

REDUCING STIGMA AND DISCRIMINATION AGAINST OLDER PEOPLE WITH MENTAL DISORDERS

A Technical Consensus Statement

This document is a technical consensus statement jointly produced by the Old Age Psychiatry section of the World Psychiatric Association and the World Health Organization, with the collaboration of several NGOs and the participation of experts from different Regions.

It is intended to be a tool for (i) promoting debate at all levels on the stigmatisation of older people with mental disorders; (ii) outlining the nature, causes and consequences of this stigmatisation; and (iii) promoting and suggesting policies, programmes and actions to combat this stigmatisation.

KEY WORDS: old age psychiatry / psychogeriatrics / elderly people / stigma / discrimination / mental health / mental health care.

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STIGMA, DISCRIMINATION AND MENTAL DISORDERS IN OLD PEOPLE

Both WHO and WPA have recognized that the stigma and discrimination attached to mental disorders are strongly associated with suffering, disability and economic losses. Recent social, economic and demographic changes have brought a series of challenges to the elderly, which jeopardize their role in society. Older people with mental disorders therefore carry a double burden which merits special attention. The technical consensus statement here presented (i) highlights the nature, causes and consequences of this stigmatization, and (ii) promotes and suggests policies, programmes and action to combat it.

As was the case with previous technical consensus statements on psychiatry of the elderly, this one was produced in a collaborative, multidisciplinary way, involving the following organizations relevant to this topic in addition to the World Psychiatric Association and the World Health Organization: Alzheimer's Disease International, International Association of Gerontology, International Council of Nurses, International Federation of Social Workers, International Psychogeriatric Association, International Union of Psychological Science, World Association for Psychosocial Rehabilitation, World Federation for Mental Health and the World Federation of Occupational Therapists.

We are profoundly indebted to all these organizations and their representatives (see List of Participants in Annex I) who generously contributed their ideas and time to produce this technical statement. Our gratitude is also extended to the Rapporteurs, Professor James Lindesay and Professor Cornelius Katona, who put together all the ideas presented at the meeting and the comments suggested during the extensive consultation process, and to the Chair, Dr Nori Graham who, in skilfully and gracefully conducted the sessions of the meeting. Last, but not least, our appreciation goes to the Service Universitaire de Psychogériatrie of the University of Lausanne, and to Dr Carlos A. de Mendonça Lima, Director of the WHO Collaborating Centre for

Research and Training in Old Age Psychiatry at that University, for having initiated and organized the meeting.

We are confident that readers of this statement will find it useful in combatting the stigma and discrimination attached to older people with mental disorders and thereby improving their quality of life.

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BACKGROUND

This Technical Consensus Statement is dedicated to the esteemed memory of Jean Wertheimer. In the tradition he established as Chairman of the World Psychiatric Association Section of Old Age Psychiatry, the members of his department – Drs. de Mendonça Lima, Gaillard and Camus, undertook to organize a Consensus Meeting to produce this, the Section's Fourth Technical Consensus Statement. The Consensus Group, representing many organizations, is to be congratulated for producing such a succinct, relevant and practical document.

The destigmatization of people with mental disorders is central to the current agenda of action within the WPA. Its Section of Old Age Psychiatry is proud to be involved in the production of this document.

It is hoped that, through its dissemination within the professions, governments, NGOs, the WHO affiliated bodies and member societies of WPA, this Technical Consensus Statement will contribute substantially to the process of destigmatization.

We encourage all those who read this Technical Consensus Statement to engage actively in reducing stigma and discrimination against older people with mental disorders in order to enable them to enjoy a better quality of life.

Edmond Chiu, A.M.
Chairman
WPA Section of Old Age Psychiatry

FOREWORD

This fourth consensus statement is a contribution to the World Health Day and Report 2001. WHO has chosen Mental Health as theme for the WHD 2001, for the second time since 1950. The slogan for this day - Stop exclusion, Dare to care - summarises the main message that WHO wanted to spread all around the world: *there is no justification for excluding people with a mental illness or brain disorder from our communities*

Dr Gro Harlem Brundtland, Director-General of WHO, wrote in the World Health Report: "*Many of us still shy away from, or feign ignorance of such individuals as if we do not dare to understand and care*".

