NICE National Institute for Health and Care Excellence

NICE guideline

Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence

Clinical guideline

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Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the Yellow Card Scheme.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Contents

This guideline is partially replaced by NG5.

This guideline is the basis of QS149.

Overview

This guideline covers medicines adherence in people aged 18 and over. It recommends how to encourage adherence to medicines by supporting and involving people in decisions about their prescribed medicines. It aims to ensure that a person's decision to use a medicine is an informed choice.

Who is it for?

- Healthcare professionals
- Adults receiving prescribed medicines and their families and carers

Introduction

It is thought that between a third and a half of all medicines prescribed for long-term conditions are not taken as recommended. If the prescription is appropriate, then this may represent a loss to patients, the healthcare system and society. The costs are both personal and economic. In this guideline 'medicines' is used as a general term to refer to prescribed medicines that are self-administered and includes tablets, syrups, ointments, eyedrops and suppositories.

Adherence presumes an agreement between prescriber and patient about the prescriber's recommendations. Adherence to medicines is defined as the extent to which the patient's action matches the agreed recommendations. Non-adherence may limit the benefits of medicines, resulting in lack of improvement, or deterioration, in health. The economic costs are not limited to wasted medicines but also include the knock-on costs arising from increased demands for healthcare if health deteriorates.

Non-adherence should not be seen as the patient's problem. It represents a fundamental limitation in the delivery of healthcare, often because of a failure to fully agree the prescription in the first place or to identify and provide the support that patients need later on.

Addressing non-adherence is not about getting patients to take more medicines per se. Rather, it starts with an exploration of patients' perspectives of medicines and the reasons why they may not want or are unable to use them. Healthcare professionals have a duty to help patients make informed decisions about treatment and use appropriately prescribed medicines to best effect.

There are many causes of non‑adherence but they fall into two overlapping categories: intentional and unintentional. Unintentional non‑adherence occurs when the patient wants to follow the agreed treatment but is prevented from doing so by barriers that are beyond their control. Examples include poor recall or difficulties in understanding the instructions, problems with using the treatment, inability to pay for the treatment, or simply forgetting to take it. Intentional non‑adherence occurs when the patient decides not to follow the treatment recommendations. This is best understood in terms of the beliefs and preferences that influence the person's perceptions of the treatment and their motivation to start and continue with it. It follows that to understand adherence to treatment we need to consider the perceptual factors (for example, beliefs and preferences) that influence

motivation to start and continue with treatment, as well as the practical factors that influence patients' ability to adhere to the agreed treatment.

Applying this approach in practice requires:

- a frank and open approach which recognises that non-adherence may be the norm (or is at least very common) and takes a no-blame approach, encouraging patients to discuss non-adherence and any doubts or concerns they have about treatment
- a patient-centred approach that encourages informed adherence
- identification of specific perceptual and practical barriers to adherence for each individual, both at the time of prescribing and during regular review, because perceptions, practical problems and adherence may change over time.

This guideline makes recommendations about how healthcare professionals can help patients to make informed decisions by facilitating the involvement of patients in the decision to prescribe, and how they can support patients to adhere to the prescribed medicine. We have not made separate recommendations for carers and families. The principal relationship is between patient and healthcare professional, and the patient has a right to decide who should be involved in their care. With the patient's consent, carers should have access to appropriate levels of information and support.

An increasing number of healthcare professionals are now involved in the prescribing, dispensing and reviewing of medicines. It is not within the remit of a guideline to recommend which healthcare professional carries out these roles. All healthcare professionals should be aware of and work within legal and professional codes.

