Closing the gap:
Applying health and socio-demographic surveillance to complex health transitions in South and sub-Saharan Africa

Stephen Tollman
2008
Dedication

To my parents, Shirly Jacoby and Ted Tollman, for giving me more than they can imagine –

And to Kathy, for the same reason –
Abstract

Background The challenge of research in resource-poor settings remains a profound concern and is closely linked to African social development. Work of this thesis spans the end of apartheid and first decade of the democratic era in South Africa, along with emergence of the HIV/AIDS pandemic. It also covers the founding decade of the INDEPTH\(^a\) Network.

Aims Through appraising health and population research in a rural Southern African sub-district over the past decade, to evaluate the utility of health and socio-demographic surveillance in rural African settings for:

• capturing the dynamics of health, population and social transitions
• supporting a mix of research designs, and
• contributing to policy and programme development and evaluation.

To extend this appraisal by examining the multi-site opportunities offered by the INDEPTH Network.

Methods Work was sited in the Agincourt sub-district, a heavily populated border area of rural north-eastern South Africa. Health and socio-demographic surveillance, introduced in 1992, involved prospective follow-up of the entire sub-district population of 70,000 people (including some 30% Mozambican immigrants) who lived in 11,700 households and 21 villages. Annual census rounds systematically updated household membership and recorded all vital events (births, deaths and migrations) since the previous census. A maternity history was asked of women of reproductive age and a verbal autopsy carried out on all deaths recorded. The resulting ‘data and research platform’ – a core feature of all INDEPTH field sites – provided data for computation of trends in vital events and supported an extensive interdisciplinay project portfolio. The population under surveillance can be disaggregated into cohorts selected by age, sex or other criteria. Analyses are possible at multiple levels (individual, family/household or neighborhood) and can include socioeconomic factors.

Findings The Agincourt community experienced a serious worsening of mortality among most age-sex groups, rapidly declining fertility to near replacement level, and changing patterns of labour migration. This resulted in major changes in population structure and household composition. The rising burden of chronic disease involved both chronic infectious illness (HIV/AIDS and tuberculosis) and non-communicable disorders (such as stroke and related vascular disease). The burden of illness requiring chronic care increased disproportionately to that needing acute care. Potential contributions of field sites based on health and socio-demographic surveillance to local and national health policy are considerable yet remain under-exploited.

Interpretation Rural South and southern Africa is in the midst of multiple, interrelated transitions with implications for health, social and development sectors. Health and socio-demographic surveillance systems are effective research instruments that can capture the rapidly-changing dynamics of health and social transitions in developing settings. Similarly, they can support a range of observational and intervention study designs including policy evaluations. The INDEPTH Network should boost much-needed comparative research; yet singly, and as a group, many of these sites have yet to fulfil their undoubted potential.

Keywords: demographic surveillance system, health transition, mortality transition, fertility transition, health policy, primary health care, South Africa

\(^a\) INDEPTH: International Network for the Demographic Evaluation of Populations and Their Health
Original papers

The thesis is based on the following original papers:


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<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethical considerations</td>
<td>19</td>
</tr>
<tr>
<td>Data sharing</td>
<td>20</td>
</tr>
<tr>
<td><strong>Results</strong></td>
<td>21</td>
</tr>
<tr>
<td>Mortality transition and its measurement</td>
<td>21</td>
</tr>
<tr>
<td>Determining cause of death: Re-validation of verbal autopsy instrument</td>
<td>22</td>
</tr>
<tr>
<td>Detecting a reversal in mortality</td>
<td>22</td>
</tr>
<tr>
<td>The dynamics of epidemiological transition</td>
<td>23</td>
</tr>
<tr>
<td>Contrasting male and female cause-of-death patterns</td>
<td>25</td>
</tr>
<tr>
<td>Maternal mortality: a deepening concern</td>
<td>28</td>
</tr>
<tr>
<td>Fertility transition and changing social relationships</td>
<td>28</td>
</tr>
<tr>
<td>Migration and mortality</td>
<td>31</td>
</tr>
<tr>
<td>A synthesis of findings on ‘transition’ in Agincourt</td>
<td>32</td>
</tr>
<tr>
<td>Applications of data and findings to policy</td>
<td>35</td>
</tr>
<tr>
<td><strong>Discussion</strong></td>
<td>37</td>
</tr>
<tr>
<td>Mortality and fertility trends in Agincourt, 1992-2005</td>
<td>38</td>
</tr>
<tr>
<td>‘Transitions’ theory in light of Agincourt findings</td>
<td>40</td>
</tr>
<tr>
<td>Study design: cumulative experience</td>
<td>41</td>
</tr>
<tr>
<td>Optimising use of data</td>
<td>43</td>
</tr>
<tr>
<td>Positioning surveillance systems: decentralisation and the district level</td>
<td>47</td>
</tr>
<tr>
<td>Creativity in study design</td>
<td>48</td>
</tr>
<tr>
<td>Innovation in study design: an INDEPTH perspective</td>
<td>50</td>
</tr>
<tr>
<td>Representivity and generalisability</td>
<td>53</td>
</tr>
<tr>
<td>HDSS stakeholders: host communities</td>
<td>54</td>
</tr>
<tr>
<td><strong>Conclusion</strong></td>
<td>57</td>
</tr>
<tr>
<td><strong>Acknowledgements</strong></td>
<td>59</td>
</tr>
<tr>
<td><strong>References</strong></td>
<td>61</td>
</tr>
</tbody>
</table>
Foreword

I am fortunate to have enjoyed wonderful mentoring and comradeship from outstanding colleagues over the course of my professional life; equally, to have lived through a defining period in the history of South Africa and the continent. This has informed and taught me most of what I profess to know or understand.

To have walked this path with my colleague and life-partner, Kathy Kahn, almost from the start, has been a rich blessing. The dawn of our careers in public health, while still medical students at Wits University, coincided with approaching evening in the lives of Sidney and Emily Kark, but we continued for many years to reap the benefit of their wisdom and generosity. Nothing meant more, in 1992, on their only visit to Agincourt, than to hear their unqualified endorsement of our earliest efforts.

To younger and newer colleagues at Umeå University, sincere and warm thanks for absorbing us – seemingly effortlessly (and we know nothing is without effort) – into your world which we now share. It is no accident that an important milestone for Agincourt and for us – a special issue of the Scandinavian Journal of Public Health, published in 2007 and entitled ‘Health, population and social transitions in rural South Africa’ – took shape during our sabbatical in Umeå in 2005.

And as constant as Kathy, so are my vital associations with the people of Agincourt, deeply valued colleagues in the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), and much respected partners and colleagues at Wits, in public service, in INDEPTH, and in universities and research groups further afield.

Steve Tollman
2008
Background

The challenge of research in resource-poor settings remains a profound concern. In Africa – the world’s second largest and most-populous continent after Asia, with some 14, 2% of the world’s population numbering about 922 million people¹ – the limited research base is not only a serious scientific concern but, equally, one closely linked to the region’s social development and a reflection of the inequalities evident in the global distribution of research capacity. The call for every country, no matter how small or limited its resources, to build the capacity for “essential national health research” remains as timely today as when it was first articulated more than 15 years ago.²

The work presented in this thesis was initiated in 1992 during the last years of South Africa’s apartheid era. The half-century from 1948 to 1994 was a dark period for millions of the country’s people – when the great majority with a birthright to citizenship were denied this right based on a confusing mix of religious, political and supremacist justifications imposed by force. Apartheid South Africa was an inward-looking society, a state with few friends internationally and increasingly the focus of international boycotts and, finally, United Nations-endorsed trade and political sanctions.

Yet its ruling elite achieved some success in implementing the spurious apartheid philosophy of “separate but equal”. As a result, many of the country’s least hospitable areas – a geographic patchwork comprising some 13% of the country’s land-mass, usually on its habitable margins – were designated “homelands”. Through a complex legislative web,³ enforced by the South African Police and the judiciary, the majority of Africans were expected to live, build homes and communities, and exercise their ‘rights’, in these underdeveloped settings. Notwithstanding the injustice intrinsic to such a political dispensation, the apartheid regime was able to skilfully ‘buy off’ certain tribal chiefs and ethnic leaders who, suitably rewarded, accepted positions of political authority in the ‘bantustans’ – and thus played a major role in implementing the apartheid ideology.

This capacity to marginalise the bulk of the country’s population led, unsurprisingly, to great ignorance – among the urban-based political elite and the (largely white) middle class in particular – regarding the health and living conditions of the rural poor. Similarly, a preoccupation with African population growth, and a fear that this could overwhelm the white minority population, led to an exaggerated emphasis on ‘population control’ – with the study of demography and population becoming the preserve of exclusivist Afrikaner academic institutions, and correspondingly tainted elsewhere.

¹ including various Land Acts, pass-laws, and the Group Areas Act
Introduction

Early initiatives in primary health care

Surprisingly to many, South Africa is recognised internationally for its contribution to the experience and evidence underpinning what, in 1978, was adopted as the World Health Organization’s flagship initiative in primary health care.3 Dating back to an intense and fertile period of health development beginning in the late 1930s and extending over 20 years to around 1960, an enlightened academic, administrative and political leadershipb provided strong support to two young physicians,c Sidney and Emily Kark, to initiate an approach to health care practice serving remote rural communities starting with the Pholela region of KwaZulu-Natal.

The health centre practice pioneered in Pholela – based on a combination of primary care services and public health outreach informed by small-scale surveys and census studies – was later characterised as ‘community-oriented primary health care’ (COPC).4, 5 This approach became the basis for a groundbreaking Institute of Family and Community Health established in 1946 and later attached to the University of Natal’s Medical School in Durban. The Institute was expected to provide the human resources and training needed for a country-wide network of health centres that would make up the key elements of a national health system ‘available to all according to their needs’ – the primary recommendation of a National Health Service Commission (1942 - 1944) that was chaired by Henry Gluckman.d 6 Part of the advance represented by the Pholela prototype lay in its interdisciplinary and intersectoral approach – one that acknowledged the multiple determinants of population health, recognised the centrality of local customs and beliefs, and sought to integrate what are today accepted precepts of community involvement.4

Political realities

By 1960, however, South Africa’s promising but fragile experiment in primary health care collapsed, accompanied by the emigration of many of its outstanding proponents.8 It could not survive the heavy hand of a regime determined to undermine its goals as well as curtail its funding. Despite the best efforts of the Karks, the principal of Natal University, EG Malherbe, and various others, the Rockefeller Foundation too withdrew its support. At the same time, the country’s medical and nursing leadership made little protest, being more concerned with building a profitable private health sector and protecting their professional status.8

1976, the year of the Soweto uprising, saw African high school students protesting the enforced use of Afrikaans as the primary medium of instruction in schools. In reaction to the state’s attempt to suppress the protest through the use of force, student rioting spread rapidly from Soweto to other urban centres. Despite a tragic loss of life, and widespread condemnation of the use of lethal force, the students could claim victory – with Afrikaans, widely regarded as the ‘language of the oppressor’, subsequently relegated to the status of an ordinary school subject.

Ironically, the events of 1976 focused national and international attention on the country’s urban areas. Yet it was the underdeveloped rural areas that were home to South Africa’s poorest people.

b  with Jan Smuts as Prime Minister

c  graduates of the University of the Witwatersrand

d  subsequently Minister of Health in the Smuts cabinet
Rural South Africa and rural health

Partly in response to the urban-oriented events of the mid-1970s, far-sighted colleagues in the Community Health Department, University of the Witwatersrand (Wits), led by its first dedicated professor, John Gear, determined to shift their focus and establish a rural health unit. Around this time, medical student activists initiated visits to rural hospitals and, within a few years, these were formalised as part of the medical curriculum. A system of faculty ‘consultant visits’, in support of the student initiative, soon followed, and this pioneering venture in rural medical training has remained part of the medical curriculum in the Wits Faculty of Health Sciences.

Gear, with support from Eric Buch and others, motivated to the Anglo American Chairman’s Fund for resources to establish a rural base focused on health services development. Following a survey of hospitals in the then Eastern Transvaal region, and seeking a service management that could tolerate development and critique, Buch recommended the Tintswalo district hospital – headed by an affable and welcoming US missionary and surgeon, David Stephenson.\(^e\) As apartheid policies had aligned universities with particular homeland areas, to which this choice conformed, arrangements to establish the Unit were eased. Tintswalo thus became the base for what was inaugurated in 1982 as Wits University’s Health Services Development Unit (HSDU).\(^9\)

It must be appreciated that these were high apartheid years; thus relations between this fledgling unit and the homeland (and national) health authorities were tense and at times confrontational. On more than one occasion, Gear and the medical school dean, Robert Charlton – soon to become vice-chancellor at Wits – had to shuttle to Giyani, the Gazankulu homeland ‘capital’, to smooth ruffled feathers and avert potential closure of the HSDU. But the HSDU endured as effectively South Africa’s only rural health development unit, providing a formative experience for many who later became the country’s leading public health practitioners, academics and scientists.

At the outset, three programmes were initiated: in primary health care nurse (PHCN) training; village development; and health services development.\(^9\) The first of these, PHCN training, was influenced by a focus on clinical nurse training\(^f\) that emerged in the aftermath of the Soweto uprising and an exodus of doctors from Soweto primary care services.\(^10\) The Tintswalo PHCN training programme – targeting the reality that rural health care was essentially (and still is) a nurse-led service – introduced a new category of independent, clinically skilled and community sensitive nurse to the rural South African health scene. Great care was taken over curriculum development, standards setting and competency assessment. While nursing authorities dragged their heels in recognising and then accrediting the programme, this was eventually forthcoming – as was a post-graduate diploma course in PHC Education, aimed at trainers of such programmes which proliferated across the country.\(^11\) The World Health Organization (WHO) took a keen interest in the materials produced,\(^8\) purchasing hundreds of the training manuals that were later published by Heinemann in 2001.\(^12\)

\(^e\) Stephenson was the last Nazarene doctor to serve as medical superintendent of Tintswalo Hospital, a post he held until 1985

\(^f\) initiated by Lucy Wagstaff, Professor of Paediatrics and first head of the Child Health Division at Wits

\(^g\) first drafted by a team led by Clive Evian, with a second edition produced by Paul Pronyk and colleagues
INTRODUCTION

Agincourt: the local context

Interestingly, the HSDU’s health services development programme was less successful. A succession of intensive service appraisals in the mid-1980s – focused on systems development, tuberculosis and child malnutrition and resulting in a number of programmatic interventions – did not yield the changes expected. There were many reasons for this, not least the under-resourcing of services for rural South Africans coupled with the resistance to change of homeland health authorities. And also, perhaps, an over-optimistic expectation of what could be achieved by a determined but young research and development (R&D) unit operating in a conflicted environment.\(^{136, 137, 138}\)

In October 1990, the author and Kathleen Kahn joined the HSDU. The winds of political change were gusting and Nelson Mandela’s release in February 1990, along with the unbanning of the African National Congress (ANC) and South African Communist Party, heralded the opening bars of a new era. This was tangible in rural Gazankulu; erstwhile rivals on opposing sides of the political divide realised increasingly that they shared a common future and would need to build it together. Thus a period of unusual fluidity arose that permitted discussions and plans that a short while earlier seemed unthinkable.

