General Questions:

What types of compensation do you recommend for IRB members?

The types of compensation for IRB members depend upon the organizational policies of your institution. Some individuals allow for employees and faculty to receive additional financial compensation (e.g. set amount per meeting or some contribution to a discretionary fund), while some credit the IRB time and preparation to their institutional effort (therefore, essentially “relieving” the IRB member from other institutional responsibilities). Others consider IRB membership to be an expected service to the institution without additional consideration.

With regard to the compensation of unaffiliated IRB members, is there a general consensus on how much should be offered to those individuals, either per meeting or annually?

The amount of compensation should be based on geographic location, cost of living, and other comparable positions for the time and work. We recommend that you compare this effort to what volunteers on similar committees or boards at your institution or community receive. Be sure to include not only the actual meeting time but the preparation time as well.

I'm curious how many IRBs on the line pay for the committee members. I represent a state government agency with an IRB.

We can tell you that we have surveyed only a limited number of IRBs, and the practice is changing! Community members are increasingly being paid and, generally, a flat rate per meeting is offered, and that rate includes preparation time. Members are also paid only if they attend the meeting.
Some of us are at state-supported AMCs in states where the use of the term "DEI" is discouraged. What thoughts do you have to share these resources in these venues? My thought is that they could be materials supporting the "equitable subject selection" criterion.

Absolutely. we recommend focusing the discussion on inclusion, and representativeness (of the population affected by the disease or condition, etc.) rather than “diversity” or “race/ethnicity.”

How do you evaluate DEI interventions? Is there research showing outcomes in this area?

If you are considering implementing any initiatives, define specific goals for each activity and identify metrics that help measure if you are meeting those goals. For example, if you want to increase inclusion in your research, define what inclusion means for you/your institution, quantify your baseline now, then measure change over time tracked against your interventions implemented to increase inclusion. This can be tricky if you are trying to implement multiple interventions simultaneously, as attribution to a particular intervention may be difficult.

What are best practices for recruiting and engaging IRB members drawn from the community who may not have a research background? What supports exist to foster their growth?

We recommend that you use community contacts, researcher referrals of patients, and advertisements; contact other offices in your institution that interact with your community for referrals; and put brochures in waiting rooms, etc. You will need a way to vet applicants. Once you have identified new community members, use or develop training that is specific for the community member (e.g. train on research basics, terminology, and IRB processes), use a buddy system of an experienced community member, and allow them to attend meetings as an “observer” until they feel comfortable jumping in. Do hold get-togethers and/or continuing education for the community members. And remember to acknowledge their participation (e.g., send birthday cards, send annual thank you notes) and provide appropriate payment.

Any advice on supporting EDI in industry-sponsored research? If the sponsor doesn’t provide adequate support, does the onus fall solely on the PI? What about rural areas with low diversity? Any success stories with getting industry sponsors to support EDI?

Industry sponsors often will engage and provide a budget and financial support for DEI efforts. Contact them and talk with the person or office working in this area (many pharma sponsors have dedicated efforts in DEI.) We recommend that you develop a relationship with them and solve this together – we are all learning! See if you can introduce terms into a master agreement. Remember that diverse inclusion is broad: in addition to race and ethnicity, sex and gender, attend to potential participants who live in rural areas, are young or elderly, and/or have physical or cognitive disabilities, and others.
Please clarify the concept of “Belonging” to the 2024 DEIJA&B panel. Sounds exciting. Would love to know more?

Often, discussions about belonging are centered in academic and workplace settings. Belonging represents the sense of security and support a person feels that leads to feelings of acceptance and inclusion within these spaces. In our webinar, we want to consider belonging in our research spaces to include meaningful belonging practices with research participants.

How can an individual become a member of the Collaborative AAHRPP Network (CAN)?

Anyone who comes from an AAHRPP-accredited organization can join the Collaborative AAHRPP Network (CAN). Please sign up on our website for our CAN workshop in May in San Diego for a full day workshop addressing current issues. Also, if you are interested in participating in other CAN activities, please contact Michelle at mfeige@aahrpp.org.

Does AAHRPP offer discounted rates for IRBs at safety net hospitals?

We work with organizations that want to get accredited. We are a non-profit and strive to ensure that all organizations that want to go through the process can achieve accreditation. Please contact us directly to discuss. Robert Hood (rhood@aahrpp.org) is a great first contact.

Is AAHRPP accreditation mandatory?

AAHRPP accreditation is voluntary.

Regarding responding to the concerns of participants, one key barrier is that mechanisms (online forms, designated phone lines) for reporting concerns may not be available or responded to in all the languages that participants may use. Is there an institution or model that you feel has addressed this well?

We have created a Research Navigator Office to act as a liaison to answer phones during business hours to answer participant questions as well as community questions about research. The research navigators also help locate possible research opportunities for those looking to participate in studies. We are currently investigating ways to support this service such that multiple languages would be offered.

Can someone please expand on how collection of SSN/tax information is an issue? Is it pointing to the undocumented immigrants? I am confused. Thank you in advance!

Many people, for a variety of reasons, do not want to provide (or may not have) a social security number (SSN), especially for studies where payments are relatively small. This can be a concern about security, scams, etc., or an issue of trust. Why the institution needs an SSN can be difficult to explain, especially in the environment of short-term participation in a study. In
these studies, as in others, payment may incentivize participation, retention, and compliance. Conversely, it is also important to realize that payment or the method of payment may prevent some people from participating. Some people do not have checking accounts or the institutional process for issuing checks takes too long; some may not have email contacts or internet access if researchers want to provide electronic vouchers or gift cards for specific vendors such as local grocery stores.

*Most of the investigator-initiated research studies at our institution are unfunded. How do researchers of unfunded investigator-initiated studies at Mass General Brigham overcome this barrier when translation into other languages is required?*

Exactly! That is the problem. We (MGB IRB) are trying to basically have "free" translation through our clinical services for all research, so that people whose preferred language is other than English are not left out.