**Lester Firkins** **Profile**

Lester Firkins introduces himself as just an ordinary man. In some circles he may appear so – a middle-aged and middle-class white male, a retired banker who drives a safe family car. But Lester is, on the inside, extraordinary. He is a man who has found his mission in life. It is a mission made possible by the skills he developed during 35 years of banking, but inspired by the tragic death of his son, Ellis, and his spiritual beliefs. Ellis Firkins had a First Class Honours degree in Design Technology and was embarking on a career in teaching when he died in 2001 at the age of 15 from variant Creutzfeld-Jacob Disease, a rare but invariably fatal brain disease acquired by eating meat contaminated with bovine spongiform encephalopathy (BSE), sensationally known as 'mad cow' disease.

Before Ellis died, Lester never gave a thought to clinical trials or health services research. His focus was in banking where he achieved success through years of part time study for professional examinations, a natural ability to manage both teams and change well, and plenty of opportunity to hone those skills. He assumed that medicine and research were looked after by others – always in his best interest, with his money as a tax payer being well spent.

Ellis fell ill in 2000 and died in 2001. The experience uncovered a more sensitive part of Lester and at the age of 53 he was ready for change himself. Within six months, still grieving, he had left the bank and agreed to chair the Human BSE Foundation. This organization was formed by families who had lost someone to Human BSE in order to support other families going through a similar experience. Support was provided by a National Helpline, a Carer's Guide, a Website and family befriending.

This was a time of considerable mistrust. For a decade the British Government had sought to reassure people that risks from BSE were remote. This message was overturned in 1996 with the announcement that BSE had probably been passed from cows to humans, and the public felt betrayed. Aggressive lobbying prompted an enquiry. Eighty people, most of them young, had died by the time the official enquiry was completed in 2000.[1] There was much to be done in the agricultural sector, and in health services and research.

Lester had not been involved in campaigning for the enquiry and compensation. Joining the controversies later he was well suited to bridge the gap between angry families and government agencies. He had shared a desperately sad journey with other families. At the same time, his banking experience had shaped a conventional character, content with rules and structure, familiar with the performance and achievement driven culture shared by public services and research funders.

Lester was invited to a 'Consumer workshop on clinical trials for CJD'[2] in 2002. The workshop was held to 'enable consumer understanding of clinical trial design, and to provide an opportunity for consumers and researchers to share ideas on the design of trials for CJD'. This was an ambitious aim considering the past tensions. Lester did not realize how ground-breaking the meeting was, neither for the convenors nor for him. It required considerable courage for the two organizations, the Medical Research Council and the Department of Health, to reach out in this way. Success was due in no small part to the facilitator, Sally Crowe, a training and development consultant who features again later in Lester's story. It marked for Lester the start of a new direction in his life, bringing lay perspectives to research.

Strong support was expressed at the workshop for clinical trials, and for data being collected for research purposes provided it did not cause undue pain or undue stress. There was a wish for the design to be able to accommodate emerging therapies, and for families to discuss with researchers the types of patients who might participate and the follow-up they would be willing to undertake. Subsequently the MRC planned a drug trial and invited Sir Iain Chalmers to chair the steering committee. Iain had long championed both clinical trials and patient involvement in research. He laid down two conditions before accepting, one of which was that he should have a lay co-chair who had first hand experience of this terrible disease. Looking back, Iain said 'This was a leap in the dark for me as well as the MRC, but they agreed.' Iain was pointed in the direction of Lester and put the idea to him. Lester immediately recognized Iain as a man who would get things done and decided to give it a go. Iain describes lay involvement in MRC research at that time and at that level as exceptional. 'No one could have manifested the benefits of lay involvement in research more effectively than Lester has done. I am deeply in his debt.'

Lester was well received by the research community and he was soon invited to bring the perspective of vCJD families to other efforts to conduct research or use research findings. The following year, 2005, he joined another MRC group, established to provide an independent source of advice on research into the development of potential treatment or prevention. Lester co-chaired this Group with Sir Mike Rawlins, chairman of the National Institute of Health & Clinical Excellence (NICE). At the same time as looking out for future interventions, Lester joined the guideline development group convened to advise on changes that would be both practical and achievable within a short time frame.[3] As someone whose son died from vCJD, he considered even one preventable death to be one too many but this would have meant destroying all instruments after a single use. However, after being fully involved in the NICE review process throughout Lester was comfortable that the final guidance fully took into account the best research evidence as well as the cost implications for the wider NHS.

Lester has described this area of research as a 'theatre of conflict and dysfunction'.[4] He thinks the choice of treatment to be trialled was made in haste, influenced more by sensational newspaper stories of individual patients than by a systematic review of research literature that was slower to compile but more reliable in its conclusions. Lester and Iain were members of an advisory group for this systematic review of therapeutic interventions.[5] The review was not published until the Spring of 2008 amidst concern about publication being hindered by vested interests.

Overall, Lester was disappointed by the lack of international collaboration in this field and what he saw as academic jealousies that betrayed the interests of patients and their families. 'Fighting for citations' was behaviour that Lester recognized and understood from his earlier banking experience, where the fighting is for profits. He realized there was much to be done to get people to work together and he was increasingly found at the centre of controversies or conflict, working towards solutions. He chaired monthly meetings between research units to ensure that they worked together despite an increasingly competitive environment. He was also a member of an Appeal Panel, convened to consider an appeal against NICE's decision on the use of a drug treatment for breast cancer.

