Appendix E – Patient Letters and Leaflets

In this section you will find example patient letters to help you contact patients and invite them in for testing. The CLAHRC CKD team have developed some examples, drawing on knowledge and experience from the practices working with us in the Collaborative and there are a couple of example letters developed by practices.

1. CLAHRC Examples:
   a. Inviting patients for an initial eGFR test
   b. Inviting patients for a repeat eGFR test and an ACR test
   c. Inviting patients for an ACR test only

2. Letter from Ellenbrook Surgery, Salford:
   a. Inviting patients for a repeat eGFR and ACR test

3. Letters from Springfield Surgery, Stockport:
   a. Inviting patients to provide a urine sample
   b. Inviting patients for blood and urine tests

You can develop these into your own letters to send out to patients.

You will also find example leaflets for patients with CKD* – details of how to order more copies of these are available from the CLAHRC.

*Reproduced with permission from the National Kidney Federation (NKF) and the Association of Renal Industries (ARI).
As part of the practice’s aim to provide you with the best possible care we are always looking for ways to improve our service. We are currently checking patients who may be at risk of a lower than average kidney function and would like to invite you to the surgery for a simple blood test. Please do not be concerned – we have no immediate concerns for your health. We are identifying at-risk patients early so we can monitor your health better to reduce any long-term chances of health problems.

To help us with this we request that you book an appointment with the nurse on <phone number> for a blood test. This will only take a few minutes of your time but will help us keep you healthier for longer. We will then contact you shortly after to discuss your result, and invite you back in if your result suggests that your kidney function is reduced.

If you would like more information please contact the surgery on <phone number>.

Yours sincerely,

<Signature>
As part of the practice’s aim to provide you with the best possible care we are always looking for ways to improve our service. We are currently checking our records to identify patients with a reduced kidney function and we have noticed that one of your blood tests shows your kidneys may not be working as well as they could. Please do not be concerned – we have no immediate concerns for your health. We are identifying at-risk patients early so that we can monitor your health better to reduce any long-term chances of health problems.

There could be many reasons for this. Often it is just a temporary blip due to illness, like a cold, so we are inviting you to the surgery to provide a blood sample, and a urine sample in order to understand the results further. This should only take a few minutes of your time but will mean that we can look after your health better.

Please ring the surgery on <phone number> to book an appointment with the nurse to have a blood sample taken, and provide us with a urine sample (preferably from when you first pass water in the morning) on the day of your appointment in the pot provided. We will then contact you shortly after to discuss the results with you further.

If you would like more information please contact the surgery on <phone number>.

Yours sincerely,

<Signature>
Dear <Patient>

As part of the practice’s aim to provide you with the best possible care we are always looking for ways to improve our service. We are currently auditing our records of patients who have been identified as having slightly impaired kidney function, clinically defined as chronic kidney disease (CKD). You have previously been diagnosed with CKD and this should have been discussed with you by someone at the practice.

To get a more complete picture of your kidney function we request that you provide us with a urine sample which monitors another aspect of your kidney function and will improve the health advice that we are able to provide you with – reducing long-term risk of the disease.

Please provide a urine sample (preferably from when you first pass water in the morning) in the enclosed bottle and return it to the surgery before 12 noon the same day. We will then contact you shortly after to discuss the results with you.

If you would like more information please contact the surgery on <phone number>.

Yours sincerely,

<Signature>
Dear [Patient],

We have been looking into how we manage patients with kidney problems in our practice to ensure we are providing the best treatment possible. As part of this we have searched through all our patients’ blood results that monitor kidney function. This has shown that your kidney function was slightly impaired on your last blood test. This is nothing to be concerned about but we do need you to come in for a repeat kidney function test and to bring a urine sample with you. This is just to check that your kidneys are still working well.

Please do not panic about this, your health and kidneys are not in any danger. Once we have rechecked your kidney function we can see if it has either returned to normal and then no further action is necessary, or if it is still slightly impaired we will ask you to come in and see one of the doctors to discuss this.

