

UK Primary Prevention Research

A report from the Medical Research Council on the national grant portfolio in 2018

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Summary

Purpose of the analysis

This report summarises an analysis of the primary prevention portfolio of the major UK health research funders which was undertaken on behalf of the Medical Research Council (MRC) by the MRC Population Health Sciences Group (PHSG) to describe how funds were being deployed to support prevention research. An objective was to help inform the strategic direction of further investment by the UK Prevention Research Partnership (UKPRP) under its second call. We used the UK Health Research Analysis 2018 (UKHRA 18)¹ data while UKPRP was getting underway with the intention of providing a profile of prevention research in 2018 as a baseline against which future UKPRP research priorities and spend could be measured.

As part of this exercise, we asked more detailed questions about the portfolio based on input from expert advisors. We focused on primary prevention² because this had been the area highlighted as a gap in the first UK Health Research Analysis (2004) and which led to the National Prevention Research Initiative and then the UKPRP.

What we did

We applied a new coding system to the UKHRA 18 dataset. This was needed because the UK Clinical Research Collaboration (UKCRC) Health Research Classification System (HRCS) is not designed for detailed analysis of research that includes the social and environmental determinants of health which are being investigated through UKPRP and other public health research funding programmes. To ensure that we established as complete a picture as possible of UK funder support for prevention research, the new coding system was applied alongside the UKCRC system's codes so that we could include classifications incorporated in HRCS such as health category (e.g. infection, cancer, mental health) and Research Activity 3.4; vaccination.

What we found

This project identified 1156 primary prevention awards from 49 UK funders representing a total spend of £220 M in 2018. Half of this research was targeted at health overseas, mostly at studying health problems in low- and middle-income countries (LMICs). Half of all primary prevention funds were spent on infection, with a third of all the primary prevention portfolio supporting work that included research into vaccination programmes and/or the development of vaccines, including laboratory-based vaccine development.

The portfolio of research on the primary prevention of Non-Communicable Diseases (NCDs) that is focused on improving health in the UK will in future include the UKPRP awards. However, in 2018 most primary prevention research was taking place overseas and/or was focussing on infection, thus the UK NCD portfolio represented only a quarter (£54 M total value of awards) of all research grants in 2018 with a primary prevention code.



² Definitions on page 7

Overall, there was limited research on the social and environmental determinants that UKPRP will focus on. A third of all UK research on NCDs was based in healthcare settings. There was a strong portfolio of community-based research (£9 M), reflecting the contribution of the National Institute for Health Research (NIHR) Public Health Research Programme. However, a limited amount of research in the 2018 UK NCD portfolio was undertaken in the defined specific settings where people live work, travel and study, and in which the wider determinants of health exert a strong influence.

The analysis of the UK NCD primary prevention portfolio suggests that there has been progress in the application of population-level research approaches including population-level interventions when compared to the UKPRP's predecessor, the National Prevention Research Initiative (NPRI). This progress also reflects funding by the NIHR Public Health Research Programme, but also initiatives supported by other funders that started after NPRI had finished. However, research into population-level approaches, especially aimed at the prevention of NCDs in the UK, remains an area for development.

The analysis of the secondary prevention portfolio highlighted that most of the research in the £273 M 'Detection, screening and diagnosis' HRCS dataset, was directed towards prognosis and disease stratification of people with evident symptoms and not for early detection that was asymptomatic. This meant that the spend on secondary prevention using our definition was low (around £42 M) and contributed only 15% of the entire portfolio aimed at 'detection, screening and diagnosis'. The total spend on primary and secondary prevention in our analysis is therefore £262 M.

Messages to take away

The NPRI review in 2015, and other commentators since, have identified the need to better understand the complex interaction between individual behaviour and risk factors, and social, cultural, healthcare and other determinants of health in the populations in which the burden is greatest. This was still a gap in 2018. The need to increase the prevention research spend on population-level approaches as well as individual-level interventions has also been highlighted by many. In the UK NCD portfolio, we saw a small increase in the balance of research on population-level compared to individual-level approaches to prevention, including intervention trials. Counting all population-level approaches such as trials, modelling, natural experiments and policy evaluations together, the value of the grants supporting population-based research was still less than spent on research on individuals This remains a long-standing feature of the UK health research landscape, particularly in the prevention of NCDs.

These issues are integral to the UKPRP in which awards can provide multi-disciplinary systems-focused research at an unprecedented scale. This analysis of primary prevention research spend shows that UKPRP-type research is clearly needed both in relation to its aim and the scale of the funding opportunity.

The observation that early detection is much less studied than prognostic research suggests the need for policy makers to consider the balance of investment between research into different approaches to prevention.

In conclusion, this analysis confirms the continuing need to increase investment and UK capability for research into whole-system influences on behaviour and public health, to achieve deeper understanding of the complex influences and interactions needed to develop more powerful population-level interventions.

Introduction

Prevention research is a strategic priority for several funders including the Medical Research Council (MRC) and 11 other funders in the UK Prevention Research Partnership (UKPRP)³.

In 2004, an exercise led by the UKCRC drew attention to research into primary prevention, showing that it represented just over 2% of UK health research spend⁴. This galvanised 16 funders to form the NPRI which funded research between 2005 and 2011 focused on reducing the risks of NCDs through understanding or changing health behaviour, specifically relating to alcohol consumption, tobacco smoking, diet, physical activity and sedentary behaviour. NPRI funded 74 projects (total funding £34 M) and was, for much of this period, the only major national means of support for primary prevention research.

A review of the NPRI portfolio in 2015⁵ looked back at the portfolio of awards and noted both the preponderance of research where interventions targeted individuals to change single health-related behaviours and a paucity of interventions to produce large and sustained change in the 'real world'. The review recommended increased research into whole system influences on behaviour and public health, greater focus on developing interventions that act at a level other than the individual, and more research addressing areas of disproportionate need, such as in low socio-economic groups, ethnic minorities and those struggling with mental health issues.

During the 2005-11 period in which NPRI was in existence, other initiatives emerged which provided additional support for prevention research, chiefly the NIHR Public Health Research Programme, the School for Public Health Research and the UKCRC Public Health Research Centres of Excellence⁶. In 2020, the UKCRC reported⁷ that the spend on research into prevention was 5.9% of all health research, after portfolio increases in 2009 and 2014⁸.

In 2017, twelve funders joined forces to establish the £50 M UKPRP with a shared vision to undertake research to improve population health and reduce health inequalities by focusing on the upstream determinants of health. The UKPRP was intended to provide a significant impetus to primary prevention research by funding consortia to enable large-scale multidisciplinary approaches to untangling the interrelated complexities of the drivers of NCDs in the social and physical environment.

More recently, prevention has been raised as a Government priority¹⁰ with a particular objective of prolonging healthy life expectancy and reducing inequalities alongside a broader 'levelling up agenda'¹¹. The COVID-19 pandemic has re-emphasised the impact that risk factors such as obesity, ethnicity and social disadvantage have on mortality risk and have refocused attention on these major societal challenges.

³ The UKPRP partners are the British Heart Foundation, Cancer Research UK, the Chief Scientist Office (Scotland), the Engineering and Physical Sciences Research Council, the Economic and Social Research Council, Health and Care Research Wales, The Health and Social Care Public Health Agency (Northern Ireland), the Medical Research Council, the Natural Environment Research Council, the National Institute for Health Research, The Health Foundation and Wellcome.

 $^{4 \}qquad https://hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2004-05/$

⁵ https://mrc.ukri.org/publications/browse/national-prevention-research-initiative-npri-report-2015/

⁶ https://www.ukcrc.org/report-reveals-legacy-of-ukcrc-public-health-research-centres,

⁷ On a much larger group of funders than in previous 'sweeps'

^{8 (}http://hrcsonline.net/wp-content/uploads/2020/01/UK-Health-Research-Analysis-2018-for-web-v1-28Jan2020.pdf).

⁹ https://mrc.ukri.org/funding/browse/ukprp/uk-prevention-research-partnership-ukprp-consortium-and-network-awards/ukprp-consortium/

¹⁰ For example, the Green Paper, Advancing our Health: Prevention in the 2020s https://www.gov.uk/government/consultations/advancing-our-health-prevention-in-the-2020s/advancing-our-health-prevention-in-the-2020s-consultation-document

¹¹ For example, https://www.gov.uk/government/consultations/early-years-healthy-development-review-call-for-evidence

In 2019 the first UKPRP awards were starting, the MRC was considering its next steps in prevention research and UKPRP was considering its future priorities and how its progress, including its impact on the prevention landscape, could be measured. This needed to be informed by an overview of the current prevention research landscape.

As the UKCRC Health Research Analysis
Forum (HRAF) was about to deliver a
coded dataset of primary prevention
research from 146 UK funders (the
UKHRA 18), MRC's Population Health
Sciences Group (PHSG) decided to
undertake a more detailed portfolio
analysis of this dataset. An objective of the
analysis was to provide rich information about
the funding for primary prevention research that
addresses NCDs – this is the area that encompasses
the upstream determinants that research funded by



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HRCS defines research through 48 Research Activity (RA) codes divided into eight overarching code groups of which one (RA3) is 'Prevention of disease and conditions, and promotion of well-being'; it concerns primary prevention including vaccination, which is sub-categorised separately from other activities (RA3.4)¹². HRCS also codes health categories but not health intervention settings; or wider determinants or health behaviours, so a new coding system was implemented. The new system was designed to work alongside HRCS codes so that all research activities identified as primary prevention (e.g. prevention research on infectious disease) could be included, to give the fullest possible picture.

