HEALTH-FP7-2009-241604

Deliverable 13bis

Report evaluating interaction between mother-child cohort research and policy and setting recommendations for research and policy

Work Package 4

University of Bristol, United Kingdom

Work package no	4	Start date		Month 1			
Work package title	Improving the contribution of mother-child cohorts to European child health policy						
Activity type	COORD						
Participant id	1	2	3	4	5	6	**7**	8
Person-months per beneficiary	1	0.5		0.5	21	0.5	15	0.5

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Deliverable : 13bis

Title : Report evaluating interaction between mother-child cohort research and policy and setting recommendations for research and policy.

Nature : Report

WP Reference : D4.3

Dissemination level : PU

Planned : Month 36 (December 2012)

Actual : 28 December 2012

A project conducted within the European Union's 7th Framework Programme , Theme 1, Health

Contents

4.1 INTRODUCTION

The translation of birth cohort research into messages policy-makers can use, has seldom occurred at a European level, although it has in some individual countries. The lack of integration of cohorts across Europe, as well as the timing of the cohorts (many are still very young and it will take time for strong messages to filter through) have contributed to this. However, with the ageing of the cohorts, and with stronger European coordination, cohort research has the potential to play an important role. An attempt to draw the attention of policy makers to the particular strengths of birth cohorts and an effort by researchers to address the specific concerns of policy makers is over-due. Work Package 4 aimed to explore the ways in which evidence from child cohorts has been, or might, be, used in policy making in Europe and, using these findings, to develop recommendations to improve the contribution of mother-child cohort research to policy at the European level.

In recent years there has been considerable growth in the debate around evidence based policy making in Europe and elsewhere. The argument that decision makers should both take account of and actively pursue evidence has gained ground (e.g. [1, 2]). The importance of establishing an evidence base to support European level action was, for example, identified in a recent report on scientific policy making in Europe [3]. The use of research evidence in developing policy is both possible and valuable [4]. Such evidence should be able to influence policy making in at least five ways (UNICEF 2008):

- Achieve recognition of a policy issue
- Inform the design and choice of policy
- Forecast the future
- Monitor policy implementation
- Evaluate policy impact

The available evidence can be divided into that which has been explicitly commissioned by policy makers on policy-relevant questions, and non-commissioned research funded and carried out by a range of organisations for the purpose of scientific discovery, where informing policy makers may not be a goal. Currently much of what is produced outside of the commissioning process is underused by policy makers at national, regional and international levels. There is a challenge for the research community in how to that ensure findings are readily available, and disseminated in a clear format for the policy community. However, the research community also needs to develop a better understanding of the transferability of research evidence and the importance of enabling policy makers to access and use research findings in their decision making and policy formulation. The challenge for policy makers is to engage in this debate and seek research evidence, and also to develop consistent methods of referencing the evidence that they do use in ways that are clear for both expert and lay readership. In addition, there is a challenge for both sides to engage in dialogue with each other at the start of a project, as research questions are formulated, during the project as results are published, and over a longer time frame as policy is developed.

Demands have been made of both policy makers and researchers by those who wish to see more evidence informed policy. Changes in practice suggested to facilitate better interchange between policy and research are challenging to make. Researchers are asked to see policy-usefulness as a leading objective of their work and ensure they both involve policy makers and prepare readable evidence briefs for the use of policy makers [3, 5]. Researchers are often keen to increase the potential for their findings or data to be taken into account when policies are being drawn up or evaluated. Dialogue between researchers and policy makers at an early stage of research

development (for example in the design of the research) is likely to bring greater benefits including a better fit with the needs of policy makers and a better awareness on the part of the policy makers of the value of the research [6]. In addition, the underpinning evidence for policy is not always clearly articulated. Policy documents do not consistently identify the underpinning evidence in ways that allow scrutiny, and policy makers do not follow the same rules of evidence as academic writers or scientists in citing references to source material. A growing number of writers have called for 'research about research use' to understand these issues better. This report falls into that category of work and aims to inform both policy and research about how research is used, with a view to suggesting how it might be used.

4.1.1 Research influence & Policy Transfer

Common barriers to increasing research influence have been identified in the literature [4, 7-10]. Structural barriers between research and policy include competing time scales for rigorous research and political decisions, and organisational boundaries which decrease the likelihood of contact between the communities. Policy makers and researchers operate in very different contexts, and are likely to have different pressures and interests applying to them. In addition the very different cultures of debate create barriers; where academic researchers produce a discourse on a topic, exploring difference and nuance while policy makers seek consensus and solutions applicable to most (if not all). Use of research evidence can be symbolic; legitimising pre-determined position and, in this context, has been termed policy informed evidence.

A recent paper by the European Commission Director General for Research in the Socio-economic sciences and humanities [5] on communicating research findings for evidence-based policy making suggested a number of key issues in knowledge transfer between the research community and policy makers. These included the need for engagement and dialogue between the 'two communities', for researchers to ask themselves who the research 'matters to?' and for teams to disseminate their findings more comprehensively through research briefs designed for policy makers. For this to happen, researchers will need to understand more of the policy context; considering what topics are on the policy agenda and where evidence is currently being gathered.

Epistemic communities and policy networks, at national, European and international level, play a significant role in the transfer of policy ideas and solutions, and the way in which these groups identify and draw on research evidence is therefore an important element in this discussion. While many of the EU recommendations for policy relevant research dissemination refer to written and on-line material, researchers also need to engage face-to-face with policy audiences [5].
Policy makers should make explicit how they have drawn on research – what forms of research, how it was assessed and at what stage of the process. It is also the case that research evidence in the context of some health and social care policymaking will not always give clear unambiguous directions for policy makers, and the answer to 'what works' can be problematic [11]. Researchers need also to be able to share findings where the conclusions are not clear, or have a number of caveats in specific circumstances.

Policy also shapes the research environment. At the simplest level, much research is funded by national and international governmental organisations and their priorities therefore drive much research through selection for funds. Less direct influence is also important; where demand for rigorous evaluation exists, the impetus to produce research which provides such evidence for policy

makers is large. It may therefore be important not only to place research findings in the way of policy makers, but also to know and understand the up-coming information demands of policy makers such that research is geared toward a receptive audience.

4.2 Results

In order to better understand the opportunities for European birth cohorts to potential to improve the contribution of mother-child cohorts in Europe WP4 set out to:

4.1 Establish EU policy remit and review research influence to date (UoB)
4.2 Delphi study to establish information needs (EMC)
4.3 The role of policy makers in design of child cohort studies (EMC)
4.4 Recommendations to improve the impact of birth cohorts

These aims correspond to the following sections of this chapter. They report, in turn, on:

WP4.1 A review of the extent to which mother-child cohorts have contributed to current policies produced by EU, WHO and English institutions
WP4.2 The creation of an inventory of the information needs from parties involved in the development and implementation of child health policies at the European and national level using Delphi technique
WP4.3 An exploration of policy involvement in cohort planning using 3 case studies
4.4 Conclusions drawn from this research, and from discussions with the attendees at CHICOS workshops.

Further details on each of these contributions are included in appendices x-y, and are summarized here. From these, recommendations to improve the contribution of mother-child cohort research to policy at the European level were developed (WP4.4) drawing on evidence collected here and on theoretical perspectives of the relationship between research and policy.

4.2.1 Activity 4.1 Examples of research utilisation (particularly utilisation of mother-child birth cohorts) in EU, WHO and English child health policy

A review was undertaken of the ways in which research evidence (particularly considering evidence from cohort studies) is used to develop child health policy in 3 contexts: The European Union, the European Region of the World Health Organisation, and in England (University of Bristol Lead). Appendices 4.1.1, 4.1.2, 4.1.3 provide full details of work conducted within this work package

Two topics were selected case studies selected on the basis of their public health significance, policy/political importance and the potential value of birth cohort studies to contribute to knowledge for policy in the field. These two topics (Regulation of particulate matter (PM) in the air to protect child health and Policies regarding physical activity (PA) and health for children) were reviewed in each of the three policy contexts (EU, WHO, England).

In each context a defined set of policy documents relating to the topic area was brought together; in some cases it was possible to identify a closed set of documents (for example a regulatory tool and the documents recording the development of this) but in others this was not possible and a sample of documentation was used instead. Our aim was to explore examples of the ways in which research was (and was not) used during different parts of the policy process. We undertook an analysis of these various policy documents to locate and describe direct and instrumental use of research considering the purpose of research use, and the types of research used. We also sought out instances where cohort studies were cited. Finally, we considered the extent to which existing publications or data were available to address gaps identified in the research base.

Research Utilisation in EU policies

Directive 2008/50/EC on ambient air quality and 24 associated documents, along with 14 policy documents which mention physical activity were examined (Appendix 4.1.1). In both cases, the protection of human health was part of the explicit rationale for action, although reference to child health in the development the air quality directive was rare. Policies in the field of physical activity largely addressed he health consequence (obesity and overweight) of low levels of PA.

Practice differed in the explicit use of research between the two case studies. In the case of regulation of fine particulate matter, explicit references to research were concentrated in a small number of documents and most often used to describe the nature of PM exposure or to link PM exposure to health outcomes.

Explicit use of research was more common in the PA policies; research was cited more often and among more documents. Research evidence was commonly used to justify the need to address levels of PA or to justify proposed actions. Research demonstrating associations between PA and obesity and exploring determinants of levels of PA were also common. Greater use was made of systematic reviews and RCTs, suggesting a preference for these designs although no consistent approach described. Often (particularly in the PM case) reference was made to research-based claims without explicit links to evidence, and some of these instances could be considered to tokenistic. Research that was explicitly cited was often undertaken or commissioned by European institutions, advisory committees or groups to understand the likely impact of policy changes. In the case of PM, the particular contribution of cohorts in providing long-term data was noted.

Three types of research demands were made in documents relating to these 2 topics: calls for more and better routine collection of data, calls for further research on responses to the problems including best practice or current conditions in individual Member States, and finally calls for policy to draw on research findings in future, without specifying what research might best inform these policies.

Research Utilisation in WHO Recommendations

WHO's role in global health leadership and global health governance mean that EU policy should be draw on recommendations made by WHO. The core functions of WHO include shaping the research agenda and articulating evidence-based policy options, so we might expect this organisation to be generators, disseminators, and users of research knowledge. The topics selected for study correspond with 2 of the 4 Regional Priority Goals for WHO Europe; addressing obesity and injuries

through safe environments, PA and healthy diet; and preventing disease through improved outdoor and indoor air quality. Both Particulate Matter and PA have been key components of WHO Europe's priorities.

Among the documents scrutinised from WHO, patterns of research use varied by type of documents not by topic. Considering 11 PA documents as an example; among these, just 3 documents accounted for 90% of the examples explicit use of research. These were WHO Information Series on School Health, called Promoting PA in Schools (89 examples); Interventions on diet and PA: what works: summary report (105 examples); and Global recommendations on PA for health (24 examples). Implicit research use was more common in the initial declaration or policy, but in subsequent implementation guidelines and documents explicit research use became more common. Most of the research cited was produced or published by WHO, ranging from general statements to systematic evidence reviews. Although a variety of research types were used the most common types were cross-sectional and survey studies, and scoping reviews, while there were very few references to RCTs and fewer still to cohort studies (though somewhat more in PM than PA documents).

WHO recommendations were generally well evidenced, with explicit use of research including citations to sources provided. This included good examples where systematic and transparent reviews of the evidence were undertaken. There remained, however, examples of 'expert review' without description of methods or basis of inclusion. Compared to the EU documentation, there were relatively few calls for further research. Where systematic reviews are undertaken, birth cohorts will be included in these to the extent they have published findings which meet the inclusion criteria. Individual scientists are also likely to gain influence in this arena where their body of work is internationally recognised.

Research Utilisation in English Policies

We examined English rather than UK policy in response to the way in which power is devolved to the UK regions (Scotland, Wales, Northern Ireland, England). England, in common with some other countries [1], conducts Comparative Effectiveness Research (CER) to inform national practice in health and this provides a very particular context for research utilisation where there are both government departments and a government commissioned unit reviewing evidence for policy.

Reviews conducted by The National Institute for Health and Clinical Excellence (NICE) meet the highest standards of transparency in research utilisation, although these do not cover all areas of policy; review methods are subject to public scrutiny prior to the start of the review, all the reviewed evidence is carefully summarised and consultation exercises are public. Where these reviews inform policy decisions or actions in practice the route from research to policy influence and the contribution of bodies of research are clear.

In the case of PA, policy was developed making explicit use of systematic reviews to amass evidence, or adopting those produced elsewhere (in production of Australian, Canadian, and US Guidelines) Individual research outputs or whole research studies have demonstrable and transparent influence in these cases. The use of standard methods for identifying and judging strength of evidence means that standard publishing in scientific journals is sufficient to be confident of influence. In the case of PM the approach taken to research use was less transparent. Little research was explicitly cited, and vanishingly few references to childhood were found. The majority of explicit references to research

was to that undertaken or commissioned by the DeFRA, Committee on the Medical Effects of Air Pollutants (COMEAP) and the Institute of Occupational Medicine. While valuable and learned, these outputs do not address a non-expert audience, nor give a good sense of the nature and scale of the health impacts and as such lack utility for decision takers in central government.

Conclusions from Case Studies of Research Utilisation

We considered known barriers to research utilisation, and considered the extent to which these were confirmed in each case study.

Decision making structure of policy making organisation will matter	**EU**: Confirmed in appearance of research in staff working documents, but not in parliamentary proceedings. **UK**: Although both case studies relied heavily on expert groups, the different departments adopted different methods for consultation and review. **WHO**: Confirmed in appearance of research in implementation documents, use of expert evidence reviews.
Institutional and individual links between policy makers and researchers will matter	Confirmed in dominance of **WHO** in **EU** documents Use of experts by **WHO** Cross departmental and regional collaboration in **UK**, links with researchers well supported by NICE
The role of knowledge brokers may facilitate research use	Confirmed in dominance of **WHO** in **EU** documents Use of experts by **WHO** Cross departmental and regional collaboration in **UK**, links with researchers well supported by NICE
Institutional and individual links between policy makers and researchers will matter	Confirmed in relationship with **WHO**, advisory committees in **EU**, and extensively in UK development of Physical Activity guidelines.
Nature of research and adaptations of research products should support research use	**UK** Particulate Matter case shows how good research may not be useful if it does not address the questions and priorities of the public or decision makers.
The challenge of working within political constraints	**Particulate Matter was more closely linked across EU, WHO and UK policy as a result of the political role of the EU and cross border threats from air quality.** Our observation (also political) is that individual level explanations are favoured above structural (e.g. walking to school presented differently in PA policy documents (as a positive) compared with PM policy documents (as a risk factor)

4.2.2 Activity 4.2 Inventory of the information needs from parties involved in the development and implementation of child health policies at the European and national level

For prioritising research questions, information needs from parties developing and implementing child health policies at the European and national level should be considered. This sub-study considered the views of stakeholders from child health research and child health policy development on policy-relevant priorities for birth cohorts.

The opinions of stakeholders were sought using a Delphi technique[12-14]. This technique is used to obtain consensus among experts using three iterative rounds of data collection. We asked experts to indentify and prioritise information needs with regard to: (a) specific disease outcomes; (b) specific determinants of health and of inequities in health; (c) specific topics of research.

In Round 1 open questions were emailed to 51 researchers and policy makers asking for topics that may be relevant for the development of child health policy. Twenty-one (41.2%) experts responded; 73.3% were male; 80.0% aged 30-60 years; 33.3% with a European work scope and 66.6% a national or regional scope . In Round 1, 86 different topics were identified. These were grouped into: 26 topics on childhood illness/disease; 16 topics on life style and parenting factors; 10 topics on environmental factors; 9 topics on health inequalities and vulnerable groups; 6 topics on general health, health-related quality of life and well-being; 5 topics on early life and pregnancy complications; and 14 miscellaneous topics.

In Round 2, a convenience sample of 222 researchers and policy makers was asked to rank the relevance of all 86 topics identified in Round 1. Up to 3 reminders were mailed. In Round 2, 119 experts participated by completing one or more items of the questionnaire (53.6%), while 89 participants completed all items (40.1%). Almost half of the participants in Round 2 were male; 93% were in the age category 30-60 years old; 14% was involved in policy issues at the international level, 26% at the national or regional level; 3% was involved in management and governance. Of the participants, 43% was involved in policy at the international, national or regional level; almost all participants were in some way involved in research (epidemiological or child health research). Participants in Round 2 came from 20 distinct European countries and one from the U.S.A.. The participants were invited to rank the relevance of the 86 topics for the development of child health policy at the European or national level on a 1 – 7 scale (1 was ‘absolutely not relevant; 7 was ‘extremely relevant’).

The majority of the topics that resulted from Round 1 (i.e. 72 topics out of 86 topics) were considered relevant (median ≥ 6.0) for the development of child health policy at the European or national level; 14 out of 86 topics were not considered relevant (median < 6.0).