This ‘thaw’ created unusually positive conditions to reflect on the state of rural health systems in South Africa. In reality, these were hospital systems with a ragged and often poorly supported network of primary level clinics. On the other hand, a number of charismatic physicians, capitalising on the more integrated local health services that the mission hospital system had facilitated, had built up a well of experience from such mission hospital bases as Elim Hospital in the Gazankulu homeland, Gelukspan Hospital in the Bophututswana homeland, Cecilia Makiwane in the Transkei, and Manguzi, Bethesda and Charles Johnson Memorial hospitals in KwaZulu-Natal.

The question facing the HSDU was: What contribution can a small, university-linked group make to an emerging national health system – one with a policy framework intended to be district-based and centred on primary health care\(^{13}\) – but with a new leadership that, while high on ambition, was low on experience? Drawing directly on the Kark-Pholela experience, and the wider international development of COPC in industrialised, African and Asian settings,\(^{14}\) a new ‘health systems development programme’ was initiated in the HSDU. Its aims were:

To determine the current health status of local communities and investigate the determinants of this; to pilot district and local level health and development interventions based on this information; and to assess the impact of such interventions (1992).\(^{15}\)

The Agincourt sub-district in southern Gazankulu provided a setting that was genuinely rural, some distance from established towns and infrastructure, yet contained the basis for a network of decentralised primary care facilities: a health centre and several clinics that referred to Tintswalo and other hospitals within the greater Bushbuckridge district. The contribution of Paul Robert – the Swiss-born ‘Secretary for Health’ of Gazankulu at the time – should be acknowledged. Dr Robert identified with the vision of the proposed Agincourt R&D site, saw the contribution that could be made to a politically constrained and poorly performing public sector, and so was willing to shepherd a proposal through the various homeland health structures in order to overcome the inevitable opposition and obtain the requisite permissions.

As the Agincourt programme of health systems R&D got underway, a concern for effective research and evaluation strengthened. This was motivated, first, by recognition that a serious limita-
tion to the HSDU’s service development efforts of the 1980s was the absence of baseline measures on population health status, and any means to track changes over time. Further – following visits to the Matlab field site in Bangladesh and the Niakhar site in rural Senegal – Unit leadership argued that the most promising instrument for obtaining such data was a so-called ‘health and demographic surveillance system’ (HDSS). Beyond this, and with an eye to the longer-term, the leadership believed that introducing an HDSS offered the most effective path to establishing a world-class R&D initiative – one that could, albeit modestly, help right the imbalance in research stock in South Africa. This was overwhelmingly urban-oriented and urban-based and thus – not unlike what was later framed as the 10:90 global imbalance\(^h\) – was profoundly misaligned with the country’s health and development needs and priorities.

Thus in 1992/3, with support from the European Union, Kaiser Family Foundation, USA, and Independent Development Trust, South Africa – and an unexpected contribution from the National Department of Health – a baseline census was administered as part of a programme of decentralised, primary health care oriented, rural health and development.

Agincourt: early years

Early work focused on health systems R&D using a framework provided by the COPC model. Given the locally relevant and fairly extensive experience of the HSDU, the Unit emerged as central to early efforts to demonstrate the potential of district and sub-district health systems in South Africa, hosting many field visits of provincial health departments and senior national health executives, and making technical contributions to a number of provincial and NGO initiatives.\(^{16, 17}\) Recognition from the World Health Organization was also forthcoming with frequent contributions to meetings convened by WHO’s then Division for National and District Health Systems. The division was ably led by Eleuther Tarimo, a perceptive and gentle Tanzanian physician, who once remarked on the Kark-Pholela experience as ‘…perhaps the best example of its kind…’. (E Tarimo, pers comm)

But by the mid-1990s, it was evident that national health systems development was increasingly mired in the organisational effort needed to integrate a highly fragmented health service. By the end of the apartheid era, there were some 14 independent health administrations serving the homelands and different population groups. Enormous effort was devoted to building a unified system spanning national, provincial and local levels with uniform conditions of employment. In stark contrast, early findings from Agincourt suggested that the minimal evidence base informing local health development was, if anything, more flimsy than was recognised. The Agincourt sub-district, for example, had been assessed by local development agencies as numbering at most 30-35,000 people. Following the baseline census in 1992/3, this number was adjusted upwards to 58,000 people. Errors of such magnitude brought home the prevailing dearth of data and understanding. Thus Agincourt leadership resolved on a major shift, away from a focus solely on decentralised health systems development, and towards an explicit health and population research endeavour. The aim was to build an evidence base capable of informing rural health and development policy and practice in South Africa and further afield.

\(^{h}\) Strongly advocated by the Global Forum for Health Research, www.globalforumhealth.org
In important respects, the dearth of available data reflected much deeper South African realities that linked to issues of rights and citizenship. Rural-urban and cross-border migration were profoundly political issues since the control of population movement was central to the grand apartheid ideology. Apartheid – or ‘separate development’ – viewed citizenship for Africans as something to be exercised in the marginalised homelands. Full South African citizenship would be limited, by and large, to the country’s white minority. A matrix of legislation to restrict freedom of movement, harshly enforced by the South African Police and judicial system, was designed to achieve this goal. For many millions, this was the reality of ‘separate development’; a reality of pass laws, split families, stunted personal and social relationships, migrant labour and unemployment.

As a result, an initiative based on the voluntary provision of personal identifying data, from a community whose experience was of anything but the developmental purposes to which such information could be put, was bound to arouse suspicion. In fact, the start of the Agincourt initiative provoked less concern than might have been expected (or justified). Undoubtedly this was due to the local credibility of the HSDU, accumulated over many years. But the potential for a negative community reaction influenced the conduct of Agincourt study leadership. Prior to baseline data collection, much time was spent discussing its broader health and development purposes with all levels of community membership – who in turn contributed to obtaining the necessary community support. This has carried forward to an abiding commitment to pre-project discussions with community, and regular feedback of findings to villagers.

Despite the infrastructural demands it imposes, the bulk of data collection and entry occurs on-site, among host communities who are free to observe this in progress and request information.

Agincourt: stages of development

Work in Agincourt originated in efforts to contribute demonstrations of decentralized health programmes – in maternal health, sexually transmitted infections, child nutrition and mental health – to a new, district-based primary health care-oriented Ministry of Health. In the years since 1997, an interdisciplinary portfolio of research has evolved that, in 2002/3, formed the nucleus for a new South African Medical Research Council Unit focused on ‘rural public health and health transitions research’. Following the baseline census in 1992/3, work has thus progressed through three identifiable stages:

- Decentralised health systems development (1993-97) providing a prototype for national policy in response to limited experience delivering rural services
- Reorientation to a university-linked health and population research initiative (1998-2002) as serious weaknesses in the rural evidence base became apparent
- Establishing a field-based research and training programme linked with Wits University and the South African Medical Research Council (2003-07) that is central to an emerging, interdisciplinary university initiative encompassing ‘Population, Health and Society’.

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A sister primary health care initiative, led by Tim Wilson and based at the Alexandra Health Centre, a township bordering Johannesburg, added credibility to the progressive health movement by its refusal to release patient records when the township was the site of violent clashes between residents and police.
In the forthcoming period (2008-) we envisage a balance of observational and intervention research along with several multi-site collaborations. This will respond to findings from the recent research cycle (2003-2007) which involved multiple investigations into the causes and consequences of observed patterns. Such work is possible given the capacity of health and socio-demographic surveillance to capture change in variables at individual, household and population levels; and characterise the marked differences in experience and exposures of successive cohorts. HDSS infrastructure in support of individual sampling (random or purposive), stratification (by demographic, biological, geographic or social variables) and systematic follow-up of study participants is exceptional. In addition, a series of innovations sought to ensure that data would be more accessible to scientists and students, and better formatted to support multi-site collaborations.

Introducing INDEPTH

This account warrants mention of a workshop in 1997, convened by Kahn and Tollman together with supportive faculty at the London School of Hygiene and Tropical Medicine, and funded by the Andrew W Mellon Foundation and the Wellcome Trust. One purpose was a critical review of Agincourt findings as a prelude to the next phase of work. However, the meeting intentionally included colleagues from several sister HDSS sites. This gave a foretaste of the remarkable opportunity and potential that could be gained from a network of collaborating HDSS sites – or INDEPTH as it was ultimately called.

INDEPTH: International Network for the Demographic Evaluation of Populations and Their Health
Aims

Thesis aims
Research in Agincourt is based on an overarching hypothesis that:

*Understanding the dynamics of health, population and social transitions is a pre-requisite for policy, systems and programme development that is effectively targeted, affordable and sustainable, with potential to reduce the burden of illness, foster health and wellbeing along the life-course, and strengthen household coping strategies.*

Overall aim
Through appraising health and population research in a rural Southern African sub-district over the past decade:

- To evaluate the utility of health and socio-demographic surveillance in rural African settings for:
  - capturing the dynamics of health, population and social transitions
  - supporting a mix of research designs
  - contributing to policy and programme development and evaluation
- To extend this appraisal by assessing the multi-site opportunities offered by the recently established INDEPTH\(^k\) Network.

Specific aims
In the Agincourt sub-district of Bushbuckridge, South Africa:\(^l\)

- To describe the health and socio-demographic surveillance methodology employed in the Agincourt study site over the period 1992 - 2005, and to identify the range of study designs based on this infrastructure
- To describe trends in fundamental health and socio-demographic variables – including mortality, fertility and migration – over the 13-year period 1992 - 2005 in order to characterize the extent and nature of ‘transitions’ underway and investigate some of the factors responsible
- To examine the implications of these findings for health policy and practice in rural South Africa and elsewhere in the region.

\(^k\) INDEPTH: International Network for the Demographic Evaluation of Populations and Their Health

\(^l\) The Agincourt sub-district is a typical, infrastructurally weak rural area with limited vital registration. It is one of several sub-districts making up the Bushbuckridge District of Mpumalanga Province; lying adjacent to the Kruger National Park and western boundary of Mozambique, it may be considered a border region of rural Southern Africa
**Thesis themes**

*Table 1 indicates the key themes of this work and their relation to the six papers presented:*

<table>
<thead>
<tr>
<th>Themes</th>
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<td>I</td>
<td>II</td>
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<td>data and methods</td>
<td>mortality reversal</td>
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**HDSS as instrument to capture dynamics of transition**

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<th>Themes</th>
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<tr>
<td>HDSS as versatile instrument for support of observational and intervention research</td>
<td>all mortality, fertility, migration papers (II-V) serve to raise priorities, generate hypotheses, and contribute to research agenda</td>
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**HDSS with high but unexploited potential to support policy and programme development and evaluation**

**Concepts and terminology when discussing ‘transitions’**

A critical reflection on ‘transitions theory’ will follow the detailing of results. This account aims to introduce the concepts most commonly used and contrast their usage.\(^2^7\) The term ‘transitions’ in essence refers to the ‘process of change’; as used in this thesis, however, the term is used to highlight the rapid, at times dramatic, and generally profound nature of this change.

The ‘demographic transition’ focuses on the interplay in populations between two key variables or vital events, births and deaths, with consequent changes to population structure.\(^2^8\) Demographic transition theory posits that societies will traverse through several ‘stages’, the first being a stage of high mortality and high fertility characteristic of pre-industrial societies; the second involving lower mortality (and rising life expectancy) while fertility remains high as in low-income countries; this will be followed by a stage characteristic of middle-income countries where, as a result of falling fertility, population growth stabilizes; and finally a fourth and final stage, characteristic of industrialized countries, will result where both mortality and fertility are low, population growth is correspondingly low or absent, and the aging (or ‘greying’) of the population is marked. In this latter stage, the dependency ratio\(^m\) is likely to increase.

\(^m\) Technically, the dependency ratio refers to the ratio of economically dependent persons (by convention referring to those under 15 years of age and 65 years and older) to those of economically productive age (ie the age-range 15-64 years)
The term ‘epidemiologic transition’ is widely used and extends the concept of demographic transition by describing the mortality and illness (morbidity) patterns characteristic of societies as they pass – once again – through defined stages of ‘development’. Thus, as first described by Omran in 1971, the biblical-sounding ‘era of pestilence and famine’ is characterized by epidemic infectious diseases, nutritional disorders, and the complications of pregnancy and childbirth. In time this is succeeded by an ‘era of receding pandemics’ which, in due course and inevitably, will be followed by an ‘era of degenerative and man-made diseases’, notably non-communicable disease (cardiovascular disease and cancers for example) and injuries.

The expected features of both the demographic and epidemiological transitions are well described, their ‘content’ and primary drivers can be characterized in some detail, and, while time frames will differ, the well-characterized stages are assumed to follow an orderly progression over time. The terms ‘mortality transition’ and ‘fertility transition’, referring to key elements of demographic transition, are generally used to describe empirical findings specific to particular settings, rather than as primary theoretical constructs.