As she reminded us, 2001 was also the tenth anniversary of the adoption in 1991 by the United Nations General Assembly of the Rights of the mentally ill to protection and care. Some of the principles stated by this resolution are:

- *there shall be no discrimination on the grounds of mental illness as far as possible;*
- *every patient shall have the right to be treated and cared for in his or her own community;*
- *every patient shall have the right to be treated in the least restrictive environment, with the least restrictive or intrusive treatment.*

What about the respect of these principles for old persons with mental disorders? When we consider that a policy for mental health is absent in 40% of member countries of the United Nations and that care for old persons is not considered as a priority in the majority of countries in the world, we can say that there is as yet no positive answer to this question.

Mental disorders in old age are common, they are a source of massive burden and represent important costs for societies. This will increase dramatically with the ageing of populations. In this context, stigma remains a major obstacle to ensuring access to good care for older people with mental disorders.

The United States Surgeon General's Report on Mental Health published in 1999 described the impact of stigma as follows: *"Stigma erodes confidence that mental disorders are valid, treatable health conditions. It leads people to avoid socialising, employing or working with, or renting to or living near persons who have a mental disorder. Stigma deters the public from waiting to pay for care and, thus, reduces consumers' access to resources and opportunities for treatment and social services. A consequent inability or failure to obtain treatment reinforces destructive patterns of low self-esteem, isolation, and hopelessness. Stigma tragically deprives people of their dignity and interferes with their full participation in society."*

All these statements are valid for old age psychiatry. That is why the efforts of WHO and WPA to realise consensus meetings and statements in this discipline are so important. They provide a basis for further developments and constitute important reference materials for governments, policy makers, consumers' associations, families and patients. I hope that this Technical Consensus Statement can contribute to reducing the suffering of old persons with mental disorders throughout the world.

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REDUCING STIGMA AND DISCRIMINATION AGAINST OLDER PEOPLE WITH MENTAL DISORDERS A Technical Consensus Statement

The World Health Organization and The World Psychiatric Association have produced three Technical Consensus Statements on the scope of old age psychiatry¹⁻³. These describe:

- the specialty of old age psychiatry;
- the organization of services in old age psychiatry;
- education in old age psychiatry.

The aim of this fourth Technical Consensus Statement is to provide a practical tool to assist in the reduction of the stigmatisation of older people with mental disorders. Its objectives are to:

- promote debate at all levels on the stigmatisation of older people with mental disorders;
- outline the nature, causes and consequences of this stigmatisation;
- promote and suggest policies, programmes and actions to combat this stigmatisation.

The audiences for this document are governments, professionals, non-governmental organizations (NGOs), the media, families, individual sufferers, the general public - anyone who is in a position to help reduce stigma and discrimination against older people with mental disorders.

1. DEFINITIONS

1.1 Stigma results from a process whereby certain individuals and groups are unjustifiably rendered shameful, excluded and discriminated against.

1.2 Discrimination means any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights. Special measures solely to protect the rights, or secure the advancement, of persons with mental illness shall not be deemed to be discriminatory. Discrimination does not include any distinction, exclusion or preference necessary to protect the human rights of a person with a mental illness, or of other individuals⁴.

1.3 Mental disorder refers to those health problems currently classified by the WHO ICD-10 classification in its chapter on 'mental and behavioural disorders'⁵.

1.4 Older people are defined here as those aged 65 years and over, as in the previous Technical Consensus Statements. However, it should be noted that the age at which an individual is perceived as 'old' varies across cultures.

2. GENERAL PRINCIPLES

All persons with a mental disorder (or who are being treated as such persons) shall be treated humanely and with respect for the inherent dignity of the human person⁴. It therefore follows that the stigmatisation of people with mental disorders (sometimes referred to as psychiatric stigma) must be countered wherever it occurs. However, stigmatising is a common human characteristic, it is pervasive and subtle in its effects, and it is difficult to counteract without clear and conscious strategies.

To date, most focus of thought and action on this topic has been on stigma in younger adults with mental disorders⁶⁻⁸. The aim of this document is to apply the concept to older people. Since stigma against old age – independent from that against mental disorder – also occurs in many (although not all) societies, there is therefore a 'double jeopardy' for older people with mental disorders, and both issues need to be addressed in anti-stigma strategies for this age group.

