

PATIENT NEEDS AND FEEDBACK SURVEY 2011 – HERE IS WHAT YOU SAID

Earlier in the year, in keeping with our patient focussed/patient led ethos, we asked for your suggestions on what we could, or should, be doing to improve the lives of people with hepatitis C. We would like to say a big thank you to those who replied to our survey questions. The feedback and ideas you gave us were invaluable. The results of this survey can be seen in graph form online www.hepctrust.org.uk/surveygraphs, but for those of you with less of a mathematical interest (!), below is an overview of responses. Firstly, there is some information about those who replied. Following that is a section about what those people had to say about the Trust.

ABOUT YOU

We had 148 replies, and they came not only from people who have, or have had, HCV but also from carers, healthcare professionals and caseworkers,

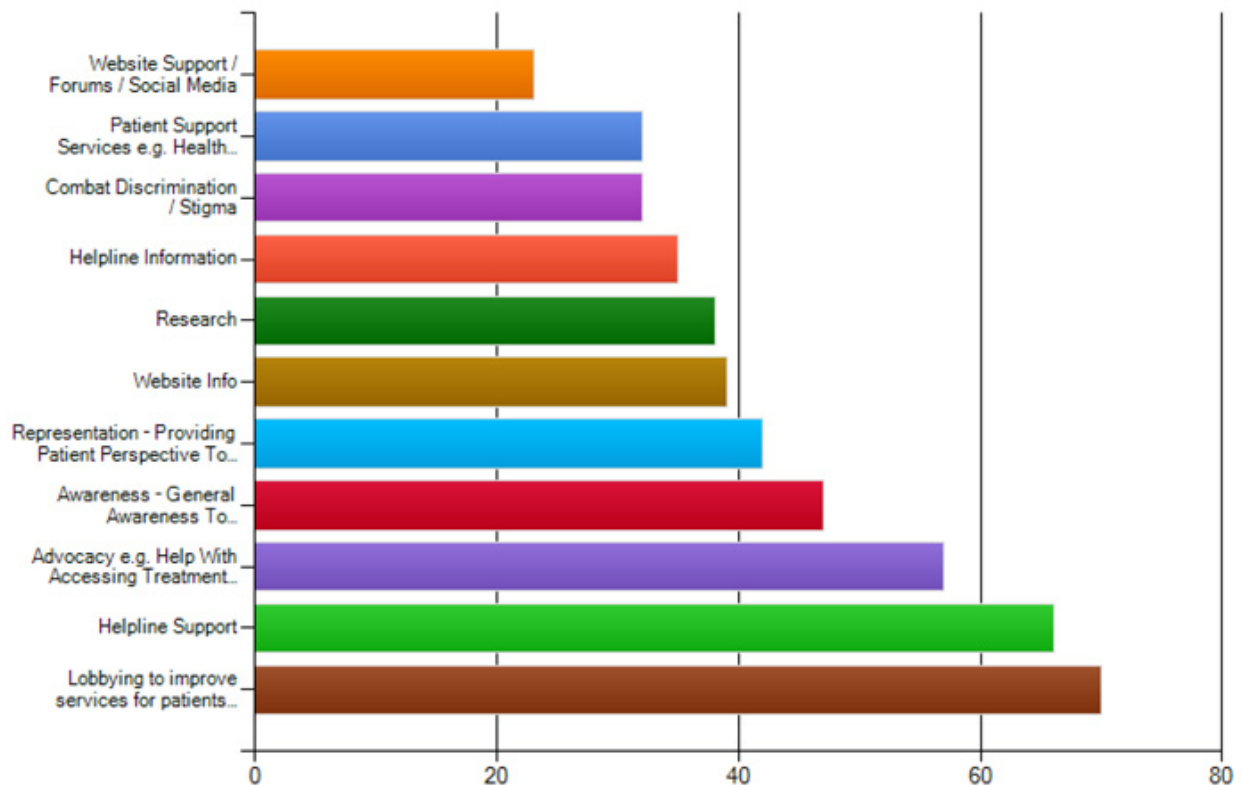
The age range of people replying was wide – from under 30 years to over 60 years. So too was the geographical range – covering the Highlands of Scotland to the south eastern reaches of England, Wales to Northern Ireland. Most replies came from people living in London.

Most replies were from people who described themselves as British and White. There were few replies from people of South Asian origin; this is disappointing given that it is such individuals who are seen to be at particular risk of hepatitis C infection. Although feedback was limited from this group, we will of course be continuing our work within the community. To this end we have a dedicated South Asian project officer who works to raise awareness and encourage testing, for example by attending melas and other community events.

