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THE DIVERSITY DIVIDEND?

Does a more diverse and inclusive research community produce better biomedical and health research?

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CONTEXT

Over the past decade, the need for greater diversity and inclusion across research systems has received greater emphasis from policymakers, funders, universities and stakeholders. It is also a priority for the Wellcome Trust, which funded this project³.

Strategies in support of diversity and inclusion need to be underpinned by the best available evidence. As a contribution to this, a multidisciplinary research team from the University of Sheffield undertook a mapping review of the evidence for a positive relationship between a diverse and inclusive biomedical and health research community, and the qualities and impacts of its research. A second stage of the project explored and evaluated the relationship between the metrics used to measure diversity, inclusion, quality and impact in health research.

“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.” Diversity challenge, Nature editorial, 16 September 2014²



CHALLENGES OF MEASURING DIVERSITY AND INCLUSION

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 and rights). There are also challenges in conceptualising and measuring diversity and inclusion, including:

- 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;
- Some axes of difference and disadvantage have had more analysis than others; other areas are less well covered in the research base;
- Measures of inclusivity (or discrimination) need to go beyond measuring the make-up of groups and representativeness to look at how they function, and degrees of inclusivity or discrimination;
- Measures that are meaningful in the UK may be irrelevant in many other settings

CHALLENGES OF MEASURING DIVERSITY AND INCLUSION

The biomedical and health research system is also complex, with many actors. Any analysis of diversity and inclusion across this system requires looking at more than simply those who primarily identify themselves as ‘researchers’. There are increasing expectations that the public, patients and carers should be active players in shaping research agendas. Individuals also play multiple roles: as researchers; research users; funding board members; journal reviewers and editors; and patients.

Different interests and views about the overarching purposes of the health research system also influence perceptions of diversity and inclusion. These include: health research as a source of wealth (new drugs and technologies etc.); health research as a means of increasing overall health; health research as a means of reducing inequalities in health outcomes between groups, populations and/or 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.

MEASURING RESEARCH QUALITIES AND IMPACTS

Similarly, ideas about what constitutes high-quality or high-impact research depend on different perceptions about the purposes of research. In recent years, researchers have come under growing pressure to measure and demonstrate the value they contribute to society. This pressure takes a variety of forms: greater demands for audit and evaluation of public investment in 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.

Policies and initiatives to promote diversity and inclusion in 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.

METHODOLOGY

A systematic mapping review is a method used to analyse a broad field, in order to identify gaps in knowledge or future research needs. Its objective differs from a formal systematic review as it does not involve data extraction, critical appraisal and synthesis of results, in an attempt to provide an answer to a specific question, but instead aims to provide a broader understanding of a wider topic or issue.

Coding for the systematic mapping review was undertaken using the PROGRESS-Plus framework, developed by the Cochrane Equity Group for analysis of equality and diversity issues in health. It aimed to identify evidence over a twenty-year period, from 1995 to 2015.

From an initial set of 1466 studies, the review generated 246 papers for detailed analysis. A full account of the search methods used can be found in the project’s review and mapping protocol⁴. The review 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.

The database collated for this review is now available as a searchable resource on Wellcome Trust’s website, to enable further interrogation of subsets of studies⁵.

1. For more details about this project, contact Prof. James Wilsdon j.wilsdon@sheffield.ac.uk

2. <http://www.nature.com/news/diversity-challenge-1.15930>

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

4. 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

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

RESULTS AND KEY THEMES FROM THE MAPPING REVIEW

Of the 246 included studies, over half were published after 2005, suggesting an upward trend in the volume of research in this area. The majority of empirical studies were US-based. 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).

Relatively small numbers of studies investigated sexual orientation, age, disability, pregnancy and maternity, and gender reassignment in relation to the health and 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 research system elements.

While the majority of papers took a national focus, a few highlighted global patterns of exclusion from health research, and the limited amount of funded health research that relates to health conditions more commonly experienced in developing countries.

Table 1 - Distribution of studies by PROGRESS-Plus dimensions and research system elements

PROGRESS+ dimensions ¹	Number of included studies
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 ²	0
Education ²	0
Other or non-specific inequalities ³	9
Research system elements ¹	Number of included studies
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: 1: multiple coding possible; 2: these factors likely subsumed under socioeconomic status; 3: included parental status; substance users; stigmatised illness.

