Exploratory Workshop Scheme

Scientific Review Group for the Bio-Medical Sciences

Scientific Review Group for Life, Earth and Environmental Sciences

Scientific Review Group for Physical and Engineering Sciences

Scientific Review Group for the Humanities

Scientific Review Group for the Social Sciences

ESF Exploratory Workshop on

EARLY DIAGNOSIS OF CANCER IN PRIMARY HEALTH CARE

6th to 8th May 2013, Örenäs Slott, Gumslöv, Sweden

Convened by:
Dr Michael Harris and Prof Peter Vedsted

SCIENTIFIC REPORT

1. Executive summary

The aim was to elaborate on differences between organisation and function of different European health care systems in relation to primary cancer diagnosis.

The exploratory workshop brought together 18 participants from 8 countries, all of whom had an interest in earlier diagnosis of cancer on Primary Care.

The workshop lasted three days (one full day, two half days).

They included researchers experienced in qualitative and epidemiological research, GPs and academic doctors.

The facilities and environment at Örenäs Slott were conducive to discussion and decision-making, as well as informal interaction.

The Convenors kept the atmosphere relaxed to encourage informal discussion.

There was a mixture of planned short presentations, large- and small-group work, as well as timetabled informal discussion outside the conference area.

The Group decided that it wanted to achieve the following:
- frame research ideas/questions, plan collaborative applications;
- get insight into other health-care systems;
- start to find some answers to the research questions;
- form connections and new collaborations;
- decide how to move forward: make a plan.

Presentations and groupwork elicited and exploreed national differences in factors influencing access to, and speed of, diagnosis.

A long list of research questions was made. This was collated and whittled down by consensus to three main areas.

Participants each allocated themselves to one of the three research areas, decided on specific research questions and made preliminary research plans with time-scales.

- A: Patient decision-making: patient/GP interface, power, access to primary care

- B: GP decision-making, including access to investigations

- C: GP referrals: GP/secondary care interface: power, guidelines, waiting times

The research groups will be overseen by Michael Harris and Peter Vedsted to ensure that there is no overlap of work.

End-of-course surveys completed by participants suggest that the conference was well-organised and productive.

The group will be called the "Örenäs Research Group".

Overall conclusions
We decided on three main research areas:

Research area A

Patient decision-making: Patient/GP interface, power, access to primary care

Questions

- What influences the way that the patient and GP meet in different countries?

- How might this affect early diagnosis

Research area B

GP decision-making, including access to investigations

Questions

- How are the processes of GP decision-making influenced by gate-keeping principles of different countries?
- With a focus on: Access to investigations; Financial systems; Access to specialist care/relationship with specialist care

Research area C

GP-Hospital interaction, power, guidelines, waiting times

Questions

- How is the pre-diagnostic work of sorting patients with cancer suspicion organised in different countries? Focusing on:
- How (means, ways) do GPs refer?
- Where is the referral received?
- Who receives the referral?
- Who is involved in the clinical triage of referral information?
- Are there standardised procedures (guidelines) for doing triage?

GP Referrals prior to diagnosis

- How are referrals done? Phone, electronically, paper, verbally
- How and where and by whom are referrals received?
- How is referral sorting done? Procedures (guidelines).

Since the conference

We plan to apply for COST Action funding to support the research coming out of this conference.

Members of the Örenäs Research Group are planning a low-cost, Europe-wide exploratory study based on previous experience from International Cancer Benchmarking Partnership.

Two primary care physicians/researchers (one from Slovenia, one from Croatia) have already heard about the Örenäs Research Group and asked to join it.

2. Scientific content of the event

Primary Care factors influencing the time to cancer diagnosis: what do we know already?
Peter Vedsted, Rikke Sand Andersen

Cancer is a common, serious disease; every third will get cancer before age 75 years. During the next 10 years we will see an increase in the cancer by 20% due to demography and decreasing mortality of other diseases. A comparison between contries shows that there is a large variation in cancer outcome, especially 1-year survival. Further, these variations are also seen between different groups (e.g.social groups and comorbidity).

