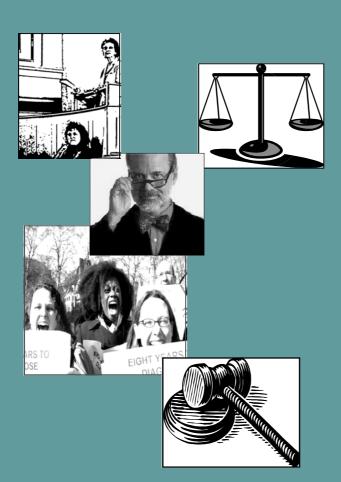
HSCNEWS INTERNATIONAL

THE VIEWS OF HEALTH AND SOCIAL CAMPAIGNERS WORLDWIDE



HEALTH CAMPAIGNERS DISCUSS MEDICAL LITIGATION

Plus

In Focus: Two prevention campaigns

Members' News, Events, and Advertorials

MARCH 2006
Published by PatientView

CONTACT DETAILS

PATIENTVIEW
HEALTH AND SOCIAL CAMPAIGNERS' NETWORK INTERNATIONAL
Health and Social Campaigners News International

Contact details for PatientView

Woodhouse Place Upper Woodhouse Knighton Powys, LD7 1NG Wales

Tel: +44-(0)1547-520-965 Fax: +44-(0)1547-528-501 email: info@patient-view.com

Internet: http://www.patient-view.com

Please note that PatientView is not responsible for, and may not necessarily agree with, the opinions expressed within the pages of *HSCNews International* by contributors or interviewees.

COPYRIGHT

© 2006 PatientView Ltd. All rights reserved.

This booklet is the property of PatientView, and no part may be reproduced without permission, or passed on to any third party without the permission of PatientView.

Registered Address for PatientView: Millennium Bridge House, 2 Lambeth Hill, London, EC4 4AJ, UK

Data protection registration number: Z7133076 VAT registration number: GB-760-985-885

Company number: 3944382

HEALTH AND SOCIAL CAMPAIGNERS' NEWS INTERNATIONAL

ISSUE 27
MARCH 2006

PUBLISHED BY PATIENTVIEW



► MICHAEL MOORE, FILMMAKER

GLOBAL VIEWS:

HEALTH CAMPAIGNERS	
DISCUSS MEDICAL LITIGATION	PAGES 5-35
► INTRODUCTION	5
► A VIEW FROM:	
EUROPE: DR GUSTAVO LÓPEZ-MUÑOZ Y LARRAZ	6-9
DENMARK: DANSK SELSKAB FOR PATIENTSIKKERHED	10
POLAND: DR ADAM SANDAUER	11-12
THE UK: JOSEPHINE OCLOO	13-25
THE USA: DR STEPHEN SCHOENBAUM	30-31
THE USA: MARTIN HATLIE	31-34
THE USA: PULSE	34-35
IN FOCUS: TWO CAMPAIGNS AIMED	
AT PREVENTING CHRONIC DISEASE	. PAGES 36-52
► THE STRANGE CASE OF DIABETES IN VIETNAM	37-45
▶ EFFORTS TO PUBLICISE WOMEN'S HEART DISEASE IN EUROF	PE 46-52
MEMBERS' NEWS	PAGES 53-56
► CONNECT FOR KIDS [USA]	
► EUROPEAN ENDOMETRIOSIS ALLIANCE	
EVENTS	PAGES 57-5 9
► 1ST ANNUAL UK HEART RHYTHM CONGRESS	
▶ WORLD CONGRESS OF CARDIOLOGY 2006	
ADVERTORIALS	PAGES 61-62
► MAINE CENTER ON AGING	



A view from the UK



HSCNews International invited Josephine Ocloo, senior lecturer in social work at London Metropolitan University, England, to look at the subject of medical litigation from the viewpoint of her own experiences. Ms Ocloo provides a critical examination of the systems of investigation that are open to victims of medical harm in the UK.

BECOMING A HEALTH ADVOCATE

Josephine Ocloo believes that the death of her 17-year-old daughter, Krista, in December 1996, was the result of medical negligence at a London hospital. Ms Ocloo mounted a campaign which led the management body (or Trust) of the hospital to hold an inquiry into children's care at the hospital. Extraordinarily, Ms Ocloo was invited by the Trust in 2001 to sit on a hospital committee charged with implementing the inquiry's recommendations. In January 2003, she became the Chairperson of the hospital Trust's Patients' Forum, where she has been successful in developing lay involvement in patient safety work. She also succeeded in getting the Trust to recognise that it had not been promoting race equality and diversity in its work (leading the Trust to make a commitment to address such issues).

