

Nivel Primary Care

Database:

An unique datasource for
(public) health research

On behalf of my colleagues at Nivel-PCD:

Nienke Veldhuijzen

Coordinator Nivel Sentinel Practices

Sciensano – Primary Care Study Day

15 October 2024



NIVEL

Research for better care





Global Handwashing Day

October 15

Reduce respiratory illnesses, like colds, in the general population by about 16%–21%

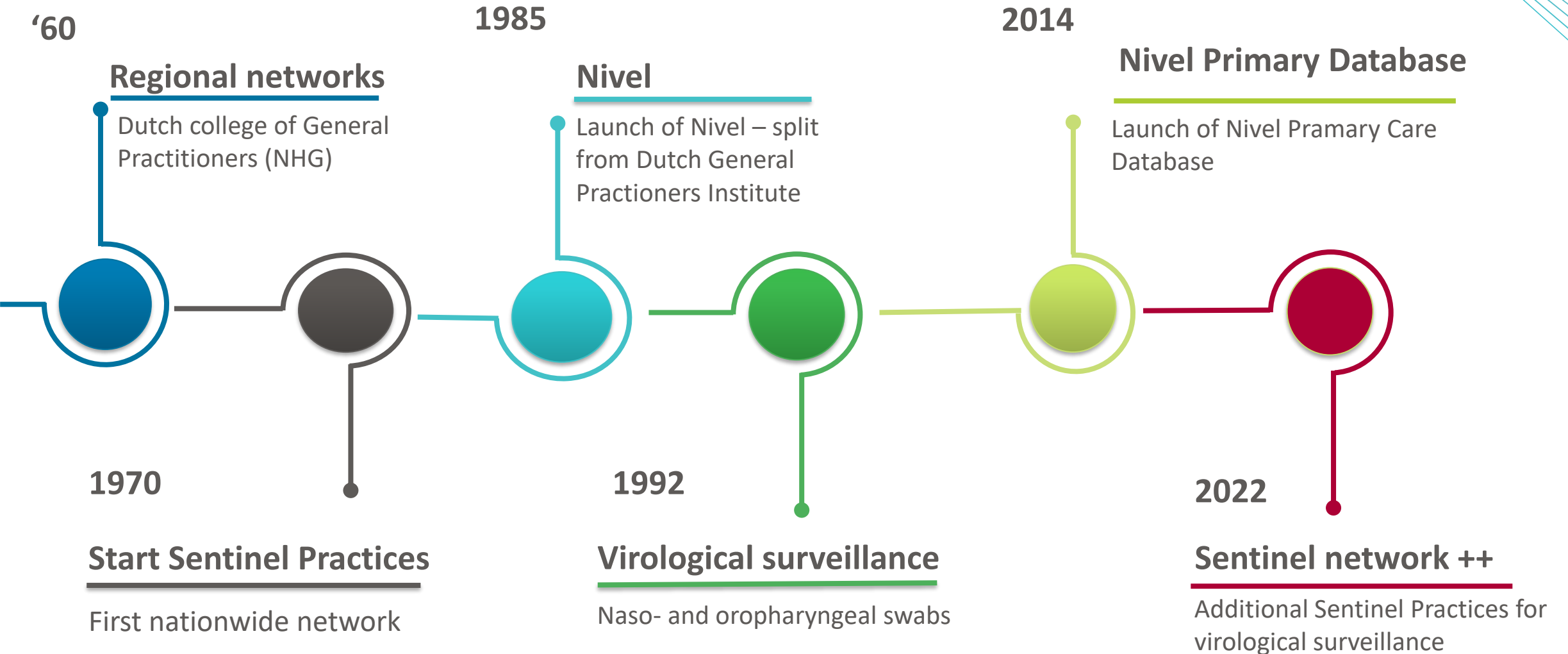
[Global Handwashing Day | Clean Hands | CDC](#)



Content

1. Nivel
2. Nivel Primary Care Database
3. Surveillance and Sentinel practices
4. Reflections on the role of Nivel PCD in pandemic preparedness

1. Nivel: short history



Office premises (Utrecht)



170 employees

- 110 researchers
- 60 research-related functions / business operations



Nivel

Mission

Nivel carries out high quality health services research with a demonstrable impact upon society.
“Research for better care”

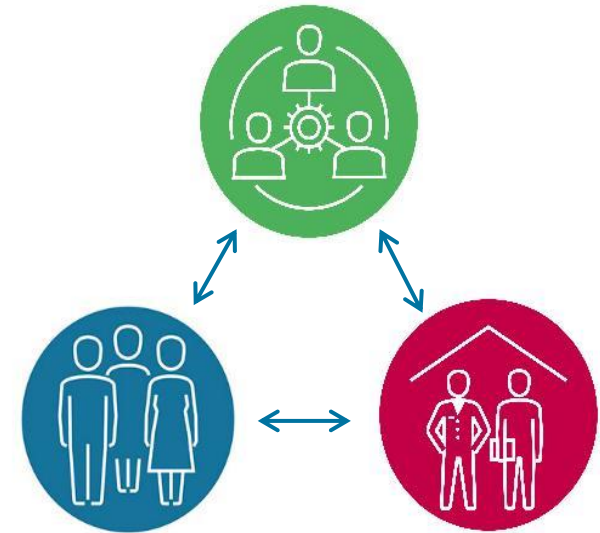
Core values

Societal relevant
Scientifically reliable
Creating connections
Independent but engaged



The organisation of healthcare (systems)

Insurers, Governments and Regulators



The users of healthcare (systems) Patients and Citizens

The care providers
GPs, Nurses, Physiotherapists,
Clinics and Hospitals

Our broad base of knowledge

2 registries and 4 panels

Nivel Primary Care Database

- **primary care data** on health and illness, care use, prescriptions, referrals
- **>400 GP practices** and data on **1.9 million patients**
- **GP out-of-hours services** covering an area of 12 ml citizens
- **paramedical data** of 450,000 patients

Healthcare Professionals Registries

- **labour market** professions in primary care
- **inflow, progress and outflow** professions and educational programs
- Example themes: **regional labour market, task shift**

Dutch Healthcare Consumer Panel

- over 11,000 citizens (general population)
- Example theme: **quality of care from the perspective of citizens**

Dutch Nursing Staff Panel

- 2,500 Nursing Assistants (NAs), Registered Nurses (RNs) and social workers
- Example theme: **collaboration between medical and social domain**

National Panel of the Chronically ill and Disabled

- over 4,000 independent living residents with chronic illness or physical disability
- Example themes: **care and (labour) participation**

Panel Living Together

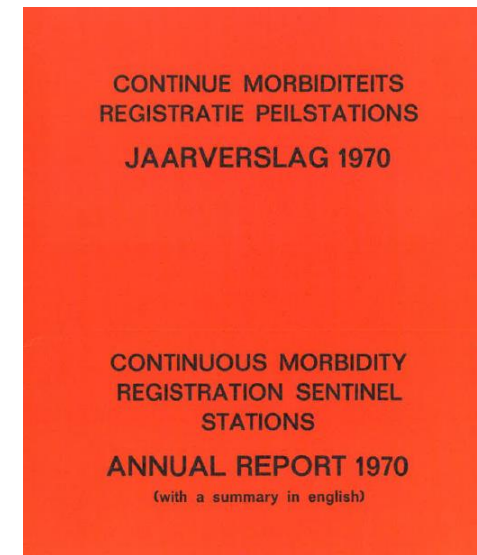
- 500 people with a mild or moderate intellectual disability and 350 relatives of people with an intellectual disability
- Example themes: **daily life, quality of life**

Data collection then

**Weekstaat t.b.v. centrale registratie
continue morbiditeitsregistraties peilstations Nederland**

		Code peilstat.		Week no.																			
		7015																					
Leeftijdsgroep	Influenza (achtig ziekkehoest)	Levenslange ontdekkings	waterpokken	Consult i.v.m. rook- verslaving ⁸⁾		Succedel(ping) ⁷⁾	Urethritis bij man ⁶⁾	CAIDS ⁷⁾ (zoorn: moed. AIDS)	Gastro-enteritis				Opgenaste zwaarfijnschap ⁹⁾	Sexuele problematiek ⁹⁾		Kinkhoest ¹⁰⁾	Sportletseis ¹¹⁾		Sexueel geweld ¹²⁾	Leeftijdsgroep	Incidenteel onderzoek		
				geen kees- kweek	kees- kweek				M	V	M	V		M	V		M	V				M	V
	M+V	M+V	M+V	M	V	M+V	M	M+V	M	V	M	V	V	M	V	M+V	M	V	M	V		M+V	
1	< 1															//						< 1	verzoek om euthanasie
2	1-4								//	///												1-4	
3	5-9			//						/												5-9	
4	10-14																					10-14	
5	15-19												/				//					15-19	
6	20-24	///						/								/						20-24	anorexia/ boulimia en vreetbui- stoornis
7	25-29													/								25-29	
8	30-34	//																				30-34	
9	35-39								/		/											35-39	
10	40-44																					40-44	
11	45-49																					45-49	terminale sedatie
12	50-54	/																				50-54	
13	55-59																					55-59	
14	60-64																					60-64	
15	65-69	///																				65-69	
16	70-74																					70-74	
17	75-79		/																			75-79	
18	80-84																					80-84	
19	≥ 85																					≥ 85	

