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Visual identifiers in the care of people with dementia

An ethical and legal analysis

Authors

Tanya Brigden, Colin Mitchell, Johan Ordish and Alison Hall

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intelligence@phgfoundation.org

A PHG Foundation report for the Developing a visual identification method for people with cognitive impairment in institutional settings (DA VINCI) Research Project and The Health Improvement Studies (THIS) Institute DA VINCI Activity 1b:

“What ethical and legal issues might affect visual identification-based interventions to assist in the care of people with cognitive impairment in hospitals”

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Disclaimer

The following is intended to provide general information and understanding of the law. It should not be considered legal advice, nor used as a substitute for seeking qualified legal advice.

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Introduction

Dementia is a syndrome—usually of a chronic or progressive nature—in which there is deterioration in cognitive function beyond what might be expected from normal ageing. It results from a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke, and can affect memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement.¹

Rates of dementia are increasing, in part due to an aging population, and it is becoming increasingly common for patients with dementia to be admitted to acute care settings for treatment of other, frequently unrelated conditions. The increasing multimorbidity of patients poses challenges for developing optimal care.

Project rationale and scope

Visual identifiers for dementia are an example of a tool which has been developed to address this challenge. These tools are used frequently within hospitals in order to indicate to staff that the patients to whom they refer have dementia (or in some instances cognitive impairment). The vast majority of hospitals have introduced a visual identifier, but these are enforced inconsistently, and a lack of national guidance means that systems are variable and have not been subject to a process of formal evaluation. The DA VINCI project aims to inform, design, evaluate and (if appropriate) roll out a system of visual identification for individuals with suspected or diagnosed dementia in the acute care setting. The project comprises a number of phases and activities. A brief overview of these is given below.

■ Phase 1

- Activity 1a—citizen science-based curation of current practice
- Activity 1b—ethico-legal analysis (conducted by PHG Foundation in this report)
- Activity 1c—a collaborative study to examine current experiences of using visual identification systems in acute hospital settings in seeking to provide high quality care to people with cognitive impairment

■ Phase 2

- Activity 2a—co-designing a system
- Activity 2b—gaining wider perspectives through citizen science

■ Phases 3 and 4 focus on piloting, trialling and evaluating a visual identification system. These are dependent upon the findings from Phases 1 and 2.

Although visual identifiers are sometimes used to indicate other causes of cognitive impairment, such as delirium, and can be implemented in a range of settings (such as care homes and emergency departments), these lie outside the scope of this project.

Aims and objectives

The aim of this report—Activity 1b—is to provide a comprehensive analysis of the key ethical and legal/regulatory issues arising from the current and potential use of visual identifiers, in order to inform future phases of this project.

Specific objectives are to:

- Conduct a broad and comprehensive review of relevant ethical and legal literatures, and the policy landscape surrounding the use of visual identifiers.
- Conduct an ethical analysis, exploring key philosophical and ethical concepts and frameworks pertinent to dementia care and identifying the challenges that visual identifiers might raise.
- Conduct a legal/regulatory analysis, considering the visual identification system for acute care dementia patients in its legal context, noting significant legal consequences, and how the system might be developed to be consistent with established legal principles, law, and regulation.
- Distil the findings from the legal and ethical analyses into a set of key principles, which will consequently inform the approach taken to developing the visual identification system in piloting in Phase 2 and implementing it in Phase 3.

Methodology

The methodology employed to inform this report includes desk based research using peer reviewed literature, grey literature and official publications, and a workshop gathering feedback on our initial findings from the Expert Collaborative Group (a group of experts convened by THIS Institute to offer support and guidance throughout the entire project).

As the legal and ethical analyses were carried out concurrently, and a workshop was held to review the principles, each aspect of the research has its own discrete methodology. More detail of these is provided within each chapter.

Chapter 1: Policy landscape

People with dementia constitute an increasing proportion of the in-patient population. With estimates ranging from 25%² to up to 50%³ of acute beds being occupied by people with dementia, claims that the care needs of this population of patients are not being fully recognised should be prioritised and strategies urgently need to be addressed.

One key concern is that people with dementia may have difficulties in communicating their needs and wishes, require assistance with nutrition and other basic activities, and may walk about (often referred to as 'wandering'). Additionally, hospital admission for a person living with dementia can render them particularly vulnerable due to the unfamiliar people and surroundings and changes to their routine. Evidence shows that for a person living with dementia, an acute hospital admission is closely associated with increased confusion and disorientation,⁴ significant functional decline,⁵ and a markedly higher risk of short term mortality.⁶

Yet it may not be straightforward for staff to determine which patients require particular care, attention and support as a result of suspected or diagnosed dementia. Visual identifiers were introduced into UK hospitals to support staff in recognising and directing attention towards the needs of those living with dementia. The term 'visual identifier' has not been formally defined, but in this context refers to the use of a symbol, identifier or alert to denote that someone has suspected or confirmed dementia, whether it be displayed on clothing, body worn items, at patient bedsides, in patient notes or on signs. Therefore, 'visual identifier' is often used interchangeably in academic and grey literature with words such as 'symbol', 'sign' and 'emblem'.

Visual identification

The importance of accurately identifying a patient's healthcare status has been addressed in hospital policy for some time. Visual identifiers, primarily wristbands, that contain the patient's name, date of birth and NHS number, have been used within hospitals in order to identify patients and give them customised care for years. There have been problems with lack of standardisation of coloured bands, with the same colours signifying different meanings in different hospitals. The National Patient Safety Agency Safer Practice Notice 2005/11 recommended that 'all hospital inpatients in acute settings should wear wristbands with accurate details that correctly identify them and match them to their care'.⁷ It advised that white wristbands with black text should be used and provides the discretion to use red bands to denote a specific risk such as an allergy or a patient who does not want to receive blood products.⁸ This guidance is now dated, but still enforced in some hospitals and was highlighted as being relevant to clinical practice by NHS Improvement in 2018.⁹

Visual identifiers, in the form of signs above beds, are used sporadically in some hospitals to draw attention to a variety of needs. Staff at the Gateshead Health NHS Foundation Trust request consent to place a falling star emblem above the beds of those patients known to be at risk of falls, to enable healthcare professionals to react quickly to the specific care needs of this group.¹⁰ Similarly, a range of symbols are used across NHS Trusts to indicate that patients require end of life care, including those of a swan,¹¹ leaf,¹² butterfly¹³ and the 'compassion symbol'.¹⁴

These symbols can also be distinguished from treatments or management tools that inadvertently act as visual identifiers. For example, a plaster cast on an individual's leg identifies them as having a broken leg, despite the fact that this is not the purpose of the cast. This is an example of the doctrine of double effect, which permits actions with a double effect, both good and bad, so long as only the good effect is intended and the harm is proportionate. In this instance, the therapeutic benefit of the cast outweighs the potential infringement on privacy that comes with making it plain to others that the person has broken their leg. This trade-off between benefits and harms may be different, however, when the condition in question is stigmatising.

For the purposes of this report, the focus will be solely on identifiers which intend to visually indicate that an individual has known or suspected dementia.

Visual identification systems for dementia: the policy context

It is estimated that there are currently 850,000 people living with dementia in the UK. This is expected to rise to one million by 2025 and continue to increase to two million by 2051.¹⁵ Given this rising trajectory, improving dementia care has remained a key national priority for health services in England and Wales for a number of years, and more recently is one of the 10 priorities identified by NHS England in the 'Five Year Forward View'. It has been suggested that the use of visual identifiers might result in people living with dementia experiencing 'better standards of care, lower levels of mistakes and misunderstandings, increased levels of knowledge and ultimately give [people with dementia] a more dignified quality of life'.¹⁶ Although there has been no explicit recommendation around the use of visual identifiers within UK health policy, The Royal College of Psychiatrists National Audit of Dementia recommended that hospitals have a system in place for recognising patients with dementia.

'Staff working within the ward and other areas of the hospital used by the patient need to be aware of the persons' dementia to anticipate their needs. Round 3 of the audit asked hospitals whether they had a system in place to ensure staff on the ward, and staff from other care areas, are aware of the person's dementia and how it affects them'¹⁷

Whilst visual identification systems are not a part of guideline based practice, they are often cited as an example of 'dementia friendly care'. The Prime Minister's challenge on dementia 2020 highlights the Butterfly Scheme as an illustration of 'improved staff awareness and understanding of the needs of patients with dementia in hospital'.¹⁸ Visual identifiers—specifically the Forget-Me-Not and Butterfly schemes—are listed in the NHS Dementia Assessment and Improvement Framework as part of best practice guidance relating to dementia care.¹⁹

More broadly, the use of visual identifiers may form part of a response to a call for 'person-centred' approaches to care—a holistic approach to care that requires healthcare professionals to recognise the individual at the heart of care, rather than caring for the condition. This is the underlying philosophy of the 2018 Alzheimer's Association Dementia Care Practice Recommendations, and the approach espoused by the National Institute of Care and Excellence in their Guideline on supporting people with dementia, reinforced by the National Dementia Strategy. However, evidence suggests that ward staff miss

opportunities to promote the personhood of people living with dementia²⁰ and that as a result ‘acute hospitals remain potentially harmful places’²¹ for these individuals.

Although there has been lots of work considering person-centred care in long term care settings, relatively little has focused on acute hospital care. The delivery of person-centred care in this setting is more challenging due to the shorter length of stay, time constraints, and the priorities of rapid diagnosis and therapeutic intervention. Relative absence of person-centred care in these contexts has also been put down to confusion around what it means to be person-centred (as there are a diverse range of interpretations), the challenges of multidisciplinary communication²² and a focus on meeting financial and productivity targets at the expense of being person-centred.²³

Perceptions of carers, patients and charities

There seem to be no formal public facing statements from charities regarding their views on the use of visual identifiers for dementia within acute care, but Dementia Action Alliance, John’s Campaign, Age UK and Alzheimer’s UK all call for a greater focus on ‘dementia friendly’ care, which, as highlighted above, is thought to include visual identifiers.

Likewise, there is little evidence available regarding patient and carer perceptions of visual identifiers. Featherstone et al. note that family, carers and people living with dementia are typically very supportive of the use of visual prompts and documentation, seeing them as a way to alert staff to an individual’s specific needs.²⁴ Additionally, anecdotal reports suggest that uptake of visual identifiers is high (see Annex 1).

However, the ethnographic research carried out in five hospitals by Featherstone et al. highlights that although supportive of visual identifiers, people with dementia often had negative experiences due to improper use. They found that signage was sometimes attached inconsistently or inappropriately, and served to simplify or stereotype staff interaction with patients. This observational data is important as there is a substantial lack of data on the experiences of patients and clinicians who use visual identifiers in acute care. However, these experiences are indicative of the poor implementation of the tools in those hospitals at that time, and cannot be taken to be representative of current use across all hospitals in the UK.

Existing visual identifiers for dementia

The organisational response to pleas for ‘dementia friendly environments’ within hospitals, has included introducing ‘technologies of attention’²⁵—simple technologies within wards, designed to draw attention to a specific diagnosis or deficit and alert busy staff to the specific needs of this patient group. The fourth round of the National Audit of Dementia suggests that 93% of hospitals audited have now introduced a visual identification system of some kind.²⁶ There is however a risk that they may not function as intended, and Featherstone et al. caution against the proliferation of technologies of attention, due to the possibility that the technologies themselves become invisible, and blend into “a wider ocean of signage, posters and notices, medical records and forms”²⁷ on the ward.

Within their scoping research, RAND Europe identified a number of visual interventions that are designed to better enable health and care staff within hospitals to recognise people with dementia, with the aim of improving the safety and quality of care that individuals receive.

Using information from their report and that available in the public domain, Table 1 identifies six visual identification aids, all of which have been implemented in one or more hospitals in the UK. These exemplify the types of identifier that are used and how they are applied in practice. It is worth noting that in some instances there is conflicting information available as the implementation of an intervention can vary between hospitals, and multiple interventions are sometimes used within a single hospital.

Table 1: Visual identification aids in use in UK hospitals

Name	Type of identifier	Condition it identifies	How does it work?	Is it used in conjunction with staff training?	Consent process
Forget-me-not scheme	Symbol	Varies between hospitals. From diagnosed dementia to any form of cognitive impairment	The blue flower symbol of the Forget-Me-Not is put in patients' case notes and above their beds to help ensure those with the condition are easily identified	Often used in conjunction with dementia awareness training	Opt in scheme. Each patient, or relative/carer needs to provide consent
Dementia friendly wristbands	Wristband	Dementia, cognitive impairment or confusion	Patients wear wristbands (often blue) in hospital so that they can be identified. This method is particularly useful when patients have wandered from their bed. Sometimes used in conjunction with other identifiers	There is evidence that in some instances the use of dementia friendly wristbands is accompanied by dementia care training	No public information available
The Butterfly Scheme	Symbol	Dementia, cognitive or memory impairment	The Butterfly is attached to patient notes and above their beds to help ensure that these patients are identified and receive appropriate care	Used in conjunction with training for all hospital staff, from porters to senior doctors	Opt in scheme. Each patient, or relative/carer needs to provide consent

Name	Type of identifier	Condition it identifies	How does it work?	Is it used in conjunction with staff training?	Consent process
The wristband project (The Purple Angel Dementia Awareness Campaign, 2013)	Wristband	Diagnosed dementia	A Purple Angel is affixed to the patient's hospital wristband and placed on their door	Hospital staff receive dementia training	No public information available
Red Tray System	Relevant related intervention	Focused on nutritional needs rather than aiding identification of dementia	Serving the person food on red trays (instead of brown) to indicate that they need additional assistance with nutritional needs e.g. needing food to be cut up or help eating	Tends to be accompanied by clear guidance about the use of nutritional risk assessment tools and guidance focused on ensuring people have sufficient time to eat and drink	No public information available
Purple slipper socks	Clothing	Cognitive impairment, confusion, delirium or dementia	Patients are encouraged to wear purple slipper socks to highlight their vulnerability to hospital staff. Particularly aimed at patients who are mobile and may become lost	No public information available	No public information available

Their report also identified tools that can be used alongside visual identifiers to improve person-centred practice. An example of this is the Alzheimer's Society (2016) 'This is me' form; a practical tool that people with dementia who are receiving professional care in any setting—at home, in hospital, in respite care or a care home—can use to tell staff about their needs, preferences, likes, dislikes and interests. This could

include information such as details about an individual's normal routine, difficulties they have with communication, cultural/religious needs and information about sleeping patterns.

How are visual identifiers currently used and assessed within UK hospitals?

The usage of signage in this context is widely accepted as representing 'dementia friendly' good practice within this setting as it alerts busy staff to the specific needs of this particular patient group. The National Audit of Dementia suggests that 93% of hospitals audited have now introduced a visual identification system of some kind²⁸—the most prolific being the Forget-me-not and Butterfly Schemes—but the audit does not identify or assess the quality, costs, or effectiveness of the various systems. In the absence of national guidance, the systems used locally appear highly variable, with no standardisation around which intervention (or combination of interventions) to use, or even consistent method of using particular visual identifiers. Implementation of any intervention varies in its specifics from hospital to hospital, in terms of target populations, consent processes and staff training. For example, Wye Valley NHS Trust explicitly state set criteria for their use of the Forget-me-not symbol on their website which includes a diagnosis of dementia,²⁹ whereas others employ this symbol more generally for all those with cognitive impairment. These disparities accentuate the risks associated with inconsistent practices.

Even within a given hospital, there is evidence to suggest that visual identifiers are used inconsistently. The National Audit of Dementia found that 9% of suggestions by staff related to information and communication in the hospital were about consistently using visual symbols to alert staff that a patient had dementia.³⁰

It appears that there have been no formal evaluations of different visual identifiers to date, and no clear evidence base of systematic analysis to justify their use. This evidence is needed in order to gauge patient and healthcare professional attitudes towards this technology and to assess clinical utility. This would also be needed in order to provide an evidence base for wider implementation outside of local settings, across the NHS. Such implementation would also require explicit publicly available information about how care delivery settings should change their practices to support and make the most of the integration of visual identifiers.

Low cost, simplicity of introduction and the fact that implementing visual identifiers allows hospitals to signal that they are responding to and supporting the needs of people with dementia, has led these tools to be widely viewed as a good thing. However, the trade-off between the benefits of recognising the different care needs of persons with dementia against the unintentional harms that can arise as a result of using visual identifiers must be carefully considered if visual identifiers are to be effectively and ethically implemented in hospitals.

The next chapters address the ethical and legal considerations arising from the current and potential use of visual identification systems to identify those with suspected or diagnosed dementia, within the acute care setting. The results of these analyses will contribute to the creation of a set of principles which shall influence the development of visual identifiers going forwards.

Chapter 2: Ethical analysis

This ethical analysis considers key concepts and frameworks relevant to ethical dementia care, and through this lens explores the challenges that might arise when using visual identification systems for people with dementia in the acute care setting.

