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Towards a new paradigm of clinical research

Prof. Robert Vermeiren, Curium-LUMC & VUMC

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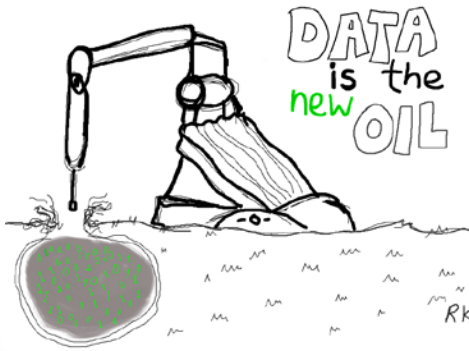
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ONDERZOEKSAGENDA NAAR

Sustainable Health

NATIONAAL PLAN ACADEMISCHE GENEESKUNDE,

BIOMEDISCHE WETENSCHAP EN GEZONDHEIDSZORGONDERZOEK



Personalised medicine

Er zijn aan de Nationale Wetenschapsagenda veel vragen gesteld over *personalised medicine*. Bijvoorbeeld:

BIOMARKERS
Hoe kan de gezondheidszorg, onder andere door gebruik te maken van biomarkers, meer gericht worden op de uniciteit van een persoon?
95

TUMOREN
Elke tumor is anders: hoe kunnen we de ziekte kanker goed genoeg begrijpen om een behandeling van elke vorm ervan te kunnen ontwikkelen?
85

GENETICA
Hoe gaat de kennis van genetica een rol spelen in het begrijpen van, screenen op en behandelen van (zeldzame) ziekten?
81

HART- EN VAATZIEKTEN
Hoe kunnen we hart- en vaatziekten (atherosclerose, hartfalen, hartritmestoornissen en trombose) op individueel niveau vroeg voorspellen, voorkomen en behandelen?
88

Big data

Aan de Nationale Wetenschapsagenda zijn veel vragen over big data gesteld, waaronder:

BIG DATA
Hoe kunnen big data en technologische innovatie (e-health) bijdragen in de zorg? Waarom vindt er in Nederland zo weinig onderzoek plaats met reeds verzamelde data?
105

INNOVATIEVE TECHNOLOGIE
Hoe kunnen we met behulp van een groter begrip van het leven, nieuwe targets identificeren voor moleculaire therapieën, antibiotica en antivirale middelen? Hoe kan de fenomenale toename van processing kracht (wet van Moore) optimaal worden ingezet voor gezondheids-/ medicijnenonderzoek?
99

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G X E X D X I

- G = genes
- E = Environment
- D = Development
- I = Intergenerational

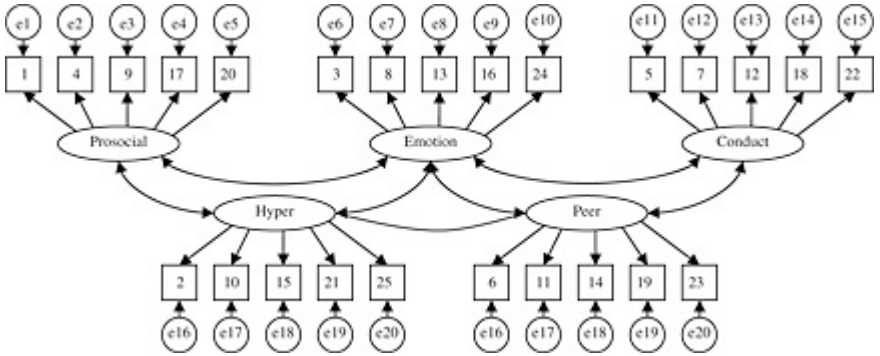
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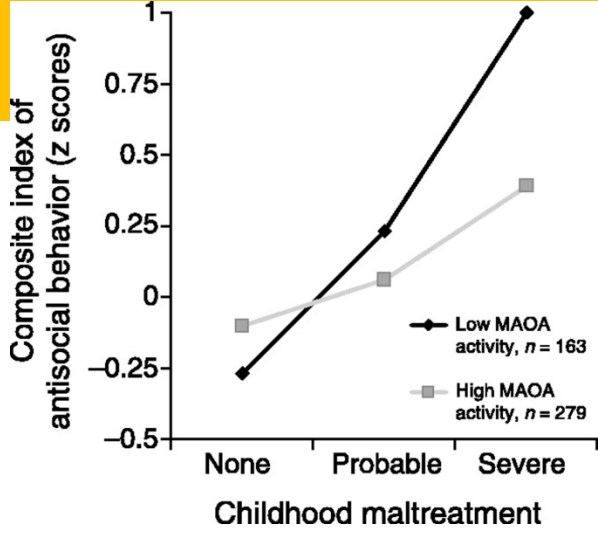
	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	☐	☐	☑
I am restless, I cannot stay still for long	☐	☑	☐
I get a lot of headaches, stomach-aches or sickness	☐	☐	☑
I usually share with others (food, games, pens etc.)	☐	☐	☑
I get very angry and often lose my temper	☑	☐	☐
I am usually on my own. I generally play alone or keep to myself	☐	☑	☐
I usually do as I am told	☐	☑	☐
I worry a lot	☐	☐	☑
I am helpful if someone is hurt, upset or feeling ill	☐	☐	☑
I am constantly fidgeting or squirming	☑	☐	☐
I have one good friend or more	☐	☑	☐
I fight a lot. I can make other people do what I want	☑	☐	☐
I am often unhappy, down-hearted or tearful	☐	☐	☑
Other people my age generally like me	☐	☑	☐
I am easily distracted, I find it difficult to concentrate	☐	☐	☑
I am nervous in new situations. I easily lose confidence	☐	☐	☑
I am kind to younger children	☐	☐	☑
I am often accused of lying or cheating	☑	☐	☐
Other children or young people pick on me or bully me	☑	☐	☐
I often volunteer to help others (parents, teachers, children)	☐	☐	☑
I think before I do things	☐	☐	☑
I take things that are not mine from home, school or elsewhere	☑	☐	☐
I get on better with adults than with people my own age	☑	☐	☐
I have many fears, I am easily scared	☐	☑	☐
I finish the work I'm doing. My attention is good	☑	☐	☐



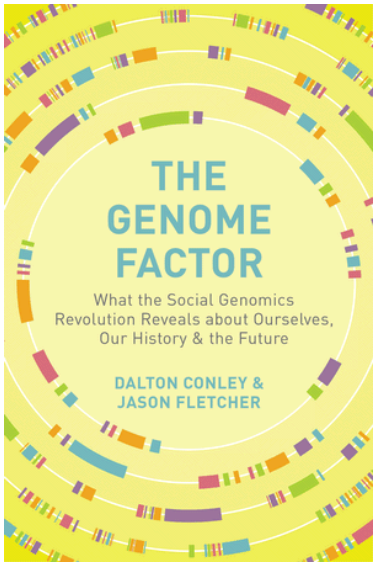
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Poli poli poli



