Guide to Using Psychotropic Medication to Manage Behaviour Problems among Adults with Intellectual Disability

Technical Document

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Technical Document Section 8: Additional Information

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www.LD-Medication.bham.ac.uk

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Recommendations for future research

The following areas have been identified as recommendations for future research. These areas were highlighted throughout the guideline development process as those with a dearth in the current evidence base. It is suggested that directions for further research in the field of learning disability and behaviour problems should include:

- Randomised controlled trials of intervention efficacy with longer durations and follow up.

- Observational studies.

- Research into adverse effects of interventions, and more specifically the tolerance of people with a learning disability to medications compared with general psychiatric populations.

- The use and development of validated outcome measures and scales.

- Research into health economics and surrounding issues.

- Research into issues for carers in relation to interventions.

- Randomised controlled trials and observational studies should include Quality of Life measures, take into account the causes of the behaviour(s) and the effect of concomitant medication and non-medication based interventions.

- Long-term follow up studies.

- The study of metabolic and haematological adverse effects of medication from their long-term use.

- Comparison of the effectiveness of different medication specific to different behaviour problems.

Dissemination of the guide

The guide has been subject to wide dissemination throughout the United Kingdom (UK). Several methods have been used to ensure that as many relevant individuals and organisations are made aware of the guide as possible.

Website

Initially a project website was established, housed within the University of Birmingham, Division of Neuroscience web pages, at: www.LD-Medication.bham.ac.uk. All relevant information regarding the guide and the conferences (see below), including contact details, was posted on the website. The website acted as a central hub for information to be presented on the project. Furthermore, the guides are all available to download and print from the site, allowing anyone with access to the site access to a copy of the guides.

All those who contacted the project team regarding the project or the conferences were listed on an email mailing list and informed of the website including the opportunity to download all three version of the guides and the leaflets.

Regional Conferences

Seven regional conferences were held throughout the UK during September and October 2006. The conferences were very widely advertised through organisational websites, newsletters, bulletins, and mail outs (both postal and email). Relevant organisations and stakeholders were contacted and provided with the flyer to distribute to members or other interested parties. This approach facilitated widespread recruitment of delegates, with the conferences heavily subscribed. On average, over 100 delegates attended each conference, with substantial numbers on reserve lists. Due to the demand for attendance at the conferences, all the presentation slides were subsequently posted on the project website along with the Quick Reference Guide, Easy Read Guide and Technical Guide. All those who showed an interest in the conferences were made aware of this.

The programme for the conferences was engineered to summarise the development and content of the guide, present the results of the systematic review and audit, and then provide perspectives from GDG members on inter-disciplinary team working and the carer's perspective.

All the delegates received a delegate pack containing both the Quick Reference Guide and Easy Read Guide, and copies of the presentation slides. Therefore, over 800 delegates received printed copies of the guides. The delegates represented a wide range of backgrounds including psychiatrists, nurses, speech and language therapists, carers, care workers,

team managers, and commissioners. The conferences proved to be very successful and received very positive feedback from the delegates.

Hyperlinks

To increase awareness of the guide, hyperlinks have been generated between relevant organisational websites and the project website. Such links include Mencap, British Institute of Learning Disabilities (BILD), Challenging Behaviour Foundation, National Autistic Society, Mental Welfare Commission for Scotland, Royal College of Speech and Language Therapists, the Royal College of Psychiatrists' Learning Disability Faculty, and Social Care Institute for Excellence.

Mail out

The GDG identified relevant organisations to receive printed copies of the guides. Such organisations covered charities (including the British Institute of Learning Disabilities, Norah Fry Research Centre, Autism Cwmru, National Autistic Society, Challenging Behaviour Foundation, Fragile X Society, and the MacIntyre Organisation), government bodies (for example the Department of Health, National Institute for Health and Clinical Excellence, Healthcare Commission, Health Foundation, and the National Patient Safety Agency), and health professional organisations (including British Association of Psychologists and College of Occupational Therapy).