- This stigma is unacceptable and everyone has the right to be protected from it.
- Counteracting stigma and discrimination is a duty of governments, NGOs, services, patients' organisations, families, and the general public. To be effective, they will need to work in partnership.
- Actions against stigma and discrimination of older people with mental disorders:
 - should be a priority of all, to achieve the state of physical, psychological and social well-being as defined by the Constitution of the WHO;⁹
 - should form part of the promotion of good mental health by professional training and public education, and should be a major component of all levels of a health and social care programme.

3. THE CAUSES AND CONSEQUENCES OF STIGMA AGAINST OLDER PEOPLE WITH MENTAL DISORDERS

3.1 Causes

Stigma has both cognitive and behavioural components, both of which need to be addressed by any actions designed to counter it. *It arises out of normal human cognitive processes* that evaluate threat and risk, organise social knowledge, and determine self-perception. In the case of older people with mental disorders, these result in:

- **Ignorance / misconceptions** of the facts regarding the nature of old age, and of mental disorders and their treatment;
- **Fear** of injury, contamination, the unknown, the burden of care, of one's own ageing;
- **Drive for social conformity and security** and the subsequent suppression of deviance;
- **Internalisation** of stigmatising ideas (self-stigma) by those affected (sufferers, families, professionals).

Stigma against older people with mental disorder is *reinforced* by:

- Cultural factors, such as differences in specific beliefs regarding the value of older members of society, of the causation of mental illness, and what it implies about the patient's family;
- Social and economic instability and crisis: war, migration, the influx of refugees, etc., encourage the stigmatisation of people with mental illness at all ages;
- The actual or perceived absence or inadequacy of preventive strategies and treatments for mental disorders;
- The lack of information systems to educate both professionals and the general public;
- Gender discrimination, which may be greater in older populations, where women outnumber men (i.e., there is a 'triple jeopardy' for elderly women with mental illness, so far as stigma is concerned);
- Any rewards for those who stigmatise: financial, denial of problems, enhanced social status, enhanced self-esteem.

3.2. Consequences

Stigma in older people with mental disorders leads to the *development of negative attitudes*, such as:

- Prejudice: for example, the 'common sense' attitudes that people with mental disorders are dangerous, weak, irresponsible, tainted, etc.
- Ageism: popular prejudices about older people include ideas that they are weak, ill, peculiar, inflexible, unproductive, etc.
- Mistaken beliefs about individuals' responsibility for their mental disorder and its consequences.
- The creation of misleading popular stereotypes of both older people and the mentally ill, often supported and reinforced by the public media.
- Damaging self-beliefs held by those who are (or who might be) stigmatised, e.g. shame, low self-esteem, unwillingness to discuss problems or access services.
- The creation of 'taboo' subjects, and lack of public discussion.

- Negative professional attitudes towards older people with mental disorders.
- Negative attitudes towards professionals and services that care for older people with mental disorders.
- Alarmist professional and popular opinions about need, burden, cost of care.

These negative attitudes lead in turn to *discrimination* against older people with mental disorders:

Against:

- Individuals,
- their families,
- those who care for them (families, professionals, agencies, etc.).

In:

- the home,
- the workplace,
- the community,
- health and social care (communities, institutions),
- research,
- legal practice,
- financial services,
- public policy,
- the media.

In terms of:

- poor quality treatment and care (access, provision, outcome, relapse),
- marginalisation within care systems,
- 'warehousing' outside the health care system,
- low status of professionals, services providing care,
- staff recruitment, retention problems,
- inadequate funding at national and local levels,

- inequity in reimbursement for treatment,
- negative impact on families (e.g. blame, marriageability, loss of friends),
- victimization, abuse, neglect,
- unnecessary institutionalisation,
- avoidance: social distancing and exclusion of the sufferers and lack of familiarity with their experiences,
- poor quality of life,
- exclusion from research, and consequent lack of evidence to inform policy and practice,
- adverse economic effects (personal and social),
- discriminatory legislation,
- unemployment, in societies where older people typically remain in the workforce,
- material and financial inequity (e.g. access to basic resources, insurance, mortgages),
- Government neglect, and lack of legislative protections,
- Derogatory language (e.g. the English expressions ‘wrinklies’, ‘crumble’, ‘gerries’).

