UK CLINICAL RESEARCH COLLABORATION
igniting our potential

Media Release

FOR IMMEDIATE RELEASE

Monday 21 November 2011

Patients and GPs encouraged to give researchers access to health records

The public are being encouraged to give researchers access to their health records to help provide vital insight into what causes illness and the steps that can be taken to develop healthcare that benefits everyone.

Research using health data helped scientists discover the link between smoking and lung cancer, has helped women make safe choices about using hormone replacement therapy and has improved the treatment of cancers, diabetes and asthma. It has found people for trials of medicines and healthcare and benefitted many people taking part in them, and has also helped us measure how successful our health services are, and continue to improve them.

Today sees the launch of a patient information booklet entitled “Your health records save lives”, which explains why access to health data is so important, how the data is used and the safeguards that exist to ensure that the data is used responsibly. The leaflet seeks to build on existing support and address concerns, such as those around data security.

The booklet has been produced by the UK Clinical Research Collaboration (UKCRC), a partnership of organisations working together to establish the UK as a world leader in clinical research by harnessing the potential of the NHS, and will be sent to over half the GP surgeries across England, Wales and Scotland.

The leaflet was developed with the input of patient groups and GPs in response to a market research commissioned by the UKCRC that found a favourable attitude amongst patients to providing access to their records, but reluctance amongst some GPs. Doctors cited time and cost as the primary reasons behind their reluctance: they felt that their time should be focused on care-giving, which is their primary responsibility. They also voiced concerns about the use and abuse of data, particularly electronic data.

Professor Sir Harry Burns, Chief Medical Officer for Scotland, says: “We have used patient data safely and effectively in Scotland for many years to understand population health, test the long term effectiveness of new treatments and evaluate the impact of public health measures. By helping people understand how health records can be used for life-saving research, the booklet will enable us to make the most of this potential in future.”

Professor Keith Lloyd Head of the National Institute for Social Care and Health Research (NISCHR), Wales says: “Putting people at the heart of research and making it easier to develop new treatments is a common goal for us all. This initiative will help with this process."

Researchers use data in different forms: identifiable data – information that identifies the patient and is used to find people to take part in trials, or answer extra questions about their health history; and anonymised data – information that cannot be traced back to a person's patient records, making it impossible to identify that person.

The UK has strict regulations to prevent the abuse of date. The Data Protection Act 1998 means that researchers face disciplinary action, or even prosecution, if they do not use patient data responsibly. An ethics committee, made up of members of the public and professionals, assesses the risks and benefits of individual research studies before they can go ahead. When people can be recognised by their data, only specific people can see the information and in a secure place.

Philippa Cowley-Thwaites is one of half million people over 40 who have allowed researchers at UK Biobank to access her records for research. She hopes that the data will allow researchers to improve the prevention, diagnosis and treatment of a wide range of serious and life-threatening illnesses.

"I answered lots of questions about my health history and lifestyle, and gave samples of my saliva, urine and blood," explains Philippa. "It was so easy to do. Over the coming years all our data will be regularly analysed to spot trends in illness and how lifestyle might affect health. If studying my history helps prevent people getting Alzheimer's, the way my dad did, or any disease, come to that, I'm all for it."

[Ends]

Contact:

Jen Middleton
Media Officer
The Wellcome Trust
T: 020 7611 7262
E: j.middleton@wellcome.ac.uk

Notes for editors

Key developments made possible through access to patient data:

- 1950s – Health data played a major part in uncovering the link between smoking and lung cancer
- 1960s – Patient data was used to establish the connection between the prescription of Thalidomide to expectant mothers and children born with birth defects
- 1970s – Several famous studies, using data, highlighted the increased risk of coronary heart disease and stroke among people with high blood pressure
- 1980s – Analysis of health data helped researchers identify that the HIV/AIDS virus may be passed from person to person by infected needles, contaminated blood and unprotected sexual intercourse

- 1990s – The health data of children with autism born since 1979 in eight UK health districts, helped scientists find out that there is no link between the measles, Mumps, Rubella (MMR) vaccination and autism
- 2000s – Researchers analysed data relating to the first 252 cases of swine flu to identify common symptoms, and the age groups most prone to the virus, helping them take steps to stop it spreading more widely
- 2010s – The EPIC (European Prospective Investigation of Cancer) study is following the eating and lifestyle habits of over 500,000 people in Europe, over many years, to unravel the link between diet, lifestyle and cancer risk. It has already discovered that alcohol causes at least 13,000 cases of cancer each year in the UK

About the UKCRC

The UK Clinical Research Collaboration (UKCRC), established in 2004, is a partnership of organisations working together to establish the UK as a world leader in clinical research by harnessing the potential of the NHS.

The Partners include the key stakeholders that shape the health research environment, including research funders, the NHS, government, industry, academia, regulators, charities and patients.

- The Association of British Healthcare Industries (ABHI)
- Association of the British Pharmaceutical Industry (ABPI)
- The Academy of Medical Sciences (AMS)
- Association of Medical Research Charities (AMRC)
- Academy of Medical Royal Colleges (AOMRC)
- BioIndustry Association (BIA)
- Department for Business Innovation and Skills (BIS)
- Cancer Research UK (CRUK)
- Department for Employment and Learning Northern Ireland
- Department of Health (DH)
- Higher Education Funding Council for England
- Higher Education Funding Council for Wales
- Economic & Social Research Council (ESRC)
- INVOLVE
- Medicines and Healthcare products Regulatory Agency (MHRA)
- Medical Research Council (MRC)
- NHS Confederation
- National Institute for Clinical Excellence (NICE)
- National Institute for Health Research (NIHR)
- HSC Research and Development Division, Public Health Agency for Northern Ireland
- Scottish Government Health Directorates
- Scottish Funding Council
- Strategic Health Authorities (SHA)
- The Wellcome Trust
- Welsh Assembly Government

Detailed information on UKCRC activities can be found on the UKCRC website at www.ukcrc.org