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**Medical Collections in the Twenty-First Century**

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# From Bottled Babies to Biobanks: Medical Collections in the Twenty-First Century

Karin Tybjerg

## Museums and Biobanks

The history of anatomical and pathological collections demonstrates the central role of collecting and preserving human material in medical practice. Yet many such collections have lost their central position in medical research and teaching as attention has shifted towards the cellular and molecular levels. Several collections are now perceived as historical rather than medical and, as a consequence, the curatorship has changed hands from doctors to historians.<sup>1</sup> Likewise, the majority of scholarship on medical museums (including hospital and university collections) concentrates on historical practices. While this chapter takes historical practices as its point of departure, its main purpose is to argue that many aspects of historical collecting practices are still in evidence in today's biomedicine. The history of anatomical and pathological collections in medical museums is thus not a story about collections in decline, but rather part of a bigger story about the enduring importance of collecting in medicine.

Today biomedical researchers relatively rarely use gross anatomical-pathological collections, but they frequently employ material from collections of frozen stored tissue samples – known as biobanks. Biobanks, compiled by research groups or institutions, have existed for the last hundred years on a local scale and, in recent years, have been joined by large national and international biobanking efforts. The larger projects have often been viewed as a new phenomenon of the twenty-first century, and they have attracted much scholarly interest, particularly pertaining to questions of governance and consent as well as the repercussions of correlating genetic information with personal data. This

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<sup>1</sup> Collections such as the Hunterian Museum in London, Surgeons' Hall Museums in Edinburgh and Medical Museion in Copenhagen are now for the first time headed by historians or historians of science. For the change in status of collections, see also Leonie Hannan, 'Whose Body Now? The Many Lives of a University Medical Collection', in *A Handbook for Academic Museums*, ed. Stephanie Jandl and Mark S. Gould, Edinburgh: Museumsetc, 2012, pp. 376–401; and Samuel J.M.M. Alberti and Elizabeth Hallam, eds, *Medical Museums: Past, Present, Future*, London: Royal College of Surgeons, 2013.

chapter will, however, sidestep these debates and consider instead how biobank practices resemble those of historical anatomical and pathological collections.

The National Biobank of Denmark constitutes an illustrative example of the links between medical museums and biobanks. On a recent visit there I saw a team of laboratory assistants transferring information from old discoloured cards, logbooks and forms onto computers, pulling out staples and unfolding handwritten notes as they went along. At the same time blood samples from the 1960s in cardboard boxes were brought in from remote storage and transferred to new vessels. The lab coats and the robotic transfer of the samples did not hide the fact that the staff were engaged in the kind of collection management seen in museum collections when old registration systems and storage solutions are updated rather than the hypermodern activities depicted in biobank imagery (see Plate 8). The case of the Danish National Biobank is unusual because Danish biobanks often have older collections with useful records. It is, however, of general relevance, because the management of 'historical' collections will become more and more important to biobanks as time goes on.

My claim is thus that anatomical-pathological collections and their associated practices are not just part of a past medical culture, but that collecting as a way of generating knowledge is still central to medical science today. As we shall see, the main difference lies in a shift in the level at which disease is studied, from macroscopic lesions in organs to biomarkers in tissue samples. In my comparison I draw on John Pickstone's idea of 'ways of knowing' – that is, methods and practices for producing scientific knowledge.<sup>2</sup> This concept is useful because it allows elements of scientific practice to be studied independently of specific theories and across different periods. While Pickstone associates collecting as a 'way of knowing' with natural historical museums, it is in no way limited to such institutions, as we shall see. I will also draw on the work of Bruno Strasser, who has discussed parallels between collecting in natural history and molecular biology.<sup>3</sup>

In the following pages, I will outline briefly practices in the nineteenth-century medical museum and today's biobanks, drawing on two examples: a historical pathological collection from the Danish Royal Maternity Foundation and collections of blood samples from the Danish National Biobank. I shall argue that, despite the apparent dissimilarities between nineteenth-century collections of gross preparations in glass containers and twenty-first-century tissue samples in liquid nitrogen freezers, the practices of collecting reveal striking

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<sup>2</sup> John Pickstone moved away from the idea of a single scientific method to different 'ways of knowing', see John V. Pickstone, *Ways of Knowing: A New History of Science Technology and Medicine*, Manchester: Manchester University Press, 2000.

