JUST LILA

Free HIV home testing – delivery and support included

An Evaluation of the JUST LILA Pilot Action

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Summary

JUST LILA promotes and offers HIV self-testing at home. The pilot action consisted of a social media campaign, free test kits including home delivery, optional remote support and counselling, and data collection using pre-order and follow-up survey questionnaires.

With more than 2000 kits delivered, the pilot action from May 2022 to June 2023 exceeded its target of distributing 1500 self-testing kits. Among its general population target, it reached younger cohorts in particular, and a large cohort of people identifying as female (39%), while still maintaining a large M*SM* client base (ca.30%).

The pilot action succeeded in reaching people who never tested before (43%), as well as routine testers affected by COVID-19 restrictions. In addition, the service reached people reporting recent unprotected anal and vaginal intercourse, and condom failures.

Service users cited low (no) cost, convenience, and confidentiality as their reasons for choosing JUST LILA. With 4.9 out of a possible 5 points, the overall satisfaction rating was very high. The offer of support and counselling also rated highly, but uptake was low (16 episodes), as was the response to the follow-up survey (22% of tests ordered). This may reflect lower support needs in users who prefer self-testing or have previous HIV testing experience.

Low rates of follow-up mean that it was not possible to count reactive results and linkage to care episodes and so assess the project's contribution to detecting undiagnosed HIV infections. Incentives and complementary data collection by confirmatory HIV testing and treatment providers could help close this knowledge gap.

Stakeholders identified the light and humorous tone of the campaign, detailed preparation of logistics, and training for counsellors (including adjusting their expectations of client support needs) as success factors. Recommendations for future development include offering the service in additional languages, targeting all age groups across key populations, and making test kits available at a low cost from a range of community-based and commercial outlets.

Promoting and distributing kits for self-testing at home is a feasible and promising strategy to increase low-threshold access to HIV testing. Self-testing kits should be widely available at a low cost. Remote support and counselling should always be available. Community-based counselling services have relevant experience and are well-placed to provide this support. Data collection should continue in collaboration with HIV confirmatory testing and treatment providers, and harmonised with CBVCT data collection to the extent possible.

'I believe that the campaign has highlighted that a home testing service responds to the 'unspoken wishes' of a general population who still finds it extremely difficult to leave the house to go to a facility to take the test. However, we must continue to work, in parallel, to break down the stigma attached to the test.'[1]

[1] Comment from the stakeholder survey conducted as part of this evaluation

About JUST LILA

JUST LILA is a pilot HIV self-testing campaign conducted in Italy as part of the 'Community Led and Based HIV Services - Key to Ending the HIV Epidemic in Europe and Central Asia' project implemented by AIDS Action Europe, the COBATEST Network, and LILA Milano. The campaign was launched in May 2022 and the pilot action concluded in June 2023.

Contributions and discussions at a COBATEST network meeting on HIV self-testing[2] indicated that HIV self-testing was available in 18 out of 28 European countries surveyed, while availability was limited in ten countries. Barriers to availability include legal constraints, the price of a self-testing kit (average of 25 euros), stigma, and providers' concerns about access to counselling during self-testing.

The proportion of late HIV diagnoses is high in Italy (63.2% of all HIV diagnoses in 2021[3]). HIV self-testing kits for home use have been available in Italian pharmacies since 2016, but this has not been well known in the population. The cost of over 20 euros is also considered a barrier. The self-testing option is intended to increase low-threshold access to HIV testing, and became even more important during the COVID-19 pandemic, when other testing options were at times unavailable.

The project consists of two main components: a promotional social media campaign and a free home delivery service for the HIV self-testing kits, complemented by a remote support service (by video link or telephone) for test kit users. The name JUST LILA is intentionally reminiscent of a prominent commercial food home delivery app with an active public profile.

Partners and stakeholders

The JUST LILA pilot action was coordinated by Fondazione LILA Milano. Project partner Diversity, a non-profit communication agency, developed the communication campaign. Local LILA units Cagliari, Como, Piemonte, Toscana, and Trentino contributed to the remote counselling team support. The project also established contact persons in regional hospitals providing HIV services in order to facilitate linkage to care.

Promotional campaign

The JUST LILA promotional campaign centred on a video and materials using one key image accompanied by a range of text components directing interested people to the dedicated JUST LILA website for more information about the testing service and access pathway.

[2] COBATEST network meeting on HIV self-testing, held 31/05/2023 (online) by COBATEST, AIDS Action Europe, CEEIS Cat, zeroing IN, and LILA Milano, with a contribution from European AIDS Treatment Group

[3] Notiziario dell'Istituto Superiore di Sanità - Volume 35 - Numero 11 Novembre 2022 https://www.epicentro.iss.it/aids/pdf/coa-2022.pdf

The campaign materials include a promotional video, a range of social media advertisements, and a brochure. Campaign messages emphasise the ease, convenience, and speed of home delivery of the test kit, discretion, and the fact that the service is free of charge.