Ms Ocloo is currently studying at the University of Surrey, Guildford, England, for a PhD on the subject of patient safety and empowerment in the NHS.

Ms Ocloo is involved in developing a new patient safety culture within the NHS. She has launched an initiative called the 'Break Through Programme', inspired as a result of the death of her daughter. Her efforts have been supported thus far by Action Against Medical Accidents [see table on page 15]. The programme, which has two pilot schemes attended by about 65 people, offers a supportive group environment to

... Continued on page 15

THE UK COMPLAINTS PROCEDURE

National Health Service (NHS) complaints procedure functions at three consecutive levels:

- Local resolution. Patient complaints are dealt with by local Trusts, which have regional responsibilities for the delivery of NHS healthcare.
- (2) Independent Review Panel (IRP). If individuals are still unhappy with their care, they may then approach the Healthcare Commission [see below]. The Commission decides whether to refer the complaint to the IPR (which was incorporated into the Commission in 2004).
- (3) Health Service Ombudsman considers complaints from members of the public about the NHS if these grievances have not been resolved to the satisfaction of the complainant. Failure to provide information is a typical subject of complaint. The Ombudsman is completely independent of the NHS and the UK government.

OTHER IMPORTANT INDIVIDUALS AND ORGANISATIONS

Chief Medical Officer (CMO) is the UK government's principal medical adviser, and the professional head of all medical staff in England. The CMO contributes to, and authors, a wide range of publications.

Clinical Governance Committees. All hospital trusts will have several clinical governance committees. These oversee the execution of the NHS' clinical governance framework. The latter was introduced with the intention of developing an integrated system of different types of activity (including risk management, the monitoring of adverse events, and the development of a new patient safety culture)—the overall aim being to improve the quality of healthcare.

Compensation Recovery Unit (CRU) compensates members of the public involved in accidents when a third party is to blame.

Healthcare Commission. Launched in April 2004, the Commission replaced inspectorates of private and NHS care. The Commission is charged

with inspecting health services, measuring the performance of NHS Trusts, and publishing the results.

Health Protection Agency (HPA) is an independent body that protects the health and wellbeing of the population by providing support and advice to other relevant government agencies.

Independent Complaints Advisory Service (ICAS) provides free, confidential advice, and allows patients to make formal complaints about their experience within the NHS.

Overview and Scrutiny Committees (OSC) came into force in January 2003. These bodies have the legal right to intervene in healthcare matters within their local area.

Trusts are financially-autonomous organisations which may run hospitals (Hospital Trusts), primary-care services (Primary Care Trusts), or other types of services (including mental health). Hospital Trusts have insurance coverage against claims made against them. Separate insurance covers their 'vicarious liability' for the acts or omissions of their employees.

National Audit Office (NAO) scrutinises public spending on behalf of the UK government.

National Health Service Litigation Authority (NHSLA) is an organisation set up in 1995 to take responsibility for negligence claims against NHS bodies in England.

Legal Services Commission (LSC) is an executive, non-departmental, government-funded body that provides financial aid to people in England and Wales who wish to pursue a legal action, but could not otherwise afford to do so. The LSC is not connected to the NHS complaints procedure

Medical Defence Unions. GPs have their own indemnity insurance cover, and are defended by medical defence unions.

National Patient Safety Agency (NPSA), established in 2001, is an independent government-financed body monitoring patient safety. It is not connected to complaints procedures. The NPSA's job is to determine ways in which avoidable and harmful patient incidents can be avoided—and to promote those interventions.

Continued from page 13

help people manage the negative emotional and psychological effects of medical harm. The programme intends to empower individuals affected by medical harm, allowing them to move forward in their lives.

Ms Ocloo feels that the legislative systems of the UK and Europe have failed her. She insists that she has a human right to establish, through fair and independent investigation, the facts surrounding her daughter's death. The last ten years have seen Ms Ocloo spend many thousands of pounds sterling in a largely unsuccessful quest

to gain legal redress in UK and European courts. The emotional and financial consequences of her struggle—coming after the tragic events of 1996—have been devastating, both for Ms Ocloo and Krista's twin sister, Kelly.

Ms Ocloo has decided to tell her story, to illustrate how victims of medical harm are routinely treated by a healthcare and medical-litigation system that she considers to have labelled and blamed them. "I would also like others to ask about my case—'Where is the justice?' ", she says.

