

Understanding The Fertility Desires And Intentions Among HIV-Positive Men Living in Ontario:  
Survey Instrument Development And Validation

**by**

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**Author's declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

## **Abstract**

Fathers living with human immunodeficiency virus (HIV) infection play a pivotal role in shaping the lives of their families and children. However, women living with HIV have received disproportionately more attention in studies of parenting and the importance of having children, with men frequently left out of the picture. In addition, there is a gap in the literature, however, as no instrument specific to the measurement of the fertility desires and intentions among men living with HIV has been validated for use for all men including, heterosexuals (straights), gays, bisexuals and others. The problem addressed by this study is the need for a well substantiated tool with multiple items which demonstrates reliable and valid assessments of fertility desires and intentions for all men living with HIV. Therefore, this study was designed to develop and validate a survey instrument. The instrument will be used by clinicians or service providers to gather information about fertility desires and intentions for men living with HIV and developing appropriate services.

The scale was developed in four phases. During the first phase, the instrument questions were developed by adapting questions from previous surveys. In phases two and three, the questions were collated and reviewed by experts and then by community members in a focus group for further evaluation in a pilot study. Specifically, content validity was maximized by undertaking a thorough literature review and consulting with experts in the fields of HIV and parenting. Face validity was evaluated via focus group of men living with HIV. Construct validity was verified for many of the questionnaire sections using confirmatory factor analysis (CFA). The test-retest reliability was assessed using Spearman's rho correlation, internal consistency was determined using Cronbach's alpha and concurrent validity was assessed. The number of agreements across items were used to assess concurrent validity. Ordinal logistic regression was used to assess the associations between fertility desire/intention and independent variables.

The draft questionnaire consisted of 14 constructs. Content validation suggested removal of seven items. Focus group participants suggested that the overall flow of the survey was smooth. In addition, they recommended 18 new items to be added. Construct analysis confirmed the predetermined model. Cronbach's alpha was above 0.70 for most of the constructs. Test-retest statistic showed a stability of the responses Spearman's rho correlation  $>0.70$ . The results showed the proportion of individuals who desire /intend to

becoming a father correspond to those of previously established measurements for the same constructs confirming evidence for good concurrent validity. In this study, sexual orientation and age were demonstrated to be associated with fertility desire and intention. In conclusion, an instrument was developed for determining the fertility desires and intentions of men living with HIV.

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## **Introduction**

Advances in HIV treatment, management and support over the past three decades have contributed to tremendous shifts in the lives of people with HIV in Canada and around the world (Antiretroviral Therapy Cohort, 2008). In Canada, over 80% of people with HIV are of reproductive age (Public Health Agency of Canada, 2014). As people with HIV live longer, questions regarding the potential for marriage and/or having children have become increasingly important. An array of intersecting factors such as age, ethnicity and partner HIV status will have important implications for people living with HIV who desire to have children (Sastre, Sheehan, & Gonzalez, 2015). Studies have identified several key factors which influence the decision to have children among men with HIV, including age, health status, fear of discrimination, community pressure and attitudes of health care providers (Nattabi, Li, Thompson, Orach, & Earnest, 2009).

Research studies have continued to focus more attention on the fertility desires of women living with HIV, while the fertility intentions of HIV-positive men appear to have been overlooked throughout the past decades. A previous study demonstrated that a significant proportion of HIV-positive women aged 18-52 years in Ontario desired (69%) and intended (57%) to have children in the future (Loutfy et al., 2009). Most HIV prevention literature considers women as especially vulnerable to HIV infection due to biological susceptibility and the risk of transmitting the HIV virus to their babies during pregnancy, delivery and breastfeeding (Amin, 2015).

Men living with HIV have a right to enjoy the pleasures of parenting and deserve equal attention from researchers in the field. It can be argued that fatherhood can bring a positive impact on the overall health of men living with HIV and therefore, research on this topic is equally valuable as that of women-centered research. Since the 2009 study in Canada, there have been appeals from medical, science and HIV communities to recognize fatherhood as an important driver in health and development for HIV families and communities. In fact, sexual behavior in heterosexual couples involves two partners and men represent half of these couples. Literature reported that family planning interventions for heterosexual couples provided better outcomes when women and men were involved together in the planning rather than those focused solely on women (Lundgren, Cachan, & Jennings, 2012). Parenting



living with HIV. Men face unique challenges when faced with the opportunity to have children and become parents and these concerns deserve equal attention from researchers in the field of HIV.

In 2012, the Canadian HIV Pregnancy Planning Guidelines (CHPPG) reported that planning for parenthood among men living with HIV was an important consideration that needed further attention. Detailed options for men and their partners living with or affected by HIV who are interested in parenting were included in these guidelines (Loutfy et al., 2012). Despite being included in the CHPPG, the absence of literature concerning the desire and intention of men to have children makes it difficult for health providers to counsel men living with HIV about parenthood. Therefore, the initiation of male-centered parenting studies are warranted in the research community (Chen, Philips, Kanouse, Collins, & Miu, 2001; V. Paiva, Filipe, Santos, Lima, & Segurado, 2003; Sherr & Barry, 2004).

Assessing fertility desires and intentions for men living with HIV is valuable and necessary for the development of policies related to parenting planning for this group of individuals. There is a gap in the literature, however, as no instrument specific to the measurement of the fertility desires and intentions among men living with HIV has been validated for use for all men including, heterosexuals (straights), gays, bisexuals and others. Therefore, the problem addressed by this study is the need for a well substantiated tool which demonstrates reliable and valid assessments of fertility desires and intentions for all men living with HIV.

Therefore, the purpose of this study was to create and validate a survey instrument with multiple items to assess fertility desires and intentions among men living with HIV. The specific objectives were to 1) develop a survey instrument to assess fertility desires and intentions among HIV-positive men; 2) assess the face, content, construct and concurrent validity as well as the reliability of the developed instrument.

The survey development and validation included draft development, expert reviews, a pretest/focus group and pilot-testing. The survey validity and reliability indicators such as content validity, face validity, construct validity, criterion validity, test-retest and inter items consistency were determined. In addition, analysis of factors associated with fertility desires and intentions were undertaken. Results from this thesis are intended to provide relevant and useful results regarding future studies. The study developed a valid and reliable tool that was used to measure fertility desires and intentions in a pilot study. We found that the instrument

associated with age and sexual orientation. This dissertation, which included a literature review, methodology and discussion, was presented to the IHPREG (Interdisciplinary HIV Pregnancy Research Group) annual conference in May 2016 and is intended for publication.

## **Background**

Since the identification of the human immunodeficiency virus (HIV) and the acquired immunodeficiency syndrome (AIDS) during the 1980s, there have been significant advances in the management and consequently, long-term prognosis for infected individuals. In the early years of the epidemic, infection with HIV led to terminal illnesses, with infected individuals living an average of ten years. The advent of combination antiretroviral therapy (cART) and the ability to reconstitute the immune system and suppress viral loads to undetectable levels has helped HIV-positive individuals live healthy and productive lives. Today, specialists no longer consider HIV a terminal prognosis due to the significant advances in ART (Deeks, Lewin, & Havlir, 2013). Subsequently, it has been estimated that the average life expectancy for people living with HIV with access to appropriate care is from 40 to 60 years after diagnosis (Antiretroviral Therapy Cohort, 2008). These medical advances have made family and pregnancy planning for the HIV community increasingly relevant as people living with HIV have the right to plan for the future and become parents (Ogilvie et al., 2007; Sarnquist et al., 2014).

It was estimated in 2013 that 31.8 (range 30.1-33.7) million adults worldwide were living with HIV and more than half of these individuals were of reproductive age (World Health Organization, 2013). In Canada, it was estimated that by the end of 2011, 71,300 persons were living with HIV and a large percentage of this population were of reproductive age (Public Health Agency of Canada, 2014). Fertility and parenthood is an important aspect of life and happiness among young adults and is equally significant for people living with HIV. It may be especially important for those living with this infection as parenthood may provide them with confidence, family-oriented planning and goals and can inspire self-confidence and pride. Both men and women living with HIV have the right to gain access to reproductive health management and support. It is important that this access be equally funded and available to both men and women living with HIV.

Epidemiological data relating to fertility and child-rearing factors in men living with HIV, both in Canada and around the world, is lacking and deserves further investigation. The inclusion of male parenting is of equal importance and should be investigated alongside the growing interest in advancing the awareness of fertility desires among HIV-positive women. One could argue that if the parameters of reproductive age and health were applied to both

men living with HIV as well as women, a considerable proportion of this population would most likely desire to have children.

Previous international studies effectively showed that men living with HIV desire and intend to have children and predictors of this desire and intention included age, stigma, number of living children, fear/discrimination, attitudes of health care providers and health status.

## **Literature review**

### **Traits-Desires-Intentions-Behavior framework**

The Traits-Desires-Intentions-Behavior framework (TDIB) for understanding childbearing states that fertility motivations of individuals produce behaviours that promote or prevent desire or intention (Miller, Rodgers, & Pasta, 2010). This model has been used to assess a large number of predictors of pregnancy decision-making among HIV-positive women in Ontario (Loutfy et al., 2009; A. C. Wagner, Ivanova, Hart, & Loutfy, 2014). However, for men living with HIV, only limited number of predictors of fertility desires and intentions including age, number of living children, health status, fear of discrimination and community disapproval, sexual orientation, attitudes of health care providers, assistance in achieving pregnancy for men living with HIV and their partners have been examined (Nattabi et al., 2009). There are other traits such as having an undetectable viral load or not, and current use or non-use of HIV medications, sexual orientation, hepatitis C, status, ethnicity that need to be considered. Each of these traits may influence whether women would contemplate reproduction. In addition, this model can use multiple items to assess fertility desires and intentions. However, for men living with HIV, only one item has been used to describe their desire or intention to have children (Finocchiaro Kessler et al., 2014; Laursen et al., 2013; Sherr & Barry, 2004).

### **Gaps in Research**

There has been a clear gender gap within the area of reproductive health care and planning within the HIV-related research community. Most research has focused solely on the needs of women who want to have children. A Pubmed literature review between the years 2000 to 2015 (accessed September 2015) generated 337 fertility articles focused on women, compared with 137 articles that focused on men. In addition, a review of determinants of fertility intention and desire among men identified 27 published articles (Appendix C), including 23 studies exploring reproduction patterns among both women and men. Of these, four studies exclusively assessed the fertility desires of men. In total, these 23 studies exploring reproduction patterns among both women and men enrolled 5220 men versus 6906 women. Therefore, women were represented approximately 1.3 more times than men throughout these research projects. This discrepancy highlights the gender gap within the study of fertility among HIV-positive individuals.

All of the studies reviewed in Appendix C enrolled heterosexual men while only four studies included the enrollment of men who have sex with men (MSM) but without providing any data about parenting planning for this latter group. One could argue that a sexual orientation gap may also exist within the research community in regards to the fertility desire of men living with HIV. The review of these articles also demonstrated that a proportionally higher number of men continued to desire having children after their diagnosis in comparison to women. This common finding among the different studies was demonstrated in various international countries and cultures. However, most of these international studies have been focused on heterosexual men living with HIV. Second limitation of existing research is the lack of published data reporting the reliability and validity of instruments measuring fertility desires and intentions for men living with HIV in Ontario. Also, it should be noted that the instrument that has been used to measure fertility desires and intentions of individuals living with HIV in Canada was validated for women study (Loutfy et al., 2009). Third, desire and intention are latent variables usually complex and not easily measured with a single item. Multiple –item scales are more reliable and less prone to random measurement errors than single-item measures. To date, available instruments have described the desire or intention to have children for men living with HIV using one question. Therefore, there is a need to assess these variables using multiple items.

Assessing fertility desires and intentions for men living with HIV is valuable and necessary for the development of policies related to parenting planning for this group of individuals. However, no instrument specific to the measurement of fertility desires among men living with HIV that integrate many items has been validated for use to men regardless their sexual orientation. This lack of a validated instrument highlights the need for a well substantiated tool which demonstrates reliable and valid assessments of fertility desires and intentions for all men living with HIV.

### **Fertility desires and intentions among HIV positive men**

We reviewed primary research papers that focused on the fertility desires and intentions among men living with HIV (appendix C). Notably, these articles reported that the majority of men being studied greatly value family and children. These articles also found that fatherhood was highly valued among different cultures and societies. For men living with HIV, fathering can provide respect and prestige and many studies have argued that not having

Mantell, Nywagi, Cishe, & Cooper, 2013). Research has shown that men continue to desire to have children even after their diagnosis with HIV. International studies have reported that 30% to 60% of men living with HIV still wanted to have children. These findings were generated from samples of men from the United States (Chen et al., 2001; Mindry et al., 2013; Nakayiwa et al., 2006), the United Kingdom (Sherr & Barry, 2004), Uganda (G. J. Wagner & Wanyenze, 2013), Tanzania (Mmbaga, Leyna, Ezekiel, & Kakoko, 2013), Kenya (Ngure et al., 2014; Wekesa & Coast, 2014; Withers et al., 2013), Malawi (Dube et al., 2012; Kawale et al., 2014), Brazil (Finocchiaro Kessler et al., 2014; V. Paiva et al., 2003; V. Paiva et al., 2007), Nigeria (Iliyasu et al., 2009; Oladapo, Daniel, Odusoga, & Ayoola-Sotubo, 2005; Olowookere, Abioye-Kuteyi, & Bamiwuye, 2013), Europe and Switzerland (Nostlinger et al., 2013; Panozzo, Bategay, Friedl, Vernazza, & Swiss Cohort, 2003), Ethiopia (Bonnenfant, Hindin, & Gillespie, 2012; Demissie, Tebeje, & Tesfaye, 2014) and South Africa (Cooper et al., 2007; Cooper et al., 2009; Mantell et al., 2014; Matthews et al., 2015; Myer, Morroni, & Rebe, 2007; Taylor et al., 2013). These findings reinforce the notion that parenting is a valued and an important concern for men living with HIV through out the world.

Unfortunately, Canada lacks any research studies that have explored the fertility desires and intentions among men living with HIV. In 2009, a cross-sectional survey study was conducted in Ontario that investigated the fertility desires and needs of HIV-positive women of reproductive age. Of 490 women who participated in this study, 69% possessed the desire to have children and 57% of these women intended to have children in the future (Loutfy et al., 2009). Furthermore, a study performed in 2007 in British Columbia found that 26% of HIV-positive women of reproductive age intended to have children in the future despite their HIV status (Ogilvie et al., 2007). But, these measures have been completed with heterosexual or bisexual men and women. In addition, there is no study about parenting planning for men living with HIV in Canada.

### **Factors influencing fertility desires among men living with HIV**

Men living with HIV may face significant challenges on the road to parenthood that are different than for the healthy population, including stigma, health status, resistance among health care providers, attitudes of the general public, availability of services, legislation, and sperm impairment due to HIV and HIV treatment (Nattabi et al., 2009; van Leeuwen et al.,

2007). In addition, sexual behavior, age, number of living children has been shown to be associated with fertility desires and intentions. Some of these factors will be discussed in the following paragraphs.

### **Sexual orientation**

Although research has not yet explored parenting among heterosexual and non heterosexual men living with HIV, the idea that parenting for non heterosexual men might be different to heterosexual men living with HIV is not new. Using data from the Ontario HIV Treatment Network Cohort Study describing the socio-demographic characteristics of older people (age 50 and over) living with HIV, a significant difference according to the number of children was found between heterosexual and non heterosexual men. In fact, 72% of heterosexual men, 14% of gay and 58% of bisexual men were found to have children ( $P < 0.001$ ) (Brennan et al., 2013) suggesting that sexual orientation might be an important determinant of fertility desires and intentions among men living with HIV.

### **Age**

Studies have found that younger age correlates directly with the desire to have children. For example, studies in the United States (Chen et al., 2001), Ethiopia (Demissie et al., 2014), South Africa (Myer et al., 2007), Europe (Nostlinger et al., 2013), Nigeria Olowookere et al., 2013), Brazil (V. Paiva et al., 2007), Uganda (G.J. Wagner & Wanyenze, 2013) and Kenya (Wekesa & Coast, 2014) have reported that younger men possess a stronger desire to become parents in comparison to older men. Similarly, men aged 36-45 were associated with a decreased desire to have children in Malawi [odds ratio (OR): 0.64 95% CI: 0.46-0.90,  $p = 0.009$ ] (Kawale et al., 2014) and in Europe [OR: 4.4 95% CI: 1.8-10.6] (Nostlinger et al., 2013).

### **Number of living children**

Eleven of the studies reviewed have reported that the number of living children significantly influenced reproductive intentions. For example, cross-sectional studies in Malawi and Tanzania concluded that men with one child, or who were childless, were more likely to want children (Kawale et al., 2014; Mmbaga et al., 2013). A South African study found that having fewer children correlated directly with fertility intention among men living with HIV [OR: 0.22; 95% CI: 0.15-0.60] (Myer et al., 2007). In addition, a British study found that men who



had children prior to their diagnosis were less likely to want more children(Sherr & Barry, 2004).

### **Health status**

Health status, duration of HIV infection and <sup>1</sup>CD4 count were relevant predictors of fertility desires and intentions in many studies. Several studies reported that people who were in good health and with higher CD4 counts (>200 cells) were more likely to desire children (Chen et al., 2001; Mmbaga et al., 2013). Furthermore, one study noted that people who were recently diagnosed with HIV (less than one year) were five times more likely to desire to have children than those who were diagnosed with HIV more than five years ago (Demissie et al., 2014).

### **Fear of discrimination and community disapproval**

Quantitative surveys and in-depth interviews of men with HIV in South Africa have shown that stigma and community disapproval were key determinants in their decision to not have children (Cooper et al., 2007). In a study conducted in the United Kingdom, more than 40% of HIV- positive men feared that they would experience discrimination if they had children(Cooper et al., 2007). Research has shown that expectations from an individual's culture and community greatly influenced their desire to have children. In Ethiopia , people facing community pressures to have a family were four times more likely to desire children than those without external pressures from a close-knit community (Demissie et al., 2014).

### **Attitudes of health care providers**

Studies in the United Kingdom have reported that 50% of men would be open to attending consultations about fertility from their health care providers. This research project also found that less than 10% of men living with HIV were given medical advice concerning having children (Sherr& Barry, 2004). Alternatively, studies in Brazil and Switzerland reported that men living with HIV felt that their questions and concerns regarding fertility planning were not adequately addressed. These studies concluded that few men received information and educational counselling about how to protect their children from transmitting the virus (V. Paiva et al., 2003; Panozzo et al., 2003).

However, these data are from international studies. There are differences between Canada and other countries such as United States, Europe, and Africa in socio-demographic characteristics of men with HIV including ethnicity, immigration status and HIV risk exposures (Brennan et al., 2013). Therefore, the absence of Canadian data makes it difficult to counsel men and their partners regarding parenting options and has created substantial disparity in the availability of these services relative to what is available for women.

### **Assistance in achieving pregnancy for men living with HIV and their partners**

The partnering status and HIV-status of a partner dictate what options are recommended to achieve a pregnancy for men living with HIV. In a series of four pregnancies achieved through natural conception with HIV-positive men and HIV-negative women, no seroconversion occurred within the first three months following conception; however, two women seroconverted at seven months of pregnancy and two others converted postpartum (Mandelbrot, Heard, Henrion-Geant, & Henrion, 1997). It is important to note that this study was performed before viral load testing was available and the viral load status of the male partners was not known at the time. However, it has been shown that a suppressed plasma viral load is not necessarily indicative of a suppressed viral load in the genital tract (Kim et al., 1999). A safer alternative is the use of the sperm washing techniques in fertility clinics, which separate actual spermatozoa from the seminal fluid, which harbours the virus.

