Australian National University

Research for the Care of Patients

Dutch Experiences with General Practice-based Networks

Presentation at the Séminaire

'*Requeil de données épidemiologiques en médicine générale, santé publique et santé au travail*'

At the occasion of PhD Awarding Aline Ramond-Roquin
Angers, 04 September 2014

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Past president of Wonca

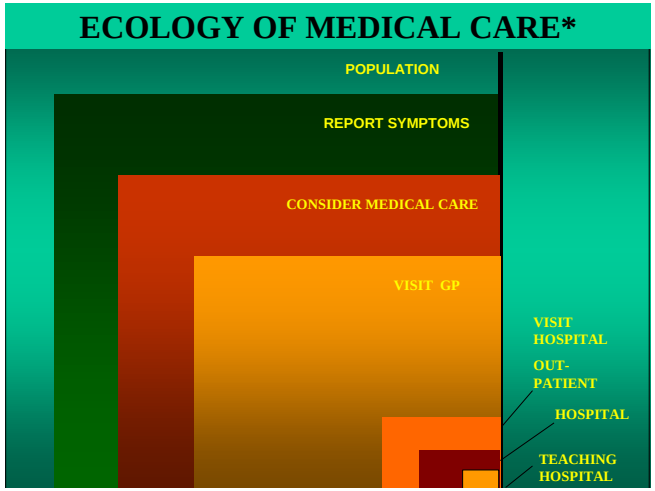
Objective of this presentation

- Present Dutch Primary Care Databases
  - Nijmegen experience, history
- Illustrate Methodology, Present Examples
  - Longitudinal data, episodes illness and care
  - Person centered structure
  - Benefits analysis ‘full’ episodes
  - Collaborative outcome studies, flow ‘care over time’
- Context Dutch Healthcare
  - Contributing to its development

Characteristics of the Dutch health care system

- Access to health care through general practice
- Primary care link community - health care system
- Gate keeper, navigator function
- Specialists, hospital, after GP referral only
- Personal listing with a practice, GP
- Practice population defined, and ‘known’
- Primary care the link to society: gouvernance, societal impact

Ecology of Medical Care[1,2]:

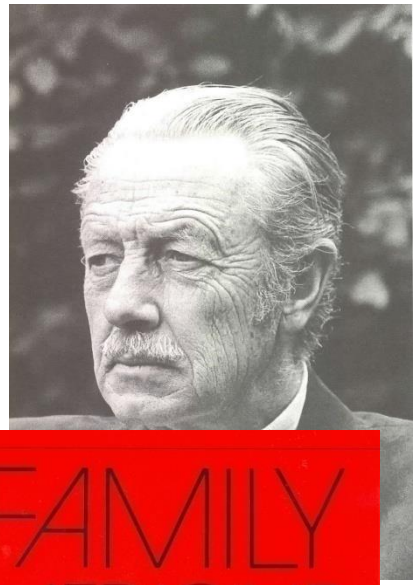


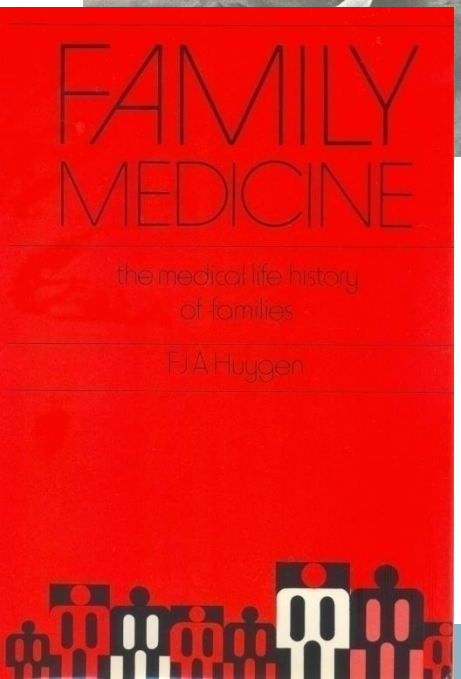
1. White et all NEJM 1961
2. Green et all NEJM 2001

Dutch healthcare

- ‘structures’ ecology model
- Need to understand model

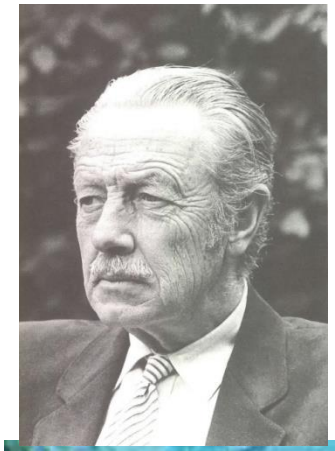
Practice-based Research Networks, the Start 1967: Nijmegen Continuous Morbidity Registration (CMR)





- Frans Huygen, inaugural chair general practice Nijmegen
- General practice in the academic arena:
  - ✓ The ‘Incident of German Measles’
- The Nijmegen CMR
  - ✓ Highlight health problems community
  - ✓ Need empirical data real life family practice
  - ✓ In-fighting to change
  - ✓ Research agenda

‘Nijmegen Continuous Morbidity Registration’ (CMR)



- CMR:
  - ✓ Oldest FP database, Netherlands
  - ✓ PBRN Department Family Medicine
  - ✓ Research Capacity Building
  - ✓ Longitudinal Research – patient careers/time

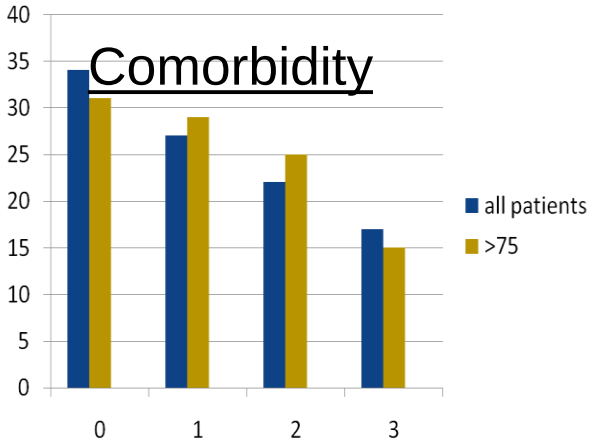
Weel C. van. The Continuous Morbidity Registration Nijmegen: background and history of a Dutch general practice database. *European Journal of General Practice* 2008; **14, Suppl 1:** 5-12**.**

- Data and Study Objectives
  - ✓ *‘If we knew what we were doing, we would not call it Research’* (Albert Einstein)
- Caveat: pre-computer experience

Most Common Health Problems in Family Practice

Acute, 'everyday'

- Respiratory tract infection
- Functional complaints
- Dermatitis
- Urinary tract infection
- Tonsillitis
- Myalgia neck, shoulder, arm
- Ear wax
- Minor trauma
- Low back pain
- Vaginitis



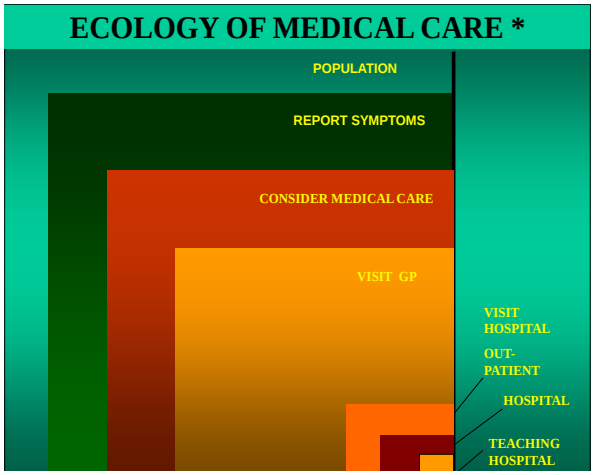
C van Weel Eur J Gen Pract 1996; 2: 17-21

