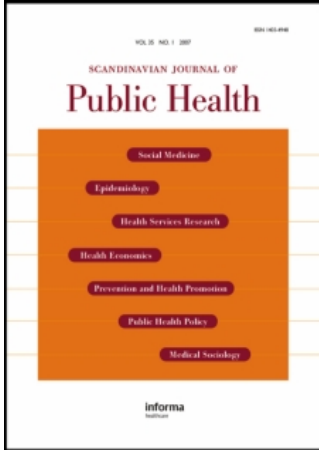


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### Research into health, population and social transitions in rural South Africa: Data and methods of the Agincourt Health and Demographic Surveillance System

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STUDY DESIGN ARTICLE

## Research into health, population and social transitions in rural South Africa: Data and methods of the Agincourt Health and Demographic Surveillance System<sup>1</sup>

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### Abstract

**Rationale for study:** Vital registration is generally lacking in infrastructurally weak areas where health and development problems are most pressing. Health and demographic surveillance is a response to the lack of a valid information base that can provide high-quality longitudinal data on population dynamics, health, and social change to inform policy and practice. **Design and measurement procedures:** Continuous demographic monitoring of an entire geographically defined population involves a multi-round, prospective community study, with annual recording of all vital events (births, deaths, migrations). Status observations and special modules add value to particular research areas. A verbal autopsy is conducted on every death to determine its probable cause. A geographic surveillance system supports spatial analyses, and strengthens field management. **Population and sample size considerations:** Health and demographic surveillance covers the Agincourt sub-district population, sited in rural north-eastern South Africa, of some 70,000 people (nearly a third are Mozambican immigrants) in 21 villages and 11,700 households. Data enumerated are consistent or more detailed when compared with national sources; strategies to improve incomplete data, such as counts of perinatal deaths, have been introduced with positive effect. **Basic characteristics:** A major health and demographic transition was documented over a 12-year period with marked changes in population structure, escalating mortality, declining fertility, and high levels of temporary migration increasing particularly amongst women. A dual burden of infectious and non-communicable disease exists against a background of dramatically progressing HIV/AIDS. **Potential and research questions:** Health and demographic surveillance sites – fundamental to the INDEPTH Network – generate research questions and hypotheses from empirical data, highlight health, social and population priorities, provide cost-effective support for diverse study designs, and track population change and the impact of interventions over time.

**Key Words:** Agincourt, demographic surveillance system, DSS, geographic information system, rural, South Africa, verbal autopsy, vital registration



### Introduction

Information is often most scant in the poorest settings where it is needed most. This serves to keep these communities invisible, and makes it more difficult to allocate resources and target policy and programmes that will produce positive health outcomes. National and even provincial data are presented as averages that mask the particular vulnerability of the poorest and thwart efforts to

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address equity gaps. This was particularly evident in apartheid South Africa where the so-called “independent” states of Transkei, Bophutatswana, Venda and Ciskei were systematically excluded from national data systems so skewing these datasets towards urban and better-off communities and rendering them redundant in identifying and addressing the pressing problems of the rural poor.

The Agincourt research site is located in a remote, rural, former “homeland” of South Africa. Its origins have been described elsewhere [1–3] and are rooted in the politics and related health-sector challenges of the early 1990s. With the anticipated demise of apartheid and associated dismantling of the homeland system, a marked reorientation of “homeland” health services got under way. The Agincourt site was initially established to introduce and evaluate innovative decentralized and primary care-oriented health programmes. In so doing, lessons learned in the demonstration site should be replicable across the adjacent provinces, with the potential to inform evolving national and district health policy and planning. Hence the research site was demarcated so as to cover an administrative sub-district, and work was undertaken largely within the resource constraints of the rural public health sector and in partnership with local health services [1,4]. A related purpose was to provide valid and reliable population-based data, absent at the time, in order to define clinic catchment populations, set service priorities, plan and evaluate health programmes, and allocate resources [1]. To this end, the Agincourt health and demographic surveillance system was introduced in 1992, and has evolved since then into a robust research infrastructure supporting advanced community-based research with studies ranging from the biomedical to the ethnographic [5,6].

In this paper, we describe the Agincourt health and demographic surveillance system with regard to its core methodological approaches, limitations and efforts made to address these, and ethical concerns. In the final section, we assess its added-value and potential.

## Material and methods

### Study setting

The Agincourt study site constitutes a sub-district of Bushbuckridge district, Mpumalanga Province, and is situated in the rural north-east of South Africa, close to the eastern border with Mozambique (Figure 1). Almost a third of the study population is of Mozambican origin, many having entered the country as refugees in the early to mid-1980s during

