

PUBLIC HISTORY

The Children of Craig-y-nos: life in a Welsh tuberculosis sanatorium, 1922-1959. Reflecting on the project's challenging issues

by Carole Reeves

Abstract: *The Children of Craig-y-nos*, a public and oral history of life in a Welsh tuberculosis (TB) sanatorium, began in 2006 as a daily blog and has achieved international recognition. Although elements of the project have been passed to the community in which it originated, as was the intention, its creators have remained the point of contact for potential spin-off projects and for troubleshooting dark and challenging issues. These include disturbing revelations of institutional abuse; long-standing misconceptions about the sanatorium and its staff which have resulted in anguished lives for some ex-patients; ethical issues relating to individual and community responsibility; and archiving the project's valuable but ephemeral resource, the blog. Lessons learned may help others contemplating a project in which digging up the past might unearth long-buried secrets and pose problems for the future.

Key words: blogs, children, sexual abuse, sanatorium, public history, tuberculosis

The Children of Craig-y-nos, a public and oral history of life in a Welsh tuberculosis sanatorium (1922-1959), was begun in November 2006 by Ann Shaw, an ex-patient and former journalist who started a daily blog to post her own memories and collect those of others.¹ An edited version was published as a print-on-demand book in 2009, co-authored by Ann and myself as the project's medical/oral historian, funded by an award of £5,000 to University College London from the Big Lottery Fund under the Awards for All Wales scheme.² The project has been the subject of newspaper, magazine and journal articles,³ as well as radio and television programmes,⁴ including most recently, a feature on BBC's *The One Show* which, due to positive audience feedback, was repeated three months

later. The project has also inspired public performance art projects involving school children, university students and young people from the Prince's Trust,⁵ and there have been three photographic exhibitions including a summer exhibition in 2008 at Swansea Museum.⁶ The online version of this exhibition was selected by the All-Party Parliamentary Group on Global Tuberculosis to feature on its home page. As far as I am aware, *The Children of Craig-y-nos* remains the only collective account by ex-patients and staff of life inside a sanatorium, although a number of personal testimonies have been published⁷ and historians have begun investigating the history and experiences of children with tuberculosis or who were considered to be at risk of catching it.⁸

The Children of Craig-y-nos project maintains



its high profile and level of activity largely because of continuing interest and involvement of the original participants who arrange reunions, curate the travelling exhibition, speak to local schools and other organisations, and host self-help groups to share and confront long-buried memories. Although it would be incorrect to claim that all experiences were negative, the long-term impact on the majority of ex-patients has been significant, sometimes shocking; and in the light of recent inquiries into alleged abuse of vulnerable institutionalised children, moderately disquieting. This article reveals some of the issues, unexpected or otherwise, that have been raised during the project's wide exposure, including: long-term responsibility for participants; accountability to non-participants affected by published testimonies; implications for oral historians debriefing people who have experienced trauma; and archiving the blog as an open access resource.

Craig-y-nos Castle

Craig-y-nos, meaning 'rock of the night', is the name of a hill that rises above the Swansea valley on the south-west edge of the Brecon Beacons National Park. The adjacent country house which took its name was built in 1840 by a local land-owning family. Within forty years, this isolated estate had been acquired by Adelina Patti (1843-1919), the world-famous Italian-born opera singer, who spent over £100,000 extending the house (also renaming it a 'castle') and grounds, thus providing an important source of employment for local people. After Patti's death, her husband Baron Olaf Cederström sold the forty-eight acre estate for £19,000 to the King Edward VII Welsh National Memorial Association (WNMA),⁹ which had been established in 1910 with a remit to prevent, treat and eradicate tuberculosis in Wales. Craig-y-nos Castle was adapted to a 100-bed sanatorium named the Adelina Patti Hospital¹⁰ and opened in August

Craig-y-nos Castle, 1950s. Rear of the sanatorium showing the conservatory (babies' ward), centre, and the children's wards with balconies in the main building, right. Photo courtesy of Beryl Lewis.



1922, the year after the Public Health (Tuberculosis) Act made it obligatory for all the county councils and county borough councils of Wales to provide treatment for people with TB. Although the Craig-y-nos project is associated with children, teenage girls and young women, the sanatorium initially admitted adults of both sexes as well as children. In 1934, for example, the ratio of adults to children was exactly half,¹¹ although there were twice as many girls and women as boys and men.¹² However, by 1946 an acute shortage of nurses resulted in the transfer of adult men and teenage boys to the South Wales Sanatorium at Talgarth, Powys, a move welcomed by the all-female nursing staff because, according to a community chest physician, Patrick Mulhall, 'TB males were difficult to control in the early days of a strict regimen',¹³ particularly those who had been invalided out of the services with tuberculosis during the Second World War.

