

An evaluation of the RCPCH Epilepsy Passport

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What is the Epilepsy Passport?

In 2015 the Royal College of Paediatrics and Child Health (RCPCH) developed the [Epilepsy Passport](#) to facilitate communication between children, families and clinical professionals. The Epilepsy Passport is a paper record containing relevant and up-to-date clinical information about a child or young person's epilepsy. It is designed to be used primarily when families access emergency healthcare, to enable clear communication and avoid unnecessary delays. It may also be used in other circumstances such as sharing information with schools, residential or respite care services.

The Epilepsy Passport is designed to be carried by the child, young person, parent or carer. When visiting a clinic, the Epilepsy Passport is completed by a paediatrician, paediatric neurologist or a specialist epilepsy nurses. The paediatrician or nurse will then save a copy of the Epilepsy Passport for future updates, and provide the Epilepsy Passport to the child, young person with epilepsy, or their parent or carer to carry at all times. This can then be presented to healthcare professionals as and when needed. It has been designed to be folded to A6 (wallet) size and carried in a small plastic purple wallet which is provided by the RCPCH.

The Epilepsy Passport was developed following a recommendation from the [RCPCH Child Health Reviews-UK programme into Epilepsy](#). Two years following the launch, the RCPCH Research and Evaluation Team carried out an evaluation to understand how the Epilepsy Passport is being used by parents, carers, children and young people and healthcare professionals, and to help inform communications planning and future development. The Research and Evaluation Team sought the advice and input of the UK Paediatric Epilepsy Programme Board, which includes representation from epilepsy specialists, parents, children and young people, and the mental health, education and the charity sectors, throughout the course of this evaluation.

How was the Epilepsy Passport evaluated?

The evaluation was carried out to understand how healthcare professionals (HCPs) and children and young people (CYP) and their families use the Epilepsy Passport, and to inform what aspects of the Epilepsy Passport have been successful and which areas need improvement.

The evaluation was carried out from July 2017 to March 2018 using two methods:

- 1) Since the Epilepsy Passport's launch in September 2015, the RCPCH has kept a record of all the Epilepsy Passport wallet enquiries and orders. These data were reviewed to determine how many wallets have been ordered and the demographic details of those individuals who placed the orders.
- 2) Two surveys were also developed; one for CYP and families and one for HCPs. The surveys were hosted on SurveyMonkey from September 2017 to January 2018. Data were downloaded from SurveyMonkey and analysed in MS Excel. The surveys consisted of both open and closed questions, closed questions were analysed in MS Excel while open questions (free text responses) were analysed by thematically coding responses in MS Excel to identify key themes.

Healthcare Professionals (HCP) Survey

To develop survey questions on how the Epilepsy Passport was being used by HCPs, all Epilepsy Passport queries that had been received via the RCPCH Epilepsy Passport webpage were reviewed. Themes were identified to inform the development of draft survey questions. Following this process, the draft questions were reviewed by the UK Paediatric Epilepsy Programme Board to ensure key questions or information were not missed. Following an initial pilot, a final online version was uploaded on to Survey Monkey.

Parents, Carers, Children and Young Peoples' (CYP) Survey

A focus group with CYP with epilepsy was held at the Lewisham and Greenwich NHS Trust on 26th July 2017. The focus group questions were developed from a review of the frequent queries reported via [the RCPCH's Epilepsy Passport 'Contact Us' webpage](#). The focus group session was audiotaped, with data transcribed and thematically coded prior to developing draft survey questions. The survey questions were then reviewed by the RCPCH CYP Engagement Team to determine their suitability for younger readers. The final survey included a series of questions to understand who and how parents, carers and CYP were using the Epilepsy Passport and was uploaded on to Survey Monkey following an initial pilot.

Dissemination of the surveys

The two surveys were disseminated through:

- Social media (RCPCH Twitter and Facebook).
- Emails to affiliated organisations involved with epilepsy, such as; Epilepsy Action and Young Epilepsy, UK Paediatric Epilepsy Programme Board, Epilepsy12 Project Board and OPEN UK.
- A clinic visit made by a member of the Research and Evaluation Team to a paediatric epilepsy clinic. This provided the opportunity to speak directly to parents, carers and children attending their epilepsy clinic appointment, and to complete a paper version of the online survey. Families had the option of completing a hard copy of the survey or verbally answering survey questions as the Research and Evaluation Team member wrote down their answers.

What were the findings?

Epilepsy Passport Wallet Orders

The Epilepsy Passport can be downloaded from the [RCPCH website](#) and must be used with a corresponding Epilepsy Passport wallet, which is distributed by the RCPCH. Orders can be placed online, over the telephone and via email.

From review of these data we found that:



10,000

Over ten thousand Epilepsy Passports wallets have been ordered from the RCPCH since the Epilepsy Passport's launch in September 2015.