The video was launched simultaneously on Facebook, Instagram, Twitter, LinkedIn, Telegram, and YouTube, with this announcement:

> We are very happy to announce that, starting today, our new service JUST LILA is active! It is a free-of-charge delivery service of HIV self-tests directly to your home, combined with remote counselling services offered by our expert staff for those of you who wish to be supported while taking this step.
> Sometimes, taking an HIV test can be an emotional and stressful experience: if you are alone, you might need someone to support you.

For this reason, LILA offers an easily accessible remote counselling service: find out how to access it on www.JUST LILA.it!

👉 Fill-in the online form
🏠 Receive your self-test kit directly at home
👨‍💻 Take the test with the support of our counsellors
🤳 Read and find out the result

Easy, fast, confidential ... and, if you wish, we can do it together!

The brochure and website provide comprehensive yet compact information on HIV, about transmission, safe sex, testing and window period, treatment, and about living with HIV, including treatment as prevention (U=U).

Test kit delivery and support

All JUST LILA promotional materials direct potential users to a dedicated website, which functions as the central user interface of the service. The JUST LILA website offers more detailed information about the service and a user pathway consisting of the following steps:

Users fill in the anonymous pre-order questionnaire

Users order the test kit, pre-book a real-time remote support appointment (optional) and give consent to be contacted for the follow-up survey (optional)

Users self-test once they receive the kit – with or without the remote, real-time psychological and practical assistance offered by LILA testing team counsellors

Users who agreed to participate in the follow-up survey are sent, fill in, and return the questionnaire

For data protection and anonymity, this pathway uses unique identifiers not linked to personal details. In addition to the detailed instructions included in the test kit, users can opt to access the video tutorial provided on the website and/or book a real-time support appointment with one of the LILA testing team counsellors – either by video link or telephone, and including access to cultural mediators.

All contributing counsellors received training on the specific test kits used, and on the process of remote assistance and counselling.

Data collection

The two anonymous questionnaires filled in by users – before ordering and after completing the self-test – collect demographic and behavioural data, as well as data on test results, user satisfaction, and intentions for future testing choices.

About this evaluation

Aim

This evaluation aims to describe the results, successes, and challenges for the JUST LILA pilot action with respect to its stated objectives. In particular, the evaluation attempts to answer these questions:

To what extent did the pilot action follow the project plan?
To what extent was the pilot action able to measure its stated indicators?
To what extent did the results match the stated objectives?
What do project partners identify as the main successes of the pilot action?
What do project partners identify as the main challenges of the pilot action?

Methodology

This evaluation uses a participatory quality improvement approach[4]. Its driving forces are self-reflection and the participation of stakeholders. It aims to identify good practice, success factors, and recommendations for improvement.

The evaluation is based on qualitative as well as quantitative data. They include the operational data collected by the project in the form of operational statistics, the pre-order and follow-up survey questionnaires, and stakeholder feedback collected as part of the evaluation.

Steps in the evaluation process include:

1. A desk review of project documentation, such as concept note, statistics, and reports
2. Defining the project objectives and indicators to be assessed
3. Stakeholder analysis and selecting feedback respondents
4. Rapid assessment survey with the selected respondents
5. Thematic analysis and reporting

This report summarises and discusses the findings of the evaluation with an emphasis on results with respect to the project's objectives (including unexpected results), and on good practice recommendations for future projects aiming to increase access to HIV self-testing.

Limitations

The data and findings of this evaluation should be considered in relation to its context: the evaluation was planned and conducted during the last three months of the pilot action's implementation period. This means that evaluation questions and methodology were developed on the basis of the existing project, including the data already collected in its pre-order questionnaire and follow-up survey.

While this evaluation makes visible and accessible the good practice, success factors, and practitioners' insights developed during implementation, it cannot assess the pilot action's impact on trends in HIV testing, late presentation, or undiagnosed HIV-infection at the population scale.

[4] Guided by the principles and methods developed for Quality Action, an EU-funded Joint Action on quality improvement in HIV prevention. For details see www.quality-action.eu .

Objectives and indicators

JUST LILA aims to contribute to the UNAIDS continuum of care goals (90/90/90)[5] by reducing the proportion of undiagnosed HIV infections through improved access to HIV testing.

