

Occupational record linkage studies

Training Course on Introduction to Occupational Epidemiology

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Outline of my lecture

- **What is a record linkage study (= registry study)?**
 - What is a register?
- **How to use registers in occupational health research**
 - How to use registers in research
 - Where to find occupational exposure data
 - Job-exposure matrix (JEM)
- **Strengths and limitations of register-based research data**



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What is a register?

- Usually administrative data, national or regional
- Collected for other purposes than research
- Definition
 - A complete listing
 - Each individual should be identifiable for updating
 - Samples and anonymized complete listings of individuals are not registers

(United Nations Economic Commission for Europe, Wallgren & Wallgren)



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Registers: Some examples

- Central Population Register
- Employment Register
- National Education Database
- Income Register

- Cancer Registry
- Causes of Death Registry
- Patient Registry (Hospital Discharges)
- Sickness Absence Register



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Registers: Some examples

- Central Population Register
- Employment Register
- National Education Database
- Income Register

Exposure or
background data

- Cancer Registry
- Causes of Death Registry
- Patient Registry (Hospital Discharges)
- Sickness absence register

Health outcome data



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How to use registers in research

- Registers must be linked through a linkage key
 - Nordic countries: Unique personal identification numbers
 - Other linkage keys: date of birth, name, address, genetic markers
 - usually a greater risk of error

How to use registers in research

- Registers must be linked through a linkage key
 - Nordic countries: Unique personal identification numbers
 - Other linkage keys: date of birth, name, address, genetic markers – usually a greater risk of error
- Norway:
 - Needs approval from Regional Ethics Committee and Registry owners for each research project
 - The linkage key is kept by an external part (usually Statistics Norway)
 - The population must be well defined
 - Requested variables must be specified in detail
- Denmark: The Danish Data Archive



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Where to find occupational exposure data

- Occupational title or code
 - International Standard Classification of Occupations
 - ISCO-88, ISCO-08, earlier versions ISCO-58, ISCO-68)
 - Other Classifications of Occupations
 - France: Professions et Catégories Socioprofessionnelles (PCS)
 - USA: Standard Occupational Classification (SOC)
 - Industry or industrial code
 - Nomenclature of Economic Activities (NACE)
 - Standard Industrial Classification (SIC)
- Exploratory (agnostic) approach
- Analyses of health outcome risk by occupation and/or industry



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ORIGINAL ARTICLE

Occupation and cancer – follow-up of 15 million people in five Nordic countries

EERO PUKKALA^{1,2}, JAN IVAR MARTINSEN³, ELSEBETH LYNGE⁴, HOLMFRIDUR KOLBRUN GUNNARSDOTTIR⁵, PÄR SPARÉN⁶, LAUFHEY TRYGGVADOTTIR⁷, ELISABETE WEIDERPASS^{3,6,8,9} & KRISTINA KJAERHEIM³

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Table 34. Observed number of lung cancer among men in the Nordic countries and standardised incidence ratios 1961–2005, by country and occupational category.

