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# Review of diversity and inclusion literature and an evaluation of methodologies and metrics relating to health research

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# Executive summary

Over the past decade, the need for greater diversity and inclusion across research systems and institutions has received greater emphasis from policymakers, funders, universities, learned societies and wider stakeholders. In this context, the impetus being placed on diversity and inclusion in Wellcome Trust's latest strategy is timely and important.<sup>1</sup>

In support of this strategy, the primary aim of this project is to undertake a systematic and critical review of the evidence base for a positive relationship between a diverse and inclusive health research community, and the qualities and impacts of the research they undertake. The review draws on evidence from across the research system, with a primary focus on health and biomedical research. It also draws on related literatures on diversity, inclusion, equality and coproduction across health systems and services, and organisational diversity and inclusion.

A second aim of the project is to evaluate the efficacy of the metrics used to measure diversity, inclusion, quality and impact in health research, and the relationship between these metrics and wider agendas for diversity and inclusion.

A mapping review was selected as the most appropriate approach for a wide-ranging consideration of diversity and inclusion across the health research system. Coding for the mapping review was undertaken using the PROGRESS-Plus framework, developed by the Cochrane Equity Group for analysis of equality and diversity issues in health. From an initial set of 1466 studies, the mapping exercise generated 246 papers for detailed analysis. This evidence was supplemented by three qualitative institutional case studies; a stakeholder workshop; and a targeted look at evidence for the relationship between research metrics, diversity and inclusion.

From the review process, we have identified ten broad conclusions about the state of the evidence base, and gaps that persist:

First, **there is a strong dominance of US-based research in the literature**, which raises questions about the transferability of findings, given the cultural specificity of some aspects of diversity and inclusion.

Second, **there is a far more extensive literature relating to gender and race/ethnicity** (although the latter also related predominantly to the US), and comparatively little on other PROGRESS-Plus axes of difference. The literature highlights persistent patterns of disadvantage, but also variability by field and subfield – particularly with regard to gender.

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<sup>1</sup> <https://wellcome.ac.uk/what-we-do/our-work/diversity-and-inclusion>

Third, **the majority of the studies we examined focused on clinical or biomedical research.** Other areas of health-related research did not feature so heavily. Given that the relevance of the PROGRESS-Plus variables differs depending on the type of health research, and on the sub-cultures and degree of diversity within health research disciplines, the transferability of evidence across disciplines is debatable.

Fourth, **the predominant level of analysis is that of individuals** (in terms of metrics, interventions etc.). Multiple (dis)advantages and inter-locking aspects of people's experience can reinforce one another. The degree of isolation and exclusion felt by women and minorities can be underestimated. There is a relative lack of attention paid in the literature to measures of diversity or inclusion at the **aggregate or organisational level.**

Fifth, **there is a focus on individual parts of the health system, and only a few examples of more holistic, systems-based and/or longitudinal approaches** that try to examine how elements interplay and (re)create disadvantage.

Sixth, **the literature predominantly takes a national, rather than international or comparative focus,** despite the fact that dimensions of diversity and inclusion look very different from a more international or global perspective.

Seventh, the studies we examined reflect **a limited amount of theoretical framing, and often rely on implicit assumptions about mechanisms of action and causality,** rather than more explicit development and testing of models and mechanisms.

Eight, there are **persistent areas of controversy and complexity,** such as how to conceptualise and operationalise race/ethnicity. These demand careful and explicit consideration.

Ninth, **trickle-down or trickle-out effects to other parts of health research systems is far from automatic:** this takes time, and requires actions to promote diversity and inclusion across all elements of the system. Gender-related initiatives can be seen as benefiting women only. Informal processes can reinforce the advantages of dominant groups. Mentoring schemes that pay attention to culture and tacit knowledge, rather than simply skills, seem more promising

Finally, we can conclude that **there is limited available evidence that directly addresses the guiding research question of this project;** and a relatively weak evidence base for processes and explanations of patterns of inequality, exclusion or lack of diversity that are visible in the health research system.

Based on this review, we identify the following recommendations for future research and related activities that Wellcome Trust could support (on its own, or in partnership with others) in order to strengthen the evidence base in these areas:

First, there needs to be **greater investment in comprehensive studies that examine interactions across the health research system, and longitudinal studies that look at changes over time at individual, collective and institutional levels.**

Second, **more work is required to improve comparability across studies, to define and standardise indicators and metrics;** and to collect data in consistent ways.

Third, **there needs to be greater experimentation and research investment in neglected aspects of diversity and inclusion,** including: aggregate measures of inclusion; axes of difference and disadvantage beyond gender and race/ethnicity; enablers and obstacles; and diversity and inclusion across health research systems.

Fourth, to achieve this more systemic perspective, there need to be **closer links between future research on diversity and inclusion in health research, and issues relating to research cultures, career pipelines, reward and recognition structures, responsible metrics and research integrity** – increasingly addressed under the broad umbrella of the “**science of science**” (Ioannidis *et al.*, 2015; Wilsdon *et al.*, 2015). Given the existing portfolio of Wellcome Trust activities, there is scope for Wellcome Trust to pioneer creative and ambitious funding, policy and advocacy strategies that draw links between these (at times) disparate and siloed agendas, to advance a more holistic understanding of links between diversity, inclusion, integrity, responsibility and public engagement.

Finally, **to help inform Wellcome Trust’s future efforts across these linked agendas, we offer an illustrative synthetic model that seeks to highlight the importance of taking a more holistic, less compartmentalised approach** than we found evident in much of the literature. We hope this is helpful in suggesting future priorities and opportunities for research.

# 1. The context for this project

## 1.1. Background

Over the past decade, the need for greater diversity and inclusion across research systems and institutions has received increased emphasis from policymakers, funders, universities, learned societies and wider stakeholders. The case for diversity and inclusion is supported by a growing body of evidence; as are persistent problems of inequality, bias and discrimination.

As *Nature* argued in the editorial of a recent special issue on diversity: “There is growing evidence that embracing diversity – in all its senses – is the key to doing good science. But there is still work to be done to ensure that inclusivity is the default, not the exception” (Nature, 2014). Recent studies of the diversity of US and UK scientific communities by the US National Academies, National Institutes of Health and Royal Society have reached broadly similar conclusions (NIH, 2012a; UW/RS, 2014).

In this context, the renewed impetus being placed on diversity and inclusion in Wellcome Trust’s latest organisational strategy is timely and important.<sup>2</sup> As with debates over open access, public engagement, science education and research careers, Wellcome’s reach and influence across biomedical, health and broader research communities means that it can help to shift the terms of such debates, and inspire wider change in cultures, policies and practices (Wilsdon, 2015).

In support of Wellcome’s strategy, the primary aim of this project is to undertake a systematic and critical review of the evidence base for a positive relationship between a diverse and inclusive health research community, and the qualities and impacts of the research they undertake. The review draws on evidence from across the research system, with a primary focus on health and biomedical research. It also draws on related literatures on diversity, inclusion, equality and coproduction across health systems and services, and organisational diversity and inclusion.

A second focus of the project is to evaluate the efficacy of the metrics used to measure diversity, inclusion, quality and impact in health research, and the relationship between these metrics and wider agendas in support of diversity and inclusion.

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<sup>2</sup> <http://strategy.wellcome.ac.uk>

## 1.2. Diversity and inclusion: complementary or competing rationales?

In any analysis of these issues, it is important to start by considering the extent to which diversity and inclusion are being treated as means to particular ends (such as efficiency or productivity), or as ends in themselves (such as equality, rights, share of the public good). Our starting assumption is that Wellcome's commitment to diversity and inclusion spans both types of rationales, but it will be necessary at various points in this analysis to tease apart one from the other.

Diversity in the workplace is often linked to positive outcomes, especially where these are dependent on a plurality of ideas and perspectives, such as information processing in teams (Dahlin *et al.*, 2005). However, some evidence indicates that there may be negative outcomes from diversity in the workplace, such as increased absenteeism, employees feeling less attached (Tsui *et al.*, 1992), poorer performance (Chatman *et al.*, 1998; Chattopadhyay, 1999), increased discrimination (Avery *et al.*, 2008) and increased levels of conflict (Jehn *et al.*, 1999).

Meta-analyses do not provide clear conclusions as to whether the main effect of greater diversity is positive or negative. This highlights the need to investigate individual (e.g. personality) and contextual (e.g. organisational culture, industry) factors (Phillips *et al.*, 2011). Research on diversity in the workplace tends to take one of the following perspectives (Guillaume *et al.*, 2013):

- (1) Distribution of differences in a cohort (a compositional approach);
- (2) Differences of an individual compared with the rest of the cohort (a relational approach);
- (3) Comparison of individuals with different demographic characteristics.

Ongoing areas of research relevant to these questions include:

- **Simple demographics:** these studies tend to investigate the negative aspects of demographic differences on the outcomes of organisational practices, such as selection, performance appraisal and compensation (Avery and McKay, 2010). There are well-documented disparities based on demographic differences.
- **Relational demographics:** These studies tend to look at the effects of being different or similar to one's colleagues on a person's effectiveness and social integration (e.g. quality of relationship with peers). Overall the findings here are inconclusive, and can perhaps be explained by looking at status differences (e.g. individual working within a group of a higher-status majority).



- **Work group diversity:** Whether the effect of diversity in teams is positive or negative is inconclusive, with evidence demonstrating both effects. This has led to investigation of moderating variables (e.g. task complexity, team interdependence, leadership style, trust, diversity beliefs), which unveil the conditions under which diversity can be translated into positive outcomes. This line of research is useful as it provides clues as to how to best manage diversity in order to facilitate the processes required for positive outcomes.
- **Diversity management:** Studies in this domain demonstrate that there have been efforts to increase diversity in the workplace in a way that leads to a more equitable representation of minorities. The effects of increased diversity however have not always been positive, indicating the need for effective 'diversity management' through the implementation of HR policies and practices (e.g. recruitment and selection from a wider pool, training & development, mentoring). Studies in this domain tend to conclude that there is a need for an integrated set of practices that will create the cultures and climates needed for inclusivity and integration of a diverse workforce (Avery and Mckay, 2010; Guillaume *et al.*, 2013).
- **Representativeness:** The extent to which a workforce is representative of clients, or to which management is representative of the rest of the workforce, has been shown to positively predict a variety of outcomes (Avery *et al.*, 2012; King *et al.*, in press; King *et al.*, 2011).

### 1.3. Measuring diversity and inclusion: challenges

Methods of conceptualising and measuring diversity and inclusion vary across disciplines and by definitions. In this review, we consider approaches that may be relevant to understanding both 'the health research community' and 'the qualities and impacts of research'.

For the health research community, challenges to bear in mind include:

- Diversity is measured in different ways according to the level of analysis; for example this may be done at a group, organisational or societal level. As a result, the groups measured (e.g. ethnic groups) may be considered differently in different settings;
- There are pros and cons of using standard groupings, and indeed groups are not 'essential' in terms of their relevance for research – what matters is how they are constructed at a particular place and time;
- Some axes of difference and disadvantage have had a lot more analysis than others (e.g. race/ethnicity, where there is a large literature in general, and in relation to health research); other areas are less well covered in the existing literature and research base;

- There is a range of collective measures of diversity, indices of diversity and diversity metrics;<sup>3</sup>
- Measures of inclusivity (or discrimination or exclusivity) need to go beyond measuring the make-up of groups and representativeness to look at how they function, and degrees of inclusivity or discrimination (Ehala *et al.*, 2016)
- There is a need also to consider the unit of analysis that is meaningful: teams; departments; organizations; disciplines at national level; or an international perspective. Conclusions about the degree of diversity and inclusiveness will vary importantly by unit of analysis.

It is particularly important to think about national versus international perspectives; for example, measures that are meaningful in the UK may be irrelevant in many other settings. This creates challenges in terms of notions of equity in research.

## 1.4. The health research system

The health research system is highly complex with many actors. The notion of the “health research community” has broadened over time, with researchers no longer isolated from the end-users of research, and increasing expectations that the public, patients and carers should be active players in shaping research agendas (see e.g. the work of INVOLVE; James Lind Alliance<sup>4</sup>).

Individuals also play multiple roles: as researchers; research users (in the case of clinician-researchers); funding board members; journal reviewers and editors; and patients. So any analysis of diversity and inclusion across this system demands we look at more than simply those who primarily identify themselves as ‘researchers’. These patterns also vary across localities and health research disciplines (e.g. lab-based biomedical versus health services research).

We also need to consider the overarching purposes of the “health research system”. Here there are a range of overlapping or conflicting interests, which influence perceptions of diversity and inclusion. These include: health research as a source of wealth (new drugs and technologies, new markets); health research as a means of increasing overall health; health research as a means of reducing inequalities in health outcomes between groups/populations/countries. Ideas about whether, why and how issues of diversity and inclusion should be addressed will depend on perceptions of the appropriate mix and priority between these different purposes.

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<sup>3</sup> See e.g. [http://www.workforcediversitynetwork.com/res\\_articles\\_diversitymetricsmeasurement\\_evaluation.aspx](http://www.workforcediversitynetwork.com/res_articles_diversitymetricsmeasurement_evaluation.aspx)

<sup>4</sup> <http://www.invo.org.uk/>; <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/>

## 1.5. Measuring research qualities and impacts

Similarly, ideas about what constitutes high quality or high-impact research depend on one's perspective on the purposes of research. Broadly speaking, over the past twenty years, researchers of all kinds have come under growing pressure to measure and demonstrate the value they contribute to society (Glasziou *et al.*, 2014; Raftery *et al.*, 2016). This pressure takes a variety of forms: greater demands for audit and evaluation of public investment in higher education and research; requests from policymakers for more strategic intelligence on research impacts; institutional needs to manage and develop research strategies; competition within and between institutions for prestige, students, staff and resources; and more availability of real-time data on research uptake, and the capacity of tools for analysing them (Wilsdon *et al.*, 2015).

Wider use of bibliometric indicators, and the more recent emergence of 'altmetrics' for measuring wider impacts at the level of individual articles, projects or researchers, can be seen supporting the transition to a more accountable and transparent research system. But this shift has been accompanied by a backlash against the inappropriate weight being placed on particular indicators – particularly journal impact factors (JIFs) – within the research system, as reflected by initiatives such as the San Francisco Declaration on Research Assessment (DORA), the Leiden Manifesto and The Metric Tide.<sup>5</sup> Researchers in the scientometric field are also increasingly concerned about the unintended effects that some metrics are having in an era of expanding academic audit (Garfield, 2006; Garfield, 1996; Hicks *et al.*, 2015; van Dalen and Henkens, 2012; Weingart, 2005). For instance, in 2012, one of the leading journals in the field – *Scientometrics* – produced a special issue concentrating on the uses and misuses of JIFs (Braun, 2012).

Policies and initiatives to promote diversity and inclusion in other parts of the research system can be undermined if the indicators used to define and measure success (in terms of “quality”, “excellence”, “impact”) reinforce existing inequalities and hierarchies.

Diversity in the choice and use of indicators is itself a priority: individual indicators may struggle to do justice to the richness and plurality of research. Too often, narrow, poorly applied evaluation criteria are “dominating minds, distorting behaviour and determining careers” (Lawrence, 2007). In part, these effects are intended: performance indicators are used to change production dynamics in research systems and to align them with policy priorities (Whitley and Glaser, 2008) That the research community and other stakeholders respond strategically may in turn have

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<sup>5</sup> [www.ascb.org/dora](http://www.ascb.org/dora); <http://www.nature.com/news/bibliometrics-the-leiden-manifesto-for-research-metrics-1.17351>; [http://www.hefce.ac.uk/pubs/rereports/Year/2015/metrictide/Title\\_104463.en.html](http://www.hefce.ac.uk/pubs/rereports/Year/2015/metrictide/Title_104463.en.html)

further unintended effects: through structural changes in research priorities, publication activities, research capacity and organisation.

Within UK health research, analysis and measurement of research impact have been strongly influenced by the requirements of the Research Excellence Framework (REF) (Greenhalgh and Fahy, 2015). With enhanced awareness that the pathways between research production and research uptake are anything but linear, evaluators have sought to accommodate indicators that capture distal, as well as proximal measures of research activity. Attempts to document the influence of research activity have looked downstream towards perceived effects on policy, and to some extent, on practice.

As a consequence, a well-recognised set of publication metrics has been augmented by efforts to demonstrate the spread and penetration of knowledge utilization (Walshe and Davies, 2013). Interest in complex (adaptive) systems, as evidenced in the organisation of research activity and the interplay of multiple stakeholders across multi-levels, has shaped an environment within which a more sensitive approach to metrics and indicators is broadly welcomed (Kislov *et al.*, 2014). Allied to this imperative is a recognition that approaches that capture only short-term direct impacts are limited and need to be enhanced to include longer term and indirect impacts (Greenhalgh and Fahy, 2015).

## 2. Methods

### 2.1. Mapping review

Based on a detailed understanding of review requirements, and informed by its knowledge of evidence synthesis methods, the research team selected the mapping review (also known as a *systematic map* or *evidence map*) as the most appropriate evidence product for the review. Formal methods of systematic mapping were first developed by the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre).

Mapping reviews are particularly useful in the context of a two-stage model of systematic review, in that they seek initially to characterise an often-diffuse evidence base. These methods facilitate identification of smaller coherent sets of studies that may be analysed, at a subsequent stage, through a more tightly focused systematic review. As such, a mapping review represents an appropriate vehicle for a wide-ranging consideration of diversity and inclusion issues across the distinct, yet related, broad topic areas of research priorities, research workforce and research participants, as well as the more focused area of research metrics.

A systematic map “collates, describes and catalogues available evidence (e.g. primary, secondary, quantitative or qualitative) relating to a topic of interest” (James *et al.*, 2016). Alongside a narrative and tabular report (the mapping review) a catalogue or database offers a searchable resource to enable further interrogation of subsets of studies of interest against pre-specified variables. A recent methodological review characterises evidence maps around five components (Miake-Lye *et al.*, 2016):

- (i) a systematic search;
- (ii) of a broad field;
- (iii) to identify gaps in knowledge and/or future research needs;
- (iv) that presents results in a user-friendly format;
- (v) often visual figures or graphs, or a searchable database.

These five components, although not all present in every published example of an evidence map, accurately reflect the review team’s understanding of the intended product.

Comparison of a mapping review with a formal systematic review (see Table 1) is helpful in specifying methods and required resources, and in managing commissioner and review team expectations. It should be noted that the mapping review is recognised as an evidence product in its own right. Chosen methods seek

to manage the demands of a time-critical decision-making environment where collective understanding of a topic must be advanced in a timely, yet systematic and explicit manner. Time-critical demands necessarily transfer the focus of the review output from a specific answer to a tightly-prescribed question, to a broader understanding of a wider topic or issue.

**Table 1 - Comparison of Mapping Reviews with Systematic Reviews**

Stage in 'evidence synthesis'	Mapping review (Systematic map)	Systematic review
Objective	Describes current knowledge for a question or topic	Addresses questions with a quantitative or qualitative answer
Question formulation	Question can be background (incompletely formulated) or foreground. Topic broad or narrow	Question is usually foreground (with fully specified components)
Search strategy	Accommodates widest range of research evidence for inclusion (e.g. primary and secondary research)	Evidence is limited to primary qualitative or quantitative research studies.
Article screening	Utilises information from Abstracts and Full-text where available	Full text usually required
Data extraction	Study description and methods. Study results not routinely extracted	Includes study description, methods and qualitative and or quantitative results
Critical appraisal	Critical appraisal not routinely undertaken	Included studies critically appraised for internal and external validity
Synthesis	Trends in the literature, knowledge gaps and clusters identified. No 'synthesis of study results'.	Qualitative or quantitative synthesis of study results (e.g. meta-analysis/meta-synthesis). Gaps identified
Report	Describes and catalogues evidence relating to topic of interest, identifies knowledge gaps and knowledge clusters. Implications for policy, practice and research.	Narrative and qualitative or quantitative synthesis study results (e.g. meta-analysis) to address primary objectives. Implications for policy and practice, and identification of knowledge gaps for future research

(Adapted from James *et al.*, 2016)

Although the methodological literature cited above reflects considerable variation in terminology (e.g. evidence map, mapping review, systematic map) this report seeks consistency in referencing the three products synonymously with the term "mapping review".

## 2.2. Framework Analysis using the PROGRESS-Plus framework

Efficient coding for a mapping review may be facilitated by use of an appropriate pre-existing framework (Dixon-Woods, 2011). The overall utility of any external framework depends upon the degree of recognition that the framework commands within a specific topic area. For these reasons the review team selected a framework developed within the specific context of systematic reviews of health equity, namely the PROGRESS framework (O'Neill *et al.*, 2014) to guide understanding of issues of equality and diversity. This framework was developed by the Cochrane Equity Group to ensure that researchers 'consider the intersecting determinants of health when designing research or an implementation plan'. PROGRESS is both an acronym and a mnemonic. The eight concepts included in PROGRESS are:

- P**lace of residence
- R**ace/ethnicity/culture/language
- O**ccupation
- G**ender/sex
- R**eligion
- E**ducation
- S**ocioeconomic status
- S**ocial capital

PROGRESS encourages consideration of the intersecting determinants of health when designing research or research strategies. The acronym prompts researchers, program planners and managers to think about these intersecting determinants of health, and their consequences on equity (National Collaborating Centre for Methods and Tools, 2015).

Explicit identification of the multiple factors that affect health inequity is intended to create opportunities to realign strategies or to redistribute resources. PROGRESS has been utilised as a framework to analyse data within individual systematic reviews. It has also been used at a meta-level to analyse the distribution of research outputs.

Subsequent to the development of the initial PROGRESS framework, it was recognized that some additional factors need to be considered. As a result, the framework was expanded into PROGRESS-Plus, with the "plus" capturing other characteristics that may indicate a disadvantage, such as age and disability (Oliver *et al.*, 2008). This expanded PROGRESS-Plus list was used as an appropriate set of criteria for the mapping and analysis associated with this review.

## 2.3. Search methods

Searching for the review was undertaken in four distinct phases. These phases did not run sequentially, but were responsive to the emerging requirements of the mapping review. We aimed to identify evidence over a twenty-year period, from 1995 to 2015, in the area of diversity and inclusion (and their measurement) in health research. A fuller account of our search methods can be found in the project's review and mapping protocol (Preston *et al.*, 2016) Appendix 7.6)

### Phase One - Initial evidence gathering

The research team, drawing on its existing expertise, added evidence that they knew existed in the area of diversity and inclusion in health research to an Excel spreadsheet. This was organised according to the PROGRESS-Plus criteria (see above) and the three areas of research topic, research workforce and research participants. Evidence was added in the early stages of the review, to shape thinking and to guide the development of literature searches.

### Phase Two - Database search

A standard database search of key sources was developed by an information specialist. An initial search strategy was developed through reference to the above Excel spreadsheet and to the review protocol. This was then shared across the University of Sheffield team and with Wellcome colleagues. Edits and amendments were made as appropriate. The searches were undertaken in Medline via Ovid, Web of Science and Scopus. Search strategies are detailed in Appendix 7.1.

### Phase Three - Citation searches

Using ten key citations (See Appendix 7.2), as identified by the research team from Phases One and Two, citation searching was undertaken by an information specialist in Google Scholar. Screening of search results was undertaken as part of the searching process. Details of relevant papers were downloaded for inclusion in the Endnote database, where further scrutiny for inclusion in the mapping and metrics reviews was undertaken.

### Phase Four - Metrics search

A targeted search for evidence for inclusion in the metrics review was undertaken in MEDLINE, Web of Science and Scopus, using a search strategy developed by the review team's information specialists and topic experts. This is available in Appendix 7.3.

It had been proposed in the study protocol to undertake specific searches in key topic areas where a paucity of research was found. However, the complementary citation searches, plus the plethora of evidence located for the mapping review,



rendered these searches unnecessary within the scope of a systematic mapping review.

Liaison with external topic experts is not a common feature of contemporary mapping reviews.(Miake-Lye *et al.*, 2016). Instead the review team drew upon its in-house topic expertise, particularly for the metrics review and case studies.

## 2.4. Methods for the mapping review

The aim of this mapping review was to provide an overall description of the evidence base related to diversity and inclusion in health research; to identify areas where research is lacking; and to identify areas where a more detailed review might be helpful.

We broadly followed the methods summarised by James *et al.* (2016). Studies were selected for inclusion if they dealt with diversity and inclusion in health research and were either descriptive (describing elements of the health research system in isolation, e.g. make-up of the workforce, profile of funding allocation etc.); intervention focused; or analytical (exploring relationships between two or more elements of the health research system but without consideration of any interventional activity).

