

The Socio-Cultural History of Polio Survivors in the U.K

CAN YOU HELP US?

We are doing a project about life histories of people who got polio as children and teenagers in the United Kingdom, and how things in their lives have changed as they grew older.

We want to talk to men and women who contracted paralytic polio between childhood and teenage years (0-18 yrs)

Background to the Project

The polio vaccine was one of the greatest achievements in the history of the NHS, leading to the elimination of the disease in the U.K.

Today, polio only exists in three countries worldwide – Afghanistan, Pakistan and Nigeria. However, during the 20th Century there were approximately 100,000 cases of poliomyelitis in the U.K. Although

the spread of the virus was slow during the early part of century, the post Second World War period marked the main phase of epidemic activity.

Polio had social, cultural, psycho-emotional and physical impacts on generations of families and communities. While the majority of poliomyelitis cases during this period did not result in disease, approximately 2% of cases experienced major disease including inflammation of the membrane covering the spinal cord and resulting in permanent paralysis. This meant the disabling consequences of the disease could be permanent or temporary. Nevertheless it became a major

public health issue and significantly influenced the advancement of British medicine, including the development of assistive technologies such as the iron lung, leg braces and techniques in viral culture. This proved useful to patients with other medical diagnoses too.

Although the poliovirus has gone from the U.K., the legacy of poliomyelitis lives on, with many survivors of childhood polio experiencing Post-Polio Syndrome (PPS) - new onset of fatigue, muscle deterioration and weakness. The British Polio Fellowship estimates that there are 120,000 people in the U.K. living with the effects of polio or PPS. They have memories of how post-war culture, polio-related treatments, practices and technologies shaped their lives as they grew up. But as polio reaches global eradication polio survivors become an 'endangered species'. So is important to capture and preserve their lived experiences.

The stories of polio survivors will bring new knowledge of individual and collective experiences of polio and Post-Polio Syndrome in a changing British society. This work will enable us to explore the social, cultural and psycho-emotional effects of the disease for the individual, family and communities across the lifespan. It will generate new knowledge about the impact of resources, treatments and social care provisions on private lives and changing bodies.

What we want to know

We want to learn about the lives of polio survivors, particularly:

- Significant times in their lives
- Relationships and networks that made a difference in their lives (e.g. friends, family, partners, colleagues)
- What or who helped or hindered choices, and chances in life
- How changes in society over time has made a difference to life experiences (i.e. changes in policy, technology, public attitudes, the labour market, or welfare services)?
- How treatment and technologies for polio and/or post-polio syndrome influenced choices, life pathways, relationships and identities over lifetime

This exciting new work aims to make sure that the voices and experiences of polio survivors are included in research and development of services, and contribute to learning resource for

21st century audiences.

We need your help

We would like to hear your stories about:

- Childhood
- School, college and other education
- Family life
- Work and training
- Times in hospital and having medical treatment
- Marriage/Partnerships
- Sex and Parenting
- Good times, bad times
- Barriers, opportunities
- Helpful people, unhelpful people
- Successes, problems

- Happiest times in your lives
- Important decisions
- Big life changes
- Regrets, dreams

And anything else you would like to tell us!

Who wants to talk?

My name is Sonali Shah. I am a researcher and lecturer in the Strathclyde Centre for Disability Research at the University of Glasgow:

<http://www.gla.ac.uk/schools/socialpolitical/research/sociology/strathclydecentrefordisabilityresearch/>

<http://www.gla.ac.uk/researchinstitutes/healthwellbeing/staff/sonalishah/>

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Project Aims

- Explore how changes in policies, environments, institutions and relationships frame the choices available to people with polio over biographical and historical time.

Project Objectives

- Capture the lived experiences of a historically (and medically) significant generational cohort who have grown up

with impairment and disability in times of great socio-cultural and political change.

- Explore how medical regimes impacted the social worlds of children with paralytic polio in terms of relationships, identities and adult attachments

- Explore the relationships between the service user and the technology, in terms of how it empowered and disempowered the participation of polio-disabled people in different social spaces and over their life course

- Use the self-told stories to inform the development of creative learning resources for

young people to learn about Polio - the forgotten disease of the 20th Century

What will happen to the research?

We wish to meet and talk to polio survivors across the U.K. and record their stories for the researcher to type up. The stories will be used to help inform knowledge about resources, treatments and social care provisions for individuals with different medical conditions living in a changing world.

We want to write about the stories we collect and share the results locally, nationally and internationally at workshops, devised theatre work, conferences and in publications to inform other people about polio and how it affects individuals, families and communities.

The stories will be anonymised and used to develop new materials and resources for young people to learn about lives of polio survivors

growing up in Britain.

Confidentiality

All the information collected in the study will be treated confidentially. Participants will be asked to select codenames to protect their identity. We will change the names of all real people and places to maximise anonymity. The codenames will be used, instead of your actual name, throughout the project to protect your privacy. Everyone will be asked for written permission for their stories to be shared.

Further Information

Interviews/talks will last 60-90 minutes but can be shorter. Place and time can be discussed. If you have any questions, would like further information about the research, or would like this information in another format, please contact: Dr Sonali Shah – Sonali.shah@glasgow.ac.uk or 0141 3304548.

Consent Form

Please highlight/circle YES or NO to indicate your

consent for each of the following, as detailed in the information sheet:

I have understood the explanation of what participation in the research project 'The Life Histories of Polio Survivors in the U.K' will involve. (YES / NO)

I meet the criteria and I would like to participate in the study. (YES / NO)

I understand that all the information I provide is confidential, and give permission for my stories to be used under a codename. (YES / NO)

I understand I am free to withdraw from the project at any point without any repercussions by informing the researcher. (YES/NO)

I am happy for the researchers to use my stories anonymously with my consent for:

- Producing learning material for young people (YES/NO)
- Presentations at conferences and workshops (YES/NO)
- Writing articles and a book (YES/NO)

Signed

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Date

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Participant Details Form

Name:

Where do you live?

(Area, City/Town, Country)

Age:

Gender:

Sexual identity (heterosexual, homosexual, bi-sexual, trans-gendered, other)

Ethnic origin?

(eg, Indian, Afro-Caribbean, White British, other)

When did you contract polio?

(age and year (i.e. 1949))

What type of polio do you have?

(e.g. spinal polio (affects the spine), bulbar polio (affects the brainstem), and bulbospinal polio (affects the spine and brainstem))

Do you have Post-Polio Syndrome (PPS)

How did you hear about the research?

How would you prefer to be contacted?

(Email, Text Message, Phone Call, Post)

Please give preferred contact details:

We would like to protect your identity, so please give an alternative name to use:

(Optional)

What do you require to fully participate in the interview? (Assistance, Sign Language Interpreter, etc.)

