

# Access and use of cancer counselling services amongst low-income patients

Report prepared for We Hear You, The Harbour and Wessex Cancer Trust

Authors: Felicity Thomas and Lorraine Hansford



## **Access and use of cancer counselling services**

### **Introduction and context**

High levels of cancer exist within low-income communities in the UK. Since the publication of best practice guidance (National Cancer Equality Initiative 2010), efforts have been made to increase parity of cancer healthcare and treatment. Yet whilst people's medical needs are increasingly well met, little attention has focused on supporting their mental health and emotional wellbeing, crucial when over half now live for ten years or more following diagnosis (Macmillan 2014). People diagnosed with cancer often report feeling overwhelmed with despair, grief and depression, factors that can be vastly exacerbated when they and their families are living concurrently with material hardship and deprivation.

The NHS Cancer Strategy (2016) calls for accelerated commissioning of support services, such as those provided through specialist counselling and psychological support. However, this is not provided routinely within NHS care, and little is known about the factors that influence referral to, or awareness of, this kind of service, or the long-term impact counselling has on service users.

'We Hear You' (WHY), Wessex Cancer Trust (WCT) and The Harbour all provide this specialist counselling across diverse social and geographical areas of the South West. The purpose of the work on which this report is based aimed to establish:

- i) the factors enabling or constraining low-income groups in using their services,
- ii) the lived experience and long-term impacts of counselling on those who do access services.

### **Methodology**

This research took place between February and July 2018. It involved an initial meeting with all partners to establish existing service provision and client base and to identify key questions for the research. Due to logistical constraints and the diversity of service provision across the three organisations, it was agreed that we should hold focus groups and/or interviews in each of the three sites. Each organisation identified and contacted people who they felt fitted the research criteria. In one site, it proved particularly difficult to recruit people from a low-income household. However, participants interviewed here had all experienced a significant drop in household income as a result of the cancer affecting them/their relative.

Focus groups were held in Bristol (The Harbour) and Portsmouth (WCT). Because of in difficulties bringing people together, a series of face-to-face and telephone interviews were undertaken with people who had been in contact

In total, 16 people (4 men, 12 women) who had been affected by e involved in this process. Ten had used the services of one of the anisations. Six were aware of the services, but 5 had chosen not to ind 1 had attended an assessment session but was not eligible. Ten s were living with cancer, 6 were carers / family members.

## Findings

### ***Impact on well-being and social networks***

Many respondents commented on the impact of cancer on their and their family's well-being and social networks. The physical effects of cancer and its associated treatments had knock-on effects for the way that people felt about themselves, with many complaining that issues such as weight gain, tiredness and impaired memory added to their low self-esteem.

People living with cancer commonly felt socially isolated from friends, family and colleagues, with some explaining that they had lost what had been important connections,

*'There are some friends that are sadly not friends anymore because they couldn't really deal with it and contact got less and less and you just... there was always an elephant in the room, if you see what I mean'*

*'I think initially a lot of close friends simply didn't know how to handle it and so they'd kind of stay away at a distance'*

Whilst people acknowledged that those in their social networks felt awkward because they did not know how to respond to them, others felt that there was also a level of stigma and rejection directed at people with cancer.

*'I think you still get that sharp intake of breath when you mention that you've got cancer...When I was first diagnosed, some friends that just couldn't deal with it, didn't know what to say. Yes. There's definitely still a stigma around it.'*

*'We had a lot of friends there and we've been involved for many, many years and they abandoned us. The support was really lacking. We were shocked to find so many people could not cope... a lot of people we knew, we sort of knew well but wouldn't say they were best friends, they'd cross the street. [Husband] was saying, "It's not catching".'*

Although people felt that awareness and understanding of cancer has improved in recent years, some people felt that there was still an element of blame or judgement in the way they were viewed by others,

*'I think there's a bit of an attitude of you must have done have done something wrong, you've got cancer, I still think that's an attitude that, you know, you must have not eaten the right things or you know, not looked after yourself anyway'*

People also explained that whilst they fully appreciated the support they received from their social networks, they felt that they could not keep burdening their family and friends with the negative experiences that they were going through.

