

Finding quality patient information

Cecilia Bethencourt-Dunning
Patient Information Librarian

- Why patient information?
- Designing and creating your own patient information resources;
- Looking at alternative resources like audio-leaflets and patient films;
- Good and bad health information and social media, including YouTube, Facebook and online forums.



Why patient information?

- Health literacy: **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.** World Health Organisation, 2015
- Patient information supports the NHS

- 42% of working age adults are unable to understand and make use of everyday health information, rising to 61% when numeracy skills are also required for comprehension. Improving health literacy to reduce health inequalities. Public Health England (2015).
- Smith S, Vart G, Wolf M. How do people interpret information about colorectal cancer screening: observations from a think-aloud study. Health Expectations 2013; 18 (703-714)
- Participants struggled with numbers, proportions, percentages, also terms like colorectal, colonoscopy, adenoma, faecal.

The human cost

- a lady who thought her “positive” cancer diagnosis was a good thing and couldn’t understand why she wasn’t getting better;
- a lady who sprayed her inhaler on her neck because she had been told to “spray it on her throat”. Nobody had checked whether she realised she had to open her mouth and inhale;
- a gentleman referred under the two week cancer wait process who didn’t turn up for his appointment because he didn’t know the sign for Radiology was the same as for the X Ray Department. He was too embarrassed to ask for directions;
- a group of young women who did not know where their cervix was;
- a group of young people who didn’t know where their waist was;
- a lady with diabetes who didn’t realise there was a connection between what she ate and her ability to self-manage her condition, and
- a lady who thought that her chemotherapy wouldn’t do her very much good because her IV line was on the other side of the body to where her cancer had been.

Jonathan Berry (Personalisation and Control Specialist in NHS England’s Person Centred Care Team)

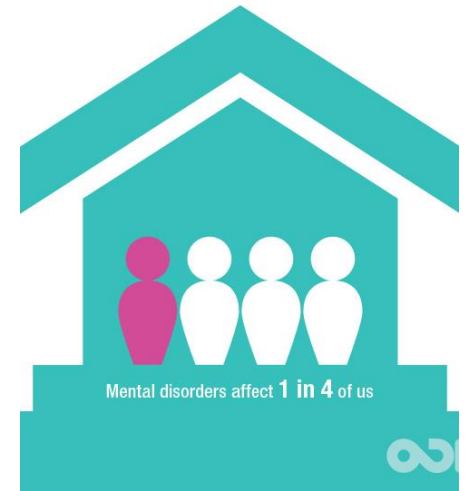
<https://www.england.nhs.uk/blog/jonathan-berry/>

Colonoscopy leaflet example

- Will I have to undress?
- What will I wear?
- What position will I be in? Will I have to lie down? On my side/back? Will someone help me?
- How big is this tube!
- Can someone I know be with me the whole time?
- Will it be in a private room? Or in a bay that's been curtained off?
- What are polyps? If they are removed, will this hurt?
- I don't understand the figures about the risks. Is it dangerous?

Hints and tips: writing patient information

- Question/answer format.
- No jargon and avoid unnecessary words.
- Bullet points.
- Plenty of white space.
- Avoid pictures unless they're absolutely necessary.
- Active not passive (ie, “we will send a letter to your doctor” not “a letter will be sent to your doctor”).
- Talk about “you” not “the patient” (ie, “you will be offered a sedative” not “the patient is offered a sedative”).
- BSUH Trust guidelines:
- <https://www.plainenglish.co.uk/files/medicalguide.pdf>



What help can I give?

