



igniting our potential

UK Clinical Research Collaboration

From Donation to Innovation

An analysis of health research funded by medium and smaller sized medical research charities



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This project was jointly managed by the AMRC and UKCRC Secretariats. Data management and liaison with the participating charities was carried out by Dr Lee-Ann Coleman and Mike Conway from the AMRC Secretariat. Dr Andrew Speakman and Dr Janet Valentine from the UKCRC Secretariat were responsible for analysis of the organisational portfolios and oversight of the research classification. Sarah Harrop assisted in the production of the report and Dominique Capostagno was responsible for the report design and desktop publishing.

Participating Organisations





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Association of Medical Research Charities

This report is a compelling narrative on the vital role played by medical research charities in funding and supporting research in the UK.

It builds on the 2006 *UK Health Research Analysis* (which included the three largest charities: Wellcome Trust, Cancer Research UK and the British Heart Foundation) by providing a detailed picture of the funding activities of a further 29 member charities of the Association of Medical Research Charities (AMRC).

These charities are diverse in nature, often meeting very different needs. But, under the AMRC banner, they are united in wishing to support research of the highest quality for patient benefit and to do so according to the highest standards.

The report provides a valuable insight into their research activities: for the charities concerned; for those they work with; and more importantly, their donors. And while it can only provide an overview of research funding by a cross-section of charities, we believe it reflects the important contribution that the wider sector makes to health and medical research across the four nations of the UK.

We hope that this study will inform the future activities of the charities involved, catalyse relevant collaborations with partners across the research community, and encourage similar and more extensive studies in the future with the aim of informing discussion and debate on the UK's research priorities.

We thank all those charities who participated in the study and the many colleagues who assisted in the production of this report. This report demonstrates the integral part charities play in the bigger picture of health research in the UK and I commend it to you.



Simon Denegri
Chief Executive, AMRC

UK Clinical Research Collaboration

The UK health research environment is changing rapidly. There is a shared desire by funding bodies from all sectors to maximise the impact of the research they fund and speed up the translation of their research for the benefit of patients. Doing this requires the development of a clear funding strategy and the ability to work jointly with other organisations when patient benefit demands it.

The advent of successful strategic partnerships such as the National Cancer Research Institute (NCRI) and the UK Clinical Research Collaboration (UKCRC) demonstrates a growing recognition of the importance of sharing information and working jointly rather than in isolation. The benefits are already being felt through the development of new national infrastructure such as the UK Clinical Research Network (UKCRN) and UK Biobank. The Government's desire to develop a single UK Health Research Strategy through the Office for Strategic Coordination of Health Research (OSCHR) further underlines the importance of strategy development.

All this presents both opportunities and challenges for medium and smaller sized charity research funders. The need to share information and understand the big picture is central to this. Key questions quickly emerge: 'What is already being done?', 'How can we make a unique contribution?' and 'How can we avoid unnecessary duplication?'

The decision of AMRC participating members to share their research portfolios is an encouraging indication of the willingness of the charity sector to embrace these opportunities and meet the challenges.



Liam O'Toole
Chief Executive, UKCRC

Executive Summary

Medical research charities play a significant role in funding and supporting health research in the UK. In 2006 the UK Clinical Research Collaboration (UKCRC) published the *UK Health Research Analysis*, an analysis of the research portfolios of the eleven largest government and charity health research funders in the UK. This was the first time any country had examined in detail where funds were being directed across different types of research activity and in different areas of health and disease. This information provided an evidence base that is being used to inform individual and joint strategic planning by research funders.

The *UK Health Research Analysis* included the portfolios of the three largest medical charities in the UK: Wellcome Trust, Cancer Research UK and the British Heart Foundation. At the time of publication it was recognised that an important next step would be to carry out a more comprehensive overview of the charity sector contribution to the UK health research environment. To this end an analysis of research funded by medium and smaller sized members of the Association of Medical Research Charities (AMRC) has been carried out. The aim of this mapping exercise is to inform strategy development by providing charities with an analysis of the research they fund. This information enables charities to compare their portfolio with other funders and to see how the research they support fits in the wider picture of UK health research funding.

In total, 29 AMRC member charities chose to take part in this exercise. Collectively they represent almost three quarters of the remaining AMRC members' research spend not included in the original *UK Health Research Analysis*. In keeping with the methodology developed for the original analysis, this analysis examines directly funded peer-reviewed research such as projects, programmes and training awards that took place

in the UK at any time between 1st April 2004 and 31st March 2005. In common with the original exercise this study is not a financial audit and therefore does not include research support costs such as administration and capital expenditure. The analysis presented in this report is an overview of a total of 1496 peer-reviewed research awards funded by the participating charities which amounts to a combined spend of £63.7 million on this type of research during this period.

A bespoke Health Research Classification System (HRCS) encompassing all types of research activity and all areas of health and disease was developed for the original analysis and this was used to classify the charity research portfolios. The HRCS is a two dimensional coding system that categorises research according to area of health or disease and type of research activity taking place. Use of this common analytical tool allows meaningful comparisons to be made across the portfolios of different organisations and between analyses. The results from this analysis are primarily based on the aggregated research portfolios of the participating charities classified by the Health Categories and Research Activity Codes of the HRCS.

A number of observations can be highlighted from this analysis:

- ▶ Approximately 50% of the combined funds are concentrated in Aetiology research into the cause and development of diseases and conditions, and 12% of funds are spent on Underpinning research aimed at understanding normal function. This observation contrasts with the original analysis where one third of combined funds are spent in Aetiology and a further third in Underpinning research
- ▶ The majority of charities participating in this analysis spend the largest proportion of their funds supporting Aetiology research

- ▶ Approximately a third of the total funds are spent across the remaining research activities (Prevention, Detection and Diagnosis, Development and Evaluation of Treatments, Disease Management and Health Services). The relative distribution across these activities is largely similar to the original analysis
- ▶ A breakdown of spending across the Health Categories reveals that 93.7% of the combined funds are focused in disease specific areas and 6.3% is spent in Generic research applicable to all diseases or relevant to general health or well-being. These figures contrast with the original analysis where 25% of total funds are spent in Generic research
- ▶ A breakdown of funds across research activities for 15 individual Health Categories reveals unique profiles for each of these areas of health and disease

This report gives a powerful insight into the distribution of funds across different research activities and areas of health funded by medium and smaller sized medical research charities. It provides valuable information for donors, patients, charity staff, researchers and for those involved in policy and strategy development. The findings from this analysis give a clearer picture of the charity sector contribution to the overall landscape of health research in the UK. It is envisaged that use of this common approach for portfolio analysis will facilitate coordination and collaboration between the charities and other health research funders in the future.

1. Purpose of the Analysis

The UK boasts a vibrant health research community that is funded by government, the charity sector and industry. In 2006, the UK Clinical Research Collaboration (UKCRC) (**Appendix 1**) published the *UK Health Research Analysis* which mapped the research portfolios of the eleven largest government and charity funders of health related research in the UK¹. It was the first time that an analysis of the distribution of funding across all types of research activity and all areas of health and disease had been carried out on this scale anywhere in the world. This information provided an evidence base that could be used to inform strategic planning and facilitate coordination and collaboration between funders. The report sparked much interest amongst the academic community, policy makers and other funders, not least other medical and health research charities, who asked 'where do we fit?'

The *UK Health Research Analysis* included the research portfolios of the three largest members of the Association of Medical Research Charities (AMRC): Wellcome Trust, Cancer Research UK and the British Heart Foundation. It was agreed that an important next step would be to work with the AMRC to carry out a similar analysis of research funded by the medium and smaller sized member charities.

There are three major benefits to carrying out this type of analysis. Firstly, it informs strategy development by providing charities with their individual profile of research activity, enabling

them to identify gaps and focus on areas of importance to their stakeholders. Secondly, by taking part in this mapping exercise, the medium and smaller sized charities have the opportunity to compare their portfolios with other funders to gain an understanding of how the research they support fits with the national picture. Finally, it provides a more comprehensive overview of charity research funding, adding to the richness of the overall picture of health research activity in the UK.

In total, 29 AMRC member charities participated in this analysis. Collectively they represent approximately three quarters of the remaining AMRC members' research spend that was not included in the original analysis. In keeping with the *UK Health Research Analysis*, this analysis is focused on the directly funded peer-reviewed research that took place in the UK between 1st April 2004 and 31st March 2005 and uses the Health Research Classification System developed for the original analysis.

The analyses presented in this report provide a valuable insight into the spending of medium and smaller AMRC member charities and illustrate the diverse roles that charity funders play in the UK health research funding environment.

2. Scope of the Analysis

2.1 Participating Organisations

Involvement in the analysis was voluntary and 29 AMRC members chose to take part. There are a variety of reasons why some charities decided not to participate, and their absence should not be taken as a comment on their research activities.

Alphabetical list of participating charities:

- ▶ Action Medical Research
- ▶ Alzheimer's Research Trust
- ▶ Alzheimer's Society
- ▶ Arthritis Research Campaign
- ▶ Association for International Cancer Research
- ▶ Asthma UK
- ▶ BackCare
- ▶ Breakthrough Breast Cancer
- ▶ Breast Cancer Campaign
- ▶ BUPA Foundation
- ▶ Diabetes UK
- ▶ Epilepsy Research UK
- ▶ Guy's & St Thomas' Charity
- ▶ Kidney Research UK
- ▶ Ludwig Institute for Cancer Research
- ▶ Marie Curie Cancer Care
- ▶ Medical Research Scotland
- ▶ Motor Neurone Disease Association
- ▶ Multiple Sclerosis Society
- ▶ Muscular Dystrophy Campaign
- ▶ National Osteoporosis Society
- ▶ Parkinson's Disease Society
- ▶ Roy Castle Lung Cancer Foundation
- ▶ SPARKS The Children's Medical Research Charity
- ▶ St Peter's Trust for Kidney, Bladder & Prostate Research
- ▶ The Stroke Association

- ▶ Tenovus
- ▶ WellChild
- ▶ Yorkshire Cancer Research

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. The aim of this analysis is to provide a tool that will inform strategy discussions within and between funding bodies. The analysis therefore focuses on directly funded peer-reviewed research which is the type of research that is normally the focus of strategic discussions. 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 have been active during the 2004/2005 financial year i.e. funding must have started, ended or been ongoing at any time between 1st April 2004 and 31st March 2005
- ▶ The 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 includes a total of 1496 peer-reviewed awards funded by the participating charities, which amounts to a combined spend of £63.7 million on this type of research during the 2004/2005 financial year.

