

HealthWatch Consultation Report 2012

Commissioned by
HealthWatch Pathfinder
Strategic Board



Report date 14 September 2012

Introduction

This research was commissioned by Who Cares, the Local Involvement Network (LINK) for Health and Social Care in North Lincolnshire. One of a LINKs role is to investigate the provision of health and adult social care in its area, including a statutory right of enter and view to enable thorough investigations to be carried out. Having investigated an area of service, the LINK submits a report to the service providers and commissioners with recommendations for improvements, if appropriate. The service provider does not have to adopt the recommendations, but does have to read the report and explain why any recommendations will not be adopted.

Some research had already been carried out on health and adult social care services in North Lincolnshire, but some more qualitative research was needed to give some evidence to support the statistics.

Voluntary Action North Lincolnshire (VANL) specialises in participatory appraisal, which produces quotes and stories to explain what people are thinking.

Aims and objectives of the research

As HealthWatch North Lincolnshire will be introduced on 1st April 2013, it is important that the views of the public are taken into account in relation to the remit of HealthWatch North Lincolnshire. This report will be submitted to the Commissioners in the hope that they will take account of the views and opinions of the general public when designing and tendering for the project. With this overall objective in mind, the further purpose of the research was as follows:

- How do people want to access HealthWatch
- How do people want HealthWatch to engage with them
- Would people use the information and signposting service if needed
- Would people use an independent complaints and advocacy service if needed

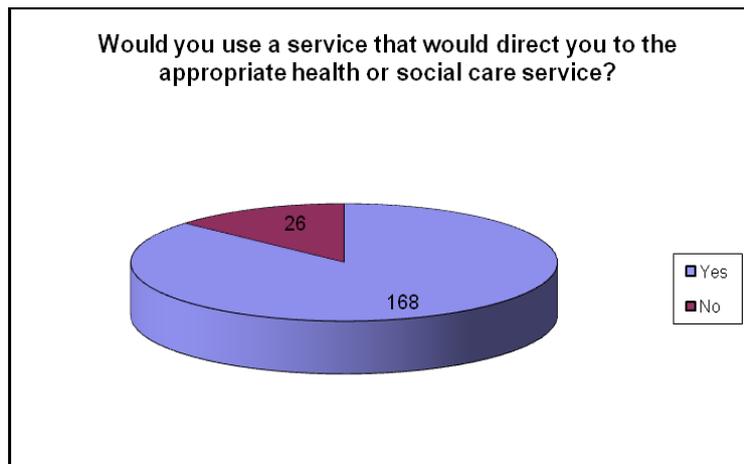
Previous research - Stage 1

Consultation on potential services that will be provided by HealthWatch took place from November 2011 to January 2012 and 199 people completed a questionnaire. The main aims of conducting this consultation were as follows:

1. To raise the profile of HealthWatch
2. To collect baseline data on use of health and social care services
3. To help identify further more in depth research
4. To help build up a database of North Lincolnshire residents who wish to help shape health and social care services in the future

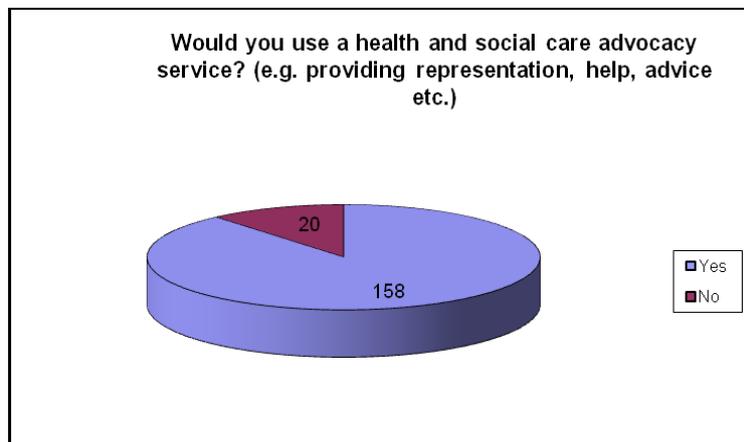
The questionnaire answers were based on both personal experience and from experiences with support to a family member, friend, or someone who is cared for.

