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Researchers, Patients and Open Access Publishing

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Participatory healthcare is a model of self management characterised by emphasis on people living with long term conditions being seen as equal partners in their own care. One essential resource to enable this is equal access to reliable information.

Before the wide availability of the Internet health information was the domain of the healthcare professional and their librarians. One of the early champions of the participatory healthcare movement, Tom Ferguson (2007) recounts a tale of a patient wishing to know more about a new treatment recommended by his doctor having to resort to telephoning the hospital library pretending to be his doctor and asking for the article to be left out for him to collect to be able to access the research that his doctor had access to.

Whilst the advent of the World Wide Web and Tim Berners-Lee's early aim of a creating a “universal linked information system" created a way of sharing information, in the early days of the Internet most research was behind pay walls, and therefore still unavailable to people who didn't have access through their organization's, or the money to buy their own access.

Many patients, especially those living with long term conditions want to be able to access high quality information, (Griffiths et al 2012) including research, and are starting to explain to healthcare professionals how they are making use of research. Liza Bernstein, a cancer survivor presented her experiences at the 2012 Stanford University Medicine X conference. The United States National Library of Medicine runs the free pubmed search engine. Some free articles are highlighted in it's search results, however users often find that whilst they can read the abstract when they try following the LinkOut option to the full text source they often find the full article is behind a pay wall.

The public have a similar problem with Wikipedia, which has been called ‘the single leading source of medical information for patients and healthcare professionals' and has been found to be used by over 50% of physcians (Hellman 2014). Pages that follow the Wikipedia guidelines include references and links to sources, however pay walls block access to many.

Where there is free access, articles have often been published through an Open Access publishing route. The economic models of open access publishing vary, some require payment for publication, and some are free to publish as well as free to access.

The Sherpa/RoMEO website in November 2015 lists 965 international publishers that allow authors to make either the publisher version or a PDF of their articles available in an Institutional Repository without restriction, and a further 82 with an embargo period of up to 12 months.

Another route for making research more widely available is the use of repositories. These include sites such as ResearchGate which Pubmed provides links to, and Institutional Repositories, now becoming a common service provided by Universities for their staff.

When thinking about where to publish research academics often think about the journals that will give the highest citation rates, or where other nurses will see our research. We should however also think about how our patients will be able to access our research. Our choice of publishers and increasing use of institutional repositories means that researchers have the power to make sure that all potential end users of our research can freely access it.