

ALISS

Access to Local Information to Support Self Management

Health Literacy Report



The impact of poor literacy on
accessing local support to manage long
term conditions

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Introduction.....	3
Background to ALISS	3
Literacy and Health.....	4
Aims	5
Process.....	5
Findings.....	8
Learners' stories	11
Conclusions.....	17
Recommendations	19
Further Information.....	20
Glossary	22
References	24

Introduction

ALISS (Access to Local Information to Support Self Management) is a Scottish Government project which aims to improve access to local support which will help people self-manage long term conditions.

There are 3 work-streams:

- Technical Architecture
- Health Literacy
- Curriculum for Excellence

Background to ALISS

People with long term conditions often report that although support to manage their condition may be available, it can be difficult to find. At the same time, many voluntary and NHS organisations are providing excellent support services which are not known to those who could benefit most. So there may be a mismatch between what is available and what is accessed.

A fundamental requirement for successfully protecting health and managing life with a long term condition is the ability to understand basic health information. Without this ability, people may be less able to make adjustments and decisions. Access to sources of support is vital to allow people to become active partners in managing their own conditions. Further information about self management and living well with long term conditions is contained in "Gaun Yersel! The Self Management Strategy for Scotland."¹

At the same time as the numbers of people living with long term conditions continues to rise, people are changing their role from being passive recipients of information to actively creating, sharing and consuming information produced by others. Digital technology is transforming health and social care but the potential for people to collaborate on new ideas remains an untapped resource.²



A Crowded Noticeboard

New social relationships are evolving as more is understood about the value of individual contributions from increasingly diverse and multicultural societies. The power of "making things together" through social networking has potential to aggregate social capital and encourage self supporting communities. The ALISS project aims to harness these developments by using existing and emerging technologies to enable people to share and comment on content to local information resources.

Literacy and Health

The project sought to learn how individuals with long term conditions who were disadvantaged by low literacy skills obtained, processed and understood information about local resources. People with poor literacy levels may have poorer health status and are 1.5 to 3 times more likely to experience a poor health outcome as they have less knowledge of self management and health promoting behaviours.³ The *International Adult Literacy Survey* found that

“23% of adults in Scotland may have low skills and another 30% may find their skills inadequate to meet the demands of the ‘knowledge society’ and the ‘information age’”⁴.

Inadequate health literacy can have profound health and financial consequences (Ad Hoc Committee on Health Literacy 1999⁵, Institute of Medicine 2004⁶, Sihota & Lennard 2004⁷). In the UK the Picker Institute, has reported that patients with low health literacy:

- have poorer health status
- are at greater risk of hospitalisation and have longer hospital visits
- have higher rates of admission to emergency services
- are less likely to adhere to prescribed treatments and self-care plans
- have more medication and treatment errors
- have less knowledge of disease management and health-promoting behaviours
- have decreased ability to communicate with healthcare professionals and share in decision-making
- are less able to make appropriate health decisions
- make less use of preventive services
- incur substantially higher healthcare costs.⁸

The US Department of Health and Human Services definition of health literacy was used to inform the project – **“the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.”**⁹

The project was less interested in information about particular health conditions and focused on questions such as “where’s the nearest exercise class?”, “is there a support group for my condition?”, “what time does it start?”, “what do others think about it?”, “does it cost anything?”

Aims

- to capture in detail the experience of learners as they obtain, process and understand information about local sources of support to manage long term conditions
- engage with disadvantaged communities who are at higher risk of poor health outcomes
- use this knowledge to inform development of other ALISS workstreams (Technical Architecture and Curriculum for Excellence, see project blog)¹⁰
- develop a method and pack for re-use by other literacy groups
- share findings with literacy, education, health, social care and voluntary organisations
- highlight link between health literacy, health improvement and self management for people with long term conditions
- add to intelligence on national approaches to health literacy

Process

CLAN (City Literacy and Numeracy)¹¹ is a Scottish Government funded partnership project based in Edinburgh. The CLAN Health and Literacy Project agreed to facilitate contact with learners in already established classes in two areas of Edinburgh, Muirhouse and Wester Hailes. The project team included two representatives from Long Term Conditions Alliance Scotland (LTCAS)¹², a national alliance of voluntary organisations that represent and support long term conditions, two from the Long Term Conditions Unit of the Scottish Government (one was a nurse) and an information consultant. There were various skills within the team which included clinical skills and knowledge of information retrieval in NHS and voluntary sector organisations.

