IRISH HEALTH RESEARCH FORUM MEETING

THEME: HOW CAN LEGISLATION FACILITATE HEALTH RESEARCH?

Report

Tuesday 10th May 2016 • Gibson Hotel, Dublin

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Chairman's Summary

The implementation of the EU Regulations on Clinical Trials (EUCT) and Data Protection (EUDP) in 2016, and the forthcoming bill on Health Information and Patient Safety (HIPS) provided the impetus for this meeting. The Forum was attended by over 80 stakeholder representatives. A series of expert presentations were given, followed by a panel discussion with audience input. The EU Regulations do not need to be transposed into Irish Law, but will require enabling infrastructure and supplementary legislation clarifying the Irish states position on a number of issues.

Clinical Trials.

The EUCT 2014 regulation takes effect by October 2018 at the latest. There will be a single EU portal for Clinical Trial applications, with a single set of documents. A Reporting Member State (RMS) will be nominated to co-ordinate the review of part 1 ("Scientific") of the documentation (which will include, inter alia , the product data, trial protocol and risk benefit assessment). Other Concerned Member states (CMS) will also review, communicating responses and queries to the RMS. A single EU response- co-ordinated by the RMS -will be given. (This may be a tall order, given the acknowledged differences in ethical philosophy-Utilitarian V Deontological, between some member states.) The single EU ethical review response must be given within 45 days, with several interim deadlines. Concerned Member States can independently review Part 11 ("National") of the documents which deals with consent forms, investigators and sites. Individual state responses are given.

It is likely that many trials will be submitted in English. This could lead to a disproportionate workload for the UK or Ireland if either are nominated as the RMS. (The issue of "Brexit" adds to this concern). The existing 12 Recognised CRECs (Clinical Research Ethics Committee) are composed of volunteers, with variable levels of administrative support. Whether Ireland is involved as a RMS or a CMS, it is imperative that an efficient, trained, and adequately resourced ethics committee is available to comply with the standards and deadlines. Failure to comply could cause serious national reputational damage. For a state of 4 million people, **a single national professional ethical committee for EUCT review seems the most sensible option. We need the HIPS legislation to establish and provide for funding to support this body.**

Data Protection.

"Data is the lifeblood of every modern organisation" -a Business Consultant

"Data is like blood, it can save lives at minimal cost to the donor" - a Patient

The EUDP 2012 Regulation has been considerably modified from the original draft. The political context of the last decade- the Snowden revelations, the sale of personal information for targeted advertising to monetise social media services; and the experience of totalitarian regimes in some EU countries resulted in different philosophies and emphasis on data security and consent across the EU. The necessary compromises have resulted in more flexibility, but also the need for each state to clarify positions in legislation. The legislation applies to all data, but Health data is different-being more private, sensitive and valuable. (By way of illustration- it is a common complaint that consent forms for treatments and clinical trials are very complex, whereas terms and conditions for internet services pose few problems, because they are rarely read before the "agree" box is ticked). Nationally, there has been progress with agreement and legislation on a single patient identifier in healthcare systems. The long awaited electronic health record has the potential to allow rapid, creative use of data to improve outcomes, subject to appropriate consents.

Data Protection regulations have been inappropriately viewed as bureaucratic intrusions on ethical research, and there is scant interest in discussion amongst the research community. Data is a vital resource, Protection a key issue, and both must be dealt with openly and constructively. Processes and individual experience should create trust in institutions. Trust in many established institutions has been eroded over the past two decades, colouring the public attitude.

Confidential personal data should be gathered carefully, sensitively and comprehensively – once. It should be respected, secure, guarded diligently and used ethically and productively, subject to the individuals consent. Consent should be considered, specific and informed. There will be occasions where consent for appropriate, important, and ethical use of data is impossible or impractical. For example, 'specific' consent for bio-bank research is difficult, as it is not possible to predict future developments and areas of interest where bio-bank data may be invaluable; a broad consent – or one that provides as much specificity as is possible at the time – may be all that is possible. It is important that national interpretation and implementation of the EUDP take such complexities into account. At the same time, we need to design systems that will reassure the public that appropriate controls are in place to ensure that waivers on consent are safe, reasonable, and optimise risk/benefit ratios.

