

## **Bronnelys**

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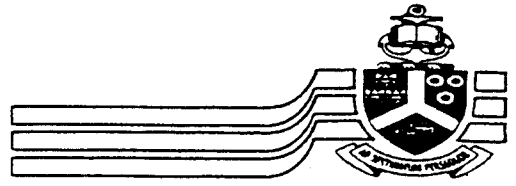
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**BYLAAG 1**  
**BRIEWE VAN TOESTEMMING VIR DIE ONDERNEMING**  
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Date: 25/03/2002

Number : S 72/2002  
 Title : African Women and HIV/Aids: A Social Work Perspective  
 Investigator : Petra Austin, Kalafong Hospital; Pretoria.  
 Sponsor : None

**This Student Protocol and Informed Consent have been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 19/03/2002 and found to be acceptable.**

Prof P. Carstens	BLC LLB LL.D (Pret) Faculty of Law
Dr J.E. Dafei	(female) MBChB; Hospital Superintendent
Prof A.P. du Toit	BA; DipTheo; BA (Hons); MA; DPhil: Philosopher
Prof S.V. Grey	(female) BSc (Hons); MSc; DSc: Deputy Dean
Dr V.O.L. Karusseit	MBChB; MFGP (SA); M.Med (Chir); FCS (SA): Surgeon
Dr S. Khan	(female) MB.ChB.; Med. Adviser (Gauteng Dept.of Health)
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Snr Sr J. Phatoli	(female) BCur (Et.Al) Senior Nursing-Sister
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Dr C.F. Slabber	BSc (Med)MB BCh, FCP (SA) Acting Head; Dept Medical Oncology
Prof J.R. Snyman	MBChB, M.Pharm.Med: MD: Pharmacologist
Prof De K. Sommers	BCbB; HDD; MBChB; MD: Pharmacologist
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Dr T.J.P. Swart	BCbD, MSc (Odont), MChD (Oral Path) Senior Specialist; Oral Pathology

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Prof S. Meij	(female) BSc(Hons); MSc
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Aan: Prof DJ Prinsloo  
Afskrif aan: Dr CL Carbonatto  
  
Fakulteit: Geesteswetenskappe  
Datum: 19 Oktober 2001

AUSTIN, P (9421343)

Die titel *African women and HIV/AIDS: a social work perspective* is 25/9/2001 goedgekeur.  
Die student het dit onder my aandag gebring dat dit egter 'n Afrikaanse verhandeling is en die  
titelregistrasie word dus dienooreenkomstig aangepas.

Aangeheg faks ter bevestiging.

Vir u kennisname



Petru Woest

GW Admin – K 6-13

420 2736

**BYLAAG 2**  
**VORM VIR INGELIGTE TOESTEMMING**

## **African Women and HIV/Aids: a Social Work Perspective**

**You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved. In the best interests of your health, it is strongly recommended that you discuss with or inform your personal doctor of your possible participation in this study, wherever possible.**

### **PURPOSE OF THIS STUDY**

The investigator would like you to consider taking part in research on the psycho-social effects of HIV/Aids on African women and their families. There will be a questionnaire to complete by answering a few questions asked by the researcher.

### **DURATION OF THIS STUDY**

If you decide to take part you will be one of approximately 50 patients. The study will last for up to 7 weeks, but you will be asked to visit the investigator only once for an 1 hour session to complete the questionnaire.

### **ETHICAL APPROVAL**

This trial Protocol was submitted to the Research Ethics Committee and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2000), which deals with the recommendations guiding doctors in biomedical research involving human/subjects. A copy of which may be obtained from the investigator should you wish to review it.

### **RIGHTS AS A PARTICIPANT IN THIS STUDY**

Your participation in this trial is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. Your withdrawal will not affect your access to other medical care. The investigator retains the right to withdraw you from the study if it is considered to be in your best interest. If it is detected that you did not give an accurate history or did not follow the guidelines of the trial and the regulations of the trial facility, you may be withdrawn from the trial at any time.

### **DISCOMFORT OR INCONVENIENCE AS RESULT OF PROCEDURES**

The procedures will not involve any discomforts or inconvenience. If you feel tired or stressed, you may take as many breaks as needed during the session. The researcher is also willing to reschedule the session if you feel that it is necessary.

### **RISKS INVOLVED IN THIS STUDY**

There are no known medical or psychological risks associated with this project.

### **WARNINGS OR RESTRICTIONS CONCERNING PARTICIPATION IN THIS STUDY**

Subjects will not be selected for this study if under 18 years of age, mentally incompetent or legally incompetent. There are no other restrictions concerning your participation in this study. The researcher will ask you to complete a questionnaire by answering a few questions as truthfully and thoroughly as possible.



### **INSURANCE AND FINANCIAL ARRANGEMENTS**

There will be no financial compensation for participating in this project and the researcher will organise the procedures in such a way that you will have no financial expenses of any sort.

### **ADDITIONAL INFORMATION**

For the duration of the study you will be assisted by Petra Austin. If you have any questions at any time during the study, please do not hesitate to contact her. The telephone number is (012) 329 4763, through which you can reach her or another authorised person.

### **CONFIDENTIALITY**

All information obtained during the course of this study is strictly confidential. Only the principal investigator and her supervisor will have access to data obtained during this study. The results of the study will be published as a Masters Dissertation by the University of Pretoria and may be published as an article by an accredited journal, but your records or identity will not be revealed unless required by law.