*'Even your parents don't understand. They just blank it. They don't want to know because they're frightened you're going to die. Like my son, he wouldn't come for counselling, he just bottles up.'*

The type of cancer that people experienced and the way that it was perceived by others was also found to impact on people's wellbeing and the support available to them. In the focus groups, participants explained that they felt that some types of cancer were given precedence over others, and that this undermined their well-being and self-esteem,

*'I never had breast cancer and it seems there is a divide - well not a divide but everything is geared for breast cancer and I didn't have breast cancer and all these little things, 'oh and if you've had breast cancer...' and it makes you think, is my cancer not good enough? I have had to have the same treatment and surgery and so why? [...] My friend, she has sadly passed away, she had breast cancer and she'd say, 'I got this and they've done that' and I thought, I got nothing, nothing.'*

Participants also commented that some less common types of cancer were poorly understood by others in their social networks and that this further increased their isolation. One person also talked about the stigma she had experienced due to people's misconceptions about her type of cancer,

*But people have almost withdrawn from me, when I, so I'd learnt very quickly not to say I had cervical cancer and just be very general about it.*

Some people also commented on the pressures they felt to show a 'brave face' and to engage in narratives of positivity and 'survivorship'. Whilst it was acknowledged that this kind of discourse could be reassuring and empowering, it was also felt that it placed enormous expectations on them, which could in turn, negatively influence the way that they felt they were perceived by family, friends and others in their social networks, particularly if they were not seen to be 'fighting hard enough' to survive.

### ***Financial implications***

Living with cancer was reported to have major financial repercussions that directly impacted on people's well-being. In most cases this resulted from loss of income when people living with cancer – and sometimes their carers - had to step back from work. This was especially problematic for those who were self-employed, or on zero-hours contracts, who explained that they could not get sick-pay, and often had no recourse to welfare support. Costs of travel to and from appointments and to visit patients were also reported to impact on household finances.

In the longer term, some people reported that they had struggled to get work after being treated for cancer, or that they were only able to secure low paid employment. The stress of having to go through the benefits assessment process to justify why they were unable to work whilst living with a serious and potentially life threatening illness was also emphasised. As one respondent stated,

*'I'm left with the consequences [of cancer] and here I am, having to go to PIP assessment like trying to justify how crap my life is'*

Another respondent explained the difficulty they experienced trying to access their entitlements, meaning that they felt forced to continue working despite their circumstances,

*'Finances were difficult, so we looked into various benefits. We were offered £11 a week from the Department of Work and Pensions, Social Security, and we said, "Well that's pretty impossible to live on," and they said, "Well that's all you can have". That was for my husband. I said, "Well if I'm not actually claiming on that, can I work part-time to try to earn some money?" "No, because your husband is getting a benefit, so you'll be in real trouble, you can't actually have any more income coming in". I said, "Well how we are supposed to live on £11 a week?" and they said, "That's not our problem". So we just carried on working... So we just carried on and we somehow muddled through and nobody told us about disability living allowance as it was then, now PIP, until 2013, is when we found out about that and applied and successfully awarded and both condoned at the highest mobility and the other one. But before that, no.'*

Others commented on the stigma associated with claiming benefits, despite the fact that they had a clear reason for doing so, and the stress of having to evidence their legitimacy to the welfare system,

*'I felt like that, claiming. I find it embarrassing. My friends that work now- I find it really difficult spending money that's not mine. I try to budget well... So, I claimed and this really pissed me off, I'm having to deal with the shin-do with tax credits and ESA. My partner is not living with me and I am going to have to prove that he wasn't living with me as they think I am claiming false benefit. Now I have to provide all the documentation and they know my situation and I think why don't these people go and chase people who they know are doing wrong.'*

Living on a lower income – especially for those who were already experiencing financial hardship, also impacted on people's standard of living and their ability to undertake activities e.g. holidays, socialising with friends, that would enhance their well-being. Some people explained how this left them feeling guilty about the knock-on effect their illness was having on their family,

