

User participation in the development of HIV self-testing sevicees: Results of co-design workshops

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The rates of sexually transmitted infections (STIs) and HIV among men who have sex with men (MSM) are increasing and the uptake of STI and HIV testing in conventional clinical settings is suboptimal. An estimated 14% of MSM are thought to have undiagnosed HIV and 30% of new diagnoses in MSM are late diagnoses^{i,ii}.

A variety of innovative strategies are required to increase uptake of HIV testing. One such approach is self-testing.

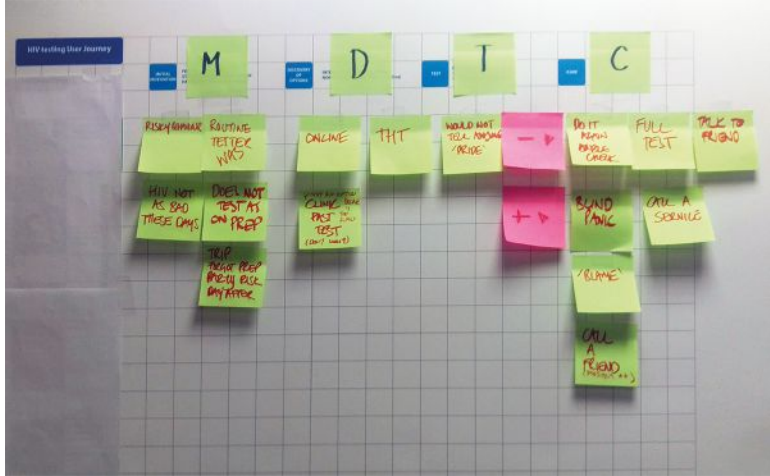
Methods:

We held co-design workshops with community volunteers, and designers attended a local LGBT community meeting. Participants were asked take part in facilitated discussions about proposals for the campaign as well as complete a questionnaire regarding their experiences and views on HIV self-testing.

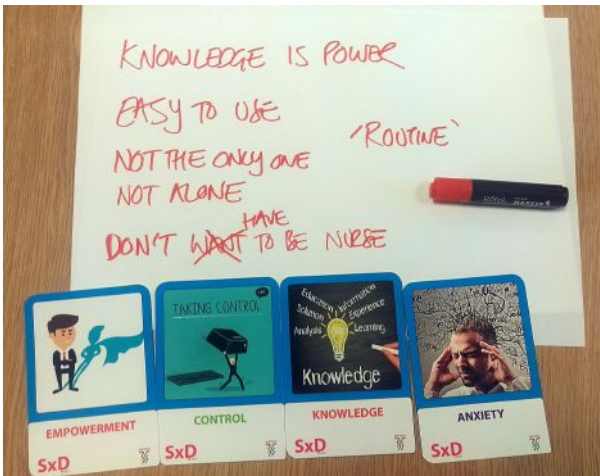
Co-design workshops utilised service design tools such as personas (the process of creating ‘characters’ to theoretically explore individual’s thoughts and behaviors), the construction of user journeys, and mock-ups for the design and likely interaction with the vending machine.



Workshop Participant developing a persona



‘User journey’ developed by workshop participants



Development of ideas based on concept cards

Results:

Key themes relating to visual campaign options were: sense of community and support; clinical versus community settings; and giving clear information.

There was excellent engagement in the process and many participants took multiple elements of different artwork to generate their own style, wording, or schema for the campaign.

Table 1 - Factors to encourage Self-testing:

AWARENESS	“knowing more about self-test would persuade me to try” QN6
AVAILABILITY	“like more available at local establishments, uni, pubs, clubs” QN1
CONFIDENCE	“how easy it may be” QN8 “Confidence in result, ease of use” WS3

Table 2 - Concerns about Self-testing:

FAITH	“little faith in reliable result” WS1 “faith in results” WS3 “to be sure it is done properly” QN4
FAMILIARITY	“did not know it existed” QN6
FEAR	“scared of blood” QN3 “may hurt myself taking sample” QN8 “fear of doing it wrong” WS3
SCREENING	“advice on sexual health, STI screening” QN8
SUPPORT	“if it was positive I'd want to talk to someone” WS3 “safe environment” QN8

The participant-generated personas led the discussion through a user journey from their discovery of options for HIV testing, to decision-making priorities, and routes to action for testing for HIV.

Workshop participants explored the benefits and disadvantages for self-testing in different populations and demographics. For example the following populations were identified as core targets for self-testing;

- regular attenders to GUM clinics with ongoing high risk and the need to test regularly.
- men who are not engaged at all with health services - the idea of being “better than nothing”.
- framing the campaign within the ‘gay scene’.