UK HEALTH CAMPAIGNING GROUPS THAT SPECIALISE IN ISSUES OF MEDICAL LITIGATION, OR IN PATIENT SAFETY	
Action for the Proper Regulation of Private Hospitals (APROP)	A Weybridge, Surrey-based group that concentrates on negligence in the private healthcare sector.
Action Against Medical Accidents (AvMA) http://www.avma.org.uk	A Croydon, Surrey-based charity that promotes better patient safety, and justice for people affected by a medical accident.
Patient Concern http://www.patientconcern.org.uk	A London-based organisation committed to promoting choice and empowerment for all healthcare users.
Patient and Public Involvement Forums (PPIFs)	One of the 572 PPIFs is based in each of England's Health Trusts. Staffed by local volunteers, the PPIFs provide input from patients on the running of local NHS issues.
Patient Protect http://www.patientprotect.org	A Whitstable, Kent-based organisation dedicated to the prevention of neglect, incompetence, and secrecy in the UK NHS.
Patients for Patient Safety http://www.who.int/patientsafety/patients_for_patient/en/	A World Health Organization (WHO) initiative on patient safety (hosted by the London-based office of the International Association of Patients' Organizations [IAPO]).
Sufferers of latrogenic Neglect (SIN) http://www.sin-medicalmistakes.org	A Nottingham-based group that provides support to victims of medical mistakes.
WITNESS http://www.popan.org.uk	London-based WITNESS is the only UK charity specialising in abuse by healthcare and care workers.

MY STORY by JOSEPHINE OCLOO

Krista, my daughter, was born in 1979 with a congenital cardiac abnormality—which was successfully repaired before her second birthday. She attended a number of follow-up reviews, but otherwise lived as a healthy and normal child for the next 15 years. At the age of 17, Krista was taking A-levels [school certificates] in maths, physics and chemistry. She had expressed a desire to become a doctor.

The problems began, however, in September 1995. Krista started experiencing regular, severe shortness of breath after the slightest exercise. A consultation at a London hospital revealed that her heart was beating abnormally—a condition known as ventricular tachycardia. A cardiac catheterisation [insertion of a thin plastic tube into the heart, to find out what is wrong] was prescribed. The procedure was performed in January 1996.

The results were reassuring. We were told that nothing had been found that should concern us. After discharge from hospital, though, Krista was not provided with any follow up. We requested a further appointment, but were not scheduled in by the hospital until January 1997—a full year after the catheterisation.

Throughout that year of waiting, Krista continued to experience symptoms of breathlessness, and to cough and feel

faint. Then, in December 1996, she developed flu-like symptoms and complained to a friend that she felt "weird". On the afternoon of December 5th 1996, Krista went to lie down in her bedroom. A few hours later, her sister found her dead.

The post-mortem examination revealed death from acute heart failure. Evidence of chronic heart failure over several months was present, too.

WHY THE SYSTEM FAILED ME

THE CORONER. Immediately following Krista's death, I wrote to the Coroner's Court, seeking an inquest. I thought that an inquest was warranted because I had a doctor's report which suggested that Krista should have attended a follow-up appointment six months after her catheterisation. In my letter to the coroner, I gueried whether my daughter would have died if she had been given the appointment. The coroner refused my request for an inquest on the grounds that Krista had died of natural causes. "Quite frankly," wrote the coroner, "what information you were given, and whether your daughter's death could have been prevented or postponed, is not a minefield I am inclined to enter".

THE HOSPITAL. I contacted the hospital about Krista's death. No one returned my calls, despite a promise to do so.

THE INDEPENDENT REVIEW PANEL

[See page 14 for more details on the IRP and other elements of the UK medical complaints procedure.]

In February 1998, I managed to get my

case heard before the Independent Review Panel (IRP, a body composed of NHS medical personnel). In its judgment, issued in June 1998, the IRP indicated that it found no evidence of clinical negligence. The Panel's report added that clinical staff at the hospital should not be reprimanded. Nor did the report recommend that any clinical staff should be referred to the General Medical

A TIME FOR JUSTICE

"As a mother whose life has been devastated by medical harm, I would like to pose two questions:

- ▶ Is enough being done to address issues of patient safety in our healthcare system, and to involve patients and the public sufficiently in this process?
- Do we have systems in place that can respond fairly and appropriately to people whose lives have been adversely affected (often very seriously) when they have suffered from a 'safety' incident?"

