



Evaluation of The Impact of The National Lockdown on Young People with HIV and The CHIVA Support Services During The COVID-19 Pandemic in the UK

March 2021

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1. Executive Summary

This report details the Children's HIV Association (CHIVA) evaluation of the impact of the first UK COVID-19 lockdown between March and July 2020, on young people aged ten to twenty-four years old, living with perinatally-acquired HIV (PaHIV), and the support services CHIVA developed during the COVID-19 pandemic. CHIVA provided updated online information on COVID-19 and HIV as well as direct support to children, young people and their families, and organised therapeutic, creative and engaging activities to offset some of the restrictions in physical movement, social interactions and the reduced access to healthcare and other services for young people.

The evaluation was carried out using a CHIVA COVID-19 young people online survey, with invitation to participate sent only to young people already known to CHIVA. It complements a national survey for professionals, examining the impact of the pandemic on HIV clinic service provision for adults, children and adolescents, led by the British HIV Association (BHIVA) and Public Health England (PHE), in collaboration with CHIVA. Results related to children and young people are summarised in this report and are also available on the CHIVA website <https://www.chiva.org.uk/chivamembers/con2020/> (members only). Thirty-one participants answered questions that focussed primarily on the impact the lockdown had on their health and well-being and the disruption they experienced, including access to healthcare services, and the way they and their families benefited from CHIVA support services.

Results showed that the majority of respondents enjoyed spending more time with their family (n=19, 63%), kept themselves busy with activities (n=22, 71%) and did not experience any issues keeping up with school work or their job (n=22, 79%). Forty-five per cent (n=14) of participants worried about COVID-19, and 10% (n=3) had lost someone from COVID-19. Eighty-seven per cent (n=26) reported knowing where to find information about COVID-19.

Concern about money or food was not significantly different among participants pre- and during lockdown. Although younger participants (10-16 years old) were more likely to think they stayed in good health during lockdown and managed taking their medicines well compared to older youth, most participants felt that they managed their HIV medicine better before lockdown (90%, n=27) than during lockdown (77%, n=23) (p=0.046).

Twenty-one participants provided more in-depth information on how COVID-19 and the lockdown had affected their lives. Recurrent themes included 1) mental health, wellbeing and social support; 2) daily routine and activities; and 3) perception of self and social experiences.

Of the six CHIVA support services available during lockdown (Art is Key; Black Lives Matter Virtual Protest; Lockdown Photo Contest; Zoom Support Sessions; Hardship Fund; CHIVA Webpages), reported use of individual services ranged between 32% and 74%. Over 75% of participants felt that CHIVA support services had helped them feel less lonely, keep in touch with peers, stay in good health and stay informed about COVID-19.

The report highlights some of the challenges young people with HIV experienced during the first UK lockdown and how it impacted not only on their daily routine but most importantly on their mental health and social wellbeing. CHIVA support services benefited those who engaged with them. Suggestions for more creative, age-specific events as well as one-to-one or group sessions in case of future lockdown were recorded.

2. Authorship and Acknowledgement

The evaluation report was written by the following writing group:

- Djamel Hamadache (CHIVA Steering Committee member)
- Amanda Ely (CHIVA CEO)
- Dr Lizzie Chappell (MRC Clinical Trials Unit at UCL)
- Marthe Le Prevost (MRC Clinical Trials Unit at UCL)
- Prof Ali Judd (MRC Clinical Trials Unit at UCL)
- Dr Amanda Williams (CHIVA Chair)

The Evaluation project was undertaken by:

- Djamel Hamadache (CHIVA Steering Committee member)
- Amanda Ely (CHIVA CEO)
- Dr Lizzie Chappell (MRC Clinical Trials Unit at UCL)
- Marthe Le Prevost (MRC Clinical Trials Unit at UCL)
- Prof Ali Judd (MRC Clinical Trials Unit at UCL)
- Dr Amanda Williams (CHIVA Chair)
- Dr Katja Doerholt (CHIVA Steering Committee member)
- Susanne Lambert (CHIVA)
- Abi Carter (CHIVA)

Thank you to all young people living with HIV in the UK who took part in the survey

For more information, please contact:

communications@chiva.org.uk

3. Introduction and background

With the WHO declaring the novel coronavirus (SARS-CoV-2) outbreak a Public Health Emergency of International Concern (PHEIC) on 30th January 2020 and a pandemic on 11th March 2020, the Prime Minister Boris Johnson announced, on the 23rd March 2020, that the United Kingdom (UK) would enter a period of lockdown. Schools, pubs, restaurants, and other social venues were to remain shut, as the number of COVID-19-related hospitalisations and deaths increased. The National Health Service (NHS) was under tremendous pressure to accommodate the increasing number of very sick patients and limit the risk of SARS-CoV2 exposure to other patients. Care pathway models were adapted swiftly, alongside already constrained capacity and resources. Clinical staff were redeployed to where demand for critical care was higher, which inevitably led to the disruption in the provision and delivery of specialist care, including HIV services where most clinics switched to virtual appointments.

To ensure children, young people and their families, living with HIV in the UK, maintained high standards of health and well-being, the Children HIV Association (CHIVA), a UK-registered charity, developed a set of support services to offset the impact of the lockdown and the rapid reduction in access to healthcare and other services. These included:

- **Art is Key Online** a project held virtually using the arts as a means to share and process feelings, thoughts and experiences, and develop creative material collectively.
- Young people were invited to **share thoughts and feelings in response to the Black Lives Matter movement** and any 'calls to action' they would like to amplify through poems, spoken words, rap, or a letter. CHIVA also hosted a 'virtual protest night' to which young people were invited to share their words, and give speeches and connect with their peers.
- **Lockdown Photo Contest** capturing moments of life and well-being during lockdown. These photos were shared on CHIVA social media and website, and the winners received a CHIVA Isolation Support Pack with items that support well-being and self-care time.
- **Weekly Zoom Support Group sessions**, held separately for young people aged 16 years and under, and 17 years and over. CHIVA also provided one-to-one telephone support to young people based on individual needs.
- A dedicated webpage section on **enhancing the health and social well-being of children and young people living with HIV** that offers tips and ways of staying well throughout the pandemic, such as recorded yoga and relaxation sessions from the CHIVA camp yoga instructor <https://www.chiva.org.uk/youth/COVID-19/well-being/>

In addition to the abovementioned services under evaluation, CHIVA provided advice on welfare and employment rights, updated its guidance for professionals and families on COVID-19 and HIV, and developed a hardship support response to families experiencing increased difficulties accessing food and household essentials. CHIVA collaborated with The Food Chain to organise supermarket deliveries and food vouchers, in addition to providing phone data top ups for young people and covering fuel costs.

