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Al and Medical Images: Addressing Ethical Challenges to Provide Responsible Access to Historical Medical Illustrations

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Abstract

This article examines the ethical considerations and broader issues around access to digitised historical medical images. These illustrations and, later, photographs are often extremely sensitive, representing disability, disease, gender, and race in potentially harmful and problematic ways. In particular, the original metadata for such images can include demeaning and sometimes racist terms. Some of these images show sexually explicit and violent content, as well as content that was obtained without informed consent. Hiding these sensitive images can be tempting, and yet, archives are meant to be used, not locked away. Through a series of interviews with 10 archivists, librarians, and researchers based in the UK and US, the authors show that improved access to medical illustrations is essential to produce new knowledge in the humanities and medical research, as well as to bridge the gap between historical and modern understandings of the human body. Improving access to medical illustration can also help to address the "gender data gap", which has acquired mainstream visibility thanks to the work of activists such as Caroline Criado-Perez, the author of Invisible Women: Data Bias in a World Designed for Men. Users of historical medical archives are therefore a diverse group, which includes researchers in medicine, history, and medical and digital humanities, as well as artists, journalists, and activists.

In order to improve discoverability and facilitate access to these archives in an ethical way, this article highlights the importance of appropriate metadata, which can be enhanced through the use of artificial intelligence (AI) tools. Indeed, AI can be used to create new metadata when original information is incomplete or is missing altogether, or when it includes problematic language. AI can also help with the disaggregation of data by gender and/or racial ethnicity. Moreover, it can recommend similar images to allow users to explore other parts of the collections. However, AI can also pose issues, for example when it suggests inappropriate metadata or similarity search results. Keeping humans in the loop is therefore essential when applying AI to sensitive medical images. Ultimately, this article argues that access to sensitive images institutions find the right balance, to provide access for research and education, and to also protect children and other vulnerable audiences from encountering images that can be described as shocking and even traumatising.

Digitisation has profoundly changed the way we conduct humanities research. The ability to search through library catalogues, archival databases, and online collections has opened new horizons of research by improving the discoverability of records (including visual records), thereby allowing them to be used as data. However, in this sea of accessible data, there is a growing issue of representation. As cultural heritage organisations continue to deal with challenges regarding gender and race, the sector is still looking for best practices to enhance diversity and make their digital collections more representative. When images are potentially harmful, or pose ethical challenges (for example, when they show images of colonialised populations described in racist terms), it is often easier to keep them hidden away and inaccessible. The vast digitisation efforts of the past two decades have therefore led to divergent outcomes: visual archival images have become more accessible, and yet, vast troves of images are difficult to discover and use —

particularly when search engines largely rely on text-based metadata.

In this article, we look at the specific case of archival medical images (taken in a broad sense, to include images used by medical professionals from ancient times to the present day, but also images documenting people who were judged as "abnormal" because of their skin colour, disability, and/or other physical characteristics). Lying somewhere between knowledge and curiosity, medical images of human bodies throughout history have been sources of health information, sociocultural beliefs, and sites of intrigue and taboo. From the highly detailed anatomical drawings in Andreas Vesalius's *De humani corporis fabrica* (1543) and the pregnant bellies depicted in midwifery manuals, to images of the "monstrous" physiognomies of criminals, illustrations of dissected, diseased, pathologized, atypical, and disabled bodies have been in circulation for centuries. In their complex and varied forms, historical medical images present a wide corpus for medical humanities researchers, as well as other medical disciplines. However, these records can create serious ethical challenges in terms of their online accessibility, particularly when illustrations move into photographs of patients or bodies that may be exploitative or of an insensitive nature. Even when these images are over a century old, with increased ethical considerations and the difficulty in categorising a diverse range of collections, historical medical images present one of the most difficult types of records to manage within the heritage sector.

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Medical images can be sensitive in multiple ways. Health-related data and data concerning a person's sex life or sexual orientation are classified as sensitive in legislations such as the European GDPR (General Data Protection Regulation). ^[1] These data are subject to specific processing conditions. However, the GDPR only protects personal data of living persons. It does not apply to the personal data of deceased persons. Archival medical images — especially those produced more than 100 years ago — can be digitised and made available with a public domain licence. These medical photographs, drawings, and illustrations are not sensitive in a narrow, legal sense, and yet they contain sensitivities, including representations of disabilities and diseases (including sexually transmitted diseases and other stigmatised conditions). Bodies that were once considered as abnormal (such as those with different skin colours or people with tattoos, scarification, or other physical characteristics) are frequently featured in medical collections. In the case of more recent collections, the data rights of living people represented in pictures are not the only considerations that archives need to consider. Some of these images can be challenging for other reasons. For example, campaigns against AIDS frequently represented explicit sex scenes to encourage people to use condoms and adopt safer sexual practices.^[2] Once digitised and put online, these images can be accessed by anyone — including children and other vulnerable users.^[3] Archival repositories therefore face a dilemma of whether to show or not show sensitive medical images — and how to decide what is or is not considered sensitive.

While this article focuses mainly on the case of *viewers* of sensitive archival images, the digitisation of such images can also be harmful for the people depicted in them. For example, images of naked children originally taken in a medical context can, once digitised, be accessed and shared without context by anyone, including sexual criminals. In the case of archival documents created in the past 100 years, individuals could still be alive, and (in theory) their consent must be obtained prior to digitisation and public release to comply with the GDPR and other data protection legislation. In practice, many libraries and archives have "take down" policies, which rely on an "opt out" basis (rather than the "opt in" requirement mandated by the law). In the past few years, this approach has been criticised on ethical grounds, with a strong emphasis on privacy and consent.^[4]

Through a series of interviews with 10 heritage professionals and academic researchers working with historical medical image records within archives, libraries, and museums, this study considers key challenges and ethical implications in making historical medical records accessible in the digital age.^[5] Artificial intelligence (AI) can and is being used to improve access to historical medical illustrations, for example by automatically creating metadata, when original metadata contains problematic language or is missing altogether. AI can also help with the disaggregation of data by gender and/or race or ethnicity, where such information is known. Furthermore, AI can be used to suggest similar images through computer vision and machine learning. The objective of such use is to encourage users to explore other parts of these collections and to discover additional materials without typing new keywords. However, AI can also pose challenges, for example by suggesting inappropriate metadata or search results, or by isolating an image from its original context. Keeping humans in the loop is therefore essential when applying AI to sensitive medical images.