Research on this topic has shown that seminal fluid does not express significant levels of HIV receptors, so it is unlikely to be a major target of HIV infection (Kim et al., 1999). To date, 300 healthy children have been born after more than 3,000 cycles of sperm washing and intrauterine insemination (IUI) or in vitro fertilization (IVF), with no reported seroconversion in either partner or child (Barnes et al., 2014; Semprini et al., 1992). Most of these reports are from Europe, with only a small number from the United States. Notably, Canada has not published a report or study regarding this issue.

Ontario is only recently beginning to center clinical attention on the feasibility of men who require surrogacy in order to conceive. Despite the fact that some fertility clinics in Canada do offer surrogacy to men, it is not yet available to men living with HIV because of Canadian legislation that prohibits the donation of fresh or frozen sperm from an HIV-positive donor even when the recipient (i.e. gestational carrier, surrogate or consenting friend) is aware of

the status of the donor (Loutfy et al., 2012). Furthermore, it should be noted that conception options which require the assistance of a fertility clinic, though medically viable, may not be accessible to HIV-positive people due to various factors. Lack of financial assistance, lack of facility in home city or province, legal and institutional regulations, lack of awareness on the part of the health care provider or the prospective parents, as well as HIV-related stigma, all impede the accessibility of surrogacy to men who require it to have children. Due to these restraints, the journey to parenthood for men living with HIV possesses many unique obstacles and challenges that differ from the female experience.

Our review confirms that men living with HIV express strong desire and intention to have children and there are many factors associated with fertility desire and intention; but research has been mainly focused on heterosexual men. Therefore, current measurement instruments have been developed to measure fertility for this group of individuals. Furthermore, our findings suggest that the fertility research priorities for all men have not been adequately addressed in the available body of literature.

## **Rationale and objectives of the study**

Men living with HIV have a right to equitable access to reproductive services. Fatherhood is an important aspect of the lives of HIV-positive men. Previous research has shown that fatherhood is a life changing experience for the male population. Fatherhood can motivate men to reevaluate their life goals, stop or decrease risky behaviours and strive for healthier life styles (Taylor et al., 2013). Therefore, one could argue that it is essential that health services in Canada provide men living with HIV unbiased support and services in order to inform decisions about sex, reproduction and family planning (Boquet, Wonganan, Dekker, & Croyle, 2008). However, it is becoming increasingly evident that HIV research concerning reproductive health and family planning has focused mainly on women. It is also evident that available studies on men have been disproportionately biased toward the perspective of heterosexual men. Studies that focus on the needs and desires of homosexual men are lacking in comparison to heterosexual males. Available tools to measure fertility desires and intentions of men living with HIV were from international studies or have been developed for women studies. However, it should not be taken for granted that instruments that have been used to study fertility intentions and desires will be equally reliable and valid. There are different reasons for this difference between Canada and other countries. The sociodemographic characteristics as well as the clinical and epidemiology presentations of HIV positive men in Canada are different than in any of the other country. In addition, available instruments use only single item to describe the desire or intention to have children for men living with HIV. Therefore, there is a need to assess these variables using multiple items in order to have a broad understanding of parenting planning of this group of individuals. Despite the fact that some fertility clinics in Canada do offer surrogacy to this population, it is not yet available to men living with HIV because of Canadian legislation that prohibits the donation of fresh or frozen sperm from an HIV-positive donor even when the recipient (i.e. gestational carrier, surrogate, or consenting friend) is aware of the status of the donor (Loutfy et al., 2012). Furthermore, it should be noted that conception options which require the assistance of a fertility clinic, though medically viable, may not be accessible to HIV-positive people due to various factors. Lack of financial assistance, lack of facility in home city or province, legal and institutional regulations, lack of awareness on the part of the health care provider or the prospective parents, as well as HIV-related stigma, all impede the accessibility of surrogacy to men who require it to have children. Due to these restraints, the

journey to parenthood for men living with HIV possesses many unique obstacles and challenges that differ from the male with other chronic diseases experience. The purpose of the study is to develop and validate a specific instrument that will be used by clinician and health care providers to assess fertility desires and intentions among men living with HIV in Ontario

Canada is currently working to improve the quality and accessibility of support groups, counselling and health and social services for people living with HIV. Family planning has become an increasingly important topic in the HIV community. Research focusing on the male perspective and the male desire for children is a slowly growing field in Canada. The Interdisciplinary HIV Parenting (previously Pregnancy) Research and Exchange (previously Research)Group (IHPREG) (Interdisciplinary HIV Pregnancy Research Group, n.d) was formed to help support multi-disciplinary and community driven research issues regarding conception, pregnancy and parenting. IHPREG is a large research endeavour that has only recently included men in its research endeavours.

By collecting information about the fertility desires and intentions of men living with HIV, this study will allow clinicians, AIDS Service Organizations (ASOs) and the HIV-positive community to become more aware of the desires, intentions and needs of men in regards to parenting. In addition, these data are fundamental in the development of services, support and resources in relation to fertility and fatherhood for men who are HIV-positive. However, before this data can be collected, an instrument is needed. Therefore, the purpose of this study is to create and validate an instrument for ascertaining the fertility desires and intentions of men living with HIV.

Our objectives are:

- To develop a survey instrument to assess fertility desires and intentions among HIV-positive men
- To assess the face, content, construct and concurrent validity, as well as test –retest and internal consistency of the developed instrument

This instrument will be used in future studies to determine the fertility intentions among HIV-positive men living in Ontario. It will also investigate the correlates of these intentions and the proportion of HIV-positive men who have become parents. This instrument will explore the experiences that men living with HIV have had with fertility services as well as highlight

the needs regarding parenting and fertility services within Ontario. These data are required to develop proper services and resources related to fertility and fatherhood among men living with HIV in Ontario.

## **Methodology**

### **Survey development**

A flow chart demonstrating the process, development and validation of the survey is provided in appendix A. Our strategy for survey development and validation included draft development, face, content, construct and concurrent validity; test-retest and internal consistency (Dillman, 2007)

### **Constructs and items selection**

Initial domains were drawn from two previously published survey instruments; one assessing fertility desires and intentions among Canadian HIV-positive women including 189 items and 14 domains (Loutfy et al., 2009) and a second assessing reproductive views among HIV-positive heterosexual men in London, England including 17 item –questionnaire (Sherr & Barry, 2004). These surveys were developed based on the framework for modelling fertility motivation which is based on the Traits-Desires-Intentions-Behaviour (TDIB) sequence that is required for pregnancy (Miller, Severy, & Pasta, 2004). Construct were selected from the instrument used by Loutfy et al in 2009 to assess fertility desires and intentions among women living in Ontario (Loutfy et al., 2009). This survey was reviewed and women specific questions were removed. We then reviewed the women and men surveys to select questions on motivations (traits), desire, intention and behaviour (s) related to the pursuit of fertility. The wording deemed most appropriate was used with minor revisions to tailor the survey instrument to the context of this study. Additionally, we conducted online literature review of prior work on determinants of reproductive decisions by men, regardless of HIV status. We searched online publications between the years 2000-2015 using the PubMed online database. The following key words “fertility+ HIV+women” were used to search for literature on women and the following key words “fertility+ HIV+ men” were used to search for literature involving men. We also used the key words “fertility + HIV+ gay men” to search for literature related to homosexual men. Relevant articles to fertility desires and intentions among men were then subsequently selected for the review process. The list of 27 studies reviewed is attached in appendix C.

## **Content validation**

The survey draft (appendix B) assessed during the content validation included 122 items. The content validation was carried out by six experts selected across Ontario, including specialists in infectious diseases (2), HIV primary care (2) and internal medicine (2). They were members of IHPREG and most of them were involved in the content validation of the survey instrument assessing fertility desires and intentions among women with HIV in Ontario (Loutfy et al., 2009)

After the items were selected and adapted to measure fertility intention and desire, two rounds of content validation were undertaken to assess whether the content of the questionnaire was appropriate and relevant for the purpose of the study. In qualitative research, experts are invited to comment on the relevance of the specific items (Safikhani, Sundaram, Bao, Mulani, & Revicki, 2013); however, in quantitative content validity, experts are invited to select the most important and correct content in an instrument using a developed validation form. There are different methods used for quantitative data analysis for individual items collected such as the content validity ratio, the content validity index (CVI) and the factorial validity index (Artino, La Rochelle, Dezee, & Gehlbach, 2014). The content validity index is the most widely used and possesses many advantages, including ease of computation, ease of understanding, based on agreement of relevance and provides both item and scale information (Polit, Beck, & Owen, 2007).

For the first round, five experts independently rated the relevance of each item using a 4-point Likert scale (1=not relevant, 2=somewhat relevant, 3=relevant and 4=very relevant) and the CVI was computed. In addition to collecting quantitative data, we asked experts to comment on the relevance of each item. This approach is particularly effective in identifying what indicators of the construct or scale are not well-represented by the existing items or whether there are enough items to cover the objective of the study (McKenzie, Wood, Kotecki, Clark, & Brey, 1999). This was of special interest because it has been demonstrated that information collected from the free-text comments and subsequent qualitative analysis can reveal information not gathered by the quantitative data (McKenzie et al., 1999). From the first round of validation the survey was updated. During the second round of validation, the overall questionnaire (updated from the first round) was reviewed by one expert. The draft online instrument was created using LimeSurvey. LimeSurvey is an application for



tools for developing and publishing on-line surveys and collecting responses. In addition, it created basic statistics necessary to check the profile of the respondents. Computer assisted personal interviewing (CAPI) model was used to administer the measure under development. CAPI offers the advantages that it can limit data entry errors since the respondent can view and check his answer when it is entering in the database by the interviewer. By guiding the respondent, the interviewer provides an efficient way to deal with the complexity of some questions. In addition, the interviewer cannot miss a question. Also, the computer can check for inadmissible or inconsistent responses (Sainsbury, Ditch, & Hutton, 1993)

### **Face validation: pretesting and focus group**

Face validity was undertaken in two steps: including pretesting and focus group. During pretesting, participants completed the online instrument under development. We used CAPI model, so research staff sat down with the participants to answer questions and input the response into Limesurvey database. Participants answered questions about demographics, contraception and sexual history, interest/desire to have children, intent to have children in the future, behaviour (s) related to the pursuit of fertility, conception and parenting, perceived support for becoming a parent, satisfaction with providers related to fertility goals, needs assessment and HIV history. Following pretesting, community members participated in a focus group. Focus group data were collected through open-ended questions. Participants were asked to provide their thoughts about the layout of the questionnaire under development in terms of the length, flow, clarity, and use of language. In addition, participants examined the content of the questionnaire by discussing each of the 10 sections (themes) including demographics, contraception and sexual history, interest/desire to have children, intent to have children in the future, behaviour (s) related to the pursuit of fertility, conception and parenting, perceived support for becoming a parent, satisfaction with providers related to fertility goals, needs assessment and HIV history. In focus group, the size of the group is important for the interaction between group members, as well as the interaction between the moderator and the group. One could argue that a group that is too large may result in some participants becoming passive and not sharing their experience. In contrast, having too few participants may increase the chance of group stagnation and hinder group participation (Wong, 2008). Five men living with HIV including three non heterosexuals and two heterosexuals from a large HIV clinic in Toronto were involved in face validity. The three non heterosexual men were Caucasian born in Canada and the two heterosexual men were

immigrants from black and Hispanic backgrounds. They were between 22 and 57 years, the median age was 44 years and the mean was 43 years. The CD4 counts of all participants were above 200 cells/mm<sup>3</sup> and they reported undetectable (<50 copies/mL) viral load. All of them were currently on HIV medication. Criteria for inclusion in the focus group were: HIV-positive, 18 years or more, identified as male and live in Toronto. Using a sample of five participants provided ample opportunity for each participant to contribute to the conversation and share their experiences. The focus group guide including themes, questions, and procedure is provided in appendix D. Roughly, the instructions and the objectives of the study were carefully read before the focus group started. Participants were allowed time to read through the consent form and respond to any questions or clarifications that they had. Then they were asked to sign the consent form once they are satisfied with the information contained. The session lasted 2.5 hours including one hour for pretesting and one hour and half for focus group. The focus group session was recorded and was further transcribed. Additionally, notes were taken. Participants were given \$30 to cover the cost of travel and other expenses.

### **Pilot study**

The aim of the pilot study was to assess the validity and the reliability of the instrument. Validity refers to how well a test measures what it is purported to measure. Reliability is the degree to which an assessment tool produces stable and consistent results. Two forms of validity were including construct and criterion validity were assessed. Also, two forms of reliability including internal consistency and test-retest reliability were undertaken. These were further described. The pilot study was completed using CAPI model.

### ***Inclusion/exclusion criteria***

Inclusion criteria included:

- Individual is HIV-positive
- Individual is 18 years of age or greater
- Individual identifies as male
- Individual is living in Toronto

## ***Recruitment***

A sample of 60 men was recruited of whom 20 also participated in the test-retest of the instrument. The sample size for pilot testing is based on the number of participants required to test the adequacy of the instrument and is aligned with recommendations from two studies which suggested a minimum of 30 participants for the preliminary survey and survey/scale development (Hertzog, 2008). Most participants were recruited from a large clinic in downtown Toronto, which provides care to more than 2500 people living with HIV, most of whom are men. The pilot testing was carried out using a cross-sectional design. Participants completed the online draft survey under development and were given \$30 to cover the cost of travel and other expenses.

***Construct validation:*** Construct validity, which refers to the degree to which the items of an instrument relate to the relevant theoretical construct was assessed for our construct of interests including desire and intention. Factor analysis was used to reduce the number of variables and provide evidence of construct validity. It is essential to have a large enough sample to enable factor analysis to be undertaken. There are different opinions and several rules-of-thumbs in the literature about sample size that do not take into account the dynamic process of factor analysis (MacCallum, Widaman, Zhang, & Hong, 1999). Early studies suggested sample sizes between 50 (very poor) to 1000 (excellent). However, a number of studies have highlighted the importance of large sample sizes, high communalities and variables per factor (MacCallum et al., 1999). Moreover, it was shown that if the levels of loading is high, the number of factors low, and the number of variables high, factor analysis can lead to reliable results even with a sample size below 50 (de Winter, Dodou, & Wieringa, 2009). Factor analysis is designed for interval data, although it can also be used for ordinal data (e.g. scores assigned to Likert scales). There are two major types of factor analysis: exploratory factor analysis (EFA) and confirmatory factor analysis (CFA). In comparison to EFA which determine the number of factors and loadings, CFA is based on an *a priori* model regarding the number of factors and assesses how well the variables measured represent the number of constructs (Williams, Brown, & Onsmann, 2010). CFA allowed us to test the hypothesis that nine items can load in the construct desire. In addition, we tested the hypothesis that five items can load in the construct intention. Therefore, whether items can load all together in a predetermined number of construct was assessed. The *a priori*

hypothesis outlining the items and domain structure of the instrument is provided in appendix E

Five main steps were followed for factor analysis:

- Estimation of the Kaiser-Meyer-Olkin (KMO), Bartlett's test of sphericity and the Root Mean Square Error of Approximation (RMSEA)
- Calculation of initial factor loading using principal components analysis (PCA): PCA is a data reduction method.
- Factor rotation: rotation makes the factor much clearer, immediately apparent and easier to interpret (Osborne, 2015). There are oblique and orthogonal rotations. We used varimax (orthogonal rotation unrelated factors). The goal of the varimax rotation is to associate each variable to at most one factor. So, each variable was to be associated to one and one only factor. Rotation was possible when there were two or more subgroups of factors.
- Estimation of the eigenvalues
- Items removal

Construct validity was assessed for our interest construct including desire and intention using confirmatory factor analysis (CFA).

**Internal consistency:** Internal consistency examines the inter-item consistency within an instrument and indicates how well the items fit together (Lavrakas, 2008). Cronbach's alpha was computed for 10 constructs including 'feelings', 'worries', 'fertility desires', 'plans to have children in the future', 'behaviour(s) related to the pursuit of fertility', 'conception and parenting', 'support for becoming a parent', 'fear', 'experiences with fear' and 'satisfaction with providers related to fertility goals'.

**Test-retest:** Test-retest reliability refers to the consistency of responses over a period of time (Lavrakas, 2008). The interval between the two tests is very important because it influences the correlation between tests in an inverse fashion. That is, the shorter the duration between tests, the higher the correlation between responses, whereas a lower correlation is observed with a longer interval between tests (DeVon et al., 2007). However, there is no clear evidence

about the optimal time interval between the test and the retest. During the test participants were asked whether they will be interested in coming back for retest and the 20 first participants who agreed were invited for retest at intervals of two to five weeks between tests. In total 15 participants were retested right after two weeks and five between two to five weeks.

**Concurrent validity:** Concurrent validity assesses the extent to which the fertility desire and intention of the developed instrument correspond to previously established measurement. Concurrent validity of the two constructs desire and intention was established. Therefore, the fertility desire and intention of the validated constructs were compared with the known fertility desires and intentions from the literature and from single item variable analysis

### **Data Analysis**

To deal with missing data, only available data were analyzed, however, the percent of missing data was very low.

### **Content validity**

The content validity index (CVI) and suggestions of the experts were used to estimate the validity of all the items. The content validity index (CVI) of each item was computed based on the representativeness of the item by counting the number of experts who rated the item as relevant and very relevant and dividing that number by the total number of experts. The first criterion of content validity was a CVI more than 0.78 (Polit et al., 2007). This is, at least four out of the five experts agree. The second criterion was the comments of experts and to some extents the importance of the variable measured. This criterion applied to items with CVI less than 0.78. Although this second criterion was more subjective, it has been demonstrated that information collected from qualitative analysis can reveal information not gathered by the quantitative data and may in turn lead to further editing and additions or subtractions of items from the survey. Following these steps, the draft underwent a final qualitative review by one expert.

### **Face validity**

The data collected from the focus group was transcribed using a verbatim style. During this process the initial thoughts and ideas were noted. The transcript was then analyzed using a

direct content analysis for participant opinions about the instrument. The goal of a directed approach to content analysis is to validate different themes. The themes discussed were pre determined by the focus group moderator and were provided on the methodology section and on the focus group guide (appendix D). The following approach was considered during content analysis:

- The recording was transcribed
- Different themes were identified
- Data were organized by themes as discussed
- A short report was developed for each theme

To ensure that important information were not missed the transcribed data was read and re-read several times. In addition, the recordings were listened several times to ensure the accuracy of the transcription. Notes taking data during the focus group were also consulted.

### **Pilot study**

Pilot study data was analyzed using SPSS 16.0. An SPSS database was created followed by data entry. Data was double checked directly against the LimeSurvey database for data entry errors. Additionally, several frequency tests were run for both databases to check for errors.