'independent' inquiry. A two-part independent paediatric inquiry at the hospital Trust was eventually commissioned towards the end of 1998 by the hospital, and was funded by the

NHS. The inquiry hoped to determine how shortcomings identified by parents of children who had died in the hospital might best be addressed.

The inquiry was hindered by a number of inbuilt limitations, including:

- ► It did not invite these families to participate in framing the terms of reference.
- ► It did not provide funding for the families to be legally represented.
- ► Nor did it afford the families an opportunity to hear evidence from the hospital's clinical staff, or to question those staff.
- Finally, it did not publish its conclusions on individual cases.

The inquiry did find, in April 2001, however, that the hospital had not been negligent in Krista's care.

Council [regulator of the professional conduct of UK doctors].

THE INDEPENDENT INQUIRY. Dissatisfied with the findings from the above investigations, and after being contacted by several other families who harboured serious concerns about their children's care, I campaigned for a broader

THE CIVIL COURT. Determined to learn the truth, and now seriously questioning the independence of the healthcare system's investigative facilities, I decided to bring a civil action against the hospital for damages for bereavement and personal injury.

The trial took place in November 2001. The judge accepted the unanimous deduction of the participating medical experts: Krista's case should have been followed up and kept under active review.

He also agreed that doctors at the hospital ought to have told Krista, her GP, and myself that her ventricular tachycardia was a cause of clinical concern that Krista needed to avoid severe physical exertion, and that she should re-attend the hospital if symptoms persisted, or other symptoms appeared.

Finally, a legal ruling of negligence against the hospital was made for failing to organise suitable further appointments for Krista. The judge accepted that the negligence caused the loss of any opportunity to test for further deterioration in Krista's condition, or to provide information to her and I about potentially developing symptoms.

But, to win a medical negligence case, you not only have to prove negligence—which I did—you also have to prove that the negligence was directly responsible (causative) for the death or injury. The judge in this trial did not accept that the negligence caused Krista's death. He said that she would have died anyway.

My claim against the hospital was accordingly dismissed, and I was ordered to pay 85% of the institution's costs of defending the claim—which were £115,000 [US\$202,000, or 167,000 Euros]. By March 2002, widespread media pressure had persuaded the hospital to accept £10,000 [US\$ 18,000, or 14,000 Euros] from me in full and final settlement of the costs order.

CLINICAL NEGLIGENCE ACTION

In a clinical negligence action in the UK, a claimant must prove four elements:

- The existence of a duty of care.
- A breach of that duty (negligence).
- That the injury or harm was caused by the breach. And ...
- . The extent of the damage.

The standard of proof is different from the maxim in use in criminal cases—'beyond reasonable doubt'. Instead, 'on the balance of probabilities' governs negligence decisions

This latter legal phrase, known as the 'Bolam test', provides the precedent for deciding whether clinical negligence has taken place, and must generally be applied to all elements of a negligence claim. The precedent was established following a court judgement ruling in the mid 1950's (Bolam v Friern Barnet Hospital), which stated: "A defendant is not guilty of negligence if his acts (or decisions not to act) were in accordance with accepted clinical practice—provided that that clinical practice stood up to analysis, and was not unreasonable, given the state of medical knowledge at the time"

A claimant then has to additionally prove that the injury or damage (and the extent of damage) was caused, on the balance of probability, by the breach of care, or that the breach materially contributed to the damage (a process known as causation).

Establishing causation has been the undoing of many claimants, given that they must prove (unlike other forms of personal injury cases, in which the injured person was probably originally healthy), that any alleged negligence was due to the clinician's actions or omissions, rather than to a progression of the underlying disease process. [Making Amends, 2003.]

Lord Chief Justice Woolf, in a review of the civil justice system in 1996, acknowledged that medical negligence cases differed from other personal injury cases in terms of the difficulties of proving causation. He also pointed to the difficulties of finding a medical opinion to support a claim when doctors and other healthcare professionals have traditionally been reluctant to criticise each other. [Final Report to the Lord Chancellor, 1996.]

THE LEGAL SERVICES COMMISSION (LSC). I wanted to appeal against the civil court decision, but was prevented from doing so by the costs order awarded against me. I later approached the LSC for legal aid. The LSC refused my application because it considered that the case did not meet a 'reasonable cost-benefit test'—even though the LSC's own funding code states that such tests should not be applied in 'cases of overwhelming importance', such as the death of a child. Nor would the LSC provide me with funding to appeal its own assessment.