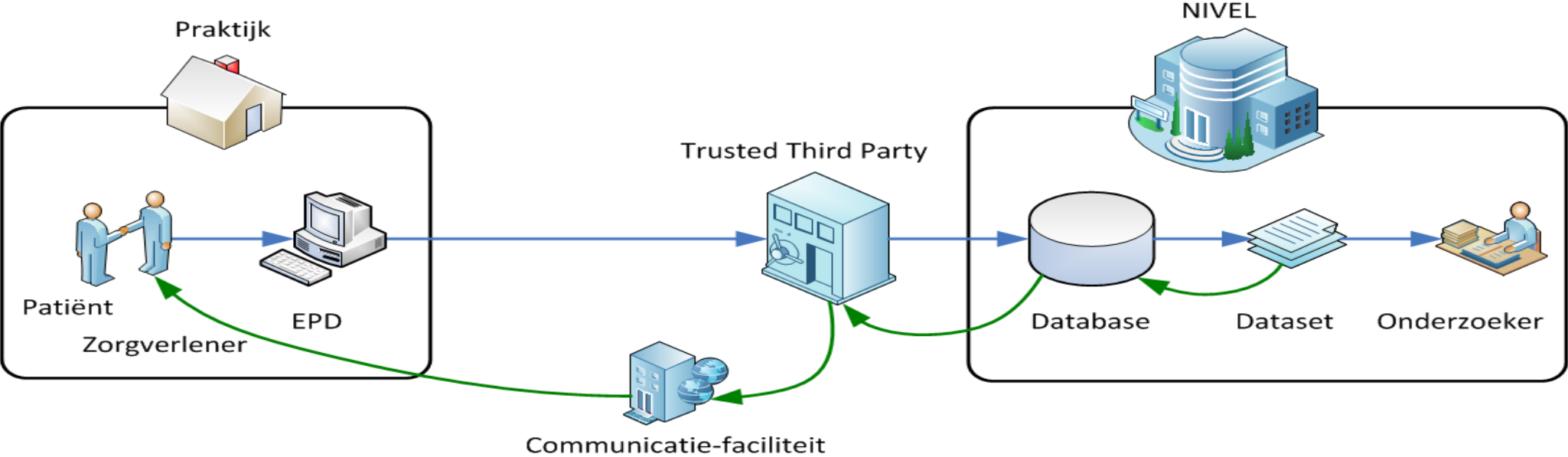
Week nummer: 49 Opgemaakt d.d.: 30-11-2005 Aantal dagen gerapporteerd (zie voetnoot 1) 0 1 2 3 4 5 6
Zie ommezijde voor voetnoten



Infectious diseases: influenza; chicken-pox; urethritis (male); AIDS; gastro-enteritis; whooping cough

Other topics: end-of-life care; smoking addiction; sexual violence; unplanned pregnancy; sexual health; sport injuries

Data collection now





Data governance and privacy

- Secondary use without individual consent allowed under Dutch law
- Opt-out for patients
- Trusted Third Party (ZorgTTP): pseudonymisation of data *before* data export out of the EHR system

- Governance structure to safeguard Nivel-PCD activities
 - Steering committee
 - Scientific committee
 - Privacy committee
 - Advisory committees



Adherence to national and international standards
(including GDPR and applicable ISO standards)

GP then



96,7%

P. Groenewegen. De opbouw van de beroepsgroep huisartsen 1970-1979 (Nederlands Huisartsen Instituut 1979)

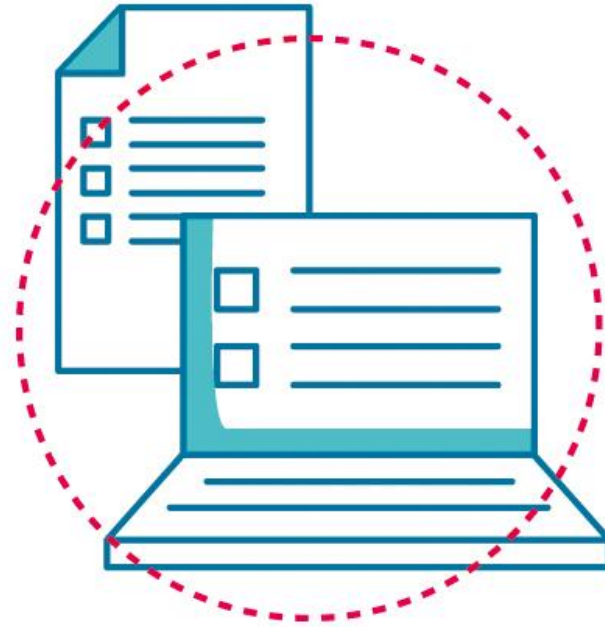
GP now



60,6%

Batenburg, R., Flinterman, L., Vis, E., Schaijk, A. van, Kenens, R.J., Duijkers, B. Cijfers uit de Nivel-registratie van huisartsen en huisartsenpraktijken: een actualisering voor de periode 2020-2022



2. Nivel Primary Care Database

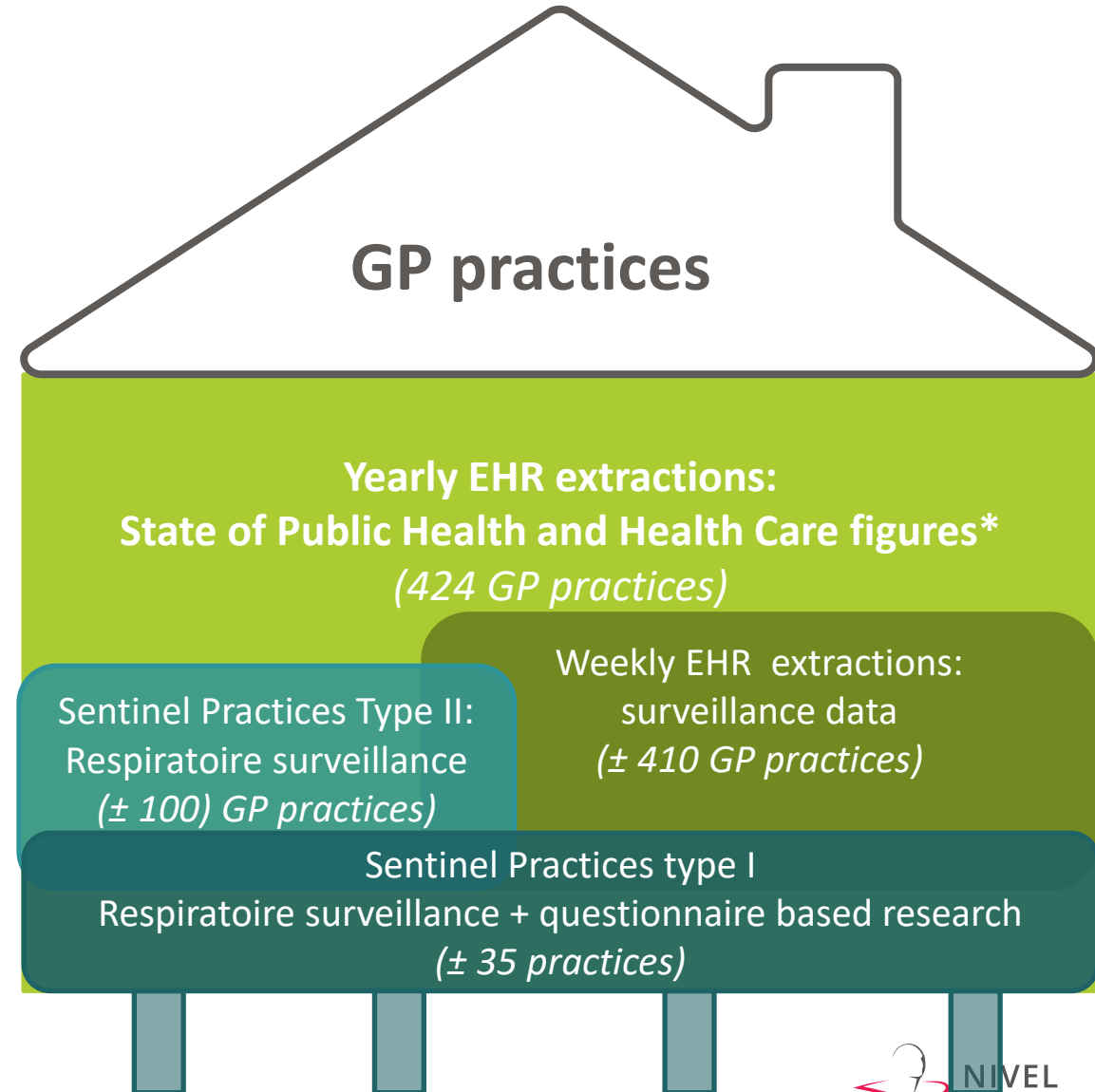




Data purpose and collection methods

What does it involve for the GP?

