

Presenter : *Ignorance is bliss* they say, but is it? That's the dilemma at the heart of a major new public survey on genetics. Rapid advances in the ability to map our entire genetic codes means scientists can now say whether or not we carry the genes for hundreds of different diseases, but with complete gene sequencing on the brink of becoming routinely available, do you want to know what's **in store** for you or your children in the decades to come? Our science editor Tom Clarke reports.

Clarke: We're all going to die of something and many of our future health problems are found out in our genes. Advances in genetic technology mean **mainstream** healthcare might soon be able to predict what awaits us. Could it be cancer, diabetes or dementia? With all the things that could kill you, do you really want to know?

Our genome written out fills 24 volumes but now it can be sequenced in a few days and new diseased genes are being identified all the time but ready access to all this information raises some profound ethical dilemmas too, and they're ones that we've never confronted before.

Katrina McArdle is one of the few people who knows what that means. Her son Zach has a range of undiagnosed developed mental problems, he's involved in one of the NHS's first **forays** in the world of genome analysis, a project to sequence the DNA of 12,000 children with serious but unknown medical conditions.

Katrina: Everyone was completely **baffled** by his condition, no one could put their finger on it, everyone had sort of **inklings**. But no one could say why he was able to do some things and not to do others.

Clarke: But what other information about Zach's future is contained in his genes? And once decoded, how much would a parent want to know?

To try to find out, researchers designed this questionnaire and now they want us all to take part.

Voice over: *In terms of a person's health researchers can spot conditions for a person is predisposed to develop, like some cancers.*

Clarke: And it's rarely black and white, some genes for things like Alzheimer's only bring up modest risk, finding a gene for breast cancer could tell you the chances of getting it is up to 77% higher. Katrina's initial reaction was to know everything, and as she learned more, her attitude changed.

Katrina: When I first completed the study, I wanted to know everything, I just went into it **with blinkers on** and it 's not until I got halfway through that I realised how much this could **unleash**. I'm not sure whether we are ready yet, to be honest, I think it's gonna change the face of the NHS completely and I'm not sure whether that's a positive thing or not.

Clarke: It turns out that same question was occurring to the scientists behind the ethics study. They're from the Wellcome Trust Sanger Institute which is analysing children's sequences.

Dr Anna Middleton: All genome technologies are going to be **implemented** in the NHS very very soon. And so many of these issues about what is in your genome and what would I want to know and what could my genes offer me are gonna be relevant to all of us very soon if we engage with the NHS.

Clarke: Initial findings for families like Katrina's reveal most people only want to know about genes for serious illnesses that can be treated though this changes as people get older. Researchers are more in

favour of sharing disease information but the medical profession, who might have to explain to patients, are more cautious. This is complicated stuff.

Prof Sally Davies: If we could tell you that with a certain set of genes you weren't gonna get lung cancer if you smoked or very unlikely to, would those people then go and smoke after all it's addictive, what impact would that have as an example to others because of passive smoking? We don't understand all these behavioural issues so we're gonna have to do lots of research about behavioural issues.

Clarke: There could be other consequences too, insurance or mortgages out of reach for a new genetic underclass, a health service burdened with demands for tests in the absence of any cure. But **handled** right, genetic information could **tailor** treatment to the individual saving lives and NHS money.

Channelfour news.

Lexical helpline.

Ignorance is bliss = "Heureux les pauvres en esprit...", moins on en sait, mieux on se porte

A dilemma = un dilemme

Map (v) = cartographier

In store = en réserve

Mainstream = traditionnel

Forays = incursions

Baffled = déconcerté

Inkling = une petite idée

With blinkers on = avec des œillères

Unleash = révéler

Implement (v) = mettre en application

Handle (v) = gérer

Tailor (v) = individualiser