THE EUROPEAN COURT OF HUMAN RIGHTS (ECHR). I subsequently applied to take my case to Europe on the grounds that the UK had violated my rights by denying me public funding to bring an appeal. This, I argued, prevented me from subjecting the events surrounding Krista's death to a fair and independent investigation. The ECHR refused my application without providing any explanation for its decision.

Finally, I turned to the **HEALTH SERVICE OMBUDSMAN**, but found that the Ombudsman's office was prevented from looking at the LSC's decision because I had tried to take my case out of the UK to the ECHR.

I then realised that, unlike in any criminal proceedings, there was nowhere further I could go to overturn this miscarriage of justice.

QUANTIFYING THE PROBLEM

Most countries now recognise that the scale of medical error is intolerable. A 2005 EU-wide public-opinion poll, financed by the European Commission's Directorate-General of Health and Consumer Protection, found that 85% of 1,334 UK respondents thought medical errors were an "important" problem in their country (only Greece, Italy, Lithuania and Poland reported higher percentages). Almost one out of every five UK citizens polled mentioned that they, or a family member, had suffered from a serious

CLINICAL NEGLIGENCE CLAIMS ARE DECLINING

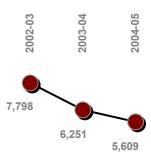
In 1998, contigency fees (fees paid only when the legal outcome is favourable to the complainant) were introduced for civil actions in the UK. Doctors were appalled, forecasting a new era of US-style medical litigation, with ever more patients bringing cases to court.

For clinical negligence cases, at least, the reverse has happened. Hidden costs within contiungency-fee arrangements have discouraged patients from initiating cases, and medical negligence claims are falling in number. The NHS Litigation Authority (NHSLA) states that 60-70% of potential claims do not proceed beyond initial contact with a solicitor. 95% of cases that do go further are settled out of court by the NHSLA.

Around 90% of clinical negligence cases receive legal aid. To qualify for legal aid, claimants must meet stringent financial-eligibility criteria, and satisfy the Legal Services Commission (LSC) that their case has prospects of success—plus that any likely damages will exceed costs.

NUMBER OF CLINICAL NEGLIGENCE CLAIMS HANDLED BY THE NHS LITIGATION AUTHORITY, 2002-2005

Source: NHSLA



SAYING "SORRY" WORKS

For the most part, patients affected by medical harm simply seek an apology or explanation. Some go further, and request an inquiry into their case. Few, however, call for disciplinary action, or financial compensation. The September 2005 National Patient Safety Agency (NPSA) report, Being Open: Communicating Patient Safety Incidents, agreed, stating: "Patients and/or their carers will often only make a litigation claim if they fail to receive any information or apology from the healthcare teams or organisations following the incident".

Legal experts concur. A 2003 textbook on healthcare law noted that the issue of accountability is an important factor when patients experience an adverse healthcare event. Such people regard litigation (alongside the NHS complaints procedure and the other disciplinary instruments that apply to the medical profession) as a tool to make healthcare professionals accountable for their actions. [J. Montgomery, Health Care Law, Oxford University Press, 2003.]

medical error in a local hospital. ['Medical Errors', *Eurobarometer*, January 2006.]

The UK public's preoccupation with patient safety seems justified, given the findings of a November 2005 National Audit Office (NAO) report, *A Safer Place for Patients: Learning to Improve Patient Safety.* The report estimated that patients attending hospital have as much as a one-inten chance of experiencing an adverse event. The NAO believes that half of the one million adverse events and near misses that occurred in NHS hospital Trusts in 2004-2005 could be avoided (although it also acknowledged that the true number of adverse events in the NHS can only be guessed at).

Making Amends, a 2003 report by the UK's Chief Medical Officer, declared that the health service had previously tolerated much higher levels of risk than would be acceptable in other walks of life. All the evidence shows that these risks remain great, wrote the Chief Medical Officer, and that the NHS is still unskilled at learning how to reduce the occurrence of medical errors.

COVER-UPS AND SILENCE

In the 2001 *Bristol Report*, the chair of the investigation, Professor Ian Kennedy (a lawyer who presently sits on the board of the Healthcare Commission), argued for the creation of an open and non-punitive reporting environment in which healthcare professionals felt safe enough to report adverse incidents. He stressed that such openness was central to the development of a new patient safety culture. Litigation, wrote Professor Kennedy, damaged any systematic attempt to learn lessons. Instead, it bred a culture of defensiveness among healthcare professionals, and was therefore counter-productive to better patient safety.

