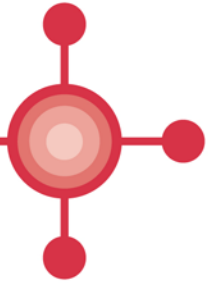


All Wales Medicines Strategy Group

Grŵp Strategaeth Meddyginiaethau Cymru Gyfan



AWMSG Patient and Public Engagement Strategy

February 2014

This report has been prepared by the All Wales Therapeutics and Toxicology Centre (AWTTC), and has subsequently been endorsed by the All Wales Medicines Strategy Group (AWMSG).

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1.0 BACKGROUND

1. The All Wales Medicines Strategy Group (AWMSG) was established in 2002 to provide advice on new and existing medicines, medicines management and prescribing to the Welsh Government's Minister for Health and Social Services in an effective, efficient, timely and transparent manner.

2. AWMSG brings together an expert panel of health professionals, scientists, health economists, industry representatives, patient advocates and lay representatives to reach a consensus on the use of new medicines and on policies that promote the best use of medicines, in order to achieve the best health outcomes for patients in Wales. All work together to aim for equity of access to the most clinically appropriate and cost-effective medicines for patients in Wales.

3. AWMSG is supported by the All Wales Therapeutics and Toxicology Centre (AWTTC). AWTTC provides medical, scientific and administrative support to AWMSG and its subgroups, and its roles include development and support of the health technology appraisal process, medicines safety and therapeutics, education, toxicology and prescribing analysis.

4. Since AWMSG began advising Welsh Government there have been occasions when it has not been possible to obtain patient/carer/patient organisation views. AWMSG membership and that of its two sub-groups include a lay member who represents the patient's perspective. However, the lay member does not always have information directly from patients/carers/patient organisations to aid this role. There may be many reasons for the lack of engagement; however, a key factor may be the lack of awareness of AWMSG and its work. Feedback suggests that patient organisations do not fully understand AWTTC/AWMSG processes and they do not always have individuals in the organisation who feel able to engage.

5. Patients, carers, patient organisations and the public are key stakeholders in AWMSG's work, and AWMSG is committed to ensuring that their voice is heard and shapes decision making and policies across the board, from the appraisal of new medicines to medicines management issues. There is a need and expectation of public bodies to listen to the views and experiences of patients and the public, who have a right to have a voice. AWMSG's Patient and Public Engagement (PPE) Strategy aims to fulfil this need and to ensure that patient/public expertise and time is used in an effective manner. AWMSG's Five-Year Strategy 2013–2018¹ states that AWMSG will ensure patients and service users are involved in its work and decisions as equal partners. The PPE Strategy aims to support the delivery of AWMSG's objectives.

6. The National Principles of Public Engagement in Wales², which have been endorsed by Welsh Government, set out clear principles for best practice which have formed the basis for the development of this strategy. This strategy has been developed in line with the AWMSG Five-Year Strategy 2013–2018¹ and the Welsh Government's publication "Together for Health"³. Through delivery of this strategy, members of the public, patients, carers and patient organisations will have a greater understanding of AWMSG, and increased involvement in its work.

2.0 STRATEGIC PRIORITIES

Four strategic priorities have been identified to improve patient and public engagement with AWMSG throughout its work:

1. To raise public awareness of the work of AWTTTC and AWMSG in promoting effective use of medicines across NHS Wales
2. To develop a better understanding of the issues affecting patients/carers and members of the public, and to provide clear information in an appropriate way
3. To facilitate input and enable everyone to have a voice in optimising medicine use
4. To establish and strengthen effective relationships to maximise engagement

1. To raise awareness of the work of AWTTTC and AWMSG in promoting effective use of medicines across NHS Wales

Many patients, carers, patient organisations and members of the public are unaware of AWMSG and the role AWTTTC plays in supporting its work. AWTTTC aims to raise the profile of AWMSG and increase public awareness. Maximising the number of people who know about AWTTTC and AWMSG is essential in ensuring that patients and carers are aware that they can have a voice in both the appraisal of new medicines and in medicines management issues. Such input could ultimately have a significant impact on patients and carers living in Wales. It is hoped that increased awareness of the opportunity itself will result in increased patient/carer input for the appraisal of new medicines, allow patient/carer views to inform medicines management issues and allow patient/carer views to shape AWMSG policies and decisions.

