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Family not to be informed? The ethical use of historical medical documentation*

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Public interest in war service, particularly in the global conflicts of the twentieth century, has led to increasingly open archival practices. The attestation papers of Australians who served in the First World War have all been digitised and are free to access online. Meanwhile, work to open up Australian post-war repatriation files is on-going. In Canada, the pension files of the roughly 200,000 disabled veterans who returned from the First World War are currently being digitised. In Britain, service records are available through genealogy websites and digital catalogues. A search of The National Archives' (TNA) records will garner the researcher information about the name, rank, regiment and pensionable disability of individuals who made claims for British post-First World War disability pensions, while the Imperial War Museum's online catalogue of manuscripts contains a range of details about donors and their families. The Wellcome Library has digitised the Royal Army Medical Corps Muniments Collection, previously held by the Army Medical Services Museum, making many previously unpublished memoirs and diaries, of both medical service personnel and their patients, freely available online. The centenary of the First World War, meanwhile, has been used by organisations ranging from community research projects to the Red Cross and the BBC both to make records more accessible via online platforms and to solicit material for such projects in the name of memory, commemoration and education.

While the increased accessibility of this range of records is of huge benefit to historians not only of the war but related historical fields, it also raises questions about the ethical use of the information being made available. Many of these archives contain comparatively unproblematic details about individuals, which form the building blocks of much social and cultural history. Some of the content, however, has the potential to reveal sensitive information about the lives of the men and their families. This has implications not only for historians who make use of personal narratives as central primary sources, but also those whose work contextualises specific, sometimes marginalised or even stigmatised, perspectives, such as historians of medicine and disability. It is the implications of accessing, analysing and disseminating sensitive material generated by the patient voice that this chapter considers. In doing so, it contextualises and complicates the analysis in other chapters in this collection, particularly those of Houston and Hanley, in its consideration of the archival afterlife of stigma and its effect on how patients are heard by historians. Creative approaches not only enable access to historic patient experience but suggest ways in which patients and their agency are understood as historical actors beyond the archival records of their conditions. Set within the context of ethical considerations and the requirements of disciplinary norms such as complete referencing, the effectiveness and utility of such approaches can be more fully understood.

Within the context of the wider collection, therefore, this chapter considers the implications of accessing and using patient voice for the policies that govern historical research, such as those relating to consent, referencing and anonymisation. Yet, as with all the chapters in this collection, this analysis also has contemporary relevance due to its focus on the case study of pension files. The sorts of sensitive medical and social material in such files continue to be collected by government departments charged with administering welfare. The collection of such information exposes the systems of state surveillance which underpin such administration. Consideration of the ethics of accessing and analysing such material highlights the role not only of the historian in perpetuating such surveillance practices, but also archivists and those engaged with policies around the digitisation of historic materials. As governments and institutions across the globe turn increasingly to digital practices to preserve data and disseminate historical material, the question of the ethics of such preservation becomes ever more important.[1]

In exploring these questions of ethical approach and their policy implications, this chapter uses as its starting point a case study of the British soldiers' pension files created during and after the First World War. The paperwork generated by the bureaucratic processes associated with the First World War, including enlistment and conscription, service and demobilisation, were collected in these files. All have the potential to reveal intensely personal details of men's bodies and lives, including as they do everything from vital statistics to marital and employment status and religious affiliation. After the end of the war, the process for applying for a pension created paper trails with the power to expose the personal experiences of disabled ex-servicemen, sometimes in intimate detail. Take, for example, the case of a British man who had been stationed in India, whose wife bore two illegitimate children while he was away at war before he succumbed to oesophageal cancer, leaving his legitimate daughter in the care of an orphanage in Kodaikanal.[2] Then there is the case of the ex-serviceman, with stricture of the anus and subsequent incontinence, who abandoned his wife and three children when he migrated to America and subsequently to Canada. The Ministry of Pensions paid his pension, in full, to his estranged wife and marked his file 'Man not to be informed' after the Ministry discovered his indiscretions. This was despite attempts by the man to get the pension commuted to a lump sum and paid directly to himself.[3] These two examples are taken from the 22,829 British Ministry of Pensions files that form the PIN 26 series at TNA. As well as publicly accessible information such as name, rank, regiment, date of birth and theatres of service, this series contains sensitive details of medical conditions and diagnoses, as well as material concerning stigmatising social circumstances, including domestic violence, prostitution, illegitimacy and even potentially criminal activity.

The potential of this archive as a resource for historians of medicine, disability and twentieth-century British society is immense, as is demonstrated by the range of scholars who have used it in their research.[4] The Men, Women and Care project at the University of Leeds, which is utilising this archive to examine the care provided to disabled ex-servicemen of the First World War in relation to religious charities, social stigma, distance and disability, is the first project to attempt a comprehensive analysis of this archive. Moreover, it is the first actively to consider the ethical implications of using such material in historical analysis. Through the process of creating a database of the demographic information in and metadata of the individual pension award records, the project is identifying a variety of information produced by both individuals and institutional bureaucracies held by these files. Analysis of this material, when read alongside related institutional and other archival records, is demonstrating the ways in which the treatment of war attributable disability shaped government policy, charitable practice and family life in Britain in the years after the First World War. Such analysis has the potential fundamentally to shape our understanding of British society at all levels, from the domestic to the global. It is built, however, on the stories of individual men, their families and associates, whose data has been captured by a historic bureaucracy.