Drawing on large, open-access medical image databases, including the Wellcome Collection database and the UK Medical Heritage Library (UKMHL), as well as significant archival collections across the UK, US, and Canada, this article considers some of the broader issues facing the cultural heritage sector and the challenges medical images present. We conducted 10 interviews with professionals in libraries, archives, and museums, as well as academics in the UK and US who had worked with digital collections of medical images open to the public. The study had a limited scope, focusing on the UK context (with predominantly UK-based interviewees). However, our in-depth interviews have revealed key information that will be useful to anyone interested in digital medical images — from professionals in libraries, archives, and museums, to scholars in the digital humanities and medical humanities, as well as medical researchers and healthcare professionals. The intention of this article is to identify challenges with digitisation, metadata, and wider concerns regarding the gender data gap, diversity, and decolonisation through the accessibility (or inaccessibility) of medical images.^[6] This article presents theoretical and practical approaches to making these important resources more accessible and/or usable to users. The decisions made regarding representation in historical medical records can be key to discussing broader issues of representation across the galleries, libraries, archives, and museums (GLAM) sector.

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The main objectives of this article are to:

- Outline the key issues and challenges associated with historical medical images, both illustrative and photographic
- · Address the ethical considerations for making medical images more accessible
- Consider the current and potential uses of AI in medical visual collections and the challenges associated with AI
- Recommend potential solutions to the problems of access to sensitive archival images, with a focus on balancing access and responsibility

The first section of this article looks at the discoverability and usability of archival medical images. We then examine issues associated with the diversity and representativeness of collections. Section 3 explores initiatives to change or enrich metadata to increase representativeness. The final section focuses on AI applied to medical images, including the ethical issues contained therein. The conclusion features take-away points to encourage GLAM professionals to find the right balance between access and responsibility, namely by paying constant attention to the needs of children and other vulnerable users.

Section 1: Discovering and Using Archival Medical Images

Current scholarly literature on the use of medical images occupies broad fields of study, from the glossy images included in art history publications, such as Domenico Bertoloni Meli's *Visualising Disease* (2018) or Richard Barnett's *The Sick Rose* (2014), to the use of historical medical images in modern medicine and AI datasets [Krasnoryadtseva, Dalbeth, and Petrie 2020] [Delp and Jones 1996] [Hajar 2011] [Rubalcava and Gadepalli 2021] [Bamba et al. 2021]. According to [Rea et al. 2017], while medical museums have often been a place of restricted access, the digitisation of medical artefacts is becoming more widespread and "can enable wider access" to the "rich history of medical science".

For example, medical illustrations can provide evidence for medical professionals studying the history of particular diseases. As one interviewee told us:

Maybe it's for diseases which people no longer get, but actually in terms of symptoms and in terms of diagnosis and just understanding how diseases have developed, that picture can tell them an awful lot about [another] disease present 200 years ago that maybe doesn't exist now or doesn't exist in that form now.^[7]

Issues such as copyright on modern images in medical textbooks mean that education providers are experiencing an increase in litigation cases for unauthorised use of copyrighted medical materials, particularly in the increasing uses of online resources in medical training [Gutman 2011] [Dmytriw, Sadler, and Neumann 2015]. But, as [Dmytriw, Sadler, and Neumann 2015] suggest, older, out-of-copyright images and those licensed through Creative Commons could be

updated using digital tools, thus improving access to anatomical illustration for educational purposes. Indeed, many medical illustrations from the earlier twentieth century are highly accurate and suitable for training modern medical practitioners, with a little updating.

Many of these older illustrations are openly accessible. There are large collections of global historical medical images available through the Wellcome Collection database^[8], a go-to for medical humanities researchers, with over 1 million items in their online catalogue. More specific digital collections include the nineteenth-century European medical records available in the UK Medical Heritage Library, which are available to search via a number of visualisations, including body parts and medical conditions.^[9] There are also extensive digitised collections in UCLA's Index of Medieval Medical Images^[10] and the University of Toronto's Anatomia Collection: Anatomical Plates 1522–1867^[11], as well as further records on Europeana.^[12] The National Library of Medicine (NLM, Maryland, US) provides an Open-I search for medical images^[13] and allows users to filter results to show images from their History of Medicine Collection.

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These large, digitised collections are often supplemented by a series of funded projects, which allow smaller institutions to make their collections accessible. As storage and digital interfaces can be important practical issues, especially for smaller institutions, this is one way to help provide access and limit the disparity of archival materials. Katie Birkwood, Rare Books and Special Collections Librarian at the Royal College of Physicians (RCP) London, told us that "in 2015 and 2016, [they] were part of the UK Medical Heritage Library project that Wellcome ran with the Internet Archive" and that the RCP "digitised about 4,100 of our nineteenth-century books, across the theme of medicine" for the site.^[14] Although the RCP does not have the capacity to host its own digital database, the Internet Archive has allowed the college to host some of their digitised materials online. While these types of digitisation initiatives are helping to make archival collections more accessible, they still come with limitations and compromises due to funding, metadata, and the practicalities of digitising potentially fragile materials. For all the visibility of the bodily forms in these historical records, many medical image collections remain inaccessible online, or else siloed within individual catalogues, often with thin metadata, out-dated terminologies, or missing contextual records. Many items are lacking the machine-readable data necessary to create meaningful connections between records. In this way, visual materials continue to pose considerable problems for institutions when it comes to cataloguing and discoverability, as well as display and dissemination [Tsafrir and Ohry 2001]. Entire collections are locked away when they are considered too sensitive (for example, images of skulls and bodies of the deceased, taken during the colonial period). Paradoxically, in the age of mass digitisation initiatives, researchers often face challenges in discovering, sourcing, and contextualising medical illustrations, which have played a significant role in our understanding of medical and social history.