4. Evaluation focus

The CHIVA COVID-19 Young People Survey collected information about experiences of the UK lockdown between March and July 2020 for young people living with HIV (aged 10-24 years old). The survey focused on the impact lockdown had on their health and well-being, the disruption it caused with accessing healthcare services, and the way in which young people and their families benefited from CHIVA support services. This evaluation complements a national survey for professionals, examining the impact of the pandemic on HIV clinic service provision for adults, children and adolescents, led by the British HIV Association (BHIVA) and

Public Health England (PHE), in collaboration with CHIVA. Results relating to children and young people's services are summarised in this report (section 9) and can be found on the CHIVA website <https://www.chiva.org.uk/chivamembers/con2020/> (members only).

5. Evaluation objectives

The objectives of this evaluation were to:

- Assess self-reported change in health, social and emotional needs of young people growing up with HIV due to COVID-19 and the lockdown period
- Measure the impact and success of CHIVA services in supporting young people living with HIV in the UK to better manage their physical, emotional and social well-being
- Identify unmet needs of young people living with HIV

Results of the evaluation will enable CHIVA to reflect on changing needs of children and young people during lockdown and lessons learned to inform development of sustainable support services in case of subsequent lockdowns.

6. Evaluation methodology

6.1. Evaluation approach

The evaluation process encompassed a collaborative approach between the CHIVA Steering Group and the Collaborative HIV Paediatric Study (CHIPS) team at the Medical Research Council Clinical Trials Unit at University College London. By using the Health Research Authority decision tool¹, CHIVA and the CHIPS team concluded that ethics approval was not required, considering young people were not recruited through HIV clinics.

The main components of the evaluation included:

- **The development of the CHIVA COVID-19 young people survey**

A CHIVA/CHIPS working group was created in June 2020 and developed an anonymous online survey, which was then reviewed and tested by the CHIVA Youth Committee. The survey became 'live' on 30th July 2020 for a period of three weeks. An invitation to participate, including the survey, was emailed, or messaged by phone, directly to young people known to CHIVA, or their parents for those aged 12 years old and under.

- **The qualitative and quantitative data analysis**

Qualitative and quantitative survey data were analysed by CHIPS members of the working group and subsequently reviewed by the rest of the group.

- **The dissemination of survey findings**

Survey findings were presented at the 14th Annual CHIVA virtual conference on the 15th October 2020 and promoted via social media during World Aids Day. This report has also been listed on the Royal College of Paediatrics and Child Health website², in a summary of studies describing young people's experiences of COVID-19 and the UK lockdown

¹ Health Research Authority: <http://www.hra-decisiontools.org.uk/ethics/>

² Royal College of Paediatrics and Child Health: <https://www.rcpch.ac.uk/resources/COVID-19-research-studies-children-young-peoples-views#introduction>

Further opportunities for sharing information at conferences and publication of findings in journals will be sought.

7. Evaluation findings

7.1. CHIVA support services data

Table 1 provides details of the number of young people who engaged in the CHIVA support services offered during lockdown. It is worth noting that young people may have attended or benefited from more than one support service.

Table 1 Number of Participants who used CHIVA Support Services

Support Services	# of participants
Advice on welfare, employment Rights, and other information	20
Hardship Fund	40
Art is Key Online	16
Black Lives Matter virtual protest	31
Lockdown Photo Contest	9
Weekly Zoom support sessions	41*
Online Information	# online views**
CHIVA COVID 19 and HIV guidance	645