Although Craig-y-nos discontinued as a TB sanatorium in 1959, it remained a hospital for a further twenty-seven years, initially admitting patients with the chronic chest diseases common to coal mining, slate quarrying and other dust-laden Welsh industries, before becoming a general hospital for the elderly. The castle's present owner purchased it in 2000 for conversion into a hotel. Its Gothic façade and rare Grade-1 listed theatre built by Patti as a concert venue and ballroom make it a popular location for weddings. Organised ghost tours exploit the legend that Patti's spirit still haunts the castle and grounds, but following discussion with Craig-y-nos survivors, audio recordings of spectral children supposedly snatched by the cold hand of tuberculosis are no longer part of the entertainment. Renovations and restorations of the buildings are ongoing and expensive, so much so that most of the old TB wards above the ground floor remain intact, even to the extent of retaining the bed lamps with their miserable forty-watt bulbs so roundly criticised by school inspectors in the 1950s.¹⁴

This combination of preservation and decay has proved seductive to journalists and film production companies seeking locations for interviews with ex-patients, every one of whom walks uncannily and without hesitation to his or her old bed-space. Now more than ever before, the castle is visited by ex-patients from around the world making a pilgrimage to their bed-spaces. For an elderly man confined as a seven-year-old to the outside balcony, removed decades ago, a familiar mark on the external brickwork serves to recall the location of his iron-framed cot.¹⁵ The castle's owner has offered the project a large derelict ward in which to create a permanent memorial to the children of Craig-y-nos. The expectation is that I will apply for Heritage Lottery or similar funding (as I did for the book) although issues regarding building access and its extreme state of dilapidation may preclude this. The project has nevertheless proved good for the tourist trade in this remote area of Wales.

Collecting the testimonies: methodology

Ann Shaw was a child in Craig-y-nos between 1950 and 1954, aged nine to thirteen, although she has lived in Scotland for much of her adult life. Her blog was launched with the aim of finding other ex-patients and to collect their memories. She also advertised for contributors in the *South Wales Evening Post*, a widely-read local newspaper, and posted an emotive appeal on a Mid Wales website dedicated to community news and history hosted by the British Broadcasting Corporation (BBC):

I sense a need for closure, not just for myself but for all the people who are still alive, and



their families too, for TB affected the whole community, not just physically but socially and emotionally. It was the disease never spoken about except in hushed whispers.¹⁶

The response to the blog and appeals was immediate. Testimonies, photographs and telephone calls began flooding in from all over the UK and many parts of the world, especially the USA, Canada, Australia and New Zealand – all common locations for the Welsh diaspora. There is no doubt that the internet made this project possible, although over ninety per cent of respondents still lived in and around the old catchment areas of the sanatorium. It transpired that other ex-patients and staff still living in the Swansea area had also been contemplating their experiences and been drawn back time and again to the old castle. Ann's appeals were the catalyst they needed to mobilise the community and assist in the story-gathering process. Between them they organised the first reunion of sixty ex-patients and staff; travelled the area talking to frail and elderly people in their homes; and enlisted the help of a community charity, the Sleeping Giant Foundation, which offered its volunteer oral historians. Children and grandchildren of ex-patients and staff made email contact possible for those without computers. The project's inter-generational nature helped secure the Lottery funding to produce the book. From its inception, therefore, *The Children of Craig-y-nos* was a public history project.¹⁷

Ann enlisted my input after searching in vain

for information about the castle's history as a TB sanatorium and my role has evolved over the years. I began by researching and contextualising the history of Craig-y-nos but also brought in historical, social and medical perspectives from the histories of tuberculosis, sanatoria, public health and psychology. I was also able to help plan the process of collaboration with Ann Shaw and members of the community so that the 'shared authority' as conceived by Michael Frisch¹⁸ (and subsequently Valerie Yow and other scholars) was embedded into the project.¹⁹ I went on to conduct half of the interviews produced for the book, as well as writing the book's historical sections and acting as overall editor. I continue to provide resource material for community volunteers and teachers as well as maintaining awareness of the project both in academic and public circles; and to facilitate spin-off projects such as those mentioned in the introduction to this article. The project has a personal resonance because my mother was born and raised near this area of South Wales in a mining family that had experienced tuberculosis.

