Patient Information Forum

For Professionals Working in Consumer Health Information

Health literacy and health information that works!

Claire Murray

Joint Head of Operations

claire.murray@pifonline.org.uk

www.pifonline.org.uk

Introduction

A little bit about PiF

- UK network & membership organisation
- Impact - Quality – Integration - Expertise
- www.pifonline.org.uk

A little bit about me

A little bit about this session

- What is health literacy & how big is the problem
- How does health information help
- What makes health information 'high quality'?
- Toolkit for creating health information that works

What is health literacy?

WHO 2015 definition
'…the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health.'

How big is problem?
- UK research found that health information is written at too complex a level for 43% of working age adults; this rises to 61% if information includes numeracy.
- The Community Health and Learning Foundation estimate that 15 to 21 million people in the UK might not have the level of skills needed to live a healthy life.

Who is affected?
- Anyone! But certain groups identified as having disproportionately low or inadequate health literacy.
- These include: more disadvantaged socioeconomic groups, migrants and people from ethnic minorities, older people, people with long term health conditions, disabled people (including those who have long-term physical, mental, intellectual or sensory impairment).

What are the impacts?
Evidence suggests: more difficulty managing medicines, higher prevalence of long term conditions, less likely to engage with screening, adopt less health behaviours, self report lower levels of health, respond less positively to public health campaigns, have greater mistrust of clinicians, general negativity towards health and care.

Useful resources
PiF '*Introduction to Health Literacy*'; Public Health England / UCL Institute of Health Equity '*Improving health literacy to reduce health inequalities*'; Health Literacy Group; Community Health & Leaning Foundation

Group discussion

How does your organisation respond to the challenges of health literacy?

How will health literacy impact the development of your health information and helpline work?

Impact

Provision of high quality health information and support has potential for significant impacts

- Improve health outcomes

- Improve patient experience

- Influence patient behaviour, including 'engagement'

- Reduce health inequalities

- Reduce use of services

- Reduce health costs

The evidence is collated in PiF's report 'Making the Case for Information' (2013).
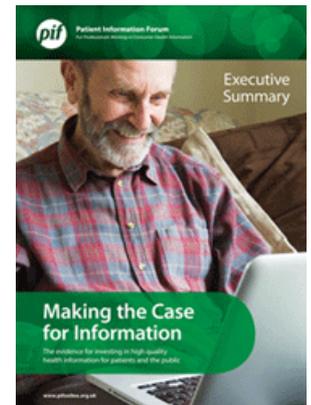
Group discussion

What are your examples of 'bad' information – what made it so?

Quality matters!

Not enough to just provide information

To be effective information must:

- Meet the needs of users
- Empower users to make choices
- Be tailored – one size doesn't fit all
- Be accurate and evidence based
- Be evaluated

Evidence also shows it needs to be 'supported' and embedded into care

Collected in PiF reports 'What does good information look like' (2014) & 'Making the Case for Information' (2013)

2013 Health Literacy Survey

Health information lack of support about how to develop information that addresses health literacy

Toolkit creating health information that works

PiF Toolkit project distilled 'quality' into four key areas for creating health information that works:

- Create accurate and evidence based information

- Communicate information clearly

- Ensure information has impact and relevance

- Involve users in creating health information

www.pifonline.org.uk/toolkit

The Toolkit includes:

- Evidence behind best practice and key steps

- Practical resources to support producers to implement key steps in their work

- Practical examples of how other organisations have approached best practice

Accurate & reliable

Key steps include

- How to make sure resources are reliable – sources of information
- Including all options, risks and benefits
- Work with clinical experts
- Be transparent about evidence base
- Keep up to date with developments
- Include published date and expected review date
- Communicate risk clearly

"Are you more likely to agree to a treatment with a 97% chance of survival, or a 3% probability of dying?"