Chapter introduction

The use of visual identifiers has been driven by an awareness of the fact that individuals with dementia in the acute care setting may often have specific or differing needs from the rest of the patient community. In other words, visual identifiers have been employed to drive attention to the existence, diagnosis and needs of people living with dementia. Their use as a care tool has morally sound objectives—to ‘see’ the *person*, make sure their needs are accounted for and make them feel ‘heard’. However, without a robust infrastructure and sensitive consultation these tools could paradoxically have the reverse effect, cause harm to the person, and inadvertently contribute to a culture that does not respond to the needs of people with dementia.³¹ This chapter aims to identify the key ethical considerations arising from the current and potential use of visual identifiers for those with suspected or diagnosed dementia, within the acute care setting. In doing so, together with the legal analysis, it informs the distillation of a set of principles to help guide the development and implementation of this technology going forward. These principles are set out in Chapter 4.

Methodology

A literature search was conducted to identify ethical literature pertaining to the use of visual identifiers for those with cognitive decline, to inform this analysis. The scope was then broadened due to an absence of literature on visual identifiers specifically, as the use of these tools and their implications have not been systematically explored. The ethical considerations arising from attaching a label to individuals with cognitive decline, including but not limited to considerations surrounding stigma, dignity, privacy, person-centred practice and autonomy, are also relevant and meet the inclusion criteria of the broader search strategy. Further details of these literature searches can be found in Annex 2.

The starting point: the impact of dementia on personhood

A theme that pervades much of the literature on dementia is the extent to which this illness erodes the core qualities of what it means to be a person. This tension is a good starting point for an exploration of ethical issues.

Personhood is a concept at the centre of all issues relating to ethical dementia care. This is in part because it is seen as an *evaluative* term, concerned with assigning rights, duties, obligations and respect³², resulting in the bearer having a particular moral status. There is much controversy surrounding the characteristics necessary for personhood, whether it can be considered to be a matter of degree, and how we ought to respond to those cases on the margins. This leads to uncertainty about what it means to recognise and respect personhood when caring for people with dementia. Therefore, an understanding of personhood in

the context of dementia, and the implications for staff and patients, is necessary when considering the development and implementation of visual identification systems.

Traditional philosophical accounts have relied upon cognitive capacities as a threshold for personhood. Locke defines a person as ‘a thinking intelligent Being, that has reason and reflection, and can consider itself as itself, the same thinking thing in different times and places.’³³ More recently, this account has been developed by Parfit, who advanced the idea that the person consists of memories, beliefs and desires that form a continuous psychological connectivity.³⁴ However, this interpretation has been criticised for the profound implications it has for those who are not able to meet these requirements.^{35,36} Dementia often results in a progressive decline in rational thinking, and memory loss. Consequently, to subscribe to this definition of personhood would mean that an individual with dementia would not be seen as the same person as their dementia progressed, or indeed as a person *at all* in the most disabling stages of dementia.

Others have conceptualised personhood more broadly, as being rooted in relationships,³⁷ or the capacity to value,³⁸ or through being biologically human—in our capacity to ‘be’ rather than to ‘do’.³⁹ These accounts claim that even if the person’s mood, behaviour and memory change profoundly, the person with severe dementia is still a person (and crucially, the same person), as before the onset of dementia. The facts of bodily identity,ⁱ and social connections, in particular, provide important grounds for considering a person as the same person throughout the full course of the illness. Adopting this position implies that those with dementia are owed respect, are recognised and valued as persons with interests and preferences, and that the views and values of the person both prior to, and following, the onset of dementia should help guide decision making.

Our starting point for this report then, is that we concur with the position espoused by the Nuffield Council on Bioethics in their 2009 report on Dementia, that ‘the person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions.’⁴⁰ This is key, as recognising those with dementia as persons is central to the ethical implementation of the visual identification system and to the dialogue surrounding the potential harms that could arise.

Consideration: Regardless of disease severity, individuals with dementia remain ‘persons’, and correspondingly hold full moral status. Visual identifiers should form part of a care response that recognises and, where possible, enhances this personhood, promoting the individual’s rights and interests and treating them with the same care and compassion that would be afforded to any other person. Therefore, when deciding whether to use a visual identification system, the views of the person with dementia should be adhered to, to the fullest extent possible.

ⁱ ‘Bodily identity’ refers to our physical continuity over time.

Dementia as a disability

Disability is a concept that is pertinent to the treatment of individuals with dementia. Many different characteristics can be considered to be disabilities. The variation and breadth of experiences and bodily states mean that a common concept of ‘disability’ is difficult to reconcile. Two common features stand out in most definitions of disability:^{41,42,43} (i) a physical or mental characteristic labelled or perceived as an impairment or dysfunction and (ii) some personal or social limitation associated with that impairment.⁴⁴ Whilst dementia is not a disability *per se*,⁴⁵ it can have disabling effects and therefore be a cause of disability in some instances.

The medical and social models of disability

The classification of people on the basis of observed or inferred characteristics raises difficult threshold questions about the extent to which the classification is based on biology or is socially constructed. As a result there are different ways of theorising about disability:

- The medical model understands a disability as a physical or mental impairment of the individual and regards the limitations faced by people with disabilities as resulting primarily, or solely, from their impairments.
- In contrast, the social model suggests that although the person with dementia may have an impairment, their disability arises from the way that they are treated by, or excluded from, society. As such, disability is not an intrinsic characteristic of the individual, but is an outcome produced by social processes of exclusion. This could include environmental factors and personal attitudes that lead to social arrangements, behaviours, norms and practices which restrict or preclude the participation of people seen as having a disability. The social model of care also seeks to understand the emotions and behaviours of the person with dementia by placing the individual within their social circumstances and biography.⁴⁶

By learning about each person with dementia as an individual, with his or her own history and background, care and support can be designed to be more appropriate to individual needs. If, for example, care providers have learned that a person with dementia has a strong dislike for a certain food, it can be understood why the person might spit it out. Without this background knowledge the person who spits out their food may just be labelled as ‘difficult’ or ‘antisocial’.

Consideration: The visual identifier should trigger a conversation about the person—their likes, dislikes, habits and values—so that the healthcare professional can be as inclusive as possible and respond to the patient’s specific care needs, albeit within the constraints of an acute care setting.

Almost all commentators acknowledge some role for both the physical impairment and the environment in causing limitations, as they are not mutually exclusive. Identifying and intervening on both a medical level (through research into clinical causes of dementia and developing pharmacological interventions) and

social level (through fostering an inclusive environment) is necessary in order to address limitations and disadvantages arising from disability.

These ways of theorising about disability are reflected in individual experience, which similarly can be approached in terms of two aspects: the experience of living with an atypical structure or function and the experience of facing stigma and discrimination based on these atypicalities. Although undoubtedly, the harms arising from cognitive decline are significant, those arising from societal stigma and the negative perceptions of others also have a detrimental impact upon the person's experience of their condition. This will be considered in more depth below.

Consideration: A difference can be made to quality of life through the way that people with dementia are supported, their interactions and their environment. The visual identifier must be part of a wider culture of care that minimises the barriers generated by poor environments and attitudes.

Stigma

The attitudes and behaviours of others affect the person with dementia and can serve to either promote or diminish their wellbeing, dignity and sense of self. This is congruous with the social model of disability, which argues that the disabling effects felt by those with impairment can be attributed to personal attitudes and environmental factors. Dementia is considered to be a profoundly stigmatising condition,⁴⁷ fuelled by negative stereotypes and misconceptions surrounding what dementia is and what it means for the individual. Stigma can broadly be defined as 'a societal reaction which singles out certain attributes, evaluates them as undesirable and devalues the persons who possess them.'⁴⁸ Therefore it has a significant impact on the way that people with dementia are treated by wider society, family and friends and healthcare professionals, and consequently, a direct impact upon individual experience of dementia.

Stigma can negatively affect the individual in many ways. It accentuates and deepens the distress experienced by the person with dementia, 'adding to their existing disability.'⁴⁹ Although it has been argued that 'all those assigned a label of mental illness take on an identity that is stigmatised',⁵⁰ this appears to be a particularly powerful facet of dementia. Milne contends that it:

'confers a 'master status' on the individual; 'having dementia' not only becomes the most prominent aspect of the person's life but it also serves to subsume all their other attributes and features into a single stigmatized identity.'⁵¹

Those with dementia are at risk of being dehumanised—viewed as a condition or a set of behaviours, rather than as a person whose condition is just one aspect of who they are. Perhaps most detrimentally, stigma influences the perception the person has of themselves. Loss of independence, and feelings of low self esteem, value and worth are widely noted in research with people with dementia.⁵²

People with disabilities who are part of other stigmatised groups may experience a distinct kind of stigmatisation that is 'more than the sum of its parts.'⁵³ For example, dementia predominantly affects

adults over the age of 65, and so ageist societal attitudes may compound the experience of dementia, rendering this group at risk of being doubly stigmatised. Older adults are sometimes stereotyped as ‘dependent’ and ‘incapable of exercising autonomy’,⁵⁴ and therefore they face a particularly high burden in overcoming these stereotypes. Aside from ageism, dementia stigma can also intersect with other dimensions of social inequality such as gender and race.

Labelling

Visual identifiers can act as a form of diagnostic label indicating that the individual to whom it is attached has suspected or confirmed dementia. As noted by Nuffield Council on Bioethics, the provision of a ‘label’ for a condition is often the first, and necessary, step for appropriate care and support to be provided.⁵⁵ Visual identifiers could serve an important purpose through efficiently indicating to healthcare professionals that the patient may have specific differing needs that go beyond the primary reason for their admission into acute care. However, despite their clear benefits, diagnostic labels also serve as cues that activate stigma and stereotypes.⁵⁶

Featherstone et al. warn against signs and symbols becoming ‘markers of stigma, assigning a label of dementia that overshadows the person, masking their individual needs.’⁵⁷ In the context of a busy acute care ward where the focus is on present and pressing medical needs, a visual identifier could act to simplify and stereotype staff interactions with patients.⁵⁸ A label may lead to assumptions of lack of capacity—for example that those who have an identifier above their bed need high levels of support at mealtimes or are not able to walk independently. Additionally, where individuals are highly dependent, there is a risk that this is seen as a long-term feature resulting from their dementia, rather than reflecting the impacts of their acute admitting condition.⁵⁹

However, much of the harm that can be derived from the ‘label’ attached to care rests upon the beliefs and attitudes underpinning that label. If care that is prompted by the label is provided on the basis that the person with dementia is valued as a person and supported to ‘live well’ with dementia within the context of their own family and other relationships, then the characteristics of the label itself becomes immaterial.

Consideration: Healthcare professionals should have an understanding of the variable etiology and impacts of different kinds of dementia, and of the highly variable and often fluctuating needs of each individual, in order to mitigate against generalised assumptions arising from the ‘label’ of dementia.

The wider care environment

Visual identification systems are intended as technologies to help overcome narrow task-based attention and encourage caring for the individual rather than the condition. The potential that they might paradoxically have the reverse effect, as highlighted above, emphasises the importance of the care

environmentⁱⁱ and medical culture within which the visual identifier operates. Fostering this medical culture will require that the identifier is accompanied by an education and training infrastructure to ensure that staff understand the variable etiology of different types of dementia and know how to use the identifier so that the full benefits for patients can be realised. Additionally, training should extend beyond clinical staff. Promoting a care environment that is reactive to the needs of people with dementia will require that *all* staff that come into contact with patients with dementia on a regular basis 'should be dementia aware and receive role specific training amid a dementia friendly environment.'⁶⁰ This applies not only to healthcare professionals across different wards, but might also include porters, cleaners, security guards, and other domestic staff. This presents challenges, especially as hospitals often have staffing contracts with external providers (for services such as catering and security). However a simple, standardised approach, recognised and adopted across the entire hospital will enable greater continuity of care for patients, and providing an appropriate level of training to facilitate person-centred interactions could have benefits for staff too. A study conducted by Ashton et al. concluded that porters and domestic staff felt 'encouraged by their attempts to support personhood and thought this added value to their work.'⁶¹

Thus, a core benefit of the visual identifier may be that its systematic implementation might act as a catalyst for additional training for both clinical and non-clinical staff.

Consideration: The infrastructure surrounding the visual identifier should include appropriate staff training and education, and it should sit within a wider medical culture of person-centred care. This training could extend beyond healthcare professionals in the acute care ward to clinical staff on other wards, and to other hospital staff who interact with these patients, such as porters and domestic staff.

ⁱⁱ Both the Royal College of Psychiatrists' 'Audit of Dementia Care in Hospitals' and the Royal College of Nursing's 'Commitment to the care of people with dementia in general hospitals' have acknowledged the critical influence of the physical care environment.

Frameworks enabling ethical dementia care

As outlined above, it is widely recognised that individuals with dementia have rights and interests that need to be protected, but which are threatened by their illness and the negative response to their diagnosis and symptoms. Different frameworks have been developed that attempt to correct these disadvantages and facilitate ethical approaches to dementia care. The themes of justice, autonomy and dignity feature in many of these frameworks, but some, in addition, highlight other qualities that exemplify ethically desirable characteristics, such as compassion or holistic care. These characteristics are particularly relevant to people with dementia and their care, and are relevant to the development and implementation of visual identification systems.

Some prominent examples of ethical frameworks of care are described below. An important feature of these is that they focus on different aspects of care: the ethical status of the decision being made (Beauchamp and Childress's four principles approach); the object of care (person-centred care); the giver of care (virtue ethics) and the nature of the care act itself (care ethics). As described above, we have selected the most relevant aspects from these approaches in constructing our key principles and recommendations for visual identifiers for dementia in the acute care setting (Chapter 4).

Beauchamp and Childress's principles

Principlism, or the 'four principles' approach is a well-established ethical framework in bioethics. It is thought that these four basic moral principles can be used as starting points for practical decision making in bioethics.

'(1) respect for autonomy (a norm respecting and supporting autonomous decisions)

(2) nonmaleficence (a norm of avoiding the causation of harm)

(3) beneficence (a group of norms pertaining to relieving, lessening, or preventing harm and providing benefits and balances benefits against risks and costs)

(4) justice (a group of norms for fairly distributing benefits, risks and costs)'⁶²

These principles represent *prima facie* binding moral norms that must be followed unless they conflict, in a particular case, with an equal or greater obligation. They are non-hierarchical, meaning that no one principle routinely 'trumps' another. Moreover, they provide only general ethical orientations that require further detail to give guidance in concrete cases. Thus, when being applied, the principles have to be specified and—if they conflict—balanced against one another. It must also be recognised that different people will assign different weights to principles and therefore balance them differently. A key factor in weighing may well be the character of the people who perform the weighing.ⁱⁱⁱ

Under this framework, the ethical implementation of a visual identifier would require it to promote these four principles as far as is possible.

ⁱⁱⁱ This also demonstrates how these frameworks can work in conjunction with one another, as a virtue ethics approach could be employed alongside principlism.

Person-centred care

Grounded in an inclusive interpretation of personhood, Kitwood's work '*Person to Person*' led to the emergence of person-centred care as a holistic approach to dementia care in the 1990s, and has since been widely advocated by policymakers across the globe as a corrective to the problem of depersonalization in healthcare.

'The person comes first' is at the heart of person-centred care. It involves seeing the individual as a unique and whole person, with individual preferences, strengths and vulnerabilities, and recognising dementia as just part of the picture, rather than as being identity-defining. 'Dementia is more than simply a matter of brain decay. People contribute a unique personality and a set of life-experiences, coping resources and social networks.'⁶³

Brooker considers person-centredness in the context of dementia care as encompassing four elements:⁶⁴

1. Valuing people with dementia and those who care for them
2. Treating people as individuals
3. Looking at the world from the perspective of the person with dementia
4. A positive social environment in which the person living with dementia can experience relative wellbeing

This framework emphasises that the visual identifier should enable a holistic approach to care that takes into account the whole person.

Virtue ethics

A virtue ethics approach is concerned not merely with the right action being performed, but requires the care provider to perform the right action, in the right way, for the right reasons. A key element of this approach is that a good character is central in providing ethical care. In virtue ethics there is no cardinal principle such as duty or utility from which we can derive secondary moral rules. There is rather a concern with what sort of people we must be if we are to act in an ethical manner.

A number of virtues have been suggested by scholars investigating which might be most appropriate for people in caring roles. A range of virtues such as courage, patience, compassion, commitment, trustworthiness, and so on, are often regarded as good dispositions to have when caring for someone with dementia. A common criticism levied is that it does not offer a decision procedure—saying that care providers should be compassionate is of little help in guiding people through the challenging scenarios that are met regularly in everyday care. Others have disputed this, contending that virtue ethics can be action guiding, in line with other ethical frameworks, as each virtue generates a prescription and each vice a prohibition.⁶⁵ Additionally, the virtues themselves are appealing insofar as they seem to capture the essence of good practice more adequately than principles.

A virtue ethics approach might require the visual identifier to be part of a compassionate system delivered by compassionate healthcare professionals. Although aspects of this seem aspirational, viewing compassion as a virtue could offer lessons for the use of visual identification systems, providing insight into the assessment of individual patient needs and ways to address these.

Ethics of care

Under the ethics of care, the moral action centres on context. It holds that the specific nature of a situation cannot be confronted adequately simply by applying rules, and so is concerned with a highly individualised approach that must be developed based on the situation, through being receptive and responsive to the person who requires care.⁶⁶ In the absence of rules or a deductive model, Ricoeur—an advocate of this theory—identified *phronesis*, or ‘practical wisdom’, as a basis for ethical judgements.

Another central characteristic of care ethics is that it places an emphasis on the moral dimension of relationships—through playing both a significant role in the development of ethical problems and acting as a strategy for resolving such conflict—and the appreciation of virtues that make relationships more stable, such as trust and compassion.

