

# Quality and the Patient Experience in Renal Services

## Preparatory workbook

**Workshop on Quality and Patient Experience**

27<sup>th</sup> February 2007  
Prospero House  
241 Borough High Street  
London, SE1 1GA

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Chair and facilitator of the day

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# Programme for the day



## Workshop on Quality and Patient Experience

27<sup>th</sup> February 2007  
 Prospero House  
 241 Borough High Street  
 London, SE1 1GA

### Purpose of the day

The purpose of the event on 27 February is to discuss how we measure experience and ensure that the voice of patients and their own carers is incorporated into care planning, commissioning and service evaluation.

The objectives of the day are for participants to contribute to a patient checklist that will enable patients to provide systematic feedback on what they consider to be the key elements in the quality of the care they receive and to consider tools to measure patient experience. This and other strategies of engagement will help the renal community to integrate patient experience into quality, planning, commissioning and service delivery agendas. Sessions will be interactive in order to give you the maximum opportunity to contribute to dialogue, debate and decisions.

### Programme

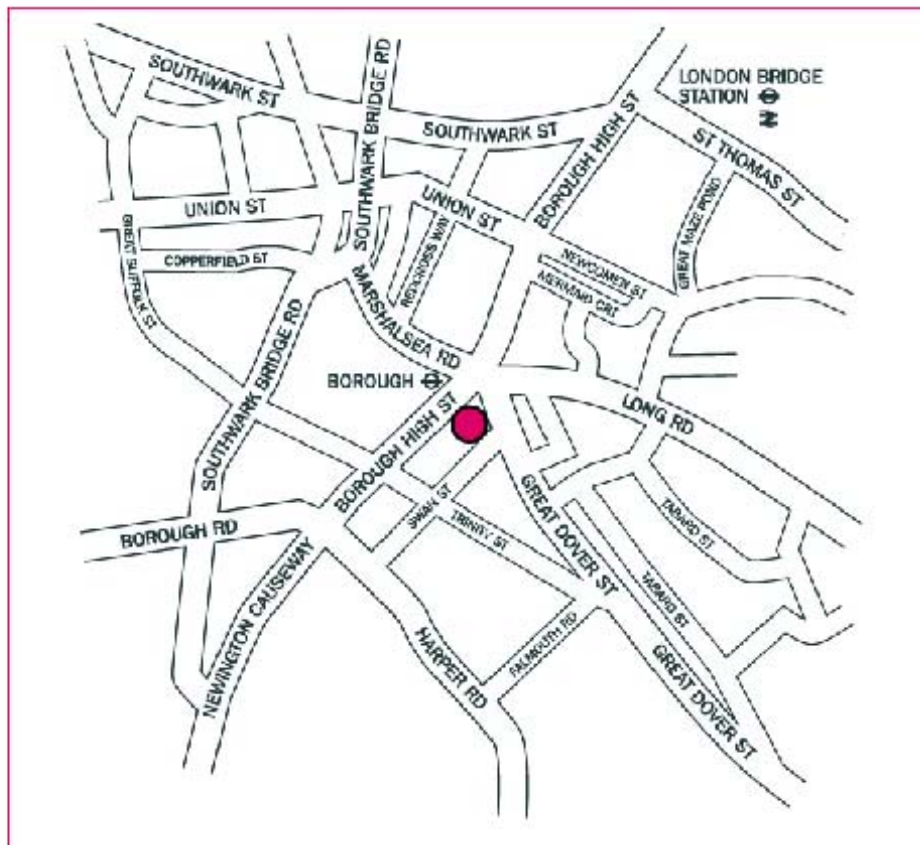
- 10.00 Refreshments and Registration
- 10.30 **Welcome and Housekeeping:** Professor Paul Stanton – Facilitator (Adviser on Standards, DH)
- 10.40 **Introduction:** Dr Donal O'Donoghue, National Clinical Director for Kidney Care
- 10.50 **The National Context of Service Improvement and Patient Led Reform:** Professor Stanton
- 11.10 **Measuring Patient Experience:** Simon Watson, Consultant Nephrologist and NHS Institute Fellow
- 11.30 **Ensuring Patient Experience Is Part of Care Planning:** Polly Moseley, Patient and Fellow of the Clore Leadership Programme
- 11.50 **Workshop Task 1: *Responding to the challenge*:** Mapping the shortcomings in current service provision for renal patients and developing a patient checklist of the characteristics of 'reliable and high quality care'
- 13.00 **Role of Patient Empowerment Champion for the Vascular Programme:** Leonard Levy, DH
- 13.10 Lunch
- 13.50 **Empowering Patients:** Shelagh O'Riordan, Consultant Geriatrician, Kent and Canterbury Hospital
- 14.00 **Workshop Task 2: *From rhetoric to reality*** – Identifying the key challenges that need to be overcome and the actions that need to occur if renal patients are actually to exercise 'choice, voice and control' at every stage in the planning, commissioning, delivery and evaluation of their care
- 15.15 Refreshments and personal action commitments
- 15.30 **Feedback/questions session**
- 16.00 **Conclusions:** Dr Donal O'Donoghue and Gerry Lynch, National Policy Lead
- 16.30 Close

# Directions

## Location map and directions to Prospero House

etc.venues – Prospero House  
241 Borough High Street  
London  
SE1 1GB

Call: 020 7105 6010  
Send: 020 7105 6001



# Introduction

This workbook contains preparatory reading and activities that you may wish to complete ahead of the Quality and Patient Experience Workshop on 27th February, 2007. Since the workshop is designed to provide a more interactive forum for critical reflection than those with which you may be familiar, this workbook offers an opportunity for you to become familiar with both the substantive content and some of the approaches that will be used on the day.

