Author's online copy of Expression of Interest in 2002 to the EU FP6

This page of the PDF: title and abstract from the cover <u>form</u>.

Subsequent 7 pages: enlargement to font 12 of the maximum 5 pages in font 10 of the <u>Additional document</u> accompanying that form.

<u>Form</u> in PDF with a *dead* link to Additional document int_28321.doc
downloaded on 1 December 2010 from the Commission's CORDIS website at
http://cordis.europa.eu/fp6/eoi/dsp_details,cfm?ID=28321
as the 75+ MB .pdf for 1.1.5 Food Quality and Safety, on page 357 (of 1068 pages).

Title of EoI
evidence-networking Application of Best-Life Education *research*

Acronym
enABLE*r*

Contact person and Organisation
David Booth, University of Birmingham (UK)

Proposed type of research
Integrated Project

Abstract

This Project will conduct behaviour-outcome research to provide individual citizens across Europe (and, when a user wishes, their professional advisors) with culturally sensitive, personally tailored and evidence-based information over the Internet on everyday practices that improve health or other well-being in their circumstances. The information that system users volunteer on current behaviour patterns (e.g. eating choices) and the present state of desired outcomes (e.g. body weight) on successive consultations of the "enABLE" service augments the research database from which the advice is computed. This enables automatic improvement and re-localisation of the service and the publication of a badly neglected sort of objective evidence on what patterns of food intake, bodily movement, self-medication / prescription-compliance etc. are most healthy, safe, performance-functional and enjoyed.

Additional document: int_28321.doc

Title:

evidence-networking Application of Best-Life Education research

Abstract:

This EoI is in an Integrated Project across Europe, for behaviour-outcome research and Internet software development that will provide culturally sensitive, personally tailored and evidence-based information to individual citizens (or, if wished, their professional advisors) on the everyday practices that improve health or other well-being in their circumstances. The information volunteered by an individual on current behaviour patterns (e.g. eating choices) and present state of desired outcomes (e.g. body weight) on that person's successive uses of this "**enABLE**" *s*ervice augments the *r*esearch database from which the advice is computed, enabling automatic improvement and re-localisation of the service and the publication of a badly neglected sort of objective evidence on what familiar patterns of eating, movement, self-care, medication/therapy-compliance etc. are most healthy, safe, performance-functional, convenient and enjoyed.

Rationale for this "enABLE*r*" Project

Evidence-based behaviour change

Some everyday practices are better than others at promoting health and other well-being. Yet the usual research methods do not pick up culturally recognised patterns of action that affect quality of life, because they use population sample data or randomised experimental groups, and describe behaviour and environs in investigator-specified terms.

Furthermore, findings from clinical trials, epidemiology, social & marketing research and consumer studies, and from the attitude psychometrics or group experiments of applied psychology, cannot be implemented directly into education of the public in better living or into design of truly functional products. Instead, these sorts of evidence are expertly reviewed in order to generate abstract conclusions (e.g., proposed dietary guidelines or approval of a new medication), which then can only be used by the public after professional translation and implementation that is not itself evidence-based.

Nevertheless, research designs have long been available in both social and experimental psychology that associate objective outcomes with self-specified behaviour at the individual level. Such approaches have begun to provide locally relevant databases from which it is feasible to compute personally tailored information in the enquirer's own terms on "**what, on the evidence, works in people like you**." This opens up the possibility of members of the public receiving evidence-based personal education how to care for themselves using available services and products, such as the advice and treatments from health professionals, over-the-counter medication, health products, food and beverage outlets (shops, cafes, bars), leisure services, transport and lifts, seating etc.

Prospective evidence from series of reports in culturally recognised terms by sets of individuals of their current activities and of measurable signs of well-being has been obtained by psychologically based research teams from three large EU States for the fast-growing and major health risk of obesity. Some of the healthiest habits they find are not in the nutritional guidelines or active lifestyle promotion nor usually in face-to-face advice on diet; some are unrelated to nutrition information on food packets or sport or exercise facilities on offer.

One of these research teams (the Contact Person's) has applied this approach also to the widespread lack of well-being from persistent tiredness, with or without a known medical basis, and to the discomfort from joints, muscles and exocrine glands (dryness) that occurs in some auto-immune diseases but is also very common in healthy ageing. The design identifies in the sufferer's own terms the optimum movement patterns, specific selections of foods and adapted dosing with preferred medications. These data also objectify the retrospective sharing of personal experience of disease self-management practices ("Expert Patients").

