De nasjonale FORSKNINGSETISKE KOMITEENE

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Generert 22. april 2016

Innhold *(26 saker fra perioden 15. april 2016 – 22. april 2016)*

Problematiske krav for deling av forskningsdata (*NRK*) . . . 3
Researchers struggle with the ethical dilemma of using hacked data (*Daily Dot – Politics*) . . . 3
Nye krav for deling av forskningsdata viktige for Norge (*Uniforum – Leserbrev*) . . . 5
Do Ethicists Hinder HIV Prevention Research? (*Medscape – News*) . . . 6
Want a favorable peer review? Buy one (*The Boston Globe – Business*) . . . 7
Should The Food Industry Fund Health Research? (*Science 2.0 – News*) . . . 8
The US'first chief data scientist says there's never been a better time to be someone interested in public data (*Public Radio International – Global Politics*) . . . 9
Doubts linger over impact of new data protection rules on research (*Science Business – ICT*) . . . 12
Should we welcome food industry funding of public health research? (*British Medical Journal*) . . . 13
Introduction (*Council of the European Union – Latest documents*) . . . 15
Uviten: Pasientene og deres forskere (*Aftenposten.no - Forsiden*) . . . 25
Fulle folk og gatelykter (*Tidsskrift for Den norske legeforening – Forside*) . . . 27
Forskerne vil lave DNA-bank over alle døde danskere (*Jyllands-Posten – Trafik & Vejr*) . . . 28
BMJ editor Fiona Godlee takes on corruption in science (*CBC*) . . . 29
Guest Post: Scientists aren't always the best people to evaluate the risks of scientific research (*Practical Ethics – Home*) . . . 31
Forskar om fuskande studenter (*svt.se - Värmland*) . . . 33
Forskningsetiske utfordringer ved kvalitative studier (*Sykepleien*) . . . 34
Den nye, bioteknologiske metoden CRISPR krever bred debatt | Bioteknologirådet (*Aftenposten.no - Kronikker*) . . . 35
Hør Frambupodcasten – episode 1 med Lisbeth Myhre og Arvid Heiberg (*Frambu – Nyheter*) . . . 36
Får forsker-refs (*Dagbladet, side 6*) . . . 36
For 1100 kroner kan du genmodifisere hva du vil (*Aftenposten.no - Kultur*) . . . 37

Barnehageeksperter kritiserer kunnskapsminister Isaksens bruk av forskning (*Dagbladet.no - Innenriks*) 40
Havforskningsinstituttet: – Banebrytende forskning (*NRK – Forsiden*) 42
Birmingham executive charged with falsifying drug trial documents – North Korea Times (*North Korea Times – Breaking Health News*) 43
Scientists tweak results in human trials (*ScienceNordic – Society & Culture*) 43
Birmingham executive charged with falsifying drug trial documents (*Big news networks – Health*) . 44

Problematiske krav for deling av forskningsdata

NRK –22. april 03:31

I forkant av en konferanse i Oslo neste uke om deling av forskningsdata, uttrykker to forskere ved Universitetet i Oslo bekymring for at kravet om datadeling kan redusere antallet industriuavhengige kliniske studier.


Problematiske krav for deling av forskningsdata

Stig (24) konfronterer mulige barnemishandlere på fritiden

Løpet som 14-åring endret livet hans

Tirsdag 26. april skal Norges forskningsråd organisere en konferanse om deling av forskningsdata, og skriver på sine nettsider at «deling av forskningsdata kan bidra til å skape nye arbeidsplasser og gi bedre folkehelse».

Førsteamanuensis Mette Kalager og professor Michael Bretthauer i Forskningsgruppen Klinisk Effektforskning frykter at datadelingen kan koste mer enn den smaker, skriver universitetets nettavis Uniforum.

Redaktørene i ledende medisinske tidsskrifter kunngjorde i en felles lederartikkel i januar nye krav for slik deling. De skrev at alle forskere som publiserer kliniske studier i ett av tidsskriftene må dele dataene som forskningen bygger på.

Kravet er banebrytende, og vil føre til store forandringer i medisinsk forskning, mener Kalager og Bretthauer, som samtidig tror det kan føre med seg uheldige virkninger som gjelder mer for Norge enn mange andre land.

De viser til norske helseregistre som gjør forskerne i stand til å utnytte ressurser, forutse fremtidens behov og teste ut ny medisinsk diagnostikk og behandling.

Motivasjonen for forskere til å gi seg ut på mangeårige prosjekter kan minske betydelig om man vet at så fort man har publisert den første artikkelen om studien vil dataene måtte legges ut for hele verden, tror de to.

De oppfordrer norske helseregistre, etiske komiteer og personvernombudene til å starte en aktiv debatt om hvordan de nye kravene skal møtes.

Researchers struggle with the ethical dilemma of using hacked data

Daily Dot – Politics –22. april 02:08

When, if ever, is it justified to use stolen data in the pursuit of academic research

That's the question put forth in a recent paper authored by two social scientists who found themselves in an ethical quandary over a hacked database. While the information it contained would undoubtedly enhance the researchers' findings—the study examined challenges facing artists who rely on crowdfunding platforms, such as Kickstarter and

Indiegogo —their team remained divided over the moral implications of utilizing the data.

In August, two scientists—Dr. Roei Davidson and Dr. Nathaniel Poor of the Council for Big Data, Ethics, and Society —began investigating methods for acquiring data on users of the website Patreon. Launched roughly three years ago, the site offers to transform fans into "patrons" of the arts, funding musicians, painters, and online content creators.

"We study crowdfunding as part of our research into cultural production and the changes and challenges faced by producers in the internet age, " write Davidson and Poor. They discovered, among other findings, the importance of personal networks for repeat crowdfunding, as producers are "hesitant to ask friends and family for financial support more than once."

In examining Patreon, the researchers initially relied on a method for extracting data known as scraping. This method typically relies on software that "crawls" through the architecture of a website, harvesting information in a mechanized fashion. Though not technically comparable in terms of scale, this approach is not unlike the way Google's PageRank system combs the Web for backlink data, which in turn determines the importance of a given website during a keyword search.

But as luck would have it, less than a month later Patreon was hacked, the entire site was dumped online, source code and all. The scholars deemed much of the data was useful, but a great deal of it was obviously never intended for public consumption.

Indeed, had this fortuitous crime not occurred, the researchers would have been limited to information scrounged from the uncooperative company; a "convenience sample, " as they put it.

"This was such a gift!" they wrote; only the team was unable to agree on whether or not the data was appropriate for use. Some felt that Patreon's data was now public, and since the information they sought did not include personal information about its users, the project was OK to proceed. But others were more hesitant: After all, ethical criteria must be met in the pursuit of scholarly research.

Facing this dilemma, the researchers examined other instances involving unauthorized data leaks and hacks. In the case of Edward Snowden, for example, they determined a crime had certainly been committed, but arguably Snowden's actions had been in service of the greater good. However, there was a clear difference between the aims of the Patreon research and, say, the articles published by journalist Glenn Greenwald, who exposed illegality in the U.S. government's surveillance apparatus.

Worse yet, the scientists drew parallels between the Patreon hack and the Rupert Murdoch phone-hacking scandal in the mid-to-late 2000s—unethical journalism that helped kill off the 168-year-old News of the World tabloid.

The Daily Dot, along with almost every other news organization, routinely adopts illegally obtained data for the purpose of news gathering. In 2015, following the dump of 400 gigabytes of Hacking Team data, for example, reporters unearthed the Milan-based cybersecurity firm's financial ties to a dictatorial regime in Sudan. When Ashley Madison was pilfered by hackers last fall, research revealed a payoff to silence allegations of sexual harassment hidden among the CEO's emails; other records proved the company secretly operated a website offering escort services. In 2014, an exclusive leak of more 5 gigabytes of sealed court records led the Dot to report on a federal informant who had instigated cyberattacks in as many as 30 foreign countries.

Most recently, a " mega-leak " of data exfiltrated from a law firm in Panama implicated many of the world's most influential leaders in an offshore holdings scandal. This enormous collaboration, in which hundreds of journalists invested their time, deposed the prime minister of Iceland less than 48 hours after publication.

Nye krav for deling av forskningsdata viktige for Norge

Uniforum – Leserbrev –22. april 00:27

En annen utilsiktet virkning av kravet om deling av data, er at det ikke lenger vil lønne seg å gjøre nye, banebrytende kliniske studier, skriver de medisinske forskerne Mette Kalager og Michael Bretthauer ved UiO i dette innlegget.


UNIFORUM

Nye krav for deling av forskningsdata viktige for Norge

Av førsteamanuensis Mette Kalager og professor Michael Bretthauer, Forskningsgruppen Klinisk Effektforskning, UiO

Publisert 22. apr. 2016 00:24

Deling av forskningsdata åpner mange nye muligheter og har med rette vært etterlyst i flere år. Gjenbruk av allerede innsamlede data kan generere ny viten og kunnskap, og derved bidra til nyskapning.

Norges forskningsråd skal den 26. april organisere en konferanse om deling av forskningsdata, og skriver på sine nettsider at «deling av forskningsdata kan bidra til å skape nye arbeidsplasser og gi bedre folkehelse».

Det høres ut som en vinn-vinn situasjon, men har ved nærmere betraktning en rekke utfordringer som vil ramme Norge mer enn andre land. Overraskende nok har nye internasjonale krav for deling av medisinske forskningsdata ført til svært lite omtale i Norge. Kravene vil føre til at deling av data kan koste mer enn det smaker om vi ikke er proaktive.

Redaktørene i de ledende medisinske tidsskriftene i verden (International Committee of Medical Journal Editors; ICMJE) kunngjorde i en felles lederartikkel som ble publisert i alle tidsskrifter samtidig den 20. januar 2016, nye krav for deling av forskningsdata. Redaktørene skriver at alle forskere som publiserer kliniske studier i et av tidsskriftene (The Lancet, New England Journal of Medicine, British Medical Journal osv.) må dele dataene som forskningen bygger på.

Redaktørforeningen har stor gjennomslagskraft fordi deres tidsskrifter er de mest anerkjente, der den beste forskningen innen klinisk medisin publiseres. Tidligere initiativer fra ICMJE har raskt blitt etablert praksis, som for eksempel registrering av kliniske studier for å sikre at negative resultater publiseres (og derved unngå såkalt seleksjonsbias). Slikt krav er i dag standard i medisinsk forskning, også i Norge.

Redaktørenes krav om deling av data er banebrytende, og vil føre til store forandringer i medisinsk forskning. Deling av dataene fra artikler som publiseres i ICMJE tidsskrifter, vil innebære at dataene er tilgjengelig for alle som måtte ønske å bruke disse til eget formål. Formålet kan for eksempel være å gjenskape forskernes analyser for å teste resultatene, gjøre nye analyser for å finne andre resultater, eller å koble dataene for å gjøre metastudier.

Vi støtter initiativet, og ønsker det velkommen. Vi tror samtidig at kravet kan føre med seg uheldige virkninger. Disse uheldige virkninger gjelder mer for Norge enn mange andre land. Vi forklarer noen av utfordringene i en artikkel som ble publisert i New England Journal of Medicine onsdag 20. april 2016.

Norge har svært gode helseregistre som de fleste andre land i verden misunner oss. Vårt unike system med landsomfattende, tilnærmet komplett registrering av helse- og livsløpsdata gjør oss i stand til å utnytte ressurser, forutse fremtidens behov og ikke minst teste ut ny medisinsk diagnostikk og behandling.

Det er unikt i verdenssammenheng at vi kan følge pasienter i registrene over mange år. Mange offentlig finansierte kliniske studier som gjennomføres av norske forskere bruker disse registrene til å evaluere nye helsetiltak. Forskningen som genereres er av høy kvalitet, og setter standard for ny forebygging eller behandling av sykdommer. Vi er bekymret for at kravet om datadeling kan føre til en reduksjon av antallet industri-uavhengige kliniske studier.

En annen utilsiktet virkning av kravet om deling av data, er at det ikke lenger vil lønne seg

å gjøre nye, banebrytende kliniske studier. Slike studier er vanskelig å gjennomføre, krever tunge forskningsmiljøer med stor kompetanse og dedikasjon over mange år, og store økonomiske ressurser.

Motivasjonen for forskere å gi seg ut på mangeårige prosjekter med ekstraordinær arbeidsinnsats, lite personlige økonomiske insentiver og uvisst resultat kan minske betydelig om man vet at så fort man har publisert den første artikkelen om studien vil dataene måtte legges ut for hele verden. Andre forskere får tilgang, spinner videre og publiserer før de som har generert dataene og kjenner dem best, har anledning til å gjøre det.

Et av våre forslag i siste utgave av New England Journal of Medicine er derfor å gjøre det mulig for forskerne som har generert dataene å reservere fremtidige analyser, for å beskytte eget arbeid og derved sikre insentiver for å gjøre gode kliniske studier. Dette krever internasjonalt samarbeid og konsensus.

Norske registre må innstille seg på den nye virkeligheten om deling av data. Tidsskriftenes krav om datadeling krever diskusjoner om nye regler for bruk og gjenbruk av norske registerdata. Dagens tilgang gis som regel til ett bestemt prosjekt, til norske forskere. Forskerne trenger veiledning og råd for hvordan de skal forholde seg til kravet om utlevering av norske helsedata etter publisering.

Norske helseregistre, etiske komiteer og personvernombudene bør starte en aktiv debatt om hvordan man vil møte de nye krav. Det nylige utspillet i Dagens Medisin om bedre tilrettelegging for bruk og gjenbruk av medisinske registerdata fra John-Arne Røttingen, leder for regjeringens Helse og Omsorg 21-satsing er et skritt i riktig retning. Diskusjonen må starte nå; ICMJE implementerer sitt nye regelverk i januar 2017 og har signalisert streng håndheving fra dag én.

Norge bør ha en nøkkelrolle i arbeidet med å utforme nye retningslinjer for deling av forskningsdata. Kravene er nylig satt av andre; vi må nå komme på banen og delta aktivt for å ivareta «smart deling og bruk av forskningsdata» som det heter i invitasjonen til konferansen i Forskningsrådet den 26. april.

Do Ethicists Hinder HIV Prevention Research?

Medscape – News –21. april 22:23
Av: Andrew M. Seaman

(Reuters Health) – Ethics panels may be hindering HIV prevention efforts by requiring gay and bisexual adolescents to get parental consent before taking part in research, experts suggest.

Fear over coming out as gay or bisexual may prevent young men from asking their parents for permission to participate in HIV prevention studies. But leaving them out of such studies would likely result in huge gaps in scientific knowledge.

"Without the science, we won't have service," said Brian Mustanski, of the Institute for Sexual and Gender Minority Health and Wellbeing at Northwestern University in Chicago. "Without the service we're going to continue to see a growing epidemic in this population."

Roughly one in five new HIV diagnoses in the U.S. in 2014 were in people ages 13 to 24, according to the Centers for Disease Control and Prevention (CDC). Most of those were in gay and bisexual males.

This high-risk group has not been a focus of research, however, thanks in part to institutional review boards (IRBs) that insist on having parental consent before a minor can take part in a study, according to Mustanski and Celia Fisher, of the Fordham University Center for Ethics Education in Bronx, New York.

For example, none of the 93 CDC-endorsed HIV prevention programs were tested in gay and bisexual males under age 18, and only four were tested in gay and bisexual young adults, Mustanski and Fisher wrote April 6 in the American Journal of Preventive Medicine.

HIV prevention strategies that work for older

gay and bisexual men may not be effective among their younger counterparts, the authors point out.

"We have many of these prevention programs, but not for the leading edge of the epidemic," Mustanski told Reuters Health.

Some states already allow minors to get HIV testing without parental permission, and the U.S. Office for Human Research Protections allows IRBs to waive parental consent in research settings, he said.

But many refuse to do so, write Mustanski and Fisher.

"I think part of it is that gut instinct that we should have parents involved," said Mustanski. "Also, there is that gut reaction of protecting the institution."

Some U.S. hospitals could not take part in an ongoing trial of an HIV prevention pill among young gay and bisexual adolescents because their IRBs refused to waive parental consent for participants.

Of 13 research institutions considering participation in the trial, known as ATN113, only seven actually joined. An analysis in the Journal of Adolescent Health found trial implementation "hinged primarily on IRB interpretations of state minor consent laws."

IRBs tend to be very conservative around issues of sex, said Dr. Robert Klitzman, director of the Masters of Bioethics Program at Columbia University in New York City.

"I would hope that IRBs would realize at points it would be impossible to get parental permission," said Klitzman, who is also the author of The Ethics Police: the Struggle to make Human Research Safe.

The problem of IRBs restricting research is not confined to HIV prevention among young gay and bisexual men, he told Reuters Health. IRBs are also reluctant to approve research in prisons or in pregnant women or people with suicidal thoughts. The result may be gaps in research.