The final round of the Delphi process (Round 3) aimed to improve consensus. Items that scored a median of ≥ 6.0 and an inter-quartile deviation (ICD) > 1.0 in Round 2 were deemed relevant, but without sufficient consensus. These were 20 topics, and they were included in Round 3. 76 experts from Round 2 participated in Round 3. In this final round, consensus was reached on14 of the 20 topics that were re-assessed. This resulted in a total of 66 topics that were deemed relevant and on which consensus was attained (i.e. IQD ≤ 1.0). These topics are listed in (Appendix for 4-2). The 66 topics covered all the categories of research topics that resulted from Round 1. Five out of these 66

topics resulted in a median score of 6.5 or 7.0, and can therefore be considered extremely relevant, namely: overweight and obesity in preschool children, socio-economic differences in health, poverty and differences in health, what health determinants are most important for child health and, which interventions are most effective to promote child health and well-being.

The list of topics indicates that not only cohort studies are needed to support the development of child health policy in Europe. For some specific topics for example, randomised controlled trials qualitative research, or systematic reviews may be more suitable. Although in the Delphi study consensus on importance of topics identified as relevant by experts was achieved for 66 topics, we were not able to clearly identify priorities because there was relatively little differentiation between topics. Topics included both common conditions and rare diseases, and both the physical and social causes and consequences of ill health. Of particular importance the participants rated topics regarding poverty and equity in health in childhood, and they specifically drew attention to vulnerable groups of children and their health and development.

4.2.3 Activity 4.3 Policy involvement in cohort planning

This sub-study aimed to assess the extent of policy involvement in cohort planning by interviewing policy makers and cohort researchers associated with ongoing birth cohort studies; the Dutch Generation R Study, the INMA cohorts in Spain and the Polish mother and child cohort study REPRO-PL. Fourteen interviews were conducted:
- Generation R Study (3 interviews with Principal Investigators (PIs); 3 interviews with policy makers; 3 interviews with stakeholders with a dissemination role)
- INMA cohort (2 interviews with PIs; 1 interview with a policy maker)
- REPRO-PL (2 interviews with a PI and a senior researcher; 1 interview with a policy maker)

Results1: Policy involvement in cohort research
- The level and nature of contacts between cohort researchers and international, national, local and regional policy makers seems to be related to (a) political structure and (b) funding structure.
- Examples of involvement of policy makers are: decisions on which topics to work on, facilitation whenever needed, and recruitment of participants.
- In most cases, policy makers involvement in cohorts follows funding. However, this is not the case where European Union was involved, when contact is rare. Where there is no funding, contacts have developed gradually.
- While interaction between policy makers (especially at the national level) and cohort researchers was intense during the design phase, later on interaction seemed to slow down.

Results 2: Influence of cohort research outcomes to policy
- While researchers are of opinion that they mostly initiate contacts with policy makers and present their results in an adequate way, the policy makers in this study put forward that researchers should share and present their research results.
- The use of cohort results by policy makers may depend on: (a) policy relevance of results, (b) quality of research, and (c) adequate translation of results used by policy.
- Policy makers and cohort researchers alike consider that both research and policy would improve by more and better collaboration.

- All researchers mentioned differences between the 'cultures' of policy-making and research. Researchers and policy makers respond to different incentives, and operate under different timelines and constraints.

Conclusions:

The relationship between international, national, regional, and local policy makers and those who plan and conduct cohort research varied between the 3 cohorts we spoke to. Although interactions existed between policy makers and researchers in all three cases, policy makers did not play a large role in cohort planning. Both policy makers and researchers agree that collaboration and communication between policy makers and researchers should be further improved.

These findings suggest that cohort researchers should involve stakeholders from policy, not only when results are final, but also during the process of research planning, data collection, analysis, and reporting. Furthermore, it is recommended to format cohort research results in a way that is accessible to policy makers and researchers should translate results into policy recommendations or implications.

Appendix 4-3 provides full details of work conducted within this work package

4.3 CONCLUSIONS AND RECOMMENDATIONS

The policy process is neither linear not uniform; policy contexts (such as governmental structures and political influence) vary widely. It is useful to consider a cycle of development, influence and decisions, illustrated in Figure 1.

Figure 1 The Policy Cycle

Taking this cycle as a framework of typical processes, we can consider where and when we might expect opportunities for research influence, where it is likely that cohort research already has a strong voice, and what actions could be taken to increase influence. In the simplest cycle of

influence findings from systematic review of research evidence can help decision makers to define or redefine the problem to be addressed, and while research which monitors policy impact could lead to further policy development. In this simple model, research has significant impact on identification of problem – research findings, well disseminated, feed into recognition that there is problem in first place directly or through influence on pressure groups and other stakeholders. Where reviews of evidence are produced individual researchers, research projects, or groups of studies will have influence to the extent that their research is deemed relevant. Both of these routes to influences coincide with the core activities of most research groups, although the first might hint at the importance of audiences outside of the academic and policy communities. Breadth of output may also be important in less obvious ways; when developing options for action in PA WHO used research looking at the impact of different interventions where these could be considered 'horizon scanning' rather than evidence based.

The critical question that is often not well considered is which group of actors is appropriate for a given part of the process. A broad group including politicians, pressure groups, wider public and media might have influence on problem identification. Research reviews will be commissioned by policy makers rather than politicians. The development of policy options is likely to be carried out by civil servants, bureaucrats who may or may not consult evidence. Reaching all these groups would require a number of different strategies, and is outwith the scope of ordinary research activity. The question then becomes who can and should we speak to, without imagining that all these audiences are within our reach. It is particularly pertinent here to compare the specialisation of researchers often across decades of research in their field, with the fleeting careers of those in political service, who will typically change their policy briefs every few years. Instrumental change as a result of particular pieces of research evidence is rare, but the accretion of evidence over the years can make a difference in the long term.

Child birth cohorts are a valuable resource. Typically they have large samples, and continue over a number of years and 'sweeps', offering policy makers an opportunity to become involved in a dialogue with researchers over the evidence base and gaps in current knowledge. They are also expensive and often wholly or largely financed through public monies. They offer opportunities for cross national comparisons, which (in the context of policy transfer) are particularly rich resources for intra-national and national policy making. There has been a shift in understanding from 'gold standards' to 'horses for courses' in understanding what types of research might be useful for policy makers [15]. This is particularly true in public health topics where randomised controlled trials are often impossible or inappropriate, and therefore high quality observational evidence should be placed high in any hierarchy. Birth cohorts are therefore of considerable value in such an approach, but their particular value in collecting data long prior to many exposures and outcomes isn't always recognised.

Drawing on the evidence presented here, we make recommendations in five areas:

1. Increasing transparency
    - The complex policy environment at the supra-national level is opaque and inaccessible for researchers (and the public)
    - Good practice guidelines in using research evidence in the development of policy would enable an 'audit trail'; increasing transparency and critical use of evidence
    - Policy makers need to make known what the information needs/research gaps are

- Researchers needs to increase access to existing data; a portal for accessing data would increase use from both other researchers and the public and policy makers

2. Moving forward the research agenda
   - Long term outcomes from early determinants are of interest and important
   - The co-operation of WHO and EU provides unique opportunities for researchers
   - Researchers should addressing gaps identified by policy makers and the public
   - Comparisons of variations between Member States in health policy and outcomes, will draw attention to specific topics and the need for action
   - Policy makers need to be aware that while some results might be available quickly, recognition is needed that some important findings will emerge over the long term
   - Social inequalities in health are high on the agenda for both policy makers and researchers, but is a topic which is affected by local political agendas, and therefore where a collective response might be particularly powerful

3. Understanding the policy arena
   - Researchers need to appreciate that the policy landscape changes
   - Appreciating the different levels at which policy making occurs, and researcher need to realise that different levels will need different outputs, and different types of engagement
   - Recognition that health determinants are connected necessitates cross-sectoral action

4. Resolving communication barriers
   - Researchers need to address a non-academic audience: interests, priorities and language
   - For researchers to respond to policy debates, these must be presented in a way that is transparent and understandable
   - Researchers would like greater input, and communication between researchers and policy advisors is likely to improve if barriers to contact are removed
5. Addressing competing timelines
   - Policy makers should make better use of rapid reviews of the research evidence when you have a problem. Policy makers need to appreciate the two different ways that researchers can help: summarising the findings from the questions already asked today and OR it can answer new questions but that takes longer
   - Important findings emerge over the long term and research funding needs to be secure to achieve this
   - The European cohorts could provide an infrastructure for research and knowledge generation by bridging the gap between rapid responses using data already collected, and new questions from collecting new data within a longitudinal study

There are many examples of good practice where these issues have been addressed. We have briefly provided information on 3 such examples.

Collaborations with Local Government in the UK: Research in practice

The UK organisation, Research in Practice (RiP) has worked as a knowledge broker to support evidence informed practice in children's services for more than 15 years [16]. They do this by providing a fee based service to local government, statutory and childcare organisations and national agencies. Each of these organisation contributes an annual fee, in return for which RiP

provide a range of in person and online 'knowledge exchange' opportunities. These include staff training, publications reporting evidence to guide decision making, monthly bulletins with research and policy updates, in person and online events when practitioners and researchers can meet. They do not conduct or commission research, nor do they operate services. Through commissioning reports and talks from researchers, and producing reports that are geared to the interests and needs of practitioners and policy makers they are able to maintain strong relationships with all parties.

Comparative Effectiveness Research (CER) organisations internationally

A number of governments have invested public monies into comparative effectiveness research and health technology assessments. The UK National Institute for Health and Clinical Excellence (NICE) , the German Institute for Quality and Efficiency in Healthcare, Australia's Pharmaceutical Benefits Advisory Committee, the French High Health Authority, and the Ontario Institute for Clinical Evaluative Sciences , the Swedish Council on Technology Assessment and the Dental and Pharmaceutical Benefits Board, the Scottish Medicines Consortium, the Pharmaceutical Care Committee in the Netherlands [17, 18]. Further, Turkey, parts of Russia and Latin America and other middle income countries are known to checking the evidence base for treatment in their own countries (for example Brazil refers to NICE guidance) [17]. While expert and scientific groups are often convened for the purpose of evidence review in preparing policy, the advantages of an organisation to undertake these is summarised by the American College of Physicians in providing an "adequately funded, trusted national entity to prioritize, sponsor, and produce comparative-effectiveness and cost-effectiveness information" [19]. NICE is, to our knowledge, the only CER to include public health topics. Use of CER resources across countries is an efficient use of the considerable investment needed to create them, but there may be scope for considering the usefulness of a European level equivalent.

Structural collaborations between stakeholders in Health in the Netherlands: Academic working places

In the Netherlands, since more than 10 years a model of 'Academic Working Places' has been developed and applied to promote the collaboration between research and education, practice and policy. In such collaborations, research questions are developed in interaction between research, practice and policy. Also, this collaboration supports (cohort) studies to be conducted. Most importantly, in interaction between stakeholders the meaning of research outcomes for practice and policy are discussed. Most often, these are regional collaborations, supporting policy development at the regional level. An 'Academic Working Place' however may also be thematic, and operate at a national scale, and maybe, in the future, at the European level.

Appendix 4-1-1 Case Studies 1 and 2: A review of the extent to which mother-child cohorts have contributed to current policies produced by EU institutions

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Findings from this review are reported in Deliverable 8 : Inventory of cohort contribution to pan-European policy and policy guidelines

The overall aim of this work package is to explore the ways in which evidence from child cohorts has been, or might be, used in policy making in Europe.
A review of current EU policy regarding child health was conducted, covering 149 policy documents located using structured searches. We included policies that target the unborn child and children up to adolescence. We did not include sexual health or workforce regulation in our review.

Six overarching policies set out broad areas of action:

1. Together for Health: A Strategic Approach for the EU 2008-2013. This forms the basis for all direct action in the field of public health.
2. EC Strategy on Nutrition, Overweight and Obesity.
3. Platform on Diet, Physical Activity and Health'.
   Both 2 and 3 respond to the rise in overweight and obesity among the European population, identifying children as a key group for action.
4. The Environment and Health Action Plan 2004-2010. This highlights the need to protect children from environmental pollution.
5. The EU Consumer Policy Strategy 2007-2013, which defines children as vulnerable consumer groups.
6. The Science, Children Awareness, Legal instruments and Evaluation initiative (under the Sixth Environment Action Programme and The European Environment and Health Strategy 2004-2010) addresses the susceptibility of children and foetuses to risks in the environment.

Flowing from these, targeted actions, some of which Member states are legally bound to uphold, are described in a number of documents across the following six policy areas:

1. Product safety: both products used by children and articles which are not intended to be used by children but which might pose a risk to children are regulated.
2. Violence and Abuse.
3. Food Safety: both particular food types (e.g. infant foods) and risks in all food are regulated.
4. Chemicals: this is through the regulation of chemicals and measures to prevent ingestion of dangerous preparations.
5. Environmental risks other than chemicals.
6. A number of Health and Health Care Policy Areas (Infection control, other Communicable Diseases, Donor Organs, Regulation of Medicines, Non-communicable Diseases, Health Inequalities, and Lifestyle-related health determinants) also receive attention.

Two case studies were identified, from these broad areas, to consider the use and potential use of research evidence to inform the development of EU policy. Cases were selected on the basis of the importance of the health problem and the potential value of birth cohort studies for the policy area. Case study 1 considered the regulation of particulate matter to protect child health. Case study 2 considered policies to promote physical activity for children.

Content analyses confirm that health was part of the explicit rationale for action in both cases. In the PM case the word 'health' was commonly used, although reference to children was rare. In case study 2 the words obesity and overweight were both very commonly used indeed.

Similarly words associated with research, evidence, and science were quite common. However, in both cases these were less evenly distributed, and were mainly found in a smaller number of documents (working papers, impact assessments, and reports from committees).

While there were more instances of explicit use of research in Case study 2 (56 explicit as opposed to 31 non-explicit) the reverse was true for Case study 1 where non-explicit uses of research (e.g. evidentiary statements without attribution to a particular study), were found more frequently.. In Case study 1 no particular research design was referred to more often than others and a very small pool of studies appears to have been used. In Case study 2 the most commonly used research designs were systematic reviews and Randomised Controlled Trials.

Research undertaken or commissioned by European institutions, advisory committees or groups to understand the likely impact of policy changes was quite commonly referred to. The use of guidance from and collaboration with the WHO regional office for Europe underpinned much action, and this provides a rationale for considering WHO guidance as case studies in the next phase of work.

Taking note of explicit uses of research probably underestimates the direct and instrumental influence of research because each document builds from preceding policy developments, which may have contained more explicit reference to research evidence.

Non-explicit uses of research (e.g. statements mentioning or indicating the use of research without citing a particular study) and instances where information was presented as fact without supporting context were more common than explicit use in Case study 1, but not in Case study 2.

Calls for future research can be divided into:

1. Research to improve knowledge of the extent of the problem.
2. Research to further knowledge of the nature of the problem or solutions.
3. Calls for policy to respond to research evidence.

The inter-relatedness of the WHO and the EU in both of these research areas suggests that the picture of research use gained from consideration of EU policy documents only is partial and conclusions and recommendations will be drawn when the remaining case studies have been completed.

Appendix 4-1-2 Case Studies 3 and 4: A review of the extent to which mother-child cohorts have contributed to current policies produced by English institutions

Patricia J Lucas, Sarah Payne; University of Bristol

Case Study 3: Research Cited in UK Policy Documents on Ambient Particulate Matter (PM10 and PM2.5)

INTRODUCTION

Much of the air quality legislation in the UK is driven by European-level legislation, since it must conform with Directive 2008/50/EC on ambient air quality and cleaner air for Europe [20]. The UK government was granted extensions to the deadline for meeting the measures laid down in this Directive in 2010 and 2011 [21-24]. However, in 2012 the European Commissioned raised objections to UK requests for extension in some areas and warned that legal action may follow [25]. Nonetheless, the UK continues to work towards these standards, and introduced the Air Quality Standards Regulations (2010) which transpose the Directive 2008/50/EC into national legislation for England with similar legislation in so Scotland, Wales and Northern Ireland [26]. The key governmental actors in this field are the Department for the Environment, Food and Rural Affairs (DEFRA), the Committee on Medical Health Effects of Air Pollutants (COMEAP) of the Department for Health and the Environmental Audit Committee of the House of Commons. While legislation is compliant with the EU Directive, the UK government adopts its own approaches, strategies and reports to control air quality. As with previous case studies, we are interested here in evidence regarding ambient particulate matter (PM).
For this case study we identified the following research questions:

RQ1 Which research evidence has been cited in the development of UK-wide policy documents addressing the impacts of PM on health, and child health in particular?

RQ2 What research topics, and in particular what data from birth cohorts, regarding impacts of PM on child health were considered in research commissioned or overseen by UK government bodies or official advisory committees?

Selection of Policy Documents

We included legislation and policy guidance (e.g. reports, strategies, consultations, parliamentary debates)which adopted by any governmental body or official advisory committee of the UK (or England), addressed health effects of any type (e.g. ultrafine particulate matter, PM10, PM2.5) of ambient PM. This didn't include documents setting out local air quality management. We considered, separately research commissioned or overseen by governmental bodies or official advisory committees using the websites of DEFRA, COMEAP and the Environmental Audit Committee (shown in Table 2).

RESULTS

Description of Policy Documents

We included 11 policy documents, which fall into one of the following categories: legal act (1), policy report from government departments (7), policy report or debate by the House of Commons (3). Table 1 provides an overview of the included policy documents.

