Beredt C19

A datalake and preparedness register - the national realtime surveillance system for covid-19

NOFE Conference Bergen 3.11.2021

Anja Schou Lindman

During the covid-19 pandemic, project manager Beredt C19
Department director, Health Service Research, FHI

MSc Physiology

Det medisinske fakultet

Institutt for medisinske basalfag

PhD
Faculty of medicine

FHI
Folkehelseinstituttet

Postdoc
Cardiovasular disease epidemiology

NOFE
Norwegian Epidemiological Association
Norsk forening for epidemiologi

kunnskapssenteret
Nasjonalt kunnskapssenter for helsetjenesten

Researcher
Health services

Department director
Infectious disease registries
MSIS, SYSVAK etc.

FHI
Folkehelseinstituttet

Department director
Health Service Research
Responsible for register analyses

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Folkehelseinstituttet

Covid-19 March 2020
🙏 Recruited people from the whole Institute to assist in the response

Welcome possibilites for new knowledge!

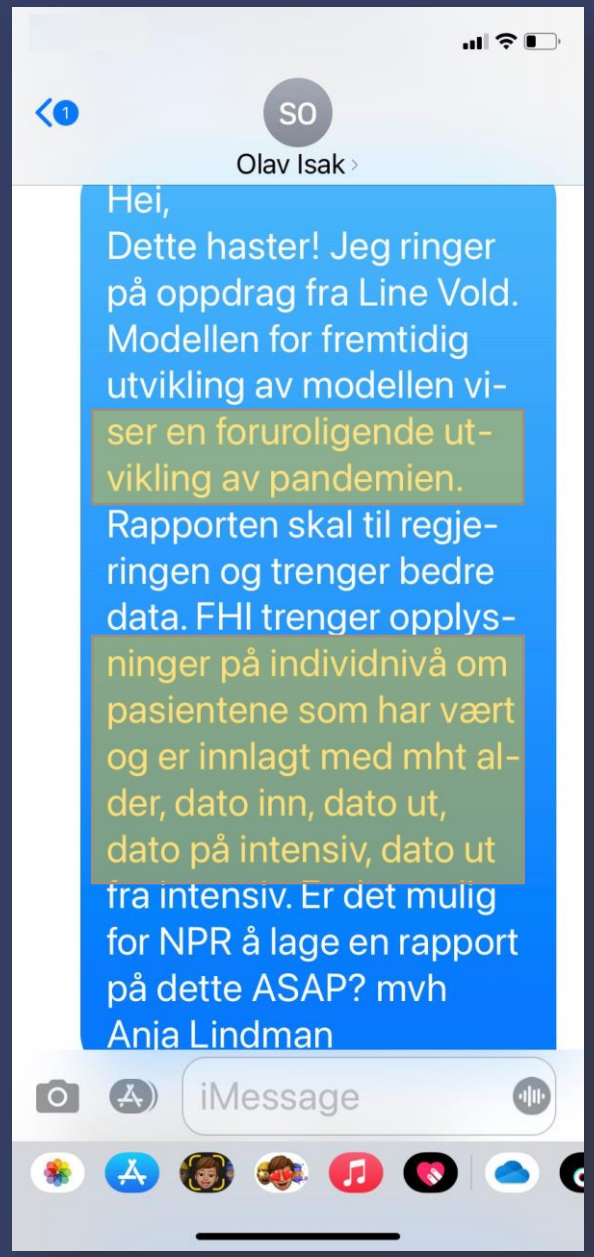
A day in March i 2020 kl. 10.17…

SMS exchange

Olav Isak Sjøflot
Department director,
Norwegian Directorate of Health

and

Anja Lindman, FHI



…2 minutes later

How to solve this?

- Legal basis for handling of personal- and health data
- Technical infrastructure to collect, store and handle data
- Analytical capacity
- Organization and routines

Experience from the swine flu pandemic

2013

Folkehelseinstituttet under influensapandemien 2009

Delrapport: **Overvåkning**

Preben Aavitsland
Olav Hungnes
Berit Feiring
Marianne A Riise Bergsaker
Hilde Kløvstad
Hanne Nøkleby

