

# RICHE – Research Inventory, Indicators, Gaps and Roadmaps for Child Health in Europe - an EU FP7 project.

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## Abstract

### *Background*

30 There is a substantial amount of research in child health published each year in the European Union. Much of this work is paid for from public funds, or from charitable donations. This work covers many areas, but it is fragmented, certain important areas are hardly covered at all, and much of it, especially that outside the indexed scientific journals, i.e. the grey literature, is difficult to discover, and hard to access.

### *Response*

The EU, as one of the major funders of child health research, has funded a project, the Research Inventory of Child Health in Europe (RICHE), to prepare a roadmap for the future of child health research in Europe. Using a life course perspective, the project sought to identify the research done, define the gaps in the research, and make recommendations for future research funding priorities.

### *Content*

40 RICHE is an FP7 funded project (contract no. 242181) tasked with preparing a roadmap, or roadmaps, for the future of child health research across Europe. Using a life-course perspective, the project has designed, and carried out, an open, transparent, and justifiable process to make recommendations for future research funding. We acknowledge that such recommendations are value judgements, and our intent was to present a careful justification for those we made.

50 The project, which had 25 partners, in 19 countries, was organised into six work packages – WP1 an inventory of child health research, including funded projects, reports, funders, and people; WP2 on ways of measuring child health, and indicators for child health; WP3 on gaps in child health research; WP4 on the roadmap for future research; WP5 maintains a platform at <http://childhealthresearch.eu/>; WP6 was responsible for project management.

### *Results*

The project has finished, and launched a report on 'Roadmaps for the Future of Child Health Research in Europe'. A key recommendation is the establishment of a European Child Health Observatory, with a focus on participation by children and young people. The work of implementing these recommendations to improve the health of European children can begin.

### *Keywords*

60 Public health; Child public health; Child health; Research strategy; Europe;

## Introduction and rationale

The RICHE project was a response to a call to identify clearly gaps in European child health research, and to provide justified guidance on priorities for investments in research over the next decade. Our aim was to improve the health of the more than 100 million infants, children and young people in Europe. Our key objective was to make the case for further and more effective investment, both in supporting healthy lives for our children, and in researching those lives.

70 European children and their lives are already the subjects of a substantial amount of research activity. This is multi-disciplinary, multi-lingual, some commissioned, some investigator initiated, funded by many different agencies, including the European Commission. However, the overall effort is far from optimal, and the results are not used as they could be, because this research is fragmented, and not effectively disseminated. A lot of research commissioned by national or regional governments and research agencies, and may be visible only in that country and in a specific language. European Commission research is funded and commissioned by one of several Directorates General, each with some responsibility for children, however, there is no one DG with the lead responsibility. It is hard to get a perspective either on the content, or the richness, of European child health research.

80 Our work was framed by the terms of the European Council decision of 2008 on the health and well-being of young people (European Council, 2008). The Council noted that, "although on the whole the health of young people in Europe is satisfactory, certain fields are of particular concern such as nutrition, physical activity, alcohol abuse, sexual and mental health; particular attention should be paid to promoting a healthy lifestyle and preventive measures, especially in the context of sexual activity, alcohol abuse and drug use, smoking, eating disorders, obesity, violence."

To meet these needs they proposed that

90 "precise knowledge of the state of health, the needs and expectations of young women and men in terms of health, as well as existing practice, experience and lessons learned in this field, all duly assessed, is required both to contribute to ensuring the efficacy and efficiency of youth health policy and to aim to better take into account, within tailored strategies, the specific nature of this group, with particular reference to potential differences within the group due, inter alia, to age, sex, place of residence or socio-economic factors and giving priority to young people with fewer opportunities." (European Council, 2008).

100 Our primary goal was to support future work to address the issues raised in the Council decision. This paper reports the overall project structure, and the rationale for some of our key design decisions. Other papers are in preparation.

