A Societal Outcomes Map for Health Research and Policy

The linkages between decisions about health research and policy and actual health outcomes may be extraordinarily difficult to specify.

We performed a pilot application of a "road mapping" and technology assessment technique to perinatal health to illustrate how this technique can clarify the relations between available options and improved health outcomes. We used a combination of datamining techniques and qualitative analyses to set up the underlying structure of a societal health outcomes road map.

Societal health outcomes road mapping may be a useful tool for enhancing the ability of the public health community, policymakers, and other stakeholders, such as research administrators, to understand health research and policy options. (*Am J Public Health.* 2006;96:441– 446. doi:10.2105/AJPH.2005. 063495) Michele S. Garfinkel, PhD, Daniel Sarewitz, PhD, and Alan L. Porter, PhD

THE HEALTH SYSTEM OF THE

United States is problematical: high levels of spending on health care parallel increasing rates of several diseases or conditions of concern, including some cancers, heart diseases in certain population subgroups, and new HIV infections. The most respected research enterprise in the world feeds into a broken public health infrastructure. An estimated 40 million Americans have essentially no health insurance. These quandaries have been dissected at length in both popular and academic venues, resulting in broad and deep agreement that the problems are real but little consensus on what to do about them.

One problem is that it is very difficult to understand the relations among the multitude of institutions, actors, and policies that may influence health outcomes. As a consequence, preferences for particular options (e.g., more money for research on breast cancer genetics vs wider availability of breast cancer screening, subsidizing participation in community-supported agriculture programs vs nutrition education programs) are advanced independently of the broader, more complex context from which health outcomes emerge.¹

In other sectors of society, where the need to achieve specified outcomes is critical but system complexity is great, decisionsupport tools have been developed and implemented successfully. One of the most effective of these tools, technology "road maps," can clarify and enhance the connections between inputs, such as research funding, commitment of personnel, education, or laws, and outcomes,² such as policy changes and program implementation. This approach, founded in engineering theory, has been shown to be particularly successful for agencies and firms focused on security or on technologies that are expensive to develop or that are potentially dangerous, ranging from consumer goods (most notably, computers³) to space exploration technologies.⁴

For example, Semiconductor Manufacturing Technology (now International SEMATECH), a public/private consortium established in 1986 to improve the design (mostly speed) of semiconductors, developed "foresight maps"³ using an iterative process of surveying customer needs and determining what was available and which actors could carry out appropriate research to achieve a desired innovation.³ Early versions required only a few printed pages; the current version needs to be stored on a CD-ROM. Other public/private enterprises have employed this approach as well,^{5–7} and private companies, including Motorola, have used the technique successfully.8

Although phrases such as "road map" and "foresight map" as used here might be unrecognizable to cartographers, these expressions are established terminology in technology research and policy communities. The inclusion of a timeline or time horizon on a map, which would be nonsensical if applied to a road atlas, is also a standard feature of technology road mapping. Technology "road maps" are perhaps then best understood as graphical overviews of potential solutions over time to specific concerns, no matter how narrowly or broadly defined.

These foresight maps or "road maps" frequently extend over long time horizons-10 years or more-but they are constantly revised on the basis of new knowledge. In all cases, what these road maps show are outcomes (what is desired) and an array of interconnected inputs (what is needed). Thus, they do not provide longterm predictions but offer interactive, iterative, and evolving guidelines that maximize, rather than limit, the number of possible research approaches.^{2,8,9} The final selection of a specific research path is left in the hands of decisionmakers such as consortium or firm executives.

The principles behind technology "road mapping" are theoretically applicable to any problem for which decisionmakers seek to clarify the inputs necessary for achieving desired outcomes. To enable a more open and knowledgeable policy debate about the roles of various players in the health system, we have initiated the development of a modified foresight mapping technique incorporating wellunderstood aspects of technology assessment and coupled with a graphical guide. By including the input of both experts and the public in formulating definitions of what "health" is and which societal-level health outcomes are desired, such a road map can begin to revealand ultimately help shape-an

overall system in all of its complexity and diversity,^{10,11} including basic research, applied research, prevention techniques, cultural and social conditions, and economics. Importantly, the process also explicitly includes minority and individual views.

