CHEC-CCT Joint Research Programme: Final Report July 2019

Thematic Area: Citizenship & Democracy:

Collaborative development of a code of ethics for research with persons with disabilities in Cape Town

Research Team:

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1. ABSTRACT

Title: Collaborative development of a code of ethics for research with persons with disabilities in Cape Town.

Background: Persons with disabilities (PWD) have been identified as a vulnerable group in the City of Cape Town's Vulnerable Groups Policy. While research among vulnerable groups (e.g. PWD) is essential to inform policy and responsive service delivery, it is often implemented by consultants or researchers who make all the decisions. Participatory processes to increase research not only about, but also with and by PWD are needed to empower this vulnerable group in active citizenship.

Aims & objectives: The main ***aim*** of the project was to develop a peer-reviewed position paper and a code of ethics for research with persons with disabilities in the Cape Town context (with possible transference elsewhere later). The study ***objectives***, or steps to achieve this aim, were:

- to explore past research experiences of persons with disabilities in the study setting
- to analyse, critique and apply evidence from past studies in developing a position paper
- to collaboratively synthesise and create a code of ethics for research with persons with disabilities in the CCT area.

Method: A mixed method study with participatory elements was planned.

Study population, sampling and participants: The study population comprised of persons with disabilities (18 years or older) in Cape Town; a combination of purposive sampling and volunteer sampling was applied through disability focused NPOs, through the City of Cape Town Office for Affirmative Action and Disability Management and through direct contact of the collaborating researchers' personal contacts. Due to administrative process delays and strict NPO gatekeeping a total of only 32 participants could be recruited.

Data collection strategies included:

- a questionnaire survey designed to be applied flexibly in order to be accessible for persons with diverse disabilities i.e. it could be (a) sent and completed electronically to purposely identified participants and/or (b) completed telephonically or (c) presented as a brief questionnaire-based interview. The questionnaire was piloted with 2 participants and minor logistical adaptations were made to assist participants with its completion.
- a focus group discussion with 13 participants (who volunteered during the questionnaire survey) to formulate a draft code of ethics for research with PWD

Data analysis: Thematic analysis was applied to the predominantly qualitative findings. Basic descriptive and visual analysis was applied to the smaller proportion of quantitative data.

Ethics approval was received from both SU and UCT and permission to do the study within specific parameters was received from the City of Cape Town.

Rigour and trustworthiness precautions included an audit trail, member checking and peer-debriefing.

Findings included participants' unanimous request for more meaningful inclusion in ***all*** stages of research studies concerning them; from topic prioritisation to planning to dissemination – not just as participants during data collection. Key messages included the imperative for researchers to take all research findings back to the research participants (as this does not usually happen) and gatekeepers not overprotecting this vulnerable group at the cost of silencing their voices.

Value of the project to knowledge generation in universities & linkages to the priorities of the CCT: The project aligned well with the CCT's strategic focus areas of 'A Caring City' and moreover 'An Inclusive City'. In addition to a public dissemination event planned in the near future, a draft code of ethics that is in process and a peer-reviewed publication to reach academic communities, the findings are also being prepared for dissemination (1) to the Public Health Association of SA (PHASA) conference later this year (abstract already accepted) and (2) to the 16th Annual International Conference on Clinical Ethics & Consultation in early 2020, pending abstract acceptance.

2. INTRODUCTION, LITERATURE REVIEW, RESEARCH QUESTIONS AND AIMS

Introduction: Persons with disabilities (PWD) have been identified as a vulnerable group in the City of Cape Town's Vulnerable Groups Policy (CCT 2013). While research among vulnerable groups (e.g. PWD) is essential to inform policy and responsive service delivery, it is often implemented by consultants or researchers who make all the decisions. Participatory processes to increase research not only about, but also with and by PWD are needed to empower this vulnerable group in active citizenship.

