

# Wellcome Trust Medical Humanities Frontiers Meeting

23–24 September 2009

Highgate House, Creton, Northampton

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## AGENDA

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### Wednesday 23 September 2009

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10.30 Registration, tea and coffee

11.00 Introduction  
*Steven King, Professor of History, Oxford Brookes University*

#### Exploring Medical History and Humanities

11.30 Medical History and Humanities: Developments at the Wellcome Trust  
*Clare Matterson, Director of Medicine Society and History, Wellcome Trust*  
*Tony Woods, Head of MSH Grants, Wellcome Trust*

11.45 Is Medical History Medical Humanities? Reflections on History, Medical History, and the Medical Humanities  
*George Rousseau, Emeritus Professor of History, University of Oxford*

12.30 Lunch

13.30 The Boundaries of Illness  
*Brian Hurwitz, D'Oyly Carte Professor of Medicine and the Arts, Kings College London*

#### Past Funding and Future Directions

14.15 The Historical Geography of Emerging and Re-emerging Diseases: A Multidisciplinary Programme Grant  
*Matthew Smallman-Raynor, Professor of Analytical Geography, University of Nottingham*

15.00 Tea/coffee break

15.30 Global Health Challenges  
*Faith McLellan, WHO Secretariat, Guidelines Review Committee*

16.15 Flex and Ply: The Body, Aesthetics, and Symbolism in Medicine and Art. Public Engagement in the Medical Humanities  
*Karen Fleming, Professor of Textile Art, University of Ulster*  
*John McLachlan, Professor of Medical Education, University of Durham*

17.00 Free time

18.15 Networking

19.00 Dinner

After-dinner speech: What is the Question?  
*Raymond Tallis, Emeritus Professor of Geriatric Medicine, University of Manchester*

### **Themed sessions**

*Day 2 revolved around workshops on a variety of themes. Participants were invited to sign up to two of the following group discussions:*

- 1) Crossing Disciplines (methodological approaches)
- 2) Paradigms (big ideas, past, present and future)
- 3) The Brain (mind-brain dualism, 'neurologising', self and identity)
- 4) Total Medicine (scientific, alternative, complementary and holistic medicine)
- 5) Transmission (of disease but also of ideas and knowledge)
- 6) Unequal World (global health challenges)
- 7) Ways of Life (lifestyle and age-related diseases, nutrition and health, lifespan)
- 8) Research Collections (conservation, preservation, digitisation of research collections)

08.00 Breakfast

09.30 Housekeeping  
Tony Woods, Head of MSH Grants, Wellcome Trust

### **Developing a Research Agenda**

09.45 Group discussions – part 1

11.00 Coffee

11.15 Group discussions – part 2

12.30 Lunch

13.30 Plenary session  
*Chaired by Mark Jackson, Professor of History, Centre for Medical History, University of Exeter*

15.00 Summary  
*Tom Treasure, Professor, Clinical Operational Research Unit, University College London*

15.30 End

## **OBJECTIVES OF THE MEETING**

The objectives of the Frontiers Meeting were to:

1. launch the Trust's new Medical History and Humanities programme
2. explore the concept of 'historically grounded' research
3. identify important questions with respect to historical and related studies on medical sciences and health
4. set an ambitious research agenda
5. consider how an interdisciplinary approach might be used to answer research questions
6. provide a forum to encourage networking and to foster collaborations.

### **Setting the scene**

The presentations on the first day introduced the findings and recommendations of the Wellcome Trust's History of Medicine Review and opened up discussion on the field of medical humanities and its development at the Trust. The discussion then widened to explore the potential for wider collaborations between history of medicine and medical humanities.

Clare Matterson and Dr Tony Woods presented the findings of the review of the History of Medicine programme, changes to the programme and its remit, and the types of funding now available.

Professor George Rousseau set the scene with a general introduction to research in medical humanities, challenging historians to work in teams in order to deal with the complexities of multidisciplinary research.

Professor Brian Hurwitz, joint winner of the Trust's Medical Humanities competition described the work of his new research programme, 'The Boundaries of Illness'. He explained how his programme had been structured in order to tackle a broad theme from a number of perspectives in medical humanities. His research centre, and that of the other joint winner, Professor Martyn Evans at Durham, would contribute to the development of the medical humanities as an academic field.

Professor Matthew Smallman-Raynor, Professor of Analytical Geography and Wellcome Trust programme grant holder, described his research on the historical geography of emerging and re-emerging diseases stimulating debate on the concept of historically grounded research and the role of the historian. He also showed how historical research could have relevance to current policy and practice.

Dr Faith McLellan chose to explore one of the biggest challenges to human health. Her topic was water and its impact on human health and wellbeing. Dr McLellan's talk explored the limits of scientific research and the need for other disciplines such as economics and politics.

Professor Karen Fleming showed the benefits and challenges of a multidisciplinary approach and the need for people from different disciplines to understand each other's cultures. The rewards were often in the shape of unexpected and exciting insights, which led to further research questions.

On the second day the delegates were split into eight groups to explore topics selected by the medical humanities team. The topics were intended to stimulate debate, to encourage delegates to think of multidisciplinary approaches, to start to identify research questions, and to continue to discuss some of the issues raised by the presentations. The topics were not intended to describe any future funding priorities for the Trust.

## **OPENING OF THE MEETING**

Professor Steve King, Oxford Brookes University  
*Chair of the Trust's Medical History and Humanities Committee*

Professor King opened the meeting and welcomed the participants on behalf of the Wellcome Trust. The delegates had been invited to help the Trust set its research agenda in the field of medical humanities. The term 'medical humanities' was open to broad interpretation, but it had been agreed that proposals to the Trust's Medical History and Humanities Committee should be 'historically grounded'. This meeting would provide the opportunity to explore this concept, generate research questions and help the Trust to develop its definition of medical humanities.