*One or more than one session

**between March and September 2020

7.2. CHIVA COVID-19 young people survey findings

➤ Participant characteristics

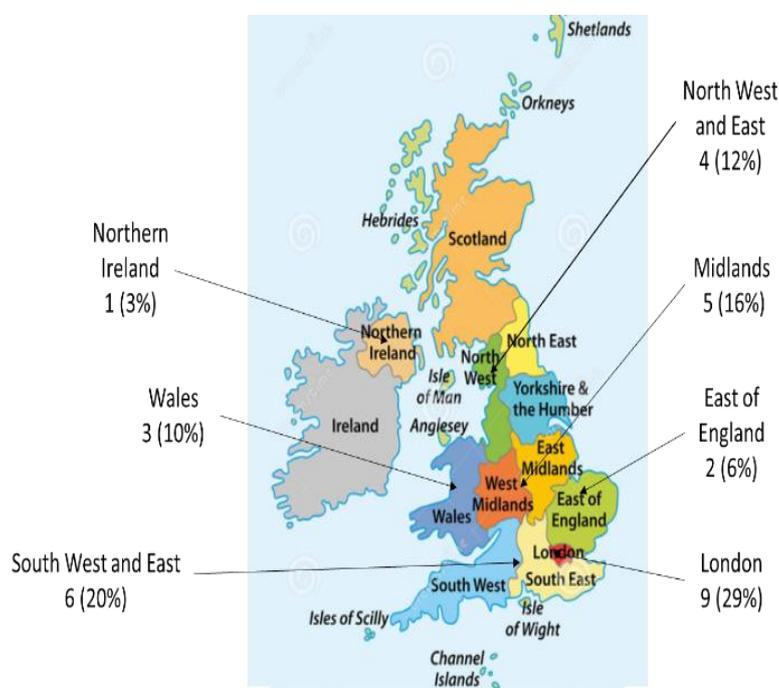


Figure 1. Geographical distribution of survey participants

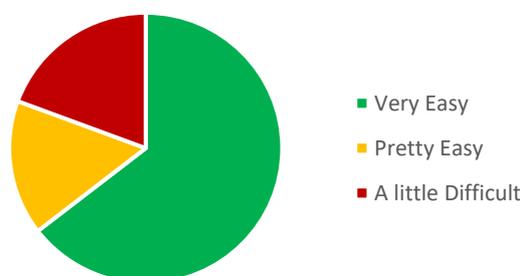
Thirty-one young people completed the CHIVA online survey. Participants responded to the questionnaire from across the UK, with the highest number from London (n=9, 29%) (**Figure 1**). One participant did not specify their geographical location. Two thirds identified as female (n=21, 68%); over half (n=18, 58%) were aged 14-16 years old and a third (n=11, 35%) were 17 years and older (**Table 2**). All participants lived with their family. Over half of the participants (n=18, 58%) reported that everyone in their home knew about their HIV status, a third (n=11, 36%) said 'not everyone was aware' and two participants did not know (6%). Of the 13 participants who said not everyone in their home knew, nearly all (n=12, 91%) said at least one person in the household was aware of their HIV status.

Table 2. Participant characteristics

Characteristic	Participants	
	n=31	(%)
Gender		
Female	21	(68)
Male	7	(23)
Transgender male	1	(3)
Missing	2	(6)
Age group		
10-13 years old	2	(6)
14-16 years old	18	(58)
17 years and older	11	(35)
Live with family		
Yes	31	(100)
No	0	

All participants reported having access to the internet at home prior to lockdown. **Figure 2** shows how easy young people’s access to internet was during lockdown. Two thirds (n=20, 65%) reported they had very easy access, and 16% (n=5) pretty easy access. However, 19% (n=6) of participants said their internet access was a little difficult.

Figure 2. Ease of internet access during lockdown

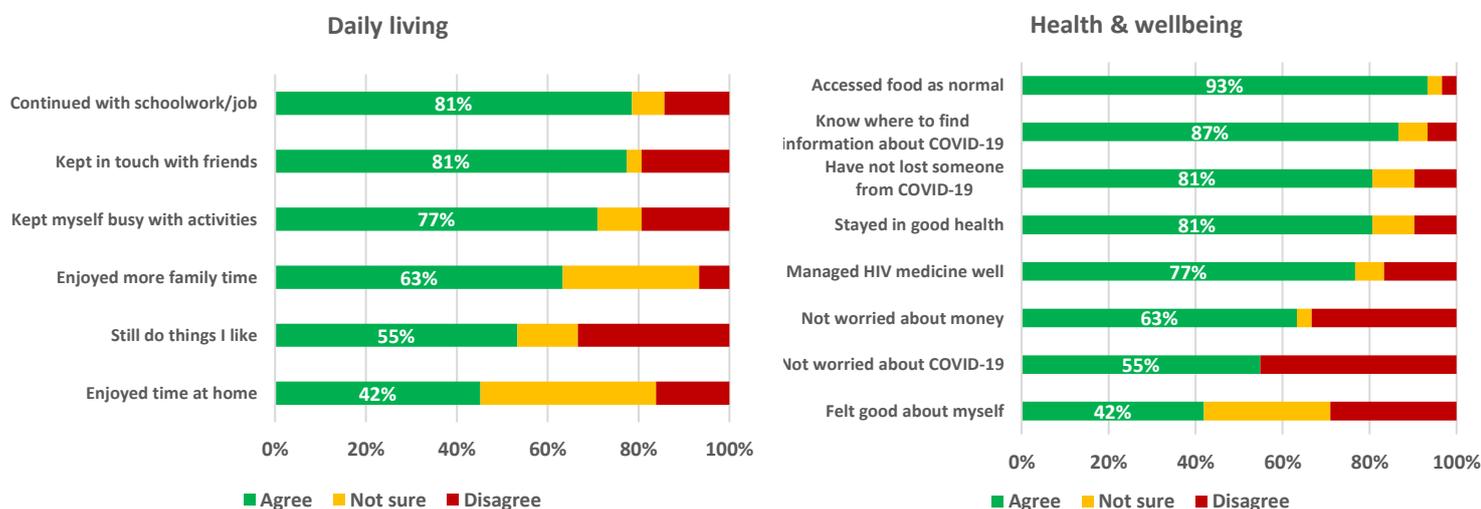


➤ **Experiences during COVID-19 pandemic and lockdown**

Experiences during lockdown are shown in **Figure 3**, with participants asked whether they agreed or disagreed with each of a set of statements. For some statements, participants were also asked how they felt prior to lockdown.

Although nearly two-third (n=19, 63%) of respondents enjoyed spending time with their family, less than half (n=13, 42%) reported feeling good about themselves and only 45% (n=13) enjoyed time at home. Nearly 80% (n=22, 79%) were able to continue with school work or their job. Only half (n=15, 53%) reported they were

Figure 3. Experiences during lockdown



still able to do things they liked and wanted to do, though nearly three-quarters (n=22, 71%) reported they had kept themselves busy with activities.

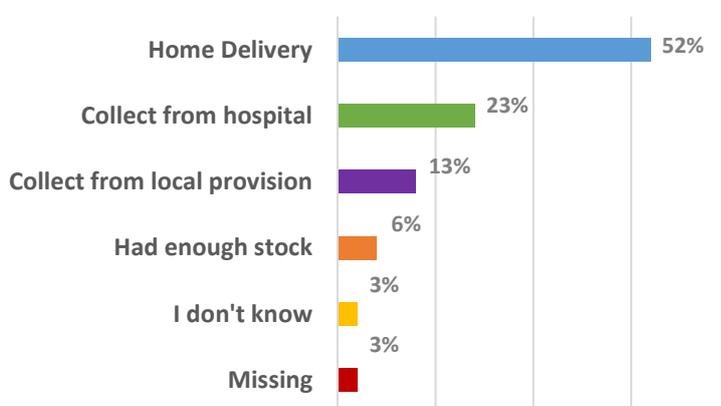
About half (n=14, 45%) of participants stated that they worried about COVID-19, and 10% (n=3) had lost someone from COVID-19. Nearly 90% (n=26, 87%) reported knowing where to find information about COVID-19.