2.3 Data Not Included in the Analysis

The analysis focuses exclusively on directly funded UK-based research awards that are associated with clear research objectives and therefore the following types of indirect research costs have not been included:

- ▶ Research support costs including:
 - ▶ building construction, maintenance and associated infrastructure and core support costs
 - ▶ administrative costs
 - ▶ membership of professional bodies
 - ▶ costs relating to attending or holding meetings
- ▶ Research funded by the participating organisations taking place outside the UK

3. Methodology

3.1 Overview

This analysis is based on the methodology developed for the *UK Health Research Analysis*¹.

A database was established to hold the portfolios of the participating research charities and all awards were classified using the Health Research Classification System. The project was overseen by the AMRC and UKCRC Secretariats.

3.2 Establishment of the Database

3.2.1 Data Collection and Processing

The database contains a total of 1496 individual awards. Details were obtained from the participating charities in the form of a common dataset of information. This included details on the principal investigator, the type, amount and duration of the award and the title and scientific abstract of the research being undertaken. The data collection process took four months to complete.

For 20 of the 29 participating charities, the initial core dataset was taken directly from the AMRC administrative database. The AMRC database does not currently include abstracts of research, so participating charities were asked to verify the data and supply a scientific abstract for each award.

In two cases, data were obtained directly from the organisation concerned. In the case of seven cancer research charities, permission was obtained to use the data supplied to the National Cancer Research Institute (NCRI) for the Cancer Research Database.

3.2.2 Ownership of the Data

Data supplied for this analysis are owned by the charities funding the research and are held in confidence by the AMRC and UKCRC Secretariats. Access to the data is restricted to the AMRC and UKCRC Secretariats and details of individual awards cannot be circulated or published. Further analyses

of the data can only be carried out if agreement is obtained in advance from the participating charities.

3.3 Classification of Research on the Database

3.3.1 Use of the Health Research Classification System

Reproducible and meaningful comparison of research funded by different organisations requires the use of a common system to classify the data. The research portfolios of the AMRC member charities were classified using the Health Research Classification System (HRCS). The HRCS was created by the major UK health research funders to carry out the original *UK Health Research Analysis*. See the *UK Health Research Analysis* for details of the development of the HRCS¹.

3.3.2 Understanding the Health Research Classification System

The HRCS is a two dimensional framework for classifying research. It contains Research Activity Codes for classifying research according to type of research activity and Health Categories to classify research according to the area of health and disease being studied. Each research award is classified with both Research Activity Codes and Health Categories. Full details of the HRCS are presented in **Appendix 4**.

Research Activity Codes

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) for the strategic analysis of cancer research in the UK³. The Research Activity Codes describe broad areas of research activity organised into eight overarching categories:

Underpinning Research (Underpinning) – research investigating normal function and processes that underpin studies 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 different categories.

Health Categories

The Health Categories are based on the International Classification of Diseases (ICD)⁴ 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 category, 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 been established as part of the UK Clinical Research Network (UKCRN) 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 classification system.

Of the 21 Health Categories, 20 relate to a specific area of health or disease. The 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 are classified in the Oral and Gastrointestinal category. The remaining category, Generic Health Relevance, is designed to capture research that is applicable to all diseases or relevant to general health and well-being. Examples of this type of research include studies of basic cell functions that are common to all cell types, or geographical evaluation of health services.

3.3.3 Classification of the Data and Quality Control Process

Staff from 20 of the 29 participating charities were trained to use the HRCS by the UKCRC Secretariat. These 20 charities subsequently classified their own research portfolios and submitted their coded awards to be confirmed by the UKCRC Secretariat.

Rigorous quality control measures were taken to ensure accurate and consistent coding across the portfolios of the different funders. Every

research award classified by the charities was independently classified by a contract coder with previous experience of using the HRCS and who had no affiliation to the participating organisations. Portfolios that had not been coded by participating charities were independently classified by two contract coders. The codes assigned to each award by the two coders were reviewed by the UKCRC Secretariat and the final standardised codes confirmed. The percentage of all allocated codes where the final code agreed with one allocated by one of the initial coders was 94% for the Research Activity Codes and 97% for the Health Categories.

Codes were applied to reflect the main aim of the research taking place within the lifetime of the funding. Each award was classified with up to two Research Activity sub-codes (with up to four sub-codes for large programmes and centre awards) and up to five Health Categories. To ensure there was no double counting of award funds in the analysis, 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.

4. Results of the Analysis

4.1. Understanding the Results of the Analysis

The analysis provides an overview of the peer-reviewed research funded by the 29 participating medium and smaller sized charities taking place in the UK during 2004/2005. It can be considered alongside the previous analysis of the eleven largest government and charity funders of health research in the UK¹.

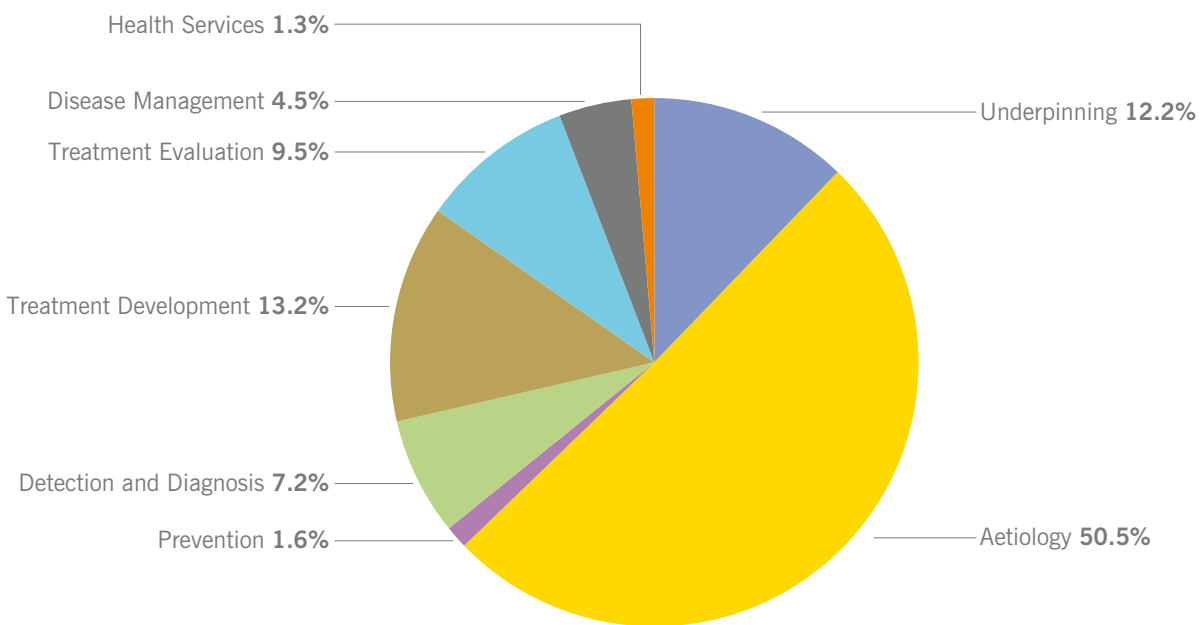
The findings from this analysis are presented as the combined research portfolios of the participating charities and also as individual profiles of research activity funded by some of the larger participating charities. It is possible to carry out a more detailed breakdown of the research on the database, and each participating charity has received a detailed analysis of its own research portfolio; however, presentation of these results is outside the remit of this report.

4.2. Distribution of Funding across Research Activities

4.2.1 Distribution of Combined Funds across Research Activities

The distribution of the collective research portfolio of the participating AMRC member charities across the eight major Research Activity Codes is shown in **Figure 1a**. Of the combined funds, 12.2% are focused on Underpinning research and approximately half (50.5%) of the funding is concentrated in Aetiology. Underpinning research is aimed at understanding normal biological, psychological and socioeconomic processes and functioning. Aetiology includes research into the risk or cause and development of ill health and disease. The Aetiology category comprises biological, environmental, psychological and socioeconomic factors involved in disease processes and includes surveillance and distribution. Most epidemiological studies are included in this category.

Figure 1a Proportion of Participating Charities' Total Spend by Research Activity



Data from 29 medium and smaller sized AMRC member charities

Figure 1a can be compared with the pattern observed in the original *UK Health Research Analysis* as shown in **Figure 1b**, where Underpinning research and Aetiology each account for a third of the research funding. The lower percentage of expenditure in Underpinning research in the charity analysis is not unexpected, given that the remit of many of the participating charities is to focus on specific diseases rather than more basic studies aimed at understanding normal or ‘healthy’ function.

As shown in **Figure 1a** a little over a third of combined charity funds are allocated to research into Prevention, Detection and Diagnosis, Development and Evaluation of Treatments, Disease Management and Health Services. A similar proportion of total funds is observed in these collective areas in the original analysis (**Figure 1b**).

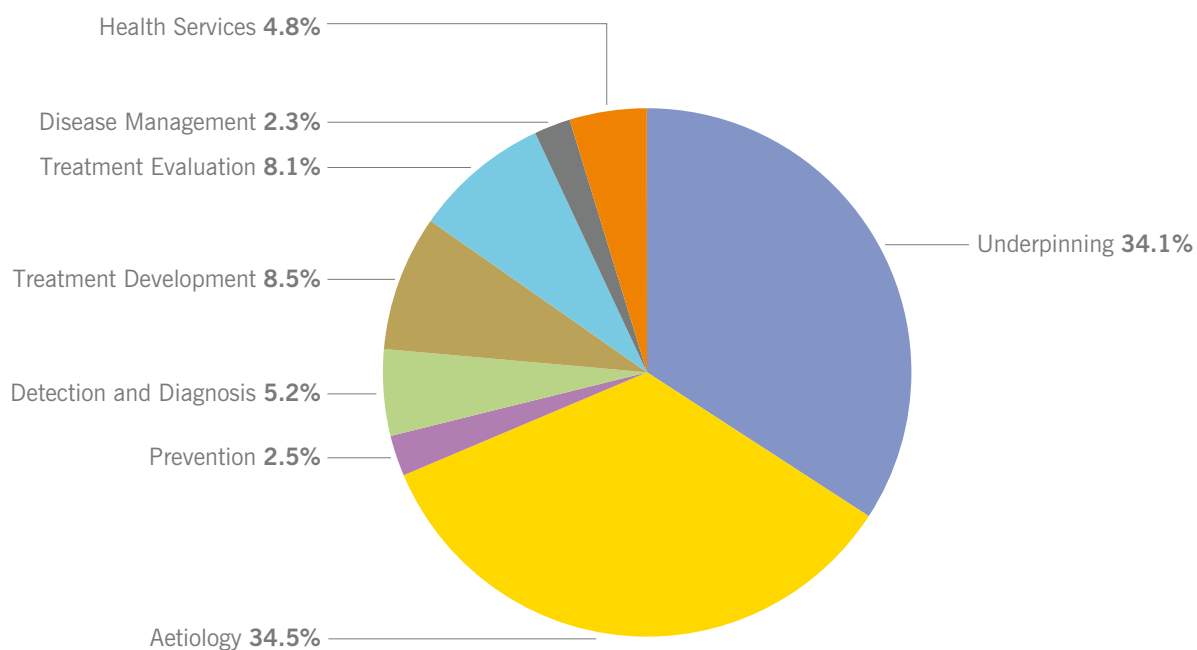
The Prevention category contains research into the primary prevention of disease or conditions, or promotion of well-being. This encompasses behavioural and environmental

interventions, vaccine development, nutrition and chemoprevention and contains 1.6% of the participating charities’ research spend. The spend in the Prevention category is also relatively low for the *UK Health Research Analysis* (2.5%). A similarly low proportion of the total spend in primary cancer prevention research was observed in the National Cancer Research Institute (NCRI) strategic analysis of cancer research funding³.

