Written Evidence Submitted by
The Association of Medical Research Charities (AMRC)
(DIV0100)

This Association of Medical Research Charities submission to the House of Commons Science and Technology Committee Inquiry into Diversity in STEM focusses on three areas outlined in the inquiry's call for evidence: what the implications are of groups such as women, ethnic minorities, people with disabilities and those from disadvantaged socioeconomic backgrounds being under-represented in STEM roles; what has been done to address under-representation – with a focus here on action by charitable funders of medical research; and what should be done by research funders to address the implications of under-representation.

About AMRC

AMRC is the membership organisation for medical and health charities funding research in the UK. We represent over 150 medical research charities, from large to small, including: Cancer Research UK, the British Heart Foundation and Wellcome. Our members have invested nearly £14.5 billion in research in the UK over the last twelve years, supporting nearly half of all publicly funded medical research. Charities play a unique role in the life sciences ecosystem; driven by patient priorities and tackling areas of unmet need, they accelerate the delivery of innovative treatments to patients.

Summary

1. The implications of groups being under-represented in STEM roles

- A diversity of thought and experience at each point in the system is important to ensure the best research is funded, conducted and communicated, and brings a maximum benefit to all patients.
- Under-representation of research participants affects the beneficiaries of research, reducing the efficacy of drugs, treatments and therapies.
- A lack of diversity in those conducting research can create a lack of trust amongst patients and the public that undermines engagement with research, further reducing the benefits that research brings.

2. What has been done to address under-representation in STEM roles

- AMRC is working with member charities to increase diversity in STEM roles, both through guidance on best practice and data collection to inform policy.
- Medical research charities consider addressing under-representation in STEM roles a priority area of work, with nearly half developing strategies on equality, diversity and inclusion.
- Charities have set up and are involved in initiatives to tackle under-representation, for example expert committees, targeted fellowships, clinical trial design, and anti-bias training programmes.

3. What could and should be done to address the issues

- AMRC supports working with partners across the ecosystem via a thematic approach to address issues of under-representation.
- Priority areas for action include: Build science capital; Take proactive steps to remove bias; Implement good practice in education settings, the workplace and the research system; Update legal frameworks and ensure dissemination and uptake of guidance; Invest in positive culture and incentives that reflect the true range of contributions; Improve consistency in the design, implementation and monitoring of interventions.

The implications of groups such as women, ethnic minorities, people with

disabilities and those from disadvantaged socioeconomic backgrounds being under-represented in STEM roles in academia and industry

Diversity of thought and experience is needed to ensure that the best research, which delivers the most patient benefit, is conducted. Diversity ensures scientific challenges are not approached from a single standpoint. When novel questions are asked and answered from differing perspectives, it can lead to novel solutions.

In addition, there is a need for diverse representation to ensure that patients and the public have trust in and an understanding of research. It is essential that diversity is fully represented in clinical trials participants, so that the research is relevant and applicable to the broadest parts of society, and in researchers, so that patients and the public can identify with those conducting research.

Groups such as women, racial and ethnic minorities, people with disabilities and those from disadvantaged socioeconomic backgrounds are currently and historically under-represented in STEM roles. Furthermore, the presence of intersectionality, where individuals may belong to more than one under-represented group, multiplies the potential problems arising from a lack of diversity in STEM roles. For example, black women make up less than 2% of the UK's professors.

This lack of diversity spans all stages of the research process. This includes:

a) those conducting research, including senior scientists who set research questions and design studies, junior scientists who carry out and deliver research, and the technical support staff who facilitate research by operation of equipment or data collection;
b) those allocating funding to research, including programme leaders within funding bodies and experts on research peer review committees;
c) the participants of research, including members of the public in clinical studies, tissue and cell samples used in basic research, and those recruited to provide patient expertise; and
d) those engaging patients in the design of research or evaluation of results, and
e) those communicating the outcomes of research with the public.

Under-representation of research participants also affects the beneficiaries of research: patients and the public who receive the healthcare, drugs, treatments and therapies arising from the research process. The efficacy of novel drugs and the likelihood of adverse side effects, for example, is a major problem for population groups that have not been adequately or historically represented in the clinical trials process.

During the Covid-19 pandemic, early reports of variation in susceptibility to severe disease between racial and ethnic groups were later suggested to be in part attributable to certain medical devices being inappropriately calibrated for biological differences between ethnic groups, creating adverse consequences in measurement and treatment. At the same time, many of the differences in Covid-19 outcomes were found to relate more to already present health inequalities and disparities than genetic differences. Covid-19 has further highlighted the need for diversity within STEM and an intersectional approach to answering the key scientific challenges we will face in the future.

