

Medicines in Mental Health Ltd

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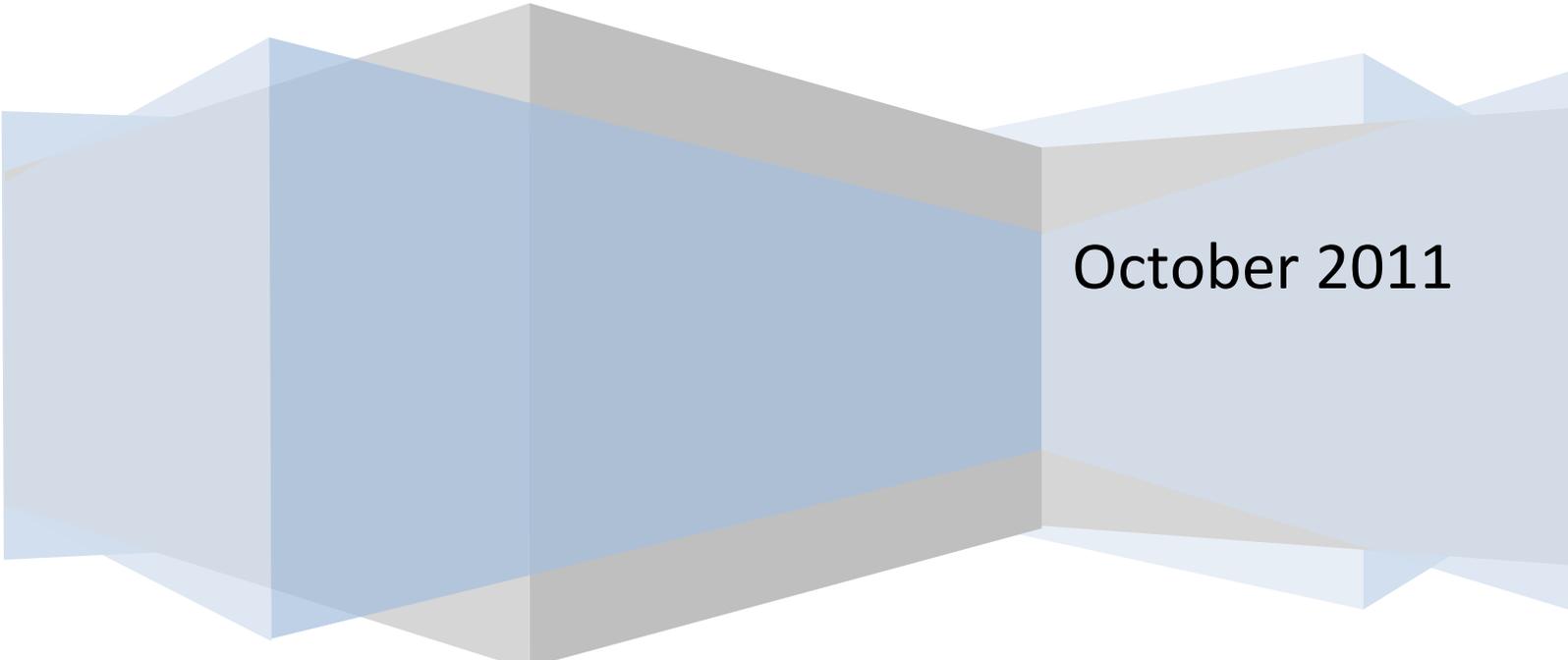
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MMH Report No.3

