Exploring people's experiences of finding out about health and social care services

Report of findings

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Acknowledgements

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Executive summary

Background and method

- This qualitative focus group study aimed to explore people's experiences of finding out about health and social care services in Essex, and understand potential ways of improving people's information-seeking journeys.
- Eight focus groups were conducted between October and December 2013 with a range of people, including young people, disabled people, informal carers and people with mental health conditions. A total of 59 people took part.

Findings

Experiences

- Participants described frequently only obtaining information or being directed to services in informal ways, for example 'stumbling across' information following chance meetings with people in similar situations to themselves.
- Health and social care professionals were perceived to be ideally placed to provide information and signposting to health and social care services but lacked time and knowledge to be effective in this role.
- Information and signposting by health and social care professionals was reactive and failed to take into account people's holistic needs, including, for example, emotional support needs and changing needs across key transition points in people's health and social care journeys.
- It was often down to luck that people received information and signposting from health and social care professionals, and sometimes only when they were in contact with professionals for a non-related reason.
- Written information was sometimes provided by professionals, but this was viewed as impersonal and unhelpful when not given in conjunction with personal communication and support.
- Use of the internet to seek information was popular, especially for personal or sensitive issues.
- Poor website design, accessibility issues, and finding information were all barriers to successful use of the internet.
- Conflicting, overwhelming, out of date and inaccurate information were all issues for people using the internet to find out about health and social care services.
- The internet was also perceived as less helpful for finding local information and personalised or individually-tailored information.

- Health and social care staff who responded to telephone queries for information were often lacking knowledge about services, listening skills and the ability to volunteer comprehensive information.
- People often had to make multiple phone calls in order to obtain information, or were passed on to other departments and services with no-one taking responsibility for answering queries and questions.
- Social Care Direct was experienced as being particularly difficult to obtain information from.
- There was a lack of information around mental health issues, including information about signs and symptoms of mental health conditions, and information about crisis support.

Suggestions for improvements
- Participants wanted a **one stop shop** for information and signposting to local health and social care services.
- A one stop shop should provide **locally-specific and detailed information** about statutory and voluntary and community sector services.
- A website and telephone helpline contact details should be **extensively publicised** to ensure broad awareness.
- Information should be available in **multiple formats** and be accessible outside normal working hours.
- Of particular importance was a physical presence where people could obtain **face to face support** with their information and signposting queries.
- Staff recruited to provide information and signposting should receive full training to ensure they have a **sympathetic and empathetic attitude**, and the skills and ability to gain a holistic understanding of an individual client's needs.
- Staff should take **ownership of queries** and ensure that clients are kept up to date with progress in obtaining information.
- **Peers** (who are paid and trained) were viewed as especially valuable in information and signposting roles.
- **Information outreach, link and liaison officer roles** within health and social care organisations would ensure that people's information and signposting needs are met at the point of care.

1. Introduction and background

Essex County Council requested that Healthwatch Essex undertake a scoping exercise to determine the potential nature of an integrated signposting resource for health and social care services across the county. The scoping exercise aimed to gather stakeholder input from the widest possible constituency of commissioners, providers and consumers and to use this to develop a model that will meet the needs of organisations as diverse as hospital trusts, CCGs, voluntary bodies and service providers.

A desktop review was conducted to understand existing research in this area. This highlighted the need for up to date and local research to understand the views and experiences of people in Essex. Evidence from existing studies shows that information needs are variable and complex, depending on people's situation and circumstances. Different people or groups face different barriers to obtaining information.

In order to develop a model that places patients, service users, carers and members of the public at its heart, Healthwatch Essex has run a series of focus groups as part of the scoping exercise outlined above. These focus groups involved a diverse range of people with a view to obtaining multiple perspectives and insights into local people's information and signposting experiences, preferences and needs.

2. Purpose and aims

The purpose of the focus group research is to ensure that the views and experiences of people who need information and signposting can be considered in proposals for county-wide information and signposting provision covering health and social care services in Essex.

The aim of the focus groups was to explore and understand people's experiences of finding out about local health and social care services, specifically:

- the sorts of information people needed in their particular situations, and why/when they needed information;
- where people got information and how easy this was to do;
- quality of information and/or signposting people received;
- people's suggestions for improvements to information and signposting services.

3. Design, methodology and ethics

A series of eight focus groups were planned and set up with the assistance of local voluntary sector organisations. In order to ensure that the views and experiences of a diverse range of 'consumers' were included in the research, Healthwatch Essex approached a range of voluntary sector organisations that work with different groups, either based on age, geography, disability, health condition or a combination of these. This recruitment approach meant individual focus groups were reasonably homogenous, ensuring a constructive group dynamic with participants that were comfortable with each other, and that the experiences of a range of people were explored across the groups.

Using focus groups to explore and understand people's information needs and highlight problems or barriers to accessing information was beneficial for this research in two main ways:

- obtaining multiple views and experiences in a short period of time;
- interaction between participants in the group setting produced useful insights, especially relating to suggestions for improvements to existing information and signposting services.

An approach letter was sent to voluntary sector organisations asking for their assistance and offering an honorarium payment for recruiting focus group participants and arranging a venue (see appendix A). These organisations then invited people to take part, sending an invitation letter and information sheet about the research on behalf of Healthwatch Essex (see appendix B/C).

Focus group participants signed a consent form prior to taking part in the group discussion (see appendix D). Each group was moderated by two researchers (report authors) using a focus group topic guide (see appendix E). Focus group discussions were digitally recorded and transcribed verbatim. Data from the focus groups were analysed using the framework approach, to identify key themes and allow for exploration of similarities and differences across the groups.

This focus group study was reviewed and granted ethical approval by Essex County Council's Research & Analysis Unit Research Governance Group (Ref: 09/10/13).