Representation of diversity is important in law because discrimination on the basis of protected characteristics is illegal under the Equality Act (2010), but also in principle because it is fair. As publicly funded research is funded from the public purse, it is especially important that the outcomes of such research address the needs of the UK population.

A lack of diversity affects awareness of and support for research and the value of academic endeavour, as well as adherence to public health measures. For example, the uptake of Covid-19 vaccines, which is lower amongst certain racial and ethnic groups. This has knock-on consequences for the persistent health disparities across all regions of the UK and for the economy, presenting a challenge to ambitions for levelling up.

Finally, greater diversity in research and the research workforce would also ensure the UK isn't left behind internationally, and is essential to support the UK's ambitions to maintain and enhance its status as a global science superpower.

What has been done to address under-representation of particular groups inSTEM roles

Under-representation is an important issue to many within our membership and AMRC has been working with member charities to increase diversity in STEM roles, both through guidance on best practice and data collection to inform policy. For example, the resource hub described below.

AMRC Equity, Diversity and Inclusion Hub

AMRC has developed an Equity Diversity and Inclusion resource hub, hosted on our website, which brings together a catalogue of helpful guidance and other best-practice materials developed across a range of organisations and sectors. The aim of the hub is to provide a one-stop-shop for AMRC's 150 members to find useful information, whether they are at the start of their journeys or looking for more detailed help on implementation. The hub is reviewed every six months to highlight new initiatives and strategies for tackling under-representation in STEM.

AMRC member charities engage in a wide range of activities and initiatives to address under-representation of particular groups in STEM roles. In a survey from 2020, 44% of members reported they were developing a strategy to address equality, diversity and inclusion in the research they fund. In addition, 22 members had started collecting, and in some cases reporting, data on the protected characteristics of researchers they fund, and we believe this number is increasing.

Below, a selection of case studies demonstrates the journey member and supporter charities are currently on in attempting to address this area.

Cancer Research UK career support for under-represented groups

Through their EDI in research action plan, Cancer Research UK (CRUK) is putting career support initiatives in place to diversify the research careers pipeline. This includes initially focusing on earlier career stages to ensure more young people from underrepresented and diverse backgrounds can enter the academic pipeline, before moving onto other stages of the career pathway. Partnering with expert charitable organisations and grassroots networks, CRUK have setup a range of initiatives, including: In2ScienceUK, which provides young school children from low-income and disadvantaged backgrounds with practical insights into the STEM sector; In2ScienceUK's In2Research programme, which supports undergraduate students from underrepresented backgrounds to progress to a PhD in cancer

Chartered Society of Physiotherapy Committee on Equity, Diversity and Belonging

In March 2022, the Chartered Society of Physiotherapy (CSP) will launch a new Equity, Diversity and Belonging Committee to sit alongside its other strategic oversight committees. Reporting into its ruling Council, the new Committee will provide expertise, insight, support and advice, ensuring that an appropriate range of members' expertise and views inform strategic decision-making. The Committee will also inform operational work such as monitoring of member data, equality impact assessments, training and development, and the evolution of the CSP corporate strategy.

Daphne Jackson Trust post-career break Fellowships

The Daphne Jackson Trust supports those returning to research careers following a career break of two years or more, taken for a family, caring or health reason. It offers Fellowships across all fields of research in universities, research institutions and industry across the UK and Republic of Ireland. Over 430 individuals have undertaken Daphne Jackson Fellowships, and over the last two decades Daphne Jackson Fellowships have saved over 1250 years of research experience and talent from being lost from the sector – worth over £37m of gross institutional costs – and Daphne Jackson Fellows have leveraged over £23m of new research funding from national and international funders, philanthropic donors, and industry. That means on average, for every £1 invested in a Daphne Jackson Fellow, they secure nearly £2 in subsequent funding. Nine out of ten Daphne Jackson Fellows stay in research or teaching at least five years after they finish their Fellowship, demonstrating high levels of returner retention to the sector. Ten former Daphne Jackson Fellows are now Professors, a rate which is five times higher than the national average.

