

Public involvement activities in 96 global genomics projects

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There is a growing need to involve the public more in genomics research¹⁻³. High-profile genomics research initiatives have made public statements about the importance of involving people^{4,5}, yet there has been no review of how people are being involved in human genomic research. This study reviewed the public-domain websites of 96 genomics initiatives affiliated with Global Alliance for Genomics and Health (GA4GH) to document the frequency, method, tasks and self-reported outcomes of involving people in genomics research.

Nearly a third of the initiatives reported they **involved people**. (32/96, 33%)

People were involved at every stage of the research cycle.



Implementation and management was the **stage** most initiatives involved people (19/32, 59%)

The **methods to involve people** reported by most initiatives were:

63% - formal working groups and committees

(20/32, 63%)



41% public events and discussion

(13/32, 41%)



Initiatives reported outcomes from involving people (5/32, 16%)

Including a mobile outreach bus  and improvements to governance frameworks

Facilitators of involvement

that were reported include:

- Reimbursement policies
- Education and learning for the public and professionals
- **Trusted** process to manage competing or conflicting interests
- **Involve people** in designing ways of involving people

Tasks specific to genomic research

that people can get involved in include

identifying phenotypes



Conclusions

- Involving people in future genomics research is essential to **maintain public trust, improve research** and ensure that access to the benefits of research is equitable
- The **method and tasks of involving people are varied**
- The **evidence for effective ways of involving people is not clear**
- **Consistent reporting** and evaluation of involving people required
- This review provides a **tool to make informed decisions about planning future involvement** in genomics research

References

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