<sup>3</sup> Bruno J. Strasser, 'Collecting Nature: Practices, Styles and Narratives', *Osiris*, 27, 2012, pp. 303–40; and Bruno J. Strasser and Soraya de Chadarevian, 'The Comparative and the Exemplary: Revisiting the History of Molecular Biology', *History of Science*, 49, 2011, pp. 317–36.

parallels. Biobanks resemble medical museum collections in three ways: first, in the way they use past diagnoses to understand diseases in the present; second, in constituting the material connection between the clinic and medical research by literally bringing parts of the patient from the hospital to the research collection; and lastly, in employing 'museum' practices for the preservation, registration and storage of human material. The comparison shows that practices of collecting remain crucially important in modern medicine and it highlights new aspects of both medical museums and biobanks. Recent research on the history of early modern and nineteenth-century collections has for instance shown that preparations often did not remain fixed in categories, but acquired new uses much as samples in biobanks do.<sup>4</sup> With regard to the biobank, the comparison highlights the importance of the materiality of the collections, which is not normally emphasized by scholars. In this way historical collections play a role in our comprehension of their modern counterparts, and vice versa.

### Collecting in Museums

Medical museums, including collections in hospitals and universities, had their heyday from the late eighteenth to the early twentieth century, when collections expanded and played a fundamental role in research, teaching and the understanding of disease. The expansion of the pathological collections, in particular, was connected to changes in medical practice associated with hospital medicine.<sup>5</sup> Patients were increasingly gathered in hospitals rather than being treated in their homes, and assembling patients in one place allowed a higher degree of comparison and systematization of cases. Physical examinations, diagnoses and – if the outcome was bad – autopsies could be compared, and collecting lesions made it possible to document and systematize pathology.

Pathology collections thus became ripe for taxonomy.<sup>6</sup> The malformed skeletons and diseased organs were treated like natural historical collections

<sup>4</sup> See for instance Marieke Henriksen, Hieke Huistra and Rina Knoeff, 'Recycling Anatomical Preparations: Leiden's Anatomical Collections', in Alberti and Hallam, *Medical Museums*, pp. 74–87; and Erin Hunter McLeary, 'Science in a Bottle: The Medical Museum in North America, 1860–1940', PhD diss., University of Michigan, Ann Arbor, 2002.

<sup>5</sup> For the changes associated with hospital medicine, particularly in France, see Michel Foucault, *The Birth of the Clinic*, London: Routledge, 2003, first published 1963; N.D. Jewson, 'The Disappearance of the Sick-Man from Medical Cosmology, 1770–1870', *Sociology*, 10, 1976, pp. 225–44; Russel C. Maulitz, *Morbid Appearances: The Anatomy of Pathology in the Early Nineteenth Century*, Cambridge: Cambridge University Press, 1987.

<sup>6</sup> Ilana Löwy, 'Labelled Bodies: Classification of Diseases and the Medical Way of Knowing', *History of Science*, 49, 2011, pp. 299–315, at p. 300.

of animals, plants or minerals, and diseases were categorized.<sup>7</sup> The resulting systematized landscape of anatomy and pathology was presented in the medical museum as an embodied atlas of disease that made the chaotic world of the hospital more ordered and predictable. While medicine is not usually defined as a 'collection science' it displays and utilizes its collections in a manner resembling natural history, and the curators of medical museums did similar work to other museum curators: conserving, ordering and registering preparations with information about the circumstances in which they were found – the case histories.<sup>8</sup>

Medical museums aggregated clinical experience in material form. They documented the experience of a doctor or an institution and allowed students to acquaint themselves with cases they had yet to come across. As the collections grew, the understanding of pathology and anatomy became more detailed and diagnoses more precise. Both doctors and students also used the collections to reveal what was not apparent in the clinic – the lesion inside the body. The doctor was limited to palpating the body or listening with a stethoscope, but this information could be related to the preparations found in the collections as well as to earlier case notes. The collection thus provided a correlation between previous and current cases and was an important tool for offering a diagnosis and a prognosis of how the disease might develop. In this way the collection linked the categories of medical research to the appearance of diseases in the clinic, and was thus a key factor in what we would today call translational medicine, that is, medical research 'translated' into diagnosis and treatment.

The preparations reflected the dominant view of disease at the time. To produce the pathological preparation the rest of the body was physically cut away from the affected organ, thus highlighting what was important and disposing of what was not. The lesion itself was identified with the disease, and it was understood as a localized phenomenon. Personal details of the patient, such as age, gender and specific symptoms, were also limited to those deemed relevant to the specific pathology.