"I think the authors put their finger on an important area," he said.

Mustanski said IRBs lose the forest for the trees, because they evaluate studies on a case-by-case basis, and denying study after study on HIV prevention adds up.

"If we don't do this research we're not going to reach the goals of the National HIV/AIDS Strategy," he said. The Strategy aims to reduce new HIV diagnoses by 25% by 2020.

SOURCE: http://bit.ly/26ffVMW

Am J Prev Med 2016.

Want a favorable peer review? Buy one

The Boston Globe – Business –21. april 21:55

Av: Ivan Oransky, Adam Marcus

W hat do Henry Kissinger and Martin Scorsese have in common? Fun fact: Both evidently review scientific manuscripts for money.

OK, maybe that's not quite true. In fact, it's not at all true. But headshots of both men appear in the bios of two purported reviewers (one of which has a woman's name, sorry, Martin!) for a company called EditPub that sells various scientific services, including peer reviews.

The EditPub site (which seemed on Thursday to be no longer up and running), is almost entirely in Chinese, but its homepage bills it as a "service center for scientific research." Its existence came to light earlier this month after the British Journal of Clinical Pharmacology retracted a 2015 article by a group from Dalian University in China. According to the journal, EditPub had "compromised" the peer review process in a way that the journal has so far refused to make public.

The retraction is but the latest in some 300 similar instances of journals pulling articles because of hacked peer reviews.

The most frequent scheme involves pairing the names of legitimate scientists with fake email addresses in order to generate positive peer reviews about manuscripts and convince editors to accept the work. Here's how : A scientist submits a pa-

per to a journal, which in turn asks the author to provide the names and email addresses of a few potential reviewers. (If that strikes you as unusual, it isn't; editors constantly need new reviewers who have different expertise, and who might not be quite as overworked.)

The vast majority of the time, the contacts are valid. But sometimes not — the author offers up real names, even of well-known individuals, but bogus email addresses that he or she controls. And the way that some editorial management software works, the editor doesn't see the email address.

Scientists can do this on their own, but many third-party editing service companies like EditPub offer this kind of fakery among their suite of products.

Such ruses can occur only when journals allow authors to recommend potential reviewers — something many continue to do despite the abuses, particularly in small fields with fewer researchers qualified to give expert opinions. When it does succeed, a researcher gets to review his or her own paper, and, not surprisingly, make a recommendation to accept it, boosting his or her CV by bypassing a quality assurance step and letting a paper enter the scientific record that may not deserve to be there.

Last year, BioMed Central retracted 43 papers for fake reviews, some of which appeared to have been conducted by "third-party agencies, " the publisher said. In 2014, SAGE said that it had uncovered a peer review "ring, " orchestrated by Taiwanese scientist Peter Chen, which led to the retraction of 60 papers. The publisher subsequently retracted another 17 papers in a different reviewing scandal.

All of this means that the peer review process is being compromised. As we've written in this space, peer review is prone to many problems. However, when it works, it's the best way of protecting the scientific literature from false information. Gaming it defeats that purpose. The situation is alarming enough that Adam Cohen, who edits the British Journal of Clinical Pharmacology, is planning to publish an editorial about the EditPub case and the larger problem of "organized crime against peer review."

Kissinger the policymaker — not the reviewer — once said, "Ninety percent of the politicians give the other 10 percent a bad reputation." In science, the equation might be flipped — but it's no less concerning.

Andre kildereferanser

Boston Globe – News . . . . . *21. april – 22:00*
STAT . . . . . *21. april – 22:12*

Should The Food Industry Fund Health Research?

Science 2.0 – News –21. april 16:05

In The BMJ today, leading experts debate whether the food industry should fund health research, and if so, under what circumstances.

The food industry is crucial, fulfills key societal needs, and employs more people than any other sector in the UK, argue Paul Aveyard, professor of behavioral medicine at the University of Oxford, and Derek Yach, executive director at the Vitality Institute in New York.

"For these reasons, government policies seek to support the industry," they say, and "from this perspective, it would be absurd for health policy researchers to shun collaborating with the food industry."

Even though "industry promotes products that undermine public health, in many cases food industry and health goals clearly align and co-funding in-kind or in direct payment from industry is appropriate."

Leading manufacturers are investing billions of dollars to improve the nutritional quality of their products well in excess of public research investment, for example.

And if strong safeguards are in place to prevent bias, the integrity of collaboration research should not be doubted, they argue.

They recommend that researchers should be responsible for the design and conduct of the study, and have no commercial interest in the product.

Independent statisticians should carry out the analyses, and all results should be published regardless of outcome.

Payments of funding should be made to the organisation, not directly to the researchers, and reflect only the cost of the research.

"There are excellent examples of best practice in industry-funded food research," they explain. "The alternatives are that the research is not done, that it is done by the company itself, or that the public pay."

But Anna B Gilmore and Simon Capewell, both professors of public health at the University of Bath and University of Liverpool respectively, say that food industry funding biases research, and "seriously constrains" the fight against the obesity epidemic.

Evidence suggests that industries manipulate evidence, influence public and political opinion, and minimise regulation and legal liability.

And while the food industry is diverse, they highlight the clear conflict between ultra-processed food and sugary soft drinks companies, and public health, and similar evidence is now emerging for these.

For example, industry funding distorts the research agenda by "enabling corporations with vested interests to determine what research is done, and crucially, what is not done."

And results of industry-funded research have "uniquely favourable outcomes," they explain, adding that "even well-meaning scientists are often subconsciously biased, even by small gifts."

Disclosure and peer review are often cited as a sufficient redress to these criticisms, but studies show these are not sufficient.

More radical funding models are needed to enable industry to fund research while protecting research from their influence, they explain, such as manufacturer taxes, license fees or legally mandated contributions.

However, "change will not occur until public health researchers refuse to take the ultra-processed food industry money," they explain, which is a "surprisingly small proportion of total research funding, less than one-tenth in the UK or US."

"It worked for tobacco; in the early 1990s all bar one UK medical school took tobacco industry funding. That is unthinkable today," they conclude.

Source:

The US'first chief data scientist says there's never been a better time to be someone interested in public data

Public Radio International – Global Politics –21. april 12:04

Av: Chau Tu

white-house.jpgThe Residence level of the White House is seen with magnolia flowers which bloomed in the Rose Garden of the White House in Washington, April 1, 2014.

It's been eight years since DJ Patil — then the data and analytics lead at LinkedIn — helped coin the term "data scientist," and the profession has already become one of the

Patil has long been involved in the data industry. As a doctoral student and later faculty member at the University of Maryland, he used open datasets from NOAA to help improve numerical weather forecasting. He was the director of strategy, analytics, and products at eBay and later spent nearly three years at LinkedIn. He's written books on the culture of data and building data products.

Last year, the White House appointed Patil as its first chief data scientist and deputy chief technology officer for data policy in the Office of Science and Technology Policy.

We chatted with Patil about what got him inter-

ested in data, what being a "data scientist" means and where he sees the industry going.

How did you first get started working with data?

I suck at math, generally speaking. I barely passed my math classes in high school, and I was very fortunate that I went to a junior college right down the street [in California] named De Anza College. The best decision I ever made was to take the same class as my girlfriend [laughs], and she took calculus, so I went and took this calculus class. And I was like, "Holy crap, I know nothing; this is hugely embarrassing."

I really had this moment of deciding to actually learn it, and also to impress my girlfriend. I kind of picked it up really quickly, and I fell in love with math.

From there I transferred to UCSD, where I started really working on a lot of data aspects around chaos theory. From there, I went to the University of Maryland, the home of chaos theory, and one of my advisors was Jim Yorke, who coined the term "chaos theory."

We started working on weather forecasting. We really stumbled across the idea that weather was not as chaotic as people had previously believed. The way we did that was by me going in every night at around 8, 9 p.m., taking over every computer in the math department secretly, and then downloading all of this data from the National Weather Service, ripping it apart, putting it together in different ways — and then leaving before 8 a.m., when anybody would come in.

And that allowed us to find these really interesting patterns. That was an "a-ha!" moment for me. I realized, "Oh wow, you can do really incredible things if you're able to go get data." After we did that, that became one of the major techniques used in weather forecasting.

You then helped to coin the term 'data scientist' (with Jeff Hammerbacher, then the data manager at Facebook), right?

Yes. It's good and bad. I think there's this interesting question of, "Well, what is a data scientist? Isn't that just a scientist? Don't scientists just use data¿' So what does that term even mean?

You've had one of my co-authors, Hilary Mason, on the show, and the thing we joke about and we wrote about together, is that the number one thing about data scientists' job description is that it's amorphous. There's no specific thing that you do; the work kind of embodies all these different things. You do whatever you need to do to solve a problem.

If you're building a self-driving car, who are those people who are building the self-driving car? They're data scientists — whether they're product managers, designers, whatever they are. They're the people who are using these techniques and ideas from economics, from statistics, from machine-learning, from artificial intelligence, from all these disciplines to specifically make it work, to make the car drive in a way that keeps you safe and others safe as well.

The best data scientists have one thing in common: unbelievable curiosity.

How has the data industry changed, and why do you think it's become popular to be a data scientist?

I think the reason the data science aspect has really blossomed now is, one, people are able to collect data far easier than before; it's not a lot of effort to do it. The second is, now that people can collect sufficient amount of data, there's this question of, okay, so what are we supposed to do with it? And who's actually going to do this?

How do you think the White House came to realize it needed a chief data scientist?

Well, one of the things that people haven't always really taken into consideration is how much focus this president has put on data from day one. Even if you step back in his campaign, he's very focused on using data in novel ways to engage with the public. Coming into the administration, he's been focused on everything from how do patients get more access to data, to how to we ensure that we're using data for transparency — increasing the amount of data that's open out there.

We've created data.gov,, where there are almost 200,000 datasets that are available for everyone to look at. How do we use data to improve services for everybody? In fact, [President Obama] has an executive order that all governmental data by default is open and machine-readable, and that data that is published using federal research dollars should be free, because who paid for it? The taxpayers. (There's a time window where we want

the [health] journals to be able to have exclusive access, but over the long term, the public shouldn't have to pay for that.)

Just like he was the first president to have a chief technology officer, he's recognized that there needs to be a team that is focused on how do we unleash the power of data to really benefit every single American.

You've now held this position for over a year. What's your proudest achievement so far?

The achievement I'm most proud of so far is that data scientists are now heavily, heavily engaged in working on these problems, and so many of the federal agencies now have a data team or a chief data scientist or a chief data officer. Take transportation, for example. They have a chief data officer who's focused on, how does the Department of Transportation think in a novel way about this? The National Institutes of Health have a person who is focused on new ways of thinking about data. So does the US Department of Agriculture. Even USAID. So everyone is thinking about data as a force multiplier.

Where do you see the future of the data industry going?

The most exciting thing for me about the future is how data is going to be part of every single conversation, and that we will make faster, higher-quality decisions as a result of that. What will happen is, we won't just look at data once every 10 years to evaluate something — we'll be looking at data very regularly and course-correcting in much more real time.

And that will allow us to have government provide better services and be more agile.

What advice do you have for someone who wants to become a data scientist?

There is never a better time to start. Just go to data.gov.. There are nearly 200,000 datasets where if you just start downloading them, play with them. One of the coolest things that you can do now is work with data at your local city level.

There's a National Day of Civic Hacking [on June 4], and what's going to happen on that day around the entire country is, people are going to have a hackathon in their local town, they're going to work on data at the local level. They get to use that data to improve their local communities.

What do you think are some of the biggest challenges facing the data industry?

Something that I think is really important, that I called for, is every single training program — whether it's undergraduate, graduate, or online courses in data science — must have data ethics as not some elective, but as a central tenet of how we do things.

When we do work with data, you have incredible opportunities to do great things with it, and you also have the ability to do something that could be very problematic. We're seeing where people have used data in ways that we think are fundamentally not OK. People have started to talk about this and what we should do about it. I think we have to have a much stronger conversation. Privacy components are equally important.

I also think we have to train a lot more people to use data. "Use data" means how to read a graph at the very basic level, all the way to doing very sophisticated things. Empowering people with data in their daily lives gets people to be in better control of their destiny. That could be something as simple as, "How do you choose college?" That's why we work so hard with the Department of Education to build the College Scorecard, which gives people transparency in a novel way.

Do you ever get any backlash in your role?

The biggest backlash I think there is is how do we manage the privacy aspect of this, and how do we simultaneously think about cybersecurity? The reason I don't think backlash is quite the right word is because everyone recognizes the value here, so it's not a "but" — it's an "and." How do use data and preserve privacy and ensure cybersecurity? I haven't gotten anybody who's angry at the problems we're working on; I think what we have as a problem is, Why aren't you working on that? Maybe that's the biggest backlash.

So how do you deal with those concerns about privacy and cybersecurity?

I'm very focused on them. In fact, they're integrated in everything we've done. For example, in the Precision Medicine Initiative, we released

privacy and trust principles that, we believe, are going to be the app going forward for anybody who is doing this kind of biomedical research. And then we released the draft security framework for any of this type of research going forward, and we'll be finalizing that very shortly. So, we practice what we preach, in that data ethics is an incredible component of every single thing we do.

Andre kildereferanser
South Dakota Public Broadcasting – News and Information . . . . . 21. april – 12:06

Doubts linger over impact of new data protection rules on research

Science Business – ICT –21. april 10:45
Av: Éanna Kelly

After getting caught in the crosshairs of the Snowden revelations, data protection reform finally got the nod. But some researchers say new rules passed last week could lead to inconsistent practices across Europe

The EU has given national governments too much leeway when it comes to interpreting tough new data protection rules, leaving the door open for member states to develop excessive safeguards and limitations that could hamper research, according to critics.

The League of European Research Universities (LERU) says it is concerned that the new EU Regulation will lead to a patchwork of different data protection and privacy rules in the EU Member States. "It will now be up to the member states – through the implementation of the regulation – to refrain themselves from introducing excessive and divergent safeguards and limitations that would hamper research," LERU says.

Giving governments some discretion on how to implement the law could lead to problems, agrees Magnus Stenbeck, a senior researcher in Sweden's Karolinska Institutet. "When you leave things up to member states there will always be variability, " he said.

For example, the legislation leaves it open for member states to set different standards for ethical research committees. "We have a system in Sweden, in Denmark they have a different one, " said Stenbeck. He believes the legislation will have to be cracked open again in the future, to confront these issues.

Lidia Borrell-Damián, director of research and innovation at the European University Association, said inconsistencies between countries' research policies may emerge, but it remains to be seen. "It will be important to follow up, " she said.

"We are very happy with the outcome, " said Beth Thompson, a policy adviser at the Wellcome Trust. "It has avoided the very damaging Parliament amendments and reached a good compromise."

"The point that LERU has picked up is that, unfortunately, the new text does not take us any further towards harmonisation, " said Thompson. "This would have been a great step forward for cross-border research. However, during the process it became clear that it would not be possible to achieve harmonisation for research without compromising the more research-friendly rules that we currently have in some member states."

"What we have achieved is similar to the status quo, rather than a step backward, " Thompson said.

Researchers were concerned that changes proposed during the bill's passage, requiring specific consent each time an individual's data was used in research, would be unworkable.

The proposal was made despite the fact that research already requires ethical approval, ensures confidentiality, and the identity of individuals is often masked.

Researchers set up the European Data in Health Research Alliance to lobby for research exemptions

in the new legislation. Its 'Data Saves Lives' petition attracted over 7,000 signatures.

The campaign said last week the result was good news for research in Europe, as the European Parliament passed the final vote on the regulation.

The new rules are intended to strengthen online privacy, streamline legislation between the 28 member states and boost police and security cooperation.

Catherine Castledine, public affairs manager at Cancer Research UK, said the research charity, "is pleased that the final text of the new law strikes a balance between protecting privacy and safeguarding research."

The rules will come into force in the summer, with member states having two years to comply.

Under the new rules universities will have to hire a data protection officer. Borrell-Damián said her team are preparing to investigate the implications of these new responsibilities.

Breach of the rules

The new rules cover all businesses that handle data of EU citizens, even those not based in Europe.

Technology firms found in breach will face fines of up to 4 per cent of their yearly revenue, which could imply billions of euros for major global online corporations.

Companies will also be obliged to report data breaches, such as hacking of databases, within 72 hours. Firms that handle significant amounts of data will have to hire data protection officers.

William Priestley, systems engineer at Varonis, an American software company, said companies will need to create incident response plans, restrict access to data and retire data when it is no longer needed.

Should we welcome food industry funding of public health research?

