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University of Worcester
Association for Dementia Studies

assura

Designing for Everyone

Guide for cognitively inclusive design in primary care environments

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This guide and assessment tools were commissioned by Assura plc in recognition that increasing numbers of patients living with cognitive impairment, including dementia and neurodiversity, are accessing primary care centres. This initiative forms part of Assura's commitment to designing and building premises that welcome and support patients, and those that accompany them, to experience the best quality primary care in the best possible settings.

Nothing in the guide or checklist supersedes organisational, statutory or regulatory requirements including building regulations, health and safety or control of infection standards.

Foreword

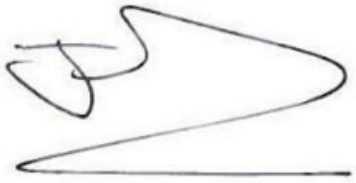
We want our healthcare buildings to improve the experience of everyone who visits them, and the working day for those who work in them. Designing for Everyone has brought together our work with the Patients Association and the Dimensions #MyGPandMe campaign to delve much deeper into individual experiences of primary care environments. We wanted to explore how the experiences of primary care places and spaces can impact on our perceptions of care and our willingness to engage with local health services.

GP surgery and primary care premises are the gateway to wider NHS services, and are the locations where most patient contact in the NHS takes place. However, these buildings are often far from ideal, particularly for our ageing and increasingly diverse population, as well as the staff who care for them.

Designing for Everyone has confirmed the critical importance of the physical environment for the patient experience and the delivery of high quality primary care services. As a company we have already recognised the importance of environmental design through our ground breaking dementia-friendly health centre at Cinderford in Gloucestershire. But we want to do more, to create buildings which offer both space and privacy in waiting areas, accessible buildings for people with disabilities and limited mobility and to counteract the impact of poor environments on patients' feelings of stress and anxiety. Guided by experts from the University of Worcester and the recommendations from the Patients Association and Dimensions reports, we have created an evidence-based guide and two assessment tools. Together, they will enable us to understand across our estate where improvements - be they quick wins or longer term refurbishments - are needed, and will inform the design of our new buildings. Designing for Everyone will become an essential and unique part of the development of our future business, but I hope these tools will also be useful to anyone seeking to improve or create new space for primary care services.

Our ambition to create Designing for Everyone started well before the Covid-19 pandemic but this has only increased our determination to make our buildings – both new and existing – reach their full potential for all patients and to support the NHS's continuing evolution of primary care services. In fact, it means that the focus on patient experience when accessing primary care in-person, is greater than ever before.

The way we design and improve public spaces is among the many factors which can help to reduce inequalities in access to health services and support. Physical infrastructure must play its part in public health's journey beyond COVID, and the principles in this guide and tools are an important place to start.



Jonathan Murphy, Chief Executive, Assura

Introduction

Designing for Everyone brings together current research, evaluation and best practice in design for cognitive impairment and neurodiversity together with reports commissioned by Assura from the Patients Association and Dimensions which focus on the patient experience of health centre buildings.

The tools and guide have been developed jointly by Association for Dementia Studies, University of Worcester and Assura plc and have been designed for use in any primary care, medical or health centre building or GP premises where primary health care services are delivered.

The vast majority of contacts with the health service take place in primary care but a visit to see a GP, nurse or other clinical staff can be a worrying time for any patient or family carer. Primary care centres therefore need to be designed to be welcoming, calm and comfortable, and to promote links to nature and the natural environment. They should also promote patients' independence, enhance their privacy and dignity and provide them with choice and control in a safe and secure environment.

This guide and the accompanying assessment tools have been developed with the Assura team as part of its work to create buildings which support the Designing for Everyone ethos. The full assessment tool will inform new builds or major refurbishments, and the shorter summary version has been developed for use by Assura's teams with local primary care staff and patients to assess the physical environment of our buildings as part of routine visits and inspections. Both tools draw on the same evidence base and focus on the key design features that are known to be important to people with cognitive impairments and neurodiversity, and the spaces that they would expect to visit while seeing a GP or other health care staff in primary care. They have been designed not to be prescriptive, but to allow for local variation and any particular circumstances that

may affect health care delivery. Each element is accompanied by a rationale explaining why it is important, a checklist so that progress can be measured and a scoring system so that improvements can be tracked over time.