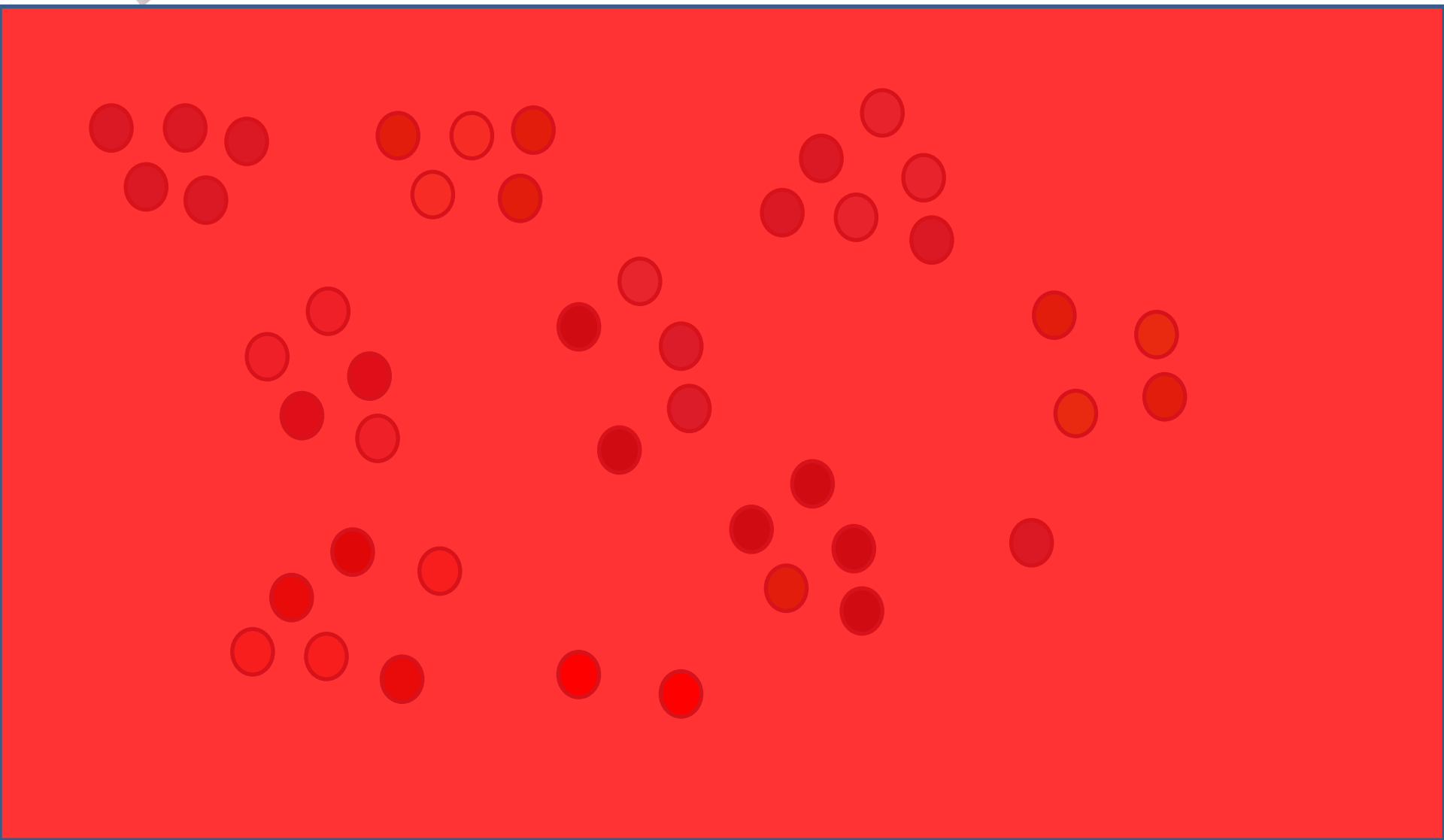
- Interaction e.g. MAO (Caspi)
- Gene – gene interaction
- Active gene – environment correlation
- Environmental specificity

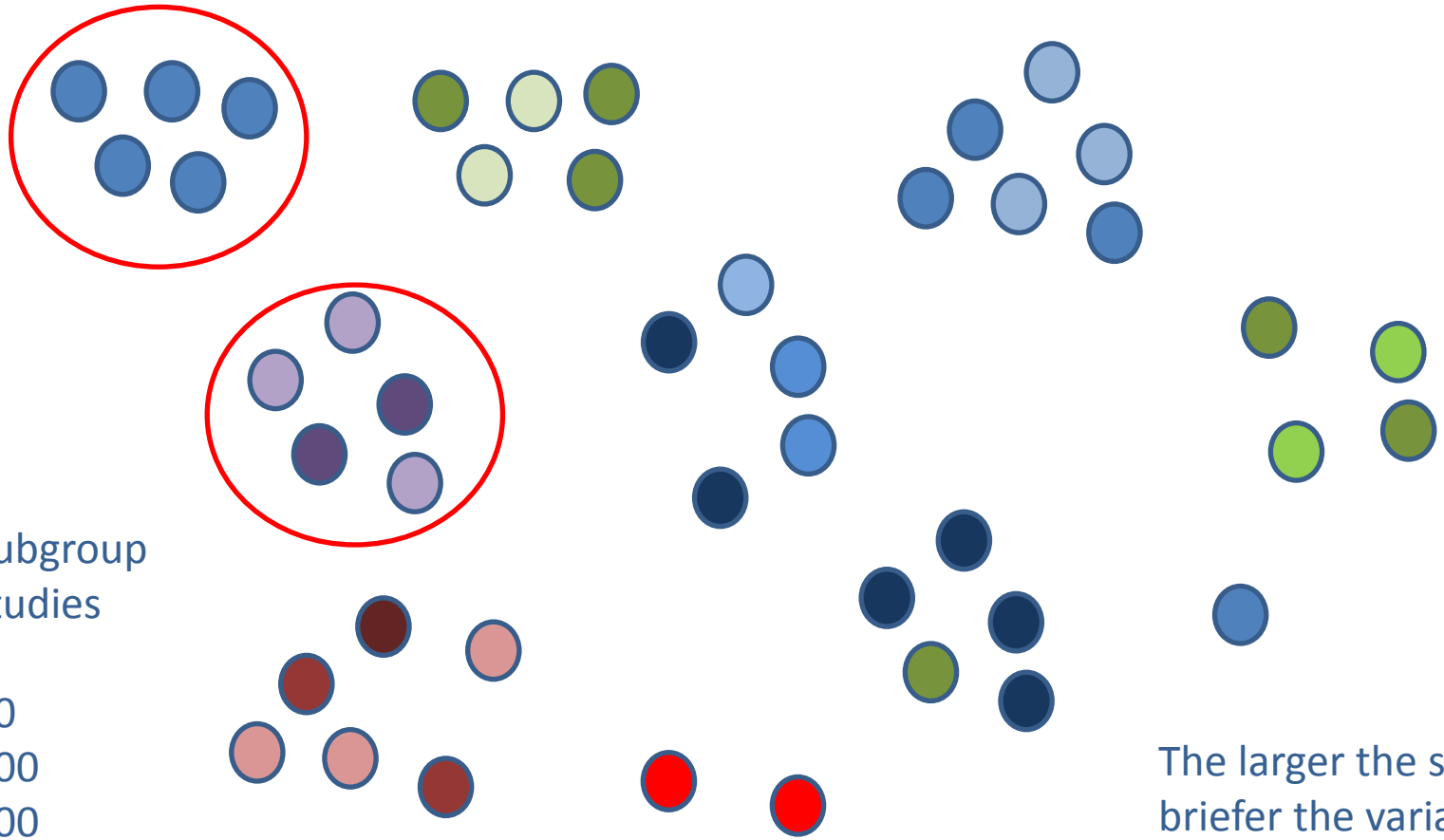


- Specific persons in specific environments will face specific outcomes

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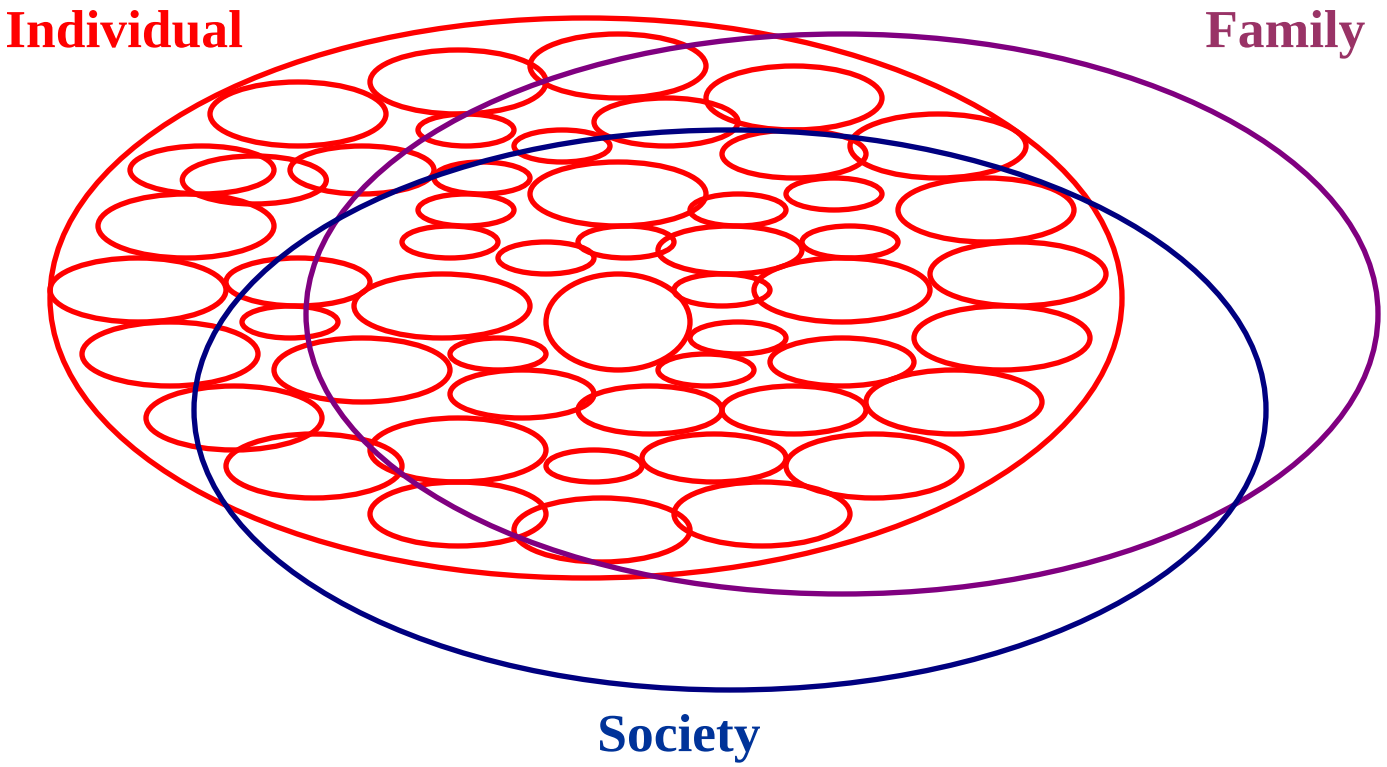
Subgroup studies