British Medical Journal –21. april 01:31

Av: Paul Aveyard, Derek Yach, Anna B Gilmore, Simon Capewell

BMJ 2016; 353 doi: http://dx.doi.org/10.1136/bmj.i2161 (Published 20 April 2016) Cite this as: BMJ 2016;353:i2161

Yes—Paul Aveyard, Derek Yach

The food industry consists of farmers, manufacturers, wholesalers, retailers, distributors, and the catering industry. If it disappeared tomorrow, most people in the developed world would die within months. It is a major employer; more people are employed in the food industry in the UK, for example, than any other manufacturing sector. For these reasons, government policies seek to support the industry. From this perspective, it would be absurd for health policy researchers to shun collaborating with the food industry.

Of course, our aims are not always allied. Many elements of the industry promote and sell food that undermines health. When faced with effective public health actions to curtail consumption of unhealthy products it sometimes fights against the cause of public health. Therefore not all cooperation is appropriate. For example, although industry's views are critical to developing public policy, its presence when such policy is decided is inappropriate.

But working with the food industry inevitably involves accepting its funding, in kind at least. Take the FLICC study, in which a supermarket searched its database to find regular consumers of processed food, often high in saturated fat and salt, and asked them to participate in the trial. The trial is testing an intervention to promote the motivation and capacity of shoppers to make better use of front-of-pack "traffic light" nutrient labels and uses loyalty card data to determine the nutritional profile of purchases. The retailer paid the costs of its staff's time used for discussion with researchers and to collect and process loyalty card data. Would the study be better if the researchers had paid the supermarket for their time and information? We

doubt anyone would seriously argue so, bearing in mind this would remove funding from other worthy research.

Reputational advantage

Why might the supermarket co-fund this study? It is because supermarket managers share the goals and values of the researchers. There is no reason they should prefer to sell less healthy food over healthier food. It may offer reputational advantage to help shoppers to make healthier choices. Only the most cynical would argue that collaborating in this way is pretending to do the right thing and merely deflects radical and unpalatable options, such as regulation.

In some cases, the interests of the food industry align so strongly with those of health researchers that industry is willing to pay the entire costs of the study. Basic research on better ways to reduce salt, sugar, and fat; intervention research on the benefits of micronutrients to health; or research on the effect of discounting healthy food on dietary patterns are examples. Leading manufacturers are investing billions of dollars to improve the nutritional quality of their products—well in excess of public research investment.

Strong safeguards

Independent researchers should be responsible for design, conduct, and analysis of the research and not the company. This implies research organisations accept direct payments from the food industry. Such payments require strong safeguards to avoid bias and the appearance of bias: researchers should have no commercial interest in the product; payments should be made to the organisation not the researchers and should reflect the cost of the research to avoid researchers feeling beholden to the company; the analysis should be done by statisticians independent of the investigators who designed and conducted the study; and researchers should publish the results regardless of the outcome. There are excellent examples of best practice in industry funded food research and other contested academic areas. The alternatives are that the research is not done, that it is done by the company itself, or that the public pays.

In many cases food industry and health goals clearly align and co-funding in kind or through direct payment from industry is appropriate. Examples of bad practice do not invalidate findings from appropriate collaborations. Providing safeguards are in place, no reasonable person should doubt the integrity of collaborative research.

No—Anna B Gilmore, Simon Capewell

Corporations are legally required to maximise shareholder profits and therefore have to oppose public health policies that could threaten profits. Unequivocal, longstanding evidence shows that, to achieve this, diverse industries with products that can damage health have worked systematically to subvert the scientific process. The research they fund produces uniquely favourable outcomes. Internal documents show how they manipulate evidence in their favour, strategically communicate that evidence to influence public and political opinion, and ultimately minimise regulation and legal liability.

The food industry is diverse, but there is a clear conflict between public health and companies that produce ultraprocessed food and sugary soft drinks. It is unsurprising, therefore, that similar evidence is now emerging for these companies. Studies they fund are generally biased in their favour. Previously secret documentation shows they are working to ensure research and researchers they fund deflect attention from their products and unwanted regulatory interventions. They promote weak or ineffective interventions aimed at individuals rather than upstream population level regulation, and emphasise physical activity and energy balance to the exclusion of diet based drivers of obesity, messaging reinforced by non-governmental organisations fronted by industry funded scientists.

16

Introduction

Council of the European Union – Latest documents –21. april 00:21

The world is witnessing a dramatic increase in the amount and variety of data being produced. Alongside the data created by billions of people using digital devices and services for personal and professional reasons, and the data generated by the increasing number of connected objects, there is data from research, from digitised literature & archives and from

public services such as hospitals and land registries. This "Big Data" phenomenon creates new possibilities to share knowledge, to carry out research and to develop and implement public policies.

It is also becoming easier to exploit this data thanks to the Cloud. The Cloud can be understood as the combination of three interdependent elements: the data infrastructures which store and manage data; the high-bandwidth networks which transport data; and the ever more powerful computers which can be used to process the data. The ability to analyse and exploit this Big Data is having an impact on the global economy and society, opening up the possibility of major industrial and social innovations. A key part of this impact is the change in the way scientific research is carried out, as we move rapidly towards Open Science.

The Cloud makes it possible to move, share and re-use data seamlessly across global markets and borders, and among institutions and research disciplines. With the current capacity available in Europe, the data produced by EU research and industry is often processed elsewhere and European researchers and innovators tend to move to the places where high data and computing capacity is more immediately available. At the same time, as Europe is the largest producer of scientific knowledge in the world, it is well placed to take the global lead in the developing of a science cloud.

To fully exploit the potential of data as a key driver of Open Science and the 4th industrial revolution, Europe needs to answer several specific questions:

• How to maximise the incentives for sharing data and to increase the capacity to exploit them?

• How to ensure that data can be used as widely as possible, across scientific disciplines and between the public and the private sector?

• How better to interconnect the existing and the new data infrastructures across

Europe?

• How best to coordinate the support available to European data infrastructures as they move towards exascale computing1?

The potential gains for science, technology, and innovation from addressing these challenges were highlighted by the scientific community itself, but also by OECD Governments. The importance for the whole economy and society of addressing these challenges was confirmed by the EU's Member States in 2015.2 This Communication proposes as a direct response a

European Cloud Initiative which can secure Europe's place in the global data-driven economy.3

1 Exa-scale computing refers to computing systems capable of at least one exaFLOPS – 1018 calculations per second – about 1.000 times faster than today's machines.

2 See th e Conclusions of the Competitiveness Council, 2015

3 Speech of President Juncker on October 2015; http://bit.ly/1Y52pGi

The European Cloud Initiative builds on the Digital Single Market (DSM) Strategy, which aims, inter alia, to maximise the growth potential of the European digital economy.4 It aims to develop a trusted, open environment for the scientific community for storing, sharing and re-using scientific data and results, the European Open Science Cloud.5 It aims to deploy the underpinning supercomputing capacity, the fast connectivity and the high-capacity cloud solutions they need via a European Data Infrastructure.6 Focussing initially on the scientific community, the user base will be expanded to the public sector and to industry, creating solutions and technologies that will benefit all areas of the economy and society.

Achieving this will require a collaborative effort open to all those interested in exploiting the data revolution in Europe as an essential compo-

nent of global growth.

The European Cloud Initiative builds on the achievements of the European Cloud Strategy

7 and the High Performance Computing (HPC) Strategy.8 It will build on initiatives such as the recently announced Important Project of Common European Interest (IPCEI) on HPC and Big

Data enabled applications.9 It takes forward the policy developed in the Communication on

Big Data10 and supports the European Open Science policy agenda which aims to increase the quality and impact of science,11 building on the achievements of Open Access.12 This

Communication marks the beginning of a process whereby the Commission will engage with the Member States and with all relevant stakeholders to ensure the European Cloud Initiative can achieve its objectives.

The European Cloud Initiative will be complemented by further action under the Digital

Single Market strategy covering cloud contracts for business users and switching of cloud services providers, as well as by the Free Flow of Data initiative.13

Five reasons why Europe is not yet fully tapping into the potential of data

First, many European businesses, research communities and public bodies are yet to tap into the full potential of data and of its potentially transformative effect on traditional sectors and on the way research is conducted.14 Data coming from publicly funded research is not always open ; likewise data generated or collected by businesses is often not shared, and not always for commercial reasons. While some still see data as an asset to be protected many in business (especially SMEs), academia and public sectors are simply unaware of the value of data sharing. Reasons include the lack of a clear structure of incentives and rewards for

4 COM(2015) 192 final

5 Preparatory work started through a Commission High Level Expert Group, tasked to issue advice on its set-up:

http://bit.ly/1RK7lhh

6 Preparatory work undertaken i.e. through advisory groups such as the e-infrastructures Reflection Group.

7 COM(2012) 529 final and results of working groups http://bit.ly/1QVrvIb

8 COM(2012) 45 final

9 The objective is to support the development of new industrial uses of HPC and to guarantee access to HPC facilities for public and private research, http://bit.ly/1RMFq0i

10 COM(2014) 442 final

11 Council policy debate (9385/15); Council Conclusions (8970/15)

12 COM(2012) 401 final

13 Possible legislative proposals will be subject to Commission better regulation requirements, in line with

Commission's Better Regulation Guidelines, SWD(2015) 111

14 This is the case in e.g. healt h http://bit.ly/1XEeaTN (and ERC projects BIOTENSORS, DIOCLES, SMAC), astronomy (e.g. SparseAstro); climate change, migration or the Internet (e.g. DIADEM, MIGRANT, RAPID, THINKBIG).

data sharing (mainly in academia), of a clear legal basis15 (mainly in the public sector) and the shortage of data-related skills and lack of recognition of their value (in all sectors). The EU data protection framework prevents restrictions to the free movement of personal data on the grounds of privacy and personal data protection. Other legal and technical barriers to the free movement of data are yet to be tackled by the upcoming DSM initiative on the Free Flow of

Data.

Second, lack of interoperability prevents addressing grand societal challenges that require efficient data sharing and a multidisciplinary, multiactor approach, e.g. climate change which cannot be addressed by climatologists alone. While interoperability and data sharing have been tackled in some sectors (e.g. location of data by the INSPIRE Directive,16 health data by the patients'rights Directive17) many data sets remain unavailable to scientists, industry, public administrations and policy makers. While interoperability of administrative data mainly requires minimum standards, legal certainty in terms of access and usage and practical support,18 sharing research data is also hampered by the size of datasets, its varied formats, the complexity of the software needed to analyse it and deep-rooted walls between disciplines. Simple'meta-data'19 to identify data and

specifications for data-sharing are needed to make them widely accessible and available to be processed through common, open source data analysis tools. Issues of long-term preservation and curation of data must also be tackled.

There are already global grassroots initiatives20 and some Member States are advancing in this area but the European participation in these initiatives is limited and those efforts are largely fragmented.

Third, fragmentation hampers data-driven science.

21 Data infrastructures are split by scientific and economic domains, by countries and by governance models. Access policies for networking, data storage and computing differ. Disconnected and slow data and computing infrastructures hinder scientific discovery, create silos and slow down the circulation of knowledge. Shareable

research data, open data analysis tools and connected computing facilities need to be available to the great majority of researchers22 in Europe, not only to top scientists of leading disciplines from key research institutions. Moreover, Europe's universities and research centres generally operate within national structures and lack a European-scale environment for computational, storage and data analysis. This makes scientific cooperation in the EU more difficult, particularly multi-disciplinary cooperation based on data.23 In a recent public consultation,24 the vast majority of the respondents

15 The INSPIRE Directive 2007/2/EC provides an acquis for the sharing of European location data. However, the scope of the application of these laws is limited to specific data and services for environmental, natural disasters and health policies and not all obstacles with regard to data policies have been lifted effectively.

16 Regulation 1089/2010 implementing Directive 2007/2/EC

17 Work on the eHealth Network set up under Directive 2011/24 on patients'rights, eHealth Digital Service

Infrastructure ePrescription and Patient Summary services to exchange of health data and the recent Joint Action supporting the eHealth Network report on the "Use of cloud computing in health" to support use of data other than for the direct care of an individual patient.

18 Tackled by the Commission's ISA Programme: http://bit.ly/24DxWUs

19 This may include high-quality statistical meta-data from official statistics to enhance data browsability, interoperability and integration.

20 Several global initiatives address this: the FAIR data principles, the G8 Principles for Open Research Data

Science, RDA guidelines, Belmont Forum recommendations, OECD principles and discipline-specific guidelines.

21 Consultation on Science 2.0 flagged the lack of integration of existing infrastructures as an obstacle for scientists'work.

22 Researchers are either unaware (54 %) or do not have a facility (37 %) to store and maintain their data

(bit.ly/206u6hm).

23 http://bit.ly/1SkL9wm answered that the European Open Science Cloud would make science more efficient by better sharing of resources at national and international level.

Fourth, there is surging demand in Europe for a world-class High Performance Computing

(HPC) infrastructure to process data25 in science and engineering. The simulation of a complete next-generation airplane; climate modelling; linking genome to health; understanding the human brain; in silico testing of cosmetics to reduce animal testing – all need exascale computing capabilities. While in the long term, quantum computing holds the promise to solve computational problems that are beyond current supercomputers,26 EU competitiveness also depends on the support of HPC for pan-European data infrastructures.

Worldwide, the USA, China, Japan, Russia and India are advancing swiftly. They have declared HPC a strategic priority, they fund programmes to develop national HPC ecosystems

(hardware, software, applications, skills, services and interconnections) and work on the deployment of exascale supercomputers.27 Europe is not participating in the HPC race in line with its economic and knowledge potential; it is falling behind other regions as it fails to invest in its HPC ecosystem and to reap the benefits of intellectual property in this field. On the supply side, EU industry provides about 5% of HPC resources

worldwide, while it consumes one third of it. As Europe depends ever more on other regions for critical technology, the risk is that it gets technologically locked, delayed or deprived of strategic know-how. Europe also lags in terms of sheer total computing power: only one out of ten leading HPC infrastructures is in the EU, Germany's Höchstleistungsrechenzentrum Stuttgart ranking 8th. The USA has five and China has the fastest world supercomputer since 2013.

No single Member State alone has the financial resources to develop the necessary HPC ecosystem, in competitive time frames with respect to the US, Japan or China.28 However to date no common action is taken to bridge the gap between internal demand and EU supply.29

The EU set up a contractual Public-Private Partnership on HPC to develop exascale technology, but there is no European framework to integrate it in large scale computing systems.

Finally, scientific data producers and users must be able to re-use data and to use advanced analytics techniques, such as text and data mining, in an environment that is at least as dependable as their own facilities. Member States have made strong reference to the importance of EU research data and to ensure that data-driven science benefits European society.30 Any use and re-use of scientific data needs to ensure that personal data are adequately protected according to the EU data protection rules.31 These and forthcoming revision of EU Copyright legislation32 provide general frameworks which are relevant in this context.

24 http://bit.ly/1JEymCY

25 Requests for computing cycles about double PRACE availability: http://bit.ly/1So2sgc

26 SWD(2016) 107

27 SWD(2016) 106

28 The US Department of Defence will invest $525 Million for acquiring 3 pre-exa-scale systems in 2017/2018

('CORAL'). Japan plans to invest $1.38 Billion to install a near-exa-scale system in 2019.

29 While PRACE allows sharing computing resources of some Member States, the procurement of HPC systems is a national decision without EU coordination or funding.

30 Council conclusions (8970/15).

31 COM (2012) 9 final

32 COM (2015) 626 final

What are the solutions?

1. European Open Science Cloud

The European Open Science Cloud aims to give Europe a global lead in scientific data infrastructures, to ensure that European scientists reap the full benefits of data-driven science.

Practically, it will offer 1.7 million European researchers and 70 million professionals in science and technology a virtual environment with free at the point of use, open and seamless services for storage, management, analysis and re-use of research data, across borders and scientific disciplines. Its development will be driven by the scientific community, who are the most advanced users and the largest producers of science in the world. The European Open

Science Cloud will be also open for education and training purposes in higher education and, over time, to government and business users as the technologies developed will be promoted for wider application.

The European Open Science Cloud will start by federating existing scientific data infrastructures, today scattered across disciplines and Member States. This will make access to scientific data easier, cheaper and more efficient. It will enable the creation of new market opportunities and new solutions in key areas such as health, environment, or transport. The

European Open Science Cloud will provide a secure environment where privacy and data protection must be guaranteed by design, based on recognised standards, and where users can be confident concerning data security and liability risks. It will leverage other actions taken by the Commission to promote Open Science in Europe, such as open access to scientific publications and data in Horizon 2020, and convene key stakeholders to co-design the next actions. The governance of the European Open Science Cloud will be determined upon conclusion of a thorough preparation process that is already under way.

Specifically, to develop the European Open Science Cloud it will be necessary to:

• Make all scientific data produced by the Horizon 2020 Programme open by default. This will

extend the current pilot,33 whereby projects implement Data

Management Plans to make research data findable, accessible, interoperable and re- usable (FAIR principles).34

• Raise awareness and change incentive structures for academics, industry and public services to share their data, and improve data management training, literacy and data stewardship skills. In parallel, principles and guidelines on access to research data in Europe35 will be reviewed to strengthen and coordinate their implementation.