The participating AMRC charities spend 7.2% of their combined research funds in Detection and Diagnosis which encompasses the discovery, development and evaluation of markers, methods and imaging technologies. This proportion is similar to the percentage observed in Detection and Diagnosis in the original *UK Health Research Analysis*.

Research into treatments and therapeutic interventions has been divided into Treatment Development and Treatment Evaluation, and attracts 13.2% and 9.5% of the participating AMRC members’ spend respectively. Both of these

Figure 1b Proportion of Total Spend by Research Activity – *UK Health Research Analysis*



Data from the 11 largest government and charity funders of health research in the UK
 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

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. The relative proportion of funds in the Development of Treatments is slightly higher than the comparable figure in the original *UK Health Research Analysis* in this area.

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. The proportions of funds spent in Disease Management and Health Services research by participating AMRC member charities are 4.5% and 1.3% respectively. This contrasts with the original analysis where the relative proportion of spend in these two areas is reversed. The higher proportion invested in Health Services research in the original analysis can be largely attributed to the participation of the UK Health Departments, whose remit includes research into the provision of NHS services. This type of applied research is generally outside the mission of the majority of charities participating in this analysis.

4.2.2 Breakdown of Combined Research Activity by Sub-code

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. The table reveals that approximately 45% of the total funds from the participating charities are directed at investigating the biological and endogenous factors that are involved in the cause, risk or development of diseases or conditions and over 11% is spent on investigating normal biological development and functioning.

Within the Detection and Diagnosis category almost a third of the funds are spent in the discovery and preclinical testing of markers and technologies and approximately half are directed at the evaluation of markers and technologies in a clinical or applied setting. Within both Treatment categories, over 50% of funds are spent in development or evaluation of pharmaceuticals. The development of cellular and gene therapies accounts for almost a third of the spend within Treatment Development but makes up only 0.1% of the funds within Treatment Evaluation.

Of the remaining sub-codes, it is noteworthy that research into the management of Individual care needs accounts for 2.5% of the total research funds of the participating organisations.

4.2.3 Profile of Individual Charities' Spend by Research Activity

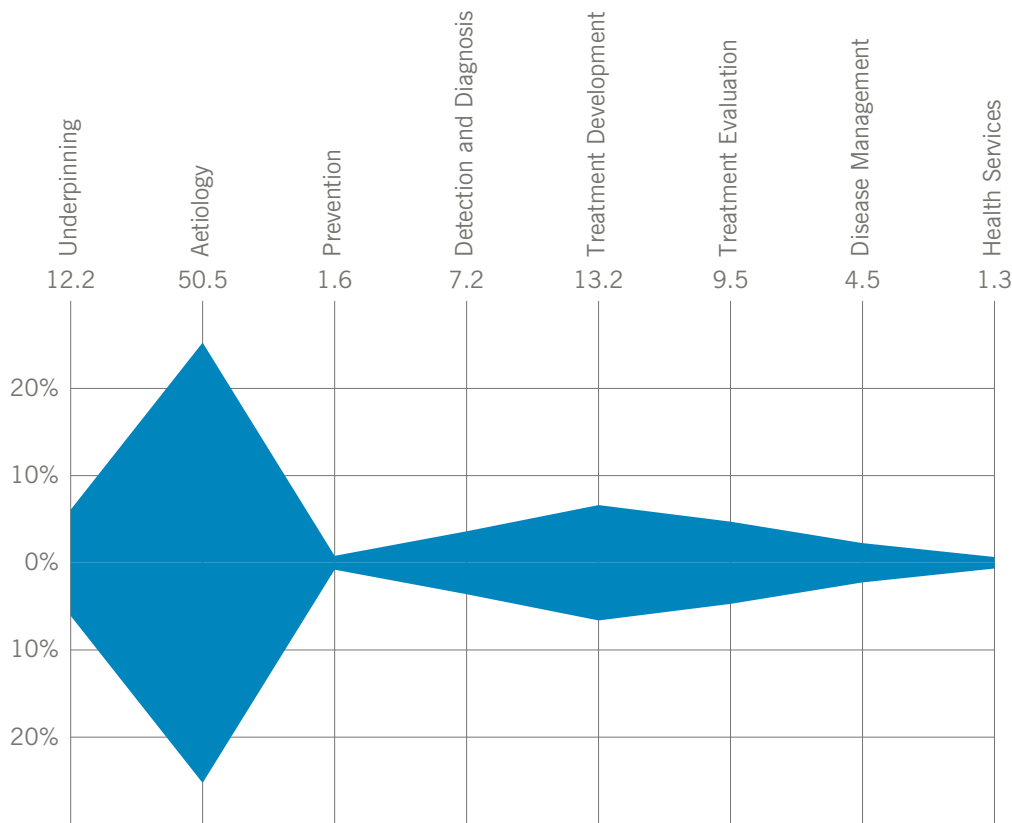
Kite diagrams were used in the *UK Health Research Analysis* to compare different spending patterns across a range of organisations, Health Categories and Research Activities. This form of presentation was developed by the NCRI³ and has been used by a range of funding bodies since then. The sum of the areas above and below the line of origin

Table 1 Breakdown of Proportion of Combined Participating Charities' Spend by Research Activity (RA) Sub-code

	% of Main RA Code	% of Total Spend
1 Underpinning 12.2%		
1.1 Normal biological development and functioning	95.7	11.7
1.2 Psychological and socioeconomic processes	0.2	<0.1
1.3 Chemical and physical sciences	0.5	0.1
1.4 Methodologies and measurements	0.9	0.1
1.5 Resources and infrastructure (underpinning)	2.6	0.3
2 Aetiology 50.5%		
2.1 Biological and endogenous factors	88.4	44.6
2.2 Factors relating to physical environment	2.8	1.4
2.3 Psychological, social and economic factors	1.5	0.8
2.4 Surveillance and distribution	3.3	1.7
2.5 Research design and methodologies (aetiology)	0.1	0.1
2.6 Resources and infrastructure (aetiology)	3.9	2.0
3 Prevention 1.6%		
3.1 Primary prevention interventions to modify behaviours or promote well-being	8.6	0.1
3.2 Interventions to alter physical and biological environmental risks	7.1	0.1
3.3 Nutrition and chemoprevention	54.0	0.9
3.4 Vaccines	30.3	0.5
3.5 Resources and infrastructure (prevention)	0.0	0.0
4 Detection and Diagnosis 7.2%		
4.1 Discovery and preclinical testing of markers and technologies	31.4	2.3
4.2 Evaluation of markers and technologies	54.2	3.9
4.3 Influences and impact	0.7	0.1
4.4 Population screening	1.2	0.1
4.5 Resources and infrastructure (detection)	12.4	0.9
5 Treatment Development 13.2%		
5.1 Pharmaceuticals	53.7	7.1
5.2 Cellular and gene therapies	32.5	4.3
5.3 Medical devices	4.3	0.6
5.4 Surgery	5.7	0.8
5.5 Radiotherapy	1.4	0.2
5.6 Psychological and behavioural	0.9	0.1
5.7 Physical	0.9	0.1
5.8 Complementary	0.0	0.0
5.9 Resources and infrastructure (development of treatments)	0.7	0.1
6 Treatment Evaluation 9.5%		
6.1 Pharmaceuticals	54.5	5.1
6.2 Cellular and gene therapies	0.1	<0.1
6.3 Medical devices	4.8	0.5
6.4 Surgery	6.3	0.6
6.5 Radiotherapy	1.5	0.1
6.6 Psychological and behavioural	4.2	0.4
6.7 Physical	17.3	1.6
6.8 Complementary	2.4	0.2
6.9 Resources and infrastructure (evaluation of treatments)	8.8	0.8
7 Disease Management 4.5%		
7.1 Individual care needs	54.7	2.5
7.2 End of life care	8.4	0.4
7.3 Management and decision making	23.3	1.0
7.4 Resources and infrastructure (disease management)	13.6	0.6
8 Health Services 1.3%		
8.1 Organisation and delivery of services	58.2	0.8
8.2 Health and welfare economics	5.4	0.1
8.3 Policy, ethics and research governance	4.9	0.1
8.4 Research design and methodologies	17.0	0.2
8.5 Resources and infrastructure (health services)	14.4	0.2

Data from 29 medium and smaller sized AMRC member charities

Figure 2a Proportion of Participating Charities' Total Spend by Research Activity – Kite Diagram



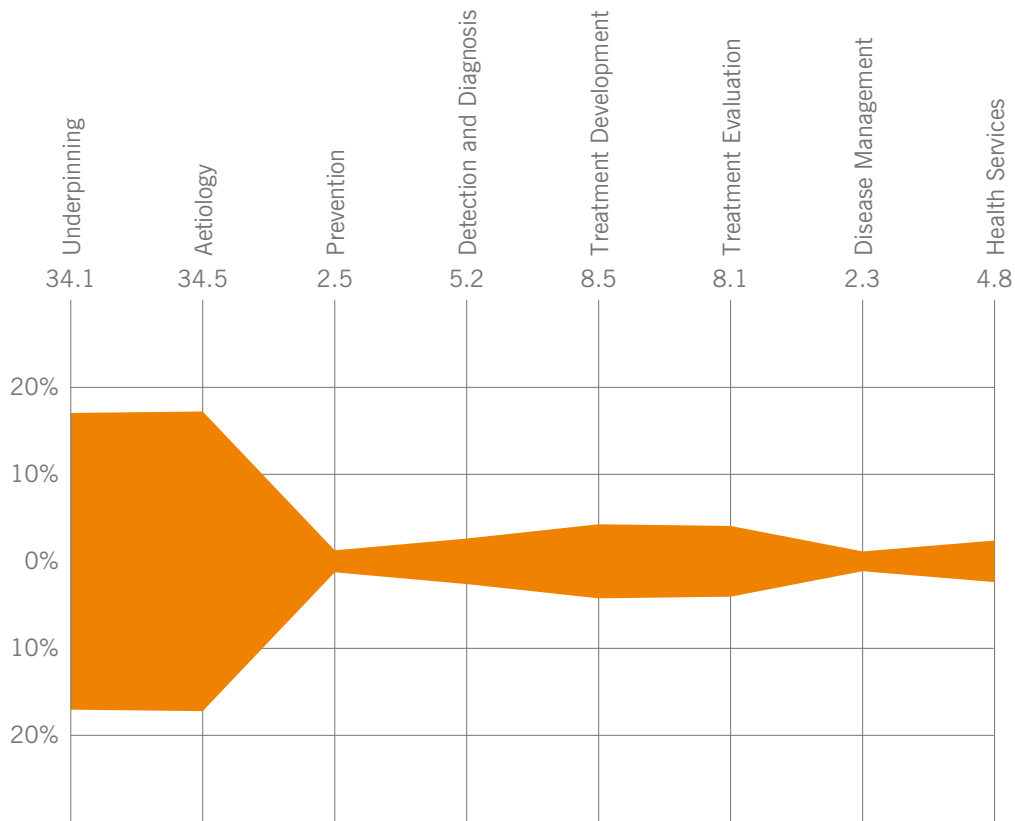
Data from 29 medium and smaller sized AMRC member charities

represents the proportion of each Research Activity Code and this figure is indicated at the top of the kite diagram. The advantage of using the kite diagram is that it produces an individual ‘footprint’ that can be readily compared with the shapes of others to reveal similarities and differences between a range of individual profiles.