Table 1 Included UK Policy Documents

No.	Author	Title	Publication Date	Notes
1	House of Commons, Environmental Audit Committee	(Uncorrected) Transcript of oral evidence taken before the Environmental Audit Committee on air Quality: a follow-up report	6 July 2011	Debate
2	House of Commons, Environmental Audit Committee	(Corrected) Transcript of oral evidence taken before the Environmental Audit Committee on air Quality: a follow-up report	8 June 2011	Debate
3	Secretary of State for Environment, Food and Rural Affairs	Government response to the Environmental Audit Committee Report on Air Quality in the UK	Nov 2010	Government response to 6
4	Secretary of State	The Air Quality Standards Regulations 2010 (SI 2010 No. 1001)	June 2010	Legal act transposes Directive 2008/50/EC to the UK and, as such, sets limit values for PM and other air pollutants
5	Department for Environment, Food and Rural Affairs	Valuing the Overall Impacts of Air Pollution	March 2010	Reports current pollution levels and likely health and ecological impact using economic models
6	House of Commons, Environmental Audit Committee	Air Quality: Fifth Report of Session 2009-2010 (Volume 1)	March 2010	Report on the EU Directive and the UK's strategy for air quality
7	Department for Environment, Food and Rural Affairs	Air Pollution in the UK 2009	2010	Reports on current air quality situation
8	Faulkner & Russell, Department for Environment, Food and Rural Affairs	Review of Local Air Quality Management: A report to Defra and the devolved administrations	Jan 2010	Report on air quality in all regions
9	Secretary of State for Environment, Food and Rural Affairs	The Air Quality Strategy for England, Scotland, Wales and Northern Ireland (Volume 1 Main Document)	July 2007	Presents air quality objectives
10	Secretary of State for Environment, Food and Rural Affairs	The Air Quality Strategy for England, Scotland, Wales and Northern Ireland (Volume 2 Evidence Base)	July 2007	Sets out the evidence base for air pollutants
11	Department for Environment, Food and Rural Affairs	An Economic Analysis to inform the Air Quality Strategy: Updated Third Report of the Interdepartmental Group on Costs and Benefits	July 2007	Assesses likely impact of air quality policies

RQ1 Which research evidence has been cited in the development of UK-wide policy documents addressing the impacts of PM on health, and child health in particular?

Health considerations played an important role in policy development in this field, and all documents make reference to the health impacts. All documents except the regulation and transcripts of oral evidence made explicit reference to research in this context, with traceable citations. These are very often concerned with evidencing the link between air pollution and impacts on human health, for example:

> "Medical evidence shows that many thousands of people still die prematurely every year because of the effects of air pollution. Air pollution from man-made particles and gaseous pollutants is currently estimated to reduce the life expectancy of every person in the UK by an average 7-8 months with estimated equivalent health costs of up to £20 billion each year". [27]

Transcripts of oral evidence by their nature are not expected to cross refer to scientific citations, but do include scientist as expert witnesses and, similarly, they comment on the impact on health of air pollution, for example:

> "the current estimation is that for the UK roughly 29,000 people in 2008 died prematurely because of air pollution" [28] p. 3 Prof Frank Kelly, Director, Environmental Research Group)

In addition to oral evidence from scientists, document 6 House of Commons report, also lists sources of written evidence which includes a number of research groups [29] p26).

The 2007 Air Quality Strategy is published with an accompanying evidence base [30], which provides a narrative review of estimating current levels of pollution in the UK, and describing common pollutants and their health effects. In describing the health effects of PM, it draws on 5 pieces of research: 3 reviews undertaken UK Government bodies, a review by WHO and a re-analysis undertaken of a US cohort of adults [31, 32]. Across the remainder of the documents this last study along with one other [33] are the only publications by groups other than UK Government commissioned (which all appear in Table 2 below) or WHO reviews cited. In all cases, these claims for health impacts seldom make specific reference to infant, child, or maternal health or early exposures in other ways. For example, the evidence base for the UK strategy of air quality states that:

> "UK work has shown that exposure to NO2 enhances response to allergens and may increase the prevalence of respiratory infections in children" (ref to doc 10)

But this is one of only two mentions of children (or infants etc) in this document. The risks to children as a vulnerable group, or reference to the impact of early exposures are not explored in these documents.

Research is also used in these documents to evidence and comment on the level of compliance with European-level legislation, comparing "existing air quality against local, national or international standards" (doc 10). Uncertainties in the scientific evidence are also widely acknowledged; difficulties in measuring PM, estimating PM levels, estimating costs, health impacts and benefits of policy options. These uncertainties result in challenges to use of research evidence to inform policy which is also discussed, in particular need for research which would allow estimates of health impacts which are "meaningful to a nonexpert audience" to describe both the nature and scale of the health impacts and that this would aid communication "to decision takers in central and local government, and to the general public"[26].

RQ2 What research topics, and in particular what data from birth cohorts, regarding impacts of PM on child health were considered in research commissioned or overseen by UK government bodies or official advisory committees?

Research commissioned or overseen by English Government and is described in Table 2. Ten publications were identified by searching Department of Health, DEFRA and Environment Audit Committee websites (we have excluded statements issued by COMEAP, as the intention was to restrict to research outputs).

Table 2 Research Commissioned or undertaken by UK Government Bodies

Publication	Research approach
A report by the Committee on the Medical Effects of Air Pollutants [34]	Expert review of air quality index considering health effects
COMEAP (2010) The Mortality Effects of Long-Term Exposure to Particulate Air Pollution in the United Kingdom [35]	Expert review and analysis of mortality data on air pollutants contributions to mortality
Supporting paper to COMEAP 2010 report: "The Mortality Effects of Long Term Exposure to Particulate Air Pollution in the United Kingdom" Working Paper: Development Of Proposals For Cessation Lag(S) For Use In Total Impact Calculations [36]	Narrative review of previous research; epidemiological studies, studies of biological mechanisms, and literature from analogous fields.
Outdoor Air Pollution, Infant Mortality And Adverse Birth Outcomes: Geographical And Time-Series Analyses[37]	Time series analysis of daily infant mortality data
Quantification Of Population Exposure Benefits Of Reducing Roadside And Urban Background Pollution Concentrations [38]	Meta-analysis using Department of Health Air Pollution Epidemiology Database
Department of Health research project (Ref: 0020015): Health effects of long-term exposure to air pollution in Scotland [39]	Re-analaysis of data from 3 adult cohorts
Miller & Hurley (2006) Comparing estimated risks for air pollution with risks for other health effects [40]	Analysis of mortality data (all ages)
Cardiovascular Disease and Air Pollution [41]	A systematic review and meta-analyses of epidemiological research (although a narrative approach to research from other fields)
Locally-generated particulate pollution and respiratory symptoms in young children.[42]	Cohort study (recruited at age 1-5 years, follow up 3 years later)
COMEAP (2000) The Health Effects Of Air Pollutants: Advice From Comeap	Expert review of health effects from air pollution

In these studies there was a greater interest in both the vulnerability of children to exposure to air pollution and to early life as a critical period for lifelong health than in the policy development. For example, "the alveoli, especially in high risk groups such the sick and infirm, or children (QUARG, 1996)." [35]. The four reviews produced are all produced by expert groups, and as such draw on the accumulated knowledge of the authors or committee. However, they do not make explicit how

relevant research was identified, nor how the importance of any given individual study was judged. The other products are new research (or at least reanalysis of existing research).

Conclusions

The approach taken to research use was less transparent in the development of UK PM than in PA policy. This may be related to the need to adopt EU Directive, so the focus was on responding to this rather than establishing the need for and nature of policy in the field. Despite a clear reliance on scientific evidence of health impacts, there was little research explicitly cited which examined the relationship between the exposure of interest here (PM) and health, and vanishingly few references to childhood health of exposures during childhood in any document. The majority of explicit references to research was to that undertaken or commissioned by the DeFRA, Committee on the Medical Effects of Air Pollutants (COMEAP) and the Institute of Occupational Medicine. The challenges of using evidence were recognised and discussed, including an observation that current estimates of impact or inaccessible to a non-expert audience and do not clearly explain the nature and scale of health impacts.

Case Study 4: Research Cited in Physical Activity Guidelines for Children in the UK

Selection of Policy Documents

The case selected here was the 2011 guidance from the UK Chief Medical Officer on the recommended volume, frequency and duration of physical activity were published [43]. The guidelines were selected as the case because they are the clearest example of policy guidance developed with the explicit aim of increasing rates of physical activity for the benefit of health, and because they are UK-wide and address physical activity across the full age range. These guidelines supersede previous guidance and were developed and adopted after the change of government in the UK in 2010, and therefore describe the current governments aims. The determinants and consequences of physical activity are recognised to be wider than individual health. Other policy areas of interest were initiatives regarding travel [44, 45] and road safety[46] published by the UK Department of Transport; Sports policy set out by the Department of Culture, Media and Sport [47]; physical education targets [48] and the healthy schools initiative [49] set by the Department for Education and we acknowledge that we are exploring here the approach taken in the development of just one policy topic.

In addition to documents published by the UK Department of Health, it is important to consider the place of The UK National Institute for Health and Clinical Excellence (NICE) in the development of public health policy. NICE provides a very particular context for the use of research evidence to inform UK health policy. The UK Department of Health (DH) refers topics to NICE, after which NICE constitutes independent groups, guided by advisory committees, to review the research evidence and produce review summaries and recommendations. The agenda for these reviews is therefore set by policy makers but the research is conducted at arms length from government. NICE is first and foremost a research organisation and their role is to conduct systematic, rigorous review that allows for open consultation with the general public and stakeholder groups. The UK is not alone is having such as arrangement for assessment of evidence for treatment effectiveness with a direct relationship to policy. The German Institute for Quality and Efficiency in Healthcare, Australia's Pharmaceutical Benefits Scheme, the French High Health Authority, and the Ontario Institute for Clinical Evaluative Sciences perform similar functions with regard to medicines [17]. Further, Brazil and other middle income countries refer to NICE guidance in checking the evidence base for

treatment in their own countries [17]. NICE impact on practice is increased in England by the existence of a national health service in the UK. In England (arrangements differ in the devolved regions of Northern Ireland, Scotland and Wales) the NHS is obliged to follow NICE guidance for clinical care. Topics and guidance on public health topics go beyond clinical care to include prevention and promotion, there is no body which is obliged to follow these recommendations and they are therefore less likely to result in changes to policy or strategy[50].

For the UK case studies the existence of NICE means that the scientific evidence available on any policy topic referred to NICE will have been thoroughly reviewed and this should be the backbone of policy development. This happens within a standard, transparent and rigorous process of evidence review. NICE guidance is not policy and, indeed, has been criticised for under-serving decision making in public health[50], but it is an essential part of the background to policy development in the UK. The work of NICE pertaining to the case study topics is therefore described here as evidence available for policy development.

For this case study we considered the following research questions:

For this case study we identified the following research questions:

RQ1 Which research evidence has been cited in the development of UK-wide policy documents addressing health effects of physical activity?

RQ2 What research topics, and in particular what data from birth cohorts, regarding determinants and levels of physical activity were reviewed by NICE?

Results

Description of Policy Documents

The policy document identified as the case, Start Active, Stay Active (document 1), sets out the process from which the guidelines were developed (p.52 [43]). Three reports preceded the policy development (Technical reports accompanying guidelines, a report on physical activity in the Early Years, and a report on sedentary behaviour) and a number of fact sheets were developed following the production of the guidelines. Table 3 summarises all documents considered for inclusion in this case study, including those produced by NICE.

Table 3 Policy documents considered for inclusion in chronological order

No.	Title	Year	Author	Notes
1.	Start Active, Stay Active: A report on physical activity from the four home countries' Chief Medical Officers	2011	DH	Include
2.	Physical activity guidelines for early years (under 5s) – for infants who are not yet walking	2011	DH	Excluded: One page fact sheet derived from "Start Active, Stay Active"
3.	Physical activity guidelines for early years (under 5s) – For Children who are capable of walking	2011	DH	Excluded: One page fact sheet derived from "Start Active, Stay Active"
4.	Physical activity guidelines for children and	2011	DH	Excluded: One page

	young people (5-18 years)			fact sheet derived from "Start Active, Stay Active"
5.	Working Paper: Making the Case for Physical Activity Guidelines for Early Years: Recommendations and draft summary statements based on the current evidence	n.d.	Reilly et al (DH)	Include: Supporting document
6.	Technical Report: Physical Activity Guidelines in the UK: Review and Recommendations	2010	DH	Include: Supporting document
7.	Technical Report: Physical Activity Guidelines in the UK: Review and Recommendations Appendices	2010	DH	Include: Supporting document
8.	Sedentary Behaviour and Obesity: Review of the Current Scientific Evidence	2010	Biddle et al (DH)	Include: Independent report commissioned by the Department of Health, with the purpose of informing policy development
28.	At least five a week: Evidence on the Impact of Physical Activity and Its Relationship to Health	2004	DH (Chief Medical Officer)	Excluded: Superseded by "Start Active, Stay Active"

RQ1 What research evidence has been cited in the development of UK-wide policy documents addressing lifespan health effects of physical activity in children?

Each document was examined to find instances where research evidence was used to support decisions or recommendations about physical activity in children (including adolescents) for benefits to health now or in the future. A similar approach to case studies 1 and 2 was taken, where text was coded according to the type of use, and the type of research.

Sources of research used

Across the documents, a total of 124 unique references were cited. Most were only used explicitly once (n=58) or twice (n=34) across all sources. Reviews conducted as part of the development of the US and Canadian Physical Activity Guidelines and the reviews undertaken by the British Association of Sport and Exercise Sciences (BASES) consensus process underpinned two documents (1 and 6) and material within is drawn from these extensively from reviews. There were 12 sources that were explicitly cited 5 or more times across all 5 documents. These were:

Table 4 Inventory of Research Use, Case Study 4

Source	Study Type
Ekelund et al (2007) Independent associations of physical activity and cardiorespiratory fitness with metabolic risk factors in children: the European Youth Heart Study [51]	Cross-sectional study
Trost (2005). Discussion paper for the Australian Department of Health and Ageing[52]	Expert review

Australian Government Department of Health and Ageing. (2009). Draft National Physical Activity Recommendations for Children 0-5[53]	Guidelines
Department of Health (2004) At least five a week: Evidence on the impact of physical activity and its relationship to health[54]	Systematic Review
Steele et al (2009). Targeting sedentary time or moderate-and vigorous-intensity activity: independent relations with adiposity in a population-based sample of 10-y-old British children[55]	Cross-sectional study
Strong et al (2005) Evidence based physical activity for school-age youth[56]	Systematic review
Health Canada and Canadian Society for Exercise Physiology (2002) Family Guide to Physical Activity for Children 6-9 Years of Age[57]	Guidelines
US Department of Health and Human Services (2008) Physical Activity Guidelines for Americans: Be Active, Healthy and Happy[58]	Expert scientific review and guidelines
Janssen (2007) Physical activity guidelines for children and youth[59]	Systematic review
Janssen & LeBlanc (2010) Systematic review of the health benefits of physical activity and fitness in school-aged children and youth[60]	Systematic review
Kesaniemi et al (2010) Advancing the future of physical activity guidelines in Canada: an independent expert panel interpretation of the evidence[61]	Systematic reviews and expert discussion
Physical Activity Guidelines Advisory Committee (2008) Physical Activity Guidelines Advisory Committee Report[62]	Expert scientific review

Of the 57 publications from European birth cohort studies that we identified concerning physical activity exposure(See WP3 report), none were cited in these documents.

Most often, research was cited to support the need to address levels of physical activity in childhood, or to support ways to intervene to increase physical activity, or for setting guidelines for physical activity. Otherwise research is used to demonstrate the relationship between physical activity and a range of outcomes (most commonly overweight and obesity), to understand the determinants of level of physical activity, and to consider which groups are at risk of low levels of physical activity.

RQ2 What research topics, and in particular what data from birth cohorts, regarding determinants and levels of physical activity were reviewed by NICE?

In 2009 NICE published guidelines on promoting physical activity for children[63]. These guidelines were the result of a number of reviews and consultations processes, with a total of 9 supporting reviews undertaken[1]. Many of the actors who took part in the process of developing the 2011 guidelines were also involved in this process. Of the 9 reviews, 3 included observational studies within their remit and these are described in the table below.

[1] Review 1: Descriptive Epidemiology (2008); Review 2: Correlates of Physical Activity in Children: A Review of Quantitative Systematic Reviews (2007); Review 3: The Views of Children on the Barriers and Facilitators to Participation in Physical Activity: A Review of Qualitative Studies (2007); Review 4: Under Eights (2008); Review 5: Intervention Review: Children and Active Travel (2008); Review 6: Intervention Review: Adolescent Girls (2008); Review 7: Intervention Review: Family and Community (2008); Review 8: Review of Learning from Practice: Children and Active Play (2008); Review 9 – Economic evidence (2008).

Table 5 NICE Activities

Doc Name	Research Questions Addressed Study types included	Weighting of evidence from cohort studies
Physical Activity and Children Review 1: Descriptive Epidemiology (2008)	To describe the evidence on the descriptive epidemiology of physical activity in children, including health benefits, levels of activity in the population, and evidence as to whether weight tracks from childhood to adulthood Surveys of physical activity in England and longitudinal data including cohorts.	Four evidence categories were used (where A was high). Observational studies were judged category C. Data from several cohort studies are reported in addition to any included in systematic reviews. Six cohort studies were included in the review of tracking of PA from childhood (including 1 birth cohort study [64]). Two birth cohorts are cited as providing evidence of links between PA and health outcomes [54, 65].
Physical Activity and Children Review 8: Review of Learning from Practice: Children and Active Play (2008)	Non-systematic review of practice and the views of practitioners and children on what they think works to promote active play Any study design included	One longitudinal study [66] and two studies reporting data from birth cohorts [67, 68] were considered for inclusion, but not cited in the text.
Promoting physical activity for children: Review 9 – Economic evidence (2008)	A rapid review of the economic evidence relating to the promotion of physical activity, play and sport. No study designs excluded.	One cohort study [69] discussed as relevant, but not included.

