

PEOPLE  
MARIE CURIE ACTIONS

**International Outgoing Fellowships (IOF)**

**Call: FP7-PEOPLE-2013-IOF**

PART B

“Minor Powers:  
Health-related quality of life, power, and self-agency of underage citizen consumer”

**STARTPAGE**

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## **B1. S&T Quality**

### **B1.1. Research/technological quality, including any interdisciplinary and multidisciplinary aspects of the proposal**

The goal of this methodological project is to create and test an innovative mixed-methods research approach that operationalizes semantic-qualitative data in quantitative methods. This empirical approach actively engages with current scholarly and policy discussions that examine institutionalized discourses in biomedicalization and health care as well as their associated issues of empowerment and power structures. In the process of developing this conceptual engine, the fellow will obtain training in advanced methods from both social sciences and public health that are necessary for the successful development and application of research tools. Through the advanced inter-disciplinary studies agenda, the fellow will achieve competence in preparation for a leadership position in individual outcome-oriented health care research projects and policy-evaluation. This will offer timely benefit to future transatlantic exchange since the merging of care markets and biomedical research areas will intensify following the conclusion of the EU-US negotiations on the Transatlantic Trade & Investment Partnership Agreement (TTIP).

The tool will be developed and tested by operationalizing minors' cognitive ideas about active participation in the era of techno-science, whether as (future) political citizens, consumers, or patients. Participation, it is hypothesized here, depends largely on a minor's – like any other patient's – perception of (a) self-agency, (b) empowerment, and (c) health-related quality of life (HrQoL). The focus of this line of inquiry is on a discourse regarding underage citizen consumers in biomedicine and mental health care. Following developments in recent cognitive research, while stressing the importance of investigating the role of social ontology, care-takers expectations, and the development of decision-making and participation in minors, the researcher aims at the development of a research tool that allows quantitatively resilient inferences from semantic qualifying data sets on (a)-(c) in a 'high-tech' setting of doctor-parent/teacher-minor interaction and a 'low-tech' setting of non-competitive martial arts training. A review of the state of the art shows that education in, practice of, and research on contemporary systems of care rarely address dimensions of political citizenship and consumer citizenship in relation to outcome-orientation, health-related-quality of life and identity development. Against meta-analytical to the contrary, these dimensions are kept separate.

This research project will, instead, provide a model that integrates these dimensions to study a macro-micro-macro perspective of cognitive policies, individual decision-making and outcome-oriented systems transformation. Using this tool, the fellow seeks to develop agent-based simulations on expectations about decision-making and participative behavior in 'low-tech' and 'high-tech' techno-scientific settings that will allow future comparative research on American and European participation effects, i.e. in academic/clinical versus alternative medical regimes, cross-cultural effects in nurse education, placebo-research, and public participation in bio-banking.

#### *Overview*

The project the fellow has developed includes on two research sites:

(i) The situation of diagnostic and therapeutic decision-making on disruptive behavior disorders, primarily ADHD, between doctors, teachers/parents, and minors as patients; and (ii) minors and adults participating in Aikido and Taekwondo classes. The novelty of this grounded, middle-range tool lies in the alignment of qualitative and quantitative methods by using focused ethnography, situational mapping and latent meaning pattern analysis to create semantic clusters that encode qualitative data of empowerment, institutionalized and discursive power in

ways that can be effectively queried and measured quantitatively by use of fractal and multivariate vector- and cluster-analysis methods.

The policy analytical frame of discursive institutionalism posits that tacit and propositional knowledge represent cognitive policies and ideas that attain relevance, i.e. meaning, in practice. Cognitive policies are plausibly open to forms semantic differential analysis that can encode robust semantic vectors and clusters measuring power in status hierarchies, health-related quality of life (HrQoL), and perceived self-agency, as well as correlations among all three semantic fields that are targeted: In other words, this operationalization obtains significant data points on tacit and propositional knowledge about (a) ideas about self-agency among minors in high-tech versus low-tech techno-scientific contexts (i.e. as patients or as martial arts students), (b) potentials for patient empowerment, and (c) health-related quality of life (HrQoL). The operationalization of these three subject matters allow the creation of agent-based models of decision-making and participation, that are indispensable for predicting, for example, the future success of health care policy-measures and biomedical research-participation, such as in biobanking.

*Hypotheses delimiting the scope of this project:*

1. Connecting situational analysis<sup>1</sup> and discursive institutionalism<sup>2</sup> in biomedical regimes to health-related quality of life measures will improve our understanding of outcome- and competitiveness-oriented transformation of care systems and effectivity of policies, by establishing a robust distinction between 'objective' and 'subjective outcomes' and yielding reliable scales of how these steer interoperability practices for different populations that relate ideas of individual patient satisfaction and participation.
2. If a global outcome is dependent on situated, individual participation, then the latter emerges as a cognitive policy<sup>3</sup> in biomedical contexts from the semantic interplay between shared meaning (social ontology) and individual perception of self-agency, power (or status hierarchy), and quality of life.
3. Meaning making can be measured by a mixed methods approach that collects semantic differential information through qualitative methods and enables a robust research paradigm for quantitative measuring<sup>4</sup> of the distribution of power and agency by way of cluster and multivariate factor analysis<sup>5</sup>. This approach leads agent-based models in semantic and institutional situational maps that allow outcome-oriented<sup>6</sup> predictions.
4. Decision-making on whether low-tech or high-tech options are chosen to aid in child development, steer ideas about HrQoL, and the formation participant/consumer-identities. These depend on factors of lifestyle, class, gender, and social milieu, and also

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<sup>1</sup> Clarke, A. E. "Situational Analyses: Grounded Theory Mapping After the Postmodern Turn." in: *Symbolic Interaction*, 26, 2003 (4): 553-576; Keller, R., *Doing Discourse Research*. London: Sage, 2012; Keller, R. "L'analyse de discours une perspective nouvelle pour les méthodes qualitatives." in: *Recherches Qualitatives. Collection Hors série 'Les actes' Nr. 3: Bilan et perspectives de la recherche qualitative en sciences humaines et sociales*, 2007: 287 - 306; Clarke, A.E. et al. eds. *Biomedicalization*. Durham, NC: Duke UP, 2010

<sup>2</sup> Schmidt, V. *Policy Change and Discourse in Europe*. London: Routledge, 2005. Schmidt, V. "Analyzing Ideas and Tracing Discursive Interactions In Institutional Change: From Historical Institutionalism to Discursive Institutionalism." *Open Forum CES Paper Series #3*. eds. Gregor Ekiert and Andrew Martin. Schmidt, V. "Discursive Institutionalism: Scope, Dynamics, and Philosophical Underpinnings." *The Argumentative Turn Revised: Public Policy as Communicative Practice*. eds. Frank Fischer and John Forester. Durham, NC: Duke University Press, 2012; Pacucki, M.A., Pendergrass, S., Lamont, M. "Boundary Processes: Recent Theoretical Developments and New Contributions." in: *Poetics* Vol. 35, 2007: 331–351

<sup>3</sup> above Fn 2

<sup>4</sup> Bartos, C., et al "Development of an Instrument for Measuring Clinicians' Power Perceptions in the Workplace" in: *Journal of Biomedical Informatics*. Vol. 41(6), 2008: 1041–1049; Sachweh, P. "Symbolic Boundaries and Subjective Approaches to Stratification An Empirical Investigation from a Mixed-Methods Perspective" in: *Zeitschrift für Soziologie*, Jg. 42, Heft 1, Februar 2013: 7–27; Kelle, U. *Die Integration qualitativer und quantitativer Methoden in der empirischen Sozialforschung. Theoretische Grundlagen und methodologische Konzepte*. Wiesbaden: VS Springer, 2008; Small, M.L., 2011: How to Conduct a Mixed-Methods- Study: Recent Trends in a Rapidly Growing Literature. *Annual Review of Sociology* 37: 57–86

<sup>5</sup> Bacher J., Pöge A., Wenzig K. *Clusteranalyse. Anwendungsorientierte Einführung in Klassifikationsverfahren*. Oldenbourg, 2010.

<sup>6</sup> Marmor, T.R., Wendt, C. "Conceptual Frameworks for Comparing Healthcare Politics and Policy" in: *Health Policy* Vol. 107, 2012: 11-20; Dent, M., et al "Medicine and User Involvement within European Healthcare: a typology for European comparative research" in: *International Journal of Clinical Practice*, Vol. 65 (12), 2011: 1218–20; **Wendt, C.**, Mischke, M., Pfeifer, M. *Welfare States And Public Opinion. Perceptions of Healthcare Systems, Family Policy and Benefits for the Unemployed and Poor in Europe*. Cheltenham: Edward Elgar Publishing, 2011.

represent symbolic boundaries that result from enculturation. Hypotheses about the influence of these factors and boundaries on power and self-agency can be tested.

5. Participation framed as a decision-making process can be shown to necessarily involve cognitive ideas about power and self agency that constitute propositional knowledge.
6. Patients and care recipients can be understood as *consumers* and/or *active participants*. In contemporary health-care and biomedical research settings, any outcome-based policy needs to conceive of the hybrid concept of *active consumer citizens*<sup>7</sup>.
7. A robust, semantic qualifying based tool to identifying propositional knowledge makes possible agent-based simulations and predicting factor strength for participation.

### *Theoretical and Methodological Context*

Expressed in a coherent inter-disciplinary framework, this project aims at the development of a research methodology that fulfills the norms for a 'strong objectivity' for understanding how the local or standpoint social ontologies and status hierarchies shared by underage-patients, guardians, and practitioners (as political participants) emerge in settings that involve both high-tech and low-tech biomedical and mental health care practices<sup>8</sup>. The fellow aims at achieving a tool for the creation of robust, sustainable, and cross-cultural understanding of how activation of political activity, 'quality of life'-related empowerment in biomedical contexts, and the difference of low-tech and high-tech practices shapes and is shaped by cognitive ideas and policies. This warrants the investigation settings that involve minors, whose cognitive ideas and policies about status hierarchies, potentials for affect learning, as well as understanding of traditional binaries, such as normal/pathological, are still under development and highly flexible.

The main line of research on lifestyles and social milieus focuses on markers of social identity, others add notions of 'symbolic boundaries' which encode resource allocation (socio-economic), recognition (ethical), and solidarity (cultural). This is, however, only one side of the coin, since processes of social identifications involve emotions, narratives, as much as rationalities that are not derived from identities but produced in social ontologies. These are multi-dimensional, class-/group-specific from a political point of view, and require integrated social psychological research perspectives: Lifestyles and milieus, like emotions and motives, are not 'natural kinds', but the product of subjective construction of interacting individuals, who are afforded with decision-making situations to choose from a complex frame of opportunities, preferences, orientations, and routines, i.e. decision-making occurs within both consciously considered parameters as described by rational choice-theories *and* the procedural-relational cultural internalisations ('enculturations').

Following recent provocative research paradigms, such as research into executive functions<sup>9</sup>, constructional psychology<sup>10</sup>, and narrative empathy<sup>11</sup>, which are challenging recalcitrant dogmas, the fellow adopts a research paradigm that emphasizes the importance of executive functions in cognitive research as well as constructionist approaches in psychology such as conceptual act theory. He shares and takes seriously the emphasis on synthesizing biological and neuro-cognitive research paradigms with insights on social context and social

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<sup>7</sup> Lamla, J. "Consumer Citizen: " in: *German Policy Studies* Volume 4, Nr. 1, 2008: 131-166; Lamla, J. "Consumer Autonomy and its Political Manifestations" in: *Krisis*, 1, 2012: 32 – 48; Weingartner, S. "Highbrow practices and frame-selection – An integrative approach to cultural consumption" in: *Kölner Zeitschrift für Soziologie und Sozialpsychologie*, Vol. 65, 2013:3–30

<sup>8</sup> Hollway, Wendy "Objectivity", in: Theo, Thomas ed. *Encyclopedia of Critical Psychology*. Heidelberg: SpringerReference, 2013  
Harding, Sandra. "Rethinking Standpoint Epistemology: What is "Strong Objectivity?" in: *Feminist Theory: A Philosophical Anthology*. Ed. Cudd, Ann E. and Robin O. Andreasen, Oxford: Blackwell Publishing, 2005.

<sup>9</sup> Diamond, A. "Executive Functions" *Annual Review of Psychology*, Vol. 64, 2013: 135-168

<sup>10</sup> Lindquist, K. A., Siegel, E. H., Quigley, K., & Barrett, L. F. "The hundred years emotion war: Are emotions natural kinds or psychological constructions? Comment on Lench, Flores, & Bench (2011)" in: *Psychological Bulletin*, 139, 2013: 255-263; Barrett, L. F. "Psychological construction: A Darwinian approach to the science of emotion." in: *Emotion Review* (online first); Lindquist, K. A., Wager, T. D., Kober, H., Bliss-Moreau, E., & Barrett, L. F. "The brain basis of emotion: A meta-analytic review." in: *Behavioral and Brain Sciences*, 35, 2012: 121-143

<sup>11</sup> Breithaupt, F. "A Three-Person Model of Empathy" in: *Emotion Review* Vol. 4, 2012: 84-91; Breithaupt, F. *Kulturen der Empathie*. Frankfurt aM: Suhrkamp, 2008

ontology. In this regard, he aims at coming at the subject area from the rear, heeding that '[t]he meaning-making process must also be understood and measured'<sup>12</sup>.

#### *Social/political science context*

The diagnostic/therapeutic decision-making situation on ADHD between doctors, parents, and under-age patients is a complex triadic agency, which can be conceptualized and analyzed through a discursive institutionalism frame of semantic patterns of power. It is subject to data acquisition through qualitative methods such as situational analysis and focused ethnography. Since ADHD is a compatible subject with the overall critical discourse on (bio)medicalization of childhood, biopolitics, and health care systems, the issue of empowerment is a critical aspect for researchers in this area, public health experts, and (health) policy-makers alike. The situation involving underage patients as a third party is a research site that does not follow the standard account of the dyadic doctor-patient interaction. As such, it has not been studied sufficiently itself nor with regard to the issue of power/empowerment as a cognitive policy of participation.

#### *Interdisciplinary nature of the project*

The project is situated within a context that transgresses disciplinary boundaries; however, the argument can be made that Studies in Science, Technology, and Society (STS) is an inherently interdisciplinary field, and this project and the fellow fall within STS's premises. The outcome-based orientation falls within more traditional areas of the social sciences, where sociology of knowledge and medical anthropology meet the sociology of medicine and health care systems .

The mixed-methods approach and the cognitive-science based fundament that integrate the theoretical and empirical contexts, however, are not only giving credit to cutting edge knowledge in human development and social progress, but are also fused by the role that semantics and social ontology play throughout them. Touching upon methods from quantitative social science, objective hermeneutics, medical anthropology and cognitive semantics (such as semantic qualifying) this mixed methods approach will be able to reliably integrate a qualitative with a quantitative approach, and create a research tool with predictive value. The fellow aims to show that this approach can make 'small science' projects work to create 'Big Science' results<sup>13</sup> as a transfer achievement, avoiding the costs and risks of Big Science projects. This will be illustrated here in developing a new mixed-methods tool for evaluating the factors of health-related quality of life, empowerment, and self-agency in meaning-making processes in low-tech/high-tech biomedical practices for predicting participation.

### **B1.2. Appropriateness of research methodology and approach**

It is suggested here that participation as a cognitive policy ought to be investigated according to the dimensions of power and self-agency, operationalized in an ethnography of latent semantic patterns that determine the dynamic conceptualizations of health, quality of life, and the body. Semantic empowerment patterns will also be studied ethnographically by following participants of Aikido and Taekwondo programs. Neurophysiological, cognitive, and psychological research has underscored positive effects of martial arts programs for the development of executive functions. Therefore, it is suggested that this research site be used to acquire semantic data on empowerment, health-related quality of life, and self-agency. The situation of children, suspected of ADHD, in a trinary interactive situation with guardians (parents/teachers) and care practitioners (doctors/nurses) serves as our second research site. Secondly, it is suggested that in order to understand the semantics of empowerment in everyday life as a goal and motif for

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<sup>12</sup> Barrett, Lisa F. 'Emotions are Real', in: *Emotion*, Vol. 12/3, 2012: 413 – 429

<sup>13</sup> Vermeulen, N. *Supersizing science; On building large-scale research projects in biology*. Maastricht: Maastricht University Press, 2009; Vermeulen, N., Parker, J.N. & B. Penders. (2010). Big, Small or Mezzo?: Lessons from Science Studies for the ongoing debate about 'Big' versus 'Little' Science. *EMBO Reports*, 11, 420-423; Parker, J.N, et al. *Collaboration in the New Life Sciences*. Farnham: Ashgate, 2010

child development, when comparing ADHD clinical care with participation in non-competitive martial arts (which research suggests as successful development program<sup>14</sup>), we require a broader base for integration of the instrument (a semantic analysis scheme) that is supposed to be developed in the course of this project.

In reviewing the meaning-making patterns of power, self-agency and HrQoL in the triadic relationship arising in the biomedicalized ADHD discourse and the semantic patterns in martial arts settings, we gain agent-based data on how children as agents are embedded in a discursively institutionalized life-world that structures the constraints and enablements for participation as cognitively accessible policies and ideas. Methods of focused ethnography, situational mapping, and discursive institutionalism will measure out the semantic range and horizons of these possible lifeworlds<sup>15</sup>.