Lester was gaining broader experience of health services research. It was time to move on from the world of vCJD, partly because much had been achieved and partly because he felt, as time passed, he risked losing credibility as a voice for these families. Now he has a new role that builds not on his past experience of bereavement but on his current people skills and new learning. Having called for patient-relevant research in an area of personal significance to his own family, Lester is now working hard to make future research relevant to patients and clinicians generally. He looks for ways to get alongside people, to help them work in new teams, to cope with change – just as he did for 35 years in the bank. Sometimes it's as simple as wearing the right clothes, a suit and tie, to make them and him feel comfortable. For Lester, it's Ellis's tie, a personal reminder of his motivation. Working with new groups of people and working with change requires an element of bravery and a willingness to work outside one's comfort zone. Lester does that, and invites others to join him.

Lester's new forum for getting patients, clinicians and researchers to work together is the James Lind Alliance (www.lindalliance.org/). The James Lind Alliance aims to identify the most important gaps in knowledge about the effects of treatments. It was been established to bring patients and clinicians together in 'Working Partnerships' to identify and prioritise the unanswered questions that they agree are most important. This information will help ensure that those who fund health research are aware of what matters to patients and clinicians. The Alliance receives funding from the National Institute of Health Research and Medical Research Council against agreed objectives and performance metrics. These are organisational features that Lester is used to and he has been a trusted key player since it began. He now chairs the Strategy and Development Group, working closely with the founder, Iain Chalmers, and original chair Sally Crowe.

Each Working Partnership includes at least one patient organisation and one clinician organisation and the aim is to identify research priorities that patients and clinicians share. The first pilot partnership was between Asthma UK and the British Thoracic Society who have a shared objective in seeking to improve the health care of people with respiratory disease. After a series of meetings and much work behind the scenes by both organisations, Lester and Sally opened a workshop at which members of both organisations would agree a list of their top ten priorities for unanswered questions about the effects of treatments. In the spirit of transparency and collective learning a description of the process[6] and an external reflective report[7] were both made publicly available.

Lester was particularly drawn to supporting the second pilot Working Partnership addressing urinary incontinence, a marginalised condition that affects all ages. The partnership has included over twenty leading patient and professional organisations, with some taking a more active role than others. Lester has played his part in helping these people share ideas and decisions. Once Working Partnerships have chosen their priorities, those that cannot be answered reliably by referring to up-to-date systematic reviews of research evidence will be collated by the Database of Uncertainties about the Effects of Treatments (DUETS) and made available through two web sites: NHS Choices and NHS Evidence. NHS Choices 'provides a single public "front door" to all NHS online information and services, while NHS Evidence will be a unified evidence base for everyone in the NHS who makes decisions about treatments or the use of resources, and for patients who want to know more about their care. Once fully established, NHS Evidence will ensure NHS staff have access to authoritative clinical and non-clinical evidence and best practice through a single portal. Lester is a member of the Advisory Board guiding this development so is now considering the value of research for all NHS users. Here he's in his element, embarking on an ambitious change project with a tight timetable and a very diverse team of stakeholders.

Lester came to health services research as a lay expert in a rare, fatal condition. In that role he drew on his personal experience of cherishing and losing Ellis, and the experiences of families sharing similar tragedies. Now engaged in health services research more widely he's contributing less expert knowledge to the content of discussions, but more interactional skills to bring together the contributions of others – patients, families, clinicians and researchers. Both roles are vital for bringing patient and carer perspectives to research.[8]

Sally Crowe has enjoyed working with him during both these stages of his new 'career' and has found him 'a breath of fresh air, respectful and tactful, mindful of what motivates and energises people. He’s comfortable with his own areas of expertise, and that of others, and able to see the big picture with clarity and wisdom’.

Those of us fortunate enough to work with Lester learn a great deal from his gentle but challenging questioning. Many others who never meet him gain from the products of his efforts.

Sandy Oliver
10 December 2008

[1] Lord Phillips (chairman) *The BSE inquiry Vol 1: findings and conclusions.* London: Stationery Office, 2000, HC 887-1.

[2] *Consumer workshop on clinical trials for CJD 26 July 2002: Report of the meeting*. Department of Health and Medical Research Council, 2002.

[3] *NICE interventional procedure guidance 196 Patient safety and reduction of risk of transmission of Creutzfeldt–Jakob disease (CJD) via interventional procedures.* National Institute for Health and Clinical Excellence, November 2006.

[4] Firkins L. The James Lind Alliance - and I. Presentation at *Priority setting for Systematic Reviews Conference US Cochrane Center, 11th July 2008.*

[5] Stewart L, Rydzewska L, Keogh G, Knight R. Systematic review of therapeutic interventions in human prion disease. *Neurology* 2008;70:1272-1281.

[6] *Research priorities in Asthma: Description of a workshop to set priorities for treatment uncertainty research in Asthma, March 2007*. James Lind Alliance, Oxford.

[7] Stewart R. *Reflective report on the James Lind Alliance Asthma Priority Setting Meeting held at the Royal Society of Medicine, 26th March 2007*. James Lind Alliance, Oxford.

[8] Collins HM and Evans R. The third wave of science studies: studies of expertise and experience. *Social Studies of Science* 2002; 32: 235 – 296.