WELLCOME TRUST MONITOR 1: KEY POINTS

The Wellcome Trust

We are a global charity dedicated to achieving extraordinary improvements in human and animal health. We support the brightest minds in biomedical research and the medical humanities. Our breadth of support includes public engagement, education and the application of research to improve health. We are independent of both political and commercial interests.

While we aim to tackle immediate priorities, our independence and long-term perspective also enable us to support research that will benefit future generations.

We seek to improve understanding of the ways science and medicine have developed, and how research affects people and society today. Medicine and science have entered most spheres of modern-day life. By their very nature, they offer great promise, yet they challenge cultural norms, beliefs and personal choices. We want to encourage people of all ages and from all walks of life to consider, question and debate the key issues of now and the future. Through our education programme we work to support teachers and inspire young people to enhance scientific literacy for all.

To enable us to do this it is important that we understand the spectrum of views held by the public. The Wellcome Trust Monitor data will be used to support our work in this way. As well as being of value to us, the report and data will be widely disseminated; we hope that it will be used by policy makers and researchers across government, charity and academic sectors.

The survey collected data across a wide range of areas and issues in order to provide a broad baseline of measures for the future. The aim of this document is to highlight some of the findings from the first survey that we have found of particular interest. We would be delighted to hear your thoughts on both the project and the findings. Please let us know what you have found interesting and the implications of this for you, your organisation or future work in this area. Also, any comments you would like to make with regards the second wave of the survey, which we will be planning soon, would be welcomed. Please email these to: monitor@wellcome.ac.uk.

The full dataset is available through the Economic and Social Data Service archives: www.esds.ac.uk.

The survey

The Wellcome Trust Monitor is a unique survey of UK adults' and young people's views of medical research and seeks to develop a more systematic approach to describing and understanding trends in public interest, knowledge and attitudes towards medical research and its associated advances and applications.

The survey will be repeated every three years in order to contribute to and build over time a robust, high-quality evidence base to allow for the collection of data to explore trends and variations across time on both general themes and specific issues. The data from this first wave of the survey will provide a useful baseline against which changes in attitude can be traced over time.

The Monitor questionnaires have been developed to provide time series data, yet also be flexible and responsive. Future surveys will thus include both core tracking questions (i.e. questions that will be repeated on each wave of the survey) and additional questions to cover new issues and areas as they emerge.

As well as incorporating the questions about medical research as administered to the adult sample, the Monitor will also track changes in young people's (14–18 years) attitudes to school science education, motivations and barriers to learning science and perceptions of careers in science more generally.

The Monitor is unique in that it:

- focuses on medical research and its applications
- provides detailed intergenerational data and comparisons by including both adults and young people
- will provide reliable tracking data and determine trends over time in relation to public awareness, knowledge, interests and attitudes to medical research.

The survey was conducted on behalf of the Wellcome Trust by NatCen. Interviews were conducted in 2009 with 1179 adults aged 18+ and 374 young people aged 14–18. All interviews were conducted in respondents' homes and lasted 45 minutes. A random stratified sampling approach was used.

Findings of particular interest to the Trust

It is not possible to present all the findings that are of interest to us across this first survey. However, in reviewing the results, several points of particular interest were apparent.

• The strong support for and willingness to participate in medical research

The Monitor shows there are extremely high levels of support for the public funding and conduct of medical research in the UK and of willingness to participate in research projects. It is important and gratifying to know that this is the case and that the work of medical research charities and the wider research endeavour is so highly valued. However, although the Monitor shows strong public support, we cannot assume that these levels can be guaranteed in the future. The data from this first wave of the survey will provide a useful baseline against which changes in attitude can be traced over time.

Of particular note is that nearly three-quarters of adults are willing both to donate tissue samples and, if anonymity is guaranteed, to allow access to their personal health information for medical research purposes. Yet, the public is far less willing to participate in clinical trials if healthy. It would be interesting to explore the factors affecting this, for example, whether this is as a result of media coverage of the Northwick Park Trials in 2006, or whether there are low levels of awareness of the need for healthy people to take part, or whether other reasons apply. Although willing to participate in research, people are not without concerns. The data demonstrate the need for effective communication with potential participants around issues of data confidentiality, the governance and regulation of projects, their benefits and purposes, and, in the case of clinical trials, the risk of harm.

• The level of interest in medical research

The public has an appetite for, and demonstrates an interest in, a wide range of medical research areas and related issues. However, the majority need to be motivated by personal saliency to actively seek information. For adults this is primarily a diagnosis of disease of either someone that they know or themselves. Young people are most likely to seek information relating to an area of their studies, which demonstrates the importance of science education as a vehicle for developing a wider interest in medical research. These factors should be used as 'hooks' to increase wider engagement and should be taken into account when planning activities.

People are most interested in the development of new drugs and vaccines and physiological issues, such as how the body and brain work. Further key areas of interest related to mental health issues, how genes work and how they affect diseases. This is of particular interest as to date many engagement activities have tended to focus on areas of innovation and those areas deemed contentious. The Monitor data demonstrate a need for activities that focus more specifically on areas of interest to the public.

