

## Impact case study (REF3)

<b>Institution:</b> University of Glasgow (UofG)		
<b>Unit of Assessment:</b> UoA 20 Social Work and Social Policy		
<b>Title of case study:</b> HIV policy formulation and prevention: driving the decision for and implementation of publicly-funded pre-exposure prophylaxis in Scotland		
<b>Period when the underpinning research was undertaken:</b> 2011–2016		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b> (1) Lisa McDaid (2) Ingrid Young	<b>Role(s) (e.g. job title):</b> (1) Professor of Social Sciences and Health (2) Research Associate; Research Fellow	<b>Period(s) employed by submitting HEI:</b> (1) 2010–present (2) 2011–2014; 2014–2016 (moved to the University of Edinburgh in October 2016)
<b>Period when the claimed impact occurred:</b> 2014–2020		
<b>Is this case study continued from a case study submitted in 2014?</b> No		
<p><b>1. Summary of the impact</b></p> <p>Men who have sex with men (MSM) are at the highest risk of contracting HIV in the UK. While changes in testing policy have reduced levels of HIV, HIV ‘literacy’ remains an issue, and around one-quarter of HIV-infected MSM remain undiagnosed. UofG research has: (i) shaped prevention policy by supplying key data needed by Scottish Government 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 and a half years, 4,100 people received PrEP, reducing HIV incidence fivefold in MSM with high-risk behaviour. An HIV literacy tool produced from UofG research to support the roll-out of PrEP: (ii) contributed to uptake being approximately twice as high as anticipated in the first year.</p>		
<p><b>2. Underpinning research</b></p> <p>The Gay Men’s Sexual Health (GMSH) survey, led by McDaid at the Medical Research Council/Chief Scientist Office Social &amp; Public Health Sciences Unit (MRC/CSO SPHSU), has been conducted in gay commercial venues every three years between 1996–2014. It has provided robust evidence on the sexual behaviours, prevention and testing activities of gay, bisexual and other men who have sex with men (GBMSM) 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 our understanding of how the effective delivery of targeted HIV prevention interventions might impact on populations at risk. This research has been at the forefront of better understanding community responses to inform future interventions.</p> <p>The 5<sup>th</sup> wave of the GMSH survey, carried out in 2011 with 1,515 GBMSM, provided updated Scottish data on high-risk behaviour and also addressed questions on awareness of and willingness to use pre-exposure prophylaxis (PrEP) with antiretroviral drugs—which reduces HIV infection in HIV-negative men by 99% if used daily [3.1]. Around one third had heard of PrEP and just over a half of participants would be willing to take PrEP on a daily basis. However, UofG-led research has also shown that a significant percentage of GBMSM did not meet current national guidelines on frequency of HIV testing and frequent HIV-testing would be needed to optimise access to PrEP [3.2]. There are also concerns that, despite offering a significant advance, new HIV prevention technologies such as PrEP and self-testing could amplify existing health inequalities among GBMSM [3.2–3.5].</p> <p>The ‘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 further work, the first mixed methods study to consider awareness and acceptability of PrEP across the UK [3.5], UofG-led research demonstrated that although there was willingness to use</p>		

PrEP factors such as perceptions of risk, patterns of sexual practice and social relationships could all affect motivation to use PrEP and how it would be used within relationships and sexual encounters. The research also found that awareness of PrEP across MSM communities varied according to traditional markers of inequality (e.g. by geography, education, 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 interventions.

The 'Developing HIV Literacy' project (2014–2017) also built on the HIV and the Biomedical study, particularly around how stigma and homophobia shapes the consumption of HIV-related knowledge. This study sought to develop a 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', identify existing local practices in this area, and identify potential opportunities for intervention [3.6].

### 3. References to the research

**3.1.** 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](#))

**3.2.** 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](#))

**3.3.** 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](#))

**3.4.** 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](#))

**3.5.** 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](#))

**3.6.** Young, I. (2019) [Making the Case for HIV Literacy: A Developing HIV Literacy Project Report](#).

**Evidence of research quality:** Outputs [3.1–3.5] are published in high-ranking, peer-reviewed journals. The research is funded via awards from the UK Medical Research Council and the Chief Scientist Office.

### 4. Details of the impact

#### 4.1. Background

There are currently 101,600 people living with HIV in the UK, with 5,484 in Scotland. Despite major advances in treatment and the 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 has the potential to significantly reduce HIV transmissions. UofG research has provided key data on the social and behavioural aspects of PrEP and HIV to facilitate key policy decisions leading to the introduction of PrEP in Scotland (as outlined in section 4.3 below). It has also underpinned the development of a PrEP literacy tool, which has enhanced the communications campaign to support policy implementation (as outlined in section 4.5 below).

