

FRAMEWORK 6

Minutes of the meeting held at Lincoln's Inn Fields on 16 December 2002, to discuss a potential Framework 6 application

Present:

Prof Tim Bishop	UK	tim.bishop@cancer.org.uk
Dr Åke Borg	Lund, Sweden	ake.borg@onk.lu.se
Prof John Burn	UK	john.burn@ncl.ac.uk
Pam Chapman	UK	p.d.chapman@ncl.uk.ac
Dr Peter Devilee	NL	p.devilee@lumc.nl
Dr Doug Easton	UK	douglas@srl.cam.ac.uk
Dr Diana Eccles	UK	de1@soton.uk
Dr Roz Eeles	UK	ros@icr.ac.uk
Dr Shirley Hodgson	UK	shirley.hodgson@kcl.ac.uk
Prof Jan Lubinski	PL	Lubinski@sci.pam.szczecin.pl
Kay Neale	UK	kneale@netcomuk.co.uk
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1. Background

The meeting was convened to determine a way to bring together the interests of two Expressions of Interest for a Network of Excellence after the initial draft work programme was published for FP6 under the thematic priority **LIFE SCIENCES, GENOMICS AND BIOTECHNOLOGY FOR HEALTH** listed a topic entitled **Networks on prevention, detection and treatment of familial cancers – NETWORK OF EXCELLENCE**

Over subsequent weeks the order of priorities changed repeatedly until a few weeks prior to this arranged meeting it became firstly a call for the second round (November 2002) and in the last draft and the final programme this subject area was removed to a list under “**future calls**”.

The initial problem to be resolved was the possibility of changing the published work programme by **lobbying** key decision makers in Brussels;

John Burn had spoken, prior to the meeting, to Rob Buckle at the UK MRC who was of the opinion that a call for the relevant topic area is definitely not in the first or second call and the next call after that will be for November 2004. However a further phone call to the MRC during the meeting secured at least a small possibility that with sufficient pressure in the relevant places, and if a budget for a second call under the subheading cancer were to materialise (zero budget is assigned to this area for the second round at present) then the priority areas may not be totally fixed for the second call (November 2003) at this stage.

Diana Eccles to prepare a list of bullet points about the joint proposal for use by all members of constituent organisations to lobby MEPs and key persons involved in decision making at the EC.

Terms of engagement

Diana Eccles reminded the meeting that the purpose of the Network of Excellence is to create a virtual centre of excellence by bringing together researchers from across Europe into a very large collaboration with exchange of expertise and that the expenditure of the Network on research must exceed that of the money granted to fund the network. In view of the funding plan optimal number of partners for a network would be 150-300. Any fewer would be too small and with too onerous a task to match the budget, any greater and the sum of money to be shared gets increasingly small per partner. Key partners would be expected to have a major commitment in both time and expertise to the goals of the Network and this needs to be considered carefully by potential partners.

There a number of key organisations mentioned in the two key NoE EoIs submitted in July 2002 and more can be included in an application:

- InSIGHT (International Society for Gastrointestinal Hereditary Tumours) is to be formed when the FAP group (Leeds Castle) join with HCG (HNPCC) in September 2002. Many of the European members have registries for hereditary cancers.
- BCLC - Breast Cancer Linkage Consortium (represented by Peter Devilee)
- ICGFBOC – an original BIOMED programme of activities including collection of biological and clinical information (represented by Diana Eccles).
- IBCCS – International Breast Cancer Collaborative study – breast cancer genetic epidemiology (represented by David Goldgar)
- Jan Lubinski, Poland, manages a network of registers of all familial cancer sites. This includes 4,000 Eastern European families from 13 centres in 11 countries. The aim of this network is to improve clinical standards and stimulate collaborative studies. He has had good experiences administering this 0.5 million euro project under Framework 5.
- British Family Cancer Record (BFCR) is a database of families with breast cancer. This is being piloted in 8 centres in the UK at present and may be a useful model on which to build the network proposal.
- Biobank (John Burn) – an infrastructure to be formed specially for the collection of half a million DNA samples with matching clinical data from 49-65 year olds. Follow-up will be for 10 years in a national effort involved 4-9 centres. Funding will be from Wellcome/MRC with final interviews due in February for John Burn and Tim Bishop. However this is not focussed specifically at familial cancers.

The meeting reviewed the final work programme (10 December 2002), and considered an application under iib) Combating Cancer; Networking of quality controlled cancer registries and repositories for molecular epidemiology etc. John Burn telephoned Mike Parkin, in IARC, who are planning an application under this heading. Their application, known as CARAVEL, will bring together 180 cancer registries in a NoE. This section did not provide a close enough fit to the aims of familial cancer network for an application under that heading to stand a good chance and it was agreed that joining the IARC bid may jeopardise future applications aimed at funding familial cancer studies.

Employment of a consultant to write the bid was discussed. Gordon McVie was proposed as a person who might have useful experience in this context and in particular, aspects of the legal, financial and contracting negotiations which would be required.