Several organisations were deemed particularly important and as such all their members were sent copies of the guides through the post. All the consultant and specialist registrar members of the Learning Disability Faculty of the Royal College of Psychiatrists were sent the Quick Reference Guide through the post (over 600 members). Similarly, all the members of the United Kingdom Psychiatric Pharmacy group (almost 500 members), the Royal College of Nursing Learning Disability Forum (approximately 100 members) and the British Psychological Society's Learning Disability Faculty (approximately 300 members) were sent the QRG through the post. Furthermore, all the recipients (over 700) of Mencap's newsletter were sent the Easy Read Guide in their November 2006 mail out. These were mainly carers and people with a learning disability. This approach ensured that both relevant practitioners and clinicians received the guide as well as service users and carers.

Due to the advertisement of the project, many personal requests were also received for additional printed copies of the guides. Examples of such requests included many consultants from Wales and England, Birmingham City Council (so all the managers of care homes for people with a learning disability in the area could receive a copy), Portsmouth Primary Care Trust (to implement the guidance in their area), and a Consultant Psychiatrist in Belfast (to implement the guidance in her practice). In addition, there has also been a request from the Division for Mental Retardation, Ministry of Social Affairs, Israel, for permission to translate the guide into Hebrew, a request for copies of the guides from the University of Toronto, Canada, and requests from

Australia from the Centre for Developmental Disability Health in Victoria and the University of Queensland.

Presentations at National and International Conferences

Data from the systematic review, audit, and clinicians' consensus questionnaire have been presented at various national and international conferences including the National Institute for Health and Clinical Excellence (NICE) Annual Conference 2005 and the Royal College of Psychiatrists' Learning Disability Faculty Annual Residential Meetings in 2005 and 2006. Furthermore, the project has been presented at the Mencap National Assembly (2007) to ensure further dissemination directed specifically to people with a learning disability.

Peer Review Journal Publications

The results from the systematic review, clinicians' consensus questionnaire and the audit have been published as scientific papers in various peer reviewed journals including the Journal of Intellectual Disability Research and the American Journal on Mental Retardation.

Validation of the guide

The purpose of the AGREE instrument is to provide a framework for assessing the quality of clinical practice guidelines. The authors suggest that the notion of quality in this context refers to 'the confidence that the potential biases of guideline development have been addressed adequately and that the recommendations are both internally and externally valid, and are feasible for practice' (The AGREE Collaboration, 2001, p2).

The appraisal involves the assessment of:
- The methods used for developing the guidelines.
- The content of the final recommendations.
- Factors linked to the uptake of the guidelines.
- The predicted validity of the guideline (the likelihood it will achieve its intended outcome).

The instrument was developed amidst concern that recently published guidelines are failing to meet basic quality criteria (The AGREE Collaboration, 2003). The instrument was designed to assess the methods used to develop guidelines and the documentation of such processes (The AGREE Collaboration, 2003). The authors aimed to produce a generic assessment tool and set of criteria that could be applied across all healthcare settings and across countries. The instrument was widely consulted on and field-tested before it was finalised with 13 countries involved in this process.

The instrument is split into six domains, each containing several items. Each item is subject to rating on a 4-point scale, from 1 'strongly agree', to 4 'strongly disagree' with space for comments.

Once all the items have been rated, the domain scores are calculated by summing the scores for the individual items in each domain and then standardising the total as a percentage of the maximum possible score for that domain, using the equation below:

Standardised domain score =

$$\frac{\text{obtained score} - \text{minimum possible score}}{\text{maximum possible score} - \text{minimum possible score}} \times 100$$

The AGREE instrument has been applied to the current guideline to evaluate the quality in accordance with the AGREE Collaboration (2001) by two members of the project team (See Appendix 1 for the completed form).

Results

The standardised scores for each of the domains are as follows:

- Scope and Purpose: 100%
- Stakeholder Involvement: 100%
- Rigour of Development: 85.7%
- Clarity and Presentation: 100%
- Applicability: 100%
- Editorial Independence: 83.3%

Documents consulted in the development of the guide

The AGREE Collaboration (2001). *Appraisal of Guidelines for Research and Evaluation (AGREE) Instrument.* Available www.agreecolloaboration.org

Aman G, Alvarez N, Benefield W, Crimson M, Green G, King B, et al. (2000). Treatment of psychiatric and behavioural problems in mental retardation. *American Journal on Mental Retardation*, 105, 159-228.