## Aims of the workbook

The workbook is intended to act as a prompt to critical reflection and imaginative engagement with the many ways in which the quality of experience of patients with renal problems could be improved. As you go through the workbook, you will be invited to:

- consider some of the strengths and some of the weaknesses in the ways that care is currently provided and the extent to which care meets the Standards set out in Parts I and II of the National Service Framework for Renal Patients (2004 & 2006) DH.
- explore ways in which patients themselves (and their own carers) can become more fully involved as active partners with professional staff at all points in the definition of the renal services that are needed for local communities, the commissioning of these services and the delivery and evaluation of care
- consider ways in which the potential of new technology, new information systems and the electronic patient record could be used as a driver and enabler of service improvement.

The workbook provides you with the opportunity to watch, to read and think about patient stories – and to begin to reflect on the stories you could tell about the process of care and the opportunities for improvement – whether your perspective is that of a patient, a carer, a commissioner or a member of a clinical team.

*'How wonderful it is that nobody need wait a single moment before starting to improve the world?'*

*Anne Frank (1929-1945) The Diary of Anne Frank*

*'Find purpose, the means will follow.'*

*M K Gandhi*

*Please note that, if you do not have access to a computer that has Windows Media Player, the digital stories will be available for you to view on the day of the Workshop, from 9.30 am and again at lunchtime.*

## Using the workbook

The workbook contains a number of tasks. You can expect to spend between one and one and a half hours if you engage fully with the activities and with the reading included in the two appendices.

It will be helpful if you could write your responses to the questions in the boxes provided. If you are prepared to share these answers, they would add significantly to the outcomes from the workshop. In any event, please bring the workbook with you to the workshop.

We hope that this workbook will be a stimulus to creative approaches to the issue of quality improvement and will help cultivate a positive and hopeful approach to the day – one which is founded in creativity and openness and a willingness to share your experiences as well as your aspirations, whether you are a patient, a carer, a clinician or a manager.

*Please don't skip the side bars – they contain text which is always useful and sometimes essential to your understanding of the main text.*

## Reflecting on experience

The enormous pressures and stresses of life for people who suffer from renal problems and those who care for them – like the pressures upon staff working within the NHS – can drain creative energy and degrade our capacity for positive and imaginative thought.

In the days before the workshop, try to make a little time to attend to those things that inspire, comfort or move you – whether this is looking out at your garden or a pleasing landscape, watching a film or reading a book that you enjoy, making some time for yourself or giving yourself a small treat.

### Task 1: Stand back and reflect

Try to think of a book, a poem, a film, a TV programme, a painting or a piece of music that seems to say something about your own experience as a recipient or a provider of care.

In the space on the next page, jot down the title of the book, film, TV programme, piece of music, picture or whatever, briefly note why it made an impression on you, and describe the key message about care and the ways in which it could be improved.

*'We do not learn from experience. We learn from reflecting on experience.'*

*John Dewey, 1939  
Experience and education*

Title	Impression it made	Key messages about care

## Task 2: Not waving but drowning

Please read the poem 'Not waving but drowning' by Stevie Smith.

What does this poem tell you about the experience of being ill in our society?

### ***Not waving but drowning***

*Nobody heard him, the dead  
man,*

*But still he lay moaning:*

*I was much further out than  
you thought*

*And not waving but drowning.*

*Poor chap, he always loved  
larking*

*And now he's dead*

*It must have been too cold for  
him*

*his heart gave way, they said.*

*Oh, no, no, no, it was too cold  
always*

*(Still the dead one lay  
moaning)*

*I was much too far out all my  
life*

*And not waving but drowning.*

### Task 3: Throwing the lifebelt

Please read the poem 'Throwing the lifebelt' by Brian Patten (in the side bar).

What does this poem tell you about the experience of being a (paid or unpaid) carer in our society?

#### ***Throwing the lifebelt***

*And the one throwing the  
lifebelt,  
Even he needs help at times;  
Stranded on the beach  
Terrified of the waves*

### Task 4: The Dormouse and the Doctor

If you have access to a computer that has Windows Media Player, you may also enjoy looking at a digital version of a deceptively simple poem written by A.A. Milne (creator of Winnie the Pooh) in the late 1920s during an illness towards the end of author's life. 'The Dormouse and the Doctor' can be found at the following web address: [www.patientvoices.org.uk](http://www.patientvoices.org.uk) by clicking on the 'Stories' tab at the top of the page and then following the link in the left margin to 'Stories from Pilgrim Projects'.

Please note your response below.

*Note: A PC will be available at the Conference Venue from 9.30 am on the morning of the 27<sup>th</sup> so that you can watch the stories, in case you do not have access to a computer that can play this, and the other digital stories referred to below.*

Has the world moved on in the last 80 years? Or are there aspects of the doctor's behaviour that have echoes of the ways in which some professional staff still behave?



You will also find at the Patient Voices website ([www.patientvoices.org.uk](http://www.patientvoices.org.uk)) a number of brief patient, carer and staff stories, some of which are mentioned later in this workbook. The stories have been told by people who have powerful messages to convey about aspects of care that mean a great deal to them. The stories are a free resource and listening to them can help us to reflect upon our own experiences with or within the health and caring services – and to consider how these experiences might be improved.

