Health Archives and Records Group

20 July 10am-12pm

Rose Room (LG7), London School of Hygiene & Tropical Medicine, Keppel Street, London, WC1E 7HT

Present:

Chris Olver, King's College London (Minutes) Geoff Browell, King's College London (Chair) Nick Baldwin, Great Ormond Street Hospital Lorna Cahill, Royal College of Veterinary Surgeons Jonathan Cates, The National Archives Katherine Chorley, University College London Teresa Doherty, Royal College of Nursing Claire Frankland, London School of Hygiene and Tropical Medicine Laura Hynds, Bart's Health Annie Linsay, University College London Hospitals Sharon Messenger, Royal College of General Practitioners Kevin Mulley, The National Archives Louise Piffero, Leeds University Elizabeth Thurlow, St George's University of London

Apologies for absence:

Paul Carlye, Derbyshire Records Office Victoria Cranna, London School of Hygiene & Tropical Medicine Emily Gresham, Birmingham and Solihull Mental Health NHS Foundation Trust Ruth Honeybone, West Lothian Health Services Sarah Lawson, UCL (Institute of Neurology) Adele Picken, Royal College Paediatrics and Child Health (RCPCH) Alistair Tough, Glasgow University

1. Welcome and introductions

Geoff Browell (GB) welcomed people to the meeting and explained the nature and format of the meeting.

2. Discussion of future direction of HARG

GB explained the background of HARG and current developments with the group and website.

Chris Olver (CO) gave a short report on recent group activity since the previous meeting in December 2015. Highlights included:

- Membership: membership circulation list has now been updated and new member information added. Since previous meeting the group has had 10 new members and now stands at 58 members.
- Organisation: The current organisational committee of the group includes: Chris Olver, Geoff Browell, Emma Hancox (Birmingham Library Archives) and Ruth Honeybone, West Lothian Health Archives.
- Collections Rescue Strategy Meeting: CO attended 'Collections Rescue Strategy Workshop' at the National Archives on behalf of HARG in February 2016, about developing a national strategy for protecting vulnerable archives. Outcome of the meeting was commissioning a piece of research, 'Understanding Collections at Risk', which will be presented to the group in Autumn 2016.
- Migration of former website: former website (web address) is now no longer available, with the domain expiring June 2016. Information on the website was exported and relevant material will appear on the new site.
- Launch of new website: The new website is currently under construction using WordPress platform, <u>www.healtharchives.co.uk</u>.
- Member survey: Member survey created by Emma Hancox was distributed around the mailing list. 12-13 responses with good feedback. Plan was to distribute it on the Archives NRA mailing list after meeting to get opinions of non-members.

3. Discussion of the future of HARG

GB introduced the subject. Old material from previous site has been migrated across and an area of the new site will be dedicated to guides produced by HARG, by Colin Gale et al. Also parts within the new website that will include areas for archivist and record managers, researchers and public engagement.

GB believed that HARG needed to respond to needs of archivists and records managers providing information about changes in the law, policy etc but also to engage more with wider communities, e.g. to have a wider purpose. In particularly, linking resources held in archives and NHS records with researchers.

GB asked members what they thought of the plans, and more widely what was the future role of the group:

Kevin Mulley (KM): At one stage, HARG- had semi-official role- particular reference for record management and health archives. That space- lot going on- IRIN merge and discussion with UK CHIP, BCS Assist. In terms of NHS side, there seems to be an amorphous group of people involved in information management. No single focus – the group discussed whether there can be one.

Teresa Doherty (TD): another big group, medical professionals working with data. Professional Health Information? Defining what the medical record should contain. Lots of people out there are working in this area.

London Museum of Health Medicine group and clinical health librarians group. Some alignment with what they are doing was suggested.

Organisations can have different offices, be devolved by countries etc.

Action: Agreed that at the next meeting we will trial using Skype or another source to broadcast meeting to include regional membership.

4. Demonstration of website

CO demonstrated an 'alpha version' of the website. The website was created on the WordPress platform and is hosted by the US site, Site grounds, until May 2017. The cost of the website was privately funded so long term financing is necessary. The ARA Special Repository have available funds and financial support will be applied for in the forthcoming months.

The site structure currently includes a simple menu divided into sections, 'Home', 'About Us', 'Activities', 'Resources', 'Blog' and 'Contact Us' page. The site will include the following features:

- Information about member organisations, including location information and contact details
- F&Q section, providing contextual information about group, health records and membership
- Archive of previous group meetings and information on forthcoming events
- Downloadable resources of previous HARG publications
- List of links to online resources and affiliated groups and institutions
- Blog and sector news, including meeting news and occasion features
- Contact page linking to the HARG Gmail account.

