One-page patient passport for people with learning disabilities


Summary
People with learning disabilities can have negative experiences in hospitals. One of the key reasons for this is the lack of time available for staff to understand individuals’ needs. This article describes the development and implementation of the one-page patient passport, designed to provide individualised information about the person for doctors, nurses and administrative staff. The results from a pilot evaluation indicate that the tool promotes high levels of support for people with learning disabilities on admission to and during their stay in hospital.

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A FUNDAMENTAL AIM OF UK government policy is enabling people with learning disabilities to lead healthy and fulfilled lives. Therefore, person-centred approaches to many aspects of life, including health, education, employment and housing, have been recommended (Scottish Executive 2000, Review of Mental Health and Learning Disability (Northern Ireland) (2005), Welsh Assembly Government 2007, Department of Health (DH) 2009). However, person-centred approaches to care are not being adopted in many health services and people with learning disabilities can experience marked inequalities in provision compared to the general population (Mencap 2007, Michael J Sir, Independent Inquiry into Access to Healthcare for People with Learning Disabilities 2008, Parliamentary and Health Service Ombudsman 2009).

People with learning disabilities are more likely than the general population to use healthcare services during their lifetime (Morgan et al 2000). The Disability Discrimination Act 1995 made it a requirement that all public agencies make reasonable adjustments to policies and services. The act made public bodies responsible for introducing a disability equality scheme, which was followed by a single equality scheme as outlined in the Equality Act 2010. These schemes aim to demonstrate how reasonable adjustments can be made to policy and practice in terms of accessibility of information, flexibility of appointments and admission to hospital, adapted facilities and partnership with carers. These adjustments can assist in providing equitable care and treatment for people with learning disabilities and other vulnerable patient groups.

There is evidence that staff, such as those working in the emergency department and ward setting, feel ill equipped to provide high quality care for people with learning disabilities (Sowney and Barr 2006, Regnard et al 2007). The quality of the healthcare experience for this vulnerable patient group can be adversely affected by poor communication, fear and distress resulting from being in an unfamiliar environment and experiencing traumatic events, in addition to lack of support and inferior care provision by healthcare providers (Cumella and Martin 2000, 2004).

Personal communication passports have been endorsed following a recent survey of NHS trusts
about reasonable adjustments as an effective strategy to reduce the negative experiences of people with learning disabilities (Hatton et al 2011). The passports contain information about the patient’s needs. They are not a new concept and have acknowledged benefits such as providing continuity of care, empowering individuals and enhancing relationships between patients and all involved in their care (Millar and Caldwell 1997). They can be used to identify individual needs and the detailed patient information may contribute to improved treatment and care (Kent 2008). However, patient passports have no legal status and while they promote good practice, they are only as good as the person completing them. Inaccurate information contained in the passport could adversely affect clinical decisions made by healthcare professionals (Powell and Kwiatek 2006). In addition, if the document is not concise it may not be completed appropriately or read properly because staff may be too busy to process the information effectively.

Person-centred approaches to service provision involve making the individual the primary focus of the service. However, to achieve a person-centred approach, it is necessary to think creatively, be active in terms of problem solving and be flexible in the use of resources (Cole et al 2000). A number of tools can help achieve a person-centred approach. Examples include personal futures planning (Mount 1990), planning alternative tomorrows with hope (PATH) (Pearpoint et al 1991) and essential lifestyle planning, incorporating the one-page patient profiles (Smull and Burke-Harrison 1992). The profiles provide information about what is important to patients and what needs to be known to meet their unique needs (DH 2002). One-page patient profiles help to promote a consistent approach for people who are likely to need treatment from a range of care providers (Sanderson 2003). Therefore, to improve the health experiences of people with learning disabilities when using hospital services in East Cheshire, a variety of services collaborated to develop a one-page patient passport.

## Development and implementation of the one-page patient passport

A working group was established with representation from East Cheshire NHS Trust; Cheshire and Wirral Partnership NHS Foundation Trust; East Cheshire Advocacy (an organisation that provides professional and volunteer advocacy support to people with learning disabilities); and the local independent sector, including David Lewis (a registered charity providing education, therapy, support and life skills development to people with epilepsy and complex learning disabilities) and The Rossendale Trust (an organisation that supports people with learning and physical disabilities). All were committed to providing quality services to people with learning disabilities.

Working group members initially sought guidance from administrative and clinical staff at Macclesfield District General Hospital’s emergency and outpatient departments to ascertain the essential information required when a person with learning disabilities accesses their services. A literature review was also undertaken to discover what information and/or documentation was available locally and nationally. The working group members agreed that if an acceptable tool to capture patient information was already in existence then this would provide a more effective and practicable solution than simply drafting another document.

