quantify the data (e.g. 'X number of participants said this') or underestimate the reflexivity and rigour required for the framework approach, as with all other qualitative research methods (Gale, Heath, Cameron, Rashid, & Redwood, 2013). However, Gale et al. (2013) recommend that a researcher without previous experience of using the framework approach should have supervisors who are familiar with the approach, which is the case with this study.

Another potential limitation of this study is researcher bias. Steps were taken to minimise the impact of researcher bias (Elliott et al., 1999). Despite this, AJ's experience of being a family member of someone with a chronic and life-limiting illness, as well as her training to be a Clinical Psychologist, may have had an impact on the analysis process.

A challenge that this study, and future research projects in this area, face is the recruitment of family members. Since the implementation of the General Data Protection Regulations, charities such as KRY's mailing lists have been significantly diminished. Many people with CKD attend renal clinics without their family members and the overall pressure on NHS services mean that clinicians often do not have the capacity to make introductions with families and actively facilitate recruitment.

#### **4.6 Implications for theory**

The assimilation model was first developed to make sense of how therapy clients assimilated unwanted or problematic experience into their sense of self within psychotherapy (Honos-Webb & Stiles, 1998; Honos-Webb et al., 1999; Stiles, 1999, 2001; Stiles et al., 1999).

Research using the assimilation model has therefore primarily focused on this process within a therapeutic context (Detert, Llewelyn, Hardy, Barkham, & Stiles, 2006; Honos-Webb et al., 1999; Laitila & Aaltonen, 1998) across different clinical populations, for example people with a learning disability (Newman & Beail, 2002) or a post-traumatic stress disorder diagnosis (Varvin & Stiles, 1999).

Its use in dementia research (Cheston et al., 2017, 2018, 2006; Lishman et al., 2016) and this study demonstrates its wider applicability within health research. The research indicates that family members who support a relative with chronic illness face changes in their identity (Beng et al., 2013; Broady, 2017; Carlander et al., 2011; Høgsnes et al., 2014; Lewis, 2015; Totman et al., 2015). Using the assimilation model in this study allowed the systematic



mapping of this process as family members assimilated a problematic experience into their sense of self. It also demonstrated how people oscillate between stages. The assimilation model analysis has implications for clinical practice by providing opportunities for HCP and people with CKD to have difficult conversations with family members. These implications are explored further in section 4.7 Implications for clinical practice.

#### *Future research*

This study demonstrates how the assimilation model can be used within health research to explore how a person and their family are coming to terms with their situation and could also prove useful for research into other health conditions. Future research should also explore whether assimilation and greater insight into the illness is associated with decreased caregiver burden and more positive outcomes for the family member, as seen in the dementia research (Cheston et al., 2018; Rocca et al., 2010).

### **4.7 Implications for clinical practice**

#### *HCP communication*

Participants talked about how HCP communication could be improved. Whilst the research suggests that HCP avoid difficult conversations due to their own anxieties and fear of distressing the patient and family (Bristowe, Horsley, Shepherd, Brown, Carey, Matthews, O'donoghue, et al., 2015; Bristowe et al., 2014; Burns & Carson, 2007; Latos, 1996; Stringer & Baharani, 2012), this study shows that family members value transparent conversations. Whilst family members are aware that HCP may be trying to protect them from bad news, they would prefer transparency. This study highlights that people with CKD and their family members do not always know that they are on a CKM pathway and do not always have the opportunity to have ACP conversations around end of life.

The study also highlights that HCP need to tailor their support to individual family members. The assimilation model analysis shows how different family members were at different stages of assimilation. It identifies opportunities for HCP to have conversations with families and patients within their zone of proximal development (ZPD; Vygotsky, 1978). The ZPD can be understood as the family members' assimilation marker level (from level 0 – 6).

Conversations that are pitched too far outside the family members' ZPD are likely to be unhelpful (Leiman & Stiles, 2001). However, if pitched correctly, family members' level of understanding and assimilation can progress from one level to another with the HCP's assistance.

The study also illustrates that, as well as assimilation differences between participants, there are also differences within participants' accounts. It demonstrates that assimilation is not a linear process and that people oscillate between stages of avoidance and acceptance. This may challenge some HCP's idea that people are either 'in denial' or 'accept the situation' and remind them to think of family members' assimilation states flexibly both within and between appointments.

#### *Support pathway for family members*

Participants' different experiences in this study highlighted the inconsistent support offered to family members and highlights the need for renal teams to develop clearer and more consistent support pathways nationally for family members. Some participants in this study had been invited to an 'open day' where they could meet other family members and patients. Other participants were either not aware of this event or their renal team was not offering this form of support. No participants were aware of any form of support offered solely to family members.

A support pathway for family members should also provide a space for family members to speak with HCP privately. Family members are more likely to feel able to speak openly about how they are coping and whether they might need any additional support. This study emphasises the importance of keeping family members, as well as patients, in mind.

### *Co-design*

Participants discussed how they would be willing to co-design information leaflets and organise support groups with HCP. The NHS encourages service user involvement in resource development and pathway design (NHS, 2019) and family members should also be involved in the planning of renal support pathways if these have not yet been developed. General information resources should be developed for all family members, as well as support resources for family members who may want or need additional services e.g. support groups, signposting to Clinical Psychology.