Historical anatomical and pathological collections thus performed multiple roles: they systematized anatomical and pathological knowledge, they gathered a material record of medical experience and they bridged the gap between

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<sup>7</sup> For links between natural history collections and medical museums, see: Simon Chaplin, 'Nature Dissected, or Dissection Naturalized? The Case of John Hunter's Museum', *Museum and Society*, 6, 2008, pp. 135–51 for an account of how John Hunter legitimized his large collection of anatomical preparations as natural history in the late eighteenth century, and McLeary, 'Science in a Bottle' for a description of plans in the nineteenth century to transform US anatomical collections into national medical museums modelled on natural history museums.

<sup>8</sup> On collection sciences see Robert E. Kohler, 'Finders, Keepers: Collecting Sciences and Collecting Practice', *History of Science*, 45, 2007, pp. 428–54.

clinical and theoretical medical knowledge. The preparations transferred the messy, personal world of the clinic into a controlled space where cases could be studied and ordered, and they allowed diagnostic and prognostic insights to find their way back into the clinic.

### The Example of Museum Saxtorphianum

Museum Saxtorphianum, now part of Medical Museion in Copenhagen, is an example of an anatomical-pathological collection. The collection was originally established by Matthias Saxtorph (1740–1800) in 1787 at the Royal Maternity Foundation in Copenhagen and comprises approximately 600 preparations, mainly of malformations and pathologies in embryos, fetuses and infants (see Figure 16.1).<sup>9</sup> Like many pathological collections, this one played a role in establishing a new area of research. At the time, obstetrics was a young field in academia, and the collection supported the academic endeavour by mapping out the field and demonstrating experience and expertise. The collections expanded



Figure 16.1 Collection of preserved infants with congenital malformations from the Saxtorphian collection. Courtesy of Medical Museion, University of Copenhagen

<sup>9</sup> For brief descriptions of the collection see Dyre Trolle, 'Museum Saxtorphianum', *Ugeskrift for læger*, 16, 1999, pp. 5054–5; and Ion Meyer, 'Døden på glas – om fostre i anatomiske samlinger', in *Memento Mori – døden i Danmark i tværfagligt lys*, ed. Michael Hviid Jacobsen and Mette Haakonsen, Odense: Syddansk Universitetsforlag, 2008.

further during the nineteenth and early twentieth centuries, and it is this period that I shall consider here.<sup>10</sup>

Preserving infants transformed them into medical entities ready for systematization and future identification of new cases. In the catalogue, the congenital disorders were divided according to pathologies and anatomical systems such as spine, head and limbs. This allowed an anatomical and pathological categorization of 'monstrous birth', which brought it into the realm of academia. The display cases filled with variations of malformed infants may be seen as closely related to collection boxes of butterflies or rocks in natural history, in terms both of presentation and of how they were used to generate knowledge – they created order and formalized informal knowledge.

Like many pathological collections the combination of the preparations and case notes established a link between past experience and clinical practice. In the catalogue of the Saxtorphian Museum descriptions of the pathologies are often supplemented with brief notes on the state of the mother, the implements that were used during delivery, and whether and how long the infant lived. In this way the collection documented past experiences of symptoms, treatments and outcomes, as well as allowing comparison with new cases. The collection is thus a material record of the past that can be accessed to aid new diagnoses and prognoses.

The specimens were not just collected and described, they were also dissected and analysed in their constituent parts. The conjoined twins in the collections bear signs of having been dissected to study their organs. A set of conjoined twins from the mid-nineteenth century was divided into three separate preparations: a dry preparation of the skin and wet preparations of the skeleton and the organs respectively.<sup>11</sup> The preparations show the malformation in its component parts analysed according to dissection, the prevalent method of investigation. At the same time, great care was taken to preserve the body for posterity. The published account stated directly that the anatomical investigation was limited by the wish to preserve evidence of the rare case.<sup>12</sup> It is always a problem for physical collections that analysis destroys the specimen and curators must weigh up the outcome of the analysis with the need to preserve it for future investigation. As we shall see, this is also the case in today's biobanks.

The collection thus performed many of the roles of the anatomical and pathological collections stated above: it brought a new area into academic

<sup>10</sup> I draw on the only preserved catalogue, which is from 1950. See Mogens Ingerslev, 'Katalog over samlingerne i Museum Saxtorphianum', The National Hospital, Copenhagen, 1950.