33 The Horizon 2020 Open Research Data Pilot currently covers : Future and Emerging Technologies, Research infrastructures, Information and Communication Technologies, the 'nanosafety' and 'modelling' topics in the

Nanotechnologies, Advanced Materials, Advanced Manufacturing and Processing, and Biotechnology WP, selected topics within the Societal Challenges: Food security, sustainable agriculture and forestry, marine and maritime and inland water research and the bioeconomy; Climate Action, Environment, Resource Efficiency and

Raw materials – except raw materials; Europe in a changing world – inclusive, innovative and reflective

Societies; Science with and for Society as well as the cross cutting activity and focus area Smart and Sustainable

Cities. Note that projects that are not part of these "core areas" can still join on a voluntary basis.

34 The existing opt-out options, where open access to data would be contrary to future commercial application or data privacy and personal data protection, security and protection of EU classified information will be maintained. The analysis of the pilot showed that most projects apply open data, but that opt-out options are also important.

35 C(2012) 4890 final

• Develop specifications for interoperability and data sharing across disciplines and infrastructures, building on existing initiatives such as the Research Data Alliance and the Belmont Forum and legal provisions such as INSPIRE. Over time, any emerging standardization needs will be addressed through the DSM Priorities for ICT

Standardisation.

• Create a fit-for-purpose pan-European governance structure to federate scientific data infrastructures and overcome fragmentation. The institutional set-up will oversee long-term funding, sustainability, data preservation and stewardship. It will build on existing structures to involve scientific users, research funders and implementers.36

• Develop cloud-based services for Open Science. Supported by the European Data

Infrastructure, they will allow researchers to find and access shared research data, to employ advanced analytical software, to use high-performance computing resources and to learn about best data-driven science practices from leading disciplines.

• Enlarge the scientific user base of the European Open Science Cloud to researchers and innovators from all disciplines and Member States, as well as from partner countries and global initiatives, so that they contribute to excellence and partake in the benefits of the initiative.37

The initiative will reinforce other Open Science actions that the Council38 and the European

Parliament39 called for, and actions in the context of the forthcoming Open Science policy agenda of the Commission. It will foster best practices of data findability and accessibility and help researchers get their data skills recognised and rewarded; allow easier replicability of results and limit data wastage e.g. of clinical trial data (research integrity); contribute to clarification of the funding model for data generation and preservation, reducing rent-seeking and priming the market for innovative research services (e.g. advanced text and data mining).

The initiative may also help address issues of data clearance and personal data protection.40

The Commission will consult stakeholders and work with R&D providers on the need for implementing guidelines for the scientific domain regarding Union policy and law in Data

Protection, and on the need to ensure that the initiative implements "by-design" the legal principles at the earliest possible stage.

Actions

Timeline

The Commission will work with global policy and research partners to foster cooperation and to

create a level playing field in scientific data sharing and data-driven science.

As of 2016

The Commission will use the Horizon 2020 Work Programmes to provide As of 2016

36 Such as ESFRI, INSPIRE, eIRG, GEANT, PRACE, ELIXIR, the Belmont Forum and similar federating initiatives.

37 New Commission initiatives may be financed under ESIF provided that the Member States agree to finance them and to modify their operational programmes accordingly.

38 Council Conclusions (8970/15).

39 European Parliament Report 2015/2147(INI).

40 While fully respecting Articles 7 and 8 of the Charter of Fundamental Rights of the European Union and current and forthcoming provisions on use of data for research purposes, the initiative may develop, for instance, services for IPR-conscious text and data mining, access control for different uses, irreversible anonymisation of sensitive data before data fusion, 'personal data spaces' to preserve privacy and foster uptake of innovative uses or rely on machine-readable licencing and privacy meta-data attached to data-sets accessible via the cloud and provide guidelines and best practices for compliant organisational processes supporting the initiative. While these are technical, by-design and by default tools and processes, they may help reduce the incidence of malpractice and reduce non-conformity with legal provisions.

funding to integrate and consolidate e-infrastructure platforms, to federate existing research infrastructures and scientific clouds and to support the development of cloud-based services for Open Science.

The Commission will make open research data the default option, while ensuring opt-outs, for all new projects of the Horizon 2020 programme.

As of 2017

The Commission will review the 2012 Commission Recommendation on access to and preservation of scientific information41 to encourage scientific data sharing and the creation of incentive schemes, rewards systems and education and training programmes for researchers and businesses to share data, in close relation with the DSM 'Free flow of data' initiative.

As of 2017

The Commission will work with Member States to connect the priority

European research infrastructures42 to the European Open Science Cloud.

As of 2017

Together with stakeholders and relevant global initiatives, the Commission will work towards an Action Plan for scientific data interoperability, including

'meta-data', specifications and certification.

By end

2017

2. European Data Infrastructure

The European Data Infrastructure, once fully implemented, will underpin the European

Open Science Cloud. Europe needs integrated world-class HPC capability, high-speed connectivity and leading-edge data and software services43 for its scientists and for other lead users from industry (including SMEs) and the public sector. This infrastructure will allow fully unlocking the value of Big Data and digital by default.44 The European Data

Infrastructure will also support the EU to rank among the world's top supercomputing powers by realising exascale supercomputers around 2022, based on EU technology, which would rank in the first 3 places of the world. Europe should aim to have at least two sources of this technology.

While the existing HPC strategy45 supports research and development of marketable HPC technologies, it does not foresee realising an exascale supercomputer. The European Data

Infrastructure will gather the necessary resources and capabilities, to close the chain from research and development to the delivery and operation of the exascale HPC systems co- designed between users and suppliers. This will include data connectivity and big data storage to make sure that supercomputing services are available across the EU, no matter where supercomputers are located. A first step was recently taken by Luxembourg, France, Italy and

Spain, with an Important Project of Common European Interest (IPCEI) on HPC and

Big Data enabled applications.46

Building on the Pan-European High Performance Computing infrastructure and services

41 C(2012) 4890 final

42 As identified by the European Strategic Forum on Research Infrastructures (ESFRI) http://bit.ly/1pfqOe7

43 Including existing services by OpenAIRE, EUDAT, EGI, IndigoDataCloud, HelixNebula, PRACE, GÉANT.

44 'Digital by default' refers to services and processes that are made available online or in a digital form by default.

45 COM(2012) 45 final

47 http://bit.ly/1QxERan

(PRACE), the trans-European high speed network (GÉANT), the contractual Public-Private

Partnership on HPC,47 the ECSEL Joint Undertaking,48 and the IPCEI on HPC and Big Data, the Commission and participating Member States will:

• foster an HPC ecosystem capable of developing new European technology such as low power HPC chips;49

• integrate technologies into system prototypes, co-designing50 solutions and procuring

HPC systems; the resulting HPC infrastructure will focus on supercomputers of top- range capabilities connected to mid-range EU national computing centres and to pan-

European data and software infrastructure to offer supercomputing as a service;

• provide seamless, high-speed, reliable and secure connectivity to make HPC accessible across the EU; the trans-European high speed network (GÉANT) and

National Research and Education Networks (NREN) already connect 50 million researchers and students; these infrastructures will be upgraded to match the increase of data volumes to be transferred and the extension of the user base.

The European Data Infrastructure will contribute to the digitisation of industry, to develop

European platforms for new, strategic applications (e.g. medical research, aerospace, energy) and to foster industrial innovation. It will widen the user base of HPC, providing easier access via the Cloud both to researchers in key scientific disciplines and to the long tail of science. Industry, particularly SMEs without in-house capabilities and public authorities (e.g.

smart cities and transport) will benefit from cloud-based and easy-to-use HPC resources, applications and analytics tools.51 In this context, the Commission will foster the deployment of processing and exploitation capacities for Sentinel satellites'data, Copernicus services information and other Earth Observation data, so as to enable the cross-fertilisation of different data sets, encourage the development of innovative products and services and maximise the socio economic benefits of Earth Observation data in Europe.

The European Data Infrastructure will work in combination with the national and regional, scientific and public data centres. It will develop and implement best practices based on certification schemes, common European and global standards and specifications52 to tackle the current lack of interoperability between national and disciplinary data centres.53

The European Data Infrastructure will include a governance structure for the management and the development of the data infrastructure and services,54 decision making on funding, long- term sustainability and security. The governance should involve users (the European Open

47 http://bit.ly/1WZH8wF

48 http://www.ecsel-ju.eu

49 Energy efficient exa-scale machines would impact the full spectrum of computing and bring Europe technical, economic and social advantages. Currently, a single exa-scale machine would need a dedicated power plant of

700MW to operate, enough to power 140.000 households for a year. Thus the need for low power chips.

50 Co-design is an approach to design aiming to actively involve customers and users in the design process to help ensure the result meets their needs and is usable.

51 http://bit.ly/1pqny20

52 RDA-Europe has started the interaction with the ICT standardisation multi stakeholder group to submit best practice implementations for data infrastructure interoperability developed in the Research Data Alliance.

53 Such as INSPIRE interoperable spatial data and services specifications.

54 Building on existing services by Ope-

nAIRE, EUDAT, EGI, IndigoDataCloud, HelixNebula, PRACE, GÉANT.

Science Cloud and other long-term users such as the public sector), implementers (PRACE, GEANT) and funders, and should build on existing governance structures.

Actions

Timeline

The Commission and participating Member States should develop and deploy a large scale European HPC, data and network infrastructure, including:

– the acquisition of two co-designed, prototype exascale supercomputers and two operational systems which will rank in the top three of the world;

– the establishment of a European Big Data centre, 55

– the upgrade of the backbone network for research and innovation

(GEANT) and the integration of European public services networks.

2016 – 2020 as of 2018 as of 2016 as of 2016

Exploiting the potential of quantum technologies

The next breakthrough in supercomputing and secure networking may be based on quantum technologies. Leading companies in Europe, Asia-Pacific and North America are starting to invest in quantum, but a higher level of investment is necessary to reach marketable products.

Europe has to be at the forefront of these future advances.56 The European Data Infrastructure should be complemented by an ambitious, long-term and large-scale flagship initiative to unlock the full potential of quantum technologies, accelerate their development and bring commercial products to public and private users. The European Commission will start the preparatory steps for the flagship, including consultation of stakeholders, impact assessment, taking into account results of the interim evaluation of the Horizon 2020 Programme by the end of 2017.57

Action

Timeline

The European Commission will start the preparatory steps for the flagship, including consultation of stakeholders, impact assessment,58 taking into account results of the interim evaluation of the Horizon 2020 Programme by the end of 2017,59 with the aim to launch the ramp up phase in 2018.60

2016 – 2019

3. Widening access and building trust

The uptake of cloud services in the public sector is uneven and slow.61 This is due to lack of trust and limited synergies between the public sector and the academia. Fragmentation in

55 E.g. hosted by JRC for multidisciplinary data but focused on INSPIRE/GEOSS/Copernicus spatial data.

56 https://goo.gl/zBVi8N

57 SWD(2016) 107

58 The impact assessment will be part of the preparatory process for relevant funding programmes under the post

2020 financial perspective. Any additional implementation measure likely to have significant impacts may require separate, individual impact assessments.

59 SWD(2016) 107

60 FET Flagships as described in Horizon 2020 reference documents.

61 SMART 2013/0043: Public sector organisations trail the private sector, with a 10% difference in 2013 in the use of cloud computing services.

terms of data infrastructures is an obstacle for building critical mass and common solutions for different user groups. The user base of the European Open Science Cloud and of the

European Data Infrastructure will be widened to the public secto r, for example through large-scale pilots involving eGovernment62 and public sector stakeholders and by progressively opening the European Data Infrastructure to users from industry and the public sector to achieve a European dimension. Over time, the European Open Science Cloud will ensure that public data is fully discoverable, accessible and exploitable by scientists, policy makers and businesses. Lessons learnt will provide concrete guidance for the adoption of cloud-based services by public administrations across Europe.

As the public sector generates massive amounts

of data (e.g. Copernicus earth observation, INSPIRE location data) and needs larger computing capacity (e.g. for real time traffic and travel information systems, for smart city applications or for policy modelling), it will benefit from economies of scale, flexibility and continuity. The public will thus benefit from cheaper, faster, better and interconnected public services and from better policy making based on affordable and secure compute- and data-intensive services.

In similar fashion, the European Open Science Cloud and the European Data Infrastructure will benefit businesses, including SMEs, that lack cost-effective and easy access to data storage, services and advanced computing. Actions will be taken to progressively widen the user base to innovative SMEs and industry, via data and software centres of excellence and data services innovation hubs for SMEs. These actions will require close cooperation with the private sector: SMEs, large scientific and industrial users of HPC and the Cloud services industry, who needs to be involved from the start.

Additionally, the European Cloud Initiative will need to meet high standards of quality, reliability and confidentiality, to ensure protection of personal data and intellectual property, and security – in terms of resilience and protection against intrusion. Existing public sector facilities – notably the Connecting Europe Facility (CEF) Digital Service

Infrastructure (DSI) building blocks related to trust and security – can be reused and deployed by the scientific community for cost savings, ease of access, and overall consistency. The general framework will be provided by the general data protection rules, the NIS Directive63 and the revision of the EU copyright legislation. Given the global nature of cloud computing, it is essential that the European data economy remains connected to the rest of the world and that the global standards of data protection are raised to a high level essentially equivalent to that in Europe.

Working on appropriate standards is part of the DSM Priorities for ICT Standardisation

Plan64 ; a suitable certification scheme will be designed at EU level to guarantee security, data portability, and interoperability in compliance with legal requirements,65 including the certification scheme already provided for in General Data Protection Regulation for personal data security. While a number of certification schemes66 exist, their scope and application vary considerably, and there is no common approach on minimum requirements in the procurement or management of public sector cloud resources. In this respect, collaboration with industry and public authorities will match the capability of industry with the requirements of science and the public sector.

62 EU eGovernment Action Plan 2016 – 2020 – accelerating the digital transformation of government

63 COM (2013) 48

64 COM(2016) 176

65 Regulation 765/2008

66 https://resilience.enisa.europa.eu/cloud-computing-certification

Widening of access to the European Open Science Cloud and European Data Infrastructure will be carried out in line with the appropriate legislation, in particular for what concerns the re-use of data for other purposes.

Actions

Timeline

In partnership with industry and the public sector, the Commission undertakes to:

– adapt HPC and Big Data solutions to a cloud environment in order to enable broad access, notably for SMEs;

– develop an ecosystem to strengthen the cloud industry in Europe, using the European Open Science Cloud as a testbed for innovative cloud technology solutions;

– create a platform for public authorities to open their data and services, creating a “Government as a Service” (GaaS) base for the

EU.

2016 – 20

In order to facilitate the uptake of big data technologies, the Commission will provide a big data test environment (large-scale pilots) for public administrations, including in the framework of the proposed IPCEI.

As of 2016

The Commission working with industry and Member States will promote the use of existing relevant certifications and standards, and – where appropriate – the creation of European-level cer-

tification and labelling, in particular to support public procurement of cloud services.

As of 2016

Financial implications

Digital transformation in Europe requires scale. Various sources of EU financing can be identified for the European Cloud Initiative:

• Horizon 2020 Framework Programme for Research and Innovation (Horizon 2020)

• Connecting Europe Facility (CEF)

• European Structural and Investment Funds (ESIF)

• European Fund for Strategic Investments (EFSI)

Different sources of financing are necessary to support the full investment cycle. Large infrastructure projects are supported initially by public grants and, as they mature, by risk- sharing and market-based instruments. However, since such initiatives require consistent and coordinated efforts, the fragmentation of available budget sources is clearly a drawback.

Existing funding under Horizon 2020 will allow to support the European Open Science Cloud and to kick-start the European Data Infrastructure. Initial estimation of the required additional public and private investment is €4.7 billion in the period of 5 years. This includes €3.5 billion for data infrastructure,67 €1 billion for a large-scale EU-wide Quantum Technologies flagship and €0.2 billion for actions on widening access and building trust. Additional provisions will be discussed with Member States for enlarging support to the European Open

Science Cloud beyond Horizon 2020. The initiative will over time generate revenue of its own as its use by the scientific community, innovative start-ups and the public sector takes off.

67 SWD(2016) 106

The Commission intends to propose how the different sources of financing at EU and national level could be blended in order to realise the objectives of the present Communication in full; it will discuss them with the Member States following appropriate evaluation, assessments of impacts and consultation. Infrastructure of this level of ambition will require strong involvement of the Member States, in particular by leveraging structural funds and EFSI68 guarantees, but also significant investments from the private sector and appropriate coordinating mechanisms. In this respect, the proposed Important Project of Common

European Interest (IPCEI) on HPC and Big Data shows the possibilities and the positive effects of Member States'engagement.

Actions

Timeline

In cooperation with Member States and stakeholders, the Commission will explore appropriate governance and financing mechanisms for the Open

Science Cloud and the European Data Infrastructure and define an implementation Roadmap.

