

RARE ALERT

Alert cards for rare disease patients



**RARE
DISEASE UK**

ABOUT RARE DISEASE UK



Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 200 patient organisations. We undertake various initiatives to improve health service provision, research and support for families. These initiatives include:



Rare Disease UK, a multi-stakeholder coalition brought together to work with the government to effectively implement the UK Strategy for Rare Diseases.



SWAN UK (syndromes without a name), the only UK-wide network providing information and support to families of children without a diagnosis.

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FOREWORD

In January 2018, NHS England committed to deliver a rare disease insert (NHS England, 2018). The rare disease insert would be a set of three new provider criteria that would sit alongside service specifications for services that treat patients with rare diseases and allow NHS England to hold providers to account for the way they treat patients with rare diseases.

One of the three new criteria was a requirement that the provider must give every patient with a rare disease an alert card, including information about: the patient's rare disease; any particular aspects of the treatment of that rare disease that needs to be taken into account in providing care to that patient; and details of how to contact an individual expert in that patient's care.

The Rare Disease UK campaign has previously published reports on the other two components of the proposed insert: Rare disease care coordination (2013) and Patient experiences of transition between care providers (2014).

An alert card usually lets others know that the bearer of the card has an important medical condition that might require special care or attention. Information on the card typically includes the name of the card's bearer, their medical condition, any medication they might take, and any allergies they might have. The purpose of the card is to alert medical staff to this information if the bearer is unable to communicate, whether that be because they are unconscious, injured, or simply want to backup what they are saying with a card. Alert cards normally take the form of a double-sided wallet sized card made of paper or plastic.

Medical alerts have the potential to improve care and treatment and save lives in emergency situations. However, two years on from this commitment from NHS England little has happened.

A model already exists for how this could be implemented, which could readily and efficiently be adopted by NHS England. With all the work already done on the digital transformation of health and social care most of the systems needed for an alert card scheme are already in place.

This report, prepared with the help of Genetic Alliance UK membership organisations, Rare Disease UK supporters and clinicians, aims to remind the Government of its commitment to implement alert cards for all rare disease patients, represent the patient experience of using alert cards, and to examine what might work well with the form of an alert card.



Jayne Spink
Chief Executive, Genetic Alliance UK

INTRODUCTION

In January 2018, NHS England committed to deliver a rare disease insert (NHS England, 2018). The rare disease 'insert' would be a response to NHS England's pledge to introduce alert cards for rare disease services. Acting on a suggestion from our Patient Empowerment Group – a council of expert patients that provides guidance to the campaign secretariat – we asked our Rare Disease UK supporters about their experiences using and developing alert cards. We asked them for details of the following:

- The format of their alert card – is this a credit card size information leaflet, a bracelet with a USB attachment, an A4 pamphlet etc.
- Was there any particular problem they were trying to solve with their alert card?
- The experiences of using the alert card – what has worked well?
- Any improvements they would make with the benefit of hindsight?
- Any broader comments they would make about NHS England's plans?

We received almost 40 responses. We then went back to some of the respondents asking more questions about their experiences. The answers we received, along with desk research, and a survey we sent to clinicians, have helped to inform this report.

MEDICAL ALERTS IN THE UK

The problem

Rare diseases are often life-long and serious, affecting multiple systems of the body. We know that many patients have numerous professionals involved in their care: for the average rare disease patient this means attending at least three clinics during every quarter (Rare Disease UK, 2016).

As such it is essential that there is coordination and communication between them all. The UK Strategy for Rare Diseases states that ‘good communication between patients, their families and professionals is essential to ensure that the primary care plan is agreed and the care team has information and appropriate specialist support.’ Information sharing is essential for patients to be treated effectively.

In 2016 Genetic Alliance UK’s campaign Rare Disease UK found that patients’ information was frequently not being shared accurately and in a timely manner between different hospital trusts, or between specialist and local services. Patients with rare, genetic or undiagnosed conditions often come into contact with health and social care professionals who know little or nothing about their conditions, and find themselves needing to explain complex details of their medical histories over and over again.

‘I find myself explaining everything and passing on test results and procedures to every doctor I see because the communication is so unreliable and patchy.’

‘I’m currently seeing eight different specialists in three different hospital trusts who are not set up for sharing information. It’s a part-time job for me just tracking and organising this and making sure that I pass information across. Often it would make sense for a set of appointments or tests to happen in a particular order, but bringing this about is virtually impossible so we end up with delays and repeat visits.’

‘The coordination of care, under 5 hospitals and 19 clinics, is done by us the parents as there is no one else to do it. We also have to inform each clinic on any findings as they do not copy each other into any reports and we have to do all the updates for them.’