The instrument that will be created to measure factor strengths will take the form of a latent semantic differential pattern analysis, resembling a questionnaire with a Likert-scale measure of power dichotomies<sup>16</sup>. However, the innovative potential of this factor-measuring is in how the baseline data coded from situational maps of discursive institutions and latent meaning patterns can be transformed through advanced factor-analytical methods into robust agent-based models for decision-making and participation.

Unlike existing instruments, the semantic categories are not really dichotomous, i.e. they are not reduced to binary oppositions (good-bad, healthy-unhealthy, powerful-powerless). Instead, we manage to encode multi-valued and inter-connected semantic clusters, which correspond to the complexities and fractal natures of power and empowerment of the actual lifeworld and enable a quantitative analysis through multi-factorial, cluster and fractal quantitative analysis, as well as account for analog and digital forms of information, i.e. we measure parametric and metric materialities of power. This allows for the creation of data that can achieve quantifiable, comparative results on which we can create models that also enable us to compare participation across the transatlantic divide of political, consumer and health-care cultures.

The methodological question answered in this project is 'How can social ontologies be operationalized, made measurable, and comparative?'

### **B1.3. Originality and Innovative nature of the project, and relationship to the 'state of the art' of research in the field**

This project connects current perspectives on biomedicalization and methodologies of situational mapping in a novel and innovative fashion with HrQoL and outcome-related measures in health care systems reform.

It does so by refining the state of the art in semantic qualifying methods<sup>17</sup>. Traditional approaches in semantic qualifying methods restrict themselves to code binary oppositions and dichotomies rather than reflect complexity, epistemic vagueness, and sequential narrative

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<sup>14</sup> Diamond, A., Lee, K. "Interventions shown to Aid Executive Function Development in Children 4-12 Years Old." in: *Science*, Vol. 333, 2011: 959-964

<sup>15</sup> see above Fn. 1-5 and Hammersley, M. "Troubles with Triangulation" in: M.M. Bergman, M.M., ed. *Advances in Mixed Methods Research*. Theories and Applications, London: Sage, 2008: 22 – 36.

<sup>16</sup> see above Fn. 4 and Cohen, T., Blatter, B., Patel, V. "Simulating Expert Clinical Comprehension: Adapting Latent Semantic Analysis to Accurately Extract Clinical Concepts from Psychiatric Narrative" in: *Journal of Biomedical Informatics*, Vol.41(6), 2008: 1070-1087; Bordage, G. " Prototypes and semantic qualifiers: from past to present." in: *Medical Education*, 41, 2007: 1117–1121; Thomas Landauer, Peter W. Foltz, & Darrell Laham (1998). "Introduction to Latent Semantic Analysis" in: *Discourse Processes* Vol.25, 1998: 259–284; Hasman, A., et al "Biomedical Informatics- A Confluence of Disciplines?" in: *Methods of Information in Medicine*, 50(6), 2011: 508-524; Holmboe, E.S, et al "Faculty Development in Assessment: The Missing Link in Competency-Based Medical Education." in *Academic Medicine*. Vol. 86(4), 2011:460-7; Bahl, B. et al. "Cognitive evaluation of user interface for Phase I clinical trials." in: *International Journal of Medical Engineering and Informatics* Vol. 1(4) 2009:490 – 503; MacKinnon, N., Heise, D. *Self, Identity, and Social Institution*, New York: Palgrave, 2010; Heise, D. "Enculturating agents with expressive role behavior", in: Payr, S., Trappl, R., eds. *Agent Culture: Human-Agent Interaction in a Multicultural World*, Mahwah, NJ: Lawrence Erlbaum, 2004: 127–142; Heise, D., Lerner, S. "Affect control in international interactions", in: *Social Forces* Vol. 85, 2006: 993–1010

<sup>17</sup> see above Fn. 16

openness<sup>18</sup> that affords real life situations of decision-making. This new approach (semantic agency theory) considers the opportunities provided in multivariate, fractal and cluster analysis: Variables need not be coded as binary opposites, but can account for latency of clusters. State of the art methods in creating agent-based models from data about propositional knowledge have recently been successfully used by Stephanie van Droogenbroeck at CWLF (return host) to account for factors in classic doctor-patient scenarios. The innovative potentials of the fellow's training/research-scheme lie in the construction of models that include (i) concrete operationalizations of empowerment, self agency, and HrQoL, and account for (ii) the more complex situation of a trinary interaction where decisions are made for an underage patient by guardians and care professionals. This situation is not yet sufficiently studied.

To complement existing research on health care outcome, lifestyle, milieu, and rational choice with the missing link of 'enculturation'/'social ontology', this project draws on insights from recent paradigm-changing research in developmental psychology and cognitive studies<sup>19</sup> to account for the operational role of semantic agency and propositional knowledge in decision-making. Therefore, it also emphasizes the gatekeeper role for outcome-related policy-change that non-academic care practitioners (e.g. nurses) inhabit. Their agency and expert knowledge—like that of children as patients - is often unaccounted for in the analysis of interactions at clinical sites and in health care policy reform, which favor the dyadic doctor-patient interaction as their analytical unit.

The project's additional innovative potentials account for the need for an integrative medicine, which considers quality-control and standardization for research and practice, by reconsidering the dichotomy of alternative versus academic medicine, to work with a multipolar and integrative continuum between low-tech and high-tech practices.

#### **B1.4. Timeliness and relevance of the project**

Health care systems and public health related research must account for transatlantic/transnational perspectives. Ongoing negotiations between the European Union and the United States on a free-trade zone (Transatlantic Trade & Investment Partnership Agreement [TTIP]) foreshadow an intensification of (e)merging of markets in medical research and care. Researchers must consider that competitiveness and outcome-orientation are an important factor in systemic health care decision- and policy-making. Research tools and (research/teaching) competencies in these and related fields require upgrading, since research subjects (including subject populations) as well as the student populations are undergoing rapid social changes. Internationalization through free-trade zones means that care service and health care product markets grow, as well as high-skill and low-skill job applicant pools will merge. (Mental) Health care and biomedical research are already substantial markets and will continue to be an area of growth. Therefore the new situation will require researchers and practitioners to be even more mobile, therefore lead them to transition between different regimes of research and care ethics. It must be stressed that research and care ethics regimes not only affect researchers and practitioners. Publics and policy-makers, for whom policy and ethics regimes exists as cognitive ideas, as participants in research and care interactions, are guided by perceptions of how much power, agency and quality of life ethics regimes enable

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<sup>18</sup> Tversky, B. "Narrative of Space, Time and Life" in: *Mind and Language* Vol. 19/4, 2004: 380 - 392

<sup>19</sup> See above Fn. 10&14 and Ratey, J. *Spark*. New York: Little Brown&Company, 2008. Langer, E., Moldeveanu, N. "The Construct of Mindfulness" in: *Journal of Social Issues*, Vol. 56, 2009: 1-9; Thompson, E. *Mind in Life* Cambridge, Ma: Harvard UP, 2010; Goldstone, R. L., et al. "Learning along with others." in: *Psychology of Learning and Motivation*, Vol. 58, 2013: 1-45; Hendrickson, et al "Re-learning labeled categories reveals structured representations." *Proceedings of the Thirty-Fourth Annual Conference of the Cognitive Science Society*, 2012: 1668-1673; Day, S. B., Goldstone, R. L. "The import of knowledge export: Connecting findings and theories of transfer of learning." in: *Educational Psychologist*, Vol.: 47 , 2012: 153-176; Fonseca, B., Chi, M.T.H. "The self-explanation effect: A constructive learning activity." in: Mayer, R. & Alexander, P., eds. *The Handbook of Research on Learning and Instruction*. New York: Routledge Press, 2011; Chi, M.T.H. "Three types of conceptual change: Belief revision, mental model transformation, and categorical shift." in: Vosniadou, S., ed. *Handbook of research on conceptual change*, Hillsdale, NJ: Erlbaum, 2008: 61-82

them to possess when they are involved as research or care subjects. Simultaneously, we are witnessing the reconstitution of patients as participants and consumers in health care at increased and transformative levels. We are currently witnessing the emergence of a novel 'subjectivity' in biomedical and health care contexts: The class of the *new chronic*<sup>20</sup>, a contemporary reconfiguration of the relationship between politics, capitalism, revolution, and the body. At the intersection of medicine, globalization, politics, and culture targeted drug therapies and biotechnology manage illness rather than cure it, while global capitalism aims not for a continual state of crisis management that perpetuates the 'iniquities of the status quo'. This opens a line of inquiry that sets the condition of the class of the *new chronics* in opposition with idea of the active, participant consumer citizen. Following the current shift in institutional analysis of health care (Wendt) and biomedicine (Clarke), it calls for analytically refined tools for outcome-oriented analysis of both existing health care systems and systems reform policies.

New tools, specifically mixed-methods approaches are also called for, since we are experiencing a paradigm shift in cognitive research that suggests a different approach to development, decision-making, cognitive learning, and social ontology: The standard 'natural kind' models of cognition and emotion have been shown to require severe revision, recent research in social psychology include accounts for executive functions and enactivism, social ontology and meaning making have yet to be investigated in the dimensions of power, self-agency, health-related quality of life. This project aims at a *praxeological* link with social science models integrating the opposition of intentional and dispositional knowledge through the concept of propositional knowledge-based frame selection. With regard to future applications, this project echoes recent emphases on an integrated role for all care practitioners (particularly nurses and nurse practitioners) and the necessity for international standards in clinical care practices and for CAM practices. This adds to the need for international standardized practices in all types of care regimes, in placebo-research, and increased efforts into uncovering the ill-understood underlying mechanism of placebo-response, its recent increase and the observed cultural variations. Finally, it will help predict factors for public support and individual participation in biobanking and related bio-medical research efforts.

This project is outcome-oriented in its understanding of social ontologies that function as the context for interventions that children as patients, martial arts students, and future political/consumer citizens are embedded in for a simple reason: As one team of cognition researchers, working on executive functions and intervention potentials, framed the socio-economic outcome-based results of their work:

“[I]nterventions that achieve even small improvements in [inhibitory control] for individuals could shift the entire distribution of outcomes in a salutary direction and yield large improvements in health, wealth, and crime rate for a nation.”<sup>21</sup>

### **B1.5. Host research expertise in the field (outgoing and return host)**

Drexel University is comprehensive global research university ranked in the top 100 in the United States; *US News* ranks Drexel as one of the most promising, innovative up and coming universities in the country. Drexel has a strong track record in health research, with innovative research and teaching by faculty in Drexel's College of Arts & Science, the School of Public Health, College of Nursing and Health Professions and the Medical School. Drexel has an Office of Faculty Development and Equity and policies dedicated to increasing gender, race, sexual orientation and other forms of diversity.

The outgoing host, the newly founded Center for Science, Technology and Society at Drexel University, has 23 affiliated faculty, a Director and one full time professional staff person.

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<sup>20</sup> Cazdyn, E. *The Already Dead: The New Time of Politics, Culture, and Illness*. Durham, NC: Duke UP, 2012

<sup>21</sup> Moffitt, T.E. et al "A gradient of childhood self-control predicts health, wealth, and public safety." in: *Proceedings of the National Academy of Sciences*, Vol. 108, 2011: 2693 - 2698

Affiliated faculty have received grants from the National Science Foundation, the National Institutes of Health, and other sources, and have established international collaborations on topics related to health (specifically medical imaging, autism, and ethical issues in health and medicine). The faculty produce award winning academic books and peer-reviewed journal articles. The proposed research fits with both Drexel and the STS center's institutional focus on health as a major research area. The Center is an independent unit in the College for Arts and Sciences, succeeding the original Program for STS, situated in the Department for History and Politics, without ending existing and planned collaborations. The Center's faculty includes members of the Departments for Public Health, Anthropology, Sociology and Criminal Justice, History&Politics, Philosophy, and the iSchool (Information School, College for Information Science and Technology). Research at the center is conducted in three interrelated fields:

(i) Environment and Sustainability. Researchers investigate how cities and regions are looking for ways to increase energy independence and create built environments that support human and animal life. Environmental effects on critical interdependent urban infrastructures, that lead to risks to communities are studied to aid in redesigning systems for sustainability and resilience. Cultural contexts are studied a layer of cognitive complexity: How we think about and react to issues such as climate risks, how arguments structure debates and decisions about new and old energy technologies, disasters and questions about biodiversity and pollution. Research topics currently investigated include food access, the use of science and technology in disaster response, the relationship between new modes of transportation and the environment, the transnational production of citrus fruits, the social dimensions of new energy sources, and ways to address the effects of climate change.

(ii) Health and Medicine. The research premise is that medicine is central to people's lived experience. People interact with medicine in a range of roles: as patients, as caregivers, as clinicians, as regulators, as insurers, as participants in human-subjects medical research, as consumers. Medical technologies from bioinformatics to pharmaceuticals are crucial to the social shaping of health and illness. Research undertaken by Kelly Joyce and Ali Kenner asks why certain forms of medical research and service delivery are favored over others; who and what drives ongoing policy debates in nations whose health system stakeholders grapple with issues like cost, accessibility and professional training; the cultural contexts that shape participation in health care professions and systems; the role marketing plays in medicine; and how definitions of disease and diagnostic categories change over time. Faculty affiliated with the STS Center currently research topics such as the rise of self-diagnosis questionnaires and their impact on healthcare, ideas about the use of MRI technology, the ethics and history of public health, the use of animals in health research, and how and why the Buteyko method is being implemented in asthma care.

(iii) Information, Identity, and Networks. Human subjectivities are shaped by security, privacy, health and wellness, assembling information and sharing knowledge, creativity, commerce and mobility. These areas of human life intersect with information and computing technologies at every corner. Everyday life is enmeshed in a web of interdependencies whose operations rely on highly complex and sometimes vulnerable information structures. The informational infrastructures are constituted by classification schemes, categorical infrastructures and taxonomies, which are social products that require critical analysis. Faculty affiliated with the STS center research topics such as the ethics of big data and algorithms, the relation between nanotechnology and a changing workforce, the relation between computers and the construction of identity, and policies that promote civic engagement with computing technologies.

The fellow will also collaborate with researchers at Drexel, not directly affiliated with the Center for STS, in the Department of Public Health (Prof. Longjian Liu), the Department of Psychiatry of the College of Medicine (Prof. Victor Lidz), the Department of Psychology

(Autism&ADHD, Prof. Felicia Hurewitz), the Program for Human Cognition Enhancement (Research Area on Decision Sciences and Pedagogy, Prof. Vadake Narayanan), and the Department of Family, Community, and Preventive Medicine (Health Care Communication and computer-enhanced medical education, Prof. Christof Daetwyler).

The research project suggested here is situated in the fields of the 'responsibilities of science' and 'information streams in biomedical practice'. These research domains are central research topics of the return host, the Center for Logic and Philosophy of Science (CLWF) with a national and international network. There is an intensive collaboration with the Center for Intercultural Communication and Interaction (CICI)

The Center for Logic and Philosophy of Science (CLWF) has developed over the years an expertise in ethno-mathematics, argumentative networks, and agent-based models. Members of the Center have been involved in two major research projects on the basis of this expertise, namely, the Interuniversity Attraction Pole (IUAP) project *The loyalties of knowledge* and the Concerted Research Action (GOA) project *Unifying Philosophy Through Dis-Unifying Science*. The general objective of the former project was to conceptualize scientific and technical activity in a democratic constitutional state, this means rethinking the relationships between science/mathematics and society by means of the inter- or cross-disciplinary study of scientific topics. The latter project elaborated on the identity of the tension between ontological and methodological monism (to strive for unification, reduction and simplicity) and pluralism (tendency towards diversity, autonomy and openness) in different fields, from the philosophy of mathematics, over the philosophy of ethnomathematics and the philosophy of physics to the philosophy of psychology/neuroscience, in order to investigate whether a unified case for disunity can be made. These projects have resulted and continue to result in PhDs and publications, both articles and books. One of the PhDs that resulted from the IUAP project was Karen François's PhD thesis (*Politiek van de wiskunde*) on the loyalties of Mathematics and Politics, a research project in the field of the externalist philosophy of mathematics, looking for interconnections between mathematics and society.

The research done within the projects on the philosophy of mathematics has also led to the Center's involvement with the establishment of the Association for the Philosophy of Mathematical Practice (APMP). The two major conferences on the philosophy of mathematical practice (PMP1, 2002 and PMP2, 2007) and the conference on the philosophy of mathematics education (2004), organized by the Center, have been instrumental in establishing an international network. December 2010 the First International Meeting of the Association for the Philosophy of Mathematical Practice was organizing its founding conference at Brussels, organized by the Center with Karen François (among other members of the Center) as local organizer of the conference. Three members of the Center take part in the APMP research community; Jean Paul Van Bendegem is a founding member.

The Center CLWF is involved in the international research group Philosophy of Mathematics: Sociological Aspects and Mathematical Practice (PhiMSAMP) whereof, among others, Karen François is an active member. The aim of this international research group is to bring researchers with foundational and sociological attitudes together and discuss a unified approach towards a philosophy of mathematics that includes both sociological analyses but is also able to deal with the status of the epistemic exception that mathematics forms among the sciences. Karen François is one of the scientific editors of a main PhiMSAMP-publication: François, Karen; Löwe, Benedikt; Müller, Thomas & Van Kerkhove, Bart (eds.) (2011) Foundations of the Formal Sciences VII. Bringing together Philosophy and Sociology of Science. Book series: Texts in Logic. London: College Publications.