*'To do things differently, we must see things differently. When we see things we haven't noticed before, we can ask questions we didn't know to ask before.'*

*John Kelsch, Xerox*

## Putting patients at the heart of care

The work of the NHS, alongside partner organisations in the independent and voluntary sectors, and in Local Government, is to commission and to provide care for local communities and for patients and others who need to use public services – as we will all need to do at different times in our life.

*'Patients should have choice, voice and control at every stage of their care.'*

The Department of Health, 2000, *The NHS Cancer Plan*

Public services can only remain up-to-date, sensitive and effective if local communities, patients and carers are:

- full and active partners in every aspect of the definition of the services that are needed
- involved in the commissioning of these services from a range of potential providers;
- full and active partners in the delivery of care
- a powerful voice in the evaluation of the quality of care that has been provided.

This recognition lies at the heart of the Government's NHS and overall system reform agenda as expressed in the 2002 DH document *Shifting the Balance of Power: Securing Delivery*.

*'The NHS Plan sets out our ambitions to create a patient-centred NHS. Our vision is to move away from an outdated system towards a new model where the voice of the patient is heard through every level of the service, acting as a powerful lever for change and improvement.'*

Specifically, this commitment lies at the heart of the National Service Framework for Renal Services (see below). The first Standard – 'A Patient Centred Service' – applies across all elements of the Framework

*'Our goal is to move away from a paternalistic model of decision making towards a model of partnership, whereby citizens have a greater connection with their local services, and have a say in how they are designed, developed and delivered.'*

Although much has been achieved in Renal and other NHS services in recent years, significant challenges still remain. 'Our Health, Our care, Our say' re-emphasised the commitment to invest in the promotion of health and well being, to move care nearer to people's homes and to make use of every opportunity presented by new technologies and by partnerships within local communities to prevent those illnesses that can be prevented and radically to improve the flexibility, the accessibility and the overall co-ordination of services to people with long term conditions. We will consider some of these opportunities later in this workbook.

Department of Health, 2002, *Shifting the Balance of Power: Securing Delivery*

The provision of care remains, however, a complex undertaking – and one in which, inevitably, it can take years to move from commitment to improved day-to-day reality. When the National Audit Office carried out their recent study of stroke services in England (NAO 2005), they commissioned Pilgrim Projects to capture some of the experiences of patients who had suffered from stroke – and their carers – in order to highlight some of the challenges that the system still needed to overcome (and to highlight the massive contribution that voluntary groups make to the promotion of health and well being, alongside the NHS and other statutory services).

Although all clinical conditions give rise to their own specific issues and challenges, a number of the themes highlighted by stroke patients appear to parallel experiences of patients with other long term conditions.

## Task 5: Fast, appropriate responses

If you have access to a computer, please go to [www.patientvoices.org.uk](http://www.patientvoices.org.uk), click on the 'Stories' tab at the top of the page and follow the link in the left margin to the 'Re-connecting with Life' stories. There you will find Andrew's story 'Fast, Appropriate Responses'. When you have watched it, please answer the questions below.

To what extent could elements of Andrew's care have happened to a patient with acute kidney problems?

What do you think were the major weaknesses in the care Andrew received?

How could Andrew's care have been improved?

What lessons are there, if any, for renal services?

The stroke stories can be seen at [www.patientvoices.org.uk](http://www.patientvoices.org.uk)

Follow the Stories tab to the 'Reconnecting with Life' stories.

The NAO report, *Reducing Brain Damage: Faster access to better stroke care* can be found at [www.nao.org.uk/publications/nao\\_reports/05-06/0506452.pdf](http://www.nao.org.uk/publications/nao_reports/05-06/0506452.pdf)

## Task 6: What good care can look like

A major contrast to Andrew's experience is provided by another of the 'Reconnecting with Life' stories: Ossie Newell's 'A Vision of the Future'. Ossie relates a real incident and the way the system responded. He concludes that this should be a model for all stroke care in the future

What are the features of the care that Ossie describes that result in such a successful experience for the patient?

## Task 7a: Think of a story of care

In order further to explore issues in relation to the care of people with kidney problems, spend a few minutes thinking about a story that captures the essence of:

- 1 the care you yourself have received, if you are a renal patient
- 2 the care that the person who you help to support has received if you are a carer
- 3 the care that a specific patient (rather than patients in general) receives if you are a clinician
- 4 the characteristics of the care that you commission if you are a commissioner.

In each case, try to consider the person's total experience of care and try to locate that within the context of their whole life. In other words, think about all the people who are touched and affected by their health problem (family, friends, carers, colleagues, etc). We will return to this story in Part b of this task. Use the space below for your notes.

*'Patients make two types of journey – disease journeys and healthcare journeys. The disease journey progresses through diagnosis to treatment, which leads to cure or lifelong co-existence. The healthcare journey is punctuated by events like consultations, operations and prescriptions, and each journey is unique.'*