The database we have developed, which is designed to be publicly accessible and searchable, contains a range of demographic and non-medical information to enable researchers to use the archives more effectively to explore relevant topics in social, cultural and medical history of Britain in the interwar period, including quantitative analysis of the sample as a whole. Men, Women and Care is not, however, a digitisation project. In part, this is a reflection of the project as one of historical analysis rather than archive preservation and curation, with all project participants undertaking significant social history research using the PIN 26 material.[5] The database will, however, enrich TNA's Discovery catalogue through its recording of details beyond name, rank, unit and pensionable disability. An equally important limit to the methodology of data circulation employed by the project, and its consequent output, has been the ethical considerations which emerged early on as a significant question about the project's methodology as a whole. These are the ethical questions we want to consider in this chapter, suggesting some strategies for tackling them but also leaving much open for further discussion as to the responsibility of historians using this material to gain a better understanding of periods and people still within living memory. In doing so, we aim to demonstrate how conscious considerations of historical practice can shape our work as historians, particularly in relation to use of the patient voice as a historical source with clear contemporary resonances.

Using material drawn from PIN 26 and the process of creating and populating the database, this chapter asks what use historians can and should make of the sort of information contained in government-generated files which record intimate medical and social information about individuals. It considers how such archives can be made more available as part of the impact agenda while adhering to ethical considerations about medical confidentiality. These questions are of relevance not only to historians of medicine and disability, but also those concerned with memory and commemoration in a field where family histories and personal narratives have formed the basis of both historiographic debates and government policy.[6] They also resonate with debates among current medical practitioners in the NHS about government mandated requirements for patients to be given online access to their medical records, debates which raise issues of resource, comprehension and state intervention in clinical practice.[7] In considering key questions of ethical and scholarly practices of research and dissemination, including informed consent and referencing requirements, this chapter demonstrates the practical issues that this sort of material raises for historical researchers in particular. It goes on to discuss the theoretical significance of historical practice in relation to these files, highlighting tensions both in the social definition of modernity (with increased government data collection leading to increased demands for personal privacy) and in the modern public sphere (through the evidence they present of individual and community agency in relation to the nascent welfare state). Finally, it considers what steps the historical community might take to articulate a code of ethics around practice that is sensitive both to family feeling and academic enquiry, and which may speak to wider questions of the digitisation of medical information.

PIN 26: First World War pensions award files

The 22,829 files that make up the PIN 26 series are described by TNA as a 2 per cent representative sample of all pension files created.[8] The files themselves contain a wealth of material, much of it medical. Even the shortest file includes service and discharge records, complete with medical histories, as well as details of the claim for the pensionable disability. The more complex files contain hospital records, doctors' notes, correspondence, receipts, reports, appeals, hospital admissions records and medical reports. Some include x-rays (almost all badly damaged due to poor preservation), while some have detailed anatomical sketches to illustrate an injury or physical complaint. While much of this material is associated with the bureaucratic processes of enlistment, discharge and pensioning in the context of a modernising military engaged in and after mass warfare, the files have the power to expose intimate details of the personal lives of their individual subjects. As such, the files form a vital record for understanding the social history of twentieth-century Britain. However, the dissemination of this material, whether through developing practices in digital humanities or through more traditional forms of historical analysis, raises a number of ethical issues.

In many cases, the details contained in the PIN 26 files are not only specific but potentially embarrassing to the descendants of these men who, although all dead themselves, may have relatives who knew them intimately while still alive. The research undertaken by the team thus far has uncovered medical histories of incontinence, venereal disease, images of facial disfigurement and reports of suspected malingering, fraud and infidelity. That such records might be perceived as shaming if made public is evident from the files themselves, which include correspondence such as that of the ex-serviceman who begged the Ministry not to alert his employer to the fact that he was in receipt of a pension for neurasthenia because 'they are not aware that I am a pensioner, if they knew my job would not be secure'.[9] Indeed, Eilis Boyle's PhD research for the project directly addresses the question of how facial disfigurement and psychological trauma, as stigmatising conditions, shaped the care and treatment of men who suffered from them, including their treatment in the workplace.[10] At the same time, the existence of personal correspondence within government generated records provides evidence of the need pensioners had to lay claim to agency in relation to their impairments. As Helen Bettinson notes in her history of the Ministry of Pensions as an institution, 'the challenge [faced by the Ministry] was to make pensions conform to the needs and expectations of the pensioner, rather than vice versa'.[11]

