ETHICAL, LEGAL, AND SOCIAL IMPLICATIONS OF GENOMICS AND PRECISION MEDICINE

WORKSHOP BY CENTRE FOR HEALTH ECONOMICS

17-18 JULY 2021
NINGBO, CHINA

Time: July 17-18, 8:30-noon (China time)
or July 16-17, 8:30pm-midnight (US EST)

Venue: Online (ZOOM)

Register at https://tinyurl.com/unncgenomics
or http://t.hk.uy/7tb
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Organizing Committee

- Professor Zhuo (Adam) Chen, Visiting Professor in Health Economics, and Director of Academics, Centre for Health Economics, School of Economics, Faculty of Humanities and Social Sciences, University of Nottingham Ningbo China; Associate Professor of Health Policy and Management and DrPH Program Coordinator, University of Georgia, USA
- Professor Cong Cao, Professor, Nottingham University Business School, China
- Dr. Xuyan Lou, Assistant Professor, School of Economics, Faculty of Humanities and Social Sciences, University of Nottingham Ningbo China
- Dr. Yang Li, Assistant Professor, School of Economics, Faculty of Humanities and Social Sciences, University of Nottingham Ningbo China
- Dr. Chen Qu, Assistant Professor, School of Economics, Faculty of Humanities and Social Sciences, University of Nottingham Ningbo China

Supporting Team

- Claudia Cai, Faculty of Humanities & Social Sciences, University of Nottingham Ningbo China
- Wei Jiang, PhD student, University of Nottingham Ningbo China
- Lan Jiang, student, University of Nottingham Ningbo China
- Jianhong Xu, student, University of Nottingham Ningbo China

Organizers

- Organized by the Centre for Health Economics, School of Economics, Faculty of Humanities & Social Sciences, University of Nottingham Ningbo China
- Co-organizer: The Graduate School, University of Nottingham Ningbo China
- Co-organizer: Department of Health Policy and Management, College of Public Health, The University of Georgia, Athens, Georgia, USA

Acknowledgement

- The organizers wish to thank the Nottingham China Health Institute for funding through the 2019 NCHI Small Research Grant.
University of Nottingham Ningbo China

The University of Nottingham Ningbo China (UNNC) is the first Sino-foreign university. It locates in Ningbo, one of China’s major ports and economic centres. Based in Ningbo Higher Education Park, this spacious, modern campus offers first-class amenities, including a library, teaching and IT facilities, accommodation for all students and staff, restaurants and shops, and a dedicated sports complex. UNNC is a place to deliver international experience in local setting. With campuses in the UK, China, and Malaysia, University Nottingham is a world-class university with a truly global perspective.

Fast facts about UNNC

- The University of Nottingham Ningbo China (UNNC) is the first Sino-foreign university opening its doors in China in 2004.
- The University is situated in a 144-acre (584,666m²) campus in Ningbo, Zhejiang Province.
- At UNNC we have around 8,000 students and approximately 10% are from overseas countries and regions including Hong Kong, Macao, Taiwan.
- We have more than 750 members of staff, split across academic and professional services.
- Our staff and students come from more than 70 countries and regions around the world.
- We have three faculties: Business, Science and Engineering, Humanities and Social Sciences.
- We offer 29 undergraduate courses and 13 postgraduate courses.
- The University has 15 research centres and institutes.
- We were awarded a license to grant PhDs in December 2008 and have over 400 PhD students.

Centre for Health Economics

CHE - Centre for Health Economics- was launched in September 2018 under the umbrella of Nottingham China Health Institute (NCHI) and based in the School of Economics, Faculty of Humanities and Social Sciences (FHSS), UNNC. CHE aims to become a leading centre on health economics and research on health sector economics and policy in China.

The key activities of the Centre

- To conduct research on health economics and health-related sciences;
- To collaborate with Chinese and international universities, form a research network though annual conferences, multiple workshops, and working paper series;
- To work closely with local health institutions such as Ningbo First Hospital, Ningbo No.2 Hospital and Ningbo Municipal Centre for Disease Control and Prevention.
The University of Georgia

The University of Georgia (UGA), a land-grant and sea-grant university with state-wide commitments and responsibilities, is the state’s flagship institution of higher education. It is also the state’s oldest, most comprehensive, and most diversified institution of higher education. The university was chartered in 1785 and has a current enrollment of over 35,000 students. The University of Georgia is classified as a Research I university based on its annual incoming external funding awards and the strength and diversity of its graduate degree programs. The University of Georgia ranked #13 in U.S. News & World Report’s 2019 list of the 50 top public universities in America.

