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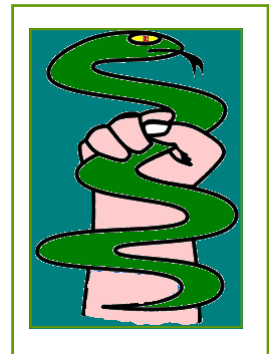
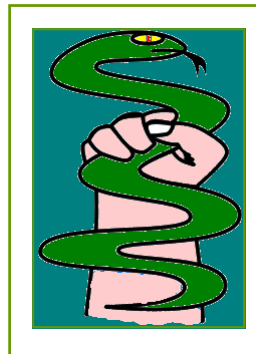
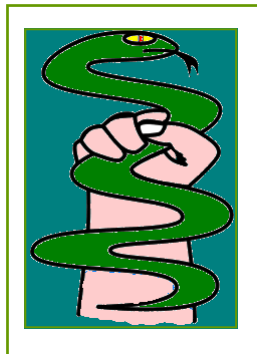
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CAMPAIGNERS'
NEWS INTERNATIONAL

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NEW INITIATIVES ON PATIENTS' RIGHTS:

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Preamble*

Patients' rights

WHY HAVE PATIENTS' RIGHTS BECOME IMPORTANT?

For centuries, patients have been relatively content to relegate the management of their healthcare to professionals—until recently. The growing number of older people in the population, coupled with a gradual rise in the incidence of chronic disease, have elevated both costs and demand to the point at which policymakers are having to ration healthcare services. Fiscal austerity measures within the healthcare system are altering the very nature of healthcare provision.

Patients are becoming unsettled about the implications of change. Patient surveys in individual countries, and worldwide, have revealed a high degree of dissatisfaction with even routine elements of healthcare. Specific concerns are the explosion in reported cases of adverse drug reactions and hospital-acquired infections (HAIs); accounts of medical negligence; and—worse still—rumours of cover-ups.

The public, patients, their families and carers are all concerned by the increasingly numerous threats to the supply of their medical care and treatment. Now that governments are striving to devolve onto individual patients more responsibility for the management of their personal wellbeing, patients and the public are pressing for greater access to medical information, for added protection from possible medical blunders, and, above all, for authority in the shaping and delivery of their own healthcare.

The next 41 pages *HSCNews International* looks at several new campaigning initiatives in patients' rights.

* Source: Patients' Rights in Europe and the UK, *Patients Association*, December 2005.

Patients' Rights in Medical Research in the UK:
Should Patients Influence
Research Priorities in Healthcare?

Patients and researchers: tackling treatment uncertainty together

On Saturday, December 3rd 2005, around 100 academics, administrators, health professionals, patients, patient representatives, and policymakers gathered at the Royal Society of Medicine (RSM) in London. The assembly discussed ways in which the public and clinicians could work jointly to ensure that medical research satisfies the needs of both communities. Specifically, the meeting wanted to identify the benefits (and any challenges) behind moving towards a research culture in which partnerships of patients and clinicians work together routinely to address treatment uncertainties, and to set priorities in research. The event was hosted by the James Lind Alliance (JLA) [see box, right]. Included below are the first two sessions of the meeting which focused on specific case studies where patients and clinicians have worked in partnership.

A RESEARCHER REVIEWS RESEARCH

Dr Jiri Chard, one of the speakers, is based at the National Collaborating Centre for Women and Children's Health, London. Prior to this appointment, he worked as a research associate at the Health Services Research Collaboration, Bristol University. At Bristol, Dr Chard and colleagues undertook a research project that examined the extent to which the requirements of consumers (including patients, clinicians and policymakers) are met in clinical research into osteoarthritis (OA) of the knee. The results of this work were published in 2000 [J. Chard, D. Tallon, and P. Dieppe, 'Epidemiology of Research into the Interventions for the Treatment of Osteoarthritis of the Knee Joint', *Annals of the Rheumatic Diseases*, pages 414-418, 2000], and Dr Chard outlined the findings at the December 2005 JLA meeting.

