

UK Clinical Research Collaboration

UK Health Research Analysis



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20 Park Crescent London W1B 1AL United Kingdom

United Kingdom Tel: +44 (0)207 670 5452 Fax: +44 (0)207 637 6067

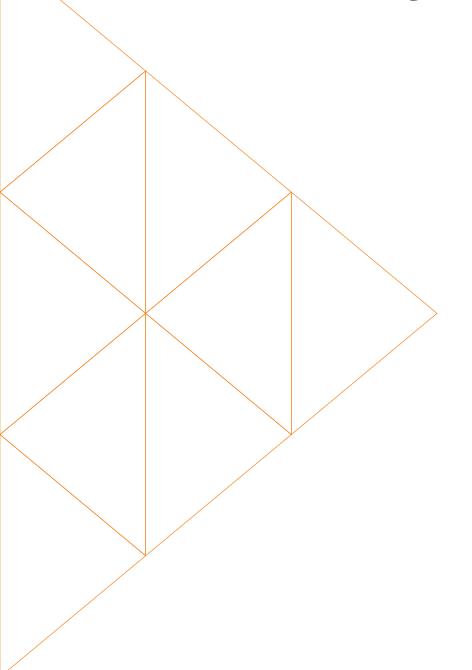
info@ukcrc.org www.ukcrc.org

May 2006



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Organisations Participating in the Analysis



Biotechnology and Biological Sciences Research Council



British Heart Foundation



Cancer Research UK



Department of Health



Engineering and Physical Sciences Research Council



Economic and Social Research Council



Medical Research Council



Research and Development Office for the Northern Ireland Health and Personal Social Services



Chief Scientist Office Scottish Executive Health Department



Wales Office of Research and Development for Health and Social Care Welsh Assembly Government



Wellcome Trust

Acknowledgements

The development of the UKCRC Research Database, the Health Research Classification System and conduct of the analysis has been a major piece of work requiring input from many different stakeholders. The work was project managed by Dr Janet Valentine from the UKCRC Secretariat. Dr Andrew Speakman developed and managed the Database. Other members of the UKCRC Secretariat have contributed to the work, particularly Hannah Brown. Dominique Capostagno was responsible for the design and production of the report.

Strategic oversight of the project was undertaken on behalf of the participating organisations by a Database Working Group (Dr George Sarna, Dr Peter Sneddon and Dr John Williams). We are also grateful to the staff of all the participating organisations for their time and effort, particularly in the development of the Health Research Classification System and in the task of providing data from their organisations. Coding was carried out by a team of freelance coders.

Many other people have provided help and input at different stages throughout the whole process. We would particularly like to thank Dr Lynne Davies and Dr Anna Smith.

The conduct of the UK Health Research Analysis was agreed as part of the overall UKCRC Workplan by members of the UKCRC Board.

Dr Liam O'Toole Chief Executive UKCRC

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Executive Summary

The UK Clinical Research Collaboration (UKCRC) is a partnership of the main stakeholders that influence clinical research in the UK. The Collaboration was set up in 2004 with the aim of establishing the UK as a world leader in clinical research. One of the goals of the UKCRC is to develop a coherent approach to funding health related research. A key step in this process is to map the current UK-wide research portfolio and create an evidence base that can be used to inform individual and joint planning and to facilitate coordination between funders.

This report presents the results of this mapping exercise - an analysis of the directly funded UK research portfolios of the 11 largest government and charity funders of health related research. Collectively the portfolios of the participating organisations represent the overwhelming majority of non-commercial health research in the UK. It is the first time a national analysis of the distribution of research funding across all types of research activity and all areas of health and disease has been carried out on this scale anywhere in the world.

There are a number of elements of funding that are essential to support research activity. This analysis focuses exclusively on directly funded peer reviewed research awards where funding can be directly attributed to a clearly defined set of research objectives such as training awards, projects, programmes, institutes and centres. It is not designed to be a national audit of all spending on biomedical and health research by the participating funders and consequently does not include indirect support costs such as administration, infrastructure and core support costs (eg for the Wellcome Trust Sanger Institute); UK Health Departments' R&D support costs for NHS providers; or research taking place outside the UK. The analysis provides an overview of research taking place in the UK

during the 2004/2005 financial year and is based on a total of 9638 peer reviewed awards, representing a total spend of £950m on this type of research during this period.

In order to conduct the analysis, a central UKCRC Research Database was established containing the directly funded health relevant research portfolios of the participating funders. A bespoke Health Research Classification System (HRCS) was developed to classify the research portfolios on the Database. The HRCS is a two dimensional analytical framework, enabling research to be classified according to the type of research activity taking place (Research Activity Codes) and according to the area of health or disease under investigation (Health Categories). The Research Activity Codes organise research into eight top level codes that cover the full spectrum of biomedical and health research. Each of these eight main codes is further subdivided to give a total of 48 Sub-codes. The Health Categories contain 21 separate groupings that encompass all diseases, conditions and areas of health.

Every research award on the Database was classified using the HRCS to reflect the central aim or 'centre of gravity' of the research taking place within the duration of the funding. Rigorous quality control measures were taken to ensure accurate and consistent coding across the portfolios of the different funders. The analysis presented in this report is primarily on the collective research portfolios of the participating organisations and focuses on the Health Categories and the main eight Research Activity Codes.

Analysis of the distribution of the combined research funding across the eight main Research Activity Codes indicates that one third of spending is concentrated in Underpinning

research, aimed at understanding normal functions and processes. Aetiology, which includes all studies into the risk, cause or development of disease, also represents one third of the total spend. The remaining third is spent on research into diagnosis of disease, development and evaluation of treatments, disease management and organisation of healthcare. A total of 2.5% of funds is dedicated to research focused on the primary prevention of disease.

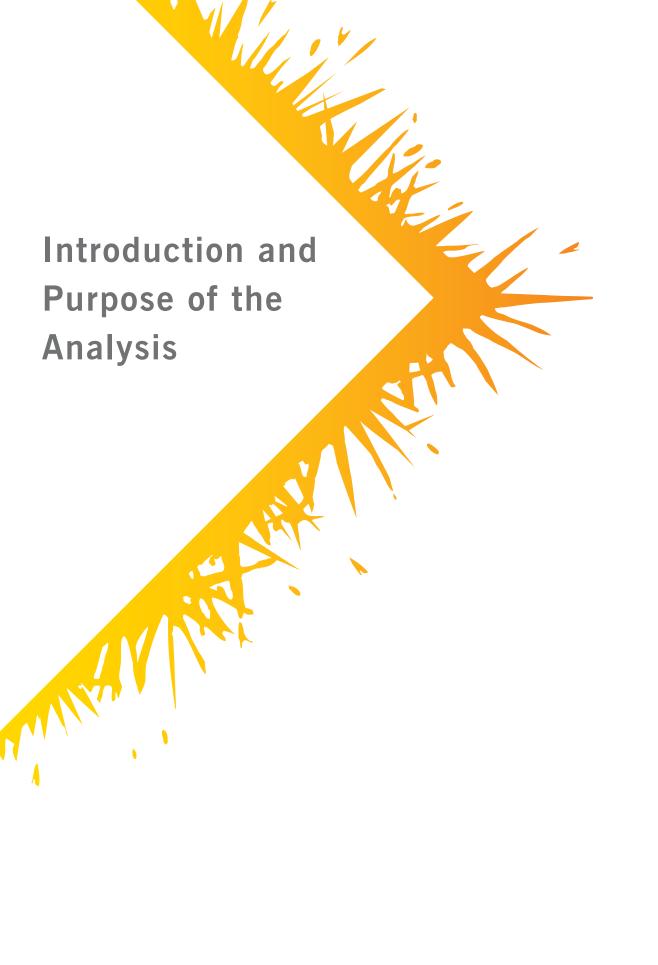
The report shows that the distribution of funds across different types of research activity varies between individual funding organisations and across different areas of health and disease. Of the total research funded, 25% is applicable to all diseases or relevant to general health and well-being, whilst 75% relates to research that can be attributed to specific diseases and areas of health. For the research funding that is specific to individual areas of health and disease, two thirds of the aggregate funds are spent on Cancer, Neurological, Infection and Cardiovascular research. In general the pattern of research funding follows the ranking of burden of disease as measured by Disability Adjusted Life Years (DALY) rates for the UK. Exceptions to this trend were observed in the areas of Respiratory, and Oral and Gastrointestinal, where the comparative research funding is lower than the relative burden of disease and for Infection, where the relative research funding is higher than the UK DALY ranking.

Analyses have previously been carried out in the UK in single disease areas such as cancer but an overview of research funding across all diseases has not been attempted before. This report provides a breakdown of the relative research funding for 19 individual areas of health and disease. A geographical distribution of funding within the UK is also provided.

The pattern of direct research funding observed in this study is a composite of 11 different research portfolios. This pattern has emerged over a period of time and has been shaped by a variety of different factors. In any given area of health related research the factors that might influence the amount of activity include: scientific opportunity; size and quality of the research workforce; 'researchability' or tractability of an area; burden of disease; and the level of charity fundraising. There is no correct or appropriate shape for the overall UK portfolio and, as this type of exercise has not been conducted before, there are no comparative national analyses available.

The funding organisations participating in the analysis are a mixture of public and charity bodies. They have different drivers and approaches to funding research and will use the findings from the analysis in different ways. The data in this report represent a snapshot of 'live' funding for the financial year 2004/2005. Since then the participating organisations have launched a number of initiatives aimed at boosting clinical research and experimental medicine, including joint initiatives developed under the auspices of the UKCRC.

The UKCRC brings together key stakeholders to address complex issues that could not be tackled by a single organisation. This analysis represents a powerful example of joint working between the main funders of health research in the UK. In the future the UKCRC Secretariat will explore the feasibility of including data from smaller medical research charities and Industry to add to the picture of health research in the UK.



