DOCUMENT TYPE: Guideline		**UNIQUE IDENTIFIER:**	
DOCUMENT TITLE: Enhanced Supportive Kidney Care Guideline		**VERSION NUMBER:** 1.0	
		STATUS: Draft	
SCOPE: Renal Department		**CLASSIFICATION:** Departmental	
AUTHOR: Andrew Nixon	**JOB TITLE:** Consultant Nephrologist	**DIVISION:** Medicine	**DEPARTMENT:** Renal
REPLACES: Analgesia in Renal Disease in the Last Days of Life v2.2 Analgesia for patients with renal impairment V4		**HEAD OF DEPARTMENT:** Dr Beng So	
VALIDATED BY: Renal evidence-based guidelines group Medicine Governance Committee		**DATE:** 10 March 2025	
RATIFIED BY: Procedural Documents Ratification Group		**DATE:** Click here to enter a date.	
(NOTE: Review dates may alter if any significant changes are made).		**REVIEW DATE:** Click here to enter a date.	

AMENDMENT HISTORY				
Version No.	**Date of Issue**	**Page/Selection Changed**	**Description of Change**	**Review Date**

Does this document meet the requirements of the Equality Act 2010 in relation to Race, Religion and Belief, Age, Disability, Gender, Sexual Orientation, Gender Identity, Pregnancy & Maternity, Marriage and Civil Partnership, Carers, Human Rights and Social Economic Deprivation discrimination? Yes
Document for Public Display: No
Evidence reviewed by Library Services 13/03/2025

CONTENTS

1. SUMMARY

Enhanced Supportive Kidney Care aims to improve the health-related quality of life for patients with established CKD. People living with chronic kidney disease (CKD) highlight that symptom assessment and management is a top priority for their care. Regardless of kidney management, patients report a high symptom burden that impacts upon health-related quality of life and life participation. Patients living with CKD are more likely to be living with frailty and associated geriatric impairments, which are associated with greater risk of adverse outcomes, including high symptom burden and worse quality of life.

This document provides guidance for health care professionals on how to assess and manage supportive care needs of adult patients with advanced chronic kidney disease, including in their last days of life. There may situations in which an alternative treatment strategy to the ones outlined in this guidance is preferred as part of person-centred care.

2. PURPOSE

The purpose of this document is to support healthcare professionals in the assessment and management of the supportive care needs of adult patients with advanced chronic kidney disease.

3. SCOPE

This document is intended for trust wide use in non-pregnant adult patients with advanced chronic kidney disease, specifically with an estimated glomerular filtration rate (eGFR) less than 30ml/min/1.73m^2, including adult patients receiving dialysis.

4. GUIDELINE

Enhanced supportive kidney care (ESKC) “involves services that are aimed at improving the health-related quality of life for patients with established CKD, at any age, and can be provided together with therapies intended to prolong life, such as dialysis. Supportive care helps patients cope with living, as well as dying, regardless of life expectancy” (1).

The Renal Services Transformation Programme identified four categories of patients to prioritise for ESKC: conservative kidney management (CKM), deteriorating despite dialysis, discontinuing dialysis, and failing transplant. This is not to say that other patient groups should not be offered ESKC as patients with advanced CKD, whether receiving dialysis or not, often experience significant symptom burden and/or may be living with frailty.

Section 1: Symptom Assessment

Patient-centred care focuses on treatments that matter most to patients, considering their goals, values, and preferences. Regular proactive symptom assessment helps ensure a patient-centred approach. Symptoms otherwise go under reported by patients and are under-recognised by healthcare professionals.

The Department of Renal Medicine has developed 'The Enhanced Supportive Kidney Care Toolkit' (Appendix 1), which should be embedded within all areas of the Renal Medicine service, including (but not limited to) advanced kidney care, haemodialysis, home dialysis therapies, transplantation and conservative kidney management (CKM). A patient version of the IPOS-Renal questionnaire, a symptom assessment tool validated for use within CKD populations, is included within the Patient Symptom Questionnaire Booklet (Appendix 2) that accompanies the toolkit. The Patient Symptom Questionnaire also includes the PHQ-4, which is a screening tool for anxiety and depression. The Enhanced Supportive Kidney Care Toolkit explains how to interpret the PHQ-4. The Enhanced Supportive Kidney Care Mental Health Signposting Toolkit provides signposting information that staff can offer to patients experiencing symptoms of anxiety and/or depression (Appendix 3).

Patients with CKD G5 (eGFR <15ml/min/1.73m^2) and CKD G5D (i.e., receiving dialysis) should be offered the opportunity to complete the IPOS-Renal questionnaire prior to and/or during clinical consultations with a healthcare professional and/or at least every 3 months of dialysis attendance. Patients with CKD G4 may also benefit from completing the IPOS-Renal questionnaire.

Symptoms should be discussed within clinical encounters and a stepwise management approach offered with non-pharmacological considered before pharmacological interventions. Suggested considerations and management for commonly experienced symptoms are detailed within Section 4 of this guideline.

Consider Renal Supportive Care MDT Meeting referral for patients with persistent, burdensome and/or complex symptoms:
RenalSupportiveCare@lthtr.nhs.uk

Consider referral to palliative care services in the following situations:

1. Symptoms not responding to initial steps in management
2. Symptoms anticipated to be challenging to manage
3. Psychological, spiritual and/or social needs

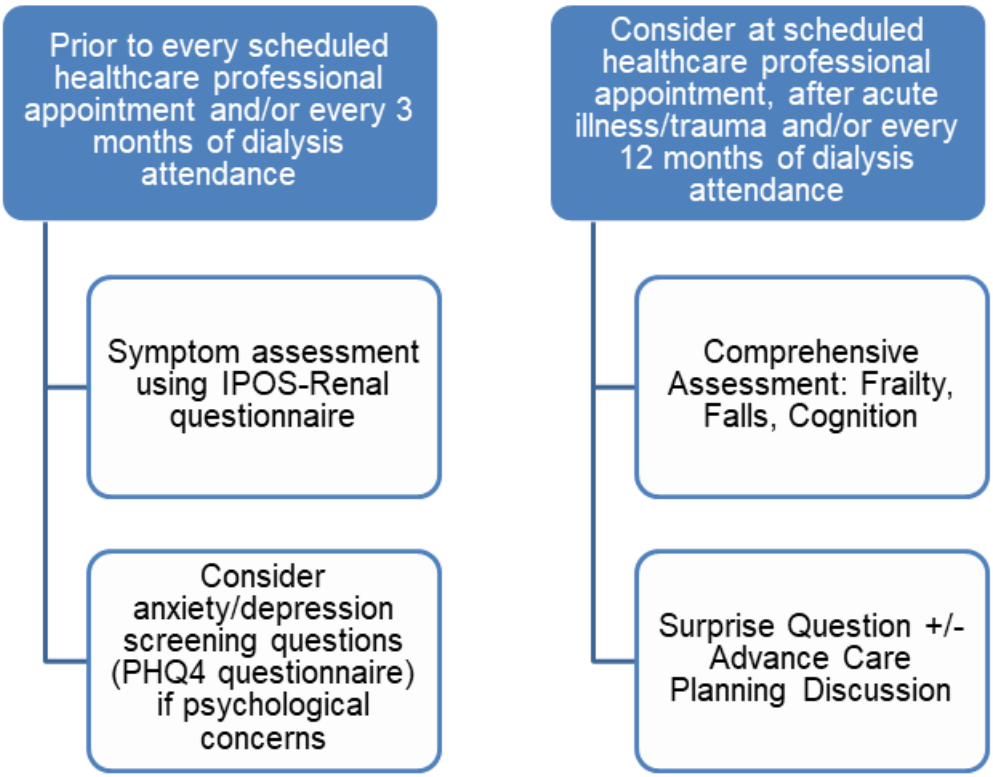

Figure 1. Enhanced Supportive Kidney Care (ESKC) Toolkit Recommendations.

Section 2: Comprehensive (Geriatric) Assessment

There is a high prevalence of frailty and associated geriatric impairments in CKD populations. Numerous studies have demonstrated that frailty is associated with adverse outcomes in nephrology populations, including CKD, dialysis and transplantation. Frailty is associated with worse symptom burden, anxiety, depression, worse quality of life, falls, starting dialysis, cognitive impairment, prolonged post-dialysis recovery, hospitalisation, and death.

The gold standard of care for older adults is Comprehensive Geriatric Assessment (CGA). CGA is "A multidimensional, multidisciplinary process which identifies medical, social, and functional needs and the development of a coordinated care plan to meet those needs" (2).

