Academy of Medical Sciences' response to the All Party Parliamentary Group on Medical Research inquiry into 'Health disparities: why medical research is a crucial tool for health equity.'

August 2022

The Academy of Medical Sciences is the independent, expert voice of biomedical and health research in the UK. Our mission is to help create an open and progressive research sector to improve the health of people everywhere. We welcome the opportunity to draw on our previous policy work and highlight the following key points regarding the role of medical research in addressing health inequalities.

Please respond with what you believe the top three priorities [from the list below] should be for Government, research bodies and NHS England to support medical research into health disparities. This will feed into our recommendations.

- Collection and use of data for research
- Communicating research to the public
- Funding of research
- Guidelines on good practice in inequity research
- Diversity of those taking part in research
- Co-production of research with community
- Working with policy makers to ensure evidence uptake
- Researcher workforce/diversity
- Priority setting to ensure key issues are addressed
- Promoting more inclusive research design (language barriers, geographical accessibility issues etc)

The Academy did not answer this question due to the interlinked and equally important nature of these priorities. They are listed above to provide context for the following questions.

Are there additional priorities or further detail you would like to include to the priorities above?

Further detail could be given on the following priorities:

i. #1: This data must be multimodal, bringing together data from a range of disciplines and sectors (see the following question for further detail).
ii. #1: Qualitative in addition to quantitative research should be undertaken to widen the scope of knowledge on health inequalities. Qualitative data can provide context to the numbers, allowing for a better understanding of the causes and impacts of inequalities, and how they might be tackled.
iii. #1: Data collection and indicators must be standardised to enable comparisons between geographic regions.
iv. #3: Funding of research should include interdisciplinary projects.
v. #4: In addition to guidelines on good practice in inequity research, guidance and infrastructure for sharing examples of good practice and coordination of health

inequality research should be put in place, for example a nationwide platform for sharing resources.

vi.   #6: Co-production of research with communities must include those who are (or will be) most affected by inequality most affected by health inequality interventions. A diverse range of voices must be included in co-production to ensure applicability of the results of research and minimise risk of creating further inequalities.

vii.   #7: In addition to working with policy makers, uptake of evidence would benefit from building capabilities in implementation science (the study of methods to facilitate the uptake of evidence-based practice into regular use by practitioners and policymakers).[1]

viii.   #2, #9 and #10: All of these priorities will benefit from working closely with communities to achieve these goals.

Additional priorities:

ix.   A range of factors contribute to creating and maintaining health inequalities, so research should be interdisciplinary, incorporating sociological, political, economic, public health, behavioural insights and other areas with medical research.

x.   There must be coordination of research between academia, the NHS, government and industry to maximise research output and prevent neglect of any research area.

xi.   Health inequalities also exist between countries, and medical research has a role to play in addressing these. International research collaboration should be pursued to gain insights from different nations and ensure interventions are tailored to local contexts.

In your view, what role does medical research have in addressing health disparities?

The Academy identified research into health inequalities as a strategic priority for government and the research sector in its report 'Improving the health of the public by 2040'.[2] More research into the causes and effects of health inequalities and the efficacy of interventions to reduce them is needed. Interventions aimed at tackling health inequalities often lack proper assessment after implementation, so there is significant additional scope for medical research to identify those interventions that are effective and those that are not. Employing a wider range of assessments would expand the capacity of medical research to identify effective interventions, for example using larger scale and innovative trial designs or using routine data to monitor natural experiments. Research should be interdisciplinary, incorporating randomised control trials, observational studies, surveys, health systems research, health economics, policy research and implementation research. Greater coordination of research funding could occur to enable these larger scale investigations.

The social determinants of health, which underlie many health inequalities, must be studied.[3] Most of these determinants lie outside of the control of the health domain, the

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[1] Peters DH, *et al.* (2013) *Implementation research: what it is and how to do it.* BMJ **347**:f6753. https://www.bmj.com/content/347/bmj.f6753

[2] The Academy of Medical Sciences (2016). *Improving the Health of the Public by 2040.* https://acmedsci.ac.uk/policy/policy-projects/health-of-the-public-in-2040

[3] The Marmot Review (2010). *Fair society, healthy lives.* http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review

Department of Health and Social Care (DHSC) and NHS England. Interdisciplinary research should be undertaken to understand the socioeconomic drivers of health inequalities. Results from this combined research effort can then be used to develop more effective healthcare interventions to address health inequalities. A concerted and coordinated effort across government to utilise research to tackle inequalities is also important.[4] The Office for Health Improvement and Disparities could lead this effort.