The Center CLWF is involved in the Educational Research project Philosophy of science and history of science applied to pedagogy. This project, involving an impressive number of research groups, wants to explore the possible connections between philosophy of science,

history of science and pedagogy. The part of the CLWF within this project is its expertise within the field of philosophy of science and mathematics. Jean Paul Van Bendegem, Karen François and Kathleen Coessens take part in this research community which resulted in co-authored publications on the philosophy of mathematics and statistics ); on the interplay of universal versus local mathematical practices and recently on the social and cultural embedding of mathematical practices.

Over the years since the existence of the Center a number of scholars have worked at the Center for one month up to one semester. We just mention: Max Cresswell (VLAC Fellow), Benedikt Löwe (VLAC fellow), Jacek Malinowski, Roman Murawski, Sal Restivo, Adriana Rine (VLAC Fellow), and Hartley Slater. During the second half year 2012 researchers at CLWF entered into a six month collaboration with the fellow's co-author Sal Restivo, researcher on the sociology of mathematics, objectivity, and the social brain, recently retired as Professor of Sociology, Science, Studies and Information Technology in the STS department at Rensselaer Polytechnic Institute, Troy, NY, former Special Professor of Mathematics Education at Nottingham University in Great Britain; and a former Hixon/Riggs Professor of Science, Technology, and Society at Harvey Mudd College; he is a founding member (1975) of and a former president (1994/95) of the Society for Social Studies of Science, and recently special Lecture Professor in STS at Northeastern University in Shenyang, China and a visitor professor at CICI-University Ghent.

#### **B1.6. Quality of the group/scientist in charge (outgoing and return host)**

Outgoing Host, Drexel University, Center Science, Technology & Society

*Supervisor/Scientist in Charge:*

Prof. Kelly Joyce, is Associate Dean for Humanities and Social Science Research for the College of Arts & Sciences; Director, Master's Program in Science, Technology & Society; Professor, Department of History & Politics.

Prof. Joyce is a renowned sociologist of medicine; her first book *Magnetic Appeal* won the American Sociological Association's Friedson Outstanding Publication Award in 2010. She has co-edited *Technogenarians* and published numerous articles and book chapters. Her research and publications on (a) social dimensions of health and illness as well as courses on the values embedded in technological design and use. (b) medical knowledge and clinical practice and (c) aging, science, and technology. Her current research takes up the use of the category autoimmune illness in medicine and examines how people live with these illnesses in daily life.

Prof. Joyce previously was an Associate Professor of Sociology at the College of William and Mary. Prof. Joyce also served as a Program Director for the Science, Technology, and Society program and the Ethics Education in Science and Engineering program at the National Science Foundation during 2009-2011. She received the Director's Award for Collaborative Integration for contributing to the education of ethical scientists, interagency collaboration, and extraordinary efforts in integrating ethical expertise with scientific knowledge in 2011. Among other honors, she received the Bok Award for Teaching Excellence, Harvard University.

In the Departments for Public Health, Psychiatry, and Family, Community & Preventive Medicine, research partners will introduce the researcher to methods in epidemiology, biostatistics, health equality, and computer-integration in medical education. Ongoing research in these departments, which involve STS perspectives and the work of Kelly Joyce focused on integrated ecological models, chronic care models and disease being unequally (not-randomly) distributed in population. The overarching goal of this research is to translate social and biological findings to practical application of control of disease and risk factors.

We will further co-operate with researchers from designated research programs within the Human Cognition Enhancement Program and the Psychology Department on 'ADHD and

Autism' and 'Decision-Making'. We will involve their research on cognition as it pertains to human performance in the workplace, at home, and in travel and entertainment, optimizing learning through environment and gaming applications, and Enhancing the quality of life through personal electronics design and information stream management, in order to complement efforts on novel clinical tools to diagnose and evaluate new treatment methods.

Researchers in these programs study how cognitive, perceptual, and motor resources are organized and coordinated towards the efficient achievement of goals in the world. Examining how humans make decisions in situations characterized by limited information and uncertainty, and how (and how well) people learn from feedback in these environments, they use a combination of empirical studies to develop state-of-the-art computational models of cognitive processes that serve as an explicit implementation of a theory, but can also have practical applications, such as monitoring human performance in real-time to aid performance or detect errors, or assess the course and extent of learning.

#### Return Host

Vrije Universiteit Brussels, Centre for Logic & Philosophy of Science (CLWF), Belgium

##### *Supervisor/Scientist in charge:*

Prof. Jean Paul van Bendegem (Professor, Director of CLWF) is a researcher in ethnomathematics, empirical mathematics, catastrophe theory, and time-dependent set-theory. Relevant interdisciplinary research currently supervised at the CLWF by Prof. van Bendegem involves generation and transmission of knowledge in representation, semiotics, metaphor, and epistemology in sciences, meta-research on embodiment (somaesthetics, social ecology, and performance), and argumentative support for and objections against basic assumptions in and simulation of doctor-patient interactions. The underlying theme, involving the issue of decision-making and participation, for this research is the function of tacit knowledge in the belief dynamics between scientists and laypersons, the positions and responsibilities of the sciences and of scientists in a democratic and constitutional state. Researchers at CLWF, under Prof. van Bendegem's supervision, have successfully created agent-based (computer) models that simulate socio-epistemic questions, such as questions concerning the roles various types of social interaction play in the acquisition and transmission of beliefs and knowledge

Cooperation with Dr. Michael Dellwing at the Institute for Macrosociology, Faculty of Social Science (FB 05 Gesellschaftswissenschaften), University of Kassel, Germany. Dr. Dellwing is a leader of research innovation in sociology focusing on labeling and interaction in mental health, deviance, dramaturgical sociology of everyday life, and advanced ethnography in triangulative (i.e. mixed) research methods.

## **B2. Training**

### **B2.1. Clarity and quality of the research training objectives for the researcher**

The main objectives of the research training at Drexel University for the fellow are as follows:

- Development of a comparative and integrative understanding of research ethics procedures between the European Union and the US. Even though the fellow has already participated in empirical research projects, and created and conducted his own research in Germany and the US separately, he has yet to develop and conduct research on his own that crosses international borders and involves human subjects.
- Acquiring advanced skills in multivariate and cluster analytical methods, semantic qualifying, and qualitative methods. While the fellow already has experience working empirically in social research and received training in multivariate and cluster analysis, as well as in qualitative methods (including ethnography, visual sociology and SYMLOG), he is not yet an expert in methods and not privy to recent advances, having spent more effort in recent years to gain competence in medical anthropology and child development, as well as gaining skills in modes of discourse analysis and semantic qualifying. The Center for STS at Drexel is an ideal place to develop these skills. STS as an interdisciplinary field originates in social research. It has strong links with the both the sociology and public health departments, where quantitative and qualitative methods are developed and taught at advanced levels.
- Develop the capability of combining discursive institutionalism, ethnography and situational mapping as a resource for semantic differential analysis methods, and triangulating these qualitative results with quantitative instruments to form a robust mixed methods approach. This is precisely the aim of the research projects outgoing phase.

Complementary training objectives for the return year at Brussels are

- Acquiring advanced skills in converting data obtained by mixed-methods approaches into fractal-logical structures of propositional knowledge.
- Developing the ability to convert the data delivered by the instrument into an agent-based simulation. This is, in short, the aim of the incoming phase.

Drexel is a very active research site, where above research objectives can be achieved and the professional maturity of the researcher strengthened. This is particularly true when considering current developments of European and American biomedical and (health) care markets and research areas continuing to merge. Acquiring broad research competencies as well as research translation and transfer competencies is even more crucial. The Center for Science, Technology & Society at Drexel will improve the fellow's research skills with major American and international experts working at Drexel as well as members of the biomedical, public health and social science networks in the area intersecting with this interdisciplinary program.

### **B2.2. Relevance and quality of additional research training as well as of transferable skills offered**

The fellow expects to acquire skills over the course of the project, that result indirectly from working at Drexel and CLWF, which contain development aspects and tacit competencies that promise to enable success of future research as well as improve in the fellow's teaching profile.

- In simultaneously undergoing an IRB process (US) and integrating the proposal with European research ethics considerations, the fellow develops skills not otherwise available to colleagues and students in international collaborations in research and knowledge-based industries who do not themselves have the direct experience of working in two different research ethics regimes. This experience does not only obtain for research ethics but also prevails in the anticipation of cross-cultural constraints and biases that stem from different (national) cultures in research practice. Prof. Kelly Joyce, based on her former position with NSF, is an excellent source for learning about this issue.

- Working with Drexel professors Yudell (STS/Public Health), Daetwyler (Family Medicine), and Lidz (Psychiatry), the fellow will gain competencies in epidemiology and biostatistics, and in the integration of large data sets from biostatistics and epidemiology ('Big Data') for research design and agent-based models.
- While the fellow has previously studied decision-making processes and models, working with Prof. Joyce, an expert on decision-making and algorithmic structures in health care systems and interactions, will greatly improve the fellow's knowledge about health bureaucracies.
- Working in the research ecology of Drexel, where medical, public health and social science intersect regularly, the fellow will engage researchers who continuously work on clinical standards and development of tools for the evaluation of such standards for research and care practices, including research areas with increasing demand for emerging standards, e.g. placebo-research or research in complementary & alternative medicine (CAM).
- The return host, Prof. van Benedegem and CLWF, provide an outstanding site for complementary skills on decision-making models and bioinformatics through the inclusion of the study of the role of propositional knowledge in cognition and embodiment research.
- Working in international academic environments, interacting with multilingual colleagues from different (national) research cultures, will greatly improve the fellow's language skills. While his English is certainly already quite proficient, full immersion for two years will prove highly beneficial. Additionally, the fellow aims at refurbishing his skills in French by taking a language course at Drexel, before immersing himself in the multilingual environment of Brussels, where he also will start to learn Dutch, continuing the development of the profile of a European polymath researcher.
- The fellow will acquire capabilities in research organization and management. Apart from management activities related to the project itself, he will be involved in the organization of seminars and workgroups, and departmental affairs at both sites.

The fellow, in summary, will gain independence and professional maturity in obtaining these complimentary skills.

### **B2.3. Host expertise in training experienced researchers in the field and capacity to provide mentoring/tutoring (outgoing and return host)**

Kelly Joyce, professor for in STS, is the Associate Dean for Humanities & Social Science Research for the College of Arts & Sciences Program, Director of the Center for Science, Technology, and Society, and, during 2009-2011, the Ethics Education in Science and Engineering program at the National Science Foundation. She received the Director's Award for Collaborative Integration for contributing to the education of ethical scientists, interagency collaboration, and extraordinary efforts in integrating ethical expertise with scientific knowledge in 2011. Prof. Joyce won several awards for excellence in teaching, including Harvard University's Bok Award for Teaching Excellence. Her research publications were awarded honors such as the Eliot Freidson Outstanding Publication Award. She served on numerous occasions as advisor for PhD and honors theses, and obtained competitive research grants of her own. Her professional service includes leading roles in editorships, committees and task forces.

Jean-Paul van Bendegem is an internationally recognized researcher in philosophy of science. He is a professor at the Free University of Brussels (VUB) and the University of Ghent. In his role as director at CLWF, he is currently supervising three PhD researcher and two postdoctoral researchers, following in an extensive list of alumnis. He has also co-organized conferences and workshops, including several 'Young Researchers Days in Logic, Philosophy and History of Science'. Under his direction, CLWF has hosted international visiting researchers. He is the VUB's representative to the CNRL-NCNL (Centre National de Recherches de Logique-Nationaal Centrum voor Navorsingen in de Logica).

### **B3. Researcher**

#### **B3.1. Research experience**

The fellow has an interdisciplinary career embedded in research and research collaboration, from his time in studying social research methods as an undergraduate student to his postdoctoral research profile in Science, Technology & Society and Medical Humanities.

##### *Research background*

As an undergraduate and graduate student (1998-2005) and PhD-candidate (2005-2008) the fellow was involved in several 'teaching research' and research projects, supervised by leaders in their fields.

- Research Assistant (Undergrad.)
  - Structures of non-profit organizations and active disability care: Staff cantina employing workers with disabilities (FAU, Prof. H.Kreutz, Dr. J.Schmidt)
  - Teaching evaluation: Social/Economic Science Faculty (FAU, Prof. H.Kreutz)
  - Medical examinations of pre-schoolers' physical and intellectual fitness for entering school (FAU, Prof. J.Bacher. Dr. R.Wittenberg)
  - Ethnography of youth event cultures: Hip-Hop in Nuernberg/Fuerth, Germany
- Research Assistant (Grad.)
  - Transnational Identities in Border Regions: Austrian/Slovenian/Slovakian Triangle, Swiss/German/French Triangle (FAU, Prof. Srubar, Prof. Bahadir)
- Research Library Assistant
  - As a member of the Library for Sociology/Political Economy, the fellow aided several research projects and activities of the faculty, tutored undergraduates in academic writing, and supported graduate students in their thesis research,

##### *Independent Research:*

As a graduate student, the fellow began exploring independent research projects of his own:

- The Co-Evolution of Concepts and Techno-scientific Practices in Biomedicine, Sociology, Philosophy, and Experimental Psychology and their Scientific Publics in the 19th and 20th century: This research began in 2001/2 and ended with research into the history of ADHD in 19th century psychophysics and fatigue research referenced in recent publications. It included the inquiry into the concepts of mediality and the body in Kantian and post-Kantian philosophy, which led to the question of the emergence of Critical Social Theories, and also the PhD project, which was awarded funding by the DAAD, to use the Harvard University Archives to investigate the institutional and conceptual inks between biology, psychophysics, and early sociology, including the human relations movement in the US.
- Genealogy and Latent Meaning Patterns of Critical Social Theory: The fellow developed a discourse analytical/institutional analytical project comparing the political and conceptual history of the Enlightenment concept in German Idealism with that of the Frankfurt school from its beginnings to recent academics and with that of Michel Foucault. His Magister (Master) thesis, which was later published as a book, focused on Horkheimer, Adorno, and Foucault and their reception of Kant's Enlightenment concept as a political and scientific program.
- Archive work: A chance discovery of files during the PhD research led to a side project, while waiting for the PhD review and attending Langer Lab. This research was also partially financed by the DAAD. In this project using Harvard University archives, the role of the DAAD founder, Carl Friedrich, in the so-called Bergstrasser affair in the 1940s was investigated. The research aim was to show in letters and memos how Friedrich's

involvement with the new concepts of 'propaganda' and 'persuasion', which he was one of the first to create university courses on, informed his decisions and politics in the Bergstrasser case. This yielded a chapter for a finished book under contract negotiation.

- **Ethnography: Disruptive Behavior and Martial Arts in Martial Arts Associations**, beginning in 2006, the fellow, as a participant observer, studied how internal and non-competitive martial arts associations in Germany function internally and act within their institutional ecology, how interactions 'on the mat'/in the dojo' affect the life-courses of adult and underage participants, and also how instructors integrate children with disruptive behavior disorders and devise special programs for them.
- **Social justice issues in biomedicalization and digitalization**: Since his PhD in 2008, the fellow has investigated the effects of biomedicalization, digitalization, and post-colonialism on social justice. This ongoing research has led to several manuscripts that are now under review or accepted and forthcoming, as well as the development of innovative and timely seminars that have been taught at Leuphana University
- **Conceptual and perceptual mechanisms of decision-making in doctor-patient interactions**: Investigating the role of propositional knowledge and techno-scientific practices in medical decision-making, interviews with cancer survivors and multiple sclerosis patients have led the fellow to inquire about the role of narratives and of images in decision-making, particularly the role of medical imaging technologies in both research and clinical practice regimes. He has presented at international conferences on this issue and a chapter is forthcoming.
- **Ethnographic Field Work: Gastronomy interaction structures and labor economies**, (2004-ongoing): Following an internship with a business consultant, the fellow began an ongoing project on ideas of labor, hygiene, hospitality and nutrition in the restaurant business (i.e. the social ontology of gastronomy). Following occasional visits to the US, he decided to include a comparative perspective and aim at a collaborative publication.
- **Semantic qualities, Metaphors and Status Hierarchies in Mass Media**: (since 2005): Following the topic of the 'Holocaust in Cultural Memory' from his Magister Exam in sociology and American culture studies, the fellow began a research into the question how representations of victim/survivor metaphors in cultural (mass)media, affect social interactions and identity-processes by creating decision-biases in narrative structures. The fellow has presented on this topic at conferences and published with open access journals. He now investigates these metaphors in doctor-patient interactions.

### *Collaborations*

The fellow has been and continues to be a collaborator in research and publications.

- The above cited project on gastronomy interaction structures and labor economies in Germany and the US is conducted since 2012 in collaboration with Gareth Edel (PhD candidate at Rensselaer Polytechnic Institute)
- The role of victim/survivor metaphors in cultural media, interaction and in identity-processes, will be continued in collaboration with colleagues at University of Kassel, where Michael Dellwing supervises a project on victimhood and media representation.
- with Sabrina M. Weiss (Ph-candidate at Rensselaer Polytechnic Institute, Visiting Assistant Professor at Rochester Institute of Technology), since 2011 an ongoing research collaboration that has yielded presentations, papers and a book:
  - ADHD, its social and institutional ecologies (several published chapters).
  - Ideas of Difference and Alterity in Culture and Cognition: Looking at the figuration of the 'zombie' in the philosophy of mind, cognitive science and, along with related concepts (alien, weird, monstrous), in both Western and non-Western pop-cultural we investigate how otherness as a cognitive policy and idea shapes modes of participation and 'being social'(forthcoming book chapter).