## LAUNCHING THE NEW MEDICAL HISTORY AND HUMANITIES PROGRAMME

The Wellcome Trust's History of Medicine programme was reviewed in 2009. A number of recommendations were subsequently agreed by the Trust's Board of Governors. In summary, the recommendations were to:

- broaden the historical research to encourage more expansive, longer-duration research on important questions at the interface of science, medicine and the humanities
- organise a Frontiers Meeting to develop the research agenda
- shift the emphasis of Strategic and Enhancement Awards away from core funding around loose research themes to research funding for focused but expansive research questions in the form of programme grants
- change the eligibility criteria to allow applicants from developing countries where the Trust has a major interest
- introduce Library fellowships to allow greater interpretation of the Wellcome Library's collections
- explore how to encourage publication of 'popular' history books – in the context of Wellcome Collection
- relaunch the Scientists and Clinicians Fellowship scheme
- reduce project grant funding to allow the allocation of resources into new initiatives
- continue to support a number of personal awards
- introduce closer monitoring of ongoing research and formal quality assessment of outputs by the funding committee
- constitute a new Medical History and Humanities Funding Committee to reflect broader remit.

Clare Matterson, the Trust's Director of Medicine, Society and History (MSH), and Dr Tony Woods, Head of MSH Grants at the Trust, reported on the History of Medicine Review and the types of funding now available.<sup>1</sup>

The Trust's Medicine, Society and History division supports research in history of medicine and biomedical ethics, research archives and collections, public engagement, and the arts. Recently the Trust has become interested in a broader definition of medical humanities as a field of enquiry, bringing new and different ways of understanding medicine. It seemed timely to explore funding opportunities in the medical humanities, and this would in turn feed into the Trust's strategic planning process.

Events at Wellcome Collection required a multidisciplinary approach and had been very successful, both in terms of visitor numbers, and as a means of fostering multidisciplinary projects within the Trust and with external partners and advisers. The new plan to digitise the Wellcome Library, and other collections, would provide a global resource open to wider audiences, encouraging different levels of interpretation.

It should always be remembered that it was the Trust's aim to "foster and promote research with the aim of improving human and animal health". Any initiative or change in strategy must take into account this aim.

The new Medical History and Humanities scheme would focus on the programme grant as the main mechanism of supporting research in the medical humanities, moving away from supporting loose research themes through Strategic and Enhancement Awards.

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<sup>1</sup> In 2010, the Trust's MSH division became the Medical Humanities and Engagement (MH&E) division, with relevant job titles changing accordingly. This report, reflecting the discussions at the Frontiers Meeting in 2009, refers to the Trust structures, policies and activities that existed at the time.

Support for personal awards would remain (studentships, fellowships, Research Leave Awards, University Awards). Pilot grants would be available to help develop programme grant applications. Applications for the clinician-scientist awards would be encouraged. Support would be available in lower- and middle-income countries where the Trust had a particular interest (i.e. where the Major Overseas Programmes were placed, and India). Library fellowships would be introduced. Grantholders would be encouraged to write books that would appeal to a wide audience. Outputs from research would be more routinely assessed for quality, and this information would be fed into subsequent funding decisions.

The new committee would be renamed Medical History and Humanities and would consider research applications addressing important questions that will develop further our understanding of the progress and socioeconomic and cultural impacts of medicine and medical sciences on human and animal health. Research will be historically grounded, drawing, where appropriate, on the wider disciplines of the humanities (for example philosophy, literature, anthropology, law etc.).

The Biomedical Ethics funding programme would not be changed, but there were opportunities for collaborations through the new Medical History and Humanities programme.

The Frontiers Meeting also provided an opportunity to update the community on recent changes to the Research Resources in Medical History (RRMH) funding scheme, and to discuss the challenges of the new thematic approach and the Library's digitisation plans.

The Trust's RRMH grants scheme will continue to support preservation, conservation, cataloguing and digitisation projects for significant medical history collections in libraries and archives in the UK and Ireland.<sup>2</sup>

Over the next few years the Wellcome Library intends to digitise its collections, and will identify a number of themes in order to prioritise its collections for digitisation. From 2010 the RRMH grants scheme will be open to applications from other libraries and archives holding material that will complement these themes and add to a rich and vibrant digital resource.

The changes to the RRMH scheme would be discussed in more detail later as one of the group discussions had been dedicated to this topic (see page 24).

The changes to the History of Medicine programme were broadly welcomed by the delegates, although there were concerns about the challenges of multidisciplinary research, the role of the historian and what was meant by 'historically grounded'. These concerns are dealt with later on in the report.

Of more general concern was the perception that the Trust was moving its research agenda towards a more 'thematic' approach. The delegates felt that the Trust should keep its broad approach, and continue to fund research in all historical periods. It was felt that response-mode funding was the key to stimulating exciting research, and the full range of funding schemes should be maintained.

Delegates were reassured to hear that the Trust would continue to support research into the historical study of all factors affecting the medical and health experience of people and animals – in all countries and at all periods. The change to the funding programme was to encourage collaborations among a broader range of disciplines. Response-mode funding

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<sup>2</sup> In exceptional circumstances, strategically important collections held in other countries may be eligible for support.



would be the norm, and there were no plans to introduce funding priorities around themes (with the exception of RRMH).

