What accessible information do health professionals provide?

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Introduction

This study was commissioned by East Lancashire Clinical Commissioning Group. The researchers set out to find out how health professionals in Lancashire work with people who have communication and accessibility needs.

The research questions were:

1. How do health professionals collect and record information about people's accessibility needs?
2. How do they share this information with other health professionals?
3. How do they adapt the information they provide to people with accessibility needs?

The research team designed an online questionnaire to find out health professionals' practices. This was circulated via email to GP and Pharmacy practices in East Lancashire. Twenty two health professionals completed the survey, eight of them were GPs, four were practice nurses and three were Pharmacists (see table 1). Those who were in the 'other' category consisted of a medicines management technician, a research nurse, a receptionist, a practice manager, an administrator, and a critical care nursing sister.

The questionnaires were analysed thematically, to collect information about how many professionals were responding in similar ways. Sometimes responses featured more than one theme per question.

Table 1 - What is your profession?

#	Answer	Count
1	General Practitioner	8
2	Practice Nurse	4
3	Pharmacist	3

4	Other (please type)	7
	Total	22

Other

Medicines management technician
Research Nurse
Reception
Practice Manager
Critical care Nursing sister
Administrator

Question 2 - In your current role, how do you decide on the format of information to give to a person with learning disabilities to help them understand their medicine/prescription?

This question asked participants to comment on how they accommodate people with learning disabilities in terms of the information they provide. The most frequent responses were that professionals decide in consultation with both the patient and their carer/support staff or family (n=9), and in discussions with carers (n=7). Four participants reported using the verbal and written information from the patient. Others mentioned referring to the health action plan (n=1) and discussing with the patient themselves (n=1). See table 2 for details.

Table 2 – Deciding on the format of information

Response	Frequency	Example comment
Talk to patient and carer	9	On an individual basis and in consultation with any family members or carer (GP)
Discuss with Carer	7	I am guided by carer information provided. (GP)
Using verbal and written information	4	Everyone is different, so an agreement is made with the patient with which is the best way to provide information to them and we try to accommodate. This could be verbal, written down, sign-posting (Pharmacist)
Health Action Plan	1	Sometimes people will have a Health Action Plan which will outline the way they wish to communicate (Nurse)

Talk to patient	1	By talking to patient & assessing their level of understanding & preferred method of communication (Nurse)

Question 3 - When you have established how a person with learning disabilities prefers to get information about their medicine/prescription, how do you record this on your systems?

This question referred to recording systems, asking how professionals record the requirements of their patients. The most frequent response was to arrange a 'pop-up' message on their clinical system (n=11). Some people commented that they can convey this information to other professionals using the 'pop-up' system. Pharmacists reported recording information in PMR records (n=2), whereas GPs reported documenting this in their consultation notes (n=7). See table 3 for details.

Table 3 – Recording the information

Response	Frequency	Example comment
EMIS/ ECR Alert/ Read code/ pop up	11	Within our clinical system there is a way to add 'pop-up' alerts on the notes. This means that when the notes are opened, or when a new prescription is added the alert flashes up. It is written in free text so any warning or info needed can be added. I see an elderly lady who is hard of hearing who prefers to be contacted by email for example, so I have added that as a pop-up. With prescription, we can also send a task via the system to the Medicines Manager so she gets the information directly (Nurse)
Document in consultation notes	7	I usually write in the consultation how I have done this--usually because I have given written as well as verbal information (GP)
PMR record	2	Make a note on PMR (Pharmacist)
Record in daily notes booklet	1	Recorded in the patients daily notes booklet and verbally passed to the next shift (Nurse)

Question 4 - How do you make sure that GPs, nurses and pharmacists know how a person with learning disabilities prefers to get information about their medicine/prescription?

This question focussed on sharing information between professionals, asking how the participant let others know about the requirements of the patient. Most participants stated that their electronic forms could include this information (n=12), and some also provided hand written notes. Others

mentioned verbally passing information on (n=2) and one pharmacist faxed the information. See table 4 for details.