In consultation with a small group of advisors and experts (see acknowledgements) a number of specific questions that the portfolio might address were drawn up in order to meet PHSG's objectives. There was interest amongst our advisors in determining the research focus on ethnicity, health inequality and mental health; and linking those to the settings, particularly schools, for research on determinants of mental wellbeing. Another topic raised was the proportion of research that included population versus individual-level interventions.

The findings of these analyses are presented in this report. Although we focused on primary prevention, as that was the focus of NPRI, and is the focus of UKPRP, we also surveyed secondary prevention to provide additional context and made some observations about tertiary prevention (see definitions in the next section).

¹² The word primary does not appear in the descriptor of the research activity, but the main inclusion criterion is 'research aimed at the primary prevention of the research activity, but the main inclusion criterion is 'research aimed at the primary prevention of the research activity, but the main inclusion criterion is 'research aimed at the primary prevention of the research activity, but the main inclusion criterion is 'research aimed at the primary prevention of the research activity, but the main inclusion criterion is 'research aimed at the primary prevention of the research activity, but the main inclusion criterion is 'research aimed at the primary prevention and the primary prevention are the primary prevention are the primary prevention and the primary prevention are the primary prevention and the primary prevention are the primary prevention are the primary prevention and the primary prevention are the primary prevention at the primary prevention are the primary prevention and the primary prevention are the primary prevention are the primary prevention are the primary prevention are the primary prevention and the primary prevention are the primary pre

Methods

A fuller description of the methods used can be found at Annex 1. Annex 2 sets out the coding structure and instructions given to the coders. Additional data supporting the findings in this report are provided in Annex 3.

We defined the types of prevention research, primary, secondary and tertiary, as follows.

Primary prevention research aims to develop or evaluate interventions (including strategies and policies) to maintain human health and prevent illness or injury from arising in the first place.

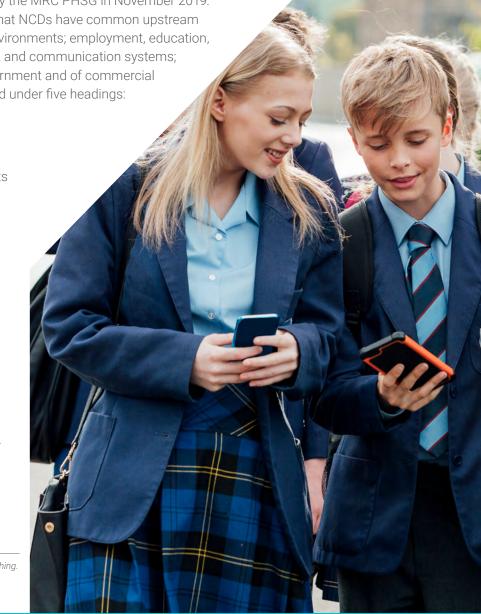
Secondary prevention requires the earliest possible detection of disease which is asymptomatic, to be able to halt progress or prevent more severe problems developing.

Tertiary prevention research, which addresses the prevention of disease progression and further multimorbidity, was out of our scope.

Following discussions with experts, we developed a coding structure for primary prevention research that was approved by the MRC PHSG in November 2019. Individual codes were chosen to reflect that NCDs have common upstream determinants such as urban and rural environments; employment, education, welfare, transport, health and social care, and communication systems; and the policies of local and central government and of commercial enterprises. The new codes were grouped under five headings:

- Settings
- Sectors
- Social and environmental determinants
- Health behaviour determinants
- Participants

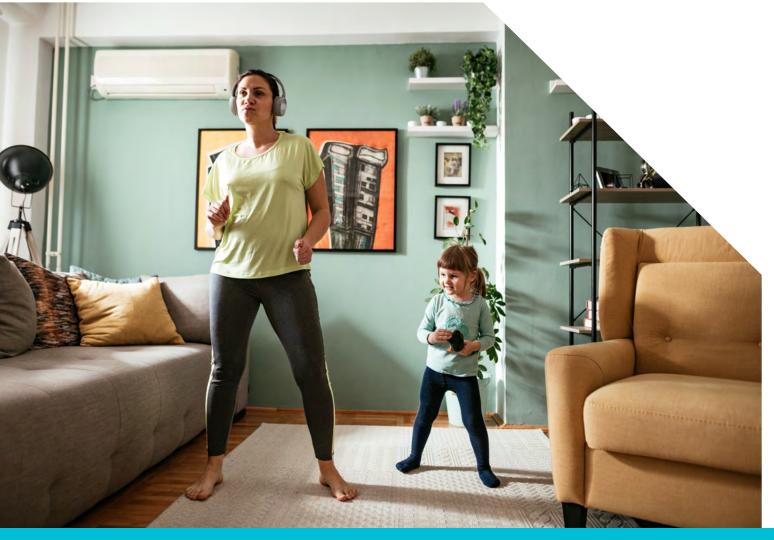
To promote inter-coder consistency, a classification guidance document was created and was supplemented with a training workshop which included an extensive live coding exercise. Several new descriptors were added to the structure based on coder feedback and the guidance was updated. An interim and final quality control (QC) analysis of intercoder variability was found to be almost fully within the limits specified for the UKHRA 18 coding (i.e. >70% precise matching and >80% partial matching)¹³.



¹³ We achieved 69% exact matching and 81% partial matching.

Main Findings

The main findings of our analysis are presented under the headings below, covering the overall spend on primary prevention, the distribution of spend between funders, the amount of spend on research targeted at international health problems or carried out overseas, and the relative spend on communicable (infectious) as opposed to non-communicable disease prevention. We also addressed whether research in 2018 had considered wider determinants and whether there had been progress in implementing population-based approaches. Finally, we looked at secondary prevention, defined as the earliest detection of disease in asymptomatic individuals.



Primary prevention across the whole portfolio

What was the overall UK spend on primary prevention research in 2018?

The project identified 1156 UK primary prevention awards with a total annualised spend of £220 M^{14} . This includes both global and UK-based prevention research.

Who are the UK funders of primary prevention research?

There are 146 participating funding organisations in the UKHRA 18 but only 49 of those support primary prevention research. The biggest financial contributors are the Medical Research Council (£50.6 M), Wellcome Trust (£47 M) and Department of Health and Social Care through the National Institute of Health Research (£38.5 M) - see Figure A, Annex 3. These three funders support nearly two thirds of all primary prevention research. The UKPRP funders¹⁵ supported 74% of the primary prevention research in the UKHRA 18 as opposed to 64% of health research overall. Major funders outside the UKPRP were the Department for International Development (replaced in 2020 by the Foreign, Commonwealth and Development Office) (£18 M; about 16% of overseas prevention research) and Innovate UK (£13.6 M).

What proportion of the UK spend is on research overseas or relevant to overseas?

Just over half (53%, £116 M) of all primary prevention research is either awarded to overseas institutions or awarded to institutions in the UK but where the research is targeted to international health problems and/or performed overseas, usually in Low- and middle-income countries (LMICs). Mostly this overseas research concerns infection, but almost a third also addresses NCDs. (See Figure Bi, Annex 3).

What is the spend on infection research?

Approximately half of the overall spend (£119 M), overlapping with the non-UK/global research figure, was attributed to infectious diseases, which was ahead of any other health category as a target for primary prevention research (Figure Bii, Annex 3). Vaccination research is a prominent part of the primary prevention research portfolio (£72 M, 33% of total) and the funding was mostly for research to develop vaccines protecting people against infectious diseases and antimicrobial resistance. It was relevant to both domestic and global health.

What are the settings, sectors and determinants that are studied?

This section refers to the application of the new primary prevention classification structure to the whole primary prevention research portfolio.

The areas which the new coding system was designed to evaluate were not well supported across the whole portfolio, reflecting the observation that many studies did not define a setting or a social or environmental context to their study. However, where they are defined, the following observations could be made (Figures Ci to Cv in Annex 3).

Settings – After 'non-UK/global research', the most prevalent setting for conducting primary prevention research was in health care (£44 M) followed by the laboratory (£34 M – the research usually being vaccine development) and the general population (£25 M – usually evaluation of public health policies and analysis of population data). Less prevalent research settings were schools, workplaces, urban and rural environments and the home – yet these are the places where the upstream determinants of health exert influence

Sectors – The health sector was also the sector to engage most often in the research with very little activity involving sectors outside the health service like transport or construction.

Social and environmental determinants – When defined, the biggest emphasis was on health inequalities, which was often a primary concern of global health studies. Little research addressed social factors, for example, how social networks might influence health outcomes.

Health behaviours – Diet was by far the commonest health behaviour studied. Combined with physical activity, this highlighted a strong emphasis on research to understand risk factors for obesity. There was strikingly little research seeking to prevent people becoming addicted to drugs and gambling.

Who is studied?

Where discernible, there appear to be fewer studies on the older population than in other age groups and less research studying populations rather than individuals.

¹⁴ The UKHRA 18 report gives the total funding coded to RA3 – primary prevention – for the UK a value of £151 M. The value of £220 M we use is the total 2018 annualised spend value of all of RA3* (i.e. including elements co-coded outwith RA3) including awards made directly to organisations overseas that were made by a UK funder. * We excluded a few records on preventing diseases in non-human animals where this was not relevant to human health.