- **Construct validity:** CFA was used to demonstrate the validity of the construct. The model fitting was assessed using KMO, Bartlett's test of sphericity and RMSEA. RMSEA was computer using the following formula.

$$\frac{\sqrt{(\chi^2 - df)}}{\sqrt{[df(N - 1)]}}$$

$\chi^2$  (approximate Chi-Square) and df (degree of freedom) that were computer using the SPSS software. N is the sample size which in this case is 60. The RMSEA ranges from 0 to 1, with smaller values indicating better model fit. A value of 0.06 or less is indicative of acceptable model fit. In small samples like ours, the cut-off value for RMSEA tends to over-reject properly specified model (Hu & Bentler, 1999). Our hypothesis was that RMSEA >0.06 due to our small sample size. When the RMSEA cutoff values are used to assess the fit of the models with small degree of freedom and sample size, Kenny et al suggested that it can falsely indicate a poor model-fit (Kenny, Kaniskan, & McCoach, 2015). The sample did not reach the recommended minimum number of participants for confirmatory factor analysis:

however, we examined the KMO and Bartlett's test of sphericity to ensure our sample met adequate requirements for analysis. The KMO statistic varies between 0 and 1. A value of 0 indicates that the factor analysis is inappropriate. A value close to one indicates factor analysis will yield distinct and reliable factors; however, the recommended acceptable value is  $\geq 0.50$ . Our hypothesis was that  $KMO < 0.05$ . For Factor Analysis to be recommended suitable, the Bartlett's Test of Sphericity must be less than 0.05. We selected the number of factors with eigenvalues of 1.00 or higher. Also, the number of variables and loadings is important in factor analysis. It was suggested that a factor is reliable if it has four or more loadings of at least 0.60 regardless of sample size (Field, 2005). In 1992, Stevens suggested a cut-off factor loading of 0.40 irrespective of sample size for interpretative purposes (Stevens, 1992). Knowing that the goodness-of-fit indices are only one aspect of CFA model evaluation; therefore, it is important to examine the interpretability and strength of these parameter estimates (Brown, 2015)

For this study: 1) the eigenvalues  $\geq 1$  was used to decide how many factors to extract; 2) items with factor loading  $< 0.40$  were removed; 3) sub-factors with less than four variables were suggested to be combined to one concept and 4) the new statistics information including internal consistency or/and factor loading were then recomputed for construct that underwent item (s) removal.

**Internal consistency:** Cronbach's alpha was used to examine the internal consistency of the survey during pilot-testing. The sample size influences the cut off value for Cronbach's alpha. Based on the sample of 60, the cut off value for Cronbach's alpha for the developed instrument was 0.7 and indicated good correlation (Hertzog, 2008; C. E. Paiva et al., 2014).

**Test-retest:** The questionnaire used for test –retest consisted of a five point Likert scale rated from strongly disagree to strongly agree. Spearman's rho is a better estimator of the relationship between test-retest according to literature when compared to intraclass correlation coefficients (Nilsson, Eneroth, & Ekdahl, 2013). The sample size influences the cut off value for a Spearman's rank-order correlation ( $\rho$ ). Based on the sample of 20, the study seeks evidence of a correlation of at least 0.7 for the test-retest reliability. For most instruments, a correlation of  $\geq 0.7$  is acceptable (Hertzog, 2008; C. E. Paiva et al., 2014). Test-retest reliability was estimated using three selected items that directly measured fertility desires and intentions

***Socio-demographic characteristics:*** Descriptive statistics were used to assess socio-demographic characteristics using medians and IQRs for continuous variables, frequencies and proportions for categorical variables.

***Concurrent validity:*** To establish concurrent construct validity, item variables in the construct were used. The variable was measured on a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree). All the men who answered agree or strongly agree were considered that they desire or intend to have children and those who reported strongly disagree, disagree, and neither disagree or agree) were considered to not desire or intend to have children (Kennedy et al., 2014). The proportion of men who desire/intend to becoming a father was computed for each single item and used as first criterion for selecting items to assess concurrent validity and logistic regression. The low and high cuts off for desire and intention were 30% and 60 % respectively based on the literature which suggested that one – third of men with HIV desire to have children; 60% is the highest fertility desire and intention that has been obtained to date from men living with HIV (Chen et al., 2001; Oladapo et al., 2005). In addition, wording was used as second criterion to discard some items. Only items that directly measure desire and intention were retained. Therefore, three and two items were used for further desire and intention analysis respectively. Concurrent construct validity was assessed using the proportion of agreement across the three items for desire and two items for intention constructs. The proportions were compared to those in the two main surveys that were used to develop this instrument (Loutfy et al., 2009; Sherr & Barry, 2004). In addition, the proportions were compared to those obtained from single item variables in the survey. The single item variable including ‘How many children would you like to parent in the future?’ (for fertility desire) and ‘How many children do you expect to parent in the future?’ (for fertility intention). The item was dichotomized to ‘No’ if answer 0 or ‘Yes’ if answer ‘ $\geq 1$ ’ (Loutfy et al., 2009).

### **Ethical approval**

This study was approved by Lakehead University and the University of Toronto Research Ethics Board.



## Results

### Domains and constructs of the survey

Table 1 shows specific domains and constructs that were identified from two previous survey instruments; one assessing fertility intentions and desires among Canadian HIV-positive women (Loutfy et al., 2009) and a second assessing reproductive views among HIV-positive men in London, England and literature search. The draft instrument includes 10 domains and 14 constructs. The TDIB model states that fertility motivations of individuals produce behaviours that promote or prevent desire or intention. So, in addition to our construct of interest including desires and intentions, we assessed other constructs and domains that provide important information on pregnancy decision-making among men living with HIV such as traits or motivations, factors and determinants of fertility desires and intentions.

**Table 1: Draft questionnaire domains and constructs**

Domain	Construct
Demographics	Demographics
Contraception and sexual history	Contraception and sexual history
Interest/desire to have children	Feelings
	Desires
Intent to have children in the future	Plans to have children
	Worries
Behaviour (s) related to the pursuit of fertility	Behaviour(s) related to the pursuit of fertility
Conception and parenting	Conception and parenting
Perceived support for becoming a parent	Support
	Fear
	Experience with fear
Satisfaction with providers related to fertility goals	Satisfaction with providers related to fertility goals
Needs assessment	Needs assessment

In total the draft questionnaire consisted of including 14 constructs. Two constructs including are related to fertility desire and intentions. The developed questionnaire included dichotomous, multiple choice and Likert-type questions (appendix B).

### Content validity

Following the CVI calculation, items that were deemed irrelevant were deleted, edited or unchanged. Table 2 shows the items that were deemed irrelevant by the CVI and the actions taken.

**Table 2: Content validity index<0.78 of the items and the action taken**

Domain	Items	CVI	Action taken
Interest/Desire to Have Children	I feel that being a father would increase my self-esteem	0.6	edited
	I would like having children but have been unable	0.6	deleted
Intent to Have Children in the Future	Because HIV medications will let me live longer, I am considering becoming a father.	0.6	no action
	I would be willing to have unprotected sex with a woman in order to become a father	0.6	deleted
	As a man with HIV, I can go to a fertility clinic and access medical help to have a child, including egg donor and surrogates	0.6	deleted
	I am worried that if I become a father, my child will be born HIV-positive	0.6	no action
Contraception and Sexual History	Have you had sexual intercourse (vaginal) with a female partner EVER in your lifetime?	0.6	skip pattern recommended
	If you have any children, has your doctor asked you about the HIV status of the person who carried that pregnancy?	0.4	deleted
Fertility and Parenting History	If you have biological children, what is your current relationship with them?	0.6	deleted
	If you have biological children, have any of these children been diagnosed with HIV?	0.6	deleted
	How many children LIVE with you now? (Include children that you care for but did not give birth to)	0.6	deleted
	If you have children that you are caring for, how old are they? (please list their ages)	0.6	deleted
Satisfaction with Providers related to Fertility Goals	Do you have a family doctor?	0.6	no action
	I can trust my family doctor	0.6	no action
HIV History	Do you currently have any of the following sexually transmitted infections?	0.6	edited

	Are you currently taking hepatitis C treatment? (This medication should not be taken when trying to have a child)	0.6	no action
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According to the CVI, a total of 16 items have CVI <0.78; therefore, they were deemed to be invalid. Of the 16 items, eight were deleted, three were revised and five were kept in their original format because they were used to measure important determinants of fertility such as the capability to fathering and the attitude of health care providers about fathering for men living with HIV (Table 1). For example hepatitis C medications such as ribavirin and pegylated interferon alters semen quality and should not be taken when trying to have a child (Pecou et al., 2009). All the remaining items were deemed valid, with CVIs ranging from 0.8 to 1.0.

Table 3 shows the new items that were suggested and added to the survey. Finally, one more expert reviewed the instrument and no changes were recommended. However, the expert suggested providing participants with the option of completing sensitive questions alone, in the absence of an interviewer. The web survey was developed with some screening/logic checks built in for heteronormative items.

**Table3: New items suggested by experts**

<b>Construct</b>	<b>Items</b>
Interest/Desires to have children	I am happy with my life without children
	I would like to become a father without parenting the child(ren)
Intent to Have Children in the Future	I am willing to pay for fertility clinic resources so as to protect woman from HIV transmission
	If I were to become a father, I would be worried that my children will experience discrimination at school

### Face validity – focus group

Participants indicated that the layout was adequate and the time to complete the survey (25-30 minutes) was appropriate. Some participants pointed out that they were presented with questions which were not relevant to their experience. In these cases, they suggested adding a ‘not applicable category so that participants would not be forced to choose an answer they were not comfortable picking. Some participants found many questions or constructs confusing and they suggested that a definition of the questions or constructs would be helpful (see appendix E for focus group guide). Wording was also the subject of comments for many of the participants who suggested re-wording and editing many items. Table 4 shows new items that were suggested to be added from the focus group discussion.

**Table 4: Face validation new items**

Construct	Items
Desires	Being diagnosed with HIV affects my decisions about not becoming a father.
	If I was in a situation where I could become a father, I would not want that to happen.
Worries	I would be worried that my HIV medications will affect my ability to care about my child.
	I would be worried that if I have children I would not focus enough on my medication.
Behaviour(s) related to the pursuit of fertility	I have spoken to my birth mother or co-parent about having a baby.
	I have spoken to a community member about having a baby.
Experience with conception/parenting	How many children have you ever parented?
	How many children have you ever parented since you were diagnosed with HIV?
Support	My community wants me to have a child.
	By having a child, it would make my community happy.

**Table 4: Face validation new items (continue)**

Fear	I am afraid of being judged negatively by my other child (ren) of trying to have more children.
Satisfaction with providers related to fertility goals	I am comfortable sharing my concerns about becoming a father with my case worker/social worker.
	I am comfortable talking to my case worker/social worker about fatherhood as a man living with HIV.
	I can trust my case worker/social worker.
	I am satisfied with the service I receive from my case worker/social worker.
	I am satisfied with the amount of parenting planning information I received from my case worker/social worker.
	Has your case worker/social worker talked to you about fatherhood?
	Has your case worker/social worker ever advised you against having children?

Most participants felt that the key aspects of fertility intentions and desires were reflected in the survey and found the study very relevant and important. However, some participants suggested the following additions to the survey:

- add the question ‘who do you live with’ on section about socio-demographics
- provide more choices for religion
- provide more answer options to question about partner’s status
- add more questions about social workers to give more choice on satisfaction with providers related to fertility goals
- add more questions about fertility desires
- add questions about medication to allow more choice on ‘worries’ domain

-add more questions on community and parents to allow more choices on ‘actions taken in the last 12 months’

-add more questions on community and parents to give more choices on ‘perceived support for becoming a parent’

-more choices on experience with conception/parenting

Overall, in response to focus group feedback, 18 items were added to the questionnaire (Table 4).

### **Pilot testing**

#### ***Demographic characteristics***

Table 5 shows the characteristics of pilot testing participants recruited in March-April 2016 from an HIV clinic in Toronto. As the table indicates, 60 men participated in the pilot testing of the survey. The majority (78.3%) identified as non-heterosexual. The age of participants ranged from 26 to 57 years, with a median age of 44 (IQR 37-52) and an average of 43.3 years (SD 10.4).

**Table 5: Demographic characteristics**

<b>Characteristics</b>		<b>Characteristics</b>	
<b>Median age (years)</b>	44 (37-52)	<b>Number of people living in the household</b>	
Average age	43.3 (SD 10.4)	1	30 (50%)
21-30	8 (13.3%)	2	19 (31.7%)
31-50	34 (56.7%)	3 and more	11 (18.3%)
>50	18 (30.0)	<b>Annual income</b>	
<b>Ethnic background</b>		<20 K	16 (26.7%)
Caucasian	33 (55.0%)	20-39K	12 (20.0%)
Black	15 (25.0%)	>40k	32 (53.3%)
Asian	5 (8.3%)		
Hispanic	3 (5.0%)	<b>Marital status</b>	
First Nation/Métis/Inuit	2 (3.3%)	Single	30 (50.0%)

**Table 5: Demographic characteristics (continued)**

Other	<b>2 (3.3%)</b>	<b>Married</b>	<b>11 (18.3%)</b>
<b>Birth place</b>		Living with a partner	7 (11.7%)
Canada	34 (56.7%)	Common- law partner	5 (8.3%)
Africa	11 (18.3%)	Never married	4 (6.7%)
Caribbean	4 (6.7%)	Divorced	2 (3.3%)
Other	11 (18.3%)	Widowed	1 (1.7%)
<b>Years in Canada</b>	33.5 (16.5-50)	<b>Education</b>	
<b>Religion</b>		Less than bachelor	33 (55.0%)
Catholic	17 (28.3%)	bachelor or higher	27 (45.0%)
Agnostic	6 (10%)	<b>Years since diagnosis</b>	11 (4-18)
Protestant	5 (8.3%)	<b>HIV risk factor</b>	
Eastern Orthodox	4 (6.7%)	Sex with a male partner	42 (70%)
Baptist	3 (5%)	Sex with a female partner	9 (15%)
Muslim	2 (3.3%)	Blood transfusion / blood product	3 (5%)
Buddhist	2 (3.3%)	From birth mother	2 (3.3%)
Aboriginal Traditional	2 (3.3%)	Sexual assault	1 (1.7%)
Other	19 (31.7%)	Needle sharing	1 (1.7%)
<b>Sexual orientation</b>		Don't know	2 (3.3)
Non heterosexual	47(78.3.7%)	<b>Recent CD4 count</b>	650 (490-840)
heterosexual	13 (21.7%)	>200 cell/mm3	100%
Cis-gender male	60 (100%)	<b>Recent VL</b>	
<b>School / Work</b>		<50	93.80%

**Table 5: Demographic characteristics (continued)**

Full/part time work	<b>24 (40.0%)</b>	Currently taking HIV medications	<b>98.30%</b>
On government assistance	15 (25.0%)	<b>Sexually transmitted infections</b>	
Full/part time school	4 (6.7%)	Hepatitis B	1 (1.7%)
Self employment	4 (6.6%)	Chlamydia	1 (1.7%)
Retired	6 (10.0%)	Syphilis	1 (1.7%)
others	7 (11.7%)	HPV (genital warts)	8 (13.3%)
<b>Hepatitis C</b>	3 (5%)	Herpes (genital)	4 (6.7%)
<b>Number of children ever parented</b>		Number of children ever parented since diagnosed with HIV	
<b>0</b>	43 (71.7%)	0	48 (80.0%)
<b>≥1</b>	17 (29.3%)	≥1	12 (20.0%)

Continuous variables presented as medians with interquartile range; categorical variables presented as N (%)

### ***Construct validation***

To verify the predetermined construct structure of a set of items, confirmatory factor analysis (CFA) was conducted for desire and intention based on the hypothesis that a relationship between items and their predetermined constructs exists.

Table 6 below shows the KMO and Bartlett coefficient and Root mean square error of approximation (RMSEA) for analyzed constructs. However, the KMO varied between 0.64 to 0.66 and the Bartlett test of sphericity for all the two constructs were less than 0.05 suggesting the suitability of our data for CFA.



**Table 6: the KMO, Bartlett coefficient and Root mean square error of approximation for interest constructs**

	<b>KMO</b>	<b>Bartlett test</b>	<b>Root Mean Square Error of Approximation (RMSEA)</b>
Desires	0.66	$\chi^2 = 233.14, df = 36, p < 0.001$	0.30
Intentions	0.64	$\chi^2 = 57.39, df = 10, p = 0.00$	0.28

**Component matrix and internal consistency reliability for ‘interest/desire to have children’**

The construct consisted of nine items. The KMO coefficient for the construct ‘interest/desire to have children’ was 0.66 and the Bartlett test of sphericity was statistically significant ( $\chi^2 = 233.14, df = 36, p < 0.001$ ), indicating a good correlation between variables for Factor analysis (table 6).

Table 7 shows the total variance explained by the principal components for ‘interest/desire to have children’. Two factor recording an eigenvalue above 1 that explains 61.69% of variance.

**Table 7: Total variance explained by the principal components for ‘interest/desire to have children’**

Component	Initial eigenvalues			Extraction sums of squared loadings			Rotation sums of squared loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3.37	37.43	37.43	3.37	37.43	37.43	3.26	36.26	36.26
2	2.18	24.26	61.69	2.18	24.26	61.69	2.29	25.42	61.69
3	0.90	9.99	71.67						
4	0.77	8.51	80.19						
5	0.68	7.53	87.72						
6	0.41	4.53	92.24						
7	0.32	3.57	95.81						
8	0.24	2.71	98.52						
9	0.13	1.49	100.00						

Table 8 shows that the PCA on the items loading on ‘interest/desire to have children’ confirmed two sub-factors. Three items (factor loadings 0.76-.093) loaded on the first of these two sub-factors and five items (factor loadings 0.32-0.82) loaded on the second sub-factor. The item ‘If I was in a situation where I could become a father, I would not want that to happen’ reported two negative factor loadings -0.74 and -0.08. So, it did not load on any of these sub factors; therefore, it is deemed to be removed. In addition, the item ‘I am happy with my life without children’ (factor loading 0.32) loaded on the second sub factor. However, the factor loading was below our cut off value (0.40). So, it is deemed to be removed.

**Table 8: Rotated component matrix and internal consistency reliability for ‘interest/desire to have children’**

	Factor loadings		Cronbach's alpha if items deleted
	Sub factor 1	Sub factors 2	
1-I would like to become a father in the future	<b>0.93</b>	0.02	0.44
2-I have thought about becoming a father in the future	<b>0.80</b>	0.08	0.42
3-If I was in a situation where I could become a father, I would want that to happen	<b>0.76</b>	0.34	0.37
4-If I was in a situation where I could become a father, I would not want that to happen	-0.74	-0.08	0.62
5-I am happy with my life without children	-0.66	<b>0.32</b>	0.57
6-Being diagnosed with HIV affects my decisions about not becoming a father	-0.10	<b>0.82</b>	0.33
7-I would like to become a father without parenting the child(ren)	-0.20	<b>0.75</b>	0.4
8-Available fertility technologies and options for people living with HIV affect my decisions about becoming a father	0.29	<b>0.71</b>	0.29
9-Being diagnosed with HIV affects my decisions about becoming a father	0.30	<b>0.57</b>	0.25

So, the ‘If I was in a situation where I could become a father, I would not want that to happen’ and ‘I am happy with my life without children’ were removed.

Table 9 shows that when the two items including ‘If I was in a situation where I could become a father, I would not want that to happen’ (4) and ‘I am happy with my life without children’ (5) were removed, the two sub factors recorded eigenvalues above 1 that explains

**Table 9: Total variance explained by the principal components for ‘interest/desire to have children’ after removal of two items**

Component	Initial eigenvalues			Extraction sums of squared loadings			Rotation sums of squared loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	2.79	39.84	39.84	2.79	39.84	39.84	2.54	36.21	36.21
2	1.87	26.73	66.56	1.87	26.73	66.56	2.13	30.35	66.56
3	0.90	12.78	79.34						
4	0.58	8.26	87.60						
5	0.46	6.59	94.19						
6	0.26	3.72	97.91						
7	0.15	2.09	100.00						

Table 10 shows that the construct including two sub factors and seven items can be combined to one factor with the final factor loadings between 0.53 and 0.94 and the final consistency reliability 0.74.