Access to such a detailed road map, and the information underlying it, could help legislators, research administrators, and federal agency heads, among many others, view outcome-oriented options and trade-offs that can shape the workings of the health system. As the road map grows, stakeholders and their representatives will also be able to critique and contribute to it. The overall approach is somewhat related to some of the technology assessment exercises widely in use^{12,13}; in particular, the Royal Netherlands Academy of Arts and Sciences has proposed a mechanism to measure the effects of applied health research on society as a whole.¹⁴

We are not proposing a road mapping approach as a solitary determinant of health policy. Rather, we wish to lay out a number of possible paths, research driven or not, for achieving desired societal health outcomes as a contribution to the development of the health research and health policy components of an overall health system. As stated earlier, the final selection of a specific path will be in the hands of decisionmakers, in this case legislators, research administrators, and so on. Furthermore, a health research and policy road map could be used, for example, as a teaching aid or a research tool. We were inspired by former Motorola CEO Robert Galvin's description of the characteristics of road maps:

[Road maps provide] an extended look at the future of a chosen field of inquiry composed from the collective knowledge and imagination of the brightest drivers of change in that field, [including] statements of theories and trends, the formulation of models, identification of linkages among and within sciences, identification of discontinuities and knowledge voids, and interpretation of investigations and experiments. [Road maps are a means to] communicate visions.15(p803)

OUTCOMES-DRIVEN MAPPING

Cataloguing Desired Outcomes

Because societal health outcomes encompass such a large number of possibilities (anything on a gradient from, for example, "a long and vital life" to lessening the impact of the side effects of a particular drug), we focused on an outcome of relatively high order: perinatal health. For the purposes of this pilot study, we used the following as proxies for expert input: mission statements of federal, nongovernmental, and private research and policy groups; surveys of the expert literature; agendas of major meetings; and expert statements to the popular press. As a health outcomes road map grows, Delphi surveys (structured iterative querying of experts in an attempt to arrive at an understanding of, and sometimes consensus on, the state of a given field) can be used to understand less accessible niches of health research and policy.¹⁶

Specification of Inputs

All recognized approaches were considered, and the "state of know-how" for each was evaluated. From this evaluation, we generated, through literature searches, lists of "what is known" and "what needs to be known," allowing us to evaluate primary and secondary (review) sources and to explore statements made by researchers and policymakers to the media. In collecting these inputs, we found that reviews and statements to the media seemed to be especially useful in characterizing generally what is not yet known about potential research and policy approaches.

Identification of Potential Research and Policy Paths

Initially, we used a commercial data management system created by Inxight Software, Inc,¹⁷ to generate preliminary potential research and policy pathways. This software also allows for interactivity via a Web site, and thus users can access the underlying data, related Web sites, and any other information that the authors of such a road map wish to provide. Here we present the maps generated in static form. However, it is important to note that the precise mode of graphic representation (e.g., the specific informationhandling software used) is not important; rather, the information content is key.

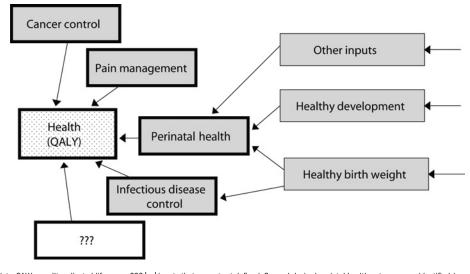
Quantitative Analysis of Literature

We used a combined scientometric and text-mining methodology called technology opportunities analysis.¹⁸ Text-mining software (in our case, Vantage-Point¹⁹) offers several tools to help discern research activity patterns from search results, such as abstract records retrieved from large databases. Such patterns can help profile research domains²⁰ and can contribute to better management of research and development programs.²¹ The software applies natural language processing to separate out noun phrases for further analyses, and it uses thesauri and fuzzy matching algorithms to clean the data. Also, statistical analyses (e.g., principal components analyses) based on co-occurrence of terms across records are conducted as part of the program, helping to reveal relationships that would otherwise be difficult or impossible to uncover.

CASE STUDY: PERINATAL HEALTH

The Topic

Perinatal health is generally accepted as setting the stage for children's subsequent robust growth and development, and it may predict adult health as well. Although definitions vary, we limited our analysis to the period of the 28th week of pregnancy to 7 days after birth.22 In simplest terms, "healthy babies" is the goal. But achieving even this apparently straightforward and universally valued objective has been mired in confusion and controversy. Why do such large disparities still exist in maternal and child mortality between Blacks and Whites? How can prenatal care be delivered to those mothers who seem not to want it? Is a state-focused or nationally focused program the more efficient approach? (Or is there another approach that has not yet been identified?) These can be overwhelming, even paralyzing, problems for setting policy and suggesting research directions. We carried out a detailed analysis to determine whether we could identify a set of policy and research paths that would result in improved perinatal health indicators.