1. INTRODUCTION AND PURPOSE OF THE ANALYSIS

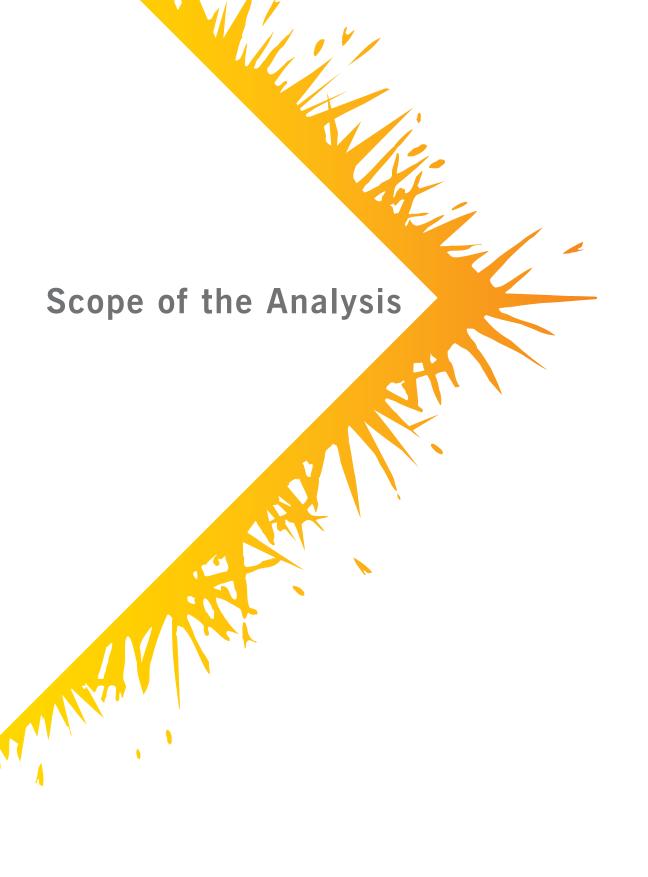
The UK Clinical Research Collaboration (UKCRC) was set up in 2004 with the aim of establishing the UK as a world leader in clinical research (see **Appendix 1**). The Collaboration is a partnership of the main stakeholders that influence clinical research including the major funders of clinical research in the UK. One of the goals of the UKCRC is to develop a coherent approach to funding health related research. A key step in this process is to map the current UK-wide research portfolio to create an evidence base that may be used to inform individual and joint planning and to facilitate coordination between the funders.

The UK has a range of health research funders from the government and charity sectors, each with a different set of drivers and approaches to funding research. Each organisation has a system for managing and monitoring research funding, however to date, it has not been possible for an individual organisation to analyse its own portfolio in the context of research funded by others. In order to bring the information together and create a comprehensive picture of health relevant research in the UK three things were needed, a central database containing the funders' research portfolios, a common coding system to classify the data and resources to carry out the work. The UKCRC Secretariat was uniquely placed to undertake this task by providing the resources and expertise necessary to conduct an independent

analysis of health related research activity in the UK.

The UKCRC Research Database has now been established to provide a tool that can be used to answer a range of questions on the distribution of research funding in the UK. The Database contains the directly funded peer reviewed health relevant research of the largest government and charity research funders in the UK. A bespoke Health Research Classification System has also been developed as a single system to classify and interrogate the research on the Database. This centralised and standardised approach allows meaningful comparison of the different research portfolios of the participating organisations.

Analyses have previously been carried out in the UK in single disease areas such as cancer¹ but an overview of research activity funding across all diseases and areas of health has not been attempted before. This is the first time a national analysis on this scale has been carried out anywhere in the world. This report describes an accurate picture of the vast majority of government and charity directly funded biomedical and health related research activity across all areas of health and disease in the UK for the year 2004/2005. The text provides a factual overview of relative funding in different areas of research during this period.



2. SCOPE OF THE ANALYSIS

2.1 **Participating Organisations**

The largest government and charity organisations that fund health relevant research in the UK have participated in this analysis (see Appendix 2).

The government bodies involved include the Health Departments of the four regional governments and four research councils. The government organisations are:

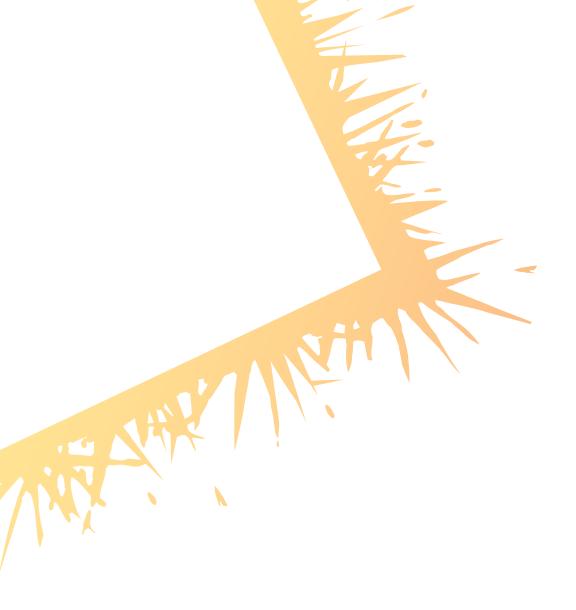
- Department of Health (England)
- Research and Development Office for the Northern Ireland Health and Personal Social Services (Northern Ireland)
- Chief Scientist Office, Scottish Executive Health Department (Scotland)
- Wales Office of Research and Development for Health and Social Care, Welsh Assembly Government (Wales)
- Medical Research Council (MRC)
- **Biotechnology and Biological Sciences Research Council (BBSRC)
- *Engineering and Physical Sciences Research Council (EPSRC)
- *Economic and Social Research Council (FSRC)

The full research portfolio of the Medical Research Council has been included in the analysis. The other three research councils have wide, nonhealth related remits but also fund health related research. The health related research portfolios of the Engineering and Physical Sciences Research Council* and Economic and Social Research Council* have been included in this exercise. The Biotechnology and Biological Sciences Research Council** provided a health relevant portfolio that is specific to ageing related research.

The three largest medical research charities in the UK were included in the analysis. Collectively they are estimated to fund more than 80% of UK charitable health related research. These organisations are:

- British Heart Foundation (BHF)
- Cancer Research UK (CRUK)
- Wellcome Trust (Wellcome)

Together the research portfolios of these 11 funding bodies represent the overwhelming majority of non-commercial health related research in the UK.



2.2 Data Included in the Analysis

There are a number of elements of funding that are essential to support research activity. These include direct costs such as peer reviewed research awards and indirect costs such as administration and building maintenance. This analysis focuses exclusively on the directly funded peer reviewed UK research of the participating funders. The criteria for inclusion in the analysis are as follows:

- Research is funded by a participating organisation
- ► Research must be taking place within the UK
- ▶ Research is of health or biomedical relevance
- The award must be active during the 2004/2005 financial year i.e. funding must start, end or be ongoing at any time between 1st April 2004 and 31st March 2005
- Research where funding can be directly attributed to a set of clearly defined research

objectives and therefore can be classified by type of research activity or area of health or disease i.e. directly funded research, including training awards, projects, programmes, institute and unit awards

The analysis is designed to provide a snapshot of directly funded peer reviewed research that was 'live' (i.e. funded research was taking place) during the 2004/2005 financial year. The Database holds a total of 9638 awards, which amounts to a combined spend of £950m on this type of research during this period.

2.3 Data Not Included in the Analysis

This analysis is not designed to be a national audit of all spending on biomedical and health related research by the participating organisations. Whilst it includes directly funded UK based research awards that are associated with clear research objectives, it does not include other indirect

research costs. Therefore the following types of research funding have not been included in this analysis:

- Research support costs including:
 - building construction, maintenance and associated infrastructure and core support costs, such as core support for the Wellcome Trust Sanger Institute
 - administrative costs
 - membership of professional bodies
 - library maintenance costs
 - costs relating to attending or holding meetings
- R&D support costs for NHS providers funded by the UK Health Departments
- Research funded by the participating organisations taking place outside the UK

It is recognised that there are other funders of health related research in the UK and inclusion of their research portfolios would add to the overall landscape of UK research activity. Obtaining these data has not been feasible at this stage, however it is hoped that it may be possible to include some of this information in future analyses. Health relevant funding that is not included:

- Industry funded health research
- Research funded by smaller UK not-for-profit organisations
- Research taking place in the UK funded by non-UK funding organisations
- Higher Education Funding Councils funding to support research infrastructure



3. METHODOLOGY

3.1 Oversight of the Process

The development of the Database, the classification system and planning of the analysis took place under the strategic oversight of the Database Working Group. This group comprised senior representatives from the UKCRC Partners and had delegated authority from the UKCRC Board to make decisions on its behalf.

Establishment of the UKCRC Research 3.2 **Database**

3.2.1 Data Collection and Processing

The UKCRC Database contains 9638 individual awards. These were collected from the participating organisations in the form of a common dataset of information that included details on the principal investigator (including location of the research), the type, amount and duration of the award and the title and scientific abstract of the research being undertaken.

One of the major reasons this exercise has not previously been attempted is the scale of effort involved. Each organisation uses a different administrative system to manage its research awards and each submitted its dataset in a different format. All of these had to be standardised prior to being imported into the UKCRC Research Database.

In several cases the funding bodies did not hold their organisation's data centrally. Data were obtained from a total of 22 individual data sources from within the 11 participating funders. Lack of electronically available data was a further complicating factor, as only 5 of the 11 funding bodies maintained all the requested dataset in an electronic format. Of the final 9638 awards included

on the Database, 4660 abstracts (48% of the total) were obtained from paper based copies. This involved copying the original paper sources, scanning and proof reading each of the abstracts and individually importing them into the Database. The data collection process took 10 months to complete with dedicated personnel from the UKCRC Secretariat working full time on the project.

3.2.2 Ownership of the Data

Data supplied to the UKCRC Research Database are owned by the organisations funding the research and are held in confidence by the UKCRC Secretariat. Access to the data will be restricted to the UKCRC Secretariat. Details of individual awards will not be circulated or published unless agreement is obtained in advance from the participating organisations.

3.3 Classification of Research on the Database

3.3.1 Development of a Bespoke Research Classification System

Reproducible and meaningful analysis of the directly funded research of different funding organisations requires a common system to classify the data. There are many different ways to classify research and a number of classification systems already exist. An initial scoping exercise was carried out to ascertain the breadth of research funded by the participating organisations, the types of analyses they would wish to carry out and the suitability of existing classification systems. Based on this information, it was decided to develop a bespoke analytical classification system that would cover the full spectrum of biomedical and health research funded by the participating organisations.

The classification system underwent extensive development and evaluation with input throughout the process from the participating funding organisations. The process also involved consultation with stakeholders from Industry and the Association of Medical Research Charities (AMRC) and a piloting exercise by research managers from the funders, using the system to classify a selection of their current research portfolios. The final version of the classification system, entitled the Health Research Classification System (HRCS), was approved by those involved in the development and was formally agreed and signed-off by the UKCRC Database Working Group on behalf of the participating funding organisations.

3.3.2 Understanding the Health Research Classification System

The Health Research Classification System (HRCS) is a two dimensional framework for classifying research awards. One dimension of the framework, the Research Activity Codes, classifies awards according to type of research activity. The other dimension, the Health Categories, classifies research according to the area of health and disease being studied. Full details of the HRCS are presented in Appendix 3.