10
100
500

The larger the study, the briefer the variables studied & vice versa

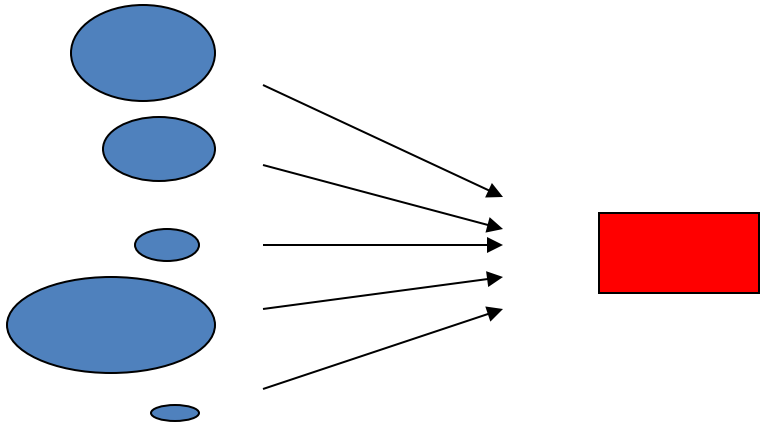
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Risk and protective factors

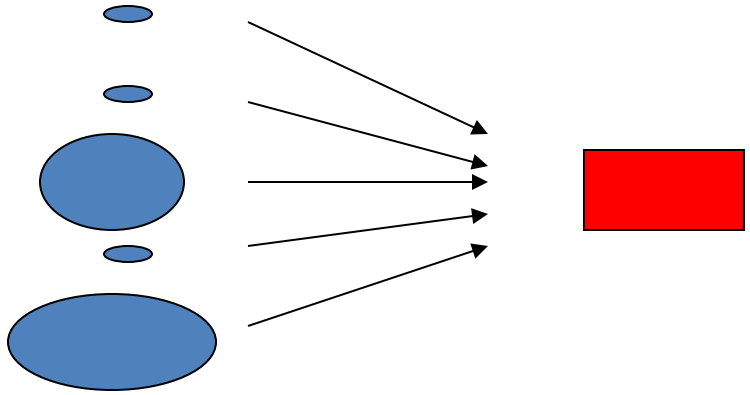


Individual interplay

Rik



Rachid



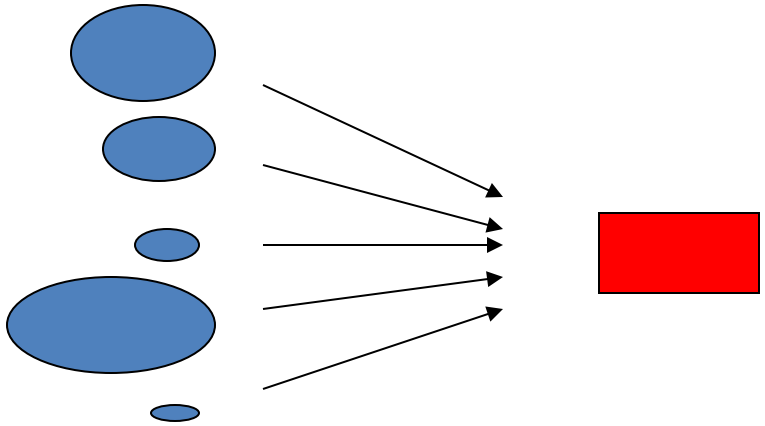
Individual interplay

Luuk

Rik

Oscar

Vlad

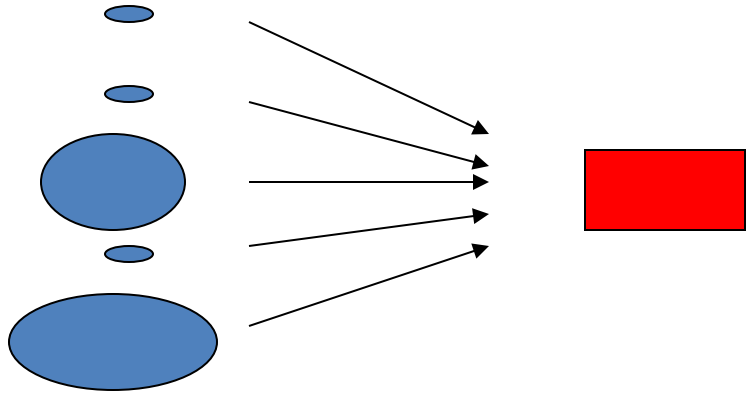