Comparing before and during lockdown, there was no significant change in the proportion who said they were not worried about money (73% before lockdown, 63% during lockdown, p=0.257) or who were not worried about access to food (97% before lockdown, 93% during lockdown, p=0.317).

Younger participants were more likely to think they had stayed in good health (90% of those aged 10-16 years compared to 64% of those aged 17+ years, p=0.073) or had managed their medications well during lockdown (89% of those aged 10-16 years compared to 55% of those aged 17+ years, p=0.003). Overall, and across both age groups, the proportion of participants who felt they managed their HIV medicine well before lockdown (90%, n=27) was higher than during lockdown (77%, n=23) (p=0.046).

Participants were then asked about HIV medicine supply. During lockdown, half of participants (n=16, 52%) had their ARVs delivered to their home, a quarter (n=7, 23%) picked them up from hospital and about one in eight (n=4, 13%) collected them from a local provision such as a GP or a local pharmacy (**Figure 4**). For nearly two thirds of the participants (n=19, 61%), the way they received their medicines did not change during lockdown. For a fifth of participants (n=6, 19%) lockdown did result in a change to the way they collected their medicines of whom most (n=4) moved to home delivery. Six participants (19%) were unsure if the way they received their medicine had changed.

Figure 4. HIV medicine supply during lockdown



Participants also had the opportunity to give more in-depth detail on how COVID-19 and the lockdown had affected their lives in a free text section. Responses from 21 participants were coded and grouped into three broad themes: 1) mental health, wellbeing and social support; 2) daily routine and activities; and 3) perception of self and social experiences.

Mental health, wellbeing and social support

Over half of all participants described ways in which lockdown had affected their mental health and wellbeing. Five participants reported increased level of anxiety and depression as a direct result of COVID-19 and the lockdown. One participant gave a detailed account of how the lockdown affected them and how this changed over time.

“At first it was fine I could isolate to get a perception on life and mindfulness but the same routine and the same people got very dull so I developed habits like not eating my food because there’s a voice telling me I don’t deserve it or binge eating because something clocked in my head or crying for no reason but toward the end I stopped talking to most people and I’m just shoving my emotions in Pandora’s box.”

Four participants shared how the lockdown disrupted their access to social support.

"It messed with my social life and took friends from me." And how this resulted in experiences of isolation following this separation: "It has kinda made be a bit lonely because I don't get to see my friends physically but at least I talked to them on phone."

Two participants describe the pressure of spending so much time with their families being compounded by the loss of their friends whom they normally rely upon as their source of social support outside the family home.

"Before COVID-19 when I want a break from home or day to day life, I can just go out with friends."

"Also, I have never really spent this much time at home with my family which has caused a lot of stress, but makes me miss my life before lockdown."

For another participant, this isolation came from a lack of access to both support from family and friends and mental health support services.

"My mental health got a lot worse due to mental health teams not being available and lack of access to real life support which I rely on a lot for my mental health."

Daily routine and activities

In the second theme, seven participants reported how COVID-19 and the lockdown impacted on their daily routine. A few participants described their lives being affected, with a perception of reduced freedom and independence.

"It affected me greatly because I was not allowed to go to school and because of my HIV my family never allowed me to go out."

"Mainly my freedom, independence. Knowing I can't go anyway without worrying about COVID and wearing a mask...."

Whilst one young person reported that the lockdown left them feeling bored, another felt they had to put their life on hold as described in the following quote:

"Yes, I feel like everything I been trying to do has been put on pause."

Two participants mentioned that the lockdown affected their school life but in very different ways. The first participants referred to not being able to keep up with schoolwork while the second reported the lockdown was an opportunity to take a break from school.

Perception of self and social experiences

In the final theme, four participants describe ways in which the effect of COVID-19 and the lockdown had impacted their friendships, sense of self and sense of place. They describe how isolation gave them time and a chance to reflect on their perspectives of self and social experiences. Quotes from two participants are shown below.

"It has helped me realise what I am passionate and about and it gave me time to focus on what I like."

"Made me think more about my importance to the people that care about me and showed me who my real true friends are and taught me responsibilities that will have to stay with me forever."

➤ Support services

Participants were subsequently asked which groups or individuals they felt well supported by (**Table 3**). Although the survey was supposed to allow participants to select all applicable responses, a formatting error meant they could only select one; responses may therefore be interpreted as who participants felt most supported by. About half (n=16, 52%) responded that they felt well supported by their family, 16% by CHIVA (n=5) and 13% (n=4) by their friends.