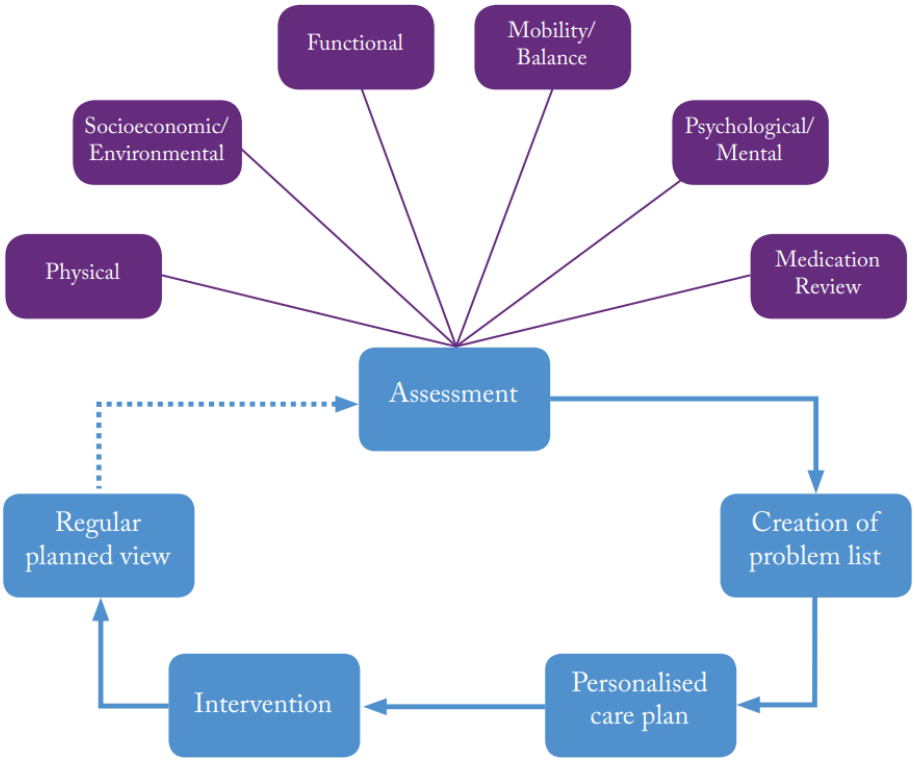

Figure 2. Comprehensive Geriatric Assessment (3).
https://www.bgs.org.uk/cgatoolkit

Principles of CGA are incorporated within the Enhanced Supportive Kidney Care Toolkit and are included in the following pages.

Frailty

Frailty is a state of increased vulnerability in which individuals may require additional care and support when exposed to a stressor event, such as a fall or infection. People living with frailty may not recover to their previous baseline following a stressor event. Age is a risk factor for frailty, although younger people can live with frailty too, especially if they have chronic health conditions, such as CKD. Importantly, frailty is associated with adverse health outcomes including worse quality of life and an increased risk of falls, hospital admission and death. Recognising those that are living with frailty provides an opportunity to introduce management strategies that aim to improve outcomes for this vulnerable group of patients and, if appropriate, consider advance care planning.

The Clinical Frailty Scale (CFS) is a frailty screening tool that provides descriptions of levels of frailty. It summarised your assessment of a patient's frailty status. Please remember it is assessment of their frailty status TWO weeks ago, i.e., their baseline, and not how the patient appears before you today. The CFS is not intended to be used in people with stable long-term disability as outcomes may be different to older people with progressive disability secondary to frailty.

Please note that patients living with frailty often have a different interpretation of the word 'frail' and may consider it to have negative connotations. Please keep this in mind during discussions with patients. Patients may relate more to "not being as fit as they used to be" and the concept of finding "it harder to bounce back" from illnesses, i.e., recover back to their previous baseline.

Please consider reviewing the Clinical Frailty Scale training module at the following link: https://www.scfn.org.uk/clinical-frailty-scale-training

Although younger people can also live with frailty, the CFS has not been well studied in people aged ≤65 years old. Please assess physical performance using the WHO performance status scale (alongside the CFS if you consider it appropriate) for people aged ≤65 years old.

Consider performing a frailty assessment, using the Clinical Frailty Scale, at scheduled appointments, after acute illness/trauma and/or every 12 months of dialysis attendance in patients aged ≥65 years old

Figure 3. Clinical Frailty Scale.

WHO Performance Status

Category	Description
0	Able to carry out all normal activity without restriction
1	Restricted in strenuous activity but ambulatory and able to carry out light work
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
3	Symptomatic and in a chair or in bed for greater than 50% of the day but not bedridden
4	Completely disabled; cannot carry out any self-care; totally confined to bed or chair

CFS Score 1-5: Fit/Mild Frailty

Continue care as usual but also consider reversible causes of frailty, e.g., malnutrition, low physical inactivity, and recurrent hospitalisations.

Interventions to consider include dietitian assessment, exercise prescription (e.g., Kidney Beam), community physiotherapy referral, falls prevention (and if appropriate falls team referral), and social prescribing (e.g. Age UK) to support self-management.

CFS Score 6: Moderate Frailty

Comprehensive Geriatric Assessment (CGA) is the gold standard approach to the care of older people. CGA involves a multidomain assessment performed by a multidisciplinary team to identify medical, social, and functional needs. Importantly, it leads to the development of a coordinated care plan to meet those needs.

Elements of CGA can be performed by you. Try to identity geriatric impairments associated with frailty, such as falls, impaired mobility, impaired function (basic activities of daily living & instrumental activities of daily living), cognitive impairment, depression/anxiety, malnutrition, incontinence, pressure areas, constipation, polypharmacy, and social isolation. Where relevant, consider the possibility of caregiver burden.

Consider referral to local hospital/community frailty services.

CFS Score 7-9: Severe Frailty

Consider aspects detailed for patients with moderate frailty. Also, consider the balance between supportive care and curative care. Enhanced supportive care is an active intervention, which aims to improve quality of life, and sometimes quantity of life.

Offer patients the opportunity to be involved in advance care planning discussions. Ask yourself the surprise question: *"Would I be surprised if this patient died in the next 12 months?"*. If the answer is "no", consider the appropriateness of advance care planning discussions (see Section 3).

Consider contacting the local Urgent/Rapid Community Response Service or Virtual Frailty Team if you are concerned that a patient may require hospital admission without additional assessment and support in the community.

Consider Renal Supportive Care MDT Meeting referral to discuss care needs and to develop a coordinated management plan for patients with moderate/severe frailty: RenalSupportiveCare@lthtr.nhs.uk

Falls

People with advanced CKD have an increased risk of falls and fall-related injuries, related to fluid shifts with dialysis, frailty, sarcopenia, and CKD-mineral bone disease. Efforts to minimise falls risk is of paramount importance for all people living with CKD. The most important predictor of future falls is a history of falling. The ESKC Toolkit suggests considering the following two questions regarding falls:

1. Has the patient fallen in the last 12 months?	Yes	No
	If yes, how many times have they fallen?	
2. Is the patient concerned about falling?	Yes	No
Please complete the Falls Risk Assessment Tool if the answer is yes to either question		

Suggested considerations for patients who have fallen or who are concerned about falling:

- Frailty, mobility & functional status
- Mobility aids, e.g., stick or frame
- Medication & polypharmacy
- Cognition
- Anxiety or depression
- Vision
- Foot problems
- Nutrition
- Continence
- Home environment
- Fall Telecare Alarm Service

Please offer patients the following Age UK leaflet:
https://www.ageuk.org.uk/siteassets/documents/information-guides/ageukig14_staying_steady_inf.pdf

Consider asking about falls and fall concern at scheduled appointments, after acute illness/trauma and/or every 12 months of dialysis attendance

Consider appropriateness of referral to the local hospital/community fall prevention or frailty team is appropriate.

Cognition

Cognitive changes can occur early in CKD, progress as kidney function declines and exist across the continuum of mild cognitive impairment to dementia. Importantly, cognitive impairment affects decision-making capacity, therefore it is important to consider cognitive screening in people with advanced CKD, especially before the shared decision-making process. Before completing a cognitive screening test, please consider the following two questions:

1. Does the patient have a known diagnosis of dementia?	Yes	No
	If yes, there is no need to perform further cognitive screening	
2. Has the patient been forgetful in the last 12 months to the extent that it has affected their life or caused them concern?	Yes	No
	If yes, progress to 6CIT cognitive screening test	

Consider performing the 6CIT cognitive screening tool if the patient has been forgetful in the last 12 months to the extent that it has affected their life or caused them concern

Consider performing a clock drawing test if you remain concerned about a patient's cognition but they have scored less than 8 on the 6CIT.

2. What month is it?	Correct: 0 points			Incorrect: 3 points		
3. Give the patient an address phrase to remember with 5 components: e.g., John, Smith, 42, High St, Bedford						
4. About what time is it (within one hour)?	Correct: 0 points			Incorrect: 3 points		
5. Count backwards from 20-1	Correct: 0 points		1 error: 2 points		>1 error: 4 points	
6. Say the months of the year in reverse	Correct: 0 points		1 error: 2 points		>1 error: 4 points	
7. Repeat address phrase	Correct: 0 points	1 error: 2 points	2 errors: 4 points	3 errors: 6 points	4 errors: 8 points	All wrong: 10 points
6CIT Score						

Consider requesting the patient's primary care team make a referral to the local memory assessment service if the patient scores 8 or above.

Section 3: Advance Care Planning

Advance care planning helps to ensure that wishes are respected throughout later life and avoid unnecessary and potentially harmful interventions.

To help identify those who may benefit from advance care planning, consider a patient's health status (including comorbidities and frailty) then ask yourself the 'Surprise Question':
"Would I be surprised if the patient died in the next 12 months?"

Indicators of poor or deteriorating health include (adapted from SPICT):

- Unplanned hospital admission(s)
- Performance or frailty status is poor or deteriorating
- Depends on others for care due to increasing physical and/or mental health problems. The person's caregiver needs more help and support
- Progressive weight loss; remains underweight; low muscle mass
- Persistent symptoms despite optimal treatment of underlying condition(s)
- Poor tolerance of dialysis with change of modality
- The person (or family) asks for palliative care, chooses to reduce, stop, or not have treatment, or wishes to focus on quality of life

Please familiarise yourself with The Gold Standards Framework Proactive Identification Guidance and consider reading the 'The Difficult Conversations Booklet' that includes advice and guidance on how to approach advance care planning discussions with people with CKD. Offer patients the 'Planning for your future care' document and signpost the My Wishes website: https://www.mywishes.co.uk/

Refer to the Renal Social Worker if you would not be surprised if the patient died in the next 12 months as they may be eligible for additional financial support.