The phrase ‘health transition’ – though less commonly used, possibly because of its less precise and more encompassing description – has the scientific appeal of extending the concepts of demographic and epidemiological transition in order to incorporate both individual behaviour and the social (or more distal) determinants of complex changes. Arguably, the term is more accessible to a lay audience. With economic and social development, and greater understanding of the drivers of observed changes, a series of component transitions – the dietary and nutritional transitions or cardiovascular transition for example – can be described and have entered the literature.
Methods

For a comprehensive account of the methods used, please refer to paper I. This section attempts to draw together the conceptual, operational and data handling elements of the Agincourt health and socio-demographic surveillance system.

Study area

The Agincourt sub-district, measuring some 402 sq km, encompassed some 70,000 people living in 21 villages in 11,700 households. The area lies in South Africa’s semi-arid rural north-east (figure 1); part of the Bushbuckridge ‘poverty node,’ it has long been a labour-sending area with limited employment opportunities despite a population density of 174 persons per sq km. Remittances from labour migrants and pension pay-outs constitute primary sources of income for most households. Located only 40 km west of the Mozambican border, the area can be regarded as a cross-border region of rural Southern Africa – indeed, former Mozambicans make up close to a third of the Agincourt population.

A well-dispersed network of 28 primary schools supports near-universal primary education. Secondary schools are well attended but progression is slow and half of 20 year olds are still enrolled. Around 6% of adults have some tertiary education but only half of these actually graduate. Outside of district hospitals, public services are staffed by nurses who receive irregular medical visits. Six clinics, distributed across the site, constitute a primary care network that refers to the better resourced Agincourt Health Centre. This links to either Mapulaneng or Tintswalo Hospital, 25 or 40 km away; referred patients rely largely on public transport.

Figure 1. Southern Africa showing Agincourt study site, and study site detail, 2007

The site was extended in 2007 to cover some 85,000 people living in 14,400 households and 26 villages.
Health and socio-demographic surveillance system (HDSS)\(^o\)

In essence, core HDSS data provide a dynamic list of all people living, and who have lived, within the geographically defined Agincourt sub-district since the baseline census in 1992.

This list records a full history of the population and describes exactly who was living in the study area at any point in time, when each event that changed the list occurred (e.g. a birth, death or migration), and with whom each person is living (or connected to). Surveillance thus involves prospective, comprehensive follow-up of the full population which, depending on research focus, can be disaggregated into cohorts selected by age, sex or other criteria. Analysis is possible at multiple levels – individual, family/household or neighborhood in the first instance – and can include a range of socioeconomic factors (household asset status for example).

![Figure 2. Generic outline of a Health and socio-demographic surveillance system (HDSS)
Adapted from INDEPTH, 2008](image)

**Data system**

The Agincourt data system is structured according to the following schema:

Each individual is linked to a household through an entity called a ‘membership episode’ that records how and when a person joined, or left, the household. Similarly, each individual is linked to a physical location through a ‘residence episode’ which records the start and end of a period of residence. These episodes often coincide, but residence can change (for reasons of foster care, marriage etc) resulting in a new residence episode in another household. Importantly:

- New individuals can only be added to the population through birth and in-migration, while enumerated individuals leave through death or permanent out-migration
- Movement within the site, and people’s attachments to new households, is carefully recorded and temporary residence outside the site is distinguished from permanent out-migration.

From these data, virtually all indicators dealing with vital event dynamics and the risk of dying and survival can be calculated. Change over time in the measures is key to evaluating the impact of interventions.

\(^o\) I am indebted to Samuel Clark for his contribution to this description
Field methods

The primary tool is a rigorous annual update of the demographic status of every member of the sub-district, conducted through a home visit and face-to-face interview. Since the baseline census in 1992/3, information on all vital events (deaths, births, in- and out-migrations) was collected through the annual update. A well-planned field operation involves visits by thoroughly trained and supervised fieldworkers to each of approximately 11,700 households in the sub-district. Fieldworkers interview the best respondent available who should be knowledgeable about household events. Verbal consent is required and refusals to-date are minimal. During interview, the fieldworker verifies existing data and systematically records new events experienced by each household member since the previous census update;\textsuperscript{21, 37} this is supplemented by a full maternity history for in-migrant women 15-54 years. Additional enquiry is via special modules which gather further personal and household data pertinent to the scientific programme.\textsuperscript{21}

The census update is conducted by four teams of six fieldworkers plus a supervisor who scrutinizes GIS\textsuperscript{p}-based maps listing every dwelling. Maps are kept current through GPS\textsuperscript{q} identification of new dwellings. A verbal autopsy (VA), with a locally validated instrument recently re-validated for HIV/AIDS assessments, is conducted on each death to establish its probable cause.

\textsuperscript{p} GIS: geographic information system
\textsuperscript{q} GPS: global positioning system
Verbal autopsy methodology
Each recorded death is the subject of a verbal autopsy (VA) in which one of five specially trained and monitored fieldworkers interviews the closest caregiver of the deceased in their mother tongue. The interview schedule is a modification of that previously used in Niakhar, Senegal. It covers all ages, has been translated into Shangaan (the main local language), and includes only culturally acceptable terminology. An open section seeks information in the respondents’ own words on symptoms and signs that preceded the death. This is followed by several filtering questions addressing primary symptoms such as ‘cough’ or ‘shortness of breath’; a positive answer leads to a more detailed schedule of questions regarding that particular symptom. Due emphasis is placed on the sequence and duration of signs and symptoms, as in a medical history. Further sections address occupation, use of traditional or modern treatments, habits and lifestyle.

Clinician assessment, involving three medical practitioners, is the basis of review of the VAs. Two medical practitioners, blind to each other’s findings, review the verbal autopsy and (as far as possible) assign a 3-level diagnosis – covering the main or underlying cause, immediate cause, and contributing factors – to each death. Where the diagnoses correspond, the cause of death is accepted. Where they differ, the practitioners review the case. If consensus cannot be achieved, a third physician undertakes a further blind assessment. If this diagnosis corresponds with one of the initial two, it will be regarded as the probable cause of death; if not, the cause of death will be regarded as ‘undetermined’. Cause-of-death categorization follows the International Classification of Diseases (ICD-9 initially, ICD-10 since 1998). Regular review of completed questionnaires is undertaken, with personalised feedback to each fieldworker.

Limitations and sources of bias in HDSS data
Given that the census and vital events update occur on an annual basis, an undercount of stillbirths and early infant deaths is inevitable. This can happen when a death occurs soon after birth and then both are not reported by the household respondent. In response, since 2000, names of the most recent child born to each mother appear on the census form in order to facilitate more detailed enquiry, by the fieldworker, into subsequent pregnancies or births (ie in the interval between the recorded birth and the next interview). This has limited the effect of this bias. In addition, drawing on the mortality structure of older children as well as model life-tables, it is possible to further compensate for such a bias. While cultural factors play a role in respondents’ decision to withhold information on early infant deaths, obtaining more complete responses regarding pregnancy events is understandably more complex. Proper reconciling of in- and out-migrations that occur within the study area is difficult but important given the high rate of moves and their possible impact on study denominators. The issue has been addressed in recent years by a ‘migration reconciliation’ field team; as the team has become more skillful, it has proved possible to undertake the bulk of this work during routine census operations rather than as a separate field exercise. Further, computer-based matching routines are now able to reconcile up to 70% of in- and out-migrations within the study site.
METHODS

Data and field innovations
Over time, the data system has been enhanced in several ways. The shift from MS Access to MS SQL Server relational database management provided a more reliable system with improved quality and consistency of data. Other advances included a modern GIS facility to manage field maps and link them to HDSS data; wide-ranging improvements in data quality and integrity through ‘re-engineering’ of field operations and quality control measures;21 implementation of form-tracking and management systems using barcode technology; improvement in documentation and archiving of data including pilot work on an e-archive; better mechanisms for extraction and provision of data to collaborating researchers and students; and general improvement to overall IT infrastructure.

Key developments included the 1-in-10 sample dataset and documentation of available to anyone wanting to work on Agincourt data; and progress on the SPEHR data model, a relational database schema involving standard definitions and designed to meet the requirements of sites operating independently and in collaboration.24, 25

Ethical considerations
HDSS-based research in Agincourt depends on stable and mutually respectful long-term relationships with local village communities. Annual feedback and dialogue regarding study findings was introduced at the start of the HDSS in 1992/3 and is integral to the Agincourt research programme.1 Individual consent is obtained at household level according to established standards; broad-based community support is generated through discussion with community leaders, pre-census community meetings, and by facilitating links to NGO and government resources. The HDSS itself, and all distinct research projects and sub-studies, are independently reviewed through the University of the Witwatersrand’s Committee for Research on Human Subjects (Medical). In 1996, a generic protocol for prospective demographic and health surveillance, including the application of verbal autopsies, was reviewed and ‘approved unconditionally’ (protocol M960720). Provincial research committees, currently being revitalised, provide a further level of oversight and accountability. Data access is carefully controlled; security is achieved by a system of password restricted access to project computers and differential levels of access to the dataset. A carefully planned system of on- and off-site data back-ups and archiving is in place and regularly reviewed. Despite these measures, heightened awareness of ethical considerations will always be justified in settings supporting long-term, longitudinal research in well-defined communities.41

As efforts to enhance data sharing gain ground - and recognising that an HDSS site in effect provides a ‘small area’ dataset - it is critical that confidentiality undertakings be honoured. The nature of informed consent will require careful consideration; and ensuring effective anonymisation of all data, including spatial identifiers, will be a necessity.

1 This is an anonymised 10% sample of the Agincourt HDSS database that retains the relational, temporal and data integrity of the full database. It is available on request for training and exploratory research purposes

2 Structured Population Event History Register

4 A document ‘Guidelines and expectations regarding research collaborations in Agincourt’ is updated regularly and is available on request
Data sharing

The developments outlined can provide the foundation for implementing policy and procedures – coupled with the necessary technology and strengthening of data management capacity – to render Agincourt HDSS data more comparable with data from other HDSS sites, more readily accessible to research partners, and more available to graduate research students. In addition, it should facilitate more rapid publication of standard data outputs, and faster turn-around of requests for secondary datasets. Pilot work is focused on technologies to facilitate password-enabled web-based data access that will vary according to the status of a collaborator.

These developments align with broad-based international initiatives to improve the archiving of data and enhance data sharing.¹ Important riders include full and appropriate credit (which may involve co-authorship) for producing such data, along with due acknowledgement of source datasets.

¹ Such as a ’Code of conduct’ for data sharing, proposed by the Health Metrics Network among others
Results

Mortality levels and life expectancy have pervaded the sub-Saharan development debate over the past two decades – with substantial lowering of life expectancy occurring in the late 1980s in east African settings such as Uganda, Tanzania and Malawi.\textsuperscript{42} Further south, in Agincourt, mortality and fertility began to change rapidly from the mid-1990s and verbal autopsy investigation dates the first confirmed cases of AIDS to 1993 (paper II figure 3).

Mortality increased – with the age groups 0-1 and 15-59 leading the way for both sexes – so that by the mid-2000s both women and men had lost over ten years of life expectancy (from about 72 to 60 years in women; and 66 to 52 years in men).\textsuperscript{43} Fertility decreased sharply at roughly the same time (paper III) with the total fertility rate falling by slightly more than one child per woman: from about 3.7 to 2.6 (figure 3).

\textit{Figure 3. Trend in total fertility rate and crude vital rates, Agincourt 1993-2005}

\textit{Figure by Samuel Clark, 2007}

Mortality transition and its measurement

Although composite measures of population health extend measures of mortality alone – with advances such as the disability-adjusted life year (DALY) incorporating assessment of disease risk and physical/mental function\textsuperscript{44} – it is the case that, for much of sub-Saharan Africa, death events are not systematically recorded in any official register. This carries serious implications for determining trends in the health of populations, examining the effects of health and development initiatives (evaluated through the Millennium Development Goals for example\textsuperscript{v}), and assessing

\textsuperscript{v} addressing child survival (MDG 4) and maternal health (MDG 5)
the impact of efforts to strengthen national health systems. It bears also on the responsibilities and obligations of states and governments to their citizenry. In the Agincourt sub-district, as many as a half of all deaths do not occur in hospital with resulting gaps in formal death registration.

There are few datasets in Africa that can offer a probable cause for almost every death recorded, along with a record of each death by age and sex, for a well defined local population over an extended period (1992-2005 in Agincourt). Such a dataset is a powerful instrument for characterising the nature of mortality change, quantifying its scale, supporting a range of sub-studies, contributing insights to comparable settings elsewhere, and informing local and national health systems development.

**Determining cause of death: Re-validation of verbal autopsy instrument**

Given the number of deaths due to HIV/AIDS, and the possibility that our verbal autopsy (VA) instrument was not sufficiently discriminating in rendering such diagnoses, a re-validation of cause-of-death diagnoses from 2001 to 2005 was undertaken to assess performance of the VA instrument in diagnosing HIV/AIDS deaths. VA diagnoses were compared with hospital reference diagnoses for all causes of death in the three district hospitals which receive referrals from the Agincourt study site. Only adequately justified hospital diagnoses were accepted as ‘gold standard’. A total of 318 hospital death records were matched to an Agincourt death. Of these, 27 had no VA and 16 had no medical diagnosis, leaving 275 records for sensitivity and specificity calculations comparing the VA diagnosis to the ‘gold standard’ medical diagnosis.