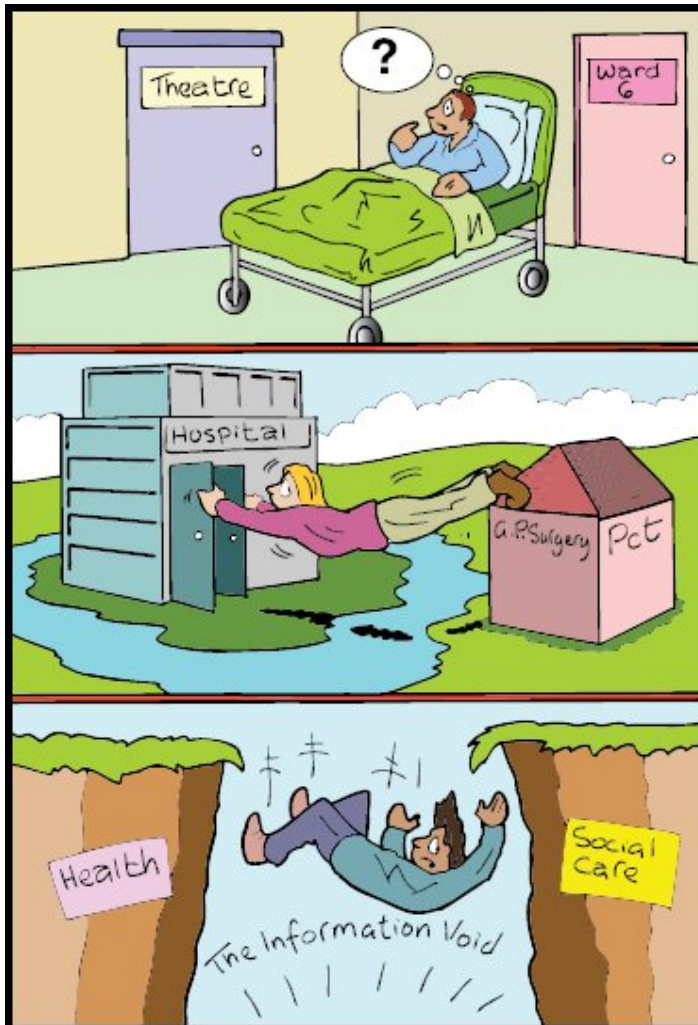
J. Muir Gray, 2002, *The Resourceful Patient*

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*'Weaknesses in any system of care are likely to be most keenly felt by patients when they move between different parts of the same health organisation (e.g. between the A& E and a ward), when they move from the care of one health organisation to another (e.g. when they move between primary care and an acute hospital and back again) or when they move from the care of a health provider to the care of a social care or voluntary sector provider.*

*The dislocation and failures of communication become more extreme with each successive step – creating risk and disruption for patients and often undoing so much good that has been done within any one of these environments.'*

Adapted from Paul Stanton 2006

As was the case with Ossie's stroke story, the effective care of renal patients depends upon co-ordination between a number of care organisations – for patients needing hospital based haemo-dialysis, for example, properly co-ordinated transport links are vital to safe and efficient provision of care . Proper coordination also keeps to an inescapable minimum the disruption to the lives of patients. In addition, renal patients come into contact with many health and other caring professionals during the course of their journey. How far do you think it is possible for their care to be seamless or are there likely to be unintended discontinuities or dislocations in their care?

**Task 7b: Reflect on your story**

In the light of these thoughts, reflect upon the story that you completed in Part a of this task that captures the essence of your own experience. Please answer the questions below.

If you were telling the story in the way that Andrew or Ossie did what would be the key points that you would want to bring out?

What would be the key messages?

Who would the messages be for?

What would you want them to do differently in order to improve the quality of care as a result of your story?

**My Bus Conductor**

*My bus conductor tells me  
he only has one kidney  
and that may soon go on strike  
through overwork.*

*Each bus ticket  
takes on a different shape  
and texture.  
He holds a ninepenny single  
as if it were a rose  
and puts the shilling in his bag  
as a child into the gas meter.  
His thin lips have no quips  
for fat factory girls  
and he ignores  
the drunk who snores  
and the old man who talks to  
himself  
and gets off at the wrong stop.*

*He gently goes to the bedroom  
of the bus  
to collect  
and what familiar shops and  
pubs pass by  
(perhaps for the last time?).  
The same old streets look  
different now  
more distinct  
as through new glasses.  
And the sky  
Was it ever so blue?*

*And all the time  
Deep down in the deserted bus  
shelter of his mind  
he thinks about his journey  
nearly done.  
One day he'll clock on and  
never clock off  
or clock off and never clock on.*

*Roger McGough*

# Developing a checklist for renal patients

One important outcome of the workshop will be the development of a checklist that will enable renal patients to make an informed judgement on the quality of the care that they receive.

Every clinical condition presents its own particular set of challenges if care is to be of a uniformly high standard for all patients. This may be especially true for renal patients because of the massively disruptive impact that their condition and its treatment can have on every aspect of life – and because of the way in which some minority communities have a specific susceptibility to kidney disease.

## Standards for Better Health

Nevertheless, every NHS patient has a right to expect that the care they receive meets their legitimate expectations. In *Standards for Better Health* (DH, 2004) the government has set down 24 'core standards' that must be met by all those who provide (or commission) NHS care.

Important as this process of quality assurance is, the Standards themselves and the process that leads to the performance rating of an entire NHS Trust can feel remote from the day-to-day experience of the individual patient and her/his carer (and remote from the direct care provided by clinicians and clinical teams). Although there are now mechanisms to gather the views of a cross section of patients (via the Patient Survey), few organisations routinely gather information from every patient who is in receipt of care. Even fewer use this information in a systematic way to review and improve the quality of the care that they provide for specific patient groups.

## The National Service Framework for Renal Services

In addition, therefore, to the 'high level' Standards set out in *Standards for Better Health*, government has developed a specific National Service Framework (NSF) for Renal Services that establish key standards and 'quality markers'. The aim of National Service Frameworks is to ensure the safety of current care, wherever in the country it may be provided and should lead to the ongoing development and continuous improvement of services.

The Renal NSF is in two parts. The first (published originally in 2004) concerns Dialysis and Transplantation services. It sets five key standards and identifies a number of 'markers of good practice' to further improvement.

