



The Information Game

A consultation about obtaining information with:

- Older people
- People with learning disabilities
- People with mental health issues
- People with physical disabilities
- Family Carers
- Diverse communities

Commissioned by Suffolk County Council
from Cultural Intelligence Ltd

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Cultural Intelligence

Cultural Intelligence is an independent research and development agency. We work with organisations from the cultural, community and learning sectors to support innovation, increase engagement and contribute to social and economic renewal.

We can be found at www.audience.co.uk 01394 388029.

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1 Introduction

We live in a world where we are surrounded by information. It's on buses and at bus stops, on posters, in books, flyers and leaflets, in public buildings and shops, on television, radio and the internet. The challenge is to find the information we want, when we need it, in a format that suits our needs, and it is a challenge, even for those of us with good literacy and strong information searching skills¹.

Almost every consultation carried out locally and nationally with the public and particularly with people who are marginalised, suggests that people feel bewildered by the range of information which confronts them. They want it better presented in ways that they can easily understand and they may need help in interpreting and understanding what they find. They also recognise that it can help to make a huge difference to their life choices and how in control they are of their life.

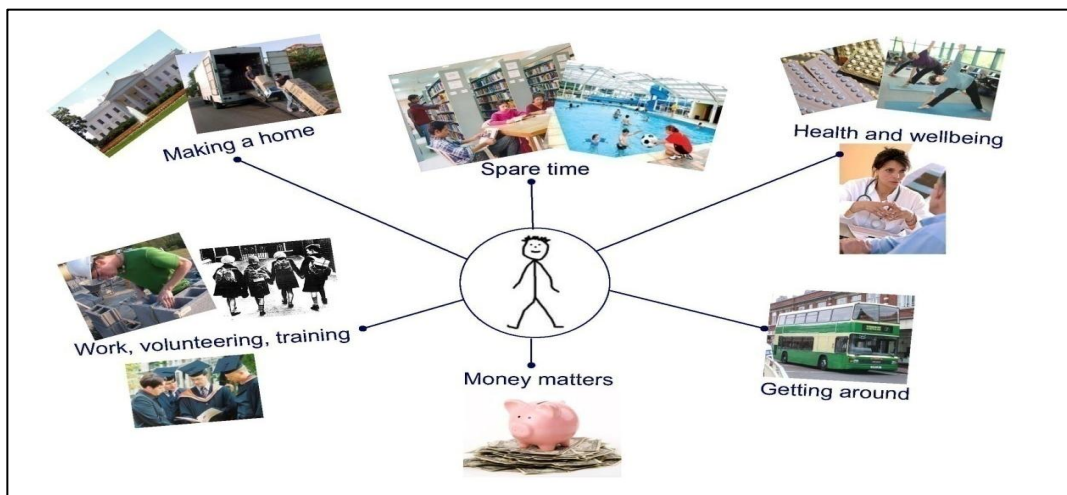


Figure 1 The Information Game

Suffolk County Council and its partners are responsible for providing a wide range of information of the kind that we all need in order to lead a full life as

¹ Taken from the project brief

members of our community. This includes information about making a home, staying healthy and safe, travel and transport, money matters, finding work, volunteering opportunities, training and ways to spend our leisure time.

The Adult and Community Service Directorate (ACS), is reviewing how it makes information available to citizens in Suffolk and will be producing an information strategy in 2010. In order to inform the development of that strategy, ACS commissioned Cultural Intelligence to conduct a consultation with its' priority customer groups. These include:

- People with learning disabilities
- People with physical disabilities
- People with mental health issues
- Family carers
- Older people
- Diverse communities including people for whom English is not a first language

The consultation was to consider:

- Peoples' experience of getting information- what it feels like
- Where, how, and when they use this kind of information
- What makes a positive experience for people seeking information
- What are the barriers to obtaining information in an appropriate form
- Suggestions for change

The consultation was primarily concerned with accessing *information* rather than obtaining individual *advice*. However, the distinction between the two can be somewhat blurred and this was reflected in the consultation as it is in real life.

The purpose of this report is to provide a full account of the findings of the consultation and to make recommendations for changes that would improve access to information for the customer groups involved in the consultation.

2 Methodology

The consultation presented a set of key challenges. These were:

- A diverse range of participant groups with significantly differing abilities
- A limited timetable in which to establish the level of trust required to consult effectively with some of the target groups
- The rather abstract nature of the topic

These challenges were addressed through the use of a creative methodology implemented through group workshops.

The Artist, Caroline Wright (www.carolnewright.com) devised an exercise called *The Information Game* which was based around a board game in which, working in small groups, participants pursued a number of information quests, experiencing setbacks or boosts in their progress through chance cards. Participants illustrated their quests on specially produced game boards.

Quests were carefully chosen to suit the participant group. A full list of the information quests used is given in Appendix 1 but examples include:

- “How will you get the information you need to choose a school for your children?”
- “Your partner’s health has deteriorated to the point where they can no longer use the stairs. Where will you turn for help?”
- “You know you should take more exercise but are unsure what is available in your area. How are you going to find out your options?”

Chance cards were delivered at strategic points in the game. Examples include:

- “It is 5 o’clock on Christmas Eve and everything is closed”
- “Your internet has gone down so you cannot access the web”
- “You have won £100 on the lottery”
- “A library has opened close to your home”
- “Your telephone is not working and you’ve lost your mobile”

“You meet someone who has had this problem before and they offer helpful advice”



Figure 2 Family Action, Lowestoft plays The Information Game

Each game was co-ordinated by a ‘Games Master’ who ensured that the group followed a series of ‘Task Cards’. At certain points in the game, the group was interviewed about their quest and their real life experience of accessing information.

The game served not only to capture evidence about the participants’ attitudes to and experience of obtaining information but also to animate group discussion of barriers, positive experiences and possible improvements.

The benefits of this approach were as follows:

- Groups found the idea of a creative workshop more attractive than a discussion group (or similar traditional approach) and were more willing to participate.

- The use of a creative approach signalled to partner agencies that we understood the constraints of working with their client groups and this engendered confidence in the process.
- The creative approach allowed us to establish non-verbal means of consultation which allowed participants who are not adept at verbal or literal communication to contribute to the consultation.
- Working in small groups allowed us to ensure that each group included an appropriate mix of complimentary abilities.
- The creative approach helped to engage participants in a number of topics which they are unaccustomed to considering.
- The design of the workshop allowed it to be easily adapted for different abilities and contexts, and to evolve as the fieldwork period progressed.
- The open nature of the game allowed players to respond with individual responses in addition to working as a group allowing a voice for those who have personal stories to contribute.
- The approach helped to establish a level playing field for all participants. The target groups and their care workers underwent a shared experience encouraging those with less confidence to respond.

Groups enjoyed the experience and many individuals commended the approach.

In addition to the creative workshops, we conducted a number of one-to-one depth interviews on the telephone and face-to-face. The aim of these was to capture more detail about some individual personal stories identified in the course of the creative workshops.



Figure 3 Information is passed in the ice breaker exercise 'Chinese whispers'

In order to quickly establish a level of trust between participants and the researchers, consultations were delivered in the context of established groups or through agencies trusted by the participants. Whilst all consultation was conducted directly with members of the target groups we are grateful to the following agencies who supported us in accessing the participants by hosting or convening groups.

- Top Time, Sudbury
- Suffolk Family Carers
- Mencap
- Age Concern
- Suffolk Befriending
- Mid-Suffolk Axis
- May Centre for Disabled People, Beccles
- Suffolk MIND
- Crossroad – Caring for Carers, Lowestoft
- Family Action in Lowestoft and Ipswich
- The InsideOut Community
- Whitehouse Enterprises
- CSV Media Centre

Thanks are also due to Alison Wheeler of the Information, Advice and Libraries Service, Suffolk County Council for her support in the development and fulfilment of this consultation.

A variety of methods were used to collect evidence including storytelling, video and group discussion and the game boards produced as part of The Information Game. Participants completed a very brief survey to collect some basic information about them and their experience of getting information. This was designed to be accessible to people with low literacy. (See Appendix 3).

The methodology was submitted for approval by the Suffolk County Council Research Governance Group and the consultation was completed in accordance with the 'Adult & Community Services and Children and Young People's Services Research Governance Guidance'. As ever, we also worked to the Ethical Code of the Social Research Association.

We conducted a total of 17 workshops and 4 individual interviews. The consultation involved approximately 50 male and 114 female participants. 12% were aged under 35 whilst 56% were aged 35 to 64 and 32% were aged 65 or more.

Group	Proportion of full sample (165 Participants)
People with learning disabilities	11%
People with physical disabilities	12%
People with mental health issues	13%
Family carers	24%
Older people	27%
Diverse communities including people for whom English is not a first language	14%

Figure 4 Mix of participants

Reading this report

It is important to understand that this was a qualitative research exercise and therefore never intended to make measurements or to attempt to quantify levels of behaviour in the wider population, or to indicate the extent to which attitudes are widely held.

Whilst it is important to avoid drawing quantitative conclusions from this report, care has been taken to indicate the extent to which views were widely expressed. Use of terms such as 'one or two', 'a few', 'quite a few', 'quite a number' and 'a majority' are used deliberately and consistently to indicate the extent to which views are widely shared by participants.

There is considerable overlap between members of groups such as **Older people** and **People with physical disabilities** and between the interests of **Family carers** and the people they care for. Quite a few of the participants could have been included within three or more of the participant groups.

The needs and interests of the specific participant groups have far more in common with each other, and the wider population, than they have differences. Findings are therefore reported as they apply to the full sample involved in the consultation. However, where findings apply to specific groups we have highlighted these.

3 Executive Summary

Introduction

In order to live life to the full, we all need information. Information on issues as diverse as leading a healthy life, making a home, getting work or volunteering and how to spend our leisure time. The challenge is to find the information we want, when we need it, in a format that suits our needs.

In December 2009, The Adult and Community Services directorate (ACS) at Suffolk County Council commissioned Cultural Intelligence to conduct a consultation programme which would explore how adults in Suffolk access information and how it can be made easier for them.

The groups involved in the study were from the ACS priority customer groups including: people with learning disabilities or with physical disabilities, people with mental health issues, family carers, older people and people from diverse communities.

The consultation considered:

- Peoples' experience of getting information- what it feels like
- Where, how, and when they use this kind of information
- What makes a positive experience for people seeking information
- What are the barriers to obtaining information in an appropriate form
- Suggestions for change

A creative consultation methodology was adopted in order to help make the subject more engaging for the client groups. The main component in this was called *The Information Game*. This was a board game devised for the project by Artist Caroline Wright www.carolinewright.com.

In addition to the creative workshops, we conducted a number of one-to-one depth interviews. The aim of these was to capture more detail about some individual personal stories. We conducted a total of 17 workshops spread across the county involving 164 people.

What, when and how of information

Many of the participants identified times of significant change in their lives as the times when they most needed important information. This included life episodes such as finding a school, retirement and bereavement as well as more routine matters such as travelling abroad, going into and leaving hospital, exploring training and volunteering opportunities and finding reliable tradesmen.

