Chapter 9. Funding questionnaire and survey

Introduction

A survey of the diabetes research funding landscape of Europe was carried out between 2008 and 2010 and gives an approximate indication of the level of diabetes funding in the region. Significant effort was made to contact and consult a wide range of public and private funding bodies across Europe from which varied quantity and quality of information was received. According to the data obtained by DIAMAP, diabetes research funding was in the range of Euro 230-340 million annually for the years 2005-2008. Given the limitations discussed here, this is probably an underestimate: perhaps the true total is closer to Euro 500 million annually.

To our knowledge, no similar survey has been undertaken previously in Europe. Unlike in the United States where information about public (Federal) funding of diabetes research from the National Institutes of Health (NIH) is centralised, there is no such body in Europe. European Commission (EC) funded projects can be ascertained through the CORDIS portal, but EC funding for diabetes research is acknowledged as being limited, with the bulk presumed to be generated from national sources. National governments support diabetes research in their own countries, and such support often exceeds EC funding. Although obtaining such information from national governments was challenging it appears that the majority of relevant sources have now been captured.

DIAMAP focussed mainly upon national and European non-governmental (NGO) funding and government funding. Because of the way in which the data were collected and the limitations to the data, this report should be considered a 'snapshot' description, to the best of our ability and resources, of the funding available in Europe for diabetes research for 2005 to 2008 inclusive. Industry was invited to provide information regarding funds for investigator-initiated (unrestricted educational) grants only. However, even with this very limited scope it was hard to capture this information (see below).

Funding for European diabetes research through non-profit organisations was easier to capture, especially from major international or pan-European funding agencies such as the Juvenile Diabetes Research Foundation (JDRF) or the European Foundation for the Study of Diabetes (EFSD), that are able to access detailed information and in any case focus only on diabetes research. Some national diabetes associations or foundations within Europe also support research, typically restricted to institutions and investigators in their own country, and information from these organisations has been included in the database.

The major goal was to capture the amount of funding specifically earmarked for diabetes research in Europe. There was no attempt to quantify 'serendipitous' funding arising principally from grants awarded to investigator-initiated projects. For example, European Research Council (ERC) grants that are based on excellence of the investigator and the project, regardless of the field of study, may end up supporting diabetes research even though this was not the intended purpose. The same applies to 'regular' grants from national research councils or agencies. There is however a grey zone of overlap. Some general funding agencies are able to identify investigator-initiated grants impacting on diabetes (through keywords). When completing the questionnaires, these agencies may have included such grants in the total funding amounts for diabetes research.

DIAMAP is set within the context of other initiatives examining European resources, such as the IDF-FEND diabetes policies audit in which policy practices in diabetes services were surveyed across the EU [The Policy Puzzle 2008 (http://www.idf.org/EU-diabetes-policy-audit)]. The European Research Area (ERA) Watch (http://cordis.europa.eu/erawatch/index.cfm?fuseaction=ri.home) descriptions of funding flows (research funding systems) was used as a resource for DIAMAP.

Aims and objectives

The objectives were to carry out a survey of funding for diabetes research, both public and private, at regional, national and European level, and to develop a database in the public domain for data extraction and analysis. Information was provided on the understanding that it would be considered confidential and not linked to the source.

Methods

Questionnaire development

The existing EURADIA funding database was used as the starting point for contact addresses. A questionnaire was then drawn up (on website www.DIAMAP.eu), in five sections:

A. General contact information
B. Management of research funds
C. Type of research supported (such as type 1 or type 2 diabetes, basic science, trials etc)
D. Funding practices
E. Annual diabetes budgets 2005-2008

The questionnaire was reviewed by the DIAMAP committees, and a limited pilot of the survey was carried out. A link was made available on the website to access the online database. It was preferred that the respondents would enter the data themselves. A 'Word' version was also available, although this meant emailing it to the DIAMAP staff for central data entry. A paper version was available, although this was discouraged due to difficulties in interpretation of handwriting. A guarantee was given to all participating organisations to protect submitted data and not to make it available to third parties. Respondents agreed that their data may be used for the project report in a compiled form.

Locating organisations of interest

The questionnaire was targeted at organisations thought to fund research into diabetes or its complications; these organisations were identified in the following manner:

- All organisations on the original EURADIA database were investigated through their websites. This was augmented with a systematic Internet search of diabetes (and related) NGOs (charities) and government ministries of health, science and education.
- Organisations outside of Europe (e.g. JDRF) were contacted if they were known to fund diabetes research within Europe.
- Papers published in *Diabetologia* and published abstracts from EASD Meetings were searched.
- Organisations were asked to publicise the questionnaire on their websites (links are mentioned on the DIAMAP website).
- EURADIA partners were asked if they provided funding for research. They were also asked to publicise the questionnaire (on websites or journals).
- IDF-Europe provided contact details for its member organisations.
- Participants in DIAMAP expert groups were contacted asking for details of national funding organisations in their countries.
- Publicity during meetings such as the EASD.
- Articles in European diabetes journals, such as *Diabetologia*.
- The questionnaire was made available on the website, and spontaneous data entry was encouraged. An interactive map was included to indicate the number of organisations from each country that had replied.
- National representatives to the EC DG Research Health Programme Committee received a letter from the acting Director of the Health Directorate, Research Directorate General, European Commission, asking them to intervene personally to ensure that national funding organisations returned completed questionnaires.