They complement the medical, social and commercial research and professional expertise that is conceptualised primarily in molecular terms, such as medications, blood tests, nutrients and gene sequences, rather than in terms of culturally recognised and personally motivated patterns of activity.

Evidence-based and evidence-generating advice service

A database of these behaviour-outcome associations from reports by people in circumstances like the enquirer can be used to calculate the personally most relevant information on how to attain a desired aspect of health or other well-being. In turn, the individual user can volunteer the information required for tailoring, to be added anonymously to the universities research database. Thus, customised education in changes in behaviour conducive to desired improvements in health and other well-being can be provided via a suitable interface to the Internet (e.g. mobile voicing) to any citizen of Europe (or, if the user agrees, to their professional advisor).

The proposed service will also allow retail customers and the "patients" of a health service (who in fact are active self-carers) to shop around for the best match to what they prefer among established and complementary therapies, health products and nutritional supplements, food and beverage brands making health claims, and foods officially characterised as healthy (e.g. "fruit and vegetables" or products labelled low in fat) and leisure, transport and work environments. This identification of each user's overall preferences among available services and products will build a database of information about what any citizens can do for themselves to attain an outcome that is widely desired in their culture, e.g. the tastiest foods having the best long-term health benefits, methods of food preparation that are both convenient and safe, or a sustainable weight-losing physical activity.

Even more radically, members of the public can begin to participate deliberately in quality-of-life research by volunteering to the universities research community those personal data that they need to report in order to get effective tailoring of advice. Current adaptations of the model of Public Understanding of Science to include Consumer Consultation fail to provide the evidence needed to promote the well-being of each citizen in Europe. Evidence-generating computational Internet services of the sort proposed will plug this scientific gap and enable Europeans to work together to promote the good life. The enABLE system's developer also builds facilities for users to interact securely with those of like interest, across the Internet and/or in groups in their physical locality.

The proposed Integrated Project will carry out the research-based development needed to make it possible for national and local governments to assure inclusive access to the localised versions of this research-based education in better living, its automatic tuning and updating to local circumstances, and the execution and publication of formative observations and controlled trials on ways to improve well-being in their region.

The approach of this Project

This **e**vidence-**n**etworking **A**pplication of **B**est-**L**ife **E**ducation research (enABLEr) can be implemented across Europe by a 4-year Integrated Project in FP6. During the operation of the enABLEr-based enABLE**s** service, the computational Internet technology exchanges personally secure information both ways between individual members of the public and the universities research community. The enABLEr Project in FP6 will both publish research papers from these anonymous data volunteered by the public and also use those data to improve and to extend the evidence-based personal advice service over the Internet. The research results will greatly augment the very limited information on associations between culturally recognised practices and outcomes for health and other well-being, as well as provide audits of the average effect of different intensities of use of enABLEs on such reported outcomes. Publications from the Project will also include comparative audits of the efficacy of different patterns of use of particular food products, medications, health products, exercise facilities etc. on reported body weight and on other reported measures of health-risk or well-being.

The developer of ethical Internet services in the Contact Person's research group has built a miniature demonstrator of this health behaviour advice system for testing in-house, with a view to implementing a broadly cardiovascular-disease preventive service for nominated users recruited via some local hospital clinics. This regional pilot is centred on effective lifelong weight control through personally patterned eating and physical activities, but it includes other tailored education in cardiovascular fitness, and in joints-friendly movement patterns or in blood glucose and fats control as relevant to musculoskeletal disease or to diabetes respectively.

The behaviour-outcome database for that mini-demo and pilot includes earlier evidence on the least and most fattening self-described patterns of eating and physical activity in that geographical region. The database also includes professional best-practice advice on healthy eating, cardiovascular fitness, physiotherapy in rheumatoid arthritis and blood glucose control in diabetes. (This research team includes qualified health and clinical psychologists, rheumatologists, a diabetologist, nutritionists and food technologists.)

The computational algorithms for tailoring advised changes in behaviour to attain the outcome desired by the user constitute a personally adapting system of condition-act routines (C.T. Post's Productions in AI). This approach was inspired by the computer-assisted personal tailoring of quarterly letters to nearly 500,000 health insurees in another EU State in the early 1990s, which was successful on a whole-group basis over 1 year in reducing body weight, total fat intake and the prevalence of rigid adherence to failed dieting practices.