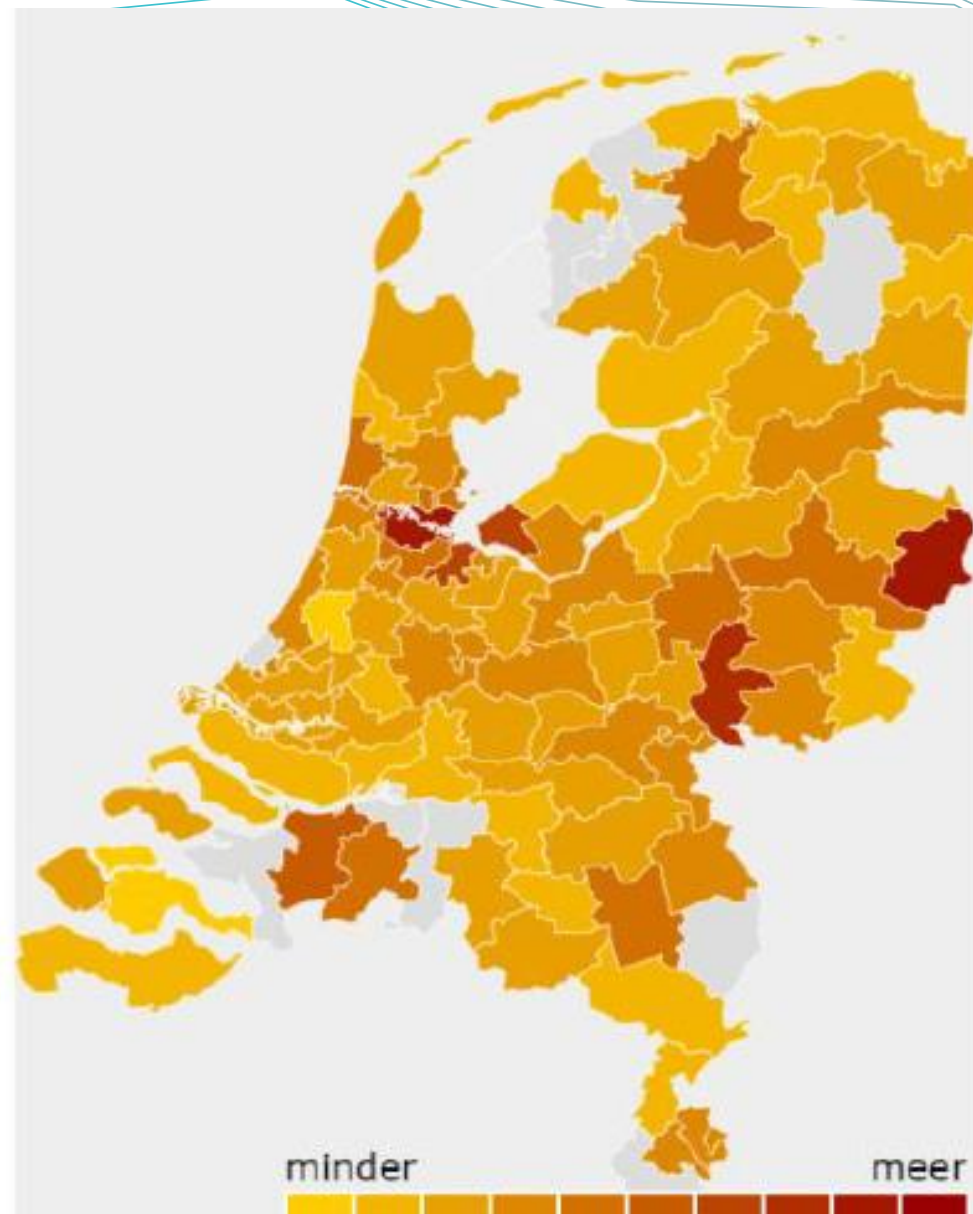
-  Active data collection
-  Passive data collection (EHR data extraction)



*example of use of yearly data in Nivel-PCD.

GP practices

- Nationwide participation
- 424 participating GP practices
- Coverage: 10% of the Dutch population
 - 1.9 million persons

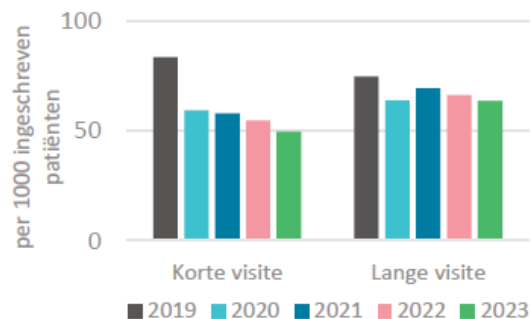


General practitioner care: key figures 2023

Care provided

More than $\frac{3}{4}$ (78,1%) of registered patients consulted the GP at least once in 2023

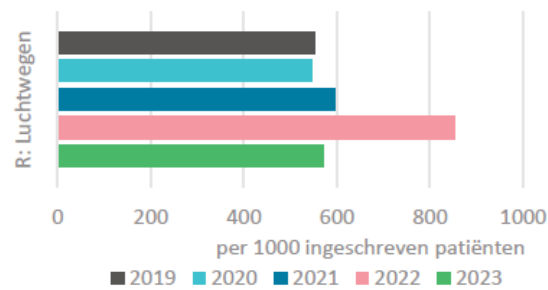
Both the number of short and long home visits have decreased compared to previous years



Health problems

Urinary tract infections the most common diagnosis in 2023 (156 contacts/1000 patients)

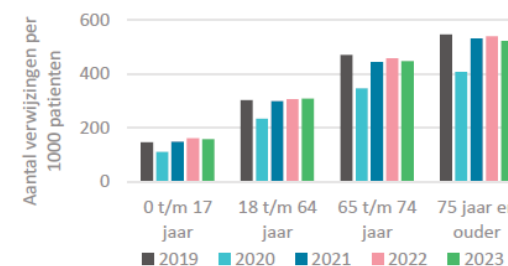
Respiratory tract symptoms and diseases decreased by 33,1% , after an increase of 43,1% in 2022.



Policy: prescriptions and referrals

0-17 years old: medication for eczema, impetigo and earinfection
18-44 year olds: contraception and hayfever medication; 45+ high bloodpressure medication.

A minor decrease in referrals among the youngest and oldest age groups.



Key figures (example):

Online table


Jaar: 2023				INCIDENTIE			PREVALENTIE		
jaar	ICPC	titel		tot	man	vrouw	tot	man	vrouw
+	2023	A01	Gegeneraliseerde pijn	4,8	3,1	6,4	5,6	3,6	7,5
+	2023	A02	Koude rillingen	0,4	0,4	0,4	0,4	0,4	0,4
+	2023	A03	Koorts	19,6	19,8	19,5	18,4	18,5	18,4
+	2023	A04	Moeheid/zwakte	49,4	32,5	66	44,6	29,8	59,3

Cijfers Ziekten op jaarbasis in Nederland - incidentie en prevalentie | Nivel


Public Health Foresight Study

- RIVM (National Institute for Public Health and Environment)
- Insight in the developments in public health and services in the period to come
- Every four year, on behalf of the Ministry of Health, Welfare and Sports

Current themes

 Pharmaceutisch Weekblad
PW

Tekorten Ozempic houden aan tot eind van het jaar —

 Therapeutic Goods Administration
<https://www.tga.gov.au/shortages> · [Vertaal deze pagina](#) ⋮


About the Ozempic (semaglutide) shortage 2022 - 2024

29 aug 2024 — The worldwide **shortage** of semaglutide started to affect Australia in early 2022 when Novo Nordisk couldn't supply enough **Ozempic** to meet an ...

 Diabetes UK
<https://www.diabetes.org.uk/our...> · [Vertaal deze pagina](#) ⋮

Our response to serious supply issues of drugs for people ...

13 sep 2024 — There is still intermittent supply and **shortages** of some GLP-1 agonists including **Ozempic**, (injectable semaglutide), and some of these are ...

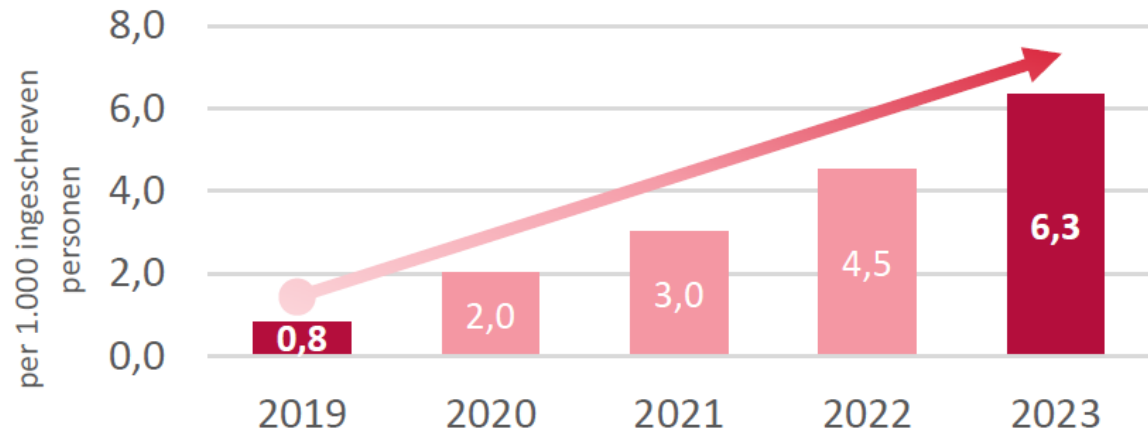
 De Standaard

Na Ozempic nu ook tekort aan tweede diabetesmedicijn

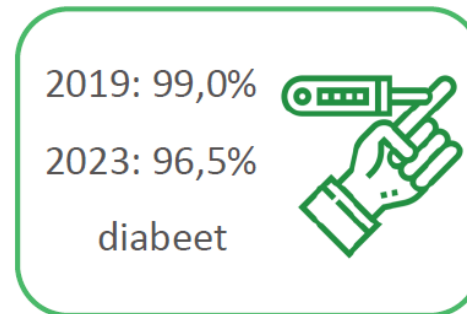
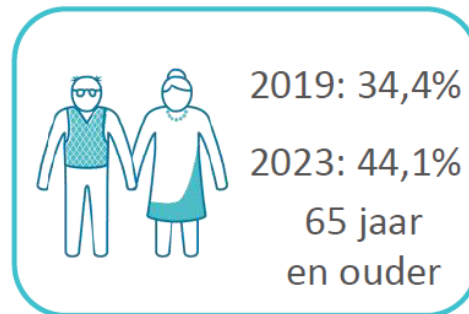
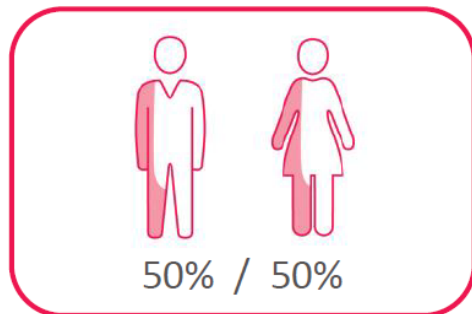
3 mrt • Van Maxie Eckert

