

**CTSA Informatics Face-to-Face Meeting**  
**October 15-16, 2008**  
**5635 Fishers Lane**  
**Rockville, MD 20852**

**Meeting Summary**

**October 15, 2008 – CTSA Informatics 2008 Orientation**

**Purpose**

The purpose of the CTSA Orientation meeting was to bring together individuals from the newest CTSA sites to review the overall structure and relationship of the national CTSA Consortium and the CTSA Informatics Consortium and to discuss start-up challenges and potential solutions.

**Welcome and CTSA Program Overview**

Dr. Bill Hersh made the opening remarks, welcoming the participants and giving a brief overview of the agenda for the Orientation and the next day's meeting. Dr. Hersh also introduced the NIH coordinator for the CTSA Informatics Steering Committee, Dr. Elaine Collier from the National Center for Research Resources (NCRR). Dr. Collier provided an overview of the CTSA governance and committee structure. A recap of the recent developments resulting from the October 6-7, 2008 CTSA Consortium Oversight Committee (CCOC) Meeting was also provided by Dr. Collier. It was noted that the overarching philosophy of the CTSA was an emphasis on flexibility. Dr. Collier noted that the CCOC had developed a strategic plan that would re-focus the priorities of the CTSA and more information would be provided at the next day's All-Hands Meeting. Dr. Brian Athey stated that Informatics would play a critical role in the success of all of the CCOC strategic plans and priorities.

Upon conclusion of Dr. Collier's overview and recap, Dr. Athey stated that the primary goal of the 2008 orientation was to enhance communication and dialogue among the Informatics committee members. The All-Hands Meeting Planning Committee hoped to achieve these goals by allowing new institutions to highlight certain activities or start up challenges, and also to ask questions to the committee leadership and 2<sup>nd</sup> or 3<sup>rd</sup> year awardees.

**Start-up Challenges Panel & CTSA Site-Snapshot Presentations**

Dr. Bob DiLaura introduced this portion of the agenda as an opportunity for open dialogue about start-up challenges and finding potential avenues for collaboration among both old and new CTSA sites. The Start-up Challenges Panel consisted of four 15 minute presentations given by Mr. Kent Anderson (UC-Davis), Dr. Mike Becich (PITT), Dr. Paul Harris (Vanderbilt), and Ms. Meredith Nahm (Duke). Each presenter was allotted 10 minutes to present, followed by 5 minutes for Q&A. The final 90 minutes of the meeting were dedicated to Site-Snapshot presentations from the 14 new CTSA sites. The list of presenters were as follows:

- Dr. Robert Friedman: Boston University
- Dr. Michael Kahn: University of Colorado – Denver
- Mr. Doug MacFadden: Harvard University
- Dr. Sean Mooney: Indiana University
- Dr. Brad Pollock: University of Texas Health Sciences Center at San Antonio
- Dr. Rex Chisholm: Northwestern University
- Dr. Phillip Payne: Ohio State University
- Ms. Sandy Mackenzie: Scripps Research Institute
- Dr. Henry Lowe: Stanford University
- Dr. Josie-Marie Griffiths: University of North Carolina – Chapel Hill
- Dr. Steve Pauker: Tufts University
- Mr. Matthew Wyatt: University of Alabama
- Dr. Bernie LaSalle: University of Utah

## October 16, 2008 – CTSA Informatics Key Function Committee Meeting

### Opening Remarks - Dr. Don Lindberg, NLM

Dr. Lindberg discussed that there are three national purposes that are not being served well in the biomedical domain. He encouraged the Informatics Key Function Committee (IKFC) to contribute in addressing 1) disaster information management, 2) climate control and 3) conflict of interest and issues of integrity in clinical trials at academic institutions.

### CTSA-Consortium Committee Strategic Plan Priorities - Dr. Julian Solway, CTSA PI Liaison

Dr. Solway, PI Liaison to the IKFC, discussed the development of the CTSA Strategic Plan. He stated that the process started when members of the CTSA Consortium Steering Committee (CCSC), formerly known as the CCOC, were polled concerning a list of strategic priorities. At the July 8, 2008 CTSA Retreat, the CCSC generated an interim list of nine strategic priorities that were to be collected, revised, and expanded. At the CCSC face-to-face meeting on October 6-7, 2008, CTSA members met to finalize the Strategic Plan. An agreement was reached upon an overall mission statement and then the group worked towards identifying implementation steps for the nine priorities as well as a specific mission statement.