To this end, the pilot action pursued the following specific objectives:

- To ensure safe HIV testing and counselling during any remaining COVID-19 restrictions affecting access to public or community-based testing services
- Raising awareness of the option and availability of HIV self-testing in Italy
- To promote self-testing as an easy, anonymous, and friendly procedure, free of charge and low-threshold
- To offer reminders of the importance of HIV testing to protect health
- To increase testing uptake among persons who do not usually access public or community-based testing services

The following indicators served to assess the level of achievement of these objectives during the pilot action:

- Social media and website statistics
- Number of people ordering a self-test kit (distribution target: 1500 units)
- Number of self-tests conducted with/without real-time online or telephone support from the LILA counselling team
- Proportion of people reached who are new to HIV testing
- Uptake among key populations, including M*SM*, people with a migration background or seeking international protection
- Number and rate of reactive tests
- Number and pathways of linkage to care

Findings

Pilot action indicators

Variable	Value	Notes
Instagram sponsored ads (7 weeks): impressions [conversions to landing page]	> 260,000 [1772]	cost: 700 euros
Reach of Instagram sponsored ads	male 25-34: 37 % male 35-44: 17 % female 25-34: 6 % female 35-44: 3 %	
Facebook sponsored ads (4 weeks): impressions [conversions to landing page]	> 173,000 [2169]	cost: 350 euros
Reach of Facebook sponsored ads	male 25-34: 23 %	

[5] https://www.unaids.org/en/resources/909090

	male 35-44: 22 % male 45-54: 25 % female 25-34: 4 % female 35-44: 7 %	
Reach of JUST LILA 'kit' promotion through social media influencers	> 1,616,000	The 'kit' is a photograph of the content of the self-test package as delivered
Landing page: average visits [bounces] per day, average time	82 [38], 00:00:38	May 2022 – May 2023
Ordering page: average visits [bounces] per day, average time	30 [8], 00:01:15	May 2022 – May 2023
FAQ page: average visits [bounces] per day, average time	2 [0.5], 00:01:29	May 2022 – May 2023
Pre-order survey responses	n=2661	
Test-kits ordered and sent [average per day]	n=2183 [5.4]	Cost per courier delivery: 9 euros
Test kits not delivered [resent]	n=43	
Remote support sessions pre-booked [carried out]	n=35 [16]	All tests carried out with remote support had a non-reactive result
Follow-up survey responses	n=475	This represents 22 % of tests ordered
Proportion new to HIV testing	43 %	
Uptake among M*SM*	> 33 %	Extrapolated based on responses to questions about gender identity and sexual practices
Uptake among people with a migration background or seeking international protection	5 %	The proportion of foreign residents in Italy is ca. 8.5 % of the population
Number and rate of reactive tests	(n=3, 0.63 %)	Test results are unknown for the majority of the test kits shipped. Only a minority used the remote support, and only 22% of pre-order respondents filled in the follow-up survey.
Number and pathways of linkage to care	unknown	See *Discussion* section for reasons

Client reach and responses

The following is a summary of responses to the two questionnaires that form part of the JUST LILA client pathway: the pre-order questionnaire filled out by all persons interested in

ordering a free self-testing kit (n=2661 responses), and the optional follow-up survey sent by email and filled in after completion of the self-testing process (n=475 responses).

An average of 22 visits per day (excluding bounces) to the ordering page resulted in an average of 5.4 test kits ordered and sent per day. These page visits may include clients initially visiting the ordering page for information only, and maybe returning later to actually order a test kit. However, website statistics also indicate that about 20% of those who started the ordering process, after having filled in the anonymous pre-order questionnaire, abandoned it incomplete at some point. This may be due to the fact that some personal data must be entered to have the test kit shipped, and therefore an indication of the effect of stigma.

The cut-off date for this analysis is 29th June 2023, coinciding with the end of the pilot action. All proportions and percentages quoted below refer to the pre-order questionnaire unless indicated otherwise.

Promotion and use

Most respondents had found out about the JUST LILA service on Instagram (55%), and the rest through friends or acquaintances (22%), the LILA website (17%), or Facebook (9%). A small number (n=41) was personally referred to the service by LILA personnel. Almost 90% reported using the service for the first time, suggesting that 10% used it more than once during the pilot action period, or thought they had used it before. Of those who responded to follow-up, 96% reported having carried out the self-test.

The most frequently reported reasons (multiple responses possible) for deciding to use the service were that it was free of charge (58%) and convenient (47%). Other frequently reported reasons were confidentiality (37%), preference for a non-clinical setting (26%), and the offer of real-time support through the LILA counselling team (23%).

Of the follow-up respondents (n=475), 97% reported not using the real-time remote support offered. Of the 16 remote support episodes reported by staff, nine were also follow-up survey respondents who reported using the support service via telephone, and four via video link .

Reported reasons for not using the real-time support service were that support was not needed/the test seemed easy to do on one's own (91%), and support from another person close-by (6%). Ten individuals selected the 'other reasons' response option, and three individuals reported having had difficulty accessing the real-time support service.