Note. QALY = quality-adjusted life-years; ??? | = | inputs that are not yet defined. General desired societal health outcomes are identified (see text for details). Inputs to perinatal health include, but are not limited to, healthy in utero development and a healthy birthweight. Stippled shading indicates the highest-level health outcome (increase in Health QALY). Shaded boxes (nodes) indicate inputs. Heavy boxes indicate outcomes. Some boxes are both inputs and outcomes.

FIGURE 1-High-level societal health outcomes and inputs.

Identification of Research and Policy Inputs

We attempted to determine as comprehensively as possible recent research and policy inputs to perinatal health ("what is known," or nearly so), as well as what knowledge, if any, seems to be "missing" (using mission statements, scientists' statements to the media, and so forth). By scouring the professional literature, we were able to define a number of lower level outcomes (e.g., healthy birthweight) that contribute to the achievement of the higher level outcome of perinatal health. We recognize that examinations of the views of defined groups such as health care workers, consumers, or bench researchers will always leave gaps in terms of defining the full constellation of research and policy inputs. However, if the search is as wide as possible, most of these gaps should be reduced, if not eliminated. As the road map evolves through incorporation of

data, opinions, and "field notes" from users, we will be able to identify the strengths of particular research or policy approaches and will be able to ensure that remaining gaps represent knowledge or intervention that can be filled through research and policy. We identified several possible inputs (illustrated in Figure 1). Two are noted briefly here.

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) is known to improve health outcomes for newborns and the developmental progress of children.^{23,24} This program is successful in terms of coverage and outcomes, yet many of those eligible are not receiving benefits.²⁵ There is a large professional literature on the topic and much discussion in the general press. Thus, much is "known" about this input.

Furthermore, on the basis of literature from governmental agencies, such as the US Department of Health and Human Services, as well as nongovernmental sources, it appears that this approach is relatively efficient (yielding a large benefit) and probably reduces health disparities. But there is an apparent gap in knowledge about why all of those who are eligible do not receive benefits. Are they unaware of the existence of the program? Do they not want to participate? Do they want to participate but feel constrained from doing so? This gap indicates a significant research opportunity supported by a good deal of knowledge and, thus, by the opportunity to increase translation of such knowledge into just and equitable outcomes.

The National Institute of Child Health and Human Development devoted a noteworthy portion of its fiscal year 2001 budget justification document²⁶ to a discussion of the need to understand the genetic underpinnings of various

developmental abnormalities or disorders. "What is known" in this case is relatively restricted. The March of Dimes and the Centers for Disease Control and Prevention, among others, estimate that 150000 babies with birth defects are born in the United States each year, with an astounding 4000 known unique causes.^{27,28} These defects as a group are responsible for 20% of first-year mortality (approximately 8000 deaths each year).²⁹ A number of these abnormalities are preventable, or their severity can be lessened with good prenatal care. A few birth defects have a known genetic lesion. Still, 70% of all cases have no apparent cause.

Heart defects are the largest single group of birth defects, afflicting 1 of every 125 newborns, yet there is very little understanding of these diseases. Should efforts be concentrated on identifying and characterizing relevant genes? Would a better understanding of environmental factors lead to a decrease in heart defects and other lesions? As more specific genes and regulatory pathways are biologically defined, what are the implications for genetic testing (a difficult issue for policymakers concerned with disparities in the distribution of the tests as well as the health care delivered to those whose tests indicate problems)? Ideally, these knowledge gaps would be researched in concert.

Mining the Research Literature

Scanning the professional literature for concepts and results is key to building a road map. We drew on scientometrics (tallying activity) and text mining (extracting prevalent terms)^{18,21,30–32} to explore perinatal health research knowledge. Fortunately, 1 international database, MEDLINE, compiles a tremendous amount of pertinent research. It does so in the form of a searchable database that provides abstracts of articles (PubMed³³). It also thoroughly indexes those articles through a hierarchical thesaurus called MeSH (Medical Subject Headings 34). It is important to note that we did not track MeSH terms per se. Rather, we searched MEDLINE for articles containing the word perinatal.