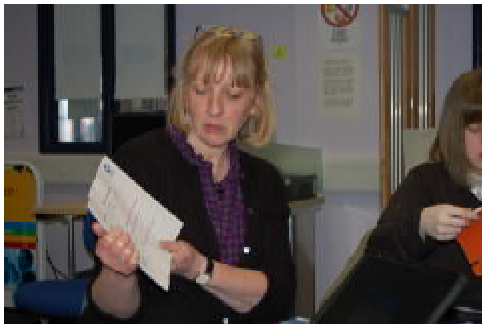
Two groups of 6 learners, already enrolled in classes, agreed to participate in the project as a learning experience. The series of 3 half day sessions were facilitated by CLAN tutors and held at weekly intervals.

People wishing to improve their literacy skills may self refer to CLAN and some are referred from the health improvement programme - Keep Well¹³(people are questioned about their level of literacy during a Keep Well consultation). Learners had enrolled in classes for a variety of reasons, including dyslexia, poor education experience and missed schooling due to poor health. The class ability in literacy and numeracy was very mixed, some were confident readers but lacked writing skills and some were poor readers with reasonable writing skills. The group was mixed gender and it was striking that despite their young age (most were in their twenties), all learners were already living with a long term condition. The conditions that people lived with included depression, neurofibromatosis, asthma, epilepsy, multiple sclerosis, breast cancer and myalgic encephalopathy. (See Glossary for explanation of terms).

The exercise aimed to capture the experience of learners as they looked for information about local sources of support. An important objective was to gather feedback on “does it all make sense?” in terms of obtaining, processing and understanding information.

In preparation for working with the group, a video¹⁴ was made which followed the journey of someone accessing local support about three topics - arthritis, depression and losing weight, making the point that accessing support to self manage was hard work. There were two reasons for producing the video, one was to use it as a way to explain the project to learners and the other was to learn more about the practicalities of capturing the learner’s experience, for instance how to record conversations and track progress. (For instance, this exercise was useful in a decision to abandon using disposable cameras to record experiences, as they would have been put in the awkward position of asking permission and gaining consent).

Week 1



Clan Tutor

The first session was held in Muirhouse and was used to allow learners to become familiar with the team and to introduce the project. Tutors described rules of confidentiality, explaining that any disclosures or personal health information shared with the group must be respected and kept private. Written permission was obtained from all involved (tutors, learners and team) to use photographs and audio record proceedings. Consent to share material by making digital stories and video was explained carefully and agreement made that all participants would have an opportunity to check their own material before it was used. The video was played to set the scene and generated a lively discussion about long term conditions and their high prevalence in Muirhouse. Stories were exchanged about personal experiences; learners confided that in most cases their difficulty with literacy remained unknown to health and social care staff. The feeling of shock and confusion when given a diagnosis of a long term condition was described by several learners. One said:

“for me it was a completely new experience but the doctor seemed to think it was a common occurrence”.

All identified with the difficulty of understanding information given at the time of diagnosis and suggested they would have appreciated being given an appointment to return with a friend or member of the family. This would allow time to think about the diagnosis and prepare questions for the next encounter. Learners described the impact on their health of living with poor literacy, such as difficulties with reading information leaflets, and following

instructions for medicines. Most relied on family, carers and friends to interpret and explain instructions, though this was not always possible.

Learners were then asked to review a display stand of health information leaflets and some health related posters. This prompted discussion about what they found attractive or off-putting and how useful particular information was. There was great debate about the colour and design of leaflets, size of text, photographs and drawings. There was a



Class discussing health information

preference for larger bold text and pictures. It was obvious in the ensuing discussion that learners were adept at compensating for their literacy difficulties. For instance, many will look for clues from pictures to help understand what a leaflet is about.

The project team asked questions such as “Who do you ask?”, “where do you go?” and “who do you turn to for information?” Most responded that health information was obtained from family, friends, neighbours and places like shops and social clubs.

Learners were then asked to prepare for the next session (the following week). They were asked to choose a long term condition of particular interest and, over the course of the week, find out all they could about local sources of support.

A prompt sheet was provided with reminders of what to look for on their journey. Prompts included, “where did you start”, “who helped you”, and “what was the best help” “did you find what you were looking for?”

Learners chose their preferred method of audio recording their experience. Although MP3 players were provided most learners preferred the familiarity of their mobile phones.

Suggestions were made about where to look for support such as the internet, community centres, voluntary organisations, GP practices, libraries and church halls. Tutors offered to accompany learners during their exercise, provided contact details and kept in regular telephone contact to offer assistance.

