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MONITORING SYSTEMS IN AFRICA

Caitlin Blaser Mapitsa & Catherine Churchill

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Section 3

EXAMPLES OF MONITORING SYSTEMS IN PRACTICE

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Chapter 8: Health and Demographic Surveillance Sites: Scalar and Spatial Monitoring

David Everatt

Introduction

This chapter analyses the challenges of monitoring via a health and demographic surveillance site (HDSS) in the heart of Gauteng, called GRT-INSPIRED. The GRT is a partnership between three major African universities, namely the University of Johannesburg, the University of Pretoria, and the University of the Witwatersrand. This HDSS node is split across three sites in Gauteng. The HDSS performs 'monitoring of a special type' which is detached from any specific programmatic intervention, focusing on one site with multiple visits each year. This monitoring system creates a data set that operates from the household through dwelling to the entire area under study, usually a population of around 100 000 people. The scale is important, as HDSS tracks individual movements in and out of their node and works with the entire nodal population, with various cohorts available for smaller studies, such as the elderly, women, or youth.

HDSS provides spatial monitoring because it is a site where every year, the people living in the node provide data on their health, demographics, socioeconomic status, migration, and the like. The HDSS measures this 'space' year after year to provide an accurate population-based form of monitoring. Data errors can be corrected because of the continuous fieldwork, and the HDSS data is a unique resource for planners and policy makers. The HDSS is also an evaluation. This is not an explicit categorisation, but an example of this is the continual measurement of the health status of poor people, which makes the HDSS an evaluation of the policy and service provision in its site.

In South Africa, the South African Population Research Infrastructure Network (SAPRIN) has linked established rural nodes with new urban nodes. The goal is to have 1% of the entire population tracked for vital statistics, migration, and many

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other issues. The HDSS approach is to annually measure everyone in each space, commonly with a ceiling of 100 000, within official boundaries. The resultant dataset, made freely available by SAPRIN, provides a remarkable picture of each node and their linkages. It also reflects ongoing monitoring and evaluation of service delivery in general, with a strong focus on health as crucial to the transformation of the lives of the impoverished.

The chapter argues that the HDSS approach may circumvent some of the power dynamics that flow from a funder seeking to influence how a monitoring system works, whom they talk to, what questions they ask, and so on, but HDSS is by no means immune to the impact of power. The HDSS strategy shares the same challenges, specifically in urban areas, as any monitoring system: access, trust, and competition for time and attention. The HDSS is another form of data collection, not a rival to other monitoring, and may offer some valuable insights.

Monitoring and HDSSs

Monitoring systems comprising the regular collection and analysis of data have appeared in virtually every aspect of public and private life. According to the UN Task Force (1984:7), both monitoring and evaluation (M&E) have "emerged both at country level and in the UN system in the early 1950s. Since then, it has evolved slowly and unevenly". While this held true in the early 1980s, M&E was ubiquitous by the turn of the century.

As this book clarifies, 'M' and 'E' are available for integration but are also very different activities. Monitoring systems are not always or automatically linked to periodic reviews or evaluations and vice versa; each has its specific role and function and methodological demands, despite being repeatedly conjoined as 'M&E'. Both can exist without the other. Nevertheless, as 'M&E', they have become a global industry, whether named as M&E or performance measurement, or translated into balanced scorecards and results-based reporting schemes, and any number of tools purported to measure and improve human progress.

M&E-related systems, departmental units, and flashy dashboards are now a near-universal requirement in government, much of the private sector, and most of the development sector. Whether this increased spread can be equated with increased efficiency, effectiveness, or impact remains debatable.

Monitoring and the associated language of "M&E" has moved from an essentially pro-poor development location and orientation to being a "management tool". Influential donors and governments rely on "M&E" to provide evidence of a return on their "investments".

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Monitoring has become a critical element of private and public sector management (performance measurement). The language of M&E, from 'smart indicators' to 'theory of change', has percolated policy and management circles and is rapidly losing meaning through repeated misuse. 'Monitoring' can also be found at the forefront of the monetisation of lifestyles. Your smartwatch or cell phone measures your performance throughout the day – steps, oxygen levels, heart rate, stress, and mindfulness.

Work-based performance measurement systems will seek to assess your efficiency at the office, using indicators you may or may not have any input into or knowledge of. All of this will be digitally captured by more or less visible cameras that will film it, and digital surveillance - in public spaces – has become literal and ubiquitous. In addition, basic machine learning allows for pattern recognition even in these massive, data-heavy systems, with obvious potential for 'monitoring as policing' to become commonplace. The Chinese 'social points' nod very heavily in this direction (Kobie 2019).

Most M&E practitioners would be appalled to be located in this space but should be aware of what type of monitoring is occurring and for what purpose. This awareness should acknowledge how developmental tools can be used for different purposes. Most of the chapters in this book engage with monitoring in a developmental context, as this chapter does, but the broader reach and consequences of monitoring should be considered.

After primarily being a development sector activity, technology has allowed monitoring to explode into our lives, but the quality of life for the impoverished has degraded. As monitoring and measurement systems have become more complex and their dashboards more colourful, the world has become increasingly unequal; the poor are faced with the direct effects of climate change, pandemics (including COVID-19) and the like. As Evans noted, "In the early years of the 21st century, it is indeed worrisome that in many parts of the world we remain 'in the dark' about life's vital events – namely birth and death" (InDepth Network 2005:7). Monitoring is itself beset by late-capitalist inequality: the rich can measure every breath they take, while the poor may live and die without being officially recorded at all. The politics of monitoring cannot be avoided.

This inequality – more pointedly, the search for health equity that it triggers – lies at the heart of health and demographic surveillance systems (HDSS), which provide accurate, longitudinal coverage of the vital events, demography, and health status of an entire population in each space. As Kahn, Collinson, Hargreaves, Clark and Tollman (2005:88) noted,

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> "Health inequities … result from differences in health status outcomes between groups that are avoidable and unnecessary, and hence unacceptable and unjust. Widening health gaps … call for careful monitoring and evaluation of interventions, not just for their impact on health outcomes but also their impact with respect to these 'equity gaps'."

To cite Evans again, HDSS starts from a progressive point of view, that "all lives count and deserve to be counted" (InDepth Network 2005:7). So too, the common assumption of HDSS is that all data should (after suitable anonymisation) be made freely available to anyone seeking to use it for research. HDSSs have yet to fall prey to the marketisation that has befallen much of M&E, not least because HDSSs, by design, are in areas of substantial poverty. Nonetheless, it would be naïve to imagine that any system generating data is not at risk of commercialisation or worse.