The combined research spend of participating AMRC members classified by Research Activity Codes can be illustrated both as a pie chart as shown in **Figure 1a** and as a kite diagram displayed in **Figure 2a**. The kite diagram of total spend by Research Activity for the *UK Health Research Analysis* is provided by way of comparison in **Figure 2b**.

The individual funding profiles of research activity of 22 of the participating charities are shown as kite diagrams in **Figure 3**. Each of the charities included in this figure contributes over 1% of the total amount on the database. Each kite represents a charity’s own research spend distributed across the eight major areas of research activity. The relative contribution of each charity to the overall research spend on the database varies, and the kites are colour coded to reflect these differences. These kites have been arranged into four groupings based on the charity’s area of interest: (a) cancer charities, (b) charities that support neurological conditions, (c) other charities that focus on a specific condition or group of diseases and

Figure 2b Proportion of Total Spend by Research Activity – UK Health Research Analysis – Kite Diagram



Data from the 11 largest government and charity funders of health research in the UK
 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

(d) charities that support a range of diseases and conditions. The individual profile of each participating charity is unique, however 18 of the 22 charities shown spend the largest proportion of their funds supporting Aetiology research.

Three different patterns of research activity funding are observed in the analysis of the seven cancer charities illustrated in **Figure 3a**. Five charities: Association for International Cancer Research, Breakthrough Breast Cancer, Breast Cancer Campaign, Ludwig Institute for Cancer Research and Yorkshire Cancer Research, predominantly support research in Aetiology with a smaller proportion of funds directed at Underpinning research, Detection

and Diagnosis or Treatment Development. The major focus of research funded by Marie Curie Cancer Care is Underpinning research followed by Aetiology. Treatment Development followed by Aetiology are the areas of research activity that receive the most funding from Tenovus. An analysis of cancer research funding by the cancer charities participating in this analysis has previously been carried out by the NCRI using a cancer specific coding system, the Common Scientific Outline⁵. Taking into account the differences between the two coding systems, the individual profiles of the cancer charities shown here are similar to the overall pattern observed by the NCRI in 2004.

Figure 3a Profile of Individual Charity's Spend by Research Activity – Cancer Charities

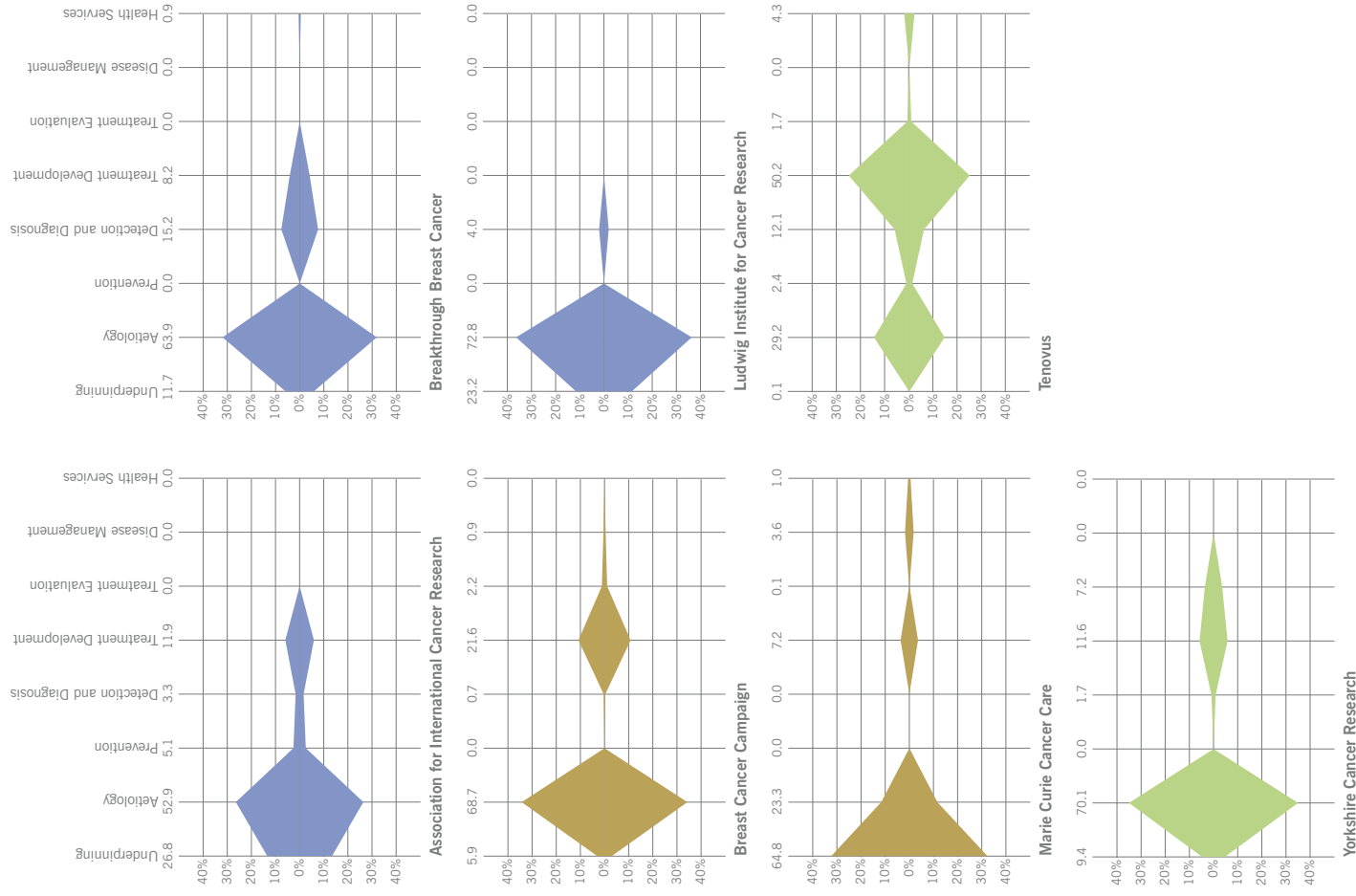


Figure 3b Profile of Individual Charity's Spend by Research Activity – Neurological Charities

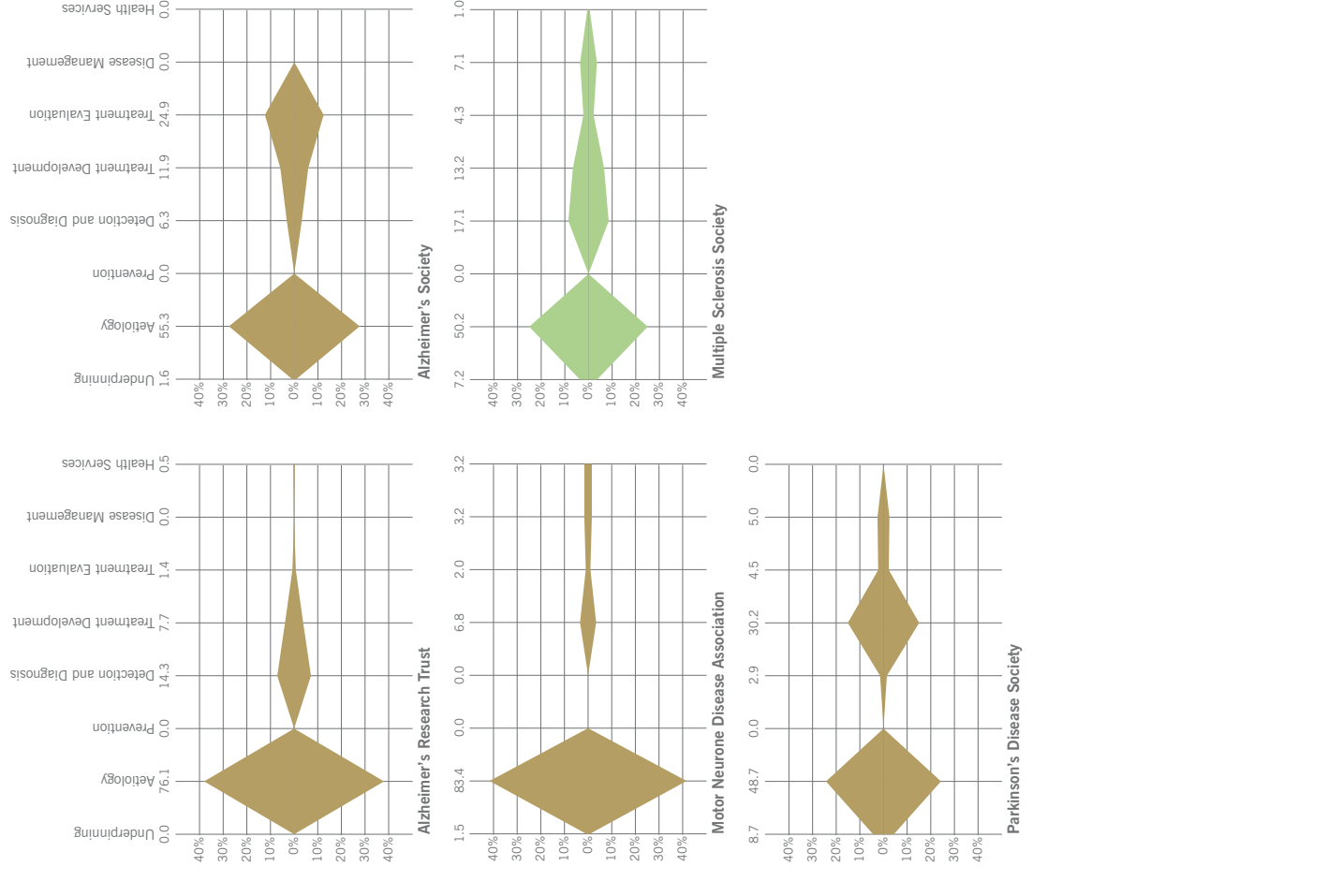


Figure 3c Profile of Individual Charity's Spend by Research Activity – Other Disease Focused Charities