folkehelseinstituttet

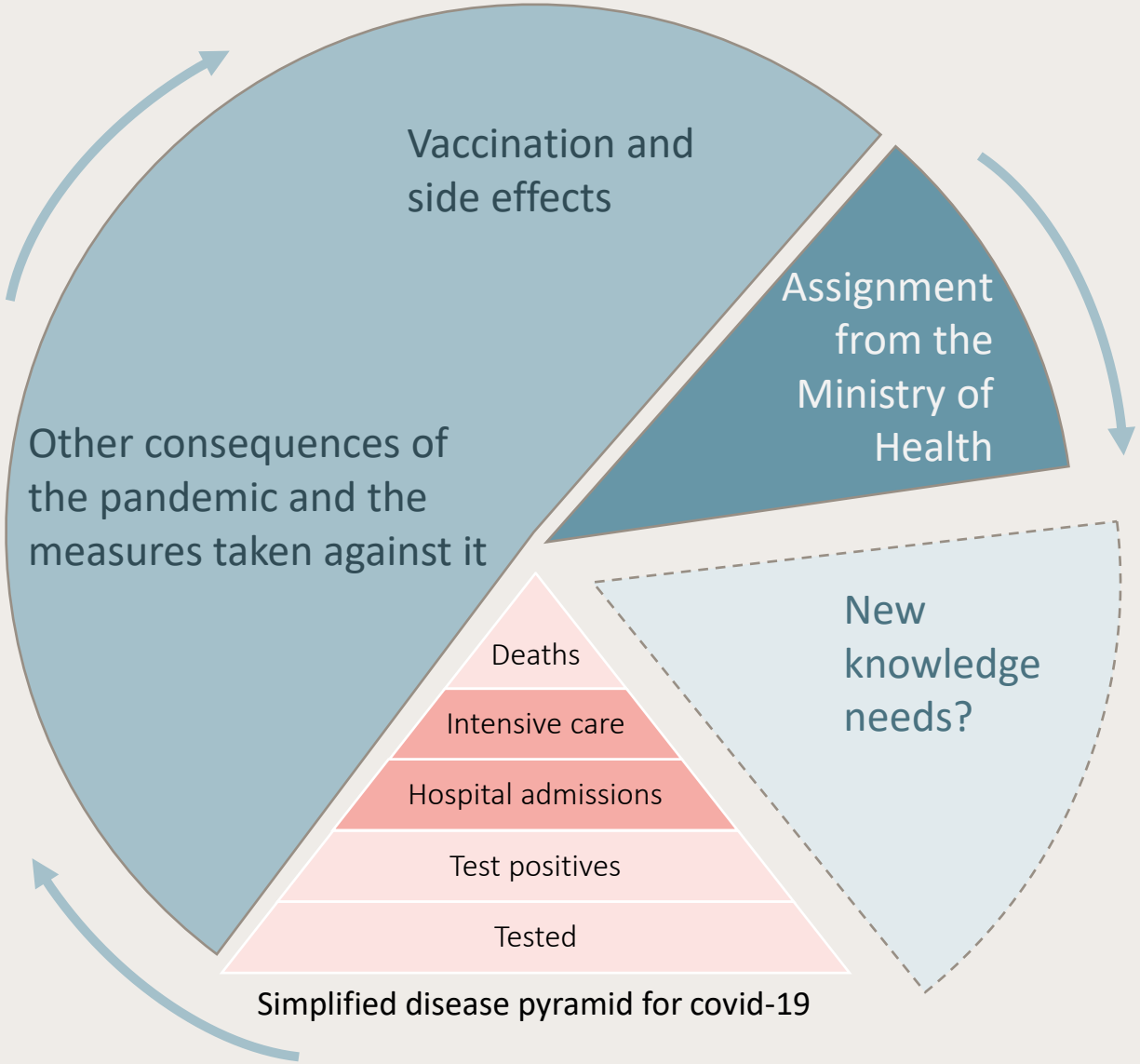
Selected points from Report: Surveillance, from NIPH, **2013**

'The Ministry should give the institute in **crisis situations** …… the **authority** to **gather information** that is necessary **in the infection control**'

'The **Ministry** should contribute to **reducing the formal obstacles** to ensure **rapid linkage** between **health registries** ……'

→ **2017** - The Health Contingency Act § 2-4

→ NIPH can establish emergency preparedness registers



Simplified disease pyramid for covid-19

The purpose of BeredtC19 is to quickly provide **overview** and **knowledge** of how the **pandemic** and the **measures** that have been implemented, affect the population's **health**, use of **health services** and **health-related behavior**

Helseberedskapsloven § 2-4
(Health Contingency Act)

The register is **temporary** - the data shall be 'deleted' when the incident is 'clarified and evaluated'

