QUESTIONS ANSWERED:

Question 01 - Health care as a consumer good

ANSWER:

Yes - freedom of choice - right to self-determination, proactive health care - potential for prevention and to reduce overall public health burden

Question 02 - Validity of information

ANSWER:

No. If people wish to access their own genomic information, why not? It's their own information, no-one else's. Given the mess surrounding scientific substantiation of health claims under the EU nutrition and health claims regulation, I wonder if anyone would want to go down that route. Is the claim a lie? If not, then why ban it? Perhaps a warning label to say that information has not been endorsed, cf FDA, but what if the info turns out to be validated? What about the harm of banning information which could have helped an individual?

Question 03 - Prevention

ANSWER:

What about cosmetogenomics? When genotype beauty treatments become available, they won't need encouragement, it will probably be a stampede. Those interested in lifestyle and health don't need to be encouraged, they just do it.

Question 04 - Who pays?

ANSWER:

Earlier diagnosis is usually followed by cheaper intervention. Pharmacogenetic testing is a way to ensure that if your GP does prescribe a drug, the individual can check that it has been properly prescribed to suit them.

Question 05 - Your experiences

ANSWER:

No - but hope to. Easy format, personal control. Not likely to end up open access on the internet, or details found in some NHS car park in Slough. Can't imagine anyone would want their personal genome on an NHS server.

Question 06 - Your experiences

ANSWER:
Quick, no waiting for hours in GP surgery if its not necessary. Especially if it means taking time off work.

Question 07 - Your experiences

ANSWER:
No. If it were cheaper and I needed the drug, then I would get generic or cheapest source.

Question 08 - Advertising health care products

ANSWER:
yes - as long as they meet the provisions of the Unfair Commercial Practices Directive

Question 09 - Your experiences

ANSWER:
No - depends on the nature of the test and the information you may get from it.

Question 10 - Who pays?

ANSWER:
Yes - why would it necessarily be more expensive? Telemedicine can be used by more than those in rural locations. Saves waiting room time.

Question 11 - Your experiences

ANSWER:
Yes. Personally and professionally very useful. First test used was Sciona You and Your Genes - good little profile but the advice was pretty basic. Other tests, Genovations, good but expensive but are not available direct to public.

Question 12 - Regulation

ANSWER:
Self-profiling is already available. 23andme and the like offer direct access to

raw data and dynamic profiles, which can change as evidence changes, so accounts are updated regularly. But they are only looking at part of the information, i.e. SNPs, not e.g. chromosomal rearrangements: it's only a part of the picture.

Question 13 - Responsibility for harm

ANSWER:
This should not be approached from the view of those who only deal with single gene disorders. The default position of the human organism is not to be diseased - natural selection tells us that. Clearly genes linked to high penetrance disorders should be flagged for special treatment. Most people are more distressed when they get on their scales in the morning!

Question 14 - Quality of information

ANSWER:
If quality and usefulness are the criteria, there are a lot of things which would need to be taken off the market. If the companies are treating customers unfairly, then Consumer Trading Act 2008 is the way to go.

Question 15 - Other issues

ANSWER:
It is a shame that evolutionary biologists don't sit on more committees - they understand gene-environment interactions in a way that medical geneticists don't.