2. To develop a better understanding of the issues affecting patients/carers and members of the public, and to provide clear information in an appropriate way

Communicating effectively is an important part of reaching out to patients/carers and the public. AWTTTC and AWMSG aim to develop a better understanding of this target audience. By gaining insight, AWTTTC plans to develop messages accordingly, which can then be communicated through appropriate channels and mediums for that target audience. The engagement process needs to be clear and the information provided should be jargon-free and easily accessible.

In addition, AWTTTC aims to improve the AWMSG tools and templates for engagement to help ensure that the issues affecting patients, carers and the public are captured adequately and effectively in order for AWMSG to develop a better understanding of those issues. This will inform the appraisal of new medicines and medicines management issues and allow patient/carer views to shape decision making and policy development.

3. To facilitate input and enable everyone to have a voice in optimising medicine use

It is important to ensure that the process for submitting the patient/carer view is clear, user friendly, efficient and effective. The information, tools and templates provided by AWTTTC/AWMSG are integral to ensuring that this is achieved. In addition, internal processes need to ensure that the maximum opportunity is extended to patient/carers/patient organisations in a timely manner. Whilst all individual patients, individual carers and patient organisations may actively refer to the AWMSG work programme and provide input accordingly, AWTTTC needs to ensure that the most relevant patient organisations are contacted and that enough time is devoted to aiding and encouraging input.

AWTTTC aims to facilitate the development of a group to support patients/carers/patient organisations in engaging with AWTTTC/AWMSG, in line with other national advisory

bodies. This group would act as a forum for patient/carer/patient organisation concerns and issues, with members effectively having a support network. AWTTTC would provide input to the group to ensure clarity and provide guidance where needed. In addition, AWMSG will set up a Citizens' Jury to advise on specific issues in relation to access to medicines, such as social value judgements.

It is important to identify barriers, such as disability or cultural needs, which may prevent or discourage public engagement with AWTTTC/AWMSG. AWTTTC will endeavour to overcome such barriers wherever possible, making provisions to allow patients/carers/patient organisations to engage should they wish to do so. Vulnerable people and minority groups may require specific engagement opportunities and approaches.

4. To establish and strengthen effective relationships to maximise engagement

AWTTTC aims to establish and strengthen relationships with patient organisations as a priority, to improve engagement in the appraisal of new medicines, medicines management and AWMSG policies and decisions. As there are a vast number of patient organisations in existence for a wide range of conditions/diseases, an early task will be to identify key patient organisations with whom there will be the most mutual advantage in engagement and develop relationships with them. AWTTTC needs to ensure that senior members of patient organisations recognise the importance of their role in the work of AWTTTC/AWMSG in order for them to allocate the role of engagement to named member(s) of the organisation. The importance of the patient/carer voice in the work of AWTTTC/AWMSG also needs to reach individual patients and carers, including vulnerable people and those from minority groups.

AWTTTC will work with partner organisations to avoid duplication of work and ensure that patient/public expertise and time is used in an effective and efficient manner. This should further strengthen relationships with patient organisations and encourage ongoing engagement.

AWTTTC recognises the importance and need for timely and effective feedback. AWTTTC aims to provide feedback to all participants that have contributed to AWMSG's work, ensuring that the approach and methods used are appropriate for the individuals and/or groups involved. Ensuring transparency is a key aim for AWMSG and the organisation strives to conduct its work in an open manner. Participants have a right to know how their views were used, the impact they had, and the final outcomes or decisions that were made. AWTTTC aims to ensure that the channels of communication remain open throughout the process and that participants are fully informed and feel valued, which will hopefully encourage future engagement with AWTTTC/AWMSG.

It is important to increase patient/carer/patient organisation engagement with AWMSG in line with other national advisory bodies. Patients, carers, patient organisations and the public are key stakeholders in AWMSG's work and it is important that their voice is heard and shapes decision making and policies across the board, from the appraisal of new medicines to medicines management issues. The evaluation of engagement is vital to measure its success and needs to consider not only the number of people/groups engaging, but the effectiveness of that engagement. AWTTTC will monitor the process of engagement and the experiences of participants to ensure that lessons are learnt and are utilised to improve processes moving forward.

REFERENCES

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3. Welsh Government. Together for Health - A Five Year Vision for the NHS in Wales. Feb 2012. Available at: <http://wales.gov.uk/topics/health/publications/health/reports/together/?lang=en>. Accessed Jun 2013.