The majority of individuals and families affected by rare conditions will have experienced the difficulties that can result from poor communication of patient data and how this can have a direct negative impact on the quality of care they receive. We hear many stories of patients being treated inappropriately because health and social care personnel lack knowledge of the specifics of their condition, such as for example a different response to a medicine than patients with a similar, more common condition. Appropriate mechanisms for sharing information safely with those who need it have the potential to immensely improve patients’ experience of care.

Rare diseases unknown to emergency medical staff pose a particularly serious problem. If a patient is unable to communicate in an emergency situation (eg if they are unconscious) mistakes can be made

in the accurate diagnosis, treatment and care of an individual; in some cases this can have fatal consequences.

The policy context

The UK Strategy for Rare Diseases (2013) recognised the importance of coordinating care across the boundaries between different healthcare services so that care is effective, accessible and convenient to patients. At that time, all four countries of the UK committed themselves to several actions to promote care coordination; to develop a generic care pathway that will include an appropriate care plan for all patients with a rare disease (Commitment 23), and that specialist clinical centres should as a minimum standard coordinate care and ensure their expertise is available to families and their healthcare teams (Commitment 24).

The proposal to develop alert cards as part of the implementation of the Strategy emerged in England, and so far there is no specific commitment to develop alert cards in Scotland, Wales or Northern Ireland.

England

In their 'Implementation Plan for the UK Strategy for Rare Diseases' published in January 2018, NHS England proposed as a core action to implement their objective of improving care coordination to develop (in 2017/18) and implement (in 2018/19) a rare disease insert that would sit alongside service specifications for services that treat patients with rare diseases, involving up to three criteria (depending on the nature of the service):

- 'That the provider must ensure that there is a person responsible for coordinating the care of any patient with a rare disease
- That the provider must give every patient with a rare disease an "alert card" (including information about: the patient's rare disease; any particular aspects of the treatment of that rare disease that need to be taken into account in providing care to that patient; and details of how to contact an individual expert in that patient's care)
- That the provider must ensure that every paediatric patient with a rare disease has an active transition to an appropriate adult service, even if that adult service is not the commissioning responsibility of NHS England.'

NHS England also committed in 2018/19:

- 'to explore with the Royal College of Emergency Medicine how alert cards could be clinically recognised in A&E departments;
- to evaluate the impact of the rare disease insert and consider whether it has a wider potential for other NHS contracts; and
- to explore with NHS Digital the benefits and feasibility of inserting a "red flag" onto the summary care record of any patient with a rare disease whose life would be at risk if they were treated incorrectly'.

NHS England signalled its intention to implement the insert in its annual contracting letter to providers for 2019/20 (NHS England, 2019). Providers have been asked to self-assess the quality of their service against the new insert, and trusts were expected to report on this self-assessment in September 2019.

Rare Disease UK was informed in October 2019 that a report with findings including results and examples of good practice would be published in early 2020. However, the rare disease insert is not

publicly available and NHS England have stated that they are unable to provide any further information about the implementation of the insert or about when the report will be published (personal communication, 2020).

Wales

In 2014 the Welsh Government and NHS Wales published guidance recommending ‘individual care plans’ be developed for all people with a long term condition, if they wanted one (NHS Wales/Welsh Government, 2014). According to the guidance, a copy of the individual care plan should be held by the patient, and ‘act as a common point of reference for the professionals involved, avoiding the need for the individual to repeat information, and supports co-ordinated and integrated care across professionals and organisations’. The individual care plan should also ‘list all people involved in the ongoing care and support of the individual, including carers, family, friends, neighbours and the local community as well as professionals, their role, the actions they are responsible for and how they can be contacted’ and ‘includes information on what to do in an emergency.’

In the ‘Welsh Rare Diseases Implementation Plan’, published in 2017, the development of individual care plans for patients with rare conditions was listed as a key action to deliver coordinated care. However, our networks tell us that as yet few patients with rare conditions in Wales have been offered an individual care plan in a patient-held, easily portable format.

Given the substantial overlap in both content and format of a patient-held individual care plan, Rare Disease UK recommends NHS Wales liaise with NHS England to ensure compatibility of the two schemes.

Scotland

The Scottish Government Rare Disease Strategic Oversight Group have identified care coordination as a priority area in order to meet their commitments from the Strategy by 2020. A short-life working group is being formed to work on the topic. Rare Disease UK will be engaging with this process.

At a meeting of the Scottish Parliament Cross Party Group on Rare, Genetic and Undiagnosed Conditions on the topic of care coordination held in December 2019, there was widespread support for a universal alert card for rare conditions. Other similar schemes outside rare disease were cited as examples of good practice, such as Healthcare Improvement Scotland’s My Anticipatory Care Plan and Pamis Patient Passports.

Northern Ireland

In the ‘Northern Ireland Implementation Plan for Rare Diseases’ published 2015, the Health and Social Care Board and Public Health Agency committed to ‘take into consideration the Generic Rare Disease Annex for all service specifications which is being developed by NHS England’ (the insert was previously referred to as an annex). Alert cards and the implementation of the insert are to be discussed at the next meeting of the Northern Ireland Rare Disease Implementation Group in February 2020 (personal communication, 2020).