Week 2



Some members of the class and project team

This session was in two parts. Learners returned their prompt sheets, notes and recordings (which were downloaded to a laptop for later editing) and there was some brief feedback time.

The second part of the session was used by the team to reflect on progress. There was unanimous agreement that the workstream was developing well.

Week 3

This session was comparatively longer. Films, digital stories and photos from Weeks 1 and 2 had been processed by the team during the week and were shared with the group. This provided quick feedback to learners and tutors, which was very enthusiastically received.

Learners swapped stories and shared examples of information gathered. In cases where they had been unsuccessful and still needed information, representatives from LTCAS provided appropriate information which was easy to understand.

This format of 3 weekly sessions was repeated 4 weeks later with the second group in Wester Hailes. After completion of the Wester Hailes sessions, both groups were invited to a final gathering, which was the first time learners from the different areas met. Each person was given an opportunity to view their own film to be sure they were content with it before sharing with the whole group. This was a particularly enjoyable session as films and digital stories were shared.

Findings

This workstream provided a useful and enjoyable learning experience for all. Both Muirhouse and Wester Hailes groups felt they were taking part in something of value. Learners were positive and enthusiastic, felt “listened to” and were particularly happy to be contributing to a Scottish Government project. There was a high degree of trust within the group and tutors’ well established relationships with learners played an important part in the success of the project. Learners were impressively supportive of each other and there were many instances of one finding out something on behalf of others.

A number of clinical issues arose during the sessions, and so it was a benefit to have a nurse in the team. There were interesting conversations about

health beliefs, nutrition, particular conditions, concerns about family members, as well as accessing information. Many misconceptions and misunderstandings about health were shared and some resolved as the group became familiar and confident with each other.

The LTCAS were keen to learn more about health literacy and access to health information which they could share with their member organisations. This learning will be useful in developing services in order to better support people with long term conditions to self manage. The contribution of LTCAS staff was also very useful in class discussions. An unexpected benefit was that LTCAS staff were able to signpost learners to sources of support that they had not been able to find in their own communities.

“It was a two-way street for us. We were really happy to be involved and get information from the group but also really pleased to be able to give information back and really what we found with the learners is that they’re no different to any other group. They were struggling with information, struggling to know what was right and what was wrong...what information would be helpful ..” (Representative of LTCAS)

It was evident that tutors are involved in many aspects of learners’ lives, which are often very complicated. Tutors often offer support on a one-to-one basis over long periods of time and so form similar relationships to those formed by doctors and nurses in primary care. Tutors become familiar with learners and their families and so there are valuable opportunities to promote health improvement approaches, broker information and signpost to other professionals.



Discussing design of leaflets

made aware of previously unknown sources of support in the community.

Tutors recognised the value of having community health information as a regular class topic. Health and wellbeing related topics offer a natural conduit to promote health improvement and personal development while improving literacy and numeracy skills. Tutors described the project as being a personal learning experience as they heard more about the impact of living with a long term condition and were

“ ...it reinforced how difficult it is for people to access and use information and how encountering a barrier can just stop somebody dead in the tracks” (Tutor)

As learners shared the successes and disappointments of their journeys, a number of common themes emerged:

Local sources of support may be there but not found



Colourful Leaflets

Learners search for local sources of support was often unsuccessful. A number of good local resources were missed. For example a particularly useful website (Pilton Community Health) was found on the internet by just one learner, but with guidance from a local librarian. The learner had searched using the term “Muirhouse” and not “Pilton”, the neighbouring area. There were instances of “it didn’t make sense”, when learners did find a resource

such as a leaflet, internet site, poster in library, but could not understand the information or relate it to their condition.

Attitude of staff

One of the most significant influences on success or failure to access information was the attitude of those who were approached for help. Learners shared the common experience of an assumption being made that they could read and understand the information supplied. A number of learners reported uncomfortable experiences in libraries and GP practices where they felt hurried and embarrassed when offered written information which they couldn’t understand.

Response to learners’ requests for help made an important contribution to their discoveries. Helpful, friendly reception staff were particularly important in assisting learners to find and understand information. Success or failure often depended on how skilled people were at interpreting what it was they were being asked, and how patient they were in exploring the request.

Informal sources of information

A good deal of information about resources in the community was discovered through word of mouth. When asked “how did you find out about that ..” learners would often reply “from a neighbour, “from someone at the bingo”, “from a friend”, “from my auntie”. Most conversations about health and wellbeing took place in families and with tutors, unless there was a reason to visit the doctor or nurse at the local practice. When attending the GP practice, learners thought there was sometimes not enough time to discuss issues properly. However others had positive experiences when they had built relationships with a particular doctor or nurse over a long period of time. This was the case with one young learner who found a hospital consultant

doctor a particularly well trusted source of emotional and psychological support.

