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### **Making the Case for HIV Literacy: A Developing HIV Literacy Report**

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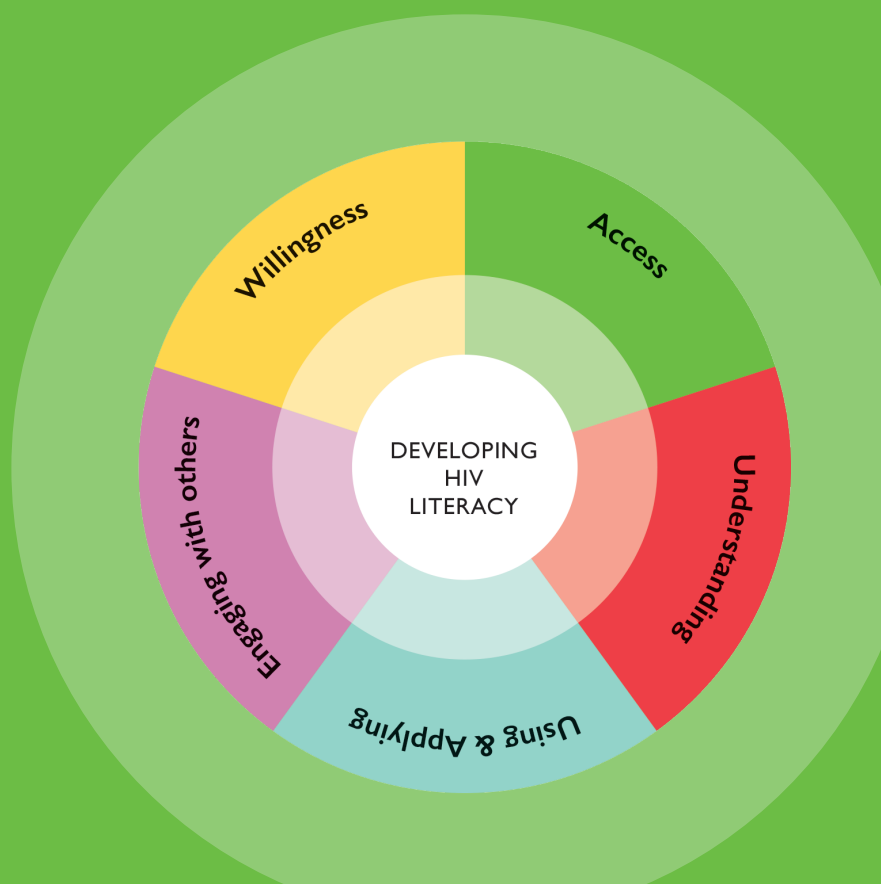
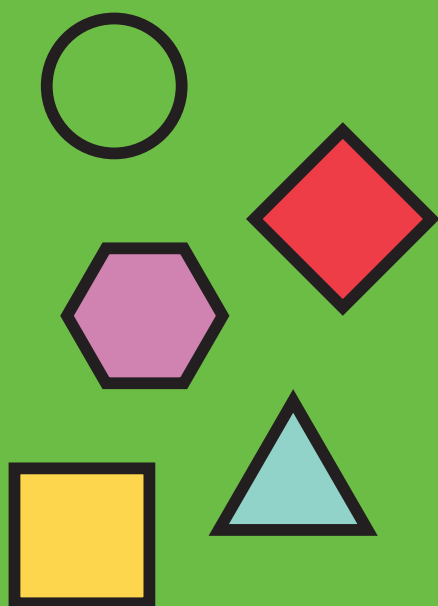
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# Making the Case for HIV Literacy:

## A Developing HIV Literacy Project Report

Ingrid Young



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## Why HIV Literacy

The landscape of HIV prevention - and sexual health more generally - has changed dramatically due to biotechnological developments such as pre-exposure prophylaxis (PrEP), treatment as prevention (U=U) and HIV self-testing.

Communities and health practitioners are now more reliant on complex processes and measurements such as: more frequent HIV and sexually transmitted infection (STI) testing; measuring and monitoring HIV viral loads; and increasing engagement with clinical services to access drugs and support for prevention and care. This raises questions around how to ensure that these biotechnological advances in HIV prevention and care are made available in a way that communities can not only access but also actively engage with, and make use of, to improve health and wellbeing.

Health literacy as a concept has been increasingly used to consider the importance of the information skills (reading and writing) and ability (acquiring, understanding and using health information) of patients - and citizens - to make health-related decisions within and outside the clinic (Nutbeam et al 2018). More than simply providing information to patients, health literacy scholars argue that:

**“critical health literacy is, like community development, a process in which citizens become aware of issues, participate in critical dialogue, and become involved in decision making for health”**  
(Sykes 2013:2)

Critical health literacy is a complex “social practice” (Samerski 2019: 2) that involves “people in networks working together and referencing common values and cultural practices to make sense of texts in order to achieve social goals.” (Chinn 2011: 65). This means that people need to actively engage with each other, health providers, partners, peers and wider society to learn about and use new health-related information effectively and sustainably. For HIV literacy, we need to consider wider *critical* health literacy skills within the context of HIV and sexual health that go beyond the individual and understand it as a complex social practice.