### **INFORMED CONSENT**

I hereby confirm that I have been informed by the investigator, Petra Austin about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information (Patient Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the trial, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a trial report. I may, at any stage, without prejudice, withdraw my consent and participation in the trial. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the trial.

Patient's name \_\_\_\_\_ (Please print)  
Patient's signature \_\_\_\_\_ Date \_\_\_\_\_  
Investigator's name \_\_\_\_\_ (Please print)  
Investigator's signature \_\_\_\_\_ Date \_\_\_\_\_

I, Petra Austin herewith confirm that the above patient has been informed fully about the nature, conduct and risks of the above trial.

Witness's name \_\_\_\_\_ (Please print)  
Witness's signature \_\_\_\_\_ Date \_\_\_\_\_

**BYLAAG 3**  
**VRAELYS**

**P. Austin**

**Research Questionnaire**

**MA (Social Work)**

Questionnaire number: \_\_\_\_\_

**Questionnaire**

Answer all questions by making a cross (x) at the appropriate answer, or more than one cross (x) at all relevant answers, or by giving a short and concise answer when specified.

**Section 1- Biographic Particulars**

1.1 Describe only the family members living in the **same house as the respondent** by starting with the particulars of the respondent.

Age	Gender		Position in family	Level of education	Job at the moment	
<b>Respondent</b>						
	M1	F2				<b>01-08</b>
<b>Family Members</b>						
	M1	F2				<b>09-16</b>
	M1	F2				<b>17-24</b>
	M1	F2				<b>25-32</b>
	M1	F2				<b>33-40</b>
	M1	F2				<b>41-48</b>
	M1	F2				<b>49-56</b>
	M1	F2				<b>57-64</b>
	M1	F2				<b>65-72</b>
	M1	F2				<b>73-80</b>
	M1	F2				<b>81-88</b>

1.2 What language do you speak at home?

1.3 What is your sexual orientation?

<b>Heterosexual</b>	1	<b>Homosexual</b>	3	<b>90</b>
<b>Bisexual</b>	2	<b>Other (Specify)</b>		

1.4 What is your marital status/relationship status at the moment?

<b>Married by law</b>	1	<b>91-92</b>
<b>Married through lobola</b>	2	
<b>Not married/no relationship</b>	3	
<b>Not married/permanent relationship</b>	4	
<b>Not married/multiple relationships</b>	5	
<b>Divorced/no relationship</b>	6	
<b>Divorced/permanent relationship</b>	7	
<b>Divorced/multiple relationships</b>	8	
<b>Separated</b>	9	
<b>Living together</b>	10	
<b>Widowed/no relationship</b>	11	
<b>Widowed/permanent relationship</b>	12	
<b>Widowed/multiple relationships</b>	13	
<b>Other (Specify)</b>		

1.5 Who is the head of the household? \_\_\_\_\_ 93

## Section 2- Housing and Financial Data

2.1 Is your house:

<b>Owned</b>	1	<b>94</b>
<b>Rented</b>	2	
<b>Shelter/Home for people living with HIV/Aids</b>	3	

2.1.1 If the household owns the house, to which household member does the house belong? \_\_\_\_\_ 95

2.1.2 If the household rents the house, who pays the rent? \_\_\_\_\_ 96

2.2 What type of material mainly serves as building material for the house?

<b>Bricks</b>	1	<b>Grass</b>	6	<b>97</b>
<b>Plastic</b>	2	<b>Mud</b>	7	
<b>Zink sheets</b>	3	<b>Prefabricated</b>	8	
<b>Asbestos</b>	4	<b>Other (Specify)</b>		
<b>Wood</b>	5			

2.3 Specify the following:

<b>How many rooms in the house</b>		<b>98</b>
<b>How many bedrooms in the house</b>		<b>99</b>

2.4 Please mark only the applicable where available to your household:

<b>Water from tap in the house</b>	1	<b>100</b>
<b>Water from tap in yard</b>	2	
<b>Water from community tap</b>	3	
<b>Water from river/dam/other</b>	4	
<b>Electricity</b>	1	<b>101</b>
<b>Separate kitchen and stove</b>	1	<b>102</b>
<b>Refrigerator</b>	1	<b>103</b>
<b>Bath in bathroom</b>	1	<b>104</b>
<b>Moveable plastic or metal bath</b>	2	
<b>Basin</b>	3	
<b>Shower</b>	4	
<b>Flush toilet indoors</b>	1	<b>105</b>
<b>Flush toilet outdoors</b>	2	
<b>Pit toilet outdoors</b>	3	
<b>Chemical toilet outdoors</b>	4	
<b>Communal toilets</b>	5	
<b>Place for everyone to sleep</b>	1	<b>106</b>
<b>Waste disposal system</b>	1	<b>107</b>
<b>Car</b>	1	<b>108</b>
<b>Telephone</b>	1	<b>109</b>
<b>Cellphone</b>	2	<b>110</b>
<b>Television</b>	1	<b>111</b>