Contributions to current themes (examples)

Semaglutide prescriptions bij general practitioners



Number of persons with ≥ 1 semaglutide prescription



Off-label use for obesity/overweight increased from 0% in 2019 to 1,4% in 2023.

Data requests by external parties

Conditions

- The results of the concerning research must be published open access.
- At least one researcher from Nivel Primary Care Database is actively involved as a co-author in the publication of the concerning research.
- Nivel only provides data necessary for answering the research questions posed.
- Use of the provided data is only allowed for the research purpose and questions wherefor approval is given.

Approvals / advice

- The appropriate scientific committee
- The Privacy Committee in case of data-linkage with other data sources.

3. Surveillance and Sentinel Practices



Flu epidemic at its peak

Griepepidemie bereikt top

DEN HAAG, donderdag (ANP). — De griepepidemie heeft in Nederland nu haar top bereikt. Dit is de indruk van dr N. Mazurel, viroloog en hoofd van het regionaal influenzacentrum van de Wereld Gezondheids Organisatie. Dr Mazurel voegt eraan toe dat ook nu de griep haar hoogtepunt heeft bereikt, de omvang van de epidemie ver beneden die van de winter 1969—1970 is gebleven.

Deze opvatting wordt onderstreept door de cijfers van het ministerie van volksgezondheid en milieuhygiëne. In januari 1970 — het hoogtepunt van de toenmalige griepepidemie — werden door de peilstations 140 influenzapatiënten per week per 10.000 inwoners gemeld; op dit ogenblik 60 patiënten per week per 10.000 inwoners.

Bij onderzoeken op laboratoria is vastgesteld, dat de griep, die thans in Nederland heerst, behoort tot het type Hongkong A 2, hetzelfde type als in 1970.

Volgens dr Mazurel is de epidemie gelijkmatig over het land verspreid en concentreert zij zich niet op bepaalde gebieden.

Het Parool
(13/01/1972)

In Westen van het land
Eerste geval van Russische griep in Nederland

UTRECHT - Bij een achttienjarige grieppatiënt in het Westen van Nederland is het virus van de zogenaamde „Russische stam” geïsoleerd. Het is bij het ministerie van Volksgezondheid nog niet bekend, op welke manier de jongeman de Russische of Moskougriep heeft opgelopen. Het is het eerste geval van Russische griep dat in ons land is gesignaleerd.

Overigens vertonen de voorlopige cijfers van het aantal mensen met „influenza-achtige ziektebeelden” zoals het ministerie dat noemt, een dalende tendens. Voor de zesde week van dit jaar kwam men via de gegevens van de huisartsen die als „peilstations” fungeren tot een landelijk gemiddelde van 99 grieppatiënten per 10.000 inwoners. In de afgelopen week was dat waarschijnlijk nog maar 88 per 10.000. Bij al deze mensen is de griep veroorzaakt door een aan de a-Victoriastam verwant virus.

Leeuwarder courant
(22/02/1978)

First case of Russian flu in the Netherlands

Flu epidemic in the Netherlands, but fewer GP consultations for covid-19

NIEUWS

Griepepidemie in Nederland, maar minder mensen met corona naar huisarts



De jaarlijkse griepepidemie is begonnen. Afgelopen week kampten 70 op de 100 duizend Nederlanders met ‘griepachtige klachten’. Het aantal mensen met een coronabesmetting neemt daarentegen af.

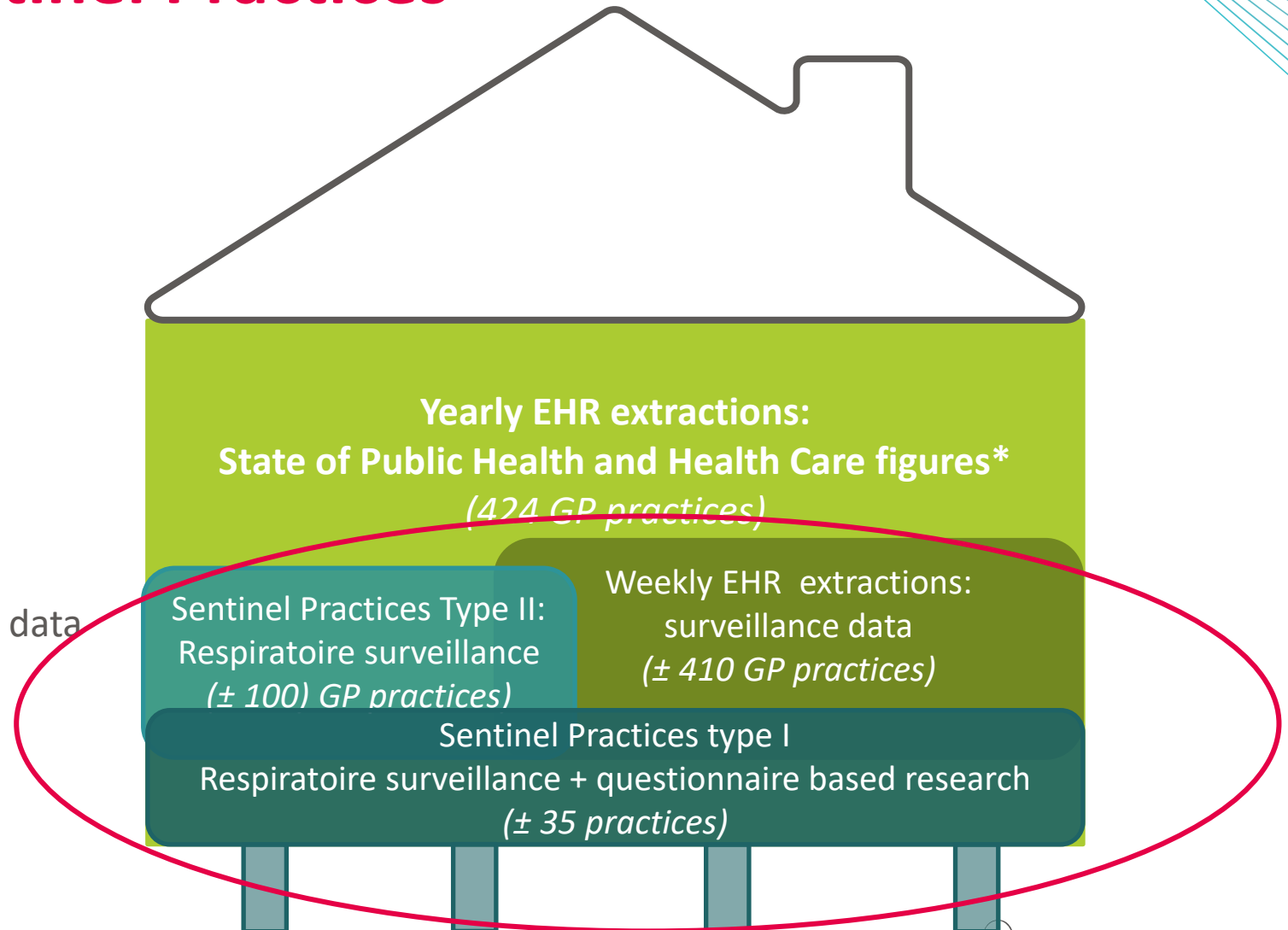
Famke Seine 24 januari 2024, 19:22

NOS (24/01/2024)

Surveillance and Sentinel Practices

What does it involve for the GP?