Assura hopes and expects that this process of assessment will be key to the start of important conversations and the improvement of understanding of the needs of people with cognitive impairment and neurodiversity within the built environment and particularly within its primary care centres as the company strives to be more inclusive and supportive of patients' mental and physical wellbeing. Assura intends to evaluate the outcomes of the implementation of Designing for Everyone as it continues to support the development of a strong evidence base for inclusive design in primary care.

Together Dimensions, Assura and the University of Worcester are making the guide and tools available as open-source points of reference for any primary care team or any supplier designing for primary care environments.

"Primary care centres... need to be designed to be welcoming, calm and comfortable..."

Why Designing for Everyone is important

Many people who visit primary care buildings are living with cognitive impairment or neurodiverse conditions such as acquired brain injury, stroke, dementias, learning disabilities, autism spectrum disorders, mental health conditions and other types of impairment which affect sensory and cognitive processing. People may also be living with multiple co-morbidities.

Research has demonstrated that the sensory elements of a building play a highly significant role in enabling people to feel comfortable and relaxed, particularly when they are anxious. The human brain is complex and its function relies heavily on optimal interconnectivity between different brain regions to maximise cognitive efficiency. People with cognitive impairment or neurodiversity may have sensory processing differences and information from the senses hearing, sight, smell, touch, taste, bodily movement and position can be interpreted differently. Each person will have a different experience of their cognitive impairment or neurodiversity, for example they may be highly sensitive to physical stimuli (hypersensitivity) or have a decreased sensitivity (hyposensitivity) to noise, smell, colour or light. The degree of sensitivity can be different for each individual and each sense: for example, a person can be hypersensitive to noise but hyposensitive to smell.

Navigation and fine motor skills can be impaired in people with cognitive impairment and neurodiversity. Although the terms proprioception and kinaesthesia are often used interchangeably, they are two distinct systems which together give a simultaneous experience, proprioception referring to the sense of self movement and kinaesthesia to the body's ability to understand how to move within that space. As a result, people with cognitive impairments or neurodiversity may have difficulties with body awareness, position sense and balance, are likely to have larger personal boundary requirements, and may also require enhanced space for mobility aids. This may mean that they can unconsciously bump into furniture or people or exhibit unusual body movements. These difficulties can be exacerbated in an unfamiliar and cluttered environment where touching something or somebody may offer reassurance or can be misinterpreted and lead to a negative reaction.

The following section gives some background information to the more common forms of cognitive impairment and neurodiversity that have been researched to inform the development of Designing for Everyone.

Dementia

Although dementia is not a natural part of ageing, the risk of developing dementia increases with age. It is estimated that there are around 900,000 people living with dementia in the UK with an additional 670,000 people acting as their primary carer. Dementia is a syndrome in which there is deterioration in cognitive function beyond what might be expected from normal ageing. Dementia may affect memory, thinking, comprehension, learning capacity, language, judgement, visual perception, orientation to time and space, mobility and fine motor skills, and the recognition of objects. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

Dementia is caused by a variety of diseases and injuries that primarily or secondarily affect the brain and there are estimated to be over 200 types of dementia. Alzheimer's disease, the most common form of dementia, has a gradual progression and can begin with symptoms such as becoming confused, word finding problems, changes in mood, and behavioural changes. People with Alzheimer's disease often feel restless and agitated and feel the need to walk. The second most common form of dementia is vascular dementia which has a staged progression. It is caused by cerebral blood flow disruptions usually caused by strokes, heart deficiencies or head trauma. Common symptoms include loss of memory, emotional outbursts, incontinence, visual disturbance, hallucinations and psychological problems. Each type of dementia will affect people differently, for example mobility is a particular issue for people

with Parkinson's Disease Dementia and dementia with Lewy bodies. These two types of dementia are closely related and share many of the same symptoms which may include difficulty in planning, spatial disorientation, trembling limbs, hallucinations and falls.

Learning disabilities

A learning disability is a lifelong condition that starts before adulthood and means that individuals have a significantly reduced ability to understand complex information or learn new skills. People with learning disabilities have a reduced ability to cope independently, impaired social functioning and experience difficulties in communicating and expressing themselves. Many people with a learning disability have greater health needs than the general population. For example, they are more likely to experience mental ill health and are more prone to chronic health problems, epilepsy, physical and sensory disabilities. In 2015 it was estimated that 2.16 % of the adult population of England had a learning disability. People with learning disabilities are four times more likely than the general population to develop dementia. Almost a third of people with learning disabilities or autism feel less likely to be treated with care and concern at the doctors and people with learning disabilities are five times more likely to end up in hospital for preventable issues that can be treated by their GP.