It has been shown that differences in organization of primary care in relation to gatekeeper role and list-system also are associatioed with cancer survival. This has led to the hypothesis that these differences in cancer outcome are rooted in the route to diagnosis and especially time from first symptom to the start of treatment.

From research we know that many people experience symptoms and signs. Most of these are self-limiting. However, differences in awareness and situation make some people postpone helath-care seeking; this might lead to delayed presentation. We also know that in Denmark and the UK at least 85% of all cancer patients start their journey to a cancer diagnosis by presenting symptoms to primary care. This means that the ease of GP access to relevant diagnostic tests is a very important way of supporting earlier cancer diagnosis in primary care.

It is therefore important to investigate the similarities and differences between the different European primary care models, as well as their possible effect on time to cancer diagnosis.

Marie Louise Tørring

Little is known of how GPs and specialists mutually influence each other in the process of diagnosing patients with potential cancer. We know that patients follow a great variety of routes from the primary to secondary health care sector and that cancer trajectories differ greatly in lengths of time. Part of this variation can be explained by clinical triage – i.e. the sorting of patients with potential cancer.

Qualitative studies have shown that GPs and hospital physicians engage in collective practices to sort out patients with potential cancer. They keep track of each other's collaborative actions and communicate levels of urgency – sometimes by using subtle categorisation – for instance in free text fields of the electronic referrals. A study in Denmark found that secretaries take active part in clinical work as well and help sort patient with potential cancer by examining the patient's condition, interpreting clinical information, monitoring the followup, and informing the patient trajectory. Thus, being positioned at the intersection of clinical and administrative practices secretaries are also part of the collaborative systems supporting the diagnosing process.

Discussion

Qualitative research has the potential of opening our eyes to the influence of context (history, policies and systems) in the clinical setting. Because we tend to take our own life worlds for granted, we can make the unseen or tacit aspects of diagnosing cancer more explicit by comparing practices across countries. Such studies and perspectives are essential for understanding the influence of clinical conventions, hierarchies and interactions on cancer detection and survival.

How do our models of Primary Care compare and contrast? In what ways might these differences influence the time to cancer diagnosis?
Short presentations from each represented country's participants ; Smallgroup discussions

Summary of key points

Influence of economy – less deprivation leads to a better outcome. Consultation length may be a key factor. There may be expectations to refer the patient. The power of the patient to get a fast initial consultation may be related to the person who makes the initial triage (receptionist/secretary/nurse/GP). There are clear national differences: geography, distance, rural, transport, general health.

Patient delay may be due to lack of awareness of significance of symptoms. GP factors include GPs' education and how they interact with patients.

Screening programmes differ between countries, as do GP training systmes and GP thinking. Access to investigations and specialists varies from country to country. In some systems a good doctor is considered to be someone with a low referral rate. Screening uptake is reducing in Sweden, and some patients there don't adhere to their recommended cancer treatment.

There are large organisational differences and similarities; there produce variations in informal practices, rules and values.

What affects the ways that patients with cancer present and GPs manage them?

Michael Harris, UWE

Starfield's hypothesis: GP first contact avoids unnecessary specialist visits. Person-focus over time avoids disease-focused care (makes care more effective). Comprehensiveness avoids referrals for common needs (makes care more efficient). Coordination avoids duplication and conflicting interventions (makes care less dangerous). But… countries like Denmark & UK, with a very strong model of primary care, where GP as gatekeeper++ are in the lowest quartile for 1-year relative survival rates in the EU; this suggests delayed diagnosis

In patients with undiagnosed symptoms, most of the GPs are only consciously aware of clinical influences on their decision-making. But there are subconscious effects: system and cultural differences affect the way that GPs think and act; these are "normal" for GPs in their own health system, so they have little awareness of the effect that they have on how they think.

There is a wide range of factors that can affect primary care doctors' actions: consciously, subconsciously, and unconsciously:

Personal factors: Doctor's own professional background, System factors, Cultural factors, Personal factors

Doctor's professional background: GP training system, holistic vs medical approach, where some "primary care" doctors are specialists.