The H.I.P.S. bill makes proposals on data sharing, ethical approval processes, patient registries, and the regulation of "non-clinical trials" research. However, in contrast to the EUCT regarding clinical trials, structures in the Bill regarding research that isn't subject to the clinical trials legislation and regulations will be voluntary rather than mandatory.

Currently Ethical committees can waive the need for written consent for research in certain prescribed conditions (e.g. where the research presents minimal risk to the subjects and is not a regulated clinical trial). The H.I.P.S. bill proposes that this waiver function will be discharged only by the Data Protection Commissioner, and a charge will be made for each application. This system may inhibit much early stage and student research. A graduated system, with DPC as final arbiter where CREC reviews are negative or are not unanimous, may represent a better option.

The move to regulate research other than clinical trials is welcome. This type of research can occasionally be simple clinical audit, and arguably is not a "secondary" use of the data. An agreed working definition of Health research is a necessary first step. For example a person has surgery for cancer; a year later a new tumour classification system is established; this patients data can help delineate risk factors, treatment response and survival outcomes for a newly categorised tumour type. Is this a primary or secondary use of patient data? Should we need patient consent to use (anonymised) personal information for this use? The proposal that HIQA regulate and recognise CRECs is not without controversy. Some form of audit and regulation is needed, but given the voluntary nature of most committees, the need for rigour must be tempered by pragmatism, especially in relation to non-clinical trials, otherwise "volunteers" will be hard to find.

The Data Protection Regulation will be implemented over the next 2 years. **Those involved in Health Research (HRB, MRCG,HPRA, HIQA etc.) need to reach consensus and communicate this to the public and Government. We must ensure that the Data Protection environment in 2018, which will be framed by legislation currently in draft stage, supports and fosters research excellence**.

Professor Gerry Loftus,
Chair of IHRF, May 2016

Opening Remarks

The Irish Health Research Forum (IHRF) hosted its first meeting of 2016 on Tuesday, May 10th in the Gibson Hotel, Point Village, Dublin 1. The title of the meeting was "How can legislation facilitate health research?"

Chairperson of the IHRF, Professor Gerry Loftus, opened the Forum and made introductory remarks. Professor Loftus said the subject under discussion was timely given recent and imminent regulatory changes that will have a significant effect on health research. These include: the EU Clinical Trials Regulation, the EU General Data Protection Regulation and the Health Information and Patient Safety legislation. He said that under the previous regulations the procedures of undertaking clinical trials in Europe were slow and cumbersome, ultimately contributing to the reduction in the number of trials in member states. The new regulations aim to simplify and streamline this process. Regarding Data Protection, Professor Loftus said it was important to strike a balance between the right to privacy and the common good that can come from sharing information. He argued that researchers would like an ethical approval process that is quick and fair, while at the same time being consistent and predictable.

In conclusion, he said that in order for this process to be as rigorous and robust as possible it will have to be well resourced.

The Department's Perspective

Mr Muiris O'Connor
Assistant Secretary and Head of Research and Development and Health Analytics, Department of Health

Assistant Secretary and Head of Research and Development and Health Analytics at the Department of Health, Mr Muiris O'Connor opened by saying he hoped to learn from the event about how legislation can facilitate health research. He said that legislation should never be an end in itself, but is an output from the policy development process intended to help achieve a desired outcome. In developing the policy that will underpin any legislation in the health research area the first two considerations that the Department of Health faces, according to Mr O'Connor, are what is the present situation and why is there a need for change?

> ***"There is not a great deal of legislation and that is not necessarily a bad thing, legislation as well as being enabling can also be inflexible where flexibility is desirable to meet new challenges."***
>
> *Muiris O'Connor*

He pointed to the legislation that established the Health Research Board and set out its functions, stating that the Board plays a central and critical role in the promotion of health research in Ireland both directly and indirectly and would be very relevant to any proposed changes in this area. Mr O'Connor also said the Health Identifiers Act will allow for unique identification of individuals and health service providers for relevant health related purposes, which highlights the interconnection and the interdependence of policies and practices in health information and in health research. Apart from these laws, he said there is not much specific legislative activity underpinning health research. It remains to be seen, according to Mr O'Connor, what the impact of the new Clinical Trials Regulation and Data Protection Regulation, will have on the area.

