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Project context and objectives

Project origins

The project call, to which RICHE is a response, read:–

“HEALTH-2009-3.3-5: European child health research platform. FP7-HEALTH-2009-single-stage. 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. Funding scheme: Coordination and Support Action (Coordinating Action)”.

To interpret this we looked at evidence on the state of health of European children, and the existing calls for action on the topic. The EU Council (1) resolution on the health and well-being of European youth, 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 the Council proposed “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.” (1). Our primary goal is to support this proposal.

Project Context

The European Region of WHO identified four principles as the basis for their health strategy for children and adolescents (2):

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

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

3. 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

4. Participation. The public and young people themselves should be involved in the planning, delivery and monitoring of policies and services.”

We fully endorse these principles, and have tried to build the RICHE project around them. Specifically we chose to use a life-course framework as one of our key frameworks for understanding and classifying child health. In addition to covering research activity on the impacts of social inequity and poverty on child health, we have sought to engage with representatives of, and advocates for, the most disadvantaged in Europe. Our approach is explicitly a child public health approach, acknowledging fully the essential contribution of many other sectors of society to the production and maintenance of child health.
Frameworks of child health

It was important to support a number of different approaches to thinking about child health, to researching child health, and to using research on child health. There are several frameworks for child health in common use, and we have used and supported many of these in our taxonomies, and the work built upon them. However, we adopted a life-course perspective as the key organising principle for our work on child health research, and our recommendations for future work.

Life course approach

A life course approach offers an interdisciplinary framework for guiding and structuring research on health, human development and ageing (3). It is the study of health and its inverse, 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 (4). That this specific approach has, for many years, been an intrinsic aspect of several scientific disciplines, including psychology, sociology, demography, anthropology, and biology, and, more recently, epidemiology, reflects how the various biological and social factors - independently, additively and multiplicatively - influence physical, mental and emotional well being.

This shift from a medical approach, one dominated by an adult model of risk assessment in understanding health, to a multidisciplinary life course perspective, reflects appreciation of the complex processes by which individual development is modified and moulded by external stimuli, and the extent by which the external environment is modified and moulded by the individual. This understanding builds on a model of health as, not simply the absence of disease, but a state of physical, social, and mental well-being.

Bio-psycho-social model

The RICHE roadmap is the end of a three year program of work designed using the concepts of a life-course approach to child health and a bio-psycho-social model of child development (See Figure 1). The implications of this approach are that we acknowledge explicitly the many ways in which external factors, and earlier experience, acting over time, influence later outcomes. It is possible to become discouraged by the sheer complexity of the interactions. We prefer to look at this as showing the many opportunities for intervention to improve outcomes in adult life.
The health of European children – a Europe that is changing

European children are regarded as enjoying reasonably good health. The last 50 years has seen a major reduction in mortality rates for all age groups in Europe. However, there has been an increase in morbidity from non-communicable diseases, which now make up the greatest burden of disease in Europe and worldwide. Mental health disorders, and other chronic long-standing illnesses, all create major challenges to human health and health services. A recent review of the health of younger children (from birth to age 12 years) in Europe (5), describes a substantial burden of preventable illness, and poor health status, with predictable consequences for ill health in adult life, for example obesity, type 2 diabetes, poor mental health, cardiovascular disease, stroke, and premature death (6). There is less systematic information about European adolescents, particularly older ones, but recent reports from the Health Behaviour of School-aged Children (HBSC) study (7) show the diverse ways in which our societies support, or fail to support, young people navigating adolescence.

There are still large numbers of children in Europe with unacceptably poor health, particularly those living in socially disadvantaged circumstances, and in those countries in which social inequalities are relatively wide. While Europe now has an agreed set of values related to health and health care (8), and a strategy (9), this needs to be implemented with a particular focus on some very marginalised groups, for example Roma children, recent migrants, and illegal or undocumented immigrants (5).

Economic Impact of Child Health Research

Economic analyses show that investment in childhood is worthwhile (10). Preventing disease is known to be a good investment, but promoting children’s health is even better (11). It is now well supported by
evidence that ‘Healthy ageing begins before conception’ (4), and so societies which wish to tackle successfully the challenges of ageing will need to start with their children.

