DANISH NATIONAL
GENOME CENTER

THOUGHTS ON PERSONALISED MEDICINE

100

Essence of the Danish National Genome Center Annual Meeting 2021 and launch of the Annual Meeting 2022

CONTENTS

Under the headline *Personalised medicine* in Denmark, the Danish National Genome Center in 2021 invited doctors, health experts and other participants to discuss, gain insight into and exchange experiences with personalised medicine.

For what are the challenges and perspectives of personalised medicine? In Denmark and internationally?

PREFACE

Personalised medicine has been part of both the clinical everyday life and the research environments for many years, but the development of personalised medicine has accelerated along with the development of new technologies. The pace of the development underscores the importance of cross-disciplinary competences working together to seize and control where we move to. We must think bravely but also wisely when, for example, we embrace new technologies, when we combine data in order to find the best treatment, and when we find new treatment options. We must be inspired and cooperate internationally. We must involve citizens and patients. Denmark must take the lead in the international collaboration. We must show the way through those who have deep insight into the work with personalised medicine, and we must bring those who do not yet have a knowledge of the new possibilities into the engine room when we jointly have to develop personalised medicine further. From politicians and authorities to patients to citizens, from researchers and doctors to clinical scientists, engineers and IT experts and more.

Personalised medicine is not only heralding a paradigm shift in the healthcare system, it is also complicated in relation to new technological advances and opportunities. These are dilemma-filled waters where Denmark must make the right legal boundaries and ethical discussions wisely. It is important that we think all the way around the further development of personalised medicine if it is to really matter to patients.

Denmark is well on its way. The annual meeting for personalised medicine 2021 presented and brought suggestions for different perspectives and paths into the further development of personalised medicine. We were also inspired by countries around us when they presented other ways of organising personalised medicine. In this document, you can read about some of the thoughts from the annual meeting 2021 with main emphasis on the international points from the day. Let it be the launch pad for the 2022 programme.

Enjoy reading and see you on 14 September 2022. Mark the date in your calendar straight away.

Bettina Lundgren
CEO of the Danish National Genome Center

WHAT CAN DENMARK LEARN FROM ITS NEIGHBOURS?

The UK, Sweden and Denmark all have national visions for genetic technologies to be disseminated in the public healthcare system, and that it is central if the vision of personalised medicine is to be fulfilled. All three countries are working to offer genetic analysis to more patients, to develop interpretation and analysis tools for healthcare professionals, and to ensure that all the genetic information collected can be used in healthcare research, so as to gain new knowledge about the human genome, and improved and new tailored treatments can be developed. The three countries therefore share the vision of wanting to develop state of the art solutions for the healthcare system of the future and patients' treatments. Therefore, Mark Caulfield, Professor of Clinical Pharmacology, former Chief Scientist of Genomics England and Richard Rosenquist Brandell, Professor of Clinical Genetics, Director of Genomic Medicine Sweden, were invited to share their countries' experiences in developing and implementing personalised medicine in a public healthcare system.

Fact

Concepts such as personalised medicine, targeted treatment, individual treatment and precision medicine all cover a common definition of being able to diagnose and classify diseases better, as well as to target the treatment to the individual patient.

More diagnoses in the UK based on whole genome sequencing

The UK is one of the pioneers in the field of personalised medicine, and many countries are looking to the UK for inspiration. In the UK, Genomics England was established as early as 2013. The core task has been to run the project "100,000 Genomes Project" until 2018. It has been a huge project, which has aimed to sequence 100,000 genomes – primarily from patients with cancer and rare diseases in the public healthcare system.

At the annual meeting, Mark Caulfield stated what the effect of using genetic analysis to a greater extent was: "Regardless of when you take a test, we see an increase of about 30% in diagnosis from a whole genome sequencing analysis. So it works."

In addition, it is cost-effective, Mark Caulfield pointed out. The cost of a whole genome sequencing analysis today is less than 700 euros.

However, the road to the success rate above has been long. Since the launch in 2013, more than 97,000 patients and families have participated in the project. Genomics England has established 13 centres that have performed the sequencing analysis and 98 local units that have recruited patients and families, obtained informed consent and collected samples. Over 5,000 health professionals participated in the project, and more than 3,000 researchers have been involved. Today, Genomics England has collected over 21 petabytes of data, all of which are stored in a national genome database.

CEO of the Danish National Genome Center Bettina Lundgren said: "Experience from Genomics England shows that the development of personalised medicine requires a lot of data, the involvement of the best experts and professionals and cross-disciplinary collaboration. It is therefore important to develop and implement the right organisational framework, as Denmark has done with a national governance model and not least to maintain and further develop an infrastructure for collecting, organising and storing large amounts of data that can come out and work in patient treatment and research in new and improved treatments."

The next step for the UK will be to implement whole genome sequencing (WGS) as an integral part of the UK healthcare system. In 2020, Genomics England launched their new strategy – "The Future of Healthcare" (2020) – which paves the way for implementing whole genome sequencing (WGS) as an integral part of the UK healthcare system. Here, there is not only a focus on improving diagnostics and treatment through whole genome sequencing, but also on prevention. The goal is to sequence 500,000 genomes, Mark Caulfield said, who until very recently has been chief scientist at Genomics England, and he has high expectations for personalised medicine in the future.

"What if we could walk around with an app on our phone that would allow us to check if the medication our doctor is recommending us is consistent with our genetics? We may not be able to do that today, but soon", he predicted.

Bottom-up approach in Sweden

Also in Sweden, there are high ambitions for personalised medicine.

"Personalised medicine is very trendy at the moment, but this is really a transformation of the healthcare system." This was stated by Richard Rosenquist Brandell, Director of Genomic Medicine Sweden (GMS) and Professor of Clinical Genetics. GMS was established in 2018 as a national Swedish infrastructure that will pave the way for personalised medicine and help improve the Swedish healthcare system.

Contrary to Genomics England and the Danish National Genome Center, which are national, coordinating units, the Swedish GMS is built around seven regional genome centres. Each regional centre is a collaboration between a region with a university hospital, a university with a medical faculty and the Science for Life Laboratory, which is a national infrastructure to strengthen Swedish biomedical research.

The Swedes have thus chosen a "bottom-up" approach, where the regional centres must build a bridge between the total of 21 Swedish regions and bind the country together. Although the approach is different from the Danish and the UK approaches, the ambition is the same.

"We want all citizens to have access to personalised medicine, no matter where they live," Richard Rosenquist Brandell said.

And the national genomics platform Localized in Västra Götalands Region must help to ensure this. Here is a supercomputer to which the genome centres in Sweden are connected. However, it is only used for sharing Covid-19 add today, because it is awaiting permission to share secondary data at a national level.