"Those implications will need to be fully teased out – because the absence of clarity on issues of data protection is undermining advances in health information and progress in health research."

Muiris O'Connor

Mr O'Connor said that the Data Protection Regulation is a hybrid between a conventional EU Regulation and a Directive in that it gives member states significant flexibility in certain areas, including health research, to introduce their own legislative rules for the processing of personal data.

The Department of Justice and Equality is working on a new Data Protection Bill that will have general applicability, and Mr O'Connor stated that the Department of Health and other government Departments will have to analyse the Regulation to identify what sectoral legislation needs to be introduced.

Mr O'Connor also spoke about the long awaited General Scheme of the Health Information and Patient Safety Bill. He stated that the Bill responded to calls for a new streamlined research ethics approval framework for health research other than research involving clinical trials on medicinal products which already has its own structure.

He said it was worth noting that the new structure in the Bill is voluntary rather than mandatory. The Bill also provides for a data protection consent exemption in certain cases of health research using patient identifiable information.

"On the research ethics side, some may think that maybe we should have a mandatory system or should have gone down a different route from the clinical trials research ethics committee model. On the consent exemption, some will undoubtedly feel that the Bill should go further while others will undoubtedly feel that it has gone too far."

Muiris O'Connor

In conclusion, he said that legislation supporting health research will work best where it enjoys the support of all stakeholders.

Keynote Address

Impact of the new EU Data Protection Regulation on Health Research

Dr Beth Thompson
Senior Policy Advisor, Wellcome Trust

The Keynote Address was delivered by Senior Policy Adviser at the Wellcome Trust Dr Beth Thompson, who spoke about the new EU Data Protection Regulation and its implications for health research. The new Regulation will replace the 1995 Data Protection Directive and covers the use of personal data across all sectors except for law enforcement. According to Dr Thompson, the Regulation, as it stands, represents a positive outcome for health researchers. This is because it does not include the restrictive amendments recommended by the European Parliament, which would have provided only an extremely narrow exemption from consent for pseudonymous data, research in the "high public interest" and where research "cannot possibly be carried out otherwise". However, Dr Thompson said that after intensive lobbying the European Council adopted a much more positive position towards research, which was closer to the original text produced by the European Commission.

"There is now an awful lot of scope for member states to apply their own interpretation," Dr Thompson said.

"So a positive outcome is still not guaranteed, it is going to need a lot of work in implementation. However, we did avoid catastrophe and that was no mean feat."

Dr Beth Thompson

Agreement on the Regulation was made in December and it will come into force at the end of May 2016. Member states will have a two year period to implement the Regulation, which will be achieved through national legislation. Dr Thompson said that the Regulation does not differ greatly from the 1995 Directive. There are a number of key changes, however. One of these, according to Dr Thompson, is around demonstrating compliance. Data controllers will now be required to demonstrate that they are processing people's personal information and data in a way that was not necessary until now.

There are also new requirements for Data Protection Officers and rules on data breaches. Another significant addition is the introduction of fines for non-compliance with the Regulation. These fines can amount to €20 million, or four per cent of global turnover. Dr Thompson said it is difficult to understand what the scale of these fines will mean for public sector organisations, but the intent behind the fining process is to demonstrate that the "regulation has teeth".

Dr Thompson then spoke about the scope of the Regulation. She said that as it only applies to personal data, the Regulation does not cover data that is fully anonymised. However, what constitutes anonymisation is not entirely straightforward, according to Dr Thompson, and member states currently take different positions on the issue. Pseudonymisation is now defined in the Regulation, however it is different than the definition that is typically used in research as there is no reference to the concept of "key coding", which is a method of de-identifying data.

"It seems that the definition of pseudonymisation in the regulation is somewhat broader than the concept of key coding that we would typically use in research. What that means, however, is not entirely clear."