There is a good general awareness of where information is likely to be found. The methods used to access information were diverse and very much determined by skills and abilities.

By far the most frequently used method for obtaining information was '*People you know*' (78% of participants had used this method in the last 12 months). **Older People**, **People with physical disabilities** and **People with learning disabilities** were often particularly reliant on members of their family, relatives or close friends for finding out information.

Perhaps surprisingly, in discussions about the reliability of information, few people had found information by word of mouth to have been significantly inaccurate.

For many people but particularly **Older People** and **People with physical disabilities** the telephone was the primary means of accessing important information (56% had used telephones to obtain information in the last 12 months). Many favoured the telephone because of the human contact it can provide.

However, there were many frustrations with telephone information services. Automated call routing was universally despised for the amount of time spent hanging-on and for the difficulty of using these services.

'The Internet' was the least used method (39%) but was the first choice for some participants who valued its' convenience and 24hr availability.

Naturally enough, the devotees of the internet were those who use it regularly and are more competent with it.

Participants with links to a specialist agency such as a day service or support group noted that these were very effective sources of information.

Libraries were mentioned by all groups as good sources of information. Even those who do not regularly use a library felt they would use it to get information if they had a need.

Local and national media were identified by many respondents as being important information sources. **Older people** in particular had the expectation that information about local events and the opening times of local public services would be available in their local paper.

People's experience of getting information

The most striking aspect of the participants' experience of accessing information was how much of a battle they find it. In the 'information age' it is a matter of concern that they should find it so.

The battle often starts with finding the right information source. Many people complained of being passed from person to person, often having to repeat their story over and over again.

This unnecessary 'struggle factor' is a matter of particular concern because for many, a quest for information comes on top of an already extremely stressful situation.

The level of frustration was mainly down to several common identifiable issues. These included 'automated call management systems', 'lack of consistency and continuity in message and service' and 'the failure of people to do what they say they will'.

Information overload was a commonly expressed frustration with many complaining that they can be overwhelmed by the sheer volume of information they are expected to digest. Information is often not presented

in a manner that provides appropriate levels of detail in a layered format that enables people to quickly identify the items they need to find.

Participants from all groups reported that they sometimes receive a careless or unsympathetic response from people who are in the position of providing information.

Alongside an increasingly complex information landscape has developed the 'faceless society' where people are expected to engage with a service by remote means. Whilst one or two participants said they favoured remote services for their accessibility and anonymity, these were considerably outweighed by the desire of many participants, to engage with a friendly face or at least a supportive and compassionate voice.

Many people expressed frustration about a lack of consistency and continuity. This was particularly true of call-centre based services where people complained about never being able to speak to the same person twice. The need to repeat the history of an issue to different people each time they call is really disheartening.

Barriers to accessing information

Whilst good information seeking skills can make a huge difference in the information game, it was clear from the consultation that most barriers result from inadequacies in 'the system' rather than in the abilities of individual information seekers.

Not knowing what you don't know

Knowing what questions to ask seems to be one of the greatest issues for adults seeking information in Suffolk. Participants frequently complained about the failure of all kinds of services, to address their situation in a wider or more holistic manner by volunteering information which anticipates their needs, rather than just responding to issues they raise.

Difficulties with telephones

For many participants, especially **Older people** and **People with physical disabilities**, the telephone is a lifeline without which they would become increasingly isolated. However, many found that their capacity to use the phone becomes increasingly impaired with age.

The lengthy time spent hanging-on for some calls is an issue for **Family Carers** who often have very limited time in which to make calls.

Not knowing where to start

The sheer diversity of third sector and community interest organisations now delivering services has created a very confusing information landscape. There is also, of course, the longstanding confusion over which local authority tiers are responsible for which services.

Difficulty in understanding information

Some people from all groups but particularly **People with learning disabilities** and some **Older people** expressed frustration that information is sometimes presented in an over-complicated format.

Difficulty with taking notes

People with a learning disability, **People with a physical disability** and some **Older people** mentioned the difficulty they have in taking notes when information is provided verbally, especially over the telephone. Supporting type-written material should therefore always be offered.

Translated material and large print

A number of people observed that the offer of a translation is often made as a note on the reverse side of a leaflet or publication. Unfortunately, it is often not possible to tell, from the look of the publication, what topic it refers to. It is unclear how a non-English speaker is to know to pick that publication up in the first place.

Even information as everyday as letters home from school, can present a worry for some **People for whom English is a second language**.

Lack of access to the internet

Some non-internet users from a number of different customer groups observed that the increasing reliance on the internet as an information channel excludes them from access to information.

What makes a positive information experience?

The information services that seemed to be most beneficial had the following characteristics:

- **Few boundaries** – they focus on the needs of the customer rather than the requirements of the information provider which leads to a more holistic approach
- **Anticipate needs** – they understand that the customer may not know the questions to ask and will therefore have a systematic approach to ensuring that possible needs are anticipated
- **Provide information in multiple channels** – in this way they can meet the needs of the customer in a manner that suits them. This would include large print or translation as appropriate
- **Provide information in a layered form** – that allows information to be accessed at a basic or more detailed level
- **Friendly, supportive and non-judgemental** – although not instrumentally important to the provision of information friendliness is a quality that is highly valued by participants in this consultation
- **Effective fulfilment** – they do what they say they will do without undue delay and if necessary stay with the issue until it is resolved
- **Communicate the alternative formats** in which information is available as a matter of course and not just on request

Solutions and opportunities

There are a number of learning points which may helpfully inform the development of policy and strategy.

Prioritise multiple formats

Different information channels suit different people. A choice of information channels is therefore as important now as it has ever been. This is particularly so for the disadvantaged and excluded groups, only a minority of whom are regular internet users and by whom personal contact is particularly valued.

Information that anticipates need and promotes entitlement

One of the most important findings arising from this consultation is the need for more systematic approaches to providing information which anticipates people's needs rather than responds to problems at the point where they are reaching a crisis.

Many information needs arise as part of a life-event or life stage so it ought to be possible to identify these and to develop a strategy which specifically addresses them.

Ensure telephone services work really well for the customer

There was considerable criticism of call-centre based services. Many of these criticisms were of a kind that could be overcome with better system design, better staff training and higher staffing levels.

Priority should be given to ensuring effective evaluation and monitoring of Customer First perhaps through the use of mystery shoppers, and maybe, case studies which follow enquiries through from start to finish. It may also be possible for (SCC) to work with its partners to arrive at guidelines for best practice or minimum standards, for the telephone information services that they offer.

Improve information searching skills

Skills for information seeking vary widely but can make a considerable difference to access to information leading to resources and opportunities.

It may be appropriate to consider using the kind of information searches discussed in this consultation as a context for Citizenship work in secondary schools in Suffolk. It may also be possible for SCC to work with its partners to explore other ways in which information searching skills can be improved for the people they are working with.

Older People who may have been perfectly competent in the information game for most of their life, struggle to sustain that ability as information systems evolve and their own capacities change. Policy and strategy relating to **Older people** should seek to sustain and reinforce the ability of **Older people** to find the information they need.

Recognise and develop info-hubs

For those engaged with such services, day services and drop-in centres are an effective method of promoting access to information and consideration should be given to ways in which this might be developed as an integrated countywide network

Develop fact sheets and common source information

Plain and simple but well crafted and thoughtfully structured fact sheets could be made available on the internet and also easily printed for manual distribution. This would provide a cheap and easily updateable form of authoritative information for primary consumption or as described above, for promotion by front-line staff including call-centre staff.

The use of a common source would help overcome lack of consistency of message which was an issue identified in this consultation. The provision of translated or large-print material could also be more effectively facilitated in this way.

Promote family and neighbourhood networks

Policy relating to information should recognise and embrace word of mouth as an important channel and should seek ways to strengthen it. For instance, many participants recommended learning from people who had already been through their situation. Maybe a network of volunteers could be developed as community speakers on different issues.

Campaign on mailing and telephone preference

During this consultation, it became apparent that many **Older People, People with a learning disability, People with a physical disability** and **People with a mental health issue** are troubled by cold callers on the telephone and to a lesser extent by volumes of junk mail.

Consideration should be given to developing an information campaign which supports disadvantaged communities in making use of the Telephone Preference Service and the Mailing Preference Service.

User-centred web delivery

This consultation suggests that enhancing the human/interactive elements of the web and ensuring a positive experience which feels 'natural' to the customer is the key. This is likely to require the ongoing convergence of web, call-centre and in-person channels. Suffolk County Council is currently conducting a review which will go a long way towards addressing these issues.

Resolve issue of access to 'what's on' information for adults with learning disabilities

Whilst advances have been made on the provision of physical access information for leisure activities, there is little information available to indicate what activities are likely to be appropriate for adults with learning disabilities.

Conclusion to Executive Summary

The consultation successfully engaged 165 people from the priority groups in a public consultation about how they access the information they need in order to live life to the full.

It produced a wide ranging set of findings with several dominant themes which could helpfully inform the development of policy and strategy relating to the provision of information for adults in Suffolk.

The struggle factor

The most striking finding to emerge from the consultation was the extent to which people find accessing information to be a struggle. This is a matter of particular concern for the marginalised groups involved in this consultation for whom day to day life can already be quite a struggle.

Whilst good information searching skills can help to overcome the struggle, it was apparent that most of the struggle factor arises from weaknesses in service delivery on the part of organisations, rather than poor capacity on the part of the information consumer.

Effective policy relating to the provision of information would make it a priority to seek to reduce the 'struggle factor'.

The importance of multiple channels and the human factor

The crucial importance of supplying information through multiple channels e.g. print, web, telephone, media, etc was confirmed. Different individuals use different channels often to the exclusion of other channels and different channels are favoured by different people for different types of information.

Channel-shift offers potential for improved access to information but there is significant danger that the most vulnerable in society could become even more marginalised if human factors are ignored.

Bound to this issue is a continuing need to provide individuals with the skills to use online services and access to the internet.

Whilst some issues require only a factual, information based response, it is evident from the consultation that there are many where this is not enough and human involvement is preferred. Certainly, the participants in this consultation place a very high value on interacting with an individual, rather than an information system. A successful information strategy is likely to acknowledge this factor and to seek to develop interactive information systems which embrace appropriate channels of information provision according to need.

Information provision that anticipates need and crosses institutional boundaries

One of the most significant advances in the provision of information would be to provide information that ignores institutional boundaries and anticipates need based on an individual's circumstances. The consultation showed that information requirements are relatively predictable at particular life stages and when particular life events occur.

Many participants complained that it is left to them to do battle with a system in order to discover opportunities that would be available to them if they only knew to ask. They were able to identify individuals and services which do take a holistic view and provide information based on the needs of the user rather than the strict terms of reference of the organisation, so this is clearly possible.

Information v Advice

The findings of the consultation serve to illustrate how, in the experience of the public, *information* seamlessly merges into the realm of *advice*. Policy and strategy relating to information will need to take account of this and avoid seeking to construct excessively stark boundaries between the two.

Finally, Suffolk County Council is to be congratulated for commissioning this consultation. Participants were very appreciative of being involved. They certainly felt that this was a valid issue for consultation and were keen that their voices be heard.