Close 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. A smaller number of papers were concerned with other aspects of the research system and/or took a more holistic approach. These two main clusters are explored in more depth below.

THE RESEARCH WORKFORCE

85 of the 246 publications coded for the review were identified as addressing research workforce issues.

RATIONALES FOR DIVERSITY AND INCLUSION

Nine 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. These papers tended to draw selectively on evidence from other sectors to make this case. Six of these papers included dual rationales, emphasising the 'business case' for greater diversity as well as an equity and fairness argument.

Arguments advanced in relation to increasing the diversity of the research workforce were also linked 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 groups. But these mechanisms were assumed, rather than demonstrated empirically. Four further papers had a single focus on equity and fairness. Two referred 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', and two focused on equity of access to opportunities and fair treatment within academia.

PATTERNS AND TRENDS OVER TIME

A number of studies examined patterns of diversity and inclusion within the research workforce, through the representation of different groups among: the academic hierarchy; authors of published papers; grant applicants and awardees; editorial boards of academic journals; and recipients of other types of research support.

The majority of these 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 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. These studies covered a wide range of medical specialties and contexts but all were based in the US except for two studies that were conducted in Spain.

A number of US studies also looked at gender differences in salaries among medical/health researchers. Several studies examined patterns of grant applications and awards by gender. Though studies tended to report greater receipt of research funding by men, findings were often complex and difficult to interpret. Three studies examined the make-up of the editorial boards of academic journals and all found women to be under-represented.

OBSTACLES AND ENABLERS OF DIVERSITY AND INCLUSION

Research into obstacles and enablers of diversity and inclusion in the research workforce focused on: family and caring responsibilities; aspirations; individual bias and institutional discrimination; and more holistic analyses.

Methods used to investigate obstacles and enablers included: 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; and qualitative methods to examine structures and processes that may operate to (dis)advantage particular groups, again with a predominant focus on gender.