### *How Clinical Psychology can help*

This study highlighted that family members face a lot of uncertainty and emotional challenges. When renal teams have access to Clinical Psychology, Psychologists may be able to offer training for renal teams on certain techniques that families might find useful. These could include mindfulness techniques if the person is feeling stressed or overwhelmed, or elements of behavioural activation if the person feeling low in mood and struggling to do things for themselves. As well as supporting renal teams to support family members, Clinical Psychology could also offer a space where renal teams could think about how to face and tolerate their own anxieties about speaking about difficult topics such as end of life e.g. a reflective practice group.

### *Future research*

Future research would be needed to evaluate any support groups or information resources. Additional research exploring the views and experiences of a more heterogeneous sample (e.g. people from different ethnic backgrounds, more children or siblings of people with CKD) would also be valuable to try to ensure that the support pathway was accessible and useful to as many family members as possible.

#### **4.7.5 Recommendations**

To summarise, the recommendations from this study's findings are:

- HCP to ensure transparent conversations and that family members are given the opportunity of have ACP conversations
- HCP to keep the assimilation model in mind when tailoring their communication to the needs of the family member, remembering that these needs might change both within and between appointments
- For renal teams to develop clear support pathways for family members, which includes space for family members to speak to HCP privately
- This pathway, as well as information and support resources e.g. support groups, to be co-designed with family members. Resources should be developed for all family members as well as people who may want or need additional support
- Clinical Psychology to offer training to renal teams on certain techniques e.g. mindfulness which may help HCP when supporting patients and family members
- Clinical Psychology to offer a space for renal teams to process their anxieties about discussing difficult news e.g. reflective practice groups

#### **4.8 Concluding paragraph**

This study explored how family members were involved in their relative's treatment decisions and illness management across all renal treatment pathways, which is a previously

un-researched area. The study's findings indicate that family members have a lack of prior knowledge of CKD but use different sources of information to learn and make sense of CKD and its treatments. Family members favour treatment and illness management decisions that keep life as normal as possible but believe their role is to support their relative to make their own decisions, as well as be strong and positive for their relative. Despite attempts to keep life as normal as possible, family members' valued activities and everyday life is impacted by their relative's illness. Family members utilise different strategies to help them cope with the uncertainty of their situation. Family members have fears and concerns for the future but keep these from their relative due to concerns about causing them additional worry. Family members assimilate their experiences at different paces, but also oscillate between different levels of avoidance and acceptance. Some felt able to think and speak about their relative's prognosis whilst others avoided this. This study also identified that family members have support needs and suggested ways that HCP could meet these needs. Family members felt they would benefit from having time alone and more transparent conversations with HCP, support groups, and additional resources. Such a support pathway could be co-designed with family members.

## LIST OF ABBREVIATED TERMS

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### List of abbreviated terms

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Chronic kidney disease	CKD
Kidney Disease: Improving Global Outcomes	KDIGO
National Institute of Health and Care Excellence	NICE
Estimated glomerular filtration rate	eGFR
Cardiovascular disease	CVD
Renal replacement therapies	RRT
Peritoneal dialysis	PD
Haemodialysis	HD
Healthcare professionals	HCP
Conservative kidney management	CKM
Advanced care planning	ACP

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## APPENDICES

### APPENDIX 1: Consent form



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Two copies of the consent form will be signed – one copy is for you as the participant and one copy will be kept by the research team at the University of Leeds. Please see the information sheet for details regarding the University's policy for storing research documents.

### People's Involvement in Family Member's Chronic Kidney Disease Choices.

#### CONSENT FORM - Participant Study Number .....

1. I have read the information sheet for the above study	
2. I have had the opportunity to ask questions about the study	
3. I understand the purpose of the study, and how I will be involved.	
4. I understand and accept that, if I take part in the study, I may not gain any direct, personal benefit from it.	
5. I understand that my interview will be audio recorded and then made into an anonymised written transcript.	
6. I consent to anonymised quotations from my interview being used in the study.	
7. I <b>would like / would not like</b> information about the study's results (please delete one). If you would like information to be sent to you, please provide your address:	

Family members' involvement in their  
relative's kidney disease management and treatment choices

8. I understand the information collected in the study is held in confidence and that, if it is presented or published, all my personal details will be removed.	
9. I understand the information collected about me may be used to support other research or develop training materials in the future.	
10. I confirm I am taking part in this study of my own free will, and I understand I may withdraw from it, at any time and for any reason, without my legal rights being affected.	

\_\_\_\_\_                      \_\_\_\_\_                      \_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_                      \_\_\_\_\_                      \_\_\_\_\_  
Name of Researcher                      Date                      Signature

<i>Project title</i>	<i>IRAS project ID</i>	<i>Document type</i>	<i>Version #</i>	<i>Date</i>
People's Involvement in Family Member's Chronic Kidney Disease Choices.	258378	Consent form	4	18/07/ 2019

## APPENDIX 2: Participant information sheet



**UNIVERSITY OF LEEDS**

### **People's Involvement in Family Member's Chronic Kidney Disease Choices.**

#### **STUDY INFORMATION SHEET**

This information describes what it means for you if you decide to take part in this study. Please take time reading the information and, if it helps, talking with others about the study.

This study aims to describe the experiences of people whose relatives are making decisions about chronic kidney disease treatments. Kidney services are interested in knowing the needs of families when a family member is living with chronic kidney disease. Kidney services would like to support and help people cope with having someone close to them who is making difficult decisions about their illness and end of life.