The Research Activity Codes are modelled on the Common Scientific Outline which is a cancer research specific classification system developed by the International Cancer Research Partners². The Common Scientific Outline has been successfully used by the National Cancer Research Institute (NCRI) Partners for the strategic analysis of cancer research in the UK¹. The Research Activity Codes describe broad areas of research

activity organised into eight overarching categories:

- Underpinning Research (Underpinning) research that underpins investigations into the cause, development, detection, treatment and management of diseases, conditions and ill health
- ► Aetiology identification of determinants that are involved in the cause, risk or development of disease, conditions and ill health
- Prevention of Disease and Conditions. and Promotion of Well-Being (Prevention) - research aimed at the primary prevention of disease, conditions or ill health, or promotion of well-being
- Detection, Screening and Diagnosis (Detection and Diagnosis) - discovery, development and evaluation of diagnostic, prognostic and predictive markers and technologies
- Development of Treatments and Therapeutic Interventions (Treatment Development) - discovery and development of therapeutic interventions and testing in model systems and preclinical settings
- Evaluation of Treatments and Therapeutic Interventions (Treatment Evaluation) – testing and evaluation of therapeutic interventions in clinical, community or applied settings
- Management of Diseases and Conditions (Disease Management) – research into individual care needs and management of diseases, conditions or ill health
- ► Health and Social Care Services Research (Health Services) – research into the provision of health and social care services, health policy and research methodology

Each of these main categories is further subdivided, to give a total of 48 Research Activity Sub-codes. The main eight Research Activity Codes can be used for a 'top level' analysis, a more detailed examination can be carried out by analysing the sub-codes of each main category, and cross-cutting analyses can be performed by combining sub-codes from across different categories.

The Health Categories are based on the International Classification of Diseases (ICD) codes³ and contain 21 separate groupings which encompass all diseases, conditions and areas of health. Where possible these Health Categories have been designed to match the ICD codes. However, as the ICD codes only describe diseases and ill health, they are not always adaptable to capture the breadth of research funded by the participating organisations. For example there is no appropriate ICD code to accurately classify studies of normal development and function of the immune system. Separate categories, such as the Inflammatory and Immune System, have been created where there is no suitable ICD code equivalent.

Some categories have been created in areas of specific interest to the UKCRC Partners. For instance a Stroke Research Network has recently been established as part of the UK Clinical Research Network and therefore a separate Stroke category has been included in the Health Categories. A further difference from the ICD codes is the Infection category, which includes all diseases caused by infectious agents regardless of the type of infection or system affected. Additionally a Generic Health Relevance category has been added to the system to classify research that

is applicable to all diseases and conditions or general health and well-being.

3.3.3 Classification of the Data and Quality Control Process

A team of coders with the appropriate research experience and no affiliation to any of the participating organisations was contracted to classify the research on the Database. The coders received training on the use of the HRCS and regular feedback and guidance throughout the coding process.

Each research award was classified with up to two Research Activity Codes (with up to four codes for large programmes and centre awards) and up to five Health Categories to reflect the main aim of the research taking place within the duration of the funding. The funding for the 2004/2005 period of the award was apportioned between assigned codes for both the Research Activity Codes and Health Categories sections of the HRCS, to ensure there was no double counting of award funds in the analysis.

Rigorous quality control measures were taken to ensure accurate and consistent coding across the portfolios of the different funders. Every research award was independently classified by two coders and the assigned codes were subsequently reviewed and standardised as necessary by the UKCRC Secretariat. The percentage of all allocated codes where the final code agreed with one allocated by the contract coders was 87% for the Research Activity Codes and 93% for the Health Categories.



4. ANALYSIS OF THE RESEARCH PORTFOLIOS

4.1 Understanding the Results of the Analysis

The analysis is designed to provide a base-line overview of the research activities of the largest government and charity research funders in the UK during 2004/2005. There are a number of factors that should be considered when reviewing the results of this analysis. Firstly, analysis of the Database can provide valuable information on the relative amounts of directly funded research activity in different areas, but it has not been designed to analyse all spending on biomedical and health research in the UK. Secondly, a research award may have a number of objectives; the Health Research Classification System is designed to capture the central aim of the research taking place rather than every facet or possible outcome of the work. The analysis described here provides an indicator of the 'centre of gravity' of the research awards held on the Database.

The 11 participating funding bodies fund research in differing ways. All use the peer review system to ensure the quality of the research they fund. Some funders commission research to answer specific questions, but the majority use 'response mode' to fund the highest quality proposals submitted to them by the research community. In light of this, there are several factors that might influence the amount of activity in any given area of health related research. These include:

- The scientific opportunity in an area
- The size and quality of the research workforce in each area
- The 'researchability' or tractability of an area
- The burden of disease in an area
- The level of charity fundraising conducted in an area

This analysis is primarily on the combined research portfolios of the participating funders and focuses on the Health Categories and the major

Research Activity Codes. It is possible to carry out a more detailed breakdown of the research using the Research Activity Sub-codes, but these analyses are outside the scope of this report.

4.2 Distribution of Funding across Research Activities

The distribution of the collective research portfolio of the funders across the eight major Research Activity Codes is shown in Figure 1. Approximately one third of the funding is concentrated in **Underpinning (34.1%)** research and one third in Aetiology (34.5%). Underpinning research is aimed at understanding normal biological, psychological and socioeconomic processes and functioning, and forms the basis for subsequent investigations into the cause, detection, treatment or management of diseases and public health research. The Aetiology category includes research into the risk or cause and development of ill health and diseases. This category comprises biological, environmental, psychological and socioeconomic factors involved in disease processes. It also includes surveillance and distribution and research designs, measures and methodologies. Most epidemiological studies are included in this category.

The **Prevention (2.5%)** category contains research into the primary prevention of disease or conditions, or promotion of well-being. This encompasses behavioural and environmental interventions, vaccine development, nutrition and chemoprevention. A similar proportion of the total cancer spend in primary prevention research was observed in the NCRI strategic analysis of cancer research¹.

Health Services 4.8% Disease Management 2.3% Treatment Evaluation 8.1% Underpinning 34.1% Treatment Development 8.5% -Detection and Diagnosis 5.2% — Prevention 2.5%

Figure 1 Proportion of Combined Total Spend by Research Activity

The participating funding bodies spend **5.2%** of their combined directly funded research in **Detection and Diagnosis** which encompasses the discovery, development and evaluation of markers, methods and imaging technologies. Research within this category includes population screening and studies of the psychological and socioeconomic factors that affect screening. Studies into the discovery, development and preclinical testing of biological markers, imaging technologies and diagnostic and predictive tests have been classified in a separate sub-code from testing and evaluation in humans. This separation allows for more in-depth analysis of this area.

Aetiology 34.5%

Research into treatments and therapeutic interventions has been divided into Treatment Development (8.5%) and Treatment Evaluation (8.1%) to reflect the UKCRC Partners' interest in experimental medicine and translational research as well as clinical trials. Both of these research areas contain all types of therapeutic interventions from pharmaceuticals to behavioural and physical therapies. Treatment Development includes discovery, development and testing in model and

preclinical systems. It also includes research into the mechanism of action of interventions and understanding side effects or adverse reactions. Treatment Evaluation involves testing and evaluation of interventions in humans in clinical or applied settings and therefore includes all therapeutic trials.

Disease Management (2.3%) and Health Services (4.8%) capture two areas of health care. Disease Management is focused at the individual patient level, encompassing individual care needs of service users such as quality of life, treatment compliance, self management and end of life care issues. It also includes studies into all aspects of management by health and social care professionals and contains much of primary care research. Health Services includes research that is aimed at investigating health and social care systems at an organisational level. This category includes all research studying service delivery and organisation, health and welfare economics and policy. It also includes the development of research designs and methodologies in health care.

A breakdown of the major Research Activity Codes into their sub-codes is shown in Table 1. Each sub-code is displayed both as a relative proportion of the major Research Activity Code and as a percentage of the total spend on the Database.

In order to present data in a format that is readily accessible and allows the 'centre of gravity' of research activity in different areas to be compared, the data can be presented as 'kite diagrams'. This methodology was developed by the NCRI¹ and has been used by a range of funding bodies since then. The combined research spend classified by research activity illustrated in the pie chart in Figure 1 is displayed as a kite diagram in Figure 2. In the kite diagram the sum of the areas above and below the line of origin represents the proportion of each Research Activity Code indicated at the top of the kite diagram.

The individual funding profiles of the research portfolios on the Database of each of the participating organisation are shown as kite diagrams in Figure 3. Each kite represents an organisation's own relative spend distributed across the eight major areas of research activity. The relative contribution of each organisation to the overall research spend on the Database varies and the kites have been colour coded to reflect these relative proportions.

The individual profiles represent the directly supported, peer reviewed research awards such as projects, programmes, units, training awards etc. The figures do not represent all the funding provided by the participating organisations. As outlined in **Section 2.3** this analysis does not include infrastructure costs such as administrative and building costs, core support costs including the Wellcome Trust Sanger Institute and the Health Departments' research and development support costs for NHS providers. It also does not include research supported outside the UK. The profiles of BBSRC, ESRC and EPSRC presented here represent the health relevant or specific ageing relevant component of each research council's total research portfolio.

The main areas of research activity of the three research charities BHF, CRUK and Wellcome Trust illustrated in **Figure 3** are Underpinning and Aetiology followed by Treatment Development. The MRC follows a similar pattern with the major emphasis being on Underpinning research and Aetiology. Of the remaining Research Activity Codes, a similar relative proportion is spent in research on Detection and Diagnosis and Treatment Development and Evaluation. In contrast, the profiles of the Health Departments are generally focused in Treatment Evaluation and Health Services, followed by Detection and Diagnosis and Disease Management. The profiles of the relevant research portfolios of the three research councils reflect their funding remits. The majority of ageing relevant research activity supported by BBSRC is in Underpinning research. The portfolio of ESRC's health relevant socioeconomic research is divided between Underpinning and Aetiology and Health Services. The EPSRC health related research funding is spread between Underpinning research, the discovery and development of Detection and Diagnostic technologies and Treatment Development.

Distribution of Funding across Health 4.3 **Categories**

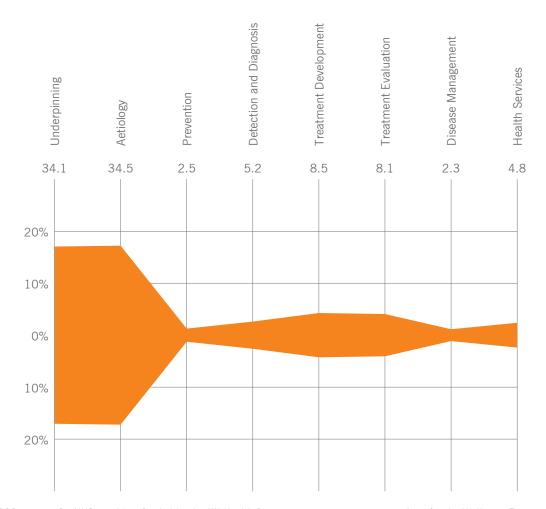
The next two sections of the report present analyses of the research on the Database using the Health Categories classification.