There are some important adverse interactions between the stigmatising attitudes towards mental disorder and towards old age. Examples include:

- The ageist notion that older people are inflexible and unable to change reinforces popular and professional beliefs that mental disorders in this age group are incurable.
- The damaging effect that a psychiatric history can have on the access to physical health care in old age.
- The adverse effects of mental disorder on professional and family attitudes towards older people’s autonomy, and their capacity to make life decisions.
- The tendency to ignore or dismiss any complaints (of e.g. abuse, neglect) made by older people with mental disorders.

- The reluctance of many professionals and services to 'own' older people with long-standing mental disorders.
- The fact that psychiatry and psychiatric services are seen as stigmatising by the older population, and so are less used by them.
- The fact that diagnostic criteria are often ageist.

4. STIGMATISATION OF PARTICULAR MENTAL DISORDERS IN OLD AGE

This section sets out some of the ways in which specific mental disorders in old age are stigmatised.

4.1 Depression

- Depression is seen as a natural consequence of ageing, loss and physical illness (by patients, their families and professionals), and is therefore not diagnosed or treated. Some symptoms of depression (e.g. anhedonia, social withdrawal) are particularly likely to be misinterpreted in this way.
- Certain treatments (e.g. ECT, drugs) that are perceived as more stigmatising than others (e.g. psychotherapy) are more likely to be offered to older people.
- Depressive cognitions (e.g. guilt, pessimism, hopelessness) and behaviours (e.g. suicidal acts) have a stigmatising impact on the sufferers and their families.
- Depression and anxiety are seen as marks of personal weakness, by others and by patients themselves.

4.2 Dementia

- Dementia is often seen as a natural part of ageing, and is therefore not recognised or managed appropriately.
- However, it is still the case that specific symptoms of dementia are powerfully stigmatising (e.g. disturbed behaviour, poor self care, incontinence), both in the community and in care settings. In some cultures, these symptoms may be regarded as evidence of neglect or failure of care by family carers, who are blamed accordingly.

- Popular (and some professional) use of the term 'dementia' is still stigmatising.
- The sufferer's loss of memory often leads to loss of their past, and their perceived conversion from a person into an object. As a result, important cultural and religious beliefs and personal preferences may be ignored.
- Older people with dementia are often perceived as having no quality of life or capacity for pleasure.
- In both developed and developing societies, a dementia diagnosis may be used to exclude individuals from some forms of care, e.g. emergency resuscitation, in-patient units, nursing homes.

However, in some cultures, the fact that dementia has an organic aetiology may reduce stigma associated with it, i.e. public awareness of this means that those affected are not regarded as 'mentally ill'. This reflects ambiguity in how it is classified, and has implications for service organisation and reimbursement.

4.3 Delirium (acute confusional states)

- In older people, this problem is usually caused by physical illness or intoxication by prescribed drugs. The poor management of delirium in inpatients is a specific example of how mental disorders arising in physical care settings are often stigmatised, resulting in non-recognition, misdiagnosis, and inappropriate treatment. The common misperception that delirium is always a florid disorder means that less obvious episodes in older people are often missed.

4.4 Psychosis

The stigmatising effect of psychosis has been well described in younger adults. The diagnosis of schizophrenia is less used in old age psychiatry, but where it is, the same stigma attaches to it.

- Psychotic older people are perceived as less dangerous (and are therefore less stigmatised) than younger individuals.
- However, there is a prejudice that all old people are odd to some extent, and older psychotic individuals consequently receive less recognition, treatment, rehabilitation, and engagement in society as a result.

4.5 Anxiety

- There is prejudice that all old people are fearful, therefore there is less recognition and treatment of anxiety disorders.
- With regard to post-traumatic stress disorder, the late consequences of early trauma are often not recognised, and is another example of how older people are often perceived as having no history.

4.6 Substance (alcohol and drug) abuse

- This is often under-diagnosed, since it is assumed to be a problem of younger adults.
- There is inappropriate therapeutic nihilism in the older age group.
- There are inappropriate age cut-offs for therapeutic services.

4.7 Personality disorder

- This is often misdiagnosed, due to ageist assumptions that all older people are peculiar.
- Older people with personality disorders are often excluded from appropriate care and treatment.

