ALEX HODSMAN, Specialist Registrar with the UK Renal Registry at Southmead Hospital in Bristol, reports on the UK Renal Registry.

2007–2008: A year in the life of the UK Renal Registry

The UK Renal Registry is a fantastic resource for the renal community and it reflects the dedication of staff caring for patients with kidney disease throughout the UK.

There are many other national and regional registries worldwide, but the UK Registry is unique in being fully electronic. This enables centre level comparison of markers of quality of care (audit standards) and places the UK in an enviable position of being able to both collect and analyse important existing and new data to plan and improve the care of patients with chronic kidney disease. It’s a pleasure to discuss some of the highlights of last year and some of our future plans.

The 2007 Annual Report

The Registry celebrated this year with the publication of the 10th Annual Report and has had several recent key aims.

The first has been to achieve 100 per cent coverage of the UK to provide complete demographic data – for example, on prevalence and incidence of renal replacement therapy (RRT) and patient survival. While five centres were unable to submit data for the 2007 report, only one centre will be outstanding in 2008 so that 100 per cent coverage is now almost a reality.

In conjunction with this the Registry published a focused commissioner’s report for the first time in 2007 to aid in service planning and this has been well received.

Timely data

The second aim has been to improve the timeliness of the report to ensure the data are as current as possible while still accurate. A sophisticated process of data cleaning and validating must take place before analysis and writing of commentary. To streamline this, an internal review of the report process was undertaken (and is still ongoing). This resulted in the publication of the report three months earlier than the previous year and we hope that some further improvement can be achieved.

One of the measures introduced to effect this change was to standardise the published analyses to facilitate year-on-year comparisons in key clinical areas for each dialysis centre. This has led to further exploration of the methodology for making comparisons between centres for markers of quality of care.

Funnel plots

Funnel plots are now widely used in the annual report to make between-centre comparisons and allow identification of true statistical differences between units. This should enable a more focused approach to identifying best practice in several areas in the management of RRT patients.

Providing timely, high quality analyses depends to a large extent on the quality of the data inputted into individual renal IT systems. There are still a number of issues with data completeness, in particular with co-morbidity and ethnicity data.

CONTINUED ON PAGE SEVEN
Welcome to our bumper edition of Nephrology News.

I am very pleased to inform you that our planned regional workshops have been very successful thus far. To commemorate World Kidney Day on 13 March, we held our first regional workshop in Cardiff. This was very well received and we followed it with another workshop in Birmingham on 22 May. The dates for future workshops in 2008 are:

- 15 July – Birmingham (fully booked)
- 18 September – Edinburgh
- 30 October – London
- 4 December – Belfast.

The workshops only cost £25 so if you haven't booked your place, please do so as soon as you can.

The RCN Nephrology Forum committee were very active at Congress in April at the Bournemouth ICC, including holding a joint fringe event on chronic kidney disease with the Anaemia Nurse Specialist Association (ANSA). Dr Chris Jones, a committee member, reports on this opposite.

Much debate at Congress centred around the Organ Donor Taskforce Report published in January and this has significant implications for renal transplantation. Dr Jane Bridger provides a detailed report opposite.

We are encouraging novice writers to share their work with nephrology nurses, so if you have completed the renal course and want to share your work with us, please send details to me. In this edition, we have Samuel Ntakirutimana, a staff nurse from Bristol, sharing his work with us on page 12.

New name next time

The Nephrology Forum committee, in our continuous attempt to modernise this newsletter, has decide to change its name to “Filtration” starting with the next edition.

We are very keen to hear from you and take forward issues on your behalf so do make contact with the committee through myself as Newsletter Editor. We look forward to your correspondence.

Mumtaz Goolam

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**Presumed Consent**

Dr JANE BRIDGER, research associate and a member of the Nephrology Forum steering committee, sends this report.

**Organ Donation Taskforce: the UK perspective**

In January the Government announced it would back the recommendations of the Organ Donation Taskforce (DH, 2008), which could see a 50 per cent increase in organ donation in the UK within five years. Although the taskforce did not consider legislative changes, such as presumed consent, it has been asked by the Secretary of State for Health to look at whether a change to presumed consent would increase the number of organ donors.

**Congress votes on presumed consent**

In the first debate, members voted against the resolution that Congress should oppose any attempt to make consent to organ donation presumed. The resolution was submitted by the RCN Pain Forum in response to calls for the introduction of an “opt-out” system of organ donation to increase the numbers of organs available for transplantation.

The current opt-in system requires individuals to give informed consent to donation, but currently less than 25 per cent of the UK population is on the NHS Donor Register.

The debate was opened by David Mathers from the Pain Forum who said that while the forum is fully supportive of the need to raise levels of organ donation, the opt-out system would provide a more holistic approach to donor registration.

**On the Congress Fringe**

Dr CHRIS JONES, consultant nurse and a member of the Nephrology Forum steering committee, reports from the recent RCN Congress in Bournemouth.

**Forum presents annual CKD workshop**

Each year the Nephrology Forum presents a workshop aimed at raising awareness of kidney disease among nurses from other specialties. We want to highlight the commonality of causes and treatments with other chronic disease areas and it also gives us an opportunity to collaborate with the Anaemia Nurse Specialist Association (ANSA), a group specialising in the treatment of anaemia, a common and costly co-morbid condition in kidney disease.

This year’s event was very well attended with approximately 50 people coming along to the workshop presented by myself and Sue Pickard from ANSA, with facilitation from the other RCN forum committee members. Topics included:

- how to measure renal function
- interpreting abnormal results
- referral criteria
- treatment advice
- co-morbid conditions.

The event finished with practical case studies highlighting the issues around managing kidney disease.

We had lots of positive feedback and were able to promote the more in-depth regional workshops being held by the forum this year.
Pain: the 5th Vital Sign

If we can learn to measure a patient’s pain as routinely as we take their pulse, blood pressure, temperature and respiration, then we will have taken a huge step towards managing it.

That was the central message to nurses across all fields of practice who attended Pain: the 5th Vital Sign, a fringe event at RCN Congress staged jointly by the RCN Pain Forum and the Chronic Pain Policy Coalition.

In the past year the Coalition has been engaging with all the royal colleges as well as patient groups, employers and the DWP, and the result is a new Pain Manifesto which received its parliamentary launch in May.