The relevant results of the consultation are detailed below:



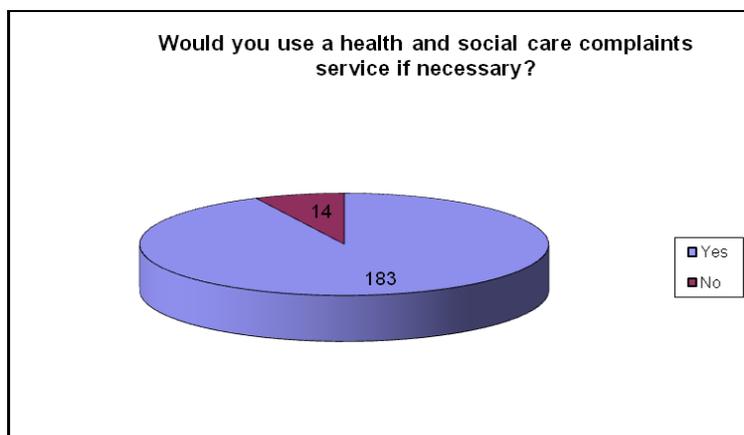
85% said yes

13% said no



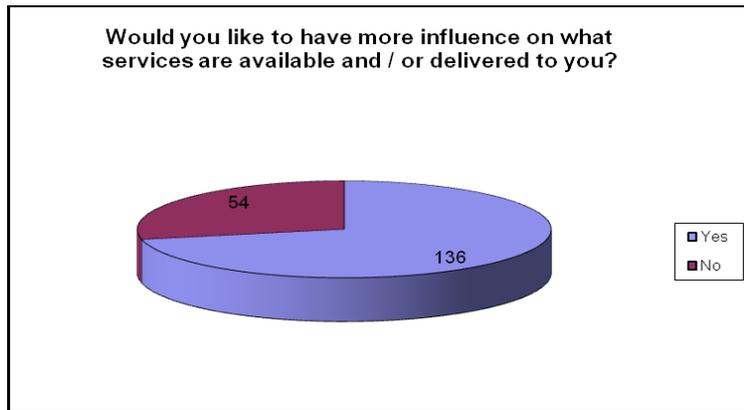
80% said yes

10% said no



92% said yes

7% said no



68% said yes

32% said no

A sample of the comments that came out of this piece of research includes:

“All doctors’ surgeries and hospitals should have a structured complaints system where you are treated with understanding”

“I would like to see that the general public had more say in NHS e.g. care in the community and be able to speak to a doctor if you are worried”

Stage 2 Research

This stage of the research is designed to drill down under the data to achieve a better understanding of how people want to be communicated with, what gets in the way of effective communication, what would help them to access information about services, and how they make complaint

The method - Participatory Appraisal, the VANL way

Participatory appraisal (PA) is a recognised method of research which is used all over the world as a way of engaging people who might not normally take part in research.

VANL uses PA tools such as large diagrams, which yield good results with general approval during the verification process. The method we use normally has three stages: the first level, where an open question is asked such as “How do you feel about health and social care in North Lincolnshire?” Responses are recorded on sticky notes and attached to the wall chart for everyone to see. Other respondents can then have a ‘discussion’ on paper, opening up new suggestions and offering different lines of enquiry. This process enables people to tell us what’s good about their area and what is needed to improve things. The results of this stage are taken away and analysed and a second batch of questions is drawn up, going into more depth on the main issues which have come out of the first level. The results of the second level are taken to the third (verification) level, where people are invited to an event where they can view the results and add their comments on them. These allow the final report to be refined and the end result is usually wide-ranging and

often produces some novel approaches to problem solving.

When we visit places where the large PA charts are not appropriate, we use “questionnaires” in the broadest sense. In effect, we take the PA tools we have used elsewhere, reduce them to a manageable size and duplicate so that each person has one sheet to themselves. We can then ask the questions in the same way as we would in a PA exercise, and the only drawback is that respondents cannot see what other people have already answered. This process was used for some sessions in this piece of research.