Care ethics also gives more weight to implicit forms of knowledge such as experiential knowledge, situational knowledge and relationship knowledge. These are necessary for dealing with ambiguity and complexity, appreciating the critical role of relationships and identifying appropriate solutions in each case. Valuing these forms of knowledge, which go beyond the confines of a formal-logical approach, is the essence of care ethics. However, a balance must be struck, and care ethics can only be applied when it draws on emotional knowledge to enable creative approaches without being absolved of the obligation to justify this through the provision of transparent and comprehensible arguments.⁶⁷

A care ethics approach to the use of visual identifiers emphasises the importance of context together with a comprehensive understanding of a patient’s values, preferences and beliefs to support the application of the identifier.

It is clear that these frameworks have different emphases, and sometimes conflict. Nevertheless they are not mutually exclusive and potentially complement one another. Ethical care could very foreseeably require both an awareness of principles and basic rights, and an individualised approach tailored to the specific person. This is due to the fact that the application of a principle comes into focus through understanding the unique features of the situation. In addition, on a practical level, a combined approach is preferable for a ‘workable’ virtue ethic in health care; one that will attract the confidence of healthcare professionals.

Grounding concepts

This section considers visual identifiers through the lens of three interconnected central grounding concepts within bioethics; justice, autonomy and dignity. These are not exhaustive, but are the focus of this analysis because they raise particular challenges for dementia on account of the fact that the mental and physical effects of dementia are often thought to reduce the person’s dignity and autonomy, and lead to unjust treatment. These concepts provide a helpful lens through which the ethical benefits and challenges of using visual identifiers can be explored.

Justice

Justice requires that equals be treated equally i.e. that we do not engage in arbitrary discrimination against someone (for example, based on their medical condition, gender, etc). Disability raises issues of justice, as those with disabilities often face disadvantages as a result of their impairment and social environments. Broadly speaking, there are two kinds of injustice that those with dementia can suffer: relational and distributive.⁶⁸

- Relational injustice refers to the injustice of certain forms of *treatment*—in particular, the treatment of some people *as* moral, social, or political inferiors on the basis of morally irrelevant characteristics. Correcting this may well require changes to social and institutional norms and practices.
- Distributive injustice refers to certain *outcomes*—in particular, outcomes in which there is an inequality of income, wealth, health, or other aspects of well-being resulting from morally irrelevant factors. Correcting this form of injustice would require a change in the distribution of resources that affect wellbeing.

The relationship and comparative importance of each form of injustice has been the subject of extensive debate, but it is widely agreed that those with disabilities often suffer from both forms of injustice, and are subject to ‘a kind of pincer movement’ between ‘misrecognition and maldistribution.’⁶⁹

Relational Justice

As the social model of disability highlights, individuals with dementia face relational injustice through stigma, invisibility and exclusion. Modest changes, such as the adoption of a visual identifier, could significantly increase inclusion at little cost, by making these hidden needs plain to those charged with their care, and help ensure that they are treated equally.

However, this also raises the question of how well we must understand others in order to treat them in a just manner as the experiences of people with disabilities differ considerably from the experiences of the able-bodied majority. The epistemic authority of people with disabilities—that is, authority that they have due to their expertise and superior knowledge, in this instance gained through lived experience of disability—is often discounted, and commentators on epistemic injustice raise criticisms that disability and its impact on individuals is often assessed through the lens of able-bodied people.⁷⁰ If a visual identifier were to be applied without appropriate training accompanying it, healthcare professionals might rely on and respond to generalised constructions of ‘the dementia patient’ and disenfranchise the ability of those individuals to have the time and space to speak for themselves. This erosion of epistemic authority

contributes towards 'misrecognition', highlighting the importance of an approach that appropriately incorporates and weighs the perspectives of people with dementia.

Consideration: The visual identifier should be used not only to draw attention to the needs of the person with dementia but to promote their epistemic authority, in this instance their authority gained through the lived experience of disability.

Distributive Justice

When considering distributive justice, it is important to distinguish between the related concepts of equality and equity. Equality concerns the equal distribution of shares (of health or health care) so that each individual receives the same amount. However, giving people equal shares can be inequitable. For example, it would not be considered fair to give a group of people equal quantities of food when one of them is starving. For this reason, Aristotle's formal principle of justice instructs that 'equals should be treated equally and unequals unequally'.⁷¹

In contrast, equity involves treating everyone justly according to their circumstances. In the context of healthcare, this will require altering approaches to care in light of relevant patient information. There is a question about what treating equals equally means in the context of dementia, given that those with dementia vary significantly in the extent and severity of their symptoms and resulting needs, and will require different levels of resources and attention.

Visual identifiers have the potential to direct resources either towards, or away from people with dementia, and when developing a visual identification system, consideration should be given to whether it directs resources in a way that is equitable. That being said, the purpose of an identifier is to draw attention to potential care needs that would otherwise not be clear. It should not act as a basis for making resource decisions, but instead is a tool to help healthcare professionals adjust their behaviour, and recognise and respond to care needs. This response may involve directing additional resources towards that individual, but as a result of the disabling nature of their condition rather than in response to the visual identifier. An additional reason why the identifier should not be used as a basis for decisions about allocating resources is that not all individuals with dementia will choose to use an identifier, and this should not negatively impact upon the care that they receive.

Consideration: Promoting justice and equality requires that those who opt out or decide against the use of an identifier should receive the same standard of care as those who have consented to its use, and are not negatively impacted by this choice. The lack of a visual identifier does not mean that the patient doesn't have dementia.

Consideration: Consideration must be given to what it means to 'treat equals equally' in the context of dementia, and how best to use the visual identifier to guide care in a way that is equitable.

Consideration: Care should be taken to avoid overreliance on visual identifiers, such as using them as a proxy for making decisions about unrelated matters such as resource allocation.

Autonomy

Autonomy has acquired increasing significance as we have moved away from a paternalistic model of the patient-physician relationship. It is often defined as 'self-rule', 'making your own choices', 'ability to live independently' or 'right to self-determination.'⁷² In other words, placing an emphasis on the ability to be self-legislating. In the context of dementia, interpreting autonomy can be difficult, as the independence and rationality thought to characterise autonomy is not always congruent with the dependency that *can* arise from dementia. This narrow interpretation of autonomy as a negative freedom (i.e. freedom from interference from others) raises several challenges for individuals with dementia:

1. There are profound implications for the people with dementia who do experience more severe symptoms and no longer possess full decision making capacity i.e. that they have lost all autonomy interests.
2. There is a general assumption that people with dementia cannot make decisions on their own. 'It is too easily assumed by the decision makers in providing care (as well as generally) that people with dementia are incapable of making choices and taking decisions (which will have a great impact on their future well-being), thereby 'de-humanizing' them.'⁷³ In reality, individuals with dementia differ with regard to the severity of their symptoms and therefore in their ability to participate fully in decision making. These assumptions might be perpetuated by the use of a visual identifier if interpreted to indicate that people with dementia have generalisable patient needs. Assumptions such as that people living with dementia need high levels of support at mealtimes, are often incontinent, not able to walk independently or at high risk of falls, could reduce autonomy by limiting opportunities for dialogue with the patient, and in the long term, to patients unnecessarily losing skills and independence that they previously had.

Supporting autonomy

Therefore, when thinking about promoting autonomy in the context of dementia, it is helpful to consider more nuanced understandings of autonomy, which do not rely on the need for self-sufficiency. These recognise the positive obligation that this principle generates—promoting autonomy will often require the provision of active support, to encourage the individual to retain and express their sense of self. This can be done through enabling them to pursue activities that they appear to enjoy, maintain skills and capacities, and foster relationships that are important to them.

‘Autonomy fundamentally involves the way individuals live their daily lives; it is found in the nooks and crannies of everyday experience; it is found in the way that individuals interact and not exclusively in the idealised paradigm of choice or decision making that dominates ethical analysis’.⁷⁴

Visual identifiers can promote autonomy through acting as a first step in a wider care response where the care provider acts as an advocate for the person with dementia, helping to establish their values and preferences, and foster their unique capabilities, skills and relationships, to actively help ‘retain their autonomy, and with it their sense of self.’⁷⁵ This is recognised by staff and was reflected in the National Dementia Audit, where 43% wanted better support skills e.g. listening, talking, and treating patients with dementia as individuals and encouraging patients to dress themselves.⁷⁶

Consideration: The promotion of autonomy will require healthcare professionals to actively support individuals to retain their capabilities, and foster their interests and relationships.

Relational autonomy

Relational autonomy goes even further in challenging the individualist interpretation of autonomy. Contrary to the view that dependence is an impediment to autonomy, relational autonomy is firmly grounded in the notion of interdependence. Because people are embedded within social networks, proponents of relational autonomy argue, sufficient weight must be given to the fact that people make decisions within the context of their relationships with others.⁷⁷ Consent is often treated as a decision made by one person, but in reality most people don’t normally make decisions, or want to make decisions, by themselves. This is particularly relevant in considering people with dementia, for as their illness progresses they become more and more dependent on others. Under relational autonomy, these individuals are still able to exercise their autonomy, as decision making isn’t a process that happens in isolation, but rather, within a social and cultural context that has an impact upon beliefs, attitudes and therefore, decisions. As a result both the individual’s family and the care team have a role to play in decision making.

Consideration: People with dementia should be actively supported to participate as fully as possible in medical decisions, including those regarding the use of a visual identifier as part of their care. In some instances, individuals may be able to make decisions themselves, but particularly where the patient is dependent on others, joint decision making may be appropriate.

Dignity

Dignity can be a difficult concept to interpret in the context of dementia, as the ravages of advanced dementia seems to erode many of the qualities we associate with dignity. People with moderate/advanced dementia may experience confusion, struggle with speech, exhibit aggression, be unable to feed themselves, or become incontinent for example. This appears to be socially unacceptable, embarrassing to others and thus ‘undignified’.

Broadly speaking, there are two categories of dignity—one a moral quality and the other subjective experience.

1. Absolute,^{iv} basic or universal human dignity is an objective type of dignity attached to human worth and equality, and which forms the foundation of human rights.
2. Personal or relative dignity is a changeable human dimension influenced by external factors.

The former is considered to be held by all humans regardless of other faculties:^{78,79}

‘People have this dignity or worth regardless of their levels of competence, consciousness or autonomy, or their ability to reciprocate in human relationships. They have this dignity purely because they are human.’⁸⁰

In contrast, the latter is experienced subjectively through the thoughts and feelings of the individual. It is ‘contingent and contextual, and can be influenced both by an internal aspect, which is the worth and self-respect one ascribes to oneself, and by an external aspect, which is the worth and value ascribed by others.’⁸¹ Seedhouse and Gallagher describe an ‘intuitive understanding of dignity’ amongst care providers, patients and their relatives.⁸² Translating this into practical care however, presents a challenge.

It is thought that a solid sense of personal dignity is essential to the individual’s overall experience of wellbeing. Those with dementia are already at risk of suffering a loss of personal dignity as a result of the direct impact the disease has on their physical and mental capabilities, identity and sense of self. Maintaining personal dignity should therefore be a consideration in the care of individuals afflicted with dementia and is highly relevant when considering the impacts of introducing tools like visual identifiers. The lack of a strong evidence base on how to embed dignity and lack of clear, practical information on how to promote it has led commentators to assert that ‘it is easier to make pronouncements about dignity than to ensure that dignified care happens’,⁸³ reflecting the challenges of embedding it into everyday practice.

^{iv} Erikson and Edlund *Theory of Caritative Caring* posits that absolute dignity is inherent, inalienable, and granted by virtue of being human, while relative dignity relates to the experience of self-worth and human value in relationships with others.

Despite the lack of studies investigating the factors that contribute to and strengthen personal dignity within an acute care setting, the following aspects have been noted:

1. It is clear that the interactions that individuals with dementia have with healthcare professionals are key to promoting or violating personal dignity. Jacobson describes these interactions as potential 'dignity encounters'.⁸⁴ Feeling respected, listened to, taken seriously, treated with kindness, given health-related information in a gentle manner, and adopting positive realism were among the most crucial dignity-preserving qualities found in these interactions.⁸⁵ This is congruent with the use of visual identifiers, which act to open up a dialogue with the patient. Interactions should be underpinned by compassion and meaningful engagement.
2. Studies also suggest that 'a key factor in maintaining a sense of personal dignity was the belief that life is still meaningful.'⁸⁶
3. The perceived priorities of the system also impacts dignity experience. Experiencing having similar status and rights as other patient groups was identified by Tranvåg et al. as a fundamental quality crucial for preserving dignity experience.⁸⁷

Policy initiatives such as the Dignity in Care campaign affirm the importance of creating caring environments and cultures that are safe, holistic and truly person-centred.

Consideration: The visual identifier should be accompanied by additional resources to supplement the basic information provided by the identifier, such as a 'This is Me' form. This could include information about routines, like and dislikes, cultural or religious needs, sleeping patterns and interests.

Consideration: A holistic, person-centred approach to care should be adopted, recognising the importance of the relational aspect of the healthcare professional/patient encounter, and in order to ensure that the patient feels respected and listened to.

Chapter conclusion

There are many ethical concepts, frameworks and ideas that are relevant to dementia care. This analysis has explored some of these, and used them as a lens to consider the challenges that might arise when using visual identifiers for people with dementia in an acute care setting. Whilst this report does not aim to preempt the work to be done during the empirical phase of the project or advise on the practical details surrounding the implementation of visual identifiers, the process of bringing together relevant ethical concepts and distilling key principles has raised some broad and tentative conclusions to be considered in future phases of the project.

- Crucially, the visual identifier must not be implemented in isolation, as its value lies in prompting a tailored care response. The ethical implementation of an identifier relies upon it being a first step in a care pathway that is sensitive and reactive to the needs of each individual, allowing healthcare

professionals to adapt their care. In doing so, it mitigates the disadvantages that can arise as a result of suffering from dementia, especially in its most disabling stages.

- Quality of life can be improved through the way that people with dementia are supported, their interactions and their environment. The visual identifier must be part of a wider culture of care that minimises the barriers generated by poor environments and attitudes.
- Thought must be given to how the visual identifier could promote the relational aspects of care which are crucial for promoting the dignity, autonomy and self-worth of the person with dementia.
- Promoting autonomy requires that people with dementia should be actively supported, both to participate as fully as possible in medical decisions, but also to retain their capabilities and foster their interests and relationships.
- Those who opt out of using a visual identifier should receive the same standard of care as those who consented to its use, and should not be negatively impacted by this choice.
- The visual identifier should trigger a conversation about the person—their likes, dislikes, habits and values—so that the healthcare professional can respond to the patient’s specific care needs, albeit within the constraints of an acute care setting.
- The infrastructure surrounding the visual identifier should include training and education for all staff interacting with these patients, so that the identifier is used in a consistent manner and staff are aware of the variable impacts of different kinds of dementia.

Overall, we emphasise that visual identification systems have the potential to be part of a wider practice of ethical dementia care. However, implementing them in a way that will maximise benefits for patients will require consideration of these conclusions and strategies to integrate them into future protocols.

Chapter 3: Legal analysis

This legal analysis considers the visual identification system for acute care dementia patients in its legal context, noting significant legal consequences, and how the system might be developed to be consistent with established legal principles, law, and regulation.

Chapter introduction

In this chapter we identify and analyse key aspects of the legal framework that influence how a visual identification system for dementia should be designed and implemented in the acute care setting. To a considerable degree, these legal factors substantiate or reinforce the key ethical considerations discussed above. We highlight the synergy between legal and ethical considerations at relevant points in this analysis. The legal framework also imposes its own specific requirements which any visual identification system for dementia in the acute care setting must comply with. These legal aspects will therefore influence the key principles set out in Chapter 4.

Method

Following initial scoping of the regulatory framework, we adopted a targeted approach to reviewing the legal environment impacting on the implementation of visual identification systems for dementia in an acute care setting. We prioritised and focused on those aspects which are likely to have the greatest bearing on how a legally sound and compliant visual identification system should be designed and implemented in the acute care setting.

What law applies?

There is a complex set of legislation, common law (judge made law), international instruments, and wider regulation that potentially apply to the visual identifier for acute care dementia patients. The legal position is further complicated by the fact that patients with dementia covered by the identifier may or may not have capacity to make decisions about their treatment and care.

The analysis covers the following broad areas of law and regulation:

1. Human rights in international, supranational, and national instruments
2. The Mental Health Act 1983
3. The Mental Capacity Act 2005
4. Consent
5. Discrimination and equality
6. Confidentiality, privacy, and data protection

Two questions

This legal analysis distinguishes between two broad questions:

1. How might the visual identification system be consistent with established legal principles, law, and regulation?
2. How can the visual identification system be applied to particular patients in a manner that is consistent with established legal principles, law, and regulation?

It is important to distinguish between the two questions as it is eminently possible to have a visual identification system that is legally sound in general but is inappropriate or that contravenes specific statutory duties when applied to an individual patient. In short, the question of legal compatibility of the visual identification system itself is very different from lawful use for a specific patient.