No	Occupational category	Denmark		Finland		Iceland		Norway		Sweden		Total		
		Obs	SIR	Obs	SIR	Obs	SIR	Obs	SIR	Obs	SIR	Obs	SIR	95% CI
1	Technical workers, etc	3 019	0.91	1 503	0.58	9	0.41	855	0.61	5 154	0.93	10 540	0.82	0.80–0.83
2	Laboratory assistants	70	1.04	55	0.89	3	0.71	51	0.75	17	0.70	196	0.87	0.75–1.00
3	Physicians	144	0.53	45	0.30	6	0.67	82	0.46	178	0.73	455	0.53	0.49–0.58
4	Dentists	36	0.46	9	0.27	[2.08]	0.00	55	0.68	59	0.47	159	0.50	0.43–0.58
5	Nurses	[3.48]	0.00	1	0.20	1	23.30	4	0.56	4	0.42	10	0.40	0.19–0.73
6	Assistant nurses	61	0.78	1	0.25	[0.97]	0.00	24	0.76	84	1.01	170	0.86	0.74–1.00
7	“Other health workers”	210	0.87	93	0.59	1	0.41	62	0.90	199	0.95	565	0.83	0.76–0.90
8	Teachers	769	0.54	371	0.33	17	0.52	428	0.43	834	0.59	2 419	0.49	0.47–0.51
9	Religious workers etc	377	0.61	296	0.51	22	1.03	253	0.50	783	0.75	1 731	0.62	0.60–0.65
10	Artistic workers	160	0.82	142	0.65	8	1.36	146	0.95	391	1.16	847	0.93	0.87–1.00
11	Journalists	85	0.94	76	0.69	6	1.80	59	0.89	169	1.08	395	0.93	0.84–1.02
12	Administrators	3 415	0.90	1 000	0.56	49	0.86	1 523	0.84	1 992	0.92	7 979	0.83	0.81–0.85
13	Clerical workers	1 412	0.85	936	0.75	64	1.00	1 177	0.84	2 432	1.04	6 021	0.90	0.88–0.92
14	Sales agents	855	0.98	1 365	0.80	44	1.35	1 604	1.01	3 796	1.12	7 664	1.01	0.99–1.03
15	Shop workers	3 803	0.98	518	0.78	20	0.90	598	0.95	1 204	1.10	6 143	0.98	0.95–1.00
16	Farmers	3 465	0.47	7 611	0.77	49	0.52	1 995	0.46	2 417	0.40	15 537	0.56	0.55–0.57
17	Gardeners	808	0.77	1 056	0.84	4	1.36	637	0.57	1 361	0.61	3 866	0.68	0.66–0.71
18	Fishermen	461	1.29	127	1.02	78	1.52	1 654	1.17	227	0.96	2 547	1.16	1.12–1.21
19	Forestry workers	139	0.88	2 074	1.41	[0.47]	0.00	486	0.60	878	0.54	3 577	0.88	0.85–0.91
20	Miners and quarry workers	48	0.97	450	1.93	1	1.18	325	1.40	621	1.57	1 445	1.58	1.50–1.67
21	Seamen	547	1.43	353	1.19	23	1.57	2 036	1.74	624	1.82	3 583	1.62	1.57–1.68
22	Transport workers	896	1.07	729	0.78	37	1.22	601	0.97	1 201	1.03	3 464	0.96	0.93–1.00
23	Drivers	3 762	1.37	2 897	1.05	46	1.07	2 415	1.44	3 762	1.34	12 882	1.28	1.26–1.31
24	Postal workers	536	1.05	312	0.72	4	0.70	278	0.88	653	1.06	1 783	0.95	0.90–0.99
25	Textile workers	527	1.07	291	0.95	6	0.62	309	0.87	721	1.02	1 854	0.99	0.94–1.04
26	Shoe and leather workers	133	1.08	148	1.07	5	2.34	159	1.07	297	1.04	742	1.06	0.99–1.14
27	Smelting workers	1 488	1.38	586	1.28	16	1.18	715	1.50	1 422	1.27	4 227	1.34	1.30–1.38
28	Mechanics	3 595	1.24	2 979	1.10	43	1.07	3 123	1.34	6 463	1.27	16 203	1.24	1.22–1.26
29	Plumbers	399	1.55	591	1.33	8	1.20	420	1.55	807	1.37	2 225	1.42	1.36–1.48
30	Welders	–	–	443	1.17	2	0.83	444	1.44	909	1.38	1 798	1.33	1.27–1.40
31	Electrical workers	777	1.15	1 055	0.96	26	1.09	1 072	1.04	1 780	1.03	4 710	1.03	1.00–1.06
32	Wood workers	2 085	1.05	3 801	1.16	17	0.71	2 370	0.88	2 668	0.77	10 941	0.96	0.94–0.97
33	Painters	858	1.30	792	1.21	8	0.81	593	1.32	1 167	1.17	3 418	1.23	1.19–1.28
34	“Other construction workers”	3 075	1.19	3 402	1.59	45	0.96	741	1.40	2 217	1.18	9 480	1.32	1.29–1.35
35	Bricklayers	899	1.24	477	1.40	–	–	344	1.28	513	1.13	2 233	1.25	1.20–1.30