VANL uses trained researchers, and some basic statistics are gathered at the same time as the PA questioning, to allow us to check that a good spread of the population with regard to age, gender and postcode is included, although all responses are anonymous.

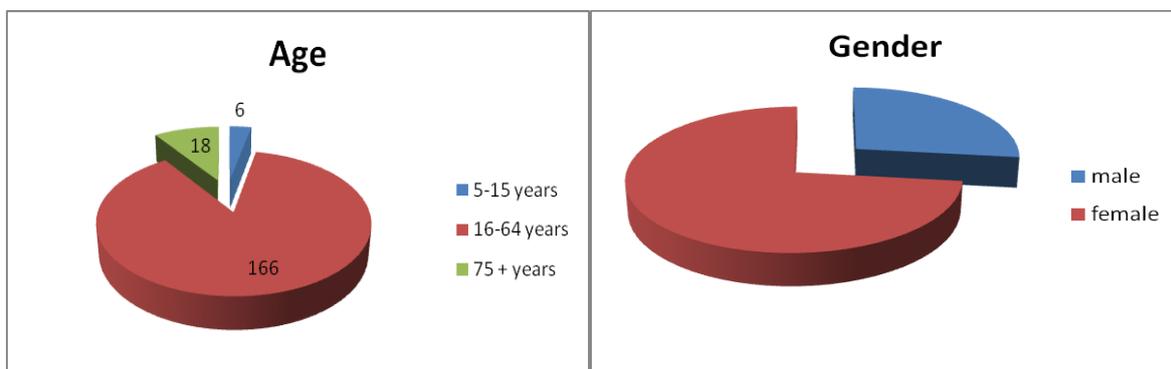
Limitations of the research

We concentrated on venues where we could reasonably expect to meet a significant number of people in a short space of time. At most venues we reached a good number of people, many of whom were the normally harder to reach males of working age. We concentrated on indoor events such as leisure centres, a strawberry tea, and craft fairs, and researchers did also visit some outdoor events including Barton Jubilee in the Park and Appleby Country Fair.

Statistics

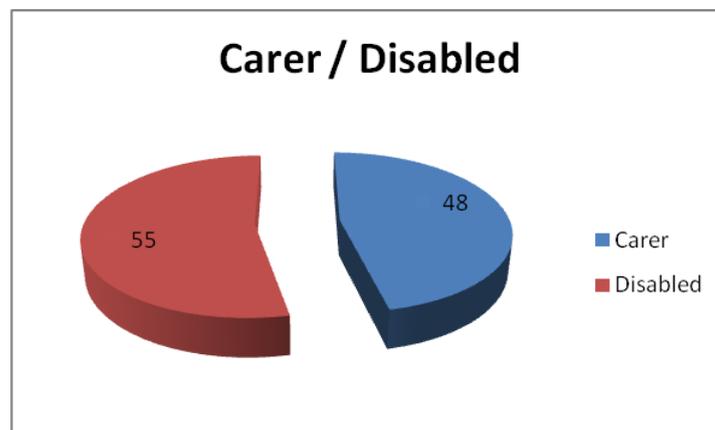
We spoke to a total of 249 people, and recorded informal comments from a handful more who did not want to take part in the full research process but had interesting comments to make.

Of the total, 67 were male and 182 female. We spoke to 6 people in the age group 5-15, 166 of working age (16-64), 59 aged 65-74, and 18 who were 75 or more years old.



242 said they were White British, 3 said they were English, 3 Irish and 1 Asian.

When asked, 177 respondents said they had their own transport, 55 people said they had a disability, 48 said they were a carer, and 2 said they were ex-carers.



Similarly, we recorded the beginning of postcodes to gain an impression of which areas respondents came from, but as we only began to do this after the first few sessions, there is little point recording numbers. The areas covered were DN9, DN14, DN15, DN16, DN17, DN18, DN19, DN20, DN21, DN35 and DN39.