4. Sample

Eight focus groups were carried out over a two-month period from late October to early-December 2013. A total of 59 people took part in the eight groups, of whom 35 were female and 24 were male. Table 1 below provides details of the focus groups and a breakdown of focus group participants.

Table 1: Focus group participants

Group	Participants
Carers (LD)	8 participants (7 female, 1 male) • Parent carers of adults and children with learning disabilities including Down's Syndrome, severe learning disabilities and autistic spectrum disorders
Disabled people	9 participants (5 female, 4 male) • 7 participants with range of disabilities including vision impairment (blindness and low vision), physical disability, developmental disability and mental health conditions • 2 participants with expertise in information and signposting for disabled people
Family carers	9 participants (6 female, 3 male) • 7 participants with full time caring responsibilities for spouses or partners with range of conditions including dementia, Parkinson's, ME, MS and mental breakdown • 2 participants with filial caring responsibilities
General users	6 participants (2 female, 4 male) • Range of health and social care experience including participant with chronic life limiting disease and participants with family caring responsibilities • Group included volunteers for Citizens Advice with experience of information and signposting for CAB clients
Mental health	4 participants (3 female, 1 male) • Group included service user and statutory and third sector service providers with experience of information and signposting for mental health service users and family carers
Older people	6 participants (4 female, 2 male) • Range of health and social care experience including family caring • Group included volunteers for Age UK with experience of information and signposting for Age UK clients
Refugees/asylum seekers	8 participants (4 female, 4 male) • Refugees/asylum seekers from Zimbabwe and Sierra Leone
Young people	9 participants (4 female, 5 male) • Aged 16 to 18 years
Total	**59 participants (35 female, 24 male)**

5. Findings

5.1 Experiences

Across the eight focus groups there was consensus that obtaining adequate information and signposting in relation to health and social care services was dependent to a large extent on luck. Participants described frequently only obtaining information or being directed to services in informal ways, for example 'stumbling across' information following chance meetings with people in similar situations to themselves.

> *"I'm new to the area and if it wasn't for the fact that I bumped into someone with a guide dog that I started talking to, I wouldn't have known about the support in the area."* (Disabled people group F12)

This situation was viewed as inadequate and people did not want to have to rely on peers for information. However, participants experienced various challenges to obtaining information through more formalised channels. These difficulties were related to the role played by health and social care professionals, use of the internet, and the skills of staff answering information and signposting queries. A key area of concern was the lack of information available relating to mental health issues. These challenges and concerns are discussed in more detail below.

5.1.1 Role of health and social care professionals

Although focus group participants felt health and social care professionals could and should play a key role in information and signposting, they were realistic about the challenges to professionals being effective in this role. Professionals were perceived to lack both the time and knowledge (especially of local voluntary and community services) to be effective. GPs and consultants, for example, were viewed as being ideally placed to provide information about health and social care services, but in reality it was often down to luck, whether people would receive adequate information and signposting from professionals or their GP practice.

> *"I think a lot of it for service users is pot luck as to where they hear about services…It's not a postcode lottery, it's like a member of staff lottery, if you get a good GP, or a good person … at the trust… that then can ...just completely widen [your] options…whereas [you] could come across a staff member that isn't so good at giving out the information."* (Mental health group F7)

"I'm very fortunate to have been referred to my local hospice but there are many people I imagine with neurological diagnosis, who may only see their consultant once a year, who don't go to a hospice. So how do they understand where they can get chiropodist or a dietician, people who can't swallow food anymore, where do they go if they're walking becomes so ... if they're a single person with an annual trip to see a neurologist, living on their own, aren't a patient of a hospice, I don't know what they do." (General users group F9)

"GPs don't put out the leaflets…they say 'You've got X condition, see you in six months'. Where is the information we need? No one is there for us." (Family carers group, M00)

Focus group participants felt that professionals tended to concentrate on health or social care issues in isolation and often failed to see the 'whole person' and how their needs were interrelated. This meant professionals did not make a holistic assessment of an individual's needs and offer sufficiently tailored information and signposting in response to these needs.

"There's always more than one thing, [but] they [medical professionals] don't seem to ... see that, they don't see you as a whole person…when it comes to supporting people emotionally, [ ] I don't think… [the NHS] recognises that and it would be better if they could link more to say 'Okay, we haven't necessarily got the time to support you emotionally but we know there's this, this and this', signposting to all of these wonderful charities." (Disabled people group F11, 23)

Focus group participants also felt that information and signposting tended to be offered in a reactive way once people had reached a point of crisis. This was frustrating as people saw information and signposting as having preventive potential, enabling and empowering individuals to access support and services that would hopefully ensure they did not reach crisis.

"They wait until you're in crisis before you get offered anything. That's the thing that's sad because I don't want to be completely disabled before my child gets support, just because nobody is listening and I'm coping." (Carers (LD) group F23)

"Doing the voluntary work, I'm now seeing people that are newly visually impaired and they're just so isolated because they're told they've got bad eyes, they're told this is going wrong, this is going to happen, this is your next hospital appointment ...

and then they're just left to get on with it and they don't know there's all these things out there and what's available and what help's available." (Disabled People Group F12)

"All through life, all the transition times, from birth and diagnosis, starting school and then the transition into secondary school and then adulthood and further education, they're all key times when you need a lot of information to be able to make the right choices for your child… you need the information to be able to be on the correct path and all the services that are available." (Carers (LD) group F11)

Focus group participants often obtained information or were signposted only by chance, following contact with a health or social care professional that was unrelated to the issue for which they needed information or signposting.