The Enhanced Supportive Kidney Care Toolkit (Appendix 1) outlines how to document advance care planning decisions. The trust is piloting a Medical Anticipatory Clinical Management Plan (Appendix 4), which is a proactive clinical plan, made in advance to guide the management of a future clinical situation, predicted or thought likely to occur.

Share advance care planning information with the patient's primary care team and request that they update the patient's EPaCCs record. This will ensure that the patient's advance care plan is visible to healthcare professionals who may be called in a crisis. Please also see the Renal Services DNACPR Guidance for Outpatients.

Consider referral to palliative care services for support with advance care planning, especially for patients estimated to be in their last 12 months of life.

Section 4: Symptom Management

Nocturnal Leg Cramps Initial Assessment & Preventative Therapies
Diagnosis
All criteria must be met: 1. A painful sensation in the leg or foot associated with sudden, involuntary muscle hardness or tightness, indicating a strong muscle contraction. 2. The painful muscle contractions occur during the time in bed, although they may arise from either wakefulness or sleep. 3. The pain is relieved by forceful stretching of the affected muscles, thus releasing the contraction.
Consider risk factors
1. Repetitive lower extremity stress, e.g. prolonged sitting, walking/running concrete floors. 2. Medications, e.g. long-acting beta agonists, thiazide and potassium sparing diuretics. 3. Secondary causes, examples: sleep disorder (e.g. restless legs syndrome, obstructive sleep apnoea), peripheral vascular disease, fluid imbalance (i.e. extracellular volume depletion), pregnancy-related leg cramps, metabolic disorders (e.g. diabetes, hypothyroidism, electrolyte abnormalities), neurological disorders, exercise-associated muscle cramping, radiculopathy, anaemia, opioid withdrawal, alcohol, and cirrhosis.
Initial preventative therapies
1. Posterior leg muscle stretching exercises: - Performed while standing with hands against the wall. - Patient leans forward with the legs kept straight and the feet kept flat on the floor. Position is held for 10 to 20 seconds. - For the first week, the patient should complete four sets of three to five stretches. Afterwards, the patient should complete three sets daily (twice in the evening and once at bedtime). 2. Other interventions to consider: - Increase exercise. - Keeping the bed covers at the foot of the bed loose and not tucked in (to prevent plantar flexion of the gastrocnemius, which may stimulate nocturnal muscle cramps). - Avoidance of drugs, alcohol, caffeine, exercise in extreme heat or on concrete floors.

Nocturnal Leg Cramps
Pharmacological Management

First Line

Supplements:

1. Limited evidence exists for Vitamin B complex (containing at least 30mg pyridoxine [vitamin B6]) one tablet three times daily and vitamin E 400 units to 800 units once daily. These are non-formulary medications that cannot be prescribed by primary care.

2. The following combination found in Vitamin B complex can be prescribed by primary care:
   - Pyridoxine 100mg once daily
   - Thiamine 50mg three times daily
   - Cyanocobalamin 1mg once daily

3. A four-week trial should be adequate to determine response.

Second Line

Gabapentinoids:

1. Gabapentin 100mg once daily (evening). Consider starting three times weekly for patients established on dialysis or with eGFR <15 ml/min/1.73m^2 and/or older patients as there is an increased risk of side effects. Titrate the dose slowly according to response. A four-week trial should be adequate to determine dose response.

2. Pregabalin can be used instead of gabapentin. The initial dose should be no more than 25mg once daily (evening). Consider three times weekly dosing for patients established on dialysis or with eGFR <15 ml/min/1.73m^2 and/or older patients as there is an increased risk of side effects. Titrate the dose slowly according to response. A four-week trial should be adequate to determine dose response.

Third Line

Quinine:

1. Quinine can be considered for patients with severe nocturnal leg cramps resistant to the above therapies. Quinine sulfate can be started at 200mg once daily (evening) and does not require dose adjustment for impaired kidney function. Quinine is not a routine treatment for nocturnal leg cramps and should only be used when cramps regularly disrupt sleep.

2. Quinine is associated with an increased risk of serious and/or life-threatening side effects (e.g. cardiac arrhythmias, thrombotic microangiopathy and severe hypersensitivity reactions), which can occur in 2 to 4% of patients. Other side effects include hypoglycaemia, confusion, nausea/vomiting, diarrhoea, bronchospasm, rashes and muscle weakness (including aggravation of myasthenia gravis).

3. After symptoms improve, reduce frequency of quinine administration to the minimum amount needed to control symptoms.

4. Stop quinine if there is no improvement after a four-week trial.

Restless Legs Syndrome (RLS)
Initial Assessment & Preventative Therapies

Diagnosis

All criteria must be met:

1. An urge to move the legs usually but not always accompanied by, or felt to be caused by, uncomfortable and unpleasant sensations in the legs

2. The urge to move the legs and any accompanying unpleasant sensations begin or worsen during periods of rest or inactivity, such as lying down or sitting.

3. The urge to move the legs and any accompanying unpleasant sensations are partially or totally relieved by movement, such as walking or stretching, at least as long as the activity continues.

4. The urge to move the legs and any accompanying unpleasant sensations during rest or inactivity only occur or are worse in the evening or night than during the day

5. The occurrence of the above features is not solely accounted for as symptoms primary to another medical or a behavioural condition (e.g., myalgia, venous stasis, leg oedema, arthritis, leg cramps, positional discomfort, habitual foot tapping)

Consider risk factors

1. Family history

2. Low iron stores

3. Uraemia

4. Neurological: neuropathy, spinal cord disease, multiple sclerosis, Parkinson disease

5. Pregnancy

6. Exacerbating medications: antihistamines (e.g. hydroxyzine), dopamine receptor blocking agents (e.g. metoclopramide, haloperidol), certain antidepressants (especially mirtazapine, possibly tricyclic antidepressants, serotonin reuptake inhibitors)

Initial therapies

1. Iron replacement if iron deficiency.

2. Trial of abstinence from alcohol.

3. Moderate regular exercise.

4. Avoidance of sleep deprivation.

5. Consider withdrawal of exacerbating medications.

6. Short daily haemodialysis for patients with end-stage kidney disease.

Restless Legs Syndrome (RLS) Pharmacological Management
First Line
Dopamine Agonists 1. Recommend trialling pramipexole 88 micrograms once daily (evening) and titrating slowly. 2. Patients receiving long-term dopaminergic therapy are at risk of augmentation (paradoxical worsening of RLS symptoms with increasing doses of medication).
Second Line
Gabapentinoids 1. Consider a gabapentinoid first line if there are concurrent symptoms that may also respond to a gabapentinoid, i.e. nocturnal leg cramps, CKD-associated pruritis or neuropathic pain. 2. Gabapentin 100mg once daily (evening). Consider starting three times weekly for patients established on dialysis or with eGFR <15 ml/min/1.73m^2 and/or older patients as there is an increased risk of side effects. Titrate the dose slowly according to response. 3. Pregabalin can be used instead of gabapentin. The initial dose should be no more than 25mg once daily (evening). Consider three times weekly dosing for patients established on dialysis or with eGFR <15 ml/min/1.73m^2 and/or older patients as there is an increased risk of side effects. Titrate the dose slowly according to response.
Third Line
Trial the medication class not used as first line, i.e. dopamine agonist if used gabapentinoid or gabapentinoid if used dopamine agonist.
Fourth Line
Consider combination therapy with a gabapentinoid, dopamine agonist and/or benzodiazepine (e.g. clonazepam 0.5mg to 1mg once daily [evening]).
Fifth Line
Opioid: 1. Consider trialling an opioid if no concerns regarding opioid use disorder. 2. Recommend oxycodone 2.5mg once daily (evening). 3. Consider oxycodone MR 5mg once daily (evening) if oxycodone does not provide adequate length of coverage. Oxycodone MR should not be initiated in opioid naïve patients.

CKD-associated Pruritus (CKD-aP)
Initial Assessment & Management

Diagnosis

1. Patients with CKD G5 or G5D
   CKD-aP is common in patients with CKD G5 (whether receiving dialysis or not) and therefore pruritus presenting in CKD G5 can be assumed to be CKD-aP unless there is evidence of another cause (e.g. primary skin lesions including inflamed papules, patches or plaques).

2. Patients without CKD G5
   CKD-aP is less common in earlier stages of CKD and therefore CKD-aP should only be diagnosed after evaluation and exclusion of causes of pruritus in the general population, e.g. xerosis (dry skin), eczematous dermatitis, urticaria, lymphoma, cholestasis etc.

Consider risk factors

1. Inadequate dialysis.

2. Hyperparathyroidism *(association not observed in all studies).*

3. Elevated serum calcium and/or phosphate concentrations *(association not observed in all studies).*

4. Xerosis.

5. Elevated serum magnesium and aluminium concentrations.

Initial management

1. Optimise dialysis prescription for patients receiving dialysis.

2. Optimise treatment of CKD-mineral and bone disorder.

3. Topical therapies to consider in suggested order:
   1. Emollient: Epimax Original
   2. Emollient containing lauromacrogols (keratin softener and hydrating agent): Balneum Plus cream
   3. Levomenthol cream *(exerts cooling effect)*

CKD-associated Pruritus (CKD-aP)
Pharmacological Management

Topical Therapies

Continue emollients throughout as xerosis will contribute to CKD-aP.

