



**Igniting our potential**

Health Research Classification System:  
Coder Training Course

November 2015  
Dr. James Carter, MRC

### Structure of the Presentation

- ▶ **Background (40 mins)**
  - ▶ Where the HRCS came from
  - ▶ What impact it has had
  - ▶ Who is using it now
- ▶ **Understanding the System (30 mins)**
  - ▶ How the HRCS is structured
  - ▶ What it can and cannot do
  - ▶ How to use it in practice

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Health Research Classification System

Background

### UKCRC Partners



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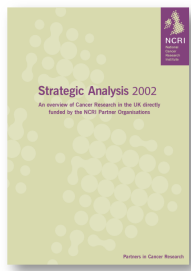
### UK Health Research Analysis

- ▶ Aim - Develop a coherent approach to funding health research
- ▶ Up until then no national picture of UK health research
- ▶ Evidence base of current funding patterns
- ▶ Analysis conducted by UKCRC Secretariat on behalf of funders to map UK Health research portfolio

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### Adopted an approach based on cancer experience

- ▶ **National Cancer Research Institute**
  - ▶ Partnership of government, charity and industry
- ▶ **Strategic Analysis 2002**
  - ▶ Overview of UK cancer research
  - ▶ Based on Common Scientific Outline
- ▶ **Major outcomes**
  - ▶ Joint strategy discussions
  - ▶ National Prevention Research Initiative
- ▶ **International Cancer Research Partnership (ICRP)**



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## Organisations Participating

- ▶ Government funding bodies
  - ▶ Health Departments (England, Scotland, Wales, N.Ireland)
  - ▶ MRC
  - ▶ ESRC, EPSRC, BBSRC (health or ageing relevant data)
- ▶ Three largest charities
  - ▶ Wellcome Trust
  - ▶ Cancer Research UK
  - ▶ British Heart Foundation



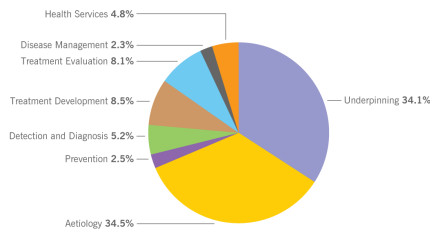
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## Methodology

- ▶ Established a central UKCRC Research Database
- ▶ 9638 UK-based directly funded peer reviewed health research awards (programmes, projects, training etc)
- ▶ Awards 'live' between 1st April 2004 - 31st March 2005
- ▶ Designed a bespoke Health Research Classification System (HRCS)
  - ▶ Research Activity Codes – types of research
  - ▶ Health Categories – areas of health and disease
- ▶ Labour intensive quality control led coding process

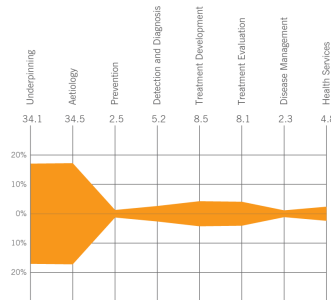
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## Proportion of Combined Total Spend by Research Activity



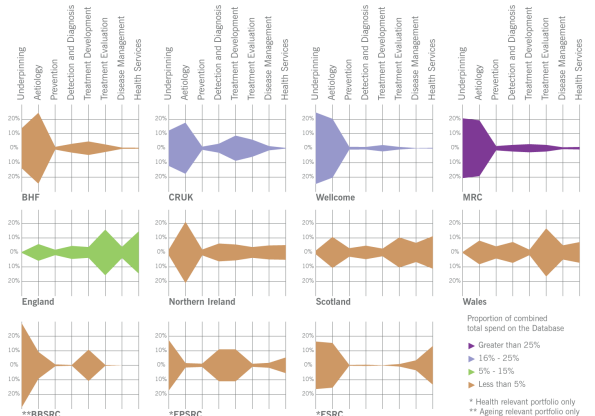
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## Proportion of Combined Total Spend by Research Activity – Kite Diagram

