

# Child's right and the environment – The need for a complete picture of the environment and health

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100 000 deaths and 6 million disability-adjusted life year (DALYs) in the European Region were attributable to five main environmental risk factors in children (outdoor air pollution – indoor air pollution – water, sanitation, and hygiene – lead – injury) (1). This is one of the unique reports with good environmental burden of disease estimates for major child health outcomes. However this report dates back from 2001 and was able to focus on only a few selected exposures. Since then very few studies have been able to compile comprehensive environmental data relevant for children and their future.

## Summary

In this written contribution, we want to emphasize the importance of linking environmental information to extensive databases of health, educational and income data that exist in many countries and that provide vast amounts of information on the cheap — as long as people consent to their use. Our contribution will feed into the **Working Group 1 – Children's exposure to environmental toxicants**.

Two recommendations are made to the UN committee (see also in annexes):

1. The right to know: State, province and local councils should allow data linkage and storage between children health outcomes and their environment while ensuring data protection. We recommend a more systematically approach of data linkage between the public health and curative health sector.
2. The right to be well represented in research, even children from minor ethnic groups, with parents with poor education or living in remote areas. Allocate funding in order to engage population at large to participate to ongoing research and programmes on environmental health.

Collecting and aggregating data on child's environment is now more than ever possible due to the existence of large data sources in the hands of national and local agencies and recent tools developed by environmental health researchers. These environmental data can be linked

to the health outcomes of children and used to prioritize public health and environmental policies with children in mind. These data can also be made available to target policies to the most vulnerable children. Engaging children and their parents in research is crucial for improving data collection and awareness. We will focus mainly on examples and ongoing work in European countries.

### **A. Filling the knowledge gap on the link between the environment and health in children**

Often, environmental data needed to understand disease origins are missing, giving rise to uncertain health risk and impact assessments. Major environmental harms such as ambient air pollution, environmental tobacco smoke, water and food contaminants, noise, pesticides and ultraviolet (UV) light may lead to serious, chronic pathologies with large societal and economic costs, especially when exposure occurs during critical periods of development in pregnancy or early life. Special susceptibility to environmental exposures during these critical windows of development requires special protection through public health action and environmental legislation. However, many associations between early-life exposures and health remain poorly characterised, important reasons being: 1) the lack of **comprehensive data** on exposure from multiple sources in early life and 2) the lack of **integration of information** on multiple environmental exposures to estimate burden on health.

Recent advances in exposure assessment, molecular biology and statistics allowed to measure the **totality of human environmental exposures** (i.e. non-genetic). In the environment, we encompass the social, physical and chemical environment from conception onwards, a concept proposed as the “**exposome**”. The key focus of the exposome is to improve and integrate currently scattered exposure data and moving towards a multiple exposure approach to understand origins of disease. An important challenge in the use of data is the **link between the data from different sources**. Environment, health, social data are not integrated. We know that poorer neighbourhoods have a greater burden of disease due to exposures. But we do not know how much this is influenced by others factors from other domains such as the **social domain**.

The exposome framework and different levels are presented in Table 1 along with sources of data available specifically for children. Children environmental exposures can be defined at the individual level up to the **molecular level**, with recent European initiatives to coordinate population biomonitoring and study of groups of chemicals instead of unique exposures (2–5). Public health perspective on the added values of molecular markers (e.g. markers of past adverse exposures during critical periods such as pregnancy and childhood) as part of personalised medicine could be of great importance in the future. At the **community level**, data on outdoor exposures can be found from remote sensors for example, up to **global** exposures such as governmental policies on substance ban or economic crises (see also report on the social exposome (6)).

Understanding the impact of environmental harm in children, in particular to chemicals, require **robust human exposure data**. Chemical risk assessments often use results from animal studies to translate the degree of toxicity of a chemical to human health. Data on actual human exposure for hazard identification (from monitoring in biological samples) are often lacking or uncertain. Reduction in uncertainty requires feeding the toxicological results with **real world** human exposures. Efforts from European projects such as COPHES are recognised and

provided the first representative population-based human biomonitoring database (2). Risk assessment of outdoor exposures such as air pollutants or noise, which are based mainly on epidemiological studies, have large uncertainties in the characterization of personal exposure.