300

Approximately 300 HCPs have ordered the Epilepsy Passport wallet overall. Numbers of wallets per order ranged from 1-200.



9

9 orders have come in from overseas (USA, Norway, Bulgaria, Canada and Australia).

150



3

150 orders of the Epilepsy Passport wallet orders came from family members and 3 from CYP with epilepsy.

Healthcare Professionals survey findings

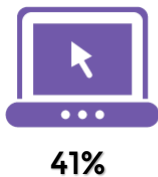
A total of 91 HCPs completed the online survey. Key findings from the HCP survey are presented below.



88% of HCPs reported that they had heard of the Passport.



37% of HCPs reported they heard of the Epilepsy Passport from a colleague i.e. a consultant or a nurse.



41% of HCPs reported they heard about the Epilepsy Passport from the RCPCH website.



2 out of 5 HCPs reported they give the Epilepsy Passport to their patients.

Parents, carers and CYP survey findings

A total of 117 completed the survey, 82% of those who responded were parents and carers and 18% were CYP. Key findings from the survey are presented below.



64%

64% of respondents had not heard of the Epilepsy Passport.



Of those who had heard of the Epilepsy Passport, approximately two out of three respondents reported that they/their child carried the Epilepsy Passport with them.



Four respondents said that they used the Epilepsy Passport in an emergency and this improved the care that they received.



Four out of five of respondents reported that the Epilepsy Passport had no impact on their life.



Approximately six out of ten parents reported that the Epilepsy Passport had made no difference in managing their child's epilepsy.



45%

45% of respondents said they had heard of the Epilepsy Passport via the internet.



36%

36% respondents had heard of the Epilepsy Passport from a HCP.

Themes from the surveys

The open questions from the HCP and CYP surveys were thematically analysed, and two key themes identified:

1. HCPs, CYP and families' responses and comments highlighted that there was confusion, and a lack of understanding of how the Epilepsy Passport can be used. Some HCPs, CYP and families suggested improvements for the Epilepsy Passport, which are already available features. For example, some comments suggested having a version of the Epilepsy Passport that was available for download and that could be saved on a computer. However, this is an available option for the use of the Epilepsy Passport.
2. Survey question responses and comments showed there was agreement amongst HCPs, CYP and families that the concept of the Epilepsy Passport would help to improve care. However, there were comments that highlighted the Epilepsy Passport was not user friendly in its current format, and this in turn is limiting its use. For example, some respondents highlighted they would prefer a version of the Epilepsy Passport that could easily be updated on their PC or laptop.

'It should be in a format such that, it is easy for the healthcare professional to add the details and print it and fold and keep it in a wallet type size, so just needs the essential information rather than the extra bits of information'– (Epilepsy Passport survey respondent- HCP).

'If it could be condensed and made into an easier to adapt format for use on all computer systems' (Epilepsy Passport survey respondent- HCP).

How can the Epilepsy Passport be improved?

Improve communication of the Epilepsy Passport

Most CYP and family members were not aware of the Epilepsy Passport. Amongst those who were aware of the Epilepsy Passport, there was still some confusion around the Epilepsy Passport's intended use.

What the RCPCH will do next: We will develop a clear communications and dissemination plan for the Epilepsy Passport. A review of all information dissemination and messaging will be undertaken to ensure that HCPs, CYP and families have a better understanding of what the Epilepsy Passport is and how it should be used.

'I really believe in this product and did think it could quite literally be a lifesaving document. I still believe in the product however as it is not automatically updated or looked for/referred to it has had no impact. I hope that something can be done to increase the awareness of it as I would hate to see it not continue - I feel as though it has never really got off the ground.'
(Epilepsy Passport survey respondent – Family member).

Improve format and content of Epilepsy Passport

HCPs, CYP and families liked the idea of the Epilepsy Passport, however, found that the Epilepsy Passport could be improved in terms of its current format. It was suggested a more digital friendly version could be produced, allowing easy completion on a PC or tablet, or the development of an electronic application.

In addition, survey respondents highlighted that information contained in the Epilepsy Passport is often the same as information available in a CYP's clinic letter or care plan. Family

members found it frustrating having to carry multiple documents, and equally, HCPs said that they did not have the time or capacity to input the same data at different points.

What the RCPCH will do next: We will review the format and content of the Epilepsy Passport in collaboration with the UK Paediatric Epilepsy Programme Board to determine if all the details are still relevant and whether they can be modified to avoid duplication.

We will also scope the potential for the Epilepsy Passport to be developed into an electronic application, to enable greater linkage with other electronic records and datasets. This could potentially allow for an integration of datasets for childhood epilepsy, thereby preventing duplication of information collected and reducing the burden of clinical administration on healthcare professionals.

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