Toon

Rachid

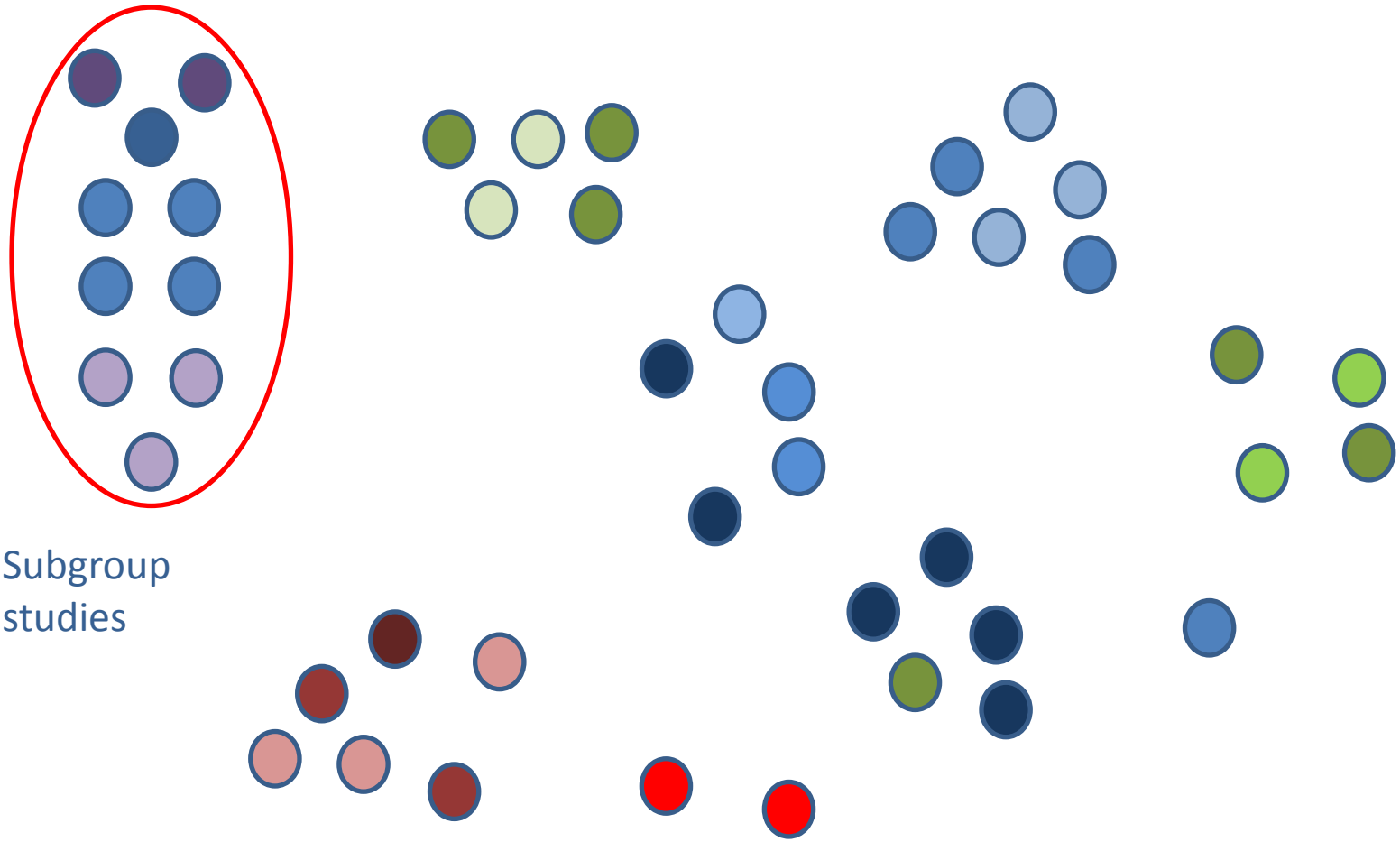
Mohammed

Sterre



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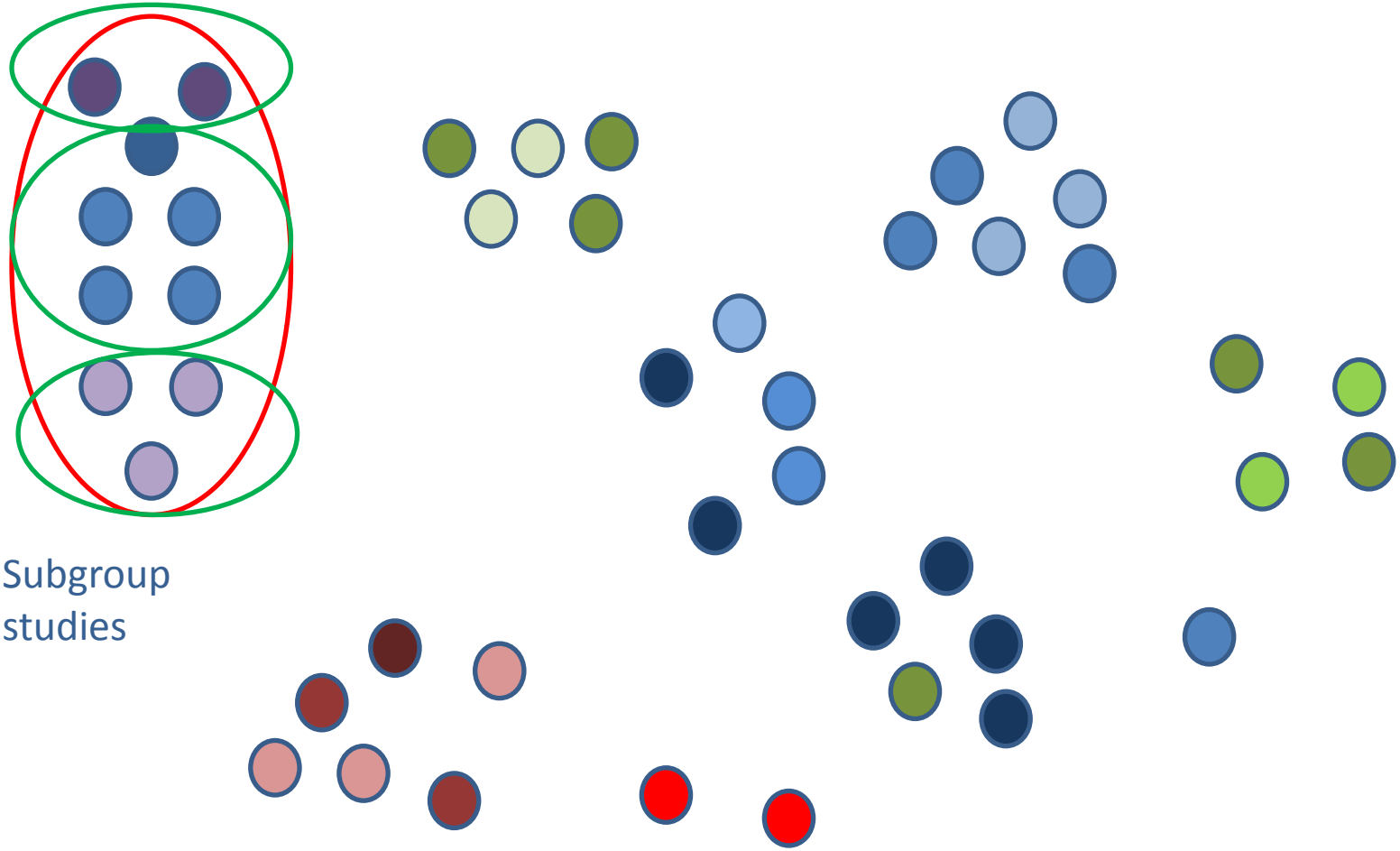
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Subgroup studies

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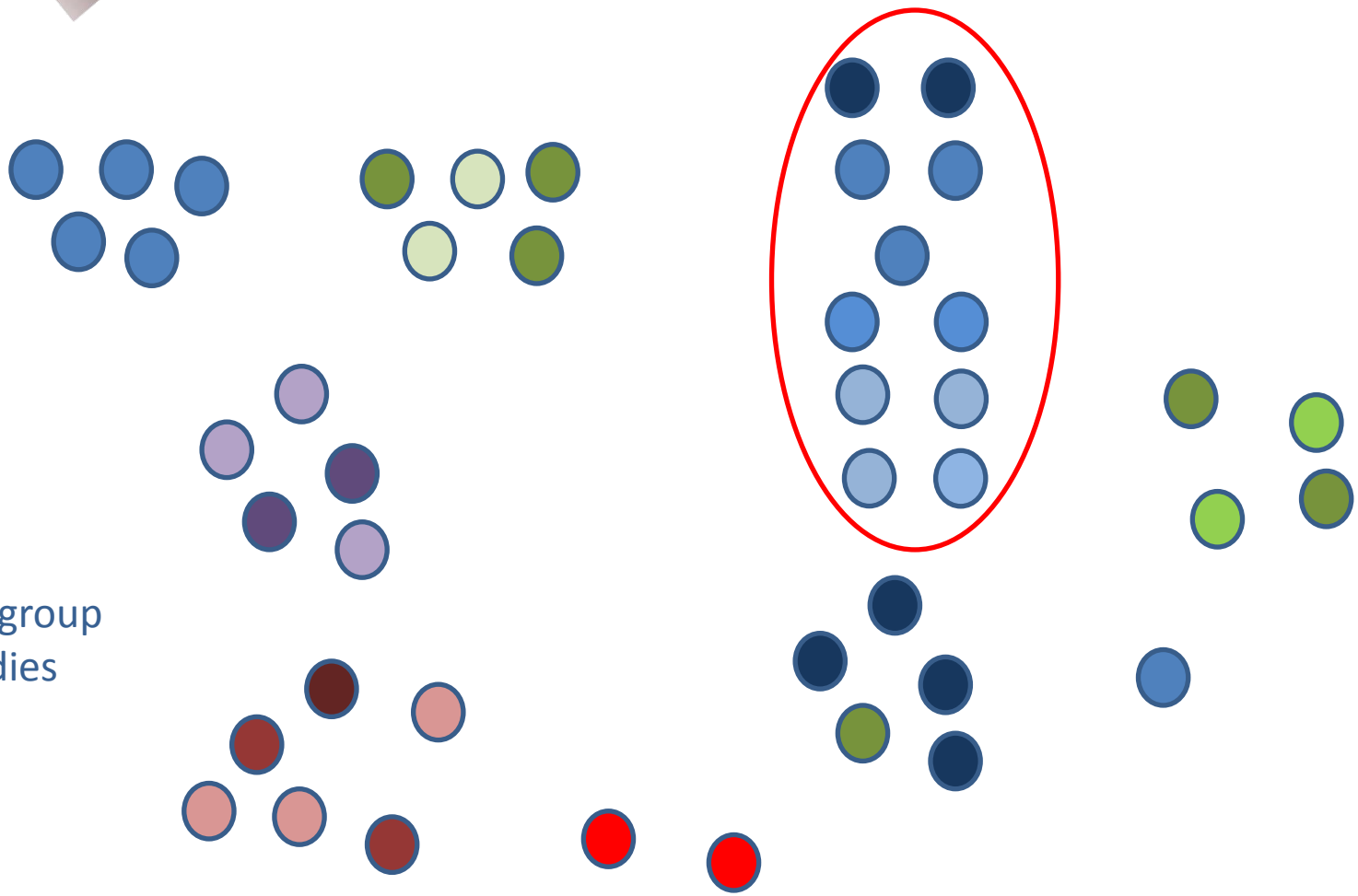
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Subgroup studies

