

Institution: Glasgow Caledonian University

Unit of Assessment: Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Increasing HIV testing amongst vulnerable populations

1. Summary of the impact (indicative maximum 100 words)

The Unit's research into HIV testing has led to impacts on health policy (WHO and NICE guidelines) and services relating to HIV testing amongst vulnerable populations across Europe, and particularly, Scotland. The policies related to the frequency of HIV testing, increases in sites available for testing, and the scope of interventions to promote testing. These policies have contributed to significant increases in HIV testing, and a reduction in undiagnosed HIV infection, HIV related ill-health and AIDS deaths. For people living with HIV, this has enabled improved quality of life, better health and contributions to society.

2. Underpinning research (indicative maximum 500 words)

Since the late 1990s there have been profound changes in treating HIV, transforming it from a deadly infection to a chronic manageable disease. There has been a shift in HIV testing policy, to reduce undiagnosed infection by encouraging HIV testing amongst vulnerable groups such as men who have sex with men and sub-Saharan Africans. Implementing this policy effectively has required a deep understanding of the barriers to HIV testing amongst often vulnerable and hard to reach populations. Our research was the first programmatic attempt to understand barriers to testing after the rollout of effective treatment for HIV in the populations most at risk of HIV. Our data sets are unique in enabling an analysis of change over time. Our research has shown that despite the success of medical developments in treating HIV, psychological and social barriers to testing remain core reasons why people do not test. Uniquely, we proposed that whilst increased testing should be recommended to make the most of effective treatments, it also had to address HIV related stigma, be culturally appropriate, and be offered within diverse settings.

Within the Unit, mixed methods research focusing upon HIV testing has been conducted through on-going partnership work and community engagement with the third sector since 1999. Third sector partners include, for example, Terrence Higgins Trust Scotland, Gay Men's Health, Healthy Gay Scotland and HIV Scotland. Academic partners have included the MRC Social and Public Health Sciences Unit at Glasgow University (Dr Lisa McDaid, née Williamson, with associated data pooling), and Centre for Sexual Health and HIV Research, University College London (Professor Graham Hart). The programme of HIV testing research began with an investigation of men who have sex with men (MSM) (Grant [1]). The results critically highlighted men's perceptions of barriers and facilitators of HIV testing. A We found although the availability of effective treatment for HV had facilitated HIV testing, it did not negate the central role of psychological and social barriers in seeking an HIV test. Subsequently, quantitative scales of barriers to testing were developed in order to construct a generalisable and population-level understanding of these barriers to testing. These quantitative findings mirrored the earlier qualitative research. In 2010, further funding (Grant [2]) enabled an additional survey to examine changes in barriers to HIV testing amongst MSM since 2000.

Together these studies have led to a major shift in understanding of testing barriers to include factors associated with the clinics themselves, problems with waiting for test results, and, critically, avoidance of the HIV test because of fears concerning the implications of a positive result which emerged as central. These fears in turn related to HIV stigma and the social dynamics of the gay



community.³ Facilitators of testing included anticipated peace of mind (for those receiving negative results) and knowledge of the availability of effective treatment for HIV. Subsequently, ESRC/MRC funded work examining the use of technologies within both HIV prevention and care (Grant [3]) amongst vulnerable populations. This project was one of the first to find comparable results concerning testing and stigma amongst African populations living within the UK.