-  Active data collection
-  Passive data collection (EHR data extraction)

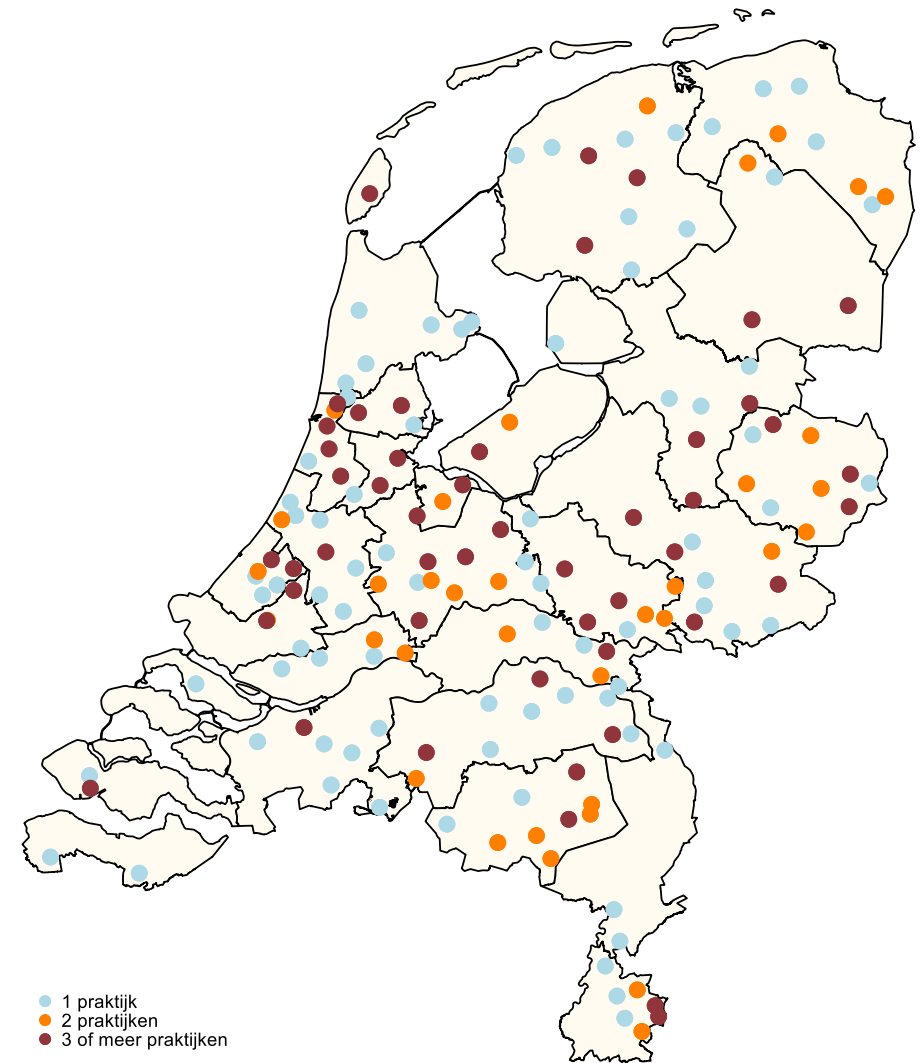


Surveillance

- **Weekly data** extraction from electronic health records
- ~410 participating general practices
- Syndromic surveillance
- Stratification by age groups, sex, region, urbanisation

➔ Signals reported to RIVM weekly meeting for infectious diseases

➔ Publication weekly Surveillance Bulletin on www.nivel.nl/surveillance



Surveillance with data general practitioners

Detection of (unusual) rises of disease and health care use

due to:

- viruses
- heat or cold
- environmental factors

but also:

- medicines (shortage)
- interventions

for:

- ➔ early warning
- ➔ awareness
- ➔ reassurance



Surveillance bulletin

Number of children (0-14 yrs) with impetigo, per week



Highest number of consultations for impetigo since years

Onderzoeksinstituut Nivel

Veel jonge kinderen deze zomer met krentenbaard naar huisarts, hoogste aantal in jaren



Example: Start of COVID-19 pandemic

- No diagnosis code yet (ICPC)
 - Advice from Dutch College of General Practitioners:
 - **Suspected case** of SARS-CoV-2 / COVID-19:
R74 - Acute upper respiratory infection AND **episode text “suspected COVID-19”**
 - Patients **with SARS-CoV-2 / COVID-19**:
R83 - Respiratory infection other AND **episode text “COVID-19”**
- ➔ ICPC codes only not specific for COVID-19 surveillance ➔ we had to use the text as well

Surveillance using routine GP data

the added value of free-text descriptions

Methods

Review of free-text description of diagnoses

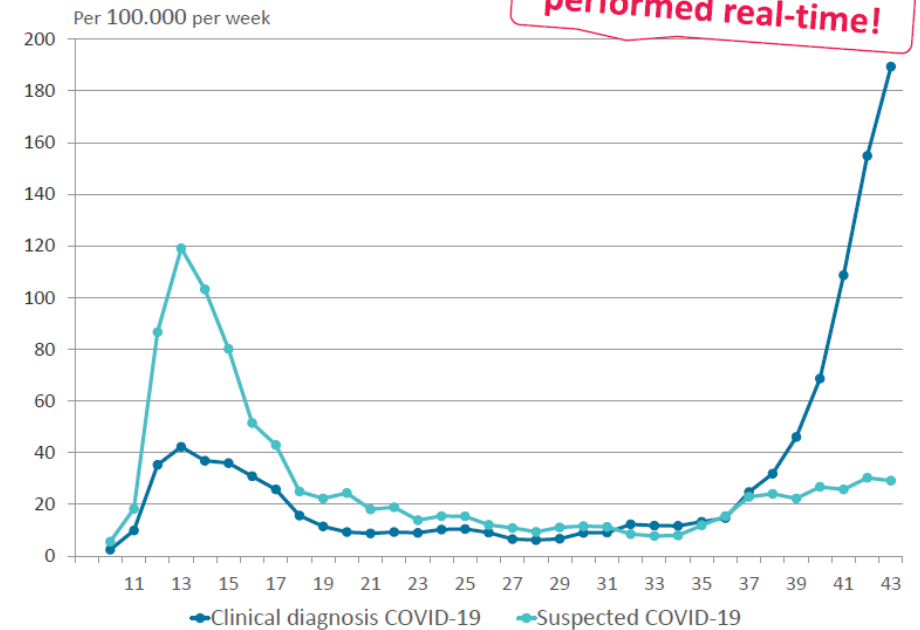
COVID-19

- Diagnoses of respiratory infections or symptoms, Feb-Oct 2020
- Professional guidelines for free text
- Search for 'covid', 'corona', 'sars'

Separate analyses for mpox and gastro-enteritis

Conclusions

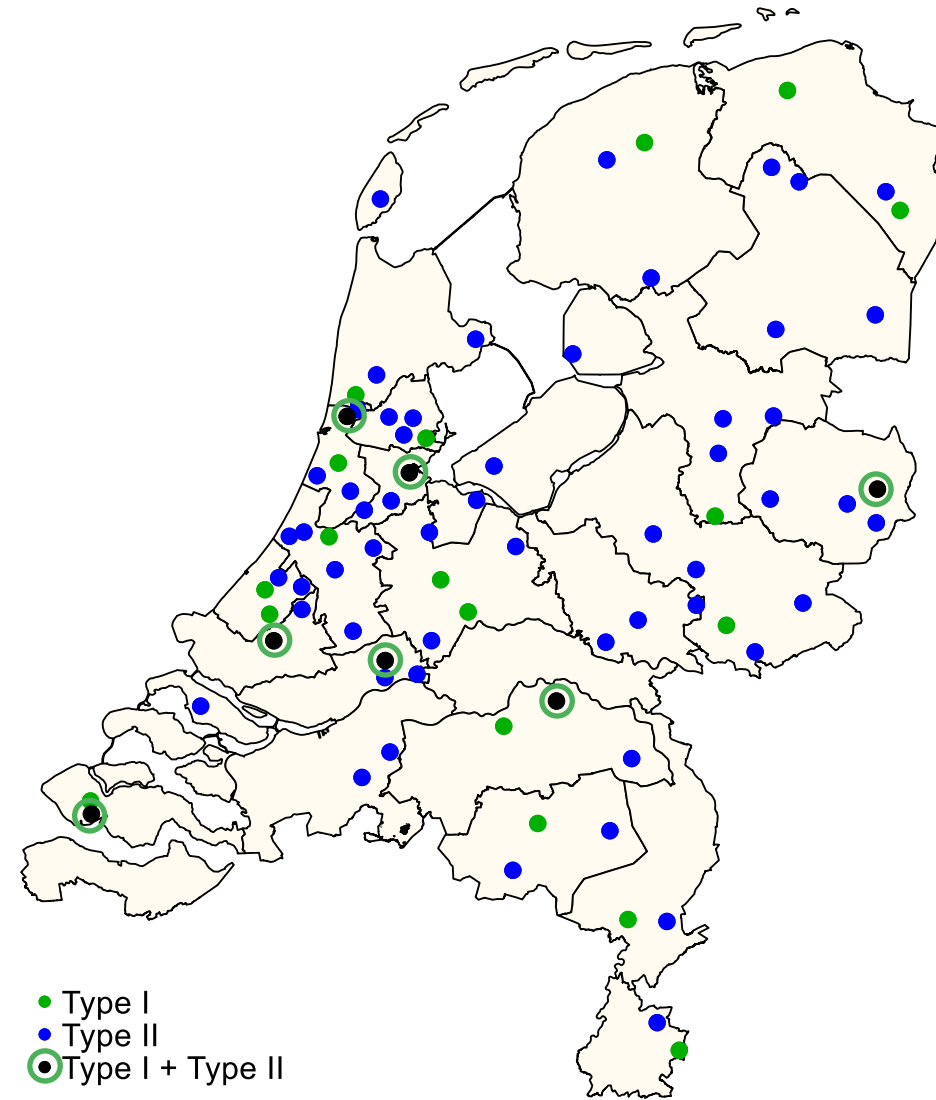
- In general, GPs make limited use of the option to add free-text descriptions to ICD-coded diagnoses.
- However, for COVID-19, there were specific recommendations by the Dutch College of General Practitioners at the beginning of the pandemic, that facilitated real-time monitoring in primary care.



