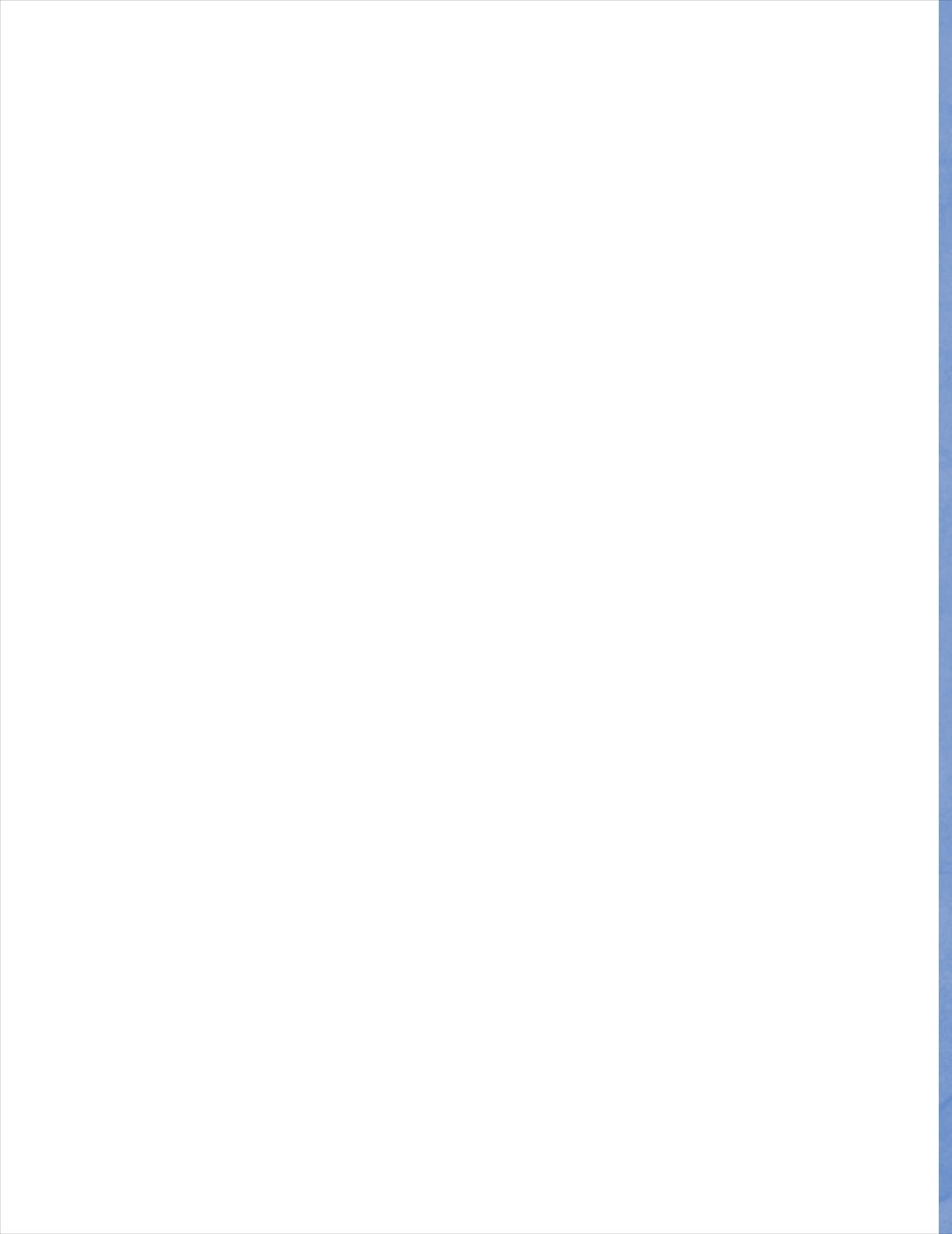


ADHERENCE TO LONG-TERM THERAPIES

Evidence for action



World Health Organization 2003



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Preface

Over the past few decades we have witnessed several phases in the development of approaches aimed at ensuring that patients continue therapy for chronic conditions for long periods of time. Initially the patient was thought to be the source of the “problem of compliance”. Later, the role of the providers was also addressed. Now we acknowledge that a systems approach is required. The idea of compliance is associated too closely with blame, be it of providers or patients and the concept of adherence is a better way of capturing the dynamic and complex changes required of many players over long periods to maintain optimal health in people with chronic diseases.

This report provides a critical review of what is known about adherence to long-term therapies. This is achieved by looking beyond individual diseases. By including communicable diseases such as tuberculosis and human immunodeficiency virus/acquired immunodeficiency syndrome; mental and neurological conditions such as depression and epilepsy; substance dependence (exemplified by smoking cessation); as well as hypertension, asthma and palliative care for cancer, a broad range of policy options emerges. Furthermore, this broader focus highlights certain common issues that need to be addressed with respect to all chronic conditions regardless of their cause. These are primarily related to the way in which health systems are structured, financed and operated.

