Reference: FOI.ICB-2526/318

Subject: ClinVar Submissions and Compliance with ACGS 2024 Guidelines

I can confirm that the ICB does not hold the information requested; please see responses below:

QUESTION	RESPONSE
The 2024 Association for Clinical Genomic Science (ACGS) Guidelines for Variant Interpretation specify that clinically interpreted variants should be submitted to ClinVar. As we approach 2026, it is clear that many UK genomic centres are not submitting variant classifications in line with this guidance. To understand the current position within your Genomic Medicine Service Alliance / genomic hub, please provide the following information:	BNSSG ICB does not hold this information. Please contact the Acute Trusts directly who may hold this information: North Bristol NHS Trust (NBT) https://www.nbt.nhs.uk/about-us/information-governance/freedom-information/request-information / foi@nbt.nhs.uk University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) https://www.uhbw.nhs.uk/p/how-we-use-your-data/freedom-of-information-foi-requests / FreedomOfInfo@uhbw.nhs.uk
Governance and Responsibility a. Copies of any internal policies, SOPs, or governance documents relating to ClinVar submissions. b. The job roles (not names) responsible for overseeing or performing ClinVar submissions. c. Any monitoring or escalation processes in place for non-submission.	

Compliance and Timelines a. The reasons why ClinVar submissions required under the ACGS 2024 Guidelines have not been routinely undertaken. b. Any identified barriers (technical, staffing, consent, legal, prioritisation decisions, or otherwise). c. The planned timeline for implementing ClinVar submissions, including any milestones or project phases.	
Volume and Scope of Data Not Submitted a. The number of variant classifications generated by your hub since 1 January 2024 that have not been submitted to ClinVar. b. Any disease areas or variant types for which submission has been paused or deprioritised.	
Remedial Actions and Planning a. Any action plans, project plans, or internal communications that outline how your hub intends to achieve compliance with ACGS guidance. b. Whether the organisation intends to publish public-facing information on compliance with ClinVar submission requirements.	
Impact Assessments a. Any equality impact assessment (EqIA) or internal assessment regarding the impact of non-submission of variant data on rare disease communities.	

The information provided in this response is accurate as of 15th December 2025 and has been approved for release by Dr Joanne Medhurst, Chief Medical Officer for NHS Bristol, North Somerset and South Gloucestershire ICB.