A Data Model for Demographic Surveillance Systems[1]

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Abstract

Longitudinal population information is a critical resource for many health intervention projects. Typically, such projects must maintain individual level information while the composition of a geographically defined population changes through births, deaths and migrations. In addition, given the strong correlation between health and socioeconomic status, many projects must maintain socioeconomic data such as marital, family relationship, and economic information. Finally, such projects often require a controlled field operation infrastructure to oversee and support data collection and entry. With these three elements in place, researchers can then easily and accurately assess rates of disease, test health interventions, and identify determinants of health. Altogether, these complex requirements create numerous difficulties in designing a computerized database system. In this paper, we present a data model that satisfies the core requirements of such longitudinal population projects. The model makes explicit the common attributes of most health and family planning studies. In addition, the model serves as a structural framework on which project specific data could be added.

Keywords

Data Model, Longitudinal, Population

Introduction

Longitudinal population information is a critical resource for many health intervention projects. Typically, such projects must maintain individual level information while the composition of a geographically defined

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population changes through births, deaths and migrations. In addition, given the strong correlation between health and socioeconomic status, many projects must maintain socioeconomic data such as marital, family relationship, and economic information. Finally, such projects often require a controlled field operation infrastructure to oversee and support data collection and entry. With these three elements in place, researchers can then easily and accurately assess rates of disease, test health interventions, and identify determinants of health. Altogether, these complex requirements create numerous difficulties in designing a computerized database system. In this paper, we present a data model that satisfies the core requirements of such longitudinal population projects.

The goal of our work is to develop consensus among working groups on the definition of a data model for maintaining longitudinal population information. The authors of this paper have had many years of experience, working independently, developing software systems for maintaining longitudinal population information. Developing such software is a difficult and time-consuming task, prone to conceptual and programmatic errors. One of the initial challenges for all software developers involved in such projects is the correct organization of data. In two conferences held in the past year, in London, England (Kahn 1997) and in Heidelberg, Germany, technical working groups considering this problem discussed possible grounds for consensus, and found considerable commonalties. The model was subsequently used as point of departure at a joint application design session for a new Demographic Surveillance System (DSS) for the Wellcome Africa Centre for Population Studies and Reproductive Health.

The goal of a standardized data model would provide many advantages to field sites in terms of exchange of information, swift formulation of site-specific software, and ability to work with data on-site. Toward this end, we present a data model that builds on the combined expertise of different sites and solves many of the difficulties of longitudinal data collection and analysis. We welcome the ideas and work of others toward our end of detailing a universal reference model that achieves the goal of efficiently and accurately managing longitudinal data in a standardized format.

Background

This work has been informed by the achievements, limitations, and future needs of projects in Bangladesh, Indonesia, Burkina Faso, South Africa, Tanzania, Senegal, Mali, Uganda, and Ghana. One of the earlier systems, The Bangladesh DSS, was developed in the 1960s and has since been used for a wide range of studies of demographic dynamics, family planning, epidemiology, health services research, and other issues (D'Souza 1984, Rahman and D'Souza 1981, Phillips 1992). The Bangladesh DSS precisely defined rules for members of a population under study; this, combined with a data system that implemented rigorous logical consistency checks, provided high quality data that resulted in thousands of research papers. A number of software systems were written based on experiences with the Bangladesh DSS, including the Sample Registration System (Mozumdar et al 1985, Leon 1986a, 1986b, and 1987, Phillips et al 1988), The Indramayu Child Survival Project of the University of Indonesia (Utomo et al 1990).

The demographic surveillance system in Niakhar, Senegal, most recently described in (Garenne 1996), has also influenced a number of projects including those in Agincourt, South Africa (Tollman et al 1995) and Prapass in Burkina Faso (Sauerborn, et al 1996). In (Garenne 1996), the important concept of entry-exit files (something we refer to as episodes) is described as a means to model intervals of residence at a location and intervals of relationships. (Garenne 1996) also provides many useful observations concerning the particular implementation of field and software systems for longitudinal population projects.

