

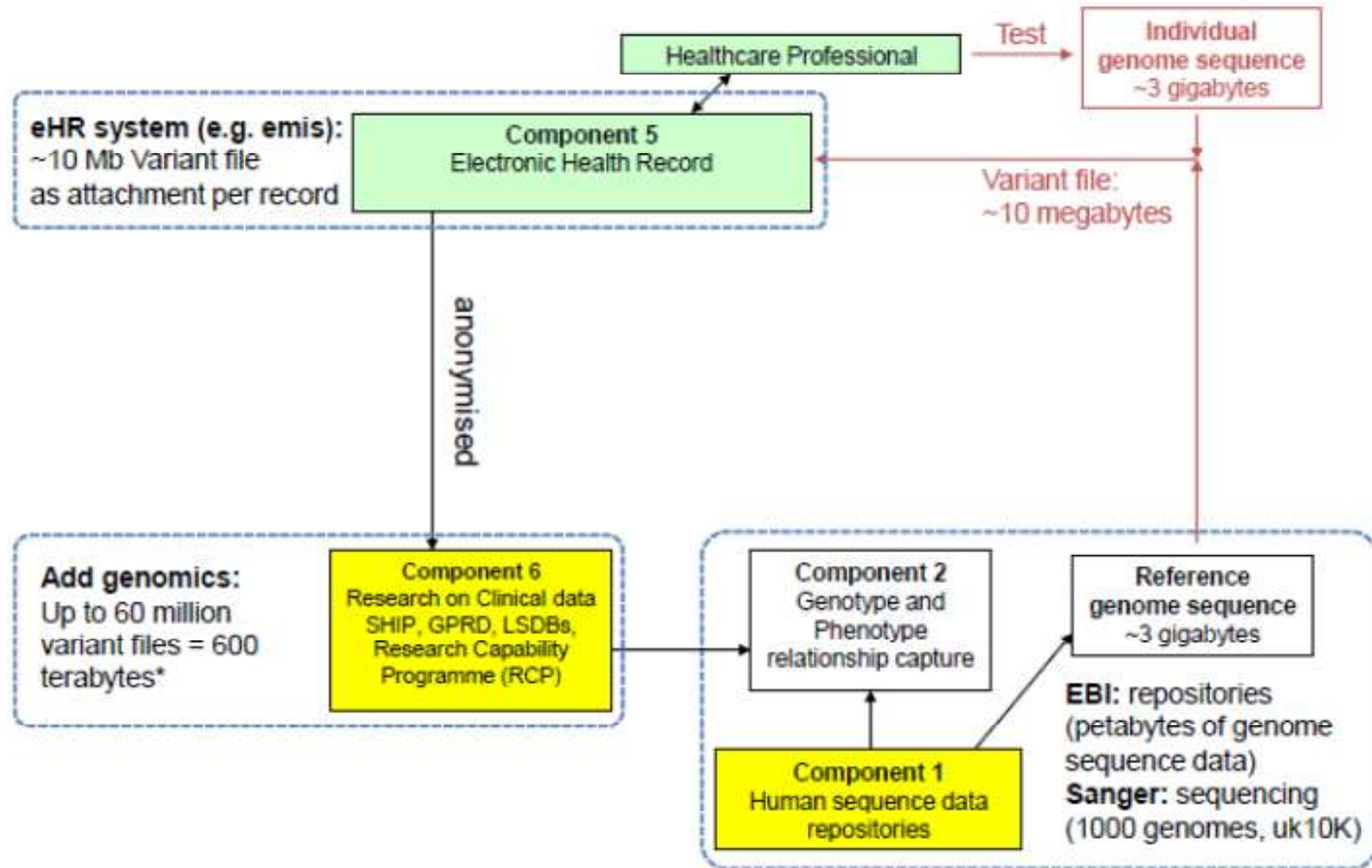
# GeneWatch UK submission to the Caldicott Review

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# Informatics for Genomic Medicine – 2012?



Source: Tim Hubbard's presentation on at AMS, 22<sup>nd</sup> February 2012

# The WT/HGSG plan involves

- Complete removal of people's right to know who is using their health and/or genomic data for what purpose (including any conflicts-of-interest) as required by the Helsinki Declaration
- Construction of a biometric database without consent: allowing tracking and categorisation of every individual and their relatives
- A massive reallocation of resources towards collecting and storing data that is mostly not relevant to a person's care
- Abandoning of screening criteria in favour of individual feedback of personalised risk predictions
- Significant scope for misuse of data for "personalised marketing" of healthcare products to individuals or their relatives

# Will “presumed consent” be valid?

- Only 7% of people approached opted in to UK Biobank: should 93% be presumed to have given their consent unless they actively refuse?
- People do not trust the system to keep their data secure or anonymised and, whilst supportive of research, want to be asked for their consent (WT/MRC 2007, CfH 2008)
- There was significant public and professional opposition to previous attempts to share data without consent (Clause 152)
- Art 8 of the ECHR requires storage of samples and genetic profiles to be necessary and proportionate
- Failure to meet these requirements led to significant loss of public trust in police use of DNA
- Data protection legislation does not appear to allow biometric databases to be built without consent: an “opt-out” process is inadequate and unworkable

# Whose vision of the NHS?

- The WT/HGSG proposal has been promoted as a vision for the NHS since at least 1999
- There has never been a public consultation on the plan
- There has never been an assessment of the costs and benefits
- There is substantial commercial interest in the plan as a means to expand the market for healthcare products (using “personalised marketing” based on individual risks)
- The idea of genetic screening was originally proposed by the tobacco industry (later backed by the food, chemical and nuclear industries) as a means to undermine public health measures

# Recommendations for the Panel

- It is essential to be open about the existence of the WT/HGSG plan
- Do not endorse the sequencing of people's genomes in the NHS without their fully informed consent
- Recognise that data-sharing of medical records on the basis of "presumed consent" removes people's right to know who has access to their data and is unlikely to be publicly acceptable
- Acknowledge that anonymisation of the entire population's medical records is impossible (and people realise this)
- Be aware that loss of public trust could damage legitimate medical research