**Table 10: Rotated component matrix and internal consistency reliability for ‘interest/desire to have children’after removal of two items (5&6)**

	Factor loadings		Cronbach's alpha
	sub factor 1	sub factors 2	
1-I would like to become a father in the future	.94		0.74
2-I have thought about becoming a father in the future	.84		
3-if I was in a situation where I could become a father, I would want that to happen	.77		
6-Being diagnosed with HIV affects my decisions about becoming a father	.	.53	
7-Available fertility technologies and options for people living with HIV affect my decisions about becoming a father		.64	
8-I would like to become a father without parenting the child(ren).		.78	
9-Being diagnosed with HIV affects my decisions about not becoming a father		.87	

**Component matrix and internal consistency reliability for ‘intent to have children in the future’**

The construct intention to have children includes five items. The KMO coefficient for this dataset was 0.64 and the Bartlett test of sphericity was statistically significant ( $\chi^2= 57.39$ ,  $df = 10$ ,  $p=0.00$ ), indicating a good correlation between variables for factor analysis (Table 6). Table 13 shows that one factor recorded an eigenvalue above 1 that explains 45.09% of variance.

**Table 11: Total variance explained by the principal components for ‘intent to have children in the future’**

Component	Initial eigenvalues			Extraction sums of squared loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	2.25	45.09	45.09	2.25	45.09	45.09
2	0.96	19.23	64.32			
3	0.83	16.62	80.94			
4	0.64	12.75	93.68			
5	0.32	6.32	100.00			

Table 12 shows that PCA analysis on the items loading on ‘intent to have children in the future’ confirms a single concept structure with the factor loadings varied between 0.47 and 0.83 (above our cut off value of 0.40). Cronbach’s alpha was computed for the internal consistency reliability of the construct ( $\alpha = 0.68$ ) was below our cut off value (0.70).

However, Table 12 suggested removal of the item ‘I would be willing to consider adoption as alternative to having a biological child’ to meet our desire Cronbach’s alpha of 0.70. So, the item was deleted.

**Table 12: Component matrix and internal consistency reliability for ‘intent to have children in the future’**

	<b>Factor loading</b>	<b>Cronbach's alpha if items deleted</b>	<b>Cronbach's alpha of the construct</b>
1-I am open to the idea of using medical techniques to help me become a father	<b>0.83</b>	0.53	0.68
2-I am willing to pay for fertility clinic resources to becoming a father	<b>0.81</b>	0.56	
3-Because HIV medications will let me live longer, I am considering becoming a father	<b>0.67</b>	0.63	
4-As a man with HIV, I can have an HIV-negative child	<b>0.49</b>	0.68	
5-I would be willing to consider adoption as alternative to having a biological child	<b>0.47</b>	0.70	

Table 13 shows the final percentage of variance of the construct ‘intent to have children in the future’ when the item, ‘I would be willing to consider adoption as alternative to having a biological child’ (5) was removed. The newly recorded percentage of variance is 53.03

**Table 13: Total variance explained by the principal components for ‘intent to have children in the future’ when one item (5) was removed**

<b>Component</b>	<b>Initial eigenvalues</b>			<b>Extraction sums of squared loadings</b>		
	<b>Total</b>	<b>% of Variance</b>	<b>Cumulative %</b>	<b>Total</b>	<b>% of Variance</b>	<b>Cumulative %</b>
1	2.12	53.03	53.03	2.12	53.03	53.03
2	0.87	21.85	74.88			
3	0.66	16.58	91.46			
4	0.34	8.54	100.00			

Table 14 shows the final statistics of the construct ‘intent to have children in the future’ when the item ‘I would be willing to consider adoption as alternative to having a biological child’ was removed. The final factor loadings varied from 0.51 to 0.84 and Cronbach’s alpha of the construct was 0.70.

***Internal consistency reliability***

Table 15 shows the final internal consistency results of the scale using Cronbach’s alpha all the constructs (included or not in Factor analysis). As the table indicates, Cronbach’s alpha were at least 0.70 for all of the constructs which indicates that the questionnaire is consistently reliable (Riley et al., 2003).

**Table 15: Cronbach’s alpha of all constructs**

	<b>Number of items deleted</b>	<b>Current number of items</b>	<b>Revised Cronbach's alpha</b>
Feelings	0	4	<b>0.88</b>
Desires	2	7	<b>0.74</b>
Plans to have children	1	4	<b>0.74</b>
Worries	0	11	<b>0.84</b>
Behaviour(s) related to the pursuit of fertility	0	9	<b>0.71</b>
Conception and parenting	0	6	<b>0.7</b>
Support for becoming a parent	0	6	<b>0.86</b>
Fear	1	6	<b>0.76</b>
Experience with fear	0	5	<b>0.74</b>
satisfaction with providers related to fertility goals	0	5	<b>0.78</b>



In addition to the items deleted from construct validation, one item was removed from the construct ‘fear’. Among the questions added to the survey following the focus group recommendation, only one was deleted suggesting that these items were needed to give more choices to participants.

***Test-retest***

Table 16 shows the Test-Retest results of selected questions that directly measured fertility desires and intentions using Spearman’s rho non-parametric test. As the table indicates there was stability in the answer of respondents between the two tests. As shown by the Spearman’s rho which was  $>0.71$  for the e selected items that measured desire and intention

**Table 16 Test-Retest results using Spearman’s rho non-parametric test and Pearson correlation**

	Test (N, %)	Retest (N, %)	Spearman’s rho	P value (sig 2 tail)
<b>Desire</b>				
1-I would like to become a father in the future			0.83	0.00
Strongly Disagree	1 (5.0)	3 (15.0)		
Disagree	8 (40.0)	6 (30.0)		
Neither disagree nor agree	3 (15.)	2 (10.0)		
Agree	3 (15.0)	4 (20.0)		
Strongly Agree	5 (25.0)	5 (25.0)		
2-I have thought about becoming a father in the future			0.71	0.00
Strongly Disagree	0 (0.0)	2 (10.0)		
Disagree	9 (45.0)	4 (20.0)		
Neither disagree nor agree	0 (0.0)	2 (10.0)		

**Table 16 Test-Retest results using Spearman’s rho non-parametric test and Pearson correlation (continued)**

Agree	<b>6 (30.0)</b>	<b>7 (35.0)</b>		
Strongly Agree	5 (25.0)	5 (25.0)		
<b>Intention</b>				
3-Because HIV medications will let me live longer, I am considering becoming a father			0.85	0.00
Strongly Disagree	0 (0.0)	2 (10.0)		
Disagree	8 (40.0)	7 (35.0)		
Neither disagree nor agree	0 (0.0)	1 (5.0)		
Agree	8 (40.0)	7 (35.0)		
Strongly Agree	4 (20.0)	3 (15.0)		

***Concurrent validity***

Concurrent validity was assessed using the validated construct. Table 17 shows the percentage distribution of desire and intention for each item in the construct. Our established range was 30-60% for desire and intention. The proportion of participants who desire to becoming a father for the item 3 & 7 were out of range and were deemed to be removed. In addition items 4 & 5 were removed because of wording issue. Therefore items 1, 2, & 6 were used to compute the proportion of individuals who desire to becoming a father. Similarly, items 3 & 4 were out of range; so they were deemed to be removed. Therefore, items 1 & 2 were used to compute the proportion of individuals who intend to becoming a father.

**Table 17: Proportion of fertility desire and intention for each item**

	<b>Proportion of desire</b>
1-I would like to become a father in the future	38.3
2-I have thought about becoming a father in the future	60.0
3-.If I was in a situation where I could become a father, I would want that to happen	55.0
6-.Being diagnosed with HIV affects my decisions about not becoming a father	33.3>30.0% (wording issue)
7-.I would like to become a father without parenting the child(ren).	13.3<30.0% (out or range)
8-.Available fertility technologies and options for people living with HIV affect my decisions about becoming a father	21.7<30.0%(out or range)
9-.Being diagnosed with HIV affects my decisions about becoming a father	38.3>30.0% (wording issue)
	<b>Proportion of intention</b>
1-I am open to the idea of using medical techniques to help me become a father [such as in vitro fertilization (IVF) or intra-uterine insemination (IUI)]	43.3
2-.I am willing to pay for fertility clinic resources to becoming a father	21.6<30% (out of range)
3-Because HIV medications will let me live longer, I am considering becoming a father	45.0
4-.As a man with HIV, I can have an HIV-negative child	78.3>60.0% (out or range)

Table 18 shows the fertility desire and intention estimated by the number of agreement across items. The variable desire and intention being summarized in the table records the number of items with agreement (0= no item with agreement; 1= 1 item with agreement, 2= 2 items with agreement and three items with agreement). We found 35.0% of fertility desire across the three items. Also, we recorded 30.0% of fertility intention across the two items being used.

**Table 18: Fertility desire and intention estimated by the numbers of agreement across items**

	Desire to be a father (# YES for items 1, 2 & 3)			Intention to be a father (# YES for items 1&3)		
		Frequency	Percent		Frequency	Percent
Number of items with agreement	0	15	25.0	0	25	41.7
	1	19	31.7	1	17	28.3
	2	5	8.3	2	18	30.0
	3	21	35.0			
	Total	60	100.0	Total	60	100.0

Table 19 shows that 53.3% of men desire to becoming a father using a single item variable. The reference instrument showed 43.8 % of desire to becoming a father(Sherr & Barry, 2004). The intention to becoming a father was 38.3% and 38.0% (average) for the single item variable and the literature respectively (Cooper et al., 2009; Olowookere et al., 2013).

**Table 19: Comparison between fertility desire and intention assessed by the construct, literature and single item variable**

<b>Fertility desire</b>	<b>60, %</b>	<b>Fertility intention</b>	<b>60, %</b>
Fertility desire (# YES for items 1, 2 & 3):	21, 35.0%	Fertility Intention (# YES for items 1& 3)	18, 30.0%
Fertility desire ('How many children would you like to parent in the future?', Yes if answer $\geq 1$ )	32, 53.3%	Fertility intention ('How many children would you like to parent in the future?', Yes if answer $\geq 1$ )	23, 38.3%
Known fertility desire from the literature	43.8%	Known fertility intention from the literature (18% and 59%)	38.0% (Average)

## **Discussion**

Fathers living with human immunodeficiency virus (HIV) infection play a pivotal role in shaping the lives of their families and children. However, women living with HIV have received disproportionately more attention in studies of parenting and the importance of having children, with men frequently left out of the picture. In addition, there is a gap in the literature, however, as no instrument specific to the measurement of the fertility desires and intentions among men living with HIV has been validated for use for all men including, heterosexuals (straights), gays, bisexuals and others. The problem addressed by this study is the need for a well substantiated tool which demonstrates reliable and valid assessments of fertility desires and intentions for all men living with HIV. Therefore, this study was designed to develop, validate and pilot-test an instrument and; determine factors associated with fertility desires and intentions among men living with HIV.

The scale was developed by adapting questions from previous surveys. Then the questions were reworded and reviewed by experts and then by community members in a focus group for further evaluation in a pilot study. Specifically, content validity was maximized by undertaking a thorough literature review and consulting with experts in the fields of HIV and parenting. Face validity was evaluated via focus group of men living with HIV. Construct validity was assessed using confirmatory factor analysis (CFA). The test-retest reliability was assessed using Spearman's rho Pearson correlation, internal consistency was determined using Cronbach's alpha and the number of agreements across items was used to assess concurrent construct validity.

Content validity helped assess whether the content was relevant to the concept of fertility desires and intentions. Quantitative and qualitative methodologies were used to assess the content of the survey instrument. The content validity index of most of the items was above of cut off value (0.80); based on the suggestions of the experts, some items with CVI below the cut off value were reworded or edited. Although face validity is the least sophisticated measure of validity, it provided important information about the clarity of the questionnaire being completed by men living with HIV. Face validation were undertaken by men living with HIV and resulted in adding and editing of many items. Particularly, items about the influence of community members and social workers on parenting planning were added to the survey. Construct validity was assessed using CFA. The evaluated constructs confirmed

that all items can load can function as one single structure. Test-retest statistic showed a stability of the responses with Spearman's rho correlation  $>0.70$ . The internal reliability reached the recommended level for a new tool and test-retest indicated stability of the responses to the items. Cronbach's alpha was above 0.70 for most of the constructs. About 35.0% and 30.0% of respondents desire and intend to have children respectively. In this study, sexual orientation and age were demonstrated to be associated with fertility desire and intention and the study confirmed good evidence of concurrent validity.

The draft questionnaire consisted of 14 constructs. This instrument was developed using the Traits-Desires-Intentions-Behavior model. Compared to other tools, the developed instrument can use multiple items to assess fertility desires and intentions among men living with HIV regardless their sexual orientation. Moreover, available instrument were focused predominantly on heterosexual men and bisexual men or women living with HIV (Berhan & Berhan, 2013; Finocchiaro Kessler et al., 2014; Loutfy et al., 2009; Nattabi et al., 2009; Sherr & Barry, 2004). The results showed that the proportion of individuals who desire /intend to becoming a father using multiple items correspond to those of previously established measurements using single confirming evidence for good concurrent validity. Using the validated construct we found that 35.0% of men desired to have children. The reference survey used to develop this instrument demonstrated that 43.8 % of men (Sherr & Barry, 2004). Other studies showed that between 19.0 % and 57.0% (average 38.0%) of men living with HIV intended to have children in the future (Cooper et al., 2009; Olowookere et al., 2013). So, concurrent validity is established. However, multiple-item scales are more reliable and less prone to random measurement errors than single-item measures. But, the reference instrument showed that 69% of women in Canada (Loutfy et al., 2009) desired to have children. This confirming that, it should not be taken for granted that instruments that have been used to study fertility intentions and desires for women will be equally reliable and valid. The developed instrument (appendix F) can be used to determine the fertility desires and intentions among men living with HIV regardless their sexual orientation.

Several limitations of the study merit emphasis. Although the recruitment of most participants from a large urban clinic expedited completion of this study, this strategy likely introduced sampling and selection bias, as these men may differ from other men in Toronto and Ontario in terms of several important aspects which include: mode of HIV acquisition,

socioeconomic status and access to health care services. Because this study was conducted in an HIV clinic, it likely captured individuals who were more adherent to clinic appointments. The instrument was developed using online model and data collected using the measure under development was through CAPI. The common concern of interview is the extent to which a participant will respond truthfully concerning behaviours that are sensitive, such as HIV risk factors. In addition, questions regarding actions taken in the last 12 months are subject to recall bias. Although CAPI offers many advantages, however, there is a risk of interviewer bias. Furthermore, not all of the items identified as relating to fertility desires and intentions can directly measure the outcome intention; however, they were identified as important because they represent proxies for other unmeasured variables.

Our wish was to bring back participants for retest after 2 weeks following the test. But some participants were followed up after 5 weeks. Therefore, we learned that some participants were not motivated to come back for retest outside their scheduled medical appointments. Another limitation is our small sample size that limit investigation of more predictors of fertility intentions desires such as stigma, discrimination, attitudes of health care providers and number of living children.

Based on data collected, it appears that the survey instrument can gather valid and reliable data on the majority of the fertility desire and intention indicators. However, in order to obtain quality data on all intended indicators, I would recommend a future larger study to:

- Recruit men from across Ontario
- Try to generate a sample that aligns with distribution of men in terms of geography and mode of HIV acquisition, socioeconomic status and access to health care services

## **Conclusion and relevance to public health**

Previous research has shown that fatherhood is a life changing experience for the male population. However, it is becoming increasingly evident that HIV research concerning reproductive health and family planning has focused mainly on women. It is fundamental to collect data in the development of services, support and resources in relation to fertility and fatherhood for men who are HIV-positive. Before this data can be collected; however, it is important to create and validate an instrument for ascertaining the fertility desires and intentions of men living with HIV. Our findings demonstrated that the developed survey instrument is reliable and valid; therefore, it can be used to measure fertility desires and intentions for men living with HIV.

Refinements of the instrument were recommended from the content and face validations. A pilot study using a small number of participants including heterosexual and non heterosexual men revealed that this tool possesses internal consistency and elevated test-retest reliability. In addition , we demonstrated using confirmatory factor analysis that pre-determined constructs can function well as single structure. The concurrent validity of the instrument was established. Further research can validate the motivation and behavior constructs and used the current validate tool to examine fertility desires and intentions of men living with HIV.

Survey development requires careful construction of instruments to ensure valid and reliable results. But having a validated comprehensive survey tool for examining various aspects of fertility desires and intentions, as well as experiences with fertility clinics, provides valuable data to policy-makers and decision-makers in Ontario. This survey tool also advances the mandate of IHPREG to supporting multiple scenarios of HIV-affected individuals and/or couples wishing to conceive. This study represents the initial phase of generating evidence-based research that supports men and couples in family planning. Researchers and clinicians will be able to use this tool to improve their understanding of the trends in fertility and issues facing men living with HIV. Canada lags behind several other countries in its ability to collect comprehensive data on this important and sensitive area of research. The pilot-testing and validation of this survey provides the opportunity for Canada to meet this challenge.