4 What, when and how of information

This section identifies the times in life when information is particularly important and the channels that participants mostly use for accessing information.

What information is most important and when is it needed?

Many of the participants identified periods of significant change in their lives as being the times when they have most needed to access information and when successfully finding that information had been most important to them.

Examples they gave included:

- Finding a home, moving home and settling in a new area
- When there were significant changes to their capacity such as changes to mobility for them, or someone close to them
- The point of diagnosis of a new condition or illness for them or someone close to them
- Finding the right school for their children
- Bereavement
- Looking for a job
- Making a Will
- Settling in a new country
- Retirement
- First pregnancy
- Leaving school

Other more perennial issues included:

- Organising finances/benefits/taxes
- Finding out about public transport
- Arranging hospital and GP appointments
- Travelling abroad
- Health, prescriptions and medical procedures

- Going into and leaving hospital
- Finding reliable tradesmen/women
- Where to eat or (more importantly they said) where NOT to eat
- For campaigning e.g. when services they use such as mental health day services were under threat
- Exploring training options/finding out where to study
- Finding accessible and appropriate leisure opportunities

People with learning disabilities tended to mention more day to day issues such as meeting friends or planning transport than they did the more pivotal issues in life. This is possibly because they receive greater individual support for the larger issues. It was also notable that, in common with **Older People**, they had a tendency to stick to more familiar systems and methods than to engage with the new or unfamiliar.

For **Older People** this tendency to stick to the familiar does appear to contribute to a gradual narrowing of their sphere of engagement. It seems likely that effective information strategies for **Older People** could contribute to helping them sustain a fuller life for longer.

“I used to be quite good with the computer but nowadays, I am not as good as I was. My girls get cross with me because I don’t persevere. My friends in Australia used to correspond by email with me all the time but now they get in touch with my daughters, not me. You get rusty.”

Older Person with physical disability

Family Carers and **People with a physical disability** tended to focus more on medical, health and social care issues.

Whilst significant advances have been made in increasing information relating to the physical accessibility of activities, one or two **Family Carers** caring for an adult with learning disabilities said they have an ongoing struggle identifying accessible and appropriate leisure opportunities for the people they care for.

It was notable that **People for whom English is not a first language** arriving in Suffolk face a particularly intense period of information gathering in the 12 months following their arrival. In fact it was this group more than any other that really does experience the 'information quests' (characterised by a story with beginning, middle and end), that were the basis of *The Information Game*.

The amount of information that new arrivals need to absorb in a short period of time is considerable particularly because they need to quickly understand local laws and conventions of behaviour. Local practise pertaining to noise late at night was cited as an example. Understanding the difference between emergency and non-emergency health services and between NHS and private dental services are further examples of this.

What methods are used to access information?

There is a good general awareness of where information is likely to be found. The methods used to access information were diverse and very much determined by skills and abilities.

"I prefer the phone for the personal contact. My husband will use the internet but I will always use the phone"

Family Carer

Frequently occurring examples of methods used included:

- Family, relatives, friends and neighbours
- Local media – particularly newspapers
- The telephone
- Leaflets and posters
- The library
- Professionals such as key workers, counsellors, community psychiatric nurses and other community nurses, advisors
- Employers
- Day services, drop-ins and specialist agencies
- Tourist Information Centres

- The internet
- Citizens Advice Bureaus

As part of *The Information Game*, participants completed a quick survey which included a question about the methods they had used to find 'important information' in the last 12 months. The responses from 165 participants are given below.

Method	% of all participants (165)
People you know	78%
Leaflets and books	61%
Telephone	56%
TV, magazines, radio	45%
Advisor, key worker, counsellor	49%
Internet	39%

Figure 5 Information methods used in last 12 months

In addition to values listed in Figure 5 the participants listed the following 'Other' methods:

At work	Audio CDs	Mail & Letters	MIND Haverhill branch
Nurse	Phone book	DVD's with info on	Occupational Physiotherapist
CAB	SFC and GP	Member Parliament	Wickham Mkt Community Club
Church	Library	Family Support Workers	Hospital

Day services and specialist agencies

Many people had experience of using the Citizens Advice Bureau which they found effective but very time consuming, (because CAB is short staffed). The Disability Advice Service (Ipswich), Bangladeshi Support Centre (Ipswich) and Suffolk Family Carers also came in for particular praise as did the Waveney Admissions Prevention Service. The factors that make these organisations particularly effective are explored later in this report. (See page 53)

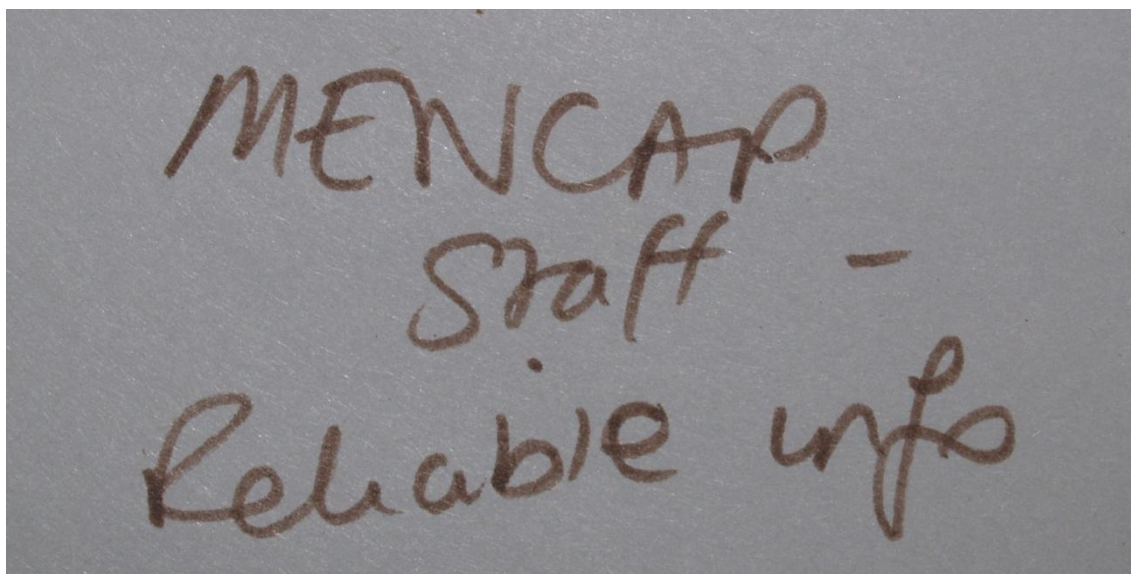


Figure 6 Specialist agencies are primary information hubs

Those engaged with a day service or support organisation frequently mentioned it as a key effective source of information for issues which often went well beyond information pertaining to the specialism of the agency.

For the groups involved in this consultation, these sources of information are clearly important and it may be appropriate to consider ways of formalising this network. (See page 59)

Several participants mention professionals such as social workers or health workers as good information sources, though praise for this group was not universal.

Friends, family and neighbours

By far the most common source of information for participants was word of mouth via family, neighbours and friends. **Older People**, **People with physical disabilities** and **People with learning disabilities** were often particularly reliant on members of their family, relatives or close friends for finding out information.

“Experience and common sense helps to tell you whether or not you can trust the advice that friends give you. You would always

pick someone who is responsible. You go to someone who you know well.”

Family carer

Perhaps surprisingly, in discussions about the reliability of information, few people had found information by word of mouth to have been significantly inaccurate. On the contrary, such sources were often more trusted than others.

My main help has been my daughter. She’s been in touch with lots of people for me.

Older Person with a physical disability

The telephone

For many people but particularly **Older People** and **People with physical disabilities** the telephone was the primary means of accessing important information. Many favoured the telephone because of the human contact it can provide.

“Phone calls are quicker and more personal [than the internet]”

Older person

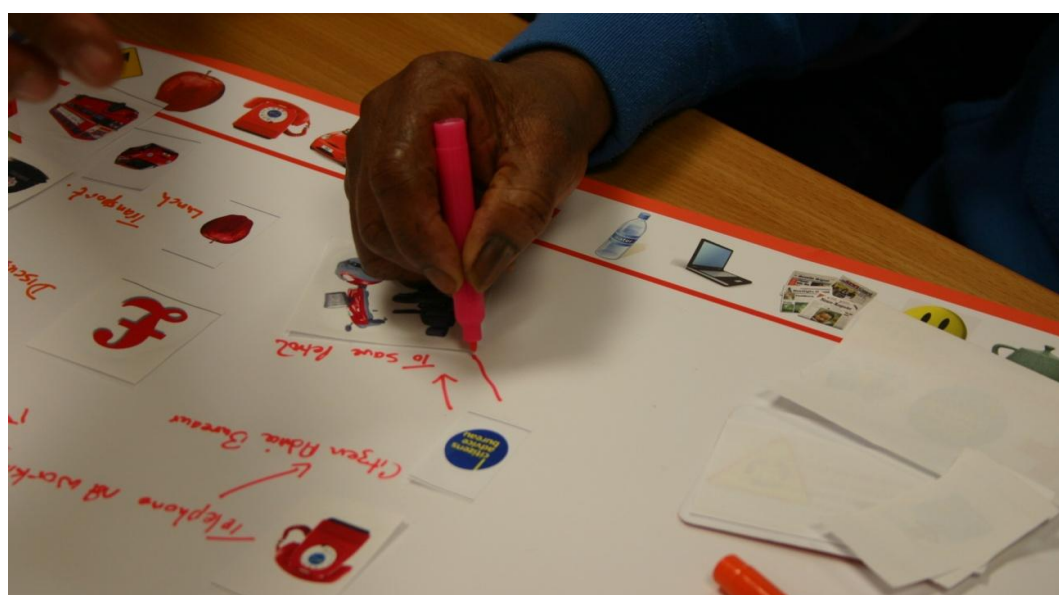


Figure 7 Telephone is the main information channel for some groups

“If I am on the phone and I don’t understand something, I can ask. If I have something on the screen that I don’t understand I find it difficult to find an answer to what I don’t understand”

Family Carer

However, there were many frustrations with telephone information services. Automated call routing was universally despised for the amount of time spent hanging-on and for the difficulty of using these services where options are often inappropriate to the caller’s need.

“The Doctor gave me lots of number’s but I didn’t get very far. My son made some calls for me. My Husband gets annoyed when it says press this, press that. I say you’ve got to listen and then do it but he gets so annoyed.”

Older Person

“We can’t get out easily so we are stuck with the phone mostly.”

Older Person

However, several **Older People** indicated that their ability to use the telephone effectively had declined with the onset of age related hearing impairment.

“I can’t use the telephone because I’m deaf. I use the internet. Email is always better for me than the telephone.”

Person with mental health issues

The internet

“I found the internet quite scary, not so much now, but when I first used it, it took me a long time to buy something. I was scared about my cards being used.”

Person for whom English is not a first language

The internet was the first port of call for some participants who valued its’ convenience and 24hr availability.

