1. What is adherence?

Although most research has focused on adherence to medication, adherence also encompasses numerous health-related behaviours that extend beyond taking prescribed pharmaceuticals. The participants at the WHO Adherence meeting in June 2001 (1) concluded that defining adherence as “the extent to which the patient follows medical instructions” was a helpful starting point. However, the term “medical” was felt to be insufficient in describing the range of interventions used to treat chronic diseases. Furthermore, the term “instructions” implies that the patient is a passive, acquiescent recipient of expert advice as opposed to an active collaborator in the treatment process.

In particular, it was recognized during the meeting that adherence to any regimen reflects behaviour of one type or another. Seeking medical attention, filling prescriptions, taking medication appropriately, obtaining immunizations, attending follow-up appointments, and executing behavioural modifications that address personal hygiene, self-management of asthma or diabetes, smoking, contraception, risky sexual behaviours, unhealthy diet and insufficient levels of physical activity are all examples of therapeutic behaviours.

The participants at the meeting also noted that the relationship between the patient and the health care provider (be it physician, nurse or other health practitioner) must be a partnership that draws on the abilities of each. The literature has identified the quality of the treatment relationship as being an important determinant of adherence. Effective treatment relationships are characterized by an atmosphere in which alternative therapeutic means are explored, the regimen is negotiated, adherence is discussed, and follow-up is planned.

The adherence project has adopted the following definition of adherence to long-term therapy, a merged version of the definitions of Haynes (2) and Rand (3):

the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.
Strong emphasis was placed on the need to differentiate adherence from compliance. The main difference is that adherence requires the patient’s agreement to the recommendations. We believe that patients should be active partners with health professionals in their own care and that good communication between patient and health professional is a must for an effective clinical practice.

In most of the studies reviewed here, it was not clear whether or not the “patient’s previous agreement to recommendations” was taken into consideration. Therefore, the terms used by the original authors for describing compliance or adherence behaviours have been reported here.

A clear distinction between the concepts of acute as opposed to chronic, and communicable (infectious) as opposed to noncommunicable, diseases must also be established in order to understand the type of care needed. Chronic conditions, such as human immunodeficiency virus (HIV), acquired immunodeficiency syndrome (AIDS) and tuberculosis, may be infectious in origin and will need the same kind of care as many other chronic noncommunicable diseases such as hypertension, diabetes and depression.

The adherence project has adopted the following definition of chronic diseases:

“Diseases which have one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation or care” (4).

2. The state-of-the-art measurement

Accurate assessment of adherence behaviour is necessary for effective and efficient treatment planning, and for ensuring that changes in health outcomes can be attributed to the recommended regimen. In addition, decisions to change recommendations, medications, and/or communication style in order to promote patient participation depend on valid and reliable measurement of the adherence construct. Indisputably, there is no “gold standard” for measuring adherence behaviour (5,6) and the use of a variety of strategies has been reported in the literature.

One measurement approach is to ask providers and patients for their subjective ratings of adherence behaviour. However, when providers rate the degree to which patients follow their recommendations they overestimate adherence (7,8). The analysis of patients’ subjective reports has been problematic as well. Patients who reveal they have not followed treatment advice tend to describe their behaviour accurately (9), whereas patients who deny their failure to follow recommendations report their behaviour inaccurately (10). Other subjective means for measuring adherence include standardized, patient-administered questionnaires (11). Typical strategies have assessed global patient characteristics or “personality” traits, but these have proven to be poor predictors of adherence behaviour (6). There are no stable (i.e. trait) factors that reliably predict adherence. However, questionnaires that assess specific behaviours that relate to specific medical recommendations (e.g. food frequency questionnaires (12) for measuring eating behaviour and improving the management of obesity) may be better predictors of adherence behaviour (13).

Although objective strategies may initially appear to be an improvement over subjective approaches, each has drawbacks in the assessment of adherence behaviours. Remaining dosage units (e.g. tablets) can be counted at clinic visits; however, counting inaccuracies are common and typically result in overestimation of adherence behaviour (14), and important information (e.g. timing of dosage and patterns of missed dosages) is not captured using this strategy. A recent innovation is the electronic monitoring device (medication event monitoring system (MEMS)) which records the time and date when a medication container was opened, thus better describing the way patients take their medications (9).
Unfortunately, the expense of these devices precludes their widespread use. Pharmacy databases can be used to check when prescriptions are initially filled, refilled over time, and prematurely discontinued. One problem with this approach is that obtaining the medicine does not ensure its use. Also, such information can be incomplete because patients may use more than one pharmacy or data may not be routinely captured.

Independently of the measurement technique used, thresholds defining “good” and “bad” adherence are widely used despite the lack of evidence to support them. In practice, “good” and “bad” adherence might not really exist because the dose–response phenomenon is a continuum function.

Although dose–response curves are difficult to construct for real-life situations, where dosage, timing and others variables might be different from those tested in clinical trials, they are needed if sound policy decisions are to be made when defining operational adherence thresholds for different therapies.

Biochemical measurement is a third approach for assessing adherence behaviours. Non-toxic biological markers can be added to medications and their presence in blood or urine can provide evidence that a patient recently received a dose of the medication under examination. This assessment strategy is not without drawbacks as findings can be misleading and are influenced by a variety of individual factors including diet, absorption and rate of excretion (15).

In summary, measurement of adherence provides useful information that outcome-monitoring alone cannot provide, but it remains only an estimate of a patient’s actual behaviour. Several of the measurement strategies are costly (e.g. MEMS) or depend on information technology (e.g. pharmacy databases) that is unavailable in many countries. Choosing the “best” measurement strategy to obtain an approximation of adherence behaviour must take all these considerations into account. Most importantly, the strategies employed must meet basic psychometric standards of acceptable reliability and validity (16). The goals of the provider or researcher, the accuracy requirements associated with the regimen, the available resources, the response burden on the patient and how the results will be used should also be taken into account. Finally, no single measurement strategy has been deemed optimal. A multi-method approach that combines feasible self-reporting and reasonable objective measures is the current state-of-the-art in measurement of adherence behaviour.

3. References