Demographic characteristics

The majority of respondents were young, Italian-born women and men.

Female self-identified were 39% of respondents, and male self-identified were 57%. Identifying as non-binary were n=48 individuals (2%), n=18 identified as male to female transgender, and n=3 as female to male transgender, while n=8 identified as none of the above. Initially, the uptake of the JUST LILA service was dominated by persons identifying as women, with a larger proportion of persons identifying as men appearing among the respondents as the pilot action progressed.

Most respondents were young adults, with two thirds of respondents between 20 and 29 years old, and another quarter between 30 and 39 years.

The vast majority (95%) of respondents gave Italy as their country of origin, with people originating from Albania, Brazil, and Ukraine among the remaining 5% of responses. For comparison, the Italian Bureau of Statistics reports five million foreign residents in Italy in 2022[6], representing ca. 8.5% of the total population. This discrepancy should be considered in relation to the fact that, during the pilot action, the service was neither promoted nor available in any languages other than Italian.

The regional distribution of responses roughly follows population proportions, with three exceptions: Lombardy had a notably larger share of responses (24% of all respondents) compared to its 17% share of the population of Italy[7]. Notably fewer respondents than their population share would suggest came from Campania (5% of respondents vs. 9% of the population).

Slightly more than half the respondents reported living in large (31%) and medium-sized (26%) cities, and slightly less than half reported living in small towns (22%) and villages (22%). For comparison, 33% of the total population of Italy live in highly urbanised areas, 42% in areas of medium urbanisation[8].

More specific questions about factors of vulnerability were considered too invasive and posing the risk of creating a barrier to testing if they had been included in the pre-order questionnaire.

Previous HIV testing experience

Almost half the respondents (43%) reported that they had never tested for HIV, and another quarter (26%) that they had tested more than one year previously. Most of the remaining respondents (23%) reported last having tested more than 3 months previously. Only a small proportion (8%) reported having had an HIV test less than 3 months previously.

Reasons for testing and results

Almost two thirds of respondents (60%) reported that they ordered the test as part of their testing routine or because they hadn't tested for a while, and 29% reported testing because of a perceived risk event. Of the follow-up respondents, 97% reported a non-reactive test result, three persons (0.63%) reported a reactive result, and 12 individuals (2.53%) reported an invalid test.

Recent sexual encounters and potential for HIV transmission

Most respondents (77%) reported sexual encounters with men in the previous 12 months. Given that 43% of respondents did not identify as men, this means that about one third of respondents are men* who have sex with other men* (M*SM*). Only 15% of respondents reported sexual encounters with women, 6% reported sexual encounters with people of any gender, and a small proportion (2%) reported no sexual encounters.

[6] http://dati.istat.it/Index.aspx?QueryId=19103 (accessed 4/5/23)
[7] https://en.wikipedia.org/wiki/Regions_of_Italy#Regions (accessed 2/5/23)
[8] https://www.istat.it/it/archivio/137001 (published 2014, accessed 4/5/23)

The most frequently reported sexual practices with a potential for HIV transmission were unprotected anal intercourse (37%), unprotected vaginal intercourse (45%), and receiving ejaculate in the mouth (46%). A significant number of respondents reported condom breakage during anal (8%) and/or vaginal (8%) intercourse. Sharing injecting equipment was reported by n=25 respondents (1%).

Recent intercourse without a condom was reported about twice as frequently among those reporting that they had never tested for HIV before than among those who reported to have tested previously: anal intercourse without a condom by 27% vs 14%, vaginal intercourse without a condom by 65% vs 30% of respondents.

PrEP and knowledge about PrEP

The pre-order questionnaire also asked respondents whether they were taking PrEP. Only n=49 (2%) responded 'Yes', while almost three quarters (73%) reported 'No'. About one quarter (26%) reported not knowing what PrEP is.

Among those reporting unprotected anal intercourse, 3% reported taking PrEP, 79% reported not taking PrEP, and 18% reported not knowing what PrEP is. Among those reporting unprotected vaginal intercourse, only 0.2% reported taking PrEP, 58% reported not taking PrEP, and 42% reported not knowing what PrEP is.

Client satisfaction

The overwhelming majority of users who participated in the follow-up survey (n=475) rated the service 'excellent' (94%) or 'good' (5%) in general. Only five individuals rated it 'average' (n=3), 'poor' (n=1), or 'terrible' (n=1). This translates to an overall score of 4.9 out of a possible 5 points. The separate components of 'test delivery', 'instructions', 'ease of use', and 'HIV information materials' received the same distribution of scores, with ca. 90% rating them 'excellent', ca. 10% rating them 'good', and very few individuals rating them lower – resulting in similar overall scores of 4.8 - 4.9 each.