Sentinel Practices

- Type I (N=~35)
 - Influenza like illness
 - Oropharyngeal + nasopharyngeal swabs
 - Questionnaire based research
- Type II (N=~100)
 - Oropharyngeal + nasopharyngeal swabs

→ Collaboration with RIVM



Epidemiological surveillance of respiratory infections

Type I Sentinel Practices

- Real-time registration influenza-like illness

ICPC-code

R74 Acute respiratory infection (upper airway)

R74.01 Common cold

R74.02 Acute pharyngitis

R75 Acute/chronic rhinosinusitis

R75.01 Acute rhinosinusitis

R77 Acute tracheitis/laryngitis

R77.01 Laryngitis subglottica

R77.02 Acute epiglottitis

R78 Acute bronchitis/bronchiolitis

R80 Influenza (excluding R81)

R81 Pneumonie

R81.01 Legionella pneumonie

R83 Andere infectie(s) luchtwegen

R83.03 SARS-CoV-2 (COVID-19)

- **Daily data** availability

ICPC code

Consult

ICPC-code

R74

Consult moment

2023-05-04

“Is this a case of ...”

Case definition

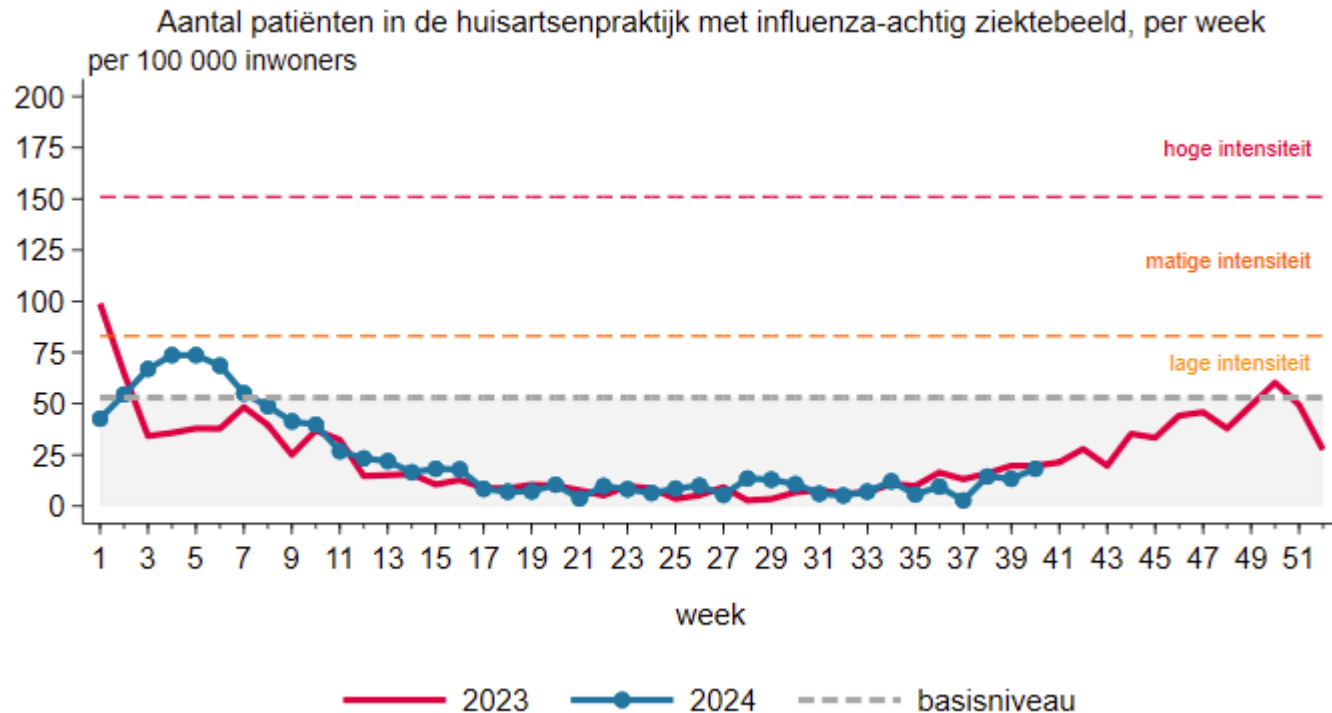
Response (yes/no)

Betreft dit een griepachtig ziektebeeld?

1. acuut begin 2. én verhoogde lichaamstemperatuur $\geq 38^{\circ}\text{C}$ (rectaal of oorthermometer) 3. én ten minste één van de volgende symptomen: hoest, neusverkoudheid, rauwe keel, frontale hoofdpijn, retrosternale pijn, myalgieën Patiënten met een complicatie die aan influenza worden toegeschreven, (b.v. pneumonie (R81) of bronchitis (R78)), dienen ook als IAZ te worden gerapporteerd - mits dat althans nog niet eerder is gebeurd - indien uit de anamnese duidelijk blijkt dat de patiënt kort geleden een influenza(-achtig ziektebeeld) heeft doorgemaakt of dit ziektebeeld nog voortdort

Ja Nee

Surveillance bulletin



Weekly number of patients presenting with influenza-like-illness at the general practitioner

Case definition Influenza Like Illness (ILI):

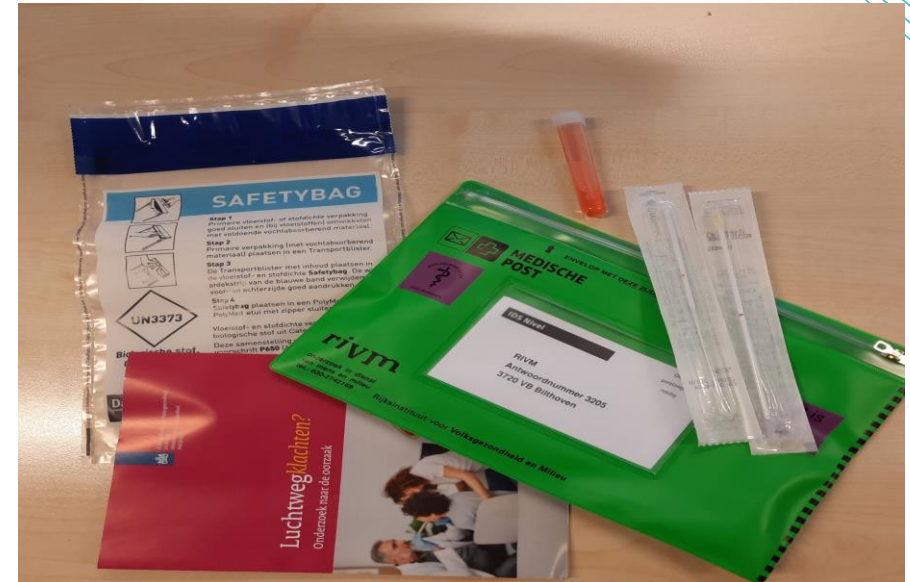
- an acute start
- temperature of at least 38° Celsius
- at least one of the following symptoms: cough, nasal catarrh, sore throat, frontal headache, retrosternal pain, myalgia

Virological surveillance of respiratory infections

Type I + Type II Sentinel Practices

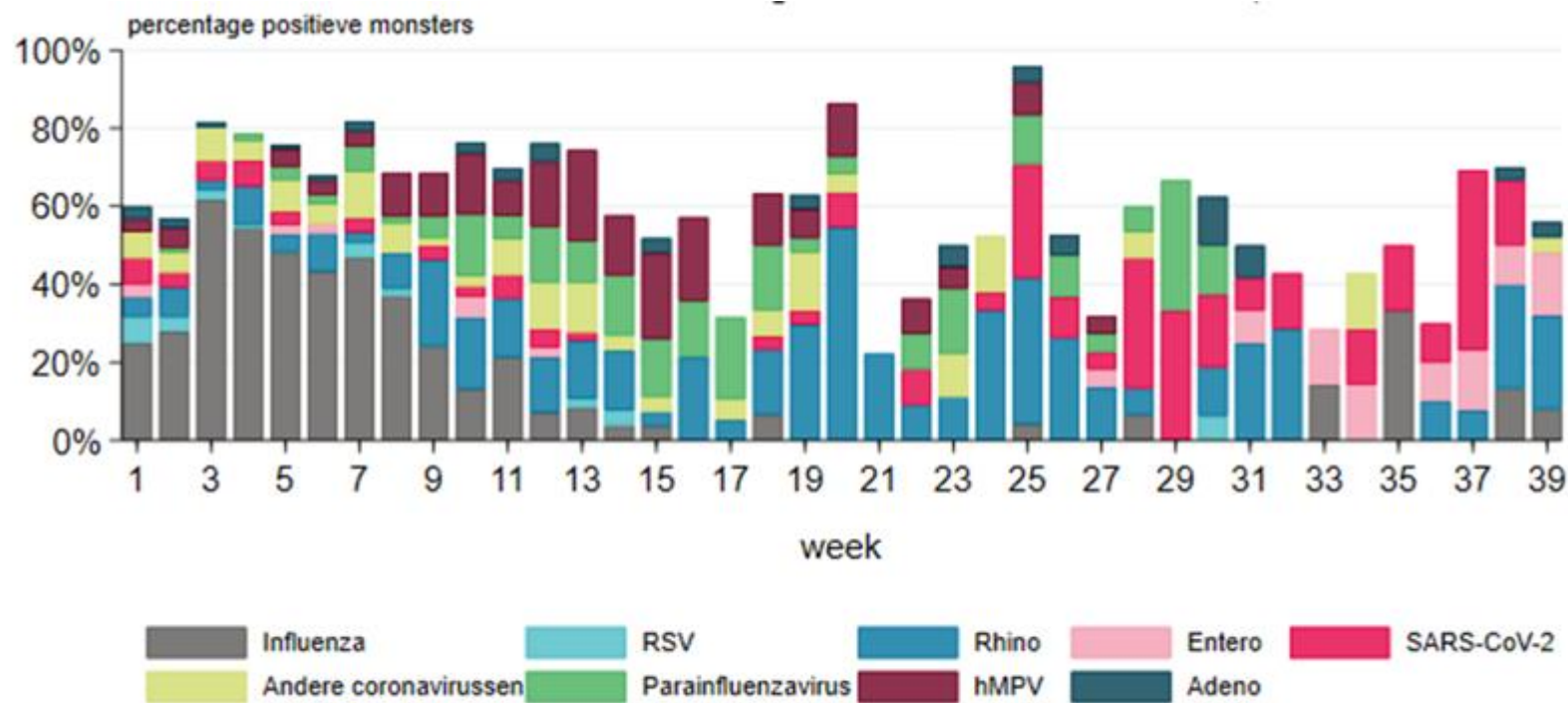
- Nasopharyngeal and oropharyngeal swab collection
 - Influenza like illness
 - Other acute respiratory infection
- 2-5 patients/week
 - At least 1 patient with influenza like illness (ILI)
 - At least 1 child < 10 years
- Preferably within 4 days of onset of symptoms