While our primary consideration in this chapter is around protecting the privacy of the patient while still enabling the patient's voice to have agency in the creation and analysis of the historical record, it is important to note that it is not only their voices present in the archive. Letters of advocacy from family members formed part of the process of applying for pensions. These included parents, siblings, in-laws and wives, with letters often discussing dependent children, some of whom may still be alive. Indeed, in Canada in 2016, there were still fifty-four First World War widows in receipt of Canadian pensions.[12] With men claiming First World War pensions into the 1980s, it is likely that some, either current or former, medical practitioners who authored the case notes and correspondence that appear in the files are still alive. This was raised as a possibility when one of us discovered her childhood GP had responsibility for the medical care of one man whose file is in the 'Overseas' subsection of PIN 26. The pensioner had migrated to Adelaide and accessed medical care there into the 1970s. The doctor in question, who wrote to the Ministry of Pensions on behalf of the pensioner as well as writing medical case notes contained in the file, died as recently as 2015. The people who appear in these files are not located in the distant past.[13]

While the detailed and explicit medical nature of these files would seem to imply that their access should be curtailed by considerations of medical confidentiality, as part of TNA these records are classified as open public records which can be viewed by anyone on request. In this they differ from Ministry of Health files from the Second World War which still remain classified, although researchers believe these files contain entirely administrative, rather than personal, material.[14] In addition, much of the medical and personal data contained in PIN 26 was generated or collected by government bodies or contractors on behalf of a government ministry and is thus covered by Crown Copyright, so can be disseminated without additional requests for permission to use from either those who are the direct subjects or their descendants. There are also powerful reasons why knowledge of the existence of these files and the material they contain should be made more accessible. The material in the files speaks to contemporary debates over the allocation and administration of state support for disabled people, the gendering of mental illness and social and medical care for veterans.[15] Additionally, the centenary of the First World War, and the investment made in its commemoration in Britain, has led to increased interest in the war from both educational institutions and individuals.[16] While the culmination of the centenary in November 2018 has led to less formal investment in community and commemorative practice around the war, the material in PIN 26 and other sections of the Ministry of Pensions archives continues to offer opportunities to foster public interest in and education about the history of not only the war years but the longer legacies of the war for British and indeed global society. How these files can be used ethically as such a tool is thus a significant and timely question, demanding that we consider the material they contain not only in terms of their utility for scholars but also as memorial and memory for their descendants. More broadly, understanding the utility of historical medical data for historians and historical understanding may be useful for the collection and preservation of such data by state actors such as the NHS today.

The ethics of consent

The dual roles of personal medical records collected by the state lies at the heart of the ethical issues around their use as a source of patient voice. The Ministry of Pensions records have formed an important source for historians exploring the social and cultural impact and legacy of the First World War over the past twenty-five years, particularly in relation to disability, gender and the body.[17] To date they have tended to be under-utilised by social and medical historians as the format of TNA's catalogues tends to prioritise information pertinent to family historians, making it more difficult to address broader historical queries as effectively. One of the goals of the Men, Women and Care database is to make it easier for historians of the First World War, disability and twentieth-century Britain to identify relevant files across the sample. Yet we must approach the method of making this information available with some care. As April Hathcock has suggested in relation to the records of vulnerable or marginalised communities, the uncritical use of such files, let alone making them readily available online through digitisation, might be construed as 'an act of aggression and oppression'.[18] Hathcock's argument centres on the issue of digitisation of historical records more widely, pointing out that digitisation projects which are made accessible via forms of Creative Commons licensing may be interpreted by those who produced the original material as ‘a form of cultural and informational colonialism, taking the works of the marginalised – such as the feminists, dissident GIs, campus radicals, Native Americans, anti-war activists, Black Power advocates, Latinos, gays, lesbians and more [...] and forcing it into (uncompensated) availability without their express consent’.[19] Those whose information is contained in historical medical records are generally the subject rather than the creators of the archive. As such, the use of these sources might be perceived as a form of ‘informational colonialism’ through the forced access to physical and psychological information that, in other contexts, would be deemed confidential. Certainly, the use of historical medical material (although not specifically historical medical records) for research purposes has been shown to be oppressive to individuals, as in the case of the HeLa cell line taken without consent from Henrietta Lacks.[20]

The subjects of the PIN 26 files are made vulnerable by their mortality, rather than their race, gender, sexuality or class. Their deaths leave them unable to provide informed, un-coerced consent. And although the dead feel no shame, their still-living descendants can. The exposure of intimate medical details of men who survived the war with impaired bodies is particularly sensitive in the context of British memorial culture which, in the words of Alex King, ‘canonised the common people’ through memorial narratives of both physical and moral courage.[21] Originally invoked in relation to those who died during the war, over the past century this narrative of commemorative canonisation has expanded to cover all those who fought in it or, in extreme instances, lived through it.[22] Combined with the narrative of family connection that underpins memorial practice in Britain and elsewhere, historians who discuss intimate and embarrassing details of the physical and psychological aftermath of the war for men, in ways that are often deeply unheroic, risk angering and alienating the descendants of these men. Is deepening our historic understanding of a particular period or social concept through open discussion of such material sufficient justification for the infliction of pain or discomfort on these descendants? This is very much an open question, as illustrated most recently by the debates around the outing as gay of Robert Wyndham Ketton-Cremer, the last squire of Fellbrigg Hall, by the National Trust as part of its Prejudice and Pride programme.[23]