How the research was carried out

At the first level we used a 'mood line', which had a sad face at one end and a smiley face at the other. Participants were asked to mark on the line how they felt about health and social care in North Lincolnshire. The researchers then asked why they had placed the cross there, and recorded all comments, which were placed below the line. Finally, respondents were asked whether they had any suggestions to improve the situation.

We spoke to 165 people at first level, and the main areas of concern were around GP surgeries, dentists and hospitals.

The second level research drew out the main issues from the first level results and asked further questions on 'Doctors and Dentists', 'Hospitals', 'Care outside hospitals' and 'Complaints and Compliments'. Each of these charts consisted of a picture to illustrate the area under discussion, and people were asked if they had experienced any problems, what improvements they would suggest, and what solutions they would like in an ideal world. This drew out a positive discussion on ways to overcome common irritations in the systems.

We spoke to 62 people at second level.

The third level of research is a way of checking that we have proposals that people will agree with. We used tables of suggestions derived from the second level research, and asked people to either vote for their top 3 or top 5 preferences. They were asked to rank the suggestions in order of their preference.

We spoke to 22 people at the third level.

Results

First and foremost, we should point out that we had many compliments for practitioners in the health services. Many people were at pains to point out what amazingly good care they had received and how good the system had been in their cases.

The table below shows the total percentage of certain categories of people consulted with over the 3 consultation periods in relation to the North Lincolnshire statistics. Please note that not everyone provided answers to all the monitoring questions. The North Lincolnshire statistics have been taken from North Lincolnshire Data Observatory at [http://nldo.northlincs.gov.uk/IAS Live](http://nldo.northlincs.gov.uk/IAS_Live)

Category	North Lincolnshire %*	Questionnaire %
Male	49.3	27.5
Female	50.7	71.7
15-64 year olds	62.8	66.3
65 + year olds	18.6	31.7
Carers	10.4	23
Disabled	19.8	23.9
BME	2.15	3.8

The gender statistics do not mirror the North Lincolnshire data and reasons for the higher percentage of respondents being female could be that women are more likely to take part in surveys, women may be more likely to access health care services than men, some sessions were carried out at Supermarkets where there was a higher proportion of women to speak to, more women were in attendance at the meetings where presentations were given, and the majority of the researchers were female which may have made women feel more comfortable and men less so, referring to both researchers and participants.

Communications

The over-riding concern throughout the research was communication, or lack of, throughout the health and social care services. We heard many instances of failures in communication, sometimes at very basic levels.

Concerns about dentists were raised as a major issue with people being unsure or unaware of how to find a dentist. This concern was taken up by Who Cares and a

Dentistry report has just been produced that details the results and can be viewed at www.who-cares-online.org.uk One of the main findings of this research confirms that lack of communication was a major issue, with people being unclear how to access a dentist, if any were available, and where to find out the information they needed. NHS North Lincolnshire have now reviewed and changed how they advertise the availability of NHS dentists.

GP surgeries were another source of concern, with the main complaint being that it was very difficult to get an appointment at some surgeries, and this problem was sometimes down to poor communication. There was some evidence gathered that indicated that both doctors and their receptionists did not listen properly, and also of not telling patients what they needed to know. There also appeared to be confusion over the way the appointment system works and the implication is that this does not seem to have been communicated very well.

Breakdowns in communication can occur within the GP surgery with some patients objecting to having to explain everything from scratch when they were part way through a course of treatment if they visited a different doctor. Hospitals were also accused of a lack of communication skills, and improvement of communication systems was the top priority for those interviewed in the verification session (which took place in the hospital outpatient departments). We heard stories of people's records being lost, of having to wait while records were transferred from one hospital to another, of GPs not being kept informed of patients' progress, and of being told to collect test results from the GP, but the results not being sent, or there being confusion over results. Patients complained of having to tell each new doctor/nurse their entire history at each step of the way. While this is used as an identity check (name/date of birth/home town), we were told of patients also having to explain past history which should have been in the records, but the records were not available. Consultants were also accused of a lack of communication skills: the way some communicated was said to cause stress. Patients also complained of a lack of communication to them outside the hospital system. There are many stories of people being 'dropped off' the waiting list for various reasons, and if you're waiting for vital treatment you need to know that it has not happened to you.