Finally, **exposures are not fixed** and may change throughout life stages or have an impact only years after the exposure occurred. In order to link environmental harm to children health and development, longitudinal data are needed to prove causation. Collected data should allow individual information on exposures, behaviours and health to be linked on the same subjects followed throughout time. Children may be exposed to harmful chemicals before being born, in the womb, then the exposure ceases during childhood but have noticeable consequences only at puberty.

**Table 1. Concept framework of the “exposome”: multiple levels of potential environmental exposures**

Levels of measurement	Sub-levels	Potential exposures	Potential data sources
<b>Individual</b>	Molecular	<ul style="list-style-type: none"> <li>- Toxic chemicals (e.g. lead, flame retardants, pesticides,...) that can be measured in biological samples indicative of internal exposure</li> <li>- Genetic damage (following radioactive exposures)</li> <li>- Biological responses to toxic exposures from smaller molecules (metabolomics), to larger molecules (proteome) and genetic products (transcriptomics and epigenomics).</li> <li>- Gut and skin microbiome (families of bacteria composing the natural flora)</li> </ul>	International database: Information Platform for Chemical Monitoring (IPChem), National public health agencies such as Canadian Health Measures Survey (CHMS), US Centers for Disease Control and Prevention (CDC) National Health and Nutrition Examination Survey (NHANES), population based research funded by EU: COPHES or HELIX
	Body	<ul style="list-style-type: none"> <li>- Medical history</li> <li>- Infections</li> <li>- Injuries</li> </ul>	Physical examinations, participant self-report, health registries, electronic medical records
	Social and physical environment	<ul style="list-style-type: none"> <li>- Socio-demographic factors such as age, education level of parents, ethnicity, poverty</li> <li>- Lifestyle, health behaviour (i.e. physical activity, diet)</li> <li>- Environmental tobacco smoke</li> <li>- Indoor air pollution ( e.g. solid fuel use)</li> <li>- Water sources and consumption patterns</li> <li>- Household allergens (e.g. pet, mould, ...)</li> </ul>	Participant self-report, Official sources of data (e.g. U.S. Census Bureau) Population-based survey (e.g. CDC’s Behavioural Risk Factor Surveillance System)
<b>Local, community</b>	Social capital	Access to schools, health services; Area-wide poverty;	Data from community organizations and federal databases, original research

	Physical “Outdoor” environment	<ul style="list-style-type: none"> <li>- Noise</li> <li>- Air pollution</li> <li>- Traffic</li> <li>- Meteo/UV light</li> <li>- Building density</li> <li>- Connectivity</li> <li>- Population Density</li> <li>- Access to Green Space and recreational area</li> <li>- Facilities: point of interest, access to health food</li> <li>Public transport access</li> </ul>	<p>Open source data such as OpenStreetMap</p> <p>Official data from municipalities (for noise), European Environment Agency, EPA air monitoring network</p> <p>Existing research projects such as ESCAPE for air pollution, HIWATE for water quality</p>
Global	Global forces	Immigration, urbanization, industrialization (or industrial decline), climate change, human trafficking, war, pandemic disease	Studies from OECD, WHO and other international governance agencies, transnational NGOs such as OXFAM and Greenpeace, Census data showing historical patterns of residential mobility
	Government policies	Environmental legislation and banned substances, Patterns of economic investment, prevention strategies	Budgetary priorities (e.g., relative spending on defence or health); State or county level rankings of community or environmental health (e.g., Robert Wood Johnson Foundations’ County Health Rankings, National Conference of Environmental Legislators)

## **B. Children's right to know while ensuring data protection**

Public concerns surround secondary use of personal data by researchers, confidentiality breaches, lack of public awareness, misuse of personal data by companies, etc... Solutions such as the creation of safe havens where data can be analysed but not extracted or re-identification of medical records from GPs, hospitals and other sources should be created. The recent reform of the EU's Data Protection Directive was designed to ensure that people have more effective control over their personal data. This should give the right to parents and children to access their environmental exposure information with their medical files when needed.

