

26th Annual Conference of the  
British HIV Association  
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# The BHIVA Invited Lecture

## Community Involvement in HIV Research

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# Declaration of Interests relating to this presentation

None

# Background of community involvement in HIV research

*Greater Involvement of people living with HIV/AIDS (GIPA)* - self-determination and **meaningful involvement** in decision-making processes as equal partners, ***not tokenistic participation.***

## Importance

- Human rights
- Improves relevance, acceptability & effectiveness
- Essential for quality of life

# Definition of community involvement

- “Involvement is **respectful engagement with, and learning** from communities” -*Meaningful involvement of women living with HIV and AIDS(MIWA)*.
- “Public involvement in research is research carried out **‘with’ or ‘by’** members of the public rather than **‘to’, ‘about’ or ‘for’** them.”

- Namiba, A., Orza, L., Bewley, S., Crone, E. T., Vazquez, M., & Welbourn, A. (2016). Ethical, strategic and meaningful involvement of women living with HIV starts at the beginning. *Journal of virus eradication*, 2(2), 110–111.
- NIHR Involve-Supporting Public Involvement in Research <https://www.invo.org.uk/>

# Some resources on involvement

- Denver Principles
- WHO Consolidated guideline on sexual and reproductive health and rights of women living with HIV (2017)
- NIHR/INVOLVE National Standards for Public Involvement

# Challenges of involvement

- Awareness & commitment
- Capacity - intersectional issues = less engagement
- Skilled vs unskilled involvement and capacity building
- Recognition vs confidentiality - stigma
- Adequate representation/diversity
- Geographical inequality

# Additional challenges of involvement

- Theory vs practice
- Reluctance to adopt community input
- Lack of monitoring/evaluation
- Community involvement -wellbeing vs burnout
- Sustainability of community representation - no investment
- Organisational funding constraints



# What works?

- Equal partnerships
- Respectful relationships
- Recognising the value of lived-experience
- Training and mentoring opportunities
- Respectful remuneration

# More of what works

- Provision for diverse representation
- Respecting priorities/contributions
- Conducive/responsive environment
- Translation of research into policy and practice



My health, My choice, My child, My life

<https://tinyurl.com/4Mproject>

# Some models of involvement



<https://www.onevoicenet.org/>



HIV TREATMENT  
ADVOCATES NETWORK

<http://www.ukcab.net/>



Salamander Trust

ON THE RIGHT(S) TRACK

<https://salamandertrust.net/>



<https://www.swift-women.co.uk/>

# The way forward for community involvement

- People living with HIV in decision making roles
- Diverse experiences & models
- Sustainable capacity building & remuneration
- Innovation & flexibility
- Sustainable investment in community representation development

# More ways forward for community involvement

- Increased geographical spread
- Increased monitoring/evaluation
- Sustainable partnerships
- Sustainable investment for community spaces
- Multi-dimensional, holistic approach addressing intersectional/quality of life priorities

# References

- Denver Principles  
[https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples\\_en.pdf](https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf)
- WHO Consolidated guideline on sexual and reproductive health and rights of women living with HIV (2017) <https://tinyurl.com/WHOSRHR17>
- NIHR/INVOLVE National Standards for Public Involvement  
[https://www.invo.org.uk/wp-content/uploads/2019/02/71110\\_A4\\_Public\\_Involvement\\_Standards\\_v4\\_WEB.pdf](https://www.invo.org.uk/wp-content/uploads/2019/02/71110_A4_Public_Involvement_Standards_v4_WEB.pdf)
- United Nations The Universal Declaration of Human Rights. 1948  
<https://www.un.org/en/universal-declaration-human-rights/>

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- 4M Net steering group and project team
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*perinatal peer mentoring project for women living with HIV*



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