The James Lind Alliance (JLA) was formed in 2004 as a partnership of organisations interested in identifying and confronting important uncertainties about the effects of healthcare treatments.

The founding partners of the JLA:

- The Royal Society of Medicine (RSM), an independent non-political organisation, formed in 1805 and headquartered in London. The RSM mission is to provide educational support to health professionals and students, and to promote the dissemination of medical facts and ideas to the medical profession and the public.

- INVOLVE, an advisor to the UK Department of Health on ways of promoting public-private partnerships in NHS research, public health and social care.

...and...

- The James Lind Library, an electronic database that hopes to help the public understand the characteristics of fair tests of medical treatments, and to see their historical evolution.

... Continued on page 19

DATABASE OF UNCERTAINTIES ABOUT THE EFFECTS OF TREATMENTS (DUETs)

<http://www.duets.nhs.uk>

The Database of Uncertainties about the Effects of Treatments (DUETs) was launched in December 2005, and falls under the aegis of the UK-based James Lind Alliance. Mark Fenton, Editor of DUETs, explains the concept behind the database:

“Many major uncertainties surround the effects of treatments. To ensure that treatments do more good than harm, uncertainties must be identified and addressed in research. Yet, at the moment, research on the effects of treatments often fails to consider questions of importance to patients (or the clinicians to whom patients turn for help). DUETs has been established to identify and publish those questions about the effects of treatments that concern patients and clinicians. Some of the questions can be found by referring to up-to-date systematic reviews of existing research evidence.”

The first condition to be put under the spotlight by DUETs is asthma. To assemble a database on the uncertainties about the effects of treating asthma, Mark Fenton used various sources, including:

- ▶ Input from patients and carers (the latter mostly parents of children with asthma) was obtained via London-based patient group, Asthma UK. NHS Direct (the UK government-funded 24-hour telephone information and support service for the public) was also a source of information about patient perceptions of treatment uncertainties. The telephone service takes about 100,000 calls a week from members of the public.
- ▶ Clinical questions were obtained from several answering services (such as ATTRACT, a Wales-based information service for physicians, and the National Library of Health’s Primary-Care Question Answering Service). The London-based British Thoracic Society also supplied input.
- ▶ Data were also collected from systematic literature reviews and clinical guidelines.

The questions suggested by these various sources can now be found on the DUETs website. Questions regarded as important by patients included:

- Is it really necessary to take preventative medication if I only have mild asthma?
- Are there any complementary therapies or supplements that help in asthma?
- What is the value of using inhaled steroids continuously, versus a short course of oral steroids when the need arises if I don’t have regular asthma attacks?

Questions asked by carers included:

- What is the minimum dosage of steroids in children with asthma?
- In children with asthma, what are the benefits of continuing to use medication, over experiencing side effects?
- My 18-month old has very unstable asthma. What is the best treatment?

The DUETs website records each question, stipulating its source, pointing out why the question is unanswered, and indicating the next research steps needed to resolve the uncertainty. Thus, the entry for the question asked by the carer of the 18-month old asthma sufferer notes that a systematic review of the literature revealed important continuing uncertainties about treatment effects. The entry advises that clinical trials are needed to determine the optimum clinical approach.



Database of Uncertainties about the Effects of Treatments (DUETs)

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What is DUETs?

The *Database of Uncertainties about the Effects of Treatments* (DUETs) has been established to publish those patients' and clinicians' questions about the effects of treatments which cannot currently be answered reliably by referring to up-to-date systematic reviews of existing research.


Systematic reviews are based on worldwide searches for reliable, relevant evidence, and analyses designed to reduce biases and the play of chance. Information about systematic reviews and fair tests of the effects of medical treatments is available in the *James Lind Library*.
DUETs does not include unanswered questions about the frequency, causes and diagnosis of health problems.

What is DUETs for?