Angharad Jones is carrying out this study as part of her professional training to become an NHS Clinical Psychologist. Angharad is supervised by Professor Hilary Bekker and Dr Joanne Smith (University of Leeds), and Dr Anna Winterbottom (St James Kidney Unit, Leeds Teaching Hospital Trust). The study is supported by kidney staff in Leeds, Bradford and Sheffield, and the charity Kidney Research Yorkshire.

For more information about the study contact Angharad Jones; email [umaj@leeds.ac.uk](mailto:umaj@leeds.ac.uk) or [phone 0113 343 0829](tel:01133430829) ([course secretary](#)). Angharad will get back to you as soon as possible. You can also contact Professor Bekker ([H.L.Bekker@leeds.ac.uk](mailto:H.L.Bekker@leeds.ac.uk) / 0113 343 2726), Dr Smith ([j.e.smith1@leeds.ac.uk](mailto:j.e.smith1@leeds.ac.uk) / 0113 34 36297) or Dr Winterbottom ([A.E.Winterbottom@leeds.ac.uk](mailto:A.E.Winterbottom@leeds.ac.uk)).

#### **What is the study about?**

This study asks people for their views and experiences of having someone in their family with chronic kidney disease. Support from families is important to people with a long-term illness like kidney disease to live their lives as well as possible. People with chronic kidney disease talk with their doctors and nurses about what is important to them about managing



their illness. Family members do not usually get to talk with doctors and nurses. Kidney staff want to know what the families of people with chronic kidney disease need when a person's illness gets worse and/or choices are made about end of life care.

### **Who can take part in the study?**

Any adult who is related to a person with kidney disease, such as a spouse, parent, child, brother or sister, and cousin. Angharad wants to interview about 15 people with different experiences of making decisions with a person who has lived with chronic kidney disease for many years, and is likely to have had treatments like dialysis, a kidney transplant, and/or conservative management.

### **What does taking part mean?**

People who want to take part can contact Angharad to arrange a time for an interview. The interviews take about an hour. They are held at a place to suit you, such as home, hospital, University and, in some cases, a phone call. Interviews are audio tape-recorded, typed up and the recordings erased. The recordings will be typed up by professional transcribers and there is a confidentiality agreement in place between the company and the University of Leeds. Personal details are removed from the typed-up versions. All typed-up versions are analysed together for the study findings.

### **Do I have to take part?**

No, it is up to you whether or not you contact Angharad. Your relative's care will not be affected by your decision to take part or not. You can withdraw from the study, after you have agreed to take part, without giving a reason.

### **What are the advantages and disadvantages of taking part?**

Some people find it helpful to talk about their experiences of having a relative with a long-term illness. The views and experiences from these interviews will help kidney staff plan how to support better people with chronic kidney disease and their families.

Some people get upset when talking about a relative's illness, and their end of life care decisions. Getting upset is a normal reaction to a difficult situation. Angharad will change the topic if you do not want to carry on talking about an issue. If people want extra support to talk through issues, the clinical psychology team details will be given to study participants.

### **Will my taking part in this study be kept confidential?**

Yes, information from the interviews is kept confidential. Angharad would only report something you say if you disclosed a serious risk to yourself or someone else. She would tell you of her concerns before passing this information to relevant services. Only Angharad will be able to tell who took part in the study. The typed-up versions have a study number on them, no names. The University of Leeds is the sponsor for this study (based in the United Kingdom). The University will be using information from you in order to undertake this study and will act as the data controller for this study. This means that they are responsible for looking after your information and using it properly. The University of Leeds will securely keep written documents for 3 years before they are then destroyed.

Your rights to access, change or move your information are limited, as the University need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, they will keep the information about you that the study has already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how the University of Leeds uses your information at <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf>.

Leeds Teaching Hospitals Trust (LTHT) will ask for your name and contact details for this research study in accordance with our instructions. LTHT will pass your name and contact details to Angharad Jones within The University of Leeds. Individuals from The University of Leeds and regulatory organisations may look at your medical and research records to check the accuracy of the research study. They will not be able to identify you and will not be able to find out your name or contact details. The only people in The University of Leeds who will have access to information that identifies you will be people who need to contact you to discuss whether you would like to take part in the study and interview you (this will be Angharad) or audit the data collection process.

### **What happens to the results of the study?**

The results are written up as part a report and published on-line as part of Angharad's thesis. The results will be presented at conferences, published in academic and medical journals, and used to train health professionals and inform patient leaflets. Angharad can post a summary of the study's results to you. If you would like to receive a summary, select this option in the consent form and supply a contact address. You do not have to do this; it is completely up to you.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance. Certain individuals from the University of Leeds and regulatory organisations may look at the research data to check the accuracy of the research study.

### Consent

If you are taking part in the study, you will be asked if you understand the study information and asked to sign a consent form. If you have worries about any part of this study, speak with Angharad and/or her supervisors, who will do their best to answer your questions.

This study has been reviewed and approved by the University of Leeds, the charity Kidney Research Yorkshire, and the NHS ethics panel [ref/ date].