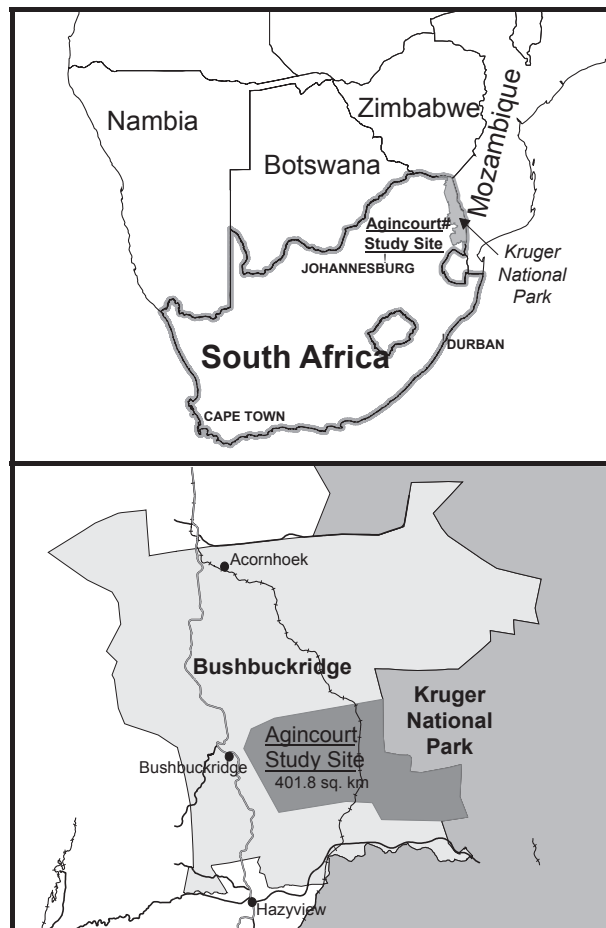


Figure 1. Maps indicating regional location of the Agincourt Health and Demographic Surveillance Site.

and after the civil war, and probably constituting the largest population of self-settled refugees under health and demographic surveillance in the world.

The study site covers 402 km<sup>2</sup> and contains 21 villages with both traditional and civic leadership: the position of *induna* or chief is inherited, whereas the 17 Community Development Forums (CDFs), aligned with (new) local government, consist of elected representatives. The area is densely populated (174 persons per km<sup>2</sup>) with some 11,700 households and a population of nearly 70,000 people, largely Tsonga-speaking. Infrastructure remains limited despite recent development initiatives including electrification and the commissioning of the sizable Inyaka dam: there is no formal sanitation system, piped water to communal standpipes is erratic, electricity is affordable to only a minority, and roads are largely gravel with minibus-taxis the predominant form of transport. All villages have a primary school and there are several high schools in the study area. Rainfall is unreliable, there is a considerable west–east gradient, and plots of land are generally too small to support

subsistence farming. High unemployment contributes to temporary labour migration of men and women (Table I).

One health centre and five satellite clinics are located within the site, with three district hospitals between 25 and 60 km away. Most people access healthcare from public and private allopathic health professionals, and traditional and faith healers. Estimates of HIV seroprevalence, based on anonymous testing of pregnant women at antenatal clinics in the two provinces adjacent to the study site, indicate an increase for the area from about 1.7% in 1992 to 25% in 2003 (average for Mpumalanga and Limpopo Provinces) [7]. Important causes of death other than HIV/AIDS are acute diarrhoea, malnutrition, and accidents in children, and non-communicable diseases (cardiovascular disease in particular), accidents, and violence in adults [8,9].

#### *Study design and measurement procedures*

Research in Agincourt covers three closely linked spheres of work: *measuring and monitoring, investigating, and responding* to health, population, and social transitions; all are based on the analytic, methodological, and evaluative strengths of the health and demographic surveillance system (HDSS) as well as its high community acceptance. The Agincourt

HDSS is unusual in scope since it captures the striking evolution of variables influencing population change over a critical period in South African sociopolitical development: the last years of apartheid and early years of a democratic era heralding the introduction of far-reaching social and legal reforms, coupled with emergence of the HIV/AIDS pandemic.

#### *Health and Demographic Surveillance System (HDSS)*

*Overall study design and population.* A key characteristic of an HDSS is the continuous demographic monitoring of an entire geographically defined population. In the case of Agincourt, this involves a multi-round, prospective community study, with systematic recording of all birth, death, and migration events, covering the whole population of the Agincourt sub-district.

*Mapping the study area.* In 1992, accurate and detailed village maps were hand-drawn by project staff. Each existing dwelling was represented and allocated its own identification number, allowing return visits to each household. Maps were updated regularly to incorporate new dwellings and other infrastructural changes.

In 1997 village maps were digitized and geo-referenced through an innovative technique that

Table I. Population characteristics, Agincourt 1992–1993 and 2003–2004.

	1992–1993	2003–2004
Mean population size		
de facto population <sup>a</sup>	49,262	52,956
de jure population <sup>b</sup>	64,385	69,753
Number of households	9835	11,737
Mean household size <sup>c</sup>	6.5	5.9
Ratio male:female	0.91	0.93
% under 5 years	16.1	11.2
% under 15 years	44.7	36.4
% over 65 years	3.8	4.7
Crude birth rate	32.0/1,000 person years	22.9/1,000 person years
Crude death rate	5.4/1,000 person years	11.1/1,000 person years
Infant mortality rate (IMR)	21.6/1,000 live births	49.8/1,000 live births
Under-five mortality rate	39.6/1,000 person years	88.1/1,000 person years
Total fertility rate	4.1 children per woman	2.7 children per woman
% male temporary migrants <sup>d</sup> (largely labour migrants)	20.7	31.3
% female temporary migrants <sup>d</sup> (largely labour migrants)	5.1	17.3
% birth registration <sup>e</sup>	5.3	57.4
% death registration <sup>e</sup>	39.7	78.1