In addition to these reviews, a consultation process was undertaken for the evidence review and guidance processes and the results of these are published as two additional documents [70, 71]. In one consultation 2 groups respond to request that data from 2 birth cohorts are introduced, suggesting that they provide more accurate assessment of levels of PA for use in Review 1 [70]. Their exclusion from the review is justified by arguing that they were outside the scope in one case and published after the search dates in another.

RQ3 What questions are raised in either development of UK policy or NICE reviews and that birth cohorts are well placed to address?

Across the policy documents a number of questions are raised for research. The technical document (document 6) sets out a number of questions addressed in preparing the guidelines, some of which the following could be addressed using data from longitudinal studies (where they collect data in sufficient detail). It further seeks comments from stakeholders in a consultation process, again some of these could be addressed in cohort studies. Finally, in the preparation of the review process important gaps in the evidence we noted. We identified 7 broad topics which may be of interest to cohort researchers:

1. Technical Document: Please comment specifically on the available evidence related to the accumulation of physical activity in multiple short periods. Please comment on i) whether this is relevant for the optimal health message and ii) whether it is or is not appropriate for any specific health conditions?
2. Technical Document: Is there sufficient evidence / knowledge of the risks associated with physical activity, particularly in early years to inform an analysis of the risks versus benefits of the physical activity guidelines? This topic was also a gap in the evidence, two documents (6 and 7) noted the lack of evidence of adverse effects of increased PA. These documents suggest that risks are probably very low compared to potential benefits, but studies do not routinely report on injuries occurring during the intervention.
1. Technical Document: Do Physical Activity Guidelines need to be modified for young people with disabilities and for young people with chronic disease? (Technical Document)
2. Stakeholder consultation: Importance of addressing perceived risks associated with increased PA
3. Stakeholder consultation: The value of exercise as an outdoor activity
4. Stakeholder consultation: Measurement techniques for physical activity in different contexts
5. Stakeholder consultation: Physical activity and maintenance of a healthy weight
6. Evidence gaps: The most commonly noted gap were questions related to more duration and frequency, type and health benefits of physical activity during childhood. These gaps noted that current evidence focuses on duration of PA, but is seldom able to comment on how often, how vigorous, what duration, what types, or what the 'dose' is needed for health benefits.
7. Evidence gaps: Evidence was noted as lacking about PA in specific population groups; most often evidence regarding PA in early years, but also in those with physical, emotional, mental and/or intellectual disabilities.
8. Evidence gaps: Document 8 notes the paucity of evidence about sedentary activity; prevalence, and health impacts.

In many cases observational data from cohorts of children could provide some evidence toward answering these questions. For example, we know of publications exist which examine associations between physical activity and behavioural or mental health outcomes [72-78].

Conclusions

Policy development in this field either used systematic review to amass evidence, or adopted reviews produced as part of policy development elsewhere (in production of Australian, Canadian, and US Guidelines). The place of individual research outputs or whole research studies on policy can easily be demonstrated because of the transparent and explicit approach to research reviews undertaken. In these cases standard methods for identifying and judging strength of evidence means that standard scientific publishing is sufficient to be confident of influence.

Appendix 4-1-3 CASE STUDIES 5 and 6: A review of the extent to which mother-child cohorts have contributed to current policies produced by the WHO

Sarah Payne, Patricia J Lucas; University of Bristol

The use of evidence in World Health Organisation policy guidance documents **relating to particulate matter and physical activity**

Introduction

Case studies 5 and 6 cover the use of evidence by an international body, the World Health Organisation, in relation to the same aspects of child health discussed in Case Studies 1-4: particulate matter and physical activity. WHO can be described as a central directing and co-ordinating authority on global health [79]. WHO's core functions are:

> "providing leadership on matters critical to health and engaging in partnerships where joint action is needed; shaping the research agenda and stimulating the generation, translation and dissemination of valuable knowledge; setting norms and standards and promoting and monitoring their implementation; articulating ethical and evidence-based policy options; providing technical support, catalysing change, and building sustainable institutional capacity; and monitoring the health situation and assessing health trends" [80].

WHO provides evidence-based policy guidance, alongside technical support to member states, and WHO's recommendations are important influences in policy making at European and national level. WHO also manages the Health Evidence Network (HEN) and the European Environment and Health Information System (ENHIS) as resources to support national level health policy-making. WHO's role in shaping the global health research agenda means that their use of research evidence is of interest, particularly in relation to the ways in which cohort research might be more widely used.

The status of WHO means that it largely does not produce policies which are legally binding on member states (the exceptions are the International Health Regulations and the 2003 Framework Convention on Tobacco Control, although this is only binding for those countries which have ratified it). However, WHO use their position to advocate national level responses to specific health threats including environmental health, and to help national governments develop policy to address health behaviours, such as levels of physical activity.

One of WHO's constitutional objectives relates specifically to children: "to promote maternal and child health and welfare and to foster the ability to live harmoniously in a changing total environment" [81]. In 2002 WHO launched a global Initiative to develop a set of Children's Environmental Health Indicators which could be collected at national level on a regular basis, to improve monitoring in this aspect of child health. Most recently these have been used in an assessment of inequalities in environmental influences on health in Europe which reported in 2012 [82]. The 14 indicators covered housing (6 indicators), injury (4 indicators) and environment-related influences (4 indicators). This last set comprised noise exposure at home, access to green spaces, second-hand smoke exposure at home, and second-hand smoke exposure in the workplace.
WHO Europe has also agreed four Regional Priority Goals (RPG) for Environment and Health, which include two of interest for this piece of research:

RPG 1: ensuring public health by improving access to safe water and sanitation;
RPG2: addressing obesity and injuries through safe environments, physical activity and healthy diet;
RPG3: preventing disease through improved outdoor and indoor air quality;
RPG4: preventing disease arising from chemical, biological and physical environments.

Case Study 5: Research cited in World Health Organisation policy documents, strategy and guidance on particulate matter

Background

The World Health Organisation's role in relation to environmental health, and particular matter, is primarily in relation to research evidence and policy leadership. The WHO Euro website describes their work in this field as follows:

> "WHO/Europe works to make sure that the available evidence on the health risks of air pollution is used in public debate and in policy-making. This includes:
> - reviewing the scientific evidence on the health effects of air pollution;
> - developing methods to quantify the health risks
> - helping countries to build capacity to assess these risks and to develop sustainable policies on air quality;
> - providing guidance, such as the WHO guidelines for outdoor and indoor air quality; and
> - supporting the implementation of international legal instruments such as United Nations Convention on Long-range Transboundary Air Pollution." [83]

WHO works closely with the EU, particularly in the development of the WHO Europe Children's Environment and Health Action Plan (CEHAPE) which was endorsed by the EU in 2004. The EU's Environment and Health Action Plan (2004-2010) was developed at this time to coincide with and support the work of WHO. In addition to this Action Plan, WHO and WHO Europe have produced a large number of other documents in this field, for a range of purposes and users.

Search strategy and selection of documents

The purpose of both case studies 5 and 6 is to explore the ways in which evidence is used in different kinds of WHO documents, the kinds of research used, how is it cited, and whether such use is implicit or explicit. In addition, we address whether and how cohort studies, particularly birth and child cohorts, are drawn on in these documents.

The search strategy used for case study 5 involved searching the WHO main website and WHO Euro website for documents which included discussion of particulate matter and child health. The search began with a focus on the use of 'particulate matter' and children in the title or URL address. The webpage found was then searched and further documents identified in sub-sections of each of the two websites[2].

[2] WHO search engines do not count the number of 'hits' found consistently.

The searches identified a large number of different kinds of documents, including more general papers which mentioned children's health, but were not specifically focused on the health effects of particulate matter for children. Documents were categorised into 3 types, each of which were relevant to our question of how research was used: (a) policy statements, action plans and guidelines; (b) evidence reviews; and (c) summary materials to disseminate the former (such as fact sheets, information sheets, and training packs). We selected sample documents within each category focusing on those which were relevant to policy relating to children and PM.

Table 6 Documents included in case study 5: WHO and Particulate Matter.

Doc No.	Title	Year	Type of document
1	Health Aspects of Air Pollution with Particulate Matter, Ozone and Nitrogen Dioxide: report on Bonn Working Group	2003	(b) evidence reviews
2	Fourth Ministerial Conference on Environment and Health - Children's Environment and Health Action Plan for Europe (CEHAPE) (EUR/04/5406267/7)	2004	(a) policy statements, action plans and guidelines
3	Health aspects of air pollution: Results from the who project "systematic review of health aspects of air pollution in Europe"	2004	(b) evidence reviews
4	Effects of air pollution on children's health and development: a review of the evidence	2005	(b) evidence reviews
5	WHO Air quality guidelines for particulate matter, ozone, nitrogen dioxide and sulfur dioxide Global update 2005 Summary of risk assessment	2006	(a) policy statements, action plans and guidelines
6	EHNIS Exposure of children to air pollution (particulate matter) in outdoor air Fact Sheet No. 3.3 Code: RPG3_Air_Ex2_PM	2007	(c) general material
7	Outdoor Air Pollution, 'Children's Health and the Environment WHO Training Package for the Health Sector	2008	(c) general material
8	Exposure to air pollution: a major public health concern	2010	(c) general material
9	Healthy Environments for Children Alliance (HECA) Issue Brief Series: Air Pollution	Un-dated	(c) general material

RQ1: How is research evidence used in WHO policy documents addressing particulate matter, in relation to child health

Table 7 below shows for each document a breakdown of research use. Unsurprisingly, those documents which were intended to inform policy and provide the evidence for decision makers contain the majority of the explicit uses of research evidence found in this study. These were also the longest documents. More surprisingly, two of the shorter general documents aimed at a wider readership also included a relatively large number of explicit references to original research However, other documents had few references to research. For example, a briefing document (Document 9) which aimed to explain key issues in an accessible way, contained one implicit reference to research, no examples of explicit use of research, and a number of statements presented as fact, for example:

> "Children breathe more air than adults do in proportion to their body weight. Children also react to certain toxicants more severely than adults because of their narrower air passages

> and their smaller size. Given their small stature, children's breathing zones are closer to the ground which can expose children to high concentrations of air pollutants. (Doc 9, p2)

Document 5 is an example of a paper written for a policy audience: "these guidelines are intended to inform policy-makers and to provide appropriate targets for a broad range of policy options for air quality management in different parts of the world" (p 5). The document includes nine explicit and thirteen implicit uses of research evidence, but also refers to a separate paper which describes the methods followed in identifying and evaluating the research evidence.

Table 7 Inventory of research use in WHO policy documents on Particulate Matter: no of times research used, and kind of research used.

Document	Research cited explicitly	Implicit reference to research[3]	Specific references to research on children	Birth/Child Cohort research	RCT	Systematic review	Other
1	167	0	9	1	1	5	160
2	4	5	9	0	0	0	4
3	22	29	14	0	0	13	9
4	143	0	101	7	0	4	132
5	9	13	0	0	0	1	8
6	18	7	10	0	0	0	18
7	27	7	16	0	0	1	26
8	16	3	2	0	0	1	15
9	0	1	0	0	0	0	0
Total	**406**	**65**	**151**	**8**	**1**	**25**	**372**

In terms of the kinds of research used, the majority of documents included in this case study drew on research described as 'other' in the table above, when they cited research explicitly. This included cross-sectional studies, time-series, panel studies and case studies of small groups of individuals. There were few examples of systematic reviews, including meta-analyses, and even fewer uses made of birth/child cohort studies.

The lead authors for the research cited were primarily researchers working in universities or independent research institutes. The second largest group of lead authors were government employees. A small number of publications had both academic and governmental authors.

Examples of explicit research use

A frequent example of explicit use of research in the WHO documents on particulate matter is in a discussion of the levels of PM which posed a threat, the kinds of health impact of PM and the specific impacts on children.

> "According to the results of the Dockery et al. (1993) study, the risks are similar in the cities with the lowest long-term PM2.5 concentrations (i.e. 11 and 12.5 µg/m3)" (Doc 5, p10)

[3] This includes statements such as 'Studies show' without reference to a source, but excludes more general statements such as 'Poor diet leads to diabetes' without mention of research.

> "In the light of the accumulated evidence, WHO revised its AQG for PM in 2005 (1). For PM2.5, the AQG values are 10 µg/m3 (annual average) and 25 µg/m3 (24-hour mean, not to be exceeded more than 3 days/year). For PM10 the corresponding values were set as 20 µg/m3 and 50 µg/m3. " (Doc 6, p2)

although research was also used to identify the health risks of PM:

> " Indoor air pollution from solid fuel use and urban outdoor air pollution are estimated to be responsible for 3.1 million premature deaths worldwide every year and 3.2% of the global burden of disease." (Doc 8 p 1)

Examples of implicit research use

Most of the examples of the implicit use of research evidence are found in Documents 3 and 5, although both documents also included a similar number of examples of explicit use of research. The kind of unsupported statements made in these documents include:

> "However, the evidence we already have of the role played by several environmental factors in determining disease and injury in children, and in inducing effects that may become manifest only in adult life, makes it mandatory to commit ourselves to coordinated and sustained action now to protect children's health, today and for the future." (Document 2, p2)
> "Overall, there is evidence implicating air pollution in adverse effects on certain birth outcomes." (Document 3 p14)

At times unreferenced statements were relatively detailed , implying underlying evidence which was cited elsewhere. For example:

> "Nevertheless, recent epidemiological studies investigating large populations have been unable consistently to establish such threshold levels, in particular for PM and ozone. Rather, they consistently show effects at the levels studied. These findings also imply that the current WHO air quality guideline for ozone of 120 µg/m3 as an eight-hour mean value does not represent a level below which no adverse effects are expected." (Document 3, p8)

While policy documents can often be presumed to be based on evidence, the audit trail between specific points made in these documents and the source that substantiates strategies or targets is often not clear.

WHO, Particulate Matter and birth cohort studies

As stated above, the documents studied drew relatively infrequently on cohort studies. Only two of the nine documents made explicit reference to birth cohort research. Document 1 included one reference to a US study based on infant mortality, infant outcome, maternal and infant characteristics, from the National Center for Health Statistics (NCHS) linked birth/infant death data files for 1989-1991[84].

The text of Document 4 included reference to a number of adult and child cohort studies,and observed that some relationships, such as the association between asthma incidence and air pollution, called for prospective cohort studies. The text included references to four birth cohort studies – PIAMA in the Netherlands[85], the German Infant Nutrition Intervention Programme

(GINI)[86], the German Influences of Lifestyle Related Factors on the Human Immune System and Development of Allergies in Children (LISA)[85], and the British Birth Cohort from Britain[87]. The lack of wider use of birth cohort evidence may reflect the relative youth of some birth cohorts compared with the length of time before some health effects may be observed. For example, the full report associated with Document 5, 'Air Quality Guidelines Global Update 2005', discusses the value of cohort studies for research on air quality and pollution, particularly in relation to age-specific mortality rates, but does not refer to birth and child cohorts specifically. Nonetheless, there are a number of publications from birth cohorts relating to this topic which were not cited more widely in these documents.

Conclusion

In this case study the documents written for a policy maker audience were more likely to include explicit references to research, and a number of these documents were very thorough in this, Documents written for wider audiences used more implicit references to the research in the field. Even when documents referred explicitly to research evidence, relatively little use was made of birth cohorts.

Case Study 6: Research cited in World Health Organisation policy documents, strategy and guidance to halt and reverse the decline in physical activity

Background

The World Health Organisation plays an important role in the promotion of healthy behaviours, including physical activities (PA) for both adults and children. As outlined in the previous case studies, a large body of evidence demonstrates the importance of PA for children and the adverse health effects of inadequate levels of activity. For this case study we were interested in the use made of research evidence in policies, strategies and guidelines produced by the World Health Organisation.

In 2001 WHO Member States identified the importance of diet and physical activity for non-communicable diseases. Following preliminary WHO statements setting out the issue and policy arena, the Global Strategy on Diet, Physical Activity and Health was endorsed by WHO in May 2004. This was followed by a number of documents detailing ways in which member states should implement, monitor and evaluate the strategy. This case study focuses on a sample of documents leading up to and following on from this strategy, including recent policy guidelines on physical activity for children.

Search strategy and selection of documents

The Case Study began with a keyword search of the WHO website, including the main WHO site and also WHO-Europe. An initial keyword search identified nearly 3000 documents on the main site and over 1000 on WHO-Europe, while a second search of keywords featured in the title of the webpage, or the URL identified only eight unique documents. We then searched the Physical Activity topic area of the WHO site, which identified documents related to the DPAS, 'WHO Publications and Documents', and WHO Europe's 'European network for the promotion of health-enhancing physical activity' (HEPA). We excluded papers on less developed countries, as our focus is the use of research in policy making in Europe and we excluded documents which were research papers. We also

excluded papers identical to another in the list - for example 'Global strategy on diet, physical activity and health: Report by the Secretariat A57/9' was virtually identical to Document 4.