The Pain Manifesto

Val Conway, Consultant Nurse, East Kent Hospitals NHS Trust, and a member of the RCN Pain Forum committee, outlined the five pledges of the CPCP manifesto and suggested how nurses can be key in implementing them.

- **Education:** “We need to make sure pain management is an integral part of all professional training. As practitioners we also need to put pressure on our employers. Nurses are closer to the patients and we must advocate for them.”
- **Empowerment:** “Whenever possible, we must develop strategies to prevent acute pain becoming chronic. Employers and PCTs must be encouraged to provide self-management courses to help people who do have chronic pain cope within a normal daily routine.”
- **Collaboration:** “Nurses cross boundaries. Within the multidisciplinary team, with GPs and occupational health practitioners – wherever we work, we have real knowledge and skills to contribute.”
- **Early access:** “We know our local areas very well so we need to make sure our patients get seen sooner to help prevent acute pain becoming chronic.”

- **Measurement:** “It’s up to us as professionals to update ourselves on how to go about measuring pain. There are cancer tools, even tools to measure acute pain becoming chronic.”

Val challenged delegates to work creatively and incorporate the five key points into their area of practice. The irony is, she concluded, most of these pledges won’t require huge additional outlays of cash or resources. “They fit well within the Government’s professed emphasis on ‘joined up’ policy-making. Find the key opinion people and then funding will follow.”

In **Northern Ireland**, the Health Minister for the Department of Health, Social Services and Public Safety (DHSSPS) has endorsed the work of the Organ Donation Taskforce: “These UK-wide recommendations should go a long way to increasing the supply of donor organs to meet demand.”

The debate on presumed consent will take place in Northern Ireland, as elsewhere, within the framework of the taskforce recommendations.
ABLE is the acronym for **A Better Life through Education and empowerment**.

The original objectives of ABLE were to:
- highlight the incidence of kidney disease in black and minority ethnic (BME) groups
- reduce the incidence of established renal failure (ERF) among such groups
- where it cannot be avoided, ensure early referral, optimal treatment and equality of access to dialysis and transplantation.

Department of Health funding enabled the support of initial general awareness and education from 2001, including the production of an important publication in the form of a statement of position. *Preventing kidney disease: the ethnic challenge* was written on behalf of the charity by Dr Elizabeth Lightstone, Senior Lecturer and Honorary Consultant Renal Physician at Imperial College, London.

The aims were to:
- define the current state of knowledge about the need and causes of ERF in BME communities
- outline the initiatives which need to be implemented to reduce the incidence and alter the outcome of renal disease in these communities.

Suggested initiatives were:
- education and raising awareness - targeting both community and health care professionals
- identification of current best practice for management of individuals "at risk"
- definition of the populations "at risk"
- promotion of research into underlying causes, prevention and treatment strategies

A pilot study took place in Brent, North London in the summer of 2002. The formal research and awareness projects then followed and these are summarised here.

**“To determine the knowledge and attitude to the prevention of renal disease among South Asians in Leicester”** (2003-2007)

Led by Professor John Feethally, Professor Azhar Farooqi OBE, a general practitioner and myself as ABLE Development Manager.

Objectives:
- Raise awareness among local "at risk" communities, thereby determining effective awareness methods. Pre- and post-intervention qualitative focus groups were undertaken to assess levels of knowledge - an educational campaign formed the intervention. A steering group and an educational group oversaw the progress of the project and the latter was informed by results from the first focus groups through an “action research” approach to deliver an appropriate educational approach and relevant resources.
- Engage with primary care to raise awareness of chronic kidney disease management. This work preceded the Quality Outcomes Framework (QOF) and the Renal NSF Part Two.

Outputs and Outcomes:
- The post intervention focus groups indicated increased awareness and positive lifestyle modification.
- The steering group developed and produced innovative multilingual educational materials – an interactive DVD and literature.
- The action research reinforced the important decision to initiate and develop "peer educators": lay local community members trained by the ABLE team in renal health promotion. They went through a 33 hour training programme and have had an excellent impact with verbal and written feedback from the communities.

**“Renal dysfunction in an ethnically diverse cohort population – a study of prevalence, risk and awareness.”** (2003-2008)

Led by Dr Liz Lightstone et al., Imperial College, London.

Objective:
- Define and compare the prevalence and correlates of CKD stage 3 in an Indian Asian (IA) community in London with local white and black communities.

Outcomes:
- It was hypothesised that kidney disease in IA and black men may deteriorate more rapidly to ERF and this requires longitudinal study (which follows here).

**The LOLIPPOP study (2008).** A prospective study to determine if kidney function declines more rapidly in UK Indian Asians than whites.

Led by Dr Lightstone et al., Imperial College.

Objectives:
- Despite having no higher rates of CKD stage 3, determine why IA patients suffer more ERF and how this may be prevented.

This project is to commence imminently.


Led by Dr Jo Adu, Dr Hugh Rayner and Sister Pat Simoyi, Birmingham; myself as ABLE Development Manager.

Objectives:
- An awareness programme targeting community and primary care.

Outcomes and outputs:
- Several community outreach awareness events have taken place
place. There is now also a national focus to this work.

- Referrals to GPs have been made as a result of simple blood pressure screening.
- Specialist literature has been produced, guided by a local steering group with community, patient and health care professional input.
- From the outset, GPs were invited to educational seminars and CKD management guidance was sent out (this was before the QOF and NSF).
- GPs and the public have been very receptive; Peer Educators have been trained and have been well received at grassroots level.

“Exploring access for the UK’s south Asian and white population with type 2 diabetic renal disease” (2006-2010)
Led by Professor Gurch Randhawa, University of Bedfordshire; Professor John Feehally, Leicester and Dr Liz Lightstone, Imperial College.

Objectives:

- Develop a culturally competent diabetic and renal service. An Asian person with diabetes is 10 times more likely to get ERF than a white person with diabetes.
- Assess what information and care/treatment are provided through audit and qualitative research interviews.

Formal research is due to be completed January 2009, followed by a final year of dissemination.

Led by Dr Anthony Warrens, Imperial College, London.

Objectives:

- Compare different attitudes about organ donation and transplantation among white, black and Asian communities, ultimately to influence public policy.

Formal research is being finalised, to be followed by a year of dissemination.