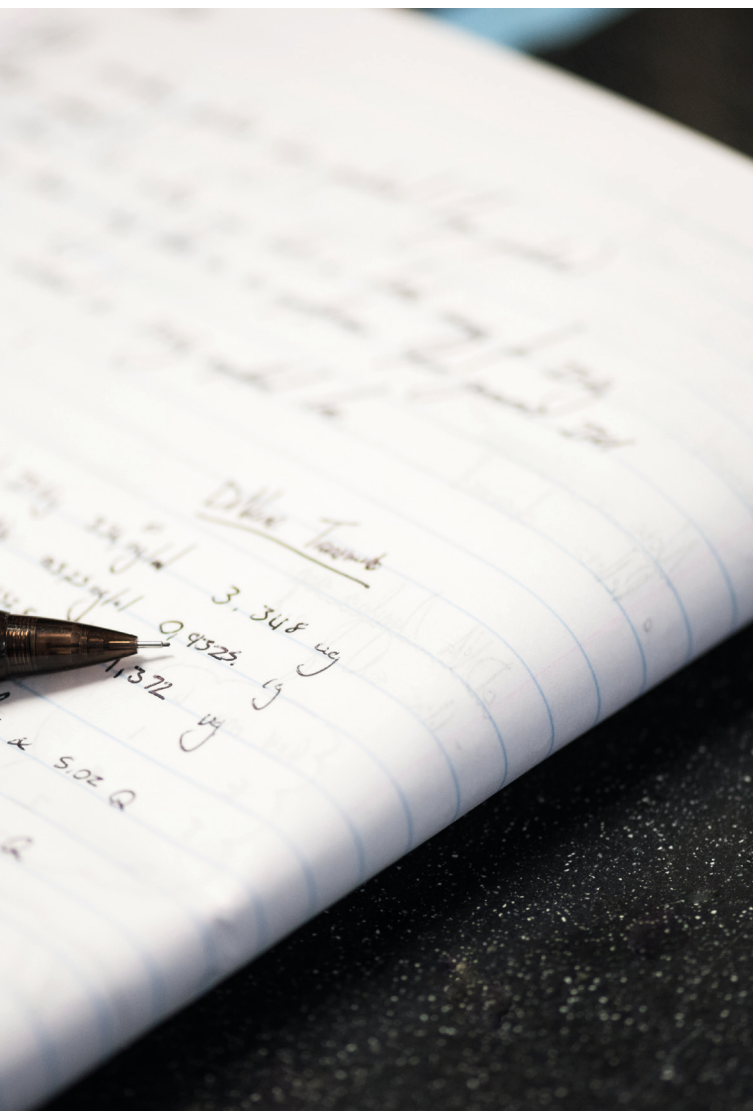
INTERVENTIONS AND INITIATIVES

The review identified a number of studies or evaluations of interventions and initiatives aimed improving diversity and inclusion within the research workforce. Most of these 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. However, study designs of the reviewed interventions are not very strong in terms of their appropriateness for establishing causality. And the 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.

The workforce-focused interventions in this review can be broadly categorised into two groups: education-focused and career-focused. The former 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. The latter 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.

Three papers reported on initiatives aimed at shifting wider cultures and structures within research organisations and the wider system. One study focused on under-represented minority racial/ethnic groups, while the other two studies focused on gender equality. Several papers dealt with more than one intervention/initiative, which could be interpreted as signifying the recognition of the need for a long-term, holistic and systemic approach.

The interventions varied in terms of scale and scope. The majority of reported interventions were conducted in the US or Canada region. The only intervention conducted in the UK dealt with the effectiveness and impact of the Athena SWAN Charter initiative, that awards excellence status to universities and departments based on their policies and practices aiming at reducing gender bias and creating inclusive workplaces in the STEM fields.



RESEARCH PARTICIPANTS, TOPICS AND AGENDAS

65 of the 246 publications coded for the review were identified as addressing research participant issues.

RATIONALES FOR DIVERSITY AND INCLUSION

Arguments in support of research being inclusive of diverse population groups relate to both scientific quality and to wider legal and ethical principles. Several studies note the shift over time away from a concern to avoid individual risk to female participants – leading to the exclusion of women from biomedical research – to a recognition of the liabilities associated with collective exclusion of women from research, and the benefits of inclusion. Parallel arguments are also presented in relation to socio-economically disadvantaged groups.

However, debates regarding the inclusion and exclusion of particular groups in different research settings continue. A number of papers 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.

PATTERNS AND TRENDS OVER TIME

A number of studies aimed to characterise research participants and the degree to which they were representative of the general population. Most of these 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 (e.g. the exclusion of the elderly and children) and disability (e.g. the exclusion of people with intellectual disability or psychiatric disorders). Most papers examined inclusion in clinical research, rather than other research types, and the majority concluded that exclusion was unjustified.

There appears to have been significant improvement over time in the gender representativeness of biomedical research samples in the US. Progress has been slower in relation to minority racial/ethnic groups. For other groups, progress is less well documented but also appears to be slower (e.g. LGBT).

Limited evidence on patterns and trends over time in the make-up of research participants was identified for countries other than the US. Some research also raises the possibility of over-representation and 'over-researching' of some marginalised communities (e.g. minority racial/ethnic participants in Phase I healthy volunteer clinical trials in the US – the most risky trials).

There are significant differences in patterns of gender inclusion across health research specialties and disciplines (e.g. nursing research is one area that tends to exclude men rather than women). There was less evidence of a consistent shift over time on the agendas and topics pursued by health researchers, and their likely positive impact on health inequalities.

OBSTACLES AND ENABLERS OF DIVERSITY AND INCLUSION

It is important to recognise both active and passive processes of exclusion from research studies. Passive exclusion can result from consent procedures for some clinical trials in the US, which actively exclude patients who do not speak English, or passively exclude individuals on linguistic or cultural grounds. Low levels of trust and negative attitudes towards medical research can also lead to a greater reluctance to participate among some groups.

Obstacles to the design and delivery of health research that addresses the health concerns of marginalised and disadvantaged groups are similarly multi-faceted. Researcher skills, confidence and tools can be insufficient to engage with research participants across social and cultural distance. Institutional cultures, structures and processes do not necessarily encourage research on minority health issues.