The book contains the testimonies of ninety-six people who were children, teenagers, young adults and staff at Craig-y-nos or who had relatives there. Over two-thirds of these were gathered during one-to-one interviews, either in person or over the telephone using a telephone recording connector (recorded with consent of the interviewees). The remainder were gathered through email correspondence with Ann Shaw or myself. Sometimes an individual contacted us

Christmas in Craig-y-nos, circa 1944. Children with their gifts, distributed by 'Santa', watch a pantomime. Photo courtesy of Glenys Jones.

by email or letter and then agreed to be formally interviewed. The constraints of the book meant that most of the published testimonies were edited to one thousand words or less, despite the duration of interviews being up to two and a half hours. The blog was used as forum to publish whole transcribed, unedited interviews in daily postings as necessary. The blog is therefore far more important than the book as an archive resource. To date (20 October 2013) it contains 930 postings, eighty-seven of which have been added since the book's publication.

Care and treatment at Craig-y-nos, 1921-1959

I am to have something called a 'phrenic' operation, a procedure later proved worthless but a very popular method of treating TB before the arrival of drugs. Your lung is collapsed and you are made to lie on your side for several months without moving. It is thought that this, along with total rest, will cure the disease [...] I am wheeled into the operating theatre, conveniently next to the morgue, not that I know this at the time [...] I lie on my left side with a pillow tucked behind my back so that I will not accidentally turn over, and my bed remains on its twelve inch blocks. And that's how I stay for the next year.²⁰

During the four decades that Craig-y-nos served as a TB sanatorium treatment options remarkably static. Even when the antibiotic streptomycin became generally available in the late 1940s, followed by PAS (para-aminosalicylic acid) and Rimifon (isoniazid), the mainstays of therapy remained fresh air, bed rest (including complete immobilisation in plaster casts), nourishing food, tonics including iron (which is recalled as causing constipation and damaging the teeth), artificial pneumothorax (a surgical procedure to collapse and 'rest' the lung), light therapy involving ultra-violet rays to kill the TB bacillus and controversial drugs such as Sanocrysin (gold therapy) which slowed replication of the bacillus but was associated with metal toxicity because its gold content was about forty per cent.²¹

The general atmosphere at Craig-y-nos during the 1950s appears to have been more relaxed and positive than in previous decades, despite a rise in beds from 100 to 136. This has been attributed, both by patients and staff, to antibacterial treatment. Streptomycin gave people hope of a cure even if this was not realised in every case. Nevertheless, the death rate from TB in children under fifteen during this decade decreased by an astonishing ninety-three per cent in England and Wales.²² Accurate death rates in Craig-y-nos are impossible to ascertain except for the year 1934,

TABLE 1. AVERAGE LENGTH OF STAY AT CRAIG-Y-NOS DURING FOUR DECADES BASED ON PERSONAL TESTIMONIES. SMALL PATIENT NUMBERS MAKE THIS A VERY CRUDE ASSESSMENT

Decade	Average stay (months)	Range (months)	No of patients
1920s	13.6	7 – 60	5
1930s	13.7	4 – 48	6
1940s	21.4	6 – 66	30
1950s	19.2	4 – 60	41

in which fifteen per cent of patients died. Of these, twelve and a half per cent were adults; and the ratio of adults to children was exactly 50:50.²³ Many interviewees recall, however, that very sick patients were often sent home to die. Similarly, official statistics for length of stay are not available but Table 1 gives a crude indication, based on personal testimonies. Children hospitalised for four or five years were generally those with bone and joint disease. These were also amongst the very youngest patients.

British public health physicians of the 1940s claimed that the greatly increased duration of stay in sanatoria over that decade was due partly to innovative but time-consuming medical and surgical treatments,²⁴ but at Craig-y-nos 'treatment' amounted to little more than prolonged immobilisation in bed:

Most of the time I was in a splint with my legs apart and straps across my chest. You could only move your head and arms [...] After I had been there about five years (1940-45) Dr Hubbard arrived [...] As soon as she came, she said: 'Get him up, get him up!' Then we – the children with TB hips – were up and home in about six months.²⁵

Craig-y-nos closed as a TB sanatorium in 1959 and the patients transferred to the South Wales Sanatorium at Talgarth. It seems the end may have been pre-empted by a confidential meeting between Dr AR Culley of the Welsh Board of Health and the District Inspector of Schools, Mr W Richards, who expressed anxiety at what was going on in the castle. In a memo he wrote, 'I hope the transfer will soon take place as the care of children at Adelina Patti was almost frightening'.²⁶ This followed a number of inspectors' reports that were highly critical of the lack of stimulation, disinclination to get children up and dressed, and 'the severe disciplinary manner to the children' of its senior physician, Dr Hubbard,²⁷ who is recalled with loathing in many of the testimonies.