The data model proposed in this paper is the first step in a process that can lead to software and data systems shared among field sites. The idea that there is a demographic "core" that is common to field stations doing longitudinal research on populations is described in (Phillips 1991, MacLeod 1991, MacLeod 1996). The HRS, a software system that implements the demographic core, maintains a consistent record of significant demographic events that occur to a population in a fixed geographic region, generates registration books which are used by field workers, and computes basic demographic rates such as birth rate, mortality rate, and total fertility rate. These core capabilities for maintaining demographic surveillance information form a computational framework onto which projects add their site-specific data and consistency specifications. The HRS formed the basis for software systems in Ghana (Binka 1995, Binka 1997), Tanzania, Indonesia, Uganda, Gambia, Bangladesh and Mali for a wide range of studies including family planning research, malaria interventions, child and maternal health, and correlates of HIV transmission. The data model described in this paper improves on the data model underlying the first version of the HRS software by allowing for the tracking of non-resident individuals, more generalized relationships other than just marital, and by separating social groups (usually the household or family) from the location[2].

The data model design we propose builds on and integrates the work from these various projects to produce a standardized model for future software development. A standardized model has many advantages, particularly in the exchange of data between field sites, and the ability to produce accurate and reusable software.

Data Model

In simple terms a demographic surveillance system is concerned with tracking the presence of individuals in a defined study area. Individuals can enter and leave the study area in a small set of well-defined ways, eg entering through birth or in-migration, and exiting through death or out-migration. In the proposed reference model events are used to record the way in which an individual enters (or returns to) and leave the study area over time. Events therefore bracket the residence of the individual in the study area. In general events occur in pairs, with one event initiating a state, eg presence in the study area, and another terminating the state. This pairing of initiating and terminating events is made explicit in the reference model through the use of episodes.

When tracking episodes, the concept of the "time resolution" of this tracking is very important. Below a certain time threshold movements into or out of a particular physical location are not recorded. If a person leaves the physical location in the morning to go to the market and return in the afternoon, this is not reflected in the DSS at all. If this period of absence increases beyond a certain threshold (6 weeks, 3 months, or any other period) it turns into an episode which should be recorded in the DSS. This threshold can vary from project to project, but must be made explicit. The time resolution for "in" episodes should be consistent with the time resolution for "out" episodes, that is, the time before a visit becomes residence or the time after which an absence becomes an out-migration.

Demographic surveillance systems are not only concerned with the physical location or residence of individuals, but also with their memberships to social groups, such as households, and with their relationships with other individuals, such as marriage. Many demographic surveillance systems also require the ability to reconstruct genealogies and to record isolated events, such as pregnancy outcomes or births and deaths external to the study area.