<sup>a</sup>De facto population: all those permanently resident, i.e. resident for six or more months each year. <sup>b</sup>De jure population: the permanent population plus temporary migrants. Temporary migrants are resident for less than six months of the year but remain closely linked to their rural household. <sup>c</sup>Based on de jure population. <sup>d</sup>Number of temporary migrants divided by the de jure population. <sup>e</sup>Percentage of births/deaths officially registered through the South African vital registration system.

made it possible to conduct queries at household level [10]. In 2003, a full geographic information system (GIS) with geo-referencing of all households was introduced. Maps are updated and edited annually to take account of spatial changes. The coordinate data, aerial photographs, and HDSS household identifiers were developed into a GIS database that has strengthened spatial analyses and fieldwork management. Current uses include: navigation (to locate sampled households); fieldwork management (more efficient workload allocation through measuring distance, assessing mobility, and determining household size); and spatial analyses (to map clustering of events such as migration or deaths, patterns of natural resource use, distribution of risk factors or health outcomes, and uptake of interventions).

*Baseline census and update rounds* (Table II). The baseline census was conducted in 1992 during which each household was visited and information on every resident recorded. The primary tool of health and demographic surveillance in Agincourt is a rigorous annual update of household membership along with individual status variables (relation to household head, nationality, marital-, residence-, and education status), followed by enquiry into vital events (pregnancy outcome, death, in- and out-migration) and full maternity histories in newly immigrant women aged 15–54 years. Enquiry into

key variables relevant to each vital event is undertaken. Since the baseline census, 11 census updates have been conducted, the last eight at strictly annual intervals (1999 to 2006) with this pattern intended to continue.

There are four data-collection teams, each composed of five fieldworkers and a supervisor. Carrying a “populated census form” and vital event forms, members of each team visit allocated households within pre-assigned villages and interview the most senior responsible adult. Up to two revisits are carried out, following which a neighbour may serve as proxy informant for basic information; more detailed information on vital events would be obtained the following year unless the family had permanently out-migrated.

*Additional data: Special modules and status observations* (Table II). Additional data are collected in the form of special census modules or “status observations” nested within each update. These provide limited information relevant to particular lines of investigation. “Status observations” involve an additional two or three questions on individuals or households. Examples include education status update (conducted every five years) and questions that screen for conditions of public health importance such as chronic cough (the basis for active pulmonary tuberculosis case-finding [1999]), and one-sided weakness (the basis for a stroke

Table II. Health and socioeconomic data collection: Agincourt health and demographic surveillance system, 1992–2006.

Round	Census update (longitudinal)	Status observations	Target group	Special modules	Target group
Baseline	1992	Education	All		
2	1993				
3	1995				
4	1997	Education	All		
5	1999	Chronic cough	≥10 yrs		
6	2000			Labour participation	≥10yrs
7	2001	One-sided weakness	≥15 yrs	Asset survey <sup>a</sup>	All hhs
8	2002	Education	All	Temporary migration	All temp migs
				Child social grants <sup>b</sup>	All hhs
9	2003			Asset survey	All hhs
				Healthcare utilization	All
10	2004			Labour participation	≥10 yrs
				Food security	All hhs
11	2005	Vital documents <sup>c</sup>	All	Asset survey	All hhs
				Child social grants	All hhs
				Union status	≥12 yrs
12	2006	Pregnancy status	Females	Education (extended)	All
			12–50 yrs	Healthcare utilization + morbidity	<5 yrs
				Adult physical and cognitive function	≥50 yrs

<sup>a</sup>Asset survey repeated regularly every second year. <sup>b</sup>Child social grants include the child support grant, the foster care grant, and the care dependency grant. Information on the old age pension can be obtained from the labour participation module. <sup>c</sup>Birth certificate or South African identity document.

prevalence study [2001]). Special census modules, introduced from 2000, provide explanatory variables on topics pertinent to understanding and monitoring transitions and thus may be repeated to assess changes over time. Examples include a labour participation module (2000, 2004), a temporary migration module (2002), child social grant uptake (2002, 2005), healthcare utilization (2003, 2006), food security (2004), union status (2005) and older adult physical and cognitive function (2006). A measure of household socioeconomic status is gained through an asset survey conducted in each household every two years (2001, 2003, and 2005).

#### *Verbal autopsy*

A full verbal autopsy (VA) is conducted on every death recorded during the annual census update. This is carried out by a specially trained fieldworker who interviews the closest caregiver of the deceased in his/her primary language. Consistent with traditional mourning practice, no VA is conducted for at least a month following a death. The interview schedule is a modification of that previously used in Niakhar, Senegal [11]. It covers all ages, was translated into Shangaan and modified to include only culturally accepted terminology. An open section elicits, in the respondent's own words, details of all symptoms and signs preceding death. Several filtering questions follow, for example "did the deceased cough?". A positive answer leads to detailed questions about that symptom. If negative, the interview proceeds to the next filtering question. Quality is enhanced by on-site supervision, regular review of completed questionnaires and fieldworker feedback. *VA review* entails assessment by three medical practitioners [12–15]. Two doctors, completely independently, review the information and assign a probable cause to each death. Where these correspond the diagnosis is accepted. Where they differ, the two clinicians discuss the case in an effort to reach consensus. Where this is not achieved, a third practitioner assesses the VA, blind to earlier findings. If the third assessment is congruent with one other, it is accepted as the "probable cause of death"; if not, the cause is coded as "ill-defined". Where possible, a main (or underlying) cause, immediate cause, and contributory factors are identified; classification is consistent with the International Classification of Diseases (ICD-10).