The starting point

The starting point for any legal analysis of persons with dementia (and indeed any mental disorder) is that they have the same legal rights as any other person to refuse treatment. Courts have underlined this, stating in strong terms the choice to accept or refuse medical treatment:

‘The ability of the ordinary adult patient to exercise a free choice in deciding whether to accept or to refuse medical treatment and to choose between treatments is not to be dismissed as desirable but inessential. It is a crucial factor in relation to all medical treatment. If it is necessarily absent, whether temporarily in an emergency situation or permanently in a case of mental disability, other things being equal there must be greater caution in deciding whether to treat and, if so, how to treat.’⁸⁸

We specifically and emphatically recommend that, unless proven otherwise, the candidate for a visual identifier should be treated as possessing capacity and not have a visual identifier applied (especially to their person) unless there is clear legal authority to do so.^v Indeed, this is also highlighted by the courts:

‘... unless clear statutory authority to the contrary exists, no one is to be detained in hospital or to undergo medical treatment or even to submit himself to a medical examination without his consent. This is as true of a mentally disordered person as of anyone else.’⁸⁹

Consideration: A candidate for the visual identifier should be assumed to possess capacity to refuse application of the visual identifier unless proven otherwise.

Where a candidate with capacity refuses the visual identifier, or where an advance refusal to have a visual identifier is in place, the visual identifier should not be applied.

^v As outlined below, this is consistent with the approach taken by, for example, section 1(2) of the Mental Capacity Act 2005.

Consideration: A candidate that has capacity to refuse the visual identifier and refuses, or has a relevant advance refusal in place, should not have the visual identifier applied.

Even where there is power to apply the visual identifier in the absence of the candidate's consent, the candidate's consent and wishes should be sought.⁹⁰ This is important for both legal and ethical reasons—legal principles requiring that the person's thoughts be included as far as possible and ethical analysis noting that the visual identifier may have a significant impact upon how the person experiences their dementia.

Consideration: Even where the visual identifier can be applied without the person's consent, where possible their consent should be sought. Failing that, their wishes should be constructed through substituted judgment or consultation.

The human rights context

Human rights protect all persons, regardless of mental disorder. As Lady Hale emphasises:

‘The whole point about human rights is their universal character. [They] are guaranteed to “everyone”. They are premised on the inherent dignity of all human beings whatever their frailty or flaws.’⁹¹

Many of the rights that might impact upon the legality of the visual identification system are not specific to those with dementia or indeed any mental disorder but general human rights, the pertinent question being what these human rights mean in this context.

There are many legal sources of human rights protections. These may be international, supranational (agreements among a group of nations), or national. As demonstrated by Annex 3, there is a great deal of consistency between the rights that these sources protect, the Convention of the Rights of Persons with Disabilities, the European Convention on Human Rights, the national implementation of this Convention the Human Rights Act 1998, and the Charter of Fundamental Rights of the European Union all containing very similar rights.^{vi}

There are many ways in which the visual identification system as a whole or a specific application of the system to an individual might be challenged on human rights grounds. In the area of mental health and disability, the most common challenges centre upon Article 3 (prohibition of inhuman or degrading treatment) and Article 8 (protection of the right to a private and family life) through the Human Rights Act

^{vi} N.B. the UK will no longer be subject to the Charter of Fundamental Rights of the European Union after the Brexit transition period but will remain subject to the European Convention on Human Rights.

1998. The UK's protection of human rights in the realm of disability has also been subject to criticism and challenge.⁹² Annex 3 lists key human rights and their sources in international, supranational and national law. Notably, these human rights instruments often underpin key pieces of domestic legislation being translated into principles either present in the legislation or accompanying codes of practice.^{93,94}

It is important to keep the human rights context for visual identification systems in mind as these rights colour the interpretation of relevant law and may be used to challenge the system as a whole or its application to specific individuals.

Mental health law and regulation

An important part of the legal framework that applies to the visual identifier is the legislation that governs the treatment of persons with mental disorders. Two key statutes apply:

1. The Mental Health Act 1983 (MHA 1983), which provides a framework for the psychiatric care and treatment of people suffering from a mental disorder, and;
2. The Mental Capacity Act 2005 (MCA 2005), that provides a framework for making decisions on behalf of people who are unable to make decisions for themselves because of a mental disorder or disability.

Both pieces of legislation can apply to the same person at the same time. That is, a person may have treatment mandated under the MHA 1983 and have treatment prescribed according to their best interests under the MCA 2005.

These Acts are primarily relevant to candidates for the visual identifier that may have it applied as a part of compulsory treatment or those that lack the capacity to consent to its application. In short, patients that have capacity and are able to consent to the application of the visual identifier are not the subjects of the MHA 1983 or the MCA 2005. In most cases, their consent should be sought if the visual identifier is to be applied.

These two Acts cover England and Wales, Scotland and Northern Ireland having different regimes for each (see Table 2). Where these regimes differ, the differences and their consequences are noted in footnotes. There are further subtle differences in process between the jurisdictions that may matter in practice. For instance, the MHA 1983 has a wider view of the kind of healthcare professional that can make applications, certain assessments, and orders under the Act, including 'responsible clinician' and 'approved mental health professional' compared to Scotland's more restrictive 'approved medical practitioner.'⁹⁵

Table 2: Scots and Northern Irish mental health law

	Scots law	Northern Ireland
MHA 1983	Mental Health (Care and Treatment) (Scotland) Act 2003	Mental Health (Northern Ireland) Order 1986 (outgoing), Mental Capacity Act (Northern Ireland) 2016 (incoming) ^{vii}
MCA 2005	Adults with Incapacity (Scotland) Act 2000	Mental Health (Northern Ireland) Order 1986 (outgoing), Mental Capacity Act (Northern Ireland) 2016 (incoming)

Mental Health Act 1983

The MHA 1983 is the primary statute under which assessment or treatment may be mandated for a person with a mental disorder. There are three preliminary issues that structure how the visual identifier might interact with the MHA 1983: the status of dementia as a ‘mental disorder’, the requirement that the patient must be ‘currently suffering’ from that mental disorder, the thorny issue of the visual identifier as ‘medical treatment’, and what is required to invoke the power to compel treatment. We consider each in turn.

Dementia as a mental disorder

If the Act is to be invoked, the person must be suffering from a ‘mental disorder.’ The MHA 1983 defines ‘mental disorder’ as ‘any disorder or disability of the mind’, specifically excluding ‘learning disabilities’ or ‘dependence on alcohol or drugs’ from this definition.^{96,viii} The MHA 1983 Revised Code of Practice (the ‘Revised Code’ published in 2015) provides a non-exhaustive list of ‘mental disorders’ explicitly including ‘dementia’ among these examples.⁹⁷ The Revised Code also clarifies that professionals should determine whether a person has a mental disorder according to ‘good clinical practice and accepted standards of what constitutes such a disorder.’⁹⁸ Notably, the mere finding that a person has a mental disorder is necessary but not sufficient to use compulsory measures under the MHA 1983.⁹⁹

^{vii} N.B. The Mental Capacity Act (Northern Ireland) 2016 is due to replace the outgoing Mental Health (Northern Ireland) Order 1986 but only partially operational, both systems operating in the interim to facilitate this change.

^{viii} N.B. The Mental Capacity Act (Northern Ireland) 2016, section 305(1) is very similar defining ‘mental disorder’ as ‘any disorder or disability of the mind’, although the Act is dissimilar, focusing on ‘capacity’ instead so as to not stigmatise those with mental disorders, see the Mental Capacity Act (Northern Ireland) 2016 Explanatory Notes, 10. The Scottish Mental Health (Care and Treatment) (Scotland) Act 2003, section 328 has a different, more specific definition, although Mason and McCall (p. 464) call this a ‘distinction without a difference’, the definitions covering roughly the same ground in how they might relate to dementia.

‘Currently suffering’?

‘Patient’ under the MHA 1985 means ‘a person suffering or appearing to be suffering from mental disorder.’^{100,ix} However, most compulsory powers under the MHA 1985 (for instance, applications for admission for treatment) require that the person be ‘currently suffering’ from the mental disorder in question.^{101,x} It is unclear what precisely ‘is suffering’ means in this context. Analogous case law regarding driving licences and epilepsy establishes that ‘so long as drugs are necessary to prevent the manifestation of disease, the disease ... remains.’¹⁰² Lady Hale interprets this to mean that ‘suffering’ requires the current presence of symptoms.¹⁰³

Ambiguity aside, it is not enough that an individual merely has a ‘disorder of the mind’, they must be currently suffering from that mental disorder. This is potentially important in the context for dementia for two reasons. First, a diagnosis of dementia itself is not sufficient to trigger compulsory powers under the MHA. For instance, mild cognitive decline is unlikely to meet the requirements for admission for treatment under section 3(2), specifically the requirement that they be ‘suffering from mental disorder of a nature or degree which makes it appropriate for him to receive medical treatment in a hospital.’ Second, the kind of impairment that might otherwise justify compulsory treatment can ebb and flow with dementia, the person having moments of clarity and days of confusion and restlessness.¹⁰⁴ In this way, dementia does not guarantee that it will be appropriate to mandate assessment or treatment; it may be appropriate one day, inappropriate the next.

Is the visual identifier ‘medical treatment’?

The primary purpose of the MHA 1985 is to provide a framework for the treatment of persons with mental disorders. More accurately, the power to compel ‘medical treatment’ is treatment relating to the mental disorder, not treatment generally. Indeed, ‘medical treatment’ is given broad definition in mental health law, the Mental Health Act 2007 providing the relevant definition: ‘medical treatment’ includes nursing, psychological intervention and specialist mental health habilitation, rehabilitation and care.^{105,106,xi} Further, the Act also provides the further clarification that:

‘Any reference in this Act to medical treatment, in relation to mental disorder, shall be construed as a reference to medical treatment the purpose of which is to alleviate, or prevent a worsening of, the disorder or one or more of its symptoms or manifestations.’¹⁰⁷

^{ix} The Mental Health (Care and Treatment) (Scotland) Act 2003 section 329(1) includes a similar definition of ‘patient.’ The Mental Capacity Act (Northern Ireland) 2016 section 3(1) operates differently, tying assessment of ‘capacity’ to ‘at the material time.’

^x The Mental Health (Care and Treatment) (Scotland) Act 2003, for example, sections 57, 64, and 72 do not have the term ‘currently suffering’ but restrict orders for treatment or detention for treatment to contemporaneous mental disorders in other ways. As noted above, the Mental Capacity Act (Northern Ireland) 2016 section 3(1), is a different scheme entirely, assessing capacity with respect to ‘at the material time.’

^{xi} N.B. The Scottish Mental Health (Care and Treatment) (Scotland) Act 2003 section 329(1) has a similar definition, although this Act does not include the term ‘specialist’. The Mental Capacity Act (Northern Ireland) 2016 focuses more on a wider category of ‘decisions’, the outgoing Northern Irish Mental Health (Northern Ireland) Order 1986 section 2(2) included the following definition of ‘medical treatment’: ‘includes nursing, and also includes care and training under medical supervision.’

In this respect, it is certainly possible that the visual identifier might constitute ‘medical treatment’, especially where the visual identifier is a part of a wider care plan to treat or alleviate the mental disorder. However, the Revised Code also states:

‘This includes treatment of physical health problems only to the extent that such treatment is part of, or ancillary to, treatment for mental disorder (e.g. treating wounds self-inflicted as a result of mental disorder). Otherwise, the Act does not regulate medical treatment for physical health problems.’¹⁰⁸

Given the acute care context of the visual identifier, we envision that patients will often be admitted for the treatment of physical conditions unrelated (or only indirectly related) to their dementia diagnosis. In this context, the primary aim of the visual identifier is to highlight the needs of the patient’s otherwise invisible condition. Accordingly, perhaps the most natural description for the visual identifier in this circumstance is ‘treatment of a mental health problem that is ancillary to treatment for a physical condition.’ The Revised Code is silent on treatment fitting this description (Category C in Table 3 below), the position of treatments like the visual identifier under the MHA 1983 being less clear as a result. To be sure, treatment for a mental disorder that is ancillary to treatment for a physical condition may be covered as ‘medical treatment’ under the MHA 1983 but the treatment for the mental disorder must itself be justified under the Act.

Table 3: Typology for ‘medical treatment’ under the MHA 1983

	Treatment for a mental disorder	Treatment for a physical condition
Treatment ancillary to the treatment of a mental disorder	A (Central case of MHA 1983 ‘medical treatment’)	B (Included as ‘medical treatment’ under the MHA 1983)
Treatment ancillary to the treatment of a physical condition	C Visual identification system would likely sit here (Position unclear)	D (Treatment does not count as ‘medical treatment’ under MHA 1983)

Admission for treatment

MHA 1983 powers can be used to compel observation or treatment of a patient suffering from a mental disorder. Could patients be compelled to have the visual identifier applied as part of such treatment? In addition to the patient having a mental disorder, currently suffering from that mental disorder, and the treatment being directed toward the treatment or alleviation of that disorder, there are other grounds that must be satisfied if an application under the MHA 1983 is to be successful. Section 2 outlines these requirements:

‘(a) he is suffering from mental disorder of a nature or degree which makes it appropriate for him to receive medical treatment in a hospital; and

(b) ...

(c) it is necessary for the health or safety of the patient or for the protection of other persons that he should receive such treatment and it cannot be provided unless he is detained under this section; and

(d) appropriate medical treatment is available for him.’

These powers of compulsion set a high bar and are a last resort. At most points it will be more appropriate to seek the patient’s consent or use the MCA 2005 powers outlined below. Consequently, there will be few cases, if any, in which the visual identifier could be mandated under the MHA 1983, and so the use of the MHA 1983 powers for this purpose be approached with extreme caution.

Consideration: The MHA 1983 powers should *not* be used to compel the application of the visual identifier—other grounds, for instance patient consent, are preferable.

Mental Capacity Act 2005

The Mental Capacity Act 2005 (MCA 2005) provides the statutory framework to treat those unable to make decisions for themselves. Three clarifications are needed to understand the MCA 2005 and its relation to the visual identifier, namely: ‘who lacks capacity under the Act’, what counts as ‘inability to make a decision’, and ‘what treatment does the Act allow where the person lacks capacity’? We consider each in turn.

Who lacks capacity?

The MCA 2005 does not only apply to mental disorders but applies more generally to those that lack capacity, this begs the question: when will a person lack ‘capacity’ under the MCA 2005?

As noted earlier, ‘capacity’ under the MCA 2005 is assumed. Unless there is a compelling reason to think otherwise, the patient has capacity to make decisions regarding their treatment and care.¹⁰⁹ As noted at the very beginning of this legal analysis, where the application of the visual identifier is concerned, capacity to refuse the visual identifier should be assumed unless proven otherwise. More accurately, the healthcare professional should take ‘reasonable steps’ to establish whether the candidate has capacity to decide to have the visual identifier applied or not.¹¹⁰ In this respect, seeking patient consent to have the visual identifier applied is the default option.

Capacity under the MCA is also decision specific,^{xii} underlined by section 2(1) which states:

^{xii} N.B. both the Adults with Incapacity (Scotland) Act 2000 section 47(1)(a) and the Mental Capacity Act (Northern Ireland) 2016 section 3(1) also assess capacity with respect to the decision in question.

‘For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.’

Section 2(1) has two key elements. First, the use of ‘impairment’ or ‘disturbance.’^{xiii} Straightforwardly, the MCA 2005 Code of Practice specifically includes dementia as an example of an impairment or disturbance of the brain.¹¹¹ Second, the requirement that this ‘impairment’ or ‘disturbance’ results in the inability to make the decision in question, the decision in this context being the use of a visual identifier to signify a care need. It is this second element that requires some subtlety in practice.

Inability to decide

Assessing whether a person has the ability to decide whether to have the visual identifier applied has two key parts, namely: how inability is assessed under the MCA 2005 and what kind of decision is in question.

With respect to how the inability to decide is assessed, section 3(1) of the MCA 2005, provides a structure to that assessment, stipulating that:

‘a person is unable to make a decision for himself if he is unable—

- (a) to understand the information relevant to the decision;
- (b) to retain that information;
- (c) to use or weigh that information as part of the process of making the decision; or
- (d) to communicate his decision (whether by talking, using sign language or any other means).’

Section 3(4) of the MCA 2005 also notes the nature of the ‘information’ used:

‘The information relevant to a decision includes information about the reasonably foreseeable consequences of—

- (a) deciding one way or another, or
- (b) failing to make the decision.’

Accordingly, if a candidate for a visual identifier is to have it applied following the MCA 2005, they must be *unable* to understand, retain, use, or weigh information relevant to the reasonably foreseeable consequences of having the visual identifier applied or be unable to communicate their decision.^{xiv} In addition to this, section 3(2) also underlines that the simplicity and method of communication is relevant to

^{xiii} N.B. The Mental Capacity Act (Northern Ireland) 2016, section 3 similarly speaks in terms of ‘impairment’ or ‘disturbance’ in the functioning of the mind. The Adults with Incapacity (Scotland) Act 2000 applies the same definition found in the Mental Health (Care and Treatment) (Scotland) Act 2003. As noted earlier, this is considered to be a distinction without difference.

^{xiv} N.B. The factors relevant to establishing ‘incapacity’ under the Adults with Incapacity (Scotland) Act 2000 section 1(6) are broadly similar, the Act adding the inability to act. The Mental Capacity Act (Northern Ireland) 2016 section 4(1) is also similar, adding ‘appreciate the relevance of’ to the weighing of information.

this assessment—the person will not be unable to decide where simple language, visual aids, and other methods would allow them to understand.