Commercially available medical alerts

Medical alerts have been commercially available since the 1950s initially in the form of medical ID jewellery (figure 1). They allow for the communication of hidden information, such as if someone has a rare disease or whether they have any allergies to medicines, to medical staff when patients are unable to explain these things.

Typically the personalised information includes the name of their condition, whether they have any particular allergies and the name of the medication they might be taking. Some jewellery includes space for a paper insert offering more information on the condition.

Range of products available

Medical alert jewellery ranges from simple silicone wristbands to personalised jewellery made from precious metals.

In most cases the jewellery offered is designed to be worn around the neck or on the wrist, but anklets, shoe tags, key rings, and charms are also available. These unusual locations can make medical alert jewellery hard for emergency services to locate and emergency staff may not think to look for hidden medical alerts.



Figure 1 – Example of a medical alert bracelet. Image courtesy of MedicAlert Foundation UK.

Also available commercially are laminated wallet style cards (figure 2). These typically will be linked to a subscription and the printed information will include name, emergency contact, medical condition, and allergies (this varies from card to card). The details on these again appear to not need to be verified and relies on self-reporting from the purchaser.



Figure 2 – Commercially available laminated wallet style cards. Image courtesy of MedicAlert Foundation UK.

Potential issues with commercial products

Some companies offer a membership service with a monthly or annual fee offering for example a 24-hour helpline enabling emergency services to find out the medical history of the patient. This relies on the member self-reporting their medical history to the card provider and keeping it up to date.

There does not appear to be any national guidance on the availability of medical alert products and the market seems to be largely unregulated (Rahman *et al*, 2017).

Having incorrect information on an alert card can prevent a patient receiving the most appropriate treatment and in some cases treatment that might harm them. The clinician is put in a difficult situation when presented with an unregulated alert card as to whether to trust the information and whether to act on it or not.

Due to the unregulated nature of the industry, some respondents to our survey also reported problems with poor quality medical alert jewellery.

Patient support group medical alerts

Responses to our survey revealed that rare disease charities quite often have their own medical alerts available to their respective patient populations. Some of our respondents also purchased commercially available medical alerts.

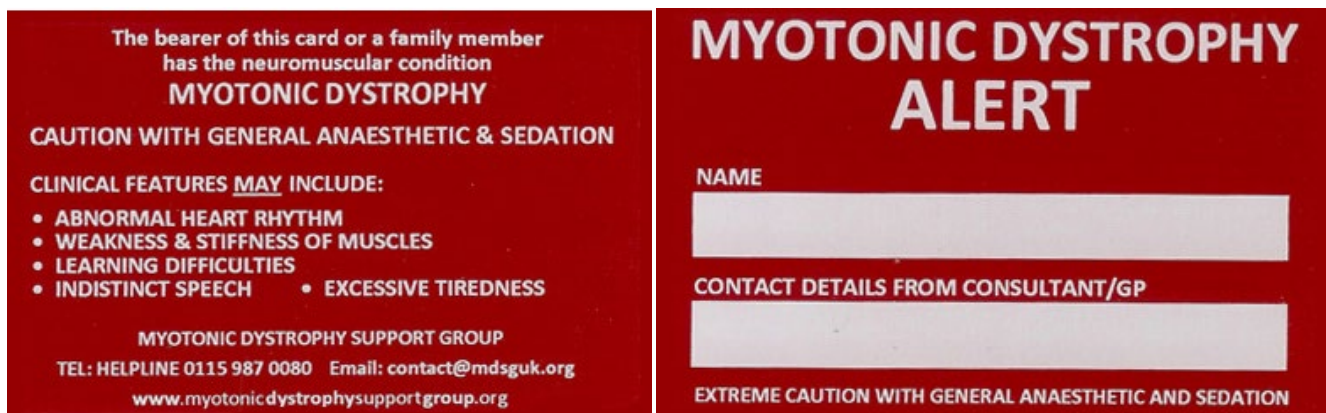


Figure 3 – Patient support group card. Courtesy of Myotonic Dystrophy Support Group.

Almost half of our respondents said that they had experience of being issued with and using a credit card sized alert card.

Figure 3 shows a typical example of an effective alert card issued by a patient support group. It has clear space for the person's name, their consultant/GP's contact details, contact details for the support group, name of the condition, and a warning to show caution with medical procedures.

Seven of our respondents said that they have been issued with or have helped develop a fold-away alert card. This allows for the inclusion of much more information such as a full list of medications, a full description of the condition, allergies, links to social-media support groups, and a description of their care needs.