“The internet is good when you can communicate with people who have been in a similar situation to you. If you are stuck at home by yourself with your partner it is a window where you can find people. On the telephone you are just speaking to that one particular person where as with the internet you have a broader circle”.

Family Carer

For some, the internet had offered solutions which are just not possible through other information platforms.

“I heard about a treatment and used the internet to find out more about it. I got in touch with someone in South Africa and another one in Florida who had this neuro-treatment and they were very pleased with it. The fact that it is international is important. It crosses boundaries. It is amazing what the internet does bring up”

Family Carer

Naturally enough, the devotees of the internet were those who use it regularly and are more competent with it. Several participants said that they had, at one point, completed an introductory training course but had failed to retain their skills. Of these, several had a computer at home either unused, or used only by other members of the family.

“We only have one old computer and my husband and my son are always using it so I can't use it.”

Person for whom English is not a first language

“I like the internet – you can find different channels – it can link to related subjects – that's what I like – one thing might send you off to another”

Person with mental health issues

Although quite a number of participants were not users of the internet themselves, they did sometimes use it by proxy with another family member actually pressing the keys on their behalf.

Some **People with mental health issues** reported a particular aversion to the internet. Some of these said that they disliked its' impersonal nature whilst others perceived it as too expensive, or had an elevated level of suspicion about online surveillance.

Home internet is great for people with disabilities

Person with mental health issues

One or two participants warned of the dangers of researching medical matters on the internet where the combination of access to high level medical information and a low level of knowledge can lead to misinterpretation.

Somebody I know has a particular condition and they looked it up on the internet and were in a complete sense of panic because it was talking about tumours. When she actually spoke to someone in authority she was told that was a worst case scenario and very rarely was that happening and the fact that they knew she had the condition meant that it won't happen but she was a whole week worrying about it. She said she wished she'd never looked it up''

Person with mental health issues

PERSONAL STORIES

Local democracy and the internet

David learned to use the internet through a short course at Beccles Library about 3 years ago. As a keen cyclist, he wanted to establish a cycle path near his home.

Having completed the course he turned first to the internet and easily identified an officer responsible for cycle paths at the Highways Department of Suffolk County Council. Using email he found out the officers name and contact details.

Through speaking to people, exchange of email and through the SCC website he identified Councillors who would support his campaign. He even sent emails to Bob Blizzard MP. *"It was the internet. Doing it by snail mail would have been impossible. I couldn't have done it".*

To date he has managed to get a feasibility study for the route conducted and is now campaigning to have the route funded.

The library

"When I've been to the library I have seen all the different leaflets and books. I know they are there if I do need them"

Older person

Libraries were mentioned by all groups as good sources of information. Even those who do not regularly use a library felt they would use it to get information if they had a need.

Among **People for whom English is not a first language**, people settling in the country were very likely to be library users. In one group only 2 out of 13 said they were not regular library users.

There was some criticism of the way leaflets are sometimes present in libraries with what's on, health, transport information mixed up together.

Our report on the public consultation on use of libraries gives some useful further detail on this topic².

Local and national media

Local and national media were identified by many respondents as being important information resources. **Older people** in particular had the expectation that information about local events and the opening times of local public services such as sports and leisure facilities and libraries would be available in their local paper.

It was noted that information from media sources attracted a relatively high level of trust.

² Suffolk Libraries Consultation conducted by Cultural Intelligence, 2009.

5 People's experience of getting information

This section describes what participants had to say about their personal experience of obtaining information. A subsequent section looks particularly at more positive experiences in an attempt to learn what works well, so this section has a tendency to feature more of the negative experiences.

"You've got to push for what you want".

Person with a physical disability

The struggle factor

The most striking aspect of the participants' experience of accessing information was how much of a battle they find it. In what has become known as 'the information age' it is a matter of concern that they should find it so.



Figure 8 Family Carers need to become experts at the information game

Whilst it is important to acknowledge that participants may dwell on their more troublesome information quests it is certainly true that the information that people struggled to obtain was often unexceptional, everyday, normal information.

The battle often starts with finding the right information source. Many people complained of being passed from person to person, often having to repeat their story over and over again.

PERSONAL STORIES **Stress of the struggle factor**

Jane cares full-time for her husband. On the day she attended a creative consultation workshop she gave a recent example that illustrates the 'struggle factor'.

"It took me three quarters of an hour this morning to get to the right person at Ipswich Hospital. It was so frustrating. They had told my husband he should come in on Thursday and that there would be a letter coming as to what time his appointment is.

Well, no letter arrived and we hadn't a clue where the appointment was so we phoned up the Imaging Department. No it wasn't there. I phoned up the MRI Department. No it wasn't there, so I phoned up the Doctor's surgery. The Receptionist didn't know and said "I'll try and find out and get back to you".

Each time you are waiting because they are so busy. Then I finally got through to the proper department and they said 1045 on Thursday. I had all that carry on and they hadn't sent the letter out and meantime I am still waiting for the Receptionist at the GP surgery to get back to me. I was so stressed."

This unnecessary 'struggle factor' is a matter of particular concern because for many, a quest for information comes on top of an already extremely stressful situation.

The 'struggle factor' also leads to a significant number of people giving up their search. This is particularly true of **Older people** and could be a factor in the gradual reduction in engagement which they seem to experience.

The level of frustration was mainly down to several common identifiable issues which are further explored under Barriers (see page 41). These were:

- automated call management systems

“You always get voicemail, even in working hours . . . and press this, press that.”

Older Person

- lack of consistency and continuity in message and service

“One person who works here is due to retire. He was sent a letter saying don't contact the pensions people more than 2 months before his retirement date but when he called the contact centre they said it takes 10 to 12 weeks to arrange the first payment!”

Person with physical disability

- the failure of people to do what they promise they will

“I got this lady from Customer First and she sounded very helpful. She was very co-operative but I never heard anything back. She must have told someone but when I called back they hadn't even got me on their records. And I'm not the only one this happens to.”

Older Person

This failure of people to do what they say they will is often the reason why an information quest can stretch over weeks and months, where it ought to be a simple and relatively quick process.

“I can only speak from experience but I think that some Councillors will fob you off. I can think of one Councillor who promised to send me information and I've asked again and again but to date he still hasn't sent me the information he promised. It depends on the individual”.

Older Person

PERSONAL STORIES **Lack of continuity and a consistent message**

Olive is the carer for her husband who has Parkinson's. When she had to go into hospital for an operation she called Customer First to find out what care would be available to him while she is in hospital and during the period after the operation, when she is unable to complete the range of physical tasks she normally helps him with.

It was agreed that he would need residential care and a period of three weeks was approved which she would have to pay for. As this came to an end she spoke again to Customer First and was told he should have received 6 weeks care free of charge at home. During the course of the six week period the care provider changed and it was found that no care plan had been provided. In a further call to Customer First she was advised that she should never have been offered six weeks free care because it was the carer having the operation, not the cared for and she would have to pay for the care that had been received.

An investigation is pending which will provide further learning points however, from an information point of view this abridged³ story illustrates a number of the issues.

Lack of continuity - three different social workers dealt with the case in the course of a few weeks

Lack of consistency - the information provider kept poor and ad hoc records which led to inconsistent information

A confusing information landscape - the complex rules keep changing so it was difficult for advisors to keep up

Importance of providing written information - information was provided by phone with little confirmed in writing

³ This story is far more complex than is presented here and we have not spoken to Customer First about this case

It was notable that some people, particularly **People with mental health issues** even suggested sitting down with a friend and a cup of tea before making a start. This illustrates the very low expectations that some people have of an easy and satisfying experience.

Too much information

Information overload was a commonly expressed frustration with many complaining that they can be overwhelmed by the sheer volume of information they are expected to digest. Motivation was clearly a significant factor with people far more prepared to spend time and effort digesting information which was pertinent to their immediate interests.

However, it is clear that information is often not presented in a manner that provides appropriate levels of detail in a layered format that enables people to quickly identify the items they need to find.

“Often you are given too much information and you struggle to find what you need in the information they have given you”.

Older person

Careless response, lack of confidence and embarrassment

Participants from all groups reported that they sometimes receive a careless or unsympathetic response from people who are in the position of providing information. **Older people, People with a physical disability** and **People with learning disabilities** described how they are sometimes treated differently to other people.

“If you have learning difficulties people don't always understand you”

“I think sometimes people take the Mickey out of you. They think, if you've got a reading problem, that you are a bit thick”.

Person with learning disabilities

Older people in particular, complained of a general lack of empathy and caring that they commonly experience from people working in call centres.

“I think sometimes they think that you are not quite with it, that you don't quite know what's going on or that you miss things”

Older person

PERSONAL STORIES **Some groups treated better than others**

Freddie has mental health issues and has lived on benefits for many years. His local drop-in centre often provides help with information and form filling.

One day Freddie had some cheques from the Council which had to be paid in. He took them to the bank but they couldn't take them and he went back to the Council reception who rudely sent him back to the bank.

The support worker picks up the story. “When the bank again declined to cash the cheques he came in here. I followed him back to the Council and stood well back. The man was most rude to him saying “I've already told you . . .!” And I stepped in and said “Excuse me, how dare you speak to him like that.” In the end the Council found they had sent the wrong cheque.”

The faceless society

“When you need help you are stressed – you're not thinking straight – you need empathy”

Family carer

Alongside an increasingly complex information landscape has developed the ever greater presence of the 'faceless society' where people are expected to engage with a service by remote means. Whilst one or two participants said they favoured remote services for their accessibility and anonymity, these were considerably outweighed by the desire, among the

groups involved in the research, to engage with a friendly face or at least a supportive and consistent voice.

Many of the issues experienced by the groups consulted have a personal or emotional dimension where just expressing the problem to a good listener would go some way towards helping the situation.

“It’s hugely time consuming because you ring up and they’re not there and you have to leave a message on an answer phone – this is a social care thing – you can’t leave messages on answer phones for somebody popping in and having a listen”

Family carer

Automated call routing is a source of frustration for almost everybody. Participants complained that menus are often inappropriate to their requirements, that they are expected to hold for unreasonably long periods of time and that they sometimes find the options confusing.

Sometimes people would go through the whole process including hanging-on for an extended period of time only to find themselves cut-off at the critical moment or put through to the wrong department and having to return to the beginning again.

“I try for so long, then I give up and have a break and try again perhaps 30 minutes later. I just don’t understand them. Eventually I give up.”

Older person

It was noticeable that many participants but particularly **Older people** and **People with a learning disability** said that they just give up when faced with these difficulties. This was not said as much of other information channels such as using leaflets or searching the internet.

Lack of consistency and continuity

“If you are put through to someone you haven't spoken to before you might wonder whether they will understand you”

Person with mental health issues

“They don't say no. You just don't get anywhere”

Family carer

Many people expressed frustration about a lack of consistency and continuity. This was particularly true of call-centre based services where people complained about never being able to speak to the same person twice. The need to repeat the history of an issue to different people each time they called is really disheartening.

Participants also complained that Social Workers and other professionals in a position of providing information often change with confusing regularity and that when this happened, the information they provided was sometimes significantly different to that offered by their predecessor.

