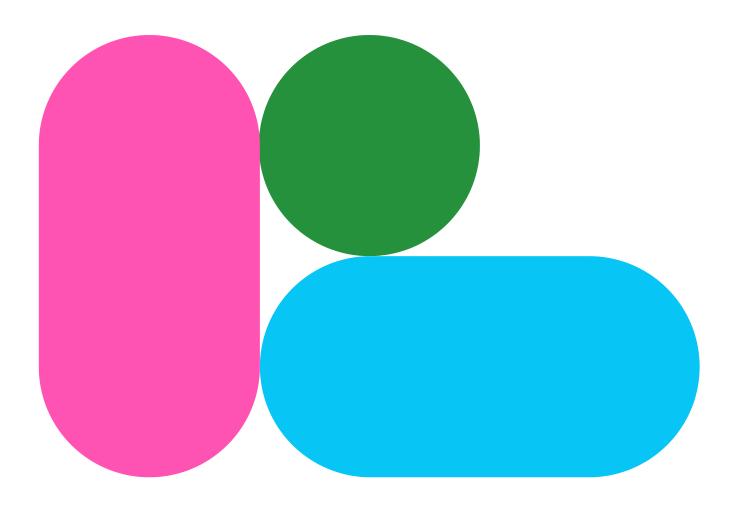


Publication Policy

Genomics England's Publication Policy POL-RM-002 v5.0

Date: 11/07/2023





1. Abbreviations / Definitions

100,000 Genomes Project	Programme announced in 2012 to sequence 100,000 genomes from patients from the NHS in England, and to link the sequence data to a standardised, extensible account of diagnosis, treatment and outcomes.
Airlock	Process by which data is securely moved in or out of the NGRL.
Clinical Research Interface (CRI)	The pathway connecting researchers accessing the NGRL with the clinicians recruiting for Genomics England studies.
Discovery Forum	Genomics England's commercial partnerships platform providing approved companies with access to the Genomics England Research Environment.
Genomics England	Genomics England Limited, Level 21, 1 Canada Square, Canary Wharf, London, E14 5AB.
Genomics England Research Network	The Genomics England Research Network is the collective term for the community of individual researchers, clinical disease experts and healthcare professionals who are given access to the data held by Genomics England for the purposes of carrying out research.
National Genomic Research Library (NGRL)	National database of genomic data, health data and samples that can be accessed for research purposes through the Research Environment; managed by Genomics England in partnership with NHS England.
NHS Genomic Medicine Service (NHS GMS)	The NHS Genomic Medicine Service (NHS GMS) is the network of seven Genomic Laboratory Hubs (GLHs) working together with Genomics England to harness the power of genomics to improve health and collect data for research, which is held by Genomics England in the NGRL.
Publication	Any published results, analysis, annotations, data, discoveries, findings and/or interpretations, including any thesis for degree accreditation, that are based on and/or derived from any Genomics England held data and/or analyses conducted within the Genomics England Research Environment.
Research Environment	The Genomics England Research Environment is the cloud-based tool that approved researchers use to access the data in the National Genomic Research Library (NGRL) and other research data held by Genomics England.
Research Management team	The Genomics England team responsible for overseeing all matters in relation to the Genomics England Research Network, and for its management, review and coordination.
Research Registry	The catalogue of all research projects being undertaken on Genomics England data, which can be <u>accessed here</u> .



2. Purpose Statement

Genomics England champions open science, knowledge sharing, and timely publication of research findings. This document sets out the policy of Genomics England regarding the authorisation of Publications on data made available by Genomics England. The Publication Policy exists to ensure the recognition of the efforts of Genomics England, our funders, and the recognition and protection of patients and participants who have provided their health data to be used for research purposes.

To view publications utilising the Genomics England dataset, please see the <u>publications page</u> on our website.

3. Scope

- a) It is the responsibility of anyone wishing to publish a Publication based on data held by Genomics England or on analyses conducted in the Research Environment to adhere to the obligations set out in this policy.
- b) This Publication Policy applies to any Publication, as defined above, including any thesis for degree accreditation. It is applicable to any Publication based on research conducted on any type of data held by Genomics England, including any data held in the National Genomic Research Library, data from the 100,000 Genomes Project, NHS Genomic Medicine Service data where Genomics England is the data controller, as well as data of any other type collected as part of a research study or cohort by Genomics England or as part of a collaboration or partnership agreement with Genomics England.