- *Worlds of ScienceCraft*: In this book, co-written with Sal Restivo (emeritus professor, RPI) we investigate the fragmentation within the sciences and between science and society, and develop a pragmatic framework for collaborative integration of epistemic communities, based on the Restivo-Weiss model of the social brain/mind and the fellow's semantic agency theory of decision-making and narratives of selves. The model is exemplified on the genealogy of ethnomathematics, the debate on brain-mind dualism, ethics of organ donations, operational diagnostics in medicine, and health care systems reform.
- *Agential Realism and New Materialism in Biology, Medicine, Neurocognitive Science, Disability Studies and Cyborg Research*: The fellow and Weiss continue to discuss recent trends in theory, and their effects on research fields they study as well as on eco- and bio-ethics. The salient issue in these studies (with publications planned or in progress) is the question of what concepts and ideas decision-makers consider as normal (or healthy) and pathological, and how they come by them, i.e. what role techno-scientific practices play in this process.

#### *Competences, Scope, and Research Profile*

The fellow has a unique set of competences, stemming from interdisciplinary training, beginning with an major in biology for his Abitur/International Baccalaureate, and leading from studies in empirical social research (quantitative and qualitative), economics, social anthropology&psychology, followed by sociology, American culture and literature studies (which included the undergraduate level of teacher training, linguistics, phonetics), philosophy, to a Dr.phil./PhD in sociology. The fellow has directed his student career by designing an expanded STS study program for himself, given the lack of Science, Technology & Society (STS) programs in Germany. Following his graduate studies, he developed an interdisciplinary, problem-oriented research scope in STS. His research profile, which seems vast at first glance, is, however, framed quite strictly by the inquiry into the relations of science and its publics on one axis, and the relations between *the* body and the State on the other axis, and the question how these axes are constituted by and, vice versa, shape the political imagination of modern consumer citizens and how individual decision-making can be explained within this frame. To conduct investigations in this research scope, he has acquired and applied a unique and extensive mixed-methods skill-set, which he seeks to further develop and integrate through research training in this project.

### **B3.2. Research results including patents, publications, teaching etc. taking into account the level of experience/ Documentation of Main Achievements**

As a researcher, teacher, and public intellectual the fellow has an impressive record for an early career as a postdoctoral researcher, including prolific publications, opportunities to design his own teaching and uphold standards of teaching excellence, and obtain competitive grants.

#### *List of selected and relevant publications, presentations and invited lectures*

##### **Books**

(forthcoming 2013, with Sal Restivo and Sabrina M. Weiss) *Worlds of Science Craft. New Horizons in Philosophical Science Studies*. Surrey/London: Ashgate

(2010) *Between Discursivity and Sensus Communis: The Co-Evolution of Biology and Social Thought from Kant to Neo-Kantianism, Pragmatism, and Harvard's Human & Social Relations Movements* Erlangen: OPUS, Univ. Erlangen-Nürnberg, 498 pages

(2009) *Aufklärung als Flaschenpost oder Anthropologie der Gegenwart. Horkheimers und Adornos Immanente Kritik und Foucaults Interpretative Analytik*, Saarbrücken: VDM, 253 pages

## **Articles**

### **submitted/accepted/forthcoming**

(submitted) "Digital Fair-Ground: Explorations of the Patient Experience Between Social Justice and the Virtualization of Health and Illness", *Current Perspectives in Social Theory*

(submitted) „The Dialectics of Technoscientific Seeing: Medical Imaging Technologies as Persuasive Technologies“ *Science in Context*

(forthcoming, with Sabrina M. Weiss) "Care, Information, Power", *Telos*

(forthcoming, with Sabrina M. Weiss) "Mindfulness as/is Care: Biopolitics, narrative empathy, techno-scientific practices" in: Langer et al, eds. Wiley-Blackwell Handbook of Mindfulness

(tentatively accepted with Sabrina M. Weiss) "The powers of distraction, attention, and abstraction in the education of the citizens of our futures: the narrative dialectics of attention ecologies for the techno-somatic class-room." *Leonardo Electronic Almanac – Special Issue: The Culture of Digital Education*, (MIT Press)

(forthcoming) "Medical imaging technologies as media of persuasion" *Media on the Brain*, edited by Michael Grabowski, Oxford UP

(forthcoming with Sabrina M. Weiss) "Between the Shell and the Ghost: A hauntology of zombies in society" Dellwing, M., Harbusch, M. eds., *Vergemeinschaftung in Zeiten der Zombie-Apokalypse: Gesellschaftskonstruktionen am fantastischen Anderen*, Springer VS

### **published**

(2013, with Sabrina M. Weiss) "ADHD and its ecologies and agencies: Before and beyond the label" *Krankheitskonstruktionen&Krankheitstreiberi*. Dellwing, M., ed., Wiesbaden: Springer VS

(2012) "Globalization", "The Social Construction of Reality", *ResearchStarters: Sociology*, EBSCO Publishing

(2012) "The Melting Pot versus the Tapestry Debate" *The Making of Modern Immigration: An Encyclopedia of People and Ideas*. P. Hayes (ed.), Santa Barbara, CA: ABC-CLIO

(2011 open access, 2012 chapter) "How to Map the Body's Spaces: Using Foucault's heterotopology for the cartography of corporeal myths." Conference Proceedings, "Myth-Making, Myth-Breaking in History" Univ. of Bucharest, C. F. Dobre, et al eds.

(2011) "Truths, Knowledge, Narratives of Selves. *The American Sociologist. Special Issue on Semiotics and Social Science*, Vol. 42, 2/3, 2011

(2011) various contributions for *Impacts of Technological Change (Sociological Reference Guide)* Ipswich, MA: Salem, including among others: "Knowledge-Based Economy", "Digital Divide", "Technology and Medicine"

(2010) "The ADHD regime and situating neuro-chemical selves in whole systems" Kopnina, H., Keune, H., eds. *Health and Environment*, New York: Nova Science Pub.

(2010) "A note on the question of *virtualization* of health and illness in the age of biological citizenship" *TelosScope (Telos, Open Access)*.

(2009, with assistance by B.Doerle and L.Antini) "Victim/Survivor Semantic" (in German) *Pompeii Project – Journal for Junior scholarship*, open access

(2008) "Structural-Functional Analysis of Health and Medicine", *EBSCO Notes*

(2008) "Visual Sociology", *EBSCO Notes*

(2007) "Procedural Memory in Reflexive Modernities: The Survivor Semantic" *Conference Proceedings* (online), Gradnet Conference *Ethics and/or Justice After Postmodernism*

### **works currently in progress**

(book proposal with J.I. [Hans] Bakker, contract under negotiation) *The Unease of the Mind: Radically Historizing the new DSM between Critical Theories in Sociology and Psychology.*

(book manuscript nearly finished, contract under negotiation) *From Class to Identity and Back Again: A Critique of Political Psychology in the Era of Technoscientific Governance 3.0*

(book manuscript in progress, contract under negotiation ) *Here there be dragons! On the hetero-topological cartography of the uncharted human body and its State.*

(book manuscript in progress, planned for publication 2015/2017) *A Critique of Medical Reason: Conceptualizations, Images, Narratives & Epistemic Defects in Doctor-Patient Interactions*

(book manuscript finished, contract under negotiation with Lexington) *Anthropos's Scaffoldings: Essays in the co-evolution of Biomedicine, Sociology, Psychology, and Philosophy (edited by David Heath, foreword by Sal Restivo)* [originally under publishing agreement with Mellen Press, contract cancelled by author following Mellen Press's questionable public conduct on matters of academic freedom, as reported in the press and media]

(editing of book finished chapter drafts with Sabrina M. Weiss. contract under negotiation) *In the Power of 3: Vital Materialism, Bioethics, Political Theory*

(paper in progress, as lead author, with American collaborator Sabrina M. Weiss, and Leuphana students Patrick Mesenbrock, and Julia Gaertner) "The Decolonization of Medical Knowledges and Cultures of Healing: Creating Relational Social Leadership from Communication Power, Postcolonial Science Studies, and Health Care beyond the Digital Divide."

### **Presentations**

Suffering and being a *survivor* in the age of mass media: Narratives, myths and metaphor machines", SSSI 2014

(Decision and planning pending, tentatively June 2013 with Michael Dellwing) Debate on "The uses and follies of theory" Univ. of Kassel

(Decision and planning pending, tentatively 2013, with Sabrina Weiss) Potential Lecture "Postdemocratic state and technoscientific governance", Drexel University, Philadelphia, PA,

(Decision and planning pending, tentatively 2014) Potential Lectures

"Postdemocratic state and technoscientific governance", STS Dept., RPI, Troy, NY,

"Digital Humanities", STS/Public Policy Dept., Rochester Institute for Technology, NY

Potential Lecture "ScienceCraft, ScienCivics, StateCraft and Other Forms of Thirded Solidarity", Univ. Oldenburg

Potential Lecture on "Civics, STS, Narrative Empathy" German Studies Dept. Prof. Beithaupt, Indiana Univ., IN

(accepted for 2013)

"Care, Power, Information: The techno-aesthetics of patients' lifecourses" ASA Annual Meeting, NYC 2013

"Before and beyond the binaries: Postcolonial perspectives on ADHD technologies" 4S 2013

"Time, Space, Image: The visual aesthetics of techno-scientific interactions of doctors, patients&publics" SSSI 2013

"Germany: Society, Politics, and Academia" RPI, STS Dept. Leadership Seminar, Section A and B, March 27, 2013

"A theory of nomadic Statehood" Eastern Sociological Association Boston March 2013 also served as stand-in for missing president

(accepted for 2013, missed because of scheduling conflict) "Radical historicity & developing systems: Sex/gender persuasion, medical images, systems biology", Systems Biology Panel (organizer: Niki Vermeulen) ICHSTM Manchester, UK, May 2013

(2012 Guerilla Paper) "Nomadic Statehood", Guerilla Talk during 4S, October 2012 (2012)

"Enlightenment, critique, and the nomadic political imagination." (with commentary by Bernhard Tilg), invited presentation for seminar 'Aufklaerung und Kritik' (Tilg/Monsorno), Leuphana College, Lueneburg, Dec.1, 2012

"Semantic gaps, epistemic deficiencies and the cyborg gaze: Medical imaging, gender, in the perspective of postcolonial philosophy of science." NeuroCultures-NeuroGenderings II, University of Vienna, 2012

"Styles of Suffering and Spaces of Pain: A narrative empathic theory", Society for the Study of Symbolic Interaction, Annual Meeting, 2012

"The post-democratic body and the bio-scientific state.", ASA, Denver, August 17-21, 2012

"Digitalized Humans in Human Ecology", Italian Society of Science and Technology Studies, Rovigo, Italy, 2012

Invited Lectures "ADHD in the classroom" English Teacher Education, FAU Erlangen-Nuernberg, May 22, 2012

(2011)

"Medical Imaging and its narratives." Northeast Popular Culture Assoc., Western Conn. State

"Medical Imaging as a persuasive technology?" Society for Social Studies of Science (4S) Conf., Cleveland

"How to Map the Body's Spaces: Using Foucault's heterotopology for the cartography of corporeal myths." Conference on *Myth-Making and Myth-Breaking in History*, Univ. of Bucharest Romania

"Bringing care back into health care: Bio-citizenship & Digital Divide", Conference on *Science and Technology in Political Sociology*, Rensselaer Polytech. Inst., Troy, NY

(2007 - 2010)

"The body in medicine and society in 19<sup>th</sup> century America" Research Colloquium, American Studies, FAU

"*Virtualization* of Health Care and Biomedicine and Social Justice", ASA 2010

„Knowing the Normal from the Pathological: The Genealogical Reconstruction of *Attention* and its Pathologies under a Whole Systems Frame of Reference." ASA 2009

"The Crisis of the Biological Citizen: ADHD as an Assemblage for the Early 21st century" The British Sociological Association 2009; Mental Health and Illness Panel

"The Constitutive/Regulative Difference in the History of German Physiology and American Sociology and in Contemporary Debates", Presentation at the British Sociological Assoc. Annual Conference (BSA) Warwick Uni.,

"Talcott Parsons as a Pragmatist? Emerson, James, Meiklejohn and Parsons ", Paper presented at the Annual Conference of the American Sociological Association (ASA) Boston, MA, USA

"Regulation and Medialitaet: Talcott Parsons Leben und Werk im Rahmen der Ideengeschichte" Invited lecture at the European Colloquium of the University of Flensburg

(1999)

"Cloning Dolly: Political and Philosophical Implications", Invited Presentation, AK Politik Sigena.

“The Debate on Cloning”, Invited Lecture, Dept. for Sociology, Empirical Social Research, and Social Anthropology, WISO Faculty, FAU Erlangen-Nuremberg

*List of relevant teaching, incl. teaching in German (G) and English (E)*

Leuphana University – College of the University Cluster “Knowledge Makes History” (*Wissen macht Geschichte*).

Winter 2013/14

- Truth or Dare, Trick or Treat? – An Introduction to Science and Technology Studies (STS) based on the human concept of ‘life’ and the concept of ‘human Life’ (E, with Sabrina M. Weiss)
- Care, Power, Information: Biomedical Ecologies, Social Justice, and Governance 3.0 (E)
- The concept of the ‘work’[‘das Werk’]: Work and authorship in literature, art, science, markets (G)
- EU-Incubator Seminar Lecturer for foreign students: Accompanying Lecture Circle ‘Money, Market, and Ethics’ (E)
- Close Reading: Max Weber’s ‘Logic of Science’ (*Wissenschaftslehre*) (G)
- Close Reading: Enrique Dussel ‘Ethics of Liberation’ (E)
- Introduction to Political Debate (G/E)

Winter 2012/13 ).

- Europe and the Enlightenment View of Humanity: Public, State, Science (D)
- The West and its Other(s): Western Ethos and Postcolonial Perspective (E)

Spring 2012

- Before the State is after the State: Technoscientific&Postdemocratic Governance (E with Sabrina M. Weiss)

Winter 2011/12 Cluster “Knowledge Makes History” (*Wissen macht Geschichte*).

- Introduction to Philosophy of Medicine (D)
- Care, Power, Information: Social Justice, Digitalization, Biopolitics&Health Care (E)

Courses given at Leuphana were evaluated to fulfill the criteria in the agreement for teaching excellence and awarded with payment upgrades for excellence. Innovative course concepts were additionally awarded competitive funding through the EU Innovation Incubator.

*Grants and Awards*

- EU Regional Development Fund, Leuphana University, 'Innovation Incubator', for innovative teaching and course design was awarded for the following courses
  - 'Care, Power, Information'
  - 'Europe and its Other(s): Western Ethos and the Postcolonial Perspective',
  - 'The Enlightenment View of Humanity: Science, Public, State'
- Fellowship DAAD: (German Academic Exchange Services) Harvard Archives: Pusey Library and Baker Library; Brown Archives: Hay Library (Euro 3155/\$4730) August – October 2008
- Travel Grant DFG: ASA Conference, Boston, MA (Euro 1180/\$1770) Aug. 1<sup>st</sup>-4<sup>th</sup>, 2008
- Fellowship DAAD: Harvard Archives, Brown Archives (Euro3355/\$4880) June – August 2007

#### *Additional research – practice transfer*

Based on his expertise, the fellow was invited in recent years to give lectures and presentations to pedagogy students and student teachers on lessons from research on cognitive development and ADHD. He developed this as the “ADHD in the classroom” program. As an interdisciplinary expert, the fellow has served widely by peer reviewer actions, such as most recently for the *Central States Philosophical Assoc. Annual Meeting*, and journals such as *Popular Anthropology*, *Anthropology & Medicine*, *EÀ:Journal of Medical Humanities and Social Studies of Science and Technology*, among others.

In 2008/9, EBSCO Publishing and Great Neck Publishing invited the fellow to serve as expert reviewer and writer for encyclopedic and textbook databases, as well as reviewer for a point/counterpoint-of-view series of texts on contemporary debates and controversies in science, ethics and politics. In 2012, based on his broad and expert knowledge, the fellow followed the invitation to serve as external reviewer for a PhD thesis in medical sociology for the Australian National University.

### **B3.3. Independent thinking and leadership qualities**

It is not only the development of an independent research direction, or theoretical framework for semantic agency theory, and subsequent invitations to teach, present, or review that are evidence of the fact that the fellow has the potential to occupy a leadership position in STS and policy areas related to his research. The fact that established publishers seek him out to lend his expertise to review the validity of Point/Counterpoint databases for students is also evidence of his intellectual leadership outside of academia.

He also has the particular honor, after having taught at Leuphana University courses he himself designed for three years in a row, to be invited to collaborate in the development of the new Leuphana Semester Structure by designing a course for international students to accompany the College Core Curriculum.

In 2012, he joined the advisory board for a new book series by Rowman&Littlefield Publishers on *Studies in Anti-Intellectualism and Academic Disengagement*. With the series editor Michael Lynch, he has already begun a constructive dialogue on the direction of the series, its internationalization to include European perspectives, and on the editorial development of the first publications in the series.