<b>Radio</b>	2	
<b>Mailing address</b>	1	<b>112</b>

2.5 How much money is available to the family on a monthly basis?

<b>R0-R200</b>	1	<b>R2501-3000</b>	6	<b>113-114</b>
<b>R201-500</b>	2	<b>R3001-5000</b>	7	
<b>R501-1000</b>	3	<b>R5001-8000</b>	8	
<b>R1001-1500</b>	4	<b>R8001-10 000</b>	9	
<b>R1501-2500</b>	5	<b>Other (Specify)</b>		

2.6 What is your source of income?

<b>Salary</b>	1	<b>115</b>
<b>Self-employed</b>	2	
<b>Pension</b>	3	
<b>Grant</b>	4	
<b>Family support</b>	5	
<b>Part-time salary</b>	6	
<b>Shelter/home pays for basic needs</b>	7	
<b>Other (Specify)</b>		

2.6.1 If self-employed, specify how income is generated e.g. own stall or business.

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2.6.2 If self-employed or receiving a salary, for how long do you think you will be able to keep on working before you get to ill?

<b>Less than a year</b>	1	<b>117</b>
<b>Between 1-2 years</b>	2	
<b>Between 2-4 years</b>	3	
<b>Between 4-6 years</b>	4	
<b>More than 6 years</b>	5	
<b>Not sure</b>	6	
<b>Other (Specify)</b>		

2.7 What are the costs of the following monthly expenses? University of Pretoria etd – Austin, P (2006)

	Less than R100	R101-200	R201-300	R301-400	R401-500	R501-600	R601-700	R701-1000	More than R1000	
<b>*W/E</b>	1	2	3	4	5	6	7	8	9	<b>118</b>
<b>Transport</b>	1	2	3	4	5	6	7	8	9	<b>119</b>
<b>Rent</b>	1	2	3	4	5	6	7	8	9	<b>120</b>
<b>School fees</b>	1	2	3	4	5	6	7	8	9	<b>121</b>
<b>Food</b>	1	2	3	4	5	6	7	8	9	<b>122</b>
<b>Clothing</b>	1	2	3	4	5	6	7	8	9	<b>123</b>
<b>Medication</b>	1	2	3	4	5	6	7	8	9	<b>124</b>

Please Specify Others Expenses:

	1	2	3	4	5	6	7	8	9	<b>125-</b>
	1	2	3	4	5	6	7	8	9	<b>126</b>

\*Water and electricity

2.8 Who or what will financially support your family when you have passed away?

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**Section 3- Disclosure**

3.1 Does any of your family members know that you are HIV-positive?

<b>Non of the family members</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Suspects it but not sure 3</b>	<b>128</b>
<b>All the family members</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Suspects it but not sure 3</b>	<b>129</b>
<b>Husband/partner</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Suspects it but not sure 3</b>	<b>130</b>
<b>Mother</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Suspects it but not sure 3</b>	<b>131</b>
<b>Father</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Suspects it but not sure 3</b>	<b>132</b>
<b>Brother(s)</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Suspects it but not sure 3</b>	<b>133</b>
<b>Sister(s)</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Suspects it but not sure 3</b>	<b>134</b>
<b>Son</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Suspects it but not sure 3</b>	<b>135</b>
<b>Daughter</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Suspects it but not sure 3</b>	<b>136</b>
<b>Extended family members</b>	<b>Yes 1</b>	<b>No 2</b>	<b>Suspects it but not sure 3</b>	<b>137</b>
<b>Others (Specify)</b>				<b>138</b>

3.2 What was the reaction of above-mentioned person(s) when you made your status known to them?

	<b>Partner</b> 139.1	<b>Children</b> 139.2	<b>Family</b> 139.3	<b>Brother</b> 139.4	<b>Sister</b> 139.5	<b>Mother</b> 139.6	<b>Father</b> 139.7	
<b>Shock</b>	1	1	1	1	1	1	1	
<b>Anger</b>	2	2	2	2	2	2	2	
<b>Denial</b>	3	3	3	3	3	3	3	
<b>Horror</b>	4	4	4	4	4	4	4	
<b>Disbelief</b>	5	5	5	5	5	5	5	
<b>Acceptance</b>	6	6	6	6	6	6	6	
<b>Support</b>	7	7	7	7	7	7	7	
<b>Rejection</b>	8	8	8	8	8	8	8	
<b>Sadness</b>	9	9	9	9	9	9	9	
<b>Other (Specify)</b>								<b>140</b>

3.3 How did your relationships with the above-mentioned person(s) change after you made your HIV-status known to them?

<b>Relationship</b>	<b>Person</b>
<b>We have a stronger relationship</b>	<b>141</b>
<b>The relationship was damaged</b>	<b>142</b>
<b>The relationship was unchanged</b>	<b>143</b>
<b>We do not have a relationship anymore</b>	<b>144</b>
<b>Other (Specify)</b>	<b>145</b>

3.4 Are any of your friends aware of your HIV-status?

<b>Yes 1</b>	<b>No 2</b>	<b>146</b>
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3.4.1 If Yes, how did your friends react?

<b>I lost all of my friends</b>	1	<b>147</b>
<b>I lost some of my friends</b>	2	
<b>All of my friends are supporting me</b>	3	
<b>Other (Specify)</b>		

3.5 Are any of your community members aware of your HIV-status?

<b>Yes 1</b>	<b>No 2</b>	<b>148</b>
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3.5.1 If Yes, how are you treated by the above-mentioned community members?