**Thank you for reading this information and deciding if you want to take part in the study. Angharad Jones, email [umaj@leeds.ac.uk](mailto:umaj@leeds.ac.uk) or phone 0113 3430829 (course secretary).**

<i>Project title</i>	<i>IRAS project ID</i>	<i>Document type</i>	<i>Version #</i>	<i>Date</i>
People's Involvement in Family Member's Chronic Kidney Disease Choices.	258378	Information sheet	4	22/07/ 2019

### APPENDIX 3: Patient invite letter

Kidney Unit headed paper
Reference / contact

#### People's Involvement in Family Member's Chronic Kidney Disease Choices.

##### INVITATION LETTER – FOR RENAL PATIENT

Dear XXXXXX,

Your kidney doctors sent this letter to ask for your help in getting in touch with a family member or spouse for my study. My study aims to describe the experiences of people whose relatives are making decisions about chronic kidney disease treatments. Your kidney service is interested in knowing what the needs of your families are when supporting you in your chronic kidney disease management decisions.

I am carrying out interviews with people who have a relative or spouse with chronic kidney disease. If you are happy for one, or more, of your family members to take part in this study, I kindly ask you pass on the study information to them. Taking part involves being interviewed once by me, for about an hour.

I am carrying out this study as part of my professional training as an NHS clinical psychologist. My study is supervised by Professor Hilary Bekker and Dr Joanne Smith (University of Leeds), and Dr Anna Winterbottom (St James Kidney Unit, Leeds Teaching Hospital Trust). This study has been given ethical approval by the ..... Research Ethics Committee.

The study is described in more detail in the information sheet. If you have any questions about this study please contact me by email ([umaj@leeds.ac.uk](mailto:umaj@leeds.ac.uk)) or phone 0113 3430829 [and leave a message with the course secretary.](#) I will get back to you as soon as possible.

Thank you for reading the letter and deciding to pass on this information to a relative.

Yours sincerely,

Angharad Jones (Clinical Psychologist in Training).

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People's Involvement in Family Member's Chronic Kidney Disease Choices.	258378	Invitation letter	2	15/04/2019

## APPENDIX 4: Social media advert



UNIVERSITY OF LEEDS

### PARTICIPANTS REQUIRED FOR RESEARCH PROJECT

#### People's involvement in family member's Chronic Kidney Disease choices.

##### What is the study about?

Angharad Jones is carrying out this study as part of her professional training to become an NHS Clinical Psychologist.

This study asks people for their views and experiences of having someone in their family with chronic kidney disease. Kidney staff want to know what the families of people with chronic kidney disease need when a person's illness gets worse and/or choices are made about end of life care.

##### Who can take part in the study?

Any adult who is related to a person with kidney disease, such as a spouse, parent, child, brother or sister, and cousin. Angharad wants to interview about 15 people with different experiences of making decisions with a person who has lived with chronic kidney disease for many years, and is likely to have had treatments like dialysis, a kidney transplant, and/or conservative management.

##### What does taking part mean?

People who want to take part can contact Angharad to arrange a time for an interview. The interviews take about an hour. They are held at a place to suit you, such as home, hospital, University and, in some cases, a phone call.

##### For further information:

Contact **Angharad Jones**; email [umaj@leeds.ac.uk](mailto:umaj@leeds.ac.uk) or phone **0113 3430829** ([course secretary](#)). Angharad will get back to you as soon as possible. Thank you.

<i>Project title</i>	<i>IRAS project ID</i>	<i>Document type</i>	<i>Version #</i>	<i>Date</i>
People's Involvement in Family Member's Chronic Kidney Disease Choices.	258378	Social media advert	1	18/04/2019

## **APPENDIX 5: Interview topic guide**

### **People's Involvement in Family Member's Chronic Kidney Disease Choices.**

#### **INTERVIEW TOPIC GUIDE**

Thank you for agreeing to take part in this study. I am interested in your experiences of having someone in your family who has chronic kidney disease. People with chronic kidney disease talk about how important their family and spouse are to them when making treatment decisions. There is little out there about relatives' experience, views and needs.

The interview is in three parts: your understanding and experience of chronic kidney disease; how you have been involved in your relative's decisions; what has helped/ not helped you when making decisions about your relative and their care.

#### *Part One - understanding and experience of chronic kidney disease*

- Who in your family has kidney disease, and what is your relationship to them?
- Do you have a role in their healthcare?
- What were your first thoughts and feelings when your relative was diagnosed CKD? (How changed? Better/ worse)
- (If relative alive) How do you feel now about your relative's diagnosis? (Has this changed from first diagnosed? Better / worse? Why? Acceptance? Oscillating?)
- Have your feelings changed from when they were first diagnosed? (Better/worse? Why? Context-dependent?)
- If there has been / was a change, what has changed about the way you think and feel about CKD now? (Does how you feel change day-to-day or has this change been consistent?)
- What does your life look like now that your relative has CKD? What is a typical day/week for you?
- What treatment is your relative receiving?
- What is your understanding of this treatment and other treatment options?

- What is your understanding of kidney disease? (Feel like know enough / or not enough? Prior knowledge / experience?).

*Part two - involvement in your relative's treatment decisions.*

- How involved do you feel in your relative's treatment decisions? (Do you want more/ less? Describe a situation you were involved in your relative's treatment decisions?)
- What makes you feel more / less involved? (Would you describe a situation where you would have liked to be involved in your relative's treatment decisions?)
- Do you feel that your involvement is encouraged by others? If not, why not / if yes, why yes?
- Do you feel able to voice your concerns / worries / thoughts about your relative's illness? With whom? If not, why not / if yes, why yes?
- Do you feel able to talk about your relative's future? With whom? If not, why not / if yes, why yes?
- Do you feel comfortable talking to somebody (e.g. other family member, professional, relative with CKD) about your relative's future and future treatment? If so, why? If not, why not?
- Do you feel it's important to talk to somebody (e.g. other family member, professional, relative with CKD) about your relative's future and future treatment? If so, why? If not, why not?

