



Guide to Patient/Carer Group Submissions

1. Patient and carer involvement in Health Technology Wales appraisal process

Health Technology Wales (HTW) is committed to meaningful patient, carer and public involvement in its processes in line with the UK National Standards for Public Involvement in Research¹:

- Inclusive opportunities
- Working together
- Support and learning
- Communications
- Impact
- Governance.

HTW will embed the Standards throughout its work because we recognise that patients and carers have unique knowledge about health technologies that cannot be found in published clinical studies. They can tell us about:

- what it is like to live with the medical condition being assessed
- experiences of current treatments and the care pathway in Wales – good and bad
- experiences and/or expectations of the new health technology being appraised.

This information might come from those who are undergoing tests for, those who currently have, or have recovered from the medical condition being studied, or their carers.

As a result, HTW is trialling a range of forms of patient involvement, learning from best practices in other health technology appraisal organisations across the world and will evaluate these according to a formal evaluation framework.

This guide provides information to enable patient groups to participate effectively in HTW appraisal processes, by providing a structured submission.

By patient groups we mean any group of patients or their carers - this could be a patient organisation registered as a charity, a less formal group of patients/carers, a social media group or other collection of patients with a common interest.

The submission form asks questions that are relevant to explore diverse patients'/carers' experiences and perspectives. It is not intended for completion by an individual patient. If you are an individual patient and would like to input, please contact the HTW Patient and Public Involvement (PPI) Officer on 029 2046 8947.

Using learning from other appraisal bodies in the UK and internationally, this guide offers suggestions about what to include in your submission to bring out patients'/carers' experiences

¹ NIHR. UK Standards for Public Involvement in Research. National Institute for Health Research. Available at: <https://sites.google.com/nihr.ac.uk/pi-standards/standards> [Accessed 18 July 2019].

and perspectives in a way that is likely to have most impact on Committees considering the health technology being appraised.

We are developing our processes and so we will provide you feedback on your submission and may ask for your views of our process.

To find out more information about HTW, our processes and examples of our appraisals, please visit our website <http://www.healthtechnology.wales/about/> or call us on 029 2046 8947.

2. Planning a submission

Completing a Patient/Carer Group Submission takes time and effort, but it is an opportunity for you to provide valuable information to HTW that can inform their Guidance for Health and Social Care in Wales. You can explain what it is like for patients² to live with a particular medical condition and use health technologies in Wales.

Planning your submission will help you collect the information needed to complete the form. You should decide whether you need to gather new information from patients and carers, or whether you already have the necessary information in your patient group. You may want to consult with your members and other patients and patient groups about the information you propose to submit, so you will need to factor this into your plan.

It is important to liaise with HTW to ensure that you do not miss the deadline for submitting. This will ensure that your submission can be shared with the Committees and inform their discussions about the evidence on clinical and cost effectiveness.

Please use plain language where possible, explaining acronyms and other non-lay terms in simple language.

If you have any questions about the health technology or our appraisal, please contact HTW at healthtechnology.wales@wales.nhs.uk or call us on 029 2046 8947.

3. What information should you include in your submission?

Please refer to the Patient/Carer Group Submission Form while reading this guidance.

We want to understand the medical condition and its diagnosis or treatment in terms of impacts on the daily lives of patients and carers. This helps us interpret the published research, which is often from international studies that may not be fully applicable to Wales. It also helps us determine the real benefits or disadvantages of a health technology.

Table 1 provides detailed suggestions on the type of information that is most helpful for the HTW Committees in each section of the Patient/Carer Group Submission Form.

When writing your submission consider the tips in Box 1.

² “patient” will be used as a generic term that refers to anyone who has direct experience of living with the condition being studied or who may be eligible to receive the technology (e.g. specific members of the public who might be invited for vaccination or to undertake a diagnostic intervention).

Box 1. Tips for writing your submission

Do

- Be as clear and concise as possible, using plain language where possible
- Include what you think is important
- Leave a section blank if you don't have relevant information
- Report on as many individuals living with this condition as possible
- Present diverse views of patients' and carers', where they exist
- Include individual quotes about the impact of the new technology on daily life
- Try to be balanced
- Make a submission, even if you cannot find patients with experience of the new health technology, your other inputs are important

Don't

- Repeat information you've already written in another section
- Feel restricted by the examples in this guide
- Feel the need to get input from clinicians or industry, as we do that
- Send us studies on clinical and cost effectiveness, as our researchers find those using rigorous processes
- Use emotive or aggressive language

Patient/Carer Group Submissions that have the most impact are balanced and acknowledge any shortcomings with the new health technology, as well as the advantages.