Practical resources linked to:

- Factsheets for communicating risk
- Introduction to different levels of evidence
- Links to NICE and other evidence databases
- Guide to searching health and care information resources

Practical examples

- Using data visualisation to explain risks – Breakthrough Breast Cancer
- End of life: a guide for people with motor neurone disease by the MND Association

Communicate information clearly

Key steps include:

- Use plain language and everyday words – avoid jargon
- Use an active voice – talk directly to your reader
- User test your language to ensure key messages are understood
- Break information down – use summary and headings to help users navigate or follow information trail
- Keep numbers simple
- Identification communication needs

Practical resources linked to:

- Introduction to Health Literacy
- Link to jargon buster
- Guide to Easy Read
- Guide to writing easy to use health websites
- Introduction to designing health information

Practical examples

- A new breast cancer risk infographic, Breast Cancer Care

Participants questioned whether it was necessary to have such a long and complex booklet to inform people about the screening programme: "This is an awful lot for people to read, this is just handed out? Hell of a lot to read isn't it?"

Am I at RISK ?

BREAST CANCER

is the

MOST COMMON cancer in the UK

55,000 cases each year

3 main breast cancer RISK FACTORS

The three main risk factors for breast cancer are **ones we can't do anything about**

GENDER

Being a woman is the single biggest risk factor for developing breast cancer

55,000 NEW CASES of breast cancer are diagnosed **each year in the UK**

of which around **400** are in men

AGE

THE OLDER the person **THE HIGHER** the risk

The lifetime risk of developing breast cancer is

ONE in **EIGHT**

therefore...

7/8 of women **WILL NOT** develop breast cancer in their lifetime.

Most breast cancers (80%) occur in women

FAMILY

5% of people diagnosed with breast cancer have **inherited a fault** in one of the known breast cancer genes **BRCA1, BRCA2 or TP53**

5%

A small number have an increased risk of developing breast cancer because they have a **SIGNIFICANT** family history

Breast cancer: am I at risk?

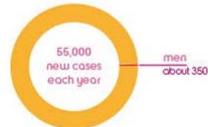**Breast cancer care** — the breast cancer support charity

The three main breast cancer risk factors are:

sex

being a woman
is the single biggest risk factor for developing breast cancer.

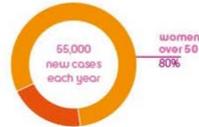**1 in 8 women**
will develop breast cancer in their lifetime.

55,000 new cases each year — men about 350

age

women over 50
Most breast cancers (80%) occur in women over the age of 50.

**men over 60**
Most men who get breast cancer are over 60.

The older the person the higher the risk

55,000 new cases each year — women over 50 80%

family

inherited genes
5% of breast cancers are due to an inherited altered gene in one of the known breast cancer genes.

family history
A small number of people have an increased risk of developing breast cancer because they have a significant family history.

55,000 new cases each year — people with an inherited altered gene 5%
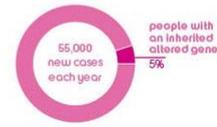
Impact and relevance

Key steps include:

- Create resources with specific purpose
- Understand needs and characteristics of target audience
- Include non clinical information
- Make info easy for users to find and access
- Link your health info with and signpost to other orgs and services

Practical resources linked to:

- A systematic development process for patient decision aids
- Assessing the quality of information to support people make decisions
- A beginner's guide to planning and developing health information
- Asking focussed questions
- What is social marketing

Practical examples:

- Your Life, Their Life – National Children's Bureau leaflets for young people living with HIV

Participants reported having used 'personal experiences' information to: recognise decisions that needed consideration; identify options; appraise options and make selections (including by developing and reflecting on their reasoning about possible choices); and support coping strategies.

Involve users

Key steps include:

- Involve users at every stage of development
- 'Real' users & all relevant groups
- Appropriate methods of engagement
- Communicate what involvement will mean
- Evaluate the impact of your resources

This underpins and is central to all elements of the toolkit!

Practical resources linked to:

- Experience based co-design toolkit
- Involving people with limited literacy in user-centred design
- Skills for life survey
- Ten Tips for co-production
- Service user involvement in delivery of mental health services

Practical examples

- Making Sense of MS – a project by the MS Trust
- Bowel Cancer Guide for the under 50s – Bowel Cancer UK

Making Sense of **MS**

pif

#Never2Young

Younger people with bowel cancer: a guide for the under 50s

- **www.pifonline.org.uk/toolkit**

- **Any questions?**

- **The power of networks**

Contact details

Claire Murray | Joint Head of Operations

claire.murray@pifonline.org.uk

www.pifonline.org.uk