Yet, five years on from the *Bristol Report*, ample evidence suggests that barriers continue to prevent UK patients from getting open and honest answers if something goes wrong with their healthcare. The healthcare system still fails to provide reasonable channels through which complainants can achieve what the Health Service Ombudsman has referred to as "just remedies". The latter include: explanations; apologies; specific actions or treatment for the patient; changes to prevent recurrence; and, when appropriate, financial compensation.

© PATIENTVIEW 2006 20 HSCNEWS ISSUE 27

Clinical negligence cases in the UK

No official records log the instances of clinical negligence in the UK. But, if figures from overseas studies* are extrapolated to the UK situation, up to a quarter of the National Audit Office's one million estimated annual hospital 'patient-safety incidents' (PSIs) may be negligent. Few of the events, though, emerge into public view. And not everybody who has suffered medical harm will litigate. Patients impaired by sub-standard medical care find that they have to grapple with a system lacking in transparency, openness and fairness. The Croydon, Surrey-headquartered national group, Action Against Medical Accidents (AvMA), suspects that thousands of UK citizens damaged by a so-called 'adverse' incident are going without compensation (which, in many instances, is desperately needed). All too frequently, these individuals feel deprived of justice, and have no choice but to accept the healthcare system's seeming lack of accountability.

REFORMS OF MEDICAL LITIGATION—A HEALTH CAMPAIGNER'S PERSPECTIVE

Three substantive areas of medical litigation have recently become the focus of reform in the UK: the NHS Redress Bill, presently going through Parliament; an overhaul of the NHS Complaints Procedures; and a review of the regulations governing doctors, conducted by the General Medical Council (GMC). However, little in the GMC's position, or in the current government's package of reforms, offers hope that the situation will change in the near future.

1. THE NHS REDRESS BILL

First mentioned in the Queen's speech in May 2005, the NHS Redress Bill aims to establish an alternative to litigation in the courts for smaller clinical-negligence claims. The Bill is facing extensive criticism by a range of groups, which feel that the proposed scheme lacks independence, provides insufficient support to patients and their families, and falls short of ensuring that doctors and hospitals learn from their mistakes.

AvMA have launched a campaign to highlight serious shortcomings in the NHS Redress Bill [supporters of the campaign are listed in the box, right]. AvMA wants three major amendments to the Bill:

© PATIENTVIEW 2006 21 HSCNEWS ISSUE 27

^{*} Non-UK clinical negligence studies

[▶] L. Leape, et al., 'Events in Hospitalized Patients: Results of the Harvard Medical Practice Study II', New England Journal of Medicine, 1991, 324 (6), pages 377-384.

[▶] R. Wilson, et al., 'The Quality in Australian Health Care Study', Medical Journal Australia, 1995, 163, pages 458-471.

- (1) An independent means of deciding upon the merits of cases for redress should be instituted—rather than decisions being made by NHS trusts or by the NHS Litigation Authority.
- (2) Provision of advice and assistance to patients (or their families) using the scheme, to help them gain some level of familiarity with medico-legal terminology and the whole subject of clinical negligence.
- (3) Robust measures introduced to make sure that lessons are learned from medical errors identified through the scheme, and action taken to improve patient safety.

2. THE NHS COMPLAINTS PROCEDURE

The NHS complaints procedure should operate openly and be responsive to patients' needs. The system is pointless unless it allows the public to have their complaints properly and fairly investigated.

New NHS Complaints Regulations were issued in 2004 after a five-year period of consultation and review by the Department of Health. These assessments found that the system was seriously

failing complainants, and was widely viewed by the people attempting to use it as biased and lacking independence.

The Health Service Ombudsman for England, Ann Abraham, was sufficiently unimpressed with the revised NHS complaints regulations to request, in her 2005 report, *Making Things Better*, that the Department of Health provide leadership in addressing continued weaknesses in the complaints system. Having had the experience of processing hundreds of complaints a year from patients and carers (all of which had already been through the NHS complaints system before they reached her office), Ms Abraham was well qualified to supply a unique overview of the complaints-handling process. She concluded in the report's foreword:

"Looking through these cases, it is clear that many complainants face severe problems in getting a satisfactory response to their complaints from healthcare providers. Furthermore, the situation remains static, as the NHS is not using the valuable information contained in complaints to improve its services and complaint-handling processes."