M&E practitioners are frequently challenged by their desire to involve community members in participatory monitoring to get local buy-in and better understand the context and local nuance. M&E systems need to account for the rhythms and requirements of local communities and operate at their pace, in the local dialect, with an appropriate understanding of, among other things, local histories, local hierarchies, politics, customs, and seasons. These are essential requirements for successful development. However, they take time and money. Those paying for the programme often want to see 'bricks and mortar' (things being built), not consultations with communities and other activities they do not regard as relevant. This has been described as "a movement away from participatory approaches and towards more top-down control amongst the donor community, with increased emphasis on results-based management" (INTRAC 2020).

There is a broader tension between northern donors and funding agencies and the realities of working in the Global South, and many similar issues affect HDSSs, though in different ways. For example: who says what questions may or may not be asked? Who has the final say over indicator selection? Who performs the analysis? Are recommendations workshopped with the local community or taken over by the donor? Does management take informed decisions that include the views of the community? Who has the power to make or break the system? Valadez and Bamberger's (1994:7) magisterial text on M&E in developing countries included the following, "… the OECD concludes that, with the exception of a small number of countries, 'interest in evaluation generally tends to be stronger among those allocating resources than among those using them'".

The situation may have been different if M&E were a partnership, not an imposition on the developing world by the North. The same is true at a community level; regardless of who is paying for the monitoring, it cannot be imposed on communities if it is intended to be developmental. Power is always at work, in M&E as in HDSSs. Power

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matters across design, implementation, analysis, reporting, and dissemination. When power is examined, the dynamics within any M&E system or HDSS become clearer. We may better understand relations between implementers and donors and the multiple actors in any developmental intervention. This is without bringing into the argument issues of indigenous research methods and the need to ensure that the community sets the pace of and is involved in the content of a monitoring system and evaluations (Chilisa 2012). Valadez and Bamberger had noted (1994:404), although without the community featuring:

> "Monitoring is a source of power to those who control the system and a threat to agencies that do not have this control. The potentially threatening nature of evaluation has had a destabilising effect on M/E systems, since those agencies being evaluated have sought to limit the use of any data that affect their budgets and programmes. Furthermore, central agencies may compete among themselves to control the systems."

Among many practitioners, the impulse behind HDSS and M&E is a similarly developmental, progressive, pro-poor approach. M&E is frequently used in impoverished settings, just as HDSSs are deliberately located in places that are poor and vital events are at risk of not being recorded. Both approaches seek to utilise participatory approaches where possible, combined with rigorous data gathering, cleaning, and analysis, to best understand what is working, what is not, why, and how the situation may be improved. In both, where developmental approaches are used, HDSS and M&E practitioners know that communities have their own pace, rhythm, and ways of operating, which are not always amenable to researchers. Both HDSS and M&E practitioners prefer open data, sharing of resources, and collaborative learning. Both need funds to do their work, which is one reason to always look at power dynamics.

HDSS staff are also paid – by the government, in the case being presented here – and so, the power dynamics implicit in any arrangement when one party funds and sets the parameters and another carries out the work also play out in an HDSS. However, they do so differently because an HDSS provides data that is absent or uneven in official statistics (vital statistics, most obviously). In South Africa, the SAPRIN network works closely with Statistics South Africa (StatsSA), providing an important additional set of analytic skills, tools, and training opportunities for the analysis of longitudinal data within StatsSA defined geography, as well as working collaboratively to verify data. Moreover, HDSS funding is of little value if it is not long-term, relying on sound relationships. The M&E field is more likely to be shorter-term contracts for specific programmes or projects, possibly lasting from a few weeks to a few years, but with a predetermined end date. This difference is critical: HDSSs are put in place for medium to long-term monitoring and analysis, and relationships reflect this. Expectations

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of HDSSs differ from monitoring systems linked to specific projects, which must account (for example) for monies spent on the project, how many days of work were created, how many people received training, etc. Monitoring is at the heart of both but plays out in different ways.

There can be a different tone to the relationship, in that (in this case) a domestic government is funding the HDSS to advise them as to what interventions (primarily health-related) are working and which are not, over time, as reflected by the population under study. SAPRIN is continually assessing and feeding data and analysis back into government systems, but unlike a programme-linked system, the HDSS is more a partner than a contractor. This is a deliberate intervention to improve the lives of the poor by developing detailed household profiles as well as linking these to official records such as child school attendance and road to health cards. For example, the HDSSs utilise Verbal Autopsies, which have proved vital for capturing things "likely to be particularly sensitive to recall bias" (Sankoh and Byass 2012:580). On precisely this issue, the Dande HDSS in Angola found that:

> "The neonatal, infant, and under-five mortalities reported by the National Institute of Statistics of Angola for the years 2011 – 2015 are 24, 44, and 68 per 1000 for the country, respectively. The total fertility rate for the period 2013 – 2016 is 6.2. Compared with the Dande HDSS data, a probable under-reporting of neonatal deaths is perceived. These events are very likely not to be reported some time after their occurrence, particularly if the child was not listed in the household registration book. Also, cultural aspects or embarrassment of respondents to talk about deceased relatives might contribute to the omission of death events. This is in line with previously published data and has been documented as one of the reasons why child mortality is most probably underestimated in many surveys in sub-Saharan Africa. Implementation of new projects around maternal and child health are planned, including a birth cohort which will enable accuracy and a thorough knowledge of these events" (Rosário, Costa, Francisco and Brito 2017:4).

Tension between programme partners is not always a bad thing and can lead to debate, discussion, and a better way forward. In an HDSS, relations between funder and implementing agent are quite specific. The HDSS is uniquely positioned to work with the government as a long-term partner, filling data gaps, assessing policy impact, adding nuance, and providing unparalleled insight into its population.

HDSSs are not cheap. Fieldwork continues for 48 weeks of the year, and very powerful databases are required to run multi-year analyses. HDSSs also design and launch smaller studies within the node, as the quotation suggests, to try and better understand the dynamics around an issue, in this case, as painful and culturally

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sensitive as neonatal mortality. An HDSS can thus commission an evaluation if it wishes, which indicates a significant difference: HDSSs are institutional and have the autonomy to carry out their own evaluations or add to their monitoring questions. Smaller studies can be on-boarded in an HDSS because all HDSSs start with a census of their node. In return, year on year, to the same dwelling and (most of) the same respondents. This kind of local, detailed, longitudinal knowledge – encoded in data rather than locked into the minds of local leaders – makes HDSS sites attractive for smaller, sampled, and focused studies.