Autism and autism spectrum disorder

Autism is a lifelong developmental condition present at birth, which is linked to how a person understands and communicates with the world around them, particularly how they communicate and relate to other

people through sensory experiences. This means people can have difficulty with: social communication, interpreting language both with and without words, social interaction and understanding social rules, social imagination predicting, recognising or understanding the attitudes or beliefs of others, processing sensory information. A person may interpret their body's signals differently.

Everyone experiences autism differently and no two people are the same. They are the expert in their own experiences and what reasonable adjustments can be made to maximise their engagement with education, work, and citizenship in general.

The term autism represents a broad spectrum reference that includes a number of historical terms (including Autistic Spectrum Disorder, Asperger's Syndrome, and Pervasive Developmental Disorders) relating to key neurological features believed to become evident by the age of three years. A diagnosis of autism does not suggest the presence of a learning disability; however, approximately 20 %-30 % of people diagnosed as autistic also have a learning disability. Previous estimates (2015) of the prevalence of autism suggest approximately 1 % of the general population was identified as autistic comprising 2 % of males and 0.3 % of females; however, it is widely accepted that this is a gross under-estimation and particularly the figure for females.

One significant feature is that autistic people are more likely to experience problems with their mental health than those who are not autistic.

Autistic people are individual and it is important to understand how any particular interests or behaviours impact on their lives and access. As noted, the continuum of the autism spectrum includes people with, and without notable developmental delay in language, cognitive functioning or developing self-help skills, adaptive behaviour, and curiosity about the environment.

Neurodiversity

Neurodiversity is a term that is being used more frequently to describe a wide cluster of people with different presentations linked to neurological origins (for example Attention Deficit Hyperactivity Disorder, Dyspraxia, Dyslexia, Dyscalculia) that differs from that of a 'neurotypical' individual. This may have specific impact in relation to particular motor, mathematical or written skills and it may also have a more generalised impact relating to social interaction, attention and responses to other people. The term describes individuals rather than a specific condition.

It is estimated that up to 20 % of the population is neurodivergent. This has resulted in a growing and dynamic neurodiversity movement that emphases the exceptional abilities that neurodiverse people may have and argues that these are better described as neurological differences rather than disabilities. The overarching concept of neurodiversity may therefore have the potential to bridge the gap between designing for separate conditions that are associated with cognitive impairment and neurodiversity, and designing for everyone.

How we developed these environmental assessment tools

Designing for Everyone has taken a developmental approach to improving health centre designing for those with cognitive impairment and neurodiversity and the patient population more generally.

This means that the tools have been developed to inform new builds, major refurbishments and for routine assessment and development rather than for audit purposes. This is an important principle as it enables Assura to assess its current health centre environments, to prioritise areas for improvements and to measure those improvements over time. Collectively, information from the assessments will also inform the ongoing programme of refurbishments and the designing of future health centres.

The literature, policy and practice reviews undertaken by the University of Worcester to inform the development of the assessment tools identified significant commonality in the design of features that could improve the experience of those living with dementia, autistic spectrum disorder and other neurodiverse conditions. It has to be recognised, however, that research on good design for neurodiversity is in its infancy and the work in relation to design for autism has mostly focused on school environments for young people.

Nevertheless, it has been possible to identify a range of design features that are important to all those with cognitive impairment and neurodiversity particularly but not exclusively around the sensory elements of design. It is however critical to acknowledge that each individual with a cognitive impairment and neurodiversity may respond to these design elements differently as, for example, they may be highly sensitive to physical or emotional stimuli (hypersensitive) or conversely under-responsive (hyposensitive) to noise, smell, touch or light. In designing health centres care therefore needs to be taken to recognise and ensure a pragmatic response to these areas of divergence.

The development of the tools has been greatly enhanced by reports from the Patients Association and Dimensions which have provided invaluable insights into the design issues that are particularly important to patients, including those with physical and mental disabilities, and those relatives or friends that accompany them to appointments. The reports highlighted the importance of the general ambience of the centre and specific issues such as the management of odours and the provision of accessible toilets.