LifeArc specialist EDI taskforce helps embed best-practice

LifeArc, a charity specialising in the early-stage translation of scientific discoveries into diagnostics and treatments, set up an equality diversity and inclusion (EDI) taskforce in 2021 to help embed EDI into their work. Over the past year they have collected baseline diversity data across the organisation, run inclusive leadership training for senior staff, and unconscious bias workshops for all staff. A review of recruitment and HR practices is helping to inform the removal of potential biases, making use of tools such as anonymised CVs when recruiting positions for industrial placements. Already under development, in 2022 LifeArc will finalise their EDI strategy, implement a new recruitment diversity monitoring system, provide 'active bystander' training, and extend their outreach work to a wider pool of talent to reach those from disadvantaged backgrounds.

Alzheimer's Research UK study identifies barriers in academic career progression

Alzheimer's Research UK has conducted work to identify and address gender disparities along the career pipeline in dementia research. Using a mix of bibliometric data (from more than 180,000 dementia research papers published between the years 2000 and 2020) and internal funding data (from more than 2,000 grant applications) they showed that female researchers leave academia at higher rates than men before transitioning into senior positions. Women occupy fewer senior positions in authors lists, despite being the majority of junior authors; they apply in lower numbers to senior grants schemes, despite being the majority of applicants to early career schemes; and they have lower success rates in obtaining funding for senior grant schemes, despite having higher success rate in junior

calls. A longitudinal analysis showed that while the overall gender gap has been closing, the rate of change at senior positions has been slower than at junior positions, which indicates that women disproportionately face barriers that make their career progression more difficult. Alzheimer's Research UK is now using this information to inform programmes that will help researchers succeed in their careers without being hindered by external factors.

What could and should be done by the UK Government, UK Research and Innovation, other funding bodies, industry and academia to address the issues identified

In our experience, possible actions to address under-representation will vary with the different groups that activity aims to reach. Therefore, a diverse, intersectional and cross-sector approach is required. AMRC supports a thematic approach, proposed by EDIS, to addressing issues of under-representation. EDIS is a coalition of organisations spanning the research sector, including AMRC, working to drive improvements across STEM roles in all aspects of the research process.

Due to the systemic nature of the problem, tackling issues at a system-level requires a focus on the entire pipeline, from early interventions in STEM education in schools and colleges, bias training in undergraduate university admissions processes, through to the processes of funding research and the research culture that currently create an unrepresentative research environment. Support for under-represented groups once in post is essential, as well as targeting support to those groups who are most under-represented. This will ensure a diversity of groups is trained and the resulting diverse workforce is retained. Collective work is needed by a number of actors to ensure that diversity is addressed in all settings and that more is delivered than is possible individually.

We believe that approaching solutions thematically acknowledges the intersectional nature of under-representation – with individuals often experiencing multiple levels of discrimination and disadvantage – and will tackle the issues at a systemic level that can overcome barriers for the largest possible number of people.

The priority areas for action, described in greater detail in EDIS' s submission are:

a) **Build science capital:** Those without access to adequate support, sponsorship or opportunities in STEM are less likely to see a career as 'for them' or to have access to enabling tools and pathways.

b) **Take proactive steps to remove bias:** Left unchecked, bias leads to nurturing, hiring and supporting those who already 'fit the mould' and leaves others behind. This includes individual bias, institutional bias, structural bias, and system-level bias.

c) **Implement good practice in education settings, the workplace and the research system:** Inconsistent application of good practice, particularly where there is strong evidence (such as for careers advice, teacher training, pedagogy, recruitment processes, funding processes, flexible working and reasonable adjustments) perpetuates challenges.

d) **Update legal frameworks and ensure dissemination and uptake of guidance:** The Equality Act (2010) needs reviewing and updating to make clearer how requirements on combined discrimination (for example, on Positive Action) applies in research settings. The application of the Public Sector Equality Duty relating to STEM funding is also unclear and inconsistently applied. This needs to be addressed at an

institutional level and with the UK Government taking accountability for advancing diversity and equality at a system level.

e) **Invest in positive culture and incentives that reflect the true range of contributions:** Scientific progress is driven by a diverse range of contributions, but the research system currently favours success metrics that reinforce individual prestige and publication history and that undervalue other important skills and activities. A sector-wide conversation about research culture has brought many of these issues into the light and highlighted priorities for action.

f) **Improve consistency in the design, implementation and monitoring of interventions:** A lack of consistency means that it is hard to assess impact and progress on interventions, to compare methods and outcomes between organisations, and to make clear recommendations about emerging good practice.

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