Case study methodology talks to the power of the case because the depth of understanding of the case (in this instance, the node) is unparalleled. However, because the case is about depth, not breadth, generalisability is unavailable (Yin 2018). The case may include local exceptions that will not be evident to the researcher due to them exclusively working in that case site. However, an HDSS can be thought of as a longitudinal, quantitative (and rather large) case study. It may be more helpful than comparing it with sample surveys or an integrated M&E system. A key issue facing many HDSS proponents is the lack of national representivity in the data (Byass, Sankoh, Tollman, Hogberg and Wall 2011). The findings cannot be generalised to a larger population, something it shares with case study methodology. It may seem odd, given that a sample of a thousand respondents can be used to generalise, within measurably accurate parameters, across the entire country, but an HDSS with a population of 100 000 under surveillance cannot. That, of course, is the benefit of sampling. Nevertheless, the HDSS has the power of an ongoing case study, resting on uniquely deep, nuanced, and longitudinal data for an entire population in each area, falling within official boundaries.

Moreover, in South Africa, SAPRIN has a network of HDSSs, surveilling hundreds of thousands of people every year, year after year. The data is merged into a single dataset, and the complaint that "conventional statistical theory is not particularly useful for addressing this question" is true of any stand-alone HDSS (Byass, Sankoh, Tollman, Hogberg and Wall 2011:1). However, improvement of statistical language may be needed to understand the power and value of this network of longitudinal, large-scale cases, where all respondents are being asked the same questions in the same way, every year. The power of this dataset does not lie in national representivity but depth and complexity, and above all, accuracy.

HDSSs generate a geospatial coordinate map of every bounded structure, then every dwelling, number of households per dwelling, vital statistics per household, as well as socioeconomic status and a raft of other questions. A Hillbrow apartment block could be considered a bounded structure; each flat is a dwelling. Within that dwelling may be a single person, groups of individuals, a household, or multiple households. All this needs to be recorded and updated annually. The focus of an HDSS is to improve the lives of the poor, and all the questions are geared at understanding health and

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socioeconomic status and assessing health and population changes. These are asked year on year so that data errors can be identified (or seen as emerging social phenomena) and corrected. So, an HDSS does not claim survey-style representivity – if that means 'the entire nation' – but the SAPRIN nodes analysing data on hundreds of thousands of poor communities, households, and individuals does mean that SAPRIN can make the case that the network is indeed representative of the poor, and as a living dataset that can self-correct via annual implementation. Aside from the sheer weight of data, the rigour of the methodology makes SAPRIN a key player in the South African data ecosystem.

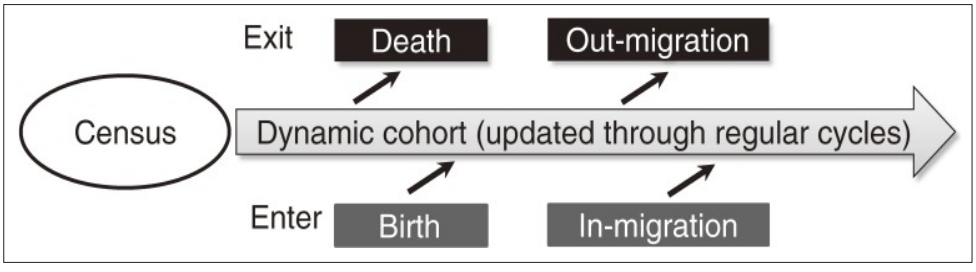

Figure 8.1: HDSS design (generic)

In a network of interlinked HDSS nodes, such as SAPRIN, the combined power of the same instrument being applied to vast numbers of people in different contexts and geographical locations suggests a unique data power, particularly when several nodes are linked, and their data is merged. This is pertinent to the added possibility of the return to precisely the same respondent within months, and again face-to-face within a year with follow-up diagnostic questions and trials.

HDSS, Monitoring and Incentives

An HDSS has the core function of measuring a given population using multiple interactions each year so that respondents keep them apprised of the entire course of significant events, such as pregnancy. This, in turn, demands that an HDSS is underpinned by robust community engagement and mobilisation, without which respondent fatigue would be rapid and inevitable. Many clinical trials offer respondents an incentive, and respondents may come to expect that this is a research norm. Mixing non-remunerated fieldwork with smaller on-boarded trials, which may offer incentives, can cause confusion and hostility, as respondents do not understand the difference between the two.

This must be handled with care. The HDSS is, by design, located within a poor node. Resources matter, particularly if respondents feel they are being denied something

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they see or hear others receiving or enjoying. Unlike survey field workers, those from the HDSS work permanently within the node. Field workers have project uniforms, tablets for capturing data, vehicles that transport them; all aspects of the HDSS, as of any development intervention, suggests that it is resource-rich, which it is within the local context. For example, in the case of GRT-INSPIRED, Hillbrow – with the highest local population densities in Africa – is a favourite site for research from all over the world, with its mixture of density, bustle, edginess, cosmopolitan culture, and overcrowding. This means that HDSS staff encounter respondents who got paid to participate in a clinical trial and who then question the lack of payment from GRT-INSPIRED. Balancing freedom to research with an appreciation of others working in the same space becomes an issue in urban areas, but less so for rural nodes.

This challenge of well-funded research activities in a poor community goes beyond the issue of clinical trial incentives. In the Nairobi HDSS, for example, the number of formal and informal gatekeepers demanding 'goodwill' to allow fieldwork to continue unabated simply grew too large, once some 'goodwill' had been dispensed (Kyobutungi 2020). The only way a successful HDSS can operate and remain operational is through continued community mobilisation, so that community leaders and members (commonly formed into a Community Advisory Board or CAB) are not merely informed about the project but are key to the feedback loop. The CAB is also able to help identify local contestation, assist with access (which is key for an urban node), and act as ongoing advisors regarding the community. Given the mobility of urban populations, it is important to keep revisiting communities and reminding them of what the HDSS is trying to accomplish for them.