Community ABLE Toolkit (“CAT”) Project (2006-2008 – now completed)
Led by Kidney Research UK.

Objectives:

- Disseminate findings and outputs of the initial ABLE projects to stakeholders within the general public and health professional settings.

Outcomes and outputs:

- Presenting four ABLE papers at BRS 2007.
- Holding community based events such as the Asian Lifestyle Show at the NEC in Birmingham.

For more information, contact Neerja Jain at: neerjajain@kidneyresearchuk.org or ring: 0121 244 0272. Also see: www.kidneyresearchuk.org/able
To remind you, our National Service Framework for Renal Services covers children and adults with all forms and stages of kidney disease. Don't worry, I'm not going to try and cover it all in this brief update, but I've picked a few highlights. Apologies if I've missed an area you feel passionately about – if that is the case, do contact me.

**Putting prevention first** will be introduced from April 2009, offering vascular risk assessment and management to all people in England between ages 40 and 74. The Department of Health is busy consulting with PCTs, GPs, pharmacy and vascular disease stakeholders, including the renal community, on how this new service should be configured.

As it stands at present, the core assessment would include a serum creatinine for eGFR if the initial blood pressure is raised and full renal evaluation including proteinuria if hypertension or diabetes is confirmed. Early detection of kidney disease is part of this programme and it represents another opportunity to engage with local PCTs and your primary care community.

Including proteinuria in the General Practice Quality and Outcomes Framework, under the rather confusing section labelled “CKD5”, is of course the key policy change to focus attention on the importance of proteinuria. The guidance, or “business rules”, makes it clear that diagnosis of proteinuria does require a laboratory assessment – not just a dipstick.

**NICE CKD Guidance**

This is due in late September and should help clarify which tests – ACR (urinary albumin creatinine ratio) or PCR (urinary protein creatinine ratio) – should be routinely used in primary care.

Following the upsurge in referrals after standardising eGRF reporting and putting CKD in QOF for 2006, I know links between primary and specialist kidney care have been strengthened in many areas.

The primary care nurses I have met recently are very interested and knowledgeable about CKD. An educational drive on proteinuria is now needed to avoid unnecessary, non-value-added, referrals. The kidney care 18 week pathway can also help us manage early CKD better.

**Advanced kidney disease**

Turning to advanced kidney disease, the impact of including dialysis capacity in the Operating Framework of the NHS, making it a service *must-do*, is starting to show. Many areas are now setting ambitious plans for renal replacement therapy and signalling them in their commissioning intentions through the local development planning (LDP) exercise which should be completed in early autumn.

The LDP is the way to get things properly resourced. Many of the regional plans have aspirations for better choice. There is a resurgent interest in home therapies, and in home haemodialysis in particular. This complements the renewal patient and professional interest in this area.

Together, we can achieve transformational change to radically improve people’s experience and outcome in advanced kidney disease – this needs capacity, availability of all modalities, early transplant listing where suitable and an accessible, supportive end-of-life programme.

**Organs for Transplant**

I’m looking forward to welcoming Chris Rudge, currently for the next few weeks.
Managing Director at UK Transplant, who will be joining me as the transplant tsar in August to drive implementation of the Organs for Transplant report that has set the target of a 50 per cent increase in deceased donors in the next five years.

That should bring us up to mid-table in European terms, but I know Chris’s ambitions are as high as those of someone like Sir Alex Ferguson – the direction of travel is up!

There are lots of other things happening at the moment. The 60th anniversary of the creation of the NHS has seen a flurry of position papers about the future. Each strategic health authority has drawn up plans for implementing the Next Stage Review. The overarching Darzi Report complements and reinforces those.

To improve this process the Registry is developing a new system of feedback to centres with a marker of timeliness for the data submission for each quarter as well a completeness report for a number of important data items. However, improving data quality relies on all clinical staff using renal IT systems to ensure patient data is as complete as possible and many hands make light work!

British Renal Society/Renal Association, Glasgow 2008

The Registry session in Glasgow highlighted our growing role as a research group. Dr C Tomson (UKRR Chairman) and Dr D Ansell (Registry Director) presented an overview of work in 2007.

There was also an opportunity to present some of the original research projects currently being undertaken, including a new transplant analysis, preliminary data from a retrospective study of the year before dialysis and an ongoing study exploring the causes of between-centre variability in achieving audit standards. Overall the session was felt to be a great success and we hope to repeat it next year.

User group meeting

The Registry hosts an annual user group meeting, held this year in June at the Queen Elizabeth Hospital in Birmingham. This brought together clinical teams, IT staff and Registry staff with the overall theme being how best we can practically serve the renal community in terms of feeding back data and analyses.

In addition to a number of presentations this informal meeting allowed an extremely informative discussion and interaction between the Registry and RRT centres about how we can best support their work. There was extremely positive feedback and this meeting is now a regular event in the Registry calendar.

Future plans

As the Registry continues to grow and expand there are number of ongoing projects. The major areas of growth are in collection of new data items and methods for both analysing and feeding back data back to the renal community.

Several new projects have been commenced to collect new data. Soon the Registry will be able to provide data on the use of certain medications – for example, those used in the management of calcium, phosphate and parathyroid hormone – and also on statin use.

Plans to collect regular vascular access data are ongoing. This will add to the data collected in the two vascular access surveys in 2005 and 2006, and provide centre comparisons to drive quality improvement in this area.

Advanced CKD

Most excitingly, the Registry is also undertaking a pilot study to collect data from all patients with Stage 5 chronic kidney disease. This should provide valuable insight into the progression and management of advanced kidney disease and, in particular, longitudinal data for those patients who opt for conservative therapy.

If this is successful it could also be expanded to collect data about Stage 4 CKD which would make the UK Registry the first advanced CKD registry.

As for analysis there is ongoing work to optimise the performance analysis published. In addition to the funnel plots, there is work looking at other methods such as statistical process control to analyse the longitudinal data collected. In the long term this will probably result in web-based interactive unit-specific reports.

In summary, we believe the Registry is a useful practical resource for all renal clinical staff. In addition there is a wealth of data available for original epidemiological research to further knowledge about patients with CKD. So 2007 was a good year for the UK Registry and we hope 2008 is even better!
If we are honest with ourselves, most of us have experienced that “sinking feeling” when we realise something has happened to one of our patients that shouldn't have happened ... or something that should have happened hasn't been done. The patient may not have come to any harm, but we know that clinical standards failed. Sometimes, unfortunately, such incidents can result in severe harm or even death.