“They all have different ideas as to what you might be entitled to or not entitled to. For instance, I had three different Social Workers all saying different things as to what we were entitled to for respite care and they all had different ideas. We finally got it all sorted with one gentleman and it took months and we had it in writing and then another social worker comes along and blew the whole thing away.”

Family carer

Poor service at weekends

A few participants complained of the lack of service at weekends. This is felt to be particularly important for matters related to health or social care where the issue is not sufficiently serious to require an emergency service but can not necessarily wait until the start of the working week.

6 Barriers to accessing information

“You go to a meeting and they say here’s your pack and you say ‘Is it available in large print?’ and they say ‘Oh no’ and you say ‘Well I did ring up and tell you last week, why isn’t it available?’ and after the meeting they say we’ll send it you but it’s too late then”

Person with physical disability

Whilst good information seeking skills can make a huge difference in the information game, it was clear from the consultation that most barriers result from inadequacies in ‘the system’ rather than in the abilities of individual information seekers.

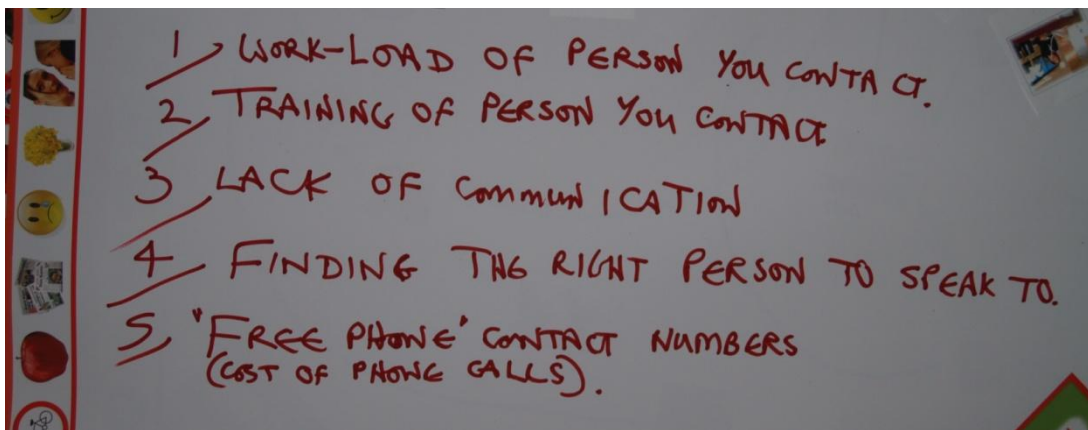


Figure 9 Common barriers

Strong information seeking skills allow individuals to feel more confident about seeking information, give them a better understanding of where to start and make them better equipped to make progress in the information game.

“I used to run my own business so I know how to find what I need”

Person for whom English is not a first language

It was apparent that one’s ability to succeed in the information game is not consistent throughout life. For instance, the consultation included active **Older people** whom a lifetime of information-based working had equipped

with all the tools they need to find what they require. The consultation also involved **Older people** with a similar background for whom growing physical incapacity and the increasing challenge of coping with illness and infirmity has depleted their skills and capacity to the point where they find it so difficult to find what they need that they often give up looking.

Whilst a number of barriers are more specific to individual groups, there are a number of barriers which are universal. This section describes the more general barriers.

Not knowing what you don't know

“Maybe years go past and then you talk to somebody else and they say ‘Do you know, you could have got this or that service’”

Person with mental health issues

Knowing what questions to ask seems to be one of the greatest issues for adults seeking information in Suffolk. Participants frequently complained about the failure of all kinds of services, to address their situation in a wider or more holistic manner by volunteering information which anticipates their needs, rather than just responding to issues they raise.

“. . . and they said to me ‘Have you got all the equipment you need’. Well how am I supposed to know what’s available?”

Family carers

Quite a number of **Family Carers** described how they had struggled for months or years but it was only when a crisis occurred that they suddenly found themselves receiving information about different options available to them.

“Before he went into hospital I never knew there was any help available!”

Family Carer

It may be that a target driven culture, or fear of stepping beyond their immediate area of expertise inhibits some professionals from taking a wider

view of a person's situation. However, it is clear that many of the events that prompt a need for information have a predictable pattern which should enable professionals to anticipate information needs.

“It is extremely difficult to know what is right and what is wrong. What you should or should not be receiving”

Family carer

“Years ago, Doctors looked after the whole family and they knew your circumstances and would be able to point things out. Nowadays, as much as I admire them, you do have to ask questions.”

Family carer

Difficulties with telephones

For many participants, especially **Older people** and **People with physical disabilities**, the telephone is a lifeline without which they would become increasingly isolated. However, many found that their capacity to use the phone becomes increasingly impaired with age.

“It gets harder to use the phone when your hearing goes or your fingers get worse”.

“My good ear is on the right hand side but my right hand stopped working at Easter so I have to do this” [demonstrates holding phone to right ear using left hand] –That’s not easy even for those of us without arthritis!”

Older people

A further problem often quoted was the use of overseas call-centres to provide information. A number of people expressed genuine difficulty in both understanding the spoken English of the person at the other end of the phone and also sometimes, in making themselves understood. The latter was a particular issue for **People with a learning disability** and some **Older people**.

The length of some calls is an issue for **Family Carers** who often have very limited time in which to make calls. One or two described holding the line for long periods only to find they had to end the call to attend to the needs of the people they are caring for just as they finally got a response to their call.

Though not strictly related to information, it was noted that many participants, but in particular **Older people** and **People with learning disabilities** find themselves considerably upset, (and potentially exploited), by cold callers. This was of particular inconvenience to **Older people** and **People with physical disabilities** who described the considerable effort they might have to make to answer a call, only to find it is a company selling mobile phones or worse a 'silent call'.

There is certainly a need for a well run information campaign to advise vulnerable groups about the telephone preference and mailing preference schemes.

Not knowing where to start

Many participants in all groups said that 'knowing where to make a start' is a barrier. There is, however, some considerable confusion over who is responsible for what. The sheer diversity of third sector and community interest organisations now delivering services has created a very confusing information landscape. There is also, of course, the longstanding confusion over which local authority tiers are responsible for which services.

However, in exercises completed as part of *The Information Game* we found that, working in small groups, they generally did manage to find an appropriate starting point.

Difficulty in understanding information

"Sometimes they keep going over the same information again and again but you think, well I'm no wiser. You want it more simplified I think. Put it in everyday language".

Person with physical disability

Difficulty with understanding information was reported by participants from all groups. Common complaints included the sheer volume of information sometimes provided and the use of technical words or jargon.

“Sometimes they come out with these long words and it is just confusing”

Person with learning disability

Some people from all groups but particularly **People with learning disabilities** and some **Older people** expressed frustration that information was sometimes presented in an over-complicated format, though there was general agreement that too much information is preferable to too little.

People for whom English is not a first language reported frequent instances where information was confusing, sometimes with serious consequences. Quite a few from this group reported having to sign legal contracts, (with banks or credit companies), without being able to read and comprehend what they were signing.

“I’m not good with money. I get confused and worried. If people explained at my pace it would be easier”

Person with learning disabilities

Difficulty with taking notes

“For blind people the telephone is essential – when they are telling you things at the other end they’ve got to give you time to write it all down. They give you a phone number and they go ‘blah blah, blah [speak really fast] and you say “Can you say that again?” and they say it again just as fast and they make you feel stupid.”

Person with a physical disability

People with a learning disability, **People with a physical disability** and some **Older people** mentioned the difficulty they have in taking notes when information is provided verbally, especially over the telephone. Supporting typed written material should therefore always be offered.

When there is a lot of information, you ask for them to send it in writing and they stick it in the post there and then in their own handwriting and you get it and you can't read it!"

Person with a physical disability

Answer services, (both staff members leaving messages on private answer phones and the widespread use of voicemail services by organisations), were a particular source of frustration because people posting messages often speak too fast. **People with learning disabilities, Older people and People with physical disabilities** in particular expressed frustration in this respect.

People will speak too fast – even on a recording machine when you can't ask them to repeat it.

Older Person

A number of participants expressed concern about leaving personal information on voice mail services. In one instance, a participant said that they contacted a social or health service about obtaining some adaptive aids and found themselves receiving sales calls from commercial suppliers.

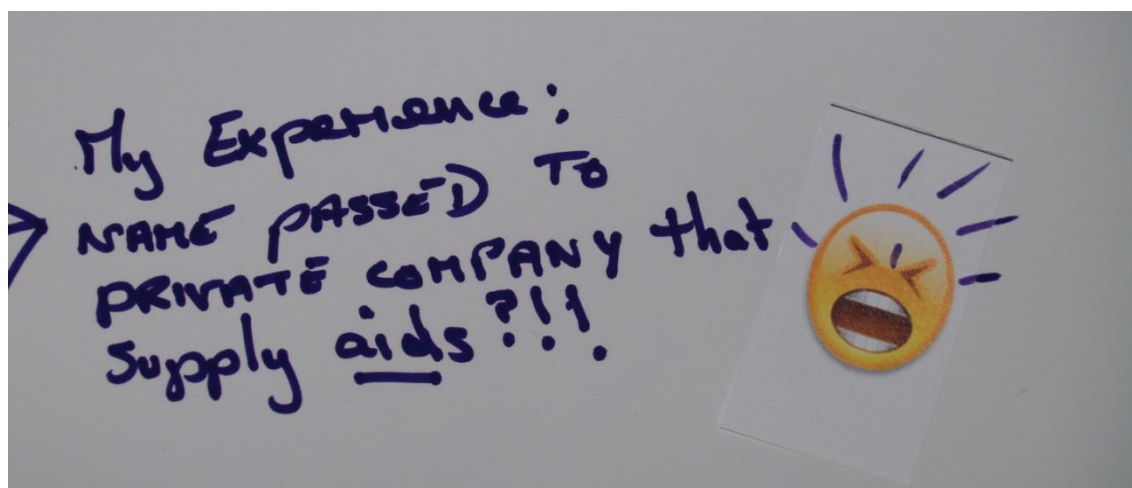


Figure 10 **One person with mental health issues** found their details passed to a commercial company

Translated material and large print

The need for a better understanding of the needs of people with a visual impairment was apparent from the comments of one participant.

“A lot of people, when you say you want it in large print, send it on large sheets of paper that you can’t look at properly. You can see it has been photocopied onto larger sheets of paper. They don’t understand that you can’t sit in a meeting with large sheets of paper while everybody else is working on normal paper.”

Person with a physical disability

The same participant also had experience of being sent material that had been printed out on A3 paper but with the print still at the original size.

Whilst some material is available in translated form, there are more than 100 languages spoken in Suffolk schools and official publications tend to be translated only into a handful of the more common languages.

A number of people observed that the offer of a translation is often made as a note on the reverse side of a leaflet or publication. Unfortunately, it is often not possible to tell, from the look of the publication, what topic it refers to. It is unclear how a non-English speaker is to know to pick that publication up in the first place.

Several participants said they felt that translated versions should be out on display with other material so that they can see that it is available. Most participants said that their tendency is to assume that a translation is NOT available and are therefore less likely to ask for one.

