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## Competence Network and Future of HIV Research

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Dear Readers,

The Competence Network for HIV/AIDS was established more than nine years ago with the aim to “consolidate and coordinate research activities in Germany”.

Now the funding ends – what remains?

At first glance, mainly a large database and a biomaterial bank comprising up to 15,000 patients.

During the last few weeks, community activists discussed the current development on our website [d@h blog](#). We present some of the postings in this HIVreport.

Almost simultaneously to the end of the Competence Network for HIV/AIDS, a new research network was established: the Centre for Infection Research, DZIF.

At the 5<sup>th</sup> German-Austrian AIDS Congress (DÖAK), DÖAK President Prof. Reinhold E. Schmidt MD presented the new centre: It is not to become a new competence network, but what will be different? We report on the “future of HIV research”.

Best regards,

Armin Schafberger and Steffen Taubert

## **Competence Network & Future of HIV Research**

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## End of Funding for the Competence Network for HIV/AIDS

### Continuation of HIV cohort impossible

Now it's official: After the end of state funding, the Competence Network for HIV/AIDS may have to call it quits. Its core project, the national patient cohort, can no longer be continued. A [joint circular](#) by the Competence Network Head Office, Deutsche AIDS-Hilfe and the Community Advisory Board is currently being distributed among study participants.

The management of the Competence Network for HIV/AIDS made every effort to find another way to finance the patient cohort, but ultimately failed to raise the considerable amount of money needed to continuously collect data, blood and DNA samples from more than 8,200 patients.

Nonetheless, the scientists are not willing to simply destroy a wealth of data collected over many years. After all, the establishment of this research network cost more than EUR 18.6 million, and several research projects are still ongoing.

Moreover, the network's Head Office continues to receive requests for data or material samples to be used in joint national or international research projects, stated Professor Norbert Brockmeyer MD.

### Data and biomaterial to be stored until 2016

At the General Assembly of the Competence Network for HIV/AIDS in March 2011, it was therefore decided not to destroy the data and biomaterial for the time being in order to maintain its availability.

As a cost-cutting measure, all blood samples, which were previously stored at several facilities, are to be transferred to one central location. According to Brockmeyer, the storage will be financed by the Ruhr University Bochum, where the network has its Head Office.

In addition to covering electricity, refrigeration and computer costs, this is meant to create a form of basic administrative structure. Until the end of 2011, a research fellow will be in charge of the project. After that period, data evaluation will be based on freelance contracts. At the urging of the Community Advi-

sory Board and Deutsche AIDS-Hilfe, the Steering Committee has determined a final closing date.

In accordance with the informed consent of the study participants, all data and biomaterial will be destroyed no later than 30 June 2016. If there are no new scientific requests for data and biomaterial before that date, the Steering Committee may decide to have it destroyed earlier.

### Glossary: Competence Network for HIV/AIDS

The Competence Network for HIV/AIDS research association was established in 2001 with the aim to consolidate and coordinate research activities in Germany.

Besides a large number of small individual research projects, the primary objective of the network's scientists, epidemiologists and aids associations was to create a national HIV patient cohort.

In this cohort, data and biomaterial was collected from a specific group of patients over an extended period of time and made available to researchers at request. The cohort contains data of about 8,200 HIV patients collected over a period of approx. seven years.

### FAQ

#### ***Where are the data, blood samples and other biomaterials stored?***

Electronically recorded patient data is pseudonymised and stored on a server of the University of Cologne at the "Centre for Clinical Studies". A copy of this data is held by the Competence Network's study coordinator, who is employed at the Ruhr University Bochum.

The majority of the blood samples are stored in freezers at the Ruhr University Bochum. Additionally, some blood samples are kept locally at HIV treatment facilities and clinics that are affiliated with the Competence Network for HIV/AIDS. Certain biomaterials such as lymph nodes or skin samples are stored at external biobanks (for a complete list of all biobanks, see [Kompl@t 3/2010](#)).

#### ***Who is responsible for the security of data and biomaterials?***

The Ruhr University Bochum is responsible for data protection as legal representative of the HIV cohort, and undertakes to ensure the proper and safe storage of blood and DNA samples at its facilities.

The security of locally stored blood samples is ensured by the responsible physician at the respective location.