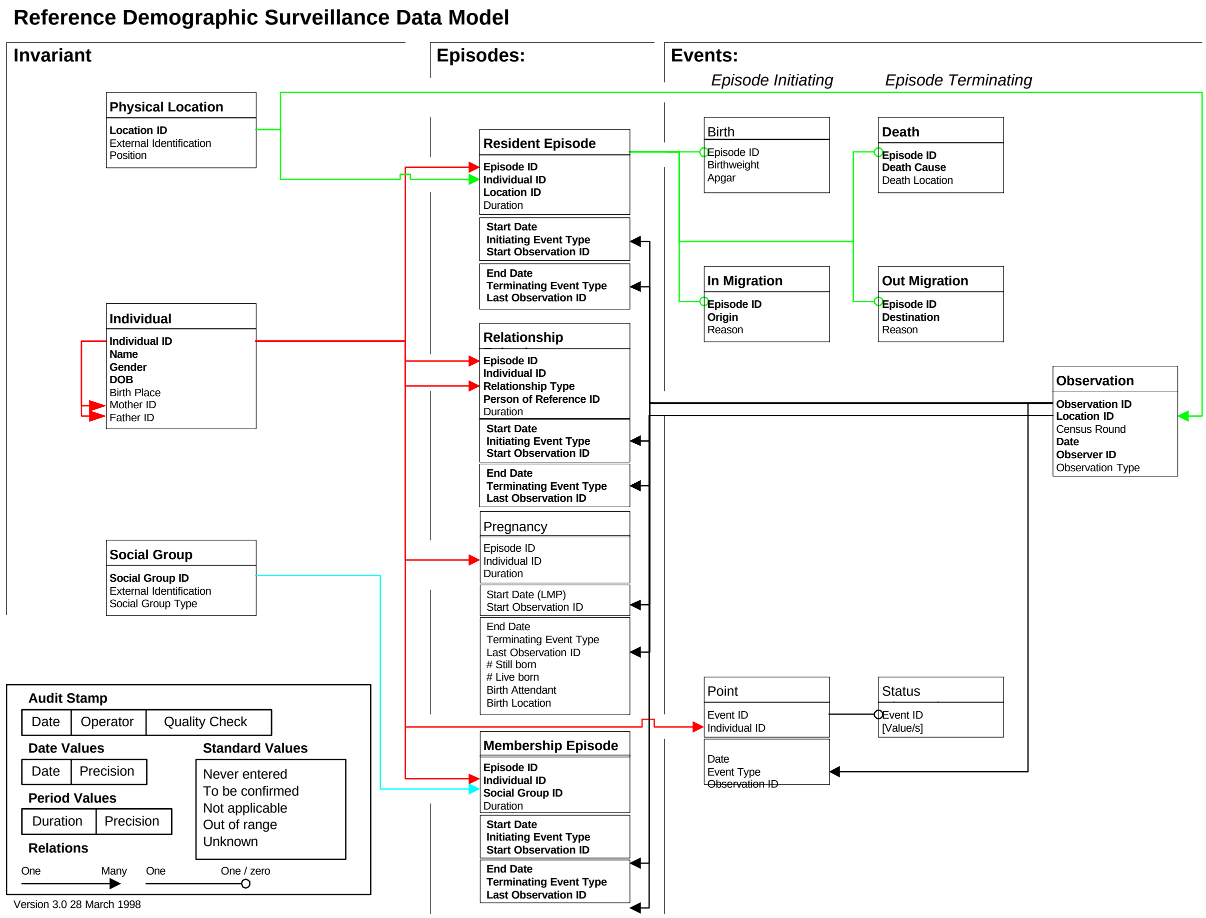

Figure 1

To support field operations and the routine cleaning of data, a demographic surveillance system also needs to keep track of where, when and who recorded a particular event. In this respect, the reference model provides a number of fields that facilitate the construction of a quality data set. Another problematic area in demographic field operations is the correct identification of migrating individuals. The reference data model provides information to resolve this problem by including fields that designate the place a migrant is moving to or coming from.

The proposed reference model addresses these requirements through the use of the following entities and the relationships between them:

Individual. This entity contains a record for every individual who resides or has ever resided in the study area. Optionally this entity may record individuals whose residence in the study area has not been recorded, but is required to complete a genealogy or relationship record. Records are uniquely identified through an individual identification value (ID). Genealogical linkages between individuals can be established by storing the IDs of the father and mother of the individual. This information (mother and father ID) can also be useful for identification purposes, especially in cases where name and date of birth are fuzzy as often is the case in sub-Saharan Africa.

Physical Location. The physical locations where individuals can stay are recorded in this entity. Each record may identify a homestead, stand, plot or any other place where individuals may stay, either singly or in groups. It should be possible to describe the position of the location through the use of a co-ordinate or series of co-ordinates, such as latitude and longitude pairs. This feature provides for an easy linkage to a geographic information system (GIS). External identification information such as stand number or address can be stored in addition to the unique location identification value. An individual is associated with a physical location at a given point in time through a resident episode.

Social Group. The information related to a defined social group, such as a household, are stored in this entity. An individual is associated with one or more social groups through one or more membership episodes.

Observation. The observation entity stores the information that a particular physical location has been observed at a given point in time. Information on the person making the observation and optional information such as the census round can also be stored as part of this entity. The observation entity is linked to all the events recorded during the observation.