We had to have the lights out at a certain time and my sister and I were talking. The nurse told us to be quiet. We were still talking and Dr Hubbard came in and said, 'Wheel those two children out into the corridor'. Next morning she said, 'You can put her back in the ward,' to my sister, but she had me locked up in a room. I was left there – it must have been at least three days. Nobody was allowed to speak to me. They were allowed to bring food in, and they had to put it on the floor and go. I was six and that memory has stayed with me for over fifty years. My sisters Pat, Sandra, and myself were there from 1956 to 1957.²⁸

It is tempting to speculate whether government administrators also suspected sexual abuse, although there is no archival evidence to suggest this.

Opening Pandora's box: why dig up the past?

Ann Shaw posed this question at the start of the project. Whilst it is the business of historians to dig up the past, there is a long-acknowledged reticence associated with talking about tuberculosis or admitting to infection. This is particularly true in Wales where by 1939, out of every 100 deaths in the age group fifteen to twenty-five, TB killed thirty-one men and fifty-three women.²⁹ Social

workers of the 1950s described this reticence as the 'leper complex',³⁰ and recent oral histories have used the words 'stigma', 'silence', 'ignorance' and 'prejudice'.³¹ The ex-patients of Craig-y-nos share these experiences but a number also expressed (and continue to express) considerable anger, directed not solely at the institution, its staff and regimen, but at their own family members who were perceived to be collaborating with the sanatorium authorities by lying, withholding information or not responding appropriately to their distress. During the year following the publication of the book, Ann Shaw and I spent many telephone hours talking to individuals who had participated in the project but wished to continue the process of unburdening with new and often disturbing revelations. This sometimes felt like counselling, something we were not trained to do and which was exhausting and worrying; but, as highlighted by Wendy Booth in her work with lonely and vulnerable people, researchers who engage in participatory projects in which interviewees may be vocalising thoughts, memories and insights for the first time, 'must be prepared to give as well as take'.³²

Late in 2009, I received a letter from a relative of a senior member of staff, deceased long before the project began, expressing concern that two ex-patients featured in the book had made allegations regarding his professional conduct, one of which related to sexual abuse.³³ She pointed

Above: Lessons on the balcony of Ward 1 with Miss White, the headmistress of the hospital school, circa 1949. Photo courtesy of Mari Friend.

Above left: Fresh air treatment for a child with TB hip, circa 1924. The foot of the child's bed is raised on bricks and the weighted sandbag keeps her leg elevated. Photo courtesy of Phil Lewis.



out that he was no longer able to defend his reputation (although he had not been named by his accuser) and that she considered the alleged abuse ('fondling') rather less serious than the sexual abuse described by her own sister (JS) at the hands of a nurse, which, she noted, we had 'chosen not to publish' in the book although it had been posted on the blog. There was a suggestion that we had been careless in our editing and had failed to consider the feelings of surviving relatives. The potential implications of this letter required a measured response, a section of which is reproduced below:

As you have noted, some of the experiences have had a significant impact on the individuals concerned and they were free to express these, knowing that they would be published. We did not coerce individuals into giving 'sensational' stories [...] it's very difficult to grade abuse according to perceived seriousness because what matters is the effect on the person receiving it.

Neither Ann nor I entered this project lightly or with intent to damage the reputations or feelings of those mentioned in the blog or the book. Neither do I believe that the people who were forthcoming with their stories did so out of malice towards the people they felt had mistreated them. We have simply given

those people who experienced Craig-y-nos, whether as patients, staff or relatives, the opportunity to be part of a collective account of the hospital over its forty-year existence.³⁴

I concluded by offering to send copies of her letter to the individuals in question to give them the opportunity of responding to her concerns about their allegations, but no further correspondence ensued. JS's account of her experience as a six-year-old in Craig-y-nos had been published on the blog two years previously in December 2007:

The worst memory – which I didn't remember till nearly forty years later when I was having counselling for depression – was of Sister 'X' who smelled of nicotine putting the screens around my bed as though she was giving me a blanket bath. She used to touch me in a place where I knew she shouldn't and manipulate me. I knew this was wrong and I felt dirty and guilty as though it were my own fault. I don't know how long it went on and I never told anyone. I'm sure this is where my claustrophobia originated.³⁵