Patient Information in Severe Mental Illness

A call to action for the National Health Service



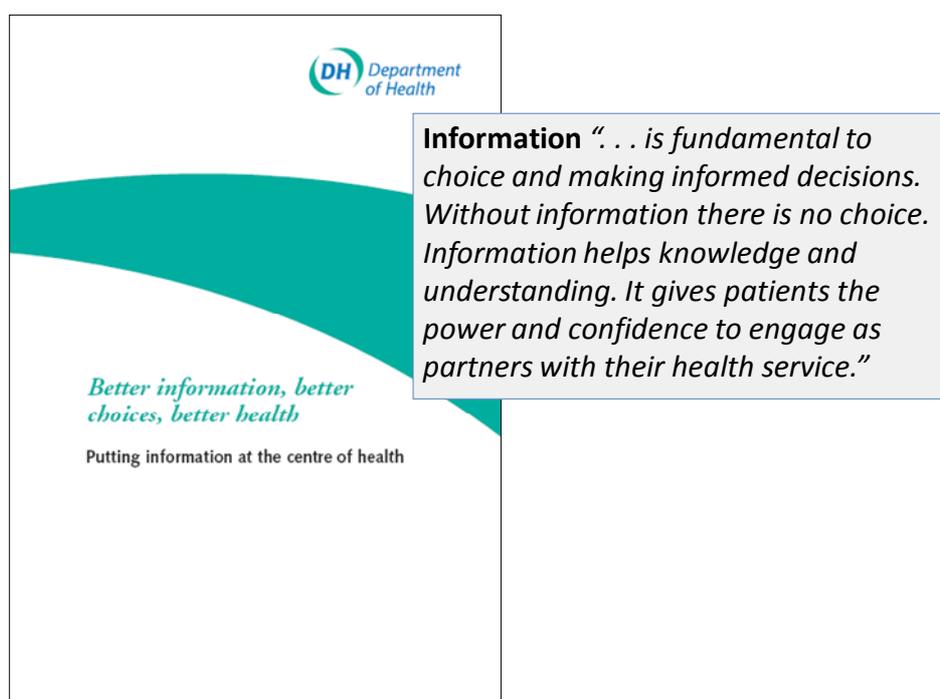
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BACKGROUND

Information for patients and carers about medicines is an essential component of high quality healthcare. In mental healthcare, information available to patients is patchy and often of poor quality, yet there are compelling reasons to improve the situation, including:

- The need to obtain informed consent for treatment
- Ethical requirements of health professions
- The rights enshrined in the NHS Constitution
- Recommendations in NICE clinical guidelines
- The need to engage patients more actively in their care
- The need to improve outcomes from the use of medicines

This report offers straightforward and systematic approach to providing high quality medicines information that will meet the needs of both patients and clinicians.



MINIMUM REQUIREMENTS FOR DEVELOPING HIGH QUALITY INFORMATION

- It must be easily understood and intuitive
- It must be evidence-based
- It must address issues that are important to patients
- Both patients and health professionals must be involved in its development
- It should be accessible and easily available during all patient-facing interactions

WEB-BASED OR PAPER-BASED?

There are advantages and disadvantages to both systems.

Web-based information

Web-based information is universally available, at any time of the day or night, provided there is internet access. In most situations it does not lend itself to consultations between a clinician and a patient, for example, in an out-patient clinic, or an outreach clinic in a GP's surgery or a home visit. It is also difficult to involve patients and clinicians in the development of this information, so neither group feels ownership of it or any real commitment to it. Where disagreements arise about the content, it is practically impossible to get them resolved.

Paper-based information.

Paper-based information is bulky and cumbersome. However, it can be used easily in most practice situations. It can be tailored to address local needs and concerns and both clinicians and patients can be involved at local level in its development so that all involved trust the information. Where questions arise about the content they can be easily resolved.

HOW CAN THE MINIMUM REQUIREMENTS FOR HIGH QUALITY INFORMATION BE MET?

Making it easily understood and intuitive

Involving patients and carers in the development means offers a method of quality assurance to eliminate jargon and terminology that patients do not understand. Using simple illustrations makes the information understandable at an intuitive level.

Making it evidence-based

Too much information given to patients is based on the personal opinion or experience of individual clinicians. This creates inconsistency and confusion when patients receive conflicting information – this happens far too often. The involvement of a small team of local clinicians in the development of the information offers a method of quality assurance to ensure that the information is based on the most up to date evidence.

Addressing issues that are important to patients

The first task in developing information is to spend time with patients and carers asking them what information they think is important and which questions they want answers to.

To this can be added the clinical knowledge of the health professionals involved, making sure that the resulting information is both tailored to local needs and wishes and is comprehensive.

Involving patients and health professionals in its development

Patients, carers, local voluntary sector organizations and clinicians should all be directly involved in the development of this information, so that all stakeholders feel ownership and commitment to it.

It should be accessible and easily available during all patient-facing interactions

Using a paper-based system, clinicians can be provided with easily-portable information packs that include flash-cards to aid discussions and individual information sheets that can be left with patients.



- The right to make choices about NHS care.
- The right to be involved in discussions and decisions about healthcare, and to be given information to enable users to do this.
- The right to accept or refuse the treatment that is offered, and not to be given any treatment unless valid consent has been obtained.
- The right to be given information about any proposed treatment in advance, including any significant risks and any alternative treatments, and the risks involved in doing nothing.

for England
21 January 2009

GOING BEYOND MERE INFORMATION

We live in the age of information. Many people think that information about medicines is an end in itself: its function is simply to inform patients and carers regarding the decisions that have been taken about their care. This is a very limited view. Taken to its full potential, information about medicines can be the means to a number of 'ends', which, taken together, offer the opportunity to improve the delivery of mental healthcare significantly.

Information impacts on knowledge, treatment decisions and the therapeutic relationship. It can – and should – be used to achieve a number of related goals.

- To educate clinicians
- To inform treatment selection and create consistency in therapeutic approaches
- To educate patients and carers
- To involve patients and carers in treatment decisions
- To strengthen the therapeutic alliance between clinicians, patients and carers
- To reinforce messages about the importance of adherence

Educating clinicians

Clinical knowledge about medicines is highly variable. It can depend on an article that has been read, a speaker one has heard at a congress, a conversation with a pharmaceutical representative, or even personal experience. Such variation results in patients being given information that is at best inconsistent, and at worst, contradictory. The implementation of evidence-based information across a service offers the opportunity to educate all clinicians, making their clinical knowledge about medicines consistent.

Informing treatment selection and creating consistency in therapeutic approaches

Treatment selection and therapeutic approaches in mental health are highly variable even within the same service and tend to be based on the preferences of individual clinicians. In contrast, NICE clinical guidelines emphasise the importance of individualising treatment. Consistency in how this is achieved across a service can be obtained by using the same information throughout, and using it to guide clinical decisions.

Educating patients and carers

Patients and carers are often poorly-informed about medicines, resulting in the rejection of treatment. There is evidence that patients' understanding of their condition and its need for treatment is positively related to adherence, and in turn adherence, satisfaction and

understanding are all related to the amount and type of information given.¹ Patients who understand the purpose of the medication are twice as likely to collect it than those who do not.² Using information about medicines in an educative way is the first step to resolving these problems.

Involving patients and carers in treatment decisions

Most patients prescribed antipsychotics do not feel involved in treatment decisions and state that they take medication only because they are told to.³ There is also evidence that the impact of side-effects is often greatly underestimated by doctors.⁴ Treatment decisions should be based mainly on the avoidance of those side effects that are of greatest concern to the patient.⁵ Evidence-based information that is trusted by both patients and clinicians offers the means by which patients and carers can be involved in decisions about which medicine is likely to be the best choice for them as individuals. For example, an individual patient may express a desire to avoid medicines that are likely to be associated with sexual dysfunction. Patient information can be used to determine which options would be most likely to meet this clinical need. This approach can be used to avoid other side effects and has the added benefit of strengthening the therapeutic relationship.

Strengthening the therapeutic alliance between clinicians, patients and carers

Good communication between patients and health professionals and clear mutual agreement at the onset of treatment to support adherence is essential.⁶ However, in practice, the process of making a joint therapeutic plan is often abbreviated. Doctors may overestimate the amount of information they have given to patients and patients often misunderstand medical terminology. It is often assumed that patients understand a reasonable amount about their illness, but in a classic study, Joyce et al showed that patients were unable to recall half of the information given to them by their physician.⁷ In addition, disagreement with or low trust in clinicians, and receipt of low levels of medical information predict poor adherence.⁸

Patient information can be used to aid communication, create consistency in the information that is provided, involve patients and carers in treatment decisions and obtain mutual agreement about treatment. It can also be used to educate them about side effects, thereby demonstrating that the clinician is being open about side effects and takes concerns about them seriously. These activities help to develop and consolidate the therapeutic alliance.