System factors: pressure on time, ease of access to investigations, and specialists, whether gate-keeper, strength of gate-keeping expectations, how paid, e.g. salaried vs. per visit & investigation, feedback (positive or negative) from secondary care or health-care organisation, awareness of financial pressures

Cultural factors: complexity of problems that GPs are expected to manage, patients' expectations, fear of litigation

And for patients? Personal factors: too busy, embarrassment… Patient's background: family history, personal experience… Cancer awareness and beliefs: national publicity, awareness of "red flag" symptoms… System factors: ease of seeing doctor, expectations of care… Cultural factors: "should not waste the doctor's time", "stiff upper lip"…

Discussion

Causes of delayed cancer diagnosis are wide-ranging and complex. They include subconscious and unconscious causes; these vary from country to country

Early Cancer Diagnosis - The Patient's Experience

Theresa Mitchell (University of the West of England, UK)

The aim of this presentation was to give voice to patients who had experience of meeting with GPs early in their cancer journey. It contrasted to previous presentations which focused on the actions of GPs, early cancer diagnosis drivers, and medical models of treatment.

Patients' raw data quotes were extracted from five qualitative studies conducted in the last five years. Although not specifically concerned with early cancer diagnosis patients usually begin the telling of their experience at the interface with their GP. To stimulate consideration of the issues for patients, the raw data quotes about patients' experiences were followed by questions about GP response or behaviour in each particular situation. Patients told of their reluctance to go early to their GP even though they suspected cancer.

GPs were criticised for overusing diagnostic tests, which gave the impression they did not know what was wrong with the patient. There was speculation that GPs who were 'good listeners' were more efficient in accurately diagnosing cancer. The data illuminated inconsistencies in the way that GPs respond to patients' suspicions and fears about having cancer and subsequent referral.

Discussion

Post presentation questions focused on the value of the patient perspective and the richness of the raw data quotes.

How easily can we access further investigations that may speed diagnosis of cancer?

Brief presentations from each represented country's participants

Norway: simple tests within-practice, direct access to CT, MRI etc, rarely refused though priority may be changed.

Sweden: direct radiology referrals, but costs come out of primary care funds so reduce GP income; may be 3-6 month wait for endoscopies.

Switzerland: a third of practices have in-house Xray & USS; strong GP-specialist network; can order almost all Ix, get results within a week; GPs pay for equipment and own training; most blood tersts analysed in-house.

UK: GPs can refer for USS, basic radiology; other Ix screened by consultants, may be refused if not within guidelines; huge pressure to reduce referrals and Ix.

Denmark: GPs get paid for in-house tests; refer to hospitals for imaging; complex imaging via double-gatekeeping, this causes delays; cancer referrals seen rapidly; patients without non-red flag sx have to wait longer because of fast-track system.

Spain: regional variations; can ask for any Ix, but waits may be for many months; some GPs do USS; occasional attempts to offer a fast-track system, but these don't last; no direct pressure to reduce referrals.

Slovenia: personal contacts important; limited capacity for Ix, there is a set budget for Ix, and pressure to reduce Ix; some waits can be up to a year; if "overspend", this reduces the budget for other primary care costs.

How does the thought of cancer arise in a general practice consultation?

May-Lill Johansen (University of Tromsø, Norway)

Various factors: basic medical lknowledge, including what was learnt at medical school; interpersonal awareness: small as well as big cues; GP's background knowledge helps, but concerns about missing cues in frequent attenders.

Intuition or "gut feeling" can be important, eg there there is a "feeling of unrest". Fear of cancer plays a role: patient's fear, also the GP's fear of missing the diagnosis.

What influences a primary care doctor's decision to arrange further investigation or onward referral?

Peter Murchie (University of Aberdeen, UK)

This presentation began with a summary of a symposium held in Aberdeen, Scotland in 2009. The presenter began the talk by outlining three key areas which he perceives to be influential in determing the how quickly, and by which route, a patient arrives at a cancer diagnosis.

The presenter briefly discussed patient factor and doctor factors. He offered the view, that based on discussion at the symposium in 2009, they were not, arguably. likely to differ sufficiently between countries to translate into major differences in cancer diagnostic delays and pathways.