Table 3. Individuals that participants felt most supported by

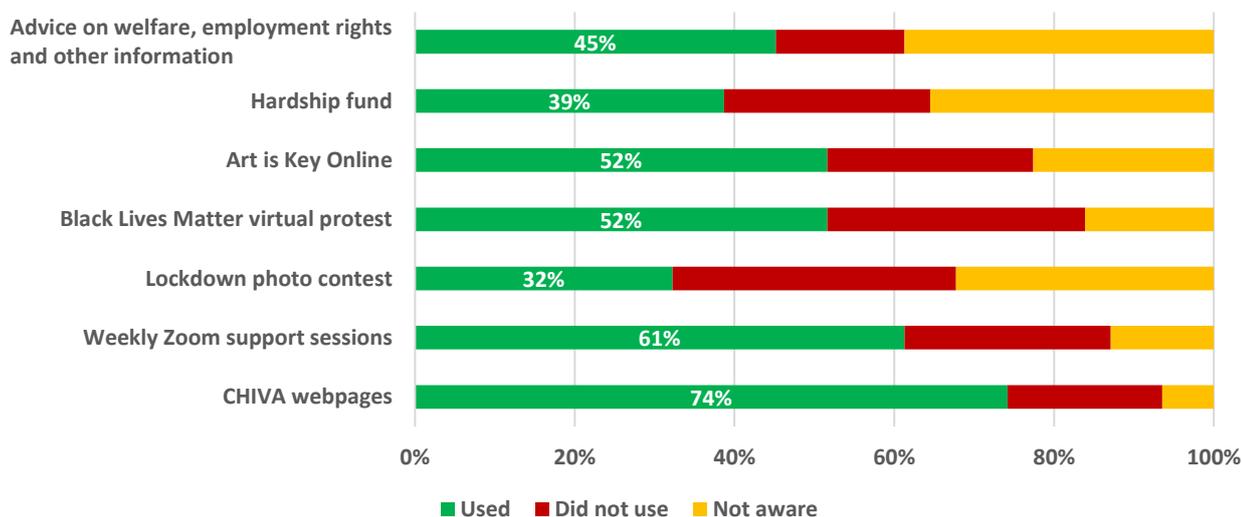
Individuals	Participants	
	n=31	(%)
My family	16	(68)
CHIVA	5	(16)
My friends/mates	4	(13)
My partner/boyfriend/girlfriend	1	(3)
My HIV doctor	1	(3)
My HIV nurse	1	(3)
My social worker	0	
My therapist/counsellor	0	
Relaxation/mindfulness app	0	
Other*	3	(10)

*Other responses: "God and myself"; "HIV Nurse, CHIVA, partner and family"; "My family, my HIV doctor and nurse"

➤ Support services offered by CHIVA

Reported use of the various CHIVA support services offered during lockdown ranged from 32% (Lockdown photo contest) to 74% (CHIVA webpages) (**Figure 5**). Of the 7 services, 20% (n=6) of participants reported they had attended none and 29% (n=9) reported they had attended all.

Figure 5. Use of each of the CHIVA support services during lockdown



Participants were subsequently asked how useful they found each of the services that they had attended (**Figure 6**), with between 81% and 92% reporting each service as being very useful or somewhat useful, compared to a little useful or not at all useful.

Over 75% of participants agreed that CHIVA support services available during lockdown had helped them feel less lonely, keep in touch with peers, stay in good health and stay informed about COVID-19 (**Figure 7**).

Figure 6. Usefulness of each of the CHIVA support services during lockdown

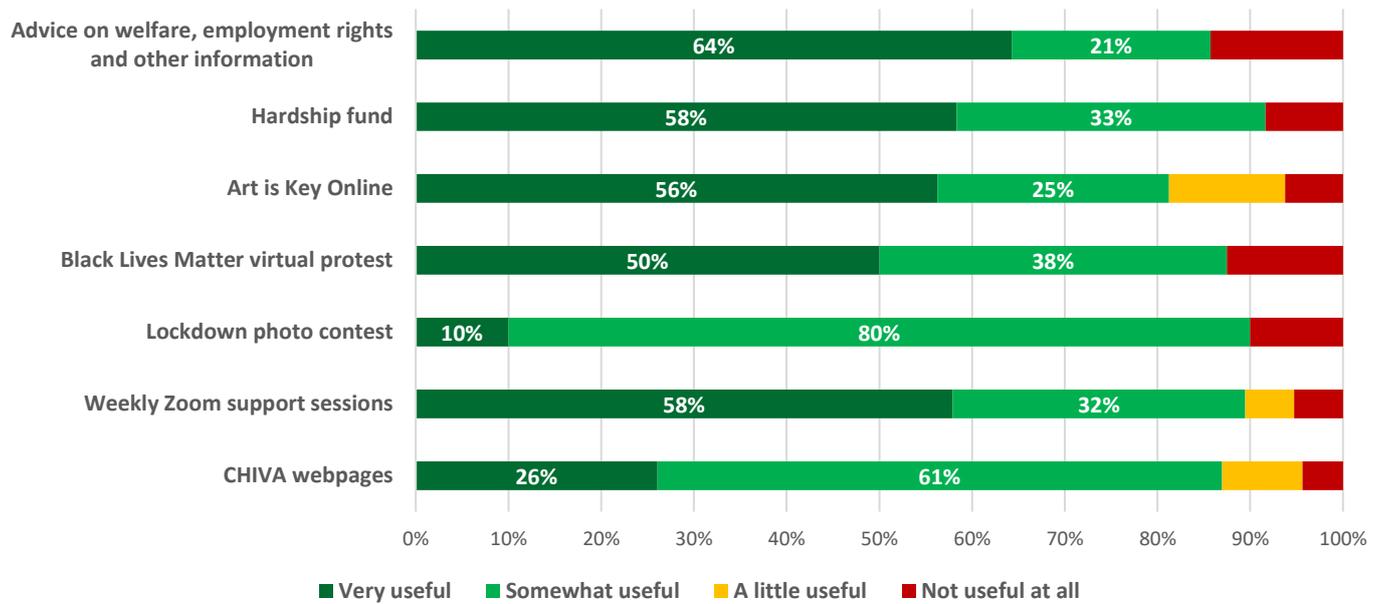
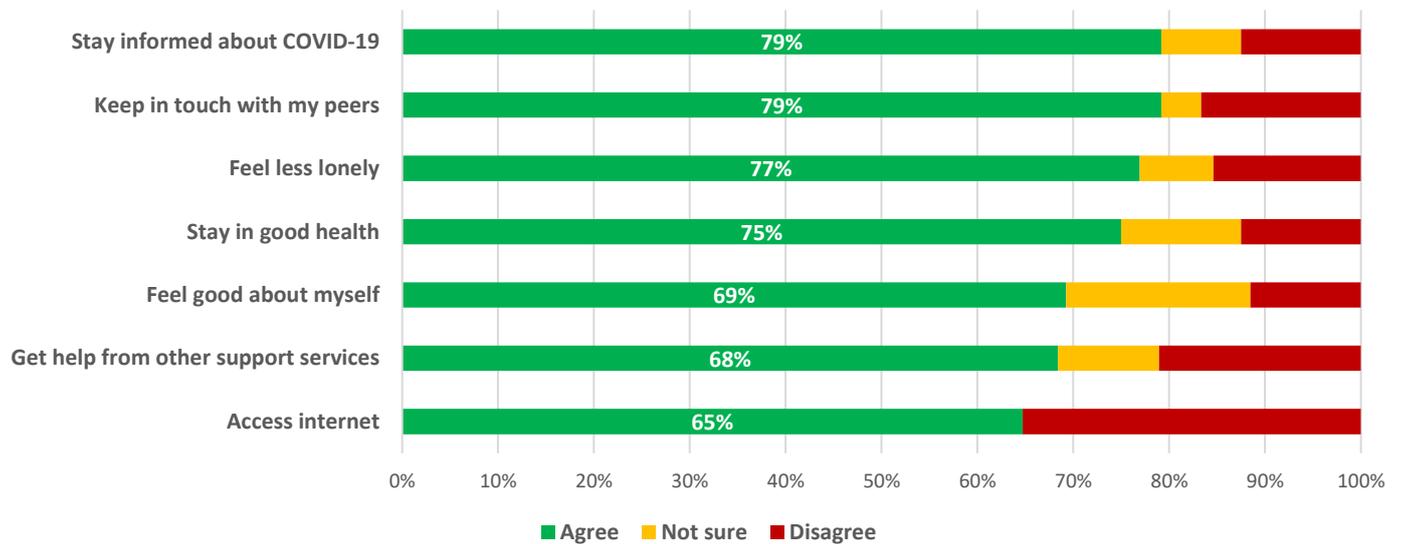


