PRESS RELEASE FROM GENETICS IN MEDICINE

(http://www.nature.com/gim/)

For a paper that will be published online on 21 March 2012

This press release is copyrighted to the journal *Genetics in Medicine*Its use is granted only for journalists and news media receiving it directly from the Nature
Publishing Group

*** PLEASE DO NOT REDISTRIBUTE THIS DOCUMENT ***

EMBARGO:

1500 London time (GMT) / 1100 US Eastern time Wednesday 21 March 0000 Japanese time / 0200 Australian Eastern time Thursday 22 March

Wire services' stories must always carry the embargo time at the head of each item, and may not be sent out more than 24 hours before that time.

Solely for the purpose of soliciting informed comment on this paper, you may show it to independent specialists - but you must ensure in advance that they understand and accept the embargo conditions.

A PDF of the paper mentioned on this release can be found in the Academic journals section of http://press.nature.com. Press contacts for the journals are listed at the end of this release.

Warning: This document, and the Academic Journal paper to which it refers, may contain information that is price sensitive (as legally defined, for example, in the UK Criminal Justice Act 1993 Part V) with respect to publicly quoted companies. Anyone dealing in securities using information contained in this document or in advanced copies of *Nature*'s content may be guilty of insider trading under the US Securities Exchange Act of 1934.

PICTURES: While we are happy for images from *Genetics in Medicine* to be reproduced for the purposes of contemporaneous news reporting, you must also seek permission from the copyright holder (if named) or author of the research paper in question (if not).

HYPE: We take great care not to hype the papers mentioned on our press releases, but are sometimes accused of doing so. If you ever consider that a story has been hyped, please do not hesitate to contact us at press@nature.com, citing the specific example.

PLEASE CITE THE JOURNAL *GENETICS IN MEDICINE* AS THE SOURCE OF THE FOLLOWING ITEM. IF PUBLISHING ONLINE, PLEASE CARRY A HYPERLINK TO www.nature.com/gim/

Guidelines for return of results: how to communicate with participants who donate to biobanks

DOI:10.1038/gim.2012.23

The growth of large-scale genetic and genomic research using biobanks and archived datasets has further fuelled the debate over whether and how to discuss individual research results and incidental findings with research participants. In a special article published online this week in *Genetics in Medicine*, 26 researchers propose that biobanks should shoulder significant responsibility for managing the findings that arise from such research studies.

Susan M. Wolf and colleagues write that biobanks need to play a major role in setting up a system to handle these findings, whether arising at sites collecting participants' samples, the biobank where samples and data are stored, or in the research conducted elsewhere with these samples and data. If

biobanks are designed so that individuals who contribute specimens and data are identifiable, the authors maintain, then findings that are analytically valid, reveal an established and substantial risk of a serious health condition, and are clinically actionable, should be communicated back to the participants who consented to receive this information. Also recommended is that broader findings—such as those revealing an established and substantial risk that is of likely health, reproductive, or personal importance—may be offered back to consenting participants.

Wolf and colleagues urge that the question of return of individual results in biobank research be better addressed by researchers, their institutions, research funders, and authorities who oversee research practice, as well as the individuals involved in the research. These questions of whether to offer incidental findings and individual research results to research study participants are of wide and general concern, and this piece will be published in print, as part of the April special issue, alongside other articles and commentaries delving into similar issues.

Author contact:

Susan M. Wolf (University of Minnesota, Minneapolis, MN, USA)

Tel: +1 612 625 3406; E-mail: swolf@umn.edu

Editorial contact:

Jan McColm (Managing Editor, Genetics in Medicine, Bethesda, MD, USA)

E-mail: gim@acmg.net

Media contact:

Kathleen Beal (Director of Public Relations, American College of Medical Genetics, Bethesda, MD, USA)

Tel: +1 301 238 4582; E-mail: kbeal@acmg.net

Press contacts:

For media inquiries relating to embargo policy for the journal, Genetics in Medicine:

Neda Afsarmanesh (Nature New York)

Tel: +1 212 726 9231; E-mail: n.afsarmanesh@us.nature.com

Ruth Francis (*Nature* London)

Tel: +44 20 7843 4562; E-mail: r.francis@nature.com

About Nature Publishing Group (NPG)

Nature Publishing Group (NPG) is a publisher of high impact scientific and medical information in print and online. NPG publishes journals, online databases and services across the life, physical, chemical and applied sciences and clinical medicine.

Focusing on the needs of scientists, *Nature* (founded in 1869) is the leading weekly, international scientific journal. In addition, for this audience, NPG publishes a range of *Nature* research journals and *Nature Reviews* journals, plus a range of prestigious academic journals including society-owned publications. Online, nature.com provides over 5 million visitors per month with access to NPG publications and online databases and services, including *Nature News* and *NatureJobs* plus access to *Nature Network* and *Nature Education's* Scitable.com.

Scientific American is at the heart of NPG's newly-formed consumer media division, meeting the needs of the general public. Founded in 1845, *Scientific American* is the oldest continuously published magazine in the US and the leading authoritative publication for science in the general media. Together with scientificamerican.com and 15 local language editions around the world it reaches over 3 million consumers and scientists. Other titles include *Scientific American Mind* and *Spektrum der Wissenschaft* in Germany.

Throughout all its businesses NPG is dedicated to serving the scientific and medical communities and the wider scientifically interested general public. Part of Macmillan Publishers Limited, NPG is a global company with principal offices in London, New York and Tokyo, and offices in cities worldwide including Boston, Buenos Aires, Delhi, Hong Kong, Madrid, Barcelona, Munich, Heidelberg, Basingstoke, Melbourne, Paris, San Francisco, Seoul and Washington DC. For more information, please go to www.nature.com.