Association for Real Change (ARC, 2005). *Managing medication in learning disability social care settings: A guide and training framework for social care organisations*. Available www.arcuk.org.uk/388/en/managing+medication.html

Birmingham and Black Country Strategic Health Authority (BBC StHA, 2003). *Care Pathway for adults with learning disabilities who are displaying challenging behaviour: Implementation Guide*. NHS West Midlands, Partnership for Developing Quality (PDQ).

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British Psychological Association (BPS, 2004). *Psychological interventions for severely challenging behaviours shown by people with learning disabilities: Clinical Practice Guidelines*. Leicester: Author.

Commission for Healthcare Audit and Inspection (2006). Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust. Available http://www.healthcarecommission.org.uk/_db/_documents/cornwall_investigation_report.pdf

Department of Health (2001). *Valuing People: A new strategy for learning disability for the 21st Century*. London: Author.

Fox P & Emerson E (2002). *Positive Goals; Interventions for People with Learning Disabilities whose Behaviour Challenges*. Brighton: Pavilion Publishing Ltd.

Leicestershire Partnership NHS Trust (2005). *The Frith Prescribing Guidelines for Adults with Learning Disability* (edited by S Bhaumik & D Branford). Oxfordshire: Taylor & Francis

National Institute for Health and Clinical Excellence (NICE, 2005). *Violence; The Short-term Management of Disturbed/ Violent Behaviour in In-patient Psychiatric Settings and Emergency Departments*. London: Author. Available www.nice.org.uk/CG025NICEguideline

National Institute for Health and Clinical Excellence (NICE, 2004). *Guideline Development Methods: Information for national collaborating centres and guideline developers*. London: Author. Available www.nice.org

Royal College of Psychiatrists (RCPsych, 2001). *Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/ mental retardation* (DC-LD, Occasional Paper OP48). London: Gaskell.

South London and Maudsley NHS Trust & Oxleas NHS Trust (2005). *The Maudsley 2005-2006 Prescribing Guidelines* (8th Edition). D Taylor, C Paton & R Kerwin. Oxon: Taylor & Francis.

Stokes T, Shaw EJ, Juarez-Garcia A, Camosso-Stefinovic J, & Baker R (2004). *Clinical Guidelines and Evidence Review for the Epilepsies: diagnosis and management in adults and children in primary and secondary care*. London: Royal College of General Practitioners.

Procedure for updating the guide

If necessary, the Learning Disability Faculty of the Royal College of Psychiatrists (UK) may be able to update the guide after four years of its publication (2011).

Useful websites

www.autismwestmidlands.org.uk
This site provides links to information about autism.west midlands, which provides details of autism specific services in the West Midlands region, offering residential and educational service, supported living and employment for adults with Asperger's Syndrome, family support, an information help-line, and training for staff, parents and professionals.

www.bild.org.uk
British Institute of Learning Disabilities (BILD). Offers advice, information, advocacy, training, research and consultancy to people with a learning disability, families and professionals. This site contains information on training courses, conferences and easy to read publications.

www.dh.gov.uk
Department of Health. Up to date news of policy issues particularly with regard to areas such as legislation, decision making and consent. Also contains links to useful organisations.

www.drc-gb.org
Disability Rights Commission. This site gives advice and information to disabled people, employers and service providers. It also supports disabled people in getting their rights under the Disability Discrimination Act.

http://hebw.uwcm.ac.uk
University of Wales site which provides access to the Welsh Centre for Learning Disability who research and publish many articles and papers on a wide range of issues for people with learning disabilities.

www.intellectualdisability.info/home.htm
St. Georges, University of London. A website with a general introduction to working with people with a learning disability. It also provides information about medical and health information and parent's issues.