Chronic

- Obesity
- Hypertension
- Chronic nervous complaints
- Deafness
- Malignancy
- COPD
- Chr. Isch. Heart disease
- Myocardial infarction
- Hyperlipemia
- Psoriasis

Context of data collection: Dutch Family Practice

- Primary care led system
  - ✓ Every Citizen personal FP
  - ➢ All episodes start with that FP
- Most health problems treated in primary care
  - ✓ 90+ % 1989 => 96+% 2002
  - ➢ FP records basis individuals' health (care)
- FP data collection longitudinal
  - ✓ Personal continuity
  - ➢ Person- and context factors
  - ✓ System continuity
  - ➢ Population characteristics
  - ➢ Use of secondary/tertiary care



* White et al NEJM 1961
Green et al NEJM 2001

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Episodes Recording: Longitudinal Data, Continuity of Care

Practice

time

Database

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Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem

Database

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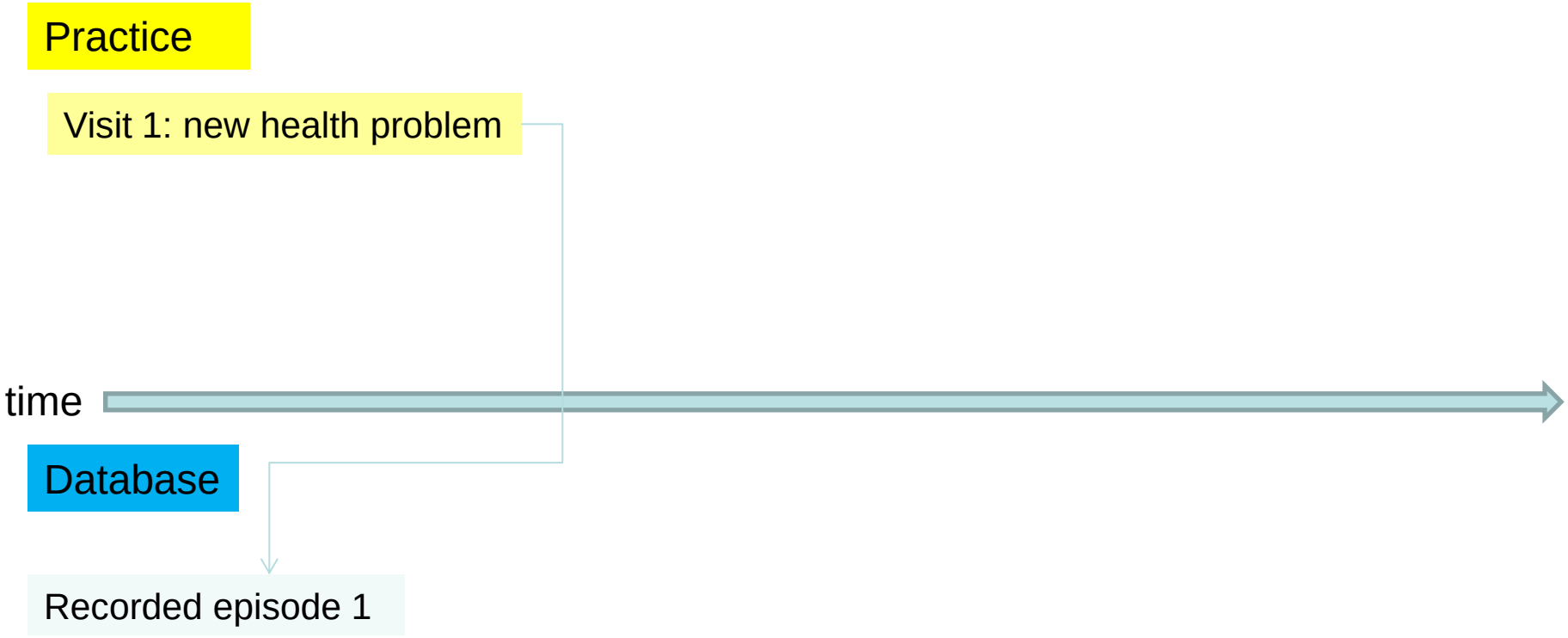
Episodes Recording: Longitudinal Data, Continuity of Care



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Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem

Visit 2: new health problem
review problem 1

time

Database

Recorded episode 1

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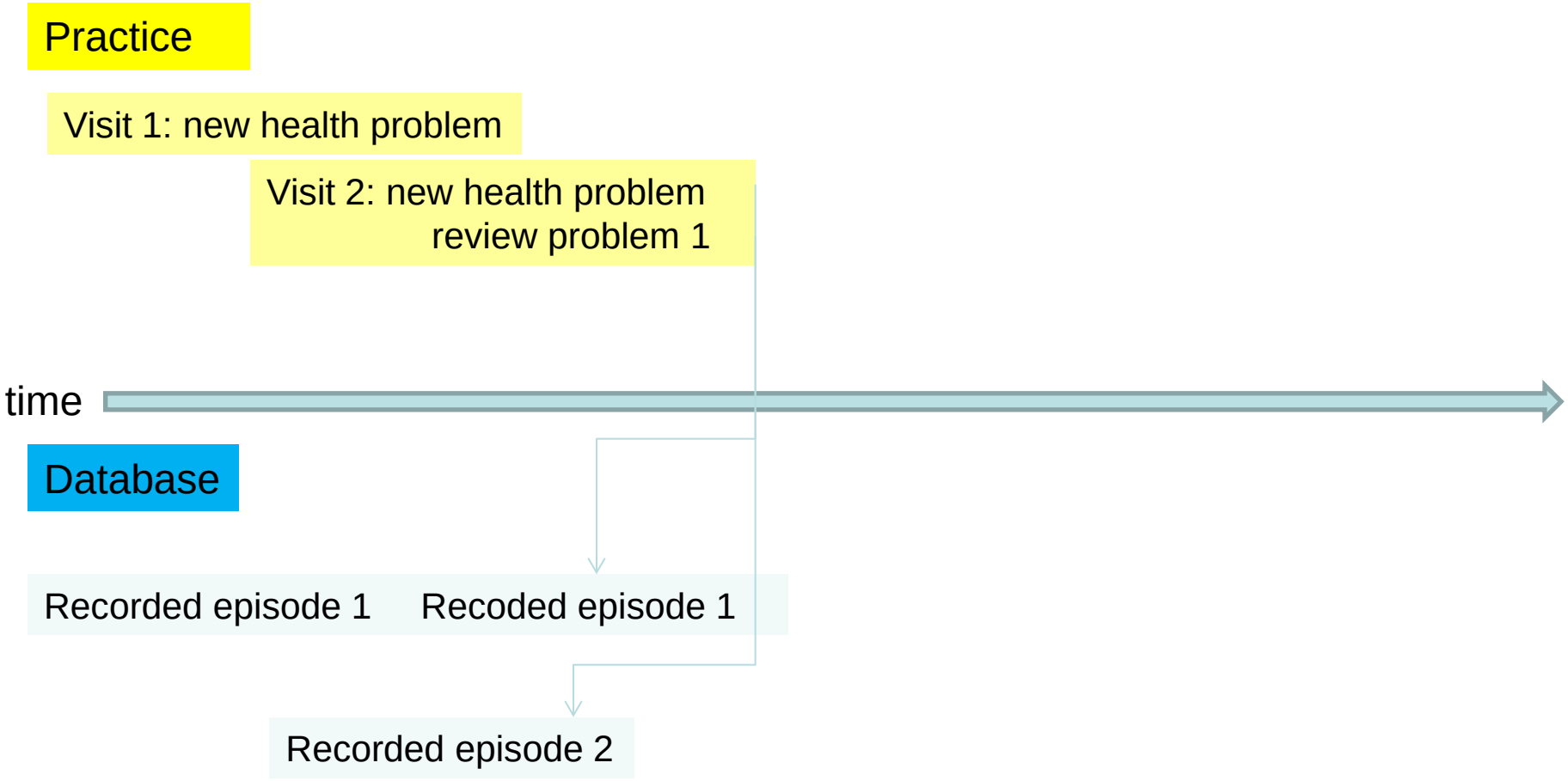
Episodes Recording: Longitudinal Data, Continuity of Care



