

## Young + Positive: Are we doing enough to support young people living with HIV?

By Lisa Wojciechowski, Louise Harms, Allison Carter, and Christy Newman

### Introduction

Young people living with HIV in contemporary Australia today receive their diagnosis in a very different context than people diagnosed in previous generations of the epidemic. A context in which their prognosis, in terms of their physical health outcomes, treatment options, prevention of onward transmission, social understandings of the virus and the stigma associated with HIV has changed -we hope- for the better. Given these changes, we ask, what is it like to be young and HIV positive in this new world, a world that includes Grindr, Tinder, PEP, PrEP and U=U? And, are we doing enough to meet the support needs of young people living with HIV in Australia today?

The successes of the Australian HIV response mean that relatively few young people aged 18-29 are living with HIV in Australia. This means that young people living with HIV risk being overlooked as a distinct group for services and health promotion. Their age and different stage of life can also mean that they feel isolated from older people living with HIV.

This article provides some preliminary findings from the 'Young + Positive' study, a PhD project and the first national study in Australia to explore whether and how young people (aged

18-29) feel connected to, and access HIV services and supports, and to identify opportunities for improving engagement around their HIV and health needs.

The research came about through the first author's work as a social worker in the HIV sector for many years. In recent times, she found herself working alongside more and more people being diagnosed with HIV under the age of 30. She was struck by how different these young people's perspectives; support needs and patterns of engagement were from their older counterparts. She was curious to know if these differences in engagement were related to their particular life stage, the context of being diagnosed in a post-crisis, contemporary Australia, or instead, the ways in which our service sector is structured.

### Background

We argue that people aged 18-29 are a distinct group with specific needs. While this cohort is considered 'adult' within the context of existing health and HIV services, evidence increasingly points to the need for a more nuanced understanding of this age group.

From a developmental perspective, we now know full human maturation, or 'adulthood', doesn't occur until well into the second and even the third decade of life. As such, this cohort can more appropriately be described as 'young adults' or 'young people' given key

differences in cognitive, physical, psychological and emotional development from older adults [1].

Social aspects of young adulthood have also undergone significant transformations over the last 20 years both within Australia, as well as internationally, with many arguing the transition period between childhood to adulthood now occupies a greater portion of the life course than ever before [2,3]. Delayed timing of role transitions, such as the completion of education, gaining employment and financial autonomy, moving out of the family home, partnership, and parenthood, continue to shift opinions of when adulthood begins. At the same time, unprecedented global and social forces including population mobility, global communications, economic development, precarious employment, and the sustainability of ecosystems are setting the future course for this generation and affecting health and wellbeing across these years [4,5].

Social generational theory also suggests that the needs, experiences and perspectives of different generational cohorts can be varied, and that young people's experiences are powerfully shaped by the particular socio-historical and economic context in which they grow up [6]. While many young people might have grown up in – and have formative memories of – the fear and

trauma that characterised the early (crisis) years of the HIV epidemic, they are now located (and being diagnosed) in a 'post-crisis' context[7]. Discourses around HIV have become increasingly normalised, with HIV now considered to be a chronic condition [8,9]. Despite these advances in the biomedical aspects of the virus, stigma still exists. And alongside that, there remains a lack of visibility and awareness of HIV in the mainstream community, leading to a pervasive sense of isolation for many young people living with HIV. The changing nature of what it means to be young, and HIV positive suggest that young people living with HIV today may have very different perspectives and needs to their older peers in terms of what they want from, and how they engage with, HIV services and supports.

Additionally, in an era of individualised healthcare, young people living with HIV are expected to have the ability to both prioritise and self-manage their health as well as navigate complex health and social support systems in order to have their needs in relation to HIV met; a set of skills which we know is complex for anyone, but particularly those earlier in their adult life.

In thinking about the various changes that have happened in the HIV sector over the past few decades, we need to think also about whether the medical and social HIV service infrastructure is catering for the needs of all people living with HIV. In particular, the needs of the current generation of young HIV positive people.

## Method

The Young + Positive study has been guided by GIPA (Greater Involvement of People Living with HIV) and MIPA (Meaningful Involvement of People Living with HIV and Affected Communities) principles at every stage. Consultation and collaboration were at the centre of the research design, primarily through the establishment of a steering committee, which valued lived experience as an important form of knowledge.

Membership of the steering committee comprised of representatives from community and hospital-based

organisations including: Sydney Children's Hospital Paediatric HIV Service; Melbourne Sexual Health Clinic; Gen Next (Living Positive Victoria), The Alfred HIV Services: Outward Program – Social Work, The Institute of Many (T.I.M) and Youth Empowerment Against HIV (YEAH) as well as three young people living with HIV.

The research had two parts, starting with an online, anonymous survey that focused on demographic and psychosocial characteristics, clinical features and interactions with services and supports. Those who completed the survey were then invited to participate in a semi-structured interview. Interviews were designed to deeply explore participants' relationships to HIV, and their health, how they related to existing services and supports, as well as suggestions for improvement.

People aged 18-29 years old, living in Australia, and living with HIV were eligible to participate in the study.

## What we found

We received a total of 60 useable surveys, and from this group, 25 participants agreed to take part in an interview. Interviews were conducted in person where possible, or by phone if not, or if participants preferred that.

There was diversity amongst those who participated in the survey. Most were Australian born and identified as gay men. Of the participants who were not born in Australia, most arrived here in the last 10 years, and selected English as the language they spoke at home. The majority of participants acquired HIV as young people, with a small number acquiring HIV at birth. These participants had a different lived experience, as well as demographic profile from their HIV positive peers in that they were mostly overseas born and identified as heterosexual men or women. Participants were mostly aged 25 to 29 at the time of completing the survey with just under half also being in this age bracket when they received their HIV diagnosis.