SIGNATORIES TO THE AVMA CAMPAIGN TO AMEND THE NHS REDRESS BILL

- Action against Medical Accidents (AvMA).
- Advice Services Alliance.
- Advice UK.
- ALERT.
- Association for Improvements in the Maternity Services (AIMS).
- Board of Community Health Councils (CHC) in Wales, The.
- Erbs Palsy Group, The.
- Help the Aged.
- Long-Term Medical Conditions Alliance (LMCA).
- MIND.
- MRSA Support.
- National Bereavement Partnership.
- National Consumer Council (NCC).
- Patients Association (PA), The.
- Patient Concern.
- Rethink.
- WHICH?
- WITNESS [formerly POPAN].

3. THE GENERAL MEDICAL COUNCIL AS REGULATOR

The fifth report of the Shipman Inquiry [see January 2005 entry in feature at bottom of page for explanation of the Shipman inquiry] into procedures to safeguard patient safety, published in December 2004, was adamant that the regulatory function of the

KEY UK GOVERNMENT INQUIRIES, GUIDELINES AND LEGISLATION ON MEDICAL ERRORS AND LIABILITY

MARCH 1999

Clinical Governance: Quality in the New NHS provided details on how the NHS should improve its service quality.

JANUARY 2001

The *Bristol Inquiry Report*, published by the Department of Health, attempted to uncover the casues of a series of unusually high death rates in children's heart surgery at the Bristol Royal Informary.

APRII 2001

The UK government outlined plans to promote patient safety in *Building a Safer NHS for Patients: Implementing an Organisation with Memory.*

JULY 2003

Making Amends, a report by the Chief Medical Officer, Department of Health, on how to reform the way that the NHS deals with clinical negligence.

JULY 2004

Standards for Better Health, published by the Department of Health, required the NHS to employ new national standards of care and services, with new bodies appointed for the setting of standards and for inspection.

JANUARY 2005

The final report of the Shipman Inquiry was published. The Shipman inquiry was set up following the conviction of Dr Harold Shipman in January 2000 for the murder of 15 of his patients while he was a GP. The inquiry report recommended changes to prevent anything similar happening again. Several other reports were also published by the inquiry team prior to 2005.

MARCH 2005

Making Things Better? A Report on Reform of the NHS Complaints Procedure in England, published by the Parliamentary and Health Service Ombudsman.

MAY 2005

At her traditional opening speech at the start of the new Parliament, the Queen announced the forthcoming introduction of a new NHS Redress Bill.

NOVEMBER 2005

A Safer Place for Patients: Learning to Improve Patient Safety, National Audit Office (NAO).

MARCH 2006

The National Patient Safety Agency (NPSA) launches a 'Being Open' Academy to train healthcare staff in dealing with medical errors.

© PATIENTVIEW 2006 23 HSCNEWS ISSUE 27

General Medical Council (GMC) was inadequate in protecting primary-care patients from the wrongdoings of GPs.

Dame Janet Smith, Inquiry Chairperson, noted in the report's conclusion:

"Having examined the evidence, I have been driven to the conclusion that the GMC has not, in the past, succeeded in its primary purpose of protecting patients. Instead, it has, to a very significant degree, acted in the interests of doctors. Of course, I accept that the GMC also has a duty towards doctors; it must be fair in all its dealings with them. But, in the past, the balance has been wrong, and, in my view, this imbalance was due to a culture within the GMC—a set of attitudes and an approach—that put what was seen as being 'fair to doctors' ahead of protecting patients".

Worse still, Dame Janet suspected that the GMC was unlikely to change:

"I would like to believe that the GMC's culture will continue to change in the right direction by virtue of its own momentum. However, I do not feel confident that it will do so".

THE ANSWER: GREATER PATIENT INVOLVEMENT AND EMPOWERMENT

Paradoxically, people affected by medical harm are rarely consulted in debates about clinical negligence—which, all too often, are dominated by the perspective of healthcare professionals. Victims are perceived as litigious, and part of a

growing 'compensation culture' that enjoys attacking the medical profession. But, if the evidence is examined objectively, it is the patients who have suffered medical harm and who are under attack—disadvantaged from the moment they endure an adverse effect, at every stage in which they attempt to find out what caused the incident, and when they try to achieve redress. Victims of medical harm are frequently labelled, misrepresented, and silenced.

Every citizen in a democracy has an interest in ensuring that public institutions can be held to account when something goes wrong. An ability to gain redress has to be a basic human right for victims of medical harm—not least because people who access healthcare services are sick. For these vulnerable individuals to then have to

INVOLVEMENT AND EMPOWERMENT

Professor Ian Kennedy argued in the 2001 *Bristol Report* that patient and public involvement (PPI) was crucial to creating a better-quality health service. PPI should encompass all aspects of planning, organisation, and delivery of healthcare.

