Patient and Public Involvement and Engagement (PPIE) Quarter 2 July-Sept 2026–27 Report

This quarter moved the PPIE portfolio from planning into delivery, with public insight shaping genomics, governance, communications and data-access activity. Genomics public deliberation findings were shared with the Core Public Advisory Group (CPAG) and through two participant feedback webinars, confirming conditional support for using genomic test data in research where there is transparency, clear public benefit, meaningful choice, strong safeguards and ongoing involvement. Learning from Genomics England and others with Citizens' Jury experience informed the approach. The findings and next steps were also shared through a PPIE Community of Practice presentation and a Lunch and Learn session, helping to build understanding of public views on clinical genomic reports and highlighting the need for the further deliberation before raw genomic sequencing data is used within the SDE.

Planning for the Genomics Citizens' Jury progressed through development of the supplier specification, clarification of facilitation and expert witness requirements, and public contributor review of the invitation to tender. We continued to strengthen external engagement and knowledge exchange through attendance at the Genomics England (GEL) Research Summit and presentation at the inaugural PEDRI Forum, providing opportunities to share our approach and learning while bringing wider insights back into the programme.

CPAG membership was expanded through recruitment and onboarding of new East Midlands members, supported by introductory meetings, buddying arrangements and induction materials. Members reviewed the Terms of Reference to reflect the merged Eastern England and East Midlands footprint, strengthening representation, governance, responsibilities and ways of working. They also advised on how public-facing materials should describe data sharing between SDEs.

Public contributors worked with communications colleagues to shape plans for raising SDE awareness. Priorities included improving public-facing materials, reaching underserved and underrepresented communities, explaining industry involvement more openly, and developing resources to help healthcare professionals discuss the SDE with patients and the public.

PPIE also contributed to the Data Access Request Form and wider data-access processes. Collaboration continued through East Midlands stakeholder mapping and multi-SDE work with other PPIE leads to support the national collaboration agreement.

Overall, the quarter strengthened public contributor influence across genomics, communications, governance and delivery. Next steps are to complete Citizens' Jury

procurement and delivery, embed new CPAG members, refresh public-facing materials and extend SDE awareness activity across both regions.