Genocentric promises

The latest wonder of the world is unveiled: the human genome is ‘completely’ sequenced. Presidents and prime ministers lauded the participants and stressed the importance of this undertaking in their profound public statements. The public attention was captured as well by the media’s portrayal of the human genome project as a race between the good and the bad guys. Just as the race to the moon was presented as the free society of the USA versus the totalitarian regime of the USSR, the sequencing of the human genome was an event with the public-minded and -funded efforts thrust against the ‘greedy’ industrial competitor: one would make the sequence freely available for everybody, the other would do so only after it had milked it for its financial benefits. The strange reality, however, is that both sides relied on results from each other to achieve the goal of a nearly complete sequence. If the whole enterprise is to be characterized as a race, then it was a relay race with the baton being passed back and forth from one team to the other. However, TIME Magazine has declared Craig Venter and Celera to be the winner and, as all who have finished second know, is likely to be what the public will remember in the future.

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The TV commentators from all over the world sent out a simple message that day: the Book of Life has been published and the medical community now has only to turn to the correct page to find the cure for whatever disease is the speciality of the ‘well-known scientist’ in front of the camera. Alzheimer’s disease, cancers of all parts of the anatomy, premature ageing, heart attacks—all would be dealt with smartly by using this new encyclopaedia. But in the midst of this hoopla, there are reasons to become concerned about this optimistic view. One particular concern is that this completely genocentric view implies a simple correlation: ‘dodgy gene equals disease’. Science has shown that most diseases are more complex than this simplification. But the way sensation-hungry editors and producers in the media have played this story to the public means that many people will now accept the idea of a direct and unambiguous link between diseases and particular genes. Not too long ago, it would have taken a major effort to convince people that genes had any role to play.

Another concern is that the public may believe the promises of the scientists and may soon feel deluded. In crude terms, the deal to finance the human genome project was: ‘give us the money to sequence the human genome and we will find cures for all ailments.’ Well, it will be payback time soon and we can just hope that the public will understand when its ‘new heroes’ explain that they have found not a single miracle cure yet. To know the sequence of the human genome is, of course, incredibly important for scientists, but it will require considerably more research efforts to convert it into something of practical benefit. A hammer is an essential tool in construction but it requires more than a hammer to build a house. And while we await the cures for all human ailments to arrive piece-meal, the public, who are currently the funders of research, will have to get accustomed to a new and hopefully more realistic message that stresses the difficulties and the unpredictable ways of discovery. In a positive presentation, this new message should highlight the need for continued basic research as a means of accumulating the knowledge on which progress is ultimately based. To ensure that the public will not react with cynicism and disbelief to requests for more support, now that the major project has been ‘finalized’, we must make sure that it develops a more balanced understanding of how research progresses.

In fact, despite the waving of the cheque-quered flag to announce the end of the race, the great undertaking for science and society has actually just begun. Although it was a spectacular achievement of international research groups, the accumulated mass of sequence data is but the first step toward the promised cures. Only the parsing, analysing and annotating of the collected data will produce the necessary knowledge to tackle most diseases. Most probably there will be no champagne celebrations for the heroes who do this work. Indeed, and perversely, the provision of funding for the major European node in this work, the European Bioinformatics Institute (EBI), has been severely compromised during the past years in the development of the fifth Framework Programme. And this is the bioinformatics institute that has, in co-operation with the Sanger Centre, developed Ensembl, an automated annotation system for the human genome. What incredibly bad timing!

If Europe wishes to continue playing its crucial role in keeping the information that comes with analysing the human genome sequence in the public domain, then solutions to those administrative problems have to be found promptly. There are many roles for other groups world-wide in the early ‘post-genomic’ era. They must cooperate fully if the benefits from analysing the sequence of the human genome are to be reaped efficiently. It is hoped that those responsible for the funding of research will recognize these needs and will provide new scales of funding for at least this aspect of the life sciences. This would allow scientists to use the wonderful new opportunities that flow from the availability of the human genome sequence for the benefit of all.

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