Including Underrepresented Groups in Research:

Challenges and Strategies for Recruitment

Outline

- Who are considered underrepresented groups?

- Barriers to inclusion in research

- Inclusion in research: Addressing the barriers

- Resources

Who are considered underrepresented groups?

In research, individuals and groups have been underrepresented based on their:

- Race and/or ethnicity
- Age
- Sexual and/or gender identity
- Faith and/or culture
- Socio-economic status
- Ability and/or mobility level
- Cognitive and/or developmental status
- Geographic location (ex. rural areas)

Known barriers to their inclusion in research:

There are known barriers that exist to underrepresented groups' inclusion in research. Some of these barriers include:

- Historical impact
    - History of medical and research abuse of certain groups and their exclusion from research. This has impacted involvement and trust in research even to today

- Language/Non-English speaker

- Access to care
    - Inability to access it or none available

- Lack of comfortability or feeling safe in seeking care

Known barriers continued:

- Accessibility of study site

- Rigidity of study procedures

- Immigration status

- Distance/travel to study site

- Timing of study visits or total time commitment

- Perceived/actual cost of participating

Inclusion in research: Addressing the barriers

To address the barriers, begin by thinking about what measures or practices can be put into place to address them. What are the lowest barriers to the groups' inclusion in research? What extra steps can be taken to ensure their inclusion? For example:

- Make the study design, including procedures, be flexible and adaptable to the needs and ability of the participant

- Take historical context into place. Ensure you are using [trauma informed language and care](). Consider if your words could be triggering. It's not just about the word choice, but the impact those words have on a person or group

- Ensure your study location is accessible. Identify if there are ramps, elevators, accessible parking or other needed accommodations within the building

- Build long-term relationships in the community, or partner with someone who has, increasing the study team's visibility and trust within it

- Have appropriate compensation for their participation in research, including time and travel, limiting the cost to the participant

- Form partnerships in rural and non-metro areas with external healthcare providers and clinics to expand your geographic reach
  - Expanding geographic reach can also include the use of mobile clinics (ex. [Casey Eye Institute Mobile Clinic](#)), e-health and tele-health options

- Have your recruitment and study materials translated to your population's primary or preferred language. Think ahead to having an interpreter available or bilingual study staff if needed

- Identify if the participant has a guardian, caregiver or legally authorized representative based on their age, cognitive status, ability level, etc. If so, it is recommended that you take into consideration their schedule, timing and needs also

- Increase the diversity of study staff, working towards your team being representative of the participants you're looking for. This can include culture, language, religion, etc. When a study team is representative and inclusive of the population they wish to work with, it helps towards building trust with them

- Make study visit times flexible to participant's work schedules. Take into consideration the type of job they have and their ability to take time away from work. This helps to ensure that your study isn't naturally excluding people of certain jobs or socio-economic status based on the timing of study visits

- Training and continuing education for study staff on inclusive research and working with specific populations

- Take the time to become aware of the needs or special restrictions of the group you're working with and take this into consideration with your study planning
    - For example, are you working with a group who has certain beliefs around blood and your study requires blood draws? If your study involves food at any time point, is it something that could be eaten by the participant (ex. the use of pork or beef products)?

- Consider what measures will be taken to avoid assumptions, and identify and address any special or additional needs of participants with varying ability and mobility levels, cognitive or developmental status, and sensitivities

- Consider the timing of your study in relation to the time of year and different cultural or spiritual events or holidays that might be happening during that time
    - For example, if your study is trying to be inclusive of different religious or spiritual groups, it would not be recommended to start the study in December as multiple faith practices celebrate a holiday during that time period, which could lead to difficulty in participant availability

- Be aware of your own bias. Often times our own biases, whether conscious or unconscious, have an impact on how we interact, what words we use, the methodologies we choose, etc.

- Ensure your recruitment materials are sensitive to and inclusive of the underrepresented group(s) you wish to work with. Review and consider what images and words are being used and how is the material being presented

Recruitment Materials: Images

Do potential participants see themselves reflected in the images of your materials? Do your chosen images represent the people and populations you are hoping to recruit?

Recruitment Materials: Words

Words matter. Words can bring clarity or confusion, they can be inclusive or divisive. In your recruitment materials and communication(s), it's important to consider:

- Are your words at a 6th grade reading level, adding to the readability and comprehension of your materials?

- Are they in plain language? Has all medical and research terminology been changed?

- Are you using people first language – putting the person before their disease or descriptor?

- Are your words sensitive to the person? This can include their state of being, disease or condition, a cultural or spiritual aspect, etc.

- Are your words in a font size large enough to be read by those with a visual impairment?

- Are your words culturally, spiritually, or otherwise competent? Do your words have the ability to be understood effectively with people of different cultures, faith practices, and communities?

- Are your pronouns appropriate? Is your communication style gender neutral or aligned with the participant's preferred pronouns?

- Are your words in the right language? What is your participant group's primary or preferred language?
    - If your materials are translated, are the words culturally relevant? Does the translation match the intended meaning?

- Are your words respectfully inclusive? Are you using language and contextual content familiar to the population that is avoidant of unintentional disrespect or appropriation?