The lack of metadata and the sensitivity of records are not the only obstacles to access. The format of the materials can also make digitisation complicated. From cheaply printed health books to fully illustrated anatomical atlases, these visual and often multimodal records vary in size and quality, featuring different types of images — from woodcuts and black-and-white prints to coloured illustrations and photographs. Medical atlases, for example, are often very large in size, are used as teaching resources, and are difficult to digitise without specialist equipment. These types of records can also require manual appraisals to make them accessible for online databases, which is often beyond the capacity of many institutions. Additionally, the formal diversity of these records poses challenges for existing automation tools trained on photographic images, such as CAMPI (Computer-Aided Metadata Generation for Photo Archives Initiative), which struggle with illustrated images.

Due to their size and fragility, non-bound illustrations are often not a priority or at times even an option for digitisation, meaning that many visual medical records are restricted to in-person reading room tables. Due to the ease of scanning and the availability of host-sites, such as the Internet Archive, it is bound books, both published and non-published, which are predominantly the items selected for digitisation. Katie Birkwood (RCP) told us that in the case of the Medical Heritage Library project, small books could easily fit on a regular scanner. Other formats were less likely to be selected for digitisation: "Anything that had to go on an oversized scanner, we had to be very picky about and so fewer of those got sent. And if something's in bad physical condition, you're less likely to send it."^[15] The RCP has a collection of 250 large-scale anatomical illustrations, which are not bound and are not available online. "We can't use the Internet Archive

and access portal because it's not really what it's for", said one archivist. ^[16] Items that have been selected for digitisation in part due to their format become more accessible, but also risk being seen as more valuable than others. And when items prioritised for digitisation, and even for preservation, are imbibed with the impression of value, it perpetuates further issues in diversity and representation.

In addition to format, external funding has an impact on the decisions to digitise some images and not others. As Daryl Green, Library and Information professional for the University of Edinburgh told us, "what's getting prioritised for digitisation is what's getting funded externally, which is not how an institution should do these things".^[17] The impracticalities that surround the digitisation for many institutions across the GLAM sector — often involving external project remits or limitations due to cost and specialist equipment — mean that there is a risk of false representation happening across the sector, which can affect the types of research being undertaken.

In short, online image collections, although vast, represent records prioritised for digitisation — items that are often selected for their potential interest to database users, their suitability for digitisation, or for specific, funded and themed projects. While images of a medical nature are only one relatively small aspect on a much broader spectrum, they continue to underpin current research in the humanities and other fields. As [Nikolaidou et al. 2022] note, the "growth of digital libraries has contributed to the research on historical documents by providing high-quality digitised images to researchers to process and analyse", meaning the availability of online records has a direct impact on what is being researched.

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Section 2: Issues of Diversity and Representativeness of Ccollections

Access to historical medical illustrations is essential to understand current issues such as ableism (i.e., discrimination and social prejudice against people with disabilities). Medical illustrations have reinforced ableist standards of the human form in medicine and popular culture throughout history. As literacy rates and printing technologies improved across the globe, and as medical texts became more available to public users, the fascination with physical and medical anomalies increased. Interest in racial and cultural differences, disabilities and physical differences, diseases, and injuries expanded throughout the sixteenth, seventeenth, and eighteenth centuries, continuing well into the nineteenth and twentieth centuries. These periods saw a huge increase in the production of medical illustrations and images, including depictions of bodies labelled as "monstrous". The depiction of "monstrous" births in reproductive manuals, for example, is indicative of the increasing public fascination in anomalies from an increasingly connected world, and, while unsympathetic and stigmatising, do demonstrate a move away from a "standard" representation of the body in historical medical works. Several of these types of images are available on the Wellcome Collection online image catalogue, for example. However, the image database also demonstrates some of the issues this article wishes to address.

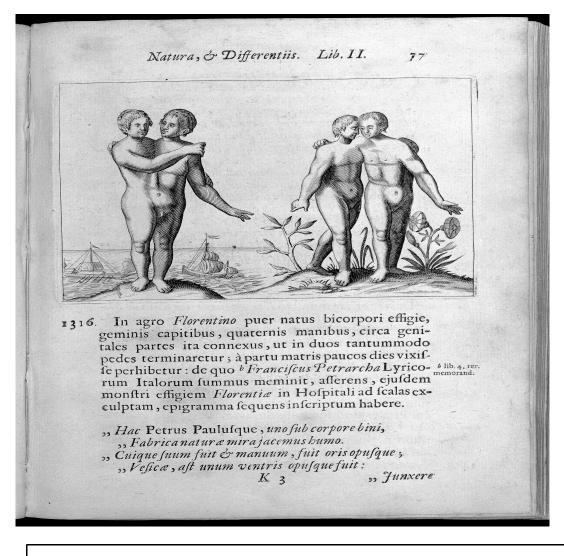


Figure 1. Two human figures with abnormalities. Public domain. Source: Wellcome Collection, https://wellcomecollection.org/works/hyy38v99.

When searching on the Wellcome's image collection for the keyword "monstrosity", a common phrase used to describe a discriminatory facet of historical medical literature, there are image results that have been entirely removed from their original context, including photographs, and some that lack any further description. Similar results occur when searching the word "abnormalities". Examples include a black-and-white printed image of baby twins conjoined at the stomach^[18] and another similar image of adult conjoined twins titled "Two human figures with abnormalities" and assigned the following subject keywords: "monsters; abnormalities; abnormality; Siamese; conjoined twins."^[19] Although these images have clearly been taken from illustrated medical texts, their tags and keywords have been generated using Al tools based on very little data. While the Wellcome Collection continues to make improvements to their image collection, their database is supplemented with an image similarity search that utilises machine learning, which, unfortunately, can present further mis-association and misinterpretation of sensitive medical images. With such thin metadata available and the evident inadequacies of similarity searches, particularly for sensitive materials, these digitised illustrations are difficult to contextualise without further research and investigation. Moreover, the limitations of historically relevant keywords present ethical considerations in the balancing of historically accurate terminology and record discoverability.