Past human rights abuses and exploitative practices in research in so-called 'developing' countries have been identified (Benatar, 2002; Emanuel, Wendler, Killen & Grady 2004). More specifically, similar issues with vulnerable groups in local contexts have been identified (Dhai 2017; Horn et al 2014). There is thus a need to develop specific ethical benchmarks to empower vulnerable groups such as persons with disabilities (PWD) to question, guide and control the nature and process of research about them.

South Africa's research ethics systems and infrastructure are regularly updated and strengthened (e.g. Department of Health 2015). Furthermore, international and southern African developments in addressing past human rights abuses specific to research with vulnerable people groups have included the recent launch of the San Code of Ethics for Research (SASI 2017). The availability of the collaboratively developed San Code of Ethics is already empowering San individuals and NPOs to respond to research needs for and by the San people. However, there remains a need for participatory processes to develop such protections for other vulnerable groups as well, for example persons with disabilities (PWD). The challenge is to ensure that justice is served by enabling their voice to be heard while avoiding any possible form of exploitation.

Non Profit Organisations (NPOs) and Disabled Persons' Organisations (DPOs) in and around Cape Town are repeatedly approached by researchers to access the respective NPO's/DPO's membership for research purposes. Ad hoc assistance with some organisation-specific research policies has been met with increasing requests for such protective policies. A code of ethics, collaboratively developed with PWD themselves and disseminated within the CCT's ambit, would empower DPOs, NPOs and individual PWD, in the CCT area in their responses to research requests within the area.

The purpose of this participatory project was thus to add to the CCT's inclusive policies and programmes by developing a position paper (to be published in an academic, peer-reviewed journal) and a code of ethics for research with persons with disabilities within the ambit of the City of Cape Town's programmes (including NPOs, DPOs).

The research questions that informed our literature review were:

- What roles have PWD fulfilled in research about/with PWD in the CCT context?
- How can the benchmarks for research in developing countries be specified/particularised/adapted/ updated/applied to address issues in research with persons with disabilities in the CCT context?
- What needs to be included in a code of ethics for research with persons with disabilities in the CCT context?

The critical **literature review** comprised searches in the areas of research with vulnerable groups in general and with persons with disabilities (PWD) in particular.

Much has been written about the power dynamics in research. This includes issues in research in the global south by researchers from the global north (Benatar 2002; Benatar & Singer 2010; Emanuel, Wendler, Killen & Grady 2004; London, 2002; Macdonald & Spiegel 2013). Furthermore, ethical issues have been identified in research with diverse vulnerable groups on the whole (e.g. London 2002; Pittaway, Bartolomei & Hugman 2010; Ruof 2004; Zion, Gillam

& Loff 2000) and in research with persons with disabilities in particular (e.g. Matthews, Ellem & Chenoweth 2013; Nuwagaba & Rule 2015; Ollerton & Horsfall 2013 and others).

Participatory approaches have been identified as imperative, and having multi-faceted benefits (Aldridge, 2007; Hartley, Yousafzai et al. 2017; Post et al 2017; Priestley, Waddington & Bessozi 2010).

A critical literature review (Grant & Booth 2009) was done to analyse and synthesise participatory processes and outcomes in developing ethically responsive research with and by persons with disabilities in (a) global and (b) local contexts. The learning from this literature review informed some of the details of the research (e.g. specific questions for interviews and strategies to make this research accessible for persons with diverse disabilities including those affecting communication).

Aims & objectives: The main aim of the project was to develop a position paper and a code of ethics for research with persons with disabilities in the Cape Town context (with possible transference elsewhere later). The study objectives, or steps to achieve this aim, were:

- to explore past research experiences of persons with disabilities in the study setting
- to analyse, critique and apply evidence from past studies in developing a position paper
- to collaboratively synthesise and create a code of ethics for research with persons with disabilities in Cape Town.

3. RESEARCH APPROACH AND METHODS

A mixed method study with participatory elements was planned.

Study population, sampling and participants: The study population comprised of adults with disabilities in Cape Town. Selection criteria included:

- adults (18y & older) with disabilities (PWD) with experiential or other knowledge of disability-related research.