Papers identified by members of the review team from their expert knowledge and personal files were included in the mapping review to supplement material identified by the searches. The inclusion of these papers was documented in the review flow diagram and the full list of included studies.

Search results from Endnote were screened by members of the review team. Records were screened by one reviewer; uncertainties were discussed with a second reviewer. Records of studies considered to be potentially relevant were imported into EPPI-Reviewer 4 systematic review software for coding.

A review-specific coding framework was developed in advance by the review team (see Appendix 7.3). Data extracted for all included studies are itemised in **Table 2**. In addition to the elements derived from the PROGRESS framework two further taxonomies were constructed. The first of these itemised “Research System Elements”. Primarily this focused on the three aspects of the Research Workforce, Participants in Research and the Agenda/Topics identified as priorities for research. Other aspects included Funders/Funding and Research Outputs and Products. The second coding taxonomy related to Research Activities or Characteristics. These covered the whole range of the research process from Recruitment and Selection through to Publications.

Additional coding was performed for studies considered most relevant to our primary research question. These were studies that:

- evaluated or described any intervention or initiative aimed at increasing diversity in the research workforce, overcoming barriers to inclusion and/or ensuring diversity issues are considered in the selection of research topics and participants;
- reported associations between increased diversity/inclusion and any measure of research output or quality/impact.

For these studies, further data were extracted as applicable (See **Table 2**).

The review team conducted a narrative synthesis of the included studies. EPPI-Reviewer 4 was used to generate frequency tables/charts, reports and crosstabs to aid visualisation of the data and identify patterns and groupings in the included studies (including evidence gaps).

**Table 2 - Extracted Data for the Mapping and Metrics Reviews**

Data common to both reviews	Mapping Review	Metrics Reviews
Study Identifier	Details of intervention/ initiative;	Label for metric being examined
Bibliographic Reference	Study Design	Description of metric
Year of Publication	Data Type	Interventions to address what was measured by the metric, or the actual metric itself
Country of Origin	Setting	Summary of the Research, reported by the authors (or summarised by the review team)
Type of Publication	Duration of the study;	
Study Country (where applicable)	Outcomes and associations reported	
Research System Elements	Rationale and/or framing of the study	
Research-Related Activity(ies)/ Characteristics	Use of a theoretical model or framework	
PROGRESS-Plus factors	Keywords (e.g. diversity, inclusion, exclusion, discrimination etc.)	
	Any definitions offered	

## 2.5. Methods for the metrics review

The search results from Endnote were screened by one reviewer. A preliminary list of included studies was drawn up and this list was scrutinised by a second reviewer. Additional references were suggested for inclusion. Data were extracted and entered into Excel for any studies where: (1) papers critiqued existing metrics; (2) papers

suggested new metrics; (3) papers described existing metrics. Additional papers where metrics are not specific to health services research or where metrics research does not relate specifically to issues of equality and diversity which were deemed useful for framing the overall study were also identified for inclusion in the supporting narrative. In accordance with current mapping review practice, no quality assessment was undertaken (Miake-Lye *et al.*, 2016). The papers were synthesised narratively and integrated for inclusion in the review.

## 2.6. Methods for the case studies

Twelve peer funders, initially identified by the Wellcome Trust, were used as a starting point for an overview of funder's websites (see Appendix 7.4) and other grey literature locatable via Google searches for '[funder name] + diversity' and '[funder name] + equality'. The preliminary exploration also included available financial data on EDI activities, but due to lack of useful information was not pursued.

Grey literature collected in the overview fell into five types of information:

- Overall strategy documents and/or action plans;
- Specific policy documents on Equality/Diversity/Inclusion (EDI);
- Pages devoted to EDI activities on funder's website;
- Information about funder's own workforce, including the use of photo galleries for staff, reviewers and grantees;
- Statistics from the main websites and downloadable reports measuring EDI activity and progress.

This was supplemented by academic literature specifically discussing the funder's EDI activities, drawn from the review database.

The quality and quantity of the grey literature for each funder was highly variable, with national public institutions having more formal and detailed documentation, while charitable foundations often offered only short promissory statements on their websites. To optimise the informational value of the case studies, the three cases to be developed were chosen based on the availability and quality of the information in relation to the three analytic categories of Workforce, Participants and Topics, with a consequent focus on publicly funded institutions in English-speaking countries.

## 2.7. Stakeholder workshop

To inform the preliminary findings of the mapping review, and to help to identify issues of importance and concern, a stakeholder workshop on "*Diversity and Inclusion in Health Research: Reviewing the Evidence Base*" was hosted by Wellcome Trust in London on July 21st 2016. Twelve external attendees took part,

along with seven members of the University of Sheffield review team, and six members of the Diversity & Inclusion and Intelligence & Analysis teams at Wellcome Trust (see Appendix 7.7 for full attendance list).

At the workshop, Lauren Couch from Wellcome Trust outlined the context for current work on diversity and inclusion. This was followed by a series of presentations from the University of Sheffield team who rehearsed the interim findings of the systematic mapping of the evidence base. Stakeholders were invited to offer their input and advice in identifying gaps, testing conclusions and suggesting ways in which Wellcome could carry forward its diversity and inclusion work.

Participants discussed the problematic nature of attempts at categorisation and the difficulty in performing meaningful and consistent analysis. Intersectionality was highlighted as an increasingly important issue. The part played by unconscious bias was also flagged as important. Interest was expressed with regard to widening public and patient participation and meaningful involvement in research. Participants also related Wellcome Trust's initiatives on diversity and inclusion to other work; for example, the Royal Society was working to make its activities more inclusive, by examining how characteristics of funding calls may use language that excludes particular applicants.

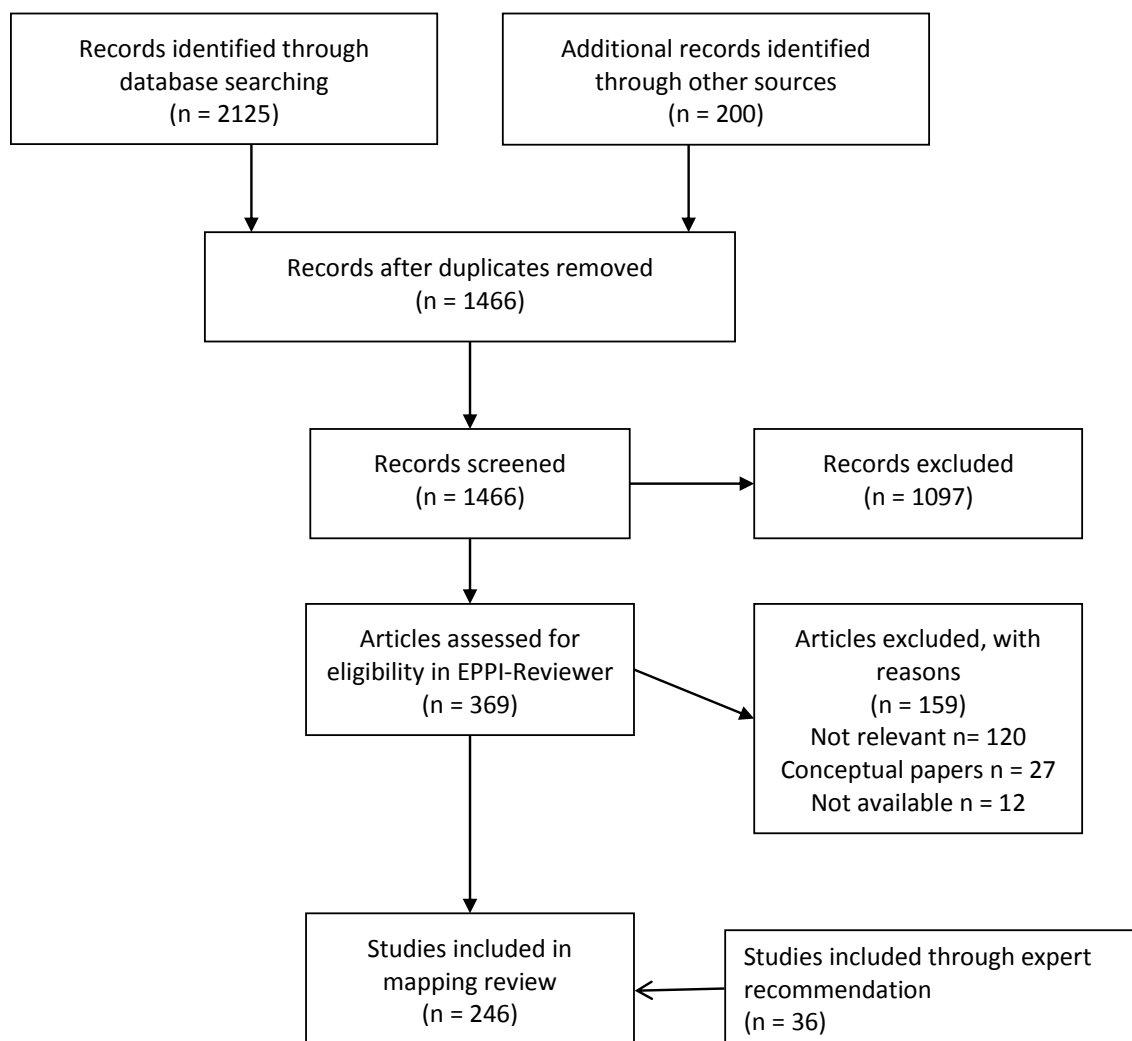
Small group discussions highlighted the importance of specific drivers, such as HESA data and the REF. Metrics may favour particular populations for example, privileging males over females. Stakeholders also emphasised the importance of taking both a research pathway (all stages of research) and research pipeline (all stages of career progression) approach.

### 3. Results of the mapping review

#### 3.1. Total studies

A total of 246 studies were included in the mapping review. An alphabetical list of the included studies is presented in Appendix 7.5. A flow diagram for the mapping review is presented below (Figure 1).

Figure 1 - Flow diagram for the mapping review



## 3.2. Distribution of studies

As **Table 3** shows, over half of the included studies were published after 2005, suggesting an upward trend in the volume of research in this area. The great majority of empirical studies were US-based. This accords with broader publication patterns and trends across these fields over time (see section 3.3).

**Table 3 - Distribution of studies by year of publication and study country/region**

Year of publication	Number of included studies
Pre-1995	7
1995-1999	12
2000-2004	37
2005-2009	40
2010-2014	98
2015-2016	51

Study country or region	Number of included studies
USA	98
UK	13
Canada	8
Australia	8
New Zealand	1
Other Europe	12
LMICs	16
Multiple countries (not LMICs) or not applicable <sup>1</sup>	90

Notes: <sup>1</sup>: includes reviews and methods papers

Gender/sex was by far the most commonly investigated of the PROGRESS-Plus dimensions, followed by race/ethnicity, socioeconomic status, and place (broadly defined to include place of residence, place of work and other relevant geographical characteristics). We found relatively small numbers of studies investigating sexual orientation, age, disability, pregnancy and maternity, and gender reassignment in relation to the health/biomedical research system.

In terms of research system elements, similar numbers of papers were coded for research participants and research workforce, and a large number of papers explored research outputs (largely referring to academic publications). Many papers were coded against multiple, related research system elements. The results are summarised in **Table 4** below.

**Table 4 - Distribution of studies by PROGRESS-Plus dimensions and research system elements**

<b>PROGRESS+ dimensions<sup>1</sup></b>	<b>Number of included studies</b>
Gender/sex	131
Race/ethnicity/culture/language	91
Socioeconomic status	29
Place	25
Age	11
Sexual orientation	9
Pregnancy and maternity	5
Disability	5
Social capital	3
Gender reassignment	2
Marriage and civil partnership	1
Religion	0
Occupation <sup>2</sup>	0
Education <sup>2</sup>	0
Other or non-specific inequalities <sup>3</sup>	9
<b>Research system elements<sup>1</sup></b>	
Research workforce	85
Research outputs	78
Participants	65
Research methodology and methods	47
Agendas and topics	35
Funders and funding	30
Research ethics and standards	19
Patient and public involvement	14
Research evidence use	2
Whole system/generic	6
Other	1

Notes: <sup>1</sup>:multiple coding possible; <sup>2</sup>: these factors likely subsumed under socioeconomic status; <sup>3</sup>: included parental status; substance users; stigmatised illness.

### **3.3. Time trends in the diversity/inclusion literature**

To contextualise our included studies against a wider snapshot of trends in the relevant literature, a series of basic analyses were conducted using the Analyze function of Web of Science (searches took place on 18<sup>th</sup> October 2016). Queries

were devised for diversity in general and for individual factors in the original PROGRESS framework.

While it is acknowledged that these search strategies necessarily lack specificity, when compared with articles selected through the mapping review process, they do offer an insight into (i) the relative literatures relating to each factor (See Table 5) and (ii) indicate a broad time trend over the period covered (1995-2016). Data for 2016 represents only a ten-month time period.

Search strategies required the presence of a PROGRESS factor (or synonym) in an article within some aspect of clinical or health research that specifically highlights diversity issues, as indicated by the terminology of diversity/equality. They do not reflect the numbers of research articles that simply report that factor within the article (e.g. a research study that reports gender).

**Table 5 – Search strategies for broad bibliometric analysis of items on specific aspects of Diversity**

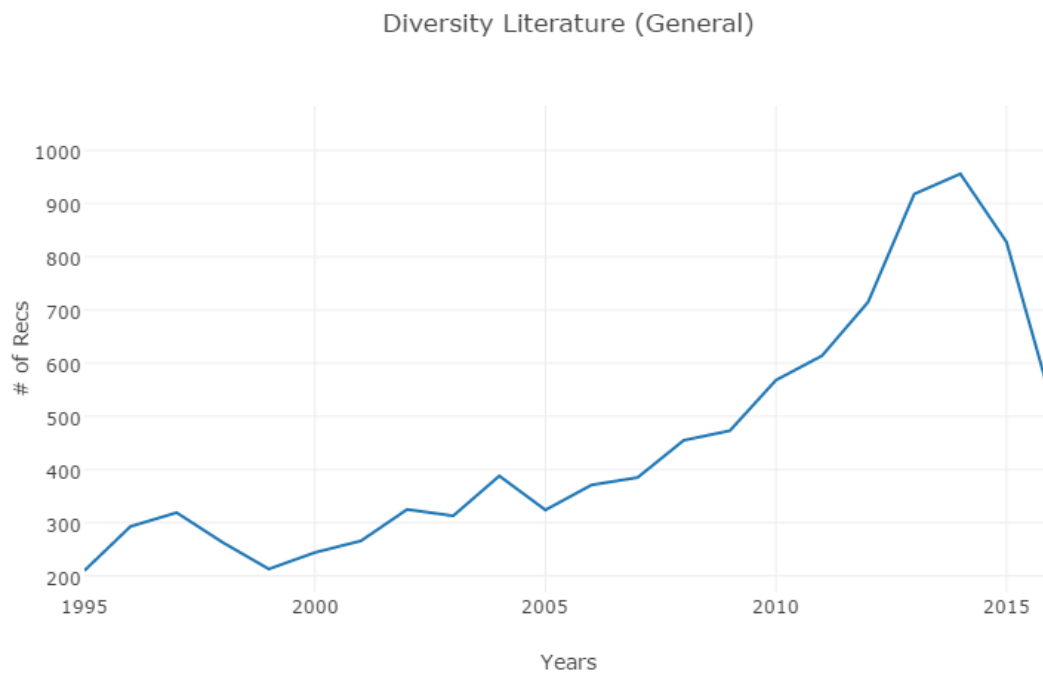
PROGRESS factor	Web of Science Strategy	Total Records (1995-2016)
Place of residence	TS=(“Geographic Variability” OR “Place of Residence”)	21*
Race/ethnicity/culture/language	TS=(Race OR racial OR ethnic OR Ethnicity OR culture OR cultural OR language)	1993
Occupation	TS=(Occupation* OR Employment)	400
Gender/sex	TS=(Gender OR Sex OR Sexual)	1034
Sexual Orientation	TS=(Lesbian* OR Bisexual* OR gay OR Transgender or homosexual* OR transvestite*)	71
Religion	TS=(Religion OR Religious)	111
Education	TS=(education* OR educational)	1212
Socioeconomic status	TS=(socioeconomic OR (social AND economic))	1123
Social capital	TS=("Social capital" OR "Social* isolat*" OR "social network*" OR "social relation*" OR "social support")	225
<b>All Diversity</b>	TS=(Diversity OR Inequalit* OR Equal* OR Equity OR Discriminat* OR Inclusiv* OR Exclusiv*) AND TS=("health research" or "health service research" or "health services research" or "medical research" or "biomedical research" or "biomedicine" or "clinical research" or "life science research" or "life sciences research")	9941
NB. All PROGRESS terms were combined with our short Diversity search string: TS=(Diversity OR Inequalit* OR Equal* OR Equity OR Discriminat* OR Inclusiv* OR Exclusiv*) AND our Research string TS=("health research" or "health service research" or "health services research" or "medical research" or "biomedical research" or "biomedicine" or "clinical research" or "life science research" or "life sciences research") * Insufficient data to identify trends		

Overall, the diversity literature reflects a sustained increase in the period 1995-2016 with the literature witnessing a 4.5 fold increase (**Figure 2**). The period 2010 onwards has witnessed a particularly steep growth (an almost two-fold increase). Although the characteristics of particular PROGRESS factors are more uneven (**Figures 3-9**), representing fluctuations on a yearly basis, partly due to the relatively

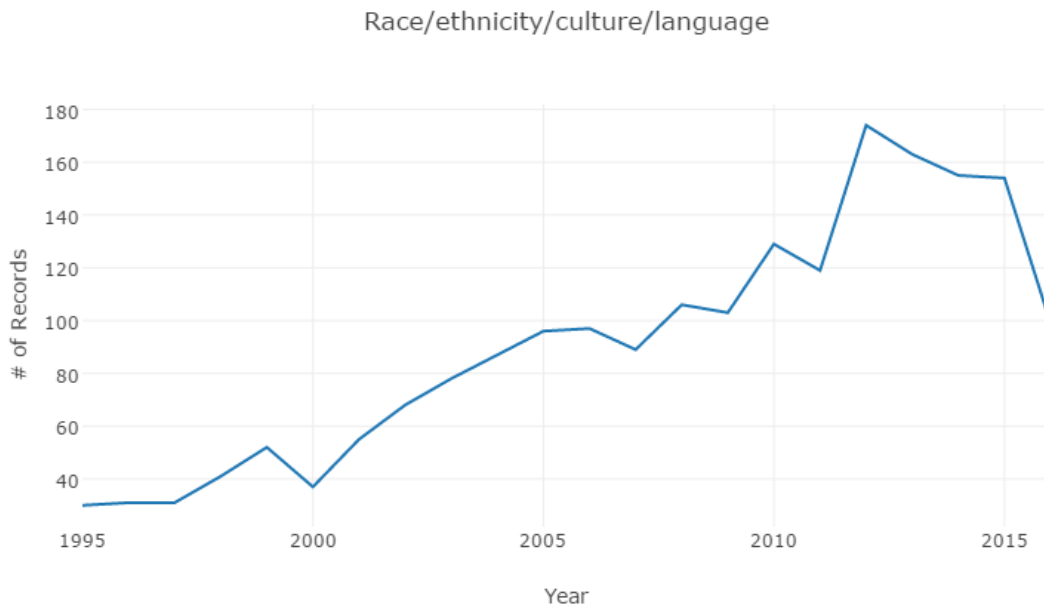


smaller numbers in the analysis there remains a trend of sustained increase across all factors. (NB. Place of Residence and Sexual Orientation involved too small a sample to permit meaningful trend analysis).

Comparison between PROGRESS factors is more problematic, largely because of differing sensitivities of the search strategies and different degrees of variation in the terminology. Nevertheless, this analysis does confirm the predominance of certain PROGRESS factors in the literature (e.g. race and gender) as well as certain areas that have been comparatively under-examined (e.g. place of residence). It should be noted that the size of the medical literature is itself increasing, so part of the growth may well reflect overall prevalence. Nevertheless, this certainly does not explain all the growth. We can therefore conclude that there is growing interest in diversity issues in the literature and these factors are being studied with increasing frequency.



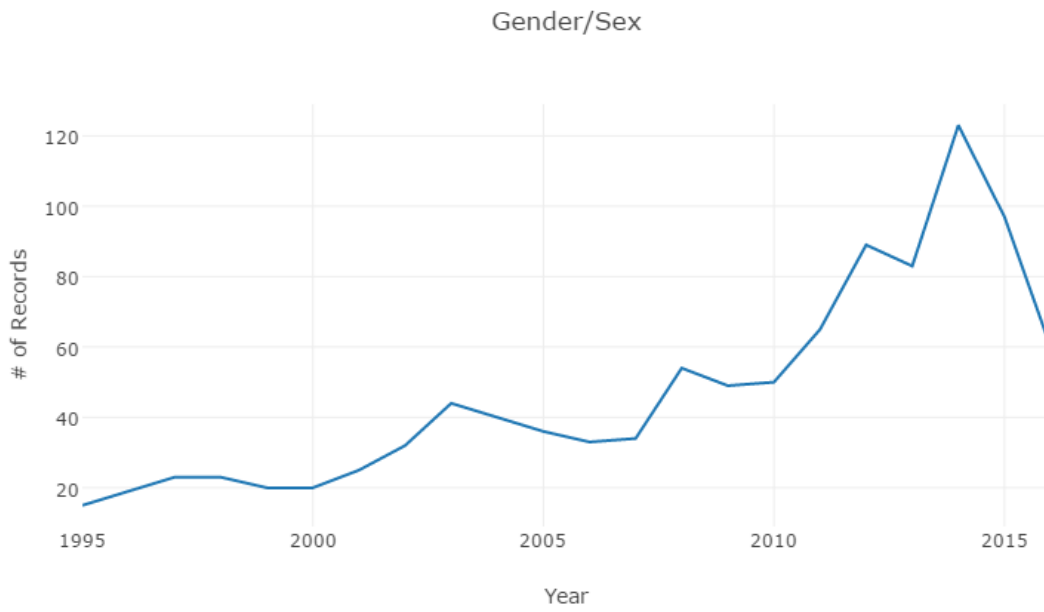
**Figure 2: Time trend of Literature on Diversity in Clinical and Health Research (Web of Science, 2016)**



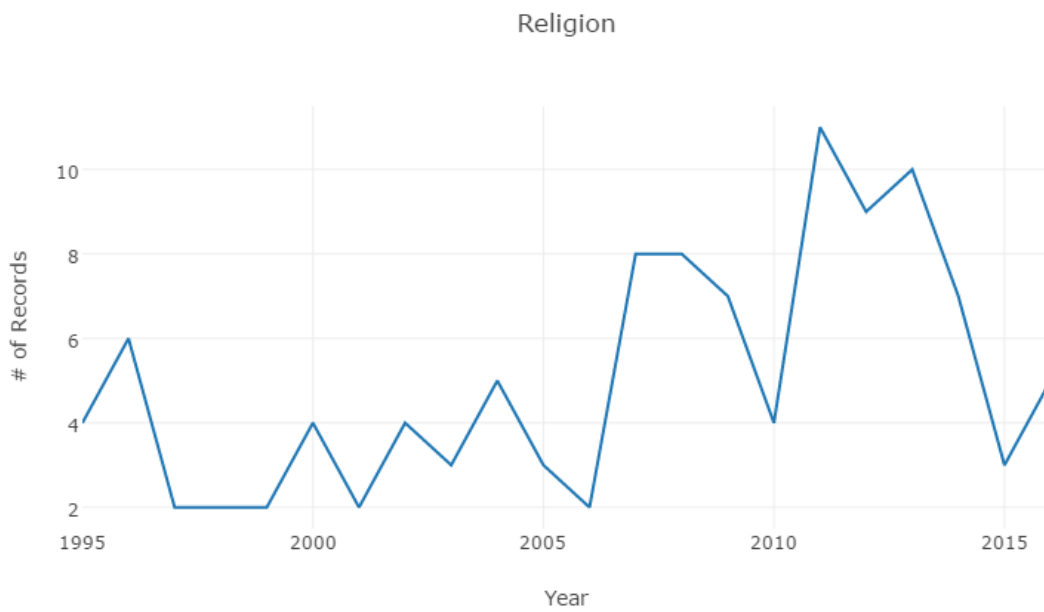
**Figure 3: Time trend of Literature on Race/Ethnicity/Culture/Language and Diversity in Clinical and Health Research (Web of Science, 2016)**



