

Introduction

- The first UK COVID-19 lockdown (March-July 2020) resulted in schools and social venues closing, and disruption to HIV service delivery.
- The Children's HIV Association (CHIVA) developed support services for children and young people living with HIV (CYPLHIV) and their families. In addition, CHIVA provided advice on welfare and employment rights, phone data top ups, fuel cost cover and collaborated with The Food Chain to organise supermarket deliveries and food vouchers.

Objectives

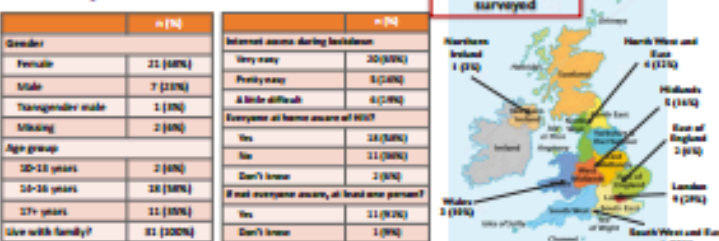
- To assess the potential change in health, social and emotional needs of families, children and young people growing up with HIV due to COVID-19 and the lockdown period
- To measure the impact and success of CHIVA support services in keeping CYPLHIV informed about COVID-19 and HIV, and better manage their physical, emotional and social well-being
- To identify unmet needs of young people living with HIV
- To reflect on lessons learned and inform progress to more sustainable support services in case of subsequent lockdowns.

Methods

- CYPLHIV were surveyed to assess the impact of lockdown on their health, social and emotional needs, and the support they accessed from CHIVA.
- The anonymous online survey was reviewed by the CHIVA Youth committee and was 'live' for three weeks in July-August 2020.
- Invitations to participate were sent directly to CYPLHIV aged 12-24 years known to CHIVA, and parents for those aged 10-11 years

Results

Participant characteristics



CHIVA COVID-19 Support Services

Guidance for professionals, young people and families on COVID-19 and HIV

Weekly Zoom Support Group sessions for young people aged under 16 years old and 16 years and over and a blog on participants reflecting on these sessions

Staying Well throughout the pandemic webpages e.g. recorded yoga and relaxation sessions

ART IS KEY Online Celebration event THURSDAY 23RD SEP From 6-7PM

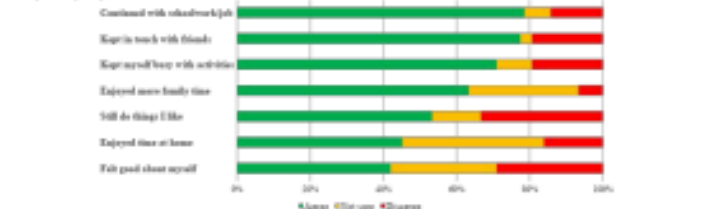
Young People engagement activities e.g. Lockdown Photo Contest capturing moments of life during lockdown that support well-being

Call to action' & 'virtual protest night' in response to the Black Lives Matter movement

One-to-one telephone support

Experience of Lockdown: Daily Living

- Although 63% (n=19) enjoyed spending time with their family during lockdown, only 42% (n=13) reported feeling good about themselves and 45% (n=14) enjoyed time at home. 79% (n=22) continued with schoolwork or their job during lockdown.
- Although only half were able to do things they liked, 71% (n=22) kept busy with activities and 77% (n=24) kept in touch with friends



Experience of Lockdown: Qualitative data

Mental health, Well-being & Social Support

Participants expressed increased anxiety and depression as a direct result of the lockdown and CYPLHIV felt isolated from friends with the lockdown disrupting access to social support

Daily Routine and Activities

Young people also felt that their freedom and independence had been reduced due to the lockdown. Respondents had mixed feelings about keeping up with school work

Perception of Self

Four participants describe ways in which the effect of COVID and the lock down had impacted their friendships, sense of self and sense of place. They describe how isolation gave them time to reflect on their perception of self and social experiences

"I missed with my social life and took friends from me"

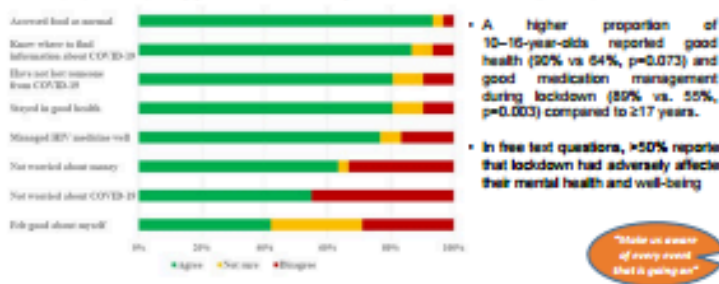
"I've found the everything I have trying to do has been put on pause"

"It affected me greatly because I was not allowed to go to school and because of my HIV my family were allowed me to go out"

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

Experience of Lockdown: Health & Well-being

- 45% (n=14) were worried about COVID-19, and 10% (n=3) knew someone who died from COVID-19.
- Comparing before to during lockdown, a similar proportion reported not worrying about money (73% vs. 63%, p=0.257) or access to food (97% vs. 93%, p=0.317)
- The proportion reporting good medication management fell from 90% to 77% (p=0.048)



CHIVA COVID-19 Support Services: Usefulness



CHIVA Support Services: Future Services

"CHIVA has done well for me I don't really know"

"More art activities and other related games"

Conclusions

- Almost everyone had someone in their household who knew about their HIV, however a significant number did not live in households where everyone knew.
- Participants appreciated more time spent with family and the ability to carry on with things they enjoyed
- Mental health and wellbeing is particularly important to consider alongside the reduced access to support YP have experienced and how isolated they may have been from usual sources of support. Wider studies indicate YP may have experienced worse mental health impacts during lockdown than older people.
- CHIVA is a trusted source of information for YP. Easy access is crucial and also having the space to explore their understanding and ask questions. We need to better communicate information and where to access support.
- CHIVA can consider how to reach the range of needs which the survey identifies. Information and social support needs can be effectively met through the online group sessions which YP have appreciated. Some mental health support is also delivered here. Continuing to provide more direct interventions, one to one support and connecting with clinic teams where more concerning mental health impacts are identified remains crucial

Acknowledgements

CHIVA Steering Group – Dr Katja Doerholt; CHIVA Staff – Suzanne Lambert & Ali Carter and special thanks to all the young people who kindly participated in the survey