

HRA LATEST

Firstly, welcome to our first newsletter. We are intending producing a free bimonthly online publication, giving news from across the research community, as well as updates on our activities. This issue summarises our Stakeholder Forum, held last month, as well as introducing two new functions transferring into the HRA from 1 April.

We would like this to be circulated as widely as possible; please ask any colleagues who may be interested in receiving this to <u>click here</u> to subscribe.

If you have any ideas for future articles, please email the editorial team at hra.comms@nhs.net; we are also very happy to publicise relevant initiatives and consultations for partner organisations.

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NEWS FROM HRA

Section 251

Section 251 of the NHS Act 2006 allows the common law duty of confidentiality to be set aside in specific circumstances where anonymised information is not sufficient and where patient consent is not practical.

This review function is transferring to the HRA from the NIGB on1 April 2013; full details can be found at http://www.hra.nhs.uk/hra-confidentiality-advisory-group/

TOPS

The Over-volunteering Prevention System (TOPS) is a database, free to all UK organisations undertaking phase 1 trials in healthy volunteers, that aims to prevent participants from taking part too often in trials of new medicines.

TOPS is currently run by an independent charity, but from 1 April 2013, its function is coming within the remit of HRA. It will become a standard condition of ethical approval, as well as part of the MHRA accreditation scheme, that all studies register research participants onto TOPs.

Full details on the scheme can be found at http://www.tops.org.uk/site/cms/contentChapterView.asp?chapter=1, which will be transferring across to www.hra.nhs.uk before 1 April.

HRA STAKEHOLDER FORUM





The HRA's first Stakeholder Forum, marking our first year of operation, took place on 6 and 7 February. We invited a wide range of people to the event including researchers, people representing patients and the public and those involved in the regulation and governance of health research, with almost 150 people attending across the two days. The feedback was overwhelmingly positive, with comments including 'I am reassured the HRA are working really hard to improve things and are so forward-thinking' and '[The HRA] asking people what they think and how we should do things is a welcome change.'



"Thank you to all those who attended and participated so enthusiastically.
The HRA can do much on its own, but its real success will come through - we are all part of the solution."

Our objectives for the Forum were for delegates to:

- Understand our ambition to make it easier to do good quality research in the NHS
- Hear what work we have delivered in our first year
- Learn about the projects within the remit of the HRA Collaboration and Development programme
- Be involved as we take this ambitious programme of events forward

All the presentations are at http://www.hra.nhs.uk/hra-news-and-announcements/hra-stakeholder-forum/; the section below gives a flavour of the discussions

Keynote presentations

lain Chalmers of the James Lind Initiative gave a thought-provoking evidence-based demonstration of how <u>regulation of therapeutic research is compromising the interests of patients</u>. His explanation of how regulation can be harmful was particularly relevant to the HRA projects to support transparency in research, including the HRA proposed practical solution to urge others to use the IRAS number and a common study title so that research can be identified. (<u>more</u>)

Adrienne Clarke of Glaxo SmithKline (GSK) welcomed recent improvements in metrics and challenged the stakeholders present to simplify the research approvals process in the UK to enable the UK to grow its share of world research. Her presentation, entitled Commercial research in the NHS - A commercial perspective recognised improvements that had been made, including those by NRES as well as demonstrating the relevance of the HRA agenda to make it easier to do good quality research in the UK (more)

Jane Robertson of the National Institute for Health Research (NIHR) gave <u>a funder</u> <u>perspective</u> supportive of the role and remit of HRA, citing great variation in the time it took to get studies from funding through to set up and successful completion and the NIHR support to working with the HRA to tackle issues and make timelines more predictable as well as shorter. (more)

Bill Davidson of the Department of Health (DH) explained <u>the government agenda</u> for delivering faster, easier clinical research, driven by improving outcomes and quality of care for people, and the direct relevance of the HRA agenda. (<u>more</u>)

Jonathan Montgomery, HRA Chair, outlined the remit and ambition 'to make the UK a great place to do research, where more money invested in research goes into carrying out relevant, good quality research' – research that makes a difference to people's health and how the role of the HRA to protect and promote the interests of patients and the public sits within the remit. (more)

Janet Wisely, HRA Chief Executive, expressed her vision of making it easier to do good guality research by working collaboratively with partners to review the whole research journey, and to resolve issues rather than move them from one part of an overall journey to another. Janet gave an overview of the HRA business plan which will be published shortly on the HRA website. (more)

Workshops

The workshops (all available at http://www.hra.nhs.uk/hra-news-and-announcements/hra-stakeholder-forum/) were in three blocks.

Practical HRA solutions provided more detail on a number of the initiatives Janet Wisely had outlined in her main presentation. These included proposals to standardise study titles and identifying number, improve the way amendments are treated and stressed the importance of collaborative working. (more)

HRA collaboration and development projects covered those projects being overseen by the Collaboration and Development Steering Group. These intensive and highly interactive 15 minute sessions were likened to speed dating by delegates! (more)

The final series of workshops explained how attendees could be involved in making our 2013 projects a success. These workshops sought detailed views on HRA initiatives including the specification for a new integrated application and approval system. (more)