Where to find occupational exposure data

- Occupational title or code
 - International Standard Classification of Occupations (ISCO-88, ISCO-08)
- Industry or industrial code
 - Nomenclature of Economic Activities (NACE)
 - Standard Industrial Classification (SIC)
- Job-Exposure Matrix (JEM) linked to occupational codes



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Job-exposure matrix (JEM)

- The JEM assigns exposure characteristics to each job code (job title)
 - Type (chemical, physical, ergonomic/mechanical, psychosocial)
 - Level of exposure
 - Proportion of exposed workers
 - Calendar period
- All workers with the same job code are assigned similar exposure characteristics
- JEMs are useful in registry studies and large population studies lacking individual occupational exposure data



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Construction of a Job-exposure matrix (JEM)

Exposure data in different occupations based on

- Measurements (noise, UV, chemicals, mechanical...)
- Survey data (ergonomic/mechanical, psychosocial)
- Expert assessment (occupational airborne chemicals)
- Combinations of methods (noise, UV, Shoulder JEM...)

Type of exposure measure

- Dichotomous: exposed/non-exposed
- > 2 categories, e.g. low/medium/high exposure, or specified levels
- Continuous measure
- Combination of level and frequency of exposure



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Construction and validation of a Norwegian JEM

Original article

Scand J Work Environ Health. 2019;45(3):239–247. doi:10.5271/sjweh.3774

Mechanical and psychosocial work exposures: the construction and evaluation of a gender-specific job exposure matrix (JEM)

by Therese Nordberg Hanvold, PhD,¹ Tom Sterud, PhD,¹ Petter Kristensen, MD, PhD,^{1,2} Ingrid Sivesind Mehlum, MD, PhD¹

- Based on data from the Norwegian nationwide Survey of Living Conditions on work environment, conducted by Statistics Norway in 2006 and 2009
- Sample:
Norwegian residents aged 18 to 66 years, randomly drawn



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Occupational classification

- Occupations (4-digit level) classified according to the Norwegian version of ISCO-88 (STYRK 1998)
 - STYRK 1998: 350 different occupational groups (4-digit level)
 - Study sample: 322 occupational groups (92 %)
- Occupational groups with small numbers (<19 respondents) were grouped, by experts, based on:
 - job titles
 - similar work tasks
 - work environment
 - educational level



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Mechanical and psychosocial work exposures

1. Heavy lifting
2. Neck flexion
3. Hands above shoulder height
4. Squatting/kneeling
5. Forward bending
6. Awkward lifting
7. Heavy physical work
8. Standing/walking

1. Psychological demands (3 dimensions)
2. Decision latitude (2 dimensions)
3. Job strain (combining psychological demands and decision latitude)
4. Monotonous work (1 item)
5. Supportive leadership (3 items)



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Agreement measures between individual- and group-based work exposures, using different cut-off levels on exposure

Work exposure	Cut off	Women						Men					
		Kappa	Sensitivity	Specificity	AUC	Exposed Groups	Exposed Indiv	Kappa	Sensitivity	Specificity	AUC	Exposed Groups	Exposed Individuals
MECHANICAL			%	%		%	%		%	%		%	%
Heavy lifting >20kg	20%	0.27	58	86	0.72	17	16	0.35	66	79	0.73	28	7
Hands above shoulder height	20%	0.25	50	84	0.67	20	17	0.42	74	80	0.77	29	12
Heavy physical work	20%	0.23	46	84	0.65	20	19	0.34	77	71	0.74	38	12
Squatting/kneeling	30%	0.34	52	86	0.69	20	18	0.51	66	89	0.77	21	16
Work with neck flexion	30%	0.22	42	81	0.61	25	21	0.23	41	83	0.62	23	25
Forward bending	30%	0.25	32	91	0.62	12	12	0.30	37	92	0.65	12	14
Awkward lifting	30%	0.29	46	86	0.66	19	13	0.28	37	91	0.64	13	15
Standing/Walking	50%	0.68	90	78	0.84	59	44	0.59	78	81	0.80	45	54
PSYCHOSOCIAL													
High psychological demands	Median	0.38	69	69	0.69	56	56	0.28	52	76	0.64	38	48
Low decision latitude	Median	0.24	79	44	0.61	68	55	0.26	49	77	0.63	34	42
High job strain	Median	0.28	53	76	0.64	33	32	0.19	53	76	0.58	11	20
Low supportive leadership	Median	0.11	57	54	0.56	50	45	0.11	55	57	0.55	48	47
High monotonous work	Median	0.37	65	73	0.68	42	41	0.32	56	75	0.65	37	40