Need and relevance

Need for European research
Implementation of a research-based, research-generating and continuously research-improved well-being self-care service to the public requires the mobilisation of research and activities and resources across Europe from the start. This is because, first, the evidence base for culturally sensitive, personal tailoring of information on the outcomes of common practices has unknown sets of commonalities and divergences between social and technological subcultures, lifestyles, stages of life and genetic loads. Secondly, the computational procedures for extending the service to additional languages, new categories of user and wider geographical locations need to be tested during their programming and research-evaluated in pilot implementation: ideally this is done in a Europe-wide project; it is essential that substantial linguistic and cultural diversity remain even in a cut-down project (see budget).

For these scientific reasons and because neither patterns of behaviour nor their outcomes for health and other well-being recognise EU/EAA political borders, it is important both that some countries in western Asia (e.g. Armenia), the Middle East (e.g. Israel) and North Africa (e.g. Egypt) are invited to participate from the start (at least as research Users), and also that a limited number of expert research teams from further afield (especially the USA) are allowed to take part if they pay their own way or operate under bilateral agreements with the EU. Excellent researchers who are sympathetic to the proposed approach but work outside Europe would add considerable strengths to the science and to the ultimate impact of the Project.

Relevance to FP6 priorities
The work behind the proposed Integrated Project started in the priority area **1.5: Food Quality and Safety**. As acknowledged in the statement of this area's aims, "the health and well-being of European citizens" depends on "environmental factors" in addition to "food intake." Hence an "end-user driven approach" and its "better understanding" are not adequately conceptualised as "health-promoting *foods*". There is a fundamental scientific flaw in food and nutrition policies up to the present date. This cannot be rectified by better dissemination of best practice among dietitians, sports & exercise professionals and communications experts, or by the most thorough consultations on public understanding of science with consumer organisations or focus groups. The effects of food on health are not

generated solely by a daily weight of chemicals passing down the average citizen's throat. For the diet to have many of its nutritional effects (e.g., on body composition, or on cardiovascular function and other disease-relevant genetic expression), the constituents of a food must be set in a wider context - not just of the contents of other foods, but also of the patterns of food consumption, including sequences within meals and timing during the day relative to the individual's other eating episodes, physical activities and requirements for intellectual, physical and social performance, i.e. the **behavioural environment** of end-uses of food products.

This research approach and the ICT service built on it are fully behavioural because usual food intake and its patterning are estimated from self-reports of actions described in terms that are widely recognised in the individual's (sub)culture. Thus, this "*research will focus on [the] overall relationship between diet and health*." It will also provide an evidence-base and a medium for "*health-promoting intervention strategies*" conceived in real-life terms rather than in the concepts and terminology from academic traditions of research and practice. In addition, the preferences module of enABLE ("Co-Pro") will measure the "*determinants of consumer attitudes towards food products and production*" at the fully consumer-disaggregated and producer-operational levels.

This Project will also make a scientifically and socially crucial, though necessarily small, contribution to the priority theme **1.1.1: Genomics and biotechnology for health** - in particular, **1.1.1.ii: Combating major diseases**. This FP6 area addresses **the ageing process** (at the end of 1.1.1.ii.a) by research on "*interactions [of molecular and cellular determinants] with environmental, behavioural and gender factors*." This is the Annex's only recognition that the functional genomics of all physical diseases (except some from single-gene defects) are environmentally contingent and behaviourally dependent. Now that the human genome has been sequenced, this scientific principle has become increasingly widely acknowledged for common chronic diseases, such as cardiovascular disease and diabetes (ii.a), some cancers (ii.b), for their links to poverty within Europe, as well as for behaviourally communicable diseases such as HIV/AIDS (ii.c), mental health problems such as depression, anxiety, stress and not excluding schizophrenia, and some neurological disorders and damage too (ii.a).

When the evidence-base for enABLE is expanded by data gathered face-to-face and over the system, the advice service and its research archive will extend to major behavioural components of these diseases' aetiology, treatment and management, *a-propos* tertiary, secondary and primary prevention. As usual in current medical practice, the enABLE service and research can address outcomes with substantial genetic determinants in the absence of information on genetic background other than family history. Nonetheless, the system could be used for genetic epidemiology and particularly for research into gene-environment interactions through behaviour.

This EoI is of course on the priority too of **1.1.2.i Applied IST research, addressing the major societal challenge** of **"e-inclusion"** for **health**. The enABLEr Integrated Project *"will focus on intelligent systems aimed at supporting health professionals, at providing patients with personalised healthcare and information, and at stimulating health promotion and disease prevention in the general population."* Unlike other approaches being developed, however, the "intelligence" of this system will be the complete adaptation of its research database to the particular circumstances of individual members of the public and to their culturally objective vocabulary.

The evidence-based personal tailoring also provides some lifelong e-Learning that can be implemented in schools, colleges and other workplaces, and in professional training and CPD in product development, health etc.