Drs. Collier and Solway informed the group that the CCSC developed a new variation to the committee structure that would impact all of the pre-existing steering committees, workgroups, project groups, interest groups and taskforces. A change in the nomenclature also resulted in the following:

- The CCOC is now the *CTSA Consortium Steering Committee (CCSC)*.
- The CCOC Operations Committee is now the *CTSA Consortium Executive Committee (CCEC)*.
- All groups formerly referred to as Steering Committees are now *Key Function Committees (KFC)*.
- All workgroups, project groups, interest groups and task forces are now *Special Interest Groups*.

The voting members of the CCSC drafted four national priority areas that would serve to group and cluster the pre-existing Key Function Committees. The four priorities areas would be called *Strategic Goal Committees* and would act as the umbrella for all of the KFCs that align with the strategic goal. The four strategic goals are:

- Strategic Goal Committee 1: *Enhancing National Clinical and Translational Research Capability*
- Strategic Goal Committee 2: *Enhancing Training and Career Development*
- Strategic Goal Committee 3: *Enhancing Consortium-Wide Collaborations*
- Strategic Goal Committee 4: *Enhancing the Health of Our Communities and the Nation*

Dr. Solway presented a list of proposed next steps as decided by the PIs:

1. Make changes to the CTSA Consortium organizational structure
2. Align committees to the CTSA Strategic Priorities by creating or assigning Strategic Goal Committees (SGCs) responsible for each goal.
3. SGC PIs will work with CCSC & CCEC & content experts to identify deliverables guided by the implementation process from the strategic planning process.
4. Consortium wide resources will be focused on the 4 key goals to ensure that the CTSA organization has identifiable objectives, milestones and outcomes- optimized to support the strategic goals of the network while also providing important networking and synergizing functions to improve and support local CTSA operations

Dr. Solway shared that the IKFC fits into each of the four strategic goals and eight of the nine original strategic priorities. Dr. Athey discussed that the many of the changes involve morphing the IKFC priorities into the CTSA strategic goals identified by the PIs. Additionally, the proper expertise across multiple KFCs will need to work together on goal committees.

In order to execute the strategic goals, some IKFC members suggested the inclusion of a management consultant or a facilitator to provide project management services. IKFC members will look for successful models in the field of biomedical research (e.g. WCCC). Dr. DiLaura stated that since the IKFC, and the

CTSA to a larger degree, is not a top-down organization, the challenge of this meeting is to determine how the IKFC processes the CTSA priorities and then provide the necessary feedback to the PIs. Dr. Athey stated that during the October 2008 CCSC meeting, the PIs approached him about conciliating priorities with the Informatics KFC.

### **Informatics & the CTSA Consortium**

Dr. Hersh stated the challenge of the IKFC is to map the committee to the CTSA strategic goals and to align them. He then showed the relationship between interest groups, which are broader groups of common interests that coalesce around particular areas, and project groups, which focus on specific projects with finite objectives, activities and deliverables. Dr. Hersh also demonstrated how the original list of projects had been whittled down to three through the national project prioritization process, which has been led by Dr. Peter Tarczy-Hornoch.

Dr. Athey discussed the importance of determining how much the IKFC can do in terms of prioritizing and accomplishing deliverables that work towards the CTSA strategic goals while also honoring the respective needs and priorities of local CTSA. Dr. Solway also outlined questions for consideration of the IKFC that deal with the alignment of priorities between Informatics and the overall CTSA Consortium, and how the focus on national priorities changes local priorities. Dr. Solway also shared risks such as, stretching the budgets of CTSA Informatics and Research IT that are already taxed, and/or the need for complex telecommunications methods as the program continues to grow.

### **General Discussion of Informatics Priorities within CTSA PI Priorities**

During the discussion of the Informatics Priorities, the following key suggestions and statements were made.

- There is a need for synergies across the CTSA. Furthermore, the success of the program will be determined by national (and not local) impact.
- On the issue of participation, resources are not required from all CTSA on every project; however, there are certain priorities (e.g. data sharing) that demand a critical mass of the CTSA to participate in order to be successful.
- The IKFC should seek inspiring, high-impact activities in determining its priorities and not solely based on resources that are presently available. This underlines the importance of recommendations made to the CCSC and CCEC by the IKFC.
- It is critical to determine the correct organizational structure with concrete priorities in mind.
- There are concerns about the additional load of local projects indicated in the original grant application that may be unmet due to redirected resources that would address national priority projects.
- There is a need to define how much local infrastructure is required to accomplish tasks