All European societies spend significant amounts of funding on children’s health (and even more on avoidable adult ill-health determined in part at least in childhood). In times of economic strain it is important that this expenditure is justified, and that services are delivered as effectively and efficiently as possible. This means our children should receive purposeful evidence-based services, and researchers must generate, analyse, and disseminate the evidence to justify, or change, them.

Project structure

A consortium, with a final total of 23 partners, and two associate (i.e. unfunded) partners, responded to this call. We designed a project with a linear structure, where the main focus of activity moved from work on the Inventory, and Indicators and Measurement, in Year 1, to work on Gaps in Year 2, finishing with the preparation of the Roadmap in year 3. The final 6 months (Year 4) were largely dissemination. The Platform, which is instantiated in our website, supported all of the other parts, and was a focus for communication and dissemination throughout the project.

Each piece focused on a specific area of work, but each fed into its successors, and all leaders and partners worked closely together. Each group produced a number of technical reports and other outputs. The final output was a Roadmap for future investment in European child health research. This has been widely disseminated, and has fed at Commission level and National level into the Horizon 2020 call preparation process.

RICHE Roadmap

The RICHE Roadmap is based upon a sound, scientific evidence base, which we had gathered as part of our earlier work. The project prepared an inventory of child health research and of measurements and indicators of child health in Europe. This was collated using a web platform – which can be found at www.childhealthresearch.eu. In addition to this exercise, a formal study of the gaps in child health research was undertaken by carrying out surveys and interviews of researchers and research users across Europe. This allowed our initial views on the research gaps to be refined and corrected by an iterative process, involving, both project partners, and the wider scientific community, so seeking grounding and validation for this key phase. These results formed the basis for the RICHE Roadmap.

The Roadmap is based on a life-course perspective. It covers the important phases of a child’s development, including maternal health, and pregnancy, through to adolescence and the protective and risk factors, and health services encountered throughout childhood and adolescence as he or she moves towards adulthood. RICHE looked upstream to identify where more work needed to be done to prevent avoidable physical and mental ill-health, disability and death in the population of European children aged 0-18 years. This shows how the many influences and outcomes of children’s health are interrelated; a pattern reflected in the Roadmap. It can be downloaded from the RICHE website (http://childhealthresearch.eu/) or from the DCU repository – http://doras.dcu.ie/19732/.

The work necessarily involved a series of value judgements, especially on setting priorities, because there are no objective and unconditionally valid answers to the question “Is there enough research on this topic?”, nor to the question “Is this a topic of significance?”. Nevertheless, the RICHE Roadmap uses an inclusive and transparent process to explain the recommendations it made, and the subjects it chose, making our values, and the reasons for judgements as explicit as possible.

The report is organised into broad subject areas, that reflect the key ‘gaps’ in knowledge about children and young people, or about particular aspects of their lifestyle and health. These key areas, and selected findings within each area, are briefly summarised here.
**Life Course and Lifestyle**

This section focuses on children as they age, and recognises the importance of continuing to research how factors before conception, during gestation and in the very early years of life can affect present and future health. The challenges that children face as they grow up are also highlighted – these can be created because of policy decisions that fail to take account of children and young people’s lives or because of the pervasive influences of individual circumstances that act as protective or risk factors for children’s actions. The concept of resilience in childhood is also highlighted, and how research needs to focus on this important and powerful means of improving children’s lives. A key issue, throughout the life course, is mental health and well-being. Fostering well-being in children from birth, and throughout childhood will provide numerous individual and societal benefits. It deserves a greater research focus.

**Socio-economic and Cultural Factors**

The socio-economic and cultural environment in which a child is born and grows up has a potent effect on a child’s health and well-being. Inequity and inequalities in health, between and within nations depending on socio-economic circumstances, are known to affect health outcomes. Those in the poorest areas have worse health, and shorter lives than those in the wealthiest areas. Other groups are at risk of marginalisation from health services and from opportunities that can maximise their health. These include migrant children where the question is how best to support their integration into their new societies and communities, while retaining their individual identity; children in the state care system have poor health and social outcomes, so improving these, by focused research is important for the future health of these children; children from minority population groups, in particular those who travel across nations, such as the Roma, need to have focused attention, to ensure that their health outcomes begin to match those of the general European child population.