## EXPLORING THE CONCEPT OF 'HISTORICALLY GROUNDED' RESEARCH

### Background

As a result of the review the History of Medicine programme has been rebranded to indicate the change in remit with the following name and remit:

Medical History and Humanities funding programme

The Wellcome Trust encourages research applications that address important questions that will develop further our understanding of the progress, socioeconomic and cultural impacts of medicine and medical sciences on human and animal health.

We expect the research to be historically grounded, drawing, where appropriate, on the wider disciplines of the humanities (for example philosophy, literature, anthropology, law etc).

Professor Matthew Smallman-Raynor's programme grant on the historical geography of emerging and re-emerging diseases illustrated how the concept of 'historically grounded' could be interpreted.

The joint Nottingham–Cambridge Historical Geography of Emerging and Re-emerging Epidemics Programme was a five-year multidisciplinary research programme that ran until December 2007. Based in the School of Geography, University of Nottingham, and the Department of Geography, University of Cambridge, the programme brought together UK and US researchers in a number of cognate fields (geography, historical demography, statistics and epidemiology) to advance historical understanding of the geographical patterns and processes of infectious disease emergence and re-emergence in the statistical period 1850–2005.

The grant had not been a 'traditional' history of medicine programme grant. There was no historian on the team and the applicants were geographers by training. Geography embraced a broad number of disciplines from engineering and the physical sciences through to the arts and humanities. The programme grant had allowed Professor Smallman-Raynor to retain and establish a multidisciplinary team, and provided the flexibility to pursue other collaborations.

The Trust was aware that the field of medical humanities had yet to be defined, and this was why it had held a competition to fund two Strategic Awards in the medical humanities. For the time being the Trust wished to proceed cautiously; the requirement for programme grants to be 'historically grounded' was a way of encouraging the history of medicine community to collaborate more widely.

The concept of being historically grounded was not intended as a means of quality control. It was accepted that contextualisation could be done from a number of disciplines. History was an analytical tool and a methodological approach.

## **IDENTIFYING IMPORTANT QUESTIONS WITH RESPECT TO HISTORICAL AND RELATED STUDIES ON MEDICAL SCIENCE AND HEALTH**

Dr Faith McLellan from the World Health Organization asked two questions: What are the biggest challenges in global health? How can the interdisciplinary work of the medical humanities contribute to solving the great problems of human health? Her presentation centred on what she saw as the biggest challenge to human and animal health in the future: water. The human race was threatened not only by the lack of water, but also by its potential to harbour disease and bring death and destruction caused by floods and tsunamis.

The themed discussions also identified examples of important questions:

### **The Brain (mind-brain dualism, ‘neurologising’, self and identity)**

Do we know any more about the brain now than phrenologists did? The brain was ripe for historically grounded research from the philosophical to the practical. Neuroscience could be contextualised within the history of science.

What is neuroscience doing to our notion of ‘the will’? Neuroscience is increasingly used in the courtroom to explain criminal behaviour – were there similar examples from the past? Reductionist approaches could be challenged.

### **Unequal World (global health challenges)**

This topic could bring a number of disciplines together (e.g. history, anthropology, political science).

History could be a key discipline as it provided a safe forum for discussing controversial issues. Historians could be seen as ‘honest brokers’ between disciplines. They needed to engage with the wider public and with journalists.

If historians are to make an impact on public health policy, they should first understand how it works and get involved in public health departments and with scientists.

The Trust could be more proactive by commissioning global health reports to not only provide historical background but also use methodologies such as witness seminars.

The role of international organisations has not been studied much.

### **Ways of Life (lifestyle and age-related diseases, nutrition and health, lifespan)**

History had much to contribute to this area, in particular, the study of change. Why do attitudes and behaviours change? This question can lead us into a number of research areas such as the study of lifestyle (e.g. addiction, obesity) and the role of youth, gender, class and occupation. The individual is important, but we should also look at the role of community at local and global levels. Who advises us on lifestyle issues? How are ideas transmitted and what makes health campaigns successful? How has life become increasingly medicalised? Lessons can be taken from previous public health campaigns (smoking then, drinking now). History can help guard against the simplistic implementation of policy.

A number of disciplines have a role to play: history, historical demography, epidemiology, economics, social sciences, geography, advertising and visual culture.

### **Total Medicine (scientific, alternative, complementary and holistic medicine)**

The boundaries of medicine are expanding to include new areas of life. The dominance of evidence-based medicine in the West ought to put doctors at the top of the tree of reason. But there are inconsistencies within society and even within individuals. There is pluralism in

health-seeking behaviour and multiple ontologies are used. The field of medical humanities can be used to explore this expansion of medicine into new aspects of life and society. It can seek to understand the inconsistencies and explore why evidence is ignored and conviction takes its place.

**Transmission (of disease but also of ideas and knowledge)**

A useful heuristic for thinking about the topic would be to ask if the spread of knowledge and the spread of disease were analogous. The topic could include research on agency, reading, learning, interaction etc. Medical humanities also had an important role to play in medical education.

***Postscript***

On 22 February 2010 the Trust launched its Strategic Plan for the next ten years. The Trust's funding will focus on:

- supporting outstanding researchers
- accelerating the application of research
- exploring medicine in historical and cultural contexts.

With regard to the third focus area, the Plan states:

We strive to embed biomedical science in the cultural landscape, so that it is valued and there is mutual trust between researchers and the wider public. By its very nature, biomedical science offers great promise, yet it challenges cultural norms and personal beliefs and choices. Understanding the social, political and historical contexts of biomedical science and its application will help to deliver its full potential for health improvement.

Five research challenges have been identified (although it should be noted that research topics in the medical humanities will not be limited to these five challenges, but can explore medicine in societal, cultural and historical contexts):

- maximising the health benefits of genetics and genomics
- understanding the brain
- combating infectious disease
- investigating development, ageing and chronic disease
- connecting environment, nutrition and health.