HDSSs grew mainly from the Community-Oriented Primary Health Care (COPC) movement. The COPC approach (like the HDSS) works in defined, poor areas and partners with communities and forms CABs. The orientation is proactive prevention, with the overall goal being support treatment and care, the prevention of disease, and the identification of people with health needs, as well as the assurance that those needs are met. The focus is on the local; in the case of our University of Pretoria colleagues, who run part of the HDSS described here, Community Health Workers accompany field workers during field work, under the guidance of a nurse, so that the HDSS is both 'giving' and 'taking'. Urban respondents are leery of being interviewed at all, let alone three times a year, and the creation of a virtuous cycle that reaps tangible benefits for respondents in return for data is essential. A COPC orientation seeks to make the relationship more balanced. No incentives are paid, but health assessments in particular take place before interviews, and, where possible, results are immediately provided to the respondent.

Moreover, the HDSS nodes in SAPRIN seek to be proactive. It may be argued that an HDSS must be proactive to remain in place with community support. The goal of data collection is not simply the production of academic papers or datasets. Even

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without formally adopting COPC, the HDSS seeks to link to official records, such as clinic records, child inoculation, and school attendance, and to provide an evaluation of the effects, or lack thereof, of government interventions to aid the poor. The data should allow local and provincial governments to target specific, identified challenges within the node. The node can aid in the identification of children who do not attend school, are not inoculated, etc., and can assist the relevant adult regarding the necessary steps to be taken. Most HDSSs also collect, analyse, freeze, and store blood samples (usually dry blood spots), meaning that they can be re-analysed years later if required. The HDSS is thus a key meeting point for the community, community leaders, academics, policymakers, and programme delivery managers.

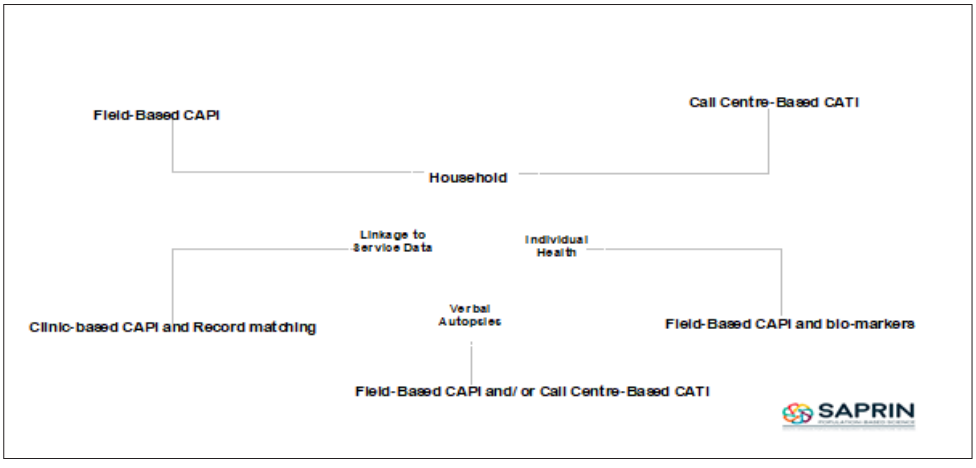

Figure 8.2: SAPRIN, *The SAPRIN model*

As Figure 2 clarifies, the considerable challenges of fieldwork rise to meet another challenge, linking the records of each person in the database with official records such as social security, health records, road to health cards for children, and school attendance.

Verbal autopsies (VA) are unavoidable in the context of poverty and poor record-keeping – although accurate, cause of death data is not merely a challenge for low and middle-income countries (LMICs). As Erin, Nichols, Byass, Chandramohan, Clark, Samuel, Flaxman, Jacob, Leitao, Maire, Rao, Riley, and Seftel (2018:1) noted, on behalf of the WHO Verbal Autopsy Working Group,

> "In low-income countries, many deaths are unregistered, unrecorded, and unnoticed by the health system. Nearly half of all countries fail to meet United Nations standards for death registration (90% coverage), while high-quality cause-of-death data are lacking for 65% of the world's population. Inadequate data on cause-specific mortality

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> patterns impede the development of sound health policy, planning, monitoring, and evaluation."

Verbal autopsies – based on questions about symptoms shown by the respondent – are now automated, with algorithm-driven diagnoses available. VAs are the best that is available, as Nichols et al. concluded:

> "Despite all improvements in design and technology, VA is only recommended where medical certification of cause of death is not possible. The method can nevertheless provide sufficient information to guide public health priorities in communities in which physician certification of deaths is largely unavailable."

HDSSs seek to influence policymakers by showing policy impacts over time, enhancing service delivery in the HDSS node by identifying health and other needs, and linking respondents with appropriate local service providers, clinics, or social security offices. Using nodes as locations for clinical trials directly impacts the node and society more generally.

HDSSs in South Africa

According to the literature, the first HDSS was established in South Africa in April 1940 (Tollman 1994) at Pholela Health Centre. However, historian Shula Marks has noted earlier Chinese (and other) experience at work; the founders of Pholela had been working in China in the 1930s, which influenced the South African experience (Marks 2013). Using a COPC approach, the HDSS was established by the Ministry of Health to identify and prevent diseases common in rural (then) Natal, such as tuberculosis, smallpox, typhoid, and measles, and to impact health policy (Ye et al. 2012:11). As Marks notes, the use of the term 'social medicine' and 'socialised medicine' in the inter-war years was based on an approach that emphasised the social determinants of health and disease, was inherently political, and influenced by socialism. According to Kark and Abramson (2003:882),

> "South Africa in the 1940s had become a major conceptual leader in the development of what later became known as community-oriented primary care, or COPC … as an effective mode of delivery of health services to the population. This found expression in the establishment in 1940 by the Health Ministry, ably led by Eustace Cluver and Harry Gear, of a demonstration health centre in a rural Zulu community (the Pholela Health Centre which Sidney Kark headed), the Gluckman Commission's far-seeing recommendation in 1945 of a nationwide network of community health centres…"

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The Gluckman Commission had made some powerful recommendations, most obviously for a national health service (influencing the later Beveridge Report in Britain) and an HDSS network. However, support waned once the political tide began to change in the immediate post-war period. When the Nationalist Party won power in 1948, that was the death knell for the Commission's work, but the recommendations were cited again in the 1990-1994 negotiations phase, suggesting that only a democratic state might finally be able to deliver on Gluckman, half a century later (Harrison 1993).

