Improving the use of data in models to inform governmental and non-governmental organizations (Work group 2)

Pre-NEF Satellite Workshop on Modeling of Infectious Diseases with a focus on Ebola

***Group members**:* Gameli Adzaho, Folashade Agusto, Abdoul Aziz Fall, Brad Greening, Mountaga Lam, Diene Ngom, Farai Nyabadza*, Juliet Pulliam*, Grzegorz Rempala. Report compiled by JP, based on discussion among all group members.
* denotes co-chairs

During the West African Ebola epidemic, modeling played an important role in instigating action and informing policy decisions within the context of US government agencies; however, within the context of on-the-ground decision-making in affected countries, models and modellers had little engagement with or influence on policy decisions. This difference arose in large part from recent efforts within the US that have begun to align the priorities of modelers and decision-makers and to increase communication and mutual understanding between these groups. These efforts include initiatives such as NIH/NIGMS's MIDAS program and the RAPIDD program of DHS/FIC, CDC's modeling unit, and the multi-agency EEID program.

Discussion during this work group focused on identification of (1) barriers to integration of models into decision-making processes, (2) strategies individual modelers can use to have an impact on policy decisions, and (3) upstream, system-level changes that are necessary to improve integration and ensure sustainable interactions between modelers and decision-makers.

Barriers to integration

A number of barriers were identified that can limit the impact of models on decision making. Some of these barriers are the result of discipline-specific cultures and perspectives. In particular, decision-makers have many competing demands on their time (especially in an emergency), must remain focused on the task or question at hand, and are eager for information that can be quickly incorporated into a decisionmaking process - which is often manifested as a tendency to focus on specific numbers, or failure to take into account underlying uncertainty (in structural assumptions and parameter values) that affects the model output (qualitative and quantitative predictions). Modelers, particularly those based in academic settings, on the other hand, are typically trained to think independently, asking their own questions, and to frame their results abstractly and emphasize technical details, which can make findings inaccessible to policy makers. A key to dismantling these barriers will be to cultivate modelers who can understand the perspectives of policy makers and adapt to their needs, while simultaneously increasing awareness among policy makers of the appropriate (and inappropriate) uses of models and their interpretation. Decision makers should be trained to view models as a communication tool that translates between a set of assumptions and information based on the data available to a potential outcome - that may or may not be robust to violation of the assumptions or availability of new information, but can be used to investigate and understand the extent of such robustness.

Technical barriers also exist. These barriers come in two primary forms: access to necessary data, on the one hand, and appropriate use of data, on the other. The Ebola epidemic highlighted both how technological advances have increased the potential for real-time dissemination of infectious disease data and the complex tensions that surround public access to such data - including privacy concerns, potential issues related to data integrity (resulting mainly from the rapidly changing context of data collection), and questions of data ownership and appropriate credit for their use. In order for the discipline of modeling to maintain credibility of decision makers, it is also essential that available data be used appropriately. This places a burden on modelers both to understand the context in which data were collected and important caveats regarding their interpretation - which will often require direct and potentially frequent communication with those collecting or curating the data - and to learn and use appropriate statistical methods for integration of data and models, which may require collaboration with statisticians or those with experience and training beyond mathematics. Overfitting - in which too many parameters are fit relative to the amount of information available in the data - is a particularly common and troublesome problem observed when modelers have insufficient understanding of the data and relevant statistical methods. Overfitted models often appear to do an excellent job of capturing the past dynamics of a system; however, their external validity is low, reducing both predictive ability and the robustness of model-based findings. Therefore, overfitting is particularly dangerous in the context of using models to inform decisionmaking.

Recommendations

- Increased emphasis on cross-training of modelers in epidemiology and public health and of public health decision makers in the use and interpretation of models. This should be achieved through a combination of integration of specialized courses on these topics into degree programs, facilitation of dual-degree options (eg, combining a PhD in mathematics, statistics, or ecology with an MPH in Epidemiology), and intensive short-term training opportunities that leverage both perspectives.
- Increased emphasis in the training of modelers on the development of a diverse quantitative toolkit, including different dynamical modeling approaches that can be tailored to different questions and datasets, as well as a variety of statistical methods, and the appropriate integration of dynamical and statistical models.
- Training in ‘soft-skills’ for modellers, with an emphasis on skills that will increase their utility to and ability to work with decision makers - in particular, communication training (including oral presentations for this audience and how to write policy briefs) and early experience and training in how to operate effectively in interdisciplinary teams.
- Establishment of data-sharing platforms that can be used in emergency situations (but should be set up ahead of time) to increase availability of real-time data for use in modeling, similar to existing platforms for routinely collected data (such as Demographic and Health Surveys, census data, and mortality records, for all of which deidentified, individual-level data can be accessed, with permission, for research purposes, following submission and review of an appropriate research proposal).