The Swedish model is thus based on a more regionally controlled process, where the experts who are to drive the development of personalised medicine have been right inside the engine room from the start. In Sweden, sequencing of entire genomes for rare diseases therefore started locally in 2015 at Karolinska Institutet. "Now, whole genome sequencing (WGS) has been implemented at three genome centres in Sweden, and close to 5,000 WGS analyses were performed in 2021, and the number is increasing, because it is going faster and faster", Richard Rosenquist Brandell said.
Currently, it takes from five days to two weeks to sequence an entire genome in Sweden.

"It is amazing and it has had a dramatic clinical effect, as 40% of previously undiagnosed patients were diagnosed", Richard Rosenquist Brandell said.

> It is amazing and it has had a dramatic clinical effect, as 40% of previously undiagnosed patients were diagnosed.
>
> **Richard Rosenquist Brandell**

Private companies' access to data

In one respect in particular, the UK differs from Denmark and Sweden. In the UK, the public healthcare system has partnered extensively with a wide range of companies.

The collaboration is primarily about access to data for the biomedical companies, but there is also collaboration with companies that specialise in handling Big Data. This is in contrast to the Swedish and Danish model, where sequencing takes place exclusively in the public healthcare system.

The British have organised the public-private partnership in the Discovery Forum, where 130 companies sit at the table. The goal of the Discovery Forum is to help the 100,000 Genomes Project and its partners turn research results into treatments, diagnostics and benefits for patients as quickly as possible.

"It is about providing the greatest possible value for patients," Mark Caulfield said at Denmark's annual meeting for personalised medicine.

In Denmark, however, all companies will be able to benefit from the genome data that the Danish National Genome Center stores. This can be done through collaborations with recognised research institutions and research groups at a university or hospital, just as access to the genome database requires the approval of the National Committee on Health Research Ethics (NVK), and data will be pseudonymised.

"A scientific ethics approval will be able to provide access to research into new treatments based on the very valuable data that will be in the Danish National Genome Center's databases, but it will be in a form where the individual cannot be identified and where we preserve public control over the use of the information," Bettina Lundgren said.

International collaboration creates value for the patients

The idea behind all three initiatives is that data should "work" as much as possible. For the same reason, Mark Caulfield also stressed the importance of international collaboration. More than 3,000 researchers from 33 different countries have used the UK data in their work, so in addition to helping patients, it also helps the research communities.

"With our data, the researchers have won grants for projects worth more than DKK 400 million," Mark Caulfield said.

Richard Rosenquist Brandell shared Caulfield's enthusiasm for international collaboration: "Since rare diseases are rare, then it is absolutely essential to share data across borders," Richard Rosenquist Brandell said.

Both Sweden and Denmark are therefore part of the European initiative 1+ Million Genomes. The aim of the initiative is to share at least one million genomes across Europe using an advanced and secure infrastructure to ensure access to genome information across borders without data being sent out of each country.

digital-strategy.ec.europa.eu/en/policies/1-million-genomes

Or as Mike Caulfield put it: "In the UK, we have worked on 1,200 disorders and standardised the information. Our data can therefore be transferred to yours in Denmark. If there are patients in Denmark, who have not been diagnosed, and patients in the UK with the same symptoms, who have not been diagnosed either, then maybe we can help each other."

> Since rare diseases are rare, then it is absolutely essential to share data across borders.
>
> **Richard Rosenquist Brandell**

Ethical considerations and involvement of patients and citizens

Another group that is also involved in the work of personalised medicine in the UK is the citizens and the patients.

The UK has a tradition of involving citizens in political decisions and initiatives. And this is also the case in the "100,000 Genomes Project", where there has been a citizen and patient panel with people who have either participated in the project themselves or are guardians of participants. At least four times a year, they meet to discuss key dilemmas and challenges related to personalised medicine.

The UK "Access Review" panel, an independent body that reviews requests for access to data from the genome database, also includes representatives from the citizen and patient panel. Patients and citizens thus have a unique opportunity to influence the development of personalised medicine in the UK.

It is with inspiration from the UK that the Danish National Genome Center has established a "National advisory board for patients, citizens and ethics", which is to advise the centre on the involvement of and dissemination to patients and citizens as well as significant ethical considerations and dilemmas that arise as a result of the development of personalised medicine.

"It is crucial for us that we have patients and citizens on board so that we can take the right steps in the information about personalised medicine and the right ethical considerations", Bettina Lundgren said about the Danish model.

In the UK, where the next step is sequencing newborns, citizen involvement becomes crucial. According to Mark Caulfield, it poses ethical challenges, but patients generally support the programme. For what if you can give all children a chance to have a better life?

"There is no one who does not want to take that chance," Mark Caulfield said.

> There is no one who does not want to take that chance
>
> **Mark Caulfield**

What does the future hold?

In the UK, they are ready to take a step further from the rare genetic diseases to cancer. Cancer treatment is for Mark Caulfield the area where whole genome sequencing can really make a difference with personalised medicine. 17,339 cancer patients are currently participating in the 100,000 Genomes Project with breast and colon cancer being the most common cancer types.

The same development is taking place in Sweden.

Two years ago, the Swedish government presented a strategy to make Sweden an international leader within the field of personalised medicine. In the coming years, Genomic Medicine Sweden will scale up diagnostics for patients with cancer, rare diseases and infectious diseases, but will later also focus on the large group of patients with complex diseases.

It is ambitious, and it pleased Richard Rosenquist Brandell: "It is an approval from the government that they support the project. We have started a comprehensive transformation of the healthcare system. I would call it a technological revolution that is now turning into a medical revolution."

Mark Caulfield shared the Swedish optimism, but in closing pointed out some challenges we must solve in order to exploit the full potential of whole genome sequencing and personalised medicine:

- We need better clinical utilisation of the analysis results.
- We must ensure that the economy is solid.
- We need to standardise the use of genetics in the healthcare system so that we ensure equal access for all patients.

If we can – also in Denmark – solve those challenges, we will in return have great opportunities to solve some of the great challenges in the healthcare system of the future, Caulfield believed.

FACTS

GENOMIC MEDICINE SWEDEN (GMS)

Focus on the evidence of genetic analysis in diagnosis in GMS
GMS primarily focuses on disease areas where there is evidence to suggest that genetic analysis can be used to make a diagnosis or where genetic abnormalities are important for prognostic assessment, choice of treatment and follow-up.

GMS primarily works with rare diseases, solid tumours, haematological malignancies, infectious diseases and pharmacogenomics. GMS also has a special focus on childhood cancer.