- stakeholders from Disabled People's Organizations, other NPOs and from within CCT Departments with experience in disability related matters and/or research.

- adults over the age of 18 who had a communication and/or intellectual disability but who understood the essence of the study and wanted to participate were included if they were able to communicate with or without assistive devices and if they were deemed to be able to give informed participant consent. Informed consent was then ascertained through presenting a simplified oral version of the informed consent form; parental/guardian consent was an additional step not a proxy step, if needed.

A combination of purposive sampling and volunteer sampling (O'Leary 2017) was applied through disability focused NPOs; through the City of Cape Town Office for Affirmative Action and Disability Management and through personal contacts.

- **<u>Challenges included</u>: Due to administrative delays and/or procedural requirements of diverse NPO gatekeepers (in their endeavour to protect their members), we were not able to recruit the originally planned, larger participant sample. Several participants were eventually invited through direct contact of the collaborating researchers' personal social networks; and a total of only 32 participants could be recruited. This also meant that we could not do the planned quantitative analysis. However, the serendipitous findings regarding the NPO gatekeepers were a valuable addition to the qualitative findings.**

Data collection strategies comprised:

Firstly, a questionnaire survey (Addendum 5) designed to be applied flexibly in order to be accessible for persons with diverse disabilities i.e. it could be (a) sent and completed electronically to purposely identified participants and/or (b) completed telephonically or (c) presented as a brief questionnaire-based interview. The questionnaire was piloted with 2 participants and minor logistical adaptations were made to assist participants with its completion. The data from the pilot participants was kept separately but then also included in the thematic analysis as these responses contributed additional, valuable information, as proposed by Van Teijlingen and Hundley (2002) and other qualitative research experts.

Secondly, a focus group discussion was held with 13 participants, who volunteered during the questionnaire survey. The purpose of this was to formulate a draft code of ethics for research with PWD. Participants were first given some background information about the project, shown the San Code of Ethics and presented with some key quotes highlighting important findings from the questionnaire surveys as triggers for what, why and how research should happen when involving PWDs. Participants then worked in four small groups to identify what they felt was important information to include in the draft code of ethics. This information was then shared by participants with the bigger group and the facilitator and co-facilitator consolidated the information for verification by the bigger group.
The originally planned, additional key informant focus group was deemed unnecessary by the team because of the wealth of experience and spread of participants involved in the above focus group.

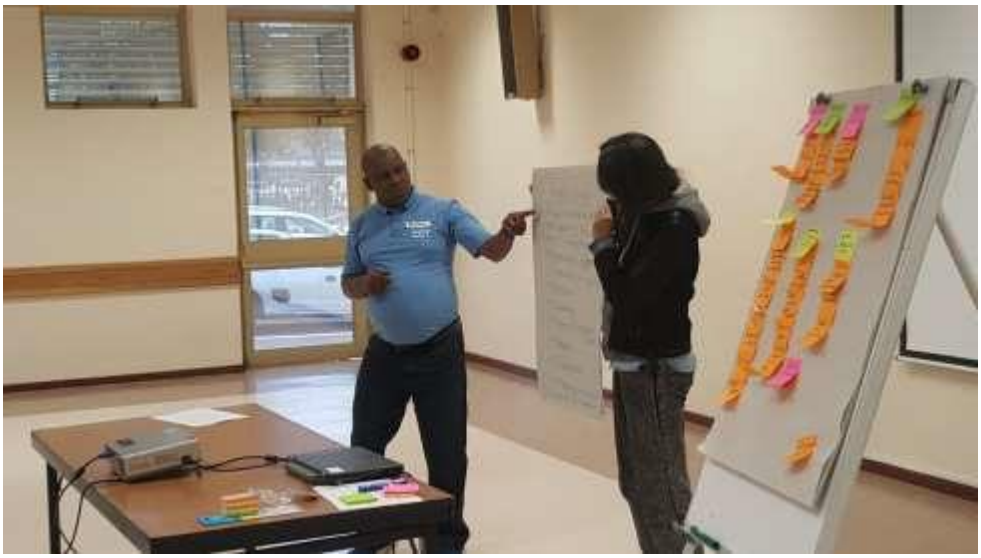

Figure 1 a & b: Participants sharing the information from their small-group discussions, while facilitators consolidated the information.