## Background

110 The state of health of European children is reasonably satisfactory, and it has significantly improved over the last fifty years. Two recent reports (Cattaneo, Cogoy, Macaluso, & Tamburlini, 2012; Currie, Nic Gabhainn, Godeau, & International HBSC Network Coordinating Committee, 2009) between them, give a good picture of the current state of European children, and the picture is generally positive. However among younger children there remains a  
120 substantial burden of preventable illness, and at every age there are signs of increasing risk of poor health status in later life. Perhaps the most significant of these, are the high levels of obesity and physical inactivity, with predictable consequences for ill health in adult life, for example obesity, type 2 diabetes, poor mental health, cardiovascular disease, stroke, and premature death (WHO, Europe, 2007). There are also significant minorities of children in Europe with unacceptably poor health status, mostly among minority ethnic groups, e.g. the Roma, and migrants, both legal and illegal (Cattaneo et al., 2012). Finally, many adolescents engage in excessive drinking and drug use, risky sexual activity, and other hazardous social behaviours (Currie et al., 2009).

The WHO Regional Office for Europe identified four principles as the basis for their health strategy for children and adolescents:-

“Life-course approach. Policies and programmes should address the health challenges at each stage of development from prenatal life to adolescence.

Equity. The needs of the most disadvantaged should be taken into account explicitly when assessing health status and formulating policy and planning services.

130 Inter-sectoral action. An inter-sectoral, public health approach that addresses the fundamental determinants of health should be adopted when devising policies and plans to improve the health of children and adolescents.

Participation. The public and young people themselves should be involved in the planning, delivery and monitoring of policies and services” (World Health Organization Regional Office for Europe, 2005).

The RICHE project was built around these four principles.

### *Life course*

140 We used a life-course framework (Kuh, Ben-Shlomo, Lynch, Hallqvist, & Power, 2003; Kuh & Ben-Shlomo, 2004) as one of our key frameworks, (along with a bio-psychosocial framework e.g. (Brunner & Marmot, 2006; Lena Lämmle, 2010)) for understanding and classifying child health. This offers an interdisciplinary framework for guiding and structuring research on health,

human development and ageing. It is the study of health, and disease, by considering the long and short term effects of environmental exposures at each stage of development: intrauterine, early childhood, adolescence, young adulthood and later adult life.

150 This use of a multidisciplinary life course perspective reflects both appreciation of the complex processes by which individual development is shaped and modified by external stimuli, and the extent to which the external environment is selected, shaped and modified by the individual. This understanding builds on a model of health as a state of physical, social, and mental well-being (Huber et al., 2011; World Health Organisation, 1986; World Health Organization, 1946), and not simply the absence of disease.

### *Equity*

160 One main message from the recent review of the health of European children (Cattaneo et al., 2012), is that much of the worst health among children in the EU is amongst the poorer sections of society, and in particular amongst migrants, both legal and illegal, and some specific indigenous groups, such as the Roma, and Irish travellers. Equity has to be a central focus if the most unacceptable areas of poor health are to be effectively tackled.

### *Inter-sectoral action*

The project focus was on child public health, that is :-

“The art and science of promoting and protecting health and well-being and preventing disease in infants, children and young people, through the skills and organised efforts of professionals, practitioners, their teams, wider organizations, and society as a whole.” (Blair, Stewart-Brown, Waterston, & Crowther, 2010)

170 Working from this concept, child public health research necessarily involves a range of professionals, and organisations. This range is reflected in the range of disciplines amongst the partners of the RICHE project, which included epidemiology, psychology, paediatrics, education, public health, disability studies, informatics, and health systems research.

### *Participation*

180 Children have an explicit right, under Article 12 of the UN Convention on the Rights of the Child (United Nations, 1989), to “express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child”. The importance of giving young people a say in research on children is well understood, although it may not be fully realised (Fleming, 2011). The RICHE project provided for consultation and engagement with advocates for children, and young people themselves during its work.

## Objectives of RICHE

The original call came under the general rubric of '*Enhanced health promotion and disease prevention*', and a key general aim was to '*provide scientific evidence for the best public health measures*'. The specific request from the Commission was to :-

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“address the diversity and fragmentation in child health research in Europe in an inclusive multidisciplinary way, identifying existing research programmes in Member States, recent advances and identification of gaps to explore road maps for the future of child health research in Europe”.

## Project Structure

RICHE had 25 partners, coming from many different disciplines, in 19 countries, and an expert advisory group, including academics and staff from international agencies. Ethical approval for elements of fieldwork was secured from the relevant local regional or national ethics committees in the appropriate partners' countries. Consent was obtained, verbally, in writing, or over the web, to take part in surveys, Delphi processes, and interviews. Full details will appear in the reports of individual pieces of work. Figure 1 shows the countries with RICHE partners, or associated, that is self-funded, partners.