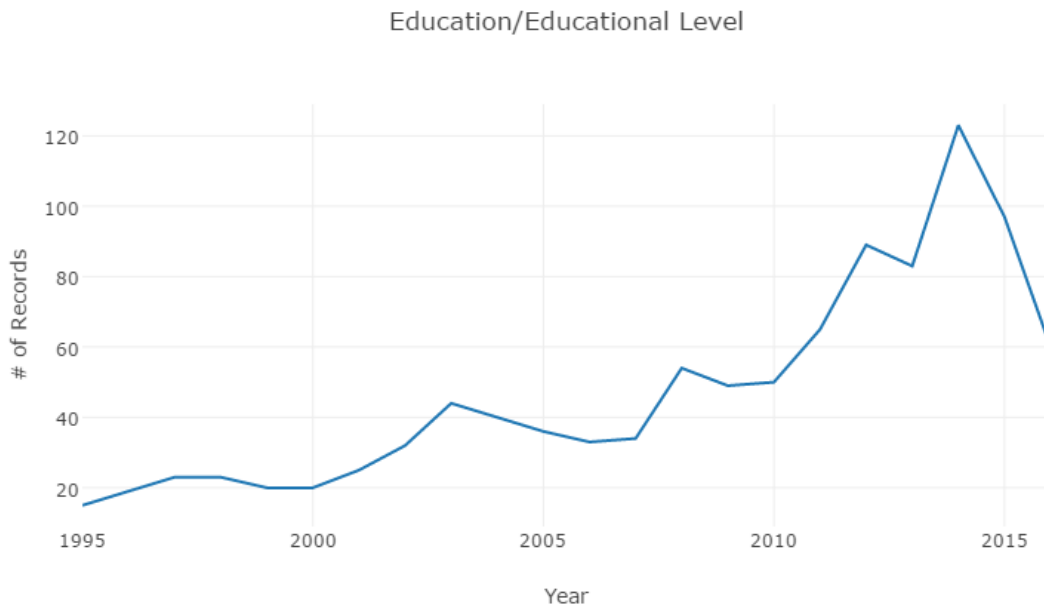
**Figure 4: Time trend of Literature on Occupation/Employment and Diversity in Clinical and Health Research (Web of Science, 2016)**



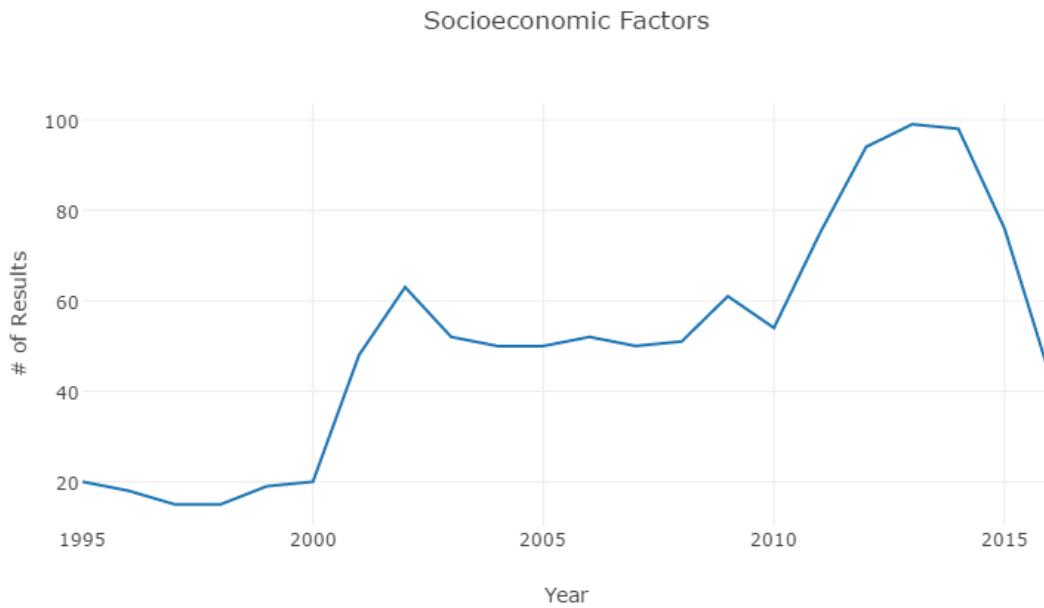
**Figure 5: Time trend of Literature on Gender/Sex and Diversity in Clinical and Health Research (Web of Science, 2016)**



**Figure 6: Time trend of Literature on Religion and Diversity in Clinical and Health Research (Web of Science, 2016)**



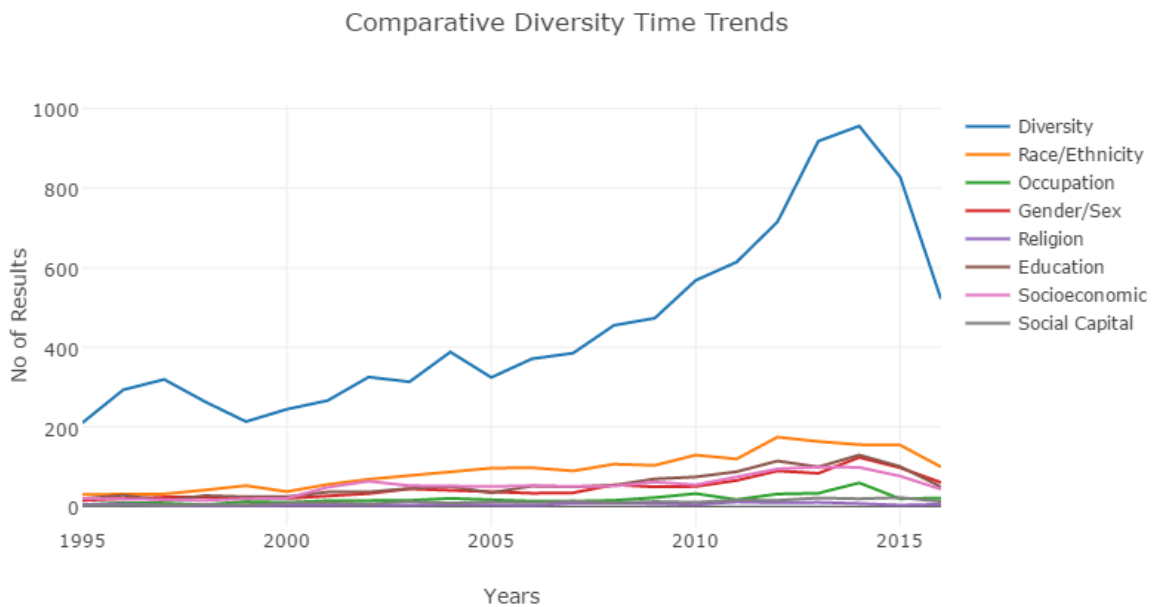
**Figure 7: Time trend of Literature on Education/Educational Level and Diversity in Clinical and Health Research (Web of Science, 2016)**



**Figure 8: Time trend of Literature on Socioeconomic Status and Diversity in Clinical and Health Research (Web of Science, 2016)**



**Figure 9: Time trend of Literature on Social Capital and Diversity in Clinical and Health Research (Web of Science, 2016)**



**Figure 10: Comparative diversity time trends (Web of Science, 2016)**

### 3.4. Narrative review of key themes

Closer examination of the retrieved papers indicated two main clusters: (i) those that focused on the diversity of the research workforce, career progression and productivity in terms of publications and grant capture, and (ii) those that focused on

diversity and inclusion in relation to research participants, topics and agendas. In both sets of papers, the bulk of the material was descriptive and non-interventional, providing only limited evidence on the relationships between elements of the research system and the focus question driving the review:

***“What evidence is there for a positive relationship between a diverse and inclusive health research community, and the qualities and impacts of the research they undertake?”***

A smaller number of papers were concerned with other aspects of the research system and/or took a more holistic approach. Papers focused on funding organisations largely related to NIH (see also Case studies, 5.2).

### **3.4.1. The research workforce**

Of the 246 publications that were coded in this review, 85 were identified as addressing *workforce* related issues. Some of these articles dealt with other elements of the research system that are closely related to the workforce, such as *research outputs and products* or *funding (grant capture)*.

#### **3.3.1.1 Rationales for diversity and inclusion in the research workforce**

The rationales advanced for a focus on increasing diversity and inclusion within the research workforce were explored for included studies that were coded as analytical or interventional and therefore extracted in detail.

Several papers included a ‘business case’ type rationale for their interest in increasing diversity and inclusion in the workforce, making reference to competitiveness, creativity, and productivity (Butts *et al.*, 2012; Byington *et al.*, 2016; Campbell *et al.*, 2013; Ghaffarzadegan *et al.*, 2014; McGee Jr *et al.*, 2012; Plank-Bazinet *et al.*, 2016; Rice *et al.*, 2014; Sopher *et al.*, 2015; Tilstra *et al.*, 2013). These papers tended to draw - somewhat selectively - on evidence from other sectors to make this case:

*There is evidence suggesting that diverse groups comprising members with varying perspectives outperform those that have members with more similar backgrounds and perspectives. (Sopher *et al.*, 2015, p. 823)*

*The low numbers of individuals from these backgrounds, especially racial and ethnic minorities, who pursue careers in science, technology, engineering, and mathematics (STEM) is often cited as one of the factors likely to impede the United States’ future scientific progress. (Campbell *et al.*, 2013, p. 394)*

Six of these papers included dual rationales, emphasising the ‘business case’ for greater diversity as well as an equity and fairness argument (Butts *et al.*, 2012; McGee Jr *et al.*, 2012; Plank-Bazinet *et al.*, 2016; Rice *et al.*, 2014; Sopher *et al.*, 2015; Tilstra *et al.*, 2013). Butts *et al.* noted the importance of recognising these dual rationales:

*The rationale for diversity has evolved over the past decade beyond focus on population parity, the need to address health disparities and expand research capacity, and social-justice rationales to include greater focus on diversity as a driver to support institutional excellence.* (Butts *et al.*, 2012, p. 499)

Interestingly, however, arguments advanced in relation to increasing the diversity of the research workforce as a route to improving the quality of research endeavours also often related to broader health equity concerns. Several papers explicitly argued that researchers from under-represented groups are better equipped and more likely to pursue research on the health needs of these under-represented groups (McGee Jr *et al.*, 2012; Rice *et al.*, 2014; Sopher *et al.*, 2015). It is important to note, however, that these mechanisms were assumed, rather than demonstrated empirically:

*One way to address the lack of African American and Hispanic participation in clinical trials is to increase representation of physician scientists from these communities.* (Sopher *et al.*, 2015, p. 823)

Four further papers had a single focus on equity and fairness, with two referring to initiatives aimed at enhancing the research workforce ability to undertake research in ways that better meet the needs of under-served groups and serve to ‘democratise knowledge’ (El Ansari, 2005; Masuda *et al.*, 2011) and two focusing on equity of access to opportunities and fair treatment within academia (Ghee *et al.*, 2014; Munir *et al.*, 2013).

In three papers the rationale for the study was found to be inexplicit (DeCastro *et al.*, 2013; Jagsi *et al.*, 2011; Wayne *et al.*, 2010).

### 3.3.1.2 Patterns and trends over time in diversity and inclusion in the research workforce

Studies examined patterns of diversity and inclusion within the research workforce via exploration of the representation of different groups among: the academic hierarchy and pay grades; authors of published papers; grant applicants and awardees; editorial boards of academic journals; and recipients of other types of research support. The majority of studies focused on gender/sex and were concerned to describe women’s disadvantaged position in comparison with men’s. Far fewer papers focused on documenting the representation of racial/ethnic

minorities within the research workforce. No papers were retrieved that described the make-up of the research workforce by any of the other PROGRESS-plus dimensions.

A large number of the studies were concerned with the so-called 'leaky pipeline', a term used to describe the poor representation of women at senior levels within academic medicine when compared to their numbers in training and entry-level positions. Studies focused on this phenomenon were published from 1996 to 2016 and covered a wide range of medical specialties and contexts. Most were based in the US, though two studies were conducted in Spain (Cameron *et al.*, 2014; Ceci *et al.*, 2015; Colomer Revuelta and Peiró Pérez, 2002; Diamond *et al.*, 2016; Ence *et al.*, 2016; Garcia-Calvente Mdel *et al.*, 2015; Holliday *et al.*, 2014b; John *et al.*, 2016; Kaplan *et al.*, 1996; Kongkiatkamon *et al.*, 2010; Lopez *et al.*, 2014; Rochon *et al.*, 2016; Sadeghpour *et al.*, 2012).

While several studies were of low quality using cross-sectional surveys with low response rates, the consistency of the gender patterns is striking. Papers that took a longitudinal approach concluded little improvement over time. For example, Kongkiatkamon *et al.* (2010) looked at Prosthodontics in the USA and concluded that there was no improvement in women's representation within leadership positions between 1995 and 2008.

Getz and Faden (2008) conducted online surveys in the US and concluded evidence of significant racial disparities among clinical investigators, with minority investigators being younger, with more limited clinical research infrastructure and less support than their white counterparts. They noted that, despite widespread recognition of racial/ethnic under-representation in the US, there are few empirical studies that describe this disparity.

A number of US studies also looked at gender differences in salaries among medical/health researchers. Male pay advantage was reported even having controlled for indicators of rank, working hours and other potential confounders (Freund *et al.*, 2016; Jaggi *et al.*, 2013; 2012).

Sidhu *et al.* (2009) analysed data on the gender of first and senior authors from the UK who had published in the British Medical Journal, Lancet, British Journal of Surgery, Gut, British Journal of Obstetrics and Gynaecology and the Archives of Diseases in Childhood for 1970, 1980, 1990, 2000 and 2004 (n=6,457). Female first authors increased from 10.5% in 1970 to 36.5% in 2004 (p<0.001) while female senior authors increased from 12.3% to 16.5% (p=0.046). Within individual journals, the largest rise was in the British Journal of Obstetrics and Gynaecology while the proportion of female senior authors declined marginally in Gut (2.8%) and Lancet (2.2%) over the period.



Several studies examined patterns of grant applications and awards by gender as an indicator of men's and women's participation within the medical/health research community. Though studies tended to report greater receipt of research funding by men, findings were often complex and difficult to interpret. For instance, Gordon *et al.* (2009) undertook a retrospective review of all applications to an internal, mentored research grant fund at a large academic paediatric residency programme in the US from 2003 to 2008. They found that men requested more money than women, obtained more favourable application scores and received higher awards than women, but that funding success rates were not statistically different between male and female applicants. Head *et al.* (2013) investigated funding awards to UK institutions for all infectious disease research from 1997 to 2010, and found that men received 78.5% of all funding and that the mean value of award was higher for men, with little change over the 14-year study period. Bedi *et al.* (2012) report on an analysis of Wellcome Trust awards. They found that women received smaller grants than did men. However, since previous research had shown that success rates for research fellowships and project grants were equivalent for men and women, they concluded that it seems likely that women are systematically less ambitious in the size of funding requests they submit. Waisbren *et al.* (2008) examined grant applications and awards in eight Harvard Medical-school affiliated institutions. Gender differences were again reported, with women submitting fewer applications, having lower success, and receiving smaller awards when successful, than men. However, they found that once academic rank was controlled for, the gender difference in grant success rate disappeared, suggesting interplay over time between the various metrics of academic success (see Chapter 4).

Ginther *et al.* (2011) reported large and significant racial/ethnic differences in grant success among applicants for NIH investigator-initiated research funding, with Asians and African-Americans being less likely than Whites to secure funding. After controlling for the applicant's educational background, country of origin, training, previous research awards, publication record, and employer characteristics, the authors reported that Black applicants remained 10 percentage points less likely than Whites to be awarded NIH research funding. Two further studies led by Ginther also report significant racial disparities in research grant awards (Ginther *et al.*, 2012; Ginther *et al.*, 2016).

Three studies examined the make-up of the editorial boards of academic journals and all found women to be under-represented (Amrein *et al.*, 2011; Ioannidou and Rosania, 2015; Mauleón *et al.*, 2013). However, Ioannidou and Rosania (2015) found important variation between the dental journals in their study and Mauleón *et al.* (2013) reported slight improvement over time in female representation on editorial boards of Spanish science journals 1998-2009, suggesting that patterns are not fixed. Bhaumik and Mathew (2015) found that representation of women editors in the Cochrane Collaboration was better than in editorial boards of medical journals, but concluded that there was still scope for better gender diversity.

### 3.3.1.3 Obstacles and enablers of diversity and inclusion in the research workforce

Some papers used multivariate modelling and other statistical techniques to try to understand more about the factors that contribute to women's reduced representation at higher ranks within academic medicine/health research. Other papers employed qualitative methods to examine structures and processes that may operate to (dis)advantage particular groups, again with a predominant focus on gender and women. There were also a number of papers that sought to understand the inter-play of various indicators of career advancement and how career trajectories vary for men and for women (Diamond *et al.*, 2016; Ence *et al.*, 2016; González Ramos *et al.*, 2015; Holliday *et al.*, 2014b), which relate to wider issues around recognition, reward and incentive structures discussed in the next chapter.

The mapping review identified very few papers that undertook similar analyses with a focus on other PROGRESS-plus dimensions. Bradford *et al.* (2001) discuss the preparedness of lesbian researchers to respond to the increased interest in research on health needs of LGBT people and highlight the fact that many such researchers have experienced significant obstacles to progress in research careers. Brogan (2001) provide a commentary on the Institute of Medicine report on lesbian health. However, neither of these papers offer any detailed empirical data or analysis.

#### Family and caring responsibilities

Unsurprisingly, several studies sought to examine the role of women's childrearing and wider caring responsibilities in shaping their participation within the medical/health research workforce. Several studies report the higher level of domestic responsibilities among women than men in similar academic roles (Holliday *et al.*, 2015; Jagsi, 2014; Jolly *et al.*, 2014). Sidhu *et al.* (2009) used data from the UK Athena Survey - ASSET2006 – and found that female respondents who were parents were less likely to have publications as sole ( $p=0.02$ ) and joint authors ( $p<0.001$ ) than male respondents. Female respondents who reported caring responsibilities for parents or a partner also had fewer publications as lead authors compared to those without carer responsibilities ( $p<0.001$ ). Some more encouraging findings are reported by Jagsi *et al.* (2011) in that, although they did find differences in career success (e.g. receiving grants, number of publications, perceiving themselves as successful) between men and women in their sample of promising investigators who had received NIH funding, they did not find evidence that parental status in itself was associated with differential success.

#### Aspirations

Several studies examined aspects of aspiration or career motivation by gender as a potential explanatory factor in differential career progression and productivity. Jones *et al.* (2016) conducted a mixed methods study focused on high achieving clinician-investigators who received prestigious NIH awards. In this elite research-oriented sample, they found generally limited gender differences in initial aspirations and concluded that these would not explain any differences in subsequent career

outcomes. In contrast, Smith *et al.* (2014) studied general UK-trained medical graduates in 2005 and reported that the gap between men and women in aspirations for a clinical academic career was apparent as early as the first year after qualification, with 6% of men and 2% of women expressing this aspiration. Paulus *et al.* (2016) surveyed faculty members at an academic medical centre where just 2 of 17 full professors were women. They found that among respondents who had not yet requested promotion, women were more likely to report that they did not think an academic promotion would benefit them (69 vs. 32 % in men,  $p = 0.01$ ), and to report a lack of encouragement for requesting promotion (50 vs. 29 %,  $p = 0.08$ ). A study in Italy found that fewer women applied for the Italian University habilitation competition (to secure a permanent academic post) than men but that their success rates were similar (Pautasso, 2015). The rates applying were felt to be particularly low given the large numbers of women in junior research positions.

Some authors have also suggested that women prefer to avoid competition and that this may explain their poorer performance on standard academic metrics. Ginther *et al.* (2016) report that their analysis of applications and success of NIH R01 awards showed a lower submission rate for women and an increased likelihood that they will submit only one proposal compared to men and suggest that this is consistent with the proposition that women avoid competition. They also refer to stereotype threat as a potential explanation, since the same patterns were observed for 'men of color', thus indicating that the underlying cause may not be specific to gender.

#### Individual bias and institutional discrimination

Several papers explored the potential role of individual bias and/or institutional discrimination in patterning the experiences and outcomes of different groups of people within the research workforce. Again, a majority of these investigations focused on gender/sex.

Moss-Racusin *et al.* (2012) report on an interesting randomized double-blind study ( $n = 127$ ) conducted with science faculty from research-intensive universities in US. Application materials from students for a laboratory manager position - randomly assigned either a male or female name - were reviewed by faculty members. Participants were found to rate the male applicant as significantly more competent and hireable than the (identical) female applicant. Participants also selected a higher starting salary and offered more career mentoring to the male applicant. Female and male faculty members were found to be equally likely to exhibit bias against the female applicant.

Van der Lee and Ellemers (2015) explored the system of grant applications and awards within the Netherlands and concluded a gender bias against women in success rates. They reported that male applicants received significantly more competitive 'quality of researcher' evaluations though their 'quality of proposal'

evaluations were no better than female applicants. They also concluded that the content of instructional and evaluation materials contained gendered language.

Holliday *et al.* (2014a) report on a study of 1,708 clinician-researchers who received NIH prestigious awards. A higher proportion of women reported inadequate access to grants administrators (34.8%) and statistical support (49.9%) than men (26.9%;  $p = 0.002$  and 43.4 %;  $p = 0.025$ , respectively). Women were more likely to have raised concerns about unfair treatment (50.2 % vs. 38.2 %;  $p < 0.001$ ) and to have asked for their clinical hours to be reduced than men (24.1% vs. 19.3%;  $p = 0.02$ ).

The informal, relationship-based approach to academic work has also been identified as a potential obstacle to diversity and inclusion. Nielsen (2015) argues that recruitment and selection procedures in academic settings are often not particularly meritocratic and that network ties and gender biases may influence the selection procedure. Using both quantitative and qualitative data he demonstrates that for senior positions there is often only one candidate being considered (40%) and that a worrying proportion of appointments are decided under closed procedures (19%). He reports that the pattern is further strengthened in cases where the post is funded externally and there is no requirement to advertise externally.

Similarly, Roth and Sonnert (2011) explored the role of bureaucracy, or lack thereof, in providing equal opportunities and reducing gender inequalities. Using a case study approach they investigated a research organisation where men attained disproportionately higher ranks compared to women. Even though the organisation under study has the characteristics of a typical bureaucratic setting, anti-bureaucratic attitudes and behaviours were in evidence in a range of settings. They identified “a high degree of flexibility in applying and enforcing regulations; a low emphasis on disseminating information through official channels; and a relatively strong reliance on informal rules and tacit knowledge” (p. 19), which were associated with promotions, information sharing, informal mentoring, lack of managerial training for principal investigators and academic leaders, and a disproportionate influence of direct managers.

A further aspect of institutional discrimination relates to the ways in which differential patterns of career support may be perpetuated. For instance, it has been argued that the under-representation of women and minority racial/ethnic groups at higher ranks within research organisations perpetuates the lack of appropriate career development and support for more junior staff from these groups. Jeste *et al.* (2009) suggest that a key obstacle to addressing the widening gap between the proportion of ethnic minority people in the American population and the number of researchers from these minority groups is the dearth of mentors for trainee researchers. However, Holliday *et al.* (2013) found no differences by gender or race in reported access to mentoring in their study of academic radiation oncologists in US accredited residency programmes. In terms of the match between mentors and mentees, there

is some evidence that having a mentor of the same gender can be beneficial. For example DeCastro *et al.* (2013) found that mentees were more likely to think of their mentor as a role model when the two were the same gender. This is reinforced by the finding that female mentees reported greater dissatisfaction regarding their work-family balance, which is an area that female mentors were more likely to emphasise and support.

#### More holistic analyses

A small number of studies attempted a more holistic analysis of the factors shaping differential representation and experiences within the research workforce. Cameron *et al.* (2014) review earlier literature and provide a useful diagrammatic representation of the relationship between the experience of science, low scientific self-confidence and the attrition of women from science. This model illustrates the inter-play of factors operating within the workplace, family, wider research system and also wider society to shape women's confidence and achievements as scientists. González Ramos *et al.* (2015) undertook a sophisticated statistical analysis that attempted to go beyond the 'leaky pipeline' cross-sectional analyses to map out men's and women's careers in science in more detailed, longitudinal manner. They aimed to assess how institutional and family conditions mutually affect scientific trajectories of men and women. Their results suggest quite different trajectories for men and women, with men's careers being more linear and women's having more interruptions, particularly linked to life-stages of motherhood and care-taking responsibilities.

#### 3.3.1.4 Interventions and initiatives aimed at increasing diversity and inclusion in the research workforce.

The mapping review identified a number of papers that described and evaluated interventions or initiatives aimed at addressing diversity and inclusion within the workforce. For the most part, the studies reported that interventions yielded desirable outcomes in terms of supporting individuals from minority and underrepresented groups to join and remain members of the biomedical or health research community as well as to progress in their careers of choice. However, study designs of the reviewed interventions are not very strong in terms of their appropriateness for establishing causality, generally reporting uncontrolled findings.