Footnotes: <sup>1</sup>Prevention of Mother To Child Transmission (PMTCT); <sup>2</sup>Mother-To-Child



## References

- Amin, A. (2015). Addressing gender inequalities to improve the sexual and reproductive health and wellbeing of women living with HIV. *J Int AIDS Soc*, 18(Suppl 5), 20302. doi:10.7448/IAS.18.6.20302
- Antiretroviral Therapy Cohort, C. (2008). Life expectancy of individuals on combination antiretroviral therapy in high-income countries: a collaborative analysis of 14 cohort studies. *Lancet*, 372(9635), 293-299. doi:10.1016/S0140-6736(08)61113-7
- Artino, A. R., Jr., La Rochelle, J. S., Dezee, K. J., & Gehlbach, H. (2014). Developing questionnaires for educational research: AMEE Guide No. 87. *Med Teach*, 36(6), 463-474. doi:10.3109/0142159X.2014.889814
- Barnes, A., Riche, D., Mena, L., Sison, T., Barry, L., Reddy, R., . . . Parry, J. P. (2014). Efficacy and safety of intrauterine insemination and assisted reproductive technology in populations serodiscordant for human immunodeficiency virus: a systematic review and meta-analysis. *Fertil Steril*, 102(2), 424-434. doi:10.1016/j.fertnstert.2014.05.001
- Berhan, Y., & Berhan, A. (2013). Meta-analyses of fertility desires of people living with HIV. *BMC Public Health*, 13, 409. doi:10.1186/1471-2458-13-409
- Bonnenfant, Y. T., Hindin, M. J., & Gillespie, D. (2012). HIV diagnosis and fertility intentions among couple VCT clients in Ethiopia. *AIDS Care*, 24(11), 1407-1415. doi:10.1080/09540121.2011.650679
- Boquet, M. P., Wonganan, P., Dekker, J. D., & Croyle, M. A. (2008). Influence of method of systemic administration of adenovirus on virus-mediated toxicity: focus on mortality, virus distribution, and drug metabolism. *J Pharmacol Toxicol Methods*, 58(3), 222-232. doi:10.1016/j.vascn.2008.07.003
- Brennan, D. J., Emlet, C. A., Brennenstuhl, S., Rueda, S., Team, O. C. S. R., & Staff. (2013). Socio-demographic profile of older adults with HIV/AIDS: gender and sexual orientation differences. *Can J Aging*, 32(1), 31-43. doi:10.1017/S0714980813000068
- Brown, T. A. (2015). *Confirmatory factor analysis for applied research* (2 ed.). New York: The Guilford Press.
- Chen, J. L., Philips, K. A., Kanouse, D. E., Collins, R. L., & Miu, A. (2001). Fertility desires and intentions of HIV-positive men and women. *Fam Plann Perspect*, 33(4), 144-152, 165.
- Cooper, D., Harries, J., Myer, L., Orner, P., Bracken, H., & Zweigenthal, V. (2007). "Life is still going on": reproductive intentions among HIV-positive women and men in South Africa. *Soc Sci Med*, 65(2), 274-283. doi:10.1016/j.socscimed.2007.03.019
- Cooper, D., Moodley, J., Zweigenthal, V., Bekker, L. G., Shah, I., & Myer, L. (2009). Fertility intentions and reproductive health care needs of people living with HIV in Cape Town, South Africa: implications for integrating reproductive health and HIV care services. *AIDS Behav*, 13 Suppl 1, 38-46. doi:10.1007/s10461-009-9550-1
- de Winter, F. C. J., Dodou, D., & Wieringa, A. P. (2009). Exploratory Factor Analysis With Small Sample Sizes. *Multivariate Behavioral Research*, 44, 35.
- Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *Lancet*, 382(9903), 1525-1533. doi:10.1016/S0140-6736(13)61809-7
- Demissie, D. B., Tebeje, B., & Tesfaye, T. (2014). Fertility desire and associated factors among people living with HIV attending antiretroviral therapy clinic in Ethiopia. *BMC Pregnancy Childbirth*, 14(1), 382. doi:10.1186/s12884-014-0382-2
- DeVon, H. A., Block, M. E., Moyle-Wright, P., Ernst, D. M., Hayden, S. J., Lazzara, D. J., . . . Kostas-Polston, E. (2007). A psychometric toolbox for testing validity and

- Dillman, D. A. (2007). *Mail and internet surveys: The Tailored Design Method 2007 update with new internet, visual, and mixed-mode guide*. Hoboken, New Jersey: John Wiley & Sons, Inc.
- Dube, A. L., Baschieri, A., Cleland, J., Floyd, S., Molesworth, A., Parrott, F., . . . Glynn, J. R. (2012). Fertility intentions and use of contraception among monogamous couples in northern Malawi in the context of HIV testing: a cross-sectional analysis. *PLoS One*, 7(12), e51861. doi:10.1371/journal.pone.0051861
- Field, A. (2005). *Discovering statistics using SPSS*. (second ed.). London: SAGE.
- Finocchiaro Kessler, S., Bastos, F. I., Malta, M., Bertoni, N., Hanif, H., & Kerrigan, D. (2014). HIV+ men need reproductive counseling too: Assessing childbearing goals and provider communication among HIV+ male patients in Rio de Janeiro, Brazil. *AIDS Patient Care STDS*, 28(5), 254-259. doi:10.1089/apc.2013.0354
- Hertzog, M. A. (2008). Considerations in determining sample size for pilot studies. *Res Nurs Health*, 31(2), 180-191. doi:10.1002/nur.20247
- Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *A Multidisciplinary Journal*, 6(1), 55.
- Iliyasu, Z., Abubakar, I. S., Kabir, M., Babashani, M., Shuaib, F., & Aliyu, M. H. (2009). Correlates of fertility intentions among HIV/AIDS patients in northern Nigeria. *Afr J Reprod Health*, 13(3), 71-83.
- Interdisciplinary HIV Pregnancy Research Group. (n.d).
- Kawale, P., Mindry, D., Stramotas, S., Chilikh, P., Phoya, A., Henry, K., . . . Hoffman, R. (2014). Factors associated with desire for children among HIV-infected women and men: a quantitative and qualitative analysis from Malawi and implications for the delivery of safer conception counseling. *AIDS Care*, 26(6), 769-776. doi:10.1080/09540121.2013.855294
- Kennedy, V. L., Serghides, L., Raboud, J. M., Su, D., Blitz, S., Hart, T. A., . . . Ontario, H. I. V. F. R. T. (2014). The importance of motherhood in HIV-positive women of reproductive age in Ontario, Canada. *AIDS Care*, 26(6), 777-784. doi:10.1080/09540121.2013.855295
- Kenny, D. A., Kaniskan, B., & McCoach, D. B. (2015). The performance of RMSEA in models with small degrees of freedom. *Sociol Methods Res*, 44, 21.
- Kim, L. U., Johnson, M. R., Barton, S., Nelson, M. R., Sontag, G., Smith, J. R., . . . Gilmour, J. W. (1999). Evaluation of sperm washing as a potential method of reducing HIV transmission in HIV-discordant couples wishing to have children. *AIDS*, 13(6), 645-651.
- Laursen, T., Kesmodel, U. S., Hojgaard, A., Ostergaard, L., Ingerslev, H. J., & Wejse, C. (2013). Reproductive patterns and fertility wishes among HIV-infected patients: survey from six outpatient clinics in Denmark. *Int J Infect Dis*, 17(10), e851-856. doi:10.1016/j.ijid.2013.01.024
- Lavrakas, P. J. (2008). *Encyclopedia of survey research methods* SAGE Publications Ltd
- Loutfy, M. R., Hart, T. A., Mohammed, S. S., Su, D., Ralph, E. D., Walmsley, S. L., . . . Ontario, H. I. V. F. R. T. (2009). Fertility desires and intentions of HIV-positive women of reproductive age in Ontario, Canada: a cross-sectional study. *PLoS One*, 4(12), e7925. doi:10.1371/journal.pone.0007925
- Loutfy, M. R., Margolese, S., Money, D. M., Gysler, M., Hamilton, S., Yudin, M. H., . . . Gynaecologists of, C. (2012). Canadian HIV pregnancy planning guidelines. *J Obstet Gynaecol Can*, 34(6), 575-590.

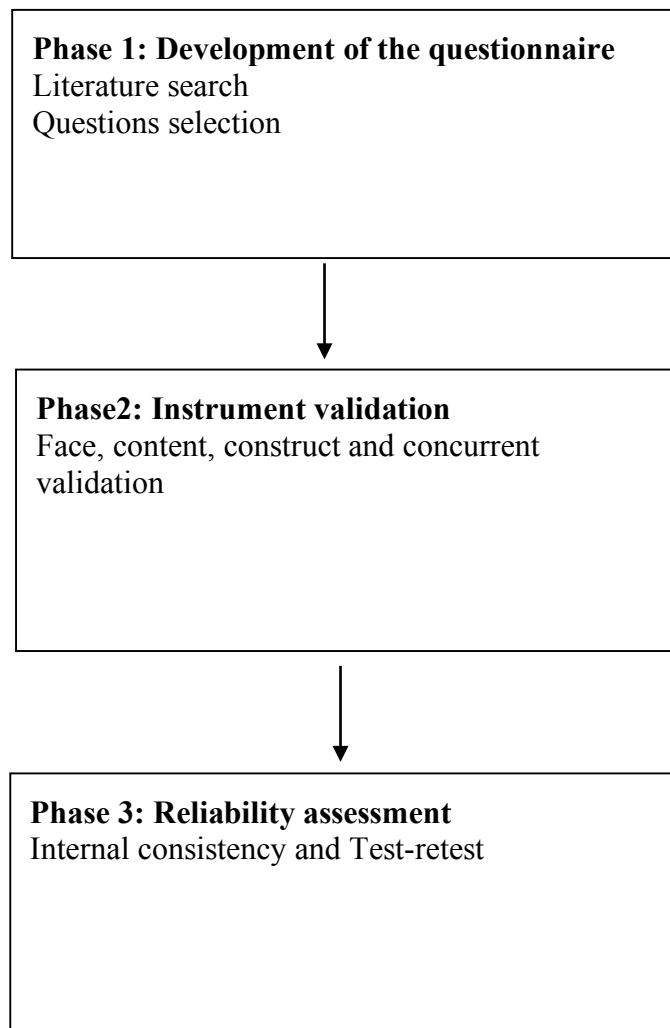
- Lundgren, R., Cachan, J., & Jennings, V. (2012). Engaging men in family planning services delivery: experiences introducing the Standard Days Method(R) in four countries. *World Health Popul*, 14(1), 44-51.
- MacCallum, R. C., Widaman, K. F., Zhang, S., & Hong, S. (1999). Sample Size in Factory Analysis. *Psychological methods*, 4(1), 6.
- Mandelbrot, L., Heard, I., Henrion-Geant, E., & Henrion, R. (1997). Natural conception in HIV-negative women with HIV-infected partners. *Lancet*, 349(9055), 850-851. doi:10.1016/S0140-6736(05)61754-0
- Mantell, J. E., Exner, T. M., Cooper, D., Bai, D., Leu, C. S., Hoffman, S., . . . Stein, Z. A. (2014). Pregnancy intent among a sample of recently diagnosed HIV-positive women and men practicing unprotected sex in Cape Town, South Africa. *J Acquir Immune Defic Syndr*, 67 Suppl 4, S202-209. doi:10.1097/QAI.0000000000000369
- Matthews, L. T., Moore, L., Milford, C., Greener, R., Mosery, F. N., Rifkin, R., . . . Smit, J. A. (2015). "If I don't use a condom ... I would be stressed in my heart that I've done something wrong": Routine Prevention Messages Preclude Safer Conception Counseling for HIV-Infected Men and Women in South Africa. *AIDS Behav*. doi:10.1007/s10461-015-1026-x
- McKenzie, J. F., Wood, M. L., Kotecki, J. E., Clark, J. K., & Brey, R. A. (1999). Establishing content validity: Using qualitative and quantitative steps. *Am J Health Behav*, 23(4), 8.
- Miller, W. B., Rodgers, J. L., & Pasta, D. J. (2010). Fertility motivations of youth predict later fertility outcomes: a prospective analysis of national longitudinal survey of youth data. *Biodemography Soc Biol*, 56(1), 1-23. doi:10.1080/19485561003709131
- Miller, W. B., Severy, L. J., & Pasta, D. J. (2004). A framework for modelling fertility motivation in couples. *Popul Stud (Camb)*, 58(2), 193-205. doi:10.1080/0032472042000213712
- Mindry, D., Wagner, G., Lake, J., Smith, A., Linnemayr, S., Quinn, M., & Hoffman, R. (2013). Fertility desires among HIV-infected men and women in Los Angeles County: client needs and provider perspectives. *Matern Child Health J*, 17(4), 593-600. doi:10.1007/s10995-012-1035-6
- Mmbaga, E. J., Leyna, G. H., Ezekiel, M. J., & Kakoko, D. C. (2013). Fertility desire and intention of people living with HIV/AIDS in Tanzania: a call for restructuring care and treatment services. *BMC Public Health*, 13, 86. doi:10.1186/1471-2458-13-86
- Myer, L., Morroni, C., & Rebe, K. (2007). Prevalence and determinants of fertility intentions of HIV-infected women and men receiving antiretroviral therapy in South Africa. *AIDS Patient Care STDS*, 21(4), 278-285. doi:10.1089/apc.2006.0108
- Nakayiwa, S., Abang, B., Packel, L., Lifshay, J., Purcell, D. W., King, R., . . . Bunnell, R. (2006). Desire for children and pregnancy risk behavior among HIV-infected men and women in Uganda. *AIDS Behav*, 10(4 Suppl), S95-104. doi:10.1007/s10461-006-9126-2
- Nattabi, B., Li, J., Thompson, S. C., Orach, C. G., & Earnest, J. (2009). A systematic review of factors influencing fertility desires and intentions among people living with HIV/AIDS: implications for policy and service delivery. *AIDS Behav*, 13(5), 949-968. doi:10.1007/s10461-009-9537-y
- Ngure, K., Baeten, J. M., Mugo, N., Curran, K., Vusha, S., Heffron, R., . . . Shell-Duncan, B. (2014). My intention was a child but I was very afraid: fertility intentions and HIV risk perceptions among HIV-serodiscordant couples experiencing pregnancy in Kenya. *AIDS Care*, 26(10), 1283-1287. doi:10.1080/09540121.2014.911808

- Nilsson, G. M., Eneroth, M., & Ekdahl, C. S. (2013). The Swedish version of OMAS is a reliable and valid outcome measure for patients with ankle fractures. *BMC Musculoskelet Disord*, *14*, 109. doi:10.1186/1471-2474-14-109
- Nostlinger, C., Desjardins, F., Dec, J., Platteau, T., Hasker, E., & Eurosupport, V. S. G. (2013). Child desire in women and men living with HIV attending HIV outpatient clinics: evidence from a European multicentre study. *Eur J Contracept Reprod Health Care*, *18*(4), 251-263. doi:10.3109/13625187.2013.801072
- Ogilvie, G. S., Palepu, A., Remple, V. P., Maan, E., Heath, K., MacDonald, G., . . . Burdge, D. R. (2007). Fertility intentions of women of reproductive age living with HIV in British Columbia, Canada. *AIDS*, *21 Suppl 1*, S83-88. doi:10.1097/01.aids.0000255090.51921.60
- Oladapo, O. T., Daniel, O. J., Odusoga, O. L., & Ayoola-Sotubo, O. (2005). Fertility desires and intentions of HIV-positive patients at a suburban specialist center. *J Natl Med Assoc*, *97*(12), 1672-1681.
- Olowookere, S. A., Abioye-Kuteyi, E. A., & Bamiwuye, S. O. (2013). Fertility intentions of people living with HIV/AIDS at Osogbo, Southwest Nigeria. *Eur J Contracept Reprod Health Care*, *18*(1), 61-67. doi:10.3109/13625187.2012.751588
- Osborne, W. J. (2015). What is Rotating in Exploratory Factor Analysis? . *Practical Assessment, Research & Evaluation*, *20*(2), 7.
- Paiva, C. E., Barroso, E. M., Carneseca, E. C., de Padua Souza, C., Dos Santos, F. T., Mendoza Lopez, R. V., & Ribeiro Paiva, S. B. (2014). A critical analysis of test-retest reliability in instrument validation studies of cancer patients under palliative care: a systematic review. *BMC Med Res Methodol*, *14*, 8. doi:10.1186/1471-2288-14-8
- Paiva, V., Filipe, E. V., Santos, N., Lima, T. N., & Segurado, A. (2003). The right to love: the desire for parenthood among men living with HIV. *Reprod Health Matters*, *11*(22), 91-100.
- Paiva, V., Santos, N., Franca-Junior, I., Filipe, E., Ayres, J. R., & Segurado, A. (2007). Desire to have children: gender and reproductive rights of men and women living with HIV: a challenge to health care in Brazil. *AIDS Patient Care STDS*, *21*(4), 268-277. doi:10.1089/apc.2006.0129
- Panozzo, L., Bategay, M., Friedl, A., Vernazza, P. L., & Swiss Cohort, S. (2003). High risk behaviour and fertility desires among heterosexual HIV-positive patients with a serodiscordant partner--two challenging issues. *Swiss Med Wkly*, *133*(7-8), 124-127. doi:2003/07/smw-10124
- Pecou, S., Moinard, N., Walschaerts, M., Pasquier, C., Daudin, M., & Bujan, L. (2009). Ribavirin and pegylated interferon treatment for hepatitis C was associated not only with semen alterations but also with sperm deoxyribonucleic acid fragmentation in humans. *Fertil Steril*, *91*(3), 933 e917-922. doi:10.1016/j.fertnstert.2008.07.1755
- Polit, D. F., Beck, C. T., & Owen, S. V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Res Nurs Health*, *30*(4), 459-467. doi:10.1002/nur.20199
- Public Health Agency of Canada. (2014). *HIV/AIDS Epi Updates .Chapter 1: National HIV Prevalence and Incidence Estimates for 2011*. Retrieved from Retrived from [www.phac-aspc.gc.ca](http://www.phac-aspc.gc.ca):
- Riley, E. D., Bangsberg, D. R., Perry, S., Clark, R. A., Moss, A. R., & Wu, A. W. (2003). Reliability and validity of the SF-36 in HIV-infected homeless and marginally housed individuals. *Qual Life Res*, *12*(8), 1051-1058.
- Safikhani, S., Sundaram, M., Bao, Y., Mulani, P., & Revicki, D. A. (2013). Qualitative

- with moderate to severe psoriasis. *J Dermatolog Treat*, 24(1), 50-59.  
doi:10.3109/09546634.2011.631980
- Sainsbury, R., Ditch, J., & Hutton, S. (1993). Computer Assisted Personal Interviewing. 3.
- Sarnquist, C. C., Moyo, P., Stranix-Chibanda, L., Chipato, T., Kang, J. L., & Maldonado, Y. A. (2014). Integrating family planning and prevention of mother to child HIV transmission in Zimbabwe. *Contraception*, 89(3), 209-214.  
doi:10.1016/j.contraception.2013.11.003
- Sastre, F., Sheehan, D. M., & Gonzalez, A. (2015). Dating, marriage, and parenthood for HIV-positive heterosexual Puerto Rican men: normalizing perspectives on everyday life with HIV. *Am J Mens Health*, 9(2), 139-149. doi:10.1177/1557988314532940
- Semprini, A. E., Levi-Setti, P., Bozzo, M., Ravizza, M., Taglioretti, A., Sulpizio, P., . . . Pardi, G. (1992). Insemination of HIV-negative women with processed semen of HIV-positive partners. *Lancet*, 340(8831), 1317-1319.
- Sherr, L., & Barry, N. (2004). Fatherhood and HIV-positive heterosexual men. *HIV Med*, 5(4), 258-263. doi:10.1111/j.1468-1293.2004.00218.x
- Stevens, J. P. (1992). *Applied multivariate statistics for the social sciences* (second ed.). NJ: Erlbaum.
- Taylor, T. N., Mantell, J. E., Nywagi, N., Cishe, N., & Cooper, D. (2013). 'He lacks his fatherhood': safer conception technologies and the biological imperative for fatherhood among recently-diagnosed Xhosa-speaking men living with HIV in South Africa. *Cult Health Sex*, 15(9), 1101-1114. doi:10.1080/13691058.2013.809147
- van Leeuwen, E., Prins, J. M., Jurriaans, S., Boer, K., Reiss, P., Repping, S., & van der Veen, F. (2007). Reproduction and fertility in human immunodeficiency virus type-1 infection. *Hum Reprod Update*, 13(2), 197-206. doi:10.1093/humupd/dml052
- Wagner, A. C., Ivanova, E. L., Hart, T. A., & Loutfy, M. R. (2014). Examining the Traits-Desires-Intentions-Behavior (TDIB) model for fertility planning in women living with HIV in Ontario, Canada. *AIDS Patient Care STDS*, 28(11), 594-601.  
doi:10.1089/apc.2014.0075
- Wagner, G. J., & Wanyenze, R. (2013). Fertility Desires and Intentions and the Relationship to Consistent Condom Use and Provider Communication Regarding Childbearing Among HIV Clients in Uganda. *ISRN Infect Dis*, 2013. doi:10.5402/2013/478192
- Wekesa, E., & Coast, E. (2014). Fertility desires among men and women living with HIV/AIDS in Nairobi slums: a mixed methods study. *PLoS One*, 9(8), e106292.  
doi:10.1371/journal.pone.0106292
- Williams, B., Brown, T., & Onsmann, A. (2010). Exploratory factor analysis: A five-step guide for novices. *Journal of Emergency Primary Health Care*, 8(3), 13.
- Withers, M., Dworkin, S., Harrington, E., Kwena, Z., Onono, M., Bukusi, E., . . . Newmann, S. J. (2013). Fertility intentions among HIV-infected, sero-concordant couples in Nyanza province, Kenya. *Cult Health Sex*, 15(10), 1175-1190.  
doi:10.1080/13691058.2013.811289
- Wong, L. P. (2008). Focus group discussion: a tool for health and medical research. *Singapore Med J*, 49(3), 256-260; quiz 261.

