



BASHH Framework for Guideline Development and Assessment

Appendix: Public and Patient Involvement

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1. Introduction

The involvement of patients and the public is integral to the development of BASHH clinical guidelines. This involvement includes, but is not limited to, patient members on writing committees, information obtained from patient interviews or surveys during the writing and/or piloting guidelines, reviewing published work on patient experiences and seeking the advice and involvement of patient associations and advocates.

The particular needs of specific and possibly vulnerable patient groups such as gay people, young people, drug users, those from black and minority ethnic groups, commercial sex workers and those with learning/physical disabilities are considered and, when appropriate, an equality impact assessment tool is used:

http://www.nice.org.uk/media/4DC/76/Item62_NEquIATTopicSelectionSMTAppB221107.pdf.

We aim to include two patient representatives in each of our guideline writing groups.

2. Definition of Lay people

For the purposes of this guidance, we define lay people as:

- Patients, service users, members of the public and of specific client groups targeted by BASHH CEG guidelines, and patient/public advocates.
- People from patient, carer, voluntary and non-governmental organisations that are run by, or directly reflect the perspectives of patients, service users, carers, or client groups targeted by BASHH CEG guidelines.

Guidelines for the management of particular sexually transmitted infections should, where possible, be written with the involvement of a patient with first-hand experience of that condition. When this is not possible, input and advice from other lay sources should be sought.

3. Generic Role Description

The role of the patient member of a guideline writing committee is:

- To help to identify and refine clinical questions for the guideline so that they cover issues important to patients.
- To help to identify knowledge gaps about the views and experience of patients.



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- To assess whether the group's draft recommendations highlight areas where patient preferences and choice may need to be acknowledged.
- To address the needs for particular patient groups.
- To address patient and carer needs for information, education and support in relation to areas covered in the guideline.
- To ensure the use of wording which is respectful to patients and carers
- To lead the development of the patient information leaflet produced alongside the clinical guideline (if applicable).

When the continued involvement of patients with a particular guideline is simply not possible, then the following can be considered:

- Focused patient questionnaires on the guideline's main issues.
- Patient focus groups where the main patient issues relating to the guideline can be voiced. This may be particularly useful for gaining the thoughts and opinions of young people who would be difficult to retain in guideline writing groups.
- Patient involvement with the development of PICO questions which are then used during the development of the guideline.
- Using different patients at different times during the guideline-writing process. Ideally, however, the same patients would be involved throughout.

4. Documentation required for each guideline

For each guideline writing group, a role description, responsibilities and duties and person specification for a patient member need to be agreed. These documents are then used to recruit a patient to the guideline group.

Documents required for each guideline group:

N.B. Example documents (for the PID guideline group) are available and can be modified as necessary.

1. Role/Job description

- Information about BASHH and the CEG.
- The membership of the guideline writing group.
- The responsibilities of the role.
- The time commitment required. This should include a timetable of involvement. The times, dates and locations of face-to-face meetings should be specified. For a simple guideline (e.g. pediculosis, balanitis, scabies, SARA, candida, donovanosis, epididymo-orchitis), 1 day (i.e. 2 half-days) may be sufficient. For a complex guideline (e.g. sexual health of HIV-infected persons, young people, PID, gonorrhoea), 2 days (i.e. 4 half-days) may be required. Milestones for a typical guideline:
 - 6 months to draft
 - 1 month for CEG review
 - 2 months for consultation
 - 2 months for writing group to respond to consultation and piloting by CEG members in their clinics
 - 1 month for final guideline and PIL to be produced, ratified and submitted for publication.



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- The training and practical support which will be offered.
- The financial support which will be offered.
- How to apply for the role
- How to find out more about the role before applying.

2. Person Specification

- This should list the personal experience and knowledge which are both essential and desirable for the role. It should also list other skills and abilities which are essential (e.g. ability to communicate via email).

3. Application Form

4. Conflicts of Interest Form

5. Recruitment

Patients / lay members can be sought in a number of ways:

- Through a direct approach from a professional member of the guideline writing group.
- Through advertisement on the public pages of the BASHH website, and dissemination of the advert through social media and other stakeholders.
- Through the BASHH public panel.
- Through a patient advice or advocacy organization (e.g. the herpes association).

6. Training, education and support

This should be tailored to the individual needs of the patient committee member. As a minimum, they should be:

1. Allocated a 'buddy' on the guideline group who is their first port of call for questions or concerns during the writing process.
2. Met by their buddy prior to the first meeting of the guideline group (this could be immediately prior to the meeting) to run through the composition of the group; the format of the guideline writing process
3. Given a glossary of terms
4. Given any previous version of the guideline being written.
5. Given a summary of GRADE and PICO methodology.