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Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem

Visit 2: new health problem
review problem 1

Visit N: new health problem
review health problem 1

time

Database

Recorded episode 1 Recoded episode 1

Recorded episode 2

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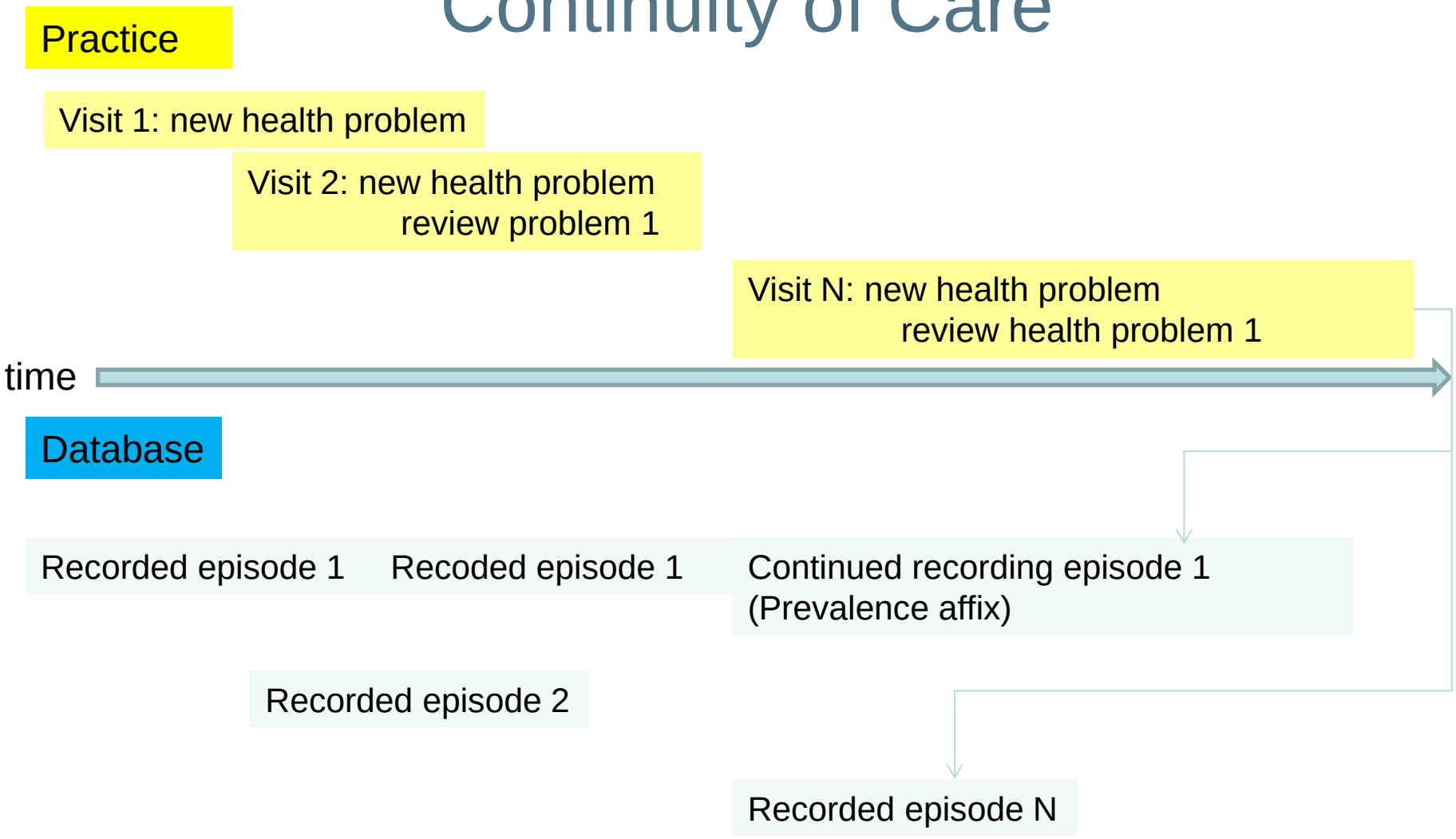
Episodes Recording: Longitudinal Data, Continuity of Care



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Episodes Recording: Longitudinal Data, Continuity of Care

Practice

Visit 1: new health problem

Visit 2: new health problem
review problem 1

Visit N: new health problem
review health problem 1

FPs code, recode
Use of referral information
Clinical judgment
Coding & classification rules

time

Database

Recorded episode 1

Recoded episode 1

Continued recording episode 1
(Prevalence affix)

Recorded episode 2

Recorded episode N

Study Designs with this database

- **Index patient and/or health problem(s)**
  - ✓ Point in time (incidence, prevalence)
  - ✓ Look forward: Historic Cohort
  - ✓ Look backward: Case Control
- **Recruit control groups**
  - ✓ Sex, age, social class, practice, morbidity
  - ✓ Set ‘dummy’ diagnosis, for observation time
- **Retrieve additional information**
  - ✓ Morbidity, mortality
  - ✓ optional: records, interviews, questionnaires
- **Establish Time Window**
  - ✓ After diagnosis
  - ✓ Prior to diagnosis

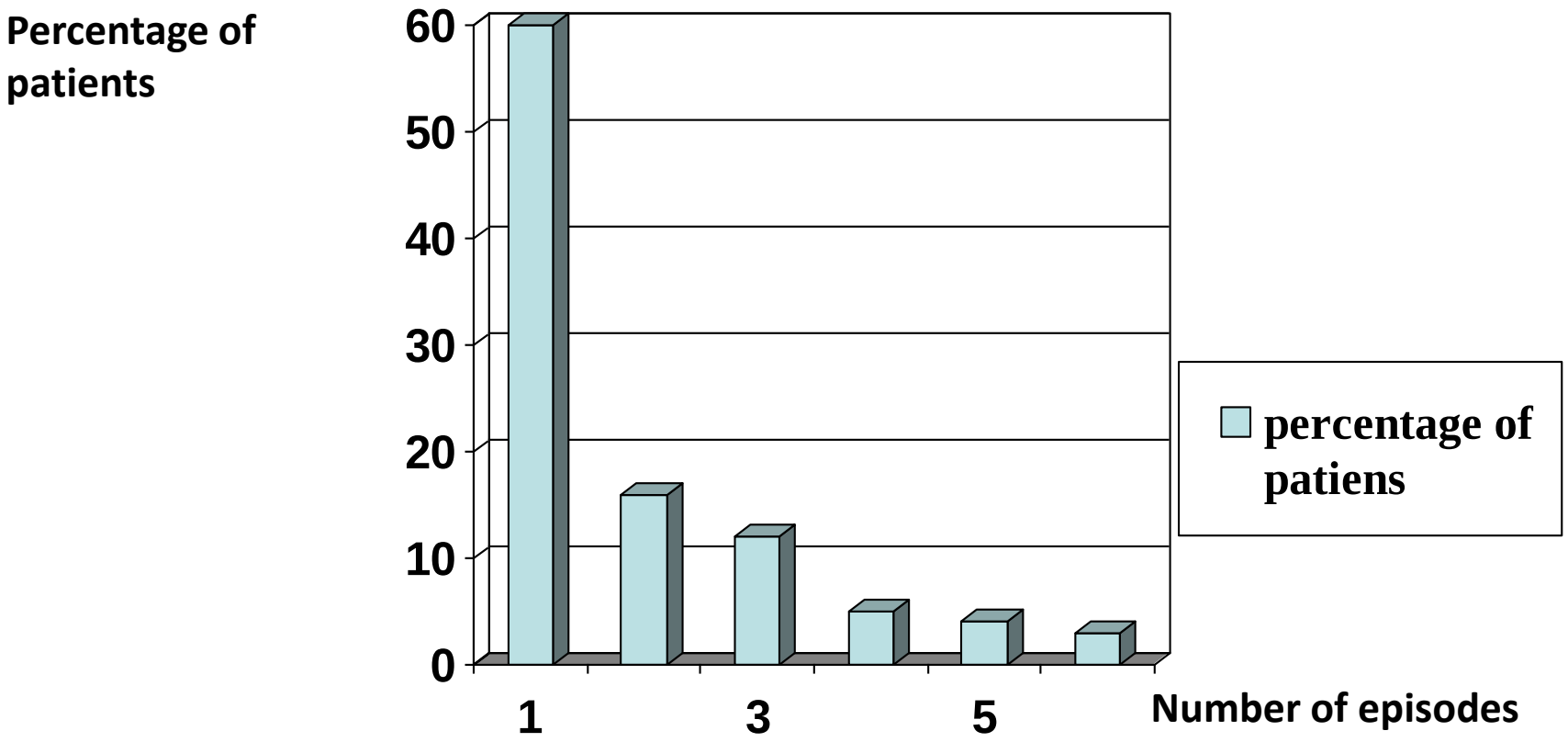
Research into the Community:
partnership with practices (PBRN)