Table 4 – Sharing information between services

Response	Frequency	Example comment
Document in records / alert	12	I would type in an additional note on the electronic prescribing form when requesting the information. This would then be submitted to the pharmacist. If there were particular concerns or risk of confusion during the consultation, I would also hand write a note that I would give to either the individual with LD or their carer to be shown to the pharmacist and then to be taken home (GP)
Verbal discussion	2	Verbally passed onto the pharmacist and ward staff on discharge and documented in nurses and Doctors' discharge letters (Nurse)
Access to EMIS	1	As a CCG employee granted access to practice IT EMIS I would flag it up to a relevant person in practice for appropriate recording (Pharmacist)
Faxed to GP	1	Information is faxed to GP surgeries (Pharmacist)
Rely on carer	1	Usually informed via their carer (Nurse)

Question 5 - Which adjustments do you offer?

This question asked services which adjustments they offer to people with communication requirements. Most professionals offered regular health checks for people with learning disabilities (n=14), and easy read health information (n=12). Ten respondents reported providing information with pictures or diagrams, and others easy read information on its own (n=6). Other services provided a BSL interpreter or hearing loop (n=5) and information in Braille (n=2). One respondent mentioned recommending videos for people. See table 5.

Table 5 – Adjustments offered

Answer	%
Regular health checks for people with learning disabilities	65%
Easy read health information	55%
Information with pictures / diagrams	45%
Easy read medication information	25%
BSL interpeter or hearing loop	20%

Information in Braille	5%	
Other	30%	

Others included: Medication review, easy access to learning Disability Nurse for info and resources and signposting videos about smear tests.

Question 6 - What are the barriers to providing information to people with learning disabilities in their preferred format?

This question asked respondents to consider the barriers to providing information in the way it is required. The most frequent answers were time restraints (n=8), and difficulties of establishing accessibility requirements (n=7). Five respondents reported that there is a lack of reliable resources for them to access and other answers focussed on cost implications (n=4). Two people mentioned the lack of training in this area. See table 6 for a more detailed breakdown.

Table 6 – Perceived barriers

Response	Frequency	Example comment
Time constraints	8	Time restraints in a busy clinic especially when careful explanation using diagrams and pictures is needed. Accessing the information promptly. Every person is different so sourcing the right kind of accessible information may need some planning and a follow up appointment (Nurse)
Establishing accessibility requirements	7	Need to identify the preferred format first. no template as such exists (GP)
Availability of resources	5	Lack of recorded information and lack of available resources - or certainly lack of awareness of any that exist (Pharmacist)
Cost	4	I would imagine that cost would have an implication and also knowing what the preferred format for the patient would be (Nurse)
Rely on carer	2	Culture of liaising with carers (paid or unpaid) rather than the patient themselves (Pharmacist)
Complexity of instructions	2	GP concern about information overload and potential for harm to patient e.g. prescribing multiple medications that need to be taken at set times, medication with changing doses or for a limited time period, all of which may be harmful if not taken as advised (GP)
Lack of training	2	General nurses have no training in this area and it usually takes time to get to know and understand the patients needs. My area is a short term area so we struggle unless carers are available (Nurse)

Other	4	Diversity of conditions
		Multiple health needs

Question 7 - Do you have any suggestions for improving the process for providing medicine or prescription information to people with learning disabilities?

This question asked for ideas for improvement of provision of medication information for people with learning disabilities. Some respondents wanted better or easier access to available resources (n=5) and others wanted longer appointment times (n=4). Two people suggested that better systems to communicate between health professionals would help, such as a shared IT system. See table 7 for details.