The University of Georgia’s College of Public Health

The University of Georgia’s College of Public Health promotes health in human populations, protects the environment, and prevents disease and injury in Georgia, the United States, and globally through innovative research, exemplary education, and engaged service. The University of Georgia’s College of Public Health, founded in 2005, was awarded full accreditation by the Council on Education for Public Health and was recently re-accredited through 2021.

The College of Public Health enjoys a research infrastructure that provides technologically-sophisticated classrooms, seminars rooms, and computing laboratories and research laboratories to promote research in the areas of environmental health science, health behavior, biostatistics, epidemiology, health administration, aging, and many others. All faculty and graduate student offices are equipped with networked computers with direct access to e-mail, internet services, statistical and other software, mainframe computing, and library resources. The research base of the College continues to grow rapidly through grants and endowments. Skilled administrative support is offered within the College for all accounting and reporting aspects of external awards. Recent significant awards have come from the National Institutes of Health, the Centers for Disease Control and Prevention, the Environmental Protection Agency, the U.S. Department of Agriculture, and numerous other private and public sources.

The Department of Health Policy and Management

The Department of Health Policy and Management seeks to advance the health of the public through excellence in research, instruction, and outreach by developing leadership and management expertise and an evidence-based approach to policy making. The department consists of a group of interdisciplinary faculty members who have research interests in the areas of aging, health services research, economic evaluation, health economics, health informatics, child and adolescent health, scientific workforce diversity, and emergency preparedness.
Forewords

Precision medicine is predicted to have an annual growth rate of 15% in the coming years, with a global market of $60 billion in 2015. China is no exception – it was one of the six countries involved in the Human Genome Project and has become a critical player in large-scale human genome research. However, concerns remain, particularly on the ethical, legal, and social and economic issues related to genetic research and applications of genomics. As the quote “The social problems raised by science must be faced and solved by the humanities” argued, we intend to convene a small group of researchers in this area to generate debates and discussions on social science and humanities research related to precision medicine and genomics research.
# Agenda

## 17th July 2021

**Venue: Online (Zoom)**

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<th>Time</th>
<th>Session</th>
<th>Moderator</th>
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| **Session 1: Ethical Issues related to Genomics and Precision Medicine** | **Opening and Welcome**  
Speaker: **Professor Patrick Chau**, Vice Provost for Research and Knowledge Exchange, Li Dak Sum Chair Professor in Information Systems and Operations Management, University of Nottingham Ningbo China (UNNC)  
**Professor Gary Rawnsley**, Dean and Professor, Faculty of Humanities and Social Sciences, UNNC | Zhuo Chen, UNNC & UGA |
| 17 July  
8:30 – 8:45AM (China time)  
16 July  
8:30 – 8:45PM (US EST) | **Keynote Talk 1: Bioethics in China, New Developments and Case Studies**  
Speaker: **Professor Xiaomei Zhai**, Professor, Executive Director, Centre for Bioethics, Chinese Academy of Medical Sciences and Peking Union Medical College |                          |
| 8:45 – 9:30 | **Presentation 1: Public Perceived Knowledge of, Attitude Towards, and Use of Genetic Testing in Urban China**  
Speaker: **Dr. Qun Wang**, Associate Professor, Dalian University of Technology | Cong Cao, UNNC |
| 9:30 – 10:00 | **Presentation 2: DTC Genetic Testing in China: Privacy Protection and Data Sharing**  
Speaker: **Dr. Li Du**, Assistant Professor, University of Macau |                          |
<p>| 10:00 – 10:30 | <strong>Break</strong> |                       |</p>
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<tr>
<td>10:45 – 11:15</td>
<td>Presentation 3: Interpretation of Human Genetic Resources Management Policy in China</td>
<td>Dr. Shangfeng Tang, Lecturer (Assistant Professor), Huazhong University of Science and Technology</td>
<td>Yan Meng, University of Melbourne</td>
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<td>11:15 – 11:45</td>
<td>Presentation 4: Ethical, Legal, and Social Implications of Genomics and Precision Medicine in China – A Scoping Review</td>
<td>Professor Zhuo Chen, University of Nottingham Ningbo China, and University of Georgia</td>
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<tr>
<td>11:45 – 12:00</td>
<td>Discussions and wrap up</td>
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**18th July 2021**  
**Venue: Online (Zoom)**