## SETTING AN AMBITIOUS RESEARCH AGENDA

The Trust was challenging researchers in the medical humanities to ask ‘big’ questions. How can creativity be stimulated? How are big ideas generated? How should research be organised? Which approaches were successful?

Professor Brian Hurwitz talked about his Strategic Award and its overarching theme, ‘The Boundaries of Illness’. He discussed the thinking behind setting up the Centre for the Humanities and Health at King’s College London, the research programme he envisaged and how its working practices would contribute to the development of medical humanities as an academic field. The aims of the programme were: to create a multi-stranded programme of research to engage scholars from a number of disciplines; to investigate what the humanities can contribute to understanding the subjective inner experience of illness; and to study personal and cultural representations of health and illness. The six strands of enquiry were: illness narrative as literature and testimony; distress and disorder; case studies of medical portraiture; nursing and identity; cultural and historical influences on psychiatric diagnosis; and concepts of health and disease.

Professor Hurwitz’s talk generated a discussion about the multidisciplinary team versus the lone researcher. There were often institutional barriers to multidisciplinary working. The best journals were focused on one discipline, making the publication of multidisciplinary research difficult. This also impacted on the REF assessment.

Given the Trust’s aim of improving human and animal health, was there a requirement for research to have an impact on policy and practice? The historian might have the role of advocate or become involved in the development of policy and practice, but there should not always be an emphasis on making research relevant to current issues.

Opinion was divided as to whether individuals needed to be grounded in one discipline before attempting multi- or interdisciplinary research, or whether people needed to be interdisciplinary from the start.

In discussing these issues, it became apparent that the nature of the research question should dictate the size of the team, the structure of the research programme, the need for a multi- or interdisciplinary research, the need for impact on policy and practice etc.

A number of suggestions came out of the deliberations in the themed discussions:

- If innovation is a prerequisite, then it is important that the funding streams are not too prescriptive. The Trust should keep its breadth of approach.
- Joint appointments would facilitate dialogue between disciplines.
- Interdisciplinarity was important, but should be a means, not an end.
- Larger grants could support the bigger questions, but it was important to keep smaller grants to encourage multidisciplinary. Support for conferences and symposia was important.
- Revolutions were happening in medicine now, and there was a need to do more recent history, although it was acknowledged that research in recent history was particularly challenging.
- Funding Committees would have to be less risk-averse.

### Postscript

The following programme grants have since been awarded under the new remit:

Professor Mick Worboys, University of Manchester, will examine bench-clinic relations since 1950. In the last decade the government, drug companies and patient groups have all emphasised the need to improve the speed and efficiency with which new remedies move from biomedical research to clinical application and practice guidelines (translational medicine). The programme will explore how and why relations between laboratory and clinic changed since 1950, focusing on conditions affecting the brain: mental disorders, dementia and stroke, plus studies of the impact of molecular biology on medicine.

Dr Abigail Woods at Imperial College London will investigate the concept of 'One Medicine'. Animals and their diseases are usually seen as marginal to the development of mainstream medicine, but in certain times and places, animal and human diseases were investigated together. Dr Woods will examine why, in certain contexts, researchers addressed both human and animal disease, and why, elsewhere, these problems were investigated separately. The goals and methods of research and the role of the animal within it will be analysed, along with the implications for science, practice and policy. The results will introduce new perspectives on the history of human-animal medicine, and inform present-day attempts to counter joint threats to human and animal health.

Professor Mark Harrison at the University of Oxford will explore naval health and medicine during the transition from sail to steam. He will seek to determine the degree to which the Navy affected the development of medicine in Britain, such as in debates about disease causation, epidemiology and public health. The programme will also examine how effectively the Navy dealt with high disease rates and casualty treatment on active operations.

A number of pilot grants have also been awarded including a substantial grant to Professor Joanna Bourke, Birkbeck College, for her project 'History of Pain from the Eighteenth Century to the Present'.

## CONSIDERING HOW AN INTERDISCIPLINARY APPROACH MIGHT BE USED TO ANSWER BIG QUESTIONS

What approaches were needed to answer the ‘big’ questions? The challenges of multi- or interdisciplinary research should not be underestimated. How can such research be encouraged? What are the benefits?

Professor George Rousseau, Emeritus Professor of History, University of Oxford, asked: “Is Medical History Medical Humanities?” He argued that theories about disciplinary arrangements over the *longue durée* have a long pedigree and tortured history, but what counts about their status in the current world is the allocation of resource to fund staff appointments and enable research projects in the culture of medicine. He considered the current profile of medical history in relation to the medical humanities, which has been developing as an entity since the 1970s. Medical history and medical humanities are configured as intellectual fields as well as institutional domains with distinct memories and specific histories, practices and goals. He challenged historians to work in teams in order to deal with the complexities of interdisciplinary research, and to maximise resources.

Karen Fleming, Professor of Textile Art, University of Ulster, spoke of her personal experiences of multidisciplinary research with her talk entitled ‘Flex and Ply: The Body, Aesthetics, and Symbolism in Medicine and Art. Public Engagement in the Medical Humanities’.

The ‘Flex and Ply’ collaboration, with John McLachlan, Professor of Medical Education, University of Durham, used textiles, body painting and projection to explore different aesthetic, scientific and symbolic meanings of the body. The products of ‘Flex and Ply’ are being used as teaching aids for anatomy students, and to challenge existing scientific ‘truths’. The collaboration is particularly interested in the overlaps between the ‘scientific’ or medical discourse and the aesthetic and symbolic meanings of the body (the latter being the idea of the body as identity and its emotional significance to the patient). Using textile creations, body painting and projection, they aim to bridge the gap between these discourses, and to challenge culturally constructed views of the body. The ‘Flex and Ply’ team developed the ‘Incisions Gown’, made of transparent white silk and resembling a hospital gown with ties at the back. This has featured in a number of exhibitions in venues that include the Museum of Science in Boston, the Palos Verdes Art Center in California and the Science Museum in London.

