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Title of dissertation:
A descriptive study of the community-based follow-up and outcomes of very low birth weight babies discharged from a regional hospital

by
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Table of Contents

9.6. Appendix 6: Patient Information Form (English version)
9.7. Appendix 7: University of Cape Town, Health Sciences Faculty, HREC Approval
9.8. Appendix 8: Provincial Health Research Committee, Western Cape Department of Health – Study approval
9.9. Appendix 9: Interview schedule
9.10. Appendix 10: Study timeline
9.11. Appendix 11: Budget summary
9.12. Appendix 12: Turn-it-in report
9.13. Appendix 13: BMC author guidelines

Declaration

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This dissertation takes the form of a publication ready format. The manuscript will be submitted for publication.

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List of tables

List of Figures

Abbreviations

MDGs	Millennium Development Goals
NMR	Neonatal mortality rate
U5MR	Under-five mortality rate
LMIC	Low/middle income countries
SA	South Africa
CDR	Child death review
SDGs	Sustainable Developmental Goals
LRTI	Lower respiratory tract infections
HCBS	Home and Community Based Services
PHC	Primary Health Care
CHWs	Community health workers
RR	Relative risk
OR	Odd's ratio
CI	Confidence interval
NPOs	Non-profit organisations
WC	Western Cape
NPs	Nurse Practitioners
NSH	New Somerset Hospital
VLBW	Very low birth weight
ECCR	Electronic Continuity of Care Record
SD	Standard deviation
IQR	Interquartile range
ELBW	Extremely low birth weight
NVD	Normal vaginal delivery
CTG	Cardiotocogram
PET	Pre-eclampsia
IE	Imminent eclampsia

APH	Antepartum haemorrhage
PP	Placenta praevia
IUGR	Intra-uterine growth restriction
CPAP	Continuous positive airway pressure
HIV	Human immunodeficiency virus
PCR	Polymerase chain reaction
TB	Tuberculosis
NPO2	Nasal prong oxygen
HFNC	High flow nasal cannula
IPPV	Intermittent positive pressure ventilation
HFOV	High frequency oscillatory ventilation
BBA	Born before arrival
KMC	Kangaroo mother care
LOE	Level of education
ID	Identity document
RTHB	Road to health book

Abstract

Background

Neonatal mortality continues to be a significant global health concern, especially in low/middle income countries. In South Africa, neonatal deaths contribute to 32% of the under-five mortality rate, with 48% of these deaths attributed to prematurity. One of the components aimed at reducing neonatal deaths in the Western Cape, is the Home and Community-Based Services (HCBS) for very low birth weight (VLBW) babies. This intervention could reduce neonatal deaths by 25%. This study aimed to describe a VLBW baby cohort discharged from a regional hospital in Cape Town over a year; the HCBS referral process; their follow-up; their outcomes and caregivers' perceptions of the service.

Methods

This was a retrospective descriptive mixed methods study. Quantitative data from an accredited database were used to describe the VLBW cohort. Meetings with stakeholders and referral form analyses were used to assess the referral pathway and follow-up. Telephonic interviews were held with VLBW babies' caregivers to obtain further quantitative and qualitative data about the HCBS programme.

Results

During 2018, 169 VLBW babies were included in the population with a mean (SD) gestational age of 30 (±2.21) weeks and median (IQR) birthweight of 1210g (1045-1390g). At delivery, 84.6% had respiratory distress with 60% requiring continuous positive airway pressure; 64% had presumed and 15.3% had suspected or proven nosocomial sepsis. Caregiver characteristics included unbooked pregnancies (10%), primigravida deliveries (15%), smoking (11%), maternal alcohol use (9%), teenage pregnancy (5%), drug addiction (3%) and babies born before hospital arrival (4%) with 14% being referred to a social worker. Folder review showed plans for HCBS referral in only 49 (43.4%) of the cohort, however only 20 (17.7%) referral forms were received by HCBS. Learning about the VLBW HCBS programme identified several challenges relating to the referral process from both the hospital and HCBS side. Overall, the caregivers interviewed had positive perceptions of the HCBS. Those not visited by HCBS felt they would have benefitted from a visit.

Conclusion

The burden of this medically and socially vulnerable VLBW cohort, who are at high risk of neonatal mortality and morbidity, remains large at this regional hospital - constituting nearly 15% of all their neonatal discharges. Despite the identified challenges, the caregivers' interviewed remained positive about the HCBS. HCBS can play an essential role in providing education, counselling and support following hospital discharge. However, for the HCBS to be fully effective, further promotion, strengthening and monitoring of the referral system is required.

Keywords: Neonatal morbidity and mortality, Very low birth weight babies, community health workers, community based follow-up

Publication-ready Manuscript

1. Background

1.1 Exploring neonatal mortality:

Neonatal mortality continues to be a public health challenge for low-and-middle income countries (LMIC). During the first month of life children have a 30 times higher risk of dying than during the post-neonatal period (1, 2). Prior to the Millennium Development Goals (MDGs) an estimated 4 million neonatal deaths occurred world-wide every year (2, 3). Globally, the neonatal mortality rate (NMR) was reduced by 47% in 2015 (3-5). However, the NMR is falling at a much slower rate compared to the mortality rate in children aged between 1 – 59 months and still comprises 45% of the global under five mortality rate (U5MR) (3-5). A large discrepancy in the NMR between countries remains, with 99% of neonatal deaths occurring in LMIC and with the highest rates occurring in sub-Saharan Africa (2, 5, 6). Similar to the global trend, the South African (SA) NMR still constitutes a large proportion of the U5MR (32%), but conversely has remained unchanged at 11-12 deaths per 1000 live births from 2012 to 2019 (3, 7).

In 2015, the leading causes of under-five-deaths globally were prematurity (15.9%), perinatal asphyxia (10.7%) and infections including diarrhoea, pneumonia and sepsis (9.5%) (2, 4). The South African data is similar with prematurity contributing to a greater proportion of deaths at 47.9% (1, 3). Low birth weight (LBW, defined as a birth weight less than 2.5kg) has been shown to be an important risk factor for neonatal mortality, being associated with 60-80% of neonatal deaths (2, 8, 9). LBW results from prematurity and/or intra-uterine growth restriction, all of which are independent risk factors for neonatal death, due to the increased risk of developing infections (2).

A child death review pilot in SA revealed that infants were most likely to die at home (68.9%) from lower respiratory tract infections (LRTI) (10). These deaths were significantly associated with prematurity and occurred soon after hospital discharge (10). Nearly 20% of neonatal and 13.3 % of all under-five-deaths were related to child abuse and neglect (10). In terms of the out-of-hospital deaths, the child death review (CDR) concluded that poor social and environmental factors, inadequate maternal support and the lack of community-based services were major contributors to under-five-deaths, particularly in vulnerable preterm babies (10). Previous Saving Babies' and Saving Children's reports found that 38% of stillbirths and neonatal deaths and 25% of child deaths respectively, had contributing modifiable family- or community-related factors (1).

To achieve the Sustainable Developmental Goals (SDG) for U5MR and NMR by 2030, it is essential that there is a greater focus on neonatal mortality both in and out of hospital (4). The implementation of a post-natal package of care with locally specific community-based interventions is imperative to reduce neonatal deaths (3, 5, 6, 9).

1.2 Understanding Home and Community Based Services (HCBS)

HCBS forms part of the national and provincial primary health care (PHC) approach aiming to decentralise health care using community health workers (CHWs) to reach a greater proportion of the population at a household level (6, 11). CHWs are not health professionals but have undergone some basic training and work either as volunteers or receive a basic salary which according to Andrews Y, coordinator CBS Southern Western substructure, (personal communication, 15th October

2022) is similar to the South African minimum wage (12). They remain closely linked with the health system, but work in their own communities by providing education, support, promotive and preventative health care, and in some countries diagnosis and treatment of conditions (6, 12, 13). A large proportion of the HCBS has a focus on maternal, child and neonatal health including vaccinations, breastfeeding, and education (12).

The positive impact that community-based interventions have on maternal, child and particularly neonatal mortality has been highlighted in several global and South African studies (6, 8, 9, 12, 14, 15). A Cochrane review found that overall community-based intervention packages significantly reduced neonatal mortality by 25% (RR 0.75; 95% CI 0.67 - 0.83) and those with home visitation by 40% (RR 0.60; 95% CI 0.49 to 0.72) (8). A study in Nepal demonstrated that even a single community-based visit resulted in mortality reduction from LBW (9). Community-based interventions also increased the caregiver's health-seeking behaviour by 42% (RR 1.42; 95% CI 1.14 - 1.77) and improvements in maternal knowledge of child health and neonatal interventions (6, 8). CHWs have also been found to increase early breastfeeding rates by 93% (RR 1.93; 95% CI 1.55 to 2.39) (6, 14).

By providing support, breastfeeding education, danger-sign recognition and early health-seeking education, CHWs could ensure that infants and children survive and thrive within vulnerable communities (9).

1.3 The South African situation

Since 2011, CHWs have formed part of the PHC re-engineering plan of shifting healthcare in SA toward emphasising health promotion and preventative care (13, 14).

In the Western Cape (WC), the HCBS is run by the WC Department of Health (13, 15). HCBS co-ordinators plan, monitor and evaluate the service in collaboration with non-profit organisations (NPOs) that employ the nurse practitioners (NPs) and CHWs (13, 15). As of 2016, there were 90 NPOs linked to the HCBS employing 3,600 CHWs with a provincial coverage of 0.77 CHW per 1000 population which is lower in comparison to other LMIC countries such as Brazil (1.25 per 1000) (13, 14). The CHWs work 4.5 hours a day, have undergone some additional training in maternal and child health and are paid a basic salary (13, 15).

In the WC, HCBS is a significant focus of the 'Health Care 2030' plan which aims for one CHW per 250 households or per 1000 people (13). Given that the role of the CHWs is to cover the paediatric as well as the adult population, this requires them to visit multiple households regularly, therefore this ratio may feasibly be challenging for the CHW to provide adequate community follow-up (14).

