PERSIMUNE Data Warehouse

Since the beginning of 2015, PERSIMUNE (PM) has been working on establishing a Data Warehouse (DWH) which is now offered as a research infrastructure for all researchers at Rigshospitalet.

What does the PERSIMUNE Data Warehouse contain?
A Data Warehouse is a collection of data from many different sources, where there is a structure that secure uniform and standardized data supply. The PERSIMUNE Data Warehouse contains both a historic and a prospective patient cohort. The historic cohort consists of immunocompromised patients hospitalized at Rigshospitalet from 2005 until 2015. The prospective cohort consists of immunosuppressed patients which have given consent for their samples obtained to be used in the PERSIMUNE biobank. There are more than 80,000 patients in the Data Warehouse and continuously, new patients are added. The data sources of the Data Warehouse cover biochemistry, microbiology, demography and diagnoses, pathology, imaging, oncology, vital signs, radiation therapy, biobank samples and medication for patients during hospitalization and new sources are constantly added. The data sources can be national, regional or local from Rigshospitalet. In the near future, the Blood bank, Tissue type lab and the ICCA database of the cardiologist will also be included.

Delivery of data to the Data Warehouse
All departments at Rigshospitalet which have patients who could be included in the historic cohort are very welcome to contact PERSIMUNE (persimune.rigshospitalet@regionh.dk) to make a cooperation agreement. In practical terms we will need a list of cpr numbers to include patients. We will be happy to retrieve data from the local databases at Rigshospitalet in order for the shared infrastructure to offer as wide a data basis as possible. Harvest of data from local sources will be based on cooperation agreements.

Finally, PERSIMUNE offers to help setting up procedures for inclusion of patients for the prospective cohort.
Transparency and Governance

In PERSIMUNE, transparency is essential and the governance structure secure that local data will not be used without authorization by the management at the clinic together with an invitation to participate in the project. Furthermore, projects will only be approved, if they do not compete with the scientific plans of the participating clinics. The application process will depend on the type of project. More information on the application process is available on www.persimune.org. For research purposes, own data can be enriched with data from regional and national sources or you could establish a whole new data set. In the fall of 2016, the implementation of a webinterface for clinically use will be initiated.

How to get involved - case stories

Carsten Utoft Niemann is heading a research group at the Department of Hematology, Rigshospitalet currently focusing on treatment outcome, overall survival and risk of infections in patients with lymphoid malignancies. Carsten explains: “We believe there is an unmet need to understand the patterns of variable immune dysfunctions within and between particular lymphoid malignancies”; and continues: “If we are able to identify these risk factors, we will have an important addition to the current diagnostic strategies and antimicrobial treatment regimens - and maybe most importantly, we may be able to individually tailor treatment.”

Carsten and his group has engaged in a collaboration with PERSIMUNE to fertilize their CLL database by means of broad spectrum capture of paraclinical, clinical and demographic data through the PERSIMUNE infrastructure. With the combined dataset and by adding functional and genetic characterisation of cells from the haematology biobank of primary malignant lymphoid cells from individual patients, the group will explore patterns predictive of infectious complications or specific courses of disease.

“This day, we have developed a variety of different treatment regimens for patients with CLL based on molecular markers, comorbidity scores and symptoms. However, some patients do not benefit from the treatment they are provided and may even suffer from severe side effects. By applying machine-learning algorithms to the PERSIMUNE based multi-dimensional database including data from functional analysis of primary CLL cells at the individual patient level, we will develop algorithms for individually tailored CLL-specific and supportive treatment. We are convinced that we can refine the current state of the art, thereby improving the outcome for these patients”, Carsten concludes.

For further inspiration please find video interviews with researchers involved in PERSIMUNE and a description of the data warehouse at www.persimune.org.

“PERSIMUNE collects all data related to infectious conditions from my patients and data from routine management. In addition blood and microbiome – i.e. stool sample as are stored for future research.”