After consideration, we did not reveal the identity of the ward sister although she had been named by JS. We were aware that website hosts may be liable for defamatory material created by

someone else but which they host,³⁶ although this may leave oral and public historians in a censorship dilemma. In her recent article on oral history ethics in the digital age, Mary Larson considers the tension between decisions to withhold detrimental material from online dissemination because of potential ramifications for community members and the need to respect the wishes of adult narrators to have an online voice.³⁷ According to IT and media lawyer Alasdair Taylor, 'the most difficult question when reviewing material for libel risks is not whether material is defamatory, but whether a potential claimant is really likely to bring proceedings.'³⁸ In the United Kingdom it has been a long-established principle that a deceased person cannot be defamed because reputation is considered personal and relatives of the deceased have no right of action unless the words used reflect upon their own reputations. In 2012 the House of Commons rejected an attempt to amend the Defamation Bill (which became law in April 2013)³⁹ so as to allow relatives of dead people to sue over allegedly libelous stories about their loved ones.

It is interesting that JS's sister expressed concern in her letter about potentially defamatory material being published in the book, yet appeared not to share the same concern about identical material posted on the blog. Indeed, her overriding anxiety was that the alleged 'fonder's' identity would be revealed to the local community, a possibility in rural areas where family relationships may be close and complex.

The 'real' Mr Christie and other childhood beliefs

The Craig-y-nos project exposed a number of long-standing beliefs and misconceptions about the sanatorium and its staff, which, had they been resolved at the time, might have resulted in lives of less anguish for the individuals concerned. For example, a life-long resentment towards his parents for not visiting 'very often because they didn't want to or they couldn't afford to' was lifted for one participant when he learned from the project that in the late 1940s, visitors to children's wards were only allowed during the first weekend of every month.⁴⁰ Had he been older than seven, he might have observed this for himself at the time.

Many individuals recall a traumatic procedure they describe as 'the tube down the throat' and still remember the smell of the red rubber tubing in question. This was gastric lavage, described in a *British Medical Journal* article of 1934 by a physician who had observed it at the Hôpital Héroid in Paris.⁴¹ The objective was to retrieve swallowed sputum from the stomach to test for TB bacilli because young children find it difficult to cough up and spit out sputum from the lungs. The child was held immobile, its mouth wedged open with a gag while the stom-

ach tube was pushed down the throat. Warm water with a trace of sodium bicarbonate was fed into the tube from a funnel and the gastric contents siphoned out. By 1944, gastric lavage was a routine procedure at Craig-y-nos. In that year eighty-two children had a total of 169 gastric lavages. Of the eighty-two children, TB bacilli were found in thirty-three.⁴² The gastric washout was sent to the Central Tuberculosis Laboratory in Cardiff to be injected into guinea pigs to see whether they developed TB; the Welsh National Memorial Association had its own guinea pig breeding establishment which was based at the farm (and home) of the professor of tuberculosis, William Howard Tytler (1885-1957).⁴³ Misconceptions about gastric lavage often persisted throughout childhood and even into adulthood: if you bit into the tube you could die; being passed over for the procedure when all your friends were having it meant that you *would* die; it was a punishment for some misdemeanour; it was the route by which drugs were poured into the body; and finally, that stomach contents were 'fed' to guinea pigs. For the majority of those who experienced gastric lavage, the real reason for it remained unknown until they were interviewed for the project.

Perhaps the most bizarre misconception is one of mistaken identity which has had traumatic consequences for a man who was in Craig-y-nos as a three-year-old in the mid 1940s. RH has always believed that the sensational London serial killer and necrophiliac John Christie (1898-1953) was a porter of the same name who used to cut his hair in the sanatorium. He still has the pocket watch ('in a wooden box on the Welsh dresser') given to him by Christie the porter after RH started crying when his hair was tugged.⁴⁴ The files relating to Christie the killer in the National Archives are very comprehensive and show beyond reasonable doubt that he was never employed at Craig-y-nos, although his association with Timothy Evans (1924-1950) from Merthyr Tydfil, erroneously hanged for strangling his wife (a crime committed by Christie), adds a further intrigue to the story.⁴⁵ Christie the porter's staff file in the National Library of Wales reveals that he was appointed Head Porter at Glan Ely Hospital, near Cardiff, on 30 April 1913, the very year that Christie the killer left school at fifteen and started work as an assistant cinema operator near his home in Halifax. Christie the porter was transferred to Craig-y-nos on 7 August 1922, soon after the hospital opened. His employment record from 1913 to 1935 is continuously documented⁴⁶ (confidentiality rules prevent access to documents after this date) and ex-staff interviewed for this project recall him being at Craig-y-nos during the 1940s when Christie the killer was living at number ten Rillington Place near Ladbroke Grove in west London.