Improving the discoverability and accessibility of medical illustrations and their original contexts could also help researchers to understand the ongoing gender data gap in healthcare. Historians such as Ludmilla Jordanova have argued that medical texts and images reinforced the idea that the white, male, able body was the standard of the human form, with the only real difference in female bodies being their reproductive systems [Jordanova 1989]. This androcentric view has been perpetuated by the availability of digital records and anatomical images. Indeed, most figure-based images included in medical literature from the fifteenth to early-twentieth century largely show explicitly

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female anatomy only to demonstrate pregnancy and birth, or to distinguish female genitalia. As Elinor Cleghorn has argued, the perception of the female body throughout history was, medically, socially, and culturally speaking, dictated by the possession of a uterus [Cleghorn 2021]. The trend in depicting mostly male bodies in historical medical materials is often put down to the lack of female test subjects. The subsequent medical studies that have developed based on male bodies are underlined as one of the major reasons why women's diseases are still being misdiagnosed [Young, Fisher, and Kirkman 2018] [Maas and Appelman 2010] [Fairweather and Rose 2004]. This trend and the gender data gap in medical research it represents continues to persist to this day [Merone et al. 2022] [Criado-Perez 2019] [Cleghorn 2021].

Efforts to address this gender data gap have acquired mainstream visibility thanks to the work of activists such as Caroline Criado-Perez, the author of *Invisible Women: Data Bias in a World Designed for Men.* According to Criado-Perez, the "male-default bias" in medicine has been evident since at least the ancient Greeks, who saw the female body as a "mutilated male", where ovaries were simply underdeveloped testicles inside the body. The perception that the able, male body is *"the* human body" [Criado-Perez 2019, 196–197] persists even though, as modern research has shown, hormonal differences have been found to affect every tissue and organ system in the entire human body [Keitt et al. 2004] [Phillips, Gee, and Wells 2022].

The over-use of the male body in history continues to plague contemporary medical knowledge. From the work of Leonardo da Vinci and Vesalius through to one of the best-known illustrated medical texts, Henry Gray's *Anatomy of the Human Body* (1859), medical illustrations of the human body have historically been idealised depictions of what was unlikely to be ideal specimens. These illustrations have been copied, altered, and reprinted over centuries — and are now the main images that get prioritised for digitisation. Indeed, many of the original drawings in Gray's *Anatomy*, wood-engravings by Professor Henry Van Carter, have appeared in subsequent editions, even to the modern day [Tsafrir and Ohry 2001]. These illustrations are not inaccurate, and they are often the images that are now most readily available in digital medical collections, including those held by the NLM and Wellcome Collection. The issue is not only one of accuracy, but of representation.

The gender data gap, reinforced by the lack of diversity in historical medical images, feeds into broader social issues. Discussing the problematic maternal mortality rates in the United States, "particularly with non-white populations", Emily Beck (Assistant Curator at the Wangensteen Historical Library of Biology and Medicine) asked:

[W]here can we see the fingers of that in earlier material? What happens when all you see are very well-fed, white male bodies in the prime of their life, and ask them, "What do your anatomy texts look like? Who is represented there? What does that do for the kinds of research that you have?"^[20]

As we have seen, historical medical images have been dominated by the standard of white, male, able bodies — but they can also feature some diversity. As highlighted by Keren Rosa Hammerschlag's investigation into Friedrich Tiedemann's *Tabulae arteriarum corporis humani* (1822), translated into English in 1829 as *Plates of the Arteries of the Human Body*, some medical atlases did feature a diverse range of anatomy from males and females [Hammerschlag 2021a]. Indeed, according to William Schupbach (Research Developer, Wellcome Collection) a "smaller number of works, mostly eighteenth or nineteenth century, which concentrate on viscera, show men and women", and the decision to represent different bodies "really all depends what the purpose of the illustration is".^[21] While the purpose of an image can draw many interpretations, taking an example from nineteenth-century surgeon Joseph Maclise's more inclusive work, *Surgical Anatomy* (1851), Hammerschlag has drawn attention to the representation of a black male subject in the London edition, as well as the deliberate removal of the same figure in the American edition published the same year in a context of heightened racial tensions [Hammerschlag 2021b]. Archival medical images can therefore offer a broad spectrum of social and cultural attitudes towards gender, race, and ability, representing key sources in tracing the dissemination of medical knowledge in any given period — but only if they are accessible.

Section 3: Changing metadata to increase representativeness

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While we consider the potentials of these images for use in the modern day, we must pause to ask: is it possible to create a more diverse archive? Precedents exist. In the 1960s and 1970s, feminist archivists and historians established new archival collections needed to write women's history. In this study, we want to highlight the specific issues that occur when women are largely invisible in archival collections.^[22]

Where records, illustrated and non-illustrated, have been digitised, the creators of these records and the people represented are seldom defined by gender, meaning that online catalogue and database searches are often unable to distinguish medical records produced by or featuring women, or other under-represented contributors. A staff member at the Wellcome Collection informed us that where gendered data is already available, such as in biographical information held in other online sources, "we will be taking on that extra metadata about gender, birth dates, death dates, locations that they were connected to".^[23] The intention to illuminate under-represented groups is a central reason for including gender in material records. But it is not without its complexities. Indeed, disaggregating data based on gender is more challenging than applying a binary categorisation. Katie Birkwood told us that items in their catalogue seldom have a marker for author's gender. She added:

[T]hat's a hugely divisive issue in the library cataloguing world, because new rules were brought out a few years ago saying that when you make a name heading file for a person, you should be including gender. And that brings up all sorts of issues with anyone who has transitioned or doesn't have a binary gender, and why should we be documenting gender?^[24]

Birkwood notes that research is being done to help illuminate female contributors and collectors, but often this work is limited by the availability and discoverability of materials. Emily Beck highlighted a similar issue, saying:

[W]e are trying to do our level best to make it easier for people to find these materials, . . . working on making bibliographies of other kinds of populations, like black populations and indigenous [people and yet] we fully acknowledge that our collection is western European. It very much elevates white male voices, and so we're just trying to do our best to address that head-on.^[25]