Furthermore, our review did not identify any studies that evidenced the link between such initiatives and the quality and impact of the research outputs resulting from increasing diversity and representation in the workforce. Some inferences can be made about the contributions and outputs of individuals from underrepresented and minority (URM) backgrounds, as studies show that certain interventions have resulted in better publication records, career progression and increased grant applications, among other indices for intervention evaluation. However, our review did not identify any studies that compare the outputs, impact and quality of research

conducted by highly inclusive and diverse groups to those of more exclusive and homogenous cohorts of researchers.

Several papers dealt with more than one intervention/initiative (Butts *et al.*, 2012; Plank-Bazinet *et al.*, 2016) For instance, Plank-Bazinet *et al.* provide an overview of two large initiatives (Research Supplements to Promote Reentry into Biomedical and Behavioural Research Careers and Building Interdisciplinary Research Careers in Women's Health) and a set of smaller initiatives developed and delivered as part of the NIH Working Group on Women in Biomedical Careers programme. These initiatives appear to be aligned and with shared objectives, and signify the recognition of the need for a long-term, holistic and systemic approach in enhancing gender representation and facilitating long-term fruitful research careers for individuals and groups who tend to be underrepresented.

Mentoring and/or training related interventions were the most common. Most of these focused on individuals who were already part of the biomedical workforce but aimed at recruiting and retaining them into research careers and enhancing research success. Papers vary in the degree of detail that they provide on mentoring programmes, but there do appear to be some potentially important variations in relation to: training of mentors; whether any payment/financial inducement is provided to mentee and/or mentor; scope/remit of mentoring relationship; and extent to which the form and content of the scheme is informed by research and/or theory around obstacles to be overcome by mentees. For instance, some programmes recognise that mentees can be disadvantaged by prevailing organisational cultures and unwritten rules and therefore focus on acculturation to the world of academia, rather than simply on skills transfer (e.g. RAMP for African American and Hispanic medical students (Sopher *et al.*, 2015); CLIMB (McGee Jr *et al.*, 2012)). Some programmes explicitly seek to develop leadership skills, rather than scientific skills alone (Byington *et al.*, 2016).

The majority of reported interventions were conducted in the US or Canada region, though they varied greatly in terms of scale and scope. The smallest scale intervention in the review was conducted by Wayne *et al.* (2010) and it involved a controlled trial designed to enhance the emergence of female leaders in small-group settings involving medical students (Wayne *et al.*, 2010). The intervention group was subject to a short 'pep talk' prior to embarking on a group activity that highlighted the benefits of engaging in leadership. This resulted in the number of emerging female leaders being proportionate to the number of female students, while in the control cohort the number was disproportionately low (27% vs. 51%). This study demonstrates how the causes of underrepresentation can be very subtle and can be overcome with minor adjustments. An example of a large scale policy intervention by the NIH is a study which evaluated the effect of capping the duration of postdoctoral positions in biomedical sciences, increasing faculty hiring, and improving education quality from kindergarten to graduate level, in an effort to increase the number and

proportion of postdocs who remain in the US and continue working in research (Ghaffarzadegan *et al.*, 2014). Using existing data and system dynamics modelling the authors provided estimates of the effects various versions of considered policy interventions might have. They found that capping the duration of post docs or increasing faculty hiring would not lead to the intended outcome of increasing the number and retaining domestic researchers in academic careers, since the intervention would result in a disproportionate increase in international researchers on the postdoc programmes, who often return to their home country following completion. However, they also estimated that improving education would result in an increase in the proportion of US nationals taking postdoctoral positions and remaining in the US to work in research.

In terms of scope, one of the widest interventions is reported by Butts *et al.* (2012), covering a series of related interventions by a single HEI (Mount Sinai School of Medicine) which range from encouraging and supporting individuals from underrepresented and minority groups to join and stay in biomedical research education and career, and involves initiatives ranging from developing skills before joining programmes of study to creating groups and networks in the organisation that support and promote inclusion of individuals from URM backgrounds.

The workforce-focused interventions in this review can be broadly categorised into two groups; education-focused and career-focused. The education-focused interventions tend to be directed to students and provide them with opportunities to take part in research-related activities as part of structured skills development programmes that often involve mentoring (e.g. Ghee *et al.*, 2014; McGee Jr *et al.*, 2012; Sopher *et al.*, 2015). The career-focused interventions relate to initiatives such as mentoring, coaching and career development awards that are aimed at increasing retention and progression of individuals in research careers, and these are discussed in terms of their capacity to improve outcomes from individuals from underrepresented groups (Campbell *et al.*, 2013; DeCastro *et al.*, 2013; Jagsi *et al.*, 2011). Three of the papers reported on initiatives aimed at shifting wider cultures and structures within research organisations and the wider system. Butts *et al.* (2012) focused on under-represented minority racial/ethnic groups, while other studies focused on gender equality (Munir *et al.*, 2013; Plank-Bazinet *et al.*, 2016). All three papers have reported an improvement either over time or in comparison to institutions that did not adopt the initiative/won award, however it is not possible to infer causality since none of the initiatives had a control group for comparison. Overall, it appears that targeted and sustained interventions tend to yield desirable outcomes especially where these are embraced and supported by senior leadership and there is encouragement for participation and involvement in initiatives across the institution.

Some of the more ambitious policy-driven interventions involved a number of institutions and inter-institutional collaboration. For example, McGee Jr *et al.* (2012)

describe two programmes organised by the Leadership Alliance of 32 institutions in the US, which involve students from minority-serving institutions engaging in research-related training and activities with research-focused institutions. The programmes have had thousands of participants over two decades and have yielded the desired effects in that large proportions of the participants continued with postgraduate studies and pursued research-focused careers. These initiatives included elements of mentoring/training schemes for scholars but also wider collaboration. A similar programme is reported by Campbell *et al.* (2013) where faculty members of teaching-intensive minority-serving institutions participated in 8-10 week internships in research-focused institutions. This initiative resulted in an increase in the number of publications and federal grants compared to a cohort of matched peers. Apart from partnerships among HEI, there have been reports of partnerships between HEI and research organisations (Sopher *et al.*, 2015) where students from minority groups worked on research-related initiatives and received mentoring. Masuda and colleagues (2011) report on a collaboration that involved medical students working alongside community-based learners to design and conduct community-based participatory research.

Even though the reported initiatives had generally positive and intended outcomes, there are some interesting findings that are surprising or counterintuitive, and give insights into the broader health research system and its inter-linking elements. For instance, Tilstra *et al.* (2013) report on a fellowship programme in veteran women's health that attracted mostly female candidates (97% of respondents). The programme struggled to recruit the intended number of candidates, possibly due to reliance on word of mouth for recruitment. The programme graduates also reported that they did not gain skills related to career progression and grant applications. They did, however, have better career progression in the following years compared to the women in the general population of academic physicians. Although the fellowship had evidently positive impacts on the participants' careers overall, there is no discussion of the implications of the overwhelming homogeneity (female) of the cohort of fellows working on women's health. The homogeneity of researcher cohorts in the women's health research seems to be a pattern, with Building Interdisciplinary Research Careers in Women's Health (BIRCWH) scholars also being overwhelmingly female (80%) (Plank-Bazinet *et al.*, 2016). In fact, Plank-Bazinet and colleagues report that while a BIRCWH-mentored career development programme yielded positive outcomes for participants' careers, the benefits were higher for women than for men in terms of successes in grant capture, demonstrating that certain initiatives might unintentionally preferentially benefit members of specific demographic groups.

The only intervention conducted in the UK deals with the effectiveness and impact of the Athena SWAN Charter initiative that awards excellence status to HEI and departments based on their policies and practices aiming at reducing gender bias and creating inclusive workplaces in the STEMM fields (Munir *et al.*, 2013). The



evaluation study involved comparison of survey data between institutions holding an Athena SWAN award and those not having the award. This was supplemented by nine in-depth case studies of organisations with awards. The survey found differences between organisations/departments holding an award compared to others on a range of indicators, including women's satisfaction with their career, the training and development opportunities available to them, familiarity with processes for promotion, reports of rewards for work and perceptions about the university's promotion of equality and diversity.

Even though these findings are promising they do not provide evidence of the causal relationship between scheme participation and outcomes, as it could be the case that the departments and institutions which apply for an Athena SWAN award are those that already have progressive and inclusive climates, cultures, policies and procedures. However, rich evidence of the mechanisms and specific department- and institution-level initiatives are exemplified in the case studies. Participation in the scheme appears to have raised the issue of equality and diversity on the strategic agenda of organisations and increased awareness of inequalities and related challenges. The case studies indicate that the work associated with preparing departmental and institutional applications for the Athena SWAN awards was valuable in promoting awareness and inclusion; however most of this work was done by women in the organisations. This indicates that perhaps men, by not participating in the preparation work, were somewhat excluded from equality and diversity promotion efforts and involvement. On the other hand, in various organisations there was no workload allocation associated with the preparatory work, indicating that the people working on the application (predominantly women) would have to make sacrifices in terms of their time and perhaps their other work objectives.

### **3.4.2. Research participants, topics and agendas**

Of the 246 publications that were coded in this review, 65 were identified as addressing *research participant* related issues. These papers also often engaged with issues of research topic selection and also research methodologies and methods. In seeking to address the guiding question of the mapping review, retrieved material relating to diversity and inclusion within research participants and research topics is relevant for two inter-linked reasons. First, dimensions of research quality can be argued to include 'representativeness' and 'relevance'. Indeed, the need for health researchers to generate an evidence base that reflects the needs of a diverse population has been federally-mandated in the United States in relation to clinical research, gender and race since 1993 (NIH, 2001), and has been formally acknowledged by the UK's Department of Health in its Research Governance Framework for Health and Social Care (DH, 2005). Second, as discussed in the introduction to this report, the boundaries of 'the health research community' are expanding, with a growing expectation that members of the public, patients and carers will be active players, both shaping and participating in research. This

engagement, it is argued, will in turn enhance the quality of research by making it more relevant, and also less likely to cause harm.

### 3.3.2.1 Rationales for diversity and inclusion in research samples and topics

The arguments put forward in support of research samples being inclusive of diverse population groups relate to both scientific quality and also legal and ethical principles. Kelty et al. set out the rationale behind the NIH inclusion guidelines for clinical research as follows; “since a primary aim of research is to provide scientific evidence leading to a change in health policy or a standard of care, it is imperative to determine whether the intervention or therapy being studied affects women or men or members of minority groups and their subpopulations differently” (Kelty *et al.*, 2007, p. 138). They go on to say “inclusion of women and minorities was based on two important needs: the need for justice in providing access to potential lifesaving therapies and the need to obtain information and address gaps in scientific knowledge.” Similarly, Oakley *et al.* (2003) argue that including diverse samples in research improves generalizability of research findings by increasing external validity, as well as respecting the right to be included in research.

Several commentators note the shift over time away from a concern to avoid individual risk to female participants and therefore the exclusion of women from biomedical research, to a recognition of the liabilities associated with collective exclusion of women from research and its discoveries and benefits (Kelty *et al.*, 2007; Merton, 1993; Stevens and Pletsch, 2002). Parallel arguments are also presented in relation to people who do not speak English (or the national language) (Bustillos, 2009; Glickman *et al.*, 2011); and socioeconomically disadvantaged groups (Dickert, 2009; Stone, 2003). However, debates regarding the ethics of inclusion versus exclusion of particular groups in particular research circumstances continue (Fisher and Kalbaugh, 2011; Glickman *et al.*, 2011). Ethical concerns are raised around disadvantaged individuals using payments linked to participation in Phase I clinical trials as an income and other strategies of recruitment. As Fisher and Kalbaugh (2011, p. 2220) note, “minorities as a group might again be assuming much of the risk of biomedical research without sharing the benefit”.

A number of papers in the review drew attention to the need to look beyond simple representation within research samples to consider: the analyses that are performed; the extent to which research addresses the health issues that are of most concern to disadvantaged and marginalised groups; and whether the outputs produced have the potential to positively impact on their health. There is increasing recognition that research can do more harm than good, both at an individual participant and at a collective level, particularly when its focus is on groups who are marginalised and pathologised in wider society (Salway and Ellison, 2012). Mir *et al.* (2013) worked with a group of experts in the UK to develop the *Leeds Consensus Statement*, a set of principles on how to research ethnicity and health. This paper, in common with a

recent review by Clarke *et al.* (2013) in the US, highlights the predominant focus of research on minority racial/ethnic people themselves as the source of poor health rather than wider social and health systems and calls for more research that tests out interventions to address health inequalities rather than simply describing such disparities. Similar concerns have been raised in relation to research on LGBT health. Sousa and Moleiro (2015) reviewed publications in PubMed 2001-11 for research on LGBT health and noted the predominant focus on sexually transmitted disease and lack of attention to other diseases or disability. So, while participation in research by minoritised groups has been advocated on the basis that “power is directly related to knowledge” (Pyett, 2002), the terms, conditions and impacts of engagement are increasingly open to scrutiny.

### 3.3.2.2 Patterns and trends over time in research participants, topics and agendas

A number of descriptive papers reported on reviews of research protocols/funded studies (Larson, 1994; Mak *et al.*, 2007) or reviews of published papers (Brooker *et al.*, 2015; Humphreys *et al.*, 2015; Murray and Buller, 2007; Oertelt-Prigione *et al.*, 2011) that aimed to characterise research participants and the degree to which they were representative of the general population. Most of these papers were concerned with the representation of women and/or of minority racial/ethnic groups. Other axes of difference were examined in a smaller number of papers, including: age, such as the exclusion of the elderly (Bugeja *et al.*, 1997; Hurlimann *et al.*, 2011) and the exclusion of children (Hurlimann *et al.*, 2011); disability, e.g. the exclusion of people with intellectual disability (Brooker *et al.*, 2015); and the exclusion of people with psychiatric disorders (Humphreys *et al.*, 2015). Most papers examined inclusion in clinical research, rather than other types of health-related research. Unjustified exclusion from research activity was concluded by a majority of papers. However, as noted above, some research also raises the possibility of unjustified over-representation and the ‘over-researching’ of some marginalised communities. Fisher and Kalbaugh (2011) report over-representation of minority racial/ethnic participants in Phase I healthy volunteer clinical trials in the US – the most risky trials.

In relation to gender, it is important to note that some significant differences in patterns of inclusion have been noted across health research specialties and disciplines (Oertelt-Prigione *et al.*, 2011) and that nursing research has been highlighted as an area that tends to exclude men rather than women (Polit and Beck, 2009; 2008; 2012). Importantly, also, there appears to have been significant improvement over time in the gender representativeness of biomedical research samples in the US. So, while papers from the 1990s highlighted the exclusion of women (Larson, 1994), later papers reported proportions of male and female participants proportionate to the general population, such as Kelty *et al.* (2007) reporting 2004 NIH data and Mak *et al.* (2007) reporting on NIMH-funded trials 1995-2004. In contrast, there appears to have been slower progress in relation to achieving good representation of minority racial/ethnic groups over time despite their

inclusion within the remit of the US Revitalisation Act (Kelty *et al.*, 2007; Mak *et al.*, 2007). Progress on inclusion of other groups is less well documented but also appears to be slower (e.g. LGBT).

Furthermore, while sex representative samples may currently more often be the norm (at least in the US), it is noted that sample sizes frequently are not large enough to sustain analyses by sex and differential results by sex are often not examined (Mak *et al.*, 2007; Rogers and Ballantyne, 2008). Clearly then, much biomedical research practice still does not deliver sex-specific findings. Similar shortcomings are discussed by Salway and Ellison (2012) in relation to ethnic group representation in research samples, and Minas *et al.* (2013) have noted that in Australia some minority ethnic groups are much better represented in research than others. Drevdahl *et al.* (2001) looked at published nursing research between 1952 and 2000 and found that the use of race and ethnicity as variables had increased over the period, but that there was little growth in studies where racial/ethnic groups other than Whites were the majority of the sample. Limited evidence on patterns and trends over time in the make-up of research participants by key inclusion and diversity characteristics was identified for countries other than the US.

Looking beyond the make-up of research samples, to the agendas and topics pursued by health researchers, and their likely positive impact on health inequalities, there was less evidence of a consistent shift over time. Sandelowski *et al.* (2009) highlighted the recurring assumption that sample inclusiveness automatically implies attention to gender, race and class in health research. In their review of research on stigma and HIV they note how infrequently health research addresses in any meaningful way how these aspects of social identity shape health. Drevdahl *et al.* (2001) reviewed papers published in *Nursing Research* between 1952–2000 and reported some increase over the period in studies employing race or ethnicity as variables. However, Williams (1994) reviewed all papers published in *Health Service Research* between 1966 and 1990, and found that race/ethnicity was used as a variable within roughly 50% of studies, with no clear trend over time. It is important to recognise contextual variation in research agendas and traditions across countries and disciplines. For example, the sharply contrasting level of attention to race/ethnicity within the health inequalities/disparities literature in the US and the UK has been highlighted (Ingleby, 2012; Salway *et al.*, 2014).

Boehmer (2002) reviewed MEDLINE English-language articles on human subjects published between 1980 and 1999 and found that 0.1% of all papers focused on health of LGBT people and that research on the health of transgender individuals, and on health issues other than sexually transmitted diseases, was particularly negligible. Coulter *et al.* (2013) examined NIH funded studies from 1989-2011 and found 0.1% focused on LGBT health. Furthermore, there is a persistent concern in the literature that research into the health needs of minoritised groups is commonly poorly theorised and executed. For instance, in relation to health research related to

racial/ethnic minority groups Drevdahl *et al.* (2006) explored the use of race and ethnicity variables in the nursing research literature by performing a content analysis of 337 original research studies published in *Nursing Research* from the years 1952, 1955, and then every 5 years through to 2000. Throughout the sample, they found substantial inconsistency related to categorization and use of variables and a lack of detail on conceptual assumptions, definitions, and context.

Many similar reviews have been carried out for other areas and disciplines within health research and reached similar conclusions over the past three decades (Ahdieh and Hahn, 1996; Anderson and Moscou, 1998; Brahan and Bauchner, 2005; Comstock *et al.*, 2004; Ellison and de Wet, 1998; Ellison, 2005; Gerrish, 2000; Mays *et al.*, 2003; Porter and Barbee, 2004; Salway *et al.*, 2011; Walsh and Ross, 2003; Wilkinson and King, 1987; Williams, 1994). Similar concerns have been raised in relation to research on health issues of LGBT people, with conceptual fuzziness and small population subgroups presenting particular challenges (Malterud *et al.*, 2008; Plumb, 2001), and people with impairments/disabilities (Bergh *et al.*, 2016).

### 3.3.2.3 Obstacles and enablers of diversity and inclusion in research participants and topics

The review highlights the importance of recognising both active and passive processes of exclusion from research studies. For instance, Glickman *et al.* (2011) note how consent procedures for some clinical trials in the US actively exclude patients who do not speak English, while Oakley *et al.* (2003) note that standard recruitment procedures often passively exclude in much the same way because they lack linguistic and cultural appropriateness. In addition, low levels of trust and negative attitudes towards medical research are identified as factors leading to a greater reluctance to participate in research among some groups. In the US, the legacy of Tuskegee and other past abuses are identified as a persistent determinant of low levels of participation in research by racial/ethnic minorities (Seto, 2001; 1994) and particularly 'women of color' (Stevens and Pletsch, 2002). Empirical studies provide some evidence that willingness to participate in medical research is lower among racial/ethnic minorities than Whites in the US (Kressin *et al.*, 2000; Svensson *et al.*, 2012). However, the picture is not consistent and it is clear that other factors, including provider perceptions and lower access to care also play a role, with some studies finding few racial differences in stated willingness to participate (Fisher and Kalbaugh, 2011; Katz *et al.*, 2007). Similarly, a large-scale study focused on South Asian patients in the UK (Hussain-Gambles *et al.*, 2004), involving both a review and primary qualitative research, concluded no evidence of antipathy to the concept of clinical trials and that 'there are more similarities than differences in attitudes towards clinical trial participation between the South Asian and the general population'. This study identified lack of time and resources and 'cherry picking' of particular patients plus language barriers as factors that reduce the recruitment of South Asian patients to clinical trials.

Obstacles to the design and delivery of health research that effectively addresses the health concerns of marginalised and disadvantaged groups appear similarly multi-faceted. Researcher skills, confidence and tools can be insufficient to work with complex concepts and engage with research participants across social and cultural distance (Papadopoulos and Lees, 2002; Porter and Barbee, 2004). Institutional cultures, structures and processes do not necessarily encourage research on minority health issues (Masuda *et al.*, 2011). Further, individuals and communities may be reluctant to get involved in research studies and some can become 'over-researched' (Johnson, 2006).

#### 3.3.2.4 Interventions and initiatives aimed at increasing diversity and inclusion of research participants and/or topics

The review identified a range of initiatives at various levels of the health research system aimed at increasing the representation of excluded groups as research participants and/or increasing the volume and quality of research that addresses health issues among minority/excluded groups. However, few of these initiatives have been evaluated using rigorous methods, and a majority of papers report on descriptive studies.

##### Legislation

The US appears to be the only country that has introduced legislation in this area, with the NIH Revitalization Act of 1993 directing the NIH to establish guidelines for inclusion of women and (racial/ethnic) minorities in clinical research, and researchers reporting on the impact of this policy on research practice (Caban, 1995). (See also Case Study 1, section 5.2).

##### Policies and guidelines

A variety of policies and guidelines have been developed at various levels and at relating to various points in the health research cycle. The UK Department of Health's Research Governance Framework for Health and Social Care sets out a number of general principles that should apply to all research and highlights the importance of diversity (see Case Study 2, section 5.3):

*'Research, and those pursuing it, should respect the diversity of human society and conditions and the multi-cultural nature of society. Whenever relevant, it should take account of age, disability, gender, sexual orientation, race, culture and religion in its design, undertaking and reporting. The body of research evidence available to policy makers should reflect the diversity of the population'* (DH, 2005, p. para 2.2.7)

The Canadian Institutes of Health Research (CIHR) have undertaken a major initiative around promoting gender equity through health research (Stewart *et al.*,

2013). This has involved various elements including the production of guidance and toolkits e.g. *Sex, Gender and Health Research Guide: A Tool for CIHR* (see Case Study 3, section 5.4). CIHR has also produced a range of other guidelines such as *Guidelines for Health Research Involving Aboriginal People* which have guided approaches to research with these marginalised groups (Boffa *et al.*, 2011). Similarly, in Australia *Guidelines on Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* have been produced and been found useful in work with other marginalised groups (e.g. Bailes *et al.* (2006) report on their utility in promoting 'respectful engagement' with Somali immigrants).

In the US, the Institute of Medicine (IOM) Committee on Lesbian Health Research reported in 1999 (IOM, 1999) with the intention of legitimising research on lesbian health, increasing funding in this area and resulting in a 'paradigm shift' (Brogan, 2001). Similarly, in 1998, the NIH issued a guideline requiring the inclusion of children to be addressed in all applications (Keltly *et al.*, 2007). A range of guidelines have been introduced by funding agencies and ethics committees in other countries that aim to address under-representation.

Guidelines have also been developed by groups of researchers e.g. the Leeds Consensus Statement on researching ethnicity and health (Mir *et al.*, 2013) and by journal editors (Ellison and M, 2002). However, commentators suggest that such guidelines alone are insufficient to change practice. For example, Woodward-Kron *et al.* (2016) note that in Australia there are few strategies in place to recruit non-English speaking participants to research despite national ethics guidelines on the inclusion of linguistic/cultural minorities. Similarly, Ballantyne and Rogers (2008) report that ethics committees in Australia do not take an active role in monitoring the sex of research participants, do not ask for or often do not receive information about the sex of participants, and that most HREC chairs do not believe that sex discrimination in research is currently a significant or widespread problem. There was an absence of papers in the review that aimed to evaluate the impact of such policies and guidelines on health research practice.

### Targeted investments

The review highlighted some areas where targeted investments by funding agencies or research institutions had aimed at fostering more research in particular areas. An example was recent NIHR investments in child health research and the recently established UK Child Health Research Collaboration (supported by Wellcome and MRC). Other investments have focused on developing the workforce (as already discussed above).