Whatever degree of harm may have occurred, all clinical incidents must be investigated, not just to fulfil statutory requirements, but also to maintain our professional standards. Reporting and investigating clinical incidents should be a non-accusatory process whereby we all learn from these incidents and change our clinical practice to the benefit of patients. By reducing risk to patients, we improve patient safety.

For the last year I have been running a pilot project set up between the Renal Association and the National Patient Safety Agency (NPSA) to look at the process of formulating and sharing solutions to clinical incidents and risk prone situations.

**Learning from the larger picture**
The NPSA collects over half a million incidents a year from all specialties in the health service through the National Reporting and Learning System (NRLS) database. These incidents are analysed to determine patterns which can be used to facilitate learning and change clinical practice.

In the Renal Association/NPSA project, clinical incidents identified from the NRLS as well as incidents directly communicated from renal units have been analysed together with input from renal units to formulate solutions. In addition, it is essential to identify risk-prone situations in advance of these risks becoming clinical incidents and this should be part of normal clinical practice and clinical governance.

Rapid reporting has been an objective of this project, with communication via email to clinical directors of renal units who then distribute the information within their units, particularly through clinical governance, which should involve all renal health care workers.

Renal units, in these multi-professional meetings, can look at how these incidents might occur in our units and implement changes in clinical practice to avoid repetition of the problems.

**Avoiding incidents**
Analysis of the NRLS database would suggest that there are over 700 renal incidents per year in renal units in England and Wales that result in moderate or severe harm, or death of patients. Thus, there will be at least 10 episodes per year occurring in each renal unit with at least one death. Evidence from the literature suggests that this probably only represents a small proportion of incidents, all of which are potentially preventable.

In the first year of the project there have been nine clinical incidents or risk prone situations that have been investigated, mostly related to haemodialysis procedures and equipment (Table 1).

### Table 1: Reported clinical incidents and risk prone situations

<table>
<thead>
<tr>
<th>Event</th>
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<tr>
<td>Dislodged venous fistula needle during haemodialysis leading to significant blood loss.</td>
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<tr>
<td>Air embolism from haemodialysis catheter disconnection.</td>
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<tr>
<td>Fatal pulmonary embolus from an attempt to unblock an occluded arterio-venous fistula.</td>
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<tr>
<td>Death due to blood loss from an arterio-venous fistula.</td>
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<tr>
<td>Hypotension on dialysis from excessive ultrafiltration.</td>
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<tr>
<td>Risk of air embolism from haemodialysis catheter as a result of inadequate closure by replacements clamps.</td>
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<tr>
<td>Lack of mixing of bicarbonate haemofiltration solutions.</td>
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<tr>
<td>Risk of intravenous injection of chlorhexidine during haemodialysis catheter insertion.</td>
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<tr>
<td>Risks with intravenous Heparin flush solutions.</td>
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</table>

Solutions to these problems commonly involve a change of clinical practice or training procedures, or might require the withdrawal of faulty equipment in the case of faulty haemodialysis catheter clamps, consideration of the introduction of new equipment, such as a device to detect blood loss, and chlorhexidine sponges for skin sterilisation.

**Risk prone situations**
In addition this project has addressed the identification of risk prone situations. From responses from renal units, the most common risk prone situations were identified (Table 2).
Table 2. Top risk prone situations
- Dislodged dialysis venous fistula needle
- Delays in achieving permanent vascular access
- Infections related to temporary and tunnelled haemodialysis catheters
- Practical procedures performed by inexperienced junior doctors
- Prescribing errors in renal failure
- Transfer of renal failure patients: Acute Renal Failure from outlying hospitals, or transferred from ICUs to renal wards and HD patients transferred from satellite units
- Lack of experienced renal staffing
- Lack of haemodialysis facilities
- Sudden loss of dialysis facilities.

The risk of dislodged venous needles was already being addressed, and the delay in achieving permanent vascular access has been the stimulus for the report from a joint working party between the Renal Association, Vascular Society and Interventional Radiology (August, 2006).

Haemodialysis catheter infections are well recognised and Department of Health documents such as Safer practice in renal medicine address methods of reducing health care associated infections. Practical procedures require rigorous training, supervision and assessment.

Prescribing errors in renal patients appear quite common, with 1,300 incidents per year resulting in 80 patients who have had moderate or severe harm, or death. Lack of suitably trained staff and risks associated with transfer of patients also results in harm and deaths. Many units have not formulated contingency plans if there was a sudden loss of dialysis facilities.

When risks increase
There are other times in the lifetime of renal patients when they may also be faced with increased risk. Unless patients with CKD are identified in the community at an early stage, there is a risk of late referral for end stage renal failure with the associated increase in morbidity, hospitalisation and mortality.

Excessive use of haemodialysis catheters, and the associated infection risk, is a major part of dialysis morbidity. Similarly failure to institute cardiovascular risk reduction measures at an early stage of CKD will result in increased risk of cardiac deaths, which is particularly prominent in CKD patients with diabetes. Time on dialysis increases risk of death and thus any delay in working up suitable patients for the transplant list will also compromise their survival.

Many renal patients are admitted for infections or other medical problems. Haemodialysis patients in particular are likely to be older, have co-morbidity and, commonly, be unstable.

The acute setting
The NPSA has also looked into the management of acutely ill patients in acute and general hospitals. In the report Safer care of the acutely ill patient: learning from serious incidents (NPSA, 2007), the issue of patients’ deterioration not being recognised or not being acted upon was investigated.

There was a pattern of three problems identified. First, no observations had been performed on acutely ill patients. Second, observations had been performed, but the deterioration was not recognised by nursing staff and medical help was not sought. Third, there were cases when nursing staff recognised a deterioration of the patient, but were unable to persuade medical staff of the severity of the patient’s condition.

It is appropriate that all renal staff should read this document, together with a second NPSA document Recognising and responding appropriate to any signs of deterioration in hospitalised patients (NPSA, November 2007) – as well as the NICE guidelines on Acutely ill patients in hospital (NICE, July 2007).

National audit
Renal services in the UK are fortunate to have a comprehensive national audit of the management of renal patients through the UK Renal Registry where renal units’ performance is compared with the Renal Association Standards Document. This is a crucial element of quality assurance in renal units.