Our search for articles related to perinatal health turned up just over 2000 for the decade 1992 through 2001. The number of articles ranged from 137 to 295 per year, showing a steadily increasing trend. The research represented by these articles was notably focused at academic institutions, at least during this period (947 publications vs 22 that were recognizably corporate, not accounting for the original funding source). Furthermore, the research was concentrated in the United States and England (1234 of the nearly 2000 articles originated in these 2 countries).

The terminology used in these perinatal health articles was diffuse. We found 5661 unique MeSH headings, of which some 300 were mentioned 10 or more times. In most science and technology research literature scans, the concentration is much more pronounced. The wide dispersion of perinatal health topic coverage makes road mapping quite challenging. One cannot simply arrange hundreds of terms in a comprehensible graphic depiction. We interpret this situation as indicating the fragmented nature of research pertinent to perinatalogy. We are not dealing with a singular problem in which

there are well-specified causes to be resolved. However, this is exactly why road mapping holds great promise in helping to elucidate opportunities. It can also facilitate the sharing of seemingly disparate knowledge, complementing other inquiries.

Mapping of multiple research strands can aid in prioritizing as well. One can spotlight particular subtopics to ascertain relative emphases. Subtopics that relate to key pathways to desired outcomes deserve attention. This is particularly so for research subtopics associated with multiple pathways (i.e., offering the prospect of serving multiple objectives). Our initial source in obtaining information was publication intensity: how many publications addressed a given subtopic? The initial data for this research-mining approach could be enriched, for instance,

by also including information from the Computer Retrieval of Information on Scientific Projects database maintained by the National Institutes of Health.³⁵

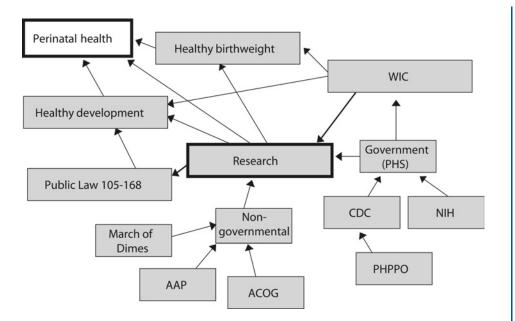
Identification of Relevant Research and Policy Paths

We used Inxight's commercial Star Tree software for information handling. The associated viewer software can be used to make the nodes in Figure 1 become live links that can connect to another Web page, to the original data set, and to other potentially useful annotations. Paths are easily visualized in that the user can "pull" subsequent nodes from an initial node, much as one might pull on a piece of string to see what is attached to it (i.e., the connection between any 2 nodes or group of nodes, no matter how distant, is revealed as one "pulls").

This interactive form, however, is not necessary for information to be gleaned from the road map, and static extracts of the map are shown here (Figures 1 and 2).

Figures 1 and 2 illustrate the connections of the nodes that were identified through the multistep analysis described earlier for perinatal health. Outcomes are indicated by bold-outlined boxes, and inputs are shown with shaded boxes. Some nodes function as both inputs and outcomes. The pathways start from the highest level outcome: "health." "Perinatal health" is an input to overall societal health as well as a desirable outcome in itself.

Figure 2 represents an analysis of "perinatal health" as an outcome unto itself. In addition to the WIC and genetics inputs mentioned, we identified several other inputs. By coupling these inputs



Note. WIC = Special Supplemental Nutrition Program for Women, Infants, and Children; PHS = Public Health Service; CDC = Centers for Disease Control and Prevention; NIH = National Institutes of Health; PHPP0 = Public Health Practice Program Office; AAP = American Academy of Pediatrics; ACOG = American College of Obstetricians and Gynecologists. Perinatal health is one of an array of desired societal outcomes as well as an input into the highest level outcome, "health" (defined here as quality-adjusted life-years; other standards could be chosen) (see text for details). This represents only a small portion of the full road map; in an extended version, there is, for example, a pathway that focuses on "government (non-PHS)" inputs alongside the "government (PHS)" input box shown here. Shaded boxes (nodes) indicate inputs. Heavy boxes indicate outcomes. Some boxes are both inputs and outcomes.



with the array of outcomes, we can outline a number of research and policy combinations that could influence these outcomes. For example, if investments in WIC were increased, improvements could result in both the immediate perinatal health outcome and a seemingly unrelated societal health outcome, infectious disease control (because WIC now has an immunization screening and referral program³⁶).