Dr Beth Thompson

She added it is also not entirely clear on how pseudonymised data fits within the scope of the Regulation. In particular there is a lack of clarity around how to prioritise the line on "data which could be attributed to a natural person with the use of additional information, should be considered information on an identifiable natural person" with another line taking into account "the means reasonably likely to be used" to identify a person.

"What is not clear from this text is how we are meant to prioritise these two sentences and I think there is going to be a big challenge there for the national implementers of the legislation to work out how we piece them together and to what extent pseudonymised data fits within the scope and to what extent it can be considered to be outside the scope if sufficient protections are in place," according to Dr Thompson.

Dr Beth Thompson

Regarding consent, like the 1995 Directive, the Regulation states that consent is generally considered to need to be specific, explicit and informed. However, there is a Recital, without using the phrase 'broad consent', which refers to the fact it is not always possible to identify the information required from people at the beginning of a study. Although Dr Thompson said it is not contained in an Article of the Regulation, she stated there is a role for the European Data Protection Board, which will issue guidance on these issues, and at a national level, to define what valid consent means in the data protection context. Also, she said that the concept of "public interest" is not well defined in the text, and there is room for member states to introduce their own interpretation. Speaking about derogations from data subject rights, Dr Thompson said it is important that a balance is struck so the public understand that there are safeguards in place to protect their data while ensuring research can go ahead. Dr Thompson said the Regulation has preserved the "Status Quo" for health research in Europe. At the beginning of the negotiation process, she recalled there was the hope that the Regulation could have achieved a harmonised framework for health research to be carried out across the Continent. However, this ambition did not prove possible.

"So in a sense we lost out on harmonisation in order to secure a framework that is more liberal, or allows member states to introduce more liberal rules if they want to.That means we will have a fragmented patchwork system across Europe so we haven't really moved on from the Directive. It is a shame and it is disappointing but if we had a harmonised system across Europe we could only have done so if we made the rules a lot less liberal."

Dr Beth Thompson

As there are no major changes to data protection rules on research Dr Thompson said that researchers who are complying with the current legislation have nothing to fear, but that guidance is needed on issues such as pseudonymisation and scope before implementation takes place.

Regulations and Ethical Challenges

Professor David Smith

Associate Professor of Healthcare Ethics RCSI and Director of the MSc in Health Care Ethics and Law in RCSI

The next speaker was Associate Professor of Healthcare Ethics Royal College Surgeons Ireland Professor David Smith, who outlined the ethical considerations of research in light of the changing regulatory environment. According to Professor Smith, the principles of ethical conduct are integrity, respect for persons, beneficence and justice. He cited the World Medical Association Declaration of Helsinki, which states that while the primary purpose of medical knowledge is to generate new knowledge, the goal should never take precedence over the rights and interests of individual research participants. The Declaration, which was made in 2013, also states that medical research involving individuals must be conducted only by researchers with the appropriate ethics and scientific education, training and qualifications. Professor Smith then turned to the new EU Clinical Trials Regulation. He said that the message from Europe was that research ethics committee would not review the scientific evidence or scientific basis for the research. Professor Smith said the committees across the member states have pushed against this argument, noting that France has recently stated that their research ethics committees will also review scientific data.

Although he outlined the benefits of the new Regulation, such as streamlining and coordinating clinical trial processes, Professor Smith said it also marked an attempt at European level to limit the role of research ethics committees.

He argued that the harmonisation of ethical review across Europe was not possible, as different countries have different ethical

views and considerations. Other issues Professor Smith identified were the ethical audit of research and access to the EU Portal specified in the Regulation. Initially it was stated that research ethics committees would not have access to the EU Portal, although it has now been decided that they will be allowed to have access. Regarding the new Data Protection Regulation, Professor Smith explained that provisions in the new rules state that if it is practically impossible to inform someone of personal data use, then it is permissible to use it. This will serve to legally protect a researcher who makes use of thousands or millions of health records. Professor Smith also highlighted HSE guidelines from 2013 regarding research involving archival material. According to the guidelines, where archival biological material or data was obtained from persons for research or clinical purposes, where the material or data is not individually identifiable, and where there are no potential harms to the person from whom the material or data was obtained, consent requirements may be waived. Research ethics committees had the power to grant this waiver, however, the Health Information and Patient Safety Bill states the waiver can be granted by the Data Protection Commissioner, which is "a significant difference".