"The first time I realised that I wasn't well informed with my sons was when – and I think it was a paediatrician when… one of them had a school medical and said, 'Of course you get DLA?', and nobody had told me that they could be entitled to that… and I said 'But nobody's ever told me about this' and that was the first time I realised that there were things I should have been told about and the boys were entitled to." (Carers (LD) group F7)

"Luckily I had another child…and the heath visitor came to visit me and my older son was in and out of hospital, he was still in nappies just before he started school and I was finding it extremely expensive and …hard to cope …She just asked me the simple question, 'How are you coping with the hospital?', I said 'That's fine, I can cope with all that and the travelling but paying for these nappies and trying to find these big nappies', she said 'Aren't you getting them free?' and that was the first I knew and then she said, 'Aren't you getting DLA?'...She made such a difference…she gave me the information to help me." (Carers (LD) group F10)

Where professionals did provide information and signposting, this was sometimes delivered in an impersonal way, without additional communication and support, and did little to reassure people. Often, printed information was out of date, containing contact information for organisations that no longer existed, or had changed their names and telephone numbers. Information was also given that was relevant for specific geographical areas within Essex only, and therefore not useful for people living outside those areas.

"Somebody lying in a hospital bed with the thought of having part of their body removed and all they get is a five or six page pamphlet from the trust saying, 'There you go, that's what happens, go away and read it', nobody comes to discuss it with them and nobody sits down with them… consultants I don't think have got the time to spend bedside manner, explaining everything but there should be a back-up to the consultant, [someone] that's coming through on the wing, to say 'Right, now we'll help you go further'." (Disabled people group M5, 12)

5.1.2 Use of the internet

Focus group participants explained that the internet was often the first port of call for seeking information. For young people and people with mental health conditions, the internet was often seen as a preferred source of information, particularly for information of a sensitive or personal nature.

"I wouldn't consider going into school and asking some of the medical staff about a problem… I'd rather just Google it." (Young people group M4)

However, a number of problems with using the internet were raised by focus groups participants. Poor website design was frustrating for many, including for people with disabilities for whom many websites offered only limited accessibility.

"More and more information [is] now web based because it is cheap to produce and easy to produce and it's easier to send people off to a website [but] so many of those websites are totally inaccessible because of their design… it isn't only sighted people that have the problem, there are different problems for different disabilities." (Disabled people group M10)

Focus group participants discussed how it could be difficult to find information on the internet, and if they were successful in finding it, there was then the issue of the extent to which information could be considered trustworthy. Information might be biased depending on who was responsible for posting the content (for example, drug companies), or unreliable and out of date. The internet also often resulted in overwhelming or conflicting information.

"I got like 50 billion things, all slightly different, there's American versions and English versions and you just don't know what one to look at because they're all slightly different… It's a bit hard because you can't really trust, if you find one website which you think you can trust then look at another one to compare and they're completely

different, that's why people don't usually trust certain websites." (Young people group F6)

"As far as the internet's concerned… older people find it difficult because there's so much information, and a lot of them don't use it because it's a lot of hassle." (Older people group F19)

The internet was also seen as less useful in relation to local information being available and kept up to date, and personalised or individually-tailored information.

"Websites are not the answer by themselves, they are part of the answer; they're particularly good at either the very technical stuff at one end of the very general stuff at the other. As soon as you need interaction and a discussion happening, then forget it, a website's hopeless." (Disabled people group M25)

"There are different services in different areas and so… it's not always relevant for the whole of an area, it's having small localised services and where do people go for that knowledge, that expertise?" (Mental health group F10)

"If I look at my condition on NHS Direct, it gives me MIND and Rethink, it doesn't delve into any local levels… what I didn't know, there was a local support group for me as well. So on a national level, I think information's a lot easier to find because you just Google it." (Disabled people group F5, 14)

Finally, the internet did not help when people did not know the questions they needed to be asking.

"If you don't know the question, how do you look for the answer? If you don't know there's something out there, you don't know to ask for it." (Disabled people group F22)

5.1.3 Skills of staff answering information and signposting queries

An area frequently reported by participants as a key cause of frustration was the skills of health and social care staff answering telephone queries and dealing effectively with those. Participants discussed a number of problems when seeking information about health and social care services including staff being unknowledgeable about the issue that they were providing the service for, poor listening skills, and not being honest and open about when

they didn't know something. In contrast assistance from staff that took the time to listen, were knowledgeable and volunteered comprehensive information, and treated people compassionately eased people's frustrations.

> *"If I talk to [one person], he's curt, rude, gives the minimum of information, only gives you what you specifically ask for. I talk to [another person] and he lays it all out in front of you and tells you what you want to know without you even asking the questions…The person that you talk to can be as nice as pie and they can help you a tremendous amount, or they can just do what they've got to do to get rid of you."* (General users group M14)

Often, focus group participants experienced being continually passed on to another department or service, sometimes going round in circles and having to make multiple telephone calls to get the information they needed. This was experienced as frustrating and emotionally draining because of the time-intensive nature of chasing information and the emotional energy required in disclosing complex personal circumstances to multiple personnel.

> *I've phoned up for something before now and it's been about my third or fourth phone call before I've got to where I need to be, to get that information. Well we haven't got time for that."* (Carers (LD) group F28)

> *"Social Services say 'Oh no, you don't need to phone me, you need to phone [the domiciliary care agency]' and then you phone [the domiciliary care agency] and they say 'No, it's the doctor that should be dealing with that', and by the time you've finished with four or five phone calls trying to get round, you end up back with the social worker… you really don't know where to go, who's responsibility it is to sort out what question."* (General users group F21)

Focus group participants described more positive experiences in relation to telephoning NHS Direct compared with Social Care Direct.

> *"They must have the right training on that phone because the phone is the first point of contact… NHS Direct took a while to get it right and I'm not sure they've done it but they're getting there."* (Disabled people group F28)

Social Care Direct seemed to be especially difficult to access information from, with participants describing long waits to get through, and then poor communication with staff who they felt lacked knowledge, did not listen properly, and were not empathetic.