Figure 7. Overall usefulness of CHIVA support services during lockdown



Participants were asked to give more detail about how CHIVA could support them better in the event of another lockdown. Seventeen participants responded. Five participants said they were happy with the services CHIVA had provided.

“They being doin (sic) everything to my satisfaction so I’m not sure what to change.”

“I think CHIVA supports me well.”

The most common response for additional services centred on the provision of more interactive creative and support services.

“I’m not sure, maybe just zoom again but with more activities. It’s hard to imagine how support would look in another lockdown, but maybe just checking in (which CHIVA already do)”

Other specific activities participants asked for were: more art activities; HIV quizzes; one to one support; age specific events; and activities during social zoom calls. In addition, two participants also asked if it would be possible to continue to have face-to-face events during a possible further lockdown.

“To reassure me that life is worth living. I was always anxious.”

“I don't think they is anyway CHIVA can support me. As great as they are. I will feel like a burden.”

Three participants either directly asked for mental health support or their responses suggested that mental health support may be helpful (also highlighted in the responses about the effect of lockdown). One participant suggested a mindfulness program might help their mental health in the event of another lockdown.

Furthermore, a number of other possible support services were suggested by a single participant, these were: food support, technology access, financial support and educational support.

8. Discussion

8.1. Managing HIV at home

HIV stigma can limit people from sharing and talking about their HIV diagnosis. This is also true for young people who may decide or are told not to tell their siblings or other members of their extended family. Evidence shows that young people do not tend to talk about their HIV status at home.^{3 4} Although most respondents had at least one person in their household who knew about their HIV, over a third lived in households where not everyone knew about their diagnosis. Switching routine health appointments from the clinic to an online format at home may increase the risk of accidental exposure of HIV status, and influence young people's level of openness and engagement with their clinician/nurse.

In spite of reduced access to support mechanisms (such as family, friends and professionals) during lockdown, a high proportion of young people felt they had remained in good health. Nevertheless, there was a concerning drop in the proportion who felt they managed their HIV medicines well from 90% before lockdown, to 77% during lockdown. Developing innovative strategies and tools to help young people better manage their treatment at home, especially when opportunities for clinical monitoring and professional support are reduced, may need to be considered. Involving parents, friends and other peers who already know about their HIV status may improve adherence. Supporting dialogue and breaking barriers about HIV within households remain important but difficult issues, requiring time and empathy.

We were particularly interested in young adults who may have left their family homes and how peer living arrangements may be experienced in relation to managing HIV at home. However, all of the participants in the survey were living with their families at the time.

8.2. Coping with changes to daily life and more time spent at home

In the survey, young people described changes to their daily life and how this affected them during lockdown. For instance, participants enjoyed spending more time with their family. Nevertheless, less than half reported feeling good about themselves and enjoyed time spent at home.

³ Fielden SJ, Chapman GE, Cadell S. Managing stigma in adolescent HIV: silence, secrets and sanctioned spaces. *Cult Health Sex.* 2011 Mar;13(3):267-81. doi: 10.1080/13691058.2010.525665. PMID: 21049313

⁴ Bernays S, Papparini S, Seeley J, Rhodes T. "Not Taking it Will Just be Like a Sin": Young People Living with HIV and the Stigmatization of Less-Than-Perfect Adherence to Antiretroviral Therapy. *Med Anthropol.* 2017 Jul;36(5):485-499. doi: 10.1080/01459740.2017.1306856. Epub 2017 Apr 5. PMID: 28379042.

Qualitative data analysis provided a more in-depth understanding of how young people were coping with changes in their daily routine, describing feeling **“restricted”**, **“having reduced freedom”**, and **“being bored”**. Changes to school life were perceived as both an appreciated break and a concern because of **“not being able to keep up with work”**.

Respondents also reflected on their frustration at not being able to see friends, viewing this as a loss of support as well as a change to their social experiences. Losing the freedom to see wider family and friends easily can be difficult, and concerns around the impact of loneliness and isolation on young people’s mental health and well-being have been shown in several studies. A study carried out by Barnardo’s ⁵ found that young people struggled with feelings associated with a lack of support, routine, freedom and social contact, as well as with boredom. Likewise, the Teenage Cancer Trust ⁶ highlighted that young people described isolation from friends and family, school or work as the hardest part of lockdown to manage.