Another approach ‘Flex and Ply’ uses to explore the overlap between the aesthetic and scientific is body painting. As part of their learning, medical students and radiographers paint different parts of the internal human anatomy onto live models. They found some unexpected inconsistencies in the translation from two-dimensional diagrams in anatomical textbooks to three-dimensional bodies. Often the textbook diagrams showed only front and back views, with no indication of what happens on the side of the body. As a result, students painting those map onto living bodies found they had a mismatched ‘side-seam’. The team found inconsistencies in diagrams between different textbooks – and sometimes between different diagrams within the same textbook.

The collaboration had been not only between different disciplines, but between two institutions located in different countries. Virtual meetings were not enough and efforts were made to have meetings face to face, and also to experience each other’s working spaces and cultures. The multidisciplinary approach had enriched both the artists and the medics involved. The historical aspects of the research had not been foreseen and new research questions had been formulated as a result. The next step was to undertake academic research into the cultural shifts in anatomical representations of the body over time. The

impact on policy and practice had to some extent been foreseen as the 'Incision Gown' had been designed to help medical students negotiate the human body, but the inconsistencies in textbooks and the public engagement potential of the gown had not been predicted.

A number of comment and suggestions came out of the deliberations of the Crossing Disciplines themed discussion:

- The Trust should not be prescriptive about how research should be conducted. A team was not always needed, and one person could be just as interdisciplinary. The research question should drive the need for interdisciplinarity.
- It was difficult to get multidisciplinary research published in good journals. The culture engendered by the RAE/REF did not encourage multidisciplinary working. The Trust was influential and should exert pressure. In assessing quality of outputs, the Trust should take account of these problems.
- Outputs should appeal to a wide audience and therefore a degree of multidisciplinary was required.



## **PROVIDING A FORUM TO ENCOURAGE NETWORKING AND TO FOSTER COLLABORATIONS**

### **Delegates**

The delegates included members of the Trust's Medical Humanities Strategy Committee, Funding Committee members (from History of Medicine, Research Resources and Biomedical Ethics), holders of Strategic Awards and Enhancement Awards, and people from a wide variety of disciplines who had expressed interest in the broader medical humanities. Professor George Rousseau commented after the meeting: "I found the meeting excellent in every way, especially in the intellectual domain...I did indeed have some very lively exchanges, an added fillip to what was already a stellar day in every way."

### **The programme**

The programme for the first day had been devised to inform the delegates of the changes to the funding programme, to stimulate discussion about medical humanities and to showcase the work of a number of current grantees. The second day revolved around themed workshops to explore research questions, research methods and archival resources. The schedule incorporated opportunities for free time and networking.

### **The venue**

Creton House situated in the Northamptonshire countryside provided an informal setting for the meeting. The atmosphere was convivial.

## THEMED SESSIONS

The sessions were intended to stimulate debate, to encourage delegates to think of multidisciplinary approaches, to start to identify research questions and to continue to discuss some of the issues raised by the presentations. They were not intended to describe any funding priorities for the Trust.

### **Summary of the main points and observations from the group discussions**

It was evident from the discussions that the delegates saw that the history of medicine, and the medical humanities more broadly, had a vital role to play in helping the Trust achieve its mission.

It is important to maintain and encourage a broad methodological and disciplinary approach to allow a range of questions to be explored, from the philosophical (e.g. what does it mean to be human?) to the policy-focused (e.g. what can we learn from previous public health campaigns?).

Expanding the geopolitical vision of medical history is an important means of motivating new questions and approaches, broadening the source base of medical history, developing more sophisticated transnational comparative studies and linking to the wider, global bioscientific and humanities aims of the Trust.

The field could and should engage more directly in issues relating to modern science, technology and medicine. History is required in order to understand the revolutionary new processes of the 21st century. Opportunities should be sought for complementing some of the funding activities in the Trust's Science Funding division, and exploring synergies with Trust-funded scientists.

The challenge for the field is to move from current concepts of research in history of medicine and science to something more extraordinary. Producing scholarly work and being creative and innovative are not mutually exclusive but mutually reinforcing.

For its part, the Trust should continue its support for the history of medicine and medical humanities, interpreting these terms broadly. A full range of funding schemes is seen as essential – the larger grants to support research on big, ambitious questions, through to smaller grants for travel and conferences to facilitate multidisciplinary approaches and collaborations.

If history of medicine and the medical humanities are to be truly multidisciplinary, then joint appointments should be supported to facilitate dialogue between disciplines. Support for training to support this multidisciplinaryity should be considered.

The field also should exploit the potential to have impact on policy, and facilitate collaborations with policy-making organisations such as the World Health Organization.

### **Crossing Disciplines (methodological approaches)**

*'Interdisciplinary' is used to describe – and praise – courses, research projects, or grant proposals, as routinely as 'full-bodied' is used to describe red wines.*

Dan Sperber (2003)

Increasingly, funding bodies are encouraging, expecting, or even demanding that academics construct project proposals that either synthesise research and methodologies from across

disciplines, or at least investigate research questions from within a number of disciplines in parallel. The Arts and Humanities Research Council, for instance, nailed its colours to the mast when, in its report *AHRC Vision and Strategy, 2007–2015*, it identified the need to “Foster interdisciplinary research within and beyond the arts and humanities” as a key objective under its primary aim (“To promote and support the production of world-class research in the arts and humanities”).

