

INNOVATIVE CARER PRACTICES

IMPACTING CARERS* AROUND THE WORLD



CARER PASSPORT

Facilitating healthcare integration through 'carer-friendly' schemes



United Kingdom

Carers are often described as the backbone of healthcare systems. Although they are vital to the provision of health and social care, carers themselves are often invisible and vulnerable. Their commitment to caring for individuals with disabilities, chronic health issues or frailty can have a significant impact on carers' physical, emotional, social and financial well-being. **This Innovative Carer Practice showcases the use of Carer Passports, a systematic approach widely adopted across the United Kingdom to recognise, value and support carers.**

CONTEXT

A 2017 global carer survey released by Embracing Carers™ revealed that 28 per cent of unpaid caregivers feel their role as a carer is not recognised within their healthcare system, despite the critical role they play in the care recipient's health.¹ While carers are resilient and continuously adapt to their multiple roles, many feel alone and receive little guidance from formal health-care providers. As a result, carers often become hidden patients themselves because they neglect their own health needs.

Recognising carers and encouraging them to self-identify is a significant challenge for most health and social care systems. Research by Carers UK confirms that over half of carers (54 per cent) take over a year to recognise their caring role, almost one in four carers (24 per cent) take over 5 years and nearly one in ten (9 per cent) take over 10 years.² Feedback from carers suggests that healthcare professionals only identify 10 per cent of carers who they come in contact with.³ Lack of identification can result in missed opportunities to provide necessary carer supports and can exacerbate a potentially harmful situation.

The use of Carer Passports as a recognition and support strategy is an innovation championed by Carers UK, in conjunction with Carers Trust, through funding from the Government Department of Health and Social Care for England. The goal is to embed identification, recognition and support for carers into the fundamental practices of an organisation or community. Hospitals have been identified as an ideal place to begin the widespread application of Carer Passports, given this is often the place where an individual's caring journey either begins or increases in intensity. By facilitating the use of Carer Passport schemes in hospitals across the UK, the result will be a more 'carer friendly' health care system.

"Carer Passports ensure our patients and their carers have a seamless journey, from admission to discharge. It creates an identity which allows carers to be part of care."

—Deputy Director of Nursing, Lister Hospital

* A carer, caregiver or family carer is an unpaid individual, such as a family member, neighbour, friend or other significant individual, who takes on a caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness. The terms caregiver, family carer and carer are used interchangeably by IACO members.



Embracing Carers is an initiative led by Merck KGaA, Darmstadt, Germany, in collaboration with leading caregiver organisations around the world, to increase awareness and action about the often-overlooked needs of caregivers. Learn more at www.embracingcarers.com.



The International Alliance of Carer Organizations (IACO) is a global coalition of 15 member nations committed to building a global understanding and respect for the vital role of family carers. Recognised as an official NGO by the United Nations, IACO works to improve the quality of life and support the needs of carers, through international partnerships and advocacy. Learn more at www.internationalcarers.org.

DEVELOPMENT AND IMPLEMENTATION

Over the past several years, Carer Passports have been used as important tools in a select number of hospitals across the UK to identify and support carers. While individual schemes have produced good outcomes, it has been challenging to encourage hospitals to invest the time and resources required to adopt a Carer Passport scheme. Passports are a simple and effective way to align carer-friendly initiatives, and ensure that appropriate help is available and that carers receive a standard level of support throughout the hospital.

CREATING A CARER PASSPORT SCHEME AND RESOURCES

The creation and dissemination of resources and educational programmes to support Carer Passport schemes across the UK were achieved through three key milestones.

1. Alignment and integration of best practices, expertise and experience

- Determination of common features among existing passport schemes and identify of best practices.
- Consultation with carers, medical professionals and representatives from the Government Department of Health and Social Care for England to ensure resources would be genuinely useful for hospitals, meet carers' needs and compliant with patients' data confidentiality.