<b>I am accepted</b>	1	<b>149</b>
<b>I was rejected</b>	2	
<b>The community supports me</b>	3	
<b>The community avoids me</b>	4	
<b>Other (Specify)</b>		

3.6 In what order did disclosure take place in your personal environment? Start by numbering the first person who was informed of your HIV-status as 1, the second person as 2 etc.

<b>Partner/Spouse</b>		<b>150</b>
<b>Children</b>		<b>151</b>
<b>Close friends</b>		<b>152</b>
<b>Extended family</b>		<b>153</b>
<b>Immediate community</b>		<b>154</b>
<b>Workplace/Colleagues</b>		<b>155</b>
<b>Public</b>		<b>156</b>
<b>Other (Specify)</b>		<b>157</b>

3.7 If you knew then what you know now, would you have told anyone that you are HIV-positive?

<b>Yes 1</b>	<b>No 2</b>	<b>158</b>
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3.7.1 If Yes, who would you have told and why?

**159**

3.7.2 If No, who would you not have told and why?

**159.1**

3.8 Who or what would you describe as your main support network?

<b>Family members</b>	1	<b>160</b>
<b>Friends</b>	2	
<b>Neighbours</b>	3	
<b>The whole community</b>	4	
<b>The Church</b>	5	
<b>Welfare organisations/Hospices</b>	6	
<b>Others (Specify)</b>		

**Section 4- Sexual Relationship(s) and Pregnancy**

4.1 The following statements refer to your sexual relationship(s) before you were informed of your HIV-status. Please mark Yes if applicable.

<b>Did you use condoms during sexual intercourse?</b>	<b>Yes 1</b>	<b>No 2</b>	<b>161</b>
<b>Were you ever forced to have sex without protection?</b>	<b>Yes 1</b>	<b>No 2</b>	<b>162</b>
<b>Do you prefer sexual intercourse without the use of a condom?</b>	<b>Yes 1</b>	<b>No 2</b>	<b>163</b>
<b>Has your ever partner abused you when you asked him to use a condom?</b>	<b>Yes 1</b>	<b>No 2</b>	<b>164</b>
<b>Do you and your partner ever communicate about sex and your sexual relationship?</b>	<b>Yes 1</b>	<b>No 2</b>	<b>165</b>
<b>Do you think your partner had other sexual relationships in the past while he was still with you?</b>	<b>Yes 1</b>	<b>No 2</b>	<b>166</b>
<b>Do you think your partner is still having sex with others?</b>	<b>Yes 1</b>	<b>No 2</b>	<b>167</b>
<b>Did you have sex with multiple partners?</b>	<b>Yes 1</b>	<b>No 2</b>	<b>168</b>
<b>Did you know about HIV and that it is transmitted during sexual intercourse?</b>	<b>I did not know 1</b>	<b>I knew 2</b>	<b>169</b>
<b>Did you know about HIV but still had unprotected sex?</b>	<b>I did not know 1</b>	<b>I knew 2</b>	<b>170</b>
<b>Do you feel that condoms are freely available in my community?</b>	<b>Yes 1</b>	<b>No 2</b>	<b>171</b>

4.2 How many sex partners did you have during the year before you were diagnosed as HIV-positive?

<b>Non</b>	<b>1</b>	<b>172</b>
<b>Other amount</b>		

4.3 Now that you are aware of your HIV-status, do you still have sex?

<b>Yes 1</b>	<b>No 2</b>	<b>Sometimes 3</b>	<b>173</b>
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4.3.1 If Yes to question 4.3, how many sex partners do you have?

<b>1 Partner</b>	1	<b>174</b>
<b>2 Partners</b>	2	
<b>3 or more Partners</b>	3	

4.3.2 If Yes to question 4.3, do you practice safe sex by using a condom?

<b>Yes 1</b>	<b>No 2</b>	<b>175</b>
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4.3.3 If Yes to question 4.3, is your partner aware of your HIV-status?

<b>Yes 1</b>	<b>No 2</b>	<b>176</b>
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4.4 Why do you think African men prefer sexual intercourse without the use of a condom?

<b>To have many children</b>	<b>Yes 1</b>	<b>No 2</b>	<b>177</b>
<b>For better sexual pleasure</b>	<b>Yes 1</b>	<b>No 2</b>	<b>178</b>
<b>African men are insulted by the use of condoms</b>	<b>Yes 1</b>	<b>No 2</b>	<b>179</b>
<b>Using a condom is not part of the African culture</b>	<b>Yes 1</b>	<b>No 2</b>	<b>180</b>
<b>African men believe that condoms are for white men</b>	<b>Yes 1</b>	<b>No 2</b>	<b>181</b>
<b>African men believe that HIV is not acquired so easily</b>	<b>Yes 1</b>	<b>No 2</b>	<b>182</b>
<b>African men do not trust women who want to use condoms</b>	<b>Yes 1</b>	<b>No 2</b>	<b>182.1</b>
<b>Other (Specify)</b>			<b>183</b>

4.5 If you have children, please complete the following statements:

<b>I planned all my pregnancies</b>	<b>Yes 1</b>	<b>No 2</b>	<b>184</b>
<b>I planned some of my pregnancies</b>	<b>Yes 1</b>	<b>No 2</b>	<b>185</b>
<b>I planned none of my pregnancies</b>	<b>Yes 1</b>	<b>No 2</b>	<b>186</b>
<b>I had no choice in getting pregnant</b>	<b>Yes 1</b>	<b>No 2</b>	<b>187</b>