Key principles

- Healthcare professionals should adapt their consultation style to the needs of individual patients so that all patients have the opportunity to be involved in decisions about their medicines at the level they wish.
- Establish the most effective way of communicating with each patient and, if necessary, consider ways of making information accessible and understandable (for example, using pictures, symbols, large print, different languages, an interpreter or a patient advocate).
- Offer all patients the opportunity to be involved in making decisions about prescribed medicines. Establish what level of involvement in decision-making the patient would like.
- Be aware that increasing patient involvement may mean that the patient decides not to take or to stop taking a medicine. If in the healthcare professional's view this could have an adverse effect, then the information provided to the patient on risks and benefits and the patient's decision should be recorded.
- Accept that the patient has the right to decide not to take a medicine, even if you do not agree with the decision, as long as the patient has the capacity to make an informed decision and has been provided with the information needed to make such a decision.
- Be aware that patients' concerns about medicines, and whether they believe they need them, affect how and whether they take their prescribed medicines.
- Offer patients information that is relevant to their condition, possible treatments and personal circumstances, and that is easy to understand and free from jargon.
- Recognise that non-adherence is common and that most patients are non-adherent sometimes. Routinely assess adherence in a non-judgemental way whenever you prescribe, dispense and review medicines.
- Be aware that although adherence can be improved, no specific intervention can be recommended for all patients. Tailor any intervention to increase adherence to the specific difficulties with adherence the patient is experiencing.

- Review patient knowledge, understanding and concerns about medicines, and a patient's view of their need for medicine at intervals agreed with the patient, because these may change over time. Offer repeat information and review to patients, especially when treating long-term conditions with multiple medicines.

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

The following guidance is based on the best available evidence. The full guideline gives details of the methods and the evidence used to develop the guidance.

Recommendation 1.4.2 has been replaced by recommendations in the NICE guideline on medicines optimisation.

These recommendations apply to all healthcare professionals who prescribe, dispense or review medicines or who have a role in making decisions about medicines with patients. Healthcare professionals are reminded of their duty under the Equality Act (2010) to make reasonable adjustments to ensure that all people have the same opportunity for health.

1.1 Patient involvement in decisions about medicines

Communication

Good communication between healthcare professionals and patients is needed for involvement of patients in decisions about medicines and for supporting adherence. Some patients may find it easier to communicate with their healthcare professional than others.

1.1.1 Healthcare professionals should adapt their consultation style to the needs of individual patients so that all patients have the opportunity to be involved in

decisions about their medicines at the level they wish.

1.1.2 Consider any factors such as physical or learning disabilities, sight or hearing problems and difficulties with reading or speaking English, which may affect the patient's involvement in the consultation.

1.1.3 Establish the most effective way of communicating with each patient and, if necessary, consider ways of making information accessible and understandable (for example, using pictures, symbols, large print, different languages, an interpreter or a patient advocate).

1.1.4 Encourage patients to ask about their condition and treatment.

1.1.5 Ask patients open-ended questions because these are more likely to uncover patients' concerns.

1.1.6 Be aware that the consultation skills needed for increasing patient involvement can be improved.

Increasing patient involvement

Patient involvement in the decision-making process requires that healthcare professionals acknowledge patients' views about their condition and its treatment, and that both healthcare professional and patient have a role in making decisions about treatment. Simple interventions to increase patient involvement do not necessarily increase the overall length of consultation and may be justified by benefits, particularly over the course of a long-term condition.

1.1.7 Offer all patients the opportunity to be involved in making decisions about prescribed medicines. Establish what level of involvement in decision-making the patient would like.

1.1.8 Discuss with the patient why they might benefit from the treatment. Clearly explain the disease or condition and how the medicine will influence this.

1.1.9 Explain the medical aims of the treatment to patients and openly discuss the pros

and cons of proposed medicines. The discussion should be at the level preferred by the patient.

1.1.10 Clarify what the patient hopes the treatment will achieve.

1.1.11 Avoid making assumptions about patient preferences about treatment. Talk to the patient to find out their preferences, and note any non-verbal cues that may indicate you need to explore the patient's perspective further.

1.1.12 Healthcare professionals have a duty to help patients to make decisions about their treatment based on an understanding of the likely benefits and risks rather than on misconceptions.

1.1.13 Accept that patients may have different views from healthcare professionals about the balance of risks, benefits and side effects of medicines.

1.1.14 Be aware that increasing patient involvement may mean that the patient decides not to take or to stop taking a medicine. If in the healthcare professional's view this could have an adverse effect, then the information provided to the patient on risks and benefits and the patient's decision should be recorded.