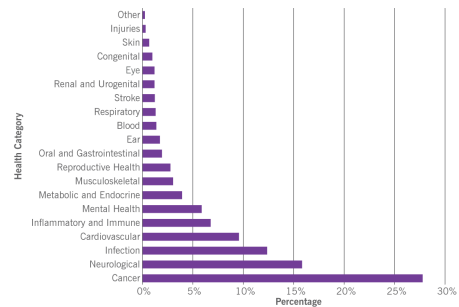


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## Profile of Each Organisation's Spend by Research Activity



## Proportion of Combined Spend on Health Specific Categories



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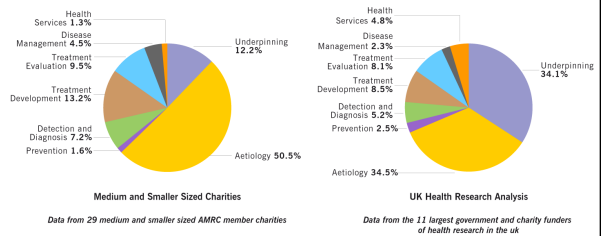
## From Donation To Innovation



- ▶ 29 medium & smaller sized AMRC member charities
- ▶ 1496 awards
- ▶ Published 2007
- ▶ Two reports together represent majority of UK government & medical research charities' funding (over £1 billion funding)

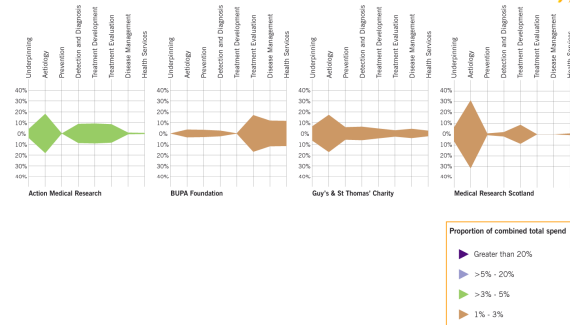
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## Distribution of Total Spend by Research Activity



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## Profile of Each Participating Charity's Spend by Research Activity – Charities Supporting a Range of Diseases & Conditions



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Data from 29 medium and smaller sized AMRC member charities

## Impact of the Analyses and HRCS

- ▶ Reports widely distributed
- ▶ Evidence base used by
  - ▶ Individual funders
  - ▶ Joint planning and coordination
  - ▶ Research community
- ▶ Classification system adopted by many UK government and charity funders
- ▶ Primary data source for Cooksey Review

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## Inter-Analysis Period (2006-2009)

- ▶ Change to Funder-Led Process
  - ▶ Health Research Analysis Forum (HRAF)
  - ▶ Chair/Lead Organisation: MRC
- ▶ International Workshop 2009
- ▶ EMRC recommendation for international adoption
- ▶ Early development of auto-coding procedures – Elsevier Team



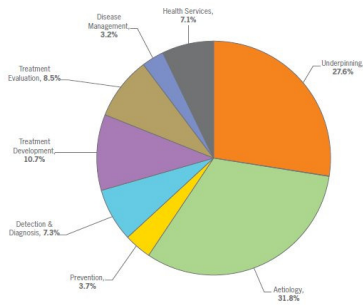
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## UK Health Research Analysis 2009/2010

- ▶ Participants
  - ▶ Original 11 funders, plus Arthritis Research UK
- ▶ Limited Budget
  - ▶ Funder led = in-house coding
  - ▶ Provision for external (contract) coding
  - ▶ BUT no quality control
- ▶ Analysis (2009/2010)
  - ▶ 12,000 awards with £1.6bn (~50% real terms increase)
  - ▶ New: Infrastructure Assessment, additional £827m
  - ▶ New: Estimation of Total UK Health Research Expenditure

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### Proportion of Combined Total Spend by Research Activity (2009/2010)



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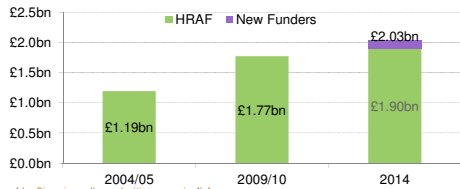
### UK Health Research Analysis 2014: Aims