There are 21 Health Categories, of which 20 relate to a specific area of health or disease. These 20 health specific categories include research into both disease and normal function, for example, studies of normal hepatic cell function and studies of liver cirrhosis will be classified in the Oral and Gastrointestinal Health Category. The remaining category, Generic Health Relevance, relates to research that is applicable to all diseases or relevant to general health and well-being, for example basic cell and molecular biology studies common to all cell types, or geographical evaluation of health services. Of the total research funded, 25% is of Generic Health Relevance, whilst 75% relates to the health

Breakdown of Proportion of Combined Spend by Research Activity Sub-code Table 1

| | | % of Research Activity | % of Total Spend |
|------|---|---------------------------|------------------|
| | nderpinning Research 34.1% | | 22.5 |
| 1.1 | Normal biological development and functioning | 84.0 | 28.7 |
| | Psychological and socioeconomic processes | 3.8 | 1.3 |
| | Chemical and physical sciences | 4.5 | 1.5 |
| | Methodologies and measurements | 0.4 | 0.1 |
| 1.5 | Resources and infrastructure (underpinning) | 7.3 | 2.5 |
| 2 Ae | etiology 34.5% | | |
| 2.1 | Biological and endogenous factors | 64.1 | 22.1 |
| 2.2 | Factors relating to physical environment | 16.0 | 5.5 |
| 2.3 | Psychological, social and economic factors | 4.7 | 1.6 |
| | Surveillance and distribution | 5.3 | 1.8 |
| 2.5 | Research design and methodologies (aetiology) | 0.7 | 0.3 |
| 2.6 | Resources and infrastructure (aetiology) | 9.2 | 3.2 |
| 3 Pr | evention of Disease and Conditions, and Promotion of Well-Being 2.5% | | |
| 3.1 | Primary prevention interventions to modify behaviours or promote well-being | 20.8 | 0.5 |
| 3.2 | | 8.2 | 0.2 |
| 3.3 | | 33.0 | 0.8 |
| | Vaccines | 36.8 | 0.9 |
| 3.5 | Resources and infrastructure (prevention) | 1.2 | < 0.1 |
| | | | 1012 |
| | etection, Screening and Diagnosis 5.2% | | |
| 4.1 | 7 1 0 | 36.1 | 1.9 |
| 4.2 | | 40.1 | 2.1 |
| | Influences and impact | 2.6 | 0.1 |
| | Population screening | 10.1 | 0.5 |
| 4.5 | Resources and infrastructure (detection) | 11.1 | 0.6 |
| 5 De | evelopment of Treatments and Therapeutic Interventions 8.5% | | |
| 5.1 | Pharmaceuticals | 45.3 | 3.9 |
| 5.2 | Cellular and gene therapies | 25.1 | 2.1 |
| 5.3 | | 8.4 | 0.7 |
| 5.4 | Surgery | 6.6 | 0.6 |
| 5.5 | Radiotherapy | 3.4 | 0.3 |
| 5.6 | Psychological and behavioural | 1.7 | 0.1 |
| 5.7 | Physical | 0.3 | < 0.1 |
| 5.8 | Complementary | 0.1 | < 0.1 |
| | Resources and infrastructure (development of treatments) | 9.1 | 0.8 |
| 6 Ev | valuation of Treatments and Therapeutic Interventions 8.1% | | |
| | Pharmaceuticals | 36.2 | 2.9 |
| 6.2 | | 3.1 | 0.3 |
| 6.3 | | 5.1 | 0.4 |
| 6.4 | | 8.7 | 0.7 |
| | Radiotherapy | 5.3 | 0.4 |
| 6.6 | | 5.1 | 0.4 |
| 6.7 | , 0 | 4.6 | 0.4 |
| 6.8 | , | 1.5 | 0.1 |
| 6.9 | Resources and infrastructure (evaluation of treatments) | 30.4 | 2.5 |
| | | 30.4 | 2.0 |
| | anagement of Diseases and Conditions 2.3% | | |
| 7.1 | Individual care needs | 48.9 | 1.1 |
| | End of life care | 3.7 | 0.1 |
| 7.3 | Management and decision making | 42.1 | 1.0 |
| 7.4 | Resources and infrastructure (disease management) | 5.3 | 0.1 |
| 8 He | ealth and Social Care Services Research 4.8% | | |
| 8.1 | Organisation and delivery of services | 53.5 | 2.6 |
| 8.2 | Health and welfare economics | 13.1 | 0.6 |
| 8.3 | | 12.9 | 0.6 |
| 8.4 | Research design and methodologies | 12.5 | 0.6 |
| 8.5 | Resources and infrastructure (health services) | 8.0 | 0.4 |
| 0.0 | nessarioss and initiastructure (neutri sorvices) | 0.0 | V.T |

Figure 2 Proportion of Combined Total Spend by Research Activity – Kite Diagram



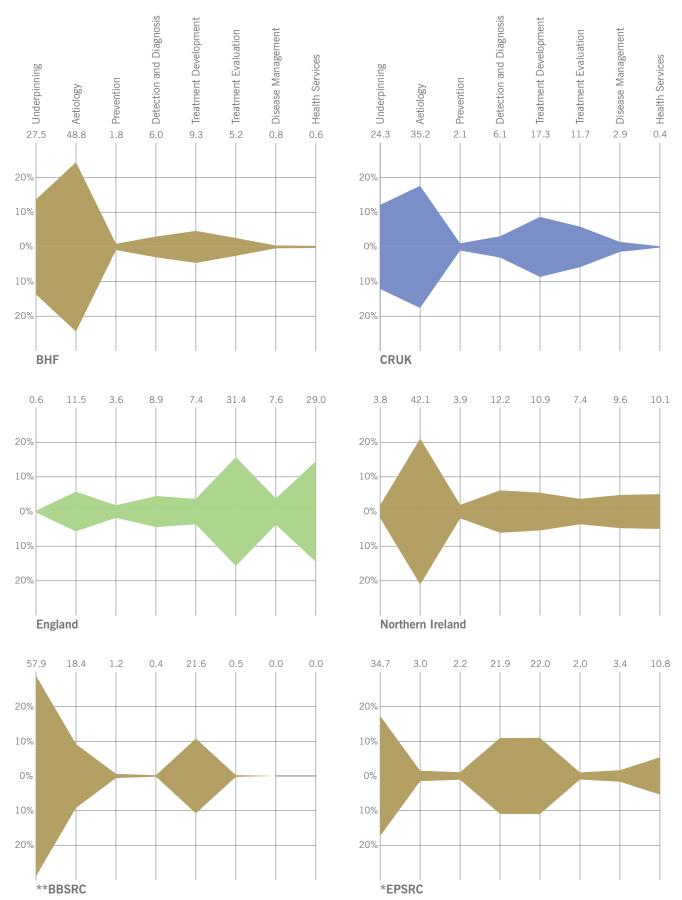
specific categories. **Sections 4.3** and **4.4** present the breakdown of this 75% of the total research spend, classified into the 20 health specific categories.

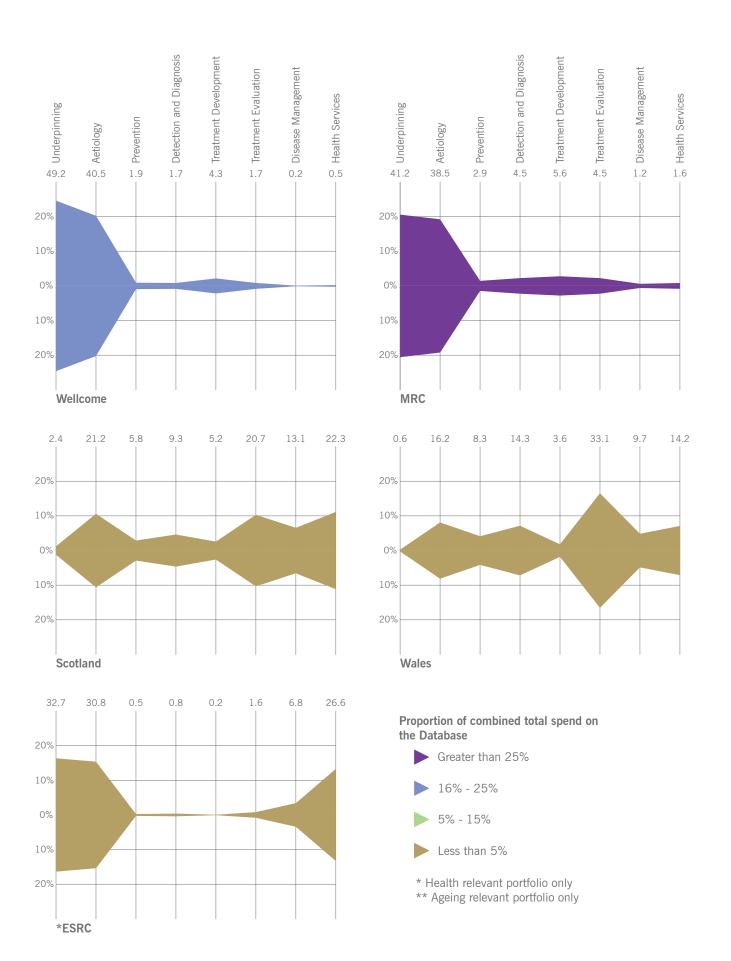
The relative distribution of research funding across the health specific categories is presented in Figure 4. The proportions range between 28% spend in Cancer which includes all types of cancers, to 0.3% in Injuries and Accidents which includes research into fractures, poisoning and burns. Research within the Cancer, Neurological, Infection and Cardiovascular categories accounts for two thirds of the aggregate health specific category funds on the Database.

As previously outlined in **Section 4.1** there are multiple factors that influence the level of research funding in any area, including scientific opportunity, research workforce capacity, 'researchability' or tractability, burden of disease and fund raising potential. Burden of disease is a measure that has previously been used as a comparator for research investment across different diseases^{1, 4}. There are many metrics to assess burden of disease such as incidence, prevalence, mortality, morbidity and length of hospital stay. Comparison with each of these can lead to different interpretations about the appropriate relationship with research funding levels.

Disability Adjusted Life Years (DALY) are frequently used as a measure of burden of disease^{4, 5}. DALYs are a measure of the sum of life years lost due to premature mortality and

Profile of Each Organisation's Spend by Research Activity Figure 3





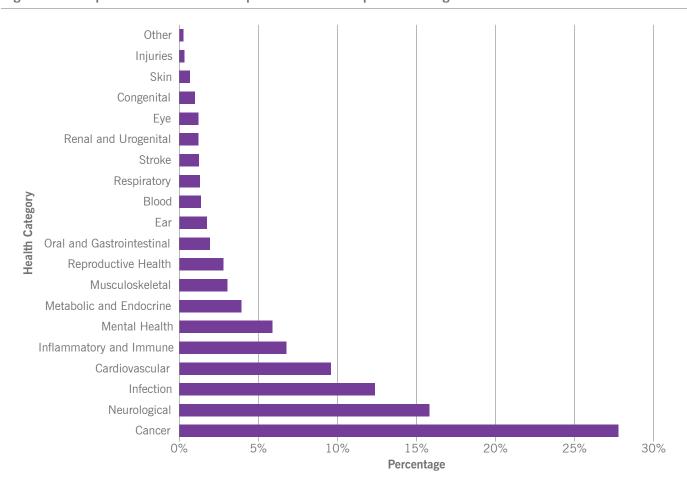


Figure 4 Proportion of Combined Spend on Health Specific Categories

years lived with a disability adjusted for the severity, and thus they take into account the impact of mortality and morbidity in a single measure. Figure 5 presents a comparison of the proportion of research funding across the health specific categories related to UK Disability Adjusted Life Years (DALY) rates from the WHO Global Burden of Disease Project⁶. The Health Categories have been combined as necessary to allow appropriate comparison with the available DALY data. The trends in the ranking of research funding generally correlate with the overall trend in the DALY ranking. Notable exceptions to this association are observed for Infection, Respiratory, and Oral and Gastrointestinal (which includes the liver). In the case of Infection the relative research funding is higher than the corresponding UK DALY ranking, whereas for Respiratory, and Oral and Gastrointestinal the relative research

funding is lower than the comparative burden of disease.