HDSSs were initially stand-alone, but in 1998 the International Network for the Demographic Evaluation of Populations and their Health in Developing Countries (InDepth) network was formed, with 36 member centres running 44 HDSSs. Of those, 32 were located in sub-Saharan Africa (Ye, Yazoume, Wamukoya, Ezeh, Emina and Sankoh 2012:12). By 2017, InDepth had 47 HDSS sites, following roughly three million people. One function of InDepth was to gather data across HDSS and establish standards for data acquisition (Herbst, Juvekar, Jasseh, Berhane, Nguyen Thi Kim Chuc, Seeley, Osman, Clark and Collinson 2022). The primary purpose of the HDSS remained observation of population dynamics in a specific geographic area to support epidemiological and other interventions. This gives some sense of the scales at work: from stand-alone HDSSs to a network including three million people in poor areas.

All data collection has weaknesses. The challenge is to identify and control these weaknesses so that survey data can offer inferential data (the search for generalisability) within measurable degrees of accuracy. Thus, while a census will give the best possible coverage, they occur at best once a decade. Sample surveys occur in-between, in multiple areas, and panel studies based on the core idea of returning to the same respondents are few and, by contrast with SAPRIN, limited in scale (the National Income Dynamics Study (NIDS) is a notable exception). Surveys are inevitably a trade-off between depth and breadth, usually governed by cost, and their results are a trade-off between accuracy and generalisability.

NIDS (using pre-COVID-19 figures) interviewed 39 400 individuals, in 10 800 households, in 2017 – the fifth outing for the study allowing face-to-face field work. SAPRIN annually gathers data on hundreds of thousands of people living in poor areas. SAPRIN uses GIS to code and map every structure in the node so that each node has a live map of every structure and specifies the multiple functions of a given structure. In urban areas, a dwelling may also be a car repair site but also a tuck shop, and may offer hair braiding, and cell phone repair. This all must be captured and combined with questions about transport, economic opportunities, etc. Once GRT-INSPIRED is fully operational (in 2022/3) and the Cape Town node (C-SHARP) a year later, SAPRIN will generate data annually on about half a million people living in poor rural and urban areas.

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Urban Fieldwork Challenges

Migration coupled with the legacy of the past has demographic effects that make Gauteng appear different than anywhere else in South Africa – it has more men than women, and almost 30% of all youth in the country (5.10 million or 28.6%) live in Gauteng (StatsSA, 2021). Far fewer older people live in Gauteng than in other provinces. This suggests that the health and demographic profile of Gauteng will differ from other, less urbanised provinces. The challenge is building trust to gain long-term access, which is made challenging by the mobility of many residents. There are many more attractions in urban areas than answering questions or giving blood samples.

In the era of big data, when 'harvesting' unverified secondary data is seen as cost-efficient, and thus attractive, the HDSS approach reminds us of the importance of accuracy in data, not the flashy dashboard, and of the value of face-to-face field work based on good community relations. This is true for all monitoring systems based on face-to-face interactions with people, which generate primary data that are measurably accurate. Repeat interventions in the same space with the same respondents build relations and improve data quality. A respondent may only open up about some vital event after a few years when they have come to trust the annual interview more or have seen benefits from participating. They may point out where they have been misleading field workers in prior interviews out of embarrassment or choice. An HDSS can make retrospective changes, which is part of the 'monitoring of a special type' an HDSS enjoys.

There is massive competition for peoples' time and attention in urban areas. In a space such as Hillbrow, there are multiple surveys, monitoring, clinical trials, and other interventions taking place. The environment combines a street economy of hustling and a 'flatland' that mixes captured buildings that are unsafe to enter, others where field workers are simply refused entry, and others that welcome field work. Access is always a challenge in urban areas, but it has led to new partnerships and may, in time, generate the need for smartphone applications to gather and send data. The sheer demographic size of Hillbrow makes it very difficult not to be sampled by any survey agency working in Gauteng. The HDSS must find purchase in this contested space, where field workers face security challenges and where respondents are preoccupied and streetwise. This contrasts with the HDSS in Morogoro, in rural Tanzania, which found that national and district officials had over-estimated numbers attending clinics for malaria treatment. The area had a 30% mortality rate because of malaria, which rose to 45% in children aged below five. Due to the HDSS data, a five-fold increase in malaria control resources was made available, and a 20-fold decrease in the under-five population (Ye, Yazoume, Wamukoya, Ezeh, Emina and Sankoh 2012:14). Any monitoring system operating in a

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cosmopolitan urban area such as Hillbrow has very little chance of such a neat match of need and supply.

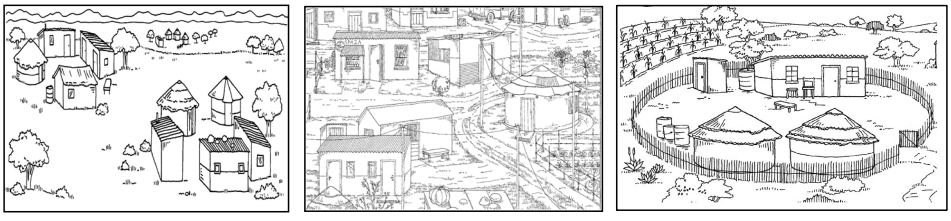

Figure 8.3: SAPRIN, *SAPRIN 'bounded structure' images*

As noted above, an HDSS is created first by completing a census of physical structures and households in the area as a baseline, followed by regular visits to each household to gather health and demographic data. The cohort is dynamic in that members are added through birth or immigration or leave the cohort through death or emigration. Tracking population migration is particularly important for HDSS data (Ginsburg, Collinson, Gómez-Olivé, Gross, Harawa, Lurie, Mukondwa, Pheiffer, Tollman, Wang and White 2021).