4.6 If you get pregnant and know that you are HIV-positive, will you consider having an abortion?

<b>Yes 1</b>	<b>No 2</b>	<b>Already had an abortion 3</b>	<b>188</b>
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4.6.1 Please motivate your answer

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189

4.7 If you have children, where will your children stay when you pass away?

<b>There is nobody to look after my children when I pass away</b>	1	<b>190</b>
<b>My children will go to a children's home when I pass away</b>	2	
<b>My family will look after my children when I pass away</b>	3	
<b>The children's father(s) will look after my children when I pass away</b>	4	
<b>My neighbours will look after my children when I pass away</b>	5	
<b>My friends will look after my children when I pass away</b>	6	
<b>My children are old enough to look after themselves when I pass away</b>	7	

### Section 5- Medical Aspects

5.1 For what period of time have you known your diagnosis?

<b>A few months</b>	1	<b>191</b>
<b>6 months to a year</b>	2	
<b>1-3 years ago</b>	3	
<b>3-6 years ago</b>	4	
<b>More than 6 years ago</b>	5	
<b>Unsure</b>	6	
<b>Other (Specify)</b>	7	

5.2 How do you think you acquired HIV?

<b>Unprotected sexual intercourse with an infected person</b>	1	<b>192</b>
<b>Contact with infected blood</b>	2	
<b>Was raped by HIV-positive person</b>	3	

5.3 Prior to testing, what made you realise that you might be infected?

<b>Had unprotected sex</b>	1	<b>193</b>
<b>Experienced early symptoms of HIV</b>	2	
<b>Husband/partner tested positive</b>	3	
<b>Husband/partner had other partners</b>	4	
<b>New born baby tested positive</b>	5	
<b>Rapist tested HIV-positive</b>	6	
<b>Had operation accompanied by blood tests</b>	7	
<b>Other (Specify)</b>		

5.4 Who informed you of the results of your HIV-test?

<b>Medical doctor/practitioner</b>	1	<b>194</b>
<b>Nurse</b>	2	
<b>Social worker</b>	3	
<b>HIV-counsellor</b>	4	
<b>Healthcare worker</b>	5	
<b>Other (Specify)</b>		

5.5 How did you experience the person that informed you of the test result?

<b>Neutral</b>	1	<b>195</b>
<b>Sympathetic</b>	2	
<b>Cold</b>	3	
<b>Sensitive</b>	4	
<b>Judgmental</b>	5	
<b>Supportive</b>	6	
<b>Unsupportive</b>	7	
<b>Other (Specify)</b>		<b>196</b>

5.6 How would you describe your medical state at this stage?

<b>Not ill</b>	1	<b>197</b>
<b>Ill but independent</b>	2	
<b>Bedridden</b>	3	
<b>Sometimes in bed, sometimes well</b>	4	
<b>Terminal/Dying</b>	5	

5.7 Are there any other household members with HIV/Aids?

<b>No</b>	1	<b>Brother(s)</b>	6	<b>198-199</b>
<b>All household members</b>	2	<b>Sister(s)</b>	7	
<b>Husband/partner</b>	3	<b>Son</b>	8	
<b>Mother</b>	4	<b>Daughter</b>	9	
<b>Father</b>	5	<b>Baby</b>	10	

5.8 Please mark any of the following symptoms you have experienced during the last six months:

<b>Swelling in the neck</b>	<b>Yes 1</b>	<b>No 2</b>	<b>200</b>
<b>Swelling in the groin</b>	<b>Yes 1</b>	<b>No 2</b>	<b>201</b>
<b>Night sweat</b>	<b>Yes 1</b>	<b>No 2</b>	<b>202</b>
<b>Fever</b>	<b>Yes 1</b>	<b>No 2</b>	<b>203</b>
<b>Diarrhoea</b>	<b>Yes 1</b>	<b>No 2</b>	<b>204</b>
<b>Loss of appetite</b>	<b>Yes 1</b>	<b>No 2</b>	<b>205</b>
<b>Weight loss</b>	<b>Yes 1</b>	<b>No 2</b>	<b>206</b>
<b>Coughing</b>	<b>Yes 1</b>	<b>No 2</b>	<b>207</b>
<b>Skin problems</b>	<b>Yes 1</b>	<b>No 2</b>	<b>208</b>
<b>Mouth ulcers</b>	<b>Yes 1</b>	<b>No 2</b>	<b>209</b>
<b>STD's</b>	<b>Yes 1</b>	<b>No 2</b>	<b>210</b>
<b>Lack of energy</b>	<b>Yes 1</b>	<b>No 2</b>	<b>211</b>
<b>Depression</b>	<b>Yes 1</b>	<b>No 2</b>	<b>212</b>
<b>Stress</b>	<b>Yes 1</b>	<b>No 2</b>	<b>213</b>
<b>Other (Specify)</b>			<b>214</b>

5.9 Do you know what a CD4 count is?

<b>Yes 1</b>	<b>No 2</b>	<b>215</b>
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5.9.1 If Yes, do you know what your CD4 count is? \_\_\_\_\_ **216**