*Part three - what has helped/ not helped you when making decisions about your relative and their care.*

- What do you think would help you support your relative to make treatment decisions? (if involved / want to be involved?)
- What would help you support your relative to live well with kidney disease?
- How easy/difficult has it been to find sources of medical information that you trust?

- What information was helpful to you? (unhelpful – with hindsight was there anything misleading about the information you were given?)
- Did you do anything that helped you make sense of the information?
- Talking to a relative about their illness and treatment can be very difficult – is there anything that would help facilitate these conversations?

### **Final Checks**

I have now asked you all the questions I had planned. Are there any issues/questions that you would like to talk about that have not been covered?

Thank you, just to say once again, everything you have told me today is confidential and completely anonymous.

Some people get upset when talking about a relative's illness, and their end of life care decisions. Getting upset is a normal reaction to a difficult situation. If people want extra support to talk through issues, the clinical psychology team details will be given to study participants (Dept of Clinical and Health Psychology, Fielding House, St James's University Hospital, Beckett Street, Leeds, LS9 7TF; 0113 206 5897).

Angharad Jones is carrying out this study as part of her professional training to become an NHS Clinical Psychologist. Angharad is supervised by Professor Hilary Bekker and Dr Joanne Smith (University of Leeds), and Dr Anna Winterbottom (St James Kidney Unit, Leeds Teaching Hospital Trust). The study is supported by kidney staff in Leeds, Bradford and Sheffield, and the charity Kidney Research Yorkshire.

For more information about the study contact Angharad Jones; email [umaj@leeds.ac.uk](mailto:umaj@leeds.ac.uk) or phone 0113 3430829 [\(course secretary\)](#).

<i>Project title</i>	<i>IRAS project ID</i>	<i>Document type</i>	<i>Version #</i>	<i>Date</i>
People's Involvement in Family Member's Chronic Kidney Disease Choices.	258378	Interview topic guide	1	25/04 /2019



**APPENDIX 6: Coding index**

Codes	Initial themes
1.1. Taking responsibility for caring 1.2. Beliefs about caring role 1.3. Uncertainty regarding caring role	1. Caring role
2.1. Maintaining normality 2.2. Negotiating treatment decisions 2.3. Weighing up pros and cons 2.4. Importance of having a choice 2.5. Involvement with treatment decisions and management 2.6. Involvement valued by others	2. Treatment decisions
3.1. Impact of caring role on family member 3.2. Impact of caring role on relationship 3.3. Impact of treatments on valued activities 3.4. Impact of treatments on everyday life 3.5. Emotional impact 3.6. Adjusting 3.7. Coping strategies <i>e.g. minimising, normalising, comparisons with others, avoidance, focus on positive, focus on present</i>	3. Impact of CKD on family member
4.1. Support and reassurance from HCP 4.2. Lack of support and reassurance from HCP 4.3. HCP transparency 4.4. Support from others with shared experiences 4.5. Other sources of support 4.6. Lack of support and understanding from others 4.7. Support needs 4.8. Importance of relationship with HCP	4. Support and reassurance
5.1. Establishing diagnosis 5.2. Making sense of illness symptoms 5.3. Making sense of treatments 5.4. Lack of prior knowledge 5.5. Lack of current knowledge 5.6. Negotiating seeking information 5.7. Sources of information 5.8. Illness timeline	5. Family member's understanding of CKD

## APPENDIX 7: Markers of the assimilation model manual

Stage	Description
0: Warded off	The person states that they have no problems. Affect is minimal.
1: Unwanted thoughts	Person acknowledges that they experience some difficulties but there is evidence of avoidance, where content is minimised or dismissed e.g. by talking around the problem, changing the conversation, telling a contradictory story.
2: Vague awareness	The person is in distress but cannot clarify the problem. Distress appears to come from an internal conflict relating to the event. Person expresses feelings of sadness, depression, anxiety, is angry or irritated, confused or overwhelmed.
3: Clarifying the problem	Person states the problem with emotional distance. They describe their reaction and responses and / or develop a clearer understanding of the problem. The person appears 'stuck' and cannot see a way out.
4: Gaining perspective	Person has a clear understanding of the problematic experience. They can discuss both positive and negative aspects of the experience, or times where their feeling or the situation was more / less acute, and / or make links between this experience and other parts of their lives.
5: Working through	Person can weigh up solutions or partial solutions to aspects of their problematic experience. There is an acknowledgement that whilst some problems cannot be fixed or cured, aspects of the problem can be managed. Person weighs up potential solutions and / or generalise these solutions to varying problems and areas of life.
6: Problem solution	Person has achieved a successful solution to a problem and achieved some change in either their understanding of what is happening or in their relationship with others with a sense of pride.
7: Mastery	Person has integrated the problematic experience into their whole life. It is acknowledged but does not define them. The person successfully uses their new solutions in new situations.