### Workforce diversification and skills development

As already mentioned above, several papers in the review argued that efforts to recruit and retain a more diverse research workforce will lead to more representative research samples and a greater volume of research addressing the health needs of

under-represented groups. For instance, Bradford *et al.* (2001) claim that having more lesbian health researchers will increase the volume of research on lesbian health issues. However, though this relationship is hypothesised, there was little by way of concrete evidence to demonstrate it in practice. A comprehensive initiative at the Mount Sinai School of Medicine included efforts to expand the volume of research focused on minority health issues as well as diversify the workforce (Butts *et al.*, 2012). Plank-Bazinet *et al.* (2016) describe the NIH Working Group on Women in Biomedical Careers which led to the establishment of Research Partnership on Women in Biomedical Careers, a grassroots group aimed at continuing the research goals brought forth through this program. They report that the grantees, 22 out of 24 of whom are women, have been highly productive in terms of publications and presentations on women in science. They also report on Building Interdisciplinary Research Careers in Women's Health (BIRCWH) a trans NIH mentored career development program that seeks to connect junior faculty BIRCWH scholars to senior faculty members with shared interests in women's health or sex differences research.

Initiatives aimed at enhancing the skills and knowledge of health researchers to undertake research with minority/excluded groups were also reported on in the review. Rubin *et al.* (2012) describe their work in Boston which they describe as 'community engaged pedagogy' and which involves a collaborative teaching approach with a diverse faculty aimed at building understanding and partnership between traditionally trained academics and community members. Masuda *et al.* (2011) report on Partnerships in Community Health Research, a similar training programme for researchers and the community research workforce at the University of British Columbia.

### Research tools and techniques

The review also highlighted a range of tools and techniques that have been developed by researchers to support recruitment of traditionally under-represented groups, for example, a web-based technology that allows anonymous data collection that had been used successfully among Native Americans (Douma and Gamito, 2007), or a tablet-based resource to increase awareness of the purpose of medical research and participation among 'culturally and linguistically diverse' (CALD) groups (Woodward-Kron *et al.*, 2016). Ejiogu *et al.* (2011) and Oakley *et al.* (2003) describe more holistic approaches to recruitment and retention employed in quantitative, community-based health research projects. Both these projects conclude that recruitment of diverse and socially disadvantaged research participants is challenging but possible with adequate resource and time investment.

Similarly, Renert *et al.* (2013) identify the following key strategies to increase recruitment of 'non-dominant' research participants:- engaging gatekeepers, using cultural insiders, developing culturally-sensitive recruitment materials, offering payment, and developing trust with participants and their communities. Wong *et al.*



(2014) and Rogers and Petereit (2005) both describe longer term partnership approaches between communities and research institutes to support recruitment of minorities to clinical trials and to build a programme of work on health disparities. Again, these papers report the success of the initiatives but highlight the significant costs involved, the effort required to build and maintain trust, and the associated challenges of sustainability. Bonevski et al.'s (2014) review of attempts to increase participation in health research among the socially disadvantaged also highlights the need for extended timeframes, increased resources and community partnerships.

#### Community engagement and participatory methods

Several papers in the review reported on initiatives aimed at going beyond recruitment as participants to actively engaging members of minority/marginalised groups and community within the research process. Such active involvement is advocated to ensure the maintenance of safety and respect, for instance in relation to processes of informed consent for marginalised groups (Stevens and Pletsch, 2002) and also on the grounds that this should increase the chances of the topics and framing of health research studies addressing the concerns of the groups in question. For instance, Plumb (2001) calls for “the involvement of the lesbian community in designing, implementing, and analyzing the research itself” (p. 874).

El Ansari (2005) report on a three-year long collaborative public health research project with five disadvantaged communities across South Africa and highlight a range of challenges particularly related to costs and clarity of relationships, roles and values. Johnson and colleagues (2013) describe the involvement of community co-researchers – female health workers or ‘promotora’ – in the Texas-Mexico border area. They conclude that the involvement of these co-researcher resulted in better research because of their ability to act as cultural brokers and represent the perspectives of community residents. Other research has, however, highlighted some of the ethical and methodological challenges of working with community researchers from diverse and disadvantaged backgrounds (Salway *et al.*, 2015). Participatory projects also often make use of novel methods for engaging participants and generating research data, such as using visual methodologies with street youth in Bogota, Colombia (Ritterbusch, 2016).

### **3.4.3. Broader concerns and holistic papers**

Importantly, while the majority of papers identified by the review take a national focus, a few papers highlight the global patterns of exclusion from health research.

Ostlin and colleagues (2005) highlight inequities in the research system in terms of the very small amount of funded health research that relate to poorer parts of the world and ill-health that afflicts poorer people and women. They note that research is often driven by the market for health products. Similarly, Pratt *et al.* (2016) argue that

processes for health research priority setting may not be fair and are dominated by elites so that the health needs of marginalised groups are over-looked. Boutilier *et al.* (2011) provide an introduction to a set of case studies of North-South research partnerships which they argue offer models for effective ways of increasing the volume and quality of research that addresses the health needs of the most vulnerable in global context. Razzouk *et al.* (2010) mapped the mental health research capacity in low-and-middle-income countries (LAMIC) for the years 1993-2003. They identified mental health researchers from 114 LAMIC in three continents and found them to be concentrated in just 10% of the countries. Horton (2003, pp. 712-3) highlighted the under-representation of individuals from LMIC on the editorial boards of leading journals that had been previously reported and argued that there is widespread systematic bias in medical journals against diseases that dominate the least-developed regions of the world, and suggests that 'ethnic biases within our journals are a pressing problem, subverting efforts to promote equity in global health'.

#### **3.4.4. Summary of interventional approaches and metrics/outcomes**

As noted above, the mapping review identified a much larger volume of descriptive and exploratory studies than interventional or evaluative studies. Table 6 summarises the 25 studies that presented some kind of evaluation of an intervention or initiative aimed at increasing diversity and/or inclusion within an aspect of the health system. Most commonly these addressed the diversity of the workforce or of research participants. The table briefly describes the type of intervention/initiative and identifies the metrics or descriptive outcomes that were assessed as indicators of intervention 'success'.

Of these studies, those which focused on Workforce issues used largely conventional indicators of academic performance such as publications written, grants secured and positions obtained. Very few metrics related to longer-term outcomes or evaluation. The most illuminative was the evaluation of Athena Swan implementation (Munir *et al.*, 2013), which examined a range of specific and cultural indicators. However, the majority of these related qualitatively to perceptions of programme success with a consequent lack of "hard" data. Only one study included an in-built critique of metrics used ([McGee Jr \*et al.\*, 2012](#)).

The studies of Participants tended to focus on quantitative aspects of recruitment, and retention to trials, although there was brief consideration of qualitative aspects of the diversity of the study sample.

The study which related to Participants/Topics in health service research priority-setting gave little detail or data on proposed interventions. Instead it focused on changing the culture of involvement to one of "deep inclusion".

**Table 6 - Indicative Metrics and Outcomes for Intervention Studies with evaluative elements (n=25)**

Study Identifier	Domain(s)	Progress+ characteristic(s)	Intervention(s)	Primary Metric/ Outcome	Secondary Metrics/ Outcomes
Boffa et al. (2011)	Participants Patient & Public Involvement	Race/ethnicity	Comprehensive approach to collaborative research methodology involving Aboriginal people	Community engagement in and support for the project	Recruitment of Aboriginal people to the epidemiological study
Bonevski et al. (2014)	Participants	'socially disadvantaged' Socioeconomic status Sexual orientation Race/ethnicity Disability	Multiple Review paper (116 studies including 31 previous reviews and 9 RCTs) Sampling strategies Recruitment strategies Retention strategies Data collection strategies	Recruitment and retention of study participants	Data completeness
Butts et al (2012)	Workforce	Race/ethnicity Gender/sex	Comprehensive plan to increase diversity	Faculty Diversity Climate Survey	Examination Pass rates; Examination Success rates; % of Black and Hispanic Students in Training Programmes
Byington et al (2016)	Workforce	Race/ethnicity Gender/sex	Institutional mentoring programme	No. of extramural awards	Retention within academic medicine; Retention within institution; Increased inclusion within institutional research enterprise
Campbell et al (2013)	Workforce	Race/ethnicity	Supporting career training and research practices	No. of refereed publications	Amount of federal grant funding Impact on professional activities and curricular practices
De Castro et al. (2013)	Workforce	Gender/sex	Mentoring linked to NIH clinician-researcher awards	Career satisfaction	Aspects of mentoring and satisfaction with mentoring
Ejiogu et al (2011)	Participants	Race/ethnicity Socioeconomic status	Multifactorial recruitment and retention strategy for study cohort including community partnerships	Recruitment and retention of study participants	Barriers and specific individual challenges (subdomains) relevant to recruitment
El Ansari et al. (2005)	Workforce Participants Patient & Public Involvement	Socioeconomic status	Community-university research collaboration	Establishment and sustainability of productive research partnerships	Changes in curricula Community development efforts
Ghee et al (2014)	Workforce	Race/ethnicity Gender/sex	Summer Research Early Identification Program (SR-EIP) and the Leadership Alliance National Symposium (LANS),	Impact on student participants' undergraduate learning experience	Subsequent academic and career outcomes

Johnson et al. (2013)	Participants Patient & Public Involvement	Race/ethnicity Socioeconomic status Place	Community-university research collaboration with local health workers as researchers	Recruitment and retention of study participants Improved data collection	Research addressing community needs Long-standing relationships between community and university
Masuda et al. (2011)	Workforce Participants Patient & Public Involvement	Socioeconomic status Place Race/ethnicity	Training programme for graduate students and community-based learners	Student readiness to undertake Community Based Participatory Research (CBPR)	Success in undertaking CBPR assessed in terms of research excellence and expectations of community partners
McGhee et al (2012)	Workforce	Race/ethnicity Socioeconomic status Disability	Interventions at post-baccalaureate and PhD levels, and novel coaching model	Completion of doctoral programme	<i>Critiques emphasis on “minimising transit time” instead of “time to develop talents” and Inability to look at “impact” instead of small- scale program evaluation</i>
Munir et al (2013)	Workforce	Gender/sex	Athena Swan Charter	Perceived Impact on women’s career progression Perceived Impact on gender issues	Satisfaction with career performance/ development review and with opportunities for training and development Familiarity with processes for promotion, likelihood of receiving rewards Rating of university for the promotion of equality and diversity Fairness of workload and transparency of the workload model Perceived visibility, self-confidence, leadership skills, ability to think about gender issues and impact on career development
Murray et al (2016)	Workforce	Other – size of research institution	Pilot program to lower standards for select grant applicants from small institutions	Research grant proposal success rate	Research grant funding level
Oakley et al (2003)	Participants	Race/ethnicity	Inclusive study recruitment procedures	Recruitment rate	Diversity of sample
Plank-Bazinet et al (2016)	Workforce	Race/ethnicity Gender/sex	Office of Research on Women’s Health (ORWH) programme to support researchers returning to workforce (Research Supplements to Promote Reentry into Biomedical and Behavioral Research Careers), career development awards via Building Interdisciplinary Research Careers in Women’s Health program, and trans- NIH involvement and activities from NIH Working Group on Women in Biomedical Careers.	Involvement in activities associated with research independence (e.g. publications, positions, grants)	Effect on scientific expertise, laboratory techniques, grant writing skills, and networking. Papers and Presentations.

Pratt et al (2016)	Participants Topics	Multiple	Model of deep inclusion based on deliberative democracy and development ethics	Involvement in health research priority-setting	Range of roles; Numbers in particular roles. Level of consultation
Qualls (2002)	Participants	Race/ethnicity	Set of recruitment strategies	Recruitment and retention of participants	
Renert (2013)	Participants	Race/ethnicity	Set of recruitment strategies	Recruitment and retention of participants	Levels of trust with communities
Rice et al (2014)	Workforce	Race/ethnicity Disability	Summer Institute Program to Increase Diversity (SIPID) mentored programmes (incl. grantsmanship skills)	Mentees' satisfaction rating about the program, grant and publications productivity and specific comments	Confidence levels in planning and conducting research
Ritterbusch (2016)	Participants Topics	Age Other: substance abusers	Research approach using visual participatory methods	Recruitment, retention and engagement of participants	Impact of research on social inclusion of stigmatised groups
Sopher et al (2015)	Workforce	Race/ethnicity	Research and Mentorship program	Increases in self-reported knowledge, professional skills, and interest in future HIV vaccine research	Qualitative data on success factors
Tilstra et al (2013)	Workforce	Gender/sex	VA Women's Health Fellowships	Pursuit of academic career	Achievement of advanced degree; Practice of clinical women's health; Time devoted to women's issues; Retention in academia; Retention in tenure stream; National presentations; Receipt of grant funding; Publication of peer reviewed publications; Development/evaluation of curricula; Awards for teaching or research; Major leadership positions; Promotion to associate professor; Promotion to Professor
Wayne et al (2010)	Workforce	Gender/sex	Brief "pep talk" on importance of experiencing a leadership role	Percentages of men and women who became group leaders	
Wong et al (2014)	Participants	Race/ethnicity	Cancer Disparities Research Partnership Program (targeting hospitals with limited funding track record)	Funding success; patient accrual	Recruitment to trials Participation in trials

## 4. Results of the metrics review

### 4.1. Diversity, inclusion and responsible metrics

Across research policy and funding, there is a growing recognition that initiatives to encourage greater diversity and inclusion in research systems are likely to prove inadequate, if the metrics and indicators that are used to define, measure, recognise and reward success within those system (through notions of research “quality”, “excellence” or “impact”) simply reinforce existing inequalities and hierarchies.

Across much of science, the continued dominance of a narrow range of conventional indicators as proxies for research quality (citations, Journal Impact Factors etc.), limits frames of measurement and assessment, shapes the way that research agendas are prioritized, and influences career pathways and trajectories. As Rafols and Molas-Gallart (2015) argue, “conventional S&T indicators are very problematic in 'peripheral' spaces. These 'peripheries' can be thought in geographical, cognitive or social dimensions...Research for marginalised social groups may also be seen as less 'central' than research aligned with the interests of dominant institutions.”

This applies as much to health research as to other domains, and has led to an emerging focus on the relationship between diversity, quality and impact in research metrics and indicators (as reflected, for example, in the theme of the 2016 International Conference on Science, Technology and Innovation Indicators; one of the larger annual meetings of the scientometrics research community.)<sup>6</sup> Scientometricians and research policy analysts are also increasingly alarmed about the effects that a small range of dominant metrics are having on research cultures (Braun, 2012; Garfield, 2006; Garfield, 1996; Hicks *et al.*, 2015; van Dalen and Henkens, 2012; Weingart, 2005; Wilsdon *et al.*, 2015). This concern is reflected in recent initiatives such as the San Francisco Declaration on Research Assessment (DORA), Leiden Manifesto and The Metric Tide.<sup>7</sup>

Scientometric data are well developed for measuring knowledge progression and use among academic audiences (particularly in the biomedical and life sciences). Newer, alternative (or “alt”) metrics have become more widespread in the past five years, particularly for article-level metrics (e.g. downloads), interest and activity on social media (e.g. tweets), and in the measurement of non-academic impacts (Ovseiko *et al.*, 2012)

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<sup>6</sup> See <http://www.sti2016.org/>

<sup>7</sup> [www.ascb.org/dora](http://www.ascb.org/dora); <http://www.nature.com/news/bibliometrics-the-leiden-manifesto-for-research-metrics-1.17351>; <http://www.hefce.ac.uk/pubs/rereports/Year/2015/metrictide/Title,104463,en.html>

The promise of metrics is that they can make the identification of research qualities or impacts more objective – and easier to administer. When one designs a metric, one also implicitly constructs a definition of quality or impact, and locks that in place. But the qualities and impacts of research are multidimensional and change over time. Because of this, we need to think very clearly about what we are assessing, and why, and select metrics appropriate to these needs.

In recognition of these challenges (Wilsdon *et al.*, 2015) proposed a framework of “responsible metrics” for the appropriate use of quantitative indicators in the governance, management and assessment of research. Responsible metrics can be understood in terms of five dimensions:

- **Robustness:** basing metrics on the best possible data in terms of accuracy and scope;
- **Humility:** recognising that quantitative evaluation should support – but not supplant – qualitative, expert assessment;
- **Transparency:** keeping data collection and analytical processes open and transparent, so that those being evaluated can test and verify the results;
- **Diversity:** accounting for variation by field, and using a range of indicators to reflect and support a plurality of research and researcher career paths across the system;
- **Reflexivity:** recognising and anticipating the systemic and potential effects of indicators, and updating them in response.

## 4.2. Narrative review of key themes

Of the 246 publications coded for this review, 43 were identified as relating to the relationship between metrics/indicators, and diversity/inclusion in health research. Closer examination of these 43 papers indicates five main clusters:

### 4.2.1. Studies that identify inequalities and/or potential biases in conventional research metrics

Akre *et al.* (2011) examine the relationship between citation rates and country of origin for 4724 papers published between 1998 and 2002 in a set of leading medical journals. They find differences in citation rates by country of origin, which suggest it may be more difficult for researchers from low to middle income countries to publish in such journals.

Cameron *et al.* (2012); Cameron *et al.* (2014) explore how conventional metrics of research success, such as H-index scores, may reinforce structural or implicit biases against female researchers, particularly those that take time out of research for

family or childcare reasons. Male researchers are also significantly more likely to self-cite than their female counterparts, which further distorts some measures. A subsequent study (Cameron *et al.*, 2016) looks in greater detail at biases in metrics of research productivity, and calls for more equitable measures of performance, particular at early career stage. This would include removing self-citations, and assessing outputs based on research-active periods, rather than entire careers.

Gender disparities in measures such as the H-index are highlighted by more detailed studies of particular fields or subfields in health research, such as dermatology (John *et al.*, 2016), ophthalmology (Lopez *et al.*, 2014), and surgery (Mueller *et al.*, 2016).

Other studies suggest a more nuanced picture in certain subfields. For example, in otolaryngology, Eloy *et al.* (2013) find that although male researchers have higher overall academic productivity, the productivity of women researchers follows a different arc, and equals or exceeds men at senior levels. Other studies reach similar conclusions with respect to academic gastroenterology (Diamond *et al.*, 2016) and gynecologic oncology (Hill *et al.*, 2015).

#### **4.2.2. Studies that focus on the relationship between research metrics and career trajectories**

Jagsi *et al.* (2011) surveyed 211 women and 378 men who were recipients of highly competitive National Institutes of Health career development awards (K08 and K23 grants) in the 2000-2001 annual grant cycle. They measured success over a subsequent 8-year period using three indicators: receipt of a grant of more than US\$ 1 million, publishing 35 or more peer-reviewed papers, or appointment to a leadership role (such as department chair or dean). They found that men were more successful in obtaining grants (male 56%, female 44%), publishing 35 or more papers (male 35%, female 24%) and attaining a leadership role (male 14%, female 11%). The study concludes that: “gender differences in career outcomes do occur, even among a select, highly able and motivated group, and simply waiting for more women to pass through the pipeline will not bring about parity” (p.1421). They also conclude that further investigation is required of the causes of gender difference in academic medical career outcomes.

Freund *et al.* (2016) examine gender differences in academic salaries at 24 US medical schools over a 17-year period. Even when adjusting for career breaks and other factors, they find that conventional metrics used to calculate salary cannot account for continued gender gap in compensation, which means that women in academic medicine on average earn 10 per cent less than their male counterparts.



### **4.2.3. Studies that examine differences in authorship, editorship and contributorship**

Macaluso *et al.* (2016) examined the gender dimension in contribution data from more than 85,000 articles published between 2008 and 2013 in PLOS journals, and found that women were more likely to be associated with roles usually perceived as less senior (such as performing experiments). Men were more likely to be associated with all other authorship roles.

Kongkiatkamon *et al.* (2010) examine gender disparities in authorship in prosthodontics journals and find no significant increase in female authorship over a thirteen-year period. Dickersin *et al.* (2010) draw attention to the importance of gender balance in journal editorship.

Mohammadi *et al.* (2011) examine the mix and balance of nationalities represented in editorial roles and the membership of editorial boards in leading international public health journals, highlighting that 95.1% of lead editors were from high income countries (with the US accounting for 39.1% of these roles and UK 31.7%).

### **4.2.4. Studies that propose new metrics for qualities and impacts**

Within scientometrics, there is growing debate about the need for new or alternative indicators of research quality and/or impact, and career progression, encouraged in part by the emergence of altmetrics as a recognised (if still fluidly-defined) subfield.

One of the selected studies ([Valsangkar \*et al.\*, 2016](#)) proposes a new metric for assessment of publications and citations that could help to offset gender differences. This study, which examines eight metrics across 4,015 faculty members at the top 55 NIH-funded departments of surgery in the United States, found gender-based differences in scholarly output across most surgical subfields, with most pronounced differences in cardiothoracic surgery and surgical oncology. They also found lower representation of female surgical faculty among full professors and in leadership roles. They suggest that the relative lack of women in leadership positions, and the fact that they have fewer publications and citations despite equivalent NIH funding, indicates problems with the metrics that are conventionally being used in promotion and tenure decisions. To overcome this, they propose a “V” (or velocity) metric, which they argue would provide a way of measuring productivity able to offset some gender differences, by diminishing the impact of certain periods of reduced productivity caused, for example, by maternity and childcare commitments.

Similarly, González Ramos *et al.* (2015), in their analysis of gender factors in scientific career promotion in Spain, highlight the “non-linear” career trajectories of many women in research, compared to men, and propose a relative indicator of

productivity (RSI) that takes better account of these differences. Westring *et al.* (2014) propose a framework to measure a “culture conducive to women’s academic success” (CCWAS). This consists of four dimensions: equal access; work-life balance; freedom from gender biases; and supportive leadership.

Heller *et al.* (2014) proposes a set of twenty-three “equity metrics” that could be used to improve the weight placed on equity in Health Impact Assessment (HIA). While the focus here on the processes and outcomes of HIA cannot be applied in a straightforward way to the assessment of research qualities and impacts, this approach does offer useful insights for work to incorporate diversity and inclusion factors into metric and indicator development in other domains.

#### **4.2.5. Studies that focus on indicators of diversity or inclusion in relation to research participants, topics and agendas**

Several studies look at indicators being used to measure diversity and/or inclusion among research participants, or in the definition of research topics, priorities and agendas (Almeida-Filho *et al.*, 2003; Bloomfield *et al.*, 2015; Bouchard *et al.*, 2015; Bugeja *et al.*, 1997; Choi *et al.*, 2007; Evans *et al.*, 2014; Hurlimann *et al.*, 2011; Kressin *et al.*, 2000; Mak *et al.*, 2007). Most of these are of limited relevance to the core questions addressed in this report, but highlight interesting areas of work in adjacent fields. Of the more relevant studies, Brooker *et al.* (2015) explore the extent to which people with intellectual disability are included and reported in public health research, and highlight definitional, selection and other barriers to inclusion.

## 5. Case studies

### 5.1. Introduction

These focus cases should be read as a companion to the systematic mapping review. Here we have used grey literature in addition to peer-review publications in order to provide a deeper contextual understanding of how some peer funders have approached their diversity and inclusion goals. Although all three funders chosen are public institutions subject to stricter oversight and legal requirements than private foundations or charities, some of the initiatives and ideas discussed may be adapted to Wellcome's specific circumstances.

Within the policies discussed below, there is overall agreement with the principle that a more diverse workforce will both enable more diversity in topics explored, and enable recruitment of the necessary diversity of participants, particularly in clinical research. Much of the argument for increased diversity for better problem solving appears to have come from the business sector (see, for example, Page, 2008), but this literature does appear to support the claim that in many circumstances groups comprised of people with different identities will bring a wider range of concerns, approaches, and tools to their work. However, there are caveats and limitations, as noted in Chapter 3. Specific to research, it is possible that targeted funding programmes may help produce the kind of cognitive diversity in groups which is required by a general movement towards larger grants, interdisciplinary teams, and focus on generation of impact. However, it is also possible that approaches which benefit women may disadvantage racial/ethnic minority men, and vice versa ([Apfelbaum et al., 2016](#)).

### 5.2. National Institutes of Health (NIH), USA.

#### Institutional Background

NIH is the largest public funder of medical research in the USA, with an operating budget of USD \$30bn allocated through the Department of Health and Human Services (DHSS). DHSS also controls the Indian Health Service, the Food and Drug Administration, and the Centres for Disease Control and Prevention, along with a number of other agencies, not all of which are directly health-related. As with all US federal agencies, NIH as an institutional employer must conform to Title VII of the Civil Rights Act (1964), which covers discrimination based on race, colour, religion, national origin, sex (including pregnancy as of 1978), and age. Additions to these categories include the Equal Pay Act (1963), the Americans with Disabilities Act (1990) and the Genetic Information Nondiscrimination Act (2008). The NIH

Revitalization Act of 1993 also directed NIH to create guidelines for the inclusion of women and racial/ethnic minorities in clinical research (see NIH, 2001).