Professor Smith also mentioned issues around the ability of medical students attached to consultant teams as part of their training to access medical records. Another major developing issue, according to Professor Smith, is audit versus research.

> ***"We get a lot of stuff coming to the research ethics committees, which are plainly audit, but what the researchers are now requesting is a letter from the research ethics committee saying this is audit not research and they need that for publication. The research ethics committee still has to read it and that takes time."***
>
> *Professor David Smith*

Biobanks is another major ethical issue in the health research domain. Professor Smith said that the problem was that there is no legislation governing biobanks. The major areas of ethical concern regarding biobanks, according to Professor Smith, are broad consent versus specific consent, privacy and confidentiality and data sharing. He said there is an emerging consensus that broad consent with ethics approval and the right to withdraw from the study is acceptable if there is a continuous flow of information on the project developments between the institution and the individual. Professor Smith added it is essential that any limitations on withdrawal are clearly outlined as part of the informed consent process. Also, he said it is worth asking whether research governance committees are fit for purpose in the governance of biobanks, given the complexity of these facilities, or should another type of oversight mechanism be considered. Regarding the Health Information and Patient Safety Bill, Professor Smith explained that a major benefit for health researchers will be the creation of a single point of contact through HIQA, which will now be the supervisory body for approved research ethics committees, as well as obtaining a single ethical approval for national or regional health research. Clarity is needed, however, on the membership of the committees. According to the Bill, an approved research ethics committee must contain expert and lay members. Professor Smith said it was important to define what is meant exactly by 'expert' and 'lay'. He also asked where 'voluntary' research ethics committees fit in the new landscape.

Patient Registries: Beyond Epidemiology

Dr Edward McKone
Consultant Respiratory Physician in the National Referral Clinic for Adult Cystic Fibrosis, St Vincent's University Hospital, and Senior Clinical Lecturer, UCD

Consultant Respiratory Physician in the National Referral Clinic for Adult Cystic Fibrosis, St Vincent's University Hospital, Dr Edward McKone, spoke about the European CF Society Patient Registry, of which he is a Director. Over 65,000 patients are now currently enrolled in registries around the world. Approximately 1,200 of these patients are here in Ireland but Europe-wide, it has been estimated that the registry includes up to 35,000 patients. Dr McKone said that there are an increasing number of research papers related to registries. He cited a pivotal 1989 study comparing outcomes in a CF centre in Toronto to one in Boston. The paper identified significant survival differences, which was attributed to a different approach to nutrition in Toronto, where a high fat diet was employed and ultimately led to a change in the way CF patients were cared for. There was also a 2013 paper published in Nature Genetics, which consisted of a comprehensive analysis of 159 CFTR mutations. Genetic data was collated with clinical data from 25 country CF registries throughout the world, which led to the development of CFTR2, a resource for clinicians and patients to identify CFTR mutations that cause CF.

Dr McKone also said that the use of CF registries has allowed stakeholders to observe the increase in survival of patients with CF and mentioned a study showing CF survival in the US and Ireland was similar. He said that registries were now becoming useful beyond epidemiological purposes. A registry can become a tool for real-time monitoring of patients in clinics, according to Dr McKone, and clinicians are now able to provide detailed information to them on the trajectory of the disease. He added it can also

be used for quality improvement and bench-marking to see how well a centre is performing, what its areas of weakness are, and where improvements can be made. Registries are also a novel way to identify suitable patients for clinical trials. Dr McKone then described a new software programme, the ECFS Tracker, which is used for CF data collection for the European registry and was launched in January 2014. A similar tool is also used in Ireland. The software, which is web-based and open source, generates annual country and centre reports in real time.

The ultimate plan is to create a patient CF dashboard.

> ***"What it will mean is that when a patient comes into your clinic and you log on to your computer, all of this information comes up and you can click on it and you can expand a graph looking at their lung function and their nutrition over time. Then what we plan to do is format this in a way that will be patient-friendly, so we can print it out and give it to the patient and give them feedback regarding their disease condition. We'll have all the information that is needed at hand."***
>
> *Dr Edward McKone*

In conclusion, Dr McKone said that registries have led to a greater understanding of CF, largely through epidemiology research, but that now they are beginning to impact on patient care through encounter-based data entry and use, through quality improving and bench-marking and a better understanding of new drugs.