**Session 2: Economic Issues related to Genomics and Precision Medicine**

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<tr>
<td>8:30 – 8:45AM</td>
<td>Opening and Welcome</td>
<td>Professors Simon Appleton, Professor and Head, School of Economics (Invited), FHSS, UNNC; Professor Mahmud Khan, John A. Drew Professor in Healthcare Administration and Head, Department of Health Policy and Management, University of Georgia (UGA)</td>
<td>Zhuo Chen, UNNC &amp; UGA</td>
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<td>8:45 – 9:30</td>
<td>Keynote Speech: When is Gene Sequencing in Hereditary Cancers Cost-effective? An Analytic Framework</td>
<td>Dr. Scott Grosse, Senior Health Economist, US Centers for Disease Control and Prevention</td>
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<td>9:30 – 10:00</td>
<td>Presentation 5: Applying a Health Equity Lens to Precision Medicine: Distributional Cost Effectiveness Analysis</td>
<td>Dr. Susan R. Snyder, Georgia State University</td>
<td>Yang Li, UNNC</td>
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<td>10:00 – 10:30</td>
<td>Presentation 6: Precision Health— Healthcare System Perspective</td>
<td>Dr. Jing Hao, Geisinger</td>
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<td>Break</td>
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<td>10:45 – 11:15</td>
<td>Presentation 7: Genoeconomics and Its Applications in Economic Studies</td>
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<td>Speaker: Dr. Chen Zhu, Associate Professor, China Agricultural University</td>
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<td>11:15 – 11:45</td>
<td>Presentation 8: How Does Birth Endowment Affect Individual Resilience to an Adolescent Adversity?</td>
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<td>Speaker: Dr. Ning Zhang, University of Pittsburgh</td>
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<td>Discussions and Wrap up</td>
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Speakers Bios

Professor Xiaomei ZHAI

Chinese Academy of Medical Sciences and Peking Union Medical College

ZHAI Xiao-Mei, PhD, Professor, Executive Director, Centre for Bioethics, Chinese Academy of Medical Sciences and Peking Union Medical College. She is a member of the National Ethics Committee of Science and Technology and Vice Chair of the National Medical Ethics Committee, National Health Commission of China.

Keynote Title: Bioethics in China, New Developments and Case Studies

Dr. Scott GROSSE

US Centers for Disease Control and Prevention

Scott Grosse is senior health economist in the National Center on Birth Defects and Developmental Disabilities, US Centers for Disease Control and Prevention, Atlanta, Georgia, USA, where he has worked since earning his PhD in public health from the University of Michigan in 1996. He conducts health services research, economic evaluations, and policy analyses on rare disorders and neurodevelopmental conditions and associated risk factors. He has more than 20 years’ experience assessing the utility and cost-effectiveness of genetic testing approaches. He has coauthored more than 250 journal articles and has a Scopus h-index of 53.

Keynote Title: When is gene sequencing in hereditary cancers cost-effective? An analytic framework
Dr. Qun WANG

Dalian University of Technology, Department of Public Administration

Dr. Qun Wang is an Associate Professor in Department of Public Administration at Dalian University of Technology. She holds a Ph.D. in health economics and health financing from University of Heidelberg and a BS from Fudan University. Dr. Qun Wang’s research interests include policies in novel biotechnologies (e.g., genetic testing) and interventions in long-term care.

Presentation Title: Public Perceived Knowledge of, Attitude Towards, and Use of Genetic Testing in Urban China

Dr. Li DU

The University of Macau, Faculty of Law

Dr. Li Du is an assistant professor at the University of Macau Faculty of Law, Macau SAR. He holds dual bachelor’s degrees in both clinical medicine and law (Wuhan University, China) and a Ph.D. in law (University of Alberta, Canada). His teaching and research interests include international law, health law, biotechnology law and policy, and privacy law. Dr. Du has led many research projects on legal and ethical implications of novel and emerging biotechnologies, e.g., genetic testing, stem cells, synthetic biotechnology, etc. He shares his research findings at international conferences frequently and publishes articles regularly in leading academic journals.