1.4 Knowledge gaps

The HCBS linked to New Somerset Hospital (NSH), draining the Western sub-district of the Cape Town Metro District in the WC, began functioning in 2015. At NSH, neonates and children referred to HCBS were to include those with very low birth weight (VLBW) (i.e., a birthweight < 1500g), severe acute malnutrition and children on anti-retroviral medication who were down-referred to PHC services for continued care (16).

Since its inception, little is known about the number of referrals and actual follow-up of VLBW babies by CHWs. There are concerns that the HCBS is underutilised. It was envisaged with respect to VLBW babies that this study could provide an understanding of the referral process and how it

could be strengthened from the hospital to HCBS thereby improving the community follow-up that has been shown to reduce the NMR.

2. Aims and Objectives

The aim of this study was to describe the HCBS referral pathway and follow-up of VLBW babies discharged from NSH during 2018.

The objectives were to describe the cohort of VLBW babies and those referred to HCBS in terms of their co-morbidities and social demographics; the referral process and adherence to the protocols; their follow up by the CHWs; their outcomes as well as some caregivers' perceptions of the service.

3. Methodology

3.1 Study setting:

The Cape Town Metro District of the WC Province is situated on the southern peninsula of the province and is divided into 8 sub-districts (Appendix 1, page 31) (17). NSH is a secondary level hospital based in Cape Town that serves the Western sub-district (17). In the Western sub-district there are two NPOs who employ seven professional nurses and three enrolled nurses to co-ordinate 192 CHWs for a population of around 60 000 (18).

3.2 Study design:

This was a retrospective descriptive mixed methods study of a cohort of VLBW babies discharged from NSH over a one-year period between 1st January to 31st December 2018. It used quantitative data from established and accredited databases, patient folders and referral forms. The qualitative data was obtained from informal meetings with NPOs and semi-structured caregiver interviews.

3.3 Study population, cohort and sub-cohort

Out of the total neonatal discharges from NSH during the study period it was only the VLBW babies that formed the ***study population*** being described. Those excluded from the study population were all babies greater than 1.5kg birthweight, all in-hospital deaths and those where folders or ECCR discharge summaries were unavailable. Those VLBW babies living in the Western sub-district formed the ***cohort for the study*** and their caregivers were eligible for the interviews. Those excluded from the study cohort were transfers to other hospitals (for further medical or surgical care at tertiary centres or to step down facilities to continue in-hospital care); deaths at other hospitals or those who were discharged to other sub-districts and not followed up by the Western sub-district HCBS team. The HCBS referral forms found from the study cohort's folders and those received by the HCBS were analysed (Appendix 2, page 32). In cases where babies died or were transferred, the caregivers were excluded from the interview process. Only those VLBW babies whose referrals had been received by the HCBS were included in the ***sub-cohort of the study*** for the caregiver interviews.

3.4 Data collection methods

Discharge records at NSH were used to identify the VLBW study population and the study cohort.

Quantitative data was extracted from an already established and accredited database, the ECCR (Electronic Continuity of Care Record). Hospital folder records were obtained and analysed when information on ECCR was incomplete. This data aided in describing the burden of VLBW babies

(gestational age, birthweight, co-morbidities and potential social risk factors) and to identify the number and percentage of those referred to the HCBS (Appendix 3, pages 33-34).

Meetings were held with the NSH staff, Western sub-district co-ordinators and the nurse practitioner (NP) from one of the NPOs to obtain information regarding the referral pathway as well as the follow-up programme of the VLBW babies.

The referral forms received by the HCBS or found in the patient's folder were used to assess completeness of the form by the referring facility and information regarding follow-up required (Appendix 3, page 34).

The sub-cohort of participants included in the interviews were those caregivers of VLBW babies whose referral forms were received by the HCBS sub-district co-ordinator and followed-up. Given the COVID-19 global pandemic, the interviews had to be converted from face-to-face interviews to telephonic interviews. The questionnaires included data regarding basic socio-demographic data of the VLBW babies, parental health education, health data of the baby (including growth, immunisation status, feeding, hospital admissions) as well as information regarding the HCBS follow-up (including number of visits and health topics covered, opinions of caregivers about the usefulness of the service and service improvement areas) (Appendix 4, pages 36-38). The questionnaires were translated and back translated into English, Afrikaans, and isiXhosa. Prior to the commencement of the study, the questionnaires were piloted which resulted in minor editing. The questionnaires were administered by the study investigator with the assistance of a trained interpreter if required. The interviews were conducted in the language preferred by the caregiver with prior verbal consent from the caregiver (Appendix 5, pages 39-40). All interviews were conducted in English and no translation was required. The interviews were recorded to confirm that the documented responses were correct, and the answers were comprehensively transcribed by a formal transcription service.

3.5 Data analysis

The quantitative data regarding the VLBW population and cohort were extracted into a Microsoft Excel 2013© spreadsheet and simple descriptive analyses done using STATA 2015 ©. No group comparisons were made, thus inferential statistics were not performed. Means with standard deviations were used for normally distributed numerical data and medians with inter-quartile ranges for the data not normally distributed. The analyses were performed by the study investigator.

The answers from the qualitative questions from the interviews with mothers from the sub-cohort of VLBW babies were categorised into themes using qualitative content analysis. The study investigator and independent researchers listened to the recordings and read the transcriptions to aid in the extraction of themes.

4. Ethical Considerations

Approval for the study was obtained from the Departmental Research Committee, School of Child and Adolescent Health as well as the Human Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town (HREC Ref 582/2019 – Appendix 7, page 44). The study was also registered with the Provincial Health Research Committee, Western Cape Department of Health (WC_201910_008 – Appendix 8, page 45).

Informed consent was obtained from all participants who were interviewed for the study (Appendix 5, pages 39-40). Information pamphlets regarding the study's purpose and interview process were

also read to the participants in their own language (Appendix 6, pages 41-43). Patient confidentiality was always maintained during the study by using study numbers for the interviews and no identifying data during data analysis.

5. Results

5.1 Description of the study population, cohort and sub-cohort:

Hospital discharges according to data records includes both deaths and transfers to other hospitals. In 2018, a total of 1172 neonates were discharged from NSH, of which 169 were VLBW babies that formed the study population. VLBW babies constituted 13.2% of the discharges home, 29.3% of transfers and 57.9% of the in-hospital deaths.

Most of the home discharges and transfers of VLBW babies were from the Western sub-district (74%) (Fig 1); the rest were from other sub-districts in the Metro. Of the VLBW babies in the Western sub-district, 19% (n=32) were discharges from the Du Noon area.

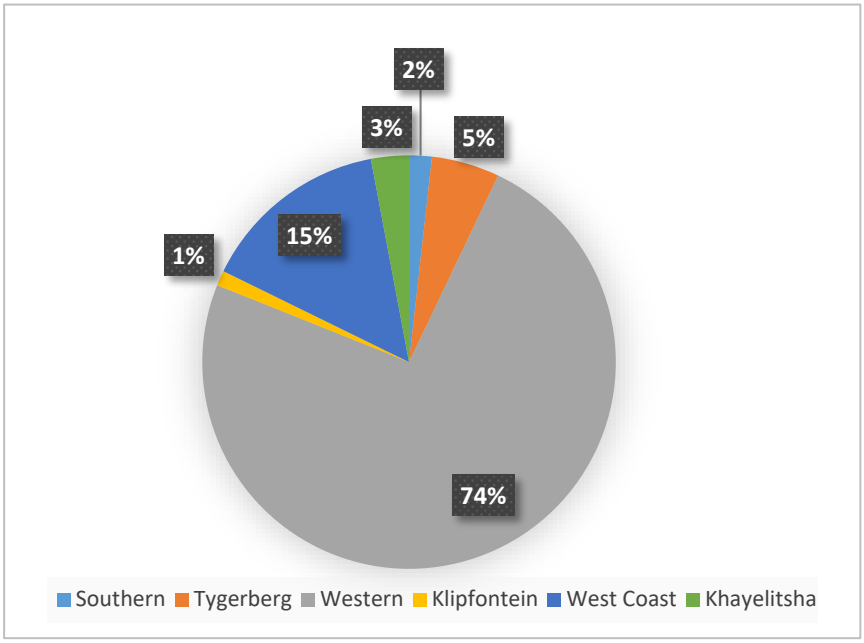

Figure 1: Sub-districts to which VLBW babies were discharged from NSH

Figure 2 depicts the determination of the VLBW study cohort and the study sub-cohort for follow-up. The 169 babies forming the overall study population were analysed for general birth information, co-morbidities and social factors. Deaths were excluded from the study population. The discharges and transfers of neonates more than 1.5kg were also excluded from the study population. One hundred and thirteen VLBW babies were included in the study cohort as they were from the Western sub-district where the NPOs functioned. VLBW babies transferred to other hospitals were excluded from the study cohort as it was not known if these hospitals would refer to HCBS or not following discharge. Only 49 (43.4%) of the discharged babies from the Western sub-district had any documentation that the HCBS referral was made and of these only 44 (38.9%) forms were found and could be analysed regarding their completeness. For the one-year period, HCBS only received 20

(17.7%) referrals which were to be included in the interview process of the study sub-cohort. However, a total of five caregivers could be located for an interview. The other caregivers could not be contacted either due to incorrect telephone numbers, telephone number no longer being in use or caregivers not responding telephonically.

