IINKCUKACHA ZALOWO UTHATHA INXAXHEBA NEFOMU YESIVUMELWANO YOPHANDO OLUNGEZIFUNDO ZEMFUZO

ISIHLOKO SEPROJEKTHI YOPHANDO:

INOMBOLO YESALATHISO:

UMPHANDI OYINTLOKO:

IDILESI:

INOMBOLO YOQHAGAMSHELWANO:

Siyakumema ukuba uthathe inxaxheba kwesi sifundo sophando esibandakanya uglahlelo ngezemfundo nokugcinwa kwegazi ixesha elide okanye inyama ethile esemzimbeni. Nceda uzinike ixesha lokufunda iinkcukacha ezichazwe apha, eziza kucacisa ngeenkcukacha zale projekthi. Nceda ubuze kwabo basebenza ngesi sifundo okanye kugqirha nayiphi na imibuzo nangayo nayiphi na into ngale projekthi ongayiqondiyo ngokupheleleyo. Kubaluleke kakhulu ukuba waneliseke ngokupheleleyo okuqulathwe kolu phando nokuba ungabandakanyeka njani. Kwakhona, ukuthatha kwakho inxaxheba **akunyanzelekanga uyazikhethela** kwaye ungala ukuthatha inxaxheba. Ukuba uthi hayi, oku akuzi kukuchaphazela ngendlela embi. Ungarhoxa kwesi sifundo nanini na, nokuba uyavuma ukuthatha inxaxheba.

Esi sifundo sivunywe **yiKomiti yoPhando ngomntu kwiYunivesithi yaseStellenbosch** kwaye luza kwenziwa ngokwemigaqo yokuziphatha ngokusesikweni evunyiweyo ekuhlaleni nakwamanye amazwe nemithetho-siseko yeSibhengezo saseHelsinki, kunye neMigaqo yaseMzantsi Afrika ka-2004 yeSebe lezeMpilo: *Iindlela zokuziphatha kuPhando lwezeMpilo: Imithetho-siseko, Ubume neeNkqubo*.

Yintoni uphando lwemfuzo?

Izixhobo zokujonga imfuzo, ezikwabizwa ngokuba yiDNA okanye iRNA, isoloko ifumane kwiisampuli ezincinci zegazi. Ngamaxesha athile izixhobo zokujonga imfuzo zifumaneka kwizinto ezifana namathe okanye ukuxilongwa kwesicwili esithathwe emzimbeni womntu ophilayo. (Isicwili esithathwe emzimbeni womntu ophilayo yintwana yenyama ethile esemzimbeni ethathwayo umz. elufeleni okanye enqatheni, ukunceda ukuba ukwazi ukuqonda isifo ngokuxilonga.) .. Iijini zifunyanwa kwiseli nganye emzimbeni womntu. Iijini zethu ziqinisekisa indlela esikhangeleka ngayo ngamanye amaxesha ukuba loluphi uhlobo lwezifo esinokuthabatheka kuzo kwilizwe jikelele, abaphandi kwizifundo zezemfuzo bafumanisa ngeenkcukacha ezintsha rhoqo ezinokunceda isizukulwana sexesha elizayo nezinokunceda abantu kule mihla, abanezifo ezithile okanye abakwiimeko ezithile.

Sibandakanya ntoni esi sifundo sithile sophando?

- *Give a brief summary in **simple language** about your particular research project and what you hope to discover? Be sure to explain terms like "genetic mutation" or "polymorphism" and also be sure to use these terms appropriately.*

Kutheni umenyiwe ukuba uthathe inxaxheba?

- *Explain briefly..*

Yeyiphi imigaqo eza kubandakanyeka kolu phando?

- *Ca Explain any procedures e.g. Volume of blood samples etc. Saliva samples etc.*
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Buza kuba yintoni ubungozi obubandakanyekayo kuphando lwezemfuzo?

- *All potential risks, depending on the specific research protocol, should be discussed transparently. These risks could include detection of unsuspected medical conditions, anxiety, group or individual stigmatisation,employment discrimination, adoption of exclusionary policies, including discriminatory insurance policies, , potential implications of the possible outcomes of the research on other family members even discovery of mis-attributed paternity*
- *The possible need for genetic councelling should also be discussed, if relevant, including who will cover the costs of this service.*
- *Please include any/all of these risks if they may be relevant to your particular research study.*

Uza kuzuza na ngokuthatha kwakho inxaxheba kwesi sifundo kwaye ingaba uza kuxelelwa na ngeziphumo zakho?

Please explain here whether or not any results will be made known to the participants. If not explain why not e.g. that blood will be stored and only tested at a later date, or that the techniques to be used are experimental and thus possibly unreliable etc. Also indicate that the research may benefit people with a similar condition in the future.
Optional wording:
*Your personal results will be made known to you **only if they indicate** that you may:*

- *Have a definite risk for developing a particular disorder.*
- *Have a condition or predisposition to developing a condition that is treatable or avoidable e.g. by a lifestyle modification.*
- *Need genetic counselling.*

Ingaba liza kugcinwa ixesha elingakanani kwaye liza kugcinwa phi?