> *"You phone somebody … and the person you're speaking to doesn't understand what you're talking about. Let's be honest, they've got to have a massive mindset to cover all the disabilities that might phone through to them and I feel for them for that, but the general, the basics are not ask silly questions and that's a polite way of putting it and having to constantly repeat yourself because they're not listening to you."* (Disabled People Group M7)

> *"You can get all sorts of really good information off [the internet] as to the sort of services that are provided … but when it actually comes to accessing those services …the actual contact then can sometimes leave a bit to be desired… The problems [we] had accessing the right sort of information and the right sort of services [for our disabled step daughter]… There was just a lot of ignorance on behalf of the social workers."* (Older people group M6)

5.1.4 Information gaps – mental health

A key theme to emerge across the focus groups was the lack of information available relating to mental health, including signs and symptoms, sources of support and local services and information about benefits.

> *"A lot of my friends started getting depression through school… I knew that they had depression; I didn't know how to help them… I wasn't aware of who to go about it and it got to a point where one of my friends was considering suicide."* (Young people group M3)

> *"My Dad had quite a heavy case of depression… my Mum and sister didn't realise and it almost got to the stage where it was too late, so it's the sort of thing that I feel there should be more put out, more information… it should be clearer in the public eye, signs of depression." (Young people group M2)*

> *"I recently went to my GP surgery, had 10 minutes to spare, walked around the notice boards, nearly every wall was covered with some kind of leaflet or campaign or public notice, there was a tiny one about mental health… I was told there are no public notices about mental health and that's true, I'd never seen an advert or a*

poster, other than dementia, never, ever seen the clinical signs of mental health and I wonder why, there's always ones for heart attacks and strokes and diabetes, why is there never one for mental health?." (Mental health group M3)

Information relating to mental health was perceived as being only available to people who had already been referred to mental health services and that information at an earlier stage, available to and aimed at both individual and family members, would provide a preventive source of support. Such information should be available in a variety of locations including GP surgeries and pharmacies.

"At the moment, information [about other support services] is only provided when someone is quite a long way down the journey…someone maybe goes into hospital or has crisis support… and it's perhaps as they're getting better…whereas it would be good if people knew about services when they were becoming unwell, or could maybe be prevented from deteriorating." (Mental health group F21)

It is of particular concern that focus group participants felt that information about how to get crisis support was confusing and not readily available.

"The last time I had a psychotic episode which was about two years ago, we didn't have a clue who to contact so we went through our GP who put us through to the trust, who said "you can phone a crisis team", couldn't get through to them, we had a horrific journey the first time because we didn't know they existed… It gets confusing, there's different numbers for different times, which is a bit of a problem." (Disabled people group F19)

"People need to know who to contact in case of a crisis. Crisis contact information is particularly important to relatives and it's not readily available." (Mental health group F6)

Mental health problems were frequently brought up in the discussion among refugee and asylum seeker focus group participants. There were particular stresses associated with their asylum seeker status, including living in overcrowded or temporary accommodation. These issues which meant there was often associated anxiety and depression, which without access to benefits and the ability to pay for prescriptions was sometimes self-medicated with alcohol.

"With Britain, all our things are not moving and one thing which is killing us, making us all sick like this is because of stress which they put you, you want a place to stay, you want a place to work, so that you can do something in this country but you can't." (Refugee/asylum seeker group F7)

"You end up going for a cheap beer in the supermarket, you drink yourself totally out!" (Refugee/asylum seeker group M15)

5.2 Suggestions for improvements

There was consensus across the focus groups in terms of suggestions for improvements to information and signposting services. Focus group participants felt that there was a clear need for a centralised one stop shop approach to the provision of health and social care information and signposting. This approach should combine a well-publicised single point of contact, comprising a website and telephone helpline. It was considered crucial that a multi-media approach to the provision of information was taken, in conjunction with a physical presence in the form of local information hubs where people could access locally-specific and face-to-face information and signposting support. Careful recruitment and training of staff was seen as vital in ensuring a quality one stop shop service. Finally, focus group participants also discussed the importance of trained (and paid) peers, or outreach/liaison workers in information and signposting roles.

5.2.1 One stop shop

Focus group participants felt there was a definite need for a centralised repository of information about local health and social care services. This would ensure that patients, service users, carers and members of the public would know that they could obtain information from a single, trustworthy source.

"[People] don't know where to go to the get the information … Particularly when things often happen very suddenly in life and things change quickly and often [people] are trying to root around to find out about housing, care, all this kind of stuff, and they don't know where to go. So to have one central point to go to who can say this is what's available, these are the kinds of things that might be available to you, this is how you contact them, is very good." (Older people group F6)

It was particularly important to focus group participants that the one stop shop would be able to provide locally-specific information, relating to statutory and voluntary and community sector services available in particular geographical areas of Essex. This information also

needed to be as detailed as possible regarding actual services provided, dates, times and venues for group meetings and information on how to get to venues including public transport provision.

> *"I'd like to be able to put my region in so that I can pick up my postcode, my local support groups, I can find out how many members each of them have, what they talk about, whether they have guests, I want as much information as possible."* (Disabled people group F14)

> *"[I want to know about] actual individual services that they provide…not just…'Here's a leaflet about the service provider with the basic list of services'. That doesn't say anything to me, I want more information."* (Mental health group M17)

> *"We don't get the right information about what services actually do."* (Family carers group F00)

Focus group participants also talked about the importance of publicising the website address and telephone helpline number for a one stop shop.