Events. Events may indicate a transition in the state of an individual, eg the transition from a resident to a non-resident in the case of an out-migration event. In these cases the information about events that initiate and terminate a particular state of interest (eg residency) are combined and recorded as an episode (eg resident episode). These types of events are known as *"paired events"*. Events, which are not intended to record the start and end of a particular state, are known as *"point events"*. The information common to all events, such as date of occurrence, type and the ID of the observation during which the event was recorded, are stored as part of the episode initiated or ended by the event (in the case of paired events) or in the Point Event table (in the case of point events). Additional data associated with an event are stored in a separate entity (see below). The following event types are proposed:

1. *Null event*. If an episode has commenced, but has not yet been terminated the terminating event type is set to null ("Never entered" in terms of the standard values). The date and Observation ID provides the date and observation during which the unterminated state of the episode has last been observed.

2. *DSS Entry*. Used mainly during the establishment of a demographic surveillance system to record the presence of individuals in the study area, as well as their membership of social groups and their participation in relationships. It can also be used to record individuals missed during the initial census.

3. *DSS Exit*. Used mainly at the termination of a demographic surveillance system to conclude all open resident, membership and relationship episodes. It can also be used to record individuals lost to follow-up.

4. *Birth*. Records all live births to residents (Still births are recorded as a pregnancy outcome event). The event is linked to the resident episode that it will initiate. It will initiate social group membership and relationship episodes as well.

5. *Death*. Records all deaths of residents. A death event will terminate all open episodes belonging to the individual. The death event record is linked to the resident episode which the event will terminate and contains additional data such as the location and cause of death.

6. *Relationship Start*. Records the start of a relationship of one individual to another. By convention relationship events are linked to the female in cases of heterosexual relationships and the younger

individual in cases of same sex relationships. In the case of care-taking relationships the relationship events are linked to the person receiving care.

7. *Relationship End*. Records the end of a relationship between two individuals.

8. *Membership Start*. Records the start of an individual's membership to a particular social group.

9. *Membership End*. Records the end of an individual's membership to a particular social group.

10. *In-Migration*. An in-migration event initiates a new or changed physical location for an individual. It records the start of a new residence episode for an individual. An in-migration can originate from with-in or from outside the study area. Additional data such as Origin, etc are usually stored in a separate entity linked to the episode via the Episode ID.

11. *Out-Migration*. An out-migration event terminates a residence episode at a particular physical location for an individual. The destination of an out-migration can be with-in or outside the study area. Additional data such as Destination, etc are usually stored in a separate entity linked to the episode via the Episode ID.

12. *Status Observation*. Any number of optional events can be defined to record status information observed from individuals. Examples include socioeconomic status, immunization status, nutrition status or educational status. Repeated status observations make no assumptions about the value of observed attributes during the observation interval, even if subsequent observations measure the same values.

Resident Episode. A resident episode records the stay of an individual at a particular physical location. A resident episode can only be initiated by a DSS entry, a birth or an in-migration event. It can only be terminated by a DSS exit, death or out-migration event.

Membership Episode. A membership episode records the membership of an individual to a particular social group. A membership episode can only be initiated by a DSS entry, a birth or a membership start event. It can only be terminated by DSS exit, a death or a membership end event.

Relationship Episode. A relationship episode records a time-dependant relationship, such as marriage, between two individuals. The episode is started by a relationship start event and concluded by a relationship end event, death event, or DSS exit. The relationship episode records the IDs of the two individuals involved in the relationship, but the events initiating and terminating the episode are linked to only one of the individuals as described above.