Please book in for a kidney function test and bring a urine sample with you.

Best wishes,
Dear «Pat.Forenames»

The practice is currently doing some work along side The University of Manchester into patients who have some abnormalities in their kidney function blood tests. These abnormalities may be quite minor and are often due to age though other factors can cause these as well, including blood pressure. The practice has been monitoring these tests for some time though as part of this research with the university and would like to do it more formally.

Your name has been flagged up as someone with these minor kidney function abnormalities – formally known as Chronic Kidney Disease or CKD.

We would be grateful if you could make an appointment at the practice to have your blood pressure taken along with a blood test to test your kidney function. We would also appreciate it if you could bring a urine sample (early morning) as this is part of the assessment also. Specimen pots will be available for collection from reception. Please ensure your full name and date of birth is on the bottle before returning it. This appointment can be with the practice nurse or any of the doctors.

If you have any queries please discuss these with the doctor or nurse at the time of your blood pressure and blood test.

The practice is dedicated to providing patients with optimum health care and so are one of the few practices in the North West of England to have been chosen to be part of this research and feel it will benefit its patients greatly long term.

Yours sincerely
Dear «Pat.Forenames»

The practice is currently doing some work along side The University of Manchester into patients who have some abnormalities in their kidney function blood tests. These abnormalities may be quite minor and are often due to age though other factors can cause these as well, including blood pressure. The practice has been monitoring these tests for some time though as part of this research with the university and would like to do it more formally.

Your name has been flagged up as someone with these kidney function abnormalities – formally known as Chronic Kidney Disease or CKD.

To complete our work we require a urine sample (early morning) to test for protein. Specimen pots will be available for collection from reception. Please ensure your full name and date of birth is on the bottle before returning it.

If you have any queries please discuss these with the doctor or nurse on your next routine blood pressure appointment.

The practice is dedicated to providing patients with optimum health care and so are one of the few practices in the North West of England to have been chosen to be part of this research and feel it will benefit its patients greatly long term.

Yours sincerely
function is declining over time, the case will be discussed with a kidney specialist, or a referral may be made to a kidney specialist.

**Treatment for CKD stage 3**
Treatment as in CKD stages 1 and 2, but with more careful monitoring for declining kidney function.

**Treatment for CKD stages 4 and 5**
Treatment as for CKD stages 1-3. Additionally, any medications should be reviewed, as the dose may need to be altered and some drugs may need to be avoided as they could damage the kidneys further. This should include prescribed drugs and any drugs bought at the chemist and complementary therapies. In CKD stages 4 and 5 it is usually necessary to get advice from a kidney specialist, especially in stage 5 because kidney failure may become life threatening.

**CKD and Diabetes**
If someone with CKD also has diabetes, extra care to control the blood pressure, blood sugar levels and cholesterol levels is required. More intensive monitoring will be performed, including extra urine tests to look for protein in the urine. This is because CKD can be a complication of diabetes. However, CKD does not cause diabetes.

For a leaflet on ‘Diabetes and Kidney Disease’ contact the Helpline on 0845 601 02 09

**What if the kidney function keeps on getting worse and worse?**
In people with declining kidney function, a treatment plan should be made with a kidney specialist team well before CKD stage 5 is reached. There are also several books and other aids that give information and help make a decision about the best treatment, some of which are available from the National Kidney Federation (for a FREE copy of ‘Help I’ve got Kidney Failure’ by Dr Rob Higgins, phone the NKF Helpline on 0845 601 02 09 (Local charge within the UK).

To find out more about Kidney related books check our website www.kidney.org.uk.

**Leading a normal life with CKD**
Most people with CKD should be able to lead normal lives. CKD does not normally run in families and routine family screening is not necessary if one person is affected. However, some specific types of kidney disease do run in families, and people should check with their health care team to see if testing of family members is needed.

For leaflets on sex and pregnancy or keeping fit contact the Helpline on 0845 601 02 09

The National Kidney Federation cannot accept responsibility for information provided. The above is for guidance only. Patients are advised to seek further information from their own doctor.