Institutional abuse

At the end of 2012, *The Children of Craig-y-nos* project came to the attention of Real Life Media Productions, an independent company that produces BBC Television's *The One Show*, a daily magazine programme featuring human interest stories.⁴⁷ A number of ex-patients and staff agreed to take part. The issue of alleged sexual abuse at Craig-y-nos was raised by me during discussions with the producers, following which BBC lawyers were consulted regarding the advisability of transmitting the programme; and Dyfed-Powys Police⁴⁸ were contacted to discover whether there was a pending investigation into abuse at the old sanatorium (there was not). I was asked whether I had considered exposing what had taken place at Craig-y-nos, such is the sensitivity of this issue in the wake of a number of high profile cases of alleged childhood abuse by staff in former care homes and other children's institutions in the UK. I made clear my role on the project and emphasised that the participants are now adults and must determine their own course of action. In the event, the programmes were first broadcast on 16 and 17 April 2013, and the Craig-y-nos blog immediately attracted a new wave of testimonies from ex-patients or their descendants. Anyone who has kept up with the blog over the past six years will appreciate that it has faithfully documented, without censorship (apart from the example above), every story revealed to the project and as a result, no additional 'exposures' from me about conduct in the sanatorium are necessary.

Ethical dilemmas and web archiving in the UK

The issue of engaging with ethics committees (or institutional review boards in the US) has been much discussed in oral history, particularly by oral historians who work with vulnerable adults both within and outside institutional settings.⁴⁹ The question of whether the Craig-y-nos project proposal should have been submitted to the university's research ethics committee remains an issue of debate. Initiated by an individual, Ann Shaw, working outside a UK institution of higher or further education, there was no obligation on her to formalise the project. However, it soon became apparent that my involvement as a university academic would be far greater than originally conceived and with hindsight I would not engage in a similar project without research ethics committee approval, although the Craig-y-nos project remains the most rewarding of my career.

The Oral History Society legal and ethical guidelines,⁵⁰ the Oral History Association principles and best practices,⁵¹ and Leeds University's *Timescapes Methods Guides* series⁵² all offer helpful guidance concerning the evolving relationships between researchers and research participants, on protection of and respect for participants over

time, as well as the support and protection of researchers. A particularly important group are those oral historians who end up, as Larson calls it, 'debriefing' people who have experienced trauma.⁵³

The Children of Craig-y-nos book contains the memories of over ninety people who were children, teenagers, young adults and staff in the sanatorium or who had relatives there. It is a print-on-demand publication but also freely available as a PDF document hosted on my UCL web page.⁵⁴ Transcripts of interviews, photographs, letters, emails, greetings cards, autograph albums and other memorabilia sent or donated by ex-patients and staff as well as material derived from the exhibitions, including visitors' books and newspaper articles, are currently being prepared for deposit in Powys County Archives Office. The online exhibition, professionally created to coincide with the first photographic exhibition in the small town of Ystradgynlais, seven miles from the castle, was archived at my request by the UK Web Archiving Consortium.⁵⁵ The blog contains 950 entries, at least half of which feature individual, largely unedited testimonies, either from transcribed recorded interviews or email correspondence. The blog has become a valuable public and academic resource for the history of tuberculosis and the history of institutions, but the UK Web Archive works on a 'rights secured' basis and the very nature of *The Children of Craig-y-nos* blog, as a site of public comment, made this potentially problematic.

Blogs are designed for ease of use and may be valuable for creating and maintaining a public history project, as we have shown with *The Children of Craig-y-nos*. Ideally, issues with archiving need to be addressed when planning a project, although the evolving nature of technology makes it difficult to foresee how today's recording might be disseminated two decades hence. The Legal Deposit Libraries (Non-Print Works) Regulations 2013,⁵⁶ designed to facilitate digital archiving of digital content, are projected to expand considerably the UK Web Archive by adding annual snapshots of the entire in-scope UK web domain. Bloggers and website owners may also submit a registration request through the Publisher Deposit Portal. However, the archived material may only be accessed from Legal Deposit Library (LDL) premises⁵⁷ unless granted permission for access outside reading rooms by the rights holders⁵⁸ who by definition are all the individuals who have posted a comment on the blog.