INTERVENTIONS AND INITIATIVES

The review identified a range of initiatives across 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. Few of these have been evaluated using rigorous methods, and a majority of papers report on descriptive studies.

Studies reporting on initiatives aimed at increasing diversity and inclusion in research participants and/or topics fell into five main categories:

- [legislation to establish guidelines for inclusion of women and racial/ethnic minorities in clinical research \(only in the US\); policies & guidelines developed at various levels and relating to various points in the health research cycle;](#)
- [targeted investments by funding agencies or research institutions aimed at fostering more research in particular areas;](#)
- [workforce diversification and skills development to encourage more representative research samples and research on the health needs of under-represented groups;](#)
- [research tools and techniques to support recruitment of traditionally under-represented groups; and](#)
- [community engagement and participatory methods going beyond recruitment of participants, to actively engage members of minority and marginalised groups within the research process.](#)

SUMMARY OF INTERVENTIONAL APPROACHES AND OUTCOMES

Overall, the mapping review identified a much larger volume of descriptive and exploratory studies than interventional or evaluative studies. 25 studies were identified 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 of these addressed the diversity of the workforce, or of research participants.

Those which focused on workforce issues used largely conventional indicators of academic performance such as publications written, citations, grants secured and positions obtained. Few metrics related to longer-term outcomes or evaluation, and only one study included an in-built critique of metrics used. Studies focused on participants tended to focus on quantitative aspects of recruitment and retention to trials, although there was some consideration of qualitative aspects of diversity in study samples.

DIVERSITY, INCLUSION AND RESPONSIBLE METRICS

Across research systems, there is a growing recognition that initiatives to encourage greater diversity and inclusion in research are likely to prove inadequate if the metrics and indicators that are used to define, measure, recognise and reward success within those systems simply reinforce existing inequalities and hierarchies.

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 trajectories. Concern about the effects that a small range of dominant metrics are having on research cultures is reflected in recent initiatives such as the San Francisco Declaration on Research Assessment (DORA), Leiden Manifesto and The Metric Tide⁶.

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: studies that identify inequalities and/or potential biases in conventional research metrics; studies that focus on the relationship between research metrics and career trajectories; studies that examine differences in authorship and editorship; studies that propose new metrics for qualities and impacts; studies that focus on indicators of diversity or inclusion in relation to research participants, topics and agendas.

6. 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>

CONCLUSIONS AND RECOMMENDATIONS

STRENGTHS AND WEAKNESSES OF THIS PROJECT:

The review presents descriptions of interventions rather than evaluating their effectiveness or impact. 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. Other relevant literature may be missing because indexing is problematic in certain areas. The review was also biased towards literature written in English.

Consultation with stakeholders allowed the review team and 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.



THE DIVERSITY DIVIDEND?

KEY FINDINGS AND OBSERVATIONS

The review highlighted ten broad conclusions about the state of the evidence in this area, and gaps that persist:

1. There is 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.
2. There is a far more extensive literature relating to gender and race/ethnicity (although the latter relates predominantly to the US), and comparatively little on other axes of difference. The literature highlights persistent patterns of disadvantage, but also variability by field and subfield – particularly with regard to gender.
3. 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 differ 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.
4. 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.
5. 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.
6. 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.
7. 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.
8. There are persistent areas of controversy and complexity, such as how to conceptualise and operationalise race/ethnicity. These demand careful and explicit consideration.
9. 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.
10. 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.

RECOMMENDATIONS FOR FURTHER WORK:

The review made four recommendations for future research that would strengthen the evidence base in this area:

- 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.
- More work is required to improve comparability across studies, to define and standardise indicators and metrics; and to collect data in consistent ways.
- 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.
- 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. Given the existing portfolio of its activities, there is scope for Wellcome Trust to pioneer creative funding, policy and advocacy that draw links between these disparate and siloed agendas, to advance a more holistic understanding of links between diversity, inclusion, integrity, responsibility and public engagement.

For more information about this research please contact Professor James Wilsdon, Director of Impact and Engagement in the Faculty of Social Sciences at University of Sheffield, on J.wilsdon@sheffield.ac.uk

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