It was somewhat concerning that when a straw poll was taken during a presentation of the Renal Association/NPSA project at the BRS/Renal Association annual conference in Glasgow, only a quarter to a third of the multi-professional audience had heard of this project. This might suggest that the communication of objectives and outcomes from this project within renal units could be improved.

All renal unit staff should be encouraged to actively participate in clinical governance and audit. This ensures that staff will constantly be looking to refine and improve clinical processes and procedures to reduce risk, improve patient safety and thus improve quality of life and outcomes for renal patients.

If you have any questions about this project or would like to share experience or solutions to new or already identified incidents or risk prone situations, then do contact Dr Rylance by email: paul.rylance@rwh-tr.nhs.uk
Patient safety during the haemodialysis procedure is priority yet reported incidences of venous needle dislodgement (VND) during haemodialysis treatment are increasing. Situations are currently being reported in which patients have died as a result of VND, causing major concern.

Dr Stephen Sandroni raised the topic of VND in the United States in an article written in 2005. He was concerned about the death of a patient there following VND and informal contact with other nephrologists suggested that the seven-to-10 deaths from needle dislodgement reported annually in the US were perhaps only a third or a quarter of the actual total.

There is very little published literature relating to venous needle dislodgement. Indeed, Dr Sandroni’s paper only appeared in abstract form as it was rejected by the meeting to which it was submitted!

Focus for discussion
Subsequently the European Dialysis and Transplant Nurses Association (EDTNA/ERCA) used Dr Sandroni’s paper as a focus for discussion with renal health professionals globally. Many contributors described incidents involving needle dislodgement or catheter disconnections in their units, and the changes in practice made to avoid further problems.

Shortly afterwards, a regional study day was organised by nephrology staff from York District General Hospital. This brought together nurses, doctors and technicians who identified various issues relating to securing needles, monitoring access and correctly setting the machine alarm limits. The study day highlighted the need for good practice guidelines and appropriate educational resources.

European guidelines
The EDTNA/ERCA Education Research is currently working to produce European recommendations to help prevent VND. These will be launched during the annual EDTNA/ERCA conference in Prague in September.

EDTNA/ERCA guidelines will centre on:
- preparation of skin prior to cannulation
- securing needles and blood lines
- monitoring the patient
- technical aspects
- identifying patients at high risk of VND.

The American experience
Further data related to the incidence of VND was collected by industry representatives from Redsense Medical during the American Nephrology Nurses’ Association (ANNA) meeting in San Francisco last October.

- Among 135 respondents, nearly all were nephrology nurses and 110 (81 per cent) had experience of VND incidents.
- Among these 110 nurses, seven had personal experience of incidents where the patient died and 31 per cent of incidents where the patient required hospital care due to VND. In the majority of incidents, the patient was (medically) unaffected.

- In the total respondents, 78 per cent had heard of incidents in other units and of those, 44 per cent had heard of not just one but several incidents.

- The large majority believed that an incident which is detected immediately without consequences for the patient would be reported, but 27 per cent of them didn’t think so or didn’t know.

JOHN SEDGEWICK, a member of the RCN Nephrology Forum steering committee, looks at a crucial area of patient safety.

Venous needle dislodgement in clinical practice: An area of concern
Opinions differed about venous pressure monitoring: only 20 per cent believed that it will, always, detect VND in time, 30 per cent were sure that it will not pick up the dislodgement and nearly half (45 per cent) had doubts and believed that venous pressure monitoring will detect it, but perhaps not in time.

**Methods of prevention**

Many different methods are practiced to prevent and detect VND, the three most common being asking patients not to cover their arm, using special dressings or special methods to secure the dressing and having staff present in the dialysis room at all times.

Asking patients not to cover their arm means that a blanket cannot be used. This can be inconvenient as patients in dialysis are often cold and tired.

To have staff present in the room at all times is a security measure taken for many reasons, but at a time where there is shortage of nephrology nurses and in a field where resources are short, this is an expensive method.

Neither of these two methods can be used with patients in self-dialysis or home dialysis, treatment forms that we know have medical as well as economical and social advantages. Other prevention methods

The fourth most frequently used method was simply to ask patients keep an eye on the needle, a responsibility which many older and hospitalised patients are unable to take. Moisture detectors were used, but only to a very small extent (0.5 per cent).

Compared to the survey made in Florence in September among 81 European nurses attending the annual EDTNA/ERCA conference, it was more common among the American nurses to have experience of VND (81 per cent compared to 55 per cent) and to have doubts in venous pressure monitoring.

**Many different methods are practiced to prevent and detect VND ...**

The fact that the US seems to be the only country with a central registry of serious incidents (MAUDE) may have increased the awareness, but this is only a hypothesis.

In summary:

- VND is a serious risk to patient safety – are we seeing just the tip of the iceberg?
- Reported cases of deaths highlight the need for urgent action – at least three deaths have been reported in the UK because of VND.
- Internal unit processes need urgent review to identify systems to prevent VND.
- Nurses play a central role in preventing VND though vigilant assessment, monitoring and reporting incidents.
- Development of practice recommendations by EDTNA/ERCA aims to further promote safety in clinical practice

**References**


**Recent publications**

All of these documents are available to read or download on the Department of Health website. Search by document title at: [www.dh.gov.uk](http://www.dh.gov.uk)

- Putting prevention first
- Driving service improvement through patient focus (report of the Phase II Renal Action Learning Sets 2006-2007 and supporting information)
- Pharmacy in England: building on strengths – delivering the future (white paper)
- Eligibility criteria for patient transport services (10 September 2007)
- Organs for transplants (report from the Organ Donation Taskforce, 16 January 2008)
- Renal haemodialysis patient checklist (19 November 2007)
- Long term conditions compendium of information: Adding life to years and years to life (14 January 2008)
- World class commissioning: vision (2 December 2007)
- Focus on preparing for end stage renal disease (5 February 2008).

HBN 07-02 on main renal units is now officially published on the Department of Health’s Estates and Facilities Division’s Knowledge and Information Portal (KIP) as is HBN 07-03 building guidance for satellite units

**New from Liverpool Care Pathway (LPC) National LPC Renal Project Group:**

Guidelines for LCP drug prescribing in advance CKD (eGFR < 30ml/L)

As renal function decreases and patients reach established renal failure (ERF), different types of renal replacement therapies (RRT) are available to improve their quality of life. SAMUEL NTAKIRUTIMANA, Staff Nurse in the Renal Unit at Bristol, sends this report.