The reality, however, is that universities, given their faculty structure, are poorly equipped to facilitate genuine multi-, inter- or transdisciplinarity. For those interested in embarking on such projects, there is often little training available. And those who have completed their projects sometimes find a limited option of outlets.

Proponents of interdisciplinarity will argue, however, that the approach is inherently worthwhile and rewarding. It enables (sometimes forces) researchers to tackle new questions with innovative methodologies, rather than pursuing less original questions with stale methodologies. And anyway, given that ‘Generation 2.0’ is waiting in the wings, a generation that has been reared on the internet and for whom interdisciplinary information is as accessible as the internet device in their pockets, isn’t it time we start preparing for them?

This workshop, then, sought to examine both the challenges that researchers face in this new funding environment, as well as to explore effective, genuine ways of building bridges and crossing disciplines.

#### **Possible research questions**

- Can genuine collaboration across disciplines work without a shared physical space?
- How do we avoid cosmetic interdisciplinarity?
- How do we avoid the problem of shared vocabulary, where the same term means different things to different disciplines?
- Given the kind of research that is being encouraged, is the principal investigator model of funding outdated?
- How do we foster interdisciplinary work beyond the arts and humanities? How do we learn to communicate with scientists?

#### **Paradigms (big ideas, past, present and future)**

In his work *The Structure of Scientific Revolutions*, Thomas Kuhn described science not as an evolutionary process but as a period of peaceful interludes punctuated by intellectually violent revolutions. Examples of these ‘paradigm shifts’ in science include the ideas of Copernicus, Darwin and Einstein. But what led these people to their ground-breaking theories? Without the agricultural revolution, the invention of the printing press, the discovery of new lands – would people have had the time, resources and knowledge to develop their ideas? Do new ideas in the arts, religion and politics stimulate scientific thinking or vice versa? Why do some ideas gain acceptance and some fail?

The WHO *World Health Report 1998* looked forward to life in the 21st century and, among other things, predicted an ageing population, an increase in ‘lifestyle’ and non-communicable diseases, and increasing urbanisation. Its 2007 report shows how the world is at increasing risk of disease outbreaks, epidemics, industrial accidents, natural disasters and other health emergencies that can rapidly become threats to global public health security. If necessity is the mother of invention, what new ideas and inventions can we predict? Will we be able to enhance our physical and cognitive skills to combat ageing? If civilisation crashes around our ears, will the past hold the key to future survival? Or would our society evolve into the

world of Margaret Atwood's *Oryx and Crake*, which explores themes such as xenotransplantation, commodification of life, research misuse and social engineering.

Accelerating globalisation and recent developments in medicine and the biosciences mean that in the 21st century the world will become increasingly integrated under biomedical imperatives. This biologisation and politicisation of life is a global phenomenon. This global environment calls for ambitious and innovative thinking. How can such thinking be encouraged?

### **Possible research questions**

- What key historical paradigms are in need of investigation? How do they shed light on contemporary developments?
- Looking into the future, where will our key challenges lie in relation to health and wellbeing?
- In light of the current trend for revisionism, is it even tenable to suggest that scientific revolutions exist at all?
- What are the political, economic and cultural contexts that encourage significant medical and scientific breakthroughs?

### **The Brain (mind-brain dualism, 'neurologising', self and identity)**

*It is strongly suspected that a NEWTON or SHAKESPEARE excels other mortals only by a more ample development of the anterior cerebral lobes, by having an extra inch of brain in the right place.*

William Lawrence (1819)

Our beliefs about the brain have come a long way since ancient Egyptian times, when the brain was apparently considered a rather insignificant organ, removed from the body via the nostrils during the embalming process.

Today, with the advent of functional MRI scans, neuroimaging is claiming to lay bare the biological bases of both 'normal' and 'abnormal' mental functions. Increasingly, biological models are being proffered to explain diseases once thought of as psychogenic. This anatomising of the mind (as opposed to the brain) is leading to the 'neurologising' of the humanities: *neuroaesthetics*, *neuro-ethics*, *neurotheology*, *neuroeconomics*, *neurohistory*, to name a few.

Of course, the promise of biological explanations for mental illness (and health) also suggests an arsenal of 'magic bullets'. From alleviating depression to the erasure of negative memories, controlling fear to controlling crowds, and the potential for enhancing our mental functions, the ethical and broader social implications of psychopharmacological interventions constitute another area that is ripe for further research and study in the medical humanities. Beyond the use of drugs to enhance mental function, the opportunities for genetic and other forms of neurological enhancement also challenge many of our assumptions about who and what we are and can be.

### **Possible research questions**

- What has prompted the burgeoning use of neuroscience as an epistemological framework in the humanities and social sciences?
- What are the implications of developments in neurobiology for our understanding of violence and crime?
- What does the growing field of cultural psychiatry tell us about the social construction of psychiatric illness and notions of wellbeing?

- What role has philosophy alongside the neurosciences in helping to push forward research (i.e. as distinct from contributing to ethical, legal and policy issues)?
- Are there lessons from history that could help us anticipate the likely social impact of research in this area (for example on stigma)?

### **Total Medicine (scientific, alternative, complementary and holistic medicine)**

*Formerly, when religion was strong and science weak, men mistook magic for medicine; now, when science is strong and religion weak, men mistake medicine for magic.*

Thomas Szasz (1973)

One of the goals of the medical humanities might be cast as a desire to move our understanding of health, illness and the practice of medicine beyond a concern with biochemical and physiological phenomena alone and to also consider them from alternative perspectives. This workshop seeks to explore the varying approaches to healing, from the folk-traditional to the biomedical, from the holistic to the alternative.