#### 4.2. Pathway to impact

UofG research in the Scottish GBMSM community is highly regarded and well known within NHS Scotland gay men's services and key Scottish Government bodies. The work is prominent within

key Scottish Government policy groups, such as the Sexual Health and Blood Borne Virus Framework (SHBBV) (2015–2020), which informs practice across Scottish NHS Boards (confirmed by report [5A]). The Co-Chair of the SHBBV and Chair of Scotland's HIV PrEP National Coordinating Group confirms that, *'over the last 10–15 years, with the discontinuation of unlinked anonymous HIV testing of sexual health clinic attendees, the survey has been Scotland's principal source of HIV and associated behavioural prevalence among higher risk MSM. 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'* (confirmed by statement [5B]).

#### 4.3. Providing data to underpin the policy decision to fund PrEP in Scotland

In 2016, the SHBBV Framework Executive Leads convened a 13-person working group, the Scottish HIV PrEP Short Life Working Group, which published a report—'PrEP in Scotland'—that recommended that, *'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'* [5C]. The group comprised clinicians, third sector, advisors from the community and academics, and also included observers from the Scottish Government and Scottish Medicines Consortium. The Chair of the Short Life Working Group invited Dr Ingrid Young to be a member in recognition of her publications on PrEP and unique insights into the social aspects of HIV and developing HIV literacy (confirmed by statement [5D]).

Key deliverables in the PrEP Short Life Working Group's recommendation drew on the UofG's GMSH and mixed method study [3.5], with the Chair noting that, *'The GMSH survey was absolutely essential to a lot of our work'* [5D]. 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 the UofG 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. The Chair of the Short Life Working Group stated that, *'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'* [5D]. Calculations, based on the GMSH survey estimated that between 1,500 and 1,900 MSM would require PrEP in Scotland, with data suggesting that around half of MSM would accept PrEP, 1,000 MSM were expected [5C].

Dr Young also influenced the eligibility criteria for PrEP—a key component for accessibility. Drawing from work on the HIV and the Biomedical study [3.4], which included migrant African men and women in Scotland as high-risk groups, Young asked the Short Life Working Group to consider and articulate PrEP as an intervention for *anyone* at the highest risk of HIV acquisition. This extends to users beyond MSM to individuals including (but not restricted to) women, and black and ethnic minority populations. The Chair of the Short Life Working Group 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'* [5D].

The 'PrEP in Scotland' report was presented to the Scottish Health Protection Network on 14 October 2016. The Co-Chair of the SHBBV and Chair of Scotland's HIV PrEP National Coordinating Group confirms that the recommendations *'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'* [5B]. The report was endorsed by the SHBBV Framework Executive Leads, and data on the eligibility and numbers expected to take-up PrEP was used as evidence by the Scottish Medicines Consortium as part of their assessment of their cost effectiveness research (confirmed by reports [5E][5F]). 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 UK nation to publicly fund PrEP on the NHS. The Co-Chair of the SHBBV and Chair of Scotland's HIV PrEP National Coordinating Group confirmed 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'* [5B].

#### 4.4. The roll-out of PrEP in Scotland

In the first three and a half years of policy implementation (between July 2017 and December 2020) 4,100 people had one or more PrEP prescriptions in 11 of 14 Scottish NHS Boards (confirmed by collated evidence [5G]) with around 100 new individuals starting on PrEP each month since January 2019. Of the recipients, at least 3,317 were MSM, 43 were high-risk non-MSM and 14 individuals registered their ethnicity as African (an at-risk population highlighted by Dr Young) (figures confirmed by the second year report [5H]). Based upon year one figures, HIV testing rates have also benefitted. Among MSM, there was a 32% increase in HIV testing in the year following PrEP compared with the year prior to PrEP, mostly among MSM who were prescribed PrEP; by comparison there was only a 10% increase among those never prescribed PrEP (confirmed by the first year report [5H]). A retrospective cohort study analysed data held at Public Health Scotland for two years before and after PrEP implementation. It found that within the PrEP period, HIV incidence among MSM with high-risk behaviour attending sexual health clinics reduced from 10.87 per 1,000 person-years to 2, which represents a fivefold reduction (confirmed by collated evidence [5G]).

#### 4.5. HIV literacy: supporting the roll-out of PrEP in Scotland

The 2016 UK National Guideline on the Sexual Health Care of Men Who Have Sex with Men [5I] cites UofG research [3.1] to support 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, materials developed by Dr Young from the Developing HIV Literacy project were used by NHS Scotland to raise awareness of PrEP during the early stages of roll-out. A 12-page literacy tool, [Know About PrEP: Prevent HIV](#), developed in collaboration with HIV Scotland, was ready when PrEP became available [5J]. In July 2017, HIV Scotland distributed these to all Scottish NHS Boards (confirmed by statement [5D]). This activity was accompanied by the launch of a website, [PrEP.scot](#), which featured the literacy tool together with links to additional services. Since July 2017, the website has received over 13,900 unique visitors, with referrers including leading international HIV charities, such as Terrence Higgins Trust, and specialist NHS sexual health services, such as Sandyford (confirmed by collated evidence [5K]).