Variance in individual-based exposure estimate explained by the occupational groups (JEM groups) – explained variance (R^2) in exposure

Mechanical work exposure	Women	Men
	%	%
Heavy lifting >20kg	7	26
Hands above shoulder height	18	29
Heavy physical work	17	29
Squatting/kneeling	15	32
Work with neck flexion	10	13
Forward bending	17	21
Awkward lifting	17	27
Standing/Walking	25	41
Psychosocial work exposure		
High psychological demands	14	8
Low decision latitude	6	7
High job strain	8	4
Low supportive leadership	1	1
High monotonous work	14	10

Associations between mechanical work exposures and low back pain the last month, using individual- and group (JEM-based) estimates

Mechanical work exposures		Women			Men		
		OR	95% CI	% change	OR	95% CI	% change
Heavy lifting > 20kg	Individual	1.6	1.3-1.9		1.7	1.5-1.9	
	JEM	1.4	1.3-1.6	13	1.4	1.3-1.6	18
Work with neck flexion	Individual	1.5	1.3-1.7		1.6	1.5-1.8	
	JEM	1.3	1.2-1.5	13	1.4	1.3-1.5	13
Hands above shoulder height	Individual	1.3	1.2-1.6		1.6	1.4-1.8	
	JEM	1.2	1.1-1.3	8	1.4	1.3-1.5	13
Squatting/kneeling	Individual	1.8	1.6-2.0		1.7	1.5-1.8	
	JEM	1.4	1.2-1.6	22	1.4	1.3-1.6	18
Forward bending	Individual	1.7	1.4-1.9		1.8	1.6-2.1	
	JEM	1.4	1.2-1.6	18	1.4	1.2-1.6	22
Awkward lifting	Individual	1.9	1.7-2.2		2.2	1.4-2.4	
	JEM	1.5	1.3-1.7	21	1.4	1.3-1.6	36
Heavy physical work	Individual	1.9	1.7-2.1		1.9	1.7-2.1	
	JEM	1.4	1.2-1.5	26	1.5	1.4-1.6	21
Standing/Walking	Individual	1.4	1.3-1.5		1.6	1.4-1.7	
	JEM	1.4	1.3-1.5	0	1.4	1.3-1.5	13

% change indicates change in OR based on JEM exposures compared to OR based on individual exposures (adjusted for age)

Associations between psychosocial work exposures and low back pain the last month, using individual- and group (JEM-based) estimates

Psychosocial work exposure		Women			Men		
		OR	95% CI	% change	OR	95% CI	% change
High psychological demands	Individual	1.2	0.9-1.5		1.3	0.9-1.7	
	JEM	1.0	0.9-1.1	17	0.7	0.5-0.9	46
Low decision latitude	Individual	1.3	1.0-1.6		1.6	1.2-2.1	
	JEM	1.5	1.2-2.0	-15	1.4	1.1-1.8	13
High job strain	Individual	1.4	1.1-1.7		1.8	1.3-2.3	
	JEM	1.2	1.0-1.9	14	0.9	0.6-1.5	50
Low supportive leadership	Individual	1.0	0.8-1.3		1.3	0.9-1.6	
	JEM	1.0	0.9-1.1	0	1.3	0.9-1.7	0
High monotonous work	Individual	1.6	1.3-2.0		1.6	1.2-2.1	
	JEM	1.2	0.9-1.5	25	1.9	1.4-2.5	-18

% change indicates change in OR based on JEM exposures and OR based on individual exposures (adjusted for age)

Advantages and disadvantages of using JEMs

Advantages

- Less resources needed for exposure assessment once the JEM is elaborated
- Exposure estimates are assigned consistently, irrespective of the disease status of the subject