Since 2012, he also serves on the membership committee of the American Sociological Association’s SKAT section (Science, Knowledge and Technology), with his explicit goal to promote further exchange between European members of ASA and European academic associations in STS and sociology.

He is currently supervising several students who attended his courses at Leuphana University in editing student papers towards publication in international peer-reviewed journals. Due to the fellow’s initiative, his American colleague and collaborator, Sabrina M. Weiss will be teaching a course on human/non-human issue in bioethics and co-teaching a course with the fellow on the concepts of life and human life in science at Leuphana University, Germany, in Winter 2013/14.

In 2013, Prof. Darbrock (Full Ordinarius at the Department of Theology at the Friedrich-Alexander-University Erlangen Nuremberg; DFG senate panel for animal experiment research and member at the “European Group on Ethics in Science and New Technologies”; and member of the German Ethics Council [Deutscher Ethikrat]) invited the fellow, together with Sabrina Weiss, to work as expert editor and science writer for the PrivatGEN research collective (private-gen.eu), a government funded, international research collective of researchers from German, Finnish, and Austrian universities, studying issues of biobanking, privacy ethics, and digital publics. The fellow and Weiss were asked to consolidate the complex research results and lengthy reports into a short, publically accessible and lucid final report.

In 2013, during a short research trip, the fellow was spontaneously invited to give lectures followed by Q&A for two 'Leadership' classes at Rensselaer Polytechnic Institute, on differences between the political and education systems in Europe, Germany, and the US, and their effect on leadership cultures and political participation.

In 2012, even though not on the official program nor officially attending the conference, the fellow was invited to give a presentation on his recent research for a panel at the 4S conference in Copenhagen, a presentation which was reported on in research news in the field, such as by Prof. Nicholas Rowland (Penn State Univ.) on the site 'Installing (Social) Order' [<http://installingorder.org/2013/01/31/viewing-the-technoscientific-state-through-th/>]

In 2008, the fellow became one of the co-creators and founding editor (2008-2013) of an experimental open access journal, *Pompeii Project*, which aimed at publishing junior rank scholars exclusively and attempting to develop new forms of publication that help less established scholars to find an outlet for innovative research.

In currently supervising 4 students in developing term papers into submissions for peer-reviewed publications, as well as his service as a mentor for the SKAT section of American Sociological Association (ASA) and for the Society for the Social Study of Science (4S), the fellow has participated in efforts to mentor American doctoral and junior postdoctoral researchers, who are interested in developing their careers in Europe, and European researchers, interested in conducting research in the US. The fellow has also attended mentorship training seminars and meetings of *ArbeiterKind.de*, a German association helping young persons from working class families with socio-economic disadvantages to gain access to higher education. As a graduate student, the fellow has also tutored students in academic writing and research development for term papers, MA and PhD theses.

Outside of academia, the fellow was the co-founder and member of the board of FPA Brands GmbH, a company dealing in logistics, brands, and coaching, from 2006 to 2009. Despite his dedication to research and teaching, the experience in the private sector and the leadership role he had in the company, was an important opportunity to gain insights into the necessities and structures of the private sector, that transcend what can be taught in a textbook or business school. Between 1997 and 2001, the fellow was also producer and director for a private theatre in Nuernberg, staging dramas and comedy performances for charity events.

#### **B3.4. Match between the fellow's profile and project**

The fellow was originally trained as an empirical social scientist at FAU Erlangen-Nuernberg in the sociology of deviance and development, where he acquired basic skills in multivariate and cluster analysis from the lead author of fundamental texts on these methods in German (Prof. J. Bacher then FAU now Linz) and in computer-assisted social research methods (by the author of the standard German book on SPSS, Dr. R. Wittenberg). He also received research practice related introductions to the use of the SYMLOG instrument (Prof. H.Kreutz, Dr. C.Marx) and in organizational sociology (Prof. Bueschges, Prof. Prosch). He was involved throughout in research projects. A profound experience was the participation in relevant teaching-research projects such as an ethnography of local hip-hop youth culture and participant and an observer guided research on psychological/medical evaluation of child school enrolment fitness.

The fellow then went on to complement his training in qualitative and theory-based studies, sociology of language and knowledge, philosophy of language and logic, linguistics, as well as bioethics and theories of action. As a graduate student at FAU, the fellow studied with Prof. Elisabeth Beck-Gernsheim, an internationally respected expert on the sociologies of family, ethnicity, and health care, who, along with her husband Prof. Ulrich Beck, developed the influential theories of reflexive modernity and risk society. The fellow's graduate studies also included work on bioethics and action/decision theory with one of Germany's leading

philosophers in this area, Ralf Stoecker (now Univ. Bielefeld, member of the Akademie fuer Ethik in der Medizin)

Eventually, in his PhD research, he investigated how shared conceptual histories of philosophy, biology, medicine, and experimental psychology shaped institutional decision-making at Harvard University's in human and social relations movements. This involved archive research across disciplines, including experimental psychology and medical research, and clinical notes.

During his early postdoc phase, the fellow has been developing the semantic agency framework and has since presented and published results on the theory and its empirical impact, including in the collaboration with Weiss and Restivo for the book *Worlds of ScienceCraft*. During this time, he was invited to visit the Ellen Langer Psychology Lab at Harvard University, where he was introduced to psychology of mindfulness research and psychological leadership studies. In 2009/10 he also worked, on the issue of system integration of health care reforms and the Triple Aim Agenda ('better population health, better care experience, reduction of per capita cost') with a former member of the lab, Jonah Friedman, who was at the time developing a (international) policy research framework to present at the Institute of Healthcare Improvement (IHI). During the fellow's attendance of Langer Lab for two months in 2008/09, he was also separately invited to create an extensive literature review on recent research on obesity, attention-deficit, and academic achievement by clinical psychiatrist and ADHD expert John Ratey, who tutored the fellow on his groundbreaking research on adult ADHD and on the connections between the attention and physical exercise. A heavily revised version of the report and the fellow's interactions with Langer, Ratey and researchers in this network became part of the fellow's contribution for the book *Health and environment* (eds. Kopnina/Keune) and subsequent publications on this issue. Around this time, he also got to establish lasting dialogue with leading voices in the field of placebo-research, Ted Kaptchuk and Peter Wayne (Osher Center, Harvard Medical), and Cathy Kerr (Family Medicine, Brown University), a trained social researcher, who now work with medical imaging technology to study the effect of low-tech care practices on the brain.

These experiences lead to the further development of the fellow's integrated research agenda on ADHD and its ecologies, cognitive semantics and decision-making, normalization practices in biomedicine, and macro-micro-macro-effects of systems integration and fragmentation of techno-scientific practices (such as the effects of fragmented statehood and post-democracy on health-care systems and cognitive ideas of citizenship). The fellow has created chapter-/paper-length publications on ADHD, cognitive science results based critique of DSM, narrative empathy and decision-making, integration of science communities, and on the use of images and imaging technologies in decision-making process between doctors and patients.

The integration of these perspectives through empirical research and agent-based models, leading to a book-length publication, as well as individual papers and presentations on methodology, health-care integration, and consumer citizenship as cognitive policy are the goal of the research part of this project. The training aspects include the creation and, above all, integration of the necessary research instruments. The aim is not just the development and integration of the tool and the agent-based models, but also the continued development of the teaching capabilities that the fellow has already displayed in this field. In particular by preparing the fellow to be able to teach non-traditional student audiences effectively (such as nurses, nurse-practitioners). The previous research of the fellow does emphasize the role that nurses and other care practitioners play, as well as the need for better and academic-based training, corroborating research and policy reports such as conducted by the German *Wissenschaftsrat* for European labor markets or the Robert Wood Johnson Foundation for the US. The fellow, because of his teaching experience, seems well-matched to develop his teaching skills along with his research skills, to include these non-traditional student population.

In addition, the fellow is fluent in speaking and writing in academic English (majority of publications in English and with internationally recognized publishers and journals, also some publications in German). He also has studied French formally for 5 years in school, and informally begun the study of Japanese.

### **B3.5. Potential for reaching a position of professional maturity**

Over the course of the fellowship, the fellow aims at developing his unique skill set further and to acquire additional competencies, particularly in regard to mixed-methods approaches to research. As a researcher, he seeks to be able to create not just sophisticated, empirical projects, but to create projects that allow a cost-effective smaller scale, which can use 'big data' schemes to contribute in aggregation to Big Science demands, for example in the question of participation in biobanking for the benefit of the ongoing development of P5 (personalized, participatory, predictive, preventive, psycho-cognitive) health care.

By immersing himself more deeply in quantitative methods, and connecting qualitative with quantitative methods, the fellow also aims at developing teaching competencies in quantitative methods. Since there is a gap between his own methods training and his current work, and never having taught methods to students, the fellow seeks to gain the competencies to create and teach not only introductory but also advanced methods courses, an ability that he currently does not have the confidence that his knowledge and training are sufficient or up-to-date enough. A more concrete teaching aspect, would be the continued development of a course profile that combines research into health care, political participation with the digital humanities, in the fellow's seminar 'Care, Power, Information: Issues of Social Justice in Biomedicine, Ecology, and Governance 3.0', which he teaches on a regular basis to undergraduate students at Leuphana University. The fellow seeks to develop this into a modular course profile for non-traditional students, as well as advanced, graduate students that enables them to develop their own research and local 'care culture' reform projects in this inter-related field.

The fellow has in the past few years already served in peer reviewer actions for internationally acclaimed journals and international conferences in medical humanities, social science, and philosophy, as well as an external reviewer for Australian PhD thesis in sociology of medicine. The fellow's ability to serve as a reviewer would be greatly improved over the course of this fellowship. Most importantly, though, is the development of the ability to review research proposals for national and international research funding through major agencies such as the European Union, or the DFG (*Deutsche Forschungsgemeinschaft*). To be able to review proposals on such a grand scale is an ability that the fellow is not yet confident that he is prolific and experienced enough, whereas the experiences and collaborations of the fellowship result in competences needed to reach this level.

With the opportunity to take advanced courses in French at Drexel University to refresh his ability to converse fluently, in the return year, the fellow will be immersed at a lively academic and political environment, where French is spoken widely, benefitting the fellow's ability to navigate in the European research and education ecology.

The fellow will continue to teach seminars to international student populations at both Drexel and Brussels, addressing non-traditional and continuing education audiences as well modern forms of teaching (online teaching) through Drexel's iSchool, the College for Information Science and Technology, which has members at the Center for STS.

Working with Kelly Joyce, Michael Yudell, and Cristof Daetwyler will enable the researcher to better navigate the complex research bureaucracies, not to mention ethics regimes, that apply to international research projects. Prof. Joyce has particular experience with NSF, an organization that is vital for all European researchers involved in collaborations with US researchers. Her current research focuses on algorithms, legal procedures, and decision-making structures in American health care markets and research. At Drexel, the fellow will also collaborate with Ali

Kenner, a newly hired assistant professor in STS, whose research focus shifts from contemporary health assemblages, such as on individual responsibility in asthma care practices, to the effect on techno-scientific practices on health care structures and vice versa at large. The differences between these sectors in the US and Europe constitute indispensable knowledge for European researchers, policy-makers and migrant research who will go on to operate under conditions of the free trade agreement between the European Union and the United States of America. The fellow will learn at the College of Medicine and the Public Health Department to work with large epidemiological data sets and public health contexts, as well as about work with international organizations, such as the WHO – the latter is an area where the fellow's experiences are limited and he welcomes the expertise of Profs. Yudell, Datwyler, and Liu.

It is important to note that the opportunity of working at Drexel's STS Center offers a unique setup, since the center is a recent addition in Drexel's continuing effort of reform and development. Grown from the STS program in the department of History&Politics, Prof. Joyce was appointed in 2011 to lead the program into an independent Center and guide its continuing development over the next few years, through expansion, prolific research, and international collaborations. In being involved in these efforts first hand, in conference organization, ethics reviews, and in a privileged observer position, the fellow can acquire competencies about building and developing a department's structures and reputation, which is not at all possible at departments that have fully established structures. The fellow's aim is to hold a future leadership position in Europe in a similar capacity as Professor Joyce .

### **B3.6. Potential to acquire new knowledge**

In the past, the fellow had to adapt to new academic and research ecologies by acquiring competencies quickly and efficiently. While conducting research during subsequent trips to the US, the invitation to visit Langer Lab at Harvard or engaging in research collaborations or active dialogues with leading researchers such as Ted Kaptchuk or John Ratey, as well with colleagues at RPI such as Sal Restivo, Ron Eglash, Ellen Esrock, Linnda Caporael or PhD candidates Sabrina Weiss and Gareth Edel, the fellow acquired knowledge which has informed the current research and training agenda profoundly: He had to learn how to conduct empirical mindfulness research with regard to the differences of the concept in complementary medicine on the one hand, and on the other hand in experimental and applied psychology, such as used by Langer for the mindfulness scale. Working with colleagues at RPI, the fellow had to learn about the particular American context the concept of biomedicalization (Edel, Weiss), as well as what theories of developmental psychology and biology contribute to our understanding of community building and participation (Caporael), not to mention the role of 'undone science'. Most important, though, was the idea that ethno-mathematics and fractal analysis could be used in a productive way in methodologies in STS (Eglash, Restivo). Working as an independent consultant for Jonah Friedman on system integration and triple aim agenda, the fellow began to carve out the particular differences between American and European health care systems and policies. A main question that he discovered– forming a chapter in the finished book manuscript *Anthropos's Scaffoldings* (contract under negotiation) – was the often under-theorized and under-researched role of community-formation in health care, an area where he studied up intensely (such as the EU Social Fund sponsored Building Healthy Communities (BHC) Thematic Network [2008-2011]), and which his dialogue with both Kelly Joyce and Linnda Caporael affirmed. In the creation of literature review and meta-analysis for John Ratey on co-relatedness of studies on academic achievement, disruptive behavior, obesity, and role-models, the researcher had to learn about recent social contagion models that are recent developments in medical sociology, epidemiology, and public health. Here, the fellow has acquired skills to identify variables and operationalize results from ethnographic research further to account for ecological factors social contagion models, which feature prominently in his publications on

ADHD, the biomedical sections in his book with Weiss/Restivo, and the manuscript for *Anthropos's Scaffoldings*.

The fellow has also attained proficiency outside of academia, if not entirely unrelated. Following an internship in 2004 with a consultant for business concepts and management in gastronomic enterprises, and the ethnographic project on gastronomic labor, the fellow has obtained knowledge that enabled him to create and teach courses on management, hygiene and human resources, as well as mixology courses, for bars and restaurants. While a member of FPA Brands GmbH, the fellow has independently gained knowledge about accounting, business plan writing, human resource allocation, as well as storage and delivery logistics.

To gain critical competencies in alternative methods in health care, while retaining a critical, scientific attitude, the fellow has learned and practiced various forms of internal martial arts, particularly yang-style hand&sword forms of Tai Chi and Qi Gong, and obtained basic knowledge about traditional Chinese medicine (TCM), as well as learned about Zen meditation and its neurological basis. The fellow's interest here lies in the neuro-cognitive mechanisms as well as in the different cultural conceptions of body, health, and illness.

Current directions the researcher is developing are in the field of bioethics in collaboration with Sabrina M. Weiss, who brings an interrogation of the role of concepts of ecology in bioethics into the mix, as well as aspects of feminist theory in STS, expanding the fellow's existing knowledge on feminist theories in identity work to include strong objectivity and situated knowledges. This direction is also present at Drexel STS Center with Kelly Joyce and Ali Kenner. This also extends to perspectives on human enhancement and augmentation ('cyborg', an area where Weiss is highly proficient), and ambient assisted living technologies, a research area that involves the challenge that an ageing population presents to systems of care and technological innovativeness, which Kelly Joyce has researched and published on extensively, coining the idea of 'graying the cyborg'. In continuing to work with Sabrina Weiss, who plans research in Philadelphia after spending a year as assistant professor at Rochester Institute of Technology, the fellow will go on to develop research perspectives on the Restivo-Weiss model of the social mind, featured in *Worlds of ScienceCraft*, that operationalizes consequences for cognitive science, medical humanities, and sociology of medicine.

With regard to methods, the fellow will be enabled to include an interrogation and advancement of his knowledge of ethnography in both the outgoing and the return phase. With Prof. Joyce and Ali Kenner at Drexel University, he will develop a reflective, comparative insight into the different ethnographic research styles, not only in textbooks but actually 'in the field'.

During the return phase, the collaboration with Michael Dellwing at the University of Kassel, the fellow has an opportunity to work with a leading expert and author of a fundamental textbook on ethnography and triangulation. The fellow has worked on issues in the sociology of knowledge and health care systems, and medical anthropology alike, which touch upon areas of public health/social medicine. Here, the fellow already had to adapt his skill profile to include advanced biographical interview techniques and expanded ethnographic methods. For his research on medical imaging, the fellow also had to include visual methods (image analysis, objective hermeneutics for visual data, visual ethnography). In working with Joyce, Kenner, and Dellwing, he seeks to include the use of focused ethnography, situational mapping, milieu&lifestyle analysis, and quantitative operationalization of qualitative data into his skill set.