Consideration: Appropriate patient decision aids should be developed to help patients understand the visual identifier, its purpose, and likely consequences.

The information relevant to the decision to apply the visual identifier is likely to be comparatively light in contrast with many of the complex treatment decisions facilitated by the MCA 2005. While the visual identifier might have wide-ranging social ramifications, changing how the person is viewed by those who understand the significance of the visual identifier, the identifier is not currently envisioned to be the basis for any further medical treatment. As such, it should not under any circumstances influence a treatment or care decision, as a recorded diagnosis might do: the use of a visual identifier for this purpose is improper, although certainly possible in an acute care setting. When deciding what kind of information should be provided, the MCA 2005 Code of Practice provides examples of what might be appropriate, also noting that ‘in some cases, a simple, broad explanation will be enough.’¹¹² Table 4 provides a non-exhaustive idea of the kind of general information that might accompany the decision to apply a visual identifier.

Table 4: General information that might be provided to patients

General information	
A	A description of the visual identifier
B	What the visual identifier signifies
C	Who is likely to recognise and understand the significance of the visual identifier
D	Decisions that may be taken as a result of the visual identifier
E	Express commitment that certain treatment and care decisions will not be based on the visual identifier
F	Specific contextual issues arising through the use of a visual identifier in combination with other factors (e.g. within a locked ward)

General information

G	How the patient may express concerns or withdraw from the visual identification system
H	When a decision to apply the visual identifier might be reviewed?

It is also important to note that the inability to make a decision may change according to the severity of the person's symptoms—forms of dementia allowing for 'lucid intervals.'^{113,114} Consequently, depending on the prognosis for that specific patient, inability to decide on one day may not preclude ability to decide the next.

Consideration: We emphasise that even if a person lacks capacity to decide whether a visual identifier should be applied, their wishes and thoughts should still be sought where possible.¹¹⁵ If the person had capacity and refused the visual identifier or had an advance decision stating as much, these views override the assessment of best interests described below.

'Best interests'

The visual identifier may be applied in the absence of consent under the MCA 2005 if the visual identifier is in the patient's best interest. What does this mean? When will the visual identifier be in a patient's best interest?

Section 1(5) unequivocally states: 'An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.'^{xv} Section 4(3) stipulates the process by which best interest is assessed, the assessor must consider:

(a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and

(b) if it appears likely that he will, when that is likely to be'^{xvi}

Given that the visual identifier may be applied to patients for the duration of their stay in acute care, the patient may well regain capacity, if only briefly in lucid intervals, meaning that their thoughts may then be sought.

^{xv} There are very few exceptions to this principle under the MCA 2005, research being one of the few.

^{xvi} N.B. The Mental Capacity Act (Northern Ireland) 2016, section 7(4) has identical provisions.

Where the person straightforwardly lacks capacity, section 4(4) requires that ‘so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.’^{xvii} In short, a lack of capacity should not typically result in a lack of participation by the patient.

Even where the person lacks capacity and is unlikely to regain such capacity, section 4(6) requires the following elements (where reasonably ascertainable) be used in constructing ‘best interests’:

- ‘(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
- (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
- (c) the other factors that he would be likely to consider if he were able to do so.’^{xviii}

Of course, these wishes, feelings, beliefs, values, and other factors may also be constructed by the duty in section 4(7) to take into account and where ‘practicable and appropriate’ consult the following people:

- ‘(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
- (b) anyone engaged in caring for the person or interested in his welfare,
- (c) any donee of a lasting power of attorney granted by the person, and
- (d) any deputy appointed for the person by the court,’

The purpose of such consultation being to consider what is in the person’s best interest.

In addition to the process outlined in the MCA 2005, the common law has also consistently emphasised the breadth of factors relevant to construing ‘best interests.’ For instance, Lady Hale in *Aintree University Hospitals NHS Trust v James*: ‘decision-makers must look at his welfare in the widest sense, not just medical but social and psychological.’¹¹⁶ Accordingly, application of the visual identifier under the MCA 2005 must be in a patient’s best interests, broadly construed, also likely taking account of the impact the visual identifier might have on their psychological welfare.

The problem of informal admission

The MCA 2005 and MHA 1983 provide a framework for the treatment of people who are currently suffering from a mental disorder or who lack capacity to make decisions about their treatment. Sometimes this will involve compulsory or ‘formal’ admission to hospital—for example, being detained or sectioned under the Mental Health Act. However, sometimes (commonly in the acute care setting)¹¹⁷ where patients with capacity volunteer for treatment or, where patients lacking capacity do not actively object, they are

^{xvii} N.B. The Mental Capacity Act (Northern Ireland) 2016 section 7(5) has very similar provisions.

^{xviii} N.B. The Mental Capacity Act (Northern Ireland) 2016 section 7(6)-(7) and (11) contains similar provisions with respect to information relevant to establishing best interests and the parties to consult outlined below. The Adults with Incapacity (Scotland) Act 2000 section 1(4)-(5) and (7) contains similar provisions with respect to the relevant information but a different set of parties to consult.

admitted ‘informally’ without relying on MCA or MHA powers.¹¹⁸ In the context of a visual identifier, this gives rise to four potential classes of patient as shown in Table 5 below.

Table 5: Classes of patient

	Patient acquiesces	Patient objects
Patient has capacity to refuse treatment	A (No special formality required)	B (Formality required, typically impermissible)
Patient lacks capacity to refuse treatment	C (Depends on the character of treatment)	D (Formality required)

Class A patients may be classed as ‘voluntary’ and so treated without any special formality under the MHA 1983 or MCA 2005. If this is the case, these patients are free to refuse the identifier at any point.

Class B patients may only have the visual identifier applied under very unusual circumstances as those with capacity typically have the right to refuse treatment.

Class D patients typically require some compulsory power under the MHA 1983 or MCA 2005. In short, unless there is an emergency, formality will be required to lawfully apply the visual identifier.

Class C patients may be treated according to the assessment of the best interests of the patient, so long as this treatment does not constitute a ‘deprivation of liberty.’¹¹⁹ If this is the case, the patient will fall within the ‘Bournewood gap’, and be subject to the deprivation of liberty scheme in the amended MCA 2005.^{120,121,xix} We do not expect the visual identifier itself to be characterised as a deprivation of liberty. Still, there is a concern that the identifier in combination with a locked ward makes the patient *de facto* unable to leave and subject to continuous supervision and control, thereby amounting to a deprivation of liberty.¹²² If this is the case, the formalities contained in the MCA 2005 must be completed.

^{xix} N.B. The Mental Capacity Act (Northern Ireland) 2016 is more ambitious than the other two jurisdictions, attempting to provide statutory footing for the common law of necessity. Accordingly, the Act attempts to largely bridge the gap left by the *Bournewood* series of cases.

Consideration: Careful thought should be given to the effect of the visual identification system when paired with other policies, for instance, whether the visual identifier paired with a locked ward might mean that patients with the identifier are then deprived of their liberty.

Consent to use of a visual identifier

As the analysis has already emphasised, where a patient has capacity to make a decision about the use of a visual identifier, this should be authorised only by obtaining their consent. This also means any refusal from a person with capacity must be respected. The courts have emphasised that incapacity in some aspects of a person's life does not prevent autonomous behaviour in others, nor does it remove the presumption of 'competence to refuse.'^{123,124} In the context of a visual identifier, any relevant advance decision refusing that specific treatment should also be complied with if it was made at a time when the person had capacity and is compliant with sections 24 and 25 of the MCA 2005. This can be invalidated if the patient has subsequently created a lasting power of attorney in favour of someone else to provide or refuse consent to the treatment.

Consent may be required for at least three related legal purposes:

- To authorise what would otherwise be unlawful touching or 'battery' (if this is involved in applying an identifier);
- As part of an evolving duty of care under the law of negligence to respect a patient's autonomy and right to self determination ('informed consent'), and;
- As the most likely means of authorising the disclosure of private and confidential patient information as part of the visual identifier.

In assessing whether a patient has the capacity to make these decisions, the same considerations discussed above in relation to the Mental Capacity Act 2005 and its associated Code of Practice are key: a person has to be able to understand, retain and weigh up the relevant information as part of their decision making. However, the meaning of 'relevant information' may vary according to the legal purpose. In this section we address the likely information standard required for the first two purposes, before considering the more complex issue of the standard required for consent to disclosure of confidential information (and related challenges this law raises for visual identifiers) further below.

Consent to physical touching

At the most basic level, the law has long required consent for lawful invasion of a person's physical or bodily integrity. The standards required for this form of consent are however, minimal. Consent to touching can be express or implied, for example by acquiescing to examination or raising an arm to a needle, and the patient only requires the capacity to understand and make a decision about the touching itself, not further

consequences or impacts. In harmony with the Mental Capacity Act 2005 Code of Practice discussed above, if the patient is informed in 'broad terms' then their consent to physical invasion will be legally valid.¹²⁵

Informed consent to use of a visual identifier

To the extent that use of a visual identifier can be conceived to be a part of medical care or a treatment, consent to that use has the important purpose of ensuring that a patient's right to self-determination and autonomy are respected. This is now a core part of the UK legal framework, following the passage of the Human Rights Act in 1998. However, the general way this is enforced by the courts is first and foremost within the established common law avenues of liability. In this context, the relevant avenue is liability for medical negligence. For a claim to succeed in negligence there will need to be a foreseeable form of legally recognised harm (such as personal injury) and evidence that negligent action or inaction caused that harm. This means that the standard of information required for an informed consent to treatment has only been sporadically discussed by the courts in cases where there has been serious and significant harm (most commonly physical injury) which has been allegedly caused by failure to properly inform or discuss material risks with the patient. This is clearly not a good fit for the context of consent to use of a visual identifier or the sorts of 'harms' that could result.

However, the case law in this area is still relevant for one key reason: over recent decades the courts have increasingly emphasised the importance, and consequences of a patient's rights to self-determination and autonomy as a guiding principle for consent to treatment. This reached a crescendo most recently in the case of *Montgomery v Lanarkshire Health Board*¹²⁶ where the Supreme Court endorsed professional guidance from the General Medical Council (GMC) and other authorities, to rule that:

'the doctor's advisory role involves dialogue, the aim of which is to ensure that the patient understands the seriousness of her condition, and the anticipated benefits and risks of the proposed treatment and any reasonable alternatives, so that she is then in a position to make an informed decision. This role will only be performed effectively if the information provided is comprehensible. The doctor's duty is not therefore fulfilled by bombarding the patient with technical information which she cannot reasonably be expected to grasp, let alone by routinely demanding her signature on a consent form.'¹²⁷

In the context of a visual identifier for dementia, this standard requires a comprehensible and sensitive explanation of the options and of any risks that could result from the use of the identifier. The Supreme Court has also ruled that the relevant risks here are not to be determined solely by health care professionals but include risks that a healthcare professional should be reasonably aware that the patient is likely to attach significance to.¹²⁸ It is difficult to identify many significant risks resulting from use of an identifier for dementia but perhaps one such 'risk' could be of stigma or discrimination, if a patient is particularly concerned about these possible consequences of using an identifier for dementia.

Ultimately, although it may be hard to imagine a consequence of flawed consent to the use of a visual identifier leading to harm so serious that it is actionable in negligence, this is the standard that would be applied to assess that consent process. Equally it is technically open to an individual to claim that a failure

to meet this standard is an unjustified infringement of their fundamental rights under the Human Rights Act 1998. Perhaps of more practical importance is that this standard of practice is required of professionals by the GMC and a failure to meet it could lead to investigation and sanction.

We noted above that this legal standard of informed consent is only likely to apply to the extent that a visual identifier can be conceived as medical care or treatment. If that is not the case then the consent standard could be less onerous, as it is for the disclosure of confidential information, an area of law very relevant to visual identifiers.

Confidentiality, privacy and the protection of personal data

A key part of the legal framework that will influence design and implementation choices for visual identification systems is the body of law that protects confidentiality, privacy and patients' personal data. This is not one single piece of law or legislation but is a collection of different legal duties and obligations with different origins, aims and requirements. There is overlap in the way that they all may apply to the same subject matter, but the differences mean that they need, for the large part, to be considered independently.

Confidentiality and the right to privacy

The courts have allowed claims for breach of confidence for over 150 years but the implementation of the Human Rights Act in 1998 led to the law of confidentiality being interpreted and applied in light of the right to respect for private and family life enshrined in Article 8 of the European Convention on Human Rights, and the jurisprudence developed by the European Court of Human Rights. This means that the approach and requirements of the law of confidentiality, the interrelated tort of misuse of private information, and an action against a public authority for infringement of human rights, should be equivalent where the information is of a private nature (e.g. medical information).

Visual identifiers as private or confidential information

The reason this law is so important in the development of visual identification systems is that such identifiers are highly likely to involve the disclosure of private and confidential medical information—a diagnosis—to all those who recognise and understand their meaning.

Not all personal information is necessarily private or confidential. The test is whether the circumstances give rise to a reasonable expectation that privacy will be protected.^{129 130} This is extremely likely to be the case in the medical context. For example, the courts have emphasised that the details of one's medical circumstances are 'obviously private'¹³¹ and deserve the full protection afforded by the law of confidence (subject to the slant given to it by the Human Rights Act 1998)—even if medical details are revealed in a public place.

To the extent that a visual identifier reveals that a patient has been diagnosed with dementia, the disclosure of that information through signs or symbols must be lawful and in accordance with the patient's right to privacy and confidentiality. The NHS has a Confidentiality Code of Practice (although it has not been updated since 2003) which sets out different approaches to the use of confidential information depending on the purpose.¹³² This approach is also followed by the GMC's 2017 guidance, Confidentiality: good practice in handling patient information.¹³³ These documents provide three main routes for lawful disclosure of confidential patient information which could form part of a visual identification system:

- Explicit consent to disclosure;
- Implied consent to disclosure as part of the healthcare of the patient;
- Disclosure in the public interest.

Explicit consent to disclosure

Perhaps the simplest way that use of a visual identifier could avoid infringement of privacy or unauthorised disclosure of confidential information is through the explicit consent of the patient to such disclosure. What is clear is that this requires information about how the information is going to be used and an agreement either orally or in writing. What is less clear is what level of information is required. In fact, there has been very little legal discussion of the informational requirements of a valid consent for the disclosure of confidential information—as opposed to consent under data protection law or (as considered above) informed consent to medical treatment.¹³⁴

Although there is at minimum a requirement for adequate information that explains in broad terms how confidential information will be used, as Chico and Taylor suggest,¹³⁵ this is not necessarily the same as importing the requirements for 'informed consent' to medical treatment established in the law of medical negligence.

In the context of a visual identification system, as we have already discussed in relation to the Mental Capacity Act 2005, an adequately informed choice is likely to require (at least) information about how the identifier is used (where it is made visible) and who is trained to recognise its meaning. If a patient who has capacity to make the decision refuses to consent, then it is possible to explore reasons for this and their understanding of the benefits and risks involved. However, this should not involve pressurising a patient and any competent refusal should be respected even if it leaves them at risk of harm.¹³⁶

As discussed above, it is a potentially challenging requirement to obtain explicit consent from patients with dementia in the acute care setting. This is because they may lack capacity to consent on a temporary or longer-term basis. The assessment of capacity must relate to this particular decision about application of a visual identification system and if it is possible to support a patient's ability to understand, retain, weigh up information, or communicate their wishes then steps should be taken to do so. Moreover, if it is possible to reasonably wait until the patient regains capacity to obtain consent, the decision should be postponed.¹³⁷ If the patient lacks capacity for this decision then the decision may be made by healthcare professionals on the basis of the best interests of the patient (as discussed above) taking into account the considerations in section 4 MCA 2005: evidence of previously expressed preferences; the views of someone close to the patient, or who the patient asks is consulted or who has legal authority to represent them; what the healthcare team know about the patient's wishes, feelings, beliefs and values and; whether the identifier is of overall benefit to the patient which outweighs any infringements to their rights and interests, including to privacy and confidentiality.

Implied consent to use of a visual identifier as part of direct care

An alternative option provided by the NHS code and GMC guidance is implied consent to sharing confidential information. Both make clear this is only available for disclosures which are for the direct care of the patient. Given the aims and purposes of visual identifiers in this context it could be strongly argued that disclosure in the form of an identifier would generally support the direct care and safety of the patient while they are in the acute care setting.

According to the GMC, 'implied consent refers to circumstances in which it would be reasonable to infer that the patient agrees to the use of the information, even though this has not been directly expressed'.¹³⁸ As Taylor and Wilson note, the implication of this and the 2003 guidance is that there *may be* circumstances where it is acceptable to assume that consent is implied by the patient's continued acceptance of care.¹³⁹

Consent cannot simply be implied without information being available to patients about how their diagnosis will be shared by a visual identifier. The GMC guidance requires that a patient has 'ready access' to such information, for example in leaflets, posters, on websites and face-to-face.

Consideration: Because visual identification systems are potentially novel, it is important that patients are made aware of this new tool and that they are not surprised by such sharing of information for their care.

