How do health professionals provide accessible information?

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Introduction

We recently worked on a study that was commissioned by East Lancashire Clinical Commissioning Group (CCG). We wanted to find out how health professionals in Lancashire work with people who have communication and accessibility needs.

There are clear health disparities between people with learning disabilities and the general population, leading to concern among professionals about the health information they provide.

The NHS England Accessible Information Standard came into force in England on 31st July 2016. The Standard states that it is the responsibility of services to make understandable information available to everyone. The principles for health services are as follows:

1. Ask: find out if an individual has any communication or information needs relating to an impairment or sensory loss and if so what they are. This must be done ‘proactively and opportunistically’ using professional judgment.
2. Record: record those needs in a clear, unambiguous and standardised way in electronic and / or paper based record. Information needs should be recorded rather than impairment or condition.
3. Alert / flag / highlight: ensure that recorded needs are ‘highly visible’ whenever the individual’s record is accessed, and prompt for action.
4. Share: include information about individuals’ information or communication needs as part of existing data sharing processes (and in line with existing information governance frameworks).
5. Act: take steps to ensure that individuals receive information which they can access and understand, and receive communication support if they need it.

The Equality Act (UK) and the Accessible Information Standard make it clear that it is the responsibility of the organisation and its staff to make information understandable in order that patients make informed decisions about their care.

For this study we wanted to find out the following:

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, and twenty two health professionals completed the survey, eight of them were GPs, four were practice nurses and three were Pharmacists. 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.

How do health professionals find out about people’s needs?

We asked people 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, and in discussions with carers alone. Four participants reported using the verbal and written information from the patient. Others mentioned referring to the health action plan and discussing with the patient themselves.

How are these recorded?

We then asked about recording systems, how professionals record the requirements of their patients. The most frequent response was to arrange a ‘pop-up’ message on their clinical system. Some people commented that they can convey this information to other professionals using the ‘pop-up’ system. Pharmacists reported recording information in PMR records, whereas GPs reported documenting this in their consultation.

What information do health professionals offer to people with learning disabilities?

We asked services which adjustments they offer to people with communication requirements. Most professionals offered regular health checks for people with learning disabilities, and easy read health information. Ten respondents reported providing information with pictures or diagrams, and others easy read information on its own. Other services provided a BSL interpreter or hearing loop and information in Braille. Others
recommended videos on You-tube for people, and offered medication reviews for people with learning disabilities.

What do services offer?

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 interpreter or hearing loop 20%
Information in Braille 5%
Other:

Answers included: Provision of medication review, offering 30% access to LD nurse, and signposting videos to explain procedures.

What are the barriers to providing accessible information?

Respondents were asked to consider the barriers to providing information in the way it is required. The most frequent answers were time restraints, and difficulties of establishing accessibility requirements. For example:

*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)*

Five respondents reported that there is a lack of reliable resources for them to access and other answers focussed on cost implications.

*Lack of recorded information and lack of available resources – or certainly lack of awareness of any that exist (Pharmacist)*

Two people mentioned the lack of training in this area.

*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)*

How can information be improved?

Finally, we 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.
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)

Others wanted longer appointment times. Some people suggested that better systems to communicate between health professionals would help, such as a shared IT system.

Same IT systems, verbal communication between colleagues. Regular MDT meetings (GP)

An important suggestion was for a centralised resource with accessible information, to draw on:

LIBRARY-preferably electronic, centralised patient information resources free of charge (Pharmacist)

What we concluded

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.

You can print a pdf of the report by clicking here: What accessible information do health professionals provide

We also asked people with learning disabilities about their requirements. You can read the report here: Helpful Information received from GP – easy read

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