While the use of gendered labelling does present further considerations and complexity in terms of representation — and risks alienating individuals who have transitioned or do not identify with a binary gender — at the same time, the decision to not disaggregate data (and a lack of guidance on how to effectively disaggregate data, particularly around gender), is disguising under-represented contributors, not least in the history of medicine. As Professor Fay Bound Alberti (Kings College London) pointed out: "what are our responsibilities to the historical subjects [as the] ways in which images are produced are always embedded in the sexism and racism of the time?"^[26]

One approach, as Lois Hendrickson (Curator, Wangensteen Historical Library of Biology and Medicine, University of Minnesota) discussed, is to recover marginalised groups and individuals in catalogue data. In a new initiative, the library is focussing on three topics — women, disability, and black history — to help improve representation within their special collections and rare books. Hendrickson is working to address gender with a colleague who took common women's names in French and English from the nineteenth and twentieth centuries and ran that against the catalogue to create a Python script to improve the records, using Open Refine.^[27] Emily Beck, continuing the discussion of disaggregating data by gender, suggested that relevant materials are "difficult to locate . . . , especially if you are relatively inexperienced in terms of searching in library catalogues, and we want to make sure that people are able to study the history of voices that are not necessarily raised up very frequently in the historiography".^[28] Beck and Hendrickson advocated that the Wangensteen Library are doing what they can to ensure that the collection is "a more robust representation of a global history of medicine".^[29] While there is a willingness to approach these prominent issues in representation, many of the potential solutions are currently siloed within individual institutions.

Current debates on representation, diversity, and language used in archival collections have also led to broader changes of metadata considered offensive or otherwise problematic. Discussing representation and search terms for images, interviewees from the Wellcome Collection described the decision to remove the term "rodent disease" from the

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headings in a nineteenth-century collection, "Gentlefolk of Leeds afflicted with disease". For example, the collection includes an 1820 oil painting representing a young man, J. Kay, "afflicted with a disease which has eaten away part of his face" (Figure 2).



Figure 2. A young man, J. Kay, afflicted with a disease which has eaten away part of his face. Oil painting, *ca. 1820.* Attribution 4.0 International (CC BY 4.0). Source: Wellcome Collection, Ref #603117i, https://wellcomecollection.org/works/gzgzm2sf.

As William Schupbach (Wellcome Collection) noted:

"Rodent disease" to mean cancer is a common nineteenth-century term. So, the original catalogue record reflects terminology of the date of the portrait. The new description is not contemporary with the portrait, but it doesn't distort — it doesn't say, "He's got cancer", or, "He's got syphilis". It just puts into plain language of the twenty-first century, and indeed twentieth century, by saying, "It appears to eat away part of his nose". Eating away is what "rodent" means, so it's simply replacing the Latin medical term with an English vernacular term.^[30]

There are several layers of metadata here, with the addition and then deletion of the phrase "rodent disease", yet the term is still searchable. The original title inscribed on the verso of the painting ("Cancer of the nose") was considered inexact by the cataloguer, who added the following metadata: "[H]e seems to have 'Hutchinson's teeth', a symptom of congenital syphilis, the inscription may be a euphemism".

Changing metadata with the intention to remove problematic terms can in turn lead to more challenges. As another staff member at the Wellcome Collection told us:

I've gone back to look at all these Leeds portraits and there's not been a uniform decision around the language. So that's one of the challenges I think we have, that there are so many of these scenarios, when do we stop and what do we do?^[31]

In making these decisions, while aligning with current equality, diversity, and inclusion initiatives, there is a significant lack of guidance and best practices in dealing with visual records, particularly those of a potentially sensitive nature. Often the decisions to change or alter records are being done in house, and those decisions, without explicit best policy guidance, are a serious challenge. As Emily Beck told us, "[T]hinking about what happens when we change the language to make it more appropriate — does that actually make it harder to locate those materials?"^[32] In updating metadata and terminology, there are "huge red flags and warning signs that come up when you start trying to explicitly tag images", as one professional at the Wellcome Collection told us.

Changing metadata is problematic, but leaving outdated terms can be an even bigger issue. "We know that every computer vision system out there is full of biases that we don't necessarily want to perpetuate within the collection", said the same Wellcome professional. They continued, "But equally the data set that we have is historical, [and] does contain all sorts of biases itself that we don't want to project forwards out into the world and the future".^[33] With growing awareness that AI systems are trained using all kinds of data (including metadata from digital archives), GLAM professionals are increasingly reluctant to leave outdated metadata unchanged. In doing so, they are departing from traditional archival thinking, which views the role of the archivist as neutral, committed only to preserving the fonds without changing anything in the records or their original classification. This thinking, which finds its origins in the nineteenth century, is increasingly being challenged by a new vision of the archivist as an activist who actively intervenes in the collection.

This change is, arguably, a necessary one in the digital age. Once online, images are continuously copied, adapted, updated, and reused — just as the earlier printed versions were, although on a far greater and more immediate scale. The Europeana database, for example, provides search results from the Wellcome Collection image database. So even when records are updated with more appropriate data, other versions can continue to carry outdated language. As one interviewee at the Wellcome Collection told us:

[T]he problem we have with those is a lot of them are already in circulation online — on Twitter, on Wikimedia — lots of different places. . . . Well, should we take them down? Should we restrict access if we know that they're already out there? Or do we try and sort of improve what we have and try and improve the accuracy by updating our record?^[34]

This issue highlights the ongoing complexities of accessibility and responsibility, particularly for images that can appear without their original contexts. How can representation be controlled in a vast sea of digital access?

Section 4: AI Applied to Medical Images

With the current mass-digitisation initiatives for many archives, the use of AI tools to process such large amounts of digitised and born-digital archival data is becoming a necessity.^[35] However, the application of AI within the cultural heritage and information management sectors is still associated with challenges and criticisms, and many of our interviewees suggested that manual processing remains the preferred technique, particularly when dealing with ethical issues and problems in representation. Daryl Green (University of Edinburgh) told us:

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[I]f you were to ask me, "I'm going to give you a hundred-thousand pounds for a year. You can put that towards just cataloguing your immense backlog of archival material or you can put that towards fooling around with AI technology", and ten times out of ten I'm going to say backlog, because that's what's needed.^[36]

In this perspective, AI is not seen as a priority when there are more urgent tasks to complete — such as cataloguing collections that are currently inaccessible.