<sup>11</sup> Carl E. Levy, *Beskrivelse af et par ved underkroppen sammenhængende levende fødte tvillingesøstre (ischiopages)*, Copenhagen, 1857; and Ion Meyer and Jane Richter, 'The Fate of a Nineteenth-Century Ischiopagus from Denmark', *Journal of the History of Collections*, 20, 2008, pp. 1–6.

<sup>12</sup> Levy, *Beskrivelse af et Par*, p. 14.

medicine by categorizing it, it gathered past experience to compare to future cases and it connected research and clinical work through the analysis of physical specimens. The practice of collecting and maintaining human material was an important part of producing medical knowledge.

### Collecting in Biobanks

In nineteenth-century medical museums diseases were presented as lesions in whole organs. Alongside the expansion of collections, however, the microscope introduced a new way of studying anatomy and pathology. In the latter half the nineteenth century increasing interest was directed at the cellular level and thereby at new ways of understanding and defining disease. Tissue samples were taken, either as biopsies from living patients or excisions during autopsies, and the small lumps of tissue were encapsulated in paraffin to make them easy to slice thinly, dye and fix onto slides.

Samples were stored, either in collection boxes of paraffin blocks or on slides arranged in cases, and they were recorded to relate them to the medical case behind them, as well as to the pathologies they showed. The manner of collecting, storing and using the samples for future reference was thus similar to that of the gross specimens, except that tissue samples needed to be accessed using a microscope. With microscopic slides, the medical museum deviated from the idea of a museum where preparations are presented visually, but the main practices continued. The microscopic slides helped in the search for indicators for diagnosis, prognosis and the understanding of disease, and they continue to do so to this day. They furthermore have the advantage that they can be produced and analysed while the patient is still alive.

Another way of studying human tissue came with the advent of tissue cultures in 1907. Tissue cultures made it possible to keep cells alive outside their organism and thereby observe living cells developing in real time rather than dead and fixed to a slide.<sup>13</sup> The living cells revealed a hitherto unsuspected level of independence. Cells from a chicken heart, for instance, contracted or 'beat' without connection to the organ or body. After the Second World War, human tissues were also successfully cultured and it became possible to create human tissue lines that could proliferate long after the death of the person from whom they derived. Most famously, a sample of cancerous cells taken from a young

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<sup>13</sup> There is a large literature on the conceptual and cultural changes that followed in the wake of tissue culture, see e.g. Hannah Landecker, *Culturing Life: How Cells Became Technologies*, Cambridge, MA: Harvard University Press, 2007; and Duncan Wilson, *Tissue Culture in Science and Society: The Public Life of a Biological Technique in Twentieth Century Britain*, London: Palgrave Macmillan, 2011.



black woman, Henrietta Lacks, shortly before her death in 1951, turned out to be highly resilient. Vast quantities of 'her' cells – known as the HeLa tissue line – are alive and used in labs today.<sup>14</sup> In this way, human cells became manipulable on the lab bench and it was possible to conduct experiments and 'treat' them independently of the body.

Many practices involving the use of human tissue changed as it became possible to preserve tissue with minimum degeneration and even to store live cells. Tissues were kept in laboratories for continual retrieval, growth or analysis and in recent years in vast biobanks. In light of this development, it is tempting to see the change of vocabulary from the 'museum' to that of the 'bank' as significant. It could be construed as signifying that human remains in museums were collected and preserved to display categories of the past, while in biobanks human samples are collected and preserved with the intention of accessing and analysing them in the future. Even when the material in biobanks is not alive, the implication is that its value will increase and that it can be brought into circulation again. It is certainly the intention behind the large biobank projects that they constitute investments in future research, diagnosis and treatment. The metaphors of bank and museum can, however, be misleading, and obscure the similarities between biobanks and museum collections.

For instance, biobanks resemble the pathological collections in that they rigorously register and link samples to the cases from which they derive. Biobank samples taken a long time ago are particularly valuable as these have a longer history of treatment and outcome for the patient. Despite the development of laboratory methods many practices associated with collecting, preserving and using samples in biobanks show similarities to those of anatomical-pathological museums. Biobank samples are often taken as part of diagnostic procedures and preserved to confirm diagnosis or to compare with other samples in the same way as specimens were kept in the medical museum for diagnosis, documentation and comparison. Likewise, both in the biobank and in the pathological museum, past diagnoses and analyses of the specimens are used to establish future diagnoses and prognoses. Hence both the biobank and the museum link past and future cases and allow new knowledge to be generated by saving bodily material as documentation.