Communication to patients about their treatment and aftercare needs to be backed up in writing. When information is imparted at a stressful appointment or quickly on the way out of hospital, it may not be assimilated. Simply printing out a handout or letter would enable the patient to take it all in when at home and comfortable. This would help to reduce mistakes over medication, forgotten appointments and other misunderstandings.

Hospital appointments were also a source of complaint. In some departments in the hospital, we heard of letters not arriving and patients subsequently being dropped from waiting lists because they had not turned up for an appointment they did not know they had.

The transition from hospital to home could also throw up communication problems. We heard of problems getting aids for mobility after treatment, problems with support services for older patients sent home from hospital, and a lack of information about what could and should be happening. Communication about returning mobility aids when no longer needed was also requested – several people told us they still had

wheelchairs, hoists and sticks after the user had passed away.

Residential care was also referred to. Better communication systems were said to be needed to ensure that both clients and their families understand what is happening in care homes, and better, unannounced, inspection and regulation of residential homes.

Complaints and Compliments

An important part of the research was an attempt to find out whether people knew who to contact when they needed to, and where and how. It was clear from the earlier stages of the research process that a simple, well publicised, easy to use route to comment on health and social care services is required, and a constructive comment should be considered and acted upon where it would improve services. However, there should be an alternative route for people who prefer to speak directly to someone with confidence that their complaint will be registered and dealt with.

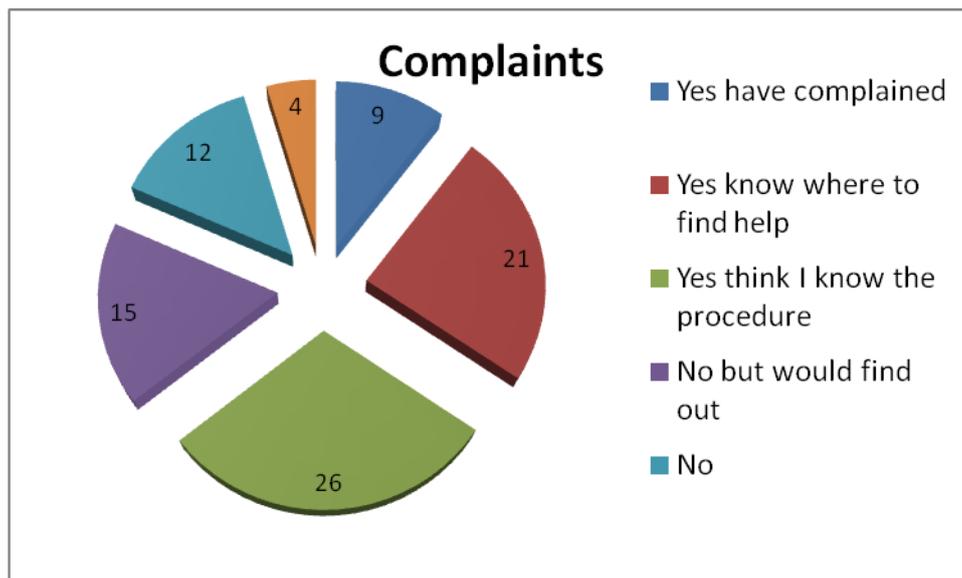
Although the priority at verification put the recommendation of “an alternative route to speak to someone when required” first, that could be a function of the average age of the people we spoke to at that session.

The people at Outpatients thought that it was most important to be able to speak to someone, but for health service requirements that any communication should be recorded in writing so that it can be referred to accurately later. It is important to note that many people still do not use the internet and need to be able to write letters and / or speak to someone. One simple cause of confusion could be that the hospital “used to have posters up displaying PALS but had to take them down due to infection control” – we found no evidence of any other way of publicising the information being found.

One respondent who had nursed a partner through terminal cancer said “I wasn’t told enough about how hard it would be as the Macmillan Nurses aren’t hands-on and the other nurses didn’t come out because of the icy weather. I did complain at the time to my GP after the surgery opened in the New Year, but I do not know if he took it any further.” Clearly in this case the respondent did not receive the necessary information, did not know where to go to find it, received no feedback in relation to the complaint, and did not know where to further complain when things went wrong. This information should be freely available before patients are sent home.