> *"I think I'd want big advertising, I'd want radio, online, TV ,newspaper, press, everything, I would want to be able to know as much about where I can get [information about] health and social care [services], as I do about how to stop smoking, put it that way. I want to know it so well that it's second nature.*" (Disabled people group F36)

> *"We all know 999, I think we're all beginning to get to know 111…but if there was a central point for people to ring in…and then that could act as the signpost to… whatever's located in your area...The most efficient way of doing it would be just to have a single number in the area which people can ring and…to spread information about that number and make sure everybody in the county has got that number, and then people can be referred on to other specialist advisers."* (Older people group M18,19)

5.2.2 Multi-media approach and a physical presence

Focus group participants felt that a one-size fits all approach was not suitable in meeting different people's information needs. They wanted information to be available in multiple formats including interactive and multi-media formats. Websites needed to be accessible

and information services should also be available outside working hours. It was felt that such measures would ensure that information was as accessible as possible.

> *"If there were a hub it's no good doing it in Braille, audio and printed, that's not good enough, you need to be read by someone who has dyslexia, you need to understand that someone with chronic fatigue syndrome will access your service at midnight, it has to be accessible to everybody and it shouldn't just be 'We'll make it as accessible as possible', that's not good enough." (Disabled people group M28)*

> *"You've got to think that most people of our age join social networks so if you used the likes of Twitter, Facebook, whatever, just use that and you'd get your point across and people would understand it."* (Young people group M21)

Perhaps most important for focus group participants was that any one stop shop should also have a physical presence. While focus group participants were keen to have a website and telephone helpline, they also wanted opportunities for face to face contact when searching for information. A variety of ways of doing this were mentioned in the groups, including having information points in existing locations (such as Post Office, pubs, GP surgeries, libraries) or via individual information champions. Village agents, Neighbourhood Watch or local area coordinators based on the Australian Local Area Coordination model were discussed as having a potential role in the provision of information and signposting for local health and social care services. For more rural areas, mobile units were also seen as a means of ensuring a physical presence for a one stop shop.

> *"People at a desk to talk to... real people! Citizens Advice are nearly there I think. The model's a good model, even if they don't have enough appointments or staff, it's a good model, having a physical base."* Disabled people group F32)

> *"I know it's gone out of fashion a long time ago, but to have a local resource presence…[a] physical presence where people can just pop in, where all the different providers, statutory or other, have some sort of investment, whether they have someone there one day a week or more than that or less than that or they make sure they keep their information up to date and everyone knows about each other."*
> (Mental health group F19)

Face to face communication was also valued as a key means of obtaining personalised and individually-tailored information that was not possible to get through other information gathering methods such as use of the internet.

> *"There's nothing like having a conversation face to face with someone and you ask them the question, 'What can I do about this?' and they tell you and then you say, 'Well yes, I understand that but in my case, I can't do that because so and so', and you can really get down to the nitty gritty of things, which you can't do on a computer. (General users group M8)*

> *"I needed the face to face to get the information I needed, to find out what information I could get, so the websites wouldn't have done it because when you're using the Screen Reader, you get bored, you get half way down, you haven't found what you want and you go away and do something else to be honest."* (Disabled people group F25)

> *"If you're speaking to an individual it's quicker than either filling in a form or looking on the internet, plus you've got your own unique questions and unique situation and a person can answer your individual questions or say, "I can come back to you", or whatever."* (Older people group F13)

5.2.3 Importance of recruitment and training

Focus group participants emphasised the importance of recruitment and training of information telephone line and helpdesk staff with the skills both to search for information and signpost, but also to reassure callers and visitors. They discussed how it was often the sympathy and empathy of people answering information queries that was most helpful, and that even if information and signposting was not provided, sympathy and empathy could be helpful to the person seeking information in beginning to cope themselves.

> *"It's partly about attitude…If that person has shown some sympathy and listened to me, even though they couldn't do anything, it would have helped me…Because you get a feeling that somebody cares about my particular problem, that's good and it makes me feel better, and actually helps me to cope in very practical ways as well. Just the simple act of talking to someone who acts sympathetically and responds sympathetically."* (Older people group M13)

"It's the personal touch, whereby people are getting support by speaking to somebody rather than sitting on their own reading something, and still not quite understanding where they are. It's very impersonal, looking up things on the internet, especially if you're upset or you're vulnerable, you probably need a little bit of comfort, a little bit of reassurance". (General users group F8)

"The relief that somebody is listening to me at long last. May not be able to do much but at least they're listening and be able to suggest which way to go… that can make such a difference…information and how it's delivered is so important." (Older people group M10)

There was also discussion of the ability of staff to ask questions of the caller or visitor that would enable them to obtain a more holistic picture of their health and social care needs. For example, an individual might call with a single issue or query, but the right questioning will reveal multiple issues for which information and signposting can be helpful.

"It's nice to be able to come to one place to be able to get information on a number of subjects…Expertise…makes a lot of difference because …[it's] the capability, I think, to be able to find the problems that people have. …They might come with one problem and actually there might be five or six more problems behind that one." (Older people group F8)

"They can sense your frustration sometimes and come to your rescue, where you wouldn't normally have asked the question, they're actually giving you information that you didn't know you wanted at one time." (Disabled people group M26)

The focus group discussion with refugees and asylum seekers also revealed the importance of cultural awareness of staff and a basic understanding of the range of needs (and obstacles to obtaining information and support) for this group.

Finally, it was important that staff took ownership of queries and made every effort to keep the caller fully informed as to the progress or otherwise being made in searching for information.

"That first contact, that person that picks the phone up is the most important person in the world, if they actually give you the impression they might know something of what you're talking about, then you've got the confidence to carry on speaking to

them…I don't mind even talking to someone if they say, 'I don't know but I'll find out'
... And as long as they come back to you with the information. Even if they come
back and say, 'Sorry, I haven't been able to find out anything but I'll keep digging for
you'." (Disabled people group M27)

5.2.4 Role of peers and information outreach/liaison workers

There was also frequent mention of the usefulness of peers in information and signposting roles. Focus group participants felt that peers who were paid and had undertaken training, were particularly helpful in empowering people through sharing their knowledge of navigating health and social care services and sources of support. Peres were able to connect with the individual searching for information, and offer their own lived experience to support others in their information seeking journeys.