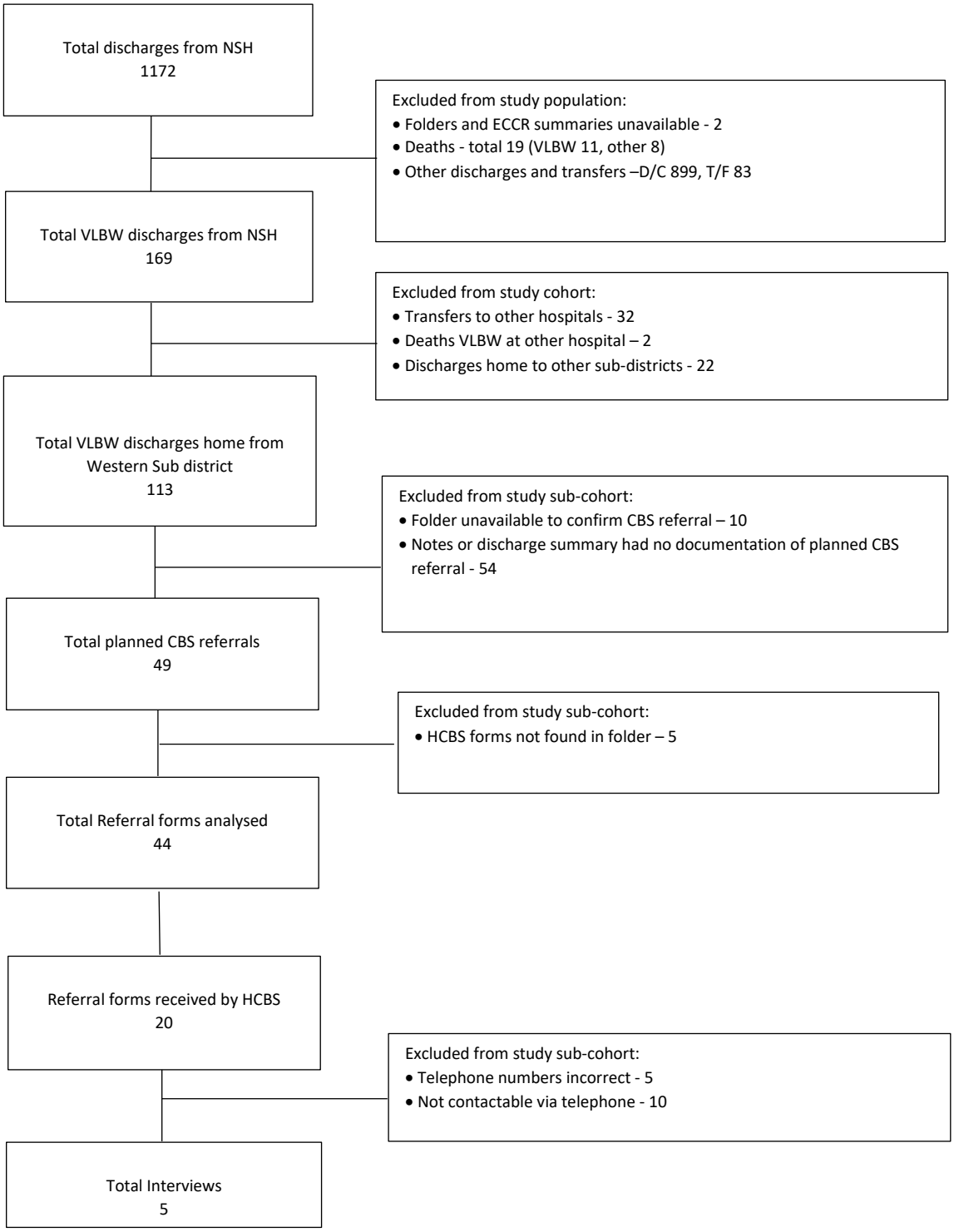

Figure 2: Flow diagram depicting the inclusion and exclusion of VLBW babies for follow-up

Of the VLBW babies discharged from NSH, the mean gestational age at delivery was 30 weeks with 11.8% of babies being under 28 weeks (Table 1). The median birthweight was 1210g with 19.5% of live births being under 1000g. Babies were hospitalised for a median of 38 days.

Table 1. VLBW birth demographics (n=169)

Mean (SD) gestation at delivery	30 (± 2.21) weeks
Number (%) of extreme premature babies (<28 weeks)	20 (11.8%)
Median (IQR) weight (g) at delivery	1210g (1045-1390g)
Number (%) of babies < 1000g (ELBW)	33 (19.5%)
Number (%) of babies with birth weight 1000 -1500g	136 (80.4%)
Median (IQR) length of stay in hospital	38 (29-51) days
Total number (%) NVD	77 (45.6%)
Total number (%) C/S	89 (52.7%)
Unknown delivery mode	3 (1.8%)

IQR = interquartile range, ELBW = extremely low birth weight, NVD = normal vaginal delivery, C/S= Caesarean Section).

The total percentage of caesarean section deliveries was only slightly higher than normal vaginal deliveries at 52.7%. The major indication for C/S was due to a pathological cardiotocogram (CTG) (67%) of which 22% of those had underlying pre-eclampsia (Fig 3). In total, 35% of the mothers undergoing C/S suffered from pre-eclampsia (Fig 3).

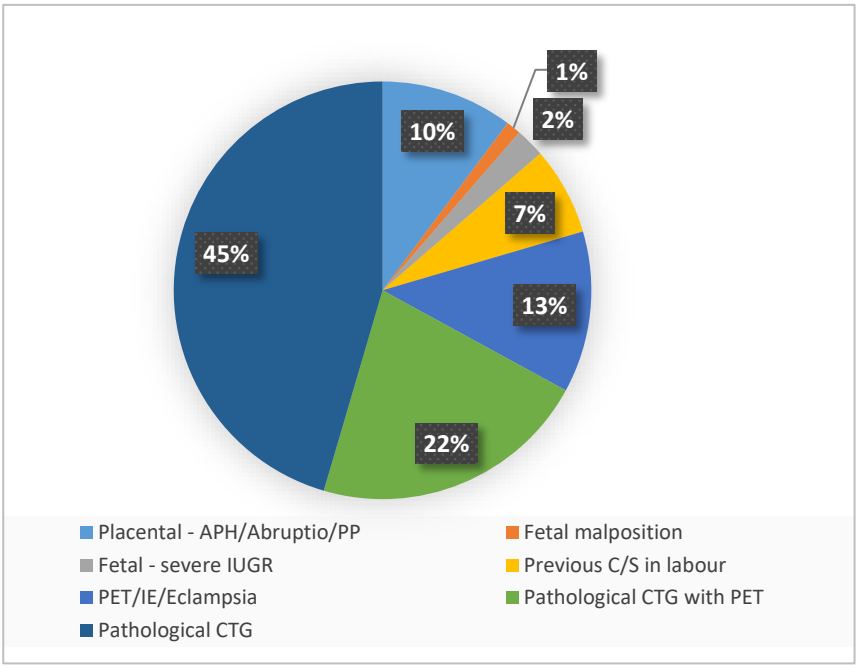

Figure 3: Indications for Caesarean sections

CTG = cardiotocogram, PET = pre-eclampsia, IE = imminent eclampsia, APH = antepartum haemorrhage, PP = placenta praevia, IUGR = intra-uterine growth restriction

Table 2 depicts the co-morbidities of the VLBW babies. A large proportion of VLBW babies (84.6%) had some form of respiratory distress with the majority requiring continuous positive airway pressure (CPAP) (59.8%). Thirty-two percent of the mothers of these neonates had not been given a dose of steroids prior to delivery. Sixty-four percent of VLBW babies were managed at delivery as having presumed sepsis, as they had two or more septic risk factors according to the hospital neonatal guidelines. Of those, 8.3% required five days of antibiotics due to high septic markers and only one baby had proven sepsis at delivery. Thirty-seven percent of the VLBW babies were managed as having possible nosocomial sepsis based on clinical signs but only 4.1% had proven nosocomial infections. Three babies' blood cultures grew *E.coli*, one *Streptococcus viridans*, one *Listeria*, one *Klebsiella pneumonia* and one *E. faecium*. Almost 25% of VLBW babies were human immunodeficiency virus (HIV) exposed, with one baby having a positive birth HIV polymerase chain reaction (PCR) test at birth. There were no tuberculosis (TB) exposed babies in this cohort.

Table 2: VLBW neonatal co-morbidities (n=169)

Co-morbidities	**Number (n)**	**Percentage (%)**
Respiratory distress at birth	143	84.6%
Maternal steroids received prior to delivery		
None	54	32%
1 dose	39	23.1%
2 doses	57	33.7%
Unknown	19	11.2%
Respiratory support required	138	81.7%
No respiratory support required	31	18.3%
NPO2	7	4.1%
HFNC	17	10.1%
CPAP	101	59.8%
IPPV/HFOV	13	7.7%
Presumed sepsis at birth (2 or more septic risk factors present)	108	64%
Possible (raised septic markers at 48 hours)	14	8.3%
Proven (culture confirmed infection)	1	0.6%
Presumed nosocomial sepsis (clinical deterioration in hospital)	63	37.2%
Possible (raised septic markers at 48 hours)	19	11.2%
Proven (culture confirmed infection)	7	4.1%
HIV exposed	42	24.8%

NPO2 = nasal prong oxygen, HFNC = high flow nasal cannula, CPAP = continuous positive airway pressure, IPPV = intermittent positive pressure ventilation, HFOV = high frequency oscillatory ventilation, HIV = human immunodeficiency virus

Nearly 10% of all VLBW deliveries included mothers with unbooked pregnancies (Table 3). Almost 15% were primigravida deliveries with nearly 5 % of births involving mothers less than 18 years of age. The average age of the VLBW mothers was 29 years. Eleven percent of VLBW pregnancies were associated with maternal smoking, nine percent were associated with maternal alcohol abuse and 3% with other maternal drug addiction. Fourteen percent of babies were referred for social worker review (excluding those for teenage pregnancy) for reasons including poor socio-economic status, abandonment and poor maternal medication compliance.

On discharge, 86% of VLBW babies were successfully breastfeeding. Seventy-nine percent were discharged home while others were transferred to higher levels of care (4.78%) or to step-down hospitals to continue care (14.2%).

Table 3: VLBW neonatal social factors (n=169)

Social factors	**Number (n)**	**Percentage (%)**
Unbooked deliveries	16	9.5%
Not recorded	9	5.3%
Babies born before arrival (BBA)	7	4.1%
Primigravida pregnancies	25	14.7%
Not recorded	10	5.9%
Teenage mothers	8	4.7%
Not recorded	11	6.5%
Maternal smoking exposure	20	11.8%
Not recorded	39	23.1%
Maternal alcohol exposure	15	8.9%
Not recorded	36	21.3%
Maternal drug addiction exposure	5	3.0%
Not recorded	4	2.4%
Required social worker referral	23	13.6%

5.2 Description of the referral pathway and follow-up

The information regarding the referral pathway that was obtained through meetings with the NSH staff, the Western sub-district's HCBS co-ordinator and the NP of one of the NPOs is summarised in Figure 4.