In the collaboration with members of the Public Health Department at Drexel, a new level of depth will be achieved. The fellow will work under the guidance of Profs. Joyce and Daetwyler to gain advanced knowledge about innovations in epidemiological models, an area where he currently only possesses rudimentary knowledge called for in medical sociology. Along this vein, the fellow has the objective of learning from these collaborators about 'Big Data', i.e. extremely large data sets and the use of biostatistics for epidemiological purposes, an area where he has yet little proficiency. As mentioned above, the project's research/training integration also involves an independent ethics committee (Institutional Review Board [IRB]) process for working

at Drexel, to complement the review for compliance with ethical guidelines for research involving human subjects in Europe. Since the fellow has yet to undertake such a process, which was never involved in his previous, and has the supervision of researchers at Drexel, as well as collaborators from an American bioethics background (e.g. Weiss), who have experience with American research ethics procedures, this important training item will prepare the fellow to undertake, supervise and expert review future transatlantic research and policy projects.

The return host at Brussels, Prof. van Bendegem and the researchers at CLWF will work with the fellow on developing the formalization of the competencies obtained during the away year to homogenize the tool and create agent-based simulations. The work on simulations and the use of ethnomathematics (fractals) is relatively new to the researcher, and an integral training component to finalize the research/training of the outgoing phase. At CLWF, research on doctor-patient interactions, conducted by doctoral student Stephanie van Droegenbroeck, will be complemented by the fellow's trinary doctor-parent-minor perspective.

Besides refreshing and improving his language skills in French, the fellow aims at beginning to learn Dutch during his return year at Brussels. Immersion into an environment, where Dutch is used in everyday affairs as well as academic and political life, the fellow expects to improve quickly, furthering his career opportunities and impact in the European research area.

Finally, it should be emphasized that in 2011, the fellow has created a proposal with a different project (on institutional history and history) for a Marie Curie fellowship, which did not score high enough to be successful. The fellow considers this an extremely important experience, from which he profited in learning about investing more effort in planning research and training, and integrating them, as well as developing a more realistic scope that includes developing methods with more clarity and creating a more lucid outline. The fellow has welcomed the challenge that the rejection presented to develop his ability to transfer his knowledge and research into a more accessible form, to reflect and effectively improve his own shortcomings, where possible.

The results of this research project will be communicated at several levels. The most evident one is the dissemination of ideas of this research in a book-length and several chapters and papers. At conferences, the fellow will engage very diverse groups of publics and scholars with paper presentations and organizing panels. Secondly, the aim is to create resources, discussion material, and online content, such in creating an web-forum for interdisciplinary junior researchers, extending and institutionalizing the experiment of the *Young Scholars for Collaborative Academe in International Perspective*. The aim is to initiate new discourses between transnational scholarship and the public on deterritorialized policy regimes in health care and biomedical research and markets, preceding the effects of the EU-US free trade agreement. This is to be achieved in a non-elitist way, by exploring how the two-way dialog can be *enabled* bottom-up, by taking serious that techno-scientific practices are affecting and emerging in what is usually considered as 'below'. A second implementation of the research results concerns the question of curriculum. The fellow wants to create suggestions for coursework and devise actual courses and public lectures through the CLWF, as well as multi-lingual handouts that will be available for free via the website of the center (<http://www.vub.ac.be/CLWF/>) that will focus on making explicit the functioning of *ways of knowing* and their plasticity, to help teachers in the fields of secondary and higher education to create options in their class-rooms, to engage all kinds of student populations, and enable rather than constrain the kind of techno-scientific and cultural *disruptive innovations* that have proved to be the life-blood of progress and development. This research will directly affect the education of the public in the creation of a sense for evaluation of the vectors that constitute normative appropriateness of the cognitive dimensions of participation as a consumer citizen in health care and biomedicine, with particular regard to the outcome of P5 medicine.



- **B4. Implementation**

**B4.1. Quality of infrastructure/facilities and international collaborations of host (outgoing and return host)**

*Outgoing Host*

Drexel University is truly a Philadelphian university. The university takes extraordinary steps to be connected to various communities and stakeholders in Philadelphia, and has developed numerous connections to health care facilities, non-profit organizations, city government departments, educational institutions and more. In terms of relevant institutes at Drexel's College of Arts and Sciences (CoAS) that cooperate with the Center for STS where outreach and collaboration activities with American and international researchers, policy-makers and publics, will be facilitated at Drexel, Prof. Joyce will introduce the fellow to her partners in the Expressive and Creative Interaction Technologies Center (ExCITE) where multi-disciplinary collaborative projects are pursued by teams of faculty, students, and entrepreneurs in engineering, fashion design, digital media, performing arts, computer and information science, product design. In congruence with the Center for STS an enriched arts-integrated learning of science is promoted (STEAM instead of STEM [Science, Technology, Engineering, Mathematics] to constitute an idea of democratic-scientific citizenship through civic, arts and culture, and industry partnerships with other institutions and organizations (a list of regional partners can be found here: <http://drexel.edu/excite/people/partners/>). The center supports small-scale projects that connect science with its public with SEED grants. With Drexel's Lindy Center for Civic Engagement, the Center for STS, and the support of his the colleagues Don Levine (Sociology, UChicago; former president Aiki-Extensions) and Charles Colten (AikidoInTheSchools), the fellow will propose a small-scale SEED project to organize an intercultural dialog between children in Brussels and Philadelphia who suffer from ADHD and who practice Aikido. This project is intended to involved also students in Public Health in both Brussels and Philadelphia, and establish a long-term collaboration. The Lindy Center generally supports academic civic engagement as well as faculty development through development grants, and organizes international exchange in its Service Immersion program.

The Center for Public Policy (CPP) is an interdisciplinary think tank located within CoAS. Case-based policy-oriented research and institutional analysis is supported by the Center in its function as an interface between faculty and relevant government agencies and nonprofit organizations.

Through the Center, the fellow will also have access to the Instructional Technology Center, where services such as Drexel Learn support and training are available. Resources include access the recently purchased MagnaPublications, an online-based resource center for professional development.

The Office of International Students and Scholars Services (ISSS) offers a vast array of programs and services to more than 3,400 international students, scholars, and faculty. ISSS staff advises Drexel's international students, scholars and faculty on immigration, cultural, financial, academic and personal concerns. In this function, the fellow will work with the ISSS case officer on relevant matters to facilitating the fellowship. The fellow's outreach activities (Marie Curie Ambassador) will be conducted in co-operation with the ISSS's Student Center for Inclusion and Culture, which coordinates Drexel's comprehensive cultural month programming and develops and implements a wide range of multicultural and social justice education. The fellow aims to create a week-end workshop on transatlantic perspectives on 'Care, Power, Information' for students at Drexel and VUB, which will involve simultaneous internet transmission and discussions in both locations.

Drexel's Steinbright Career Development Center is a resource for innovative training of professionals, advancing a paradigm of co-op education, i.e. a program that balances

classroom theory with periods of practical, hands-on experience. This extends to the international co-op program, which the fellow could become involved in, promoting opportunities for Drexel researchers and students to explore more options in the EU, particularly at VUB and Kassel.

#### *Return Host*

The Free University of Brussels (VUB [Vrije Universiteit Brussel]) with its more than 6,000 employees and more than 9,000 students, is an international hub for research, teaching, and public-private cooperation, situated in a center of European exchange and policy-making. First, the Vrije Universiteit Brussel is part of a network of first-rate Dutch-speaking social facilities in Brussels. Dutch-speaking and French-speaking Brussels citizens and commuters have access to the infrastructure of the campuses for events, sports facilities, cultural events and healthcare. The UZ Brussel (academic hospital) plays a pioneering role, as the only Dutch-speaking hospital in Brussels. This aspect is important in the contribution to the fellow's objective of language training. The close involvement of the Vrije Universiteit Brussel with the city of Brussels is also apparent at academic level. The Vrije Universiteit Brussel conducts research into the pressing issues facing Brussels and organises activities that contribute to the social and cultural life, as well as the Flemish presence and identity.

VUB has its own housing facilities for scholars and students, and, where its capabilities do not suffice, works in cooperation with the organization *Br/ik*. Cases of EEA citizens, where the national health care provider does not offer access to an European Insurance Card, there are regulations on place to obtain health insurance in Belgium. These matters will be facilitated through the International Relations and Mobility Office.

VUB is an active member of UNICA, the Institutional Network of the UNiversities from the Capitals of Europe, a network of 39 member universities in European capitals, representing approximately 1,500,000 students. On the international level the Vrije Universiteit Brussel has concluded International Collaborations at VUB include besides actions in the EU Framework program and UNICA, institutional collaboration agreements with 38 universities all over the world, and student exchange agreements with 160 universities and a number of long-standing multi-disciplinary collaborations, such as with Chinese research institutes and universities, and the China Scholarship Council, allowing jointly offered doctoral and postdoctoral scholarships.

VUB cooperates with BRIO, the Centre for Information, Documentation and Research on Brussels. Scientific research, policy information, publications and statistics regarding Brussels and its surrounding municipalities are collected and published with BRIO. The fellow and CLWF will make relevant aspects of the research accessible to BRIO, for example for martial arts instructors, nurses and health care practitioners, and care facilities in Brussels. Regarding outreach activities, VUB hosts its own Science Communication division which has as its objectives connecting scientists and the general public to disseminate information about scientific progress, to 'arouse interest in and enthusiasm for science', and, finally, to contribute to building the image of the VUB as a European institution of education and research. As a result, VUB is part of a network of six so-called WetenschapsWinkel (Science shops), along with Antwerpen University, the Catholic University of Leuven, The Catholic Univeristy of Brussels, Ghent University, and Hasselt University. WetenschapsWinkel assists non-profit organizations in transforming a social issue into a research query, wherein students are guided by experient researchers in conducting the research.

Since 2003, VUB is also the home of CROSSTALKS, a platform for exchange between science, business, and publics, and for academic and corporate networking. Its mission is bottom-up and interdisciplinary development of 'a new dynamic of knowledge exchange through thematic encounters, beyond specific disciplines and with the active participation of key players from all levels of society', ranging from small scale professional workshops to big public events. Constructive dialogues on policy probing issues stand as its main objective, engaging academic

researchers, scientists, artists, corporate leaders, and creative entrepreneurs. Its current projects surround topics such as 'Smart Logistics, Energy Efficiency, Sustainability and Changeability, Prosperity without Growth?, Bridges over Troubled Water, Cleantech and Transparency in Healthcare'. CROSSTALKS publishes its result in various venues, including its own series of 'Crosstalk Booklets'.

Since its beginning the Free University of Brussels's Center for Logic and Philosophy of Science (CLWF) has developed over the years, next to key members' expertise in the philosophy of mathematics, a core research agenda on the shared engagement of the role of science in problem solving and constitutional democracy, and the development of adaptive and interrogative perspectives, as well as the role that epistemology, language and culture play in science and democracy.. As a result, members of the Center have been involved in research projects on the basis of this expertise, namely, in the IUAP-project "The loyalties of knowledge" and the GOA-project "Unifying Philosophy Through Dis-Unifying Science".

Recent international events organized by CLWF include the conference 'The Radical Enlightenment: The Big Picture and its Details' with keynote speakers, Jonathan I. Israel (Princeton), Beth Lord (Abderdeen), Eric Schliesser (Ghent), Winfried Schroeder (Marburg), Wiep van Bunge (Rotterdam), Else Walravens (Brussels). Howard Woodhouse (Saskatchewan, Canada) recently held the Whitehead lecture 'Mathematics and Liberal Education' at the invitation of CLWF.

Over the years since the existence of the Center a number of scholars have worked at the Center for one month up to one semester, such as Max Cresswell (VLAC Fellow), Benedikt Löwe (VLAC fellow), Jacek Malinowski Warsaw and Torun, Poland), Roman Murawski, Sal Restivo, Adriana Rine (VLAC Fellow), and Hartley Slater (Perth, Australia), Rein Vos (Maastricht, Netherlands), Kirsten Walsh (Otago, New Zealand), Carlos Monteiro (Pernambuco, Brazil), Gabriel Tarziu (The Romanian Academy, Iasi Branch)

Notably, during the second half year 2012 researchers at CLWF entered into a six month collaboration with the fellow's co-author Sal Restivo, researcher on the sociology of mathematics, objectivity, and the social brain, recently retired as Professor of Sociology, Science, Studies and Information Technology in the STS department at Rensselaer Polytechnic Institute, Troy, NY, former Special Professor of Mathematics Education at Nottingham University in Great Britain; and a former Hixon/Riggs Professor of Science, Technology, and Society at Harvey Mudd College; he is a founding member (1975) of and a former president (1994/95) of the Society for Social Studies of Science, and recently special Lecture Professor in STS at Northeastern University in Shenyang, China and a visitor professor at CICI-University Ghent.

#### **B4.2. Practical arrangements for the implementation and management of the research project (outgoing and return host)**

In the months before beginning the fellowship, the fellow will begin the IRB review process for Human Research Protection with the aid of Prof. Joyce and the Office of Research. Drexel has three IRBs on site, one of which specialized in Social and Behavioral research. To expedite matters, the fellow, although residing in Europe, has been assigned a administrative status of 'Visiting Research Faculty' at Drexel, beginning with the spring semester 2013, to have access to relevant resources and information for this process. The fellow will also spend time at Brussels and Kassel in preparation in spring 2014.

The fellowship itself is set begin in summer/fall 2014 and last for 36 months. During the outgoing phase, the fellow will be permanently stationed with the Center for Science, Technology and Society at Drexel University, under the supervision of Prof. Kelly Joyce, who serves as the scientist in charge.

Nirva LaFortune, Assistant Director, Center for STS, will provide administrative support for the proposed research. Drexel will provide the following administrative support: (1) the Human Resources department will provide assistance in obtaining visas; (2) the Research Administration office will provide human subjects review; and (3) the Grants office will manage the financial distribution and audits of the grant.

Besides general availability to aid the fellow in resolving urgent issues, Prof. Joyce has agreed to hold, at the very least, bi-weekly lunch meetings with the fellow to discuss progress of the project during the semester. These opportunities will also cover matters of organization and administration of a department, which will also be covered in regular meetings with Nirva LaFortune. The fellow will also be meeting on a monthly basis with Prof. Daetwyler.

The fellow will be provided with work- and desk-space, i.e. he will have access to the use of an office with computers, printer, and office materials, as well as full library and e-library access to relevant current and past publications in the research areas. He will have access to courses in the course of his training agenda. Cooperation with other researchers at Drexel includes members of Public Health department, Psychology department, and the Program for Human Cognitive Enhancement. Members of the Center for STS and Public Health, Ali Kenner (STS), Longjian Liu and Michael Yudell (Public Health), **Vadake Narayanan**, (Stubbs Professor & Associate Dean for Research, LeBow College of Business, Decision Science & Pedagogy in the Human Cognition Enhancement Program), Felicia Hurewitz (autism research, Psychology), Victor Lidz (sociologist, Psychiatry Dept., Univ. College of Medicine), Christof Daetwyler (Family, Community, and Preventive Medicine) are providing assistance in the identification of subject populations in the Philadelphia area, and beyond through a (inter)national network of contacts (Donald Levine [Sociology, UChicago, aiki-extensions], Charles Colten [AikidoInTheSchools], Cathy Kerr [Family Medicine Brown Univ.], Eliza Beebe [Speech Pathologist, Wellesley, Harvard, Aikido instructor], Linnda Caporael, and Ron Eglash [STS, RPI]). Access to social research software is handled through the Center for STS at Drexel and for simulation generation programming at CLWF in Brussels. Mutual access is going to be facilitated online, i.e. through licensing. Prof. Liu is currently supervising a doctoral project on ADHD epidemiology using data from National Child Health survey, in which the fellow would become involved. This includes access to survey data, such as the source cited. The STS department would also offer editorial assistance for the creation of publications in English - even though the fellow has already published in English, he would seek to improve his academic writing skills in this foreign language. Also, publication opportunities would arise through readers and conference proceedings made available through the Center. While at Drexel, the fellow would be stationed there, taking courses and also be given opportunities to teach courses as fits the research/training schedule. He would be leaving the area on occasion to conduct field research elsewhere, or to attend conferences and workshops.

With an eye on future collaborations on 'disability, ableism, ethics' and in investigating the ADHD-autism link in a social pathology frame, the fellow will establish a connection with the Autism Institute, facilitated through Profs. Joyce, Hurewitz, and Daetwyler. The Drexel Autism Institute is a newly-founded multidisciplinary research institute and focused on public awareness and public health science approaches to autism spectrum disorders.

The fellow will be working with Christof Daetwyler and his inter-departmental collaborators at Drexel and international colleagues. Prof. Daetwyler's main interest lies in teaching healthcare communication skills in a blended learning setting, i.e. combining low-tech/high-tech practices. He is the co-developer in the research, development, and implementation of on-line resources to enhance education for medical students, interns, and residents. He is responsible for the creation of DocCom, a combined small group discussion and bedside teaching with e-learning resources. He is also involved in WebOSCE, an on-line technology to allow students to practice new knowledge and skills on on-line standardized patients. These tools are currently available in English only, with German versions in progress. The fellow would potentially be able to aid in

a future adaption of upgraded version into French and later Dutch. More importantly, Prof. Daetwyler (who hold a doctorate degree in medicine, has worked in interactive media labs, and has also been actively and continuously involved in developing computer applications for medical education since 1993) and the fellow will be collaborating on an attempted inversion of the online architecture of both tools, to create a implicit association and semantic differential querying instrument that can be utilized in the research and translate results into propositional knowledge-based agent simulation.