<p>Medical Information</p> <p>Consultant details:</p> <p>_____</p> <p>Telephone number:</p> <p>_____</p> <p>Consultant details:</p> <p>_____</p> <p>Telephone number:</p> <p>_____</p> <p>Registered Charity No. 326679 v3.0 Apr19</p>	<p>What is Behçet's?</p> <p>Behçet's disease (also known as Behçet's syndrome) is a multisystem condition, where potentially any organ in the body can be affected. It presents flares, then relapses.</p> <p>There is currently no cure, so the strategy for treating a patient with Behçet's today is to suppress disease activity as much as possible.</p> <p>One of the most important principles in caring for Behçet's is that patients are managed by a specialist with expertise in this rare disease, so please contact their specialist wherever possible.</p>	<p>The most common symptoms are:</p> <ul style="list-style-type: none"> • Mucocutaneous: mouth ulceration - multiple or single, taking 7-21 days to heal; genital ulceration - involving mainly scrotum in men and vulva & vagina in women; skin lesions - acne-like spots and/or tender red lumps, usually on the legs, known as erythema nodosum. • Eye involvement: inflammation inside the front and/or back of the eye known as uveitis (posterior and retinal). • Arthritis or arthralgia: may affect knees, ankles, hands, wrists and sometime shoulders and hips, either without any external evidence or with joint swelling and tenderness (synovitis) being present. • Thrombophlebitis with inflammation and thrombosis in superficial and deep veins throughout the body. • Arterial aneurysms, which may cause local pressure effects or bleeding due to rupture. • Pulmonary lesions - of particular significance is bleeding in young men. • Involvement of the central nervous system is a major source of concern. This may involve inflammation of the brain tissue itself or thrombosis of cerebral veins. • Gastrointestinal ulceration - especially of the large bowel. • Overwhelming fatigue. 	<p>ALERT CARD</p> <p>This patient has Behçet's</p> <p>www.nhs.uk/conditions/behcets-disease</p> <p>Behçet's UK</p> <p>Caring for all affected by this rare, complex and lifelong condition</p>
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This patient has Behçet's

Behçet's Medical Factsheets available at behcetsuk.org

There is no specific test for Behçet's. ESR, PV or CRP values do not correlate with disease activity, nor are there any indicative measures in blood/biochemistry.

<p>Patient Information</p> <p>Name: _____</p> <p>Address: _____</p> <p>Postcode: _____</p>	<p>Home telephone: _____</p> <p>Mobile: _____</p> <p>Emergency number: _____</p> <p>Email: _____</p>	<p>Medical Information</p> <p>Medication: _____</p> <p>Medication: _____</p> <p>GP details: _____</p> <p>Telephone number: _____</p>	<p>To Hospital Staff</p> <p>I may be on corticosteroids, immunosuppressants and / or biological medicines.</p> <p>Please do not take away any local therapies such as eye drops or topical steroids. Symptoms like mouth ulcers appear very rapidly and need to be dealt with promptly.</p> <p>If I am confused or unconscious please contact my Consultant(s) or GP.</p> <p>In emergency contact: National Behçet's Syndrome Centres of Excellence www.behcets.nhs.uk Centre Helplines: London 0203 594 6085 Birmingham 0121 507 4243 Liverpool 0151 529 8123</p>
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Figure 4 – A fold-up alert card. Courtesy of Behçet's UK.

A couple of our respondents said that they had experience using a hospital passport. These have similar information to the fold-up alert cards but are usually in a bigger A4 format and are designed for use at every hospital appointment and kept with medical notes at the end of the bed in that scenario. Emergency health plans and advance care plans also contain similar information and are often written with the support of a health care professional.

Medical alerts produced by patient support groups, be they credit style cards, fold-away cards, hospital passports, or emergency health plans, are typically designed in conjunction with patients and clinicians.

They are often available free or at low cost for patient support group members and some can be downloaded for free from the patient group website.

Medical alerts produced by patient support groups cater for a range of different scenarios: from a concise and easy way to explain a condition to family, friends, and authorities, to an emergency situation scenario. Medical alerts play a wide range of different roles.

Why use an alert card?

We asked Rare Disease UK supporters what particular problem they were trying to overcome with their alert card. What they told us is summarised below:

Appropriate care

When interacting with an unknown health care professional cards can quickly convey what the patient's medical condition is, especially in an emergency situation. This helps to support a clinical decision and avoid rare disease patients being treated inappropriately because health and social care personnel lack knowledge of the specifics of their condition, such as for example a different response to a medicine than patients with a similar, more common condition.

'Many health professionals don't know about SCAD (spontaneous coronary artery dissection) so it was a quick and easy way for patients to give succinct information in an emergency situation.'

Appropriate levels of care

Alert cards make it more likely that patients will get the appropriate care and help health care professionals recognise the fact the patient has a rare disease that needs specialised care. This can save people's lives.