All discharged VLBW babies should be referred to the HCBS co-ordinators of the Western sub-district by the discharging doctor. This plan is verbally conveyed by consultants and other senior staff to all new staff at the start of a rotation and reinforced during ward rounds prior to the discharge of a VLBW baby. The referral forms are completed by the doctor with contact details and reason for follow-up and requires the caregiver signature giving permission for a home visit. More recent forms that are pre-filled were designed to ease the form completion on discharge (Appendix 2, page 32). Once the baby is discharged, the forms are faxed by the ward clerk to the CBS co-ordinators.

Once received, the CBS co-ordinator distributes the referrals according to the VLBW babies' residential area to the specific NP of the various NPOs in that area. The NP then identifies a specific CHW to conduct the home follow-up. Currently, there is no set follow-up plan that includes the frequency and duration of visits. The follow-up plan is put together by the nurse practitioners after the CHW does their initial home visit. The NP assists the CHW in planning the required follow-up for each specific patient. The CHW will visit the home of the VLBW baby within a few days of discharge.

After the home visits, feedback sessions take place between NP and CHW. There is no structured follow-up plan. Each VLBW baby's follow-up is individualised in terms of what is monitored, discussed and the duration of follow-up. Discharge from the HCBS is decided by the NP and CHW.

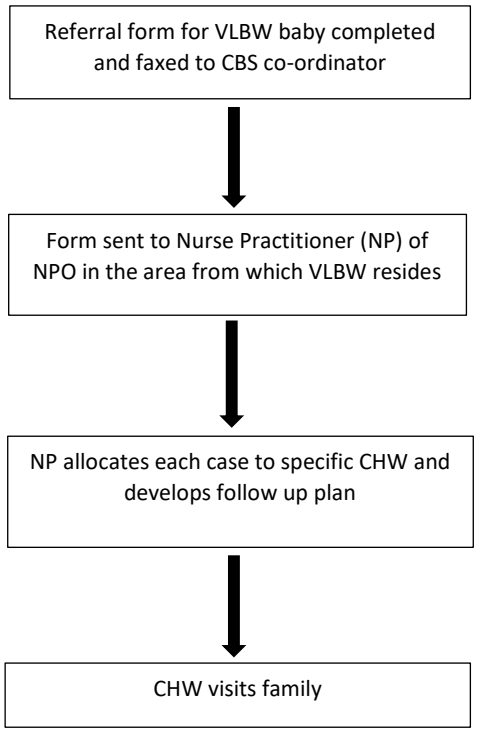

Figure 4: Flow diagram depicting the referral pathway for VLBW babies

5.3 HCBS forms and completeness:

Of the 113 VLBW cohort babies from the Western sub-district who were discharged home from NSH, only 49 (43.3%) had documentation in the folder or on the discharge summary that a referral to CBS had been completed. However, only a total of 44 (38.9%) HCBS forms were found for analysis.

The forms were completed well with most sections being more than 90% complete, however, only 84% of the forms had contact telephone numbers listed.

The commonest reasons in addition to the child being a VLBW baby that was selected for referral included breastfeeding and nutrition support (89%), newborn care (55%), growth issues (34%) and Immunisations (38%).

Of the completed forms, 88.6% were signed by the caregiver giving permission for the CHW to visit their home. Seventy-five percent of the utilised forms were the pre-filled referral forms, designed to reduce the time required for completion.

Table 4: HCBS referral form analysis (n=44)

	Number (n)	Percentage (%)
Form sections fully completed:		
Patient address	44	100,0%
Contact number	37	84,1%
Problem list	41	93,2%
Medication listed	42	95,5%
Clear indication for referral selected	42	95,5%
Reasons for referral:		
Substance abuse	1	2,3%
Newborn care/KMC	24	54,6%
Breastfeeding/nutrition support	39	88,6%
Immunisation	17	38,6%
Growth problems	15	34,1%
Social support	2	4,6%
Treatment adherence	1	2,3%
Mental health	1	2,3%
Forms signed by caregiver	39	88,6%
Pre-filled forms used	33	75,0%

HCBS = home and community-based services, KMC = kangaroo mother care

5.4 Follow-up by CHW

Only 20 (17.8%) referral forms of the 113 VLBW babies discharged from the Western sub-district were received by HCBS and followed-up in the community.

Out of the study sub-cohort, only 5 of those followed up by HCBS were eligible to participate in the interviews due to the others being untraceable and uncontactable. All caregivers were female and were the mothers of the VLBW baby with four also having other children of their own to care for at home. Only one mother was currently the daytime caregiver of the child with all other mothers having full time jobs using either an older child of 18 years who was out of school (1), a grandmother (1) or nanny (2) to help care for the VLBW baby. A total of three out of the five interviewed where foreign nationals and none of the South African mothers had a Child Support Grant. Table 4 depicts further demographic information regarding the sub-cohort.

Table 5: Demographic characteristics of the study sub-cohort involved in the interviews

	Age child at interview (years, months)	Maternal age (years)	Maternal highest LOE	Housing type	Electricity	Water	Paternal involvement	Paternal employment
Mother 1	2yr 10 mo	37	Diploma	Formal	Yes	Piped inside house	Involved and lives with family	Employed
Mother 2	2 yr 4 mo	34	Grade 12	Formal	Yes	Piped inside house	Involved and lives with family	Employed
Mother 3	2 yr 3 mo	35	Grade 12	Informal	Yes	Piped outside house	Involved and lives with family	Unemployed
Mother 4	Demised 9mo old	31	Grade 12	Formal	Yes	Piped inside house	Involved but not living with family	Unemployed
Mother 5	2 yr 4 mo	36	College degree	Formal	Yes	Piped inside house	Not involved and not living with family	Employed

LOE: Level of education

Three out of the five interviewed were followed up by the CHWs post discharge with two of those followed-up remembering being told about the upcoming visit on discharge and giving consent for the visit. One mother was very concerned about the CHW visit as she was unaware of the upcoming visit.

'I was also surprised… I didn't even know they do check-ups and the whole system. I didn't want to open the door…then they showed (their) ID.'. Mother 1.

The occurrence of the initial visits by CHWs varied with one happening within one week of discharge, one within two weeks and one occurring more than a month post discharge. The number and frequency of the follow-ups varied for each VLBW baby but all were visited by the CHWs one to five times post discharge.

The mothers of the three VLBW babies followed up were counselled on breastfeeding however the other topics covered during the CHW visits varied.

'They teach me how to breastfeed, they told me I must go for check-ups, the baby, I must do kangaroo.' Mother 2

Only one discussed the use of and how to make oral rehydration solution for gastroenteritis, one mentioned the importance of immunisations, two emphasised the importance of the road to health book but none covered the topic of danger signs and what to be concerned about in VLBW babies. The importance of Kangaroo Mother Care was another topic discussed by CHW at visits to two of the mothers. In addition to topics on breastfeeding, danger signs, immunisations and supplements, oral rehydration solution and the road to health book (RTHB), it was also felt that information about how to care for a premature baby would be useful. Two of the mothers had said that some of the topics being explored in the interviews had been explained to them before discharge from the hospital.

5.5 Outcomes and caregiver feedback

All of those visited by the CHWs scored the CHW visits as either very or extremely useful on the sliding scale. The two other mothers who didn't have a follow-up, felt that they would have benefitted from a visit by a CHW. Mother 3 said she would have liked to have known 'how I must take care of such small baby'.

None of the mothers had ever contacted the CHWs for help with other health issues and felt if their child was sick, they wouldn't contact them with questions as most would 'take them to the clinic'. Two mothers elaborated saying they did not know who the CHWs are or where to find them if the need arose and one said she would have liked to have contacted the CHW.

Out of those interviewed, there was one child who died, which was a death from gastroenteritis at the age of 9 months. This child had been living with the grandmother as the mother had to return to work after a month of maternity leave.

The other four children were all reported to be doing well. Only one child had been admitted to hospital for two days post discharge for a respiratory tract infection. One child was being followed up at the neurodevelopmental follow-up at NSH. All claimed to still be in possession of the RTHB and all children had received all immunisations. Three out of the five mothers breastfed their child for more than 6 months. The other two stopped at one month and three months respectively due to the need to return to work.

One mother expressed her concerns about how this small baby would survive:

'Is this baby going to grow up?' Mother 1.

The same mother was also worried what people would think if they saw her baby:

'Hey, your child is too small' Mother 1.

Of the four surviving children, each mother shared some ongoing stress, worry and concern about their babies. Three of the mothers had worries about the weight and feeding of their child and one had concerns about the child not being able to stand.

None of the mothers could think of ways to improve the current service.

6. Discussion

6.1 Discussion

Summary of the main findings

The burden of VLBW babies remains large at NSH making up nearly 15% of all neonatal discharges. The study identified medical and social factors relating to these VLBW babies which places them at a high risk of morbidity and mortality. A review of the folders showed plans for referral to HCBS in less than half of the cohort. However, the HCBS received only 17% of the referrals of the VLBW babies discharged home. This is despite several studies showing the effective reduction of maternal, neonatal and child mortality by CHW programmes particularly in low resource settings (6). Despite the small sub-cohort, the visits by CHW were perceived as a positive experience and beneficial for the mothers interviewed which emphasizes the important need for this service. This study also identified some challenges in the community follow-up programme from both the hospital and the HCBS side, however further research into reasons behind the challenges is required.