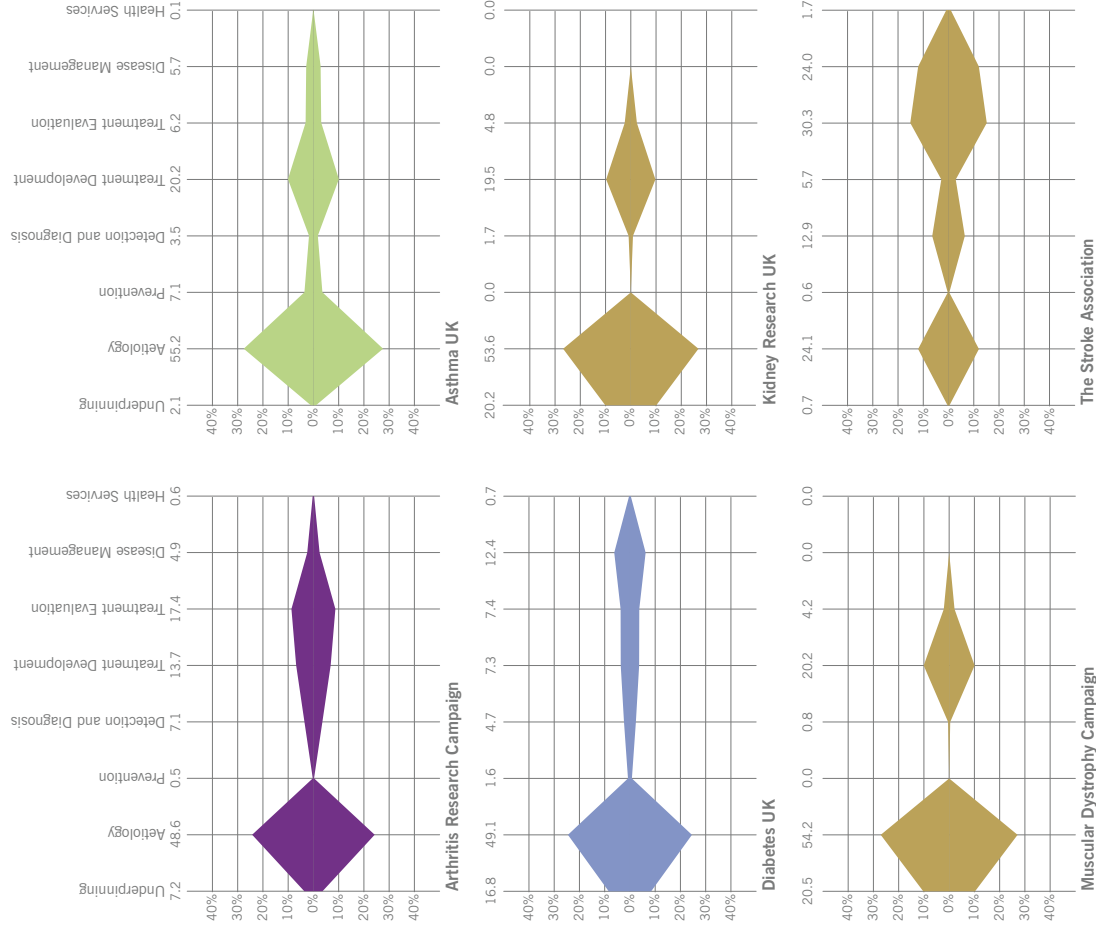
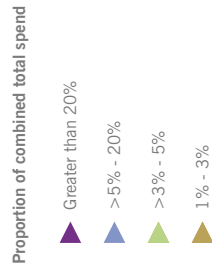
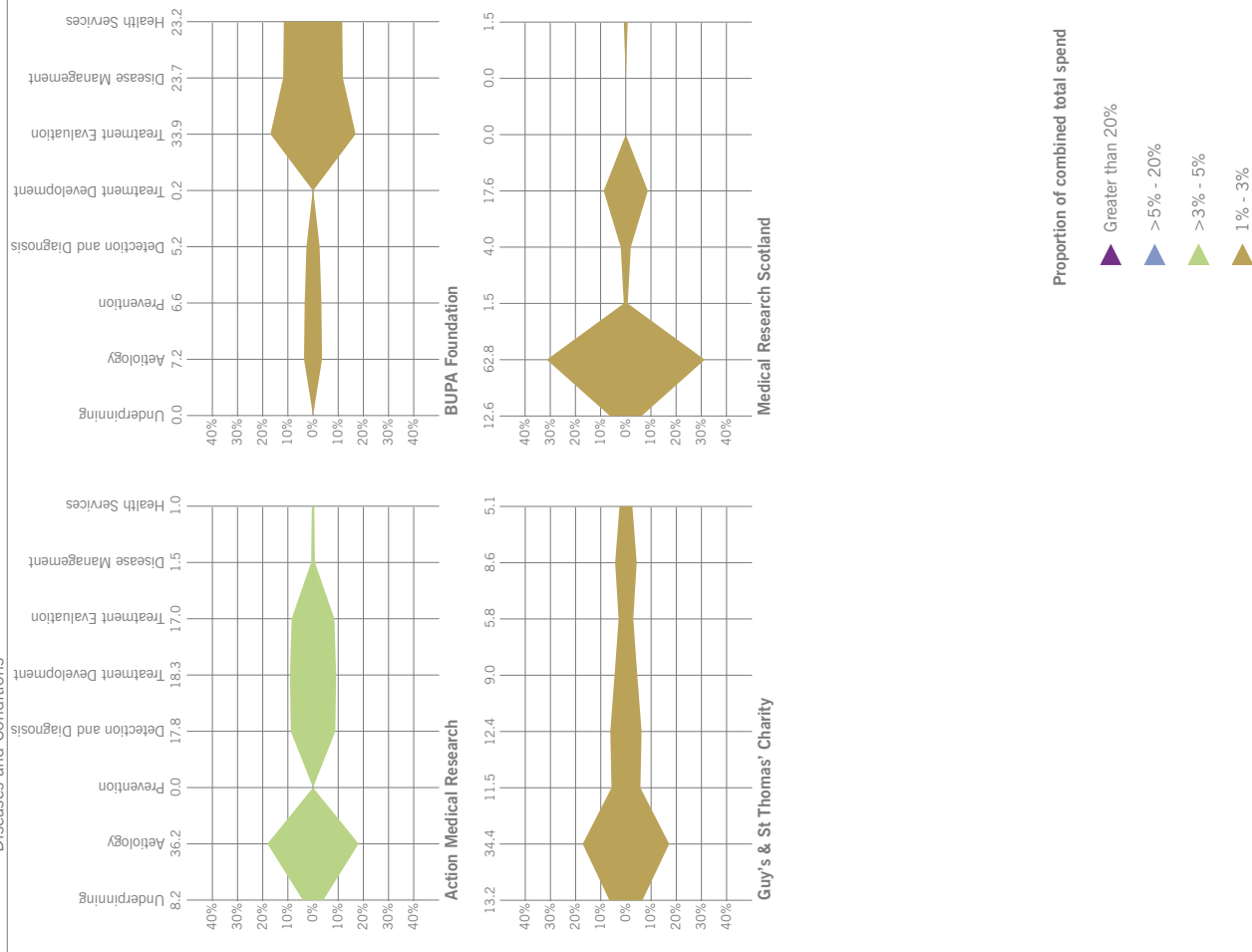


Figure 3d Profile of Individual Charity's Spend by Research Activity – Charities Supporting a Range of Diseases and Conditions



As shown in **Figure 3b**, Aetiology is the research activity with the highest spend for all five charities that support research into specific neurological conditions: Alzheimer's Research Trust, Alzheimer's Society, Motor Neurone Disease Association, Multiple Sclerosis Society and Parkinson's Disease Society. The areas that attract the next highest proportion of funds in this grouping of charities are Detection and Diagnosis, Treatment Development or Treatment Evaluation.

Aetiology is the main focus of research activity for five of the six charities that support research into a specific condition or group of diseases, namely: Arthritis Research Campaign, Asthma UK, Diabetes UK, Kidney Research UK and Muscular Dystrophy Campaign (**Figure 3c**). The areas of research activity that receive the next highest proportion of the funds differ between these charities. The Stroke Association is the exception to this pattern where funding is distributed between Treatment Evaluation, Disease Management and Aetiology.

The pattern of research activity differs for each of the four charities that support research into a range of diseases and conditions: Action Medical Research, BUPA Foundation, Guy's & St Thomas' Charity and Medical Research Scotland (**Figure 3d**). Although Aetiology is the area that receives the highest proportion of funds for three of these four charities, the distribution of remaining funds varies across the different areas of research activity for each of these charities. The portfolio of the BUPA Foundation contrasts with the profiles of the other charities, with funding predominantly divided between Treatment Evaluation, Disease Management and Health Services research.

4.3. Distribution of Funding across Health Categories

The relative distribution of combined participating charities' research funding across the 21 Health Categories is presented in **Figure 4**. The breakdown of funds ranges from 25.1% of the total spend

in Cancer, which includes all types of cancer, to 0.2% of total funds directed on Skin research. Approximately two thirds of the combined funds are spent in research in four Health Categories: Cancer, Inflammatory and Immune, Musculoskeletal and Neurological. The breakdown of spending across the Health Categories largely reflects the size and number of disease focused charities participating in this analysis. Of the 29 participating organisations, 23 have a specific disease focus. These 23 include eight cancer charities, six neurological charities and the Arthritis Research Campaign, the largest participating charity which accounts for more than 20% of the combined total funds. Interestingly, Cancer and Neurological research are the two Health Categories that also account for the largest proportion of aggregated research funds in the original *UK Health Research Analysis*.