Analysis is still underway, but there are some preliminary results from the survey data that provide important insights around the health status and

broader psychosocial support needs of young people living with HIV in Australia.

We used the indicators prioritised in the HIV cascade of care – diagnosis, retention in care, treatment and viral suppression – as a framework for understanding young people's engagement with health services and in assessing effective management of their physical health. Participants were found to match or exceed that of the general public at every stage, suggesting the physical health needs of Young + Positive participants were being met with existing services.

Interestingly, many participants achieved these health outcomes despite also managing considerable psychosocial challenges. For example, most survey participants indicated they had changed their housing arrangements at least once and up to 11 times in the 24 months prior to taking the survey. Interview participants also revealed that these changes could mean moving interstate, requiring a subsequent transfer of HIV care usually involving significant motivation and perseverance from participants to make this happen successfully. This interruption to engagement with care is not often discussed but featured often within this cohort.

Over a third of survey participants reported having been diagnosed with a mental health condition, with depression and anxiety the most commonly reported. We know that mental health issues can add greater complexity in the navigation of and access to HIV care, and through interviews, learned that for some, this contributed to interruptions to treatment.

Our preliminary analysis suggests the physical health of this generation of young people living with HIV is well managed. The findings may also challenge assumptions about young people being less able to successfully self-manage their health care (particularly within a challenging psychosocial context). However, despite this, most survey and interview participants reported experiencing difficulties with living with HIV as a young person in contemporary Australia.

These difficulties included feeling that HIV impacted life choices and restricted how these young people might otherwise have moved through that stage of their life, particularly in terms of navigating their health, sex and relationships.

Generational issues also permeated many participant's perspectives on living with HIV, in both wanting to recognise and honour those who came before them, but also wanting to differentiate their own distinct experiences of being young and HIV positive in Australia today. While many expressed a sense of gratitude to be living in a time of effective and tolerable treatment, at the same time, they expressed concern that the challenges they were experiencing in coming to terms with their diagnoses wouldn't be seen as important. Feelings of stigma and isolation also featured, and even descriptions of loss of hope and suicidality, particularly during the early stages of adjusting to their HIV diagnosis.

These responses sit in contrast to the care cascade indicators, speaking to a potential disconnect between the 'hard data' about what it looks like for a population to be doing well, and the lived experience of managing what remains a stigmatised infection for this generation of young people living with HIV.

## Discussion

What is clear from the Young + Positive data is that participants are doing well at each stage of the care cascade, yet many continue to struggle to have their non-medical needs met in relation to living with HIV.

Listening to the voices of participants, we're reminded that in a policy context that is now very much focused on an elimination agenda, it remains essential to ensure that access to medical services is well supported for all young people living with HIV.

However, while measuring and monitoring physical health indicators is of course important, this approach tells us less about improving health and wellbeing for people living with chronic conditions. Young people's narratives reveal both the psychosocial challenges

they face in adjusting to an HIV diagnosis, as well as the resilience needed to remain engaged in care despite existing social stressors. This shows there is also a need for continued investment in peer-based and health system services that can support the psychosocial needs of these young people.

Finally, this research indicates that we cannot assume existing forms of support will meet the needs of the current generation of young people living with HIV, a group who identify quite differently from their older peers. Instead, there is a continued need for the design and delivery of tailored services and information, informed by and co-produced with young people living with HIV, enabling them to live their lives to their full potential, in good health and free from discrimination.

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## Author details

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Lisa is a senior social worker with several years' experience working with people living with HIV both in hospital and community-based settings. It is through this work that Lisa became interested in the experiences and psychosocial support needs of young people living with HIV. Her work in this area led her to commence her PhD research, exploring how young people living with HIV relate to their health, services and supports.

### Lou Harms

Lou is Professor and Head of the Department of Social Work at The University of Melbourne. Lou's research is focused on people affected by a range of traumatic life experiences, including health crises and disasters. Her studies focus on understanding the interactions of stress, trauma and loss responses with resilience and growth responses, at individual, family and community levels.

Lou has published her research widely in national and international journals. She is also the author of ten books published by Oxford University Press, Cambridge University Press and Palgrave Macmillan UK. These books focus on theories and skills for practice, integrating trauma, grief and resilience perspectives.

## Allie Carter

Allie is a Research Fellow with the Kirby Institute, UNSW Sydney and an Adjunct Professor in the Faculty of Health Sciences at Simon Fraser University. Her work focuses on the social, cultural, and political issues related to sexual and reproductive health, particularly for communities who are less well-represented in research. Allie has a strong interest in critical theories and community-based research and utilizes a range of methods, including surveys, cohort studies, and the arts. Currently, she is engaged in a number of projects

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<sup>1</sup> 'Undetectable equals untransmissible', or U=U, refers to the fact that people who take antiretroviral therapy for HIV daily as prescribed, and who achieve and maintain an undetectable viral load, cannot sexually transmit the virus to an HIV-negative partner.

in Australia, Canada, and the United States with women living with HIV, young people with disability, migrant communities, and the broader population. She has published widely in international journals and writes regularly about health, sexuality, and relationships for the general public.

## Christy Newman

Christy is Associate Professor at the Centre for Social Research in Health, where she has been conducting social research on health, gender and sexuality since 2004. From 2020, she is also the inaugural Associate Dean (Enterprise,

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Christy's research interests span sexual and reproductive health, blood borne virus prevention and care, and sexual and gender diversity, exploring their ever-changing meanings and influences on the ways we configure relationships, families, and care practices today. She works in partnership with advocacy, policy and health professionals, particularly those who support LGBTQ+ people, and people affected by HIV and viral hepatitis.