Visual identifiers for people with dementia in hospitals: a qualitative study to unravel mechanisms of action for improving quality of care

Elizabeth Sutton, Natalie Armstrong, Louise Locock, Simon Conroy, Carolyn Tarrant

ABSTRACT

Background Hospitalised people with dementia (PwD) experience worse care and more patient safety incidents than non-dementia patients. Visual identifiers are commonly used to identify patients who have a diagnosis of dementia, with the aim of promoting more personalised care. However, little is known about how they work in practice, nor about the potential unintended consequences that might arise from their use. We aim to identify the mechanisms through which visual identifiers could support good care for PwD, how and why their use may have negative consequences and the conditions for their effective use.

Methods We conducted interviews with 21 dementia leads and healthcare professionals, 19 carers and two PwD, and produced case studies of visual identification systems in four UK acute hospital trusts between 2019 and 2021. Analysis drew on the concept of classification to identify and explore mechanisms of action.

Results We identified four mechanisms through which visual identifiers could help towards providing good care for PwD: enabling coordination of care at organisational level; signalling eligibility for dementia-specific interventions; informing prioritisation of resources on wards; and acting as a quick reference cue for staff. But identifier effectiveness could be undermined by: lack of standardisation and consistency; a lack of closely coupled information about individual needs; and stigma associated with a dementia diagnosis. Identifier effectiveness was dependent on their implementation being supported through staff training, resources directed and efforts to develop a supportive culture for caring for this patient group.

Conclusion Our research highlights the potential mechanisms of action of visual identifiers and their possible negative consequences. Optimising the use of identifiers requires consensus on the rules of classification and the symbols used, and closely coupled patient information. Organisations need to provide support, offer the right resources and training and engage meaningfully with carers and patients about the use of identifiers.

INTRODUCTION

Approximately a quarter of hospital beds in the UK are occupied by someone...
living with dementia. Evidence suggests that people with dementia (PwD) experience longer stays, higher readmissions, greater numbers of patient safety incidents and a higher risk of mortality than those without dementia. PwD have specific additional needs when in hospital, which are not always met, including needs related to communication, nutrition, continence and managing confusion and distress. Importantly, PwD have a need for genuine connections and empathetic communications with staff to feel safe. Previous studies also highlight many missed opportunities in providing person-centred care for PwD in acute care settings.

To address these concerns, many hospitals within the UK, and in other countries including Australia and the USA, have introduced visual identifiers for PwD. These typically take the form of symbols—such as a butterfly—added to wristbands or displayed on bedside signs with the aim of raising staff awareness that a patient may have additional needs. Identifiers are often used in combination with other interventions, such as staff training on providing care to PwD in an effort to promote an approach that better meets the needs of PwD and supports the delivery of person-centred care. While identifiers are hypothesised to have value for improving the care of PwD in hospitals, potential problems with their use have also been raised. These include risks of obscuring the person behind the diagnosis, resulting in less personalised care, problems with misclassification of patients and concerns about the consistency and reliability of their use.

Over 90% of hospitals in England have identification systems in place for PwD. Despite their widespread use in practice, none of these schemes have been fully evaluated. Given that visual identifiers for PwD are in routine use across hospitals in the UK and beyond, there is a pressing need to understand their potential mechanisms of action: how they function to improve care. It is also important to pay attention to their potential ‘dark logic’: to consider how, why and under what circumstances their use might lead to negative unintended consequences, either on the outcomes of interest (‘paradoxical effects’) or other outcomes (‘harmful externalities’). This understanding will be valuable in informing decisions about whether and how to use identifiers and in what form, and in developing approaches to counter possible harms from their use.

Based on a qualitative study with health professionals, PwD and their carers, we analyse mechanisms through which visual identifiers work in practice, what problems they can address and when and how they might generate negative consequences. This understanding will inform future efforts to use identifiers more effectively to support good care for PwD.

