

TON Meetings – 08/04/2020 and 15/04/2020 Record of Meetings

Present:

Vic Perri (VP), Ruan Uys (RU), David Crawford (DC), Satiro Istiko (Tiko), Kristy Machon (KM), Lionel Rabie (LR), Marcus Bogie (MB), Neil MacKellar-Stewart (NMS), Heather Mugwagwa (HM)

John Rule (JR), Adrian Ogier (AO), Charlie Tredway (CT)

MINUTES:

Over the course of these two separate meetings certain topics regularly emerged so for the purposes of the minutes the perspectives gathered will be grouped into themes.

TREATMENT:

- DC- Said that a large portion of his work has been around fielding enquiries about Treatment and Treatment access during COVID-19. That includes supporting those people who are ineligible for Medicare and people from overseas who are stuck here to access medications. PLNSW have been communicating importance of having 1-month supply of medications from the Pharmacy.
- VP- Generally people in Victoria are able to get 2 months' supply of medications at a time. The major concern is fears around availability and communicating that those fears are not warranted.
- KM- Raised concerns about other drug supply chain issues for items like asthma medication.
- DC- Spoke about compassionate access availability but that it might not necessarily be the pre-existing regimen that they were on.
- NMS- Said there were some supply chain issues for people who were on unusual regimens.
- DC- Reiterated that there were supply issues with things like Zyban for nicotine replacement
- JR- Said that medications like Nizatadine which might be used by PLHIV were also unavailable.
- AO- said 2 months is the standard s100 prescribing guidelines currently during COVID-19, but it should be 1 month for life saving meds. He reiterated that you shouldn't have to pay two lots of dispensing fees, and to that end Gilead have provided postage bags to pharmacies to help keep PLHIV accessing their treatments.
- DC- said that with a visitors visa you can access 2 months compassionate access from drug companies. We also need to be communicating about how to send meds overseas if required.

COMMUNICATION:

- DC- Positive Life NSW have crafted and released a position statement on the use of PPE and masks. There are supply issues of these and the communication from Pos Life was not about taking them from front-line workers but communicating how to use them properly if that's what people were doing.
- VP- LPV has been working with Thorne Harbour Health to make sure they have fully updated COVID-19 section with current information.
- KM- was concerned that communicating responsibly so that demand doesn't exceed supply. We need to be clear about priority populations such as people over 65.
- KM- said that there needs to be unequivocal and clear communication that HIV medications won't protect you from getting COVID-19 and that there has been no clinical evidence of this.

- DC- echoed that, saying that in regard to mooted Truvada & chloroquine clinical trials that we have to sit back and wait. It is a risk to be seen to be leaning into unsubstantiated stuff.
- TIKO- expressed the view that non-stop fact sheets about COVID-19 can be frustrating; rather than the focus being on COVID-19 we should be focusing on how our community is going. Tiko raised that with online community engagement there is a question around how frequently we should be communicating and what was the capacity to engage in online activities for some people.
- KM- We are not COVID-19 experts, we need to ask what the specific gaps/deficits that will affect PLHIV are. The rest is not our place. (this discussion is raised again in relation to service provision, and received general assent from those in the meeting.)

SERVICE PROVISION:

- VP- LPV have changed their program arrangements and is looking at webinars to replace activities where appropriate. He wants to speak to Ruan & Lionel about their online programs.
- RU- BGF have taken all programs online and identified specific needs and challenges like clients with AOD history and issues around clients not having access to broadband or technology supports.
- DC- Raised that we should still be delivering what we were doing; but delivered differently.
- KM- said that it was about expectation management with their clients and that PLHIV orgs exist in a network of service providers all of whom play important roles and may be positioned to do some things that PLHIV organisations cannot do.
- VP- The best practice for peer support is knowing who to refer to; we can't be experts in everything. (this was echoed by KM & Tiko)
- TIKO- What is our role, what does peer support look like in COVID-19
- JR - said we could ask clinicians how they think we could do that would be most helpful.
- LR- ACON is offering referrals for recently diagnosed, zoom support. He raised that being diagnosed while isolated is a heightened challenge. ACON is doing training for volunteer peer navigators and is looking at Zoom webinars with breakout spaces for support.
- LR- to speak to DC- about Genesis workshops in COVID-19
- MB- Still doing direct client work. He said people are "getting" social distancing but it is more challenging the longer it goes on. Their Genesis program operates differently. Possible Zoom catch up fortnightly could be a model for ACT.
- NMS- ACON Northern Rivers- shopping for housebound people, advocating for meals on wheels.
- HM- Positive Women VIC have been providing client support, updating referral lists and supporting clients on student visas. They are looking into virtual peer support group pilot starting with additional Q&A for clients.
- RU- Happy to knowledge share and collaborate on operating online programs.

HOUSING:

- DC- Raised that the biggest problem they are encountering is around housing and security of housing in COVID-19. One of their housing programs is having an attempted takeover by St Vincent's to be used as COVID-19 beds. Losing their homelessness services to this crisis is a challenge at that they need a guarantee that anything that gets subsumed by COVID-19 gets returned to its original purpose. No options for placement in NSW.
- MB- Accommodation and homelessness is going to be a big issue, people who were couch surfing during COVID-19 have been moved on.
- NMS- asked about evictions during COVID-19 (CT- said there had been a couple on TIM before the freeze on evictions came through but there has been unclear communication on those laws)

EXTERNAL LINKS PROVIDED and SHARED:

<https://livingpositivevictoria.org.au/covid-19-changing-way-interact/>
<https://thorneharbour.org/covid19/>
<https://thorneharbour.org/covid19/covid-plhiv/>
<https://insidestory.org.au/so-you-want-to-wear-a-mask-in-public/>
https://www.health.nsw.gov.au/news/Pages/20200331_01.aspx
<https://minister.homeaffairs.gov.au/davidcoleman/Pages/Coronavirus-and-Temporary-Visa-holders.aspx?fbclid=IwAR1nRWfsELC2Uoe50ecPhTWVqlsZRTLToVYiBTKJiWKbh30YNioyodQ2aQ>
<https://www.tga.gov.au/media-release/limits-dispensing-and-sales-prescription-and-over-counter-medicines>
<https://fromthefrontline.com.au/>
<https://www.aidsmap.com/news/apr-2020/covid-19-barcelona-first-cases-people-living-hiv-reported?fbclid=IwAR19InYoeeUkz4dfee7lQQQB98pD2KBdelzbt4nHYaJve0DYvGJ37t2fGFA>