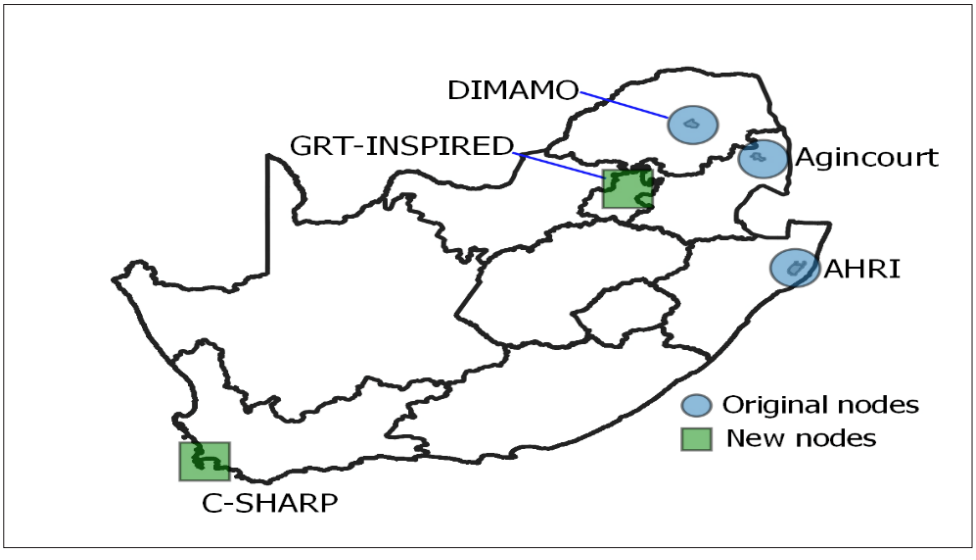

Figure 8.4: SAPRAN, *SAPRIN nodes*

As Figure 4 suggests, SAPRIN plans additional nodes in the Eastern Cape and eThekwini. As a result, migration should become an even more important work area for SAPRIN.

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A Quick Overview of GRT-Inspired

The Gauteng Research Triangle is a partnership between three major universities, each taking responsibility for different sites or parts of sites. The University of Pretoria, acting via the Department of Family Medicine, is responsible for all fieldwork in Melusi and Atteridgeville. Together, they generate data on 50 000 people. The University of Johannesburg and the Wits Reproductive Health Institute have divided the Hillbrow sub-place roughly in half. Each is responsible for data on 25 000 people, making up the other half of the 100 000-strong node. The selected Small Area Layers from StatsSA form a single contiguous space for each site. These three sites comprise the node.

Sankoh and Byass (2012:2) noted the following challenge:

> "In practical terms, one important consideration is whether the final population is defined as being within a contiguous area or in a collection of small areas (e.g., discrete villages) within a wider area. This has important logistic implications in terms of organising and maintaining on-going surveillance, as well as affecting the definition of migration events..."

The exact impact of these three separate sites remains to be seen. In Nairobi, the HDSS was in two slum sites but is currently redesigning to move into more spaces (Kyobutungi 2020). Given the complexity of the urban form in Gauteng, it was deemed important to spread the sites comprising the node to cover different spatial areas within Gauteng, but also very different urban forms.

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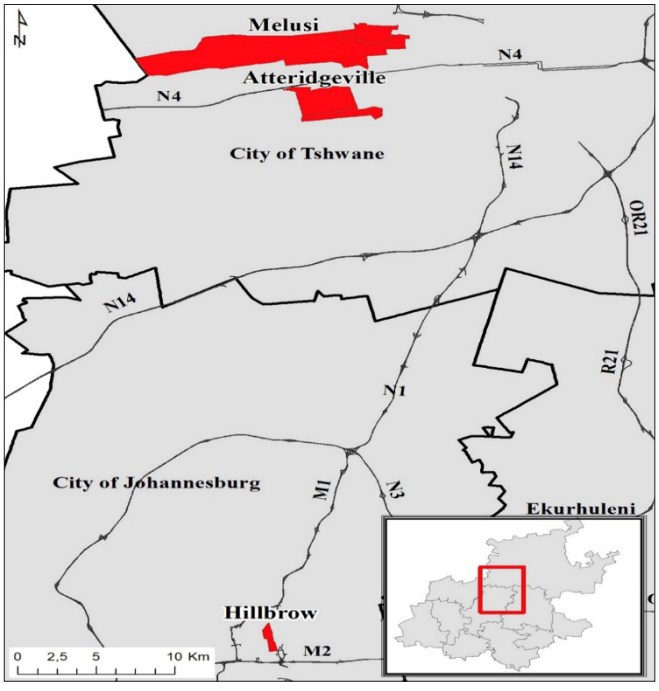

Figure 8.5: GRT-INSPIRED, *The three sites of GRT-INSPIRED (sub-places)*

The node is entitled 'GRT–INSPIRED: The Gauteng Research Triangle Initiative for the Study of Population, Infrastructure, and Regional Economic Development' because the approach from design onwards was multidisciplinary. Health and demography underpin the entire strategy but are integrated with urbanism and the built environment to understand the relationships between health outcomes and inequality, class, socioeconomic status, and related issues. Climate change is also key, and the relationship between it and health, demographics, and economics is a cross-cutting concern. GRT-INSPIRED will be installing thermometers in 10% of sampled dwellings to measure temperature change generally as well as extreme weather events and their relationship with disease. The critical issue of migrancy – internal and (in stark contrast to rural nodes) international – will be a significant focus.

In contrast with the rural homestead sketch above, Frith (s.a.), using Census 2011, calculated Hillbrow (the sub-place) was only 1.08km^2 yet had a population of 74 131 at a staggering density of 68 418/km^2.

As Figure 6 clarifies, densities are high in much of Gauteng, especially showing apartheid spatial architecture, but all are dwarfed by Hillbrow (the higher the spike

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on the image, the greater the density). If Hillbrow stands out due to density and sheer volume, Atteridgeville, the second site, is an old apartheid township. Like most townships, the small gardens of formal structures now mostly boast additional living quarters (for rent), ranging from formally built outside rooms to garages, tents, shacks, caravans, and abandoned old cars. People will do what they must to gain a toehold in the city.