We hope that readers of this report will recognize that simplistic approaches to improving the quality of life of people with chronic conditions are not possible. What is required instead, is a deliberative approach that starts with reviewing the way health professionals are trained and rewarded, and includes systematically tackling the many barriers patients and their families encounter as they strive daily to maintain optimal health.

This report is intended to make a modest contribution to a much-needed debate about adherence. It provides analysis and solutions, it recommends that more research be conducted, but critically acknowledges the abundance of what we already know but do not apply. The potential rewards for patients and societies of addressing adherence to long-term therapies are large. WHO urges the readers of this report to work with us as we make the rewards real.

Derek Yach
January 2003

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Special appreciation goes to the scientific writers who provided their ideas and the material for the report. Their dedication and voluntary contributions have been central to this work. Thanks are also due to all the participants from WHO and the Adherence Network who by their continuous involvement and input during the planning, resource collection and writing phases of this project have given breadth and depth to the report.

Special thanks go to Steve Hotz for his intellectual sharpness and hard work on helping to integrate the behavioural knowledge and its practical implications. Several International professional associations, in particular the International Pharmaceutical Federation, the International Society of Behavioural Medicine, the International Union of Psychological Sciences, the International Council of Nurses and the World Organization of Family Doctors have played an important role in providing moral support and valuable input to the report.

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All scientific writers were invited to participate because of their proven record of publication on adherence issues. Their contributions were made voluntarily and have been incorporated following the directions of the editor of this report. All of them signed a Declaration of Interests. The scientific writers are listed in alphabetical order by topic. (Team leaders are indicated with an asterisk.).

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With the active support of the WHO-NMH/MNC/CRA unit

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Introduction

Objectives and target audience

This report is part of the work of the Adherence to Long-term Therapies Project, a global initiative launched in 2001 by the Noncommunicable Diseases and Mental Health Cluster of the World Health Organization.

The main target audience for this report are policy-makers and health managers who can have an impact on national and local policies in ways that will benefit patients, health systems and societies with better health outcomes and economic efficiency. This report will also be a useful reference for scientists and clinicians in their daily work.

The main objective of the project is to improve worldwide rates of adherence to therapies commonly used in treating chronic conditions.

The four objectives of this report are to:

- summarize the existing knowledge on adherence, which will then serve as the basis for further policy development;
- increase awareness among policy-makers and health managers about the problem of poor rates of adherence that exists worldwide, and its health and economic consequences;
- promote discussion of issues related to adherence; and
- provide the basis for policy guidance on adherence for use by individual countries.

This report fulfils two of the main WHO core functions:

- articulating consistent, ethical and evidence-based policy and advocacy positions; and
- managing information by assessing trends and comparing performance, setting the agenda for, and stimulating, research and involvement.

How to read this report

As this report intends to reach a wide group of professionals, with varied disciplines and roles, the inclusion of various topics at different levels of complexity was unavoidable. Also, during the compilation of the report, contributions were received from eminent scientists in different fields, who used their own technical languages, classifications and *definitions* when discussing adherence.

For the sake of simplicity, a table been included for each disease reviewed in section 3, showing the factors and interventions cited in the text, classified according to the five dimensions proposed by the project group and explained later in this report:

- social- and economic-related factors/interventions;
- health system/health care team-related factors/interventions;
- therapy-related factors/interventions;
- condition-related factors/interventions; and
- patient-related factors/interventions.

The section entitled “Take-home messages” summarizes the main findings of this report and indicates how readers could make use of them.

Section I:

Setting the scene, discusses the main concepts leading to the definition of adherence and its relevance to epidemiology and economics.

Section II:

Improving adherence rates: guidance for countries, summarizes the lessons learned from the reviews studied for this report and puts into context the real impact of adherence on health and economics for those who can make a change.

Section III:

Disease-specific reviews, discusses nine chronic conditions that were reviewed in depth. Readers with clinical practice or disease-oriented programmes will find it useful to read the review related to their current work. Policy-makers and health managers may prefer to move on to the Annexes.

Annex 1:

Behavioural mechanisms explaining adherence, provides an interesting summary of the existing models for explaining people's behaviour (adherence or non-adherence), and explores the behavioural interventions that have been tested for improving adherence rates.

Annex 2:

Statements by stakeholders, looks at the role of the stakeholder in improving adherence as evaluated by the stakeholders themselves.

Annexes 3 and 4:

Table of reported factors by condition and dimension and Table of reported interventions by condition and dimension, provide a summary of all the factors and interventions discussed in this report. These tables may be used to look for commonalities among different conditions.