The impact of poor literacy on accessing and understanding health information

“It’s not always that you can’t read, it’s that you can’t understand what you’ve read.” Linda

All learners reported practical difficulties accessing local sources of support and sometimes getting to resources and appointments presented challenges. A variety of barriers such as cost of transport, understanding maps and bus timetables and conditions which limited mobility disadvantaged those who wanted information from a particular location. One learner with Multiple Sclerosis was unsuccessful in her effort to access information from a specialist centre in another part of the city. She depended on a family member for transport, and he was working night shifts.

Up-to-date information at the right time

Learners noted out of date leaflets and local information web sites with no start or finish dates. This led to a feeling of mistrust of websites and reluctance to try again. This feeling of losing trust was seen in another example when a learner received inaccurate information which led to a wasted journey to the opposite side of town.

Learners’ stories

The following stories record some individual experiences of finding information during the week. Names have been changed.

Susan

Susan, who joined the group to improve her numeracy, used the exercise to find information about cardiac conditions, as she was pregnant and her partner had a heart murmur. She wanted to know if there was any risk to her unborn child and if there was action she should be taking. She had reasonable reading skills and was successful in obtaining information online. However the information was presented in a 32 page booklet, which contained difficult language, including words like hypercholesterolemia, which she and the team thought was too complicated and intimidating.

Emma and Rachel

Emma and Rachel are twins who enrolled in CLAN to improve their literacy skills. Both have dyslexia, and Rachel has myalgic encephalopathy (ME) and non-epileptic seizures. Emma has asthma and scotopic sensitivity which led to difficulties with reading and concentrating at school. Both have

considerable difficulties with reading and writing and have been attending adult education classes for many years.

Emma related her experience of caring for Rachel and in particular learning what action to take when Rachel has a seizure. Most of Emma's information came from a first aid course at school and the rest from friends and the internet. She taught the rest of the family how to position Rachel safely and call for help. Emma recalls **"when we went to the doctors and they diagnosed you and they never gave you any leaflets they never gave us any numbers for like support groups or anything like that. We just knew fae word of mouth how to help Rachel."**

During the project, Rachel found information about a self help group. The information from the internet stated the group met in the coffee shop of a city centre department store, and gave a date and time. Rachel decided to go along as she thought it would be helpful to talk to others with the same condition. However she reported back to the group that: **"it sort of knocked my confidence because I turned up and nobody was there."** (This may have been due to the group being poorly resourced; many such groups are run by just one or two people who are often themselves unwell).

Later in the week, Rachel visited a friend in hospital and took the opportunity to ask for information about her condition. She was disappointed at staffs' reaction; felt she was 'fobbed off' despite being alongside posters and leaflets declaring 'It's OK to Ask.' Her impression was that staff were either unaware, uninterested or had no time to signpost to sources of information.

Emma commented on a health information display in a library. She thought she probably missed relevant information, because the front cover of the leaflets didn't seem to be about asthma. Emma's example was a leaflet which portrayed a woman and baby in a field of corn (meant to symbolise pollen and allergy), which she thought would have been more useful if the image of an inhaler was included.

Emma and Rachel were very motivated and made valuable contributions to the project. Emma remarked.. **"It wasn't until I came across this group that I found out loads of informationloads of people had itit was a really common thing. I didn't realise that."**

Linda

Linda joined the literacy class as she was keen to improve her writing skills. Her aim was to "get a job" and get back to normal after a period of chaos in her life which left her feeling unwell, depressed and under confident. Linda experienced a bad episode of a stress related illness and as a result of a "breakdown", was hospitalised for two weeks. Her experience of being discharged from hospital made a lasting impression.

When Linda left hospital, she was given an information leaflet which listed contact details for national and local support organisations. However, she recalled a feeling of isolation and lacked the courage needed to make the first phone call. The leaflet directed her to the 'stress centre' which was in her community and sounded useful. However, when she went along she found the building draped in barbed wire and thought it was "really intimidating". She walked away from the building which she later discovered would have provided vital support after discharge from hospital.

"The building itself was very anti-social and I was too timid to go to it, it was too frightening. So I chose the Women Supporting Women."

Another organisation noted in the leaflet was 'Women Supporting Women' at Pilton Community Health. Linda was reluctant to try this as she felt sure it would be **"about sticking pins in men"**. However after hearing it was good, she attended and was offered counselling and support which she described as "brilliant". ("Women Supporting Women" subsequently referred Linda to CLAN when they realised she wanted to improve her literacy skills).