### **National Informatics Priority Survey and Proposed Projects**

Dr. Tarczy-Hornoch gave an overview of the Informatics KFC national collaboration and project prioritization process. He reviewed the town-hall style meeting that convened at the Spring 2008 AMIA conference and the need for a prioritization process that would select 3 or 4 projects for national collaboration with buy in from the majority of the IKFC directors. An original list of more than 10 projects was eventually vetted through a series of prioritization surveys, leaving 3 up for presentation and discussion. The three presentations were as follows:

#### **Project #1: Education – Drs. George Klee (Mayo) & Bill Hersh (OHSU)**

Dr. Hersh stated that this project would develop competencies and a curriculum for educators to integrate Informatics into MS and PhD clinical research programs.

The goals of the project are (1) to develop shareable modules for meeting educational competencies and teaching objectives for research protocols, and (2) to share and evaluate these across CTSA. Members noted that the project still needed to determine who the recipients of the proposed training would be and formulate a more concrete picture of the curriculum.

**Project #2: Data Sharing Framework Demonstration Project – Drs. Nick Anderson (U Washington), Michael Kamerick (UCSF), Doug MacFadden (Harvard), Jonathan C. Silverstein (Univ. of Chicago) & Rob Wynden (UCSF)**

Dr. Silverstein provided brief remarks on this project which aims to provide distributed federated data sharing query frameworks of anonymized, summarized data or metadata across integrated data repositories of CTSA.

The key outcome of this project is for researchers to have the ability to perform federated queries across multiple institutions. Dr. Silverstein expressed concern about trust and security issues in unlocking data repositories for wholesale data sharing, and stated that a workflow template was needed to get institutions to comply.

Dr. Kahlon urged the project leads to think about governance policies surrounding data use in parallel with project implementation. Dr. Dan Masys suggested that the leads should use technology to inform the policy.

**Project #3: Inventory of Resources Project – Dr. Mike Becich (PITT)**

Dr. Becich described the aims of this project, which are as follows:

1. Develop, rapidly implement and prototype metadata to allow query for biomedical informatics resources across CTSA
2. Implement open source ontology (Biomedical Resource Ontology – BRO) that interoperates with other biomedical resource inventories (e.g BioSiteMaps and NCBCs)
3. Build scalable/portable toolkit

**Next Steps for Proposed Informatics Priority Projects**

Dr. Tarczy-Hornoch prefaced this portion of the discussion by asking IKFC members to brainstorm the best method for delivering the proposed Informatics priority projects and recommendations to the CCSC/CCEC. Dr. Tarczy-Hornoch summarized that the IKFC would need to create actions, determine metrics, and allocate local and national resources in order to effectively communicate and align the priorities of the IKFC to the CCSC Strategic Plan. During the general discussion, the following actionable recommendations were offered:

- Suggest to the CCSC/CCEC that the priority projects identified by the IKFC are aligned with the Consortium Strategic Goal #3: Enhancing Consortium-Wide Collaboration and may serve as a straw man for the goal projects.
- Propose that, in order to execute against the goal projects, the IKFC participants will need to reallocate resources assigned to local CTSA projects to the national projects. Support for this reallocation will need to be provided by the local PIs.
- Suggest that the strategic priorities that may be acted upon by the Strategic Goal Committees later on in the five year plan may need to have foundational work done through the KFCs in the interim. For example, the IKFC may work with the Communications KFC and other KFCs on defining and developing a common understanding of social networking. Providing a “background framework” before the inception of an executable project.
- Develop a 3x38 matrix of interest/participation, mapping the current CTSA’s to the three informatics priority projects to gauge local interest in the projects.
- Modify the IKFC structure diagram to show that the IKFC structure and process is aligned with the vision and strategic plan of the CCSC.
- Have a small group within the IKFC develop a pitch to the CCSC.
- Use eMERGE Network as a way to jumpstart the national phenotyping program.

In an effort to reconcile the perspectives expressed on the strategic priority areas from the Informatics KFC and the CCSC, Dr. Tarczy-Hornoch recommended a three-tiered approach:

1. Communicate that the Informatics priorities fall in line with the CTSA’s four strategic goals and treat them as shared projects.
2. Continue to utilize the existing interest group model which leads to the national project prioritization process.

3. Have the bulk of resources address the local effort.

### Proposed Motions

Dr. Tarczy-Hornoch reviewed the CCSC strategic goals and captured a set of six proposed motions for the IKFC's consideration. Following a discussion which further shaped the motions, there was a motion to accept motions #1, 3 and 5. The motion was seconded by Dr. Becich and unanimously accepted by a vote of 38 for, zero against and zero abstained.