To order any leaflets from the Kidney Matters series ring the Helpline on 0845 601 02 09

**A ‘Friend’ at the end of the phone.**
The National Kidney Federation operates the:

**NATIONAL KIDNEY PATIENTS’ HELPLINE**
The patient’s helpline is run by patients-for patients

**0845 601 02 09**

This essential service enables the NKF to provide immediate telephone support at local rates.

**‘Friends’ on the Internet.**
As a friend of the NKF you will be given (via ‘our quarterly magazine’) the necessary passwords to enable you to access pages on the NKF website www.kidney.org.uk that are hidden from public view. The site itself contains a mass of renal information, medical reference, and news.

For information on how to become a friend please either telephone our Helpline or join on line at our website.

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What is chronic kidney disease (CKD)?
How common is CKD?
How does someone know if they have CKD?
What causes CKD?
Measuring kidney function - eGFR
What are the stages of CKD?
What is the treatment for CKD?
CKD and Diabetes?
What if the kidney function keeps on getting worse and worse?

Leading a normal life with CKD
**Key Points**
- CKD is very common, but less than 1 in 10 people with CKD ever require dialysis (artificial kidney treatment) or a kidney transplant.
- Someone with CKD is at increased risk of heart attack or stroke, especially if they smoke or are overweight.
- People with CKD should have regular checks of their kidney function, and have treatment if their blood pressure is 140/85 or more.

**What is chronic kidney disease (CKD)?**
Kidney disease is a term used by doctors to include any abnormality of the kidneys, even if there is only very slight damage. ‘Chronic’ means a condition that does not get completely better. Some people think that ‘chronic’ means severe. This is not the case, and often CKD is only a very slight abnormality in the kidneys.

**How common is CKD?**
Recent research suggests that 1 in 10 of the population may have CKD, but it is less common in young adults, being present in 1 in 50 people. In those aged over 75 years, CKD is present in 1 out of 2 people. However, many of the elderly people with CKD may not have ‘diseased’ kidneys, but have normal ageing of their kidneys. Although severe kidney failure will not occur with normal ageing of the kidneys, there is an increased chance of high blood pressure and heart disease or stroke, so that medical checks will be helpful.

**How does someone know if they have CKD?**
In most cases CKD does not cause any symptoms, and is detected because tests are abnormal. These may be urine tests for blood or protein; an X-ray or scan of the kidneys; or a blood test to measure kidney function. For leaflets on blood in the urine or protein in the urine contact the Helpline on 0845 601 02 09.

**What causes CKD?**
There are many causes of CKD, and two of the commonest causes are high blood pressure and ageing of the kidneys. Very few of the causes of CKD are completely curable, so it is often not necessary to do extensive tests to find a cause, so long as blood tests show the kidney function is stable. If someone has markedly reduced kidney function, declining kidney function, or associated problems such as kidney pain, a scan of the kidneys will be performed. Some people will also have tests such as a cystoscopy (flexible tube to look inside the bladder), or a kidney biopsy (a small piece of kidney is removed with a needle and looked at under the microscope).

**Measuring kidney function - eGFR**
A test called the eGFR (estimated glomerular filtration rate) is used to measure kidney function. The eGFR is calculated by the laboratory from the level of a chemical called creatinine in the blood.

A normal eGFR is about 100 ml/min in young adults, so the eGFR is sometimes referred to as the percentage of normal kidney function, as the number is the same.

Some young adults with normal kidneys will have an eGFR as low as 75 ml/min, and this falls by about 1 ml/min per year as people get older, so many healthy people aged 75 will have an eGFR of 50-60 ml/min.

