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Global Alliance for Genomics and Health: FRAMEWORK FOR INVOLVING AND ENGAGING PARTICIPANTS, PATIENTS AND PUBLICS IN GENOMICS RESEARCH AND HEALTH IMPLEMENTATION

Preamble

This document is the Global Alliance for Genomics and Health's (GA4GH's) Framework for involving and engaging participants, patients and publics in genomics research and health implementation (hereafter, *Engagement Framework*). It recognises that the benefits of genomics must be global, yet the practices might impact, benefit and harm people and communities in different ways and builds on the mission of the GA4GH, its [*Framework for Responsible Sharing of Genomic and Health-Related Data*](#) and commitment to [*Diversity and Inclusion*](#).

I. Context

1. Why is engagement important in genomics?

Genomics is increasingly central to the provision of health care. To ensure alignment with social expectations and values with the use of genomics, all who work in this area need to consider the interests and concerns of those who choose to give their genomic data, or who are impacted in other ways by genomics: (1) participants of studies that inform scientific development in genomics, (2) patients who may be directly affected by genomics science, and (3) members of the public globally. This is best done by involving and engaging with those participants, patients, and publics.

2. What are the benefits of involving and engaging participants, patients, and publics?

Involvement and engagement practices, done well, can enhance trust, support understanding of diversity and the impact of research, increase the value, relevance and quality of genomics and support societal alignment over the life course of genomics research and implementation. Involvement and engagement in genomics can foster greater fairness and justice.

- *Trust*: Researchers and clinicians depend on people providing large amounts of personal data. While transparency in how personal data is used is important, transparency of how and to what extent participants, patients and publics will be involved, can support the building of trustworthy relationships - that is, it can lead to gaining the trust of people

whose data is being investigated. Such relationships of trust may facilitate people providing their data, and so engagement can be a way to help ensure accountability and transparency in science especially, but not exclusively, where activities are publicly funded.

- *Collaboration*: Genomics is a collective endeavour, bringing together professionals from many disciplines as well as participant, patient and public stakeholders from all walks of life. Improved collaboration across these different groups allows for the identification of new research and clinical priorities.
- *Diversity*: Genomics research and clinical practices are most effective when they capture data from people across the widest possible demographic and geographic backgrounds.
- *Impact*: Depending on the project's design, genomics can reveal significant study results and information about individuals and their families. It can also tell us about unrelated people who are part of the same community. Not all such information is welcome, and stakeholders may not be affected by, or respond to, this information in the same way. Engagement will help to identify potential positive and negative impacts at both the individual and community level.
- *Value*: Engagement with participants, patients and publics stakeholders on research and clinical care can leverage real-world evidence to maximise the utility and outputs of genomic information and practices. Engagement can help create additional value within projects through closer alignment of professional objectives to participant, patient and public interests and concerns. Such added value can in turn be made apparent through systematic evaluation of the participant, patient and public involvement and engagement process. What are the *Engagement Framework's* key components?
- *Relevance*: Participant, patient and public stakeholders have experience which gives them unique knowledge and expertise of the potential impact of genomics in their lives. They are well placed to help shape genomics research and transform clinical work. Involving them in genomics initiatives ensures that genomics research is relevant to those impacted by its findings.
- *Quality*: Involving participant, patient and public stakeholders in research can improve not only the relevance and impact of genomics, but the quality and quantity of data collected. Better data means better science, which in turn enriches the experience of genomics for everyone involved.
- *Longitudinality*: Genomic analysis produces new knowledge long after a genome has been collected and sequenced. Ongoing engagement with participant, patient and public stakeholders as knowledge is generated (after initial data collection and sequencing) is important to see whether the findings and the knowledge are acceptable. As new genomic technologies continue to emerge, the knowledge and technologies should be explored with different participant, patient and public stakeholders.

3. Framework Genesis and Purpose

This *Engagement Framework* is for all those involved in genomics activities across different GA4GH initiatives and projects, who are interested in engaging with different stakeholders around genomics and data sharing. It might also be of interest to the broader genomics communities outside of GA4GH, who are interested in public engagement. The *Engagement Framework* is underpinned by principles of fairness and justice.

