

## Patient and Carer Organisations search tool

The purpose of a patient and carer organisation search is to identify organisations, support groups & networks that support people with a medical condition or social care need, in order to approach them regarding their potential involvement in an appraisal.

Topic
<p><i>[please enter details of the topic and the disease/condition]</i></p>

The following sources are suggested sources for patient and carer organisation searches. Note that it may not be necessary to search all sources for every topic.

Resource	Results
<b>Previous HTW appraisals</b>	
<p><a href="#">HTW</a>  <i>Has HTW carried out an appraisal on a similar topic or patient population?</i></p> <p><i>If so, with whom did HTW engage?</i></p>	
<b>General</b>	
<p><a href="#">Google</a>  <i>Search on 'charity' or 'organisation' as well as the condition/population.</i></p> <p><i>Do this first as it should bring up key organisations. Make sure that they're UK based organisations.</i></p>	
<b>NHS patient information resources</b>	
<p><a href="#">NHS Choices</a> (Health A-Z)</p>	
<p><a href="#">NHS Direct Wales</a> (Health A-Z)            Look up topics and scroll to the bottom, there is a 'selected links' section.</p>	
<p><a href="#">NHS Direct Wales</a>  <i>Search for towns in North Wales as well as South Wales to retrieve as many hits as possible.</i>  <i>There are links to 'All Wales Health, Wellbeing &amp; Support Providers' at the bottom of this page, following the search results.</i></p>	
<p><a href="#">NHS Inform</a></p>	

<i>in particular the 'Health &amp; Wellbeing services' under 'Scotland's service directory'</i>	
<b>Patient information resources (non-NHS)</b>	
<a href="#">Patient UK</a> <i>At the end of each leaflet on a topic there are links to relevant organisations</i>	
<a href="#">HealthUnlocked</a> <i>Look at the list of communities on the homepage to see if there is a relevant community</i>  <i>You must register to have full access.</i>	
<a href="#">Self Help UK</a> <i>Specifically for help in the Nottingham area, but there are links to national UK bodies</i>	
<a href="#">National Association for Patient Participation</a> <i>Resources section, need to be a member to access</i>  <i>Check the 'Useful Links' page:</i> <a href="http://www.napp.org.uk/links.html">http://www.napp.org.uk/links.html</a>	
<a href="#">Health Talk</a> <i>Search for topic of interest, there is a 'Resources &amp; Information' section for each topic</i>	
<a href="#">NIHR Involve</a> <i>Communities and Charity Involvement Directory</i>	
<a href="#">National Voices</a> <i>List of members</i>	
<a href="#">Dying Matters: organisations by disease</a>	
<b>UK Evidence based resources</b>	
<a href="#">NICE Guidance</a> <i>Is there a NICE clinical pathway for this topic?</i>	
<a href="#">NICE Evidence Search</a> <i>Restrict search to 'Information for the Public' &amp; 'Patient Decision Aids'</i>	
<a href="#">NICE - Get Involved</a>	
<a href="#">Healthcare Improvement Scotland</a>	
<a href="#">SHTG</a>	

Has SHTG published anything on this or a similar topic?	
<u><a href="#">SIGN</a></u> Check both the published guidelines and the patient involvement pages. There may be a plain language or patient version.	
<b>Research centres/organisations</b>	
<u><a href="#">The King's Fund</a></u> search the database as well as the website: <a href="https://koha.kingsfund.org.uk/">https://koha.kingsfund.org.uk/</a>	
<u><a href="#">Centre for Qualitative Research</a></u>	
<u><a href="#">Campbell Collaboration</a></u> The Campbell Collaboration systematic reviews can be found here: <a href="https://onlinelibrary.wiley.com/journal/18911803">https://onlinelibrary.wiley.com/journal/18911803</a>	
<u><a href="#">Iriss</a></u> <i>Institute for Research and Innovation in Social Services (Iriss)</i>	
<u><a href="#">NIHR CLAHRC Projects</a></u> <i>NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRC)</i>	
<b>Condition/disease specific websites (delete if not appropriate)</b>	
<b>Cancer specific</b>	
<u><a href="#">Cancer advice</a></u>	
<u><a href="#">Cancer-UK: National Organisations</a></u>	
<u><a href="#">ESMO</a></u>	
<b>Diabetes specific - pages containing lists of organisations/charities</b>	
<u><a href="#">Juvenile Diabetes Research Foundation Ltd (JDRF)</a></u>	
<u><a href="#">Welsh Endocrine and Diabetes Society</a></u>	
<u><a href="#">Diabetes.co.uk</a></u>	
<b>Heart disease specific - pages containing lists of organisations/charities</b>	
<u><a href="#">Wikipedia heart disease organisations</a></u>	
<u><a href="#">Cardiomyopathy</a></u>	

Date of search:

Concepts used:

Search undertaken by: