

# EACME ANNUAL CONFERENCE 2019: Rethinking Ethics In 21st Century Europe

# #EACME2019 www.ethox.ox.ac.uk/EACME2019









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# Welcome to the EACME Annual Conference, 2019: Rethinking Ethics in 21st Century Europe

We are delighted to welcome you to the University of Oxford for the 36th EACME conference, which will be on the theme of Rethinking Ethics in 21st Century Europe. The conference is being hosted by The Ethox Centre and Wellcome Centre for Ethics and Humanities.

The emergence of bioethics in the 20th Century made a major contribution to the achievement of higher ethical standards in healthcare practice and medical research. Despite these valuable contributions however, new challenges are increasingly being presented to established ways of thinking in bioethics by advances in neuroscience, big data, genomics and global connectedness, and by their convergence. Personalised medicine and big data approaches in healthcare systems are changing the focus of medicine and increasingly blurring boundaries between clinical and research activities. Together, these developments raise important questions about the extent to which 20th Century ethics continues to be fit for purpose.

In addition to these changes in technology, Europe is also undergoing a shift in research agendas and a redefinition of normative as well as national boundaries in Europe (yes, we are thinking of Brexit here!), and beyond. These changes raise the question as to whether medical ethics in the 21st century needs to revisit its principles and approaches to be adequate to the tasks with which it is confronted. Do we need to rethink bioethics for the 21st Century? The 2019 EACME conference in Oxford will address this and related questions, and respond to a pressing need for ethics, humanities and social sciences research on these new challenges.

We look forward to discussing these challenges together with you over the next three days, and we hope you enjoy the conference!

On behalf of the conference committee: Ruth Horn, Michael Parker, Mary Foulkes and Aileen Mooney, Michael Dunn, Nina Hallowell, Angeliki Kerasidou, and Mark Sheehan

We also thank the EACME Bureau for their support: Roven Porz, Bert Molewijk, Ruth Horn and Angelique Heijnen

#### **About EACME**

**EACME**, in full the European Association of Centres of Medical Ethics, was founded in the early 1980s by a small group of theologians, philosophers and medical doctors who were involved in the new discipline of medical ethics or, as it is now often called, bioethics. These so-called 'founding fathers', had the intention to create a network of centres of medical ethics in Europe with the purpose to strengthen the teaching, research, communication and debate on ethical issues in medical practice, health policy and medical sciences. The official starting date of EACME is the 2nd of December 1986 when representatives of six centres came together in Lyon to create this new organisation. The centres (including the Bulletin of Medical Ethics) were located in France (Lyon, Paris), Spain (Barcelona), Belgium (Brussels), the Netherlands (Maastricht) and the United Kingdom (London). Though the 'founding fathers' were predominantly catholic theologians, EACME has from the start put a lot of effort in being pluralist in its approach to bioethical issues. The association expanded in the nineties, when bioethics centres in Europe were increasingly cooperating in research and teaching projects funded by the European Commission. This development was the background for the professionalisation of the young association, strengthened by an efficient organisation and administration under the guidance of the EACME Board and Bureau. New centres joined the organisation, from all over the European continent, stimulating and strengthening the pluralist character of EACME. Currently, about 60 centres are members of EACME, including associate members. The most important activity of EACME is the Annual Conference, organised by one of its members with support by the members of the Bureau. The conference presents an open platform for research contributions and debate about ethical issues in health care practices, policies, and medical sciences as well as new approaches in clinical ethics, research ethics and ethics teaching. While in the early days EACME conferences were in general meetings for senior bioethicists, the current annual conferences of EACME are offering opportunities for both senior and junior researchers to present their work for a broad international audience. To conclude, EACME has developed from a relatively closed meeting space for pioneer bioethicists towards an open and vibrant community for senior and junior researchers with the aim to develop and strengthen the discipline of bioethics in the European context.

For more information about EACME and the advantages of EACME membership, please visit: www.eacmeweb.com

### Ethox Centre

The Ethox Centre is a multidisciplinary bioethics research centre located within the University of Oxford's Nuffield Department of Population Health. Ethox was established in 1998 with the aim of improving ethical standards in healthcare practice and in medical research through education and research in bioethics, and the provision of ethics support to health professionals and medical researchers. The Centre has a staff of more than 20 researchers, postgraduate students and administrators and enjoys a regular flow of visiting researchers because of its many international research collaborations and its annual Caroline Miles Visiting Scholarships Programme.

The Ethox Centre aims in all its activities to be close to practice and seeks to engage with ethical issues faced by real world actors in real world settings. An implication of this is that particular value is placed on approaches to research bringing together empirical social science research and ethical analysis. As a consequence, the Centre has a strong research interest in the theoretical and methodological aspects of what has come to be known as empirical bioethics. The Centre has four major research programmes: global health ethics; clinical ethics; research ethics; and population health ethics. The Centre's Director is Professor Michael Parker.

www.ethox.ox.ac.uk

Follow Ethox on Twitter: www.twitter.com/Ethox\_Centre



### Wellcome Centre for Ethics and Humanities

The Wellcome Centre for Ethics and Humanities (WEH) is based at the University of Oxford's Big Data Institute. It is a partnership between the Ethox Centre; the Oxford Neuroscience, Ethics and Society Group; the Oxford Uehiro Centre for Practical Ethics; and the Wellcome Unit for History of Medicine.

The Centre conducts research on the ethical and societal challenges presented by advances in neuroscience, big data, genomics, and global connectedness and their convergence. The Centre responds to a pressing need for a robust and flexible multidisciplinary research platform in ethics and the humanities capable of engaging successfully with new and profoundly difficult ethical and social challenges presented by the form, scale, scope, and societal implications of these developments.

Engaging successfully with such challenges requires a paradigm shift and a change of scale in approaches to ethics and the humanities more generally. The Centre brings together multi-disciplinary teams of medical scientists, bioethicists and researchers in the humanities and social sciences to rethink ethics and the humanities for the 21st Century.

Through its public engagement activities, the Centre aims to lead debate on the ethical requirements for successful 21st Century scientific research in the context of well-founded public trust and confidence.

The Wellcome Centre for Ethics and Humanities is funded by a Wellcome Centre Grant (203132)

www.weh.ox.ac.uk

Follow WEH on Twitter: www.twitter.com/WEH\_Oxford

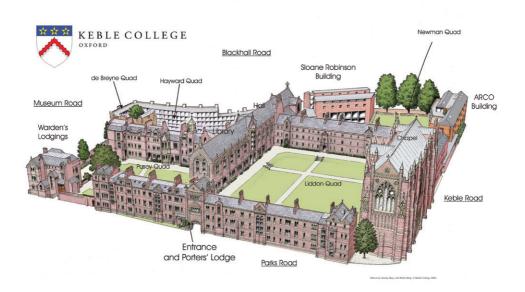


### General information

#### Conference venue

Keble College, founded in 1870, is one of the largest of the constituent colleges of the University of Oxford with 425 undergraduate and 400 graduate students. The distinctive polychromatic brickwork of its main buildings is unique in Oxford, and the magnificent dining hall is rivalled

in size only by that of Christ Church College. In addition to the original college buildings, there are fully equipped conference facilities in the Sloane Robinson Building and the Arco Building, which makes Keble an attractive venue for conferences and events.



#### Wifi Access

Wireless internet is available in all bedrooms and meeting space

#### For Wi-fi access please connect to:

#### Keble

Then use password RedBrickOxford

Next open your web browser to be redirected to the Keble registration website, click the "Begin Registration" button, select the name of the conference you are attending and follow the prompts on screen.

### The conference password is: EACME19

Note: If you are not redirected to the Keble registration website then just try to browse to any non-https webpage (such as www.it.ox.ac.uk) to force the redirection.

If you are attending the meeting as a day delegate (not staying overnight at Keble) please follow the above instructions, when room number is requested enter 0000.

### Accommodation at Keble College

If you have accommodation booked at Keble College, please go to the Porter's Lodge to get your key and information sheets. Please check that the number of nights you are residing at Keble is correct. Should you have any queries regarding your room, please feel free to direct them to the staff at the Porter's Lodge. They are very helpful and friendly. If you need to call Keble College their telephone number is: +44 (0)1865 272727.

Check-in is available from 2pm on the day of your arrival and you must check out by 10am on the day of your departure. Luggage storage is available at the Porter's Lodge 24/7.

There is wired internet access in all the bedrooms, and WiFi in the conference centre. Please see attached WiFi information sheet for more details of how to gain access to it.

#### Conference secretariat

Mary Foulkes and Aileen Mooney +44 (0)1865 287887

admin@ethox ox ac uk

Mary and Aileen will be available at the reception desk for any queries you might have during the conference.

#### **Guidelines for presenters**

All Plenary sessions are 1 hour. We would expect speakers to talk for 40 minutes to allow 20 minutes of questions.

Each talk in the parallel sessions is 20 minutes in total. We would expect speakers to talk for 15 minutes with approximately 5 minutes of questions each. There is a small amount of extra time included to allow for change overs etc.

Audio visual equipment will be available in all rooms. Please upload your slides as early as possible on the day of your talk. If you have any media content such as video or animation, please contact a member of the conference organising team in plenty of time beforehand, so that we can check compatibility with the system.

#### **Posters**

Posters must be printed on AO sized paper and in portrait format (height 1189mm, width 841mm).

Please deliver your poster to the registration desk from 12:00 on 12th September. A member of the conference organizing team will display your poster in the Douglas Price Room.

There will be poster sessions during the afternoon coffee break on day 1 and the morning coffee break on day 2. This is an opportunity for delegates to discuss the posters with their authors, so please be available near your poster during these sessions.

#### **Programme**

Please see the back of this booklet for the main programme. There is a separate programme in your delegate pack detailing the parallel sessions. All abstracts are available to view on the online programme, which can be found on the conference webpage or by going to:

https://app.oxfordabstracts.com/ events/748/program-app/program



# Keynote speakers



#### Christoph Rehmann-Sutter

Professor Christoph Rehmann-Sutter, born 1959 in Laufenburg, Switzerland, is Professor of Theory and Ethics in the Biosciences at the Institute for History of Medicine and Science Studies of the University of Lübeck, Germany (since 2009) and Visiting Professor at the Department of Global Health & Social Medicine, King's College London. He holds a diploma degree in molecular biology from the Biozentrum of the University of Basel (1984) and then studied philosophy and sociology at the Universities of Basel and Freiburg i. Brsq. Doctoral degree in philosophy 1995 from the Technical University of Darmstadt with a book on what biology 'does' (in practical and ethical terms) when it describes life. Habilitation thesis in philosophy at the University of Basel 2000 on philosophical foundations of bioethics. Between 1996 and 2008 he was head of the Unit for Ethics in the Biosciences at the University of Basel and conducted various research projects on bioethical issues, including the risks of biotechnologies, the philosophy of genomics, ethics of gene therapies, genetic testing, stem cell research and end-of-life issues, always interested in integrating insights from qualitative research (interviews) with philosophical analysis. 1999-2002 he was President of the Swiss Society of Biomedical Ethics, 2016-2019 President of the European Society of Philosophy, Medicine and Healthcare. From 2001 to 2009 he chaired the Swiss National Advisory Commission on Biomedical Ethics, advising the Swiss parliament and government. With interdisciplinary bioethics research teams in Basel and Lübeck he has tackled a broad range of topics including wishes to die of palliative care patients, bone marrow transplantation between siblings as children, new developments in prenatal diagnosis such as non-invasive-tests and precision medicine.



#### Annelien L Bredenoord

Prof Annelien L. Bredenoord PhD (1979) is a full professor of Ethics of Biomedical Innovation at the University Medical Center Utrecht and Utrecht University, The Netherlands, as well as member of the Senate of the Dutch Parliament, on behalf of the political party Democrats 66 (D66).

Her research group seeks to identify, evaluate and promote policies and practices that ensure that biomedical innovation develops in an ethically and socially responsible matter. Recent advances in biological and medical research, such as regenerative medicine and stem cell research, next generation DNA sequencing, genome editing, reproductive technologies, biobanking and Big Data, continuously raise ethical and societal challenges: how to translate biomedical innovations from basic research into clinical care and society in an ethically sound way?

Annelien is member of several international committees among which the former Chair of the Ethics Committee of the International Society for Stem Cell Research (ISSCR), member of the Scientific Board of the European Meeting on Psychosocial Aspects of Genetics (EMPAG) and The Hinxton Group. In The Netherlands, she is member of the Young Academy of the Royal Netherlands Academy of Arts and Sciences (KNAW), member of the Board of the Netherlands Organisation for Health Research and Development (ZonMw), the National Indication Committee Pre-implantation Genetic Diagnosis, the L'Oréal UNESCO: For Women in Science Award Committee, and UMC Utrecht's Research Ethics Committee (IRB).