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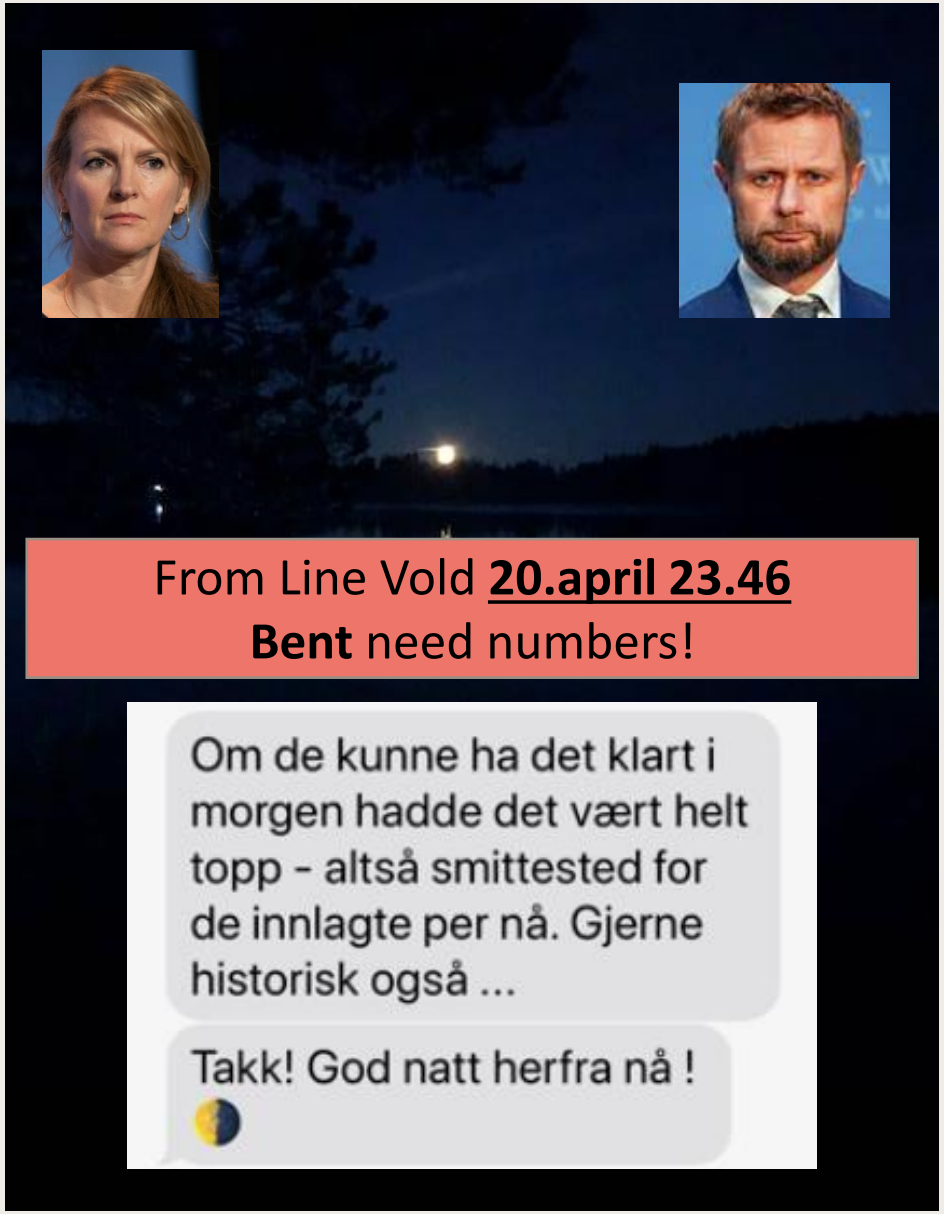
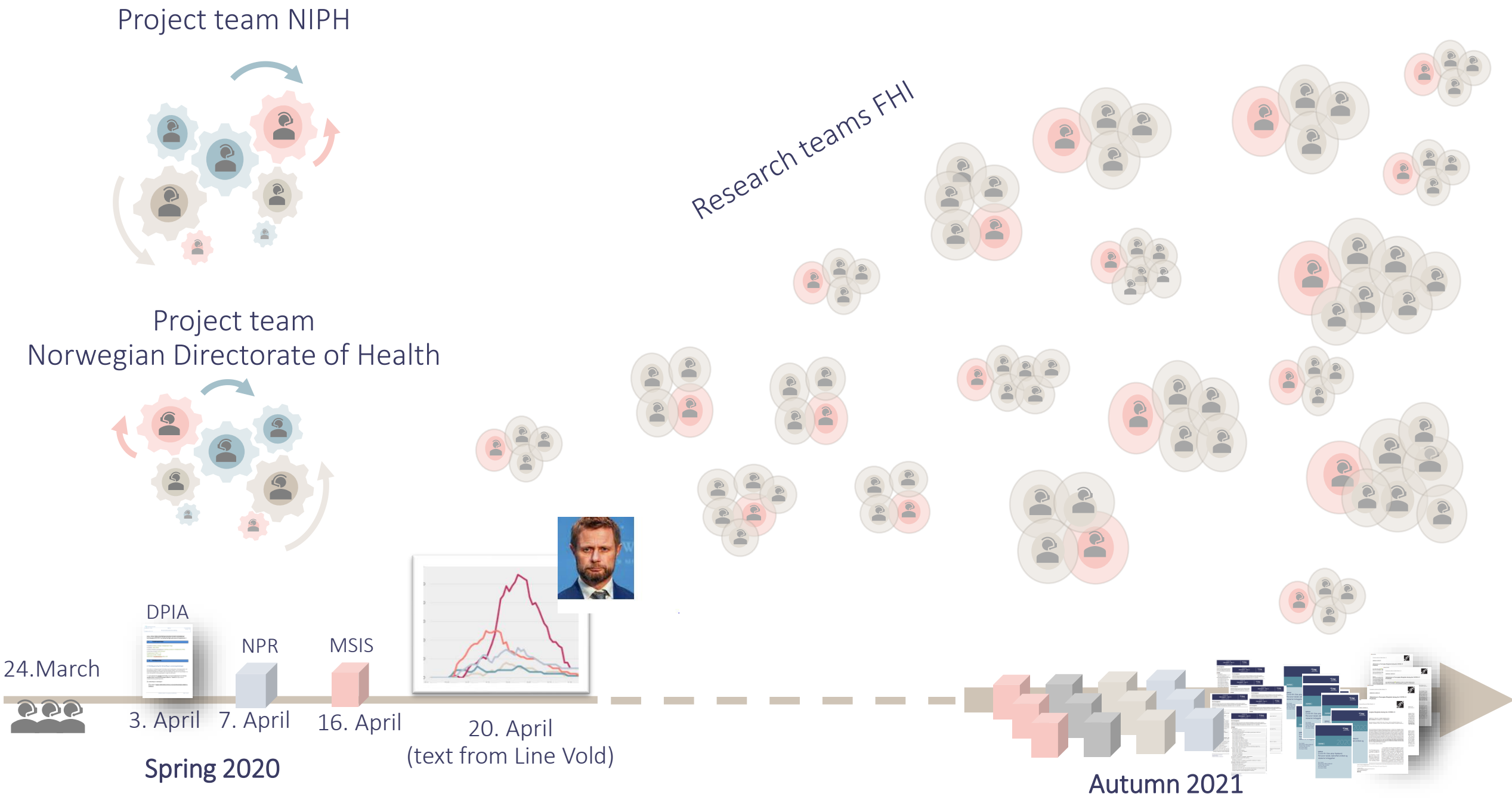
Efficient and good work