- Improve speed of report production
  - Greater availability of data in more easily extracted format
  - The majority of awards already coded
- Increase number of participating organisations
  - More medium/small charities and other public funders
- Improve consistency and quality of coding
  - Review HRCS, update guidance and standardise approach
- Make the data openly accessible
  - Considerable interest in further use of UK HRA data
  - Pre-agreement of HRAF members to release full public dataset

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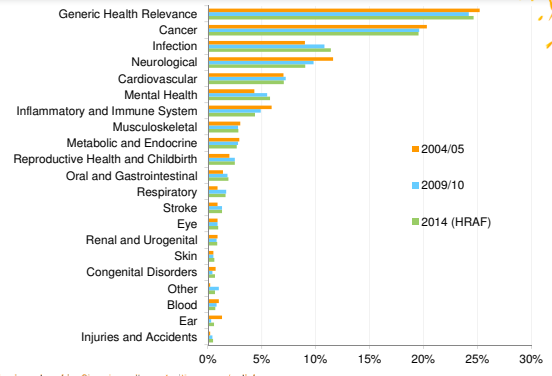
### 2014 Results – Total Analysis Spend

- Increased participation (64 funders)
- 17,021 awards - £3.01bn spend
  - ~£2bn on direct awards ('projects')
  - ~£1bn on indirect awards ('infrastructure')
- Increase in 5 and 10 year reporting
  - Rate slowing (CAGR 8.2% 04-09, 1.4% 09-14)



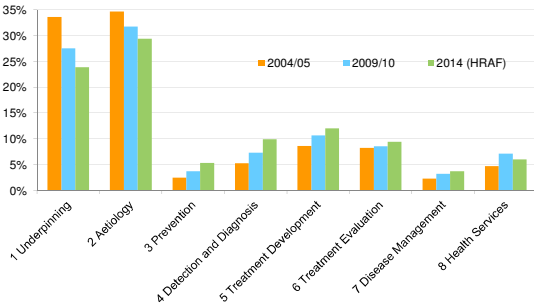
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### 2014 Results – Health Categories



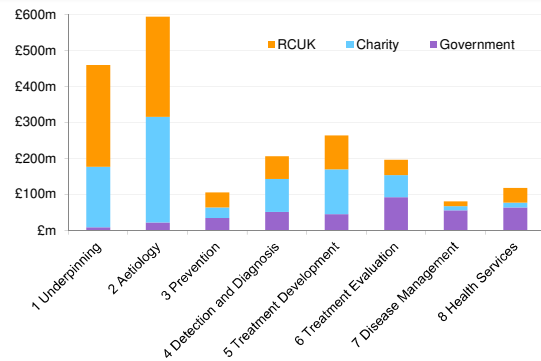
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### 2014 Results – Research Activities



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### 2014 Results – Charity / Public Distribution



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## Future of HRCS

- Continue working to International Standard
- Improve Coding Reliability
- Increase reporting efficiency (auto-coding)
- Begin plans for next analysis...?

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## Igniting our potential

Health Research Classification System

Understanding the System

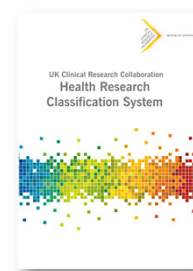
## What is the HRCS?

- ▶ A system for classifying and analysing health and biomedical research funding
- ▶ Designed collaboratively by a range of funders for the following purposes:
  - ▶ To cover the full spectrum of all types of research across all areas of health and disease
  - ▶ To provide a single stable common system allowing meaningful comparisons across time and between different portfolios
  - ▶ To answer strategic questions about investment
  - ▶ To give a "broad brush" overview of funding patterns

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## Structure of the HRCS

- ▶ Two dimensional system
  - ▶ Health Categories
  - ▶ Research Activity Codes
- ▶ Health Categories
  - ▶ All areas of health or disease
  - ▶ 21 individual categories
  - ▶ Based on **WHO International Classification of Diseases**
- ▶ Research Activity Codes
  - ▶ All types of research activity from basic to applied
  - ▶ 48 codes in 8 groups
  - ▶ Based on cancer **Common Scientific Outline**