www.learningdisabilities.org.uk/index.cfm
The Foundation for People with Learning Disabilities works to promote the rights, quality of life and opportunities of people with learning disabilities and their families. It undertakes research and develops projects that promote social inclusion and citizenship; provides advice to support local communities and services to promote inclusion. It advises on services and service development; and disseminates knowledge and information through a variety of media.

www.learningdisability.co.uk
This site provides information, education and services to both members of the public and those with a commercial interest. The site is primarily aimed at providing education information for people with a learning disability, their

carers, advocates, friends, professional carers, social and health care workers, students and those who have an active interest in promoting equality of opportunity for people with a learning disability.

www.medicines.org.uk
This gives details of the manufacturer's information. It can be helpful if you need to know how common the side effects are and what the exipients ('fillers') are in a tablet in case there are allergy problems.

www.mencap.org.uk
The Mencap site, containing information and current issues relating to learning disability. It is also a site for good practice stories and news.

www.mentalhealth.org.uk
Mental Health Foundation: contains information about a wide range of mental health needs.

www.nas.org.uk
National Autistic Society website provides information, advice and support on autism and Asperger's syndrome for families and professionals.

www.nice.org.uk
National Institute for Health and Clinical Excellence (NICE). This site includes information mainly for health professionals. NICE have issued good practice guidelines on mental health issues.

www.bris.ac.uk/Depts/NorahFry
Norah Fry Research Centre. Its principal interests are the evaluation and development of services for people with a learning disability. It produces a number of research and policy documents, many of which are produced with the involvement of people with a learning disability.

www.paradigm-uk.org
This site is updated weekly, contains learning disability related articles, links, information on training courses, UK government policy (in the forefront for supported living and person centred planning).

www.rcpsych.ac.uk
This is the site of the Royal College of Psychiatrists. It offers a wide range of information on many aspects of mental health, including material accessible to people with a learning disability.

www.rnib.org.uk
The Royal National Institute for the Blind (RBIB) website provides information, support and advice to people with visual impairments.

www.rnid.org.uk
The Royal National Institute for the Deaf website provides information about hearing loss.

www.sane.org.uk
This site is aimed at everyone affected by mental illness and has a telephone help line.

www.scope.org.uk
This site provides information about cerebral palsy. It provides information on campaigns, research and support.

www.tellusmore.org
This site, provided by the Birmingham Learning Disability Partnership Board, contains information on medication for carers of people with learning disabilities and has links on a variety of issues.

www.ukppg.org.uk
This is the website of the UK Psychiatric Pharmacy Group which collates useful information on psychiatric medicines and related issues.

www.valuingpeople.gov.uk
This is the website of the Valuing People Support Team. It has information for people with learning disabilities; it also has a section on health, Health Action Plans and Person-Centred Planning. There are also links to regional pages.

References

The AGREE Collaboration (2003). Development and validation of an international appraisal instrument for assessing the quality of clinical practice guidelines: the AGREE project. *Quality and Safety in Health Care*, **12**, 18-23.

The AGREE Collaboration (2001). *Appraisal of Guidelines for Research and Evaluation (AGREE) Instrument*. Available www.agreecollaboration.org.

Appendix 1: Completed AGREE appraisal instrument

USER GUIDE

AGREE

SCOPE AND PURPOSE

1.

This deals with the potential health impact of a guideline on society and populations of patients. The overall objective(s) of the guideline should be described in detail and the expected health benefits from the guideline should be specific to the clinical problem. For example specific statements would be:
- Preventing (long term) complications of patients with diabetes mellitus;
- Lowering the risk of subsequent vascular events in patients with previous myocardial infarction;
- Rational prescribing of antidepressants in a cost-effective way.

2.

A detailed description of the clinical questions covered by the guideline should be provided, particularly for the key recommendations (see item 17). Following the examples provided in question 1:
- How many times a year should the HbA1c be measured in patients with diabetes mellitus?
- What should the daily aspirin dosage for patients with proven acute myocardial infarction be?
- Are selective serotonin reuptake inhibitors (SSRIs) more cost-effective than tricyclic antidepressants (TCAs) in treatment of patients with depression?

3.

