

PAS 278:2015

Principles for the provision of information and advice to individuals to support independent living – Code of practice

Future

A man and a woman are sitting on a dark wooden bench with light-colored cushions. They are seen from behind, looking towards a large white wall. On the wall, the word 'Future' is written in large, bold, black letters. The man is wearing a light blue and white striped shirt and blue jeans. The woman is wearing an orange top and a silver belt. To the right of the bench, there are two shopping bags, one blue and one white. The floor is a light grey, and a white pillar is visible on the right side of the frame.

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Foreword

This PAS was sponsored by Innovate UK. Its development was facilitated by BSI Standards Limited and it was published under licence from The British Standards Institution. It came into effect on 30 April 2015.

Acknowledgement is given to the following organizations that were involved in the development of this PAS as members of the steering group:

- Age UK
- Consumer Empowerment Alliance
- Innovate UK
- Institute of Financial Planning
- Longhurst Group
- NHS Choices
- Office of the Public Guardian
- Patient Information Forum (PIF)
- Public Health England
- Society of Later Life Advisers (SOLLA)
- Tunstall

Acknowledgement is also given to the members of a wider review panel who were consulted in the development of this PAS.

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This PAS is not to be regarded as a British Standard. It will be withdrawn from publication of its content in, or as, a British Standard.

The PAS process enables a code of practice to be rapidly developed in order to fulfil an immediate need in industry. A PAS can be considered for further development as a British Standard, or constitute part of the UK input into the development of a European or International Standard.

Use of this document

As a code of practice, this PAS takes the form of recommendations and guidance. It should not be quoted as

if it were a specification and particular care should be taken to ensure that claims of compliance are not misleading.

Any user claiming compliance with this PAS is expected to be able to justify any course of action that deviates from its recommendations.

Presentational conventions

The provisions of this PAS are presented in roman (i.e. upright) type. Its recommendations are expressed in sentences in which the principal auxiliary verb is “should”.

Commentary, explanation and general informative material is presented in italic type, and does not constitute a normative element.

The word “should” is used to express recommendations of this standard. The word “may” is used in the text to express permissibility, e.g. as an alternative to the primary recommendation of the clause. The word “can” is used to express possibility, e.g. a consequence of an action or an event.

Notes are provided throughout the text of this standard. Notes give references and additional information that are important but do not form part of the recommendations.

Contractual and legal considerations

This publication does not purport to include all the necessary provisions of a contract. Users are responsible for its correct application.

Compliance with a PAS cannot confer immunity from legal obligations.

Particular attention is drawn to the following specific regulations:

- Care Act 2014 [1];
- Data Protection Act 1998 [2];
- Mental Capacity Act 2005 [3];
- Privacy and Electronic Communications Regulations 2003 [4].

Innovate UK statement

Innovate UK – the new name for the Technology Strategy Board – is the UK’s innovation agency. We fund, support and connect innovative businesses to accelerate sustainable economic growth.

Timely, consensus-based use of standards plays a vital role in ensuring that the knowledge created in the UK’s research base is commercialized and brought to market as well as playing an important role in driving innovation.

Innovate UK is working with BSI, the Research Councils and Catapults to establish new standards earlier in the development of technologies. We are collaborating in four areas of innovation to define standards that will accelerate the development of those technologies and services to provide UK businesses with a competitive “first mover advantage”, including the subject of this document; assisted living.

The demand for support of those with long term health conditions is set to grow rapidly over the next 15 years and beyond. If the NHS and other UK organizations are to continue to offer high standards of health and care services, they will need to embrace more technology enabled products, services and systems to provide more home-based care and self-care.

Innovate UK’s Long Term Care Revolution work is aimed at changing conventional thinking about the institutional approach to long term care and stimulating disruptive innovation. If there is to be a significant move away from institutionalized care, this disruptive innovation will need to be supported by a range of standards and set out the principles for provision in the new environment, help to manage the risks involved, and provide clarity and consistency for consumers.

Through the Independent Living Innovation Platform, Innovate UK is delivering a wide-ranging programme to enable the ageing population and those with long term health conditions to live with greater independence.

In 2012 the Independent Living Innovation Platform launched Dallas (delivering assisted living ‘lifelines’ at scale), a large scale demonstrator of independent living products and services, joint funded by the National Institute for Health Research and the Scottish Government. Read more here:

<https://connect.innovateuk.org/web/dallas>

More widely, health and care is a key priority area in our work – with major innovation programmes to stimulate the development of new technologies, products and services. Building on the UK’s world-class science and technology base and its global presence in the biopharmaceutical and health technology sectors.

Read more about Innovate UK and our plans in health, care and other areas here:

www.innovateuk.gov.uk or contact

support@innovateuk.gov.uk

Introduction

There are more than 17 million UK adults living with long term conditions.¹⁾ These are health issues which cannot be cured, but can be controlled by medicines and other therapies. Long term conditions can affect many parts of an individual's life, including work, relationships, housing and education, and may require ongoing care and support.

Illness and disability can affect anyone of any age but long term conditions become more prevalent with age. As people grow older their health is more likely to be affected by one or more long term conditions, such as dementia or arthritis, reduced mobility or sensory impairment.

The older population of the UK is increasing rapidly. There are currently 10 million people, aged 65 years or over. This is predicted to rise to over 15 million in 20 years and around 19 million by 2050.²⁾

Many people continue to be active and independent into their later years. But it is likely that the growing older population may put increased pressure on health care and support services. As the UK population profile changes it is also likely that individuals may need to take more responsibility for planning for their future needs, relying on third party information and advice services to help them make choices about their later years and maximize opportunities for independent living. Policy makers and service providers need to have plans in place to deal with this demographic shift.

It is vital that individuals are able to trust the information and advice that they are given, and that it is accessible, easily understood, accurate, relevant and of a consistently good quality.

PAS 278 contains recommendations for good practice and is intended to:

- raise standards in the quality of advice and information provided;
- empower individuals to take control of their personal journey;
- encourage proactive forward planning; and
- ensure that individuals are given the necessary information, advice and support to make informed choices about independent living and possible future care needs.

¹⁾ Further information on these statistics is available from: www.gov.uk (15 million in England) and www.scotland.gov.uk (2 million in Scotland).

²⁾ For further information see the *House of Commons Briefing Paper: The Ageing Population* [5].

1 Scope

This PAS gives recommendations for the provision of information and advice to enable individuals to make informed choices about long term care and support needs, and maximize opportunities for independent living.

The PAS is applicable to any person or organization in the UK that provides information or advice about financial matters, health and wellbeing, care or housing to individuals planning for independent living, their families or carers.

2 Terms and definitions

For the purposes of this PAS, the following terms and definitions apply.

2.1 accessibility

usability and availability of a product, service, environment or facility by people with the widest range of capabilities

NOTE The concept of accessibility addresses the full range of user capabilities and is not limited to users who are formally recognized as having a disability.

2.2 accessible format

method of presenting information about products and services that makes them usable by the widest possible range of people, regardless of their different needs and abilities

2.3 advice

guidance and recommendations to help service users (2.18) make choices that are best for themselves (or the individual that they are representing) in regard to care and support options

NOTE For example, by giving information that is relevant to the individual's situation, explaining options and benefits and identifying further action that may be taken.

2.4 adviser

member of staff (2.20) that interacts with service users (2.18) to deliver information and advice

2.5 advocacy

organization speaking or acting on behalf of an individual, with their consent, to achieve a specific outcome

NOTE This may involve providing practical help, such as contacting organizations and filling in forms.