Funding data collection: emailing of questionnaire and telephone interviews

Between April 2008 and March 2010 more than 430 organisations were identified, for which a database was developed in Excel with telephone and email of a contact person. Information was also collected, if available, on funding practices, type of diabetes research funded, budgets and geographic area.

Of these 430, we contacted 398 organisations (Table 9.1) individually by email from the DIAMAP project steering committee. A follow-up message was sent after 1 month. A telephone call was made and an appointment made to speak with the appropriate person. The questionnaire was emailed prior to the telephone interview. The process of locating organisation-specific information and making contact with an appropriate contact person took on average 6 months and several telephone calls. The same person undertook the task of telephone interviewing to minimise variation.

Data checking and quality control

All data entered into the database underwent quality control. If in doubt, the respondent was re-contacted directly.

Results and interpretation of data

Government and NGO funding

The DIAMAP office retains a record of the number of times each organisation was contacted by telephone and email, and all information collected. Of the 113 organisations that provided complete information (total in *green* columns Table 9.1) up to 10 organisations replied (with completed questionnaire) per country. Organisations from several countries did not provide any information at all, for a variety of reasons (12 countries). In some instances, it was impossible to make contact with any organisation in certain countries. On other occasions, when contacted, the appropriate person

did not respond despite several emails and telephone calls, or specifically said their organisation did not fund diabetes research. Language barriers may have been a reason for lack of information although the staff person from DIAMAP was familiar with five European languages.

Completed questionnaires with information suitable to be analysed (113) were mainly obtained from European Union (EU) countries, but a limited number also came from European non-EU countries with a small international input mainly from organisations based in the United States:

EU 27	93 (82%)
European non-EU	15 (14%)
International	5 (4%)

The types of organisation that responded to the questionnaire were as follows:

Government	50 (44%)
NGO	60 (53%)
Private (non-pharmaceutical)	3 (3%)

For some organisations contact information was not accessible as their website was in a language not spoken by DIAMAP staff. Thus, the total number of contacts to organisations was reduced to 398. Entries were recorded in the database from organisations not included in the original contact list. These were spontaneous entries (data could be freely entered via the DIAMAP website); at other times an organisation would also pass the questionnaire to other organisations (also unknown to us). If budget information was collected by means other than the questionnaire it has been included in the calculations.

Universities were not included in our survey of organisations, as they do not generally *generate/provide* funding specifically for diabetes. However, it is acknowledged that there are certain institutes or groups of institutes that fund specific research programmes [e.g. the German Diabetes Centre (Deutsches Diabetes Zentrum) in Duesseldorf and CIBERDEM in Spain] utilising funding directly from government, industry and health service sources. Research institutes wholly owned by a pharmaceutical company (i.e. Hagedorn Research Institute, Gentofte, Denmark) were also excluded. It is acknowledged that the traditional model of research funding coming from government is changing to a mix of private plus public. This may not always be reflected in the data collected and in fact may have confused our interpretation.

In Europe, unlike the USA, salaries for senior investigators are paid by universities, national research organisations or health services. To the extent that the salaries are not understood by the payers to be directly related to diabetes research, they are not featured in the database.

When organisations were contacted to ascertain how much funding they devoted to diabetes research (Fig 9.1) there was no surprise in that diabetes-focussed bodies spent the majority of their funds on diabetes or diabetes complications (they were not asked what the other funds were spent on, but these were minimal and only concerned a small number of organisations). Of the general funders just under half spent up to 25 percent of their funds on diabetes (they were not asked how their budget broke down across other funding areas). A surprising number (20) did not give any information on diabetes-specific funds despite acknowledging that they did fund such research (marked as zero automatically by the database even if the question was simply left unanswered).

When organisations were asked about percentage of funding spent on type 1 compared with type 2 diabetes there were 92 replies with the bulk of funding directed to type 2 diabetes (Figs 9.2 and 9.3). In terms of the diabetes epidemic perhaps this is not so surprising (approximately 90 percent is type 2 diabetes). Both general and diabetes-specific funders tended to apply funding in this direction (note: we did not analyse the actual budgets). However, these data must be interpreted with caution. The numbers refer to the *percentage* of funds from any given organisation devoted to type 1 or type 2 research, broken down into quartiles. No data are available concerning the *total amount* of money devoted to type 1 compared with type 2 diabetes. The importance of this distinction is manifest when considering the single example of the Juvenile Diabetes Research Foundation (JDRF). It is public knowledge that this NGO provides substantial support for type 1 diabetes research in Europe, more than any other single organisation supporting any area of diabetes research, but the magnitude of this support is not reflected in the organisation data in these Figures. The total *amount* of money spent by NGOs in Europe for type 1 diabetes research is in all probability higher than that spent on type 2 diabetes research, simply as a result of the substantial support provided by JDRF.

'Other types of diabetes' funded included gestational diabetes, monogenic diabetes including maturity onset diabetes of the young (MODY) along with some responses, such as travel, insulin therapy, and foot care, indicating a possible misinterpretation of the question (data on file).

The broader question of the 'discipline' of research into which the funding was directed is indicated in Figure 9.4 (to which multiple responses could be given). As expected, the bulk of funding is directed to basic and/or clinical research followed by epidemiology and public health. Responses provided under 'other' included translational research, engineering science and humanities, occupational and nutritional research.

Funding practices (data on file) indicate that the bulk of funding from national organisations as expected is applied to research undertaken nationally (occasionally further stratified by local region). From these responses we cannot ascertain if any of this research is carried out in collaboration with other countries but again as expected, national organisations fund very little if any *pan-European* research. Three diabetes organisations based in Europe stated that 76-100 percent of their funds were spent outside of Europe while another six (of which three were diabetes-focussed) stated they spent 1-25 percent of their funds outside of Europe (e.g. Australia/New Zealand, Africa, Asia or North and South America).