- Upstream of all of these considerations, access to the scientific literature remains a barrier for many modellers based at academic institutions within developing countries, and this gap should be broadly addressed.

Strategies for individual modelers

Given the diversity of experience among group members, which ranged from pure mathematicians to a member of CDC's modeling team (BG), a substantial amount of discussion focused on steps that individual modelers can take to increase their impact on and relevance of their work to public health decision-making. Recommendations for individual researchers are outlined in the appendix below. These recommendations are drawn from presentations given by Dr. Juliet Pulliam at the pre-NEF minisymposium (entitled "Models Meet the Real World: Lessons from Ebola in West Africa") and Dr. Brad Greening at the workshop (Panel 1: Lessons Learned from Ebola), with modifications informed by the group discussion.

System-level changes and infrastructure requirements

The group worked toward developing a shared vision for what interactions between modellers and decision makers should look like. We believe that, in an ideal scenario, relationships should be initiated well before emergencies arise, should consist of coordinated interdisciplinary relationships with long-term engagement, should include frequent communication and integration of both perspectives throughout the process - with modellers helping prioritize data collection and decision makers' questions informing model development. In addition, any systematic attempt to improve interaction between modellers and decision makers should include - from the get-go - strategies the assess interactions and initiatives to improve these interactions, and should facilitate adjustments on the basis of these assessments, to help establish long-term sustainability of relationships and initiatives.

Recommendations

- Enable interdisciplinary career paths (including within academic institutions)
    - Partnerships between sectors can be built via internships (enabling entry into career pathways other than academic research, and leading to embedded expertise within governmental organizations and NGO's)
    - Establish/understand career trajectories for young modelers interested in having interdisciplinary research focus
- Invest in development and training (of modelers) in tools that allow decision makers an ability to investigate assumptions (web interfaces, etc)
- Coordinate among existing institutions to bring model generators and consumers together. While progress of this type has recently been made in the US (e.g., BARDA's Ebola and Zika Modeling Coordination Groups, which also has a substantial focus on disseminating modeling results to policy makers), no such forums currently exist within or across Africa, and they should be established. An increased emphasis (in both the US and Africa) is also warranted on coordination outside of emergency situations. Programs such as MIDAS, RAPIDD, and the AAAS fellows program have begun to address this

gap within the US, and such programs should be expanded within the US, and similar programs developed within and across Africa. In addition, an essential component of all such programs will be engagement of junior researchers (ie, those at the graduate or postdoctoral level).

- Understand and leverage existing incentive structures for decision makers, to promote communication and cooperation
- Develop forums for communication among modelers in different institutions / settings, across Africa, that will allow them to share their experiences and ideas

Appendix: Recommendations for modelers who would like to engage with policy makers and inform public health decisionmaking

Keys to success

- Establish connections and relationships with decision makers before a crisis occurs. If they don't know you and your potential contributions ahead of time, they are unlikely to seek your advice, and it may be difficult to get access to those who could use your expertise. To establish these connections, it will help if you:
    - Go to conferences and seminars outside your direct area of study, and talk to those who are presenting.
    - Seek training in communication (writing, oral presentation) for non-specialist audiences, and provide your connections with accessible summaries of your ongoing work that is relevant to their interests.
    - Engage in conversation with policy makers and data collectors. Learn about their situation and what would be useful to them. Be persistent, and congenial, in seeking shared understanding.
    - Seek out training in areas of current weakness, such as public health and public policy (eg, take online courses or sit in on classes at your university if there is a public health school). Learn as much as you can about the biology of infections and the field of public health, including *the language* decision makers use to communicate about the decisions they're making and the information they are taking into account. Once you have an understanding of the language, tailor your presentation of your work to their needs (policy briefs, conference presentations).
- Accumulate a diverse quantitative toolkit (different modeling approaches, including dynamical modeling and statistical modeling), and know which nails to hit with which hammer. Cultivate collaborations and interact with interdisciplinary groups, with diverse approaches and experiences.
- Produce results quickly, in a useable format. In addition to providing findings and your interpretation, to decision makers, seek training or collaborators with expertise in software development, so you can provide a mechanism for decision-makers to investigate the consequences alternative assumptions and parameter values.
- Recognize that academic papers are not the way to have an impact on decision-making. While they can have value, even within the policy realm, they are a separate endeavor without the same type of urgency.

- Be scrappy! Use the information that's available, without overinterpreting your results. Be transparent about where you don't have sufficient information to inform complex models or answer specific questions.
- Modelers are most useful to leadership during an emergency response when they are accessible, providing fast and frequent updates. It helps for modelers to be on-site, with decision makers, to facilitate communication (including a shared understanding of the data and context in which it was collected, as well as of the question to be addressed through models).

A modeler must...

- Build models to examine a well-articulated question
- Clearly state all assumptions
- Interpret results clearly and in light of the question at hand
- Make adjustments as necessary to provide needed information