• The ways of accessing information

Both adults and young people primarily use internet search engines to seek information. Although the users are primarily seeking medical advice, information about medical research more explicitly is widely sought. In nearly all cases people reported that they had found the information they were looking for with ease and had found it useful. It would be pertinent to explore in more depth which websites are accessed, the validity of information found and whether the information about medical research provided is understandable to the lay reader.

Despite the primacy of the internet, television (both factual and fictional programmes with a scientific storyline) and to a lesser extent newspapers remain critical in disseminating information about medical research.

Thought will need to be given to how information is communicated and how audience reach is maximised given the future evolution of television across multi-media platforms and the increased availability of programming on demand.

• The degree of trust in relation to medical research

A mismatch exists between reliance on the media to be kept up-to-date and very mixed views about the accuracy of media reporting (and a lack of trust in journalists more broadly). Advances have been made in terms of the reporting of science in recent years, including the number of dedicated science journalists and an increase in the number of scientists engaging with the media. It is to be hoped that these changes will provide a foundation that helps to promote the need for effective, responsible and better-informed media reporting.

Medical practitioners, scientists working in universities and medical research charities are the most trusted individuals and organisations to provide reliable and accurate information about medical research. This clearly demonstrates the value of scientists participating in public engagement and the importance of work done to support scientists to enable them to do so.

• The level of understanding of the research process and terminology

The Monitor has illustrated that a majority of both adults and young people lack a clear understanding of the nature of the scientific process. As a priority there is a need for widespread engagement around 'how science works', and an increased focus on this within school science. Also, terms such as DNA and stem cell are not generally understood. As good practice, where scientific terms are used these should be prefaced by clear, descriptive explanations.

• The high expectations for future advances

The public take a utilitarian view of medical research and have very high expectations for future advances within a short timeframe. A majority believe cures for cancer, HIV/AIDS and schizophrenia will either "definitely" or "probably" be found within 50 years. There are also very high levels of optimism in relation to the potential advances that genetic research will bring. Indeed, a public concern identified in the Monitor is that research is not progressing fast enough. This signals a need for clear messages around potential timescales for delivery to market, and as noted above increasing understanding of the incremental nature of the scientific process.

The data relating to the expectations for cures of specific diseases highlight that the public differentiate between physical and mental diseases. Far fewer adults and young people thought that a cure for schizophrenia would be found than for cancer and HIV/AIDS. Given the high levels of public interest in how the brain works and mental health issues, it could be of use to explore the nature of this differentiation and better understand why this is the case.

• The plurality of beliefs

Although there is very strong support for medical research there is evidence of a plurality of views among the public. A significant minority believe that homeopathy is as good as, or better than, conventional medicines. Nearly a fifth of the public reject evolution, believing that living things were created by God and have always existed in their current form. This clearly demonstrates that this is no time for complacency and the need for both good-quality public engagement and science education.

• The attitudes to science education

Young people's perception of and interest in school science is of critical importance to the future, both in terms of retaining the UK's prominence as a world leader of science, and in increasing levels of scientific literacy more generally. The Monitor strongly demonstrates that young people are interested in and engaged with school science. This may be a sign that national STEM education initiatives are beginning to have a positive effect. However, there is room for improvement in terms of increasing the number who find school science "very" rather than "fairly" interesting. Over time the data will help us to assess whether changes have occurred and whether success is being achieved.

Both the quality of teaching and the opportunity to conduct practical activities are shown to be critical to the enjoyment of and motivation to learn science. Such a finding reinforces the continuing need to support the provision of high-quality subject-specific professional development for science teachers through the national network of Science Learning Centres¹ and Project Enthuse.²

The Monitor also challenges the assumption that interest in science decreases between primary and secondary school, with young people overwhelmingly finding secondary science of more interest. Only limited questions were included about this on the Monitor. It is an area where further research to explore this in more depth would be useful.

¹ The network of Science Learning Centres consists of the National Science Learning Centre, funded by the Wellcome Trust, and nine regional centres funded by the Department for Children, Schools and Families.

² Project ENTHUSE is a partnership between the Wellcome Trust, the Department for Children, Schools and Families and industrial partners: AstraZeneca plc, AstraZeneca Science Teaching Trust, BAE Systems, BP, General Electric Foundation, GlaxoSmithKline, Rolls-Royce, Vodafone plc and Vodafone Group Foundation.

• The attitudes to careers in science

Young people are also very positive about careers in science, believing that these would be inherently interesting, and that science offers a diversity of jobs and the chance to make exciting discoveries. This was true even among those who themselves were not interested in a future career in science. The Monitor data identify a link between levels of interest in a scientific career and those in school science, highlighting the importance of engaging young people through formal education. However, although young people are positive about careers in science, this does not follow through into the current numbers choosing to take up employment in science. This would point to a need for research to better understand why this occurs. Levels of parental interest in science also were found to impact on young people's views of scientific careers, this finding clearly demonstrates the need and value of public engagement.

In summary, the key findings for the Wellcome Trust are:

- the very positive attitudes towards the medical research endeavour in the UK
- young people's attitudes towards school science education are more positive than previous research has suggested
- however, given the above, there is still work to do across both public engagement and formal science education.

Please do let us have your comments on the project or findings. Email: <u>monitor@wellcome.ac.uk</u>.