Another similarity between 'old' pathological collections and 'new' biobanks is that core practices from the museum such as preservation, storage and cataloguing are still in evidence in biobanks. The difference lies mainly in the tools of analysis: from visual practices using the dissection scalpel to tissue culture, biochemical analysis of biomarkers and genetic sequencing. Many

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<sup>14</sup> Landecker, *Culturing Life* and Wilson, *Tissue Culture*. The case is controversial, because neither Henrietta Lacks nor her family knew until recently that she had been the source of a highly successful tissue-line.

national biobanks have been founded with the aim of sequencing genomes and thus matching knowledge of individual medical histories with genomic markers. Likewise, the size of the samples used to diagnose and document pathologies has changed: from lesions in gross preparations to biomarkers and so-called SNPs (i.e. variations in the genetic sequence – pronounced ‘snips’). Biobanks may thus be seen as contemporary medical museums of tiny samples accessed through laboratory tests.

### The Example of the Danish National Biobank

To illustrate the practices of biobanks I shall consider the Danish National Biobank (see Plate 8). It opened in 2012 and includes both laboratories and storage facilities. At the opening, the minister for research drew on the bank metaphor and the future potential in his speech, stating that, ‘the currency of this bank is biological samples and the return is research results that will benefit the whole population.’<sup>15</sup> Despite the focus on the future, the main advantage of the Danish National Biobank is that it includes extensive older – we might even say historical – collections. As stated earlier, this makes it a good example for studying collecting practices that will become more significant as biobanks age. The old samples are valuable because – due to the introduction of national health insurance in Denmark as early as 1971 – it is possible to trace case histories over decades. The bank therefore not only collects new samples for future research, but also transfers old samples to modern storage and re-registers old protocols. The Danish case makes it clear that key practices at biobanks closely resemble the museum work of maintaining old collections while adding new material.

One of the most important older collections held by the Biobank is the tiny blood samples taken from newborn infants to test for a number of serious, but treatable, metabolic diseases (the PKU test). A few drops of blood are taken from the heel, dripped on a special card with filter paper and tested in a laboratory. After the test the material is kept in a locked freezer. The accumulation of the cards means that the biobank holds blood tests from every person born in Denmark since 1982, with close to 100 per cent coverage. As is the case with many older collections the tests were originally performed solely with a diagnostic purpose, but the material was later made accessible to researchers. Although the samples are small – only three drops of blood – technological developments allow tests on smaller and smaller samples. It is now possible to amplify the entire genome

<sup>15</sup> Speech by minister for research Morten Østergaard at the opening of the Danish National Biobank. ‘Storslået åbning af ny biobank’, 21 March 2012, accessed 6 July 2013, [http://www.ssi.dk/Aktuelt/Nyheder/2012/2012\\_03%20Storslaet%20aabning%20af%20ny%20biobank.aspx](http://www.ssi.dk/Aktuelt/Nyheder/2012/2012_03%20Storslaet%20aabning%20af%20ny%20biobank.aspx). Translation by author.

from a small circle punched in the card so that tests can be performed for series of genetic markers. Using the large quantity of centrally registered information, researchers can identify biomarkers detectable at birth that are associated with disease later in life. As Kristian Hveem, the director of the Biobank, put it: the PKU test offers a zero point for investigations of a person's health and disease. The collection can thus be used to perform long-term studies of causes of disease.<sup>16</sup> Thus while diagnosis, treatment and death came in close succession in the Saxtorphian Museum, the timeframe has been extended in the modern biobank.

A new collection, *Better Health for Mother and Child*, attempts to extend the range of factors under investigation for multi-causal diseases. This collection is designed for research rather than diagnostics, and it follows a cohort of mothers and their children from pregnancy onwards. The participants have offered blood samples, umbilical cord tissue and extensive background information. Both mothers and children – now teenagers – answer questionnaires on their health and lifestyle. The questions cast the net widely, ranging from nutrition and the onset of puberty to social factors such as bullying. Researchers may thus 'compare the life conditions and environmental impacts on the children throughout a whole life with the diseases they may suffer from in youth or adulthood'. Rather than the nineteenth-century link between the examination of the sick patient at the hospital and the lesion at the autopsy, medical science has now moved down the causal chain to factors that might predispose to, worsen or trigger disease.