Ethical concerns raised over the failure to gain consent from vulnerable groups for the use of sensitive personal material would seem to suggest that historians should avoid using such material. But there are equally important arguments supporting the identification of vulnerable actors within the historical narrative. Hathcock's concern relates to the particular types of Creative Commons license used for digitised archives that allow for their manipulation; the simple dissemination of the material has the power to bring these groups visibility that would otherwise be denied them. In the case of those who died in war, the practice of naming as a way of making visible has, since the mass casualties of the First World War, become a central element of commemorative practice. This was evident in Britain where state policy to not repatriate the war dead meant that the naming of the dead became a primary site of mourning.[24] Similar policies enacted in Australia were compounded by the great distances between families and the graves of their loved ones.[25] The importance of this naming practice – of making the dead visible as historic actors – can be seen in the proliferation of lists of names on war memorials around the world. In the United States, the practice arguably reached its apotheosis in Maya Lin's Vietnam War Memorial where 'the names act as surrogates for the bodies of the Vietnam War dead'.[26] As Jay Winter points out, the memorial 'brought the American dead of the Vietnam war back into American history'.[27] The inclusion of names and stories in historical analysis can potentially play a similar role in memorialising individuals by making them historically visible.[28]

Additionally, the academic analysis of personal information and material relating to medical conditions has the potential not only to cause pain and discomfort but also to nuance understandings of particular conditions in ways that challenge historical understandings of stigma. This is particularly relevant to histories of facial injury, where the detailed medical records kept by pioneering surgeons such as Harold Gillies and Archibald McIndoe have enabled a range of significant studies into the importance of their work for their patients.[29] This in turn has led to work such as Boyle's which has supplemented the medical record with personal narratives to show that facially disfigured men such as Reg Evans were not necessarily isolated in post-war Britain but rather were able successfully to reintegrate into their local communities as active members.[30] To show how men were able to negotiate social challenges, such analysis requires discussion of potentially uncomfortable details, such as the embarrassment Evans faced when eating in company as his impairment made chewing difficult. These examples suggest that there is value to be gained, not from unrestricted dissemination, but from the study and thoughtful broadcast of historical medical material. Scholars, society and even family members stand to gain a more nuanced picture.

As we have already indicated, the Men, Women and Care project is attempting to address the question of sensitive public dissemination by harvesting almost exclusively demographic and archival information only for inclusion in the database. We are opening up the files to researchers through improved metadata rather than through the dissemination of their content. The only reference to medical information that will be available will be the recorded pensionable disability, an indication of whether the pensioner received hospital treatment as part of his care and a general indication as to whether files contain medical records without details of what, precisely, those records consist. Researchers will be able to use this information to identify files that they wish to explore in more detail and make their own (informed) decisions on how they disseminate the material they find. In this way, we aim to make the men whose lives are captured, at least in part, in these files, more visible without wantonly exposing them to a public scrutiny to which they are unable to consent. However, there is an analytic element to the project, which goes beyond capturing data and metadata. Using material from selected files, we are exploring questions of how the care provided to these men was gendered. This raises additional important issues about how we undertake our historical analysis and what our professional responsibilities as historians are when it comes to using this material. In our work, this question has crystallised around the anonymisation of subjects and professional norms of referencing in our subject area.

The professional paraphernalia of history

To the hapless undergraduate, finishing essays at the last minute and frantically sorting out their referencing, their tutors' obsession with style and footnotes can be a source of frustration. Yet proper referencing is not only an important tool of scholarship that supports reproducibility and the development of argument and analysis, but also a moral act. In his 2016 meditation on the craft of history, Tom Griffiths describes the moral contract historians have with the past. Griffiths writes: ‘Footnotes are not defensive displays of pedantry; they are honest expressions of vulnerability, generous signposts to anyone who wants to retrace the path and test the insights, acknowledgements of the collective enterprise that is history.’[31] He portrays this collective enterprise as a conversation both between historians and between the historian and the past, asking where our responsibility lies. Griffiths continues,

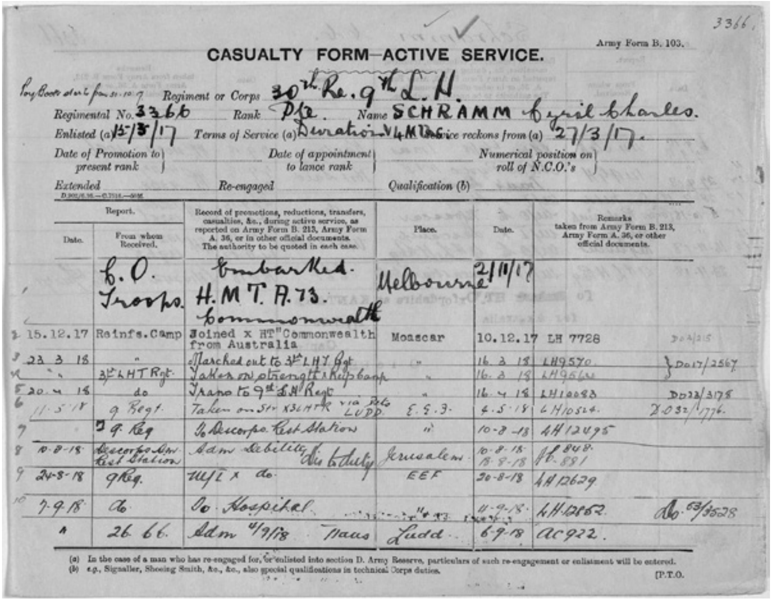
> Historians feed off the power of the past, exploiting its potency […] but historians also constantly discuss the ethics of doing that. To whom are we responsible – to the people in our stories, to our sources, to our informants, to our readers and audiences, to the integrity of the past itself? How do we pay our respects, allow for dissent, accommodate complexity, distinguish between our voice and those of our characters? The professional paraphernalia of history has grown out of these ethical questions.[32]