First Line

Antihistamines:

1. The evidence base is stronger for gabapentinoids than antihistamines in CKD-aP. However, an oral antihistamine can be trialled. Generally, CKD-aP is worse overnight and therefore a sedating antihistamine may be effective, e.g. hydroxyzine 10mg to 25mg once daily (evening).

1. Some patients find hydroxyzine overly sedating and therefore may prefer a less sedating antihistamine, e.g. cetirizine 10mg once daily.

2. Stop antihistamines after one week if inadequate response.

Gabapentinoids:

1. Gabapentin 100mg once daily (evening). Consider starting three times weekly for patients established on dialysis or with eGFR <15 ml/min/1.73m^2 and/or older patients as there is an increased risk of side effects. Titrate the dose slowly according to response.

2. Pregabalin can be used instead of gabapentin. The initial dose should be no more than 25mg once daily (evening). Consider three times weekly dosing for patients established on dialysis or with eGFR <15 ml/min/1.73m^2 and/or older patients as there is an increased risk of side effects. Titrate the dose slowly according to response.

3. Stop gabapentinoids after four to six weeks if inadequate response.

Second Line

Difelikefalin:

1. Consider difelikefalin for patients receiving haemodialysis refractory to best supportive care (including a gabapentinoid unless contraindicated). Difelikefalin is a peripherally restricted selective kappa-opioid agonist that is administered intravenously (0.5micrograms/kg) three to four times a week (max per dose 100 micrograms). It should be administered via haemodialysis access after the dialysis session. *A Blueteq request form is required prior to difelikefalin initiation and difelikefalin should be discontinued after 12 weeks if there has been an inadequate response.*

Sertraline:

1. For patients not receiving haemodialysis, a trial of sertraline 25mg (half of 50mg tablet) to 50mg once daily can be considered. Sertraline should be stopped if an inadequate response is observed after four to six weeks**.**

Third Line

Phototherapy:

1. Consider phototherapy (UVB) if persistent symptoms that have not responded to the above options (or these treatments have not been tolerated). UVB therapy is associated with an increased risk of carcinogenesis and should not be used in patients who are receiving immunosuppressive therapy**.**

Pain
Initial Assessment & Management

Causes

1. Nociceptive pain

Usually due to tissue injury. Examples of nociceptive pain common to patients with advanced CKD include osteoarthritis, renal osteodystrophy, dialysis-related amyloid arthropathy, and kidney or liver capsule distension from autosomal dominant polycystic kidney disease.

2. Neuropathic pain

Due to abnormal neural activity secondary to disease, injury, or dysfunction of the nervous system. Examples of neuropathic pain common to patients with advanced CKD, include diabetic neuropathy, phantom limb pain, and carpel tunnel syndrome.

3. Mixed nociceptive/neuropathic pain

Ischemic pain is usually mixed nociceptive and neuropathic. Examples common to patients with advanced CKD, include pain from peripheral vascular disease, calciphylaxis, and vascular steal syndrome.

Important Management Considerations

1. There is no “safe” dose of NSAIDs for patients with CKD and they therefore should be avoided. However, there may be specific situations in which NSAIDs are considered the best pain management option. All patients with CKD who receive long-term NSAIDs should have close monitoring of their eGFR (i.e. every 3 months) with discontinuation of NSAIDs if eGFR declines faster than expected.

2. People with CKD have an increased risk of toxicity with opioid medication. **Opioid toxicity signs include myoclonus (jerking), agitation, drowsiness and respiratory depression.** Pinpoint pupils are a classic sign of opioid toxicity; however, opioid toxicity can also occur without pinpoint pupils.

3. Weak opioids (e.g. codeine, dihydrocodeine, tramadol) should be avoided as they have a variable response in advanced CKD, including unpredictable risk of fatal overdosing with small doses and/or poor analgesic effect with administration of standard doses. They also have a similar rate of dose-dependent adverse effects as low-dose strong opioids.

4. The strong opioids morphine and pethidine should be avoided due to the significant risk of side effects in patients with advanced CKD.

5. Patients whose kidney function declines require increased monitoring for opioid toxicity even if the dose of their opioid regimen has not changed.

6. Concern about reduced kidney function should not stop or delay the use of opioid analgesia for adequate pain control. Use available opiates in urgent scenarios whilst sourcing more appropriate forms for subsequent doses.

7. Consider referral to specialist pain management or palliative care teams for symptoms not responding to management.

Nociceptive Pain
Pharmacological Management

First Line

Paracetamol 500mg to 1g four times daily (max 2g/daily if bodyweight <50kg; max 3g/daily if bodyweight ≥50kg and risk factors for hepatotoxicity)

Second Line

Continue paracetamol and introduce a strong opioid at low doses:

1. Oxycodone 1mg to 2mg four times daily and titrating slowly according to response.

2. Consider conversion to Buprenorphine patch if oxycodone is well tolerated AND the patient has chronic pain requiring a total daily oxycodone dose of ≥8mg:

Morphine 24hr Total	Oxycodone 24hr Total	Buprenorphine *Weekly* Patch
12 mg	8 mg	5 mcg/hr patch *weekly*
24 mg	16 mg	10 mcg/hr patch *weekly*
48 mg	32mg	20 mcg/hr patch *weekly*
72 mg	48 mg	30 mcg/hr patch *weekly* (20mcg/hr patch + 10cmg/hr patch)
Note: Buprenorphine patches of strength ≥35mcg/hr are changed every 4 days		

When equal doses are not possible, consider using different strength patches to achieve equivalent dose. For example, using 20 mcg/hr patch AND 10mcg/hr patch to achieve total of 30mcg/hr. When equal doses are not possible, prescribe patch(es) that achieves closest equivalent dose, using clinical judgement.

3. Oxycodone can be used for breakthrough pain for patients prescribed a Buprenorphine patch. The dose of breakthrough oxycodone prescribed should be one sixth the total daily dose of opioid analgesia. The BNF and the North West Coast Clinical Network Palliative Care Clinical Practice Summary equivalent doses of opioid analgesics.

Additional Points:

1. A fentanyl patch can be used instead of a Buprenorphine patch. However, please note that the lowest strength Fentanyl patch (12micrograms/hour) is equivalent to an oxycodone daily dose of 20mg, therefore a Fentanyl patch should only be considered if patients are receiving an oxycodone daily dose of 20mg or more.

2. A buprenorphine patch is preferred to modified release oxycodone for the management of chronic pain as buprenorphine is completely metabolised by the liver. Its two major metabolites, buprenorphine-3-glucuronide (B3G) and norbuprenorphine, are primarily excreted via the faecal route, and only 10 to 30 percent of these are excreted in the urine. B3G is inactive, with no analgesic properties, whereas norbuprenorphine has an analgesic effect without the ability to cross the blood-brain barrier and produce toxic neurological side effects.

Neuropathic Pain Pharmacological Management
First Line
Gabapentinoids: 1. Gabapentin 100mg once daily (evening). Consider starting three times weekly for patients established on dialysis or with eGFR <15 ml/min/1.73m^2 and/or older patients as there is an increased risk of side effects. Titrate the dose slowly according to response. 2. Pregabalin can be used instead of gabapentin. The initial dose should be no more than 25mg once daily (evening). Consider three times weekly dosing for patients established on dialysis or with eGFR <15 ml/min/1.73m^2 and/or older patients as there is an increased risk of side effects. Titrate the dose slowly according to response.
Second Line
Tricyclic Antidepressants: 1. Consider tricyclic antidepressants for neuropathic pain unrelieved by the maximum safe dose of gabapentin or pregabalin. 2. Recommend starting amitriptyline 10mg once daily (evening). 3. It can take up to six weeks, including two weeks at the highest dose tolerated, for an adequate trial of treatment with tricyclic antidepressants.
Third Line
Carbamazepine: 1. Carbamazepine is a tricyclic compound chemically related to tricyclic antidepressants and requires no dose reduction in patients with advanced CKD. 2. Recommend starting carbamazepine 100mg once to twice daily. 3. Slowly increase the dose by 100mg per day to a maximum of 1200mg per day in divided doses.

Mixed Nociceptive and Neuropathic Pain Pharmacological Management
First Line
Introduce Paracetamol 500mg to 1g four times daily (max 2g/daily if bodyweight <50kg; max 3g/daily if bodyweight ≥50kg and risk factors for hepatotoxicity) and a gabapentinoid as detailed in the Neuropathic Pain Pharmacological Management Table.
Second Line
Add in a low dose of a strong opioid. This can be introduced in the same way detailed in the Nociceptive Pain Pharmacological Management Table. Methadone has been recommended as the preferred opioid for mixed nociceptive/neuropathic pain. Methadone may be effective for severe neuropathic pain because of its activity against the NMDA receptor antagonism. Methadone should only be introduced by health care professionals experienced in its initiation and management, e.g. pain management service, palliative care.

Nausea and Vomiting
Non-Pharmacological and Pharmacological Management

Considerations

1. Symptoms of anorexia, nausea, and vomiting may signify advancement of kidney disease or overall decline.

2. Contributing factors can include metabolic acidosis, medications (e.g. opioids and antidepressants), and gastrointestinal disturbances (e.g. constipation or delayed gastric emptying).

Non-Pharmacological Management

1. Nonpharmacologic management of nausea and vomiting is important due to the adverse effects of many of the commonly used antiemetics.