Take-home messages

Poor adherence to treatment of chronic diseases is a worldwide problem of striking magnitude

Adherence to long-term therapy for chronic illnesses in developed countries averages 50%. In developing countries, the rates are even lower. It is undeniable that many patients experience difficulty in following treatment recommendations.

The impact of poor adherence grows as the burden of chronic disease grows worldwide

Noncommunicable diseases and mental disorders, human immunodeficiency virus/acquired immunodeficiency syndrome and tuberculosis, together represented 54% of the burden of all diseases worldwide in 2001 and will exceed 65% worldwide in 2020. The poor are disproportionately affected.

The consequences of poor adherence to long-term therapies are poor health outcomes and increased health care costs

Poor adherence to long-term therapies severely compromises the effectiveness of treatment making this a critical issue in population health both from the perspective of quality of life and of health economics. Interventions aimed at improving adherence would provide a significant positive return on investment through primary prevention (of risk factors) and secondary prevention of adverse health outcomes.

Improving adherence also enhances patients' safety

Because most of the care needed for chronic conditions is based on patient self-management (usually requiring complex multi-therapies), use of medical technology for monitoring, and changes in the patient's lifestyle, patients face several potentially life-threatening risks if not appropriately supported by the health system.

Adherence is an important modifier of health system effectiveness

Health outcomes cannot be accurately assessed if they are measured predominantly by resource utilization indicators and efficacy of interventions. The population health outcomes predicted by treatment efficacy data cannot be achieved unless adherence rates are used to inform planning and project evaluation.

"Increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments"¹

Studies consistently find significant cost-savings and increases in the effectiveness of health interventions that are attributable to low-cost interventions for improving adherence. Without a system that addresses the determinants of adherence, advances in biomedical technology will fail to realize their potential to reduce the burden of chronic illness. Access to medications is necessary but insufficient in itself for the successful treatment of disease.

Health systems must evolve to meet new challenges

In developed countries, the epidemiological shift in disease burden from acute to chronic diseases over the past 50 years has rendered acute care models of health service delivery inadequate to address the health needs of the population. In developing countries, this shift is occurring at a much faster rate.

¹ Haynes RB. Interventions for helping patients to follow prescriptions for medications. Cochrane Database of Systematic Reviews, 2001, Issue 1, 2001.

Patients need to be supported, not blamed

Despite evidence to the contrary, there continues to be a tendency to focus on patient-related factors as the causes of problems with adherence, to the relative neglect of provider and health system-related determinants. These latter factors, which make up the health care environment in which patients receive care, have a major effect on adherence.

Adherence is simultaneously influenced by several factors

The ability of patients to follow treatment plans in an optimal manner is frequently compromised by more than one barrier, usually related to different aspects of the problem. These include: the social and economic factors, the health care team/system, the characteristics of the disease, disease therapies and patient-related factors. Solving the problems related to each of these factors is necessary if patients' adherence to therapies is to be improved.

Patient-tailored interventions are required

There is no single intervention strategy, or package of strategies that has been shown to be effective across all patients, conditions and settings. Consequently, interventions that target adherence must be tailored to the particular illness-related demands experienced by the patient. To accomplish this, health systems and providers need to develop means of accurately assessing not only adherence, but also those factors that influence it.

Adherence is a dynamic process that needs to be followed up

Improving adherence requires a continuous and dynamic process. Recent research in the behavioural sciences has revealed that the patient population can be segmented according to level-of-readiness to follow health recommendations. The lack of a match between patient readiness and the practitioner's attempts at intervention means that treatments are frequently prescribed to patients who are not ready to follow them. Health care providers should be able to assess their patient's readiness to adhere, provide advice on how to do it, and follow up the patient's progress at every contact.

Health professionals need to be trained in adherence

Health providers can have a significant impact by assessing risk of nonadherence and delivering interventions to optimize adherence. To make this practice a reality, practitioners must have access to specific training in adherence management, and the systems in which they work must design and support delivery systems that respect this objective. For empowering health professionals an "adherence counselling toolkit" adaptable to different socioeconomic settings is urgently needed. Such training needs to simultaneously address three topics: knowledge (information on adherence), thinking (the clinical decision-making process) and action (behavioural tools for health professionals).

Family, community and patients' organizations: a key factor for success in improving adherence

For the effective provision of care for chronic conditions, it is necessary that the patient, the family and the community who support him or her all play an active role. Social support, i.e. informal or formal support received by patients from other members of their community, has been consistently reported as an important factor affecting health outcomes and behaviours. There is substantial evidence that peer support among patients can improve adherence to therapy while reducing the amount of time devoted by the health professionals to the care of chronic conditions.

A multidisciplinary approach towards adherence is needed

A stronger commitment to a multidisciplinary approach is needed to make progress in this area. This will require coordinated action from health professionals, researchers, health planners and policy-makers.