Pregnancy. Pregnancy is recorded as an episode, with certain attributes completed on the first observation of the pregnancy and others when the outcome of the pregnancy is known. One lesson the authors have learned is that if you want to do a good job in child registration, you have to register pregnancies first. If a pregnancy is not observed, but only the outcome, the start of the pregnancy episode is still recorded as the date of the last menstrual period (LMP) prior to the pregnancy. In this case the start and last observation IDs will point to the same observation instances. If the pregnancy is terminated by the woman's death or out migration the reason for termination is recorded as the terminating event type and the episode concluded. In the normal course of events the pregnancy outcome could be recorded in the terminating event type as spontaneous abortion, induced abortion, normal delivery, assisted delivery, or caesarean section. The birth location field refers to the delivery environment, eg the name of a hospital or clinic where the delivery took place.

Figure 1 provides a graphic representation of the proposed entities and relationships. Fields and entities that are mandatory are displayed in a bold font while optional fields and entities are displayed in a normal (not-bold) font.

Data Integrity

A DSS needs to maintain a large volume of data over an extended period of time. If specific data integrity measures are not taken data integrity will suffer and consequently the accuracy and reliability of the information in the system as well. The most important measure that can be taken is to base the system on a well-defined relational model. A number of additional measures can support the data integrity of the system:

- Audit stamp. The audit stamp is part of every record in the database and records the operator and date-time of the last update to the record. In addition a quality check indicator may record whether the record has been verified, e.g. through a double entry process.
- Standard values. Standard values should be used consistently through-out the database to indicate the status of a particular data value. The following standard values are proposed:
    - **Never entered.** The default value for all data fields in a newly created record.
    - **To be confirmed.** Reason exist to query the value as it appears on the data input document and follow-up action needs to be taken.
    - **Not applicable.** Given the data in related fields or records, a value for this data field is not applicable.
    - **Out of range.** The value on the input document is out of range and could not be entered. Follow-up action yielded no better information or is not applicable.
    - **Unknown.** The value is not known. Follow-up action yielded no better information or is not applicable.

    The actual values used to indicate the standard values depend on the data type of the field and the natural value range of the data item. Care should be taken to exclude these values during numerical analysis of the data.
- Date values: Are of particular importance in a DSS and recording the precision of date values is recommended. Each date or duration field should have an associated precision field where

the precision of the date value can be recorded, e.g. minutes, hours, days, weeks, months, quarters, semesters, years, decades.

Example

An example will help to understand how "real life" is translated into records of the reference data model. It deals with four somewhat related individuals, who are followed within a DSS over a period of eight years.

The demographic surveillance starts in 1990. During the baseline census the household H1, resident at this place since several years, is registered at the location L1. For the only two household members husband A and wife B, married since several years as well, this initial registration means one DSS Entry event each, initiating their resident and membership episodes and the relationship episode between them (attributed to wife B).

In 1991 an In-Migration event is recorded in the nearby household H2 at the location L2. It concerns a 31 year old migrant worker, coming back to his father's household. This single man C was absent for several years, but he always contributed to the household economy by regularly sending money.

In the household H1 a first child D was born in 1992. The little girl became resident at L1 and member of H1 by birth. One year later her father A died. His death terminates his residence at L1, his membership in H1 and his wife's relationship to him.

During the following years an informal relationship developed between the young widow B and the now settled ex migrant worker C. In 1995 they decided to marry and to build up a common hut near the household H2. This decision has quite a lot of consequences in the database and affects quite a lot of episodes: The household H1 was dissolved; man C, woman B and her daughter D moved to the new location L3 and formed the new household H3 there. Woman B and her daughter C each have an Out-Migration event from household H1 and an end of membership in household H1 event. There are also In-Migration events for B, C and D at location L3 as well as Membership Start events in household H3. B's

Relationship Start to husband C and her daughter D's Relationship Start to her new father in law C as her caretaker (beside her mother B) are recorded as separate events.

In 1996 they all moved to a new and bigger house at the other edge of the village. Apart from their change of residence from L3 to L4 no other episodes are affected. All three are still members of the same household H3.

Finally, in 1997 the man C got a new contract outside the surveillance area and the whole family left. All pending episodes of household H3 members are terminated, including the still ongoing membership of man C in his father's household H2. There is only one Out-Migration event for each of the three household members in the real world.