Presentation Title: DTC genetic testing in China: privacy protection and data sharing
Dr. Shangfeng TANG

Huazhong University of Science and Technology

Dr. Shangfeng Tang is a Lecturer (Assistant Professor) at Huazhong University of Science and Technology, and holds a PhD in Management. He was seconded to China National Center for Biotechnology Development (CNCBD) and the 14th Five-Year Planning Class of the Ministry of Science and Technology of the People’s Republic of China. His research interests include health policy, public health management, proactive health medicine, and integrated medical care. He has presided over 3 projects of National Natural Science Foundation of China, Humanities and Social Sciences of the Ministry of Education, Development Research Center of the State Council, 3 key research and development sub-tasks of the Ministry of Science and Technology, and 2 projects of independent innovation fund of Huazhong University of Science and Technology. In the past five years, he has published 28 SCI/SSCI papers, 8 Chinese core and CSSCI papers as the first author/corresponding author. He published a monograph through China Social Science Press, and participated in the compilation of a book, which won the health management award of China Medical Science and Technology award. At the same time, he was invited to serve as a reviewer of more than ten journals including America Journal of Public Health and BMJ Open.

Presentation Title: Interpretation of human genetic resources management policy in China

Dr. Zhuo CHEN

University of Nottingham Ningbo China and University of Georgia

Dr. Zhuo (Adam) Chen is Associate Professor of Health Policy and Management and DrPH Program Coordinator, College of Public Health, University of Georgia, Athens, Georgia, USA, and Visiting Professor of Health Economics (0.2FTE) and Director of Academics, Centre for Health Economics, School of Economics, University of Nottingham Ningbo China. He earned his Ph.D. in Economics and M.S. in Statistics from the Iowa State University. Dr. Chen’s current research interests include health economics, social determinants of health, genomics, and economic evaluation. His works have been published in Lancet, Journal of Health Economics, Genetics in Medicine.

Presentation Title: Ethical, Legal, and Social Implications of Genomics and Precision Medicine in China – A Scoping Review
Dr. Susan R. SNYDER

Georgia State University

Susan R. Snyder, PhD, MBA is an Associate Professor and Precision Medicine and Population Health Next Generation Scholar in the Department of Health Policy and Behavioral Sciences at Georgia State University’s School of Public Health in Atlanta, Georgia, USA. Her current research focus is improving the impact of precision medicine applications. She has previous experience working as a health economist and health services researcher at Geisinger, Battelle and the U.S. Centers for Disease Control and Prevention (CDC) in diverse areas of public health and healthcare.

Presentation Title: Applying a Health Equity Lens to Precision Medicine: Distributional Cost Effectiveness Analysis

Dr. Jing HAO

Geisinger, Department of Population Health Sciences and Genomic Health Implementation Institute

Jing Hao, Ph.D., M.D., MS, MPH is an Assistant Professor at Department of Population Health Sciences and Genomic Health Implementation Institute at Geisinger. Her research focuses on economic evaluations of health services and programs that aim to improve patient outcomes through promoting personalized/precision healthcare, especially in areas of cancer screening and prevention and genome sequencing. She serves as MPI, site-PI and co-Investigator for multiple NIH R01 and U01 funded projects in the field. Dr. Hao is a recipient of an Early Career Investigator Award from the national Health Care Systems Research Network. She earned her medical degree from Shanxi Medical University, an M.S. in Immunology from Shanghai Jiaotong University School of Medicine in China. She received M.P.H. and Ph.D. in Health Policy and Management from University of Massachusetts Amherst. And she was a 2014 AcademyHealth Delivery System Science Fellow at Geisinger.

Presentation Title: Precision Health-Healthcare System Perspective
Dr. Chen ZHU

China Agricultural University, College of Economics and Management

Dr. Chen Zhu is an Associate Professor at China Agricultural University, College of Economics and Management. She holds a Ph.D. in agricultural and resource economics from University of Connecticut and a BS in biology from Nanjing University. Her current research has focused on integrating genetic data to gain new insights into economic behaviors.

Presentation Title: Genoeconomics and Its Applications in Economic Studies

Dr. Ning ZHANG

University of Pittsburgh

Dr. Zhang is an economist with research interests in public economics and labor economics, in particular family, housing, and labor market dynamics. Dr. Zhang’s primary research agenda focuses on the effects of affordable housing policies and educational loans on household behavior, welfare, and inequality. Beyond that, Dr. Zhang has a broad interest in applied microeconomics, with a special focus on migration, the opioid crisis, and family transfers. Dr. Zhang’s work involves both structural form and reduced form analysis. In Fall 2021, Dr. Zhang will be joining the University of Oxford as a Postdoctoral Research Fellow.

Presentation Title: How Does Birth Endowment Affect Individual Resilience to an Adolescent Adversity?