Community and clinical practitioners working with at-risk groups have described how the literacy tool is especially helpful to use with people who have little or no PrEP knowledge. The simplicity of the tool and the succinct information presented is often contrasted with other available PrEP material. Practitioner B said, *'I've had one woman who we diagnosed as HIV-positive and she was worried about her relationship and wanted to be sexually active [...] so I gave her that information and the leaflet 'cause she genuinely knew nothing about PrEP, so in that sense the leaflet was useful for her and her partner'*. Practitioners also reported using the booklet as a means to enable discussions about PrEP and related HIV prevention issues. Reflecting upon the use of the literacy tool at health fairs, Practitioner C said, *'I've been met with what seems to be some interest, but then you move onto the effects of the drug itself, how the drug works [...] and at that point it seems to resonate with them'* (confirmed by follow-up study [5L]).

The Chair of the Short Life Working Group confirms that the rapid uptake of PrEP in Scotland, which was approximately twice as high as anticipated in the first year, suggests that the literacy tool has contributed to improved uptake (confirmed by statement [5D]). There are also encouraging signs that the wider PrEP communications campaign, and associated HIV literacy levels, are beginning to have an impact. For instance, since PrEP was introduced in July 2017, there has been an increase in attendances at sexual health services, with some individuals attending for the first time to access PrEP. Uptake data indicates that one quarter of all PrEP recipients had no attendance recorded at any time prior to initiation of the programme (confirmed by the June 2020 PrEP update [5H]).

## 5. Sources to corroborate the impact

**[5A]** [Sexual Health and Blood Borne Virus Framework 2015-2020 Update](#) Edinburgh: Scottish Government, 2015. (Government policy agenda providing an update on progress made since the original Framework document was published in 2011. The framework informs practice across the Scottish NHS Boards and refers to the work of the MRC/CSO SPHSU throughout; on the topic of attitudes to PrEP it cites Young I et al. (2014) [BMJ Open](#) [3.3] (ref.41, p.25/26)) **[PDF available].**

**[5B]** Testimony from the Co-Chair of SHBBV Framework and Chair of Scotland's HIV PrEP National Coordinating Group (12 October 2020) **[PDF available].**

**[5C]** 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) **[PDF available].**

**[5D]** Testimony from the Chair of the Scottish HIV PrEP Short Life Working Group **[PDF available].**

**[5E]** [HIV Scotland papers in the SG Health & Sport Committee Agenda, 2018](#) (p.16 states, 'The report was subsequently used by the SMC as part of their wider cost effectiveness research') **[PDF available].**

**[5F]** [SMC approval of emtricitabine/tenofovir disoproxil \(Truvada\)](#) (March 2017) (Short Life Working Group report cited p.13) **[PDF available].**

**[5G]** Collated evidence: (i) Estcourt et al. (2020) Population-level effectiveness of a national HIV preexposure prophylaxis programme in men who have sex with men. *AIDS* (Published ahead of print), doi: [10.1097/QAD.0000000000002790](https://doi.org/10.1097/QAD.0000000000002790); (ii) News article on the study, NAM (HIV & AIDS charity) (21 January 2021); (iii) Prescription data provided by Professor Estcourt (confirms that 4,100 people received PrEP between July 2017–December 2020) **[PDF available].**

**[5H]** (i) [Implementation of PrEP in Scotland: first year report](#). NHS National Services Scotland (26 February 2019) (also highlights 'Know about PrEP' pamphlet and website, p.13); (ii) [Implementation of PrEP in Scotland: second year report](#); (iii) [Implementation of PrEP update](#) (23 June 2020) **[PDFs available].**

**[5I]** 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) **[PDF available].**

**[5J]** [Know about PrEP: Prevent HIV booklet](#) (July 2017) (Although Dr Young had moved to the University of Edinburgh at this stage, the University of Glasgow is included as an official institution on all Developing HIV Literacy work due to the role of the underpinning research) **[PDF available].**

**[5K]** (i) [PrEP.scot](#) webstats; (ii) Website referrers **[PDFs available].**

**[5L]** Young, I. and Valiotis, G. (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* (doi: [10.1136/bmjopen-2019-033849](https://doi.org/10.1136/bmjopen-2019-033849)) **[PDF available].**