'The hospital passport travels with my brother when he has any medical appointment – in a hospital or in primary care etc. It helps the practitioners who meet him for the first time to get a rapid idea of his medical history and his ability to understand them, advice on the best way to communicate with him and any accommodations that they may need to offer for his anxiety/sensory needs etc. Most of the time practitioners are pleased to have the information presented in an accessible way'

Timely care

Quite often people with rare diseases are forced to unnecessarily wait in emergency departments.

'This [the card] means she can go straight to the ward any time of day or night avoiding A&E, which was previously one of our biggest issues. With a compromised immune system the last place we wanted her to be was in a busy A&E waiting area.'

Awareness and avoidance of misunderstanding

Sometimes symptoms of a rare disease can be misunderstood or confused for something else. In these situations an alert card can be a useful tool for awareness raising, serving a social as well as a medical purpose.

'Our clients (with narcolepsy) experience uncontrollable sleep attacks any time, any place, anywhere. Likewise with cataplexy, where people may collapse in public, and are unable to speak and when coming round appear to be drunk. Our aim is to avoid people being misunderstood as well as to avoid emergency services being called to situations where they are not required.'

Experience of Medic Alert UK

MedicAlert is a UK charity that fully backs the requirement for alert cards. Founded 55 years ago, we provide alert cards to people with rare diseases and other medical conditions which put them at risk in an emergency. We understand the importance of vital medical conditions being available to medical professionals at the point when treatment decisions are being made.

MedicAlert's service includes a full eco-system of support, focussed around members' comprehensive medical records which are available 24/7 via our dedicated emergency line. New and updated records are reviewed by our Registered Nurses, who contact members if needed.

MedicAlert members also wear a medical ID, either a bracelet or necklace, which show their most vital details, membership number and our 24/7 emergency telephone number. Emergency and healthcare services are trained to look for a medical ID in the event of an emergency, so the medical IDs are probably the most well-known element of our service.

Alert cards contain more details than the medical IDs (conditions, allergies, medications, history etc.) and include next of kin, doctor and hospital details. These are typically carried by the member and supplied to a medical professional or pharmacist, as required.

MedicAlert records can also hold scanned documents, like clinical reports or Advance Decisions. Members can securely access their record for updates and also give authority for others to instruct MedicAlert on their behalf. Many doctors and specialist illness clinics actively recommend MedicAlert to their patients. A MedicAlert member explained, 'Once I received my MedicAlert bracelet, I gained the confidence to go out and do stuff. I had the confidence to be me again; I knew if I had an issue in public with my MedicAlert bracelet on, people could see what my condition was.'

Kirsten Giles – Chief Executive, Medic Alert UK

ALERT CARD EXPERIENCES

Alert cards work

Alert cards, that have been designed collaboratively and implemented thoughtfully, can work; yielding positive results both for patients and health care professionals.

For example, a study on the role of patient-held alert cards in promoting continuity of care for heart failure patients (McBride et al, 2014) within the Greater Manchester area found that as well as ensuring appropriate treatment the alert cards were connected with a feeling of empowerment for patients, enabling them to take a more active role in their care and prompting them to learn more about their condition.

The implementation was also found to give patients confidence in their communications with hospital staff – having something official meant that they could not be doubted. Importantly it also enabled continuity of care, by including NHS number, details about their condition, emergency contact details for their heart failure nurse, and details of their last test, as well as the patient's name and the NHS logo. Similarly, research into an NHS-branded patient-held alert card for a bacterial infection found positive responses to the alert card from health care professionals (Poole *et al*, 2016).

HEART FAILURE ALERT CARD **NHS**

THIS PATIENT HAS HEART FAILURE

FULL NAME: _____

NHS NUMBER: _____

Show this card at all medical appointments including hospital admissions

DATE OF LAST ECHO: _____

EJECTION FRACTION: _____

LV FUNCTION: _____

IN CASE OF HOSPITAL ADMISSION PLEASE CONTACT:

Heart Failure Nurse: _____

Tel: _____

Sponsored by NIHR CLAHRC for Greater Manchester
© Reproduced courtesy of North Cumbria University Hospitals NHS Trust

Figure 5 – Heart failure alert card produced by Greater Manchester Collaboration for Leadership in Applied Health Research and Care. Available via license: CC BY-NC 3.0

The introduction of alert cards for people with autism in Scotland (MacBean, 2013) showed how multiple agency involvement (in this case the NHS, the National Autistic Society, police, and the local council) in the development of an alert card helped people explain their condition in both emergency and everyday situations. The cards were used, for example, in shops, play areas, and in contact with the police and helping to explain certain behaviours which helped to defuse difficult situations and improve interactions and outcomes with the emergency services.

Portugal – Rare Disease Patient Card

Portugal’s implementation of a Rare Disease Patient Card (Cartão da Pessoa com Doença Rara, CPDR) offers us a model of what could be achieved in the UK.