Over the years, the instrument has been strengthened by adding questions on symptoms of HIV/AIDS, refining questions on cardiovascular symptoms (e.g. on shortness of breath to determine exertional dyspnoea or orthopnoea), and extending

sections on maternal death, modern and traditional treatments, lifestyle practices (alcohol, smoking, drugs, physical activity), occupation (mining in particular) and children's feeding practices.

Since the VA approach remains a prototype technique, validation of the instrument is necessary to determine its accuracy and reliability. Final diagnoses were compared with hospital reference diagnoses (which satisfied strict inclusion criteria) and sensitivity, specificity, and predictive values were calculated for broad categories and individual causes of death [16]. A further validation of deaths occurring between 2001 and 2005 provides information on performance of the VA when making a diagnosis of HIV/AIDS specifically.

#### *Data management*

The Agincourt data management system was first held in FoxPro but was rewritten in MS Access 95 in 1996 along with improvements to the data model. In 1999 this was upgraded to Access 97, with a data model brought up to the standards of the INDEPTH population reference data model [17]. The system was upgraded in 2002 from MS Access 2000 to Microsoft SQL Server 2000, and in 2001 the operational database was converted to SQL Server, enabling a higher standard of database technology including data protection and improved means of querying the database. Overall, these developments ensure a more robust and stable environment for the rapid increase in both data volume and complexity.

A custom-made data entry programme sits on top of the SQL Server database and, by mirroring the format of the data forms, provides an easy-to-use interface between users and the database. Data are captured via simultaneous data entry with five networked computers writing to the HDSS database located on a server. Despite infrastructural limitations, data are entered within the field site to facilitate the relationship between data and field teams and so enhance quality. The system incorporates built-in validation checks to filter out implausible or unusual data. Raw data are archived in fire-proof filing cabinets with ready access to hard-copy forms from the preceding five years.

Data are stored in related tables: the main or "Individual" table stores key information on all individuals; the "Residence" table provides information on individual residence episodes; a "Memberships" table records information on entry and exit from a particular household; there is also a table for each vital event category. A range of status observation and special module tables record other "point observation"

information that describes the status of individuals or households at a particular point in time.

HDSS data are handled by a custom-designed relational database based on the “Reference data model” [17,18] blueprint designed specifically for longitudinal population data. It has a strong focus on the temporal nature of the data and facilitates linkage between episodes (periods of time in a given state) and events (an occurrence which opens or closes an episode). The core “entity” in this model is the individual; each is computer-assigned a unique identity number when first encountered in the field. This provides the link between the “Individuals” table and the information that describes them. Each individual is thus linked to events and episodes, stored in other tables, that together comprise their life history while under surveillance. Manipulation of this database allows calculation of person-time at risk (exposure) and counts of various events; together this allows the calculation of probabilities and rates, and supports the range of multivariate analyses.

#### Quality control

This occurs at five levels with forms checked at three field levels – fieldworkers themselves on a daily basis,

cross-checks by fellow team members on a weekly basis, and random checks by team supervisors (Figure 2). Errors are corrected in field offices, otherwise a household revisit is conducted. Forms are then transported to the main Agincourt field office where a specialized “checker” carries out a final review with errors recorded and, where indicated, forms returned to the field for correction. Checkers also conduct in-service training on common problems. Thereafter a form passes to the data room for data entry. Programmed computer checks identify invalid codes, missing values, and inconsistent or duplicate entries; data that do not pass the pre-determined validation rules are blocked and an error message produced, resulting in the form being manually re-checked and returned to the field if necessary.

Random duplicate visits on a 2% sample are undertaken by census supervisors; these allow constructive feedback and an assessment of error rates. Information on quality is fed back to the site manager and team supervisors at weekly meetings.

#### Ethical issues

Ethical clearance for health and demographic surveillance in Agincourt was granted by the