Although only n=13 of the follow-up respondents reported having used the real-time support service, n=217 gave it a score. As it cannot be ascertained which of these had actually used the service, the results can only be interpreted as indicating how respondents rated the fact that a real-time support service was offered at all, and in which way it was offered, rather than how well the service performed. Of these 217 respondents, 91% rated the (offer of) real-time support 'excellent', 5% rated it 'good', and 4% rated it average'. Two individuals rated it 'terrible'. This equates to an overall score of 4.8 out of 5 possible points.

Correspondingly, 99% of follow-up respondents indicated that they would use the service again in the future.

Users' intentions for future HIV testing

When asked which mode of HIV testing they prefer, 79% of follow-up respondents selected 'self-test at home', 14% selected 'blood test in a clinical setting', and 7% selected 'rapid test at a community organisation or checkpoint'.

The follow-up survey also gave respondents the option to indicate how they would like to obtain a self-testing kit in future, with multiple selections possible. Most popular were 'online ordering' (79%) and 'vending machines' (55%)[9], followed by 'going to an HIV community organisation' (35%), and 'buying it at the supermarket' (33%) or 'at a pharmacy' (31%).

Stakeholder feedback

This section summarises the responses from a brief survey of stakeholders involved in JUST LILA. There were eight respondents, including four LILA staff from various regional branches, one member of the social marketing team, one from the website development team, and two representatives of the overarching European project. Their roles in JUST LILA include developing and designing the campaign, constructing and maintaining the web interface, managing orders, dispatching test kits, responding to enquiries, data management and reporting, and remote support and counselling.

The survey asked about overall impressions of the project, anything that could have been done differently in hindsight, and about recommendations to organisations intending to develop similar projects.

Overall impressions of JUST LILA

The tone of the responses indicates that those involved were proud and pleased to be working on a project that lowered some of the known barriers to HIV testing. They also mentioned the light and humorous approach taken in the campaign messaging, and a spirit of collaboration and team work. Respondents were universally impressed with the project results overall, and report that these exceeded some of their expectations.

> *'The opportunity to facilitate access to the test by overcoming a range of difficulties: cost, unavailability of the kit, distance from HIV testing facilities, feeling insecure ...'*[10]

When asked what surprised them, respondents mentioned the high response rate – the number of daily orders and shipments were (reluctantly) limited for a time. Stakeholders were also surprised by the fact that the majority of clients identified as female during the first part of the pilot action, and that so many of them had never tested for HIV before. The low response rate to the follow-up survey was also unexpected for some.

> *'The strong response of the population – to the extent that, in the early part of the project period, it became necessary to limit the available kits to 30 per day.'*

> *'And also the number of women – not being a common target audience for HIV testing – who wanted to get tested. It indicates that there is still stigma around women's sexuality. It also proves the importance of self-testing as an addition to the 'classic' set of testing tools.'*

One response suggested that the reach of the social media campaign may reflect generational preferences, and that future campaigns should consider this aspect to ensure

[9] This score should be interpreted in relation to its country-specific context, please also see the *Discussion* section further below.

[10] All quotes are translated and/or paraphrased for clarity from the Italian/English originals.

that promoting self-testing also reaches older population cohorts across key population groups.

> *'… it seems that there is a 'digital divide' due to generational differences (use or understanding of technology, ability to follow self-testing instructions without help) that creates further inequity in the uptake of such beneficial services by key population groups.'*

Responses also indicate that counsellors had not expected the relative ease with which they were able to maintain their own standards in remote counselling mode.

> *'Being able to effectively manage the counselling, even on the telephone, supporting the person throughout the process of performing the test and reading the result.'*

LILA staff found the online training for counsellors useful and successful. While the JUST LILA pilot action was the primary reason to organise it, it turned out to be an important opportunity to harmonise remote client support services among the different LILA branches more generally. Due to the COVID pandemic, all LILA branches transferred support services to online platforms, but had never before shared their experiences using them and exchanged best practice ideas. Training events that bring together participants with common interests can result in unexpected benefits, such as the development of best practice models for remote counselling and support services in general, not just for those offered to users of self-test kits.

<u>What could have been done differently</u>

When asked to reflect on this question, respondents thought of some aspects of the pilot action that could have been improved given additional time, knowledge, and/or resources. At the coordination level, budget planning could have included a contingency for a greater than expected response.

Suggestions included additional creative ideas for extensions to the campaign, such as videos of celebrities receiving a test-kit delivery and performing the self-test, or 'guerrilla marketing' with branded bicycle delivery riders carrying QR codes for the project on their backpacks. Also, future campaigns should take into account multiple characteristics of its target groups, including generational differences and preferences.

One suggestion was to target a similar project specifically to key populations at risk of HIV, and to see if the demographic characteristics of users turn out to be similar, and how they compare to those of clients of in-person HIV testing services such as CBVCT.