2. Development of a series of resources, (accessible at www.carerspassports.uk), to support application of the Carer Passport scheme within governance and context of each hospital site with recognition that one model does not fit all

- Creation of over 30 customisable templates (e.g. staff information, application forms) to address each hospital's preference and branding.
- Development of comprehensive guides to building and implementing a Carer Passport scheme, including case studies of hospitals with a successful scheme in place.
- Profiling passport benefit statements in a series of animations that can be easily shared and used to explain the concept.

3. Extensive programme of dissemination with professionals and carers

- Hosting webinars for professionals to learn about Passports, ask questions and hear from a hospital with a successful scheme in place.
- Using various communication channels and social media to promote the concept of a Carer Passport to the broader public.

DISSEMINATION AND IMPACT

Many hospitals are using Carer Passport schemes in a variety of ways and at their most effective, they are delivered as part of a broader strategy to create a carer-friendly hospital. Evidence shows that a Carer Passport scheme benefits carers, patients and hospital staff.

BENEFITS TO CARERS

- More carers are identified earlier and given the support needed to be able to care without negatively impacting their own health.
- An increased number of individuals recognise their role and self-identify as carers.
- Carers are more confident about what they can expect from hospital staff and informed about available support
- Carers feel valued and able to communicate the patient's need to hospital staff.
- Carers receive financial benefits from reduced costs of visiting the hospital (e.g. free car parking).

BENEFITS TO PATIENTS

- Care and health outcomes are improved through better co-ordination, understanding and communication between hospital staff and carers (e.g. reduced falls, improved nutrition and hydration, smoother hospital discharge).
- Patients' anxiety is eased when carers are involved and act as a buffer to the busy and often hectic hospital environment.

BENEFITS TO HOSPITAL STAFF

- Hospital staff are fully aware of hospital guidelines around carers, and can identify and engage family and friends who are caring.
- Hospital staff can access the expertise and knowledge of carers to inform patient-centred care.

The value of implementing a Carer Passport scheme nationally has been calculated using Social Return on Investment (SROI) methodology.⁴ This scheme has been found to save the equivalent of £3.6 million a year, including £239,000 in avoided health services costs. The financial savings are almost equally divided between the government (state) at £1.9 million and the individual at £1.7 million. Efforts to introduce more Carer Passport schemes in hospitals have been positively received. Since the launch in April 2018, there have been over 900 views of the Passport animation videos and 1500 downloads of the resources.

100% of carers and patients thought that staff were available to discuss care and treatment, compared to 35% before the trial

—Trial at Central Manchester University Hospital NHS Foundation Trust

Considerations for a Carer Passport scheme in a hospital

A Carer Passport is a basic tool that helps to identify and recognise a carer and provide a range of benefits and support uniquely targeted to carer needs. The aims and principles of the Carer Passport in various hospitals are similar, but the delivery mechanisms differ. Despite the variation, the essential elements of a Carer Passport scheme should include:

Easy Identification



The Carer Passport can be a card, badge or booklet that is easily recognised by hospital staff, identifies the passport holder as a carer and includes the name of the care recipient (patient). This enables carers to not only self-identify, but also to ensure hospital staff are aware of their role as a carer and to involve and consult them in the care and treatment of their family member or friend.



Practical Help



Passports should include practical offers and financially assist carers during their hospital experience (e.g. concessions on the cost of hospital car parking, discounts in the canteen, flexible or extended visiting hours). These are useful ways to show carers they are acknowledged and valued.

Coordinated Roll-out



Hospitals that choose to implement a scheme either on specific wards, or through a more standardised approach across all wards, need to support staff and embed the new approach. Coordinated information sessions help staff understand what carers are entitled to, how the Passport scheme works, why it is important to support and involve carers, and the benefits to staff and patients. Including volunteers in the information sessions supports wide-spread understanding of the Passport scheme.