As of 2016

The Commission will put forward approaches for blending different funding streams, for discussion with Member States and stakeholders, in order to realise the objectives of this Communication.

2016

CONCLUSIONS

The European Cloud Initiative is designed to help science, industry and public authorities in

Europe access world-class data infrastructures and cloud-based services as they become the decisive factors for success in the digital economy.

A European Cloud Initiative should open up to every research centre, every research project and every researcher in Europe the world-class supercomputing, data storage and analysis capacity which they need to succeed in the global, data-driven innovation system.

The Initiative will make it possible to widen the user-base of the infrastructures and services to the public sector and to industry, including SMEs, guaranteeing an adequate level of security, data portability, interoperability as well as compliance with EU legal requirements.

The extent to which the Member States and private sector embrace the gains to be made from addressing this challenge, and commit to working together to address them will determine the success of the initiative.

68 Advisory services of EIB under the European Investment Advisory Hub will also be involved.

Document Outline

Introduction

Five reasons why Europe is not yet fully tapping into the potential of data

What are the solutions?

1. European Open Science Cloud
2. European Data Infrastructure
3. Widening access and building trust

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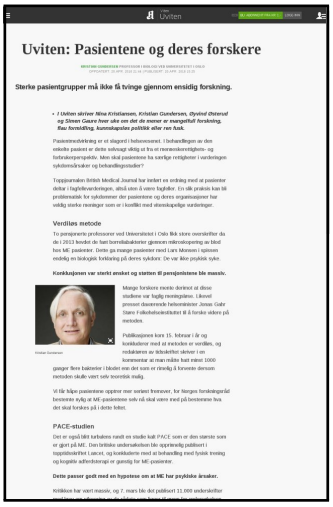
Uviten: Pasientene og deres forskere

Aftenposten.no - Forsiden –20. april 22:04

Av: Kristian Gundersen

Sterke pasientgrupper må ikke få tvinge gjennom ensidig forskning.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Verdiløs metode

Konklusjonen var sterkt ønsket og støtten til pensjonistene ble massiv.

PACE-studien

Dette passer godt med en hypotese om at ME har psykiske årsaker.

Pasientmedvirkning er et slagord i helsevesenet. I behandlingen av den enkelte pasient er dette selvsagt viktig ut fra et menneskerettighets- og forbrukerperspektiv. Men skal pasientene ha særlige rettigheter i vurderingen sykdomsårsaker og behandlingsstudier?</p> Toppjournalen British Medical Journal har innført en ordning med at pasienter deltar i fagfellevurderingen, altså uten å være fagfeller. En slik praksis kan bli problematisk for sykdommer der pasientene og deres organisasjoner har veldig sterke meninger som er i konflikt med vitenskapelige vurderinger.

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Mange forskere mente derimot at disse studiene var faglig meningsløse. Likevel presset daværende helseminister Jonas Gahr Støre Folkehelseinstituttet til å forske videre på metoden. Publikasjonen kom 15. februar i år og konkluderer med at metoden er verdiløs, og redaktøren av tidsskriftet skriver i en kommentar at man måtte hatt minst 1000 ganger flere bakterier i blodet enn det som er rimelig å forvente dersom metoden skulle vært selv teoretisk mulig.

Publikasjonen kom 15. februar i år og konkluderer med at metoden er verdiløs, og redaktøren av tidsskriftet skriver i en kommentar at man måtte hatt minst 1000 ganger flere bakterier i blodet enn det som er rimelig å forvente dersom metoden skulle vært selv teoretisk mulig. Vi får håpe pasientene opptrer mer seriøst fremover, for Norges forskningsråd bestemte nylig at ME-pasientene selv nå skal være med på bestemme hva det skal forskes på i dette feltet.

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PACE-studien

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Personangrep

Personangrep Redaktøren av Lancet sier han aldri har opplevd en slik reaksjon på en publikasjon: «Et orkestrert forsøk på å undergrave kredibiliteten til studien og forskerne fra pasientgrupper». Selv en del av den mer seriøse kritikken av PACE-studien er iblandet personangrep.

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PACE-forskerne selv svarer godt for seg vitenskapelig sett, men vikles ubønnhørlig inn i en fiendtlig diskusjon om sin egen integritet. Dersom sterke pasientgrupper vil at samfunnet skal godta nesten hva som helst av elendig forskning som støtter hypoteser de liker (oslopensjonistenes), mens man krever det perfekte av forskere som konkluderer annerledes (PACE), vil man få et skjevt bilde av virkeligheten.

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Det er ikke hensikten med vitenskapelig debatt. Vil du lese mer spennende vitenskapsstoff skrevet av forskere? Følg Aftenposten Viten på Facebook og Twitter!

Vil du lese mer spennende vitenskapsstoff skrevet av forskere? Følg Aftenposten Viten på Facebook og Twitter!

Fulle folk og gatelykter

Tidsskrift for Den norske legeforening – Forside –19. april 17:35

Av: Per Vaglum, Tore Gude

Forskning skal kaste lys over verden. Politikk er å foreta veivalg i det lyset. Derfor er politisk misbruk av forskning farlig

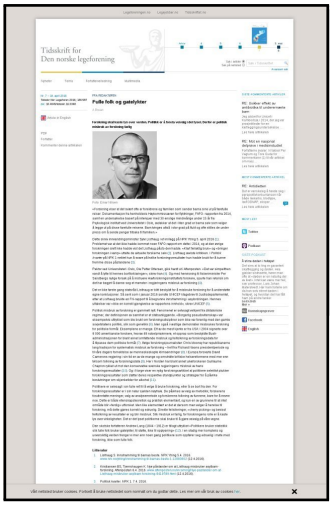

Foto: Einar Nilsen

«Forskning viser at det svært ofte er foreldrene og familien som sender barna sine ut på farefulle reiser. Dokumentasjon fra henholdsvis Høykommissæren for flyktninger, FAFO- rapporten fra 2014, samt en undersøkelse basert på intervjuer med 30 enslige mindreårige under 15 år fra Psykologisk institutt ved Universitetet i Oslo, avdekker at det i liten grad er barna selv som velger å legge ut på disse farefulle reisene. Barn tvinges altså i stor grad på flukt og ofte stilles de under press om å sende penger tilbake til familien.»

Dette skrev innvandringsminister Sylvi Listhaug i et innlegg på NRK Ytring 5. april 2016 (1). Problemet var at det ikke hadde kommet noen FAFO-rapport om dette i 2014, og at den øvrige forskningen slett ikke hadde vist det Listhaug påsto den hadde. «Klart feilaktig bruk» og «bringer forskningen i vanry» uttalte de aktuelle forskerne selv (2). Listhaug avviste kritikken. I Politisk kvarter på NRK 1 nektet hun å svare på hvilke forskningsresultater hun hadde brukt for å kunne fremme disse påstandene (3).

Rektor ved Universitetet i Oslo, Ole Petter Ottersen, gikk hardt ut i Aftenposten. «Det var simpelthen vondt å lytte til hennes bortforklaringer», skrev han (4). Og med henvisning til fiskeriminister Per Sandbergs nylige forsøk på å instruere Havforskningsinstituttets forskere, spurte han retorisk om det har begynt å danne seg et mønster i regjeringens misbruk av forskning (4).

Det er ikke første gang statsråd Listhaug er blitt beskyldt for å misbruke forskning for å understøtte egne konklusjoner. Så sent som i januar 2016 sendte UNICEF klagebrev til Justisdepartementet, etter at Listhaug brukte en FN-rapport til å begrunne innstramming i asylordningen. Hennes uttalelser var «ikke en korrekt gjengivelse av rapportens innhold», skrev UNICEF (5).

Politisk misbruk av forskning er gammelt nytt. Fenomenet er selvsagt velkjent fra diktatoriske regimer, der definisjonen av sannhet er et statsanliggende. «Borgerlig pseudovitenskap» var eksempelvis uttrykket som ble brukt om forskningsdisipliner som ikke var forenlig med den gamle sovjetstatens politikk, slik som genetikk (6). Men også i vestlige demokratier misbrukes forskning for politiske formål. Eksemplene er mange. Ett av de mest kjente er fra USA: I 2004 signerte over 9 000 amerikanske forskere, hvorav 49 nobelprisvinnere, et opprop som beskyldte Bush-administrasjonen for blant annet omfattende misbruk og feiltolkning av forskningsdata for å tilpasse dem politiske formål (7). Ifølge forskningsjournalisten Chris Mooney har republikanerne lang tradisjon for systematisk misbruk av forskning – helt fra Richard Nixons presidentperiode og til våre dagers fornektelse av menneskeskapte klimaendringer (8). I Europa forsvarte David Camerons regjering i sin tid en av de mange og omstridte britiske helsereformene med mer enn tvilsom tolkning av forskningsdata

(9). Her i Norden har blant annet ulveforskeren Guillaume Chapron rykket ut mot den konservative svenske regjeringens misbruk av hans forskningsresultater (10). Og i Norge viser en nylig forskningsartikkel at politikere selektivt plukker forskningsresultater som støtter deres respektive standpunkter og strategier for å påvirke beslutninger om skjenketider for alkohol (11).

Politikere er selvsagt i sin fulle rett til å velge å bruke forskning, eller å se bort fra den. For forskningsresultater er i sin natur sjelden nøytrale. De påvirkes av valg av metodikk, forskerens forutinntatte meninger, valg av analysemetode og forskerens tolkning av funnene, bare for å nevne noe. Dette er både vitenskapsteoretisk og praktisk elementært, og kun en av grunnene til at intet område blir «ferdig» utforsket. Men like elementært er det at dersom man velger å henvise til forskning, må dette gjøres korrekt og edruelig. Direkte feilsiteringer, «cherry picking» og bevisst feiltolkning av resultater er og blir misbruk. Slik misbruk er farlig, for forskningens rolle er å kaste lys over virkeligheten. Det er det lyset politikerne skal bruke til å gjøre veivalg på våre vegne.

Den skotske forfatteren Andrew Lang (1844 – 1912) er tillagt uttrykket «Politikere bruker statistikk slik fulle folk bruker gatelykter; til støtte, ikke til opplysning» (12). I en stadig mer kompleks og uoversiktlig verden trenger vi mer enn noen gang politikere som oppfører seg edruelig i møte med forskning, ikke som fulle folk.

Forskerne vil lave DNA-bank over alle døde danskere

Jyllands-Posten – Trafik & Vejr –19. april 17:33

Hvis vi begynder at indsamle DNA fra alle døde danskere nu, vil vi i løbet af 10 år have informationer om en halv million menneskers genomer. Men er det etisk forsvarligt? Og hvordan skal det i så fald gøres?

I disse år finder forskerne hele tiden nye genvarianter, som betyder snart det ene og snart det andet. Med én genvariant får du brystkræft, med en anden forebygges Alzheimer. Det skriverVidenskab.dk..

Vi bliver med andre ord hele tiden klogere på menneskets arvemasse – men vi er slet ikke kloge nok, lyder det fra en gruppe forskere fra Statens Serum Institut.

Problemet? De mennesker, hvis arvemasser, vi studerer, er stadig i live.

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Læs mere:Nu skal danskernes arvemasse kortlægges

»Jeg er 55 år. Mange af mine genvarianter har ikke givet mig en sygdom, men hvem ved, om jeg om 5 år sidder på et plejehjem og er svært syg med Alzheimer? For at kunne finde ud af, hvad en genvariant egentlig betyder for et liv, er man nødt til at have levet hele det liv,«forklarer overlæge Michael Christiansen fra Statens Serum Institut til Videnskab.dk.

Sammen med sin gruppe på SSI har han foreslået, at vi laver et DNA-arkiv over alle døde danskere. Et slags 'biologisk rigsarkiv'.

Forslaget er udgivet i form af et såkaldt Letter i det anerkendte tidsskrift Science.

»Vores ide er at samle DNA ind fra alle døde danskere. Hvis vi i løbet af et år gjorde det, ville vi have genomer fra 60.000 danskere med et helt levet liv. I løbet af 10 år ville vi have en halv million. Og det er meget, meget bedre information end det, vi laver nu,«fastslår overlægen.

Det strømmer ind med nye, videnskabelige gennembrud på genfronten. En afgørende forudsætning for forskningen er muligheden for at benytte digital adgang til patientoplysninger og store biobanker med DNA. Faktisk er Danmark i særklasse, når det kommer til at sikre forskerne adgang til DNA-materiale og samtidig beskytte anonymiteten for menneskene bag.

Læs mere:Prutter og bøvser kan blive fremtidens beviser i retssalen

Det er bare ikke så godt, som det kunne være, mener Michael Christiansen ifølge Videnskab.dk.

»Vi drager konklusioner fra DNA, som i de fleste tilfælde er hentet fra relativt unge mennesker. Så med hvilken sikkerhed udtaler vi os egentlig om, hvad der giver sygdom? Vi mennesker adskiller os med fire millioner basepar, og mens én genvariant for nogle udløser sygdom, gør den det ikke for andre. I virkeligheden er vores konklusioner på nuværende tidspunkt meget usikre,«siger overlægen og fortsætter:

»Vi tænker, at hvis vi nogensinde skal have en viden, vi kan bruge til noget, er vi nødt til at have meget, meget mere data og flere levede liv at regne ud fra. På den måde kan vi få svar på, om den og den variant, som, vi tror, er sygdomsfremkaldende, nu også rent faktisk er det.«

Med et DNA-arkiv over alle afdøde, vil vi kunne få svar på, hvordan genetikken ser ud for mennesker, som dør pludseligt, fortæller Michael Christiansen. Vi vil tilsvarende blive klogere på i hvilke tilfælde en genvariant, som ellers er relateret til en sygdom, ikke ser ud til at bryde ud.

Derudover mener han, at man vil kunne spare meget – både økonomisk og for den enkelte – med den viden, som et biologisk rigsarkiv vil kunne give os.

Læs mere:Kan dyr sørge over de døde?

Ideen om et DNA-arkiv er god, hvis man spørger professor Lars Bolund. Ikke kun fordi man meget hurtigt ville kunne indsamle et meget stort og pålideligt datasæt, men også fordi det løser nogle af de etiske problemstillinger, der ellers kan være ved at indhente oplysninger om enkeltpersoners gener.

»Et tilbagevendende argument lyder, at information om vores genvarianter og risiko for sygdom måske kan blive misbrugt – men man kan ikke gøre skade på nogen, som er død. På den måde er det her en løsning, som kan imødegå nogle af den type indvendinger,«siger Lars Bolund, som arbejder ved Institut for Biomedicin på Aarhus Universitet.

Andre vanskelige problemer eksisterer dog stadig. Selvom du ikke selv er i live til at blive påvirket af oplysninger i dit genom, er dine slægtninge det jo ofte stadig, skriver Videnskab.dk.

»Man kunne forestille sig, at vi samler genomer fra en masse døde, og så viser det sig, at 100 af dem har genetiske varianter for nogle alvorlige sygdomme. Skal deres børn så have besked?«spørger Michael Christiansen og fortsætter:

»Man kunne måske være tilbøjelig til at sige, at okay, så glemmer vi bare alt om, at vi nogensinde har set de varianter, og så er problemet løst. Men er det etisk forsvarligt?«

De etiske dilemmaer og udfordringerne omkring den politiske ramme, der skal til, før en DNA-bank kan blive virkelighed, kan du læse mere om i artiklen påVidenskab.dk..

Andre kildereferanser

Jyllands-Posten VIP – Teater, Dans & Ballet . . . . . *19. april – 17:28*
Nordjyske – Nyheder . . . . . *18. april – 20:59*

BMJ editor Fiona Godlee takes on corruption in science

CBC –19. april 15:01

'Medicine and science are run by human beings, so there will always be crooks,'says journal editor

Dr. Fiona Godlee, editor of BMJ, playfully demonstrates the hidden strings drug companies use to influence scientific research. (CBC)

About The Author

Kelly Crowe is a medical sciences correspondent for CBC News, specializing in health and biomedical research. She joined CBC in 1991, and has spent 25 years reporting on a wide range of national news and current affairs, with a particular interest in science and medicine.

It's unusual to watch one of the world's most powerful editors in scientific publishing play with a marionette puppet.

But Dr. Fiona Godlee, editor of the BMJ, specializes in the unexpected.

The puppet she's holding is dressed as a doctor, complete with a stethoscope around its neck. Its strings represent the hidden hand of the pharmaceutical industry.

Godlee keeps it on her desk to remind her of the dark forces at work in science and medicine. And she is blunt about the results.

"I think we have to call it what it is. It is the corruption of the scientific process."

There are increasing concerns these days about scientific misconduct. Hundreds of papers are being pulled from the scientific record, for falsified data, for plagiarism, and for a variety of other reasons that are often never explained.

Sometimes it's an honest mistake. But it's estimated that 70 per cent of the retractions are based on some form of scientific misconduct.