Comments:

KM: Site should avoid placing researchers, archivists and records management into silos, as lot of intersection between groups. Also need to communicate better between archivists and research data management specialists.

GB: could develop case-studies for new researchers beginning archive based research projects.

TD: Researchers tend to dip in and out of various subjects. One thing to provide information to general audience of what records are available, another to have archivists working alongside academics, like the business archive council. Far harder to sustain.

Sustainability – site has to be maintained, workable. Too many under-developed resources will not work. Good example of a site working well is the London Museums of Health and Medicine.

Long list of collections are bad practice, users will not engage. Far better to list keywords that would be helpful in using catalogue databases.

Jonathan Cates: TNA colleagues would be interested in contributing to the blog. Search rankings are improved with user comments

KM: needs to provide for first time users, a guide to the health service sector and health records.

KM: money available for creating data visualisation of old NHS structure- e.g. like a family tree

TD: Wikipedia - of commonly used abbreviations in healthcare to help RM/A with enquiry work.

Action: CO agreed to set up Wikipedia page - members will contribute and provide initial examples once structure is created.

5. Discussion of the impact of open data on health sector (led by Katherine Chorley, University College London)

Katherine Chorley (KC) reported on her research for her MA dissertation and into an INTERPARES report on web publishing of data. Research focused on an NHS Trust based in the South of England. Research focused on case study but also including a brief comparison of recordkeeping in similar environments.

KC circulated a survey to HARG members with some her findings:

- Had a good range of responses from records managers, information managers, including a response from another NHS Trust. Responsibilities were quite varied but all respondents were united in managing sensitive data.
- Over half of respondents felt they had enough guidance, with a quarter having some and only a small number having inadequate support.
- Respondents felt pressure to publish data online (40%), which contrasted with case study findings. The pressure came from researchers who were requesting material under the FOI Act, and provided an additional pressure to services to provide information at a minimal cost.

- 75% of the respondents said that their organisation did pro-actively publish information online. The rational publishing data was wide-ranging with the most popular reason demonstrating transparency and accountability, and to allow easy access to information, increasing public awareness of activities.
- Main barrier for online publishing was lack of resources.

Comments:

GB asked what the areas of conflict were. KC answered that there was a feeling that NHS should publish information about decisions being made and money spent. Open data would allow people to find information about local health services more easily than through FOI requests. In the findings from her case study, KC stated that those interviewed did not feel like publishing data would add more to their current work responsibility with the main barrier convincing people higher up in the organisation to participate.

TD: because of devolution of NHS it is up to each Trust as to how to keep and publish their data.

KM: stated that in his own experience most NHS Trusts found publishing data to be burdensome and already had been forced by Central Government to publish a lot of data.

Laura Hynds (LH): mentioned that a lot of material was already being published and questioned what would the incentive be for Trusts to publish more material, considering dwindling resources.

6. Sector News

CO read out an update from the Wellcome Trust about a new task force to improve conversations about using medical data. The taskforce will develop a framework for open and honest discussions with the public, patients and healthcare professionals. It will develop innovative approaches and tools, to talk about how and why data can be used for care and research, what's allowed and not allowed, and how personal information is safeguarded. The hope is that it will help build public confidence so that data can be used more effectively to improve health. The taskforce will be hosted by Wellcome, with support from the Medical Research Council, Economic and Social Research Council and UK Clinical Research Collaboration partners. The Taskforce is expected to start in the autumn and continue for two years. More information will be forthcoming shortly, but we thought that members of HARG might like a heads up.

Members might also be interested in a recent publication on public attitudes to commercial access to health data which can be found on the Wellcome website (https://wellcome.ac.uk/sites/default/files/public-attitudes-to-commercial-access-to-health-data-wellcome-mar16.pdf).

GB discussed his involvement with the Medical Heritage Library visualisation project, chiefly his work plotting the co-ordinates from the Hosprec database to provide geo-referencing

service to the digital library, therefore linking publications to the hospitals that originally published them. Will be launched later on this summer.

AIM25 is meeting with Archivematica and there will be a workshop in the autumn on how to adopt ICA-ATOM or Archivematica as a service, and this will be followed by other workshops potentially around the country.

Claire Frankland (London School of Hygiene & Tropical Medicine) gave an update about new exhibition, 'Re-structuring the Shakespeare Hut', an HLF funded exhibition about a temporary mock Tudor house that occupied the ground on which the School was built, and which housed Anzac troops during the First World War. Another exhibition is currently on display in the foyer area, 'Changing Face of Keppel Street'. A new Wellcome cataloguing project on the Whitehall partners has been delayed but the team will be appointing a project cataloguer soon.