Most laboratories now report: eGFR alongside their measurements of blood creatinine levels and this is the most reliable way to obtain an eGFR result. It is possible to use on-line calculator (e.g. at the Renal Association’s website - www.renal.org/eGFRcalc/GFR.pl) by putting in age, sex, blood level of creatinine and racial origin. However, different laboratories use different methods to measure serum creatinine, and each of these methods gives slightly different answers. The eGFR that the laboratory reports take account of these differences, but the on-line calculators do not; so the results that they give are not quite as accurate.

**What are the stages of CKD?**
CKD is divided into 5 stages:

- **CKD stage 1** is eGFR greater than 90 ml/min, with some sign of kidney damage on other tests (if all the other kidney tests are normal, there is no CKD).

  - **CKD stage 2** is eGFR 60-90 with some sign of kidney damage (if all the kidney tests are normal, there is no CKD).
  - **CKD stage 3** is eGFR 30-59 ml/min, a moderate reduction in kidney function
  - **CKD stage 4** is eGFR 15-29 ml/min, a severe reduction in kidney function
  - **CKD stage 5** is eGFR less than 15 ml/min, established kidney failure, when dialysis or a kidney transplant may be needed.

**What is the treatment for CKD?**
There are some things that everyone with CKD should try to do. These are:-

- Lose weight (if overweight), and take regular exercise
- Stop smoking
- Reduce the amount of salt in the diet in order to help control the blood pressure
- Eat a healthy balanced diet
- Drink about 2 litres of fluid a day (2 litres is about 10 cups or 6 mugs). There is no benefit in drinking large amounts of fluid, except in people who get lots of urine infections, or in a few other special cases
- Consider buying an automatic blood pressure monitor to check the blood pressure at home
- Have an annual ‘flu jab (influenza vaccination), and have the pneumonia (pneumococcal) vaccine once (talk to your GP about this)

**Treatment for CKD stages 1 and 2**
The blood pressure should be treated carefully. If it is above 140/85, tablets are usually needed, and the aim is to get the blood pressure down to 130/80 or lower. The cholesterol should be checked, and some people will be advised to take a daily aspirin tablet. A blood test to check eGFR should be performed once a year. If the urine tests show a lot of protein in the urine, or the kidney
What can be done about Chronic Kidney Disease (CKD)?

First steps
When tests first show signs of CKD your doctor may need you to attend for further checks to confirm the findings and to look for the cause. Sometimes an ultrasound scan of the kidneys is needed. A few patients will need to see a hospital specialist depending on the results of all the tests and if there are particular problems such as difficulty in controlling blood pressure or if the kidney tests are getting worse.

Routine checks
It will be important for you to have regular checks of blood pressure, blood and urine tests with your doctor or nurse. How often will depend on the CKD stage, whether the GFR test is changing and if there are problems with blood pressure or diabetes. Really careful blood pressure control is very important in CKD. Generally speaking blood pressure should be no more than 130/80 (even lower - 125/75 - in some kidney conditions).

NB For many people tablets known as ACE Inhibitors or Angiotensin Receptor Blockers are the best treatment for blood pressure but very occasionally they can affect the kidney and have to be stopped. If you do need them, your doctor should check your GFR first and repeat the test after 2 weeks and after any increase in dose to be on the safe side.

What can I do to help myself?
• take regular exercise
• keep weight down
• don’t smoke
• avoid excess salt and alcohol

And with your doctor’s help
• careful blood pressure control
• careful diabetes control
• check cholesterol

Remember – all this is designed to protect the heart and circulation as well as the kidneys.

When is dialysis or a transplant needed?
This only happens to a small minority of people with CKD. Part of the routine steps in stage 4 or 5 is for your doctor to discuss your tests with your local kidney specialist. If it seems likely that you will need dialysis the different types of treatment will be explained in detail – but even at this stage the kidneys don’t always carry on getting worse.

What are the symptoms of CKD?
In most people the early stages of CKD do not cause any symptoms. Sometimes there are none at all until a few weeks before dialysis. Symptoms that can occur in later stages are:
• feeling tired
• difficulty concentrating
• itchy skin
• swollen ankles
• breathlessness on exertion
• poor appetite and weight loss
• feeling sick

Of course these can be caused by something else but they may mean that an extra check-up is needed.