Disadvantages

- Similar exposures are assigned to all with the same job title; therefore, exposure may be misclassified for a substantial proportion of the subjects
- Limited to the occupations and specific exposures of the JEM

ORIGINAL ARTICLE

Construction of job-exposure matrices for the Nordic Occupational Cancer Study (NOCCA)

TIMO KAUPPINEN¹, PIRJO HEIKKILÄ¹, NILS PLATO², TORILL WOLDBÆK³,
KAARE LENVIK³, JOHNNI HANSEN⁴, VIDIR KRISTJANSSON⁵ & EERO PUKKALA⁶

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The Nordic Occupational Cancer (NOCCA) project

- The largest and, in many aspects, also qualitatively, the most unique research study ever done on occupation and cancer incidence
- A follow-up study on the entire working populations of Denmark, Iceland, Finland, Norway and Sweden
- 3 million cancer cases diagnosed 1961–2005
- Risks of 84 cancer types in 54 occupational categories
- Nordic Job Exposure Matrix (NOCCA-JEM) converts the individual job histories of all Nordic people to quantitative estimates of exposure to potentially cancer-related factors
- Many of the results on dose-response associations between exposures and cancers have been novel findings or have confirmed (or not) findings from earlier smaller studies
- The NOCCA network still produces new publications from the old data

(E. Pukkala, FIOH, Abstract ICOH 2018)



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[Home](#) / [Projects](#) / NOCCA New: New wave of joint Nordic studi[...]

NOCCA New: New wave of joint Nordic studies on work and cancer

The Nordic cooperation project NOCCA is the largest and in many aspects qualitatively, the most unique research study ever done on occupation and cancer incidence. NOCCA New will update and expand previously estimated cancer risks and carry out new analyses on cancer and occupational exposure in the modern work life

ORIGINAL ARTICLE

Update of an occupational asthma-specific job exposure matrix to assess exposure to 30 specific agents

Nicole Le Moual,^{1,2} Jan-Paul Zock,^{3,4,5} Orianne Dumas,^{1,2} Theodore Lytras,^{3,4} Eva Andersson,⁶ Linnéa Lillienberg,⁶ Vivi Schlünssen,⁷ Geza Benke,⁸ Hans Kromhout⁹

Development of an occupational airborne chemical exposure matrix

S. S. Sadhra¹, O. P. Kurmi², H. Chambers³, K. B. H. Lam¹, D. Fishwick³ and The Occupational COPD Research Group*

*The Occupational COPD Research Group: Paul Cullinan⁴, Lesley Rushton⁴, Sara De Matteis⁴, Sally Hutchings⁴, Debbie Jarvis⁴ and Jon G. Ayres¹

RESEARCH ARTICLE

Occupational exposures and exacerbations of asthma and COPD—A general population study

Stinna Skaaby^{1*}, Esben Meulengracht Flachs¹, Peter Lange^{2,3,4,5}, Vivi Schlünssen^{6,7}, Jacob Louis Marott^{4,5}, Charlotte Brauer¹, Børge G. Nordestgaard^{4,5,8}, Steven Sadhra⁹, Om Kurmi^{10,11}, Jens Peter Ellekilde Bonde^{1,2}

Development and Validation of a Job Exposure Matrix for Physical Risk Factors in Low Back Pain

Svetlana Solovieva^{1,2*}, Irmeli Pehkonen³, Johanna Kausto^{1,2}, Helena Miranda⁴, Rahman Shiri^{1,2}, Timo Kauppinen⁵, Markku Heliövaara⁶, Alex Burdorf⁷, Kirsti Husgafvel-Pursiainen^{1,2}, Eira Viikari-Juntura²

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Original article



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Scand J Work Environ Health. 2021;47(1):5–14. doi:10.5271/sjweh.3919

The influence of occupational class and physical workload on working life expectancy among older employees

by Jolinda LD Schram, MSc,¹ Svetlana Solovieva, PhD,² Taina Leinonen, PhD,² Eira Viikari-Juntura, MD, PhD,² Alex Burdorf, PhD,¹ Suzan JW Robroek, PhD¹