We heard several times that while health and social care services have been good in the case of the respondent concerned, it was only after constant complaints that they had reached that level. People expect the services they need to be provided (or at least offered) when needed. In fact, they often had to research what should be available and pester until they get it. Anecdotally, people from older generations were brought up not to make a fuss and not to complain, confirmed by a participant who stated when asked did they know how to make a complaint, answered “No, and I do not like to complain”.

Below is a table that gives some statistical data in relation to feedback we got in answer to the question of if people had previously complained and also, if they had complained, did they know where to go to do so. This question was only asked of the people who had discussed complaints.



Complaints recorded for 2011-2012

Primary Care Trust's Patient Liaison Service (PCT PALS) received a total of 37 complaints in the year April 2011 to March 2012. Within the same year, a total of 256 complaints were made direct to GP's (229) and dentists (27). PCT PALS also received 46 compliments within that time.

The Independent Complaints Advocacy Service (ICAS), which provides a complaints and advocacy service in North Lincolnshire, dealt with 17 cases in the same year. Out of these, 14 were in relation to hospital care and 3 in relation to Primary Care. 5 of these cases are still being progressed and remain at this time unresolved.

The number of complaints taken to ICAS appears to be very small and this could be for a number of reasons, namely;

1. the level of care in North Lincolnshire is very good,
2. people do not want to complain, which is partly supported by the results of Stage 2 of the research
3. People do not know where to go to complain, again partly supported by the results of Stage 2 research
4. As ICAS is located in Hull, people may not view the service as having the local expertise needed. Anecdotally, a few people have expressed the view that they do not want to deal with an organisation based in Hull but want to be able to access a local service

Summary of main issues raised in Stage 2 research

During the research, a number of health and social care issues were raised and these included:

- Inability to get an appointment with their GP when they need it
- Inconsiderate attitude of receptionists at GP surgeries
- Inability to find a dentist, particularly an NHS dentist
- Cost of travel to appointments, particularly at Hull hospital
- Care of the elderly
- Hospital food
- Not being treated as an individual but as a number

These issues and the comments made will be passed to Who Cares for their consideration for further action.

Third Stage Research

Further research was undertaken during August and September 2012 primarily in the form of a questionnaire. The aim of this piece of work was to fill the gaps in particular groups and to make sure that the views of the traditionally hard to reach groups (BME communities, young people, carers' and the disabled) were well represented. The intention was that the views of these groups would be represented at a much higher level than the percentage of the population in North Lincolnshire. This was achieved. The results are indicated below.

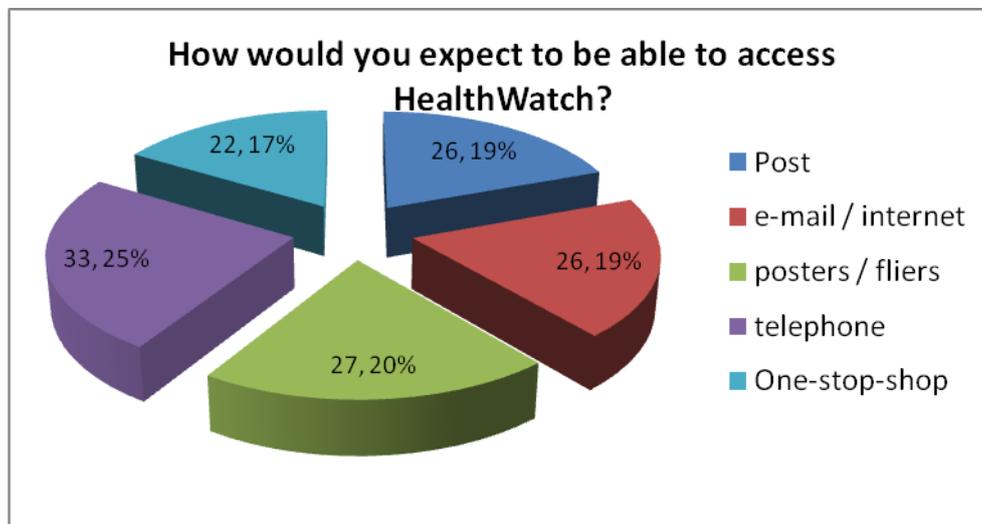
The table below shows the percentage of people that stated they would use the new services that may be incorporated in HealthWatch. These figures are comprised from the results of the first and third pieces of research only and the total number of responses received was 271.