Clear Expectations



A Carer Passport should explain what the carer can expect from hospital staff (and what form this will take). This may include statements that articulate how carers will be involved and consulted in decisions about the patient's care and treatment. A lead staff member should be designated to support carers on the ward or throughout the hospital. The contact details of the designated staff member should be added to the Carer Passport. When a carer applies for the Carer Passport, a signed statement should clearly lay out their scope of involvement in patient care and health information privacy considerations.

Connect Health and Social Care



Leaflets or other documents provided alongside the Passport should contain contact information for social services and other brief important information on carers' rights and support, as well as details of organisations that can provide further advice or information (e.g. local carers' support services and relevant helpline) during the hospital stay and upon discharge.

ELEMENTS FOR SUCCESS

The following elements contribute to the successful implementation and use of Carer Passport schemes in a hospital setting:

- **Clarity** about who can access the Carer Passport (i.e. what defines a carer), the purpose and what it entitles the carer to.
- **Consistency** in the use of Passports within and across departments, including record keeping, monitoring, measuring outcomes and evaluating the impact of the initiative.
- **Insight** from professionals and carers when planning, implementing and evaluating the initiative.
- **Engagement** from designated hospital staff to provide carers with face-to-face, knowledgeable and effective support.
- **Inclusivity** of a whole family approach when identifying carers, recognising that children and young people may also undertake caring responsibilities.
- **Awareness** through hospital-wide communications, and training, to ensure that all staff are aware of the Carer Passport scheme, understand the purpose and value, and know how to use them.
- **Leadership** from senior leadership to ensure a whole-system approach to championing the initiative from ward to board level.
- **Widespread implementation** including carers' support from community health service providers (e.g. primary care, emergency services, pharmacies, private care providers).

Nationally, Carer Passport schemes have resulted in a savings of £3.6 million a year, including £239,000 in avoided health services costs.

References:

1. Embracing Carers™. 2017. Global Carer Survey.
2. Carers UK. 2016. Missing Out: The identification challenge.
3. Carers UK. 2013. Carers Week Prepared to Care? Exploring the impact of caring on people's lives.
4. The SROI Network. 2012. A Guide to Social Return on Investment. Available at: <http://www.socialvalueuk.org/app/uploads/2016/03/The%20Guide%20to%20Social%20Return%20on%20Investment%202015.pdf>

FUTURE OPPORTUNITIES

While the most extensive use of Carer Passports is currently in hospitals, they can be used in many other contexts. In particular, Carer Passports are gaining traction in employment settings as an easy way to identify working carers, document their unique needs and effectively support their work-life balance. Passports help create a supportive working culture where staff are recognised and open communication encourages managers to respond to working carers, needs and apply policies more consistently across the organisation. Adoption is increasing across the UK in employment settings, meaning that more of the millions of working carers are supported to balance their work and caring responsibilities. More information about this context is available at www.carerspassports.uk/employment

Carer Passports can also be used in community care, long-term care, educational institutions and mental health trusts. Carers UK has developed a series of application resources to support the use of Passports in these settings.

- Community based carer organisations use Carer Passports to identify carers and provide discounts in shops and with local businesses alongside information and advice to support their caring role.
- Educational institutions use Carer Passports for students who need adjustments to their schedule or classes to balance their studies and caring role.
- Mental health trusts use Carer Passports to identify carers and reduce the number of times a carer must re-tell their story to health care staff.

While each caregiving experience is unique, all carers need recognition, understanding and support from health and social care providers. Carer Passports are an innovative and effective way of shedding light on the unique role of carers and building carer-friendly communities that can positively impact the health and well-being of carers, improve patients' health outcomes and contribute to effective and sustainable health and social care for all.

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As the UK's only national membership charity for carers, Carers UK is both a supportive community and a movement for change. In the last year alone, over 2 million unique visitors viewed help and advice content on Carers UK's website. For the past 50 years the organisation has been driven by carers raising their voices together to call for change and seek recognition and support. Carers UK was a founding member of the International Alliance of Carer Organisations and continues to work alongside carer organisations across the world to make life better for carers. For more information on the programme, contact:

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