METHODS
As part of a broader programme of research into the use of visual identification systems for PwD in hospital, we conducted a qualitative study involving in-depth case studies and interviews with health professionals, PwD and their carers between 2019 and 2021. We selected four acute care sites as case studies: two large and two smaller hospitals (based on the number of beds) in different regions of England. In consultation with experts in dementia care, sites were selected to include hospitals using a range of identifiers (including the national butterfly scheme and locally developed identifiers) and with varying levels of performance in implementing their dementia strategies. In each of the four sites, we interviewed the dementia lead or senior dementia nurse about their organisation’s approach to quality of care for PwD. We gathered documentation including dementia strategies and any dementia-related information displayed in each site. We also recruited front-line healthcare professionals with experience of working with PwD across diverse roles within the case study sites (three to seven per site). An additional five health professionals who worked with PwD were recruited through their willingness to take part in an interview after completing a national survey that formed part of the wider research programme to gain insight into practices beyond the four case study hospitals. Interviews with health professionals explored experiences of providing hospital care for PwD and how visual identifiers and related interventions worked in practice.

We also conducted interviews with PwD and their relatives. Participants were recruited through the ‘Join Dementia Research’ network and via social media. Interviews explored experiences of hospital care, and views on visual identifiers and related interventions. Patient and carer topic guides were piloted with a person with dementia and a carer (see online supplemental materials 1 and 2 for topic guides).

Due to the COVID-19 pandemic, all interviews were conducted by telephone or online, with written informed consent. All interviews were conducted by an experienced non-clinical qualitative researcher (ES), and lasted between 30 and 90 min. Interviewing continued until no new themes were identified. Interviews were audio recorded, transcribed verbatim and analysed using a thematic analysis approach. ES conducted initial open coding of transcripts by hand. This coding was inductive and included the way that identifiers could impact both positively and negatively on care quality. This informed the development of a coding framework, where codes were grouped into higher order themes (see coding frame in online supplemental material 3). This was refined and revised in discussion with CT, and used to code subsequent transcripts using NVivo V.12 software. We used compiled narrative case studies for each site. In each case, we mapped out the type of tools and approaches...
used to identify and support PwD. We interrogated the themes and case studies to explore the practices and meanings associated with the use of visual identifiers, and perceptions of their impact on quality of care for PwD. This was undertaken by comparing and contrasting the views of healthcare professionals, relatives of those with dementia and those living with dementia, and the documentation from each site. In particular, we contrasted the ‘official’ reports of how identifiers should be used in each site with what individuals told us about how they worked in practice and the consequences of their use.

RESULTS
Twenty-one healthcare professionals, 19 relatives of PwD and two people living with dementia took part in the interviews. Quotation identifiers explain the type of person interviewed. For health professionals, identifiers also show either the case study they were from or that they were recruited from the survey. In this section, we first present findings on the case studies of how visual identifiers were being used in practice. We then articulate several ‘mechanisms of action’ through which the use of such identifiers could lead to better care and outcomes for PwD. Finally, we consider some of the potential failures and unintended consequences of such tools.

Visual identifiers: classifying patients and signalling category membership
The application of a visual identifier acted as a visible classification system—identifying people as belonging to a specific group or category, that of ‘people with dementia’ (and/or with suspected dementia or delirium). Visual identifiers used across sites were multiple and varied, and included alerts on hospital electronic systems, stickers and magnets on notes and whiteboards, and bedside signs and wristbands displaying a symbol (eg, a forget-me-not flower or butterfly). Table 1, based on case study analysis of the four sites drawing on key documents and interviews with dementia leads, summarises the variation in use of identifiers across the sites.

Mechanisms of action: how visual identifiers could support good care
We identified several mechanisms through which visual identifiers could positively support the delivery of good care for PwD: through enabling care coordination at organisational level, signalling eligibility for dementia-specific initiatives, allowing allocation of resources at ward level and acting as a quick reference cue to prompt assessment of needs. For detailed quotes see table 2.

The ability to mark people as belonging to the category ‘person with dementia’ opened up possibilities to improve coordination and delivery of care at organisational level. For example, flags on electronic systems could help identify and locate PwD within the hospital, which could then help to support the coordination of their care pathways, including avoiding unnecessary moves around the hospital. Identifiers also helped with efforts to audit, monitor and improve the quality of care for this patient group as a whole.