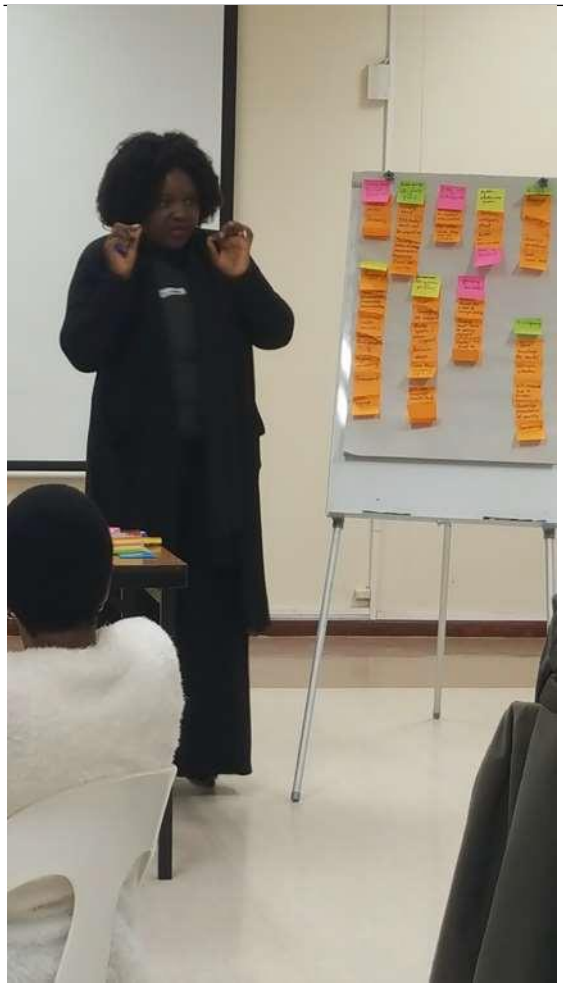

Figure 2 Dr Chioma Ohajunwa verifying themes contributed by the small groups

Data analysis: Thematic analysis was applied to the predominantly qualitative findings. Basic descriptive and visual analysis was applied to the much smaller proportion of quantitative data.

Ethics approval was received from both Stellenbosch University (N17/10/102 – Addendum 1) and the University of Cape Town (HREC Ref. 634/2018 – Addendum 2) and permission to do the study within its ambit was received from the City of Cape Town (OPPRR-0085 - Addendum 3).

Ethics principles, as determined in the updated Declaration of Helsinki (World Medical Association 2013) and described by the Department of Health (2015), were upheld in the implementation of this study in the following ways:

-*Autonomy:* participation in each stage of the study was entirely voluntary and participants were informed that they could withdraw from the study at any time. An informed consent form was used in explaining the details of the study to potential participants.

-*Beneficence*: there appeared to be some immediate benefit to the participants as several of them expressed appreciation for the opportunity to have an input in research about and for PWD during some of the interviews and particularly during the focus group. In line with Department of Health (2015) and Stellenbosch University Health Research Ethics Office Guidelines, participants were reimbursed for travel and other possible expenses (R100 per interview or focus group).

-*Non-maleficence:* in this minimal to no risk study, arrangements were in place (but not needed) for counselling and support should any participants have experienced emotional discomfort or distress in the course of the interviews or focus group sharing.

-*Confidentiality:* all participant questionnaire and/or interview responses were anonymised with a code

-*Justice:* any person, regardless of gender, race, language or socio-economic background was eligible to participate in the study if they met the selection criteria.

Rigour and trustworthiness precautions included an audit trail, member checking and peer debriefing.