## Appendices

## Appendix A Flow chart demonstrating the process used in the study



## **Appendix B Survey draft assessed during the content validation**

Understanding The Fertility Desires And Intentions Among HIV-Positive Men Living In  
Ontario, Canada: Survey Instrument Development and Validation

Study Survey Instrument (Draft)

### Questionnaire

**This document is confidential and anonymous.**

Do not write your name anywhere on this document.

Please answer each question to the best of your abilities. If you do not understand a question, you may ask a staff member to assist you.

Your participation is optional. We understand that some of these questions may be difficult to answer. It is important that you are honest in this questionnaire. We appreciate you taking the time to fill out this questionnaire.



FERTILITY DESIRES AND INTENTIONS IN MEN LIVING WITH HIV IN ONTARIO  
STUDY

Have you filled out this questionnaire before? (Please check the box that applies)

yes

no

**Section A :Interest/Desire to Have Children**

**The following questions ask you about your FEELINGS.**

**1**

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
a) Being a father is important to me.					
b) I think I would feel fulfilled by caring for children.					
c) I feel that being a father would increase my self-esteem.					
d) Children give meaning to life.					
e) I would like having children but have been unable					

**The following questions ask you about your DESIRES**

**2**

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
a) I have thought about becoming a father in the future					
b) I would like to become a father in the future.					
c) HIV affects my decisions about becoming a father.					
d) If I was in a situation where I could become a father, I would not want that to happen					
e) I would like to learn more about fertility technologies and options for people with HIV.					

**3**

- a) How many children would you like to parent in the future?  
0    1    2    3    4    5    6    7    8    9 or more
- b) What would be the best timeframe for you to become a father?  
I don't want to be a father now or at any time in the future  
I would like to be a father now  
I would like to be a father within a year.  
I would like to be a father in a few years  
I am currently expecting a child/awaiting an adoption  
I don't know

## Section B (Intent to Have Children in the Future)

**The following questions ask you about your PLANS to have children.**

**4**

- a) How many children do you expect to parent to in the future?  
0    1    2    3    4    5 or more
- b) How soon in the future do you plan to become a parent?  
Never  
I am expecting a child now/awaiting adoption  
Within 6 months  
Within 1 year  
Within 2 years  
Within 3 years  
Within 4 years  
Other  
I don't know

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
c) I am open to the idea of using medical techniques to help me become a father [such as in vitro fertilization (IVF) or intra-uterine insemination (IUI)].					
d) I would be willing to have unprotected sex with a woman in order to become a father					
e) Because HIV medications decrease HIV transmission to sexual partners, I am considering becoming a biological father.					
f) Because HIV medications will let me live longer, I am considering becoming a father.					
g) As a man with HIV, I can have an HIV-negative child.					
h) As a man with HIV, I can go to a fertility clinic and access medical help to have a child, including egg donor and surrogates.					
i) I would be willing to consider adoption as alternative to having a biological child					

**The following questions ask you about your WORRIES.**

**5**

If I were to become a father, I would be...

(If you are currently expecting a baby, please answer how you feel currently)

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
a) worried that I will not have enough help from friends or family to care for children in the future.					
b) worried that being a father will affect my health.					
c) worried that if I become a father, my child will be born HIV-positive.					
d) worried that I will not be healthy enough to care for children into adulthood.					
e) worried that I will not live long enough to care for children into adulthood.					
f) worried about infecting my intimate partners when trying to get pregnant. (heterosexual only)					
g) worried that I will not have enough money to care for children					
h) worried that I don't feel mature enough to be father					

## Section C (Behaviour(s) Related to the Pursuit of Fertility)

The following questions ask you about your **ACTIONS** in the last **12 months**, as a man with HIV trying to have a child.

6

	YES	NO
a) I have approached my partner/spouse/other about having a baby (other = significant other, friend or other person that a man would consider having a child with)	1	2
b) My partner/other has approached me about having a baby.	1	2
c) I have spoken to my doctor about becoming a father.	1	2
d) I have stopped using a birth control method with my partner in <u>the past 12 months</u> in order to become a father.	1	2

7

Have you searched for information on fatherhood in the past 12 months?

Yes

No

If Yes, where have you searched for information? Check all that apply.

Internet, Magazines, Newspapers

AIDS Service Organization (such as your local AIDS Committee)

A Community Health Centre

Family doctor

HIV specialist An Obstetrician / Gynaecologist (OB/GYN)

Other HIV-positive fathers

Other,

## Section D (Contraception and Sexual History)

The following questions ask you about your **SEXUAL HISTORY**. If you do not feel comfortable answering any of these questions, skip to the next one.

8

Have you had sexual intercourse (vaginal) with a female partner **EVER** in your lifetime?

Yes

No, I have **NEVER** been intimate with women

I have been intimate with women, but **NEVER** had sexual intercourse (vaginal)

I have only been intimate with male partner(s)

**9**

Have you had sexual intercourse (vaginal) with a female partner in the last 12 MONTHS?

Yes

No

**10**

What is your current relationship status?

I am single.

I do not have a partner

I have one partner

I have more than one partner

**11**

In case you have partner how long have you been with your partner?

(mm/yy) \_\_\_\_\_

**12**

a) In case you have partner what is your partner's HIV status?

HIV-positive

HIV-negative

I do not know

I prefer to not answer this question

b) If you have any children, has your doctor asked you about the HIV status of the person who carried that pregnancy?

Yes

No

I don't know

I have never been a biological parent

**The following questions ask you about your use of BIRTH CONTROL. If you do not feel comfortable answering any of these questions, skip to the next one. (HETEROSEXUAL ONLY or some contact with female in 12 months? –**

**13**

a) Are you heterosexual or have had female in 12 months?

Yes

No

b) if yes do you CURRENTLY use a method of birth control when intimate with a female partner?

Yes

No

c) if yes Which methods of birth control have you or your female partner used in the past six months? (Check all that apply)

None	Implant (Norplant)
Condoms for birth control	Contraceptive cream
the “pill” (oral contraceptive)	Contraceptive patch
Diaphragm	Contraceptive vaginal ring
Intrauterine Devices “iud”	Contraceptive sponge or foam
Injection (Depo-Provera)	My partner has had her “tubes tied” (tubal ligation)
“Morning after pill”	I have had a vasectomy (male sterilization)
Rhythm method	I do not have sex with women
Withdrawal	Other
Female condom	

## Section E (Fertility and Parenting History)

### 14

How would you describe your behaviour at the present time in regards to sexual intercourse with women?

- I use some kind of birth control every time I have sex to avoid pregnancy
- I use some kind of birth control when I think there is a risk of pregnancy
- I don’t use any kind of birth control and I wouldn’t be unhappy about pregnancy
- I don’t use any kind of birth control but I am not trying to achieve a pregnancy
- I don’t use any kind of birth control and I am trying to achieve a pregnancy
- I do not have sex with women
- I am currently expecting a child

**The following questions ask you about your experience with CONCEPTION. If you do not feel comfortable answering any of these questions, skip to the next one.**

### 15

a) How many times have you EVER achieved a pregnancy with a female partner? (Include abortions and miscarriages)

0    1    2    3    4    5    6    7    8    9 or more

b) How many of these pregnancies were planned: \_\_\_\_\_

c) How many times have you EVER achieved a pregnancy with a female partner SINCE you were diagnosed with HIV? (Include abortions and miscarriages)

0    1    2    3    4    5    6    7    8    9 or more

d) How many of these pregnancies were planned: \_\_\_\_\_

### 16

a) How many biological children have you had in your lifetime?  
 0 1 2 3 4 5 6 7 8 9 or more

b) How many biological children have you had SINCE you were diagnosed with HIV? (If you were diagnosed during the pregnancy of a partner, include that child)  
 0 1 2 3 4 5 6 7 8 9 or more

**17**

a) If you have biological children, what is your current relationship with them?

- Active parent
- Shared or co parent
- No longer active as a parent in their life
- The baby was conceived and I had no further involvement in their life

b) If you have biological children, have any of these children been diagnosed with HIV?

- Yes
- No
- I do not have children
- I do not know

**18**

a) How many children LIVE with you now? (Include children that you **care** for but did not give birth to)

0 1 2 3 4 5 6 7 8 9 or more

b) If you have children that you are **aring** for, how old are they? (please list their ages)

Child #1 is \_\_\_\_\_ years old  
 Are you the biological parent of this child? Yes No  
 If yes, was this child planned? Yes No

**Section F (Perceived Support for Becoming a Parent)**

**19**

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
a) My family wants me to be a father.					
b) By having a child, it would make my family happy.					



**Answer these questions only if you have an intimate partner.**

**20**

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
a) My partner wants to be a parent in the future.					
b) If we had a child, it would make my partner happy.					

**The following questions ask you about your experience with FEAR. If you do not feel comfortable answering any of these questions, skip to the next one.**

**21**

	Definitely False	Somewhat false	Neither true nor false	Somewhat true	Definitely true
a) I am afraid of being judged negatively by <b>a friend</b> for trying to become a father					
b) I am afraid of being judged negatively by <b>a family member</b> for trying to become a father					
c) I am afraid of being judged negatively by <b>a physician</b> for trying to become a father					
d) I am afraid of being judged negatively by <b>other health care professionals</b> for trying to become a father					
e) I am <b>not</b> afraid of being judged negatively by anyone for trying to become a father					

**The following questions ask you about your EXPERIENCES. If you do not feel comfortable answering any of these questions, skip to the next one.**

**22**

	Definitely False	Somewhat False	Neither True nor False	Somewhat True	Definitely True
a) I have experienced being judged negatively by <b>a friend</b> for trying to become a father					
b) I have experienced being judged negatively by <b>a family member</b> for trying to become a father					

c) I have experienced being judged negatively by <b>a physician</b> for trying to become a father					
d) I have experienced being judged negatively by <b>other health care professionals</b> for trying to become a father					
e) I have <b>not</b> experienced being judged negatively by anyone for trying to become a father					

## Section G (Satisfaction with Providers related to Fertility Goals)

The following questions ask you about your health care providers.

23

Do you have a family doctor?

- Yes
- No

24

If yes, please complete the questions below. If you do not have a family doctor, please skip this set of questions.

	Definitely False	Somewhat False	Neither true nor false	Somewhat true	Definitely true
a) I am comfortable sharing my concerns about becoming a father with my family doctor.					
b) I am comfortable talking to my family doctor about fatherhood as a man living with HIV.					
c) I can trust my family doctor.					
d) I am satisfied with the treatment I receive from my family doctor.					
e) I am satisfied with the amount of parenting planning information I received from my family doctor.					

f) Has your family doctor talked to you about fatherhood?

- Yes
- No
- I don't know

g) Has your health family doctor ever advised you against having children?

- Yes
- No
- I don't know

## 25

**Do you see an HIV Specialist?**

- Yes
- No

If yes, please complete the questions below. If you do not see an HIV Specialist, please skip this section

	Definitely False	Somewhat False	Neither true nor false	Somewhat true	Definitely true
a) I am comfortable sharing my concerns about becoming a father with my HIV Specialist.					
b) I am comfortable talking to my HIV Specialist about fatherhood as a man living with HIV.					
c) I can trust my HIV Specialist.					
d) I am satisfied with the treatment I receive from my HIV Specialist.					
e) I am satisfied with the amount of parenting planning information I received from my HIV Specialist..					

f) Has your HIV Specialist talked to you about fatherhood?

- Yes
- No
- I don't know

g) Has your specialist ever advised you against having children?

- Yes
- No
- I don't know

## Section H (Needs Assessment)

## 26

Which of the following resources would you need to help you with your decisions to become a father?  
(Check all that apply)

- I would need information booklets and publications on becoming a father
- I would need to talk to a health professional with fertility expertise
- I would need to talk someone with fertility expertise from my community
- I would need access to a fertility clinic

- I would need an obstetrician/gynaecologist
- I would need a trained midwife
- I would need access to egg banks/surrogates
- I would need educational seminars on conception
- I would need educational seminars on taking care of a baby
- I would need educational seminars on raising a child
- Other

## Section I (HIV History)

**The following questions ask you about your HIV infection. If you do not feel comfortable answering any of these questions, skip to the next one.**

**27**

In what YEAR did you test positive?

**28**

How do YOU think you got HIV? (Check all that apply)

- Sex with a male partner
- Sex with a female partner
- Needle sharing with infected person
- Blood transfusion / blood product
- From Your birth mother
- Occupational exposure / needle stick injury
- Sexual assault (rape)
- I don't know

**29**

Do you currently have any of the following sexually transmitted infections? (Check all that apply)

- Hepatitis C
- Hepatitis B
- Chlamydia
- Gonorrhea
- Syphilis
- HPV (genital warts)
- Herpes (genital)
- Never been diagnosed
- None
- I do not know

**30**

**Please tell us the LAST TIME you were told your CD4 cell count, and what your CD4 cell count was at that time. (CD4 cells are also known as “T cells” or your “immune cells”, and they are usually between 0 and 1000).**

Have you ever had a CD4 test?

Yes

No

I don't remember / I don't know

If yes, when were you told your last CD4 count (mmYY): /

If yes, write your last CD4 cell count number here:

### 31

**Please tell us the LAST TIME you were told your viral load, and what your viral load was at that time. (Usually, viral loads range from undetectable to 100,000+)**

Have you ever been told your load?

Yes

No

I don't remember / I don't know

If yes last time you were told your viral load (monthYY): /

If yes, please write your last viral load here:

### 32

Have you EVER taken HIV medications?

Yes

No

If yes, when did you start taking HIV medications? /  
(month)(year)

### 33

Are you currently taking HIV medications?

Yes

No

### 34

a) Are you currently taking hepatitis C treatment? (This medication should not be taken when trying to have a child)

Yes

No

I don't know

b) If YES, have any of your doctors told you that Hepatitis C treatment is not recommended for people trying to conceive?

Yes

No

I don't know

## Section J (Demographics)

Here are some basic questions about YOU. Please do not write your name on this form. Remember, all of your answers are confidential and you cannot be identified by any of the pieces of information you provide on this, or any other sheet in the questionnaire package.

**35**

a) Today's Date \_\_\_\_\_

b) Age (in years) \_\_\_\_\_

c) In what country were you born? \_\_\_\_\_

d) How long have you lived in Canada? (in years) \_\_\_\_\_

e) In what city do you currently live?

**36**

Please check the appropriate box or boxes for the following questions about religion:

- Catholic
- Protestant
- Christian (if not catholic or protestant)
- Jewish
- Muslim
- Hindu
- Sikh
- Buddhist
- Eastern Orthodox
- African Traditional
- Aboriginal Traditional
- New Age
- Agnostic
- None / Atheist
- Other

**37**

Ethnic Background (check as many as apply to you):

- African
- Caribbean Asian Middle Eastern
- European

- British
- French-Canadian
- Hispanic / Latina
- Aboriginal
- Other

**38**

In the previous question, there was a list of ethnic backgrounds. However, this list may or may not specify how you identify. Regardless of your answer to the previous question, how do you identify your ethnic background (s)?

Ethnically, I identify as: \_\_\_\_\_

**39**

How would you describe your sexual orientation?

- Heterosexual
- Bisexual
- Gay
- Two-spirit
- Other sexual orientation

**40**

What gender do you identify as?

- Cis gender male
- Trans gender male
- Two-spirit
- Other

**\*Cis-gender male is one who is biologically and phenotypically male; it is the opposite of “trans”**

**41**

Please indicate who (if anyone) you live with (you may check more than one box)

- By myself
- Roommates
- Own house
- Rent house
- Parents
- Grandparents
- Partner
- Children
- Other Family Members
- Group or residential program
- Shelter
- Homeless
- Other

**42**

School / Work: Please check all that apply to you:

- Full time work
- Full time in school
- Part time work
- Part time in school
- Self employment
- On government assistance
- Other

### 43

a) Are you currently in a romantic and/or sexual relationship?

- Yes
- No

b) If you are currently in a relationship, have you had the same romantic partner over the past 12 months?

- Yes
- No

c) Are you currently in a monogamous romantic (single-partner) relationship?

- Yes
- No

### 44

What is your marital status (check as many as apply):

- Divorced
- Widowed
- Never Married
- Living with a partner (but not married or in a common-law relationship)
- Married
- Common-law partner

### 45

What is the highest level of education you completed?

- Did not attend high school
- Some high school education
- High school diploma
- Some university, college or technical school education
- College diploma or technical certificate
- Bachelor's degree
- Some graduate or professional school
- Graduated graduate or professional school

### 46

a) Please indicate your yearly household income.

- \$0-19,999
- \$20,000 - 39,999
- \$40,000 - 59,999
- \$60,000 - 79,999
- \$80,000 - 99,999



\$100,000 - 119,999

\$120,000 or more

I do not know

b) How many people live on this household income?