Other Considerations

When including underrepresented groups in research, other best practices and key considerations include:

- Plan early and implement considerations into study planning and protocol

- Consider the inclusion of different groups from the beginning. Think more expansively and intentionally about the data being collected and study procedures and how this relates to the group(s) you desire to work with. Be intentional in the inclusion of underrepresented groups into your study

- Incorporate feasibility into your study planning. What is the number/percentage of participant's you need? Will oversampling be needed to reach an appropriate number? Are your enrollment goals realistic?
  - Through feasibility checks you can determine early if you will need to obtain collaborators, have multiple sites, etc. to reach your target enrollment

- Budget enough time and resources to consider possible barriers and solutions to address them. You may need to budget in additional time for the recruitment process, accommodations for study procedures, more funding for adequate staffing, translated materials, etc. Think about what your study might need and how to accommodate it

- Have a Plan B available. What study teams expect and what happens don't always align. Think ahead to those "so now what?" moments and become familiar with the resources available to you if needed. For example, maybe it's a need for translated materials or collaborating with community groups

- Collaborate. Determine what groups are working with this population and align and learn from them

- Have more of a community-based approach when working with underrepresented groups. Focus on the relationship and take it from that aspect

- Understand that it will take work ahead of time to build relationships, trust, and break down historical barriers for certain groups. This isn't only about recruitment for one study, but should be thought about as long-term relationship building for continued collaboration

- Don't claim to know the different groups, learn from them

- Show respect

Learn more about community engagement and collaboration, which includes underrepresented groups, through OCTRI's "[Recruiting in the Community](#)" guidance document, available on the [OCTRI Recruitment website](#)

Resources

OHSU Departments and Support Services

OHSU Center for Diversity and Inclusion (CDI)
https://www.ohsu.edu/center-for-diversity-inclusion

OHSU Institute on Development and Disability (IDD)
https://www.ohsu.edu/institute-on-development-and-disability

OHSU - University Center for Excellence in Developmental Disabilities (UCEDD)
https://www.ohsu.edu/university-center-excellence-development-disability

OHSU Transgender Health Program
https://www.ohsu.edu/transgender-health

OHSU Oregon Rural Practice Based Research Network (ORPRN): Research and Programs
https://www.ohsu.edu/oregon-rural-practice-based-research-network/research-and-programs

OHSU OCTRI: Community Research Hub
https://www.ohsu.edu/community-research-hub

<u>Imagery</u>

OHSU Communications: Photo Sources
https://o2.ohsu.edu/communications/services/photography/stock-photo-sources.cfm

Creative Commons
https://oldsearch.creativecommons.org/

Pixabay
https://pixabay.com/

Pexels.com
https://www.pexels.com

Broadly: The Gender Spectrum Collection
https://broadlygenderphotos.vice.com/

CDC Public Health Image Library
https://phil.cdc.gov/

Communication

OHSU Interpretation & Translation Services
https://o2.ohsu.edu/language-services/index.cfm

CDC – "Simply Put: A guide for creating easy-to-understand materials"
https://www.cdc.gov/healthliteracy/pdf/Simply_Put.pdf

CDC – "Everyday Words for Public Health Communication"
https://www.cdc.gov/healthcommunication/everydaywords/

UofM - "Plain Language Medical Dictionary"
https://www.lib.umich.edu/taubman-health-sciences-library/plain-language-medical-dictionary

CDC – "Communicating With and About People with Disabilities"
https://www.cdc.gov/ncbddd/disabilityandhealth/materials/factsheets/fs-communicating-with-people.html

U.S. Department of Health & Human Services: Multi-Cultural Resources for Health Information
https://sis.nlm.nih.gov/outreach/multicultural.html

CDC: Health Literacy
https://www.cdc.gov/healthliteracy/index.html

<u>Specific Groups and Topics</u>

OHSU - Disability Awareness Training: Creating a More Inclusive Culture through Communication
https://www.youtube.com/watch?v=ia1o69fcfXQ

OHSU CDI – "Cultural Awareness Guide: Religious and Spiritual Accommodations"
https://o2.ohsu.edu/diversity-and-inclusion/upload/2019-2021-Religious-and-Spiritual-Observances-Calendar-1.pdf

OHSU CDI – Culture Vision
https://www.crculturevision.com/subscribers/welcome.aspx

OHSU CDI – "Diversity and Multicultural Resources"
https://o2.ohsu.edu/diversity-and-inclusion/upload/ResourceGuide_Interactive.pdf

National LGBT Health Education Center
https://www.lgbtqiahealtheducation.org/resources/type/learning-module/

UCSF LGBT Resource Center: Education and Training
https://lgbt.ucsf.edu/lgbtqia

<u>Groups/topics continued:</u>

FDA – Enhancing the Diversity of Clinical Trial Populations
https://www.fda.gov/media/127712/download

Person-Centeredness of Research (PCoR) Scale
https://www.ccphealth.org/wp-content/uploads/2018/11/Person-Centeredness-of-Research-Scale-Wilkins-et-al-Scoring-2018.pdf

UIC – "Priority Populations Toolkit"
https://ccts.uic.edu/tools/community-engagement-toolbox/priority-population-toolkit/

NIH – NIA: Recruiting Older Adults into Research (ROAR) Toolkit
https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit

Courserra: "Faster Together, Enhancing the Recruitment of Minorities into Clinical Trials:
https://www.coursera.org/learn/recruitment-minorities-clinical-trials

Recruitment Innovation Network: Community Outreach Guide
https://trialinnovationnetwork.org/wp-content/plugins/artifact-library/dl-file.php?artifact-file-id=131

For more information, additional resources, and to request a recruitment consultation, please visit our website at https://www.ohsu.edu/octri or email us at octrirecruitment@ohsu.edu

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