Patient groups
- Childhood cancer
- Complex diseases
- Haematology
- Infectious diseases
- Rare diseases
- Solid tumours

genomicmedicine.se/en

DANISH NATIONAL GENOME CENTER

Focus on equal access for patients in Denmark
Denmark has adopted some Guiding Principles, which must be taken as a starting point when selecting patient groups at national level to receive genetic analysis in connection with patient treatment.

The Guiding Principles are based on the national strategy for personalised medicine 2017-2020, the political establishment of the centre and the application for funding from the Novo Nordisk Foundation:

Guiding Principles
- Overall principle: Equal access for patients nationally
- Professionalism and value for the patient
- Access to fast and better treatment nationally
- Socio-economic considerations
- Broad effect

The first patient groups selected at the national level for whole genome sequencing
0. Children and young people with rare diseases*
1. Children and young people with cancer
2. Hereditary haematological diseases
3. Endocrinological patients
4. Young adults and hereditary cancer
5. Primary immune deficiency
6. Hereditary hearth disease
7. Psychiatry (children and young people)
8. Kidney failure
9. Incurable cancer
10. Haematological cancer
11. Neurogenetic patients
12. Fetal medicine
13. Rare diseases in adults*
14. Ophtalmology
15. Audio Genetics
16. Hereditary skin diseases
17. Hereditary cholestatic and fibrotic liver diseases

eng.ngc.dk

GENOMICS ENGLAND

Genomics England is owned by the Department of Health & Social Care. "100,000 Genomes Project" is mainly funded by the National Institute for Health Research and National Health Service (NHS) England. The Welcome Trust, Cancer Research UK and the Medical Research Council have also contributed to funding research and infrastructure.

In 2018, the UK extended the "100,000 Genomes Project" to include one million whole genomes sequenced by the NHS and UK Biobank, and the UK launched an ambitious vision for genomic medicine in the NHS with a plan to sequence five million genomes over the next five years.

Read more about Genomics England: genomicsengland.co.uk
OR read more about Genomics England's "Newborn Genomes Programme": genomicsengland.co.uk/newborn-sequencing

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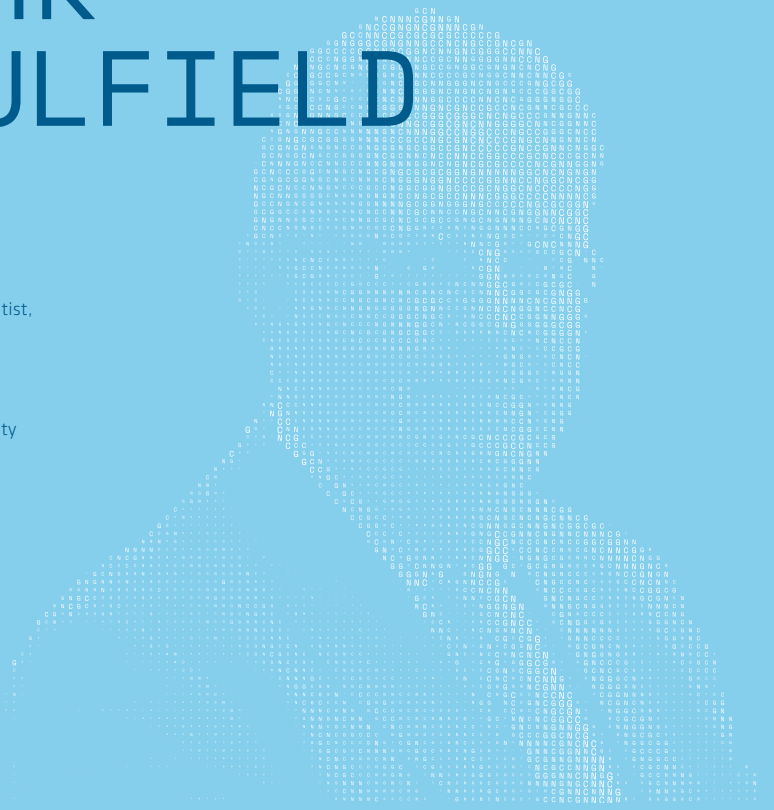
Richard Rosenquist Brandell

PRESENTERS' SUGGESTIONS FOR THE MOST PROMISING PERSPECTIVES AND GREATEST CHALLENGES

MARK CAULFIELD



Title
Professor of Clinical Pharmacology, (formerly Chief Sceintist, Genomics England)

Organisation
Barts Life Sciences, Queen Mary University of London

Most promising perspective for personalised medicine

Whole genome sequencing offers;

- A precision diagnosis that end a diagnostic odyssey in rare disease
- A molecular tumour signature that tailors precision cancer care
- The potential of a global pathogen surveillance to identify new public health risk
- The potential of pharmacogenomics to avoid harmful drugs and possible treatment failure

Biggest challenge

Ability: Technologies are evolving and the role of long read, multi-omics and cell free DNA need definition

Analytical: Genomic analytics are still improving but we need greater clinical utility

Affordability: We need to make the economics work

Adoption: We need to mainstream and standardize genomics in healthcare to ensure equity for patients

RICHARD ROSENQUIST BRANDELL

Title
Professor of Clinical Genetics

Organisation
Genomic Medicine Sweden, Karolinska Institutet

Most promising perspective for personalised medicine
Clinical implementation of high-throughput sequencing technologies has paved the way for improved diagnosis and personalised treatment and care in patients with rare diseases and cancer. By broadening to other disease areas, such as complex diseases, and using different omics/imaging technologies, this holds great potential to realise early diagnosis and disease prevention, i.e. precision health.

Biggest challenge
- To be able to offer equal access for patients to precision diagnostics and precision therapies
- To secure competence provision and provide training of healthcare professionals
- To develop long-term financing models for precision medicine approaches
- To solve legal aspects of data sharing

