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Code of practice needed to ensure good use is made of tissue samples donated by clinical trial participants: a biobank perspective

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Code of practice needed to ensure good use is made of tissue samples donated by clinical trial participants: a biobank perspective

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As academics closely involved in UK biobanking, we welcome the suggestions made by Coleman et al[1] to develop guidelines to make the transfer of human tissue samples collected from trials into biobanks a more streamlined and transparent process. Patient-derived material/data is a valuable resource for contemporary biomedical research. Tissue from trials is especially valued due to the well-defined population and rigour of patient sampling and data curation.

Biobanking is a relatively new discipline which, in a short time, has rapidly expanded beyond simply storing samples in a freezer. Costs associated with biobanking are often hidden and absorbing multiple samples of different formats from existing collections is often beyond the capability of even the most well-resourced biobanks. While most biobanks operate on a cost recovery basis the full costs associated with the collection, storage and curation of samples are rarely met. The accompanying data is a key facet that is frequently overlooked, requiring secure curation, storage and updating, all of which need appropriate infrastructure and incur cost. Challenges also exist in linking the longitudinal patient's journey (primary and/or secondary care) to biological samples and updating this information, the latter especially true in samples from clinical trials and when multiple stakeholders may be involved. Coleman et al highlight complexities surrounding data sharing agreements and intellectual property concerns[1], which can place additional burden on biobanks.

It is deeply regrettable that so many samples, donated by patients in the D-CARE trial[2] in the good faith that these would be used to enhance our understanding of breast cancer, have not been used

to their full potential. We strongly support the establishment of a working group to develop guidelines to ensure that samples and data collected during clinical trials in future are used to their best effect, upon conclusion of the trial and irrespective of its outcome. These discussions should involve biobanks to ensure situations like this are avoided in future.

315 words (excluding title)

VS, CC and JLJ were involved in the creation of the Breast Cancer Now Tissue Bank. VS, AC, CC and JLJ are involved in the running of the Breast Cancer Now Tissue Bank and receive funding from Breast Cancer Now. CC was involved in the creation and subsequent running of the Pancreatic Cancer Research Fund Tissue Bank and receives funding from the Pancreatic Cancer Research Fund. RAA is the Clinical Director of the Wales Cancer Biobank and Director of the CRUK Cancer Division of the Centre for Trials Research at Cardiff University. JAJ is the Director of the Northern Ireland Biobank.

References

1. Coleman R, Chan A, Barrios C, et al. Code of practice needed for samples donated by trial participants. Lancet Oncol 2022; 23: 89–90.
2. Coleman R, Finkelstein DM, Barrios C, et al. Adjuvant denosumab in early breast cancer (D-CARE): an international, multicentre, randomised, controlled, phase 3 trial. Lancet Oncol 2020; 21: 60–72.