Table 7 – Suggestions for improvement

Response	Frequency	Example comment
Better access to resources / easy read info	5	Easy read prescription sheet format for the patient, with a brief explanation/description as to what each medication is for. Perhaps a picture of each tablet / medication next to the name of medication on this form. A way for the GP to access this form - we often don't know what the different tablets look like (GP)
Longer appointments	4	Double slots and sometimes 30mins slots if more than one problem (GP)
Better communication between professionals	3	Same IT systems. Verbal communication between colleagues Regular MDT meetings (GP)
Ask both patients and carers	2	Perhaps contacting patients/carers and finding out what they would like (Nurse)
Training	2	Training for health professionals. LIBRARY-preferably electronic, centralised patient information resources free of charge (Pharmacist)
Other	2	Pharmacy to provide easy read info
		Template on computer system

Question 8 - Please share any examples of effective practice in providing information to people with learning disabilities that you have seen.

This was an open question to elicit any innovative ideas that respondents had seen in use. Eleven respondents answered this question, describing effective practices that they have used or that have been used by their colleagues. Four respondents described adjustments such as taking time to provide explanations and offer guidance, and others provided information that they had put together which included pictures (n=2) or sharing YouTube videos with

the patient (n=2). Two respondents recommended that medicine chart blister packs should be available. Other examples of good practice were using blister packs with charts on (n=3) and providing person centred information on hand held notes (n=2). See table 8 for responses.

Table 8 – Examples of good practice

Medicine chart blister packs	• Clear blister packs separating out the medications by day and time. • I am aware that pharmacies can provide blister packs of medication to assist people with learning difficulties • Medicine charts blister packs
Hand held notes	• Information packs providing information on the patient's background and previous health problems • Usually patients come with a care plan of their likes and dislikes etc. This helps a lot. We had a patient with Down's syndrome who had this. He didn't like light but loved mirrors. This info helped us keep him less agitated and comfortable
Paper resources	• Printing of the white side of script and allowing patient to tick items needed • I have put together sheet with pictures on to aid carers in medicines administration where concordance was an issue, this is the only occasion in my role I have used this sort of approach • Big words and writing is not always effective if patients are unable to read. Using diagrams and pictures of food on computer helped with a discussion about healthy eating for a patient with diabetes • Pictorial instructions on some Pills
Online resources	• As described above using an easily accessible website with pictures/diagrams helped a lady with LD understand about cervical smears • I shared a YouTube video recently showing a minor surgery procedure to LD that helped him understand the procedure and ask direct questions that he wouldn't have done otherwise
Explanation and guidance	• One lady with a LD brought a bag of her shopping to the surgery so we could look at the food labels and help her identify which foods were high in sugar. Sometimes you just have to be creative and work with the patient to find out what works for them. • I have discussed medication such as inhalers for example with some of our LD patients with chronic diseases such as asthma and COPD and discussed the importance of the medication and tried to find effective ways to help concordance, for example one young man now has an alarm on his phone to remind him when to take them. • We offer help to patients with learning disabilities - eg help with navigating e-referral process. • Speaking clearly to individual about meds and what each med is taken for, and providing weekly scripts instead of monthly.

Health Checks	• At this practice we offer annual health checks for everyone on the LD register, involving our Healthcare Assistant and a Doctor in the same clinic. This means only one trip to the surgery for the patient, and offers physical checks such as BP, weight and bloods for example, as well as preventative health care such as smoking cessation, physical activity and diet advice. The Doctor then does a more medical check and goes through medication etc with the patient and carer. I think this system works well for the patient as many don't like leaving their home and so they need only come once instead of repeat visits.
Timing of appointments	• Routinely giving double appointments and arranging them around times when a friend or carer is also available to attend the appointment.
Information systems	• Notifications that come up on the ECR when entering a patient's file e.g. only takes medications in liquid form.

Conclusion

We concluded that there is a need for a central resource for the use of health professionals and patients that provides health and medication information accessibly. There are a number of online resources available but it is difficult to know which to choose and services are relying on local solutions. There is also a need for improved IT systems which share information and flag up individual requirements.