

Health Archives and Records Group meeting

15th March 2018, 2.00-5.00pm

**Sarah Swift Room (G01), Royal College of Nursing, 20 Cavendish Square, Marylebone,
London, W1G 0RN and RCN Office, 42 South Oswald Road, Edinburgh, EH9 2HH**

No attendees list.

- 1. Welcome and introductions**
- 2. Creating a digital repository: implementing a digital archive service at the Royal College of Nursing**
- 3. Managing sensitive medical data within the archives of the National Spinal Injuries Centre- Mary Brown, Hannah Blithel-Vaughan and Emma David (Centre for Buckinghamshire Studies)**

Mary Brown, Project Archivist:

Founded during the Second World War by Sir Ludwig Guttmann using vocational and sports therapies which directly led to the establishment of the Paralympic games. Material from NSIC International Wheelchair and Amputee Sports Federation (IWAS) and Wheelpower. Wellcome Trust funded research into the history of the Paralympic movement. The records contain a lot of sensitive personal data including details of family members, court cases (including Saville enquiry) and private lives. Does not include general hospital records, just the spinal unit.

Hannah Blithel-Vaughan, Trainee Archivist:

Screening of researchers through the NSIC to ensure validity. Family historians must provide a death certificate and a letter of permission from the next of kin. Psychology impact files very sensitive – depression, suicide attempts etc. and encompasses the family and services offered to them. Will be unlikely to know that these files still exist. Kept separate from medical files. Not always separate and sometimes misfiled.

Access requirements and guidelines in place include assuming a life span of 100 years, screening research requests and requesting death certificates and/or permission from family

Some information inappropriately appears in files so have had to remove this. These are confidentially destroyed. Some issues have arisen due to changes of name and address of patients, making it difficult to determine life status.

Emma David, Conservator Technician:

Went from military to ministry of health and then to NHS files. Subject to NHS retention policy. Drawings in files – some now CD-ROM which are not accessible off site for the council. 60 years chosen as an average closure period – a lot of injuries are less restricting of lifespan than they used to be. Storing and handling discs is difficult. Also medical imagery which is physical and digital. Consideration of issues associated with maintaining access to obsolete storage types.

Determining whether or not files are graphic or not, especially for images. This includes nudity, photos of minors and vulnerable adults which were automatically considered to be graphic. Also, clinically graphic such as wound images. Some images have no context which helps disguise which part of the body they are on and changes impression of image. Graphic images are highlighted in the file so people can make a decision about access based on research need (family history or medical research). Hand drawn images are considered to be less graphic than photographic images, also black and white photographs can be deemed less graphic than colour. Researchers need to be isolated in search room to prevent accidental exposure of graphic images.

Procedures had to be modified to account for staining by bodily fluid – can't ask the public to wear gloves all the time. Ran risk assessments. Have had to place threats into Perspex to be viewed and handled. Must avoid contamination risk for public.

Questions covered Saville enquiry – did this increase awareness of sensitivity? Most requests concerned proof of location of patients at certain times.

Problems of off-site storage, slowing process of sorting/access/conservation/cataloguing. Adopting pre-existing sensitivity guidelines for the collection and issues that arise when introducing new types of records to the archive.

Recommendation from GB to contact Clare Button for advice on dealing with similar types of sensitive records.

4. Minutes and matters arising relating to last meeting

No matters arising from last meeting.

5. HARG Committee Report and Upcoming plans

No major changes in administration. Laura Hinds is cutting back on time spent on HARG. She brought information governance and records management to the group so it would be good to get a replacement.

Membership has slightly increased to 124 members. 138 followers on Twitter since September 2017. Facebook page has recently been established.

Website: slight change to membership pages to include new institutional members – logo of service and contact information, blogs and link to your catalogue.

First newsletter (planned biannually) mainly electronic but some hard copy distributed at events.

Geoff Browell to speak about second sensitivity conference. Oversubscribed – decided to look at wearable IT, sharing medical information on patients between providers or devices. Lots of explanatory talks, cut back on workshop component. Will include representation from software and hardware providers, clinicians and technicians, from archivists and from hospitals and clinics who could use it. Will be looking at collecting and using this type of data and the future.

6. Update from the Scottish NHS Group (Ruth Honeybone)

Diverse membership named in Scottish Public Records Act. Support group to discuss records issues. Met in July 2017, two largest pieces of work – RM code of practice for Scotland – lobbied to have a revision – other parties had concerns. Upcoming health archives workshop to discuss health archives in arts and less mainstream use of health archives etc. Offer of support for other archives considering Archives Accreditation. Also offer of advice on cataloguing sensitive health records, due to experience of working with Norman Dott archive.

7. UK National Archives health sector update (Kevin Mulley)

Transfers of records under new NHS act – mixed picture, just processing returns now. What comes over is that the number of accessions are normal but the volume has reduced. Transfers from 31 NHS trusts – there were circa 200 – so therefore many NHS trusts still not transferring on a regular basis.

GDPR guidance available from information Commissioner's Office.

Changes to Discovery catalogues online tool now available on website.

Accreditation standard update underway – likely to be light touch rather than radical changes.

8. Sensitivity surgery: a group discussion of sensitivity queries by HARG members

A short report summarising some of the issues raised in the discussion is available in the HARG newsletter, spring 2018, which can be found on the HARG website.

End of meeting.