Historians, then, must hold in tension these sometimes conflicting responsibilities. When publishing our research based on the PIN 26 files, how do we respect the people whose stories we are telling while also enabling our readers to follow our footsteps in the archive?

As we work through the files in PIN 26 and enter them into the database, we are giving each of the men an individual anonymisation code. This code consists of their first and last initials and a randomly generated number. Anonymisation is a standard tool of social studies research, with its own set of methodological practices.[33] Yet, in the case of the pensions archives, as we use these codes to discuss the details of files and the personal experiences of disabled ex-servicemen, we are confronted with the problem that the men are still identifiable because of how their records have been archived. In this chapter, and in previous historians’ use of PIN 26, references have included the file number listed in TNA’s Discovery catalogue (e.g. PIN 26/18).[34] Yet, if we reference in this way, all a reader needs to do to discover the identity of the pensioner is to search for that number in TNA’s catalogue. The search will return the soldier’s name and pensionable disability. A recent Friends of The National Archives project to enhance the catalogue record as part of TNA's range of projects commemorating the centenary of the war means that there is now more information useful to family historians readily available through the catalogue system, compounding this problem for academic historians. At present, we have no answers for how we might address this particular challenge.[35] The Men, Women and Care project currently has an agreement with our funding body that any publications will be scrutinised by our faculty's research ethics committee to assess the suitability of our referencing practice, a compromise which has a number of practical drawbacks, principally the additional time and burden of labour that this will add to the publication and dissemination process.

The problem of anonymity is not confined to British records and is particularly problematic if using the digitised and openly accessible Australian Imperial Force attestation papers at the National Archives of Australia (NAA). The archival reference for these files is the name of the man who served (e.g. B2455/Schramm Cyril Charles), making it difficult simultaneously to preserve anonymity and maintain professional standards of referencing.[36] While, in theory, these files do not contain medical information, they do contain details of when and for what reason a man transferred between different units, including when and why he was admitted to a medical unit.

Previous histories that have made use of these files have used pseudonyms when discussing sensitive details of individual's lives, thus concealing their identity but also preventing the sources from being traced in the archive.[37] This practice reflects wider treatment of sensitive archival material within the history of medicine, particularly the treatment of asylum records by historians of psychiatry and mental health. The choice of whether the privacy of individuals or disciplinary referencing standards are prioritised is dependent on the researcher's interpretation of the sensitivity of the information in the files, as well as the practice prescribed by the particular archive, which can vary enormously. While researchers working within institutions can be guided by the recommendations of ethics committees in instances such as these, independent and enthusiast researchers, who author a large proportion of the publications in military history and war studies, do not necessarily have equivalent resources to turn to. When adherence to copyright law is the sole or primary standard required for publication, as is increasingly



3366.

Army Form B. 103.

CASUALTY FORM–ACTIVE SERVICE.

Pay Book start from 31.10.17 Regiment or Corps 30th Re. 9th L.H.

Regimental No. 3366 Rank Pte. Name SCHRAMM Cyril Charles.

Enlisted (a) 15/3/17 Terms of Service (a) Duration & 4 Mths. Service reckons from (a) 27/3/17.

Date of Promotion to present rank ______ Date of appointment to lance rank ______ Numerical position on roll of N.C.O.'s ______

Extended ______ Re-engaged ______ Qualification (b) ______

D.902/6.16.—C.7316.—50M.

	Report.		Record of promotions, reductions, transfers, casualties, &c., during active service, as reported on Army Form B. 213, Army Form A. 36, or in other official documents. The authority to be quoted in each case.	Place.	Date.	Remarks taken from Army Form B. 213, Army Form A. 36, or other official documents.
	Date.	From whom Received.				
1		C.O. Troops.	Embarked. H.M.T. A.73. Commonwealth	Melbourne	2/11/17	
2	15.12.17	Reinfs.Camp	Joined x HT "Commonwealth from Australia	Moascar	10.12.17	LH 7728 D04/215
3	23 3 18	"	Marched out to 3rd LHT Rgt	"	16 3 18	LH9570 } D017/2567
4	"	3rd LHT Rgt.	Taken on strength & Reps Camp	"	16 3 18	LH9564
5	20 4 18	do	Trans to 9th LH Regt	"	16 4 18	LH10083 D023/3178
6	11.5.18	9 Regt.	Taken on Str x 3rd LHTR via Rels LUDD	E.S.3.	4.5.18	LH10524. D032/1776.
7		9. Reg	To Descorps Rest Station	"	10-8-18	LH12495
8	10-8-18	Descorps Dm. Rest Station	Adm debility Dis to duty	Jerusalem	10-8-18 13-8-18	848. 881
9	24-8-18	9 Reg.	M/L x do	EEF	20-8-18	LH12629
10	7-9-18	do	To Hospital		4-9-18	LH12862 Do 63/3528
11		26 66.	Adm 4/9/18 Naus	Ludd	6-9-18	AC922.