Table 1. Information that you may wish to include in each section

Section	Type of information
1. Describe any sources you used to gather information for this submission.	<p>State where the information comes from, for example:</p> <ul style="list-style-type: none"> • surveys • quality of life questionnaires • focus groups • workshops • online forums • one to one discussions • patient group databases, such telephone helpline enquiries • published or unpublished research about patients' experiences or preferences • is the information from Welsh patients or elsewhere – have any patients used the health technology (please specify). <p>Tell us briefly about your sources – how have you gathered information and numbers of patients involved? Are there groups of patients that you could not contact? Did you engage with patients who had experience of using the health technology being assessed?</p>

Section	Type of information
<p>2. What is the health condition and how does it affect the day-to-day lives of patients and their carers?</p>	<p>Patients</p> <ul style="list-style-type: none"> • Types of patients that are most affected by the condition (for example men, women, children, and black, Asian and minority ethnic groups). • Average age of onset of condition and extremes (e.g. 10% below 18, 5% above 90) • Does the condition progress similarly in all patients? • Most challenging symptoms (for example pain, fatigue, difficulty in breathing, joint pain, diarrhoea, nausea, etc.) and their implications (unable to concentrate and so unable to work, loss of mobility, inability to drive, unable to dress oneself, loss of confidence to go out, unable to do shopping, to go to school, social exclusion). • Support required for daily living and impacts on family life. • Emotional issues such as fear, anxiety, uncertainty, stigma, embarrassment. <p>Carers</p> <ul style="list-style-type: none"> • Challenges faced by family and friends who support the patient, such as disruption to usual need to reduce employment. • Pressures on carers' daily life such as emotional/psychological issues, relationship challenges, organisation of care, fatigue, stress, anxiety, depression, physical challenges, financial issues.
<p>3. How is the health condition currently diagnosed and/or treated?</p>	<p>Patients</p> <ul style="list-style-type: none"> • Main health interventions currently used by patients for this condition, or if there are none, state that. • Extent to which currently available health interventions control or reduce the most difficult/distressing aspects of the condition • Issues that are not addressed by current interventions (e.g. treat symptoms but do not modify health condition) • The burden of currently available health interventions on daily life (e.g. difficulty in using the interventions, challenges in recovering after treatment, need for rehabilitation, special clinic visits for treatments and examinations) • Side effects associated with currently available health interventions that are distressing or difficult to tolerate • Financial implications such as costs of purchasing the intervention <p>Carers</p> <ul style="list-style-type: none"> • State if administration of current interventions requires carer support or impacts family life

Section	Type of information
<p>4. What do patients and carers expect from the health technology?</p>	<p>Aspects of patients' needs or expectations that it is hoped the new health technology will address (explaining specific issues for particular stages of disease). For example:</p> <ul style="list-style-type: none"> • If used by patient, easier operation of device. • More convenient, less invasive treatment. • What outcomes matter to patients, such as longer life, longer time to next stage of disease, reduced dependency on oxygen, increased mobility, ability to care for oneself, ability to return to work, reduction in pain, reduction in side effects that are difficult to manage. • Explain what the level of improvement in the clinical studies means to patients in their everyday lives. • Do patients understand the risks with the new health technology and is that something they are willing to accept for the potential benefit? • Groups of patients who might particularly benefit or who might benefit less from the new health technology than others (for example those who are unable to have surgery, or those who have other diseases, those in rural areas who cannot access services). <p>Carers expectations</p> <ul style="list-style-type: none"> • Reduced dependency and greater comfort of patient. • Potential improvements in quality of life.
<p>5. What difference did the health technology make to the lives of patients that have had it?</p>	<p><i>(Leave blank if you didn't contact anyone who had experience of the health technology.)</i></p> <ul style="list-style-type: none"> • Reasons patients do or don't like the health technology (for example, less invasive than current interventions, able to use at home and manage own condition, has made a real difference to quality of life). • Ease of use. • Extent to which the health technology improves the most difficult aspects of the disease (For example pain is greatly reduced allowing near-normal physical functioning and interactions with family, and return to work, able to sleep at night enabling better mental state during the day, no longer breathless and able to walk to shops, able to dress oneself). • Limitations of the health technology. • Any aspects of the health technology that patients would like to change.

Section	Type of information
6. Additional information you believe would be helpful for HTW to consider.	This section is optional and can be used for any additional information relevant to your submission.
7. Summarise the key points of your submission in up to 5 statements. <i>When we present your submission, we will present these first.</i>	It is important that you concisely capture the key messages of your submission here. These might include one sentence about each of the following: <ul style="list-style-type: none"> - Severity and impact of this condition on daily life. - Limitations of current health interventions. - Major benefit of this new health technology. - Disadvantages of new health technology. - Groups that would be particularly benefit from this technology.
8. Please give us details of anyone outside your group that had a role in preparing your submission.	Indicate role of person and organisation. For example <ul style="list-style-type: none"> • Health economics researcher at XX university led preference study • UK commercial lead at manufacturer shared survey results covering Wales • Consultant from YY led preparation of submission • Expert doctor at ZZ hospital reviewed the submission.
9. Do you consent for your group to be named in the HTW reports?	It is helpful and transparent to acknowledge the patient/carer group(s) that have submitted information for an appraisal. However, lack of consent for the group to be named in HTW reports will not prevent the submission from being utilised.
10. Have you completed the Declaration of Interest form?	It is important to highlight declarations of interest for openness and transparency. Patient/carer groups often have interests that need declaring, but that would not prevent consideration of the submission.