At the Center for Logic and Philosophy of Science (CLWF) at the Free University of Brussels (VUB), Prof. van Bendegem as supervisor and scientist-in-charge, supported by the Advisor for European Research Projects of the Research & Development Office at VUB, Nik Claesen, would oversee all the administration and budget of the fellowship. At CLWF, the fellow's arrangement regarding office space and access is identical to the set-up at Drexel University. Access to survey data, not easily available through CLWF is made possible through the collaboration with Michael Dellwing at the FB 05 Social Science and the Dept. for Macrosociology, where the fellow has already been listed as a visiting researcher.

Prof. van Bendegem and senior colleagues would collaborate with the fellow on a comparative evaluation of research ethics processes on the protection of (adult and child) human subjects in social and behavioral research Europe and the US. One objective is the creation of a comprehensive brochure and report (similar to the work the fellow has created as scientific editor for the PrivatGEN collaborative) on research ethics and human subject protection that incorporates the reality of merging markets and research areas that will follow in the conclusion of the EU-US trade Agreement (TTIP). The integration of this objective with VUB's Technology Transfer Interface will be an additional yet vital component in the outcome-orientation of the fellow's research&training agenda.

Besides Prof. van Bendegem, Prof. Karen Francois and PhD student van Droogenbroeck would be involved in the translation of the qualitative and quantitative data into an agent-based model.

### **B4.3. Feasibility and credibility of the project, including work plan (below)**

The project the fellow has developed focuses on two research sites: The situation of diagnostic and therapeutic decision-making on disruptive behavior disorders, primarily ADHD, between doctors, teachers/parents, and minors as patients; and minors and adults participating in Aikido and Taekwondo classes. The novelty of this grounded, middle-range tool lies in the alignment of qualitative and quantitative methods by using focused ethnography, situational mapping and latent meaning pattern analysis to create semantic clusters that encode qualitative data of institutionalized and discursive power and empowerment in ways that can be then queried and measured quantitatively by use of fractal and multivariate vector- and cluster-analysis methods. Tacit and propositional knowledge about health-related quality of life, patient empowerment, and ideas about self-agency of minors in high-tech versus low-tech techno-scientific contexts (i.e. as patients or as martial arts students) are the three subject matters under investigation with this method. Tacit and propositional knowledge present cognitive policies and ideas that attain relevance, i.e. meaning, in practice, and are therefore open to forms semantic differential analysis that can encode robust semantic vectors and clusters measuring power in status hierarchies, health-related quality of life (HrQoL), and perceived self-agency, as well as correlations among all three semantic fields.

While the time-planning of this project has been done carefully, and all steps are conducted in dialog with the hosts, an advantage of the use of the two research sites and a mixed methods approach is, that these can be disentangled should the need arise from

unforeseen circumstances. Having to focus on only one site, or reducing the methodological scope would certainly affect the goals and objectives of the project, however, this would not doom the project. Advanced training could still go forward, even if, for example, the final research step in triangulation could not be undertaken. Results of only one site, from using only discursive institutionalism or situational mapping, would still yield novel insights into the subject matter, and promote career development. Also, should one of the individual training steps fail, this could be compensated through local experts with whom training could be informally conducted. Additionally, method training is not consecutive.

The proposed research and training, see below, can be divided into steps will inform the distribution into concrete work packages (WP) for both the outgoing and the incoming phase.

Preparation Phase before taking up the fellowship (Kassel/Brussels), 2-3 months:

#### Research

1. Further development of the scope of project with partners in Kassel and Brussels
2. Identifying concrete research populations. Establish/expand collaborations with clinical psychiatrists, local researchers, martial arts associations, and set up concrete schedules for meetings during the research phases.
3. Identify operationalizable variables and controls needed for agent-based simulations
4. Research ethics US/EU: Set in motion IRB procedure in the US. (Full procedure can take up to 1.5 yrs, depending on suggestions for revisions., Accounting for the fact that parts of the research will occur in the second year of the project, IRB will be started before the decision on the funding is made.)

#### Training

- a. Training with M.Dellwing on focused ethnography as interactionist triangulation (Kassel)
- b. How to work with propositional knowledge in the form of semantic differentials (Brussels)

I. Outgoing Phase (Drexel), two years:

#### Research (RO)

1. Defining scope of and collecting situational and institutional information for the creation of situational semantic maps for health-related quality of life qualifiers and empowerment (focused ethnography, situational analysis, latent meaning pattern analysis).
2. Creation of the non-binary semantic clusters for measuring in high-tech and low-tech techno-scientific contexts empowerment, health-related quality of life, and perception of self-agency.
3. Conduct field work using qualitative methods for the semantic coding in the clusters
4. Development of practical model for integration of qualitative and quantitative research frames
5. Develop applicable version of the research tool and evaluation frame
6. Conduct actual research in the field applying the tool

#### Training (TO)

- a. Introduction to qualitative methods (advanced [A]<sup>22</sup>)
  - i. Situational Analysis

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<sup>22</sup> Advanced [A] indicates the fellow's objective is to further develop prior training and competencies in an area

- ii. Ethnography compared in US/EU-research contexts [A]
  - iii. Institutional discourse analysis: Embedded values as algorithms in technology design (high/low tech) [A]
- b. Introduction to (advanced [A]) quantitative Methods
  - i. Multivariate/cluster analysis methods [A]
  - ii. Biostatistical Methods
  - iii. Qualitative-quantitative translations
- c. Theory/theory-practice
  - i. Population health methods [A]
  - ii. Epidemiology/biostatistics in mental health/development
- d. Working with American IRB [A]
- e. Working with 'big data' sets/ in population health [A]
- f. Language Learning: French Courses [A]

## II. Incoming Phase (Brussels), one year:

### Research (RI)

1. Correct for cross-cultural differences in using the tool, including translation of semantic variables into German, French, and Dutch
2. Development of a final framework for an agent-based simulation based on the tool's variables
3. Conduct research using the tool (in cooperation with Kassel)
4. Create agent-based simulations for comparative analysis of participation/decision-making on outcome-related high-tech/low-tech setting in health care systems, involving minors as patients
5. Create research report and publication of final research results and efficacy of the tool

### Training (TI)

- a. Introduction to agent-based modeling and simulation
- b. Fractal analysis in social science methods
- c. Coordinating American/EU-research practices and ethics (in cooperation with Kassel)
- d. Language Course: Dutch (Basic)

### Career Reintegration (CR)

- α. Research Report
- β. Full immersion for language training: French
- γ. Comparative Research Ethics brochure, web-based documentation
- δ. Planning Helmholtz Virtual Institute Funding Proposal for iSchool

## Timetable and Work Packages

36 month fellowship begins with WP 1 (Outgoing) move to Philadelphia between July and August 2014.

Stage	Year	Month	Description of Work Packages (WP)	Output (incl. ' <u>Milestones</u> ')
Prep TO d	2014	n/a	Adjust for EU ethics recommendations. Set IRB process in motion. Contact physicians/psychiatrists, martial arts instructors. Conduct ethnography exercise 'on the mat' in Kassel. Analyze model developed by van Droogenbroeck in dialog. Introduction, agent-based simulation. Literature review of recent developments in methods and ADHD research.	<u>Be prepared:</u> Updated research plan IRB Forms Prepare ethnography exercise as paper for SSSI annual meeting and development into publication in <i>Symbolic Interaction</i> Prepare a literature report on ADHD-research and constructional psychology, submit to <i>Emotion Review</i>
WP 1 TO a, i-iii TO b, i TO d, f RO 1	2014	1-6	Arrival Event at Center for STS. Advanced research methods training with Kelly Joyce, and member of sociology dept. Attend <sup>23</sup> 'Regression Methods', 'Applied Multivariate methods' 'Public Health Independent Study' (PubH) Immerse in Public Health/College of Medicine Contact and meet local teachers, psychiatrists, martial arts instructors to coordinate research. Introduction to interface architecture of WebOSCE and DocCom with C.Daetwyler Situational/institutional mapping of ADHD ecology and martial arts ecology in Philadelphia, with K.Joyce French class	<u>Mapping biomedical ecology for ADHD</u> paper at SSSI meeting, August 2014 paper on methods triangulation for ASA meeting, August 2014 Teaching 'Care, Power, Info' seminar Workshops 'ADHD in the classroom', November, December
WP 2 TO b, ii-iii TO c i, ii TO f	2015	7-12	Attend 'Principles of Epidemiology', 'Principles of Biostatistics' (PubH), Develop community outreach with K.Joyce IRB recommendations, upgrading research plan Develop cluster-framework for semantic differential analysis with K. Joyce Redesigning of software with C.Daetwyler and testing semantic differential tool in the field French class	<u>Confidence in Public Health Expertise</u> Organized Workshop on fellow's research at Center for STS Draft report on different research ethics
WP 3 TO c i TO e, f		13 - 18	Attend 'Decision Analysis in Public Health and Medicine', 'Design and Analysis of Clinical Trials' (PubH), Advanced research methods training, with members of psychiatry dept. French class	
WP 4			French class	
WP 5				
WP 6				
WP 7				

<sup>23</sup> Titles from current catalog 2012/2013 of courses regularly taught per quarter. Fellow attends ca. two quarterly courses/WP (outgoing)

**B4.4. Practical and administrative arrangements, and support for the hosting of the fellow (outgoing and return host)**

At Drexel, the fellow will be given an office, email account, and access to all libraries and facilities. Christy Vanella, International Students and Scholars Services, will assist with visas. Drexel's Human Resources department has a comprehensive Working Here website that details contacts at Drexel as well as resources related to transportation, schools and social life in Philadelphia, PA. Drexel University hosts a new faculty orientation each September, and the fellow will be invited to attend. The Center for STS will organize and host a welcoming event for the fellow to introduce him to faculty, staff and students. Nirva LaFortune, Assistant Director, Center for STS, will provide accounting and reimbursement support for the researcher.

There will be an annual workshop held at Drexel for academics and community members on the fellows topic, which will be organized by the fellow at the Center under the supervision of Kelly Joyce and Nirva LaFortune. Besides workshops and outreach activities, the fellow will be invited to contribute to teaching at the Center with courses designed in his 'Care, Power, Information' profile. The fellow has suggested a course load of one course per semester, with the possibility for teaching an additional course in a related field in the final year.

## **B5. Impact 4 PAGES**

### **B5.1. Impact of competencies acquired during the fellowship on the future career prospects of the researcher, in particular through exposure to transferable skills training**

The researcher will be enabled during the fellowship to enhance his career within academia as a researcher and teacher. Several skills and competencies acquired also open up connections in the arena of public and private governance. Advanced research methods, particularly the upgrading of his quantitative skills, ensure the fellow's growth as a researcher that will enable him to design or collaborate in research involving larger research populations. The fellow would be enabled to participate in research and policy analysis of biostatistical and epidemiological relevance. It would become possible for the fellow to collaborate with a greater range of partners in the public health research and policy arena, as defined by the European Core Health Indicators (ECHI): To achieve the goal of acquiring competencies that allow the fellow's transition from medical sociology and anthropology to public health/health policy research and analysis, the fellow is working directly with members of the Public Health Department at Drexel and those members of CLWF at Brussels whose research experience include the transfer of knowledge and information streams between science experts and their publics, which included policy-makers. To this end, the fellow will also engage biostatistics, epidemiology and comparative public health directly in attending courses and colloquia, and regular dialogs with ranking experts at Drexel.

Outcome-oriented analysis in health care policy and implementation of innovative technologies, for example in e-governance, depends on predicting which factors affect participation. CWLF specializes in the creation of agent-based simulations that allow the modeling and evaluation of such scenarios. Being equipped with this skill-set, complemented by the exposure to transatlantic differences to be accommodated in such models, the fellow will achieve the potential of becoming a leading expert on the long-term effects of new forms of e-governance and of the transatlantic merging of markets and research areas in health care policy, biomedical innovation, and consumer citizen identities.

The fellow is committed to improve his basic skills in French and to reach distinguished levels through advanced courses at Drexel and full immersion in Brussels, where he also will begin to learn Dutch. Speaking four European languages, the fellow's potential to create research throughout the EU research area, or also contribute as a policy analyst and public health expert reaches a new level that could not be achieved in a framework other than the EU Marie Curie fellowship. Since the fellow's goal is to contribute to rigorously outcome-oriented research that has an impact on global levels, this language-training component is crucial.

Even if the fellow's career were to take him outside academia, he aims at continuing to teach courses in higher education, focusing on non-traditional student audiences and continuing education from the health care sector. Still, after the fellowship, the fellow aims to occupy a position in the European research area, preferably at a university or research institute and preferably situated with agencies outside Germany. However, there exist opportunities in Germany to continue the career at one of the major research institutes there, as well as formalize connections with Kassel and Leuphana University through a habilitation grant from the DFG (*Deutsche Forschungsgemeinschaft*) or a Diltney fellowship.

With the EU Social Fund including e-health, ageing, and health-promotion, the fellow also considers a full-time or part-time career as a health and research policy analyst or consultant for projects in this funding scheme, which involve small grants that require effective planning. To include this perspective into teaching, the transferable analytical competence profile here is focusing on the area of health care/biomedicalization in the 'knowledge triangle' in e-science. In the fellow's recent work, this was coined as *medical relevance in Governance 3.0* and is a core theme in the course profile 'Care, Power, Information'. This course profile, originally developed

as a seminar for Leuphana University, will be developed further, with courses to be taught at Drexel and VUB. In the form that is intended, it will become a modular system that can be adapted to the teaching requirements for the above cited student population, and tie into research policy reform and evaluation platforms connecting health care practitioners and policy-makers internationally in a Governance 3.0 digital ecology, integrating public outcome and individual health-related quality of life. A plan for such a project in the form of an iSchool for Public Health and Care, which could initially take the form of a Helmholtz Virtual Institute, is a conversation the fellow has begun with his partners at CLWF and Kassel, and which it will take several years to fully to develop and for the fellow to gain the experiences and competencies he has marked as an objective in this research and training scheme.

## **B5.2. Contribution to career development or re-establishment where relevant**

To aid the development of an iSchool project as just described, the Marie Curie fellowship creates a unique opportunity for conducting research and training at the Center for Science, Technology, and Society at Drexel at this time is the fact that the Center is a recent addition to Drexel University, and set in a lively international health care research and industry ecology in the Philadelphia area. The Center includes a multi-disciplinary faculty comprised by young research innovators and experienced researchers who each hold many leadership positions in academia and outside and have garnered substantial grant awards. The Center's director and host for this project, Kelly Joyce, is an internationally renowned expert in her field and an experienced research manager and administrator. As director of the Center, its institutional development is a key challenge, which the fellow would be a privy to in all aspects. The competencies and skills of organizing and directing a research center, some of which can only be observed and transferred as tacit knowledge, are an indispensable training component for the fellow's future career, enabling a high degree of independence and confidence to manage and direct a research group or institute.

The fellow's teaching skills are also improved on by the acquisition of advanced and broad quantitative skills: A pragmatic aspect is that the competencies gained in methods fulfill a general need for teaching in departments for social and behavioral sciences, and public health. It is just a simple fact that even in tight academic markets, superior skills in methods teaching, particularly in quantitative methods, prove to be to the advantage for any job candidate on the academic market. In the acquisition of advanced quantitative and qualitative methods skills at Drexel, the fellow plans to create courses and workshops for his return phase that are to be taught in Brussels, and, subsequently, in workshop style seminars at Kassel and Leuphana University. In creating the research instrument, outlined as the main objective of this project, the fellow's independence and his research and teaching career profile will be equally improved.

But as has been indicated, the aim is not to occupy a position fixed on teaching alone, although the fellow emphasizes his conviction that research, policy design, and teaching should go hand in hand to be truly effective. The aim is the creation of an integrative project, that brings outcome analysis, education, and research together in an STS perspective that is meaningful for public health. To create funding, the success of grant writing is imperative, not just for the fellow's own projects, but for those of his associates and students he seeks to supervise. In order to gain these competencies and immediately apply them, the fellow will be involved in NIH, NICE, and NSF grant-writing at Drexel university, where Kelly Joyce, Ali Kenner, and colleagues have concrete designs for a number of grant initiatives over the next three to four years, some involving partners of the fellow, such as Sabrina Weiss.

At CLWF, grant writing activities supervised and aided by Prof. van Bendegem are many and intensely collaborative processes, and the fellow will continue to be involved in such activities, after already having aided in the drafting of a proposal for the FWO (Fonds Wetenschappelijk

Onderzoek), to enable the fellow's American colleague Sabrina Weiss to conduct bioethics and policy research in Brussels from 2014-17.

In conducting teaching at Drexel, the new issues of e-teaching and open access will be present at every stage; since members of Drexel iSchool, such as Kristene Unsworth at the Center for ST , are present in every department. The fellow will continue development of e-teaching upon his return, under the supervision of Prof. van Bendegem and Karen Francois, including the development of online resources for information and teaching of the 'Care, Power, Information' profile made available through CLWF. This includes also an upgraded version of the experimental online journal for junior scholarship, which the fellow has co-created and served for as founding editor. Similar initiatives in this direction have been created in recent years, which require new concepts for institutionalization to ensure quality control and selection, nor are there many European with a public health or medical humanities background that aim at non-traditional audiences in higher education. The fellow's work with Drexel iSchool and STS, and CLWF will include conversation about e-publication of public health-related research.