Linda reflected that, perhaps because she didn't have a major psychiatric illness, or fit any particular category, she didn't justify a special nurse or care plan. However because of her level of anxiety, it was difficult to manage alone. Linda reflected afterwards, that she would have appreciated **"just a helping hand to make that first phone call"** to local sources of support.

Linda was an enthusiastic participant and during the project looked for information for her elderly neighbour who had recently been diagnosed with diabetes. Linda's neighbour and his wife told her about their experience of being given a diagnosis of diabetes and being asked if they had any questions – **"well you've just been told a major bombshell ...so how can you possibly think of questions, where do you start – like, should I stop putting sugar in my tea? His wife had a big fear that he might go into a diabetic coma and she wouldn't know what to do"**.

They had been told that he must diet which puzzled them as he is so slim – **"they keep saying – diet, diet, diet – but why do I need to diet?"**

The couple had difficulty finding out about benefits and carer's allowance. During the project, Linda helped by finding out about "Dial a Bus" and organised transport for appointments which proved a great benefit for them.

Craig

Craig enrolled in CLAN literacy classes to improve his handwriting skills, grammar and punctuation. He had missed schooling because of poor health and in particular a comparatively rare condition called Neurofibromatosis 2 (nF2). He explained that throughout his early childhood he attended hospital for six monthly checkups. These appointments were always very short and when asked how he was feeling, he would reply "fine" and be asked to return in 6 months. He stopped attending as he didn't feel he was achieving anything and was losing time at work to attend. A period of about 15 years elapsed during which time he had no contact with health services.

After leaving school Craig became a window cleaner and as time went past he became interested in learning more about his condition. He made contact with doctors and nurses but his experience seemed to be fraught with misunderstandings and confusion. Craig couldn't understand why medical staff were alarmed that he was a window cleaner **"because I knew so little about my condition"**.

Craig made bold efforts to find information about neurofibromatosis, including going to a medical bookshop. He searched the indexes of clinical books, but where he found the word "neurofibromatosis" it said - "see von Recklinghausen Disease" when he looked up "von Recklinghausen Disease" it said "see neurofibromatosis" ... **"so I was none the wiser"**.

Eventually Craig found contact details for a national support group, a voluntary organisation. Here is how he obtained this information:

"One day.. I was cleaning windows at the Astley Ainslie Hospital and went into one particular room where it had a coffee table that had neurological self-help groups, so great – picked it up. Found the self-help group for the Neurofibromatosis and it was the Nf2 Association. Contacted them and then the ball started rolling."

After contacting the Association and speaking to others with the same condition, Craig sought medical advice which led to examinations and tests. Doctors advised him it would be safer if he gave up window cleaning and driving, which made a significant impact on his life.

"It did take a lot of pursuing to get the help that was needed."

Craig gained confidence through attending meetings, which has made him feel better about talking about his condition. He joined the literacy group as a result of his increased confidence and is now keen to continue investigating health issues.

Mary

Mary, who joined the class to improve her numeracy skills, was only 16 years old when diagnosed with Multiple Sclerosis (MS). She recalls finding it very hard to adjust. **“They said – we’re not saying you’ve got MS but we’re labelling it as MS. Have you any questions? Well I was just 16, the doctors at the hospital don’t realise this is new for you – it’s not new for them. I thought just old people got MS....”**

Mary’s son Martin, aged 8 years, is her carer and she has good family support. Mary has a good understanding about food and nutrition which has been very useful in advising her mother, who has heart disease. She is particular about her own diet and tries to ensure that her mother eats well. **“I’m always getting my mum to eat porridge, I did home economics at school so I know about porridge being good for your cholesterol.”**

Mary used the exercise to find information about support for MS and found people very friendly and helpful. A charity organisation (Swanfield Multiple Sclerosis Therapy Centre in Edinburgh) was particularly helpful **“they couldn’t do enough for me, told me about loads of things for people with MS.”**

Local library staff were also friendly and helped with internet searches and when Mary contacted the MS Society she was impressed that their newsletter and other useful information arrived just 2 days later. The information included sources of support including opportunities to go on an MS Retreat. However Mary wasn’t keen to do this ..