Skilled and really nice people
(all in the same ‘team boat’)




Project team NIPH
Research teams FHI
Project team
Norwegian Directorate of Health
DPIA
NPR
MSIS
24.March
3. April
7. April
16. April
20. April
(text from Line Vold)
Spring 2020
Autumn 2021

Beredt C19 – A data lake with ‘raw data’

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Source/register
Raw data

Secure transport
Separate per source

Database, Backup restore
SPTP

Fil, GUI
Mapper i sikkersone

Filoverføring,
SPTP

Database
SQL –> SQL

Webservice

Storage
Datalake

Data minimization
Link/analyse

Analytical rooms
R/Stata

Team Modellering

Team Overvåkning

Team Grense

Team Smittesporing

Team CoronaVAX

SAFE ZONE

SQL-database (!)

Additional data minimization

Filter
- fields/variable
- rows/populaton

Masking
of codes
(i.e ICD-10)

Unique serial number for linkage per team/ analysis room

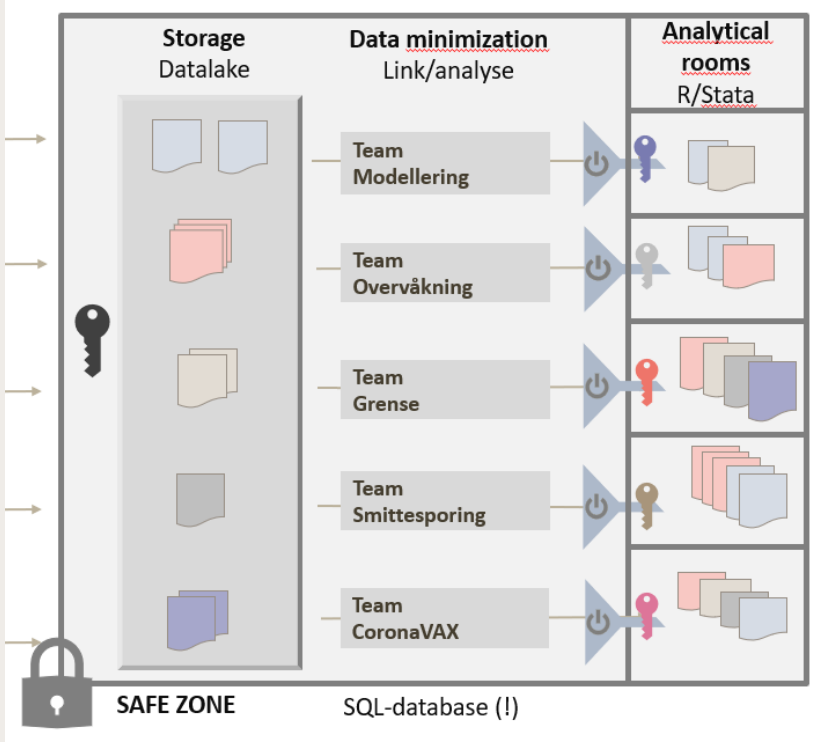
Competent analysts!
Raw data before quality control
Beware data quality, methods and interpretation!

Built-in ‘privacy’ functionality

GDPR - rules relating to processing of personal data

- **No directly personally identifiable** information in Beredt C19 (personal identification number (fødselnummer), name etc)
- **Separate serial numbers** for each team – cannot link data across team
- **Data minimization** routines and built-in functions
- **Strict access** control

- Only analyses within the overall aim of Beredt C19 – knowledge to handle this pandemic



All Norwegian residents included – and combined with health and other information!