The enABLE system applies state-of-the-art personal security, mobile technologies, and input/output options for all (however handicapped), within the limits of local penetration of the Internet and those peripherals to the public.

The research loops of enABLE will address the complex social problems of evidence-based policy and of inclusive services, by restoring an ancient intimacy between the scholarly community and the local community, both now 'world villages', and exploiting the current growth of ethical developments of the Internet, i.e.: not-for-profit services; personal security; the software placed on Open Source; the dynamic database publicly archived.

Scale of ambition and critical mass

The Project must obtain sufficient amount and diversity of research data to ensure that the relevance of the advice makes users "stick" with enABLE after their first interaction, as well as to test the principles of automated generalisability (i.e. relocalisation of the evidence-base and the interfacing). These objectives require a <u>critical mass</u> of partners in several contrasting regions of Europe in order to gauge how much commonality there is in health-relevant practices. The processes for adapting enABLE to divergences in behaviour patterns between cultures permit the Project to <u>scale up</u> to include the majority culture in each European country (and indeed around the world) where a trainable research team can be found and financed. Research-based localisations of enABLE on such a scale will also ensure the robustness of the algorithms that will later adapt the interfacing to minority categories of user within the countries given access by the Integrated Project.

Integration

The Plan of Execution (below) outlines the proposed Project's integrative training in effective research techniques, innovative technological development, pilot demonstration of integrated research data collection based on information services from personally tailored and culturally sensitive evidence, collaborative research on outcomes of behaviour for peer-reviewed publication, and full-scale demonstration of the evidence-based service to any European citizen having access to the Internet.

The Contact Person and research collaborators have links with many research networks in food, nutrition, health behaviour, clinical medicine and applied psychology through which, subject to the Commission's input, participants in a full response to a Call for Proposals can be recruited, with the partnership further augmented by a 'snowball' process directed to under-represented countries in the European area.

Scientific and technological objectives

- Collect & publish associations of behaviour with outcomes in local majorities & minorities.
- Build a sustainable service of evidence-based personal advice on healthy behaviour.
- Initiate direct participation of the public in research into outcomes of common practices.

Plan of execution

Offline pilot research. A Project team first downloads draft protocols for structured interviewing to ascertain behaviour-outcome associations, and staff attend Project workshops to top-up/adapt prior data-collection and analysis skills. Raw data are logged on a central database for Project-wide analysis and use, with the option of local analysis for publication and/or for professional dissemination/training.

Up-scaling of enABLE demo. The existing demonstrator of the research-based and -generating service for nominated local users will be scaled up for localisation and use around Europe within the FP6 Integrated Project.

Online pilot research. A few bilingual users at each site will translate an English version to the local language and substitute for the behaviour patterns and product/service-types in the initial database that differ from those in the local culture. Interactions by diverse nominated users (N > 100) with the re-localised system will evaluate recognition of the self-described practices and behaviour-outcome associations in that cohort over 1 month or more. Results will be analysed and written up centrally, with the local research team's option to publish too.

Service demonstration. Provide the localised enABLE service to selected users, process-evaluate and adjust the technology, including re-localisation procedures for unselected multicultural users who volunteer "translations."

Automated updating of research base. Program algorithms to augment enABLE's behaviour-outcome evidence base from user-volunteered data showing any specialisation of associations to the circumstances of the individual user, e.g. preferred language, geographical location, age, gender, ethnic group, medical condition etc.

Research for publication. Expand availability of localised service (Ns >300) to provide data for publication by the whole Project or one or more partner teams, on: behaviour-outcome associations; relationships of amount of use of the enABLE service to average changes in outcome assessments; and prospective audits of the effects of consumption of different products or services on reported outcomes and on product-usage pattern itself.

Sustainability. Add modules for training/CPD of recognised practitioners in health services, commercial supply of retail products (e.g. foods to support eating patterns avoiding/reducing overweight), environmental design (buildings, transport) and public health policy strategies. Add modules for recognised researchers to conduct controlled trials of educational content and audits of product/service efficacy. Set up procedures to transfer updates of the enABLE database to one or more academically public archives of social data.

This research process will be organised into a number of outcome-oriented *Workpackages*, for example: Healthy Eating; Healthy Activity; Behavioural Genomics; Self-Care (chronic disease prevention & management); Behavioural Thermodynamics (weight control); Service & Product User Behaviour; Food Marketing; Functional Foods; Public Health Strategies; Research/Technology Interface.