BETTINA LUNDGREN

Title
CEO

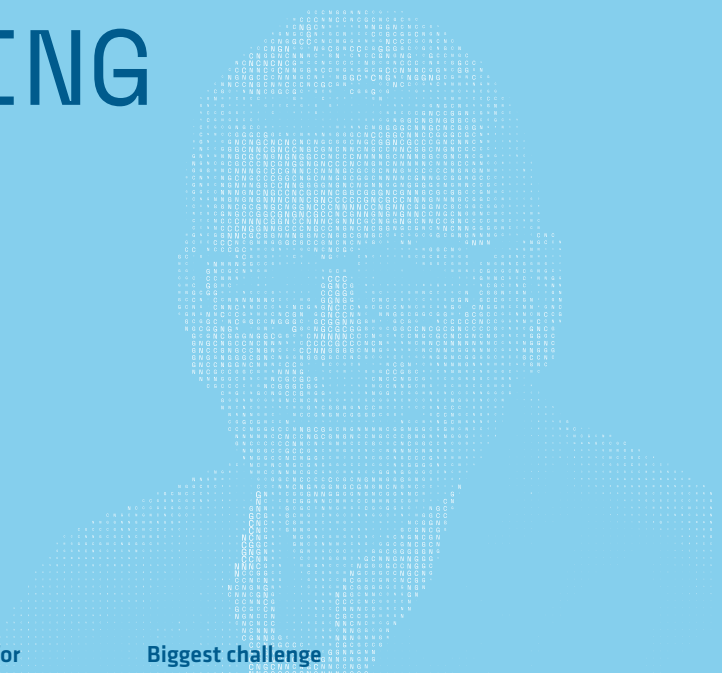
Organisation
Nationalt Genom Center

Most promising perspective for personalised medicine
With the Danish National Genome Center, Denmark will have a stronger national collaboration, which Danish patients will benefit from by the doctors being able to treat more precisely based on knowledge of their genes. We must be brave. We must adopt new technology, and we must utilise data for personalised medicine far more than we have done before, so that we can offer a better future for patients in Denmark. The Danish effort is unique in three areas.

1. We focus on personalised medicine benefiting patients immediately.
2. We have public control over the use of information from Danish patients.
3. We develop personalised medicine nationally, so that patients receive the same offer, no matter where in Denmark they are in the hospital.

Biggest challenge
Personalised medicine cannot be developed using knowledge of the genome alone. Therefore, there is a great demand in the research communities in relation to combining different data sources, if Denmark is to further develop and maintain its international position in personalised medicine. The Danish National Genome Center therefore has a joint task together with other stakeholders in relation to the further development of personalised medicine and the use of data in combination. Focus on patients in the further development must be maintained.

ERIK JYLLING



Title
Executive Vice President,
Health Politics

Organisation
Danske Regioner

Most promising perspective for personalised medicine
Better diagnostics and more targeted treatment for the benefit of the individual patient.

When I look at personalised medicine, the most promising perspective is that we can to a much greater extent adapt prevention and treatment to the individual patient's individual biology and needs. This means that we can aim to direct our services in the healthcare system to the life situation in which the individual finds himself or herself, and avoid unnecessary treatments. We can offer a personalised treatment supported by personal data. It can be both data of a genetic nature, but also data based on the known treatment data or on the citizen's self-generated data from apps and the like.

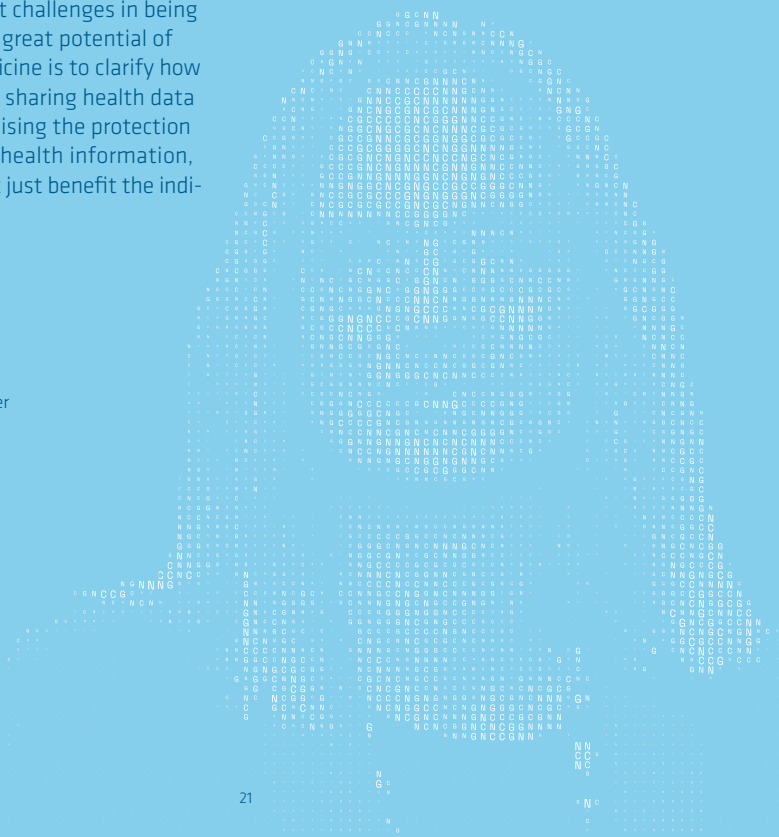
Biggest challenge
Need for investments in infrastructure and competencies

In Denmark, we are in the process of implementing personalised medicine in our hospitals. But if we are to compete with the very best in the world, there is a need to invest further in infrastructure, analysis tools and competencies in the hospitals. At the same time, personalised medicine requires that we ensure the necessary information of the citizens in relation to the area. Should I answer what the absolute biggest challenge is, I will highlight the whole transformation we are going through in our healthcare system; from an assumption that "one size fits all", with most to most, and over to a healthcare system where the service offered is far more personalised.

BIRGITTE NYBO JENSEN

Most promising perspective for personalised medicine
There are many important perspectives, but as a doctor, one of my primary focus areas is that personalised medicine will be able to offer patients with many different disease states a more tailored treatment – and we are already well underway.

Biggest challenge
One of the biggest challenges in being able to utilise the great potential of personalised medicine is to clarify how we can succeed in sharing health data without compromising the protection of Danes' private health information, so that it does not just benefit the individual patient.



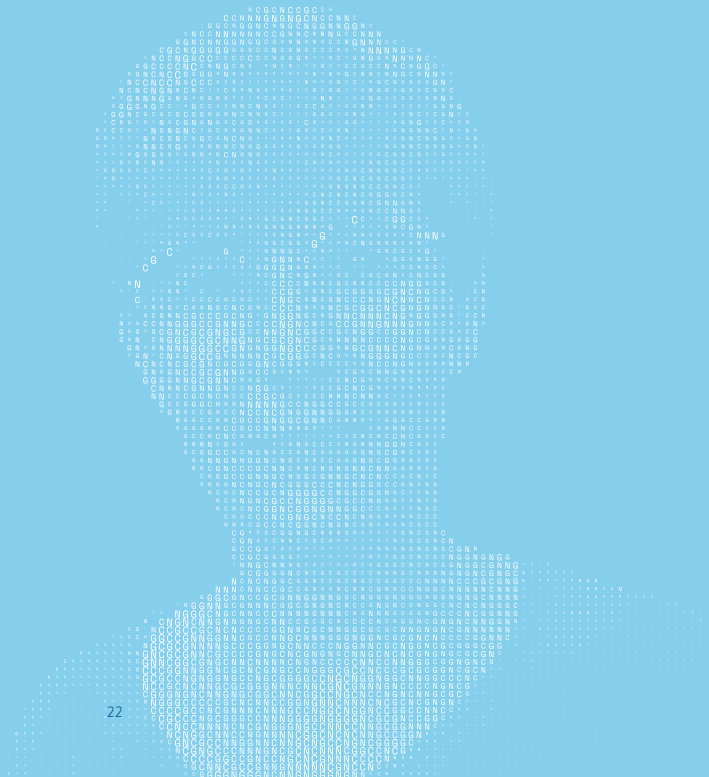
Title
CMO

Organisation
Nationalt Genom Center

SABINE GRØNBORG

Most promising perspective for personalised medicine
Faster diagnosis of congenital metabolic diseases can allow for early onset specific treatment with a positive effect on the prognosis, because “time is brain”.