### ***How do study participants receive information about what happens to their data?***

Every study participant has the right to know what is done with their data and biomaterial. Many patients indicated on the consent form that they “always want to be informed whenever the Competence Network gains new insights into HIV infection”.

The patient’s primary point of contact is the relevant physician at the practice where he/she signed the informed consent form.

Additionally, all general information about the Competence Network for HIV/AIDS can be viewed on its official site, [www.kompetenznetz-hiv.de](http://www.kompetenznetz-hiv.de). However, it is not certain how up-to-date that information will be in the future, when there is no longer a financed administrative structure.

### ***How will the patient representation be organised from now on?***

The end of funding for the Competence Network also affects the project of Deutsche AIDS-Hilfe, which will no longer be a part of the Steering Committee.

Nevertheless, the honorary Community Advisory Board will ensure the continuation of a patient representation. Its spokesperson is also a member of the Steering Committee. This position is currently held by Siegi Schwarze. The Community Advisory Board can be reached by e-mail at [patientenbeirat@gmx.net](mailto:patientenbeirat@gmx.net).

### **Continue or quit? Study participants get to choose**

Since the discontinuation of the administrative structure and the end of continuous data

collection is causing major changes in the overall project, it is understandable that many study participants are now asking themselves if they should continue to make their data and biomaterial available for research purposes. For the network’s scientists, the answer is clear: Quitting now would not make any sense, because there is still data being evaluated, and there may be more to come (see overview on [www.kompetenznetz-hiv.de](http://www.kompetenznetz-hiv.de)).

But for study participants, there are also other questions to consider: Is my data still secure? This should be carefully evaluated: At the Ruhr University Bochum, data and biomaterials are stored using the established protective mechanisms of university research, which includes collection and storage under pseudonyms (encoded with a consecutive number). This means that the researchers of the Competence Network for HIV/AIDS do not have access to any personal data related to blood and biomaterial samples.

Only the patient’s attending physician can match a pseudonym with a name (for a detailed presentation of this data protection concept, go to [www.kompetenznetz-hiv.de](http://www.kompetenznetz-hiv.de)). Only individuals who are authorised by the Steering Committee have access to the samples and data.

However, concerns over unauthorised access can only be allayed within the Competence Network for HIV/AIDS’s sphere of influence on the use of data. Could it be possible for the authorities, insurance companies or employers to somehow gain access to research data in the future?

The German Ethics Council investigated this matter and released an official statement on biobank research in June 2010. The statement pointed out that research data – unlike a patient’s medical records – can still be seized in legal proceedings.

Additionally, researchers are not bound by confidentiality. In legal proceedings, it would be relatively easy to seize research data. The German Ethics Council has therefore been demanding a specific biobank privacy law for some time now (see our report in *Kompl@t* 3/2010).

So far, the legislature has not taken any action, even though laws to protect the rights of patients are urgently needed, considering that biomaterial research is becoming in-

creasingly international, while genetic information is also attracting commercial interest.

Relying on pseudonymisation or anonymisation alone is not enough to be safe. Because when a certain amount of individual data is exceeded, there is a greater probability of being able to identify a person, despite anonymised data sets, by employing data matching (with the help of other databases) and sufficient computing capacities.

With the help of reference material (comparing samples), it is already possible to identify anonymised biomaterial (German Ethics Council 2010, p. 11 ff).

It should be emphasised that the informed consent of study participants does not make it possible to identify participants that way. Any exceptions could only be granted by court order.

For the time being, the Competence Network for HIV/AIDS is still holding up fairly well. By being involved in the Steering Committee, the patient representatives have a relatively good overview of ongoing research projects. Prior approval by the Steering Committee is required before blood samples can be handed out to external partners. Let's hope it will stay that way, now that the "financed administrative structure" is coming to an end.

The good news: No study participant will have to decide within the next few weeks. If you do nothing, you will automatically remain a participant. If you want to quit, you can directly notify your physician. The DAH website offers a downloadable [form](#) for those who want to exit the cohort.