¹⁵ The Health Foundation is a UKPRP funder which supports prevention research but does not submit data to HRCS.

Primary prevention research on NCDs in the UK

Given the preponderance of research on infection studies and research addressing global health issues, we developed a data subset of the primary prevention research portfolio that addressed NCDs in the UK. Such a dataset would provide a baseline from which to track the contribution of the UKPRP awards. To identify awards that could fall within the remit of the UKPRP ('UKPRP-like'), we filtered the data where:

- (a) the research is not infection (HRCS Health Category)
- (b) the research is not coded non-UK/global with the new classification system
- (c) the research is not related to vaccine development (HRCS RA3.4)
- (d) the funding is not for research infrastructure or a shared resource (HRCS RA3.5)¹⁶

This left a dataset of 482 awards. This UKPRP-like portfolio equated to a spend of £54 M and accounted for 25% of the value and 42% of the number of awards in the primary prevention portfolio. In contrast to the full portfolio, the largest single Health Category (£8.7 M, 16% of spend) of the research now addresses 'generic health relevance' (see figure D, Annex 3). Taking the UK NCD (the dataset that would include research funded by UKPRP¹⁷) portfolio and applying the new prevention classification structure to this portfolio, some differences and similarities emerged compared to the whole portfolio.

Settings and sectors – The profile of research settings was similar to that for the whole primary prevention research portfolio with health care (primary care mainly) now the biggest investment in a setting (£15.6 M) for conducting primary prevention research (see Figure 1) once non-UK research has been removed. Health systems were associated with by far the biggest spend on any sector (£20.9 M). When health systems and social care sectors are removed from the sector data, the food system was the most frequently studied sector (£6.6 M spend), reflecting an overall focus on diet as a key health-related behaviour. Less than a fifth of the research spend was for research based in schools, workplaces and the home. There was very little research that had been coded as primary prevention that engaged the construction and transport sectors.

Social and environmental determinants - The strongest focus in the social and physical environment (Figure 2) was on factors that affect mental health and mental wellbeing, including violence and bullying (£8.6 M spend). Research considering the effect of policy on health was well supported (£8.4 M). There was a welcome focus on inequalities (£3.7 M) although this research was often secondary data analysis of outcomes rather than experiments designed to prevent inequalities widening. Given the increased risk to chronic disease (and now COVID-19) in some ethnic groups, there was a surprising absence of investment in primary prevention research looking at ethnic and cultural factors and how social networks and marketing might contribute to inequality. While there has been a growing body of research looking at the environment, we did not find much prevention research on pollution, climate change or the built environment as a determinant of health.

Health behaviours – Diet and physical activity represent almost three quarters of all UK NCD research by value (£24.6 M, Figure 3) although this research is mostly carried out within a healthcare setting. This was also reflected in the NPRI portfolio and is in line with the growing focus over the last few years on research into obesity prevention and treatment, with a diminishing focus on smoking and alcohol misuse.

Who is studied?

Research spend is slightly greater for research grants that undertook research on individuals (49%) than populations (42%)¹⁸ (Figure 4). This observation is discussed further in the next section. Where this was specified, the percentage of spend on research projects conducted in childhood was 22%, in adulthood it was 26%; and in older adults it was 13%. For 39% of the spend, no particular age-group was specified or all ages were considered together, for example when the study was taking a whole population approach.

¹⁶ Awards coded as 'HRCS Resources and Infrastructure' often support a range of research activities beyond prevention. For this reason, 78 awards, associated with a spend of £11.9 M, were excluded from the analysis. However it should be noted that this exclusion in particular understates the number of prevention awards made by NIHR, which invests significantly in infrastructure (20 awards, £2.5 M).

¹⁷ UKPRP seeks to build and support interdisciplinary research teams to enable change within complex adaptive systems to prevent NCDs.

¹⁸ In studies representing 9% of spend (£4.8 M) we could not discern who was being studied from the information provided in the abstract.

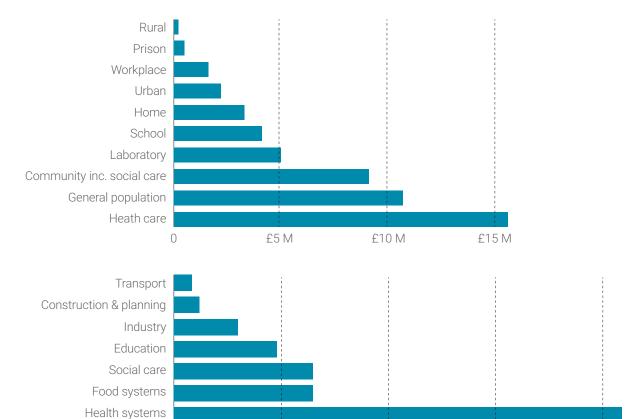
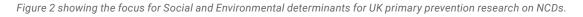
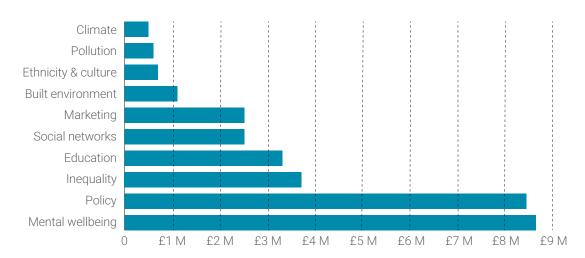


Figure 1 showing the focus for settings (above) and sectors (below) for UK primary prevention research on NCDs.



£5 M

0



£10 M

£15 M

£20 M

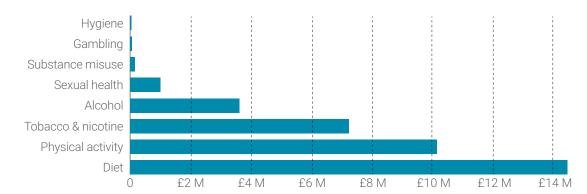
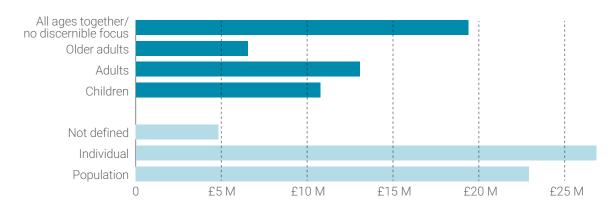


Figure 3 showing the focus for Health Behaviour determinants for UK primary prevention research on NCDs.

Figure 4 showing the focus for Population and Individual interventions for UK primary prevention research on NCDs.



Research on populations and individuals in the UK NCD dataset

The research portfolio on population-level research included studies without experimental manipulation but many of these were laying the groundwork for population-level interventions or seeking causal inference through modelling population data. We identified a few natural experiments, or examinations of the effects of policy interventions at the population-level as proposed by several UKPRP awards which are relevant to the population-level 'agenda'¹⁹. In figure 3A (p18) of the NPRI review it is reported that 37% of all its awards (by number) were for population-level interventions²⁰. In the UK NCD portfolio, the corresponding figure was 42% suggesting a small increase.

When we divided the NCD dataset by individual and population-level approaches and then linked these two datasets to the different social and environmental determinants, (see Tables 1 and 2, Annex 3) the overall spend on the different determinants was low and no major trends were seen, except for a slightly greater population emphasis on policy and ethnicity. Similarly, taking the group of 113 awards (around £10 M spend) on physical activity and dividing the awards between population-level and individual-level approaches to prevention, (Table 3, Annex 3) shows that a third of this research was conducted in the health care sector. A similar picture was obtained when conducting this sub-analysis with different health behaviours.

¹⁹ The number of awards that were specifically for population-level interventions in trials, including intervention development, was around 62% of the population-level awards.

²⁰ Including intervention development.

Research into secondary prevention

Coders were asked to identify awards based on a strict definition of secondary prevention as the earliest detection of asymptomatic disease. This type of research was found almost exclusively in HRCS RA4 'Detection, screening and diagnosis' and includes:

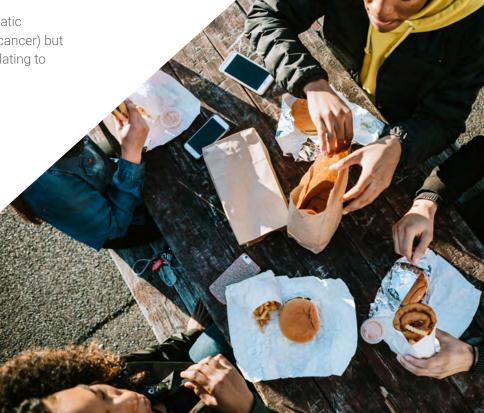
- Pre-clinical marker development for early detection, diagnosis and screening
- Development and evaluation of markers in humans
- Factors affecting screening uptake
- Population screening
- Infrastructure for early detection, diagnosis and screening

The RA4 dataset was dominated by studies on patients; those clearly showing symptoms of disease, for example where there was already a confirmed cancer diagnosis. The scope of the research in this RA was wide-ranging including the identification of markers (e.g. in blood, saliva or human breath) to diagnose and monitor the progression of disease (dementia was a particular focus) or using such markers to select patients for specific treatment or management (almost half of the research in RA4). Technology was a frequent focus, for example medical imaging.