Identifiers on wristbands and patient documents also played a role in the delivery of hospital-wide initiatives for enhanced care for this patient group—such as meaningful activity coordinators (site 2), dementia volunteer support, fast tracking through X-ray pathways or additional support for nutritional or other needs. Identifiers acted as a marker that signalled their eligibility for these dementia-specific initiatives. Visual identifiers also acted to alert individual ward staff interacting with a patient, at the point of care, that a patient had dementia. This was perceived to have value, by both staff and relatives, in prompting

Table 1  Variation in identifiers used across the case study sites

<table>
<thead>
<tr>
<th>Symbol used</th>
<th>Location of identifier</th>
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<tbody>
<tr>
<td>Butterfly for confirmed dementia diagnosis, outlined butterfly for suspected dementia/delirium</td>
<td>Site 1 (red) Site 3 (blue—part of national scheme)</td>
</tr>
<tr>
<td>Forget-me not flower for confirmed dementia diagnosis</td>
<td>Site 2 Site 4</td>
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<tr>
<td>Sunflower for ‘Hidden disabilities’</td>
<td>Site 3</td>
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<tr>
<td>Chrysanthemum for delirium</td>
<td>Site 4</td>
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<tr>
<th>Consent to apply identifier</th>
<th>Site 1</th>
<th>Site 2</th>
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<tr>
<td>Express consent needed</td>
<td>Site 3</td>
<td>Site 4</td>
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<tr>
<td>Opt-out/no consent needed</td>
<td>Site 1</td>
<td>Site 2</td>
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<tr>
<th>Personalised patient documents</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
<th>Site 4</th>
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<tbody>
<tr>
<td>Booklet—‘This is me’, ‘Reach out to me’</td>
<td>Site 2</td>
<td></td>
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<tr>
<td>Patient profile</td>
<td>Site 3</td>
<td>Site 4</td>
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<tr>
<td>Poster at bedside—‘What’s important to me’</td>
<td>Site 1</td>
<td>Site 4</td>
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</table>
ward staff to consider the needs and limitations associated with the membership of the category ‘person with dementia’. While this often meant drawing on generalised knowledge about dementia, rather than information about the individual patient, being able to identify someone as belonging to this category had the potential to improve interactions and quality of care. It could help staff to make sense of a person’s behaviour in the context of a dementia diagnosis, tailor their communication approach to avoid distress and take into account likely limitations in a person’s memory or communication ability.

At ward level, visual identification systems were seen as particularly helpful in enabling managers to organise and plan their resources for day-to-day care within the ward. A visual overview of the number of patients on the ward with dementia—from the e-system, whiteboard magnets or bedside identifiers—could provide accessible information to inform assessments of availability of staff with relevant expertise and guide allocation of staff or requests for additional staffing.

By providing a quick reference cue, identifiers on wristbands also supported efforts to protect the safety of patients who may have left their ward and become vulnerable to many PwD, for example, prompting staff to consider fall risks, or enabling identification of staff or requests for additional staffing.

Enabling or supporting coordination and improvement at organisation level

[With the alert system, the operations centre and patient flow, particularly the hospital at night team, could actually see where our patients with dementia were. And it’s part of the trust policy... in accordance with National Audit of Dementia recommendations –... trying to now reduce those transfers around the hospital. (Dementia lead, 001, Survey)]

Signalling eligibility for dementia-specific interventions

Anybody who comes in to ED, who’s identified through the forget-me-not scheme, is immediately assessed by the meaningful activity service. (Executive nurse, 006, Site 2)

When someone’s got dementia, they get a laminated card so if they’ve got four people in front (waiting for an x-ray), they go ‘actually I’ll take that one first’, because that person’s obviously got [dementia] and we’re gonna get them, fast-track them through a bit quicker. (Dementia lead, 07, Site 3)

Helping to prioritise resources at ward level

I mean I like I’ve just picked up my handover, the first patient I see, I don’t have to read anything and I can see that he’s got dementia so even though I don’t know anything more... I’m just looking at my identifiers. And I can see that this patient is probably going to need quite a lot of assistance that day. (Senior nurse, 002, Site 1)

Providing quick reference cue to additional needs of patient

For these kind of people, we know that we have to... have more patience with them, to know about them, what they like, what they dislike. Because they can feel very lost, they don’t know us, they are in a very strange environment, with different people every day, so this will affect their behaviour and their eating, drinking. (Senior nurse, 003, Site 1)

[A wristband] is just a simple thing, you know, and you put it on, and the world just takes a step back and thinks, ‘Oh, we might need to approach it differently.’ [...] It just makes everybody just a little bit kinder. (Daughter, 13)