“I don’t like groups, I don’t like joining groups, I know fine well people are going to judge me. Problem is sometimes people think I’m a fake – they’re all in wheelchairs and I’m not. Receptionists always think I’m a carer, but I’m not – I’ve got MS ... ”
Mary also described her experience of using public transport: **“buses are a nightmare older people think I’m terrible for taking a seat... sometimes I want to show them my bit of paper ... show them my bus pass....”**

Heather

Heather joined the literacy classes to help build her skills and confidence after being diagnosed with breast cancer two years ago. Heather was particularly interested in taking part in the project because she wanted to know what information was available to support her in her present situation and also to help her sister who has serious arthritis. She used the exercise to find information about arthritis, most of which she got from the internet.

During her treatment in hospital, Heather was impressed with the quality of emotional and psychological support and information she and her family received. She later experienced similar excellent support from the primary

care team, which left her in no doubt about the importance of health information and support to manage.

Heather feels her confidence returning through her local contact with Keep Well, CLAN and other adult learning classes and enjoyed discussing long term conditions with others. She plans to continue her exploration of health issues, literacy and computing classes.

...and a member of the team's story

Unfortunately, a member of the team became unwell during the course of the project. The learners' experiences were fresh in his mind as he made his own journey of obtaining, processing and understanding health information. He particularly sympathised with the comments about attitude of staff and the challenge of "making sense of it all".

"There was a problem with my appointment and suddenly I was made to feel quite uncomfortable about the whole thing and I remember some of the adult learners reporting back similar situations - they'd been made to feel uncomfortable for whatever reason and it completely changed the nature of your experience".

The importance of delivering health information and messages at the right time became clear as he sat in a hospital outpatient's area - although surrounded by information on posters and leaflets, he felt too unwell and exhausted to look through it.

"I also remember sitting there waiting for my appointment and looking up and seeing a whole bank of leaflets of patient information and I remember thinking at that point that I should be looking through these things...but I felt so ill ... I really didn't have the energy or the inclination ... It occurred to me then that there are certain times when you do want information and you can handle it and process it and there are other times when you simply can't."

He was unsure what information he was looking for and where to start. This was highlighted when trying to think of an appropriate search term when using the internet.

"I couldn't think of the search term – what would I put in? How did it feel? It was very difficult to put into words how I felt and also what kind of help I might be looking for."

Conclusions

The health literacy workstream achieved the key aim of confirming that local support may be available but is hard to find, and made more difficult if a person has poor literacy skills. A person with poor literacy requires help and support to obtain process and understand information which has a major impact on their ability to self manage long term conditions.

This project was considered a success by all involved, and CLAN tutors, who have recognised the benefits, have formed a new literacy group which will focus on health. Tutors have developed a pack which can be used by other adult literacy groups who wish to replicate the exercise. Living with multiple conditions and poor literacy skills represent difficult challenges for people, their families and carers. The complexity of living with more than one condition in an area of high deprivation is now the subject of a Chief Scientist Office research programme, "Living Well with Multiple Morbidities".¹⁵

The following key points emerged from the project:

- Although there is a large literature confirming the link between low levels of literacy and poor health outcomes, the young age of most of the learners and complexity of their lives provided dramatic evidence of the need to address this problem. It was clear that literacy programmes provide a vital contribution to protecting the health of the nation.
- Once support is identified another hurdle is the degree of self confidence required to join in if someone wants to. The act of "joining in" is a significant barrier to accessing support and may be harder if disadvantaged by poor literacy skills.
- Health care staff did not appear to recognise or adequately address the needs of people with poor literacy. Opportunities for encouraging self management were missed due to misunderstanding and poor knowledge of "what's wrong", "why is it important" and "what should I be doing about it?" This is supported by a study in USA of people with diabetes and poor functional literacy which concluded that when physicians (doctors) used interactive communication approaches (such as repeating back and checking recall of information) people were more likely to have good control of diabetes.¹⁶
- Acknowledgement and adjusting to a diagnosis of a long term condition is imperative to understanding and confidence to manage.¹⁷ People confronted with new diagnosis may have to make changes to their lives, and this may be harder for people with poor literacy skills. Often there is no emotional or psychological support at this critical stage which can hinder subsequent ability to manage.