Biggest challenge
Early identification of patients in need of rapid comprehensive genetic diagnosis. Interpretation and application of the genetic results in the clinic as well as dissemination of the study results.



Title
Consultant

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Department of Paediatrics and Adolescent Medicine,
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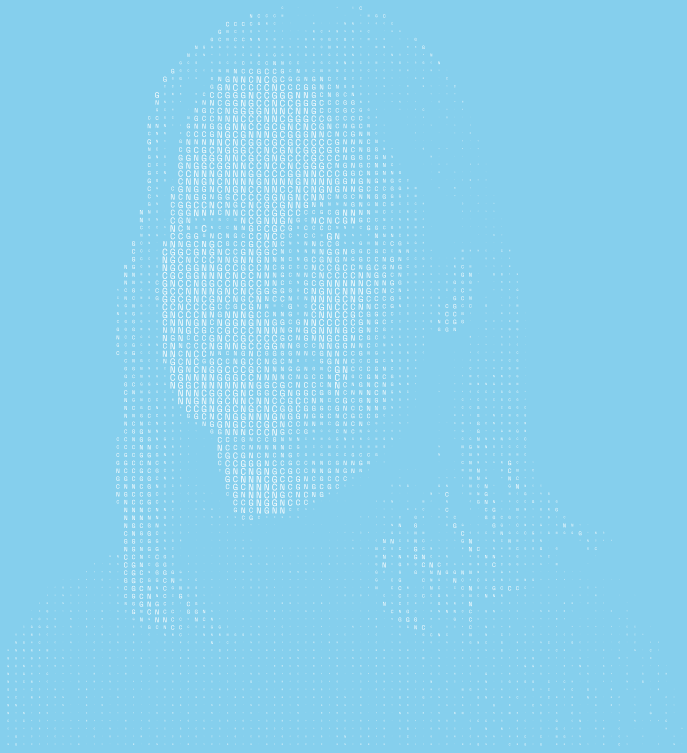
INGE SØKILDE PEDERSEN



Title
Clinical Laboratory Geneticist,
Professor

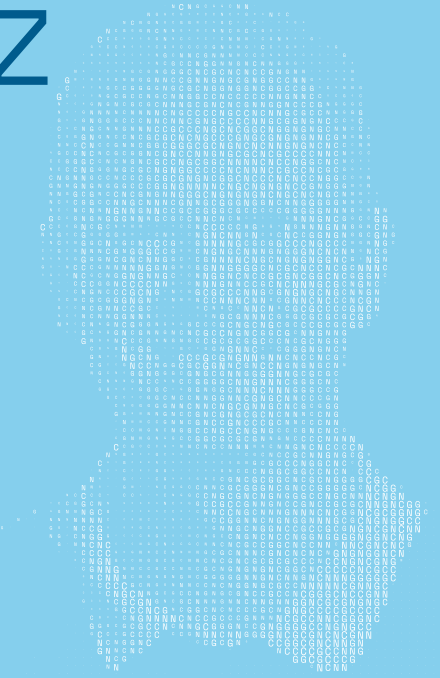
Organisation
Aalborg University Hospital,
Department of Clinical Medicine,
Faculty of Medicine,
Aalborg University

Most promising perspective for personalised medicine
Targeted diagnosis, prevention and treatment have already proved their worth for patients with rare diseases or cancer.

Improvement for the treatment of patients with cancer must, however, be expected to gain extra momentum as we gain enough knowledge to apply the extensive molecular profiling of cancer cells at the beginning of the course of treatment.

Biggest challenge
The challenge is not to generate high quality data but to interpret data. We have a simplistic approach to the interpretation of genetic data, and we direct the treatment towards a single change in the genome. We lack the tools to predict the effect of several changes in interaction, and the complexity increases when other types of data need to be integrated.

DANIEL SCHWARTZ BOJSEN



Title
Director of Health,
Social and Engineering

Organisation
University College
Absalon

Most promising perspective for personalised medicine
Better patient treatment.

Biggest challenge
To ensure that the right information and the good dialogue with citizens/patients is present every time. To ensure that the right competencies are present with the relevant staff in the healthcare system.

SISSE RYE OSTROWSKI

Most promising perspective for personalised medicine
Access to high-quality health data from registers, patient records, biobanks etc. gives Denmark a unique opportunity to excel in personalised medicine with expected better prevention, diagnosis and treatment and ultimately increased healing and quality of life for patients.

Biggest challenge
Legislation and regulatory authorities are not synchronised with the rapid development of health technology and new types of health data as well as techniques for processing these. It entails legal obstacles that delay and prevent the development and use of personalised medicine.

