Embracing the information revolution from ‘across the pond’

Kate Arnold
katearnold64@yahoo.co.uk
SLA President 2014
PHTD spring meeting Baltimore 1 April 2014
Ever wonder what a month of American medical bills looks like, when, in that month, you had a baby? Now you know.
The health & care system from April 2013
The National Health Service (NHS)

- 1.7 million staff
- Over 63.2 million patients
- £108.9 billion budget 2012/13
- Deals with 1 million patients every 36 hours

Source: www.nhs.uk
In 2012 our services reached more people than ever before – 5.7 million in total.

These 5.7 million people used our services 9.9 million times.

We divide our personal support into four different services:

- **Healthcare**: 735,570 people
- **Information**: 586,362 people
- **Financial**: 180,780 people
- **Practical and emotional**: 59,133 people

**Healthcare**

735,570 people

Our healthcare professionals are valued for improving the quality of care and experience of people living with and beyond cancer – people just like Paul.

People like Cathryn, my Macmillan doctor, are so important. They help you get on with your life.

Paul

**Information**

585,362 people

Having access to the right information enables people affected by cancer to feel more in control and less stressed.

91% of callers to our Support line said we listened to them and understood their needs.

**Financial**

180,780 people

Our expert financial support and guidance service makes sure people affected by cancer don’t face money worries alone.

In 2012 we helped people affected by cancer access £245.6 million in benefits, grants and other financial support.

**Practical and emotional**

59,133 people

We help people cope with the emotional effects of cancer and also provide practical support to do everyday things like shopping and gardening.

We helped Beverley set up the Support group ‘Keeping Ahead’ for women diagnosed with breast cancer facing reconstructive surgery.
Information Strategy for health and social care 2012

• transform how info is used across system
• ‘Digital first’ approach
• access to information through single portal – curation vs creation
• access to health records online by 2015
Taking the hassle out of healthcare

Access to good information is an important part of making sure people stay healthy and get the best care. By making it easier for you to look at and share your health and care records, you will be able to take more control of your own care, and work with professionals to make sure that there is 'no decision about me without me'.

1. Accessing your GP records online will give you more control over your care
2. Booking appointments will be quicker and easier when you can do it online
3. You’ll need fewer phone calls when you can communicate with professional teams electronically
4. You’ll have less paperwork in your life when your healthcare letters are available online
5. You’ll know where to go for health and care information when there is one trusted website
6. Services will do more to offer you support to use and understand information if and when you need it
7. You won’t have to repeat yourself when your information is shared between health and care professionals
8. You’ll be confident that your feedback is being listened to and helping to improve services
9. You will have more information to help you choose the best services and treatments for you
Evolution of patient information

- **Passive information received**
- Information overload
- Clinician driven
- Confusion with data
- Low profile and low priority

- **More active process**
- Based on assessed need
- Tailored to point of need
- Personalised

- **Proactive process with outcomes**
- Informed
- Supported
- Empowered
- Shared decision making
- Self-management

-SLA
Connecting People and Information
Making the case for information

Patient Information Forum (www.pifonline.org.uk)

• Consumer health info:
  – Benefits of providing
  – Harms of not providing
What works

• One size does not fit all
• Quality is paramount
• Info must be converted into knowledge
• Written info aids recall and understanding
• Info needs change over time
• Simpler materials address health literacy
• Websites are not the only answer
What works

• Patients need support to help them access, understand & act on info
• Info is part of a broader communication
• Active support has to accompany info

‘It is an essential service in its own right and its provision cannot be left to chance.’
Information Standard

- Accreditation programme which reviews the process used to create and develop high quality written health information in England
- [http://www.theinformationstandard.org/](http://www.theinformationstandard.org/)
Information Prescription

“An Information Prescription is a source of personalised information that lays out clearly and simply the salient points about an individual’s consultation with a healthcare professional about their diagnosis, treatment and/or care plan ..”

Cancer Backup 2007
SLA Connecting People and Information
Information issues

• Variable quality of content on offer
• Booklets describing whole journey – overwhelming
• Duplication of content
• Lack of information on non-medical areas (financial and emotional support)
• Lack of consistency in what was given out
National Cancer Information pathway
(Key information points)

Prevention & early detection

signs & symptoms → referral → tests & investigations → diagnosis

living with cancer & survivorship

ongoing & follow up care → treatments

palliative care & end of life → recurrence & secondary cancer
Information Prescription Service

- Search by condition
- Search by treatment

www.nhs.uk/ips
Different types of content:
- general material from NHS Choices encyclopaedia;
- more in depth content from specialist charity providers.
In depth content categorised by stage of pathway and available to preview or add to prescription. Includes written and audio visual content.
Smaller sections of text which can be selected as appropriate for summary print out for patient
Sources

• About the NHS: [http://www.nhs.uk/NHSEngland/thenhs/about/Pages/overview.aspx](http://www.nhs.uk/NHSEngland/thenhs/about/Pages/overview.aspx)


• PIF ‘Making Case for Info’: [www.pifonline.org.uk](http://www.pifonline.org.uk)

• Information Standard: [http://www.theinformationstandard.org/](http://www.theinformationstandard.org/)

• Info Prescriptions: [http://www.nhs.uk/ips](http://www.nhs.uk/ips)
Thank You

http://www.sxc.hu/photo/1238333