5.10 Where do you receive medical treatment?

<b>At a Hospital</b>	<b>Yes 1</b>	<b>No 2</b>	<b>217</b>
<b>At a Clinic</b>	<b>Yes 1</b>	<b>No 2</b>	<b>218</b>
<b>From a Traditional Healer</b>	<b>Yes 1</b>	<b>No 2</b>	<b>219</b>
<b>From a private medical practitioner</b>	<b>Yes 1</b>	<b>No 2</b>	<b>220</b>
<b>Other (Specify)</b>			<b>221</b>

5.11 How accessible are the hospitals/clinics in your community?

<b>Easily accessible</b>	<b>1</b>	<b>Difficult to access</b>	<b>2</b>	<b>Not accessible</b>	<b>3</b>	<b>222</b>
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5.11.1 If difficult or not accessible, please specify reasons. \_\_\_\_\_

**223**

5.12 If medication is prescribed, who pays for it?

<b>Household</b>	1	<b>224</b>
<b>Government</b>	2	
<b>Medical scheme</b>	3	
<b>Self</b>	4	

5.12.1 If the answer is *self* please specify the amount you pay for medication prescribed every month. R \_\_\_\_\_ **225**

5.13 Please indicate if you receive treatment/help from any of the following persons.

<b>Medical doctor</b>		<b>226</b>
<b>Nurse</b>		<b>227</b>
<b>Occupational therapist</b>		<b>228</b>
<b>Physiotherapist</b>		<b>229</b>
<b>Dietician</b>		<b>230</b>
<b>Psychologist</b>		<b>231</b>
<b>Pastoral counsellor</b>		<b>232</b>
<b>Social worker</b>		<b>233</b>
<b>Home carer</b>		<b>234</b>

### Section 6- Emotional and Psychosocial Issues

6.1 When your diagnosis was made known to you, what was your first reaction?

<b>Sadness</b>	<b>Yes 1</b>	<b>No 2</b>	<b>235</b>
<b>Cried</b>	<b>Yes 1</b>	<b>No 2</b>	<b>236</b>
<b>Anger</b>	<b>Yes 1</b>	<b>No 2</b>	<b>237</b>
<b>Shock</b>	<b>Yes 1</b>	<b>No 2</b>	<b>238</b>
<b>Denial</b>	<b>Yes 1</b>	<b>No 2</b>	<b>239</b>
<b>Fear</b>	<b>Yes 1</b>	<b>No 2</b>	<b>240</b>
<b>Shame</b>	<b>Yes 1</b>	<b>No 2</b>	<b>241</b>
<b>Wanted to commit suicide</b>	<b>Yes 1</b>	<b>No 2</b>	<b>242</b>
<b>Other (Specify)</b>			<b>243</b>

6.2 Do you currently experience any of the following emotions?

<b>Anger</b>	<b>Yes 1</b>	<b>No 2</b>	<b>244</b>
<b>Sadness</b>	<b>Yes 1</b>	<b>No 2</b>	<b>245</b>
<b>Helplessness</b>	<b>Yes 1</b>	<b>No 2</b>	<b>246</b>
<b>Hopelessness</b>	<b>Yes 1</b>	<b>No 2</b>	<b>247</b>
<b>Fear</b>	<b>Yes 1</b>	<b>No 2</b>	<b>248</b>
<b>Shame</b>	<b>Yes 1</b>	<b>No 2</b>	<b>249</b>
<b>Guilt</b>	<b>Yes 1</b>	<b>No 2</b>	<b>250</b>
<b>Uncertainty</b>	<b>Yes 1</b>	<b>No 2</b>	<b>251</b>
<b>Isolation</b>	<b>Yes 1</b>	<b>No 2</b>	<b>252</b>
<b>Rejection</b>	<b>Yes 1</b>	<b>No 2</b>	<b>253</b>
<b>Loneliness</b>	<b>Yes 1</b>	<b>No 2</b>	<b>254</b>
<b>Other (Specify)</b>			<b>255</b>

6.3 Please mark all applicable answers:

<b>My life is meaningful</b>	<b>Yes 1</b>	<b>No 2</b>	<b>256</b>
<b>I am scared to die</b>	<b>Yes 1</b>	<b>No 2</b>	<b>257</b>
<b>I am in control of my life</b>	<b>Yes 1</b>	<b>No 2</b>	<b>258</b>
<b>I have no control over my life</b>	<b>Yes 1</b>	<b>No 2</b>	<b>259</b>
<b>I am ready to die</b>	<b>Yes 1</b>	<b>No 2</b>	<b>260</b>
<b>I am still thinking about suicide</b>	<b>Yes 1</b>	<b>No 2</b>	<b>261</b>
<b>Other (Specify)</b>			<b>262</b>

6.4 How do you perceive your future?

<b>I am hopeful</b>	<b>Yes 1</b>	<b>No 2</b>	<b>263</b>
<b>I fear the future</b>	<b>Yes 1</b>	<b>No 2</b>	<b>264</b>
<b>I do not think about the future</b>	<b>Yes 1</b>	<b>No 2</b>	<b>265</b>
<b>I have no hope for the future</b>	<b>Yes 1</b>	<b>No 2</b>	<b>266</b>
<b>I will enjoy all the time that is left</b>	<b>Yes 1</b>	<b>No 2</b>	<b>267</b>
<b>Other (Specify)</b>			<b>268</b>