Despite these challenges, participants also demonstrated resilience through keeping busy with activities and continuing with their school work (70% and over). Nevertheless, a report by the Children’s Commissioner⁷, involving 1500 children aged eight to seventeen years old, shows that half of participants expressed some concerns about the struggle to catch-up with their schoolwork, and a third thought they would require additional help when schools reopened.

Although most young people reported having little or no difficulty accessing the internet during lockdown, a survey by Teach First⁸ found that 37% (n=2,514) of participating parents had at least one child with no exclusive use of a device for schoolwork, and 6% (n=407) with no access to a device at all. Ofcom⁹ also estimated that 1.1 million to 1.8 million (9%) of children in the UK were lacking access to a laptop, desktop or tablet at home during lockdown, including approximately 880,000 who lived in a household with only a mobile internet connection.

8.3. Mental health and well-being

Over half of participants stated that the national lockdown had impacted on their mental health and well-being, with some reporting increased levels of anxiety.

Larger studies on young people share similar findings. In a report by The Diana Award ¹⁰ on the views of young people and staff and the impact of lockdown, 85% identified mental health and well-being as a top priority need for support.

A survey of 5,000 adults by the Royal Society for Public Health ¹¹ during the first UK lockdown found that those aged 18 -to-24 years old were more likely to experience poor mental health and wellbeing than older adults; 70% of young people reported feeling anxious about the future more often than normal (compared with 47% of over 75s) and 62% experienced feelings of loneliness (compared with 21% of 65–74-year-olds).

⁵ Barnardos: ‘Devalued (By Forces Beyond Your Control)’ Report from in depth interviews with young people and round table discussions (113 YP aged 13-25) (August 2020)

⁶ Teenage Cancer Trust: ‘Cancer X Coronavirus’: The impact on young people (June 2020)

⁷ Children’s Commissioner: Some Sort of Normal (<https://www.childrenscommissioner.gov.uk/report/some-sort-of-normal/>) (November 2020)

⁸ Teach First Over a third of parents have children with no exclusive use of a device to work from home <https://www.teachfirst.org.uk/press-release/ongoing-digital-divide> (February 2021)

⁹ Ofcom <https://www.ofcom.org.uk/data/assets/file/0023/202856/Population-estimates-for-UK-children-without-access-to-broadband-and-connected-devices.xlsx>

¹⁰ The Diana Award <https://diana-award.org.uk/wp-content/uploads/2020/04/The-Needs-of-Young-People-During-Covid-19-THE-DIANA-AWARD.pdf>

¹¹ RSPH <https://www.rsph.org.uk/about-us/news/rsph-calls-for-more-mental-health-support-for-young-people-in-lockdown.html>

The Prince's Trust¹² echoed these concerns, reporting that 43% of young people had increased anxiety during lockdown, with 32% describing being overwhelmed by feelings of panic and anxiety on a daily basis, and 60% describing feeling their world was on hold.

Assessing the mental health and well-being of young people living with HIV is an integrated part of CHIVA Standards of Care¹³ and Psychology Standards¹⁴ within the HIV care pathway for children and young people, and is particularly important at times when routine access to support services is disrupted. Peer-support has proven to be very effective for those who experience health-related challenges, and may be a good alternative, but not a substitute to professional support.

8.4. Providing information for young people

Early on during lockdown, CHIVA zoom sessions focused primarily on clarifying and providing youth-friendly information available about COVID-19, answering questions on how the infection and mitigating measures could affect children and young people with HIV. Regular updates on COVID-19 and HIV were developed and remain available on the CHIVA website.

The survey demonstrated that a high proportion of respondents used the CHIVA webpages as a reliable resource for finding out information about COVID-19. In addition, a high percentage of young people reported that the COVID-19 zoom sessions were useful.

This reinforces CHIVA's commitment to help children and young people access relevant information in a trusted, friendly and age-sensitive manner.

CHIVA will therefore continue to include updated information about COVID-19 as one of its services for young people. Young people reflected that they trusted CHIVA as a source of information and that the online groups were a helpful opportunity to explore their understanding and worries, as well as ask questions.

9. BHIVA, PHE and CHIVA clinic survey feedback

Between July and September 2020, a survey questionnaire was sent out to all HIV services within the United Kingdom on behalf of BHIVA, PHE and CHIVA. Participants were requested to reflect on their experiences at the peak of the first wave of COVID-19. Twenty-eight paediatric and four adolescent clinics from England, Scotland and Wales submitted responses. The survey data is being prepared for publication.

The pandemic resulted in a significant change in the way consultations were delivered. There was a shift from almost entirely face-to-face appointments to mainly telephone consultations and less than half of the usual routine appointments were provided. There was a reduction in routine monitoring and blood tests, although prescription of medication continued as usual.

Issues with remote consultations were frequent with reports of problems with NHS technology and patients having access and technical issues. Clinicians reported difficulty in being able to take forward sensitive discussions including naming of HIV, sexual health and transition in a virtual clinic, although benefits of virtual consultations were also acknowledged.

Many respondents identified negative mental health impacts during the pandemic, while also noting a reduction in access to mental health services, psychology and support services. Clinics were aware of

¹² Young people in Lockdown: A report by The Prince's Trust and YouGov (2020)

file:///C:/Users/DJ/Downloads/LOCKDOWN_2020.pdf

¹³ CHIVA Standards of Care (2017) https://www.chiva.org.uk/files/5215/3987/5455/CHIVA_STANDARDS_2017.pdf

¹⁴ Psychology Standards (2018) https://www.chiva.org.uk/files/6415/4454/4932/PsychologyStandards-summary_2018.pdf

instances of food poverty and problems with fuel poverty, housing security. Domestic abuse was also identified.

The survey findings demonstrate how clinics had to rapidly adapt to new ways of delivering services during the first wave of the COVID-19 pandemic and show the wider impacts on the provision of patient care, and, particularly on mental health.