Reinforcing messages about the importance of adherence

It is a cliché but nonetheless true: medicines don't work if they are not taken. This message should be included in all patient information materials, and emphasized repeatedly by clinicians.

TRAINING FOR HEALTH PROFESSIONALS

Patient information does not end with the production of a leaflet which the clinician can pull out with a flourish at the opportune moment. Clinicians – doctors, nurses, pharmacists – all need to be trained so that they become familiar with the content of the leaflets, are able to discuss them knowledgably, and are able to apply this knowledge in practice, as discussed above.

ROLE OF MEDICINES IN MENTAL HEALTH

Medicines in Mental Health Ltd is an independent health sector provider dedicated to improving outcomes from the use of medicines in mental health. We have worked with many stakeholders in mental health including the NHS, professional organizations, academic institutions, the voluntary sector and the pharmaceutical industry. We have experience in creating patient information and provided the majority of the clinical input in the development of the Depression Alliance user information website <http://whatyoushouldknow.depression-alliance.co.uk/>

We will work with any providers of services to deliver interventions to develop patient information that is designed to meet local needs.

We envisage a process where the Trust would appoint a small steering group: a senior psychiatrist, a senior nurse and a senior pharmacist. We would work with them to:

- Work with patients and carers, including local or national voluntary sector organizations to develop the content for patient information
- Develop all the materials including patient information, materials to support patient and carer education and materials to support staff training
- Develop a 'Train the Trainers' programme to cascade education throughout the trust

Standards of business

We believe that patients should be the focus of everything we do. Our mission is to work in partnership with stakeholders, including the NHS, the pharmaceutical industry and patient organisations to develop interventions that directly improve clinical outcomes.

Medicines in Mental Health Ltd will:

- Always put the interests of patients and the duties and responsibilities of the NHS first.
- Respect the independence and impartiality of NHS employees or organisations.
- Respect and maintain confidentiality at all times.
- Be transparent in disclosing sources of funding or sponsorship.

CONCLUSIONS

Patient information is an essential component of high quality mental healthcare. However, it offers opportunities to improve the delivery of care and outcomes beyond the simple provision of information including:

- To educate clinicians
- To inform treatment selection and create consistency in therapeutic approaches
- To educate patients and carers
- To involve patients and carers in treatment decisions
- To strengthen the therapeutic alliance between clinicians, patients and carers
- To reinforce messages about the importance of adherence

Medicines in Mental Health will work with mental health service providers to develop high quality patient information that meets all of these objectives.

MMH reports on adherence in severe mental illness can be obtained from www.mentalmeds.co.uk

REFERENCES

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- 1 Mitchell AJ, & Selmes T. Why don't patients take their medicine? Reasons and solutions in psychiatry. *Advances in Psychiatric Treatment* 2007;13:336–346
 - 2 Daltroy L, Katz J, Morlino C et al. Improving doctor patient communication. *Psychiatric Medicine* 1991;2: 31–35
 - 3 Gray R, Rofail D, Allen J et al. A survey of patient satisfaction with and subjective experiences of treatment with antipsychotic medication. *Journal of Advanced Nursing* 2005;52:31–37
 - 4 Roose SP. Compliance: the impact of adverse events and tolerability on the physician's treatment decisions. *European Neuropsychopharmacology* 2003;13(suppl.3):S85–92
 - 5 National Institute for Health and Clinical Excellence. Core interventions in the treatment and management of schizophrenia in adults in primary and secondary care. Clinical Guideline 82. March 2009.
 - 6 Stevenson FA, Cox K, Britten N et al. A systematic review of the research on communication between patients and health care professionals about medicines: the consequences for concordance. *Health Expectations* 2004;7:235–245
 - 7 Joyce CR, Cagle G, Mason M et al. Quantitative study of doctor–patient communication. *Quarterly Journal of Medicine* 1969;38:183–194
 - 8 Piette JD, Heisler M, Krein S, et al. The role of patient–physician trust in moderating medication non-adherence due to cost pressures. *Archives of Internal Medicine* 2005;165:1749–1755