6.5 Do you handle your illness in any of the following ways?

<b>By not thinking about the illness</b>	<b>Yes 1</b>	<b>No 2</b>	<b>269</b>
<b>By not talking about the illness</b>	<b>Yes 1</b>	<b>No 2</b>	<b>270</b>
<b>By blaming yourself</b>	<b>Yes 1</b>	<b>No 2</b>	<b>271</b>
<b>By wishing the illness away</b>	<b>Yes 1</b>	<b>No 2</b>	<b>272</b>
<b>By not taking responsibility for the illness</b>	<b>Yes 1</b>	<b>No 2</b>	<b>273</b>
<b>By crying all the time</b>	<b>Yes 1</b>	<b>No 2</b>	<b>274</b>
<b>By being angry all the time</b>	<b>Yes 1</b>	<b>No 2</b>	<b>275</b>
<b>By seeing the illness as an opportunity to still grow</b>	<b>Yes 1</b>	<b>No 2</b>	<b>276</b>
<b>By trying to infect others</b>	<b>Yes 1</b>	<b>No 2</b>	<b>277</b>

6.6 How do you feel about your body? Please mark all applicable answers.

<b>I think my body looks healthy</b>	<b>1</b>	<b>278</b>
<b>It feels as if this body is not mine</b>	<b>2</b>	
<b>I still feel confident enough about my body to go out into the community and see my friends</b>	<b>3</b>	
<b>I do not want the community or my friends to see me the way I look now</b>	<b>4</b>	
<b>I do not care what other people think when they see my body</b>	<b>5</b>	
<b>Only my family still sees me</b>	<b>6</b>	
<b>HIV has changed my body in such a way that I do not even want my family to see me anymore</b>	<b>7</b>	
<b>Other (Specify)</b>		<b>279</b>

6.7 How do you feel about death?

<b>I do not think about death</b>	<b>Yes 1</b>	<b>No 2</b>	<b>280</b>
<b>I fear death</b>	<b>Yes 1</b>	<b>No 2</b>	<b>281</b>
<b>Death will be peaceful</b>	<b>Yes 1</b>	<b>No 2</b>	<b>282</b>
<b>Death will be shameful</b>	<b>Yes 1</b>	<b>No 2</b>	<b>283</b>
<b>Other (Specify)</b>			<b>384</b>

### Section 7- Counselling Needs

7.1 Are you aware of any counselling services in your community?

<b>Yes 1</b>	<b>No 2</b>	<b>285</b>
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7.2 If counselling services are available, please mark where these services can be found in your community:

1 Clinics	Yes 1	No 2	286
2 Hospitals	Yes 1	No 2	287
3 Hospices	Yes 1	No 2	288
4 Churches	Yes 1	No 2	289
5 Welfare Organisations	Yes 1	No 2	290
6 Non Governmental Organisations	Yes 1	No 2	291
7 Private counsellors	Yes 1	No 2	292
8 Traditional Healers	Yes 1	No 2	293
Other (Specify)			394

7.2.1 Have you received help from any of the above-mentioned?

Yes (1) I received help from	295	No 2	296
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7.2.2 If Yes, for what period of time did you receive counselling?

Only once or twice	1	297
1-4 weeks	2	
1-3 months	3	
3-6 months	4	
6 months to 1 year	5	
Still receives counselling	6	

7.3 Did the counsellor help you in any of the following ways?

By giving information on HIV and testing	Yes 1	No 2	Not relevant 3	298
By giving support when test result came back	Yes 1	No 2	Not relevant 3	299
By supporting you during the process of adjusting to you diagnosis	Yes 1	No 2	Not relevant 3	300
By giving information on treatment, use of medication and symptoms	Yes 1	No 2	Not relevant 3	301
By discussing emotional, sexual or family problems you experienced	Yes 1	No 2	Not relevant 3	302
By discussing disclosure to significant others and in the workplace	Yes 1	No 2	Not relevant 3	303
By helping you to plan your children's future	Yes 1	No 2	Not relevant 3	304
By helping you with financial planning	Yes 1	No 2	Not relevant 3	305

By helping you to change any risk behaviour	Yes 1	No 2	Not relevant 3	306
By referring you to other relevant services	Yes 1	No 2	Not relevant 3	307
Other (Specify)				308

7.4 Did you experience any of the following problems and needed to change your behaviour or habits?

<b>Sex worker/Prostitution</b>	<b>Yes 1</b>	<b>No 2</b>	<b>309</b>
<b>Husband/Partner with multiple partners</b>	<b>Yes 1</b>	<b>No 2</b>	<b>310</b>
<b>Drug abuse</b>	<b>Yes 1</b>	<b>No 2</b>	<b>311</b>
<b>Alcohol abuse</b>	<b>Yes 1</b>	<b>No 2</b>	<b>312</b>
<b>Unhealthy diet</b>	<b>Yes 1</b>	<b>No 2</b>	<b>313</b>
<b>Personal hygiene</b>	<b>Yes 1</b>	<b>No 2</b>	<b>314</b>
<b>Hygiene in and around the house</b>	<b>Yes 1</b>	<b>No 2</b>	<b>315</b>
<b>Had to start using condoms</b>	<b>Yes 1</b>	<b>No 2</b>	<b>316.1</b>
<b>Smoking</b>	<b>Yes 1</b>	<b>No 2</b>	<b>316.2</b>
<b>Others (Specify)</b>			