**HIV literacy is the ability and skills of individuals and communities that means they are equipped and willing to engage with HIV, have access to and understand HIV information, able to apply learned HIV information within their sexual practice and able to engage with others about this HIV knowledge, and related sexual practices.**

What this definition highlights is that HIV literacy is not only about individuals having the right knowledge and set of skills, but that it is also dependent on supportive partners, peers and communities, engaging health services, and a wider environment in which HIV prevention and care is not constrained by social and structural barriers.

**This means that repeating simple HIV messages is not enough to improve HIV literacy.**

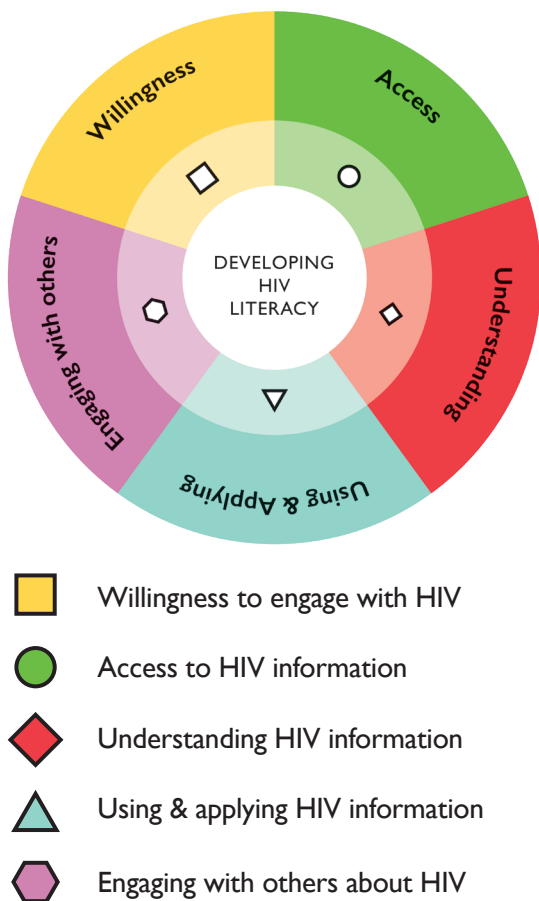
# The Developing HIV Literacy Framework

Developing HIV Literacy began as a 3-year project which aimed to understand and support HIV literacy for communities affected by HIV in the context of increasing biomedical HIV prevention.

The project worked collaboratively with clinical, third sector and community organisations and members through participatory workshops that drew on the professional and lived experience of participants. Together, we created the **Developing HIV Literacy Framework** to help clinical, third sector and community members more easily understand and engage with HIV literacy.

The framework has **5 domains**. These are different areas of HIV literacy which each play an important, and often overlapping, role in supporting and creating the environment for individuals and communities to realise good HIV literacy.

## Developing HIV Literacy Framework Domains



Importantly, the framework encourages practitioners to focus not only on the individual, but to also consider wider factors that play a role in, and shape, HIV literacy practices. To help with this, we identified **5 categories** of HIV literacy and suggest that *factors relating to and/or about* these categories need to be considered *within and across* each of the domains.

## Developing HIV Literacy Framework Categories:

- Individual
- Sexual Partners
- Communities
- Organisations
- Social/Structural

It is important to recognise how these categories may overlap and intersect with each other. While it may not be possible to directly influence or bring about change in all categories, it is important to understand how and where those categories *intersect and shape* elements that might be changed.

Examples of how categories interact with each other from Pre-exposure prophylaxis (PrEP)

- Community & third sector organisations (*community, organisations*) work together to influence and change policy (*social/structural*)
- Media representations of PrEP (*social/structural*) influence attitudes about and access to PrEP (*community, individual*)
- Third sector organisations (*organisations*) could help provide the tools to support people in talking about PrEP with their sexual partners (*individual, sexual partners*)

Developing HIV Literacy Framework Categories

Includes:

Consider:

**Individual**



motivation,  
self-confidence,  
functional literacy,  
mental health  
& wellbeing

**Sexual Partners**



*regular,  
casual or  
multiple partners*

power dynamics,  
norms of communication,  
trust in information shared  
within relationship,  
risk perception from or  
to sexual partner(s)

**Communities**



*peers,  
physical and/or  
virtual networks*

role of community identities,  
trust & advice from peers,  
information available through  
peer networks, shared moral  
codes & social norms,  
norms of discussions  
(digital, in person)

**Organisations**



*third sector,  
health, policy & education  
organisations, and other  
public & private entities*

integrity of service providers,  
trusted systems, presence  
of campaigns & outreach work,  
availability of materials,  
messages and interventions

**Social/Structural**



*legislation, regulation,  
policy, criminalization,  
media, stigma,  
racism, sexism*

political climate,  
media framing, public attitudes,  
diversity & location of services,  
cultural representations of  
sexual health, funding for  
services

## PrEP community tool in Scotland

Grounded in the Developing HIV Literacy Framework and in collaboration with the community organisation HIV Scotland, the project developed a PrEP literacy community tool to respond to PrEP policy developments in Scotland.