ABOUT THE HEPATITIS C TRUST

The survey also asked about the services the Hepatitis C Trust provides – founded on the four key objectives of awareness, support, information and representation. The graph below shows that support is ranked high on the list of what you want from us – for example, by way of our Helpline and our lobbying for improvement of patient services.

As you will be aware, The Hepatitis C Trust currently provides a range of services and projects founded on four key objectives: Awareness, Support, Information and Representation. We would very much like to know what you feel are the most important ones we should be focussing our efforts on over the next 3-5 years.(tick only 3)



Below is a round-up of responses about our services under the headings of Newsletter, Helpline, Website, Health Days, Support Groups, Information Leaflets, and Awareness Campaigns.

The Newsletter

Several issues emerged from questions about our Newsletter. Some people who answered the survey told us that they did not read the Newsletter – and the reasons they gave included concern about confidentiality. We would like to take this opportunity to reassure all our readers that their contact details are held securely on a password protected database and are not shared with anyone else. Whenever we send a copy of our Newsletter by post (or other information materials, as requested), then we always ensure it is in a plain envelope.

Another concern was that the Newsletter seemed to be targeted at a younger audience. We very much hope that our Newsletter has something for, and from, everyone of all ages – patients and professionals included. However, some of the work we do is specifically targeted at younger people in an effort to get the prevention message across (for example the reports we provide on the Get Tested! project).

However, the vast majority of the people who did read the newsletter were happy with the content and layout. They particularly liked to hear about the work of the Trust, found personal stories very

interesting and helpful, and were interested in updates on issues around hepatitis C and new treatments and their availability,

A few suggestions and ideas were received – about layout, information, content and treatments. For example, it was suggested that we use larger print, and that we should not use a coloured background. In response to this, we have now decided to make the font larger, which we hope will make it easier to read. In terms of information and content, concern was expressed that our updates on new therapies/treatments were not always up to date. The explanation for this is that research is currently so fast moving that the Newsletter – because it only comes out three times a year – is not the best forum for this. However, for those of you that have access to the internet, all news is reviewed frequently and continually updated on our website, www.hepctrust.org.uk. We have also now introduced an e-letter with supplementary information about our work, which may include updates on new treatments in the future.

Some ideas that were proposed for the content were to include more photographs, letters and ‘fun’ items; we have always encouraged people to send in their suggestions or contributions – so please get writing and let us know about items you would like to include! We would particularly like to hear your feedback on things that have been helpful to you in terms of well-being, and how you managed your hepatitis C from day to day.

The Helpline

The feedback about the Helpline was particularly important, given that the Helpline is at the heart of our patient centred focus. We were interested in exploring why people do not call the Helpline as well as finding out from those who do call what they think about the service.

Reasons for NOT phoning the Helpline included the somewhat worrying comment that people had not been told that it existed. More positively, there was preference expressed for using on-line support/information resources, or talking to clinicians.

For those that had used the Helpline service, the vast majority felt the information received was clear and easy to understand, and that the staff were supportive and knowledgeable. Furthermore, it was felt that the Helpline was a valuable resource. Although overall, the Helpline hours were considered convenient, there was some suggestion that opening hours should be extended – something we would love to be able to provide. When we start the Helpline we did stay open until 7 p.m., but found it was very unusual to get calls after 5 p.m. From a staffing, funding and volunteering point of view it would be impossible for us to provide a 24/7 and/or weekend service at this time, although we will continue to monitor call rates and respond to demand wherever we can.

The Website

In response to the section on the website, the feedback was very positive. Most people expressed the view that the site was easy to navigate, and that the information was clear, easy to understand and relevant to their needs. Although it seemed that a few people were having some issues getting used to the new look website, most liked the new style and layout. The information provided was felt to be trustworthy. This is particularly positive feedback, given the recent hard work we have invested in achieving Information Standard certification. This accreditation is awarded for reliability

of information, including continual reviewing of all materials (not just the website) for their suitability, and updating them as appropriate.

In terms of improving the site, we were asked to include a welfare benefits section. You'll be pleased to hear that the construction of such a section is underway. We are also busy making some existing pages easier to find, for example by making the location of events and reports information more obvious. And we are going to add a glossary of terms, for all those short forms and acronyms so popular with 'those in the know'.

Health Day

Our Health Day continues to be popular, with a lot of positive feedback about how it has empowered those who could attend. There was concern expressed that people could not attend because of the travelling involved. The sad news is that our original funding for this service, provided by the Department of Health, was for a limited period only. Because this period is now over, our coverage is restricted. However, the good news is that we are exploring other funding sources. In the meantime, we do try to cover as many areas as possible outside London (where the Health Day organiser is based), and this year we have held Health Days in Scotland and Wales, Manchester and Coventry. In the meantime, for those of you with access to the internet, do check our website pages on diet and other wellbeing issues (under the Caring for Yourself section). The dates for upcoming Health Days are also on our website.