"Medicine and science are run by human beings, so there will always be crooks," Godlee says.

"There will be commercial pressures, academic pressures, and to pretend otherwise is absurd. So we have to have many more mechanisms, much more skepticism, and much more willingness to challenge."

As the editor of one of the oldest and most influential medical journals, Godlee is leading several campaigns to change the way science is reported, including opening up data for other scientists to review, and digging up data from old and abandoned trials for a second look.

She has strong words about the overuse of drugs, and the influence of industry on the types of questions that scientists ask, and the conclusions that are drawn from the evidence.

"It's not my job to be popular, I'm very clear about that," she says from her office in the historic British Medical Association building in central London.

"She's taken her licks, as it were, because other people don't like the level of transparency she is bringing to the process," says medical writer Dr. Ivan Oransky, who writes about flawed science on his blog Retraction Watch.

Dr. Ivan Oransky of Retraction Watch tries to shine a light on science's dirty secrets. (CBC)

Based in New York City, Retraction Watch is fascinating reading for anyone interested in what goes on behind science's closed doors.

Every day there are one or two new examples of research that has been quietly withdrawn.

"People leak us things, people send us documents, we get reports from universities that aren't supposed to see the light of day," Oransky says.

"There does remain a really entrenched problem with institutions, when asked to investigate allegations of misconduct. They will tend to close down, will tend to prefer not to investigate, will tend to hide any evidence and see it as a damage to their own reputation if they were to take action," Godlee says.

So retractions are, paradoxically, a good thing.

"I think this trend toward journal retraction is a positive sign against what we've known to be going on for quite a long time," Godlee says.

Godlee admires Oransky's work, although they've never met.

"It's doing a good and important job," she said. "It's doing more than retractions, it's looking at misconduct in research."

In that sense, Godlee says, they are on the same page. But Godlee says the journals themselves are part of the problem.

It is up to the journals to decide what science gets published, and they usually choose positive findings. That means a study showing that a treatment or theory doesn't work rarely makes it into a high-profile journal.

It's called "publication bias" and it distorts the scientific record.

"All along the way, the system tends to encourage a sort of optimistic positive view of new drugs and drug treatments generally," Godlee says

Her solution? Transparency. Throw open the windows, let everyone see everything.

"I do have a belief in the fundamentality of science to correct itself. We can't do that under the blanket of secrecy," she says.

"We also need to have more independence in science, less commercial bias, less ability of academics to follow their own biases. All sorts of checks and balances of that sort. But in the end, transparency, to me, seems like the only correct route."

Her policy is already changing the scientific record.

Just last week, the BMJ published the results of a second look at a long abandoned clinical trial testing the hypothesis that a diet high in unsaturated oil would reduce heart disease and death.

The new conclusion? Not only did corn oil not improve health, the data also showed a higher risk in death from the high corn oil diet.

Two years earlier, the BMJ published an analysis of another lost trial, by the same team. After digging the data out of a box in an old garage, they came to a similar conclusion about the effect of a so-called ”healthy“ oil on health.

Guest Post: Scientists aren't always the best people to evaluate the risks of scientific research

Practical Ethics – Home –19. april 11:52

Written by Simon Beard, Research Associate at the Center for the Study of Existential Risk, University of Cambridge

How can we study the pathogens that will be responsible for future global pandemics before they have happened? One way is to find likely candidates currently in the wild and genetically engineer them so that they gain the traits that will be necessary for them to cause a global pandemic.

Such 'Gain of Function' research that produces 'Potential Pandemic Pathogens' (GOF-PPP for short) is highly controversial. Following some initial trails looking at what kinds of mutations were needed to make avian influenza transmissible in ferrets, a moratorium has been imposed on further research whilst the risks and benefits associated with it are investigated.

The group Scientists for Science argues that such caution is not necessary and that it is damaging the progress of vital research into infectious diseases. They also point out that "The results of such research are often unanticipated and accrue over time" making the analysis of risks and benefits "difficult to assess accurately."

This is no understatement. So far two assessments of the risks associated with GOF-PPP research have been produced. They give a range of estimates for the probability of a pandemic resulting from accidental release of engineered pathogens from a laboratory between 1 in 1,000 (Lipsitch and Inglesby 2014) and 1 in 33,000,000,000 (Fouchier 2015) per laboratory year.

Despite this, our natural tendency towards precaution regarding this research may be damaging. One recent study by the National Bureau of Economic Research found that the expected costs associated with global influenza, at around 0.7% of global income, are comparable with the long-term costs of climate change. Much of this cost results from the expected 700,000 deaths associated with influenza per year, mostly amongst vulnerable groups in less developed countries.

How then are we to make progress on these issues?

Scientists for Science have proposed that the only way to make progress is for scientists to debate the ethics of GOF-PPP research between themselves. However, they make two claims that do not stand up. Firstly they argue that, "If there is going to be further discussion about these issues, we must have input from outside experts with the background and skills to conduct actual risk assessments based on specific experiments and existing laboratories."

The problem is that, due to its novelty, GOF PPP research is not amenable to risk assessments based on specific experiments and existing laboratories. For instance, one of the big differences between the two assessments of the risks of GOF PPP research that have been produced is how they work out the likelihood that a lab worker might become infected with a pathogen they are studying.

The more pessimistic Lipsitch and Inglesby as-

sume that the probability of such an occurrence will reflect the background rate of laboratory infections. They point out that "Data on the probability of a laboratory-associated infection in U.S ... show that 4 infections have been observed over <2,044 laboratory-years of observation, indicating at least a 0.2% chance of a laboratory-acquired infection per BSL3 laboratory-year."

The more optimistic Fouchier on the other hand points out that none of these infections occurred at the, safer, BSL3+ laboratories at which GOF PPP research takes place and that none of them involved viruses. He therefore argues that "the risks of LAIs associated with work on viral pathogens should thus be estimated as less than 1 per 2,044 ($<5 \times 10-4$ per laboratory-year)."

Both of these estimates are flawed. Whilst Fouchier is right to point out that infections that occur in lower security laboratories cannot be used to estimate the risk in higher security laboratories, he is wrong to assume that just because there have been no accidents so far at such laboratories they are therefore safe. Only a tiny proportion of the research in infectious pathogens is conducted at such laboratories and it may have been that scientists working in these institutes have just been lucky thus far.

As Gordon Woo, a professional catastrophist at Risk Management Solutions, points out, "All manner of unforeseen surprising catastrophes have been close to occurring, but ultimately did not materialize." Our failure to take account of such counterfactual catastrophes, and to focus only on specific experiments and existing laboratories, can easily lead us to underestimate catastrophic risks.

In fact there have recently been three events, each of which could be seen as a narrowly avoided catastrophe, relating to smallpox, anthrax, and avian influenza. These events did not lead to any infections and it could be argued that they did not pose significant risk of infection either. However, they do provide the basis for a counterfactual analysis of the risks associated with GOF PPP research. Unfortunately such counterfactual analysis does not come naturally to practitioners in the life sciences, who are trained to look for evidence of what is, rather than what might have been.

This leads me to the second troubling statement from Scientists for Science. They argue that discussion about the future of GOF PPP research would be best facilitated by scientific organizations such as "the International Union of Microbiological Societies or the American Society for Microbiology, " or national academies, "such as the National Academy of Sciences, USA." However, some of the most pressing concerns with such research fall outside of the domain of the life sciences.

Since 1700 there have been 6 severe flu pandemics (associated with over 2 million excess deaths), one of which has been 'very severe' (the 1918 flue pandemic, which caused around 50 million excess deaths). This suggests a natural occurrence of severe flu pandemics that is far in excess of even the most pessimistic estimates about the risk of GOF-PPP research. Therefore, if there is even a moderate chance that GOF-PPP research will produce an effective treatment for pandemic influenza it is likely to prove worthwhile on a risk-benefit analysis.

However, finding a treatment for pandemic influenza may not be the most economically viable form of GOF PPP research. Far more lucrative would be research into seasonal influenza, providing more effective treatments for a small number of people in the developed world.

On the other hand the costs a pandemic of genetically engineered super flu would be borne disproportionately by people who cannot afford effective medical treatment. This mismatch between those who are most likely to reap the benefits of GOF PPP research and those who are most likely to bear the costs creates a moral objection to GOF PPP research that is far more serious than the difficulties in assessing its associated risks and benefits.

Most scientists would aspire to producing research that will be to the benefit of all of humanity; however, sadly, this is not always under their control. It forms part of a wider discussion about the funding of scientific research and the allocation of global healthcare resources. Usually this discussion is about who gains the benefits from medical research; however with GOF-PPP research the debate also extends to who is likely to bear the potential costs of that research as well.

Meanwhile debate within the scientific community shows no sign of abating. Perhaps the time has come when, despite its controversial status, the ethics of GOF-PPP research needs to be debated outside of the scientific community as well.

Forskar om fuskande studenter

svt.se - Värmland –19. april 10:49

Plagiat är den vanligaste typen av fusk och det här intresserar en lärare vid Karlstads Universitet som nu forskar i hur studenter hanterar sitt skrivande.

– Tesen är väl att studenter som upplever stora utmaningar i skrivandet i en del fall tar genvägar på olika sätt. De hittar egna strategier att lyckas med sina studier och det är det jag vill veta mer om, säger Camilla Grönvall

I cirka tio år har Camilla Grönvall arbetat med studenters skrivande, bland annat med skrivhandledning där studenter får råd och stöd i det akademiska skrivandet. Det här har väckt hennes intresse för hur studenter hanterar svårigheter och lett till ett femårigt avhandlingsprojekt vid Karlstads universitet.

– Många studenter som kommer hit möter ett krav i skrivandet de inte är beredda på. Många uttalar väldigt tydligt att de inte fått med sig så mycket från grundskolan och gymnasiet som de känner krävs här, säger Grönvall.

Plagiat är den vanligaste typen av fusk vid de svenska lärosätena och Camilla Grönvall menar att det saknas kunskap om hur studenter tänker och arbetar med sin skrivprocess. Hon vill ta reda hur studenter konkret gör när de använder andras texter. Hon undrar bland annat om de mestadels kopierar genom copy-paste eller använder egna ord och formuleringar.

– Jag kommer göra en undersökning som innehåller flera delar, men bland annat kommer jag med en speciell sorts dataprogram, eller tangentloggningsprogram, kunna studera hur en text växer fram i datorn och där kan man bland annat se hur exempelvis stora inkopierade partier kommer in i texten, förklarar Grönvall.

En pilotstudie hon gjort väcker, tillsammans med tidigare forskning, flera frågor. En handlar om vilket privat stöd studenter får i sitt skrivande av till exempel en hjälpsam mamma eller pappa och nu vill Camilla Grönvall ta reda på i vilken omfattning det förekommer:

– Att ha stöttande resurser med familj eller vänner kan ju vara en tillgång vid studierna men det finns ju en gräns för vad som är ok. Hur mycket får man till exempel hjälpa till med en skrivuppgift som förälder?

Vad är problemet med för mycket hjälp?

– Problemet blir ju att vi som lärare till slut kanske inte vet vem som har skrivit texten som lämnas in och då är det ju inte tillåten hjälp längre, säger Grönvall.

Forskningsetiske utfordringer ved kvalitative studier

Sykepleien –19. april 09:08

I vitenskapelige artikler finner man sjelden en inngående redegjørelse for forskningsetiske vurderinger.

Vanligvis gis det kun en kort konstatering om at studien er i tråd med gjeldende reguleringer og er godkjent av Regional Etisk Komité (REK) eller Norsk samfunnsvitenskapelig datatjeneste (NSD). Men, for at en studie skal bli godkjent har den gjennomgått en rekke forskningsetiske vurderinger. I det følgende vil jeg presentere noen forskningsetiske betraktninger og bruke eget doktorgradsarbeid om «Prioriteringshensyn i intensivavdeling» som bakteppe, sammen med relevant litteratur, publikasjoner fra Nasjonale Forskningsetiske Komiteer og forskning som aktualiserer noen utfordringer (1 – 4).

Reguleringer

Historien har vist at hensynet til forskningssubjektene ikke er en selvfølge (2). Av den grunn finnes det flere reguleringer som ivaretar forskningssubjekter og forskningsetiske hensyn ved gjennomføring av medisinske og helsefaglige forskningsprosjekter. Toneangivende er Helsinkideklarasjonen, som de fleste andre reguleringer bygger på (5). I Norge regulerer Helseforskningsloven forskning innen medisin og helsefag (6). Da denne loven kom i 2008 forenklet den prosedyrene for godkjenning av forskningsprosjekter. En tommelfingerregel er at alle prosjekter som involverer sårbare grupper skal godkjennes i REK. Sårbare grupper defineres oftest som pasienter. Her kan det være aktuelt å forespørre REK ved tvil. Prosjekter som krever konsesjon fra taushetsplikt, skal vurderes særskilt i forhold til dette. De prosjekter som kun skal godkjennes av NSD, søkes direkte dit. Dette kan gjelde for eksempel prosjekter som involverer tidligere pasienter, pårørende og foreldre, eller kun helsepersonell.

Kvalitativ forskning

«Kvalitative metoder bygger på teorier om fortolkning og menneskelige erfaringer» (1, s. 7). I mitt doktorgradsarbeid var jeg opptatt av å få fram dybdekunnskap om hvilke handlinger og valg intensivleger og intensivsykepleiere sto ovenfor i vanskelige prioriteringsspørsmål om å avgrense intensivbehandling. Til å gjennomføre en slik studie var kvalitativ metode et hensiktsmessig valg. På bakgrunn av studiens problemstillinger var det to svært mye brukte datainnsamlingsmetoder som var relevante; deltakende observasjon og dybdeintervju. I kjølvannet av metodevalg og datainnsamlingsstrategier fulgte flere forskningsetiske vurderinger.

Hensynet til forskningssubjektene

Det bærende element i forskningsetikk er hensynet til forskningssubjektene og deres integritet. Et avgjørende prinsipp for å kunne ivareta forskningspersoners integritet er det frivillige informerte samtykke. Men, samtykke er ikke tilstrekkelig. Forskningen skal frambringe kunnskaper som enkeltpersoner eller gruppen av personer har nytte av, samt at forskningen skal innebære ingen eller liten risiko for aktørene. Forskningssubjekters sårbarhet, eller sårbarhet hos personer som indirekte blir involvert i forskningen, har stor betydning for hvordan man tar de forskningsetiske vurderingene (1 – 3,5,6). I mitt doktorgradsarbeid var utfordringen at jeg gjennom å bruke deltakende observasjon fikk tilgang til opplysninger om sårbare, ikke samtykkekompetente pasienter, til tross for at fokuset mitt var leger og sykepleiere som ga frivillig og skriftlig informert samtykke (1). En måte å løse slike dilemmaer på er å innhente samtykke fra pårørende, som da på vegne av den syke, kan nekte deltakelse. Dette ble alternativet i min studie, sammen med konsesjon fra taushetsplikten. Det er viktig å merke seg at forsker er underlagt taushetsplikt, og i min studie ble det undertegnet taushetserklæring i de aktuelle intensivavdelinger (1).

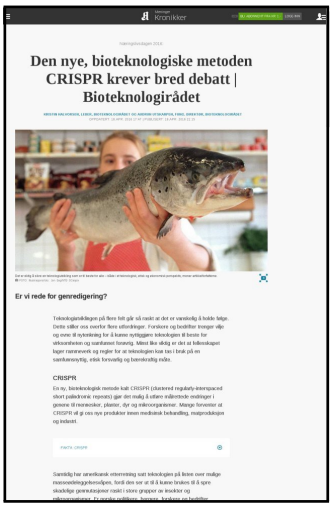
På den annen side var ikke samtykke fra pårørende en forskningsetisk uproblematisk løsning, blant annet begrunnet i faren for at pårørende feilaktig kunne få den oppfatning at deres kjære var med i et forskningsprosjekt. Det er også slik at pårørende ikke alltid har samme oppfatning som pasienten ville ha hatt. Det viser seg også at REK'ene vurderer forskjellig i saker som omhandler observasjon av helsepersonell i kliniske avdelinger, der det vil være mulig å få innsyn i taushetsbelagt informasjon om pasienter. I en annen norsk observasjonsstudie fra klinisk praksis med fokus på sykepleieres ansvarspraksis har det, så vidt det framkommer i studien, ikke vært etterspurt samtykke fra verken pasienter eller pårørende. Kun frivillig, skriftlig samtykke fra helsepersonellet involvert, er innhentet (7). Hem et al. løfter fram i en artikkel i Nursing Ethics, hvordan strenge forskningsetiske krav om samtykke nesten satt stopper for å gjennomføre deltakende observasjoner i en akuttpsykiatrisk avdeling (4). I artikkelen argumenterer Hem et al. for at det i enkelte tilfeller kan bli så vanskelig å slippe til i et forskningsfelt, at verdifull forskning med liten risiko for pasienten, men med stor betydning kan gå tapt.