*Steffen Taubert, Armin Schafberger*

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### **Commentary (Competence Network)**

#### **"The research in the Competence Network for HIV/AIDS will go on"**

The Competence Network for HIV/AIDS has been networking HIV/AIDS research at national level since 2002 and has been documenting the health development of HIV-

positive people in Germany in its HIV cohort for about seven years. Since the BMBF funding of the network regularly ran out in April 2011 and no follow-up funding in the required amount has so far been found, the documentation of cohort data and biomaterial had to be discontinued. The DAH, the Community Advisory Board and the Head Office of the Competence Network have sent out a circular informing the participants of the current developments, which were discussed at the last General Assembly (GA) at the Munich AIDS Workshop in March 2011.



#### **Storage according to the principles of Good Clinical Practice (GCP)**

An essential part of the regulation, under direct involvement of the Community Advisory Board, which was resolved by the Steering Committee and the GA, is that the data and material samples can be used for research until June 2016 in accordance with the regulations of the informed consent signed by the patient, unless otherwise desired by the specific patient. Should the funding and thus the documentation not be continued, all data and material samples will be destroyed by the Ruhr University Bochum according to GCP (Good Clinical Practice). As a result, any ongoing research projects, e.g. studies investigating various aspects of HIV/HCV co-infection, can be continued and concluded on schedule, and the valuable data pool can be used in new projects until 2016 for the benefit of science and thus for that of our patients.

#### **Biobank anonymously networked**

The biobank of the Competence Network for HIV/AIDS was also successfully integrated into the P2B2 project funded by the BMBF. This makes it one of the first six biobanks in Germany to be cross-linked via the web-based "Project Portal in the German Biobank Register", enabling a more efficient use of the

samples for biomedical research (we reported about this in [Kompl@t 4/2010](#)).

The project portal is based on many years of preparatory work by the TMF – Technologie- und Methodenplattform für die vernetzte medizinische Forschung e.V. [Technology, Methods and Infrastructure for Networked Medical Research] and the Fraunhofer Institute for Biomedical Technology (IBMT). Exclusively anonymous data is used and the data transfer is governed by a “database contract” containing German and European data protection regulations.

The provisions of the Competence Network’s informed consent are fully implemented therein. This project offers the patients in the Competence Network for HIV/AIDS an ethically and legally secure basis for dealing with their samples and data and opens up an additional way of conducting research for their benefit using the samples provided.

The biomaterial samples will be stored centrally at the Ruhr University Bochum as the fiduciary providing, and generously also financing, the required infrastructure.

The end of the BMBF funding also means that, since May, Deutsche AIDS-Hilfe has no longer been involved in a project that was until that point funded by the Competence Network for HIV/AIDS itself.

What about the future? The Competence Network for HIV/AIDS will go on; the existing patient cohort will be continued until June 2016, however, without any further data being recorded. It is to be emphasised that the Community Advisory Board will continue its activity in the Competence Network for HIV/AIDS on an honorary basis and the Head Office of the Competence Network will also continue its work.

entific manner, thus using them for the purpose for which they were provided by the patients – namely for research together with and for the benefit of the patients.

The child and pregnancy cohort will also be continued and new studies will be conducted. The well-established network structure of the last few years will continue to be used on national and international scale, e.g. in MITOC or COHERE, in order to coordinate investigations outside the network and promote the transfer of knowledge into practice.

Since its establishment, the Competence Network for HIV/AIDS has been able to initiate and successfully implement a great number of scientific projects, either through state funding, donations or with the support of the industry, and has made the results accessible to the public in more than 300 publications (see also [www.kompetenznetz-hiv.de](http://www.kompetenznetz-hiv.de)).

This year alone, four publications have so far been published or approved for publication.

The Competence Network for HIV/AIDS will go on. We will make every effort to evaluate all cohort data in the next five years and further advance patient-oriented research in order to improve the quality of life of our patients, who have always supported us.

The cohort continues to offer many opportunities – let’s use them!