The value of the identifier was dependent on collective understanding of its meaning and what it signified. But we found a lack of standardisation of symbols used across different sites which undermined their value as a quick reference tool (table 1 and table 3 for quotes), and no universal understanding of what the symbols meant across the workforce within and across sites. This lack of standardisation was perceived as particularly problematic when staff were locums or bank staff who might work at several different hospitals. The confusion that different identifiers, and ways of using them, might cause to patients and their families was also a concern. Additional resources were in place alongside visual identifiers in all hospitals we studied to provide staff with this personal information for PwD (in the form of a booklet or poster). These resources were designed to help staff better understand the interests and individual needs of a person. Staff felt, however, that personal information documents were poorly completed and used inconsistently. In addition, some accompanying personal information booklets, originally designed to be used in long-term care, were relatively detailed and dense. They focused on providing rich details about the person behind the diagnosis of dementia. Although specialist dementia staff and volunteers reported this was valuable in helping them find out more about the person, this format did not meet the needs of clinical staff for quick and easy access to key information. Booklets tended to be put away at the back of patients’ notes or at the bedside, and clinical staff tended not to prioritise taking time to read detailed personal information documents in the context of a time-pressured environment. In contrast, posters that provided personal information ‘at a glance’ provided limited information for dementia specialists and volunteers, but were felt to work well as a means of communicating relevant

<table>
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Table 3 Potential failures and unintended consequences of visual identifiers

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<tr>
<th>Potential failure/unintended consequence</th>
<th>Quote</th>
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<tr>
<td>Lack of standardisation of symbols undermined their value as a quick reference cue.</td>
<td>For example, if the patient comes to one hospital, and the next of kin are being told about this identifier, and then they go […] during the night to another hospital, which has completely different ones, it can be confusing. And doctors which move hospitals, benefit from [standardisation]. Because it’s not something new to them. They know how to approach it. (Ward clerk, 011, Site 4)</td>
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<td>Inconsistencies in application of identifiers created inequalities.</td>
<td>The lady I saw just now […] on the Medical Assessment Unit…she’ll probably end up on one of the care of the elderly wards, she’ll be on The Butterfly Scheme and that’s fine. But if she ends up on a medical ward…, they may or may not remember to use it. (Dementia lead, 01, Site 3) By not having [an identifier], they will not receive the additional support that they might [have] received, if people had known that they had got dementia. (Wife, 11)</td>
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<td>Lack of closely coupled information about individual needs hindered person-centred care.</td>
<td>It feels like the label has to […] direct them to more information. (Daughter, 03) All it does is an identifier that they have [dementia]… And then it’s everything else, … what this person’s like, what they need, what they’re like at home, what they like to drink, how they like their tea, you know, all that sort of thing. You can’t get that from a butterfly, you can’t get that from … anything really other than knowing your patient. (Senior nurse, 02, Site 1)</td>
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<td>Signalling category membership could result in stigma and discrimination.</td>
<td>If people … base assumptions about the diagnosis… without finding out about the patient… Then you could, you could be at risk of decompensating them really, because you start doing things at them and for them, rather than letting them try to do things themselves and support them. (Senior dementia nurse, 018, Survey) You’ve got the Reach Out To Me [booklet] in the [patient] documentation, why have [staff] not read that and why have you not seen what he likes and what he doesn’t like? […] If somebody can’t see, if they haven’t got their glasses, that’s why they can’t see. (Dementia lead, 07, Site 3)</td>
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<tr>
<td>Effectiveness was dependent on staff training and resources.</td>
<td>I mean I just honestly can’t stand the way that people judge dementia patients, it’s just horrible, they just think there’s nothing more you can do with them, and that’s it, you just give up. (Dementia lead, 07, Site 3) [Staff attitude was] ‘Oh well he ain’t bothered because he has got dementia?’ Neglect is what I would have said. (Daughter, 012)</td>
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information about a patient to busy clinical, ward and support staff.