0    1    2    3    4    5    6    7    8    9 or more

### Appendix C Summary of studies about fertility desires and intentions for men living with HIV (presented in alphabetic order)

Authors/Country/Year	Sample characteristics	Sexual orientation of men	Study type and description	Key findings
<b>Bonnenfant <i>et al</i></b> Ethiopia 2012	631 men 631 women	heterosexual	Interview, before and after HIV testing investigating the relationship between HIV diagnosis and fertility intentions	<ul style="list-style-type: none"> <li>➤ 11.3% of men stopped desiring to have children</li> <li>➤ Stop desiring to have children was associated with older age, being in serodiscordant relationship (aOR 12.1 vs. seroconcordant relationship) and urban residence (aOR 2.58 vs. rural)</li> </ul>
<b>Chen <i>et al.</i></b> USA 2001	361 men 377 women	heterosexual and bisexual	Computer-assisted self or personal interview describing fertility desires and intentions	<ul style="list-style-type: none"> <li>➤ 28% of men desired to have children</li> <li>➤ 59% of those desiring to have children desired to have more than one child</li> <li>➤ the desire to have children was higher among those who were younger, have few children and good overall self-rated health status.</li> </ul>
<b>Cooper <i>et al.</i></b> South Africa 2007	20 men 40 women	heterosexual	In –depth interviews investigating reproductive intentions and influencing factors	<ul style="list-style-type: none"> <li>➤ HIV positive status modified reproductive desires but did not remove the wish to have children</li> <li>➤ Community disapproval, fear of infecting partners and infants were the main reasons for not wishing to have children</li> </ul>

<b>Authors</b>	<b>Sample characteristics</b>	<b>Sexual orientation of men</b>	<b>Study type and description</b>	<b>Key findings</b>
<b>Cooper <i>et al.</i></b> South Africa 2009	174 men 285 women	heterosexual	Questionnaire interview Investigating the fertility intentions and associated health care needs	<ul style="list-style-type: none"> <li>&gt; 57% of men intended to have children</li> <li>&gt; Having few children was positively associated with the intentions to have children</li> </ul>
<b>Demissie <i>et al.</i></b> Ethiopia 2014	126 men 214 women	heterosexual	Survey assessing fertility intentions and desires among HIV positive women and men in Ethiopia	<ul style="list-style-type: none"> <li>&gt; The prevalence of fertility desire among men and women was 39.1% .</li> <li>&gt; factors associated with fertility desire were: younger age, had no biological living children community pressure, duration HIV diagnosis≤1y.</li> </ul>
<b>Dube <i>et al.</i></b> Malawi 2012	1766 monogamelous couples	heterosexual	Questionnaire interview Analysing the relationship between fertility intentions and hiv awareness and how spousal differences in fertility intentions influence use of contraception	<ul style="list-style-type: none"> <li>&gt; 73% of HIV-positive men and 35% HIV negative did not want to have children</li> <li>&gt; concordant HIV positive couples were more likely than concordant HIV negative couples to desire to have children</li> </ul>
<b>Iiyasu <i>et al.</i></b> Nigeria 2009	60 men 177 women	heterosexual	Open-ended questions Studying reproductive desires and their predictors	<ul style="list-style-type: none"> <li>&gt; 61.2% of men desired to have children</li> <li>&gt; the majority wanted to have more than one child</li> <li>&gt; there were significant associations between religion, number of children, duration of HIV and desire to have children</li> </ul>

Authors/Country/Year	Sample characteristics	Sexual orientation of men	Study type and description	Key findings
<b>Kawale <i>et al.</i></b> Malawi 2014	75 men 127 women	heterosexual	In depth interviews understanding the factors associated with desire for a child among men	<ul style="list-style-type: none"> <li>➤ 39.37% of men desired to have children</li> <li>➤ being in a relationship (OR: 3.48) and duration of HIV more than two years (OR: 2.00) were significantly associated with increased odds of desire for a child among males and females.</li> <li>➤ age 36-40 years (OR: 0.64) was associated with decreased odds of desire for a child.</li> <li>➤ having a living child (OR: 0.24) was associated with decreased odds of desire for a child</li> </ul>
<b>Kessler <i>al.</i></b> Brazil 2014	311 men	heterosexual and bisexual	Interviewer-administered 12 items survey assessing communication with HIV providers about reproductive plans and factors associated with having such communication	<ul style="list-style-type: none"> <li>➤ 51% of men accepted attitudes of childbearing</li> <li>➤ 39% of men desired to have a future child</li> <li>➤ 19% of men intended to have a future child</li> <li>➤ there were no differences about the desire and intentions to have children between heterosexual and bisexual men</li> </ul>

<b>Authors/Country/Year</b>	<b>Sample characteristics</b>	<b>Sexual orientation of men</b>	<b>Study type and description</b>	<b>Key findings</b>
<b>Mantell <i>et al.</i></b> South Africa 2014	91 men 106 women	heterosexual	Face-to-face interview Examining factors associated with pregnancy intent among recently diagnosed HIV-positive women and men	<ul style="list-style-type: none"> <li>➤ more men than women intended to have children</li> <li>➤ 3/5 of men intended to have children in the next 6 months</li> </ul>
<b>Matthews <i>et al.</i></b> South Africa 2015	15 men 20 women	heterosexual	In-depth interviews Exploring barriers and promoters to patient-provider communication around fertility desires and intentions	<ul style="list-style-type: none"> <li>➤ the majority of participants hadn't discussed personal fertility plans with providers</li> <li>➤ discussions about pregnancy focused on maternal and child health</li> <li>➤ participants reported that they had received safer conception advice</li> </ul>
<b>Mindry <i>et al.</i></b> USA 2013	68 male men and 24 women	heterosexual and non-heterosexual	Brief survey and focus groups Assessing the childbearing desires and the experiences of health care providers serving this population	<ul style="list-style-type: none"> <li>➤ 39% of the participants reported a desire to have children</li> <li>➤ 66% of clients had not discussed their desires, or methods of safe conception, with providers</li> <li>➤ providers reported challenges in providing safe conception services in resource poor settings</li> </ul>

<b>Authors/Country/Year</b>	<b>Sample characteristics</b>	<b>Sexual orientation of men</b>	<b>Study type and description</b>	<b>Key findings</b>
<b>Mmbaga <i>et al.</i></b> Tanzania 2013	146 men 264 women	heterosexual	Face-to-face interview Assessing fertility desire and intention	<ul style="list-style-type: none"> <li>➤ 37.1% of men and women desired to have biological children</li> <li>➤ factors associated with increased fertility desire including, good perceived health status and CD4 count <math>\geq 200</math> cells</li> <li>➤ factors associated with reduced desire included having more than 2 children among females, divorce or separation.</li> </ul>
<b>Myer <i>et al.</i></b> South Africa 2007	74 men 227 women	heterosexual	30-45 min semi-structured questionnaire investigating the prevalence and determinants of fertility intentions among women and men receiving ART	<ul style="list-style-type: none"> <li>➤ 36% of men versus 26% of women wanted to have children in the future</li> <li>➤ increased fertility desires among males was associated with gender (OR:2.58) and being in a relationship of less than 5 years (OR: 3.93)</li> </ul>
<b>Nakayiwa <i>et al.</i></b> Uganda 2006	488 men 604 women	heterosexual	Face-to-face interview Examining the influence of knowledge and attitudes towards <sup>2</sup> MTCT and <sup>2</sup> PMTCT on fertility desire and pregnancy risk behaviour	<ul style="list-style-type: none"> <li>➤ 27 % of men desired to have more children</li> <li>➤ the desire to have children is higher among men than women</li> <li>➤ “need to leave ancestry” and importance of children for the spouse were the main reason behind the decision to desire to have more children</li> </ul>

Authors/Country/Year	Sample characteristics	Sexual orientation of men	Study type and description	Key findings
<p><b>Ngure <i>et al.</i></b> Kenya 2014</p>	<p>27 men 29 women</p>	<p>heterosexual</p>	<p>In-depth interviews and focus group discussions exploring fertility intentions and HIV risk considerations</p>	<ul style="list-style-type: none"> <li>&gt; All participants desired to have children</li> <li>&gt; motivations for pregnancy included: satisfying desired family size, desire for biological children, maintaining stability of the union, and sociocultural pressures</li> <li>&gt; couples desired strategies to reduce HIV risk during conception</li> </ul>
<p><b>Nöstlinger <i>et al.</i></b> Europe 2013</p>	<p>197 men 229 women</p>	<p>heterosexual</p>	<p>Self-administered questionnaire Identifying factors influencing desire for children among women and men living with hiv</p>	<ul style="list-style-type: none"> <li>&gt; 43% of men and women desired a child</li> <li>&gt; being younger than 36 years was positively associated with fertility desire among men</li> <li>&gt; discrimination by health care providers was positively associated with fertility desires among men</li> </ul>

Authors/Country/Year	Sample characteristics	Sexual orientation of men	Study type and description	Key findings
<b>Oladabo <i>et al.</i></b> Nigeria 2005	95 men 52 women	heterosexual	Face-to-face 38-item, questionnaire-based interview  Determining the fertility desires and intentions and assessing how these may vary by their sociodemographic and health-related factors	<ul style="list-style-type: none"> <li>➤ 53.8% of men and 68.4% of women desired to have children</li> <li>➤ 71.5% and 93.8% of men and women who desired children intended to have <math>\geq 2</math> children</li> <li>➤ decreasing age, shorter time since diagnosis of HIV infection and nondisclosure of serostatus to partner significantly increase the odds of desire for childbearing, while having no children and a poor CD4 count decreased the odds</li> </ul>
<b>Olowookere <i>et al.</i></b> Nigeria 2013	80 men 286 women	heterosexual	Face-to-face questionnaire  Investigating issues of sexuality and reproduction	<ul style="list-style-type: none"> <li>➤ 27 of women and 17% of men intended to have more than two children</li> <li>➤ 28% of women and 15% of men reported that their partners had similar fertility intention.</li> <li>➤ 73% respondents intending to have children desired male children</li> <li>➤ predictors of fertility intention were younger age, having no child, and having higher education</li> </ul>



Authors/Country/Year	Sample characteristics	Sexual orientation of men	Study type and description	Key findings
<b>Paiva et al.</b> Brazil, 2007	206 men 533 women	bisexual and heterosexual	Face- to -face questionnaire Describing attitudes toward parenthood and identify factors associated with desire to have children	<ul style="list-style-type: none"> <li>&gt; 50.1% of men versus 19.2% of women desired to have children</li> <li>&gt; bisexual men were more likely to desire having biologic children</li> <li>&gt; younger age, having 0–2 children and being in a heterosexual relationship were associated with desire to have children</li> </ul>
<b>Paiva et al.</b> Brazil 2003	250 men	heterosexual	Face-to-face questionnaire Investigating issues of sexuality and reproduction	<ul style="list-style-type: none"> <li>&gt; most participants considered that health professionals were not supportive about HIV-positive men having children,</li> <li>&gt; 43% of sample wanted children, especially those who had no children.</li> <li>&gt; few men received information about treatment options that would protect infants from HIV infection</li> </ul>
<b>Panozzo et al.</b> Switzerland 2003	68 men 46 women	heterosexual	114 item-questionnaires evaluating fertility intentions and condom use	<ul style="list-style-type: none"> <li>&gt; 45% of HIV-positive women and 38% of HIV-positive men expressed the desire for children</li> <li>&gt; 50% of women and men felt that health care providers did not sufficiently address their reproductive needs</li> <li>&gt; 73% of HIV-discordant heterosexual couples consistently use condoms</li> </ul>

Authors/Country/Year	Sample characteristics	Sexual orientation of men	Study type and description	Key findings
<b>Sherr et Barry</b> England 2004	32 men	heterosexual	17-items-questionnaires assessing fertility intentions among HIV positive heterosexual men	<ul style="list-style-type: none"> <li>&gt; only 9.4% men were given medical advice on reproduction and 22% felt fully informed</li> <li>&gt; 50% would value fertility consultations, up-to-date information and quick referral to fertility clinics</li> <li>&gt; 44% had considered having children</li> <li>&gt; 41% believed they would experience discrimination if they conceived a baby</li> <li>&gt; 25% would withhold their HIV status when attending antenatal clinics</li> <li>&gt; 81% believed that a child gave meaning to life and something to live</li> </ul>
<b>Taylor et al.</b> South Africa 2013	57 men	heterosexual	Semi-structured interviews Exploring notions of fatherhood and their linkages to fertility desires and intentions	<ul style="list-style-type: none"> <li>&gt; cultural imperative of biologically-connected fatherhood and safer conception aimed at minimizing the risk of HIV transmission were perceived as threats to paternity.</li> </ul>
<b>Wagner et al.</b> Uganda 2013	261 men 506 women	heterosexual	Interviewer-administered questionnaires Examining the correlates of fertility desires and intentions, including condom use	<ul style="list-style-type: none"> <li>&gt; equal proportion of men and women (45%) desired and intended to have children</li> <li>&gt; 27% men and women were told by a health care provider that they should not bear a child because of their HIV status</li> <li>&gt; younger age, higher CD4 count, having fewer children and a primary partner were associated with fertility desires and intention</li> </ul>



## **Appendix D: Focus group guide**

Understanding The Fertility Desires And Intentions Among HIV-Positive Men Living In Ontario, Canada: Survey Instrument Development And Validation

THIS DOCUMENT IS CONFIDENTIAL

### **1. INSTRUCTIONS TO FOCUS GROUP FACILITATOR:**

*Start by handing out the informed consent form to all participants.*

*Please read the following instructions carefully before commencing the focus group.*

*Read the following statements to participants:*

The lives of people living with HIV have changed. Because of this many people with HIV now want to have a family. Research has focused a lot of women with HIV and their plans for a family. Men living with HIV have been overlooked. Parenting for men living with HIV may be different than for women both when plans and opportunities are considered. We would like to know about the experiences and opinions of HIV-positive men who are of fathering age. The information collected in this study will be used to better understand the parenting and fatherhood planning. For your information, this group is comprised of other HIV-positive men who are interested in the topic of discussion.

The purpose of this focus group is to learn about your opinions and ideas regarding a questionnaire, and usability of LimeSurvey system, a computer-assisted web *interviewing* system that will be used in a larger research project to understand the fertility desires and intentions among HIV-positive men and the correlates of these intentions in Ontario. The results of this validation study will help us to identify issues related to the comprehensibility and clarity of the concepts being asked within the questionnaire. In addition, it will help us to ensure that LimeSurvey system is user-friendly and will allow us to finalize our provincial survey instrument. We are particularly interested in your feedback on the flow, content, and language used within the questionnaire and how this affects how well you understand the content. We also are interested in your ability to navigate through the survey. Finally we are interested in how you think the questionnaire could be improved and if the questions are addressing what we are aiming to determine

This project is supported and led by the University of Toronto Women's College Research Institute. This project has been funded by Women and HIV Research Program.

Participation in the focus group discussion is optional and completely voluntary. You are free to withdraw at any time.

If you agree to participate, this session will last up to 2.5 hours. At the beginning of the session, you will be asked to fill out the questionnaire, keeping in mind any issues, concerns, or problems that may arise for you while completing it. Finally, after completion of this questionnaire, we will begin the focus group discussion. During this time, you will be tape recorded so that we don't miss any important points that are raised in the discussion. The recorded information will be destroyed once it is transcribed. Your answers to the questionnaire will be destroyed too one we don't need them. Also, during this time, you are free to use your real name or a pseudo name (which ever name will help you feel most comfortable). If you do use real names of individuals or institutions, the transcriber will not transcribe any of these actual names – they will be replaced by the word “NAME”, preserving anonymity of your responses.

Your privacy and confidentiality will be respected throughout the entire study. All personal information and raw research materials collected – whether you choose to participate or not – will be kept confidential and will not be made available to anyone not involved in carrying out the study. We would also like to ask that all participants are asked to keep personal information discussed during this focus group confidential, including the names of individuals who are in attendance; however, please note that we cannot necessarily guarantee that participants will keep information confidential.

The session cannot commence until everyone has read and signed the informed consent form. You are entitled to a copy of the signed informed consent form and we recommend you take one as it has the principal investigator, and the research ethics board's information if required in the future. Please complete reading the consent form and feel free to ask any questions that you have.

After you have signed the informed consent form, you will be directed to a computer to fill out the survey. This should take 1 hour or less to complete. Following this, the focus group discussion will begin.

Finally, you will receive a \$30.00 compensation for the expenses that you incurred to be present at this focus group.

***Follow these instructions:***

Give the participants time to read through the consent form and respond to any questions or clarifications that may arise.

Ask the participants to **sign the consent form** once they are satisfied with the information contained.

Provide the participants with a copy of the **signed consent form**.

Provide participants with computers and invite them to take the **Questionnaire**. Give each participant a blank paper and explain that they should pay attention and mark down on the paper if any questions are difficult and don't make sense. The key is that they are reviewing the questionnaire and generating their opinions on the instrument. Give the participants time to fill out the questionnaire. Advise participants that this is a non-judgmental environment and that if they require assistance filling out the form, it is available.

## **2. QUESTION THEMES:**

### **Section A**

**The purpose of this section is to talk about the layout of the questionnaire, in terms of the length, flow, clarity, and use of language.**

1. What are your initial thoughts and impressions of the questionnaire?
2. What are your thoughts on the length of the questionnaire?
3. How do you feel about the flow of the questions?
4. How do you feel about the level of language in the questionnaire? Was there anything that was confusing or hard to understand?  
**(Note to focus group facilitators – Specific questions will be reviewed in detail in the next section.)**
5. Is there any part of the questionnaire that does not make sense to you?  
**(Note to focus group facilitators – Specific questions will be reviewed in detail in the next section.)**

### **Section B**

**The purpose of this section is to examine the content of the questionnaire by having you spend time discussing each of the sections.**

The questionnaire is broken out into several sections. We would like to go through the questionnaire, section by section for your feedback.

SECTION A: Demographics

SECTION B: Interest/desire to have children

SECTION C: Intent to have children in the future

SECTION D: Behaviour(s) related to the pursuit of fertility

SECTION E: Contraception and sexual History

SECTION F: Fertility and parenting History

SECTION G: Perceived support for becoming a parent

SECTION H: Satisfaction with providers related to fertility Goals

SECTION I: Needs assessment

SECTION J: HIV history

The facilitator should cover the following questions within each of the sections:

**(Note to focus group facilitators – Facilitator should remind participants of Study Research Question and to keep that in mind when answering these questions.)**

6. As you were answering the questions in this section, was there anything that you felt needed clarification?
7. Are there problem words or phrases within this section?
8. What was missing from the section?
9. What could be excluded from the section?

After the facilitator and participants have gone through all of the sections, ask the following questions:

**(Note to focus group facilitators – Facilitator should remind participants of Study Research Question and to keep that in mind when answering these questions.)**

10. What is your general opinion of the questionnaire overall?
11. Is there a section that you feel should be added to the questionnaire? Is there anything that you feel should be excluded?

## Section C

**The purpose of this section is to wrap up the focus groups and collect any concluding thoughts from the participants.**

12. Do you think that the questionnaire is complete and easy to understand for those who are participating in the survey instrument development and validation study?
13. Do you think the information asked in the questionnaire is relevant to HIV-positive men in Canada? Were all important items to HIV-positive men captured? Was there anything missing overall?
14. Is there anything else that you would like to share?

### **3. INSTRUCTIONS TO FOCUS GROUP FACILITATOR:**

**GIVE COMMUNITY MEMBERS A BLANK PIECE OF PAPER.**

**STATE:** Please write down any issues relevant to this topic that you did not feel comfortable sharing in the group and that you are also available to hear their concerns privately if they are not willing or able to write them.



**Appendix E The *a priori* hypothesis outlining the items and domain structure of the instrument**

**Desires**

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
1)I have thought about becoming a father in the future.					
2)I would like to become a father in the future.					
3)I am happy with my life without children.					
4)I would like to become a father without parenting the child(ren).					
5)Being diagnosed with HIV affects my decisions about becoming a father.					
6)Being diagnosed with HIV affects my decisions about not becoming a father.					
7)If I was in a situation where I could become a father, I would want that to happen.					
8)If I was in a situation where I could become a father, I would not want that to happen.					
9)Available fertility technologies and options for people living with HIV affect my decisions about becoming a father.					

**Intentions**

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree

10) I am open to the idea of using medical techniques to help me become a father [such as in vitro fertilization (IVF) or intra-uterine insemination (IUI)].					
11) I would be willing to have unprotected sex with a woman in order to become a father					
12) Because HIV medications decrease HIV transmission to sexual partners, I am considering becoming a biological father.					
13) Because HIV medications will let me live longer, I am considering becoming a father.					
14) As a man with HIV, I can have an HIV-negative child.					
15) As a man with HIV, I can go to a fertility clinic and access medical help to have a child, including egg donor and surrogates.					
16) I would be willing to consider adoption as alternative to having a biological child					

**Appendix F Final questionnaire**

Study Survey Instrument

Questionnaire

This document is confidential and anonymous.

Do not write your name anywhere on this document.

Please answer each question to the best of your abilities. It is important that you **provide the answer most reflective of your intentions or desires** in this questionnaire.

The staff research assistant will assist you by reading out the questions and answers for you to choose.

Your participation is optional. We understand that some of these questions may be difficult to answer. **You do not have to answer any questions and you can skip any, as needed.** We appreciate you taking the time to fill out this questionnaire.