In contrast to the case histories in the medical museum, disease no longer follows an easily traceable course from detection of symptoms to full-blown disease with limited treatment options. Both the span between the detection of risk factors and the onset of a disease and the length of treatment regimes have been extended. Disease can no longer be seen as a local phenomenon either. It cannot be understood through a lesion and a simple case history, but is rather understood as a complicated web of influences that connects the disease to biomarkers and environment. In gathering material that covers a new area – the environment – and making it part of medicine, this collection is akin to the Saxtorphian Museum. Just as the Saxtorphian made obstetrics and monstrous birth a part of academia, *Better Health for Mother and Child* makes the environment of mother and child part of the medical understanding of disease. Despite the extension in time and the range of factors, the biobank therefore performs the same function as the museum by carefully safeguarding and cataloguing the bodily links between disease, diagnosis and prognosis.

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<sup>16</sup> B. Norgaard-Pedersen and D. M. Hougaard, 'Storage Policies and Use of the Danish Newborn Screening Biobank', *Journal of Inherited Metabolic Disorders*, 30, 2007, pp. 530–36.

## Collection Matters

As stated at the start of this chapter, the medical importance of pathological collections of gross specimens has declined during the last half century, and collections such as the Saxtorphian are now deemed to be of minor importance. Disease is now studied in the laboratory, and is often diagnosed at the level of cells, molecules or biomarkers. In this process, biomedical research has increasingly moved away from hospital clinics and specific diseased bodies. This development fits neatly with the grand narrative of how biology and medicine converged and transformed into the laboratory science of biomedicine.<sup>17</sup>

The strong focus on laboratory experimentation and its attendant scientific credentials for biomedicine has obscured the existence of other scientific practices in biomedicine, however. Taking a wider view of knowledge and practice produces a richer picture, where collection can be seen to play an important role in biomedicine. If we trace ‘ways of knowing’ – in John Pickstone’s sense of epistemic and material practices<sup>18</sup> – the practices of collection and categorizing turn out to be central to medical research. In fact collection practices endure while concepts of disease and tools of investigation change.

Inspired by Pickstone’s ways of knowing, Bruno Strasser recently used collection as a central category to recast the grand narrative of biology.<sup>19</sup> Strasser argued persuasively that the traditional story of the transformation of biology from the museum science of natural history to experimental biology in laboratories has failed to recognize the ongoing importance of collections of crystallography, proteins or genetic data, and hence the collection practices in molecular biology and biological data banks such as GenBank. Strasser does not draw a direct historical link from nineteenth-century collectors of natural history to comparative practices in molecular biology and the data deluge, but he does argue that the practices are analogous.

The ongoing importance of collections is perhaps even clearer in the case of medicine than in natural history and biology, despite the fact that medicine

<sup>17</sup> Andrew Cunningham and Perry Williams, *The Laboratory Revolution in Medicine*, Cambridge: Cambridge University Press, 1992; and William F. Bynum, *Science and the Practice of Medicine in the Nineteenth Century*, Cambridge: Cambridge University Press, 1994.

<sup>18</sup> Pickstone distinguished four ‘ways of knowing’: *reading* (creating meaning, e.g. natural philosophy); *natural history* (describing and classifying natural history or humeral medicine, for example), *analysis* (reducing compound objects to their elements, e.g. chemical elements or tissues), and *synthetic experimentation* (creating systems out of elements or controlled experiments). See Pickstone, *Ways of Knowing* and idem, ‘Working Knowledges Before and After circa 1800 – Practices and Disciplines in the History of Science, Technology, and Medicine’, *Isis*, 98, 2007, pp. 489–516.

<sup>19</sup> Strasser, ‘Collecting Nature’; and Strasser and De Chadarevian, ‘The Comparative and the Exemplary’.

is not traditionally defined as a collection discipline. In the medical museum the predominant way of knowing was akin to the collecting of natural history. As we have seen, pathology was treated as a natural landscape that could be categorized and systematized. While it is easy, then, to be seduced by the proliferation of laboratory work in the early twentieth century and dismiss the importance of collections, the collections of gross preparations and pathological slides remained primary sites of medical knowledge up to the mid-twentieth century.<sup>20</sup> Moreover, small collections of tissue held by individual researchers also provided the raw material for research throughout the twentieth century. Literally bringing the body of the patient into the laboratories, the collections bridge the gap between the clinic and biomedical research, and these practices have now been systematized further in twenty-first-century national biobanks.