- Professor Paul Flowers (Lecturer at time of research)
- Dr Christina Knussen (Reader Lecturer at time of research)
- Dr Barbara Duncan (Lecturer)
- Dr Jamie Frankis (Research fellow)
- Dr Stephanie Church (Research assistant at time of research, start date, June 1999, end date Dec, 2000)
- 2. References to the research (indicative maximum of six references)
- 1. Williamson LM, Flowers P, Knussen C, Hart GJ (2009). HIV testing trends among gay men in Scotland, UK (1996-2005): Implications for HIV testing policies and prevention. *Sexually transmitted infections*, 85(7): 487-8. DOI: 10.1136/sti.2008.033886.
- 2. Flowers P, Duncan B, Knussen C (2003). Re-appraising HIV testing: an exploration of the psychosocial costs and benefits associated with learning one's HIV status in a purposive sample of Scottish gay men. *British Journal of Health Psychology* 2003, 8 (2):179-194. DOI: 10.1348/135910703321649150.
- 3. Flowers P, Duncan B, Frankis J (2000). Community, responsibility and culpability: HIV risk-management amongst Scottish gay men. *Journal of Community and Applied Social Psychology*, 10 (4), 258-300. DOI: 10.1002/1099-1298(200007/08).
- 4. Flowers P, Knussen C, Church S (2003). Psychosocial factors associated with HIV testing among Scottish gay men. *Psychology and Health*, 18 (6), 739-753. DOI:10.1080/0887044031000116016.
- 5. Flowers P, Davis M, Hart G, Rosengarten M, Frankis J, Imrie J (2006). Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK. *Psychology and Health*, 21[1], 109-122. DOI:10.1080/14768320500286286.
- 6. Flowers P, Knussen C, McDaid L, Li J (2013). Has testing been normalised?: An analysis of changes in barriers to HIV testing among men who have sex with men between 2000 and 2010 in Scotland, UK: *HIV Medicine*, Feb;14 (2):92-8. DOI: 10.1111/j.1468-1293.2012.01041.x

Relevant grants:

- 1. Flowers, P (P.I.). 'HIV testing barriers', Healthy Gay Scotland (1999-2001) £13.1K.
- 2. Flowers P (P.I.). Knussen C and McDaid L. 'Evaluating the 'positions' social marketing campaign', NHS Greater Glasgow, Lanarkshire, Ayrshire and Arran (2009-2010) -£82.3K.
- 3. Flowers P (P.I.) Imrie J, Hart G and Davis M. 'Transitions in HIV management: the role of innovative health technologies'. L218252011. ESRC/MRC (2001-2003) £213K. This large qualitative project focused upon the role of innovative health technologies in the contemporary management of HIV. It was a dual site project with researchers based in Glasgow and London (UCL).
 - 3. Details of the impact (indicative maximum 750 words)

Our research¹⁻⁶ has enhanced and shaped European policy (S1, S2), National Policy (S4) and local service provision (S6 and S7). It has been vital in shaping policy optimising testing service design in ways that challenge barriers to testing, facilitate increases in HIV testing and reduce undiagnosed HIV. Together these factors reduce new HIV infection at the population level and increase the health and well-being of those living with HIV, reducing AIDS diagnoses and AIDS



deaths. In the last decade across Europe late HIV diagnosis has reduced (Mocroft et al., 2013) and within the UK, HIV diagnosis amongst gay men has increased (HPA, 2012). Moreover, within the WHO European region, between 2010 and 2012, HIV testing amongst MSM increased in 50% of countries. Equally, the number of AIDS cases has continued to decline in Western Europe with numbers stabilising in Central Europe. This reduction directly relates to increased HIV testing and better access to treatments.

Our work has underpinned one of the ten principles in the WHO European Region's (53 countries) policy framework (S1) on scaling up HIV testing and counselling across the region (aimed at policy-makers, national AIDS programme planners and non-governmental organisations) which was presented at the European Parliament on World AIDS Day 2010. It sets out the essential components to achieve universal access to HIV prevention, treatment, care and support. The second policy principle 'Expanded HIV testing and counselling must be tailored to different settings, populations and client needs' draws extensively on our research quoting,⁴: "It is not so much the changing medical aspects of HIV that shape contemporary testing decisions, but the social meaning and social consequence of HIV diagnoses" (p7494).

Other GCU work⁵ was cited and quoted in a 2011 report commissioned by the European Centre for Disease Control (a European Union agency which aims to strengthen Europe's defences against infectious diseases)(S2). It summarised research concerning HIV testing and counselling for migrant populations and ethnic minorities in the region in order to inform future policy and practice to improve access to services for these groups. The report concluded that approaches to the promotion and provision of HIV testing should address testing in community settings, and focus upon partnerships with communities and community organisations.