- Bring practice to research
- Bring research to practice
- Relation university
- Practice basis academic staff

Example Cohort Study: Depresssion in family practice (1994)

- Increased public awareness of depression
  - ***chronic, recurrent nature***
- Availability antidepressants
  - Promotion early detection, proactive (drug) treatment
- Most literature
  - Referred patients
  - Short term observations
- Lack of insight
  - Prognosis depression in primary care
- Historic cohort analysis CMR Database after a first life episode depression
  - Recurrence rate, quality of life, psychiatric health status
  - 10 year+ observation after first episode

Number of episodes during first 10 years after diagnosis

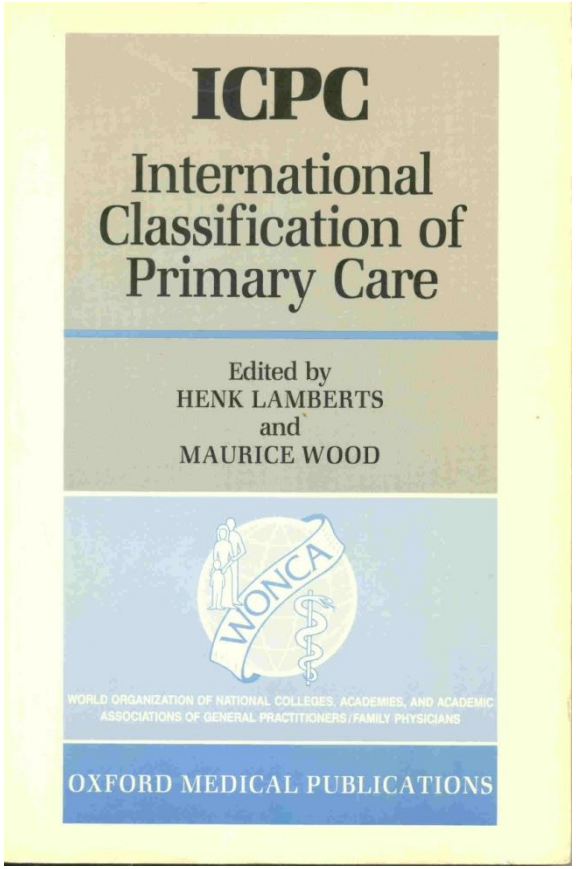


Perceived health and quality of life, health status

(> 10 years after (first) episode depression, compared healthy controls)

- Patients with depression (major depression 79 %)
  - Frequent mental health symptoms
  - Impared quality of life
  - Impared mental and physical health status
  - ‘Coping’: ‘Learning’ experience
- Patients with recurrent nervous-functional symptoms
  - Comparable to patients with depression on all aspects
  - Poorer ‘coping’

The Language and Terminology PHC: International Classification of Primary Care ICPC



- Developed by Wonca
  - 1987, WICC
  - Henk Lamberts, Maurice Wood
- Primary care focus
  - Specificity of generalist
- Relation with other classifications
  - ICD (relation WHO, family classifications
  - SNOMED
- International Standard
  - Europe, Australia
  - The Netherlands: standard EMR

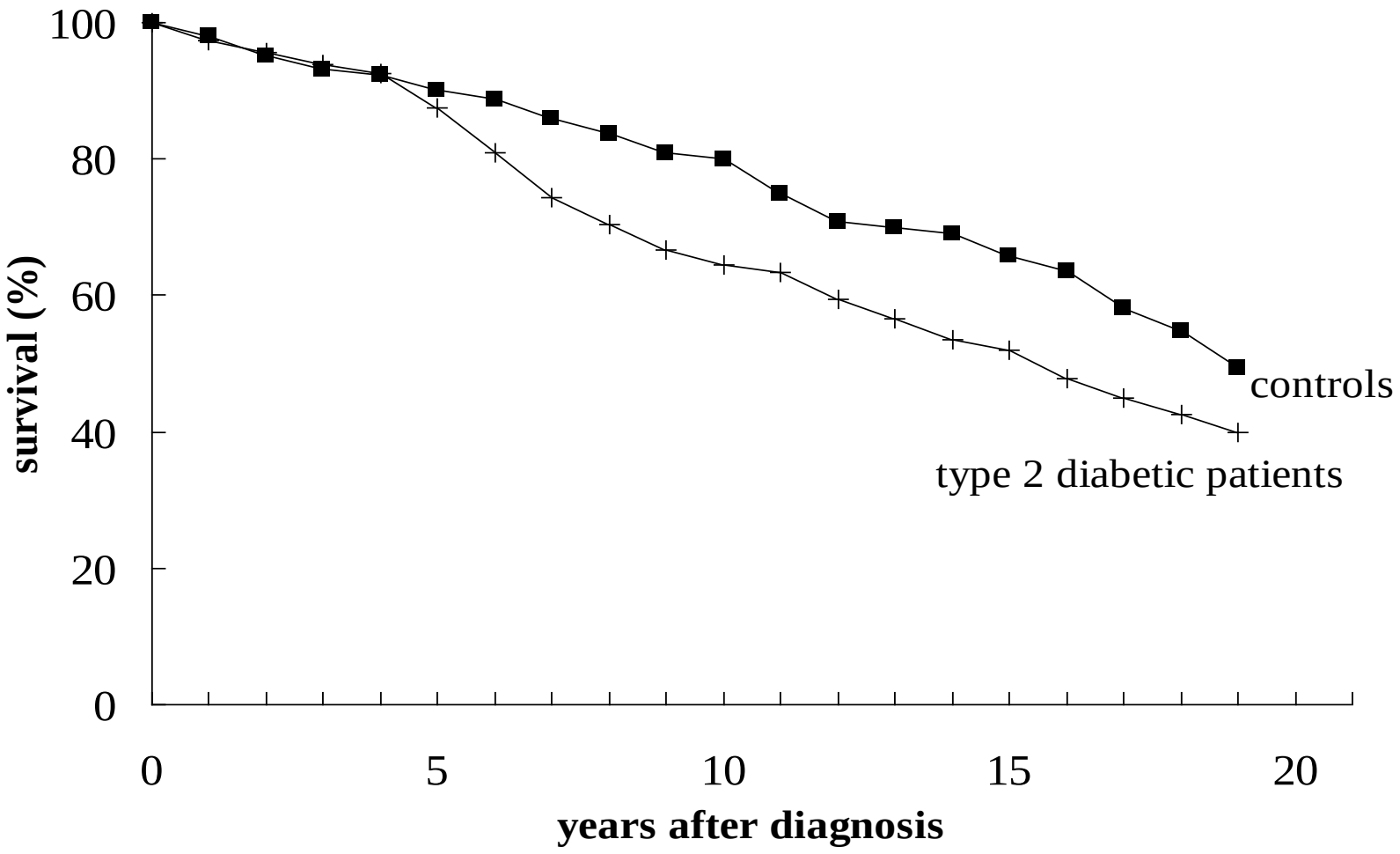
Diabetes Mellitus in primary care: 1988 – 1993