Information in DUETs will help those responsible for promoting and supporting research on the effects of treatments take into account the information needs of patients and clinicians. This may entail providing support for the preparation of up-to-date systematic reviews of existing evidence, if these are not available, or for research to generate additional evidence if up-to-date systematic reviews make clear that this is necessary.

[\[More about uncertainties...\]](#)

What does the DUETs logo mean?

Many people are familiar with the ancient apothecaries' symbol  because it is still used today on some treatment prescriptions [\[more about the history of the symbol...\]](#). The question mark emphasises that we need to identify and record important uncertainties about the effects of treatments.

Produced by [Unclint Software Ltd](#)

... Continued from page 16

During the late 1990s, said Dr Chard, the Bristol team systematically reviewed 930 studies in the field of knee OA to identify the research priorities of the clinicians working in the area.

The Bristol review found a clear prevalence of investigations that sought to validate specific medical interventions. Half (461) of the 930 published articles were reports about trials of specific drugs, while just over a quarter of the reviewed articles assessed surgical interventions (238). Only 5% of the studies focused on alternative therapies, and 3% on education.

Around 90% of the studies obtained a positive effect—suggesting that whatever is studied, works. One reason for the bias towards positive outcomes, Dr Chard told the JLA gathering, is that the commercial bodies supporting clinical drug trials will invest in studies that aim to offer evidence of the benefit of their products.

These above-mentioned results were then compared with the research priorities of consumers, as expressed to the Bristol team by the patients, clinicians and policymakers. The respondent patients stated that they wanted more information on OA, more information on whether physiotherapy has any value, and more information on interventions that might minimise the side-effects of medicines. Respondent patients insisted that their number-one research priority was research into knee replacement. The views of other consumers were similar.

I. TYPES OF STUDIES CARRIED OUT IN
KNEE OSTEOARTHRITIS

% of the number of studies examining an intervention, out of the total number of published studies considered (930)

DRUG (ORAL)	49.6%
SURGERY	25.6%
DRUG (INJECTED)	9.6%
PHYSIOTHERAPY & EXERCISE	6.4%
COMPLEMENTARY THERAPY	5.3%
EDUCATION	3.5%

II. TYPES OF STUDIES WANTED BY PATIENTS
WITH KNEE OSTEOARTHRITIS

% of patients that ranked the intervention as their number-one choice (number of patients = 67)

KNEE REPLACEMENT	35.8%
EDUCATION AND ADVICE	20.9%
PHYSICAL THERAPY	14.0%
COMPLEMENTARY THERAPY	6.0%
TABLETS	4.5%
INJECTIONS IN THE KNEE	4.5%

Source: Dr Jiri Chard, JLA meeting at the Royal Society of Medicine, December 3rd 2005.

Dr Chard concluded:

“Clinical research is dominated by drug trials. Yet consumers want more research in non-pharmaceutical areas. There is a mismatch between the evidence currently being gathered and the evidence required by consumers. The mismatch is likely to be the result of commercial and researcher interests.”

Questions and answers following Dr Chard’s presentation

During the discussion that followed Dr Chard’s presentation, the audience learned of a similar, but more recent, review of patient attitudes to cancer research. Entitled the Macmillan Listening Study, and initiated by Macmillan Cancer Relief, a London-based patient organisation, the Study is close to being finished. Results are expected to be published in January 2006 [see feature, right].

The importance of the contributions made by academics or clinical researchers should not be underestimated, emphasised one participant during the JLA discussion session. Scientists possess the vision to produce radical leaps in innovation—a skill not always available to patients. Another attendee warned that the people working in the healthcare arena needed to dissipate their prevailing tribalism—a clannish, closed-shop attitude that encourages doctors, academics, and researchers to associate professionally only with those peers from their own immediate sphere of interest.

Various members of the audience endorsed the importance of patient participation in research. The formation of scientific networks that include patient representatives was considered to be a step in the right direction.

MACMILLAN LISTENING STUDY

The Macmillan Listening Study is a UK-wide survey commissioned and funded by Macmillan Cancer Relief. The study, which began in 2004, intends to discover what people affected by cancer (and their carers) think about ongoing research into their condition. Patients and carers sharing their opinions with the project were also asked about their personal research priorities.