Confidentiality regarding children's data is very important since disclosure of information can put the children and their rights at risk. The kind of information provided to children and their parents should protect children's feelings. Particular precaution should be given when communicating about exposures that have irreversible lifelong consequences. Certain exposures can be modifiable through lifestyle management (e.g. mercury and fish consumption) whereas other will need local council or state actions (air and water management) or temporary solutions might be found. Parents and children have the right to know in order to take appropriate actions. Researchers and carers also have to achieve a balance between the parent's right to know and the child's right to privacy.

## **C. Engaging children and parents**

Engagement in research and civil activities around the topic of environmental health impact of children and parents is crucial to monitor harmful exposures in the population, to raise their awareness and improve environmental policies. However, people lives are getting busier and parents' minds are getting more and more solicited. New engagement methods should be sought.

Monitoring of children's environments and impact on their health is traditionally done through public funded projects and surveys. Birth-cohort studies for example are important to reveal associations between factors early in life, such as poverty or a mother's diet in pregnancy, and outcomes later on, ranging from diseases to cognition and earnings. For research findings to be translated into improved policy at the city or country levels, the population should be represented at large. Children of all types of backgrounds have the right to be represented in such environmental health research. However, researchers currently face difficulties to engage the parents and adolescents into environmental health research. For example, an ambitious study that had planned to collect information on 80,000 British babies throughout their lives ended just 8 months after its official launch because not enough prospective parents signed up and consumed \$13.8 million (7).

Two solutions exist: scientists can exploit existing data sources more, as we detailed in Section A Table 1, and also invest in following up existing cohorts that were successful at engaging their participants. European projects were successful at pooling such studies into larger cohorts of up 32,000 children with information from conception to adolescence, (see HELIX study <http://www.projecthelix.eu/>). The second solution is to invest funds in innovative ways to engage the parents and children through mobile phone applications for example,

where they could record environmental and mobility data that would be used by researchers to feedback information to the participants. The private sector such as google and environmental scientists may play a role in combining their knowledge and building capacities to provide such platforms.

By improving engagement of parents and children and education on the health impact of their environment they will be better equipped to make decision about protective actions and risk benefit trade-offs. The current evaluation and assessment of environmental policies affecting adults and children cannot take into account parents believes about what is the best trade-off. Children do not have command over financial resources and may not understand the trade-offs involved. However, we can instead ask parents to value risks on their children's behalf. Adults may be willing to pay more to alleviate environmentally-related health risks to children than to themselves. By improving understanding of environmental harm and valuation of health risk, governments can promote more cost-effective allocation of local and state environmental protection resources.

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## Annexes:

## Recommendations

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## **RECOMMENDATIONS**

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**1. The right to know: State, province and local councils should allow data linkage and storage between children health outcomes and their environment while ensuring data protection.**

We recommend a more systematic approach for data linkage between the public health and curative health sector. For example, information on environmental exposures (at large see the different levels in Table 1 in main document) can be found in governmental databases and can be linked to remote sensor for air pollution or water sources and linked to disease outbreaks or long term impacts. These data should also be available at the individual level through medical records.

Child's right to privacy and protection from research results should be carefully considered before recruitment and release of the results. The UNICEF recently released a charter found here <http://childethics.com/>. In addition, national ethical committee will have specific requirements.

**2. The right to be well represented in research: Allocate funding in order to engage population at large to participate to ongoing research and programmes on environmental health.**

Recruitment for public health research is difficult, a challenge intensified by the remit to include a substantial proportion of families from ethnic-minority and disadvantaged groups, who have historically been particularly hard to recruit. State incentives should help engage children in schools and parents in order to provide a larger samples of the population and



provide a representative sample of the population. This is essential for policy translation and to not leave the most vulnerable children behind.