*Standards for Better Health is available at*

[www.dh.gov.uk/assetRoot/04/13/29/91/04132991.pdf](http://www.dh.gov.uk/assetRoot/04/13/29/91/04132991.pdf)

*NHS Trusts are judged by the Healthcare Commission on the basis of their compliance with these standards. A performance rating is published each October as a result of the Commission's Annual Healthcheck – and this information is available to the general public, to local communities and to individual patients.*

*The National Service Framework for Renal Services can be found at*

[www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Renal/RenalInformation/RenalInformationArticle/fs/en?CONTENT\\_ID=4102636&chk=sTeHxa](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Renal/RenalInformation/RenalInformationArticle/fs/en?CONTENT_ID=4102636&chk=sTeHxa)

The second part of the Framework (published in 2005) deals with 'Chronic Kidney Disease, Acute Renal Failure and End of Life Care' and sets out four quality requirements 'designed to bring about improvements in the overall health experience for people with kidney disease'.

The four quality requirements specify the elements of good practice in relation to:

- prevention and early detection of chronic kidney disease
- minimising the progression and consequences of chronic kidney disease
- acute renal failure
- end of life care.

Crucially, in the context of the Workshop on 27th February, the National Service Framework explicitly states that the first Standard, 'A Patient Centred Service', although set out in relation to Dialysis and Transplantation "applies across the whole of this NSF".

It is not easy, however, to know whether this Standard is being routinely met in the day-to-day delivery of care. For this reason we want to develop a checklist for renal patients so that they can make an informed judgement about the quality of care they receive. This information needs to identify and highlight those issues that matter most to renal patients. Agreeing this checklist will form one key task of the Workshop Groups on the 27th February.

In order to think about the questions that might go into such a checklist, you may like to consider the outcome of work already undertaken with patients and patient groups by the late Ian Kramer. Ian was a remarkable and gifted man who worked, during the last years of his life, as an Expert Patient and Associate Director in the National Clinical Governance Support Team.

You can hear Ian and learn from some of his experiences at the [www.patientvoices.org.uk](http://www.patientvoices.org.uk) website by clicking on the 'Stories' tab at the top of the page and then following the link in the left margin to Ian Kramer's stories.

*The five key standards define what should be expected in relation to:*

- a patient-centred service
- preparation and choice
- elective dialysis access surgery
- dialysis
- transplantation.

*The Standard states that*

*'All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.'*

*In particular, you might be interested in Ian's 'Introduction' and 'Serving the patient's needs'.*

## Task 8: Patients' rights

In the table on the next page are listed the specific rights that Ian and his patient and carer colleagues believed that everyone is entitled to expect.

Do you think that some or all of them should apply to renal patients? If you think they should apply, do you believe that they actually apply now?

Please place a tick next to any statements with which you agree and then say whether you think that right is currently enjoyed by **all**, **some** or **no** renal patients.

Finally, please make a note of any specific elements or rights relating to renal patients that you feel are missing from the list.

As a patient, I have a right to:	Agree	All renal patients	Some renal patients	No renal patients
be a full and active partner in my own care				
receive care that recognises me as a whole person with spiritual, emotional, social and health needs				
be consulted and listened to – even when I don't agree with the care that I am offered				
give or to withhold consent to treatment that is offered to me				
choose where and by whom I will be treated				
receive information about all aspects of my condition and the treatment that is prescribed for me in a form that I can understand				
decide who can have access to information about me and my condition				
nominate a carer or carers to become full partners in all aspects of my treatment and care				
know what the side effects of any treatment are likely to be				
receive joined up care when I move between different health and/or social care providers				
<b>Other rights that should relate to renal patients:</b>				



## Task 9: Patients' responsibilities

Rights and responsibilities go hand in hand.

Please consider the five key responsibilities that Ian and his colleagues believed that patients should exercise. Place a tick next to any of the statements with which you agree, particularly in relation to renal patients.

I have a responsibility to:	Agree
take the best care I can of my own health	
seek help in a timely fashion if my condition deteriorates	
comply fully with treatment that has been prescribed for me and that I have agreed to	
work positively and in partnership with those who care for me	
provide feedback on the positive and the negative aspects of my care and suggest ways in which care could be improved	

## Working in real partnerships

It is interesting that much of what Ian and his patient and carer colleagues describe, like the first Standard in the Renal Services NSF, emphasises the importance of patients working with professionals and with health and other care organisations as full and active partners.

At the workshop, we would like to consider how we can make real progress in the development of real and effective partnerships.

At the highest level, all NHS organisations have a legal obligation to involve local communities and patients in all aspects of the planning, delivery, monitoring and evaluation of their care (under the Health & Social Care Act 2000 - what is often referred to as the Section 11 duty).

Nevertheless, this duty is not easy to exercise in practice. In order to grapple with its demands it is probably best to think of it as two separate (though closely-related) duties:

- a 'duty to involve the public and those who represent local communities or patients with specific conditions in policy formulation and in resultant strategies and plans of action'
- a 'duty to involve all individual patients and their own carers' as full and active partners in their own care'.

*'My best advice to health providers is to think of us as partners. Treat us like partners. Tell us that you need our help too. You might think about setting up training sessions to help staff know how to ask questions that get the best answers. .... We need to take responsibility also. We need to learn to ask questions better. I would recommend more training for us. Remember we want to be part of the solution.'*  
 Toni Cordell, Adult Learner and Literacy advocate  
[www.tonicordell.com](http://www.tonicordell.com)

## The duty to involve the public

At a national level this duty is discharged, by trying to ensure that:

- the public are fully consulted in relation to major policy initiatives (as, for example, with the nation-wide consultation that gave rise to the priorities set out in *Our Health, Our Care, Our Say*),
- those who make policy work in close collaborative partnerships with national voluntary sector organisations that represent patients and carers (for example, Carers UK).