Sensitivity and specificity for HIV/AIDS was 60% and 80% respectively, and for tuberculosis 37% and 88%. Of the 58 false negative HIV/AIDS deaths, 24 were classified as TB and 21 as unknown. Of the remaining 13 cases, 5 were attributed to conditions that frequently present in HIV/AIDS patients (diarrhoea, pneumonia, septicaemia). Thus misclassification with co-morbid conditions, particularly tuberculosis, reduced the sensitivity for both conditions. The number of unknown diagnoses raised the possibility of correcting for undiagnosed cases; this will be explored in the future. When combining HIV/AIDS and TB into a single category, sensitivity increased markedly to 78% and specificity remained at 80%; this reinforced the need for a combined HIV and tuberculosis category. These results corroborate those found in northern KwaZulu-Natal46 and Tanzania.47

**Detecting a reversal in mortality**

Paper II, published in 1999 and based on four years of mortality surveillance, provided early evidence for a worsening (or ‘reversal’) in the Agincourt population’s previously documented improvement in mortality and life expectancy. The effect was most evident in women 20-49 years old. This group experienced a 42% rise in mortality between the mid-1980s and early 1990s, a finding obtained by comparing retrospective and prospective mortality trends using indirect and direct demographic methods (figure 2, paper II). There was little change in the cause-of-death pattern over the period 1992/3 and 1994/5 with the notable exception of the infectious and parasitic disease category (specifically deaths related to HIV infection: AIDS, tuberculosis and chronic diarrhoea).
The dynamics of epidemiological transition

Paper V, published in 2008 some nine years after our initial description of mortality reversal, was based on an extension of that dataset: a robust longitudinal dataset that captured the ‘flow’ of mortality trends and deaths by cause over the 13 years from 1992/3 to 2005. The dataset thus spanned a period of intense social and political change in South Africa – following the country’s first democratic election in 1994 – as well as a period of major health and population transition. In essence the dataset is a straightforward one, obtained entirely from careful counting of deaths, applying the VA instrument to each of these, and deriving mortality rates from regularly updated denominator measures of person-years by age and sex. Yet grouping patterns by period, and comparing the earliest period 1992-1994 with the latest one 2002-2005, provided profound insights:

• A dramatic extension of the reversal reported in paper II, with a fall in life expectancy at birth of some 12 years in females and 14 years in males over the 13 year period 1992/3-2005

• A six-fold rise in deaths from infectious and parasitic causes (RR=5.98; CI 4.85-7.38; p<0.0001) which was driven by HIV and tuberculosis: the change in female risk of death (RR=15.06; CI 8.88-27.76; p<0.0001) was almost double the change in male risk (RR=8.13; CI 5.55-12.36; p<0.0001). This resulted in a near doubling of age-standardised mortality from 593 per 100,000 person years to 1,111 per 100,000 person years (RR=1.87; CI 1.73-2.03; p<0.0001) (table 1, paper V)

• An overall increase in deaths from non-communicable diseases (RR=1.15; CI 0.99-1.33; p=0.066) with a significant increase among adults 30 years and older (RR=1.22; CI 1.02-1.46; p=0.026). Deaths due to diabetes increased significantly although numbers were small (RR=2.57; CI 1.20-6.32; p=0.008); deaths due to vascular disease were up by 65% among those 65 years and older (RR=1.65; CI 0.99-2.76; p=0.056); and deaths due to malignant neoplasms more than doubled (RR=2.20; CI 1.04-4.66; p=0.040) (table 1, paper V)

• A ranking of cause-of-death by age and period provided a detailed picture of the ‘flow’ of mortality change with time, highlighting the complexity of the mortality transition underway (table 2, paper V). While non-communicable disease was most prominent among middle-aged and older adults (≥ 50 years) in the early 1990s, with vascular diseases ranked first, HIV and tuberculosis took first place by the mid-1990s among those 50-64 years old. Similarly, in children under-5 years, acute diarrhoea and malnutrition constituted nearly 40% of deaths in the early 1990s; however, by the late-1990s, HIV and tuberculosis accounted for nearly a quarter of all deaths, rising to over a third by 2002-05.

w RR: relative risk; CI: confidence interval
x stroke, ischaemic heart disease, and hypertensive diseases
y excluding female genital malignancies
RESULTS
Contrasting male and female cause-of-death patterns

Further analysis to establish variation in cause-of-death patterns by gender was undertaken. Table 2 provides a detailed record of the top 5 causes of death, by sex, for selected age-groups and time-periods. In addition to many common features, and the overriding dominance of deaths due to HIV/AIDS and tuberculosis, some important differences can be detailed:

- Among children under-5 and 5-14 years (not tabulated), sex differences were unremarkable with the exception of external causes: over the period 1992-1997, accidents and injuries ranked high in boys under-5 but not in girls; while suicide ranked among the top-5 causes of death in 5-14 year old boys for the period 1995-2001

- In the 15-29 year age-group:
  - suicide was prominent in men but was not a feature among women
  - external causes-of-death in men ranked far higher than among women with a relative risk of death of 3.65 (CI 2.46-5.54; p<0.0001)
  - in only the fourth period, from 2002, did HIV and tuberculosis outrank external causes of death among men; in women, this was the case from the second period 1995-1997

- In the age-group 30-49 years, where HIV and tuberculosis ranked first among causes-of-death in both sexes from 1995:
  - external causes were also prominent among men
  - among women, maternal causes and malignancies of the female genital tract (mainly cervical cancer) were prominent causes of death
  - vascular disease ranked third among women from 2002

- In the age-group 50-64 years:
  - vascular disease was prominent in both sexes and ranked highest in women over the period 1992-2001; it ranked first for both sexes in the period 1992-1994
  - chronic liver disease – largely cirrhosis associated with alcohol consumption – was more evident in men aged 30-64 years

- Among those 65 years and older (not shown):
  - HIV and tuberculosis was a prominent cause-of-death among men
  - vascular disease was prominent in both sexes over the full study period but ranked first in women from 1995 onwards.

On the evidence available, these findings represent the more advanced end of the rural sub-Saharan ‘transitions’ spectrum. There is good evidence regarding the rise of vascular disorders, including stroke and hypertension, elsewhere in East and West Africa – which suggests that health transitions are well underway in a number of settings; and that any perception that the burden of disease in sub-Saharan Africa is composed pre-dominantly of infectious and nutritional conditions is flawed.

\[z\] external causes include vehicle accidents, assault, suicide and accidental injury

\[aa\] made up of stroke, hypertension and ischaemic heart disease
Table 2. Five most common causes of adult death by age, gender and time period in Agincourt subdistrict, 1992-2005

<table>
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<tbody>
<tr>
<td>15-29 years</td>
<td>N=22</td>
<td>N=36</td>
<td>N=110</td>
<td>N=236</td>
</tr>
<tr>
<td>1 Vehicle accident</td>
<td>2 (9%)</td>
<td>HIV/TB</td>
<td>5 (14%)</td>
<td>HIV/TB</td>
</tr>
<tr>
<td>2 Assault</td>
<td>2 (9%)</td>
<td>Vehicle accident</td>
<td>2 (6%)</td>
<td>Other NCDs</td>
</tr>
<tr>
<td>3 Other NCDs</td>
<td>2 (9%)</td>
<td>Other NCDs</td>
<td>2 (6%)</td>
<td>Other infectious</td>
</tr>
<tr>
<td>4 Maternal</td>
<td>2 (9%)</td>
<td>Diarrhoea</td>
<td>2 (6%)</td>
<td>Malaria</td>
</tr>
<tr>
<td>5 HIV/TB</td>
<td>1 (5%)</td>
<td>Other infectious</td>
<td>2 (6%)</td>
<td>Vehicle accident</td>
</tr>
<tr>
<td>30-49 years</td>
<td>N=45</td>
<td>N=52</td>
<td>N=176</td>
<td>N=432</td>
</tr>
<tr>
<td>1 Neoplasms</td>
<td>5 (11%)</td>
<td>HIV/TB</td>
<td>15 (29%)</td>
<td>HIV/TB</td>
</tr>
<tr>
<td>2 Other cardiac disorders</td>
<td>5 (11%)</td>
<td>Neoplasms</td>
<td>7 (14%)</td>
<td>Female genital neoplasm</td>
</tr>
<tr>
<td>3 Maternal</td>
<td>5 (11%)</td>
<td>Female genital neoplasm</td>
<td>6 (12%)</td>
<td>Malaria</td>
</tr>
<tr>
<td>4 Vehicle accidents</td>
<td>4 (9%)</td>
<td>Maternal</td>
<td>3 (6%)</td>
<td>Neoplasms</td>
</tr>
<tr>
<td>5 HIV/TB</td>
<td>3 (7%)</td>
<td>Vehicle accidents</td>
<td>2 (4%)</td>
<td>Maternal</td>
</tr>
<tr>
<td>50-64 years</td>
<td>N=35</td>
<td>N=61</td>
<td>N=93</td>
<td>N=178</td>
</tr>
<tr>
<td>1 Vascular disease</td>
<td>7 (20%)</td>
<td>Vascular disease</td>
<td>5 (8%)</td>
<td>Vascular disease</td>
</tr>
<tr>
<td>2 Chronic liver disease</td>
<td>5 (14%)</td>
<td>HIV/TB</td>
<td>4 (7%)</td>
<td>Female genital neoplasm</td>
</tr>
<tr>
<td>3 Other cardiac conditions</td>
<td>5 (14%)</td>
<td>Neoplasms</td>
<td>4 (7%)</td>
<td>Malaria</td>
</tr>
<tr>
<td>4 Female genital neoplasm</td>
<td>3 (9%)</td>
<td>Other cardiac conditions</td>
<td>4 (7%)</td>
<td>HIV/TB</td>
</tr>
<tr>
<td>5 Accidental injuries</td>
<td>2 (6%)</td>
<td>Female genital neoplasm</td>
<td>3 (5%)</td>
<td>Other cardiac conditions</td>
</tr>
</tbody>
</table>

NCD=non-communicable diseases
1 Includes disorders not included in other categories, such as anaemia, dementia, chronic obstructive airways disease, asthma, peptic ulcer disease etc
2 All malignant neoplasms excluding those of female genital organs
3 All circulatory system diseases excluding hypertensive disease, ischaemic heart disease, cerebrovascular disease
4 Cerebrovascular disease, ischaemic heart disease, hypertensive disease
5 Excludes all infectious causes
### Table 2. Five most common causes of adult death by age, gender and time period in Agincourt subdistrict, 1992-2005

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<tr>
<td><strong>MALES</strong></td>
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</tr>
<tr>
<td>15-29 years</td>
<td>N=30</td>
<td>N=54</td>
<td>N=84</td>
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<tr>
<td>1 Assault</td>
<td>12 (40%)</td>
<td>Assault</td>
<td>HIV/TB</td>
<td>HIV/TB</td>
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<tr>
<td>2 Vehicle accident</td>
<td>4 (13%)</td>
<td>8 (15%)</td>
<td>Assault</td>
<td>Assault</td>
</tr>
<tr>
<td>3 HIV/TB</td>
<td>2 (7%)</td>
<td>HIV/TB</td>
<td>Vehicle accident</td>
<td>Vehicle accident</td>
</tr>
<tr>
<td>4 Other cardiac conditions</td>
<td>2 (7%)</td>
<td>Suicide</td>
<td>HIV/TB</td>
<td>HIV/TB</td>
</tr>
<tr>
<td>5 Acute respiratory infect</td>
<td>1 (3%)</td>
<td>Other NCDs</td>
<td>Acute respiratory infect</td>
<td>Acute respiratory infect</td>
</tr>
<tr>
<td>30-49 years</td>
<td>N=62</td>
<td>N=109</td>
<td>N=239</td>
<td>N=495</td>
</tr>
<tr>
<td>1 Assault</td>
<td>11 (18%)</td>
<td>HIV/TB</td>
<td>Vehicle accidents</td>
<td>Vehicle accidents</td>
</tr>
<tr>
<td>2 HIV/TB</td>
<td>7 (11%)</td>
<td>Assault</td>
<td>10 (9%)</td>
<td>21 (9%)</td>
</tr>
<tr>
<td>3 Suicide</td>
<td>5 (8%)</td>
<td>Vehicle accidents</td>
<td>Suicide</td>
<td>Vehicle accidents</td>
</tr>
<tr>
<td>4 Neoplasms</td>
<td>5 (7%)</td>
<td>Vascular disease</td>
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<td>4 (7%)</td>
<td>Vehicle accidents</td>
<td>5 (6%)</td>
<td>Vehicle accidents</td>
</tr>
<tr>
<td>50-64 years</td>
<td>N=70</td>
<td>N=93</td>
<td>N=124</td>
<td>N=275</td>
</tr>
<tr>
<td>1 Vascular disease</td>
<td>13 (19%)</td>
<td>HIV/TB</td>
<td>Vehicle accidents</td>
<td>Vehicle accidents</td>
</tr>
<tr>
<td>2 Neoplasms</td>
<td>6 (9%)</td>
<td>Assault</td>
<td>8 (9%)</td>
<td>11 (9%)</td>
</tr>
<tr>
<td>3 Other NCDs</td>
<td>6 (9%)</td>
<td>Other cardiac conditions</td>
<td>Other NCDs</td>
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</tr>
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<td>4 HIV/TB</td>
<td>4 (6%)</td>
<td>Other NCDs</td>
<td>Neoplasms</td>
<td>Vascular disease</td>
</tr>
<tr>
<td>5 Chronic liver disease</td>
<td>3 (4%)</td>
<td>Vehicle accidents</td>
<td>Chronic liver disease</td>
<td>Neoplasms</td>
</tr>
</tbody>
</table>

NCD = non-communicable diseases

1 All circulatory system diseases excluding hypertensive disease, ischaemic heart disease, cerebrovascular disease

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3 All malignant neoplasms

4 Cerebrovascular disease, ischaemic heart disease, hypertensive disease

5 Excludes all infectious causes
Maternal mortality: a deepening concern

Maternal mortality in Agincourt, computed directly by dividing maternal deaths by live births, was close to the average for South Africa in the early 1990s (about 160 per 100,000 live births). The maternal mortality ratio (MMR) has increased steadily since, reaching over 260 per 100,000 in the recent period\textsuperscript{a,b}.\textsuperscript{54} Unpublished estimates suggest that the MMR is today well above 300 per 100,000, with the rapid rise essentially due to the impact of HIV/AIDS. Indeed, Garenne et al concluded that 'Indirect causes of maternal deaths appear much more important than direct obstetric causes. The MMR appears no longer to be a reliable measure of the quality of obstetric care or a measure of safe motherhood'.\textsuperscript{55}

Agincourt data (and its counterpart Africa Centre site in Hlabisa district, KwaZulu-Natal) provide a rare independent estimate of maternal mortality levels and were used to validate 2001 census data that produced very high estimates for the country overall. This documented rise in maternal mortality calls for targeted action in the context of the Millennium Development Goals. It also raises the possibility of a revision to the current WHO definition of a maternal death so as to separate direct obstetric causes from HIV/AIDS, tuberculosis and related deaths occurring during the maternal risk period.