The *Engagement Framework* acknowledges the importance of reflexivity, thinking deeply, about the purposes and strategies of engagement. Such reflexivity aims to recognise the diverse demographic and geographic backgrounds in genomics engagement. Reflexive approaches also recognise the importance of evaluating engagement strategy/strategies to enhance learning and future work.

This *Engagement Framework* was collaboratively developed with stakeholders and members of the GA4GH community¹, drawing on knowledge and expertise on engagement from within GA4GH especially from its driver projects and the Genomics in Health Implementation Forum (GHIF), the Your DNA Your Say study, and from other collaborators interested in genomics and engagement. A range of engagement activities undertaken by driver projects and initiatives within the GHIF ([GHIF and Driver Projects Resource Catalogue](#)) illustrate some of the breadth of engagement activities already being undertaken.

4. How to use the *Engagement Framework*

The *Engagement Framework* is intended to support those working in genomics research and medicine to reflexively approach participant, patient and public involvement and engagement work. The *Engagement Framework* enables consideration of the aims and purposes of engagement, and reflection on the strengths, limitations and/or likely outcomes and impacts of various approaches that engagement might bring. It does this by providing a series of reflexive questions for those developing involvement and engagement plans/activities. These questions explore how involvement and engagement can reflect different participant, patient and public stakeholders' demographics and geographies.

The *Engagement Framework* does not promote a singular understanding or approach to engagement. Nor does it rehearse the benefits and limits of particular forms of involvement and engagement as this is ably done elsewhere REFS.

¹ Please see the Acknowledgements section.



To guide genomics activities towards core GA4GH values and principles four themes are central to participant, patient and public stakeholder engagement.

- Fairness
- Context
- Heterogeneity
- Recognising tensions and conflict

Section II outlines the key considerations for reflexively developing involvement and engagement strategies. It provides a definition of each theme and proposes reflexive questions to guide readers of the *Engagement Framework* through the process of thinking critically about engagement work and considering how to choose an approach best suited to their project. Although the themes are discussed individually, in practice, each impacts the application of the others. As such, the themes are meant to be read as complementary rather than standalone. Section III directs the reader to engagement methods resources and highlights the importance of evaluation and learning from involvement and engagement activities. Sections IV to VIII provide a conclusion, practical information about the Framework, and points to available resources.

II. Developing engagement reflexively

1. Fairness

Incorporating participant, patient and public stakeholder perspectives and experiences into genomic research and health implementation is essential for scientific and ethical reasons. Fairness ensures that research and healthcare are undertaken [responsibly](#) and do not produce inequity or exacerbate inequalities that people already face. Management of genomic data must now commonly adhere to FAIR principles (Findable, Accessible, Interoperable, Reproducible) (Wilkinson et al., 2016), but trying to achieve those principles may cause inequities and inequalities. The *Engagement Framework* therefore argues that *all* genomic activities must aim to be equitable and researchers responsible to their communities. This aim for equity and responsibility can lead to fairness as it encourages listening to and incorporating diverse participant, patient and public stakeholder voices (Fricker, 2007; Kaye et al., 2018; Pratt & Hyder, 2016). Considering society means re-evaluating what being fair from participant, patient and public perspectives may look like. This ensures that: (1) impacts on people – individually or collectively – are considered; (2) power differentials between professionals and non-professionals are considered and rebalanced where possible; and (3) different perspectives are considered in relation to who asks the questions and who answers them. For each of these points, how stakeholders might benefit or whether they have a say in those matters are important additional issues to consider. To this end, the [CARE Principles for Indigenous data](#)



[governance](#) are a good resource that can help projects think further about involvement and engagement.

