DIAMAP: a new way of working to develop a future research strategy

S Hills*

Introduction and background

The DIAMAP project was funded by the European Commission FP7 programme in 2008 for two years. It was written to specifically address the information gap across Europe of the funding available for diabetes research that is spent by governments, NGOs and industry, and then who is doing what and where among the research community. In the light of the epidemic and the increasing costs of this disease¹ it was felt that it was time to carry out a kind of 'inventory' of what research was happening and how much funding was available and from where. An impetus for the DIAMAP project was the high level workshop 'Diabetes: Europe rising to the research challenge', back in 2004 at which FEND was represented. This displayed how little was known about available research resources at the European level especially in relation to the US.

In 2007, EURADIA applied for and was awarded a grant from the European Commission FP7 to carry out DIAMAP, a road map for diabetes research in Europe. The final report published in September 2010 and an accompanying slide set are available online on www.DIAMAP.eu.

Rationale

Diabetes is one of the major health challenges of the 21st century. This

Author

Sarah Hills, DIAMAP Project Manager, Executive Director of EURADIA (Alliance for European Diabetes Research)

*Correspondence to: Sarah Hills, e-mail: sarah.hills@euradia.org

Summary

The epidemic of diabetes and the burden of mortality and morbidity from complications can only be tackled by research. The present investment in research is not sufficient for the exponential rise in the number of people with diabetes across Europe and the rising costs of treatment and care at such a time of economic uncertainty. It is known that the direct and indirect costs of diabetes far outstrip the investment in research in Europe. There are no real data available on how much is actually spent on research, although this information is easier to obtain from European sources (e.g. European Commission) than national sources. There is also no strategic research plan at the European level for diabetes research, although several member states do have such a plan. EURADIA developed the DIAMAP (road map for European diabetes research) project to attempt to address these issues with two large-scale surveys and a multi-national and multi-professional expert task force. DIAMAP is now coming to a close with the publication of a major report and presentations during the FEND and the EASD meetings. The future road map report has undergone a public consultation period and garnered feedback from across Europe. This article recounts the approach taken to the surveys, database development and structuring the research road maps to ensure that the patient was at the centre.

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chronic disease has reached epidemic proportions in all regions of the world and the prevalence of diabetes in both its major forms is expected to continue to rise inexorably if nothing is done to prevent this.²

The challenge of curing diabetes, preventing its onset and improving care and its delivery can only be met through increased research. Europe is well placed to play a leading role in this research effort in terms of existing expertise. However, success will depend not only on increased funding but also on more rational use of research funds and better coordination of research.

Major goals

The aim of DIAMAP was to chart the future of diabetes research in Europe for the benefit of the patient. In support of this mission a survey was carried out of the European diabetes research landscape, and a strategic road mapping exercise for diabetes research in Europe was undertaken. The DIAMAP report comprising the road maps and reports from seven sub-groups is intended to guide investment in diabetes research in Europe up to approximately 2019 and to suggest ways to improve coordination. The two public DIAMAP databases provide insight into the current research landscape. The databases have been created with the intention that they will be searchable and open for additional entries after the project is completed.

Methods

The database was developed specifically for the project and adapted as requirements have changed; the databases are integrated with the website, which is also the repository of project documentation (internally) and provides external links to online and print journal articles. This means that the framework remains in place in-house for future work. The survey questionnaires on research activity and funding were





developed and piloted before the project began. The EURADIA network of members and association journals was used to publicise and distribute the questionnaires. Information in the databases is based on questionnaires returned by investigators and major funding agencies (public and non-profit) across Europe, who were encouraged to complete the questionnaires directly online to avoid transcription errors.

The diabetes research road mapping took a multidisciplinary and multi-professional approach and involved 55 experts from all areas of diabetes research. Individuals with diabetes were represented on the Steering Committee, alongside researchers from academia and industry. A guideline document was carefully drawn up to guide participants through each stage of the road mapping process with examples. As well as written guidelines there was a major meeting held at a strategic point in the mapping process.

When the research maps were drawn up, demographic trends and lifestyle factors were taken into consideration as well as ageing of the European population. Ethical issues as well as research in health economics and public health also feature across the various road maps and these form a major part of the Horizontal Issues report.

Diabetes research was considered in its broadest sense embracing, where possible, all aspects of this complex field. The development of areas of research can be traced through the road maps from the basic sciences to individualised treatment. Prevention and treatment are viewed throughout from the population level to the individual.

Results

Road maps and reports

The DIAMAP report provides a blueprint for future diabetes research in Europe that takes a broadly all-encompassing viewpoint. The starting point to each road map track is based on major advances in each of the fields of research covered by DIAMAP over approximately the last 10 years that influence current thinking. This tracks progress to reach a common endpoint - an overarching research goal considered of particular importance for improved treatment or prevention of diabetes with several interim research milestones along the way. Each goal and milestone is considered in a practical way to guide people who are taking research to the patient and especially for programme managers of research funds.

The groups were also invited to consider the feasibility of the milestones, as well as the specific opportunities for European research. The road maps from each sub-group -(1)genetics/epidemiology; (2) islets; (3) pathophysiology/metabolism/integrated physiology; (4) clinical science and care incorporating a European Diabetes Research Collaboration; (5) microvascular complications; and (6) macrovascular complications are not independent but part of a whole, stressing the need for crosscutting, interdisciplinary research. Basic research proposed by the specialist groups is translated into clinical studies in the clinical science and care road map.

Each step of the mapping process was focused on the patient; for example, each milestone is described in terms of how the patient will benefit.

Creation of a European Diabetes Research Collaboration would allow centralisation of information, with an increased involvement of patients and clinical research staff and improved sharing of knowledge, data and samples.

Databases

The two databases are freely accessible and remain open as tools for the community. The Research Database provides information regarding who (senior/independent investigators) is doing what type of diabetes research (keyword search for topics and technology/methodology) and where (country, city, academic institution) in Europe. With over 1200 entries, this is the first searchable database of its kind ever developed for European diabetes research. The Funding Database and accompanying report provide a best estimate of total funding for diabetes research in Europe by public agencies and non-profit foundations as well as information on unrestricted grants from industry.

Future perspectives for DIAMAP

Aside from the primary goal of using the road maps to guide choice of research areas for future funding and to ensure such research is coordinated, in the longer term this project cannot succeed unless there is constant monitoring of progress. It will also be essential to evaluate the impact of this innovative research strategy in terms of development of new therapies, approaches to treatment and health care planning, and improved quality of life for individuals with diabetes.

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Further information on the DIAMAP project, including access to the full DIAMAP report and accessible databases, can be found on www. DIAMAP.eu from 22 September 2010.

Parts of this article have been published elsewhere (Halban,³ Halban and Hills,⁴ and DIAMAP Report on www.DIAMAP.eu; European Commission publication DIAMAP').

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