In the patient-centric healthcare system envisaged by the *Darzi Report*, the varying and often contradictory expectations that an individual patient brings to the consultation room can be difficult to negotiate. As Michael H Cohen observes in his *Healing at the Borderland of Medicine and Religion* (2006): “The kind of integrated health care many patients seek dwells in a borderland between the physical and the spiritual, between the quantifiable and the immeasurable.”

But what is it that drives an increasing number of people in the West to seek advice from alternative or pre-scientific medicine? Is it because of a perceived lack in the way conventional, scientific medicine approaches healthcare? Have our expectations of scientific medicine become excessive or unrealistic? And is it really the role of the medical humanities to fill this gap, and consequently to train ‘better doctors’? Narrative medicine has recently developed as a method to investigate and understand relationships between patients, doctors and the public, as well as between individuals and their illnesses. What other innovative methodological approaches could be developed to deal with the perceived shortcomings of the patient experience, or to enhance wellbeing? And are there aspects of health and wellbeing that must be sought elsewhere than from healthcare, conventional or otherwise?

### **Possible research questions**

- What makes alternative, non-Western, non-evidence-based approaches to healthcare so attractive to health consumers?
- Do these other approaches reflect a broader range of sources of our wellbeing than the bodily focus of conventional medicine?
- What does the placebo effect teach us about the intangible and the non-quantifiable aspects of health and illness?
- How can historical research into Western and non-Western, folk-traditional and conventional, alternative and holistic conceptions of medicine enhance our understanding of health and illness?
- Are our expectations of scientific medicine realistic?
- Is the current trend towards patient-centric healthcare really useful? Do patients want choice? Do they prefer direction? Or both?

## **Transmission (of disease but also of ideas and knowledge)**

*The warm hand-shake has, in a very great measure, degenerated into the timorous offer of two or three clammy fingers extended dubiously, as with a fear of microbes.*

Marie Corelli (1905)

This workshop examined the issue of ‘transmission’ and its many connotations. Knowledge is transmitted between researchers, between doctors and patients, between countries and institutions, and between experts and lay people. Knowledge also moves through time. This understanding has been used in, for example, the idea of the inheritance of memes. Our understanding of this affects not only the way we write history but also what we choose to preserve for the future.

Of course ‘transmission’ is also closely associated with disease – infectious and inherited. As our knowledge of genetics increases we have become more aware of the transmission of inherited diseases, but have we learned more about how this knowledge of genetics has moved between researchers and patients or within families? Similarly, emerging and spreading diseases present new challenges. Can knowledge from the past – or from different geographies – help us understand them better? Can the Black Death teach us anything about swine flu? Can historical accounts of syphilis tell us anything about AIDS?

### **Possible research questions**

- How do we choose what to pass on to the future?
- How can we study the transmission of knowledge in the digital age?
- How much can past pandemics illuminate today’s?
- How is academic knowledge disseminated and understood by the public?
- How does academic publishing affect the spread of knowledge? Will open access make a difference?

## **Unequal World (global health challenges)**

*The physicians surely are the natural advocates of the poor and the social problem largely falls within their scope.*

Rudolf Virchow (1848)

The UN Millennium Development Goals present ambitious proposals for poverty and hunger reduction. They also discuss means of tackling ill-health, gender inequality, educational disparities, unequal access to clean water and environmental degradation. However, progress has been limited. Serious inequalities continue in sectors such as child and maternal mortality, and several indicators have suggested the high risk of dying in pregnancy or childbirth in sub-Saharan Africa and southern Asia. Analysts have identified the lack of skilled health workers, urban-rural health imbalances, economic disparities, vagaries of market-driven reforms and cases of governmental inaction or corruption as contributory factors. Other suggestions for the achievement of health equity have, therefore, made an appearance in recent times. The WHO Commission on the Social Determinants of Health has reported on problems caused by socioeconomic inequalities and recommended wide-ranging solutions. Similarly, the WHO has presented a reinvigorated scheme of primary healthcare as a means of ensuring equitable access to healthcare facilities. UNICEF continues to advocate its young child survival and development projects worldwide, while the Food and Agriculture Organization has worked hard to raise global awareness of the differential effects of soaring food prices and its Special Programme for Food Security.

Global agencies are largely united in accepting the importance of promoting health equity and accept that disparities continue to exist locally, even in the world's richest nations. Yet a number of disagreements persist. Free trade and the market are presented as the basis for effective healthcare reform by some; others, though, consider continued state investment in the health sector absolutely necessary. These views are of relevance in a situation where commentators have noted that effective health systems can contribute to social and economic development, and also accelerate the democratisation of political frameworks. Issues of health equity and reform have thus historically been intertwined with larger discussions about political responsibility, societal contracts with governments, and the right of humans to a dignified and just existence. But would a utopian world free of pain and unhappiness, such as Aldous Huxley's *Brave New World*, be the answer? Could equality mean an end to 'difference' and the outlawing of genetic variance, as envisaged in John Wyndham's *The Chrysalids*?

### **Possible research questions**

- What are the explanations for the root causes of health inequalities? How do they differ on a local and global scale?
- How do political, economic and sociocultural factors affect their identification and measurement?
- How can inequalities be overcome? Do we require global action to redress inequalities?
- Do plans for reducing inequalities need to be sensitive to political and cultural specificities?
- Do societies and individuals always like to be identified as suffering from inequalities?
- Who is responsible for tackling inequalities? Who certifies the achievement of equality?
- Who sets the limits for inequalities? Are there limits of inequality?
- Will inequalities in wealth, political power and health always be part of societal terrains?
- Is inequality always unethical? Are inequalities acceptable?

