



**A map of health research undertaken  
on children in Ireland:  
January 2000 to mid-November 2008**

**Findings from a systematic examination  
of peer-reviewed journal publications**





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OFFICE OF THE MINISTER FOR CHILDREN AND YOUTH AFFAIRS



**About the authors:**

Study design was by **Dr. Anne McCarthy** of the Child Health Epidemiology Division, Health Research Board (HRB), Dublin, who also drafted the report. **Sinead Foran**, also of the HRB, expanded the study research strategy, carried out the main part of the data collection, and the coding and development of the data collection manual. The database and associated information arising from this work can be accessed in full at [www.childrensdatabase.ie/Irish-child-health-database/](http://www.childrensdatabase.ie/Irish-child-health-database/)

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# Executive Summary

This report presents a summary of the published journal peer-reviewed health-related literature on children in the island of Ireland for the period January 2000 to mid-November 2008. The database and associated information arising from this work can be accessed in full at the website [www.childrensdatabase.ie/Irish-child-health-database/](http://www.childrensdatabase.ie/Irish-child-health-database/).

A total of 5,516 papers were identified from the bibliographic databases of MEDLINE, PsycINFO, SocINDEX, CINAHL, EMBASE and ScienceDirect, in response to the search criteria using the keywords 'Neonate', 'Infant', 'Child' or 'Children', and 'Ireland' or 'Irish'. The study inclusion/exclusion criteria identified 3,229 papers eligible for inclusion in the study. Papers were indexed according to: paper type (study article or other commentary); study nature (i.e. the nature of the study – analytical or descriptive); study type; topic area, classified to International Classification of Diseases (ICD-10), International Classification of Diseases for Oncology, 3rd edition (ICD-O-3) or themed and grouped under 23 health categories where these outcomes were not classifiable by ICD-10 or ICD-O-3; and specific demographic characteristics, including person type, population type and population geographical region.

There were 2,156 papers reporting study findings on over 1,200 individual health-related outcomes. The remaining articles represented varying classes of discussion paper. Studies were indexed according to recognised international definitions as one of the following: randomised controlled trial; studies on the sensitivity and specificity of a measurement tool; audit; case control study; case report; case series study; case study; cohort study; comparison study; cross-sectional study; economic study; epidemiology studies on incidence, prevalence and/or trends; intervention study; legal notes; longitudinal study; other study type, mainly related to the effectiveness of measurement tools; qualitative studies, including those of an anthropological and ethnographic nature; screening study; studies on the practice/knowledge of professionals or parents; surveillance study; and validation study.

Studies reported findings on four broad population types:

- hospital population (mother and child);
- hospital population (children and adults);
- school population;
- 'population other', a heterogeneous category consisting of:
  - children other than children attending hospital or special clinic – children with an intellectual disability, athletic, healthy purposeful sampled children, offspring of opium users, victims of sexual abuse;
  - families of children with a genetic condition or disability – consisting of triads (mother, father, child groups) and the index or proband case (i.e. the child with the outcome of interest). The most common conditions reported were attention hyperactive deficit disorder, autism and neural tube defects;
  - health professionals – medical doctors, surgeons, physicians, psychiatrists, general practitioners, nurses, midwives, public health nurses, other healthcare workers, psychologists;
  - other professionals – teachers, social workers;
  - other person – perpetrators of sexual abuse.

The studies represented populations from the following geographical spread: the Republic of Ireland (60%); Northern Ireland (23%); Northern Ireland and the Republic of Ireland (0.7%); Republic of Ireland and the United Kingdom (6%); the United Kingdom inclusive of Northern Ireland (3%); and international (7%).



Meta-analysis and systematic reviews of specific topic areas are the methodologies frequently employed to summarise current knowledge on specific areas of health, healthcare and health-related interventions. However, mapping the nature of research for a defined population demographic for an entire geo-political entity has not, to the knowledge of the authors, been previously undertaken. Therefore, the findings from this project represent a unique insight into the contemporary nature of child health-related research on the island of Ireland and cover almost a decade of such work. Unexpected findings included identification of a more heterogeneous population group examined in relation to child health research than hitherto anticipated, with children comprising just over 50% of the studied subjects included in this work.

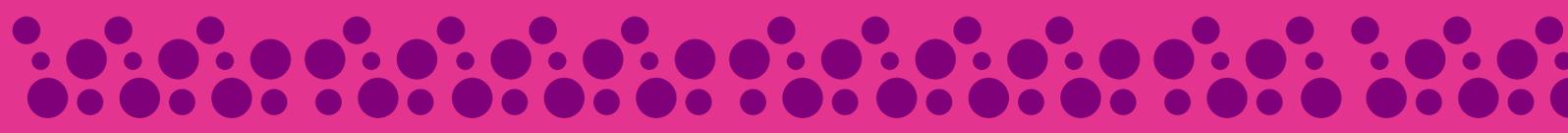
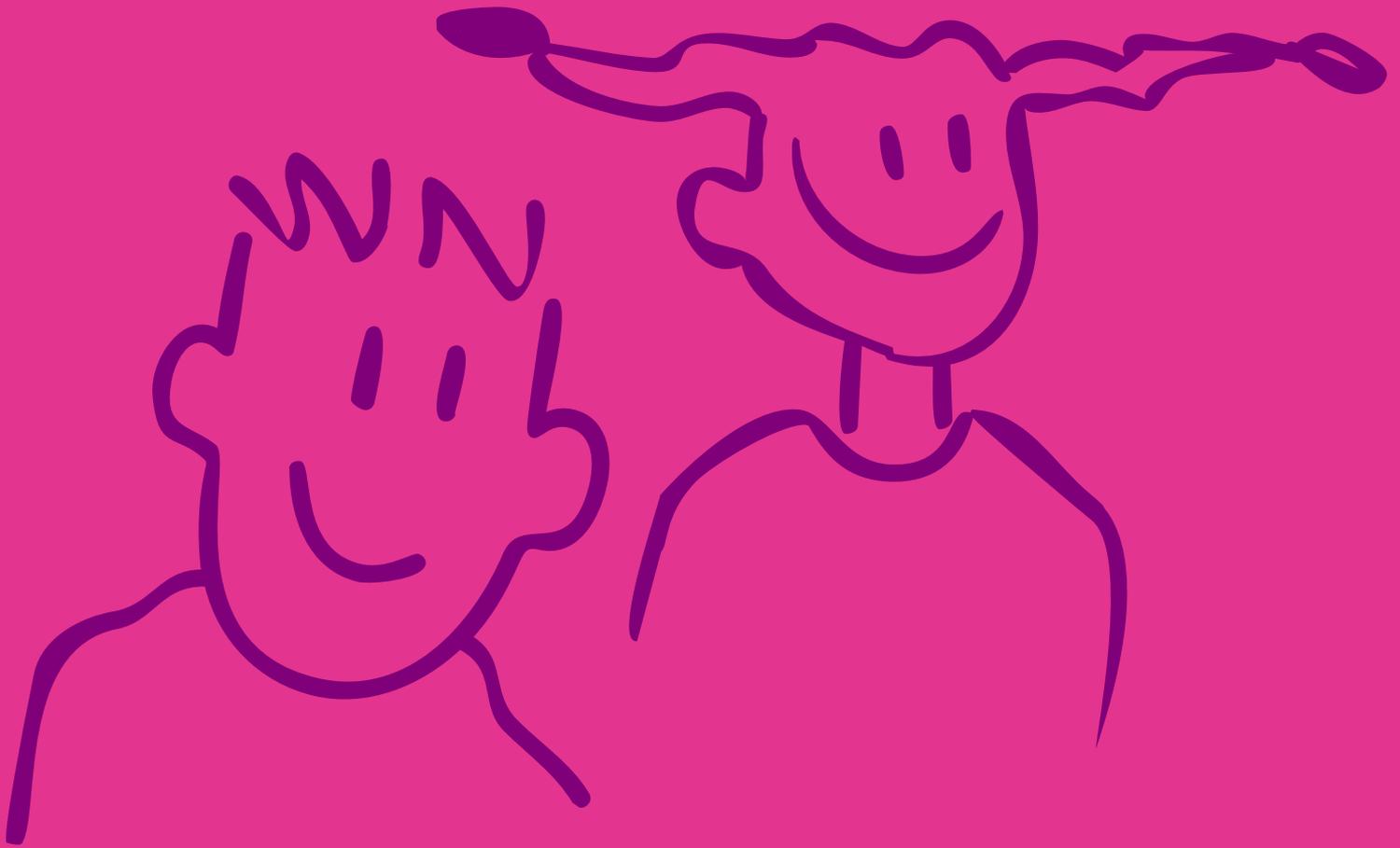
To allow a methodological assessment of the nature of studies, background and definitions are provided on research study types, indexing and classifications systems. The evolutionary nature of research reflecting epidemiological transitions is discussed. Recommendations to achieve more sophisticated and dynamic mapping of health research on children in Ireland are made. The place of research, as a complement to the collection of routine health-related data, is contextualised.

The findings of this report and the database developed from the project provide a rich setting from which to develop clearly stated scientific questions in the area of child health research. It is hoped that the results will be of benefit in developing further work in this area.



# 1

## Background to study



## Routine methods of measuring child health

The factors that influence childhood health and development are diverse and reflect genetic composition (Weedon *et al*, 2005), intergenerational, intrauterine (Davey-Smith *et al*, 2007) and early life exposures (Fraser *et al*, 2008). The family–social milieu (Reading and Allen, 1997), political, health and educational structures, together with factors from wider spheres of influences, such as climate conditions (McFarlane, 2010; Morris, 2010), also determine health. Data from international and national population censi and vital statistics databases, stratified by an array of demographic, political and socio-economic factors, provide cross-sectional views on health outcomes by the determinants of health. These health determinants are represented by various indicators of age, sex, socio-economic position, geographical distribution and ethnicity. The sensitivity and specificity (i.e. the precision or accuracy of each factor to measure health) varies according to the indicator selected and the demographics of the population being examined. Publications of trends from these data sources provide information on the effectiveness of political and social policy by measuring secular changes in population health over time (Eurostat, 2009; UNICEF, 2010).

However, the secular changes in health outcomes reported from population censi and survey data are not normally able to illuminate disease aetiology (causality) or changes in the health profile of new, emerging minority groups; neither can they examine the effectiveness of new health technologies. Research studies, with specifically stated, scientifically based questions or hypotheses, are required to understand health-related issues less readily answered by routine data sources.

Research studies are frequently commissioned and often driven by the requests of national governments or advocacy groups. They are commonly descriptive in nature and serve to characterise a specific aspect of, or report on statistical measures of, health not available from routine data sources. Investigator-led research may be more idiosyncratic and focused on disease aetiology. However, in practice, the distinctions between these two types of research are not so clear and there exists varying degrees of overlap between characterising and measuring a health-related outcome and exploring its aetiology.

## Time points and time ranges employed in research-based measures of health

Research studies can be cross-sectional, comparative or longitudinal in nature. *Cross-sectional studies*, descriptive in nature, provide a snapshot of current patterns and statistical measures of disease, but are unable to address issues of aetiology. *Comparison studies*, which may also be cross-sectional in nature, allow examination of the magnitude of the statistical measure of health in one population in contrast to another population, with comparators such as gender, ethnicity, geography and time enabling evaluation of the effect of geo-social-political influences. *Longitudinal studies* examine the same population over time and, in this manner, facilitate our understanding of individual-level disease progression through elimination of time or national socio-economic cohort effects.

The plotting of data from repeated cross-sectional studies illustrates trends in population health and disease patterns (McCarthy and Kirke, 2010). Comparison studies provide data on equalities in health between the populations examined with regard to the health determinant of interest. Case control studies, a specific form of comparative study, can illuminate issues of disease aetiology, while longitudinal studies provide information on individual-level trajectories of growth and development, and identify hypotheses regarding determinants of health and disease.



## Frameworks for child health research

There are several frameworks for the effective organisation of child health research. The epidemiological transition (Omran, 1971) has shifted the major emphasis in understanding disease and health from a germ-based approach, and its associated health interventions, to a focus that includes the examination of a range of biological adaptation processes and over longer time periods (Kuh *et al*, 2003). These focuses range from a biochemical approach to understanding metabolic pathways and cycles, across a genetic approach to understanding the differences between heredity and embryology (Morange, 1998), to the much wider framework of examining health in a social context. A life course approach has been offered as an optimum way of seeking to understand health outcomes by offering an interdisciplinary framework for guiding and structuring research on health, human development and ageing (Kuh, 2002). It is the study of health and its inverse, disease, by considering the long- and the short-term effects of environmental exposures at each stage of development – intrauterine, early childhood, adolescence, young adulthood and later adult life (Kuh, 2004; Ben-Shlomo and Kuh, 2002). That this 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.

The relatively recent shift from a medical approach to understanding health (an approach dominated by an adult model of risk assessment) to a multidisciplinary life course perspective reflects appreciation of the complex iterative process whereby individual development is modified and moulded by external stimuli (Odling-Smee *et al*, 2003), the latent period that may exist between exposure and disease, and an understanding of the cumulative effect of repeated exposures on health and disease. Moreover, knowledge that the seeds of much of adult health are determined in early life is premised on clear biologically based hypotheses. It also understands that health is not simply the absence of disease, but is complete physical, social and mental well-being.

One framework by which a life course approach to health can be structured centres on recent work from the field of epidemiology, a discipline which has formalised biologically plausible, hypotheses-driven conceptual models to understand trends in secular diseases and inequalities in health. These conceptual models, illustrated in Figure 1, examine the causal pathway of disease in relation to time (purple), the timing of the causal action (blue) and mechanisms of change (green). There is evidence from the biological sciences that the plasticity of cells and organs in early life makes the intrauterine, infant and early stages of life particularly amenable to influence, with some periods of exposure likely to be of greater aetiological importance than others. The models illustrate these factors by showing the extent to which events help or harm health, the extent to which these effects may be modified, the reliance on the timing on the causal pathway, and the timing of the causal action and the mechanism. The varying effects of time, magnitude, duration and aetiology apply similarly to development of physical, emotional and mental health.

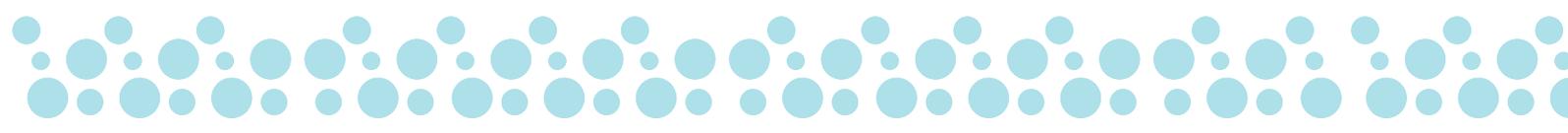


Figure 1: Life course conceptual models of health development (adapted from Ben-Shlomo and Kuh, 2002)



## Defining and classifying health and health-related research

The World Health Organization states that ‘*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*’ (WHO, 1946). However, the shift from what is essentially a philosophical concept of health to developing a logical framework to measure and describe health and health-related research requires the use of precise and valid measurement tools. A range of systems exist by which health outcomes are indexed. The ability of each system to measure what it seeks to measure varies in terms of accuracy, precision, validity, reliability, repeatability and reproducibility. Economic costs, acceptable trade-offs (sensitivity *versus* specificity) and issues of comparability are all determining factors in choosing an indexing system. The tools required to effect good and comparable indexing methods include employment of thesauruses, taxonomies and classification systems. A range of study designs or study types exist by which health-related research can be defined. The ability of each study type to measure what it seeks to measure and to infer from the study findings varies according to the nature of the study population and the presence, or not, of a comparable group.

### Thesauruses, taxonomies and classifications

Thesauruses reduce the ambiguity inherent in normal human languages by using predefined vocabularies. Bibliographic databases of peer-reviewed journal articles use specific named thesauruses to address problems of homographs, synonyms and polysemes to achieve bijection (a process where every term can be mapped to another and no unmapped term exists) between concepts and authorised terms.

Taxonomy is the practice and science of classification. It allows classification of the factor of interest in a hierarchical structure, with the relationship typically ranked in a supertype-subtype manner. The ordered ranking into appropriate categories is made based on the relationship between the factors of interest. Thus, the nature of the relationship between two factors of interest determines the taxonomy of choice. Most commonly, taxonomy is an empirical science, relying solely on practical experience and classifying only at the final step of the process.

Classifications use ‘*an exhaustive set of mutually exclusive categories which aggregate data at a pre-prescribed level of specialization for a specific purpose*’ and cluster factors of interest according to logical rules (Madden *et al*, 2008). Ideally, a classification should be characterised by (1) *naturalness*: the classes correspond to the nature of the thing being classified; (2) *exhaustiveness*: every member of the group is fitted into one (and one only) class in the system; (3) *usefulness*: the classification is practical; (4) *simplicity*: the subclasses are not excessive; and (5) *constructability*: the set of classes can be constructed by a demonstrably systematic procedure.

The use of each of these methods of defining and classifying health provides a way to organise knowledge for subsequent retrieval.

### Study design

Study designs broadly consist of two types – comparative studies and descriptive studies. Studies with a comparative dimension illuminate differences between population groups – for the factor or health-related outcome of interest – according to the characteristics of interest. However, unless confounding is adequately controlled for, alternative explanations for the observed relationship are possible, and are often likely. (Confounding is the presence of an extraneous variable in a statistical model that correlates (positively or negatively) with both the outcome of interest and the factor under examination. Such a variable may, potentially, be the true causal factor in the relationship being examined.) Descriptive studies measure one or more characteristics of a study population, including statistical measures of health. A range of comparative and descriptive study types exist (*see Table 3*). Key features of the major study designs are described below.



**Case control studies** select their index cases by disease status and match with a control. They can therefore examine only one disease, but many risk factors. This approach is optimal for rare diseases or diseases that take a long time to develop, and allows the examination of a smaller sample size than that required for a cohort study. If well-balanced and equally matched, case control studies can also evaluate confounding and interaction in a reasonably persistent manner. They are also very suitable for transient risk factors, such as infectious diseases. However, because individuals with the disease are recruited to the study, case control studies cannot measure the chance of disease (incidence or prevalence).

**Cohort studies** follow a group of defined individuals over time to record the instance of disease and thus measure incidence. Their strength lies in their ability to identify the order of happenings. Cohort studies consist of an initially disease-free population and they mimic the condition of an intervention study by providing observation of two groups – those exposed to, or with, the factor of interest and those without. However, since they are neither assigned (i.e. randomly allocated) or match with a control, there may be systematic differences between those with and without the factor of interest over and above that of the exposure being examined. Thus confounding is not controlled for and is often a problem. Well-executed case control studies and cohort studies are the optimum method by which to evaluate disease aetiology.

**Comparison studies** allow statistical measures of health-related outcomes to be compared between groups. They measure equality between populations. However, as known and unknown confounding factors are not controlled for, they are unable to identify specific causes of aetiology. Nevertheless, such studies can provide evidence for hypothesis generation and a more scientific evaluation of differences and the reasons for these differences between groups.

**Case reports** describe interesting or unusual occurrence of disease and may form the bases for the generation of hypotheses. However, as they frequently reflect rare or unusual events and, as such, are anecdotal findings, extrapolations from these findings with regard to the general population should not be made.

**Case series studies** allow examination of the effect of treatment, but due to the nature of selection, they are frequently confounding by selection bias. In addition, the population represents a hospital and not the general population.

**Cross-sectional studies**, the simplest form of observation study, provide a snapshot of risk factors, exposure and disease status. They measure only the prevalence of disease. They add to the collection of routine data by allowing collection of data of specific interest and the linking of data items person by person. They are most useful as descriptive studies. Issues of sampling and compliance must be considered, and random sampling is required to protect against various biases.

**Randomised controlled trials** evaluate situations of clinical equipoise and assess the effectiveness of medical procedures and treatments by effectively eliminating confounding, thereby allowing unbiased estimates of effect to be calculated.

The essential characteristic of an **intervention study** is that the investigators assign the ‘treatment’ and observe what happens prospectively. The allocation can be manipulated so the groups are comparable, thus seeking to take account of problems of confounding. However, only randomisation can effectively deal with confounding and interventions studies may suffer from investigator bias.

## Some major classifications systems and thesauruses

The list of health-related classification systems and thesauruses is extensive. However, for the purpose of this study, a subset of these indexing systems is presented here, either the most commonly employed in the coding of the retrieved published health-related research or the most appropriate for use in classifying the data in this study. The *World Health Organization Family of International Classifications* (Madden *et al*, 2008) currently consists of two ‘reference classifications’ – the International Classification of Diseases (ICD) and



the International Classification of Functioning Disability and Health (ICF). The ICD-10 consists of 22 blocks of three-digit rubric, each of which is further stratified into four-digit rubric. It is a coding of diseases and signs, symptoms, abnormal findings, complaints, social circumstances and external causes of injury or diseases, as classified by the WHO. It has more than 12,420 different codes and permits tracking of many new diagnoses and procedures, significantly expanding on the 6,969 codes available in the ICD-9.

In addition to these reference classifications, there exists a set of six 'derived classifications'. One of these, the International Classification of Diseases for Oncology, 3rd edition (ICD-O-3), is a multi-axial classification of the site, morphology, behaviour and grading of neoplasms. The topography axis uses the ICD-10 classification of malignant neoplasms (except those categories which relate to secondary neoplasms and to specified morphological types of tumours) for all types of tumours, thereby providing greater site detail for non-malignant tumours than is provided in the ICD-10. In contrast to the ICD-10, the ICD-O-3 includes topography for sites of haematopoietic and reticuloendothelial tumours. The morphology axis provides five-digit codes ranging from M-8000/0 to M-9989/3. The first four digits indicate the specific histological term. The fifth digit after the slash (/) is the behaviour code, which indicates whether a tumour is malignant, benign, in situ or uncertain (whether benign or malignant). A separate one-digit code is also provided for histological grading (differentiation). Electronic versions of the ICD-10 and the ICD-O-3 are available on the WHO website (see [www.who.int/classifications/en/](http://www.who.int/classifications/en/)).

The Medical Subject Headings (MeSH<sup>®</sup>) is a comprehensive controlled vocabulary for the purpose of indexing journal articles and books in the life sciences; it also serves as a thesaurus that facilitates searching (see [www.nlm.nih.gov/mesh/](http://www.nlm.nih.gov/mesh/)). Created and updated by the United States National Library of Medicine (NLM), it is used by the MEDLINE/PubMed article database and by NLM's catalogue of book holdings. The 2009 version of MeSH contains a total of 25,186 subject headings, also known as descriptors. Most of these are accompanied by a short description or definition, links to related descriptors and a list of synonyms or very similar terms (known as entry terms).

The thesaurus of Psychological Index Terms (PsycINFO<sup>®</sup>) is a database of abstracts of literature in the field of psychology (see [www.apa.org/pubs/databases/psycinfo/index.aspx](http://www.apa.org/pubs/databases/psycinfo/index.aspx)). It is produced by the American Psychological Association. The 11th edition contains more than 8,400 controlled terms and cross-references, which are arranged in hierarchical, alphabetical and by subject arrangements. The records are indexed with the most specific applicable terms. Major and minor terms are assigned, with a maximum of 15 total terms. It has 22 major categories and 135 subcategories. Each record is assigned to one or two classifications.

The Cumulative Index to Nursing and Allied Health Literature (CINAHL<sup>®</sup>) is an index of English-language and selected other-language journal articles about nursing, allied health, biomedicine and healthcare (see [www.ebscohost.com/cinahl/](http://www.ebscohost.com/cinahl/)). These subject headings were developed to reflect the terminology used by nursing and the allied health professionals. CINAHL subject headings follow the structure of the Medical Subject Headings (MeSH) used by the US National Library of Medicine. This structure has been used to develop 12,714 CINAHL subject headings.

## Limitations to understanding health-related research through the classification of health-related outcomes

Classifications facilitate data comparison on health outcomes within and between populations, but provide only limited information on health determinants, a major area of interest when seeking to understand and index health-related research. At a high level of aggregation, health determinants can be grouped under four main factors: socio-economic factors, environmental factors, health behaviours or practices factors, and biomedical and genetic factors. The specific indicator employed in quantifying the health determinants of interest differs according to the required levels of sensitivity and specificity. For example, when reporting



on inter-country population health, taking account of socio-economic status, gross measures such as Gross National Income (GNI) per capita or debt services can be employed to report on the relationship between socio-economic status and health status at a national level. However, when reporting on intra-country population health, more sensitive measures are required, with individual-level outcomes reported stratified by an occupation, or educational, measure of socio-economic position. However, currently it appears that only nationally representative measures of some health determinants (such as socio-economic position) exist. This limits the ability to classify these indicators in a manner that facilitates international comparison.

## Identifying health-related research

The findings from specific hypotheses and scientific-based questions are presented in publications termed 'grey literature' and 'peer-reviewed literature'. Peer-reviewed literature is literature that has undergone the scrutiny of other experts in the same field and is generally – and for the purpose of this study, always – published in national and international scientific journals. Grey literature refers to literature not obtained through conventional channels such as publishers, *'but which is frequently original and usually recent'* (Debachere, 1995). Frequently, but not definitively, journal publications represent findings that have a wider focus of interest, often beyond national boundaries, while grey literature reports findings of a more local significance.

## Aim of study

The aim of this study was to determine the nature and typography of contemporary Irish child health research. The potential areas for examination included:

- examination of data from routine health information systems (e.g. population census, vital statistics, primary care statistics, hospital statistics (the Hospital In-Patient Enquire (HIPE) system) or other registers (such as the cancer register), EUROCAT and the disabilities information systems);
- examination of the grey literature;
- examination of the peer-reviewed papers published in scientific journals.

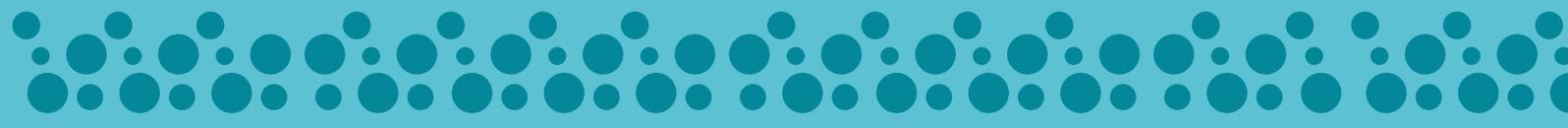
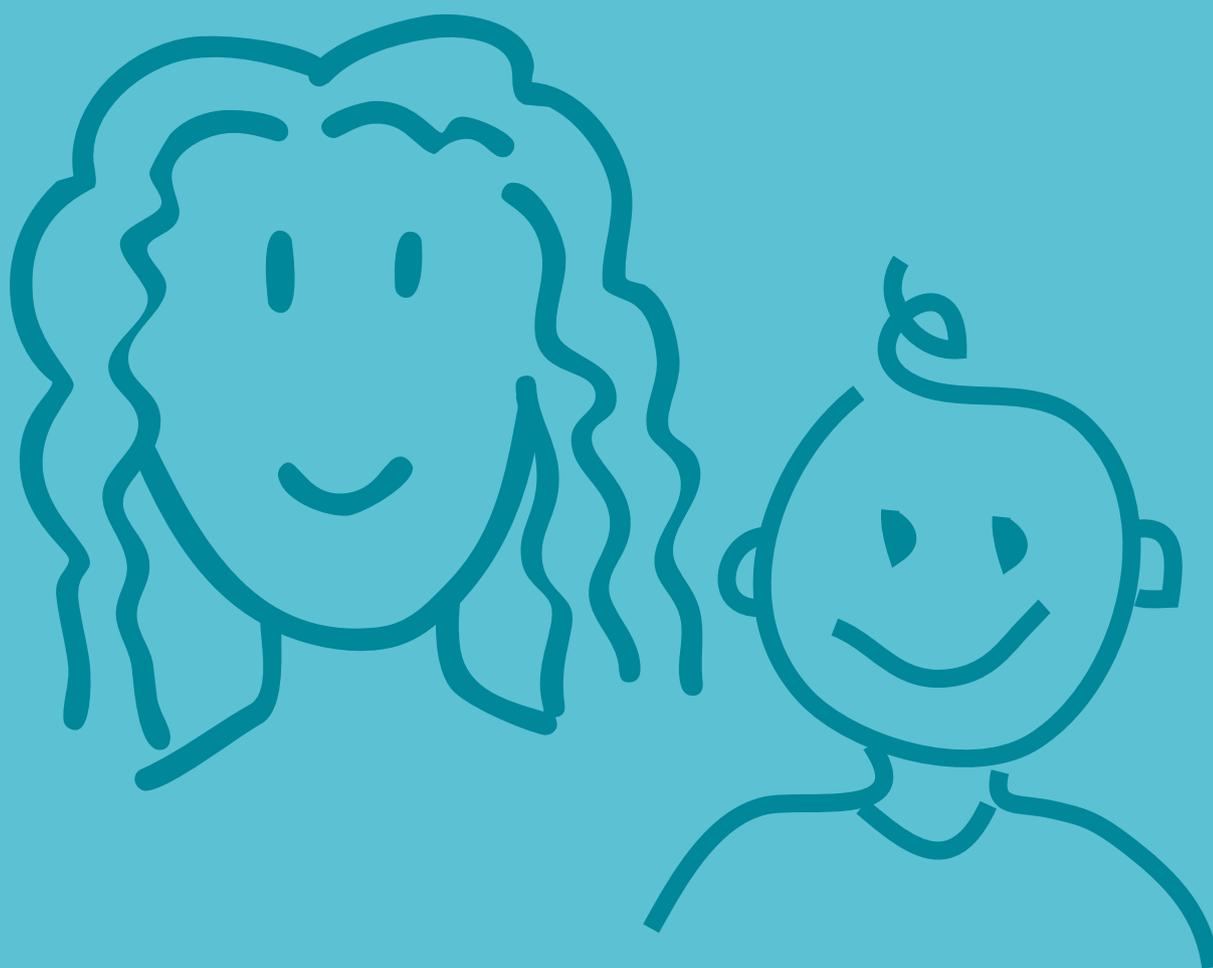
For the purpose of this study, research was defined as work reviewed in bibliographic databases of papers from peer-reviewed scientific journals. The age range for children considered for inclusion in the study spanned the period from conception up to 18 years of age. The time range for which peer-reviewed papers were retrieved spanned the years 2000 to 2008. Initially, the literature review covered work from the Republic of Ireland, but the remit was broadened to cover the island of Ireland. The data from this study, including full references for all of the peer-reviewed literature, are located on the website [www.childrensdatabase.ie/Irish-child-health-database/](http://www.childrensdatabase.ie/Irish-child-health-database/). Tags of the specific characteristics by which these study papers were examined (*see Chapter 3, Results*) are also available on the website and each paper has a short statement (255 alphabetic characters or less) on the aims and objectives of the study or paper. Where possible, the original statement of the paper's author was transcribed. However, for almost 50% of the papers, no clear statement of purpose was made and in these instances, the present authors have drafted a statement summarising the aims and objectives as understood by them.

The present study was undertaken by the Child Health Epidemiology Unit of the Health Research Board, Dublin, in collaboration with the Office of the Minister for Children and Youth Affairs of the Department of Health and Children. This report represents a brief synopsis of the study's findings, an interpretation of these findings and recommendations on areas for consideration when planning health research on children for the future. The full findings of the study can be found on [www.childrensdatabase.ie/Irish-child-health-database/](http://www.childrensdatabase.ie/Irish-child-health-database/).