There should be a clear description of the target population to be covered by a guideline. The age range, sex, clinical description, comorbidity may be provided. For example:
- A guideline on the management of diabetes mellitus only includes patients with non-insulin dependent diabetes mellitus and excludes patients with cardiovascular comorbidity.
- A guideline on the management of depression only includes patients with major depression, according to the DSM-IV criteria, and excludes patients with psychotic symptoms and children.
- A guideline on screening of breast cancer only includes women, aged between 50 and 70 years, with no history of cancer and with no family history of breast cancer.

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AGREE APPRAISAL INSTRUMENT

SCOPE AND PURPOSE

1. The overall objective(s) of the guideline is (are) specifically described.

Strongly Agree | 4 | 3 | 2 | 1 | Strongly Disagree

Comments

Clearly defined bullet points regarding objectives in the 'Aims of the guideline' section. Objectives are also expressed in other areas such as the 'Analysis of Need for the guideline' section. The overall aim of improving the healthcare of adults with a leaning disability and behaviour problems is clearly stated. It is acceptable for this aim to be broad as the guide addresses broad issues that should lead to a general improvement of practice surrounding the use of medication to manage behaviour problems in adults with a learning disability.

2. The clinical question(s) covered by the guideline is (are) specifically described.

Strongly Agree | 4 | 3 | 2 | 1 | Strongly Disagree

Comments

Clinical question defined in 'Scope of the guideline' section. The clinical questions are also implicitly defined throughout the document, particularly in the sections covering initiation, monitoring and withdrawal of psychotropic medication. Further clinical questions are covered in specialised areas such as PRN medication, rapid tranquillisation and the sample clinic letter etc.

3. The patients to whom the guideline is meant to apply are specifically described.

Strongly Agree | 4 | 3 | 2 | 1 | Strongly Disagree

Comments

Very clear outline of the target population covered by the guideline.

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STAKEHOLDER INVOLVEMENT

A G R E E

4.

This item refers to the professionals who were involved at some stage of the development process. This may include members of the steering group, the research team involved in selecting and reviewing/rating the evidence and individuals involved in formulating the final recommendations. This item excludes individuals who have externally reviewed the guideline (see Item 13). Information about the composition, discipline and relevant expertise of the guideline development group should be provided.

5.

Information about patients' experiences and expectations of health care should inform the development of clinical guidelines. There are various methods for ensuring that patients' perspectives inform guideline development. For example, the development group could involve patients' representatives, information could be obtained from patient interviews, literature reviews of patients' experiences could be considered by the group. There should be evidence that this process has taken place.

6.

The target users should be clearly defined in the guideline, so they can immediately determine if the guideline is relevant to them. For example, the target users for a guideline on low back pain may include general practitioners, neurologists, orthopaedic surgeons, rheumatologists and physiotherapists.

7.

A guideline should have been pre-tested for further validation amongst its intended end users prior to publication. For example, a guideline may have been piloted in one or several primary care practices or hospitals. This process should be documented.

AGREE APPRAISAL INSTRUMENT

STAKEHOLDER INVOLVEMENT

4. The guideline development group includes individuals from all the relevant professional groups.

| Strongly Agree | 4 ✓ | 3 | 2 | 1 | Strongly Disagree |

Comments

A multidisciplinary guideline development group sourcing individuals from a wide range of relevant backgrounds who have in-depth knowledge of the care of adults with a learning disability has developed this guideline. They have been clearly listed in Section 1.

5. The patients' views and preferences have been sought.

| Strongly Agree | 4 ✓ | 3 | 2 | 1 | Strongly Disagree |

Comments

Continuous service user input obtained through service user advisory group. Service user representatives were also included as members of the guideline development group. The guideline was also circulated to service user organisations as part of the external review process. This process has been clearly documented.

6. The target users of the guideline are clearly defined.

| Strongly Agree | 4 ✓ | 3 | 2 | 1 | Strongly Disagree |

Comments

The target users of the guideline have been clearly listed in the 'Audience for the guideline' section.