Den nye, bioteknologiske metoden CRISPR krever bred debatt | Bioteknologirådet

Aftenposten.no - Kronikker –18. april 19:15

Av: Jon Eeg

Kristin Halvorsen, leder, Bioteknologirådet og Audrun Utskarpen, fung. direktør, Bioteknologirådet


Den nye, bioteknologiske metoden CRISPR krever bred debatt | Bioteknologirådet

Er vi rede for genredigering?

Dette skiller CRISPR fra tradisjonelle former for genmodifisering, som i hovedsak gjøres ved å sette inn gener fra andre organismer, og derfor er sporbare. Men selv med mer presise metoder er genetikk komplisert. Genene virker sammen på komplekse måter og i samspill med miljøet. Det kan være vanskelig å si med full sikkerhet at det å endre et gen ikke har ukjente bieffekter.

Til beste for alle

Fordi CRISPR-metoden er enklere og mer målrettet enn tidligere metoder for å endre i gener, gjør den det lettere for forskere å utforske nye spørsmål. For eksempel: Hva skjer om vi «skrur av» et gen som bidrar til sykdom i en mus?

Kan slike endringer løse et problem – og kan det hende at de skaper et nytt?

Kraftfulle teknologier kan ofte brukes til både gode og dårlige formål. Derfor er det viktig å sikre en teknologiutvikling som er til beste for alle – både i et teknologisk, etisk og økonomisk perspektiv. La oss komme med to eksempel med stor relevans for Norge: Fra oppdrettsnæringen og kreftforskningen.

Ansvarlig og bærekraftig

Den norske oppdrettsnæringen har vunnet et stort marked i utlandet blant annet ved å være åpen for nyvinninger og ved å jobbe målrettet med avl og genetikk. Likevel sliter fiskeoppdretterne med problemer. To av de største er lakselus som skader fiskebestanden, og oppdrettsfisk som rømmer og formerer seg med villaks. Hvordan kan forskning og teknologisk utvikling bidra?

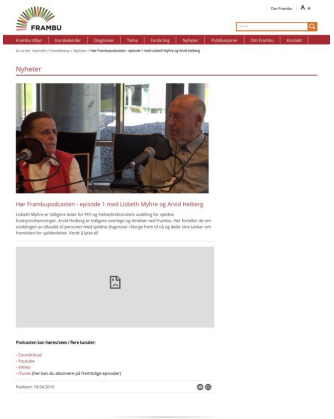
Det har vært gjort flere forsøk på å utvikle metoder for å gjøre oppdrettsfisken steril, så den ikke kan formere seg med villaks hvis den rømmer. Nå har forskere i Bergen funnet et gen som er sentralt for kjønnsmodning i laks, ved hjelp av CRISPR. De prøver å lage en vaksine som påvirker dette genet slik at laksene ikke blir kjønnsmodne. Dermed kan suksessfullt vaksinerte oppdrettsfisk ikke formere seg.

Andre kildereferanser
Aftenposten.no – Kronikker . . . . . *18. april – 21:19*

Hør Frambupodcasten – episode 1 med Lisbeth Myhre og Arvid Heiberg

Frambu – Nyheter –18. april 15:55

Lisbeth Myhre er tidligere leder for FFO og Helsedirektoratets avdeling for sjeldne funksjonshemninger. Arvid Heiberg er tidligere overlege og direktør ved Frambu. Her forteller de om utviklingen av tilbudet til personer med sjeldne diagnoser i Norge frem til nå og deler sine tanker om fremtiden for sjeldenfeltet. Verdt å lytte til!



Får forsker-refs

Dagbladet, side 6 –18. april
Av: Torun Støbakk

Gryende barnehageopprør mot statsråden BARNEHAGE Torbjørn Røe Isaksen beskyldes for å plukke forskningsresultater etter egen smak i omstridt barnehagemelding.

Et barnehageopprør har reist seg etter at kunnskapsminister Røe Isaksen i midten av mars la fram stortingsmeldinga om barnehager.

Pedagogikk-professor Solveig Østrem ved Høgskolen i Lillehammer beskylder ministeren for å bruke eksempler fra Oslo til å forsvare meldinga som skal gjelde hele landet. Andre kritiserer ministeren for å legge fram en politikk som ikke er faglig fundert.

Påstandene kommer bare en drøy uke etter at beskyldninger om statistikk-feilbruk haglet mot regjeringskollega Sylvi Listhaug (Frp)

– De legger til grunn en svartmaling av situasjonen og setter inn tiltak ut fra et veldig smalt utvalg forskere, sier Østrem om regjeringen.

En av tingene hun reagerer på, er at ministeren flere ganger har forsvart meldinga ved å vise til statistikk fra Oslo-skolen som viser at 25 prosent av alle barn i Oslo starter på skolen med så dårlige språkkunnskaper at de ikke klarer å følge undervisningen.

Hun mener det er det misvisende å bruke tallene til å si noe om barnehage, og at det er barn som ikke har gått på barnehage som sliter mest med språket. Oslo-rektor Siri Ytterstad er enig i den siste beskrivelsen.

– Lemfeldig – Barn som har gått i barnehage siden de var 2 – 3 år opplever vi at har vært lenge

nok i barnehage til at de får inn begrepsapparatet, men problemene er knyttet til barn som har vært kort tid i barnehage eller ikke har gått i barnehage, sier Ytterstad, som er rektor ved Veitvet skole.

Førsteamanuensis Anne Greve ved Høgskolen i Oslo og Akershus sier dette:

– Dette er er lemfeldig bruk av statistikk fra Røe Isaksen om Oslo-skolen. Eksemplet er bare brukt muntlig av Røe-Isaksen, og står ikke i selve meldinga.

Kritikerne mener Røe Isaksen i meldingen legger opp til å gjøre barnehagene mer like skolene, gir barna mindre tid til lek og snikinnfører læringsmål under betegnelsen «veiledende norm». Hovedtrekket er at regjeringen vil erstatte lek i barnehagene med mer fag og resultatkrav, mener de.

Dette avviser Røe Isaksen, som sier meldinga verken innfører fag eller resultatkrav, men at den bygger på læring gjennom lek.

Avvises – Stortingsmeldingen bygger på de nasjonale tallene som er 9,1 prosent, men det jeg har sagt som et eksempel er at rundt 25 prosent av elevene i Oslo er så dårlige i norsk når de begynner på skolen at de ikke klarer å følge undervisningen. Tallet brukes ikke engang i meldinga, så spørsmålet er om det er illegitimt å bruke disse tallene, og det mener jeg det ikke er, sier Røe-Isaksen.

En analyse av hvor mange av barna som sliter med norsk som ikke har gått i barnehage – slik Østrem etterlyser – eksisterer trolig ikke.

– Vi har ikke individdata på disse personene så vidt jeg vet, men SSB-tall fra 2015 viser at 98 prosent av femåringene med minoritetsbakgrunn i Oslo gikk i barnehage, sier Røe-Isaksen.

– Du beskyldes også for «cherrypicking»

– Jeg avviser på det sterkeste at vi har cherrypicket eller manipulert forskningen for å passe vårt virkelighetsbilde, men forskningen kan allikevel ikke tas til inntekt for tiltakene som foreslås. De politiske standpunktene er jo våre, men stortingsmeldingen er ikke basert på å plukke ut tilfeldige studier som bare skal underbygge vårt syn.

– Hvis man skal komme om påstander om juks med forskning, som er en veldig alvorlig påstand, må man kunne underbygge det. Hvis ikke er det akademisk uredelighet.

«DETTE ER ER LEMFELDIG BRUK AV STATISTIKK.

ANNE GREVE,

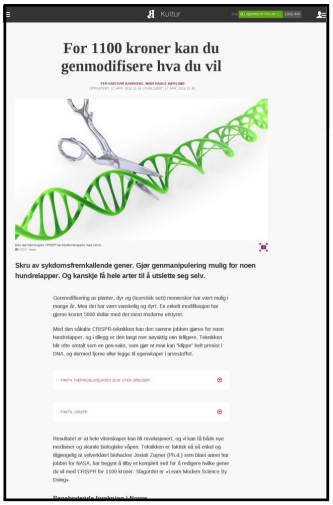
Førsteamanuensis“

For 1100 kroner kan du genmodifisere hva du vil

Aftenposten.no - Kultur –17. april 21:47

Av: Per Kristian Bjørkeng, Mina Hauge Nærland

Skru av sykdomsfremkallende gener. Gjør genmanipulering mulig for noen hundrelapper. Og kanskje få hele arter til å utslette seg selv.



Genmodifisering av planter, dyr og (teoretisk sett) mennesker har vært mulig i mange år. Men det har vært vanskelig og dyrt. En enkelt modifikasjon har gjerne kostet 5000 dollar med det mest moderne utstyret.

Med den såkalte CRISPR-teknikken kan den samme jobben gjøres for noen hundrelapper, og i tillegg er den langt mer nøyaktig enn tidligere. Teknikken blir ofte omtalt som en gen-saks, som gjør at man kan “klippe” helt presist i DNA, og dermed fjerne eller legge til egenskaper i arvestoffet.

Hør flere debatter og foredrag om CRISPR og bioteknologi på Næringslivsdagen 2016: Uten grenser tirsdag 19. april. Se mer om programmet på facebook.com/aftenposten og følg konferansen direkte på ap.no.. Les også Kristin Halvorsen, leder for Bioteknologirådet, i morgen: “Kan vi si med full sikkerhet at det å endre et gen ikke har ukjente bieffekter¿‘ CRISPR står for Clustered regularly-interspaced short palindromic repeats. Teknikken

blir ofte omtalt som en gen-saks, som gjør at man kan ”klippe“ helt presist i DNA, og dermed fjerne eller legge til egenskaper i arvestoffet.

Resultatet er at hele vitenskaper kan bli revolusjonert, og vi kan få både nye medisiner og skumle biologiske våpen. Teknikken er faktisk nå så enkel og tilgjengelig at selverklært biohacker Josiah Zayner (Ph.d.) som blant annet har jobbet for NASA, har begynt å tilby et komplett sett for å redigere hvilke gener du vil med CRISPR for 1100 kroner. Slagordet er «Learn Modern Science By Doing».

Banebrytende forskning i Norge

I Norge har en rekke forskningsmiljøer, blant annet på universitetene i Oslo, Bergen, Trondheim og NMBU på Ås, begynt å bruke CRISPR. Forskningsgruppen til Anna Wargelius ved havforskningsinstituttet i Bergen har brukt metoden til å lage en oppdrettslaks uten kjønnsceller, slik at den ikke kan formere seg hvis den rømmer.

De planlegger å lage en vaksine basert på resultatene.

Det er foreløpig ikke tillatt å ta i bruk slik genmodifisert laks i Norge eller EU, men den kan brukes i land med mindre strengt regelverk, som USA, Japan og Brasil.

Først på menneskers sykdom

Forsker Simon E. Nitter Dankel ved Klinisk institutt 2 ved UiB har bidratt i de aller første studiene som brukte metoden på menneskeceller for å korrigere en sykdomsmutasjon.

– Det er en spennende utvikling vi har vært med på. CRISPR er veldig positivt for medisinsk forskning og vil gi ny forståelse og nye behandlinger. Dette kommer til å bli standard når man skal endre DNA, sier han.

For å forstå hva han har forsket på, må vi ned til de minste bestanddelene av genene våre:

– DNA består av over rundt 3,3 milliarder byggestener, og medfødte ombyttinger av enkelte av disse kan øke risikoen for å utvikle en bestemt sykdom. Du kan for eksempel ha økt risiko med en A (disse byggestenene gis bokstav-navn: A, T, C eller G) der andre har en T, forklarer Dankel.

Med CRISPR kan man klippe ut en “uheldig” A og erstatte med en T.

– Vi gjorde de første analysene i 2013 for å vise hvordan en bestemt bokstavombytting i DNA bidrar til diabetes. Vi brukte CRISPR og lykkes i å gi fettcellene en bedre funksjon.

Dankel samarbeider med miljøer rundt Harvard og MIT i Boston, og arbeidet ble ledet av Melina Claussnitzer.

Ny vitenskap

CRISPR ble første gang beskrevet vitenskapelig i 2013, og er faktisk basert på naturens egne forsvarsmekanismer. Deler av den aller nyeste utgaven av verktøyet ble funnet i en database over bakterier, som bruker muligheten til å klippe og lime i DNA til å forsvare seg mot virus.

I motsetning til tradisjonell genmodifisering er CRISPR både mer pålitelig og presis. I tillegg er det altså billig og enkelt, og forskerne regner med at enhver masterstudent i biologi vil være i stand til å genmodifisere om kort tid. Dermed øker også risikoen for at genmanipulering kan bli brukt på farlige måter.

Foreløpig er det ikke kommet noe gjennombrudd som gjør det enkelt å redigere bort sykdomsfremkallende gener i levende mennesker. I dyr og planter, derimot, stiller det seg annerledes.

Forskerne har oppdaget at CRISPR kan brukes til såkalt gene drive, som på norsk kan oversettes med genkjøring. Dette er en metode for å injisere et gen som så kan “smitte” en hel populasjon gjennom arv. Et normalt CRISPR-redigert gen som ikke gir arten store fordeler vil normalt bli sjaltet ut gjennom naturlig seleksjon. Med genkjøring, derimot, spres det injiserte genet som en gressbrann nedover i generasjonene, til hele populasjonen har det.

Forskere ved flere universiteter jobber allerede med tanke på genkjøring av malariamygg. Hvis arten gradvis utrydder seg selv og en million liv vil være spart årlig. Det forskerne ikke vet så mye om, er hvilke roller malariamyggen spiller for andre arter i økosystemet, og om en slik genmodifisering vil kunne få uante negative konsekvenser.

Etisk vanskelig

I september 2015 publiserte Claussnitzer, Dankel og de andre forskerne en ny forskningsartikkel i New England Journal of Medicine.

– Vi brukte samme metode på en genetisk variant som er blitt knyttet til økt kroppsvekt. Etter forsøkene fikk de manipulerte fettcellene økt varmefunksjon og bedre forbrenning, bare ved å bytte ut en enkelt bokstav i DNA, forklarer Dankel.

– Dere har forøkt dette på en og en celle. Kan man bruke CRISPR på alle fettcellene av denne typen hos en pasient?

– Nei, det vi driver med er grunnforskning. Dette er vanskelig å få til i en levende organisme. Foreløpig finnes det ikke noen metode for å endre DNA i bare en bestemt celletype inne i et menneske. Da må du manipulere eggceller, eller stamceller man dyrker i laboratoriet som så overføres til et organ i kroppen.

Kina skaper strid

Men CRISPR blir allerede brukt på befruktede eggceller. I Kina har forskere nå f or annen gang brukt CRISPR-metoden på menneskelige embryo. Forskerne mener arbeidet er etisk forsvarlig siden de befruktede eggcellene hadde en kromosomfeil som gjør at de ikke kunne blitt til mennesker uansett, og donorene hadde godkjent forsøkene.

Studien gikk ut på å gjøre fostrene resistente mot hiv. I forsøket rapporteres det at fire av 26 embryo ble vellykket modifisert.

Nylig godkjente britiske myndigheter en lignende studie. Britiske forskere har fått tillatelse til å bruke CRISPR på embryo for å forstå hvorfor noen svangerskap ikke fører frem.

Siden CRISPR ble oppdaget i 2012, har interessen fullstendig eksplodert. Det store spørsmålet er om alle som nå får verktøyet i hendene vil bruke det like konstruktivt.

Biofysiker Josiah Zayner står bak gjør-det-selv-med-CRISPR-pakker og selger dem fra 130 dollar på nettstedet Indigogo. Du kan for eksempel teste CRISPR-teknikken på gjær, eller bakterier.

– Responsen har vært overveldende, folk er helt ville etter å drive med vitenskap, skriver han på epost etter at Aftenposten tar kontakt.

Det er uklart om Zayner har sendt pakkene til kundene enda, frem til nå har man kunnet forhåndsbestille.

– Jeg vokste opp på en bondegård og var heldig nok til å kunne gå på universitetet og til sist ta min Ph.d. Mange har ikke den muligheten. Hvor mange briljante vitenskapsmenn finnes det ikke der ute som ikke fikk den sjansen jeg fikk? Spør Zayner.

– Er du ikke redd noen vil misbruke teknologien?

– Frykten for at genmodifisering skal gå galt er svært overdrevet.

Barnehageeksperter kritiserer kunnskapsminister Isaksens bruk av forskning

Dagbladet.no - Innenriks –17. april 21:02
Av: Torun Støbakk

– Hvis man skal komme om påstander om juks, må man kunne underbygge det, svarer ministeren.


Dagbladet Nyheter

Barnehageeksperter kritiserer kunnskapsminister Isaksens bruk av forskning

- Hvis man skal komme om påstander om juks, må man kunne underbygge det, svarer ministeren.