(a) In the case of a man who has re-engaged for, or enlisted into section D. Army Reserve, particulars of such re-engagement or enlistment will be entered.
(b) e.g., Signaller, Shoeing Smith, &c., &c., also special qualifications in technical Corps duties.

[P.T.O.

2.1 Cyril Charles Schramm Casualty Form – Active Service

the case, the deeply personal medical histories of servicemen (as well as other groups under state care) can make their way into the public realm. Indeed, this has happened already with the uncritical publication of lists of Australian First World War soldiers who had contracted various venereal diseases (VD) in the early stages of the war.[38] The men listed sought medical care for VD prior to the Australian Army Medical Corps changing its policy on recording the names of men who were infected. The policy was changed after publicity and shame were identified as significant factors preventing men from becoming active agents in the maintenance of their sexual health.[39] The identification of VD as a stigmatising condition was not sufficient to prevent the publication of the men's names while their immediate descendants are still alive. These variations in policy towards recording and disseminating identifying information across time highlights the complexity of responses to stigmatising conditions explored by Lloyd (Meadhbh) Houston and Anne Hanley in this collection. The case also highlights the potential contemporary relevance that the treatment of such records has well beyond their import for historical understanding.

The vast quantities of evidence created by various countries' wartime bureaucracies and now made easily accessible may yet cause difficulties for the descendants of pensioners, beyond concerns of shame. Given that these records contain information about all types of ailments that become apparent during military service, including heritable conditions and not just those incurred on the battlefield, further protections are needed to prevent the unethical use of this information. As a result of the 'Code on Genetic Testing and Insurance', an agreement between the British government and the Association of British Insurers, insurance companies are prevented from making underwriting decisions based on predictive (as opposed to diagnostic) genetic test results and customers are not required to disclose predictive results.[40] Originally signed in 2014 as the 'Concordat and Moratorium on Genetics and Insurance', the 2018 Code recognises that 'a minority of patients might be deterred from taking predictive genetic tests, if they are unaware that the Concordat protects their fair rights of access to insurance'.[41] Historical medical documentation, like that in the PIN 26 files, is not covered by this agreement and it is doubtful that all countries with accessible medical documentation have protections. Should this type of information be released in subsequent years for later wars, individuals with traditions of military service (or potentially state care) in their family could be at a distinct disadvantage if they also had a heritable condition in their family's medical history. As historians increasingly seek to engage with the public and to mobilise history to intervene in discussions over public policy, it is worth considering how our practice may have unintended as well as intended effects on both individuals and society.

Bureaucracy and personal privacy: tensions in the First World War archive

These questions are not only significant because of the methodological implications for historians working in this space. From a more analytical perspective, the systematisation of this post-war provision and the development of new processes and procedures provide evidence for the increasing bureaucratisation of the modern state and the development of what would become the welfare state. These developments have important implications for our understanding of the concept of privacy, an idea of particular significance to historians of medicine and one that, as Margaret Pelling has noted, is multi-layered and historically contingent.[42] The questions raised by the pension records relate both to definitions of modernity as a process of bureaucratisation and debates over the nature of the modern public sphere and the way it can be shaped by the mobilisation of the private body.[43] The ways in which patients used their voices in reaction to these processes serves to blur the line between public and private, with implications for the role of the historian in using them.

Roger Cooter and Steve Sturdy, in their discussion of the relationship between war, medicine and modernity, centre their arguments on Max Weber's definition of modernity, which they define as the crystallisation of 'a constellation of social processes', most notably in the era of the First World War.[44] These processes, symptomatic of the shift from a 'traditional' society to a 'rational' one, included 'the growth, differentiation and integration of bureaucracy and other organisational and managerial systems; the standardisation and routinisation of administrative action; and the employment of experts to define and order such systems'.[45] The relationship between medicine and bureaucracy, standardisation and expertise in the First World War is well documented.[46] What is less clear is how these expressions of modernity translated into the interwar period. It is here that pension files, including the medical information they contain, can play a key role in our developing understanding. Cooter and Sturdy suggest that the processes of medical modernisation during the First World War resulted in the emergence of new ways of thinking about how best to harness resources, especially manpower, for the national effort. From this point on, they argue, war was perceived as:

> a process of technical, strategic and social innovation that tested the vigour and adaptability, not just of the military, but of the social organism as a whole. In this context, medicine in both its military and civilian aspects was increasingly seen to fulfil a vital function in the organisation, mobilisation and management of entire societies.[47]

The First World War as a total war, then, resulted in the blurring of boundaries between civilian and military concerns in the decisions to allocate resources.[48]

In the early twentieth century, the emergence of the health of its people as integral to the economic and military success of an industrialised society resulted in the application of modern processes of organisation and bureaucratisation to welfare provision. As a result, 'the welfare and the warfare state increasingly become indistinguishable from one another'.[49] The British Ministry of Pensions, established during the war to address the problems with the previous system of pensions that were created by conscription, functioned at the intersection of welfare and warfare.[50] Thus the PIN 26 files provide the source material to enable an analysis of a new government department as it transferred bureaucratic management methods from the military in wartime to the administration of demobilised men during and after war. Mark Harrison has called for further research into whether attitudes learnt in military service had a lasting effect on medical practice after the war.[51] Because the Ministry of Pensions relied on the expertise of demobilised medical personnel, the PIN 26 files also provide evidence for the influence of military service on the development of the nascent welfare state.