SYN-JEM: A Quantitative Job-Exposure Matrix for Five Lung Carcinogens

Susan Peters^{1,2*}, Roel Vermeulen^{1,3}, Lützen Portengen¹,
Ann Olsson⁴, Benjamin Kendzia⁵, Raymond Vincent⁶,
Barbara Savary⁶, Jérôme Lavoué⁷, Domenico Cavallo⁸,
Andrea Cattaneo⁸, Dario Mirabelli⁹, Nils Plato¹⁰,
Joelle Fevotte¹¹, Beate Pesch⁵, Thomas Brüning⁵,
Kurt Straif⁴ and Hans Kromhout¹

Exposure assess

ORIGINAL ARTICLE

Upper arm elevation and repetitive shoulder movements: a general population job exposure matrix based on expert ratings and technical measurements

Annett Dalbøge,¹ Gert-Åke Hansson,^{2,3} Poul Frost,¹ Johan Hviid Andersen,⁴
Thomas Heilskov-Hansen,⁵ Susanne Wulff Svendsen⁴

Original Article

A Quantitative General Population Job Exposure Matrix for Occupational Noise Exposure

Zara Ann Stokholm^{1,○}, Mogens Erlandsen², Vivi Schlünssen^{3,8},
Ioannis Basinas^{4,○}, Jens Peter Bonde⁵, Susan Peters^{6,○}, Jens Brandt⁷,
Jesper Medom Vestergaard¹ and Henrik Albert Kolstad^{1,*}

ORIGINAL ARTICLE

Job-exposure matrices addressing lifestyle to be applied in register-based occupational health studies

Sesilje Bondo Petersen,¹ Esben Meulengracht Flachs,¹ Eva Irene Bossano Prescott,²
Anne Tjønneland,³ Merete Osler,⁴ Ingelise Andersen,⁵ Knud Juel,⁶
Esben Budz-Jørgensen,⁷ Henrik A Kolstad,⁸ Vivi Schlünssen,^{9,10} Jens Peter Bonde¹

OMEGA-NET:

2 online searchable inventories



INVENTORIES



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Welcome to OccupationalExposureTools.net

OccupationalExposureTools.net aims to provide an inventory of all meta-data on existing occupational exposure information and tools, to support research on occupational epidemiology. It includes meta-data on job exposure matrices (JEMs), national exposure databases (indicating linkage to existing cohorts in the Omega-Net cohort Inventory, where relevant), national and international occupational coding systems and crosswalks to convert between them.

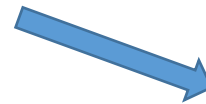
This inventory will serve as a platform to facilitate harmonization of occupational exposure data to allow pooling and replication of findings.

Please also see our complementary inventory of occupational cohorts at: [OccupationalCohorts.net](#).

For more information [about OccupationalExposureTools.net](#) and to register your exposure assessment tool in the inventory please click below.



A. View the complete inventory of Occupational Exposure Tools by category



B. Search by selecting specific criteria below

Tool

C. Search by country

- Select tool...
- Job-Exposure Matrix
- Exposure Measurement Database
- Other Exposures Databases
- Coding Systems
- Coding Crosswalk

D. Search by keyword

Occupational Exposure Tools

Occupational Exposure Tool	Number
Job-Exposure Matrix	39
Exposure Measurement Database	10
Other Exposures Databases	1
Coding Systems	30
Coding Crosswalks	3



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EPHOR: Exposome Project for Health and Occupational Research



The working life exposome:

All occupational and related non-occupational (i.e. general environment, lifestyle, behavioral and socio-economic) exposure factors

- Applying the exposome concept to working life health
- Providing better insights into:
 - Working life – health relationships
 - Vulnerable life stages and groups
- Laying the groundwork for prevention:
 - Evidence-based
 - Cost-effective
- 2020–2024
- 19 partners from 12 countries

How: combined approach

APPROACH

Mega Cohort

Large scale pooling of EU cohorts



Case Studies

Focus on respiratory disease

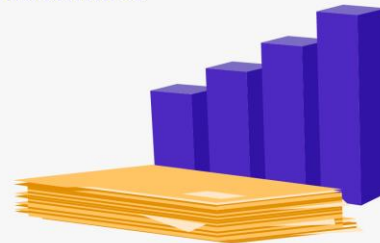
Focus on shift work



EXPOSOME DATA

Existing Data

Cohorts, job exposure matrices, databases



Also New Data

External: individual level, high resolution, many exposures

Internal: biomarkers and omics



EXPOSURE-RESPONSE DATA

Increased Power

Associations between (interacting) working life risk factors and NCDs, vulnerable life periods or sub groups, e.g. gender, SES



Increased resolution

Biological pathways, markers of exposure or disease, multiple short term exposures related to acute effects



HEALTH AND ECONOMIC IMPACT

Based on working life exposure-response data.