Other sources of information
Renal Association: www.renal.org.uk
British Heart Foundation: www.bhf.org.uk
Diabetes UK: www.diabetes.org.uk

National Kidney Federation:
http://www.kidney.org.uk/Medical-Info/ckd-info/index.html

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If you would like further copies of this leaflet please contact the ARI Secretariat at Email: info@ari-uk.net Web: www.ari-uk.net

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Chronic Kidney Disease (CKD) rarely means dialysis

When people think of kidney disease they usually think of dialysis or kidney transplants but there is much more to it than that. Chronic Kidney Disease (CKD) is really quite common and affects as many as 1 in 10 of the general population. Remember that the words ‘chronic disease’ as a medical term mean any long-lasting condition and not an illness that it is bound to be very serious or immediately life-threatening. Only a very small minority of people with CKD end up needing dialysis or a transplant.

What are the tests for Kidney Disease?

Both blood and urine tests are used to diagnose kidney disease. A blood test called GFR (Glomerular Filtration Rate) tells us roughly how well the kidneys are working as a % of normal. Simple urine tests sometimes show protein or blood cells. This often means an infection but it can be a sign of early kidney disease.

These are routine every-day tests which are done for various reasons such as

- if someone is ill to check if a kidney problem could be the cause.
- part of routine checks in people with high blood pressure or diabetes.
- because there has been pain or difficulty passing urine.
- routine tests when starting a new job.

Who is more likely to get Chronic Kidney Disease?

Anyone can develop CKD but it is more common with increasing age and in people of South Asian and African/Caribbean origin largely because they are more likely to get diabetes and high blood pressure.

What do the tests mean?

There are 5 categories of CKD, called stages.

- **Stage 1**
  - This covers people with problems such as protein in the urine whose GFR is normal.
  - **Action:** see ‘What can be done about CKD?’ in this leaflet.

- **Stage 2**
  - This covers people with problems such as protein in the urine whose GFR is 60-89%.
  - **Action:** see ‘What can be done about CKD?’ in this leaflet.
  - Otherwise GFR 60-89% does not mean CKD.

- **Stage 3**
  - **GFR 30-59%**
  - This means the kidneys are not working so well
  - **Action:** see ‘What can be done about CKD?’ in this leaflet.

- **Stage 4**
  - **GFR 15-29%**
  - This means more marked kidney changes
  - **Action:** More frequent checks needed. Explain dialysis and transplant options.

- **Stage 5**
  - **GFR less than 15%**
  - Approaching need for dialysis
  - **Action:** More frequent checks needed. May need to start dialysis or have a transplant.

Why does GFR matter?

Because a lot can be done to prevent future health problems. People with CKD tend to have high blood pressure which can cause narrowing of the arteries and lead to heart and circulation problems. High blood pressure can also make kidney conditions worse. Regular checks, and in particular careful blood pressure control, can be a big help in preventing these problems and in stopping the kidneys getting worse. Other steps that can be taken are described over the page.

What do kidneys do?

Most people have two kidneys, one on each side of the spine, at the back of the waist. Each kidney is about the size of a clenched fist.

Healthy kidneys do a number of important things. They remove wastes and toxins from the body by filtering the blood, and by varying the amount of urine passed (depending on how much we drink) the kidneys make sure the body retains the right amount of water.

What causes Chronic Kidney Disease?

The commonest causes are high blood pressure (also called hypertension) and diabetes. In both of these it usually takes many years before the kidneys become affected. It is more common if the blood pressure or the diabetes hasn’t been as well controlled as it should be. Other less common conditions are caused by inflammation (glomerulonephritis) or infections (pyelonephritis). Sometimes CKD is inherited (polycystic disease) or the result of longstanding blockage (such as enlarged prostate or kidney stones). Some drugs can cause CKD, especially some pain-killing drugs (analgesics) if taken over a long time. Often it isn’t possible to say what has caused the problem.