- Specialist literature
  - Premature death, increased risk CV morbidity
  - Case of tight metabolic control
  - Case of pro-active treatment
- Primary care experience
  - Health problem of the elderly
  - Risk overtreatment
  - Case of masterly inactivity
- Empirical data: long term outcome diabetes mellitus FP
  - Historic cohort analysis CMR

Historic Cohort Analysis DM type-2

- All new cases CMR-database diabetes mellitus 1967-1989
- Verification of diagnostic criteria (WHO, 1985): 265
- Non-diabetic controls, matched at time of diagnosis:
  - Sex, age, social class, practice
- Outcome from time of diagnosis – 1989:
  - Mortality
  - Cardiovascular Morbidity
- Mean observation period 6.8 year (8 months – 22 years)

22-year Mortality in type 2 diabetic patients



Long term outcome DM type-2 in primary care: implications for practice (1993 – 2002)

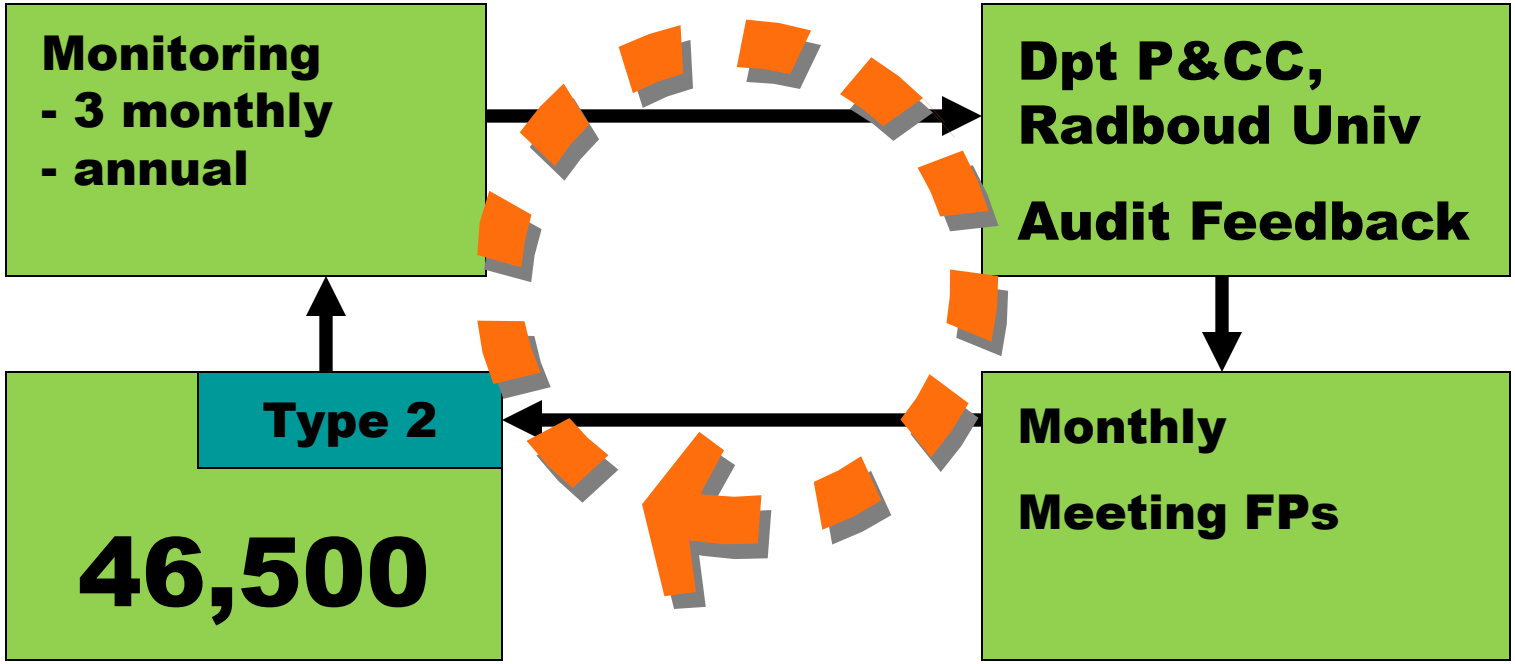
- Increased mortality diabetes mellitus
- Increased cardiovascular morbidity
  - ✓ Mortality
  - ✓ Cardiovascular Morbidity
- Diabetes in primary care matters: lower life expectancy, QoL
- Implications for practice:
  - ✓ Supervision and control
- Move from practices' role:
  - ✓ From data collecting to practice building on data (EBM)
- Essential Practice Based Research Network (PBRN)

Research into the Community:
partnership with practices (PBRN)

- Bring practice to research
- Bring research to practice
- Relation university
- Practice basis academic staff

Practice based Diabetes Monitoring

Audit & Feedback



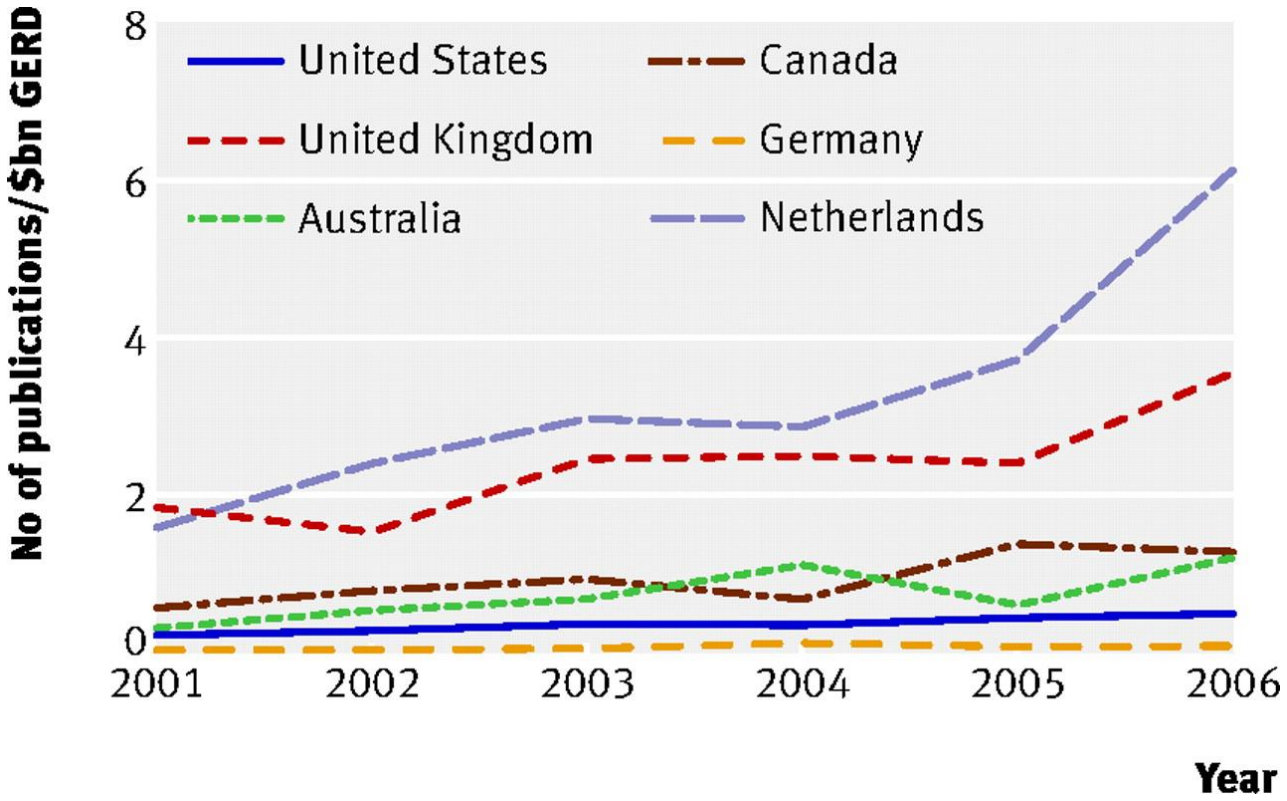
Outcome of care DM with audit and feedback