In addition to medical research being crucial in understanding the causes of and testing interventions for health inequalities, there is also a need to ensure that all biomedical and health research, including basic research, pre-clinical and clinical research is carried out in a way that doesn't maintain or worsen health inequalities, as outlined in the response to the following question.

Health inequalities exist within countries but also between them, so medical research should continue to address international inequalities. Recommendations from a series of global health inequalities workshops co-organised by the Academy and the InterAcademy Partnership identified a set of priorities for the research response that overlap with this consultation's suggestions: engaging communities, including marginalised populations in all stages of research; collection, sharing and use of health inequality data; identifying effective interventions through a range of research types; interdisciplinary research incorporating sociology, epidemiology, economics, demographics and ethics with medical research; and engaging policy makers so results are acted upon.[5]

What challenges and barriers exist in putting research into practice to tackle health inequalities?

Barriers facing the conduct and implementation of medical research to understand causes of or test interventions for health inequalities

Data collection and use

Comprehensive data is vital to understand and tackle health inequalities. More data is required to map existing health inequalities in different populations and provide indicators for progress. Data gaps on ethnic groups, LGBTQ+ people and people living with disabilities should be addressed[6] e.g., the last representative ethnically 'boosted' survey of mental health was conducted more than two decades ago.[7] Data should be captured in standardised formats to allow comparison, and standard indicators of health and social metrics developed. Data and insights need to be shared in an 'open data' approach to accelerate improvements globally.[8] Analysis of the impact of a broad range of social determinants on health outcomes is required. Increased and secure linkages between datasets are therefore necessary, as well as greater access for more researchers of different disciplines.

[4] The Academy of Medical Sciences and the British Academy (2021). *Historic and Geographic Patterns of Health Inequalities.* https://acmedsci.ac.uk/more/events/geographic-and-historic-health-inequalities
[5] The Academy of Medical Sciences (2022). *Global Health Inequalities workshops.* https://acmedsci.ac.uk/policy/policy-projects/global-health-inequalities-
[6] Office for Statistics Regulation (2021). *Improving health and social care statistics, lesson 4.* https://osr.statisticsauthority.gov.uk/publication/improving-health-and-social-care-statistics-lessons-learned-from-the-covid-19-pandemic/pages/4/
[7] Blanchard M, *et al.* (2002*). Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC) - Quantitative Report.* http://data.parliament.uk/DepositedPapers/Files/DEP2008-3141/DEP2008-3141.pdf
[8] The Academy of Medical Sciences (2022). *Global Health Inequalities workshops.* https://acmedsci.ac.uk/policy/policy-projects/global-health-inequalities-

Interdisciplinary research as a priority

Health inequalities have complex causes, and research should be carried out in an interdisciplinary way to better understand the issues. Multiple types of evidence should be included in addition to quantitative data, for example narrative accounts of disease and other qualitative data.[9] A good example is the University of Glasgow Institute of Health and Wellbeing, where five Research Groups combine medical, public health and social research into health inequalities across three research themes.[10]

Translation of evidence into policy and practice

It is important to ensure that research into health inequalities supports the identification and implementation of solutions. Medical researchers must work closely with policy makers to ensure the most pressing health inequalities are identified, data gathered is of relevance to policy makers, and that interventions are implementable and sustainable. Capacity in implementation science related to health inequalities should be developed to facilitate evidence uptake.

Barriers facing the design of all medical research so that it doesn't exacerbate inequalities

Public and patient involvement

Patient and public involvement is a vital component of the development, implementation and evaluation of medical research, helping to ensure interventions designed to tackle one inequality do not inadvertently widen others. Involvement of the public must be meaningful and requires long-term engagement. Lack of trust can hamper involvement in research and uptake of health interventions, so relationship-building exercises may need to be routed through trusted intermediaries, community leaders, and civil society organisations. Activities and outcomes must reflect the intersecting identities of ethnicity, gender, disability, sexuality, and other protected characteristics of the people within local communities. This must continue during times of crisis, such as the COVID-19 pandemic, to ensure inequalities are not amplified.[11,12]

Public involvement in research projects should ideally be mandated at all levels, from funding bodies, through to institutions and to project leads, although funding bodies will have most influence.[13]

Research workforce diversity

Research teams investigating health inequalities should be diverse and inclusive to capitalise on the widest pool of experience and reduce risk of bias. For example, despite making up 49% of entry level positions, women make up only 24% of executive level and 14% of board level positions in the life sciences industry.[14] Diverse research teams

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[9] *Ibid.*

[10] School of Health and Wellbeing, University of Glasgow. https://www.gla.ac.uk/schools/healthwellbeing/