While there is some resistance to applying AI to collections, cataloguing and manually adding metadata to huge numbers of digital images is often not possible and can inadvertently create a larger backlog. In order to automate the process, AI can be used to create new metadata when original information is incomplete or missing altogether, or when it includes potentially harmful or outdated language. Using computer vision, it is possible to identify people featured in images, in order to enrich the metadata and humanise individuals who were frequently described with generic, discriminatory, and sometimes racist language. AI can also serve to disaggregate data by gender and/or race or ethnicity, and it can provide sensitivity reviews. Following recommendations on gendered metadata [Havens et al. 2022] [Lee, Guo, and Nambudiri 2022], it is possible to enrich historical medical images and medical texts with such data. Improving access to historical medical record through digital technologies and data categorisation is crucial to furthering medical humanities research in the digital age. Such improvements would allow the cultural heritage sector and researchers to engage more readily with concerns in the representation of disability, gender, and race in historical records [Akers et al. 2021] [Massie et al. 2021] [Parker, Larkin, and Cockburn 2017] [Brilmyer 2018] [White 2012] [Whelan 2020].

While this may be possible for some archives, we also acknowledge that these technologies are not widely available and that they require specific skills and funding to implement. An alternative to active intervention on the metadata is to suggest similar images, thus providing more context on a collection. This is the option currently chosen by the Wellcome Collection, which utilises a machine learning algorithm to provide a "visually similar images" search feature across their collection. While this visual search allows for certain images to be brought together without relying on accompanying metadata, computer vision tools for historical images and illustrations are notoriously inaccurate [Foka 2021] [Aske and Giardinetti 2023]. As one staff member at the Wellcome told us:

When you type in the word "skeleton", the search engine doesn't look at the images at all. It looks at the descriptions of those images — the captions, the titles, the whatever — and if a thing matches those titles, then you get a result. But the results are not always great, particularly in a collection of data that is as messy as ours. . . The example at the front of my mind is that there was a very kind of tight cluster of words that related to food, and in the visual features that we extracted from images, it was hard for the computer vision algorithm to differentiate between pictures of meat and pictures of gory surgery. An algorithm doesn't necessarily know how to differentiate that context.^[37]

There are other examples of inappropriate images suggested by the "visually similar images" tool. For example, the Wellcome Collection catalogue features a poster of a breastfeeding mother used in a health campaign in Belgium after the Second World War, alongside a photograph of a male prostitute.^[38] The caption of the latter image ("A rent boy offers himself subject to use of a condom; an advertisement for safe sex by the Deutsche AIDS-Hilfe") and the date provided for picture (the 1990s) bear little resemblance to the metadata for the breastfeeding poster. The visual aspects of the two pictures are also dissimilar, with two women and a baby on the one side, and a young man on the other side. And yet, these two images are presented as "visually similar". A disclaimer states: "We use machine learning to find images in our collection with similar shape and features". Users are invited to get in touch if "something doesn't look right". The onus to report problems is therefore transferred to users, instead of resting with the archival institution.

While the accuracy of such tools is still in development, image-based searches cannot fully replace text-based research queries, even if both have their limitations. As suggested by the team behind *Towards a National Collection: Deep Discoveries* at the end of their recent project examining use of computer vision within the cultural heritage sector, archival databases need to provide users with hybrid search options or "generous interfaces", enabling both keyword and visual searches, to increase accessibility and representation.^[39] But this is still a long way from being the standard practice.

Further to the issue of enabling access is being able to responsibly manage that access. Ethical issues regarding digital medical images are often associated with the changing audience for these images — from a restricted readership to anyone who has access to the internet. When records are made openly available online, they can be accessed by viewers who might be shocked by what they see. Explicit images of surgery or of sexual practices are clearly not

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suitable for children, and yet, they are widely available. According to the sociologist Deborah Lupton, medical illustrations have

moved from being exclusively the preserve of medical students and surgeons to being open to the gaze of all. Online technologies now allow anyone with access to a computer to view highly detailed visual images of the inside of the body. Although these images may have been produced for medical students and medical practitioners and other healthcare workers, they are readily available to the general public. [Lupton 2014, 172]

Digitisation of medical images therefore comes with a number of serious ethical considerations considering what should and should not, be made available to the public.

As Temi Odumosu highlights, navigating potentially sensitive images is an enormous ethical challenge for cultural heritage institutions [Odumosu 2020]. Indeed, the identification of racially and culturally insensitive records and the decolonisation of archives are at the forefront of current policy changes across institutions, as decolonisation statements are being made available to users of online archival databases across the UK, US, and Europe. These policies address the use of outdated language, insensitive terminology, and the cultural prejudices prevalent at the time of record production, acting as a pre-warning for database users. Moreover, informed consent doctrines have guided data collection endeavours for several decades, particularly in the medical and science sectors concerning human subjects. However, according to Vinay Uday Prabhu and Abeba Birhane, the age of big data has gradually eroded issues of consent, privacy, and agency. Large-scale image datasets, like ImageNet, have troublesome labelling, as well as a lack of sources or context. Yet such datasets are being widely used to train machine learning and computer vision models [Odumosu 2020].

Indeed, as [Yang, K. et al. 2020] suggest, computer vision technology is being used by many, but it is representative of only a few. Computer vision has indeed faced challenges in its poor performance regarding underrepresented groups. For example, it is notoriously bad at accurately identifying non-white faces. This is because most computer vision and machine learning tools are trained using images from internet-based sources, containing high quality, colourised images with a clear subject focus, but often lacking diversity.

While facial recognition tools are still trained on images of similar-shaped faces, such automation leaves images of faces and bodies that are not considered the norm undeterminable and, as a result, largely invisible on online archival databases, even where visual image searches are enabled. Such medical images therefore provide serious ethical and practical challenges for archival record managers. As Tsyng-Yi Lin et al. acknowledged in an influential essay published in 2014, recognition systems perform fairly well on iconic views of objects (profile, centralised, and unobstructed), but struggle to recognise objects otherwise [Lin et al. 2014]. Much progress has been made in the field of computer vision since then, but the tools remain imperfect. Moreover, as [Wang et al. 2019] have discovered, even when datasets are balanced, for example in terms of gender, trained models can significantly amplify the association between labels and gender, even to the same extent as if the data had not been balanced. A biased dataset, according to [Deviyani 2022], is one that generally has attributes with an uneven class distribution, meaning that tools trained on these datasets perform badly for minority classes. In the case of computer vision and image recognition software for images of persons, the distribution of racially and gender-diverse images, as well as the types of images, will have a direct effect on the efficiency of the tool.