Description of the study population, cohort and sub-cohort:

In this population of VLBW babies, almost 20% and 10% had extreme low birth weight (ELBW) and extreme prematurity (<28 weeks), respectively. These babies remain a vulnerable and high-risk group and as in this and other studies account for the high proportion of neonatal mortality and morbidity including long-term health and neurodevelopmental issues (19). Most of this VLBW study population were delivered having respiratory distress and required respiratory support. Although the duration of the latter was not established, it highlights the vulnerability of the respiratory system of these babies which continues following their discharge. A South African birth cohort showed that in cases of community acquired pneumonia, 19% and 21% were premature and low birth weight babies, respectively (20). Sepsis in neonates can be difficult to diagnose as they often develop non-specific signs. Given the risk-benefit ratio, the babies in this study were treated for sepsis whilst awaiting their results. Despite 64% of babies at delivery and 37% during hospital admission developing signs of infection, only a small percentage had possible (high inflammatory markers but no proven infection) or proven infection. This highlights the importance of identifying these non-specific and often subtle signs of infection early both in-hospital and by caregivers following discharge as a large proportion of premature babies die shortly after being discharged home as reported by the Child Death Review group (10). The benefits of breastfeeding are well known, and the data in this study was positive with 3 out of 5 sub-cohort caregivers indicating their exclusive breastfeeding for 6 months. Given the compromised health and nutritional status of these babies, the HCBS can play a vital role in assisting with the reduction of long-term health implications, counsel caregivers about danger signs and early health-seeking behaviour, promote and support breastfeeding, promote clinic attendance for immunisations, ensure neurodevelopmental follow-up and be a link to the health system for assistance.

In the VLBW study population, numerous social problems were identified. Fourteen percent of the caregivers needed the assistance of social workers. About one in five were first time mothers who in addition to this had the added stress of taking home a vulnerable small baby. Albeit a small sample, one out of the five interviewees indicated that there was no paternal involvement or support. VLBW or premature babies are known to cause additional stress for the parent(s) with a study reporting 40-50% of parents suffering from postpartum anxiety and depression (19). This highlights the

essential role CHWs can play in providing education, counselling and support for these mothers following hospital discharge.

Sixty percent of those interviewed were foreign nationals who don't qualify for a social support grant which puts strain economically on the family. It is concerning that none of the South African caregivers had a child support grant, which is shown to be an important alleviant of poverty (21).

A significant proportion, 15%, of the discharged VLBW babies were from the West Coast district. As NSH is the secondary level drainage hospital for this district, the distance to travel for these patients is large. There is currently no HCBS program in this district and therefore these VLBW babies do not benefit from the follow-up by CHWs.

Referral pathway, forms and follow-up

In ensuring success of the HCBS follow-up for the VLBW babies, all steps in the referral pathway need to be successfully completed. Several constraining factors were identified in the study.

Despite referral to HCBS being a requirement for all discharged VLBW babies, less than half had a planned HCBS referral. Exploring the reason for the lack of referrals received was out of the scope of this study, however some plausible reasons were deduced. There are many rotating junior and senior staff in the neonatal department of NSH which may influence the compliance with the discharge package of care for these VLBW babies. However, poor record keeping may be the reason why there were plans to refer but no corresponding documentation. It is likely that the referral forms found in the hospital folders indicate that these were never handed to the clerk to be faxed to the HCBS. Without adequate referral to the service by the health professionals, these babies were not followed and adequately supported in the community. Possible reasons at that time for the limited referrals could have been the lack of a monitoring system for referrals, no relationship with HCBS, no feed-back information loop and staff not appreciating the vital role that CHWs play in the follow-up and support of VLBW babies.

The forms received by HCBS are distributed to the respective areas by the HBCS co-ordinator for the district. This also remains a paper-based system where the loss of forms may occur.

Overall, completion of the forms by staff was good. However, key contact information such as telephone numbers were not documented in nearly a fifth of referrals. The relevance of this information needs to be viewed in relation to the inability to undertake 25% of the interviews due to incorrect telephone numbers. Ensuring multiple contact numbers as well as the correct residential addresses is essential to ensure the CHW can visit and make the vital contact with the family.

The CHWs that visit the families are employed by NPOs that service different areas. Currently, some CHWs have additional training in maternal and child health but this is not standardised. In a CHW study in South Africa, CHWs expressed feeling they lacked knowledge and skills and suggested further training and ongoing supervision being beneficial (15). Given that there is no set follow-up plan for the frequency and duration of visits as well as no standardised procedure for what is discussed and covered at the CHW visits, it is challenging to compare the visits between caregivers and VLBW babies. It was difficult to determine the frequency of visits performed by CHWs and what the discharge criteria were as there is no formal record kept of the visits. The nurse practitioner does meet regularly with the CHWs to identify issues raised during any visits so that they can be dealt with swiftly and the HBCS co-coordinators also have regular meetings with the nurse

practitioner to ensure smooth and efficient functioning of the service and feedback of information. There is no current formal feedback system between the HCBS and the health professionals at NSH, however this is currently being explored.

It is important that the caregivers are informed about the up-coming CHW visit after discharge and that all CHWs have identification with them. Given the crime in South Africa, the caregivers need to feel safe letting the CHWs into their homes.

There needs to be an improvement in linkages between the nearby primary health facilities, the referral hospitals and the HCBS to facilitate the success of this programme. A Ugandan study assessing newborn home visits also highlighted the importance of these community linkages with health facilities in improving neonatal outcomes (22). The discussion of caring for a VLBW baby needs to start in-hospital and continue into the CHW visits. Caregivers and those living in the communities should know who the local CHWs are so that they can be contacted easily if there are any queries or worries. Mothers in a South African CHW study mentioned the benefits of knowing they could quickly contact a CHW if there was a problem and that the CHW understood the needs of the mothers in the community (15). CHWs should be easily able to refer patients to the health facilities if they have concerns.

The appreciation for the CHW visits that was found in this study has also been identified in other research into CHW follow up in other areas of South Africa (15).

6.2 Limitations

There are several limitations of this study.

This study was conducted early in the history of the HCBS at NSH. The number of HCBS referrals relating to existing VLBW babies may differ from the 2018 cohort as the forms are now handed directly to the clerk for faxing and kept in a file for record keeping. There are anecdotal reports that in 2021 and following this study, there was an increase in referrals to HCBS post promotional drives, but this requires further research. The fewer numbers from 2018 resulted in smaller study numbers for the interviews.

Given the study time was 2018, many participants were uncontactable due to incorrect contact numbers or changing location resulting in loss to follow-up. This reduced the number of interviews that could be performed.

This is a retrospective study and therefore there is a risk of recall bias occurring during the interviews.

Due to COVID-19, the interviews were changed to telephonic interviews. The child's clinic books could not be analysed and therefore some outcomes could not be assessed. Home visits could not be performed which may have resulted in more participants if the caregiver's number, but not home address, had changed since discharge.

6.3 Recommendations

Given that 35% of VLBW caesarean sections are related to maternal hypertension complications and that 64% of VLBW babies had septic risk factors at delivery, there needs to be a large public health focus on maternal care in order to aid in the prevention of VLBW deliveries (3) . However, until that

is done there needs to be adequate services to manage these babies in the community post discharge.

There is limited data about the effectiveness of HCBS and other community interventions in preventing deaths and morbidity in VLBW and premature babies, therefore more quantitative and qualitative research into the HCBS needs to be undertaken. Further research should also include research from the angle of the CHW and the HCBS to ensure all aspects of the service are assessed to successfully address the problems in all areas.

Some data supports CHWs being involved in the treatment of some childhood illness, thus reducing mortality in LBW babies (9). This, however, remains a debatable topic but one that should be explored as this service may be required to offer sufficient decentralised care to a large population such as in South Africa.

The WHO have put together recommendations for a postnatal package of care which has been included into a Western Cape postnatal check list. This could be adapted to develop a post-discharge package of care which is used by CHWs for the follow-up of VLBW babies. This could standardise the follow-up care and ensure specific topics are addressed. This could also assist in specific standardised child health training on topics for CHW. It would be advisable that all HCBS co-ordinators, CHWs and doctors are involved in planning for these VLBW follow-up visits. Further advancements with the use of electronic referrals via email or on the ECCR discharge system may also be ways to ensure all VLBW babies are referred, and their referrals are received by the correct HCBS team.

Clearly defined standard operating practices for referrals to HCBC should also be developed for all health facilities.

A systematic review of CHWs highlighted the essential role that integration and collaborative relationships in the health system needed to have with the CHW programmes to strengthen these programmes (12). Developing a feedback loop system between the referring health facilities, the HCBS and the CHW would also be very beneficial. This would help ensure that all children referred are seen at follow-up and issues identified by the CHW or the hospital can be easily fed back to the other.

Educating health professionals, including students, about CHWs and this service is essential as it not only ensures that all VLBW (and other appropriate paediatric patients) are referred to the HCBS, but it ensures further promotion of this service continues and thereby hopefully aids in increased utilisation and expansion of the service. For VLBW babies this helps to ensure caregiver support and education; children's optimal growth and development; and the prevention of morbidity and mortality.

Community education regarding the HCBS and CHWs needs to be strengthened with clear understanding of the CHW's roles, where to find them and the referral pathways in order for community members to seek help if required.

7. **Conclusion**

Neonatal mortality and morbidity remain a global public health concern. To achieve the SDGs and reduce the NMR there needs to be focus on neonatal care, community-based interventions, and follow-up of high-risk neonates. Several studies have demonstrated the positive outcomes from community-based interventions (3, 5, 6, 9).

In SA, the HCBS is a valuable and essential service that needs further expansion, promotion and a strengthened referral system from healthcare facilities to reach all those in need and have the desired impact in communities.