Panel Discussion with Audience Participation

How does the research environment need to be underpinned by legislation?

CHAIRED BY:

Dr Sarah Barry,
Research Fellow, Centre for Health Policy and Management, Trinity College Dublin/ Academic Editor for the HRB PhD Scholars Programme, TCD

PANEL MEMBERS:

Dr Patricia Clarke Lead Programme Manager – Policy and EU Funding, HRB

Dr Derick Mitchell CEO, IPPOSI

Dr Eucharia Meehan CEO, Irish Research Council

Professor Anthony Staines Professor of Health Systems, DCU

Dr Kieran Doran Senior Healthcare Ethics Lecturer, School of Medicine, University College Cork

Mary Fitzsimons Principal Physicist, Department of Medical, Physics and Clinical Engineering, Beaumont Hospital

For the discussion, **Dr Barry** asked panel members what was their biggest worry regarding this legislative agenda and were there any opportunities to progress the cause of health research in Ireland.

Dr Mitchell said that his biggest worry was the length of time policy development and legislation implementation take in Ireland. The slow process regarding the implementation of the Human Tissue Bill and the Health Information and Patient Safety Bill were typical of the legislative delays that occur in Ireland. Dr Mitchell said that opportunities were presented in the areas of patient registries and biobanking, but that patients needed to be included more in the health research conversation than they have until now.

Professor Staines said he was optimistic that there finally appears to be recognition among health leaders that the information systems used in hospitals and the health service in general are unfit for purpose. He explained that data for research should be a by-product of data for running a system. Professor Staines stated, however, that that there is clear evidence that healthcare is provided by organisations that put their own interests ahead of the interests of their patients, which is a continuing reason for pessimism. He argued that organisations do not understand how they can work to optimise patient outcomes because they fundamentally are not patient-centred in their philosophy.

Dr Doran said that he had grown "weary" of positions declaring the patient and the doctor are diametrically opposed to one another, and that the "us against them" dynamic had to end. He said that he was optimistic that this situation can be changed. Dr Doran stated that the information provided to patients was often too dense, with patient information leaflets often resembling "telephone books".

He said there is an opportunity for legislation to reinforce the common law rules of understand, retain, weigh and communicate so that the information provided to patients, when seeking consent for clinical trials and other health research initiatives, can be made more comprehensible.

Ms Fitzsimons said that patients need to be consulted more often about issues such as health research and data protection. She said not a lot of people give much thought to the area of data protection and there was an onus on healthcare leaders to raise awareness of the issue. Ms Fitzsimons said that although there were many challenges facing the health service, these could be overcome with proper planning. One opportunity she identified was the need to capture data at a patient's point of entry into the health service. This data could then be put to multiple uses, including research. Also, she said that there was the need for legislation in order for collaboration and information sharing to take place across the health service.

Dr Clarke said that data protection issues affect all corners of the health service, especially regarding research. She argued there was a need to agree on definitions so that health researchers can speak with a unified voice. Agreeing with the other speakers, Dr Clarke said there was a need for a broader range of groups to be part of the health research conversation. Large research projects,

such as Horizon 2020, provided the opportunity for health researchers to collaborate with colleagues to examine issues like integrated care and the intra-operability of e-health standards.

Dr Meehan said, like Dr Clarke, that there needs to be an awareness that Ireland is part of the wider European community. While it is important to develop our own patient databases and registries, she said that some other European countries were well advanced in these areas, and could provide models for Ireland to follow. For example, Dr Meehan said that Denmark was a global leader in the field of biobanking. She also said that there was the opportunity for clinical researchers to imbed gender considerations in their research, which is a growing field of interest.

Closing remarks

Professor Gerry Loftus

In conclusion, Professor Loftus said the meeting raised many interesting points regarding the relationship between legislation and health research. He said that the presentations and discussion highlighted how legislation is not going to provide "panacea" for researchers. Any legislation should reflect the informed will of the public, according to Professor Loftus. He added that the education of the public, in terms of health research and related issues, was vital.