[11] The Academy of Medical Sciences (2020). *FORUM workshop report: Public involvement and engagement in research during the COVID-19 pandemic.* https://acmedsci.ac.uk/file-download/77957062

[12] The Academy of Medical Sciences (2021). *COVID-19: Preparing for the future.* https://acmedsci.ac.uk/file-download/4747802

[13] The Academy of Medical Sciences (2020). *FORUM workshop report: Public involvement and engagement in research during the COVID-19 pandemic.* https://acmedsci.ac.uk/file-download/77957062

[14] Liftstream (2017). *Opening the Path to a Diverse Future.* https://www.liftstream.com/pathtodiversity.html

are better at problem solving, so lack of diversity hampers innovation.[15] Researchers and healthcare professionals are also trusted more when their teams reflect the diversity of the communities they serve, increasing uptake of interventions by the community. Initiatives such as the Academy's SUSTAIN programme should be replicated in other institutions.[16]

Recognising community heterogeneity

Community heterogeneity must be accurately represented in data collection to ensure different ethnic and social groups are not excluded. Many research cohorts lack wider applicability due to the 'healthy cohort effect', where participants show lower rates of morbidity and mortality than the general population in the same age groups.[17] Cohorts and trials are often under-representative of different groups, so concerted efforts are required to identify and remove the barriers that prevent these groups from participating in research.[18,19] Research should be designed inclusively, for example avoiding language barriers and including participants from all regions. Preclinical research should also ensure the use of both sexes of animals, tissues and non-immortalised cells as default in research proposals.

National versus international considerations

Countries face being left behind if medical research is not implemented everywhere. Collaboration between nations should be encouraged to increase research output and dissemination of effective interventions, with each country tailoring responses according to local and regional contexts. Power imbalances exist between researchers in low- and middle-income countries and high-income countries, therefore funders and principal investigators from high-income countries should commit to equitable partnerships.[20]

Please provide a summary of your activity on health disparities (impactful research examples, examples of good practice, organisational priorities etc.).

Strategy

The Academy's 10-year strategy commits to tackling health inequalities and fostering a research community that is diverse, collaborative and inclusive. It also commits to proactively broadening the range of people and disciplines engaged in biomedical and health research and supporting and recognising their talents in different ways, including through the Academy's grant schemes and programmes.[21]

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[15] Hong (2004). *Groups of diverse problem solvers can outperform groups of high-ability problem solvers.* PNAS **101**:16385-9

[16] Limb M (2015). *Barriers facing female researchers are tackled by Academy of Medical Sciences scheme.* The BMJ **350**.

[17] Fry A, *et al.* (2017). *Comparison of Sociodemographic and Health-Related Characteristics of UK Biobank Participants with Those of the General Population.* Am J Epidemiol **186**, 1026-1034.

[18] The Academy of Medical Sciences (2021). *Response to the DHSC's Women's Health Strategy Call for Evidence.* https://acmedsci.ac.uk/file-download/22836484

[19] Khunti K, *et al.* (2021). *Promoting inclusion in clinical trials-a rapid review of the literature and recommendations for action.* Trials **22**:880.

[20] The Academy of Medical Sciences (2022). *Global Health Inequalities workshops.* https://acmedsci.ac.uk/policy/policy-projects/global-health-inequalities-

[21] The Academy of Medical Sciences (2022). *Strategy 2022-2032.* https://acmedsci.ac.uk/about/ourwork/strategy-2022-2032

Policy work

i. The Academy co-hosted a joint virtual roundtable with the British Academy on geographic and historic patterns of health inequalities.[22]
ii. The Academy co-organised with the InterAcademy Partnership a series of international workshops on the COVID-19 pandemic's impact on health inequalities, with a specific focus on the role of Universal Health Coverage.[23]
iii. The Academy's report 'Improving the health of the public by 2040' recommended the establishment of the Strategic Coordination of Heath of the Public Research committee (SCHOPR).[24] In the Health of the Public Research Principles and Goals set out by SCHOPR, the first overarching principle is to 'Undertake research to identify the most cost-effective methods to prevent ill-health, increase healthy life expectancies and reduce health inequalities.'