NIH is divided into 27 Institutes and centres, largely by research topic (cancer, alcohol, deafness, etc) but there are also specific Institutes for Child Health and Human Development, Aging, and Minority Health and Health Disparities, which have policies for inclusion of these constituencies in clinical research. All heads of individual Institutes have either a medical degree or a PhD, sometimes both. Nineteen of these are headed by men. Fifteen of the men and all the female heads appear (via photo gallery) to be white.<sup>8</sup> This does not reflect the diversity of the overall institutional workforce of 17,889 (as of September 2015), which is in fact 58% female, 20% Black and 18% Asian, and may be more reflective of the structural difficulties women and minorities have in reaching the top levels of scientific fields.

- Diversity within the institutional workforce is not necessarily reflected by recipients of research funding.
- Overall, the majority of all-important first grants are still captured by white males.
- Black applicants and women both submit fewer applications as a group, and are more likely than white males to be discouraged from further submissions when grant applications fail.
- Schemes to increase diversity and support applications from women and minorities can suffer from lack of adequate funding and may not be able to provide places for all who would qualify, so that systemic change appears minimal.

### Specific EDI areas

NIH has an Office of Equity, Diversity and Inclusion (EDI)<sup>9</sup> which handles compliance with US employment law, and develops bottom-up strategy for diversifying the workforce.<sup>10</sup> A 2012 policy statement from Francis Collins, Director of NIH, states that 'leveraging perspectives from individuals from different backgrounds gives rise to creativity and innovation that not only benefit the NIH but the public we serve' (NIH, 2012b), a statement which appears to support the idea that a more diverse research workforce will produce better and more impactful research. The 2016 statement, however, reads 'diversity inspires innovation and elevates unlimited success in pursuing our mission' (NIH, 2016), leaving out the creation of public value and reflecting an overall rhetorical shift towards identifying the NIH workforce as EDI's 'customers'.<sup>11</sup>

<sup>8</sup> See <https://www.nih.gov/institutes-nih/directors-nih-institutes-centers>.

<sup>9</sup> Formerly the Office of Equal Opportunity and Diversity Management.

<sup>10</sup> <http://edi.nih.gov/>

<sup>11</sup> <http://edi.nih.gov/people/edi-365>

EDI has an all-female, multi-racial team of four general diversity and inclusion 'strategists',<sup>12</sup> and a team of seven (4 women) special emphasis strategists, each with a particular portfolio of advocacy for employees in an area of identity they themselves represent (Women, Asian Americans and Pacific Islanders, Blacks, Hispanics, Native Americans, and Sexual and Gender Minorities). This section of the website and its activities is separate from the main NIH website, which focusses on grants.

### Funding policies and programmes

NIH has a number of programmes aimed at diversifying the overall research workforce. These include Minority Health and Health Disparities International Training, which provides grants for postdoctoral scientists to carry out research in other countries, the Bridges to the Future Programme, which aims to smooth the transition from masters to PhD or medical school, and two institutional-level programmes, the Minority Biomedical Research Support programme, and the Competitive Research programme, both of which support research by faculty members at institutions with substantial minority enrolment overall. There are also highly targeted programmes specifically advertised for diversifying the workforce, such as Pre-doctoral fellowships for disabled students, and re-entry programmes which are most likely to benefit women who have taken career breaks for motherhood,<sup>13</sup> as well as opportunities within NIH institutions (particularly for doctoral students) which are aimed at racial and ethnic minorities, people with disabilities and the 'disadvantaged' (but not specifically women). The National Institute of General Medical Sciences has supplementary funding to support diversity of early career and student researchers working on these grants.<sup>14</sup>

New initiatives in mentoring, strengthening infrastructure for under-resourced institutions, and better evaluation of approaches have recently been funded under the Enhancing the Diversity of the NIH-Funded Workforce programme to address some of these concerns. These include the National Research Mentoring Network (NRMN) and the Building Infrastructure Leading to Diversity (BUILD) Initiative, which was awarded in 2014 to 10 U.S. universities that met eligibility criteria for being under-resourced as defined by the funding announcement (Valantine and Collins, 2015). BUILD awards are intended to transform undergraduate research training and mentoring, support the design and implementation of innovative programs, strategies and approaches, and support institutional and faculty development to enhance the training environment. The program targets under-represented minority students, students with disability, students from the foster care system together with economically disadvantaged students (Crespo, 2014), adding approximately 150 students per year. It includes a number of awards for experimental approaches such

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<sup>12</sup> <http://edi.nih.gov/consulting/strategy/strategist>

<sup>13</sup> <https://www.nia.nih.gov/research/dea/nih-programs-diversify-research-workforce>

<sup>14</sup> <https://www.nigms.nih.gov/Research/Mechanisms/Pages/PromoteDiversity.aspx>

as part-tuition payment and mentored research experience at the undergraduate level and continuing for up to 2 years post-graduation, and training and development for both students and faculty at poor, rural or minority-population institutions (DPC, 2016; NIGM, 2016; Wilder *et al.*, 2013). The underpinning philosophy of the BUILD programme is based in part, on the success of the NIH IRP Undergraduate Scholarship Program and, in part, on the “Race to the Biomedical Top” programme (Valantine *et al.*, 2016).

NIH also funds initiatives to address diversity in patient recruitment as a matter of trust, for example, through the Center for Health Equity at the University of Maryland, which has developed a multimedia website aimed at explaining how minority involvement in research can help reduce health disparities.<sup>15</sup>

### Obstacles identified

Research carried out in 2011 showed that black PhDs submitted just 1.4% of R01 (first major grant) applications, and although their chances of success were roughly equal if scored highly, applications from black PhDs as a whole scored lower or were less likely to be scored than applications from whites, Hispanics and Asians, and captured less than 1% of funded grants (Ginther *et al.*, 2011). As NIH grant applications are reviewed blind, a number of more subtle reasons than outright racism were offered as avenues for further research, including the hypotheses that black candidates were reluctant to submit proposals because they did not expect to be fairly assessed, that they benefitted less overall from early training programmes than white scientists, and the possibility of unconscious bias (Kaiser, 2011). A follow-up study concentrating on gender carried out by the same PI using a similar methodology found similar disparities in outcome by race for both PhDs and MDs, but little difference by gender within those categories, until viewed across careers. There, women of all races were much less likely to have ever received an R01 award, and overall submitted fewer applications. Both women and minority men were also more likely than white males to give up if their first proposal was not successful (Ginther *et al.*, 2016). This research suggests that there are still strong obstacles for women and minorities seeking to obtain their first NIH grant -- which is the key to achieving a successful career -- despite a great deal of effort at diversification.

There is, however, still an open debate about unconscious bias which such initiatives cannot address. For example, a random double-blind control trial found that faculty of both sexes rated job applications submitted by students with a female name lower than those submitted by students with a male name, despite the applications being exactly the same (Moss-Racusin *et al.*, 2012). In further studies, members of the same team found that despite a growing preponderance of evidence, male STEM academics were much less likely than women to evaluate unconscious bias research

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<sup>15</sup> <http://buildingtrustumd.org/about-project>

highly, suggesting that there is still significant resistance to acknowledging subconscious (let alone conscious) bias (Handley *et al.*, 2015).

Generally, the BUILD initiative has been welcomed positively. However observers conclude that, although the BUILD Initiative and other diversity-related scientific initiatives are commendable, they will prove largely ineffectual in the absence of other changes to the grants review process (Oh *et al.*, 2015). It is also possible that, as targeted programmes tend to be extremely competitive and substantially over-subscribed, the overall success of these strategies in meeting larger diversity goals may be compromised by limited funding, and so cannot provide enough places to significantly change the overall demographics of the research workforce.

### **5.3. Research Councils UK/Medical Research Council (RCUK-MRC)**

#### Institutional background

RCUK is the main public funder of research in the UK, with an annual budget of £3b, allocated through the Department for Business, Energy & Industrial Strategy (BEIS).<sup>16</sup> RCUK publishes its delivery plans as part of the UK Government's spending review, detailing how this money will be spent. In 2015, £810m went to MRC, topped up by a further £118m from other sources, for a total budget of £928.

RCUK has duties dictated by the Equality Act 2010 (and predecessors), which expanded EDI categories from race, gender and disability to also include age, gender reassignment, marriage & civil partnership, pregnancy & maternity, religion & belief, sex (as a category separate from gender) and sexual orientation. It collects data on four of these protected categories – age, gender, disability and ethnicity<sup>17</sup> – comparing grant and fellowship applicants to HESA estimates of the overall workforce.<sup>18</sup>

#### Specific EDI actions

RCUK has recently launched a new Action Plan on EDI,<sup>19</sup> building on its Statement of Expectations for Equality and Diversity (2013), and using Athena SWAN and Higher Education Statistics Agency (HESA) data as metrics to assess progress. The

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<sup>16</sup> Formerly the Department for Business, Innovation and Skills.

<sup>17</sup> Disability, however, did not appear as a category in these tables until 2016, and only as new students. The Ethnicity category groups all BME and 'other' applicants together.

<sup>18</sup> Unlike the USA, disclosure of demographic data in the UK is voluntary, and some councils (ESRC, EPSRC, NERC in particular) have noted that significant numbers of applicants choose not to disclose their ethnicity in particular.

<sup>19</sup> <http://www.rcuk.ac.uk/documents/documents/actionplan2016-pdf/>

seven research councils are bound by, but not limited to, these policies and several, including MRC, have developed their own.

MRC's website has a section on E&D in which it states that 'the potential rewards of diversity are significant: recruiting staff from the widest possible pool will unleash talent and develop better understanding of its customers and stakeholders.'<sup>20</sup> Its Equality and Diversity Vision (2013)<sup>21</sup>, produced after broad internal consultation, is accompanied by an Action Plan (this will be reviewed in 2016). At present the Plan focuses on MRC as an employer (which includes researchers in its own units and institutes), and promises a number of actions including the development of 'Equality Champions' and an annual E&D progress report. The 2015/16 Annual Report shows progress on employment of women in senior positions, and the achievement of Athena Swan accreditation for some MRC units, but does not provide any further information.

### Funding policies and programmes

MRC encourages diversity in research participants, particularly in clinical research, and has a public-facing section of its website explaining the many ways for people to get involved, although this does not target any specific groups.<sup>22</sup> It has specific ethical guidelines covering children, adults who cannot give informed consent, and participants in developing countries.<sup>23</sup> MRC also has guidelines on research ethics in general and medical research ethics in particular, but does not have governmental mandates for diversity and inclusion with regard to research participants in the same manner as the NIH. The MRC's Equality and Diversity Vision (MRC, 2016), however, includes 'increased participation and empowerment of under-represented groups' (pg.17) as an over-arching goal.

- Most of the seven UK Research Councils have developed their own EDI policies.
- MRC follows guidelines for inclusion of participants developed by the Department of Health, but does not have legal mandates, as in the USA.
- Increased participation of patients and under-represented groups is part of its Equality and Diversity Vision.
- However, this requires trust which may be difficult to achieve, particularly where there is no identity coherence between researchers and participants.

The Research Governance Framework for Health and Social Care (2005) covers much of MRC's research field, and uses the Progress + categories. This framework

<sup>20</sup> MRC (2016) *Equality & Diversity*. Medical Research Council.

<http://www.mrc.ac.uk/about/information-standards/equality-diversity/>.

<sup>21</sup> <https://www.mrc.ac.uk/publications/browse/mrc-equality-and-diversity-vision/>

<sup>22</sup> <https://www.mrc.ac.uk/about/taking-part-in-research/>

<sup>23</sup> <https://www.mrc.ac.uk/research/policies-and-guidance-for-researchers/>



does explicitly call for diversity of researchers and participants as a means of providing policymakers with better evidence (DH, 2005, p. 8 para 2.2.7). However, in the present revised version of this document which was offered for public consultation earlier this year, there is no mention at all of diversity amongst either researchers or participants.<sup>24</sup> Instead, the document focuses mainly on how responsibilities will be allocated amongst the different parts of the research system within the new Health Research Authority (HRA).

Several of MRC's programmes target global health inequalities, in particular a matched collaboration with the Newton Fund, which is aimed at partnerships with researchers in emerging economies. Other programmes have included a Joint Global Research Programme in women's and children's health in collaboration with the Department of Biotechnology in India. There is also a strategy group on Global Health which focusses exclusively on topics relating to the developing world, employing foresight analysis to try to predict which emerging topics will be of most concern. External events, therefore, also play some part in the development of discussions of diversity in recruitment of participants, as a matter of being prepared for the sudden appearance of new research priorities for which a more diverse workforce might be more quickly responsive. For example, due to Zika there is a renewed interest in the ethics of including pregnant women in clinical and pre-clinical research.

### Obstacles identified

Data from the MRC from 2011 – 2015 shows that although the overwhelming majority of grant applicants are male, success rates for female applicants are within 2% of their male counterparts and in 2014/15 fellowship awards were equal (RCUK, 2016). One possibility mooted for the lack of female grant applicants is that the universities most active in applying to MRC also have a lower population of female staff than the HESA average of 40%, particularly at the higher levels required to apply for major grants. Non-disclosure of demographic data remains a problem, although rates have improved with time, particularly amongst fellowship applicants. In 2011 22% did not disclose their ethnicity, whereas this number had dropped to just 4% by 2015. However, the success rates for white applicants in this category has increased since 2011, suggesting the possibility that the majority who had chosen not to disclose ethnicity were white.

Unlike the other research councils, MRC has removed all years-from-PhD restrictions from its New Investigator fellowships, so that speed is no longer a key criterion for demonstrating capacity to progress to research independence, as this

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<sup>24</sup> <http://www.hra.nhs.uk/?p=206468>. The HRA is a non-departmental body which took over health research governance functions in January 2015.

was felt to disadvantage women and other researchers whose career paths had not been linear (Bryan, 2015).<sup>25</sup>

While MRC also has a commitment to recruitment of diverse participants in clinical research, research shows that trust may be deeply affected by the past experiences of an identity group,<sup>26</sup> as well as by social factors which include economic position in society, and lack of identity coherence between researchers and researched. The equation of broader diversity with better results is not straightforward, as discussed in Chapter 3.4.2, above.

## **5.4. Canadian Institutes of Health Research - Institute of Gender and Health (CIHR-IGH)**

### Institutional Background

CIHR is divided into 13 Institutes with a total annual budget of CAN \$1bn. Its Governing Council of 18 is half male, half female, but as with its scientific directors nearly all appear (from photographs supplied on CIHR's website) to be white.<sup>27</sup>

As with NIH, there are also individual Institutes focussing on Aging, Child and Youth Health, and Aboriginal People's Health.<sup>28</sup> The Institute of Gender and Health focusses not only on research on gender-related health issues, but also on mainstreaming sex and gender as analytic foci within all research projects, down to the cellular level. Its commitment is to develop new research themes, as well as support researchers seeking to integrate sex and gender into established lines of research, with priority initially on developing four topic areas: violence and health, sexual and reproductive health, clinical interventions and work (CIHR-IGH, 2009). The goal is to improve the evidence base in order to improve health outcomes for Canadians, but also to promote attention to sex and gender-based differences which affect the research system as a whole, such as the predominance of male tissue samples and male animal models in biomedical research (CIHR-IGH, 2014).<sup>29</sup>

CIHR works closely with the International Development Research Centre (IDRC) on programmes for global health research, and is part of the GENDER-NET programme, a policy initiative funded under the EU's FP7, which aims at gender

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<sup>25</sup> By comparison, the cut-off for similar schemes is four years at the ESRC and six at AHRC. As of this writing, RCUK is still in the process of being reconfigured into UKRI. It is not yet known whether there will be some harmonisation with regard to grant eligibility criteria at different career stages.

<sup>26</sup> For example, see Seto, B. (2001) 'History of medical ethics and perspectives on disparities in minority recruitment and involvement in health research', *American Journal of the Medical Sciences*, 322(5), pp. 248-52..

<sup>27</sup> See <http://www.cihr-irsc.gc.ca/e/6953.html> and <http://www.cihr-irsc.gc.ca/e/2890.html> for scientific directors.

<sup>28</sup> <http://www.cihr-irsc.gc.ca/e/193.html#institutes>

<sup>29</sup> According to this report, 81% of biomedical studies do not account for either sex or gender.

equality in the research workforce. Overall, its research is structured into four main themes: biomedical, clinical, health services, and social, cultural, environmental and population health. CIHR also has a Strategy for Patient-Oriented Research (SPOR) which brings patients together with a broad range of medical stakeholders to develop new approaches and bring them quickly into the health care system, and to improve care of patients in less-populated provinces and territories (CIHR, 2015).<sup>30</sup>

### EDI Activities

The Institute of Gender and Health (IGH) is an unusual example of institutionally embedded diversity and inclusion, directing funding not so much towards women researchers and women's health as toward transforming a protected category into a primary research agenda. Created in 2000, since 2010 CIHR-IGH has required that all applicants integrate sex and gender into their research insofar as applicable, whether considering gender of participants or sexed attributes of tissue and cells. Overall, it aims to mainstream sex and gender into all health research as a matter of meeting federal Health Portfolio requirements.

Although much of the research inevitably seeks to improve knowledge about female tissue and women's bodies and experiences in areas where male models, issues and participants have traditionally been the norm, IGH also seeks to encourage research that considers topics which have been neglected areas for men, for example eating disorders and management of lupus; as well as looking at discrimination within medical procedures, such as the tendency not to recommend joint replacement for women, and areas where outcomes can differ unexpectedly between the sexes, such as the finding that women are 20% more likely to develop lung cancer than men who smoke the same amount (CIHR-IGH, 2014).

- The Institute of Gender and Health is dedicated to the embedding of sex and gender in all CIHR-funded research
- Since 2010, CIHR requires all applicants to indicate whether and how sex and gender is being integrated in their proposal
- The number of applicants doing so increased from 25% to 48% within the first year
- IGH has also broadened the scope of topics researched, focussing on men and boys as well as women's health.

### Funding programmes and policies

IGH's overall rationale is that the integration of sex and/or gender will make health research 'more rigorous, more ethical, and more applicable to the needs of all people' (CIHR-IGH, 2014, p. 12). Its overall budget in 2012-13 was CAN\$59.1m, with \$8.6m earmarked for strategic initiatives. Its goals include greater integration within the Canadian medical system, developing new methodologies and promoting international partnerships to increase knowledge transfer and clinical impact. Policy

<sup>30</sup> See also <http://www.cihr-irsc.gc.ca/e/41204.html>.

documents in general stress the connection between considerations of sex and gender and better, more useful research, highlighting research that would not have taken place and major findings which would not have been known were it not for IGH (See CIHR-IGH, 2012, a casebook of IGH-funded research).

In addition to steadily increasing funding streams, IGH also has developed materials which are available on its website, including training modules on Sex and Gender in Biomedical research, Primary Data Collection with Humans, and Analysis of Data from Human Participants.<sup>31</sup> These are aimed at both applicants and grant reviewers, with a particular stress on being able to distinguish between the categories of sex and gender and use them appropriately (Sharman and Johnson, 2012).

### Obstacles identified

Although initially limited in its research capacity, funding for CIHR has grown and expanded from its initial focus on clinical trials. This has increased its ability as an institution to build partnerships across the sector and create opportunities in what was otherwise a niche area, as well as generating extensive new knowledge (Stewart *et al.*, 2013).

Initial research on CIHR's initiatives showed that 75% of applicants overall indicated that they were not taking either gender or sex into account (Sharman and Johnson, 2012, p. 1815). This figure has improved, but the still-high number of biomedical researchers in particular who do not – a lacuna not confined to Canada (see Wood *et al.*, 2011 on similar findings in the US) -- is worrisome, as this is often research which forms the basis of later clinical interventions.<sup>32</sup> In terms of impact, the complexity of other factors, as well as the ways in which identity categories are constructed and used by researchers, can also hamper validation and uptake of results, as can the ongoing dilemma of how research strategies which aim to explore difference can be implemented without increasing bias (Sharman and Johnson, 2012).

Since the 1990s the NIH's Office of Research on Women's Health has had a similar broad emphasis on sex and gender issues, however, in practice much of this has been geared towards filling gaps in knowledge about women's health and increasing numbers of women in clinical research. IGH is considered to have had a strengthening effect on the women's health community as well, but has also funded an increasing number of projects focussed on men's and boys' specific health issues as part of demonstrating the importance of sex and gender to all research.

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<sup>31</sup> <http://www.cihr-irsc.gc.ca/e/32019.html>

<sup>32</sup> In 2012, 48% of successful grants included information about consideration of sex and gender (CIHR-IGH, 2014), indicating not only that more applicants were willing to answer the question than the year before, but that those who answered positively might be more likely to be funded.

## 6. Conclusions and recommendations

### 6.1. Strengths and weaknesses of this review

With greater emphasis being now being placed on the importance of diversity and inclusion across research systems worldwide, and in support of Wellcome Trust's own strategy in this area, the primary aim of this project was to undertake a systematic and critical review of the evidence base for a positive relationship between a diverse and inclusive health research community, and the qualities and impacts of the research they undertake. A second focus of the project was to evaluate the efficacy of the metrics used to measure diversity, inclusion, quality and impact in health research, and the relationship between these metrics and wider agendas in support of diversity and inclusion

The mapping review followed current best practice with regard to review methods. The close focus on the requirements of Wellcome Trust enabled completion within an abbreviated timescale and ensured that key considerations were targeted by the review. Selection of the MEDLINE and Web of Science databases ensured a close match of review evidence with the scientific funding remit of the Wellcome Trust. The absence of a quality assessment process, in conformance with accepted mapping review methods, means that the review presents descriptions of interventions rather than evaluating their effectiveness or impact.

Consultation with stakeholders at the July 2016 workshop, and through informal interactions, allowed the review team and the Wellcome Trust to gain a rapid understanding of the area under inquiry, and some of the constraints of existing practices. It confirmed the importance of taking a whole systems approach to diversity and inclusion. However, this holistic view was not well accommodated by approaches used in the literature, which tended to focus on individual interventions or programmes targeted at specific stages of the research process.

Further targeted searches and synthesis on the value of specific interventions, as a counterpoint to this broad map of activity, may be a direction for future activity. The literature revealed a lack of studies using rigorous evaluation designs. Initiatives reported in the literature tended to focus on those conducted in the United States, with other countries being correspondingly less well represented. The value of more primary data collection on existing UK practice from other research organisations remains to be explored.

We are also aware of some missing literature and that indexing may be particularly problematic for some areas of relevant material. For example, searching for material on age inequality/inequity is very difficult as age-related terms appear in many

papers and extracting relevant studies can be unwieldy. Other areas of relevant material are not necessarily indexed along the lines of diversity and inclusion, but are relevant to the core questions of the project e.g. the growing body of work on participatory and co-produced research.

Our case studies were focused on English speaking countries, and it is possible that further examples of good practice may be identified from non-English speaking countries. Information for case studies was restricted to information in the public domain. Richer, more detailed information could be obtained from interviews with key informants. This particularly impacted in terms of the limited availability of data on financial aspects of initiatives that featured in the case studies.

## 6.2. Mapping review: key findings and observations

From the mapping review, we can draw ten broad conclusions about the state of the evidence and gaps that persist.

First, **there is a strong US dominance in the literature**, which raises questions about the transferability of findings, given the cultural specificity of some aspects of diversity and inclusion.

Second, **there is a far more extensive literature relating to gender and race/ethnicity** (although the latter also related predominantly to the US), and comparatively little on other PROGRESS-Plus axes of difference. The literature highlights persistent patterns of disadvantage, but also variability by field and subfield – particularly with regard to gender.

Third, **the majority of the studies we examined focused on clinical or biomedical research**. Other areas of health-related research did not feature so heavily. Given that the relevance of the PROGRESS-Plus variables differs depending on the type of health research, and on the sub-cultures and degree of diversity within health research disciplines, the transferability of evidence across disciplines is debatable.

Fourth, **the predominant level of analysis is that of individuals** (in terms of metrics, interventions etc.). Multiple (dis)advantages and inter-locking aspects of people's experience can reinforce one another. The degree of isolation and exclusion felt by women and minorities can be underestimated. There is a relative lack of attention paid in the literature to measures of diversity or inclusion at the **aggregate or organisational level**.

Fifth, **there is a focus on individual parts of the health system, and only a few examples of more holistic, systems-based and/or longitudinal approaches** that

try to examine how elements interplay and (re)create disadvantage.

Sixth, **the literature predominantly takes a national, rather than international or comparative focus**, despite the fact that dimensions of diversity and inclusion look very different from a more international or global perspective.

Seventh, the studies we examined reflect **a limited amount of theoretical framing, and often rely on implicit assumptions about mechanisms of action and causality**, rather than more explicit development and testing of models and mechanisms.