Reflexive questions to enable fairness-sensitive engagement:

- What is the purpose of the activity I choose? What do I want to achieve?
 - What is the best way to achieve that purpose (strategies, methods/activities and practice)?
- How am I defining my stakeholder groups?
- Why do I want to engage this stakeholder group? Why choose them rather than another group of stakeholders?
- How inclusive is this stakeholder group?
 - What promises have been made to invite, engage and involve that audience? Are they achievable?
 - How will the chosen stakeholders be involved in the project pathway?
 - When is the ideal time to involve different people?
 - What might different audiences think of the results of the project/activity?
 - Could the way a stakeholder group, research question/purpose or activity is defined cause or reproduce:
 - misconceptions, stigma, oppression, etc?
 - inequalities?

2. Context

The context in which an activity occurs includes the range of circumstances under which research or health implementation takes place. Context reflects many different elements such as a genomic project's stage of development, its connection to other projects, the genomic/health condition in question, where the project's activities are conducted, and potential project funding priorities. Context also evolves as priorities and people change over time and so will drive decisions on who is involved in engagement. Because of this, it is important to think about how solutions in one set of circumstances may cause unwanted or unexpected results in another. These circumstances, and therefore the contexts they occur in, shape engagement work by influencing what is needed, what is possible, what is acceptable and what is achievable. Good engagement practices will involve regularly adapting strategies to ensure that the purpose of engaging stakeholders aligns with the context being considered.

Reflexive questions to support context-sensitive engagement:

- What is the context of the initiative?
- In this context, whose perspective is being championed by the engagement activity?
 - Could a different perspective provide more benefit or value to everyone involved?



- Is the engagement activity in this context a sustainable solution?
 - As the project evolves, is the same engagement activity with the same stakeholders sufficient or does something need to change?
- Is the purpose of pursuing this specific engagement, in this context, enough to ensure fairness to all involved?

3. Heterogeneity

Where context refers to circumstances, heterogeneity refers to the diversity and inclusivity among and within the groups of people involved in a project and its subsequent engagement work. Like considerations of context, heterogeneity acknowledges that the nature and scope of engagement may need to be tailored to both differences and similarities among people within specific settings. A single project might use one or more engagement strategies¹ at different times and with different people. This way, engagement can involve diverse stakeholders or achieve different sets of outcomes.

participant, patient and public stakeholders and institutions bring unique experiences, knowledge and values. It is useful for the person/team choosing the engagement strategy to remember that none of these groups are the same, and not to expect the same outcomes out of engagement practices. Being open to potential differences between and within groups allows those undertaking engagement work to explore a diversity of potential engagement activities before deciding on specific strategies.

Reflexive questions to support heterogeneity-sensitive engagement:

- How can multiple perspectives be heard and incorporated into genomics initiatives?
- Are there potential perspectives not being heard?
 - What does diversity look like? Why do you want to pursue it?
- How can these differences shape the purpose of the engagement overall?
 - How can they shape the purpose of the engagement from the time a decision to undertake engagement is?
- What decisions around engagement in the project have been taken before and what might need to be changed?
 - What will be the potential impact on people's lives?

4. Recognising tensions and conflict

Genomics initiatives can create both excitement and anxiety. These can lead to tensions, and, on occasion, disagreements between stakeholders. The central aim of engagement - to bring different perspectives together - inevitably draws attention to differences in opinions, values and beliefs



which may be described or experienced as tensions or conflict. All stakeholders in genomics should be given opportunities to acknowledge and question one another without prejudice or penalty. Tensions, even disagreements, can indicate when people may not be willing to modify or change their views. These should not be seen as damaging or a sign of failure, as they present opportunities for dialogue where there is a mutual desire to achieve an outcome. Transparent engagement processes can offer a way to address tensions and stakeholders must be supported and able to highlight areas of concern which may be leading to tensions, differences and conflicts. When professionals are open to exploring why participant, patient and public stakeholders might be responding in a particular way, such openness can promote better understanding of what causes tensions and can promote fairness in how professionals respond.