It was decided that members of the group would lobby those with power to bring forward the section in the work programme “Networks on prevention, detection and treatment of familial cancers....” Into the second call for November 2003.

John Burn to contact Chris Patten (EU Commissioner), Bill Baig, Judy Marsden (CRUK), Rob Buckle (MRC), and Edith Olah, Chairman of the European Association of Cancer Research. John Burn to find out from Rob Buckle who the National Representatives are on the committee for November’s Framework 6 call. Emphasis would be made on European ability to excel in this area, and to make clinical gain for Europeans.

2. Plan for Application: Network of Excellence for studies in inherited cancers in Europe

When the application is made, it was suggested that we present a matrix of work packages which are currently ongoing or planned bringing together basic science and clinical practice. Diana Eccles detailed a grid describing such passages; which would bring together expertise in a “Virtual Centre of Excellence” and these activities would count towards the expenditure of the Network thereby helping to offset the investment of the EC in the Network. The bid would include a requirement to fund a data person in each partner centre (potentially up to 200 centres across up to 20 European partner countries). The principle goal of the Network would be to set up a system for collecting data and biological samples for more basic scientific studies in a consistent and standard way so that Europeanwide collaborative studies are facilitated - both clinical and basic scientific work. Partners who can map their current activities onto the grid would fit well – the grid is just an example at present with various other cells that could be added as in the original EoI applications (acronyms ENSIFAB and InSiGHT) – these can still be viewed on the cordis website

Sites	Prevention	Detection	Treatment	Low Penetrance Genes	Modifier Genes	ELSI
Breast	IBIS	MARIBS	POSH	I	B	EMBRA CE
GUT	CAPP	Faecal markers		B	F	
Gynae-uterus & vary				C	C	
Prostate		IMPACT		CS	R	

Acronym

John Burn suggested the name ICE (Inherited Cancer in Europe) for the project

Ideally the network should be about 200 (150-300) centres should be involved to get the optimal grant. John Burn telephoned Rob Buckle (MRC) who felt that the more approaches, to the FRAMEWORK 6 committee between now and March, the better would be the chance of bringing the topic into the next call.

If the likelihood of a move into November 2003 improves European meetings will need to be held, with potential partners present representing each of the various aspects in the virtual Centre of Excellence.

Clinical, Scientific and Ethical standards would be set with the NoE, with a working principle of taking part in research wherever possible.

Information Technology developments will be key and would need to be standardised to form a well linked network and meet the aim of a valid “virtual centre of excellence”. Bioinformatics SME’s would be engaged to help achieve this e.g. Kintrack, Progeny, Oxigene, IDgene. Subspecialty training will be addressed .

3. Writing the Proposal

John Burn suggested employing a management company or obtaining matching funds from his Knowledge Park funding for a manager.

Diana Eccles was happy to help write a full proposal, but felt contract negotiations would require some expert input. Jan Lubinski was happy to help with contracts and emphasised that this had been straightforward in Framework 5. A pyramidal structure was envisioned with a credible figurehead required to chair the network. A steering group elected from amongst the 200-250 partners with a representative from each country and each area of research interest making up the membership but with the ability to change steering group members as appropriate during the course of the programme of work.

Payment to partners would be an important topic to work out. It was suggested that a price per million population (accessible for data) linked to GDP would be appropriate. It was felt that some performance related payment was essential involving quality and quantity of data shared.

Realistically, the databank would include DNA, family history, clinical history and a list of pathological specimens stored. Although Jan Lubinski had collected 1,500 samples, (with 3 affected individuals, all cancer sites), from a population of 1.5 million, this would not represent other countries who rely on referrals.

4. Long-term Plans

Integrated projects and other grant applications will be able to utilise the ICE structure to access clinical and biological material. These potential future projects will be mentioned in the ICE application but not costed. However, some projects will be integral and could be included in the network application. It may therefore be necessary to build into the costing the aliquotting and barcoding of DNA. Once DNA is banked with relevant consent, projects will naturally evolve.

5. Action Plan

- All members to lobby appropriate people with potential power to change the current timescale of calls for proposals – bullet points for lobbying are as follows
 - i. Hereditary cancer is a powerful scenario for testing clinical management strategies (prevention, screening, treatment) because of the higher number of cancers diagnosed in this population with potentially wide application for cancer in general
 - ii. Mapping all potential cancer genes will be important for developing much more sophisticated risk assessment and management programmes
 - iii. Understanding genetic predisposition to cancer and how this can be best utilised for the benefit of all cancer patients and their families requires a clear exchange of expertise in molecular genetics, bioinformatics, ethical and social issues and given the differences across Europe in legal frameworks, a clear understanding of these issues will be vital to ensure a common approach to this subject.
 - iv. The Network is already established in general terms and a very compelling application could be constructed.

- All potential network partners to be asked to nominate an ICE leader

- A senior representative to be sought from each country with a CV and a statement as to why they are a representative

- A further meeting involving all key partners will have to be held. A date of 9th July 2003 was suggested depending on how the framework 6 calls work out.

Pam Chapman 15.1.03