1.1.15 Accept that the patient has the right to decide not to take a medicine, even if you do not agree with the decision, as long as the patient has the capacity to make an informed decision and has been provided with the information needed to make such a decision.

1.1.16 Assess the patient's capacity to make each decision using the principles in the Mental Capacity Act 2005. To lack capacity patients must: (a) have an impairment of or disturbance or malfunction of brain and mind, and (b) demonstrate lack of capacity to:

- understand the information relevant to the decision
- retain information for long enough to use it in the decision
- use or weigh information as part of the process of making the decision
- communicate the decision (whether by talking, using sign language or any other means).

More information is available in NICE's guideline on decision-making and mental capacity.

1.1.17 If the patient has specific concerns, record a summary of the discussion, because this may be helpful in future consultations.

1.1.18 Encourage and support patients, families and carers to keep an up-to-date list of all medicines the patient is taking. The list should include the names and dosages of prescription and non-prescription medicines and herbal and nutritional supplements. If the patient has any allergic or adverse reactions to medicines, these should be noted.

Understanding the patient's knowledge, beliefs and concerns about medicines

There is evidence that patients make decisions about medicines based on their understanding of their condition and the possible treatments, their view of their own need for the medicine and their concerns about the medicine.

1.1.19 Be aware that patients' concerns about medicines, and whether they believe they need them, affect how and whether they take their prescribed medicines.

1.1.20 Ask patients what they know, believe and understand about medicines before prescribing new treatments and when reviewing medicines.

1.1.21 Ask if the patient has any specific concerns about their medicines, whenever you prescribe, dispense or review medicines. These may include concerns about becoming dependent on medicines and concerns about adverse effects. Address these concerns.

1.1.22 Be aware that patients may wish to minimise how much medicine they take.

1.1.23 Be aware that patients may wish to discuss:

- what will happen if they do not take the medicine suggested by their

healthcare professional

- non-pharmacological alternatives to medicines
- how to reduce and stop medicines they may have been taking for a long time, particularly those known to be associated with withdrawal symptoms
- how to fit taking the medicine into their daily routine
- how to make a choice between medicines if they believe they are taking too many medicines.

Providing information

Patients need information about their condition and possible treatments if they are to be involved in making informed decisions about medicines. The format and content of the information provided should meet the needs of individual patients.

1.1.24 Offer patients information about medicines before the medicines are prescribed.

1.1.25 Offer patients information that is relevant to their condition, possible treatments and personal circumstances, and that is easy to understand and free from jargon.

1.1.26 Check that patients have any information they wish about medicines when the medicines are dispensed.

1.1.27 Discuss information on medicines with the patient rather than just presenting it. The discussion should take into account what the patient understands and believes about the condition and treatment.

1.1.28 Do not assume that the patient information leaflets (PILs) that patients receive with their medicines will meet each patient's needs. Address concerns that patients may have after reading the standard PILs.

PILs contain information for patients on how medicines should be used. It is a legal requirement that this information is included on the label or within the packaging of a medicine.

1.1.29 Patients differ in the type and amount of information they need and want. Therefore, the provision of information should be individualised and is likely to include, but not be limited to:

- what the medicine is
- how the medicine is likely to affect their condition (that is, its benefits)
- likely or significant adverse effects and what to do if they think they are experiencing them
- how to use the medicine
- what to do if they miss a dose
- whether further courses of the medicine will be needed after the first prescription
- how to get further supplies of medicines.

1.1.30 Be careful not to make assumptions about a patient's ability to understand the information provided. Check with the patient that they have understood the information. Information for patients should be clear and logical and, if possible, tailored to the needs of the individual patient.

1.1.31 Suggest where patients might find reliable information and support after the consultation: for example, by providing written information or directing them to other resources (for example, the NHS website).

1.1.32 Provide inpatients with the same information as patients in other settings. Information should include:

- what the medicine is
- how the medicine is likely to affect their condition (that is, its benefits)
- likely or significant adverse effects and what to do if they think they are experiencing them
- how to use the medicine

- what to do if they miss a dose
- whether further courses of the medicine will be needed after the first prescription
- how to get further supply after discharge.