Tensions can be present at the start of a project or emerge over time. Management of tensions may not be required (or appear to be required) at the time, but an awareness of those tensions can help to explore different viewpoints early in the engagement process. A transparent process therefore helps stakeholders evaluate whether their concerns have been dealt with appropriately or not. Thus, providing time to discover differences in experience, knowledge and values, which may necessitate difficult discussions, may reduce the chances of engagement becoming unproductive or leading to engagement itself being seen as a tick-box exercise.

Good practice means that project leaders take responsibility for coming up with acceptable approaches to manage or resolve tensions. Understanding the experiences and potential worries of participant, patient and public stakeholders allows genomic researchers and health care professionals to adapt their practices to specific communities. One key approach includes having a good communication strategy. However, communication alone is sometimes only one element of dealing with tensions or conflict. When communication focusses only on one-directional information flows instead of dialogue and feedback, engagement may not be very effective. Achieving good communication means listening with intent to the different views that stakeholders may hold. This approach to communication can be useful for resolving conflict. Good communication is therefore fundamental for establishing respectful, sustainable relationships thus requires committing to listening with the intent to create action (if required), rather than listening for its own sake. Giving people regular opportunities to express their views and acting on those views is important as it can lead to improved outcomes for all people involved. Additionally, project leaders should be willing to seek independent support, if needed, to resolve tensions and to change the direction of their projects in response to participant, patient and public stakeholder concerns.

Engagement addressing tensions/conflict considers the following questions:

- How can the initiative support better engagement between stakeholders so that it avoids long-term damage and loss of trust?



- How are activities, intentions and findings/outcomes being communicated in ways that encourage diverse feedback?
- What might be a source or cause of tension?
 - Who is responsible for managing or responding to that tension?
 - How could responses to people's concerns or differences of opinion avoid blame, shame, and stigma, and instead, create better outcomes for all?
- How can different perspectives work together constructively?
- How are tensions and conflicts resolved and managed at different levels and times in the project?
 - How will differing or conflicting perspectives be accommodated and accounted for?
- How do researchers show they are listening and responding to different perspectives?

III Engaging Effectively

Having considered the key components and questions above, the next steps when thinking about, or choosing, an engagement approach is to align the purpose of the engagement with the approach(es) chosen. There is a wealth of information about the various engagement activities the GA4GH GHIF and driver projects are undertaking (details are available in the GA4GH Engagement resource catalogue¹).

As part of the process of considering engagement approaches, we also suggest building in time and resources to evaluate those approaches. In so doing, the value of engagement can be considered in view of the intended aims and outcomes of the project. It is desirable to evaluate engagement practices against project aims and outcome goals as an ongoing process both during and after the project. Outcomes themselves can additionally be evaluated against the aims and reasons of conducting engagement. Assessing outcomes of engagement activities can be done quantitatively or qualitatively (Russell et al., 2020). The potential ways of conducting evaluations of engagement are not covered in the *Engagement Framework*, but models such as [STARDiT](#), and resources provided by [INVOLVE](#), [Consumer and Community Involvement Program](#), [Imperial College London's public involvement resource](#), [National Institute for Health Research](#) and the [International Association for Public Participation](#), and others, offer specific approaches to evaluating engagement that might be useful. Considering the strengths and limitations of each engagement activity (i.e. what it can and cannot do), will better equip those running such activities to evaluate whether their chosen approach was fit for the purpose or achieved what they had intended.

The type and impact of engagement, the spectrum of strategies, and the level of interaction between different groups or people therefore forms a complex landscape of strategies and outcomes. Despite this complexity, the underlying principles of fairness and justice must remain of central importance.



Evaluating different approaches to engagement

The following questions can also be useful to support the analysis of the strengths and limitations of the different strategies of an engagement approach. These questions can guide decisions about which forms of engagement to use and can help ensure these align with the overall aims of the project:

- How will I assess the outcome of the strategy or engagement activity?
- Does the choice of engagement activity support the context?
- What are the limitations of the activity chosen - what can it do and what can it not do?
- Is the chosen activity appropriate to the purpose of the research and the resources available?
- Are the outcomes of the activity in line with the purpose of engagement?
- How might the activities or outcomes have been different with or without participant, patient and public involvement and engagement?