	1993, n=432	**1999**, n=594	p
Annual review %	73	84	0.01
HbA1c available % Mean %	50 8.3	82 7.1	 0.001
RR available % Mean mmHg	72 150/84	83 150/82	
Chol available % Mean mmol	69 6.2	83 5.4	 0.001

Research Capacity building background: ‘the death of the clinician-researcher’

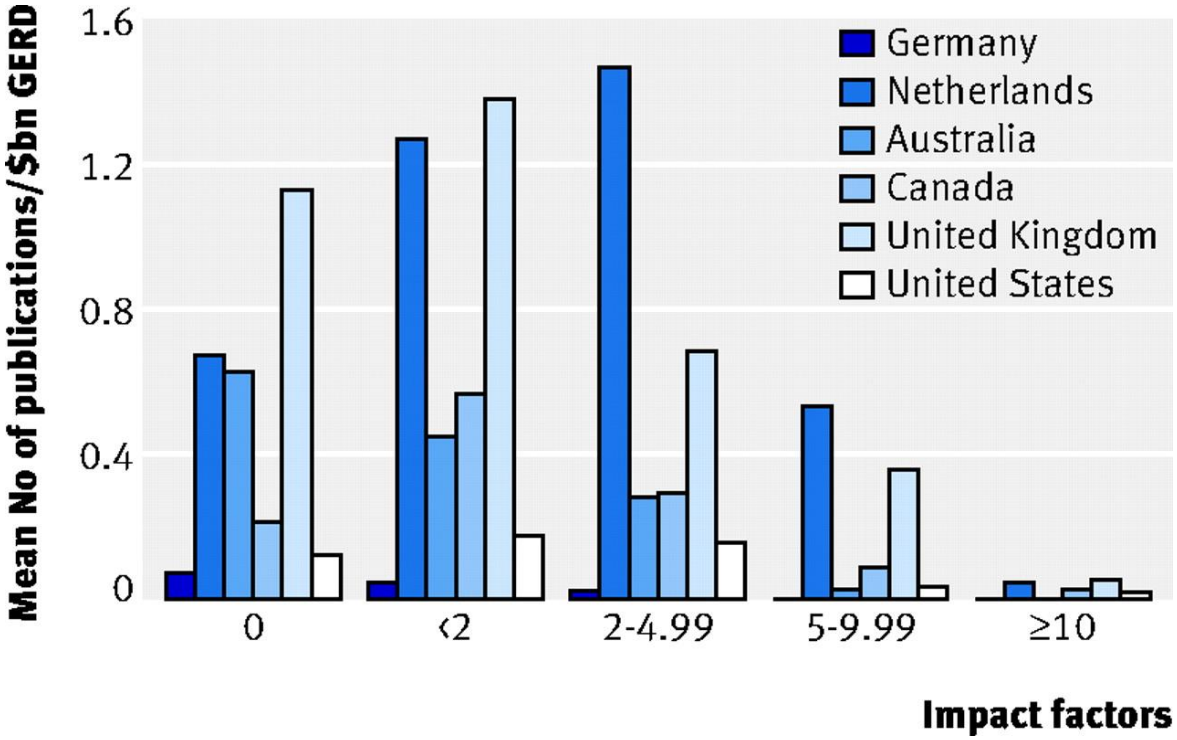
- 1986 – 1996 capacity building through MRC program
  - Focus on GPs and relevant (clinical) problems in primary care
  - Four year full-time researcher , outcome PhD
  - Department/professor of general practice as applicant, supervisor
  - Primary care – secundary care collaboration
- Since 1998 combined specialty – research training
  - Comprehensive programme, 6 – 7 years
  - Outcome specialty qualification and PhD
  - Flexible timing of its clinical and research parts
- At basis: Collaboration Universities – Dutch College GPs
  - guidelines development progamme

Fig 2 Number of research publications (15% sample) by authors from primary care in journals with ISI impact factor per billion dollar gross domestic product spent on research (GERD).



Glanville J et al. BMJ 2011;342:bmj.d1028

Fig 3 Mean number of research publications by authors from primary care (2001-6, 15% sample) per billion dollars gross expenditure on research and development (GERD) and by journal impact factor.



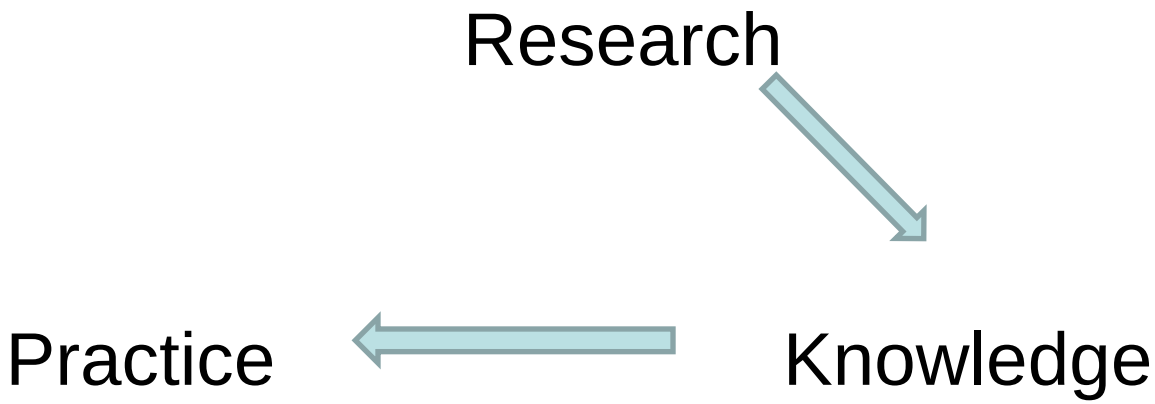
Glanville J et al. BMJ 2011;342:bmj.d1028