At a UK level, the National Institute of Clinical Excellence (NICE) Public Health guidance on HIV Testing⁹ (issued March 2011) draws directly and indisputably upon research published by GCU. This guidance was for NHS UK and commissioners, managers and practitioners who have a direct or indirect role in, and responsibility for, increasing the uptake of HIV testing among MSM. Their recommendations were based upon systematic reviews of effectiveness, cost-effectiveness and qualitative evidence concerning interventions to increase the uptake of HIV testing. Several evidence statements relate to the GCU research directly^{2,3} (evidence statements 3, 8, 9, 10, 12, 13, 18; IDE (inference derived from evidence) (S3). In addition, Professor Flowers was asked to

give expert testimony to discuss the contribution of the GCU work regarding HIV testing within the finalising of the guidance (S4) (http://www.nice.org.uk/nicemedia/live/13413/53675/53675.pdf). This guidance was later endorsed by 'The House of Lords Select Committee on HIV and AIDS report (September 2011)'. Similarly, he was asked to give expert testimony to the Chief Medical Officer of the UK on December 2nd 2012 regarding the future of HIV public health policy.

In sum, the Unit's research has led to an ethical, socially and culturally sensitive approach to HIV testing policy in the UK. The guidance and the concomitant changes in service provision have been associated with widespread increases in HIV testing within the UK. Within Scotland the research has had local significance in helping to change decisions to provide HIV testing services within community settings (for example the work of Terrence Higgins Trust Scotland and their Fast Test Clinic) rather than solely offering tests within genitourinary medicine clinics and, to ensure that HIV testing services in such non-clinical settings are socially and culturally sensitive and are shaped to reduce barriers to testing. In this way, service providers such as Terrence Higgins Trust Scotland (S5) and Gay Men's Health (S6) have developed testing services in line with the NICE guidelines and WHO policy framework (see above) and also directly in relation to the corpus of work produced by GCU.



This partnership approach to impact has been complemented by research dissemination to a wide range of professional workers across Scotland (such as NHS Board Strategic Leads for Sexual Health; Health Promotion / Health Improvement Specialists; Primary Care Staff; Social Work Staff) (S6) to enable them to ensure that national, regional and local sexual health policy is implemented in ways which meet the specific sexual health needs of gay and bisexual men in Scotland.

- 4. Sources to corroborate the impact (indicative maximum of 10 references)
 - S1. Scaling up HIV testing and counselling in the WHO European Region. Policy framework (2010)http://www.euro.who.int/en/what-we-do/health-topics/communicable-diseases/hivaids/publications/2010/scaling-up-hiv-testing-and-counselling-in-the-who-european-region.-policy-framework (See Principle 2, page 5)
 - S2. HIV testing and counselling in migrant populations and ethnic minorities in EU/EEA/EFTA

Member States (2010)

http://www.ecdc.europa.eu/en/publications/Publications/1108_TER_HIV_in_migrants.pdf

S3. NICE Guidance - Increasing the uptake of HIV testing among men who have sex with men

PH34 Increasing the uptake of HIV testing among men who have sex with men: review of effectiveness, cost-effectiveness and barriers (2010) http://www.nice.org.uk/nicemedia/live/13413/53687/53687.pdf

- S4. http://www.nice.org.uk/nicemedia/live/13413/53675/53675.pdf
- S5. National Director, Terrence Higgins Trust Scotland

"Research at GCU concerning the barriers to HIV testing remains central to the ways we deliver and develop our innovative testing services. We have regularly utilised the work led by Professor Flowers and colleagues to help shape the way in which Terrence Higgins Trust Scotland has elaborated our approach to testing. Though this we have established a Fastest clinic in Glasgow and developed a community testing service in Lanarkshire. As well as being influential on a UK and wider stage, this research helps to reassure local commissioners and policy makers that there is evidence with a Scottish context. Understanding of the needs of people at risk of HIV infection – in all their forms – is invaluable not only for our own testing services but also in our campaigning for improved testing services across Scotland. The work that the team at GCU does has proved highly useful and will continue to be so."

S6. Chief Executive of Gay Men's Health, Scotland

"Professor Flowers's research has been highly influential in giving direction and design to initiatives and work around HIV undertaken by Gay Men's Health across Scotland. His research into testing barriers directly led to Gay Men's Health creating a programme of work and a specific full time post aiming to reduce the barriers associated with HIV testing. Influences have also led to GMH developing specific fast test clinics in its premises across Scotland. The thorough understanding of our client group demonstrated by Professor Flowers' team ensures his research is relevant and that it will continue to influence partnership approaches with community organisations."

S7. http://www.gaycon.org.uk/index.php/presentations