# 2

## Methods



## Introduction

Six bibliographic databases – MEDLINE, PsycINFO, SocINDEX, CINAHL, EMBASE and ScienceDirect – were searched to identify all published papers associated with health-related research on children in Ireland. Potentially significant papers were downloaded into the management reference package EndNote® and examined for relevance. Abstracts or full papers were screened. The criteria for inclusion or exclusion in the study were refined. Papers deemed eligible for the study were examined to determine:

1. paper type (study article or other commentary);
2. study nature (i.e. the nature of the study – analytical or descriptive);
3. study type (e.g. case report, cross-sectional study, randomised control trial);
4. topic area (classified to ICD-10, ICO-O-3 or themed and grouped under 23 health categories where these outcomes were not classifiable by ICD-10 or ICO-O-3);
5. demographic characteristics, including person type, population type and population geographical region.

## Bibliographic databases

The bibliographic databases, a description of their contents and the specific thesaurus employed by their operating organisation are detailed in Table 1. The six EndNote databases were merged into one and electronically identified duplicates were deleted.

**Table 1: Bibliographic databases of peer-reviewed scientific literature, main content description and thesaurus used in each database**

| DATABASE      | CONTENT DESCRIPTION  | SEARCH ENGINE         | THESAURUS                              |
|---------------|--|-----------------------|--|
| MEDLINE       | Life sciences with a concentration on biomedicine                              | PubMed                | Medical Subject Headings (MeSH)        |
| PsycINFO      | Psychology and related behavioural and social sciences                         | EBSCO                 | Thesaurus of Psychological Index Terms |
| SocINDEX      | Sociology, encompassing all sub-disciplines and closely related areas of study | EBSCO                 | Sociology Thesaurus                    |
| CINAHL        | Nursing and allied health disciplines  | EBSCO                 | CINAHL subject headings                |
| EMBASE        | Biomedicine and pharmacology   | <i>not applicable</i> | EMTREE                                 |
| ScienceDirect | Science, technology and medicine   | <i>not applicable</i> | <i>not applicable</i>                  |

## Study criteria

The criteria for papers included in the study are detailed in Table 2. Papers identified using these criteria, but deemed not eligible for the study, as detailed in the exclusion criteria, were excluded from subsequent analysis.



## Inclusion criteria

**Table 2: Inclusion criteria**

| DESCRIPTOR              | DESCRIPTOR DETAILS   |
|-------------------------|--|
| Databases               | MEDLINE, PsycINFO, SocINDEX, CINAHL, EMBASE, ScienceDirect   |
| Timeframe               | 1st January 2000 to 19th November 2008   |
| Papers                  | Peer-reviewed published journal articles   |
| Search terms*           | 'Neonate', 'Infant', 'Child', 'Children', 'Ireland', 'Irish'   |
| Age group               | Children up to and inclusive of 18 years of age  |
| Geography               | Children studied <i>in</i> Ireland   |
| Other population groups | Parents, health professionals, educationalists or other persons whose knowledge, practice or actions impacted on children's health or well-being |
| Animal studies          | Including conditions that commonly occur in childhood, but where ethical or other considerations prevent or limit human studies                  |
| Other                   | Studies that evaluated the effectiveness and efficiency of procedures utilised in providing healthcare to children                               |

\* The search terms were combined to create a set of citations relevant to the area under investigation using the Boolean logic operators 'AND', 'OR' and 'NOT' with search terms such as 'Ireland AND Neonate', 'Ireland OR Irish AND Child', 'Ireland AND Child OR Children'.

## Exclusion criteria

**Papers tangential to the study:** For example, instances where the search terms yielded papers where medical equipment manufactured in Ireland was cited, or where the first, other author or institution had the word 'Ireland' or 'Irish' in their name.

**Papers on study populations outside of Ireland:** Irish children studied outside of Ireland, such as migrant children or offspring of Irish parents in another country.

**Papers reporting early life exposures and adult outcomes:** Outcomes resulting from early life, childhood or adolescent exposures examined in adulthood.

## Screening, grouping and classifying study papers, study topics and study population

Initially, study papers were divided into one of two sets:

- **Set 1** consisted of papers that discussed aspects of health research on children, but were not individual studies. This set included discussion papers, reviews, commentaries and letters, in addition to a small number of errata or abstracts on conference proceedings..
- **Set 2** consisted of papers reporting research findings. Papers in Set 2 were further stratified into the following groups:
  1. the nature of the study subjects;
  2. research type;
  3. methodology employed;
  4. study type – defined and ranked by strengths and weaknesses of study type;
  5. study topic area;
  6. population characteristics.

1. **The nature of the study subjects** included both humans and animals. Papers reporting findings from animal studies were retained in the electronic database, but not subjected to further analysis in this report.
2. **The research type** was defined as primary or secondary; secondary research reported findings from systematic reviews or meta-analyses. Papers reporting findings from systematic reviews or meta-analysis studies were retained in the electronic database, but not subject to further analysis.
3. **Methodology employed** was defined as analytical or descriptive. Studies adopting an analytical approach posed and tested hypotheses. Studies of a descriptive nature reported the characteristics or the magnitude of the outcome of interest, but did not specifically examine disease aetiology. The descriptive studies were sub-grouped as follows:
  - 3.1 those with a comparative dimension (time, geography, procedure or treatment);
  - 3.2 those without a comparative dimension;
  - 3.3 those measuring aspects of effectiveness;
  - 3.4 those with a health technology dimension (HTA).

**Analytical studies** consisted of case control studies and cohort or longitudinal studies. Case control studies compare two subject groups: cases and controls. They are suitable for generating and testing hypotheses. Ideally, cases and controls are matched for a range of characteristics. However, in practice, this was not observed in all cases. Some studies matched for demographic characteristics, such as age and gender. In other studies, no matching was undertaken. Cohort and longitudinal studies follow up sub-groups of their population to detect difference in outcomes between groups who experience different exposures. However, while cohort studies provide strong evidence regarding disease aetiology, the inability to control for confounding variables limits inference regarding causality.

**Descriptive studies** describe the characteristics of a population without a control group. They are therefore unable to test, but may generate, hypotheses. Descriptive studies with a comparative dimension compare the characteristics of interest in the studied population with findings from populations from a different cultural, geo-political or socio-economic background. Studies measuring aspects of effectiveness describe the characteristics of a population taking account of best practice (as in audit studies), professional or parental knowledge or practice, the effectiveness of the intervention, or the validation of a methodology. Studies with a health technology dimension measure treatments or tests used by those working in the health services to promote health prevention and treat disease.

4. **Study types** were defined using definitions from Last's (1995) *A Dictionary of Epidemiology*. Study type definitions are presented in Table 3. The strengths and weaknesses of the various study types are presented in Table 4. A small number of studies identified in the literature review were not well explained by classic definitions. In these instances, a working definition has been supplied by the authors of this report. Both the classic and working definitions are fully referenced in the table of definitions (*see Table 3*). In the present study, papers were grouped, not classified, by these definitions. Groupings were undertaken under a 'most suitable' rationale, which was subjective in nature and the opinion of the authors.



5. **Study topics**, where possible, were classified according to internationally recognised outcomes of health and disease. Mostly, this consisted of the ICD-10 three- or four-digit rubric. The 22 ICD-10 four-digit rubric blocks are detailed in Table 5. The more detailed four-digit rubrics are presented in the actual tables of results in Chapter 3 of this report.

A range of conditions did not directly map to ICD-10's four-digit rubric, but reflected outcomes best grouped within these classifications. These included conditions under:

O00 – O99 Pregnancy, childbirth and the puerperium.

P00 – P96 Certain conditions originating in the perinatal period.

To allow for differential between the more accurate classification methodology and the less precise 'grouping' under the ICD rubric classifications, these are indicated within the actual tables of results in Chapter 3 as:

□ for actual classifications which directly map the four-digit rubric of ICD-10;

\*\* for 'grouped' classification for which there is not a corresponding four-digit rubric in ICD-10.

A small number of studies were classified to the International Classification of Diseases for Oncology, 3rd edition (ICD-O-3). Table 6 gives examples of the morphology axis of this classification system.

Papers downloaded from the various bibliographic databases are tagged with keywords by the coders of the various databases from which they are retrieved. The original key words assigned by the coders are based on the individual thesaurus used by the specific bibliographic database. These were retained in the study database and serve to identify key factors of the papers. However, there is some variation in the manner of coding differences across the various bibliographic databases. It was decided to group the remaining non-classified outcomes under a range of themed outcomes to aid in understanding the nature of the research. A thematic approach resulted in 23 additional categories. These included health-related outcomes grouped under the following headings: (1) microscopic organisms; (2) immunology; (3) neurology; (4) psychology; (5) sociology; (6) drugs; (7) breastfeeding; (8) deaths; (9) disabilities; (10) health services; (12) organ transplants; (13) syndromes; (14) prematurity; (15) anatomy; (16) growth and development; (17) diet and lifestyle; (18) physical activity; (19) education; (20) dental; (21) biological markers; (22) legal issues; and (23) other.

Because this approach to grouping the outcomes is not reliant on a recognised indexing system, the working definitions of groupings are given in Table 7. This is a subjective grouping, arising from the use of natural language, indexing language and free indexing language, rather than the use of a controlled indexing language from a specified thesaurus. The specific words or terms used by the authors of the original papers were retained and reported in the actual tables of results in Chapter 3, to allow alternative interpretation of the defined grouping as described by the authors of this report.



6. **Population characteristics** consisted of person type, population type and geographical region of the study population.
- The **person type population** consisted of:
    - children-only populations;
    - mother and infant populations;
    - children and adults populations;
    - children, with or without 'Other' population types. The group 'Others' consisted of parents and/or other family members; health, health-related and other professionals working with children; and sex offenders.
  - The **population type population** consisted of:
    - hospital-based populations;
    - community-based populations;
    - schoolchildren populations.
  - The **geographical region population** consisted of:
    - Republic of Ireland;
    - Republic of Ireland and the United Kingdom (including Northern Ireland);
    - Northern Ireland and Republic of Ireland only;
    - Northern Ireland only;
    - United Kingdom (including Northern Ireland);
    - international (Ireland and one or more countries outside of the United Kingdom; these countries were predominantly European);
    - a small number of studies were grouped as United States of America or Scotland, where some aspects of the geographical origins of the population were not clear.

### Research study groups

An additional area of interest in understanding the current picture of child health research, but which is not examined in further detail in this report, was identified from the study papers. This is a list of various research study groups. The identified groups are listed in Appendix 1 of this report under national research groups, research groups of Ireland, the United Kingdom and European and international study groups.



Table 3: Study type definitions (adapted from Last, 1995)

| STUDY TYPE   | DEFINITION   |
|--|--|
| Case control study                                 | Papers reporting observational epidemiological study of persons with the disease (or other outcome variable) of interest and a suitable control (comparison, reference) group of persons without the disease. The relationship of an attribution to the disease is examined by comparing the diseased and non-diseased with regard to how frequently the attribute is present or, if quantitative, the levels of the attribute, in each of the groups.   |
| Cohort and Longitudinal studies                    | Papers reporting an analytical method of epidemiology study in which subsets of a defined population can be defined who are, have been, or in the future may be, exposed or not exposed, or exposed in different degrees, to a factor or factors hypothesised to influence the probability of occurrence of a given disease or other outcome. The main feature of a cohort study is observation of large numbers over a long period (commonly years) with comparison of incidence rates in groups that differ in exposure levels (syn: concurrent, follow-up, incidence, longitudinal, prospective study). For the purpose of this study, papers identified as cohort papers represent cohorts for which the data are not yet representative of longitude analysis. They are, in methodology, cross-sectional in nature. The alternative terms for a cohort study (i.e. follow-up, longitudinal and prospective study) <b>describe the essential feature of the method</b> and report observations of the population for a sufficient number of person-years to generate reliable incidence or mortality rates in the population subsets. This generally implies study of a large population, study for a prolonged period (years), or both. |
| Comparison study                                   | Papers reporting a group with which the statistical measures of the outcomes of interest in the index group are compared with those of an external population. Comparison undertaken in papers reported on in this study included internal and external population group comparisons, over time and across geographical regions.   |
| Epidemiology – incidence, prevalence and/or trends | Papers reporting a specific statistical measure of disease occurrence – incidence, prevalence, or trends of these measures – or (of) other health-related characteristics in human populations. Generally, observations concerned the relationship of disease to basic characteristics, such as age, sex, race, geographical location, occupation and social class. <b>Incidence:</b> The number of instances of illness commencing, or of persons falling ill, during a given period in a specified population. More generally, the number of new events, e.g. new cases of a disease in a defined population, within a specified period of time. <b>Prevalence:</b> The number of events, e.g. instances of a given disease or other condition in a given population at a designated time; sometimes used to mean prevalence rates. When used without qualification, the term usually refers to the situation at a specified point in time (point prevalence). <b>Trends:</b> A long-term movement in an ordered series, e.g. a time series. An essential feature is that the movement, while possibly irregular in the short term, shows movement consistently in the same direction over the long term.                                  |
| Case report  | Papers reporting a case report (in medicine), a detailed report of the symptoms, signs, diagnosis, treatment and follow-up of an individual patient. They contain a demographic profile of the patient, but usually describe an unusual or novel occurrence in one of the following categories: (1) an unexpected association between diseases or symptoms; (2) an unexpected event in the course of observing or treating a patient; (3) findings that shed new light on the possible pathogenesis of a disease or an adverse effect; (4) unique or rare features of a disease; (5) unique therapeutic approach. A case report is a type of anecdotal evidence. As such, it is less scientifically rigorous than controlled clinical data involving a larger sample size.   |
| Case study   | Papers reporting an intensive study of a single <b>group, incident, or community</b> . Rather than using samples and following a rigid protocol to examine limited number of variables, case study methods involve an in-depth, longitudinal examination of a single instance or event: a case. They provide a systematic way of looking at events, collecting data, analysing information and reporting the results. Case studies lend themselves to both generating and testing hypotheses. It is a research strategy, an empirical inquiry that investigates a phenomenon within its real-life context.   |
| Cross-sectional study                              | Papers reporting a study that examines the relationship between disease (and other health-related characteristics) and other variables of interest as they exist in a defined population at one particular time (syn: disease frequency survey, prevalence study). The presence or absence of disease and the presence or absence of the other variables (or, if they are quantitative, their level) are determined in each member of the study population or in a representative sample at one particular time. The relationship between a variable and the disease can be examined (1) in terms of the prevalence of disease in different population subgroups defined according to the presence or absence (or level) of the variables; and (2) in terms of the presence or absence (or level) of the variables in the disease <i>versus</i> the non-diseased.  |

Table 3: Study type definitions (*continued*)

| STUDY TYPE   | DEFINITION   |
|--|--|
| Surveillance study                                     | Surveillance studies are studies with continuous analysis, interpretation and feedback of systematically collected data, generally using methods distinguished by their practicality, uniformity and rapidity, rather than by accuracy or completeness.  |
| Case series  | A case series (or clinical series) is an observational medical research study that tracks patients with a known exposure given similar treatment or examines their medical records for exposure and outcome. Retrospective or prospective, it usually involves a small number of patients. Case series may be consecutive or non-consecutive, depending on whether all cases presenting to the reporting authors over a period of time were included or only a selection. They are frequently confounded by selection bias, limiting statements on the causality of correlations observed.   |
| Audit  | Audit papers are papers that measure the extent of implementation of best practice as defined by research or expert opinion. Inclusion criteria for an audit are defined as (1) addressing a healthcare topic; (2) developing an audit standard; (3) evaluating actual practice; (4) comparing practices against the standard. The final criterion of audit is (5) the dissemination of information and re-audit (O’Gorman, 2007).   |
| Practice or knowledge of health professional or parent | Papers reporting studies grouped under this heading reported on diseases, treatments or healthcare procedures experienced by children, where the knowledge, application of best practice guidelines and/or practice norms, executed by health and health-related personnel (including teachers and parents), were examined. ( <i>Authors’ own working definition</i> )   |
| Intervention study                                     | Papers reporting on investigations involving intentional change in some aspect of the status of the subjects (e.g. introduction of a preventive or therapeutic regimen) or designed to test a hypothesized relationship.   |
| Validation study                                       | Papers reporting on a process involved in establishing that the method under examination is sound for the purpose for which it is being used.  |
| Other studies – measuring effectiveness of tools       | Studies related to the effectiveness of measurement tools, where a measure of sensitivity or specificity was not specifically reported. ( <i>Authors’ own working definition</i> )   |
| Screening study  | The presumptive identification of unrecognised disease or defect by the application of tests, examinations or other procedures that can be applied rapidly. Screening tests are not diagnostic.  |
| Economic study   | Studies that use, in some measure, a decision model incorporating cost, relative effectiveness and valuations of health statuses (utilities) for different treatment models.   |
| Sensitivity and specificity of a measurement tool      | Papers that examine the sensitivity or specificity of a measurement tool. <b>Sensitivity</b> is the proportion of truly diseased (or positive) findings in a screened population; it is a measure of the probability of correctly diagnosing a case or the probability that any given case will be identified by the test. <b>Specificity</b> is the proportion of truly non-diseased (or negative) findings that are so identified by the screening test; it is a measure of the probability of correctly identifying a non-diseased person with a screening test. ( <i>Authors’ own working definition compiled from Last’s definitions of sensitivity and specificity</i> )   |
| Randomised controlled trial                            | Papers reporting on an epidemiological experiment in which subjects in a population are randomly allocated into groups, usually called <b>study</b> and <b>control groups</b> , to receive or not to receive an experimental preventive or therapeutic procedure, manoeuvre or intervention. The results are assessed by rigorous comparison of rates of disease, death, recovery or other appropriate outcome in the study and control group, respectively.   |
| Qualitative studies                                    | Papers reporting on observation or information characterised by measurement on a categorical scale (i.e. a dichotomous or nominal scale) or if the categories are ordered, an ordinal scale. These included <b>ethnographic</b> studies – papers reporting on the gathering of empirical data on human societies/cultures; data collection is often done through participant observation, interviews and questionnaires; focus group study – studies of qualitative research in which a group of people are asked, interactively, about their perceptions, opinions, beliefs and attitudes towards a product, service, concept or idea. They also included <b>anthropology</b> studies – papers reporting on ‘the study of humanity’; methods vary according to the anthropology specialty: (1) biological or physical anthropology; (2) social anthropology or cultural anthropology; (3) archaeology; and (4) anthropological linguistics. |
| Legal notes  | Studies that address topic areas with a civil law dimension. ( <i>Authors’ own working definition</i> )  |

**Table 4: Study type – strengths and weaknesses (adapted from Susser *et al*, 2006)**

| METHODOLOGY         | STUDY TYPE   | STRENGTHS  | WEAKNESSES   |
|---------------------|--|--|--|
| ANALYTICAL studies  | Case control study   | Relatively straightforward   | No randomisation potential for bias and confounding  |
|                     | Cohort and Longitudinal studies                                    | The exposure predates the outcome  | Can be expensive to maintain and subject to high attrition   |
| DESCRIPTIVE studies | Comparison study   | Allows comparison of characteristics between groups  | Cannot distinguish cause and effect  |
|                     | Epidemiology – incidence, prevalence and/or trends                 | Allows examination of the occurrence of new disease, the number of persons in the population with disease and changes in the occurrence of disease with time | Not possible to test hypotheses since there is no comparison group and with regard to incidence and prevalence cannot distinguish cause and effect                                       |
|                     | Case report  | Cheap and easy way of generating hypotheses  | Liable to coincidence, error, bias and confounding   |
|                     | Case study   | Cheap and easy way of generating hypotheses  | Liable to coincidence, error, bias and confounding   |
|                     | Cross-sectional study  | Identifies patterns of disease   | Cannot distinguish cause and effect  |
|                     | Surveillance study   | Identifies prevalence and frequency of disease   | Cannot distinguish cause and effect  |
|                     | Case series  | May be the best information on very rare diseases  | No comparison group, so cannot test hypotheses   |
|                     | Audit  | Gives information on service delivery  | Unreliable estimates of effectiveness  |
|                     | Practice or knowledge  | Gives information on knowledge of health delivery  | Unreliable estimates of the application of knowledge   |
|                     | Intervention study   | Gives information on whether an intervention can work  | Cannot explore all issues that determine if an intervention will work  |
|                     | Other studies – mainly related to measuring effectiveness of tools | Quantifies the effectiveness of a tool to measure what it intends to measure   | Estimates on the sensitivity or specificity of the measurement tool not provided   |
|                     | Validation study   | Quantifies sensitivity and specificity of the process being validated  | Caution needs to be applied in extrapolating findings to a wider context   |
|                     | Screening study  | Allows assessment of the approximate magnitude of disease in a population  | Is not diagnostic  |
|                     | Economic study   | Allows quantification of the cost implication of procedures or treatment   | Data derived from static economic modelling reflect specific conditions  |
|                     | Sensitivity and specificity of a measurement tool                  | Quantifies the effectiveness of a tool to measure what it intends to measure   | The recorded sensitivity and specificity of the measurement tool apply only to the specific circumstances in which they were gauged, thus care should be taken in extrapolating findings |
|                     | Randomised controlled trial  | Randomisation reduces selection bias and confounding   | Expensive and time-consuming   |
| Qualitative study   | Can illuminate complex issues                                      | May be unreliable  |  |

**Table 5: International Classification of Disease, Version 10 (ICD-10), three-digit rubric**

| BLOCK   | THREE-DIGIT RUBRIC  |
|---------|---|
| A00-B99 | Certain infectious and parasitic diseases   |
| C00-D48 | Neoplasms   |
| D50-D89 | Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism |
| E00-E90 | Endocrine, nutritional and metabolic diseases   |
| F00-F99 | Mental and behavioural disorders  |
| G00-G99 | Diseases of the nervous system  |
| H00-H59 | Diseases of the eye and adnexa  |
| H60-H95 | Diseases of the ear and mastoid process   |
| I00-I99 | Diseases of the circulatory system  |
| J00-J99 | Diseases of the respiratory system  |
| K00-K93 | Diseases of the digestive system  |
| L00-L99 | Diseases of the skin and subcutaneous tissue  |
| M00-M99 | Diseases of the musculoskeletal system and connective tissue  |
| N00-N99 | Diseases of the genitourinary system  |
| O00-O99 | Pregnancy, childbirth and the puerperium  |
| P00-P96 | Certain conditions originating in the perinatal period  |
| Q00-Q99 | Congenital malformations, deformations and chromosomal abnormalities                                |
| R00-R99 | Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified             |
| S00-T98 | Injury, poisoning and certain other consequences of external causes                                 |
| V01-Y98 | External causes of morbidity and mortality  |
| Z00-Z99 | Factors influencing health status and contact with health services                                  |
| U00-U99 | Codes for special purposes  |

**Table 6: Examples of axes of classification and coding strata within these axes in the International Classification of Diseases for Oncology, 3rd edition (ICD-O-3)**

| ONCOLOGY AXES  | OUTCOMES classified to the ICD-O-3  |
|----------------|---|
| 1.1 Morphology | 1.1.1 (8000-8009) Not otherwise specified   |
|                | 1.1.1.2 (8010-8790) Epithelial  |
|                | 1.1.1.3 (8800-9370) Connective tissue   |
|                | 1.1.1.4 (9380-9589) Nervous system  |
|                | 1.1.1.5 (9590-9999) Hematologic (leukemias, lymphomas and related disorders)  |
|                | 1.1.1.6 – Lymphoid leukemias and related disorders  |
|                | 1.1.1.7 – Myeloid leukemias and related disorders   |
|                | 1.1.1.8 – Other   |
| 1.2 Topography | The topography axis is for the topographical codes of the tumour's site. It is standardised with the C section of ICD-10. |

**Table 7: Study type – themed, non-classifiable, health-related outcomes with working definitions**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | WORKING DEFINITIONS  |
|---|--|
| (1) MICROSCOPIC ORGANISMS                       | Includes bacteria, viruses, fungi, and antibiotic resistant organisms  |
| (2) IMMUNOLOGY                                  | Outcomes related to physiological functions of the immune system   |
| (3) NEUROLOGY                                   | Neurological-related outcomes  |
| (4) PSYCHOLOGY                                  | Outcomes of a psychological nature, with psychology defined as ‘the scientific understanding of human mental functions – such as perception, introspection, memory, creativity, imagination, conception, belief, reasoning, volition, emotion – and behaviours’                  |
| (5) SOCIOLOGY                                   | Outcomes of a sociological nature, with sociology defined as ‘the development and refinement of a body of knowledge about human social activity. A process which endeavours to unify history, psychology and economics through the scientific understanding of the social realm’ |
| (6) DRUGS                                       | Outcomes related to drugs, including licit (e.g. tobacco or alcohol), illicit (e.g. cocaine) and prescribed pharmacological preparations (e.g. prescribed by a medical practitioner)   |
| (7) BREASTFEEDING                               | Outcomes related to breastfeeding – including the nature, type, duration, and barriers and supports to same  |
| (8) DEATHS                                      | Death-related outcomes where the specific cause of death was not specified   |
| (9) DISABILITIES                                | Disability-related outcomes where the specific cause of disability was not specified   |
| (10) HEALTH SERVICES                            | Health service provision, utilisation or uptake rates  |
| (11) MEDICAL PROCEDURES                         | Medical procedures, including surgical, medical, treatment and imaging   |
| (12) ORGAN TRANSPLANTS                          | Health outcomes among organ transplant recipients  |
| (13) SYNDROMES                                  | Conditions of a syndromic nature, with syndromes defined as ‘the association of several clinically recognisable features, signs and symptoms, where the presence of one feature can alert the physician to the presence of other features’                                       |
| (14) PREMATUREITY                               | Health outcomes in pre-term infants. The time point at which the outcome is examined may be at the time of birth or in later childhood   |
| (15) ANATOMY                                    | Anatomical structures where a specific disease or pathology is not named   |
| (16) GROWTH AND DEVELOPMENT                     | Normal and abnormal growth patterns – including anthropological measures, neurological measures and psychological measures of growth and development   |
| (17) DIET AND LIFESTYLE                         | Papers where the topic area examines aspects of diet and lifestyle   |
| (18) PHYSICAL ACTIVITY                          | Papers where the topic area examines areas of physical activity  |
| (19) EDUCATION                                  | Papers where the topic area reports on formal and informal education   |
| (20) DENTAL                                     | Papers where the topic area reports on dental issues   |
| (21) BIOLOGICAL MARKERS                         | Papers where the topic area reports on biological markers, not classifiable by ICD-10  |
| (22) LEGAL ISSUES                               | Papers where the topic area reports on issues with a legal dimension   |
| (23) OTHER                                      | Outcomes not elsewhere grouped   |



# 3 Results



## Introduction

The study search terms identified 5,516 peer-reviewed published papers across the six bibliographic databases (*see Chapter 2 for details*). Of these, 796 were duplicates and were deleted. Each of the 4,720 remaining papers was examined with reference to the study inclusion/exclusion criteria and 3,229 papers (59%) were identified as eligible for inclusion in the study. These papers represented reports from a total of 1,003 national and international scientific journals (*see Appendix 2*).

Of the 3,229 eligible papers, 977 (30%) were papers reporting commentaries, reviews, editorials or letters, and are the component papers of Set 1. These articles were retained in the electronic database (available on the website [www.childrensdatabase.ie/Irish-child-health-database/](http://www.childrensdatabase.ie/Irish-child-health-database/)), but were not examined further for this study.

Set 2 consisted of 2,252 papers (70%) reporting research findings, including 69 papers (3.2%) reporting primary research on animals, as well as findings from 25 systematic reviews (1.1%) and 2 meta-analyses (0.09%). Individual research studies with findings on humans were retained in the database, but were not examined further for this study (*see Figure 2*).

The remaining 2,156 papers (67% of the 3,229 eligible papers) reported research findings on humans, mainly from primary research studies (*see Figure 3*). These papers consisted of 209 analytical studies (9.7%), 1,941 descriptive studies (90%) and 6 papers of a 'legal' nature (0.03%).

**Note:** The figure 2,156 represents the reference baseline for numbers reported in Figure 3 and the subsequent reporting of findings in Tables 8-47. Percentages accompanying reported counts are rounded and may thus vary by up to 1% from expected totals.

The **209 analytical studies** (approx. 10%) consisted of:

- 163 case control studies (7.5%);
- 46 cohort or longitudinal studies (2%).

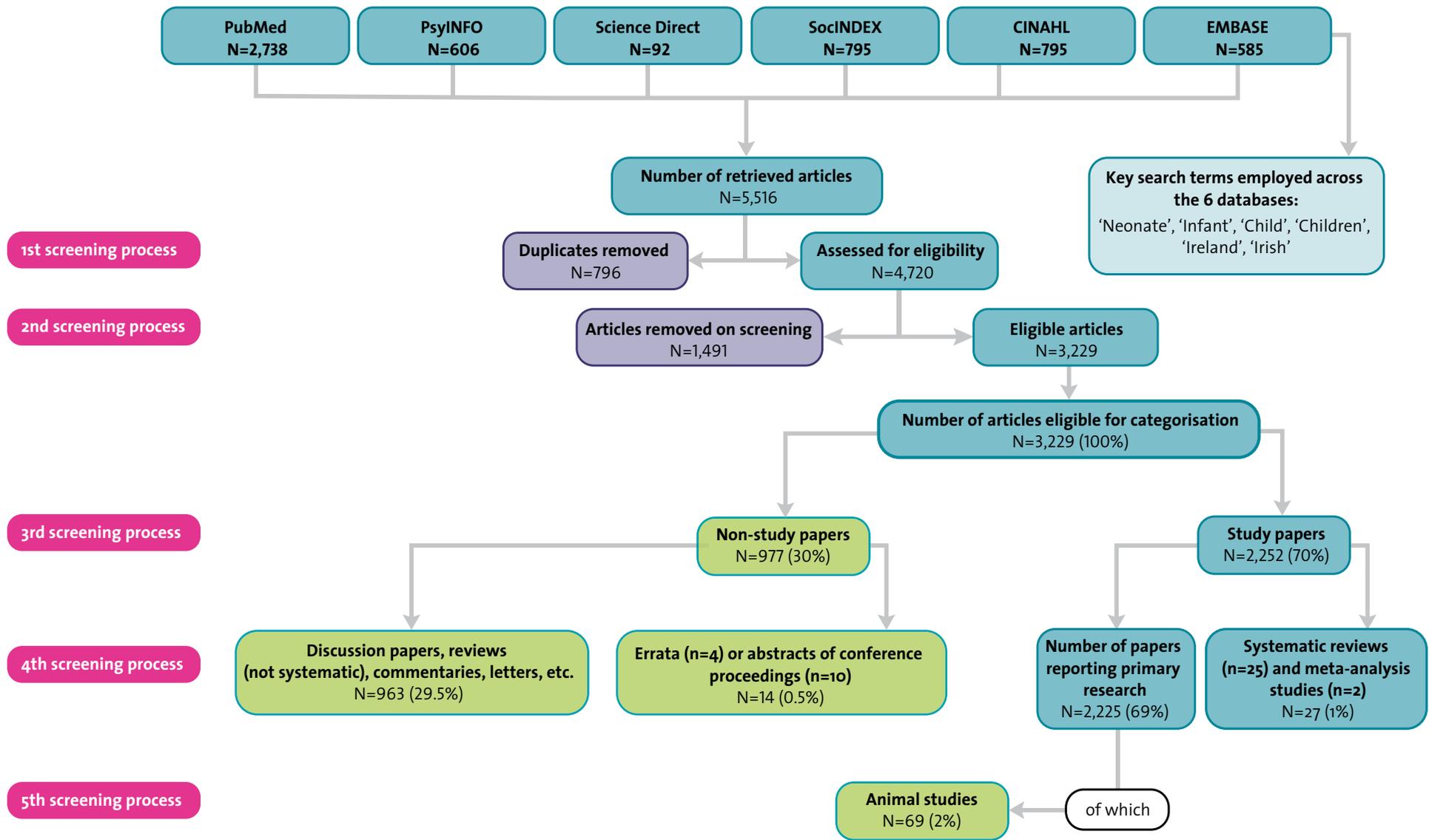
The **1,941 descriptive studies** (approx. 90%) consisted of:

- 250 comparison studies or epidemiology studies of incidence, prevalence and/or trends of diseases (11.5%);
- 1,262 studies without a comparative group (58.5%), consisting of 302 case reports, 664 case studies, 57 cross-sectional studies, 16 surveillance studies and 223 case series studies;
- 187 studies measuring aspects of effectiveness (8.7%);
- 140 studies examining aspects of health technology assessment (6.5%);
- 102 qualitative studies (4.7%).