Table 8 Documents included in case study 6: WHO and Physical Exercise

Doc No	Title	Year
1	Diet, physical activity and health: Report by the Secretariat A55/16 [88]	2002
2	Integrated prevention of non-communicable diseases: Global strategy on diet, physical activity and health: process of development and draft resolution EB113/44 [89]	2003
3	Integrated prevention of non-communicable diseases: Draft global strategy on diet, physical activity and health. EB113/44 Add.1[90]	2003
4	Global strategy on diet, physical activity and health (incorporates WHA57.17)[91]	2004
5	A guide for population-based approaches to increasing levels of physical activity. Implementation of the WHO Global Strategy on Diet, Physical Activity and Health[92]	2007
6	WHO Information Series on School Health Document 12: Promoting Physical Activity in Schools. An important element of a health-promoting school[93]	2007
7	School Policy Framework. Implementation of the WHO Global Strategy on Diet, Physical Activity and Health [94]	2008
8	WHO Global Strategy on Diet, Physical Activity and Health: a framework to monitor and evaluate implementation[95]	2008
9	Interventions on diet and physical activity: what works: summary report [96]	2009
10	Population-based prevention strategies for childhood obesity: report of a WHO forum and technical meeting [97]	2009
11	Global recommendations on physical activity for health [98]	2010

Table 8 shows documents included in this case study: key documents produced by WHO in the lead up to 2004 DPAS, documents relating to the implementation, monitoring and evaluation of the strategy following its endorsement in 2004, and more recent documents following on from DPAS. The timeframe for Case Study 5 therefore is 2001 through to December 2011.

RQ1: How is research evidence used in WHO policy documents addressing physical activity, in relation to child health

How did WHO use research in developing policy guidelines addressing this aspect of child health? We found differences in the extent to which research was used, reflecting stages of the 'policy cycle'. Early documents identifying the need to address physical activity among adults and children made few explicit references to research, included more implicit reference to research, and contained a number of examples of statements written as 'fact' without either implicit or explicit reference to the research. Where citations are used in early documents these are often to internal (WHO) reports. Later documents which developed more specific guidelines for policy makers, however, cited research more often, more explicitly and drew on external sources.

Table 9 below shows the use of research evidence across all 11 documents studied. In total, 10 of the 11 documents referred to research evidence either explicitly or implicitly. Two of the documents, Document 6 (the Information Series on School Health Document 12: Promoting Physical Activity in

Schools) and Document 9 (Interventions on diet and physical activity: what works: summary report) produced the majority (80%) of the citations.

Table 9 Inventory of research use in WHO policy documents on physical activity: no of times research used, and kind of research used.

Document	Research cited explicitly	Implicit reference to research[4]	Specific references to research on children	Birth/Child Cohort research	RCT	Systematic review	Other
1	2	1	0	0	0	0	2
2	0	0	0	0	0	0	0
3	4	4	1	0	0	0	4
4	2	5	1	0	0	0	2
5	8	10	0	0	0	0	8
6	89	1	83	0	9	2	79
7	6	6	12	0	0	0	6
8	1	0	0	0	0	0	1
9	105	0	66	0	42	0	63
10	4	10	11	0	0	0	10
11	24	0	5	0	0	6	18
Total	**245**	**37**	**179**	**2**	**51**	**8**	**191**

Document 11, Global recommendations on physical activity for health, offers an example of how research was used. The document offers guidance for national policy makers on the health benefits of physical activity as a means of preventing non-communicable diseases, focusing particularly on dose-response relationships. It includes recommendations for physical activity levels for children and adults, and guidance on how to implement these. Sections contain referenced narrative summaries of the evidence, while a series of Appendices detail the methodology used to develop the guidelines and also the evidence. The narrative summaries make explicit use of evidence reviews and the conclusions of these reviews are summarised – for example, "children and youth aged 5-17 should accumulate at least 60 minutes of moderate- to vigorous-intensity physical activity daily" (p20).
The document includes an evidence table which breaks down the different kinds of effect of physical activity (enhanced cardio-respiratory health, metabolic health, musculo-skeletal health) and for this age group, refers to two sources of evidence: i) the 2008 *Physical Activity Guidelines Advisory Committee Report* published by the US Department of Health and Human Services [99]; and ii) evidence reviews carried out by Janssen (2007) and Janssen and Leblanc (2009) [59, 60] which underpinned the Canadian government's physical activity guidelines. The references to the 2008 US paper are specific, citing different parts of the paper, while the references to the Canadian material are simply to the two key studies cited above.

Examples of explicit research use

Examples of when and how these WHO documents make explicit reference to research include :

[4] This includes statements such as 'Studies show' without reference to a source, but excludes more general statements such as 'Poor diet leads to diabetes' without mention of research.

> ”The hazards of overweight and obesity to the health of individuals and populations were demonstrated in a recent WHO report”(Doc 1, p 2).
> “Trials in China, Finland and the United States of America show that among high-risk individuals, close to 60% of type 2 diabetes cases could be prevented by modest changes in diet and physical activity. In the latter trial, the impact of these measures was double that of drug intervention.” (Doc 1 p2).

This last example illustrates both explicit and implicit use of research, as the two references cited refer to a US study, but do not refer specifically to the trials in China and Finland.

A third explicit example of research use shows how later documents drew on specific studies in policy guidelines:

> “The Assessing Cost-effectiveness (ACE) in Obesity Project, conducted in Victoria, Australia … compared 13 specific interventions for preventing unhealthy weight gain in children and adolescents in terms of their potential impact (measured as expected reduction in BMI units per person), the size of the population reached by the intervention, the resultant health benefit to the population overall (measured as disability-adjusted life-years saved) and the cost of the intervention. The ACE analysis found that the greatest health benefit for prevention of childhood obesity is likely to be achieved through … multi-faceted school-based programmes with an active physical education component (Doc 10, p12)

Document 9, ‘Interventions on diet and physical activity: what works: summary report’ is written for policy makers, and based on a systematic review of evidence published elsewhere. The document refers explicitly to this evidence with 395 references drawing on 261 interventions on diet and/or physical activity, for children and adults. The document also describes the process used to identify relevant evidence, including a 4 page methods section on the search strategy, and comments on the quality of the research and the type of outcomes measured.

Examples of implicit research use

Implicit use of research is more frequent in earlier documents than later. At times, although the source of research is not cited, the reference to findings is very detailed. For example:

> “In North Karelia, Finland, where the coronary mortality rate of the 35-64 year old population was reduced in 25 years by 73% during a community-based and national programme, it was concluded that more than half of this decline could be attributed to changes in the diet of the population.” (Doc 1 p2)

More commonly, the implicit use of research was generalised, to endorse a course of action or the need to address physical activity:

> “Recent research has contributed to understanding of the benefits of healthy diets, physical activity, individual action and population-based public health interventions. Although more research is needed, current knowledge warrants urgent public health action.” (Doc 4 p4).
> “Nutrition and physical activity education and acquisition of media literacy, starting in primary school, are important to promote healthier diets, and to counter food fads and misleading dietary advice.” (Doc 6 p7)

While the earlier documents have a limited focus on children, there is recognition of a life course approach to physical activity and diet; and that programmes for children and adolescents should emphasise healthy diets across life course, although this argument is not referenced.

WHO, Physical activity and birth cohort studies

In the 11 documents reviewed in this case study, there were only two references to explicit research based on child 'cohort' studies (Document 6). However, these were both intervention studies with school-aged cohorts rather than birth cohorts. As part of the analysis we also checked for the use of the word 'cohort' across all 11 documents, which confirmed that there were no explicit references to birth cohorts. Document 11 referred to two pieces of research, one a literature review by US government and one a systematic review by a university, which in turn included cohort research in their review.

The approach used by WHO, in particular their use of commissioned evidence reviews and working group reviews prior to the formulation of policy, suggests that it may be sufficient for birth cohort researchers to publish their research in those journals which are included in leading academic databases, but that titles and keywords are significant to ensure these papers are identified in research reviews. In addition, birth cohort researchers might find it valuable to review WHO output to be aware of the kinds of information policy makers are seeking. For example Document 8, on monitoring and the evaluation of the strategy, highlights the kinds of data needed at national level by policy makers to assess implementation of strategy and health outcomes. A number of indicators are suggested, and such a list could be of value for researchers in planning data collection – for example, the list of suggested indicators for physical activity includes 'percentage of population with access to safe places to walk (p15) and 'percentage of children walking and bicycling to school' (p24).

Appendix 4-2 Inventory of the information needs from parties involved in the development and implementation of child health policies at the European and national level

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For prioritising research questions, information needs from parties developing and implementing child health policies at the European and national level should be considered. In this sub-study we explore the opinions and ideas of relevant experts concerning child health research and child health policy development to identify what is the most policy relevant information that child cohort studies should provide.

We applied a so-called three round Delphi consultation. The Delphi study was intended to summarize and prioritize information needs with regard to: (a) specific disease outcomes; (b) specific determinants of health and of inequities in health; (c) specific topics of research.

1. Round 1 of the Delphi to gather a long list of topics that may be relevant for the development of child health policy

Our Delphi study was performed to inventory of the research priorities with regard to the development of child health policy at the European, national, or regional level according to a selected group of experts. In our study the experts were either child health researchers, especially involved in child cohort studies, or experts involved in child health policy making at the regional, national or European level.

Round 1 of the Delphi project consisted of a questionnaire with open questions that was mailed to a relatively small group of experts (researchers and those involved in child health policy); this was a convenience sample. The purpose of round 1 was to generate a list of all potentially relevant research topics (disease or health outcomes, determinants, special topics). This information was used to compile a long questionnaire with closed questions (seven answer options ranging from absolutely not relevant to extremely relevant).

Round 1 was mailed to 51 experts from research and policy. This resulted in a response by 21 experts, of which 15 experts completed all questions (see

Table 10). Most of them were male (73%); aged 30-60 years (80%); with a European (33%), national (60%), or regional scope in their work (see Table 11).

The information from round 1 resulted in a list of 86 topics for round 2 (26 childhood conditions or diseases and other health outcomes; 26 life style factors, parenting factors and other determinants; 10 environmental factors; 9 topics on health inequalities and vulnerable groups; 6 topics on general health, health-related quality of life and well-being; 5 topics on early life and pregnancy complications; and 14 miscellaneous topics); please refer to Table 12. In round 2 these 86 topics

were included in a questionnaire that was mailed to a broad group of experts to make an inventory of the priorities in such a varied group of experts.

2. Round 2 of the Delphi to assess the level of relevance among experts

Two-hundred-twenty-two (222) experts, a convenience sample, were invited to participate in round 2. Up to 3 reminders were mailed. In round 2, 119 experts participated by completing one or more items of the questionnaire (53.6%), while 89 participants completed all items (40.1%). Table 11 shows the characteristics of participants. Almost half of the participants in round 2 were male; 93% were in the age category 30-60 years old; 14% was involved in policy issues at the international level, 26% at the national or regional level; 3% was involved in management and governance. The major part of participants was involved in epidemiological or child health research. Participants in round 2 come from 20 distinct European countries and one from the U.S.A.

With regard to the data gathered in round 2, for each response a median and an interquartile deviation (IQD) was calculated (see Table 12). The median represents the 50th percentile value of opinions and was used to determine the relevance for each item. The IQD represents the distance between the 25th percentile and the 75th percentile values in opinions and was used to determine the degree of consensus on each item, with a smaller IQD indicating larger consensus.

Items that scored a median of ≥ 6.0 on relevance were considered relevant. Items that scored a median of < 6.0 on relevance were deemed not relevant.

Items with an IQD ≤ 1.0 were considered to have achieved consensus. Such items with a median score on relevance of ≥ 6.0 were no longer included in the third round. Items that scored a median of ≥ 6.0 and an IQD > 1.0 were deemed relevant, but without sufficient consensus and were included in round 3. The items that were considered irrelevant in round 2, were not included in round 3.

Results of round 2 (see Table 12) show that the majority of topics (i.e. 72 topics out of 86 topics) were considered relevant for the development of child health policy at the European or national level; 14 out of 86 topics were not considered relevant (median < 6.0). Despite the heterogeneity of experts that responded to the study, on many topics that were scored as relevant, consensus was reached according to the criterion mentioned above (i.e. with regard to 55 topics of the 72 topics that were considered relevant or extremely relevant, consensus was reached in round 2); with regard to 17 topics that were considered (extremely) relevant, no consensus was reached in round 2 (see Table 3). The relevance of these 17 topics was re-evaluated in round 3, with the purpose to improve the level of consensus among the participating experts.

Please note (see Table 14) that 3 relevant round 2 topics with consensus in Table 12, did not reach the cut-off for the level of consensus in the subsample of round 2 participants that completed all items. These three topics were also included in round 3.

3. Round 3 of the Delphi to promote level of consensus among experts

In the third round of the Delphi study, the same panel of experts that completed the whole questionnaire in round 2 (N=89) were presented with a web-based questionnaire containing the items that scored high on relevance, but on which there was no consensus, as listed above. They were given the opportunity to re-evaluate their agreement in view of the group's response (for each topic in round 3, median and IQD of round 2 were given) using the same scale.

A total of 89 experts were invited and 76 participated (85%; see Table 1). Results of round 3 show that consensus was reached on 14 of the 20 (17 plus 3) topics; no consensus was reached on 6 topics in round 3 (see Table 12).

Consensus was therefore attained on a total of 66 topics, which are summarized in Table 13. This selection of topics, that was considered most relevant for child health policy development in this study, covers all the categories of research topics that resulted from round 1: 17 childhood conditions or diseases and other health outcomes; 13 life style factors, parenting factors and other determinants; 7 environmental factors; 9 topics on health inequalities and vulnerable groups; 6 topics on general health, health-related quality of life and well-being; 5 topics on early life and pregnancy complications; and 9 miscellaneous topics.

Five of the 66 topics that were considered relevant and that reached consensus in the study, resulted in a median score of 6.5 or 7.0 (extremely relevant). These are:

- Overweight and obesity in preschool children (median 6.5; IQR 1.0);
- Socio-economic differences in health (7.0; 1.0);
- Poverty and differences in health (7.0; 1.0);
- What health determinants are most important for child health (7.0; 1.0);
- Which interventions are most effective to promote child health and well-being (7.0; 1.0).

4. Discussion

A broad range of 66 topics were deemed relevant for child health policy development by a varied panel of experts in the field of policy and research. These topics can be used to further guide child cohort research and improve the policy, and thereby societal, relevance of child cohort studies. Clearly the 66 topics cover a wide area of child health issues that are both important for child health policies, and which can generally be studied very well by applying a cohort design and using the wealth of information gathered by the currently ongoing European birth cohort studies. There are several topics that cover prevalent (e.g. asthma, infections, obesity) and rare but serious (e.g. cancer) conditions and diseases in the physical domain. But they also cover developmental, emotional, behavioural and social domain, as well as highly serious circumstances such as neglect violence and abuse and substance abuse. There is also clear attention for a wide range of lifestyle issues, including unsafe sex, resilience, parenting styles and practices and parents as example for the children. A range of 7 environmental topics are included in the list ranging from air and housing quality to safety, green facilities, and the presence of effective education and training for children. Nine topics regarding health inequalities and vulnerable groups are among the 66 topics, varying from socio-economic, ethnic, financial and geographical differences in health to attention for specific groups such as new immigrants, refugees, Roma or traveller's children. Additionally social and ethnic differences to care and to school education and training are included among the 66 topics. Six topics cover general health, health-related quality of life and well-being with regard to physical, mental and social issues. Five topics relate to the importance of health in early life, i.e. around pregnancy and giving birth; the prevention of pregnancy complications are included here. The list is completed by 9 miscellaneous topics including the impact of European policy on child health, impact of early

development and exposures on adult health (two topics), importance of determinants of health in general, effectiveness of interventions (two topics), children's unmet health care needs, impact of urban life on children, and the impact of gene-environment interactions on children's health and development. This broad range of 66 relevant topics covers the current concerns of European and national child health policies, and reflects the areas of attention of current child cohort studies.

However, results should be interpreted with caution.

An advantage of the Delphi approach was that there was inter-participant anonymity. Views could be expressed, and consensus without prejudice and interpersonal relationships introducing bias. Further, because of controlled feed-back and the iterative process, participants could change their minds in round 3, after they had seen the results at the group level after round 2[14].

Although we selected a broad variety of participants for this study, there is a potential bias given the nature of the convenience sampling approach that was applied, and given non-response. Furthermore, relative more experts with a research background were included, compared to experts with a background in international or national child health policy. Despite relatively low numbers in subgroups, we may in a next phase explore differences between these two groups.

This Delphi study was limited in the number of topics that could be offered to the participants in round 2. Despite the relatively long list of 86 topics offered to be rated in round 2, the information was on a rather general level. For example, with regard to potentially important topics such as asthma, eczema and allergies, and overweight and obesity, it was possible to make a distinction between three stages in child life (preschool, school period, and adolescence and young adulthood); this was not possible for the majority of topics to reduce respondent burden. Furthermore, outcomes and determinants were offered as topics separately in round 2. However it was not possible to invite the respondents to rate all possible combinations between determinants (in various areas) and outcomes (in various areas and age periods). Given this restriction, the results of the study of a relatively general nature. Obviously, to further guide child cohort research and improve child health policy, future measurements and studies require in-depth discussion and elaboration.