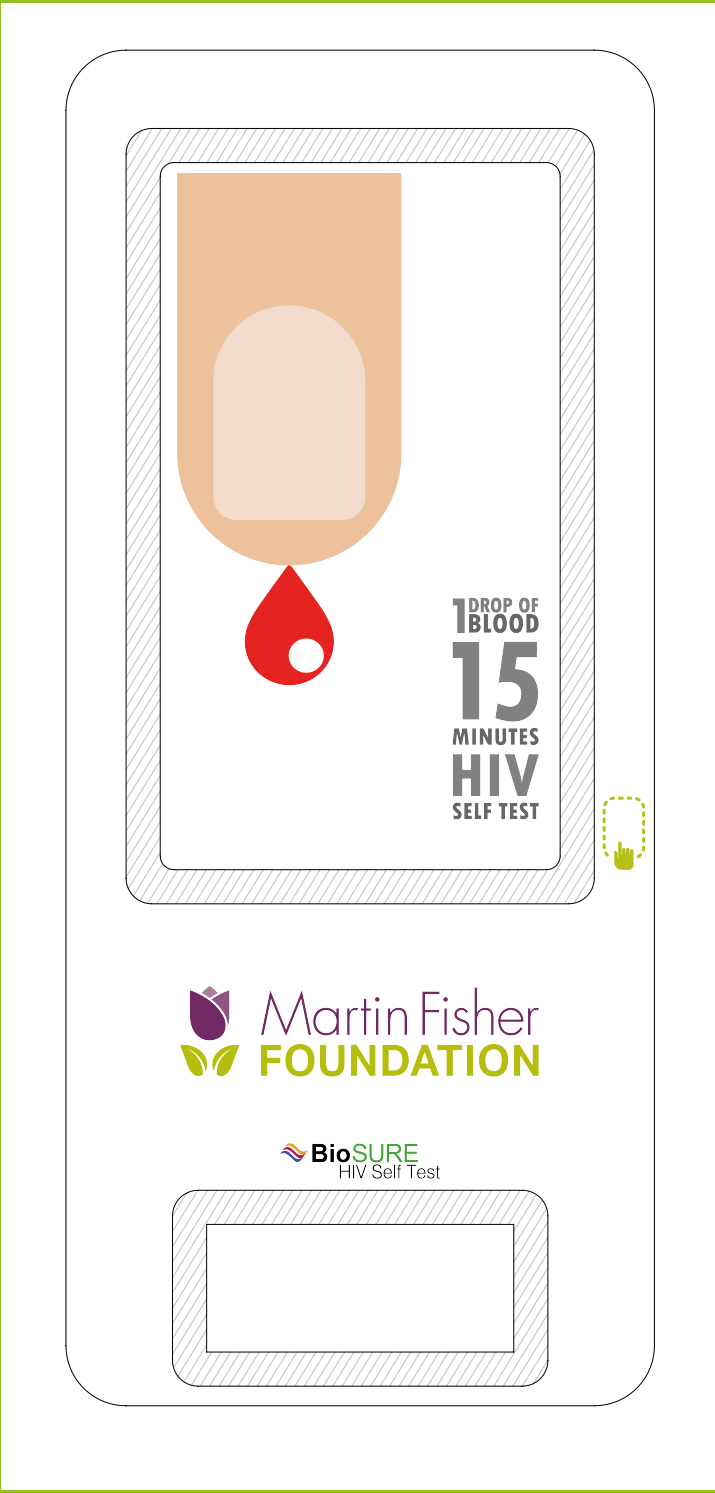
There were 11 respondents to the questionnaire. Eight were aged <25, two 25-34 and one 45-64 years. Eight respondents had previously tested for HIV, although only one of those was within the last 3 months. Two participants had self-tested in the past, one of whom had used both blood and saliva self-sampling tests.

Discussion:

To our knowledge vending machines have not been used to deliver HIV self-testing kits in the UK. There has been one previous study in the USⁱⁱⁱ, although the population studied and method of self-testing were not comparable. Our previous research in the sauna venue has demonstrated extremely high levels of acceptability for HIV self-testing as well as an unmet need^{iv}.

In order to deliver patient driven care we used co-design strategies to create and perfect our materials. This approach has been used successfully in medical and surgical specialties as well as emergency and drug and alcohol services^v.

We have developed a pilot service to promote HIV self-testing among MSM using saunas in Brighton. This includes the introduction of a vending machine distributing HIV self-test kits and a campaign to increase awareness of self-testing.



Vending machine concept image

Limitations:

We intended to work with service users and community volunteers, however we were not able to recruit any service users to participate in the workshops. The use of hypothetical scenarios and the absence of service users in the co-design process risks creating different perspectives and introducing bias.

Conclusion:

Few participants had previously self-tested.

Improved knowledge and availability were the most important factors for promoting self-testing.

Collaboration with designers and communities ensures a user-centered approach to HIV self-testing.

i) Public Health England. HIV diagnoses, late diagnoses and numbers accessing treatment and care. HIV official statistics overview: 2016. PHE publications gateway number: 2016349.
ii) Skingsley A, Yin Z, Kirwan P, Croxford S, Chau C, Conti S, Presanis A, Nardone A, Were J, Ogaz D, Furegato M, Hibbert M, Aghaizu A, Murphy G, Tosswill J, Hughes G, Anderson J, Gill ON, Delpech VC and contributors. HIV in the UK – Situation Report 2015: data to end 2014. November 2015. Public Health England, London.
iii) Young SD, Daniels J, Chiu CJ, Bolan RK, Flynn RP, Kwok J, et al. (2014) Acceptability of Using Electronic Vending Machines to Deliver Oral Rapid HIV Self-Testing Kits: A Qualitative Study. PLoS ONE 9(7): e103790. doi:10.1371/journal.pone.0103790
iv) Acceptability of HIV self-testing among men who have sex with men attending a sex on premises venue in Brighton: a cross sectional survey. Contact Dr Jaime Vera, BSMS for full details j.vera@bsms.ac.uk
v) Donetto, S., Tsianakas, V. & Robert, G. (2014). Using Experience-based Co-design to improve the quality of healthcare: mapping where we are now and establishing future directions. London: King’s College London.