2. Recommend eating smaller, more frequent meals, and eating slowly.

3. Recommend avoiding alcohol.

4. Recommend avoiding foods that are greasy, spicy, or excessively sweet.

5. Minimise aromas, such as cooking odours, perfumes, and smoke.

6. Encourage loose fitting clothing and a relaxed, upright position after meals.

Pharmacological Management

Consider the following medications for persistent nausea and vomiting:

1. Ondansetron 4mg every eight hours
   - Selective 5-HT3-receptor antagonist
   - Evidence for managing nausea and vomiting in CKD
   - Side effects include constipation
   - Risk of QT interval prolongation

2. Haloperidol 0.25mg - 0.5mg every eight hours
   - Dopamine antagonist with antiemetic properties
   - Should not be prescribed with Metoclopramide
   - Avoid in decompensated heart failure, recent acute myocardial infarction, Parkinson disease and dementia with Lewy bodies
   - Side effects include extrapyramidal reactions
   - Risk of QT interval prolongation

3. Metoclopramide 5mg - 10mg every eight hours
   - Dopamine antagonist that has both antiemetic and prokinetic properties
   - Should not be prescribed with Haloperidol
   - Avoid in Parkinson disease and dementia with Lewy bodies
   - Side effects include extrapyramidal reactions
   - Risk of QT interval prolongation

Section 5: Last Days of Life Anticipatory Medication Prescribing

Last Days of Life Anticipatory Medication Prescribing
Nausea and Vomiting
1. Subcutaneous haloperidol 0.5mg to 1.5 mg eight hourly when required (max 5mg in 24 hrs). 2. If eGFR less than 10ml/min/1.73m^2 or receiving dialysis: - Subcutaneous haloperidol 0.25mg to 0.5mg eight hourly when required (max 5mg 24 hrs) Seek specialist palliative care advice for patients requiring doses above 5mg in 24 hrs. Consider a continuous subcutaneous infusion if three or more doses are required over 24 hrs.
Pain and Breathlessness *(opioid naïve)*
1. Oral oxycodone 1mg to 2mg two hourly when required. 2. Subcutaneous oxycodone 1mg two hourly when required, OR: - Subcutaneous Fentanyl 12.5 microgram to 25 micrograms two hourly when required. Consider lower doses and longer duration between doses for breathlessness, e.g. four hourly. Consider a continuous subcutaneous infusion if three or more doses are required over 24 hrs. **Considerations for patients already prescribed opioids:** 1. Consider seeking specialist palliative care advice for patients who are already prescribed opioids. 2. If pain is controlled on current opioid regimen and there is no evidence of toxicity, there is no urgent need to alter – simply monitor for signs of opioid toxicity, such as myoclonus, confusion, drowsiness and respiratory depression. 3. The BNF and the North West Coast Clinical Network Palliative Care Clinical Practice Summary equivalent doses of opioid analgesics.
Respiratory Tract Secretions
1. Subcutaneous glycopyrronium 100 micrograms to 200 micrograms one hourly when required (max 1200 micrograms in 24 hrs). Seek specialist palliative care advice for patients requiring doses above 1200 micrograms in 24 hrs. Consider a continuous subcutaneous infusion if three or more doses are required over 24 hrs.
Agitation
1. Subcutaneous midazolam 1mg to 2.5mg one hourly when required (max 30mg in 24 hrs). Seek specialist palliative care advice for patients requiring doses above 30mg in 24 hrs. Consider a continuous subcutaneous infusion if three or more doses are required over 24 hrs.
Specialist Palliative Care Advice
Specialist palliative care teams are available to provide any advice needed: 1. The LTHTR palliative care team can be contacted in working hours on extension 2055. 2. St Catherine's Hospice advice line can be called for advice out of hours: 01772 629171.

5. AUDIT AND MONITORING

This guideline is not subject to audit as it is continually monitored.

6. TRAINING

TRAINING Is training required to be given due to the introduction of this policy? No		
Action by	**Action required**	**Implementation Date**

7. DOCUMENT INFORMATION

ATTACHMENTS	
Appendix Number	Title
Appendix 1	Enhanced Supportive Kidney Care Toolkit
Appendix 2	Enhanced Supportive Kidney Care Toolkit Patient Symptom Questionnaire
Appendix 3	Enhanced Supportive Kidney Care Mental Health Signposting Toolkit
Appendix 4	Medical Anticipatory Clinical Management Plan
Appendix 5	Equality, Diversity & Inclusion Impact Assessment Tool

OTHER RELEVANT / ASSOCIATED DOCUMENTS	
Unique Identifier	Title and web links from the document library
EBG00698	Providing Care for Adults in the Last Days of Life
EBG00704	Renal Services DNACPR Guidance for Outpatients
	North West Coast Clinical Network. Palliative Care Clinical Practice Summary. November 2021. Available at: https://www.england.nhs.uk/north-west/wp-content/uploads/sites/48/2022/11/20211124-NWC-LSC-and-CM-Palliative-Care-Clinical-Practice-Summary-2nd-Edition-V2.pdf

SUPPORTING REFERENCES / EVIDENCE BASED DOCUMENTS

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Checked by Library ET 13/03/2025

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DEFINITIONS / GLOSSARY OF TERMS	
Abbreviation or Term	Definition
eGFR	Estimated Glomerular Filtration Rate
CGA	Comprehensive Geriatric Assessment
CFS	Clinical Frailty Scale
CKD	Chronic Kidney Disease
CKD-aP	CKD-associated Pruritis
CKM	Conservative Kidney Management
ESKC	Enhanced Supportive Kidney Care
RLS	Restless Legs Syndrome

CONSULTATION WITH STAFF AND PATIENTS

Enter the names and job titles of staff and stakeholders that have contributed to the document

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Katherine Stewart	Palliative Care Clinical Director	06/01/25
Judith Todd	Supportive Kidney Care Specialist Nurse	07/02/25
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DISTRIBUTION PLAN	
Dissemination lead:	Andrew Nixon
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If yes, in what format and where?	Electronic, heritage library system, hard copy
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Document Library	
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Appendix 1: Enhanced Supportive Kidney Care Toolkit

NHS
Lancashire Teaching Hospitals
NHS Foundation Trust

Version 7 01/02/2024

Enhanced Supportive Kidney Care

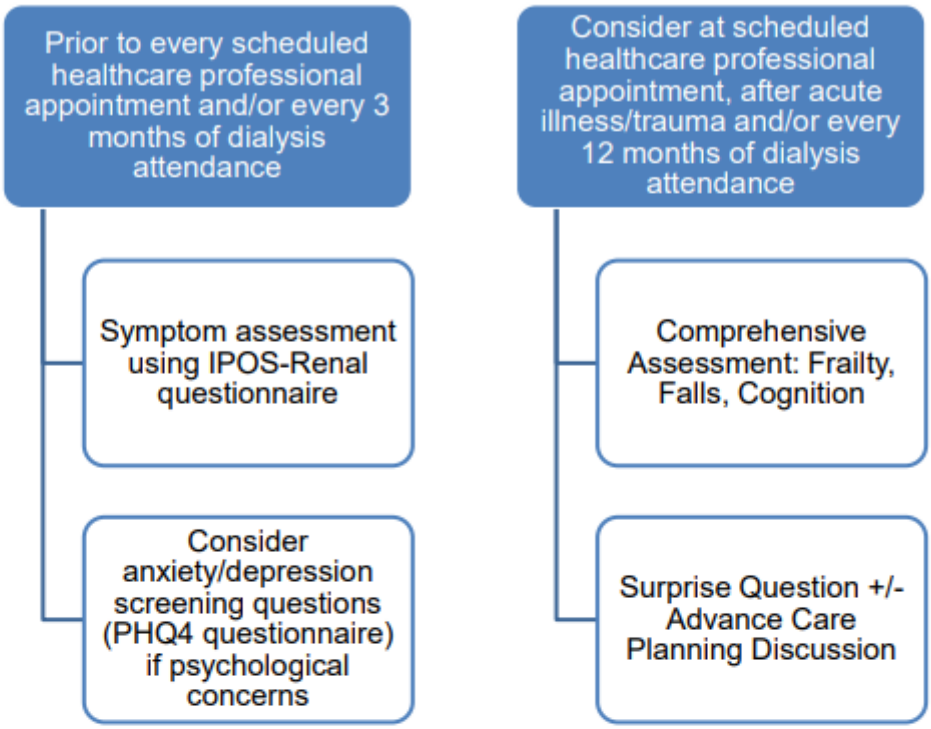
The Enhanced Supportive Kidney Care (ESKC) Toolkit is intended to be used as an aid to the assessment and management of supportive care needs in people living with chronic kidney disease (CKD). Patient assessment and management should be person-centred and consider individual goals, values, and preferences.

Supportive care is defined as involving "services that are aimed at improving the health-related quality of life for patients with established CKD, at any age, and can be provided together with therapies intended to prolong life, such as dialysis. Supportive care helps patients cope with living, as well as dying, regardless of life expectancy." Kidney Int. 2015;88(3):447-59

There are many aspects of a person's life that cannot be captured by blood tests or physiological recordings. This is particularly true for patients with CKD as you will know. We hope that, by using this Toolkit, we can get a better idea of how they are, any difficulties they might be having, any views they want to share and how we might help. It should be used from their first Kidney Choices review all the way through their kidney care and treatment. It should help us avoid or mitigate potential crises in their lives that, if not addressed, could lead to life threatening problems, or require emergency admission. The purpose of this Toolkit is to help patients tell us about their views on a range of issues, such as social or psychological problems, troublesome symptoms, hopes and worries for the future and, where appropriate, advance care planning.

