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**Key principles for the  
development and implementation  
of visual identification systems**

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December 2020

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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?'

We thank Graham Martin and Karolina Kuberska from THIS Institute and the other collaborating partners for their support.

### 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.

URLs were correct as of September 2020

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We are a registered company, no. 5823194

The DA VINCI project is supported by the Health Foundation's grant to the University of Cambridge for The Healthcare Improvement Studies Institute.



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## Key principles

This document identifies, and briefly explores, key principles to inform the development and implementation of visual identification systems. For the purposes of this project, visual identifiers are understood to be 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.

## The DA VINCI project

These principles are one of the deliverables of Activity 1b of The DA VINCI project - a research project led by THIS Institute, which 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. As part of the first Phase of this project, the PHG Foundation drafted a report containing a comprehensive analysis of the key ethical and legal/regulatory issues arising from the current and potential use of visual identification systems. The findings from these analyses have been distilled into the key principles below, which will consequently inform the approach taken to piloting a novel visual identification system in Phase 2 and implementing it in Phase 3.

## Methodology

Constructing these principles has been an iterative process. Common themes, tensions and challenges identified as part of the early findings from the ethical and legal analyses were distilled into principles which were identified as key to the development and implementation of visual identification systems. Draft principles were presented to an Expert Collaborative Group (a group of experts convened by THIS Institute to offer support and guidance throughout the entire project) at a workshop on 6 July 2020. The principles and aspects of the analyses were then further refined 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.

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 is 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*).**<sup>1</sup> 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.

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<sup>1</sup> In Aristotelian terms, *phronesis* is wisdom developed through practical experience.

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