Professor Loftus said that trust is a significant area in terms of health research. "It takes a long time to build up trust and a very short time to destroy it. It means we will have to work very hard to maintain trust to make sure we don't overstep the boundaries on consent. It requires constant vigilance and being very careful about the quality of information that we give."

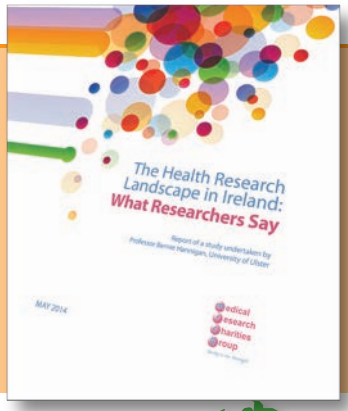
Also, Professor Loftus said it would continue to be a challenge for regulations to keep pace with developments in IT and technology, as already seen in the area of data protection.

Visit **www.ihrf.ie** to download Forum documents and view speaker presentations, videos and photos of the event.

IHRF **Factsheet**

About the Forum

The Irish Health Research Forum (IHRF) has been established by the Medical Research Charities Group (MRCG) on foot of their major report "The Health Research Landscape in Ireland: What Researchers Say". The IHRF is a partnership of organisations and stakeholders that aims to influence health research in Ireland and allows these bodies to work together to enable high quality research, to support research careers and to promote the involvement of service users. The Forum will consider key health research issues, identify constructive solutions and seek consensus at twice annual Forum meetings of Health Research stakeholders.



STEERING GROUP

The role of the Steering Group is to execute the work of the forum, to identify topics and issues for consideration and prepare for the Forum meetings.

Gerry Loftus, Chairperson, Emeritus Professor of Paediatrics, NUI Galway

Eilish McAuliffe, Professor of Health Systems, School of Nursing, Midwifery and Health Systems, UCD

Grace Cappock, Head of Communications and Public Affairs, MRCG

Maeve O'Brien, Research & Policy Officer, HSE Sexual Health & Crisis Pregnancy Programme, HSE

Lucy Cusack, Senior Policy Advisor, DJEI*

Rebecca Cramp, Scientific and Regulatory Affairs, IPHA

Jacinta Kelly, Chief Executive, National Children's Research Centre

Avril Kennan, Head of Research and Advocacy, DEBRA Ireland

Mairéad O'Driscoll, Director of Research Strategy and Funding, HRB*

Noelle Cotter, Institute of Public Health

Eucharia Meehan, Director, Irish Research Council

Fionnuala Hickey, Irish Research Staff Association

Conor O'Carroll, Consultant

Philip Watt, Chairperson, MRCG & CEO, CF Ireland

Martin O'Donnell, Professor, NUI Galway

Suzanne Miller-Delaney, Irish Universities Association

*DJEI and HRB have observer status on the Steering Group.

The IHRF is a partnership of organisations and stakeholders that aims to influence health research in Ireland

Previous Forum Meetings

Public and Patient Involvement (PPI) in Research
4th November 2014

PPI ensures the active involvement of the public in all forms of research by bringing together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.

Process to Prioritise Research Questions for Policy, Practice and Services
12th May 2015

The purpose of research prioritisation is to make the most efficient use of limited resources in order to meet organisational, national and international objectives and ensure that patients, service users and the wider economy benefit from research efforts.

If research is such a GOOD THING, why do we make it so HARD for researchers?
3rd November 2015

The purpose of this Forum was to lay out the career challenges facing researchers in the clinical and academic environment. It was attended by a wide range of key health research stakeholders, from researchers to funders, academic and health institutions, health charities and policymakers.

Documents from the Forum

The IHRF has produced valuable documents to assist our followers produce the best qulaity research they can. All are available on **www.ihrf.ie**

NOTES

Irish Health Research Forum
c/o MRCG, Digital Office Centre, 12 Camden Row, Dublin 8, Ireland
Telephone: + 353 1 4793234 www.ihrf.ie