She is frequently invited in Dutch popular media to discuss the ethical aspects of biomedicine.

Twitter: @albredenoord

Website (in Dutch): www.annelienbredenoord.nl



#### Nikola Biller-Andorno

Prof. Dr. med. Dr. phil. Nikola Biller-Andorno directs the Institute of Biomedical Ethics and History of Medicine, University of Zurich, Switzerland, which serves as WHO Collaborating Centre for Bioethics. She co-leads the PhD program "Biomedical Ethics and Law" and serves as Vice-President of the Clinical Ethics Committee of the University Hospital Zurich. She is also a member of the Research Ethics Committee of the Federal Institute of Technology Zurich, and an expert advisor to the Swiss Medical Board, an HTA agency providing clinical and cost effectiveness analyses of diagnostic and therapeutic interventions. From 2009 to 2011 she acted as President of the International Association of Bioethics. She has been a Commonwealth Fund Harkness Fellow (2012-13), a Safra Network Fellow (2013-14) and a Visiting Professor of Biomedical Ethics (2012-14) at Harvard University. In 2016, she was elected as Fellow of the Collegium Helveticum, an Institute of Advanced Study sponsored by the University of Zurich, the Federal Institute of Technology Zurich, and the Zurich University of the Arts. In 2018, she obtained an additional qualification in Health Business Administration (MHBA).

www.ibme.uzh.ch/en/about/Direction.html www.ncbi.nlm.nih.gov/pubmed/?term=biller-andorno



#### Richard Ashcroft

Professor Richard Ashcroft is Deputy Dean of the School of Law at City University, London, and a Fellow of the Alan Turing institute. He has worked in bioethics for more than 20 years, specialising in research ethics and public health ethics. Amongst other public roles, he is a member of the Tobacco Advisory Group of the Royal College of Physicians of London and has recently completed a term as a member of the ethics committee of the Faculty of Public Health. He served on the recent working party of the Nuffield Council on Bioethics on genome editing in human reproduction.

### Social events

#### **Drinks Reception**

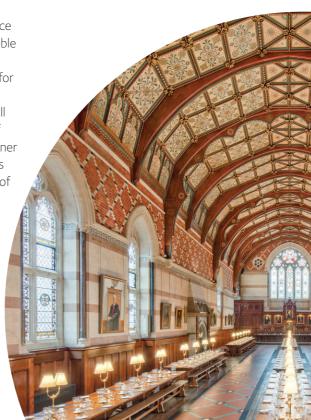
There will be a drinks reception in the Oxford University Museum of Natural History from 6:30pm to 8pm on Thursday 12th September. The museum is located on the opposite side of the road from Keble College's main entrance. All delegates are welcome to join us for drinks and canapés among the dinosaurs!



#### **Conference Dinner**

The conference dinner will take place in the magnificent Dining Hall at Keble College at 7pm on Friday the 13th September. If you have registered for the dinner you will have a ticket in your delegate badge, which you will be given at the registration desk. If you have not registered for the dinner and would like to, please contact us (admin@ethox.ox.ac.uk). The cost of the dinner is £30 and is subsidised by the Wellcome Centre for Ethics and Humanities.

There is no dress code for the conference dinner or the drinks reception.



# EACME Paul Schotsmans prize

If you would like to give a talk at the annual conference and if you are a PhD student you could apply for an EACME Paul Schotsmans prize. A maximum of 3 prizes is available – 500 Euro each. The selection is based on your abstract that you send to the conference committee to be considered for presentation. The selection criteria are based on the scientific quality of your abstract, its coherence, innovativeness and research context. The selection is directed by the Bureau of EACME.

EACME is also now offering Visiting Scholarships: www.eacmeweb.com/visiting-scholarship.html

And the EACME Collaboration Prize: www.eacmeweb.com/eacme-collaboration-prize.html

All PhD Students are invited to join Rouven Porz, the president of EACME, for lunch in the Dining Hall on Friday 13th September.