4. Publication Requirements and Acknowledgement

- a) All Publications which include or make use of Genomics England data must be associated with an approved research project registered in the <u>Research Registry</u> and one of the authors must be listed as a contributing researcher for that project.
- b) All Publications to which this policy applies must be reviewed by Genomics England as outlined in section 5 below to ensure data protection and privacy of individuals whose data Genomics England is a custodian of.
- c) Presentations, ideas, and results from Genomics England Research Network activities presented at internal meetings and conference calls are privileged communications. Anybody wanting to publish such communications, whether they are a Research Network member, Discovery Forum member or Genomics England staff, must register details of the proposed publication in the Research Registry. Data cannot be extracted for publication via Airlock until the registered project has been approved.
- d) Genomics England does not allow publication of identifiable data, including unmasked phenotype counts of five (5) or fewer, without explicit consent from the individual participants concerned. All Genomics England data in any Publication must have come through the Genomics England Airlock process and transfer or publication of this data is subject to the Airlock Policy and approval by the Airlock Committee. Contravention of the Airlock Policy, for example by 'screen-shots' of the Research Environment or copying data long hand, is a serious breach of the terms of data access.
- e) Additional clinical data may be published where the consent of these patients has been obtained through the Genomics England Clinical Research Interface, or through another pathway provided that this falls under the terms of an existing ethics agreement or separate consent. Where this is the case, it



- should be noted to the Genomics England Research Management Team upon submission of the publication for review. Proof of consent may be requested by Genomics England.
- f) All of the authors and co-authors of each publication should be listed in accordance with the guidelines issued by the International Committee of Medical Journal Editors (ICMJE).
- g) The "Genomics England Research Consortium" is no longer used and should not be added to the list of authors in order to acknowledge the contributions of Genomics England or individual employees of Genomics England. If any individual from Genomics England has contributed directly to warrant authorship, they should be listed individually as an author and Genomics England may insist upon this as a prerequisite to submission.
- h) All Publications must include the following credit information in the main body of the document (e.g. in the acknowledgement or methods section):

This research was made possible through access to data in the National Genomic Research Library, which is managed by Genomics England Limited (a wholly owned company of the Department of Health and Social Care). The National Genomic Research Library holds data provided by patients and collected by the NHS as part of their care and data collected as part of their participation in research. The National Genomic Research Library is funded by the National Institute for Health Research and NHS England. The Wellcome Trust, Cancer Research UK and the Medical Research Council have also funded research infrastructure.

For abstracts and posters, the following short text must be included:

This research was made possible through access to data and findings in the National Genomic Research Library via the Genomics England Research Environment.

- i) Genomics England can be cited in the following way: The National Genomic Research Library v5.1, Genomics England. https://doi.org/10.6084/m9.figshare.4530893.v7
- j) Adherence to the Publication Policy is the responsibility of each publication author and failure to incorporate changes to a publication where reasonably requested by Genomics England will be considered failure to comply with this Publication Policy.

5. Review of Publications by Genomics England

- a) Genomics England requires that the manuscript or draft of any Publication is sent to Genomics England at least two (2) weeks before it is submitted for peer review in whatever format (e.g., paper journal, online report, meeting abstract), allowing 10 working days for review and approval for publication by the Genomics England Research Management Team. The Publication Review Request Form to submit a Publication for review can be found here:
 - https://www.genomicsengland.co.uk/research/publications/publication-policy
- b) In any communication with Genomics England regarding a Publication, authors should include the title and Project ID of the registered research project that their Publication corresponds to as captured in the Research Registry.
- c) Genomics England will use this review to confirm that authors have adhered to the Publication Policy and any other relevant Genomics England policies, the data access and acceptable uses criteria as outlined in the NGRL Protocol, and that no potentially identifiable data has been included in the Publication.



d) If Genomics England determines that the content of the Publication is in breach of this Publication Policy, the Genomics England Airlock Policy or any other relevant Genomics England policies or agreements, at the point of Publication review or at any point thereafter, then Genomics England will inform the lead and corresponding author(s) and reasonably request necessary changes. Failure to comply with such requests will result in the matter being escalated to the independent Access Review Committee and in sanctions that are at Genomics England's discretion, including but not limited to revoking access to the Genomics England Research Environment and/or seeking the retraction of the Publication.

6. Requirements for Publication on COVID-19 Data and Other Cohort Data

a) Genomics England may hold and make accessible data collected as part of research cohorts separate to the 100,000 Genomes Project and NHS Genomic Medicine Service. These data may come under separate agreements with external collaborators. In such cases, access to these datasets may be restricted and publication on these data will need to adhere to the data exclusivity and/or publication embargo process that is outlined separately for that cohort. Researchers may be asked by Genomics England to reference or acknowledge these cohorts specifically in any Publication where data from these cohorts has been used.