*'You feel that your adjustments that you are making are maybe holding not only you back but holding your family back as well. You think oh blimey this is kind of my fault. Obviously it isn't but you do kind of feel like that and I certainly felt like that, as I said earlier, about the financial pressures that were placed on my wife at the time'*

### ***Experiences of counselling***

In all three study areas, people explained that they had not been aware of the support services available for people affected by cancer before their/their relative's diagnosis. Even then, it was felt that knowing about the services

available was often a matter of chance, and 'luck', with word of mouth, or the fortuitous spotting of a leaflet in a GP surgery being the main routes in.

Most people who had attended counselling offered by The Harbour, WHY and WCT were positive about their experience. One of the main benefits of the counselling was that it enabled people to talk through their experiences and concerns and feel listened to without having to worry about further burdening family members.

*'It was certainly beneficial to speak to somebody that was completely divorced from the situation and didn't have any of the baggage that everybody else has that you kind of talk to in regards to friends and family circles. So that was really good to be able to talk openly and confidentially.'*

*'I think what's nice about it is that it's your time and you can be selfish with it. You don't have to do small talk or think about how the other person feels about what you are saying, you don't have to moderate yourself in that way, so that's really good space to have. When you are spending a lot of time worrying about other people – dad, mum, brother, it's nice to have that space that's just for you.'*

Having a counsellor who understood cancer was felt to be especially helpful in enabling people feel that their experiences were being understood and taken seriously, and meant that people did not have to keep explaining medical terminology that they felt others may not understand,

*'I got the impression the counsellors were all people who themselves were affected by cancer in some way, so you did feel an affinity I guess with the person that was taking the session. I guess that probably helped you to relax and stuff and made it feel more natural I guess, because I think they probably understood some of the terminology maybe that you forget sometimes and you start talking in hospital speak and you don't realise that not everybody understands what it is you are on about.'*

The targeted support offered was felt to be infinitely more relevant and helpful than the more generic counselling that some had also received. That waiting lists were relatively short and that it was possible to see the same counsellor each time was especially valued by those who had experienced other counselling services.

*'This lady from WHY, she was brilliant because she just basically listened to me and just said, "Well this is your space, this is your time. How do you feel about what's happened to you, blah-blah-blah-blah?" And that was brilliant because what I needed really was someone to talk to but also to sort of gently point me in the right direction rather than just... I felt like with the CBT, personally, it was just like you were following the form, ticking the boxes for them.'*

*'She was completely different. She was understanding, listening. I didn't feel as if I was just a tick-box. It was personal to me. It was relevant to me'*

*because she would always be... I don't know what the... I never know if the right word is sympathetic or empathy really but both'*

A key benefit of the counselling received was that people felt better equipped to reflect on, understand and accept the process they were going through, and that this had helped them to move forward, rather than dwell on the negatives,

*'The whole process was really about understanding where I was kind of thing with the illness and the fact that I was still able to function and still able to live my life, it's just that I had to live a different kind of life.'*

*'Had I not had counselling and had I just coped on my own or tried to, I think that there are things that I would now not feel so positive about, so comfortable, I wouldn't have a sense of acceptance.'*

Others commented on the importance of being able to receive support in a non-clinical space. This was particularly important for respondents in Portsmouth, who explained that they had felt intimidated by the MacMillan service available at the hospital, but greatly valued the informal atmosphere of the WCT support centre. The importance of a welcoming environment was echoed by a respondent who stated of the local hospice,

*We went up there once but it was such a cold building and the atmosphere was dreadful, the staff were really miserable and [husband] said, "I can't do this. I don't want to come here. I really don't want to do this*

The fact that the counselling on offer was free to users was seen as a major benefit, particularly to those from low-income households. A minority of people (using WHY) felt that they would be able and willing to contribute a small contribution (£10-20) for each counselling session. However, most people felt that this kind of charge would prevent them from accessing services, particularly when they were already experiencing adverse financial impacts,

*'If you're in a position and like struggling on benefits but you still have to pay whatever you're getting on JSA for the week for a counselling session, do you know like, if it's you, you're almost having to decide between keeping a roof over your head or...'*

All participants were keen to state that they wanted to support the organisation, and many commented that they regularly donated small amounts into collection tins when they attended more informal support groups. People also explained that they tried to 'pay back' to the organisation through fundraising activities, and that they felt more comfortable with doing this than being asked to make an upfront payment for services received.