'Topics that scored low on relevance'

The cut-off values for relevance (median >=6.0), and consensus (IQR <=1.0) were arbitrary and relatively strict[14, 100]. This is important when interpreting the items that had a median score regarding relevance <6.0. These 14 items had a median score regarding relevance of 5.0, and in one case 5.5; these are not particularly low scores. Half of these 14 items had an IQR of 2.0. This indicates that there was a relatively low level of consensus here, with experts providing both higher (i.e. relevant) scores, as well as lower scores. Such topics require further discussion.

Examples of these 14 topics include rare phenomena such as 'complex, rare (inherited) conditions (rare phenomena would require very large cohort studies); sexually transmitted diseases and problems with (sexual) relationships; issues regarding impaired fertility (4 times); water and soil quality and noise in the environment; antibiotics misuse and immunological defence issues, and the impact of genetic profiles on child health. With regard to the latter, with the current state of

knowledge and possibilities, the topic of genetics might be considered as relatively less relevant to child health policy development; although this might be considered a high priority research issue in general. Other topics might require other types of research than cohort research. And/or, as stated above, more discussion is required.

'Topics that did not reach consensus'

There were six topics that were considered relevant with regard to median relevance score of 6.0. However, even in round 3, no consensus was reached (IQD=2.0). Clearly, these topics require further discussion. One of these topics is unintentional injuries. Although these have a high burden of disease in childhood, they may be difficult to study in a typical cohort setting, given the relative low incidence. The presence of adequate material or emotional family resources is another topic without consensus. Topics regarding inequity and poverty were rated extremely relevant; maybe the mix of material and emotional factors in one topic resulted in relatively low consensus. The importance of parenting issues (two times) in the context of cohort studies and child health policy also requires further discussion. Maybe this is not considered a health issue by all participants in the Delphi study. The last two topics with relative disagreement refer to the impact of policy on child health, and the impact of (health) care on child health. These research issues might be considered, by a part of the panel, to be themes for other types of research than cohort research.

'Topics that were considered extremely relevant'

Clearly, overweight and obesity are among the topics currently considered (extremely) important for child health policy; this is a so-called 'hot topic'. Despite the wide variation of participants in the Delphi study, 'socio-economic differences in health' and 'poverty and differences in health' are among the top 5 of most relevant topics for child health policy development. On the one hand this may be because equity in health in childhood is a longstanding issue and a matter of concern among policy makers, and on the other hand cohort studies are suitable to study these issues, enabling a life course perspective.

Another topic in the 'top 5' is 'what health determinants are most important for child health'. Again, this is obviously of major concern for policy makers in order to develop effective policies, and for this type of research question child cohorts are highly suitable.

The last topic in the 'top 5', 'which interventions are most effective to promote child health and well-being', is an example of a highly relevant and important topic for research, which is however not especially suitable to be studied in the context of mother and child cohorts. Cohort studies however may contribute to important insights in these matters.

Conclusion

The experts that participated in this Delphi study provided a broad overview of relevant topics to be studied in birth cohort studies in Europe, in order to support and improve the effectiveness of child health policies at the European, national and regional level. The topics include prevalent common conditions as well as seldom diseases and conditions with a high impact on child health and development; these conditions and diseases include the physical, mental, and social domains, as well as lifestyle and parenting domains. Equally important are considered topics that relate to the environment (biological, chemical, physical, structural and behavioural) of children at the macro, meso, and micro level. Issues related to long-term effects of early life circumstances are amongst the

topics with priority to support child health policy; to study such topics, by nature, the strength of the longitudinal design of birth cohort studies will be used. Of particular importance the participants rated topics regarding poverty and equity in health in childhood, and they specifically drew attention to vulnerable groups of children and their health and development.

Figure 2 Flow chart of the Delphi study

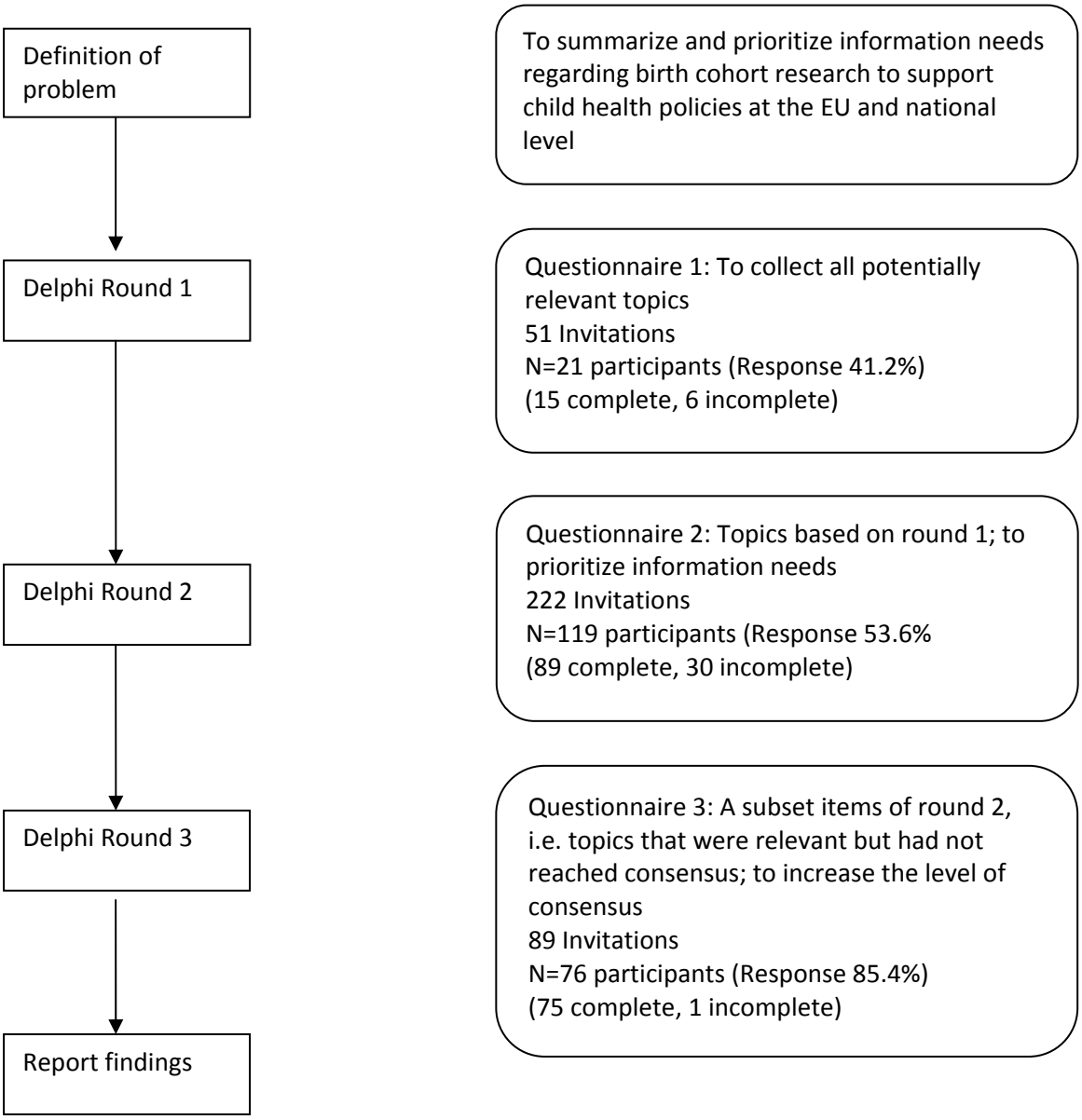

Table 10: Response rates in the Delphi study

	Round 1		Round 2		Round 3	
	N	% response	N	% response	N	% response
Invited	51		222		89	
All response[1]	21	41.2	119	53.6	76	85.4
Complete response[2]	15	29.4	89	40.1	73	82.0

[1] One or more items were completed; [2] All items of the questionnaire were completed

Table 11 Characteristics of the participants in round 1 (N=15) and round 2 (N=119) of the Delphi study

	Round 1		Round 2	
	Total N	**%**	**Total N**	**%**
Gender (%male)	15	73.3	103	48.5
Age (%)	15			
<30		0.0	108	5.6
30-60		80.0		92.6
>60		20.0		1.9
Area of work (% yes)			119	
Policy at international level				14.3
Policy at national/regional level				26.1
Management & governance				2.5
Social epidemiological research				21.0
Clinical epidemiological research				10.9
Environmental epidemiological research				20.2
Epidemiological research (general)				31.9
Child health research (general)				48.7
Research in general				8.4
Other				13.4
Work scope (% yes)	15			
European		33.3		
National		60.0		
Regional		6.7		
Country of work (% yes)	15		106	
Austria				4.7
Denmark				4.7
Estonia				0.9
Finland				1.9
France				4.7
Iceland				0.9
Netherlands				17.0
Slovakia				0.9
Spain				0.9
Switzerland				3.8
UK		6.7		14.2
Czech republic		6.7		0.9
Belgium		13.3		3.8
Ireland		6.7		6.6
Germany		6.7		6.6
Sweden		6.7		4.7
Lithuania		6.7		0.9
Poland		6.7		3.8
Slovania		6.7		0.0
U.S.		6.7		0.0
Norway		6.7		0.9
Other (e.g. virtual)		6.7		0.0

Table 12 Results of the Delphi study per topic in the 2nd round (N=119 participants that completed 1 or more items) and 3rd round (N=76 participants that completed 1 or more items). The 'relevance' was rated on a 1-7 scale (1 is 'absolutely not relevant'; 7 is 'extremely relevant'). Median and interquartile range (IQR) are reported per topic.

Topics		Relevance Median (IQD) All response (N=119) Round 2		Relevance Median (IQD) All response (N=76) Round 3
Q1. Childhood conditions	N		N	
1. Asthma, eczema and allergies in preschool children?	102	6.0 (1.0)		
2. Asthma, eczema and allergies in school-aged children?	102	6.0 (1.0)		
3. Asthma, eczema and allergies in adolescence and young adulthood?	102	6.0 (1.0)		
4. Other respiratory disease (including infections)?	102	5.0 (1.0)		
5. Infectious diseases and immunological disorders?	102	6.0 (1.0)		
6. Overweight and obesity in preschool children?	102	6.5 (1.0)		
7. Overweight and obesity in school-aged children?	102	6.0 (1.0)		
8. Overweight and obesity in adolescence and young adulthood?	102	6.0 (1.0)		
9. Endocrine disorders (e.g. diabetes)?	96	6.0 (1.0)		
10. Complex, rare (inherited) conditions?	96	5.0 (2.0)		
11. Childhood cancer?	96	6.0 (1.0)		
12. Unintentional injuries (including accidents at home, traffic accidents, drowning)?	96	6.0 (2.0)	74	6.0 (2.0)
13. Intentional injuries (including neglect, domestic violence, child abuse, sexual abuse)?	96	6.0 (1.0)		
14. Emotional and behavioural problems (including anxiety and depression) in preschool children?	96	6.0 (2.0)	74	6.0 (1.0)
15. Emotional and behavioural problems (including anxiety and depression) in school-aged children?	96	6.0 (1.0)		
16. Emotional and behavioural problems (including anxiety and depression) in adolescence and young adulthood?	96	6.0 (1.0)		
17. Bullying?	96	6.0 (1.0)		
18. Substance abuse (alcohol, drugs, medicines) and other addictions (e.g. gambling)?	96	6.0 (1.0)		
19. Sexually transmitted diseases?	93	5.0 (1.0)		
20. Problems with peer relations (including sexual relations)?	93	5.0 (1.0)		
21. Impaired growth and other growth disorders?	93	6.0 (1.0)		
22. Impaired development, including psychomotor development, neurocognitive- and behavioral development?	93	6.0 (1.0)		
23. Impaired fertility in mothers?	93	5.0 (2.0)		
24. Impaired fertility in fathers?	93	5.0 (2.0)		
25. Impaired fertility in girls?	93	5.0 (2.0)		
26. Impaired fertility in boys?	93	5.0 (2.0)		
Q2. Lifestyle behaviour and parenting issues				
27. Children's feeding/eating patterns and healthy diet?	92	6.0 (1.0)		
28. Children's playing outside, physical activity and doing sports?	92	6.0 (1.0)		
29. Children's television watching?	92	6.0 (1.0)		
30. Children's playing computer games and/or being on the	92	6.0 (1.0)		

Internet?				
31. Children's listening to very loud music (e.g. iPod, MP3 player, Discotheque or pop concerts)?	92	6.0 (1.0)		
32. Children's starting and continuing with smoking?	92	6.0 (1.0)		
33. Exposure of children to passive smoking?	92	6.0 (1.0)		
34. Children's starting and continuing with drinking alcohol?	92	6.0 (1.0)		
35. Children's starting and continuing with using drugs?	92	6.0 (1.0)		
36. Children's starting and continuing with unsafe sex?	92	6.0 (2.0)	75	6.0 (1.0)
37. Presence of adequate family resources (material or emotional)?	92	6.0 (2.0)	75	6.0 (2.0)
38. Resilience?	92	6.0 (1.0) [a]	75	6.0 (1.0)
39. Adequate parenting styles and parenting practices with preschool children?	92	6.0 (2.0)	75	6.0 (2.0)
40. Adequate parenting styles and parenting practices with school-aged children?	92	6.0 (2.0)	75	6.0 (2.0)
41. Adequate parenting styles and parenting practices with adolescents and young adults?	92	6.0 (1.0)	75	
42. Healthy life style of parents as example for the children (diet, exercise, TV, Internet, smoking, drinking, drugs)?	92	6.0 (1.0) [a]		6.0 (1.0)
Q3. Environmental factors				
43. Air quality?	91	6.0 (1.0)		
44. Water quality in the environment?	92	5.0 (1.0)		
45. Quality of the soil in the environment?	92	5.0 (2.0)		
46. Noise levels in the environment (e.g. traffic noise)?	92	5.0 (2.0)		
47. Food quality and safety?	92	6.0 (1.0)		
48. Safety in the neighbourhood (violence, crime, traffic)?	92	6.0 (1.0)		
49. Safety in and around the school (violence, crime, traffic)?	92	6.0 (2.0)	75	6.0 (1.0)
50. Quality of housing in the neighbourhood?	92	6.0 (1.0)		
51. Availability and quality of green facilities and parks in the neighbourhood?	92	6.0 (1.0)		
52. Quality and effectiveness of education and training (preschool, primary school, secondary school, or tertiary education)?	92	6.0 (1.0)		
Q4. Health inequalities/vulnerable groups				
53. Socio-economic differences in health?	91	7.0 (1.0)		
54. Ethnic differences in health?	91	6.0 (2.0)	75	6.0 (1.0)
55. Geographical differences in health?	91	6.0 (1.0)		
56. Poverty and differences in health?	91	7.0 (1.0)		
57. Health disadvantage in new immigrants?	91	6.0 (2.0)	75	6.0 (1.0)
58. Health disadvantage in children of refugees?	91	6.0 (2.0)	75	6.0 (1.0)
59. Health disadvantages in specific minority groups such as Roma or traveller's children?	91	6.0 (2.0)	75	6.0 (1.0)
60. Social and ethnic differences in access to care?	91	6.0 (1.0)		
61. Social and ethnic differences in access to school education and training?	91	6.0 (1.0)		
Q5. General health				
62. Perceived well-being?	91	6.0 (1.0)		
63. Perceived overall health-related quality of life?	91	6.0 (1.0)		
64. Physical health?	91	6.0 (1.0)		
65. Mental health?	91	6.0 (1.0)		
66. Social health?	91	6.0 (2.0)	75	6.0 (1.0)
67. Functioning at school and school results?	91	6.0 (1.0) [a]		6.0 (1.0)
Q6. Early life and pregnancy complications				

68. (Very) preterm birth?	90	6.0 (2.0)	75	6.0 (1.0)
69. (Severe) Intra uterine growth restriction (IUGR)?	90	6.0 (2.0)	75	6.0 (1.0)
70. Smoking, drinking and drug use in pregnancy?	90	6.0 (1.0)		
71. Healthy life styles during pregnancy?	90	6.0 (1.0)		
72. Environmental (adverse) exposures during pregnancy?	90	6.0 (1.5)	75	6.0 (0.0)
Q7. Other				
73. Antibiotics use and misuse?	90	5.5 (1.0)		
74. Impact of European policy on child health?	90	6.0 (1.0)		
75. Impact of national policy on child health?	90	6.0 (2.0)	75	6.0 (2.0)
76. Impact of early development of children on adult health?	90	6.0 (1.0)		
77. Prenatal and early exposures on later obesity and cardiovascular health?	90	6.0 (1.0)		
78. Immunological defence against viruses and bacteria?	90	5.0 (1.0)		
79. What health determinants are most important for child health?	90	7.0 (1.0)		
80. Which interventions can positively affect child health determinants?	90	6.0 (1.0)		
81. Which interventions are most effective to promote child health and well-being?	90	7.0 (1.0)		
82. What is the impact of (health) care on children's health and development?	90	6.0 (2.0)	75	6.0 (2.0)
83. What are children's greatest unmet (health) care needs?	90	6.0 (1.0)		
84. What is the impact of urban life and urban lifestyle on children's health and development?	90	6.0 (1.0)		
85. The impact of specific polymorphisms (genetic profiles) on children's health and development?	90	5.0 (1.0)		
86. What is the impact of specific gene-environment interactions on children's health and development?	90	6.0 (1.0)		

[a] No consensus reached (IQD=2.0) when considering complete response of round 2 (N=89); See Annex 1.