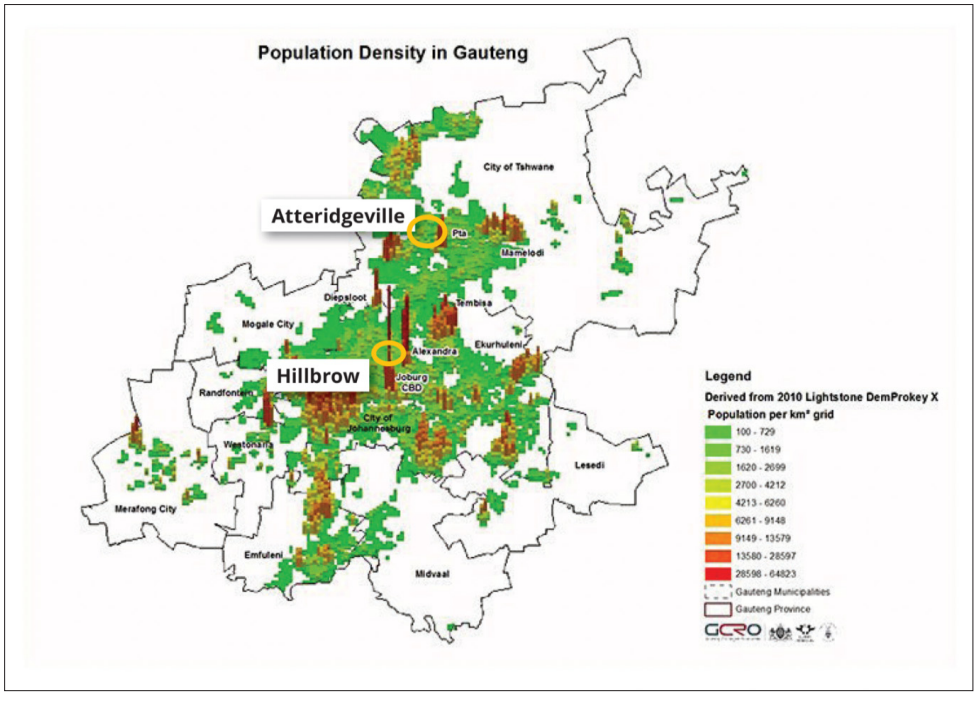

Figure 8.6: GCRO, *Population densities (and the GRT sites)*

The need for a toehold in the city is made clear in a different way in Melusi, which did not appear in Census 2011. However, by 2021 it had an estimated population of over 40 000 people, and the area is becoming a site and service settlement. The University of Pretoria (UP) had begun working in the area using a shipping container that was re-purposed as a community clinic, and Community Health Workers (CHWs) were deployed in the area by the provincial government to work with UP in providing COPC. Those CHWs are now part of the field team, accompanying field workers, and more proactively link residents with available services.

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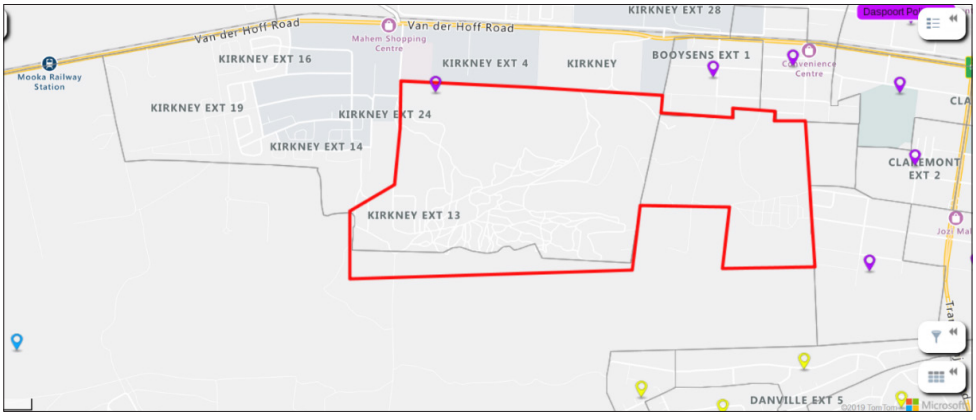

Figure 8.7: University of Pretoria, *Melusi*

The map, using official boundaries (sub places), does not give a sense of what is happening on the ground in Melusi. The Google Earth image below paints a somewhat different picture:

Figure 8.8: Google Earth, *Melusi with detail*

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The use of unclean water from the nearby abandoned quarry is self-evident from the image, which underscores the importance of the government as a partner in this intervention. If services are not provided, especially reticulation of potable water and sanitation, the pollution and disease that will follow (and are already present) are clear. However, the provision of services often attracts further growth. Gauteng grows at some 2.6% per year in population, as services and opportunities attract people. Policy interventions to better understand how to manage informality are inseparable from policy interventions to improve health outcomes.

Another reason for splitting the node into sites, aside from capturing different urban forms as well as different parts of Gauteng geography, came from the *South African Research Infrastructure Roadmap* (Department of Science and Technology 2016:35), which notes that South Africa faces "several challenges, including high levels of inequality … an unemployment rate of 25% [now 29%] … a poverty headcount ratio of 57% as well as colliding epidemics of HIV/TB and non-communicable diseases". In other words, separating any single issue from the 'colliding' challenges concentrated in Gauteng may miss a more complex picture, particularly of cause and effect. Gauteng is the smallest province in South Africa but has the largest population share (at 26% - 15 176 115 people), generating 34% of the national GDP (Katumbe and Everatt 2021).

The poverty headcount ratio is far lower (29,3%) than nationally, but the province has 1.9 million people living with HIV, second only to KwaZulu-Natal. The province includes Johannesburg, the most unequal city on the planet (Economist 2021). As StatsSA (s.a.) noted some years ago, Gauteng's economy is roughly the size of Morocco's national economy. It is the 7th largest in Africa but is far from equally shared.

Demographic surveillance in Gauteng must consider the province's urban, demographic, socioeconomic, and other characteristics. Gauteng is not simply 'urban' – it is a highly complex, profoundly unequal, racialised, and fragmented space comprising three metropolitan areas that form a continuous urban area. Gauteng offers a panoply of urban forms exacerbated by inequality and race, although the HDSS is not required in gated communities, lifestyle estates, or suburbia. A multi- or transdisciplinary approach and teams of analysts that locate HDSS longitudinal data in the varied contexts Gauteng offers, focusing on poorer areas, is vital. GRT-INSPIRED needs to locate health and demographic change in the messy realities of urbanism, which is no small task.

Our partners from the University of Johannesburg (UJ), for example, bring a different kind of science via their Water and Health Research Centre (WASH) and opportunities for non-health students to get into the field. UJ is a field partner for the SAPRIN protocols and has an additional intervention analysing the use, storage, and safety of stored water and sanitation. This involves getting access to high rise apartments in

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Hillbrow and the various forms of sanitation in Atteridgeville (formal and backyard), and Melusi. This is also important for community education. In the Angolan Dande HDSS, a water, sanitation, and hygiene (WASH) programme was launched within the node to reduce anaemia and malnutrition, and to protect preschool children (Rosario et al.). In coastal Kenya, 'pop up' questions, in addition to the protocol, include water sources and health (Kaneko, K'opiyo, Kiche, Wanyua, Goto, Tanaka, Changoma, Ndemwa, Komazawa, Karama, Moji and Shimada 2012:5). With COVID-19, this area of work became even more critical. Many households are still obliged to share sanitation facilities. Even a shared cloth for cleaning may become an agent of transmission, as with water stored in open containers. This also provides immediate feedback to the respondent.