Norwegian Institute of Public Health

Positive covid-19 cases (MSIS)
Tested covid-19 positive and negative (MSIS-lab)
Tested flu positive and negative (MSIS-lab)
Vaccinated covid-19, influenza, pneumococcus (SYSVAK)
Side effects covid-19 and flu vaccine (BIVAK)
Births (mother and child) (MFR)
Death and cause of death (DÅR)
The Medicines Register - on the way in

Norwegian Directorate of Health

Hospitalizations (NPR)
GP, emergency room etc. (KPR)
Nursing Home Residents (KPR)

Bergen Health Trust

Respiratory patients and intensive care (NiPaR)

Statistics Norway

Income, education, social security, living conditions, cramped living conditions
Immigrant background

The Norwegian Tax Administration

The population register
The entire population, age, gender municipality of residence, family relations, country of birth

The Norwegian Medicines Agency

Side effects covid-19 vaccine
Side effects flu vaccine

NAV

Occupation and workplace (Aa)
Residents of old age and nursing homes (Inst2)

DSB

Cross border registration (IRRS)

KS Fiks smittesporing (*ReMin/PasInfo*)

'Smittesporing'
Infection tracing

Realtime and historical data
'Admitted yesterday – in Beredt C19 today'

Beredt C19
Beredskapsregisteret for covid-19

KNOWLEDGE PRODUCTION
MAKES MANY DIFFERENT ANALYSIS POSSIBLE

Covid-19 infections and testing

Smitte i skoler

Senfølger etter covid-19

Alvorlig sykdom i ulike grupper

Vaccination

Bivirkninger av vaksine

Tilgang og bruk av helsetjenester

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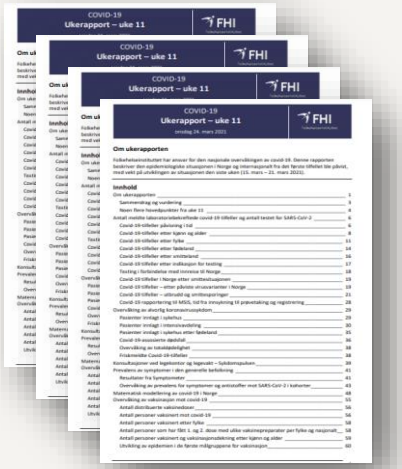
Knowledge from Beredt C19

To handle this pandemic - knowledge must be useful now or in the near future

Daily and weekly reports



‘Skreddersydd’ statistikk **(anonym!)**

Internal counseling FHI - Outbreak group and
Covid-19 vaccination program
Media and municipalities
The Minister of Health, Stortinget, Norwegian Directorate of Health

Korona Commission, Holden Committee

Modelling reports

Risk assesments

Reports

Articles (incl. MedRxiv)

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Knowledge ‘production’

Teams in Beredt C19

Team **Modellering**
Birgitte de Blasio

Team **Overvåkning**
Rob Whittaker

Team **Helsetjenester**
Karin Magnusson

Team **Helsevern**
Anne Reneflot

Team **Rus**
Anne Reneflot

Team **Skade**
Anne Reneflot

Team **Risikogrupper**
Hanne Gulseth

Team **CoronaVax**
Hanne Gulseth

Team **CoronaPreg**
Maria Magnus

Team **Institusjon**
Hanne Eriksen-Volle

Team **SoMiCO**
Anna Godøy

Team **Skole**
Petter Elstrøm

Team **Tiltak**
Petter Elstrøm

Team **NytteKost**
Hege Gjefsen

Team **Grense**
Anja Kristoffersen

Team **Smittesporing**
Elisabeth Madslien

Team **MIS-C**
Margrete Greve-Isdal

Team **Vaksineeffekt**
Hinta Meijerink

Team **Vaksinedekning**
Andrè Einhaug

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Infection in various occupational groups

Knowledge to the authorities, measures and assessment of effect of the measures

Results

4. November 2020

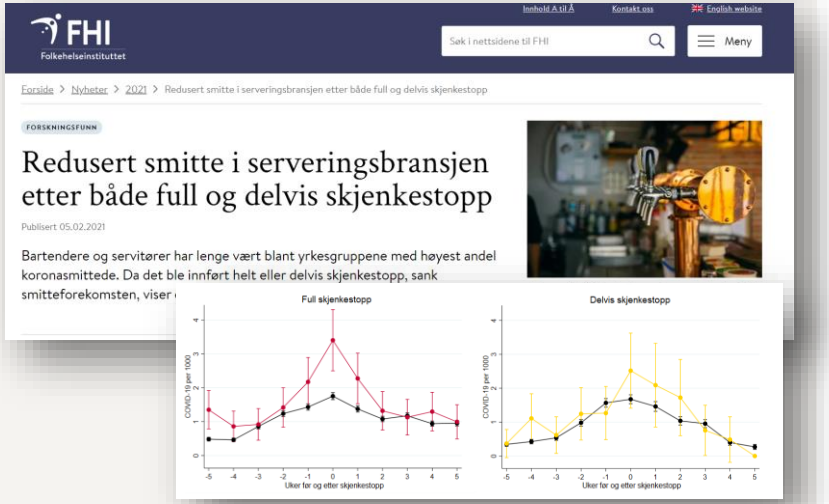
Measures

7. November 2020

One of several arguments for the introduction of 'skjenkestopp' (closing of bars and reduced alcohol serving)

Possible to evaluate effects

5. February 2021



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Border crossing cases - the authorities needed advice!

