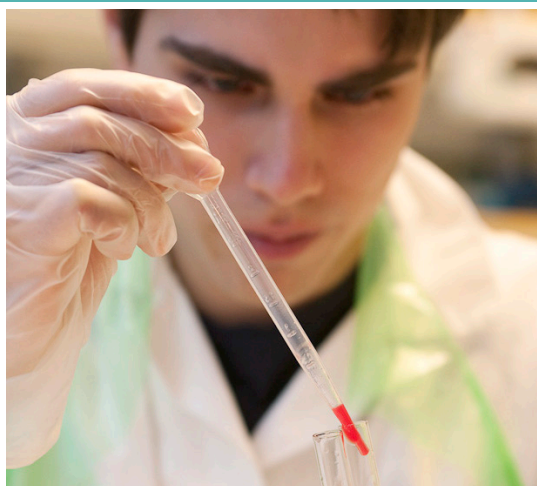


Programme 4D – bridging the gap between healthcare and research



The individual and patient of today is well-informed and ready to be an engaged partner and co-producer in future development of the healthcare process. This insight is fundamental to the Programme 4D, that focuses on creating generic models for the most prevalent diseases making the patient, or individual, a central partner in information exchange and knowledge building. The choice to focus on personalized health and care is informed by ageing of the European population, an increasing burden from chronic disorders, and fall-out from the economic crisis. In combination, these factors are jeopardizing sustainability and equity of European health and care systems, on which Europe already spends nearly 10% GDP.

Healthcare, patient and research interaction

Programme 4D ("D" as in diagnoses) is a collaboration programme between Karolinska Institutet (KI) and the Stockholm County Council (SCC). The aim is to improve conditions for healthcare and research to enable the rapid transfer of knowledge to personalized prevention, early diagnostics and treatment. The objective is to design generalizable models suitable for the majority of diagnoses. The programme, which extends over the period 2012-2017, is intended for subsequent wide implementation in healthcare and research.

The four diagnoses were chosen based on their high prevalence and health impact: arthritis, breast cancer, diabetes type 2 and heart failure. Programme 4D also includes a separate project for informatics to enable the linkage of medical records, patient e-health accounts, quality registers and biobanks.

Personalized prevention and the individual's participation

The individual plays a central role in this interaction either being a well-informed patient participating actively in treatment and research findings or by understanding the impact of personalized prevention. Simply put, this collabora-

tion programme makes healthcare more accessible to patients and to clinical research, as well as making clinical research more accessible to patients and healthcare. ICT-supported infrastructure will narrow the gaps in the patient's clinical pathways in order to enable patient co-production in care such as prevention, risk-screening, diagnostics and treatment.

Unique patient registries in Sweden

Sweden is known for its clinical research, particularly due to our systems of individually unique personal registration numbers and access to national demographic and patient registries in long time-series.

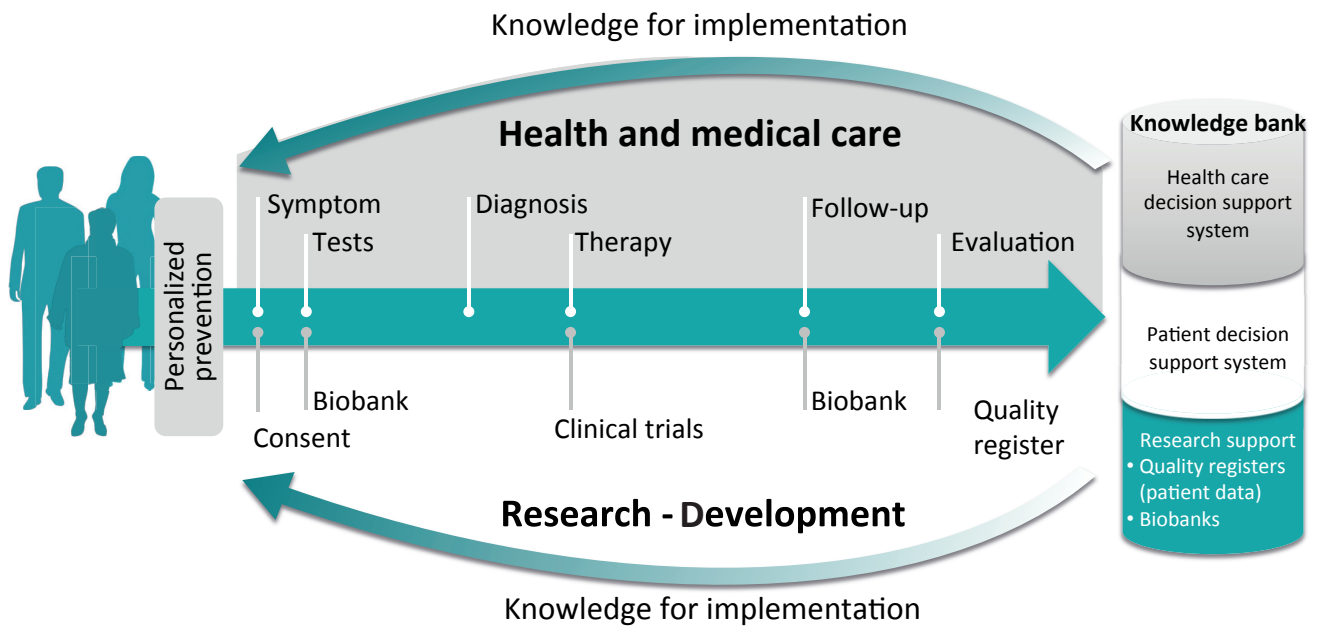
Programme 4D is a Swedish collaboration between



**Karolinska
Institutet**


**Stockholms läns
landsting**

Stockholm County Council



Systematic data collection and analysis enables knowledge building

The programme will investigate how information from different sources, such as the patient’s medical records, patient registries, biobanks and imaging banks may be tapped for research purposes, including clinical integration of research activities such as biobanking. The diagnosis-specific patient registries collect comprehensive, high-quality data and present outcome data of patients. The new Stockholm Medical Bio-

bank coupled to the registries, will be crucial to gain information about diseases. Together, this will lay the ground for “big data” management and is at the heart of the programme.

Achievements so far

Examples of generalizable models being developed with the informatics project are summarized below.

1 Online screening, living habits and form management. Digital tools for screening symptoms are developed for many diagnoses. Result data is transmitted to electronic journals to serve as knowledge support for patients and doctors.

2 Patient self-tests. With the help of supporting information systems and upon doctor approval, patients are given the option of doing their own referrals for lab tests. Test results are reported to the patient via the online system “My Healthcare Contacts” and are simultaneously transmitted to the patient’s medical record for evaluation by the care provider.

3 Consent management. The patient consent for biobank storage of samples and participation in research studies has increased significantly by means of a developed app accessible by tablet.

4 Biobanking. A model is being developed for the standardized maintenance, storage and collection of blood and tissue samples. The model will be applied at all involved clinics and laboratories to ensure that stored samples – and associated data – are comparable and available to the healthcare system and to research.

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Learn more at ki.se/en/4d or vardgivarguiden.se/4d (Swedish only)