Alternatively, a biomedical research path could be taken. Understanding the mechanisms underlying birth defects or low birthweight could lead to a medical solution for these problems. Another path would be essentially legal in nature: the Birth Defects Prevention Act of 1998 (Pub L No. 105-168) was meant specifically to establish the federal infrastructure necessary to "prevent birth defects." and it mandates that the Centers for Disease Control and Prevention collect and analyze data, operate regional centers, and inform and educate the public.³⁷ From a policy perspective, it might be worth having "provision of services" clearly defined, or it might be that this overlap and fuzziness is desirable.

An interesting emergent property of the road map is the apparent importance of "research" as an outcome as well as an input, indicating the value accorded it by society. What kind of research is done and its relative importance to other inputs are determined by policymakers and science administrators, among others; the data used to populate maps such as these, and the graphic itself, could be of great value to such decisionmakers.

The graphic representation indicates connections that already exist, and, when the road map is as filled in as rigorously as possible, we can see where useful connections that could be made are absent. Thus, we can discover *policy options* from this type of analysis. Access to programs is a key determinant of outcomes. Biochemical and molecular explorations of genetic developmental diseases have yielded large amounts of data, but at present, some states are not able to carry out even the most basic newborn screening tests. Thus, for example, at the federal level, more research on the lack of participation of women eligible for WIC, research on the value of screening newborns for specific diseases, and continued funding in the area of genetic origins of birth defects (but perhaps ratcheted down somewhat) via the National Institute of Child Health and Human Development might represent a reasonable portfolio of activities.

Alternatively, decisionmakers may conclude, for a completely different set of reasons, that more investment in genetics research and less investment in understanding service use patterns are warranted. In all cases, the cost of such programs would be subject to trade-offs: through reducing other programs judged to be less effective, through invoking higher taxes, and so forth. More important, decisionmakers can develop a more comprehensive view of the relationships between factors that contribute to a vitally important social outcome: perinatal health.

CONCLUSIONS

By explicitly illustrating alternative causal chains linking inputs to outcomes, mapping can help inform trade-offs such as those discussed here. At this stage, we are beginning to identify alternative paths that might be taken to pursue and, we hope, achieve given desired outcomes. The point, of course, is that decisions, costs, and vested interests will differ from path to path. Thus, as such analyses progress, input from those affected by the choice of particular research or policy paths, including scientists, caregivers, and other citizens, will be continually fed into-and will continually enrich-the road map.

Development of Decision Options

In road mapping for technology development, a single approach is eventually chosen to develop the relevant technologies. However, given the more complex case of health outcomes, one of the strengths of this kind of tool is its flexibility and usefulness for diverse stakeholders in support of both informed public discourse and decisionmaking. Iterative analyses could easily be conducted by deliberative bodies concerned with health outcomes from the community to the global level. In all cases, economics, fairness, and the social purposes of research and policy can be addressed as needed for the purposes of the user.

Policy Implications

Modified road mapping and technology assessment techniques, as illustrated by our prototype outcome map for perinatal health research and policy, can contribute to a more open and knowledgeable policy debate about the roles of science and policy in the health system of the United States. Such tools would help enable policymakers and stakeholders to comprehensively view outcome-oriented policy options and trade-offs.

This approach will be most pertinent when diverse stakeholders can contribute to and extract lessons and information about alternative policy pathways from it. Such interactivity can easily be incorporated into a Web-based road map. As has been seen in the case of the World Health Organization's report on health systems,38 circulation and subsequent critique of new frameworks for assessing health outcomes are crucial in producing a more useful product.^{39,40} If the road map is made publicly available (both interactively through the World Wide Web and through distribution of semicustomized products such as brochures for users with specific needs in distinct health policy areas) and can be continuously updated, stakeholders can participate in decisionmaking aimed at defining and pursuing desired societal health outcomes.

Ultimately, tools such as the one described here can enable much greater contextual awareness among stakeholders and decisionmakers alike. We hope that the prototype we have presented stimulates other groups to develop their own maps and mapping methodologies and to share them with the health research policy community.

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Contributors

M.S. Garfinkel co-originated the study; identified, catalogued, analyzed, and interpreted data; and drafted and revised the article. D. Sarewitz co-originated the study, contributed to the analysis and interpretation of data, and drafted and revised portions of the article. A.L. Porter conducted the technology opportunities analysis, interpreted the data derived from that analysis, and drafted and revised corresponding sections of the article.

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Human Participant Protection

No protocol approval was needed for this study.

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