- *Phendula lo mbuzo ngokwezinto ozifumene kuphando. Yiba phandle ngento kwaye ubandakanye neenkcukacha ezaneleyo. Kwaye ukuba ufuna ukuthumela imizekelo egciniweyo kwelinye ilizwe ngoku okanye ngomnye umhla, oku kufuneka kucaciswe kwangethuba.*

Ukuba igazi lakho kuza kufuneka ligcinwe ingaba akhona na amathuba okuba liza kusetyenziswa kolunye uphando?

Igazi lakho liza kusetyenziswa kuphela kuphando ngezemfuzo olunxulumene ngqo kwi…………………………………………………. (*the disease or condition or reason for your original research*). Kwakhona ukuba umphandi unqwenela ukusebenzisa igazi lakho eligciniweyo **kolunye uphando kwesi sifundo** kuza kufuneka bafake isicelo sokufumana imvume yokwenza oko kwiKomiti yokuziphatha kuPhando ngomntu kwiYunivesithi yaseStellenbosch.

Ukuba awunqweneli ukuba isampuli yakho yegazi igcinwe emva kokuba olu phando lugqityiwe uza kuba nethuba lokwenza isicelo sokuba ilahlwe emva kokuba utyikitye ifomu yesivumelwano.

Ingaba kuza kukhuselwa njani ukuba yimfihlelo kwezinto zakho?

- *Please explain this in detail. This is particularly important with collaborative research when the specimens will be shipped to a laboratory abroad. Will the specimens be anonymised, or linked only to demographic/clinical information or will it remain possible to link the specimens to identifying information. Is there a remote possibility that information that comes to light in the future may be beneficial to the participant or possibly have unpleasant implications? If so will an attempt be made to contact participants?*

Ingaba wena okanye abaphandi baza kuzuza imali na kolu phando?

Awuzi kuhlawulwa ngokuthatha kwakho inxaxheba kwesi sifundo. *although your out-of-pocket expenses may be reimbursed (include if applicable).*

Iinkcukacha ezibalulekileyo: Xa kunokwenzeka ukuba olu phando lukhokelela kuphuhliso lwesicelo sorhwebo okanye isigulane, wena okanye usapho lwakho anizi kufumana nayiphi na inzuzo okanye iimali ezihlawulwayo kumnini wento

Isivumelwano salowo uthatha inxaxheba

Ngokutyikitya ngezantsi, Mna ……………………………..………… ndiyavuma ukuthatha inxaxheba kwisifundo sophando ngezemfuzo esinesi sihloko *(insert title of study)*.

Ndiyavuma ukuba:

- Ndizifundile okanye ndizifundelwe ezi nkcukacha nale fomu yesivumelwano kwaye zibhalwe ngolwimi endilwaziyo nendiziva ndikhululekile ukulusebenzisa.
- Ndibenalo ithuba lokubuza imibuzo kwaye yonke imibuzo yam iphendulwe ngendlela eyanelisayo.
- Ndiyakuqonda ukuba ukuthatha kwam inxaxheba kwesi sifundo akunyanzeliswanga ndizikhethele kwaye khange ndifakwe xinezelelo ukuba ndithathe nxaxheba.
- Ndifumene ikopi etyikityiweyo yale fomu yesivumelwano ukuze ndizigcinele.

☐ Ndiyavuma ukuba igazi lam okanye isampuli esemzimbeni wam igcinwe, kodwa ndingakhetha ukucela nanini na ukuba isampuli yam egciniweyo ilahlwe. Ndinelungelo lokufumana isiqinisekiso sokuba isicelo sam senziwe. *(NB if the specimens will be anonymised then this statement should be changed appropriately)*

OKANYE

☐ Nceda uyitshabalalise isampuli yam yegazi kanye nje xa igqitywa iprojekthi yophando. **(Phawula oko ukukhethayo**)

Ityikitywe (*indawo*) ....….......…………….. nge-…………...………..(*umhla*).

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Ukutyikitya kwalowo uthatha inxaxheba .... Ukutyikitya kwengqina

Isivumelwano somphandi

Mna *(igama)* ……………………………………………..……… ndiyavuma ukuba:

- Ndizicacisile iinkcukacha ezikolu xwebhu ku …………………………………..
- Ndimkhuthazile ukuba abuse imibuzo kwaye athathe ixesha elaneleyo ukuba ayiphendule.
- Ndanelisekile ukuba uyiqonda ngokupheleleyo yonke imiba ekolu phando, njengoko bekuchaziwe ngentla
- Ndiyisebenzisile/andiyisebenzisanga itoliki. *(If a interpreter is used then the interpreter must sign the declaration below.)*

Ityikitywe (*indawo*) ....….......…………….. nge- …………...………..(*umhla*) ngo-2005.

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Ukutyikitya komphandi **Ukutyikitya kwengqina**

Isivumelwano setoliki

Mna *(igama)* …………………………………………..……… ndiyavuma ukuba:

- Ndimncedisile umphandi (*igama*) ………………………………………. ukucacisa iinkcukacha ezikolu xwebhu (*name of participant*) ku-……………..…………………………….. ndisebenzisa ulwimi lwesiBhulu/lwesiXhosa.
- Ndanelisekile ukuba lowo uthatha inxaxheba ukuqonda ngokupheleleyo oko kuqulathwe kolu xwebhu lwesivumelwano kwaye yonke imibuzo yakhe iphenduleke ngokwanelisayo.

Ityikitywe (*indawo*) ....…........……………….. nge-…………...…………(*umhla*) ngo-2005.

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Ukutyikitya kwetoliki **Ukutyikitya kwengqina**