One significant area that has faced backlash within the field of computer vision is the recent reanimation of the ancient, pseudo-medical practice of physiognomy^[40] within machine learning algorithms applied to images of faces at scale [Stark and Hutson 2022] [Goldenfein 2019] [Zhang et al. 2017]. When facial-recognition algorithms are trained on large, existing datasets such as IMDB-WIKI, the largest dataset of human faces with age and gender tags, the bias towards conventionally attractive, "celebrity" faces directly informs the effectiveness of the tool. According to Luke Stark and Jevan Hutson, the use of such facial recognition datasets is a matter of "urgent concern". The automated reading of a human's bodily composition, gender, race, expression, and physical characteristics based largely on "celebrity" images mirrors the ancient and unequivocally ableist practice of physiognomy — idealising conventionally attractive faces — in

a way that Stark and Hutson deem to be "oppressive and unjust" [Stark and Hutson 2022]. While there will always be drawbacks to the use of AI in the recognition of images, especially those of human beings, we must proceed cautiously, especially as AI becomes a greater part of the world. We must continue to build more diverse databases, and the diversity of human figures in medical image collections could offer a way to help to address this current imbalance. If more images of the human body in all its varied forms were available as machine-readable datasets, automated visual identification technologies could be better trained to identify a wider diversity of bodies using explainable AI approaches.

Conclusion

This article has argued that access to archival medical images is generally advisable, although the subject demands further discussion and communication between researchers and professionals in data and record management. Keeping entire collections hidden because they contain potentially harmful or outdated metadata, or because they represent scenes that we find disturbing, is not sustainable. There is no point keeping archival materials that are never used. Moreover, the reliance of AI systems on high-quality data means that it is risky to restrict the sources used to train these systems. Without diverse sources, the risk is that AI relies too much on similar datasets (for example, images of male, able bodies). In turn, this can lead to unsatisfactory outcomes when AI is used to add metadata, in the case of missing or incomplete data. Likewise, when AI is used to improve search functionalities based on image similarity, it produces better results when it has been trained on large and diverse datasets. Well-trained AI systems can lead users to discover images in parts of the collections they would not have encountered without computational assistance.

However, access cannot be separated from responsibility. The digital revolution has evolved in a landscape of permissiveness and lack of regulation, leading to the loss of privacy and other socially disastrous consequences.^[41] In the case of Molly Russell, a 14-year-old British girl who died by suicide after viewing harmful social media content, the inquest into her death found that tech companies such as Instagram and Pinterest were not doing enough to protect vulnerable users. The images that Molly viewed should not be pushed to children's accounts by algorithms, the senior coroner found. The family's legal representative compared the impact of the digital revolution on children with that of the industrial revolution: "It is a feature of all revolutions that they tend to put progress first and safety of the vulnerable second" (quoted in [Milmo 2022]). This parallel between the lawlessness of the digital revolution and that of earlier revolutions has famously been developed in Shoshana Zuboff's *The Age of Surveillance Capitalism* (2019). The toxicity of online content is also at the heart of Gaia Bernstein's *Unwired: Gaining Control over Addictive Technologies* (2023), which compares the disastrous consequences of the unregulated digital revolution to the ravages of the once unfettered tobacco industry.

There is not a lot of difference between encountering harmful content on Instagram or Pinterest and encountering it on the digital platform of a GLAM institution.^[42] For example, a child preparing a school project could come across explicit photographs on the Wellcome Collection platform, as we have seen in the introduction. More should be done to protect these vulnerable users. For collections that contain sexually explicit or violent images, platforms should implement age verification using an independent third party.^[43] This is the model that the French government has recently pushed for, in its attempt to regulate the online pornography industry. Keeping humans in the loop is essential when applying Al to sensitive medical images. It is not responsible to use Al to suggest "visually similar images" without human control. At the very least, sensitive images should only be viewed after age verification and after clicking to indicate consent following a content warning.^[44]

Finding the right balance between access and responsibility is not easy. It requires regulations at the national level to protect minors and other vulnerable users from encountering potentially distressing, violent, and sexually explicit online content. But it also requires professional guidelines to determine *how* to show potentially harmful images to an audience of non-vulnerable users. In the absence of guidelines, GLAM professionals are too often left on their own to design alternative metadata in the case of outdated, racist, or otherwise problematic language. They are again left on their own when it comes to displaying sensitive images. Releasing vast amounts of sensitive content without any oversight could lead to unintended consequences, the severity of which for vulnerable users cannot be underestimated.

Following Gaia Bernstein's example, we would like to offer these takeaway points to encourage further discussion and

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research in the topic of access to sensitive images:

- Hiding sensitive medical images is not a viable option for several reasons: archives are meant to be used, not locked away; having more images available would diversify datasets, potentially leading to social good — including addressing ableism and decreasing the gender data gap.
- Al can be used to make images including sensitive images more discoverable and accessible. For example, Al can be used to add a new layer of metadata, or to suggest similar images in other parts of the collection, and to offer users content warnings.
- However, access cannot be separated from responsibility. It is not responsible to release sensitive images without any oversight, or to push sensitive content to users who have viewed images considered similar.
- More national regulations and professional guidelines are needed to prevent children and vulnerable users from encountering sexually explicit, violent, or otherwise problematic images.

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Notes

[1] See Article 4(13), (14), and (15) and Article 9 and Recitals (51) to (56) of the GDPR.

[2] For examples of explicit sexual images made available via the Wellcome Collection online catalogue, see *A naked man shaving*... (https://wellcomecollection.org/works/k2effvut), *Two Naked Men Holding Penis Models*... (https://wellcomecollection.org/works/actceyfe), *Two Men Performing Anal Sex*... (https://wellcomecollection.org/works/e4avd4xz), and other advertisements by the "Core Program".