When asked from where their funds originated, the 60 responding NGOs indicated a mixed source of income mainly from private contributions or from members, with the second stream from industry (Fig 9.5). It was assumed all government funding originated from taxation.

The most important information for DIAMAP concerned actual budget resource allocations made between 2005 and 2008 for research on diabetes or its complications (Tables 9.2 and 9.3). The Tables indicate annual spending when this information was provided or average annual spending based on total funds committed divided by the number of years of the commitment. This allowed us to overcome the inherent problem in distinguishing between funds *allocated* each year from funds actually *spent* in that year. For example, most funding agencies would register the entire amount committed for a 5-year grant in the year of that award, and not distributed equally over the 5 individual years. Data for 2008 are likely incomplete since they may not have been available when the questionnaire was completed.

We are concerned that there may be important discrepancies in reporting practices especially for national organisations. For example, the UK reported much higher total government support for diabetes research than any other country, which was confirmed in a UK Parliament publication. A top-down request within the responsible government departments may have encouraged civil servants to search for data more diligently. We do not know how this sum was arrived at, and it seems likely that national funding bodies in some other large European countries spend as much as the UK but this is not captured in their response to the questionnaire. Maybe they use different criteria, take into consideration smaller areas of focus or simply could not make the information available because they had not been asked to do so previously by a higher governmental authority.

This is the first time a serious attempt has been made to estimate the amount of money devoted specifically to diabetes research in Europe. According to the data obtained by DIAMAP, this was in the range of Euro 230-340 million annually for the years 2005-2008. Given the limitations discussed here, this is probably an underestimate: perhaps the true total is closer to Euro 500 million annually. In any case, we believe that the DIAMAP estimate provides a useful number for comparison with investment in diabetes research in other parts of the world.

Industry funding

DIAMAP was interested in also collecting information on funding from the pharmaceutical industry, as this is another major means of non-governmental research support.

This was the most challenging part of all the surveys. A questionnaire was devised initially based upon the questionnaire sent to NGOs and governments. Even though this was piloted among EURADIA industry partners it became obvious that the companies would not be able to respond to the questionnaire in any meaningful way. The questionnaire was revised twice, the second time towards the end of the project when it was considerably shortened. The contact process consisted of personal letters from the Chair of EURADIA and also a direct personal request from the Scientific Officer at DG-Research during the DIAMAP final meeting. It was explained clearly to representatives of the pharmaceutical industry that the questions were considered appropriate and that detailed answers were expected by the Commission.

The survey requested information on external (third party, academic) funding for investigator-initiated diabetes research (so-called 'unrestricted educational' grants). DIAMAP was not concerned with research undertaken within the company or by their academic or commercial sub-contractors. It was made clear that all data would be presented in collated form without any way of tracing information back to any named company.

Twenty companies were targeted through a known contact person. The criterion for inclusion in the list of targeted companies was that the company was considered a 'major' player in European diabetes research. Each of the companies is known personally to the EURADIA officers; however, a search was also conducted through:

- EURADIA partner organisations
- companies listed in the research survey
- companies exhibiting during EASD Meetings

The difficulty arose when our contact person within the company had to obtain information from within the hierarchy (our contacts were senior director level, either in research affairs or advocacy and professional relations). Often the information was simply not available in the format requested by DIAMAP; there was no way for example to find information about funding of type 1 compared with type 2 diabetes. Because funding would be provided for a 'project' there was no way of knowing the type of staff employed using these funds (number of nurses for example). The fact that companies also operate from European and national level affiliates also confused the picture as well as having offices in the United States.

The decision to allow information to be included in the survey was often apparently made by a person more remote within the company hierarchy. We have had three negative responses responding to our question about research budgets:

Companies contacted	20
Responses (any kind)	11
Providing budget information	6
Budget declared confidential	3

Figure 9.6 indicates the annual budget amounts indicated in the six positive replies. Other information that was provided included application processes for third party funding and how funds were managed within the company.

The average annual amount indicated per company is approximately Euro 800,000.00. Extrapolated to 20 companies an annual amount of Euro 16 million is reached, even though there is no validated basis for such an extrapolation especially given the known disparity in R&D investment between companies that presumably extends also to such third party funding. From the Research Questionnaire the amount indicated by researchers themselves (current funding from industry) is Euro 44.9 million (Fig 8.10). When divided by 3.1 years (indicated as approximate duration of research grants) this suggests annual support from industry of Euro 14.5 million. Such a crosscheck indicates concordance between the two surveys that provides reassurance without formal validation of either total amount.

Although it was extremely challenging to obtain the information, it should be noted that pharmaceutical company support is 'captured' at other points in the DIAMAP surveys; 1. from the researcher survey (Figs 8.10 and 8.11 within 'Industry' and 'multiple' funding sources); 2. NGO funding is often noted to originate from industry (Fig 9.5); 3. as funding practices are changing it is possible that government funding also contains support from industry that we cannot distinguish; 4. it is known that an appreciable amount of support comes from industry for infrastructure that would not show up at all in this survey – for example general funding of laboratories and scanning centres that is not formally linked to diabetes research. Note that funding for commercial clinical trials was *not* included in DIAMAP, nor were travel grants or support for meetings (even if they dealt with research).

