

Information and readability issues for psychiatric patients: e-learning for users

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Aims and method The level of reading ability required to understand written information about key mental health issues designed for service users is examined. Information was taken from four reputable internet sources and analysed for readability. The relevant literature in relation to psychiatric patients and literacy is reviewed and potential solutions are proposed.

Results A considerable proportion of the available information has a reading age at or above 14 years. Some organisations appear better than others in providing information at a more appropriate level of reading ability.

Clinical implications Written information aimed at users of psychiatric services may not take into account that they are more likely to have impaired reading ability, even though they might not have an identified intellectual disability. Professionals who develop written materials can use tools in word processing software to assist with the appropriate development of these materials. Information technology could in the future provide information directed at users of psychiatric services that does not rely so heavily on written material.

Declaration of interest None.

There is a medico-legal imperative to provide patients with relevant information so that they can make informed choices and be aware of all the risks and benefits of treatment.¹ It has long been observed that improved patient comprehension generally increases adherence to treatment.² However, healthcare organisations and individual healthcare professionals often assume that the majority of their patients have reasonable abilities to read and assimilate information that is important to them.

People with limited literacy have less knowledge of disease management and health-promoting behaviours, report poorer health status and are less likely to use preventative services than those with average or above average literacy skills.³ Poor reading skills negatively affect a person's ability to obtain cost-effective care and may result in inappropriate in-patient and out-patient treatment.^{4,5} People with poor reading skills also have significantly higher healthcare costs than more literate patients.⁶

Patient comprehension is a prerequisite to adherence to medical instruction. Despite that, a variety of written materials (including questionnaires, surveys, information about legal rights or educational materials) can be given to patients with little regard to their ability to comprehend the information they contain.⁷ This is not an issue exclusive to healthcare. The Plain English Campaign (www.plainenglish.co.uk) has been lobbying and providing

standards for improved access to clear and accessible information for the UK public for over 30 years.

The National Health Service (NHS) Toolkit (www.nhs.uk/identity.nhs.uk/tools-and-resources/patient-information) gives guidelines about the development of written information for patients, stressing the avoidance of jargon and acronyms and reminding that a significant number of patients may have literacy problems.

Written information for patients comes from a variety of sources. For most in-patients in psychiatric settings it is supplied in traditional paper format but this may change as paper records gradually give way to electronic media.

Some authors distinguish between literacy, which is the ability to read and understand language, and 'health literacy', which is the ability to read, understand and act on health information.⁸ Health literacy has also been defined by the US Department of Health and Human Services as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.⁹

For out-patients seeking health information (including mental health information) the source is increasingly the internet, although it is still predominantly in text form and relies on a person's ability to read and comprehend the written word. The amount of information potentially available is significant. Using the search words 'mental

health information leaflets' on Google produced approximately 950 000 hits.

New paradigms around the transfer of health information have been developed, primarily the concepts of 'health informatics' and 'e-health literacy'. Health informatics was originally designed to serve the needs of healthcare professionals, but increasingly is reaching consumers and patients via computers and telecommunication systems.¹⁰ It appears that obtaining healthcare information from these new sources will require some new skills in addition to reading.

E-health literacy is defined as the ability to use information and communication technology (especially the internet) to improve or enable health and healthcare,¹¹ or the ability to seek, find, understand and appraise health information from electronic sources and apply the knowledge gained to address or solve a health problem.¹² It is clear that this is going to be an increasingly dominant way of obtaining health information in the 21st century, including information about mental health disorders and treatment.

There is one major longitudinal research study comparing international literacy achievement by country, the Programme for International Student Assessment (PISA) by the Organisation for Economic Co-operation and Development (OECD). The study results are available for 15-year-olds at the National Literacy Trust website (www.pisa.oecd.org). The UK performs above the OECD average for scientific literacy.

In the USA, the National Adult Literacy Survey was undertaken in 1992 and profiled the functional English literacy skills of over 26 000 adults. It found that over half had limited or low literacy skills⁹ and it was estimated that up to 20% of the American population were functionally illiterate, that is they were unable to read material above a US 5th grade level (10–11 years old).¹³

The UK statistics are available on the Department for Business, Innovation and Skills website (www.dfes.gov.uk/readwriteplus_skillsforlifsurvey). They show that in 2003 in England about 16% of the population had a literacy level at or below an expected attainment for an average 11-year-old and the proportion of the population with low attainment was larger in regions such as Wales (about 25%).