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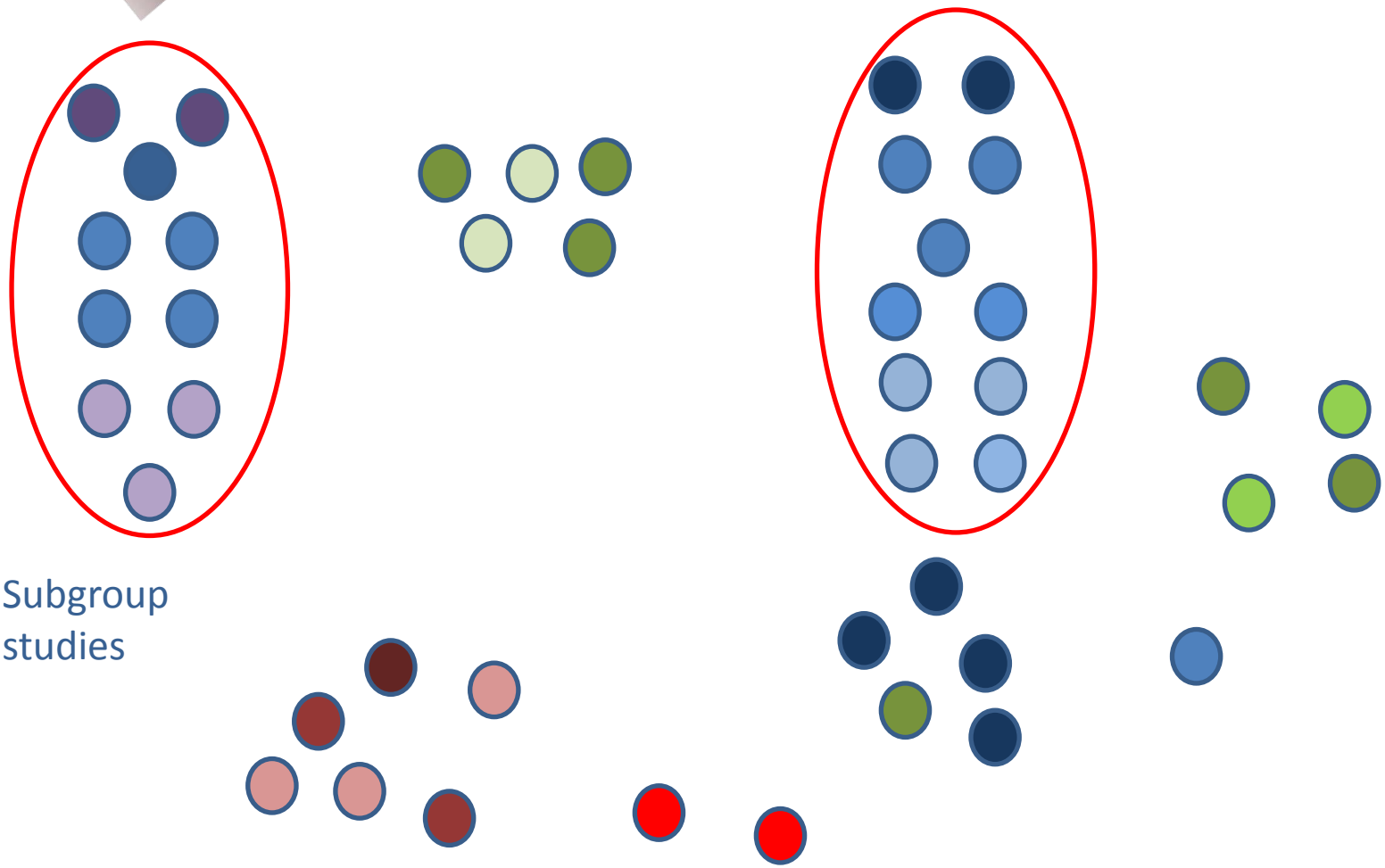
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Subgroup studies

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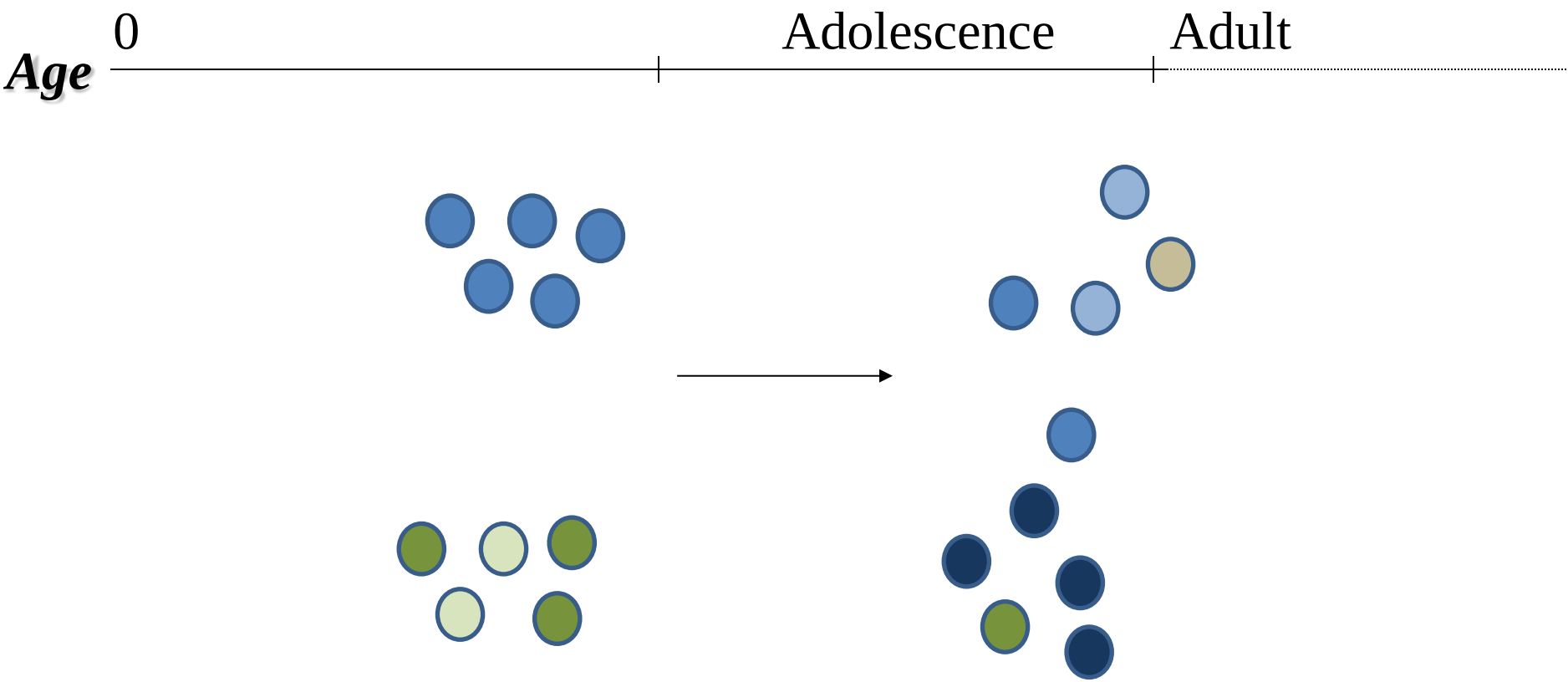
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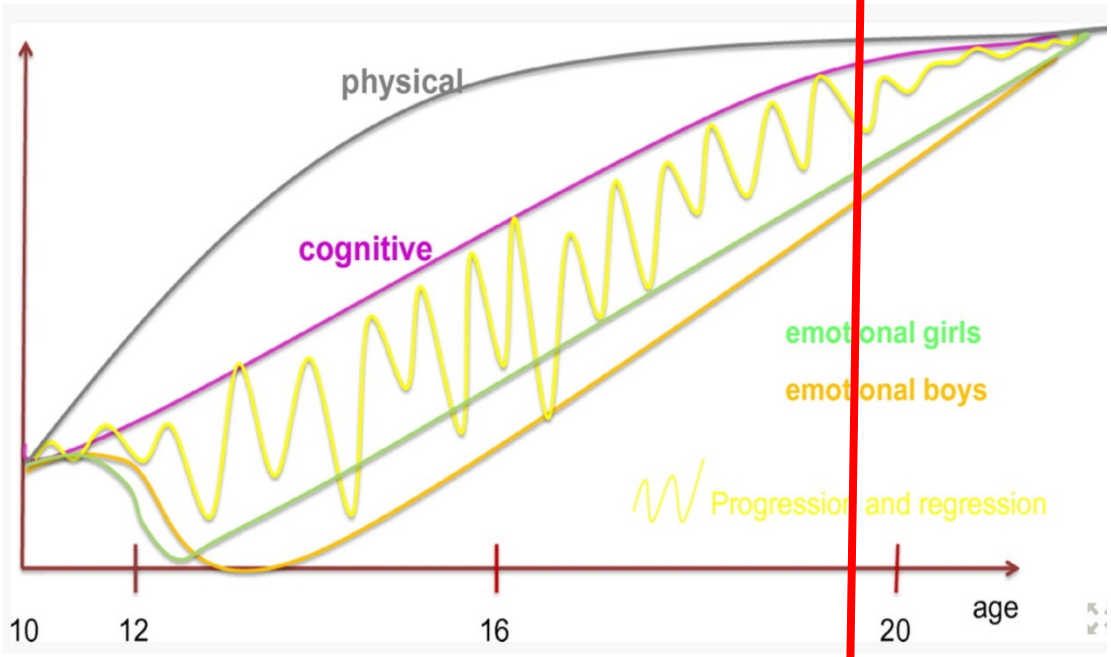
Subgroup studies