A search was also made of corporate websites using various terms such as research grants, corporate/social responsibility etc; although there was often considerable information on the application process, lists of actual grants and amounts awarded could not be located. We acknowledge that we may not have searched in the right places.

Challenges in obtaining information: for all funding organisations

- Language of the contacted organisations' websites was not always spoken by DIAMAP staff (who were familiar with English, French, German, Italian, Spanish and Swedish). To help counteract this problem a multi-lingual research assistant with experience in European and national governments was contracted.
- Some organisations no longer existed despite information on the Internet etc.
- EURADIA and the DIAMAP project seemed not to carry sufficient 'authority' to elicit the necessary response from some government ministries, although others were exceptionally helpful. The added weight of two communications via the EC helped somewhat but not in all cases.
- It was rare that an organisation replied immediately; on average it was at least 4 months of telephoning and emailing before *any* contact was established with an appropriate person. Frequently this person then had to make several requests internally before a useful response was elicited.

- There was some confusion between academic organisations (universities) rather than bona-fide *funding* organisations, only the latter being relevant to DIAMAP (several universities entered information directly in the database).
- Incomplete questionnaires were always queried with the organisation but many times responses indicated that information was not available, or that the information was confidential.
- Email messages from DIAMAP were occasionally destroyed before being read, reflecting the importance of having an internationally recognised central agency, such as the EC, undertake such a survey.

Limitations in the data

- The assumption was that DIAMAP would be able to obtain data from all relevant institutions, and we have attempted systematically to contact major organisations in each European country. Difficulties arose when funding originated from different sources or was managed by different agencies in each country. It is acknowledged that not all organisations may have been contacted.
- Linked to the above, funding is often obtained from mixed sources – government, industry (public-private partnerships) and NGO/charity. Because the funding is channelled via multiple agencies and the origin of the funding is obscured it has not always been possible to discern if we are looking at the same funding but at different points in the funding stream.
- DIAMAP searched specifically for funding for research on 'diabetes' (and its complications), with obesity and cardiovascular disease only when related to diabetes. It is acknowledged that there is also funding for research in areas such as agriculture, nutrition, urban planning and transport, and bioengineering and the basic sciences, which may have been missed because 'diabetes' is not used as a key word.
- The funding questionnaire was written in English only. This meant that some information returned might not be reliable as responses are influenced by the interpretation of the questions.
- The data reflect funding for the years 2005-2008 and were collected over an 18-month period. Even within this limited period changes in funding practice can be seen, with some organisations stopping funding completely and others increasing (although our information is limited on such details). The survey was carried out before the present economic crisis, which will have impacted in ways not reflected in this report.
- Further information on the DIAMAP surveys can be obtained from info@EURADIA.org.

Table 9.1. Contact with funding organisations and funding questionnaire (FQ) completion (by country)

Country	Contacted organisations (n)	Complete FQ General Funding (n)	Complete FQ Diabetes organisations (n)	Other information (e.g. email) (n)	No reply (n)	Replies received (%)
Albania	**1**	0	0	0	1	0
Armenia	**0**	0	0	0	0	0
Austria	**14**	5	1	7	1	93
Azerbaijan	**2**	0	0	1	1	50
Belarus	**1**	0	0	0	1	0
Belgium	**10**	3	1	3	3	70
Bosnia and Herzegovina	**0**	0	0	0	0	0
Bulgaria	**4**	1	0	3	0	100
Croatia	**2**	0	0	0	2	0
Cyprus	**4**	1	0	2	1	75
Czech Republic	**9**	0	0	7	2	78
Denmark	**10**	3	2	5	0	100
Estonia	**5**	4	0	1	0	100
Faroe Islands	**1**	0	0	0	1	0
Finland	**17**	5	1	9	2	88
France	**27**	3	3	9	12	56
Georgia	**3**	1	2	0	0	100
Germany	**32**	7	2	17	6	81
Greece	**8**	1	0	3	4	50
Hungary	**11**	2	1	3	5	55
Iceland	**6**	1	0	3	2	67
Ireland	**14**	4	1	6	3	79
Israel	**3**	1	0	0	2	33
Italy	**13**	2	2	3	6	54
Kazakhstan	**1**	0	0	1	0	100
Kyrgyz Republic	**1**	0	0	0	1	0
Latvia	**6**	1	0	4	1	83
Lithuania	**3**	1	0	1	1	67
Luxembourg	**6**	2	0	4	0	100
Macedonia, FYR	**1**	0	0	1	0	100
Malta	**2**	0	0	0	2	0
Moldova (Republic of)	**1**	0	0	0	1	0
Netherlands	**11**	2	1	6	2	82
Norway	**5**	2	1	0	2	60
Poland	**9**	2	1	1	5	44
Portugal	**8**	1	2	0	5	38
Romania	**4**	3	0	1	0	100
Russian Federation	**3**	0	0	2	1	67
Serbia	**5**	1	0	2	2	60
Slovakia	**8**	2	1	5	0	100
Slovenia	**6**	0	0	3	3	50
Spain	**14**	1	2	4	7	50
Sweden	**23**	3	1	5	14	39
Switzerland	**9**	1	2	4	2	78
Turkey	**5**	2	2	0	1	80
Ukraine	**1**	0	0	0	1	0
United Kingdom	**23**	9	2	6	6	74
USA	**2**	0	0	0	2	0
Uzbekistan	**2**	0	0	1	1	50
International Organisations	**42**	2	3	10	28	33
Total	**398**	**79**	**34**	**143**	**143**	**64%**