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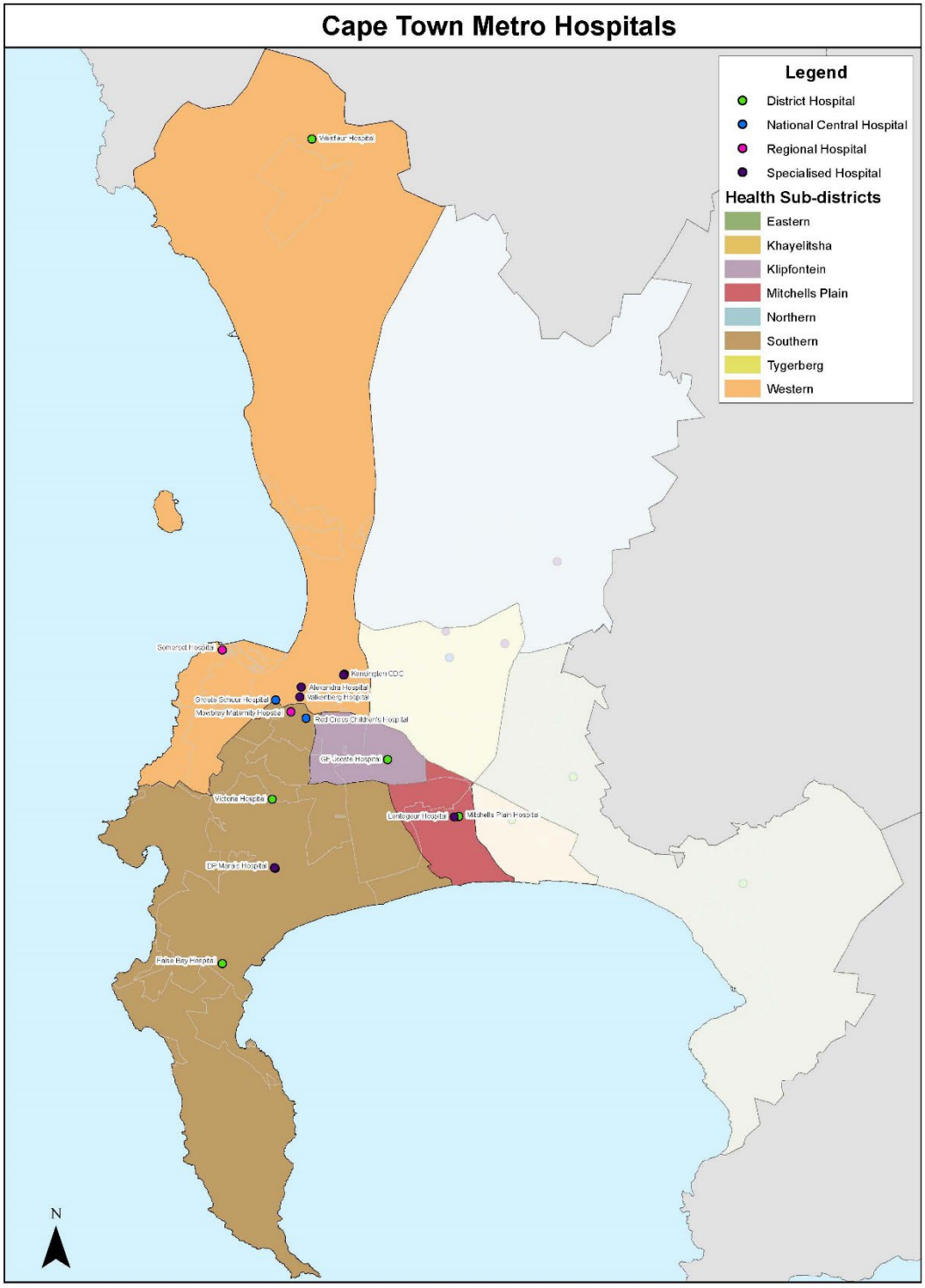
9. **Appendices**

1. Map of Health Sub-districts of Cape Town Metro District of Western Cape
2. Pre-filled HCBS VLBW referral forms
3. Data Collection Sheet
4. Questionnaire
5. Consent form (English version)
6. Patient Information Form (English version)
7. University of Cape Town, Health Sciences Faculty, HREC Approval
8. Provincial Health Research Committee, Western Cape Department of Health – Study approval
9. Interview schedule
10. Study timeline
11. Budget summary
12. Turn-it-in report
13. BMC author guidelines

9.1 Appendix 1: Map of Health Sub-districts of Cape Town Metro District of Western Cape



Western Cape Government
Health
BETTER TOGETHER.

Date of admission:	
Expected date of discharge:	

District Health Services: Neonatal referral form to Home and Community Based Care (HCBC)

Email to: beulah.newhoudt-arendse@westerncape.gov.za or fax to: 086 523 3214 (Southern)

yvette.andrews@westerncape.gov.za or fax to: 086 263 3325 (Western)

Baby Name & Surname:	BABY STICKER	**Tel:** Home Language:	Primary caregiver if not parent:
		Home Address (current):	
DOB:			Name of ref facility:
Folder number:			Date of referral:

Ward: _____

Please circle relevant						
Mother Unbooked	Y	N	Lacks family support	Y	N	
Mother RVD positive	Y	N	Mother VL unsuppressed	Y	N	
Unplanned pregnancy	Y	N	Breastfeeding	Y	N	
Teenager	Y	N	Baby born prematurely	Y	N	
Previous child death (0-5yrs)	Y	N	Baby Birth weight	0-1 kg	1-2kg	>2kg
Informal housing	Y	N	Baby birth PCR positive	Y	N	NA
Substance use	Y	N	Mother on family planning	Y	N	
Mother name and surname			Mother Signature (consent to visit home)			

Other Notes/Concerns	Discharge Medication (delete if not applicable)	
	Kiddievits 0.6ml daily	Nevirapine ____ml daily
	Ferrodrops 0.6ml daily	Zidovudine ____ml 12 hourly

NSH Sept 2019

9.3 Appendix 3: Data Collection sheet

Data Collection Sheet

Study number (allocated) _____

Hospital number_____

Data Variables from ECCR:

- Gestation at delivery _____
- Date of birth: -_____
- At delivery: weight (grams)_____ Length (cm): _____
  Head Circumference (cm):_____
- Weight at discharge (grams)_____
- Duration in hospital: _____days/_____weeks/_____months

- Co-morbidities - using ICD codes on ECCR:

ICD 10 code	ICD description	Patient Co-morbidities	
P07.3	Premature 28-37 weeks	□ Yes	□ No
P07.2	extreme prematurity <28 weeks	□ Yes	□ No
P22.0/P23.9	HMD/Cong pneumonia – any respiratory issues	□ Yes	□ No
P93.9/93.91/93.92	CPAP/IPPV/ HFOV - needed respiratory support	□ Yes	□ No
P91.6	Hypoxic ischaemic encephalopathy	□ Yes	□ No
P39.9/ P77.X	presumed sepsis/NEC	□ Yes	□ No
Z20.6	HIV exposed	□ Yes	□ No
Z20.1	TB exposed	□ Yes	□ No

- Co-morbities and other medical information– using folders:
  - If found HIV exposed: Birth PCR result: □ positive □ negative □ unknown
  - If found TB exposed, was the child:
    □ TB infected on treatment □ TB exposed, on INH prophylaxis □ unknown
  - Feeding choice upon discharge:
    □ breastfeeding □ formula feeding □ unknown

- Social Issues: using ICD codes on ECCR:

ICD 10 code	ICD description	Patient Social factors	
Z38.1	BBA (Born before arrival)	□ Yes	□ No
P04.4	maternal drug addiction	□ Yes	□ No
Z59.9	poverty	□ Yes	□ No
94.49	referral to social worker	□ Yes	□ No

Social Issues: obtained in the ECCR text:

ICD 10 code	Other social issues	Patient Social factors		
	Unbooked	□ Yes	□ No	□ Not documented
	Teenage mother	□ Yes	□ No	Not documented
	Smoking use	□ Yes	□ No	□ Not documented
	Alcohol use	□ Yes	□ No	□ Not documented

Social Issues: from the folder:

- Was there any concern of maternal depression or mental health issues?
  □ yes □ no □ unknown

- Was referral made to CBS on discharge: □ yes □ no □ unknown

Referral forms

- Patient referral form available? □ yes □ no
- Completed information on the form:

Information	Completeness		
Patient address	□ complete	□ partially complete	□ incomplete
Patient contact number	□ complete	□ partially complete	□ incomplete
Patient problem list	□ complete	□ partially complete	□ incomplete
Medication discharged on	□ complete	□ partially complete	□ incomplete
Clear indication for referral?	□ complete	□ partially complete	□ incomplete

- Requirements of referral (back page of form lists the options)

Referral Requirements	Required	
Postnatal care	□ Yes	□ No
Substance abuse	□ Yes	□ No
Newborn care/ KMC	□ Yes	□ No
Breastfeeding/ food support and nutrition screening	□ Yes	□ No
Immunisation promotion	□ Yes	□ No
Nutritional/ growth problems	□ Yes	□ No
Development problems	□ Yes	□ No
Social support	□ Yes	□ No
Chronic health problems	□ Yes	□ No
Treatment adherence	□ Yes	□ No
Mental health	□ Yes	□ No
Other, specify_____	□ Yes	□ No

- Consent signed by caregiver? □ yes □ no

CBS notes:

- Patient folder available? □ yes □ no
- Was the patient followed up? □ yes □ no
- If there was no follow up: Reason for no follow up:
  - □ incorrect contact information
  - □ unable to contact family
  - □ other
- Number of visits: _____
- Duration of follow up: _____days/_____weeks/_____months
- Topics discussed documented:

Topics discussed		
Breastfeeding	□ Yes	□ No
Danger signs: what to watch for in your child to alert you when to take the child to hospital	□ Yes	□ No
Making ORS	□ Yes	□ No
Immunisations: the importance of them and where to go to get them	□ Yes	□ No
Vitamin A and deworming: - the importance of it and where to go to get them	□ Yes	□ No
The Road to health booklet (RTHB): what is it used of, the importance of bringing it to all hospital or clinic visits, useful information in the RTHC	□ Yes	□ No
Other: Specify_____	□ Yes	□ No

- Outcome of follow up:

Child Outcome	Required	
Discharged from follow up	□ Yes	□ No
Lost to follow up	□ Yes	□ No
Demised	□ Yes	□ No
Still being followed up	□ Yes	□ No

- Other useful information from CBS notes:

9.4 Appendix 4: Questionnaire

University of Cape Town
Department of Paediatrics
MMed Research: Questionnaire

Research Study Title: A descriptive study of the community-based follow-up and outcomes of very low birth weight babies discharged from a regional hospital

---

Thank you for completing the questionnaire. Please write answers in the provided spaces. Where to select an answer, please tick the appropriate answers.