**Social and Community Networks**

The main influences on children and young people are their immediate family and community networks. This extends from the influence of the family as a warm and nurturing environment in which to grow up – and conversely a place of the most profound danger and threat if such a family environment is toxic; to the wider influence of school, and finally the broader community. Becoming engaged and involved in community life is beneficial for the entire population, not just for the children and young people directly involved. It is an aspect of children and young people’s experience that is important for well-being and social inclusion.

**Environment**

The term ‘environment’ covers several different concepts, and the RICHE Roadmap describes the physical, virtual and also the perceived environment – all of which interlink in children’s lives, and have a profound effect on their health and development. These include the physical environment, the virtual (digital) environment, physical safety, including injury prevention, and protection from crime, anti-social behaviour and violence (both as perpetrators and victims).

**Complex Health Issues**

The majority of children in Europe are healthy, and ill-health is not a characteristic of this population as it is in, for example, an ageing population. However, there are certain health issues that affect children, and as such can blight an entire lifetime. Our Roadmap does not cover clinical issues, but takes a population perspective. There are certain disorders that have a population-wide effect and are prevalent enough in the child population to warrant particular attention from a public health viewpoint. Four specific areas of concern were identified – overweight and obesity, mental health, sexual and reproductive health, and neuro-developmental disorders.
Health Services

The main research needs of the health services focuses on the prevention of poor health. Comparing health services across Europe and evaluating the means of conveying health promotion messages are important directions for health research to investigate. Indicators need developing which reflect the effect of preventive actions, particularly among younger children. Vulnerable populations, such as those in deprived communities, need to have health prevention services particularly targeted. There is little systematic evaluation of such interventions, which compromises the development of new interventions and their implementation. Those who do not access services and those who need particular attention can be identified.

Public Health Infrastructure

Health surveillance is essential so that health needs can be identified and addressed effectively for the benefit of the child population. Yet, many existing sources of data are neither analysed, nor made available in a child-centric way. Children need to be made more visible in the data so that they can have more effective health promotion and health care on a population level. Specific examples include work on autism and morbidity due to injury. Europe also needs to establish proper measures and indicators of children’s health and children’s lives. We cannot act properly without first identifying and measuring the problem. Electronic health records are an emerging technology that has great potential, both for research, and for improved access to care. They need to be developed and investigated further to encourage their use across the European Union.

Improving Research Capacity

It is necessary to ensure that there are enough resources, both to do research, and to make use of the research findings. To sustain research activity, specialist training for junior child health researchers is needed, as are sufficient resources to maintain a critical mass of researchers and provide attractive career paths for them. Children and young people as subjects of research need to continue to be safeguarded by a consistently ethical framework, and information collected about children needs to be accurate, comprehensive and used intelligently so that interventions and services can be correctly directed.

Using the roadmap

The roadmap is a complex document, addressed to a number of different stakeholders. One key group are those who make decision bout research finding priorities. We have disseminated the roadmap widely at EU level, to reach into the process of priority setting for Horizon 2020. This has been done thought National Contact Points in each partner country, through relevant NGO’s, and by sending copes to and meeting with relevant parts of the European Commission. Readers using the roadmap will most likely use it in two ways, first to make a general case for investment in Child Health Research, and secondly to target that investment, by considering the questions we have identified, and reviewing our justifications for these choices. We do not expect our work to determine future investments in child health, but we are confident that using our work would lead to better decisions overall.

Conclusions

Our core value is to put children first in our work. We take the rights of the child seriously, and we are conscious that many children do not have the opportunity to exercise the right to health and healthcare that European children they ought to have. The topics in this Roadmap are pragmatic in that they are researchable (within the grasp of presently available research methods and resources) and that are likely to have a significant effect on the lives of European children. This will go a considerable distance in improving the health and well-being of European children who may not have benefited from Europe’s good fortune up until this point. At the very least, the RICHE Roadmap aims to begin a serious
There is a need for children to become substantially 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 societies, children’s circumstances are invisible as data are collected from the perspective of economically active adults, or households.