*Adriane Skaletz-Rorowski, Judith Coenenberg, Klaus Jansen, Norbert H. Brockmeyer*

### **Hoping for further studies**

Besides the administration of the biobank and the database, not only the ongoing projects need to be further supervised but also new studies need to be initiated and logistically and conceptually supervised in order to analyse the collected data and samples in a sci-

## Commentary (Carsten Schatz): “Quit before it comes thick and fast!”

<http://blog.aidshilfe.de/2011/05/23/kompetenznetz-hivaid-5-raus-bevor%e2%80%99s-ganz-dicke-kommt/http://blog.aidshilfe.de/2011/05/23/kompetenznetz-hivaid-5-raus-bevor%e2%80%99s-ganz-dicke-kommt/>



Carsten Schatz (Photo: Andreas Fux)

**Collecting data from HIV-positive people is a delicate matter in the first place. Deutsche AIDS-Hilfe (DAH) is now no longer able to advocate their interests in the Competence Network. At the same time, the network exhibited construction faults from the very beginning. For DAH Member of the Board Carsten Schatz, the consequence is as follows: Quit. The data and biomaterial must be verifiably destroyed.**

All efforts to uphold the government funding of the Competence Network for AIDS/HIV and thus the Competence Network itself have failed. The end of the funding at the end of April this year also means the end of the network's supervision by Deutsche AIDS-Hilfe (DAH). As a result, the study participants will lose an important point of contact.

The patient newsletter, for many people the only source of information, is no longer published. Participants are only able to obtain information at the specialist practices. The Community Advisory Board will continue its work on a mere honorary basis. (Actually, who will pay for the meetings and the work of the committee?) So much for the unpleasant state of affairs.

The General Assembly of the Competence Network has decided to nevertheless continue its work for the time being, because important studies are still ongoing. I'm not a scientist, so I prefer not to make any state-

ments on the significance of these studies. However, nobody even tried to explain their significance to me. One thing is certain: Until 2016, all data and biomaterial of the participants are to be stored centrally at Bochum University.

The Community Advisory Board and the DAH have sent out a circular to all participants, explaining to them the possibilities of dealing with the situation in a neutral manner:

**Doing nothing:** In this case, the data and samples will remain at the researchers' disposal until their destruction in 2016.

**Quitting:** For this purpose, Deutsche AIDS-Hilfe offers a downloadable form, which is to be handed over to the physician. The data will be deleted; the biomaterial will immediately be destroyed.

For me personally, the second option is definitely the way to go: Quit before it comes thick and fast!

During the foundation phase of the Competence Network, I advised many people with HIV/AIDS to get involved, relying upon the involvement of Deutsche AIDS-Hilfe in the Community Advisory Board and the independent government funding.

As early as in late 2006, the first scandal was revealed: Without obtaining their consent, participant data was transferred abroad, where it is not subject to the same level of data protection we are used to in Germany.

### **Sloppy data entry, lack of communication, false trust in the physician-patient relationship**

In mid-2007, the next bad news followed: About half of the cohort's original participants dropped out of the network because of major mistakes during data entry. Notification of participants? No chance!

Back then, many people reached out to me, asking why they had not been notified. Unfortunately, I was not able to answer this question ad hoc. Only after a time-consuming Internet search was I able to explain this informational disaster: The Community Advisory Board had no direct contact with the participants – this was predominantly taken over by the participating medical practices and treatment centres. But what interest would a medical practice have in telling the patients in the waiting room: “By the way, we no longer participate in this important research project because of sloppy data entry.”

At a further point, the Competence Network gives rise to the question of physician-patient relationship. We should take our knowledge seriously and should not pretend everything was all right. After all, we are committed to informing and educating patients about this disease, because for most people with HIV/AIDS it is difficult to ask their questions and tell their problems to a physician. So we can't just go and say: Well, if you've got any questions about the Competence Network, go ask your doctor!

**The data is not protected against seizure, while some public prosecutors are aiming to identify "virus spreaders"**

In this respect, the Competence Network had a construction fault from the very beginning. I told myself that people can refer to the DAH and the Community Advisory Board. Since this is no longer the case, my statement is clear: That's it. Quit now!

The second point: The data is not protected against seizure, for example in the course of criminal proceedings. This was made clear by both a study commissioned by us and a statement of the German Ethics Council on the security of human biodatabases. As long as public prosecutors in Germany are going around, thinking that they can do prevention by prosecuting "virus spreaders", I consider even the collection of this data to be highly delicate – no matter on what grounds.

And again: Back then, we told the participating scientists and physicians: Let's fight together to change this situation. So far, I have not seen any progress in this respect. My hope for more is limited. The fact that the data is now planned to be stored in a central place instead of locally as before makes it even more easily accessible in its entirety.