Collections still lie at the heart of diagnostics and prognosis. This central use of collections emerged in the nineteenth-century medical museum, where students and doctors learned to diagnose by drawing inferences from the examination of the diseased patient to the pathological preparation of the lesion. The material in biobanks opens similar possibilities. The collection of PKU samples in the Danish National Biobank, with its links to medical records, provides the same possibilities of inference from clinical diagnostic tests to the final outcome as an anatomical-pathological museum collection, only on a grander scale. The difference is one of methods – lab tests rather than vision, hearing and touch – and timescale. When a disease was diagnosed in the nineteenth century, the timeframe was short and the therapeutic possibilities often limited, but when biomarkers at birth can be linked to disease whose onset is not until later in life, therapeutic options may be better. It may be due to this difference in timescale that museums are viewed as places that document the past, while the biobanks are associated with cures for the future. Both, however, combine the museum's categorizing and documenting and the bank's safekeeping of samples for recirculation and creation of new knowledge.

Another important aspect of collection practices in biobanks and medical museums is the materiality of the samples and specimens collected. This aspect of collection is underplayed by both Pickstone and Strasser, but it is emphasized by Robert Kohler, in his analysis of 'collection sciences'. He maintains that while all scientists are 'finders' in some way or other, only collection scientists are 'keepers'.<sup>21</sup> As Kohler points out, defining natural categories is best done on the basis of large quantities of physical material, and both the categorizations of congenital malformation in the Saxtorphian Museum and today's attempts to understand multi-causal disease through biobank samples rely on

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<sup>20</sup> Samuel J.M.M. Alberti, *Morbid Curiosities: Medical Museums in Nineteenth-Century Britain*, Oxford: Oxford University Press, 2010, pp. 197–204; and McLeary, 'Science in a Bottle'.

<sup>21</sup> Kohler, 'Finders, Keepers', p. 432.

such collections. Kohler also emphasizes the real and practical task of building and maintaining physical collections, which requires institutional support of exactly the kind supplied by museums and biobanks. Interestingly, Kohler does not include medicine in his list of collection sciences, although it seems to fit his account closely. However, this merely reflects the fact that the practice of collection is generally unrecognized in medicine.

Another reason why physical material is central to medical museums and biobanks is the knowledge latent in specimens. Physical specimens hold information that cannot be copied in the way that a genetic sequence, case history or test result can.<sup>22</sup> Samples in biobanks may yield information not yet known and not accessible at the time of collection. This is also the reason why tests taken for diagnostic purposes often turn out to be invaluable material for research. The uniqueness of the material is also reflected in the care taken in deciding how to use the material: how far to destroy a specimen when dissecting it, and which tests to run on a limited sample of tissue.

Collecting, preserving and categorizing human material thus remain central to medical practice despite the changes between the museum collections of nineteenth and twentieth centuries and the biobanks of the twentieth and twenty-first centuries. They provide systematized stand-ins for the messier world of the clinic, which may be seen as the 'field' of the collection science of medicine. Of course there are also important differences between medical museums and biobanks. Some of these are associated with the different societal and political roles played by museum collections and national biobanks. Yet, the changes in the way knowledge is extracted from preparations, tissues and cells interestingly often reflect changes in the concept of disease rather than changes in the importance of collecting.

One prominent change in the understanding of disease is related to the amount of information gathered about specimens. In historical pathological collections, precious little information is given about the person whose body part or child was made into a specimen. In the Saxtorphian collection mothers are described as '35-year-old I para' – that is, her age and number of previous births are stated (though intriguingly the catalogue does further describe two women as 'Swedish maids'). In contrast, detailed information about the life and environment behind the specimens is almost a defining feature of the biobank. The BBMRI, which is a European research infrastructure for biobanks, defines biobanks as 'collections, repositories and distribution centres of all types of human biological samples, such as blood, tissues, cells or DNA and/or related

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<sup>22</sup> Cathy M. Gere and Bronwen C. Parry 'The Flesh Made Word: Banking the Body in the Age of Information', *Biosocieties*, 1, 2006, pp. 83–98.

data such as associated clinical and research data.<sup>23</sup> Lifestyle factors, medical history and family history are central to the use of the collections.<sup>24</sup>

In fact, the establishment of national biobanks really took off in the wake of the human genome project, when it became clear that the newly mapped genome was not enough to understand disease and its causes. Non-infectious diseases are not simply a product of the genes, but also of the body's constant interaction with its environment. And it is this interaction that the biobanks are trying to capture, by collecting material from the body as well as information about its environment. While diseases in the nineteenth-century medical museum could be identified by lesions, diseases are now understood as vast causal webs with nodes both at the molecular scale of the body and in the environment from the womb onwards.<sup>25</sup>

When biobanks collect information both on the particularity of the environment and on specific characteristics of genes and biomarkers, their collections hold highly personalized information about the individuals whose tissues they store. This may be contrasted to the nineteenth-century medical museum, which has often been described as anonymizing and objectifying the body. The diagnoses provided by pathological museums were more general – akin to species in natural history – while biobanks are linked to the promise of 'personal medicine'. That said, the change towards personal medicine is easily overstated. The nineteenth-century medical museum included the specific information found relevant to the resolution of its diagnostic categories; this was just much less information than is thought relevant today. Today's biobanks hold detailed information, but collections are still used to categorize diseases and predispositions. The grid of categories in 'personal medicine' is simply more fine-grained, and it is possible to pinpoint small groups of patients who might benefit from a particular treatment.