Secondary prevention included systematic population-based screening (often for cancer) but also technological developments translating to resource-poor settings.

Research that sought to identify the earliest manifestations of disease in individuals or populations that were currently asymptomatic was comparatively uncommon. Only 349 awards met our criteria for secondary prevention, accounting for £42 M spend of which £10 M was for global health problems. The largest proportion of spend on secondary prevention was for the evaluation of potential diagnostics in humans, for example, developing markers for early signs of dementia in those with mild cognitive impairment. Studies developing new methods for population screening or the improvement of the uptake of existing screening methods, were identified but tended to be smaller awards.

Cancer was the most common disease for research in secondary prevention (Figure D, Annex 3), with ~40% of spend across all health categories and was well supported in terms of research into screening programmes for example. A comparison of spend in HRCS Health Categories against the World Health Organization's Disability Adjusted Life Years suggested that cancer received more than double the secondary prevention research funding relative to its burden on UK health care, while mental health receives less than a quarter.



Summary of findings

This analysis provides a snapshot of the UK primary prevention research portfolio in 2018 which we anticipate will be of interest to funders and policy-makers.

Where the money goes

UK funders spent £220 M²¹ in 2018 on awards that supported primary prevention research. According to the HRAF 2018 report, prevention research received 5.9%²² of total health research spend, up 3.4% in real terms since 2004. However, this portfolio review has shown that once the spend on infections research and assorted infrastructure is removed, the spend on research to prevent NCDs for UK health, is around a quarter of all research grants that support primary prevention research.

Analysing the secondary prevention portfolio highlighted that there was less focus on research into the early detection of disease compared to prognosis and disease stratification for patients who have already been referred to services based on evident symptoms. The data gives a funding value for primary and secondary prevention research of £262 M, which for UK health problems amounts to £132 M.

Within the UK NCD primary prevention research portfolio, a third of all research participants are in contact with services – for example to be referred to an individual focused prevention programme such as a stop-smoking service or a commercial weight loss provider. This is valuable for those individuals at higher risk and for those able to access services, but it does not address the wider determinants of disease and may have the potential to widen rather than narrow inequalities if access is unequal.

The NPRI report recommended that research needs to better understand the complex interaction between individual behaviour and risk factors, and social, cultural (as well as healthcare) and other determinants of health. This needs to be studied in the places where people spend most of their time (homes, workplaces and schools for example). Compared to the NPRI portfolio, there seems to have been modest progress by 2018.

There was a welcome focus on inequalities, but this research was often secondary data analysis of the consequences of interventions that had not been designed specifically to address health inequalities. There was a surprising absence of research into social factors like ethnicity and culture and while there was a growing body of research looking at the built environment, there was little prevention research that was explicitly based in the urban environment.

Research on population and individuals

Population-level interventions have the greatest potential to achieve sustained improvements in population health. Although individual-level interventions have a bigger effect size, their impact is often only on a small percentage of the population. The NPRI review called for a rebalance of individual-level and population-level interventions in 2015. UKPRP has taken up this challenge although interventions are now sought more frequently from complex systems modelling as well as trials.

Where it was possible to determine the approach from the abstract, we found that around half of the spend on grants in 2018 was to support research on populations, of which two thirds by number was for population-level interventions. The remainder were to change or monitor specific health behaviours using individual-level approaches, of which almost 80% by number were trials. This suggests that there has been some progress since the NPRI review which is likely to be attributable to the establishment of the NIHR Public Health Research

²¹ The UKHRA 18 report gives the total funding coded to RA3 – primary prevention – as £151 M, the differences in these values are explained on p19 of Annex 1. 22 Figure 3, p26 http://hrcsonline.net/wp-content/uploads/2020/01/UK-Health-Research-Analysis-2018-for-web-v1-28Jan2020.pdf

Programme and other initiatives which have encouraged such approaches to meet policy makers' needs. However, this report highlights an ongoing need for more funding for capacity building and direct research in this area, especially for research that takes account of the wider social and environmental determinants of health.

The different types of prevention research are not funded at equivalent levels

The review identified £273 M of investment in research on disease detection and diagnosis. However, it was very clear that only a small body of this research was aimed at early detection of disease in asymptomatic individuals. The much larger body of research funding was directed towards prognosis and disease stratification for patients already in the healthcare system who have evident symptoms.

In addition to the total level of prevention research, the balance within the prevention portfolio of research into different levels of prevention is a matter of concern. The Office for National Statistics UK Health Accounts (2018) state that preventive care, which covers activities designed to avoid diseases and risk factors (primary prevention) and the early detection of disease (secondary prevention), accounted for 5% of government healthcare expenditure²³. Similar challenges exist for research into different types of prevention.

What needs to change?

This report has identified some positive trends for prevention research. Firstly, investment in this area is rising. Secondly, funders (the health departments, UKRI and major charities) have provided ring-fenced funding for response mode and strategic investments. Thirdly, the portfolio showed that research was being directed at issues like inequalities, mental health, physical activity and diet. The report, however, highlights some concerns, most notably the paucity of research on prevention that deals with the complexity of health drivers in the community before contact with services and the need to strengthen research into population-level approaches including interventions.

The findings in this report came from a portfolio analysis based on research funding data from 2018. Future health research analyses will include the UKPRP awards which will increase the spend on research into NCD primary prevention by up to £10 M (roughly 20%) in 2021, if other funding remains equal. This report provides a baseline against which the impact of the UKPRP can be monitored.

UKPRP provides an opportunity to carry out research which is conceptually difficult by providing an unprecedented funding opportunity. It is likely that future funding initiatives will need to be of similar or greater scale.

In conclusion, this analysis suggest that UK funders still need to increase research into whole-system influences on behaviour and public health, to achieve a deeper understanding of the complex influences and interactions that will inform the development of more powerful population-level interventions.

The impact of the COVID-19 pandemic on prevention research

The research described in this report was active during 2018, with half of it still underway in 2019. The COVID-19 pandemic will have a currently unknown, impact on the future prevention research portfolio. The impact that risk factors such as obesity, ethnicity and social disadvantage have on COVID-19 mortality risk has re-emphasised the importance of research on addressing these major societal challenges.

Acknowledgements

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Dr Joe McNamara, former Head of Population Health at MRC, and Dr Catherine Moody, current Head

Dr Helen Walters, Consultant in Public Health Medicine/Consultant Advisor, NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)

Rachel Conner, Research Programmes Branch of the Science, Research and Evidence Directorate of the Department of Health & Social Care

In total 19 MRC staff joined the project which was led by Gavin Malloch. James Carter, who ran the UKHRA 18, led on the data analysis and his input was critical to delivering the project. We would like to thank the following for undertaking the coding and Quality Control analyses: Alexandra Winn, Elaine Boylan, Katherine Dunne, Catherine Moody, Sherie Wright, Sophie Liddle, Heather Cook, Charlotte Allen, Barbara Haenzi, Rachel Harris, Claire Henderson, Louise Armstrong, Emily Stephens, Mel Bundhoo and Rosie Timbrell.

Finally, Professor Nick Wareham, Joe McNamara, Catherine Moody and Katherine Dunne all provided guidance on the drafting of this paper.



Annexes

Annex 1

National Prevention Research Portfolio

Methods

A1.1 Primary data source and the UK Health Research Analyses 2018

Since the first Health Research Analysis conducted in 2006, the UK has established a quadrennial process for analysing the national health research portfolio using the Health Research Classification System (HRCS). The latest analysis in this series, published in January 2020, was carried out using data from awards beginning or active in the 2018 calendar year (UKHRA 18). This dataset was an excellent starting point for our analysis of prevention because, as described below, one of the HRCS codes is primary prevention.

The HRCS¹ classifies research based on a reading² of the proposal abstracts according to:

- Eight 'Research Activities (RAs), which define the research approach, for example, underpinning research, early detection and screening, treatment; and health service management. Each of the RAs has a number³ of sub-codes, 3.1, 3.2 etc which were not useful for our primary prevention analysis except 3.4 which is vaccine development and vaccination research such as community-based vaccine trials.
- Twenty-one 'Health Categories', which encompass all diseases, conditions and areas of health, for example: 'cardiovascular', 'neurological' and 'musculoskeletal'; and includes one called 'Generic Health Relevance' where four or more of the other twenty Health Categories were applicable.

A1.2 Prevention definitions and fit to HRCS terminology

We defined the types of prevention research as follows.

- **Primary prevention** research aims to develop or evaluate interventions (including strategies and policies) to maintain human health and prevent illness or injury from arising in the first place.
- **Secondary prevention** requires the earliest possible detection of disease which is asymptomatic, to be able to halt progress or prevent more severe problems developing.
- **Tertiary prevention** research, which addresses the prevention of disease progression and further multimorbidity, was out of our scope.

For primary prevention, HRCS Research Activity 3 (RA3) is 'Prevention of disease and conditions, and promotion of well-being'; this category covers 'research aimed at the primary prevention of disease, conditions or ill health, or promotion of well-being'. As this encompassed the definition of primary prevention used in our analysis, this was an excellent starting point for identifying all of the funded research in this area.

¹ http://www.ukcrc.org/research-coordination/health-research-classification-system/

² Increasingly these are machine-read but the prevention grants were manually coded.

³ Usually five.