So now it's our turn to take action. The data and biomaterial must be verifiably destroyed. In other words: That's it. Quit now!

**Deutsche AIDS-Hilfe overestimated itself when it decided to ride the tiger**

The third point is a point of self-criticism. I think Deutsche AIDS-Hilfe and its community overestimated themselves when they decided to ride the tiger. As indicated in the article by Bernd Vielhaber, the Competence Network always had to struggle with conflicting interests; for example, there was tension between clinical researchers and registered physicians. The former were pulling in one direc-

tion, the latter in another direction, at the bottom they were pushing, and at the top, people ran away.

In this situation, we often had the feeling of being almost the only player who is still interested in the success of the overall project. Whereas others were aiming for money and power, we tried to represent the interests of people infected with HIV/AIDS. However, we had to sacrifice this mission on the altar of compromise and diplomacy far too often.

In the future, we will be lacking our most important team mate in this game: the Federal Government. Being the sponsor, it is accountable to the public and is influencable by political pressure. This corrective is no longer available. Hence, advocating the interests of people with HIV/AIDS clearly means once again: That's it. Quit now!

The Competence Network is an important chapter in the history of HIV in Germany. This fact is not affected by its failure either. After all, the transfer of data abroad has opened up data privacy issues for debate. There were discussions about the purpose of studies and discussions about the representation of interests of people with HIV/AIDS.

I hope that this process is not yet finished, since we need these lessons for the upcoming disputes. To me, this also includes not wheeling and dealing behind closed doors but discussing publicly – for example on the websites of the DAH.

Before we keep historicising and discussing, however, we need to convey a clear message to people with HIV/AIDS in Germany who trust the Aids service organisations. In my opinion, this is: Take things in your own hands. Print out the request form for deleting your data and destroying your biomaterial. And if you have any questions, consult confidants or your AIDS service organisation. Hand over the completed declaration to your doctor. Quit.

*Carsten Schatz*



## **Commentary (Siegi Schwarze): “Hope is the last to die”**

**The Competence Network for HIV/AIDS teeters on the brink of collapse, but research will be continued with the information and biomaterial stored. Patients are now wondering whether the privacy of their data is still ensured or whether they should demand that their data be deleted and their samples destroyed. Member of the Community Advisory Board Siegi Schwarze says: It would be fatal to quit now.**



*Siegi Schwarze, Spokesman of the Competence Network's Community Advisory Board*

There is no money left – this fact cannot be denied. Now the question is: What is the best way to use the remainders of the cohort? Some research projects are still ongoing and many researchers still have ideas how the data and biomaterial collected can be evaluated in an intelligent way.

The only problem is that many questions are “serial”, i.e. you first have to wait for the evaluation of a database inquiry before you can start another one. In other words: The evaluations will take some time, possibly even several years.

Therefore, it would be fatal if many patients now decided to “quit” and demanded the deletion of their data and the destruction of their blood and tissue samples.

This step is frequently justified with the argument of data privacy. However, the end of the project and the centralisation of the data and samples in Bochum rather facilitate data privacy, since data can be monitored more easily when stored in a central place.

Although Deutsche AIDS-Hilfe will no longer be involved in the project, both the Steering Committee and the Community Advisory Board will continue their work and supervise the proper handling of the data and materials.

Most of the laboratory results are uninteresting in terms of data privacy anyway. What is most interesting is the question of the HIV status, i.e. the fact that all patients in the cohort are HIV-positive. However, the fact that the data of the cohort are not protected against seizure constitutes no real disadvantage: All information stored is pseudonymised; it is recorded under a code consisting of the name of the city, the number of the treatment centre and the consecutive number assigned to the patient (e.g. Berlin02-38). Only the respective attending physician is able to match the data and samples with the specific patient – and he/she is bound by medical confidentiality.

### **No reason to quit**

By the way, it has never happened yet that data obtained in a study was used as evidence in legal proceedings. Even in – the extremely hypothetical – case that a public prosecutor intended to prove on the basis of the Competence Network's biomaterial that patient A has infected patient B, this would not be possible anymore just a few months after taking the blood sample, since without treatment the virus changes so radically within a short period of time that its similarity to a virus in another patient is no longer distinct enough. While the virus is not able to multiply or change during successful treatment, the patient is also virtually no longer infectious at a viral load below the detection limit.