Instead more focus should be directed at systems factors. Within these the presenter suggested that the presence of guidelines could be important, noting that there was a great reliance on these in the UK, a relatively poorer performing country. Access to guidelines could also be important and seems to differ widely across Europe, with GPs in the UK apparently having more restricted access than elsewhere. Similarly, relationships within the health system, particularly hierarchical attitudes could influence delay.

The presenter concluded by suggesting that these three areas were worthy or further urgent qualitative study.

Discussion

The discussion highlighted several differences between participating countries with respect to guidelines (a greater reliance in the UK - the world leader). Additionally, there were marked difference in which investigations GPs could carry out directly themselves, access directly or require vetted access to. Relationships too differed, some reporting a rather more collegiate attitude than elsewhere. The meeting agreed that the issues were worthy of further exploration.

Our research groups: planning the next steps

Smallgroup discussions

Summarised in next section

3. Assessment of the results, contribution to the future direction of the field, outcome

Overall conclusions

We decided on three main research areas:

Research area A: Patient decision-making: Patient/GP interface, power, access to primary care

Questions
- What influences the way that the patient and GP meet in different countries?
- How might this impinge on early diagnosis
- Focus to be decided

Plans: review of the literature, divided tasks within group, secondary analysis of data that are already there.

Research area B: GP decision-making, including access to investigations

Questions
- How are the processes of GP decision-making influenced by gate-keeping principles of different countries?
- With a focus on: Access to investigations; Financial systems; Access to specialist care/relationship with specialist care

Methodology
- Factual data collection, descriptions, mapping systems
- Questionnaire with scenarios/vignettes, surveys
- Fieldwork (observation, focus groups, interviews, cross-cultural view to pick up cultural and social influences)
- Include Netherlands, 2 Eastern European & 2 Southern European countries (European GP Research Network as possible source)

Where to from here?
- Core Örenäs team needs to coordinate the groups; ensure no overlap with Group C
- Our group will develop this, Michael will coordinate
- Can bring in other members if group agrees
- Who and when?
- Plan work packages, structure by methods or sub-questions

Timescale
- Draft from M in 4 weeks, our group in another 2 weeks, respond to wider group suggestions in another 4 weeks, i.e. complete proposal 10 weeks from now.

Research area C: GP-Hospital, power, guidelines, waiting times

Questions
- How is the pre-diagnostic work of sorting patients with cancer suspicion organised in different countries? Focusing on:
- How (means, ways) do GPs refer?
- Where is the referral received?
- Who receives the referral?
- Who is involved in the clinical triage of referral information?
- Are there standardised procedures (guidelines) for doing triage?

GP Referrals prior to diagnosis
- How are referrals done? phone, electronically, paper, verbally
- How and where and by whom are referrals received?
- How is referral sorting done? Procedures (guidelines)

Where will the research be done?
- Croatia, Denmark, England, Norway, Scotland, Slovenia, Sweden, Spain, Switzerland,

What data collection methods
- Focus groups w GPs, administrators, secretaries
- Participant / non participant observations
- Individual interviews w GPs, administrators, secretaries
- Written info, referral notes etc. - How access this data? Ethics approval needed

Data analysis methods
- Ethnography; Grounded Theory; Survey

4. Final programme

Monday 6th May 2013

Morning	*Arrival*
12.00	*Light lunch available*

13.00-17.30 **Afternoon Session, Day 1**

13.00-13.30 **Welcome by Convenors**
Michael Harris (University of the West of England, UK) and **Peter Vedsted** (Aarhus University, Denmark)

Introductions and backgrounds

All delegates

13.30-13.45 **Presentation of the European Science Foundation (ESF)**
Krešimir Pavelić (Scientific Review Group for the Bio-Medical Sciences; University of Rijeka, Croatia)

13.45-14.30 **Primary Care factors influencing the time to cancer diagnosis: what do we know already?**
Peter Vedsted, Rikke Sand Andersen, Marie Louise Tørring

14.30-15.00 *Coffee / Tea Break*

15.00-16.00 **How do our models of Primary Care compare and contrast?**

Short presentations from each represented country's participants

16.00-16.45 **In what ways might these differences influence the time to cancer diagnosis?**
Smallgroup discussions

16.45-17.30 Plenary and **Summary of Day 1**

Convenors

19.00 *Dinner, informal discussion and development of research collaborations*

Tuesday 7th May 2013

09.00-12.30 **Morning Session, Day 2**

09:00- 09:10 Summary of Day 1 and goals for Day 2

Convenors

09:10- 09:40 How might different models of primary care influence the way that patients with cancer initially present and GPs manage them? What evidence is there about cancer patients' initial consultations with GPs?