7.4.1 If Yes to any of the above-mentioned, how long did it take you to change your behaviour?

<b>Did not change behaviour</b>	1	<b>317</b>
<b>Changed my behaviour immediately</b>	2	
<b>Between 0-6 months</b>	3	
<b>Between 7-12 months</b>	4	
<b>Between 1-2 years</b>	5	
<b>More than 2 years</b>	6	

7.5 Which of the following potential HIV-counsellors will you be more comfortable with and why will you be more comfortable with this person? 318

I will be more comfortable with a <b>Nurse</b> because	1
I will be more comfortable with a <b>Health care worker</b> because	2
I will be more comfortable with a <b>Social worker</b> because	3
I will be more comfortable with a <b>Pastoral counsellor</b> because	4
I will be more comfortable with a <b>Traditional healer</b> because	5
I will be more comfortable with a <b>Psychologist</b> because	6
I will be more comfortable with a <b>Trained volunteer from own community</b> because	7

7.6 Which of the following aspects are important for you when receiving counselling?

<b>It will be suitable if the counsellor speaks English</b>	1	<b>319</b>
<b>It will be suitable if the counsellor speaks Afrikaans</b>	2	
<b>The counsellor must speak my own language</b>	3	
<b>The counsellor must be of the same culture</b>	4	
<b>If the counsellor is not of the same culture, insight of my culture is still important</b>	5	
<b>I do not think culture is important when it comes to counselling</b>	6	
<b>The counsellor must be of the same ethnicity</b>	7	
<b>I do not care if the counsellor is from a different ethnic group</b>	8	
<b>The counsellor must come from a community similar to mine</b>	9	
<b>The counsellor can be from any community</b>	10	

7.7 Which of the following do you see as important concerning the HIV-counsellor?

	<b>Yes</b>	<b>No</b>	
<b>The counsellor should be a good listener</b>	1	2	<b>320</b>
<b>The counsellor should be well informed and able to give me relevant information</b>	1	2	<b>321</b>
<b>The counsellor should have a warm personality</b>	1	2	<b>322</b>
<b>The counsellor should be neutral and keep a professional distance</b>	1	2	<b>323</b>
<b>The counsellor should treat me as a friend</b>	1	2	<b>324</b>
<b>The counsellor should not be afraid to touch me</b>	1	2	<b>325</b>
<b>The counsellor should keep a distance and rather not touch me</b>	1	2	<b>326</b>
<b>The counsellor should treat all information as confidential</b>	1	2	<b>327</b>
<b>The counsellor should help me to function on my own and to not get too attached to him/her</b>	1	2	<b>328</b>
<b>The counsellor should be able to help me confront my needs in a practical manner</b>	1	2	<b>329</b>

7.9 When do you think counselling on dying and death is necessary?

<b>When I am ready to talk about death and dying</b>	<b>Yes 1</b>	<b>No 2</b>	<b>330</b>
<b>When I get very sick</b>	<b>Yes 1</b>	<b>No 2</b>	<b>331</b>
<b>When I am still well enough to discuss important issues with my family</b>	<b>Yes 1</b>	<b>No 2</b>	<b>332</b>
<b>When it is obvious that my family is mourning</b>	<b>Yes 1</b>	<b>No 2</b>	<b>333</b>
<b>When I feel uncertain and fearful of death</b>	<b>Yes 1</b>	<b>No 2</b>	<b>334</b>
<b>Other (Specify)</b>			<b>335</b>

7.10 What do you think should be discussed during counselling on dying and death?

<b>Fear of death</b>	<b>Yes 1</b>	<b>No 2</b>	<b>336</b>
<b>Religion</b>	<b>Yes 1</b>	<b>No 2</b>	<b>337</b>
<b>Practical matters e.g. life insurance/policies</b>	<b>Yes 1</b>	<b>No 2</b>	<b>338</b>
<b>My will/testament</b>	<b>Yes 1</b>	<b>No 2</b>	<b>339</b>
<b>The future of my children</b>	<b>Yes 1</b>	<b>No 2</b>	<b>340</b>
<b>My funeral</b>	<b>Yes 1</b>	<b>No 2</b>	<b>341</b>
<b>The fear my family members experience</b>	<b>Yes 1</b>	<b>No 2</b>	<b>342</b>
<b>How to find peace of mind</b>	<b>Yes 1</b>	<b>No 2</b>	<b>343</b>
<b>Unresolved issues with other people</b>	<b>Yes 1</b>	<b>No 2</b>	<b>344</b>
<b>Other (Specify)</b>			<b>345</b>

7.11 Do you want your family to receive bereavement counselling after you have passed away?

<b>Yes 1</b>	<b>No 2</b>	<b>346</b>
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7.12 Which family members do you think will benefit from bereavement counselling more? Please specify reason for answer.

<b>Family member(s)</b>	<b>Reason</b>	
<b>Children</b>		<b>347</b>
<b>Partner(s)</b>		<b>348</b>
<b>Brother(s)/Sister(s)</b>		<b>349</b>
<b>Parents</b>		<b>350</b>
<b>Other (Specify)</b>		<b>351</b>

**Thank you for your co-operation.**