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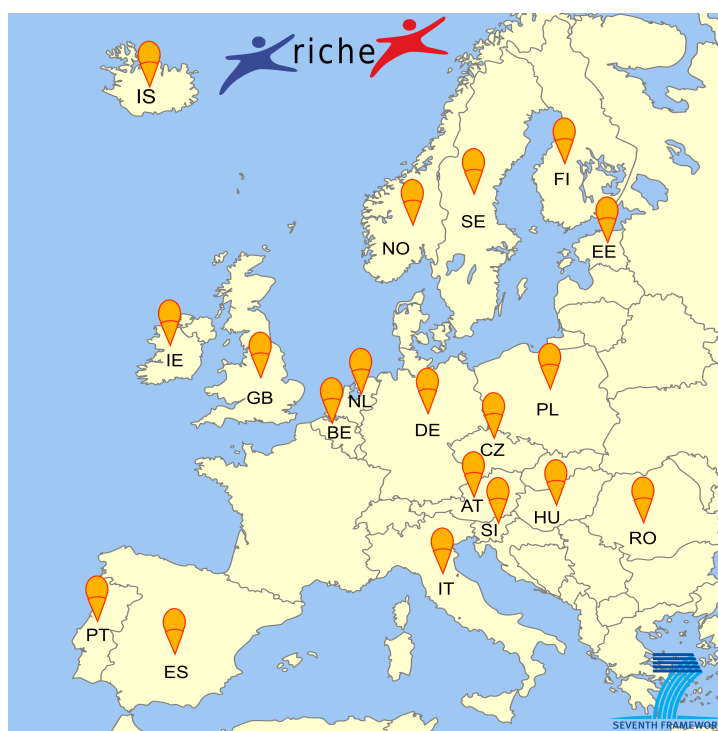


Figure 1: Countries with RICHE partners (Base map source - Wikimedia Commons).

The RICHE project was built from six key activities, or work packages (WP) in

the EU terminology, working together to achieve the project objectives :-

1. WP1 – Child health research, an inventory and a taxonomy
2. WP2 – Child health measurement and Indicators
3. WP3 – Gaps in Child health research
4. WP4 – Roadmaps for Child health research
5. WP5 – Platform for Child health research
6. WP6 – Project management

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Figure 2 shows how these activities related to each other.

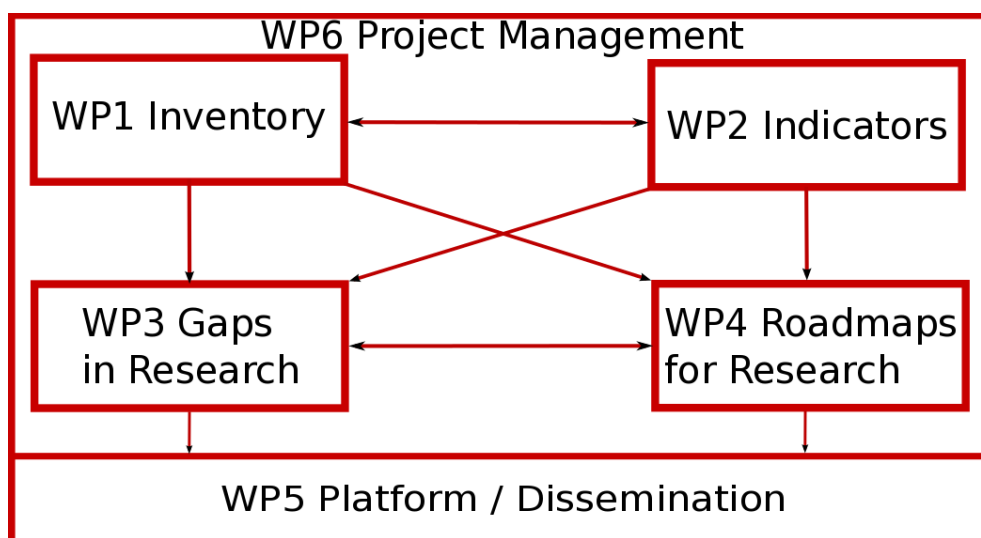


Figure 2: The RICHE project structure

*WP1 – Child health research, an inventory and a taxonomy*

Leader Prof Michael Rigby, NHV (SE); Deputy Dr Aleš Bourek, MU (CZ)

This WP has prepared an inventory of research activity on child health in Europe, and a taxonomy to classify research projects, research outputs, and the research interests of individuals. The taxonomy was prepared in English, and has been translated into ten further European languages (Alexander, Bourek, Kilroe, Rigby, & Staines, 2013).