- Conversations about the difficulty of managing medicines revealed a potential for serious accidents. Some learners had little understanding of why they were taking a drug, how it worked or how to take it. Sources of mistakes described included drugs with similar names being taken in error, confusion about generic and trade names and poor numeracy causing difficulty with calculating doses. This is alarming when parents are administering medicines and measuring out milk powder to babies and young children.
- There is also a safety issue when people with poor literacy negotiate health services. There are many challenges such as understanding options for treatment and written information such as appointment letters, signing consent forms, personal management of medicines and on behalf of others.
- There were numerous examples of people misinterpreting or mishearing health information which may have been a reflection of poor intuition and listening skills of some professionals. There were many thought-provoking conversations as the disadvantages of poor literacy skills became apparent. The feeling of confusion and exclusion can permeate all aspects of lives such as employment, health, housing and family relationships.
- The stories from learners highlighted the power of the conversations with health care staff, words used by both staff and people to describe and explain sometimes difficult concepts are vitally important. It is a great relief in a consultation if a health care professional makes a connection by perfectly describing a symptom using words which “hit the mark”. Metaphors, analogies and pictures are a powerful way to influence health and describe symptoms and health. Their use in health care is widespread in daily consultations, yet they are not collected and shared. The use of metaphors and analogies are described in a study which explored the language used in GP consultations.¹⁸ The study reported that although doctors and patients use different metaphors to explain disease, they were always useful.
- Learners showed a great interest in finding out more about ways to live better with long term conditions. A great deal of information and beliefs about health was exchanged between neighbours, friends and family in places such as shops and adult learning classes.
- “Local” meant “local”, most learners preferred to stay close to their own area which may result in support not being accessed in neighbouring areas.

Recommendations

- Consideration should be given to developing health and social care systems and workforce competence in identifying and supporting people with poor literacy. Health care professionals and staff could be offered basic education in communication and human relationship skills, literacy and numeracy, personalising care and brokering health information. This training should take account of the quality of information and support provided by voluntary organisations, LTCAS could play an important part in this process.
- Health care professionals should ensure people have fully understood and adjusted to their condition by using clear and simple words. Existing techniques such as “Ask me 3”¹⁹, “Teach Back”²⁰, and leaflets such as It’s OK to Ask,²¹ should be widely used.
- Poor levels of literacy are an important safety issue. Safety may be compromised by poor reading and understanding when accessing healthcare services.
- Literacy groups are a natural target for health improvement programmes. A more direct link between anticipatory care programmes, primary care and literacy groups could be developed. For instance shared learning opportunities for primary care staff and literacy tutors to allow pooling of expertise. This could include education in health improvement, supporting people with long term conditions, literacy and numeracy tools and techniques to use in consultations. Because of their valuable contact with learners, literacy tutor’s role within anticipatory care programmes could be explored and developed.
- Literacy classes could test health information materials, which could be organised through national information services.
- Consideration could be given to developing a Scottish Medical Analogy Library to explain complex health issues, such as “what is my main problem?”
- The act of “joining in” deserves further examination (approaches which can be used to engage and encourage people to access support).
- Literacy programmes form a valuable reference group which could be harnessed when developing public, local health and social care services. For instance literacy classes could collaborate with health care professionals to build templates for primary care, design electronic access to personal health information, written materials and signage in health care settings. Classes could contribute creative ideas about ways to deliver information such as use of podcasts, video and texting.

Further Information

Long Term Conditions Alliance Scotland

<http://www.ltcas.org.uk/>

Managed Knowledge Network for self management and rehabilitation:

<http://www.enablinghealth.scot.nhs.uk/home.aspx>

Co Creating Health, Health Foundation

http://www.health.org.uk/current_wor...ng_health.html

Long Term Conditions Collaborative:

<http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/Delivery-Improvement/1835/210369>

Adult Literacy

Learning Teaching Scotland

<http://www.ltsotland.org.uk/literacyandnumeracy/>

Adult Literacy Online (has resources)

<http://www.aloscotland.com/alo/sitesearchresults.htm>

National Literacy Trust

<http://www.literacytrust.org.uk/policy/scotland.html>

American Medical Association Foundation Health Literacy Initiative

<http://www.ama-assn.org/ama/pub/category/8115.html>

Scottish Government adult literacy and numeracy campaign website

www.thebigplus.com

National Patient Safety Foundation – Ask Me Three

www.npsf.org/askme3

Improving communication

www.plainlanguage.gov/

Quick guide to health literacy (has resources)

www.health.gov/communication/literacy/quickguide/healthinfo.htm

Less is |More – the art of the clean language

<http://www.cleanlanguage.co.uk/CleanLanguage.html>

The Altoona List of Medical Analogies

<http://www.altoonafp.org/analogies2.htm>

Patient Experience

Better Together – Scotland Patient's Experience Programme

http://www.bettertogetherscotland.com/bettertogetherscotland/CCC_FirstPage.jsp

UK website for people to share experience and contribute to blog

<http://www.patientopinion.org.uk/>

Patients like me – sharing experience and helping research / clinicians

<http://www.patientslikeme.com/>

Patient Safety

Scottish Patient Safety Programme

<http://www.patientsafetyalliance.scot.nhs.uk/>

National Patient Safety Foundation – Ask Me Three

www.npsf.org/askme3

Information for public and staff

NHS24

<http://www.nhs24.com/content/>

Self Management and Rehabilitation mkn

<http://www.rehabilitationmkn.scot.nhs.uk/home.aspx>

Elibrary – Health Education Scotland

<http://www.elib.scot.nhs.uk/portal/elib/pages/index.aspx?referer=AAS&un=nousername>