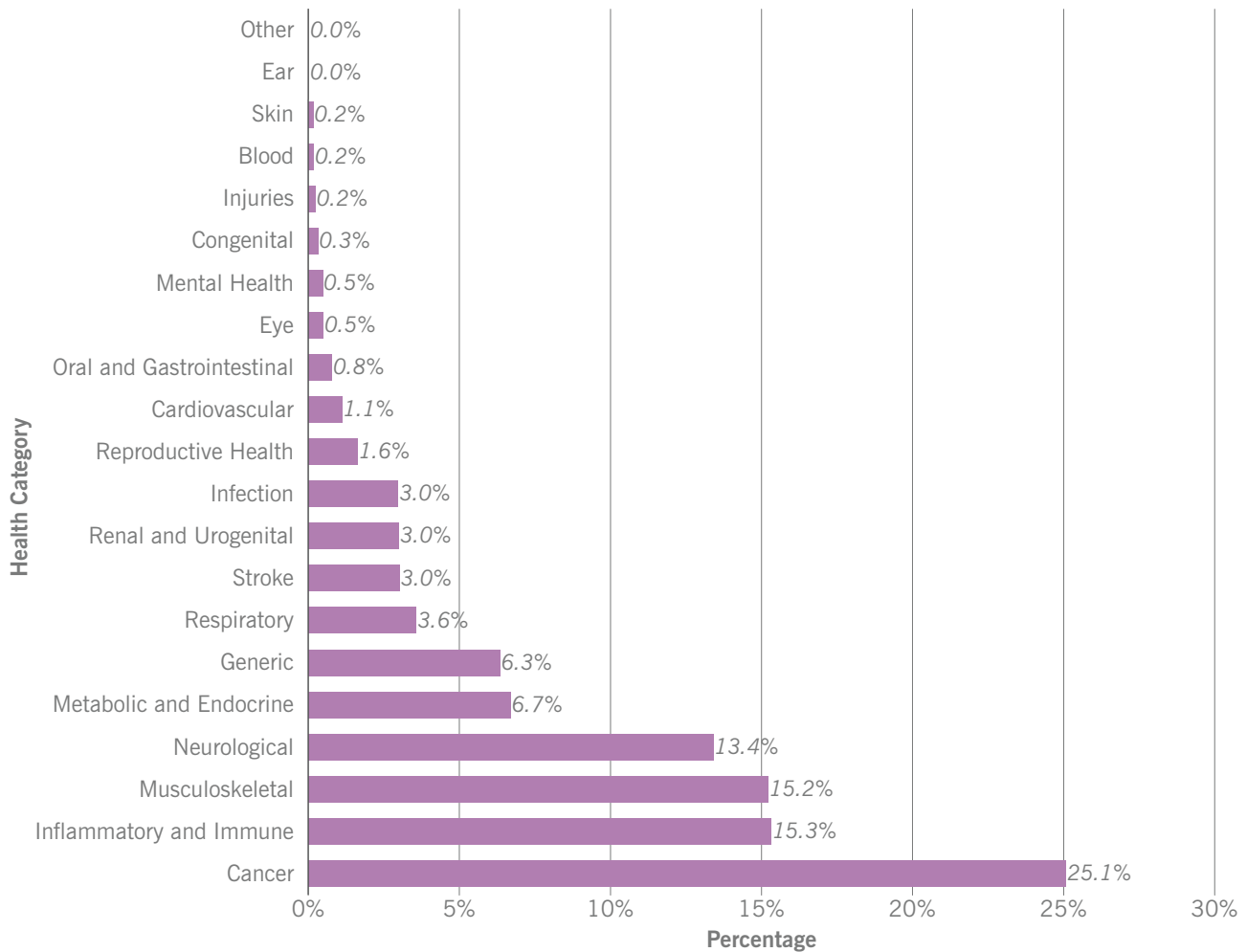
As shown in **Figure 4**, of the total research funded by the participating charities, 6.3% is of Generic Health Relevance - research that is applicable to all diseases or relevant to general health or well-being - and 93.7% is focused in disease specific areas. This figure contrasts with the original *UK Health Research Analysis* in which 25% of the total combined research spend of the participating funders is of Generic Health Relevance.

4.4. Analysis of Funding within Individual Health Categories

Figure 5 presents a breakdown of spending across the main areas of research activity for 15 individual Health Categories accounting for 25% to 0.5% of the total combined funds (see **Figure 4**). 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 Health Category.

Each Health Category demonstrates a unique overall profile of funding across the different types of research activity. A common feature shared by most Health Categories is that the largest proportion of funding is associated with research activity in

Figure 4 Proportion of Participating Charities' Spend in All Health Categories



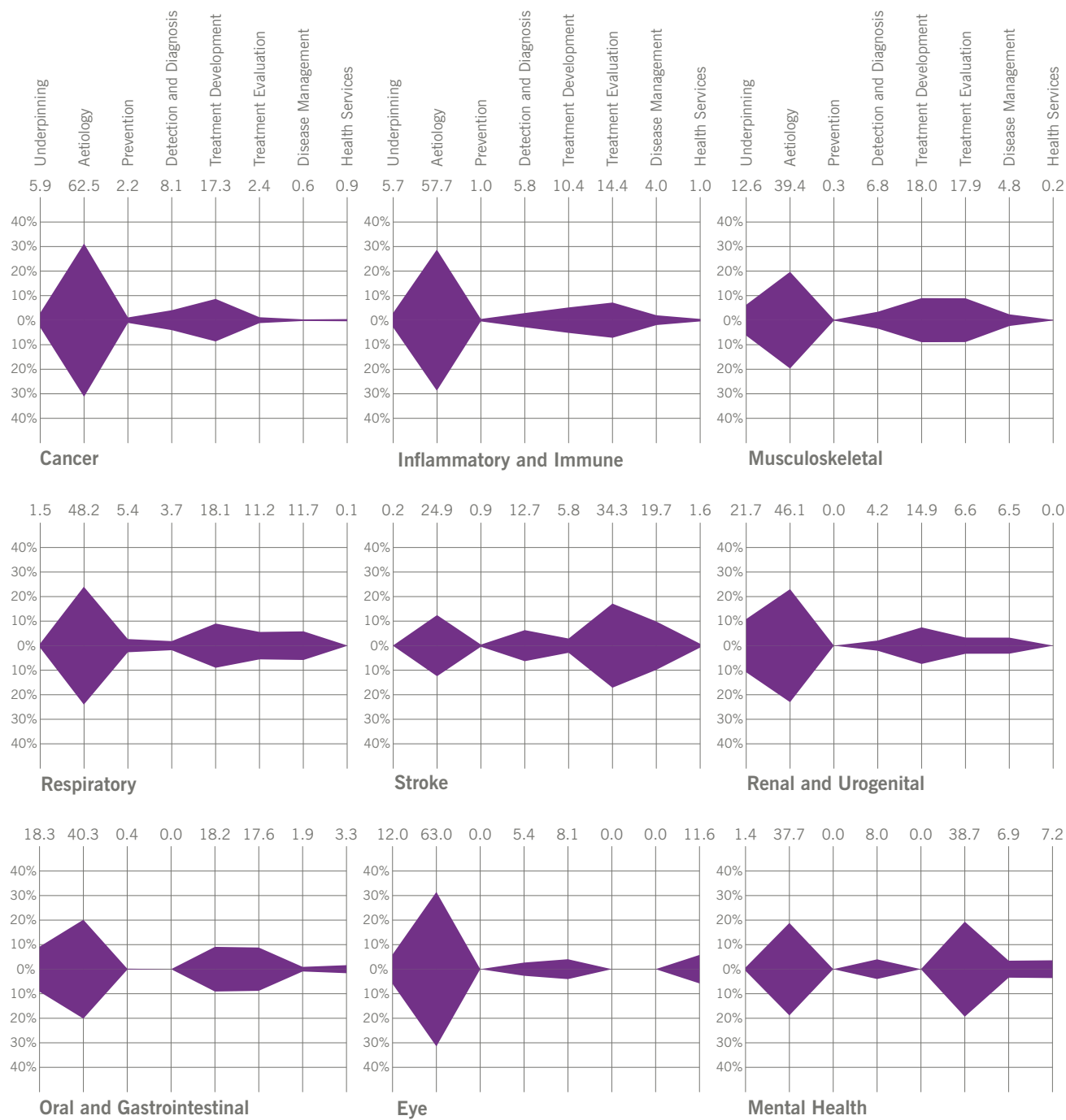
Data from 29 medium and smaller sized AMRC member charities

Aetiology. This finding is not unexpected given that over 50% of the participating charities' funds go towards research in Aetiology (see **Figure 1**). The patterns for many of the individual Health Categories in this analysis differ from the patterns observed for the same Health Category in the original analysis¹.

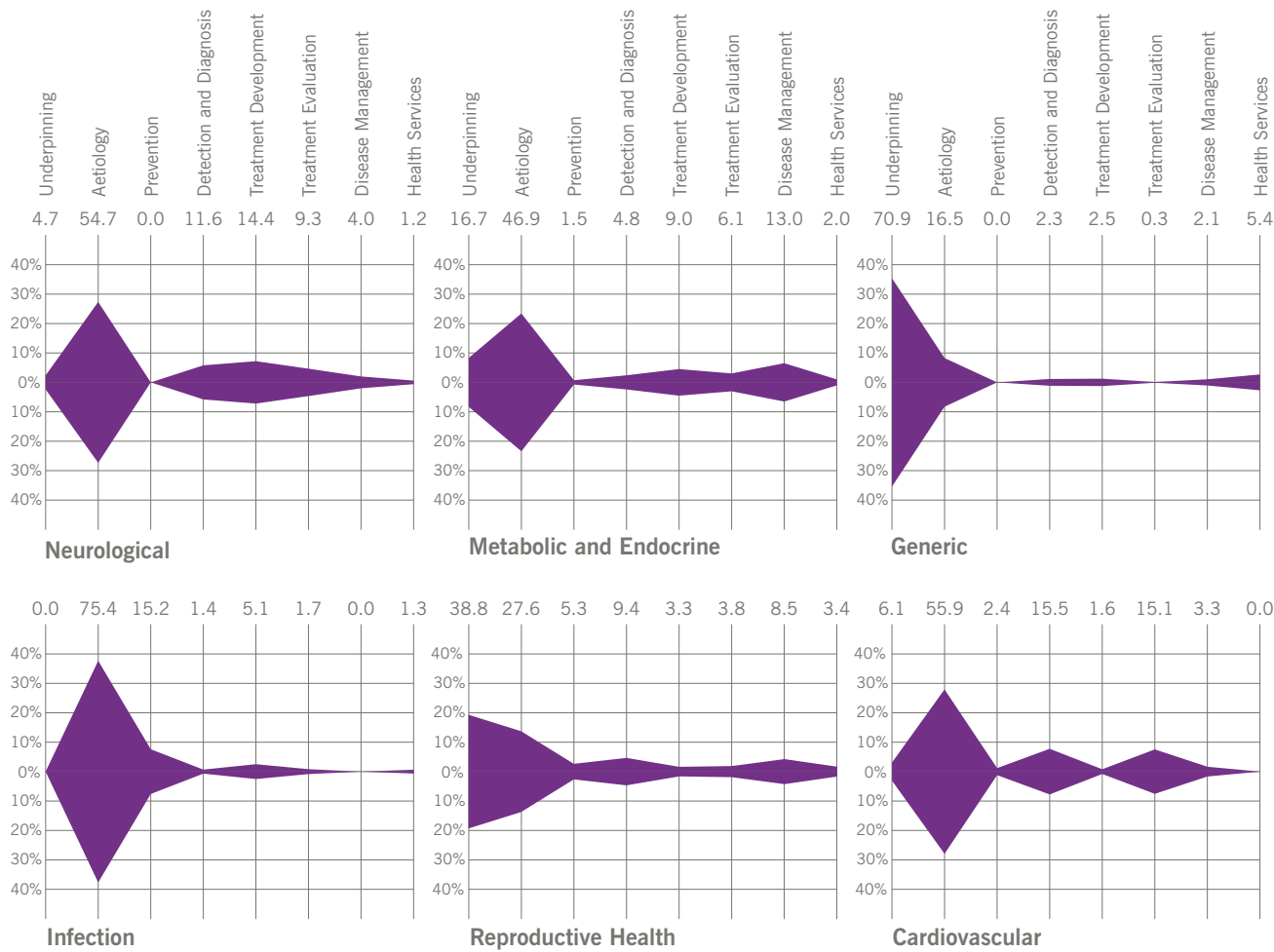
The profiles of several Health Categories are similar to the research activity profiles of individual funders active in the area. For example, the pattern of research activity in the Musculoskeletal and Inflammatory and Immune Health Categories is