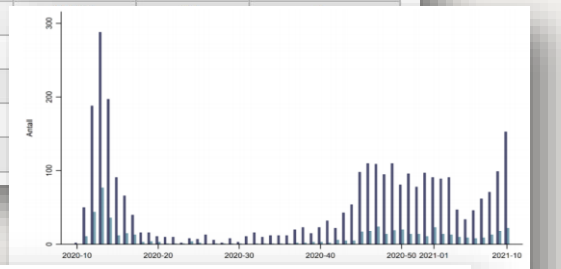
Short time from data in - to analysis out, advice and measures

Received border crossing data (IRRS/DSB)
17. March 2021

Results

23. March 2021

	Antall reisende med oppgitt fødsels- - eller d- nummer	Prosent testet innen 2 dager	Prosent positiv innen 10 dager
Europa			
-Polen			
Asia			
-Pakistan			
Afrika			



FHI: Mye importsmitte fra Afrika og Asia

Det er mye importsmitte blant innreisende fra Asia og Afrika. Fra Pakistan var det hele 12 prosent som var smittet, går det fram av et notat fra Folkehelseinstituttet.

Tormod Strand
@tormodstrand
Journalist

Publisert 23. mars kl. 18:43
Oppdatert 23. mars kl. 19:40

NRK 23.mars 2021

Advice

FHI har en liste med forslag til ulike tiltak kan vurderes for å redusere risiko for importsmitte knyttet til fritidsreiser.

- Tydelig informasjon om reiseråd (se også oppdrag 403), inkludert
  - hva som er definert som en "nødvendig reise" (vurdere dokumentasjonskrav)
  - risiko for smitte
  - krav om test og om opphold på karantenehotell ved ankomst
- Sikre bedre etterlevelse av krav om test 7 døgn etter ankomst, og tilrettelegging for å få tatt slik test for de som er i karantene.
- Kontrollsenteret bør prioritere oppfølging av innreisende fra Asia, Afrika, Sør-Amerika og Polen, samt de som har testet positivt og de som skal gjennomføre karantene i eget hjem.
- Forlenget opphold på karantenehotell, eventuelt i hele karantenetida.
- Krav om forlenget opphold på isoleringshotell eller annet egnet isoleringssted ved positiv test. Dette forutsetter at de syke får et forsvarlig helsetilbud

Assignment 409
Reinforced measures
FHI /The Norwegian Directorate of Health

Measures

26. March 2021

Regjeringen.no

Det ble den 26.03.2021 gjort flere endringer i reglene om karantenehotell. Hovedregelen er fremdeles at tilreisende til Norge plikter å gjennomføre karantenetiden på karantenehotell, men det ble gjort endringer i hvilke grupper som er unntatt fra denne plikten og hvor lenge de må oppholde seg på karantenehotell. Den viktigste endringen er at personer som er bosatt eller har fast bopel i Norge som returnerer til Norge etter unødvendig utenlandsreiser må på karantenehotell i hele karanteneperioden. Disse kan ikke lenger teste seg ut av karantenehotellet

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Side effects of vaccination Astra Zeneca

Opportunity to follow events in real time

Collaboration with Danish researchers / health authorities

Results March / April 2021

Outcome	IR DK	IR NO	Exp	Obs	SMD (95%CI)	SMR (95% CI)
THROMBOCYTOPENIAS AND COAGULATIVE DISORDERS	0.60	0.75	14.31	22	8 (-1 to 19)	1.54 (0.96 to 2.33)
Thrombocytopenias	0.15	0.38	5.07	16	11 (4 to 21)	3.16 (1.80 to 5.13)
Idiopathic thrombocytopenic purpura	0.07	0.06	1.34	n<5	NR	NR
Other primary thrombocytopenia	0.00	0.01	0.09	0	-0 (-0 to 4)	0.00 (0.00 to 39.63)
Secondary thrombocytopenia	0.01	0.18	1.65	n<5	NR	NR
Thrombocytopenia unspecified	0.09	0.20	2.77	10	7 (2 to 16)	3.60 (1.73 to 6.63)
Coagulative disorders						
Coagulative disorders, purpura	0.45	0.38	9.42	6	-3 (-7 to 4)	0.64 (0.23 to 1.39)
Disseminated intravascular coagulation (DIC)	0.01	0.02	0.27	0	-0 (-0 to 3)	0.00 (0.00 to 13.55)
BLEEDINGS AND ANEMIAS	2.75	3.04	54.31	68	14 (-2 to 32)	1.25 (0.97 to 1.59)
Anemias from bleeding	2.67	2.96	52.43	68	16 (0 to 34)	1.30 (1.01 to 1.64)
Anemia from bleeding, unspecified	0.11	-	1.30	n<5	NR	NR
Bleeding from respiratory tract	0.85	0.87	14.30	33	19 (8 to 32)	2.31 (1.59 to 3.24)
Bleeding, not specified	0.15	0.05	2.20	8	6 (1 to 14)	3.63 (1.57 to 7.16)
Hematuria	1.43	1.50	27.71	21	-7 (-15 to 4)	0.76 (0.47 to 1.16)
Intestinal bleeding	0.18	-	1.58	n<5	NR	NR
Hemolytic anemias *	0.09	0.09	2.01	0	-2 (-2 to 2)	0.00 (0.00 to 1.84)

Advice from NIPH

15.4.2021

NYHET

FHIs anbefaling om Astra Zeneca

Publisert 15.04.2021

Folkehelseinstituttet har anbefalt å stoppe videre bruk av AstraZeneca-vaksinen koronavaksinasjonsprogrammet.