"Empathy, the first point is empathy. If you speak to someone who's been there,
understands it, you've got a connection straightaway, this is what the peer support
training does." (Mental health group M13)

"You feel like you're on your own and I feel parents and carers are a very good
support for each other because without having to say anything, you already know half
their life story because you've been there." (Carers (LD) group F11)

Whether staffed by peers or not, focus group participants also placed value on outreach, link worker and liaison officer roles within health and social care organisations. Such roles were seen as vital in providing local information and signposting for people at point of diagnosis, consultation or treatment.

"They're calling it a 'carers advisor' but call it what you like, the label is not relevant is
it? It's the role and somebody should be able to say 'I've made you an appointment
with Mrs Jones and she will be able to talk you through all the kind of things that are
local', and you can ask her, and she should be able to know all these things, but they
get rid of these people and then just keep printing brochures – but actually get rid of
the brochures and get some people!" (Carers (LD) group F21)

"Having a dementia support worker at our hospital is a really good thing to do…It's
right on the spot…you don't have to go looking for them. They know what's out there,
I hadn't got a clue" (Family carers group F00)

6. Summary

This qualitative focus group study aimed to explore people's experiences of finding out about health and social care services in Essex, and understand potential ways of improving people's information-seeking journeys. Eight focus groups were conducted between October and December 2013 with a range of people, including young people, disabled people, informal carers and people with mental health conditions. A total of 59 people took part.

The study found that people's experiences of information and signposting in relation to health and social care services were variable, dependent to a large extent on luck, and lacked local detail. Various challenges to obtaining information were discussed, including:

- the lack of time and knowledge among health and social care professionals to effectively listen to patients, carers and services users and provide individually-tailored information and signposting;
- conflicting and unreliable or out of date information obtained via the internet; and,
- poor communication skills of staff and a lack of care and compassion being shown when answering information and signposting queries.

A further key area of concern was the lack of information available relating to mental health issues.

There was widespread consensus that a new, centralised and consolidated approach to health and social care information and signposting was needed. This one stop shop approach should combine a well-publicised single point of contact, comprising a website and telephone helpline. Focus group participants wanted a multi-media approach to the provision of information, as well as a physical presence in the form of local information hubs where people could access locally-specific and face-to-face information and signposting support. Careful recruitment and training of staff was seen as vital in ensuring a quality one stop shop service was provided where service users felt they were treated with care and compassion. Finally, focus group participants also discussed the importance of trained (and paid) peers, or outreach/liaison workers in information and signposting roles.

7. Appendices

healthwatch Essex

RCCE House
Threshelfords Business Park
Inworth Road
Feering
Essex
CO5 9SE

[insert date] 2013

Dear [insert contact name for organisation/group],

Request for assistance with research project

I am writing to you about a research study looking at people's experiences of finding out about local health and social care services. The study is being funded and carried out by Healthwatch Essex. Healthwatch Essex is the new independent consumer champion created to gather and represent the views of people who use health and social care services. The purpose of the research is to ensure that the views and experiences of people who need information and signposting in relation to health and social care services can be considered in proposals for county-wide information and signposting provision covering health and social care in Essex.

In order to understand people's views and experiences of finding out about local health and social care services, we are running several focus groups across Essex. We would be very grateful if you would assist us with recruiting participants for one of these focus groups. We would like to run a focus group with six to eight people that you are in contact with. The focus group could take place either at your organisation or another suitable local venue that you could suggest to us. The focus group would be run by an experienced focus group moderator/facilitator and would last between 1.5 and 2 hours. The topics covered in the focus group will include:

- The sorts of information people have needed in their particular situations, and why/when they have needed information;
- Where people have got information needed and how easy this was to do;
- Quality of information and/or signposting people have received;
- Suggestions for improvements to information and signposting services.

We will provide you with copies of a letter and information sheet to give out to potential participants (please see attached) and will liaise with you regarding the date, venue and time of the focus group.

Continued overleaf

As a thank you for your assistance in recruiting a focus group on our behalf Healthwatch Essex will make an honorarium payment to your organisation. If you would like any further information please contact me by phone on 01376 572829 or email clarissa.penfold@healthwatchessex.org.uk.

We really hope that you will be able to assist us in this research which will allow us to understand people's views and experiences in more depth.

Yours sincerely,

Clarissa Penfold

Lead Researcher, Healthwatch Essex

healthwatch
Essex

RCCE House
Threshelfords Business Park
Inworth Road
Feering
Essex
CO5 9SE

[insert date] 2013

Dear [organisation to insert name]

Invitation to take part in a focus group

I am writing to you about a research study looking at people's experiences of finding out about local health and social care services. The study is being funded and carried out by Healthwatch Essex. Healthwatch Essex is the new independent consumer champion created to gather and represent the views of people who use health and social care services. The purpose of the research is to ensure that the views and experiences of people who need information and signposting in relation to health and social care services can be considered in proposals for county-wide information and signposting provision covering health and social care in Essex.

In order to understand people's views and experiences of finding out about local health and social care services, we are running several focus groups across Essex. We have asked [insert name of organisation/group] to help us organise a focus group, and they are inviting people to take part on our behalf.

We would like to invite you to take part in a focus group to discuss your views and experiences relating to accessing information about health and social care services. Focus groups will last between 1.5 and 2 hours and will take place in [insert location & venue at [insert time and date OR a specific time and date to be arranged]. The topics covered in the focus group will include:

- The sorts of information you have needed in your situation, and why/when you have needed information;
- Where you have got information you needed and how easy this was to do;
- Quality of information and/or signposting you have received;
- Suggestions for improvements to information and signposting services.