Figure 9.1. Percentage of funding spent by organisations on diabetes-related research compared with other diseases. Possible replies: 0%, 1-25%, 26-50%, 51-75%, 76-100%. 0% also default for 'unknown' or 'unanswered'

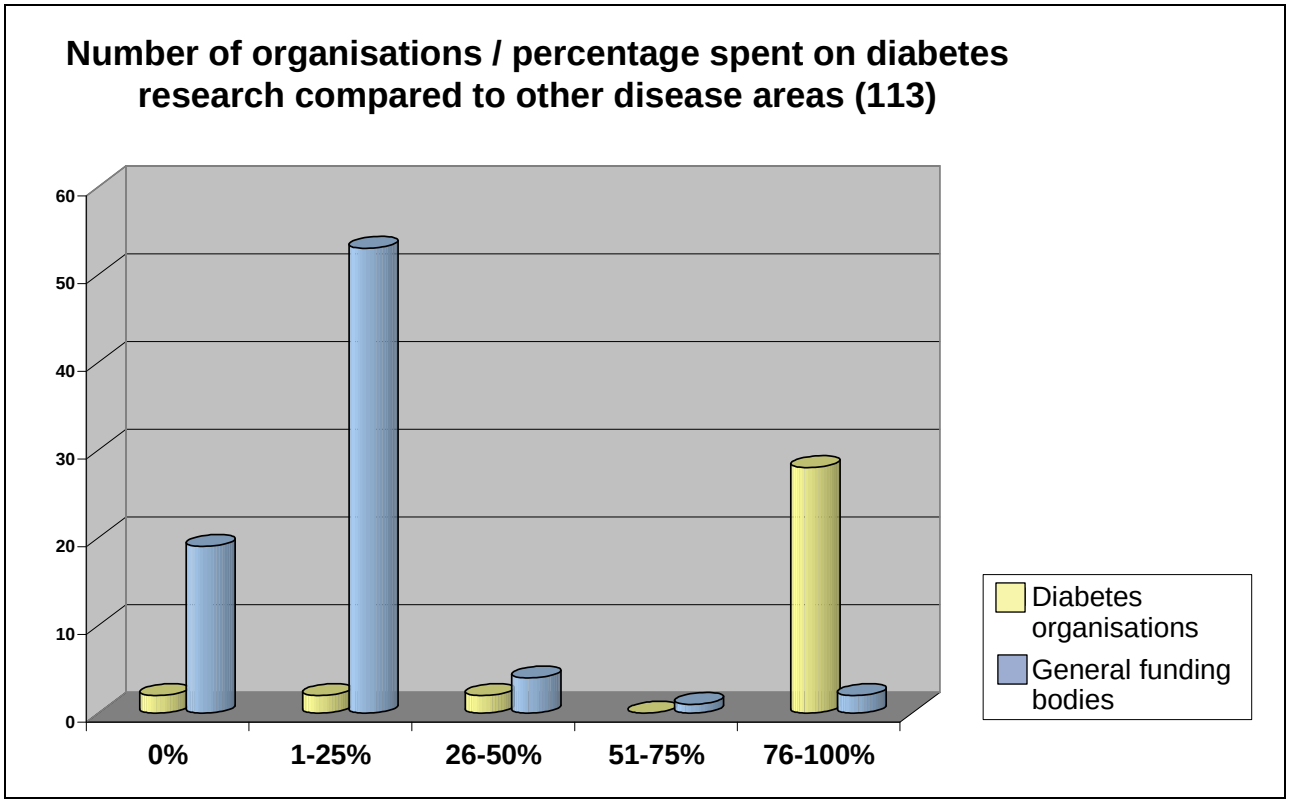


Figure 9.2. Percentage of funding allocated to type 1 diabetes within organisations.
Possible replies: 0%, 1-25%, 26-50%, 51-75%, 76-100%. 0% was also default for 'unknown' or 'unanswered'