Where condition-specific national policies or initiatives are concerned, links should be made with groups who represent patients who suffer from these specific conditions (for example the NKF).

### Task 10: Involving patient organisations

To what extent do you believe that organisations representing patients with renal problems have been involved at national level in the formulation of policies and implementation strategies?

How could national engagement be improved?

Patient organisations have been/are involved in the following ways:

National engagement could be improved by the following means:

At a local level, every Primary Care Trust, Foundation Trust and other NHS Trust has a duty to work pro-actively with local communities and those who represent them. This is achieved through:

- close collaboration with Local Authorities
- support to and engagement with the Local Involvement Networks (LINKS), the successor bodies to the Patient Forums.

Additionally, in order to ensure that they promote equity, local organisations must have strategies in place that reach out to disadvantaged or marginalised groups so that their voices is heard and their needs are factored in to local priorities for action – an issue of

*Section 11 states that there is a 'duty to involve the public and those who represent local communities or patients with specific conditions in policy formulation and in resultant strategies and plans of action'.*

particular importance in relation to the prevention and effective management of renal problems..

At this level of specific clinical conditions those who commission care, as well as those who provide it, should develop ongoing collaborative relationships with local groups that represent patients with these specific conditions (e.g. the Northamptonshire and the Royal Free KPAs).

Where necessary, they should support these groups to reach out to members of 'hard to reach' communities who may not otherwise be appropriately represented. In this way, the needs of all patients can be factored in to the establishment of overall local priorities and the planning and shaping of specific clinical and service improvement initiatives.

### Task 11: Involving individual patients

To what extent do you believe that patients with renal problems have been involved at local levels in the formulation of policies and implementation strategies?

How could local engagement be improved?

Patients with renal problems and local groups which represent them are involved in the following ways:

Local patient engagement could be improved by the following means:

## The duty to involve patients and carers

To ensure that the voice of the individual patient is heard at the highest levels, the Government has appointed a 'Patient Czar' (Harry Caton). He and his team within the Department work with Ministers, National Clinical Directors (including the National Clinical Director of Kidney Care, Dr Donal O'Donoghue) and with the senior management of the NHS to ensure that the patient perspective informs all policy development and implementation priorities.

*Section 11 states that there is a 'duty to involve all individual patients and their own carers' as full and active partners in their own care'.*

At local levels the discharge of this aspect of the Section 11 duty requires every NHS organisation to have clear and explicit policies to ensure their staff (and those contractors who deliver services on their behalf) involve each individual patient (and, where required by the patient, their own carer/s) as full and active partners in their own care.

This should be true in relation to all aspects of care – but is absolutely vital in the planning, delivery and evaluation of care for those patients (such as those with renal problems) who live with long term conditions.

### Task 12: Patients and carers as partners in care

Standard 1 in the Renal Services NSF states that individual patients with renal problems should be ‘full and active partners’ in all aspects of their own care.

Please consider your experience, or the experiences of people you know and answer the questions below.

To what extent do you think renal patients are truly partners in care?

How could the situation be further improved?

To what extent do you believe that individual patients’ own carers are ‘full, active and valued members of the care team’?

How could the situation be further improved?

*You might find it interesting to watch Alison Ryan’s story about caring for her husband, Ian.*

*Go to [www.patientvoices.org.uk](http://www.patientvoices.org.uk), click the ‘Stories’ tab and follow the links to Alison Ryan’s stories. The story is entitled ‘Who cares?’*

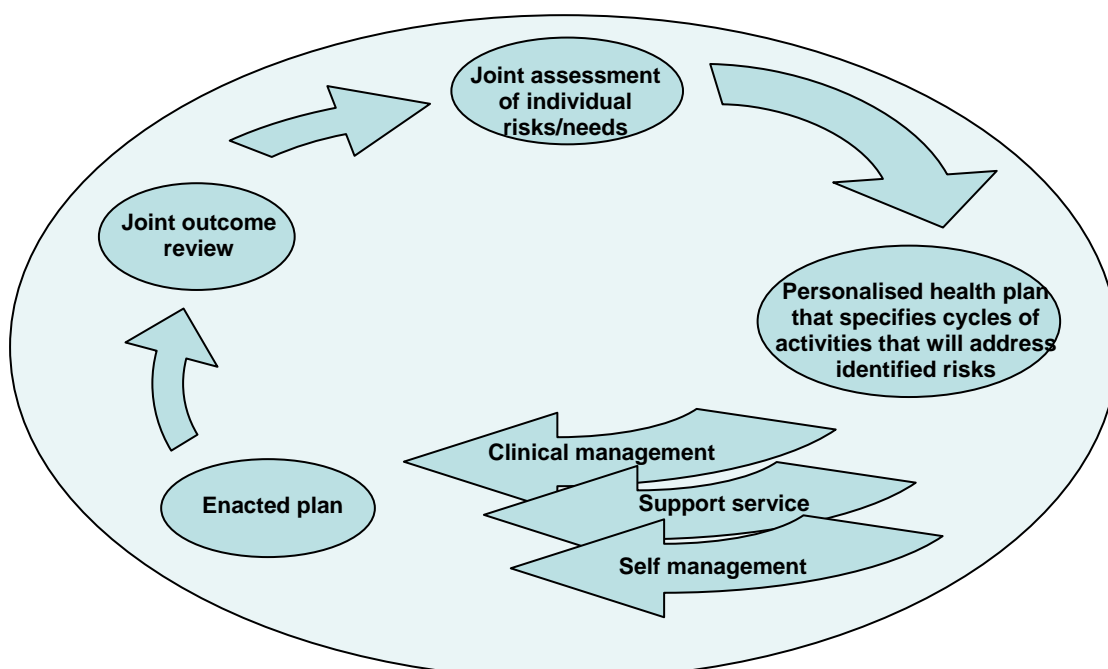
*More stories told by carers can be seen under Carers’ Resource, Harrogate, Craven and Airedale*