Individual	Description	BirthDate
A	man / husband1	1965
B	woman / wife	1970
C	man / husband2	1960
D	child / daughter	1992

1 Observation

1 Event

Date	Loc.	Individual	Event type	initiates	*terminates*
1990	L1	A	DSS Entry	Resident Episode at location L1	
				Membership Episode in household H1	
		B	DSS Entry	Resident Episode at location L1	
				Membership Episode in household H1	
				Relationship Episode to husband A	
1991	L2	C	In-Migration	Resident Episode at location L2	
				Membership Episode in household H2	
1992	L1	D	Birth	Resident Episode at location L1	
				Membership Episode in household H1	
1993	L1	A	Death		*Resident Episode at location L1*
					Membership Episode in household H1
		B	Relationship End		*Relationship Episode to husband A*
1995	L1	B	Out-Migration		*Resident Episode at location L1*
			Membership End		*Membership Episode in household H1*
		D	Out-Migration		*Resident Episode at location L1*
			Membership End		*Membership Episode in household H1*
1995	L2	C	Out-Migration		*Resident Episode at location L2*
1995	L3	B	In-Migration	Resident Episode at location L3	
			Membership Start	Membership Episode in household H3	
			Relationship Start	Relationship Episode to husband C	
		C	In-Migration	Resident Episode at location L3	
			Membership Start	Membership Episode in household H3	
		D	In-Migration	Resident Episode at location L3	
			Membership Start	Membership Episode in household H3	
			Relationship Start	Relationship Episode to caretaker C	
1996	L3	B	Out-Migration		*Resident Episode at location L3*
		C	Out-Migration		*Resident Episode at location L3*
		D	Out-Migration		*Resident Episode at location L3*
1996	L4	B	In-Migration	Resident Episode at location L4	
		C	In-Migration	Resident Episode at location L4	
		D	In-Migration	Resident Episode at location L4	
1997	L4	B	Out-Migration		*Resident Episode at location L4*
					Membership Episode in household H3
					Relationship Episode to husband C
		C	Out-Migration		*Resident Episode at location L4*
					Membership Episode in household H3
					Membership Episode in household H2
		D	Out-Migration		*Resident Episode at location L4*
					Membership Episode in household H3
					Relationship Episode to caretaker C

Figure 2

Figure 2 provides a summary of the changes that occur in the example population and the effects that these changes have on the entries in the Reference Data Model.

Extensions

While the Reference Data Model (RDM) is thought to cover the common aspects of most Demographic Surveillance Systems (DSS), it can't foresee their more particular needs, created by specific research questions or individual characteristics of each site. The RDM should however allow easy integration of additional components in order to respond to a wide spectrum of specific needs without losing its clear overall structure. Several ways to do this are presented in this section.

Adding fields to existing entities: This is the easiest way to include additional information, if this information can be interpreted as fix attributes of already implemented objects, events or episodes. Examples are: inauguration date of a physical location, ethnic group, rhesus factor or weaning age of an individual, or presence of a supervisor during an observation.

The entity "Status Observation" provides a very flexible interface to include any attributes of special interest related to an individual at a given point in time. It can easily be adapted to store specific information about individuals interviewed or examined during either cross sectional or panel surveys. For example, if one would like to document development of malaria parasitemia and body temperature in children during a bednet trial, a specific status observation table can be designed having the additional fields "Parasites/ml" and "Temperature/C", and records could be created and filled for all children in the trial during repeated weekly observations. This event can also be used to record maternal histories.

Defining new types of social groups and relationships: Whenever interaction between individuals can be formalized in a way, which allows to define a start and an end point of this interaction, it can be expressed in terms of social group membership (interaction with all other individuals being members of the same social group at the same time) or of relationship to just one other individual. We already mentioned household membership and marital and care-taking-relationship as interactions which are typically important to be recorded in most DSS. Other types of membership might be scholarship, enrollment in health insurance or prepayment schemes, participation in women groups, youth groups or professional associations. Relationship can also concern a patient's relationship to his health care provider or a tenant's relationship to his land-owner.