Public involvement and engagement

i. The Academy is a signatory on the Shared Commitment to embedding public involvement in health and social care research.[25]
ii. The Health Research Authority and INVOLVE produced a summary with case studies for how public involvement can help in the ethical design and conduct of research.[26]
iii. The Academy is increasingly looking to involve patients and the public in all areas of work and at all stages of project planning, delivery and governance.
iv. Examples of our public involvement activities include:
   a. Planet DIVOC-91, a series of digital comics designed by young adults from the UK, India and South Africa exploring the impact of the COVID-19 pandemic on their lives.[27]
   b. COVID-19 People's Perspectives on how the UK should prepare for COVID-19 challenges in winter 20/21 and 21/22, produced by a diverse group of patients and carers.[28,29]
   c. The Departure Lounge, a creative pop-up installation which aimed to engage local and national communities in conversations around death and dying and to inform policymakers and end-of-life researchers.[30]
   d. Health of the Public 2040 public dialogues project with under-represented groups, exploring how research can address the health challenges the population will face by 2040.[31]
v. We have commissioned Ipsos MORI to conduct a literature review on health inequalities work involving patients and the public to date across the UK.

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[22] The Academy of Medical Sciences and the British Academy (2021). *Historic and Geographic Patterns of Health Inequalities.* https://acmedsci.ac.uk/more/events/geographic-and-historic-health-inequalities
[23] The Academy of Medical Sciences (2022). *Global Health Inequalities workshops.* https://acmedsci.ac.uk/policy/policy-projects/global-health-inequalities-
[24] The Academy of Medical Sciences (2016). *Improving the health of the public by 2040.* https://acmedsci.ac.uk/file-download/41399-5807581429f81.pdf
[25] The Academy of Medical Sciences (2022). *Embedding public involvement in health and social care research.* https://acmedsci.ac.uk/file-download/13499142
[26] Health Research Authority / INVOLVE (2016). *Impact of public involvement on ethical aspects of research.* www.invo.org.uk/posttypepublication/public-involvement-in-researchimpact-on-ethical-aspects-ofresearch
[27] The Academy of Medical Sciences (2020-21). *Planet DIVOC-91.* https://acmedsci.ac.uk/policy/uk-policy/coronavirus/planet-divoc-91
[28] The Academy of Medical Sciences (2021). *People's Perspective COVID-19: Preparing for the future.* https://acmedsci.ac.uk/file-download/57914133
[29] The Academy of Medical Sciences (2020). *People's Perspective: Preparing for a challenging winter 2020/21.* https://acmedsci.ac.uk/file-download/39133546
[30] The Academy of Medical Sciences (2019). *The Departure Lounge.* https://acmedsci.ac.uk/policy/policy-projects/the-departure-lounge
[31] The Academy of Medical Sciences (2015). *Health of the Public 2040. Overview of four one-day workshops with the public in England.* https://acmedsci.ac.uk/file-download/41592-57e4e941485e5.pdf

Promoting diversity in the STEM workforce

    i. The Academy responded to the House of Commons Science & Technology Committee written consultation on Diversity in STEM earlier in 2022 outlining ways to improve diversity in the STEM workforce[32].
    ii. The Academy is a member of the Equality, Diversity and Inclusion in Science and Health (EDIS) network, the Proud Science Alliance (PSA) and the Employer's Network for Equality and Inclusion (ENEI).
    iii. The Academy's SUSTAIN programme supports the careers of female researchers.[33,34]
    iv. The Academy's international grant schemes build capacity in low- and middle-income countries, helping to reduce international health inequalities.[35,36,37]
    v. The Academy is developing its Equality, Diversity and Inclusion (EDI) strategy to embed EDI and representation throughout all its teams, associates, programmes and outcomes.

This response was prepared by Iwan Williams, Policy Intern. For further information, please contact Dr Alice Fletcher-Etherington, Policy Officer (Alice.Fletcher-Etherington@acmedsci.ac.uk).

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[32] Science and Technology Committee, House of Commons, UK Government. https://committees.parliament.uk/work/1639/diversity-and-inclusion-in-stem/publications/
[33] The Academy of Medical Sciences. *SUSTAIN programme.* https://acmedsci.ac.uk/grants-and-schemes/mentoring-and-other-schemes/sustain
[34] Meagher and Kettle (2021). *SUSTAIN programme evaluation, 2015-2021.* https://acmedsci.ac.uk/file-download/57168160
[35] The Academy of Medical Sciences. *Newton International Fellowships.* https://acmedsci.ac.uk/grants-and-schemes/grant-schemes/newton-international-fellowships
[36] The Academy of Medical Sciences. *Newton Advanced Fellowships.* https://acmedsci.ac.uk/grants-and-schemes/grant-schemes/newton-advanced-fellowships
[37] The Academy of Medical Sciences. *Global Challenges Research Fund Networking Grants scheme.* https://acmedsci.ac.uk/grants-and-schemes/grant-schemes/gcrf-networking-grants