4.8 Learning disability

- Health and social services for this group are ill equipped to provide for older people with learning disabilities.
- Older people with learning disabilities are often excluded from appropriate care and treatment if they develop a mental disorder.

5. ACTION AGAINST STIGMA AND DISCRIMINATION

5.1 A strategic approach

Changing stigma mainly involves education to change beliefs and attitudes, while changing discrimination has a primarily legal agenda. The main goals of a strategy to reduce stigma and discrimination in the context of mental disorders in old age are to:

- Ensure that appropriate health and social care systems are in place that can meet the needs of older people with mental disorder and their carers;

- Position mental health of older people on the public agenda – mental disorder is as important in old age as in earlier life (this includes encouraging positive notions of ageing);
- Promote a greater understanding and acceptance of older people with mental disorder;
- Create more supportive environments for older people with mental disorder;
- Encourage more research into effective, non-stigmatising treatment and care for older people with mental disorder.

Achieving these goals will involve:

- Examining our own attitudes and practices;
- Increasing awareness;
- Supporting empowerment;
- Stopping exclusion;
- Ensuring appropriate treatment and care;
- Credible advocacy;
- Effective public and professional education;
- Equitable allocation of health, welfare and research budgets ;
- Effective planning for projected changes in national demographics.

Although governments have primary responsibility in reducing both stigma and discrimination, other groups and individuals also have major roles to play. The duties, responsibilities and opportunities of a range of groupings are summarised below. It is neither exhaustive nor mutually exclusive, and is intended primarily as a check list of possibilities both for direct action and for lobbying. When considered in the context of specific local needs it should provide a basis for developing a local action plan. Such a plan will involve collaboration between several of the groupings, often led by NGOs and/or professionals, and should be *realistic/achievable, time limited, and where possible evaluated*.

It is also useful for the local action plan to contain appropriate 'key messages'. These might include any or all of the following:

- *'Most older people are fit and well',*

- *'Mental disorder in old age can be treated'*,
- *'Depression is a treatable illness, not a weakness'*,
- *'All people with dementia can have a reasonable quality of life'*,
- *'If you are low or forgetful, go and see your doctor'*,
- *'Stigma is destructive and obstructive'*,
- *'Stigma and discrimination hurt - face them'*,
- *'Next time, it could be you or yours'*.

5.2 Roles, responsibilities and opportunities

Policy-makers, including Government (national/ local)

- Health and social services for older people should be planned, funded and provided as part of general health and social care system and in accordance with the guidelines in previous WHO/WPA consensus statements. This will require:
 - adequately trained, compensated staff,
 - a safe working environment,
 - credible information systems both for needs assessment and to ensure service delivery,
 - the development of distinct services for older people with secondary needs, and
 - financial incentives for primary care workers to carry out regular assessments of older people.
- Specific policies and laws around stigma/ discrimination need to be developed at all levels of government;
- The issue of mental disorder in old age should be featured in political party agendas;
- Necessary resources should be allocated for the development and realisation of information campaigns within education and through the media. In particular, government should ensure that mental disorders in older people are included in school curricula;
- Politicians should ensure that professionals, family carers and patients have a 'voice' – and listen to it;

- National and local justice systems should provide explicit effective and accessible protection against stigma and discrimination;
- Services should be planned to ensure equity of provision to older people with mental disorders. These include:
 - adequate pensions,
 - an appropriate range of age-sensitive community facilities and activities, and
 - age sensitive public transport.
- Opportunities for medical and social science research into mental health issues should be promoted to increase understanding and encourage evidence-based practice.

NGOs (international/national/local) have a crucial role in

- Developing appropriate and relevant policies for their country/locality;
- Raising awareness (lobbying);
- Leading collaboration with other stakeholders and coordinating multi-agency working;
- Ensuring a 'voice' for older people with mental disorders and their carers;
- Selecting and supporting effective spokespersons;
- Developing and maintaining:
 - campaigns (including mass media campaigns),
 - advice lines,
 - websites,
 - information leaflets,
 - educational links with schools and universities;
- Maintaining close liaison with journalists;
- Media packs;
- Face to face contact;
- Seminars for journalists, involving journalists directly in NGO activities;

- Media watch (correcting misleading media material);
- Modelling acceptance and understanding through their own employment and supportive care policies.