288 cancer patients and carers were recruited from hospitals and hospices (and one support group) for 24 focus groups nationwide. Participants had different forms of cancer and came from diverse ethnic backgrounds. Initial results were presented at the National Cancer Research Institute Conference, October 5th 2005. The study has so far identified 15 research areas of priority to patients and carers—the top five of which are:

- The effect that cancer has on people; how to live with cancer; related support issues.
- Risk factors, and potential causes of cancer.
- Prevention and early detection of cancer.
- The general information needs of cancer patients.
- The use and effectiveness of complementary and alternative therapies.

The Study believes that its full results (due to be published in January 2006) may exert just enough impact upon cancer’s clinical research community to ensure that “the views of patients and carers are listened to when considering the direction that cancer research might take in the future.”

<http://www.mru.nursing.soton.ac.uk/mls/default.htm>

A PATIENT TALKS ABOUT PATIENT INPUT INTO RESEARCH

Another of the speakers at the December 2005 James Lind Alliance meeting was Mr Derek Stewart. Mr Stewart was treated for cancer of the larynx in 1995. Until 2004, he acted as chair of the Consumer Liaison Group of the National Cancer Research Institute (NCRI). Formed in 2001, the NCRI is a partnership between the charitable and commercial sectors in the UK, and the government. It aims to develop joint strategy, and to foster co-operation between NCRI partners. Mr Stewart told the audience about his experiences within the Liaison Group.

Mr Stewart explained that, from the outset, the NCRI included consumers (patients, clinicians and policymakers) on its selection panels, boards, committees, management reviews and conferences. However, he added, the patient role was, for the most part, a passive one. And patients are only permitted to join the Group by invitation.

Mr Stewart believed that patients with cancer may too readily concur that traditional clinical research systems are best. He advised that patients, by contrast, assertively challenge conventional practices and procedures. But many clinicians are reluctant to acknowledge that patients have a contribution to make. Patients may have to fight their corner against academics and doctors, cautioned Mr Stewart.

Latterly, matters have improved, judged Mr Stewart. Patient involvement in the clinical research process appears to be an increasingly acceptable concept. Time and experience has allowed even the Consumer Liaison Group to function as advocate. Patient representatives on the Group question, for instance, why certain research is to be conducted. They ponder whether improvements in the quality of life should be considered as important and valuable benefits of a clinical intervention.

But, despite the passing of these milestones, patients still do not feel fully embraced in the clinical research process, underlined Mr Stewart. Recognition of them often remains token.

COMMENTS FROM THE FLOOR

Clinical research concentrates on achieving a single goal—discovering whether the benefits of an intervention outweigh its risks. But the forces that impinge upon most patients are far wider than that—and, hence, so too is their perspective on research. Patients would therefore prefer scientists to take a more holistic view during clinical research.

Consumers also place a different emphasis on the value of clinical outcomes to that of many scientists. They try to balance the reduction in quality of life imposed by some treatments with the longer life expectancy that the treatments can bestow.

Additionally, patients put a high priority on obtaining clinical evidence about the value of non-medical interventions (such as education, psychosocial support, or physiotherapy). Few funds are available for research into these non-medical areas.

Patients argue that health professionals who incorporate the patient perspective are more likely to enhance the satisfaction of patients with their treatment—thereby improving compliance.

And, like academics and scientists, patient advocates have yet to learn how to collaborate with one another's groupings. Without such co-operation, patients can overlook (and fail to have any input into) important scientific endeavour, regarding the research in question as being outside the core interest of their particular set of patient organisations. Fortunately, that short-sightedness is changing, too, observed Mr Stewart. He quoted the example of Cancer Research UK, Macmillan Cancer Relief, and CancerBACUP each giving small amounts of money towards projects that the three groups would be unlikely to sponsor individually—a positive start, declared Mr Stewart.