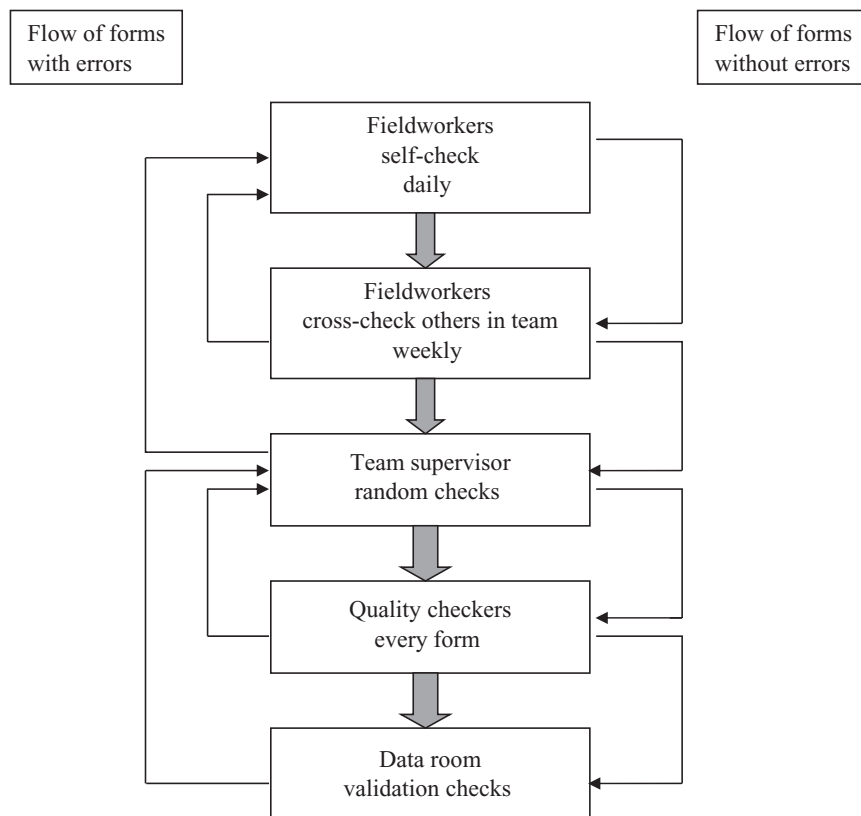


Figure 2. Quality control, Agincourt Health and Demographic Surveillance System.

University of the Witwatersrand's Committee for Research on Human Subjects (Medical) (No. M960720). This entails verbal informed consent from respondents; community consent was obtained from both civic and traditional leadership at the start of population monitoring. All other research is required to apply independently for ethical clearance, including signed informed consent where indicated.

Formal ethical clearance is not sufficient when undertaking prospective, household-based research. Surveillance over a prolonged period rests on stable long-term relationships which need to be nurtured and regularly renewed. Primary relationships are between the Unit's LINC office and elected Community Development Forums which cover all villages in the study site (the LINC office promotes Learning, Information dissemination, and Networking with Community). Interaction aims to increase community involvement in research governance at all stages of the research process. Routine interaction includes informing village leaders and communities of forthcoming census updates and research projects, well-prepared feedback and discussion of research findings at village meetings, and regular production of village-specific "fact sheets" to support local development initiatives. Contributions from all projects conducted in the site are expected. Since 2002, the LINC office has compiled and updated information directories on development and educational resources for the use of community leaders and organizations. There is a strong commitment to working with service providers (health and welfare, education, environmental affairs, and others), bringing policy-relevant research findings to their attention, and then participating in programme development (see Box 1 for an example).

Dealing with health and social problems encountered by fieldworkers during household visits is of concern. Fieldworkers are provided with comprehensive information on available services in the area – government, NGO, and church – to which they may refer individuals and families. In qualitative work involving multiple, lengthy interviews with the same individual or household, food parcels have been provided at the end of the data-collection period (participants were unaware of this at the time of recruitment). With escalating mortality, it has become necessary to provide trauma debriefing workshops for verbal autopsy fieldworkers and fieldworkers conducting in-depth qualitative interviews in death-affected households.

Ensuring confidentiality in small-area research is critical. Data are captured in a secure computer room onto an isolated local area network. The

**Box 1. Working with service providers and local government: increasing access to the child support grant**

The child support grant is a South African government-issued non-contributory social security grant introduced in 1998 that supplements the income of poor households with children up to the age of 14 years, thereby providing for basic needs and promoting the well-being of the child. Access to the child support grant was assessed through inclusion of a special module in the 2002 Agincourt census update. Main reasons for non-access were lack of vital documentation and long distances from service points, particularly for poorer households; hence the government intervention was failing to reach those most in need. The Agincourt Unit, through its LINC office, presented these findings to provincial and local Departments of Home Affairs, Education and Social Security, resulting in 2004 in:

- Two-day mobile home affairs and social security campaigns in 20 villages, during which 8,000 people applied for identify documents and birth certificates
- Two *imbizos* (community workshops) providing information on services for orphans and vulnerable children
- The introduction and specialized utilization of six child support grant extension officers employed by the Department of Social Security
- A partnership between the Agincourt Unit, Wits University's Acornhoek Advice Centre, the Department of Home Affairs, and the Mozambique Consulate in ongoing planning to assist former Mozambican refugees who are stateless
- A partnership between the Agincourt Unit, local municipality, and NGOs to form a multi-departmental district task team on orphans and vulnerable children.

database is secured using two levels of user access control: a password to log on to the operating system and a second password to log in to the database. A hierarchy of database access exists with the research and data managers having full access, the data supervisor restricted access, and data typists' data-entry access only.

*Limitations, challenges, and efforts to address these*

*Reducing missing perinatal deaths.* Census update rounds are conducted once a year. This makes an

undercount of abortions, stillbirths and early infant deaths likely. To minimize perinatal deaths missed, the last child born to each woman is printed on the populated census form, and fieldworkers use this prompt to probe for any pregnancies since this last birth. In addition, starting 2006, fieldworkers ask if any woman in the household is currently pregnant, and if so the expected delivery date.