Bottom line: All scenarios used as an argument in favour of exiting the Competence Network are more or less hypothetical and cannot withstand a more profound consideration. So let's give the researchers enough time to make optimum use of the remaining data and biomaterial, since if you quit now, a major part of the efforts (and expenses) were for the birds.

And, who knows, perhaps we will yet manage to find another source of funding. The database could then easily be reactivated and the recording of data and biomaterial could be continued after just a short interruption.

*Siegi Schwarze*

**Commentary (Bernd Vielhaber):  
Sit down! You've failed!**

The Competence Network and the HIV cohort are a never-ending story of human failings, vanity, stupidity and lack of farsightedness.

The basis for this debacle is the way research is being funded by the government – i.e. with taxpayers' money – in Germany. You are terrified to see that research on diseases is largely left to the discretion of the pharmaceutical industry, which is, of course, mainly interested in doing research in a product-oriented manner. The ultimate goal is a marketable product.

Profit-oriented business enterprises can hardly be reproached for this; however, the consequences for the general public (the community), most notably for the individual patients and their attending physicians, are devastating. There is hardly any research conducted on drug efficacy, drug safety and the cost-benefit ratio. The government – the legislature – yet does not take action but leaves research to the manufacturers almost completely.

Being granted taxpayers' money for drug research (which is not based on interests) is an absolute rarity in Germany (at least in the field of HIV), by contrast to the USA, where the large clinical research network ACTG (<https://actgnetwork.org/>) has been funded by the government since 1987. However, the funding ends there too.

This – well, let's stay polite – missing farsightedness of policymakers is aggravated by the personal vanity and human failings of scientists and physicians involved in HIV research. Mutual competition and the missing willingness to become involved (without being paid) led to absurd situations, especially in the first few years of the HIV cohort.

For instance, at the beginning of the HIV cohort, entering an individual ART dose into the database system was just as impossible as entering the accompanying medication because this simply involved too much effort for the ladies and gentlemen. So it took some time until the data collection (what data is collected?) reached a promising quality level.

Just like other cohorts, the HIV cohort had had its teething troubles, which was probably also necessary, before it yielded real benefits. If I remember correctly, the ClinSurv cohort of

the RKI did not produce real benefits either until about six years after its start.

However, since neither the competition could be used in a constructive way, nor the vanity became less (on the contrary, actually), nor were the sponsors infected with farsightedness over the course of time, the disaster took its course unabated.

By that time, the HIV cohort reached a size which made it really competitive on an international scale. Large data volumes involve problems. The more data is entered, the more likely are errors to occur during data entry, which, of course, need to be identified and rectified; an expensive undertaking requiring extensive personnel.

The sponsor took action and demanded that the number of patients be halved. In my opinion, the last nail in the coffin was the subsequent process of selecting the partner centres of the cohort that were permitted to continue entering and admitting patients. It led to a substantial intensification of intrigues against the Competence Network.

Since you cannot help having the impression that politics in Germany is much more influenced by lobbyism than by farsightedness, all attempts to keep the cohort alive were in vain.

In my opinion, the Competence Network is not exclusively a victim of politics. It has substantially contributed to its own downfall by the way it acted (the way of mutual interaction). In this respect, I restrain my sympathy.

From the perspective of a HIV-positive person and from a scientific point of view, I can only say: The discontinuation of the HIV cohort is unacceptable and inexcusable.

Shame on you all! –

Sit down! You've failed!

*Bernd Vielhaber, Therapy Activist*

## The Future of HIV Research

### All eyes on tenders: Scientists looking for funding

The end of the funding for the Competence Centre does not mean the end of HIV funding. The Federal Ministry of Education and Research (BMBF) issues tenders on a regular basis. According to the ministry's statement, the current project funding provided by the BMBF in the field of HIV/AIDS amounts to a total of EUR 12 million (as of June 2011), added the funding by the [German Research Foundation \(DFG\)](#).