One support worker who had requested a translated version of an official publication found a lack of willingness to provide it.

“Even when I have called to get a leaflet translated for someone, I was asked whether I was sure because it will cost a lot. If that is the reaction I am getting, what is it like for them?”

Support worker

Lack of access to the internet

“. . . you are a second class citizen if you are not computer literate”

Family Carer

Some non-internet users from a number of different customer groups observed that the increasing reliance on the internet as an information channel excludes them from access to information; however, this view was not as prevalent as might have been expected.

Having said this, it must again be emphasised that the majority of participants were not internet users and non-internet-based information channels are as important as they ever were. (See page 25)

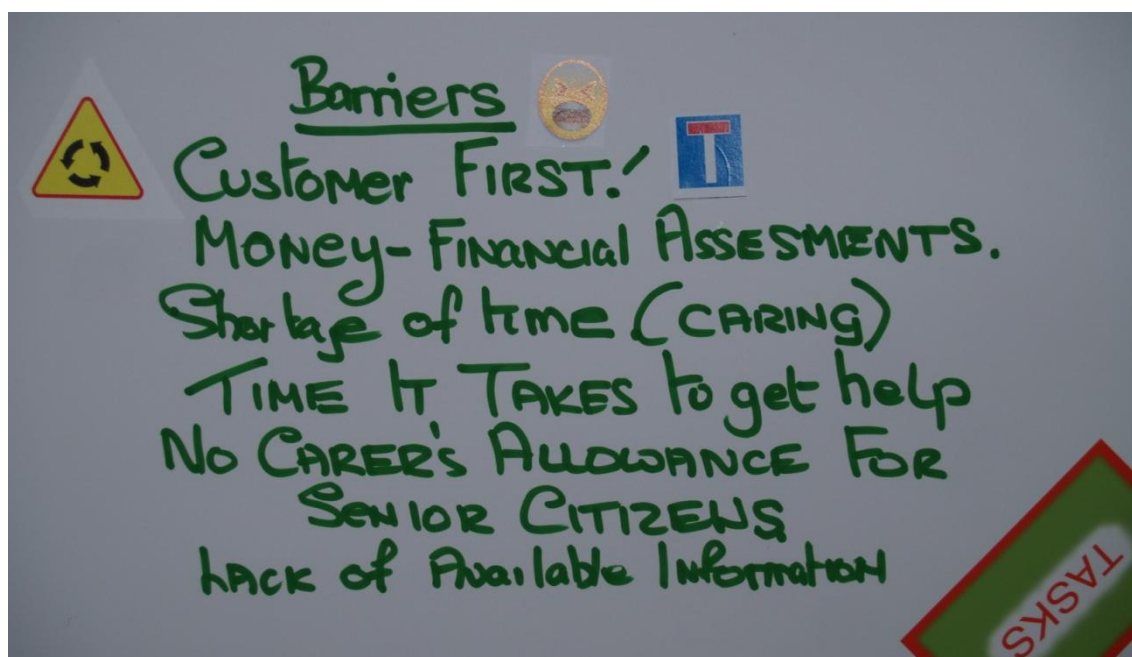


Figure 11 Barriers quoted by Family Carers

Cultural mores

For many **People for whom English is not a first language**, it is not just language issues that present the greatest problems. Difficulty understanding cultural expectations present as much of a challenge.

Many matters, which people raised in the UK take for granted, are quite alien to people from other cultures. Much of this 'assumed knowledge' needs to be made explicit to people from other cultures.

"I am from Portugal. We don't have Council Tax and benefits are very difficult to get. The system of National Insurance social security is complicated for us. I talked to people and visited all the places. Friends who had lived here a long time helped me saying you have to go there, then you have to go there and sort everything out."

Person for whom English is not a first language

New arrivals have a number of simultaneous information quests but unfamiliarity with the culture makes it hard for them to prioritise them.

Information, in particular that relating to health, financial and legal matters, is often presented in a form of English which is unfamiliar to them. This problem is particularly acute in money matters. Several participants had found themselves signing up to bank accounts without understanding the terms and conditions and had later found themselves tied in to costly services that they do not need.



Figure 12 Legal and financial information can be especially difficult to understand

People for whom English is not a first language often tend to be working in poorly paid occupations which require them to work long hours or do shift work in order to make a living wage. This makes them short of time for information searches.

People from this group often lack transport and this can present a barrier to searching for information especially where going in person is preferred because of the language barrier.

Even information, as everyday as letters home from school, can present a worry and challenge for some **People for whom English is a second language**. Whilst the child is often able to help translate this is not always the case.

“My English is very difficult to understand. For example, I have got a very official letter from a school to ask what health reactions my daughter has got. I have called them many times to say I need help”.

Person for whom English is not a first language

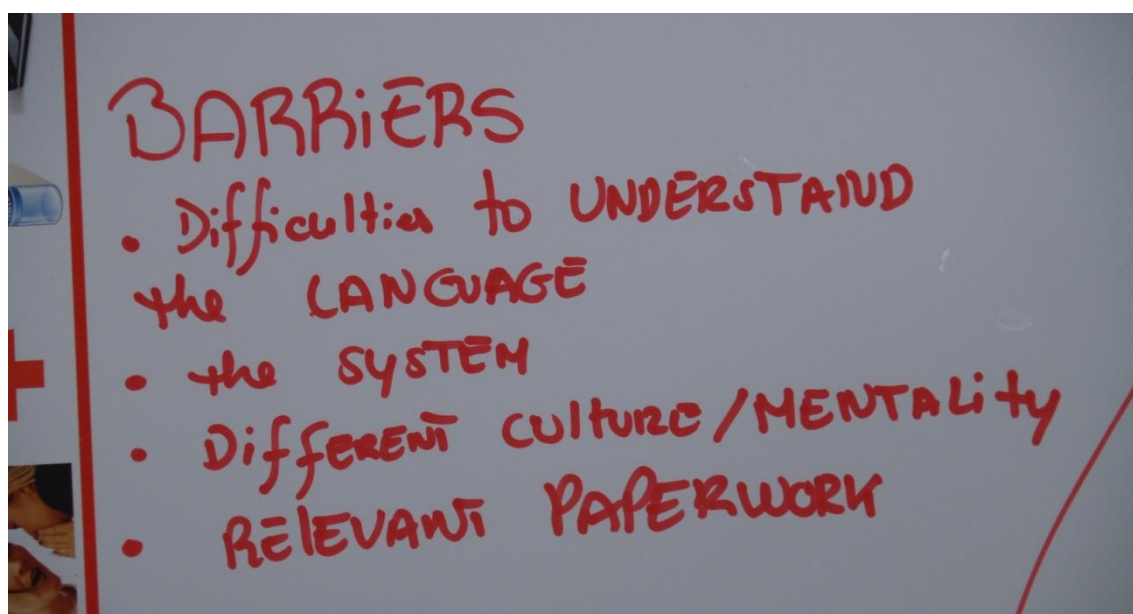


Figure 13 Barriers to people for whom English is not a first language

Some participants indicated that some information needs can be difficult to broach because they can be embarrassing. However, the internet and to a lesser extent, the telephone were recognised as channels where embarrassment might be less of an issue.

Several **People with mental health issues** pointed out that a level of confidence and trust is necessary before they would feel able to ask for information or help. An unsympathetic response is likely to compound lack of confidence which was identified by a few **People with mental health issues** and also some **Family Carers**.

“I had a phobia about telephones”

“I have a computer phobia”

People with mental health issues

Living in a remote rural location

One or two **People with physical disabilities** observed that living in a remote rural location presents a barrier to their access to information. This they put largely down to restrictions on their mobility.

This contrasts with **Older people** in Sudbury, (A market town in Suffolk), who observed that living close to a compact market town gave them relatively easy access to services because everything is close together, e.g. library, tourist information centre, volunteering centre.

Lack of money

While a lot of information is offered free of charge, there is often a cost to getting it. This may include mobile phone charges, bus fares or missing work to make a visit in person. Quite a number of people without home internet gave ‘high cost’ as the reason why they lacked internet access at home.

Some people noted how confusing call charges to different telephone services can be. It can be particularly difficult to predict the duration of calls

to call-centre services where a simple enquiry may require some considerable time holding the line. A number of the participants involved in the consultation, particularly asylum seekers and migrant workers, are dependent upon mobile phones, which attract significant call charges.

Patient confidentiality

One **Family Carer** who is also a **Person for whom English is not a first language** told how patient confidentiality had been a factor in preventing her obtaining the information she needed to care adequately for her daughter. Suffolk Family Carers have confirmed that this is an issue faced by quite a number of carers.

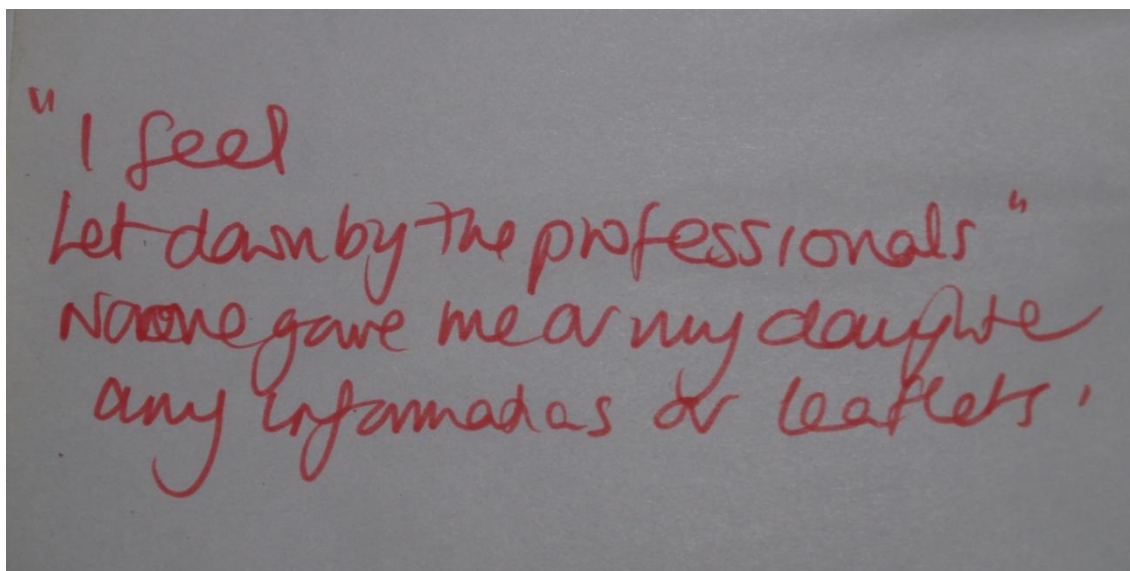


Figure 14 Lack of appropriate information can have serious consequences

7 What makes a positive information experience

“When you’ve been treated the same as everyone else.”

Person with physical disability

Participants in the consultation were also asked to consider their positive experiences of obtaining information. It was notable that they found it harder to identify these. This may be because many positive information exchanges can pass almost unnoticed because they proceed so smoothly.