Future patients will need to learn to ask relevant questions, he said, ensuring that they are in a position to influence the agenda and encourage meaningful research by bringing their varying skills and knowledge to bear.

Questions and answers following Mr Stewart's presentation

One academic told the JLA meeting that patients can sometimes suffer from conditions that have no firm diagnosis—from diseases with no names. Such patients become disenfranchised from the clinical process, since only identifiable medical problems can be examined in clinical trials. Even studies to assess prevalence cannot be performed on these ailments. Another member of the audience mentioned that the skill of doctors to produce accurate diagnoses was, at best, variable. Sometimes, reported this attendee, doctors fail to reach any diagnosis at all.

A member of the audience described doctor's language as a barrier to patient participation. Clinicians converse and write in a jargon largely incomprehensible to patients, noted this individual.

Another participant observed that very little is known about the scale of consumer involvement in clinical research decision-making—or, for that matter, in any of the policymaking committees within the UK NHS. The government-funded Medical Research Council (MRC), however, has published an intention that any public health research it funds should benefit patients.

WHY PATIENTS AND RESEARCHERS CAN BE FRIENDS

The James Lind Alliance meeting was given a shared presentation by Mrs Enid Quest, a patient diagnosed with rheumatoid arthritis (RA) in December 1998, and Professor John Kirwan, consultant rheumatologist at the University of Bristol. The latter explained to the audience that rheumatoid arthritis is a nasty disease capable of afflicting many joints. The condition strikes people of all ages, causing severe pain, stiffness, fatigue and disability. Sufferers find that their symptoms can vary unpredictably, day to day. RA in the acute state, though, will shorten life expectancy

by 10 years. RA costs the NHS £1.2 billion (Euros 1.8 billion; US\$ 2.1 billion) each year.

Mrs Quest, a former school teacher, described how RA first “crept up” on her. She initially experienced aches. Then her joints were swollen and hot. Later, she suffered a major attack and lost the use of her right hand. Her immediate concern about the pain she was suffering changed over time to feelings of anxiety over her future and potential loss of independence.

Following diagnosis in 1998, Mrs Quest was prescribed many medicines. Her present treatment seems to have worked for the past three years. Her main medical problem now is coping with fatigue, which she says can come on quite suddenly. Mrs Quest described the symptoms as: “a wiped-out feeling ... all you want to do is lie down and sleep.”

Mrs Quest recounted that her involvement in clinical RA research began with OMERACT [Outcome Measures for Rheumatology Clinical Trials], an international movement of clinicians, formed in 1992. A decade ago, OMERACT established a set of measures to gauge the value of RA interventions.

The OMERACT network meets biannually to discuss aspects of RA research. Nine patients (including Mrs Quest) were invited to OMERACT’s 2002 conference. During most of the congress, the nine patients struggled to comprehend the jargon wielded by the participating professionals. The more intimate setting of the workshops, however, permitted the patients to express views on RA research entirely at odds with those of the convention’s scientific delegates. Clinicians were surprised to learn that subjects of minor interest to them absorbed the full concentration of patients—for example, patients would like researchers to appreciate the distress caused to them by fatigue.

Following an almost unanimous vote for patient participation, OMERACT now underwrites the activities of the 20-strong patient advisory group. The patient panel, which compiled a glossary of RA technical terms for patients, has indicated patient preferences among RA research priorities. OMERACT has adapted its core set of measures to accommodate the opinions.

The patient team at OMERACT are currently preparing for the network’s May 2006 conference. Aside from fatigue, topics high on the patient agenda include: patient needs in early-stage disease; wellbeing; the effective consumer; and drug safety.

PATIENT INVOLVEMENT AT LOCAL
LEVEL: THE CASE OF BRISTOL

Formed in 2001, the Patient Advisory Group (PAG) is a group of rheumatology patients and staff who meet regularly to exchange ideas and develop suggestions for improving and using the services supplied by the United Healthcare Bristol NHS Trust, at Bristol, in the West of England.