Social Networking

Some people felt that this was not for them, because of age, lifestyle or confidentiality issues. And not many had asked their friends to sign up to the Trust's Facebook and Twitter sites. However, those who did make use of our social networking found the posts interesting. They particularly wanted to see more patient experiences and research articles. We are currently posting all new research and treatment information on Facebook. We are also using Facebook as a Helpline resource; questions can be posted on the page, or Facebook can be used to contact the Helpline via e-mail. There are a few people also beginning to use Facebook to report regularly, like a Blog, on their experiences of hepatitis C, for example their treatment.

We asked whether those of you with a smart phone would like a hepatitis C app to be created, and if so what they would like it to be able to do. Among the suggestions received was that information about the latest research and treatment be available via an app.

Support Groups

It is clear from the survey that an increase in the number of local support groups would be appreciated. This perhaps explains the low number of people that responded to this specific section of the Patients' Needs and Feedback Survey. Those who did respond were generally satisfied with the support groups offered by The Hepatitis C Trust, saying that they were friendly, supportive and informative. However, some people felt reluctant to attend support groups because they did not feel happy talking in a group. We know that a lot of people feel daunted by attending a support group for the first time, but it is very much hoped that you would consider attending one of ours if you are in the London or Coventry area. Our groups are very friendly and informal and there is no pressure to

participate if you do not want to – sometimes people just come to listen – others may have questions – what we can assure you is that you will be welcomed and we will do our best to make sure you feel comfortable. We are also considering starting a series of more therapeutically based group sessions run by an experienced therapist to explore in detail the feelings that come up around diagnosis, treatment, stigma and relationships – please contact Samantha May at the Trust if you would be interested in taking part in this initiative.

Another issue that was raised in the feedback about support groups was that hospital and clinics do not seem to hold (or perhaps pass on?) information to patients about local support groups. This is hopefully something that is being addressed via our Patients' Association project, where we commit to visit all treating hospitals each year, ensuring they have up to date and relevant information about hepatitis C and the Trust, as well as making sure clinical staff are referring patients to our varied support services.

Information Leaflets

It was interesting to see that there was little difference in numbers between those who preferred written/hard copy information and those who preferred looking things up on the internet. For those who preferred hard copy information, our information leaflets were considered clear, easy to understand and relevant. However, there did appear to be a preference for more detailed information, in the form of e.g. a booklet rather than the leaflets we currently supply. In 2012 we will be undertaking a review of our written information resources, looking at which resources are of most use, areas we are not currently covering, as well as which format is most user-friendly,. We also have a panel of volunteers who kindly 'test' our information (mainly so far on our website) so if you are interested in joining that please contact stuart.smith@hepctrust.org.uk.

Awareness Campaigns

You told us that you felt billboards were an effective way to raise awareness, and to this end we will continue our relationship with Clear Channel, who have kindly donated space for our posters for some time now, both in the form of billboards and also bus stop poster sites. Although there was mixed feedback about whether people felt our campaigns encourage people to get tested, with a lot of replies saying they did not know if such campaigns were effective, responses did confirm that our awareness-raising seemed to help reduce the stigma associated with hepatitis C.

Among the suggestions made in the feedback were that we make short film pieces of people talking about hepatitis C. We have already made videos of our patient (excuse the pun!) volunteers talking about why they volunteer, and their experiences of hepatitis C – watch this space, as these are yet to be edited for uploading on our website.

A further suggestion was that we aim to raise our profile. We are continually working towards this, at several different levels. Most importantly, we aim to introduce ourselves to as wide a possible range of people affected by hepatitis C. We do this not only via our support and information services, but also by launching initiatives such as our GP Awareness Project, which includes in its remit making sure that GPs have information about the Trust, and our training events, which we offer to service providers in prisons, hostels and clinics for example. Furthermore, we are actively involved in

national policy making, for instance regularly auditing the performance of the NHS in England in relation to hepatitis C.

...and finally

So in conclusion we would like to say thank you so much to everyone who took the time to participate in this survey – we hope you will be pleased to see that we have already taken action on some of the issues you raised and we were delighted to hear that you were happy with a lot of what we are doing already. Your views are really important to us so keep in touch with us and let us know how we are doing. We aim to conduct regular needs and feedback surveys as they really help to inform our work and ensure we are providing the right types of services for the people who matter most – those with hepatitis C.