Therefore, an overarching recommendation in this road map is the establishment of a **European Child Health Observatory** with a simple remit to make European Children, and their lives, health and attainment of rights more visible.

We also recommend continuing and extending the discussion to the edge of existing child health boundaries, to address topics such as the effects on children’s health of urban design and architecture, fiscal policy (which can affect many health issues), welfare, or health effects of immigration policy.

The RICHE Roadmap hopes to point the way in which children can be fully recognised and respected as forming a valuable population and whose health and well-being contributes to the health of our present and future European society.

**Potential impact**

The main impact of our work is to contribute to the European debate about how best to support our children in the many transitions which they must negotiate successfully from conception onwards, to establish an independent and satisfactory adult life for themselves. This is not often considered as a purely health issue. One of our key conceptual bases is, of course, that health is a tool to achieve certain social and individual goals. These goals may be constrained in various ways, for example by permanent bodily impairment, but individuals, families, communities and societies have a duty and an obligation, now codified in the UN Convention on the Rights of the Child (31) to support children in achieving these goals. From this perspective, education, for example, is at least as important to child health, as, say, acute hospital services.

We have come to two key conclusions which will bear repeating. The first is the observation, that for the topics we considered, there is more often an implementation gap, than a knowledge gap. This means that there is at least some pertinent evidence on how to manage a particular problem affecting children, but there is less, often much less, information on how to put this knowledge in to practice. In other words, we may well know what to do, or at least have some good ideas on the subject, but there are few guides as to how to do it.

This is a critical deficiency. It makes it impractical for many service providers to adopt and adapt innovative programs from elsewhere. A partial solution is to make it easier to prepare and deposit reports of implementation studies on the Internet, and the RICHE project platform was established to do just that. We recommend a much more systematic approach to gathering and sharing information on the implementation of child health and well-being programs.

The second observation is that there is very little routinely available information across Europe which allows us to see the lives of our children. There are, of course, very valuable surveys, in which RICHE partners take a full part, such as Kidscreen (35–37), and HBSC (7,38). These studies have added hugely to our knowledge of the lives and well-being of European children. However, examining the website of EUROSTAT, the OECD, and even the WHO, there is very little specific information on children. For adults, there are many specialist surveys, but there is also a large volume of routine data, on their health, their housing, their work, their educational achievement, and many other topics.

By contrast, there is limited visibility of the lives of children in our societies. What does this mean? For many critical aspects of the lives of children we depend on one-off surveys for information. We do not in any way underestimate the value of these surveys, indeed many of the best attested pieces of knowledge about children's lives come from them. However, these surveys are inevitably based on samples, often...
small enough samples, of the total child population. They may also cover a limited number of countries. Such studies are invaluable to point out problems, concerns and issues. However, they do not support the kind of analyses which would allow more effective service planning. This is a task better suited to large scale routine data systems.

As one example, a survey might identify that a small percentage of children fail to transition from primary to secondary school. Good routine data would tell you where those children lived, which schools they attended, and permit both locating the individual children to give them, and their families, appropriate individual support, and intervening in the specific schools and communities to minimise the problem in the future.

**European Child Health Observatory**

One part of a solution to this, is to establish a European Child Health Observatory. One possible structure for this is a two-site centre linking and supporting child health relevant specific European Networks of interest. Broadly, this could be a hybrid between an Age Platform function (see www.age-platform.eu) but for children, a virtual centre of expertise, and a COST-type network.

The Cores would host the overseeing Director and Deputy respectively, and each would have the dedicated time of (initially) 0.5 whole time support staff, to ensure timely responses. The Dual Core structure is to ensure operational and policy resilience, stability from organisational changes, and balance of professional views; the specific functions of each core would be complementary but deeply linked (on a similar model the Health Behaviour of School-aged Children (HBSC) organization links between the Universities of St. Andrews (UK) and Bergen (Norway), each having a specific role, and each supporting a network of national links).

