

Institution: University of Glasgow (UofG)		
Unit of Assessment: UoA2 (Public Health, Health Services and Primary Care)		
Title of case study: HIV policy formulation and prevention: driving the decision for and implementation of publicly-funded pre-exposure prophylaxis in Scotland		
Period when the underpinning research was undertaken: 2011–2016		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
(1) Prof. Lisa McDaid	(1) Programme Leader Track; Programme Leader; Professor of Social Sciences and Health	(1) 2010–2012; 2012–2017; 2017–present
(2) Dr Ingrid Young	(2) Research Associate; CSO Research Fellow	(2) 2011–14; 2014–2016
Period when the claimed impact occurred: 2014–present		
Is this case study continued from a case study submitted in 2014? No		
<p>1. Summary of the impact</p> <p>In the UK, men who have sex with men (MSM) are at the highest risk of contracting HIV. While changes in testing policy have reduced HIV levels, HIV ‘literacy’ remains an issue and around one-quarter of HIV-infected MSM remain undiagnosed. UofG researchers contributed essential data and understanding needed by Scottish policymakers to plan and fund pre-exposure prophylaxis (PrEP) for HIV prevention. In July 2017, Scotland became the first UK nation to fund PrEP on the NHS. In the first three years, 4,100 people received PrEP, reducing HIV incidence five-fold in MSM with high risk behaviour. An HIV literacy tool produced from UofG research to support PrEP implementation contributed to take-up being approximately twice as high as anticipated in year one.</p>		
<p>2. Underpinning research</p> <p>The Gay Men’s Sexual Health (GMSH) survey, led by McDaid, has been conducted in commercial venues used by the gay community every three years between 1996–2014. It has provided robust evidence on the sexual behaviours, prevention and testing activities of gay and bisexual men who have sex with men (MSM) in Scotland and the wider UK. The GMSH survey has been complemented by two qualitative research projects (‘HIV and the Biomedical’ and ‘Developing HIV Literacy’), and online surveys of gay and bisexual MSM (Social Media, Men who have Sex with Men, Sexual and Holistic Health Study, SMMASH)—the latter in collaboration with Glasgow Caledonian University. Together, these have furthered understanding of how the effective delivery of targeted HIV prevention interventions might impact on populations at risk. UofG research has been at the forefront of better understanding community responses to inform future interventions.</p> <p>The 5th wave of the GMSH survey (2011) provided updated Scottish data on high-risk behaviour, awareness of and willingness to use pre-exposure prophylaxis (PrEP)—a drug that reduces HIV infection in HIV-negative men by 99% if used daily [3.1]. Of the 1,515 gay, bisexual and other men who have sex with men (GBMSM) surveyed, around one third had heard of PrEP and just over a half of participants indicated their willingness to take PrEP on a daily basis. However, UofG-led research has also shown that a significant percentage of GBMSM fall short of current national guidelines on frequency of HIV testing and the levels required to optimise access to PrEP [3.2]. There are also concerns that, despite offering a significant advance, new HIV prevention technologies such as PrEP, treatment as prevention (use of anti-retroviral drugs), and self-testing could amplify existing health inequalities among GBMSM [3.2–3.5].</p> <p>The UofG-led ‘HIV and the Biomedical’ study (2016) was the first qualitative study of the views and understanding of biomedical HIV prevention among the communities most affected by HIV in the UK (GBMSM, and migrant African communities) [3.4]. It is significant because it found that understandings of PrEP effectiveness and concerns about maintaining regular adherence were barriers to potential PrEP uptake and use.</p> <p>In the first mixed methods study to consider awareness and acceptability of PrEP across the UK, the UofG research demonstrated that there was willingness to use PrEP [3.5]. The study, which</p>		

integrated HIV and the Biomedical and SMMASH data, revealed that factors such as risk, patterns of sexual practice and social relationships could all affect motivation for and nature of use of PrEP within relationships and sexual encounters. Furthermore, awareness of PrEP across MSM communities varied according to traditional markers of inequality (e.g. by geography, education, frequency of gay scene use and HIV proximity) [3.3, 3.5]. These studies demonstrate that understanding how prevention is incorporated into individual and community practices is important to optimise future intervention delivery.