When the entire population is the sample: strengths and limitations in register-based epidemiology

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Abstract Studies based on databases, medical records and registers are used extensively today in epidemiological research. Despite the increasing use, no developed methodological literature on use and evaluation of population-based registers is available, even though data collection in register-based studies differs from researcher-collected data, all persons in a population are available and traditional statistical analyses focusing on sampling error as the main source of uncertainty may not be relevant. We present the main strengths and limitations of register-based studies, biases especially important in register-based stud-

Research based on databases, medical records and registers are used more extensively than ever. During the eighteenth and nineteenth centuries few disease registers existed, with the Leprosy Registry in Norway [1] as the oldest followed by several tuberculosis registers [2]. In many countries, e.g. United Kingdom, Canada and Australia, research databases have been implemented [3]. The breakthrough in use of Nordic registers happened with the introduction of the unique personal identification number in 1964–1969 making individual-level linkage between registers possible in a reliable manner [4–7]. Administrative and research regis-

Strengths of register-based research data (1)

(Thygesen LC, Ersbøll AK. Eur J Epidemiol, 2014)

1. Data already exist
2. Large sample size
3. Data are complete for the persons in the target population
 - Limited/no selection bias
 - No attrition bias (loss to follow-up)
 - Possible to study rare exposures and outcomes and population subgroups
 - Information of exposures and outcomes for the whole population



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Strengths of register-based research data (2)

(Thygesen LC, Ersbøll AK. Eur J Epidemiol, 2014)

4. Data are collected independently of research questions
 - Prospective data collection
 - No differential misclassification
5. Valuable time has passed – possible to study
 - diseases with long latency
 - diseases in families (generation studies)
6. Some confounders of high validity available to the whole population
 - e.g. education, income, vital status, hospitalization, drug prescription
7. Sometimes registers have the information of exposure and outcome of interest



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Limitations of register-based research data

(Thygesen LC, Ersbøll AK. Eur J Epidemiol, 2014)

1. Data are pre-collected by others than researchers
 - Necessary information may be unavailable or misclassified
 - Limited to use variables available in the register
 - Coding in registers may not be detailed
 - Often hard to know exactly how data are generated
 - Variation in coding between persons and institutions
2. Lack of important confounder information



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Limitations of register-based research data

(Thygesen LC, Ersbøll AK. Eur J Epidemiol, 2014)

3. Missing data difficult to handle
 - Difficult to know what missingness means (did not happen / not registered)
4. Unknown data quality, often difficult to validate
5. Left truncation (at start of registration)
6. Data dredging (data fishing) and misleading post hoc analysis
7. Unimportant differences become statistical significant
 - The size of the risk estimates and public health relevance are important



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Bias in register-based studies

(Thygesen LC, Ersbøll AK. Eur J Epidemiol, 2014)

- Lack of data of important confounders or crude information on confounders may lead to residual confounding
- Non-differential misclassification will tend to underestimate the true association
- Include only individuals who are at risk, when they are at risk
 - e.g. conditioning on the future, immortal risk time
- Missingness is difficult to interpret
- Validity of register
 - Completeness
 - Validity of the variables



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Register-based studies – conclusion

- “...epidemiological studies with inclusion of all persons in a population followed for decades ... are important data sources for modern epidemiology, but it is important to acknowledge the data limitations.”

(Thygesen LC, Ersbøll AK. Eur J Epidemiol, 2014)

- Challenges
 - Defining population at risk
 - Defining/creating meaningful exposure and outcome variables, and covariates
 - Statistical abilities
 - Administrative work with several register owners
- A multitude of possibilities!



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