

Institution: University of Edinburgh		
Unit of Assessment: UOA20 Social Policy and Social Work		
Title of case study: Securing equitable policy and practice for HIV pre-exposure prophylaxis (PrEP) in the UK		
Period when the underpinning research was undertaken: 2016- 2020		
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:
Ingrid Young	Chief Scientist Office Chancellor's Fellow	Oct 2016-present
Nicola Boydell	Research Fellow	April 2017-present
Period when the claimed impact occurred: 2016-2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>HIV pre-exposure prophylaxis (PrEP) is a newly repurposed pharmaceutical that prevents HIV. Its potential to improve health depends on availability but also on 'HIV literacy' among all populations affected by HIV. Young's research enhanced understanding of experiential inequalities in accessing HIV services, especially for women and Black African populations in the UK. She worked with non-academic partners to campaign for equitable access to PrEP across the UK and advise the Scottish and UK policymakers on PrEP implementation, leading to expanded, more inclusive clinical criteria. She also co-developed and evaluated evidence-based PrEP literacy tools through action research. These have been adopted by NHS Scotland and are widely used by community organisations across the UK in developing 'HIV literacy'.</p>		
2. Underpinning research		
<p>PrEP is a newly repurposed pharmaceutical that, taken daily or intermittently, prevents HIV. Activists and politicians claim that it will 'end AIDS', but it will have limited and potentially inequitable consequences unless it is widely available <i>and</i> well understood by diverse populations. Young's collaborative qualitative and action research has built evidence for a critical approach to HIV literacy implementation (3.1, 3.2), and for the need to tackle intersectional disadvantage in access to and use of PrEP.</p> <p>Young's research demonstrated that debates around PrEP, and controversies about its availability on the NHS, have focused almost exclusively on gay and bisexual men (3.1, 3.3), and that sexual health research more generally often fails to recognise the distinct needs and preferences of disparate social groups (3.4, 3.5, 3.6). Exploring the experiences and needs of diverse groups via research projects with, particularly, women of colour, has demonstrated inequalities of access in relation to gender, sex, race and geography across the UK (3.1, 3.4, 3.5), and identified the social complexities of PrEP knowledge across diverse communities (3.1, 3.4, 3.5).</p> <p>Young showed that equitable access to PrEP requires sensitive and appropriate support for 'HIV literacy', identifying the need for health promotion to go beyond simply disseminating accurate information (3.1, 3.2). In collaboration with third sector organisations, she co-designed and evaluated critical HIV literacy-informed information materials to support wider understanding of PrEP, attending to diverse community and practitioner requirements (3.1, 3.5, 3.6).</p>		

Young's research particularly explored the extent to which particular populations at increased risk of HIV, notably Black African/Black Caribbean women in the UK, were neglected in mainstream policy and health promotion practice (3.4, 3.5). This research identified the need to expand existing clinical eligibility criteria, which are oriented towards cis-gendered gay men, and exploring delivery of PrEP outside traditional sexual health services to account for the social practices and gendered and raced inequalities present in current NHS services (3.4, 3.5).

Ingrid Young, (University of Edinburgh (October 2016 – present); University of Glasgow Nov 2011 – Sept 2016) has led this programme of research on PrEP and inequalities as Principal Investigator of a CSO Fellowship (GBP173,000, 2014 - 2017), a Wellcome Trust Seed Award (GBP94,000; 2018 - 2019); as co-investigator on CSO Evaluation of PrEP health services with PI Claudia Estcourt, Glasgow Caledonian University/NHS Greater Glasgow and Clyde (GBP300,000, 2018 - 2020) and through collaborative community research with Sarah Nakasone (Chicago), Maryam Shamanysh (UCL) and Claudia Estcourt (GCU) (2018).

3. References to the research

3.1 Young, I & 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* 10:4. <http://dx.doi.org/10.1136/bmjopen-2019-033849>

3.2 McDaid, L, Flowers, P, Ferlatte, O, Young, I, Patterson, S, Gilbert, M (2020) Sexual Health literacy among gay, bisexual and other men who have sex with men: a conceptual framework for future research. *Culture, Health and Sexuality*. <https://doi.org/10.1080/13691058.2019.1700307>

3.3 Young, I, Boydell, N, Patterson, *et al* (2020) Configuring the PrEP user: Framing Pre-exposure Prophylaxis in UK newsprint 2012 – 2016. *Culture, Health and Sexuality*. <https://doi.org/10.1080/13691058.2020.1729420>

3.4 Nakasone, S, Young, I, Estcourt, C *et al* (2020) Risk perception, safer sex practices and PrEP enthusiasm: Barriers and facilitators to oral HIV pre-exposure prophylaxis in Black African and Black Caribbean women in the UK. *SMJ Sexually Transmitted Infections* 96:349-354. <https://sti.bmj.com/content/96/5/349>

3.5 Young, I & Calliste, J (2019) PrEP & Women in Scotland Roundtable: A Community Report, Edinburgh. https://www.research.ed.ac.uk/portal/files/99026554/PrEP_Women_in_Scotland_report_FINAL_2019.pdf.