Importance of patient choice in renal replacement therapy

For the past three years I have been working on a renal unit, caring for patients with decreased or complete loss of renal function. Looking after these patients I found I was questioning myself about whether they’d had choice of what treatment to go for and it came to the point where I started asking them.

Many patients told me that they were given choice, but some said they were not given any choice at all – such as “crash landers”, admitted in emergency situations between life and death, and the next thing they hear is doctor telling them they are going to have a neck line or femoral line for dialysis.

Without any preparation, this caused anxiety and depression. (Karalis et al., 2007). It was all was happening around them and they were not in a good position to discuss choices in RRT. They were obliged to take a highly uncertain and risky choice as they were under extraordinary physical and emotional stress with time constraints placing high cognitive demand on the compromised individual (Hilhorst et al., 2005).

Highly vulnerable

The time of discussion and the order of RRT impact on treatment choice (VHL, 2005). Patients with ERF are among the vulnerable population, perhaps living in the realm of being medically underserved concerning the issue of their perceived choice among RRTs (Landreneau et al., 2006).

After this experience I decided to do an assignment on the importance of patient choice in renal replacement therapy as it is one of the ingredients in delivering a high quality service tailored to people’s real needs, improving the patient’s experience and also leading to efficient use of resources (Wilson, 1999 and DH, 2003).

Thus I looked at the importance of patient choice in RRT where I am working – the types of RRT, barriers in implementing patient choice and lessons to be taken out for the future to improve patient care and help patients achieve their self actualisation.

Types of RRT

Different types of renal replacement therapy are used to improve the quality of life of renal patients. All have advantages and disadvantages.

- **Haemodialysis** involves a dialysis machine, using an artificial kidney to clean the blood. Patients need to have access (arteriovenous fistula, graft or haemodialysis catheter) formed prior to starting dialysis.

- **Peritoneal dialysis** (CAPD or APD) infuses fluid into the peritoneal cavity via a catheter and leaves it there for sufficient time to allow metabolic waste products to diffuse through the peritoneal membrane into the dialysis fluid and be drained away (NICE, 2007).

- **Renal transplant** requires a kidney from a donor, either live or cadaveric.

- **Conservative management** is for people who do not want to go for other types of RRT for whatever reason.

Why patient choice?

Patient choice is especially important in this vulnerable population who feel underserved regarding the issue of their perceived choice (Landreneau et al., 2006). It can help them influence a decision that affects them and also has a positive impact on self-esteem and self-confidence (DH, 1999).

Choice is also at the heart of the Government’s public service reform agenda to empower patients, reduce inequalities in access to health and improve health outcomes for all patients. Choice appears to be a desirable pathway to fairness, equity and individual freedom (NHS, Choice matters, 2007).

However, it can suddenly become perversely impossible to manage and be divisive (Molenaar, 1997).

Choice has been found to serve only the few people who are able to find their own way through or who have friends or relatives who know the system, perhaps working for NHS (Reid, 2003).

**Better at choosing?**

Providing more choice to patients increases inequity as the better off are more able to exercise choice when its offered. Disadvantaged groups are not as experienced at making choices: the rich are “better at choosing” (Reid, 2003 and Fotaki et al., 2005).

I do agree to some extent with this statement. For example, take two patients with renal failure coming from different classes, both wanting home haemodialysis. Because one lives in a big house with a spare room for the dialysis machine, this patient will be able to have home haemodialysis. The other one, living in a small house or renting accommodation, cannot have it owing to lack of space or a landlord not wanting a dialysis machine in his house.

Milburn (2003) disagrees with this statement, saying that greater choice can increase social cohesion, not diminish it.

In today’s world of media advertising the latest technology, people makes choices about buying car or booking a holiday based on information gleaned from TV, radio or a website.

It is the same regarding patient choice. Patient choice is meaningful when supported by timely, relevant and accessible information (NHS, 2006 and Mythen, 2004). Without this neither clinician nor patient can make a fully informed choice about therapy (Landreneau et al., 2007).
Informed choice
The Renal NSF also recommends that a patient with established renal failure should be given information about different forms of treatment so that an informed choice can be made (NSF, 2005).

Providing information has been found to improve people's understanding of drugs and treatment, and contribute to better recovery with less depression and anxiety (Olszewski et al., 1998).

Thorough patient assessment is needed before giving out the information as it can affect a patient's adherence to treatment. Saran et al (2003) said that “assessing when patients are most amenable to listening and/or receiving information regarding their diet or any other information related to treatment can lead to increased adherence”.

Not just any information
And the way we communicate with patient has impact on how successful they are in adapting to their treatment (Karalis et al., 2007). Information needs to be provided in different languages to reach people who do not speak English as there is a higher risk of renal failure in Afro-Caribbean and South Asian people than white people (Renal NSF, 2004).

The NHS needs to provide reliable, relevant information in a way people can understand it (Milburn, 2003). Information can be given pre-start of any type of RRT through patient education when patients are informed about renal disease, dietary restrictions, physical exercise, the impact of chronic renal failure on economy, family and social life, treatment choice and ways to promote self-care (Birgitta, 1998). Education provides the knowledge needed to make choice work (Milburn, 2003).

However, this is not possible with our “crash lander”, admitted to hospital in a compromised situation without preparation time. To these patients, continued support and education are needed to help them exercise their right to choose as choice is a set of cognitive skills that change overtime and through experience. (Landreneau et al., 2006). A patient can move from one type of RRT to another one without problems as long as the conditions allows.

Barriers
Implementing patient choice is not easy for various reasons: shortage of staff, lack of expertise, time and money (Shepherd, 2001). John Read (2007) admitted that it will be impossible to implement patient choice without increasing the capacity of the NHS.

People are treated differently depending on where they live which leads to inequality in services offered in the NHS (Renal Association, 2004). Because of this “postcode lottery” patients may not be able to choose what type of RRT to go for.

For haemodialysis, for example, NICE recommends that patients with ERF who are suitable for home dialysis should be offered a choice between home haemodialysis and hospital dialysis, irrespective of where they live (NICE, 2000).

