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*NEW WRITING**

A chance to be heard: what motivates people to tell their healthcare stories?

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Dr Emma Tonkin is the Education Development Officer for the nursing professions at the NHS National Genetics Education and Development Centre. In this role she is raising awareness about genetics applied to nursing practice, and is involved in supporting education and training in genetics at both pre- and post-registration levels.

Dr Rhian Morgan is the Project Officer for *Telling Stories, Understanding Real Life Genetics*. In this role she is working to expand the resource with a specific focus on developing the site to support teaching and learning for medical education.

Summary

In this article, members of the *Telling Stories* team look at why individuals have provided their stories for use on a public (internet) education site for health professionals. The team also discusses some of the responsibilities they have to their storytellers.

* Though this article is newly written for IQJ, some elements, such as the storyteller quotes, have already been used on the *Telling Stories* website and in presentations.

Introduction

Launched in June 2007, *Telling Stories, Understanding Real Life Genetics** is a free, web-based resource that uses real life stories to promote the understanding of genetics, its impact on everyday life and its relevance to

healthcare practice. The relevance and importance of genetics to all healthcare professionals continues to increase, and their education must prepare them appropriately in this area in order to ensure effective practice and care. In health professional education, patient and staff stories can enhance teaching by providing real life examples, which are engaging and motivating and help link theory to clinical practice.

As part of a broader government initiative to help practitioners learn more about the subject, *Telling Stories* was created. Whilst primarily developed for healthcare educators, students and practitioners, it is also a useful resource for patients, families and carers.

Stories are collected from people with, or at risk of, a genetic condition, or from family members, carers and health professionals and currently cover a range of genetic conditions including cystic fibrosis, Down syndrome, muscular dystrophy, inherited cancers and inherited cardiac conditions. So far almost one hundred stories have been collected from men and women aged between 18 and 75 years. Our storytellers, who are assigned a pseudonym from the outset, come from all backgrounds and all walks of life. One thing they all have in common is the motivation to tell their stories to help others understand what 'real life genetics' means for ordinary people.

In ensuring that the stories are utilised to the best possible effect to educate others, *Telling Stories* guides its users to explore the story content fully and identify aspects that they can use for personal development or organisational change that will improve the care and support provided to those dealing with the complex health needs associated with a genetic condition. This is achieved by setting the stories within an educational context with explicit links to learning outcomes for health professionals and supplementing them with a 'toolkit' of learning activities, model answers, pertinent quotes, points for reflection, expert commentaries from specialist health professionals and links to further information.

Whilst the *Telling Stories* project was initiated with the primary aim of promoting understanding of genetics amongst health professionals, one finding that has emerged from the stories contributed to date is that they proffer far more than just factual information about the genetics of a particular condition. Rich in their content, the stories often offer a powerful and informative insight into some of the experiences and complexities that can surround genetic conditions and how they affect the everyday lives of those concerned.

Why get involved?

So, what motivates people to tell their story and disclose what are often sensitive and emotive experiences such as reproductive decision-making, ethical issues surrounding genetic testing or sharing potentially sensitive information which might have a direct impact on the health of other family members?

Participants agree to contribute to the *Telling Stories* project for a variety of reasons, but in evaluating the feedback from our storytellers, it is apparent that the opportunity to tell their story provides an outlet for altruism, with the desire that some good may come out of an adverse situation, and that others may benefit and learn from their own experiences.

Storytellers felt that participation in the project provided them with an opportunity for their voice to be heard and some felt it was a cathartic experience:

> *I think that for me, it was a form of therapy – I needed to 'shout out' and it's taken me 24 years! Thanks for giving me that release!* (Brenda; Huntington disease)

> *It's nice to know that my story has been accepted, as it has given me some faith that it will be read.* (Andrew; Klinefelter syndrome)

> *I would like to thank you for the opportunity to tell my story. I hope my experiences can help*. (Diane; Familial Adenomatous Polyposis)

> *I am glad to have had the opportunity to share my story.* (Heulwen; Duchenne Muscular Dystrophy)

Some storytellers contributed as they wanted to help increase awareness of sometimes rare genetic conditions about which little information is often available or accessible:

I love my children and I love my husband and I didn't want it happening again and that's the reason I am doing this now. (Helen; Long QT syndrome)

I feel I could be helping in the next big step to understanding this sort of epilepsy. (Mary; Epilepsy)

Hopefully, the story will get messages across about genetics and risk factors. (Graham; Myocardial infarction)

A commonly recurring motivating factor for many participants was to contribute to improving the education of health professionals and others, ultimately leading to improved care:

As long as you get some sort of educational understanding about it that would please me. (Tony; Sickle-cell anaemia)

I enjoyed the experience and it will be even more rewarding if it helps in the training of healthcare professionals. In turn this will help the public. **(Graham; Myocardial infarction)**