Figure 2 summarises the papers retrieved from the study databases and their subsequent screening and eligibility in the study, while Figure 3 details the individual study types and the number of papers examined within each of these groupings.



Figure 2: Number of papers retrieved from study databases, number of papers removed following screening and number of papers eligible for inclusion in the study





## Analytical studies

The 209 analytical studies (9.7%) consisted of 163 case control studies (7.5%) and 46 cohort studies (2.1%), with 19 of the cohort studies examining data of a longitudinal nature.

Among the 163 **case control studies**, 121 (5.6%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 41 (1.9%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (4); immunology (5); psychology (1); sociology (6); drugs (3); breastfeeding (2); deaths (1); disabilities (1); health services (3); medical procedures (1); organ transplants (2); syndromes (3); prematurity (2); anatomy (4); biological markers (2); and Other (1). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 8 and 9**.

Among the 46 **cohort and longitudinal studies**, 10 (0.5%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 36 (1.7%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: psychology (6); sociology (2); drugs (1); breastfeeding (2); deaths (1); health services (2); organ transplants (1); prematurity (3); anatomy (1); growth and development (2); diet and lifestyle (2); physical activity (2); education (2); biological markers (2); and Other (7). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 10-12**.

**Table 8: Case control studies – ICD-10**

| BLOCK   | TITLE   |
|---------|---|
| A00-B99 | <b>Certain infectious and parasitic diseases [4]</b> <ul style="list-style-type: none"> <li>❑ Other bacterial diseases – meningococcal disease (2)</li> <li>❑ Viral hepatitis – hepatitis C (1)</li> <li>❑ Viral infections characterised by skin and mucous membrane lesions – measles (1)</li> </ul>  |
| C00-D48 | <b>Neoplasms [2]</b> <ul style="list-style-type: none"> <li>❑ Neoplasms – lymphoblastic leukemia (2)</li> </ul>   |
| D50-D89 | <b>Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism [1]</b> <ul style="list-style-type: none"> <li>❑ Other diseases of blood and blood-forming organs – neutropenia (1)</li> </ul>   |
| E00-E90 | <b>Endocrine, nutritional and metabolic diseases [10]</b> <ul style="list-style-type: none"> <li>❑ Diabetes mellitus – type 1 diabetes mellitus (2)</li> <li>❑ Metabolic disorders – cystic fibrosis (3)</li> <li>❑ Metabolic disorders – homocystinuria (1)</li> <li>❑ Metabolic disorders – phenylketonuria (1)</li> <li>❑ Other – diabetic nephropathy (2), diabetic ocular changes (1)</li> </ul>                           |
| F00-F99 | <b>Mental and behavioural disorders [15]</b> <ul style="list-style-type: none"> <li>❑ Behavioural and emotional disorders with onset usually occurring in childhood and adolescence – attention deficit hyperactivity disorder (9)</li> <li>❑ Mental retardation – intellectual disabilities (2)</li> <li>❑ Schizophrenia, schizotypal and delusional disorders – schizophrenia (3)</li> <li>❑ Other – psychosis (1)</li> </ul> |
| G00-G99 | <b>Diseases of the nervous system [2]</b> <ul style="list-style-type: none"> <li>❑ Cerebral palsy and other paralytic syndromes – spastic hemiplegia (1)</li> <li>❑ Polyneuropathies and other disorders of the peripheral nervous system – Charcot-Marie-Tooth Disease (1)</li> </ul>  |
| H00-H59 | <b>Diseases of the eye and adnexa [1]</b> <ul style="list-style-type: none"> <li>❑ Disorders of choroid and retina – retinopathy of prematurity (1)</li> </ul>  |
| I00-I99 | <b>Diseases of the circulatory system [1]</b> <ul style="list-style-type: none"> <li>❑ Diseases of arteries, arterioles and capillaries – spider naevi (1)</li> </ul>   |
| J00-J99 | <b>Diseases of the respiratory system [4]</b> <ul style="list-style-type: none"> <li>❑ Chronic lower respiratory diseases – asthma (3)</li> <li>❑ Other – respiratory disease (1)</li> </ul>  |

**Table 8: Case control studies – ICD-10 (continued)**

| BLOCK   | TITLE  |
|---------|--|
| K00-K93 | <b>Diseases of the digestive system [5]</b> <ul style="list-style-type: none"> <li>□ Diseases of appendix – appendixes (2)</li> <li>□ Non-infective enteritis and colitis – ulcerative colitis (2)</li> <li>□ Other diseases of intestines – intestinal obstruction (1)</li> </ul>   |
| L00-L99 | <b>Diseases of the skin and subcutaneous tissue [2]</b> <ul style="list-style-type: none"> <li>□ Dermatitis and eczema – eczema (1)</li> <li>□ Papulosquamous disorders – psoriasis (1)</li> </ul>   |
| M00-M99 | <b>Diseases of the musculoskeletal system and connective tissue [5]</b> <ul style="list-style-type: none"> <li>□ Arthropathies – arthritis (1)</li> <li>□ Osteopathies and chondropathies – Perthes' Disease (2)</li> <li>□ Papulosquamous disorders – psoriatic arthritis (1)</li> <li>□ Systemic connective tissue disorders – dermatomyositis (1)</li> </ul>  |
| N00-N99 | <b>Diseases of the genitourinary system [15]</b> <ul style="list-style-type: none"> <li>□ Diseases of the genitourinary system – reflux nephropathy (11)</li> <li>□ Renal tubulo-interstitial diseases – vesicoureteric reflux (4)</li> </ul>  |
| O00-O99 | <b>Pregnancy, childbirth and the puerperium [9]</b> <p>** Cephalopelvic disproportion (1), coagulation activation associated with pre-eclamptic pregnancy and with over-spills into the foetal circulation affecting the foetal haemostatic system (1), labour (1), macrosomic infant (1), neonatal encephalopathy (1), quantification of the relationship between precise angle of episiotomy from the perineal midline and risk of third-degree tear (1), tests the hypothesis that exposure to antenatal risk factors for sepsis alters the perinatal neutrophil phenotype (1), examines effects of maternal diabetes on foetal iron status (1), anal sphincter function (1)</p>  |
| P00-P96 | <b>Certain conditions originating in the perinatal period [2]</b> <ul style="list-style-type: none"> <li>□ Other – brachial plexus paralysis (1), neonatal polycythaemia (1)</li> </ul>  |
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [38]</b> <ul style="list-style-type: none"> <li>□ Chromosomal abnormalities, not elsewhere classified – Down's Syndrome (2)</li> <li>□ Cleft lip and cleft palate – Cleft lip and/or palate (2)</li> <li>□ Congenital malformations and deformations of the musculoskeletal system – congenital diaphragmatic hernia (4)</li> <li>□ Other congenital malformations of the digestive system – congenital hypertrophic pyloric stenosis (5)</li> <li>□ Other – congenital anomaly (1)</li> <li>□ Congenital malformations of the circulatory system – patent ductus arteriosus (2)</li> <li>□ Congenital malformations of the urinary system – dysplastic kidney (2)</li> <li>□ Neural tube defects – condition (7)</li> <li>□ Other congenital malformations of the digestive system – Hirschsprung's Disease (13)</li> </ul> |
| R00-R99 | <b>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified [5]</b> <ul style="list-style-type: none"> <li>□ Ill-defined and unknown causes of mortality – Sudden Infant Death Syndrome (5)</li> </ul>  |

**Table 9: Case control studies – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (1) MICROSCOPIC ORGANISMS                       | Haemophilus influenzae (1), Helicobacter pylori (1), adenovirus and rotavirus (1), Epstein-Barr virus (1)   |
| (2) IMMUNOLOGY                                  | Neutrophil migration (1), neutrophil responses (1), neutrophils and bacterial infection (1), responses and infection (1), thymic emigrants (1)  |
| (4) PSYCHOLOGY                                  | Bullying (1)  |
| (5) SOCIOLOGY                                   | Sexual abuse – demographic characteristics (1), psychological and psychosocial characteristics (1)<br>Programmes – Parenting Plus Programme (1), Stay Safe Programme (2), teenage mothers (1) |

**Table 9: Case control studies – themed, non-classifiable, health-related outcomes (continued)**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (6) DRUGS                                       | Illicit drugs dependence (1), licit and illicit drugs exposure (1), licit drugs – parental penicillin (1)                              |
| (7) BREASTFEEDING                               | Breastfeeding +/- formulae milk (2)  |
| (8) DEATHS                                      | Deaths – infants (1)   |
| (9) DISABILITIES                                | Disabilities – developmental (1)   |
| (10) HEALTH SERVICES                            | Health service provision (2), vaccination (1)  |
| (11) MEDICAL PROCEDURES                         | Ureteropelvic junction obstruction (1)   |
| (12) ORGAN TRANSPLANTS                          | Antithymocyte globulin as induction immunotherapy (1), kidney (1)  |
| (13) SYNDROMES                                  | Intestinal hypoperistalsis (1), megacystis microcolon intestinal hypoperistalsis (1), megacystis-microcolon-intestinal peristalsis (1) |
| (14) PREMATUREITY                               | Births (1), children (1)   |
| (15) ANATOMY                                    | Brodmann's area (1), myenteric plexus (1), inflammatory bowel disease – non-specific (1), renal dysplasia – non-specific (1)           |
| (21) BIOLOGICAL MARKERS                         | Transcription factors – nuclear factor of activated T cell 1 expression (1), pouchitis – condition (1)                                 |
| (23) OTHER                                      | Barriers to prenatal care (1)  |

**Table 10: Cohort studies – ICD-10**

| BLOCK   | TITLE   |
|---------|---|
| A00-B99 | <b>Certain infectious and parasitic diseases [5]</b><br><input type="checkbox"/> Human immunodeficiency virus disease – HIV (5)   |
| C00-D48 | <b>Neoplasms [2]</b><br><input type="checkbox"/> Cancer (generic) (1)<br><input type="checkbox"/> Malignant neoplasms – lymphoblastic leukaemia (1)                                   |
| F00-F99 | <b>Mental and behavioural disorders [1]</b><br><input type="checkbox"/> Psychiatry (1)  |
| O00-O99 | <b>Pregnancy, childbirth and the puerperium [1]</b><br><input type="checkbox"/> Pregnancy, childbirth and the puerperium – perinatal death in twin pregnancies (1)                    |
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [1]</b><br><input type="checkbox"/> Chromosomal abnormalities, not elsewhere classified – Down's Syndrome (1) |

**Table 11: Cohort studies – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (4) PSYCHOLOGY                                  | Mother-infant attachment (1), temporal orientation (present/future) concept (1) |
| (5) SOCIOLOGY                                   | Sexual abuse – patterns in disclosure, investigation and outcomes (1)           |
| (7) BREASTFEEDING                               | Infant feeding (1)  |
| (8) DEATHS                                      | Deaths (1)  |
| (10) HEALTH SERVICES                            | Vaccination (1)   |
| (12) ORGAN TRANSPLANTS                          | Cadaveric (1)   |
| (14) PREMATUREITY                               | Births (2), children (1)  |
| (15) ANATOMY                                    | Corneal thickness (1)   |
| (16) GROWTH AND DEVELOPMENT                     | Growth and development – motor development (1)                                  |
| (17) DIET AND LIFESTYLE                         | Diet and lifestyle (1)  |
| (19) EDUCATION                                  | Education (2)   |
| (21) BIOLOGICAL MARKERS                         | Iron status (1), taste (1)  |

**Table 12: Longitudinal studies – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (4) PSYCHOLOGY                                  | Self-competence and self-esteem (1), self-perceptions (1), childhood trauma and self-reported experiences of hallucinations (1), stressfulness of negative familial, academic and social events (1)   |
| (5) SOCIOLOGY                                   | Stability of childhood (1)  |
| (6) DRUGS                                       | Illicit drugs cocaine (1)   |
| (7) BREASTFEEDING                               | Breastfeeding and weight gain (1)   |
| (10) HEALTH SERVICES                            | Health service provision – primary care utilisation rates (1)   |
| (16) GROWTH AND DEVELOPMENT                     | Developmental pathways of adolescents (1)   |
| (17) DIET AND LIFESTYLE                         | Energy and nutrient intake (1)  |
| (18) PHYSICAL ACTIVITY                          | Physical activity (1), aerobic fitness and birth weight (1)   |
| (23) OTHER                                      | Classification of overweight (1), psychotic disorders (1), maternal characteristics, particularly body mass index and infant birth weight (1), maternal dietary patterns and childhood asthma (1), cardiovascular disease or coronary heart disease (3) |

## Descriptive studies

The 1,941 descriptive studies (90%) consisted of 250 studies (11.5%) that included a comparative dimension of time, geography, procedure or treatment; 1,262 studies (58.5%) without a comparative dimension; 187 studies (8.7%) that measured aspects of effectiveness; and 140 studies (6.5%) with a health technology dimension. The remaining 102 descriptive studies (4.7%) were of a qualitative nature and included 21 studies that predominantly employed a focus group methodology and 10 that were anthropological or ethnographic in nature.

### Descriptive studies with a comparative dimension

Of the 250 descriptive studies with a comparative dimension, there were 101 comparison studies (4.6%) and 149 epidemiological studies (6.9%) reporting statistical measures of incidence, prevalence and/or trends.

Among the 101 **comparison studies**, 40 (1.9%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 61 (2.8%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (4); psychology (7); sociology (10); drugs (2); breastfeeding (2); deaths (3); disabilities (1); health services (5); medical procedures (6); organ transplants (2); prematurity (1); growth and development (4); diet and lifestyle (1); education (1); dental (6); biological markers (1); and Other (5). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 13 and 14**.

Among the 149 **epidemiology studies**, 89 (4.1%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 60 (2.8%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (19); psychology (1); drugs (2); deaths (4); disabilities (3); health services (3); medical procedures (1); syndromes (4); prematurity (1); growth and development (3); diet and lifestyle (4); education (1); dental (5); biological markers (5); and Other (4). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 15 and 16**.

Table 13: Comparison studies – ICD-10

| BLOCK   | TITLE  |
|---------|--|
| A00-B99 | <b>Certain infectious and parasitic diseases [4]</b> <ul style="list-style-type: none"> <li>❑ Human immunodeficiency virus [HIV] disease – HIV (1)</li> <li>❑ Intestinal infectious diseases – gastroenteritis (1)</li> <li>❑ Other bacterial diseases – meningococcal disease (1)</li> <li>❑ Viral infections characterised by skin and mucous membrane lesions – varicella (1)</li> </ul>  |
| E00-E90 | <b>Endocrine, nutritional and metabolic diseases [4]</b> <ul style="list-style-type: none"> <li>❑ Obesity and other hyperalimentation – obesity (4)</li> </ul>   |
| F00-F99 | <b>Mental and behavioural disorders [2]</b> <ul style="list-style-type: none"> <li>❑ Mental retardation – intellectual abilities (1)</li> <li>❑ Mental retardation – intellectual disabilities (1)</li> </ul>  |
| G00-G99 | <b>Diseases of the nervous system [2]</b> <ul style="list-style-type: none"> <li>❑ Cerebral palsy and other paralytic syndromes – cerebral palsy (2)</li> </ul>  |
| H00-H59 | <b>Diseases of the eye and adnexa [1]</b> <ul style="list-style-type: none"> <li>❑ Disorders of choroid and retina – retinopathy of prematurity (1)</li> </ul>   |
| I00-I99 | <b>Diseases of the circulatory system [1]</b> <ul style="list-style-type: none"> <li>❑ Other forms of heart disease – left ventricular dysfunction (1)</li> </ul>  |
| J00-J99 | <b>Diseases of the respiratory system [2]</b> <ul style="list-style-type: none"> <li>❑ Chronic lower respiratory diseases – asthma (1)</li> <li>❑ Other – respiratory symptoms (1)</li> </ul>  |
| K00-K93 | <b>Diseases of the digestive system [3]</b> <ul style="list-style-type: none"> <li>❑ Diseases of appendix (2)</li> <li>❑ Other diseases of intestines – intestinal ischaemia-reperfusion injury (1)</li> </ul>   |
| M00-M99 | <b>Diseases of the musculoskeletal system and connective tissue [2]</b> <ul style="list-style-type: none"> <li>❑ Arthropathies – arthritis (1)</li> <li>❑ Dorsopathies – scoliosis (1)</li> </ul>  |
| N00-N99 | <b>Diseases of the genitourinary system [1]</b> <ul style="list-style-type: none"> <li>❑ Renal tubulo-interstitial diseases – vesicoureteric reflux (1)</li> </ul>   |
| O00-O99 | <b>Pregnancy, childbirth and the puerperium [4]</b> <ul style="list-style-type: none"> <li>❑ Pregnancy, childbirth and the puerperium (4)</li> </ul>   |
| P00-P96 | <b>Certain conditions originating in the perinatal period [5]</b> <ul style="list-style-type: none"> <li>❑ Other congenital malformations of the digestive system – biliary atresia (2)</li> <li>❑ Cleft lip and cleft palate – cleft lip and/or palate (1)</li> <li>❑ Congenital malformations of the circulatory system – patent ductus arteriosus (1)</li> <li>❑ Congenital malformations of the nervous system – spina bifida (1)</li> </ul> |
| S00-T98 | <b>Injury, poisoning and certain other consequences of external causes [9]</b> <ul style="list-style-type: none"> <li>❑ Fractures (2)</li> <li>❑ Injury (6)</li> <li>❑ Unintentional injury (1)</li> </ul>   |



**Table 14: Comparison studies – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (1) MICROSCOPIC ORGANISMS                       | Campylobacter jejuni with Campylobacter upsaliensis with Haemophilus influenzae (1), Campylobacter upsaliensis (1), Haemophilus influenzae (1), rotavirus (1)   |
| (4) PSYCHOLOGY                                  | Moral reasoning (1), problematic behaviours (1), family support group (1), Parents Plus Programme (1), field-independence and problem solving (1), self-esteem (1), self-perceptions (1)  |
| (5) SOCIOLOGY                                   | Adolescent concern with social issues (1), homelessness (1), fathers' and mothers' participation in childcare/household (1), sexual abuse: child sex offenders' profiles (1), sexual abuse: demographic characteristics (1), sexual abuse: perceptions of paedophiles (1), war, violence and conflict (4) |
| (6) DRUGS                                       | Alcohol (1), surfactant administration (1)  |
| (7) BREASTFEEDING                               | Breastfeeding +/- formulae milk (2)   |
| (8) DEATHS                                      | Deaths – by location of birth (1), economic inequality (1), neonatal (1)  |
| (9) DISABILITIES                                | Disability-free life expectancy (1)   |
| (10) HEALTH SERVICES                            | Health services (4), vaccination (1)  |
| (11) MEDICAL PROCEDURES                         | Maxillary expansion (1), maxillofacial operations (1), neonatal ventilation (1), otorhinolaryngology (1), Snodgrass hypospadias (1), tonsillectomy (1)  |
| (12) ORGAN TRANSPLANTS                          | Renal (1), bone marrow (1)  |
| (14) PREMATURETY                                | Infants (1)   |
| (16) GROWTH AND DEVELOPMENT                     | Height and weight (1), neurodevelopmental and respiratory outcomes (1), social disadvantage on motor development (2)  |
| (17) DIET AND LIFESTYLE                         | Diet and lifestyle (1)  |
| (19) EDUCATION                                  | Education (1)   |
| (20) DENTAL                                     | Dental (6)  |
| (21) BIOLOGICAL MARKERS                         | Vitamin D (1)   |
| (23) OTHER                                      | Outcomes at A&E (1), clinical condition of newborn (1), clinical monitoring in the post-discharge period (1), historical representation (1), neonatal seizures (1)  |

**Table 15: Epidemiology studies of incidence, prevalence and/or trends – ICD-10**

| BLOCK   | TITLE  |
|---------|--|
| A00-B99 | <b>Certain infectious and parasitic diseases [15]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Diarrhoea (1)</li> <li><input type="checkbox"/> Helminthiases – toxocaral eye disease (1)</li> <li><input type="checkbox"/> Human immunodeficiency virus disease (2)</li> <li><input type="checkbox"/> Other bacterial diseases – meningococcal disease (2)</li> <li><input type="checkbox"/> Tuberculosis – tuberculosis (1)</li> <li><input type="checkbox"/> Viral hepatitis – hepatitis B (1), hepatitis C (3)</li> <li><input type="checkbox"/> Viral infections characterised by skin and mucous membrane lesions – herpes labialis (1), varicella (1)</li> <li><input type="checkbox"/> Other viral diseases – mumps (2)</li> </ul> |
| D50-D89 | <b>Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism [1]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Haemolytic anaemias – sickle-cell disease (1)</li> </ul>  |
| E00-E90 | <b>Endocrine, nutritional and metabolic diseases [12]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Other disorders of glucose regulation and pancreatic internal secretion – hypoglycaemia (1)</li> <li><input type="checkbox"/> Obesity and other hyperalimentation – obesity (3)</li> <li><input type="checkbox"/> Diabetes mellitus – type 1 diabetes mellitus (5), type 2 diabetes mellitus (1)</li> <li><input type="checkbox"/> Metabolic disorders – cystic fibrosis (2)</li> </ul>  |
| F00-F99 | <b>Mental and behavioural disorders [5]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Behavioural and emotional disorders with onset usually occurring in childhood and adolescence – attention deficit hyperactivity disorder (1), anorexia nervosa (1), eating disorders (1)</li> <li><input type="checkbox"/> Other – mental health (1), mental health status (1)</li> </ul>  |

Table 15: Epidemiology studies of incidence, prevalence and/or trends – ICD-10 (*continued*)

| BLOCK   | TITLE   |
|---------|---|
| G00-G99 | <b>Diseases of the nervous system [11]</b> <ul style="list-style-type: none"> <li>□ Cerebral palsy and other paralytic syndromes – cerebral palsy (5)</li> <li>□ Demyelinating diseases of the central nervous system – multiple sclerosis (3)</li> <li>□ Inflammatory diseases of the central nervous system – meningitis (1)</li> <li>□ Other disorders of the nervous system – idiopathic intracranial hypertension (1)</li> <li>□ Systemic atrophies primarily affecting the central nervous system – spastic paraparesis (1)</li> </ul>  |
| H00-H59 | <b>Diseases of the eye and adnexa [2]</b> <ul style="list-style-type: none"> <li>□ Disorders of vitreous body and globe – endophthalmitis (1)</li> <li>□ Other – visual disorders (1)</li> </ul>  |
| I00-I99 | <b>Diseases of the circulatory system [4]</b> <ul style="list-style-type: none"> <li>□ Cerebrovascular diseases – subdural haematoma (1)</li> <li>□ Diseases of arteries, arterioles and capillaries – abdominal aortic aneurysm (1)</li> <li>□ Other forms of heart disease – sudden cardiac death (2)</li> </ul>  |
| J00-J99 | <b>Diseases of the respiratory system [5]</b> <ul style="list-style-type: none"> <li>□ Chronic lower respiratory diseases – asthma (3)</li> <li>□ Other acute lower respiratory infections – bronchitis (1)</li> <li>□ Other diseases of upper respiratory tract – peritonsillar abscess disease (1)</li> </ul>   |
| K00-K93 | <b>Diseases of the digestive system [2]</b> <ul style="list-style-type: none"> <li>□ Disorders of gall bladder, biliary tract and pancreas – pancreatitis (1)</li> <li>□ Other – acute gastroenteritis (1)</li> </ul>   |
| L00-L99 | <b>Diseases of the skin and subcutaneous tissue [1]</b> <ul style="list-style-type: none"> <li>□ Other disorders of the skin and subcutaneous tissue – systemic lupus erythematosus (1)</li> </ul>  |
| M00-M99 | <b>Diseases of the musculoskeletal system and connective tissue [1]</b> <ul style="list-style-type: none"> <li>□ Osteopathies and chondropathies – Perthes' Disease (1)</li> </ul>  |
| O00-O99 | <b>Pregnancy, childbirth and the puerperium [3]</b> <ul style="list-style-type: none"> <li>□ Pregnancy, childbirth and the puerperium (3)</li> </ul>  |
| P00-P96 | <b>Certain conditions originating in the perinatal period [2]</b> <ul style="list-style-type: none"> <li>□ Haemorrhagic and haematological disorders of foetus and newborn – neonatal alloimmune thrombocytopenia (1)</li> <li>□ Other viral diseases – cytomegalovirus (1)</li> </ul>  |
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [9]</b> <ul style="list-style-type: none"> <li>□ Congenital malformations and deformations of the musculoskeletal system – developmental dysplasia of the hip (1)</li> <li>□ Chromosomal abnormalities, not elsewhere classified – Down's Syndrome (1)</li> <li>□ Cleft lip and cleft palate – cleft lip and/or palate (2)</li> <li>□ Other congenital malformations – neurofibromatosis type 1 (1)</li> <li>□ Other – congenital abdominal wall defects (1), hypospadias (1), neural tube defects – condition (2)</li> </ul> |
| R00-R99 | <b>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified [3]</b> <ul style="list-style-type: none"> <li>□ Ill-defined and unknown causes of mortality – Sudden Infant Death Syndrome (1)</li> <li>□ Abnormal findings on examination of blood, without diagnosis – hereditary hemochromatosis (1)</li> <li>□ Symptoms and signs involving the digestive system and abdomen – hyperbilirubinaemia (1)</li> </ul>   |
| S00-T98 | <b>Injury, poisoning and certain other consequences of external causes [9]</b> <ul style="list-style-type: none"> <li>□ Femoral fractures (1), fractures (1), injury (5), poisoning (2)</li> </ul>  |
| V01-Y98 | <b>External causes of morbidity and mortality [4]</b> <ul style="list-style-type: none"> <li>□ Intentional self-harm – self-injury (1), suicide (3)</li> </ul>  |

**Table 16: Epidemiology studies of incidence, prevalence and/or trends – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (1) MICROSCOPIC ORGANISMS                       | Coxiella burnetii (1), enterobacteriaceae (1), enterococci and streptococci (1), Escherichia coli O157 (1), Group B Strep (1), Haemophilus influenzae (2), Helicobacter pylori (2), invasive pneumococcal (1), pneumococcal disease (1), Pseudomonas aeruginosa (1), staphylococci (1), Staphylococcus aureus (1), Streptococcus pneumoniae (1), methicillin-resistant Staphylococcus aureus (1), adenovirus (1), rotavirus (1), fungi (1) |
| (4) PSYCHOLOGY                                  | Bullying (1)   |
| (6) DRUGS                                       | Cannabis (1), smoking (1)  |
| (8) DEATHS                                      | Cause-specific (1), homicides (1), infants (1), intrapartum foetal death (1)   |
| (9) DISABILITIES                                | Disabilities (1), child blindness (1), congenital brachial palsy (1)   |
| (10) HEALTH SERVICES                            | Health service provision (2), vaccinations (1)   |
| (11) MEDICAL PROCEDURES                         | Tonsillectomy (1)  |
| (13) SYNDROMES                                  | Auto-immune polyendocrinopathy-candidiasis-ectodermal dystrophy (1), cyclic vomiting syndrome (1), hemolytic uremic (1), Kabuki (1)  |
| (14) PREMATUREITY                               | Premature infants (1)  |
| (16) GROWTH AND DEVELOPMENT                     | Height and weight (2), primary reflexes (1)  |
| (17) DIET AND LIFESTYLE                         | Diet and lifestyle (4)   |
| (19) EDUCATION                                  | Education (1)  |
| (20) DENTAL                                     | Dental (5)   |
| (21) BIOLOGICAL MARKERS                         | Vitamin D (1), Vitamin K (1), blood pressure (1), heart muscle disease-induced heart failure (1), inflammatory bowel disease – non-specific (1)  |
| (23) OTHER                                      | Chimeric transcripts (1), malignancy (1), toxoplasma infection (2)   |

### Descriptive studies without a comparative dimension

Descriptive studies without a comparative dimension consisted of 302 case reports (14%), 664 case studies (30.7%), 57 cross-sectional studies (2.6%), 16 surveillance studies (0.7%) and 223 case series studies (10.3%).

The 302 **case reports** differed substantively in nature from all other studies in that they reported on the characteristics of one person or one family group and are of interest because they represent unusual observations or phenomena. However, these observations should not be considered representative of the general population. Of the 302 studies, 192 reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 110 examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (3); neurology (3); psychology (2); sociology (1); health services (11); medical procedures (3); organ transplants (2); syndromes (45); dental (6); legal issues (13); and Other (19). In addition, there were 2 cases classified to ICO. Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 17-19**.

Among the 664 **case studies**, 266 (12.3%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 398 (18.4%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (37); immunology (4); psychology (37); sociology (34); drugs (17); breastfeeding (6); deaths (6); disabilities (11); health services (40); medical procedures (21); organ transplants (4); syndromes (6); prematurity (7); anatomy (4); growth and development (10); diet and lifestyle (8); physical activity (9); education (22); dental (23); biological markers (28); legal issues (28); and Other (36). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 20 and 21**.

Among the 57 **cross-sectional studies**, 18 (0.8%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 39 (2%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: psychology (6); sociology (3); breastfeeding (1); health services (3); medical procedures (1); growth and development (1); diet and lifestyle (10); physical activity (5); education (2); dental (3); biological markers (2); legal issues (1); and Other (1). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 22 and 23**.

Among the 16 **surveillance studies**, 9 (0.4%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 7 (0.3%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (3); health services (3); and Other (1). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 24 and 25**.

Among the 223 **case series studies**, 118 (5.5%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 105 (4.8%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (1); drugs (1); deaths (1); health services (2); medical procedures (48); organ transplants (14); syndromes (10); prematurity (1); and biological markers (26). In addition, there was one case classified to ICO-O-3. Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 26-28**.