IV Conclusion

The four key components in the *Engagement Framework* – Fairness, Context, Heterogeneity and Recognising tensions and conflict – provide a framework to assist those involved in genomics to use to reflect on and consider the strengths and limitations of the engagement decisions they make for their initiatives. These can include the strategies selected, the participant, patient and public stakeholders chosen, and the anticipated outcomes. Trying to define fair outputs and participation in such situations are important ethical discussions that are out of the scope of the *Engagement Framework*. However, as multiple stakeholders have diverse expectations, working through some of the many issues and questions we have raised, can help to take those views into account when designing appropriate engagement approaches requires. By considering the strengths and limitations of what may be achieved by different approaches to engagement, it becomes possible to evaluate whether engagement work is achieving its intended purpose, and to identify where it may be further improved.

Finally, in the spirit of promoting and using diversity to improve genomics initiatives, we encourage those involved in genomics to always think about the underlying principles of fairness and justice and maintain a reflexive orientation by coming back to the question:

- What would involvement and engagement look like if a different method had been used or a different group had been approached?

V Implementation Mechanisms and Amendments

Attention should be paid to the interrelation of the *Engagement Framework* with other GA4GH guidance (e.g., [Consent Policy](#), [Privacy and Security Policy](#), [Security Infrastructure](#)).

Any stakeholder adhering to the *Engagement Framework* may propose one or more amendments to the present *Engagement Framework* by communicating the amendments to the GA4GH's Regulatory and Ethics Work Stream (REWS). The REWS shall publicly circulate such amendments for comments and possible inclusion in the *Engagement Framework*.

The REWS, in collaboration with biomedical, patient advocacy, and ethical and policy organizations and committees, will track the adoption of the *Engagement Framework* and its application. It will also routinely review its provisions, be aware of advances in basic research and technology, and ethical and legal developments, and attempt to ensure that the *Engagement Framework* is fit for purpose.

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VII Engagement resources

GA4GH Resources

[GA4GH Framework for Responsible Sharing of Genomic and Health-related Data](#)

[GA4GH Your DNA, Your Say \(Participant Values Survey\)](#) and [Middleton et al., \(2020\)](#)

[GA4GH Consent Policy](#)

[GHIF and Driver Projects Resource Catalogue](#)

External Resources

Consumer and Community Involvement Program: <https://cciprogram.org/researcher-services/types-of-community-involvement/>

GIDA – Global Indigenous Data Alliance. Care Principles of Indigenous data governance: <https://www.gida-global.org/care>

H3Africa – CEBioGen. Developing best practices of community engagement for genomics and biobanking in Africa: <https://h3africa.org/index.php/developing-best-practices-of-community-engagement-for-genomics-and-biobanking-in-africa-cebiogen/>

International Association for Public Participation (www.iap2.org):
https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/Spectrum_8.5x11_Print.pdf

INVOLVE 2015: <https://www.invo.org.uk/wp-content/uploads/2017/08/Values-Principles-framework-Jan2016.pdf>

National Institute for Health Research (NIHR) School for Primary Care Research -
<https://www.spcr.nihr.ac.uk/PPI/what-is-patient-and-public-involvement-and-engagement>

OmicsXchange Podcast, Episode 9 (27 August 2020) The importance of diverse perspectives in standards development: An interview with Laura Paglione. <https://www.ga4gh.org/news/omicsxchange-podcast-episode-9-the-importance-of-diverse-perspectives-in-standards-development-an-interview-with-laura-paglione/>

MESH community engagement network: <https://mesh.tghn.org>

Public involvement – Imperial College London Patient Experience Research Centre
<https://www.imperial.ac.uk/patient-experience-research-centre/ppi/>

STARDIT: Standardised Data on Initiatives: Alpha Version. Nunn, J. S., Shafee, T., Chang, S., Stephens, R., Elliott, J., Oliver, S., ... Orr, N. (2019, September 20). <https://doi.org/10.31219/osf.io/5q47h>

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