1.2 Supporting adherence

Assessing adherence

Patients do not always take their medicines exactly as prescribed, and healthcare professionals are often unaware of how patients take their medicines. The purpose of assessing adherence is not to monitor patients but rather to find out whether patients need more information and support.

1.2.1 Recognise that non-adherence is common and that most patients are non-adherent sometimes. Routinely assess adherence in a non-judgemental way whenever you prescribe, dispense and review medicines.

1.2.2 Consider assessing non-adherence by asking the patient if they have missed any doses of medicine recently. Make it easier for them to report non-adherence by:

- asking the question in a way that does not apportion blame
- explaining why you are asking the question
- mentioning a specific time period such as 'in the past week'
- asking about medicine-taking behaviours such as reducing the dose, stopping and starting medicines.

1.2.3 Consider using records of prescription re-ordering, pharmacy patient medication records and return of unused medicines to identify potential non-adherence and patients needing additional support.

Interventions to increase adherence

Patients may need support to help them make the most effective use of their medicines. This support may take the form of further information and discussion, or involve practical changes to the type of medicine or the regimen. Any interventions to support adherence should be considered on a case-by-case basis and should address the concerns and needs of individual patients.

1.2.4 If a patient is not taking their medicines, discuss with them whether this is because of beliefs and concerns or problems about the medicines (intentional non-adherence) or because of practical problems (unintentional non-adherence).

1.2.5 Be aware that although adherence can be improved, no specific intervention can be recommended for all patients. Tailor any intervention to increase adherence to the specific difficulties with adherence the patient is experiencing.

1.2.6 Find out what form of support the patient would prefer to increase their adherence to medicines. Together, you and your patient should consider options for support.

1.2.7 Address any beliefs and concerns that patients have that result in reduced adherence.

1.2.8 Because evidence supporting interventions to increase adherence is inconclusive, only use interventions to overcome practical problems associated with non-adherence if a specific need is identified. Target the intervention to the need. Interventions might include:

- suggesting that patients record their medicine-taking
- encouraging patients to monitor their condition
- simplifying the dosing regimen
- using alternative packaging for the medicine
- using a multi-compartment medicines system.

1.2.9 Side effects can be a problem for some patients. If this is the case you should:

- discuss how the patient would like to deal with side effects
- discuss the benefits, side effects and long-term effects with the patient to allow them to make an informed choice
- consider adjusting the dosage
- consider switching to another medicine with a different risk of side effects
- consider what other strategies might be used (for example, timing of medicines).

1.2.10 Ask patients if prescriptions charges are a problem for them. If they are, consider possible options to reduce costs.

1.3 Reviewing medicines

Patients may use medicines long term. The initial decision to prescribe medicines, the patient's experience of using the medicines and the patient's needs for adherence support should be reviewed regularly. The patient's own list of medicines may be a useful aid in a medicines review.

1.3.1 Review patient knowledge, understanding and concerns about medicines, and a patient's view of their need for medicine at intervals agreed with the patient, because these may change over time. Offer repeat information and review to patients, especially when treating long-term conditions with multiple medicines.

1.3.2 Review at regular intervals the decision to prescribe medicines, according to patient choice and need.

1.3.3 Enquire about adherence when reviewing medicines. If non-adherence is identified, clarify possible causes and agree any action with the patient. Any plan should include a date for a follow-up review.

1.3.4 Be aware that patients sometimes evaluate prescribed medicines using their own criteria such as their understanding of their condition or the symptoms most troubling to them. They may, for example, stop and start the medicine or alter the

dose and check how this affects their symptoms. Ask the patient whether they have done this.

1.4 Communication between healthcare professionals

Patients may be under the care of healthcare professionals from different disciplines and specialties at the same time; responsibility for patients' care may be transferred between healthcare professionals, and medicines reviews may be carried out by healthcare professionals other than the prescriber. Therefore good communication between healthcare professionals is required to ensure that fragmentation of care does not occur.

1.4.1 Healthcare professionals involved in prescribing, dispensing or reviewing medicines should ensure that there are robust processes for communicating with other healthcare professionals involved in the patient's care.