**Table 17: Case reports – ICD-10**

| BLOCK   | TITLE   |
|---------|---|
| A00-B99 | Certain infectious and parasitic diseases [8]   |
| C00-D48 | Neoplasms [10]  |
| D50-D89 | Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism [5] |
| E00-E90 | Endocrine, nutritional and metabolic diseases [16]  |
| F00-F99 | Mental and behavioural disorders [18]   |
| G00-G99 | Diseases of the nervous system [9]  |
| H00-H59 | Diseases of the eye and adnexa [6]  |
| H60-H95 | Diseases of the ear and mastoid process [3]   |
| I00-I99 | Diseases of the circulatory system [20]   |
| J00-J99 | Diseases of the respiratory system [6]  |
| K00-K93 | Diseases of the digestive system [14]   |
| L00-L99 | Diseases of the skin and subcutaneous tissue [8]  |
| M00-M99 | Diseases of the musculoskeletal system and connective tissue [19]                                       |
| N00-N99 | Diseases of the genitourinary system [4]  |
| O00-O99 | Pregnancy, childbirth and the puerperium [1]  |
| P00-P96 | Certain conditions originating in the perinatal period [11]   |
| Q00-Q99 | Congenital malformations, deformations and chromosomal abnormalities [25]                               |
| S00-T98 | Injury, poisoning and certain other consequences of external causes [7]                                 |
| V01-Y98 | External causes of morbidity and mortality [2]  |

**Table 18: Case reports – ICO-O-3**

|                  |   |
|------------------|---|
| ICD-O: 9540/3    | Penile malignant peripheral nerve sheath tumour Neurofibrosarcoma (1) |
| ICD-O: 8800-9059 | Connective/soft tissue tumours and sarcomas (1)                       |

**Table 19: Case reports – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (1) MICROSCOPIC ORGANISMS                       | Mycobacterium virus (1), parvovirus B19 infection (2)  |
| (3) NEUROLOGY                                   | Neurological (3)   |
| (4) PSYCHOLOGY                                  | Psychosocial functioning (2)   |
| (5) SOCIOLOGY                                   | Community – segregation and conflict (1)   |
| (10) HEALTH SERVICES                            | Health service provision (11)  |
| (11) MEDICAL PROCEDURES                         | Chest wall reconstruction (1), post-dural puncture headache (1), surgical repair – arterial anastomoses (1)  |
| (12) ORGAN TRANSPLANTS                          | Allogeneic hematopoietic stem cell transplantation (1), liver (1)  |
| (13) SYNDROMES                                  | Gianotti-Crosti (1), IPEX (1), acute respiratory distress (1), Antley-Bixler (1), Asperger's (1), carbonic anhydrase II deficiency (1), central hypoventilation (1), Cohen (1), cold auto-inflammatory (1), de Lange (1), femoral hypoplasia – unusual facies (1), foetal carbimazole (1), Fraser (1), Freeman-Sheldon (1), Frey's (1), genitopatellar (1), hypoplastic left heart (1), Jacobsen (1), Job (1), Kabuki (3), Kallmann (1), Katargener's (1), Kawasaki (2), Keipert (1), Kenny-Caffey (1), Knobloch (1), Malpuech (2), Moya Moya (1), neonatal abstinence (1), oculo-facio-cardio-dental (1), Parry-Romberg (1), Prader-Wili (1), Rothmund-Thomson (1), Turner's (1), Walker-Warburg (1), VATER Syndrome vertebrae, anus, trachea, oesophagus, and renal (1), Other (5) |
| (20) DENTAL                                     | Dental (6)   |
| (22) LEGAL ISSUES                               | Legal or care issues (13)  |
| (23) OTHER                                      | Carbonic anhydrase II deficiency-condition (1), complex IV respiratory chain deficiency (1), diagnostically challenging case (1), enterocolic venopathy (1), gastric stromal tumours (1), growth and development – craniosynostosis (1), hyperandrogenism (1), iatrogenic event (1), kidney disease (1), latex allergy (1), lipomyelocele (1), long chain fatty acid oxidation defects (1), microgastria (1), microtia (1), nasal chondromesenchymal hamartoma (1), nephrocalcinosis (1), raised acute phase reactants (1), rhombencephalosynapsis (1), severe factor X deficiency (1)   |

**Table 20: Case studies – ICD-10**

| BLOCK              | TITLE  |
|--------------------|--|
| B20-B24<br>A00-B99 | <b>Certain infectious and parasitic diseases [24]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Human immunodeficiency virus [HIV] disease (9)</li> <li><input type="checkbox"/> Intestinal infectious diseases – cryptosporidiosis (2)</li> <li><input type="checkbox"/> Viral hepatitis – hepatitis C (3)</li> <li><input type="checkbox"/> Viral infections characterised by skin and mucous membrane lesions – measles (1)</li> <li><input type="checkbox"/> Other bacterial diseases – meningococcal disease (1)</li> <li><input type="checkbox"/> Helminthiasis – ocular toxocariasis (1)</li> <li><input type="checkbox"/> Mycoses – onychomycosis (1), Tinea capitis (1)</li> <li><input type="checkbox"/> Tuberculosis – tuberculosis (3)</li> <li><input type="checkbox"/> Viral infections characterised by skin and mucous membrane lesions – varicella (2)</li> </ul> |
| C00-D48            | <b>Neoplasms [9]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Malignant neoplasms – lymphoblastic leukemia (1), lymphoid malignancies (1), neuroblastoma (5), pheochromocytoma (1), thyroid medullary carcinoma (1)</li> </ul>  |
| D50-D89            | <b>Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism [3]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Other diseases of blood and blood-forming organs – chronic granulomatous disease (1)</li> <li><input type="checkbox"/> Haemolytic anaemias – haemolytic disease (1)</li> <li><input type="checkbox"/> Coagulation defects, purpura and other haemorrhagic conditions – thrombocytopenia (1)</li> </ul>  |
| E00-E90            | <b>Endocrine, nutritional and metabolic diseases [20]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Obesity and other hyperalimentation – obesity (5)</li> <li><input type="checkbox"/> Diabetes mellitus – type 1 diabetes mellitus (4)</li> <li><input type="checkbox"/> Metabolic disorders – cystic fibrosis (8), glutaric aciduria type 1 (1), hyponatraemia (1)</li> <li><input type="checkbox"/> Other – Familial Glucocorticoid Deficiency (1)</li> </ul>  |

Table 20: Case studies – ICD-10 (*continued*)

| BLOCK   | TITLE  |
|---------|--|
| F00-F99 | <b>Mental and behavioural disorders [48]</b> <ul style="list-style-type: none"> <li>□ Behavioural and emotional disorders with onset usually occurring in childhood and adolescence – attention-deficit hyperactivity disorder (24)</li> <li>□ Disorders of psychological development – autism (8)</li> <li>□ Disorders of psychological development – dyslexia (2)</li> <li>□ Disorders of psychological development – learning disabilities (4)</li> <li>□ Mental retardation – intellectual disabilities (6)</li> <li>□ Mood [affective] disorders – bipolar affective disorder (1), depression (1)</li> <li>□ Other ill-defined mental health problems (1)</li> <li>□ Schizophrenia, schizotypal and delusional disorders – schizophrenia (1)</li> </ul>               |
| G00-G99 | <b>Diseases of the nervous system [20]</b> <ul style="list-style-type: none"> <li>□ Cerebral palsy and other paralytic syndromes – cerebral palsy (13), spastic paraplegia (1)</li> <li>□ Episodic and paroxysmal disorders – epilepsy (2), obstructive sleep apnea (1)</li> <li>□ Extrapyramidal and movement disorders – dystonia-Parkinsonism (1)</li> <li>□ Inflammatory diseases of the central nervous system – meningitis (1)</li> <li>□ Systemic atrophies primarily affecting the central nervous system – Friedreich's Ataxia (1)</li> </ul>   |
| H00-H59 | <b>Diseases of the eye and adnexa [5]</b> <ul style="list-style-type: none"> <li>□ Disorders of ocular muscles, binocular movement, accommodation and refraction – myopia (1)</li> <li>□ Disorders of choroid and retina – diabetic retinopathy (1), retinopathy of prematurity (2)</li> <li>□ Disorders of sclera, cornea, iris and ciliary body – uveitis (1)</li> </ul>   |
| H60-H95 | <b>Diseases of the ear and mastoid process [2]</b> <ul style="list-style-type: none"> <li>□ Other disorders of ear – deafness (2)</li> </ul>   |
| I00-I99 | <b>Diseases of the circulatory system [2]</b> <ul style="list-style-type: none"> <li>□ Ischaemic heart disease (2)</li> </ul>  |
| J00-J99 | <b>Diseases of the respiratory system [15]</b> <ul style="list-style-type: none"> <li>□ Chronic lower respiratory diseases – asthma (7), chronic lung disease (1)</li> <li>□ Influenza and pneumonia – influenza (1)</li> <li>□ Lower respiratory pathogens (1)</li> <li>□ Other acute lower respiratory infections – bronchiolitis (1)</li> <li>□ Pneumonitis (1)</li> <li>□ Other – respiratory/tract (3)</li> </ul>   |
| K00-K93 | <b>Diseases of the digestive system [4]</b> <ul style="list-style-type: none"> <li>** Appendectomy (1)</li> <li>□ Non-infective enteritis and colitis – Crohn's Disease (1)</li> <li>□ Other diseases of the digestive system – Coeliac Disease (2)</li> </ul>   |
| L00-L99 | <b>Diseases of the skin and subcutaneous tissue [3]</b> <ul style="list-style-type: none"> <li>□ Dermatitis and eczema – atopic dermatitis (1), eczema (2)</li> </ul>  |
| M00-M99 | <b>Diseases of the musculoskeletal system and connective tissue [11]</b> <ul style="list-style-type: none"> <li>□ Dorsopathies – scoliosis (6)</li> <li>□ Osteopathies and chondropathies – avascular necrosis (1), Caffey's Disease (1), Perthes' Disease (1), dermatomyositis (2)</li> </ul>   |
| N00-N99 | <b>Diseases of the genitourinary system [8]</b> <ul style="list-style-type: none"> <li>□ Other diseases of urinary system – upper urinary tract (1)</li> <li>□ Renal tubulo-interstitial diseases – vesicoureteric reflux (4)</li> <li>□ Glomerular diseases – type 2 membranoproliferative glomerulonephritis (1), membranoproliferative glomerulonephritis type III (1)</li> <li>□ Other – renal failure (1)</li> </ul>  |
| O00-O99 | <b>Pregnancy, childbirth and the puerperium [25]</b> <ul style="list-style-type: none"> <li>** Chorioamnionitis (2), active management of labour (1), birth weight (1), breastfeeding (2), caesarean section (4), delivery outcomes (1), diabetes and pregnancies (1), elective induction for post-term pregnancy (1), foetal cortisol and labour (1), foetal macrosomia and non-diabetic women (1), hydramnios (1), immigrant women (2), labour and epidural analgesia effects on plasma alpha1-acid glycoprotein concentration (1), maternal antenatal emotional attachment (1), pelvic floor musculature (1), perinatal factors and pre-term delivery (1), postnatal care (1), seasonal variation in birth weight (1), twin-to-twin transfusion syndrome (1)</li> </ul> |

Table 20: Case studies – ICD-10 (*continued*)

| BLOCK   | TITLE  |
|---------|--|
| P00-P96 | <b>Certain conditions originating in the perinatal period [2]</b> <ul style="list-style-type: none"> <li>□ Haemorrhagic and haematological disorders of foetus and newborn – Haemolytic Disease (1), Rhesus D Hydrops foetalis (1)</li> </ul>  |
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [33]</b> <ul style="list-style-type: none"> <li>□ Other viral diseases – congenital cytomegalovirus (2)</li> <li>□ Other – congenital anomaly (1), congenital velopharyngeal insufficiency (1), other congenital malformations – Kabuki Syndrome (1), congenital malformations (1), congenital vertebral anomaly (2), clubfoot (1), heart disease (1), neural tube defect – condition (3)</li> <li>□ Cleft lip and/or palate (3)</li> <li>□ Chromosomal abnormalities, not elsewhere classified – Down’s Syndrome (6)</li> <li>□ Congenital malformations and deformations of the musculoskeletal system – dysplasia of the hip (1), exomphalos (1)</li> <li>□ Other congenital malformations of the digestive system – Hirschsprung’s Disease (1), hypertrophic pyloric stenosis (2)</li> <li>□ Congenital malformations of the circulatory system – patent ductus arteriosus (1), perimembranous ventricular septal defect (1), pulmonary atresia (2), spina bifida (2)</li> </ul> |
| R00-R99 | <b>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified [6]</b> <ul style="list-style-type: none"> <li>□ Ill-defined and unknown causes of mortality – Sudden Infant Death Syndrome (4)</li> <li>□ Symptoms and signs involving the circulatory and respiratory systems – epistaxis (2)</li> </ul>  |
| S00-T98 | <b>Injury, poisoning and certain other consequences of external causes [22]</b> <ul style="list-style-type: none"> <li>□ Injury (21), poisoning (1)</li> </ul>   |
| V01-Y98 | <b>External causes of morbidity and mortality [4]</b> <ul style="list-style-type: none"> <li>□ Intentional self-harm – deliberate self-harm (1), suicidal ideation/behaviour (1), suicide (2)</li> </ul>   |

Table 21: Case studies – themed, non-classifiable, health-related outcomes

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (1) MICROSCOPIC ORGANISMS                       | Bacterial monitoring (1), Burkholderia cepacia (1), Campylobacter upsaliensis (1), Chlamydia trachomatis (1), Enterobacter sakazakii (2), genus Bifidobacterium (1), Helicobacter pylori (3), Lactobacillus (1), Lactobacillus salivarius (1), Lactobacillus, Lactococcus, Pediococcus and Bifidobacterium (1), Mycoplasma pneumoniae (1), non-b Haemophilus influenzae disease (1), Staphylococcus aureus (1), Streptococcus (1), Streptococcus pneumoniae (2), Candida albicans (1), Candideamia (1), methicillin-resistant Staphylococcus aureus (3), vancomycin-resistant enterococci (2), vancomycin-resistant Enterococcus faecium (1), Escherichia coli serotype O26:H11 (2), BK polyomavirus (1), herpesvirus (1), norovirus (1), Norwalk-like viruses, astroviruses (1), rotavirus (4)  |
| (2) IMMUNOLOGY                                  | Interleukin-2 (1), neutrophils (1), primary immunodeficiency disorders (1), thymic emigrants (1)   |
| (4) PSYCHOLOGY                                  | Psychosocial effects of illness (1), psychotic effects of traumatic event (1), self-esteem (3), applied behaviour analysis (1), bullying (6), community-based youth counselling services (1), children’s understanding of illness and injury (1), concepts of well-being (1), aberrant behaviour (1), historical thinking (1), intergroup forgiveness (1), language (2), maternal well-being (1), parental – perceived parental expectation and criticism (1), parents’ perceptions of their interactions with their children (1), perspective-taking (1), positive attachment in early infancy (1), post-partum family experiences (1), psychological health (1), reasoning ability (1), reflection (1), religion (3), same-sex attraction (1), self-reported health (1), shock (1), sustained attention (1), theory of planned behaviour (1) |

Table 21: Case studies – themed, non-classifiable, health-related outcomes (*continued*)

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (5) SOCIOLOGY                                   | Assessment of vulnerable children (1), child-initiated play versus adult-directed activities (1), cross-border partnership (1), cross-community marriage (1), cross-cultural conditions (1), cross-cultural experiences (1), cross-cultural minority-majority group intermarriages (1), cross-national collaboration through information and communications technology (1), demographics of a Northern Irish town (1), domestic violence (1), elderly relatives' supervision of children (1), families: community needs (1), families: policy and practice (1), health and social functioning (1), homelessness (1), leaving State care (1), maternal employment characteristics (1), parental school involvement (1), political awareness (1), programme – Belfast Youth Development Study (1), programme – parent training programme on child conduct problems (1), racist (1), racist harassment (1), social disadvantage (1), socio-economic disadvantage (1), work/life balance (1), working in childhood (1), young people's heroes (1), war, violence and conflict (6) |
| (6) DRUGS                                       | Abuse (1), cigarettes (1), cisaprid ranitidine (1), diclofenac extraction (1), investigating use (1), misuse profile (1), non-licensed use (1), problem use (1), self-injectable epinephrine dispensing (1), smoking and alcohol (1), specialised drug (1), therapy (1), tobacco (2), drugs, pharmacological treatment – adverse reactions (1), anti-depressants (1), delivery systems (1)  |
| (7) BREASTFEEDING                               | Breastfeeding +/- formulae milk (6)   |
| (8) DEATHS                                      | Colorectal cancer (1), in one family (1), infanticide (1), lung cancer (1), neonatal (1), while exercising (1)  |
| (9) DISABILITIES                                | Community nurses (1), diagnostic criteria (1), information needs of parent (1), multiple (1), non-specific (2), physical (1), physical or intellectual disabilities (1), reduced vision (1), vision accommodative responses (1), visual impairment (1)  |
| (10) HEALTH SERVICES                            | Vaccination (5), health service provision (34), home support services (1)   |
| (11) MEDICAL PROCEDURES                         | Aenotonsillectomy (1), amplatzer septal occluder (1), aortoplasty (1), cataract surgery (1), caudal epidural anaesthesia (1), cochlear implant (1), fluid-attenuated inversion recovery MRI sequence in providing better margin visualization (1), Ganz osteotomy (1), island flap reconstruction, congenital incomplete syndactyly (1), limb amputations (1), non-bronchoscopic bronchoalveolar lavage (1), ochidopexy (1), optic nerve sheath ultrasound (1), otorhinolaryngological (1), paediatric foreign bodies (1), paediatric surgery (1), renal replacement therapy (1), spinal fusion (1), submandibular duct relocation (1), EEG measures (1), whole-body MR (1)   |
| (12) ORGAN TRANSPLANTS                          | Bone marrow (1), liver (1), renal (2)   |
| (13) SYNDROMES                                  | Beckwith-Wiedemann Syndrome (1), Coen (1), Turner (1), inflammatory response (1), Megacystis-microcolon-intestinal hypoperistalsis (1), Schinzel-Giedion (1)  |
| (14) PREMATUREITY                               | Babies (1), children (2), infants (3), neonates (1)   |
| (15) ANATOMY                                    | Schoolchildren's posture (1), testicular sperm (1), the human gut (1), inflammatory bowel disease – non-specific (1)  |
| (16) GROWTH AND DEVELOPMENT                     | Anthropometry – infant weight (1), growth and development – effect of baby walkers on the achievement of normal locomotory milestones (1), height, weight (1), infant physiological and movement responses (1), parental reporting of selected variables related to development (1), psychological data (1), algorithm to measure gait (1), gait in children with cerebral palsy (1), locomotor ability in children with cerebral palsy (1), gait using modelling software (1)  |
| (17) DIET AND LIFESTYLE                         | Diet and lifestyle (8)  |
| (18) PHYSICAL ACTIVITY                          | Physical activity (9)   |
| (19) EDUCATION                                  | Education (22), including papers on education and care (1), education and violence (1) and endangered language (1)  |
| (20) DENTAL                                     | Dental (23)   |

**Table 21: Case studies – themed, non-classifiable, health-related outcomes (continued)**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (21) BIOLOGICAL MARKERS                         | Prion protein gene (1), apoptosis-programmed cell death (1), autologous dendritic cells (1), bile salt-stimulated lipase (1), bone cells (1), cardiac troponin I (1), Cobb angle (1), cord blood T-cell biology (1), folate and folic acid (2), gestational iron status (1), ilioinguinal/iliohypogastric nerve block (1), intervertebral disc (2), intestinal aganglionosis (1), intraocular pressure (1), maternal and cord leptin concentrations (1), mesangioproliferative glomerulonephritis (1), mesenteric cysts (1), mitochondrial cytopathies (1), natural-killer (NK) cell deficiency (1), oxidative stress marker (1), oxygen saturation in flights (1), paediatric brain at autopsy (1), severe recurrent abdominal pain (1), sigmoid sinus thrombosis (1), Vitamin D (1), Vitamin K (1)  |
| (22) LEGAL ISSUES                               | Adoption (7), child abuse (2), child neglect (1), child protection (3), consent (1), legal or care issues (7), the Police Ombudsman (1), sexual abuse – assault (1), sexual abuse – demographic characteristics (1), sexual abuse – generic (1), sexual abuse – offenders (1), sexual abuse – perpetrators (1), sexual abuse – policy, practice and service delivery (1)  |
| (23) OTHER                                      | Aacrylamide (1), bone-anchored hearing aids (1), cardiopulmonary resuscitation instruction (1), chronic and/or life-threatening illness (1), chronic illness (1), constipation (1), exposure to food-packaging migrants (1), fertility (2), genome-wide linkage scan (1), health status measure (1), herbal medicine (1), homocysteine-lowering treatment (1), impaired vocal quality (1), isoflavone intake (1), life-threatening event (2), life-threatening illness (1), low systemic flow (1), mid-year population estimates (1), non-syndromic trigonocephaly patients (1), pain (2), parenteral nutrition-dependence (1), pollution (1), radon/radon levels (2), resolution acuity (1), respiratory health of children (1), rhombencephalitis (1), Salmonella bredeney (1), the Irish Roma gypsy population (1), neonatal seizures (4). (Also 1 abstract from a conference for which the actual paper was included in the mapping study.) |

**Table 22: Cross-sectional studies – ICD-10**

| BLOCK   | TITLE   |
|---------|---|
| E00-E90 | <b>Endocrine, nutritional and metabolic diseases [4]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Obesity and other hyperalimentation – obesity (2)</li> <li><input type="checkbox"/> Diabetes mellitus – diabetes mellitus (2)</li> </ul> |
| F00-F99 | <b>Mental and behavioural disorders [2]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Disorders of psychological development – dyslexia (1)</li> <li><input type="checkbox"/> Mood [affective] disorders – depression (1)</li> </ul>        |
| G00-G99 | <b>Diseases of the nervous system [2]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Cerebral palsy and other paralytic syndromes – cerebral palsy (2)</li> </ul>  |
| H00-H59 | <b>Diseases of the eye and adnexa [1]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Disorders of ocular muscles, binocular movement, accommodation and refraction – cycloplegia (1)</li> </ul>  |
| J00-J99 | <b>Diseases of the respiratory system [1]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Chronic lower respiratory diseases – asthma (1)</li> </ul>  |
| O00-O99 | <b>Pregnancy, childbirth and the puerperium [2]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Pregnancy, childbirth and the puerperium (2)</li> </ul>   |
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [2]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Chromosomal abnormalities, not elsewhere classified – Down's Syndrome (1), neural tube defects (1)</li> </ul>     |
| R00-R99 | <b>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified [1]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Ill-defined and unknown causes of mortality – Sudden Infant Death Syndrome (1)</li> </ul>      |
| S00-T98 | <b>Injury, poisoning and certain other consequences of external causes [2]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Injury (2)</li> </ul>  |
| V01-Y98 | <b>External causes of morbidity and mortality [1]</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Intentional self-harm – suicidal (1)</li> </ul>   |

**Table 23: Cross-sectional studies – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (4) PSYCHOLOGY                                  | Drugs – alcohol (1), bullying (2), supportive relationships (1), loneliness (1), self-reported health (1) |
| (5) SOCIOLOGY                                   | War, violence and conflict (1), social status and social exclusion (1), vulnerable families (1)           |
| (7) BREASTFEEDING                               | Breastfeeding +/- formulae milk (1)   |
| (10) HEALTH SERVICES                            | Health service provision (1), vaccinations (2)  |
| (11) MEDICAL PROCEDURES                         | Procedures (1)  |
| (16) GROWTH AND DEVELOPMENT                     | Epiphyseal union (1)  |
| (17) DIET AND LIFESTYLE                         | Diet and lifestyle (diet and skeletal growth) (10)  |
| (18) PHYSICAL ACTIVITY                          | Physical activity (5)   |
| (19) EDUCATION                                  | Education (2)   |
| (20) DENTAL                                     | Dental (3)  |
| (21) BIOLOGICAL MARKERS                         | Vitamin D (1), lateral preference (1)   |
| (22) LEGAL ISSUES                               | Human rights (1)  |
| (23) OTHER                                      | Alternative medicines (1)   |

**Table 24: Surveillance studies – ICD-10**

| BLOCK   | TITLE   |
|---------|---|
| A00-B99 | <b>Certain infectious and parasitic diseases [4]</b> <ul style="list-style-type: none"> <li>☐ Intestinal infectious diseases – cryptosporidiosis (1)</li> <li>☐ Intestinal infectious diseases – salmonellosis (1)</li> <li>☐ Other viral diseases – mumps (1)</li> <li>☐ Protozoal diseases – malaria (1)</li> </ul> |
| J00-J99 | <b>Diseases of the respiratory system [4]</b> <ul style="list-style-type: none"> <li>☐ Influenza and pneumonia – influenza (4)</li> </ul>   |
| L00-L99 | <b>Diseases of the skin and subcutaneous tissue [1]</b> <ul style="list-style-type: none"> <li>☐ Infections of the skin and subcutaneous tissue – staphylococcal scalded skin syndrome (1)</li> </ul>   |

**Table 25: Surveillance studies – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED                  |
|---|--|
| (1) MICROSCOPIC ORGANISMS                       | E. coli (2), norovirus (1)                 |
| (10) HEALTH SERVICES                            | Vaccinations (3)                           |
| (23) OTHER                                      | Surveillance – contaminated city water (1) |



Table 26: Case series – ICD-10

| BLOCK   | TITLE  |
|---------|--|
| A00-B99 | <b>Certain infectious and parasitic diseases [4]</b> <ul style="list-style-type: none"> <li>□ Viral infections characterised by skin and mucous membrane lesions – plantar warts (1), measles (1)</li> <li>□ Human immunodeficiency virus [HIV] disease (1)</li> <li>□ Bacterial, viral and other infectious agents – respiratory syncytial virus infection (1)</li> </ul>   |
| C00-D48 | <b>Neoplasms [8]</b> <ul style="list-style-type: none"> <li>□ Malignant neoplasms – retinoblastoma (1), posterior fossa tumours (1), pheochromocytoma (1), leukemia (1), Hodgkin's lymphoma (2)</li> <li>□ Benign neoplasms – respiratory papillomatosis (1), haemangioma (1)</li> </ul>   |
| D50-D89 | <b>Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism [3]</b> <ul style="list-style-type: none"> <li>□ Coagulation defects, purpura and other haemorrhagic conditions – haemophilia (3)</li> </ul>  |
| E00-E90 | <b>Endocrine, nutritional and metabolic diseases [4]</b> <ul style="list-style-type: none"> <li>□ Metabolic disorders – glutaric aciduria type 1 (2)</li> <li>□ Disorders of the thyroid gland (1)</li> <li>□ Adrenal disease (1)</li> </ul>   |
| G00-G99 | <b>Diseases of the nervous system [2]</b> <ul style="list-style-type: none"> <li>□ Nerve, nerve root and plexus disorders – non-traumatic brachial plexopathy (1)</li> <li>□ Cerebral palsy and other paralytic syndromes – cerebral palsy (1)</li> </ul>  |
| H00-H59 | <b>Diseases of the eye and adnexa [12]</b> <ul style="list-style-type: none"> <li>□ Disorders of ocular muscles, binocular movement, accommodation and refraction – esotropia (1), myopia (1)</li> <li>□ Visual disturbances and blindness – amblyopia (1)</li> <li>□ Glaucoma (1)</li> <li>□ Disorders of vitreous body and globe – endophthalmitis (1)</li> <li>□ Disorders of lens – paediatric aphakic glaucoma (1), ectopia lentis (1)</li> <li>□ Disorders of choroid and retina – diabetic retinopathy (1), retinopathy of prematurity (3), Coats' Disease (1)</li> </ul> |
| H60-H95 | <b>Diseases of the ear and mastoid process [3]</b> <ul style="list-style-type: none"> <li>□ Diseases of middle ear and mastoid – otitis media (2), mastoiditis (1)</li> </ul>  |
| I00-I99 | <b>Diseases of the circulatory system [1]</b> <ul style="list-style-type: none"> <li>□ Ischaemic heart disease (1)</li> </ul>  |
| J00-J99 | <b>Diseases of the respiratory system [1]</b> <ul style="list-style-type: none"> <li>□ Acute upper respiratory infections – sinusitis (1)</li> </ul>   |
| K00-K93 | <b>Diseases of the digestive system [10]</b> <ul style="list-style-type: none"> <li>□ Other diseases of the digestive system – Coeliac Disease (1)</li> <li>□ Other diseases of intestines – intussusception (1)</li> <li>□ Non-infective enteritis and colitis – Crohn's Disease (1), ulcerative colitis (1)</li> <li>** Appendixes (1), appendicoliths (2), appendectomy (2), anal sphincter achalasia (1)</li> </ul>  |
| N00-N99 | <b>Diseases of the genitourinary system [15]</b> <ul style="list-style-type: none"> <li>□ Renal tubulo-interstitial diseases – vesicoureteric reflux (12)</li> <li>□ Other disorders of kidney and ureter-ureterocele (1)</li> <li>□ Other diseases of urinary system – urinary tract infection (2)</li> </ul>   |
| O00-O99 | <b>Pregnancy, childbirth and the puerperium [5]</b> <ul style="list-style-type: none"> <li>□ Pregnancies with non-Rh-D antibody (1), pregnancies in diabetic women (1), outcome of pregnancies with singleton breech presentation at term (1), obstetric antecedents for pre-term delivery (1), cardiac function in pre-term infants (1)</li> </ul>  |
| P00-P96 | <b>Certain conditions originating in the perinatal period [1]</b> <ul style="list-style-type: none"> <li>□ Digestive system disorders of foetus and newborn – necrotising enterocolitis (1)</li> </ul>   |

Table 26: Case series – ICD-10 (*continued*)

| BLOCK   | TITLE  |
|---------|--|
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [23]</b> <ul style="list-style-type: none"> <li>❑ Other congenital malformations of the digestive system – Symptomatic Meckel's diverticulum (1), oesophageal atresia (1), jejunal atresia (1), Hirschsprung's Disease (3), biliary atresia (1)</li> <li>❑ Other congenital malformations – exomphalos major (1), epidermolysis bullosa (1)</li> <li>❑ Congenital malformations of the nervous system – spina bifida (1)</li> <li>❑ Congenital malformations of the circulatory system – congenital heart disease (1), atrioventricular septal defects (1), anomalous left coronary artery (1)</li> <li>❑ Congenital malformations of genital organs – undescended testis (1), cryptorchid (1)</li> <li>❑ Congenital malformations of eye, ear, face and neck – congenital nasolacrimal duct obstruction (1)</li> <li>❑ Congenital malformations and deformations of the musculoskeletal system – scaphocephaly (1)</li> <li>❑ Cleft lip and cleft palate – cleft lip and/or palate (1)</li> <li>❑ Chromosomal abnormalities, not elsewhere classified – Down's Syndrome (1)</li> <li>❑ Others – congenital vertebral anomaly (1), congenital cataract surgery (1), congenital and developmental cataract (1), congenital coagulation disorders (1)</li> </ul> |
| R00-R99 | <b>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified [2]</b> <ul style="list-style-type: none"> <li>❑ Symptoms and signs involving the circulatory and respiratory systems – epistaxis (1)</li> <li>❑ General symptoms and signs – hyperhidrosis (1)</li> </ul>  |
| S00-T98 | <b>Injury, poisoning and certain other consequences of external causes [24]</b> <ul style="list-style-type: none"> <li>❑ Poisons (1), near drowning (1), injury (13), fracture (9)</li> </ul>  |

Table 27: Case series – ICD-O-3

|               |                     |
|---------------|---------------------|
| ICD-O: 9200/0 | Osteoid osteoma [2] |
|---------------|---------------------|

Table 28: Case series – themed, non-classifiable, health-related outcomes

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (1) MICROSCOPIC ORGANISMS                       | Bacterium – <i>Helicobacter pylori</i> (1)   |
| (6) DRUGS                                       | Drugs – analgesia (1)  |
| (8) DEATHS                                      | Death – serum albumin and mortality (1)  |
| (10) HEALTH SERVICES                            | Hospital infection – in a neurosurgical unit (1), in a neonatal intensive care unit (1)  |
| (11) MEDICAL PROCEDURES                         | Ablation for ingrown toenails (1), alveolar bone grafts (1), bilateral intraocular lens implants (1), bone grafting of alveolar cleft (1), cholecystectomy (2), cochlear implant (2), congenital diaphragmatic hernia repair (1), distal hypospadias repair (1), endoscopic correction and contralateral reflux (1), femoral epiphysis fixation (2), FEV <sub>1</sub> (1), foreign bodies extraction (1), heminephrectomy (2), heminephrectomy (1), hydroxyapatite orbital implants (1), invasive surgery (1), lumbar interbody fusion (1), myelomeningocele (1), orchidopexy (1), pacing lead (1), paediatric mitral repair (1), penetrating keratoplasty (1), percutaneous transhepatic broviac insertion (1), perioperative antimicrobial therapy (1), preputioplasty (1), pulmonary function studies (1), radiotherapy on abdominopelvic tumours (1), sedation with oral chloral hydrate (1), septorhinoplasty (1), subscapularis muscle release (1), surgery for canal wall down mastoid (1), surgery for primary avulsion of posterior urethral valves (1), surgical repair of retinal dialysis (1), titanium elastic nails (1), tonsillectomy (2), treatment of acute deep vein thrombosis (1), treatment of acute scrotal pain (1), trigonocephaly (2), unilateral inguinal hernia repair (1), velopharyngeal (1), ventricular septal defect closure (1), video-assisted thyroidectomy (1) |
| (12) ORGAN TRANSPLANTS                          | Bone marrow (3), cadaveric (1), cryopreserved homografts (1), kidney (2), renal (7)  |
| (13) SYNDROMES                                  | Auto-immune polyendocrinopathy (1), auto-immune polyendocrinopathy-candidiasis-ectodermal dystrophy (1), Bertolotti's (1), cyclic vomiting (1), Hurler (1), Kawasaki (1), Pendred (1), Sturge-Weber (1), toxic shock (1), Turner (1)   |
| (14) PREMATUREITY                               | Premature – infants (1)  |

**Table 28: Case series – themed, non-classifiable, health-related outcomes (continued)**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (21) BIOLOGICAL MARKERS                         | Acute airway admissions (1), anomalous left coronary artery (1), antenatal diagnosis of pelvi-ureteric junction obstruction (1), cardiac murmurs (1), haemostatic response (1), hernia (2), inflammatory bowel disease – non-specific (1), internal hip rotation gait (1), kidney disease (1), laryngeal clefts (1), intestinal neuronal dysplasia (1), nasal foreign bodies (1), nostril stenosis (1), perivillous fibrinoid (1), refractory hypertension (1), rupture of the urethra (1), superior vena cava flow (1), translevator anal anomalies (1), trauma admissions (1), tumour necrosis factor alpha (TNFalpha) (1), tumours of the ovary – condition (1), variants in the paediatric orthopaedic population (1), vascular birth marks (1), ventricular stoma (1), neonatal seizures (1) |

### Descriptive studies that measured aspects of effectiveness

Of the studies that measured aspects of effectiveness, there were 41 audit studies (1.9%); 105 studies (4.8%) that examined the practice or knowledge of health professionals, health-related professionals or parents; 30 intervention studies (1.4%); and 11 validation studies (0.5%).