For secondary prevention HRCS Research Activity 4 (RA4) 'Detection, screening and diagnosis' contained the research we wished to identify but also other aspects of research that we needed to exclude. The different approaches to coding primary and identifying secondary prevention are covered in sections A1.3 and A1.4 below.

A1.3 Coding the primary prevention portfolio

Coding of individual awards was done manually in a blinded fashion by a team of coders with a scientific background. Derivation of the dataset for coding and the coding structure is described below.

Derivation of dataset for coding

The project started with a subset of the UKHRA 18 data where at least one RA3 code had been applied. We then deleted thirteen awards that coders agreed were not prevention research. We were left with a dataset amounting to £179 M spend (see definition of spend used in this report below) in 2018, attributable to 49 of the 146 organisations participating in UKHRA 18. We also added awards made to institutions overseas from 10 organisations excluded from the UKHRA 18 report. This is because we were intending to show the fullest possible extent of UK funder support for prevention research wherever the money went. The result was a portfolio worth £220 M.

This is a different figure for primary prevention than reported in the UKHRA 18 report (£151 M), not only because some overseas awards were included, but also because UKHRA 18 only reported the spend attributable to prevention in each grant (that is the percentage of each award's spend that was attributable to RA3), to produce the £151 M value. We used the whole award value as it would have been impossible to say what percentage of each of the new codes were only applicable to the prevention element of the proposal. We know, however, that any award for prevention research is coded as 76% prevention on average, therefore, by and large, other research activities are a relatively minor part of the 'average' prevention award.

Coding methods

A coding structure for primary prevention research was approved by the MRC Population Health Sciences Group in November 2019. A key objective was to enable a rich description of primary prevention research in terms of the wider social and environmental determinants of health and NCDs that encompasses the focus for UKPRP. However, we also wanted to include other research activities properly identified as primary prevention, particularly the prevention of infectious diseases, so we used the new codes alongside the existing HRCS codes to identify such research.

To ensure as much inter-coder consistency as possible during the main coding, a classification guidance document was created and a coder workshop was held to introduce the aims of the analysis, the classification structure; and to provide the opportunity for test coding of ~10 records per person. From that initial feedback, several new descriptors were added to the structure and the guidance was updated. No further changes were made to the coding structure or guidance (Annex 2).

Quality control

To test whether coding practice was consistent across different coders, we conducted a Quality Control (QC) analysis of intercoder variability on 10% of the dataset. This was a double-blind test, where coding from two independent coders was performed, then unmasked. A tertiary 'decision-making' process was conducted by the project leads in coordination with the original coders in the case of obvious discrepancies⁴ – this happened on ad-hoc basis (i.e. when and if spotted) in the main coding exercise as well. We established that the coding was 69% precise matching and 81% partial matching – the limits specified for HRCS are >70% precise matching and >80% partial matching).

Notes on data analysis including caveats

- As reasoned on p19 we chose to use the full award value of grants with a prevention code to allow interrogation of the data between headings. This allowed us, for example, to assign a value to the amount of research conducted in Settings (e.g. School) that is Health Behaviour (e.g. Diet).
- As all data were sourced from the UKHRA 18, the spend data presented in this report is presented in the same way as in the UKHRA 18 to allow a consistent approach across multiple funders and funding mechanisms. The spend data presented in the UKHRA series represent 'annualised spend', that is the total value of the award divided by how many years it was awarded for.
- We chose to distribute the value of the award evenly across however many descriptors were applied within a given heading (e.g. Settings). For example, an award of £500,000 given two descriptors (Home and School) for Settings would present a value of £250,000 for each descriptor. The five headings are independent therefore the values would be five times the total if simply summed. In practice, the majority of awards had only one code assigned and 81% of awards had three or less codes applied across all five headings⁵.

A1.4 identifying the secondary prevention portfolio

Coding of individual awards was done manually in a blinded fashion by a team of coders with a scientific background. Derivation of the dataset for coding and the coding methodology is described below.

Derivation of dataset for coding

We anticipated that secondary prevention would all be found in the HRCS RA4 'Detection, screening and diagnosis' category. However, to ensure that we were not missing a considerable amount of secondary prevention projects in other Research Activities in the HRAF 18 dataset, we carried out spot checks of grant records in two other Research Activities, RA6 (Evaluation of Treatments); and RA7 (Management of Diseases and Conditions). We searched the titles and abstracts in these datasets using the search terms 'early detection', 'secondary prevention', 'diagnosis', 'screening' and 'asymptomatic'.

⁴ This was primarily to address obvious coding error rather than coding disagreements and coders agreed not to change their initial decisions unless they had made a mistake.

⁵ Settings and Social/Environmental determinants were the headings most likely to have three codes applied (13% and 6% of awards respectively) but 31% of awards were single coded in all five headings. In contrast less than 4% of awards had more than 10 codes in total (on average two coders per heading).

As expected, this picked up many false positives but there was also some research that genuinely concerned detection and diagnosis. However when we looked at these records, we found that they were already co-coded with an RA4 sub-code except for two cases, which means that they were already taken into account. The exceptions were both where we would have coded the records differently. We concluded that estimating the amount of secondary prevention in the RA4 subset of the HRAF 18 data, was a valid way of estimating the amount of secondary prevention across the complete span of HRAF 18 data.

Coding methods

In the case of secondary prevention, coders only had to decide whether the proposal was in the category of secondary prevention as defined on p18. This was done on all 2,813 records in the RA4 dataset using additional guidance that we describe in Annex 2, p31. We were then able to use existing HRCS coding to divide the research that we had defined as secondary prevention into subcategories such as preclinical marker development, testing of markers in patients; and population screening.

Quality control

In addition to the main project to identify secondary prevention in the entire RA4 dataset, we ran an exercise where coders duplicated decisions in blinded pairs on 10% of the RA4 dataset. This resulted in an inter-coder agreement of 69%, which is below the 80% standard for HRCS. Coders subsequently looked at the secondary prevention classifications alongside the level of information provided and concluded that the disputed decisions arose from abstracts that were ambiguous or lacked sufficient detail.

Annex 2

National Prevention Research Portfolio

Prevention Coding Project:

Coder guidance and descriptors

This document provided the coders with the rationale for the primary and secondary prevention coding exercises and is the final guidance issued to the coders on how to apply the codes for primary prevention. The coding descriptions for primary prevention are based on scientific guidance from MRC's Population Health Sciences Group, and were updated following issues that challenged the coders in a test run, and which the coders agreed would have impacted on QC without further clarification.

Introduction

The 'prevention coding project' aims to further classify the whole UK Health Research Analysis 2018 (UKHRA 18) portfolio of primary and secondary prevention, which used the Health Research Classification System (HRCS) to categorise awards. The coding you will undertake uses a new classification system, not HCRS.

The immediate objective is to provide a landscape analysis of current prevention funding. This could inform the next round of UK Prevention Research Partnership (UKPRP) investments (valued at £20 M: February 2020) and provide a baseline for monitoring the change in the UK funding in prevention generally as well as the impact of UKPRP awards.

There are two phases in the project.

- 1. To provide a more detailed classification of primary prevention-relevant awards than is possible with any existing classification structure.
- 2. To identify secondary prevention in an 'enriched' dataset taken from the UKHRA 18. Once identified, secondary prevention needs no further coding.

The classification processes

The exercise uses an HRCS sample of prevention-relevant awards. HRCS is an exemplar of a universally acceptable approach to coding and classification, however it was not intended to describe the richness of UK primary prevention research. Therefore, a bespoke prevention classification structure (Figure 1, p4) was designed for primary prevention. Not all HRCS codes may be 100% compatible with this new classification structure.

Key definitions

Prevention aims to stop people from getting diseases in the first place or to stop a disease from getting worse. It is usually subdivided into primary, secondary and tertiary prevention, which are described below.

Primary prevention

Primary prevention research aims to develop or evaluate interventions (including strategies and policies) to maintain human health and prevent illness or injury from arising in the first place.

Primary prevention measures include vaccinations, altering risky behaviours (poor eating habits, tobacco use), and banning substances known to be associated with a disease or a health condition and can act at the individual or population level. In HRCS primary prevention is classified by Research Activity Group 3 – "Prevention of disease and conditions, and promotion of well-being".

Secondary prevention

Secondary prevention requires the earliest possible detection of disease which is asymptomatic, to be able to halt progress or prevent more severe problems developing.

Secondary prevention research is not itself just diagnosis, but the treatment that follows. However, most definitions of secondary prevention just refer to early diagnosis and screening tests (e.g. mammograms to detect breast cancer) because it is assumed that there would be immediate treatment to prevent the disease progressing.

At the time of this exercise, HRCS defines secondary prevention as the evaluation of strategies to prevent previous conditions that are currently absent, from reoccurring. This is not the definition we are using.

Tertiary prevention

Tertiary prevention research, which addresses the prevention of disease progression and further multimorbidity, is out of our scope.

Tertiary prevention research is the management of a long-term, ongoing disease to prevent further complications arising. Examples of tertiary prevention include cardiac or stroke rehabilitation programmes which will often include lifestyle changes.

The primary prevention coding structure Terms and guidance

General approach to coding

The strategic aim of this coding is to provide granular detail about the target population and condition alongside other key factors which influence prevention research approaches and outcomes. However, as with all grant coding, **the main objective** is to describe the research taking place during the lifetime of the award and not the background or future potential downstream applications of the research (often referred to in the first or last sentence of the abstract).