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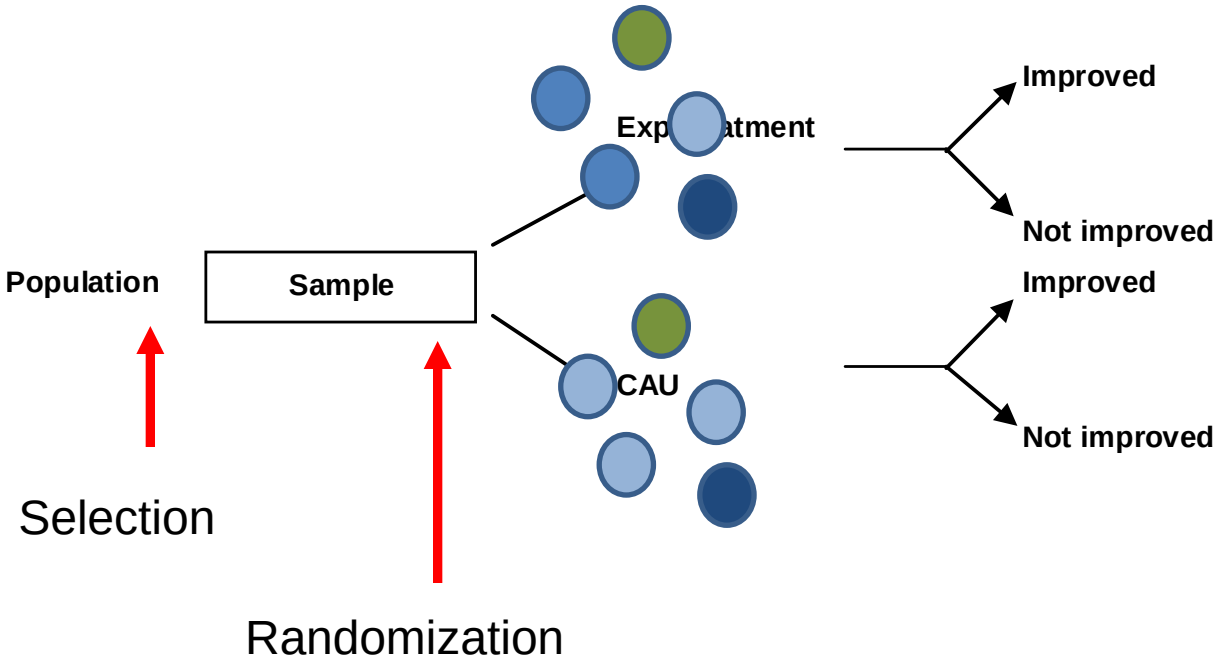


18 - | 18 +



Kaltiala Heino 2015

Heterogeneity within group



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Research agenda on sustainable behavioural health



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To do

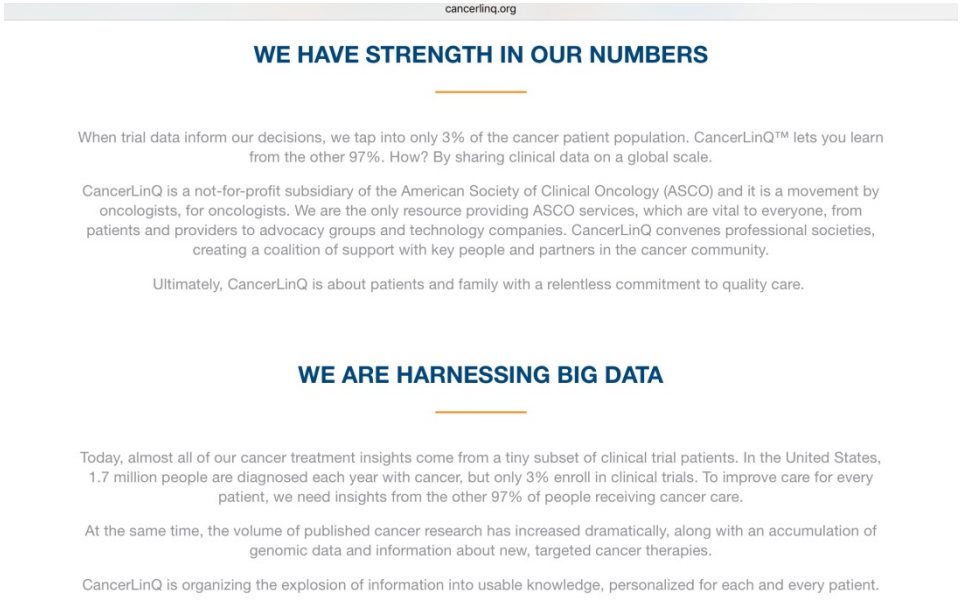
- Systematically collect clinical information
- Develop an (inter)national infrastructure

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To do

- Systematically collect cli
- Develop an (inter)nation


cancerlinq.org

WE HAVE STRENGTH IN OUR NUMBERS

When trial data inform our decisions, we tap into only 3% of the cancer patient population. CancerLinQ™ lets you learn from the other 97%. How? By sharing clinical data on a global scale.

CancerLinQ is a not-for-profit subsidiary of the American Society of Clinical Oncology (ASCO) and it is a movement by oncologists, for oncologists. We are the only resource providing ASCO services, which are vital to everyone, from patients and providers to advocacy groups and technology companies. CancerLinQ convenes professional societies, creating a coalition of support with key people and partners in the cancer community.

Ultimately, CancerLinQ is about patients and family with a relentless commitment to quality care.

WE ARE HARNESSING BIG DATA

Today, almost all of our cancer treatment insights come from a tiny subset of clinical trial patients. In the United States, 1.7 million people are diagnosed each year with cancer, but only 3% enroll in clinical trials. To improve care for every patient, we need insights from the other 97% of people receiving cancer care.

At the same time, the volume of published cancer research has increased dramatically, along with an accumulation of genomic data and information about new, targeted cancer therapies.

CancerLinQ is organizing the explosion of information into usable knowledge, personalized for each and every patient.


