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BSGM response to ABPI and BIA

Introduction

Published in 2025, the UK Industrial Strategy and Life Sciences Sector plan along with the NHS 10 year plan for England, have aligned in promoting genomic medicine and building upon previous government efforts that aimed to see the UK grow both in diagnostics and treatments within this field.

The British Society for Genetic Medicine (BSGM), as a UK-wide group of professionals working in this space representing clinicians, scientists, and academics in genomic medicine, is excited to see genomics play a crucial part in these strategy documents and the future of healthcare in the UK. BSGM welcomes and commits to working towards a future where the UK population, across all devolved nations, will benefit from informed and personalised genomic healthcare. We have previously commented on these key documents and are committed to engaging with stakeholders from government as well as colleagues from ABPI, BIA and NIHR to help realise these goals.

Recent reports from ABPI and BIA; UK industry clinical trials: “Translating actions into impact and From Innovation to Impact”, and “Unlocking Patient access to Innovative Rare Disease Medicines” respectively, comment on the gap between discovery and patient benefit in the context of precision medicine and rare disease. Our membership is at the core of clinical, scientific and research delivery in both rare/inherited disease and precision medicine and is invested in seeing patients access timely diagnosis accompanied with effective interventions, research opportunities and treatments.

Rare and inherited disease research has challenges throughout its cycle; starting from basic research, natural history of disease studies, interventional studies and observational studies. The ABPI and BIA documents provide an accurate and detailed picture on the state of interventional rare disease studies. System fragmentation as outlined in the BIA report, is seen across the patient and clinician journey in the context of rare disease.

Our suggestions:

- We suggest that Commercial Research Delivery Centers are supported by a UK wide genomics and rare disease group under NIHR. This should include scientists, clinicians and academics practicing in this space, acting as advisors and catalysts in study recruitment.
- BSGM supports the suggestion of a renewed Rare Diseases framework across discovery diagnosis, access and care. Not only should we strive for reducing and eliminating the diagnostic odyssey, we should eliminate the post-diagnostic odyssey. The development of

rare disease hubs across the UK, would be welcome by our community; to serve as diagnostic, research and management hubs for rare conditions.

- Clinical and laboratory specialists should be included in discussions around the delivery of genomics and rare disease, in order to ensure operational feasibility and readiness.

The health and economic benefits of a thriving life sciences industry, working hand in hand with clinicians, scientists and academics are immense. Failure to engage with operational representatives at this stage, will further increase access gaps and trivialise the efforts of the UK government to imagine a future centered around personalised medicine, a healthier population and a growing life sciences industry.

Building on this shared vision and momentum, BSGM looks forward to actively collaborating with all partners to translate these ambitious strategies into tangible, equitable progress. By uniting expertise across government, industry, and the NHS, we are confident that the UK can lead the world in delivering the transformative promise of genomic medicine—improving patient outcomes, strengthening our health system, and securing a brighter, healthier future for all.

Yours sincerely,

Demetra Georgiou

Chair

On behalf of the British Society for Genetic Medicine