The Project Team

The project is a collaborative one and the team comprises members from the Genomics Policy Unit, University of Glamorgan; University of Plymouth; Genetic Interest Group; the Wales Gene Park and the NHS National Genetics Education & Development Centre:

- Professor Maggie Kirk
- Professor Heather Skirton
- Mr Kevin McDonald
- Ms Buddug Williams
- Dr Emma Tonkin
- Mr Rajesh Summan
- Dr Juping Yu
- Ms Silvana Ioannou
- Dr Rhian Morgan (Project Officer)

Do you have a story that you would like to share?

We are continuing to gather stories from all areas of the UK and from all ethnic groups. We are keen to receive stories from patients, carers, 'significant others', family members and health professionals – in fact, anyone with a story to tell that is related to genetics. This could be a personal account of what it is like to have, be at risk of developing, or care for someone with a genetic condition, or a condition with a known genetic component. It may be that a storyteller has had an experience as a health professional that has had an impact on how he or she views practice. Please get in touch if you would like to tell your story.

Contact us:

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Project Officer Telling Stories Understanding Real Life Genetics
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Help us to improve the site:

We are continually working to enhance the site. If you use the resource for your teaching and learning, please take a few minutes to complete our new online questionnaire which can be found on our homepage (http://www.tellingstories.nhs.uk) and tell us what you think.

Acknowledgements

The original project to develop this education resource was funded by a Wellcome Trust People Award grant. Further funding from the Wales Postgraduate Deanery has helped to expand the resource to support genetics in medical education. The NHS National Genetics Education and Development Centre (web host) is funded by the Department of Health and Welsh Assembly Government. Many people have supported us in developing this resource and we are grateful to them all. We have been particularly grateful to the storytellers, educators and web-learning specialists for feedback during the piloting phase. Most of all, we wish to thank the storytellers for helping us to understand 'real life genetics' through their stories.

National Genetics Education and Development Centre

A collaborative project funded by the Wellcome Trust

January 2010

Telling Stories
Understanding Real Life Genetics

Telling Stories, Understanding Real Life Genetics: A User's Guide

www.tellingstories.nhs.uk

Telling Stories, Understanding Real Life Genetics
www.tellingstories.nhs.uk

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The Storytellers
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- Catalogue

Background to the project:
How the resource has been developed
Ethical issues
Educational framework
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Welcome to 'Telling Stories

- Telling Stories, Understanding Real Life Genetics is an innovative learning and teaching resource which uses real life stories to help promote the understanding of genetics.
- Each story is supported with learning activities and points for reflection, a glossary of terms and specific information on the genetic condition with contact details of associated support groups.
- The stories can be read on screen, and selected video clips are available for some stories. Alternatively, the full text with the teaching and learning 'toolbox' can be printed as a PDF document.

This resource has been developed to support educators and mentors who may not have their own stories to tell, providing them with a rich resource that demonstrates the complexity of life 'beyond the textbook'. For learners this site offers and opportunity to engage with genetics and provides an environment in which they can actively learn.

"I was so often dismissed as being a neurotic mother and I'm not a neurotic mother. … 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

The storytellers

One hundred storytellers have contributed to the resource so far and over 60 are currently available on the site. Individuals from a diversity of cultural backgrounds, aged 18-75 years old include those with or at risk of a genetic condition, family members, carers and professionals. They have been recruited mostly via voluntary organisations and support group newsletters and networks, and through presentations at national and local meetings and conferences.

All of the storytellers' names used in the resource have been changed.

Telling Stories
Understanding Real Life Genetics
www.tellingstories.nhs.uk
Winners: Best use of new media award 2009

Educational framework

A collection of stories by themselves would be insufficient to help the educator or learner make the links to practice in order to promote competence in genetics. It was clear that the stories would need to be set in an educational framework that would help nursing professionals work towards achieving agreed standards of competence in genetics. This approach is a key feature of the resource.

The stories have been organised into eight themes to help plan learning and teaching: genetic condition, inheritance, genetic intervention, issues raised, professional role, clinical specialism, life-stage and nursing competence. The latter theme relates to the nursing competence framework developed by team members in 2003. Seven competence standard statements set out the knowledge, skills and attitudes in genetics that all nurses, midwives and health visitors should be able to demonstrate at the point of registration as qualified health professionals. Each story has been reviewed against this framework and linked to one or more competence statements. In doing so, it makes explicit how the individual story relates to professional practice.

Ongoing evaluation has shown that the resource is used to good effect across a range of educational contexts including individual and group learning, and continues to be accessed by health professional groups and the public. In 2009 alone it has received over 10000 visitors from more than 100 countries or territories, with over 60000 page views.

Initially developed for the nursing professions, the resource is currently being expanded to incorporate learning outcomes and activities specific to other health professional groups, including doctors.