In Agincourt, reported barriers to care included weak integration of maternity and HIV/AIDS services, lack of emergency transport, high taxi fares, and dissatisfaction with the public sector leading to costly private and traditional care. Delays in seeking care occurred following use of non-medical healers and the need to involve multiple family members ('therapy referees') in decision-making.\textsuperscript{56}

Fertility transition and changing social relationships

Among the population and development community, fertility levels in sub-Saharan Africa are a constant subject of debate since they are markedly higher than elsewhere and also because recently documented declines appear to have stalled in certain settings.\textsuperscript{57, 58} This is coupled with concerns that the 'Cairo consensus' of 1994 – which took the position that fertility levels primarily reflect the education, social status, and empowerment of women – gave insufficient attention to the consequences of high birthrates for child survival, maternal mortality, and child, adolescent and women's development.\textsuperscript{59}

In rural South Africa, the picture is a contrasting one, accessible through a combination of (a) a detailed maternity history asked of every women of childbearing age living within (or entering) the Agincourt site, and thus providing retrospective assessment of fertility trends; and (b) prospective documentation of every live birth and, to the extent possible, other pregnancy outcomes (stillbirths, abortions) gained through the annual census update.

Fertility patterns in Agincourt showed a steady decline from a total fertility rate (TFR) of around 6.0 children per women in the late 1970s (retrospective data) to 2.3 children per women in 2004 (prospective data; figure 1, paper III). This amounted to an almost completed fertility transition over 25 years (highly unusual in rural sub-Saharan Africa). In fact, the reduction in fertility was

\textsuperscript{a,b} estimate has wide confidence intervals due to small numbers

28
RESULTS
such that the net reproduction rate (NRR) over the prospective period (1992-2004)\textsuperscript{ac} suggested that the Agincourt population was close to replacement fertility (and could even fall below it in years to come) (paper III). To our knowledge, Agincourt is the first rural area in sub-Saharan Africa where the phenomenon of approaching replacement fertility has been documented.

Despite the fall in overall fertility levels, adolescent fertility remained high well into the 1990s. This produced an unusual pattern involving high fertility among adolescents (with up to 40% of adolescent girls bearing a child by 19 years),\textsuperscript{19} followed by a prolonged period of lower fertility that was boosted when women reached their late 20s and early 30s and formed longer-term unions, usually through marriage (figure 4).\textsuperscript{60} Although explanations for this pattern are multifaceted, and include profound changes in gender relations and female autonomy that occurred over several decades,\textsuperscript{61} the inability of sexually active adolescents to access contraceptive services was a major problem. Contraception and family planning were readily available by the 1980s, a legacy of the early provision of these services by a government ‘worried about the implications of differential growth rates of the African and white population of the country’.\textsuperscript{58} Access, however, was controlled by conservative clinic nurses who would provide contraception to married women only, and to those women who had already given birth.

These findings prompted Garenne and Zwang to undertake a comprehensive analysis of premarital fertility in sub-Saharan Africa.\textsuperscript{62, 63}

\textbf{Figure 4.} Two components of fertility rates: premarital and marital fertility, Agincourt subdistrict, South Africa, 1992-97 (Reprinted from source reference 60)

\textsuperscript{ac} Technically, the net reproduction rate (NRR) is the mean number of female births making up the next reproductive generation and produced by women of the preceding generation; hence the NRR includes a fertility component (children born during the reproductive period), a mortality component (survival of women from birth to reproductive age), and a sex ratio at birth.
While the effect of HIV/AIDS on fertility appeared relatively small over the full period of fertility decline, Garenne et al note that, in recent years’… a situation of 25% HIV-positive pregnant women experiencing a 35% negative effect of HIV on the total fertility rate could result in a 9% fertility decline – about a fifth of the total decline observed during the prospective period.\(^{60}\)

Migration and mortality

Associations between migration of the individual and transmission of infection – most recently the human immunodeficiency virus – have been well documented.\(^{64}\) Recent Agincourt findings challenged stereotypes by showing that the likelihood of male migrant labourers having two or more concurrent partners was highest among locally employed men, while this likelihood was lowest among labour migrants who returned home on a monthly basis.\(^{65}\)

In South and Southern Africa, levels of labour migration remain extremely high and involve some 60% of male migrants over the course of their working life; increasingly this pattern extends to female labour migrants.\(^{66}\) Despite the demise of apartheid and the web of legislation supporting it, family and social ties between migrants and their rural homes and communities remain strong.\(^{67}\)

We hypothesised that urban-based labour migrants, on falling seriously ill at their places of work, would return to their rural homes for care and support, and possibly to die. We investigated this using discrete time event history analysis to examine the likelihood of dying among recently returned migrants (stratified by age and sex), compared with the likelihood of dying among the longer-term returning migrants. Analyses were carried out for an earlier (1992-1997) and a later (1998-2004) period. Paper IV presents these findings. Controlling for period, we found that recently returned migrants have odds of dying that are between 1.1 and 1.9 times greater than residents and long-term returning migrants. Further, that the odds are greater in the more recent period (1998-2004) compared with 1992-1997 (figure 1, paper IV). The greatest difference in the likelihood of dying was for women 20-59 years and occurred in the later period 1998-2004 when comparing short-term returning migrants and residents.\(^{68}\) Examining cause-of-death data, a significant increase in the proportion of deaths due to HIV/AIDS and tuberculosis was evident among recent returnees; this too was more marked in the later period.
A synthesis of findings on ‘transition’ in Agincourt

The accumulated evidence suggests that rural South Africa is in the midst of multiple, interrelated transitions that have led to marked changes in population structure over the past decade (figure 5).

Figure 5. Population pyramid, Agincourt subdistrict, 1994 and 2005

- Rapid narrowing in the base of the population pyramid is consequent on fertility decline augmented by rising child mortality. Declining fertility and net out-migration has reduced population growth substantially, with fertility now approaching replacement level. In spite of this, the number of households has grown significantly as average household size decreased. A dual burden of kwashiorkor and acute diarrhoeal illness in children under five, and emerging non-communicable disease, particularly stroke, in adults 50 and above, typified the cause-of-death profile in the mid-1990s. By the end of the decade these conditions persisted but in the face of dramatically escalating HIV/AIDS and pulmonary tuberculosis. A dismaying decrease in life expectancy of 12-14 years over the past decade is markedly influencing expectations and aspirations.
• Evidence for a non-communicable and, particularly, cardiovascular disease transition – with older women seemingly at more immediate risk – remains compelling.\textsuperscript{37, 43} Lifestyle, dietary and occupational change among adults is fostering an epidemic of high blood pressure, obesity in middle-aged women and stroke.\textsuperscript{73} Stroke prevalence is about double that elsewhere in sub-Saharan Africa\textsuperscript{74, 75} with asymptomatic peripheral atherosclerosis detectable in the general population.\textsuperscript{76} The capacity of primary care systems to support secondary prevention is weak.\textsuperscript{77} Management of non-communicable disease and associated risk factors is thus of major concern,\textsuperscript{78} particularly in a setting where chronic infectious disease is dominating service development.

• Albeit off a low base relative to the continent,\textsuperscript{79} under-5 mortality doubled since 1993.\textsuperscript{43} While worsening child survival is due largely to HIV/AIDS, deaths due to diarrhoea and malnutrition independent of HIV reflect ongoing poverty and deprivation.\textsuperscript{27, 43} Further, inequities in mortality distribution probably reflect differential experience of social adversity and who were health service access.\textsuperscript{80, 81} Stunting is persistently high: 45\% of children under-five selected as normal controls.\textsuperscript{82} Poor nutrition is associated with death or non co-residence of the mother (persisting when maternal female relatives substitute as caregivers), and lack of financial support from the father.\textsuperscript{83} Conversely, male labour migration is positively associated with children’s education due to remittance of income.\textsuperscript{84}

• Results highlight the health impact of changes in the social environment, where growing numbers of rural women are joining the migrant labour force\textsuperscript{85} coupled with a well-established fall in fertility rate.\textsuperscript{60} Despite high adolescent fertility, many women delay bearing a second child until their late 20s, suggesting changes from more traditional marriage patterns.\textsuperscript{60, 86} The likelihood of multiple sexual partners appears lowest among male migrants who return regularly;\textsuperscript{65} mortality is highest, however, among recently returned migrants of both sexes, imposing high demands on health services and communities.\textsuperscript{68} Households with a female pensioner miss meals less frequently and are more likely to ensure that girls attend school.\textsuperscript{87, 88} More broadly, older women are playing key roles in child care and schooling while having to meet health care and funeral costs\textsuperscript{89} – a critical response to the impact of HIV/AIDS on the parental generation. Pressures on the ‘near-old’ – women under 60 not yet eligible for a pension – can be considerable.\textsuperscript{90} Food security among poorer households remains precarious, with harvesting of natural resources an important buffer against ‘shocks’ such as the death of a breadwinner.\textsuperscript{91, 92} While clearly taking strain, family support systems remain vitally important to individual and community wellbeing.\textsuperscript{71, 83}

These findings graphically convey the extent and nature of ‘transition’ underway in rural South Africa and, to varying degrees, elsewhere in the region. They highlight strengths of the Agincourt HDSS at a time when the imperative for a knowledge base could not be greater.
Applications of data and findings to policy

Papers V and VI address the policy and programme applications of data and findings produced by field sites based upon health and socio-demographic surveillance. Such information may have relevance well beyond health care systems – to welfare and social systems, educational systems, and management of the environment for example – although health system examples are used here.

Paper V was based on the mortality data that contributes much of the substance of this thesis. On the basis of a fine-grained account of the evolution of mortality patterns over the period 1992/3-2005, supplemented by available information on morbidity, risk factors and their management by local services, the implications for primary health care systems were considered. The overall care burden on the health system increased significantly; notably, however, the burden of disorders requiring chronic care grew disproportionately (RR=2.63; CI 2.30-3.01; p<0.0001) relative to the burden needing acute care (RR=1.31; CI 1.12-1.55; p<0.0003 (paper V, table 1 and the accompanying figure). Core findings were that:

- a systematic, localised understanding of mortality and cause-of-death data, at a time of rapid health transition, can provide the empirical, outcomes-oriented information necessary to inform health systems reform
- in rural South Africa, and to varying degrees regionally, there is now the evidence to justify managing – in integrated fashion – chronic infectious disease (such as HIV/AIDS and tuberculosis) and chronic non-communicable disorders (including stroke, hypertension, diabetes and various cancers)
- widespread HAART\textsuperscript{ad} initiatives, aiming to make anti-retroviral therapies generally available, are the obvious vehicle with which to strengthen the capacity of African health systems; in our view, failure to do so will result in a deteriorating alignment between public services and personal and community health needs.

These findings carry the implication that research and development efforts, and the attention of senior policymakers, will need to be concerted applied if the necessary health systems development is to result. A marked scale-up in service-research partnerships will be critical to these efforts.

Paper VI poses a broader question: why is it that the contributions of HDSS field sites to national health policy and practice have been limited – especially given widespread moves to decentralise health and other services? Indeed, this thesis argues that the scope and potential for greater contributions is considerable (while recognising that these sites played major roles in the testing of interventions ranging from vaccines, to oral rehydration therapy and vitamin A, to bednets, to skilled birth attendants).\textsuperscript{94} Concerted efforts are underway in selected settings to render HDSS sites more integral to national health policy and planning – the Tanzania Essential Health Interventions

\textsuperscript{ad} HAART: Highly active anti-retroviral therapy
Project (TEHIP)\textsuperscript{95} and the Adult Morbidity and Mortality Project (AMMP)\textsuperscript{96} in Tanzania, and the Community Health and Family Planning intervention in Ghana, being recent examples.\textsuperscript{97} But the absence of wider involvement is apparent and may be attributed to:

- limited appreciation of the importance of quality, descriptive information – often regarded in HDSS sites as simply numerator/denominator data or intermediate rather than final output – for health sector and development planning.\textsuperscript{98} As stated (paper VI):

  ‘Simple, descriptive information on population distribution and health characteristics, demographic composition and change, socio-economic characteristics, and the distribution and challenges facing potentially vulnerable groups such as single-parent households or the elderly, is vital for the effective targeting of district programmes and assessing access to health services... The intelligent use of local information is vital for the effective functioning of district health systems. The collection and interpretation of information in a more sustained, reliable and regular manner may be especially helpful.’

- the complex issue of site leadership which may be split between southern and northern scientists and their institutions – with the balance of power and resources at times favouring northern partners over their southern counterparts.

However, and crucially, the limited demand for such data/information from the leadership and senior management of middle- and low-income health ministries must be acknowledged; this too is a pre-requisite to the enhanced applications of HDSS data to national policy, programming and practice (see table 1, paper VI).
Discussion

This thesis seeks to demonstrate that health and socio-demographic surveillance systems:

- are exceptionally well-suited to capturing the dynamics of health and social change or ‘transition’
- are versatile research and development platforms able to support a diversity of observational and intervention research designs
- have high but often unexploited potential to support policy and programme development and evaluation.

To inform this discussion, scientists at the recent INDEPTH Annual General and Scientific Meeting held in September 2008 in Dar-es-Salaam were asked to complete a self-answering questionnaire. The questionnaire addressed issues of data utilization, study design options, and the representivity and generalisability of findings from HDSS sites (see figure 6). The response rate was high with 24 out of 30 (80%) site leaders – 16 from Africa and 8 from Asia – returning a completed questionnaire; and 9 of 11 key informants doing so. A thematic analysis of responses was undertaken and findings will be referred to in the course of this discussion.