### **Ways of Life (lifestyle and age-related diseases, nutrition and health, lifespan)**

*Once considered a problem only in high-income countries, overweight and obesity are now dramatically on the rise in low- and middle-income countries, particularly in urban settings.*

World Health Organization

So-called 'lifestyle' diseases are gaining prominence throughout the world and are intricately connected with the ways in which we live our lives. From differences in food consumption in the North and South to age-related diseases brought about by improvements in healthcare, to the emergence and spread of new diseases brought about by a changing climate and the settlement of previously uninhabitable areas.

The WHO says that "population ageing can be seen as a success story for public health policies and for socioeconomic development, but it also challenges society to adapt". What are these challenges and how will they influence our relationship with death and living? The last six months of a person's life account on average for the majority of healthcare spending on their health.

Of course, many of these questions are not new. Societies have faced these issues in the past and have discussed and resolved them with varying degrees of success. How, then, can we learn from the past?

### **Possible research questions**

- How do we understand the meaning of 'lifestyle disease'? Is this a problematic term?
- Will increased knowledge of nutrition change our relationship with food?

- How will our relationship with healthcare change as populations age?
- What are the ethics of treating lifestyle-linked ailments?
- How much is influencing behavioural change an aspect of healthcare? What are the ethics and repercussions?
- In what ways have past societies addressed similar lifestyle issues, and with what outcomes?

## **Research Collections (conservation, preservation, digitisation of research collections)**

*Books constitute capital. A library book lasts as long as a house, for hundreds of years. It is not, then, an article of mere consumption but fairly of capital.*

Thomas Jefferson (1821)

The Trust's recent History of Medicine Review made a number of recommendations that are likely to have important consequences for the RRMH scheme and the UK library, archives and research communities. They are: a) the inclusion of the wider medical humanities in the research funding programme, to include the history of biomedical sciences, and also potentially involving collaborations with other disciplines such as the social sciences and the arts; b) the inclusion of International activity; and c) the stipulation that projects should be 'historically grounded'.

At the same time, changes to the RRMH scheme have been announced, linking its future activity to the Wellcome Library's digitisation project, which includes plans for the integration of some third-party digital content alongside the large-scale digitisation of its own collections. From January 2010 RRMH funding will be used to identify and prepare significant external collections for digitisation, beginning with a one-year pilot based around the theme of 'Modern Genetics and its Foundations'. An Advisory Panel, set up to establish a framework for evaluating suitable collections for funding, will take the place of the existing RRMH Funding Committee. Following the pilot, subsequent themes will be identified, such as mental health or public health (these are examples only and may change).

While other workshops at this meeting seek to explore possible research directions, it is also important to think about the sources that will be needed for this research, since both repositories and researchers have a shared interest in ensuring appropriate levels and methods for providing access to such collections, whether on site or online.

Set against the background of the History of Medicine Review and repositioning of RRMH grants, and focusing on the broad themes of access, preservation and funding, this session offered a timely opportunity to consider how forthcoming changes are likely to affect the ability of UK repositories to maintain and improve access to the best collections.

### **Possible research questions**

- Taking into account the needs of both the academic community and those charged with the care and provision of research material, what are the main issues and challenges for the new Advisory Panel to consider?
- What sources will applicants to the new Medical History and Humanities programme need? If these sources do not fall within the funding priorities for library digitisation, would it be appropriate for an applicant to request funds on a programme grant?
- Do we know where all the important collections are?
- What are the challenges of digitising third-party collections, and their subsequent integration into the Wellcome Library?
- What digitisation treatments are needed for research?



Participants in this workshop were updated on the plans to digitise the collections of the Wellcome Library and other third-party collections, and were asked to think about the issues and challenges of implementation.

#### *Digitisation vs preservation, conservation and cataloguing*

With limited resources in the UK (not to mention archives in developing countries), should funds be diverted away from looking after the physical content? It would be helpful to be clear why collections should be digitised and who the audiences were.

#### *Collections to be prioritised according to themes*

The first theme was 'Modern Genetics and its Foundations'. Future themes might be public health, mental health and infectious diseases. The first theme was a challenging choice – most of the content would be recent, and this would present legal and ethical issues. Intellectual property and copyright issues would have to be considered. Some collections will not be in depositories yet. In general, the thematic approach might have the unintended consequence of narrowing rather than expanding research opportunities. The phasing of the themes might be problematic.

#### *Identifying third-party collections*

How would collections be identified? The process to identify relevant collections should be open and transparent.

#### *Ingesting third-party collections*

Digitisation might enhance the profile of certain collections and the archives and libraries in which they are held, but there may be some reluctance to hand over control and rights to the Wellcome Library. There may be concerns about reduced footfall.

#### *Cataloguing*

Collections will have to be preserved and catalogued before they are digitised.

#### *Other modes of funding*

It was suggested that the conservation and cataloguing of collections could be funded through the programme grant mechanism.

#### *Other digitisation projects*

JISC had dealt with a number of these issues, and their knowledge and experience could help.

### ***Postscript***

Since the Frontiers Meeting a number of principles have been agreed:

- RRMH will continue as a grants scheme to preserve, conserve and catalogue archives and collections that are important to researchers in the history of medicine.
- Funds for digitisation will be available through RRMH but will be limited to using digitisation as a preservation tool, or for small digitisation projects e.g. for illustrating a catalogue.
- Once material is catalogued, funds will also be available through the Library for digitisation.
- There will be themed calls for proposals, the first being 'Modern Genetics and its Foundations'.
- Themes will be interpreted broadly.
- Small grants will be available for collections to undertake scoping activities to prepare for future themes.

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