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## Key Features of the HRCS

- ▶ Coding is based on the main research objective
  - ▶ Not a keyword system
  - ▶ Does not capture all potential downstream outcomes
  - ▶ Complements existing coding systems
  - ▶ Fit for purpose
- ▶ Coding is linked directly to associated funding
  - ▶ Codes based on lifetime of the award
  - ▶ Exact percentages with every code
  - ▶ But is not a financial audit tool
- ▶ System provides a broad overview of the centre of gravity of research
  - ▶ An aggregate population summary
  - ▶ Fine grained expertise not required

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## Key Aspects of HRCS Coding Process

- ▶ Tried and Tested
  - ▶ Accumulated experience began in 2005
  - ▶ Several major analyses, thousands of awards
  - ▶ Range of organisations, award types and settings
- ▶ Stable and Consistent
  - ▶ HRCS is openly available but not for alteration
  - ▶ Simple reproducible rules – equal proportions, minimum number of codes
  - ▶ Value lies in ability to compare over time and between settings

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## HRCS Online website

- ▶ Makes all existing information and resources accessible
- ▶ Overarching aim to promote sustainability of the system
- ▶ Guidance for naïve users wanting to learn how to use the system
- ▶ Reference source for experienced users
- ▶ Provides further contextual help, summaries and linkages



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## Health Categories

- ▶ Blood
- ▶ Cancer
- ▶ Cardiovascular
- ▶ Congenital Disorders
- ▶ Ear
- ▶ Eye
- ▶ Infection
- ▶ Inflammatory and Immune System
- ▶ Injuries and Accidents
- ▶ Mental Health
- ▶ Metabolic and Endocrine
- ▶ Musculoskeletal
- ▶ Neurological
- ▶ Oral and Gastrointestinal
- ▶ Renal and Urogenital
- ▶ Reproductive Health and Childbirth
- ▶ Respiratory
- ▶ Skin
- ▶ Stroke
- ▶ Generic Health Relevance
- ▶ Other

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## Notes on Health Categories (1)

- ▶ Cancer
  - ▶ all types - not coded by site e.g. lung cancer
- ▶ Cardiovascular
  - ▶ includes atherosclerosis
- ▶ Congenital Disorders
  - ▶ multiple syndromes - excludes single focus syndromes like congenital heart disorders
- ▶ Infection
  - ▶ all types - not coded by site e.g. respiratory tract infections
- ▶ Inflammatory and Immune System
  - ▶ about immune system (not just immune response) - includes rheumatoid arthritis
- ▶ Mental Health
  - ▶ includes normal behavioural and cognitive function – and all abnormal conditions defined by behaviour

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## Notes on Health Categories (2)

- ▶ Musculoskeletal
  - ▶ includes osteoarthritis
- ▶ Neurological
  - ▶ about brain function and 'wiring' – includes BSE and dementias
- ▶ Reproductive Health and Childbirth
  - ▶ includes all aspects of pregnancy and the new born
- ▶ Respiratory
  - ▶ includes asthma



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## Notes on Health Categories (3)

- ▶ Generic Health Relevance
  - ▶ all areas of health or general health
  - ▶ Or >5 Health Categories
- ▶ Other
  - ▶ A few very specific areas including Gulf War syndrome and chronic fatigue syndrome
  - ▶ Not a dustbin category
- ▶ Note: Each category includes normal/healthy and disease processes
- ▶ Note: Categories are not always deducible from causation, symptoms, or site of action

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## Guidance Topics on Health Categories

See specific guidance on:

- ▶ Sequelae
  - ▶ When a condition is a consequence or side effect of a pre-existing condition
  - ▶ If double coding, does one code make sense without the other?
- ▶ Multiple diseases and conditions
  - ▶ Health category list for use in four areas – Alcohol; Diet / nutrition; Physical activity / exercise; Tobacco / smoking
  - ▶ Use only in the absence of other information



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## Overview of Research Activity Code Groups