3.6 Kneale, D, French, R, Spandler, H, Young, I *et al* (2019) Conducting sexualities research: an outline of emergent issues and case studies from ten Wellcome-funded projects. *Wellcome Open*. <https://wellcomeopenresearch.org/articles/4-137>

4. Details of the impact

Around 100,000 people in the UK live with HIV, which is associated with high costs of care and high mortality if untreated and remains a significant public health issue. PrEP offers an important new and highly effective prevention option. Young's research enabled and shaped the implementation of PrEP in the UK, with wide health benefits, particularly among specific groups experiencing entrenched health inequalities.

Enabling and improving the roll-out of PrEP in Scotland

Scotland was the first country in the UK, and one of the first internationally, to provide PrEP through national health services in 2017. Young's research helped to secure this availability. In the first two years of provision, 3,354 individuals were prescribed PrEP across Scotland: 27% of all of these had no previous sexual health service attendance, indicating that PrEP is reaching new sections of the Scottish population (5.1, p.4). Young was invited to join the PrEP Short Life Working Group, as part of the Scottish Government's Sexual Health and Blood Borne Virus (SHBBV) Framework (Mar-Oct 2016). This group made specific recommendations for NHS services, co-authored by Young and citing her research (5.2, p.13) which were approved by Scottish Government in October 2016. Young's interactions with community stakeholders

contributed to the “*collaborative approach*” across sectors credited by the chair of Scotland’s HIV Clinical Leads as having “*led directly*” to securing early approval of PrEP (5.3). Young sat on expert panels alongside clinical and community practitioners in five national community engagement events (Aberdeen, Glasgow, Dundee, Edinburgh, online via Twitter) in November-December 2016 to answer questions around PrEP provision and policy with communities affected by HIV (5.4). The campaign to secure PrEP access in Scotland was awarded the 2018 Cracking Campaign prize at the Scottish Charity Awards (5.4).

Co-designing ‘Know about PrEP’: an evidence-based approach to HIV literacy for PrEP

Young collaborated with HIV Scotland as part of Chief Scientist Office-funded action research to co-design ‘Know about PrEP’, a suite of printed & digital PrEP information materials, which promote HIV literacy in an inclusive and accessible way. The project evaluation identified that materials were “*a useful resource to introduce PrEP to people with low or limited HIV literacy*” (5.5).

The Scottish Health Protection Network selected these materials as the key Scotland-wide information resource for the PrEP roll-out across all Health Boards (5.6) and through third sector organisations. Young created an accompanying website, which was endorsed by the Scottish National PrEP Coordination Group as the primary site for PrEP material for the roll-out in July 2017 (5.7, p.13) and which remains the key information source in Scotland, with 2-5,000 visitors per year. Waverley Care (Scotland’s HIV and Hepatitis Charity) SX Project Manager states: “*If we didn’t have this kind of information that developed in this way by Ingrid... organisations would be going off in their own direction... It’s made the key messages about PrEP be consistent across the board and that’s been a really important outcome*” (5.8).

Young’s PrEP materials have been used and adapted across the UK, including within relationship and sexual education for schools (5.9 slide 16), by community organisations at Pride events (5.8), and for innovative online use by Waverley Care. Waverley Care’s SX Project Manager states: “*We’ll use [socio-sexual] apps like Grindr and a guy will message us and tell us that he’s interested in PrEP or might have had a sexual exposure that he’s wanting to talk about. And what’s really useful is that the [Know About PrEP] resource has been provided by Ingrid as JPEG files so...we can just upload the image to Grindr. So if somebody says ‘what’s PrEP’ you can upload the image and it tells you what PrEP is. ‘how do I take PrEP’? You can upload that image. So it’s really useful at getting that information across to people*” (5.8).