Michael Harris and **Theresa Mitchell** (University of the West of England, UK)

09:40- 10:30 What are our experiences of how patient delays and types of presentation have delayed diagnoses of cancer?

Smallgroup discussions

10:30- 10:45 *Coffee / Tea Break*

10:45- 11:15 **Summaries from each group**

11.15- 12.00	How easily can we access further investigations that may speed diagnosis of cancer?
	Brief presentations from each represented country's participants
12.00- 12.30	How does the thought of cancer arise in a general practice consultation?
	May-Lill Johansen (University of Tromsø, Norway)
	What influences a primary care doctor's decision to arrange further investigation or a referral to a specialist?
	Peter Murchie (University of Aberdeen, UK)
12:30- 13:30	*Lunch*
13.30-17.15	**Afternoon Session, Day 2**
13.30- 15.30	Walk & Talk: Holistic, medical, or somewhere in between: how do our different models of primary care affect the way that primary care doctors think? What influences a primary care doctor to actively consider cancer in a patient?
	Smallgroup discussions
15:00- 15:30	*Coffee / Tea available*
15.30- 16:30	**Summaries from each group** and development of consensus
16.30- 17.15	Possible research questions
	Smallgroup discussions
19.00	*Dinner, informal discussion and development of research collaborations*

Wednesday 8th May 2013

09.00-12.30	**Morning Session, Day 3**
09:00- 09:10	Summary of Days 1 & 2 and Goals for Day 3
	Convenors
09:10- 09:40	What research methods are open to us?
	Brief presentations
09:40-10:45	Discussion of possible research methods
	Smallgroup work
10:30- 10:45	*Coffee / Tea available*
10:45- 11:30	Our research groups: planning the next steps
	Smallgroup discussions
11.30- 12.15	**Summaries from each group**
12:15- 12:30	Overall summary & the way forward
	Convenors
12:30- 13:30	*End of Workshop, lunch and departure*

5. Final list of participants

Convenor: Michael HARRIS, University of the West of England, United Kingdom

Co-Convenor: Peter VEDSTED, Danish Research Centre for Cancer Diagnosis in Primary Care (CaP), Denmark

Rikke Sand ANDERSEN, Danish Research Centre for Cancer Diagnosis in Primary Care (CaP), Denmark

Ueli BOLLAG, Universität Bern, Switzerland

Christina CARLSSON, Lund University Hospital, Sweden

Magdalena ESTEVA, Atenció Primaria Mallorca, Spain

Carmen FONT MOREY, Santa Maria Health Centre, Mallorca, Spain

Peter FREY, Universität Bern, Switzerland

Adrian GÖLDLIN, Universität Bern, Switzerland

May-Lill JOHANSEN, University of Tromsø, Norway

Jörgen MÅNSSON, Göteborg University, Sweden

Theresa MITCHELL, University of the West of England, United Kingdom

Peter MURCHIE, University of Aberdeen, United Kingdom

Bernardino OLIVA-FANIO, Calvia Heath Center, Mallorca, Spain

Tonka POPLAS SUSIČ, University of Ljubljana, Slovenia

Abby SABEY, University of the West of England , United Kingdom

Hans THULESIUS, Lund University, Sweden

Marie Louise TØRRING, Danish Research Centre for Cancer Diagnosis in Primary Care (CaP), Denmark

ESF Representative: Krešimir PAVELIĆ, University of Rijeka, Croatia

6. Statistical information on participants (age bracket, countries of origin, M/F repartition, etc.) The statistics to be provided under section 6 can also include repartition by scientific specialty if relevant.

Females:	9
Males:	9
Denmark	3
Great Britain	4
Norway	1
Slovenia	1
Spain	3
Sweden	3
Switzerland	3
General Practitioners	16
Reearchers	2
Age brackets	Information not requested