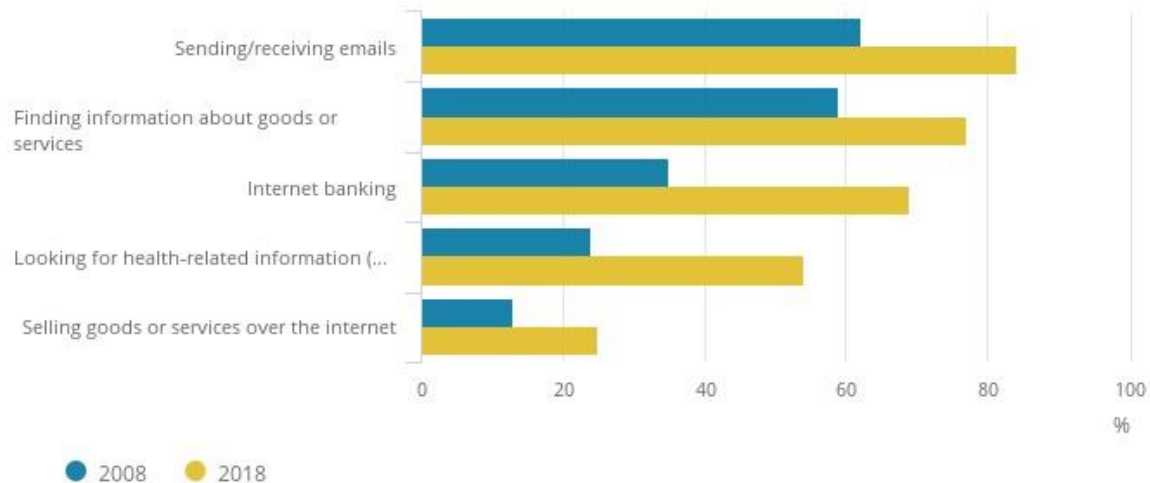
- Evidence searches
- Drafting information
- Scanning for readability
- Spotting jargon
- Suggesting further resources for the patient
- Alternative formats

<https://soundcloud.com/user-865959463/fatigue-audio-leaflet/s-z5K6d>

Finding information online

Figure 6: Internet activities in Great Britain, 2008 and 2018

Within the last 3 months



Source: Office for National Statistics

Internet access – households and individuals, Great Britain: 2018. Office of National Statistics.

<https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2018>

- Accredited places: the information standard



- What about the unaccredited places? Do they have value/what value?

Is online information helpful?

- <http://www.healthtalk.org/peoples-experiences/cancer/ductal-carcinoma-situ-dcis/information-about-dcis>
- Example 1: Beverly
- Example 2: Carol
- Healthtalk.org

YouTube

- Default view is Relevance
- Keywords, number of views, how long it's watched, how many positive ratings and comments it has
- “YouTube contains misleading information, primarily anecdotal, that contradicts the reference standards and the probability of a lay user finding such content is relatively high...the retrieval of relevant videos is dependent on the search term used; and...videos from government organizations and professional associations contained trustworthy and high-quality information.”

Healthcare information on YouTube: A systematic review

Kapil Chalil Madathil, A Joy Rivera-Rodriguez, Joel S Greenstein and Anand K Gramopadhye
Clemson University, USA 2014

- https://www.youtube.com/results?search_query=colonoscopy

Facebook

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David Ross Ive been told by an old filipino guy that if you get about 5 mango leaves boil them in water in a pan once the water has boiled keep boiling for 5 minuites let the liquid cool drink the liquid on an empty stomach it will bring your sugars down to a safe level they reckon bayleaves does the same thing

2w



Diabetes UK Hi David, thanks for your comment. We have not heard of any evidence supporting this treatment, but we also acknowledge that more research needs to be done in this area. Please see our following webpage for our position on herbal and food supplements:

<https://www.diabetes.org.uk/.../herbal-and-food-supplements>



DIABETES.ORG.UK

Herbal and food supplements

2w

↪ View more replies

Discussion forums

- [MS Society](#)
- [Carers UK](#)
- Supportive, sharing experiences and emotions, not necessarily expert medical advice.
- Often asking for someone with a similar experience as they are expert in their own condition (or the condition of the person they're looking after), but they want to feel they are not alone.
- Anonymous

Cole J, Watkins C, Kleine D. Health Advice from Internet Discussion Forums: How Bad Is Dangerous? J Med Internet Res 2016;18(1):e4. URL: <http://www.jmir.org/2016/1/e4/> doi:10.2196/jmir.5051. PMID:26740148

Tips for using social media

- Acknowledge that patients will look online and have different levels of ability when it comes to critically appraising what they see
- Find the good source first, then look for their social media outlets
- Virtual relationships can be a source of comfort and support, not just information

- Questions?