Young worked with PrEPster, a London-based PrEP and sexual health activist organisation, to adapt Know about PrEP materials for campaigning use across the UK and internationally (5.10). PrEPster used these materials to structure community education sessions and adapted and translated the material for regional organisations (funded by Public Health England Innovation Fund) who work primarily within Black, Asian and gender-diverse communities in England and Wales [5.10]. Glasgow’s Health Improvement Lead states: “*The impact of Ingrid’s resources is to accessibly raise awareness of PrEP and I think it’s successfully demystified what PrEP is and I think they contribute to a reduction in HIV stigma*” (5.6).

Advocating for implementation and support to be inclusive of underserved population groups

Although PrEP is effective for people of all genders and sexualities, the majority accessing PrEP are gay and bisexual men, and most PrEP services are oriented towards this community. Young’s research has called attention to gendered inequalities and stigma. On the PrEP Short Life Working Group, Young advocated for the addition of an eligibility criteria inclusive of diverse genders and sexualities: “*individuals, irrespective of gender, at an equivalent highest risk of HIV acquisition*” (5.2, Category 4, p.11). The Group’s Chair states that “*without [Young] we wouldn’t have the eligibility criteria... which was phrased as being ‘individuals irrespective of gender with the highest risk of HIV acquisition’*”, and confirms that Young’s work has “*really been very*

influential” in that this general category and emphasis on flexibility has subsequently been included in PrEP eligibility criteria in England and internationally (5.3).

Following the rollout of PrEP, Young worked with community organisation PrEPster to convene a roundtable with community and clinical partners on PrEP and women in Scotland (5.10). This event reported a clear set of recommendations for community and clinical practitioners (3.5) which contributed directly to PrEPster’s ongoing programme of campaigning in relation to PrEP and women (5.10).

Young’s research has continued to inform Health Protection Scotland’s PrEP rollout (5.6). With colleagues, Young developed specific health promotion materials for potential PrEP users who are trans*, Black African and/or people who use drugs (5.6, 5.10). Health Protection Scotland awarded the group funding (GBP20,000; 2020) to develop two short films to complement existing Scottish PrEP resources. Working in partnership with the African Health Project (Waverly Care), Hwupenyu Health and Wellbeing and Scottish Trans Alliance, these films will be launched on NHS Inform and other NHS Scotland websites in 2021 (5.6).

Young’s research with Black African communities led to an invitation to join the British HIV Association (BHIVA) Clinical PrEP Guidelines group (2016 – 2019), and she is a co-author of those guidelines (5.11). Young advocated to incorporate the clinical and social needs of Black African women and men, leading to the inclusion of non-clinical indicators for PrEP. This supports the assessment and provision of PrEP to groups not typically assessed for PrEP (such as some women, and migrant communities).

5. Sources to corroborate the impact

5.1 Health Protection Scotland (2020). *Implementation of HIV PrEP in Scotland: Second Year Report*. Glasgow: Health Protection Scotland.

5.2 Report of the Scottish HIV Pre-Exposure Prophylaxis Short Life Working Group (2016) PrEP in Scotland, Scottish Health Protection Network, Glasgow.

<https://web.archive.org/web/20201204170101/https://www.hiv.scot/news/prep-in-scotland-report>

5.3 Consultant NHS Greater Glasgow & Clyde, Non-Executive Director, Public Health Scotland: testimonial

5.4 Former CEO of HIV Scotland: testimonial

5.5 Ingrid Young (2019) Making the case for HIV literacy: A Developing HIV Literacy Report, University of Edinburgh.

5.6 Health Improvement Lead, NHS Greater Glasgow & Clyde: testimonial

5.7 Health Protection Scotland & Information Services Division (2019). *Implementation of HIV PrEP in Scotland: First Year Report*. Edinburgh: Health Protection Scotland, Information Services Division.

5.8 Waverley Care Sx Project Manager, Gay & Bisexual Men’s Sexual Health and Wellbeing project: testimonial

5.9 Relationships, Sexual Health & Parenthood Scotland (2019) The Local and Global Impact of HIV Slide Set. <https://rshp.scot/wp-content/uploads/2020/04/Part-2.-The-Local-and-Global-Impact-of-HIV-Slides-April-2020.pptx>

5.10 PrEPster Co-founder: testimonial

5.11 Brady, M et al (2019) BHIVA/BASHH guidelines on the use of HIV pre-exposure prophylaxis (PrEP) 2018 *HIV Medicine* S20: 52: s2-s80.

<https://onlinelibrary.wiley.com/doi/full/10.1111/hiv.12718>