The 'Developing HIV Literacy' project (2014–2017) also built on the 'HIV and the Biomedical' study, particularly around how stigma and homophobia shapes consumption of HIV-related knowledge. This sought to develop a framework and resource to address inequalities in HIV literacy among those infected with HIV. It used participatory workshops with an intervention development group comprised of health, HIV and community stakeholders, including community members from target populations (MSM, migrant African men and women living in Scotland, people living with HIV). The workshops mapped out the experiences of key stakeholders to inform the clarification and contextualization of the HIV literacy 'problem' and identify existing local practices in this area and potential opportunities for intervention [3.6].

3. References to the research

1. Young, I., Li, J. and McDaid, L. (2013) [Awareness and willingness to use HIV pre-exposure prophylaxis amongst gay and bisexual men in Scotland: implications for biomedical HIV prevention](#). *PLoS ONE*, 8(5): e64038. (doi:[10.1371/journal.pone.0064038](#))
2. McDaid, L.M., Aghaizu, A., Frankis, J., Riddell, J., Nardone, A., Mercey, D., Johnson, A.M., Hart, G.J. and Flowers, P. (2016) [Frequency of HIV testing among gay and bisexual men in the UK: implications for HIV prevention](#). *HIV Medicine*, 17(9): 683-693. (doi:[10.1111/hiv.12373](#))
3. Young, I., Flowers, P. and McDaid, L. (2014) [Barriers to uptake and use of pre-exposure prophylaxis \(PrEP\) among communities most affected by HIV in the UK: findings from a qualitative study in Scotland](#). *BMJ Open*, 4(11): e005717. (doi:[10.1136/bmjopen-2014-005717](#))
4. Young, I., Flowers, P. and McDaid, L. (2016) [Can a pill prevent HIV? Negotiating the biomedicalisation of HIV prevention](#). *Sociology of Health and Illness*, 38(3): 411-425. (doi:[10.1111/1467-9566.12372](#))
5. Frankis, J., Young, I., Flowers, P. and McDaid, L. (2016) [Who will use pre-exposure prophylaxis \(PrEP\) and why?: Understanding PrEP awareness and acceptability amongst men who have sex with men in the UK - a mixed methods study](#). *PLoS ONE*, 11(4): e0151385. (doi:[10.1371/journal.pone.0151385](#))
6. Young (2019) [Making the Case for HIV Literacy: A Developing HIV Literacy Project Report](#)

Grants:

- a. UK Medical Research Council (MRC) core funding (MCU130031238/MCUU12017/2): GMSH: Gay Men's Sexual Health survey, led by McDaid from 2005–2014; (funded ref.1)
- b. HIV & the Biomedical (2012–2013) (qualitative research component) MRC Core funding (funded ref. 3 and 4)
- c. Developing HIV Literacy (2014–2017), Chief Scientist's Office, Scotland Fellowship to Young.
- d. Social Media, Men who have Sex with Men and Sexual Health (SMMASH2) (2016) NHS Greater Glasgow and Clyde and NHS Lothian (UofG Co-Is: Young, McDaid)

4. Details of the impact

Background

There are currently ~101,600 people living with HIV in the UK, with 5,484 in Scotland. Despite major advances in treatment and availability of testing, HIV still has a major impact on individual health, the healthcare system and the economy. PrEP is a game-changing prevention tool that could significantly reduce HIV transmissions. UofG research has provided the key data and understanding on social and behavioural aspects of PrEP and HIV underpinning policy decisions that led to the introduction of PrEP in Scotland. It also underpinned the production of a PrEP literacy tool, which has enhanced the communications campaign to support HIV PrEP implementation.