7. The guideline has been piloted among target users.

| Strongly Agree | 4 ✓ | 3 | 2 | 1 | Strongly Disagree |

Comments

The QRG has been externally reviewed by its target users including the Royal College of Psychiatrists' Learning Disability Faculty, a large number of stakeholders and through a multi-centre audit. The Easy Read Guide has been piloted amongst its target users, namely people with a learning disability. This process has been clearly documented.

RIGOUR OF DEVELOPMENT

AGREE

8.

Details of the strategy used to search for evidence should be provided including search terms used, sources consulted and dates of the literature covered. Sources may include electronic databases (e.g. MEDLINE, EMBASE, CINAHL), databases of systematic reviews (e.g. the Cochrane Library, DARE), handsearching journals, reviewing conference proceedings and other guidelines (e.g. the US National Guideline Clearinghouse, the German Guidelines Clearinghouse).

9.

Criteria for including/excluding evidence identified by the search should be provided. These criteria should be explicitly described and reasons for including and excluding evidence should be clearly stated. For example, guideline authors may decide to only include evidence from randomised clinical trials and to exclude articles not written in English.

10.

There should be a description of the methods used to formulate the recommendations and how final decisions were arrived at. Methods include for example, a voting system, formal consensus techniques (e.g. Delphi, Glaser techniques). Areas of disagreement and methods of resolving them should be specified.

11.

The guideline should consider health benefits, side effects, and risks of the recommendations. For example, a guideline on the management of breast cancer may include a discussion on the overall effects on various final outcomes. These may include: survival, quality of life, adverse effects, and symptom management or a discussion comparing one treatment option to another. There should be evidence that these issues have been addressed.

AGREE APPRAISAL INSTRUMENT

RIGOUR OF DEVELOPMENT

8. Systematic methods were used to search for evidence.

Strongly Agree	4	3	2	1	Strongly Disagree

Comments

The methods used to search for evidence are clearly defined and systematic. The search strategy is documented along with the search terms used, sources consulted and the dates of the literature covered.

9. The criteria for selecting the evidence are clearly described.

Strongly Agree	4	3	2	1	Strongly Disagree

Comments

The inclusion/ exclusion criteria for selecting the evidence are explicitly described with reasons.

10. The methods used for formulating the recommendations are clearly described.

Strongly Agree	4	3	2	1	Strongly Disagree

Comments

The description of methods used for the formulation of the recommendations are clearly described. A consensus gathering exercise was also undertaken to assist in the development of the recommendations. The recommendations are graded according to a hierarchy of evidence used by NICE.

11. The health benefits, side effects and risks have been considered in formulating the recommendations.

Strongly Agree	4	3	2	1	Strongly Disagree

Comments

The health benefits of the recommendations are clearly considered. Side effects or risks of medications are considered in the systematic review section (based on the available evidence) and in the recommendations on monitoring of interventions.

USER GUIDE

RIGOUR OF DEVELOPMENT

12.

There should be an explicit link between the recommendations and the evidence on which they are based. Each recommendation should be linked with a list of references on which it is based.

13.

A guideline should be reviewed externally before it is published. Reviewers should not have been involved in the development group and should include some experts in the clinical area and some methodological experts. Patients' representatives may also be included. A description of the methodology used to conduct the external review should be presented, which may include a list of the reviewers and their affiliation.

14.

Guidelines need to reflect current research. There should be a clear statement about the procedure for updating the guideline. For example, a timescale has been given, or a standing panel receives regularly updated literature searches and makes changes as required.

AGREE APPRAISAL INSTRUMENT

RIGOUR OF DEVELOPMENT

12. There is an explicit link between the recommendations and the supporting evidence.

| Strongly Agree | 4 | 3 | 2 | 1 | Strongly Disagree |

Comments

There is an explicit link between the recommendations and the supporting evidence. However, it is stated that as the systematic review demonstrated an overall paucity of good quality evidence for the efficacy of medications, no recommendations could be given relating to which medications should be used in which circumstances. Therefore, the guide contains good practice recommendations based on the consideration of existing guidelines and documents and the clinical expertise of the GDG and hence they are graded as Good Practice Points.