The literature review highlighted useful examples of tools. The working group thought the most appropriate starting point, in terms of design and content, was a patient passport from Humber Foundation Trust; East Cheshire Advocacy, was a patient passport from Humber Mental Health Teaching NHS Trust et al (2009), a professional’s summary taken from a larger health passport produced by Buckinghamshire’s learning disability service (Talkback Health Passport 2008) and a comprehensive hospital assessment booklet containing a number of brightly coloured bordered pages in a traffic lights format (Home Farm Trust 2008). However, the working group was concerned that these tools were not sufficiently user-friendly to be embraced enthusiastically by busy hospital staff.

The person-centred planning co-ordinator from East Cheshire Health and Wellbeing Board suggested that she had been using with patients who had learning disabilities. One-page profiles in a variety of pictorial formats had been introduced to learning disability services in East Cheshire in 2008, initially in local authority services and subsequently other independent sector organisations. Neill et al (2008) stated that the purpose of a one-page profile is to encapsulate the following aspects—obtained through discussion with the patient and anyone who knows the person—in an easily accessible format:

- What people like and admire about the person.
- What is important to the person.
- How the person can best be supported.

The one-page profile, demonstrated to the working group, provided a good starting point for the development of a person-centred passport. It had already been modified before presentation to the group to include headings.
illustrating key aims, including how the person communicates, tips on supporting the individual, and their likes, dislikes and hobbies. The working group agreed to combine this format with a traffic lights system for each area to denote order of importance of personal information.

Over the course of several months the working group designed a new A4 format for the patient passport that would ultimately turn out to be double-sided. There were four boxes on the front page (similar to the one-page profile demonstrated by the person-centred planning co-ordinator) with key headings in order of importance, ranging from medical information and communication needs in red to support needs in amber and environmental factors in green.

A personal information page (on the reverse) provided information that administrative and clinical staff from the emergency and outpatient departments had identified as important in terms of what hospital staff would need to know about the patient.

A comprehensive user guide was developed for carers. This included a guidance document, an easy-to-read consent form for having a patient passport and two fictitious examples. The guide emphasised that the passport should follow the individual throughout their hospital stay, so that medical and administrative staff could keep the passport updated as the patient’s needs changed.

Discharge co-ordinators play a fundamental role in fulfilling the objectives of effective discharge planning, including a decrease in the length of hospital stay or unplanned re-admissions, and improvement in the organisation of service provision following hospital discharge (Shepperd et al 2010).

The importance of informing the discharge co-ordinator of an admission was reflected in the passport by the inclusion of a discharge co-ordinator signature and date box. Figure 1 shows an initial draft of the patient passport.

The working group agreed that, before full implementation, a pilot study should be carried out. This was completed during October 2009 in collaboration with Macclesfield District General Hospital (part of East Cheshire NHS Trust) and the two independent service providers: David Lewis and The Rossendale Trust. Residential managers from each service were trained to use the passports by members representing organisations from the working group. The managers, in turn, introduced the passports to frontline care staff working directly with service users. In addition, the health facilitator from Cheshire and Wirral Partnership NHS Foundation Trust, who is a registered learning disabilities nurse, introduced the concept of patient
Learning through experience

During the course of the pilot it became apparent that not all staff at Macclesfield District General Hospital were aware of the patient passports. Discharge co-ordinators and modern matrons had received literature directly from the hospital’s patient and public involvement department and knew about the forms. However, a key area, the emergency department, was not familiar with the passports. Subsequent investigation identified that this was because the emergency department had not yet had the opportunity to send representation to the awareness sessions. Specific awareness sessions were therefore arranged for key areas, for example the pharmacy and emergency departments.

The results of the pilot study were reviewed at the end of October 2009. The initial feedback gained from discussion groups held by working group members and staff involved in the pilot was positive. Staff found the patient passport to be a useful document because it enabled them to provide pertinent, person-centred information about the service user in a simple, clear format. This saved time on admission. The document was also easy to carry around. It was later agreed that the passports should be stored at the nursing station for safekeeping, where they were easily accessible to all staff working with the patient.

A recommendation was made to amend the patient passport consent form by extending the section (on the reverse side) relating to the patient’s understanding of how information on the passport would be collected, who would be involved and how the passports would be used (Figure 2). A clear set of tick box prompts was included to cover the extent to which the patient had agreed to the passport being prepared. These

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**FIGURE 2**

Revised copy of the patient passport consent form

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A patient passport can help you when you go to the hospital.

It will tell the doctors and nurses important information about you and the help that you need when you go to the hospital.

Your patient passport is for you.

To make your patient passport:

- I will talk to you.
- You can tell me what is important to you.
- I will talk to people who support you.

I will only talk to other people if you tell me that it is okay.

The people I am happy for you to talk to:

Other people can have a copy of your patient passport if you say this is okay.

The people I am happy to have a copy of my patient passport:

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"*This form does not need to be taken to the hospital*"
Success of the patient passport

Since the completion of the pilot study and the decision to implement the passport, there have been a number of presentations about the document to learning disability forums in Cheshire and the main Cheshire East Partnership Board. Partnership boards were established in 2001 in all local authority areas to help improve existing services for people with learning disabilities (DH 2001). They are meant to involve service users, their families, learning disability services, and health, housing, leisure, education and employment staff.