4.4 Analysis of Funding within Individual **Health Categories and Research Activities**

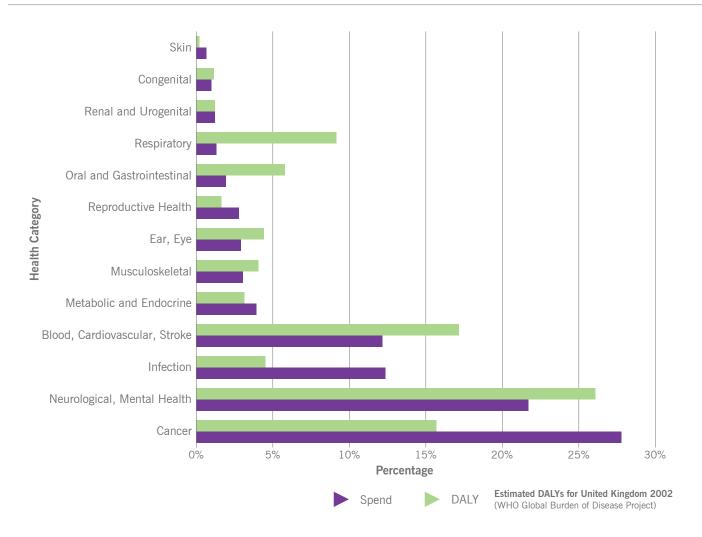
The NCRI strategic analysis examined the distribution of funds between different types of research activities in cancer research¹. Up until now it has not been possible to analyse and compare the balance of research activity in other disease and health areas. Figure 6 presents a breakdown of research on the Database across 19 individual disease and health areas as classified by Health Category. The data are displayed as a series of kite diagrams where the Research Activity Codes are shown as a proportion of the relative spend for each of the Health Categories.

Each Health Category has a unique overall funding profile across the different types of research activity. These variations probably reflect the strength of the different drivers and influences in different areas of health research. The distribution of research activity in Cancer shown here is similar to that observed in the NCRI strategic analysis, although there are some differences between the figures reflecting differences in the classification systems used for these two exercises¹. The profile of research activity in the Cancer category shown here can be compared and contrasted with the different patterns of research activity observed for the first time in other diseases and areas of health. A common feature of the profiles of all the Health Categories is that the largest proportion of research activity funding is associated

with Underpinning or Aetiology, reflecting the proportion of funding in these areas observed in the combined portfolio (see **Figure 1**).

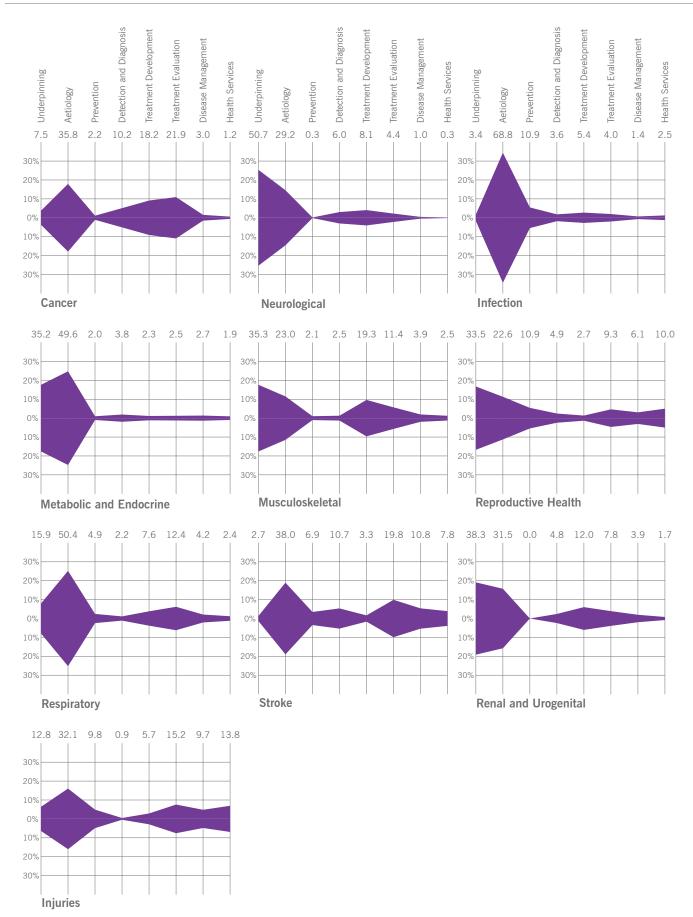
The relative distribution of funds across different areas of health and disease can be further analysed within each of the main areas of research activity. The relative funding of eight Health Categories within each of the main Research Activity Codes is shown in **Figure 7**. The selected Health Categories are those with the highest proportion of spend as illustrated in **Figure 4**, namely, Cancer, Neurological, Infection, Cardiovascular, Inflammatory and Immune, Mental Health, Metabolic and Endocrine and Musculoskeletal. The sum of the funding associated with the 12 remaining health specific categories is indicated as 'Remainder' on the

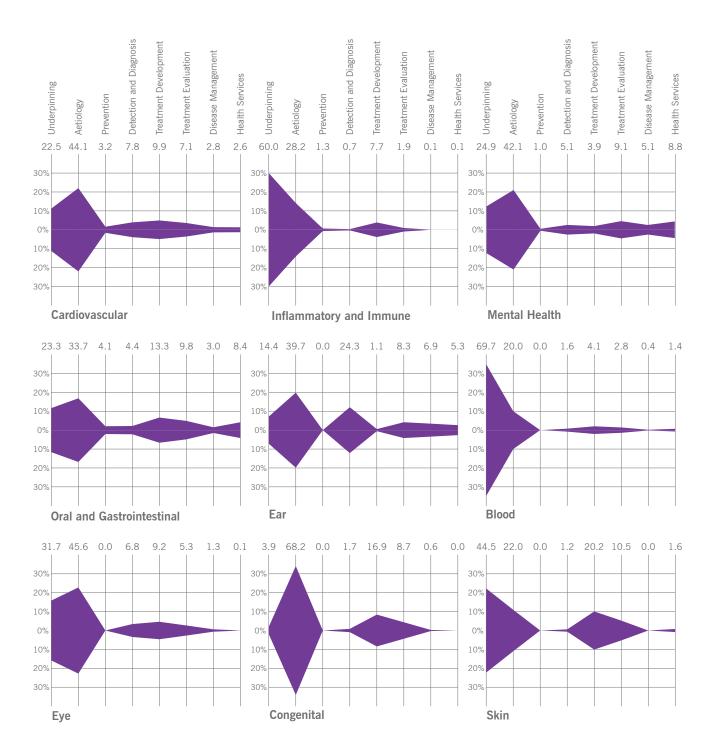
Figure 5 Proportion of Combined Spend on Health Specific Categories Compared with DALY Rates



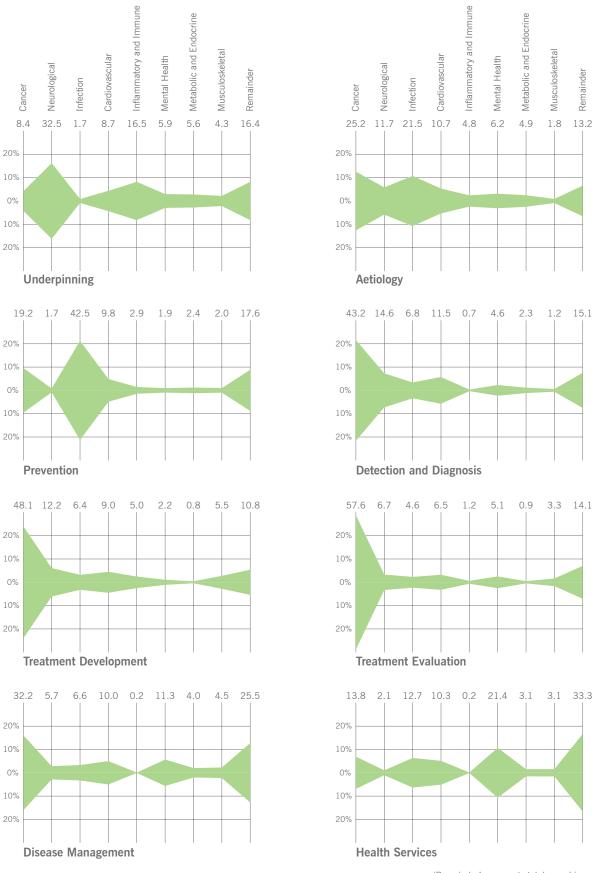
Data excludes R&D support for NHS providers funded by the UK Health Departments, core support costs (e.g. for the Wellcome Trust Sanger Institute) and research taking place outside the UK.

Proportion of Combined Spend by Research Activity for Individual Health Categories Figure 6



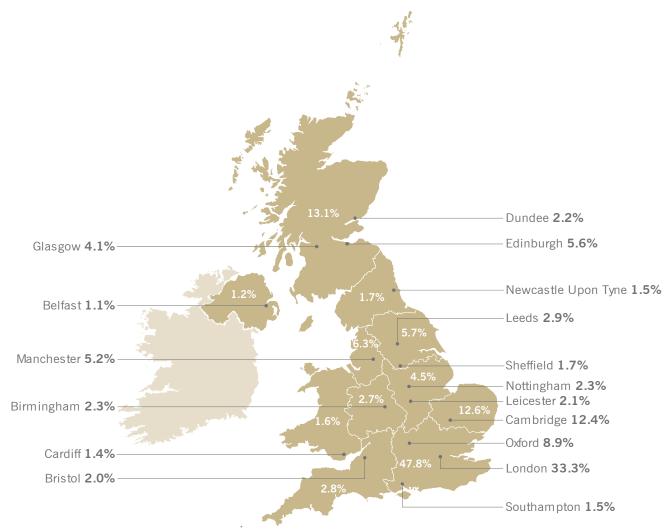


Proportion of Combined Spend on Health Specific Categories for Individual Research Activities Figure 7



'Remainder' represents total spend in remaining health specific categories

Figure 8 Geographical Distribution of Combined Research Funding in the UK



Note: Proportion of total spend is displayed within each region. Cities displayed have $\geq 1\%$ of total spend

Data excludes R&D support for NHS providers funded by the UK Health Departments, core support costs (e.g. for the Wellcome Trust Sanger Institute) and research taking place outside the UK.

kite diagram. In general the funding profiles for each of the research activities are different, however, there are similarities between Detection and Diagnosis and the two treatment categories. Although Cancer receives comparatively the highest level of combined health specific funding (see **Figure 4**), this is not reflected across all of the different research activities. For example, in Prevention over 40% of the funds are spent on Infection, and Mental Health receives the highest proportion of funds within Health Services.