PHC Development:
in, by, from, through, with community

Primary Care Development

journey through unfamiliar grounds

The traditional model: guidance to lead deficient pratice



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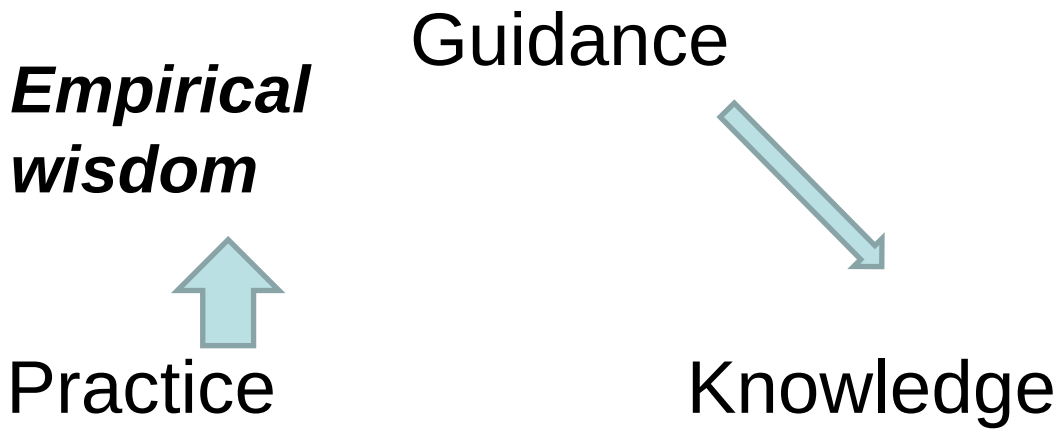
Primary Care Development

journey through unfamiliar grounds

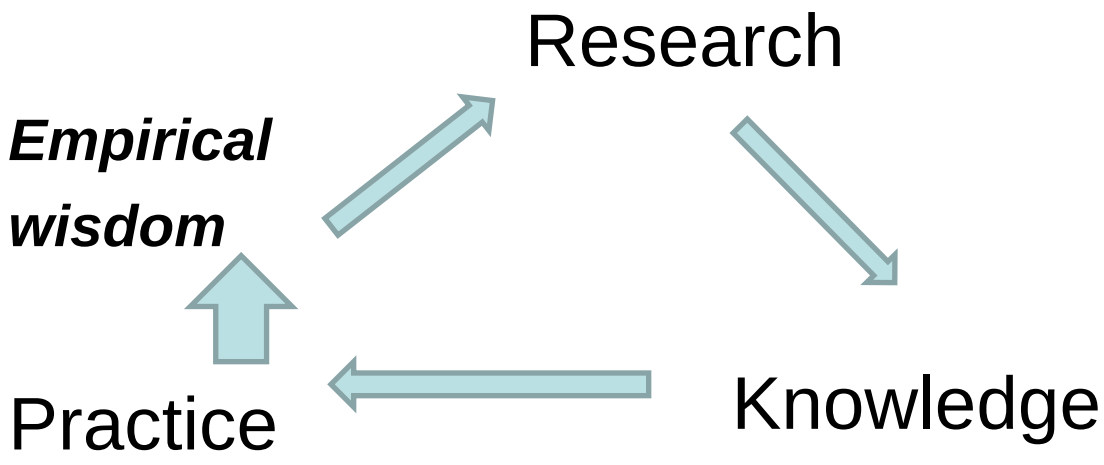
The reality: guidance and practice are resources in their own kind



Primary Care Development

journey through unfamiliar grounds

The challenge for patient care: to connect different worlds



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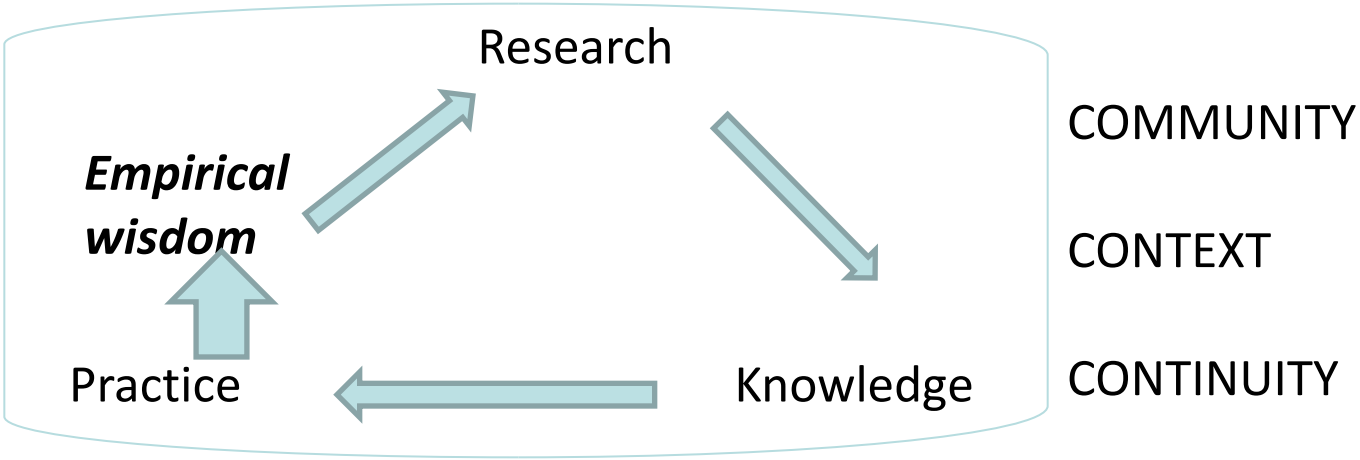
Health Care Development

journey through unfamiliar grounds

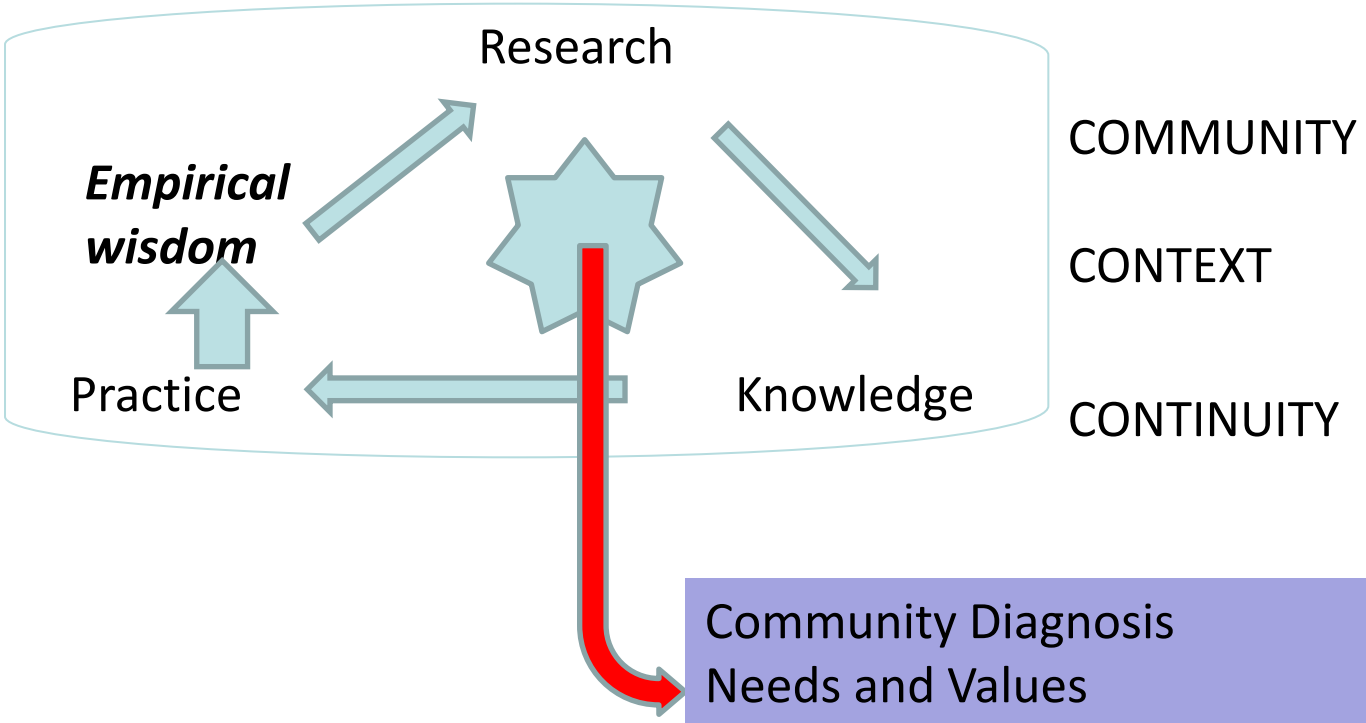
The challenge for patient care: to connect different worlds