<table>
<thead>
<tr>
<th>INDEPTH site leaders / key informants</th>
<th>Sept 2008</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Q1 One often hears the opinion that “…data from HDSS sites are ‘under-utilised’.”</strong></td>
<td></td>
</tr>
<tr>
<td>a) Do you agree with this statement? .................................................................</td>
<td></td>
</tr>
<tr>
<td>b) If yes, can you suggest measures to improve this? ........................................</td>
<td></td>
</tr>
<tr>
<td><strong>Q2 An exceptional feature of an HDSS is its potential to support a range of study designs. From a policy or program perspective, please:</strong></td>
<td></td>
</tr>
<tr>
<td>a) Highlight any design that you and/or colleagues have used that you regard as an innovative use of HDSS .................................................................</td>
<td></td>
</tr>
<tr>
<td>b) Comment on designs that you may not have used but which could be productive .................................................................</td>
<td></td>
</tr>
<tr>
<td><strong>Q3 Quite often one hears the criticism that “HDSS sites are not representative – which reduces the generalisability of findings”.”</strong></td>
<td></td>
</tr>
<tr>
<td>In brief, what arguments would you use to counter such a charge? ..........................</td>
<td></td>
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</tbody>
</table>

*Figure 6. Questions asked of INDEPTH site leaders and key informants, Dar-es-Salaam 2008*
Mortality and fertility trends in Agincourt, 1992-2005

By any metric, the nature of change in Agincourt, and the pace at which it occurred, would have confounded predictions based on the data, theory and analysis available from an earlier period. By implication, certain of the assumptions informing modelling and forecasting exercises were flawed.

Scholars studying health transition consistently emphasise the need for empirically-derived data from contrasting local contexts in order to examine the trajectory of variables and the interactions between them. By strengthening this evidence base, the scope for contributions to national policy and programme development will be immeasurably strengthened (paper V); similarly, the degree of confidence in the assumptions informing modelling efforts will be higher.

Table 3 situates Agincourt mortality indices in a national and regional context, using the year 2000 to maximise the data available from contrasting sources. The HDSS data captures much of the rural spectrum that falls to a profound low in the Africa Centre – Hlabisa district of KwaZulu-Natal. The passage of time has seen a corresponding – though not quite as extreme – worsening of mortality in Agincourt. The provincial figures do not deviate too dramatically from those derived from the surveillance areas, with the exception of the maternal mortality ratio which, for Agincourt, is twice that indicated for Mpumalanga. Similarly, there is some discrepancy in levels derived from the Dikgale HDSS and those reported for Limpopo Province (infant and under-5 mortality for example). Relative provincial levels accord with the ranking suggested by the HDSS data. Mortality figures from Limpopo – a rural, landlocked province that provides a base for the Dikgale HDSS – are the least bad; those for KwaZulu-Natal, epicentre of the South African AIDS epidemic, are clearly deeply disturbing.
Table 3. Comparison of selected mortality indices: Agincourt HDSS with other HDSS, national and provincial figures (sexes combined)

<table>
<thead>
<tr>
<th>Indicators</th>
<th>South African HDSS sites</th>
<th>Provinces</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Agincourt1</td>
<td>Dikgale2</td>
</tr>
<tr>
<td>Life expectancy at birth</td>
<td>63.0</td>
<td>64.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Crude death rate (per 1,000)</td>
<td>7.7</td>
<td>7.5</td>
</tr>
<tr>
<td>Infant mortality rate (per 1,000 live births)</td>
<td>36.9</td>
<td>16.1</td>
</tr>
<tr>
<td>Under-5 mortality rate (per 1,000 live births)</td>
<td>61.1</td>
<td>32.2</td>
</tr>
<tr>
<td>Adult mortality 45q15*</td>
<td>33.4</td>
<td>26.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal mortality ratio (per 100,000 live births)</td>
<td>243</td>
<td>-</td>
</tr>
</tbody>
</table>

* 45q15: probability of dying between age 15 and 60 years

Sources of data:
The tragedy implicit in these numbers can be gauged by comparison with Swedish experience. In the early 1990s, life expectancy in Agincourt was approaching 70 years among women – a level comparable to that of men in Sweden in the mid-twentieth century. The ensuing loss of 12 to 14 years of life expectancy over twelve years – a loss of one year for every calendar year between 1993 and 2005 – reduced life expectancy in Agincourt to the levels prevailing in Sweden some 50 years earlier at the beginning of the twentieth century.101

The importance of the South African response to this reality cannot be exaggerated. The country is clearly in the midst of a national emergency. It is crucial that the scale of the roll-out of highly active anti-retroviral therapy, now underway, reach levels of coverage that can produce a significant population impact. Recent findings from an HDSS site in Malawi show that mortality impact is indeed possible, and in the relatively short term.102

‘Transitions’ theory in light of Agincourt findings

Dramatic and far-reaching socioeconomic change – underway in South Africa and regionally – is reflected in marked demographic and epidemiological change that does not conform to the linear progression expected from established ‘transition’ theory.29, 30, 103 Equally, the nature and pace of such change does not follow a path typical of that experienced by high-income countries.100 In Agincourt and elsewhere this is exemplified by:

• the growing burden of illness imposed on families, communities and health and social systems by non-communicable disease104, 105 in the face of persisting excessive burdens of infection due particularly to HIV/AIDS (papers II, IV and V)

• the extreme reversal in mortality affecting young children and the economically productive age-groups that is paralleled by rapid declines in fertility and growing independence of women (papers II, III, IV, V)

• the complex pressures on rural households that result in various coping strategies – notably female as well as male labour migration (paper IV) – and demanding care-giving roles being taken on by older persons, women especially.

These outcomes – backed by robust, longitudinal data – confound predictions derived from mainstream transitions theory. Moreover, they pose difficult challenges to public policy and effective social and developmental responses. Health systems, for example, face the challenge of widespread chronic illness among vulnerable communities at a time when the dominant delivery paradigm is one of acute care. There are few good examples of how to adjust this model, still less an understanding of how to introduce extensive change into delivery systems, primary health care in particular (paper V).

While interaction between rapid health, population and social transitions is clearly evident in African settings, the dynamics of how this occurs, in what sequence and with what consequences for individuals, households, health/social systems and society is little understood and hard to predict – yet the data to support such investigation are limited. Key features of health and socio-demographic surveillance that are uniquely suited to tracking the dynamics of change, and their multi-level effects on persons and communities, include their prospective basis and longer-term time-horizon, comprehensive coverage of defined populations, and sensitivity to local context.
These qualities contribute to growing understanding that transition-related effects on individual health can occur at multiple points over the life-course (papers II, III, IV, V) – and that these effects are cumulative with insults in early life carrying serious consequences for later health and productivity.  

In 1994, Murray and Chen drew attention to the multiple and non-uniform nature of health transitions underway in diverse settings. Similarly, Kahn, Kahn, and Frenk and colleagues highlighted the importance of empirical research in order to understand actual transition experience – well illustrated by reference to the Russian mortality transition of recent decades. The 37 sites comprising the INDEPTH Network, some 25 of which are located in sub-Saharan Africa, constitute a unique resource for mapping the contours of transition in a range of geographic and social contexts. Such depth of information would be invaluable for strengthening our understanding of health, population and social transitions in low- and middle-income settings, and guiding revisions or modification to existing transitions theory.

Of special import is the potential for such evidence to inform national policy responses which currently are lacking. This is vital if social institutions – health, welfare, education, labour, natural resources etc, representing the organised efforts of society – are to respond meaningfully to the demands imposed by transition. Similarly, the impact of societal responses – on programme coverage and access, or health and social outcomes – must be evaluated and cannot be assumed. This adds to the justification for public health and other social institutions to build the capacity to absorb, sift and apply data/findings.

**Study design: cumulative experience**

Paper I and the Methods section describe essential features of the Agincourt health and socio-demographic surveillance system (HDSS). The core elements – regular updating of household membership and comprehensive recording of vital events, coupled to a relational database schema – are common to all such systems and constitute the basic requirements for membership of the INDEPTH Network. Findings from effective surveillance – as detailed in Results – can be highly influential in generating hypotheses and questions for future research (table 4 and paper I). Commonly, the surveillance infrastructure established for a particular purpose – a phase 3 vaccine or therapeutic trial for example – can be easily applied to other purposes that may range from behaviourally-based trials to phase 4 effectiveness designs to the evaluation of complex interventions or externally introduced policies.

The scientific justification for such adjustment draws on the versatility of study designs – i.e. the multiple possibilities – offered by an HDSS infrastructure: standard or unusual sampling practices, long-term follow-up of cases/controls, descriptive studies (including trend analyses and input to modelling exercises), the range of analytic study types, and a breadth of intervention-based designs. There is also scope for creatively applying quantitative and more qualitative social research methods (paper I).

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ae www.indepth-network.org
<table>
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<tr>
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<tbody>
<tr>
<td>High under 5 mortality due to malnutrition</td>
<td>Determinants of kwashiorkor &amp; Anthropometric survey 0-20 years</td>
<td>MAPITS: Managing adolescent pregnancy (includes infant nutrition intervention)</td>
</tr>
<tr>
<td>Chronically adverse environment with stress of high adult mortality</td>
<td>Baseline mental health study in school children 10-12 years</td>
<td>Kulani child resilience project (includes school-based intervention to promote coping)</td>
</tr>
<tr>
<td>Increasing mortality and risk due to NCDs, especially stroke</td>
<td>Southern Africa Stroke Prevention Initiative (SASPI)</td>
<td>Secondary prevention of cardiovascular disease</td>
</tr>
<tr>
<td>Increasing NCDs indicate need for chronic care services</td>
<td>SASPI</td>
<td>Epidemiology and treatment of epilepsy</td>
</tr>
<tr>
<td>Ageing population with high ‘parental’ responsibility</td>
<td>Physical &amp; cognitive function in adults 50+</td>
<td>Self reported health and function in older adults</td>
</tr>
<tr>
<td>High levels younger adult mortality</td>
<td>PIME: prevalence, incidence, molecular epidemiology of HIV &amp; sexual behaviour survey</td>
<td>Trials site development</td>
</tr>
<tr>
<td>Inequitable access to health and social services</td>
<td>Southern Africa Costs and Coping Study (SACOCO)</td>
<td>REACH: Researching equity in access to health care</td>
</tr>
<tr>
<td>Food insecurity in households with adult death</td>
<td>Use of natural resources to offset adversity</td>
<td>Natural resources and household vulnerability / resilience</td>
</tr>
<tr>
<td>Changing household structure given young adult mortality</td>
<td>Roles of older women</td>
<td>Social role of elders</td>
</tr>
<tr>
<td>High levels temporary migration; increasing in younger women</td>
<td>Impact of female migration on child mortality</td>
<td>Migration, health &amp; well-being</td>
</tr>
</tbody>
</table>

**KEY: Applications of HDSS**
- Study design/sampling frame  
- Special HDSS module  
- Multisite or comparative research  
- Follow-up participants/outcomes  
- Historical information & household characteristics
Pragmatically, there is good sense in distributing the start-up investment in effort, cost and human resources over time and multiple scientific initiatives. While design options for single sites are clearly legion, there are limits to the scale of work feasible, and limits may be reached through forms of randomised design (e.g. cluster-randomisation) where a larger population or range of settings (high numbers of clinics or schools) is required to test an intervention. Nevertheless, skilful application of HDSS capability can support ambitious provincial or national efforts to scale-up interventions – in part because HDSS generally operate at the decentralised district or sub-district level that is basic to most health care systems. The many African and Asian sites that make up the INDEPTH Network provide an exceptional opportunity for multi-site research and systems development.

Agincourt experience to-date can illustrate these points:

- Table 4 shows the important relationship between surveillance-based descriptive findings and subsequent evolution of a research and intervention portfolio
- Table 5 provides a case-study of the range of study designs planned or proposed to support the Agincourt site’s forthcoming programme of intervention-research and policy and programme evaluation.

**Optimising use of data**

There was an unqualified consensus among INDEPTH key informants and site leaders that ‘…data from HDSS sites are under-utilised’. All key informants expressed this view, along with 20 out of 24 site leaders. Of the remaining 4 site leaders, 2 were equivocal and 2 answered ‘no’.

As detailed in table 6, optimising data utilization is desirable but not straightforward and will take time and require resources – as well as a commitment to ‘levelling the playing field’ between northern and southern institutions. There was no substantive divergence in views between key informants and site leaders (nor any meaningful contrast between Asian and African site leaders). Ideas on how to improve the use of longitudinal data from HDSS sites fell into several categories including: increasing numbers of on-site staff; training in analytic capacity (from statistics to data systems); technical aspects of data management (including harmonisation of variables across sites and better documentation of datasets (metadata)); and more effective efforts to increase publication rates and foster the application of findings to policy (see table 6).

The relative importance of such measures will vary by site. However higher productivity for many sites will depend on a marked strengthening of capacity and not simply incremental improvement.

These are important issues for HDSS sites and for the INDEPTH Network, with a groundswell of interest that is concerned to make a difference over the shorter-term – reflected in several multi-site initiatives supported by major funders. These include: building the capacity of local universities and strengthening ties between universities and field sites; enhancing site-based
DISCUSSION

doctoral and post-doctoral training opportunities; and expanding cross-site research, analysis and publication efforts. Major efforts to improve the cross-site compatibility of routine data collection, document datasets, strengthen data management and archiving, and render data more easily accessible (including secondary analysis by the wider scientific community) are all underway – reflected in INDEPTH efforts to regularly publish cross-site ‘minimum datasets’, and the proposed INDEPTH Data System (IDS).

