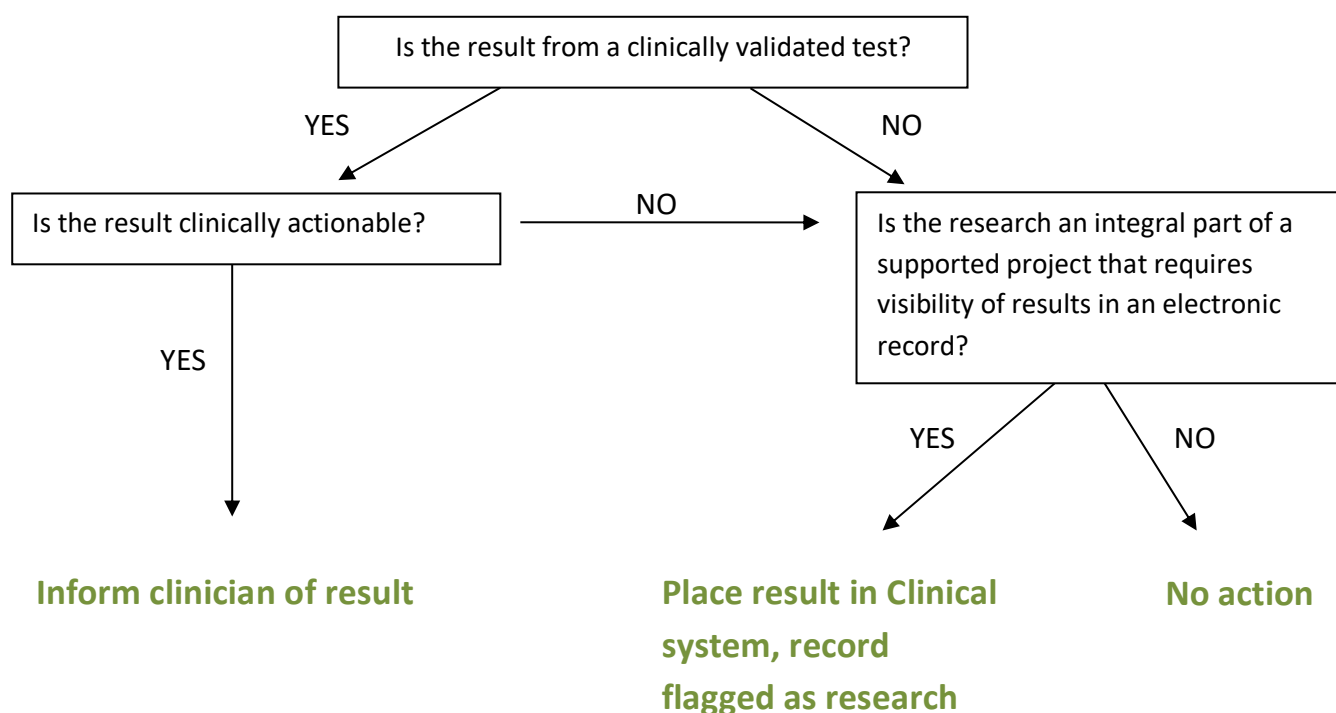


Return of research results to individuals

Results from research done on samples and/or data donated to the Wales Cancer Biobank (WCB) will not routinely be fed back to the individuals who donated those samples. Samples donated to biobanks are generally used for broad research that may lead to future discoveries, not for discovering information about each individual. It is future generations that will benefit from the generous donation of samples and data to biobanks.

In the WCB patient information sheet it states that 'Results for individual patients from research studies will not normally be relayed back to you or your doctor. Very occasionally, some research projects could identify genetic changes that may indicate an inherited disease that may affect you or your family members. Your hospital doctor will be notified if any information that becomes known as a result of the research may affect you or your family's future care. We are unable to contact you directly regarding research results.'

The majority of the research using samples donated to WCB is done in research laboratories and is therefore **unlikely** to return any clinically actionable results or findings. The following criteria will be used to decide the actions taken:



All applications for use of samples are evaluated on receipt to see whether they involve clinically validated tests which have the potential to generate clinically relevant findings. Those that do will be flagged and the possible actionable results investigated and noted. List of clinically validated tests will be regularly updated in conjunction with the All Wales Medical Genomics Service www.medicalgenomicswales.co.uk