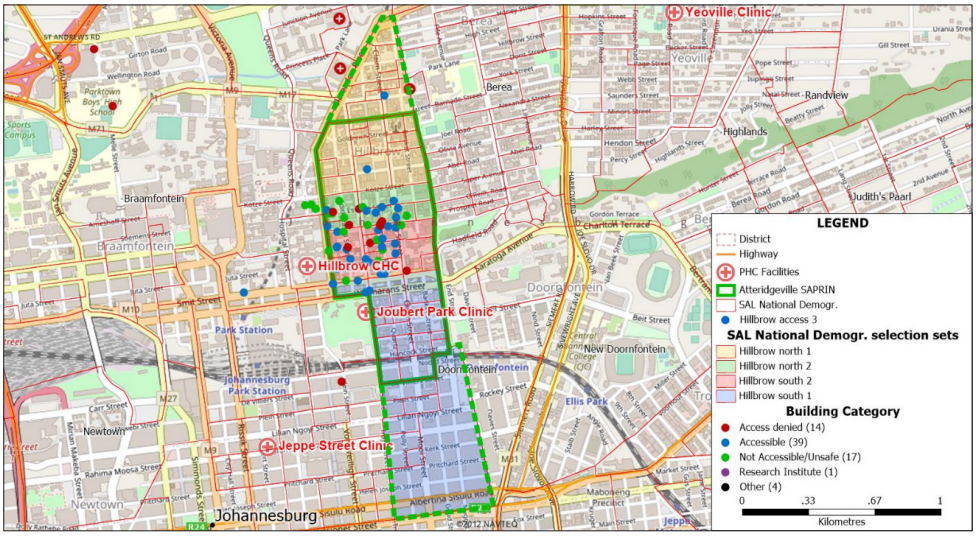

Figure 8.9: University of Pretoria, *The Hillbrow sub-place*

The challenge of access was expected to be primary in an urban HDSS, exactly as it is for survey or monitoring system fieldworkers, for reasons outlined above. Our Wits partner, the WRHI, has been working in Hillbrow since 2002, using CABs and other forms of community engagement. Given Hillbrow's reputation for criminal activities combined with massive diversity and similar population density, WRHI needed both a physical and reputational presence.

To contrast with the uniqueness of Hillbrow's high rise buildings and the informality of Melusi, Atteridgeville was selected as a classic 'township' designed by the apartheid regime to house black Africans who had managed to win rights to remain in the urban space. After democracy, many township households split, because, for the first time, there were no race-based restrictions on where they could live. Younger

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members frequently took the first step out of home into an informal settlement (Everatt, Jennings and Gotz 2005). The density challenge was somewhat reduced by the ability to move, even though economics firmly dictated where people could (afford to) move.

In Atteridgeville, GRT-INSPIRED found formal dwellings with various other structures in their backyards. Every household in every structure must be enumerated. Access was less of a challenge because the UP Family Medicine Department has been working from Kalafong Hospital in the area for years. Community mobilisation is a critical mainstay of GRT-INSPIRED in all areas but has been most needed in Atteridgeville. The layout makes planning somewhat more manageable, as Figure 10 suggests.

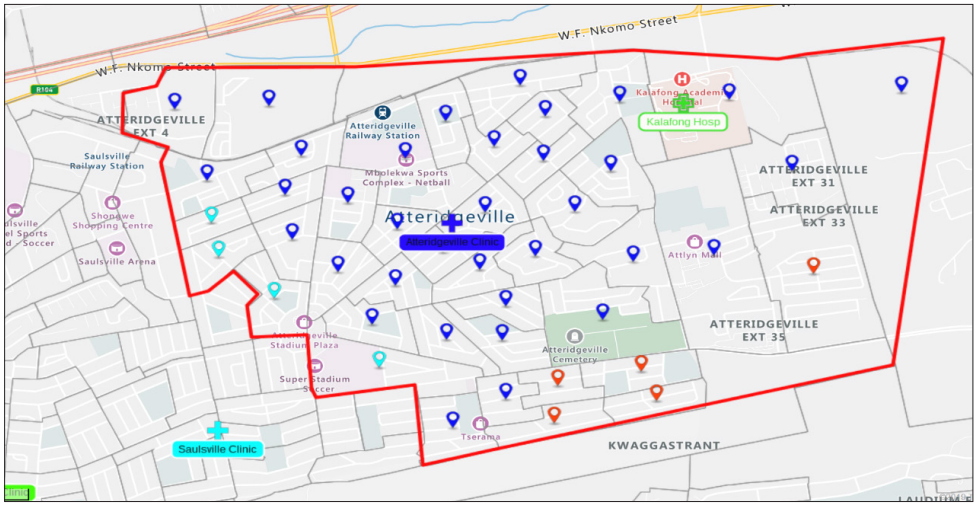

Figure 8.10: University of Pretoria, *Mapping fieldwork in Atteridgeville*

Conclusion

Monitoring is not value neutral. Monitoring is done with a purpose, which generally involves reaching evidence-based conclusions that can inform programmes, policy, and planning. The chapter opened by warning of the dangers, in a monitoring system or an HDSS, of being misused (such as digital imagery) or hi-jacked to become a commodity. Monitoring, as discussed here, is developmental. It is in place to help impoverished communities by providing some immediate benefits (such as COPC), but also for the long-term health of the community by linking findings to official records and partnering with the government to identify key areas of intervention that may be needed. The HDSS will still be in place after that intervention and can then evaluate its efficacy for the next cycle.

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HDSSs are not a rival or a substitute for monitoring or M&E systems. It is a different approach to data and understanding population dynamics, as well as development priorities, rather than being linked to a specific programme or project. However, all have the same goal, which is to work for improved quality of life in poor areas. This requires the government to pay attention to the findings, and strong governance to ensure that benefits intended for the poor reach them to help move people out of ill health and poverty, and towards the South Africa envisioned in 1994.

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