1 Underpinning Research	Research that underpins investigations into the cause, development, detection, treatment and management of diseases, conditions and ill health
2 Aetiology	Identification of determinants that are involved in the cause, risk, or development of disease, conditions and ill health
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
4 Detection, Screening and Diagnosis	Discovery, development and evaluation of diagnostic, prognostic and predictive markers and technologies
5 Development of Treatments and Therapeutic Interventions	Discovery and development of therapeutic interventions and testing in model systems and preclinical settings
6 Evaluation of Treatments and Therapeutic Interventions	Testing and evaluation of therapeutic interventions in clinical, community or applied settings
7 Management of Diseases and Conditions	Research into individual care needs and management of disease, conditions or ill health
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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## Notes on Research Activity Codes (1)

- ▶ 1 Underpinning
  - ▶ normal / healthy / non-diseased
  - ▶ pain, immune responses, pregnancy, ageing, cell death DNA repair are considered normal
  - ▶ not just biological = chemistry, psychology, social
- ▶ 2 Aetiology
  - ▶ not just causation – describing development, progression and life course of disease
  - ▶ includes epidemiology and observational studies

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## Notes on Research Activity Codes (2)

- ▶ 3 Prevention
  - ▶ excludes secondary prevention (prevention of a condition recurring)
- ▶ 4 Detection and Diagnosis
  - ▶ markers / screening / monitoring / prediction
  - ▶ 4.1 – pre-clinical / lab based
  - ▶ 4.2 – clinical studies in humans
- ▶ 5 Treatment Development
  - ▶ pre-clinical / lab based - including patient samples



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## Notes on Research Activity Codes (3)

- ▶ 6 Treatment Evaluation
  - ▶ clinical studies in humans – including all **therapeutic** trials phases I-IV
  - ▶ includes economic evaluation and assessing quality of life as part of study measures
- ▶ 7 Disease Management
  - ▶ personal perspective – research into activities of health professionals and/or needs of patients
- ▶ 8 Health Services
  - ▶ institutional perspective – research into organisations and service delivery

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## Guidance Topics on Research Activity Codes

See specific guidance on:

- ▶ Repeated terms and concepts
  - ▶ Trials, policy, education, evaluation etc.
- ▶ Methodology
  - ▶ Appears in 3 Groups
- ▶ Resources and infrastructure
  - ▶ Appears in all 8 Groups



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## Approach to Coding

- ▶ Identify **main** aim(s) and health focus(es) of research within lifetime of award
- ▶ Allocate the **minimum** number of codes to reflect these
- ▶ Assign **equal** percentages adding to 100% for both Health Categories and Research Activity Codes (unless there are clear reasons not to)
- ▶ Example coding of one hypothetical award:
  - ▶ A clinical trial in humans to test a new drug therapy for treating lung cancer
  - ▶ 6.1 Pharmaceuticals -> 100%
  - ▶ Cancer -> 100%



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## Rules For Assigning Health Categories

- ▶ Identify the main health or disease focus(es) of the award
  - ▶ Ignore background work often listed as **being relevant** and future potential downstream outcomes
- ▶ Match each to a Health Category obeying the specific inclusion criteria
  - ▶ e.g. "testing a treatment for **lung cancer**" -> *Cancer not Respiratory*
  - ▶ Knowledge of pathogenesis, symptoms and disease site may not always be relevant
- ▶ Assign up to a maximum of 5 Health Categories
  - ▶ *Generic Health Relevance* should be assigned if more than 5 categories apply or there is wide health relevance
  - ▶ The *Other* category is only for **very** specific cases – do not use if you are uncertain
- ▶ Special rules
  - ▶ studies of alcohol, diet, exercise and smoking
  - ▶ consequences or side effects of a pre-existing condition

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## Rules For Assigning Research Activity Codes

- ▶ Identify the main aim(s) of the award
  - ▶ Ignore background work often listed as **being relevant** and future potential downstream outcomes
- ▶ Match each to a Research Activity Code **group**
  - ▶ e.g. "a trial in humans testing a new therapy" -> *6 Treatment Evaluation*
  - ▶ Note that HRCS code names and research concepts are repeated across code groups
    - ▶ e.g. **trials** are not always therapeutic trials
    - ▶ e.g. studies of **therapies** can be in humans or pre-clinical
- ▶ Then select appropriate code from within group
  - ▶ e.g. "it is a drug trial" -> *6.1 Pharmaceuticals*
- ▶ Assign up to 2 Research Activity Codes (4 for large programmes)

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