Please note that there are hyperlinks within the electronic version of this document that will take you to relevant online resources.

ESKC Toolkit Overview



Please document assessments & patient/family discussions within the Supportive Care section of Vital Data

Symptoms

People living with kidney disease highlight that symptom assessment and management is a top priority for their care. Regardless of kidney management, patients report a high symptom burden that impacts upon health-related quality of life and life participation.

Patient-centred care focuses on treatments that matter most to patients, considering their goals, values, and preferences. Regular proactive symptom assessment helps ensure a patient-centred approach. The IPOS-Renal questionnaire is a symptom assessment tool validated for use within CKD populations. *A patient version of the IPOS-Renal is included in the accompanying Patient Symptom Questionnaire Booklet.*

The ESKC Toolkit recommends that patients with CKD G5 (i.e., eGFR ≤ 15 ml/min/1.73m^2), regardless of kidney management, are offered the opportunity to complete the IPOS-Renal questionnaire prior to and/or during clinical consultations with a healthcare professional and/or at least every 3 months.

Troublesome symptoms should be discussed within clinical encounters and a stepwise management approach offered with non-pharmacological considered before pharmacological interventions.

Consider Renal Supportive Care MDT Meeting referral for patients with persistent, burdensome and/or complex symptoms: RenalSupportiveCare@lthtr.nhs.uk

Consider referral to the Renal Social Worker for patients reporting practical problems, e.g., financial or personal.

Depression/Anxiety PHQ-4 Questionnaire

The PHQ-4 questionnaire is a brief screening tool for anxiety and depression and can be considered for patients who describe psychological symptoms.

Please note that there is a version of the PHQ4 without scoring information that can be given to patients in the accompanying Patient Symptom Questionnaire Booklet.

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed, or hopeless	0	1	2	3

The total score is determined by adding together the scores of each of the 4 items.

Scores are rated as normal (0-2), mild (3-5), moderate (6-8) and severe (9-12).
Total score ≥3 for the first 2 questions suggests anxiety.
Total score ≥3 for the second 2 questions suggests depression.

Consider assessing a patient's mental health risk if they score ≥3 by asking if they have had thoughts that they would be better off dead or of hurting themselves in some other way.

Please refer to the Mental Health Signposting Toolkit for patients that score ≥3 and any other patients that you think may benefit from mental health support.

Comprehensive Assessment: Frailty, Falls & Cognition

Frailty

Frailty is a state of increased vulnerability in which individuals may require additional care and support when exposed to an apparently small insult, such as a fall or infection. Age is a risk factor for frailty, although younger people can live with frailty too, especially if they have chronic health conditions, such as CKD. Importantly, frailty is associated with adverse health outcomes including worse quality of life and an increased risk of falls, hospital admission and death. Recognising those that are living with frailty provides an opportunity to introduce management strategies that aim to improve outcomes for this vulnerable group of patients and, if appropriate, consider advance care planning.

The Clinical Frailty Scale (CFS) is a frailty screening tool that provides descriptions of levels of frailty. It summarised your assessment of a patient's frailty status. Please remember it is assessment of their frailty status TWO weeks ago, i.e., their baseline, and not how the patient appears before you today. The CFS is not intended to be used in people with stable long-term disability as outcomes may be different to older people with progressive disability secondary to frailty.

Please note that patients living with frailty often have a different interpretation of the word 'frail' and may consider it to have negative connotations. Please keep this in mind during discussions with patients. Patients may relate more to "not being as fit as they used to be" and the concept of finding "it harder to bounce back" from illnesses, i.e., recover back to their previous baseline.

Please consider reviewing the Clinical Frailty Scale training module at the following link:
https://www.scfn.org.uk/clinical-frailty-scale-training

The Clinical Frailty Scale app is very useful and can be downloaded for Apple and Android devices:
https://www.scfn.org.uk/cfs-app

Although younger people can also live with frailty, the CFS has not been well studied in people aged ≤65 years old. Please assess physical performance using the WHO performance status scale (alongside the CFS if you consider it appropriate) for people aged ≤65 years old.

WHO Performance Status

Category	Description
0	Able to carry out all normal activity without restriction
1	Restricted in strenuous activity but ambulatory and able to carry out light work
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
3	Symptomatic and in a chair or in bed for greater than 50% of the day but not bedridden
4	Completely disabled; cannot carry out any self-care; totally confined to bed or chair

CFS Score 1-5: Fit/Mild Frailty

Continue care as usual but also consider reversible causes of frailty, e.g., malnutrition, low physical inactivity, and recurrent hospitalisations.

Interventions to consider include dietitian assessment, exercise prescription (e.g., Kidney Beam), community physiotherapy referral, falls prevention (and if appropriate falls team referral), and social prescribing (e.g. Age UK) to support self-management.

CFS Score 6: Moderate Frailty

Comprehensive Geriatric Assessment (CGA) is the gold standard approach to the care of older people. CGA involves a multidomain assessment performed by a multidisciplinary team to identify medical, social, and functional needs. Importantly, it leads to the development of a coordinated care plan to meet those needs.

Elements of CGA can be performed by you. Try to identity geriatric impairments associated with frailty, such as falls, impaired mobility, impaired function (basic activities of daily living & instrumental activities of daily living), cognitive impairment, depression/anxiety, malnutrition, incontinence, pressure areas, constipation, polypharmacy, and social isolation. Where relevant, consider the possibility of caregiver burden. Please also consider referring patients living with frailty to the local community frailty services.

CFS Score 7-9: Severe Frailty

Consider aspects detailed for patients with moderate frailty. Also, consider the balance between supportive care and curative care. Enhanced supportive care is an active intervention, which aims to improve quality of life, and sometimes quantity of life.

Offer patients the opportunity to be involved in advance care planning discussions. Ask yourself the surprise question (*'Would I be surprised if this patient died in the next 12 months?'*). If the answer is 'no', consider the appropriateness of referral to a local palliative care team.

Consider contacting the local Urgent/Rapid Community Response Service if you are concerned that a patient may require hospital admission without additional assessment and support in the community.

Consider Renal Supportive Care MDT Meeting referral to discuss care needs and to develop a coordinated management plan for patients with moderate/severe frailty:
RenalSupportiveCare@lthtr.nhs.uk

Falls

People with advanced CKD have an increased risk of falls and fall-related injuries, related to fluid shifts with dialysis, frailty, sarcopenia, and CKD-mineral bone disease. Efforts to minimise falls risk is of paramount importance for all people living with CKD. The most important predictor of future falls is a history of falling. The ESKC Toolkit suggests considering the following two questions regarding falls:

1. Has the patient fallen in the last 12 months?	Yes	No
	If yes, how many times have they fallen?	
2. Is the patient concerned about falling?	Yes	No
Please complete the Falls Risk Assessment Tool if the answer is yes to either question		

Suggested considerations for patients who have fallen or who are concerned about falling:

- Frailty, mobility & functional status
- Mobility aids, e.g., stick or frame
- Medication & polypharmacy
- Cognition
- Anxiety or depression
- Vision
- Foot problems
- Nutrition
- Continence
- Home environment
- Fall Telecare Alarm Service

Please offer patients the following Age UK leaflet: https://www.ageuk.org.uk/globalassets/age-uk/documents/information-guides/ageukig14_staying_steady_inf.pdf

Consider if referral to the local hospital or community falls team is appropriate.

Cognition

Cognitive changes can occur early in CKD, progress as kidney function declines and exist across the continuum of mild cognitive impairment to dementia. Importantly, cognitive impairment affects decision-making capacity, therefore it is important to consider cognitive screening in people with advanced CKD, especially before the shared decision-making process. Before completing a cognitive screening test, please consider the following two questions:

1. Does the patient have a known diagnosis of dementia?	Yes	No
	If yes, there is no need to perform further cognitive screening	
2. Has the patient been forgetful in the last 12 months to the extent that it has affected their life or caused them concern?	Yes	No
	If yes, progress to 6CIT cognitive screening test	

Consider performing the 6CIT cognitive screening tool if the patient has been forgetful in the last 12 months to the extent that it has affected their life or caused them concern:

Six-item Cognitive Impairment Test (6CIT)						
1. What year is it?	Correct: 0 points			Incorrect: 4 points		
2. What month is it?	Correct: 0 points			Incorrect: 3 points		
3. Give the patient an address phrase to remember with 5 components: e.g., John, Smith, 42, High St, Bedford						
4. About what time is it (within one hour)?	Correct: 0 points			Incorrect: 3 points		
5. Count backwards from 20-1	Correct: 0 points		1 error: 2 points		>1 error: 4 points	
6. Say the months of the year in reverse	Correct: 0 points		1 error: 2 points		>1 error: 4 points	
7. Repeat address phrase	Correct: 0 points	1 error: 2 points	2 errors: 4 points	3 errors: 6 points	4 errors: 8 points	All wrong: 10 points
6CIT Score						
Consider requesting the patient's primary care team make a referral to the local memory assessment service if the patient scores 8 or above.						

Advance Care Planning

Advance care planning helps to ensure that wishes are respected throughout later life and avoid unnecessary and potentially harmful interventions.

To help identify those who may benefit from advance care planning, complete an assessment of comorbidity (using the Charlson Comorbidity Index [CCI]) and frailty status (using the CFS), then ask yourself the 'Surprise Question' *(please see the Table on the next page)*.