4. How to collect information that may be helpful in your submission

You may have sufficient information to complete the Patient/Carer Group Submission Form. It is not an expectation or requirement that submissions include data collected specifically for the submission, particularly as timescales to provide information will be relatively short. If you want to collect additional information, the type of information you collect will depend on the questions you want to answer. Information can be grouped into two categories: quantitative (numerical information) and qualitative (descriptive information).

The way you present information will depend on the types of questions that you asked. Remember that the HTW committee is looking for an overview of experiences or themes. The way you present quantitative information (closed-ended questions in surveys) is different from how you should present qualitative information (descriptive, open-ended questions in surveys, and interviews).

It is important to be as clear, concise and fair as possible when presenting your information, so that your submission has maximum impact.

The following sub-sections summarise key issues about collection and presentation of quantitative and qualitative information. We recommend that if you want to run definitive surveys or qualitative research you collaborate with academics who have relevant expertise. This guidance is just to help you run a simple study to provide key insights.

4.1. Quantitative information

Quantitative information is either counted or measured, such as:

- Age at diagnosis
- Number of years living with the condition
- How much time do you spend getting to your appointments?
- How long did it take you to get the correct diagnosis?
- How many times did you adjust your dose of treatment as a result of the home monitoring kit in the past week?

One common way to collect this type of information is by using closed questions within surveys, where answers are selected from a predetermined set of responses, for example using ratings on a numbered scale or multiple choice. You can then report the average response or how many times a particular response is chosen.

To summarise quantitative information (data), it is helpful to combine responses as averages, frequencies or counts (number of people), or proportions (percentages). It is best to keep the statistics simple.

Example

The 22 patients who responded to the survey ranked 'infections' as the most important, with 72% rating it as 10, a 'very important' aspect of controlling cancer. 'Infections' were followed by 'kidney problems', 'pain', 'mobility', 'neuropathy', 'shortness of breath', and 'fatigue'. More

than 50% of respondents rated these aspects as a 10, 'very important' to control. In all cases, the rating average was greater than 8, which meant that all listed symptoms were considered important.

4.2. Qualitative information

It is also important to collect the thoughts, opinions, stories, and feelings of patients and carers. This input is described as qualitative information and answers questions, such as:

- How does side effect X affect your life?
- What is it like to have condition Y?
- What would you like to be able to do next year, that you can't do now?
- Can all patients access the health technology in the same way?

There are many ways to collect qualitative information. Some are very simple and quick, for example posting a question on a social networking website, such as Twitter or Facebook, or online discussion forums. You can also use group discussions, interviews or open-ended questions in surveys. These allow participants to explain their experiences in their own way. Electronic questionnaires can also be an easy and convenient way to collect key information.

A good way to present qualitative (descriptive) information is to identify the common themes emerging among participants and any major divergences of opinion. Then include quotes from participants to illustrate the different viewpoints. If you begin by selecting quotes without looking for common themes, you may not realise that there are specific themes that most participants collectively discussed.

The findings should be in the voice of the participant, for example what participants expressed, reported, said or described. You should make it clear that this result was taken directly from the participant's experiences, rather than the opinions of your patient group.

Example

In the focus group of eight participants with chronic wounds who had received the health technology in Scotland, issues about impaired mobility and restrictions to lifestyle were raised by several participants (Ps).

“It's terrible, you can't even get up and walk.” (P2)

“I walked in the door today to come down here, that's the most I've walked in about a year.” (P5)

“That's the most I've been walking in a long time too.” (P7)

Please don't identify patients or carers by their full names. Instead use initials or first names only and remember to take special precautions to maintain the confidentiality of the information given to you. See these [guides](#) detailing ethical considerations when gathering patient experiences - [long](#) and [short](#) guide.

5. Does the information have to be from Welsh patients and carers?

It is best to gather information from patients in Wales who may benefit from receiving the new health technology. Their experience of the NHS in Wales provides valuable information. We realise that for some health technologies, such as those used to treat rarer conditions, this is not always possible. If you are unable to gather information from the local population, it is fine to include information from a wider pool of patients and carers from outside Wales, such as England where the health system is similar to ours.

6. Useful resources

Health Technology Assessment International (HTAi) provides a variety of educational and learning [tools](#) for helping patient groups capture patient and carer experiences.

Accessibility

You can read and download this document from our website. If you would like us to consider producing this document or the Patient/Carer Group Submission Form in an alternative format, please contact HTW at healthtechnology.wales@wales.nhs.uk or call us on 029 2046 8947.

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Patient and Public Involvement Officer
Health Technology Wales (HTW)
The Life Sciences Hub
3 Assembly Square
Cardiff
CF10 4PL
United Kingdom

Email: healthtechnology@wales.nhs.uk

Tel: 029 2046 8947