Among the 41 **audit studies**, 32 papers (1.5%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 9 (0.5%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: deaths (1); medical procedures (4); organ transplants (2); dental (1); and Other (1). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 29 and 30**.

Among the 105 studies that examined the **practice or knowledge of health professionals, health-related professionals or parents**, 13 papers (0.6%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 92 (4.2%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: psychology (1); sociology (3); breastfeeding (1); deaths (2); disabilities (1); health services (48); medical procedures (16); syndromes (1); education (7); dental (3); legal issues (6); and Other (4). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 31 and 32**.

Among the 30 **intervention studies**, 8 papers (0.4%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 22 (1%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (1); psychology (8); sociology (3); health services (1); medical procedures (1); diet and lifestyle (2); physical activity (1); education (2); dental (2); and biological markers (1). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 33 and 34**.

Among the 11 **validation studies**, 3 papers (0.1%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 9 (0.5%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (1); drugs (1); physical activity (1); and Other (6). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 35 and 36**.



Table 29: Audit studies – ICD-10

| BLOCK   | TITLE  |
|---------|--|
| A00-B99 | <b>Certain infectious and parasitic diseases [3]</b> <ul style="list-style-type: none"> <li>☐ Viral infections characterised by skin and mucous membrane lesions – cytomegalovirus (1)</li> <li>☐ Human immunodeficiency virus [HIV] disease (1)</li> <li>☐ Other viral disease – viral warts (1)</li> </ul> |
| E00-E90 | <b>Endocrine, nutritional and metabolic diseases [2]</b> <ul style="list-style-type: none"> <li>☐ Other glycaemic control (1), unexplained hypoglycaemia (1)</li> </ul>  |
| G00-G99 | <b>Diseases of the nervous system [2]</b> <ul style="list-style-type: none"> <li>☐ Episodic and paroxysmal disorders – epilepsy, status epilepticus (2)</li> </ul>   |
| L00-L99 | <b>Diseases of the skin and subcutaneous tissue [2]</b> <ul style="list-style-type: none"> <li>☐ Other disorders of the skin and subcutaneous tissue – scleroderma (1)</li> <li>☐ Disorders of skin appendages – ingrown toenails (1)</li> </ul>   |
| O00-O99 | <b>Pregnancy, childbirth and the puerperium [2]</b> <ul style="list-style-type: none"> <li>☐ Antenatal care of high-risk patients (1)</li> <li>☐ Timing of birth and obstetric and neonatal outcomes (1)</li> </ul>  |
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [1]</b> <ul style="list-style-type: none"> <li>☐ Other congenital malformations of the digestive system – hypertrophic pyloric stenosis (1)</li> </ul>   |
| S00-T98 | <b>Injury, poisoning and certain other consequences of external causes [1]</b> <ul style="list-style-type: none"> <li>☐ Other – injuries (1)</li> </ul>  |
| V01-Y98 | <b>External causes of morbidity and mortality [4]</b> <ul style="list-style-type: none"> <li>☐ Accidents – characteristics of all-terrain vehicles-related trauma (1)</li> <li>☐ Accidents – paediatric burns, stab or gunshot wounds (2)</li> <li>☐ Unclear – trauma (1)</li> </ul>                         |
| Z00-Z99 | <b>Factors influencing health status and contact with health services [15]</b> <ul style="list-style-type: none"> <li>☐ Persons encountering health services for examination and investigation (15)</li> </ul>   |

Table 30: Audit studies – themed, non-classifiable, health-related outcomes

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED                                      |
|---|--|
| (8) DEATHS                                      | Perinatal and neonatal (1)                                     |
| (11) MEDICAL PROCEDURES                         | Tonsillectomy (2), Hakim valve implants (1), gastroscopies (1) |
| (12) ORGAN TRANSPLANTS                          | Liver (1), cardiac (1)   |
| (20) DENTAL                                     | Oral disease in children with disability (1)                   |
| (23) OTHER                                      | Fasting time in care-givers (1)                                |

Table 31: Assessing knowledge and practice of professionals/parents – ICD-10

| BLOCK   | TITLE   |
|---------|---|
| E00-E90 | <b>Endocrine, nutritional and metabolic diseases [2]</b> <ul style="list-style-type: none"> <li>☐ Diabetes mellitus – type 1 diabetes mellitus (1)</li> <li>☐ Disorders of thyroid gland – Hashimoto's encephalopathy (1)</li> </ul>  |
| F00-F99 | <b>Mental and behavioural disorders [2]</b> <ul style="list-style-type: none"> <li>☐ Behavioural and emotional disorders with onset usually occurring in childhood and adolescence – attention deficit hyperactivity disorder (1)</li> <li>☐ Mental and behavioural disorders – psychiatric care (1)</li> </ul> |
| J00-J99 | <b>Diseases of the respiratory system [3]</b> <ul style="list-style-type: none"> <li>☐ Diseases of the respiratory system – asthma (3)</li> </ul>   |
| K00-K93 | <b>Diseases of the digestive system [1]</b> <ul style="list-style-type: none"> <li>☐ Diseases of oesophagus, stomach and duodenum – infantile hypertrophic pyloric stenosis (1)</li> </ul>  |

Table 31: Assessing knowledge and practice of professionals/parents – ICD-10 (*continued*)

|         |   |
|---------|---|
| O00-O99 | <b>Pregnancy, childbirth and the puerperium [1]</b><br><input type="checkbox"/> Pregnancy, childbirth and the puerperium – practices of obstetric intervention (1)  |
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [1]</b><br><input type="checkbox"/> Congenital malformations of eye, ear, face and neck – congenital cataracts (1)  |
| R00-R99 | <b>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified [2]</b><br><input type="checkbox"/> Abnormal findings on examination of blood, without diagnosis – haemochromatosis (1)<br><input type="checkbox"/> Ill-defined and unknown causes of mortality – Sudden Infant Death Syndrome (1) |
| S00-T98 | <b>Injury, poisoning and certain other consequences of external causes [1]</b><br><input type="checkbox"/> Injury (1)   |

Table 32: Assessing knowledge and practice of professionals/parents – themed, non-classifiable, health-related outcomes

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (4) PSYCHOLOGY                                  | Sexual abuse – good practice in relation to youth who have experienced abuse (1)  |
| (5) SOCIOLOGY                                   | Critical incidents (1), domestic violence (1), men's abuse of women (1)   |
| (7) BREASTFEEDING                               | Breastfeeding (1)   |
| (8) DEATHS                                      | Intensive care neonatal deaths (1), infant death necropsy reporting (1)   |
| (9) DISABILITIES                                | Intellectual, physical and sensory disability among Traveller children (1)  |
| (10) HEALTH SERVICES                            | Paediatric ambulatory assessment service (1), paediatric endocrine services (1), vaccinations (3), service quality health-promoting services (1), antibiotic and antifungal policies in neonatal units (1), antifungal prophylaxis (1), asthma prescribing pattern (1), current service configuration (1), antenatal care (1)<br><br><b>Policies and practice:</b> neonatal examination (1), neonatal intensive care (1), neonatal nutrition policies (1), neonatal service planning (1), palliative care (1), use of oesophageal and precordial stethoscopes for monitoring (1), resuscitation (1), oxygen in anaesthesia (1), propofol infusion (1), orthodontic (1), regional paediatric surgical services (1), spirometry measurements (1), maternity care (1), issues in regional neonatal units (1), neonatal seizures (1), non-accidental injury (1), paediatric non-accidental injury (1), psychiatric disorder (1), severe chronic lung disease (1), special needs children (1), parents with acute psychiatric illness (1), management of a screaming child with a penetrating eye injury (1), ethical decision-making in neonatal intensive care unit (1), general consultations (1), general paediatric surgery (1), genetic investigations (1), HIV-guidelines (1), Tx onsteroidal anti-inflammatory drugs (1), prescribing practices (1), radiation dose (1), Vitamin K (1), Vitamin K prophylaxis (1), intravenous fluids (1), anticoagulation (1), treatment of children (1), blood pressure (1), bronchiolitis (1) |
| (11) MEDICAL PROCEDURES                         | Anaesthesia (1), analgesia in dental practice (2), anaesthesia and immunisation (1), conscious sedation (1), impact of Cochrane Report on paediatric anaesthetic practice (1), episiotomy (1)<br><br>Enteral tube feeding in the community (1), resuscitation of thermal injury (1), correct tracheal tube placement (1), blood gas monitoring (1), chronic lung disease oxygen requirements (1), insertion of central venous catheters (1), bone-anchored hearing aids (1), cochlear implants (1), trauma and orthopaedics (1)   |
| (13) SYNDROMES                                  | Androgen insensitivity syndrome inguinal hernias (1)  |
| (19) EDUCATION                                  | Education (5), literacy and competency (1), Index of Orthodontic Treatment Need (1)   |
| (20) DENTAL                                     | Avulsed permanent incisors (1), dental (1), dental caries (1)   |
| (22) LEGAL ISSUES                               | Child abuse (2), child neglect (1), child physical abuse (2), child protection register (1)   |
| (23) OTHER                                      | Computer-related ergonomics (1), knowledge and accessibility of services to young families (1), radiography (1), child psychiatry (1)   |

Table 33: Intervention studies – ICD-10

| BLOCK   | TITLE  |
|---------|--|
| E00-E90 | <b>Endocrine, nutritional and metabolic diseases [2]</b> <ul style="list-style-type: none"> <li>☐ Diabetes mellitus – type 1 diabetes mellitus (1)</li> <li>☐ Obesity and other hyperalimantation – obesity (1)</li> </ul>   |
| F00-F99 | <b>Mental and behavioural disorders [3]</b> <ul style="list-style-type: none"> <li>☐ Mental retardation – intellectual disabilities (1)</li> <li>☐ Disorders of psychological development – learning disabilities (1)</li> <li>☐ Behavioural and emotional disorders with onset usually occurring in childhood and adolescence – selective mutism (1)</li> </ul> |
| J00-J99 | <b>Diseases of the respiratory system [1]</b> <ul style="list-style-type: none"> <li>☐ Chronic lower respiratory diseases – asthma (1)</li> </ul>  |
| M00-M99 | <b>Diseases of the musculoskeletal system and connective tissue [1]</b> <ul style="list-style-type: none"> <li>☐ Osteopathies and chondropathies – Perthes' Disease (1)</li> </ul>   |
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [1]</b> <ul style="list-style-type: none"> <li>☐ Neural tube defects – condition (1)</li> </ul>  |

Table 34: Intervention studies – themed, non-classifiable, health-related outcomes

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (1) MICROSCOPIC ORGANISMS                       | Staphylococcus aureus (1)  |
| (4) PSYCHOLOGY                                  | Sexual abuse – evaluate a group-based intervention (1), effectiveness of individual therapy (1)<br>War, violence and conflict (1), bullying (1), children's behaviour and the levels of stress experienced by parents (1), poor social-emotional health (1), perceptual processes (1), exemplar training (1) |
| (5) SOCIOLOGY                                   | Parenting programmes (1), family programme (1), sibling support programme (1)  |
| (10) HEALTH SERVICES                            | Hospital infection (1)   |
| (11) MEDICAL PROCEDURES                         | Cardiopulmonary resuscitation (1)  |
| (17) DIET AND LIFESTYLE                         | Diet and lifestyle (2)   |
| (18) PHYSICAL ACTIVITY                          | Switch Off – Get Active (1)  |
| (19) EDUCATION                                  | Education (2)  |
| (20) DENTAL                                     | Dental (2)   |
| (21) BIOLOGICAL MARKERS                         | Reactions to sunscreen chemicals (1)   |

Table 35: Validation studies – ICD 10

| BLOCK   | TITLE   |
|---------|---|
| F00-F99 | <b>Mental and behavioural disorders [1]</b> <ul style="list-style-type: none"> <li>☐ Disorders of psychological development – autism (1)</li> </ul>   |
| K00-K93 | <b>Diseases of the digestive system [1]</b> <ul style="list-style-type: none"> <li>☐ Disorders of gall bladder, biliary tract and pancreas – hereditary pancreatitis (1)</li> </ul>   |
| R00-R99 | <b>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified [1]</b> <ul style="list-style-type: none"> <li>☐ Ill-defined and unknown causes of mortality – Sudden Infant Death Syndrome (1)</li> </ul> |

**Table 36: Validation studies – themed, non-classifiable health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED*   |
|---|--|
| (1) MICROSCOPIC ORGANISMS                       | Metapneumovirus (1)  |
| (6) DRUGS                                       | Reliability of drug use reports (1)  |
| (18) PHYSICAL ACTIVITY                          | Physical activity (1)  |
| (23) OTHER                                      | Child health questionnaire (1), Family Affluence Scale (1), Health of the Nation Outcome Scales for Children (1), gastric pepsin (1), parental recall (1), serum bilirubin (1) |

\* Discrepancy of 1

### Descriptive studies with a health technology dimension

The last group of descriptive studies reported on the effectiveness of tools of measurement for the outcome of interest, on screening for the outcome of interest, on economic cost related to the outcome of interest, or the statistic on the sensitivity and specificity of a tool in measuring the outcome of interest.

Among the 31 **other study types – mainly related to measuring tools effectiveness**, all 31 papers (1.4%) examined the themed, non-classifiable, health-related outcomes. These outcomes included: psychology (4); sociology (1); health services (1); dental (2); and Other (23). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Table 37**.

Among the 24 **screening studies**, 16 papers (0.7%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 8 (0.4%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (1); organ transplants (2); prematurity (1); dental (2); and Other (2). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 38 and 39**.

Among the 12 **economic studies**, 5 papers (0.2%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 7 (0.3%) examined the themed, non-classifiable, health-related outcomes. The themed groupings, and the number of individually reported topics within these groups, were: microscopic organisms (1); health services (5); and medical procedures (1). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 40 and 41**.

Among the 32 **studies on the sensitivity and specificity of a measurement tool**, all 32 papers (1.5%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: microscopic organisms (6); and Other (26). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Table 42**.

Among the 40 **randomised controlled trials**, 22 papers (1%) reported health-related outcomes classified to one of the three- or four-digit rubric of ICD-10, while 18 (0.8%) examined the themed, non-classifiable, health-related outcomes. The themed groups, and the number of individually reported topics within these groups, were: psychology (4); medical procedures (12); and Other (2). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 43 and 44**.

**Note:** The discrepancy in numbers above reflects the one paper in the database which was a commentary and not a study.

**Table 37: Other study types – mainly related to measuring tools effectiveness – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (4) PSYCHOLOGY                                  | Children's Depression Inventory (2), cognitive distortions among sex offenders (1), perceptual assessment controlled speech stimuli (1)  |
| (5) SOCIOLOGY                                   | Children's Environmental Attitudes and Knowledge Scale (1)   |
| (10) HEALTH SERVICES                            | Effectiveness of measurement tool – a logistic regression model to predict need for admission (1)  |
| (20) DENTAL                                     | Fluoride ingestion (2)   |
| (23) OTHER                                      | <p>Compilation of the Northern Ireland Cerebral Palsy Register (1), detection of multiple allergen-specific IgEs (1), determinants of radiation dose for helical CT (1), development of an optical biosensor inhibition immunoassay (1), ECG-based classifier system (1), multi-channel EEG-based neonatal seizure detection (1), Gaussian process modelling of EEG for the detection of neonatal seizures (1), effect of antimicrobial drug use and infection control practices on nosocomial MRSA (1), effective extraction procedure for three pupal neuropeptides (1), mathematically rigorous definition of pelvic angles (1)</p> <p>Molecular cytogenetic analysis (1), one-step multiplex PCR assay (1), PCR-RFLP subtyping methods (1), optical density (1), parent interview data – in the Millennium Cohort Study (1), polyacrylamide gel electrophoresis (1), quality in services (1), reconstructing 3D volume-reformatted 'transparency' images using insufflated air as a negative contrast medium (1), reproducibility of a standardised photographic technique for recording fluorosis (1), Stay Safe Programme (1), temperature sensitive of Y42H mutation in medium-chain acyl-CoA dehydrogenase (1), the feasibility of using glucometer measurement of blood glucose on fresh blood sample (1), three-dimensional transthoracic echocardiography (1)</p> |

**Table 38: Screening studies – ICD-10**

| BLOCK   | TITLE   |
|---------|---|
| A00-B99 | <b>Certain infectious and parasitic diseases [3]</b> <ul style="list-style-type: none"> <li>☐ Tuberculosis and viral hepatitis – tuberculosis and hepatitis B (1)</li> <li>☐ Viral hepatitis – hepatitis B (1), hepatitis C (1)</li> </ul>  |
| C00-D48 | <b>Neoplasms [1]</b> <ul style="list-style-type: none"> <li>☐ Malignant neoplasms – leukaemia (1)</li> </ul>  |
| D50-D89 | <b>Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism [2]</b> <ul style="list-style-type: none"> <li>☐ Antenatal and neonatal haemoglobinopathies (1)</li> <li>☐ Beta thalassaemia (1)</li> </ul>  |
| E00-E90 | <b>Endocrine, nutritional and metabolic diseases [3]</b> <ul style="list-style-type: none"> <li>☐ Other – neonatal thyroid-stimulating hormone (1), thyroid dysfunction (1)</li> <li>☐ Endocrine, nutritional and metabolic diseases or diseases of the digestive system – Addison's Disease and Coeliac Disease (1)</li> </ul> |
| F00-F99 | <b>Mental and behavioural disorders [3]</b> <ul style="list-style-type: none"> <li>☐ Disorders of psychological development – autism (1)</li> <li>☐ Disorders of psychological development – learning disabilities (1)</li> <li>☐ Other – psychiatric disorders (1)</li> </ul>  |
| I00-I99 | <b>Diseases of the circulatory system [1]</b> <ul style="list-style-type: none"> <li>☐ Ischaemic heart disease (1)</li> </ul>   |
| N00-N99 | <b>Diseases of the genitourinary system [1]</b> <ul style="list-style-type: none"> <li>☐ Renal tubulo-interstitial diseases – vesicoureteric reflux (1)</li> </ul>  |
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [1]</b> <ul style="list-style-type: none"> <li>☐ Neural tube defects – condition (1)</li> </ul>   |
| S00-T98 | <b>Injury, poisoning and certain other consequences of external causes [1]</b> <ul style="list-style-type: none"> <li>☐ Toxic effects of substances chiefly non-medicinal as to source – lead toxicity (1)</li> </ul>   |

**Table 39: Screening studies – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (1) MICROSCOPIC ORGANISMS                       | Anti-parvovirus B19 (1)  |
| (12) ORGAN TRANSPLANTS                          | Organ transplants – renal (2)  |
| (14) PREMATUREITY                               | Premature – infants (1)  |
| (20) DENTAL                                     | Dental (2)   |
| (23) OTHER                                      | Algorithm – ‘musculoskeletal sepsis’ (1), multiple organ dysfunction score (1) |

**Table 40: Economic studies – ICD-10**

| BLOCK   | TITLE   |
|---------|---|
| C00-D48 | <b>Neoplasms [1]</b><br><input type="checkbox"/> Malignant neoplasms – acute lymphoblastic leukemia (1)                   |
| H60-H95 | <b>Diseases of the ear and mastoid process [1]</b><br><input type="checkbox"/> Stapedial reflexes (1)                     |
| P00-P96 | <b>Certain conditions originating in the perinatal period [1]</b><br><input type="checkbox"/> Extreme premature birth (1) |
| S00-T98 | <b>Injury, poisoning and certain other consequences of external causes [2]</b><br><input type="checkbox"/> Injury (2)     |

**Table 41: Economic studies – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (1) MICROSCOPIC ORGANISMS                       | Rotavirus (1)  |
| (10) HEALTH SERVICES                            | Health service provision – transport (1), health service provision – re-admissions (1), health service provision – service use data (1), vaccinations (1), vaccination 7-valent pneumococcal conjugate (1) |
| (11) MEDICAL PROCEDURES                         | Cochlear implantation (1)  |

**Table 42: Study of the sensitivity and specificity of a measurement tool – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (1) MICROSCOPIC ORGANISMS                       | Diagnostic tool laboratory – adenovirus (1), Burkholderia cepacia (2), E. sakazakii (2), norovirus (1)  |
| (23) OTHER                                      | Algorithms or statistical analysis to measure neonatal seizures (1), and gait (1), biological measure to assess encephalopathy (1), glucocorticoid measures (1), patent ductus arteriosus (1), in-hospital mortality (1), and a biomotion sensor to measure wrist-actimetry (1), endoscopy to examine rectal bleeding (1), duodenal biopsy (1), field technique to measure total energy expenditure (1), imaging techniques to measure chorionicity in twin pregnancies (1), and renal parenchymal defects (1), the quality of transmitted scans (1)<br><br>Inclusion/exclusion criteria to assess the severity of disease (1), publication criteria in reporting on perinatal mortality (1), questionnaire or other measurement scale to examine Family Affluence Scale (1), food intake (1), quality of life (1), diagnostic tool laboratory to measure ranitidine hydrochloride (1), using doubly labelled water to measure energy intake and expenditure (1), and urea breath test to test for Helicobacter pylori (1), effectiveness of homeopathy treatment for otitis external (1), observer effectiveness in Mayo early language screening test (1), person and time – scoring levels (1), screening tool – predictability of herring classification (1), vaccinations – optimal strategy for mumps (1) |

Table 43: Randomised controlled trials – ICD-10

| BLOCK   | TITLE  |
|---------|--|
| A00-B99 | <b>Certain infectious and parasitic diseases [1]</b> <ul style="list-style-type: none"> <li>□ Certain infectious and parasitic diseases – viral infections characterised by skin and mucous membrane lesions – warts (1) treatments</li> </ul>   |
| C00-D48 | <b>Neoplasms [2]</b> <ul style="list-style-type: none"> <li>□ Malignant neoplasms – leukaemia (1) treatments</li> <li>□ Malignant neoplasms – neuroblastoma (1) treatments</li> </ul>  |
| E00-E90 | <b>Endocrine, nutritional and metabolic diseases [1]</b> <ul style="list-style-type: none"> <li>□ Diabetes mellitus (1) screening</li> </ul>   |
| H00-H59 | <b>Diseases of the eye and adnexa [1]</b> <ul style="list-style-type: none"> <li>□ Disorders of choroid and retina – retinopathy of prematurity (1) treatments</li> </ul>  |
| K00-K93 | <b>Diseases of the digestive system [1]</b> <ul style="list-style-type: none"> <li>□ Diseases of appendix – appendectomy (1) treatments</li> </ul>   |
| L00-L99 | <b>Diseases of the skin and subcutaneous tissue [1]</b> <ul style="list-style-type: none"> <li>□ Other – dermatological care (1) treatments</li> </ul>   |
| O00-O99 | <b>Pregnancy, childbirth and the puerperium [2]</b> <ul style="list-style-type: none"> <li>□ Oedema, proteinuria and hypertensive disorders in pregnancy, childbirth and the puerperium – maternal hypotension (1) treatment</li> <li>□ Other – intrapartum meconium monitoring on managing pregnant women (1) screening</li> </ul>  |
| P00-P96 | <b>Certain conditions originating in the perinatal period [7]</b> <ul style="list-style-type: none"> <li>□ Respiratory and cardiovascular disorders specific to the perinatal period – lung disease (5) treatments</li> <li>□ Disorders related to length of gestation and foetal growth parenteral glutamine in pre-term neonates (1) treatments</li> <li>□ Other – ultrasound examination on the developing mother and child relationship (1) screening</li> </ul> |
| Q00-Q99 | <b>Congenital malformations, deformations and chromosomal abnormalities [5]</b> <ul style="list-style-type: none"> <li>□ Congenital malformations and deformations of the musculoskeletal system – hip dysplasia (3)</li> <li>□ Congenital malformations of the circulatory system – congenital heart disease (1) screening</li> <li>□ Congenital malformations of the nervous system – dynamic equinus spasticity (1) treatments</li> </ul>                         |
| S00-T98 | <b>Injury, poisoning and certain other consequences of external causes [1]</b> <ul style="list-style-type: none"> <li>□ Injuries to the elbow and forearm – radius buckle fractures (1) treatments</li> </ul>  |

Table 44: Randomised controlled trials – themed, non-classifiable, health-related outcomes

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (4) PSYCHOLOGY                                  | Evaluation of the effectiveness of programmes – interventions of smoking prevention programme (1), parental training programme (1), training programmes on life skills (1), community-based interventions of parenting skills (1)  |
| (11) MEDICAL PROCEDURES                         | Evaluation of the effectiveness of procedures – airway maintenance (1), cardiotocography (1), chimaeric – analysis of molecular structures (1), consultation approach – mental health (1), interventions on nutrition on fruit and vegetable intake (1), intubation (1), glucose monitoring (1), prevention of blood contamination (1), tele-dermatology v. conventional assessment of clinical features (1), biophysical ultrasound in antenatal population (1), methods of assessing clinical hip instability (1), ventilation methods (1) |
| (23) OTHER                                      | Evaluation of the effectiveness of treatments – anaesthetic drugs (1), wound dressing (1)  |

## Qualitative studies

There were a total of 102 studies (100%) that examined outcomes using a qualitative methodology. Among these, 21 papers (20%) adopted a focus group approach and 10 (9.5%) employed an anthropological or ethnographical approach.

Some outcomes have been classifiable to one of the three- or four-digit rubric of ICD-10. However, as the studies themselves were qualitative in nature, outcomes are reported under the themed, non-classifiable, health-related outcomes. The themed groupings, and the number of individually reported topics within these groups, were: psychology (37); sociology (18); drugs (7); breastfeeding (1); disabilities (2); health services (8); diet and lifestyle (1); physical activity (1); education (8); dental (2); legal issues (14); and Other (3). Details of the classified outcomes and the individual topics aggregated to create the themed health-related outcomes are detailed in **Tables 45-47**.

**Table 45: Qualitative studies – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED   |
|---|---|
| (4) PSYCHOLOGY                                  | Perceptions of risk (1), issues during pregnancy, childbirth and the puerperium: miscarriage or stillbirth (1), ultrasound diagnosis of foetal abnormality (1), women's experiences of receiving an adverse diagnosis at a routine second trimester ultrasound examination (1), congenital malformations, deformations and chromosomal abnormalities – neural tube defects (1), endocrine, nutritional and metabolic diseases, metabolic disorders – cystic fibrosis (1), mental and behavioural disorders, disorders of psychological development – learning disabilities (2), other psychological perspectives (12), mental and behavioural disorders, mental retardation – intellectual disabilities (2) |
| (5) SOCIOLOGY                                   | Ethnicity (2), fathering role – after a relationship has ended (1), fathering role – among lesbian parents (1)<br>Relationships – family and social support and early mother-child bonds (1), racial attitudes and identities (1), critical incident (1), perceptions of youth with mental health (1), war, violence and conflict (1)   |
| (6) DRUGS                                       | Drugs – alcohol (1), smoking (4), stimulant medication (1)  |
| (9) DISABILITIES                                | Disabilities – questionnaires (1)   |
| (10) HEALTH SERVICES                            | Health service provision (7), vaccinations (1)  |
| (18) PHYSICAL ACTIVITY                          | Physical activity (1)   |
| (19) EDUCATION                                  | Education (8)   |
| (20) DENTAL                                     | Dental (1)  |
| (22) LEGAL ISSUES                               | Adoption/foster care (3), legal and care issues (1), family support in the context of child protection work (1), sexual abuse – cognitions and the problematic use of the Internet (1), men convicted of downloading child pornography (1), therapists' experiences (1), children's rights (2), incarcerated babies (1), police officers (1)  |
| (23) OTHER                                      | Packaging materials used for foods (1), impact of research project (1), methodologies – the use of focus groups (1)   |

**Table 46: Anthropological studies – themed, non-classifiable, health-related outcomes**

| GROUPING          | WORKING DEFINITION  |
|-------------------|---|
| (4) PSYCHOLOGY    | 'Visible-ness' (1), intelligence (1), language (1), cystic fibrosis (1), the use of 'catch' questions (1) |
| (5) SOCIOLOGY     | War, violence and conflict (1), racial and cultural adaptive mechanisms (2)                               |
| (9) DISABILITIES  | Disability (1)  |
| (7) BREASTFEEDING | Breastfeeding (1)   |

**Table 47: Focus group studies – themed, non-classifiable, health-related outcomes**

| THEMED NON-CLASSIFIABLE HEALTH-RELATED OUTCOMES | SPECIFIC TOPICS ADDRESSED  |
|---|--|
| (4) PSYCHOLOGY                                  | Other – diseases of the nervous system – cerebral palsy (1), attitudes, needs, perceptions – families (1), first-time mothers (1), young people and risk (1), young women (1), educational psychology (1), professionals working with children – staff mental health link worker for adolescents (1), views of social workers using a ‘systematic assessment of the psychological and emotional needs of children on the edge’ (1), living with or caring for individuals with depression (1), self-harm (1) |
| (5) SOCIOLOGY                                   | Children’s perceptions of – domestic violence (1), sectarianism (1), growing up in Northern Ireland (1), the right to work (1), issues of masculinity in disadvantaged areas (1), promotion of health and social well-being (1)  |
| (6) DRUGS                                       | Drugs – attitudes to use (1)   |
| (17) DIET AND LIFESTYLE                         | Diet and lifestyle (1)   |
| (20) DENTAL                                     | Dental (1)   |
| (22) LEGAL ISSUES                               | Child protection (1), children’s interests and their rights following parental separation (1)  |

## Demographic characteristics of the study population

Characteristics of the study population consisted of person type, population type and the geographical location of the study population.