Study number: _____

Date completed (dd/mm/yyyy):_____ Time completed: _____

Consent Granted for participation: □ Yes □ No

---

1. Demographic Information:

1.1. What is the current age of your child? _____years _____ months

1.2. When was your child discharged from New Somerset Hospital after they were born dd/mm/yyyy)? _____

1.3. What sort of housing do you live in? □ Formal □ Informal dwelling

1.4. How many people are living in the home? _____

1.5. How many rooms are in the home? □ 1 □ 2 □ 3 □ > 3

1.6. Do you have access to water?
□ yes, there is a tap inside the house
□ yes, there is a tap outside
□ yes, we have to walk to get water
□ no, we don't have access to water

1.7. Do you have electricity? □ Yes □ No

1.8. What do you use for cooking?
□ electricity
□ wood fire
□ gas/paraffin

1.9. Do you have a toilet? □ Yes, inside the home □ Yes, outside □ No

1.10. Who is the primary care giver for the child? □ mother
□ father
□ grandmother or grandfather
□ other? Please specify_____

1.11. Information about the mother:

1.11.1. What is the mother's DOB and age? _____

1.11.2. What is the highest level of education she achieved? ,

□ never attended school □ Grade 7 or less □ Grade 8 or 9
□ Grade 10 □ Grade 12 □ Diploma □ University Degree

1.11.3. Is the mother working? □ Yes □ No

1.11.4. If not, is there a reason why not? _____

1.12. Information about the father:

1.12.1. What is the father's DOB and age? _____

1.12.2. What is the highest level of education he achieved?

□ never attended school □ Grade 7 or less □ Grade 8 or 9

□ Grade 10 □ Grade 12 □ Diploma □ University Degree

1.12.3. Is the father working? □ Yes □ No

1.12.4. If not, is there a reason why not? _____

1.13. Do you get a social grant for this child: □ Yes □ No

1.13.1. If so, which social grant? □ CSG (Support grant) □ CDG (Dependency grant)

1.14. Are there smokers at home? Including those smoking outside □ Yes □ No

2. Regarding the Community Health Worker (CHW) visits:

2.1. Were you visited by CHWs after you were discharged from New Somerset Hospital?

□ Yes □ No

2.2. How many days after your discharge did they visit you?

□ 1 day □ 2 -3 days □ 4-6 days □ 1 week □ > 1 week

2.3. How many times did they visit you in total?

□ Once □ 1-5 times □ 5-10 times □ > 10 times

2.4. What topics did the CHW discuss with you? Please answer Yes or no for each option:

2.4.1. Breastfeeding – the importance, advice on how to breastfeed □ Yes □ No

2.4.2. Danger signs – what to watch for in your child to alert you when to take the child to hospital □ Yes □ No

2.4.3. How to make ORS (oral rehydration solution) □ Yes □ No

2.4.4. Immunisations – the importance of them and where to go to get them □ Yes □ No

2.4.5. Vitamin A and deworming - the importance of it and where to go to get them □ Yes □ No

2.4.6. The Road to health booklet (RTHB) –what is it used of, the importance of bringing it to all hospital or clinic visits, useful information in the RTHC □ Yes □ No

2.5. Were there any other topics that were discussed?

_____

_____

_____

2.6. Did you find the information helpful? On a scale from 1 to 5 where 5 is extremely helpful and 1 is not helpful at all? Put a circle around your answer

_____

1 2 3 4 5

2.7. What other topics would you find helpful?

_____

3. Outcomes of child:

3.1. How is you child doing?

□ well □ chronically unwell, if so what is wrong?_____

□ passed away, If so at what age and from what did the child die?

_____

3.2. Do you have RTHB and can they produce it? □ Yes □ No

3.2.1. If no, what is the reason for no RTHB?

□ lost □stolen □ burnt □ at another home □never had one

3.3. Are your child's Immunisations UTD? CHW to check on the RTHB:

□ Yes □ No □ no RTHB

3.4. What is your child's most recent weight (rounded up to 1 decimal place)? Either verbally or on RTHB date of it (dd/mm/yyyy)_____

3.5. What is your child's most recent length in cm (rounded up to 1 decimal place)? Either verbally or on RTHB date of it (dd/mm/yyyy)_____

3.6. For how long, in months, did you feed your baby only breast milk and no other liquids including water or solids?

□ < 1 month □ 1month □ 2-3months □ 4-5 months □ 6 months □ > 6 months

3.7. Has the baby ever been admitted to hospital? □ Yes □ No

3.7.1. If your answer is yes, how many times where they admitted?_____

3.7.2. If your answer is yes, why was the baby admitted:

□ diarrhoea □ breathing problems □ infection

□ other:

3.8. Did you ever make contact with the CHW after the visits? □ Yes □ No

3.8.1. If your answer is yes, what was the reason you went to the CHW?

_____

_____

_____

3.9. Or if baby ever became sick or you had questions about your child, would you ever contact the CHW for help? □ Yes □ No

4. In summary:

4.1. Are there any other ways in which the CBS would be helpful for you or other caregivers?

_____

_____

_____

Thank you for completing the questionnaire!

9.5 Appendix 5: Consent form (English)

University of Cape Town
Department of Paediatrics
MMed Research: Consent form

Research Study Title: A descriptive study of the community-based follow-up and outcomes of very low birth weight babies discharged from a regional hospital

---

Please write answers and sign in the provided spaces.

Study number: _____

Date completed: _____ Time completed: _____

Declaration by participant

By signing below, I …….. agree to take part in a research study entitled: The community based follow up and outcomes of very low birth weight babies discharged from a Regional hospital.

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

Signed at (*place*) ..... on (*date*) …….. 2019.

....

Signature of participant **Signature of witness**

Declaration by CHW

I *(name)* …… declare that:

- I explained the information in this document in a simple and clear manner to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ..... on (*date*) ……..…….. 2019.

....

Signature of CHW **Signature of witness**

Declaration by interpreter

I *(name)* …… declare that:

- I assisted the investigator (*name*) ……. to explain the information in this document to (*name of participant*) …….. using the language medium of Afrikaans/isiXhosa/other:…….
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her questions satisfactorily answered.

Signed at (*place*) ..... on (*date*) ……..……..

....

Signature of interpreter **Signature of witness**

References:

1) Human Research Ethics Committee. **Informed Consent**. Faculty of Health Sciences, Stellenbosch University. December 2009. [cited 2019 April 10] Available from: http://www.sun.ac.za/english/faculty/healthsciences/rdsd/Pages/Ethics/Forms-Instructions.aspx

9.6 Appendix 6: Patient Information sheet (English)

University of Cape Town
Department of Paediatrics
MMed Research: Patient information regarding study

Research Study Title: A descriptive study of the community-based follow-up and outcomes of very low birth weight babies discharged from a regional hospital

Researcher: Dr Thandi de Wit/ Prof. M Hendricks

What is a research study?

'A research study is a very careful way of looking at something (a problem or a question) and the process of gathering information about what is being looked at. It can be as simple as asking a few questions such as in a survey or in an interview. Or it can be more difficult and may look at a particular sickness or testing new treatments for a particular sickness'.(1)

What is a researcher?

A researcher is the person who is doing the study and collecting all the information.

What is a research participant?

'A research participant is a person who agrees to take part in a research study. This is completely voluntary. As a research participant you will be helping the researcher to answer the questions in the study. You can decide you no longer want to be in the study at any time.' (1)

What is this study about and why is it being done?

South Africa, and in particular the Western Cape, has started a program to provide follow up care for patients with various medical conditions at their homes and in their communities. This service is called the Community Based Service and it involves community health workers who are trained to visit the homes of those that require follow up and provide the needed care/assistance/support.

There are a few reasons why children are also followed up after they are discharged from a hospital or clinic. One of the reasons why children are followed up is because they are born small with a very low birth weight of less than 1.5kg. When babies are very small they are vulnerable and it can be stressful and challenging having a very small baby at home, therefore it is important that they are followed up. Children that are born this small and discharged from New Somerset Hospital are referred to the Community Based Service and community health workers are meant to follow up the children at their home to provide the caregiver with extra support and education about breastfeeding, looking after their baby and also to see how the baby is doing at home.

We don't have much information about how many small babies need follow up and how the follow up is going as well as any feedback from the caregiver about how they experienced the service and follow up. We therefore are using this study to gain more information about the service.

Why are you being asked to take part in this study?

We are asking you to be a research participant. Your child was born with a very low birth weight, under 1.5kg, and on discharge you were referred, with your permission, to the Community Based Services. We are wanting to find out how you experienced the Community Based Service and follow up so that we can continue to improve and expand the program to reach other caregivers and children.

What do you have to do if you agree to take part in the study?

If you agree to be a part of the study you will first need to sign a consent form. Once completed you will need to complete a short questionnaire, by answering the questions asked by the community health worker who will then complete the form. The questionnaire shouldn't take more than about 30 minutes.

What happens if you do not wish to be part of the study?

It is not compulsory to participate in this study; it is your choice. We would really appreciate you participating as it will help us gather information and see how we can improve the service. If you do not wish to participate, the researcher will contact you via telephone to ask a few questions to see if you were unhappy about anything or if you had any further questions.

What are the risks of this study?

There are no risks for taking part in this study.

Are there any benefits to you for being in the study?

The benefits for you for this study is that this questionnaire allows space for you to give feedback about your experience. It also will help us to provide the people running the service with information about the service which will continue to help to expand the service and therefore help other children who are also born very small, just like your child.

Will you receive any reward (money or food vouchers) for taking part in this study?

You will not receive any reward for taking part in the study.

Who will see the information which is collected about you during the study?

The information collected remains confidential and your contact information will not be included in the study. The information will be seen by the researcher who will put it together into a report. This information in the report will not contain any of your personal information that can identify you or your child. The report will be shared with the people who run the service as well as other paediatric medical doctors to educate them about the service and to make recommendations on how the service could be improved.

Who do I speak to (or contact) if I have any questions about the study?