Also mentioned was the limit put on daily shipments in response to waves of overwhelming demand and limited capacity for processing. If this had been anticipated, it may have been possible to work around it without having to impose a limit, which potentially frustrated some clients.

Respondents also wondered if additional strategies could have been developed to increase the number of follow-up survey responses received, and to promote the uptake of remote support, especially in the event of a reactive self-test result. One suggestion was to inform

users of the value of their feedback, how it can be used to improve services, and about its role in securing funding for self-testing kits.

Advice for future self-testing projects

Respondents to the stakeholder survey articulated specific recommendations for teams intending to develop and implement similar projects:

> Think carefully about target audience(s), potential size of the demand, and sustainability.
>
> Explore options for partnering with commercial organisations for the home delivery component of the project.
>
> Explore partnering with test kit manufacturers to bring down the cost of test kits.
>
> Use digital marketing channels to reach sponsorship targets.
>
> In the social marketing campaign, use a light and playful tone to move away from the narrative of fear and anguish often still associated with the topic if HIV. Also consider the characteristics and needs of different generational groups within key populations to ensure they benefit equally from options such as self-testing kits.
>
> Do not be intimidated by, but invest time in planning the ordering, shipping and data management algorithm, pathway, and logistics. Details matter, especially in relation to communication, privacy, and confidentiality. Don't underestimate the amount of 'behind the scenes' effort required to manage shipments. Consider automated data collection systems.
>
> The design of the ordering and booking system on the website interface was tailored to the regional structure of LILA branches. If your organisational structure is different, the website interface would have to be adapted accordingly.
>
> When developing and conducting training for remote counsellors, take into consideration that moving away from an in-person to a remote counselling setting can be intimidating for counsellors without remote counselling experience.
>
> Promote participation in follow-up data collection by informing users of the importance of data for service improvement and securing funding.

Discussion

Reach

The pilot action's social media-focused campaign was particularly successful in reaching younger cohorts, but may have failed to reach older generations who would also have considered using self-testing at home. The pilot action also reached a significant number of people identifying as female (39%). At the same time, it also reached M*SM* as a key population group for HIV infection (at least one third of respondents). The pilot action reached a significant number of people who had never tested for HIV before (about half of the respondents) as well as regular testers.

JUST LILA also successfully reached people reporting sexual practices with a potential for HIV transmission: high rates of unprotected anal and vaginal intercourse are reported by the respondents, and twice as frequently by those reporting never to have tested for HIV before.

Self-Testing, potential for HIV transmission, and PrEP

Cross-referencing some of the survey results points to an opportunity for targeting PrEP information:

> 43% of respondents reported that they had never tested before.
>
> Of those who never tested before, one third reported recent anal intercourse without a condom, and two thirds reported recent vaginal intercourse without a condom.
>
> Of those who reported not knowing what PrEP is, 17% reported recent anal intercourse without a condom, and 42% reported recent vaginal intercourse without a condom.

Taken together, these results may indicate lower levels of interaction with HIV/STI/sexual health services in general, and therefore less exposure to PrEP information. Self-testing services such as JUST LILA may be reaching people for whom PrEP information – and potentially PrEP use – may be particularly relevant.

> *Self-testing campaigns may be an opportunity for targeted PrEP information.*

As 57% of the respondents had tested for HIV before, and about two thirds report they ordered the self-test as part of their regular testing routine, it can be assumed that a large proportion of users were more or less familiar with HIV testing before ordering their self-testing kit. This indicates that the pilot action offered a viable alternative to other testing options that were unavailable during COVID-19 pandemic-related restrictions to public life.

Given that around half of respondents identified 'no cost' and 'convenience', another third 'confidentiality', and more than 90% of follow-up respondents indicated that they found the test easy to use, even without real-time support, the pilot action could probably have reached even more people for whom these factors are attractive. This includes people with a

migration background or seeking international protection, those living in rural areas, and those living in regions of Italy with limited access to other types of HIV testing services. CBVCT, for example, is not available in small cities and rural areas in Italy. However, some of those who are most vulnerable, for example people seeking international protection, may not even have the postal address and/or internet access needed to order a home-delivered self-test.

Project staff report that they did not discuss the use of languages other than Italian for the pilot action. At least five other languages would have needed to be included, and the costs for translation would not have been able to be covered for this pilot action.
Considering the manageable volume of text used in the campaign and on the website to achieve these positive responses, the service should be promoted and made available in additional languages if it continues in any form – as long as the test kit instructions are also available in the selected languages. Project staff consider that this would be very helpful to reach non-Italian speakers who experience barriers in accessing healthcare facilities or CBVCT services.