Preliminary evaluation report

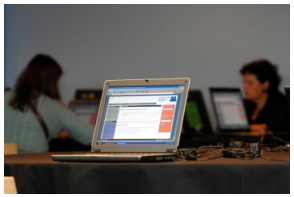
Users' views

Launched on June 19th 2007 at the Millennium Stadium Cardiff, feedback to date has been overwhelmingly positive. This resource continues to be developed and we welcome all feedback from users to inform the changes that we make. See back page for contact details.

Seeing the videos was the most positive aspect because it grounded my learning as not just textbooks but human experience.
Website launch delegate

"Telling Stories" provides a powerful testimony of the needs of rare disease patients in the context of the general medical milieu.
Orphanet 'News'

I will use the site and recommend it to colleagues.
Nurse Educator, UK



Great resource to use - thanks.
Genetic counsellor, UK

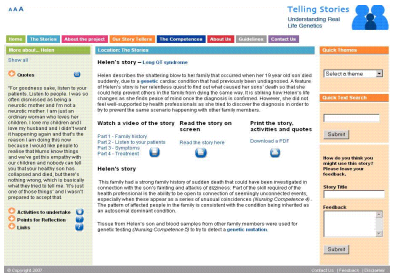
Our first impression was that it is an excellent aid for teaching. We looked at some of the case stories and again everyone was delighted with the type of information provided.
Nurse Educator, UK

Thank you for this wonderful website... it has been very helpful as we begin to educate our nursing staff about providing "personalized health care".
Ohio State University, Medical Centre

Background to the project:

How the resource has been developed

Genetics is an important and relevant part of healthcare and all health professionals need to have appropriate knowledge, skills and attitudes in genetics to underpin their practice. Understanding *how* genetics relates to their work is a challenge if a health professional has had little guided exposure to this aspect of practice during training or in post. Without mentorship from those with experience of genetics, practitioners may only 'see what they know' rather than 'knowing what they see' when they do encounter individuals and families who need genetics information and support.



In 2005 the project team secured funding from the Wellcome Trust People Award scheme to develop an education resource for nurses, midwives and health visitors. Stories from those living with, or at risk of a genetic condition, their families and carers, are the basis for the resource. From their collective experience in genetics, the team knew how powerful such real life stories could be in helping health professionals to appreciate the relevance of genetics to their practice, and to understand how genetics can impact on the daily lives of people.

Once ethical approval had been gained, storytellers were recruited from across the UK. Following an informed consent process, the storytellers either submitted a written story, or met with the Project Officer to be interviewed. A few questions were provided as prompts for both written stories and interviews. The interviews were video-recorded and transcribed verbatim.

The stories collected were anonymised and edited by the project team, adding notes for the additional features that make up the resource. These include points for reflection, suggested learning activities, and an explanation of how the stories link to professional practice. The formatted and edited stories are reviewed by the storyteller before they are posted on the website.

As well as preparing the additional features, the stories have been organised into eight key themes, to help make searching easier, and to help inform teaching and learning approaches.

Website design has been an important consideration to produce a site that follows the principles of web-based learning resources. Visual appeal, ease of navigation, 'searchability' and accessibility have been key factors in design. Once a sufficient number of stories had been uploaded onto the website, the resource was piloted amongst storytellers and educationalists and further revisions made. The website is hosted by the NHS National Genetics Education and Development Centre.

Ethical issues

Securing informed consent to involve storytellers has been a fundamental consideration by the project team, and a rigorous process was followed to do so. We require that the ways in which the stories are used to support teaching and learning, at all times respects the dignity and privacy of the people who have provided them.

Ethics approval for this educational project has been granted by the Faculty of Health, Sport and Science Ethics Committee, University of Glamorgan. The project is also registered with the Birmingham Women's NHS Foundation Trust R&D Management Services.

Telling Stories
Understanding Real Life Genetics

www.tellingstories.nhs.uk

Winners: Best use of new media award 2009

Helping develop knowledge, skills and attitudes in genetics for healthcare staff

Using the resource:

Finding your way around the website

From the homepage, the website is divided into 6 main areas:

- **How to use the stories**
  An on-line guide to the structure and organisation of the stories and details of how to find the right story for your education needs.
- **Selecting a story**
  This page allows you to find a story by selecting from the menu offered under each theme.
- **About the project**
  Background to the resource, and the project team.
- **Our storytellers**
  Information about contributors who shared their story.
- **Catalogue**
  A list of all the stories in the resource.
- **Contact us**
  Information on how to contribute to the resource or feedback on the website.

How to use the stories

Selecting a story

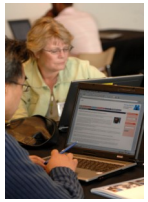
About the project

Our storytellers

Catalogue

Contact us

Finding the right story



The stories have been organised in a number of different ways in order to help you find the story you need – you might want to learn about a particular genetic condition, or you might be interested in stories that relate to a professional role. On the other hand, you might want to select a story to help you in teaching about a particular issue, such as communication, or to support one of the nursing competences in genetics.