- **Nature and extent of the engagement and role(s) of the CCT partner**

The CCT partner, Mr Selwyn Morris, played a strategic and very active role in the project. Examples of his contributions to the collaborative project included but were not limited to:

- Guiding us at the proposal writing stage in terms of CCT policies with which to align our research aims.
- Arranging an accessible venue for our focus group meeting (i.e. Bellville Civic Centre).
- Recruiting study participants within the CCT as per the CCT permission and guidelines.
- Arranging and implementing some of the data collection by emailed questionnaires.
- Assisting primary investigator with logistics of two further questionnaire interviews.
- Ongoing support and inputs in planning, brainstorming and problem solving as a very active and supportive member of the research team.
- Inviting the Research Team to actively participate in and present an introduction to the study at the CCT International Disability Day Celebrations on 5 December 2018.

An additional and very positive outcome of the collaboration has been that the CCT partner, Mr Selwyn Morris, has registered for and is making good progress in the Stellenbosch University Masters in Human Rehabilitation Studies degree programme (by Coursework).

4. CONCLUSIONS & RECOMMENDATIONS FOR FOLLOW-UP ACTION

Conclusions:

Findings included participants' unanimous request for more meaningful inclusion in ***all*** stages of research studies concerning them; from topic prioritisation to planning to dissemination – not just as participants during data collection. Key messages included the imperative for researchers to take all research findings back to the research participants (as this does not usually happen) and gatekeepers not overprotecting this vulnerable group at the cost of silencing their voices.

The project aligned well with the CCT's strategic focus areas of 'A Caring City' and moreover, as pointed out by participants themselves; 'An Inclusive City'.

A first draft of the Code of Ethics was compiled using the information collaboratively decided on during the focus group. This was circulated to focus group members for their further comments in terms of content and format in order to prepare a second draft of the Code of Ethics.

A public dissemination event is planned for 28 August 2019 (pending venue confirmation), following which a third draft of the Code of Ethics will be ready to be shared on the CCT website for public use. It will also be emailed or delivered in hard copy to all 32 participants.

In order to reach the academic community and specifically researchers engaged in disability-related research:

- an academic paper is in advanced preparation to be submitted for publication to a peer-reviewed, accredited, international journal i.e. '*Research Ethics' (SAGE Journal)*
- a poster presentation is planned for the forthcoming Public Health Association of SA (PHASA) conference – our abstract has been accepted (Addendum 5) and three team members (including the CCT collaborator) have been registered as presenters at this conference.
- a participatory symposium session is planned for presentation by the team and some of the study participants at the 16th Annual International Conference on Clinical Ethics & Consultation in 2020 (Addendum 6 and https://iccec2020.co.za/), pending abstract acceptance.

Recommendations for follow-up action:

Recommendations in terms of further **research**:

- For researchers and supervisors of student research: mandatory feedback of study findings to participants (especially where participants with disabilities are involved and have been excluded from such feedback in the past)
- For persons with disabilities who are approached by researchers to be recruited for research:
  - to negotiate parameters before signing informed consent
  - to engage in active research advocacy to question, guide and control the nature and process of research about them.
- For universities and other research institutions (e.g. NRF, MRC) to provide more development support for disability-related 'insider-research' (i.e. by researchers with disabilities themselves).

Recommendations in terms of **policy development and implementation** (developed and informed through engagement with the CCT partner):

- For local research ethics committees: inclusion of a person with a disability and meeting all other National REC member requirements, should be considered (similarly to the current policy requirement of each committee including at least one community member)
- For the CCT to encourage and monitor the use of the third draft code of ethics on their website, with revisions by 2021 based on feedback from PWDs.
- For the CCT to utilise the fourth draft code of ethics on their website as a guide when consulting with PWDs from 2022 about the 2024 statutory Employment Equity Plan for approval by the Department of Labour so that relevant sections can be included and thus given more weight.