In this exercise, the records you will be coding have already been classified as Primary Prevention by HRCS, so you will be re-coding to provide additional richness. There is no need to allocate a percentage for each descriptor as in HRCS. The analysis will allocate multiple codes as an equal proportion of the total award value, as although there are five overlapping headings, this is the relative – not actual amount – spent on these awards within a category.

Filling in the spreadsheet

- Add your chosen descriptors to the relevant cell and separate multiple descriptors in the same cell by semi-colons.
- Apply the whole word of the descriptor with correct spelling. DO NOT use the number sub-headings (e.g. 2.1, 5.6 etc) in the guidance
- It is important to use the minimum number of codes to reflect the focus of the research and in any event do not apply more than four without good reason.

Explanations of coding hierarachy for primary prevention

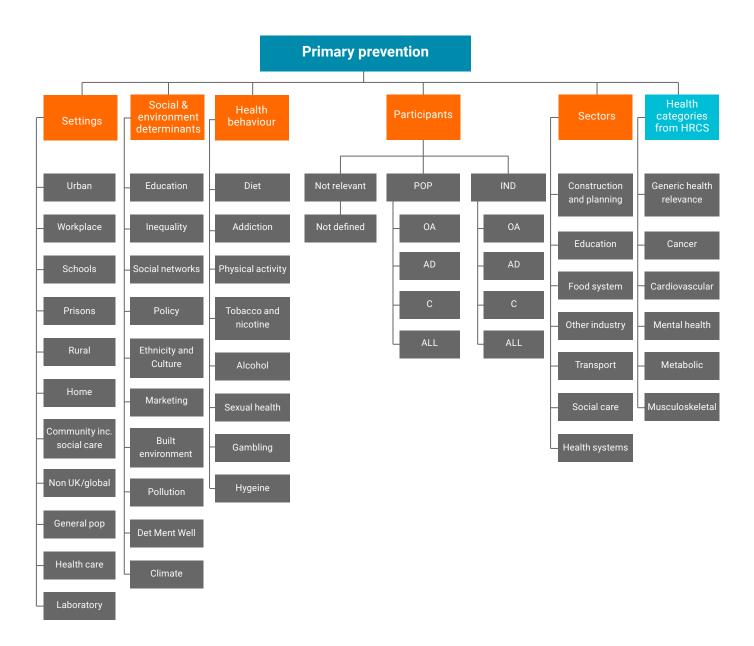
The coding structure is shown in Figure 1 on page 25. It is divided into:

- 1. **Headings** *shown in the orange boxes*.

 These represent the five key themes which require additional granular detail when assessing prevention research.
- Descriptors shown in the grey boxes.
 These represent the most common categories into which each theme is subdivided. They are not meant as an exhaustive list of all possible descriptors.

The aim of the structure is to provide a straightforward approach to categorisation, so each **Heading** and **Descriptor** should be relatively self-explanatory from the title. However, in this section we provide more detailed descriptions of the **Headings** and specific guidance on each **Descriptor** as well, to ensure clarity and consistency across all coding and coders.

Figure 1: Primary prevention coding structure.



Heading and descriptors

The headings are the orange boxes in Figure 1 (blue for health categories) and the descriptors are the grey boxes underneath. Your task is to allocate descriptors under each heading. The information provided by HRCS (under the blue box) concerns health categories. In this section we provide the scope of the orange headings and specific guidance on each descriptor as well, to ensure clarity and consistency across the coding. Health Categories are explained in the HRCS website: https://hrcsonline.net/health-categories

Please note that the grants you are coding are also coded in HRCS, so we are not duplicating those codes. HRCS includes a code for infrastructure and adds a percentage value of the amount of primary prevention in the award. So, some of the awards that contain basic research may have been co-coded by HRCS to recognise that, for example one of the RA1 codes with RA3.

1. SETTINGS

The setting is the place where the field research is being carried out. Only one of the descriptors is geographical (non-UK).

1.1 URBAN

Studies that take place in any town, city or large residential development. It is not applied to another setting (e.g. a GP surgery) just because it was sited in an urban area.

1.2 WORKPLACE

Where people work/are employed. The Workplace setting for teachers is Schools and so studies of teachers should be co-coded as Workplace and Schools.

1.3 SCHOOLS

Infrastructure to support primary and secondary education both state and private. Not further education colleges and universities. Research using secondary analysis of data gathered in schools would not count but the Education Sector descriptor should be applied.

1.4 PRISONS

Any penal institute where felons are incarcerated including young offenders' institutions. For prison staff the setting could be co-coded Workplace and Prisons.

1.5 RURAL

Research in rural areas such as agricultural areas, where access to infrastructure and resources may be more challenging. Similar to urban, this is to be applied only when the rural setting is specifically referenced and relevant.

1.6 HOME

Studies within a residence such as the monitoring of human behaviour within the home. Includes care and residential homes but not prisons.

1.7 COMMUNITY INCLUDING SOCIAL CARE

This setting was applied to any non-NHS setting that was geographically local and accessed mostly by the local community. It was also applied to social care settings and community-based interventions.

1.8 NON-UK/GLOBAL

This is applied to studies based outside the UK, or based in the UK but studying health isues relevant to other countries, most often in sub-Saharan Africa, South East Asia and South America.

1.9 GENERAL POPULATION

This descriptor is a default for where the setting is only distinguished geographically either as a country or a region.

1.10 HEALTH CARE

This descriptor is for prevention studies (usually for individual behaviour change) in the health service.

1.11 LABORATORY

For research that takes place in the laboratory or office, this is a setting to cover underpining/basic research. As all research has some element of laboratory or office-based research, coders are asked to apply this descriptor to those studies that are primarily lab or office-based including studies that are almost entirely analysis of data.

2. SOCIAL AND ENVIRONMENTAL DETERMINANTS

These are the 'determinants' of health in the environment (physical or social) that impact on health that are being studied in the research. They are different to health-related behaviours, which are also 'determinants'.

2.1 EDUCATION

This was applied to research looking into the effects of education and/or literacy/numeracy affecting health or access to social care and health care.

2.2 INEQUALITY

This is a widely used and generic term for any disparity in health status. It is applied to any research on deprivation or where there was inequality of opportunity that affects health e.g. postcode prescribing.

2.3 SOCIAL NETWORKS

This descriptor is to be applied broadly to any social networks that might include peers, friends, work colleagues, family, most often joined by social media platforms where health messaging are circulating. It should be co-coded with 'Det Ment Well' when the research covers cyberbullying linked to social media but not when a researcher is simply testing an app.

2.4 POLICY

This descriptor should be applied to the evaluation of a specific policy but also when the impact of health or public health policy is being included in the study. It should not be applied when the applicant(s) propose that the research would change policy, there has to be some consideration of existing policy.

2.5 ETHNICITY AND CULTURE

This is applied to research looking at categories of people who identify with each other, usually based on a presumed common genealogy, history, culture or nation, but also to faith and religious beliefs.

2.6 MARKETING

This includes 'traditional' advertising (e.g. newspapers, billboards, TV/ radio) and any form of social marketing through social media and can be co-coded with social networks if the marketing 'messages' are delivered through a social network.

2.7 BUILT ENVIRONMENT

Factors relating to physical environment associated with human built structures and consideration of the interconnecting space between elements of the built environment. It includes design of the built environment.

2.8 POLLUTION

This descriptor concers research where the measurement and presence of environmental pollutants is suspected to be involved in the cause, risk or development of disease. Also includes radiation and pollution chemicals, such as pesticides, but also noise and light pollution.

2.9 DETERMINANTS OF MENTAL WELLBEING (DET MENT WELL)

This descriptor concerns the panoply of determinants being investigated when research is looking at factors that affect mental wellbeing like violence, abuse, stress, anxiety, loneliness and social isolation.

2.10 CLIMATE

This includes looking at the consequences of climate change, for example, research looking at flooding and heatwaves, and impacts on air quality. It should not be applied when climatic factors (e.g. sunlight) are being studied when climate, or climate change, is not a factor.

3. HEALTH BEHAVIOURS

These are behaviours associated with risk of disease or which mitigate risk/promote well-being, that are commonly targeted by primary prevention research. In principle, research participants should be able to change these behaviours, e.g. give up smoking or take more exercise.

3.1 DIET

Covers food and non-alcoholic drinks and approaches to reduce obesity by changes in diet, and/or aspects of the environment impacting on diet. It is not applied when the research concerned the basic science of food formulation.

3.2 ADDICTION

This descriptor concerns any addictive behaviour excluding gambling. It is applied when the study concerned alcoholics, heavy smokers or people addicted to food, even though there are separate headings for these determinants.

3.3 PHYSICAL ACTIVITY

This includes any approach to improving general health and well-being through increased physical activity such as cycling, sport, walking; physiotherapy/ exercise regimes, or aspects of the

environment impacting on physical activity such as environmental design. It should also be applied to investigations of the effect of physical activity on health behaviours, approaches to reducing obesity as this is a major risk factor for disease. It must also be applied to a study addressing sedentary behaviour.

3.4 TOBACCO AND NICOTINE

This covers all aspects of tobacco and nicotine use including 'traditional' cigarette smoking and passive/ second hand tobacco smoke exposure. It also includes vaping and taking snuff; and chewing tobacco, nicotine patches and gum. Includes research looking at legislation on smoking and smoking policy such as fiscal measures like taxation. It should be co-coded with addiction when the study concerns heavy smokers.