Service use

One remarkable result is the low uptake of the real-time support available for the service. The COBATEST network also reported at a recent meeting that the uptake of remote support for self-testing offered by community-based HIV counselling and testing (CBVCT) providers is low in general. Possible explanations include:

- People who select self-testing are less likely to have high needs for support.
- People who select self-testing do so because they prefer not to have real-time personal contact.
- The information, video tutorial, and FAQ sections on the website and the instructions in the test kit satisfied the support needs of most users.
- Given that more than half the respondents had tested for HIV before, this cohort may have acquired sufficient knowledge and awareness through previous contact with HIV testing services.

The fact that, despite the low uptake, a quarter of respondents reported that the availability of the real-time support service was one of their reasons for using the service, may indicate that the availability of this form of support provides an important level of reassurance – even if it ends up not being needed or accessed by most users. Respondents may also have included the information provided on the JUST LILA website and the instructions included in the test kit in their interpretation of ‘support’.

User Satisfaction

User satisfaction among the follow-up respondents was close to universal and extremely high. However, it is unknown whether those who elected not to take part in the follow-up survey (84% of those who filled in the pre-order questionnaire) would have been as likely or less likely to report similarly high levels of satisfaction with the service.

Close to 80% of follow-up respondents indicated that their preferred testing mode is self-testing at home, reflecting their motivation to use the service and the high satisfaction ratings. The remaining ca. 20% of follow-up respondents – and these are also individuals who gave self-testing a serious chance and were highly satisfied with it – indicated that they

prefer to use clinical and community-based testing services. This may be the cohort who used the self-testing option because of other testing modes being unavailable due to COVID-19 pandemic restrictions.

Responses about preferred ways of obtaining self-testing kits reflect the success of the pilot action's online ordering system, but also indicate that target groups may prefer a variety of access points, including over-the-counter options such as community organisations, pharmacies, and supermarkets.

The high score for 'vending machines' (55%) as a potential future access point should be interpreted in relation to its country-specific context: some pharmacies in Italy have external vending machines by their shop windows through which they sell condoms, lubricant, band aids, sun protection, menstruation products, and other small items. While this is currently uncommon, a few of them are also stocked with self-testing kits.

Project staff suggest that users who do not experience a price of around 25 euros as a barrier may find it easier to purchase the kit from a vending machine rather than ordering it online – where they would need to fill in a pre-order questionnaire and the order form, and perhaps even have another person accept the delivery for them if they are not at home during the day. Obtaining the kit from a vending machine would also increase the perceived level of confidentiality.

Linkage to care

The self-testing user pathway means follow-up is optional for clients, and the JUST LILA statistics show that the uptake of remote support and follow-up is low. In addition, there is no documented instance of a JUST LILA self-test user accessing one of the regular LILA helpline counselling services and reporting a reactive result. No service providers among the JUST LILA network of stakeholders reported any such instance either.

As discussed above, the low uptake of remote support and follow-up does not necessarily reflect negatively on the mode of self-testing at home nor on the particular system JUST LILA used to provide self-testing. It can also be interpreted as evidence for a maturing population response to HIV where the infection and testing are normalised and approached pragmatically. It is important to separate support needs as perceived by users from the expectations of counsellors, which may be influenced by extended careers of responding to those most in need of support.
At a recent COBATEST meeting, the network reported that CBVCT providers in Europe have similar experiences of a low demand for support and follow-up when providing self-testing. This means that the numbers of reactive results, confirmatory tests and their results, and episodes of successful linkage to care are largely unknown.

The specific contribution that self-testing as one strategy in a portfolio of testing services makes to finding undiagnosed infections cannot be determined on the basis of data collected by the providers of self-test kits. This stands in contrast to other types of low-threshold (e.g. CBVCT) testing services with an ability to reach priority populations. Their operational statistics have shown that they are making significant contributions to finding undiagnosed infections, and therefore to reducing the risk of late diagnoses. It may be

possible to increase follow-up data collection by informing self-testing users of the importance of their responses.

This trade-off between low-threshold access and the resulting uptake by previously unreached populations on the one hand, and provider-initiated follow-up and linkage to care on the other, could be mitigated by asking HIV confirmatory testing and treatment providers to survey those who are newly diagnosed about their previous testing history. Project staff report that there is increasing interest among these stakeholders in documenting reactive self-testing results. Most hospitals connected to the JUST LILA pilot action now include 'self-test' among the response options when asking clients requesting confirmatory HIV testing how they obtained their initial reactive rapid testing result. However, no data have yet been reported.

Conclusions

JUST LILA implemented its project plan as intended. It developed and ran its social media campaign to promote self-testing for HIV at home, established an online ordering system, trained counsellors and offered optional remote counselling support, and collected a range of operational statistics and user data.