Eight, there are **persistent areas of controversy and complexity**, such as how to conceptualise and operationalise race/ethnicity. These demand careful and explicit consideration.

Ninth, **trickle-down or trickle-out effects to other parts of health research systems is far from automatic**: this takes time, and requires actions to promote diversity and inclusion across all elements of the system. Gender-related initiatives can be seen as benefiting women only. Informal processes can reinforce the advantages of dominant groups. Mentoring schemes that pay attention to culture and tacit knowledge, rather than simply skills, seem more promising

Finally, we can conclude that **there is limited available evidence that directly addresses the guiding research question of this project**; and a relatively weak evidence base for processes and explanations of patterns of inequality, exclusion or lack of diversity that are visible in the health research system.

### **6.3. Case studies: key findings and observations**

The case studies reflect a general agreement that a more diverse workforce will create more diversity of topics researched, and that inclusion is a matter of ethics, justice, and pathways to better knowledge. Even without a clear evidence base in the included studies, this assumption permeates the grey literature, most likely drawn from discussions of diversity in business.

However, the academic literature also suggests that even robust participant recruitment strategies such as those mandated by NIH have been assessed as not necessarily reaching this goal (Oh *et al.*, 2015). While there has been some success in diversifying the workforce, this does not generally continue into the highest career stages, particularly in the more technical disciplines, continuing the historical dominance of white men at the top of the research system.

Adequate funding is also a common concern. The wider range of grants at all career stages is greater in the US than in the UK, where women tend to be over-represented in earlier career stages, particularly as fixed-term researchers who are not always eligible to apply for key RCUK grants (Blake and La Valle, 2000, p. 31), while at the same time the number of early-career fellowships leading to research independence available has decreased, sometimes by as much as half, from five years ago.<sup>33</sup> MRC's policies suggest that funders can address this lacuna by changing their own eligibility criteria, for example, by extending the time frame for 'early career', or by creating specific fellowships for researchers who are well into their careers, but have not secured permanent posts.

Although diversity of research topics is the least studied area, it appears clear from the grey literature that all three areas are seen by funders as strongly influencing each other. In other words, it is not considered possible to increase diversity in topics, without first increasing the social diversity of researchers who are more likely to propose different questions, and are therefore more likely to include different populations of research participants in their work.

The conclusion that systemic change is needed is broadly in line with the conclusions of the *Who Applies for Research Funding* report (Blake and La Valle, 2000). However, most of the peer funders examined do not reflect much diversity at the top of the management structure, mirroring the 'leaky pipeline' effect which contributes to a similar lack of diversity amongst professorial level academics, particularly for mathematically-informed areas of STEM.<sup>34</sup> In theory, diversifying the management structure at the very top should have help provide the more supportive environment many studies have shown to be required in order to achieve the goal of better science through diversity of researchers, participants and topics.

## 6.4. Recommendations to Wellcome Trust

Based on this review, we identify the following recommendations for future research and other activities that Wellcome Trust could support (on its own, or in partnership with others) in order to strengthen the evidence base for a positive relationship between a diverse and inclusive health research community, and the qualities and impacts of the research they undertake:

First, there needs to be **greater investment in comprehensive studies that examine interactions across the health research system, and longitudinal studies that look at changes over time at individual, collective and institutional levels.**

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<sup>33</sup> See <https://www.rcuk.ac.uk/documents/documents/researchcouncilsdiversitydataapril2016.pdf>

<sup>34</sup> The Ford Foundation, now devoted exclusively to research on inequalities, is a notable difference.



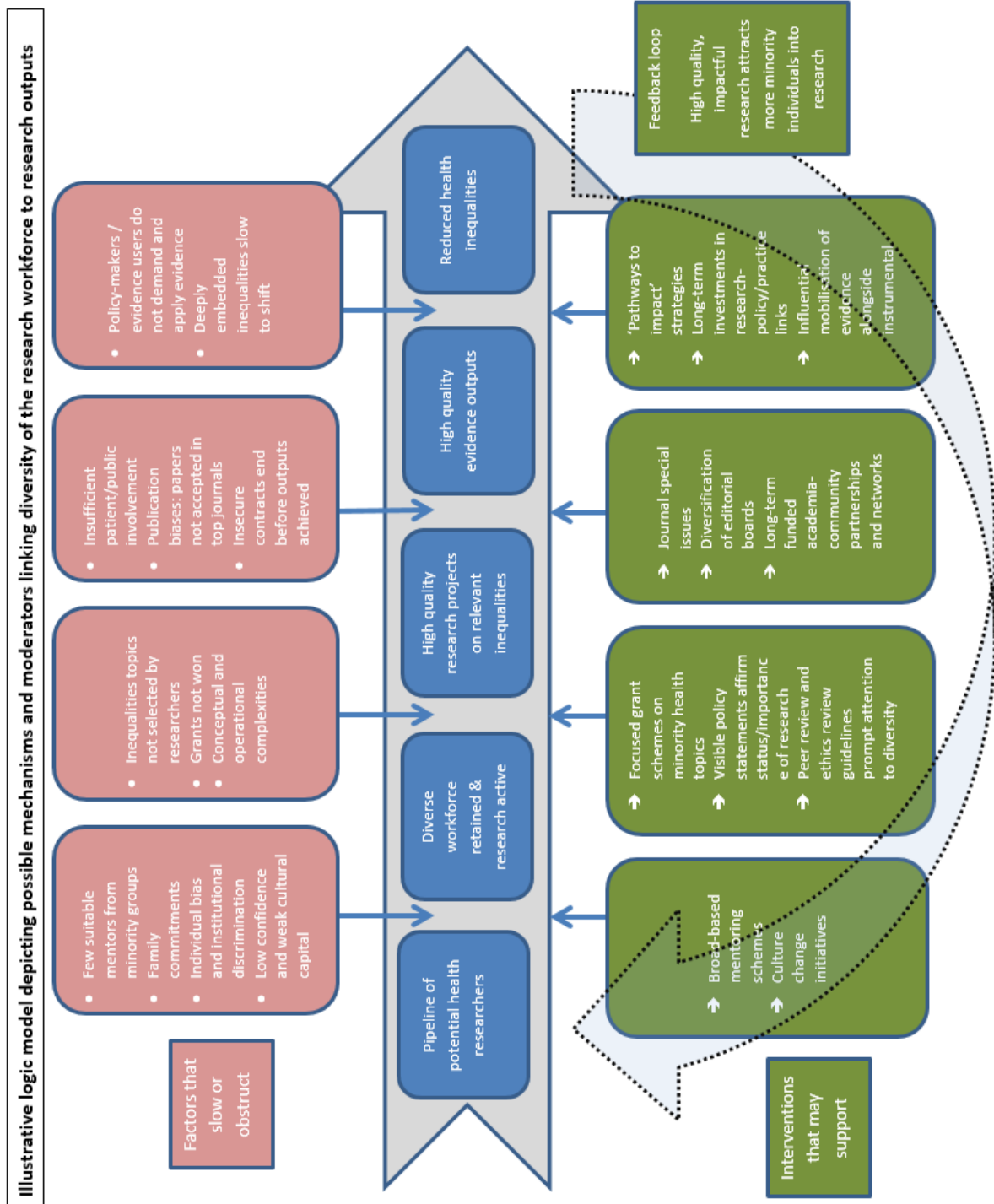
Second, **more work is required to improve comparability across studies, to define and standardise indicators and metrics;** and to collect data in consistent ways.

Third, **there needs to be greater experimentation and research investment in neglected aspects of diversity and inclusion,** including: aggregate measures of inclusion; axes of difference and disadvantage beyond gender and race/ethnicity; enablers and obstacles; and diversity and inclusion across health research systems.

Fourth, to achieve this more systemic perspective, there need to be **closer links between future research on diversity and inclusion in health research, and issues relating to research cultures, career pipelines, reward and recognition structures, responsible metrics and research integrity** – increasingly addressed under the broad umbrella of the “**science of science**” (Ioannidis *et al.*, 2015; Wilsdon *et al.*, 2015). Given the existing portfolio of Wellcome Trust activities, there is scope for Wellcome Trust to pioneer creative and ambitious funding, policy and advocacy strategies that draw links between these (at times) disparate and siloed agendas, to advance a more holistic understanding of links between diversity, inclusion, integrity, responsibility and public engagement.

Finally, **to help inform Wellcome Trust’s future efforts across these linked agendas, we offer an illustrative synthetic model that seeks to highlight the importance of taking a more holistic, less compartmentalised approach** than we found evident in much of the literature (see below) This is one way of mapping the relationships between inputs and outputs - there are other ways of taking a slice through the system, defining other inputs and other outputs of interest. But we hope this is helpful in suggesting future priorities and opportunities for research.

**Figure 11- Illustrative logic model depicting possible mechanisms and moderators linking diversity of the research workforce to research outputs**



# 7. Appendices

## 7.1. Search strategies - Phase Two

### Medline via OVID

1. (diversity or diverse).ti.
2. \*Cultural Diversity/
3. (inclusion or inclusive or inclusivity).ti.
4. (exclusion or exclusive or exclusivity).ti.
5. (equality or equalities or equity or equities).ti.
6. (inequality or inequalities or inequity or disparit\* or disadvantag\*).ti.
7. ((equal adj opportunit\*) or (unconscious adj bias) or discriminat\*).ti.
8. 1 or 2 or 3 or 4 or 5 or 6 or 7
9. "health research".ti.
10. "health service research".ti.
11. "medical research".ti.
12. ("biomedical research" or biomedicine).ti.
13. ("clinical research" or "life science\*").ti.
14. (((STEM or STEMM) adj2 (subject\* or research\*)) not cell\*).ti.
15. ((academic or research or clinical) adj (workforce or work force or worker\* or scientist\*)).ti.
16. (publish\* or author\*).ti.
17. ((pay adj gap) or (glass adj ceiling)).ti.
18. (research adj (organisation or organization of funder\*)).ti.
19. (research adj (involve\* or partner\* or participant\*)).ti.
20. (coproduction or co production).ti.
21. (PPI or (patient adj public)).ti.
22. 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
23. 8 and 22

### Web of Science

- #1 TI=(diversity or diverse)
- #2 TI=(inclusion or inclusive or inclusivity)
- #3 TI=(exclusion or exclusive or exclusivity)
- #4 TI=(equality or equalities or equity or equities)
- #5 TI=(inequality or inequalities or inequity or disparit\* or disadvantag\*)
- #6 TI=((equal NEAR/1 opportunit\*) or (unconscious NEAR/1 bias) or discriminat\*)
- #7 #6 OR #5 OR #4 OR #3 OR #2 OR #1
- #8 TI=("health research" or "health service research" or "health services research" or "medical research" or "biomedical research" or "biomedicine" or "clinical research" or "life science research" or "life sciences research")
- #9 TI=(((STEM or STEMM) NEAR/1 (subject\* or research\*)) not cell\*)
- #10 TI=("academic workforce" or "academic work force" or "academic worker\*" or

"academic scientist\*" or "research workforce" or "research work force" or "research worker\*" or "research scientist\*" or "clinical workforce" or "clinical work force" or "clinical worker\*" or "clinical scientist\*")

#11 TI= (publish\* or author\*)

#12 TI= ((pay NEAR gap) or (glass NEAR ceiling))

#13 TI=("research organisation" or "research organization" or "research funder\*" or "research involve" or "research partner\*" or "research participant\*")

#14 TI=("coproduction" or "co production" or "PPI" or "patient NEAR public")

#15 #14 OR #13 OR #12 OR #11 OR #10 OR #9 OR #8

#16 #15 AND #7

Limit to 2005-2016 and Language English

## Scopus

(( ( TITLE ( ( "health research" OR "health service research" OR "health services research" OR "medical research" OR "biomedical research" OR "biomedicine" OR "clinical research" OR "life science research" OR "life sciences research" ) ) ) OR ( TITLE ( ( ( stem OR stemm ) W/1 ( subject\* OR research\* ) ) not cell\* ) ) ) OR ( TITLE ( ( "academic workforce" OR "academic work force" OR "academic worker\*" OR "academic scientist\*" OR "research workforce" OR "research work force" OR "research worker\*" ) ) ) OR ( TITLE ( "research scientist\*" OR "clinical workforce" OR "clinical work force" OR "clinical worker\*" OR "clinical scientist\*" ) ) OR ( TITLE ( ( publish\* OR author\* ) ) ) ) OR ( ( TITLE ( ( ( pay W/1 gap ) OR ( glass W/1 ceiling ) ) ) ) OR ( TITLE ( ( "research organisation" OR "research organization" OR "research funder\*" OR "research involve" OR "research partner\*" OR "research participant\*" ) ) ) OR ( TITLE ( ( "coproduction" OR "co production" OR "PPI" OR "patient W/1 public" ) ) ) ) ) AND ( ( TITLE ( ( diversity OR diverse ) ) ) OR ( TITLE ( ( inclusion OR inclusive OR inclusivity ) ) ) OR ( TITLE ( ( exclusion OR exclusive OR exclusivity ) ) ) OR ( TITLE ( ( equality OR equalities OR equity OR equities ) ) ) OR ( TITLE ( ( inequality OR inequalities OR inequity OR disparit\* OR disadvantage\* ) ) ) OR ( TITLE ( ( ( equal W/1 opportunit\* ) OR ( unconscious W/1 bias ) OR discriminat\* ) ) ) ) ) AND ( LIMIT-TO ( PUBYEAR , 2016 ) OR LIMIT-TO ( PUBYEAR , 2015 ) OR LIMIT-TO ( PUBYEAR , 2014 ) OR LIMIT-TO ( PUBYEAR , 2013 ) OR LIMIT-TO ( PUBYEAR , 2012 ) OR LIMIT-TO ( PUBYEAR , 2011 ) OR LIMIT-TO ( PUBYEAR , 2010 ) OR LIMIT-TO ( PUBYEAR , 2009 ) OR LIMIT-TO ( PUBYEAR , 2008 ) OR LIMIT-TO ( PUBYEAR , 2007 ) OR LIMIT-TO ( PUBYEAR , 2006 ) OR LIMIT-TO ( PUBYEAR , 2005 ) )

## 7.2. Citations for Phase Three

Citation	Domain	No of Citations (Google Scholar – July 2016)
Amrein, K., Langmann, A., Fahrleitner-Pammer, A., Pieber, T. R., & Zollner-Schwetz, I. (2011). Women underrepresented on editorial boards of 60 major medical journals. <i>Gender medicine</i> , 8(6), 378-387.	Gender	32 Citations
Brogan, D. J. (2000). Implementing the Institute of Medicine report on lesbian health. <i>Journal of the American Medical Women's Association</i> , 56(1), 24-26.	Sexuality	10 Citations
Dickersin, K., Fredman, L., Flegal, K.M., Scott, J.D. & Crawley, B. (1998) Is there a sex bias in choosing editors? Epidemiology journals as an example. <i>JAMA: The Journal of the American Medical Association</i> , 280, 260–264.	Gender	55 Citations
Ginther, D. K., Schaffer, W. T., Schnell, J., Masimore, B., Liu, F., Haak, L. L., & Kington, R. (2011). Race, ethnicity, and NIH research awards. <i>Science</i> , 333(6045), 1015-1019.	Race & Ethnicity	161 Citations
Gordon MB, Osganian SK, Emans SJ, Lovejoy FH Jr. Gender differences in research grant applications for pediatric residents. <i>Pediatrics</i> . 2009 Aug;124(2):e355-61. doi: 10.1542/peds.2008-3626.	Gender	12 Citations
Moss-Racusin C, Dovidio J, Brescoll V, Graham M, Handelsman J (2012) Science faculty's subtle gender biases favor male students. <i>Proceedings of the National Academy of Sciences, USA</i> 109: 16474–16479. doi: 10.1073/pnas.1211286109	Gender	641 citations
Ostlin P, Braveman P, Dachs N; WHO Task Force on Research Priorities for Equity in Health; WHO Equity Team. Priorities for research to take forward the health equity policy agenda. <i>Bull World Health Organ</i> . 2005 Dec;83(12):948-53. Epub 2006 Jan 30. PubMed PMID: 16462988; PubMed Central PMCID: PMC2626494.	Equity – General	67 Citations
Östlin, P., Schrecker, T., Sadana, R., Bonnefoy, J., Gilson, L., Hertzman, C., ... & Muntaner, C. (2011). Priorities for research on equity and health: towards an equity-focused health research agenda. <i>PLoS Med</i> , 8(11), e1001115.	Equity – General	69 Citations
Ovseiko, P. V., Oancea, A., & Buchan, A. M. (2012). Assessing research impact in academic clinical medicine: a study using Research Excellence Framework pilot impact indicators. <i>BMC health services research</i> , 12(1), 1.	Metrics – General	23 Citations
Lesbian Health: Current Assessment and Directions for the Future. Institute of Medicine (US) Committee on Lesbian Health Research Priorities; Solarz AL, editor. Washington (DC): National Academies Press (US); 1999. The National Academies Collection: Reports funded by National Institutes of Health.	Sexuality	299 Citations

## 7.3. Search Strategies - Phase Four

### Medline

1. (diversity or diverse).ti.
2. \*Cultural Diversity/
3. (inclusion or inclusive or inclusivity).ti.
4. (exclusion or exclusive or exclusivity).ti.
5. (equality or equalities or equity or equities).ti.
6. (inequality or inequalities or inequity or disparit\* or disadvantag\*).ti.
7. ((equal adj opportunit\*) or (unconscious adj bias) or discriminat\*).ti.
8. 1 or 2 or 3 or 4 or 5 or 6 or 7
9. (Metric\* or Bibliometric\* or indicator\* or benchmark\*).ti.
10. Peer review\*.ti.
11. 9 or 10
12. 8 and 11
13. limit 12 to (english language and humans

### Web of Science

1. TI=(diversity or diverse)
2. TI=(inclusion or inclusive or inclusivity)
3. TI=(exclusion or exclusive or exclusivity)
4. TI=(equality or equalities or equity or equities)
5. TI=(inequality or inequalities or inequity or disparit\* or disadvantag\*)
6. TI=((equal NEAR/1 opportunit\*) or (unconscious NEAR/1 bias) or discriminat\*)
7. #6 OR #5 OR #4 OR #3 OR #2 OR #1
8. TI=(Metric\* or Bibliometric\* or indicator\* or benchmark\*)
9. TI="Peer review\*"
10. #9 OR #8
11. #10 AND #7

### Scopus

(( ( TITLE ( diversity OR diverse ) ) OR ( TITLE ( inclusion OR inclusive OR inclusivity ) ) OR ( TITLE ( exclusion OR exclusive OR exclusivity ) ) OR ( TITLE ( equality OR equalities OR equity OR equities ) ) ) OR ( ( TITLE ( inequality OR inequalities OR inequity OR disparit\* OR disadvantag\* ) ) OR ( TITLE ( equal W/1 opportunit\* ) ) OR ( TITLE ( unconscious W/1 bias ) ) OR ( TITLE ( discriminat\* ) ) ) ) AND ( ( TITLE ( metric\* OR bibliometric\* OR indicator\* OR benchmark\* ) ) OR ( TITLE ( "peer review\*" ) ) ) )

## 7.4. Other peer funders considered for case studies:

The Commonwealth Fund (US) claims DI as 'core values', and is one of the few foundations in the world established by a single woman. It focusses on health research for better outcomes for the poor, minorities, the very old and young, and the uninsured. It has a specific funding stream for fellowships in Minority Health Policy, but this is public policy training for physicians, rather than research. Its policy on inclusiveness and diversity appears to be aimed at its own employees, rather than on its grantees.

The Royal Society (UK) has good documentation overall, and a specific programme to increase diversity amongst STEMM researchers. Raw data from this programme is available from the website. However, clinical research is specifically excluded from its grants programme, which is mainly geared towards basic research in the life sciences.

Ford Foundation (US) has shifted the entirety of its research funding to addressing inequality, but not all of this is devoted to health. It has the most diverse staff based on available photo galleries. However, other publicly available documentation is sparse.

### Excluded for lack of useful documentation

Cancer Research UK

Riksbankens Jubileumsfond, Netherlands

Stiftung Volkswagen, Germany

Bill and Melinda Gates Foundation, US

### Excluded for too broad or mostly out-of-remit focus

European Research Agency (ERC), Europe

National Science Foundation (NSF), US

International Development Research Centre (IDRC), Canada

## 7.5. List of included studies (mapping review, n=246)

Short identifier	Bibliographic details
Ahdieh (1996)	<i>Ahdieh, L. and Hahn, R. A Use of the terms 'race', 'ethnicity', and 'national origins': A review of articles in the American Journal of Public Health, 1980–89. Ethnicity and Health . 1996. 1:95-8</i>
Akre (2011)	<i>Akre O, Barone-Adesi F, Pettersson A, Pearce N, Merletti F, Richiardi L. Differences in citation rates by country of origin for papers published in top-ranked medical journals: do they reflect inequalities in access to publication? Journal of Epidemiology &amp; Community Health. 2011;65(2):119-23</i>
Almeida-Filho (2003)	<i>Almeida-Filho N, Kawachi I, Filho AP, Dachs JN. Research on health inequalities in Latin America and the Caribbean: bibliometric analysis (1971-2000) and descriptive content analysis (1971-1995). American Journal of Public Health. 2003;93(12):2037-43.</i>
Amrein (2011)	<i>Amrein K, Langmann A, Fahrleitner-Pammer A, Pieber TR, Zollner-Schwetz I. Women underrepresented on editorial boards of 60 major medical journals. Gender medicine. 2011;8(6):378-87.</i>
Anderson (1998)	<i>Anderson, MR, and Moscou, S. Race and ethnicity in research on infant mortality. Family Medicine. 1998;30:224-7</i>
Bailes (2006)	<i>Bailes MJ, Minas IH, Klimidis S. Mental health research, ethics and multiculturalism. Monash Bioethics Review. 2006;25(1):53-63.</i>
Bailey (2002)	<i>Bailey CE, Pryce J, Walsh F. Trends in author characteristics and diversity issues in the Journal of Marital and Family Therapy from 1990 to 2000. Journal of Marital &amp; Family Therapy. 2002;28(4):479-86.</i>
Ballantyne (2008)	<i>Ballantyne AJ, Rogers WA. Fair inclusion of men and women in Australian clinical research: Views from ethics committee chairs. Medical Journal of Australia. 2008;188(11):653-6.</i>
Barfield (2016)	<i>Barfield WL, Plank-Bazinet JL, Austin Clayton J. Advancement of Women in the Biomedical Workforce: Insights for Success. Acad Med. 2016;91(8):1047-9.</i>
Bates (2016)	<i>Bates C, Gordon L, Travis E, Chatterjee A, Chaudron L, Fivush B, et al. Striving for Gender Equity in Academic Medicine Careers: A Call to Action. Acad Med. 2016;91(8):1050-2.</i>
Bauman (2014)	<i>Bauman, MD. Howell, LP. Villablanca, AC. The Women in Medicine and Health Science program: an innovative initiative to support female faculty at the University of California Davis School of Medicine. Acad Med. 2014; 89(11): 1462-6.</i>
Bedi (2012)	<i>Bedi G, Van Dam NT, Munafo M. Gender inequality in awarded research grants. Lancet (London, England). 2012;380(9840):474.</i>
Beigay (2007)	<i>Beigay TM. Children in research: human subjects considerations for the inclusion of children as research participants. Progress in Transplantation. 2007;17(1):54-6.</i>
Benach (1995)	<i>Benach de Rovira J. Bibliometric analysis of health inequities in Spain (1980-1994). Gaceta sanitaria / SESPAS. 1995;9(49):251-64.</i>