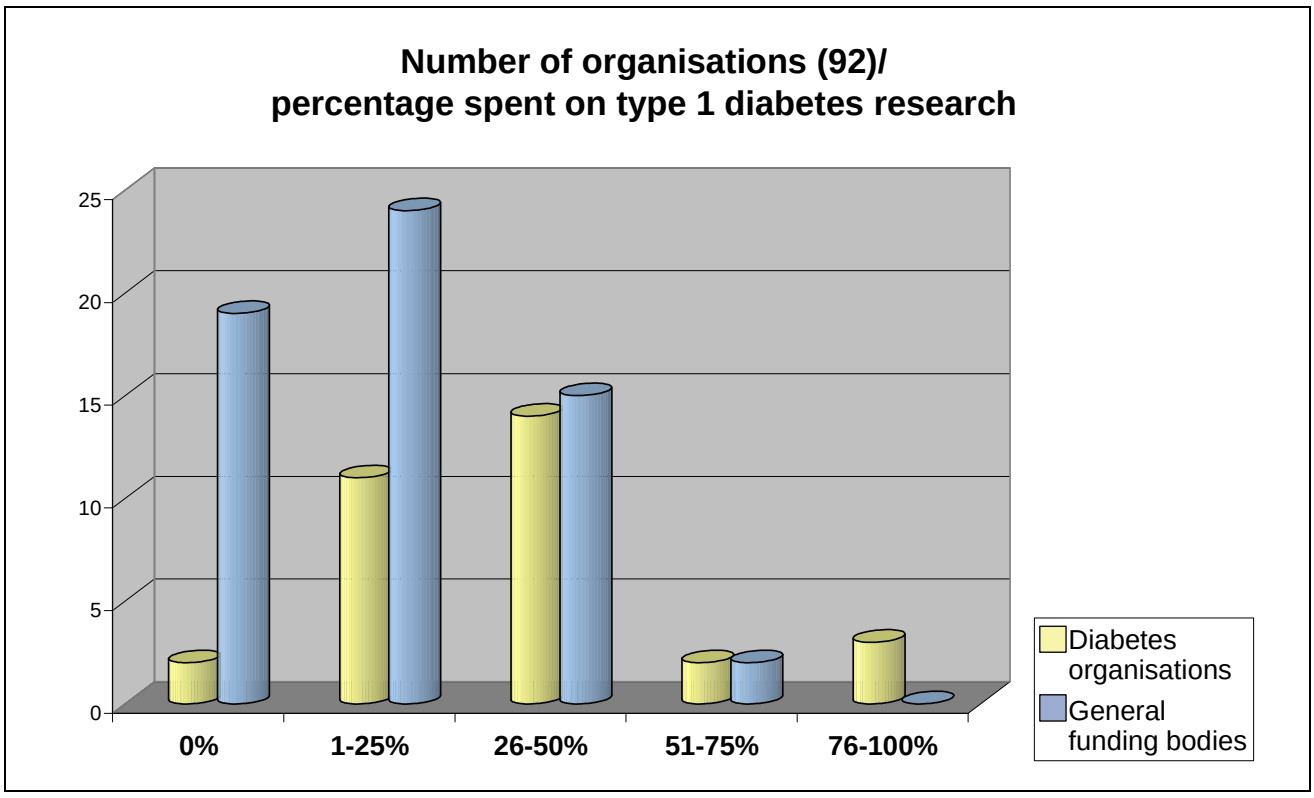


Figure 9.3. Percentage of funding allocated to type 2 diabetes within organisations
Possible replies: 0%, 1-25%, 26-50%, 51-75%, 76-100%. 0% was also default for 'unknown' or 'unanswered'

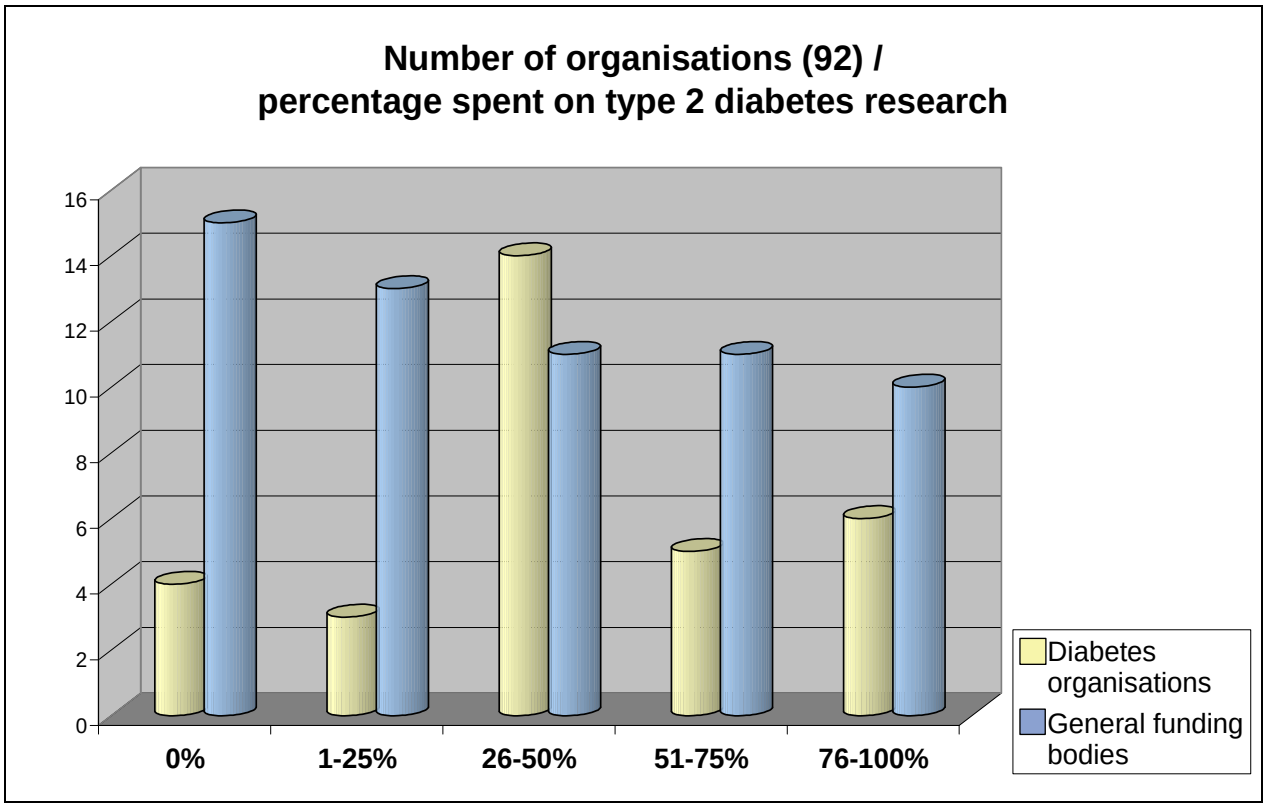


Figure 9.4. Research disciplines funded (multiple choices were possible)