FERTILITY DESIRES AND INTENTIONS IN MEN LIVING WITH HIV IN ONTARIO STUDY

Survey ID:

Have you filled out this questionnaire before? (Please check the box that applies)

Yes

No

## Section A: Demographics

Here are some basic questions about YOU. Please do not write your name on this form

**1**

- a) Today's Date \_\_\_\_\_
- b) Age (in years) \_\_\_\_\_
- c) In what country were you born? \_\_\_\_\_
- d) How long have you lived in Canada? (years ) \_\_\_\_\_
- e) In what city do you currently live? \_\_\_\_\_

**2**

Ethnic Background (check as many as apply to you):

- Caucasian
- Black
- Hispanic

- East Asian
- South Asian
- Middle Eastern
- First Nation/Métis/Inuit
- Other; Specify: \_\_\_\_\_
- I don't know
- Prefer not to answer

### 3

In the previous question, there was a list of ethnic backgrounds. However, this list may or may not specify how you identify. Regardless of your answer to the previous question, how do you identify your ethnic background (s)?

Ethnically, I identify as: \_\_\_\_\_

### 4

How would you describe your sexual orientation (check all that apply)?

- Straight
- Gay
- Bisexual
- Queer
- Questioning
- Two-spirit
- Other sexual orientation; Specify: \_\_\_\_\_

### 5

What gender do you identify as?

- Cisgender male
- Transmale
- Two-spirit
- Queer gender
- Other; Specify: \_\_\_\_\_

- I don't know
- Prefer not to answer

\***Cisgender male** is someone whose gender corresponds to their assigned sex

## 6

School / Work: Please check all that apply to you:

- Full time work
- Full time in school
- Part time work
- Part time in school
- Self employment
- On government assistance
- Retired
- Other; Specify: \_\_\_\_\_
- I don't know
- Prefer not to answer

## 7

Please check the appropriate box or boxes for the following questions about religion ( drop down menu)

- Jewish
- Catholic
- Protestant
- Baptist
- Evangelical
- Born -Again
- *Jehovah's Witness*
- Muslim
- Hindu
- Sikh
- Buddhist
- Eastern Orthodox

- African Traditional
- Aboriginal Traditional
- New Age
- Agnostic
- None
- Atheist
- Other
- I don't know
- Prefer not to answer

## 8

a) Are you currently in a romantic and/or sexual relationship?

- Yes
- No

b) If you are currently in a relationship, have you had the same romantic partner over the past 12 months?

- Yes
- No

c) Are you currently in a monogamous romantic (single-partner) relationship?

- Yes
- No

## 9

What is your marital status (check as many as apply):

- Married
- Common-law partner
- Living with a partner (but not married or in a common-law relationship)
- Divorced
- Widowed
- Never Married
- Single



## 10

What is the highest level of education you completed?

- Did not attend high school
- Some high school education
- High school diploma
- Some university, college or technical school education
- College diploma or technical certificate
- Bachelor's degree
- Some graduate or professional school
- Graduated graduate or professional school

## 11

a) Please indicate your yearly household income (as an individual).

- \$0-19,999
- \$20,000 - 39,999
- \$40,000 - 59,999
- \$60,000 - 79,999
- \$80,000 - 99,999
- \$100,000 - 119,999
- \$120,000 or more
- I do not know
- Prefer not to answer

b) How many people in addition to you live on this household income?

0 1 2 3 4 5 6 7 8 9 or more

C) Who do you live with?

- Family
- Friend (s)
- Partner
- Spouse
- I live alone

- Others

## Section B: Contraception and Sexual History

The following questions ask you about your **SEXUAL HISTORY**. If you do not feel comfortable answering these questions with the interviewer, you can answer them on your own.

12

- a) Have you had sexual intercourse (vaginal) with a woman EVER in your lifetime? (**skip pattern**)
- Yes
  - No
- b) Have you had sexual intercourse (vaginal) with a woman in the last 12 MONTHS?
- Yes
  - No

13

- a) What is your current relationship status?
- I am single.
  - I do not have a partner
  - I have one primary partner (**skip pattern**)
  - I have more than one partner
- b) If you have a primary partner how long have you been with your partner?  
(mm/yy) \_\_\_\_\_
- c) What is your partner's status?
- HIV-negative
  - HIV-positive, not on antiretroviral therapy
  - HIV-positive, on antiretroviral therapy
  - HIV-positive, don't know if on antiretroviral therapy
  - I do not know

- I prefer to not answer

**The following questions ask you about your use of BIRTH CONTROL. If you do not feel comfortable answering any of these questions with the interviewer, you can answer them on your own. (Skip pattern to be inserted: FOR – Yes to contact with female in 12 months?)**

**14**

d) Have you had a female partner in the last 12 months? (**skip pattern**)

- Yes
- No

e) Do you CURRENTLY use a method of birth control when intimate with a female partner?

- Yes
- No

f) Which methods of birth control have you or your female partner used in the past six months? (Check all that apply)

<ul style="list-style-type: none"> <li>• None</li> <li>• Male condoms for birth control</li> <li>• Female condoms</li> <li>• the “pill” (oral contraceptive)</li> <li>• Diaphragm</li> <li>• Intrauterine Devices “IUD”</li> <li>• Injection (Depo-Provera)</li> <li>• “Morning after pill”</li> <li>• Rhythm method</li> <li>• Withdrawal</li> </ul>	<ul style="list-style-type: none"> <li>• Implant (Norplant)</li> <li>• Contraceptive cream</li> <li>• Contraceptive patch</li> <li>• Contraceptive vaginal ring</li> <li>• Contraceptive sponge or foam</li> <li>• My partner has had her “tubes tied” (tubal ligation)</li> <li>• I have had a vasectomy (male sterilization)</li> <li>• I do not have sex with women</li> <li>• Other</li> </ul>
---	--

## Section C: Interest/Desire to Have Children

The following questions ask you about your **FEELINGS** (Feelings are emotions).

15

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
• I think being a father is important to me.					
• I think I would feel fulfilled by caring for children.					
• I think that being a father would increase my worth in life.					
• I think children give meaning to life.					

The following questions ask you about your **DESIRES** (Desires is the want for something)

16

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
• I have thought about becoming a father in the future.					
• I would like to become a father in the future.					
•					
• I would like to become a father without parenting the child(ren).					
• Being diagnosed with HIV affects my decisions about becoming a father.					

• Being diagnosed with HIV affects my decisions about not becoming a father.					
• If I was in a situation where I could become a father, I would want that to happen.					
•					
• Available fertility technologies and options for people living with HIV affect my decisions about becoming a father.					

## 17

a) How many children would you like to parent in the future?

0   1   2   3   4   5   6   7   8   or more

b) What would be the best timeframe for you to become a father?

- Never
- Now
- Within 6 months
- Within 1 year
- Within 2 years
- Within 3 years
- Within 4 years
- Within 10 years
- I do not know
- I prefer to not answer

## Section D: Intent to Have Children in the Future

**\*Intention is what we are going to do**

**The following questions ask you about your PLANS to have children.**

**18**

a) How many children do you expect to parent in the future?

0    1    2    3    4    5    6    7    8 or more

b) How soon in the future do you plan to become a parent?

- Never
- I am expecting a child now/awaiting adoption
- Within 6 months
- Within 1 year
- Within 2 years
- Within 3 years
- Within 4 years
- Within 10years
- I do not know
- I prefer to not answer

**19**

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
<ul style="list-style-type: none"> <li>• I am open to the idea of using medical techniques to help me become a father [such as in vitro fertilization (IVF) or intra-uterine insemination (IUI).</li> </ul>					
<ul style="list-style-type: none"> <li>• Because HIV medications will let me live longer, I am considering becoming a father.</li> </ul>					

<ul style="list-style-type: none"> <li>As a man with HIV, I can have an HIV-negative child.</li> </ul>					
<ul style="list-style-type: none"> <li>I am willing to pay for fertility clinic resources to becoming a father.</li> </ul>					

**The following questions ask you about your WORRIES.**

**20**

If I were to become a father	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
<ul style="list-style-type: none"> <li>I would be worried that I will not have enough help from friends or family to care for children in the future.</li> </ul>					
<ul style="list-style-type: none"> <li>I would be worried that being a father will affect my health.</li> </ul>					
<ul style="list-style-type: none"> <li>I would be worried that my child will be born HIV positive.</li> </ul>					
<ul style="list-style-type: none"> <li>I would be worried that I will not be healthy enough to care for children into adulthood.</li> </ul>					
<ul style="list-style-type: none"> <li>I would be worried that my HIV medications will affect my ability to care for my child</li> </ul>					
<ul style="list-style-type: none"> <li>I would be worried that if I have children I would not focus enough on my medication</li> </ul>					
<ul style="list-style-type: none"> <li>I would be worried that I will not live long enough to care for children into adulthood.</li> </ul>					
<ul style="list-style-type: none"> <li>I would be worried about infecting the woman who carried the pregnancy (regardless of my relationship with her).</li> </ul>					

<ul style="list-style-type: none"><li>• I would be worried that my children will experience discrimination at school.</li></ul>					
<ul style="list-style-type: none"><li>• I would be worried that I will not have enough money to care for children.</li></ul>					
<ul style="list-style-type: none"><li>• I would be worried that I don't feel mature enough to be become a father.</li></ul>					



## Section E: Behaviour(s) Related to the Pursuit of Fertility

The following questions ask you about your **ACTIONS** in the last 12 months,

**21**

	YES NO N/A
<ul style="list-style-type: none"> <li>I have approached my partner/spouse/friend/other about having a baby (other = significant other, friend or other person that a man would consider having a child with)</li> </ul>	
<ul style="list-style-type: none"> <li>I have spoken to my birth mother or co-parent about having a baby</li> </ul>	
<ul style="list-style-type: none"> <li>I have spoken to a community member about having a baby</li> </ul>	
<ul style="list-style-type: none"> <li>My partner/spouse/friend/other has approached me about having a baby.</li> </ul>	
<ul style="list-style-type: none"> <li>I have spoken to my doctor about becoming a father.</li> </ul>	
<ul style="list-style-type: none"> <li>I don't take actions to avoid having children</li> </ul>	
<ul style="list-style-type: none"> <li>I went to sessions about adoption</li> </ul>	
<ul style="list-style-type: none"> <li>I filled out application forms with adoption organizations</li> </ul>	
<ul style="list-style-type: none"> <li>I looked into organizations that broker surrogacy agreements</li> </ul>	

**22**

- a) Have you searched for information on fatherhood in the past 12 months?
- Yes

- No
- b) If Yes, where have you searched for information? Check all that apply.
- Internet
  - Magazines
  - Newspapers
  - AIDS Service Organization (such as your local AIDS Committee)
  - Community Health Centre
  - Family doctor
  - HIV specialist
  - Obstetrician / Gynaecologist (OB/GYN)
  - Other HIV-positive fathers
  - Networks
  - Talking to friends/acquaintances
  - Other

## Section F: Sexual intercourse and Conception/Parenting History

**23**

- a) How would you describe your behaviour at the present time when you have sexual intercourse with women?
- I do not have sex with women
  - I use some kind of birth control every time I have sex to avoid pregnancy
  - I use some kind of birth control when I think there is a risk of pregnancy
  - I don't use any kind of birth control and I wouldn't be unhappy about pregnancy
  - I don't use any kind of birth control but I am not trying to achieve a pregnancy
  - I don't use any kind of birth control and I am trying to achieve a pregnancy

**The following questions ask you about your experience with CONCEPTION/PARENTING.**

24

a) How many children have you ever parented?

0 1 2 3 4 5 6 7 8 or more

b) How many children have you ever parented since you were diagnosed with HIV?

0 1 2 3 4 5 6 7 8 or more

c) How many times have you EVER gotten a woman pregnant? (Include abortions and miscarriages)

0 1 2 3 4 5 6 7 8 or more

d) How many of these pregnancies were planned: \_\_\_\_\_

e) How many times have you EVER gotten a woman pregnant SINCE you were diagnosed with HIV? (Include abortions and miscarriages)

0 1 2 3 4 5 6 7 8 or more

f) How many of these pregnancies were planned: \_\_\_\_\_

## Section G: Perceived Support for Becoming a Parent

25

a)

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
• My family wants me to be a father					
• By having a child, it would make my family happy					

**b)**

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
• My community wants me to have a child					
• By having a child, it would make my community happy.					

**C (skip pattern)**

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
• My partner wants me to be a parent in the future.					
• If we have a child, it would make my partner happy.					

**26**

**The following questions ask you about your experience with FEAR. If you do not feel comfortable answering any of these questions, skip to the next one.**

**27**

	Definitely False	Somewhat false	Neither true nor false	Somewhat true	Definitely true
• I am afraid of being judged negatively					

By a friend for trying to become a father					
• I am afraid of being judged negatively By a family member for trying to become a father					
• I am afraid of being judged negatively by my other child (ren) for trying to become a father					
• I am afraid of being judged negatively By a physician for trying to become a father					
• I am afraid of being judged negatively By another health care professional for trying to become a father					
•					
• I am confident I would be able to meet other HIV+ parents to share experiences with if I had children of my own					

**The following questions ask you about your EXPERIENCES. If you do not feel comfortable answering any of these questions with the interviewer, you can answer them on your own.**

**28**

	Definitely False	Somewhat False	Neither True nor False	Somewhat True	Definitely True
• I have been judged negatively by a friend for trying to become a father					
• I have been judged negatively by a family member for trying to become a father					
• I have been judged negatively by a physician for trying to become a father					

• I have been judged negatively by another health care professional for trying to become a father					
• I have not been Judged negatively by anyone for trying to become a father					

## Section H: Satisfaction with Providers related to Fertility Goals

The following questions ask you about your health care providers.

29

a) Do you have a family doctor?

- Yes
- No

b) If yes, please complete the questions below. If you do not have a family doctor, please skip this set of questions

	Definitely False	Somewhat False	Neither true nor false	Somewhat true	Definitely true
• I am comfortable sharing my concerns about becoming a father with my family doctor.					
• I am comfortable talking to my family doctor about fatherhood as a man living with HIV.					
• I can trust my family doctor.					
I am satisfied with the treatment I receive from my family doctor.					
• I am satisfied with the amount of parenting planning information I received from my family doctor.					

c) Has your family doctor talked to you about fatherhood?

- Yes
- No
- I don't know
- I prefer not to answer

d) Has your health family doctor ever advised you against having children?

- Yes
- No
- I don't know
- Prefer not to answer

### 30

a) Do you see an HIV Specialist?

- Yes, Same doctor as my family doctor
- Yes, Different doctor than my family doctor
- Yes, Different doctor than my family doctor and also my family doctor – both are my HIV Specialists
- No

b) If yes, please complete the questions below. If you do not see an HIV Specialist, please skip this section

	Definitely False	Somewhat False	Neither true nor false	Somewhat true	Definitely true
• I am comfortable sharing my concerns about becoming a father with my HIV Specialist.					
• I am comfortable talking to my HIV Specialist about fatherhood as a man living with HIV.					
• I can trust my HIV Specialist.					
• I am satisfied with the treatment I receive from my HIV Specialist.					

<ul style="list-style-type: none"> <li>I am satisfied with the amount of parenting planning information I received from my HIV Specialist.</li> </ul>					
---	--	--	--	--	--

c) Has your HIV Specialist talked to you about fatherhood?

- Yes
- No
- I don't know
- Prefer not to answer

g) Has your specialist ever advised you against having children?

- Yes
- No
- I don't know
- Prefer not to answer

**31**

a) Do you see case /social worker?

- Yes
- No

b) If yes, please complete the questions below. If you do not see a case worker/social worker, please skip this section (skip pattern)

	Definitely False	Somewhat False	Neither true nor false	Somewhat true	Definitely true
<ul style="list-style-type: none"> <li>I am comfortable sharing my concerns about becoming a father with my case /social worker</li> </ul>					
<ul style="list-style-type: none"> <li>I am comfortable talking to my case /social worker about fatherhood as a man living with HIV.</li> </ul>					
<ul style="list-style-type: none"> <li>I can trust my case /social worker</li> </ul>					
<ul style="list-style-type: none"> <li>I am satisfied with the service</li> </ul>					



I receive from my case /social worker.					
<ul style="list-style-type: none"> <li>I am satisfied with the amount of parenting planning information I received from my case /social worker</li> </ul>					

c) Has your case /social worker talked to you about fatherhood?

- Yes
- No
- I don't know
- I prefer not to answer

d) Has your case /social worker ever advised you against having children?

- Yes
- No
- I don't know
- I prefer not to answer

## Section I:Needs Assessment

32

Select which resources would help you with your decisions to become a father? (Check all that apply)

- I would need information booklets and publications on becoming a father
- I would need to talk to an HIV-positive man who is already a parent
- I would need to talk to a health professional with fertility expertise
- I would need to talk someone with fertility expertise from my community
- I would need access to a fertility clinic
- I would need an obstetrician
- I would need a trained midwife
- I would need to talk to a social worker
- I would need access to egg banks/surrogates

- I would need educational seminars on conception
- I would need educational seminars on taking care of a baby
- I would need educational seminars on raising a child
- I need courses in adoption
- I need to talk to adoption organizations
- I need to talk to organizations that broker surrogacy agreements
- Other

## Section J:HIV History

**The following questions ask you about your HIV infection. If you do not feel comfortable answering any of these questions skip to the next one.**

**33**

In what year did you test HIV positive?

**34**

How do you think you got HIV? (Check all that apply)

- Sex with a male partner
- Sex with a female partner
- Sexual assault (rape)
- Needle sharing with infected person
- Blood transfusion / blood product
- From your birth mother
- Occupational exposure / needle stick injury
- Other; Specify: \_\_\_\_\_
- I don't know
- Prefer not to answer

**35**

Please tell us the LAST TIME you were told your CD4 cell count, and what your CD4 cell count was at that time. (CD4 cells are also known as “T c your “immune cells”, and they are usually between 0 and 1000).

- a) Last time you were told your CD4 (mm/yyyy):
- b) CD4 cell count. Please write the number here:
- c) I don't remember / I don't know
- d) I have never had a CD4 test
- e) I prefer not to answer

### 36

Please tell us the LAST TIME you were told your viral load, and what your viral load was at that time. (Usually, viral loads range from undetectable 100,000+)

- a) Last time you were told your viral load (mm/yyyy)
- b) Viral load: **or** UNDETECTABLE (<50)
- c) I don't remember / I don't know
- d) I have never had a viral load test
- e) I prefer not to answer

### 37

- a) Have you EVER taken HIV medications?
  - Yes
  - No
- c) If Yes, when did you start taking HIV medications (mm/yyyy)?

### 38

- a) Are you currently taking HIV medications?
  - Yes
  - No
- b) If yes do have concerns that the HIV medications you take could affect your child?
  - Yes
  - No

## 39

Do you currently have any of the following sexually transmitted infections? (Check all that apply)

a)

- Hepatitis B
- Chlamydia
- Gonorrhea
- Syphilis
- HPV (genital warts)
- Herpes (genital)
- Never been diagnosed
- None
- I do not know
- I prefer not to answer

b) Hepatitis C (skip pattern)

Yes

No

c) If yes, are you currently taking hepatitis C treatment? (This medication should not be taken when trying to have a child)

- Yes
- No
- I don't know
- Prefer not to answer

d) If YES, have any of your doctors told you that Hepatitis C treatment is not recommended for people trying to conceive?

- Yes
- No
- I don't know
- Prefer not to answer

THANK YOU FOR TAKING THE TIME  
TO ANSWER THIS QUESTIONNAIRE