*Within-site migration reconciliation.* Movement from one household to another within the study site is common. An individual is registered in only one household at a point in time within the HDSS database. On moving to another household, an internal migrant would be assigned a new identification number and hence would appear in the database twice. To overcome this, full internal migration reconciliation, to ensure that every in-migration within the field site is matched with its counterpart out-migration, was introduced in 2003. This involves the tracking of internal migrants to link the household of origin and destination for each move made, thereby ensuring a single unique identifier for each individual, and removing the potential of one person being concurrently registered in two households. Individuals retain this same unique identifier when they move and can therefore be readily followed up, strengthening studies of household and individual migration behaviour, and improving follow-up of subjects enrolled in cohort studies or clinical trials.

*Limiting demand on study participants.* Intensity of household visits in Agincourt is lower than in those sites where update rounds are conducted every three or four months [19]. However, Agincourt households participate in additional surveys and studies that draw on the HDSS research infrastructure. Fatigue of study households and participants is a risk that we guard against by maintaining a database of all households sampled for different projects. This serves as a tool to monitor and control household participation beyond the annual census update.

*Maintaining a high response rate.* After nearly 15 years of longitudinal follow up, participant fatigue may be expected to result in increasing numbers of refusals. This is not the case and the response rate remains high. In 2006, 96% of verbal autopsies were completed ( $n=766$ ); 4% were not done ( $n=29$ ) due to lack of information on the terminal illness following out-migration, deaths that occurred away from home, or unavailability of a knowledgeable respondent; and less than 1% refused ( $n=4$ ). Reasons for refusal were

given as excessive stress associated with multiple deaths in a single household, or death of a breadwinner. Refusal to participate in the annual census update is far lower than this.

### Quality of data

Despite rigorous training and thorough fieldwork operations and quality control measures, it is difficult to comprehensively evaluate the completeness and accuracy of HDSS data given the absence of a gold standard against which to measure findings. Useful insights can derive, however, from comparing key findings with national data sources. Comparisons between Agincourt surveillance data and national data indicate that trends and the direction of change for vital events follow the same patterns (increasing mortality in children and young adults; declining fertility; increasing migration among economically productive females) despite some variation in levels.

Levels of adult mortality in Agincourt are generally consistent with national and provincial estimates based on census data; infant and child mortality rates, while lower than national estimates in the early years, are now more in line, suggesting some success in field strategies to address the under-reporting of perinatal and young infant deaths [20]. The correlation between Agincourt and national fertility rates, based on 1996 and 2001 census data, is high with the trend in general fertility rate virtually identical from the mid-1990s [21]. Further, the total fertility rates derived from two rural HDSS sources, Agincourt and the Africa Centre in Hlabisa district of northern KwaZulu-Natal, are clearly consistent [22].

While a comparison of levels of migration from different data sources is complicated by varying definitions, patterns of migration can be usefully compared. Congruent trends between the Agincourt HDSS, national census, and national surveys include increasing migration over the past decade, and increasing feminization of migration with more women moving into the mobile workforce [23]. Regarding household change, national data show an increase in the importance of single-person households, a finding not reflected in Agincourt data where an increase in three-generation linear households is evident, single-person households becoming relatively less common [24]. In measuring migration and household transitions, demographic surveillance has the strengths of consistent data structure and regular prospective data collection from the same household, as well as the capacity to record links between non-resident household members.

### **Strengths of the Agincourt health and demographic surveillance system**

Unlike clinical studies in which the individual alone is investigated, health and demographic surveillance also has the community as object of study, which it follows prospectively [25]. This fundamental concept gives rise to far-reaching strengths: generation of research questions that derive directly from empirical data, cost-effective support for a diversity of study designs to address these questions, and the capacity to track population change and the impact of interventions over time.

#### *Generating research questions and prioritizing a research agenda*

Rural north-eastern South Africa is in the midst of a major health transition with marked changes in population structure (Figure 3) and characteristics (see Table I) over the past decade. Baseline data [2,3], and findings on escalating mortality [8,9], declining fertility [26], and complex migration patterns [23,27] have been published elsewhere. Of note is a rapid narrowing in the base of the population pyramid, consequent on fertility decline augmented by rising child mortality. This example of empirical findings diverging from demographic transition theory is probably driven by change in fertility preference coupled with the mortality impact of the HIV/AIDS epidemic. Declining fertility and net out-migration has reduced population growth substantially [26]. However, a documented trend towards smaller households [24] explains the substantive increase in the number of households despite only marginal increase in population size. A dual burden of kwashiorkor and acute diarrhoeal illness in children aged under five, and emerging non-communicable disease, particularly stroke, in adults over 50 years, typified the cause-of-death profile in the mid-1990s [8]. By the end of the decade, these conditions persisted but in the face of dramatically escalating HIV and AIDS.

While highlighting the rapid and far-reaching transitions under way, these findings raised research questions pertinent to the development of health and social policy which informed the next phase of research [6]. In 1997/98, the Agincourt site transformed from a primary focus on health systems research & development (R&D) to a broader community-based health, population and social research agenda [5]. Agincourt is not alone in having reconsidered its primary purpose and “reinvented” its focus and scope of work – other DSS sites have

shifted from disease-oriented studies to family planning or nutrition research, and vice versa [28].

