

# Guide to Support Patient Organisation Submissions

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## Acknowledgements

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## What information should you include in your submission?

We want to understand the experiences of those living with, and caring for people with, the health or medical condition being assessed. To help you provide that information, this section offers suggestions on what to include in your submission and things to consider when presenting your information.

Table 1 provides detailed suggestions on the type of information that is most helpful for the SHTG in each section of the submission form.

**We want you to help us understand the issues patients and carers in Scotland face and what really matters to them.**

**Below are some points to consider alongside the guidance in Table 1.**

- **Please be as clear and concise as possible.**
- **Sometimes it may be difficult to assign information to only one section of the form. You do not need to repeat information, just put it in the most relevant section.**
- **Not all sections will be relevant to every submission. It is fine to leave a section blank.**
- **Don't feel restricted by the examples we give.**

**Include what you think is important to describe the medical condition you represent and what patients and carers have told you about their experiences.**

**It is important to report on the experiences of as many individuals living with this condition as possible, rather than exceptional cases. It is helpful to highlight the special needs of certain groups and also differences in opinion.**

Focus on the implications of the medical condition and its diagnosis or treatment in terms of the quality of life of patients and carers. This helps us interpret the published research, which is often from international studies that may not be fully applicable to Scotland. It also helps us determine the real benefits or disadvantages of a health technology.

You don't need to get input from clinicians or manufacturers as we do that. We find all the relevant published studies on clinical and cost effectiveness.

It is not helpful to use language which is overly emotive or that appears to be the opinion of your organisation rather than patients and carers themselves. This detracts from your key points and may be detrimental to your submission.

**Patient Organisation Submissions that have the most impact are generally 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
<p>1. Tell us about the sources you used to gather information for this submission.</p>	<p>Where does the information come from, for example:</p> <ul style="list-style-type: none"> <li>• surveys</li> <li>• quality of life questionnaires</li> <li>• focus groups</li> <li>• workshops</li> <li>• online forums</li> <li>• one to one discussions</li> <li>• patient organisation databases, such telephone helpline enquiries</li> <li>• published or unpublished research about patients' experiences or preferences</li> <li>• is the information from Scottish patients or elsewhere (please specify).</li> </ul> <p>Tell us briefly about your sources – how have you gathered information and numbers of patients involved.</p> <p>Are there groups of patients that you could not contact?</p> <p>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"> <li>• Types of patients that are most affected by the condition (for example men, women, children, ethnic groups).</li> <li>• Average age of onset of condition and extremes (e.g. 10% below 18, 5% above 90)</li> <li>• Does the condition progress similarly in all patients?</li> <li>• 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).</li> <li>• Support required for daily living and impacts on family life.</li> <li>• Emotional issues such as fear, anxiety, uncertainty, stigma, embarrassment.</li> <li>• Technologies currently used and any issues with them.</li> <li>• Financial impact, such as personal cost of support aids to overcome symptoms.</li> </ul> <p>Carers</p> <ul style="list-style-type: none"> <li>• Challenges faced by family and friends who support the patient, such as disruption to usual daily routines.</li> <li>• Pressures on carers daily life such as emotional/psychological issues, relationship challenges, organisation of care, fatigue, stress, anxiety, depression, physical challenges, financial issues.</li> </ul>

Section	Type of information
<p>3. What do patients and carers want 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"> <li>• If used by patient, easier operation of device.</li> <li>• More convenient, less invasive treatment.</li> <li>• 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.</li> <li>• Explain what the level of improvement in the clinical studies means to patients in their everyday lives.</li> <li>• Do patients understand the risks with the new health technology and is that something they are willing to accept for the potential benefit?</li> <li>• 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).</li> </ul> <p>Carers expectations</p> <ul style="list-style-type: none"> <li>• Reduced dependency and greater comfort of patient.</li> <li>• Potential improvements in quality of life.</li> </ul>

Section	Type of information
4. What difference did the health technology make to the lives of patients that have used it?	<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"> <li>• 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).</li> <li>• Ease of use.</li> <li>• 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).</li> <li>• Limitations of the health technology.</li> <li>• Any aspects of the health technology that patients would like to change.</li> </ul>
5. Additional information you believe would be helpful for SHTG to consider.	This section is optional and can be used for any additional information relevant to your submission.
6. Please summarise the key points of your submission in up to 5 statements.	<p>It is important that you concisely capture the key messages of your submission here. These might include one sentence about each of the following:</p> <ul style="list-style-type: none"> <li>• Impact of this condition.</li> <li>• Limitations of current health interventions.</li> <li>• Major benefit of this new health technology.</li> <li>• Disadvantages of new health technology.</li> <li>• Groups that would be particularly benefit from this technology.</li> </ul>

Section	Type of information
<p>7. Please give us details of anyone outside your organisation that had a role in preparing your submission.</p>	<p>Indicate role of person and organisation. For example</p> <ul style="list-style-type: none"> <li>• Health economics researcher at XX university led preference study</li> <li>• UK commercial lead at manufacturer shared survey results covering Scotland</li> <li>• Consultant from YY led preparation of submission</li> <li>• Expert doctor at ZZ hospital reviewed the submission.</li> </ul>
<p>8. Do you consent for your submission to be posted on the SHTG website?</p>	<p>If you consent to sharing your submission, please make sure it doesn't contain confidential information. We will place it online with the other papers relating to the assessment.</p>



## How to collect the required 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 SHTG 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 and concise 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.

### 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 xxx 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.

## 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 organisation.

## **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 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.

Please remember when writing your submission that some of its readers will be either non-specialist in the area or condition, or lay members of SHTG. Use plain English and avoid technical language, whenever possible.

## **Does the information have to be from Scottish patients and carers?**

It is best to gather information from patients in Scotland who may benefit from receiving the new health technology. Their experience of the NHS in Scotland 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 Scotland.

Please mention in the submission form if your information is not from the Scottish population.

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