The pilot action was able to measure all its stated indicators, with the exception of linkage to care. The uptake of remote support and follow-up means that the number of reactive self-test results and subsequent episodes of linkage to care is not known. However, this is more likely reflecting a smaller than expected need for support and follow-up among the population reached than any gaps in the design of the project.

The results of the pilot action reached or exceeded its stated objectives. The social media and online campaign achieved an extensive reach with a large potential of raising awareness of the option and availability of HIV self-testing. This resulted in the target of 1500 distributed test kits being exceeded by a large margin (2183 kits delivered by the end of the pilot action). JUST LILA was successful in reaching first time testers (43% of respondents to the pre-ordering survey). It also contributed to bridging the services gap during COVID restrictions, as routine testers who prefer other testing modes also used the service.

The pilot action successfully reached the general population, especially younger cohorts and persons identifying as female, but also people living outside metropolitan areas, and including a large proportion of M*SM*. The proportion of users with migration experience or seeking international protection was smaller than their share of the population, perhaps limited by the pilot action operating in the Italian language only.

Due to the limited number of remote support and follow-up contacts mentioned above, the number of reactive results and therefore the project's contribution to reducing the number of undiagnosed HIV infections, and the number of episodes of successful linkage to care are unknown.

The main positive aspects of the pilot action as identified by project partners and stakeholders include the light and humorous tone and feel of the social media campaign,

lowering barriers to HIV testing access, the successful inclusion of remote modes into existing counselling services, and managing the complex logistics of a country-wide, online ordering and delivery system while collecting important operational statistics and survey data.

The main challenges as identified by project partners and stakeholders include reaching all age cohorts across key populations, the high cost per client of the test kit and shipping, coping with demand peaks that exceeded anticipated order volumes, low returns of follow-up survey data, and maintaining counsellors' sense of fulfilling their duty of care when faced with the low uptake of support associated with self-testing at home.

Outlook and good practice recommendations

The greater-than-expected response to the pilot action and intentions for future testing reported by follow-up respondents suggest that a free or low-cost self-test ordered online should be one of the main modes offered for HIV testing. In addition, self-testing kits should also be available from community based and commercial outlets at affordable prices. Self-testing should be promoted to all age cohorts across key populations, taking into account their characteristics and needs profiles.

While a low uptake is likely and not necessarily problematic, remote support and counselling should be available and promoted to all users of self-test kits, no matter how they obtained them. Community organisations with their extensive experience in providing client-focussed, non-judgemental support are well placed to provide these services. All self-testing kits distributed should contain locally relevant contact information.

Data collection including operational statistics and voluntary client surveys should continue in collaboration with client feedback collected by HIV confirmatory testing and treatment providers, and be harmonised as far as feasible with data collected for other testing modes such as CBVCT. Participation in follow-up data collection should be promoted.

The following good practice recommendations are based on the professional experience and reflections of project stakeholders, and are offered here as signposts for organisations and teams intending to develop similar projects.

<u>Planning</u>

Identify and describe target audience(s), including barriers to uptake and likely support needs.

Explore potential partnerships/sponsorships with test kit suppliers and shipping providers to lower the costs of test kits and deliveries.

Take plenty of time to plan the logistics and client pathways, and consider automated systems for order processing and data collection. Keep levels of privacy and confidentiality as high as possible. Customise interfaces and automated systems to your organisation's service structure.

Promotion

Adopt a light and humorous tone in promotion to normalise HIV testing as part of maintaining health and well-being.

Consider the characteristics and preferences of all age cohorts when designing campaigns promoting self-testing at home.

Training

Organise training for counselling and support staff who will provide services in remote mode (online platforms, telephone).

Include a segment on the requirements of the specific self-testing product(s) selected. This ensures the user pathway for self-testing is quality-assured and consistent across participating support and counselling providers.

Offer opportunities for training participants to reflect on their expectations of clients' needs for support and follow-up. These are likely to be less than those of users of in-person testing services.

Include personal experiences of professional peers who have already provided counselling in remote mode to address the fears of counsellors who are new to this mode of not being able to establish rapport with clients.

Ordering and shipping

Take plenty of time to plan the ordering and shipping process in detail, in order to respond to waves of strong demand.

Consider using automated components of the ordering, shipping, and data collection processes.

Support and linkage to care

Offer clients multiple access points for support: online information (including FAQ and video tutorial), pre-booked remote support and counselling sessions (video link and telephone), spontaneous access via general helplines and online support formats (chat).

Engage with HIV confirmatory testing and treatment providers and ask them to collect data on self-testing when asking their clients where they obtained their reactive test result.

Inform self-testing clients of the value of follow-up data collection to service development and funding acquisition in order to maximise survey data returns.

Structural barriers

Consider providing the service in multiple languages to reach groups who face additional barriers in accessing low-threshold HIV testing services.