The eight themes available are:

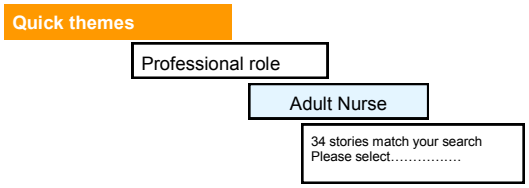
- **Genetic condition:** Select from an alphabetical list of inherited conditions.
- **Inheritance:** The common modes of inheritance, including Mendelian, chromosome imbalance and multifactorial.
- **Genetic intervention:** Provides an alphabetical list of interventions an individual/family may experience. Most deal with different types of genetic tests.
- **Issues raised:** Identifies particular topics such as reproductive choices and ethical issues.
- **Professional role:** Select from a list of health professions.
- **Nursing competence:** Select one of the seven nursing competences in genetics.
- **Clinical specialism:** Select from an alphabetical list of clinical areas.
- **Life-stage:** Select from a list of life-stages from pre-natal through to end of life.

Selecting one of these themes will then take you to a drop-down menu of sub-themes so that you can refine your search.

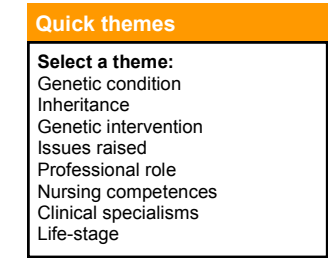
Quick search

Quick themes

- To make searching easier, the eight themes into which stories have been categorised are listed in a drop down box on the right hand side of all main pages. Select the theme of interest to you.
- Users will then be offered a number of sub-headings to choose from to refine the search further. Once you have selected a particular theme, each subheading links to all the available stories for that category.

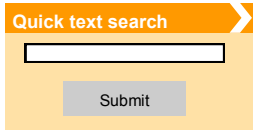


- For example, if you are looking for a story that could be used for adult nurse training, we have classified the stories by professional branch and specialist areas.



Quick text

A free text option is also available that you can use to search the text of each story.



How to use the stories

- Each has been categorised against the eight themes and can be searched on that basis when entering 'selecting a story' page or using the 'Quick Themes' option.
- The stories are linked to a glossary of terms, with specific information on the genetic condition.
- Each story contains additional features to support teaching and learning - the Story toolbox.

The stories are set out in a consistent format so that for each story, the left-hand side of the page provides the menu for the 'Story toolbox' (next page) and the main window presents the story itself. At the end of each story, there is an outline of how the story relates to professional practice with links to the nursing competence framework in genetics. The right-hand section of each webpage offers the 'Search' facility.

Icons identify the available ways in which individual stories can be accessed. Click on the associated text to select the preferred format.

Icon key

Video clips available for this story.

Read the story on screen and view the accompanying toolbox features.

Print the story and all the toolbox features as a PDF document.

The Story toolbox

Each story is accompanied by a 'toolbox' of additional features containing learning activities and links to patient support groups and further information.

Icons for each of the features can be found on the left-hand side of every story page. Clicking on the icon reveals the content and allows users to consider particular points for reflection etc whilst reading the story.

The toolbox information is also included on the PDF of each story.

Points for reflection

View selected quotes for you to think about in relation to your own professional practice, or to discuss with others.

Activities

Suggested activities for individual learners, or learning groups. These may include role play, re-telling a story, drawing a family tree, devising a care plan, or directions to a specific book chapter or article.

Quotes

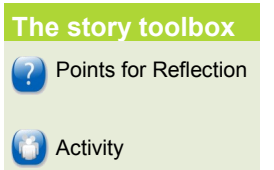
Selected verbatim quotes.

Further information

Links to additional information; support group websites; further reading and stories on other websites.

Expert commentary

Comment is invited on aspects of the stories from professionals with expertise across healthcare practice. Commentaries provide additional perspectives to supplement the stories for teaching and learning.



New Frequently Asked Questions Guide

Provides information and guidance on using audio and video clips from the stories, including how to use clips in PowerPoint presentations. The guide is available to view online or download as a PDF.

Catalogue

The catalogue is a list of all the stories currently available online.

Each story is identified by its main title and a brief, informative sub-title. This information generally identifies the name of the storyteller, the genetic condition involved, and the mode of inheritance for that condition. Although not intended to provide the main approach to selecting a story (using the 'Selecting a story' tab or 'Quick Themes' option are recommended), it can be used to browse through the list. View an individual story by clicking in the title box. For example when browsing the stories you may be interested to find out about Leanne's journey to diagnosis.