Bennett (2008)	<i>Bennett B, Karpin I, Ballantyne A, Rogers W. Gender Inequities in Health Research: An Australian Perspective. Law and Bioethics: Current Legal Issues. 112008.</i>
Bergh (2016)	<i>Bergh, M. Atkin, K. Graham, H. Hatton, C. and Thomas, C. Implications for public health research of models and theories of disability: a scoping study and evidence synthesis. Public Health Research. 2016; 4(8).</i>
Bhaumik (2015)	<i>Bhaumik S, Mathew RJ. Representation of women as editors in the Cochrane collaboration. Journal of evidence-based medicine. 2015;7(4):249-51.</i>
Bloomfield (2015)	<i>Bloomfield GS, Baldrige A, Agarwal A, Huffman MD, Colantonio LD, Bahiru E, et al. Disparities in cardiovascular research output and citations from 52 African countries: a time-trend, bibliometric analysis (1999-2008). J Am Heart Assoc. 2015;4(4).</i>
Boehmer (2002a)	<i>Boehmer U. Twenty years of public health research: inclusion of lesbian, gay, bisexual, and transgender populations. American Journal of Public Health. 2002;92(7):1125-30.</i>
Boehmer (2002b)	<i>Boehmer, U. Kressin, NR. Berlowitz, DR. Christiansen, CL. Kazis, LE and JA Jones. Self-reported vs. administrative race/ethnicity data and study results. American Journal of Public Health. 2002;92: 1471-3.</i>
Boffa (2011)	<i>Boffa J, King M, McMullin K, Long R. A process for the inclusion of Aboriginal People in health research: lessons from the Determinants of TB Transmission project. Social Science &amp; Medicine. 2011;72(5):733-8.</i>
Bonevski (2014)	<i>Bonevski B, Randell M, Paul C, Chapman K, Twyman L, Bryant J, et al. Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. BMC Medical Research Methodology. 2014;14:42.</i>
Borsuk (2009)	<i>Borsuk RM, Aarssen LW, Budden AE, Koricheva J, Leimu R, Tregenza T, et al. To name or not to name: The effect of changing author gender on peer review. BioScience. 2009;59(11):985-9.</i>
Bouchard (2015)	<i>Bouchard L, Albertini M, Batista R, de Montigny J. Research on health inequalities: A bibliometric analysis (1966-2014). Social Science &amp; Medicine. 2015;141:100-8.</i>
Boutilier (2011)	<i>Boutilier Z, Daibes I, Di Ruggiero E. Global health research case studies: lessons from partnerships addressing health inequities INTRODUCTION. BMC International Health and Human Rights. 2011;11.</i>
Bradford (2001)	<i>Bradford J, Ryan C, Honnold J, Rothblum E. Expanding the research infrastructure for lesbian health. American journal of public health. 2001;91(7):1029-32.</i>
Brahan (2005)	<i>Brahan, D. and Bauchner, H. Changes in reporting of race/ethnicity, socioeconomic status, gender, and age over 10 years. Pediatrics. 2005;115 e163-6</i>
Brogan (2001)	<i>Brogan DJ. Implementing the Institute of Medicine report on lesbian health. Journal of the American Medical Women's Association (1972). 2001;56(1):24-6.</i>
Brooker (2015)	<i>Brooker K, van Dooren K, Tseng CH, McPherson L, Lennox N, Ware R. Out of sight, out of mind? The inclusion and identification of people with intellectual disability in public health research. Perspectives in Public Health. 2015;135(4):204-11.</i>
Bugeja (1997)	<i>Bugeja G, Kumar A, Banerjee AK. Exclusion of elderly people from clinical research: a descriptive study of published reports. BMJ. 1997;315(7115):1059.</i>

Burchard (2003)	<i>Burchard, EG, Ziv, E, Coyle N. et al The importance of race and ethnic background in biomedical research and clinical practice. New England Journal of Medicine. 2003;348:1170-5.</i>
Burford (2013)	<i>Burford BJ, Welch V, Waters E, Tugwell P, Moher D, O'Neill J, et al. Testing the PRISMA-Equity 2012 reporting guideline: the perspectives of systematic review authors. PloS one. 2013;8(10):e75122.</i>
Bustillos (2009)	<i>Bustillos D. Limited English proficiency and disparities in clinical research. Journal of Law, Medicine &amp; Ethics. 2009;37(1):28-37.</i>
Butts (2012)	<i>Butts GC, Hurd Y, Palermo AG, Delbrune D, Saran S, Zony C, et al. Role of institutional climate in fostering diversity in biomedical research workforce: a case study. Mount Sinai Journal of Medicine. 2012;79(4):498-511.</i>
Byington (2016)	<i>Byington CL, Keenan H, Phillips JD, Childs R, Wachs E, Berzins MA, et al. A Matrix Mentoring Model That Effectively Supports Clinical and Translational Scientists and Increases Inclusion in Biomedical Research: Lessons From the University of Utah. Academic Medicine. 2016;91(4):497-502.</i>
Caban (1995)	<i>Caban CE. Hispanic research: implications of the National Institutes of Health guidelines on inclusion of women and minorities in clinical research. Journal of the National Cancer Institute. 1995;Monographs.(18):165-9.</i>
Cameron (2012)	<i>Cameron EZ, Gray ME, White AM. Is publication rate an equal opportunity metric? Trends in ecology &amp; evolution. 2012;28(1):7-8.</i>
Cameron (2013)	<i>Cameron EZ, White AM, Gray ME. Equal opportunity metrics should benefit all researchers. Trends in ecology &amp; evolution. 2013;28(6):320-1.</i>
Cameron (2014)	<i>Cameron EZ, White AM, Gray M. Maternity, metrics and morale: Addressing the continued attrition of women from science. New Zealand Science Review. 2014;71:62.</i>
Cameron (2016)	<i>Cameron EZ, White AM, Gray ME. Solving the Productivity and Impact Puzzle: Do Men Outperform Women, or are Metrics Biased? BioScience. 2016:biv173.</i>
Campbell (2013)	<i>Campbell A G; Leibowitz M J; Murray S A; Burgess D ; Denetclaw W F; Carrero-Martinez F A; Asai D J. Partnered research experiences for junior faculty at minority-serving institutions enhance professional success. CBE - Life Sciences Education, 2013 12:394-402</i>
Carr (2014)	<i>Carr A, Pullar J, Forbes L, Rosengrave P. Working mothers are disadvantaged by limited funding for health research. New Zealand Medical Journal. 2014;127(1398):138-40.</i>
Carson (1999)	<i>Carson DP, Eagles JM. Disparities in the geographical distribution of authorship between invited and peer reviewed papers. Scottish Medical Journal. 1999;44(5):149-51.</i>
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Ceci (2015)	<i>Ceci SJ, Ginther DK, Kahn S, Williams WM. Women in Academic Science: A Changing Landscape. Psychological science in the public interest : a journal of the American Psychological Society. 2015;15(3):75-141.</i>

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Darling (2015)	Darling ES. Use of double-blind peer review to increase author diversity. <i>Conservation Biology</i> . 2015;29(1):297-9.
de Wit (2016)	de Wit M, Campbell W, Coates LC, Gladman DD, James J, Lindsay CA, et al. Let's Talk about Inclusion: A Report on Patient Research Partner Involvement in the GRAPPA 2015 Annual Meeting. <i>Journal of Rheumatology</i> . 2016;43(5):970-3.
DeCastro (2013)	DeCastro R ; Griffith K A; Ubel P A; Stewart A ; Jagsi R. Mentoring and the career satisfaction of male and female academic medical faculty. <i>Aced Med</i> . 2014. 89(2): 301-311
Del Boca (2016)	Del Boca FK. Addressing sex and gender inequities in scientific research and publishing. <i>Addiction</i> . 2016.
Del Carmen (2003)	Del Carmen Davo M, Vives C, Alvarez-Dardet C. Why are women underused in the JECH peer review process? <i>Journal of epidemiology and community health</i> . 2003;57(12):936-7.
Denny (2015)	Denny SG, Silaigwana B, Wassenaar D, Bull S, Parker M. Developing Ethical Practices for Public Health Research Data Sharing in South Africa: The Views and Experiences From a Diverse Sample of Research Stakeholders. <i>Journal of Empirical Research on Human Research Ethics</i> . 2015;10(3):290-301.
Di Pietro (2014)	Di Pietro NC, Illes J. Disparities in Canadian indigenous health research on neurodevelopmental disorders. <i>Journal of Developmental &amp; Behavioral Pediatrics</i> . 2014;35(1):74-81.
Diamond (2016)	Diamond SJ, Thomas CR, Jr., Desai S, Holliday EB, Jagsi R, Schmitt C, et al. Gender Differences in Publication Productivity, Academic Rank, and Career Duration Among U.S. Academic Gastroenterology Faculty. <i>Acad Med</i> . 2016;91(8):1158-63.
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Dotson (2011)	<i>Dotson B. Women as authors in the pharmacy literature: 1989-2009. American journal of health-system pharmacy. AJHP : official journal of the American Society of Health-System Pharmacists. 2011;68(18):1736-9.</i>
Douma (2007)	<i>Douma M, Gamito EJ. A culturally appropriate, web-based technology for anonymous data collection for public health research in culturally diverse populations. Journal of Cases on Information Technology. 2007;9(3):15-26.</i>
Drevdahl (2001)	<i>Race and ethnicity as variables in Nursing Research, 1952–2000. Nursing Research. 2001;50: 305-313.</i>
Drevdahl (2006)	<i>Uncontested categories: the use of race and ethnicity variables in nursing research. Nursing Inquiry. 2006; 13(1): 52-63.</i>
Ejiogu (2011)	<i>Ejiogu N, Norbeck JH, Mason MA, Cromwell BC, Zonderman AB, Evans MK. Recruitment and retention strategies for minority or poor clinical research participants: lessons from the Healthy Aging in Neighborhoods of Diversity across the Life Span study. Gerontologist. 2011;51 Suppl 1:S33-45.</i>
El Ansari (2005)	<i>El Ansari W. Collaborative research partnerships with disadvantaged communities: challenges and potential solutions. Public Health. 2005;119(9):758-70.</i>
Ellison (1997)	<i>Ellison, GTH. and de Wet, T. The use of 'racial' categories in contemporary South African health research. South African Medical Journal. 1997;87: 1671-9.</i>
Ellison (2002)	<i>Ellison, GTH. and Rosato, M. The impact of editorial guidelines on the classification of race/ethnicity in the British Medical Journal. Journal of Epidemiology &amp; Community Health. 2002; 56(2): A25.</i>
Ellison (2005)	<i>'Population profiling' and public health risk: when and how should we use race/ethnicity? Critical Public Health. 2005; 15: 65-74</i>
Eloy (2012)	<i>Eloy JA, Svider P, Chandrasekhar SS, Husain Q, Mauro KM, Setzen M, et al. Gender disparities in scholarly productivity within academic otolaryngology departments. Otolaryngology--head and neck surgery : official journal of American Academy of Otolaryngology-Head and Neck Surgery. 2012;148(2):215-22.</i>
Ence (2016)	<i>Ence AK, Cope SR, Holliday EB, Somerson JS. Publication Productivity and Experience: Factors Associated with Academic Rank Among Orthopaedic Surgery Faculty in the United States. The Journal of bone and joint surgery American volume. 2016;98(10):e41.</i>
Evans (2014)	<i>Evans JA, Shim JM, Ioannidis JP. Attention to local health burden and the global disparity of health research. PLoS ONE [Electronic Resource]. 2014;9(4):e90147.</i>
Feramisco (2008)	<i>Feramisco JD, Leitenberger JJ, Redfern SI, Bian A, Xie XJ, Resneck JS, Jr. A gender gap in the dermatology literature? Cross-sectional analysis of manuscript authorship trends in dermatology journals during 3 decades. Journal of the American Academy of Dermatology. 2008;60(1):63-9.</i>
Fischer (2011)	<i>Fischer, JA. and Kalbaugh, CA. Challenging assumptions about minority participation in US clinical research. American Journal of Public Health. 2011; 101(12): 2217-2222.</i>

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Foreman (2015)	<i>Foreman H, Weber L, Thacker HL. Update: A Review of Women's Health Fellowships, Their Role in Interdisciplinary Health Care, and the Need for Accreditation. Journal of women's health (2002). 2015;24(5):336-40.</i>
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Garcia (2011)	<i>Garcia I, Tabak LA. Global oral health inequalities: the view from a research funder. Advances in dental research. 2011;23(2):207-10.</i>
Garcia-Calvente (2015)	<i>Garcia-Calvente Mdel M, Ruiz-Cantero MT, Del Rio-Lozano M, Borrell C, Lopez-Sancho MP. [Gender inequalities in research in public health and epidemiology in Spain (2007-2014)]. Gaceta sanitaria / SESPAS. 2015;29(6):404-11.</i>
García-Carpintero (2010)	<i>García-Carpintero E, Granadino B, Plaza LM. The representation of nationalities on the editorial boards of international journals and the promotion of the scientific output of the same countries. Scientometrics. 2010;84(3):799-811.</i>
Gardin (1992)	<i>Gardin JM. Inclusion of Elderly Individuals in Clinical Research: An Idea Whose Time has Arrived. American Journal of Geriatric Cardiology. 1992;1(5):30-1.</i>
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Getz (2008)	<i>Getz K, Faden L. Racial disparities among clinical research investigators. American Journal of Therapeutics. 2008;15(1):3-11.</i>
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Ghee (2014)	<i>Ghee M, Collins D, Wilson V, Pearson Jr W. The Leadership Alliance: Twenty Years of Developing a Diverse Research Workforce. Peabody Journal of Education. 2014;89(3):347-67.</i>
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## 7.6. Mapping Protocol

### Review of diversity and inclusion literature and an evaluation of methodologies and metrics relating to health research: systematic mapping protocol<sup>35</sup>

Louise Preston, Duncan Chambers, James Wilsdon, Andrew Booth  
University of Sheffield, July 2016

#### Introduction

This systematic mapping protocol forms part of a project being undertaken by a multidisciplinary team from the University of Sheffield, which aims to inform and support the focus on diversity and inclusion in Wellcome Trust's new strategic plan (see <http://strategy.wellcome.ac.uk>).<sup>36</sup>

As with debates over open access, public engagement and science education, Wellcome's reach across biomedical, health and broader research communities means that it can help to influence the terms of such debates, and support change in cultures, policies and practices.

To inform Wellcome Trust's work on diversity and inclusion, this review aims to "undertake a systematic and critical review of the evidence base for a positive relationship between a diverse and inclusive health research community and the qualities and impacts of the research they undertake".

As a methodology, systematic mapping does not attempt to answer a specific question, in the way that a systematic review would do, "but instead collates, describes and catalogues available evidence...relating to a topic of interest. The included studies can be used to develop a greater understanding of concepts, identify evidence for policy-relevant questions, knowledge gaps...and knowledge clusters." (James et al., 2016)<sup>37</sup>

This protocol sets out our plan for the review in terms of the literature search and how the retrieved literature will be screened for inclusion in the main review, extracted and then assessed.

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<sup>35</sup> Previously published on Figshare in July 2016, and available here (accessed 20 October 2016): [https://figshare.com/articles/Review\\_of\\_diversity\\_and\\_inclusion\\_literature\\_and\\_an\\_evaluation\\_of\\_methodologies\\_and\\_metrics\\_relating\\_to\\_health\\_research\\_systematic\\_mapping\\_protocol/3483140](https://figshare.com/articles/Review_of_diversity_and_inclusion_literature_and_an_evaluation_of_methodologies_and_metrics_relating_to_health_research_systematic_mapping_protocol/3483140)

<sup>36</sup> The team is drawn from the University of Sheffield's School of Health and Related Research (ScHARR), Management School and Department of Politics. For more information about the project, please contact James Wilsdon ([j.wilsdon@sheffield.ac.uk](mailto:j.wilsdon@sheffield.ac.uk)).

<sup>37</sup> James, K L, Randall, N P and Haddaway, N R (2016) A methodology for systematic mapping in environmental sciences. *Environmental Evidence* 5:7.

The preliminary literature search and scope refinement stage aims to “scope the terrain, identify relevant literatures and sharpen the framing and approach”. In particular we are interested in diversity, inclusion, equality and co-production across health systems and services. This is likely to include the diversity and inclusivity of the health research community and biomedical research and also evidence from research policy.

Due to the variety of evidence that we are interested in, a search approach combining traditional database searching and searches of the internet will be the most fruitful. Given the rapid nature of the review, we will be designing search approaches that allow us to identify key evidence in the topic area, rather than an exhaustive search of the evidence which will result in an unmanageable number of records to screen. This process will be managed by the entire research team capitalising on their discrete areas of subject knowledge.

This review is not a systematic review – we will be searching in a limited number of databases and not undertaking full data extraction. Any quality assessment undertaken will be for the purposes of informing the review findings, rather than determining inclusion or exclusion in the review.

## **Literature Search**

The literature search will have five phases, to identify both academic literature (as identified and retrieved via database and citation searches) and grey literature (typically in the form of reports which are accessed via the WWW). Database/citation searches will be limited by date from 1996-2016 and to English Language studies only. Searches will be undertaken in three databases, Medline (via Ovid), Scopus and Web of Science.

*Phase 1 (Whole team) - Identification of evidence known by our research team.* Evidence will be mapped against the PROGRESS-Plus framework (see appendix) and saved in a spreadsheet.

*Phase 2 (LP) - General search for literature about diversity and inclusion in health research.* There are likely to be a multiple different types of evidence of interest - observational evidence about how specific groups are or are not included in research, empirical evidence from interventions to improve diversity in health research and policy evidence about how best to improve diversity in health research. We will search in both academic databases and on the internet. An indicative search is presented in the appendix.

*Phase 3 (LP) - Targeted searches for specific aspects of diversity and inclusion, where a lack of evidence retrieved via Phase 2 has been identified.* For this we will base the search on a validated search strategy by Welch et al (2015) which

considers specific equity related concepts (gender, age, ethnicity, sexual orientation, socioeconomic status/social capital, educational status, religion, place of residence). Other concepts that may need to be added to the search strategy include occupation, disability, gender reassignment, marital status and maternity. We will also liaise with internal and external topic experts to ensure that the evidence retrieved matches their understanding of the discipline.

*Phase 4 (AB) - Citation searches of included literature, particularly from Phase 1.*

This stage will also involve checking the reference lists of included and relevant evidence in order to identify additional studies. This stage will not run sequentially, but rather will underpin the entire search process, with regular discussion between AB, LP and DC. This method has been used successfully in numerous projects undertaken by LP and AB and offers an alternative route of access to evidence.

*Phase 5 (LP) - Supplementary searches specifically on research metrics and diversity (1996-2016).* For this phase, we will develop a search strategy using our general diversity search terms (used in Phase One) combined with terms for metrics, harvested from 'The Metric Tide' (Wilsdon *et al.*, 2015) and in liaison with our topic experts.

Screening the search results

Search results will be stored in a reference management database (EndNote). Screening of results against inclusion criteria will be performed by at least three members of the research team, with a degree of cross-checking to ensure consistency, depending upon the volume of evidence to be screened. Uncertainties over the inclusion or exclusion of specific items or types of literature will be resolved by discussion and consensus.

Criteria to be used for screening are:

- Participants: organisations and individuals/teams involved in pure or applied research relevant to health (including research funders)
- Types of study:
  - Descriptions or evaluations of programmes or policies aimed at increasing diversity in the research workforce, overcoming barriers to inclusion and/or ensuring diversity issues are considered in the selection of research topics and participants;
  - Evaluative documents - quantitative or qualitative research reporting associations between increased diversity/inclusion and any measure of research output or quality;
  - Descriptive documents - relevant policy documents produced by research organisations or funders
- Comparator: comparative and noncomparative studies will be eligible for inclusion

- Outcomes: any measure of diversity/inclusion in relation to research workforce, topics or participants; any measure of research quality or impact; other actual or perceived benefits of increased diversity
- Excluded: Editorials and opinion pieces without any substantive data or evidence.

Screening will take place in Excel. Bibliographic information will be downloaded and screened for inclusion. If studies are deemed 'include', additional data will be captured on (1) the PROGRESS plus framework element that is being captured, (2) whether the evidence is examining workforce, participant or topic (3) The study type (descriptive, intervention, policy, empirical or other) and (4) The research activity being undertaken

### **Data extraction**

The objective of the systematic mapping exercise is to provide an overall description of the current evidence base; to identify areas where evidence is lacking; and to identify areas where a more detailed review may be helpful. We will broadly follow the methods summarised by James et al. (2016).

A coding framework will be developed in advance. Table 1, in the appendix, presents a preliminary list of variables for coding. We will use EPPI-Reviewer 4.0 software for coding the included studies and producing summary tables. This software was developed by the EPPI Centre at the UCL Institute for Education, University of London, and is particularly well suited to mapping reviews covering a range of different types of literature.

In parallel with the mapping and data extraction process, we propose to develop a separate map of the sub-set of literature covering diversity and inclusion metrics. This will be developed in Excel and will cover proposed metrics as well as those that have been used in practice. Metrics will be mapped against the PROGRESS-Plus framework and the three broad areas of research topics, workforce and participants. This process will enable us to develop a complementary output in conjunction with the main evidence map that can be used to match metrics with topics and to identify gaps in the literature related to metrics.

### **Critical appraisal**

Critical appraisal of the included literature will concentrate on the overall strength and robustness of the evidence base, rather than providing a detailed investigation of study internal validity (risk of bias) as is normal for a systematic review. Study design may be considered as a partial proxy indicator of robustness of evidence (e.g. Table 2 in the Appendix).

## Presentation of data

Coding and tabulation of the included studies will be used as the basis for a succinct descriptive overview of the included evidence. Although evidence maps do not routinely extract detailed results or findings of included studies (in order to avoid vote counting), the report will provide a basis for future work to investigate more fully the evidence for a relationship between diversity and inclusion and the quality and impact of research. The research team will ensure that any key areas of interest, that are outside the remit of the review are noted in an Appendix and any key evidence retrieved through the search and associated with this area is included.

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## Appendices

### PROGRESS-Plus

Following initial team meetings, it was decided to adopt the PROGRESS-Plus framework<sup>1</sup> to guide our understand of issues of equality and diversity. The PROGRESS -Plus framework was developed to ensure that researchers “ consider the intersecting determinants of health when designing research or an implementation plan”. The concepts included in PROGRESS are **P**lace of residence, **R**ace/ethnicity/culture/language, **O**ccupation, **G**ender/sex, **R**eligion, **E**ducation, **S**ocioeconomic status, **S**ocial capital. In addition to these, PROGRESS Plus includes **A**ge, **D**isability, **G**ender reassignment, **M**arriage and Civil Partnership, **P**regnancy and Maternity and **S**exual Orientation.

## Indicative search strategy for Phase Two

Concepts for diversity	AND	Concepts for health research
Diversity, diverse, inclusion, inclusive, inclusivity, equality, equity, inequality, inequity		Health research, health service research, medical research, biomedical research, STEM, STEMM, workforce, scientist, publishing, contributing, authorship, pay gap, glass ceiling, research organisation, research funder, research participants, research involvement, research partners, co production, PPI

## Indicative search strategy for Phase Five

Concepts for diversity	AND	Concepts for metrics
Diversity, diverse, inclusion, inclusive, inclusivity, equality, equity, inequality, inequity		metric*, benchmark*, bibliometric, indicator*, "peer review"

**Table 1: Potential coding variables**

Coding variable	Information recorded	Comments
Full reference	Authors, title, bibliographic details	
Year of publication		
Publication type		
Study country	Name of country/countries	
Linked study	Other articles reporting the same study	
Data type	e.g. Quantitative or qualitative	
Study design	Descriptive, intervention, policy, empirical or other. Descriptive (what needs to happen due to an identified problem, the scale and nature of the problem) or Evaluative (propose or explore interventions for addressing the problem)	
Setting		
PROGRESS-plus factors investigated		

Research area addressed	Workforce, participant or topic	
Intervention described/evaluated?	Details of intervention	
Association reported?		
Outcome(s) assessed		
Metrics used		
Length/period of study		
Sampling strategy		
Funding body (if information supplied)		

**Table 2: Approximate hierarchy of study designs**

	Quantitative	Qualitative
Stronger	Randomised or cluster randomised	Interviews or focus groups
	Cohort; case-control; controlled before/after; interrupted time series	Survey/questionnaire
	Uncontrolled before/after; case study; modelling or simulation	
Weaker	Expert opinion	

## 7.7. Stakeholder workshop: list of attendees

Attendee list for project workshop on “Diversity and Inclusion in Health Research: Reviewing the Evidence Base”, held at Wellcome Trust, London, 21 July 2016.

<b>Attendee</b>	<b>Institution</b>
Ahu Tatli	Queen Mary, University of London
Steve Frost	Frost Included
Tom Secker-Walker	Frost Included
Raafi Alidina	Frost Included
Lenna Cumberbatch	Royal Society
Vijaya Nath	The Kings Fund
Andrea Brand	University of Cambridge
Vicky Jones	HEFCE
Patrick Johnson	University of Manchester
Uduak Archibong	University of Bradford
Paula Wray	INVOLVE, NIHR
James Wilsdon	University of Sheffield
Duncan Chambers	University of Sheffield
Andrew Booth	University of Sheffield
Anna Topakas	University of Sheffield
Sarah Salway	University of Sheffield
Stevienna de Saille	University of Sheffield
Lauren Couch	Wellcome Trust
Kal Puvanendran	Wellcome Trust
Anne Kirtley	Wellcome Trust
Briony Rayfield	Wellcome Trust
Ethan Greenwood	Wellcome Trust
Keziah Jones	Wellcome Trust



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