

# Public involvement activities in 96 global genomics projects

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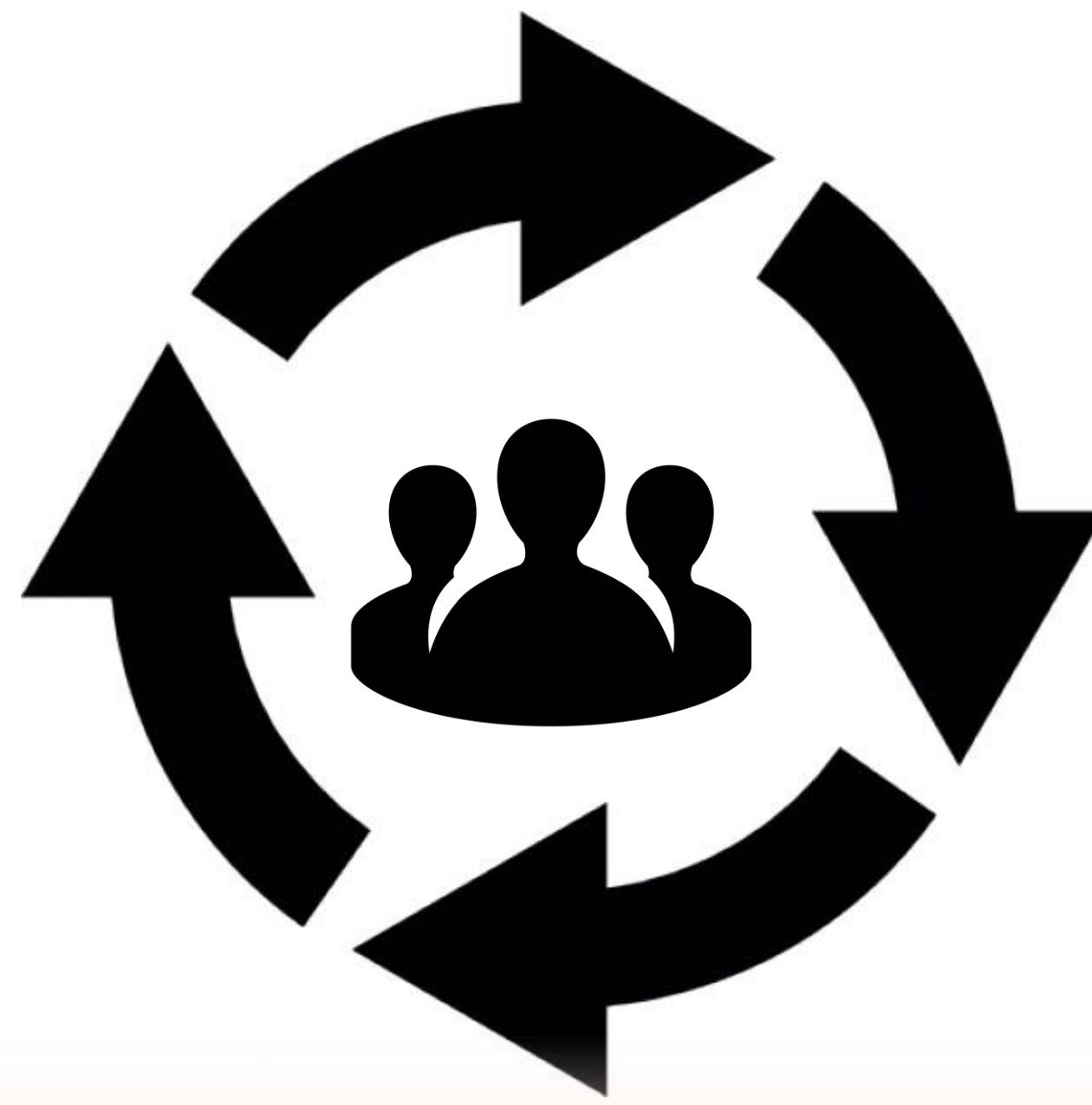
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There is a growing need to involve the public more in genomics research <sup>1-3</sup>. High-profile genomics research initiatives have made public statements about the importance of involving people <sup>4,5</sup>, yet there has been no review of 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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Written in 2018 from data collected in 2017.

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