Title
Professor,
Interim Head of Studies for Master in Personalised Medicine,
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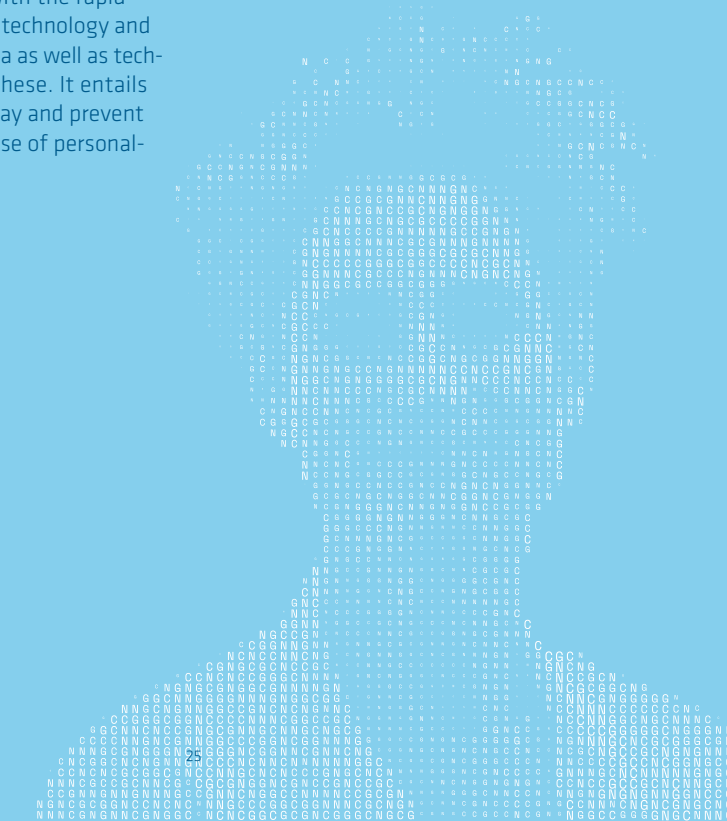
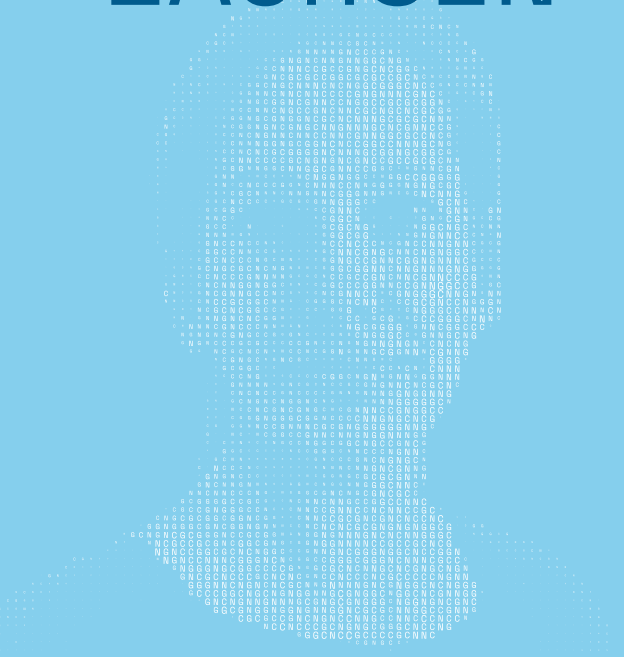
Center, Rigshospitalet



BRITT ELMEDAL LAURSEN



Title
Consultant,
Associate Professor,
PhD

Organisation
Department of Molecular Medicine (MOMA)
Oncology Unit,
Aarhus University Hospital,
Department of Biomedicine

Most promising perspective for personalised medicine
In oncology, the most promising perspective is to be able to improve the prognosis for patients with cancer at all stages of the disease in the form of earlier detection, more accurate diagnosis, earlier detection of relapse and more targeted treatment of the disease.

Biggest challenge
Access to targeted antineoplastic drugs. To generate solid evidence for effect.

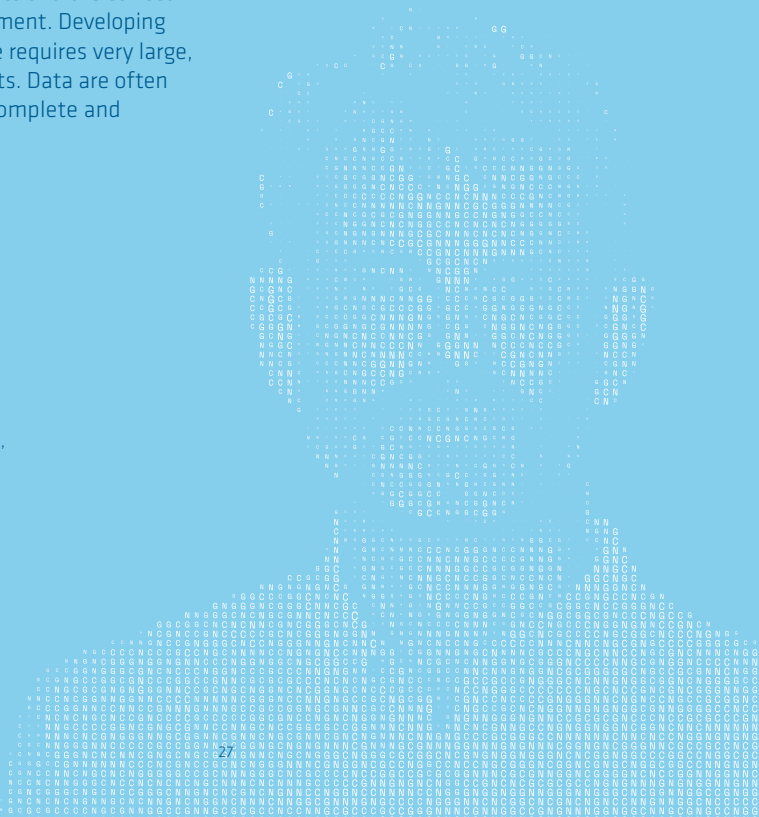
ANDERS KROGH

Most promising perspective for personalised medicine
I see the biggest prospects in better cancer treatment. The molecular "fingerprint" from a tumour, I think, can help to find the best treatment more quickly, for example with the help of artificial intelligence.

Biggest challenge
The biggest challenge is to find the connection between the disease's molecular fingerprints and the correct diagnosis and treatment. Developing artificial intelligence requires very large, high-quality datasets. Data are often heterogeneous, incomplete and difficult to access.

Title
Professor,
Center Director

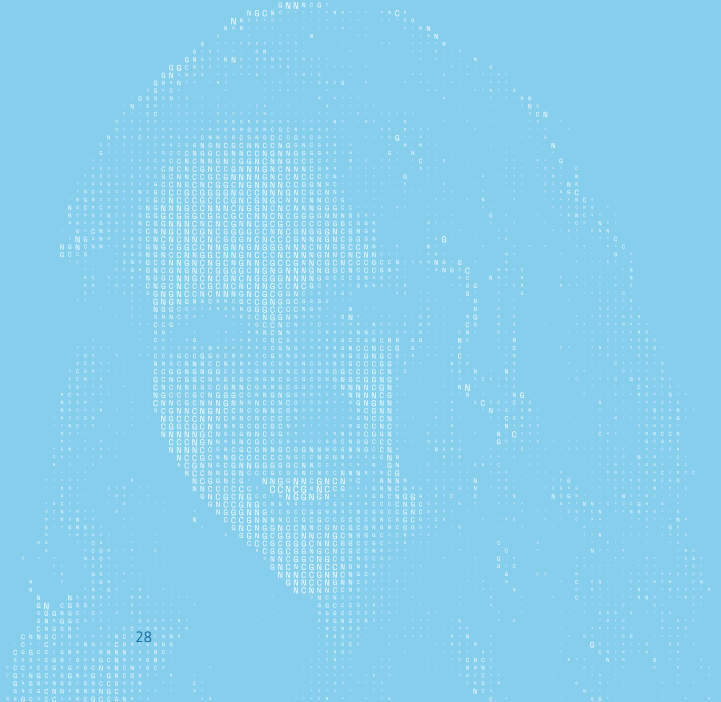
Organisation
Department of Computer Science,
University of Copenhagen,
Center for Health Data Science



JENNIFER BARTELL

Most promising perspective for personalised medicine
Is in fitting the right diagnosis/treatment to the right patient and doing this in a manner that protects patient trust in health systems.

