

## **Ageing with HIV and the intractable problems of shame and stigma: building community based research approaches to facilitate impact**

Thanks to medical advances in the treatment of HIV the population of people living with HIV in the UK is ageing, up from about 5% over 50 in 2003 to around 27% in 2013. It is already known that older people living with HIV experience difficulties medically and clinicians are developing various interventions to mitigate these. However, some of the most intractable issues are around the shame and stigma associated with HIV; and whilst this is not new in relation to HIV as a whole, Dr Nagington (School of Nursing, Midwifery and Social Work, UoM) and Dr Hutchinson (School of Interdisciplinary Studies, MMU) are looking to explore how shame and stigma functions in relation to the growing demographic of older people living with HIV. Nagington has a robust background in the health and sociological literature on HIV and ageing, whilst Hutchinson has studied in-depth the concepts of shame and stigma. Whilst a literature review by Nagington demonstrates that research is clearly needed in this area, what is not clear is how the research should proceed. Therefore, this project aims to begin robust community engagement to help understand the most appropriate research methods and strategies to ensure that any future substantive work on this area can increase its chances of having a substantive social impact by reducing shame and stigma for older people living with HIV.

In order to undertake this work Nagington and Hutchinson have partnered with the Terrence Higgins Trust (a national HIV charity) and George House Trust (a Manchester based regional HIV charity), both of whom are currently running projects that aim to address the broader needs of older people living with HIV such as: long term health management, financial management, and peer mentoring. Focus groups with the five local groups across England will be undertaken and participants will be encouraged to explore ideas such as:

1. What the research needs to address: i.e. does there need to be a greater focus on healthcare professional's attitudes, or should the focus be more on society as a whole.
2. How research needs to address this: i.e. are in-depth interviews useful, if so who should be conducting these interviews and how often?
3. What sorts of output would be most beneficial: i.e. would a web-based resource be helpful, how about artistic projects?

Hutchinson and Nagington hope that through robust community engagement, and a combining of their expertise on HIV, shame and stigma that a novel approach to addressing these issues can be developed. They will then be developing a larger bid to undertake such work in line with the findings of this consultation.

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