Reported educational levels are not necessarily a good guide to reading performance, with some studies showing over half of people tested had a reading age median of 5 years below their reported educational level.¹⁴

Many psychiatric conditions impair brain function, so issues around the comprehension of written material are even more relevant to the practice of mental healthcare. Historically, around half of young adult patients admitted to in-patient psychiatric facilities were found to be functionally illiterate,¹⁵ and a similar level was found in long-stay adult patients.^{16,17} In community settings about three-quarters of patients at a walk-in psychiatric clinic had a reading age below the 8th grade (13 years old).¹⁸

Poor reading skills are also associated with a range of psychiatric disorders in young people.¹⁹ For example, patients with schizophrenia not only achieve fewer years of education but their illness may cause a decline in

standardised reading performance.²⁰ Poor levels of literacy are common among other populations who have high levels of psychiatric morbidity, including juvenile offenders.²¹

Therefore a significant proportion of psychiatric patients (outside those formally recognised as having intellectual disabilities) are likely to have significant literacy problems. The concept of specific reading impairment has been accepted since the 1970s.²² Most patients with literacy problems are actually of average IQ and they try and conceal their literacy deficits using other cognitive abilities.²³

Doctors have been shown to significantly overestimate the literacy ability of their patients.²⁴ Studies in physical healthcare have shown that there is commonly a 5- to 7-year gap between the average reading age and the materials that are produced for patient education.²⁵

Previous studies of psychoeducational materials designed for psychiatric patients have shown that high levels of reading ability are required in order to comprehend these and this is even more of an issue in linguistically diverse populations where English may not be the patient's first language.²⁶ The consent forms for psychiatric patients partaking in research have also shown to have a significantly higher readability level than the reading ability of participants.²⁷

Patient information leaflets are promoted to psychiatrists to help communicate information to patients about psychotropic medication, although it is recognised that modified leaflets may need to be used for patients who are recognised as having lower levels of understanding.¹ Many patients are reluctant to admit they have literacy problems due to feelings of shame and many recount serious medication errors as a result of poor reading ability.¹⁴

Some studies recommend that all patient education materials should generally be written at a 6th-grade (12 years old) or lower reading level.²⁸

Readability is defined by the Merriam-Webster Dictionary both as 'able to be read easily' and 'interesting to read'. Whereas the latter part of the definition is subjective and difficult to assess, the former may be measured by the Flesch–Kincaid readability tests.²⁹ These tests are designed to indicate level of comprehension difficulty for contemporary written English. They were originally developed by Flesch in the early 1940s and are now widely accepted. There are two tests, the Flesch Reading Ease and the Flesch–Kincaid Grade Level. Both use measures of word and sentence length but they have different weighting factors and may not correlate exactly. They can be routinely obtained for documents of more than 100 words in Microsoft Word 2003 as part of the spell check function.

Method

A selection of information leaflets about mental health issues that were freely available to the public and to mental health services were downloaded from four sources: the Department of Health (www.dh.gov.uk), NHS Direct (www.nhsdirect.nhs.uk), the Royal College of Psychiatrists (www.rcpsych.ac.uk) and Mind (www.mind.org.uk). These were chosen from the first page of the Google search results

for 'mental health information leaflets'. The information was converted into Microsoft Word 2003 documents and then subjected to analysis using the Flesch Reading Ease and the Flesch–Kincaid Grade Level tests. There were 34 patient information leaflets from three sources and 15 leaflets devoted to explaining the Mental Health Act from the Department of Health.

Results

There was considerable variation in the range of Flesch–Kincaid Grade Level in information about mental health issues designed for users from three sources: 10 years when material designed for service users with intellectual disability was included and 5.7 years when this material was excluded. The average Flesch–Kincaid Grade Level for NHS Direct was 10.5 and for Mind it was 10.2; both equate to a reading age of 15–16 years. For the Royal College of Psychiatrists, average Flesch–Kincaid grade was 7.6 and increased slightly to 8 (reading age 12–13 years) when the

two items developed specifically for service users with an intellectual disability were removed (Table 1). The average Flesch–Kincaid Grade Level for a selection of leaflets related to the Mental Health Act available from the Department of Health was 8.4, which equates to a reading age of about 14 years (Table 2).

Discussion

Patient literacy (and the emerging concept of e-health literacy) should be the concern of every healthcare organisation and healthcare professional, not just those working with patients with identified intellectual disabilities.

A number of patient information leaflets designed for users of psychiatric services and available on the internet from reputable sources require a reading age that is above 14 years. This would make them difficult to understand by a large proportion of service users without significant assistance.