### Person and population types

The person and population characteristics of the study population consisted of (*see Table 48*):

- **Mother–infant dyad**, mainly in a hospital setting. The time periods in which this pairing was examined included the period during pregnancy, the delivery period or the puerperium period (the first 6 weeks of life).
- **Children and adult populations** in a hospital setting, mainly undergoing treatment for pathological conditions.
- **School-aged children** in the general population, including nursery (under 4 years), primary (4-12 years) and secondary school (13-18 years).
- **Other populations**, including health and other professional groups (such as teachers, parents) and sex offenders.

Overall, 5.8% of the studies examined a mother–infant dyad, the mother during pregnancy, the mother and child during delivery or the child in a hospital setting in the first 6 weeks of life. The percentage of studies undertaken in this setting ranged from 1% (among epidemiological studies investigating incidence or prevalence) to 17% (among studies examining the sensitivity or specificity of a measurement tool). Other studies that examined outcomes in this population included, in ascending order of magnitude, comparison studies, cross-sectional studies, case series, qualitative studies, case control studies, case studies, screening studies and audits.

At 39.5%, studies conducted in a hospital setting represented the second most frequently studied population type grouping. The percentage of hospital-based studies ranged from 10% (in studies of a cross-sectional nature) to 100% (in studies with an economic dimension).

Just over 13% of the studies reported outcomes in school-aged children. While it was not the case for all outcomes examined, in general, this represented a population with non-pathological measures of health and was representative of the general population for their specific demographic characteristics of age and sex. The percentage of studies undertaken in this population ranged from 6% to 45%, with randomised

controlled trials and qualitative studies sitting at the lower end of the scale, and intervention studies at the upper end. Other studies that examined outcomes in this population type included, in ascending order of magnitude, case studies, screening studies, cohort studies, other studies – mainly related to measuring the effectiveness of tools, validation studies and cross-sectional studies.

The final population grouping, 'other populations', consisted of:

- children who were a specific outcome of interest, along with other family members;
- health and health-related professionals examined regarding their knowledge or skills in a specific area;
- parents, or other family members, regarding the impact of living with an individual with a specific condition;
- sex offenders.

These 'other' groups represented 41% of the population types from the study papers examined. Among the study types that assessed issues of practice – including longitudinal studies, reports from legal cases and focus group studies – this heterogeneous study population type represented 90% or more of the studied population.

**Table 48: Person and population characteristics of the study population stratified by study type**

| STUDY TYPE   | HOSPITAL (MOTHER AND CHILD) | HOSPITAL (CHILDREN AND ADULTS) | SCHOOL-AGED POPULATION | OTHER POPULATIONS | DETAILS OF 'OTHER POPULATIONS'  |
|--|-----------------------------|--------------------------------|------------------------|-------------------|---|
| Audit  | 15%                         | 69%                            | 0%                     | 16%               | <ul style="list-style-type: none"> <li>• Children other than children attending hospital or special clinic.</li> <li>• Children with an intellectual disability, athletic, healthy purposeful sampling, offspring of opium users, victims of sexual abuse.</li> <li>• Families – of children with a disability consisting of triads (mother, father, child groups) and index or proband case (i.e. the child with the outcome of interest). The most common disabilities were attention hyperactive deficit disorder, autism and neural tube defect.</li> <li>• Health professionals – e.g. medical doctors, surgeons, physicians, psychiatrists, general practitioners, nurses, midwives, public health nurses, other healthcare workers, psychologists.</li> <li>• Other professionals – e.g. teachers, social workers.</li> <li>• Other persons – perpetrators of sexual abuse (sex offenders).</li> </ul> |
| Assessing practice/knowledge                                     | 0%                          | 0%                             | 0%                     | 100%              |   |
| Case control study   | 12%                         | 67%                            | 0%                     | 21%               |   |
| Case study   | 12.5%                       | 42%                            | 6.8%                   | 38.7%             |   |
| Case series  | 8.5%                        | 91.5%                          | 0%                     | 0%                |   |
| Case report  | 16%                         | 78%                            | 0%                     | 6%                |   |
| Cohort study   | 25%                         | 25%                            | 25%                    | 25%               |   |
| Comparison study   | 2%                          | 82%                            | 6%                     | 10%               |   |
| Cross-sectional study  | 2.5%                        | 10%                            | 39%                    | 48.5%             |   |
| Economic study   | 0%                          | 100%                           | 0%                     | 0%                |   |
| Epidemiology studies   | 1%                          | 71%                            | 15%                    | 13%               |   |
| Intervention studies   | 0%                          | 0%                             | 45%                    | 55%               |   |
| Legal notes  | 0%                          | 0%                             | 0%                     | 100%              |   |
| Longitudinal studies   | 0%                          | 0%                             | 0%                     | 100%              |   |
| Other studies  | 0%                          | 32%                            | 30%                    | 38%               |   |
| Randomised controlled trials*                                    | 5%                          | 35%                            | 6%                     | 5%                |   |
| Qualitative study  | 9.3%                        | 0%                             | 25%                    | 65.6%             |   |
| Screening studies  | 14%                         | 43%                            | 7%                     | 36%               |   |
| Sensitivity and Specificity studies                              | 17%                         | 18%                            | 0%                     | 65%               |   |
| Surveillance studies   | 0%                          | 50%                            | 0%                     | 50%               |   |
| Validation studies   | 0%                          | 29%                            | 36%                    | 35%               |   |
| Focus studies  | 0%                          | 0%                             | 10%                    | 90%               |   |
| Qualitative studies, including anthropology and ethnography work | 0%                          | 33%                            | 34%                    | 33%               |   |
| <b>TOTAL (100%)</b>  | <b>5.8%</b>                 | <b>39.5%</b>                   | <b>13.4%</b>           | <b>41.3%</b>      |   |

\* Some randomised controlled trials (RCT) were followed up as cohort studies after the initial trial was completed.

## Geographical location of the study population

Taking each paper as representative of an individual population group, the geographical distribution of the studied populations was (see Table 49):

- Republic of Ireland – 60% (n = 1,296);
- Northern Ireland – 23% (n = 495);
- Northern Ireland and Republic of Ireland – 0.7% (n = 15);
- Republic of Ireland and the United Kingdom (UK) – 6% (n = 137);
- Republic of Ireland and geographical regions outside the UK (international) – 7% (n = 142);
- United Kingdom inclusive of Northern Ireland – 3% (n = 71).

Note that the geographical distribution of all populations studied differed when examined as an aggregate, as opposed to the geographical distribution of the population within each of the individual study types. The various study types, stratified by geographical population distribution, are presented below.

- **Case control studies**  
The 163 papers (7.5%) represented findings from the Republic of Ireland (n = 136); Northern Ireland (n = 12); Republic of Ireland and UK (n = 4); Republic of Ireland and geographical regions outside the UK (n = 5); and the UK inclusive of Northern Ireland (n = 4).
- **Cohort and longitudinal studies**  
The 46 papers (2%) represented findings from the Republic of Ireland (n = 15); Northern Ireland (n = 17); Northern Ireland and Republic of Ireland (n = 1); Republic of Ireland and UK (n = 9); Republic of Ireland and geographical regions outside the UK (n = 1); and the UK inclusive of Northern Ireland (n = 3).
- **Comparison studies**
- The 101 papers (4.6%) represented findings from the Republic of Ireland (n = 43); Northern Ireland (n = 25); Republic of Ireland and UK (n = 3); Republic of Ireland and geographical regions outside the UK (n = 21); the UK inclusive of Northern Ireland (n = 8); and the USA (n = 1).
- **Epidemiology studies of incidence, prevalence and/or trends**  
The 149 papers (6.9%) reporting measure of incidence, prevalence and/or trends represented findings from the Republic of Ireland (n = 65); Northern Ireland (n = 27); Northern Ireland and Republic of Ireland (n = 5); Republic of Ireland and UK (n = 28); Republic of Ireland and geographical regions outside the UK (n = 13); the UK inclusive of Northern Ireland (n = 11); and Scotland (n = 1).
- **Case reports**  
The 302 papers (14%) represented findings from the Republic of Ireland (n = 245); Northern Ireland (n = 55); Northern Ireland and Republic of Ireland (n = 1); and Republic of Ireland and geographical regions outside the UK (n = 1).
- **Case studies**  
The 664 papers (30.7%) represented findings from the Republic of Ireland (n = 358); Northern Ireland (n = 194); Northern Ireland and Republic of Ireland (n = 2); Republic of Ireland and UK (n = 38); Republic of Ireland and geographical regions outside the UK (n = 49); and the UK inclusive of Northern Ireland (n = 22).
- **Cross-sectional studies**  
The 57 papers (2.6%) represented findings from the Republic of Ireland (n = 32); Northern Ireland (n = 8); Northern Ireland and Republic of Ireland (n = 2); Republic of Ireland and geographical regions outside the UK (n = 13); and the UK (n = 2).



- **Surveillance studies**  
The 16 papers (0.7%) represented findings from the Republic of Ireland (n = 11); and the Republic of Ireland and geographical regions outside the UK (n = 5).
- **Case series studies**  
The 223 papers (10.3%) represented findings from hospital-based populations in the Republic of Ireland (n = 184); Northern Ireland (n = 29); Republic of Ireland and UK (n = 7); the UK (n = 2); and the USA (n = 1).
- **Audits**  
The 41 papers (1.9%) represented findings from the Republic of Ireland (n = 31); Northern Ireland (n = 5); Republic of Ireland and UK (n = 2); and the UK (n = 3).
- **Assessment of practice or knowledge of professionals working with children**  
The 105 papers (4.8%) represented findings from the Republic of Ireland (n = 42); Northern Ireland (n = 22); Northern Ireland and Republic of Ireland (n = 2); Republic of Ireland and UK (n = 27); Republic of Ireland and geographical regions outside the UK (n = 5); and the UK inclusive of Northern Ireland (n = 7).
- **Intervention studies**  
The 30 papers (1.4%) represented findings from the Republic of Ireland (n = 13); Northern Ireland (n = 14); Republic of Ireland and geographical regions outside the UK (n = 1); and the UK inclusive of Northern Ireland (n = 2).
- **Validation studies**  
The 11 papers (0.5%) represented findings from the Republic of Ireland (n = 6); Northern Ireland (n = 3); Republic of Ireland and geographical regions outside the UK (n = 1); and the UK inclusive of Northern Ireland (n = 1).
- **Other studies – mainly related to the effectiveness of measurement tools**  
The 31 studies (1.4%) that examined the effectiveness of diagnostic measurement tools represented findings from international papers (n = 3); Northern Ireland (n = 11); Republic of Ireland (n = 13); Republic of Ireland and Northern Ireland (n = 3); and the UK (n = 1).
- **Screening studies**  
The 24 studies (1.1%) that screened for a range of health-related outcomes represented findings from Northern Ireland (n = 6) and the Republic of Ireland (n = 18).
- **Economic studies**  
The 12 studies (0.5%) that examined economic costings represented findings from international papers (n = 2); Northern Ireland (n = 2); Republic of Ireland (n = 6); Republic of Ireland and UK (n = 1); and the UK (n = 1).
- **Studies measuring the sensitivity and specificity of a measurement tool**  
The 32 studies (1.5%) reporting on the sensitivity and specificity of a measurement tool represented findings from international papers (n = 4); Northern Ireland (n = 14); Republic of Ireland (n = 11); Republic of Ireland and Northern Ireland (n = 2); and the UK (n = 1).
- **Randomised controlled trials**  
The 41 randomised controlled trials (1.9%) represented findings from international papers (n = 5); Northern Ireland (n = 10); Republic of Ireland (n = 15); Republic of Ireland and UK (n = 10); and the UK (n = 1).
- **Qualitative studies**  
The 102 qualitative studies (4.7%) represented findings from the Republic of Ireland (n = 50); Northern Ireland (n = 35); Northern Ireland and Republic of Ireland (n = 2); Republic of Ireland and UK (n = 3); Republic of Ireland and geographical regions outside the UK (n = 10); and the UK inclusive of Northern Ireland (n = 2).

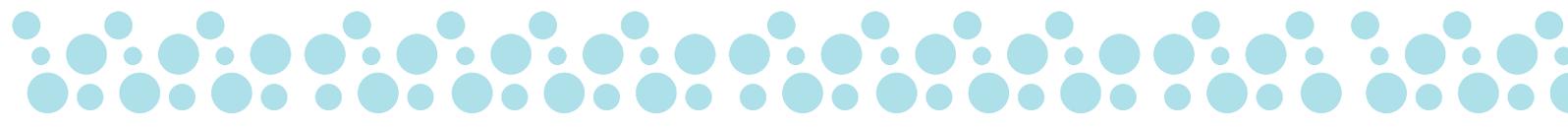


Table 49: Study population stratified by study type and geographical location

| STUDY TYPE  | REPUBLIC OF IRELAND    | NORTHERN IRELAND      | NORTHERN IRELAND AND REPUBLIC OF IRELAND | REPUBLIC OF IRELAND AND UNITED KINGDOM | INTERNATIONAL*                          | UNITED KINGDOM       | TOTAL          |
|---|------------------------|-----------------------|--|--|---|----------------------|----------------|
| Randomised controlled trial   | 15<br>(0.7%)           | 10<br>(0.5%)          |  | 10<br>(0.5%)                           | 5<br>(0.2%)                             | 1<br>(0.05%)         | 41<br>(2%)     |
| Sensitivity and specificity studies of a measurement tool                   | 11<br>(0.5%)           | 14<br>(0.6%)          |  | 2<br>(0.1%)                            | 4<br>(0.2%)                             | 1<br>(0.05%)         | 32<br>(1.5%)   |
| Audit   | 31<br>(1.4%)           | 5<br>(0.2%)           |  | 2<br>(0.1%)                            |   | 3<br>(0.1%)          | 41<br>(2%)     |
| Case control study  | 137<br>(6.3%)          | 12<br>(0.5%)          |  | 4<br>(0.2%)                            | 5<br>(0.2%)                             | 4<br>(0.2%)          | 162<br>(7.5%)  |
| Case report   | 245<br>(11.3%)         | 55<br>(2.6%)          | 1<br>(0.05%)                             |  | 1<br>(0.05%)                            |                      | 302<br>(14%)   |
| Case series study   | 184<br>(8.5%)          | 29<br>(1.3%)          |  | 7<br>(0.3%)                            | 1 <sup>USA</sup><br>(0.05%)             | 2<br>(0.1%)          | 223<br>(10.3%) |
| Case study  | 358<br>(16.6%)         | 194<br>(9%)           | 2<br>(0.1%)                              | 38<br>(1.8%)                           | 49 <sup>plus Scotland 1</sup><br>(2.3%) | 22<br>(1.02%)        | 664<br>(31%)   |
| Cohort study  | 11<br>(0.5%)           | 4<br>(0.2%)           |  | 9<br>(0.4%)                            | 1<br>(0.05%)                            | 2<br>(0.1%)          | 27<br>(1.3%)   |
| Comparison study  | 43<br>(2%)             | 25<br>(1.2%)          |  | 3<br>(0.1%)                            | 21 <sup>plus USA 1</sup><br>(1%)        | 8<br>(0.4%)          | 101<br>(4.7%)  |
| Cross-sectional study   | 32<br>(1.5%)           | 8<br>(0.4%)           | 2<br>(0.1%)                              |  | 13<br>(0.6%)                            | 2<br>(0.1%)          | 57<br>(2.6%)   |
| Economic study  | 6<br>(0.3%)            | 2<br>(0.1%)           |  | 1<br>(0.05%)                           | 2<br>(0.1%)                             | 1<br>(0.05%)         | 12<br>(0.6%)   |
| Epidemiology – descriptive, incidence, prevalence and/or trends             | 65<br>(3%)             | 27<br>(1.3%)          | 5<br>(0.2%)                              | 28<br>(1.3%)                           | 13<br>(0.6%)                            | 11<br>(0.5%)         | 149<br>(7%)    |
| Intervention study  | 13<br>(0.6%)           | 14<br>(0.6%)          |  |  | 1<br>(0.05%)                            | 2<br>(0.1%)          | 30<br>(1.4%)   |
| Legal notes   |                        | 6<br>(0.3%)           |  |  |   |                      | 6<br>(0.3%)    |
| Longitudinal study  | 4<br>(0.2%)            | 13<br>(0.6%)          | 1<br>(0.05%)                             |  |   | 1<br>(0.05%)         | 19<br>(0.9%)   |
| Other study type – mainly related to the effectiveness of measurement tools | 13<br>(0.6%)           | 11<br>(0.5%)          |  | 3<br>(0.1%)                            | 3<br>(0.1%)                             | 1<br>(0.05%)         | 31<br>(1.4%)   |
| Qualitative study, including anthropology and ethnography work              | 40 [6] [4]**<br>(2.3%) | 20 [11] [4]<br>(1.6%) | 2 [0] [0]<br>(0.1%)                      | 2 [1] [0]<br>(0.1%)                    | 6 [2] [2]<br>(0.05%)                    | 1 [1] [0]<br>(0.05%) | 102<br>(4.7%)  |

Table 49: Study population stratified by study type and geographical location (*continued*)

| STUDY TYPE   | REPUBLIC OF IRELAND | NORTHERN IRELAND | NORTHERN IRELAND AND REPUBLIC OF IRELAND | REPUBLIC OF IRELAND AND UNITED KINGDOM | INTERNATIONAL* | UNITED KINGDOM | TOTAL           |
|--|---------------------|------------------|--|--|----------------|----------------|-----------------|
| Screening study  | 18<br>(0.8%)        | 6<br>(0.3%)      |  |  |                |                | 24<br>(1.1%)    |
| Practice/<br>knowledge of<br>professionals or<br>parents | 42<br>(2%)          | 22<br>(1%)       | 2<br>(0.1%)                              | 27<br>(1.3%)                           | 5<br>(0.2%)    | 7<br>(0.3%)    | 105<br>(4.9%)   |
| Surveillance<br>study                                    | 11<br>(0.5%)        |                  |  |  | 5<br>(0.2%)    |                | 16<br>(0.7%)    |
| Validation study   | 7<br>(0.3%)         | 3<br>(0.1%)      |  |  | 1<br>(0.05%)   | 1<br>(0.05%)   | 12<br>(0.6%)    |
| <b>TOTAL (%)</b>   | 1,296<br>(60%)      | 495<br>(23%)     | 15<br>(0.7%)                             | 137<br>(6%)                            | 142<br>(7%)    | 71<br>(3%)     | 2,156<br>(100%) |

\* Studies under the heading 'International' but represented by only one country (e.g. USA) indicate studies where there is some ambiguity regarding the nationality of the studied population.

\*\* The subtotals in square brackets (e.g. [6] [4]) represent the number of anthropological and ethnographic studies, respectively, included in the study type 'Qualitative study'.



# 4 Discussion



## Overview of principal findings

In the period 2000 to 2008, 3,229 peer-reviewed articles, published in 1,003 scientific journals (*see Appendix 2*), were identified which fulfilled the study's inclusion criteria. The articles reported findings from 2,156 primary research studies; the remaining 1,073 articles discussed health-related outcomes, reported findings from secondary research or reported primary research findings on animals. The primary research peer-reviewed articles were examined to identify the nature of the research, demographic characteristics of the studied populations and the nature of the health-related outcomes examined. Analytical and descriptive methodologies were employed to understand the distribution and determinants of health-related outcomes.

The peer-reviewed research reported on a diverse array of health-related topics. Specific health-related topics were examined using aetiological and descriptive study designs. National, cross-border and international studies were reviewed. There was a strong health technology assessment dimension to the work. Four types of study population were observed:

- a mother–infant dyad and child–adult grouping, both of which were hospital-based;
- schoolchildren of various ages;
- a heterogeneous grouping consisting of one or more of the following types: children, siblings, parents, health-related professionals, other professionals;
- a final, rather idiosyncratic group – including sex offenders.

## Nature of the research

### Study type

There were 209 papers (9.7%) of an aetiological nature and 1,941 papers (90%) that described outcomes but did not address specific issues of causality, although many study papers made comparisons for a range of demographic characteristics. The descriptive papers consisted of studies with (9.7%), and without (58.8%) a comparative dimension; studies that examined aspects of effectiveness (8.7%) – either the assessment of practice and knowledge of professionals working with children or children's family members, or the evaluation of health-related interventions or treatments; and finally, studies that had a health technology dimension (6.5%).

- **Case control and cohort studies**  
Papers indexed as aetiological in nature consisted of 163 case control studies (7.5%) and 46 cohort studies of a longitudinal nature (2%).
- **Comparison studies, epidemiological studies measuring prevalence, incidence and/or trends, case reports, case studies, cross-sectional studies, surveillance studies and case series studies**  
Descriptive studies *with* a comparison dimension included 101 studies (4.6%) that compared findings for the health-related outcome of interest across time, geographical region or treatment type; and 149 studies (6.9%) reporting measures of incidence, prevalence and/or trends.  
  
Descriptive studies *without* a comparative dimension (58.8%) consisted of case reports, case studies, cross-sectional studies, surveillance studies and case series studies.
- **Audits, practice or knowledge of professionals or parents, intervention studies and validation studies**  
Descriptive studies that examined aspects of effectiveness (8.7%) included audit studies; studies that reported on the practice or knowledge of professionals, parents or other adults working, or associated, with children; studies that examined health interventions; and studies that assessed the validity of a measurement tool.



- **Other studies – mainly related to measuring tools effectiveness, screening studies, economic studies, studies on the sensitivity and specificity of a measurement tool, and randomised controlled trials**  
Studies with a health technology dimension (6.5%) examined the effectiveness of a measurement tool, screened for a range of health-related outcomes, inspected economic costs of specific treatments or procedures, examined the sensitivity and specificity of a measurement tool and/or evaluated the effectiveness of treatments using randomised controlled trial methodologies.

## Demographic characteristics

- **Population type**  
The majority of study populations were hospital-based (46%), of which 6% reported on mother–infant dyad during pregnancy or the peripartum period. The outstanding hospital-based populations represented child–adult combinations with specific pathological conditions requiring treatment or follow-up. Health-related outcomes or behaviours among school-aged children accounted for just over 13% of the studied papers. The remaining population type, representing 41.3% of the study papers, comprised heterogeneous groupings of various cluster types and cluster numbers. These clusters were comprised of children, parents, siblings, teachers, health professionals, other professionals working with children and sex offenders.
- **Geographical distribution**  
The majority of papers – 1,296 (60%) – studied populations from the Republic of Ireland. The remaining populations were from Northern Ireland (495 or 23%), the geographic island of Ireland (15 or 0.7%), the political region of the United Kingdom (71 or 3%) and international groups (142 or 7%) where, in addition to an Irish population, a population from at least one other country outside Ireland and the UK was examined.

## Health-related outcomes

There were 1,220 different health-related outcomes reported in the 2,156 papers. ICD-10, or to a much lesser extent ICD-O-3, accounted for the method of classification for 962 (45%) of the 2,156 study papers. The remaining 1,194 study papers (55%) examined the themed, non-classifiable, health-related outcomes of: microscopic organisms; measures of immunology and neurology; measures of a psychological or sociological nature; a range of behavioural practices, including issues related to drug use, breastfeeding, diet and lifestyle and physical activity. Other outcomes examined included generic outcomes of death and various disabilities; issues related to organ transplant and prematurity; biological markers; measures of anatomy; a range of syndromes; health services issues; dental outcomes; normal and abnormal patterns of growth and development; issues related to education; a small number of legal issues; and a final heterogeneous group called 'Other' representing outcomes not embodied in the other categories.

Full details on each of the papers included in the study are available on the website [www.childrensdatabase.ie/Irish-child-health-database/](http://www.childrensdatabase.ie/Irish-child-health-database/).

## Individual studies – main features

Key features of health-related outcomes and demographic characteristics by study types examined are presented below.

- **Case control and cohort studies**  
The ICD-10 four-digit rubric of Attention Deficit Hyperactivity Disorder (ADHD), reflux nephropathy, congenital diaphragmatic hernia, congenital hypertrophic pyloric stenosis, neural tube defect, Hirschsprung's Disease and Sudden Infant Death Syndrome accounted for 54 of the case control papers. A further 93 case control papers, accounting for almost half of the studies examined,



looked at risk factors for 'endocrine, nutrition and metabolic disease', 'mental and behavioural disorders', 'diseases of the musculoskeletal system and connective tissue', 'symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified' and 'congenital malformations, deformations and chromosomal abnormalities'. The remaining 27 papers examined three or less risk factors among ICD-10 classified outcomes. The 35 themed health-related outcomes concentrate predominantly on the areas of: microscopic organisms, immunology and sociology. However, only one risk factor for each of the individual outcomes was examined.

The most commonly investigated outcomes in the cohort studies were health-related outcomes among infants born to a cohort of pregnant women who were HIV-positive. In total, 5 HIV-related outcomes were examined. The remaining areas of interest represented a total of 42 different health-related outcomes in the physical, mental, sociological, behavioural and health service provision areas. Case control studies mainly reported outcomes on hospital-based patients (79%), of which 12% were mother–infant dyads. Cohort study populations were split evenly across the four population types (hospital-based population, including mother–infant dyad; school-based population; and mixed populations of adults and children), while those of a longitudinal nature represented persons working with children or other population types.

- **Comparative studies**

Less than half of the 101 comparative studies examined ICD-10 classifiable outcomes. The remaining 61 papers examined themed, health-related outcomes. The comparisons made included contrasting measures of time, geography and a range of socio-demographic characteristics. In general, the time comparison compared findings from two periods, often comparing outcomes before and after the introduction of a new procedure. Geographical comparisons were national and international. The socio-demographic characteristics represented a range of measures of socio-economic position, cultural backgrounds and measures of education. Various aspects of health service provision, including the type of treatment or types of procedures, were compared. In the main, comparison studies reported findings from hospital-based populations (82%).

- **Epidemiology studies of incidence, prevalence and/or trends, and cross-sectional studies**

Epidemiology studies and cross-sectional studies reported measures of prevalence, incidence and/or trends of disease. The epidemiological studies reporting on international populations reported measures of health-related outcomes with regard to body size, injury, bullying, metabolic outcomes, congenital malformations, psychiatric care and suicide. For many of these outcomes, findings were based on representative populations of schoolchildren or from data registers which allowed population representative estimates of statistical measures. The predominantly national epidemiology studies reported findings mainly from a hospital-based population (71%). The remaining population type reported findings from school populations and persons working with, or involved with, children. The cross-sectional studies focused on school populations (39%) or persons working with, or involved with, children and family members (48.5%).

- **Case reports and case series studies**

Case reports identified unusual treatments or characteristics for a disease in one person or a family – 192 ICD-10 classifiable outcomes were reported and almost 70 themed, health-related outcomes. Case series studies reported findings on hospital-based populations with regard to the treatment of a range of health-related outcomes. The treatments included pharmacological and surgical interventions, and imaging techniques. Case reports and case series papers reported outcomes on hospital-based patients (100%), of which between 8% and 16%, respectively, represented a mother–infant dyad.



- **Case studies**

The case studies examined 398 themed non-classifiable outcomes. The most frequently occurring outcomes were: bacteria, virus and fungi (37); biological markers and measures of anatomy (41); education (22); health service provision (40); medical procedure (21); psychology and sociological issues (64); legal issues – adoption, abuse, neglect (22); and Other (44). Among the 266 ICD-10 classifiable health-related outcomes, the most frequently occurring outcomes were: certain infectious and parasitic diseases (24); congenital malformations, deformations and chromosomal abnormalities (33); diseases of the genitourinary system (8); diseases of the musculoskeletal system and connective tissue (11); diseases of the nervous system (20); diseases of the respiratory system (15); endocrine, nutritional and metabolic disease (20); injury, poisoning and certain other consequences of external causes (22); mental and behavioural disorders (48); and pregnancy, childbirth and the puerperium (25). Populations for the case studies were divided across the four population types, with a hospital-based population (42%) and persons working with, or involved with, children and family members (39%) representing the greatest proportion of these groupings.

- **Surveillance studies**

The surveillance studies reported on a range of diseases of an infectious nature, or in a small number of papers on vaccination processes.

### Assessment of aspects of effectiveness regarding knowledge or practice in relation to health-related outcomes

- **Audit**

Audits of adherence to guidelines, of procedures or of knowledge on treatments for a range of health-related outcomes were undertaken. The majority of audits were conducted in a hospital setting and included issues related to dysplasia of the hip; glucose metabolism; the provision of hospital services for injuries and day-surgery; orthodontic treatment; transportation; burns; and status epilepticus. An audit of emergency contraception use among Irish teenagers was also undertaken.

- **Practice or knowledge of health professionals**

The practice or knowledge of health professionals working with children was assessed in relation to an array of factors, including antenatal care, anaesthesia, blood transfusion and steroid use. Studies also examined the knowledge and practice of teachers in an educational setting or other health-related workers, such as social workers.

- **Intervention studies**

A range of healthcare interventions was evaluated with regard to asthma treatment, including issues related to oral health and treatments for fungal and bacterial infections. Areas of family support where children had significant learning and intellectual disabilities or behavioural problems were also examined. Interventions were evaluated in hospital settings, in the community or in school settings.

- **Validation studies**

The validity of the Family Affluence Measurement Scale, of recall among parents and adolescents, and of laboratory diagnostic tests was examined. Studies were evaluated in school populations (45%) and persons working with, or involved with, children and family members (55%).