- 1. Given integral role of informatics to strategic goals IKFC recommends to CCEC/CCSC informatics representation on each SGC as follows; 1 IKFC representative on SGC #1, 1 IKFC representative on SGC #2, 3 IKFC representatives on SGC #3, 1 KFC representative on SGC #4**
2. Given that informatics core resources are finite IKFC recommends to CCEC/CCSC a small number (2-3) of informatics heavy SGC projects in the short term (12-24 months) that require commitment of informatics resources from most of the currently funded CTSA's. It is the expectation that each site will participate in at least one of these projects. It is also the expectation that at least one of these projects will involve most of the 38 sites. IKFC also recommend PIs work with informatics cores to reallocate resources or identify additional resources to carry out these projects.
- 3. Formally inform CCEC/CCSC that IKFC has identified via a serial prioritization process 3 high priority projects (those discussed today) for SGC to consider for the short term (12-24 months). IKFC recommends the CCEC approve and adopt these prioritized projects for Fiscal Year 09, as they are also CTSA Strategic Goals**
4. IKFC to adopt policy that all IKFC sanctioned projects must specify timelines, deliverables, expected participants, expected participation
- 5. IKFC to adopt policy that all IKFC sanctioned pan-national (most of the currently funded CTSA's) CTSA collaborative projects be only those that are also SGC projects. IKFC will determine informatics priorities annually for CTSA collaborative projects that are consistent with the Strategic Goals of the CCSC; and IKFC will forward those identified informatics priorities to the CCEC for their consideration for that year.**
6. IKFC to adopt policy that each year a small number (approximately n = 5 max) of formally sanctioned IKFC collaborative projects/ IGs that involve a subset of CTSA's which will be identified using a formal prioritization process

### CTSA Informatics Business Meeting

Dr. Athey shared that Drs. Bob DiLaura and Shawn Murphy were elected to serve on the IKFC Operations Group. He also thanked Drs. Hersh and Perry Miller for their dedicated service. It was also announced that Dr. Hersh's term as the Chair of the IKFC will end in December 2008 and Dr. Dan Masys will assume a 2-year term as Co-Chair along with Dr. Brian Athey (1-year term).

### CTSA Abstracts Presentations

An open call was given for each of 38 CTSA Institutions to submit a one-page abstract that highlights achievements, challenges, projects and/or program overviews. All submitted abstracts were uploaded and viewable on the CTSA Informatics wiki. Of the submitted abstracts, six were chosen to be presented at the meeting. The IKFC Operations Group chose the 6 abstracts to be presented based on a diversity of:

- Geography
- Award Year
- Program Size
- Project Subject Matter
- Program Maturity
- Program Scope

The following 6 institutions were chosen to present their abstracts:

1. Dr. Henry Lowe: Stanford University

2. Dr. Jonathan Silverstein: University of Chicago
3. Ms. Diana Gumas: Johns Hopkins University
4. Dr. Dan Masys: Vanderbilt University
5. Dr. Steve Pauker: Tufts University
6. Dr. Stephen Johnson: Columbia University

### **Reports from Various Working Groups**

Following the presentation of abstracts from local institutions, 4 Interest/Project groups of the IKFC gave brief presentations that provided an overview of the project, project progress, ways to join and the proposed deliverables. The presentations were as follows:

1. Dr. Ida Sim: Human Studies Database Project Group
2. Dr. Mini Kahlon: Collaboration Facilitation Interest Group
3. Dr. Mike Becich: Inventory of Resources Project Group
4. Dr. Michael Kamerick: Integrated Data Repositories Interest Group

### **Research Centers in Minority Institutions Translational Research Network Presentation**

The final presentation of the day was given by Dr. M. Edwina Barnett from the Research Centers in Minority Institutions Translational Research Network (RTRN). Dr. Barnett gave an overview of RTRN's current projects and encouraged the IKFC to seek out potential avenues for collaboration with RTRN.

### **Summary and Closing Remarks**

Drs. Athey and Collier thanked the group members for their continued hard work and flexibility during the growth of the CTSA Consortium. It was announced that the Informatics KFC would continue to have face-to-face meetings each Autumn and save-the-date emails would be sent in the Spring.

All slides and abstracts from the 2008 meeting will be made available via the Informatics KFC Face-to-Face Meeting wiki site: <https://www.ctsawiki.org/wiki/x/NgxFAQ>