3.5 ALCOHOL

Any consumption of alcohol irrespective of whether it is hazardous

3.6 SEXUAL HEALTH

This descriptor should be applied to any state of physical, mental and social well-being that is studied in relation to sexuality and not just communicable disease related to sexual activity. Studies of teenage pregnancies and sexual violence should be coded here.

3.7 GAMBLING

This descriptor concerns gambling including online gambling. It is applied even when the behaviour is not addictive.

3.8 HYGEINE

This is applied to any study where preventing disease through better hygiene is to be studied.

4. PARTICIPANTS

There are ten descriptors which cover populations/individuals and lifecourse stage as follows:

| Not defined | defined Age not stated nor whether population or individuals | |
|--------------|--|--|
| POP C | Population Child (0-18) | |
| POP AD | Population Adults (18 – 65) | |
| POP OA | Population Older Adults (over 65) | |
| POP ALL | General Population Studies | |
| IND C | Individual Child (0-18) | |
| IND A | Individual Adult (18 -65) | |
| IND OA | Individual Older Adult (over 65) | |
| IND ALL | No distinction in age defined | |
| Not relevant | When there were no human participants in the research | |

POPULATION (POP) or INDIVIDUAL (IND)

Populations are not just nations, but also smaller groups such as communities, employees, professions/a workforce, ethnic groups, disabled persons, prisoners, pregnant women etc; when being treated together. POP is applied to high-risk groups when the members of that group were being treated as a population.

A response to a population-level intervention is often mandated or involuntary. Population-level interventions include education campaigns and legislative and fiscal changes – a ban in smoking in public spaces is an example of this as is water fluoridation where (apart from purchasing bottled water) there is no choice on whether or not to drink fluoridated tap water.

IND is applied when single humans are being studied or receiving an intervention as individuals distinct from a group. All vaccination studies should be coded IND as individuals are vaccinated irrespective of whether the objective is to vaccinate everybody in the population. Any social media, legislative or education campaign, about vaccination should be coded POP.

Note on not defined for participants

The intended use of this descriptor is when the coder had no alternative for any other descriptor.

LIFE-COURSE STAGES (C, AD and OA)

The human life-course has been segmented by legal/societal definitions and not life course stages like adolescence etc (see note below) because of the variation in these terms. Therefore:

- Childhood (C) up to but not including age 18.
- Adulthood (AD) is achieved at the age of majority in the UK, which is 18. AD is therefore 18 and up to 65.
- The Older Adult (OA) category should be applied to studies of people having reached or exceeded the age of 65.

5. SECTORS

This heading concerns the public services and elements of commerce and industry relevant to the research when they are mentioned as stakeholders or collaborators but are not the research setting. These sectors are usually broad and have interconnected elements, for example, the food system.

5.1 CONSTRUCTION AND PLANNING

This is applied to any development that is being built or at the planning/design stage including, but not exclusively, house building. It also refers to the broader environment when health considerations are pertinent to planning and design, such as in the provision of recreational space (that is often called blue or green space), facilities for physical activity or infrastructure providing opportunities for the promotion of wellbeing.

5.2 EDUCATION

To be used when studies involve some aspect of the education system but where the setting is not necessarily schools, for example when researchers are using educational data. Education is also a determinant under 'Social and environmental factors'.

5.3 FOOD SYSTEM

This category is for any aspects of the system that grows, processes, distributes and/or sells food. Could be linked to Diet, Marketing, (in terms of food advertising), or Education.

5.4 OTHER INDUSTRY

'Other Industry' refers to any aspect of the private sector providing services and is not to be used exclusively for manufacture.

5.5 TRANSPORT

Applied to all forms of transport not requiring physical exertion and elements of the transport system. Includes access to transport. It does not apply to so called 'active transport' for example cycling, unless this is part of a broader perspective of the 'transport system'. This descriptor might often be co-coded with 'physical activity' and/or with 'construction and planning'.

5.6 SOCIAL CARE

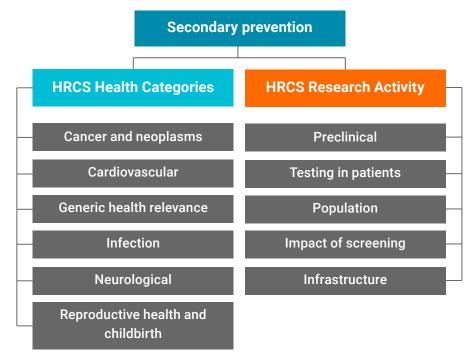
This is aplied when an apect of the social care system was relevant to the research but was not the setting for the research.

5.7 HEALTH SYSTEMS

This is aplied when health care systems are relevant to the research but was not the setting for the research.

The secondary prevention coding structure Terms and guidance

Figure 2: The secondary prevention coding framework.



Note: Not all the Health Categories are shown.

The following guidance was provided to coders

The definition of secondary prevention is defined below earlier in this guidance but requires the **earliest possible detection of disease**, which is usually asymptomatic, so the disease is not apparent to the sufferer or a clinician based on current knowledge.

Secondary prevention is not itself just diagnosis, but the treatment that follows. However, the research that underpins secondary prevention is about early diagnosis and screening tests (e.g. mammograms to detect breast cancer) because it is assumed that there would be treatment (not supported by the grant) to prevent the disease progressing if a disease is detected. The treatment could be a long way off – i.e. at some future point if the line of research continues to be fruitful, so early detection research can also be laboratory based underpinning work that will not lead to immediate treatment after the grant has finished. For this analysis we are including such grants.

The real distinction is that the research must be looking at the first presentation of the disease and not developing biomarkers of prognosis or guiding later decision-making in disease management. Nor is it preventing symptoms that arise due to the disease progression. Most of the biomarker research in this dataset is for prognosis and disease management not the **first** detection when disease is not obvious.

What you need to do

Review the grant abstracts provided in an excel sheet which each have a unique identifier code. Then say in the appropriate column whether you agree (Y) or do not agree (N) that they meet the definition provided for secondary prevention.

Please include

- any study aiming to improve access to treatment, reduce health care costs, increase effectiveness for diagnosis and reduce delay of undiagnosed disease, for example increased diagnostic capacity or uptake of screening programmes
- imaging or detection techniques in the methodology, where the primary aim of the research is to diagnose the disease for the first time.

We have interpreted early detection as earliest detection since in some cases we found studies identifying disease that had been present for many years, for example cancer can be present undetected years before advanced metastatic presentation.

Please exclude

studies of prognosis and decision making which includes most precision medicine which are often about disease stratification to help clinicians evaluate a patient's individual disease risks and their optimal therapeutic pathway, and management development of lab techniques and tools for basic research.

Notes on research activities1

- 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 includes biological and psychological markers, diagnostic and monitoring devices, imaging, scanning, predictive and diagnostic tests; and development and characterisation of models.
- Testing and evaluation of markers and technologies in humans for use in detection, diagnosis, prediction, prognosis and monitoring in clinical, community or applied settings includes 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.
- Studies investigating population screening programmes includes feasibility studies, pilot studies and trials; evaluation of effectiveness, benefits and economic evaluation; and impact on health services and policy issues.
- Studies investigating impact of screening and factors affecting uptake includes attitudes and beliefs including cultural and religious practices, issues relating to gender, age and ethnicity; and genetic counselling and decision making.

¹ Adapted from the HRCS Research Activity guidance for codes 4.1 through 4.4 – see https://hrcsonline.net/research-activities/4-detection-screening-and-diagnosis/

Annex 3

National Prevention Research Portfolio

Supplementary data

This annex contains additional data in graphic or tabular form which are referenced, but not included in the main report of the national grant portfolio in 2018. The headings used in the main report and some of the data reported are duplicated to help orientate the reader.

Summary

An analysis of the primary prevention portfolio of the major UK health research funders was undertaken to see how funds were being deployed to support prevention research. We used the 2018 UK Health Research Analysis (UKHRA 18)¹. To the UKHRA 18 dataset, we applied a new coding system for detailed analysis of research that includes, for example, the social and environmental determinants of health.

Main findings

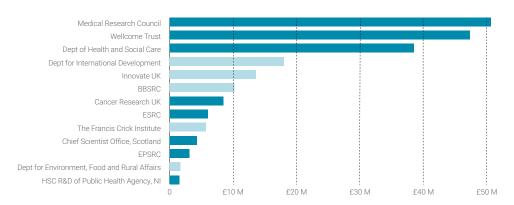
Primary prevention across the whole portfolio

The project identified 1156 UK primary prevention awards with a total annualised spend of £220 M². This includes both global and UK-based prevention research.

Who are the UK funders of primary prevention?

There are 146 participating funding organisations in the UKHRA 18 but only 49 of those support primary prevention research (Figure A).

Figure A: The UK funders of primary prevention research.



Note: The bar chart shows only the top 13 supporters of primary prevention research. Solid bars are UKPRP partners. Although the Francis Crick Institute is not a funder, there has been no consensus amongst the funding partners on the attribution, so the funders agreed to opt for including Crick as a 'funder'. There is narrative on this in Annex 1 In the UKHRA 18 report.

¹ https://hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2018/

² The UKHRA report gives the total funding coded to RA3 – primary prevention – for the UK a value of £151 M. The value of £220 M we use is the total 2018 annualised spend value of all of RA3* (i.e. including elements co-coded outwith RA3) including awards made directly to organisations overseas that were made by a UK funder.