## Papers with health technology dimension

- **Other studies – mainly related to measuring tools effectiveness**

An examination was undertaken on the effectiveness of a range of diagnostic laboratory tests, the completeness of data registers or information systems, changes in sensitivity and specificity estimates across a range of demographic characteristics and the positive predicative value of specific biological markers in relation to a range of health-related outcomes.
- **Screening studies**

Screening was undertaken for dental outcomes, genetic mutations, polymorphisms, congenital malformations, mental and behavioural disorders and a range of viruses. The majority of screening programmes were undertaken on hospital-based populations, but also included persons working with, or involved with, children and family members.
- **Economic studies**

The economic costs were evaluated for injury-related hospital admissions, pharmacogenomics for acute lymphoblastic leukaemia, cochlear implants, patients' transports costs, vaccination programmes and other health-related programmes. Cost-effective studies were undertaken in hospital-based populations.
- **Studies on the sensitivity and specificity of a measurement tool**

The sensitivity and specificity of a range of questionnaires, across a variety of topics, were evaluated. The accuracy of tools employed in measuring energy intake and radiograph imaging techniques was assessed. The effectiveness of early language screening tests and measures of socio-economic position were also reported.
- **Randomised controlled trials**

Randomised controlled trials (RCTs) were reported on treatments among premature infants of chemotherapies for neuroblastoma and severe aplastic anaemia, imaging techniques, interventions for nutrition in premature infants, glucose monitoring in pregnant women, intervention programmes for children with intellectual disabilities, smoking educational programmes and parental training programmes. In the Republic of Ireland, both hospital-based and community-based trials were undertaken. Some RCT populations were followed up over time and in effect these studies are more accurately described as cohort studies. The hospital-based trials included evaluation of surgical and imaging techniques and of specific treatments. The community-based trials evaluated smoking educational programmes.

## Strengths and weaknesses of the study

This study maps all the peer-reviewed health research papers on children in Ireland published over a 9-year period. The nature of the study allows not only a comprehensive view of the health-related topics examined, but also, by examining the topics stratified by study type, gives a picture of how this research informs various aspects of healthcare provision – including epidemiology, public health, health technology assessment, surveillance and education. The systematic search strategy limits the potential for missing data and the picture provided should be regarded as a current depiction of the nature of health research on children in Ireland with regard to the peer-reviewed literature.

The principal method of presentation – by study type – was deliberately chosen to provide an appreciation of the nature of research in Ireland. The case control and cohort studies examined specific risk factors for a range of health-related outcomes. Epidemiology studies of incidence, prevalence and/or trends and cross-sectional studies estimated statistical measures of disease. Case studies, case reports and case series



studies allowed a better characterisation of a range of outcomes, but the nature of the populations studied reflected limitations in the degree to which study findings could be generalised. The surveillance studies undertook a rapid assessment of the nature of a range of infectious disease outbreaks.

The subsequent studies under the umbrella grouping of 'Assessment of aspects of effectiveness regarding knowledge or practice in relation to health-related outcomes' and studies with a health technology dimension examined issues that facilitated the accurate measurement of factors associated with health-related outcomes, rather than health-related outcomes themselves. Broadly speaking, they included evaluation of medical or health-related knowledge, intervention studies for medical or health-related treatments, the effectiveness of screening studies, economic cost of studies and evaluation of best treatment or intervention.

The second method of presentation – by study topic – provides a count of the total number of papers and the total number of topics examined. However, there are a number of difficulties in mapping research by this method. Reporting on the nature of the topic says little about the nature of the research with regard to aetiology, measures of disease frequency or the representativeness of the study, even though two of these issues are addressed through the examination of study type and population type. No reference is made with regard to the risk factors examined, and little reference is made to the nature of the determinates, controlled for in aetiological studies or examined in the comparative studies to assess equality. The nature of the statistical analysis employed in the papers is not examined and therefore measures of estimates of effect are not reported. Neither are issues of representativeness or generalisability examined – important factors in contextualising the relevance of the study findings. However, it was clear that a wide range of health-related outcomes – over 1,220 – was examined in the study period. Nevertheless, counts tell little with regard to the measure of the magnitude of the problem posed by each health-related outcome within the population, among persons with the disability of interest, or of the cost to society of the factor of interest. Investigation of other information systems is required for this.

More structured methods to group the themed, non-classified, health-related outcomes are required. Each of the thesauruses employed in the bibliographic databases employs different criteria for creating subcategories and categories. A more rigorous understanding of the rationale behind such categories and justification in choosing a specific method is required to provide internationally comparable groupings of those outcomes not classifiable to ICD-10.

One approach to this will be the application of the methodological approaches of and findings from the RICHE project ('Research Inventory of Child Health in Europe'). This EU project will *'address the diversity and fragmentation of child health research in Europe, by establishing an innovative, iterative and sustainable European platform for child health research across different disciplines'*. (It arose in response to the European Union's 7th Framework Programme for Research and Technological Development (FP7), covering the years 2007-2013.) This integrated virtual platform will help the different stakeholders to build the future of European child health research and thus promote child health in Europe and beyond. The core of the RICHE project is the development of the platform – the public face of the project – and this part of the work (called Work Package 5 or WP5) is being led by Professor Anthony Staines of Dublin City University, with Dr. Anne McCarthy of the Irish Health Research Board as Deputy Lead. Among its objectives is the development of a more structured method of indexing child health-related research, with a focus on grey literature. Findings from RICHE will be used to update the work identified in this present child health mapping project. For more information, see [www.childhealthresearch.eu/about-us/project-overview](http://www.childhealthresearch.eu/about-us/project-overview).

The third method of presentation – by population type – clearly demonstrates the predominantly hospital-based nature of the study groups. This population can be stratified into two groups: one group comprised a mother-child dyad from the prenatal and antenatal period, while the second group comprised populations



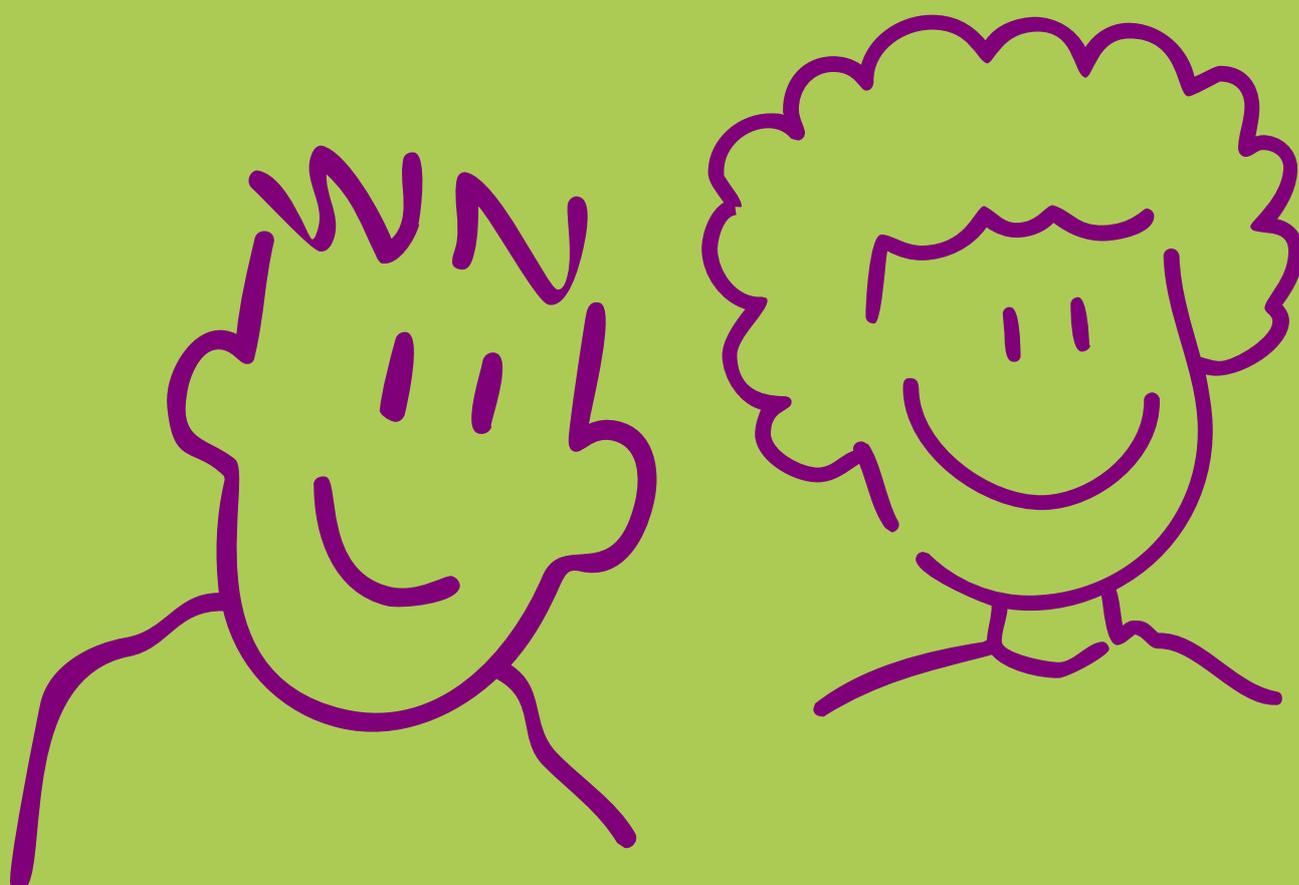
attending hospital for a range of pathological conditions. However, there were a number of surprising findings. The first was the numbers of persons studied who care for, work with or were studied due to their relationship with children. The second was the small proportion, less than 20%, of children-only studies.

There are other weaknesses inherent in this study. For example, each study paper has been assigned to a specific study type. However, a single indexing of each paper is imperfect. A more specific indexing system – indicating not simply the single nature of the study type of each paper but, where relevant, the occasion of multiple study types within a single paper – would be more discriminating. Secondly, there is a degree of subjectivity in the indexing methodology. A more rigorous, clearly defined checklist, appraising the individual factors denoted to define a study type, is required to address this weakness.

Each study group has been assigned to one of four broad population types. This approach has assisted in identifying specific population groups with regard to health-related outcomes and with regard to the nature of the population. Further stratification of these groups would aid in better understating the heterogeneous character of these groups. The general hospital population (i.e. excluding the mother–infant dyad) needs to be more clearly delineated with regard to age range and child–adult ratio. The mother–infant dyad needs further qualification to examine the frequency of pairs or single persons representing this composite. The heterogeneous clustering of health and other professionals, family groups of various composition and populations of children not from hospital or school settings also requires greater examination to allow clearer representation.



# 5 Conclusions



## Overall conclusion

Ireland has a substantive amount of peer-reviewed published research on children. Harnessing knowledge from this research is a worthwhile aim, with much to be learned from the studied health research outcomes, the methodologies employed and the nature of the population cluster types examined. It would also assist in the very important task of translating evidence into practice, while disseminating knowledge to the interested communities.

The nature of the current research emphasizes a descriptive approach to characterising health or evaluating interventions in health. Research results present part of the picture in providing an evidence-based approach to prioritising health-related research. However, a truly evidence-based approach requires the juxtaposition of current findings against clearly identified national frameworks for health, against national frameworks in prioritising health research, and against health-information systems that allow assessment of the incidence, prevalence and current trends in health.

In general, research studies should address questions not answered by routine information systems. However, a diversity of unmapped research across an assorted array of outcomes and of a miscellaneous nature can serve to obscure what research gaps exist. The continuous mapping of 'grey' and peer-reviewed literature will both serve the research community and aid the identification of priority gaps in health-related research in these economically challenging times.

The objective of the present study was to map the nature of health research on children in Ireland, which has been accomplished. The use of internationally accepted definitions of study types and international classifications of health-related outcomes has provided a standardised coding methodology by which to view these papers. The retention of the original study authors' language, under the 23 themed, non-classifiable, health-related outcomes, allows the reader to determine alternative grouping frameworks. The study of Irish child health research shows a surprisingly diverse population group. However, this work is simply a first stage in the examination of the subject. There remain many legitimate entry points by which to further understand the nature of Irish health research on children and the part it plays in illuminating aspects of health in Ireland.

## Specific conclusions

There are four main specific conclusions arising from this work – namely, the importance:

- to maintain and expand the collection and mapping of Irish child health-related research;
- to examine findings from this mapping exercise by the juxtaposition of the current research against stated national research priorities and national information databases;
- to develop a nationally accessible working framework on prioritising research into health;
- to identify the type and number of frameworks by which child health-related research is to be undertaken.

## Mapping research

It would be very helpful to have a single database (or related mechanisms to support mapping) of Irish child health-related research – including both peer-reviewed and grey literature – that is maintained and updated annually. In addition to including fully referenced peer-reviewed publications, the database could accommodate the following:

- Each publication should be tagged for a range of specific characteristics. Initially, these characteristics should include study type, topic area, population type, health determinants and types of statistical analysis. Subsequent tags can be added as required.



- International classifications should be used in coding these tags. New classification systems should be added as these become more available on the Internet.
- An e-Government approach should be used to facilitate an interactive forum in which researchers can upload and tag their publications in an interactive manner. This would also facilitate the development of a peer review group to mould and develop the grouping, indexing and classifying of national research. The RICHE project is addressing the methodological issues around the development of such an approach (see Chapter 4).

### Juxtapose current research against national research priorities

A range of national strategies for health exists in Ireland, including, for example, the *National Children's Strategy* (Department of Health and Children, 2000) and the *National Action Plan for Social Inclusion 2007-2016* (Office of Social Inclusion, 2007). The priorities within these strategies allow legitimate entry points in tackling health. Development of a matrix cross-referencing the areas identified by the national strategies with the areas on which research is undertaken, taking account of national information systems, would allow for a more comprehensive and dynamic picture of the actions instigated in achieving the stated national strategies' goals, as well as highlighting the remaining gaps.

### Nationally accessible working framework on prioritising research into health

Priority-setting in research is complex, but a number of frameworks have been developed by which to guide this process. One WHO framework (Ranson and Bennett, 2009) includes the following guidelines:

- processes for initiating priority-setting based on the principles of legitimacy and fairness;
- general guiding principles for the application of methods and tools for health research priority-setting;
- effective follow-up of commitments and outcomes.

Again, the juxtaposition of outputs against this framework would facilitate an understanding of the picture with regard to research and potential research gaps. However, regardless of the chosen national research framework, nested child health research frameworks need to be considered within the national parameters.

### Establishing a framework of child health

There exists a range of frameworks by which to structure child health research. The type, or types, of framework chosen reflects the nature of the research, economic considerations, available expertise and national and international research priorities. The epidemiological transition (i.e. the reduction of infant and childhood mortality from infectious disease) requires a greater emphasis on child health research in the areas of genetics, health technology, global migration, social and biomedical epidemiology, and public health. We are now becoming increasingly aware of the long-term consequences of the intrauterine and early childhood environment on early life development and the development of chronic diseases in later life. The foetal original hypothesis, although rather deterministic in nature, has highlighted awareness of the importance of a life course approach to understanding mental, physical and emotional health.

However, a life course approach to guiding health-related research is not the only available framework. Advances in various areas of health technology have also increased the chance of survival among previously 'at risk' infants, particularly very pre-term infants. This improvement in survival rates is coupled with increased healthcare requirements and other related factors such as educational costs. Globalisation also brings with it many changes to health priorities through cultural diversity and alterations in our disease profiles. In addition, there is substantive evidence that relative, and not absolute, levels of wealth within a country are the single greatest determinant of national health. Internationally, increased levels of violent crime, mental illness, drug addiction, illiteracy and obesity are observed among those nations that internally exhibit wide gaps between those 'who have' and those 'who have not' (Wilkinson, 2010; Siegrist, 2006; Dorling, 2010).

The research methodologies required to address health indicator cluster types differ according to the outcomes and the time point of measuring these outcomes. They also differ according to the nature of the inquiry – a clinical health perspective, a public health perspective or programmes of national equity. The European Union’s forthcoming 8th Framework Programme for Research and Technological Development (FP8) has identified a ‘life course perspective on health’ and the area of ‘inequalities’ as the main health-related foci of importance for the coming decade. This framework has many legitimate entry points through which the area of health-related research on children can be developed. The character of the framework Ireland chooses to adopt will reflect our priorities.



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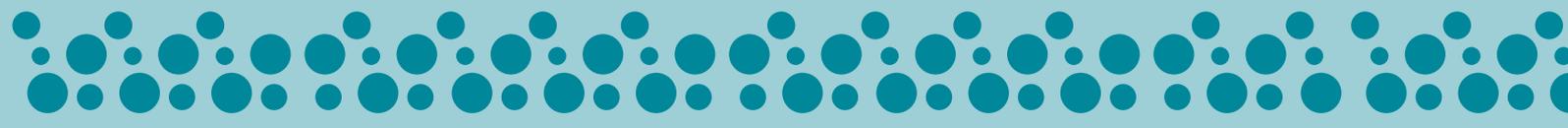
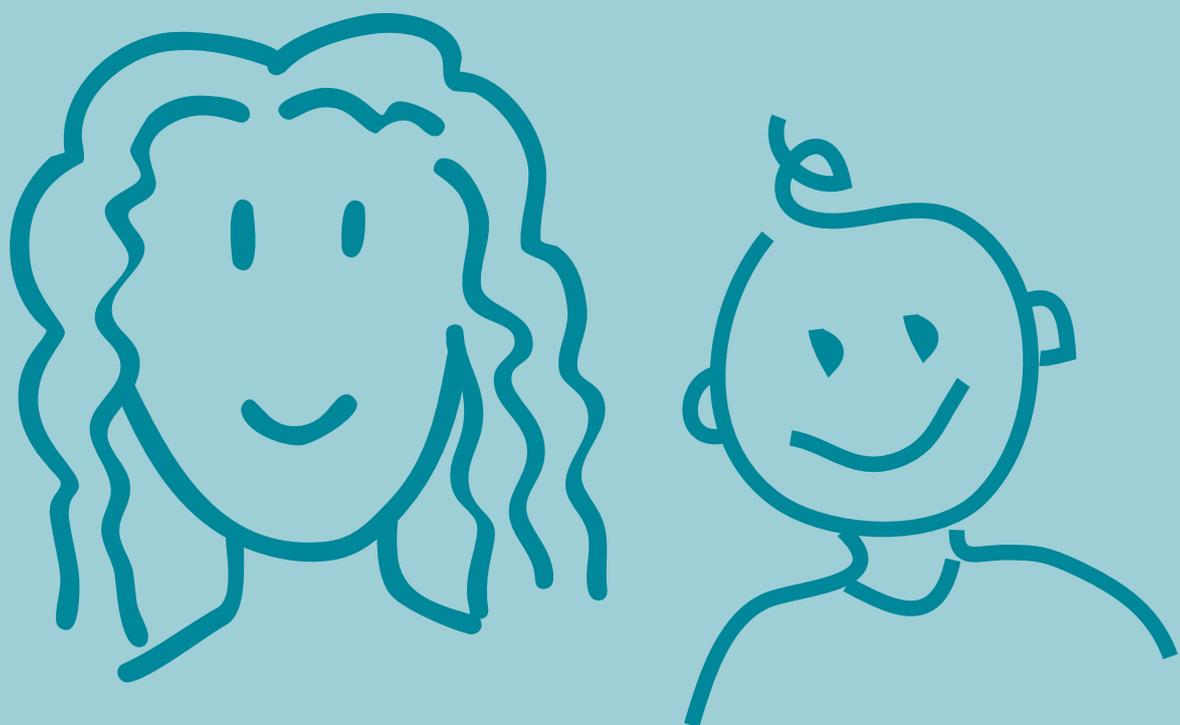
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## Appendices



## Appendix 1: National research groups, research groups of Ireland, the United Kingdom and European and international study groups

|  |   |
|--|---|
| Association of Paediatric Anaesthetists of Great Britain and Ireland   | Health Behaviours in School-aged Children (HBSC) Survey – Multinational European and North American adolescent school-based survey on health behaviours |
| Births Defect Research Group, Republic of Ireland  | Hospital Data Project (HDP)   |
| Autism Genetic Research Exchange Consortium (world's first collaborative gene bank for autism)                         | High-frequency Oscillation Study Group  |
| Bone-anchored Hearing Aid® centres   | Hvidore Study Group on Childhood Diabetes   |
| Hospital-based centres across the United Kingdom and Ireland   | International Blood and Marrow Transplant   |
| Boyne Research Institute<br>Study of Genetic Factors in Neural Tube Defect, Republic of Ireland                        | International Association for the Evaluation of Educational Achievement Pre-primary Project   |
| British Association for Paediatric Nephrology  | INFOSCAN database   |
| British Association of Paediatric Surgeons   | International Multi-centre ADHD Genetics (IMAGE) Project  |
| British Cochlear Implant Group   | International Child Care Practices Study  |
| British Association of Perinatal Medicine  | International Study of Asthma and Allergies in Childhood  |
| British HIV Association (BHIVA)  | Invasive Meningococcal Disease Database   |
| British Ophthalmic Surveillance Unit   | Irish Faculty of Paediatrics  |
| British Paediatric and Ophthalmic Surveillance Unit  | Irish Lung and Transplant Programme   |
| British Paediatric Neurology Association   | Juvenile Dermatomyositis Research Group   |
| British Paediatric Surveillance Network of the Royal College of Paediatrics and Child Health                           | Irish Paediatric Surveillance Unit (established in 1996 to facilitate surveillance of uncommon paediatric disorders on the island)                      |
| British Paediatric Respiratory Society   | LACE – the Study Group on Barriers and Incentives to Prenatal Care in Europe: Perinatal Care Incentives in Europe                                       |
| Child Health, British Society of Gastroenterology Research Unit  | Lifeways Cross Generation Cohort, Republic of Ireland   |
| Child Health, Scottish Centre for Infection and Environmental Health   | Medical Research Council, National Cancer Research Network, Childhood Leukaemia Working Party   |
| Paediatric Register of Inflammatory Bowel Disease  | MIDAC Study (Microalbuminuria in diabetic children) – study in population with insulin-treated diabetes   |
| British Society for Antimicrobial Chemotherapy (BSAC), Bacteraemia Surveillance Programme                              | Multi-agency Outbreak Control Team  |
| BSAC Bacteria Resistance Surveillance  | Millennium Cohort Study   |
| British Society for Paediatric Endocrinology and Diabetes  | National Blood Users Group  |
| Child and Adolescent Self-harm in Europe (CASE) Study  | National Centre for Inherited Metabolic Disorders   |
| Child Nutrition Panel  | National Children's Food Consumption Survey   |
| Children's Cancer and Leukaemia Group  | National Teen Food Survey   |
| Collaborative HIV Paediatric Study (CHIPS)   | Irish Food Packaging Database (IFPD)  |
| Clinical Effectiveness Group, Association of Genitourinary Medicine, Medical Society of the Study of Venereal Diseases | National Children's Food Consumption Survey   |
| National Study of HIV in Pregnancy and Childhood   | National Children's Food Survey (NCFS)  |
| Confidential Enquiry into Maternal and Child Health  | National Disease Surveillance Centre  |

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| Congenital Anomalies Register of the Department of Public Health   | National Neonatal Screening Programme   |
| EPICure Study Group<br>(established in 1995 to determine survival and health status of children born in United Kingdom and Ireland at less than 26 weeks' gestation) | Northern Ireland Young Hearts Project<br>(longitudinal cohort)  |
| The EPISA study (antimicrobial susceptibility of <i>Staphylococcus aureus</i> )  | PERISTAT Project: Monitoring and evaluating perinatal health  |
| EUROCAT: European Concerted Action on Congenital Anomalies and Twins (established in 1979)   | Open Study of Early Corticosteroid Treatment, Northern Ireland  |
| Ethics Working Group of the Confederation of European Specialists in Paediatrics   | Public Health Laboratory Service, Group B <i>Streptococcus</i> Working Group                                    |
| EUROCOST Reference Group   | Randomised Controlled Trial, Dexamethasone in Neonatal Chronic Lung Disease                                     |
| EURODIAB Europe and Diabetes ACE Study Group   | Respiratory Resistance Surveillance Programme   |
| Euro-growth Longitudinal Study<br>(designed as a multicentre longitudinal cohort study)  | Royal College of Obstetricians and Gynecologists  |
| EuroNatal Working Group  | United Kingdom Transplant Support Service Authority   |
| European Antimicrobial Resistance Surveillance System  | Society for Paediatric Anaesthesia of New Zealand and Australia   |
| EURONIC Project: Instruments and methodologies   | United Kingdom and Ireland Collaborative Study of Pulmonary Atresia with Intact Ventricular Septum              |
| European Basic Surveillance Network  | United Kingdom and Ireland Medos Shunt Audit Group  |
| European Cerebral Palsy Study  | United Kingdom-based Cohen Syndrome Support Group   |
| European Collaborative Study of Early Onset Homogeneous Bipolar Affective Disorder   | United Kingdom Children Cancer Study Group and the United Kingdom Cancer Cytogenetics Group                     |
| European Influenza Surveillance Scheme   | United Kingdom Collaborative Hip Trial Group  |
| European Neuroblastoma Study Group   | Paediatric Intensive Care Society Study Group   |
| European Multi-centre Steroid Study Group  | United Kingdom Paediatric Traumatic Brain Injury Study Group  |
| European Registry for Hereditary Pancreatitis and Familial Pancreatic Cancer   | Vaccine European New Integrated Collaboration Effort (VENICE) Project, Gatekeepers Group                        |
| European Resistance Surveillance System (EARSS)  | Scottish Centre for Infection and Environmental Health  |
| European Respiratory Society (ERS) Taskforce   | National Prospective Tonsillectomy Audit  |
| European Sero-epidemiology Network (ESES2)   | Neonatal Intensive Care Outcomes Research and Evaluation (NICORE) Group   |
| EUROSAVE Working Group   | Neonatal Ventilation with Inhaled Nitric Oxide v. Ventilatory without Inhaled Nitric Oxide for Pre-term Infants |
| European Surveillance of Congenital Anomalies  | Severe Respiratory Failure, INNOVO Trial Collaborating Group  |
| French-Language Society of Paediatric Anaesthesiologists   | North/South Ireland Food Consumption Survey, the National Children's Food Survey, the National Teen Food Survey |
| Faculty of Paediatricians in the Royal College of Physicians of Ireland  | Northern Ireland Diabetes Group, Ulster Obstetrical Society   |
| Great Britain and Ireland Paediatric Pain Services   | Northern Ireland Paediatric Diabetes Study Group  |



## Appendix 2: Peer-reviewed journals reporting published findings on health research on children in Ireland

|   |  |
|---|--|
| Accident & Emergency Nursing  | Journal of Antimicrobial Chemotherapy  |
| ACOG Clinical Review  | Journal AOAC [Association of Official Analytical Chemists] International                 |
| Acta Biomed   | Journal of Applied Behaviour Analysis  |
| Acta Neurologica Scandinavica   | Journal of Applied Microbiology  |
| Acta Ophthalmologica Scandinavica   | Journal of Asthma  |
| Acta Orthopaedica Belgica   | Journal of Bacteriology  |
| Acta Paediatrica  | Journal of Behavior Therapy and Experimental Psychiatry                                  |
| Addiction   | Journal of Bone and Joint Surgery (American)   |
| Addiction Research & Theory   | Journal of Bone and Joint Surgery (British)  |
| Adolescence   | Journal of Bone and Mineral Research   |
| Adoption & Fostering  | Journal of Cardiac Surgery   |
| Advances in Child Development and Behavior                                  | Journal of Cardiovascular Risk   |
| Advances in Experimental Medicine and Biology                               | Journal of Cataract Refract Surgery  |
| Advances in Neonatal Care   | Journal of Child Psychology and Psychiatry   |
| Aggression & Violent Behaviour  | Journal of Chromatography B: Analytical Technologies in the Biomedical and Life Sciences |
| Aggressive Behaviour  | Journal of Clinical Endocrinology and Metabolism   |
| AIDS  | Journal of Clinical Epidemiology   |
| AIDS & Hepatitis Digest   | Journal of Clinical Microbiology   |
| AIDS Care   | Journal of Clinical Oncology   |
| AIMS Journal  | Journal of Clinical Orthodontics   |
| AJNR American Journal of Neuroradiology                                     | Journal of Clinical Pathology  |
| AJR American Journal of Roentgenology                                       | Journal of Clinical Paediatric Dentistry   |
| Alimentary Pharmacology & Therapeutics                                      | Journal of Clinical Rheumatology   |
| All Ireland Journal of Nursing & Midwifery                                  | Journal of Clinical Virology   |
| Allergy   | Journal of Control Release   |
| American Journal of Otolaryngology  | Journal of Critical Care   |
| American Journal of Medical Genetics  | Journal of Cystic Fibrosis   |
| American Academy of Ophthalmology   | Journal of Dental Education  |
| American Educational Research Journal                                       | Journal of Dental Research   |
| American Journal of Epidemiology  | Journal of Development and Behavioural Pediatrics  |
| American Journal of Gastroenterology  | Journal of Epidemiology and Community Health   |
| American Journal of Clinical Nutrition                                      | Journal of Evaluation in Clinical Practice   |
| American Journal of Genetics  | Journal of Food Protection   |
| American Journal of Human Genetics  | Journal of Forensic Legislative Medicine   |
| American Journal of Kidney Diseases   | Journal of The British Society for Surgery of the Hand                                   |
| American Journal of Medical Genetics  | Journal of Health Communication  |
| American Journal of Medical Genetics, Part A                                | Journal of Health Economics  |
| American Journal of Medical Genetics, Part B (Neuropsychiatric Genetics)    | Journal of Health Services Research & Policy   |
| American Journal of Medical genetics, Part C (Seminars in Medical Genetics) | Journal of Helminthology   |

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| American Journal of Medical Genetics (Neuropsychiatric Genetics)       | Journal of Hospital Infection                                |
| American Journal of Nursing  | Journal of Human Genetics                                    |
| American Journal of Obstetrics & Gynecology                            | Journal of Human Lactation                                   |
| American Journal of Ophthalmology                                      | Journal of Human Nutrition and Dietetics                     |
| American Journal of Perinatology                                       | The Journal of Immunology                                    |
| American Journal of Transplantation                                    | Journal of Infection   |
| American Journal of Physiology: Lung Cellular and Molecular Physiology | Journal of Inherited Metabolic Disease                       |
| American Journal of Preventive Medicine                                | Journal of Intellectual Disabilities                         |
| American Journal of Psychiatry   | Journal of Intellectual Disability Research                  |
| American Journal of Respiratory Critical Care Medicine                 | Journal of Interprofessional Care                            |
| American Sociological Association                                      | Journal of Invasive Cardiology                               |
| Anaesthesia  | Journal of Investigative Dermatology                         |
| Annals of Allergy Asthma Immunology                                    | Journal of the Irish Colleges of Physicians and Surgeons     |
| Annals of The Royal College of Surgeons of England                     | Journal of The Irish Dental Association                      |
| Annals of Thoracic Surgery   | Journal of Laryngology & Otology                             |
| Annals of Allergy Asthma and Immunology                                | Journal of Maternal-Fetal and Neonatal Medicine              |
| Annals of Clinical Biochemistry  | Journal of Medical Genetics                                  |
| Annals of Plastic Surgery  | Journal of Microbiological Methods                           |
| Annual Review of Nursing Research                                      | Journal of Nervous and Mental Disease                        |
| Annual Review of Sociology   | Journal of Neurology, Neurosurgery & Psychiatry              |
| Antiviral Therapy  | Journal of Neurosurgery                                      |
| Applied and Environmental Microbiology                                 | Journal of Nutrition   |
| Applied Nursing Research   | Journal of Obstetrics and Gynaecology                        |
| Archives of Biochemistry and Biophysics                                | Journal of Adolescent Health                                 |
| Archives of Environmental Health                                       | Journal of Advanced Nursing                                  |
| Archives of Ophthalmology  | Journal of Allergy Clinical Immunology                       |
| Archives of Oral Biology   | Journal of Antimicrobial Chemotherapy                        |
| Archives of Otolaryngology Head Neck Surgery                           | Journal of Applied Behavior Analysis                         |
| Archives of Pathology and Laboratory Medicine                          | Journal of Applied Microbiology                              |
| Archives of Paediatrics and Adolescent Medicine                        | Journal of Applied Research in Intellectual Disabilities     |
| Archives of Disease in Childhood – Fetal and Neonatal Edition          | Journal of Attention Disorders                               |
| Archives of Diseases in Childhood                                      | Journal of Autism & Developmental Disorders                  |
| Archives of Orthopaedic Trauma Surgery                                 | Journal of Beliefs & Values: Studies in Religion & Education |
| Archives of Pathology Laboratory Medicine                              | Journal of Biosocial Science                                 |
| Arthritis Rheumatism   | Journal of Bone and Joint Surgery – Series A                 |
| ASAIO Journal  | Journal of Cataract Refractive Surgery                       |
| Assessment in Education  | Journal of Child Psychology & Psychiatry                     |
| Assessment in Education: Principles, Policy & Practice                 | Journal of Child Psychology and Psychiatry                   |
| Association for Improvements in Maternity Services Journal             | Journal of Children & Poverty                                |
| Attachment and Human Development                                       | Journal of Children's Services                               |
| Australasian Radiology   | Journal of Clinical Microbiology                             |