Biggest challenge
Is finding the right balance between patient privacy rights and potential gains to be made as massive health data sets are gathered, integrated and analysed. Education of patients and physicians as well as new data science trainees on the boundaries of health data science is critical, and biases in collected data need to be addressed.



Title
Project Coordinator,
Data Scientist

Organisation
Center for Health
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University of Copenhagen

ULRIK LASSEN

Title
Executive Consultant,
Professor in Clinical
Oncology and Personalised
Medicine

Organisation
Department of Oncology,
Centre for Cancer and Organ
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Department of Clinical
Medicine, University of
Copenhagen

Most promising perspective for personalised medicine
With personalised medicine, we can better target the treatment of the individual patient based on the characteristics and genetic expression of the disease and thus potentially be able to achieve a better effect. And if we simultaneously utilise our health data, then we can become a learning healthcare system so that the treatment of patients today can improve the treatment of the patients of the future.

Biggest challenge
We must ensure a flow for handling samples and analyses that live up to security requirements and anonymity based on informed consent, so that data can be made available and used by researchers, both public and private. Training of staff and lawyers is required.

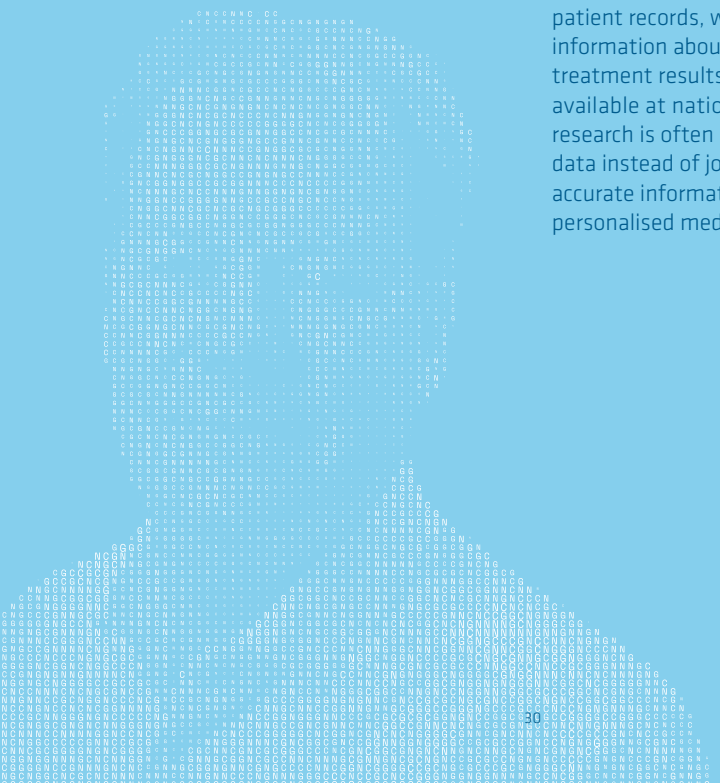
SØREN BRUNAK

Title
Professor in Disease Systems Biology

Organisation
Novo Nordisk Foundation Center for Protein Research, University of Copenhagen

Most promising perspective for personalised medicine
In the short term, to arrive more quickly at a more accurate diagnosis for the individual patient, avoid overtreatment with ineffective medication and reduce side effects associated with polypharmacy; in the long term, to develop new treatment that matches the relevant patient subgroups that are genetically found in the Danish population.

Biggest challenge
Deep phenotypic data from Danish patient records, which contain detailed information about patient profiles and treatment results, are not sufficiently available at national level. Therefore, research is often performed on registry data instead of journal data that contain accurate information that is crucial to personalised medicine.



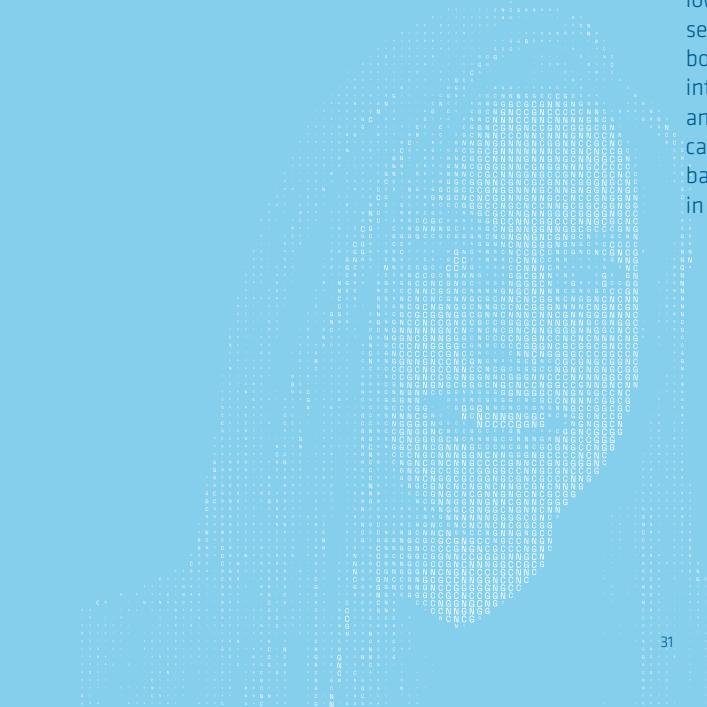
MIE SEEST DAM

Title
Assistant Professor

Organisation
University of Copenhagen

Most promising perspective for personalised medicine
Personalised medicine can mean treatment for selected patients without any other options. By virtue of that potential, the ethical, organisational, and legal challenges of personalised medicine can motivate binding collaborations across the health sciences, social sciences, and humanities that will contribute to a more robust healthcare system.