Journal of oncology practice

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Big Data Infrastructure for Cancer Outcomes Research: Implications for the Practicing Oncologist

Anne-Marie Meyer, PhD, Ethan Basch, MD

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Need for Big Data in Oncology

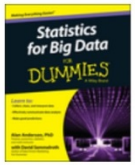
The term big data has become a buzz word in many fields, including oncology. It represents many things, from next-generation DNA sequencing to electronic medical records to linked registry and insurance claims data.[1] For outcomes research, specifically, the development of big data infrastructure holds immense promise becaus it enables research involving patients who are not typically represented in clinical trials Although clinical trials often define treatment guidelines and influence practice, less than 3% of the cancer population is represented in these studies, and thus, clinical trial do not answer questions regarding treatment effectiveness in the real world.[2,3] However, big data resources now allow researchers to observe large, retrospective, and heterogeneous cohorts of cancer patients from screening to end-of-life care though linkages between observational studies or data sets that are designed for purposes othe than research (eg, administrative, delivery of care).[4–7] The big data infrastructure, with data on real-world patients and practices, is essential for answering questions regardin treatment effectiveness and long-term outcomes.[8–10]

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BIG DATA AND WEATHER FORECASTING



RELATED BOOK
Statistics for Big Data For Dummies

By Alan Anderson, David Semmelroth

Weather forecasting has always been extremely challenging, given the number of variables involved and the complex interactions between those variables. Dramatic increases in the ability to gather and process data have greatly enhanced the ability of weather forecasters to pinpoint the timing and severity of hurricanes, floods, snowstorms, and other weather events.

Another example of using big data in weather forecasting took place during Hurricane Sandy in 2012 — the "storm of the century." The National Hurricane Center was able to use big data technology to predict the hurricane's landfall to within 30 miles a full five days in advance. That is a dramatic increase in accuracy from what was possible even 20 years ago. As a result, FEMA and other disaster management organizations were far better prepared to deal with the mess than they might have been had it occurred in the 1990s or earlier.

PARTNER CONTENT STEVE HAMM, IBM

HOW BIG DATA CAN BOOST WEATHER FORECASTING



Typhoon Sanba. *Image: NASA*

Menaced by such destructive weather phenomena, South Korea is upgrading its national weather information system with the goal of understanding weather patterns better and predicting better the location and ferocity of weather events. The upgrade being installed by the Korean Meteorological Administration increases the agency's data storage capacity by nearly 1000% to 9.3 petabytes, making it Korea's most capable storage system. IBM provides the storage hardware and software.

Byte	B	10^0	1
Kilobyte	KB	10^3	1,000
Megabyte	MB	10^6	1,000,000
Gigabyte	GB	10^9	1,000,000,000
Terabyte	TB	10^{12}	1,000,000,000,000
Petabyte	PB	10^{15}	1,000,000,000,000,000
Exabyte	EB	10^{18}	1,000,000,000,000,000,000

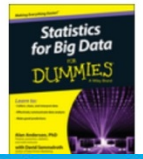
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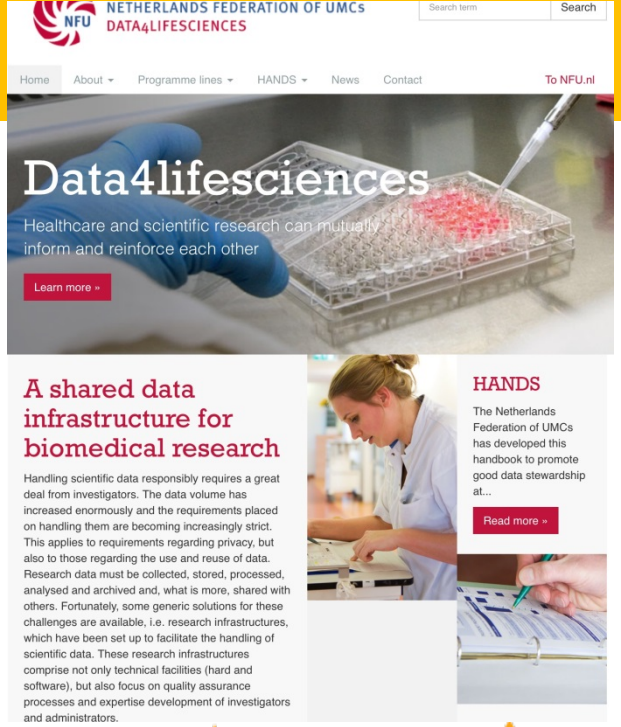


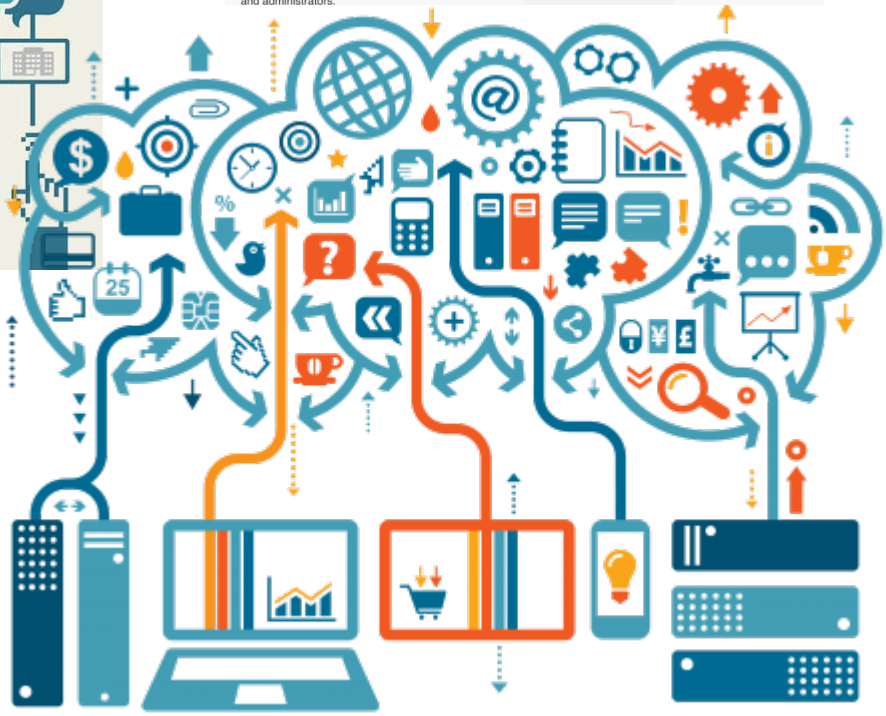


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To do

- Systematically collect clinical information
- Develop an (inter)national infrastructure
- Build national networks of collaboration
- Build network of expertise