### **B5.3. Potential for creating long term collaborations and mutually beneficial co-operation between Europe and the Other Third Country**

Following this project, the fellow plans future research that involves collaborations in comparative public health, and future research on low-tech/high-tech practices in care systems, including placebo research and the issue of participation and decision-making, with a additional focus on situations when patients require a legal guardian. Two projects are possible to conduct involving researchers at Drexel and it can be explored during the course of the fellowship if a transatlantic collaboration is truly feasible: (i) It seems reasonable, based on the state of the art of research, that there are pathways for a mutual research design for 'social contagion' model for the autism-ADHD link. Through Felicia Hurewitz at the Psychology Department and the Human Cognitive Enhancement Center, where such an avenue of research is considered, a social contagion research project can be devised.

Another line of investigation (ii), which the fellow will conduct with Sabrina M. Weiss at a future stage, is the question how care industries, care systems, and care&research ethics must be designed in order to avoid the so-called ableism-bias, i.e. how not to conceive severe mental and physical differences from a perspective of normality as 'disabilities' but to create a new approach to techno-scientific and ethical practices. Weiss, who considers working at Drexel or Brussels in the years to come, aims at securing a grant either in the US or in Europe. As such, she is aiming to facilitate our collaboration through an FWO grant or a grant within the new European research framework (Horizon 2020). As mentioned above, the fellow has begun discussing plans for a project for an iSchool for Public Health and Care, which could take its beginning in the form of a Helmholtz Virtual Institute, and would involve the fellow in a leadership role. This discussion and planning is in its early stages and will take a few years to be turned into concrete realities of funding proposals. It currently involves Dr. Dellwing in Kassel, and Prof. van Bendegem in Brussels, Sabrina Weiss in the US (currently RIT, Rochester, NY and RPI, Troy, NY). Planning includes an institutional transatlantic collaboration, pending the free trade agreement, and the inclusion of further European sites, potentially we are also considering inclusion of a non-Western site, if there is a justification for this in integrating our design with a funding agency, given that we depend on issues of health care policy reform, which are culturally and geographically constrained by institutional and legal factors. Since integrated health care reform models are affected by the timing and details of the pending free trade agreement, and the form that the merging of markets and research areas will take, the fellow aims at continuing to collaborate on this issue with his partners at Drexel, Weiss RIT, Ron Eglash and Linnda Caporael at RPI (US), the Methods Center at Leuphana Univ., The Dept. for Macrosociology at Univ. of Kassel (Germany), and CLWF at VUB in Brussels (Belgium), but also use the meetings

of the ASA, 4S, the American Society for Bioethics and Humanities and Public Health Association meetings to facilitate new opportunities. However, outreach in this area must exceed academia, and in this regard the fellow will address agencies that work in EU-US trade, beginning but not ending with the German-American Chamber of Commerce, which is based in Philadelphia.

The fellow would like to point out that the importance he places in transatlantic cooperation in research, which was one of the reasons that he was offered to become a visiting research faculty at the STS Center, without this offer depending on a concrete or existing grant. The offer was extended on the basis of the project and the fellow being considered a prolific and promising postdoctoral researcher. On this basis, the option to obtain competitive grants through US funding agencies, such as NIH and NSF, which would make a career in the US possible, was provided as an option. The fellow's stated preference is, however, to obtain a grant, preferably a Marie Curie fellowship, which would advance transatlantic research collaborations but make it possible to place the future center of his career in Europe, and, thus, not make it necessary to explore the non-European options.

#### **B5.4. Contribution to European excellence and European competitiveness through valuable transfer of knowledge during the return phase**

In health care and biomedical research, the ethical, political, legal and socio-economic situation between the European Union and the US can be characterized as highly fragmented. Fragmentation in this area is also found between EU member states themselves (for example in the question of privacy regimes and biobanking), where every party in this constellation has their own rules and standards – sometimes less, sometimes more rigorously binding. The tensions between the boundaries for reform and transformation exist as a result of the tensions that publics perceive between regulatory contexts, bioinformational context and the realities of research and care, and the potentials for individual participation, which are constituted by the perception people have of themselves as citizens, as consumers, as patients, and as research subjects. Standards emerging in the continuous process of a merging of markets and research areas – the EU-US free trade agreement will result in an increased activity - need to go beyond mere normative demands disguised as blanket recommendations with little margin of appreciation for any scope of application, there is need for increased awareness of the ethical concerns, health-related factors for the quality of life, and the adherence to best interoperability practices that engage publics as active consumer citizens. Therefore, the core objectives of this project that focus on the development of the fellow into an expert in this field, to understand the practical requirements of issues of governance and the recalcitrant challenges for policy-making that will occupy researchers, and European policy-makers and publics alike.

The project will help improve standardization and education issues through integrative perspectives on health care, pharmaceutical and complementary and alternative medicine research and markets, which include e-governance/governance 3.0 architectures for health care consumers, by explaining how participation and decision-making in health care are constituted and link to outcome, an important aspect in increasing overall EU competitiveness. Competitiveness is also increased by considering cost effectivity, which means to be able to better understand the role of patients in biomedical research and health care markets, and to evaluate the effects of innovation. These can be identified in three areas in particular:

(a) The rising costs of care are correlated with innovation in high-tech biomedical practices. Against Western medicine, variously understood as academic, high-tech, or clinical medicine (German: 'Schulmedizin'), a growing movement supports a vast field of Complementary and Alternative Medicine (CAM) which includes, however, both effective as well as sham practices, yet knows few resilient standards for research or practitioner training. In the US, a National Center for Complementary and Alternative Medicine (NCCAM) has been established as part of

the National Institutes of Health (NIH) in 1998 to create research and evaluation of practices in this field. The present research offers an alternative view from an STS perspective, suggesting that there should be a shift to a perspective of integrative medicine, conceiving of practices falling in a high-tech/low-tech spectrum, making room for increased standardization and scientific evaluation in research and care practice, and including the aspect of participation and consumer citizenship in health care systems. This is suggested by recent research in cognitive studies (micro-perspective) and outcome-orientation in health care systems analysis (macro-perspective). This project aims at an integration of these research modes (macro-micro-macro model) to create a robust and rigorous fundament for understanding improvement and participation in care systems, one of the key challenges for European governance and competition (for example with an ageing population/work force) of the 21st century. (b) For this purpose it is imperative to better train and prepare not only doctors but the entire growing workforce of care practitioners, in particular nurses, who are required to participate in a work environment with increasing technological and human interaction demands. In the EU, the demand that they receive better training has been made repeatedly, and they represent a current and future non-traditional and continuous student population for whom specialized training at higher education institutions is yet at its infancy and requires further development. An outcome of this project's research and, in particular, training phase, is to contribute to the development of a concise European program and education concept for these audiences, that are based on their daily interaction as gatekeepers in care systems with actual patients in techno-scientific practice ecologies. (c) With increasing costs not just for health care but also research, questions have been raised how research costs can be dealt with more efficiently, for example through small projects that contribute to 'Big Science' through co-opting large data sets while upholding research ethics. The fellow's aim is to train in these matters and create accessible guidelines with his colleagues at CLWF, in the form of open access brochures, presentations and workshops at major sociological and public health conferences, such as meetings of the Medical Sociology Group of the British Sociological Association.

In Europe, a Brussels-Kassel-based initiative of an iSchool for Public Health and Care is a plan currently developed by the fellow and his collaborators. This would be an innovative contribution to the European Research area and European Health Care systems and Biomedical Research, beginning with a modest financing to set up an information architecture and open access education and research infrastructure. The fellow's training in agent-based simulations, and advanced research methods, as well as with internationally recognized STS and Social Medicine/Public Health experts, who inhabit key administrative positions in their institutes, represents a crucial step for the fellow towards planning and executing such an ambitious endeavor. On a smaller scale and more immediately, contributions in the VUB Technology Transfer Interface, can directly affect local care markets, through courses and workshops for nurses and practitioners by engaging agencies like the European Public Health Alliance (EPHA), the European Confederation of Care Home Organizations (ECHO), European Academy of Childhood Disability, or the European Federation of Nurse Associations.

Additional future and ongoing benefits include the researcher's relations with internationally renowned and promising junior researchers in the US, who can be interested in pursuing careers in Europe. The fellow is also being enabled to help with easy facilitation of transatlantic research projects, wherein researchers must negotiate American IRB process and EU research ethics, as well as different research cultures.

In conclusion, the instrument, research results, and competencies gained in the course of this project deliver outcome-oriented perspectives for the development of health care systems and markets, by delineating the differences and future potentials of the citizenship construct and participation in the European Union and the United States. Two models of participation are at stake, which European policy-makers and research commissioners can go on to develop further: The health care recipient as a passive/active consumer (US) or as an agency-

possessing consumer citizen (EU). This project creates an investigation of these models, the policy opportunities they represent, which steering practices and ethical standards will help enable transparent governance and participation in of current health care and research infrastructures. This project is a contribution to create applicable knowledge on networked interoperability, harmonization of existing civic, ethical, and legal practices, and finally, to promote public engagement and participation to create feasible, effective, and more efficient synergies for interdisciplinary research and interoperability. On the most practical levels, the research potentials and competencies that the fellow will realize, aim to advance the outcomes of business integration, competitiveness, and public engagement in the EU.

### **B5.5. Impact of the proposed outreach activities**

Outreach activities in the course of this project fall in two categories: (i) Continuation of regular activities of the fellow that coincide with suggestions for activities, and (ii) activities that derive from the nature of the project and will be further developed through the fellowship and continue after.

ad (i): As a Marie Curie Ambassador, the fellow will continue to address schools and community organizations, and above all ADHD interest groups (for example run by parents and teachers) and martial arts associations. Here he will explain and discuss the practical implications of latest research on ADHD and physical education, as well as differences in American and European approaches to health, development and academic achievement. The fellow will continue his efforts to give lectures for students in training to become school teachers and to discuss with students and teachers these issues in his program 'ADHD in the classroom' in the Philadelphia and Brussels area. As a result of the training, he will also be able to prepare this program in French, and, one day, in Dutch. He will continue and expand his dialog with local martial arts instructors on the impact that public health, neuro-cognitive, and sociological studies have 'on the mat', as well as what working with children with ADHD means. The fellow plans to expand his classroom work with his own students, helping them develop individual learning styles, adapting to learning difficulties with the help low-tech means by understanding the impact of cognitive science. The goal is to create a one day-long workshop, to be held at schools in Philadelphia and Brussels, where pupils and students along with parents and teachers can explore options of learning techniques, including mindfulness techniques and playful physical education such as developed by Ellen Langer and John Ratey.

ad (ii) The fellow will also enter directly into dialog with business representatives in the care and biomedical industry to elaborate on the issue of cultural differences and care ethics. In Philadelphia, the German American Chamber of Commerce in Philadelphia is one partner where the fellow is exploring options to speak to members in relevant industries and businesses on consumer citizenship and consumer protection in European health care markets, with a special emphasis on the role of children as patients. The fellow plans to develop and hold workshops at Drexel and VUB for health practitioners and nurses on future challenges through internationalization and integration of health care markets, biomedicalization, and the techno-scientific nature of work environments. In both, the dialog with entrepreneurs and nurses, special emphasis is given to the role of e-governance and governance 3.0.

The fellow aims to work with interdisciplinary groups students in Philadelphia, Brussels, and Kassel on the creation of a collaborative online project on the documentation of health experiences in all three countries. Tools used for his class-room work, such as audio-documentations or wikis, are to be combined for a comprehensive online project, documenting the highly individualized everyday challenges that people face in staying healthy, getting well, or having bodies that are 'labeled' other than the norm. The project aims not only on creating an innovative avenue for this important documentation, but also on emphasizing the need for

international collaboration, while teaching students about research ethics and sensitive information, as well as the difficulties of negotiating these issues between different research cultures. The role of a public intellectual does include media relations, such as presenting research in local news outlets. The fellow will establish these connections through colleagues. Prof Joyce and Prof. van Bendegem have been very active in these areas. The fellow will also aim to secure the opportunity of a TED talk through Professor van Bendegem.

## **B6 Ethics Issues (No page limit)**

### **MAIN ETHICAL ISSUES**

The quantitative and qualitative methods applied in the course of this project are social science research methods. No biological/biomedical 'invasive' research will be undertaken, no biological samples are being collected, and no experiments will be conducted. Sensitive socio-economic data may involve information such as family-income, education, and social status. Sensitive biomedical data collected may involve self-reported information such as height, weight, diet, as well as medical prescriptions, i.e. ADHD medication and therapeutic regimes. Biographical and narrative interviews may be recorded for later transcription. Video footage of interaction 'on the mat' during Aikido/Taekwondo-training, such as often recorded by instructors may be used as sources for written analyses. Therefore, ethics issues derive from issues that require informed consent, privacy and data protection, and the fact that part of the participant population are children. It has to be emphasized that the project is required to undergo two ethics reviews: One review from the European side and an IRB process in the US. This is, however, intentional. The different research ethics procedures are a key component of the training program, allowing the fellow to develop transferable competence in negotiating research ethics regimes in international collaborations.

1. Participant Population: The proposed project will involve the anonymous and voluntary participation of children, adult women and adult men.

The design of the studies will maximize the inclusion of equal number of males and females, and participants representing a wide range of cultural and ethnic backgrounds.

2. Research Material: Participants will be subject to participant observation and biographical interviews by the researchers for ethnographic research. They provide anonymous written responses in the studies. It is possible that image or voice recordings may be used in the course of the research for later analysis, but kept confidential. Questionnaires, which include semantic quantifying scales will be distributed to parents, clinicians, nurses, children, martial arts instructors.

3. Recruitment and Consent Procedures: Written consent will be obtained from all participants. The consent form will describe details of the research procedures and the general aims of the study. Participants will be assured that the studies are completely voluntary and that they are free to choose not to participate or to withdraw at any stage of the study and for any reason without penalty. The consent form will include academic contact information (email address, home and office telephone numbers of my research unit) so that participants can get in touch with the researcher directly to discuss their questions or concerns.

Scientists in charge have ample experience dealing with ethical issues in the context of research. The researcher will attend additional training on the Protection of Human Research Subjects, if required by the scientists in charge and reviewers.

4. Risks: The fellow foresees no potential risks to the participants as the confidentiality of their responses will be always assured.

5. Minimizing risks and protecting confidentiality: We will make every effort to maintain confidentiality of data at all times. No names or other identifying information will be required during data-collection, standard anonymization procedures apply. No person will have access to the data except for the fellow, the scientist-in-charge, and trained research assistants.

6. Risks in relation to benefits: We will provide a report of the (overall) results of the studies to all interested participants. Finding of the studies will enrich our understanding of the strength of factors of participation, self-agency, empowerment and health-related quality of life for health care outcome.

Given the minimal risks associated with these studies, I believe that the benefits to the participants, educators, and practitioners outweigh the risks.

## ETHICAL ISSUES TABLE

(Guidance notes on informed consent, dual use, animal welfare, data protection and cooperation with non-EU countries are available at: [http://cordis.europa.eu/fp7/ethics\\_en.html#ethics\\_sd](http://cordis.europa.eu/fp7/ethics_en.html#ethics_sd))

	<b>Research on Human Embryo/ Foetus</b>	<b>YES</b>	<b>Page</b>
	Does the proposed research involve human Embryos?		
	Does the proposed research involve human Foetal Tissues/ Cells?		
	Does the proposed research involve human Embryonic Stem Cells (hESCs)?		
	Does the proposed research on human Embryonic Stem Cells involve cells in culture?		
	Does the proposed research on Human Embryonic Stem Cells involve the derivation of cells from Embryos?		
	I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL	YES	

	<b>Research on Humans</b>	<b>YES</b>	<b>Page</b>
	Does the proposed research involve children?	YES	
	Does the proposed research involve patients?	YES	
	Does the proposed research involve people not able to give consent?		
	Does the proposed research involve adult healthy volunteers?	YES	
	Does the proposed research involve Human genetic material?		
	Does the proposed research involve Human biological samples?		
	Does the proposed research involve Human data collection?	YES	
	I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL		

	<b>Privacy</b>	<b>YES</b>	<b>Page</b>
	Does the proposed research involve processing of genetic information or personal data (e.g. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)?	YES	
	Does the proposed research involve tracking the location or observation of people?	YES	
	I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL		

	<b>Research on Animals</b>	<b>YES</b>	<b>Page</b>
	Does the proposed research involve research on animals?		
	Are those animals transgenic small laboratory animals?		
	Are those animals transgenic farm animals?		
	Are those animals non-human primates?		
	Are those animals cloned farm animals?		
	I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL	YES	

	<b>Research Involving Developing Countries</b>	<b>YES</b>	<b>Page</b>
	Is any material used in the research (e.g. personal data, animal and/or human tissue samples, genetic material, live animals, etc) :		
	a) Collected and processed in any of the ICPC countries?		
	b) Exported to any other country (including ICPC and EU Member States)?		
	I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL	YES	

	<b>Dual Use</b>	<b>YES</b>	<b>Page</b>
	Research having direct military use		
	Research having the potential for terrorist abuse		
	I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL	YES	

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PART B

“Minor Powers:  
Health-related quality of life, power, and self-agency of underage citizen consumer”

**ENDPAGE**

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PART B

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