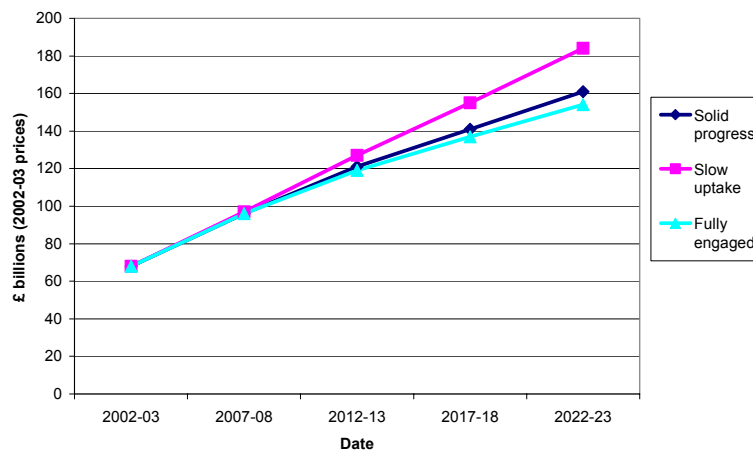


GeneWatch submission to the Cooksey review July 2006

GeneWatch UK is a policy research group concerned with the science, ethics, policy and regulation of genetic technologies. We are concerned that health research funding decisions have tended to prioritise genetic and biomedical research over potentially more useful public health research. We welcome the opportunity to respond to the current review and hope that it will include proposals to address this imbalance.

- The 'wealth creation' model of science and technology almost entirely ignores the enormous potential benefits of public health research. Not more than 0.4% of current academic and research output is relevant to public health intervention research¹.
- A scenario in which the public are "fully engaged" in disease prevention could save billions as well as improving health².

NHS spending (Wanless scenarios)



- The pharmaceutical industry and other industries, including the tobacco and food industries, develop and implement R&D strategies based on their own strategic interests. Research that does not lead to marketable products or is of little scientific interest is unlikely to be funded³.

A possible consequence [of the low status of public health] is that pharmacological solutions might become the focus of primary prevention with considerable financial implications. Substantial investment, or reprioritisation, is necessary if this imbalance in research funding is to be addressed. Wanless, 2004⁴.

- Government develops its own health priorities and policies but does not link *health policy* and the needs of the NHS with *science policy* and funding decisions.

“The dearth of [public health] evidence is not unrelated to the lack of funding of public health intervention research - with funding from research organisations and the private sector heavily directed towards clinical, pharmaceutical, biological and genetic research – and the lack of a clear and coherent set of Government priorities for the public health research which does exist”. Wanless, 2004⁴.

- Government also appears to lack the capacity to assess the relative merits of different research strategies and their implications for health policies. For example, UK Biobank has been criticised by many geneticists and others^{5,6,7}. The underlying health strategy (“genetic prediction and prevention”) will not work for most diseases in most people⁸ and has cost implications which have been described as “staggering”⁹.

“[The Director of the US National Human Genome Research Institute] and many others have outlined scenarios where all individuals have a battery of genetic tests early in life so that the knowledge of ‘susceptibility’ can be used to avoid development of disease. Biomedical sectors would profit from acceptance of the above approach, but it is doubtful whether it is the approach most likely to increase the health of populations.” Professor Patricia Baird, Department of Medical Genetics, University of British Columbia, Canada⁸.

- The major public health challenges of tobacco and obesity will be tackled most effectively by a public health approach, not by genetic research.

“...it is vital that the more conventional approaches of epidemiology and public health, particularly as they relate to tobacco-induced diseases and other aspects of lifestyle, continue to be pursued with vigour. This is particularly important as there are still major uncertainties about the predictive role and cost of genomics for controlling common diseases.” World Health Organisation, 2002¹⁰.

“A variety of social and situational factors have influenced the increasing trend in obesity. These are important to consider as, whilst there may be an interaction between individual genetic make up and environment, this in no way accounts for the dramatic trends in overweight and obesity. The current trend in obesity is attributable to two factors: diet and physical activity.” Wanless, 2004⁴.

- The Government’s new science Framework makes a welcome commitment to ensuring that the publicly-funded research base responds to the needs of public services as well as the economy, but it identifies no mechanisms to achieve this.
- The public should be involved in setting medical research priorities and health strategies^{11,12}. This is particularly important in public health, where public reactions and compliance are critical to the success or failure of different strategies. Without public involvement it will be impossible to answer the question posed by the Wanless review: “What are the priorities in public health over the next 20 years that will help us to meet the fully engaged scenario?”. The Science Framework’s proposals to involve the public in decisions about science are welcome but need to move ‘upstream’ to include decisions about research priorities.

- The Cooksey Review should consider institutional arrangements that: (i) redress the imbalance between research focused on marketable products and research that takes a public health approach to reducing the incidence of common diseases; (ii) utilise new mechanisms to involve members of the public in helping to determine research priorities; (iii) develop incentives for investigators to study issues of public health importance, particularly where there is no commercial incentive to do so; and (iv) consider the potential adverse impacts on research priorities of existing systems of research reward (including gene patenting; research assessment exercises and incentives to attract commercial funding); (v) consider how to retain the scientific capacity to assess the validity, utility, efficacy and safety of new innovations independently of commercial interests.

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