The second requirement for a valid consent to be implied is that the patient must have an opportunity to object. This could be—depending on the mode of implementation—on the application of the visual identifier to the individual patient. Such an objection should be respected unless there is an overriding 'public interest' (see below) or the patient lacks capacity and the use of the visual identifier has been determined to be in their overall best interests.

However, there is a challenge to basing the disclosure of confidential information in the form of a visual identifier on the implied consent of the patient for purposes relating to their direct care. The relevant guidance provides that such consent is only available where the disclosure is to other members of the direct care team (i.e. other healthcare professionals). This is likely to be a central aim of a visual identification system. However, it could be that some systems will also aim for identifiers to be understood by a wider group, including hospital visitors, domestic staff or even other patients.

Indeed, if information is made available (as it must be) about the visual identifier then it is likely to be the case that other patients will be aware of its meaning and thereby recognise the confidential information (the diagnosis) it contains.

At present, this wider audience for a potential visual identifier would not fit within the implied consent framework for direct care purposes. However, recent work by Mark Taylor and James Wilson has proposed an alternative way of recognising when confidential medical information may be disclosed; by determining when disclosure is within the 'reasonable expectations' of the patient.¹⁴⁰ This concept is not alien to the courts because they have already established that, in assessing whether a right to privacy is engaged, the key question is whether there is a reasonable expectation of privacy in the circumstances.^{141,142,143} As Taylor and Wilson suggest, it is only logical that there are circumstances where there has been no invasion of privacy because the disclosure of information is within the 'reasonable expectations' of the patient. They argue that this could be the case where there are sufficient indications of a respect for individual autonomy and dignity (including signs of notification and acceptance) and that the courts have adopted an objective approach to assessing reasonable expectations of privacy. This means that neither the recipient nor patient's *actual* expectations will determine the matter. Instead, the courts adopt an 'objective' perspective and will consider the issue from the perspective of a hypothetical 'reasonable person' who is in the position of the patient. From this perspective, the courts will take a wide range of factors and considerations into account when they determine whether an expectation of privacy is *reasonable* in the circumstances. Taylor and Wilson argue that this should include the significance or sensitivity of the information, whether there has been notification and acceptance by the patient and any research that provides a more in depth understanding of patients' expectations.

If this alternative approach is adopted by the courts it could potentially legitimise sharing information in the form of a visual identifier where that use of information can be shown to be within the reasonable expectations of patients in acute care settings. As Taylor and Wilson propose, this could be approached like the concept of 'no surprises' using two questions:

- What has been done to ensure that people have reason to expect this use?
- What has been done 'to ensure that they accept it'?¹⁴⁴

Consideration: At present, the 'standard' approach to confidentiality means that use of an identifier which may be recognised by other patients and those outside the direct care team is not likely to be justified on the basis of implied consent.

Because of the difficulty this presents, there may need to be a renewed assessment of how visual identifiers fit with existing guidance and, if there is reliance on implied consent, whether this is only ever appropriate if disclosure is made exclusively to members of the direct care team. The novel approach to confidentiality based on reasonable expectations may be a better frame for this scenario than an overstretching of the concept of implied consent.

Public interest

Confidentiality is not absolute, so without express or implied consent it may be possible to lawfully disclose information as long as it is justified in the public interest for important public benefits. Similarly, the right to private life in Art 8 European Convention on Human Rights is not absolute, and is qualified by interference which is necessary in a democratic society to protect objectives such as health or the rights and freedoms of others. However, it would be difficult to justify the disclosure of confidential information in using visual identifiers by appealing to public interest, because any public interest justification has to meet a very high threshold of not only outweighing a patient's interest in autonomy and confidentiality but also the public interest in maintaining confidentiality of medical information. The GMC guidance makes clear this will only apply in exceptional circumstances such as when there is a significant risk of serious harm.¹⁴⁵ This means that the 'public interest' this is unlikely to be an appropriate basis for the disclosure of confidential information in the form of visual identifiers.

Statutory basis

One further way that confidential information could be lawfully disclosed as part of visual identification systems is if there is a further statutory basis which sets aside the duty of confidentiality. Some are provided in the Health Service (Control of Patient Information) Regulations 2002,^{xx} subject to approval by the Secretary of State or the Confidentiality Advisory Group of the Health Research Authority. However, none of these currently provide a justification for disclosure as part of visual identification systems.

Implications for visual identifiers for dementia in the acute care setting

The key implications of this legal framework for the design and implementation of visual identifiers for dementia in the acute care setting are:

- Privacy and confidentiality require that identifiers should be as discrete and minimally disclosing of private information as possible.
- Either explicit consent of the patient, or, if the patient lacks capacity, a decision that the use of an identifier is in their best interests, are the most robust means of justifying disclosure of a diagnosis in the form of a visual identifier.
- If visual identifiers can be developed that are only recognised by those providing care to the patient then it is possible that consent may be implied, providing information about the visual identifier has been made available and the patient does not object.

^{xx} Enabled by the National Health Service Act 2006 (as amended), s 251.

- The need to make information about the visual identification system available and requirements of practicality and effectiveness may lead to identifiers being understood by those outside the care team (i.e. other patients). If so, consent to such disclosure cannot easily be implied based on existing guidance.

There is a potential trade-off between developing visual identification systems that are immediately recognisable, simple and effective in the acute care setting, and ensuring that disclosure of private, confidential information is as limited as possible. However, it is possible to obtain explicit consent to disclosure so long as the patient is made adequately aware of the nature of the visual identification system. This does not necessarily require a fully ‘informed consent’ in the way the courts have required when deciding on a medical course of action (i.e. as recently emphasised by the Supreme Court in *Montgomery*). Patients should be supported to make such choices as far as possible. If they lack capacity then it must be determined whether it is reasonable to wait until they may regain it or whether a decision can be made, drawing on evidence of the patient’s values and wishes, and consulting carers and relatives, in the patient’s best interests.

Such decisions and consent conversations will need to be on a sensitive case-by-case basis and no blanket policy or approach can be applied to all circumstances.

Visual identifiers as ‘personal data’

A further related and important part of the regulatory framework is data protection law, which is concerned with the ‘processing’ of ‘personal data’. In the UK and EU/EEA this is governed primarily by the EU General Data Protection Regulation (GDPR). This Regulation aims to protect the right to privacy as well as the related right to data protection, and sets out legally binding principles, rights and obligations that must be met when carrying out almost any form of operation (‘processing’) with or using personal data. ‘Personal data’ means any information relating to an identified or identifiable individual¹⁴⁶ (the data subject) and any personal data relating to the physical or mental health of a person fall within a category of ‘data concerning health’ which are subject to higher protection under Article 9 of the GDPR.

Information does not have to take a particular form, e.g. a written form, to be personal data and it is possible for simple signs or symbols to constitute ‘personal data’ if they provide information about an identifiable person. This means that any visual identifier that is connected to an individual patient is certain to be regulated as personal data (and also data concerning health) under the GDPR.

The GDPR will require a lawful basis for using the identifier (and that an Article 9 condition for processing health data is met). As with the disclosure of confidential information, one possibility is the explicit informed consent of the patient to the specific use of their data as part of a visual identification system. However, as well as the challenges of consent already mentioned in this context, there are high standards for consent under the GDPR. In particular, there is caution against situations where there may be an ‘imbalance of power’ between the data controller and the data subject (in particular where the data controller is a ‘public authority’ as it would be in the case of the NHS) and consent to use of an identifier would be invalid if it was a condition for receipt of ‘normal’ care.

Unlike confidentiality, there are arguably better alternatives to consent available as a lawful basis for the use of visual identifiers. In the NHS context, a visual identifier could be justified as necessary for the performance of a task in the public interest (Art 6(1)(e)) and Art 9(2)(h) specifically allows the processing of health data if it is necessary for the provision of health or social care or treatment.

Data protection law has a close relationship with confidentiality however, and the UK's Data Protection Act requires that processing for health purposes under Art 9(2)(h) is only carried out:

- '(a) by or under the responsibility of a health professional or a social work professional, or
- (b) by another person who in the circumstances owes a duty of confidentiality under an enactment or rule of law.'¹⁴⁷

Because this allows processing 'under the responsibility' of a health professional, it is likely to legitimise (for data protection purposes only) the use of an identifier in the acute care setting even where some other colleagues and members of the public are likely to recognise its meaning.

The GDPR places emphasis on transparency about how and why data are being processed and sets significant standards for information that must be made available to data subjects (Articles 13 & 14). However, the Regulation allows different modes of providing information so long as they are appropriate and proportionate to the processing taking place, which means that notices, leaflets or other methods could be acceptable ways of informing patients about an identifier.

A range of further rights and obligations will apply to the processing of personal data in the form of a visual identifier, and there may need to be an up-front assessment of the precautions and safeguards that should be put in place in the form of a written data protection impact assessment. The Information Commissioner's Office provides useful guidance on relevant legal and practical issues.¹⁴⁸

Beyond the need to carefully consider and justify the processing of personal data as part of a visual identifier, data protection law does not present any barrier to the development of a wide range of different types of visual identifier.

Consideration: Visual identifiers will need to be as limited as possible in terms of the information they provide and the range of those who recognise their meaning, while still achieving their goals.

Non-discrimination and equality

We have already considered ethical aspects related to equity, fairness and justice. These are also all relevant to, and reinforced by, parts of the regulatory framework that require decision-makers to have regard to the impact of their decisions on certain groups, including dementia patients, and to guard against unjustified discrimination in their care.

At the level of fundamental rights, the European Convention on Human Rights enshrines the right not to be discriminated against in the enjoyment of the rights and freedoms set out in the Convention (Art 14) on

multiple grounds, including the grounds of disability, medical conditions or genetic features.^{xxi} This right is transposed into UK law through the Human Rights Act 1998 which makes it unlawful for public authorities (such as NHS trusts) to act in a way that is incompatible with these convention rights.¹⁴⁹ This is relevant to the development of visual identification systems and it will guide courts in their interpretation of other legislation and their decisions.

However, the principles of non-discrimination, equity and equality are given more substantive protection by the Equality Act 2010, which applies to England, Wales and Scotland (with some slight differences). This consolidates and updates multiple previous anti-discrimination laws and implements an EU Directive¹⁵⁰ to protect against discrimination based on certain characteristics such as sex, race, religion, age and disability.

The Equality Act 2010 is relevant to the implementation of a visual identification system for dementia in acute care settings in a number of ways. At a general level, it imposes a public sector equality duty (PSED)¹⁵¹ on public authorities such as NHS Trusts to advance equality of opportunity between those with protected characteristics and those without. This includes having due regard to minimising disadvantages and the need to ‘take steps to meet the needs of persons who share a relevant protected characteristic that are different from the needs of persons who do not share it.’¹⁵² At a more specific level, the Act sets out further duties such as a duty to make ‘reasonable adjustments’—changes to practice to prevent disadvantage—in the provision of a service, such as health care.¹⁵³

Although the Equality Act 2010 does not apply in Northern Ireland, very similar general and specific duties will apply to the development and implementation of visual identification systems in the acute care sector under separate legislation.^{xxii}

What this means for the design and implementation of visual identification systems is that NHS Trusts and other public authorities are required to carefully consider how a visual identification system could impact dementia patients and to ensure that it does not lead to increased disadvantage for them or other patients.^{xxiii} One specific consideration could be to ensure that the use of an identifier does not act as a proxy for a diagnosis of dementia and that patients who are not offered the identifier, or who choose not to accept it, should not receive inappropriate care as a consequence.

However, the positive impact of this law for the development of visual identifiers is it also provides a potential imperative for healthcare providers to apply them if they can be shown to develop appropriate visual identification systems to meet the specific needs of dementia patients, and as a ‘reasonable adjustment’ to reduce disadvantages in the care they receive.

^{xxi} The European Court of Human Rights has confirmed that the scope of Article 14 of the Convention and Article 1 of Protocol No. 12 included discrimination based on disability, medical conditions or genetic features (*Glor v Switzerland* ECHR 2009-III, [80], *G.N. and Others v Italy* App no 43134/05 (ECtHR, 1 December 2009), [80], *Kiyutin v Russia* ECHR 2011-II, [57].)

^{xxii} A general duty is applied by section 75 of the Northern Ireland Act 1998 and the specific duty to make reasonable adjustments applies under section 21 of the Disability Discrimination Act 1995 (as amended).

^{xxiii} This may be via an equality impact assessment, although these are no longer mandatory in England.

Consideration: If developed appropriately, visual identifiers could help fulfil the legal duty to take specific steps to meet the needs of patients with dementia. However, there must be care that the identifier does not lead to disadvantage to patients who choose not to accept it.

These requirements are also reinforced by multiple aspects of the regulatory and policy framework governing the NHS, such as high-level duties to have regard to the need to reduce inequalities in outcomes or provision of health services^{xxiv} and by the NHS Constitution.¹⁵⁴

Chapter conclusion

There are many areas of law and regulation relevant to visual identifiers for dementia. This analysis has explored the most important of these, noting potential challenges for the development of visual identifiers and how they might be developed to be consistent with established legal frameworks. Many of these challenges and legal considerations will depend upon the specific protocol (or protocols) settled upon by future phases of the DA VINCI project. Consequently, we encourage those developing and implementing the visual identification system to consider the conclusions of this legal analysis and make necessary adjustments.

In particular, we highlight the following points:

- There are two broad questions that should be kept in mind: how can the overall visual identification system be consistent with established law and whether the application of the visual identification system can be lawfully applied to any given individual.
- The starting point for any legal analysis of the visual identification system is that patients with dementia have the same legal rights as any other individual.
- Wherever possible, consent should be sought for application of the visual identifier to specific patients. This consent sought may require consent to physical touching where the identifier is applied to the patient themselves and must meet the professional and legal standards set.
- Appropriate patient decision aids should be developed to support the use of the visual identification system—this should be done to maximise the pool of patients able to consent.
- Even where a patient is unable to consent, they should be involved in the decision to apply the visual identifier to the fullest extent possible.
- MHA 1983 powers should not be used to compel the application of the visual identifier—alternative grounds should be sought wherever possible.

^{xxiv} This applies to the Board of NHS England for example under the NHS Act 2006 (as amended by the Health and Social Care Act) s.13G.

- The visual identification system when combined with other policies may have concerning legal consequences, for instance, the visual identifier in combination with a locked ward policy may constitute a ‘deprivation of liberty’, thereby requiring special formalities.
- Implied consent is unlikely to be a secure basis to share confidential patient information or as a legal basis for the sharing of personal data.
- The visual identification system should have explicit limits on the level of confidential patient information communicated and the range of individuals who will recognise their meaning. The nature and amount of confidential patient information shared must be proportionate to the aims of the visual identification system.
- Refusal of the visual identifier should not disadvantage patients.

Overall, we emphasise and underscore that the visual identification system has the potential to assist healthcare professionals (and others engaged in patients care) in the fulfilment of their primary legal duty: to provide the highest standard of health for patients regardless of condition, in this case, dementia.¹⁵⁵ The next chapter distils the ethical and legal content discussed in previous chapters into a set of key principles—which should help ensure that any visual identification system adopted fulfils its full potential.

Chapter 4: Key principles

This chapter, which is also available as a standalone document, identifies key principles to inform the development and implementation of visual identification systems. This report interprets visual identifiers as signs or symbols placed on or near a person with dementia in an acute care setting, in order to make their dementia visible to hospital staff.

Methodology

Constructing these principles has been an iterative process. Common themes, tensions and challenges identified as part of the early findings from the ethical analysis (Chapter 2) and legal analysis (Chapter 3) were distilled into key principles which were identified as key to the development and implementation of visual identification systems. These draft principles were presented to an Expert Collaborative Group (ECG) at a workshop on 6 July 2020, details of which can be found in Annex 1. We then further refined the principles and aspects of the analyses in response to their feedback.

The principles

Key principles are outlined below, and in each instance are translated into the dementia care context, accompanied by examples of the ways in which visual identification tools could affect the application of the principle, and be interpreted in line with the relevant legislation. The aim of this document is to illustrate the significance of each principle in this context and to demonstrate how its application can optimise the potential benefits and minimise harms, enabling a more ethical approach.

This set of principles is comprehensive, although not exhaustive, and is intended to draw attention to the potential benefits and harms of using these tools. This aims to be a useful resource for all relevant stakeholders developing and implementing visual identification systems.

These principles are not absolute and can conflict, leaving it unclear what one should do in a particular situation. Balancing these principles will depend heavily upon the particular context and setting. Some principles may be given more or less weight in the high pressure, fast paced setting of acute care. Additional factors which might influence the outcome include issues such as timeliness—is there urgency for the decision being made—and the character and values of the individual weighing them up. Sometimes the principles might motivate similar actions, but in other situations, they might be in opposition, creating opportunities for professional judgement. We address how the principles might be balanced with each other, at the end of the document.

Autonomy

■ Interpreting this principle in the context of dementia

Conceptions of autonomy that primarily value rationality, independence and capacity are not sufficient in the dementia care context. Instead, a more nuanced interpretation that views autonomy as consistent with dependency should be adopted. Rather than conferring solely a negative obligation to protect from harm or interference, a key facet of this principle is a positive obligation to promote autonomy through encouraging individuals to retain and express their sense of self. In some instances this might manifest through aspects of daily life—relationships, interests and values—rather than medical decision making.