But, indicated the *Report*, if the public was to be involved, it first had to be 'empowered'. Public empowerment meant: "A public that is sufficiently informed as to be able to formulate meaningful views about quality and direction in the planning and delivery of healthcare—which views are listened to, and acted upon, by commissioners and providers of NHS healthcare at the core of their decision making".

PPI in the area of patient safety continues on a tokenistic level, however. Clinical governance committees rarely benefit from patient and public input. When they do, the public's representatives are unlikely to be people directly affected by medical harm.

negotiate systems that effectively brand them as aggressors, and which erect every conceivable barrier in their way to prevent them from finding out what happened, can surely only be regarded as unfair and indecent by every right-thinking person.

A new agenda for patient safety

The existing complaints procedure continues to leave everybody exposed and vulnerable. The true nature and scale of the problems is persistently obscured. Fashioning a new agenda that is truly capable of resolving patient-safety issues must therefore involve the creation of an open reporting system in which lessons can be learned. Healthcare professionals should be able to report adverse incidents in a non-punitive environment—as called for by Professor Ian Kennedy in the 2001 report on the Bristol Inquiry. The new scenario has to ensure that victims are no longer blamed and punished for simply trying to gain a truthful account of what happened to them. Access to justice and accountability—as in every other area of public life—has to be a human right that is open to all survivors of medical harm.

Patients and their representatives also need to gain a real voice and a say in any discussions of the issues. In short, if they are to play an integral part in finding solutions to the problem of patient safety, they need to be empowered. I believe that the time has come to really start listening to the experiences of people directly affected by patient-safety problems. These individuals are the true experts on the subject; to involve them in the process of change is the only responsible course of action. They will make sure that the lessons from the numerous inquiries into patient-safety concerns are properly absorbed. Only then may tragedies like that which befell my 17-year-old daughter, Krista, be relegated to history.

© PATIENTVIEW 2006 25 HSCNEWS ISSUE 27

HEALTH and SOCIAL CAMPAIGNERS' NEWS INTERNATIONAL

THE WORLD'S ONLY INDEPENDENT PUBLICATION THAT KEEPS YOU IN TOUCH
WITH THE OPINIONS OF HEALTH ADVOCATES
—THEIR HOPES, THEIR FEARS, AND THEIR PLANS FOR THE FUTURE

MOST RECENT BACK ISSUES OF HSCNEWS

Issue 13/14 (January 2005)

- √ Actions in 2004 and plans for 2005: an *HSCNews* global survey of campaigners.
- √ Interview article: the Health Minister of Argentina—on patient empowerment.

Issue 15 (February 2005)

- √ A review of the latest annual reports of 125 health campaigning groups.
- √ Interview article: the Depression and Bipolar Support Alliance (DBSA) of the US.

Issue 16 (March 2005)

- √ The regulation of children's medicines: an HSCNews survey of the views of European health campaigners.
- √ Interview article: Menudos Corazones of Spain.
- √ Health Savings Accounts (HSAs) in the USA: an HSCNews survey of the views of American health campaigners.

Issue 17 (April 2005)

- √ Tackling childhood obesity: interviews with six key campaigners from around the world.
- √ What 25 health campaigners achieved in 2004 and plan for 2005.

Issue 18 (May 2005)

√ Hospital-acquired infections: an HSCNews global survey commissioned by the Irish Patients'
Association (IPA).

Issue 19 (June 2005)

√ From market-driven to needs-driven drug research: Médecins Sans Frontières drafts a strategy to promote the development of drugs for neglected diseases.

Issue 20/21 (Summer 2005)

√ Users' perspectives of national healthcare systems: an HSCNews global survey.

Issue 22 (October 2005)

√ Clinical trials registration: the views of three key health campaigners.

Issue 23 (November 2005)

√ Users' views of electronic medical records: an HSCNews global survey.

Issue 24 (December 2005)

√ New initiatives on patients' rights.

Issue 25/26 (January/February 2006)

√ Annual review of health campaigners' activities worldwide.

HSCNews International

PUBLISHED BY:

PATIENTVIEW
WOODHOUSE PLACE
UPPER WOODHOUSE
KNIGHTON
POWYS, LD7 1NG
WALES

TEL: 0044-(0)1547-520-965 FAX: 0044-(0)1547-528-501 EMAIL: INFO@PATIENT-VIEW.COM HTTP://WWW.PATIENT-VIEW.COM

March 2006

Registered Address for PatientView: Millennium Bridge House, 2 Lambeth Hill, London, EC4 4AJ, UK