5. BUDGET

Detailed description of budget line item:	CREDITS:	Amounts Budgeted as per proposal:	DEBITS	
			Amount spent to date (30.06.19)	Amount committed (before 30.11.19)
2017/2018 CHEC-CCT JRP	100 000			
2019 Stellenbosch University Temporary Research Assistance (awarded to PI) (see Addendum 4)	29 705			
Interest	xxx			
SU Health Research Ethics fee (for funded project not for degree purposes)			00 800 (not budgeted)	
Research assistance (skilled, post-graduate) for literature review, document searches and data analysis: R150 per hour x 180 hours		27 000 (+ 29 705)	39 329.70	16 374 *incl budget for transcription
Research Participant Reimbursement for expenses: 50 x R100		05 000	03 600	01 400
Travel (between SU/UCT/CCT planning workshop, regular team meetings, researcher travel to participant interviews etc.: itemised trips as per time line in Section 5 above) @ R3.00/km		03 180	00 534	
Catering (for half-day team events i.e. planning workshop; project wrap-up workshop)		01 250	00 960	00 300
Transcription services: *R350 – R550 per recorded hour x 10 interviews @ 1-1.5 hours each*		06 000		*06 000 (towards gen research Assistance)
Final focus group and Dissemination Event: *Conference catering for focus group and for half-day event: (i.e. catering for half day welcome coffee/morning tea/lunch @ R150 per person x 100)*		15 000	02 390.00 (for focus group on 20.06.2019)	12 500 (for half-day dissemination event in August)
Delegate packs*: for attendees at dissemination event (R30 x 100) (includes R 1000 donated material) i.e. R3000 – R1000 = R2000)*		02 000	00 916.54 (used for focus group stationary packs)	01 000
Printing/postage of CPD certificates: for attendees at dissemination event		00 500		00 500
Dissemination of findings (beyond the dissemination event**):** Printed Pamphlets, posters, professionally prepared Podcast/video/web features etc.		20 000	PHASA poster **R 585** PhASA conf Early Bird Reg R3700 x3 = **R11 100**	
Academic publication: *Journal submission fees; +- 10 pages @ R1500 per page (= R15 000) + editing @ R 5 000*		20 000		20 000 (ICCEC 2020: ?? X R5500
TOTAL	**129 705**	**99 930**	*	To be confirmed

* awaiting some outstanding claims/ payment authorisations

6. REFERENCES USED

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Addendum 1: Stellenbosch University HREC approval

UNIVERSITEIT STELLENBOSCH UNIVERSITY

Health Research Ethics Committee (HREC)

Approval Notice

New Application

19/01/2018

Project Reference #: 1699

HREC Reference #: N17/10/102

Title: Collaborative development of a code of ethics for research with persons with disabilities in Cape Town

Dear Dr Martha Geiger,

The **New Application** received on 25/10/2017 was reviewed by members of the **Health Research Ethics Committee 2 (HREC 2)** via **expedited** review procedures on 19/01/2018 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **19-Jan-2018 – 18-Jan 2019**

Please remember to use your **protocol reference number [1699]** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Please note you can submit your progress report through the online ethics application process, available at: https://applyethics.sun.ac.za/Project/Index/1863 and the application should be submitted to the Committee before the year has expired. Please see Forms and Instructions on our HREC website for guidance on how to submit a progress report.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Departement of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website Links Application Form Direct Link

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Included Documents

STELLENBOSCH UNIVERSITY
Health Research Ethics Committee
1 9 JAN 2018
Page 1 of 2
STELLENBOSCH UNIVERSITEIT
Gesondheidsnavorsing Etiekkomitee

Addendum 2: UCT HREC approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

27 September 2018

HREC REF: 634/2018

A/Prof Judith McKenzie
Disability studies
F45, OMB

Dear A/Prof McKenzie

PROJECT TITLE: COLLABORATIVE DEVELOPMENT OF A CODE OF ETHICS FOR RESEARCH WITH PERSONS WITH DISABILITIES IN CAPE TOWN

Thank you for submitting your request to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study via a reciprocal review process with University of Stellenbosch REC reference number N/17/10/102.