# Useful information about Oxford

#### Getting around

Oxford is a small city and the centre can easily be covered on foot. If you plan to travel outside the centre, there is a good bus network. For information on transport, as well as tourist activities, see: www.experienceoxfordshire.org

There is also a map in your delegate packs showing the colleges, museums and other places of interest connected to the University.



#### Places to eat

#### On a budget:

*Al Shami*, 25 Walton Crescent (Excellent Lebanese food)

The White Rabbit, 21 Friars Entry (small, lively pub serving Italian style stone-baked pizzas)

Wagamama, 8 Market Street (Japanese canteen restaurant)

Leon, 44-46 Cornmarket (Mediterranean, counter-serve restaurant)

#### Mid-range:

Branca, 111 Walton Street (Modern Italian)

*Turl Street Kitchen,* 16–17 Turl Street (Modern British, local ingredients)

*Zheng*, 82 Walton Street (Chinese and Pan-Asian)

*Moya,* 97 St Clements Road (Slovak cuisine, and cocktails)

Gees, 61 Banbury Road (Mediterranean cuisine in a 19th Century Glasshouse)

Chiang Mai Kitchen, 130A High Street (Thai food in a beautiful 17th Century building)

#### High-end:

Cherwell Boathouse, Bardwell Road (European cuisine, riverside restaurant)

*Quod,* 92-94 High Street (European, brasserie style restaurant)

The Parsonage Grill, 1-3 Banbury Road (Classic British, and the best afternoon tea in Oxford)

#### Pubs and bars:

The Turf Tavern, 4-5 Bath Place (food as well as drinks)

The Kings Arms, 40 Holywell Street (food as well as drinks)

The Lamb and Flag, 12 St Giles'

*The Rose and Crown,* 14 North Parade Avenue

Raouls Cocktail bar, 32 Walton Street

The Oxford Wine Café, 32 Little Clarendon Street

In the UK the standard tip in restaurants is 10% - 15% (a bit more if you receive particularly good service). Service is usually only included in the bill if it is a large group. You do not need to tip at the bar in pubs. Tipping is optional in cocktail bars.



#### Programme

For details of parallel sessions, please see the separate supplement in your delegate pack.

For all abstracts, please see the online programme: https://bit.ly/2LOyyFJ

#### Day 1: 12 September 2019

		Location
12:00	Registration and lunch	Sloane Robinson Building
13:00	Opening Session Michael Parker, Ruth Horn and Rouven Porz	O'Reilly Theatre
13:30	Plenary 1 chair: Zuzana Deans Christoph Rehmann-Sutter University of Lübeck Reflexivity in Bioethical Research	O'Reilly Theatre
14:30	Paul Schotsmans PhD Prize	O'Reilly Theatre
14:40	Short Break	
14:50	Parallel Sessions I	
16:20	Coffee Break and Poster Session	Arco Building
16:50-18:20	Parallel Sessions II	
18:30-20:00	Drinks Reception	Oxford University Museum of Natural History

#### Day 2: 13 September 2019

		Location
08:45	Registration	Sloane Robinson Building
09:15	Plenary 2 chair: Joanna Różyńska Annelien Bredenoord University Medical Center Utrecht Ethics parallel research: evaluating the ethics of new technologies	O'Reilly Theatre
10:15	Coffee Break & Poster Session	Arco Building
10:45	Parallel Sessions III	
12:15	Lunch (including PhD Student Lunch)	Dining Hall
13:30	Parallel Sessions IV	
15:00	Coffee Break	Arco Building
15:30	New Funding Opportunities at Wellcome Dan O'Connor Wellcome Trust	O'Reilly Theatre
16:00	Plenary 3 chair: Angeliki Kerasidou Nikola Biller-Andorno University of Zurich 'Deep ethics': How machine learning can support moral decision-making in health care	O'Reilly Theatre
17:00-18:00	EACME AGM – open to all	O'Reilly Theatre
19:00-21:30	Conference Dinner	Dining Hall

#### Day 3: 14 September 2019

		Location
09:20	Plenary 4 chair: Richard Huxtable Richard Ashcroft City University Public Health Ethics in an Age of Populism: Rethinking the Role of National Policy in the Face of Emerging Diseases	O'Reilly Theatre
10:20	Coffee Break	Arco Building
10:45	Parallel Sessions V	
12:15-12:45	Closing Session	O'Reilly Theatre