I hope that this project will help the Nursing staff understand how we as individuals feel towards our lives. **(Andrew; Klinefelter syndrome)**

I think you have accurately edited my story and feel any medical person studying it cannot fail to learn more about ataxia. (Bob; Ataxia)

We feel that this website could make an important difference to the training of professionals and its application and use should be widened to include doctors at ALL levels. (Simon; Niemann-Pick disease)

'Telling Stories' provided an ideal opportunity for me to help pass on my own experience not only to a consultant or GP but anyone who had an interest. Hopefully quite an audience. (Paul; Familial Adenomatous Polyposis)

I feel the more people that read about experiences such as mine, the more understanding and help is likely to become available…Reading the page 'information and teaching' made me feel so pleased that I took part in your project as this is what I set out to do, tell the people who are able to help people such as myself. (Geraint; Brugada syndrome)

It helped me and hopefully will make people think and give better care. (Collette; Turner syndrome)

Some hoped their stories would be a source of help and information for others in similar situations:

If it is possible to offer help, confidence and encouragement to other ataxians through this medium, then I will feel the whole experience to have been worthwhile. (Bob; Ataxia)

The [Telling Stories] website seems a way forward…It has helped me to write about my experience but hopefully it will help other people…(Geraint; Brugada syndrome)

I have been very happy to do it and hope it may help other disabled people in the future. (Ian; Ataxia telangiectasia)

Some participants felt that their stories might help improve the understanding of the impact a genetic condition can have on people's lives:

I am glad I have told my story and I really hope people will understand how hard it can be when faced with the news your child has a disability. (Paula; Prader-Willi syndrome)

Thank you for printing my story hopefully this way KS [Klinefelter syndrome] may be understood as sometimes I felt it was similar to a freak of nature and no-one was interested…(**Andrew; Klinefelter syndrome)**

Working within an ethical framework

Whilst the storytellers are very motivated to tell their stories, we recognise that their eagerness to take part and share their experiences in what is a very public way could potentially make them vulnerable. As such, responsibility to our storytellers is of paramount importance and their care within an ethical framework is assured by:

- Viewing storytellers and their representatives as partners. Indeed, storytellers have a very inclusive role to play in the project. They are contacted throughout the process of collecting and publishing their stories and several were involved in evaluating the pilot website prior to its launch.

- Ensuring that storytellers are fully aware of the objectives of the project, and understand that they can amend or withdraw their story at any time.

- Ensuring informed consent, and by assigning a pseudonym to each storyteller (and any family member mentioned) in order to promote a degree of privacy.

- Publishing the stories in an accurate way. Stories are reproduced in the words or voice of the storyteller, are unedited and not taken out of context, allowing the authentic voice of the storyteller to be heard (whilst ensuring that the accuracy of the website as an educational resource is maintained).

- Setting their stories within a context that will help to educate others.

- Requesting that visitors to the website use its content - which is freely available for educational purposes – in a way which is consistent with the ethos of the project and maintains respect for the storytellers.

From the feedback received to date, storytellers view the experience of telling their story and their participation in the project as very positive and worthwhile. Several have commented on their experience of being a storyteller:

> *No pressure was put on me to include sensational bits or to include family members who might be concerned. At the end I felt worn out and yet really pleased at being given the opportunity to be part of a new way of training where patients' stories would really be appreciated and help fill the gaps that textbooks are unable to do.* (Paul; Familial Adenomatous Polyposis)

> *It was sad for me revisiting it and seeing how much I had gone downhill in the last year. You don't realise it so much when it's incremental.* (Fran; Hyper mobility syndrome)

> *Going back over 50 years was quite a daunting experience. As a family we probably made mistakes but the end result isn't too bad!* (Josephine; Ataxia telangiectasia)

> *We feel that the story offers a very true portrayal of our experience…During the process, every effort was made by the researchers to make this a comfortable process and we found them very sensitive towards us and the difficulty in discussing such as emotive subject.* (Jeff & Helen; Long QT syndrome)

> *Enjoyed writing – if difficult to sum up all points in short space! Good that a pseudonym was used.* (Sian; Turner syndrome)

> *I wouldn't have minded using my own name – I have nothing to hide.* (Rob; Von Hippel Lindau syndrome)

Our ongoing evaluation of the *Telling Stories* resource includes the feedback received from our storytellers to ensure their thoughts and comments are captured and their voices continue to be heard.

Whatever the motivation for participating, the storytellers are at the heart of *Telling Stories*, and without their input, the project would not be possible. What they have to say plays an integral role in improving the education of health professionals and others, with the ultimate aim of providing better care for those with, or at risk

of, a genetic condition. It is hoped that *Telling Stories* not only provides a successful education resource to help accomplish this, but might also have the additional benefit of serving to provide an appropriate outlet for storytellers to be heard.

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* Telling Stories, Understanding Real Life Genetics: www.geneticseducation.nhs.uk/tellingstories