Indicators of poor or deteriorating health include (adapted from SPICT):

- Unplanned hospital admission(s)
- Performance or frailty status is poor or deteriorating
- Depends on others for care due to increasing physical and/or mental health problems. The person's caregiver needs more help and support
- Progressive weight loss; remains underweight; low muscle mass
- Persistent symptoms despite optimal treatment of underlying condition(s)
- Poor tolerance of dialysis with change of modality
- The person (or family) asks for palliative care, chooses to reduce, stop, or not have treatment, or wishes to focus on quality of life

Charlson Comorbidity Index

Total score is the sum of the comorbidity points

Age	<50 years: 0	50-59 years: +1	60-69 years: +2	70-79 years: +3	≥80 years: +4
Myocardial infarction History of definite or probable MI		No: 0		Yes: +1	
Congestive heart failure Including LV or biventricular impairment/failure		No: 0		Yes: +1	
Peripheral vascular disease Grafts or angioplasty to improve blood supply		No: 0		Yes: +1	
Cerebrovascular disease Stroke or TIA ("mini-stroke")		No: 0		Yes: +1	
Dementia Chronic cognitive deficit		No: 0		Yes: +1	
Chronic obstructive pulmonary disease (COPD)		No: 0		Yes: +1	
Connective tissue disease For example, rheumatoid arthritis		No: 0		Yes: +1	
Peptic ulcer disease		No: 0		Yes: +1	
Liver disease Mild: chronic hepatitis (or cirrhosis without portal hypertension) Moderate: cirrhosis & portal hypertension but no variceal bleeding history Severe: cirrhosis, portal hypertension & variceal bleeding Hx		None: 0	Mild: +1		Moderate/severe: +3
Diabetes mellitus		None or diet-controlled: 0	Uncomplicated: +1		End-organ damage: +2
Hemiplegia		No: 0		Yes: +2	
Moderate to severe CKD Moderate: creatinine >265 Severe: dialysis or kidney transplant		No: 0		Yes: +2	
Solid tumour		None: 0	Localised: +2		Metastatic: +6
Leukaemia		No: 0		Yes: +2	
Lymphoma		No: 0		Yes: +2	
AIDS		No: 0		Yes: +6	

CCI Score Total	
CFS Score (See Frailty Section)	

Surprise Question

Would I be surprised if the patient died in the next 12 months?	Yes	No

If no, please consider advance care planning discussions & please consider referral to Renal Social Worker as the patient may be eligible for additional financial support

Training Suggestions

It can be difficult to start advance care planning discussions with patients, relatives, and caregivers. Please be familiar with The Gold Standards Framework Proactive Identification Guidance and consider reading the 'The Difficult Conversations Booklet' that includes advice and guidance on how to approach advance care planning discussions with people with CKD.

Please also consider attending the 'Mayfly - Advance Care Planning & Communication Skills' course (education@stcatherines.co.uk).

Advance Care Planning Resources

Consider offering patients the 'Planning for your future care' document.
If considered appropriate, please signpost the My Wishes website: https://www.mywishes.co.uk/

Advance Care Planning Documentation		
Patient Consent to Share with Primary Care		
GSF Status		
Resuscitation Discussion Summary		
Resuscitation Status		
Advance Care Planning Discussion Summary		
Preferred Place of Care at the End of Life (PPC)		
Preferred Place of Death (PPD)		
Lasting Power of Attorney (Health and Welfare)		
Lasting Power of Attorney (Property and Finance)		
Please share the ACP information with the primary care team requesting that they update the patient's EPaCCs record		
ACP shared with GP	Yes	No
Completed by:		
Staff Member Name:		
Designation:		
Date:		

Scoring Summary

This summary page can be used to record scores prior to documenting onto the Supportive Care section of Vital Data. *Please note that it may not be necessary or appropriate to perform all assessments at the same time.*

Year												
Month	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
IPOS-RENAL Total Score												
PHQ4 Total Score												
CFS Score												
WHO Score												
Fall History												
Cognition Concerns												
CCI Score												
Surprise Question Answer												
Advance Care Plan Completed												
Year												
Month	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
IPOS-RENAL Total Score												
PHQ4 Total Score												
CFS Score												
WHO Score												
Fall History												
Cognition Concerns												
CCI Score												
Surprise Question Answer												
Advance Care Plan Completed												

Appendix 2: Enhanced Supportive Kidney Care Toolkit Patient Symptom Questionnaire

Enhanced Supportive Kidney Care Toolkit: Patient Symptom Questionnaires

Name: **Named Nurse:**

NHS Number: **DOB:**

Date:

There are many aspects of a life that cannot be captured by blood tests or physiological recordings.

We hope that, by using these questionnaires, we can get a better idea of how you are, any difficulties you might be having, any views you want to share and how we might help.

It would be helpful if you could complete the enclosed symptom questionnaires. However, do not worry if you are unable or do not wish to do this.

IPOS-Renal Patient Version

www.pos-pal.org

Patient name : .....

Date (dd/mm/yyyy) : .....

Patient number : ..... *(for staff use)*

Q1. What have been your main problems or concerns over the past week??

1. .....

2. .....

3. .....

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week?

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0☐	1☐	2☐	3☐	4☐
Shortness of breath	0☐	1☐	2☐	3☐	4☐
Weakness or lack of energy	0☐	1☐	2☐	3☐	4☐
Nausea (feeling like you are going to be sick)	0☐	1☐	2☐	3☐	4☐
Vomiting (being sick)	0☐	1☐	2☐	3☐	4☐
Poor appetite	0☐	1☐	2☐	3☐	4☐
Constipation	0☐	1☐	2☐	3☐	4☐
Sore or dry mouth	0☐	1☐	2☐	3☐	4☐
Drowsiness	0☐	1☐	2☐	3☐	4☐
Poor mobility	0☐	1☐	2☐	3☐	4☐
Itching	0☐	1☐	2☐	3☐	4☐
Difficulty Sleeping	0☐	1☐	2☐	3☐	4☐
Restless legs or difficulty keeping legs still	0☐	1☐	2☐	3☐	4☐
Changes in skin	0☐	1☐	2☐	3☐	4☐
Diarrhoea	0☐	1☐	2☐	3☐	4☐
Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past week?					
1._____	0☐	1☐	2☐	3☐	4☐
2._____	0☐	1☐	2☐	3☐	4☐
3._____	0☐	1☐	2☐	3☐	4☐

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worried about your illness or treatment?	0☐	1☐	2☐	3☐	4☐
Q4. Have any of your family or friends been anxious or worried about you?	0☐	1☐	2☐	3☐	4☐
Q5. Have you been feeling depressed?	0☐	1☐	2☐	3☐	4☐

	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	0☐	1☐	2☐	3☐	4☐
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0☐	1☐	2☐	3☐	4☐
Q8. Have you had as much information as you wanted?	0☐	1☐	2☐	3☐	4☐

	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0☐	1☐	2☐	3☐	4☐

	None at all	Up to half a day wasted	More than half a day wasted
Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests	0☐	1☐	2☐

	On my own	With help from a friend or relative	With help from a member of staff
Q11. How did you complete this questionnaire?	☐	☐	☐

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse

IPOS-Renal Patient IPOS-Renal –P7-EN 21/05/2015

PHQ-4

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed, or hopeless	0	1	2	3

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?			
Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult

Completed by:	
Patient Signature:	**Patient Name:**
Date	
Completion on behalf of the patient and with the patient's consent	
Staff Member Name:	**Designation:**

Appendix 3: Enhanced Supportive Kidney Care Mental Health Signposting Toolkit

NHS
Lancashire Teaching Hospitals
NHS Foundation Trust

Mental Health Signposting Kit

Options for Routine Support

1) **Contact with GP**

Patients can be signposted to the GP in the first instance, for an initial consultation, to explore local options for support, and to consider medication, if appropriate.

2) **If distress is renal-related and the patient wants therapy/psychology input**

Patients can be signposted to **Kidney Care UK** counselling service. They offer free help, emotional support and guidance to both kidney patients and their families/loved ones. Kidney care UK can offer an initial 30-minute conversation with a counsellor, and up to six 50-minute follow-up counselling sessions, conducted online or via telephone.

- Ring 01420 541 424 to refer yourself in.
- Email info@kidneycareuk.org with your telephone contact or email details ,and your request for support.

Patients can access the **Renal Psychology Service** offered by Lancashire Teaching Hospitals. We offer 1-1 assessment and therapy input for patients under the care of the adult renal team and presenting with renal-related distress, or which are significantly affecting the way they manage their condition or its' treatment.

- Referrals can be made via Flex Order Block. If you require any support with this, please contact Sara Gallagher, Renal Secretary on sara.gallagher@lthtr.nhs.uk or ring RPH x2273.
- Patients experiencing a mental health emergency, including actively suicidal patients, patients experiencing psychosis, or those at serious risk of harm to themselves or others are not suitable for the renal psychology service, as we are not an emergency service. These patients would need to be referred urgently to community single point of access or crisis teams, liaison psychiatry, or emergency services (see below).

3) **If the distress is not renal-related and the patient wants input**

Patients can be signposted to their local **NHS Talking Therapies** service. They offer CBT- and counselling-based approaches for depression, generalised anxiety, social anxiety, panic and agoraphobia, other phobias, OCD, PTSD, IBS and body dysmorphic disorder (please note patients do not need a mental health diagnosis to access support). The service will offer a suggested treatment plan following an initial triage appointment – these are usually conducted face-to-face, online, or via telephone.