There were practical challenges with labelling patients, particularly in relation to the use of wristbands, bedside signs and whiteboard magnets. Across all the sites, many healthcare professionals were uncertain about whose responsibility it was to apply an identifier, and at what point in the patient’s journey this should happen. Staff reported a lack of consistency about the point in the patient’s journey at which they were applied and variable engagement across different types of ward. In practice, visual identifiers were not used consistently to flag eligible patients for the additional support that they needed. As a result of this lack of consistency, patients who should have benefited from additional dementia support could be overlooked. By default, the lack of an identifier implicitly classified them into the ‘non-dementia’ category, leading to inequalities in care provision. There were also ambiguities and differences of opinion about who was, and who should be, eligible to have a visual identifier applied (only patients with confirmed dementia, or patients with suspected dementia and delirium). This resulted in inconsistencies across hospitals in terms of which types of patients would have access to the pathways and initiatives designed for patients with additional needs.

Even if appropriately applied, identifiers in and of themselves did not guarantee better care. The identifier directed attention to the dementia diagnosis, but did not provide any information about the individual person behind the diagnosis, their abilities, needs and preferences. Staff described how classifying and identifying people as belonging to the category ‘person with dementia’ could lead to over-reliance on assumptions based on category membership. While awareness of the dementia diagnosis could alert staff to use a more dementia-friendly approach in their communication with a patient (as described above), it could also result in staff acting on assumptions about the limitations of patients with dementia, which could disempower patients and impact negatively on their independence and functional ability. Relatives recognised the limitations to what a visual identifier on its own could achieve, unless it was coupled with efforts to enable a more personalised response based on information about individual needs.

Although the staff, relatives and PwD we interviewed mostly felt that identifiers were potentially of benefit (even if this benefit was not fully realised in
practice), some family members felt that their loved one would not want their diagnosis to be made visible. The use of an identifier was seen by some as having the potential to lead to negative consequences due to negative cultural representations of dementia. Some staff, relatives and PwD had concerns that marking patients with an identifier could result in prejudice and discrimination within the healthcare setting, if staff held negative beliefs about patients with dementia. Some relatives described their loved one experiencing discrimination in practice.

Both staff and relatives recognised that identifiers alone had limited potential to improve the care of PwD. Lack of in-depth training (particularly for bank or locum staff) on the skills and knowledge required to communicate and support PwD in hospitals, lack of local expertise in dementia and limited resources to provide the additional support required all made it more likely that an identifier would be ineffective in improving care. The extent to which identifiers could enable better care was dependent on their use being supported through staff training, resources directed at the needs of PwD and efforts to develop a more informed and supportive culture for caring for PwD.

**DISCUSSION**

Our research shows how classifying people as belonging to the ‘dementia’ category, and visibly signalling this category membership, could support improvements in the quality of care delivery for PwD in hospital. In particular, our participants perceived such classificatory tools as having the potential to play an important role in: enabling coordination of care at an organisational level; signalling eligibility for dementia-specific interventions; informing prioritisation of resources on wards; and acting as a quick reference cue for staff interactions with patients. Provided staff have the skills and time to engage effectively with PwD, and are working within a supportive and well-resourced environment, they can use this information to tailor their interactions with patients in line with the broad needs of PwD. But such tools can fail to deliver on their promise, and potentially have negative consequences, when there is a lack of standardisation and consistency, a lack of closely coupled information about individual needs and a risk of discrimination associated with making the condition visible.

Featherstone and colleagues have been particularly critical of the use of signs and symbols for PwD in hospitals. In line with some of our findings, they argue that these ‘technologies of attention’ obscure the person, risk misclassification and can lead to depersonalised care. A recent national survey on the use of visual identifiers found drawbacks to the use of visual identifiers, such as concerns about disclosure and discrimination as well as practical challenges to their use. There is a danger, however, of arguing against the use of visual identifiers as an approach to optimising care for PwD on the basis of their potential to generate negative consequences. It is not that the principles of classification and labelling themselves are problematic—our research shows that being able to classify and mark patients as belonging to a vulnerable group with additional needs can (at least potentially) bring significant benefits in terms of optimising the organisation and delivery of care. Rather, we argue that we need instead to understand *when* and *why* such classification systems can generate negative consequences (their potential ‘dark logic’), and consider how to mitigate against these. This is particularly important as our and others’ work would seem to suggest that unintended consequences in this context are primarily on the outcomes of interest (so-called ‘paradoxical effects’), meaning that there is a very real risk that care for this vulnerable group of patients is made worse rather than better. Inconsistencies in the application of, and attribution of meaning to, the marker could create confusion and inequalities in care. We recommend that, at a national level, healthcare organisations gain consensus on the rules of classification, the process of applying the marker and the symbol to be used. To overcome the risks of assumptions and depersonalised care associated with a classification system, any markers applied to patients should act as a *flag* to staff to seek out personal information, rather than merely operate as a *label* to show a patient is a member of a category.