The key elements of cognitively inclusive design

There is considerable agreement and a growing body of evidence that appropriate design of the environment can promote inclusion, independence and quality of life for people living with dementia.

Although the evidence base for other cognitive impairments and neurodiversity is not yet as extensive, it has been possible to identify - with appropriate modifications - the elements of good design for this group, as well as for those living with dementia that also apply to the general population, as evidenced by the Patients Association and Dimensions reports.

These are:

- the critical importance of the general ambience and cleanliness of primary care premises to the wellbeing of patients and to the delivery of person centred, high quality primary care services
- the key role that design should play in enhancing a person's privacy and dignity, independence, choice and control
- the importance of recognising differences in the sensory experience of those living with cognitive challenges and neurodiversity
- the adaptability of spaces to meet individual needs and circumstances
- the importance in relation to the built environment of:
  - approach and access to buildings
  - spatial sequencing and transition zones
  - design of reception areas and waiting spaces
  - provision of alternative spaces
  - toilet provision for the disabled
  - decoration, furnishings and signage

The key elements of cognitively inclusive design have been identified as safety, the sensory environment, building design, interiors and outdoor spaces which provide an environment that promotes accessibility and support, care and comfort, independence and privacy, safety and security. These principles apply both to the external and internal environment.

Although it is not possible to adapt the health centre environment for each individual patient, the design should offer as much flexibility as possible so as to be inclusive and to meet the needs of those with cognitive impairment, neurodiversity and physical or other disabilities.

"...the design should offer as much flexibility as possible so as to be inclusive..."

Introduction to the assessment tools

The environmental assessment tools have been developed in partnership with a Reference Group drawn from Assura's portfolio managers and other staff and representatives of external organisations including the Patients Association, Dimensions and Dementia UK. It has been based on the format of the very successful The King's Fund's Enhancing the Healing Environment assessment tools which have enabled and supported significant changes in the understanding of the critical importance of the environment of care for the wellbeing of people living with dementia. The tool has been tested in situ with one of Assura's recent developments; wider testing in primary care has not yet been possible due to the constraints and pressures of the pandemic for general practice through 2020 and 2021, but the tools will continue to evolve with feedback from operational use.

Both the full assessment tool and the summary tool focus on those aspects of the physical environment known to impact on people living with cognitive impairment and neurodiversity. They have been developed to be as flexible as possible to take account of the varied nature of primary care premises, and not all questions necessarily apply to every building. The rationale for each element explains why the particular element is important, and working through these may help to identify potential staff training needs to ensure a common understanding of the importance of the physical environment in providing high quality patient care.

The full assessment tool contains four sections:

- First impressions
- Core design features which apply across the health centre
- Specific design features which apply to particular areas
- Additional considerations during a pandemic

The summary tool contains two sections:

- Core design features which apply across the health centre
- Specific design features which apply to particular areas

The summary tool follows a similar format as the full assessment tool but in a shorter form.