Table 5. Study designs to support intervention-research and policy/programme evaluation: Forthcoming work in the Agincourt HDSS site, 2008-2013

<table>
<thead>
<tr>
<th>Study design</th>
<th>Agincourt project</th>
<th>Target group</th>
<th>Key outcome measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Randomised trial</td>
<td>MAPITS*</td>
<td>Young mother &amp; infant pair</td>
<td>• HIV status • birthweight; growth; feeding practices; child care practices • cognitive development; child stimulation</td>
</tr>
<tr>
<td>Cluster-randomized trial</td>
<td>Kulani child health and resilience</td>
<td>Primary school children aged 10-12 years</td>
<td>• emotional &amp; behavioural difficulties • symptoms of depression, anxiety, chronic trauma • school achievement</td>
</tr>
<tr>
<td>Randomised trial with linking of HDSS data to health facility records</td>
<td>Household-based voluntary counseling and testing</td>
<td>Males and females 15-64 years</td>
<td>• differences in take-up rates of HAART ¶ • CD4 at HAART enrolment • AIDS-related mortality</td>
</tr>
<tr>
<td>Phase IIb/III vaccine trial</td>
<td>HIV vaccine trial: Phase IIb/III</td>
<td>Males and females 18-40 years</td>
<td>• HIV infection • viral load • IFN-γ ELISpot assay • HIV plasma viral RNA &amp; CD4 count</td>
</tr>
</tbody>
</table>

¶ Refers to the highest CD4 count achieved during HAART.
<table>
<thead>
<tr>
<th>Study design</th>
<th>Agincourt project</th>
<th>Target group</th>
<th>Key outcome measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population-based surveillance of impact of new national policy</td>
<td>Evaluating introduction of pneumococcal conjugate and rotavirus vaccines into South African EPI programme (2009)</td>
<td>• Children under 5 years</td>
<td>• morbidity and mortality due to severe acute respiratory illness or diarrhoea • viral strains</td>
</tr>
<tr>
<td>MRC Phase II evaluation of complex intervention</td>
<td>2° prevention of vascular disease &amp; cardiac failure: • acceptability and effect of interventions, sustainability, unexpected effects</td>
<td>• Patients, allopathic health care workers, traditional &amp; faith healers, community</td>
<td>Multiple, including: • clinic attendance • appropriate treatment • medication compliance • patient records • knowledge and attitudes</td>
</tr>
<tr>
<td>Prevalence study Incident case-control Health systems R&amp;D</td>
<td>Burden of epilepsy and its treatment</td>
<td>• Whole population • Cases of epilepsy</td>
<td>• excess mortality • treatment gap</td>
</tr>
<tr>
<td>Before-and-after comparative study with controls</td>
<td>Evaluation of public &amp; private HAART delivery • control clinics provide standard of care</td>
<td>• HIV + people eligible for treatment • Health facilities</td>
<td>• treatment coverage • adherence • VCT # uptake • mortality</td>
</tr>
<tr>
<td>Prospective study of household dynamics in response to intervention</td>
<td>Impact of HAART on household livelihoods • comparison of households with eligible people on treatment, eligible not on treatment, HIV negative</td>
<td>• HIV + people eligible for treatment and their households</td>
<td>• mortality • household structure • role of elders • migration • employment • household assets, income</td>
</tr>
</tbody>
</table>

* MAPITS: Managing adolescent pregnancy in transitional settings; ¶ HAART: Highly active antiretroviral therapy; § PIME: HIV prevalence, incidence, molecular epidemiology; # VCT: voluntary counseling and testing
**Table 6. Approaches to increasing utilisation of HDSS data, INDEPTH key informants and site leaders, 2008**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Key Informants (n=9)</th>
<th>Site Leaders (n=24)</th>
</tr>
</thead>
</table>
| Increase number of staff and range of skills within HDSS sites | Strategies:  
- dedicated core funding  
- links to universities  
Staff needed:  
- data managers, scholars, students, fellows, collaborators, statisticians, information scientists | Strategies:  
- funding for analytic staff  
- strategic collaborations with other institutions eg universities, northern partners  
- posts for PhDs and postdocs  
- links to universities  
Skills needed:  
- preparation of analytic datasets  
- data analysis  
Challenges:  
- attract and retain skilled staff  
- make HDSS careers attractive through part-time university appointments for HDSS staff; masters/PhD training. |
| Training to enhance capacity of HDSS staff | Areas in which training needed:  
- data management; data analysis; biostatistics  
Training needed on-site. PhD-level important. | Strengthen scientific and analytic capacity within sites.  
Cross-site analysis workshops.  
Training on how to transform findings to policy. |
| Strategic approaches to increasing utilisation | Plan analysis before data collection. Collect only what can be analysed. Develop routine analytic approach for mortality, fertility etc. | “Analysis networks” generate new ideas.  
Cross-site activities eg monograph production  
Promote data sharing:  
- address fears regarding data sharing  
- develop transparent collaborations  
- create a healthy mechanism for greater sharing of data with external constituencies  
- create equity between data producers and users.  
Data should be made available subject to certain conditions eg protected time in which site scientists have sole access; co-authorship; acknowledgement.  
Graduate student research projects / theses. |
| Technical approaches to increasing utilisation | Make metadata available.  
Increase public access with adequate documentation.  
Increase compatibility of data between sites so allowing pooled analyses. | Strengthen data quality, processing, archiving and extraction process in sites.  
Use of open-source web-based database servers.  
New users of data should contribute expertise.  
Data extraction should be paid for.  
High quality data dictionary. |
Positioning surveillance systems: decentralisation and the district level

Delegates to the INDEPTH 10th anniversary AGM believe, with justification, that the Network ‘at 10’ carries much scientific promise. Arguably, however, far more can be made of sites’ strategic location at the district or sub-district level. Indeed, preoccupation with global initiatives may deflect attention from the reality that local health action is required for local development, and for this sub-national data is key. Sites’ position – at the pivotal implementation level in the organisation of health and social systems – provides unusual opportunity to engage government and civil society with site output: data, research findings, and the outcome of intervention and policy evaluations (paper VI). Responsibility for effective partnership lies with both site and public leadership – at a time, however, when the need for evidence is overwhelming, both parties tend to fall short. The point is notable given the resurgence of interest in primary health care and the development of integrated health systems.108–110 Given weak public health systems, ongoing efforts to strengthen health care delivery and new concerns about how best to manage the expanding burden of chronic illness, the opportunity to trial innovation in district health systems could not be greater (paper V).
Creativity in study design

Thus there is a constructive convergence in the operating scale of surveillance systems, and the primary element in decentralised health care, namely the district (or sub-district) administrative area. This explains the appeal of surveillance systems to the Tanzanian and Ghanaian national health services which invest directly in these research and development platforms. In Tanzania, with six HDSS sites spanning rural, urban, coastal and inland settings, districts across the country are making full use of burden of disease data to prioritise new funding and track progress in attaining the MDGs. Indeed, provided the national trend in improved child mortality between 2000 and 2004 is maintained, Tanzania could well attain the Millennium Development Goal for child survival (MDG 4). A key issue, therefore, is how to better exploit the methodological strengths of health and socio-demographic surveillance in support of intervention-research and health systems development.

A central challenge is to complement the randomised controlled trial (RCT) – gold-standard for efficacy trials of therapeutics or specific medical technologies – with alternate study designs that carry high validity and can provide sound evidence for public health interventions and policy. This is particularly important for health systems R&D and other community-focused behavioural or social interventions where (a) it may not be feasible to randomise individuals or communities to pre-specified treatments; (b) ‘treatments’ (ie interventions) may involve multiple interacting components – so-called ‘complex interventions’ that cannot be deconstructed into independently testable elements; and (c) their effects may depend on fostering social interaction (eg reciprocal behaviour between individuals and peer groups), making it difficult to attribute an outcome to a single, tightly specified exposure.

The application of RCT methodology is by and large to efficacy (or phase 3) trials ie evaluations that, by design, minimise bias and the impact of real world effects. This may not be possible or even desirable when considering public health interventions. As discussed in paper VI, an earlier generation of pilot projects was vexing to health planners as these attracted excess resources that were applied in rarified circumstances somewhat detached from the public sector. Their impact on health systems development was thus well below that anticipated. For scientists focused on population health, an overriding concern is to understand the impact of a policy or programme when applied to real world settings – hence the growing attention to so-called effectiveness (or phase 4) trials. As Victora et al put it ‘for evaluating large-scale interventions, studies with plausibility designs are often the only feasible option and may provide valid evidence of impact’.

Community-oriented variants of RCTs – that capture some of the statistical benefits of randomisation – are increasingly used. These include cluster-randomised trials, with randomisation of areas, communities or institutions (clinics, schools, workplaces etc); or step-wedge designs – which allow for the full introduction of an intervention to a large area or many neighbourhoods, but in phases according to a pre-selected, potentially random sequence so as to maximise the statistical power of inter-cluster comparisons. The need to give due attention to considerations of design and analysis in such studies should be appreciated; a review of cluster-randomised trials in sub-Saharan Africa reported that only 10 of 51 trials took clustering into account in sample size or power calculations; while less than 40% accounted for clustering in the analysis.
Even where randomisation of communities is theoretically preferred, this may be ethically or practically unfeasible, opening up possibilities for creative, quasi-experimental designs – as was used to evaluate the population impact and personal effects of a programme addressing cardiovascular disease in northern Sweden (Västerbotten);\textsuperscript{120} or the ‘non-randomised intervention cohort design’ used in rural KwaZulu-Natal to evaluate the differential impact of exclusive breastfeeding and other modes of infant feeding on mother-to-child transmission of HIV-1 infection in the first 6 months of life.\textsuperscript{121} Victora et al argue cogently that public health and policy relevant research, given their complex causal pathways that may involve supply (service delivery) and demand side (access, adherence, acceptability) factors, can seldom be adequately addressed through RCTs alone.\textsuperscript{115}

Certainly HDSS sites have limitations. The limited area they cover restricts the number of clusters available and matching or control clusters may need to be obtained outside of the HDSS area. Such design considerations are critical when evaluating interventions ‘at scale’. This is increasingly called for\textsuperscript{122, 123} but will depend on a research programme that is based on strong and workable relationships with government – where the Mexican example is noteworthy.\textsuperscript{124}

A key message in this discussion is simply to emphasise the basics: the importance of sound study design to suit the question being posed, while paying attention to feasibility considerations and the overall purposes to which findings will be put. HDSS sites have exceptional design, analytic and contextual strengths, and there is every reason to take good advantage of these. Their locus at district level is a real asset at a time when world attention is re-focusing on general health systems strengthening and more integrated programme development, particularly at the primary health care level. The evidence gap regarding which interventions work, how they should be introduced, and their effects in transitional settings such as rural South Africa underscores this point (paper V).

The demand for complex interventions\textsuperscript{af} will undoubtedly grow – thus the emphasis in this discussion on the evaluative strengths of HDSS field sites. To illustrate: Heikens et al assert that ‘Populations in which undernutrition and HIV are rampant…must integrate nutritional support and HIV care…’\textsuperscript{125} Coates et al, addressing the critical need for multi-level behavioural interventions highlight ‘…the limitations… from randomised trials testing the efficacy of interventions in individuals and small groups… no attempts have been made to show how (such strategies) might produce region-wide or country-wide reductions in HIV incidence or prevalence’.\textsuperscript{40} Similarly, in relation to strengthening health systems to provide integrated chronic infectious and non-communicable disease care (paper V), we argue for ‘… a serious research and development agenda that addresses which aspects of service integration are likely to be effective, how best to introduce them, and ensuring that assessment is based on rigorous study designs’. The Commission on Social Determinants of Health, with its deep concern for equitable development, highlights issues ranging from early childhood development to the support of older persons to integrated prevention-promotion programmes – all of which will require formative testing and rigorous evaluation.\textsuperscript{126}

\textsuperscript{af Complex interventions can be described as “… built up from a number of components, which may act both independently and inter-dependently. The components usually include behaviours, parameters of behaviours (eg frequency, timing), and methods of organising and delivering those behaviours (eg types of practitioner, setting and location). It is not easy precisely to define the “active ingredients” of a complex intervention. …”\textsuperscript{114}
Innovation in study design: an INDEPTH perspective

The question ‘From a policy or programme perspective, highlight any design that you and/or colleagues have used that you regard as an innovative use of HDSS’ was most fruitful, eliciting an extensive set of responses (detailed in table 7). Since there was little divergence in the perspectives of key informants and site leaders, responses have been combined and are discussed together.

Consistent with the discussion above, cluster-randomised trials and other forms of quasi-experimental evaluation of complex interventions were highlighted. Similarly, the ‘observatory’-type capacity of sites to monitor and evaluate new or unusual treatments, vaccination schedules or development policies; or capture the effects of war, civil strife, famine or flooding were recognised. Engagement with various levels of government and community was emphasised – including the use of data to strengthen their understanding and decision-making.

A number of respondents drew attention to the strengths of incident case-control studies which can be easily nested in prospective studies; this makes possible the selection of several controls per case, allowing for measures of absolute risk. Also noted was the value of long-term surveillance for constructing cohorts retrospectively: birth cohorts for example, or to examine outcomes in relation to newly recognised exposures (arsenic, severe maternal malnutrition). Opportunities for unusual sampling were cited, for example formerly married couples now living apart; and the growing opportunity for spatial analyses that combine data from linked surveillance and geographic information systems (and potentially climate monitoring technology). The opportunity to simultaneously apply multiple methods and forms of data collection – social and behavioural research, quantitative methods and clinical investigation (including biomarkers) – was emphasised.

The many possibilities created by linking population-based data to administrative records – clinic and hospital records in particular – were noted and will enable studies of service access and utilisation. Such work can highlight the characteristics of those retained / lost to follow-up / excluded – and thus are especially useful in assessing the equity dimensions of service provision and access.

Possibilities for multi-site intervention-evaluations (with some sites experimental, others control) were noted; also the potential to adapt and introduce externally devised surveys (often cross-sectional) and apply them across multiple sites. The seldom recognised opportunity to include HDSS data in modelling exercises was mentioned – and can contribute to evaluating interventions effects.

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ag Persson and Wall state that ‘a prospective cohort study avoids, by its very nature, two of the most important sources of error in case-referent studies, namely, those related to the selection of cases and referents, and the specification of the conditions of exposure.’ 135
Representivity and generalisability

Questions on the representativeness and/or generalisability of findings from health and socio-demographic surveillance sites are commonly posed, whether by members of the scientific, lay, government or funding community. These questions bear on this discussion in relation to (a) findings from the Agincourt sub-district, presented as a robust characterisation of the dynamics of transition in much of rural South and southern Africa; (b) the case being made regarding the value of diverse study designs, including intervention and policy evaluations, that can be supported by surveillance systems; and (c) assertions regarding the comparative advantage that arises from HDSS sites’ decentralised position.

While the terms certainly overlap, they have distinct meanings and should not be conflated. ‘Representivity’ refers to the extent to which the context of a site – its geographic features and the cultural, religious and social characteristics of local communities – approximate those of other areas nearby or farther afield. ‘Generalisability’ relates to the extent to which conclusions arising from scientific experimentation – the association between an exposure (or event or intervention) and an outcome or effect, together with an explanation of factors mediating or modifying the relationship – can plausibly be applied more widely.