	Total	Total	NL %	Signposting		Complaints		Advocacy	
	Number	%		Number	%	Number	%	Number	%
13 to 25	34	12.5	8.25*	32	94	30	88	26	76
BME	25	9.2	7.14*	21	84	14	84	17	68
Disability	74	27.3	5.4	57	77	57	77	56	76
Carer	68	25.1	10*	62	91	61	90	59	87

Please note that the figures marked * are best estimates from the available information

As can be seen, the percentage of people from the traditionally harder to reach groups have a higher desire to access the signposting and advocacy services that may be accessible through HealthWatch.

The graph below shows the different ways that people would like to be made aware of HealthWatch and for HealthWatch to engage with them and indicates that a variety of methods will need to be employed to ensure that all sectors of the community have equality of access and information.



Conclusions

The majority of people who participated in the different elements of the research said that they would, if needed, use a complaints and advocacy service and a signposting service if it was available. However for these to be effective and used, people stated that they needed information on how and where they could access these, and what they could expect as a result of using them. Although at present there are a variety of methods open to people to complain, get advice and assistance, or to progress a concern, there is no uniform or clear route for people to follow. This confusion appears to deter people from using these services which could be detrimental to both the individual and to the service because of poor experiences being shared with others.

The research showed that a variety of methods of communication were preferred to allow people to find out about services they may need and on how to access them, including advertising by poster in health, social care and community venues, by post, by e-mail and internet. Many people, unprompted, referred to a "one-stop-shop" as being the ideal method of being able to access the range of services referred to above, access the information they may need and to receive personalised advice on where to go.

Recommendations for HealthWatch in North Lincolnshire

1. Initial research indicates that consideration should be given to providing a one-stop-shop approach that contains all elements including signposting, information, complaints and advocacy services, as well as patient participation. This would provide local services and support people to access the right service at the right time and reduce confusion.
2. Ensure that the services of HealthWatch and the way that people can access them is provided in easily accessible ways by a variety of methods including:
 - a. Face to face
 - b. Internet and e-mail
 - c. Telephone
 - d. Advertising through posters and other local media
3. Ensure that any marketing and publicity is heavily promoted through traditionally hard to reach groups as well as county wide.
4. Ensure that an easily recognised “brand” is used to identify HealthWatch to ensure that it is clearly recognisable
5. Currently, the lack of public knowledge on how to access complaints, advice and support services appears to be a major issue, therefore it is recommended that HealthWatch is widely and constantly promoted in the community, in health and social care buildings, but also, and most importantly, by health and social care professionals. “Mystery shopping” tests could be carried out to find out if HealthWatch is being advertised and promoted.
6. Provide training / education to health and social care professionals on the benefits and opportunities of HealthWatch to ensure that services are clearly communicated in a consistent way
7. As the PALS service will continue to be provided by NHS North Lincolnshire, policies will need to be put in place to ensure a procedure for data sharing is agreed that maintains patient confidentiality. There will be a need for HealthWatch to liaise closely with PALS to make sure that there is no duplication in relation to progressing complaints, and also for HealthWatch to build up a complete picture of issues of concern in North Lincolnshire as this will help to direct future work streams.

Acknowledgements

Grateful thanks are extended to all the researchers, the venues, groups and organisations that welcomed the researchers into their premises, and most importantly, all the people who took the time and effort to participate in this research.

This report can be found at www.who-cares-online.org.uk
or a copy can be requested by contacting who.cares@vanl.org.uk
or by phoning 01724 845155

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