### **Barriers to counselling**

Six of the participants had not received any counselling from cancer support charities. Of these, 4 had chosen not to. One person hadn't known about the service being available until 2 years after her family had experienced cancer

and did not feel she needed the support at that stage. One person had wanted to access counselling to specifically talk about supporting a terminally ill family member through the dying process, but after an assessment session was told that she was ineligible as she was already receiving counselling from another organisation related to other personal issues.

The time and cost of travelling to attend a counselling session were seen as a significant barrier for low-income participants, particularly when people were reliant on public transport and had little money available to pay for transport.

*'I know there are lots of support groups that run out of Bristol but I don't really get involved simply because of the travel time to Bristol. It takes me about 50 minutes to an hour to get to Bristol, so I don't really do that, on the bus.'*

The investment of time and energy needed to commit to a counselling session was also a deterrent for some people, particularly when they had work or other commitments to attend to, or when appointments only available in the day time meant taking more time out of work,

*'I remember feeling, ooh, I've just finished work and now I've got a 40-minute journey to Frome, I'm expected to talk quite emotionally for an hour and then I've got to get home....it didn't stop me but I can understand that it probably would.'*

*'When life is already really complicated and you are already asking your employer to be flexible in so many other ways, the idea of asking for even more flexibility is not... it certainly isn't something that I would have been comfortable with'*

In some cases, people were not aware that counselling was available to them, even though they regularly used other services provided by the cancer support organisation.

In discussion about barriers to accessing counselling services, many participants felt that preconceptions about what counselling would involve would deter some people, and talked about common stereotypes of counsellors as middle-class people with whom some people would have little in common,

*'I think counsellors tend to be a certain type of person as well, like, because I remember once working for a certain organisation and I described my, the new person being appointed above me as she dresses like a counsellor, and by that I meant she wore a Laura Ashley dress and had beads and my psych at the Harbour didn't dress like that but they were the still same sort of like certain age-range, certain type of person, you know'*

Some people also felt that the idea of accessing counselling was quite intimidating for some people and that the experience itself could be quite difficult,



*'I felt that there was quite a power imbalance to be honest, I sort of felt that I was, they seemed to have a lot, perhaps it was just the way I was feeling, but I didn't feel particularly comfortable personally I have to say'*

Previous negative experiences of other types of counselling received were also a deterrent,

*'Well it [counselling from the hospital] was damaging for a few weeks but it could have been incredibly damaging for other people who maybe didn't discuss it. So he [husband] refused to have any more counselling at all, he said, "I don't want it. I'll just stick with my family, friends, my wife, my kids, they can all... We'll deal with it ourselves"'*

There was also reluctance amongst people from low-income backgrounds to talk openly about their feelings. Resonating with findings from other research, this study found that this was particularly evident amongst men, for whom a need for help was considered a weakness.

*'When I've been involved in support groups, there's often evidence of male attendees at those groups who very much head in the sand, ignored it, no, no, no, I'm not going to show any emotion.'*

*'I think, again, for me, it was my own fault. It's probably the sort of... stigma is too strong a word but I'm too bloody minded really. I'm sort of, "I don't need that, I'm alright". I suppose that comes back to my parents, my dad mainly telling you, "Oh for God's sake, pull yourself together". That sort of attitude. "I went through the war and nobody had counselling then," and all that sort of thing. So it's probably pride. That's probably the word, isn't it? Pride.'*

One person pointed out that access to, and a continuing relationship with, a local GP is extremely difficult in some low-income areas, and that this creates a barrier to referral. They also talked about a concern that in a close community other people would find out,