The Portuguese Government have rolled out a card that is available to all rare disease patients in Portugal. The card was introduced in 2014 as part of the Portuguese Government’s national programme for rare diseases, initially as a pilot project with six hospitals (Santos *et al*, 2015).

The card exists in both printed and digital formats.

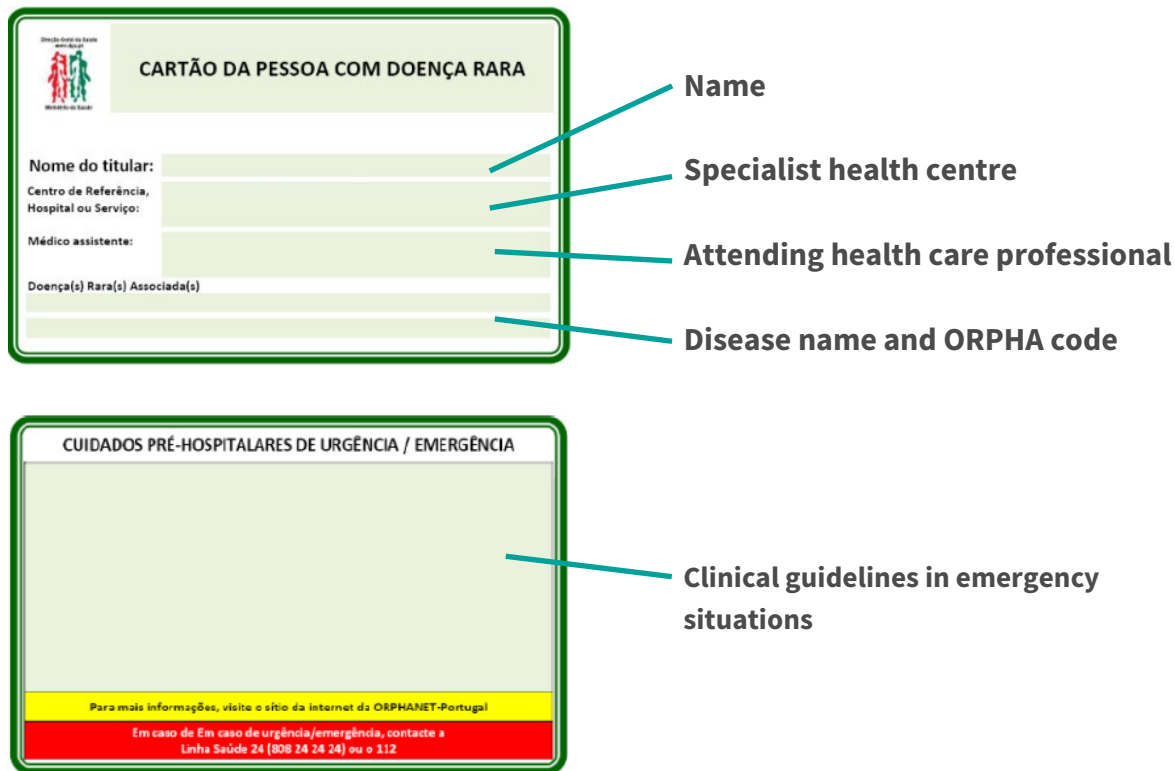


Figure 6 – Portuguese Rare Disease Patient Card (Cartão da Pessoa com Doença Rara, CPDR). Image courtesy of Departamento da Qualidade na Saúde, Portugal.

To obtain a card, a patient’s clinician must make a request through the individuals’ electronic patient record on the Portuguese Health Data Sharing Platform (Plataforma do Registo de Saúde Eletrónico). They complete an online form which asks for:

- The name and NHS number of the patient;
- The name of a specialist who should be contacted in an emergency;
- Name of the specialist service attended by the patient;
- Name and Orphacode of the patient’s rare condition;
- Appropriate emergency pre-hospital and hospital procedures;
- Signed consent form from the patient.

Once the card has been requested by a clinician, the patient must activate it online. The card would then be sent to the patient’s address (prior to 2018) or can be printed out by either the clinic or the patient (after 2018) (Norma nº 001/2018 de 09/01/2018: Cartão da Pessoa com Doença Rara (CPDR)).

Health care professionals can then consult a patient's card via the Professional Portal to the Portuguese Health Data Sharing Platform on any computer in the National Health Service. Access is also available to private health care professionals, both those operating in public and private clinics.

In the future, an automated alerting system is planned for the clinical IT programmes, so that any health care professional will immediately be alerted that the patient has a rare disease when their patient record is accessed (Departamento da Qualidade na Saúde, Portugal, 2017).

The patient is also able to view their card via the National Health Service Citizen's Portal, a service which also allows them to make appointments and order repeat prescriptions.

The card is managed and regulated by the Portuguese General Directorate of Health, a public body of the Portuguese Department of Health. Responsibility for keeping the card updated lies with the clinician or clinic that requested it.