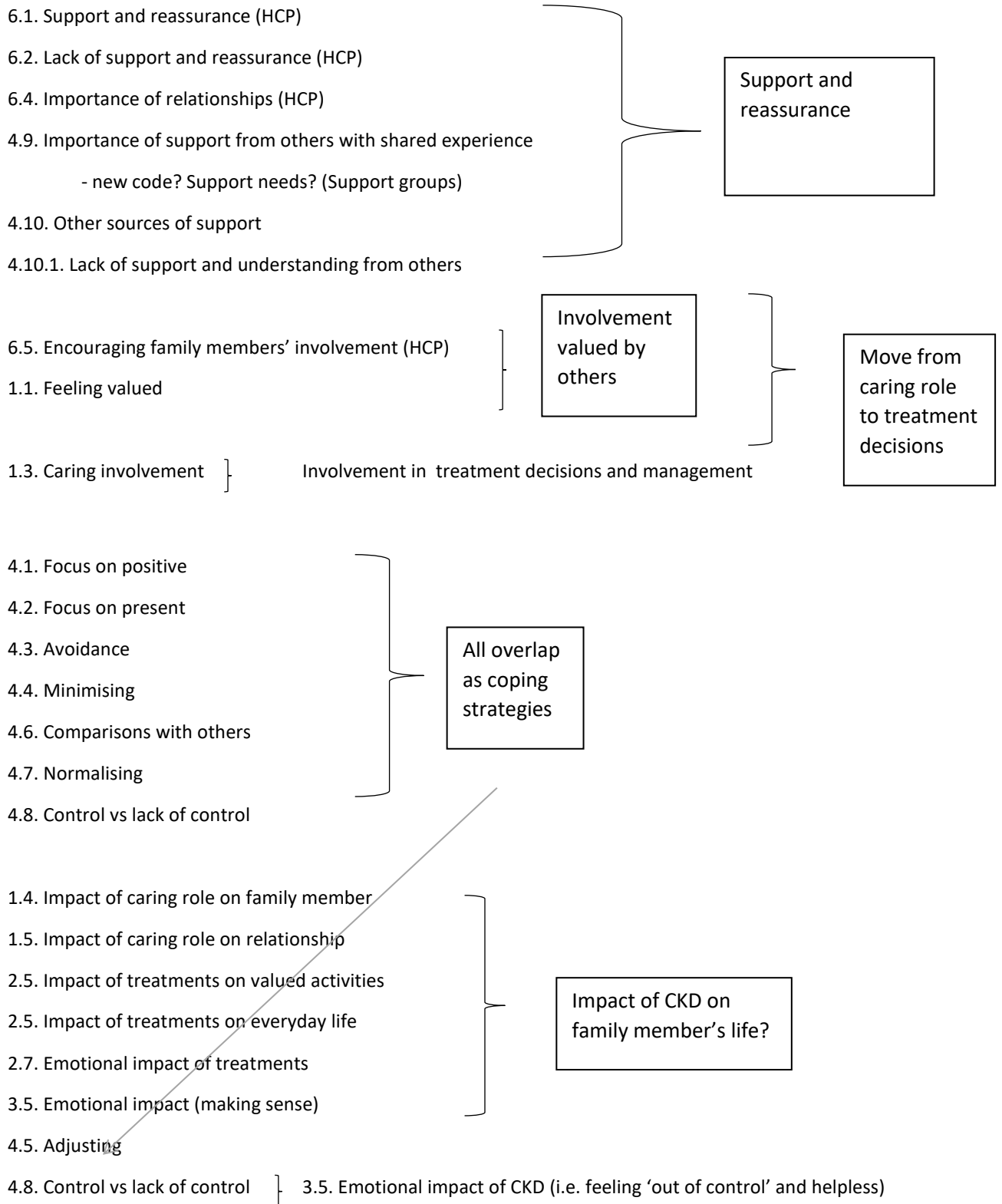
## APPENDIX 8: Development of the coding index

### Initial coding index:

Codes	Initial themes
1.1. Feeling valued 1.2. Taking responsibility for caring 1.3. Caring involvement 1.4. Impact of caring role on family member 1.5. Impact of caring role on relationship with person with CKD 1.6. Beliefs about caring role 1.7. Concern for person with CKD 1.8. Uncertainty regarding caring role	1. Caring role
2.1. Maintaining normality 2.2. Negotiating treatment decisions 2.3. Weighing up pros and cons 2.4. Importance of having a choice 2.5. Impact on valued activities 2.6. Impact on everyday life 2.7. Emotional impact of treatments	2. Treatment decisions
3.1. Illness symptoms 3.2. Treatments 3.3. Illness timeline 3.4. Establishing diagnosis 3.5. Emotional impact	3. Making sense
4.1. Focus on the positive 4.2. Focus on the present 4.3. Avoidance 4.4. Minimising 4.5. Adjusting 4.6. Comparisons with others 4.7. Normalising 4.8. Control vs lack of control 4.9. Importance of support from others with shared experiences 4.10. Other sources of support 4.10.1. Lack of support / understanding from others	4. Coping
5.1. Lack of prior knowledge 5.2. Lack of current knowledge 5.3. Knowing enough vs too much 5.4. Negotiating seeking information 5.5. Sources of information	5. Information seeking
6.1. Support and reassurance 6.2. Lack of support and reassurance 6.3. Transparency 6.4. Importance of relationships 6.5. Encouraging family members' involvement	6. Healthcare professionals' input

**Coding index development:**

Examined where different codes / themes overlap. I merged some codes / themes and sometimes created new codes / themes.