■ Issues arising from the visual identifier

If not implemented properly, visual identifiers might threaten individual autonomy through drawing attention to the label of ‘dementia’ and inadvertently fostering a generalised understanding of patient needs (for example that a patient is unable to walk independently or in need of high levels of support at mealtimes). Rather than solely identifying a condition, this tool must be used as a first step in a wider care response where the care provider acts as an advocate for the person with dementia or suspected dementia, helping to foster their unique capabilities, skills, relationships and preferences. These are necessary for self-expression and the promotion of personal autonomy.

■ Legal considerations

Autonomy is a core legal and bioethical principle, represented across key pieces of legislation, international instruments, and case law. It mirrors the ethical obligation, encouraging the active promotion of autonomy, beyond non-interference, to the extent that this is reasonable and possible. The starting point, enshrined in national legislation, is that a person must be assumed to have capacity unless a lack of capacity is established (Mental Capacity Act 2005). If a person with capacity refuses the visual identifier then this refusal must be respected. Even if a lack of capacity is established, people should be supported to participate as fully as possible in any decision about their care, treatment or support. This will often include being asked for their consent to a proposed intervention. Any intervention selected should be the least restrictive option, that maximises a person’s independence, and it should be delivered in a manner that shows respect for individual autonomy, recognising the freedom to make one’s own choices.

In the context of a visual identification system this suggests that the principle of autonomy should be integrated throughout the process of applying and using visual identifiers.

■ Recommendations

1. Patients should participate as fully as possible in decisions about using a visual identifier as part of their care. In particular, this will require appropriate consent processes to be put in place for instigating visual identifiers, which embed consultation and discussion of patient and carers’ views.

Where a patient is unable to voice their views, substituted judgment—where healthcare professionals and family members try to make the decision that the patient would have made if he or she were able to—may be sought to construct their wishes.

2. Beyond this, the promotion of autonomy will require healthcare professionals to help individuals retain their capabilities and foster their interests and relationships.

Beneficence and non-maleficence

■ Interpreting this principle in the context of dementia

In dementia care, as in all healthcare, the bioethical principles of non-maleficence (avoiding doing harm) and beneficence (doing good) are considered to be pillars of medical practice. These parallel principles generate overarching moral duties to protect and promote patient safety, and are considered essential for fostering trust between the physician and patient. The former gives rise to a constant duty to avoid causing harm or injury to the patient, through act or omission, whereas the latter calls for positive and direct steps to promote health. However, the reality of medical practice is that 'doing good' almost always involves some aspect of 'doing harm' and so they have to be balanced against one another, as well as against other competing interests. In addition, what constitutes 'harm' or 'benefit' in a particular context for a particular patient is not always clear, and to act on these principles without taking into consideration others (such as autonomy), can lead to paternalism and hinder the provision of ethical care. This is a common concern in dementia care, where individuals do not always have the capacity to make significant medical decisions.

■ Issues arising from the visual identifier

Although visual identification systems aim to promote beneficence i.e. through drawing attention to the specific needs of the individual, there are a number of potential harms that should be guarded against. Key concerns include that the labelling of the individual with a dementia diagnosis could lead to stigma, the dehumanisation of the patient and the loss of autonomy and privacy. Further harms (as well as opportunities) are possible, including practical side-effects, e.g. that a simple identifier becomes relied upon to tailor patient care, in place of a more thorough assessment of their needs and wishes. Therefore, the ethical use of visual identifiers relies upon careful evaluation of how to balance these possible harms against the potential benefits to patient safety and wellbeing. Tolerances for, and views of what constitutes a 'harm,' are integral for this assessment.

■ Legal considerations

The general legal framework that underpins mental health law often goes further than the general bioethical, legal, and professional duties of beneficence and non-maleficence, requiring (if the patient lacks capacity) that the treatment be in their *best* interest. Determining this may not be straightforward and should not be based on assumptions about age, appearance or a condition the person has.

Often, ascertaining the patient's wishes may involve a discussion with family members. The Mental Capacity Act 2005 requires (where practicable and appropriate) that anyone the patient names or 'anyone interested in his welfare' is consulted when establishing best interests. The views of the family do not act as a proxy, but they may be able to provide insight into the patient's preferences, for example, by recalling conversations about the person where they expressed a view which relates to their current circumstances, or sharing how they responded to similar treatments or interventions in the past.

■ Recommendations

1. Those designing visual identification systems need to carefully consider the potential harms associated with their implementation and take steps to ensure that their cumulative benefits outweigh any risks of negative impacts.
2. Once visual identification systems are implemented, healthcare professionals will need to ensure that the benefit of using an identifier outweighs the potential harms for each individual patient and that it is in their best interests if they lack capacity to decide for themselves.

Dignity

■ Interpreting this principle in the context of dementia

Basic human dignity is considered to be intrinsic to all humans, regardless of faculties, acting as a ground for human rights. Personal dignity, however, is a type of dignity that is subjectively experienced by an individual and relates to a sense of worthiness. It can be influenced both by an internal aspect (the worth and self-respect an individual ascribes to themselves) and by an external aspect (the worth and value ascribed by others). Those with dementia are particularly at risk of suffering a loss of personal dignity as the result of the direct impact the disease has on their physical and mental capabilities, identity and sense of self. This can be exacerbated by relational interactions with healthcare professionals and family or carers, which can serve to promote or undermine personal dignity.

■ Issues arising from the visual identifier

Personal dignity means different things to different people, and is dependent to some extent upon cultural and societal norms. Therefore, what is important for each individual in order to preserve their dignity can vary. There has been much debate about how to achieve dignified care with emphasis being placed on aspects such as compassionate care, genuine respect for the person, person-centred environments and maintaining the individual's sense of meaning and purpose. Consideration of whether the visual identifier enables attitudes, behaviours and practices that affirm the individual's self-worth is crucial, as human interactions have the potential to be 'dignity encounters' that can either preserve or violate dignity.

■ Legal considerations

Multiple international instruments have dignity as a core principle, including the UN Convention on the Rights of Persons with Disabilities which lists 'respect for inherent dignity' and 'respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.' Codes of practice also note the core importance of dignity. For instance, the revised Mental Health Act 1983 Code of Practice includes dignity as a guiding principle, noting: 'patients and carers should be treated with respect and dignity. Practitioners performing functions under the Act should respect the rights and dignity of patients and their carers, while also ensuring their safety and that of others.' Indeed, the Code of Practice goes further in establishing dignity as the means of preventing potentially harmful outcomes, such as discrimination and breaches of patient privacy.

■ Recommendations

1. In this context, dignity is most strongly felt as a respect for difference. The visual identification system should be sensitive to the needs of individual patients and so the use of a visual identifier may not be appropriate for all patients.

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2. The identifier should provide as rich a resource as possible to understand the patient and their needs, keeping in mind the demands of confidentiality and privacy. For example, different identifiers could be used for confirmed and suspected diagnoses of dementia.

Equality and justice

■ Interpreting this principle in the context of dementia

Human dignity presupposes that humans all possess ‘basic equality’, being owed equal concern and respect. Discrimination is one way in which this basic equality may be violated, in turn causing an injustice. Discrimination viewed as a form of injustice is morally objectionable because it violates the formal principle of justice to ‘treat equals equally.’ The question in the context of dementia care is what it means to treat ‘treat equals equally’, given that those with such cognitive impairment often require more resources and attention.

■ Issues arising from the visual identifier

The intention of the visual identification system is to make the patients’ otherwise hidden needs plain to those charged with their care. In doing so, it seeks to be a tool to promote inclusion. However, where implemented incorrectly and without an appropriate care response, the identifier also has the potential to facilitate stigmatisation and to disenfranchise the ability of those individuals to have the time and space to speak for themselves.

Promoting equality and non-discrimination will also require that those who opt out or decide against the use of a visual identifier receive the same standard of care, and are not negatively impacted by this choice.

■ Legal considerations

Non-discrimination also forms a core part of the human rights framework, for example, Article 14 of the European Convention on Human Rights enshrines the right not to be discriminated against on the grounds of disability, medical condition or genetic feature (amongst others). In the UK a variety of further laws establish more specific rights and corresponding duties on public authorities such as NHS trusts, for example, to minimise disadvantages, tailor care and meet the needs of patients. This means that NHS Trusts and other public authorities are required to carefully consider how a visual identification system could impact patients with dementia and to ensure that it does not lead to increased disadvantage. However, this also provides a potential imperative for healthcare providers to develop appropriate visual identification systems to meet the specific needs of patients with dementia and as a reasonable adjustment to reduce disadvantages in the care they receive.

■ Recommendations

1. Using ‘dementia’ as a label as part of a visual identification system should not obscure the differences between patients.
2. The use of the visual identification system should not disenfranchise individuals from having their voices heard and recognised.

3. Equally, refusing a visual identifier should not negatively impact upon the care that the individual receives.

Confidentiality, privacy and the protection of personal data

■ Interpreting this principle in the context of dementia

Confidentiality, patient privacy and their right to data protection are integral to good medical practice. These separate but related concepts are particularly important in this context where highly sensitive information about a person is disclosed on the basis of trust and confidence that it will not be misused, shared without authorisation, or result in an invasion of privacy or other harms. A disclosure of a diagnosis of dementia for the direct care of the patient is part and parcel of healthcare. However, the risk of deliberate or unintentional disclosure of dementia diagnosis beyond those caring for the patient makes it challenging to establish an ethical and legal basis for wider communication.

■ Issues arising from the visual identifier

Visual identifiers raise significant challenges for confidentiality, privacy and rights to data protection. This is because their aim is to disclose sensitive medical information—a diagnosis—to professionals and service staff who have been trained to understand their meaning. However, certain symbols, such as the forget-me-not flower, could be more widely recognisable as a symbol of dementia and have the potential to disclose a diagnosis to visitors and other patients. Patients' privacy, confidentiality and rights to data protection are not absolute. Where possible, the ethical and legal framework seeks to ensure that these principles and rights are not infringed by adopting mechanisms to obtain consent or authorisation from the individual. However, where a proposed visual identifier generates conflict, a careful balancing is required between these principles as well as associated rights and interests, and the benefits from the corresponding care response.

■ Legal considerations

Confidentiality, privacy and data protection engage separate but interrelated parts of the legal framework. Taken together, they give rise to some important considerations for the design and development of visual identifiers. One is that the more widely recognisable the identifier, the greater the potential conflict with these principles and the harder it will be to justify its use. It is also the case that the more information an identifier conveys, the greater a potential invasion of privacy and breach of confidentiality. A further challenge is that, under current guidance and precedent, it is most likely that explicit patient consent will be required for the use of a visual identifier *if* the identifier is understood by people who are not providing direct care to the patient (e.g. other patients and visitors). If a patient lacks capacity to make this decision, then a decision must be made as to whether an identifier is in their best interests (as considered above). Either way, information will need to be provided, at least at a general level and in the form of leaflets or other accessible forms, about the visual identification scheme and how patient information is intended to be used. Unfortunately, this creates a direct challenge to the use of visual identifiers, limiting the range of people who understand what an identifier means.

■ Recommendations

1. The principles of privacy and confidentiality require that visual identifiers for dementia should be as discreet and minimally disclosive of private information, to as few people, as possible while still achieving the benefits and aims of the identifier.
2. Some information will need to be provided to patients about the visual identifier but this will require careful consideration because it may widen the range of people who will recognise its significance.
3. If visual identifiers are understood by people who are not providing direct care to a patient (e.g. other patients or visitors) patients should be supported to make an informed choice about the use of an identifier. If they lack capacity, then it must be determined whether it is reasonable to wait until they may regain it or whether a decision can be made, drawing on evidence of the patient's values and wishes and consulting carers and relatives, in the patient's best interests.

Compassion

■ Interpreting this principle in the context of dementia

Compassion is not a traditional ethical principle, but instead is a character trait or emotion that is widely considered to be a key component of quality dementia care. Virtue ethics (a theory of morality grounded in character centred moral judgements) argues that feeling compassion regulates action, and so calls for individuals to *be* compassionate. In other words, the compassionate person will not only feel compassion but act compassionately. According to virtue ethics, it is not sufficient for the visual identifier to be beneficial, but it must be used in the right way and for the right reasons if it is to be virtuous. Although aspects of this seem aspirational, viewing compassion as a virtue could offer lessons for the use of visual identification systems, providing insight into the assessment of individual patient needs and ways to address these. In the context of dementia care, being compassionate could be beneficial, for example, where the patient's wishes must be constructed through substituted judgement. However, to feel compassion for someone *solely* because they have dementia, rather than because of the burdens that this may cause for them is to feel compassion for the wrong things in the wrong way. Additionally, to feel too much or too little compassion can be harmful.

■ Issues arising from the visual identifier

The primary motivation for the implementation of the visual identifier should be to make the specific needs of the person with dementia plain, rather than for administrative convenience. The implementation and delivery of the visual identifier should reflect the compassion that motivates its use. In other words, it should be a facet of a compassionate system, and be performed by compassionate healthcare professionals. The environment, medical culture and organisational structure of the hospital are key to facilitating compassionate care, as is the education and training of the healthcare professional to enable them to identify, understand and respond to care needs.

■ Legal considerations

There are no legal duties to act compassionately *per se*, but meeting the standard of care required of medical professionals, and complying with the duties arising from the other principles outlined in this document, are highly likely to be supported by and fulfilled through compassionate care.

■ Recommendations

1. The primary motivation for implementing and applying the visual identifier should be as part of a compassionate and empathetic care response to the specific needs of those with dementia, not administrative convenience or a shorthand in order to save time.

2. Delivering a visual identification system in a compassionate way is likely to require embedding it within a wider practice of empathetic care, which involves formal training and support for both clinical and non-clinical staff.

Holistic care

■ Interpreting this principle in the context of dementia

Increasingly, policymakers and healthcare professionals are advocating the adoption of a holistic, person-centred approach to dementia care. This involves seeing the individual as a unique and whole person. Rather than solely focussing on disease or symptoms, healthcare professionals should take into account other dimensions affecting individual wellbeing, such as abilities, interests, needs and preferences.

■ Issues arising from the visual identifier

Visual identifiers are used to aid the recognition of hospitalised people with dementia and their individual needs. In doing so, they bring this diagnosis and its associated symptoms to the fore. As a result, attention may primarily be awarded to the physical and medical dementia-related needs of a patient, highlighting the visibility of the diagnosis whilst inadvertently reinforcing the invisibility of the person and any other relevant medical or non-medical needs they may have.

However, within a culture where the diverse requirements of individuals with dementia are recognised, visual identifiers may promote holistic care, so long as generalised understandings and expectations of 'dementia needs' are replaced by a wider appreciation of individual care needs. Placing an emphasis on the importance of the relational aspects of the healthcare encounter further promotes holistic care through enabling patients to feel respected and listened to.

■ Legal considerations

Many of the assessments required by the framework of mental health legislation and case law require a broad view of the patient's welfare and 'best interests.' Supporting case law on the interpretation of 'best interest' clarifies that 'in considering his [the patient's] best interests, the clinical team have to consider the patient's welfare in the widest sense, not just his medical but his social and psychological welfare.'

■ Recommendations

1. Healthcare professionals should have a clear understanding of the variable etiology and impacts of various types of dementia and the highly variable, fluctuating needs of the individual. They should take into account the impacts of, and reasons for, acute admission.
2. When assessing whether the visual identifier will be beneficial to the patient, the patient's welfare should be construed broadly, also taking into account their social and psychological welfare.

Interpreting principles

It is widely accepted that ethical principles, virtues, and their legal equivalents cannot be interpreted in isolation. Sometimes, these principles will overlap and reinforce each other where elements of principles are found in other distinct principles. For instance, often the course of action that is autonomy-promoting is also the action that will preserve the patient's dignity and vice versa. Nevertheless, it is also widely accepted that these bioethical principles and their legal equivalents may conflict with each other, there being friction between the competing claims of each. In this way, if we were to take actions only according to the principle of beneficence, this would inevitably, at some stage, conflict with, and come at the cost of, the principle of autonomy. Accordingly, we should envisage situations where these principles conflict and consider how to resolve any such friction.

The literature on moral judgment and the balancing of principles is complex and contested. However, the following rules may assist when balancing principles.

Where possible, there should be close scrutiny which assesses whether, in fact, the principles are in conflict. This could be helped by:

1. Where a conflict between principles is envisaged, the principles should be specified as far as possible to avoid conflicts. For instance, where the patient wishes not to have the visual identifier applied to them, is this truly a conflict between autonomy and beneficence, or does their disagreement also reduce the benefit of using the visual identifier in this instance?
2. Where values or principles conflict, the moderating principle of proportionality should be invoked. This principle should make us consider whether the action that promotes one principle is proportionate to its associated cost. For instance, given the individual patient's context, if the visual identifier is invoked primarily to ensure their needs are clearly signalled, is there another strategy that meets this need that does not come at the cost of patient privacy?
3. Where a conflict cannot be avoided via specification or by application of the principle of proportionality, the patient's thoughts should be sought or constructed through substituted judgment as this may tip the balance in favour, or against, the application of the visual identifier. We note that where a patient with capacity expressly wishes not to have the visual identifier applied, this will often be determinative.

Where there is an unavoidable conflict and a moral dilemma exists, the following strategy may be helpful:

The key to proper balancing of principles is practical wisdom (*phronesis*).^{xxv} There is no substitute for experience in dealing with moral dilemmas in their context. In this regard, advice should be sought from colleagues who have developed attuned professional judgment through practical experience or expertise.