Pathways to impact

UofG research in the Scottish GBMSM community is well known and highly regarded within NHS Scotland gay men's services and key Scottish Government bodies, including the Scottish Health Protection Network (SHPN) Sexual Health and Blood Borne Viruses (SHBBV) Framework, which integrates policy on sexual health, wellbeing, HIV and viral hepatitis across Scotland. A 2015 SHBBV Framework progress report highlights the UofG-MRC/CSO unit's research on HIV prevalence and undiagnosed infection amongst MSM in Scotland as "*important for HIV testing and prevention policy*", recommending that "*NHS boards and other partner's should ensure that future prevention and testing strategies in this at-risk group are informed by*" such evidence (p.25). The report also confirms that the UofG study on at-risk communities' attitudes to PrEP [3.3] will inform future work (p.25/26) [5.A].

The Chair of the body implementing HIV PrEP in Scotland (the HIV PreP National Coordinating Group), who is also Co-Chair of SHBBV Framework Executive Leads confirms that "*work undertaken by Lisa McDaid and her team (especially that relating to the GMSH Survey) has been critical in informing Government policy, strategic direction and the evaluation of interventions relating to transmission of HIV among MSM over two decades.*"

"Behavioural data, particularly those relating to rates of unprotected sexual intercourse with casual partners, not only ensured that this issue remained a high profile one from the public health perspective but, also, constituted an evidential cornerstone in the case for HIV PrEP implementation in Scotland as a matter of urgency. Indeed, the importance of the GMSH is manifested by the fact that Public Health Scotland has continued to fund the survey and play a major role in its coordination" [5.B].

Providing data to support Scotland's decision to fund PrEP

In 2016 the SHBBV Framework Executive Leads and Scottish Government convened the 13-member Scottish HIV PrEP Short Life Working Group, whose report — 'PrEP in Scotland' — recommended "*people at the highest risk of HIV in Scotland are provided with the option of PrEP as part of a wider targeted national prevention programme*" [C]. The group comprised clinicians, third sector, advisors from the community, epidemiologists and academics. The group also included observers from Scottish Government and Scottish Medicines Consortium. The Chair of the Working Group invited Dr Ingrid Young to become a member in recognition of her publications on PrEP and unique insights into social aspects of HIV and developing HIV literacy [5.D].

Key deliverables in the Working Group's recommendation, issued in 2016, drew on the UofG GMSH survey and mixed method studies [3.5] and HIV and the Biomedical Study, with the Chair noting that, "*The GMSH survey was absolutely essential to a lot of our work*" [5.D]. Deliverable 1 was a needs assessment, to estimate how many individuals in Scotland might require PrEP—necessary for budgetary and service planning purposes. This determined which and how many individuals might be eligible for PrEP in Scotland, i.e. those at highest risk of HIV acquisition. The group triangulated known epidemiological data with other behavioural factors that were relevant to the populations in Scotland, the latter drawn from GMSH and SMMASH studies. This identified high-risk individuals as MSM who are HIV-negative with recent rectal sexually transmitted infection and/or condomless anal intercourse (CAI) with two or more partners in the previous 12 months. Quantifying the number of such individuals required the latest GMSH data on STIs and particularly CAI. The Chair stated, "*Without the data on CAI, drawn from the latest round of the GMSH survey, to inform deliverable 1, we would have struggled, and would have had to make a much less informed guess*" [5.D]. Calculations based on the GMSH survey estimated that between 1,500 and 1,900 MSM would require PrEP in Scotland and, with GMSH and SMMASH data suggesting that around half of MSM would accept PrEP, 1,000 MSM were expected to comply [5.C].

Dr Young also influenced the eligibility criteria for PrEP—a key component for accessibility to PrEP. Drawing from work on the HIV and the Biomedical study, which included migrant African men and women in Scotland as high-risk groups, Young asked the SLWG to consider and

articulate PrEP as an intervention for *anyone* at the highest risk of HIV acquisition. This extends users beyond MSM to individuals including (but not restricted to) women, and black and ethnic minority populations [5.C, 5.D]. The Chair said, “*Eligibility criterion 4, to include ‘Individuals, irrespective of gender, at an equivalent highest risk of HIV acquisition, as agreed with another specialist clinician, would not have been included were it not for Dr Young’*” [5.D]. The criterion is now recorded as ‘PREPe4’ in the national sexual health IT system.