Table 1 Clinical patient information leaflets

Patient leaflet title	Flesch Reading Ease score ^a	Flesch–Kincaid Grade Level score ^{a,b}	Chronological reading age, years
Royal College of Psychiatrists			
Your guide to taking medicine for behaviour problems	82.3	2.8	7–8
Cognitive–behavioural therapy	71.3	6.8	11–12
Tiredness	71.5	6.9	11–12
Sleep problems	70.1	7.1	12–13
Alcohol our favourite drug	69.6	7.7	12–13
PTSD	51.6	7.9	12–13
Depression	65.8	7.9	12–13
Antidepressants	59.1	8.7	13–14
Bipolar disorder	58.8	8.7	13–14
Bereavement	65.2	8.8	13–14
Depression in people with learning disabilities	56.8	9.3	14–15
Cannabis	56.6	9.5	14–15
Mind			
Understanding bereavement	64.4	8.1	13–14
How to cope with sleep problems	60.9	8.6	13–14
Understanding eating distress	56.4	9.2	14–15
Understanding depression	56.6	9.3	14–15
Understanding addiction and dependency	53.3	9.6	14–15
Understanding ADHD	56.9	9.9	14–15
Understanding bipolar disorder	49.4	10.6	15–16
Understanding psychotic experiences	48	11	16–17
Understanding PTSD	48.5	11.3	16–17
Making sense of antidepressants	39.1	11.9	16–17
Cannabis and mental health	41.5	12.5	17–18
NHS Direct			
Antidepressants	51.1	8.7	13–14
Insomnia	57.9	8.8	13–14
Drug addiction	56.7	9.2	14–15
Eating disorders	49.4	10.4	15–16
Bipolar disorder	50.5	10.6	15–16
Depression	50.6	10.7	15–16
ADHD	49.7	11.2	16–17
Alcohol	49.9	11.3	16–17
What is psychosis	44	11.4	16–17
Addiction	48	11.5	16–17
PTSD	43.3	11.5	16–17

PTSD, post-traumatic stress disorder; ADHD, attention-deficit hyperactivity disorder.

a. Based on word and sentence length.

b. Relates to the US Grade System.

Table 2 Department of Health legal information for patients

Patient leaflet title	Flesch Reading Ease score ^a	Flesch–Kincaid Grade Level score ^{a,b}	Chronological reading age, years
Admission to hospital without restrictions	72.3	7.2	12–13
Nurses' power to detain Section 5(4)	74.7	7.3	12–13
Admission to hospital with restrictions	71.1	7.4	12–13
Interim Hospital Order	71.9	7.4	12–13
Admission under Section 136	72.2	7.5	12–13
Admission to hospital for assessment Section 2	71.1	7.5	12–13
Admission to hospital for treatment Section 3	69.3	8	13–14
Guardianship	64.2	8.4	14
Revocation of a CTO for treatment under Part 3	66.2	8.6	14
Recall for CTO	65.3	8.9	14–15
ECT for patients	64.5	9.1	14–15
Your nearest relative under the MHA	63.3	9.3	14–15
Your right to complain to the MHAC	61.1	9.7	14–15
Supervised community treatment for Part 3	58.8	10	15–16
Supervised community treatment for Part 2	57.6	10.2	15–16

CTO, community treatment order; ECT, electroconvulsive therapy; MHA, Mental Health Act, 1983; MHAC, Mental Health Act Commission (Care Quality Commission from April 2009); Part 2, civil sections (Section 2 or 3) of the Mental Health Act 1983; Part 3, hospital orders (Section 37 or 38) of the Mental Health Act 1983.

a. Based on word and sentence length.

b. Relates to the US Grade System.

About 10% of internet users already report using it to find information about mental health issues.³⁰ However, the information is variable, with non-sponsored, governmental, professional and charitable sites being of superior quality to other sources.³¹ Information available on the internet about some psychiatric conditions such as schizophrenia still has a reading age that is inappropriately high.³² However, there may be some subjects (e.g. involving complex psychopharmacology) where it is difficult to communicate information in a way that is coherent, using text-based information, with a reading age below 12–14 years.

Although there has been long-standing concern about the potential adverse influence of the internet on mental health, including suicide,³³ Holloway states that the opportunities offered by legitimate health informatics outweigh the disadvantages.³⁴ Innovative new services have been developed on the advantages and flexibility of this emerging technology.^{35,36} The Royal College of Psychiatrists has been at the forefront of using information technology for educational purposes for its members.³⁷

Some development of patient information for service users with intellectual disabilities who take medication has been undertaken in the UK that incorporates pictures rather than traditional symbols, as this has been shown to be more acceptable to such users.³⁸ Alternatives to written materials have been suggested as potential solutions to problems with literacy in healthcare, including audiovisual material.³⁹ These options continue to increase with new technologies. Multimedia e-learning for patients might be one potential solution to limited reading skills in those users with appropriate e-health literacy skills. This approach has been associated with very high levels of user satisfaction and an improvement in understanding of some concepts in cancer care.⁴⁰

Mental health organisations have a responsibility to provide patient information that is accessible and understandable by the vast majority of patients in their care. Tools are available to healthcare organisations and professionals to comprehensively assess the written information that they provide to patients. New technologies may be utilised in the future to improve the communication of key information to patients, including those with limited literacy.

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