- Most patients will be able to find their local talking therapies service here: https://www.lscft.nhs.uk/talkingtherapies
- Otherwise, patients can find your local talking therapies service using their postcode here: https://www.nhs.uk/service-search/mental-health/find-an-NHS-talking-therapies-service/
- Once you have selected your local talking therapies service, you can self-refer by completing an online referral form detailed on the website.

Escalating Risk

1) The Initial Response Service

Several localities across Lancashire and South Cumbria have access to the "Initial Response Service", where residents who need to access mental health help and support are now able to via one number, 24 hours a day, seven days a week.

Call handlers and Mental Health Practitioners take calls and manage referrals from patients, service users, families, carers and professionals, aiming to ensure callers are connected to the right professional in a timely manner.

The team may arrange for the patient to receive support over the phone or for a mental health practitioner to see them at home, at a GP practice or another mutually agreed place to allow further information about current mental health needs. Information about other services that could assist will also be shared, if appropriate.

- East Lancashire & Blackburn with Darwen, AKA "IRS Pennines": 0800 013 0707
- IRS Central & West Lancashire: 0800 013 0708
- IRS Blackpool & the Fylde Coast: 0800 013 0709
- Lancaster, Morecambe & South Cumbria, AKA "IRS The Bay": 0800 013 0710

2) Urgent Help

If the patient needs urgent help because they are in significant mental health distress, then there is always someone they can call.

The LSCFT Mental Health Crisis Line is available on 0800 953 0110, 24 hours a day, seven days a week. It is staffed by trained mental health professionals who are able to provide assessment and referrals to appropriate services. Ring it if the patient needs to access services or if you need for advice about someone who needs treatment or support.

The LSCFT Wellbeing Helpline and Texting Service phone lines are available:

- Monday to Friday 7pm to 11pm
- Saturday to Sunday 12pm to Midnight

Thes are staffed by volunteers and those with lived experience, who can offer emotional support – patients can ring if they want to chat about your mental health or are lonely. They can contact the helpline on 0800 915 4640 or by texting Hello to 07860 022 846 between 10am and 11pm Monday to Friday. The texting service is also available at weekends 12pm to Midnight.

3) Immediate Help

If a patient needs help immediately where risk represents risk to life, please direct the patient to 999 or A+E, and support to attend if possible.

Appendix 4: Medical Anticipatory Clinical Management Plan

PILOT DOCUMENT

Medical Anticipatory Clinical Management Plan

This document aims to guide healthcare professionals to do what you want if you are unable to tell them.

THIS IS NOT A LEGALLY BINDING DOCUMENT

Full Name	
Preferred Name	
Date of Birth	
Address	
NHS number	

Has the individual got any communication difficulties? *If yes; explain what and how they're supported.*	**Y** **N**
Does the individual have capacity to make decisions about the medical anticipatory clinical management plan? *(if the patient lacks capacity the decisions on this form should reflect decisions made in the patients best interest)* ****If no – capacity assessment/date***	**Y** **N**
Is there a Lasting Power of Attorney (LPA) for health and welfare decisions? Details:	**Y** **N**
Has any Advance Decisions to Refuse Treatment (ADRT) been made? Details:	**Y** **N**
Does the individual have an existing advance care plan? (e.g. MyWishes) Details:	**Y** **N**
Relevant medical conditions and current treatment plan:	
Have there been any discussions about CPR? *(If yes, please detail)*	**Y/N**
Is there a do not attempt cardiopulmonary resuscitation (DNACPR) form in place? *If yes, where is it located:*	**Y/N**
Have there been discussions about other treatment limitations/ ceiling of treatment? (Please include circumstances when it would/ would not be appropriate to consider admission to hospital) **In Hospital:** **In the Community:**	

PILOT DOCUMENT

Plan for management of any anticipated medical issues relevant to current medical conditions: *(e.g. Palliative care/ oncology emergencies, symptoms of Parkinson's Disease or exacerbations of COPD)*	
Plan for management of future infections *(e.g. IV/oral/no treatment choices)*:	
Plan for management of nutrition and hydration: *(This might include oral intake, management of swallowing difficulties and any plans to reduce or withdraw artificial nutrition or hydration in the event it is no longer tolerated)*	
Does the individual have a pacemaker/implantable cardioverter defibrillator (ICD) in situ? **If an ICD is in situ, is there a plan for this to be deactivated?** *(What is the plan)*	**Y** **N** **Y** **N**
Any other specific management plans *(for example management of falls)*: **Any other relevant information:**	
Is there anticipatory medication in place?	**Y/N**
Preferred Place of Care: **Preferred Place of Death:**	
Has the individual given consent for this document to be shared?	**Y/ N**

Who has been involved in discussions about this plan

	Name (role if applicable)	Date
Patient		
Family / Carer		
Healthcare Professional		
Other		

Healthcare Professional completing this form: **Name** **Signature** **Role**	**Date**

Healthcare professionals informed and systems updated there is an ACMP in place	NWAS	GP	Family relatives	Hospital	Out of Hours	District Nurses	Hospice
	Y N	Y N	Y N	Y N	Y N	Y N	Y N

Reviews with comments	Date

Appendix 5: Equality, Diversity & Inclusion Impact Assessment Tool

Equality, Diversity & Inclusion Impact Assessment Form

Department/Function	Renal			
Lead Assessor	Andrew Nixon			
What is being assessed?				
Date of assessment				
What groups have you consulted with? Include details of involvement in the Equality Impact Assessment process.	Equality of Access to Health Group	☐	Staff Side Colleagues	☒
	Service Users	☐	Staff Inclusion Network/s	☐
	Personal Fair Diverse Champions	☐	Other (Inc. external orgs)	☐
	Please give details:			

1) What is the impact on the following equality groups?			
Positive: ➢ Advance Equality of opportunity ➢ Foster good relations between different groups ➢ Address explicit needs of Equality target groups		**Negative:** ➢ Unlawful discrimination, harassment and victimisation ➢ Failure to address explicit needs of Equality target groups	**Neutral:** ➢ It is quite acceptable for the assessment to come out as Neutral Impact. ➢ Be sure you can justify this decision with clear reasons and evidence if you are challenged
Equality Groups	**Impact** (Positive / Negative / Neutral)	**Comments:** ➢ Provide brief description of the positive / negative impact identified benefits to the equality group. ➢ Is any impact identified intended or legal?	
Race (All ethnic groups)	Neutral		
Disability (Including physical and mental impairments)	Neutral		
Sex	Neutral		
Gender reassignment	Neutral		
Religion or Belief (includes non-belief)	Neutral		
Sexual orientation	Neutral		
Age	Neutral		
Marriage and Civil Partnership	Neutral		
Pregnancy and maternity	Neutral		
Other (e.g. caring, human rights, social)	Neutral		

2) In what ways does any impact identified contribute to or hinder promoting equality and diversity across the organisation?	

3) If your assessment identifies a negative impact on Equality Groups you must develop an action plan **to avoid discrimination and ensure opportunities for promoting equality diversity and inclusion are maximised.** ➢ This should include where it has been identified that further work will be undertaken to further explore the impact on equality groups ➢ This should be reviewed annually.

ACTION PLAN SUMMARY		
Action	**Lead**	**Timescale**

HOW THE NHS CONSTITUTION APPLIES TO THIS DOCUMENT

WHICH PRINCIPLES OF THE NHS CONSTITUTION APPLY? Click here for guidance on Principles	Tick those which apply	WHICH STAFF PLEDGES OF THE NHS CONSTITUTION APPLY? Click here for guidance on Pledges	Tick those which apply
1. The NHS provides a comprehensive service, available to all.	√	1. Provide a positive working environment for staff and to promote supportive, open cultures that help staff do their job to the best of their ability.	√
2. Access to NHS services is based on clinical need, not an individual's ability to pay.	√	2. Provide all staff with clear roles and responsibilities and rewarding jobs for teams and individuals that make a difference to patients, their families and carers and communities.	√
3. The NHS aspires to the highest standards of excellence and professionalism.	√	3. Provide all staff with personal development, access to appropriate education and training for their jobs, and line management support to enable them to fulfil their potential.	√
4. The patient will be at the heart of everything the NHS does.	√	4. Provide support and opportunities for staff to maintain their health, wellbeing and safety.	√
5. The NHS works across organisational boundaries.	√	5. Engage staff in decisions that affect them and the services they provide, individually, through representative organisations and through local partnership working arrangements. All staff will be empowered to put forward ways to deliver better and safer services for patients and their families.	√
6. The NHS is committed to providing best value for taxpayers' money.	√	6. To have a process for staff to raise an internal grievance.	√
7. The NHS is accountable to the public, communities and patients that it serves.	√	7. Encourage and support all staff in raising concerns at the earliest reasonable opportunity about safety, malpractice or wrongdoing at work, responding to and, where necessary, investigating the concerns raised and acting consistently with the Employment Rights Act 1996.	√

WHICH AIMS OF THE TRUST APPLY? Click here for Aims	Tick those which apply	WHICH AMBITIONS OF THE TRUST APPLY? Click here for Ambitions	Tick those which apply
1. To offer excellent health care and treatment to our local communities.	√	1. Consistently deliver excellent care.	√
2. To provide a range of the highest standard of specialised services to patients in Lancashire and South Cumbria.	√	2. Great place to work.	√
3. To drive innovation through world-class education, teaching and research.	√	3. Deliver value for money.	√
		4. Fit for the future.	√