In the longer term this structure might well develop into a cohesive action collaborative akin to the European Innovation Partnership (EIP) for Active and Healthy Ageing, involving civil society and commerce as well as research and policy. Initially the vision is broadly the model of European collaboration on rare diseases, which started as a facility for networking, and has grown steadily to become a series of linked actions and platforms on networking, information, policy, and action, benefiting European citizens and society.

**Functions**

The Observatory would not be a physical centre in the sense of housing professional staff, physical bibliographies or repositories, or regular courses. Rather, it would act as a reference point both for enquiries, and to initiate, stimulate, and where needed coordinate responses to new opportunities and new needs. Part of this would be to seek to promote Children’s Health in Europe in a similar way (eventually) to the Age Platform (www.age-platform.eu) (an EIP for Healthy Childhood might be a logical further outcome).

It would also be a hub for special interest, expertise, and advocacy networks, stimulating them, while enabling them to form, grow, and gain strength, through appropriate coordination and facilities – the experience and outcomes of the European Child Safety Alliance, and the EURO-Peristat series of perinatal data projects, are models of what can be achieved. It would aim to draw together the many interest groups and activities promoting child public health or specific aspects, seeking not to impinge on their autonomy but to enable strengthening through coordination and sharing, while at the same time facilitating the channelling of expertise and advice to newer action lines. A biennial Child Health Policy and Research conference might be a particularly useful function, complementing other events.

**Physical Resources**

The Observatory would have modest initial resources in the first instance :-

- The part-time staff of the Dual Cores
- Serviced offices in the host institutions, including access to a Treasury or Research Support
Office function

- Access to other Centres/Projects of Expertise, some of which would be network nodes
- Access to specialist networks as they developed
- Access to individual experts who on a specific topic could be commissioned to produce topic papers and/or represent the Observatory at meetings
- A web presence based on the current Child Health Research site (http://childhealthresearch.eu/).

Financial Resources

The initial cost of the Observatory would be small, with core funding for the resources described, and support for travel to key meetings and strategically selected conferences, for an initial three years, when a review would be undertaken. Support in kind would be welcomed, provided it did not impinge on the Observatory’s independence, and its responsibility to consider all counties equally. The Observatory would be active, with relevant contacts, in exploring other funding sources, not least issue- and topic-specific ones. These would include not only Commission sources, but (among others) COST and ESF programmes and charitable benefactors.

Networks

A key function of the Observatory would be to stimulate topic-specific networks, which would be largely self-governing as regards their technical work. Broad models are the European Child Safety Alliance and their projects and programmes, and COST networks.

Examples of new networks which might emerge are:

- Data Pooling/Harmonisation, encouraging national child public health data centres to harmonise definitions, collate sub-national data, and extend the data collected to subjects recommended by the CHILD, ENHIS (Environment and Health Information System), and other projects, with an understanding that there would be mutual sharing of published data to enable comparisons, and a degree of shared European analysis (building in part on RICHE WP2). The UK has pioneered a child health and maternity intelligence network which might act as a model for other EU countries – see http://www.chimat.org.uk.
- The Cohort Study coordination function to be recommended by our sister FP7 project - CHICOS which developed a Child Cohort Research Strategy for Europe
- Development of methodologies to listen to younger children’s voices
- Children’s Health Advisory Panel network, building on the work of the European Patient’s Forum (EPF), and other similar experience
- Electronic record and child minimum data set network to pool experience and harmonisation to enable big data functions
- Quality in children’s healthcare network, covering all aspects of child health services, not just hospitals.

Such networks, once established, would be largely self-managing, but would be strengthened by inter-network linkages, not least on issues such as data definitions, or mutual sharing of methods or evidence. The Observatory would also welcome links with other specific networks, such as the European Commission cross-DG group in child health issues and the EPHA-led Child Health Working Group, and would welcome creative relationships on child health with other initiatives such as the European Health Systems Observatory.

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