Professionals (including paid care workers) should

- Ensure that their own practice is free from stigma and discrimination;
- Join with government, NGOs and patients and carers to plan and develop services, and ensure that they avoid stigma and discrimination;
- Ensure that all educational and continuing professional development curricula contain:
 - appropriate material on mental disorders in old age,
 - training to develop awareness of stigma and discrimination,
 - training to ensure that assessments and planned care provision take positive account of aspects of mental health and of ageing, and
 - continuous supervision (coaching).
- Ensure that due weight is given to issues of mental disorders in old age in the professional research agenda;
- Ensure that professional bodies have policies in place to identify and reduce stigma and discrimination;
- Ensure that local workplace policies are in place to identify and reduce stigma and discrimination;
- Provide information and advice to individual patients' carers and families regarding:
 - disorders,
 - treatments,
 - local community and specialist services, and
 - the work of relevant NGOs.
- Help patients, families and other professional carers to cope with the stigma and discrimination that they experience;
- Provide accurate information to journalists;

- Disseminate good evidence-based practice to ensure early identification and effective treatment of mental disorders in older people;
- Assure and regulate the competence of care providers.

Carers and families can be effective by

- Joining (or where necessary, forming) associations and support groups;
- Providing information regarding their issues and experiences to service providers, NGOs and government;
- Going public about their experiences with mental disorder and of caring and discrimination;
- Increasing contacts within their local communities;
- Participating in the planning of services that avoid stigma and discrimination;
- Seeking and using services that combat stigma and discrimination;
- Acting as advocates (e.g. calling attention to problems, changing systems) where stigma or discrimination occur;
- Challenging and reporting any professional practice that is stigmatising or discriminatory.

Older people with mental disorders should, where possible, be encouraged to

- Go public and share their experience of old age, of illness and of discrimination;
- Participate in information and education campaigns;
- Join (or where necessary form) associations and support groups;
- Express their needs to service providers, NGOs and government;
- Join in planning services that avoid stigma and discrimination;
- Challenging and reporting any professional practice that is stigmatising or discriminatory.

The general public can

- Exert constructive influence on policy and decision makers (e.g. initiating government debate, referenda);

- Press for adequate services for older people with mental disorders, including citizenship rights;

The Media should

- Ensure that policies are in place to avoid the dissemination of stigmatising and discriminatory material;
- Recognise their potential for creating or sustaining myths about mental disorders in old age – and take appropriate steps to avoid such myths;
- Recognise their responsibility for promoting truth about mental disorders in old age;
- Ensure that journalists are properly informed about mental disorders in old age;
- Take all possible opportunities to report
 - appropriate information/stories about mental disorders in old age,
 - malpractices, abuses, and good practices,
 - adverse effects of stigma and discrimination, and
 - positive stories and good practice.
- Raise the need for services;
- Provide public information about services, support groups, and associations.

The Corporate sector should

- Ensure that non-discriminatory policies are in place (e.g. health insurance, supporting carers in work, policies re mandatory retirement);
- Sponsor educational and media campaigns;
- Ensure that employers are sensitive to the mental health needs of their older workers and those taking care of older relatives;
- Ensure employees have access to and means to pay for appropriate services for themselves and their older relatives;
- Ensure that older people and those with mental disorders have fair access to the goods and services they provide.

Schools, Universities and Vocational training groups (e.g. police, fire service) should

- Ensure a range of opportunities for intergenerational contact (e.g. lifelong learning programmes);
- Include aspects of mental health and ageing in their curricula.

6. CONCLUSION

Stigma and discrimination against older people with mental disorders are widespread and their consequences are far-reaching. More research is clearly needed both to identify such stigma and discrimination where they do occur, and to define their effects. Equally important, research is needed to identify the most effective ways of intervening to bring about lasting reductions in stigma and discrimination.

Meanwhile, this consensus statement attempts to summarise some of the available evidence and to make practical suggestions for action. The development of effective, well-regarded health and social support services for older people with mental disorders should be the first priority of any strategy to reduce stigma and discrimination. Action against stigma and discrimination needs to be developed locally to ensure that it is sensitive to, and specific for, an area's needs and culture.

Local multi-agency workshops using this consensus statement as their starting point may be a useful way of developing appropriate national or local action plans.

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