## The ‘co-production’ of care

Professor Bob Sang has pioneered an approach that fully involves patients. This approach is often referred to as ‘co-produced care’ – that is, an approach to the delivery of care that generates forms and patterns of care that are based around the needs of the patient rather than the needs of the system. For this to occur, patients (and their own carers) need to work alongside professional staff and organisational managers in defining the services that are needed, the shortcomings in existing provision and the steps that are needed to generate real improvements in the quality and effectiveness of care. This approach changes in quite profound ways the power relationship which historically existed between powerful professionals and ‘grateful’ (or ‘ungrateful’) patients. It makes different demands upon professional staff – and places additional responsibilities upon patients.

The key elements of the process, in line with Standard 1 of the Renal Services NSF, focus on building a personalised care plan *with* (as opposed to *for*) every person who has a long term condition. This plan aims both to improve the quality of individual life and minimise unnecessary dependence on, or avoidable use of, clinical resources.

Whilst working in collaborative partnerships inevitably takes time – it can be a vital investment that delivers important dividends to everyone concerned. The following diagram, from the Year of Care, captures key stages in the process.



*Professor Peter Degeling and his team at the University of Durham have described how this approach can be applied to work with Long Term Conditions. The Year of Care model that he has developed is being used in a number of PCTs in the UK.*

*You can learn more about Peter Degeling’s work at [www.dur.ac.uk/ccmd/](http://www.dur.ac.uk/ccmd/)*

*His Year of Care model is described at [www.researchoption.co.uk/hostpage.aspx?hid=XNTkJg+sUx7eiD2fZGXTA==&pd=ZY8nOkW8+zz1MZ7LF6vbTw](http://www.researchoption.co.uk/hostpage.aspx?hid=XNTkJg+sUx7eiD2fZGXTA==&pd=ZY8nOkW8+zz1MZ7LF6vbTw)*

### Task 13: Why collaborate?

Some of the benefits of collaboration are well described by Cath Lovatt from the Heart Improvement Programme in her story 'Why collaborate?' Cath's story can be found at [www.patientvoices.org.uk](http://www.patientvoices.org.uk).

Please watch the story and then answer the questions below.

*Click on the 'Stories' tab at and follow the link in the left margin to 'Stories from the NHS Heart Improvement Programme'*

How far do you think that these approaches could be used more extensively in the development of services for people with renal problems?

What changes and improvements might this generate?

## New opportunities

The 21st century is sometimes referred to as the 'new technological' age. Whilst not all 'innovations' are necessarily welcome, many can add to our personal comfort or our pleasure. Equally, so far as the prevention and management of ill health are concerned many opportunities are presented by new information management systems, new technologies and computer-assisted care.

### Task 14: A technological innovation

Technological innovation touches every aspect of all of our lives.

Think of one particular technological innovation that has made a contribution to the quality or comfort of your personal life since the new millennium.

Note the key characteristics that have enabled you to benefit from it.

My innovation is:

The characteristics that have enabled me to benefit are:

Technological innovations – if sensitively developed and used appropriately – also have the capacity to transform some elements of the process of care – even though, inescapably, its inter-personal dimensions will also continue to be vital. As Dame June Clark (2006) has observed, properly managed, new technologies ‘can be both an enabler and a driver of service improvement’.

In the Workshop, we will want to define some of the ways in which new technologies and information systems could be used to improve the quality of the patient experience for those with renal problems.

One early way in which innovation in health and social care is being pursued is through the development of better means to record and share information.

## Task 15: Assuring a flow of vital information: the Electronic Patient Record

If you can access the Patient Voices website ([www.patientvoices.org.uk](http://www.patientvoices.org.uk)), click on the ‘Stories’ tab at the top of the page and follow the link in the left margin to Monica Clarke’s Stories. There you will find ‘A part of the team’. Please watch the story and then consider the questions below.

To what extent might these kinds of problems impact upon renal patients?

To what extent could new forms of information transfer have eliminated the problems that Monica and her husband encountered?

*‘The Impact of ICT on Health, Healthcare and Nursing in the next twenty years’*

June Clark, 2006

*‘Assure a substantial flow of vital information ... so that the information derived would be helpful to all and harmful to none’.*

Bobbie R Allen, quoted in R Hardy, 1990 *Callback: NASA’s Aviation Safety Reporting System*

For renal patients it is vital the right information is available at the right time to all of those involved in the delivery of care. There has, however, been some controversy surrounding the development of an electronic patient record. Like all forms of innovation, it poses some ethical and practical questions in new and challenging forms - about, for example, the confidentiality and the safe handling of data, and the 'standardisation' of terminology. However, if these problems are overcome, the EPR has real potential to tackle some of the long standing problems that have arisen in relation to providing 'seamless' care.

## Task 16: The right information at the right time

To what extent do you think that an Electronic Patient Record can improve the process of care for renal patients?