Approval is granted for one year until the 30th September 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

Addendum 3: City of Cape Town Approval

CITY OF CAPE TOWN
ISIXEKO SASEKAPA
STAD KAAPSTAD

Date : 28 December 2018
To : DIRECTOR: ORGANISATIONAL POLICY & PLANNING
Ref : OPPRR-0085

Research Approval Request

In terms of the City of Cape Town System of Delegations (July 2018) - Part 29; No 2 Subsection 4, 5 and 6 "Research:

(4) *To consider any request for the commissioning of an organisational wide research report in the City and approve or refuse such a request*

(5) *To grant authority to external parties that wish to conduct research within the City of Cape Town and/or publish the results thereof*

(6) *To after consultation with the relevant Executive Director: grant permission to employees of the City of Cape Town to conduct research, surveys etc related to their studies, within the relevant directorate.*

The Director: Organisational Policy & Planning is hereby requested, in terms of subsection 5, to consider the request received from

Name	: Martha Geiger
Institutions:	Dr. Martha Geiger is based with the Centre for Rehabilitation Studies: Faculty of Medicine and Health Sciences at the University of Stellenbosch (SUN)
Short Title	: Collaborative Development of a Code of Ethics for Research with Persons with Disabilities in Cape Town

Taking into account the recommendations below (see Annexure for detailed review):

Recommendations

That the CCT via the Director: Organisational Policy & Planning grant permission to Martha Geiger, the Primary Investigator in this research study, and the team, to conduct interviews & focus group discussions with CCT officials identified, on condition that:

- No more than 30 officials be interviewed/surveyed in Round 1 and that each interview/survey not exceed 30 minutes;
- No more than 10 officials participate in the focus group in Round 2 and that the focus group not exceed 90 minutes;
- No more than 5 officials participate in the focus group in Round 3 and that the focus group not exceed 90 minutes;
- The CCT contact person [Selwyn Morris] assist with the identification of potential CCT participants for Round 1;
- The names of the identified officials be presented to their respective Director for support to participate;
- The willingness of City officials to participate in the research, on a voluntary basis;
- Anonymity of CCT officials and their inputs;
- Use of the City's logo or branding not being permitted;
- A clear acknowledgement in the report that the views of the CCT staff/members are not regarded as official CCT policy;
- Submission of the final draft report to the Director: Organisational Policy & Planning for input before submission and/or distribution of the final report; and
- Submission of the completed research report to the Director: Organisational Policy & Planning, the Manager: Research Branch – Organisational Policy & Planning and the Director: Human Resources, within 3 months of completion of the research report.

Approved [✓] Comment: Acting In order

Not Approved [ ] Comment: ____________________

Vc-wright 28/12/2018

31/12/2018
Date

Hugh Cole Acting Director: Organisational & Policy Planning

CIVIC CENTRE IZIKO LEENKONZO ZOLUNTU BURGERSENTRUM
12 HERTZOG BOULEVARD CAPE TOWN 8001 PRIVATE BAG X9181 CAPE TOWN 8000
www.capetown.gov.za

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Addendum 4: SU FMHS funding for Temporary Research Assistance

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

8 November 2018

Dr Martha Geiger
Department of Global Health
Faculty of Medicine and Health Sciences

Dear Dr Geiger

TEMPORARY RESEARCH ASSISTANCE FOR 2019

With regards to your application for the abovementioned funding opportunity, it is with pleasure that I can inform you that an amount of R29705 has been awarded to you for part-time research assistance for the following project:

Collaborative development of a code of ethics for research with persons with disabilities in Cape Town

Funds will be transferred into the relevant K cost centre as stipulated by the Division of Finances. Guidance regarding the hourly rate and appointment of personnel against this award **must** be done in consultation with Human Resources. **You must please take note that this amount includes statutory levies, skills levy and unemployment insurance as applicable.**

Spouses and/or other family members should normally not be employed for full time or part time assistance work. In special circumstances and with thorough motivation (recommended by Head of Department), the possibility could be considered.

It is trusted that the research assistance made available to you will find deposition in the form of high quality research publications in accredited journals.