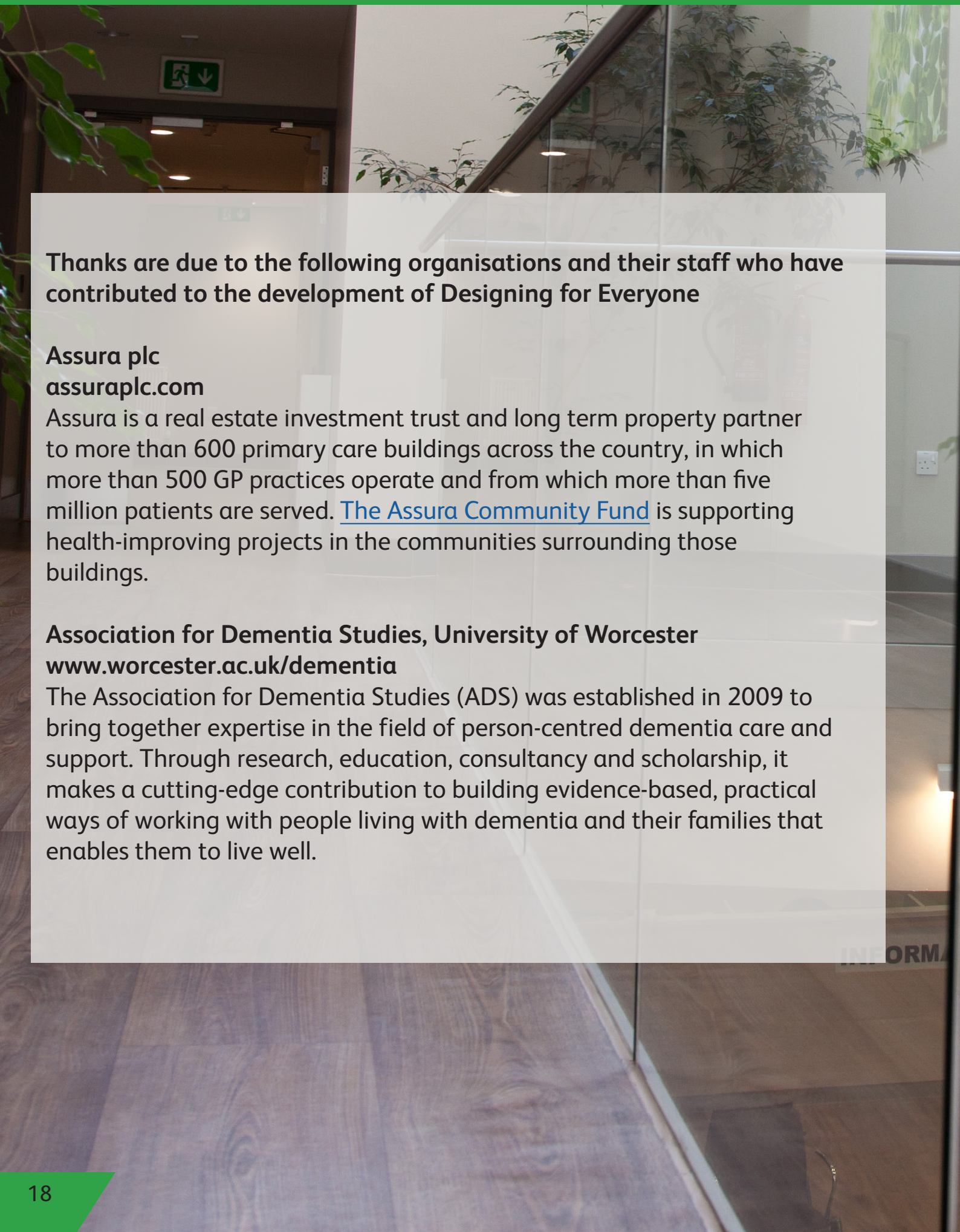
The assessment can be undertaken by an individual but ideally it should be used with others including patients, practice managers or maintenance staff as this can offer opportunities for different perspectives and prompt constructive discussion about improvements.

Each section contains a number of questions which should each be scored 1-5 where 1=barely met and 5=totally met, together with a rationale for effecting change in primary care settings for people with cognitive impairments and neurodiversity which recognises that many people will also have co-morbidities and sensory impairments. A comments section has been provided for each section so that any issues that have arisen during the assessment can be noted e.g., if it was not possible to score a particular question. A score summary sheet can be found at the end of the tools.

The assessment should be undertaken during normal working conditions and all relevant permissions should be obtained before it is undertaken. Photographs can provide a very helpful record provided all relevant permissions are in place in line with patient confidentiality requirements and organisational policies.

Where you need further information or clarification, please refer to the full assessment tool and to this guide. The pandemic section from the full assessment tool should be used when appropriate.