Long Term Conditions Alliance Scotland member organisations – LTCAS can signpost people to these and a variety of other voluntary organisations

<http://www.ltcas.org.uk/>

Scottish Council for Voluntary Organisation (SCVO) voluntary sector database

<http://www.scvo.org.uk/scvo/Information/VolSecHome.aspx>

Scotland's Health on the Web - SHOW

<http://www.show.scot.nhs.uk>

Information Services Division Scotland (ISD)

http://www.isdscotland.org/isd/CCC_FirstPage.jsp

Glossary

Asthma: Narrowing of tubes that carry air in and out of in the lungs which can lead to coughing, wheezing, difficulty in breathing and tightness in the chest.

Dyslexia: A condition affecting a child or adult's ability to read and write. It may affect **short-term memory, concentration and co-ordination.**

Epilepsy: Disorder of brain function which may cause sudden seizures. **A brief disturbance in the brain's normal electrical activity causes the nerve cells to fire off random signals. The result is like an electrical storm that causes a temporary overload in the brain.**

Some seizures end in seconds while others may last several minutes. People might lose their awareness of what is happening or where they are during a seizure. They may lose consciousness altogether.

Hypercholesterolemia: A very high concentration of fat in the blood. It is more commonly known as high-cholesterol. This condition may lead to diseases of the circulation.

Multiple Sclerosis (MS): This condition affects the central nervous system, resulting in a variety of symptoms. Common symptoms include shaky movement of the limbs, problems with speech and difficulties with balance. For some people, MS is characterised by periods of relapse and remission while for others it has a progressive pattern. For everyone, it makes life unpredictable.

Myalgic Encephalopathy (ME): A fluctuating condition characterized by extreme fatigue and also known as chronic fatigue syndrome (CFS). Symptoms may include overwhelming or persistent fatigue, feeling generally unwell, pain, sleep difficulties, concentration and memory difficulties.

Neurofibromatosis type 2 (NF2): An inherited condition that causes noncancerous tumours to grow around nerves. The most common first symptoms of NF2 are: gradual hearing loss tinnitus (ringing or roaring in the ears) unsteadiness, particularly when walking on uneven ground or in the dark.

Scotopic Sensitivity: A neurological condition that may affect, approximately 12% of the population and is somehow caused by the brain and/or eye incorrectly processing/interpreting what the eye is seeing. These people will have increased difficulty reading and studying. Symptoms can include contrast problems, light sensitivity, headaches and migraines.

Annexe

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- 8 Patient Focussed Interventions- A Review of the Evidence, Coulter; Ellins, Picker Institute 2006
- 9 US Department of Health and Human Services, "Healthy People 2010, Understanding and Improving Health", November 2000
- 10 Project blog: <http://www.aliss.scot.nhs.uk>
- 11 City Literacy and Numeracy www.clanedinburgh.org
- 12 Long Term Conditions Alliance Scotland www.ltcas.org.uk
- 13 Keep well is a free health check for people aged 45 – 64 living in certain areas of Scotland <http://www.keepwellscotland.com/>
- 14 A Patience Story: <http://vimeo.com/8717594>
- 15 The Scottish School of Primary Care; http://www.sspc.ac.uk/living_well.htm
- 16 Closing the Loop, Physician Communication with Diabetic Patients Who Have Low Health Literacy, Dean Schillinger, et al, *Archives of Internal Medicine*, Vol 163 (1) 83 – 90, Jan 2003
- 17 De Ridder, et al; Psychological adjustment to chronic disease; *The Lancet*, Vol 372, 246 – 255, July 2008
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- 19 National Patient Safety Foundation – Ask Me Three www.npsf.org/askme3
- 20 Teach Back – Quick Guide to Literacy: <http://www.health.gov/communication/literacy/quickguide/healthinfo.htm>
- 21 It's OK to Ask, Leaflet. <http://www.scotland.gov.uk/Resource/Doc/215694/0057709.pdf>