10. Conclusion and key considerations

Findings from the CHIVA survey indicate that young people's experiences of the national lockdown varied between participants. In spite of the immense challenges they were facing, a number of respondents demonstrated resilience and an ability to cope. For others, the changes to daily life, isolation from friends and wider family, compounded by reduced access to support services such as schools and clinics, had a negative impact on their mental health and well-being.

Young people living with HIV are already dealing with many complex physical and mental health issues. With increasing evidence showing how COVID-19 and its lockdown exacerbated health inequalities, worsening social determinants of health, mental health and well-being have become as concerning as the sole physical and immunological impact of SARS-CoV-2.

When external sources of support are reduced, and time spent at home increases, difficulties in the home environment become amplified in young peoples' day to day lives. Developing a better understanding about the home context and experiences related to managing HIV, such as the secrecy surrounding HIV status, hiding medicines and how young people are supported in managing their treatment must remain a priority, alongside the search for reliable information on COVID-19 and ways to overcome systemic and structural inequalities.

Virtual support and provision of COVID-19 information from CHIVA have been well received. Providing a space where knowledge and understanding can be explored and 'myth busting' discussions held is important as the pandemic continues. Young people are managing rapidly changing and often confusing information, and CHIVA can provide an important service supporting young people's ongoing information needs.

Limitations of the evaluation include the relatively small sample size of respondents for the survey, with all participants already known to CHIVA, and thus potentially more likely to respond positively to CHIVA service provision. Due to the importance of surveying young people in a timely manner and the delays that seeking ethics would introduce, we were unable to distribute the survey to patients attending HIV clinics, and this may have given us a different perspective on young people's lives during lockdown, and reasons why they may or may not seek support from CHIVA during this time.

Ensuring more young people living with HIV are able to access CHIVA services and support remains a challenge. This requires strong collaborative work between CHIVA, clinical teams and other stakeholders.

11. Bibliography

1. Health Research Authority. Is my study research? [Internet]. 2021 [cited 2020 Oct 14]. Available from: <http://www.hra-decisiontools.org.uk/ethics/>
2. Royal College of Paediatrics and Child Health. COVID-19 - research studies on children and young people's views [Internet]. 2020 [updated 2021 Jan 25; cited 2020 Oct 14]. Available from: <https://www.rcpch.ac.uk/resources/COVID-19-research-studies-children-young-peoples-views#introduction>
3. Fielden SJ, Chapman GE, Cadell S. Managing stigma in adolescent HIV: silence, secrets and sanctioned spaces. *Cult Health Sex.* 2011 Mar;13(3):267-81. doi: 10.1080/13691058.2010.525665. PMID: 21049313
4. Bernays S, Papparini S, Seeley J, Rhodes T. "Not Taking it Will Just be Like a Sin": Young People Living with HIV and the Stigmatization of Less-Than-Perfect Adherence to Antiretroviral Therapy. *Med Anthropol.* 2017 Jul;36(5):485-499. doi: 10.1080/01459740.2017.1306856. Epub 2017 Apr 5. PMID: 28379042.
5. Sewel K, Harvey-Rolfe L, Stagg E. Devalued by Forces Beyond Your Control: Experiences of COVID-19 lockdown restrictions and visions for the future, from young people who are supported by Barnardo's. Barnardo's (UK); 2020 Aug. 40 p. Report
6. Sundell B, Soanes L. 'Cancer X Coronavirus': The impact on young people. Teenage Cancer Trust (UK); 2020 Jun. 16 p. Report
7. UK. Children's Commissioner for England: Some Sort of Normal: what children want from schools now [Internet]. 2020 [cited 2021 Feb 15] Available from: [\(https://www.childrenscommissioner.gov.uk/report/some-sort-of-normal/](https://www.childrenscommissioner.gov.uk/report/some-sort-of-normal/)
8. Hobby R, Ashley J. Over a third of parents have children with no exclusive use of a device to work from home [Internet]. 2021 [cited 2021 Feb 15]. Available from: <https://www.teachfirst.org.uk/press-release/ongoing-digital-divide>
9. Ofcom. population estimates for UK children without access to broadband and connected device [Internet]. 2020 [cited 2021 Feb 21]. Available from: https://www.ofcom.org.uk/_data/assets/file/0023/202856/Population-estimates-for-UK-children-without-access-to-broadband-and-connected-devices.xlsx
10. The Diana Award. The needs of young people during COVID-19 [Internet]. 2020 [cited 2021 Feb 12]. Available from: [https://diana-award.org.uk/wp-content/uploads/2020/04/The-Needs-of-Young-People-During-Covid-19 THE-DIANA-AWARD.pdf](https://diana-award.org.uk/wp-content/uploads/2020/04/The-Needs-of-Young-People-During-Covid-19_THE-DIANA-AWARD.pdf)
11. Royal Society for Public Health. RSPH calls for more mental health support for young people in lockdown [Internet]. 2020 [cited 2021 Feb 12]. Available from: <https://www.rsph.org.uk/about-us/news/rsph-calls-for-more-mental-health-support-for-young-people-in-lockdown.html>
12. The Prince's Trust. Young people in Lockdown [Internet]. 2020 [cited 2021 Feb 12]. Available from: file:///C:/Users/DJ/Downloads/LOCKDOWN_2020.pdf
13. Children's HIV Association. CHIVA Standards of Care [Internet]. 2017 [cited 2021 Feb 28]. Available from: https://www.chiva.org.uk/files/5215/3987/5455/CHIVA_STANDARDS_2017.pdf
14. Children's HIV Association. Psychology Standards [Internet]. 2018 [cited 2021 Feb 28]. Available from: https://www.chiva.org.uk/files/6415/4454/4932/PsychologyStandards-summary_2018.pdf



Children's HIV Association

Orchard Street Business Centre
13 Orchard Street
Bristol BS1 5EH

0117 9055149

<https://www.chiva.org.uk/>

<https://www.chiva.org.uk/about/contact/>