The PAG was established as a result of changing NHS attitudes to patients and an new institutional awareness of the need to acknowledge the expertise of patients in the management of their own disease.

The Group’s aspiration is to provide rheumatology patients and carers in Bristol with a way of being involved in the delivery of their own care. The Group’s first meeting was open and widely publicised via posters and flyers. 34 people attended. Key discussion topics were identified (including patient involvement in research).

The PAG has arranged for Bristol RA patients to act as teaching partners to medical students, to pass on the all-important perspective of patients.

Positive views expressed by Group members encourage the PAG to continue nurturing patient involvement in research planning and in the development of the local rheumatology services.

“I’ve been in charge of my own body for over 70 years. But, every time I go to the hospital, I’m expected to leave my responsibility at the door.”

—Florence, a patient

PATIENTS’ VIEWS ON THE PRIORITIES OF RESEARCH INTO ALZHEIMER’S DISEASE

Another speaker at the James Lind Alliance meeting was Mr Harry Cayton. Mr Cayton holds the title of National Director for Patients and the Public at the English Department of Health, where he advises ministers and civil servants on the tasks involved in creating a patient-centred NHS, and on patient and public involvement.

Between 1992-2003, however, Mr Cayton was chief executive of the London-based Alzheimer’s Society. During his time there, the Society, which is a major funder of dementia research, conducted a study into methods by which patient perspectives could be incorporated into clinical trials. The work also considered whether trials could be improved by involving patients in defining outcomes that really matter to them. The results of the exercise, which sampled the opinions of 2,000 carers and people with dementia, were published in the *CPD Bulletin of Old Age Psychiatry* [‘New Drugs for Alzheimer’s Disease’, by J. Cream and H. Cayton, volume 2, 2001, pages 82-83].

Following the successful conclusion of this study, the Society’s Quality Research in Dementia (QRD) Programme [<http://www.qrd.alzheimers.org.uk>] was established as the main vehicle through which the Society funded dementia research. QRD became an award-winning model of consumer involvement in all stages of the research process. Until QRD, said Mr Cayton, clinicians used to measure the impact of interventions on Alzheimer’s disease in a way that was meaningless to carers.

Mr Cayton emphasised the importance of patient involvement in research. He spoke of the valuable contribution being made by the James Lind Alliance through its various initiatives—including DUETs. Mr Cayton commented that pharmaceutical research dominates the research agenda, and many patients take multiple medicines. Yet over half of the treatments prescribed are not taken properly, resulting in an unnecessary increase in side-effects.

Clinical research, stated Mr Cayton, focuses on maximising the benefits of an intervention, while also trying to eliminate side-effects. Though side-effects are therefore not of paramount importance to researchers, they are of critical significance to patients—the latter fact confirmed by the results of the 2003 National Patient Survey, funded by the UK government. In cases where medicines do not have the desired effect of making the patient feel better, said Mr Cayton, patients can be too frightened to tell their GP, and may stop taking the drug.

Mr Cayton noted that the Alzheimer's Society's study into patients' attitudes to research had revealed that carers and patients hold realistic expectations about dementia treatments and prognosis. In the UK, he said, unpaid carers deliver most of the care to people with Alzheimer's. Most of the carers are partners or spouses; many are elderly and frail themselves.

Mr Cayton argued that research in which the outcomes have been user-defined can produce numerous benefits, including:

- ▶ Patients' needs are met more precisely.
- ▶ Patients are less likely to maintain unrealistic expectations about their treatments.
- ▶ The intervention under study relates more closely to the context of people's lives.
- ▶ And patients are more likely to stick to their treatment regimens.

Summing up his presentation, Mr Cayton recommended the work of the '10/66 Group'—so named because less than one tenth of research into dementia has been directed towards the two thirds or more of the people who have dementia and who live in developing countries. Billions of dollars are spent on Alzheimer's drugs—for the benefit of just 1% of the patients, protested Mr Cayton. The 10/66 Group, an international collaboration of researchers, aims to encourage the development of support services for carers in developing countries, and to test the effectiveness of the new services.