^{xxv} In Aristotelian terms, *phronesis* is wisdom developed through practical experience.

Conclusion

In preceding chapters of the report we have reviewed relevant literature, legislation and case law relating to the development and use of a visual identification system to support people with dementia in an acute care setting.

There are many instances in which the ethics and legal analyses complement each other: autonomy, justice and dignity emerge as strong themes which are reflected both in the ethical and the legal literatures. Other concepts feature predominately in either the ethical or the legal frameworks, such as the philosophical underpinnings of personhood, and values of holistic care (for the ethical analysis) or the constraints and protections bound up in the assessment of legal capacity and valid consent (for the legal analysis).

Put simply, the findings from our analyses suggest that when considered in tandem, the ethical and legal frameworks work together to create an environment in which the personal rights of patients are respected through an interconnecting set of obligations (including ethical obligations of dignity and non-maleficence); that standards of care are optimised through compliance with legal requirements such as professional standards for privacy and confidentiality and statutory requirements such as the Mental Capacity Act; and the professionalism of caregivers is sustained by qualities of compassion and the somewhat aspirational requirements of ethical frameworks such as virtue ethics.

Taken together, these frameworks seem to provide a robust structure which is compatible with the development and use of a visual identification system.

However, our analyses highlight the key role that education and training play in developing and implementing such systems. This is vital to ensure that they are used to promote and support the interests of patients rather than undermine them. This is particularly important given empirical evidence that in some settings, the visual identifier was used as a proxy for a diagnostic label, which, without underpinning systems of education and awareness raising, could quickly become an instrument for stigmatisation and discrimination.

A further caution prompted by the legal analysis, is the potential friction between the need to protect the privacy interests of patients through limiting the use of the visual identifier to those professionals who are directly involved in health care delivery, and extending the reach of the system to staff not directly involved in patient care, but who may nevertheless have meaningful, if fleeting, contact with patients such as ward receptionists, cleaners and porters. The strong feedback from the workshops with Expert Collaborative Group members (described in Annex 1) suggested that those team members without a direct care relationship with the patient might have most to gain from the use of a visual identification system: our ethical analysis suggests that a mechanism for this might be through nurturing the relational aspects of care, however our legal analysis provides some caveats to implementing such a system.

The key principles document represents a distillation of these ethical and legal themes. We have set out the broad underpinnings of each theme, developed it in the context of a visual identification system and proposed some recommendations for further phases of the research and for the eventual development and implementation of one or more exemplar visual identification systems.

These are not an exhaustive list of considerations. These findings should be interpreted in light of findings from subsequent phases of this research project, the specific protocol developed for a visual identifier and the wider context of implementation. For example, if an identifier is applied to the patient themselves, special care should be taken to avoid the criminal charge of battery and the tort of trespass to the person, as forcible, (albeit trivial) violation of a right to bodily integrity could be caused by application of the identifier. Furthermore, if this causes the patient distress, there may even be potential liability for damages.

We encourage the visual identifier coordinators and implementers to develop the visual identifier with these analyses and principles in mind, and suggest that once a specific protocol has been agreed, the ethical and legal position of the visual identifier may need to be reassessed, given that the ultimate test of these principles and the analyses on which they are based is how well it performs within the wider context of a particular setting.

Annex 1: Workshop report

On Monday 6 July 2020, an online workshop was held with the DA VINCI Expert Collaborative Group (ECG).

The primary purpose of the workshop was to seek feedback on initial findings from Activity 1b—the ethical and legal analysis, specifically the set of ethical and legal principles that had been developed.

In advance of the workshop, the ECG were sent Draft ethical and legal principles for the development and implementation of visual identification systems for individuals with dementia in the acute care setting ‘Draft Principles document’. The final version of this document that includes modifications suggested by the ECG can be found earlier in the report at Chapter 4.

We are extremely grateful to all attendees from the ECG for their time and valuable insights. What follows describes the proceedings of the day and lists those delegates in attendance.

Proceedings

The workshop consisted of two sessions.

Session 1 consisted of a presentation followed by a question and answer session. The presentation broadly outlined Activity 1b of the DA VINCI project, including:

- The purpose of the phase and how it fits with other parts of the DA VINCI programme of work.
- Summary of the findings of the policy analysis.
- Summary of the interim findings of the ethical analysis.
- Summary of the interim findings of the legal analysis.
- Introduction to the Draft Principles document with more detailed focus on each principle, how it applies to the visual identifier for dementia in an acute care setting context, and specific issues that the principle might raise for this context.
- Explanation of the concept of ‘role obligations’ and its relevance to the interpretation of the draft principles.

Session 2 was split into two small groups of six delegates, to optimise opportunities for discussion and encourage detailed feedback from each delegate. Each group contained a mix of expertise, including both patient/carer representatives, health care professionals and academics/researchers. The aim of these sessions were to solicit detailed feedback on the Draft Principles document, asking delegates to respond to a number of broad, framing questions. These questions and key findings in response to each question can be found below:

Are there any ethical or legal principles relevant to the visual identifier and its context that have been left out?

Key findings included:

- Delegates felt that input from family and carers is critical, given the crucial role that they play through advocating for the patient or being a part of their support system.
- The principle of non-discrimination and justice should be framed more positively, to reflect an emphasis on inclusion.

Are there any ethical or legal principles in the document that are irrelevant or should be removed for another reason?

Key findings included:

- There was agreement amongst the delegates that all existing principles were relevant.

Do these ethical and legal principles reflect your experience with the setting in which the visual identifier will be applied?

Key findings included:

- It was queried how possible it is to balance the principles within the constraints of a busy clinical environment.
- Although we can think deeply about the ethos of the principles, if a visual identifier were to be fully embedded into NHS practice, we have limited control over the culture into which it is introduced. More thought is needed around the culture into which it will be implemented and how this can be influenced. This may vary not only between hospitals, but ward to ward.
- Implementing a system that is widely adhered to will require that the system is simple and standardised. Training needs to be provided across different wards to overcome the challenge that, as it currently stands, staff in a geriatric ward are far more equipped to identify and provide care to a dementia patient than a cardiac ward for example. Given the frequency with which dementia patients are moved around the hospital an identifier that can be recognised across wards would help overcome some of the challenges encountered within a hospital setting.

Given your role (and so role obligations) how would you interpret these principles? Might different roles emphasise different principles?

Key findings included:

- Interpreting the principles in order to turn them into general design rules is important from a co-design perspective i.e. if you want to achieve x in situation y, then act according to z. This might tease out potential conflicts and ground the principles in practical application.
- As a nurse working in the emergency department whose job involves conducting comprehensive geriatric assessments, promoting autonomy is particularly important, with a focus on what the patient *can* do.

Given your role, is there any particular principle that you would find more important than the others?

Key findings included:

- The delegates did not identify any single principle as holding more importance than the others.

These ethical and legal principles are likely to conflict (or appear to conflict), how would you manage and resolve that conflict?

Key findings included:

- Delegates identified that beneficence and compassion often conflict with confidentiality in clinical practice.
- They also identified a potential conflict between compassion and autonomy. Healthcare professionals have to act as an advocate for independence and autonomy, sometimes against the instinct of wishing to protect the patient. How do we avoid the unintended consequence of the visual identifier arousing the instinct to protect when the promotion of autonomy should also be a key consideration?

How can the visual identifier be introduced in such a way that best promotes these principles?

Key findings included:

- The use of visual identifiers should be accompanied by patient centred care information. A care document akin to the 'This is me' or 'What's important to me?' forms, used alongside the identifier, would enable the healthcare professional to adopt a more holistic view of the patient. It was suggested that it could include information such as what frustrates or calms the patient and important aspects of their routine. One delegate gave the example of a patient who was able to express that he didn't like noise, and so was moved to a quieter part of the ward.

- The importance of training and education was emphasised as essential in order to promote these principles. Some examples included:
 - To help facilitate a wider structure of care that supports the use of the identifier. Unless staff are given the time and training to support patients, respond to their individual needs, and practice compassionate care then they are unable to do so.
 - In order to foster a common understanding amongst staff, as diversity within hospitals may lead to differences in how staff approach dementia.
- The culture of the ward or hospital was seen to be very important for the promotion of the principles. Extending training around a visual identification system to porters, kitchen staff and security staff can help to improve interactions with dementia patients and contribute towards an overarching medical culture.
- Delegates felt that in order to promote the principles, it was important that the visual identifier did not become the default, or 'the done thing', but is instead considered on an individual basis.

Not all of the discussion followed these framing questions, additional key findings included:

- Delegates broadly agreed that in their clinical experience, uptake of the visual identifier was high and feedback following its use was positive. One delegate expressed concerns about positive discrimination, as she had been approached by other families and patients without cognitive impairment, who felt that people with dementia were receiving a different standard of care.

List of delegates

We thank the following members of the DA VINCI Expert Collaborative Group for their time, engagement, and insights:

- **Jackie Bridges**, Professor in Older People's Care, University of Southampton
- **Lesley Carter**, Clinical Lead for Professionals and Practice, Age UK
- **Jill Cunliffe**, Practice Education Facilitator and Nurse Specialist for Older People, St Helens & Knowsley Teaching Hospitals NHS Trust
- **Maria Da Costa**, Specialist Support Nurse, Cambridge University Hospitals NHS Foundation Trust
- **Jan Gollop**, Former carer
- **Barbara Hodgkinson**, Founder and Director of The Butterfly Scheme and former carer, The Butterfly Scheme
- **Chloe Hood**, Programme Manager, Royal College of Psychiatrists
- **Arda Lavelle**, Family Care Coordinator, Caring Together
- **Annabel Price**, Associate Specialist Director for Palliative Care, Cambridge Institute of Public Health
- **Allyson Rigby**, Dementia Champion and Emergency Department Senior Healthcare Assistant, Lancashire Teaching Hospitals NHS Foundation Trust
- **Glenn Robert**, Professor of Health Care Quality & Innovation, King's College London
- **Jacqueline Young**, Dementia Specialist Nurse, Cambridge University Hospitals NHS Foundation Trust

Annex 2: Literature search methodology

Objectives

This literature review aimed to identify literature discussing ethical considerations that are relevant to visual identifiers for dementia in the acute care setting.

Methods

Computerised searches were carried out using Pubmed, SCOPUS, Medline, CINAHL and ProQuest (APA PsychInfo (1806 – current) and British Nursing Index (1994 – current)), in order to identify academic literature discussing ethical considerations that arise as a result of using visual identifiers for dementia. Due to the limited literature available on visual identifiers, the inclusion criteria were broadened to identify relevant analogous literature.

Additional search strategies included snowballing, and targeted searches on specific topics/issues.

Search terms

Search terms were trialled on Pubmed and adapted to other databases, which were selected to cover a range of relevant perspectives including science, psychology, nursing and humanities. Key words such as logo, sign*, tag, safety and accept* have multiple meanings and increased the number of irrelevant results significantly and so were not included in the final search strategy. The search strategy used covered the following search terms:

dementia OR 'cognitive impairment' OR Alzheimer*

AND

emblem* OR symbol* OR wristband* OR label* OR butterfly OR forget-me-not OR 'visual identif*' OR 'patient identif*' OR bracelet*

AND

stigma OR dignity OR ethic* OR attitud* OR privacy OR moral* OR autonomy

The search was limited to English-language articles, but not limited by date. All literature identified by the database searches were assessed for relevance to this report based on title and abstract. Additional searches were undertaken using references from papers identified through previous searches and through analysing grey literature.

Inclusion criteria

Papers met the inclusion criteria if they:

- Discussed ethical considerations arising from the visual identification (use of a sign, symbol, tag or emblem) of individuals with cognitive decline.

This was then broadened to include papers that:

- Discusses ethical considerations in relation to cognitive decline in the healthcare context that might impact the use of visual identifiers.

Exclusion criteria

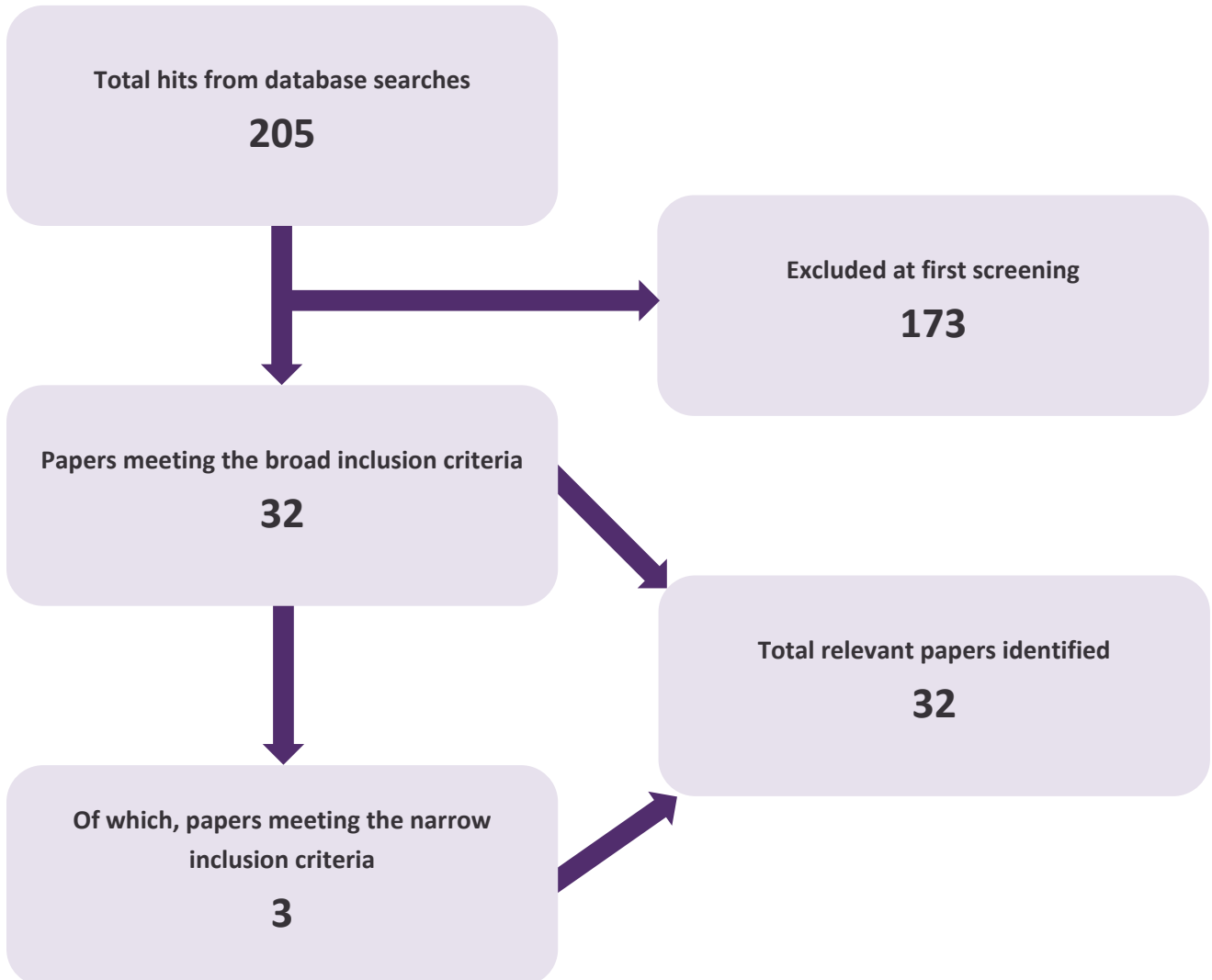
Papers were excluded where they:

- Referred to 'visual identifiers' that were not relevant to this project (i.e. not a sign, symbol, tag, emblem or wristband), or;
- Did not discuss ethical considerations or practical considerations with ethical implications.

Results

Using the outlined search strategy 205 papers were identified for retrieval across the databases. Only 3 met the initial inclusion criteria highlighting the lack of existing literature pertaining to the use of visual identifiers for cognitive decline. However, 32 relevant papers were identified once the inclusion criteria were broadened.

Flow diagram of study selection



Annex 3: Human rights instruments

There are many legal sources of human rights protections. These may be international, supranational (agreements among a group of nations), or national. The table below lists human rights instruments most relevant to the protection of persons with dementia.

Table 6: Human rights principles and their sources

Principle (some variation in content and interpretation)	Represented in ^{xxvi}
Right against inhuman or degrading treatment	Convention of the Rights of Persons with Disabilities, European Convention on Human Rights, Human Rights Act 1998 , Charter of Fundamental Rights of the European Union.
Right to physical or mental integrity/security	Convention of the Rights of Persons with Disabilities, European Convention on Human Rights, Human Rights Act 1998 , Charter of Fundamental Rights of the European Union.
Right to private life	Convention of the Rights of Persons with Disabilities, European Convention on Human Rights, Human Rights Act 1998 , Charter of Fundamental Rights of the European Union.
Prohibition against discrimination	Convention of the Rights of Persons with Disabilities, European Convention on Human Rights, Human Rights Act 1998 , Charter of Fundamental Rights of the European Union, and Equality Act 2010 .

^{xxvi} N.B. Bolded instruments are pieces of national legislation for England and Wales.

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