similar to the organisational profile of the Arthritis Research Campaign, which supports research in these two areas of health (see **Figure 3c**). Similarly the distribution of funds across the Stroke Health Category resembles the organisational profile of The Stroke Association and the funding pattern observed in the Metabolic and Endocrine Health Category is similar to the pattern of research activity for Diabetes UK (see **Figure 3c**).

Figure 5 Proportion of Participating Charities' Spend by Research Activity for Selected Health Categories



Data from 29 medium and smaller sized AMRC member charities



5. Summary and Discussion

This analysis examines the peer-reviewed research funded by 29 medium and smaller sized charities that took place in the UK between 1st April 2004 and 31st March 2005. Through the use of a validated common coding system, the pattern of research funding by the participating charities can be compared with the original analysis of the collective portfolios of the eleven largest government and charity health research funders in the UK. A number of observations can be highlighted from this analysis:

- ▶ Approximately 50% of the combined funds are concentrated in Aetiology research into the cause and development of diseases and conditions and 12% in Underpinning research aimed at understanding normal function. This observation contrasts with the original analysis where one third of combined funds are spent in Aetiology and a further third in Underpinning research (see **Figure 1**)
- ▶ Approximately a third of the total funds are spent across the remaining research activities (Prevention, Detection and Diagnosis, Development and Evaluation of Treatments, Disease Management and Health Services). The relative distribution across these activities is largely similar to the original analysis
- ▶ The profile of research activity funded by each of the participating charities varies, although the majority of charities devote their largest proportion of funds to research in Aetiology, as demonstrated in **Figure 3**
- ▶ In the breakdown of funding across the different Health Categories, 93.7% of the total spend is in disease specific areas and 6.3% is spent in Generic research that is applicable to all diseases or relevant to general health or well-being (see **Figure 4**). This figure contrasts with the original analysis where 25% of total funds are spent in Generic research
- ▶ A breakdown of funds across research activities for 15 individual Health Categories reveals unique profiles for each of these areas of health and disease (see **Figure 5**)

This analysis of the research activities of medium and smaller sized UK medical research charities is a valuable addition to the picture of health research funding in the UK that emerged from the *UK Health Research Analysis*¹ in 2006. The original analysis included the three largest AMRC member charities: Wellcome Trust, Cancer Research UK and the British Heart Foundation. By analysing the portfolios of 29 additional charities, we now have an accurate overview of 96% of AMRC members' research funds, distributed across different research activities, diseases and areas of health. Taken together these two analyses provide a comprehensive overview of non-commercial health research funding in the UK and give a clear picture of the charity sector contribution to this landscape.

Taking part in this analysis provides the participating charities with an opportunity to review their own portfolio and directly compare it with the activity of other funders, enabling each charity to see where they fit in the national picture. This information will enable:

- ▶ Ongoing debate and decision-making about future research strategy among researchers, staff and patients associated with the charities that took part
- ▶ Discussion about potential collaboration and cooperation between organisations across medical and health research
- ▶ Strategy and decision-making on the UK's overall future health research priorities

The classification system used in this analysis has been adopted by many of the larger funders participating in the original analysis. It is envisaged that widespread use of this common system will enable ongoing comparison of research funding within and between organisations and will aid coordination between research funders in the future. It is anticipated that one of the outcomes from this analysis will be that medical research charities adopt the Health Research Classification System to classify and analyse their research funding on an ongoing basis. Using this common system will also facilitate discussions between public and charity sector funders active in areas of mutual interest, enabling them to identify gaps and strengths and jointly address these issues.

This report has contributed to the overall map of the distribution of UK health research funds, however the real power of this analysis is that it will enable research charities to examine their funding activities using a shared, robust analytical tool. Moreover this exercise contributes both to strategy setting and AMRC members' desire to be transparent and maximise the impact of the research they fund.

References

1. **UK Health Research Analysis (2006)** UK Clinical Research Collaboration.
2. **Common Scientific Outline** International Cancer Research Portfolio.
<http://www.cancerportfolio.org/cso.jsp>
3. **Strategic Analysis 2002 An overview of Cancer Research in the UK directly funded by the NCRI Partner Organisations (2002)** National Cancer Research Institute.
4. **WHO International Classification of Diseases (10th revision) (2003)** World Health Organisation.
<http://www.who.int/classifications/icd>
5. **National Cancer Research Institute 3 Year Progress Report 2001 – 2004 (2004)** National Cancer Research Institute.

Abbreviations

AMRC	Association of Medical Research Charities
HRCS	Health Research Classification System
ICD	International Classification of Diseases
NCRI	National Cancer Research Institute
NHS	National Health Service
RA	Research Activity
R&D	Research and Development
UKCRC	UK Clinical Research Collaboration
UKCRN	UK Clinical Research Network
WHO	World Health Organisation

About the UK Clinical Research Collaboration

The UK Clinical Research Collaboration (UKCRC), established in 2004, is a partnership of organisations working together to establish the UK as a world leader in clinical research by harnessing the research potential of the National Health Service (NHS). The Partners comprise the key stakeholders that shape the health research environment, including research funders, the NHS, government, industry, academia, regulators, charities and patients.

The UKCRC Partners are working together to address a broad agenda of issues affecting clinical research through several interconnected areas of activity. These are: developing the infrastructure to underpin clinical research in the NHS, building up an expert workforce to support clinical research, streamlining the regulatory and governance environment, developing incentives for research in the NHS and coordinating research funding. The Partners have already implemented many of the changes needed to transform the clinical research environment in the UK.

Investment in research infrastructure has been high on the agenda, with clinical research networks established across the UK to support the delivery of high quality clinical studies. The UK's capacity for experimental medicine research is also being strengthened through a coordinated initiative to develop Clinical Research Facilities designed to support innovative research from both academic and commercial sectors.

Further investment by the UKCRC Partners has established new training and career structures designed to ensure the development of an expert research workforce of clinicians, nurses and allied health professionals to support all aspects of clinical research in the NHS.

Work to streamline the regulatory and governance environment has already made an impact. The model Clinical Trials Agreement for commercial research in the NHS has been widely accepted and used. The UKCRC Regulatory and Governance Advice Service is up and running, and a more efficient approach to issuing honorary research contracts, the Research Passport, is being rolled out nationally. An integrated system for the permissions and approvals needed to initiate clinical research as well as a streamlined approach to R&D approvals in the Health Service are also in development.

The Association of Medical Research Charities is one of the UKCRC Partners and is playing a key role in promoting the opportunities presented by the new research environment to the charity sector.

Detailed information on UKCRC activities can be found in the *UKCRC Progress Report 2004 – 2006* which is available on the UKCRC website:

www.ukcrc.org

About the Association of Medical Research Charities

The Association of Medical Research Charities (AMRC), a UKCRC Partner, is a membership organisation of the leading medical and health research charities in the UK. Established in 1987, AMRC's membership comprises 113 charities that fund research aimed at combating diseases such as heart disease, cancer and diabetes, as well as rarer conditions such as cystic fibrosis or motor neurone disease. In 2005/06 AMRC members together allocated over £716 million to medical and health research in the UK.

Working together with member charities and partners, AMRC aims to support the sector's effectiveness and advance medical research by developing best practice, providing information and guidance, improving public dialogue about research and science and influencing government. Reflecting its strategic priorities of Support, Leadership and Influence, it develops policies and guidelines, through consultation with members, to help them improve their effectiveness; particularly in the area of grant-making.

AMRC member charities abide by principles which reflect their commitment to supporting medical and health research of the highest quality. Members must use a system of peer review in their allocation of funding for research grants and they must also have in place a research strategy to outline their priorities and goals in supporting research. AMRC believes that by having a strategy, charities can define areas where they can add value, identify gaps in the research agenda or obstacles to research activity and focus on issues of importance to their stakeholders. In developing their strategies, it is important that charities define not only the research they wish to support, but also how their portfolio of research activity fits with the national or international picture of research.