[3] In this article, "vulnerable" refers to "a person in need of special care, support, or protection", for example because of age or disability. See "vulnerable (adj.), additional sense", Oxford English Dictionary, March 2024, https://doi.org/10.1093/OED/1825525669.

[4] In a 2017 article, Michelle Moravec used the example of the feminist magazine *Spare Rib* to encourage other researchers to ask the following question before using digitised archives: "Have the individuals whose work appears in these materials consented to this?" [Moravec 2017, 186]. Making such documents available on the internet has raised the issue of consent as well as the ethics of widely releasing sensitive or private materials intended for other uses.

[5] For a discussion on ethics in relation to medical images, see [Keet and Kramer 2022].

[6] While the authors recognise that the global scope of these interviews is limited, interviewees were approached based on their work with large-scale, digital medical image libraries available to search in English that are publicly accessible within the UK. This meant focussing on major UK institutions with open-access digital medical image collections. Further interviewees were sourced through their work with or curation of these medical image collections to explore practical uses of medical images as research tools. In addition to the largely UK focus, we have included interviews with professionals exploring the educational uses of historical medical images in modern medical training at the University of Minnesota

[7] Anon., interview, 14 December 2022, via MS Teams.

[8] See https://wellcomecollection.org/images

[9] See https://ukmhl.historicaltexts.jisc.ac.uk/home.

[10] See https://digital.library.ucla.edu/catalog/ark:/21198/zz0002fn7s

[11] See https://anatomia.library.utoronto.ca/. This collection features approximately 4,500 full page plates and other significant illustrations of human anatomy selected from the Jason A. Hannah and Academy of Medicine collections on the history of medicine at the Thomas Fisher Rare Book Library at the University of Toronto. Each illustration has been fully indexed using medical subject headings (MeSH), and techniques of illustration, artists, and engravers have been identified whenever possible. There are 95 individual titles represented, ranging in date from 1522 to 1867.

[12] See https://www.europeana.eu/en.

[13] See https://openi.nlm.nih.gov/.

[14] Katie Birkwood, interview, 14 December 2022, via MS Teams.

[15] Katie Birkwood, interview, 14 December 2022, via MS Teams.

[16] Anon., interview, 14 December 2022, via MS Teams.

[17] Daryl Green, interview, 12 January 2023, via MS Teams.

[18] See https://wellcomecollection.org/works/x9gb8vkw.. This image is also available through the same keyword search on the University of Toronto's Anatomia library, but there is more contextual information provided: https://collections.library.utoronto.ca/view/anatomia:RBAI072_0107.

[19] See https://wellcomecollection.org/works/hyy38v99.

[20] Emily Beck, interview, 12 January 2023, via MS Teams.

[21] William Schupback, interview, 12 January 2023, via MS Teams.

[22] Work in this area is ongoing. For example, see the UK-based project for recovering women's contribution to the book trade within archival collections, led by Helen Williams and Ruth Frendo, "Communicating Women's Work in the Historical Archive", available at: https://womenmakingbooks.wordpress.com/projects/.

[23] Anon., interview, 13 January 2023, via MS Teams.

[24] Katie Birkwood, interview, 14 December 2022, via MS Teams.

[25] Emily Beck, interview, 12 January 2023, via MS Teams.

[26] Fay Bound Alberti, interview, 17 January 2023, via MS Teams.

[27] Lois Hendrickson, interview, 12 January, via MS Teams.

[28] Emily Beck, interview, 12 January 2023, via MS Teams.

[29] Lois Hendrickson, interview, 12 January 2023, via MS Teams.

[30] Schupback, interview, 12 January 2023, via MS Teams.

[31] Anon., interview, 12 January 2023, via MS Teams.

[32] Emily Beck, interview, 12 January 2023, via MS Teams.

[33] Anon., interview, 13 January 2023, via MS Teams.

[34] Anon., interview, 12 January 2023, via MS Teams.

[35] For specific case studies and examples where AI has been successfully applied to archival collections, see [Jaillant 2022] and the special issue of the *Journal on Computing and Cultural Heritage* (Volume 16, Issue 4, 2023) on "Applying Innovative Technologies to Digitised and Born-Digital Archives" (list of articles available at https://www.aeolian-network.net/outcomes/).

[36] Green, interview, 12 January 2023, via MS Teams.

[37] Anon., interview, 13 January 2023, via MS Teams.

[38] The breastfeeding poster can be found here: https://wellcomecollection.org/works/wsqmrqfj. Then, click "View 1 image" to reach the Images section of the catalogue. Clicking on the image will produce "visually similar images", including the picture of the male sex worker. Clicking on this photo will then lead to sexually explicit pictures associated with health campaigns against AIDS.

[39] See https://tanc-ahrc.github.io/DeepDiscoveries/index.html and https://blog.nationalarchives.gov.uk/deep-discoveries-exploring-a-new-wayof-discovering-and-connecting-digitised-collections/.

[40] Physiognomy refers to "the study of the features of the face, or of the form of the body generally, as being supposedly indicative of character; the art of judging character from such study". See "physiognomy (n.), sense I.1.a", *Oxford English Dictionary*, September 2023, https://doi.org/10.1093/OED/6988649344.

[41] On the lack of regulation, see Zuboff's "Surveillance Capitalism Has Had 20 Years Unimpeded By Law" (quoted in [Kavenna 2019]) and [Zuboff 2019].

[42] We are not arguing that commercial platforms and not-for-profit digital platforms in the GLAM sector are similar. Instead, we are arguing that the viewers' experience of encountering harmful content is not dissimilar on these different platforms.

[43] For more on age verification via independent third parties, see the recommendations of the CNIL (France's national data protection agency) as delinieated in "Online Age Verification: Balancing Privacy and the Protection of Minors", 2022, https://www.cnil.fr/en/online-age-verification-balancing-privacy-and-protection-minors.

[44] For a discussion on content warnings, see Dentler et al., "Sensitivity and Access: Unlocking the Colonial Visual Archive with Machine Learning" in this special issue.

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