Yet some areas in the UK cannot offer home haemodialysis. Haemodialysis three times a week, which is the standard option, and peritoneal dialysis are used despite strong medical indications that haemodialysis is necessary.

In other areas of the UK nephrologists are forced to make patients wait longer than needed before starting dialysis (Renal Association, 2004), which impacts on their right to choose.

And in some areas the situation is worse with patients being refused life saving treatment because of their age (BBC, 2000). Age should not be a barrier to dialysis; the benefit of dialysis to older people should be considered. (Lamping et al., 2000).

Services are overstretched
Where I work, for example, although patients are given a choice of all types of RRT, there is not enough staff to look after them – nor enough facilities. Without enough slots for dialysis for the area we cover, people sometimes do not have a choice of which slot to go for although we try to accommodate them.

Regarding staff, we are one of the units which always has vacancies and is looking for newly-qualified nurses. Because of this there is a lack of expertise from experienced nurses who might give patients the right information – instead they spend their time helping and supervising junior nurses, new to the unit, or agency nurses who have no idea about RRT. So patients are not able to get the right information and this plays a key role in their choice.

There is also evidence of a lack of knowledge necessary for haemodialysis patients to make an informed treatment choice at the medically appropriate time (Landreneau et al., 2007). Because of obstacles in implementing choice, some doctors condemn the patient choice initiative as not being real at all, saying it fails to deliver a real choice to patients and is just a “political gimmick” (Llandudno Zosia Kmeitowicz, 2004). It is not possible to deliver unconstrained choice in a constrained health and social care budget (RCN, 2005).

If nothing is done about these issues, the renal unit will not be able to cope in offering patient choice, especially as the number of people with CKD is rising in the UK and around the world. In England the numbers receiving treatment for EKF, particularly among black and minority ethnic groups and older people, is expected to grow by 50 per cent over the next 10 years (Renal NSF, 2004).

CAPD
There no age limit and everybody can have continuous ambulatory peritoneal dialysis except those with a contraindication such as a history of an abdominal operation. However, because of shortage of staff, patients deciding to go for CAPD may not be able to get the right information or support for carrying out this type of dialysis which happens sometimes on a ward.

For example, especially after insertion of the catheter when patients need the CAPD flush post operation to check the catheter’s position, they may be told to wait until somebody who knows about CAPD becomes available. As a result, they end up having anxiety and stress which can affect the outcome of their treatment. (Gordon and Sehgal, 2000).

It’s also important to mention the

CONTINUED ON PAGE 14
facilities at home. Having enough room for fluid storage can limit people’s choice and access to this type of RRT.

Renal transplant
Renal transplant is considered the RRT of choice for many patients as quality of life and survival are often improved. (Berns, 2006). However, not all patients with renal failure are able to exercise their choice for this treatment. Some people are not encouraged to consider transplant because of their age (older people may be considered to have too many morbidity issues which may incorrectly rule them out from transplant).

Others may be disadvantaged because of ethnic background (Stralta et al., 2003). There are not enough donors in minority ethnic backgrounds, which reduces the chance of a successful match being found, so there is an urgent need for more black people to become organ donors. (UK Transplant, 2008)

Conservative management
The Renal NSF Part Two states that people with established renal failure should receive timely evaluation of their prognosis, information about choices available to them and, for those nearing the end of life, a jointly agreed palliative care plan around their individual needs (NSF, 2004).

Summing up
While patient choice in RRT is very important to delivering high quality care which meets individual needs, there are many barriers to implementing it, mainly related to financial issues such as staffing. However, empowering patients to make choices regarding their treatment will lead to efficient use of resources and, as a result, more money will be saved (Wilson, 1999 and DH, 2003).

To achieve this, education is important for all patients with ERF before and after RRT as it provides essential information. Without this neither patient nor clinician will be able to make fully informed choices about therapy.

References on request from the Editor.
with their PCTs to improve detection, early management and referral.

New renal codes for CKD based on the Edinburgh Consensus Conference have been published:

<table>
<thead>
<tr>
<th>CKD</th>
<th>Proteinuria</th>
<th>Code</th>
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<td>1Z15</td>
</tr>
<tr>
<td>Stage 3B</td>
<td>Without</td>
<td>1Z16</td>
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<tr>
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<td>With</td>
<td>1Z17</td>
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<tr>
<td>1</td>
<td>Without</td>
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<td>1Z19</td>
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<td>2</td>
<td>Without</td>
<td>1Z1A</td>
</tr>
<tr>
<td>3</td>
<td>With</td>
<td>1Z1B</td>
</tr>
<tr>
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<td>Without</td>
<td>1Z1C</td>
</tr>
<tr>
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</tr>
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<td>5</td>
<td>Without</td>
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**The National Kidney Care Audit**

This is the latest clinical audit that the Healthcare Commission has commissioned the NHS Information Centre to provide. Delivered through its National Clinical Audit Support Programme (NCASP), the audit will help identify the best ways to improve renal services, measuring two distinct areas which have a big impact on the quality of life for kidney patients: vascular access and patient transport. More at: www.ic.nhs.uk/NCASP

**Payment by results**

The PBR group, set up to provide advice on indicative tariffs for renal services for 2009/2010, has completed the first round of a clinical and costing exercise focusing on dialysis. (HRGs: LCO1A, LCO2A, LCO3A, LCO4A). The working group is made up of clinical directors and finance leads of 17 acute renal provider trusts, commissioners and officials, together providing over 40 per cent of dialysis services in England. The exercise revealed large variation in returns, even when considering the effect of market forces. The group produced a checklist to help trusts complete their reference cost returns more accurately in the next collection round, and this has been sent to all renal units.

They provided their recommendations on the level of any indicative tariff to the central PBR team in May. Further work may be undertaken by the group to consider how progress can be made with pre renal replacement therapy care, acute kidney injury, and supportive and palliative care which are not covered in HRG4.