**KNOW ABOUT PrEP**  
(Pre Exposure Prophylaxis)  
**PREVENT HIV**

Introductory panel

PrEP is for HIV negative people who are at high risk of getting HIV.

Who is it for?

PrEP is available on the NHS in Scotland or it can be bought online.

Where can I get PrEP?

PrEP is a pill that can stop the person taking it from getting HIV.

What is PrEP?

Taking PrEP involves:

- taking pills (usually daily)
- regular HIV and STI tests

What is involved in taking PrEP?

Different tools work for different people at different times. Choose what works best for you.

How does PrEP work with other HIV prevention tools?

PrEP offers a new option to reduce HIV rates, which remain high.

Why do we need PrEP?

Once the drug reaches protective levels it stops HIV from staying in your body.

How does it work?

Is PrEP right for me? Find out more from [www.prep.scot](http://www.prep.scot)

Where can I find out more?

PrEP is extremely effective at preventing HIV when taken as directed, with few side effects.

Does it work?

PrEP only prevents HIV. Condoms prevent other STIs.

What about condoms?

Developed by:  
Developing HIV Literacy and HIV Scotland  
@HIVScotland  
@dev\_HIVliteracy

HIV Scotland  
preventing positive change

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University of Glasgow

Who made this leaflet?

This tool was also developed in the context of negative UK media coverage of PrEP in 2016, where HIV - and PrEP - stigma was hindering PrEP learning and discussions in public fora and community settings, and between sexual partners.

Aimed at the *Willingness & Understanding* domains and the *Individual, Sexual Partners* and *Community* categories of the framework, the tool primarily sought to support the introduction of PrEP to people who knew very little about it. It was designed

to be used not only by health and community practitioners, but also by community members to help *support PrEP conversations* with sexual partners and peers. The community tool was a multi-fold business-card sized leaflet with visual images and minimal text (max 15 words) that answered common questions about PrEP, helped structure conversations and could be shared discretely.

The community tool helped support the roll-out of PrEP in Scotland. It was used and distributed by community and clinical partners across Scotland from June - October 2017. To see how the tool was used and to learn more about HIV literacy in the context of PrEP provision and support, we conducted interviews with 30 clinical and community practitioners who work with gay and bisexual men and/or African heterosexual men and women across 9 NHS Board areas across Scotland.

We found that the community tool was well received by community partners and in many clinical settings. The tool was seen as a useful resource to introduce PrEP to people with low or limited HIV literacy and/or people who are unfamiliar with PrEP. It helped to structure conversations for community practitioners and also enabled the introduction of other key factors in relation to PrEP, including the need to understand treatment as prevention (U=U) and work with communities of people living with HIV.

We also found that PrEP discussions raised many issues for practitioners and community members that went far beyond PrEP itself.

Some of these included:

- discussing and assessing risk
- the cost of drugs and public health interventions
- the impact on, and equity of, access across sexual and reproductive health services
- interpreting clinical eligibility and the role of community involvement in clinical decisions
- imagining who PrEP users might be
- imagining PrEP as a wider intervention, beyond HIV prevention

These discussions reflect how HIV literacy is a complex social practice that is affected not only by the provision of information, but the wider social context that includes links to and impacts on other health experiences, rights and access to services, navigating professional and organisational boundaries and concerns about the organisation and sustainability of the health system.

The PrEP literacy community tool has since been used, modified and adapted by a range of UK community organisations, including by PrEPster, Waverley Care and the Sophia Forum.

## **HIV Literacy Implications for policy and practice**

- HIV literacy is a complex social practice that is grounded in ongoing dialogue and learning within and across communities and health practices.
- Supporting HIV literacy requires more than providing new information to individuals and repeating simple HIV messages.
- Practitioners, activists, educators and community members need to consider the role of wider social networks of people accessing HIV information, as well as the many domains and settings in which HIV related information will be used.
- Practitioners, activists, educators and community members involved in the provision of new HIV information should consider the multiple and creative ways in which this information will be accessed, taken up and shared and should be open to how communities can and will modify information to suit their needs.

The *Developing HIV Literacy Framework* enables a detailed mapping of HIV literacy problems and a means of identifying potential responses to these problems. It accounts for structural factors such as stigma, regulation and availability of services, as well as the role of social, cultural, psychological and material inequalities at each stage of identifying, taking up and using HIV information.

A tool based on the *Developing HIV Literacy Framework* is now available to help practitioners and community organisations identify and respond to HIV literacy issues within and across communities.

## Further References

For more information on health literacy, sexual health literacy and PrEP literacy, see:

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[@dev\\_HIVliteracy](https://www.instagram.com/dev_HIVliteracy)