13. The guideline has been externally reviewed by experts prior to its publication.

| Strongly Agree | 4 | 3 | 2 | 1 | Strongly Disagree |

Comments

The draft guideline has been sent to members of the Royal College of Psychiatrists' Learning Disability Faculty and over 80 stakeholders for comments/ review. The methods used for this external review process and a summary of the comments received and how these were dealt with has been included in section 1 of the guide.

14. A procedure for updating the guideline is provided.

| Strongly Agree | 4 | 3 | 2 | 1 | Strongly Disagree |

Comments

A brief summary of how the guideline may be updated is provided in a separate section.

USER GUIDE

CLARITY AND PRESENTATION

AGREE

15.

A recommendation should provide a concrete and precise description of which management is appropriate in which situation and in what patient group, as permitted by the body of evidence.
- An example of a specific recommendation is: Antibiotics have to be prescribed in children of two years or older with acute otitis media if the complaint last longer than three days or if the complaint increase after the consultation despite adequate treatment with painkillers; in these cases amoxycillin should be given for 7 days (supplied with a dosage scheme).
- An example of a vague recommendation is: Antibiotics are indicated for cases with an abnormal or complicated course.

However, evidence is not always clear cut and there may be uncertainty about the best management. In this case the uncertainty should be stated in the guideline.

16.

A guideline should consider the different possible options for screening, prevention, diagnosis or treatment of the condition it covers. These possible options should be clearly presented in the guideline. For example, a recommendation on the management of depression may contain the following alternatives:

    a. Treatment with TCA
    b. Treatment with SSRI
    c. Psychotherapy
    d. Combination of pharmacological and psychological therapy

17.

Users should be able to find the most relevant recommendations easily. These recommendations answer the main clinical questions that have been covered by the guideline. They can be identified in different ways. For example, they can be summarised in a box, typed in bold, underlined or presented as flow charts or algorithms.

18.

For a guideline to be effective it needs to be disseminated and implemented with additional materials. These may include for example, a summary document, or a quick reference guide, educational tools, patients' leaflets, computer support, and should be provided with the guideline.

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AGREE APPRAISAL INSTRUMENT

CLARITY AND PRESENTATION

15. The recommendations are specific and unambiguous.

Strongly Agree | 4 ✓ | 3 | 2 | 1 | Strongly Disagree

Comments

The recommendations are clear and unambiguous. However, as the guide is not a strict clinical guide and provides good practice recommendations rather than strict clinical guidelines, the recommendations are more broad than stating that such an intervention should be used in certain circumstances.

16. The different options for management of the condition are clearly presented.

Strongly Agree | 4 ✓ | 3 | 2 | 1 | Strongly Disagree

Comments

Different options for the management of behaviour problems are clearly considered. However, they are not extensively presented as it is out of the remit of the scope for the guideline. Furthermore, another recent guideline that considers non-medication based interventions has been published, the guide directs readers to that guide.

17. Key recommendations are easily identifiable.

Strongly Agree | 4 ✓ | 3 | 2 | 1 | Strongly Disagree

Comments

The key recommendations are easily identifiable as they are highlighted in the 'Main recommendations' section.

18. The guideline is supported with tools for application.

Strongly Agree | 4 ✓ | 3 | 2 | 1 | Strongly Disagree

Comments

The guideline has been extensively disseminated through various methods. These are clearly described in the document. Furthermore, additional materials have been supplied to aid the implementation of the guideline including several example proforma, an easy read version, a quick reference guide, patient information leaflets, and audit criteria.

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USER GUIDE

APPLICABILITY.

AGREE

19.

Applying the recommendations may require changes in the current organisation of care within a service or a clinic which may be a barrier to using them in daily practice. Organisational changes that may be needed in order to apply the recommendations should be discussed. For example:

   i. A guideline on stroke may recommend that care should be co-ordinated through stroke units and stroke services.

   ii. A guideline on diabetes in primary care may require that patients are seen and followed up in diabetic clinics.

20.

The recommendations may require additional resources in order to be applied. For example, there may be a need for more specialised staff, new equipment, expensive drug treatment. These may have cost implications for health care budgets. There should be a discussion of the potential impact on resources in the guideline.