In a wider sense membership might not always be limited to social groups, but might cover for instance "membership" of a chronically ill individual in the group of people suffering from a certain disease, or membership in a nested cohort study (where fulfillment of some predefined criterions might be the start event and arise of others the end event). If religion is recorded, it depends on the focus of a DSS and the habits of the covered population, whether religion is defined as a fix attribute of individuals or whether each individual can go through subsequent membership episodes to different religious groups during his life.

Adding new types of episodes and events: As shown above, the four "predefined" types of episodes - recording relationship episodes of individuals to either physical locations (residence), social groups (membership) or other individuals (relationship) - can already respond to very different purposes. If one doesn't want to stress the meaning of "social group membership" too much, other types of episodes can be defined in order to follow virtually all kinds of non-constant attributes of interest. Apart from illness episodes this can be for instance episodes of risk exposure (e.g. smoking, mine work), specific behavior (e.g. use of contraceptives) or occupation. Where attributes can subsequently have different values, point events indicating a value change may be more appropriated than episodes.

New event types can help to store supplemental information, which is applicable only under specific conditions, while keeping the corresponding episode record lean. If for instance a study wishes to collect detailed data on traditional marriage, it would make better sense to create a well adapted marriage event table rather than add a set of new fields to the relationship episode. Adding slightly modified birth and death tables (linked to individuals instead of episodes) would allow to record these vital events not only for residents, but also for external individuals, which joined the DSS later, left it before or never were part of it.

Defining events and episodes for physical locations and social groups: In the RDM events and episodes refer always to individuals, sometimes relating them to other objects. In an extended model we can define additional events and episodes, which refer to physical locations or social groups. Point events (value change type) and status observations can be defined to record information collected or observations done on physical locations (e.g. housing type, water supply, number of rooms) or on social groups (e.g. ID of household chief, monthly household income, agricultural production), if we deal with non-constant attributes.

Sometimes episodes may be more appropriate, for example if we record households' rather than individuals' enrollment in health insurance or prepayment schemes or if we want to document periods, when a physical location is equipped with impregnated mosquito curtains.

Social groups can be related to other social groups, or "first-level" social groups like households can be members of "second level" social groups like clans or other types of networks. DSS interested in the interaction between households might want to define relationship episodes and membership episodes for social groups in order to store information about this topic.

Households are normally associated with one homestead even if members of the household may reside at more than one physical location. When using social groups to record households this association can be depicted by an episode, which records the start and termination of occupation at a particular physical location. Households also normally have a head of household. This head may change with time, but the household will still retain its identity. The head of household can either be recorded as an updateable attribute “Current head of household” of the Social Group entity or if the temporal dimension is important as an episode linking the household to the individual acting as head of household.

Conclusions

This paper presents a data model that three system developers, working in three areas of the world, believe is appropriate for modeling a population as it changes over time. The model makes explicit the common attributes of most health and family planning studies. In addition, the model serves as a structural framework on which project specific data could be added.

Much work remains though. While the authors have had extensive experience in rural settings and believe the model will work in more urban research environments, the model has not been tested in a project that requires an urban demographic system. The process of adding project specific data needs to be better understood and clarified. If the process is better understood, there is potential for automating the addition of project specific data. More work is needed for sites that require better data privacy than simply restricting access to the data set. Certainly, separating the name from the ID field is the first step in providing better data privacy. Finally, a software system that maintains the information in the reference data model as well as supports the more routine aspects of a field system is needed. In this regard, work is already underway to incorporate features of the reference data model into the HRS software system.

We believe that reaching consensus on this data model will have a number of positive outcomes. Projects, which failed in the past due to faulty data designs, will have a reference point for organizing data. Different field sites can share data if there is agreement on the organization of information. Finally, a broadly accepted data model could serve as the basis for shared system development efforts. The authors welcome questions, comments and suggestions toward this end of building a broad based consensus.

NOTES

1. The authors for this paper appear in alphabetical order.
2. The most recent version of the HRS (HRS2) incorporates these features into the system.

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