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| Australia New Zealand & Journal of Obstetrics & Gynaecology         | Journal of Clinical Endocrinology and Metabolism |
| Bacteriologia, virusologia, parazitologia, epidemiologia (Romanian) | Journal of Clinical Excellence                   |
| Behavioral & Brain Sciences   | Journal of Clinical Immunology                   |
| Behavioral Medicine   | Journal of Clinical Microbiology                 |
| Benefits: The Journal of Poverty & Social Justice                   | Journal of Clinical Nursing                      |
| Best Practice Research in Clinical Gastroenterology                 | Journal of Clinical Pathology                    |
| Best Practice Research in Clinical Obstetrics & Gastroenterology    | Journal of Clinical Virology                     |
| Bioethics   | Journal of Community & Applied Social Psychology |
| Bioethics Forum   | Journal of Comparative Social Welfare            |
| Biology of the Neonate  | Journal of Computer Assisted Learning            |
| Biologicals   | Journal of Dental Education                      |
| Birth Defects Research  | Journal of Dental Research                       |
| BJOG: An International Journal of Obstetrics & Gynaecology          | Journal of Dentistry                             |
| British Journal of Urology International                            | Journal of Early Childhood Literacy              |
| Blood   | Journal of Environmental Education               |
| Blood Cells, Molecules, and Diseases                                | Journal of Environmental Psychology              |
| BMC Genomics  | Journal of Ethnic & Migration Studies            |
| BMC Health Services Research  | Journal of Family History                        |
| BMC Medical Genetics  | Journal of Family Issues                         |
| BMC Paediatrics   | Journal of Family Practice                       |
| BMC Public Health   | Journal of Gender Studies                        |
| BMC Surgery   | Journal of General Virology                      |
| BMJ: British Medical Journal  | Journal of Health Psychology                     |
| Bone Marrow Transplant  | Journal of Hospital Infection                    |
| Brain   | Journal of Human Genetics                        |
| Brain Injury  | Journal of Human Hypertension                    |
| British Association of Public Health Dentistry                      | Journal of Immunology                            |
| British Dental Journal  | Journal of Infection                             |
| British Journal of Biomedical Science                               | Journal of Infectious Diseases                   |
| British Journal of Cancer   | Journal of Inherited Metabolic Disorders         |
| British Journal of Dermatology                                      | Journal of Intellectual Disabilities             |
| British Journal Nurse   | Journal of Intellectual Disability Research      |
| British Journal of Anaesthesia                                      | Journal of Interpersonal Violence                |
| British Journal of Clinical Pharmacology                            | Journal of Interprofessional Care                |
| British Journal of Community Nursing                                | Journal of Interventional Cardiology             |
| British Journal of Criminology                                      | Journal of Law & Society                         |
| British Journal of Developmental Psychology                         | Journal of Learning Disabilities                 |
| British Journal of Educational Psychology                           | Journal of Learning Disabilities                 |
| British Journal of General Practice                                 | Journal of Medical Engineering & Technology      |
| British Journal of Haematology                                      | Journal of Medical Ethics                        |
| British Journal of Hospital Medicine                                | Journal of Medical Genetics                      |
| British Journal of Learning Disabilities                            | Journal of Medical Virology                      |



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| British Journal of Medical Psychology             | Journal of Microbiology   |
| British Journal of Midwifery                      | Journal of Neonatal Nursing   |
| British Journal of Neurosurgery                   | Journal of Neuroimmunology  |
| British Journal of Nursing                        | Journal of Neurology  |
| British Journal of Nutrition                      | Journal of Neurology, Neurosurgery, Psychiatry                                |
| British Journal of Ophthalmology                  | Journal of Nursing Management   |
| British Journal of Plastic Surgery                | Journal of Obstetrics & Gynaecology   |
| British Journal of Psychiatry                     | Journal of Oral Rehabilitation  |
| British Journal of Social Psychology              | Journal of Orthodontics   |
| British Journal of Social Work                    | Journal of Orthopaedic Nursing  |
| British Journal of Sociology of Education         | Journal of Paediatric Neurology   |
| British Journal of Special Education              | Journal of Paediatric Surgery   |
| British Journal of Sports Medicine                | Journal of Paediatric Nursing   |
| British Journal of Surgery                        | Journal of Paediatric Urology   |
| British Journal of Urology                        | Journal of Perinatal Medicine   |
| British Journal of Oral and Maxillofacial Surgery | Journal of Personality Assessment   |
| British Journal of Sociology                      | Journal of Plastic, Reconstructive & Aesthetic Surgery                        |
| Bulletin of the WHO                               | Journal of Precision Teaching & Celeration                                    |
| Burns   | Journal of Psychiatric and Mental Health Nursing                              |
| Cambridge Journal of Education                    | Journal of Research in Special Educational Needs                              |
| Canadian Journal of Cardiology                    | Journal of Science & Medicine in Sport  |
| Canadian Journal of Anaesthesiology               | Journal of Sexual Aggression  |
| Cancer Genetics and Cytogenetics                  | Journal of Social History   |
| Carcinogenesis                                    | Journal of Social Issues  |
| Cardiology in the Young                           | Journal of Social Policy  |
| Caries Research                                   | Journal of Social Psychology  |
| Catheterisation & Cardiovascular Interventions    | Journal of Social Welfare & Family Law  |
| Cellular Microbiology                             | Journal of Social Work  |
| Child & Adolescent Mental Health                  | Journal of Social Work Practice   |
| Child & Family Law Quarterly                      | Journal of Social Work Practice in the Addictions                             |
| Child & Family Social Work                        | Journal of Social Work Research and Evaluation                                |
| Child & Youth Care Forum                          | Journal of Sport & Social Issues  |
| Child & Youth Services                            | Journal of Substance Abuse Treatment  |
| Child Abuse & Neglect                             | Journal of Substance Use  |
| Child Abuse Review                                | Journal of Systemic Therapies   |
| Child and Adolescent Mental Health                | Journal of The American College of Cardiology                                 |
| Child Care in Practice                            | Journal of The American Academy of Child & Adolescent Psychiatry              |
| Child Maltreatment                                | Journal of The American Association for Paediatric Ophthalmology & Strabismus |
| Child Psychology & Psychiatry Review              | Journal of The American Heart Association                                     |
| Child Welfare                                     | Journal of The Canadian Dental Association                                    |
| Child: Care, Health & Development                 | Journal of the History of Sexuality   |
| Childhood   | Journal of The International Association of Physicians in AIDS Care           |
| Childhood: A Global Journal of Child Research     | Journal of Thoracic and Cardiovascular Surgery                                |

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| Children & Society                          | Journal of Trauma & Dissociation                         |
| Children & Young People Now                 | Journal of Urban History                                 |
| Children & Youth Services Review            | Journal of Urology                                       |
| Child's Nervous System                      | Journal of Virological Methods                           |
| Chinese Journal of Contemporary Paediatrics | Journal of Virology                                      |
| Circulation                                 | Journal of Wound Care                                    |
| Cleft Palate Craniofacial Journal           | Journal of Youth and Adolescence                         |
| Clinical Biomechanics                       | Journal of Youth Studies                                 |
| Clinical Chemistry                          | Journal of Oral and Maxillofacial Surgery                |
| Clinical Endocrinology                      | Journal of Oral Pathology Medicine                       |
| Clinical Evidence                           | Journal of Orthodontics                                  |
| Clinical Linguistics Phonetics              | Journal of Paediatrics                                   |
| Clinical Otolaryngology                     | Journal of Paediatric Endocrinology and Metabolism       |
| Clinical Otolaryngology and Allied Sciences | Journal of Paediatric Gastroenterology and Nutrition     |
| Clinical Radiology                          | Journal of Paediatric Hematology Oncology                |
| Clinical & Experimental Allergy             | Journal of Paediatric Nursing                            |
| Clinical & Experimental Immunology          | Journal of Paediatric Ophthalmology and Strabismus       |
| Clinical & Experimental Rheumatology        | Journal of Paediatric Orthopaedics                       |
| Clinical Child Psychology & Psychiatry      | Journal of Pediatric Orthopaedics, Part B                |
| Clinical Dysmorphology                      | Journal of Paediatric Psychology                         |
| Clinical Experimental Dermatology           | Journal of Paediatric Surgery                            |
| Clinical Gastroenterology and Hepatology    | Journal of Perinatal Medicine                            |
| Clinical Genetics                           | Journal of Perinatology                                  |
| Clinical Infectious Diseases                | Journal of Pharmaceutical and Biomedical Analysis        |
| Clinical Laboratory Haematology             | Journal of Pharmacy and Pharmacology                     |
| Clinical Microbiology & Infection           | Journal of Proteome Research                             |
| Clinical Neurophysiology                    | Journal of Psychiatric and Mental Health Nursing         |
| Clinical Neurology & Neurosurgery           | Journal of Psychiatric Research                          |
| Clinical Nutrition                          | Journal of Public Health                                 |
| Clinical Otolaryngology                     | Journal of Public Health Medicine                        |
| Clinical Paediatrics                        | Journal of the Royal Society for the Promotion of Health |
| Clinical Radiology                          | Journal of Radiological Protection                       |
| Clinical Rehabilitation                     | Journal of Reproductive Medicine                         |
| Clinical Science                            | Journal of Spinal Disorders and Techniques               |
| Clinical Transplantation                    | Journal of Surgical Orthopaedic Advances                 |
| Clinics in Dermatology                      | Journal of Surgical Research                             |
| Clinics in Liver Disease                    | Journal of Telemedicine and Telecare                     |
| Cochlear Implants International             | Journal of Thoracic and Cardiovascular Surgery           |
| Cochrane Database Systematic Review         | Journal of Trauma  |
| Cognitive & Behavioural Practice            | Journal of Ultrasound Medicine                           |
| Collegium Antropologicum                    | Journal of Vascular and Interventional Radiology         |
| Colorectal Disease                          | Kidney International                                     |
| Communicable Disease and Public Health      | Lancet Infectious Diseases                               |
| Community Care                              | Lancet Neurology   |
| Community Dental Health                     | Language and Speech                                      |

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| Community Dentistry & Oral Epidemiology  | Language & Intercultural Communication                             |
| Community Practitioner   | Language and Education   |
| Community Safety Journal   | Laryngoscope   |
| Community, Work & Family   | Laterality   |
| Comparative Education  | Leukemia   |
| Computer Methods: Biomechanics and Biomedical Engineering                      | Literacy   |
| Computational Statistics & Data Analysis                                       | Logopedics Phoniatrics Vocology (Norwegian)                        |
| Computer Fraud & Security  | Lung Cancer  |
| Conference Proceedings of the IEEE Engineering in Medicine and Biology Society | Mammalian Genome   |
| Conference Papers – American Sociological Association                          | Maternal Child Nutrition   |
| Conference Papers – Law & Society  | MCN: American Journal of Maternal and Child Nursing                |
| Conference Papers of the American Sociological Association                     | Medical and Biological Engineering and Computing                   |
| Conflict Resolution Quarterly  | Medical Education  |
| Congenital Heart Disease   | Medical Image Analysis   |
| Contact Dermatitis   | Medicine and the Law   |
| CornerStone  | Medicine, Science and the Law                                      |
| Cortex   | Medicine and Science in Sports and Exercise                        |
| Counselling Psychology Review  | Medical Letter on the CDC & FDA                                    |
| Crime, Media, Culture  | Mental Health Nursing  |
| Criminal Behaviour & Mental Health   | Mental Health Practice   |
| Criminal Law & Criminology   | Mental Health, Religion & Culture                                  |
| Critical Care  | Mental Retardation and Developmental Disabilities Research Reviews |
| Critical Social Policy   | Methods in Molecular Biology                                       |
| Critique of Anthropology   | Methods in Molecular Medicine                                      |
| Cultural Dynamics  | Microbial Ecology in Health and Disease                            |
| Current Treat Options in Gastroenterology                                      | Microbiology   |
| Current Allergy and Asthma Reports   | Midwifery  |
| Current Gastroenterology Reports   | Midwifery Today  |
| Current Infectious Disease Reports   | Midwifery Today with International Midwife                         |
| Current Issues in Criminal Justice   | Midwives   |
| Current Issues in Molecular Biology  | Minerva Pediatrica   |
| Current Medicinal Chemistry  | Molecular and Cellular Probes                                      |
| Current Opinion in Critical Care   | Molecular Psychiatry   |
| Current Opinion in Gastroenterology  | Molecular Vision   |
| Current Opinion in Investigational Drugs                                       | Molecular Genetics and Metabolism                                  |
| Current Opinion in Paediatrics   | Mortality  |
| Current Opinion in Psychiatry  | Movement Disorders   |
| Current Opinion in Urology   | Multiple Sclerosis   |
| Current Opinion in Obstetrics and Gynecology                                   | Multicultural Review   |
| Current Treatment Options in Gastroenterology                                  | Mutation Research  |
| Cyber Psychology & Behaviour   | Mycoses  |
| Cytogenetics and Cell Genetics   | Naturwissenschaften  |

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| Cytogenetics Genome Research                                      | Neonatology   |
| Death Studies   | Nephrology Dialysis Transplantation   |
| Dental Traumatology   | Neuropsychological Rehabilitation   |
| Dental Update   | Neuroendocrinology Letters  |
| Developmental Psychology  | Neurology   |
| Developmental Review  | Neuronal Hypertrophy in Acute Appendicitis                                    |
| Development   | Neuropaediatrics  |
| Developmental Disabilities Research Reviews                       | Neuropharmacology   |
| Developmental Medicine & Child Neurology                          | Neuropsychologia  |
| Developmental Neurorehabilitation                                 | Neuropsychopharmacology   |
| Deviant Behaviour   | Neuroreport   |
| Diabetic Medicine   | Neuroscience Letters  |
| Diabetes  | Neurosurgery  |
| Diabetes Care   | Neurourology and Urodynamics  |
| Diabetes Metabolic Research Review                                | New Directions for Youth Development  |
| Diabetologia  | New England Journal of Medicine   |
| Digestive and Liver Disease                                       | Novartis Foundation Symposium   |
| Diseases of the Colon and Rectum                                  | Nurse Education in Practice   |
| Disability & Rehabilitation                                       | Nursing & Health Sciences   |
| Disability & Society  | Nursing History Review  |
| Drug and Alcohol Dependence                                       | Nursing in the Community  |
| Drug Safety   | Nursing Standard  |
| Drugs   | Nursing Times   |
| Drugs: Education, Prevention & Policy                             | Nutrition Reviews   |
| Dyslexia  | Obstetrics and Gynecology   |
| Ear, Nose & Throat Journal  | Occupation and Environmental Medicine   |
| Early Child Development & Care                                    | Occupational Therapy International  |
| Early Childhood Research Quarterly                                | Ocular Surgery News   |
| Early Education & Development                                     | Omega: Journal of Death & Dying   |
| Early Human Development   | Oncologist  |
| Early Years: An International Journal of Research and Development | Ophthalmic and Physiological Optics   |
| Education & Training  | Ophthalmic Epidemiology   |
| Educational & Treatment of Children                               | Ophthalmic and Physiological Optics   |
| Educational and Child Psychology                                  | Ophthalmology Clinics of North America  |
| Educational Psychology  | Optometry and Vision Science  |
| Educational Psychology in Practice                                | Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology and Endodontology |
| Educational Studies   | Otology and Neurotology   |
| Emergency Medical Journal   | Otolaryngology Head and Neck Surgery  |
| Emergency Nurse   | Pace  |
| Emerging infectious Diseases                                      | Paediatric Anaesthesia  |
| Emotional & Behavioural Difficulties                              | Paediatric Drugs  |
| Endodontics & Dental Traumatology                                 | Paediatric and Perinatal Epidemiology   |
| Environmental Health Perspectives                                 | Paediatric Respiratory Reviews  |
| Environmental Impact Assessment Review                            | Paediatric Nursing  |

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| Epidemiology & Infection   | Palliative Medicine                              |
| Epilepsia  | Parasitology                                     |
| Ergonomics   | Pastoral Care in Education                       |
| Ethics and Social Welfare  | Pathophysiology of Haemostasis and Thrombosis    |
| Ethnic & Racial Studies  | Patterns of Prejudice                            |
| European Addiction Research  | Peace & Conflict                                 |
| European Archives of Paediatric Dentistry                              | Peace and Conflict: Journal of Peace Psychology  |
| European Eating Disorders Review                                       | Paediatric Allergy Immunology                    |
| European Heart Journal   | Paediatric Cardiology                            |
| European Journal of Anaesthesiology                                    | Paediatric Critical Care Medicine                |
| European Journal of Biochemistry                                       | Paediatric Dentistry                             |
| European Journal of Cancer   | Pediatric Dermatology                            |
| European Journal of Clinical Microbiology and Infectious Disease       | Pediatric and Development Pathology              |
| European Journal of Dental Education                                   | Paediatric Diabetes                              |
| European Journal of Echocardiography                                   | Paediatric Emergency Care                        |
| European Journal of Emergency Medicine                                 | Paediatric Endocrinology Reviews                 |
| European Journal of Epidemiology                                       | Paediatric Infectious Disease Journal            |
| European Journal of Gastroenterology and Hepatology                    | Paediatric International                         |
| European Journal of Health Economics                                   | Paediatric Nephrology                            |
| European Journal of Nutrition  | Pediatric Pulmonology                            |
| European Journal of Obstetrics and Gynecology and Reproductive Biology | Pediatric Pulmonology Supplement                 |
| European Journal of Anaesthesiology                                    | Paediatric Surgery International                 |
| European Journal of Cancer Care  | Paediatric Transplant                            |
| European Journal of Cardiothoracic Surgery                             | Paediatric Anesthesia                            |
| European Journal of Child & Adolescent Psychiatry                      | Paediatric Blood Cancer                          |
| European Journal of Clinical Nutrition                                 | Paediatric Cardiology                            |
| European Journal of Contraception & Reproductive Health Care           | Paediatric Dermatology                           |
| European Journal of Crime, Criminal Law & Criminal Justice             | Paediatric Diabetes                              |
| European Journal of Emergency Medicine                                 | Paediatric Drugs                                 |
| European Journal of General Practice                                   | Paediatric Endosurgery and Innovative Techniques |
| European Journal of Health Law   | Paediatric Hematology & Oncology                 |
| European Journal of Human Genetics                                     | Paediatric Nephrology                            |
| European Journal of Migration & Law                                    | Paediatric Neurology                             |
| European Journal of Oncology Nursing                                   | Paediatric Pulmonology                           |
| European Journal of Orthodontics                                       | Paediatric Radiology                             |
| European Journal of Paediatric Dentistry                               | Paediatric Rehabilitation                        |
| European Journal of Paediatrics  | Paediatric Research                              |
| European Journal of Public Health                                      | Paediatric Surgery International                 |
| European Journal of Radiology  | Paediatric Transplant                            |
| European Journal of Social Work  | Paediatrics                                      |
| European Journal of Special Needs Education                            | Perceptual and Motor Skills                      |
| European Journal of Vascular and Endovascular Surgery                  | Perfusion  |

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| European Journal of Ophthalmology  | Personality & Individual Differences                                |
| European Journal of Paediatric Neurology   | Pharmacogenomics  |
| European Journal of Paediatric Surgery   | Physical & Occupational Therapy in Pediatrics                       |
| European Journal of Prosthodontics and Restorative Dentistry   | Physical Therapy Reviews  |
| European Journal of Public Health  | Plastic Reconstructive Surgery                                      |
| European Journal of Surgery  | Population Trends   |
| European Paediatric of Neurology Society   | Postgraduate Medical Journal  |
| European Radiology   | The Practising Midwife  |
| European Respiratory Journal   | Practical Diabetes International                                    |
| European Sociological Review   | Practice  |
| European Spine Journal   | Practice Nurse  |
| European Urology   | Practising Midwife  |
| Eurosurveillance   | Prenatal Diagnosis  |
| Evidence-based Nursing   | Primary Dental Care   |
| Experimental Brain Research  | Proceedings of The National Academy of Science, USA                 |
| Experimental and Molecular Pathology   | Proceedings of The Nutrition Society                                |
| Expert Opinion on Pharmacotherapy  | Professional Nurse  |
| Eye  | Prosthetics and Orthotics International                             |
| Facial Plastic Surgery   | PsycCRITIQUES   |
| Family Advocate  | Psychiatric Genetics  |
| Family Law Quarterly   | Psychiatric Bulletin  |
| Family Matters   | Psychological reports   |
| Family Practice  | Psychological Record  |
| Feminist Review  | Psychology, Crime & Law   |
| Feminism & Psychology  | Public Administration   |
| FEMS Immunology and Medical Microbiology   | Public Finance  |
| FEMS Microbiology Ecology  | Public Health   |
| Fertility Sterility  | Public Health Nutrition   |
| Fetal Diagnosis and Therapy  | Public Health Reports   |
| Focus on Alternative & Complementary Therapies   | Quarterly Journal of Experimental Psychology                        |
| Folia phoniatica et logopaedica: Official Organ of the International Association of Logopedics and Phoniatics                              | Quarterly Journal of Medicine: An International Journal of Medicine |
| Food Additives and Contaminants  | Quality and Safety in Health Care                                   |
| Food and Nutrition Bulletin  | Qualitative Research  |
| Forum: Qualitative Social Research   | Qualitative Health Research   |
| Fungal Genetic and Biology   | Quality of Life Research  |
| Gait and Posture   | Race, Ethnicity & Education   |
| Gastroenterology   | Radiation Protection Dosimetry                                      |
| Gender & Education   | Radical History Review  |
| Genes & Immunity   | Radiography   |
| Genetic Testing and Molecular Biomarkers   | RCM Midwives  |
| Genetic Epidemiology   | RCM Midwives Journal  |
| Graefe's Archive for Clinical and Experimental Ophthalmology (Albrecht von Graefes Archiv für klinische und experimentelle Ophthalmologie) | ReCALL: Journal of EuroCall   |

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| Group Analysis   | Recherches sociologiques et anthropologiques  |
| Gut  | Renal Failure   |
| Haemophilia  | Reproductive Health   |
| Hand Surgery   | Research in Developmental Disabilities  |
| Health & Social Care in the Community                                | Research on Social Work Practice  |
| Health Care Management Science                                       | Respiratory Medicine  |
| Health Education   | Resuscitation   |
| Health Education Research  | Revue de laryngologie – otologie – rhinologie   |
| Health Policy  | Annual Review of Neuroscience   |
| Health Promotion International                                       | Revista portuguesa de cardiologia: Órgão oficial da Sociedade Portuguesa de Cardiologia (Portuguese Journal of Cardiology: An Official Journal of the Portuguese Society of Cardiology) |
| Health Statistics Quarterly  | Rheumatology  |
| Heart  | Rheumatology  |
| Haematologica (Italian)  | Scandinavian Journal of Occupational Therapy  |
| Hepatogastroenterology   | Scandinavian Journal of Primary Health Care   |
| Higher Education Quarterly   | Schizophrenia Bulletin  |
| History of Education   | Schizophrenia Research  |
| HIV Medicine   | Scottish Journal of Political Economy   |
| Homeostasis in Health and Disease                                    | Seizure   |
| Hospital Medicine  | Seminars in Hematology  |
| Human and Experimental Toxicology                                    | Seminars in Neonatology   |
| Human Fertility  | Seminars in Fetal & Neonatal Medicine   |
| Human Mutation   | Seminars in Paediatric Infectious Diseases  |
| Human Psychopharmacology   | Seminars in Paediatric Surgery  |
| Human Reproduction   | Sex Roles   |
| Human Immunology   | Sexualities   |
| Human Pathology  | Singapore Dental Journal  |
| Human Rights Quarterly   | Skeletal Radiology  |
| Human Vaccines   | Sleep   |
| IEEE Transactions on Biomedical Engineering                          | Social Science & Medicine   |
| IFE Psychologia: An International Journal                            | Social work in Health Care  |
| Immunoematology  | Social Analysis   |
| Infant & Child Development   | Social Development  |
| Infection & Immunity   | Social Indicators Research  |
| Injury   | Social Policy & Administration  |
| Injury Prevention  | Social Psychiatry and Psychiatric Epidemiology  |
| International Dental Journal   | Social Science & Medicine   |
| International Ophthalmology  | Social Work and Social Sciences Review  |
| Intensive Care Medicine  | Social Work Education   |
| Interactive Cardiovascular and Thoracic Surgery                      | Sociological Origins  |
| International Immunology   | Sociological Studies of Children & Youth  |
| International Journal of Antimicrobial Agents                        | Sociology   |
| International Journal of Behavioural Nutrition and Physical Activity | Sociology of Crime, Law & Deviance  |

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| International Journal of Clinical Practice   | Special Care in Dentistry   |
| International Journal of Development Biology   | Spinal Cord   |
| International Journal of Drug Policy   | Spine   |
| International Journal of Emergency and Mental Health   | Sports Biomechanics   |
| International Journal of Food Microbiology   | Sports Medicine   |
| International Journal of Food Science and Nutrition  | Statistics in medicine  |
| International Journal of Language and Communication Disorders                                      | Studies in Health Technology Information  |
| International Journal of Nursing Studies   | Suicide & Life –Threatening Behaviour   |
| International Journal of Obesity   | Support for Learning  |
| International Journal of Obesity and Related Metabolic Disorders                                   | Surgical Infections   |
| International Journal of Obstetric Anesthesia  | Surgical Neurology  |
| International Journal of Adolescent Medicine and Health  | Surgical and Radiologic Anatomy   |
| International Journal of Behavioral Development  | Surgeon   |
| International Journal of Bilingual Education & Bilingualism  | Teachers College Record   |
| International Journal of Children’s Rights   | The American Journal of Orthopedics   |
| International Journal of Consumer Studies  | The Association for Family Therapy & Systemic Practice  |
| International Journal of Disability, Development & Education                                       | The British Association of Plastic Surgeons   |
| International Journal of Diversity in Organisations, Communities & Nations                         | The British Journal of Radiology  |
| International Journal of Drug Policy   | The Canadian Journal of Gastroenterology  |
| International Journal of Early Years Education   | The Elementary School Journal   |
| International Journal of Epidemiology  | The FASEB Journal : Official Publication of the Federation of American Societies for Experimental Biology |
| International Journal of Health Care Quality Assurance incorporating Leadership in Health Services | The History of the Family   |
| International Journal of Health Promotion & Education  | The International Journal of Children’s Rights  |
| International Journal of Inclusive Education   | The International Society for Microbial Ecology Journal   |
| International Journal of Infectious Diseases   | The Journal of Alternative & Complementary Medicine   |
| International Journal of Injury Control & Safety Promotion   | The Journal of Bone & Joint Surgery   |
| International Journal of Law, Policy & the Family  | The Journal of Infectious Diseases  |
| International Journal of Mental Health Promotion   | The Journal of Laryngology & Otology  |
| International Journal of Nursing Practice  | The Journal of Neuroscience   |
| International Journal of Nursing Studies   | The Journal of Neurosurgery   |
| International Journal of Obesity   | The Journal of Paediatrics  |
| International Journal of Oral Maxillofacial Surgery  | The Journal of The American Academy of Psychiatry & the Law   |
| International Journal of Paediatric Dentistry  | The Journal of The Society for the Anthropology of Europe   |
| International Journal of Paediatric Otorhinolaryngology  | The Lancet  |
| International Journal of Reality Therapy   | The Psychologist  |
| International Journal of Social Welfare  | The Society of Thoracic Surgeons  |
| International Journal of STD & AIDS  | Theory & Psychology   |
| International Journal of the Care of the Injured   | Theory Into Practice  |
| International Journal of the Sociology of Law  | Therapy Today   |

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| International Journal of Paediatric Dentistry  | Thorax   |
| International Journal of Palliative Nursing  | Thrombosis and Haemostasis   |
| International Journal of Paediatric Obesity  | Thrombosis Research  |
| International Journal of Paediatric Otorhinolaryngology  | Thyroid  |
| International Journal of Pharmaceutics   | Transfusion  |
| International Journal of Sports Medicine   | Transfusion Medicine   |
| International Journal of Technology Assessment in Health Care  | Transplant International   |
| International Journal of Vitamin and Nutritional Research  | Transplant Proceedings   |
| International Orthopaedics   | Transplantation  |
| International Social Work  | Treatments in Respiratory Medicine   |
| International Studies in Sociology of Education  | Trends in Microbiology   |
| Interventions: The International Journal of Postcolonial Studies   | Tuberculosis   |
| Investigative Ophthalmology & Visual Science   | Ulster Medical Journal   |
| Irish Journal of Medical Science   | Ultrasound in Obstetrics & Gynecology : The Official Journal of the International Society of Ultrasound in Obstetrics and Gynecology |
| Irish Journal of Psychological Medicine  | Urology  |
| Irish Journal of Psychology  | Vaccine  |
| Irish Journal of Sociology   | Value Health   |
| Irish Medical Journal  | Vector-borne Zoonotic Disease  |
| Irish Studies Review   | Vulnerable Children & Youth Studies  |
| Issues in Comprehensive Paediatric Nursing   | Women's Studies  |
| The Journal of the American Medical Association (JAMA)   | Women's Studies International Forum  |
| JBR-BTR: Organe de la Société Royale Belge de Radiologie (SRBR) (Orgaan van de Koninklijke Belgische Vereniging voor Radiologie) | World Journal of Gastroenterology  |
| Journal of Acquired Immune Deficiency Syndromes  | World Journal of Surgery   |
| Journal of Adolescence   | World of Irish Nursing   |
| Journal of Advanced Nursing  | World of Irish Nursing & Midwifery   |
| Journal of the American Academy of Child Adolescent Psychiatry   | Youth & Policy   |
| Journal of the American Academy of Dermatology   | Youth & Society  |
| Journal of the American Podiatric Medical Association  | Youth Justice  |
| Journal of the American Society of Nephrology  | Zoonoses Public Health   |
| Journal of Anatomy   |  |
| Journal of Animal Science  |  |





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