Shirley Nurock co-presented this session with Mr Cayton. Ms Nurock cared for her husband for 16 years until he died in 2003 from Alzheimer's disease. Today, Ms Nurock is the London Region Co-ordinator for the QRD Consumer Network Programme. She also sits on the Advisory Group on Public Involvement at the MRC, and is chairperson of the Royal Borough of Kensington and Chelsea Dementia Liaison Group.

OUTCOME MEASURES IN DEMENTIA
—AS EMPLOYED BY CLINICIANS

- ▶ Improved cognitive function (memory, language, praxis and orientation).
- ▶ Delay in moving into institutional care.
- ▶ Maintenance of activities in daily living.

CLINICAL OUTCOMES OF IMPORTANCE
TO
DEMENTIA CARERS AND PATIENTS

- ▶ Improvement in patient's mood.
- ▶ Reduction in patient's challenging behaviour.
- ▶ Reduction in carer's fear, distress, and anxiety.
- ▶ More sleep for carers.

Ms Nurock’s presentation described the position of the QRD programme today. Thus far, the programme has attracted 150 patients and carers. They assess the value of proposed research projects, determining which would be most helpful to patients and carers. Recommended projects then obtain funding from the Alzheimer’s Society. To enable a fair appraisal, a consumer scoring system was created. A mostly high score would reflect a proposal that prioritises improvements in care, an understanding of the causes of dementia, and possible cures. QRD-funded studies also feature realistic outcome measures (for example, the training of GPs in diagnosis).

NICE AND ANTI-DEMENTIA TREATMENTS

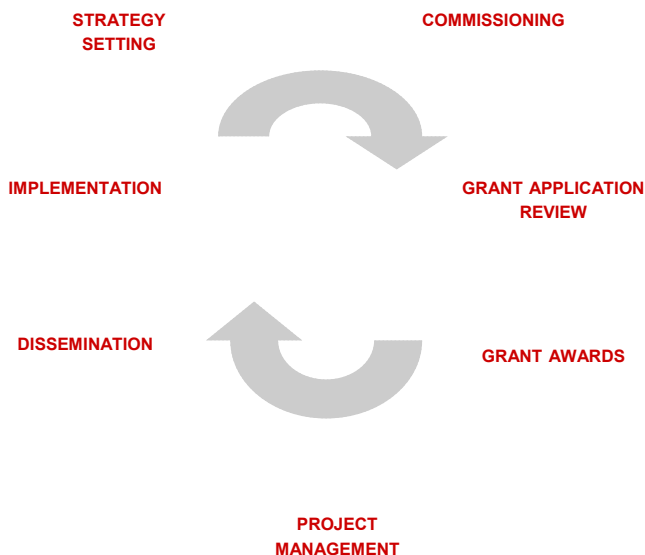
Since the late 1990s, donepezil (Aricept), rivastigmine (Exelon), galantamine (Reminyl), and memantine (Ebixa) were licensed and passed by the UK National Institute of Clinical Excellence (NICE). These drugs help delay and (in certain cases) improve memory loss.

But, in 2004, NICE announced that they planned to review whether this class of drugs should be available within the UK NHS. In March 2005, NICE issued a warning that the drugs were not cost-effective, and should be withdrawn. The drugs cost about £900 (US\$ 1,600 and Euros 1,400) per person per year.

The NICE decision caused an uproar in the UK. At the December 2005 RSM meeting, Ms Nurock noted that NICE bases its cost-appraisals on Quality-Adjusted Life Years (QALYs), a measure which places an economic value on the extension of a healthy life, and on avoidance of a disease. But, declared Ms Nurock, QALYs are only valid measures for patients who have a disease from which it is possible to get better. This is certainly not a prospect with dementia, she said. Nor does NICE include the cost of family care in its cost-benefit calculations. Yet carers are the main healthcare providers for people with dementia.