Our findings suggest that documents such as the ‘This is me’ booklet, designed to provide this personal information, were not immediately accessible for busy clinical staff and were rarely consulted by the staff providing care. Bedside posters provided a more easily accessible reference point for busy hospital staff. We suggest a need for more closely coupled personalised information to be integrated with the visual identifier. Such a resource should include the key information about individual needs and preferences that is most relevant to the person’s hospital care, and should be immediately accessible to all staff.

Simply implementing dementia-friendly initiatives such as visual identifiers and patient profiles without supporting staff with resources or training will fail to bring about good dementia care. The extent to which identifiers could enable better care was dependent on their use being supported through staff training, resources directed at the needs of PwD and efforts to develop a supportive culture for caring for PwD. Others have argued that dementia-friendly interventions such as visual identifiers need to be accompanied by efforts to build staff understanding of dementia, a framework for providing good dementia care and support from local change agents to bring about good care. Hospitals have to provide a supportive context for good dementia care to take place, and dementia care has to be embedded in an organisational commitment to optimise the delivery of care and ensure that systems are in place to support it. There is a real need
for regular and in-depth training to enable effective responses to the classification of dementia. This training should seek to provide understanding of the common issues but also the spectrum of diversity in the group to avoid stereotyping, discrimination and stigma based on group membership. Impactful training should include input from patient and relative experiences and highly skilled facilitators. It should be available for all staff, including locum and agency staff. Finally, and very importantly, organisations need to ensure the engagement of patients and their carers in terms of their attitudes towards classification and their consent to be labelled. It is vital that discussions are held with relatives and patients to address the implications of being classified, having a marker applied and addressing concerns about stigma and discrimination.

Strengths and limitations

Our study included a small sample of four hospitals yet these all used a varying range of identifiers. In addition, our approach to site selection ensured we included sites with diversity in levels of engagement with their dementia strategies. Interviewees included dementia leads who were involved with the implementation of identifiers. While these staff are likely to have positive views of identifiers, we also interviewed frontline staff involved in the care of PwD to explore the realities of the way identifiers worked in day-to-day practice. We were only able to recruit two PwD to participate in interviews: we intended to recruit via in-person visits to hospitals, local groups and dementia cafes, but this was not possible due to the COVID-19 pandemic. We also were unable to undertake planned visits to hospitals to observe the use of identifiers in practice. Observation is a powerful method in uncovering the (often unconscious) gap between rhetoric and reality in dementia care, and future observational research would be of value. However, we were able to produce comprehensive case studies of local practices across four hospitals by interviewing a range of staff and drawing on a range of documentation used in each site.

Characterising visual identifiers as an example of a classification system provides us with new insights into the underlying principles of their use and the mechanisms through which they might work. Classification is argued to involve segmenting the world to conduct some form of work—in this case, the intention is to delineate a population of patients who are likely to require (and are eligible for) additional support while in hospital. However, as we have shown, the classificatory act in and of itself is not sufficient to deliver better care to those identified. In order to deliver meaningfully on their promise, classificatory tools such as visual identifiers need to be used in contexts which are capable of effectively delivering the work required to generate the desired outcomes of having classified.

CONCLUSION

Interviews with staff, PwD and their relatives reveal the mechanisms through which visual identifiers could play an important role in improving the quality of care for PwD. Characterising visual identifiers in terms of classification can help in understanding the mechanisms through which they can generate positive or negative consequences, as well as informing efforts to optimise their effectiveness in practice.

Twitter Elizabeth Sutton @LizSule, Natalie Armstrong @dnrarmstrong and Carolyn Tarrant @carolynctarrant

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Contributors ES conducted the analysis and wrote the initial draft. NA, LL, SC and CT contributed to editing and revising the draft. CT led on the qualitative methodology and design and is guarantor.

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Patient consent for publication Obtained.

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Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

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