4.5 Geographical Distribution of Funding within the UK

The establishment of a central database allows the opportunity to map the directly funded research of the participating organisations by geographical location within the United Kingdom. A breakdown of funding by individual cities is illustrated in **Figure 8**. For practical reasons only those cities where the proportion of funds are greater than or equal to 1% of the total funding on the Database are displayed on the map. The proportion of total spend within each region is also displayed on the map.



5. SUMMARY AND NEXT STEPS

5.1 Summary

This analysis provides, for the first time, an overview of the majority of UK government and charity research funding across all types of research activity and all areas of health and diseases, for the year 2004/2005. A number of observations can be made regarding this analysis:

- Classification using the common Health Research Classification System indicates that approximately two thirds of the combined participating funders' research funding is spent in understanding normal function and processes and investigating the determinants of the cause and development of diseases and conditions
- A total of 16.6% of the combined funds are spent on research into treatments. This is equally divided between treatment development and evaluation
- A relatively low proportion of funds are dedicated to primary prevention of disease and promotion of well-being
- In general the distribution of funding across the Health Categories follows the pattern of burden of disease as measured by Disability Adjusted Life Years (DALY) rates for the UK. Exceptions to this trend were observed for Respiratory, and Oral and Gastrointestinal,

- where the comparative research funding is lower than the relative burden of disease and for Infection, where the comparative research funding is higher than the UK DALY ranking. The DALY rates presented in this analysis are for the UK. It should be noted that infectious diseases have the highest DALY ranking for total global burden of disease⁷
- The distribution of funds across different types of research activity varies between individual funding organisations and across different diseases and areas of health

The pattern of direct research funding observed in this study is a composite of 11 different research portfolios. This pattern has emerged over a period of time and has been shaped by a wide variety of different factors. There are no similar national analyses to compare this to and there is no correct shape for the overall portfolio. The analysis represents a 'snapshot' of live funding for the 2004/2005 financial year. Since work began on the analysis, participating organisations have launched a number of initiatives aimed at boosting clinical research and experimental medicine. Many of these are single organisation initiatives but some of these are joint initiatives developed under the auspices of the UKCRC. The funding associated with these new initiatives is too recent to appear in this analysis.



The UKCRC is a partnership of the main organisations that influence clinical research in the UK. It provides a forum for strategic discussions and enables key stakeholders to work together in a new way to address issues that could not be tackled by a single organisation. This analysis is an example of joint working between the main funders of health research in the UK.

5.2 **Next Steps**

This report provides an overview of current funding patterns and illustrates the type of analysis that can be performed using the data on the Database. Additional analysis of the data will be conducted following discussion with participating funders and the UKCRC Partners.

The UKCRC Research Database contains the vast majority of government and charity funded research. However, it does not include the smaller medical research charities, nor does it include any industry funded research in the UK. In the future the UKCRC Secretariat will work closely with AMRC to include smaller medical research charities and with the Association of the British Pharmaceutical Industry (ABPI), the BioIndustry Association (BIA) and the Association of British Healthcare Industries (ABHI) to explore the feasibility of including industrial data in the Database. Mapping these additional data onto the current picture of government and charity funded health research would create a more comprehensive overview of the UK health research environment.

References

- Strategic Analysis 2002 An Overview of Cancer Research in the UK Directly Funded by the NCRI Partner Organisations (2002) National Cancer Research Institute.
- 2. Common Scientific Outline International Cancer Research Portfolio. http://www.cancerportfolio. org/cso.jsp
- WHO International Classification of Diseases (10th revision) (2003) World Health Organisation. http://www3.who.int/icd/vol1htm2003/fr-icd.htm
- Gross CD, Anderson GF, Powe NR. The Relation between Funding by the National Institutes of Health and the Burden of Disease (1999) New England Journal of Medicine 340:1881-1887.
- Fox-Rushby JA. Disability Adjusted Life Years (DALYs) for Decision-Making? An Overview of the Literature (2002) Office of Health Economics.
- Death and DALY Estimates for 2002 by Cause for WHO Member States (2002) World Health Organisation Burden of Disease Project. http://www.who.int/entity/healthinfo/statistics/bodgbddeathdalyestimates.xls
- Estimates of DALYs by Sex, Cause and WHO Region for 2002 (2002) World Health Organisation Burden of Disease Project. http://www.who.int/entity/healthinfo/statistics/gbdwhoregiondaly2002. xls

Abbreviations

ABHI Association of British Healthcare Industries

ABPI Association of the British Pharmaceutical Industry

AMRC Association of Medical Research Charities

BBSRC Biotechnology and Biological Sciences Research Council

BHF British Heart Foundation

BIA BioIndustry Association

CRUK Cancer Research UK

CSO Common Scientific Outline

DALY Disability Adjusted Life Year

EPSRC Engineering and Physical Sciences Research Council

ESRC Economic and Social Research Council

HRCS Health Research Classification System

ICD International Classification of Diseases

MRC Medical Research Council

NCRI National Cancer Research Institute

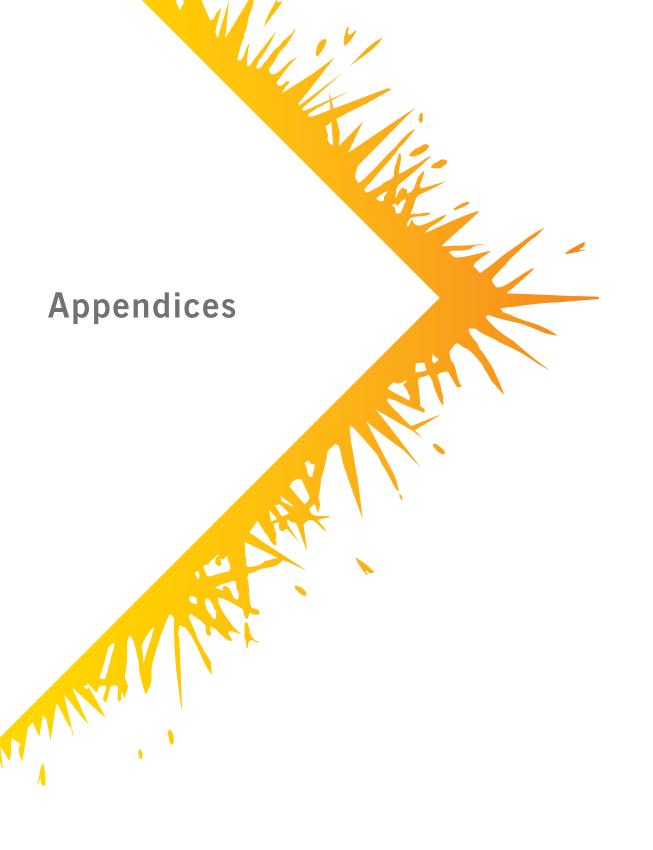
NHS National Health Service

R&D Research and Development

UK United Kingdom

UKCRC UK Clinical Research Collaboration

WHO World Health Organisation





What is the UK Clinical Research Collaboration (UKCRC)?

The UKCRC is a partnership of organisations committed to making the UK a world leader in clinical research. The UKCRC is also a new way of working by which complex long-standing issues are tackled by key stakeholders working together. In this way each organisation maximises their individual impact for the benefit of patients and the public.

Why was the UKCRC set up?

The National Health Service should provide the perfect environment in which to carry out high quality clinical research in order to benefit patients. Whilst a lot of good research takes place, there is now consensus that conducting clinical research in this country is much harder than it need be.

The issues that need to be addressed in order to strengthen clinical research in the UK were highlighted in two key reports from the Academy of Medical Sciences and Biosciences Innovation and Growth Team. The Government recognised the need for further investment and the importance of a collaborative approach through the Research for Patient Benefit Working Party and from this the UKCRC was established.

Who is involved?

The Partners of the UKCRC are:

- ► The Association of British Healthcare Industries (ABHI)
- Association of the British Pharmaceutical Industry (ABPI)
- Association of Medical Research Charities (AMRC)
- Academy of Medical Royal Colleges (AOMRC)
- The Academy of Medical Sciences (AMS)
- ▶ BioIndustry Association (BIA)
- Cancer Research UK (CRUK)
- Department of Health (DH)
- ► INVOLVE
- ► Medical Research Council (MRC)
- Medicines and Healthcare products Regulatory Agency (MHRA)
- National Institute for Health and Clinical Excellence (NICE)
- NHS Confederation
- Office for Science and Innovation (OSI) / Department of Trade and Industry (DTI)
- Research and Development Office for the Northern Ireland Health and Personal Social Services
- Scottish Executive Health Department
- Strategic Health Authorities (SHAs)
- ► UK Higher Education Funding Councils
- Wellcome Trust
- Welsh Assembly Government

The UKCRC aims to engage with patients and the public throughout its activities. It works closely with a number of other key stakeholders that have particular expertise within UK clinical research including Council of Heads of Medical Schools, Universities UK, Association of University Hospitals, the UK Research Base Funders Forum, NHS R&D Forum and Council for Science and Technology.

The principles for working are to engage stakeholders through consultation and negotiation rather than representation, develop a 'solutions-based' rather than

'recommendations-based' approach and to build on structures and activities that are already working well.

UKCRC Activities

The UKCRC Partners have agreed to focus on a number of interconnected areas of activity aimed at improving the UK clinical research environment. Each of the activities is led by one of the Partners or by the UKCRC Secretariat, which is funded by all the UKCRC Partners. The five major areas are outlined below:

Infrastructure in the NHS

The UKCRC is coordinating a national approach to provide the NHS infrastructure needed to support clinical research in the UK. This involves the establishment of a UK Clinical Research Network (UKCRN) providing new clinical infrastructure in the NHS and development of the UK capacity for experimental medicine.

Regulatory and Governance Environment

The UKCRC is working to promote a streamlined regulatory and governance environment that facilitates high quality clinical research whilst protecting the rights. dignity and safety of patients.

Research Workforce

The UKCRC is working to develop an expert research workforce of clinicians, nurses and allied health professionals to support all aspects of clinical research in the NHS. Addressing issues such as training and career structure is a key part of this work.

Coordinating Research Funding

The UKCRC is carrying out an analysis of health research activity in the UK across all areas of health and disease to provide an evidence base that can be used to inform future research planning. The UKCRC is also developing a coherent approach to research funding in specific highlighted areas.

Incentives for Research in the NHS

The UKCRC is developing both individual and institutional incentives to ensure that high quality clinical research becomes a 'core business' of the NHS and that involvement in research is appropriately rewarded.