➔ Swabs sent to RIVM for laboratory processing



Viral detection

Respiratory viruses detected in naso- and oropharyngeal swabs from patients presenting with influenza-like-illness, Nivel Sentinel Practices (2024)

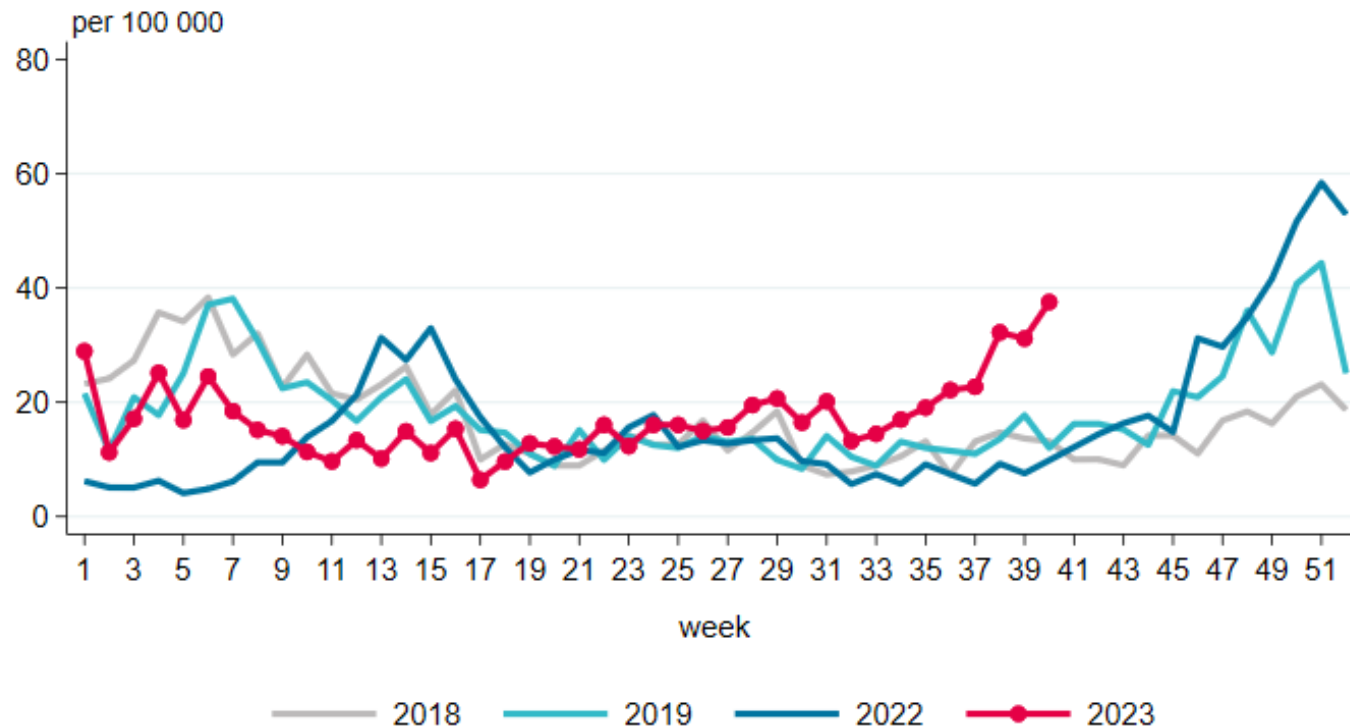


Bron virusgegevens: RIVM-IDS virologie

Example: unusual increase in pneumonia (August 2023)

R81

5 – 14 years

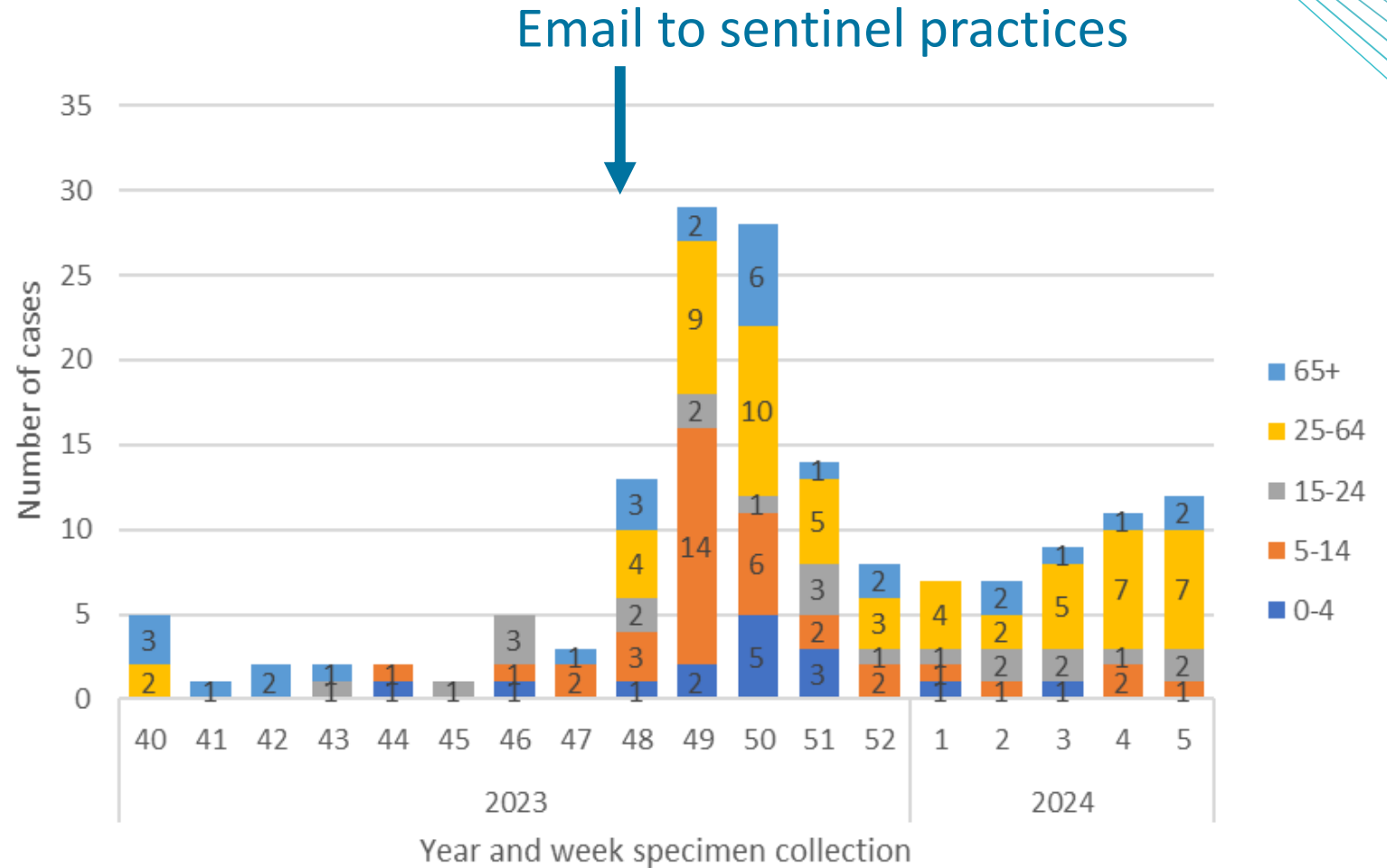


- No signals from virological surveillance in Sentinel Practices
- No signals from participatory surveillance or hospital surveillance
- October 2023: increase in detections of *Mycoplasma pneumoniae* in Dutch laboratories
- November 2023: WHO statement pneumonia among children in China