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The taxonomy for child health research was developed by an iterative collaborative process, starting with examining other taxonomies in the field of health, and in the social sciences. The taxonomy is multi-axial, for instance having dimensions for by age-group or life stage, by health topic or functional aspect, and by type of research, among others (Alexander et al., 2013).



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The inventory of child health research was a major task. It focused on more recent work, from 2000 onwards, and particularly on collecting details on funded research projects, and on grey literature. It had (and has) a special focus on work commissioned by major national and international funders, such as the European Commission, major charities, and national research councils. Several methods were used to locate material, including bibliographic searches, contacts in our partners network, approaches to international agencies, and national governments.

#### *WP2 – Child health measurement and Indicators*

Leader Prof Anders Hjern, NHV (SE); Deputy Dr Mitch Blair, ICL (GB)

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Developing and implementing sound indicators, based on good measurements, for various aspects of child health and its determinants is essential for the future development of child health within the EU (M. J. Rigby, Köhler, Blair, & Metchler, 2003; M. Rigby & Köhler, 2002). For example, benchmarking of treatment methods based on indicators drives quality work in clinical practice; comparison of health policies in the EU demands high quality indicators of policy and health for reliable analyses.

Based on data on the incidence and prevalence of ill health, and studies with the focus on processes and outcomes, potential indicators and gaps were highlighted by reviewing existing sources of data, analysing possible research gaps, and further aspects that have to be considered in future research.

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The outputs included, for the first time, a detailed inventory of validated indicators of child health; reviews of national and sub-national child health indicators; a review of methodological issues in the analysis of secondary data; and a case study of the use of a national child health electronic health record.

#### *WP3 – Gaps in Child health research*

Leader Dr Matilde Leonardi, INN CB (IT); Deputy Dr Giorgio Tamburlini, BURLO (IT)

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Our work on identifying gaps in research started by defining research gaps, and child health needs. This work identified a range of important clinical and public health problems that affect children's health, but that are under-served by the contemporary mix of commissioned research on child health (World Health Organisation, 2003). The importance of a 'gap' was measured in two ways, first, first at population level, using burden of disease measures (Lopez, Mathers, Ezzati, Jamison, & Murray, 2006; Valent, Little, Bertollini, et al., 2004), and second as impacts on vulnerable groups of children – for example the most marginalised (Abdalla et al., 2010; McGorrian et al., 2012; Zoon, 2001).

The major children's health problems that European countries face today, such as obesity, behaviour disturbance, injury, pre-term births, low birth weight, birth defects, asthma, allergy, diabetes, and behavioural and psychiatric disorders, have complex origins (Valent, Little, Tamburlini, & Barbone, 2004).

270 Some work has recently been done using burden of disease studies to evaluate organisational priorities in funding child health research and interventions (Rudan et al., 2008; Stuckler, King, Robinson, & McKee, 2008). Much of this work has focussed on child health in developing countries. However, we believe that the same principles can be applied to identifying gaps in European child health research.

A range of methods was used, building on the results from other studies such as the Global Burden of Diseases and the Comparative Quantification of Health Risks (Ezzati, Lopez, Rodgers, & Murray, 2004), to establish the relative importance of different issues for child health. These studies were also used to identify possible emerging health issues.

280 Information on gaps and priorities was collected from various sources, including surveys of stakeholders, and meetings with national experts. An analysis of selected national and European child health surveys was done. Their contents were linked to the International Classification of Functioning, Disability and Health – Children and Youth version (ICF-CY) (World Health Organization, n.d.) and the International Classification of Diseases, version 10, (ICD-10) (World Health Organization, 2003) identifying areas commonly covered, and the gaps. They were further mapped to a biopsychosocial model of health and disability (Brunner & Marmot, 2006; Lena Lämmle, 2010), so discovering which elements, for example body functions, body structures, activity and participation, and environmental factors, were commonly considered in the survey questions.

290 These results were combined, and a draft report on gaps was prepared, and reviewed by the project team, and external experts.

A second survey was done, recruiting international specialists from different disciplines to take part in a Delphi study. The aim was to validate the results of the draft report on gaps, and to help with setting priorities. This provided useful further inputs to the work on roadmap for child health research (WP4).