1.4.2 This recommendation has been replaced by recommendations in section 1.2 in the NICE guideline on medicines optimisation.

1.4.3 Healthcare professionals involved in reviewing medicines should inform the prescriber of the review and its outcome. This is particularly important if the review involves discussion of difficulties with adherence and further review is necessary.

Recommendations for research

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and patient care in the future. The Guideline Development Group's full set of recommendations for research is detailed in the full guideline.

1 Developing effective, equitable interventions to support adherence to appropriate prescriptions

What are the most clinically effective and cost-effective methods for identifying and addressing the perceptual barriers (such as beliefs and concerns about medicines) that influence motivation to start and continue with treatment, and the practical barriers (such as limitations in personal capacity and resources) that limit an individual's ability to implement intentions to adhere to medicines?

Why this is important

The Guideline Development Group identified a priority for the systematic development of effective, realisable, efficient and equitable interventions to facilitate informed choice and optimal adherence to appropriately prescribed medicines.

Systematic reviews of adherence interventions show that although adherence can be improved, the effects were generally modest and there is considerable room for improvement. Few previous interventions have been developed systematically using appropriate theoretical models, and they have not been modelled and piloted with assessment of process variables as well as outcomes.

Interventions should be developed using an appropriate theoretical framework with a phased approach to testing that includes assessment of process (that is, the things that are targeted for change) as well as outcomes and a need for an individual approach. (Campbell NC, Murray E, Darbyshire J et al. 2007)

2 Informed choice and shared decision-making

What are the most clinically effective and cost-effective ways of communicating the potential benefits and risks of medicines to promote informed choice and optimal adherence?

Why this is important

The principles of informed choice and shared decision-making have largely been developed from theoretical and conceptual models. The competencies listed for shared decision-making consist of a number of different skills, and patients have shown that they may value different aspects of shared decision-making. Although the right of patients to be involved in decision-making in regard to their own healthcare is accepted, the practice of shared decision-making may mean that healthcare professionals and patients play different roles than they have to date in healthcare consultations. This may have implications for legal and professional responsibility and accountability. Patients and professionals enter decision-making with very different levels of knowledge and access to information. Improving patient knowledge and information may require structural changes to health services and their delivery. Patient-reported outcomes also need to be included.

3 Support processes: prescribing-related consultations and medicines review

How can practitioners and patients be supported to improve the quality of prescribing-related consultations and medicines reviews so that they facilitate informed choice and optimal adherence to medicines?

What are the effects of medicines reviews by healthcare professionals other than the prescriber on patients, prescribers and outcomes? How can the process of medicines review be enhanced or improved to address issues of informed choice and adherence?

Why this is important

Non-adherence is often a hidden problem. Many patients are reluctant to express doubts and concerns about medicines because they fear that it will displease the healthcare professional. We need better methods for overcoming this problem and promoting honest and open discussions about medicines and adherence.

There are an increasing number of non-medical prescribers (such as pharmacists and nurses) This is a key context issue and there are a range of questions relating to patient perspectives on new prescribers and to new and existing prescribers' perceptions and skills. The effects of new prescribers on patient adherence to medicines should be included in any studies designed to evaluate new prescribers. The inclusion of formal procedures for medicines review within the Pharmacy Contract in England provides an opportunity for improved support for patients. We need a better understanding of the effects of non-prescriber reviews on medicines usage and outcomes, and how reviews might be improved to benefit patients and society.

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE topic page on medicines management.

For full details of the evidence and the guideline committee's discussions, see the evidence reviews. You can also find information about how the guideline was developed, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting our guidelines into practice, see resources to help you put NICE guidance into practice.

Update information

Minor changes since publication

September 2019: Reference to Disability Discrimination Act (2005) changed to Equality Act (2010). Recommendation 1.1.16 amended to add cross-reference to the NICE guideline on decision-making and mental capacity (NG108).

March 2015: Recommendation 1.4.2 has been replaced by recommendations in section 1.2 in the NICE guideline on medicines optimisation.

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