*'I know quite a few people who lived in quite deprived neighbourhoods up north and for them, do you know, speaking to the GP and you know, getting counselling and that, I know my mates who'd be like, that ain't going to happen in a million years - it's either weakness...or other people who, if it you was looking at one of those tower blocks or whatever, everyone would, as soon as one person knew, everyone would know'*

As previously discussed, many participants felt that experiences of cancer had had a negative impact on their self-esteem. Some participants who had accessed counselling explained that it took them a long time to take that step, and that one reason was a feeling that they were not 'worthy' or that their needs were not as important as others. This was especially true for family members,

*'Cos the thing is right, when you're accessing these kind of services and you need this kind of help, do you know how much is inside of your head and how bad it is relative to anyone else...I felt like a bit of a fraud...I'm not the one*

*suffering from a life-threatening illness, I'm not the one who's got the difficult diagnosis'*

In one focus group this was a common feeling, and people talked about having to reach 'the darkest place' before asking for help.

A minority of people who had received counselling from the three organisations felt that it had not been helpful to them. In such cases, the person felt that they had not connected with the counsellor, and did not feel that they could ask to see someone different. One person in remission felt that the counselling concentrated too much on their diagnosis, stating that the counsellor *'made me feel as though I was still ill.'*

### ***The value of informal support***

Whilst the experience of counselling was deemed important for those who had received it, the benefits provided through more informal support and activities were particularly positively received. For most people, this meant attending regular informal drop-in sessions with other people living with cancer. Such sessions provided a link to people in a similar situation, who people felt they could talk to about their experiences and concerns without having to worry that they were 'burdening' or 'boring' them. People explained how they valued these groups for the friendship and camaraderie that they enabled, particularly important when people had lost previously important social networks. At the same time, it was widely felt that this kind of informal support enabled people to recover or re-invent their identity, and to 'be themselves' without being smothered by concerned family and friends.

*'Although the counselling didn't work, all the support and things I've had since, just the dietician phoning up and asking how I am and talk to me and things like that, going to the drop-in meetings, going to the physio, things like that, together they are counselling, you know collectively, and it's the....I can relate to that counselling and it's done me the world of good. I'll even look forward to going to these meetings and I know it's a bit sad, it's a loads of old dears having cups of coffee and things, but you know, it's quite funny 'cos I - because I'm not at work and I've not got work mates around me, I sort of miss that and that's a bit depressing in itself. But going in on a Wednesday morning and, like they all say, oh 'here comes the kid' and things like that, you know'*

*'It's just being ourselves again. You know, it's like, I think what it is, the way I look at is, when you're ill or when you've got cancer and all the rest of it, you feel as though you're outside of things, you're like, there's something wrong with you and you've been sort of cast out'*

For participants in Portsmouth, the wide array of free services provided in addition to counselling (e.g. massage, reflexology, mindfulness courses) by WCT were especially welcome. Not only did the services make them feel 'pampered' and 'relaxed', but participants were also extremely aware that they were experiencing services that they would not be able to afford in their 'normal'

lives. These kinds of 'luxuries' were therefore considered a welcome, albeit small, counter-balance to the stresses of living with cancer.

Being able to discuss experiences and concerns with staff in support centres and the hospital on an informal basis was also seen as important and therapeutic process, enabling people to feel that they were genuinely being cared for,

*'You phone up the dieticians and we rabbit on about any old rubbish, you know and the last time I spoke to [name], I was on there for an hour or more and half of that time it wasn't about diets and things it was just general things and going to the pub in the afternoon and whatever, you know, and they really do feel - all the ones I've known so far, everybody - they make you feel like they're genuinely interested, which I think they are. And they're more like family than, well they're not nurses and things, and doctors, they're like my friends, you know and they treat me with respect and you know, they're just amazing people'*

*'It's just having someone who cares, I think that's makes the world of difference. Because you've got your own family and that but you, it's nice to know somebody that knows what they're talking about, cares, if you know what I mean.'*

Despite the value of these informal links, people commented that they did not always feel comfortable phoning up such staff as they knew they were busy and did not want to 'waste their time'. This meant that people sometimes did not always know where they could turn to get advice on issues such as treatments, diet and side effects.