#### *An established research infrastructure to support diverse study designs*

The Agincourt HDSS provides a research infrastructure able to sustain a diversity of study designs ranging from the biomedical to the ethnographic (Table III). Multidisciplinary research is valued and supported, and options for triangulation of research findings abound. Studies, both quantitative and qualitative, use the Agincourt surveillance infrastructure in different ways and to varying extent. It is most commonly used as a sampling frame: households and individuals can be sampled by a number of variables including age, sex, migration status, socio-economic status, and experience of death. Agincourt-generated data are used to enrich survey analyses (the asset survey permits socioeconomic stratification of study households), and longitudinal HDSS data are used in conjunction with cross-sectional survey data.

Demographic surveillance systems (DSS) are charged with being expensive. While the cost of most studies is well below that of establishing a DSS, the cost of setting up individual research infrastructures for multiple projects in a common setting – an inefficient approach – would rapidly exceed the cost of maintaining a DSS. Status observations and special modules add great analytic value at marginal additional cost given that they are nested within the routine HDSS data-collection infrastructure. In Agincourt, the asset survey and healthcare utilization modules permit equity-oriented analyses [29,30], labour participation and temporary migration modules extend our understanding of complex migration patterns [27], and status observations such as chronic cough and one-sided weakness were introduced as screens to identify samples for active tuberculosis case-finding [31] and a stroke prevalence study [32]. Nested case-control studies, with incident case identification, are another example of a low-cost application of health and demographic surveillance.

#### *Evaluating interventions*

An intervention-research programme is evolving in response to findings. As part of health systems R&D, voluntary counselling and testing services were piloted in Agincourt clinics in 1999, evaluated and then scaled up to other clinics in the province [33]. A special module to measure access to the child

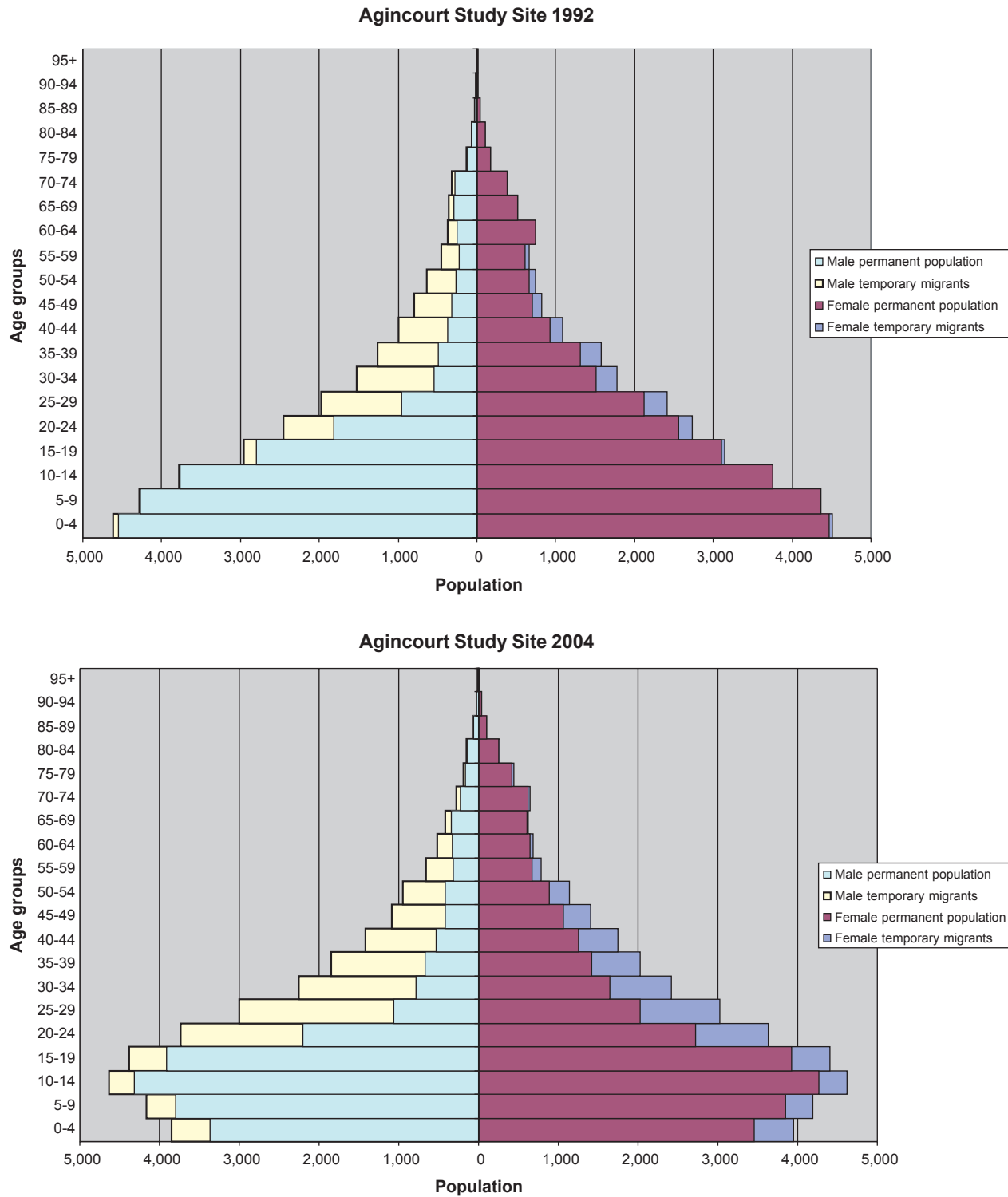


Figure 3. Population pyramid, Agincourt health and demographic surveillance site, South Africa, 1992 and 2004.