If there are any further questions that cannot be answered by the community health worker then the community health worker will make contact with the researcher, Dr Thandi de Wit who will make contact via telephone with you to answer questions directly. (Note: Please leave 2 contact numbers with the community health worker in order for the researcher to contact you)

References:

1) Human Research Ethics Committee. **Informed Consent, Standard Operating Procedure**. Faculty of Health Sciences, University of Cape Town. December 2013

9.7 Appendix 7: University of Cape Town, Health Sciences Faculty, 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 6492
Email: sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

13 September 2019

HREC REF: 582/2019

Prof M Hendricks
Department of Paediatrics & Child Health
Red Cross War Memorial Children's Hospital
Rondebosch

Dear Prof Hendricks

PROJECT TITLE: A DESCRIPTIVE STUY OF THE COMMUNITY-BASED FOLLOW UP AND OUTCOMES OF VERY LOW BIRTH WEIGHT BABIES DISCHARGED FROM A REGIONAL HOSPITAL OVER ONE YEAR PERIOD (MASTER OF MEDICINE - DR T M G DE WIT)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study, subject to adding the UCT FHS HREC contact details to the informed consent document.

Approval is granted for one year until the 30 September 2020.

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)

The HREC acknowledge that the student: Dr Thandi De Wit will also be involved in this study.

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.

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

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

9.8 Appendix 8: Provincial Health Research Committee, Western Cape Department of Health – Study approval

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 0866: fax: +27 21 483 6058
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201910_008
ENQUIRIES: Dr Sabela Petros

University of Cape Town
Anzio Road
Observatory
Cape Town
7925

For attention: DR Thandi de Wit and PROF Michael Hendricks

Re: A descriptive study of the community-based follow up and outcomes of very low birth weight babies discharged from a regional hospital over a one year period

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.
Please contact the following people to assist you with any further enquiries in accessing the following sites:

New Somerset Hospital	**Dr Donna Stokes**	**021 402 6504**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE:
CC

Dr Melvin Moodley
Director: Health Impact Assessment
03 DEC 2019

9.9 Appendix 9: Interview Schedule

Table 1 depicts the estimated Interview Schedule for the research study. This is dependent on Ethics approval, initial data collection to determine accurately the study population as well as the availability of the community health workers assisting with the study. The interview Schedule will have to be adjusted once Ethical approval is obtained and the CHW are employed and can express which days and times they are available.

Table 1: Interview Schedule	
Task	*Estimated Time duration*
Transport to 1st interview	15-30 min
1st interview	1 hour
Transport to 2nd interview	15-30 min
TOTAL TIME per interview	2 hours (per interview)
TOTAL TIME all interviews (50 interviews)	100 hours

9.10 Appendix 10: Timeline for Dissertation

Table 2 depicts the estimated timeline for the completed of my MMed dissertation.

Table 2: Timeline	
Task	*Anticipated date of completion*
Protocol Development	
1.Draft 1 – literature review	February 2019
2.Draft 2	May 2019
3.Submission for Departmental Approval	June 2019
4.Submission for Ethical Approval	August 2019
5. Data Collection	Dec 2019 – Feb 2020
6. Interview Process	Feb – April 2020
7. Data Analysis	Feb – April 2020
Write-up	
1.Draft manuscript	May 2020
2.Draft dissertation to supervisors	June 2020
3.Feedback and corrections	June 2020
4.Finalisation of dissertation	July 2020
Submissions	
1. UCT submission	End 2020
2. Journal submission	End 2020

9.11 Appendix 11: Budget Summary

Table 3 depicts the estimated budget for the research study.

Table 3: Budget Summary	
Item	*Estimate amount*
Stationary	
1. Pens (R8 per pen, 4 per CHW)	R32
2. Clipboards (R23 per clipboard, 1 per CHW)	R23
3. Printing (questionnaires, consent forms, patient information forms) R 0.75 per page if > 100 pages	R150 (200 pages)
4. Voice recorders (R650 per CHW)	R650
Interviews	
1. CHW salary (1 x CHW @ R50 per hour for 100 hours) – UCT pay class 1 for support staff on fixed-term contracts (2019 ranges) [1]	R5000
2. Transport (R25 per transport trip on public transport) 2 trips per interview	R2500
3. Training (refreshments, stationary)	R300
Total estimated amount for 1 CHW	R8655
Total estimated amount for 2 CHW	R9360

Reference:

1. University of Cape Town. Human Resources. **Cost of employment (COE) ranges and costing information for fixed-term contract staff (2018)**. [cited 2019 May 10]. Available from: http://www.hr.uct.ac.za/hr/benefits/remuneration/coe_ranges/contract_staff#rates

9.12 Appendix 12: Turn-it-in report

dwttha001:Final_MMed_draft_for_turnitin.docx

ORIGINALITY REPORT

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Exclude bibliography	On		

9.13 Appendix 13: BMC author guidelines

These guidelines are available from: https://bmchealthservres.biomedcentral.com/submission-guidelines/preparing-your-manuscript/research-article

Research article

Criteria

Research articles should report on original primary research, or present a new experimental or computational method, test or procedure. Manuscripts reporting results of a clinical trial must conform to CONSORT 2010 guidelines. Authors of randomized controlled trials should submit a completed CONSORT checklist alongside their manuscript, available at www.consort-statement.org. Research articles may also report on systematic reviews of published research provided they adhere to the appropriate reporting guidelines which are detailed in our editorial policies. Please note that non-commissioned pooled analyses of selected published research will not be considered. Studies reporting descriptive results from a single institution or region will only be considered if analogous data have not been previously published in a peer reviewed journal and the conclusions provide distinct insights that are of relevance to a regional or international audience. Please note that the journal does not consider research focused on:

- Clinical research
- The clinical knowledge, decision-making, and practice of healthcare professionals
- Increasing for-profit healthcare revenue. For example, monetizing healthcare or personal health data, or marketing for-profit healthcare, including health and insurance products

Data sharing

BMC Health Services Research strongly supports open research, including transparency and openness in reporting. Further details of our Data availability policy can be found on the journal's About page.

BMC Health Services Research strongly encourages that all datasets on which the conclusions of the paper rely should be available to readers. We encourage authors to ensure that their datasets are either deposited in publicly available repositories (where available and appropriate) or presented in the main manuscript or additional supporting files whenever possible. Please see Springer Nature's information on recommended repositories. Where a widely established research community expectation for data archiving in public repositories exists, submission to a community-endorsed, public repository is mandatory. A list of data where deposition is required, with the appropriate repositories, can be found on the Editorial Policies Page.

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Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section.

Please note that your manuscript must include a 'Declarations' section including all of the subheadings (please see below for more information).

Title page

The title page should:

- present a title that includes, if appropriate, the study design e.g.:

    - "A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"
    - or for non-clinical or non-research studies a description of what the article reports
- list the full names and institutional addresses for all authors
    - if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the "Acknowledgements" section in accordance with the instructions below
- indicate the corresponding author

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the CONSORT extension for abstracts. The abstract must include the following separate sections:

- **Background:** the context and purpose of the study
- **Methods:** how the study was performed and statistical tests used
- **Results:** the main findings
- **Conclusions:** brief summary and potential implications
- **Trial registration:** If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be in stated in this section. If it was not registered prospectively (before enrollment of the first participant), you should include the words 'retrospectively registered'. See our editorial policies for more information on trial registration

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

The methods section should include:

- the aim, design and setting of the study
- the characteristics of participants or description of materials
- a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses
- the type of statistical analysis used, including a power calculation if appropriate

Results

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusions

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations

All manuscripts must contain the following sections under the heading 'Declarations':

- Ethics approval and consent to participate
- Consent for publication
- Availability of data and materials
- Competing interests
- Funding
- Authors' contributions
- Acknowledgements
- Authors' information (optional)

Please see below for details on the information to be included in these sections.

If any of the sections are not relevant to your manuscript, please include the heading and write 'Not applicable' for that section.

Ethics approval and consent to participate

Manuscripts reporting studies involving human participants, human data or human tissue must:

- include a statement on ethics approval and consent (even where the need for approval was waived)
- include the name of the ethics committee that approved the study and the committee's reference number if appropriate

Studies involving animals must include a statement on ethics approval and for experimental studies involving client-owned animals, authors must also include a statement on informed consent from the client or owner.

See our editorial policies for more information.

If your manuscript does not report on or involve the use of any animal or human data or tissue, please state "Not applicable" in this section.

Consent for publication

If your manuscript contains any individual person's data in any form (including any individual details, images or videos), consent for publication must be obtained from that person, or in the case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.

You can use your institutional consent form or our consent form if you prefer. You should not send the form to us on submission, but we may request to see a copy at any stage (including after publication).

See our editorial policies for more information on consent for publication.

If your manuscript does not contain data from any individual person, please state "Not applicable" in this section.

Availability of data and materials

All manuscripts must include an 'Availability of data and materials' statement. Data availability statements should include information on where data supporting the results reported in the article can be found including, where applicable, hyperlinks to publicly archived datasets analysed or generated during the study. By data we mean the minimal dataset that would be necessary to interpret, replicate and build upon the findings reported in the article. We recognise it is not always possible to share research data publicly, for instance when individual privacy could be compromised, and in such instances data availability should still be stated in the manuscript along with any conditions for access.

Authors are also encouraged to preserve search strings on searchRxiv https://searchrxiv.org/, an archive to support researchers to report, store and share their searches consistently and to enable them to review and re-use existing searches. searchRxiv enables researchers to obtain a digital object identifier (DOI) for their search, allowing it to be cited.

Data availability statements can take one of the following forms (or a combination of more than one if required for multiple datasets):

- The datasets generated and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS]
- The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.
- All data generated or analysed during this study are included in this published article [and its supplementary information files].
- The datasets generated and/or analysed during the current study are not publicly available due [REASON WHY DATA ARE NOT PUBLIC] but are available from the corresponding author on reasonable request.
- Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.
- The data that support the findings of this study are available from [third party name] but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of [third party name].
- Not applicable. If your manuscript does not contain any data, please state 'Not applicable' in this section.

More examples of template data availability statements, which include examples of openly available and restricted access datasets, are available here.
BioMed Central also requires that authors cite any publicly available data on which the conclusions of the paper rely in the manuscript. Data citations should include a persistent identifier (such as a DOI) and should ideally be included in the reference list. Citations of datasets, when they appear in the reference list, should include the minimum information recommended by DataCite and follow journal style. Dataset identifiers including DOIs should be expressed as full URLs.
With the corresponding text in the Availability of data and materials statement:
The datasets generated during and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS].[Reference number]
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