For further information on UKCRC activities see the UKCRC website: www.ukcrc.org



Biotechnology and Biological Sciences
Research Council

Polaris House, North Star Avenue Swindon, SN2 1UH www.bbsrc.ac.uk

Cancer Research UK

61 Lincoln's Inn Fields London, WC2A 3PX www.cancer.org.uk

Engineering and Physical Sciences Research Council

Polaris House, North Star Avenue Swindon, SN2 1ET www.epsrc.ac.uk

Medical Research Council

20 Park Crescent London, W1B 1AL www.mrc.ac.uk

Chief Scientist Office Scottish Executive Health Department

St Andrew's House, Regent Road, Edinburgh, EH1 3DG www.show.scot.nhs.uk/cso/

Wellcome Trust

Gibbs Building, 215 Euston Road London, NW1 2BE www.wellcome.ac.uk British Heart Foundation 14 Fitzhardinge Street London, W1H 6DH www.bhf.org.uk

Department of Health

79 Whitehall London, SW1A 2NL www.dh.gov.uk

Economic and Social Research Council

Polaris House, North Star Avenue Swindon, SN2 1UJ www.esrc.ac.uk

Research and Development Office for the Northern Ireland Health and Personal Social Services

12-22 Linenhall Street Belfast, BT2 8BS www.centralservicesagency.com

Wales Office of Research and Development for Health and Social Care

Welsh Assembly Government
National Assembly for Wales, Cardiff Bay
Cardiff, CF99 1NA
www.wales.gov.uk



Health Research Classification System

The Health Research Classification System has been developed by the UKCRC for the classification and analysis of all types of health research. It is openly available for use as a research management tool provided the use is not for commercial gain. The UKCRC reserves the right to control the content of this and any subsequent versions. For detailed terms and conditions see the UKCRC's website:

http://www.ukcrc.org/activities/coordinatingresearchfunding.aspx



Health Categories

| Category | Includes |
|------------------------------------|--|
| Blood | Haematological diseases, anaemia, clotting and normal development and function of platelets and erythrocytes |
| Cancer | All types of cancers (includes leukaemia) |
| Cardiovascular | Coronary heart disease, diseases of the vasculature and circulation including the lymphatic system, and normal development and function of the cardiovascular system |
| Congenital Disorders | Physical abnormalities and syndromes that are not associated with a single type of disease or condition including Down's syndrome and cystic fibrosis |
| Ear | Deafness and normal ear development and function |
| Eye | Diseases of the eye and normal eye development and function |
| Infection | Diseases caused by pathogens, acquired immune deficiency syndrome, sexually transmitted infections and studies of infection and infectious agents |
| Inflammatory and Immune System | Rheumatoid arthritis, connective tissue diseases, autoimmune diseases, allergies and normal development and function of the immune system |
| Injuries and Accidents | Fractures, poisoning and burns |
| Mental Health | Depression, schizophrenia, psychosis and personality disorders, addiction, suicide, anxiety, eating disorders, learning disabilities, autistic spectrum disorders and studies of normal psychology, cognitive function and behaviour |
| Metabolic and Endocrine | Diabetes, thyroid disease, metabolic disorders and normal metabolism and endocrine development and function |
| Musculoskeletal | Osteoporosis, osteoarthritis, muscular and skeletal disorders and normal musculoskeletal and cartilage development and function |
| Neurological | Dementias, transmissible spongiform encephalopathies, Parkinson's disease, neurodegenerative diseases, Alzheimer's disease, epilepsy, multiple sclerosis and studies of the normal brain and nervous system |
| Oral and Gastrointestinal | Inflammatory bowel disease, Crohn's disease, diseases of the mouth, teeth, oesophagus, digestive system including liver and colon, and normal oral and gastrointestinal development and function |
| Renal and Urogenital | Kidney disease, pelvic inflammatory disease, renal and genital disorders, and normal development and function of male and female renal and urogenital system |
| Reproductive Health and Childbirth | Fertility, contraception, abortion, <i>in vitro</i> fertilisation, pregnancy, mammary gland development, menstruation and menopause, breast feeding, antenatal care, childbirth and complications of newborns |
| Respiratory | Asthma, chronic obstructive pulmonary disease, respiratory diseases and normal development and function of the respiratory system |
| Skin | Dermatological conditions and normal skin development and function |
| Stroke | Ischaemic and haemorrhagic |
| Generic Health Relevance | Research applicable to all diseases and conditions or to general health and well-being of individuals. Public health research, epidemiology and health services research that is not focused on specific conditions. Underpinning biological, social, psychological, economic or methodological studies that are not specific to individual diseases or conditions |
| Other | Conditions of unknown or disputed aetiology (such as chronic fatigue syndrome/myalgic encephalomyelitis), or research that is not of generic health relevance and not applicable to specific health categories listed above |



Overview of the Research Activity Codes

| 1 | Underninning Deceased |
|-----------------|--|
| 1 1 | Underpinning Research Normal higherical development and functioning |
| 1.1 | Normal biological development and functioning |
| 1.2 | Psychological and socioeconomic processes |
| 1.3 | Chemical and physical sciences |
| 1.4 | Methodologies and measurements |
| 1.5 | Resources and infrastructure (underpinning) |
| 2 | Aetiology |
| 2.1 | Biological and endogenous factors |
| 2.2 | Factors relating to physical environment |
| 2.3 | Psychological, social and economic factors |
| 2.4 | Surveillance and distribution |
| 2.5 | Research design and methodologies (aetiology) |
| 2.6 3 | Resources and infrastructure (aetiology) |
| | Prevention of Disease and Conditions, and Promotion of Well-Being |
| 3.1 | Primary prevention interventions to modify behaviours or promote well-being |
| 3.2 | Interventions to alter physical and biological environmental risks |
| 3.3 | Nutrition and chemoprevention |
| 3.4 | Vaccines (assessment of the street of the st |
| 3.5 | Resources and infrastructure (prevention) |
| 4 4.1 | Detection, Screening and Diagnosis |
| | Discovery and preclinical testing of markers and technologies |
| 4.2 | Evaluation of markers and technologies |
| 4.3 | Influences and impact |
| 4.4 | Population screening |
| 4.5 5 | Resources and infrastructure (detection) |
| 5.1 | Development of Treatments and Therapeutic Interventions Pharmaceuticals |
| 5.2 | |
| 5.3 | Cellular and gene therapies Medical devices |
| 5.4 | |
| 5.5 | Surgery Radiotherapy |
| 5.6 | Psychological and behavioural |
| 5.7 | Physical |
| 5.8 | Complementary |
| 5.9 | Resources and infrastructure (development of treatments) |
| 6 | Evaluation of Treatments and Therapeutic Interventions |
| 6.1 | Pharmaceuticals |
| 6.2 | Cellular and gene therapies |
| 6.3 | Medical devices |
| 6.4 | Surgery |
| 6.5 | Radiotherapy |
| 6.6 | Psychological and behavioural |
| 6.7 | Physical |
| 6.8 | Complementary |
| 6.9 | Resources and infrastructure (evaluation of treatments) |
| 7 | Management of Diseases and Conditions |
| 7.1 | Individual care needs |
| 7.2 | End of life care |
| 7.3 | Management and decision making |
| 7.4 | Resources and infrastructure (disease management) |
| 8 | Health and Social Care Services Research |
| 8.1 | Organisation and delivery of services |
| 8.2 | Health and welfare economics |
| 8.3 | Policy, ethics and research governance |
| 8.4 | Research design and methodologies |
| 8.5 | Resources and infrastructure (health services) |
| 0.0 | Accountage and initiatital and an analysis of the state o |



| 1 | Underpinning Research | Research that underpins investigations into the cause, development, detection, treatment and management of diseases, conditions and ill health |
|-----|---|--|
| 1.1 | Normal biological development and functioning | Studies of normal biology including penes and gene products molecular, cellular and physiological structures and function biological pathways and processes including normal immune function developmental studies and normal ageing bioinformatics and structural studies development and characterisation of model systems |
| 1.2 | Psychological and socioeconomic processes | Studies that do not address health directly but cover issues that may have a bearing on health and well-being including • perception, cognition and learning processes • social and cultural beliefs • individual or group characteristics and behaviours • politics, economies and urban development • development and characterisation of model systems |
| 1.3 | Chemical and physical sciences | Research in chemical and physical sciences that may lead to the future development of diagnostic tools or medical treatments including bioengineering and biophysics chemical structures, interactions and properties molecular modelling material science |
| 1.4 | Methodologies and measurements | Development of novel underpinning research measures and analytical methodologies including development of statistical methods and algorithms for genomic analysis development of mapping methodologies and novel data comparison methods development of biological, psychological and socioeconomic research measures |
| 1.5 | Resources and infrastructure (underpinning) | development and/or distribution of resources for use by the research community including equipment, cell lines, DNA banks, and genomic and proteomic sequence resources infrastructure to support research networks, consortia and centres |



| 2 | Aetiology | Identification of determinants that are involved in the cause, risk or development of disease, conditions and ill health |
|-----|---|---|
| 2.1 | Biological and endogenous factors | Identification and characterisation of endogenous factors known or suspected to be involved in the cause, risk or development of disease, conditions or ill health including genes and gene products, molecular, cellular and physiological structures and functions biological factors linked to ethnicity, age, gender, pregnancy and body weight endogenous biological factors or pathways involved in responses to infection or damage by external factors metastases, degenerative processes, regeneration and repair complications, reoccurrence and secondary conditions bioinformatics and structural studies development and characterisation of models |
| 2.2 | Factors relating to physical environment | Environmental or external factors associated with the cause, risk or development of disease, conditions or ill health including physical agents, occupational hazards, environmental surroundings, radiation and pollution chemicals and nutrients infection by pathogens and studies of infectious agents |
| 2.3 | Psychological, social and economic factors | Research into psychological conditions, or research into the cause, risk or development of disease, conditions or ill health associated with social, psychological and economic factors including individual or group behaviours and lifestyle cultural or religious beliefs or practices ethnicity, age and gender differences socioeconomic factors |
| 2.4 | Surveillance and distribution | Observational studies, surveys, registries, and studies that track incidence, prevalence, morbidity, co-morbidity and mortality including ongoing monitoring of large scale cohorts |
| 2.5 | Research design and methodologies (aetiology) | Development of aetiological and epidemiological research designs, measures and methodologies including • methodological innovation and modelling complex epidemiological data • development and evaluation of novel research designs • development of epidemiological research measurements including outcome measures • development of analytical and statistical methods to understand disease cause, susceptibility and risk including genetic linkage and association studies |
| 2.6 | Resources and infrastructure (aetiology) | development and/or distribution of resources for general use by the research community including equipment, cell lines, tissue and DNA banks, and genomic and proteomic sequence resources infrastructure to support research networks, consortia and centres |