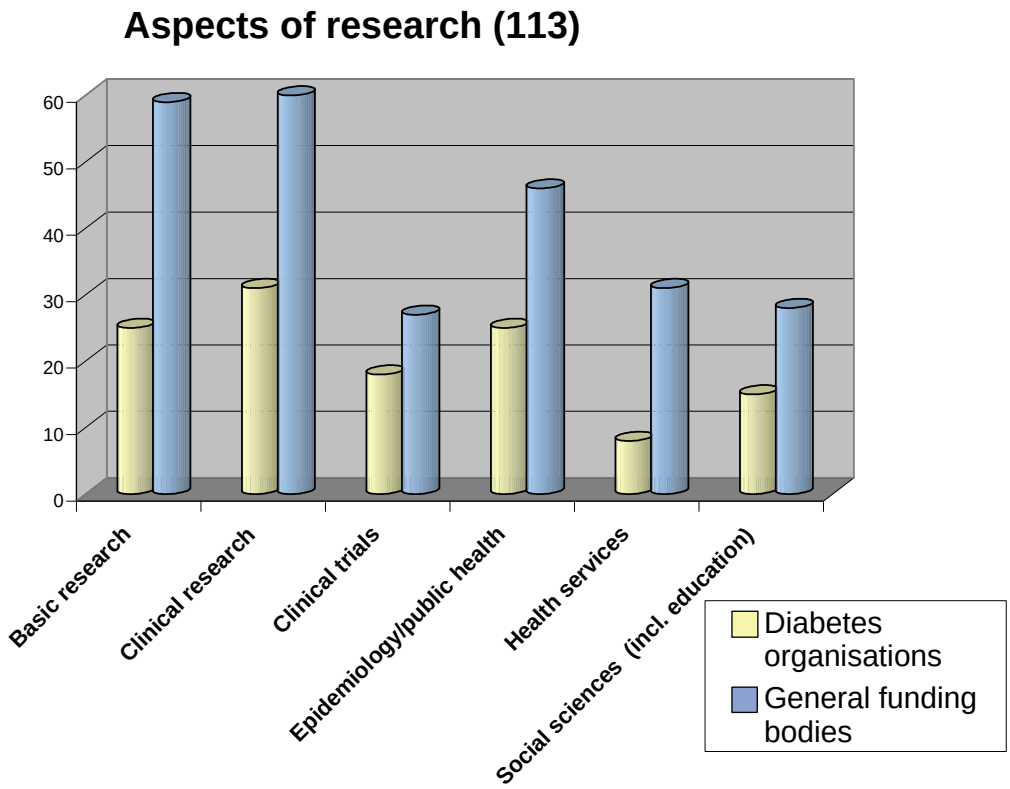
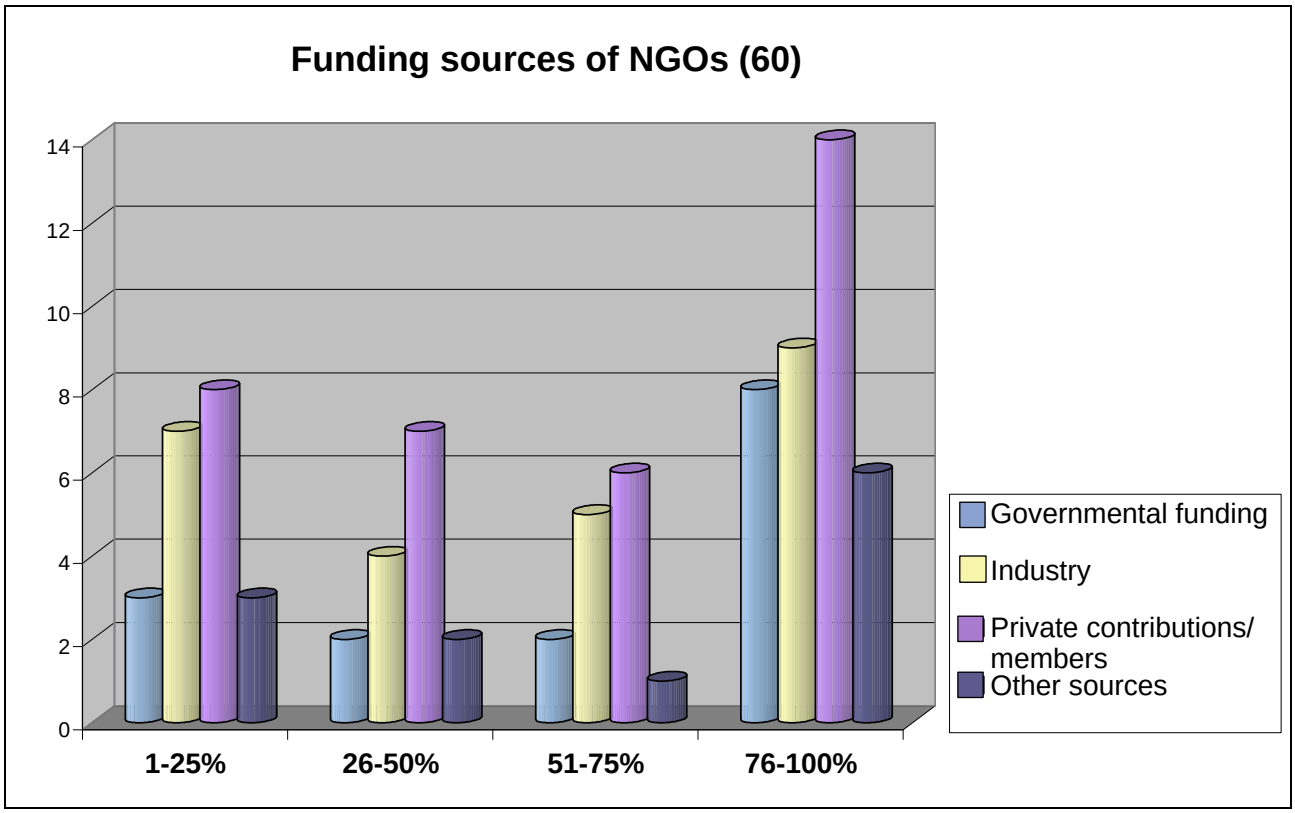