Participants' roles and skills

Each research team's role is to execute a series of Project-wide agreed research protocols within an agreed local context. Findings obtained by traditional interview, questionnaire and physical measurement techniques will be included in the Project's service-generated research database and subsequently pooled across the Project for publication in co-authored journal papers and book chapters, with publication of other aspects of the data by the local team alone if they wish, and acknowledging their role in the Community-supported Integrated Project.

Each team's skills have to be led by someone who has been trained (and preferably is experienced) in publishing full papers in peer-reviewed international journals. The team members who execute the research protocols have to be at least graduates (preferably doctorates) in a relevant discipline, involving behavioural and/or social research, e.g. education, applied experimental or social psychology, applied or action sociology, anthropology, public health, behavioural medicine, social/behavioural nutrition, consumer sciences, marketing research, evidence-based media studies. Each of the Community-supported research staff will be required to attend multi-team training workshops, whether to learn some of the principles of design, data collection and analysis, and reporting of this type of research, or to contribute to the detailing of the general protocols to the circumstances of the locality or special group being addressed by their own team.

The proposed Coordinating team's skills include a unique combination of scientific and technological experience and achievement suited to leadership of the Integrated Project.

Over 30 years ago the university scientist directing that research team initiated the experimental analysis of biological and social influences on healthy practices, in particular the cognitive mechanisms of food choice and eating patterns that result in cumulative energy intake and thereby contribute to weight control. The theory was successfully embodied in computer simulations of human meal patterns and body composition, and also causal network (path) analyses of questionnaire data. However, the new data-collecting methods were and continue to be widely misused to label foods and even nutrients as "palatable" or "satiating." Nutrition policy realised in food regulation on medical advice was and remains based on the nutrient contents of marketed food items, underpinning a fallacious conception of functional foods, rather than on provision of food products that support patterns of eating that promote well-being. Paper versions of the research protocols for individual differences in behaviour

and outcome have been developed and are to be grafted onto the existing enABLE mini-demonstrator. Measurements of service/product differences in individual choice (demand mapping) need software that has now been professionally rebuilt; Access and Excel programs are available for incorporation as soon as the funds needed have been obtained from national research grants or from fees for professional training courses.

The Internet services developer in the university team has created a system of secure personal spaces for children in public care on funds from the national charity for this group - now assigned 1.5 million Euro by national government for regional Social Services to offer the service to their clients. The programming of the mini-demonstrator of enABLE has been pump-primed by untied grants from pharmaceutical companies, with a view to using the demo to attract funding from the public relations arms of social and medical charities for the service to the public and for training and support to professionals, and from governmental and charitable bodies supporting academic research for the generation of peer-research publications and dissemination to policy.

Organisation and management

Before a full proposal of the Project is submitted, the Commission's advice will be sought on the target number of research teams and the initial structure and modes of evolution of the partnership. The Project Coordinator (also leading one university research team) will work in close liaison with the Commission and be advised by a panel of research-experienced health psychologists, clinical psychologists, public health sociologists, academic physicians, consumer goods marketers and user-modelling educational technologists.

The Project will open with a plenary conference of team leaders, to finalise detailed principles of the plan of execution. Management and technical meetings will be held twice a year on average (more frequently initially). The Research Teams operating within each Workpackage will report regularly to the Coordinating Team, who will edit reports to the Commission at the required intervals.

Dissemination and exploitation

The behaviour-outcome research database will be regularly transferred to Data Archive(s) accessible to recognised researchers under conditions determined by that Archive. Training modules for practitioners of academic research, healthcare, product development etc. will also be available from enABLE over the Internet.

In regions with limited access to the Internet at home or in community centres etc., local subsidy may be needed for the public to exploit enABLE. This presumably should not be on the Community's research budget. Disadvantaged regions can seek Community support for access to Internet services via governmental channels.

The evidence-networking system is expected to be financially self-sustaining following the Integrated Project. The Contact Person's team has found that commercial, charitable and governmental bodies are willing to pay licence fees for their own target users of the system at rates that cover scaling up and maintenance. The personal preferences (CoPro) module of enABLE provides totally disaggregatable maps of service demand from end-users, e.g. for food products that support healthy eating habits, and so supply companies may wish to buy reports on their own brand's performance relative to the competition.

Furthermore, the enABLE technology will be put onto Open Source so that others are free to test other financial models on their own version of the computational Internet service.

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Website outlining the enABLE-*r/s* approach to research and services for wellbeing and QoL: (formerly www.qualityliving.org - domain name stolen by US realtors; now:) www.wwiyc.org or http://www.what-works-in-your-circs.org