From the card's introduction to December 2018 6,112 cards had been requested spread over 923 rare diseases, with the number of hospitals issuing the cards growing each year (Departamento da Qualidade na Saúde, Portugal, 2019).

A review of the implementation of the card in 2015 found that the card has increased clinical and public awareness of rare diseases and helped to empower rare disease patients which, in turn, is helping to improve their care in Portugal (Santos *et al*, 2015).

Awareness of emergency department health care professionals

Health care professionals are, on the whole, aware of medical alerts and know to look for them when the patient is unable to respond. Research has demonstrated that identification schemes are well known (99% of respondents to one survey had heard of emergency identification schemes (i.e. alert cards) and that it was routine for ambulance respondents to check for worn cards or emblems (97% said they did) but less so for emergency department staff (71%) (Morton *et al*, 2002).

When emergency responders are aware of medical alerts and know to look for them it can save lives. The study mentioned above highlighted the issue of patients with implanted heart valves (Morton *et al*, 2002). The valves were prone to fracture, leading to catastrophic heart failure – only the knowledge of the fact that the patient has this valve would, in the event of valve fracture, be able to save their life. Knowing this, the Department of Health sent letters to emergency departments asking them to advise staff both to look for the symptoms of the valve failure and to look for emblems or cards related to this. Those patients sent to hospitals with the facilities to deal with the valve failure, were found to have a much better survival rate. Though not an example from rare disease, this clearly shows that information on pre-existing medical conditions can ensure prompt and appropriate treatment, as well as giving an example of a previous government/NHS driven initiative around alert cards.

The experiences of using the alert card – what has worked well?

We asked our Rare Disease UK supporters about their experiences of using an alert card and what has worked well; what they told us is summarised below:

- Clearly-presented accessible information works well for health care professionals
- Some respondents to our survey have described the added credibility they feel when carrying an alert card. This allows the individual to feel comfortable, confident, and empowered
- Respondents reported that clinicians welcomed the card they were carrying as it gave the information needed to care for the patient appropriately
- Contact details for either the patient’s specialist doctor or GP worked well. This was particularly important when caring for patients with a complex condition and needs. An alert card alone is not enough
- It facilitated communication and forged links between health care professionals
- Emergency health plans work well for those with complex conditions or whose condition impacts different people variably and for whom it was felt alert cards could not convey enough information

‘They [patients] feel comforted that they have something they can show health care professionals so they will hopefully get the best treatment’

‘The card contains the concise and necessary critical information about the patient’

‘We believe it adds credibility to our members when telling people they have a disability’

‘Patients feel very empowered carrying these. It also allows other practitioners to get in touch with us and helps with communication’

The experiences of using the alert card – what would you change?

A high number of respondents told us that they felt their cards would carry more weight if it was nationally recognised and had an NHS logo. NHS health care professionals are understandably cautious when it comes to trusting information on a medical alert from sources they have not heard of.

‘Make sure that there is the NHS logo clearly displayed as doctors are always wary of any instructions which may not be from a reliable source.’

‘There should be a nationally recognised alert card which all medics are legally obliged to take seriously. Even senior doctors can get it wrong... It will be a big help to ambulance crew too, especially as some of them are not trained paramedics.’

‘The only way that this well-meaning initiative on alert cards will be of use to the wider public is if they feature the NHS logo – plain and simple.’

Though it is possible for third party organisations such as national patient groups to use the NHS logo in some circumstances, they have to get permission from NHS England’s national communications team. In deciding whether to allow use of the NHS logo, NHS England considers criteria such as the appropriateness of the subject matter and whether the campaign supports the principles and values underpinning the NHS identity (NHS England, undated). An example of a patient group alert card using the NHS logo is in Figure 7.

Friendship information	I have a medical condition: ataxia
 First name: _____ Surname: _____ Ataxia UK Friendship Number: _____ Issue date: _____ To find out more about ataxia please visit nhs.uk/conditions/ataxia 	<p>Symptoms include slurred speech, as well as problems with balance and coordination making it look like I'm drunk. I'm not. I have ataxia.</p>  Ataxia UK. www.ataxia.org.uk 12 Broadbent Close, London, N6 5JW Helpline: 0845 644 0606 <small>Registered charity no. 1102391 (England) and SC040607 (Scotland)</small>

Figure 7 – Ataxia UK ‘I’m not drunk’ ID cards. Image courtesy of Ataxia UK.

The case studies below clearly show the value of a card which is taken seriously by health care professionals and that without an NHS card for rare disease patients are at best being caused stress and anxiety and, at worst their lives are being put at risk.

'I went to A&E at my local hospital because I was feeling faint and dizzy and had ear pain. I am a Cushing's patient and hydrocortisone dependent. As such I am at risk of life-threatening adrenal crisis.