### *Improving services*

As reported, keeping the counselling services free at the point of access was considered to be very important for most participants, particularly given changes in their financial circumstances as a result of a cancer diagnosis. Participants explained that financial circumstances can change very quickly when impacted by illness and bereavement. One person commented that their salary did not reflect their circumstances as they had incurred debts through the costs of caring for a close relative in another area,

*'My opinion is, the moment someone just says to you, what's your salary, and then starts making a decision at that point, it doesn't really reflect circumstances...I accumulated a lot of debt, so I was heavily in debt and my credit cards and everything like that, so I'm having to make massive repayments to credit cards at the moment and to deal with all the executor's stuff that comes with that and pay for everything out of my own like pocket'*

Although a small number of people said that they would be willing to pay a nominal fee for counselling, the majority felt that merely having a conversation about their ability to pay, as well as the actual payment, would create a barrier,

*'I think it would be perfectly reasonable to contribute at least £10 for each session if it had been £10 a session or something of that ilk, that wouldn't have stopped me doing it. If it was, say, like £15, £20 or £25 a session, I think that would have made me consider, oh do I really need to do that, because that's quite a lot of money and with everything else going on'*

*'You can make people feel as if they don't deserve having any help because they can't afford to pay for it'*

Because of the difficulty in accessing services, particularly for people who felt that they were isolated in rural areas, some participants felt that an online counselling service would be helpful

*'if they offered some sort of virtual online interaction, that would be good, especially if you are struggling and travelling is difficult'*

This kind of service is already being offered by WHY, with positive feedback suggesting that this may be a viable option for some. However, it is important to recognise that accessing the internet in a private space is not always possible for people from low-income backgrounds.

Some participants suggested that in order to become more accessible to low-income communities the charities should offer outreach services in those areas, which would raise awareness of their availability as well as addressing transport and other access difficulties,

*'Because people might feel comfortable in their own, like, community environment like in a local community centre or something like that...if people knew they were there on a regular day or something'*

Whilst recognising the limited resources available to the organisations, people also felt that access to services could be improved if they were able to offer more appointments outside of standard working hours, for example during evenings or weekends,

*'Part of the problem would be, you know, getting, 'cos I mean at the Harbour, they only operate certain hours during the day, during the week and you know, people might be at work'*

Participants also valued opportunities to link with organisations that could provide advice on poverty-related issues such as debt advice. In Portsmouth for example, people greatly valued the opportunities that were made available for them to see staff from the Citizen's Advice Bureau within the WCT support centre.

It was also agreed that more information could be made available to people about the different types of counselling that were available, the process they would go through, and the person they would receive as a counsellor. This, it was felt, would help dispel negative preconceptions around counselling and help people better prepare and inform themselves.

*'I think a little bit of information about them, a bit about their background and you know, because I actually looked up my therapist on the website and I couldn't find her anywhere, I looked through hundreds of people and I thought they were supposed to be registered but I couldn't find this person. So I was a bit surprised and just wanted to know a bit more about the background and stuff, but I was sort of made to feel that that wasn't really right to be asking questions'*

*'I was very grateful for what I had, but it wasn't what I expected particularly'*

Some participants also felt they were in a vulnerable position when they accessed counselling and would have liked to have more choice about the therapist that they saw. They stressed the importance of ensuring that you feel comfortable and 'click' with the practitioner and their approach in order to build a relationship,

*'it was like this is what you're getting. You see I didn't feel there was that choice'*

A number of participants explained that they felt that they couldn't access services until they were facing significant challenges. Similarly, some carers felt that they didn't feel like they were entitled to support when their role as carers ceased following the recovery or the death of the patient. Ensuring that people know that they are able to access counselling at any point and that they can do so before they reach crisis point is important.

Many participants felt that there was generally a lack of knowledge of the services' existence, even within health services, and that this was a major barrier to access. The most potentially effective referral routes were felt to be through healthcare professionals and settings, including hospital cancer wards, cancer support nurses and GP surgeries. Many people had sought support through Macmillan as a high profile cancer support service, and felt that this would be another important referral route.