#### *WP4 – Roadmaps for Child health research*

300 Leader Prof Ulrike Ravens-Sieberer, UKE (DE), Deputy Leader Prof Maria Margarida Nunes Gaspar de Matos, CEES/FMH/UL (PT)

WP4 aimed to provide a roadmap for the future of child and adolescent health research, so as to close the gaps between current expert knowledge, and that which is needed, as identified in the previous WPs, and especially in WP3.

For the sake of overcoming the fragmentation of the European public research base, it was important to create a framework for the exchange and cooperation between stakeholders and researchers within and between the member states to increase the coherence of actions in different policy and research sectors (European Commission DG SANCO, 2009). The roadmap was intended to :-

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- provide guidelines for prioritising future research on child health, research resources, research types and research methods
  - ensure that future research calls as well as national and international

applications for grants prioritise on the gaps identified

- enable a better fit between research priorities and health care practitioners' and stakeholders' (policymakers, research advocates, health care system advocates and health insurance advocates) needs for information
- support the translation of research into policy for different stakeholders
- make better use of research for evidence based planning, monitoring and evaluation of health policy actions

320 To achieve these aims, a range of methods were used including systematic review of documents, expert focus group interviews, and Delphi methods. These had been shown to be effective in earlier work (Detmar et al., 2006; Herdman et al., 2002; Ravens-Sieberer et al., 2001), and to allow the review and collation of the information in a way which supported the project aims.

330 One important feature of this work was the development of a formal frame for the report, within which research and policy topics, were presented. Based on a review of existing theoretical research frameworks, such as life course approaches (Kuh et al., 2003), or biopsychosocial models (Brunner & Marmot, 2006), a formal structure was developed within which to present the priorities of the roadmap report.

340 For the first time a systematic roadmap covering a set of areas, in a lifecourse perspective, for future research on child health in Europe, has been developed. This includes a matrix within which priorities are specified on the following dimensions :-

- Roadmaps on maternal and child health; pre-school children; primary school age children; adolescents and young adults life-course stages;
- Roadmap for developing the availability of measures and indicators; roadmaps on policy-, societal- and individual citizens' determinants;
- Roadmaps on training and flow of competent researchers; development of research infrastructure; improvement of research institutions; effective knowledge sharing; international cooperation in science and technology.

350 Together these roadmaps form the basis for an improved coordination of research programmes and priorities and thereby could help to overcome the fragmentation of European research, and also the neglect of important research aspects. The final child health research roadmap report has now been published (Ottova et al., 2013), and is available online, and on the RICHE website.

#### *WP5 – Platform for child health research*

350 Leader Prof Anthony Staines, DCU (IE), Deputy Leader Dr Anne McCarthy, HRB (IE)

The platform is a tool which formed the core of the RICHE project. It started as a web-based tool to support the other WPs in their work. Functions included

document repositories, document search, user registration and secure access. Content for the platform came from WP1, WP2 and WP5 initially, but all partners contributed material. Lists of contacts, list of researchers, funders, organisations, research projects, research reports, and so on were generated, and are hosted on the platform. The site is also be the public face of the project, providing information on its work, its progress, and its achievements to the public. As WP1 and WP2 developed, more of the site became publicly accessible, and it is possible for non-partners to register and contribute material. Our aim was to secure the engagement of the research community and the wider set of stakeholders with the platform, by making it useful to them.

As the inventory grew, it became possible both to contribute material to it, and to search for information on it, in several different languages, using the taxonomy (Alexander et al., 2013). The platform provides an innovative faceted search interface to the material stored on the site (Tunkelang, 2009). The lasting value of the platform is the large well curated collection of grey literature on child public health stored there. Our ultimate objective was (and is) to secure a long term future for the platform, now that the project has finished. If the platform is to continue to provide genuine added value to the community of researchers and research users across Europe, it will need to be sustained into the future.

## Conclusions

RICHE is one of a series of EU funded projects looking at planning future European investment in research. Others include CHICOS (Bousquet et al., 2013), which has a similar role for cohort studies; ROAMER which defines a roadmap for mental health research (ROAMER Project group, 2012); WHYWEAGE, which looks at ageing research (WHYWEAGE Project Group, 2008); ITECH looking at health technology (ITECH Project group, 2013); and EUROVISIONNET looking at visual deterioration (EUROVISIONNET Project group, 2008). These projects may signal a new, more soundly based, approach to setting research priorities for EU funded health research. However, to derive the full benefits from this work, the recommendations from these projects should be adopted by the European Commission for the Horizon 2020 research programme, and carefully considered by other major funding agencies.