While the PIN 26 files provide substantial evidence of bureaucratisation, they also enable analysis of opposing facets of the social definition of modernity. Jay Winter has noted that the bureaucratisation of medical care led, in turn, to demands for personal privacy. Ana Carden-Coyne argues this period also saw increasing discussion of patient rights,[52] while Mark Harrison suggests that in the First World War medical care was an important facet of the relationship between soldier and the state, forming an unwritten social contract or covenant supported by the humanitarian ideals and political will of British society.[53] All these arguments draw on the state's records of men's bodies and bodily health as part of their evidence base.

The historian's analysis thus has the power to intervene in debates about the bodily autonomy of the soldier, both historic and contemporary. With the act of enlistment – a process that entailed at some level the soldier signing over his body to the state – an individual person made his health a matter of government concern. As such, it became part of the public record, to be archived and preserved in line with state policy rather than the personal wish of the individual. Those records are now available *because* a man either enlisted or was conscripted into military service.[54] Indeed, conscription serves to highlight the limits of consent around bodily autonomy in relation to military service during the war. As Lois Bibbings has demonstrated, the body became the site of protest by conscientious objectors to forced military service through their refusal to attend medical inspections or to wear military uniform. In response, the state mobilised shame and punishment to coerce consent.[55] The existence of such protests raises questions about the consent of all conscripts to having their bodies inspected and their data recorded, creating yet another ethically grey space of research and analysis.

For the disabled ex-serviceman, his service may have lasted five years but, if he sought financial assistance for illness or injury associated with the war, his body continued to be inspected by the state and subject to government decision-making until either the end of his pension or his death. The state has subsequently made information that might otherwise have been considered private or for a limited audience available publicly, including (potentially) to people who knew him intimately. By making such material the subject of analysis, the historian plays a part in exposing the soldier's body to further scrutiny, well beyond the time limits of his military service. The practice of this form of history is thus implicated in the ethics of state data collection and storage practices, much of which occurs without the permission of the subjects of such analysis. While the lack of informed consent could be said to apply to all subjects of historical analysis, the practice of naming the war dead arguably places them in a public space within historical memory that they may or may not have themselves consented to occupy. The narrative of family-centred commemorations which have grown up in the centenary period, particularly in Britain, exerts a countervailing pull towards the rights of descendants to retain control over the memories and family narratives of their ancestors. Thus, tensions persist over who has the right to use and interpret the voice of an individual captured and preserved by a public body. It behoves us, therefore, to question the ethics of our practice, whoever the subject of our research may be.

While the use of the PIN 26 files forces us to question the ethics of our historical practice, it also demonstrates the ways in which the work of social historians of medicine which uses patient voice contributes to formative debates in and on civil society. As the contributors to Steve Sturdy's 2002 collection on *Medicine, Health and the Public Sphere in Britain, 1600–2000* consistently demonstrate across the period, medical history approaches provide a useful methodology for challenging the pessimistic view of the modern public sphere and its relation to the welfare state taken by Jürgen Habermas in *The Structural Transformation of the Public Sphere* (1962).[56] They also, Sturdy argues, demonstrate the ways in which 'concerns about configuring the private were central to many areas of public activity, and might even be regarded as one of the primary purposes of public association'.[57] Medical institutions, and the political bodies designed to regulate them, developed and now function at the boundaries between the private body and the public good, the individual and the collective, the intimate and the mass.

Sturdy suggests that historical critiques and analyses of the Habermasian public sphere have tended 'to neglect the extent to which institutions of various kinds were implicated in the structuration of the public sphere itself'.[58] But institutions are themselves made up of individuals whose identities become implicated in the public discourse. In medico-political institutions, these identities are related to the private body and private life. The PIN 26 archives allow insight into the variety of ways individuals attempted to engage with the state to shape its provision of care for themselves and for others. These strategies could include the detailing of physical incapacity, domestic breakdown and failure to achieve social norms. CE1, for example, laid bare his failures to fulfil the male breadwinner norm, writing: 'I am now living on my wife's people, being unable to follow employment, and having no means to carry on. […] [T]he public would make a great outcry if the facts of my case were made known to them. And I shall feel compelled, unless something definite is done *this week*, to obtain help in a way which may cause publicity.'[59] Here, CE1 placed his private domestic circumstances within the public discourse as a way of gaining leverage in relation to the bureaucratic state. While such interventions do not necessarily correlate with Habermas's definition of the authentic bourgeois public sphere as collective discussion among individuals emancipated from identification with the state, they do provide evidence of a sense of agency among recipients of state care and their advocates.