## **Recommendations**

### Impact on well-being and social networks

1. Parents and carers should be routinely signposted by health professionals to the psychological support that is available.
2. Clinical Commissioning Groups should support activities at a local level that can bring people together to share experiences and offer advice and guidance in appropriate and accessible settings in the community.
3. Investment by commissioners in local charities and organisations that are delivering psychological support services to enable them to develop programmes of activity, and share best practice would be welcomed.
4. Organisations working to support people from low-income backgrounds should work with this patient group to develop programmes of support that are appropriate to their needs. Investment by commissioners in this kind of co-created and engaged work would be welcomed.

### Financial implications

1. Funding and collaboration amongst local organisations to develop a cancer community transport scheme that could help people travel to hospital appointments and access support would help to make services more accessible to low-income, and other patients.
2. Links should be enhanced with local CAB offices and others working with people from low-income backgrounds to enhance signposting.
3. Funding for Care/Financial Co-ordinators who would help individuals and families navigate the benefits system to ensure that those eligible are able to claim for the support they require would be welcomed.
4. There is a need for sustained local investment in the development of activities that are free to access, and enable individuals and families to participate whatever their income.

### Experiences of Counselling

1. The value of specialised/relevant counselling services was said to be “infinitely more relevant” than generic psychological support. We recommend that resources from the NHS are focused on this area for cancer patients and their families, as the life expectancy of cancer patients continues to rise, so does the demand for the limited, often charitable, services that are provided currently.
2. Further is required into the longer term impact of specialist counselling, particularly as a support mechanism to enable people to feel better equipped to understand and accept their situation.
3. Our report shows that specialist support is best delivered in a community setting, with travel often being cited as a difficulty for people. Investment by charities, and the NHS in new technologies, such as online, telephone or email counselling is required to ensure that those with limited mobility, or finances are still able to receive the support they require.

### Barriers to Counselling

1. Financial constraints are a significant barrier for those from low-income families to accessing psychological support. We recommend that investment is made to support people to access these services – this could be, for example, through facilitating transport through travel grants, or volunteer driving schemes, and/or for counselling work to be supported within the local community through outreach services.
2. It is recommended that further resourcing is allocated to raising awareness of the services that currently exist, as some participants were not aware of support that was available to them.
3. Perceptions of counselling in some instances acted as a barrier to accessing support. Those providing specialist counselling need to understand this in more detail to help them improve their communication about the services that are available.
4. Health professionals, including hospital staff and GPs often act as gatekeepers for psychological support services. It is vital therefore that health professionals are aware of the services available in their locality. Further awareness raising is required by those providing community services to the relevant clinics both in hospitals and at community GP services to ensure that staff are aware of the support that is available and can signpost people to those services.

### Value of informal support

1. Those providing counselling should consider the development of, or signposting to, local peer-to-peer support networks such as drop in clinics and coffee mornings, as the support gained by meeting people in a similar situation was found to be very therapeutic by those we interviewed.
2. We would recommend that organisations continue to offer a diverse range of services, and where appropriate link to other services that may be able to offer this additional support. Services such as massage, reflexology and mindfulness were felt by participants to contribute to a therapeutic experience.

### Improving Services

1. Continuing to keep counselling services free at the point of need was felt to be extremely valuable and should continue.
2. Investment by the charities into new technologies would be advised, this would help with some of the issues around travel and accessibility, although internet coverage does need to be considered when setting up such a service.
3. Organisations providing counselling should co-operate with other local service providers working with low-income communities to explore the

possibilities of developing outreach or drop in support sessions more locally.

4. Investment in promotion of the services is vital if awareness is to be raised. This can be done through a number of channels and locations and may also help to break down some of the barriers and misconceptions of counselling. Working with low-income patients to devise promotional materials will ensure they are relevant, engaging and appropriately targeted.
5. Offering services at more flexible times, e.g. evenings and weekends would make support easier to access for those working and should be considered.