JC (National Archives) gave an update on TNA Discovery: close to having an 'alpha' version for uploading and managing content on Discovery. Testing will begin in September and if things go well will have a wider 'beta' launch in October.

KM (National Archives) gave an update to the group on recent activities:

- 1- Discussion with Department Health Research regarding their new Health Data Finder service (<u>http://www.hdf.nihr.ac.uk/datasets</u>) for medical researchers, which allows users to browse health related datasets, at a fairly granular level. Have agreed to explore whether we could expose data about historical sources more effectively, added placemakers for potential historical material.
- 2- 20 Year Rule transition: KM has run 40 training sessions to NHS organisations about the transition, covering roughly 50% of NHS Trusts. Of those who attended, 40% of people, knew little or nothing about the Public Records Act. Having reasonable impact on people's awareness. Looking to put some training online, but will still need to do some face to face training to get people more engaged with resources that are available.

Agreement in principle from NHSE to look at adding our annual 20YR compliance survey to the IG Toolkit process for NHS bodies, as occurred in the pre-20YR survey of 2013. Will publish the data from the latter shortly on National Archives website, alongside the similar data gathered from Whitehall departments.

3- Independent Inquiry into Child Sexual Abuse (IICSA): working with the research team, including having knowledge sharing sessions, which they seem to have found useful, and have hopefully made them aware of both the potential value of archives to their work, but also some of the practicalities and constraints in using them. From looking at TNA records, IICSA team are interested in expanding enquiries with historical records.

Louise Piffero, (Leeds University) gave an update on her new Wellcome Trust Research Resources funded project to cataloguing medical collections at Leeds University. Papers include manuscript collections from the Leeds School of Medicine, lecture notes, case books, personal papers and nursing collections. There are plans to digitise some of the material in the near future and to link the new collections to various teaching modules at the university. The project is scheduled for completion in May 2018.

Nick Baldwin (Great Ormond Street Hospital) gave an update on the service, including plans for a new public display case; supplying material to other institutions, with a new exhibition at the Foundling Museum on children with disability; promotion of assistant records manager to records manager; involvement with Hospital school on using material but also filming archives for future teaching us and offered a large collection from the Maxillo-Facial Department regarding a project they undertook in Sri Lanka in the 1990s: records deposited in the Institute of Child Health.

LH (Bart's Health): RGA website launching. Update on getting an EDRM in place.

Annie Linsay, (University College London Hospitals): Penny McMahon, continuing to catalogue the Middlesex Hospital archives and was recently invited to participate in a local festival in Fitzrovia to talk about the work and history of the Hospital. She has also been working on an oral history project that has resulted in increased donations. Reported on ongoing art and heritage project relating to the opening of two new buildings by 2018. Planning a historic exhibition on matrons for October 2016.

Sharon Messenger (Royal College of General Practitioners): did a lot of work with the heritage committee on a Radio 4 2-part programme, <u>Farewell</u>, <u>Dr Finlay</u>, on the history of general practice. New exhibition on research and general practice and recruited a records manager.

Lorna Cahill, (Royal College of Veterinary Surgeons): took position in October 2015, first ever archivist. Currently cataloguing the papers of Major General Frederick Smith, who served in the Army Veterinary Service during the Boer War and the First World War. Also digitising material from across the collections, and interested in adopting the Wellcome Trust developed Universal Viewer, commissioned Digerati to help adapt the viewer for RCVS material.

TD (Royal College of Nursing): Centenary this year, with lots of talks and collecting. New website launched in December 2015, in particularly around centenary pages including film and exhibitions. In Library pages, running new subject guides, producing lot of interest from members. New exhibition on the centenary, co-curated by History of Nurses Society and an exhibition planned for the autumn on public health. Alongside exhibitions, there is an events programme, contemporary and historic, including a well-attended debate on ageing featuring Joan Bakewell. Currently advertising for an archivist based in Edinburgh. Finally,

call for more material for The Florence Nightingale Digitization Project, which has been running for over three years and currently includes material from 14 partner organisations.

Elizabeth Thurlow (St George's Hospital) reported on her new roles as the first professional archivist at St George's University, London. Recently, took part in some filming with a Japanese broadcaster on the surgeon, John Hunter. Useful for securing further funding for post and budget for the archives. Currently trialling access to the archives for medical students who undertake a history of medicine special subject and working on a Wellcome grant bid for further funding for the archives.

7. Date of the next meeting:

To be held at the Centre for Research Collections, University of Edinburgh on Friday 23rd September.