Health Care Development

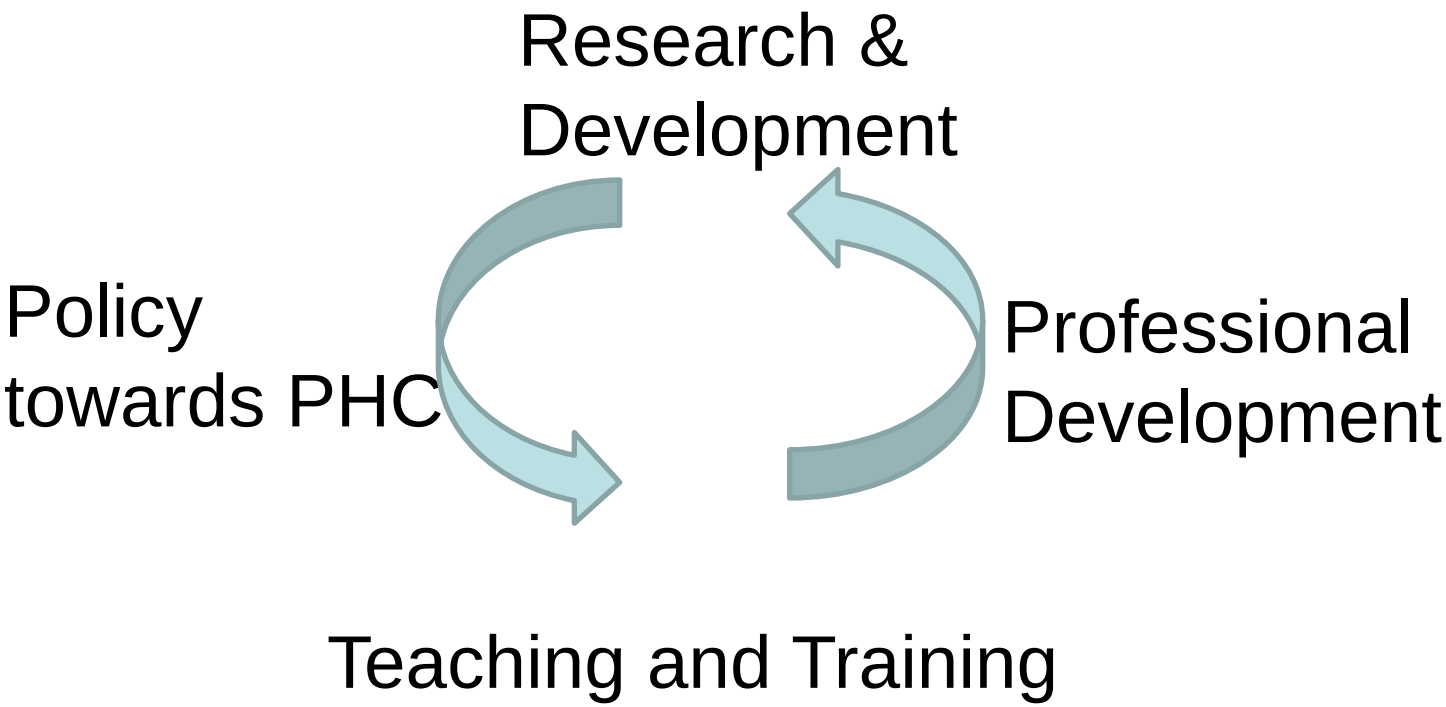
journey through unfamiliar grounds

The challenge for patient care: to connect different worlds



Community Diagnosis
Needs and Values
Priorities
Evidence for people and populations

Primary Care Development Chain



Key Publications Depression CMR Nijmegen

van Weel-Baumgarten EM, van den Bosch WJ, Hekster YA, van den Hoogen HJ, Zitman FG. **Treatment of depression related to recurrence: 10-year follow-up in general practice**. *J Clin Pharm Ther.* 2000;**25**:61-6.

van Weel C, van Weel-Baumgarten EM, Mold J. **The importance of longitudinal studies in family medicine: Experiences of two practice-based research networks**. *JABFM* 2006;**19:**69-74.

Two Key Publications Monitoring Diabetes Mellitus Nijmegen

Grauw WJC de, Lisdonk EH van de, Gerwen WHEM van, Hoogen HJM van den, Weel C van. **Insulin therapy in poorly controlled type 2 diabetic patients: does it affect quality of life?** *Br J Gen Pract* 2001;**51**:527-32

Grauw WJC de, Lisdonk EH van de, Gerwen WHEM van, Verstappen MMH, Hoogen HJM van den, Willems JL, Weel C van. **Microalbuminuria in patients with type 2 diabetes mellitus from general practice: course and predictive value**. *Diabetic Med* 2001;**18:**139-43.

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olde Hartman TC, Lucassen PLBJ, Lisdonk EH van de, Bor JHJ, Weel C van. **Chronic functional somatic symptoms: a single syndrome?** *Br J Gen Prac*t 2004;**54:**922-7.

van Weel-Baumgarten E, van den Bosch W, van den Hoogen H, Zitman FG. **Ten year follow-up of depression after diagnosis in general practice**. *Br J Gen Pract.* 1998 **48:**643-6.

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van Weel-Baumgarten EM, van den Bosch WJ, van den Hoogen HJ, Zitman FG. **The longterm perspective:a study of psychopathology and health status of patients with a history of depression more than 15 years after the First episode.** *Gen Hosp Psychiatry* 2000;**22:**399-404.

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Grauw, W.J.C. de, Lisdonk, E.H. van de, Hoogen, H.J.M. van den, Gerwen, W.E.H.M. van, Willems, J.L., Weel, C. van, Bosch, W.J.H.M. van den. Screening for microalbuminuria in Type 2 diabetic patients: the evaluation of a dipstick test in general practice. *Diabetic Med* 1995; **12**: 657-663.

Grauw W.J.C. de, van de Lisdonk EH, van den Hoogen HJM, & Weel, C. van (1995). Cardiovascular morbidity and mortality in type 2 diabetic patients: a 22-year historical cohort study in dutch general practice. *Diabetic Med* 1995; **12:** 117-122.

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Klein Woolthuis EP, Grauw WJC de, Gerwen WHEM van, Hoogen HJM van den, Lisdonk EH van de, Metsemakers JFM ,Weel C van. Identifying people at risk for undiagnosed type 2 diabetes using the GP's electronic medical record. *Fam Pract* 2007; **24:**230-6.

Klein Woolthuis EP, de Grauw WJC, van Gerwen WHEM, van den Hoogen HJM, van de Lisdonk EH,. Metsemakers JFM, van Weel C. Yield of Opportunistic Targeted Screening for Type 2 Diabetes in Primary Care: The Diabscreen Study. *Annals of Family Medicine* 2009**; 7:**422-430

Episodes Recording: Longitudinal Data, Continuity of Care