Read in English Del/tips Skriv ut

Measures

15.4.2021

Regjeringen.no

Bredere beslutningsgrunnlag om virusvektor-vaksiner

Nyhet | Dato: 15.04.2021

Regjeringen vil ta den endelige beslutningen om bruk av covid-19-vaksinene fra AstraZeneca og Janssen. Det settes ned et ekspertutvalg med medlemmer fra inn- og utland som får i oppdrag å se på konsekvensene av å bruke eller ikke bruke disse vaksinene i vaksinasjonsprogrammet.

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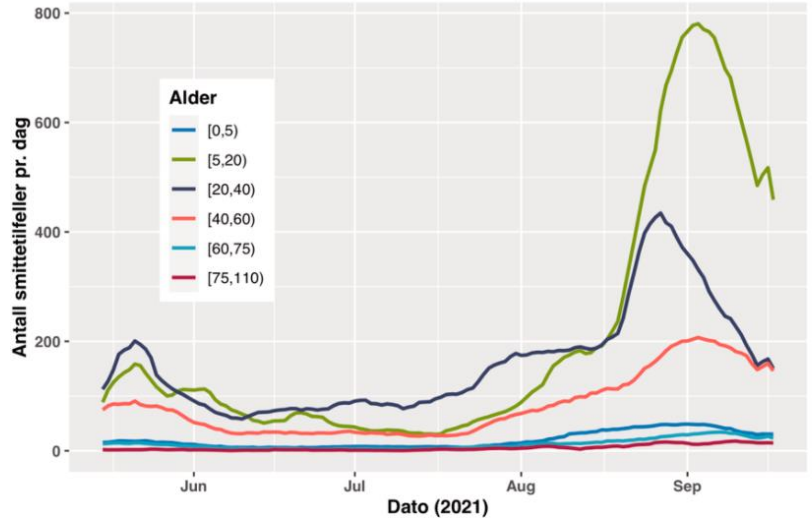
Other decisions important for the public based on Beredt C19

VG 21.september 2021

VG LIVE VGTV VG+ SPORT TV-GUIDE PENT

Antall smittetilfeller pr. dag i aldersgrupper, siste månedene

7 dagers glidende gjennomsnitt



DALER: Disse grafene viser at smitten går sterkt ned i aldersgruppene 5–20 og 20–40. Dette er en klar vaksineeffekt. Gruppen 40–60 går svakt nedover. Dette er en gruppe som har vært vaksinert i en tid, som forklarer hvorfor den ikke går så bratt nedover 75–110 år: dette er den eneste som går svakt oppover, men stigningen er marginal. Foto: Skjermbilde

Dette er grafen som kan åpne Norge

Dagens medisin 11. October 2021

DAGENS Medisin

Nyheter DMTV Debatt Pharma DM Arena Om oss

Nylig gikk Folkehelseinstituttet ut med en oppfordring om at menn under 30 år bør vurdere å velge koronavaksinen fra BioNTech og Pfizer, Comirnaty. FHI har også anbefalt at personer under 18 år får tilbud om samme vaksine.

Norske data fra registeret Beredt C19, viser at bivirkningen myokarditt, hjertemuskelbetennelse, har oppstått hyppigere etter vaksinasjon med Modernas koronavaksine, Spikevax, enn Cominaty.

Mer enn 4 millioner personer har fått første dose koronavaksine og 3,6 millioner personer har fått andre dose koronavaksine i Norge.

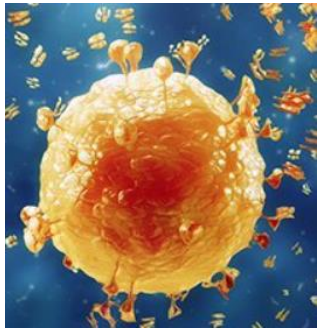
Av disse har 28 personer vært innlagt på sykehus med myokarditt etter første dose og 61 personer etter andre dose.

– Selv om bivirkningen er sjelden, ser vi at det er en høyere forekomst av myokarditt blant unge menn etter andre dose Spikevax, sier assisterende direktør Geir Bukholm ved **Folkehelseinstituttet til FHIs nettsider.**

Men below 30 years should not receive the Moderna Vaccine

FHI Folkehelseinstituttet

Swineflu 2009



www.fhi.no og The New England Journal of Medicine, 16.1.2013

Four years after the pandemic

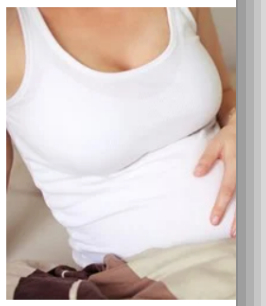
Forside > Nyheter fra FHI > 2013 > Pandemivaksinasjon økte ikke risikoen for dødfødsel

FORSKNINGSFUNN

Pandemivaksinasjon økte ikke risikoen for dødfødsel

Publisert 16.01.2013 Oppdatert 01.03.2016

Gravide som under pandemien ble vaksinert mot influensa hadde ikke økt risiko for dødfødsel. Gravide som fikk influensasykdom hadde derimot økt risiko for dødfødsel. Dette viser en registerstudie med kvinner som var gravide under svineinfluensapandemien i 2009. Studien er publisert i The New England Journal of Medicine .