Organisations Participating in the Analysis

Action Medical Research

Vincent House
Horsham
West Sussex, RH12 2DP
<http://www.action.org.uk>

Alzheimer's Research Trust

The Stables
Station Road
Great Shelford
Cambridge, CB22 5LR
<http://www.alzheimers-research.org.uk>

Alzheimer's Society

Gordon House
10 Greencoat Place
London, SW1P 1PH
<http://www.alzheimers.org.uk>

Arthritis Research Campaign

Copeman House
St Mary's Court
St Mary's Gate
Chesterfield
Derbyshire, S41 7TD
<http://www.arc.org.uk>

Association for International Cancer Research

Madras House
St. Andrews
Fife
Scotland, KY16 9EH
<http://www.aicr.org.uk>

Asthma UK

Summit House
70 Wilson Street
London, EC2A 2DB
<http://www.asthma.org.uk>

BackCare

16 Elmtree Road
Teddington
Middlesex, TW11 8ST
<http://www.backcare.org.uk>

Breakthrough Breast Cancer

246 High Holborn
London, WC1V 7EX
<http://www.breakthrough.org.uk>

Breast Cancer Campaign

Clifton Centre
110 Clifton Street
London, EC2A 4HT
<http://www.breastcancercampaign.org>

BUPA Foundation

BUPA House
15 - 19 Bloomsbury Way
London, WC1A 2BA
<http://www.bupafoundation.com>

Diabetes UK

Macleod House
10 Parkway
London, NW1 7AA
<http://www.diabetes.org.uk>

Epilepsy Research UK

PO Box 3004
London, W4 4XT
<http://www.epilepsyresearch.org.uk>

Guy's & St Thomas' Charity

Guy's Hospital
The Counting House
St Thomas Street
London SE1 9RT
<http://www.gsttcharity.org.uk>

Kidney Research UK

Registered Office
Kings Chambers
Priestgate
Peterborough, PE1 1FG
<http://www.kidneyresearchuk.org>

Ludwig Institute for Cancer Research

Cell and Molecular Biology
Courtauld Building
91 Riding House Street
London, W1W 7BS
<http://www.ludwig.ucl.ac.uk>

Marie Curie Cancer Care

89 Albert Embankment
London, SE1 7TP
<http://www.mariecurie.org.uk>

Medical Research Scotland

Princes Exchange
1 Earl Grey Street
Edinburgh, EH3 9EE
<http://www.medicalresearchscotland.org.uk>

Motor Neurone Disease Association

PO Box 246
Northampton, NN1 2PR
<http://www.mndassociation.org>

Multiple Sclerosis Society

MS National Centre
372 Edgware Road
London, NW2 6ND
<http://www.mssociety.org.uk>

Muscular Dystrophy Campaign

61 Southwark Street
London, SE1 0HL
<http://www.muscular-dystrophy.org>

National Osteoporosis Society

Camerton
Bath, BA2 0PJ
<http://www.nos.org.uk>

Parkinson's Disease Society

215 Vauxhall Bridge Road
London, SW1V 1EJ
<http://www.parkinsons.org.uk>

Roy Castle Lung Cancer Foundation

200 London Road
Liverpool
Merseyside, L3 9TA
<http://www.roycastle.org>

SPARKS The Children's Medical Research Charity

Heron House
10 Dean Farrar Street
London, SW1H 0DX
<http://www.sparks.org.uk>

St Peter's Trust for Kidney Bladder & Prostate Research

South House, Block A, Room 5
Royal Free Hospital
Pond Street
London, NW3 2QG
<http://www.ucl.ac.uk/uro-neph/spt>

The Stroke Association

Stroke House
240 City Road
London, EC1V 2PR
<http://www.stroke.org.uk>

Tenovus

43 The Parade
Cardiff, CF24 3AB
<http://www.tenovus.com>

WellChild

16 Royal Crescent
Cheltenham, GL50 3DA
<http://www.wellchild.org.uk>

Yorkshire Cancer Research

39 East Parade
Harrogate, HG1 5LQ
<http://www.ycr.org.uk/web/ycr>

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, psychosocial, 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	Underpinning Research
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	Resources and infrastructure (aetiology)
3	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
3.5	Resources and infrastructure (prevention)
4	Detection, Screening and Diagnosis
4.1	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	Resources and infrastructure (detection)
5	Development of Treatments and Therapeutic Interventions
5.1	Pharmaceuticals
5.2	Cellular and gene therapies
5.3	Medical devices
5.4	Surgery
5.5	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)

Research Activity Codes

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	<p>Studies of normal biology including</p> <ul style="list-style-type: none"> ▶ genes 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	<p>Studies that do not address health directly but cover issues that may have a bearing on health and well-being including</p> <ul style="list-style-type: none"> ▶ 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	<p>Research in chemical and physical sciences that may lead to the future development of diagnostic tools or medical treatments including</p> <ul style="list-style-type: none"> ▶ bioengineering and biophysics ▶ chemical structures, interactions and properties ▶ molecular modelling ▶ material science
1.4	Methodologies and measurements	<p>Development of novel underpinning research measures and analytical methodologies including</p> <ul style="list-style-type: none"> ▶ 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)	<ul style="list-style-type: none"> ▶ 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

Research Activity Codes

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 <ul style="list-style-type: none"> ▶ 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 <ul style="list-style-type: none"> ▶ 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 <ul style="list-style-type: none"> ▶ 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 <ul style="list-style-type: none"> ▶ 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)	<ul style="list-style-type: none"> ▶ 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

Research Activity Codes

3 Prevention of Disease and 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 <ul style="list-style-type: none"> ▶ 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 <ul style="list-style-type: none"> ▶ 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 <ul style="list-style-type: none"> ▶ 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 <ul style="list-style-type: none"> ▶ discovery, development and testing of vaccines and vaccination in model systems ▶ mechanism of action ▶ development, implementation and evaluation of vaccination programmes and studies to increase uptake ▶ decision making, outcomes from vaccination and evaluation of evidence to inform policy
3.5 Resources and infrastructure (prevention)	<ul style="list-style-type: none"> ▶ 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

Research Activity Codes

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	<p>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</p> <ul style="list-style-type: none"> ▶ 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	<p>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</p> <ul style="list-style-type: none"> ▶ 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	<p>Studies investigating impact of screening and factors affecting uptake including</p> <ul style="list-style-type: none"> ▶ 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	<p>Studies investigating population screening programmes including</p> <ul style="list-style-type: none"> ▶ 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)	<ul style="list-style-type: none"> ▶ 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

Research Activity Codes

5 Development of Treatments and Therapeutic Interventions	Discovery and development of therapeutic interventions and testing in model systems and preclinical settings
5.1 Pharmaceuticals	<p>Identification and development of pharmaceutical small molecules, therapeutic vaccines, antibodies and hormones including</p> <ul style="list-style-type: none"> ▶ drug screening and development of delivery systems ▶ mechanism of action including side effects and drug resistance ▶ pharmacogenetics, prediction of genetic variation and responses to drugs ▶ testing in <i>in vitro</i> and <i>in vivo</i> model systems
5.2 Cellular and gene therapies	<p>Discovery and development of cellular, tissue and gene therapies including</p> <ul style="list-style-type: none"> ▶ gene therapy, stem cells therapy, <i>in vitro</i> fertilisation and tissue engineering ▶ development of delivery systems ▶ development of culture systems ▶ testing in <i>in vitro</i> and <i>in vivo</i> model systems
5.3 Medical devices	<p>Discovery and development of medical devices including</p> <ul style="list-style-type: none"> ▶ 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	<p>Development of surgical, obstetric and dental interventions including</p> <ul style="list-style-type: none"> ▶ histocompatibility, 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	<p>Discovery and development of interventions including</p> <ul style="list-style-type: none"> ▶ radiobiology, radiotherapy, radioimmunotherapy, radiosensitisers, microwaves, ultrasound, laser and phototherapy ▶ development of delivery systems ▶ investigation of mechanisms of action and side effects ▶ testing in <i>in vitro</i> and <i>in vivo</i> model systems
5.6 Psychological and behavioural	<p>Development of psychological and behavioural interventions including</p> <ul style="list-style-type: none"> ▶ cognitive behavioural therapy, electro-convulsive therapy, counselling, therapy and social interventions ▶ testing in model systems
5.7 Physical	<p>Development of physical interventions including</p> <ul style="list-style-type: none"> ▶ physical therapies, physiotherapy, occupational therapy, speech therapy, dietetics, exercise and osteopathy ▶ mechanisms of action ▶ testing in model systems
5.8 Complementary	<p>Discovery and development of complementary approaches to conventional medical therapies including</p> <ul style="list-style-type: none"> ▶ hypnotherapy, meditation, massage, acupuncture and homeopathy ▶ mechanisms of action ▶ testing in model systems
5.9 Resources and infrastructure (development of treatments)	<ul style="list-style-type: none"> ▶ 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

Research Activity Codes

6 Evaluation of Treatments and Therapeutic Interventions	Testing and evaluation of therapeutic interventions in clinical, community or applied settings
6.1 Pharmaceuticals	<p>Clinical application and evaluation of pharmaceutical small molecules, therapeutic vaccines, antibodies and hormones in humans including</p> <ul style="list-style-type: none"> ▶ 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	<p>Clinical application and evaluation of cellular, tissue and gene therapies in humans including</p> <ul style="list-style-type: none"> ▶ small scale and pilot studies ▶ phase I, II, III and IV trials ▶ gene therapy, stem cell therapy, <i>in vitro</i> fertilisation, tissue engineering ▶ evaluation of applied delivery systems
6.3 Medical devices	<p>Application and evaluation of medical devices in humans in a clinical, community or applied setting including</p> <ul style="list-style-type: none"> ▶ implantable devices, mobility aids, dressings, medical equipment and prostheses ▶ validation of design and post market surveillance
6.4 Surgery	<p>Clinical and applied application and evaluation of surgical, obstetric and dental interventions in humans including</p> <ul style="list-style-type: none"> ▶ 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	<p>Clinical application and evaluation of interventions in humans including</p> <ul style="list-style-type: none"> ▶ 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	<p>Application and evaluation of psychological and behavioural interventions in humans in clinical, community and applied settings</p> <ul style="list-style-type: none"> ▶ phase I, II, III and IV trials ▶ cognitive behavioural therapy, electro-convulsive therapy, counselling, therapy and social interventions
6.7 Physical	<p>Testing and evaluation of physical interventions in humans in a clinical, community or applied setting including</p> <ul style="list-style-type: none"> ▶ physical therapies, physiotherapy, occupational therapy, speech therapy, dietetics, osteopathy and exercise
6.8 Complementary	<p>All aspects of testing, evaluation and provision of complementary approaches to conventional medicine in humans in a clinical, community or applied setting including</p> <ul style="list-style-type: none"> ▶ 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)	<ul style="list-style-type: none"> ▶ 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

Research Activity Codes

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 <ul style="list-style-type: none"> ▶ 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 <ul style="list-style-type: none"> ▶ 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 <ul style="list-style-type: none"> ▶ 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 ▶ testing and evaluating management regimes and strategies
7.4 Resources and infrastructure (disease management)	<ul style="list-style-type: none"> ▶ development and/or distribution of resources and equipment for use by the community including informatics systems ▶ infrastructure support for trials, networks, consortia and centres

Research Activity Codes

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
8.1 Organisation and delivery of services	<p>Examining the organisation and provision of health and social care services and evaluating factors affecting the quality of care</p> <ul style="list-style-type: none"> ▶ 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	<p>Economic evaluation of health and social care interventions and delivery including</p> <ul style="list-style-type: none"> ▶ 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	<ul style="list-style-type: none"> ▶ 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	<p>Development of research designs and novel methodologies for health care including treatment, management and health services research</p> <ul style="list-style-type: none"> ▶ 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)	<ul style="list-style-type: none"> ▶ development and distribution of resources for use by the community including informatics systems ▶ infrastructure support for networks, trials, consortia and centres

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