**IT functionality**

A Connecting for Health (C4H) project will specify what functionality clinicians need to manage kidney care across a patient’s pathway. Clinical comment was provided in a workshop in March. Next steps include comment by primary care stakeholders, then submission to C4H Clinical Affairs Board for sign-off

**Workforce planning**

NHS National Workforce Projects have been commissioned to support workforce development across the range of kidney disease pathways. After a scoping meeting in May, work is being conducted in co-operation with the professional communities. More at: www.healthcareworkforce.nhs.uk

**Spring 2008 NSF workshops**

- 18 week event – London, Lead: Philippa Robinson, 18 Week Implementation Director
- IT Challenge – London, Lead: Helen Hood, Senior Project Manager, Connecting for Health
- End-of-life Care Workshop – London, Lead: Jane Heaton, Renal and Vascular Policy Lead, DH
- Renal Specialised Commissioners
- Renal Advisory Group
- BRS/RA conference.

**DH Renal Policy Team**

- Juliette Kingcombe, Renal Team Leader (juliette.kingcombe@dh.gsi.gov.uk)
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- Monica Acheampong, Renal and Vascular Project Lead (monica.acheampong@dh.gsi.gov.uk)
- Justina Olotu-Adiele, PA to Dr O’Donoghue (tempprenal@dh.gsi.gov.uk)
- Beverly Matthews, NHS Kidney Care Implementation Adviser (beverley.matthews@dh.gsi.gov.uk)

**NHS Choices**

The kidney pages have been updated with more content and more links, including a Map of Medicine pathways. The NHS Choices website at: www.nhs.uk provides information on healthy lifestyles, an A-Z of medical conditions and details on services and performance to assist patient choice. It takes feeds directly from NHS Direct.

**End-of-life Care Strategy**

The publication of the End-of-life Care Strategy is likely to be linked to the next stage review of Our NHS, our future.

A multi-professional project team lead by Dr Stephanie Gomm (Consultant Palliative Care Physician, Salford) and Professor Ken Farrington has been established to help support implementation of this section of the NSF for Renal Services. A very popular workshop took place in April and will inform a delivery strategy of the coming 18 months for renal end-of-life care.

**Away from Base Unit Dialysis**

The Renal Advisory Group (RAG) working party, established under the chairmanship of Bob Dunn, met in February and again in May.
Here’s a quick roundup of what the politicians have been doing and saying about current issues in nephrology.

THE OFFICIAL LINE

... at Westminster
Some exchanges from the House of Commons Hansard. More at: www.publications.parliament.uk/pa/cm/cmhansrd.htm

Salt levels in food
Q. Ann Winterton MP: What recent meetings have occurred with Consensus Action on Salt and Health?
A. Dawn Primarolo MP, Public Health Minister: While Ministers have not met with CASH recently, Food Standards Agency officials and the FSA chair have met Professor MacGregor and Jo Butten to discuss the review of the voluntary salt reduction targets which is currently underway. CASH has also been present at 19 recent stakeholder meetings held by the FSA to inform the review of the targets.

Home testing
Q. Lord Acton: What evidence is available to support the use of home testing of blood sugar for type 2 diabetes?
A. Lord Darzi, Parliamentary Under Secretary of State for Health: In September 2002, NICE issued clinical guidelines on Management of Type 2 diabetes-management of blood glucose. The guidelines include advice on the self-monitoring of blood glucose and state that self-monitoring can have benefits, but should be carried out as part of an integrated self-care package and when the purpose is clear and agreed with the patient.

QOF: CKD data 2006/2007
A Department of Health publication specifically looks at points relating to the identification and management of CKD stages 3-5. See: http://www.publications.parliament.uk/pa/cm/cmhansrd.htm

Organs for Transplant Report
NHS Medical Director Sir Bruce Keogh has written to all NHS chief executives outlining the Department of Health’s initial plans for implementing the Organ Donation Taskforce’s 14 recommendations. See: www.dh.gov.uk/en/Publicationsandstatistics/Publications/www.dh.gov.uk/en/Publicationsandstatistics/PublicationsPolicyAndGuidance/DH_084231

... at the National Assembly for Wales
Health, Wellbeing and Local Government Committee
A variety of papers into the presumed consent for organ donation are available at: www.assemblywales.org/bus-home/bus-committees/bus-committees-third1/bus-committees-third-hwlg-home/bus-committees-third-hwlg-agendas.htm

The committee took evidence for its inquiry into the potential for making changes to the way body organs are donated in Wales. The Welsh Kidney Patients Association gave its views, but members also wanted to hear the opinions of the public during an open microphone session on 7 May. The committee is looking at whether a system of presumed consent can or should be introduced in Wales. See: www.assemblywales.org/newhome/new-news-third-assembly.htm?act=dis&id=83331&ds=4/2008

... at NICE
Chronic kidney disease: final scope
www.nice.org.uk/nicemedia/pdf/CKDFinalScope.pdf

Diabetes (type 2) – newer agents
www.nice.org.uk/guidance/index.jsp?action=byID&o=11866

Diabetes – type 2 (update)
Project team amendment: Guidelines Commissioning Manager is now Sue Latchem. www.nice.org.uk/guidance/index.jsp?action=byID&o=11635

... from the Labour Party
NHS on your side is a Labour announcement on improvements in NHS Services, which it states will enable you to see a doctor at a time and place convenient to you.

A new deal with GPs means that most GP practices will be open at times more suited to people at work
• an extra three hours on average each week, either on a Saturday morning or more weekday evenings
• introducing 152 new state-of-the-art health centres in every town and city
• open seven days a week from 8am to 8pm
• bringing better health care closer to home
• extending the role of pharmacies to prescribe for and deal with minor ailments on the NHS.

See: www.labour.org.uk/nhs_on_your_side

... in Europe
Improved system for organ donations
Members of the European Parliament have voted on proposals to improve the system for organ donations in Europe. While Conservatives welcomed the broad outline of the proposals, they warned against implementing a system that would duplicate existing practices and add administrative burden.

John Bowis MEP, Conservative spokesman on health in the European Parliament, said: “It is important that each member state implements its own tailor-made solution to the problem, working closely with other neighbours to exchange ideas on best practice.

More research is urgently needed and alliances between national transplantation organisations in member states should first be facilitated to avoid the duplication of work.

“The European Parliament report makes some excellent suggestions for improvement and now we must look at the practical implications involved. A transplant ‘hotline’ with a single telephone number managed by a national transplantation organisation and manned 24 hours a day is a superb idea, but it has to be paid for.”

This newsletter is published by the Royal College of Nursing, 20 Cavendish Square, London W1G ORN.
Tel: 0845 772 6100 Website: www.rcn.org.uk

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