I showed my alert card to the triage nurse, the junior doctor and the A&E consultant. None of them took any notice of it. I had to wait four hours to even see a doctor. I asked them to contact my endocrine consultant but they refused, stating it was not an emergency and it was a Sunday so it was out of hours.

When they finally did my cortisol levels, I knew the result to be far too low. Despite this they sent me home with no treatment, without checking if I had hydrocortisone at home, and with no advice. When I told my consultant he was very concerned and has now flagged my notes that he is to be contacted immediately if I am ever taken into hospital again. I later received an apology from the A&E consultant. My consultant later commented to me: "We were lucky this time, we got away with it."

My point is, people's lives should not have to depend on luck.'

Amanda – Cushing's patient

'A recent case study is both timely and apposite in this regard. Over the previous Bank Holiday weekend – Friday 1700 hrs to about 1500 hrs on the following Tuesday – I spent considerable time trying to assist a patient diagnosed with Behçet's by one of our national (NHS England) Behçet's Syndrome Centres of Excellence. The patient was admitted to hospital (referred by her GP) with severe inflammation in the mouth. No one in the hospital had any knowledge of Behçet's (at least they admitted it!) but instead of assuring the patient by saying something like "No I don't, but I will get in touch with someone who does ..." they compounded anxiety, basically making matters worse for the individual.

Stress is a well-acknowledged aspect that compounds a Behçet's flare. The patient had variously been prescribed 12 different drugs, most of which being concurrently taken, and appears to have been merely treated as a 'random patient' admitted with severe inflammation.

A 'formally recognised' alert card would have gone a long way to alleviate the lack of unawareness and whom to contact'

Tony – Behçet's UK

Alert wrist-bands were seen by some of our respondents as a useful complementary item to wear in addition to carrying an alert card. Alert cards were seen by some as items that one might not always carry whereas a silicone wrist-band with the person's name, date of birth, condition, would always be worn. As one response we had put it:

'The potential problem I was addressing was to ensure that, in the event of having a stroke (or, indeed, any accident which rendered me unconscious), medics would have some basic medical and contact information. So far – luckily – I've never been in a position where the band was needed. I think the NHS England plans are useful. But I think that something like a wrist band would be better than a card, to cater for those situations where I am not carrying a wallet – for example, when I'm in the gym.'

Survey respondent

Silicone wrist-bands typically will clearly state that it's a medical alert and the commercially available options will allow the purchaser to insert their own text. As in figure 6 the contained information would normally be name, allergies, contact details, and any medication the person may be taking

In our survey of health care professionals 70% of respondents said that, in an emergency, both an alert card and an alert wrist-band would be best rather than to have just one or the other.

Other feedback included:

- Cards are better printed and laminated or made of hard-wearing plastic
- A space for hand-written information on the card was an improvement some would have made with hindsight
- The card should cover all the conditions a person might have
- The card should include communication and access needs
- Some of our respondents would have wanted more information on their card but recognised that health care professionals in emergency situations need clear and succinct details

'The provision of a care co-ordinator and of alert cards for people living with a rare disease is long overdue. Whilst charities attempt to fill the crucial gap in NHS Provision with an alert card (I am certain that most charities would be happy to share pro-forma alert cards with the NHS), provision of an appropriately trained professional, a Band 8 Nurse for example, is absolutely critical for the NHS to ensure that unnecessary hospitalisations are avoided and the optimisations of medicines becomes a reality for these high cost patients.'

Liz – Trustee of UK Primary Immune-deficiency Patient Support and member of the Rare Disease UK Patient Empowerment Group

CONCLUSION

As the current UK Strategy for Rare Diseases' implementation period comes to its end, coordination of care remains a key priority for the rare disease community. Many patients still do not receive care at a specialist clinic or have access to a named care coordinator, and have no choice but to devote significant time and effort to managing their health and social care and support from other public services. Rare Disease UK will continue to press for improved coordination of care for all rare disease patients, including through a refreshed UK Strategy for Rare Diseases.

Alert cards are not a panacea, and will not solve all the problems of care coordination for UK rare disease patients. However, they have the potential to play a powerful role in addressing current issues with sharing of information to support the direct care of individuals with rare, genetic and undiagnosed conditions in the absence of a joined up and effective IT infrastructure that works across geographical and organisational boundaries.

NHS England's pledge in January 2018 to: 'give every patient with a rare disease an "alert card", including information about their condition, treatment regime and contact details for the individual expert involved in their care' is a welcome one, and Rare Disease UK supports the implementation of alert cards for rare disease patients.

As we have shown, alert cards can be highly effective, offering benefits to both patients and health care professionals, and can ultimately save lives.

The development and implementation of alert cards for rare disease patients must be designed and planned in collaboration with rare disease patients and patient organisations as well as clinicians, and should learn from existing examples both in the UK and internationally. There are also a number of questions that need to be answered, such as how alert cards will fit in with broader NHS digital strategy and how patients who are not under the care of a specific specialised service will be supported.

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