Table 13 Topics with a median ≥ 6 and an IQD <=1.0 after completion of round 2 or 3

Topics	**Relevance Median (IQD)**
Q1. Childhood conditions	
1. Asthma, eczema and allergies in preschool children?	6.0 (1.0)
2. Asthma, eczema and allergies in school-aged children?	6.0 (1.0)
3. Asthma, eczema and allergies in adolescence and young adulthood?	6.0 (1.0)
4. Infectious diseases and immunological disorders?	6.0 (1.0)
5. Overweight and obesity in preschool children?	6.5 (1.0)
6. Overweight and obesity in school-aged children?	6.0 (1.0)
7. Overweight and obesity in adolescence and young adulthood?	6.0 (1.0)
8. Endocrine disorders (e.g. diabetes)?	6.0 (1.0)
9. Childhood cancer?	6.0 (1.0)
10. Intentional injuries (including neglect, domestic violence, child abuse, sexual abuse)?	6.0 (1.0)
11. Emotional and behavioural problems (including anxiety and depression) in preschool children?	6.0 (1.0)
12. Emotional and behavioural problems (including anxiety and depression) in school-aged	6.0 (1.0)

children?	
13. Emotional and behavioural problems (including anxiety and depression) in adolescence and young adulthood?	6.0 (1.0)
14. Bullying?	6.0 (1.0)
15. Substance abuse (alcohol, drugs, medicines) and other addictions (e.g. gambling)?	6.0 (1.0)
16. Impaired growth and other growth disorders?	6.0 (1.0)
17. Impaired development, including psychomotor development, neurocognitive- and behavioral development?	6.0 (1.0)
Q2. Lifestyle behaviour and parenting issues	
18. Children's feeding/eating patterns and healthy diet?	6.0 (1.0)
19. Children's playing outside, physical activity and doing sports?	6.0 (1.0)
20. Children's television watching?	6.0 (1.0)
21. Children's playing computer games and/or being on the Internet?	6.0 (1.0)
22. Children's listening to very loud music (e.g. iPod, MP3 player, Discotheque or pop concerts)?	6.0 (1.0)
23. Children's starting and continuing with smoking?	6.0 (1.0)
24. Exposure of children to passive smoking?	6.0 (1.0)
25. Children's starting and continuing with drinking alcohol?	6.0 (1.0)
26. Children's starting and continuing with using drugs?	6.0 (1.0)
27. Children's starting and continuing with unsafe sex?	6.0 (1.0)
28. Resilience?	6.0 (1.0)
29. Adequate parenting styles and parenting practices with adolescents and young adults?	6.0 (1.0)
30. Healthy life style of parents as example for the children (diet, exercise, TV, Internet, smoking, drinking, drugs)?	6.0 (1.0)
Q3. Environmental factors	
31. Air quality?	6.0 (1.0)
32. Food quality and safety?	6.0 (1.0)
33. Safety in the neighbourhood (violence, crime, traffic)?	6.0 (1.0)
34. Safety in and around the school (violence, crime, traffic)?	6.0 (1.0)
35. Quality of housing in the neighbourhood?	6.0 (1.0)
36. Availability and quality of green facilities and parks in the neighbourhood?	6.0 (1.0)
37. Quality and effectiveness of education and training (preschool, primary school, secondary school, or tertiary education)?	6.0 (1.0)
Q4. Health inequalities/vulnerable groups	
38. Socio-economic differences in health?	7.0 (1.0)
39. Ethnic differences in health?	6.0 (1.0)
40. Geographical differences in health?	6.0 (1.0)
41. Poverty and differences in health?	7.0 (1.0)
42. Health disadvantage in new immigrants?	6.0 (1.0)
43. Health disadvantage in children of refugees?	6.0 (1.0)
44. Health disadvantages in specific minority groups such as Roma or traveller's children?	6.0 (1.0)
45. Social and ethnic differences in access to care?	6.0 (1.0)
46. Social and ethnic differences in access to school education and training?	6.0 (1.0)
Q5. General health	
47. Perceived well-being?	6.0 (1.0)
48. Perceived overall health-related quality of life?	6.0 (1.0)
49. Physical health?	6.0 (1.0)
50. Mental health?	6.0 (1.0)
51. Social health?	6.0 (1.0)
52. Functioning at school and school results?	6.0 (1.0)
Q6. Early life and pregnancy complications	
53. (Very) preterm birth?	6.0 (1.0)

54. (Severe) Intra uterine growth restriction (IUGR)?	6.0 (1.0)
55. Smoking, drinking and drug use in pregnancy?	6.0 (1.0)
56. Healthy life styles during pregnancy?	6.0 (1.0)
57. Environmental (adverse) exposures during pregnancy?	6.0 (0.0)
Q7. Other	
58. Impact of European policy on child health?	6.0 (1.0)
59. Impact of early development of children on adult health?	6.0 (1.0)
60. Prenatal and early exposures on later obesity and cardiovascular health?	6.0 (1.0)
61. What health determinants are most important for child health?	7.0 (1.0)
62. Which interventions can positively affect child health determinants?	6.0 (1.0)
63. Which interventions are most effective to promote child health and well-being?	7.0 (1.0)
64. What are children's greatest unmet (health) care needs?	6.0 (1.0)
65. What is the impact of urban life and urban lifestyle on children's health and development?	6.0 (1.0)
66. What is the impact of specific gene-environment interactions on children's health and development?	6.0 (1.0)

Results of the Delphi study per topic in the 2nd round (N=89 participants that completed **all** items) and 3rd round (N=73 participants that completed **all** items). The 'relevance' was rated on a 1-7 scale (1 is 'absolutely not relevant'; 7 is 'extremely relevant'). Median and interquartile range (IQR) are reported per topic.

Table 14 Results of the Delphi study per topic

Topics	***Relevance Median (IQD) Complete response (n=89)*** **Round 2**	***Relevance Median (IQD) Complete response (n=73)*** **Round 3**
Q1. Childhood conditions		
1. Asthma, eczema and allergies in preschool children?	6.0 (1.0)	
2. Asthma, eczema and allergies in school-aged children?	6.0 (1.0)	
3. Asthma, eczema and allergies in adolescence and young adulthood?	6.0 (1.0)	
4. Other respiratory disease (including infections)?	5.0 (1.0)	
5. Infectious diseases and immunological disorders?	6.0 (1.0)	
6. Overweight and obesity in preschool children?	7.0 (1.0)	
7. Overweight and obesity in school-aged children?	6.0 (1.0)	
8. Overweight and obesity in adolescence and young adulthood?	6.0 (1.0)	
9. Endocrine disorders (e.g. diabetes)?	6.0 (1.0)	
10. Complex, rare (inherited) conditions?	5.0 (2.0)	
11. Childhood cancer?	6.0 (1.0)	
12. Unintentional injuries (including accidents at home, traffic accidents, drowning)?	6.0 (2.0)	6.0 (1.5)
13. Intentional injuries (including neglect,	6.0 (1.0)	

domestic violence, child abuse, sexual abuse)?		
14. Emotional and behavioural problems (including anxiety and depression) in preschool children?	6.0 (1.0) [b]	6.0 (1.0)
15. Emotional and behavioural problems (including anxiety and depression) in school-aged children?	6.0 (1.0)	
16. Emotional and behavioural problems (including anxiety and depression) in adolescence and young adulthood?	6.0 (1.0)	
17. Bullying?	6.0 (1.0)	
18. Substance abuse (alcohol, drugs, medicines) and other addictions (e.g. gambling)?	6.0 (1.0)	
19. Sexually transmitted diseases?	5.0 (1.0)	
20. Problems with peer relations (including sexual relations)?	5.0 (1.0)	
21. Impaired growth and other growth disorders?	6.0 (1.0)	
22. Impaired development, including psychomotor development, neurocognitive- and behavioral development?	6.0 (1.0)	
23. Impaired fertility in mothers?	5.0 (2.0)	
24. Impaired fertility in fathers?	5.0 (2.0)	
25. Impaired fertility in girls?	5.0 (2.0)	
26. Impaired fertility in boys?	5.0 (2.0)	
Q2. Lifestyle behaviour and parenting issues		
27. Children's feeding/eating patterns and healthy diet?	6.0 (1.0)	
28. Children's playing outside, physical activity and doing sports?	6.0 (1.0)	
29. Children's television watching?	6.0 (1.0)	
30. Children's playing computer games and/or being on the Internet?	6.0 (1.0)	
31. Children's listening to very loud music (e.g. iPod, MP3 player, Discotheque or pop concerts)?	6.0 (1.0)	
32. Children's starting and continuing with smoking?	6.0 (1.0)	
33. Exposure of children to passive smoking?	6.0 (1.0)	
34. Children's starting and continuing with drinking alcohol?	6.0 (1.0)	
35. Children's starting and continuing with using drugs?	6.0 (1.0)	
36. Children's starting and continuing with unsafe sex?	6.0 (2.0)	6.0 (1.0)
37. Presence of adequate family resources (material or emotional)?	6.0 (2.0)	6.0 (2.0)
38. Resilience?	6.0 (1.5)	6.0 (1.0)
39. Adequate parenting styles and parenting practices with preschool children?	6.0 (1.5)	6.0 (2.0)
40. Adequate parenting styles and parenting practices with school-aged children?	6.0 (2.0)	6.0 (1.5)

41. Adequate parenting styles and parenting practices with adolescents and young adults?	6.0 (1.0)	
42. Healthy life style of parents as example for the children (diet, exercise, TV, Internet, smoking, drinking, drugs)?	6.0 (1.5)	6.0 (1.5)
Q3. Environmental factors		
43. Air quality?	6.0 (1.0)	
44. Water quality in the environment?	5.0 (1.0)	
45. Quality of the soil in the environment?	5.0 (1.5)	
46. Noise levels in the environment (e.g. traffic noise)?	5.0 (1.0)	
47. Food quality and safety?	6.0 (1.0)	
48. Safety in the neighbourhood (violence, crime, traffic)?	6.0 (1.5)	6.0 (1.0)
49. Safety in and around the school (violence, crime, traffic)?	6.0 (2.0)	6.0 (1.0)
50. Quality of housing in the neighbourhood?	6.0 (1.0)	
51. Availability and quality of green facilities and parks in the neighbourhood?	6.0 (1.0)	
52. Quality and effectiveness of education and training (preschool, primary school, secondary school, or tertiary education)?	6.0 (1.0)	
Q4. Health inequalities/vulnerable groups		
53. Socio-economic differences in health?	7.0 (1.0)	
54. Ethnic differences in health?	6.0 (2.0)	6.0 (1.0)
55. Geographical differences in health?	6.0 (1.0)	
56. Poverty and differences in health?	7.0 (1.0)	
57. Health disadvantage in new immigrants?	6.0 (2.0)	6.0 (1.0)
58. Health disadvantage in children of refugees?	6.0 (2.0)	6.0 (1.0)
59. Health disadvantages in specific minority groups such as Roma or traveller's children?	6.0 (2.0)	6.0 (1.0)
60. Social and ethnic differences in access to care?	6.0 (1.0)	
61. Social and ethnic differences in access to school education and training?	6.0 (1.0)	
Q5. General health		
62. Perceived well-being?	6.0 (1.0)	
63. Perceived overall health-related quality of life?	6.0 (1.0)	
64. Physical health?	6.0 (1.0)	
65. Mental health?	6.0 (1.0)	
66. Social health?	6.0 (2.0)	6.0 (1.0)
67. Functioning at school and school results?	6.0 (1.5)	6.0 (1.0)
Q6. Early life and pregnancy complications		
68. (Very) preterm birth?	6.0 (2.0)	6.0 (1.0)
69. (Severe) Intra uterine growth restriction (IUGR)?	6.0 (2.0)	6.0 (1.0)
70. Smoking, drinking and drug use in pregnancy?	6.0 (1.0)	
71. Healthy life styles during pregnancy?	6.0 (1.0)	
72. Environmental (adverse) exposures during pregnancy?	6.0 (1.5)	6.0 (0.5)

Q7. Other		
73. Antibiotics use and misuse?	5.0 (1.0)	
74. Impact of European policy on child health?	6.0 (1.0)	
75. Impact of national policy on child health?	6.0 (2.0)	6.0 (2.0)
76. Impact of early development of children on adult health?	6.0 (1.0)	
77. Prenatal and early exposures on later obesity and cardiovascular health?	6.0 (1.0)	
78. Immunological defence against viruses and bacteria?	5.0 (1.0)	
79. What health determinants are most important for child health?	7.0 (1.0)	
80. Which interventions can positively affect child health determinants?	6.0 (1.0)	
81. Which interventions are most effective to promote child health and well-being?	7.0 (1.0)	
82. What is the impact of (health) care on children's health and development?	6.0 (2.0)	6.0 (2.0)
83. What are children's greatest unmet (health) care needs?	6.0 (1.0)	
84. What is the impact of urban life and urban lifestyle on children's health and development?	6.0 (1.0)	
85. The impact of specific polymorphisms (genetic profiles) on children's health and development?	5.0 (1.0)	
86. What is the impact of specific gene-environment interactions on children's health and development?	6.0 (1.0)	

[b] No consensus reached (IQD=2.0) when considering all response of round 2 (n=119); See Table 12.

Appendix 4-3 Policy involvement in cohort planning

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ABBREVIATIONS

HWS = Health Welfare and Sport

ZonMw = The Netherlands Organisation for Health Research and Development

WHO = World Health Organization

NWO = The Netherlands Organisation for Scientific Research

GGD = Public health services

SUMMARY

Aim:

This study assessed policy involvement in cohort planning. The main question was: Were representatives of the European Union, national or local governments involved in the design and follow-up phase of the relevant child cohorts, and if so, how?

Methods:

A case study, including three ongoing cohort studies; the Dutch Generation R Study, the INMA cohorts in Spain and the Polish mother and child cohort study REPRO-PL. In total, 14 interviews with both policy makers and cohort researchers were conducted.

Results:

1. Policy involvement in cohort research

- The level and nature of contacts between cohort researchers and international, national, local and regional policy makers seems to be related to (a) political structure and (b) funding structure.

- Examples of involvement of policy makers are: decisions on which topics to work on, facilitation whenever needed, and recruitment of participants.

- In most cases, policy makers involvement in cohorts follows funding. However, this is not the case where European Union was involved, when contact is rare. Where there is no funding, contacts have developed gradually.

- While interaction between policy makers (especially at the national level) and cohort researchers was intense during the design phase, later on interaction seemed to slow down.

2. Influence of cohort research outcomes to policy

- While researchers are of opinion that they mostly initiate contacts with policy makers and present their results in an adequate way, the policy makers in this study put forward that researchers should share and present their research results.

- The use of cohort results by policy makers may depend on: (a) policy relevance of results, (b) quality of research, and (c) adequate translation of results used by policy.

- Policy makers and cohort researchers alike consider that both research and policy would improve by more and better collaboration.

- All researchers mentioned differences between the 'cultures' of policy-making and research. Researchers and policy makers respond to different incentives, and operate under different timelines and constraints.

Discussion and conclusions:

These findings suggest that the relationship between international, national, regional, and local policy makers and those who plan and conduct cohort research varies between cohorts. Although interactions exist between policy makers and researchers in all three studied cases, policy makers did not play a large role in cohort planning. Both policy makers and researchers agree that collaboration and communication between policy makers and researchers should be further improved.

These findings suggest that cohort researchers should involve stakeholders from policy, not only when results are final, but also during the process of research planning, data collection, analysis, and reporting. Furthermore, it is recommended to format cohort research results in a way that is accessible to policy makers and researchers should translate results into policy recommendations or implications.

Lessons for policy makers:
- For researchers to respond to policy debates, these must be presented in a way that is transparent and understandable.
- Researchers would like greater input, and communication between researchers and policy advisors is likely to improve if barriers to contact are removed.

Lesson for researchers:
- Addressing interests and priorities and using language appropriate for a non-academic audience.
- Involve stakeholders from policy, not only when results are final, but also during the process of research planning, data collection, analysis, and reporting.

INTRODUCTION

Background

Policy and decision makers need a solid evidence base for the development and implementation of public health interventions and the incorporation of health goals in the definition and implementation of all policies, including those focused on child health. Messages emerging from mother-child cohort research are not always filtering through to policy at the national, let alone the European, level.

Aim

The aim of this case study was to describe the role of policy makers with regard to decisions concerning the design of child cohort studies. This study assessed the role, if any, of the policy makers in the construction and design of data collection or data publication of ongoing cohort studies.

The main question was: Were representatives of the European Union, national or local governments involved in the design and follow-up phase of the relevant child cohorts, and if so, how?