“Bacteria in our gut seem to have a huge impact in the interplay with the immune system – and by the treatment of our patients we maximally impact their immune system, especially related to transplantation and chemotherapy. When we have analyzed specimens from the biobank, the PERSIMUNE infrastructure makes it easy to draw and merge data. This is a welcome support for our research.”
“We see the infrastructure in PERSIMUNE as a kind of scaffolding in our research projects within thorax anesthesiology. This means that I can spend my time on what I do best – manage thoracic anesthesia topics and less on data management, biobanking and statistics.”

“PERSIMUNE Scientific Interest Group for immunology, among other things, is responsible for developing and validating an immunological characterization panel. The development has been a unique opportunity to prepare a panel of a very high laboratory quality. The work was done in an international collaboration with Institute Pasteur and was reviewed by international key opinion leaders. The characterization panel will be used both for patients at Rigshospitalet in clinical management as well as for PERSIMUNE research projects.”

“One of the strengths of joining the PERSIMUNE collaboration is that you get a lot for free – all the work that goes into standardizing and validating data has been done or will be done. In modern research it is an absolute requirement that others can reconfirm your results and have the possibility to understand how you came from raw data to results – for every element the path back to source data must be clear and the description of the cleaning procedures transparent.”

“By collecting data across specialties and clinics great strength is achieved – we can identify patterns that would have been impossible to reveal in smaller sample sizes from our own clinic.”

“A data warehouse is a collection of data from many different sources, organized in a structure that ensures a uniform and standardized data delivery. By means of the PERSIMUNE data warehouse you have the opportunity to receive data from one source and enter into a collaboration that ensures you get the correct data for your project. When receiving data from the data warehouse you will also receive documentation and a quality evaluation on your data. In other words, you are relieved of the burden of cleaning your data.”

PERSIMUNE - Data Warehouse Housewarming

On Wednesday 22nd June 2016 14.00-15.00 Rigshospitalet will be hosting PERSIMUNE Data Warehouse Housewarming.

Please find full programme for the housewarming here.

Annual report from The Danish National Research Foundation
PhD students and projects in PERSIMUNE

Theis Aagaard, MD
Theis has been involved in PERSIMUNE since November 2015 and is focusing on febrile neutropenia among cancer patients on chemotherapy. The aim is to develop a risk assessment tool based on analysis of historic patient cases to guide personalised patient management. As part of the process, the tool will be validated in the PERSIMUNE prospective cohort. A number of follow-up studies are under development.

Emma Elizabeth Ilett, MD
Emma is a new PhD student in PERSIMUNE. Emma started in PERSIMUNE May 2016 and is focusing on developing an Immunosuppression Score by analysing the reactivation of cytomegalovirus (CMV) as a model for immunosuppression to determine the influence of different immunosuppressive treatments in SOT and HSCT patients. Further projects will involve looking at long term side-effects of immunosuppressive treatment and which patient groups are at greatest risk of developing these side-effects.

Christina Ekenberg, MD
Christina Ekenberg is a new PhD student in PERSIMUNE as of June 1st. Christina is MD and has previously worked within the fields of Infectious Diseases at both Odense University Hospital and Rigshospitalet as well as Clinical Microbiology at Hvidovre Hospital. She has previously worked with the MATCH Program and will also be joining the MATCH group here.

Next Immunologic Colloquia:

Please note the dates for the next immunologic colloquia.

31 August 2016
PERSIMUNE Data Warehouse, Pernille Iversen

21 September 2016
Personalized Treatment of CLL, Carsten Utoft Niemann

19 October 2016
Potential biomarkers for prediction or early diagnosis of cancer, Jan Stevang

PERSIMUNE Publications 2015 & 2016

2016


2015
Development and Validation of a Risk Score for Chronic Kidney Disease in HIV Infection Using Prospective Cohort Data from the D:A:D Study. A Mocroft, JD Lundgren, M Ross, M Law, P Reiss, O Kirk, C Smith, D Wentworth, J Neuhaus, C A. Fux, O Moranne, P Morlait, MA Johnson, L Ryom, D:A:D study group, the Royal Free Hospital Clinic Cohort,