**Final coding index:**

Codes	Initial themes
1.1. Taking responsibility for caring 1.2. Beliefs about caring role 1.3. Uncertainty regarding caring role	1. Caring role
2.1. Maintaining normality 2.2. Negotiating treatment decisions 2.3. Weighing up pros and cons 2.4. Importance of having a choice 2.5. Involvement with treatment decisions and management 2.6. Involvement valued by others	2. Treatment decisions
3.1. Impact of caring role on family member 3.2. Impact of caring role on relationship 3.3. Impact of treatments on valued activities 3.4. Impact of treatments on everyday life 3.5. Emotional impact 3.6. Adjusting 3.7. Coping strategies <i>e.g. minimising, normalising, comparisons with others, avoidance, focus on positive, focus on present</i>	3. Impact of CKD on family member
4.1. Support and reassurance from HCP 4.2. Lack of support and reassurance from HCP 4.3. HCP transparency 4.4. Support from others with shared experiences 4.5. Other sources of support 4.6. Lack of support and understanding from others 4.7. Support needs 4.8. Importance of relationship with HCP	4. Support and reassurance
5.1. Establishing diagnosis 5.2. Making sense of illness symptoms 5.3. Making sense of treatments 5.4. Lack of prior knowledge 5.5. Lack of current knowledge 5.6. Negotiating seeking information 5.7. Sources of information 5.8. Illness timeline	5. Family member's understanding of CKD

**APPENDIX 9: Development of the concepts and themes from coding index**

Original codes	Final themes	Core concepts
1.1. Taking responsibility for caring 2.5. Involvement with treatment decisions and management	1.1. Attempts to gain control in an uncertain situation	1. Uncertainty
1.2. Beliefs about caring role 1.3. Uncertainty regarding caring role 3.7. Coping strategies e.g. <i>minimising, normalising, comparisons with others, avoidance, focus on positive, focus on present</i> 3.8. Beliefs about coping	1.2. Different ways of coping	
3.6. Adjusting	1.3. Learning to live with uncertainty	
3.1. Impact of caring role on family member 3.2. Impact of caring role on relationship 3.5. Emotional impact	1.4. Emotional toll	
2.1. Maintaining normality 2.3. Weighing up pros and cons 2.4. Importance of having a choice	2.1. Making treatment decisions that keep life as normal as possible	
3.3. Impact of treatments on valued activities 3.4. Impact of treatments on everyday life	2.2. Barriers to a 'normal life'	
3.6. Adjusting 3.7. A 'new normal'	2.3. A 'new normal'	
5.1. Establishing diagnosis 5.2. Making sense of illness symptoms 5.3. Making sense of treatments 5.4. Making sense of diagnosis 5.5. Relative's comorbidities 5.6. Lack of prior knowledge 5.10. Illness timeline	3.1. Making sense of CKD	3. Developing an understanding
5.9. Sources of information	3.2. Sources of information	
5.8. Negotiating seeking information 2.2. Negotiating treatment decisions	3.3. Family members developing an understanding of their role	
4.1. Support and reassurance from HCP 4.2. Lack of support and reassurance from HCP 4.3. HCP transparency 4.8. Importance of relationship with HCP 2.6. Involvement valued by others	4.1. How Healthcare Professionals (HCP) can effectively support family members	
4.4. Support from others with shared experiences 4.5. Other sources of support 4.6. Lack of support and understanding from others 4.7. Support needs and preferences	4.2. Facilitators and barriers to family members feeling supported	

## APPENDIX 10: Extract of assimilation analysis

I didn't think anything about it (the kidney disease). I just thought it was something you got LEVEL 0 WARDED OFF. You know I've had breast cancer; IS SHE VOICING AN AWARENESS THAT KIDNEY FAILURE ALSO SERIOUS ILLNESS I've just got over that. You just get on with your life; you don't dwell on it, LEVEL 1 AWARENESS OF SOME DIFFICULTY BUT AVOIDANCE you know my son's had cancer SOME AWARENESS??? at 34, so you just have to get on with it don't you. Just face whatever it is and just get on with it so whatever happens we'll just deal with it LEVEL 1 but I had no thoughts about it because I didn't know what it was; I didn't know what your kidneys did at that stage. LEVEL 0 – WARDED OFF

I'm not a pessimistic person; I'm a very positive person. If anything happens, that's it, we deal with it and we learn all about it. LEVEL 1 I mean I'm fascinated by it. I love that machine up there so I mean I know everything about it, learnt everything about it; I asked all the questions about it. I know when something's not right with it. You just have to, you just have to get on with it LEVEL 0 AND 1 – WARDED OFF /UNWANTED THOUGHTS, SEEKING INFO LEVEL 3 BUT SEEKING 'SAFE' INFO ABOUT MACHINE NOT ILLNESS ITSELF

I can't say my life has changed a great deal LEVEL 0 because we've always done things together [partner] and I. We just go through things together. A 'THING' TO GO THROUGH LEVEL 1 I mean when I had cancer SOME AWARENESS??? he was there for me. I don't have any worries or concerns. LEVEL 0

You know psychologically it wouldn't have been-one thing I will say, because I forgot to say, initially, psychologically, it's, it's, it hits you; you can be, think umm, you just think, oh well my life's over now. This is it. This is what we're left with; and you're just tied to that machine every night. So I think from time to time psychologically, it can impact on you LEVEL 3 DESCRIBING RESPONSE AND REACTION but you haven't to dwell on that. LEVEL 1 AWARENESS OF SOME DIFFICULTY BUT AVOIDANCE