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<sup>23</sup> Biobanking and Biomolecular Resources Research Infrastructure (BBMRI-ERIC) Statutes, Chapter 1, Article 1, <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2013:320:0063:0080:EN:PDF>, accessed 13 October 2014.

<sup>24</sup> The Danish National Biobank relies on samples taken for diagnostic purposes and the Civil Registration System; the Icelandic Health Sector Database combines collected samples, healthcare data and the Book of Icelanders tracking family relations; the UK Biobank started its collection from scratch, gathering both samples and information from a group of volunteers who have agreed to be followed. For accounts of a number of large national biobank projects see Herbert Gottweis and Alan Petersen, eds, *Biobank Governance in Comparative Perspective*, London: Routledge, 2008.

<sup>25</sup> This shift in practice between the nineteenth-century medical museum and twenty-first-century bank is mirrored by changes in general museum practices. Museums have also extended their interest from the object itself to include the culture and environment that created it, see e.g. Eilean Hooper-Greenhill, *Museums and the Shaping of Knowledge*, London: Routledge, 1992.

Biobanks thus offer a longer timescale, include the environment around the body and provide a higher resolution in diagnostic categories, but they still seek to establish diagnoses, best treatment and prognosis on the basis of stored material from past patients' bodies.

## Conclusion

Through an analysis of collecting practice in the anatomical-pathological museums and today's biobanks I have argued that collecting human material is not limited to historical practice. On the contrary, the medical museum and the biobank are closely related institutions. They share a range of practices: collecting, preserving and scientific categorization based on material collections. They provide a bridge between specific cases in the clinic and medical research. Medicine and biomedicine should be considered collection sciences – not exclusively, but in addition to being experimental lab sciences or data sciences.

Viewing biobanks in conjunction with historical collections also puts the body back into modern biomedicine. My analysis runs counter to the argument that the ever smaller specimens collected by biobanks are contributing to the disappearance of the body from modern biomedicine.<sup>26</sup> In this view, the human body is no longer the unit of interest for biomedicine, and the biobank decomposes it into collections of proteins, serums or pathological tissue samples. While it is true that preparations have become smaller, it is by no means a new practice to divide the human body to investigate it. Nineteenth-century anatomical and pathological museums dissected the body into organ-sized parts – thus matching the understanding of disease at the time – and disregarded the importance of the body as a whole. The main difference is in the sample sizes, not in a move away from the physical material of the body. The biobank can be viewed as a biomedical museum.

The small samples and especially the non-public face of the biobank do, however, remove its collections from 'the body as we know it'. In contrast, many historical collections such as the Saxtorphian collection show recognizable bodies and body parts. Because of the connections between the anatomical-pathological collection and the biobank, historical museum collections may play an important role in understanding and communicating the practices of the biobank. The historical specimens can highlight the fact that the body is still collected in modern-day practice, while modern practices can make the historical pathological collections seem less alienating.

<sup>26</sup> Herbert Gottweis, 'Biobanks in Action: New Strategies in the Governance of Life' in *Biobanks: Governance in Comparative Perspective*, ed. Herbert Gottweis and Alan Petersen, London: Routledge, 2008.



This chapter has shown how biobank practices of collecting, preserving and categorizing human material bear strong and important resemblances to the practices in historical medical museums. By comparing medical museums, often associated with the past, with biobanks, often associated with the future, new aspects of both become apparent. Biobanks are and will inexorably become related to the past as the persons and patients from whom the samples derive age. This will be felt in a very practical manner when registration and storage systems need to be updated. Conversely, in its own time, the medical museum was made for the future – for doctors to diagnose new patients on the basis of knowledge from the past. Both anatomical-pathological collections and biobanks thus provide not only material links to the past, but also windows to the future.



Plate 8      New freezer with robotic arm providing storage space for future samples at the Danish National Biobank. Photo: SSI

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