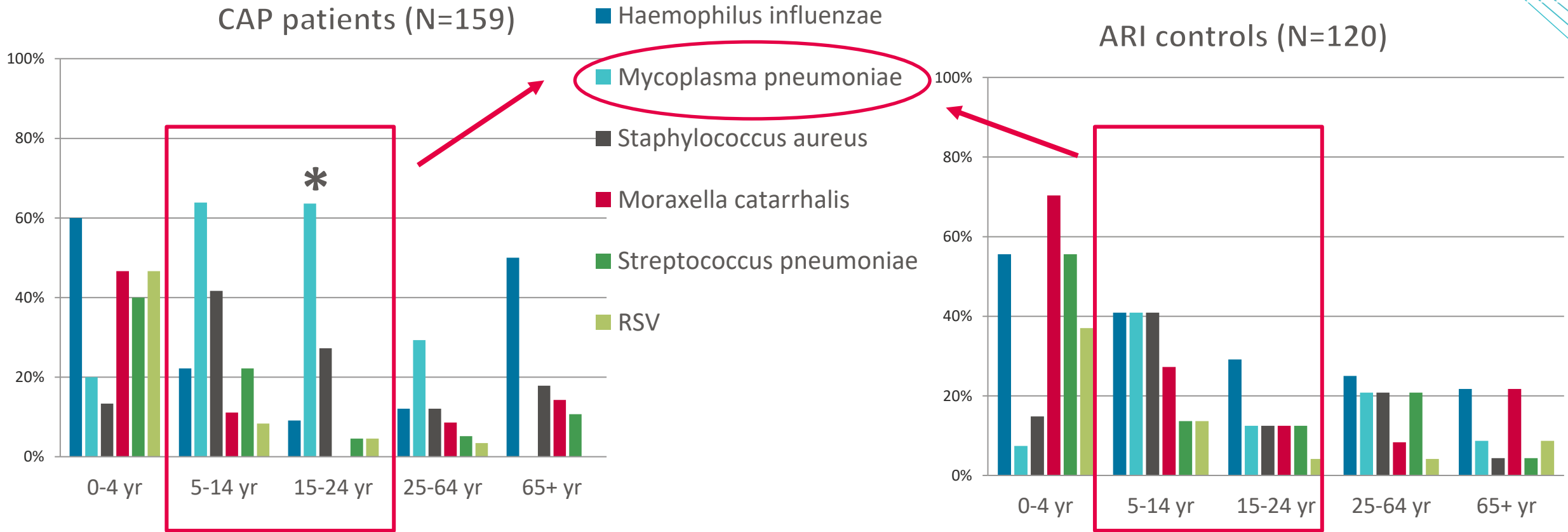
November 2023: enhancing surveillance

Coordination by RIVM

Additional sampling of pneumonia cases



Top-5 bacteria and RSV in CAP patients and controls



* Statistically significantly different (p<0.002)

Findings

- *Mycoplasma pneumoniae* more often in 5-14 yrs and 15-24 yrs with pneumonia (CAP) compared to ARI controls
- *Haemophilus influenzae* often found in CAP 0-4 yr and 65+ age groups

=> Example of good synergy between broad, but less detailed diagnoses from electronic health records, and a flexible system of a smaller group of sentinel practices collecting specimens

U-swab: controlled trial



Recruitment Sentinel Practices (2022)

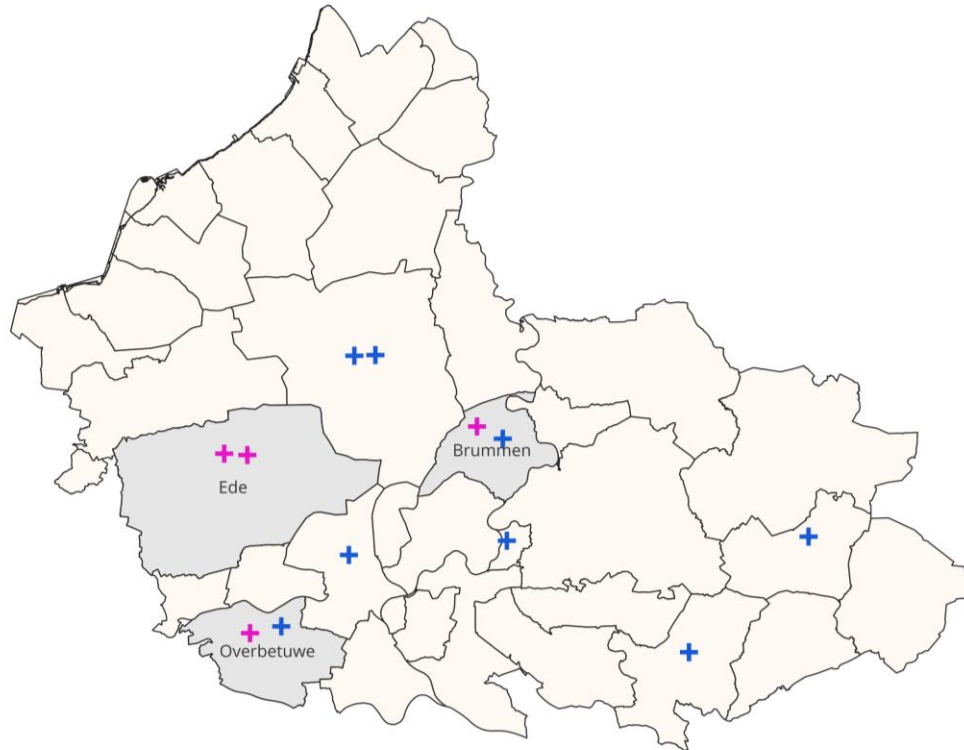
Additional Sentinel Practices for virological surveillance

Context GP practice

- High workload
- Reduced willingness to swab collection among patients
- More emphasis on self-care and remote care

→ Evidence-based innovation of the primary care respiratory surveillance methodology

Intervention and control practices



Nivel Peilstations

+ Controlepraktijken

+ U-swab praktijken

■ Gemeenten

■ Noord- en Oost & Midden Gelderland

- Recruitment of GP practices is almost completed.
- Nov 2024: recruitment of patients for self-swabbing
- Duration: trial period until week 20 2026 (two seasons)
- Results expected Q3/Q4 2026

Questionnaire based research

	2021	2022	2023
End-of-life care	490	212	225
Eating disorders	57	39	41
Palliative care	119	71	
Blepharitis			231

RESEARCH

Open Access


Nudging General Practitioners to explore suicidal thoughts among depressed patients

Elke Elzinga^{1,2*}, Derek P. de Beurs³, Aartjan T.F. Beekman^{4,5}, Otto R. Maarsingh⁶ and Renske Gilissen¹



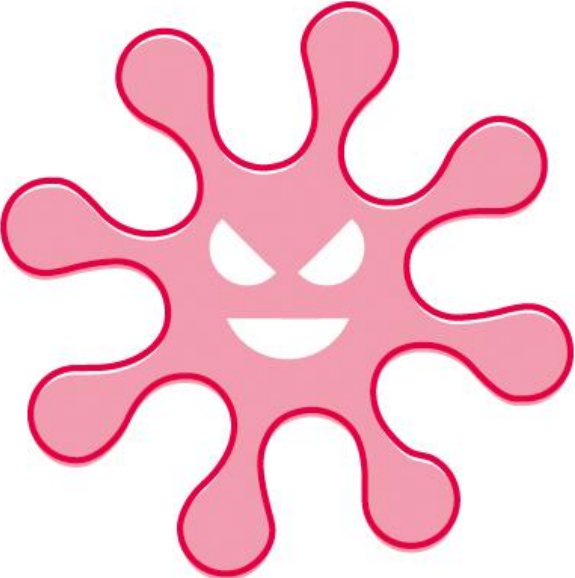
Elzinga *et al. BMC Primary Care* (2023) 24:88
<https://doi.org/10.1186/s12875-023-02043-3>

Increase in incidence of anorexia nervosa among 10- to 14-year-old girls: A nationwide study in the Netherlands over four decades

Annelies E. van Eeden MD , Daphne van Hoeken PhD, Janneke M. T. Hendriksen MD, PhD, Hans W. Hoek MD, PhD

First published: 29 September 2023 | <https://doi.org/10.1002/eat.24064>

Pandemic preparedness



Opportunities

- 😊 GP is first professional to contact
- 😊 All citizens enlisted with a GP → denominator
- 😊 Nationwide representative network
- 😊 Real-time data collection
- 😊 Mutual strengthening of syndromic surveillance network and sentinel practices network
- 😊 Responsive to emerging themes
- 😊 Collaborator in the National Influenza Network
- 😊 Partner of the University Network Primary care (consortium for among others Covid research)

Challenges

- ☹️ Sample; not for case finding or small outbreaks
- ☹️ ICPC not always specific
- ☹️ Impact of changes in healthcare seeking behaviour
- ☹️ Recruitment and retainment of sentinel practices

Thank you for your attention



Special thanks to : Bart Knottnerus; Lucy Overbeek; Joost Vanhommerig; Mariette Hooiveld; Cathrien Kager

Research
for better care

Dr. Nienke Veldhuijzen

COORDINATOR NIVEL SENTINEL PRACTICES

www.nivel.nl/n.veldhuijzen@nivel.nl



NIVEL

Research for better care