The Cheshire East Partnership Board takes the lead on learning disability policy and practice in the region. Those attending the Cheshire East Partnership Board presentation included service users, parents, senior managers from social services and health (including health commissioners) and representatives of Jobcentre Plus, Connexions (a careers and lifestyle advisory service for young people), Macclesfield College of Further Education (a careers and lifestyle advisory service for young people), Macclesfield College of Further Education and the independent sector. At this presentation, an advocacy co-ordinator from East Cheshire Advocacy provided, by request of the working group, a positive example relating to the use of the passports (Box 1).

Immediately after the presentation, there were requests for it to be repeated at the newly formed Cheshire East Provider Forum (a sub-group of the Cheshire East Partnership Board) and the Macclesfield self-advocacy group Speaking Up, Speaking Out. The Jobcentre Plus representative indicated that the patient passport would be a useful way (if adapted slightly) of introducing clients to employers and is looking to develop the concept further. Patient passports have also been highlighted as an area of good practice in East Cheshire NHS Trust’s monthly newsletter (East Cheshire NHS Trust 2010). Senior staff at HM Prison Styal, a women’s prison in Cheshire, were also informed about the patient passport. The initial feedback was that it could be an invaluable tool in improving the healthcare experiences of women in the jail, many of whom are vulnerable and have a history of poor healthcare experiences.

Patient passports have been well received by services and, thus far, have helped improve the hospital stay of people with learning disabilities. This is evident from the feedback received from services that have used the passports.

BOX 1

Case study: Susan’s story

Jane works for a charitable trust which provides residential care for people with learning disabilities. The staff at the trust helped each resident to make a patient passport in case they were admitted to hospital. Jane worked with Susan, a woman aged in her 50s who had a moderate learning disability and had been in residential care all of her adult life. One afternoon, Susan became ill.

Jane packed Susan’s passport and accompanied her to the emergency department. Jane gave Susan’s passport to the hospital staff. The passport was passed on quickly. As soon as Susan saw someone new the staff members were delighted with the simplicity yet effectiveness of the passport. It enabled them to understand quickly what sort of help Susan would need and how to make the visit more comfortable for her. Susan had to stay in another department in the hospital. Emergency department staff made sure that Susan’s passport went with her, so that all staff would know how to help her.

Jane often has to accompany people to hospital. She could not believe the difference the passport made: ‘I can explain what Susan needs, but I could not be with her for the whole of her stay in hospital. Usually, I worry about our residents who are left in hospital. There is no one who knows them well and who can explain what they need. As soon as I saw how quickly staff members were taking on board the information in Susan’s passport, I knew that they would respect her wishes. For example, Susan does not like to take medicine in tablet form. As soon as the staff realised this, they arranged for her to take it in liquid form during her stay.’

The passports are user-friendly, easily recognisable and simple to store and update. It is recommended that they are reviewed at least quarterly or as patients’ needs change. However, awareness of the passports in the hospital, including the emergency and outpatient departments, needs to be improved. There also needs to be increased awareness in the wider provider services of East Cheshire. This would ensure every individual with a learning disability requiring a patient passport receives the correct information, training and support to be able to prepare one. Further dissemination outside East Cheshire would be advantageous. Interest in the concept has been expressed by other hospitals.

The reasons for the passport’s success include the simple design, a co-ordinated approach and effective partnership working. The commitment and enthusiasm for the patient passport among senior colleagues in East Cheshire NHS Trust, for example, patient and public involvement staff, modern matrons and discharge co-ordinators, has enabled information about the passport to be disseminated to all hospital departments.

The patient passport has enabled agencies involved in delivering services to people with learning disabilities outside the NHS to have input into policy developments and the sharing of best practice with their local hospital. The working group is now developing an admission and discharge guide (including an easy-to-read version). This will provide an invaluable resource for people with learning disabilities and those involved in their care when using local hospital services.
The DH (2008) has advocated that individuals should be empowered to take control of their lives. Collaboration of private and voluntary organisations has long been encouraged. In 2000 the DH set out its aims for reducing adverse health experiences of vulnerable people such as older adults, children and those with chronic conditions such as dementia. The one-page patient passport provides a template that could easily be adapted for use with these vulnerable patient groups.

**Conclusion**

Going into hospital can be a difficult experience for vulnerable individuals, such as those with learning disabilities. One of the main problems is lack of effective communication. Therefore, it is crucial that, in today’s NHS, where time can be limited, healthcare professionals and administrative staff are able to elicit important information about a vulnerable person, quickly and effectively.

The patient passport that has been developed in East Cheshire is a simple, but effective tool for supporting people with learning disabilities. It enables the delivery of essential, individualised information to doctors, nurses and administrative staff, in an easy-to-read format. The results from a pilot study indicate that this tool provides opportunities to deliver high quality, accurate information to key hospital personnel, leading to positive experiences of healthcare for people with learning disabilities.

**References**