### Between "masculinity in Cape Town" and HIV-positive children: DFG funds 127 projects

The DFG funds individual scientists or entire research teams. Its main focus is basic research. Theoretically, any scientist with a good idea can apply at the DFG. Moreover, there are tenders, for example in the fields of humanities and social science.

DFG projects can receive funding for up to nine years. Interdisciplinary "special research areas" even have funding periods of up to 12 years. The Internet database [GEPRIS](#) lists more than 127 ongoing projects dealing with HIV research. The programme ranges from social investigations relating to "masculinity and AIDS in Cape Town" to clinical questions such as the evaluation of therapy-free periods in HIV-positive children and immunological basic research.

The annual amount of funding provided by DFG for HIV research is not reported. Since basic research projects often deal with various diseases, the funding cannot be accurately distributed among the diseases, according to the DFG's statement.

On inquiry of HIV report, the DFG stated that funding amounting to more than EUR 566.7 million was granted for the entire medical area.

### Hector Foundation regularly awards HIV/AIDS research prize

Besides the BMBF and the DLR, also private foundations promote HIV/AIDS research projects. A prominent example in Germany is the Hector Foundation, which has recently published a large-scale tender for "HIV and Age"

and awards a research prize amounting to EUR 150,000 every two years.

### Goodbye Competence Network – Welcome to the Centre for Infection Research

The German research landscape is currently being reorganised. The go-ahead for the [German Centre for Infection Research \(DZI or DZIF\)](#) has just recently been given, which is supposed to develop new therapeutic approaches, vaccines, vaccination procedures and pharmaceuticals against pathogens in the future.

Regarding its goals, the DZIF is similar to the various other medical competence networks: It is also aimed at establishing a national research network for the patients' benefit. It involves 31 universities, clinics and research centres at seven locations throughout Germany. The project sponsor is the Helmholtz Research Centre in Braunschweig. The DZIF is expected to commence its work in autumn 2011.

At the 5<sup>th</sup> DÖAK in mid-June 2011, Prof. Sebastian Suerbaum MD and Prof. Reinhold Schmidt MD from the Hannover Medical School presented the current developments.

The DZIF focuses on eleven main issues: Firstly, the major infectious diseases HIV/AIDS, malaria, viral hepatitis and tuberculosis as well as gastrointestinal diseases, secondly, it intends to address comprehensive issues such as resistance to antibiotics in connection with nosocomial ("hospital-born") infections.

Research on "emerging infections" such as bird flu, EHEC and similar diseases are also supposed to be a major topic.

Suerbaum reported that it was also important to involve the economy, NGOs and politics in DZIF's work. Concrete ideas on how this can be implemented were not yet presented at the DÖAK.

Hence, HIV/AIDS will be just one of numerous other topics and will have to compete with other diseases. Whether this is an advantage or a disadvantage remains to be seen.

It could be an advantage that research teams think outside the box more often, creating useful synergy effects in basic research or in the investigation of concomitant diseases

such as hepatitis or other sexually transmitted diseases.

However, it could result in HIV funding being further reduced, which would hardly be noticed in the large overall funding pot of "infectious diseases" due to internal reapportionments.

### **DZIF has no place for HIV cohort**

The data of the Competence Network's HIV cohort has definitely no place in the new association. Prof. Schmidt reported that the new projects would require different data and the scientists of the DZIF would only be interested in the DNA database, if at all. The last chance to use the HIV cohort thus seems to be lost.

German researchers who intend to investigate the long-term development of HIV will again have to increasingly rely on cohort data from other countries or the significantly smaller ClinSurv cohort of the Robert-Koch Institute.

It is doubtful whether the establishment of the DZIF will solve the problems which led to the failure of the Competence Network for HIV/AIDS. The DZIF will also need reliable, long-term funding in order to be able to do independent research.

For the first five years, the BMBF intends to grant the DZIF funding amounting to EUR 89 million in total, a considerable amount, which, however, has to be distributed among many more scientists than in the Competence Network for HIV/AIDS. The future will show whether it will intensify cooperation or competition.

One major difference between the DZIF and the Competence Network for HIV/AIDS is already becoming apparent: The participation and involvement of patient associations has so far not been a major issue at DZIF. At the DÖAK, Suerbaum somewhat vaguely stated that this was being planned. So let's wait and see what happens until autumn 2011.

*Steffen Taubert*

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