Ms Nurock argued that QALYs were the wrong parameter to assess the value of anti-dementia treatments. She cautioned that if a forthcoming final decision by NICE on the subject goes against these drugs, memory clinics up and down the land could be closed, “sending us back into the dark ages”.

THE QRD CYCLE AND CONSUMER INVOLVEMENT



ASSEMBLING A BIBLIOGRAPHY

Iain Chalmers, of the James Lind Alliance, is now compiling a bibliography of studies that elicit therapeutic questions and treatment outcomes of importance to patients and clinicians. For a list of references collected thus far, see box on next page. If any reader of *HSCNews International* is aware of other peer-reviewed articles on this subject, Sir Iain would be most grateful to receive the references.

Please send relevant additional references, preferably together with an electronic or hard copy, to:

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A BIBLIOGRAPHY OF STUDIES THAT ELICIT THERAPEUTIC QUESTIONS AND TREATMENT OUTCOMES OF IMPORTANCE TO PATIENTS AND CLINICIANS

Grant-Pearce C, Miles I, Hills P (1998). Mismatches in priorities for health research between professionals and consumers: a report to the standing advisory group on consumer involvement in the NHS R&D Programme. PREST: University of Manchester, UK.

Cohen C, D'Onofrio A, Larkin L, Berkholder P, Fishman H (1999). A comparison of consumer and provider preferences for research on homeless veterans. *Community Mental Health Journal* 35:273-279.

Feussner J (1999), Priorities for patient-centered research', *Medical Care*, 37: 843-845.

Tallon D, Chard J, Dieppe P (2000). Relation between agendas of the research community and the research consumer. *Lancet* 355:2037-2040.

Tallon D, Chard J, Dieppe P (2000). Exploring the priorities of patients with osteoarthritis of the knee. *Arthritis Care Research* 13:312-9.

Cream J, Cayton H (2001). New drugs for Alzheimer's disease – a consumer perspective. *CPD Bulletin Old Age Psychiatry* 2:80-82.

Chard J, Dickson J, Tallon D, Dieppe P (2002). A comparison of the views of rheumatologists, general practitioners and patients on the treatment of osteoarthritis. *Rheumatology* 41:1208-10.

Griffiths KM, Jorm AF, Christensen H, Medway J, Dear KBG (2002). Research priorities in mental health, Part 2: an evaluation of the current research effort against stakeholders' priorities. *Australian and New Zealand Journal of Psychiatry* 36:327-339.

Cayton H, Denegri S (2003). Is what's mine my own? *J Health Services Research & Policy* 8 Suppl 1,S1 33-35.

Soanes L, Gibson F, Hannan J, Bayliss J (2003). Establishing nursing research priorities on a paediatric haematology, oncology, immunology and infectious diseases unit: involving doctors and parents. *European Journal of Oncology Nursing* 7:110-9.

Whitstock MT (2003). Seeking evidence from medical research consumers as part of the medical research process could improve the uptake of research evidence. *Journal of Evaluation in Clinical Practice* 9:213-24.

Guyatt G, Montori V, Devereaux PJ, Shüneman, Bhandari M (2004). Patients at the center: in our practice, and in our use of language. *ACP Journal Club*, Jan/Feb.

Caron-Flinterman JF, Broerse JEW, Teerling J, Bunders JFG (2005). Patients' priorities concerning health research: the case of asthma and COPD research in the Netherlands. *Health Expectations* 8:253-63.

Kirwan J, Ahlmèn M, de Wit M, Heiberg T, Hehir M, Hewlett S, Katz PP, Minnock P, Quest EM, Richards P (2005). Progress since OMERACT 6 on including patient perspective in rheumatoid arthritis outcome assessment. *Journal of Rheumatology* 32:2246-9.

Kirwan JR, Hewlett S, Heiberg T, Hughes RA, Carr M, Hehir M, Kvein T, Minnock P, Newman SP, Quest EM, Taal E, Wale J (2005). Incorporating the patient perspective into outcome assessment in rheumatoid arthritis – progress at OMERACT 7. *Journal of Rheumatology* 32.0-6.

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