The report was presented to the SHBBV Framework Executive Leads 14th October 2016 at the Scottish Government headquarters. The Co-Chair said, “*The recommendations of the SLWG were submitted to the Executive Leads Group for consideration; these were well received and then forwarded to the Scottish Government, including the Minister of Public Health, for consideration. The Minister of Public Health approved the recommendation of the SLWG; accordingly, HIV PrEP implementation commenced in July 2017*” [5.C]. The data on the eligibility and numbers expected to take-up PrEP were used as evidence by the Scottish Medicines Consortium as part of their assessment of their cost effectiveness research [5.E, 5.F]. In April 2017 the Scottish Government agreed to make PrEP available to those considered to be at high risk of contracting HIV, and in July 2017 Scotland became the first and only UK nation to publicly fund PrEP on the NHS.

Implementation of PrEP across Scotland

By December 2020, over three years following policy implementation, 4,100 people had one or more PrEP prescriptions in 11 of 14 Scottish NHS Boards—around 25% of the MSM population attending Scottish sexual health services in this period [5.H]. This reflects the considerable acceptance within a population that has traditionally been difficult to engage. The NHS PrEP implementation 2nd year report revealed that 43 recipients were PREPe4 coded (high-risk non-MSM)—a group that would not have been eligible without Dr Young’s input. The report also highlighted that over a quarter of all PrEP recipients were attending a sexual health clinic for the first time, driven by the availability of PrEP [5.G]. In the first year of PrEP there was also a 32% increase in testing among MSM, mostly those who had been prescribed PrEP (from 2,000 tests to over 4,700), compared with a 10% increase in testing among MSM never prescribed PrEP [5.G]. A retrospective cohort study analysed national surveillance data held at Public Health Scotland (PHS) for the 2 years before and after PrEP implementation [5.H]. This found that within the first two years of PrEP implementation:

- there was a 17% increase in the number of MSM attending sexual health clinics (from 14,319 to 16,723);
- the risk of HIV infection reduced by 75% in MSM prescribed PrEP compared with 32% in those not prescribed PrEP; however, among MSM with high-risk behaviour prescribed PrEP the risk reduced by 83%; and,
- the HIV incidence over time among MSM with high-risk behaviour attending sexual health clinics reduced five-fold, from 10.87 per 1000 person years to 2 in the PrEP period [5.H].

HIV literacy: supporting roll-out of PrEP in Scotland

The 2016 UK National Guideline on the Sexual Health Care of Men Who Have Sex with Men [5.I] has embraced UofG research [3.1] on awareness and willingness to use PrEP to support strong recommendations that at-risk MSM should be ‘*made aware of the availability of PrEP*’ at all services providing sexual health care. In line with these recommendations, NHS Scotland used materials developed by Dr Young from the Developing HIV Literacy project [3.6] to raise awareness of PrEP during the early stages of roll-out of the Scottish PrEP programme. The materials, [Know About PrEP: Prevent HIV](#), were developed in 2016 in collaboration with HIV Scotland NHS clinicians in anticipation of future PrEP availability. It comprised a 12-page community tool booklet to answer common questions about PrEP and was intended to support and encourage PrEP conversations [5.J]. In July 2017, HIV Scotland distributed the booklet to all Scottish NHS Boards [5.D, 3.6]. The tool was well received among clinical and community practitioners. A qualitative study of 30 practitioners within the gay and HIV communities, conducted between March–October 2017, reported on the helpfulness of the tool in engaging with potential PrEP users; structuring PrEP conversations undertaken during community

outreach and health promotion; and for community members to discuss PrEP with their sexual partners, peers and family [5.K].