The attached information sheet provides more information about the research and what taking part will involve.   **Continued overleaf**

If you would like to take part in a focus group, please would you let [insert nominated person from organisation] know, either in person or by telephone. Taking part is voluntary and completely up to you. Healthwatch Essex will write a report summarising key findings from the focus groups but no-one looking at the study findings will be able to identify you in any way. Helping with study will not affect any support you receive.

We really hope that you will be able to take part in this research which will allow us to understand people's views and experiences in more depth. We will feed back what we discover to the authorities, who have a legal responsibility to use our findings to shape and improve services.

If you would like any further information please do not hesitate to contact me by phone on 01376 572829 or email clarissa.penfold@healthwatchessex.org.uk

Yours sincerely,

Clarissa Penfold

Lead Researcher, Healthwatch Essex

Appendix C – Participant information sheet

PARTICIPANT INFORMATION SHEET

Research Study:

Exploring people's experiences of finding out about local health and social care services in Essex

We would like to invite you to take part in a focus group for an independent research study. This research study is being carried out by Healthwatch Essex.

Before you decide whether to take part you need to understand why the research is being carried out and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you like more information - our contact details are at the end of this sheet.

What is the purpose of the study?

This research study will explore people's experiences of finding out about local health and social care services. The purpose of the research is to ensure that the views and experiences of people who need information and signposting in relation to health and social care services can be considered in proposals for county-wide information and signposting provision covering health and social care in Essex.

In order to understand people's views and experiences of finding out about local health and social care services, we are running several focus groups across Essex.

What is the role of Healthwatch Essex in this research?

Healthwatch Essex is funding and carrying out this research. Healthwatch Essex is the new independent consumer champion created to gather and represent the views of people who use health and social care services. Healthwatch Essex will play a role at both national and local level and will make sure that the views of the public and people who use services are taken into account. Healthwatch Essex has a network of volunteers and also works with existing voluntary and community groups to find out what matters to our citizens. Healthwatch Essex also funds a research programme and undertakes research projects, including this study, to try and understand people's views and experiences in more depth. We will feed back what we discover to the authorities, who have a legal responsibility to use our findings to shape and improve services.

What will happen to the results of the research study?

Presentation, reports or publications resulting from the research will not identify any one who has taken part. Anonymous results from the study will be presented to key people responsible for commissioning or delivering health and social care services in Essex. There will also be a short written report of the research findings, which will be available to access via the Healthwatch Essex website. Findings may also be published in academic journals and presented at professional and academic conferences.

Why are you inviting me to take part?

We have approached a range of voluntary sector organisations to help us recruit people to take part in focus groups for this research. Each organisation is approaching people they are in contact with and inviting them to take part in a focus group. By recruiting focus groups in this way we hope to ensure that we capture a diverse range of views and experiences, and are able to understand people's different information needs and preferences.

Do I have to take part?

Involvement in this research study is entirely voluntary and it is completely up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect any current or future support you receive in any way. Throughout all aspects of the research you have a right to:

- withdraw from the study at any time;
- choose not to share information with us.

What will happen to me if I do take part?

You will be given the date, time and venue for the focus group in advance. On the day, you will meet with between five and seven other people who are also taking part. All people taking part will be in contact with the same organisation that gave you the invitation letter, so you may know them. Everyone taking part will be reminded to keep what they hear during the group confidential.

The focus group will be run by an experienced focus group moderator or group facilitator who will introduce topics and keep the discussion going, ensuring everyone gets an opportunity to contribute. The focus group will last between an hour and a half and two hours and the discussion will cover people's personal experiences of accessing information about local health and social care services.

Topics covered in the group discussion will include:

- The sorts of information you have needed in your situation, and why/when you have needed information;
- Where you have got information you needed and how easy this was to do;
- Quality of information and/or signposting you have received;
- Suggestions for improvements to information and signposting services.

The focus group discussion will be tape-recorded so we have an accurate record of what people say. The tape recording will be transcribed, and anonymised. The recording will be deleted after transcription. The data will then be analysed by the research team.

The focus group moderator/ facilitator will ask you to sign a consent form agreeing to take part in the interview.

Are there benefits in taking part?

There are no direct benefits to you as an individual. We will be making an honorarium payment to the organisation that has given you letter about this research. This is to thank them for their time in selecting people to take part and helping us to organise the focus group. We hope that this research will generate knowledge that will inform policy more widely in relation to future commissioning and provision of information and signposting services.

Will my taking part in the study be kept confidential?

Your responses are completely confidential. All data will be given a code to ensure anonymity and stored in a locked filing cabinet or on a password protected computer secured against unauthorised access. No-one else will know you have taken part unless you choose to tell them.

If you tell us something that indicates there is a risk of harm to yourself or someone else, then we will follow a 'disclosure protocol'. This involves seeking advice on whether we should disclose (tell a relevant agency or authority) this risk. Someone will contact you first to talk about it before taking further action.

Has this study been reviewed by a research ethics committee?

Research undertaken by Healthwatch Essex is considered by an independent group of people, called a research ethics committee, to protect your interests. This study has been reviewed and approved by Essex County Council Research & Analysis Unit Research Governance Group (Ref: 09/10/13).

healthwatch
Essex

Participant Identification Number:

Exploring people's experiences of finding out about local health and social care services in Essex

Essex County Council Research & Analysis Unit Research Governance Group ethical approval ref: 09/10/13

CONSENT FORM FOR FOCUS GROUP PARTICIPANTS

Name of focus group moderator/facilitator: [INSERT NAME]

Lead researcher contact details: *Clarissa Penfold, Healthwatch Essex, RCCE House, Threshelfords Business Park, Inworth Road, Feering, Essex, CO5 9SE.*
Tel: 01376 572829; Email: clarissa.penfold@healthwatchessex.org.uk

You will be given a copy of this consent form to keep

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and my responses are completely confidential. I am free to withdraw at any time, without giving any reason, without my employment or legal rights being affected.