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- Sli iversity

How Companies Learn Your Secrets

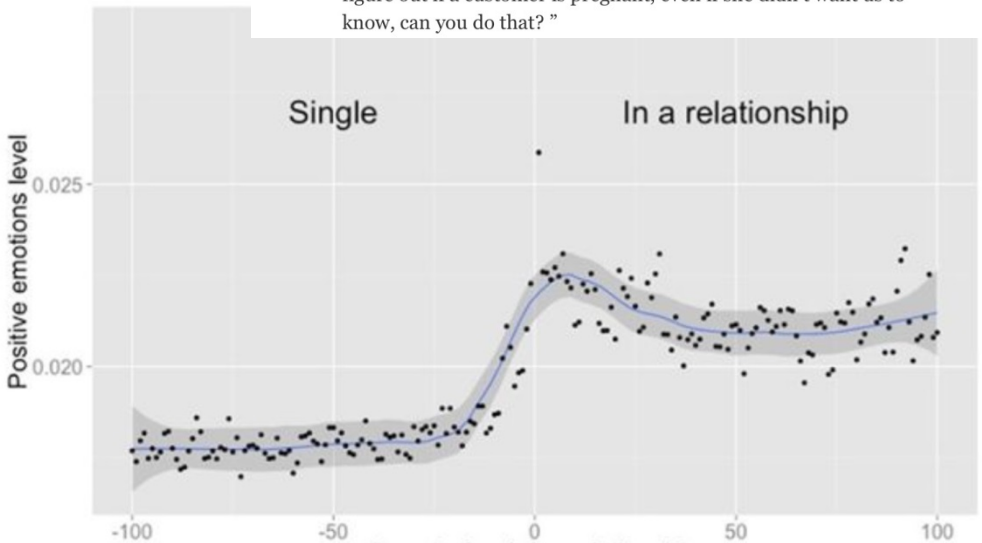
CHARLES DUHIGG FEB. 16, 2012 570

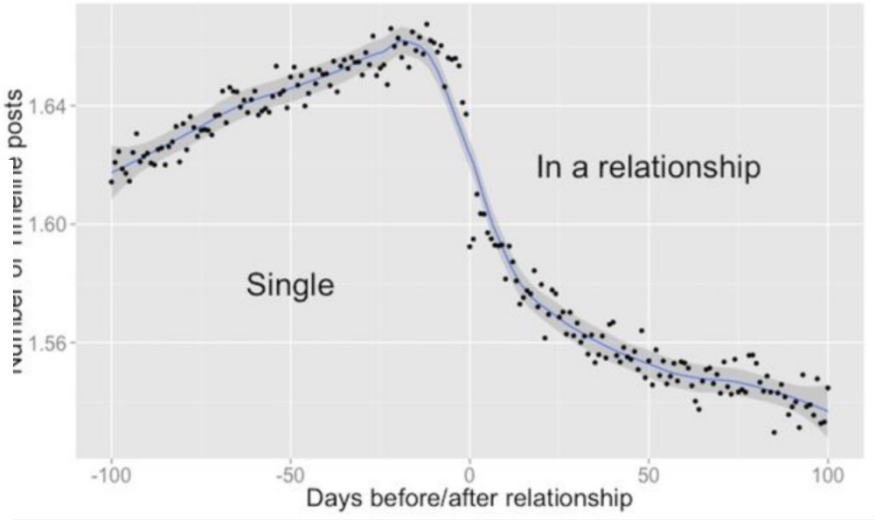


Antonio Bolfo/Reportage for The New York Times

Andrew Pole had just started working as a statistician for Target in 2002, when two colleagues from the marketing department stopped by his desk to ask an odd question: "If we wanted to figure out if a customer is pregnant, even if she didn't want us to know, can you do that? "







Mining Facebook Data for Predictive Personality Modeling

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Abstract

Beyond being facilitators of human interactions, social networks have become an interesting target of research, providing rich information for studying and modeling user's behavior. Identification of personality-related indicators encrypted in Facebook profiles and activities are of special concern in our current research efforts. This paper explores the feasibility of modeling user personality based on a proposed set of features extracted from the Facebook data. The encouraging results of our study, exploring the suitability and performance of several classification techniques, will also be presented.

one (Goldberg 1992). Regularity in someone's behavior over time and situations uniquely identifies her personality type along Big Five dimensions: Openness to experience, Neuroticism, Extraversion, Agreeableness and Conscientiousness.

This research builds upon previous interdisciplinary research works regarding personality as it pertains to the design of intelligent interactive systems. The new communication technologies have brought more information to consider, though the process of their utilization is far from straightforward. Intelligent technologies are expected to play a prominent role in bringing these data to a new level of usability.

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2008 - now

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MAYSI / SDQ 2500

Academische Werkplaats
Forensische Zorg voor Jeugd

File information

CBS

Recidivism

GP - GGD

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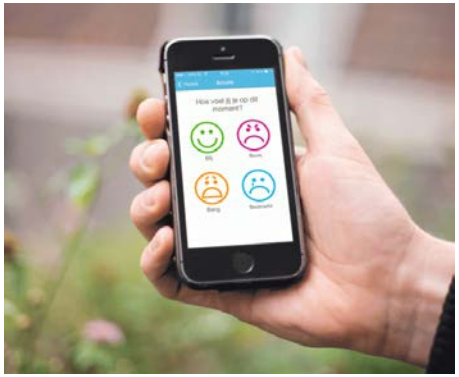
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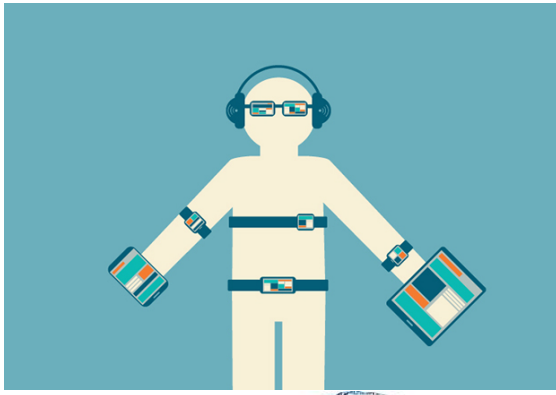






















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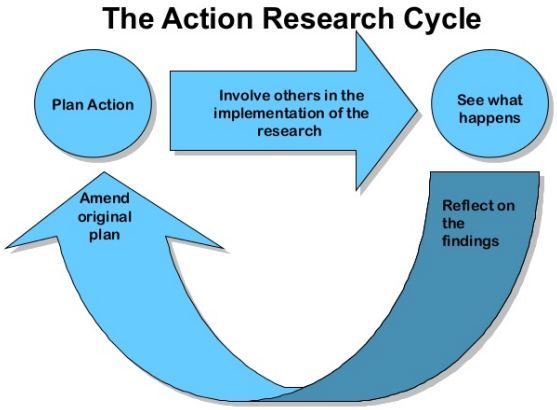
Alternative designs

- Qualitative
- Quasi-experimental (stepped wedge)

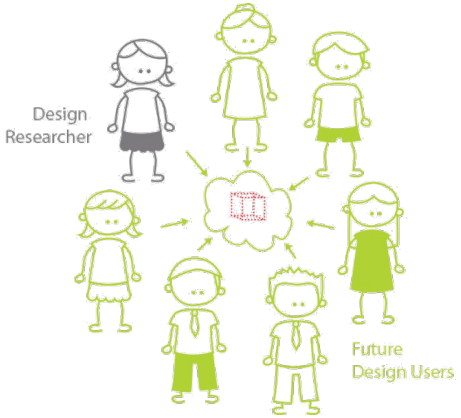
	Time periods			
	First	Second	Third	Fourth
Base 1	Control 1	Intervention 1	Intervention 2	Intervention
Base 2	Control 2	Control 4	Intervention 3	Intervention
Base 3	Control 3	Control 5	Control 6	Intervention



Action research



Participatory research



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To do

- Systematically collect clinical information
- Develop an (inter)national infrastructure
- Build national networks of collaboration
- Build network of expertise
- Alternative research methods

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The Economist

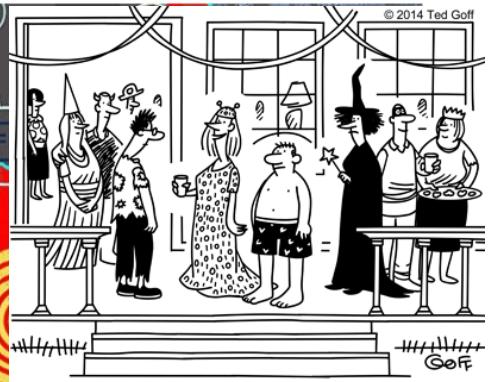
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Big data, meet Big Brother

China invents the digital totalitarian state

The worrying implications of its social-credit project





"I'm Big Data, and this is my friend No Privacy."

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Dec 17th 2016 | BEIJING

GARY SHTEYNGART'S novel of 2010, "Super Sad True Love Story", is set in a near future when the Chinese yuan is a global currency and people all wear an "apparat" around their neck with RateMe Plus technology. Personal details are displayed in public on ubiquitous Credit Poles, posts on street corners with "little LED counters at eye level that registered your Credit ranking as you walked by." The protagonist's are summed up thus:

CIRCLE

DAVE EGGERS

SCIENTIFIC AMERICAN

English

Sign

The digital revolution is in full swing. How will it change our world? The amount of data we produce doubles every year. In other words: in 2016 we produced as much data as in the entire history of humankind through 2015. Every minute we produce hundreds of thousands of Google searches and Facebook posts. These contain information that reveals how we think and feel. Soon, the things around us, possibly even our clothing, also will be connected with the Internet. It is estimated that in 10 years' time there will be 150 billion networked measuring sensors, 20 times more than people on Earth. Then, the amount of data will double every 12 hours. Many companies are already trying to turn this Big Data into Big Money.

Everything started quite harmlessly. Search engines and recommendation platforms began to offer us personalised suggestions for products and services. This information is based on personal and meta-data that has been gathered from previous searches, purchases and mobility behaviour, as well as social interactions. While officially, the identity of the user is protected, it can, in practice, be inferred quite easily. Today, algorithms know pretty well what we do, what we think and how we feel—possibly even better than our friends and family or even ourselves. Often the recommendations we are offered fit so well that the resulting decisions feel as if they were our own, even though they are actually not our decisions. In fact, we are being remotely controlled ever more successfully in this manner. The more is known about us, the less likely our choices are to be free and not predetermined by others.

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To do

- Systematically collect clinical information
- Develop an (inter)national infrastructure
- Build national networks of collaboration
- Build network of expertise
- Alternative research methods
- Discuss ethical issues

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- Enthusiasm and willingness!

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