Repositories and practitioners remain in dialogue regarding ethical issues of oral history in a rapidly evolving digital age. Best practice guidelines are reviewed as issues continue to arise, but as Mary Larson reminds us, the onus is on individuals and institutions to maintain awareness of parameters and guidelines so that we have clear points of reference when navigating uncharted waters.⁵⁹

Conclusion

The Children of Craig-y-nos continues to attract academic, public and media interest and to inspire community arts and performance projects. Behind the scenes, however, there have been many challenges which, far from contributing to the closure anticipated by Ann Shaw at the launch of the project, have opened a number of painful doors for participants and their relatives in the community that could not have been foreseen. It has also raised questions about long-term responsibilities to interviewees and communities, the health implications of oral historians de-briefing trauma victims and issues around the archiving of digital-born content. Perhaps the most important lessons learned from this project relate to a new understanding of the myriad ways in which individuals internalise traumatic life events and an increased appreciation of the historical context in which painful memories are laid down and carried through life. For example, the John Christie murder story first appeared in the press early in 1953, nearly eight years after RH was discharged from Craig-y-nos as a four-year-old boy. RH says that he immediately 'recognised' Christie the porter from the newspaper photograph and despite the derision of his parents continued in his conviction that the two men were the same. Why did RH reveal this story to Ann and me after sixty years and what were our reactions? I *should* be

ashamed to admit that we experienced a thrill of excitement, which quickly changed to incredulity and a desire to uncover the 'truth' and relieve RH's misery, whilst half-hoping his belief would be verified. In the event we were disappointed on two fronts: research disproved the connection between the men, but we suspect that RH remains only half-convinced by this evidence although he has always been one of the project's most stalwart supporters.

The lives of individuals who were children in Craig-y-nos have been shaped by the sanatorium experience in unique and sometimes disquieting ways. Some years ago, when I spoke about the project at an annual conference of the Oral History Society, it was put to me that I was perhaps infantilising ex-patients by referring to them as 'The Children of Craig-y-nos' when most are now in their seventies, eighties and nineties. In fact, this is the term they themselves have chosen. The project was originally called *The Lost Children of Craig-y-nos* because the objective was to find as many ex-patients as possible. However, this caused considerable indignation amongst people who did not consider themselves in the least bit lost and who also disliked the connotation that the sanatorium experience had somehow cast them into Peter Pan's 'Neverland'. Step into the vicinity of Craig-y-nos Castle, however, and the transportation to a land that time forgot is eerily realised.

ACKNOWLEDGEMENTS

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NOTES

1. *The Children of Craig-y-nos* [website].

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2. Ann Shaw and Carole Reeves, *The Children of Craig-y-nos: Life in a Welsh Tuberculosis Sanatorium 1922-1959*, London: Wellcome Trust Centre for the History of Medicine at UCL, 2009. Freely downloadable and accessed online at www.ucl.ac.uk/sts/staff/reeves/outreach/children_of_craigynos/Cyn_book, 23 August 2013.

3. Including Carole Reeves, 'Finding the lost children of Craig-y-nos', *Wellcome History*, vol 37, 2008, pp 15-16; Caroline Boyce, 'The sanatorium children', in *The Oldie Annual 2012*, London: Oldie Publications Ltd, 2012, first published in *The Oldie*, February 2010, pp 34-35.

4. *The Jamie and Louise Show*, BBC Radio Wales, transmitted 6 September 2007; *Bed Rest, Pine Trees and Fresh Air: Welsh Sanatoria*, BBC Radio Wales, transmitted 31 August 2008; *Making Britain Count*, BBC One, transmitted March 2011.

5. 'Generale Staten', devised by Dutch artist

Mieke Van de Voort and developed in collaboration with CASCO, Office for Art, Design and Theory, Utrecht NL. We brought this project to London in July 2010 as '627K', hosted by The Showroom, a London arts organisation supported by the Arts Council.

6. The exhibitions comprise photographs taken in the sanatorium by the children and teenagers. The project has collected over 1,200 photographs that have been digitised.

7. Rosemary Conry, *Flowers of the Fairest*, Dingle: Brandon Books, 2002; Isabel Gillard, *Circe's Island: A Young Woman's Memories of Tuberculosis Treatment in the 1950s*, Glasgow: Unbound Press, 2010; Cynthia Coultas (ed), *Good Food, Rest, and Plenty of Fresh Air: A History of The Marguerite Hepton Memorial Hospital, Thorp Arch*, Somerset: Cynthia Coultas, 2010; Chris Dell, *Black Notley Blues: Diary of a Teenage TB patient, 1958-1959*, Bishops Stortford: Stortford Documentation Services, 2013.