3. I agree to take part in a focus group facilitated by the focus group moderator/facilitator named above and for the focus group discussion to be tape-recorded.

4. I agree to the anonymised data being archived for up to five years after the end of the research, for use in this study. I understand that data will be destroyed after this period and that all identifying information about me will be removed to protect my identity.

5. I agree to take part in the above study.

Participant name [please print]	Date	Signature

Moderator/facilitator name [please print]	Date	Signature

Information & signposting – understanding people's experiences of finding out about local health and social care services

Focus Group Topic Guide

Purpose of research:

The purpose of the research is to ensure that the views and experiences of people who need information and signposting in relation to health and social care services can be considered in proposals for county-wide information and signposting provision covering health and social care in Essex.

Research aims/objectives:

To explore and understand:

- how patients, service users, carers and members of the public currently find out about local health and social care services;
- how easy it is for people to get the information they need;
- people's experiences of the quality of information and signposting
- people's perspectives on how information and signposting services could be improved.

---

1. **Welcome & introduction**

- Before start, check everyone has signed consent form.

- Welcome from moderator /facilitator.

- Introduce Healthwatch Essex and explain research (part of wider project to determine the potential nature of an integrated signposting resource for health and social care services across the county).

- Explain nature and purpose of focus groups – to explore and understand people's experiences of finding out about health and social care services. Explain that there are several focus groups taking place.

  o Style of questioning
  o No right/wrong answers
  o 'Obvious' questions as don't want to make assumptions about views/experiences

- During focus group discussion we will explore:

  o The sorts of information each of you has needed for your situation, and why/when you have needed information;
  o Where you have got information you needed and how easy this was to do;
  o Quality of information and/or signposting you have received;
  o Suggestions for improvements to information and signposting services.

- Remind discussion should last about an hour to an hour and a half. Remind discussion will be tape recorded to make sure we get an accurate record of what is said. Recording will be transcribed and analysed for the report. Everything people say will remain anonymous – all names will be removed and no comments will be attributable to any identifiable individual.

- Remind participants that we ask them to respect each other's confidentiality about any personal details shared today.

- Any questions before start? Explain that we'd like to hear about their own personal experiences but are happy for participants to talk more generally if they wish.

(*BEGIN RECORDING*)

2. Background

Ask each participant to introduce themselves, including:

- Their name
- Where they live
- Brief description of contact they have (or have had in the past) with health and social care services

Prompts (contact with health and social care services – themselves or relative/friend)

- Health services e.g. -
  o GP
  o Pharmacy
  o Health centre
  o A&E
  o Hospital (outpatient / inpatient)
  o Community nursing team
  o Health & wellbeing clinics / classes
  o Hospice
- Social care services e.g. –
  o Equipment, aids and appliances
  o help in the home (home care services e.g. personal care, meals on wheels, home help)
  o residential care home (for yourself or a relative)
  o community support and activities
  o support groups
  o day centres
  o respite care
  o help for people with disabilities including learning disabilities
  o financial support / benefits
  o information and advisory services, and advocacy
  o support for carers

3. Information needs

Ask participants to talk about the sorts of information they have needed in their situation:

- What information did they need, and
- Why did they need information at that time (i.e. triggers)?

Use prompts for section above (information needs about) and:

- condition-specific information (e.g. treatments available)
- making a complaint
- advocacy services

4. Sources of information and accessibility

Ask participants **where** they got the information they needed – how they got in touch, how easy was this to do? Explore difficulties getting certain types of information
[Co-moderator to make a note of information sources on flipchart to refer back to in next section (section 5)]

Prompts (information sources):

- GP surgery/pharmacy
- health professional
- alternative therapists
- social services
- community or support group
- library
- information centre
- CAB

- school
- Post Office
- faith organisation
- internet
- media
- friends/family
- NHS Direct/111/PALS/ Social care direct

5. Quality of information and/or signposting

Views of information / signposting accessed:

What was **good** about it:

- Quality of information / signposting
- Was information / signposting useful / helpful – probe: why / in what way?
- Was format of information appropriate/accessible
- For face-to-face / telephone / email – ask how helpful staff were
- Web-based material – ability for people to manage their own information needs

What was **not so good** about it?

- Conflicting information from different sources
- Information / signposting not helpful – why not / in what way?
- Information formats
- Unhelpful staff

6. Suggestions for improvements to information and signposting services

Ask participants to reflect back on the information and signposting support they have received and what has come up in the group discussion, and think about:

Preferences for getting information about local health and social care services and other sources of support. What would make it easier? How could provision of information be improved?

Prompts (how, where, when, who):

- Format
  - Face-to-face / in person
  - Print
  - Internet/website
  - Local directories
  - Telephone
  - Information in other languages
  - Text messages
- Location
  - GP surgeries
  - Pharmacies
  - Libraries
  - Supermarkets
  - Central information point/one-stop shop
- Opening hours

Probe reasons for preferences:

Awareness - how could information & signposting services be promoted so people are aware of how to access them? How and where should information & signposting services be advertised?

Patient and service user feedback – 'NHS choices' and 'Patient opinion' websites where you can rate services – do people use these? 'Trip advisor' type information – would something like this be useful in finding out about / choosing services? What do people think?

Any other comments and concluding thoughts: [to explore important things that people designing an integrated signposting resource ought to consider/think about] In an ideal world what would be the easiest way for you to get information about your local health and social care services?

(RECORDER OFF)

Thank everyone for their participation and final reminder about confidentiality

- What will happen next [findings will be included in report for Essex County Council]

- Questions about the research [spare copies of participant information sheet available if people would like one to take away]

- Contact details if further questions [provide leaflets 'Have you heard of Healthwatch Essex?' & 'Volunteer for us']