For enquiries, kindly contact Vusi April (vpa@sun.ac.za or 021 938 9665).

Kind regards

Dr Tania Brodovcky
Head: Research Funding and Capacity Development
RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG CAMPUS)
Tel: 021 938 9150 / 9820; e-mail: taniab@sun.ac.za

Medicine and Health Sciences
Geneeskunde en Gesondheidswetenskappe
EzoNyango nezeeNzululwazi kwezeMpilo

Addendum 5: Questionnaire

Questions:	Responses:	
1. In what research project(s) have you been involved?		
2. What was your role in that research: (tick all that apply)	Participant	
	Field worker	
	Research assistant	
	Interpreter	
	Research planning	
	Proposal development	
	Raising funds	
	Other (please specify)	
3. Do you feel that the research was conducted in a way that was respectful of your community?	Yes	
	No	
	Please explain	
4. How do you think research can help to improve the lives of people with disabilities?		
5. What do you think are the most important and urgent areas for research?	Education	
	Employment	
	Health conditions Sport and recreation	
	Social inclusion	
	Other	e.g.:
6. In your experience, how did the research (or how could it in the future) help you or your clients?		
7. Do you think that the research could produce findings that could be used in your community?	Yes	
	No	
Please explain your answer.		
8. Do you think that the researchers went to the right people to get the answers to their questions?	Yes	
	No	
Please explain		

Did participating in the research make the participants feel uncomfortable or vulnerable in any way?	Yes	
	No	
Please explain		
9. Do you feel that the study was worth your participation?	Yes	
	No	
How?		
10. Research proposals are reviewed by universities to see if they are scientific and ethical and will produce good research. What would you like to tell these committees that would help them to make good decisions?		
11. How were participants recruited for the study?		
Did the community/organisation have any say over this recruitment?	Yes	
	No	
If yes, what did they contribute?		
How were families consulted about the participation of one of their members?		
Did you feel the study was explained to you clearly enough?		
12. How did you feel that you were treated in the study?		
13. Were there any aspects of the research process that you were not happy with or felt could have been done better?		
14. What do you think should be done to ensure that research is conducted in an ethical manner?		
15. Would you be willing to help develop a code of ethics?		

Thank you for your time and for participating!

Addendum 5: Acceptance letter for poster presentation at national PHASA Conference

PHASA
Annual Conference 2019
College of Cape Town
Cape Town, 16- 18 September

YEARS 25
The right to health
25 years into our constitutional democracy

Dear Dr Martha Geiger,

We are pleased to inform you that your abstract/s as detailed below has been accepted and will be included in the provisional programme for the PHASA Conference 2019 to be held at College of Cape Town, Cape Town from 16th - 18th September 2019.

Presentations

Title	Collaborative development of a draft code of ethics for research with persons with disabilities in Cape Town
Paper Number	270
Presentation Type	Poster
Theme	5. The state of SA public health research - Operational Research Approaches
Presenting Author	Dr Martha Geiger Affiliations: Stellenbosch University
Presenting Author	Dr Chioma Ohajunwa Affiliations: Stellenbosch University
Presenting Author	Ass. Prof Judith McKenzie Affiliations: University of Cape Town
Co-Author	Dr Brian Watermeyer Affiliations: University of Cape Town
Co-Author	Mr Selwyn Morris Affiliations: Stellenbosch University

Specific information for your presentation(s) will follow in due course.

For the Organising Committee to finalise your participation, please ensure that you have registered and paid for your attendance by 22nd July.

In order to register please click on the link below and login with your email address and

password and follow the prompts. The conference fees and the cancellation policy are listed on the registration page.

https://confco.eventsair.com/phasa-conference-2019/individual-registration

Thank you for your valuable contribution to the PHASA Conference 2019. It promises to be a most memorable and exciting event.

Kind regards,

PHASA Conference 2019 Organising Committee

Queries - Joanne Bezuidenhout
The Conference Company
Tel: +27 31 303 9852

Addendum 6: ICCEC Conference Call