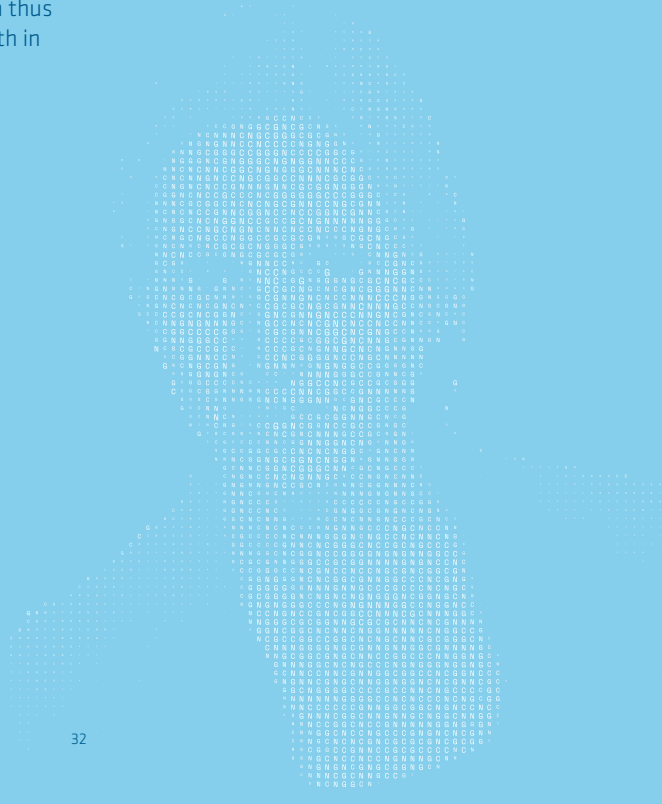
Biggest challenge
Personalised medicine is selective medicine. With the vision of adapting medical treatment to the individual follows a fine-meshed and opaque patient selection, which places great demands both on the professionals who have to interpret more and more types of data, and on the politicians who have to take care of the financial priorities and thus balance considerations to the individual in the interests of the collective.



SIDSEL VINGE

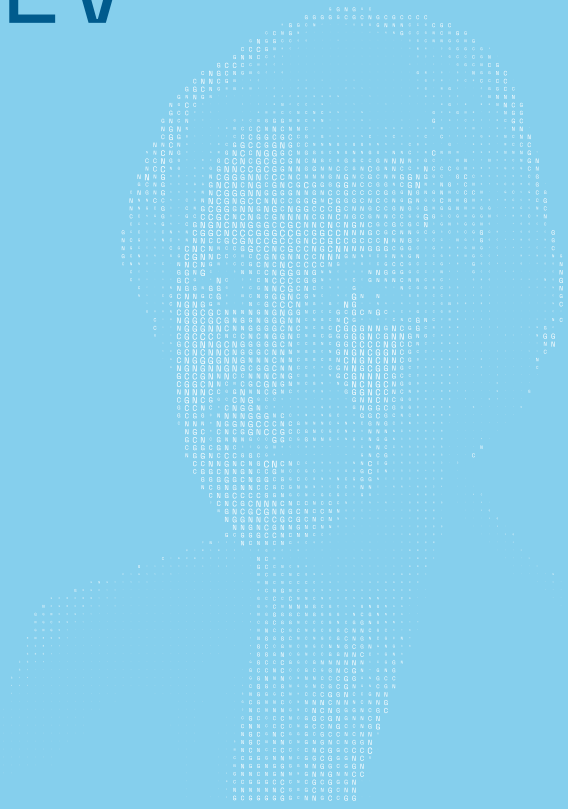
Most promising perspective for personalised medicine
That personalised medicine can result in significant and documentable improvements in the outcome of major disease areas and that the improvements are commensurate with the cost of personalised medicine.

Biggest challenge
That small and not always well-documented improvement in results a disproportionate amount of resources from the large disease areas, which thus actually risk being downgraded, both in terms of research and financially.



Title
PhD, MSc in Economics

METTE HARTLEV



Title
Professor

Organisation
Faculty of Law,
University of Copenhagen

Most promising perspective for personalised medicine
The most promising perspective is the potential to be able to offer the population a more precise and targeted preventive effort and treatment, which is not only based on biological conditions, but also includes, for example, socio-economic and environmental conditions.

Biggest challenge
To ensure that personalised medicine is available to all, that there is adequate awareness of the risk of bias, and that society is robust enough to avoid discrimination against persons and groups exposed to personalised medicine. It is also a great challenge to get the legislation to ensure both an ethically robust and innovation-promoting framework for the use of data for research in personalised medicine.

NEW MASTER IN PERSONALISED MEDICINE

Personalised medicine is evolving at lightning speed, and therefore there may be a shortage of healthcare professionals with competencies in the field. This applies to highly specialised researchers and doctors who work specifically with whole genome sequencing and related techniques. But this also applies to other academics such as molecular biologists, computer scientists and engineers, as well as nurses and other professionals who, in their daily work, will more and more often meet patients who have genetic tests done and have to relate to them.

Continuing education is one of the answers to the great challenge. Therefore, the faculties of health and medical sciences at the University of Copenhagen, Aarhus University, Aalborg University and the University of Southern Denmark together with the Technical University of Denmark have established a new professional master's degree programme on personalised medicine.

The programme has admitted its first team of students with study start in September 2021.

Sisse R. Ostrowski, professor and consultant at the Diagnostic Center at Rigshospitalet, is the study leader for the new "master in personalised medicine" and gave at the annual meeting 2021 a brief insight into what the education consists of and who applies:

- **Scope:** One year of full-time study taken part-time over two to six years.
- **Focus:** Interdisciplinary collaboration on personalised medicine.
- **Target group:** Professionals who work clinically with, or research in personalised medicine. Must have a minimum of two years' work experience.
- **Educational background:** Best suited for graduates from health sciences, natural and life sciences as well as the technical sciences.
- **Applicants:** In the first round, two-thirds were doctors, the rest were pharmacists, biologists, human biologists, molecular biologists, bioinformaticians etc. About half of the applicants had a PhD degree. 80% of the applicants were employed at hospitals.
- **Content:** Introduction to personalised medicine, Health data and data processing, Genomics, Communication and collaboration, Clinical decision making and decision support tools, Evidence and documentation, Ethics, law and organisation of personalised medicine.

For more information about the programme, please visit: personligmedicin.ku.dk

INVITATION

ANNUAL MEETING 2022
14 SEPTEMBER
PERSONALISED MEDICINE IN DENMARK

WHAT Personalised Medicine in Denmark
WHERE Radisson Blu, Amager Boulevard 70, Copenhagen, Denmark
and online (hybrid meeting)
WHEN 14 September 2022
SIGN UP eng.ngc.dk/news
– and get an email when you can sign up for the conference.

Conference Moderator: Ida Donkin doctor, PhD, researcher

PROGRAMME SKETCH: WHAT CAN YOU LOOK FORWARD TO?

- Denmark's goals for Personalised Medicine in the future
- The benefit for the patients today
- Clinical and research use of the Danish National Genome Center
- Health data in Denmark and abroad

PARTICIPATION IS FREE