*Note:* Permanent population: resident for at least six months of the year. Temporary migrants: resident for less than 6 months of the year but remain closely linked to their rural household.

support grant is an example of public policy evaluation (see Box 1), as is the forthcoming evaluation of antiretroviral treatment roll-out.

An experimental school-based intervention to promote child coping and resilience is in its formative phase.

Table III. Diversity of study designs supported by health and demographic surveillance: Illustrative examples from Agincourt, 1992–2006.

Methodological approaches	Study design	Focal area	Use of HDSS	Project and period
Observational	Cohort	Mortality, fertility	Annual census and vital events updates Verbal autopsy	Health & demographic surveillance (1992 to present)
	Cross-sectional/ prevalence	Stroke	Status observation followed by clinical validation	Southern Africa Stroke Prevention Initiative <sup>a</sup> (SASPI) (2001–2004)
		Cardiovascular risk factors Tuberculosis	Random sample of non-migrant adults >35 years Status observation followed by survey and sputum testing	Active case finding <sup>b</sup> (1999)
	Case-control	Severe child malnutrition	Prospective enrolment of cases, selection of controls	Determinants of child malnutrition <sup>c</sup> (2003–2004)
Intervention	Policy evaluation	Child support grant	Special module on access to grant	Health equity (2003 and 2005)
	Experimental	Cluster randomized school-based intervention to promote child resilience	Measurement of child outcomes: education, morbidity, mortality	Kulani child health and resilience project <sup>d</sup>
Qualitative		Meanings of life and death	Focus-group discussions; key informant interviews; in-depth household phase with repeated semi-structured interviews	Meanings of life and death <sup>e</sup> (2003–2006)
		HIV/AIDS: impact on older women	Repeated semi-structured interviews	Hidden impacts: Older women's experiences with HIV/AIDS <sup>f</sup> (2004–2006)
Mix of approaches	Cross-sectional and in-depth qualitative	Role of natural resources in buffering household impact of adult mortality	Random sample of 240 households, with and without a death 15–49 years, in strata based on household size and wealth class + 25 in-depth interviews	Population health and natural resource use <sup>g</sup> (2003–2005)

Collaborating institutions: <sup>a</sup>Department of Neurology, Wits University; University of Warwick and University of Edinburgh, UK; <sup>b</sup>RADAR: Rural AIDS & Development Action Research Programme, Wits University, South Africa; <sup>c</sup>Division Child Health, Department of Paediatrics and Child Health, Wits University, South Africa; <sup>d</sup>University of Oxford, UK and Harvard School of Public Health, USA; <sup>e</sup>Wits Institute for Social and Economic Research (WISER); <sup>f</sup>University of Colorado at Boulder, USA; <sup>g</sup>African Ecology, Wits University and University of Colorado at Boulder, USA.

## Conclusion

Vital registration is generally lacking in infrastructurally weak areas where health and development problems are most pressing. Improving the health of poor communities is best informed by a population evidence base yet national studies, while sampled across a breadth of settings, living conditions and communities, cannot progress beyond serial cross-sections or panel studies and seldom provide data usable at local or district level – despite a worldwide emphasis on decentralised development. In response, prospective studies based on health and demographic surveillance have been conducted since the 1930s in Africa, Asia, and Latin America. These have made seminal contributions to understanding interactions between infection and malnutrition;

links between breastfeeding, child mortality, and fertility; the concept of weanling diarrhoea; the impact of maternal tetanus toxoid vaccine on child survival; vitamin A supplementation, oral rehydration therapy and the effects of impregnated bednets to list only a few [28].

Building on the work of these earlier studies, and acknowledging the growing number of new ones, the INDEPTH Network (International Network for the Demographic Evaluation of Populations and Their Health) was established in 1998 to “harness the collective potential of the world’s community-based longitudinal demographic surveillance initiatives in resource constrained countries to provide a better, empirical understanding of health and social issues, and to apply this understanding to alleviate the most severe health and social challenges” (<http://www.indepth-network.org/>).

indepth-network.org). Agincourt, a founding member of INDEPTH, is one of 37 member sites in 19 countries across sub-Saharan Africa, Asia, Oceania and Latin America; it is involved in collaborative research on mortality and health equity, and leads multi-site studies on adult health and ageing, and migration and urbanization.

Three INDEPTH sites are located in South Africa: the Africa Centre in Hlabisa district of northern KwaZulu-Natal, and the Agincourt and Dikgale DSS sites in Mpumalanga and Limpopo provinces respectively. Agincourt commenced in 1992 and provided key support to the establishment of the Dikgale site in 1995 [34,35], while the Africa Centre was launched in 2000 [36]. These sites have unusual potential to contribute evidence to policy and development in a middle-income country with intractable inequality. Leaders of the sites, scientists and policy-makers should exploit this potential to its full effect.

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