The information services that seemed to be most beneficial had the following characteristics:

- **Few boundaries** – they focus on the needs of the customer rather than the requirements of the information provider which leads to a more holistic approach
- **Anticipate needs** – they understand that the customer may not know the questions to ask and will therefore have a systematic approach to ensuring that possible needs are anticipated
- **Provide information in multiple channels** – in this way they can meet the needs of the customer in a manner that suits them. This would include large print or translation as appropriate
- **Provide information in a layered form** – that allows information to be accessed at a basic or more detailed level
- **Friendly, supportive and non-judgemental** – although not instrumentally important to the provision of information friendliness is a quality that is highly valued by participants in this consultation
- **Effective fulfilment** – they do what they say they will do without undue delay and if necessary stay with the issue until it is resolved
- **Communicate the alternative formats** in which information is available as a matter of course and not just on request

In addition to describing positive experiences, participants were also able to describe a number of techniques or approaches that they find most effective from the point of view of the information customer.

Be pushy and persistent

“It was when I started being a little assertive, shall we say, that I began to get somewhere and things started happening”

Family carer

Whilst participants had many practical tips for what works well in obtaining information, there was a clear belief that being assertive is more likely to lead to success.

“You need persistence and bloody mindedness. The people who aren’t persistent and bloody minded get squashed. They go down”

Family carer

“We had to push for my Mum. She was in a home. My Sister and I would go and see her and Mum would be in a wheelchair and we’d say it’s not good for Mum to be in a wheelchair and they made a mistake when they said ‘Its more convenient’ and we said ‘For whom?’”.

Person with physical disability

Have an ally

Many **Older People** were dependent on having a family member who would take on the task of finding information.

“I get my niece to do it”

“My son sorts everything out for me”

“My husband does all that”

Older people

“A lot of it is family pushing.”

Person with physical disability

One of the benefits of the approach of the Citizen Advice Bureau is that they will follow an issue through from start to finish, providing a powerful and authoritative ally to someone on an information quest.

*“In one case my Support Worker wrote a letter to the Council.
Until somebody officially acts, you are not in control at all.”*

Person with mental health issue

People with learning disabilities are also often more dependent upon friends, relatives and neighbours, especially when it comes to explaining written information that they have difficulty understanding.

Of course there were some people who had no one to take on the role of seeking information for them, in which case some were fortunate to have a good case worker or other professional to help.

*“I haven’t got anybody but I find social services are very good.
They care and talk through what you need”*

Older person

*“My social worker helps me - she comes every week. Sometimes I
ask her for information and she helps me fill in forms. I trust her”*

Person with mental health issues

*“I heard about this group [Age Concern Day Service] from a
Community Police Officer” (mobile community police station
visits her village each week)*

Older person

Be connected

For those people engaged with a support service or making use of day care or drop-in facilities, these services are a vital information source.

“They often say, if you’ve got any problems bring it in here”

Person with learning disabilities

Many **Family Carers** engaged with Suffolk Family Carers spoke extremely highly of the way in which that organisation recognises and anticipates their information needs.

“Suffolk Family Carers have been fantastic in pointing me in the right direction. They think of the things you don’t think about”.

Family carer

People with learning disabilities tended to have established strategies for ensuring that they understand information from official sources. This normally involved a supportive relative, friend or neighbour, or a day service.

“If you are on benefits, they send you forms. You just take them back to the Social and they sort it all out for you so that’s what I do”.

“Sometimes I take it to the health centre and they explain it to me because I’ve got learning difficulties and sometimes I get confused”

People with learning disabilities

Many **People with learning disabilities** told of particular difficulty they have with utility providers such as telephone, gas and electricity providers who had a universally poor reputation with this group. **People for whom English is not a first language** also complained bitterly about the utility companies.

Know someone who has been there before

Many participants were able to quote instances where meeting or knowing someone who had had their problem before was key to their success in finding information relating to their situation. This emphasises the importance of networking both face to face and through virtual means.

Other tips for success

During the course of the workshops, participants produced many examples of what they find works well for them:

- Ask for names and write them down

- 'Information on Prescription' is good
- Libraries are good and free!
- Suffolk Family Carers are brilliant – you have to know to phone them though!
- Pick and choose what information is relevant to you
- Ask someone who has been through the problem before
- Relatives are helpful as are good friends
- Personal recommendation is reliable
- Word of mouth especially from people who have had the problem before you
- Share problems with a friend and go at it together
- You need information written down as well as given verbally

People for whom English is not a first language made the following points which particularly apply to people in their situation

- Make an effort to learn good English
- Get a job for some money then solve any other problems
- Have a really good dictionary
- Make it a priority to go to College or CSV Media to get more language
- Get a base like CSV Media or College. Somewhere to belong
- It is vital to integrate

An 'English for speakers of other languages' (ESOL) teacher mentioned the welcomepack.org.uk website though this was not mentioned by any of the participants from this group

For **People with a learning disability**, one person pointed out that the magazine provides a very accessible format for the provision of information (health promotion, personal safety, etc).

Tips for knowing the information is reliable

Participants also quoted the following factors which encourage them to trust the information they are given.

- If the information provider seems authoritative

What Makes a Positive Information Experience

- If you hear the same information from different people/sources
- If the information makes sense or seems logical
- If information sources do not have a vested interest

8 Solutions and opportunities

“People need to listen so that they can give you the information you need”

Person with learning disabilities

There are a number of learning points arising from the consultation which may helpfully inform the development of policy and strategy relating to the provision of information for adults in Suffolk.

Prioritise multiple formats

Different information channels suit different people. Many, for physical, skill-based or economic reasons, simply do not have the choice to switch channels. A choice of information channels is therefore as important now as it has ever been. This is particularly so for the disadvantaged and excluded groups involved in this consultation, few of whom were regular internet users and by whom personal contact is particularly valued.

Information that anticipates need and promotes entitlement

One of the most important findings arising from this consultation is the need for more systematic approaches to providing information which anticipate people's needs rather than responding to problems at the point where they are reaching a crisis.

This links to another point raised in this consultation. That is, a tendency for people to be expected to *discover* for themselves, benefits and services which may be available to them rather than for 'the system' to actively *volunteer* them.

Many information needs arise as part of a life-event or life stage so it ought to be possible to identify these and to develop strategy which specifically addresses them. It should be possible to assemble information packs or kits which respond to such issues but also go beyond immediate needs to address wider or forthcoming issues.

Such information packs would enable front-line staff to easily provide up-to-date and authoritative information which may sit slightly outside their own field of expertise. This would help overcome the 'bunker' approach which was an issue identified as part of this consultation and along with training, could help promote a 'no boundaries' culture.

Several participants quoted 'discharge from hospital' as a good example of when 'the system' works in a proactive manner to provide information that anticipates need.

Ensure telephone services work really well for the customer

Many people involved in the consultation, but particularly **Older People** and **People with a physical disability** are dependent upon the telephone as a primary channel for information. However, there was considerable criticism of call-centre based services. Many of these criticisms were of a kind that could be overcome with better system design, better staff training and higher staffing levels.

Whilst Suffolk County Council (SCC), clearly has limited capacity to influence third party call-centre services such as those of the utility companies, it does control the Customer First service. Priority should be given to ensuring effective evaluation and monitoring of this service perhaps through the use of mystery shoppers, and maybe, case studies which follow enquiries through from start to finish.

It may also be possible for (SCC) to work with its partners to arrive at guidelines for best practice or minimum standards for the telephone information services that they offer.

One simple improvement would be to introduce the practice whereby staff members are encouraged to give a date by which they hope to have implemented an action. In this way the caller would know how long to leave it before, chasing them up, thus reducing frustrating unnecessary delay.

Consideration should be given to reminding all frontline SCC staff to be aware of the needs of **Older People, People with learning disabilities**

and **People with physical disabilities** when leaving voice mail and to speak slowly and clearly especially when leaving telephone numbers

Improve information searching skills

It was apparent from this consultation that the participant's skills for information seeking vary widely but can make a considerable difference to their access to information leading to resources and opportunities. Also, that such skills can go out of date or that an individual's capacity to use them can change over their lifetime.

The National Curriculum for Citizenship requires that Key Stage 3 & 4 students . . . "research, plan and undertake enquiries into issues and problems using a range of information and sources, analyse and evaluate sources used⁴".

It may be appropriate to consider using the kind of information searches discussed in this consultation as a context for this work in secondary schools in Suffolk.

This consultation involved mostly participants who left school before the provision of the National Curriculum for Citizenship. It might therefore be desirable to ensure that information searching skills are adequately covered on relevant training courses such as those offered to new **Family Carers**, for those on 'expert patient' programmes and the life skills college courses for **People with a Learning Disability**.

It may be possible for SCC to work with its partners to explore other ways in which information searching skills can be improved for the people they are working with.

⁴ <http://curriculum.qcda.gov.uk/key-stages-3-and-4/subjects/citizenship/index.aspx>

Recognise and develop info-hubs

Many people involved in the consultation identified day services or drop-in services as key information hubs. Many of these, along with specialist agencies are partnered by the County Council and in some cases information dissemination is recognised as a core part of their service.

For those engaged with such services, this is an effective method of promoting access to information and consideration should be given to ways in which this might be formalised, enhanced and developed as an integrated countywide network. GIS mapping and Suffolk Infolink may have a role here.

For **Older People**, as greater consumers of health services, GP services would appear to offer an opportunity for information networking which could go well beyond health issues. For instance, surgeries offering a well-person health check at 65yrs could perhaps signpost information about wellbeing, transport, volunteering, etc.

Develop fact sheets and common source information

Plain and simple but well crafted and thoughtfully structured fact sheets could be made available on the internet and also easily printed for manual distribution. This would provide a cheap and easily updateable form of authoritative information for primary consumption or as described above, for promotion by front-line staff including call-centre staff.

The use of a common source would help overcome lack of consistency of message which was an issue identified in this consultation. The provision of translated or large-print material could also be more effectively facilitated in this way.

Promote family and neighbourhood networks

Word of mouth via family friends and neighbours is the primary source of information identified in this consultation. Significantly, whilst participants were aware of the potential unreliability of information passed in this way,

very few had experience of such problems – perhaps because such information is used more to signpost than to directly act upon.

Policy relating to information should recognise and embrace word of mouth as an important channel and should seek ways to strengthen it.

For instance, many participants recommended learning from people who had already been through their situation. Maybe a network of volunteers could be developed as community speakers on different issues.

Campaign on mailing and telephone preference

“You get people ring up and they ask you about your bank details.”

Person with learning disability

During this consultation, it became apparent that many **Older People, People with a learning disability, People with a physical disability** and **People with a mental health issue** are troubled by cold callers on the telephone and to a lesser extent by volumes of junk mail.

Consideration should be given to developing an information campaign which supports disadvantaged communities in making use of the Telephone Preference Service and the Mailing Preference Service.

Consider one stop shops

Several participants suggested adopting the ‘one stop shop’ approach which they had noted in other local authority areas. With this approach council service are accessed via a single portal on the high street.