The following discussion draws freely on comments made by INDEPTH respondents to the question: “Quite often one hears the criticism that ‘HDSS sites are not representative – which reduces the generalisability of findings’. In brief, what arguments would you use to counter such a charge?”.

The ‘observatory’ function of HDSS sites – monitoring the levels and trends of vital events and related variables over time, and potentially in response to externally introduced policies and programmes – raises questions regarding the applicability of findings elsewhere (representivity). In general, this can be addressed by forms of triangulation – with national data such as censuses\(^{127}\) or the demographic and health surveys,\(^{128}\) by comparison with other regional or national surveys,\(^{ah}\) through contrasting with other HDSS sites, and by special surveys to assess differences with non-HDSS areas. Irrespective, several INDEPTH respondents asserted that concerns about site representivity are exaggerated; they argued that the exceptional features of HDSS sites set them apart from national cross-sectional studies – including their fine-grained description of local settings, the quality of data generated, and the ability to investigate cause and effect. A paper by Tatem et al\(^{129}\) is persuasive regarding the extent of sub-Saharan environmental coverage contributed by the collective of INDEPTH sites. Drawing on three variables – middle infrared radiation, land surface temperature and normalised difference vegetation index – they conclude that the African INDEPTH sites ‘… provide comprehensive coverage of much of the range of climates and environments found across sub-Saharan Africa, particularly the southern Sahel and central tropical regions’ and that similar analyses could assist with ‘… the appropriate synthesis and meta-analyses of epidemiological information from wide geographical areas…’\(^{129}\)

Ten countries host at least two HDSS sites and seven (six in Africa\(^{ai}\)) host three or more sites providing good opportunity to contrast findings. In Tanzania, the disposition of multiple HDSS

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\(^{ah}\) in South Africa, the labour force or household / income surveys mounted by Statistics South Africa

\(^{ai}\) African countries hosting three or more INDEPTH sites include: Burkina Faso, Ghana, Kenya, Senegal, South Africa, Tanzania; in Asia, Bangladesh hosts several HDSS sites
Table 7. Innovation in study design, INDEPTH key informants and site leaders, 2008

<table>
<thead>
<tr>
<th>Theme</th>
<th>Comments – Key Informants (n=9)</th>
<th>Comments – Site Leaders (n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study designs</td>
<td>• Case-control studies: nested</td>
<td>• Nested case-control studies</td>
</tr>
<tr>
<td></td>
<td>• Cohorts: retrospective long-term*; multiple; birth-to-death</td>
<td>• Cohorts: prospective °; historical «</td>
</tr>
<tr>
<td></td>
<td>• RCTs: complex; cluster</td>
<td>• RCTs: cluster ~</td>
</tr>
<tr>
<td></td>
<td>• Effectiveness study θ</td>
<td>• Effectiveness study: impact of prioritized health interventions</td>
</tr>
<tr>
<td></td>
<td>• Disease surveillance +</td>
<td>• Integration of HDSS with GIS (geographic information system)</td>
</tr>
<tr>
<td></td>
<td>• Spatially-based analyses – infer community rates of disease by analyzing geographic patterns of health facility attendance</td>
<td>• Plausibility design with multiple sites ¶</td>
</tr>
<tr>
<td></td>
<td>• Panel survey of households using modular architecture; event history calendar for retrospective data</td>
<td>• Screening for morbidity using household membership roster ¥</td>
</tr>
<tr>
<td></td>
<td>• Nesting external survey (eg SAGE, STEPS) into HDSS to achieve longitudinal perspective</td>
<td>• Mixed research methods: qualitative, social science</td>
</tr>
<tr>
<td></td>
<td>• Sampling of unconventional populations §</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Mixed methods easily facilitated #</td>
<td></td>
</tr>
<tr>
<td>Monitoring &amp; Evaluation: health services, policies, programmes, “natural experiments”</td>
<td>• Coverage</td>
<td>• Evaluation of national or local programmes within HDSS site with independent dissemination of findings</td>
</tr>
<tr>
<td></td>
<td>• Equity-effective coverage of key interventions</td>
<td>• Health system observatory: generate policies based on findings †</td>
</tr>
<tr>
<td></td>
<td>• District observatory function: monitoring of large-scale impacts of change</td>
<td>• Monitoring impact of “natural experiments” ^</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Monitoring impact of new health programmes =</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Monitoring health spending « »</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Policy evaluation</td>
</tr>
<tr>
<td>Modeling</td>
<td>• Using HDSS data as input to modeling</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Combining HDSS with census and DHS data in models</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Modeling using HDSS data for evaluating interventions</td>
<td></td>
</tr>
<tr>
<td>Adding depth to HDSS database</td>
<td>• Linkage of HDSS with additional individual-level variables, including behavioural, social, economic, biological markers, risk factors</td>
<td>• Linkage of health outcomes to social/developmental characteristics such as agricultural production, safe water sources, roads</td>
</tr>
</tbody>
</table>
### DISCUSSION

**Theme Comments**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Comments – Key Informants (n=9)</th>
<th>Comments – Site Leaders (n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linking HDSS with other databases</td>
<td>• Linking HDSS and health facility data (clinic, hospital) in a single computerized system Interface with other databases eg insurance database</td>
<td>• Linking HDSS to health facility data through a real-time computerized data management system</td>
</tr>
<tr>
<td>Validation of national datasets</td>
<td>• Validation of DHS and census against HDSS</td>
<td>• Comparing HDSS with DHS (Demographic and Health Surveys)</td>
</tr>
<tr>
<td>Application of HDSS findings to policy and practice</td>
<td>• Convening multi-sectoral policy-makers, from national and local government, on implications of results • Raising awareness among range of stakeholders • Health service applications of GIS, HDSS data</td>
<td></td>
</tr>
</tbody>
</table>

#### Notes to Table 7.

**Examples of innovative uses of HDSS data (INDEPTH survey 2008)**

- Genetic birth cohort, to study influence of genetic makeup on future health of children
- Measure impact of “best practice bundle” including universal vaccination, early treatment of malaria, anti-retroviral rollout
- HIV seroprevalence
- Butajira birth cohort, Ethiopia
- Formerly married couples now living apart
- Concurrent use of social, quantitative and clinical research methods, including repeat medical and laboratory tests
- Reconstruction of water drinking histories to measure impact of arsenic exposure on pregnancy and child survival. Impact of in-utero exposure to famine and adult health outcomes eg diabetes
- RCT of circumcision; cluster RCT of information-education-communication programme
- In country with multiple sites, used two sites for implementation and one as control
- Screening questions added to regular household update can establish samples for new studies eg chronic cough (active case-finding for tuberculosis); one sided weakness (prevalence of stroke)
- Generating policies for resource allocation based on burden of disease
- War; lack of vaccines; post-election violence
- New vaccination strategy; mother’s self-treatment of malaria; health worker motivation to improve maternal and child health; IMCI (integrated management of childhood illness)
- Use of voucher scheme; use of health providers
sites permits a high quality sentinel surveillance system to operate, making vital contributions to the work of various ministries including Health and Social Welfare and the Treasury. However, where sites support active intervention-research agendas, it is likely that this will affect HDSS communities with some reduction in representativeness over time.

Generalising from HDSS sites relates essentially to research carried out and the applicability of the findings – which may be widely relevant where work has a biological basis (focused on disease risk or genetic) or is based on strong research designs supporting intervention-evaluation. Generalisability may be less widely applicable when findings relate mainly to behaviour or attitudes or highly specific social/cultural environments. However, judging the generalisability of findings cannot be seen as simply a mechanical process; as Rothman succinctly puts it: ‘… we hope to generalise from research findings, a process based more on scientific knowledge, insight, and even conjecture about nature than on the statistical representativeness of the actual study participants’.

**HDSS stakeholders: host communities**

From the start of the Agincourt HDSS in 1992/3, and in preparatory discussions with community leadership, Agincourt scientists made a firm commitment to discuss research proposed and to regularly feedback findings to local communities. This ongoing dialogue forms part of the study team’s ‘contract’ with the Agincourt communities, one that is regarded as inviolable. It parallels efforts to ensure that, as far as possible, data entry occurs on-site and is visible to villagers whose steady participation renders the Agincourt HDSS a viable and productive long-term endeavour.

The process of feedback has matured over time and is now coordinated by the LINC office which tutors field staff regarding their feedback presentations. Apart from meetings with organised groups – health committees, community development forums, the community advisory group

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\[ a^j \] LINC: Learning, Information Dissemination and Networking with Community
etc – presentations are given to each village community in the site. Attendance can range as high as a few hundred people, and these feedback and dialogue sessions tend to spark animated discussion. For several years, ‘fact sheets’ oriented to the village and sub-district level have been used as a basis for research-oriented discussions with community leaders. Part of the rationale is to foster a greater critical awareness of research among participating communities. A recent innovation seeks to make links between expressed community needs and NGO and public sector resources.

Certain groups make good use of HDSS data and approach the surveillance team for up-to-date information to guide development initiatives (water reticulation or pre-school construction for example). Nevertheless, great scope exists to rigorously evaluate the LINC feedback process and experiment with ways to enhance its impact. This concern – to better understand how to enhance host communities’ use of the very data that characterises their situation – should resonate across the INDEPTH Network. Beyond this, the HDSS team would willingly respond to community-generated requests to collect new data. However such a request has yet to be made.
Conclusion

The essence of this thesis relates to the strengths of health and socio-demographic surveillance: its capacities as a research instrument, uniquely equipped to monitor the dynamics of health, population and social transitions in settings that lack effective vital registration; and its versatility as a research platform able to support a range of observational and intervention-type study designs. These qualities should render surveillance systems as much valued contributors to local and national health and social development. Yet, in many settings, such potential has still to be fulfilled. In part this relates to limited public sector capacity to absorb, sift, interpret and respond to findings – and highlights the effort justified to overcome this constraint.

Much of this argument is based on work in the Agincourt HDSS – a field site covering a poor, rural South African sub-district – marginalised under apartheid – and adjacent to the country’s border with Mozambique. While many acknowledge the health and development challenges that exist, few are aware of the depth of momentum that characterises changing life in these settings. Grasp of this ‘transition’ is critical to appreciating the complexity of change underway, its impacts on personal and community health, and the potential for development efforts to make a difference.

The INDEPTH Network, a southern-led scientific association of some 37 field sites in 19 African, Asian and Latin American countries, recently celebrated the 10th anniversary of its founding in Dar-es-Salaam in 1998. Its executive director, Osman Sankoh, expressed the Network’s vision as: ‘INDEPTH shall be top-of-mind when funders and policy-makers are looking for empirical information to inform health policy in developing countries’. Thus the potential of INDEPTH: to harness an exceptional array of sites, scientists, international collaborations and committed funders to the challenges of local and global development. INDEPTH’s depth of capacity can extend the reach and impact of any single HDSS site and can contribute much to enhancing their local and national contributions.

As this thesis goes to press, interest of the world community in primary health care is being rekindled. The 30th anniversary of the Declaration of Alma-Ata is focusing a powerful searchlight on the fundamental role of national health systems, and re-igniting support for the inclusive value system underpinning PHC. Given the decentralised, community-oriented features of HDSS sites, and their capacity for rigorous monitoring and evaluation, such global interest warrants a vigorous response from the INDEPTH Network. The report of the Commission on Social Determinants of Health adds unreserved support for such efforts.

In 2009 South Africa will elect its fourth government of the democratic era, following a decade of centralising rule by the Mbeki administration. The African National Congress, certainly the party that will again take on the mantle of executive leadership, is experiencing complex and vocal challenges to its long-standing tradition of values-based governance – and at the time of writing, the possibility of a breakaway group forming a new political party is a real one. Within the ANC, a movement for renewal and a fresh beginning is emerging and fostering a much-needed fluidity of ideas.
CONCLUSION

This is reflected in new thinking about the shape of the health care system, responsibilities of the public service and metrics to assess achievement. The struggle to ensure that evidence and rational debate inform policy action is long and hard. But critical to this struggle — the ‘necessary though not sufficient’ — is robust data that capture the direction of change over time. The denialist stance on HIV/AIDS of former president Thabo Mbeki and his cabinet was profoundly detrimental to health development in South Africa. Less recognised was the hostility and mistrust of data and research that accompanied it. Progress in health in South Africa will require a new openness and receptiveness to evidence if, as a country, we are to confront the reality of our situation.

A spirit of collegiality, common cause and shared problems across institutions, including academia, is hesitantly emerging. Notwithstanding some scepticism and uncertainty, this spirit may offer the best chance in a decade for re-invigorating a failing national health system — and thus the best opportunity to strengthen the applications of research to health and social policy and practice — a unique contribution open to advocates of health and socio-demographic surveillance.
Acknowledgements

It is a true pleasure to acknowledge many exceptional people who, in various ways, have helped bring me to this point:

First, the Agincourt research team: a committed, values-driven and highly talented group that ranks among the very best. Its leaders, Mark Collinson and Kathleen Kahn, and those with whom they work, are taking strides, making waves and ‘closing the gap’ ... may it always be so. Also, Michel Garenne, a colleague, friend and mentor for over 15 years – and a person whose ability to make numbers ‘sing’ always dazzles me...

Those who have supported and worked closely with me for many years – Zubeida Bagus, Violet Chela, Lazarus Mona, Doreen Nkuna, Dereshni Ramnarain, Mildred Shabangu and Obed Mokoena: beyond your professionalism, often far more than that extra mile, you’re a great group and continue to bring credit to us all.

Samuel Clark, much valued colleague, whose ability with data and data systems is paralleled by his keen insight and skill with language. Sincere thanks for helping me articulate the essence of health and socio-demographic surveillance in this thesis and elsewhere.

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In one way or another I’ve been connected with the Wits School of Public Health since 1990/91. Over the past several years, the School has been the institutional base for the Health and Population Division, the MRC/Wits-Agincourt Unit and the University Population Programme. The School has enjoyed outstanding leadership from John Gear, William Pick and Sharon Fonn: Your efforts, constant support and friendship have provided the professional environment necessary for Agincourt to flourish – and ensured that, in public health, Wits is the place to be.

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* Key informants: P Byass, S Clark, R Lozano, D de Savigny, D Ross, R Sauerborn, P Smith, T Smith, B Zaba
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