| 3 | Prevention of Disease and | Passageh aimed at the primary provention of disease |
|-----|---|---|
| 3 | Conditions, and Promotion of Well-Being | Research aimed at the primary prevention of disease, conditions or ill health, or promotion of well-being |
| 3.1 | Primary prevention interventions to modify behaviours or promote well-being | Development, implementation and evaluation of interventions to modify personal or group behaviours and lifestyles affecting health and well-being including risk behaviours associated with diet, tobacco use, physical activity, alcohol consumption, sexual health and substance misuse age, gender, cultural or religious practices public health policy, health communication and educational interventions behavioural, psychological, social and physical interventions |
| 3.2 | Interventions to alter physical and biological environmental risks | Development, implementation and evaluation of interventions surrounding physical, biological and environmental risk factors including radiation, second-hand smoke, physical and chemical agents, occupational hazards and environmental surroundings contraceptive devices infectious agents policy, educational and physical interventions |
| 3.3 | Nutrition and chemoprevention | Research on chemopreventative agents and health protective effects of nutrients including • development, characterisation and mechanism of action • chemical contraceptives • testing and evaluation in model systems and clinical, applied and community settings • evaluation of evidence to inform policy |
| 3.4 | Vaccines | Research on vaccines for prevention of disease including I discovery, development and testing of vaccines and vaccination in model systems I mechanism of action I development, implementation and evaluation of vaccination programmes and studies to increase uptake I decision making, outcomes from vaccination and evaluation of evidence to inform policy |
| 3.5 | Resources and infrastructure (prevention) | development and/or distribution of resources for use by the research community including equipment, cell lines, tissue and DNA banks infrastructure to support research trials, networks, consortia and centres |



| 4 | Detection, Screening and Diagnosis | Discovery, development and evaluation of diagnostic, prognostic and predictive markers and technologies |
|-----|---|--|
| 4.1 | Discovery and preclinical testing of markers and technologies | Discovery, development and preclinical testing of novel markers (that may be derived from patient samples) and technologies for use in detection, diagnosis, prediction, prognosis and monitoring including biological and psychological markers diagnostic and monitoring devices, imaging, scanning, predictive and diagnostic tests development and characterisation of models diagnostic measures and methodologies |
| 4.2 | Evaluation of markers and technologies | Testing and evaluation of markers and technologies in humans for use in detection, diagnosis, prediction, prognosis and monitoring in clinical, community or applied settings including assessment of sensitivity, efficacy, specificity, predictive and prognostic value, reproducibility and safety medical devices, imaging, diagnostic and predictive tests evaluation of diagnostic models, methods and methodologies in clinical or applied settings |
| 4.3 | Influences and impact | Studies investigating impact of screening and factors affecting uptake including • attitudes and beliefs including cultural and religious practices • issues relating to gender, age and ethnicity • genetic counselling and decision making • psychological, social and economic factors • development, implementation and evaluation of interventions to promote screening including policy, education and communication |
| 4.4 | Population screening | Studies investigating population screening programmes including • feasibility studies, pilot studies and trials • evaluation of effectiveness, benefits and economic evaluation • impact on health services and policy issues • models of population surveillance |
| 4.5 | Resources and infrastructure (detection) | development and/or distribution of resources for use by the research community including equipment, cell lines, tissue and DNA banks, and informatics systems infrastructure support for research trials, networks, consortia and centres |



| 5 | Development of Treatments and Therapeutic Interventions | Discovery and development of therapeutic interventions and testing in model systems and preclinical settings |
|-----|---|---|
| 5.1 | Pharmaceuticals | Identification and development of pharmaceutical small molecules, therapeutic vaccines, antibodies and hormones including Including Including and development of delivery systems Including side effects and drug resistance Including side effects and drug resistance |
| 5.2 | Cellular and gene therapies | Discovery and development of cellular, tissue and gene therapies including • gene therapy, stem cells therapy, in vitro fertilisation and tissue engineering • development of delivery systems • development of culture systems • testing in in vitro and in vivo model systems |
| 5.3 | Medical devices | Discovery and development of medical devices including implantable devices, mobility aids, dressings, medical equipment and prostheses biological safety assessments and investigation of adverse events sterilisation and decontamination of equipment or surfaces testing in <i>in vitro</i> and <i>in vivo</i> model systems |
| 5.4 | Surgery | Development of surgical, obstetric and dental interventions including histocompatability, transfusions, transplantations including xenograft studies and bone marrow transplants mechanisms of recovery, tolerance, rejection and side effects including infection testing in <i>in vitro</i> and <i>in vivo</i> model systems |
| 5.5 | Radiotherapy | Discovery and development of interventions including radiobiology, radiotherapy, radioimmunotherapy, radiosensitisers, microwaves, ultrasound, laser and phototherapy development of delivery systems investigation of mechanisms of action and side effects testing in in vitro and in vivo model systems |
| 5.6 | Psychological and behavioural | Development of psychological and behavioural interventions including cognitive behavioural therapy, electro-convulsive therapy, counselling, therapy and social interventions testing in model systems |



| 5.7 | Physical | Development of physical interventions including |
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| | . nyoloa: | physical therapies, physiotherapy, occupational therapy, speech therapy, dietetics including nutritional supplements, exercise and osteopathy mechanisms of action testing in model systems |
| 5.8 | Complementary | Discovery and development of complementary approaches to conventional medical therapies including I hypnotherapy, meditation, massage, acupuncture and homeopathy I mechanisms of action I testing in model systems |
| 5.9 | Resources and infrastructure (development of treatments) | development and/or distribution of resources for general use by the research community including equipment, cell lines, tissue and DNA banks infrastructure support for networks, consortia and centres |



| 6 | Evaluation of Treatments and Therapeutic Interventions | Testing and evaluation of therapeutic interventions in clinical, community or applied settings |
|-----|--|--|
| 6.1 | Pharmaceuticals | Clinical application and evaluation of pharmaceutical small molecules, therapeutic vaccines, antibodies and hormones in humans including • small scale settings and pilot studies • phase I, II, III and IV trials • assessing sensitivity, efficacy, specificity, relapse, survival, therapeutic value, pharmacokinetics, reproducibility and safety • studies monitoring response, outcome, drug resistance and side effects |
| 6.2 | Cellular and gene therapies | Clinical application and evaluation of cellular, tissue and gene therapies in humans including I small scale and pilot studies I phase I, II, III and IV trials I gene therapy, stem cell therapy, in vitro fertilisation, tissue engineering I evaluation of applied delivery systems |
| 6.3 | Medical devices | Application and evaluation of medical devices in humans in a clinical, community or applied setting including implantable devices, mobility aids, dressings, medical equipment and prostheses validation of design and post market surveillance |
| 6.4 | Surgery | Clinical and applied application and evaluation of surgical, obstetric and dental interventions in humans including small scale and pilot studies phase I, II, III and IV trials procedures including organ and bone marrow transplantation, tissue grafts and transfusions monitoring outcomes, side effects and rejection |
| 6.5 | Radiotherapy | Clinical application and evaluation of interventions in humans including small scale and pilot studies phase I, II, III and IV trials radiotherapy, radioimmunotherapy and radiosensitisers, microwaves, ultrasound, laser and phototherapy monitoring side effects |
| 6.6 | Psychological and behavioural | Application and evaluation of psychological and behavioural interventions in humans in clinical, community and applied settings • phase I, II, III and IV trials • cognitive behavioural therapy, electro-convulsive therapy, counselling, therapy and social interventions |



| 6.7 | Physical | Testing and evaluation of physical interventions in humans in a clinical, community or applied setting including ▶ physical therapies, physiotherapy, occupational therapy, speech therapy, dietetics including nutritional supplements, osteopathy and exercise |
|-----|---|---|
| 6.8 | Complementary | All aspects of testing, evaluation and provision of complementary approaches to conventional medicine in humans in a clinical, community or applied setting including hypnotherapy, massage, acupuncture and homeopathy issues relating to health and social services and health care delivery attitudes and beliefs of patients and health care professionals |
| 6.9 | Resources and infrastructure (evaluation of treatments) | provision and distribution of resources related to clinical and applied therapeutic interventions infrastructure support for clinical and applied research networks and trials, consortia and centres |



| 7 | Management of Diseases and Conditions | Research into individual care needs and management of disease, conditions or ill health |
|-----|---|---|
| 7.1 | Individual care needs | Studies of patients and service user care needs including quality of life, management of acute and chronic symptoms, management of side effects, rehabilitation, long term morbidity and reproductive issues psychological impact of illness social and economic consequences of ill health behaviour affecting disease management including secondary prevention, compliance to treatment and attitudes and beliefs relating to seeking treatment assessment of social care and health services needs educational or communication interventions to promote self-care or improve health care by carers impact on carers |
| 7.2 | End of life care | Studies involving all issues related to palliative care and end of life care including • assessment of patient, service user and carer needs • provision and evaluation of palliative and end of life care services • quality of life for patients and carers • evaluation of interventions for health and social care professionals • social, economic and policy issues • pain management for terminally ill people • bereavement |
| 7.3 | Management and decision making | Studies into all aspects of the management of diseases, ill health and conditions by health and social care professionals attitudes, beliefs and behaviours of health and social care professionals investigation of decision making including factors influencing diagnosis, treatment, referral and management strategies educational interventions and communication practices development of guidelines, interventions or models to assist decision making and management, including identifying symptoms, predicting outcomes and identifying individuals at risk |
| 7.4 | Resources and infrastructure (disease management) | development and/or distribution of resources and equipment for use by the community including informatics systems infrastructure support for trials, networks, consortia and centres |



| 8 | Health and Social Care Services Research | Research into the provision and delivery of health and social care services, health policy and studies of research design, measurements and methodologies |
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| 8.1 | Organisation and delivery of services | Examining the organisation and provision of health and social care services and evaluating factors affecting the quality of care • workforce and career issues • organisation and management of services • access to health and social care and geographical variations in outcomes • effectiveness of different care settings and models of service delivery • evaluating quality of care including patient safety issues • evaluation of experiences of service users • assessment of current and future health care demands • development and evaluation of interventions to improve services |
| 8.2 | Health and welfare economics | Economic evaluation of health and social care interventions and delivery including cost-benefit analysis of services including economic modelling cost effectiveness or economic feasibility of implementing new interventions or technologies within health services economic assessment of service productivity and outcomes health care costs development and evaluation of economic models of health care |
| 8.3 | Policy, ethics and research governance | evaluation of local, regional and national healthcare policy impact of legislation synthesis and evaluation of evidence to inform policy dissemination and implementation of research evidence research ethics including use of personal data and biological material, consent and confidentiality research governance and regulation processes including interpretation of guidelines issues surrounding research subjects and donor recruitment |
| 8.4 | Research design and methodologies | Development of research designs and novel methodologies for health care including treatment, management and health services research • analytical innovation, methodological research, statistical methods and modelling • development of research measurements including outcome measures • development of methods of research assessment and evaluation • development and evaluation of research designs and methodologies |
| 8.5 | Resources and infrastructure (health services) | development and distribution of resources for use by the community including informatics systems infrastructure support for networks, trials, consortia and centres |





UK Clinical Research Collaboration

20 Park Crescent London W1B 1AL

United Kingdom
Tel: +44 (0)207 670 5452
Fax: +44 (0)207 637 6067
info@ukcrc.org

www.ukcrc.org