The core value of the project was to put children first. Europe ought to take all the rights of the child very seriously, and the project team are very conscious that too many children in Europe today do not have the opportunity to exercise the right to health and healthcare that they ought to have (United Nations, 1989). We hoped to show how children can be fully recognised and respected, as forming a valuable population in their own right, whose health and well-being matters to our present, and future, European society.

The topics identified by this project can all be researched (i.e. they lie within the grasp of presently available research methods and resources), and all are likely to have a significant effect on the lives of European children. At the very

least, the RICHE project aims to begin a serious conversation across Europe about the need for research to focus on children and how this will ultimately benefit all members of the European population.

400 There is a need for children to become much more visible in European society. At present many children's lives are invisible to health surveillance and to research. Sometimes they are submerged with their families, as in the case of Roma or for children of illegal and undocumented immigrant families. Even in well-documented social groups, children's circumstances are invisible as data are collected from the perspective of economically active adults, or households. Too often, the voices of children and young people are not heard. Therefore, an overarching recommendation from the project is the establishment of a **European Child Health Observatory** with a simple remit to make European children, their voices, the quality of their lives, their health, and the attainment of their rights more visible.

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Table 1 – List of partners in the RICHE project

Partners	Country	Staff involved
Dublin City University	IE	Anthony Staines; Jean Kilroe; Rachel O'Sullivan; Treasa McVeigh.
Burlo Garofolo	IT	Giorgio Tamburlini; Laura Cogoy
Egészség Monitor	HU	Csilla Kaposvari
Erasmus Universitair Medisch Centrum Rotterdam	NL	Hein Raat
Nasjonalt Folkehelseinstitutt	NO	Else-Karin Groholt
Centro de Estudos de Educação para a Saúde, FMH /Universidade de Lisboa	PT	Margarida Gaspar de Matos; Gina Tomé; Teresa Santos; Tania Gaspar; Lucia Ramiro
The Health Research Board	IE	Anne McCarthy
Imperial College of Science, Technology and Medicine	GB	Mitch Blair; Lauren Brennan
Fondazione IRCCS Istituto Neurologico Carlo Besta	IT	Matilde Leonardi; Milda Cerniauskaite; Paolo Meucci
Institute of Public Health of the Republic of Slovenia	SI	Polonca Truden-Dobrin
Johannes Kepler University Linz, Institute of Health System Research	AT	Reli Mechtler
Nordic School for Public Health	SE	Michael Rigby; Anders Hjern; Lennart Kohler; Denise Alexander
Nofer Institute of Occupational Medicine	PL	Kinga Polańska; Wojciech Hanke
Open Applications Consulting Limited	IE	Con Hennessy; Mel McIntyre
School of Health and Education, Reykjavik University	IS	Geir Gunnlaugsson
National Research and Development Centre for Welfare and Health	FI	Mika Gissler
Masarykova Univerzita, Center for Healthcare Quality	CZ	Aleš Bourek
University of St. Andrews	GB	Candace Currie; Antony Morgan
Universitätsklinikum Hamburg-Eppendorf	DE	Ulrike Ravens-Sieberer; Veronika Ottová-Jordan; Carsten Rasche
University of Newcastle upon Tyne	GB	Allan Colver
Universitatea Babeş Bolyai	RO	Livia Popescu; Maria Roth
Universiteit Maastricht, Centre for Public Health Genomics	NL	Angela Brand
Tervise Arengu Instituut	EE	Toomas Veidebaum
<b>Associated partners</b>		
Sociedad Española de Pediatría Social	ES	José Díaz Huertas
PERU, Université Libre de Bruxelles	BE	Sophie Alexander

Table 2 List of advisory group members

Name	Affiliation
Bernadette Melnyk	Arizona State University, later Ohio State University
Karen McAuley	Office of the Ombudsman for Children, Dublin, Ireland
Judith Hollenweger	Pädagogische Hochschule, Zürich, Switzerland.
Auke Wieggersma	Rijksuniversiteit Groningen, Netherlands
David Parker Leonardo Mencini	UNICEF Innocenti centre
Vivian Barnekow	WHO Regional Office for Europe

All advisory group members served in a personal capacity

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