8. Cynthia A Connolly, *Saving Sickly Children: The Tuberculosis Preventorium in American*

Life, 1909-1970, New Brunswick, New Jersey: Rutgers University Press, 2008; Teemu Ryymin, 'Tuberculosis-threatened children: the rise and fall of a medical concept in Norway, c.1900-1960', *Medical History*, vol 52, 2008, pp 347-64; Susan Kelly, "'Suffer the Little Children": Childhood Tuberculosis in the North of Ireland, c.1865-1965', unpublished PhD thesis, University of Ulster, 2008; Susan Kelly, 'Education of tubercular children in Northern Ireland, 1921 to 1955', *Social History of Medicine*, vol 24, no 2, 2011, pp 407-425; Susan Kelly, "And so to bed": Bone and joint tuberculosis in children in Ireland, 1920-1950', in Anne MacLellan and Alice Maugher (eds), *Growing Pains: Childhood Illness in Ireland 1750-1950*, Dublin: Irish Academic Press, 2013.

9. Deeds and documents relating to the Adelina Patti Hospital, A1982/64, Box 15, Llyfrgell Genedlaethol Cymru/National Library of Wales (LGC); Conveyance between WNMMA and John Jones, 13 November 1931, A1982/64, Box 15, LGC.

10. Setting up of the Committee of Enquiry

- into the Anti-Tuberculosis Service in Wales, 1937, p 15, A1982/64, Box 6, LGC. Although officially the Adelina Patti Hospital, it was more commonly known as Craig-y-nos.
- 11.** *Twenty-Third Annual Report*, WNMA, year ending 31 March 1935, p 88, A1982/64, Box 13, LGC.
- 12.** Adelina Patti Hospital School for Handicapped Children, School Inspectors' Report 1936, p 1, ED 224/23, National Archives.
- 13.** Dr PPM, Shaw, 2009, p 140.
- 14.** Adelina Patti Hospital School for Handicapped Children, School Inspectors' Report 1953, pp 1-2, ED 224/23, National Archives.
- 15.** Interview with HB, 17 July 2007.
- 16.** Ann Shaw, BBC Mid Wales Abercraf, *The Children of Craig-y-nos*. Accessed online at www.bbc.co.uk/wales/mid/sites/abercraf/pages/annshaw.shtml, 3 December 2007 (site no longer available).
- 17.** Valerie Raleigh Yow, *Recording Oral History: A Guide for the Humanities and Social Sciences*, second edition, Lanham, Maryland: AltaMira Press, 2005, chapter seven.
- 18.** Michael Frisch, *A Shared Authority: Essays on the Craft and Meaning of Oral and Public History*, Albany: State University of New York Press, 1990.
- 19.** Yow, 2005, p 191.
- 20.** AS, Shaw, 2009, p 93.
- 21.** Holger Moellgaard, 'The Sanocrysin treatment of tuberculosis', *British Medical Journal*, 4 April 1925, pp 643-647; Mireya Diaz and D Neuhauser, 'Lessons from using randomisation to assess gold treatment for tuberculosis', *JLL Bulletin: Commentaries on the History of Treatment Evaluation*. Accessed online at www.jameslindlibrary.org, 3 October 2013.
- 22.** Godias J Drolet and Anthony M Lowell, 'Tuberculosis mortality among children: the last stage. A statistical review of the 1950-1959 decade in Canada, the United States, England and Wales, and France', *Chest*, vol 42, 1962, pp 364-371.
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- 28.** ST, Shaw, 2009, p 81.
- 29.** *Thirty-third Annual Report*, WNMA, year ending 31 March 1945, p 51, A1982/64, Box 13, LGC.
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- 31.** Simon Guest, 'Infection and reaction: tuberculosis in Ireland, 1932-1957', *Oral History*, vol 32, no 2, 2004, pp 63-72; Susan Kelly, 'Stigma and silence: oral histories of tuberculosis', *Oral History*, vol 39, no 1, 2011, pp 65-76.
- 32.** Wendy Booth, 'Doing research with lonely people', *British Journal of Learning Disabilities*, vol 26, 1998, pp 132-134.
- 33.** JW, Shaw, 2009, p 126.
- 34.** Correspondence between Carole Reeves and WM, October 2009. Every person whose story appears in the book signed a release form allowing their stories to be published.
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Address for correspondence:
c.reeves@ucl.ac.uk