Whilst this might be particularly relevant in areas of greater need, the approach of enabling and encouraging a more holistic service from existing information providers is likely to more effectively overcome the barriers identified in this report .

User-centred web delivery

Whilst only 40% of participants had used the internet to find important information in the last 12 months, (compared to 80% using word of mouth), it is clear that the internet has a hugely significant role to play.

This consultation suggests that enhancing the human/interactive elements of the web and ensuring a positive experience which feels 'natural' to the customer is the key. This is likely to require the ongoing convergence of web, call-centre and in-person channels.

Suffolk County Council is currently conducting a review which will go a long way towards addressing these issues.

Resolve issue of access to 'what's on' information for adults with learning disabilities

Although this issue was raised only by one or two participants, it is none the less worthy of consideration. Whilst advances have been made on the provision of physical access information for leisure activities, there is little information available to indicate what activities are likely to be appropriate for adults with learning disabilities.

Refreshing the skills of Older people

From this consultation it was clear that significant changes in life, such as changing mobility, produce a more intense need for information. Also, that **Older People** who may have been perfectly competent in the information game for most of their life, struggle to sustain that ability as information systems evolve and their own capacities change.

Policy and strategy relating to **Older people** should seek to sustain and reinforce the ability of **Older people** to find the information they need. It is important that policy and strategy relating to **Older people** and to Information should recognise this.

9 Conclusion

The consultation successfully engaged 165 people from the priority groups in a public consultation about how they access the information they need in order to live life to the full.

It produced a wide ranging set of findings with several dominant themes which could helpfully inform the development of policy and strategy relating to the provision of information for adults in Suffolk.

The struggle factor

The most striking finding to emerge from the consultation was the extent to which people find accessing information to be a struggle. This is a matter of particular concern for the marginalised groups involved in this consultation for whom day to day life can already be quite a struggle.

Whilst good information searching skills can help to overcome the struggle, it was apparent that most of the struggle factor arises from weaknesses in service delivery on the part of organisations, rather than poor capacity on the part of the information consumer.

Effective policy relating to the provision of information would make it a priority to seek to reduce the 'struggle factor'. Issues that contribute to the 'struggle factor' include:

- Difficulty in knowing what organisation is the best source of information
- Failure of the service provider to do what they say they will do – (like returning a phone call)
- Lack of continuity - like never getting to speak to the same person twice
- Confusing or inconsistent messages – often because information is interpreted differently by different frontline staff

The importance of multiple channels

The crucial importance of supplying information through multiple channels e.g. print, web, telephone, media, etc was confirmed. Different individuals

use different channels often to the exclusion of other channels and different channels are favoured by different people for different types of information.

Channel-shift offers potential for improved access to information but there is significant danger that the most vulnerable in society could become even more marginalised if human factors are ignored.

Bound to this issue is a continuing need to provide individuals with the skills to use online services and access to the internet so that they can use them.

The importance of the human factor

Whilst some issues require only a factual, information based response, it is evident from the consultation that there are many where this is not enough and human involvement is preferred. Certainly, the participants in this consultation place a very high value on interacting with an individual, rather than an information system.

A successful information strategy is likely to acknowledge this factor and to seek to develop interactive information systems which embrace appropriate channels of information provision according to need.

Information provision that anticipates need and crosses institutional boundaries

One of the most significant advances in the provision of information would be to provide information that ignores institutional boundaries and anticipates need based on an individual's circumstances. The consultation showed that information requirements are relatively predictable at particular life stages and when particular life events occur, such as moving house or going to college.

Many participants complained that it is left to them to do battle with a system in order to discover opportunities that would be available to them if they only knew to ask. They were able to identify individuals and services which do take a holistic view and provide information based on the needs of the user rather than the strict terms of reference of the organisation so this

is clearly possible. However, it is likely to require close collaboration from multiple agencies.

Information v Advice

The findings of the consultation serve to illustrate how, in the experience of the public, *information* seamlessly merges into the realm of *advice*. Policy and strategy relating to information will need to take account of this and avoid seeking to construct excessively stark boundaries between the two.

Finally, Suffolk County Council is to be congratulated for commissioning this consultation. Participants were very appreciative of being involved. They certainly felt that this was a valid issue for consultation and were keen that their voices be heard.

Appendix 1 - The Information Game, Quest and Chance Cards

Information quests were carefully selected to be appropriate to the group.

- You have realised that you are deeply **in debt** and are reaching a crisis point. How will you find out what to do now?
- Someone you are close to has been behaving **violently** towards you. How will you find out where to turn for help?
- Your **neighbours** are keeping you awake every night with loud music. How will you find out what can be done?
- How will you get the information you need to **choose a school** for your children?
- You have lost your driving license due to heavy drinking and those around you say you have a **drink problem**. How will you resolve the problems this presents?
- You want to contact your local **County Councillor**. How will you go about it?
- You live in a **rural location** but work in a town ten miles away but you do not drive. How will you research transport options?
- You believe you are being **discriminated against** and want to know what you can do about it.
- You are worried about **Swine Flu** and need advice. Where do you turn?
- Your partner's health has deteriorated to the point where they can no longer use the **stairs**. Where will you turn for help?
- You wish to report that **street lighting** has failed on a major trunk road close to your home. How will you find out who to contact?
- You have recently arrived in the UK and speak or read little English. You have received an **official letter** in the post. How will you find out what your options are?
- You have developed an **injury** that prevents you doing your normal work. How will you find out about your rights?
- You have been made **redundant** from a job you have held for 10 years. How will you find out your options?

- You know you should take more **exercise** but are unsure what is available in your area. How are you going to find out your options?
- You want to be more healthy and decide to take more **exercise**. How will you find out what your options are?
- You want to go and see your local **football team** play their next match at their home ground. What information will you need and how will you get it?
- You suspect your **employer** may not have given you all the money you are due. How will you find information on what you can do about it?
- You have been suffering mild toothache and need to register with an **NHS Dentist**. How will you find out what to do?

Chance cards were delivered to participants at key points in the game and were used to extend the scope of the quests.

- The information you have received is written in English which you find hard to understand
- Someone has offered to help translate for you
- Your internet has gone down so you cannot access the web
- You have become desperately short of money
- You meet someone who has had this problem before and they offer helpful advice
- It is 5 o'clock on Christmas Eve and everything is closed
- Someone has offered to drive you around for a day
- You have won £100 on the lottery
- A library has opened close to your home
- You are totally fed up with being passed from person to person. You just want an answer NOW
- Your telephone is not working and you've lost your mobile

Appendix 2 - Introduction to target groups

Family Carers

A '**Family carer**' is someone who, without payment, provides help and support to a partner, child, relative, friend or neighbour, who could not manage without their help. This could be due to age, physical or mental illness, addiction or disability⁵.

The Joint Strategic Needs Assessment for Suffolk 2008-11 projects a 49% increase in the population aged over 65 years with a consequent increase in the number of **Family carers** in the County.

It should be borne in mind that those caring for **Older people** are very often 'older' themselves and the findings relating to **Older people** may also relate to **Family carers**. Also, there is considerable overlap between the interests of **Family carers** and the people they care for (often people with physical and/or a learning disability or a mental health issue).

People with a physical disability

A person with a physical disability has a physical impairment which has a substantial, long-term, adverse affect on their ability to carry out normal day to day activities⁶.

Little reliable information is available regarding the number of people in Suffolk who have a physical disability but an estimate for those who meet the definition given in the Disability Discrimination Act (DDA), which includes those with a mental impairment, suggests that 20% of the UK population are covered by the Act. There are 8,000 individuals listed on the SCC database of service users as having a physical disability.

⁵ Definition from Suffolk Family Carers

⁶ As defined by the Disability Discrimination Act

For the purposes of this consultation, the category of **people with physical disabilities** included those with a sensory disability. The needs of the group of **people with physical disabilities** often had significant overlap with that of **older people** and to a lesser extent with those **people with a learning disability**.

People with a learning disability

National figures⁷ for the UK population suggest that between 1% and 3% of the population have a mild learning disability and 0.4% to 0.6% of the population have a severe learning disability.

This equates to between 5000 and 15,200 adults in Suffolk with a mild learning disability, and between 2000 and 3000 adults with a severe learning disability. There are approximately 1,900 **adults with learning disabilities** who receive services from Suffolk County Council's Adult and Community Services.

People with mental health issues

Research carried out by the Suffolk Primary Care Trust in 2006 found that, around 17% of adults in the UK have a mental health problem. Many people with a Learning disability, or physical disability also have a mental health issue.

In the Suffolk PCT area⁸, the expected number of people suffering from a mental health problem every year is 147,000-178,000. These figures do not include people in Waveney, so the numbers are likely to be much higher for the whole of Suffolk.

⁷ Joint Strategic Needs Assessment for Suffolk 2008-11

⁸ Joint Strategic Needs Assessment for Suffolk 2008-11

Research published by the Alzheimer's Society in 2007 forecast a rise of 45% in cases of dementia in England over the next 15 years. These findings were also reflected in work conducted by the district area in Suffolk into the prevalence of dementia over the next 20 years. Not surprisingly, there is a strong relationship between the projected growth in the elderly population and the rise in Dementia⁸.

Older People

A key challenge identified in the Joint Strategic Needs Assessment for Suffolk 2008-11 for commissioners and providers, both now and for the future, is the growth in the elderly population which increases with successive age bands. It projects a 49% growth in the over 65s and a 90% growth in the over 85's by 2021. This implies a significant rise in demand for all age related services and support.

Many of the workshops with members of other target groups such as **People with physical disabilities** included **Older people**. We also ran workshops with able and independent **Older people** aged over 65 and the findings in this section of the report focus mostly on these people. Many of the findings given in other sections of this report, particularly those relating to **Family carers**, **People with physical disabilities** and **People with mental health issues** also apply to **Older people**.


Diverse communities

The ethnographic profile of Suffolk is currently in a phase of rapid change. The first major wave of international migration to Suffolk after 1945 originated mainly from India, Pakistan, Bangladesh, Africa and the Caribbean, and settled mostly in the Ipswich area. Over the years and up to the present, other groups of people have arrived in Suffolk seeking asylum, for example from Iraq and Kosovo.

Children in Suffolk schools now have a total of more than 100 different mother tongues.


Appendix 3 – Short survey form

Participants in the workshops were asked to complete a short form to collect permissions and some basic data from them.



What is your first name?











We will take photographs or videos during the workshop to record your views.



Is it okay if we use pictures of you in publicity about the project possibly including, the project report, magazine or newspaper features, displays, web pages and presentations?

Yes, it is fine No thank you

How old are you? Please put a mark on this chart ✓

10yrs 	20yrs 	30yrs 	40yrs 	50yrs 
60yrs 	70yrs 	80yrs 	90yrs 	100yr 

What methods have you used to get important information this year? Please put a mark on this chart ✓

 People you know <input type="checkbox"/>	Leaflets and books <input type="checkbox"/> 	 Telephone <input type="checkbox"/>
 TV, magazines, radio <input type="checkbox"/>	Internet <input type="checkbox"/> 	 Advisor, key worker, councillor <input type="checkbox"/>
Other (Please write) _____		