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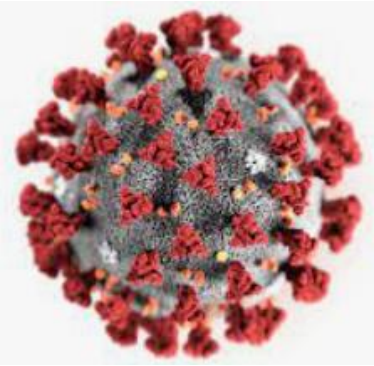
Read in English Skriv ut

Covid-19 2021



New England Journal of Medicine 20. October 2021

The NEW ENGLAND JOURNAL of MEDICINE

CORRESPONDENCE

Covid-19 Vaccination during Pregnancy and First-Trimester Miscarriage

TO THE EDITOR: Pregnant women with coronavirus disease 2019 (Covid-19) are at increased risk for adverse outcomes, and Covid-19 vaccination is recommended during pregnancy.[1,2] However, safety data on Covid-19 vaccination during pregnancy remain limited.[3,4]

vaccination and miscarriage or confirmation of ongoing pregnancy was 19 (Fig. S2). Among women with miscarriages, the adjusted odds ratios for Covid-19 vaccination were 0.91 (95% confidence interval [CI], 0.75 to 1.10) for vaccination in the previous 3 weeks and 0.81 (95% CI, 0.69

Aftenposten 20. October 2021

Aftenposten A-magasinet Oslo Sport Meninger Søk

Ingen tegn til økt risiko for spontanabort etter koronavaksinasjon i første trimester

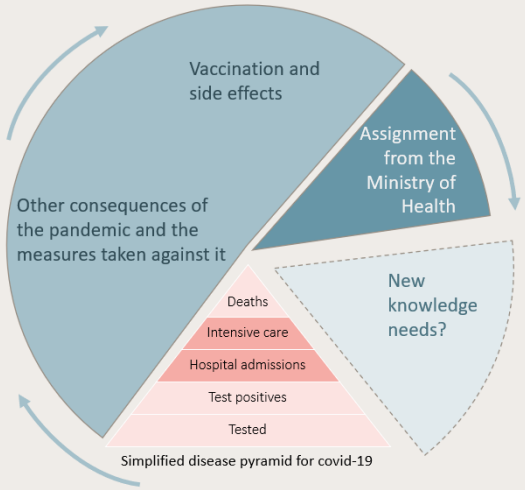
The way forward – Beredt C19

Step 1

Extend until 2022 with the same aim – knowledge to handle ***this pandemic*** - ***<u>New date 31.12.2022</u>***

Step 2

The Health Contingency Act § 2-4 – The Ministry of Health can decide to further extend the duration of a preparedness register to after the pandmic is *«over and evaluated»* - ***when it is necessary to provide knowledge about long-term effects***



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Success to learn from and build on

- We learned from the previous pandemic and created such an opportunity in the Health Contingency Act
- Expertise in central health administration (FHI and Hdir) to actually make this happen
- Good willingness to cooperate between those involved
- Utilized the value in Norwegian health data and registers (both real-time and historical data)
- Researchers spend time on analysis instead of obtaining data…..

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Lessons to learn from - for future work

Some processes took longer than needed, i.e. for the reasons below

- Legal barriers and ambiguities in the use of various registers (especially beyond health data)
- Lack of infrastructure for big data in FHI
- Limited analysis capacity
- No possibility for researchers outside FHI to access data
- Uncertain duration
- How ‘realize’/produce such knowledge potential between crises?

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Thanks to

All registries – especially the Norwegian Directorate for Health and NIPH

Project team members and all contributors

Teamleaders and researchers – for knowledge production and project contribution

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Folkehelseinstituttet

Helseberedskapsloven § 2-4 siste ledd

‘Opplysningene skal slettes eller anonymiseres når hendelsen er avklart og evaluert. Departementet kan bestemme at helseopplysninger likevel kan behandles etter at hendelsen er avklart. Dette kan bestemmes når det er nødvendig for å gi kunnskap om langtidseffekter og samfunnets interesse i den videre behandlingen klart overstiger ulempene som kan påføres den enkelte’

‘The information must be deleted or anonymised when the incident has been clarified and evaluated. The Ministry may decide that health information may be **processed after the incident** has been clarified. This can be determined when it **is necessary to provide knowledge about long-term effects** and society's interest in the further treatment clearly exceeds the disadvantages that can be inflicted on the individual.’

Organizaton – in the shadow of ‘Smittestopp’

Project owner (datansvarlig): Gun Peggy Knudsen, ass.dir. FHI

Steering comitte: Leader Kjetil Telle

- Approve analytical teams ‘Mini-protocols’

Project manager: Anja Lindman

Technical project manager: Gutorm Høgåsen

Team leaders and analysts – DUGNAD and joint effort

Contributors – legal, IT and a several others of others

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