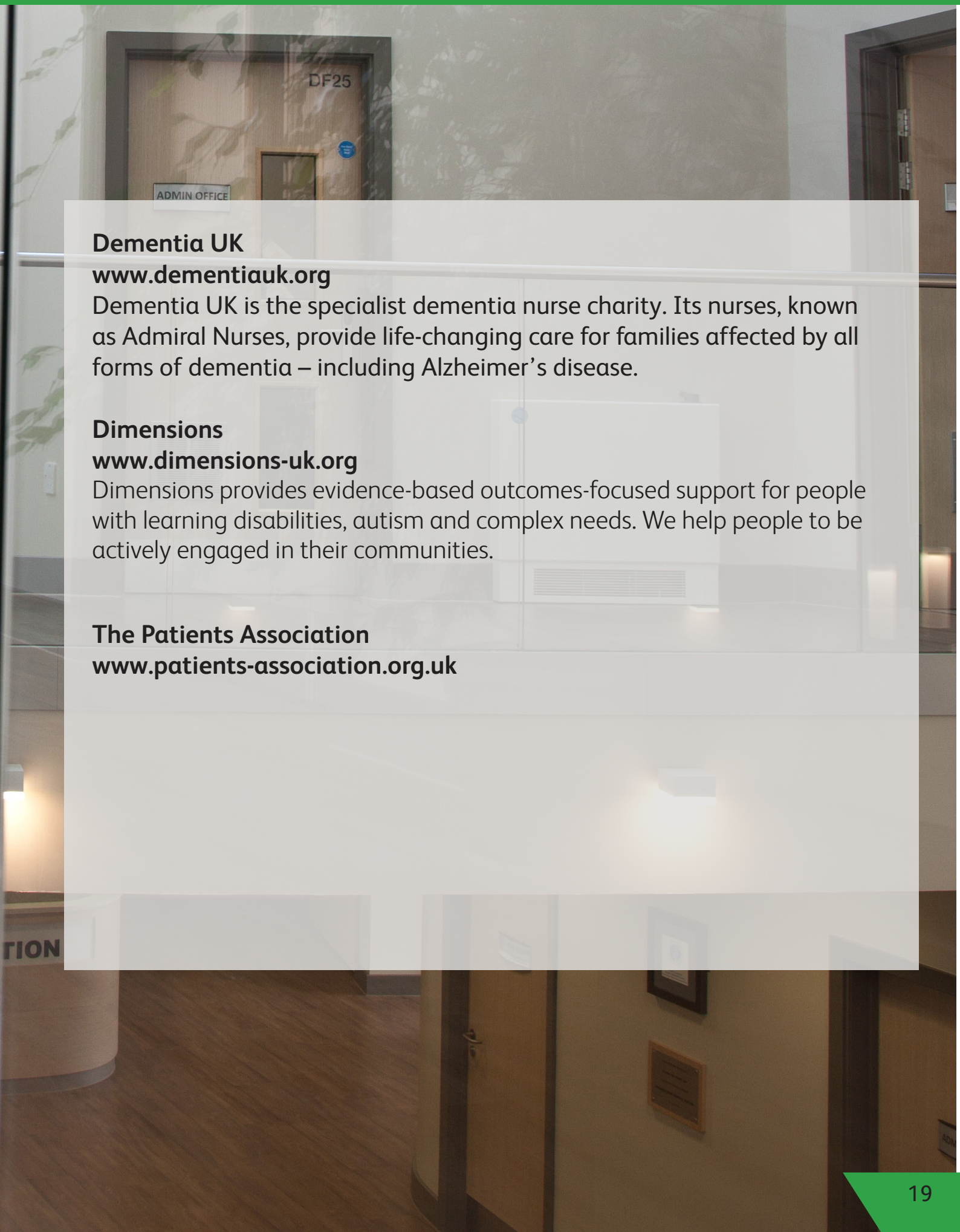
Acknowledgements



Thanks are due to the following organisations and their staff who have contributed to the development of Designing for Everyone

Assura plc
assuraplc.com
Assura is a real estate investment trust and long term property partner to more than 600 primary care buildings across the country, in which more than 500 GP practices operate and from which more than five million patients are served. The Assura Community Fund is supporting health-improving projects in the communities surrounding those buildings.

Association for Dementia Studies, University of Worcester
www.worcester.ac.uk/dementia
The Association for Dementia Studies (ADS) was established in 2009 to bring together expertise in the field of person-centred dementia care and support. Through research, education, consultancy and scholarship, it makes a cutting-edge contribution to building evidence-based, practical ways of working with people living with dementia and their families that enables them to live well.



Dementia UK
www.dementiauk.org
Dementia UK is the specialist dementia nurse charity. Its nurses, known as Admiral Nurses, provide life-changing care for families affected by all forms of dementia – including Alzheimer's disease.

Dimensions
www.dimensions-uk.org
Dimensions provides evidence-based outcomes-focused support for people with learning disabilities, autism and complex needs. We help people to be actively engaged in their communities.

The Patients Association
www.patients-association.org.uk

This guide is to accompany the full and summary environmental assessment tools.
Find them at:
www.dimensions-uk.org/designing-for-everyone

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