7. Payment for time, travel and subsistence

Payment should be offered to patient members of guideline writing groups to compensate their time, travel and subsistence costs.

Payment is offered at the following rates (subject to review from time to time):

1. Payment for time

- £150 per full-day (four hours or longer) meeting or an equivalent amount of



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- time spent working on the guideline at home.
- £75 per half-day meeting (shorter than four) or an equivalent amount of time spent working on the guideline at home.

N.B. These rates are fixed and are based on the planned duration of the meeting. Lay contributors will not receive less than the agreed amount if finishes early or more if it over-runs. The payments do not mean that NICE's lay contributors have a contract of employment with BASHH.

All payments will be made directly to the individual. They may decline to accept the payment if they wish. If lay contributors accept any payments for contributing to BASHH's work, it is regarded, by Her Majesty's Revenue and Customs as part of their overall income. Each lay contributor is personally responsible for any liability with regard to Income Tax or National Insurance contributions. Lay contributors are asked to acknowledge this responsibility each time they claim the payment. BASHH does not deduct tax or National Insurance contributions from the payments at source.

2. Payments for subsistence

Maximum subsistence payment of £20 a day, which will not be considered as earnings.

- If away from home for 24 hours, a maximum of £20 should be paid if meals are not provided at the meeting or accommodation.
- If away for more than 10 hours, £15 can be claimed for a meal (after 7pm) provided they are staying away from home for more than 10 hours and returning home after 7pm OR are absent overnight but had a free lunch.
- If away from home for more than 10 hours, but home before 7pm, then £10 can be claimed for a meal.
- If away for over 5 hours or overnight, but dinner was provided free, then £5 can be claimed for a meal.

3. Payments for travel and accommodation

The following travelling expenses will be reimbursed:-

- Rail travel (First class allowable for journeys over 100 miles; first class tickets bought on day of travel will not normally be reimbursed). Members should use advance purchase schemes wherever possible.
- Bus/coach/tube (economy class fare only). Use annual/season tickets where possible. Up to £8 for a return oyster journey allowable without receipt.
- Car mileage will be at the 2011-12 approved HMRC mileage rates of 45 pence per mile regardless of engine size. If you are using a company car the mileage rate will be 15 pence per mile under 1400cc engines, 18p per mile for 1401 to 2000 cc and 26 pence per mile for over 2000cc engines.
- Taxi only outside central London or Manchester where public transport options more limited. Can be used in event of a strike or other disruption.
- Hotel accommodation: £125/night in London, £100 elsewhere. For early morning or late afternoon where travel on the day not appropriate. £25 if stay with a friend or relative. No additional expenses in hotel allowed (newspapers,



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rooms service etc).

3. Payment for carer expenses

These are payable when the patient member would be unable to attend without carer costs covered. They can include:

- Payment of a carer to accompany the person to the meeting.
- Payment to replace the lay members caring duties.
- Childcare

These payments are subject to a maximum of £15 per hour. The hours are to be reasonable and 24 as a maximum. Carer's travel and subsistence can be claimed if they accompany the patient.

8. Guideline publication and authorship

All BASHH guidelines are published on the BASHH website and many BASHH guidelines are also published in the Internal Journal for STD/AIDS.

We support the inclusion of lay members as guideline authors, but their consent for inclusion as an author must be obtained prospectively.

We recommend that lay members of guideline groups be asked, via email, whether they are happy for their name to be included as a guideline author. If submitted for publication, it is the responsibility of the lead/corresponding author to comply with journal guidance to ensure that all authors have reviewed the manuscript and are happy for its publication and their inclusion as an author.

If a lay representative is unhappy to be included as an author, then acknowledgement of the contribution of a lay member should be made in the 'contributors' (or similar).



9. Checklist for Patient involvement in a guideline group

Define level of patient involvement required (e.g. focus group, patient member on committee).	<input type="checkbox"/>
Nominate a member of the writing group to lead patient recruitment. <ul style="list-style-type: none"> ○ Liaise with public panel as necessary ○ Liaise with webmaster re advertising 	<input type="checkbox"/>
Nominate a member of the writing group as the patient 'buddy'.	<input type="checkbox"/>
Set timetable/milestones for guideline <ul style="list-style-type: none"> ○ To include meeting dates and locations 	<input type="checkbox"/>
Assemble required documents and send to public panel chair for review (publicpanel@bashh.org) : <ul style="list-style-type: none"> ○ Role description ○ Person Specification ○ Plan for education and training ○ Glossary of terms ○ Reading useful for the patient member of the committee 	<input type="checkbox"/>
Ensure all necessary paperwork complete <ul style="list-style-type: none"> ○ Application form ○ Conflict of interest form ○ Expense forms (as necessary) 	<input type="checkbox"/>