21.

Measuring the adherence to a guideline can enhance its use. This requires clearly defined review criteria that are derived from the key recommendations in the guideline. These should be presented. Examples of review criteria are:

• The HbA1c should be < 8.0%.
• The level of diastolic blood pressure should be < 95 mmHg.
• If complaints of acute otitis media lasts longer than three days amoxicillin should be prescribed.

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AGREE APPRAISAL INSTRUMENT

APPLICABILITY.

19. The potential organisational barriers in applying the recommendations have been discussed.

Strongly Agree | 4 | 3 | 2 | 1 | Strongly Disagree

Comments

The potential organisational barriers in applying the recommendations have been discussed in the 'How to implement this guide' section and throughout. Separate recommendations have been provided to give advice on what action organisations should take for the guide to be implemented.

20. The potential cost implications of applying the recommendations have been considered.

Strongly Agree | 4 | 3 | 2 | 1 | Strongly Disagree

Comments

The guide discusses the potential impact on resources in the 'How to implement this guide' section and throughout. The guide fully recognises that lack of resources may hamper the implementation of the recommendations. Furthermore, the health economics surrounding the use of medication have been discussed as thoroughly as possible in the health economics section. However, due to a lack of available data, a strict health economic evaluation was not possible, this is clearly stated in the health economics section.

21. The guideline presents key review criteria for monitoring and/or audit purposes.

Strongly Agree | 4 | 3 | 2 | 1 | Strongly Disagree

Comments

A clear set of review or audit criteria have been included in the guide. These have been derived from the main recommendations.
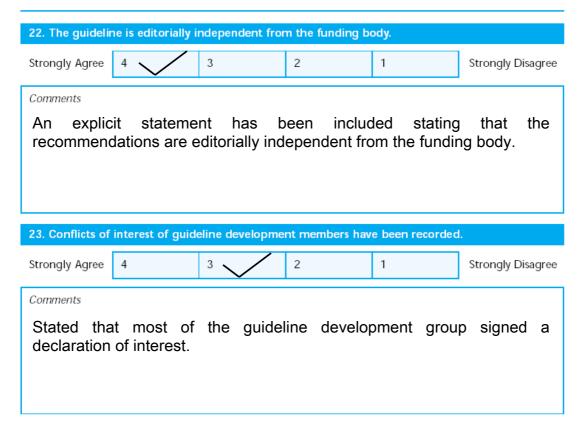
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USER GUIDE

EDITORIAL INDEPENDENCE

AGREE

22.

Some guidelines are developed with external funding (e.g. Government funding, charity organisations, pharmaceutical companies). Support may be in the form of financial contribution for the whole development, or for parts of it, e.g. printing of the guidelines. There should be an explicit statement that the views or interests of the funding body have not influenced the final recommendations. Please note: If it is stated that a guideline was developed without external funding, then you should answer 'Strongly Agree'.

23.

There are circumstances when members of the development group may have conflicts of interest. For example, this would apply to a member of the development group whose research on the topic covered by the guideline is also funded by a pharmaceutical company. There should be an explicit statement that all group members have declared whether they have any conflict of interest.

AGREE APPRAISAL INSTRUMENT

EDITORIAL INDEPENDENCE

22. The guideline is editorially independent from the funding body.

Strongly Agree	4	3	2	1	Strongly Disagree

Comments

An explicit statement has been included stating that the recommendations are editorially independent from the funding body.

23. Conflicts of interest of guideline development members have been recorded.

Strongly Agree	4	3	2	1	Strongly Disagree

Comments

Stated that most of the guideline development group signed a declaration of interest.

FURTHER COMMENTS

This guideline emphasises the issue of the lack of good quality evidence to allow specific evidence based recommendations to be made regarding specific medications for specific behaviour problems. Therefore, the guideline is more of a good practice guide which depended heavily on consensus techniques and the expertise of the guideline development group. However, it is evident that very extensive consultations were undertaken before finalising the documents. This external consultation process included service users, carers and a wide range of health professionals.