The community tool was also featured on a website, [PrEP.scot](#) together with links to additional services. [PrEP.scot](#) received over 14,000 unique visits between July 2017 and May 2020, with referrals into the site tracked from the websites of key community stakeholders including The Terrence Higgins Trust (the UK's leading HIV and AIDS charity), both directly (3,140 referrals) and via their PrEP advocacy campaign 'iwantprepnw.co.uk' (5,118 referrals); search engines; and individual NHS Scottish boards sexual health services [5.J].

The Chair of the Short Life Working Group confirmed that the rapid uptake of PrEP in Scotland, which was twice as high as anticipated in the first year, suggests that the community tool has contributed to improved uptake [5.D]. The PrEP literacy community tool has since been used, modified and adapted by a range of UK community organisations, including by PrEPster (English PrEP advocacy group), Waverley Care (Scottish HIV charity) and the Sophia Forum (women with HIV forum).

Scotland is one of the few countries worldwide to publicly fund PrEP, making it a model internationally of how to implement PrEP into HIV prevention programmes.

5. Sources to corroborate the impact (PDFs uploaded for all listed items)

- A. [Sexual Health and Blood Borne Virus Framework 2015-2020 Update](#) Edinburgh: Scottish Government, 2015. [*The framework informs practice across the Scottish NHS Boards. p.11 points to old SPHSU landing site ([archive www](#)), and on topic of attitudes to PrEP it cites Young I et al. (2014) [BMJ Open](#) [3.3] (ref.41, p.25/26)*]
- B. Testimony from the Co-Chair of SHBBV Framework Executive Leads and Chair of Scotland's HIV PrEP National Coordinating Group.
- C. [PrEP in Scotland](#) Nandwani R & Valiotis G, on behalf of the Scottish HIV Pre-Exposure Prophylaxis Short Life Working Group. Scottish Health Protection Network, October 2016 [the GMSH survey was directly cited, p.4–5 of SLWG report as a key source]
- D. Testimony from Sexual Health and HIV Consultant (NHS Greater Glasgow & Clyde) and Chair of the HIV PrEP Short Life Working Group.
- E. [HIV Scotland papers in the SG Health & Sport Committee Agenda, 2018](#) (p.16, 3rd from last para states, 'The report was subsequently used by the SMC as part of their wider cost effectiveness research')
- F. [SMC approval of emtricitabine/tenofovir disoproxil \(Truvada\)](#), March 2017. (Short Life Working Group report cited on p.13)
- G. PrEP implementation reports, NHS National Services: (1) [First year report](#), February 2019 (see full report: prescription data, p.2; testing data, p.28; report also highlights 'Know about PrEP' pamphlet and website, p.13); (2) [Second year report](#), Dec 2019 (prescription data, p.4; eligibility codes, p.10).
- H. HIV PrEP implementation outcomes study: (1) Estcourt *et al.* (2020) Population-level effectiveness of a national HIV preexposure prophylaxis programme in men who have sex with men. AIDS (ePub ahead of print), doi: [10.1097/QAD.0000000000002790](#); (2) [news article on the study](#), NAM (HIV & AIDS charity); (3) July 2017–December 2020 prescription data provided by Estcourt.
- I. UK British Association of Sexual Health and HIV [2016 National Guidelines for Sexual Health Care in Men who have Sex with Men](#) (awareness, cites 3.1 and 3.3, p.23)
- J. [Know about PrEP: Prevent HIV booklet](#) (July 2017). The University of Glasgow is included as an official institution on all Developing HIV Literacy work.
- K. Survey of clinical and community practitioners (March–October 2017): Young & Valiotis (2020) Strategies to support HIV literacy in the roll-out of pre-exposure prophylaxis in Scotland: findings from qualitative research with clinical and community practitioners. *BMJ Open*, 10:e033849 (doi: [10.1136/bmjopen-2019-033849](#))
- L. [PrEP.scot](#) webstats