(Dagbladet): Anklagene har haglet fra fagmiljøene etter at kunnskapsminister Torbjørn Røe Isaksen i midten av mars la fram stortingsmeldinga om barnehager.

Pedagogikk-professor Solveig Østrem ved Høgskolen i Lillehammer beskylder ministeren for å bruke eksempler fra Oslo til å forsvare meldinga som skal gjelde hele landet.

Andre barnehage-eksperter kritiserer dessuten ministeren for å legge fram en politikk som ikke er faglig fundert, og mener han driver cherrypicking, å plukke forskningsresultater etter egen smak. Isaken avviser anklagene.

Påstandene kommer bare en drøy uke etter at beskyldninger om statistikk-feilbruk haglet mot regjeringskollega Sylvi Listhaug (Frp).

– De legger til grunn en svartmaling av situasjonen og setter inn tiltak ut fra et veldig smalt utvalg forskere, sier Østrem til Dagbladet.

Det hun reagerer mest på, er at ministeren flere ganger har forsvart meldinga ved å vise til statistikk fra Oslo-skolen som viser at 25 prosent av alle barn i Oslo starter på skolen med så dårlige språkkunnskaper at de ikke klarer å følge undervisningen.

– Nærmest konstruert

Hun mener det er det misvisende å bruke tallene til å si noe om barnehage, og at barna som ikke har gått på barnehage som sliter mest med språket.

Det sa også Oslo-rektor Siri Ytterstad ved Veitvet skole i et intervju med Klassekampen i starten av april. Overfor Dagbladet bekrefter hun beskrivelsen:

– Barn som har gått i barnehage siden de var 2–3 år opplever vi at har vært lenge nok i barnehage til at de får inn begrepsapparatet, men problemene er knyttet til barn som har vært kort tid i barnehage eller ikke har gått i barnehage, sier Ytterstad.

Østrem mener det er tendensiøst av Røe Isaksen å bruke eksemplet.

– Det er en måte å snakke på som tar utgangspunkt i «andres barn». Regjeringen spør hvordan kan vi unngå denne katastrofen som ikke er reell, i stedet for å se på hvordan vi kan lage en bedre barnehage for alle barn. Det er ingen ambisjoner for barnehagen som går ut fra at de fleste barn har det ganske bra, sier Østrem til Dagbladet.

Hun mener dessuten at hele stortingsmeldinga er basert på et altfor tynt faggrunnlag, og får støtte fra blant annet Utdanningsforbundet.

Anne Greve, førsteamanuensis ved Høgskolen i Oslo og Akershus, er også kritisk til måten forskningen er brukt på i meldinga.

– Jeg synes det er veldig snever bruk av forskning i stortingsmeldinga, og veldig mye forskning som ikke er nevnt i det heletatt, og som det er rart at ikke er nevnt. Når man plukker hvilken forskning man har lyst til å bruke på den måten, synes jeg svekker troverdigheten til meldinga. Dessuten står det flere steder i meldinga "forskning viser at" uten at det vises til hvilken forskning som sier det, sier hun.

– Reagerer

I likhet med Østrem reagerer også Greve på det hun kaller lemfeldig bruk av statistikk fra Røe Isaksen om Oslo-skolen. Eksemplet er kun brukt muntlig av Røe-Isaksen, og står ikke i selve meldinga.

Greve mener likevel at han burde vært mer forsiktig med å bruke Oslo-tallene.

– Det kan godt være at han ikke bruker statistikken i selve meldinga, men alt han går ut og sier muntlig skal skape en opinion for eller mot meldin-

ga, og de aller fleste folk i Norge leser ikke selve meldinga. Dette er noe folk reagerer veldig på ute i distriktene, og rektorene har dessuten gått ut og sagt at de ikke kjenner seg igjen i beskrivelsen, sier hun.

Kritikerne mener Røe Isaksen i meldingen legger opp til å gjøre barnehagene mer like skolene, gir barna mindre tid til lek og snikinnfører læringsmål under betegnelsen «veiledende norm». Hovedtrekket er at regjeringen vil erstatte lek i barnehagene med mer fag og resultatkrav, mener de.

Dette avviser Røe Isaksen, som sier meldinga verken innfører fag eller resultatkrav, men at den bygger på læring gjennom lek.

Mer politisert

Stortingsproposjonen som nå kritiseres, er spesielt viktig fordi den viser de overordnede føringene fra regjeringen på ny rammeplan for barnehagene.

Rammeplanene tilsvarer skolenes lærerplaner, og skal komme til høsten. Mens rammeplanene tidligere har vært laget av et fagråd, er det for første gang departementet som skal stå for rammeplanen. For flere i fagmiljøene ses dette på som et eksempel på at politikk trumfer barnehagekompetanse.

Kunnskapsministeren tar anklagene om feilbruk av forskning alvorlig – og avviser dem på det sterkeste.

Står ikke i meldinga

– Stortingsmeldingen bygger på de nasjonale tallene som er 9,1 prosent, men det jeg har sagt som et eksempel er at rundt 25 prosent av elevene i Oslo er så dårlig i norsk når de begynner på skolen at de ikke klarer å følge undervisningen. Tallet brukes ikke engang i meldinga, så spørsmålet er om det er illegitimt å bruke disse tallene, og det mener jeg det ikke er, sier Røe-Isaksen.

En analyse av hvor mange av barna som sliter med norsk som ikke har gått i barnehage – slik Østrem etterlyser – eksisterer trolig ikke.

– Vi har ikke individdata på disse personene så vidt jeg vet, men SSB-tall fra 2015 viser at 98 prosent av femåringene med minoritetsbakgrunn i Oslo gikk i barnehage, sier Røe-Isaksen.

– Du beskyldes også for cherrypicking?

– Jeg avviser på det sterkeste at vi har cherrypicket eller manipulert forskningen for å passe vårt virkelighetsbilde, men forskningen kan allikevel ikke tas til inntekt for tiltakene som foreslås. De politiske standpunktene er jo våre, men stortingsmeldingen er ikke basert på å plukke ut tilfeldige studier som bare skal underbygge vårt syn.

– Er meldinga basert på for snevert forskningsgrunnlag?

– Meldingen er basert på oppdatert og ny kunnskap, blant annet fra longitudinelle studier. Man kan sikkert mene at det er andre forskningsprosjekter vi også burde ha med, men det er noe annet å si at vi driver med cherrypicking, sier han.

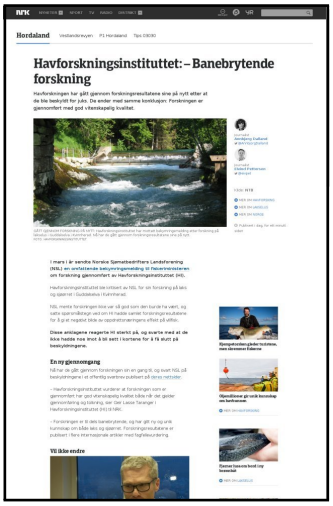
– Hvis man skal komme om påstander om juks med forskning, som er en veldig alvorlig påstand, må man kunne underbygge det. Hvis ikke er det akademisk uredelighet.

Havforskningsinstituttet: – Banebrytende forskning

NRK – Forsiden –15. april 07:33

Av: Annbjørg Dalland, Eivind Pettersen

Havforskningsinstituttet har gått gjennom forskningsresultatene sine på nytt etter at de ble beskyldt for juks. De ender med samme konklusjon: Forskningen er gjennomført med god vitenskapelig kvalitet.


Havforskningsinstituttet: – Banebrytende forskning

I mars i år sendte Norske Sjømatbedrifters Landsforening (NSL) en omfattende bekymringsmelding til fiskeriministeren om forskning gjennomført av Havforskningsinstituttet (HI).

Havforskningsinstituttet ble kritisert av NSL for sin forskning på laks og sjøørret i Guddalselva i Kvinnherad.

NSL mente forskningen ikke var så god som den burde ha vært, og satte spørsmålstegn ved om HI hadde samlet forskningsresultatene for å gi et negativt bilde av oppdrettsnæringens effekt på villfisk.

Disse anklagene reagerte HI sterkt på, og svarte med at de ikke hadde noe imot å bli sett i kortene for å få slutt på beskyldningene.

En ny gjennomgang

Nå har de gått gjennom forskningen sin en gang til, og svart NSL på beskyldningene i et offentlig svarbrev publisert på deres nettsider.

– Havforskningsinstituttet vurderer at forskningen som er gjennomført har god vitenskapelig kvalitet både når det gjelder gjennomføring og tolkning, sier Geir Lasse Taranger i Havforskningsinstituttet (HI) til NRK.

– Forskningen er til dels banebrytende, og har gitt ny og unik kunnskap om både laks og sjøørret. Forskningsresultatene er publisert i flere internasjonale artikler med fagfellevurdering.

Vil ikke endre

HI skriver i brevet at det i bekymringsmeldingen har vært misforståelser og faktiske feil. Disse har man prøvd å påpeke og rette opp.

Havforskningsinstituttet mottok ett nytt innsynskrav i går 13. april 2016 fra Steenstrup Stordrange DA som skal besvares så snart som mulig.

– Vil dere gjøre noen endringer i forskningsresultatene?

– Havforskningsinstituttet mener at omstridte publikasjonen om sjøørret holder mål. Vi ser imidlertid at artikkelen kunne ha gitt enda mer utfyllende beskrivelse av forsøksoppsett og rådata.

Havforskningsinstituttet lover å legge rådata og andre forsøksdetaljer ut på sine nettsider slik at andre kan etterprøve resultatene.

Møttes til et oppvaskmøte

NSLs advokat Lars Alsaker sendte en bekymringsmelding til fiskeriminister Per Sandberg (Frp) 2. mars i år der det stilles en rekke spørsmål om instituttets forskning i Guddalselva og Etneelva i Hordaland.

I møtet mellom partene ba Sandberg om en uavhengig gjennomgang av HIs villaksforskning. Sandberg ba partene inn til et oppvaskmøte, etter lengre tid med konflikt mellom arrangørene.

Fiskeriministeren opprettet et fagråd som skal gå gjennom HIs forskningsrapport fra Guddalselva, og vurdere kritikken fra NSL.

Sandberg fikk refs fra både politisk hold og fra forskningsmiljøer etter å ha uttalt at HI skal være et næringsvennlig institutt.

– Statsråden opptrer som om han skal sensurere forskere og skaper tvil rundt HI sin forskning. Det er helt vanvittig. Slike ministre trenger vi ikke i Norge, sa Torgeir Knag Fylkesnes (SV) i næringskomiteen på Stortinget til NRK.

Senere avviste statsråden at han forsøker å påvirke forskningen.

LES OGSÅ:

Birmingham executive charged with falsifying drug trial documents – North Korea Times

North Korea Times – Breaking Health News –15. april 07:31

Business Journal Friday 15th April, 2016

Mark Hamilton, president and founder of Choice Research of Birmingham LLC, has been charged with falsifying documents related to clinical drug trials.

Comments

Featured Story

Scientists tweak results in human trials

ScienceNordic – Society & Culture –15. april 06:31

Av: Anne Ringgaard

Scientists all too often fiddle with the results of human trials to make new drugs or treatment plans appear more effective than they actually are. Keywords: Health, Scientific misconduct, universities

Scientists who receive public funding may not have financial interests in the success of new drugs or treatments, but there are still many examples of data-tweaking in human trials that make treatments seem more effective than they actually are, shows new research.

"When the research is based on public funds it's important that it generates credible information for the public good. But our study shows that even researchers who are independent of industry often publish their results in such a way that they appear more positive than they actually are," says lead-author Louise Berendt who conducted the research at Bispebjerg Hospital, Denmark.

"The implication is that doctors and patients might choose the wrong treatment because they're basing a decision on incorrect evidence, " she says.

The new results are published in BioMed Central.

Scientists 'handpick' data

Berendt examined 95 publically funded clinical trials from Denmark, published between 1999 and 2003. She found problems regarding the credibility of their results in 61 of these studies.

"There's often a difference between what the scientists have been authorised to investigate and what they've published," says Berendt.

Researchers can handpick the best data needed to achieve a positive result and leave out other data, or change their methods or hypotheses when they attempt to publish the results.

This publication bias distorts the knowledge base upon which doctors make decisions for treatments, and in the worst-case scenario, it can cause unnecessary suffering and even death of patients.

End-goal of trials are adjusted

This problem is not new. Previous studies have shown similar results in both publically and privately funded clinical trials.

"There were serious discrepancies in over 50 per cent of the studies we reviewed--both privately funded and publicly funded trials. Basically it's a big problem," says Asbjørn Hrobjartsson, a professor of evidence-based medicine and clinical research methodology at University of Southern Denmark.

The biggest problem that Hrobjartsson came across in his own work was that scientists tended to change the end-goal of their research and did not investigate the research questions in their original funding applications.

Doctors risk prescribing the wrong treatment

Hrobjartsson agrees that this kind of behaviour cannot be described as honest.

"Doctors try to find a reasonable balance between efficacy and side effects of different treatments, by reviewing various studies, " says Hrobjartsson.

"If the scientists handpick their data to publish a better result, it skews the balance between harmful and beneficial effects of a treatment,"he says, and adds that there is a tendency to publish results in a positive light while holding back on publishing the harmful side-effects.

Publication bias is a breach of good scientific practice, according to the The World Medical Association (WMA). And according to EU rules, scientists are obliged to obtain official authorisation to make significant changes to their studies, including changes to the number of trial participants, the doses of the test medication, and their methods or hypotheses.

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Read the Danish version of this story on Videnskab.dk

Birmingham executive charged with falsifying drug trial documents

Big news networks – Health –15. april 05:43

Mark Hamilton, president and founder of Choice Research of Birmingham LLC, has been charged with falsifying documents related to clinical drug trials.

According to court documents, Hamilton has agreed to plead guilty to one count of making a false statement to the federal government.

Hamilton admitted to falsifying a physician's signature on a physical examination worksheet months after the physician had left his practice and was no longer attending to patients in the clinical trial, according...

Register

?</p, 25

Arvid Heiberg, 36
avhandlingsprojekt, 33

Bioteknologirådet, 35

britiske und, 26

dlingen a, 25
donorene, 39

Effektforskning, 3, 5
ethical, 3, 4, 12
ethics, 3, 6, 7, 11, 12, 31, 32
etisk, 3, 6, 28, 29, 34, 35, 38, 39

falsified, 30
falsifying, 43, 44
forskning, 3, 5, 6, 27, 28, 33–42
forskningsartikkel, 28, 38
forskningsdata, 3, 5, 6, 27
forskningsdisipliner, 27
forskningsetikk, 34
forskningsetiske, 34, 35
Forskningsetiske Komiteer, 34
forskningsfelt, 35
forskningsgrunnlag, 41
Forskningsgruppen, 3, 5, 38
forskningsjournalisten, 27
forskningsmiljøer, 6, 38, 42
forskningspersoners, 34
forskningsprosjekter, 34, 35, 41
forskningsrapport, 42
forskningsresultater, 27, 28, 36, 40, 42
forskningsråd, 3, 5, 6
forskningssubjektene, 34
forskningssubjekter, 34
Forskningssubjekters, 34

gen, 35, 37, 38
gener, 35, 37, 38
genetikk, 27, 35
grunnforskning, 39
g å fo, 26

havforskningsinstituttet, 27, 38, 42
Helse, 6
Helsedirektoratets, 36
helsefag, 34
helsefaglige, 34
Helseforskningsloven, 34
helsepersonell, 34, 35

informert samtykke, 34

juks, 37, 40–42

Komité, 34
kreftforskningen, 35
kyld, 42

manipulate, 9, 14
medisinsk, 3, 5, 6, 34, 38
misconduct, 30, 43
mt og bør, 26

nanosafety, 19
Nanotechnologies, 19
n er ver, 26
nklusjon: Forskningen, 42

open access, 16, 18, 19

personvernombudene, 3, 6
Plagiat, 33

REK, 34, 35
research, 3, 4, 6–10, 12–22, 24, 29–32, 43, 44
researcher, 8, 12, 24
researchers, 3, 4, 8, 9, 12–15, 17–21, 43
researchers22, 17

sannhet, 26

scandal, 4, 8
science, 6, 8–11, 15–25, 29–32
sciences, 29, 32
scientists, 3, 4, 7–11, 14, 16–18, 20, 22, 30–32, 43, 44
Selv en , 26
stamceller, 39

t gjennom forskningsresultatene, 42
ttigheter, 25

ulveforskeren, 28
unethical, 4
universitetet, 3, 27, 33, 38, 39
uredelighet, 37, 41
utforske, 35

Videnskab, 28, 29
videnskabelige, 28
villaksforskning, 42
vitenskap, 38, 39
vitenskapelig, 34, 38
vitenskapsmenn, 39
vitenskapsteoretisk, 28