## **APPENDIX 11: Extract of reflective journal**

Extract from reflective journal, dated December 14<sup>th</sup> 2019 (after interviews were done but prior to analysis)

*“When Aunty Mags was ill, I knew this [the cancer] would kill her. I remember mam asking me one day, ‘do you think she’ll be ok?’ I panicked and said, ‘I don’t she’s not going to die of old age mam’. Mam was upset by my answer and I remember wishing I had pretended that everything would be fine, but also feeling frustrated about this. I suppose in my job, I’m there to help people face things that they would rather avoid and, if I’m honest, I can sometimes think it’s ‘stronger’ to look at something face on and not hide from it. I know that this isn’t really the case and that there are also different levels of ‘knowing’ something. I’m sure mam knew, like I did, that the cancer would kill Aunty Mags but she was choosing not to know it at that time. In the interviews I’ve done, some of the participants were extremely avoidant of what was going to happen in the future... they’d put up a big wall of ‘everything is fine, nothing’s wrong’. I’m going to have to be aware of my own feelings around this during analysis... I know that I warmed more towards the participants who could really ‘feel’ their situation and talk about it openly...”*



## APPENDIX 12: Confirmation of HRA approval



Professor Hilary Bekker  
University of Leeds - Worsley building level 10  
Clarendon way  
LS2 9NL



Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)  
[HCRW.approvals@wales.nhs.uk](mailto:HCRW.approvals@wales.nhs.uk)

23 July 2019

Dear Professor Bekker

**HRA and Health and Care  
Research Wales (HCRW)  
Approval Letter**

<b>Study title:</b>	<b>People's involvement in family member's treatment choices about chronic kidney disease: a survey using qualitative methods.</b>
<b>IRAS project ID:</b>	<b>258378</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>REC reference:</b>	<b>19/YH/0170</b>
<b>Sponsor</b>	<b>University of Leeds</b>

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

### **How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

**What are my notification responsibilities during the study?**

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **258378**. Please quote this on all correspondence.

Yours sincerely,

Katherine Ashley  
Approvals Specialist

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: Jean Uniacke, Sponsor Contact

Miss Angharad Jones

**APPENDIX 13: Confirmation of NHS ethical approval (South Yorkshire Research Ethics Committee)**



**Health Research Authority**

**Yorkshire & The Humber - South Yorkshire Research Ethics Committee**  
NHSBT Newcastle Blood Donor Centre  
Holland Drive  
Newcastle upon Tyne  
NE2 4NQ

Telephone: 0207 1048091

**Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval**

08 July 2019

Professor Hilary Bekker  
University of Leeds  
Worsley Building Level 10  
Clarendon way  
LS2 9NL

Dear Professor Bekker

**Study title:** People's involvement in family member's treatment choices about chronic kidney disease: a survey using qualitative methods.  
**REC reference:** 19/YH/0170  
**Protocol number:** N/A[##IfProtocolRef##]  
**IRAS project ID:** 258378

Thank you for your letter of 1 July 2019, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The further information has been considered on behalf of the Committee by the Chair.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

#### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

#### Registration of Clinical Trials

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database. For this purpose, clinical trials are defined as the first four project categories in IRAS project filter question 2. For clinical trials of investigational medicinal products (CTIMPs), other than adult phase I trials, registration is a legal requirement.

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee ( see here for more information on requesting a deferral:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.



**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**After ethical review: Reporting requirements**

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

**Ethical review of research sites**

**NHS/HSC sites**

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Non-NHS/HSC sites**

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Study poster]	1	02 April 2019
Copies of advertisement materials for research participants [Social media advert]	1	18 April 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Leeds University indemnity certificate]	1	17 September 2018
Interview schedules or topic guides for participants [Interview topic guide]	1	25 April 2019
IRAS Application Form [IRAS_Form_01072019]		01 July 2019
IRAS Checklist XML [Checklist_01072019]		01 July 2019
Letter from funder [Letter for panel from Dclin course]	1	25 April 2019

Family members' involvement in their relative's kidney disease management and treatment choices

Letter from sponsor [Confirmation of sponsorship (email)]	1	25 April 2019
Letters of invitation to participant [Email invite to participant]	1	18 April 2019
Letters of invitation to participant [Patient invitation letter]	2	15 April 2019
Other [Fieldwork assessment form]	3	12 November 2015
Other [Research panel constitution for panel from Dclin team]	1	25 April 2019
Other [Panel requirements checklist]	1	29 June 2019
Participant consent form [Participant consent form]	3	29 June 2019
Participant information sheet (PIS) [Participant Information sheet]	3	29 June 2019
Research protocol or project proposal [Study protocol]	2	15 April 2019
Summary CV for Chief Investigator (CI) [CV for Chief Investigator (Prof Hilary Bekker)]	1	25 April 2019
Summary CV for student [Angharad Jones CV]	1	25 April 2019
Summary CV for supervisor (student research) [Summary CV for supervisor (AW)]	1	25 April 2019
Summary CV for supervisor (student research) [Summary CV for supervisor (JS)]	1	25 April 2019

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:  
<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

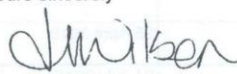
**HRA Learning**

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:  
<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

**19/YH/0170** **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

  
 pp  
**Dr Ian Woollands**  
**Chair**