Within such agency can be found articulations of how pensioners and their families defined their own sense of privacy in relation to their conditions. Whether demanding that the Ministry not make the details of a man's pension available to his employers or threatening public exposure of perceived ill treatment in the press, pensioners' own relationship to their impaired bodies complicated the status of those bodies as either public or private. In mobilising their bodies and domestic lives as part of public discourse aimed at shaping state policy, pensioners may be said to have entered the public sphere, laying claim to agency in relation to the nascent welfare state in the process. For historians, to refrain from critically examining such interventions because of concerns over privacy is potentially to deny these men the very agency over their subjective understandings of their disability that they sought in writing to the Ministry. As Jennifer Wallis has noted in relation to medical images: 'by presenting the face and body of a patient to public view [without identifying information] we also run the risk of reducing the patient to an abstract representation of a disease'.[60] If those whose lives are recorded in PIN 26 have anything to tell us, it is that their identities were defined by far more than their pensionable illness or injury. Thus, if we should respect the right to privacy of the historical subject, we should also respect the right of the subject to be heard. What they have to tell us may have significant implications for our understanding of the power of the public sphere to shape state practice both historically and in the present. Fostering such understanding through respecting the right of historical actors to be heard also forms part of our duty of care as historians to the individuals whose lives and views are the subject of our research.

Conclusions: towards a code of ethical practice

What this chapter points to is the number of tensions that exist when it comes to the ethics of accessing and analysing patient voice as captured by state bureaucracies. On the one hand, patients may fall into the category of vulnerable subjects, particularly when speaking about their illness. Consent, therefore, forms an important criterion for considering using their stories in historical analysis. Yet historical subjects cannot give consent from beyond the grave. Not to use such voices in our work because they cannot consent, however, may deny visibility to marginalised groups whose histories deserve to be told and to those who actively sought to locate themselves and their personal histories within the public sphere. While anonymisation offers one option for using patient voice ethically, archiving practices, particularly those associated with official government records, create forms of traceability when referencing conventions are fully applied. These tensions between concern for the subject and rigorous historical practice have implications not only for the holders of records and the writers of history, but also the families of the patients involved, whose sense of personal history, both narrative and genetic, may be exposed and challenged. The use of official records as a source for patient voice also implicates the historian in the bureaucratic processes of bodily and mental assessment and surveillance, giving them an often-unwitting role in the continuation of these practices long after the individual patient's death. Such a role may serve an important purpose in shaping our understanding of the past in ways which resonate with contemporary concerns over the recording and accessing of medical data. It remains important to acknowledge this aspect of the historian's work, along with its role in constructing historical actors *as* patients.

While this article does not seek to provide concrete answers as to how to resolve these tensions, the questions they raise are important ones for scholars in the field. One avenue for discussion that is relevant to these issues is the development of a code of ethical practice for historians. Indeed, in his 2008 book *Responsible History*, Antoon De Baets sets out a 'proposed code of ethics for historians', drawing on the UNESCO Recommendation Concerning the Status of Higher-Education Teaching Personnel (1997) and the Constitution of the International Committee of Historical Sciences (2005).[61] The Royal Historical Society has also produced a Statement of Ethics, originally published in 2004 and republished in 2015. Unfortunately, even with this update, neither document directly deals with the challenges posed by digitisation to the dignity to be accorded to the historical subject and their descendants or to the historian's role in scholarly analysis and dissemination. Indeed, the Royal Historical Society explicitly states that the maintenance of professional ethical standards involves 'observing the ethical and legal requirements of the repositories and collections they use' without any reflection on the ethical implications attached to extracting the data from the archives for analysis.[62] Similarly De Baets, while on the one hand arguing that 'aware of the universal rights of the living and the universal duties to the dead, historians shall respect the dignity of the living and the dead they study', also suggests 'that maximal, free, and equal access to information is the rule and that restrictions are exceptional and only for purposes prescribed by law and necessary in a democratic society'.[63] At present, the laws governing the digitisation of archives and access to information contained therein are such as to ensure the latter condition, but in ways, we would suggest, that contravene the former.

This is not to say that a code of ethics relating to the digitisation of historical archives and historians' use of such material would not be useful, simply that it has not yet been written. This, to some extent, reflects wider debates around the open internet and its emerging use as a repository, including those among current medical practitioners and politicians. As the examples given already indicate, the process of digitisation has enabled the work of non-professional historians, who may not view themselves as bound by a professional code of ethics even if it did exist. It also has the power to make previously hidden historic actors publicly visible in ways that positively affirm their identities, experiences and social and cultural significance. Nonetheless, if the transformation of the historical record into a digital resource is a genie that cannot be returned to its bottle, for those of us who do engage with history as professionals, these are questions that demand our attention. As we gather and analyse data, we must think about the tools that we utilise for the purposes of preservation, just as we must think about our citation practice and the work of surveillance that our analysis may do, however unintentionally. Doing so with care is a duty that we, as historians, owe to the living and the dead.

Notes

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