^{*} We excluded a few records on preventing diseases in non-human animals where this was not relevant to human health.

What proportion of the UK spend is on research overseas or relevant to overseas?

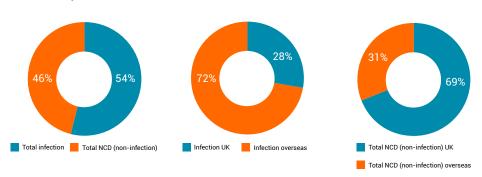
Just over half (53%, £116 M) of all primary prevention research is either awarded to overseas institutions or awarded to institutions in the UK but where the research is targeted to international health problems and/or performed overseas, usually in LMICs. Mostly this overseas research concerns infection, but almost a third also addresses NCDs (Figure Bi).

What is the spend on infection research?

Half of the overall spend (£119 M), overlapping with the non-UK/global figure, was attributed to infectious diseases, which was ahead of any other specific health category as a target for primary prevention research (Figure Bii). Vaccination research is a prominent part of the primary prevention research portfolio (£72 M, 33% of total) and the funding was mostly for research to develop vaccines protecting people against infectious diseases and antimicrobial resistance. It was relevant to both domestic and global health.

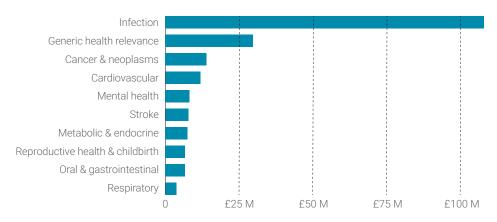
Figure Bi. Infection and non-infection prevention research overall and in the UK and overseas.

Awards £m spend in 2018



Note: We assume that non-infection is a rough approximation for NCD research and prevention of accidents, but because we later develop a comparator dataset for UKPRP; which we call a UK NCD research portfolio (see section 5.3) then we are calling this non-infection for clarity.

Figure Bii. 2018 spend weighted by HRCS Health Category (top 10).



Note: HRCS Health Categories describe the disease/condition/physiological system that is the focus of a research award. Generic Health Relevance is used when the research is applicable to all areas of health/wellbeing, non-specific research; or research with more than five health categories applicable.

What are the settings, sectors and determinants that are studied and who is studied?

This section refers to the application of the new primary prevention classification structure to the whole primary prevention portfolio.

The areas which the new coding system was designed to evaluate were not well supported across the whole portfolio, reflecting that many studies did not define a setting, social/environmental context; or a health behaviour (Figures Ci to Civ).

Figure Ci and Cii showing the focus for settings (top) and sectors (below) for primary prevention research across the whole portfolio.

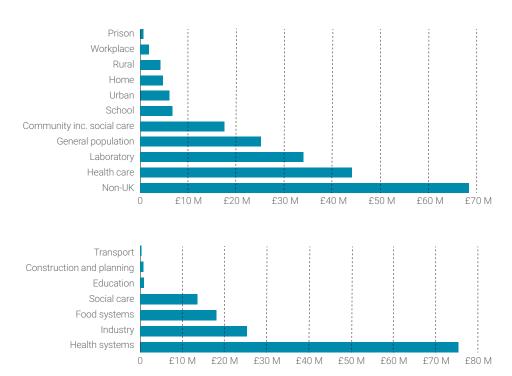


Figure Ciii showing the focus for social and environmental determinants for primary prevention research across the whole portfolio.

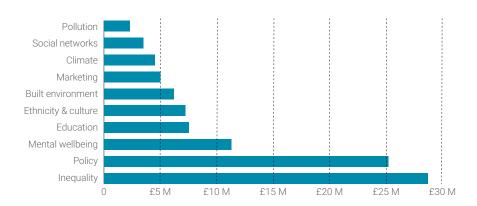
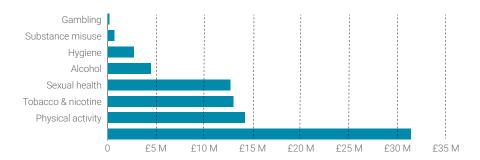
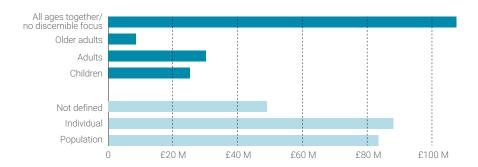


Figure Civ showing the focus for health behaviour determinants for primary prevention research across the whole portfolio.



Where discernible, there appears to be slightly less research targeting whole populations (Figure Cv) versus studies at the individual level. Studies on the older population are less prevalent than other age groups. However, the age of the study participants and the approach to populations was frequently not clear from the abstract.

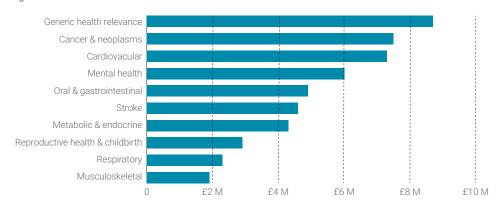
Figure Cv showing the participants (where discernible) in primary prevention research.



Primary prevention addressing NCDs in the UK

Given the preponderance of research on infection studies and research addressing global health issues, we developed a data subset of 482 awards. This UK-NCD portfolio equated to a spend of £54 M and accounted for 25% of the value and 42% of the number of awards in the primary prevention portfolio. In contrast to the full portfolio, the largest single Health Category (£8.7 M, 16% of spend) of the research now addresses 'generic health relevance' (see Figure D).

Figure D: Health focus of research on NCDs in the UK.



Note: UKPRP awards were made in 2019 and are therefore not included in the analysis.

When we divided the NCD dataset by individual and population-level approaches and then linked these two datasets to the different social and environmental determinants, (see Tables 1 and 2) the overall spend on the different determinants was low and no major trends were seen, except for a slightly greater population emphasis on policy, inequalities and ethnicity.

Table 1: Population versus individual level approaches addressing different social and environmental determinants in the UK NCD portfolio of primary prevention.

| Social and environmental determinants* | Participants | Spend in 2018 (£M) |
|--|--------------|-----------------------|
| Det Ment well | Individual | 5.1 |
| | Population | 3.4 |
| Policy | Individual | 2.5 |
| | Population | 5.6 |
| Marketing | Individual | 1.2 |
| | Population | 1.0 |
| Social networks | Individual | 1.6 |
| | Population | 1.0 |
| Ethnicity and culture | Individual | 0.2 |
| | Population | 0.4 |
| Marketing | Individual | 1.2 |
| | Population | 0.5 |

^{*}not all determinants shown

Table 2 : Population versus individual level approaches addressing health behaviours in the UK NCD portfolio of primary prevention.

| Health behaviours* | Participants | Spend in 2018 (£M) |
|----------------------|--------------|-----------------------|
| Smoking and nicotine | Individual | 4.3 |
| | Population | 2.9 |
| Diet | Individual | 5.9 |
| | Population | 6.0 |
| Physical behavior | Individual | 5.8 |
| | Population | 4.1 |

^{*} not all health behaviours shown

Similarly, taking the group of 113 awards (almost £10 M spend) on the most prevalent health behaviour to be studied (physical activity) and dividing the awards population-level versus individual-level approaches (Table 3), did not show anything significant other than that around a third of this research still has the health sector as the setting for the research.

Table 3: Population versus individual level approaches addressing physical activity by research setting.

| Setting where health behaviour is physical activity only* | Participants | Spend in 2018 (£M) |
|---|--------------|-----------------------|
| General population | Individual | 0.5 |
| | Population | 1.0 |
| Health | Individual | 2.0 |
| | Population | 0.9 |
| Community | Individual | 1.5 |
| | Population | 0.5 |
| School | Individual | 0.7 |
| | Population | 0.5 |
| Urban | Individual | 0.1 |
| | Population | 0.4 |
| Workplace | Individual | 0.4 |
| | Population | 0.2 |

^{*}not all settings shown

Secondary Prevention

Coders were asked to identify awards based on a strict definition of secondary prevention as the earliest detection of asymptomatic disease. This type of research was found almost exclusively in HRCS RA4 'Detection, screening and diagnosis' and includes:

- Pre-clinical marker development for early detection, diagnosis and screening
- Development and evaluation of markers in humans
- Factors affecting screening uptake
- Population screening
- Infrastructure for early detection, diagnosis and screening

The RA4 dataset was dominated by studies on patients; those clearly showing symptoms of disease, for example where there was already a confirmed cancer diagnosis. The scope of the research in this RA was wide-ranging including the identification of markers (e.g. in blood, saliva or human breath) to diagnose and monitor the progression of disease (dementia was a particular focus) or using such markers to select patients for specific treatment or management (almost half of the research in RA4). Technology was a frequent focus, for example medical imaging.

Secondary prevention included systematic population-based screening (often for cancer) but also technological developments translating to resource-poor settings.

Only 349 awards met our criteria for secondary prevention, accounting for £43 M spend of which £10 M was for global health problems. Cancer is the most common disease for research in secondary prevention (see Figure D), with $\sim\!40\%$ of spend across all health categories, and is well supported in terms of screening programmes for example.

Figure D: Secondary prevention research: 2018 spend weighted by HRCS Health Category (top 10).