What concerns, if any, do you have about its introduction?

I think the EPR may improve care for renal patients in the following ways:

My concerns about the introduction of the EPR are:

## Other forms of technological innovation

The *London Metro* newspaper recently reported that the first proto-types of 'Nursebots' would be on our wards and undertaking routine information giving and other tasks by 2010 (*London Metro*, January 22<sup>nd</sup>, 2007).

Even without such futuristic scenarios, the systematic, imaginative and co-ordinated harnessing of the power of existing telecommunications and computer technology can make massive contributions to the quality of life of patients with long term conditions and to the effective use of scarce clinical resources.

*'Tele-informatics "presents new opportunities to deliver and configure services and...new opportunities for professional development. ...If we are to realize [its] potential, we must be willing to communicate and work across professional*

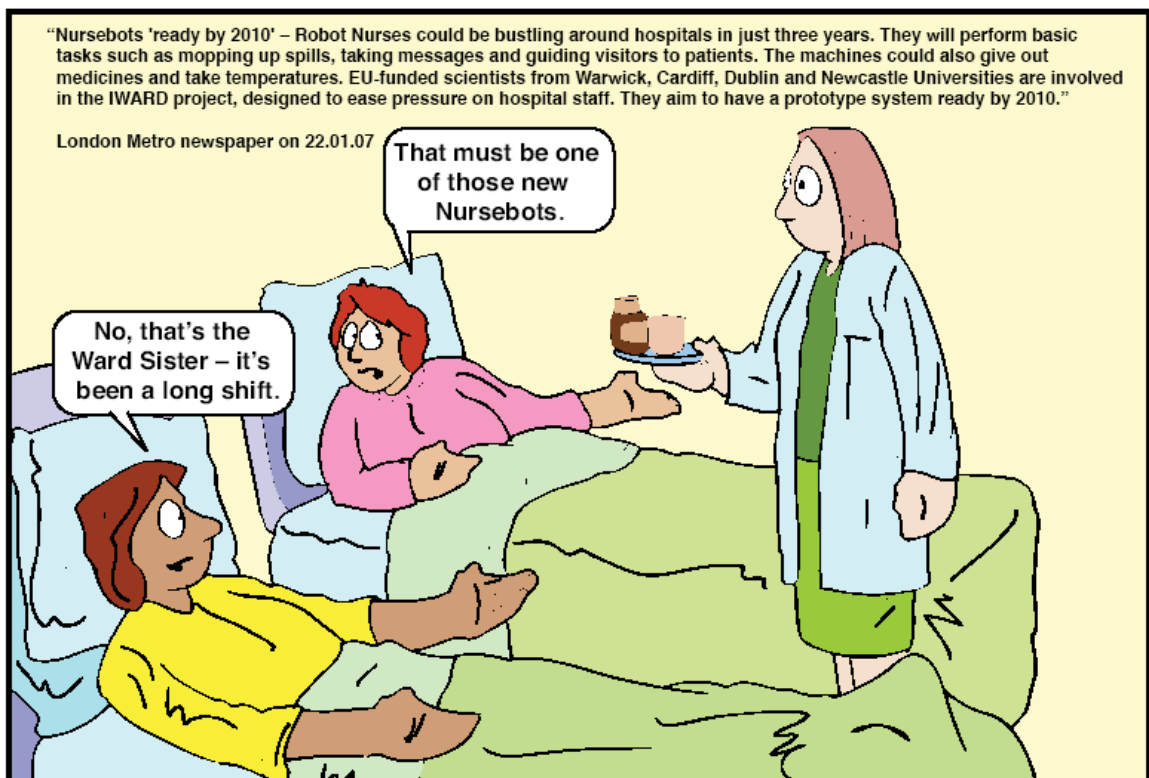


Here are just a few examples:

- online consultations with condition-specific tele-carers have been used to support people with asthma and reduce the frequency and severity of their acute episodes of illness;
- 'smart' houses can now provide 24-hour monitoring of frail and vulnerable older people
- there is an increasing use of text messaging to remind people to take essential medication or exercise.

*and organisational boundaries."*

May, C, Finch, T, Mair, F, Mort, M (2005) 'Towards a Wireless Patient: Chronic Illness, Scarce Care and Technological Innovation in the United Kingdom'



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## Task 17: Improving quality and safety

Give some thought to the examples given above. Do you think they could be used to improve the quality and safety of care to renal patients?

What other technological innovations do you think might be developed through collaboration between renal patients, their carers, clinical staff and technologists?

*This is a theme to which we will return on the 27th as part of Workshop 2.*

Technological innovations that could improve the quality and safety of care to renal patients:

## Conclusion

This workbook is meant to provide an introduction to what we hope will be a stimulating and productive workshop on the 27th of February. We hope you have found it helpful.

Even if you do not have the time to engage with the activities within this workbook before the day, please make use of it afterwards and feel free to share it with your colleagues and/or your friends.

Remember that we would also find it extremely helpful if you would share with us your answers to the tasks included in the workbook. In this way we can begin to build a Community of Practice dedicated to improving the quality and safety of renal services.

## Evaluation

Finally, we would be grateful if you would take a few minutes to answer the following questions about the workbook.

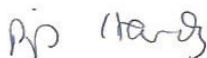
To what extent has the Workbook helped you to prepare for the Workshop on 27<sup>th</sup> February?

What elements of it have you found particularly useful?

How could the Workbook have been made more useful?

Any other comments?

Thank you.



Pip Hardy

Pilgrim Projects



Paul Stanton

On behalf of the DH Renal Services Improvement Team