Subtopics of interest were:

1. Policy involvement in cohort research
2. Influence of cohort research outcomes to policy

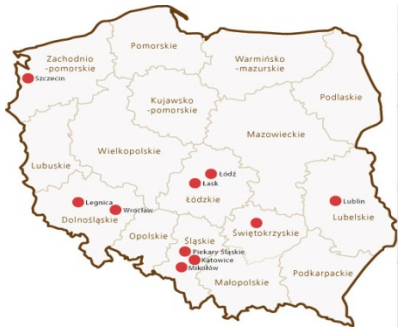
METHODS

Participanting Cohorts

Three cohort studies in three Member States of the European Union were selected for case studies: The Generation R Study in the Netherlands, INMA (Infancia y Medio Ambiente) in Spain and the Polish mother and child cohort study REPRO-PL in Poland. These cohorts were selected to include both recent and well established cohorts, and one each of Northern, Southern and Eastern European cohorts. The three member states included also differ in the extent to which they devolve to their regions: i.e. Poland and Spain are the most devolved, the Netherlands the most centralised (all participants are resided in Rotterdam) (see Figure 3).

Figure 3: Geographic localization of study areas in three member states.

The Netherlands (Generation R)



Poland (REPRO-PL)

Spain (INMA)

Four participant groups were targetted for each cohort:

1) Prinicipal Investigators of the original study
2) Current researcher on the cohort
3) Policy maker with some current or past role in cohort administration, management, governance or funding, operating on the international or national area of prevention, (child) health (welfare and sport), or local public health services)
4) Cohort employees with a role in disseminating findings to policy makers or politicians

Interviews

Individual, in-depth interviews were conducted. Interview questions were defined by the research team. The interviews followed a funnel structure, progressing from broader and open-ended questions to more structured questions with specific probes to clarify issues as needed [Krueger RA, 1994]. To collect information from Poland and Spain, telephone interviews were used. Individual face-to-face interviews were done with Dutch policy makers and researchers. At the request of the participant, in one case a written response to questions was submitted in place of an interview, to avoid language translation problems. The interviews were audiotaped and transcribed (EH). Each interview ran for up to 40 min and was conducted by the same investigator, except one interview which was done by another member of the research team (SSch). One study investigator (EH) read each transcript creating and structuring data in a table, which included all collected data, which was relevant to the purpose of the present study.

Cohorts description

The Netherlands: The Generation R Study

The Generation R Study is a population-based prospective cohort study, conducted in Rotterdam, the second largest city of the Netherlands. Generation R is designed to identify early environmental and genetic causes of normal and abnormal growth, development and health from fetal life until young adulthood. Generation R focuses on four primary areas of research: (1) growth and physical development; (2) behavioural and cognitive development; (3) diseases in childhood; and (4) health and healthcare for pregnant women and children [101].

Further details of the Generation R study have been described previously [101-103].

The general aims of the study are [102]:

(1) To describe normal and abnormal growth, development and health from fetal life until young adulthood;

(2) To identify biological, environmental and social determinants of normal and abnormal growth, development and health from fetal life until young adulthood;

(3) To examine the effectiveness of current strategies for prevention and early identification of groups at risk.

In total, 9778 mothers, with a delivery date between April 2002 and January 2006, were enrolled in the study. Additionally, 71% (n = 6347) of all fathers were enrolled [102]. The Generation R study received funding from the state (the Ministry of Health Welfare and Sport), the Netherlands Organisation for Scientific Research (NWO), The Netherlands Organisation for Health Research and Development, Dutch Asthma Fund, Capability Fund grants, Erasmus MC University, private individual funding, as well as financial support from corporate enterprises. State funding was received after the study was set up, when the child reached the age of 5 years.

Dutch political & health care system

The constitutional character of the Dutch state is expressed through the Trias Politica (separation of powers) and an extensive political and health care system of checks and balances [104].

ZonMw is a fund that aims to improve prevention, care and health by stimulating and financing research, development and implementation. ZonMw is mainly commissioned by the Dutch ministries as well as the Dutch Organization for Scientific Research (NWO) to study priorities and problems in health care. To tackle these issues, ZonMw formulates programmes, in which research and health care institutes have (to compete for) the opportunity to conduct research and to develop, test and implement innovations.

The Dutch health care system is currently in transition, with the introduction of a single compulsory social health insurance scheme, in which multiple private health insurers compete for insured persons. For more details about financing, see figure 3. The government changed its role from directly steering the health care system to safeguarding the process. Responsibilities have been transferred to health insurers, providers and patients. Through these reforms, managed competition for providers and insurers became a major drive in the Dutch health care system. The government presumes that this will increase efficiency and quality in the health care system as well as make care more demand-driven [104].

Poland: REPRO-PL

The Polish Mother and Child Cohort (REPRO-PL) is a multicentre (in 8 different regions of Poland) prospective study. The aim of the study is to evaluate the impact of exposure to different environmental factors during pregnancy and after birth on pregnancy outcome and children's health, specific exposures include heavy metals, polycyclic aromatic hydrocarbons (PAHs), environmental tobacco smoke (ETS) and the nutritional status of pregnant women. The final cohort is intended to comprise 1300 mother-child pairs to be recruited within 4-year period (2007–2011) [105].

REPRO-PL received funding from the state (the Ministry of Science Higher Education) and a grant from Norway through the Norwegian Financial Mechanism within the Polish-Norwegian Research Fund. State funding was received during the establishment of the cohort and the state fundingis ongoing. However, the project is not yet fully financed.

Polish political and health care system

Poland is divided into 16 administrative units. The administrator of each unit is appointed by the central government [106]. The President has a veto over any legislative proposal or action which can be re-passed by a three-fifths majority vote in the presence of at least half of the statutory number of members of the parliament. Health services delivery plans are elaborated by the National Health Fund on the basis of the national health plans approved by the Minister of Health. At each level of self-government administration, health authorities are responsible for general strategy and planning based on the identified health needs, health promotion and the management of public health care institutions in a given region. Levels of public funding for health care have fallen slightly since 199[106].

Spain: INMA Cohort

INMA - INfancia y Medio Ambiente, (Environment and Childhood) is a prospective population-based cohort study. It is a network of seven birth cohorts in Spain; Ribera d'Ebre (n=102), Menorca

(n=530), the cohort of Granada (n=668), Valencia (n=855), Sabadell (n=657), Asturias (n=494) and Gipuzkoa (n=638) [107].

Further details of the INMA cohort have been described previously [107]. The INMA cohort has 3 general objectives [107]:

1) To describe the degree of individual prenatal exposures to environmental polluting agents and the internal doses of these polluting agents during gestation to birth and during childhood in Spain;
2) To evaluate the impact of the pre and postnatal exposures to different environmental polluting agents in growth, health and development of the children, from the foetal early stages to the adolescence;
3) To evaluate how genetic and nutritional factors may modify the effects of the environmental polluting agents in children's growth.

INMA has never received state funding, yet continuous to be successful in obtaining funding through competitive (national and international) grants.

Spanish political and health care system

Territorially, the political organization of the Spanish state is made up of the central state and 17 autonomous communities (AC), which have respective parliaments and governments. Each of the autonomous communities elects a regional parliament, which in turn elects the President by majority [108].

The Spanish health system is made up of a conglomerate of public and private organizations, resulting in a totally decentralized system. The national health system has a regional organizational structure. At central level the Spanish Ministry of Health and Consumer Affairs is responsible for national health, general coordination and basic health legislation. Further Health policy-making is carried out at the regional level.

RESULTS: CASE STUDY FINDINGS

In total 15 interviews were conducted. See **Table 15**.

Table 15 Overview of recruited participants to interview.

	Generation R	INMA	REPRO-PL
Prinicipal investigators (PI's)/researchers	3 PI' s recruited of the total amount of 13 PI' s in the study team	2 members recruited of a steering committee of 14 members	1 PI and 1 researcher recruited. These 2 do all research.
Policy Makers	1 local government policy makers 2 national policy makers	1 local government policy maker	1 policy maker (WHO), No local government policy maker related to REPRO-PL available
Dissemination role	2 program managers of ZonMw 1 Public Relations Advisor	No such role	1 Project manager (=also researcher)

Policy involvement in cohort research

All studied cases had contacts between cohorts and policy makers. Differences between the studied cases were found regarding the start of relationships between cohorts and policy makers: involvement of policy makers in cohorts started during the design of the cohort study (INMA), after assignment of funding by policy (REPRO-PL) or developed gradually during follow-up of the cohorts (Generation R). While some cohorts particularly has contacts with local and regional policy makers (Generatio R and INMA), other cohorts particularly has contacts on the national level (REPRO-PL). In the Netherlands, both the funding structure for the cohort and the importance of (national) government mean that close relationships exist between the policy makers and cohort researchers.

When asked about formal relationships between policy makers and cohort studies, researchers and policy makers give slightly different reports. Each policy maker could name the points of contact between themselves and cohort researchers. They all report some level of co-operation, and in one case also co-appointment between local administration and the cohort. Researchers in two cohorts reported there were relationships between national and international policymakers, but they aren't formalised. These relationships had taken some time to develop, but researchers reported that they are keen to hear from policy makers (although they were not certain how much influence they had). Researchers in the third cohort reported that where policy makers had provided money or resources, they influenced the topics of research, but where they provided none they were not involved.

In this last cohort, although the European Union was involved in funding, prominent interaction with policy makers at the European Union level did not happen.

Interaction between cohort researchers and policy makers is facilitated by research seminars and meetings, flyers, publicity, working visits, newsletters, telephone calls, e-mail contacts, research reports and fact sheets. The frequency of contacts between cohort researchers and policy makers in the three studied cohorts was at least one time a year, and in the case of REPRO-PL up to 4 times per year. Two of the three cohorts said that frequency of meetings varied according to the perceived need of the project.

All studied researchers and policy makers agreed that policy involvement in cohort research is important: e.g. a researcher who also is involved in policy making state: "Policy makers not only should be involved when results are coming, it is especially interesting to have in consideration the opinion of policy makers when the team is elaborating information for the families or for the rest of the community". Other policy makers state that: "I think researchers and policy makers should co-operate much more", "Frequent interactions between policy makers and researchers are necessary to have a clear insight into the interests of each other" and "There should be a continuous interaction between policy makers and researchers".

Researchers opinions are: policy makers should inform researchers about their interests of topics to work on. Policy makers describe that they are important to involve in cohort research: policy makers should facilitate cohort research whenever needed, help to recruit participants and they could help to prevent loss-to-follow-up.

The Influence of cohort research outcomes on policy

This case study shows that policy makers are aware of the scientific importance of cohort research results. Policy makers mentioned the importance of cohort studies and role as expertise center is increasing in health-making policy: e.g. policy makers state "The role of a cohort study as expertise center is important to policy makers" and "research can help improving the knowledge of the main health determinants".

However, cohort researchers consider that policy makers should be more aware of the advantages of cooperation with cohorts, because until now policy makers lack knowledge about benefits of collaboration between research and policy. One researcher state: “In general, policy makers are not aware of the benefits of cooperation between cohorts and policy. Lack of knowledge of benefits of cooperation is a problem. This should be solved; e.g. it could be helpful when policy makers have a background of research”.

Researchers are of opinion that they mostly initiate contacts with policy makers and present their results in an adequate way. Mostly, policy makers are contented about the interactions with cohorts.

A policy maker state: “Some researchers have great ability to translate scientific research to the social and public level”. Some policy makers in this study put forward that researchers should share and present their research results: Researchers publish their research results in scientific papers, but do not translate their research results to policy makers or to the community. It seems difficult for cohort researchers to translate their research results into practice relevance. “Researchers publish their new knowledge in scientific papers, but kept the information. That is not enough. Policy makers need this information”. Policy makers suggested that cohort studies should make more use of existing research sources. “Policy makers and researchers should turn the conversation on to collaboration.

Researchers should match, share, release data and cooperate in projects. New technologies (ICT) could play an important role in this”.

Some researchers criticize:

- Policy makers will not recognize their results or will not be able to put the recommendations derived from research into practice. Policy makers do not know how to handle scientific results and information to public population.

- Policy makers may be more interested in cross-sectional studies compared to cohort studies

- Research questions which were raised by policy were very difficult to solve within a cohort study.

- Policy makers are pressed by political questions, issues that change to one day from another.

- When researchers provide information to policy makers in issues above policy interest, policy makers would not listen to researchers.

Although this study found no example where cohorts had influenced policy. All policy makers agreed that cohort research could make an important contribution to policy by improving knowledge of:

1. Revealing trends, and helping policy makers to distinguish events from trends.

2. Investigating the impact of risk factors within society over time.

Policy makers mention that the use of cohort results may depend on: (a) policy relevance of results, (b) quality of research, and (c) adequate translation of results used by policy.
Policy might, however, influence research. Policy makers make decisions on which topics are important to research on the basis of relevance and priority (as defined policy, practice or research): and topics that are important to society.

Policy makers distinguish ‘need to know data’ and ‘nice to know data’. Policy makers prefer topics concerning ‘Need to know data’. Beside societal and public health requirements, also previous

research results and future explorations play a role in making decisions on which topics to work on by policy.

Decisions on which topics to work on by research are mostly defined by principle investigators. One case study shows some influence from regional government in making decisions on which topics to work on.

All researchers in the three studied cohorts mentioned some differences between the 'cultures' of policy-making and research. Researchers and policy makers respond to different incentives, operate under different timelines and constraints.

Policy makers and cohort researchers alike consider that both research and policy would improve by more and better collaboration. Policy makers and cohort researchers suggest that intermediaries between cohort research and policy and supervision in cooperation could bridge the gap between those two areas and bring them together to improve cooperation. This study shows one example of such a collaboration: a "follow up committee" was created to ensure a fluid communication between cohort researchers, professionals and policy makers.

Table 16 Views of researchers and policy makers on 4 factors that may influence the cooperation between cohort planning and policy.

Factor	Researcher Views	Policy Makers Views
Use of intermediaries /research translation	Not mentioned	Seen as useful by one policy maker
Researchers starting the conversation	-Two cohorts mention that they have to contact policy makers frequently. -Researchers are not interested in policy relevent questions. -Policy makers do not see the benefit in cooperating.	Seen as useful in two countries "facilitating an easy way of contact and a fluent communication"
Policy makers should inform researchers what they would like to know	Some agree, but not all. For instance: "Policy makers should inform researchers about their interests of topics to work on" and another researcher state that "involvement of policy makers in cohort planning is not so important. Policy makers mostly are driven by public concern and things which they think are important and they mostly are not interested in health issues on their own initiative".	Seen as useful: "Agenda-setting is one example to transfer issues of importance from policy to research. This is a way of influencing research questions".
Research quality	High quality research is time consuming, and policy makers do not like this. Policy makers prefer other study designs (e.g. cross sectional).	High research quality is seen as important. One of the problems is that the questions which were raised by politicians were very difficult for the cohort study to solve. To solve these problems, policy makers have to act quickly. They accept more uncertainty compared to scientific researchers, who strongly aimed to reduce uncertainties and increase scientific evidence.

DISCUSSION

These findings suggest that the relationship between international, national, regional, and local policy makers and those who plan and conduct cohort research varies between cohorts. Although interactions exist between policy makers and researchers in all three studied cases, policy makers did not play a large role in cohort planning.

Where funding was provided, involvement of policy makers in cohorts followed this, either started during the design of the cohort study or after assignment of funding. Where no funding was provided relationships between cohorts and policy makers developed gradually. Involvements of policymakers in cohort planning included: suggestions of topics to work on (by regional government) and facilitating logistics, recruitment of participants and reduction of loss-to-follow-up (by local government).

The aim of both cohort researchers and policy makers was to improve and protect child health (and that of women of reproductive age). Although policy makers and researchers had this same aim, most researchers and policy makers in the three studied cohorts mentioned some differences between the 'cultures' of policy-making and research. Cohort researchers and policy makers responded to different incentives, and operated under different timelines and constraints. One possible explanation is that researchers and policy makers have different approaches to the same issue. Researchers are likely to focus on theories of its origins, considering their work never fully completed [109]. Their findings often result not in calls for action, but in calls for more research. Policy makers, on the other hand, are likely to be coming to the topic through legislation. They make decisions within short timelines and want information at hand to inform these decisions.

Prior studies indicate that policymakers rarely turn to University-based researchers for information in their work [110-112]. Instead, studies indicate that policymakers are more likely to rely on close-in sources, such as other policy makers and legislative staff.

Policy makers and cohort researchers alike consider that both research and policy would improve by more and better collaboration. Until now, there are relatively few successful examples of close partnerships. Cohort studies in particular can comment on the nature of the health problems, understanding the complexity of multiple causal factors and the balance of risk and protective factors. Furthermore, cohort studies have been particularly important in establishing causal relationships in areas where for practical or ethical reasons randomised controlled trials are not possible, for example maternal cigarette smoking, foetal and infant growth or environmental toxin exposure. New knowledge could result in mandates to improve health. Therefore it is important to translate research results to policy recommendations. Translation of cohort research results into messages that policy makers can use needs attention.

Lessons for policy makers:
- For researchers to respond to policy debates, these must be presented in a way that is transparent and understandable.
- Researchers would like greater input, and communication between researchers and policy advisors is likely to improve if barriers to contact are removed.

Lesson for researchers:
- Addressing interests and priorities and using language appropriate for a non-academic audience.
- Involve stakeholders from policy, not only when results are final, but also during the process of research planning, data collection, analysis, and reporting.

CONCLUSION

In conclusion, in all three studied cohorts there is interaction between policy makers and researchers. Both policy makers and researchers agreed that collaboration and communication between policy makers and researchers should be further improved.

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