Figure 9.5. NGO Funding sources. Multiple replies possible: Government funding, Industry, Private contributions/members, other. 1-25%, 26-50%, 51-75%, 76-100%



Three private companies / enterprises replied with a completed questionnaire:

- 1 received 76-100% funding from governments
- 1 received 76-100% funding from a bank (other sources)
- 1 received 76-100% funding from industry and from clinical trials

Figure 9.6. Responses to the industry questionnaire on third party funding budgets (total annual amounts based on responses from all the six companies that replied to this question)

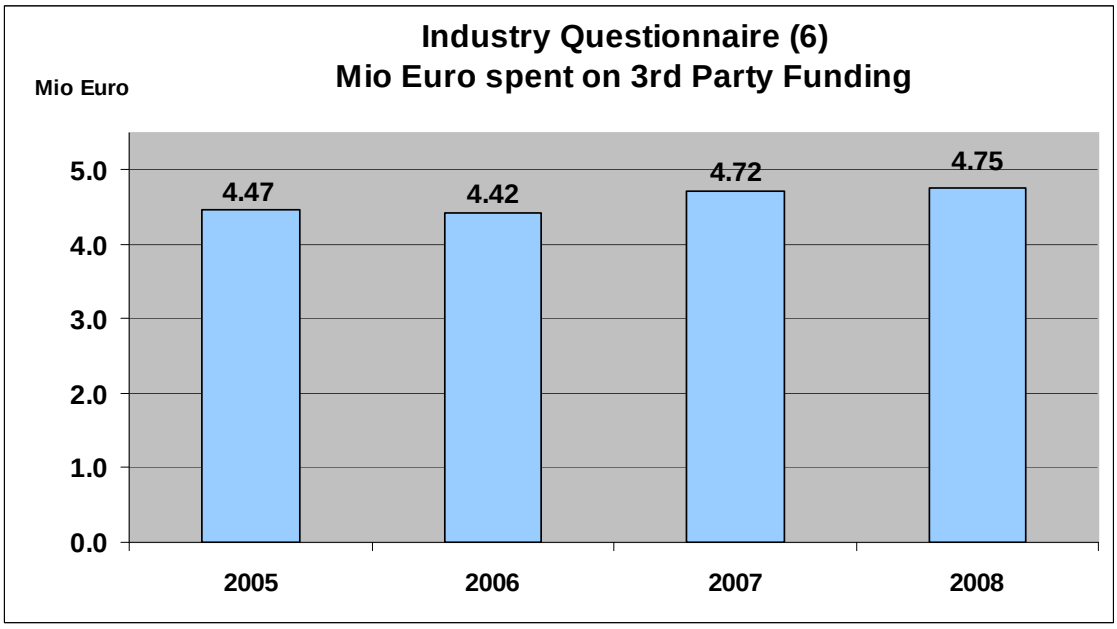


Table 9.2. Allocation of research funds from 2005-2008 (inclusive), estimated / approximated funds spent on diabetes research and/or its complications

	Euro 2005	Euro 2006	Euro 2007	Euro 2008
NGOs/charities	61,449,986	64,886,046	76,786,102	78,841,809
National Governments[1]	90,569,735	128,099,865	187,337,072	127,633,448
European Commission*	87,786,640	56,586,266	67,189,775	79,913,882
Private company/ enterprise	705,073	691,199	448,072	1,221,340
Pharmaceutical companies	4,470,930	4,422,257	4,721,257	4,752,918
Estimated total[1]	**244,982,364**	**254,685,633**	**336,482,278**	**292,363,397**
National Institutes of Health (USA) (USD 40,636,367) **Funds marked for Europe**	http://projectreporter.nih.gov/reporter.cfm			30,698,447
Grand total	**244,982,364**	**254,685,633**	**336,482,278**	**323,061,844**

[1] Amount for 2008 may not be complete because statistics were not finalised when information was gathered
* Calculations based on total project grant award divided by total project months multiplied by project months in the year of interest, e.g. 2005-2008

Table 9.3. Detail of European Commission funding (included in Table 9.2)

	Total Euro 2005-2008	References	Funding Type 1 diabetes	Funding Type 2 diabetes
FP6 'Diabetes' projects	195,415,692	http://cordis.europa.eu/fp6/projects.htm	1-25%	76-100%
FP7 'Diabetes' projects (as of 03/10)	20,299,505	http://cordis.europa.eu/fp7/projects_en.html	1-25%	76-100%
DG Sanco 'Diabetes' projects	7,189,589	http://ec.europa.eu/eahc/projects/database.html		
EUREKA 'diabetes' projects	68,571,777	http://www.eurekanetwork.org/project		

Since 2009 **IMI** has supported diabetes research with Euro 80,000,000 per year (thus not included above). Their first programme runs over 5 years. IMI funds include support from the EC and from the pharmaceutical industry (in kind). Marie Curie funding to support 'diabetes' research are included in the tables above.