Respecting privacy in care services

By Peter Bates and Brendan McLoughlin

Introduction: Confidentiality versus privacy

Despite its place in faith traditions, ancient law, the Universal Declaration of Human Rights, and the Constitutions of over 150 countries [Constitute 2019], privacy lacks a clear, shared definition [Koops et al 2016, Green et al 2018]. It is, however, distinct from confidentiality.

> *"Confidentiality pertains to the treatment of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others without permission in ways that are inconsistent with the understanding of the original disclosure."*
>
> *"Privacy is the control over the extent, timing, and circumstances of sharing oneself (physically, behaviourally, or intellectually) with others*." [University of California 2019]

Thus, confidentiality is about how information is used, whereas privacy is concerned with controlling how the self is shared. Discussions relating to privacy and confidentiality can focus on avoiding confidentiality breaches, whereas upholding privacy is about protection from unwarranted intrusion. Woogara (2005) seeks to distinguish the two by using the terms "information" privacy and "person" privacy. Confidentiality is largely regulated by law and professional ethics. Privacy is not.

Privacy provides people with the opportunity to develop as unique individuals, exercise autonomy, unwind from emotionally stressful experiences, be creative, engage in self-evaluation, and share confidences [Rawnsley 1980]. However, for these positive consequences to be realised, privacy needs to be set in a rich environment. The person needs to be able to make independent choices so that they can enjoy relaxation, select from a choice of activities, share an intimate moment with a friend or a lover, or capture the outputs of reflection for future use. Few of these things can be accomplished where there is undue intrusion or scrutiny.

A review of the literature relating to care home residents' right to privacy has been conducted in a search for definitions of privacy and descriptions of best practice. Significantly, recent researchers have found that care home environments fail to uphold human rights, including the right to privacy (Green et al 2018, Steele et al 2019)

This paper will explore privacy in the context of health and social care teams in the UK, and later with particular reference to care homes. Privacy here will be approached from two perspectives. First, we consider confidentiality v privacy in the conversations that take place within staff teams with a focus on the intellectual/emotional perspective. Second, we take a broad view of privacy and its potential impact on all aspects of care homes including physical and behavioural perspectives.

The legal status of privacy

Privacy has a low status in the United Kingdom [Privacy International 2007] and the advance of digital technology and social media means that ordinary citizens and especially people living in care settings are subject to a rapid increase in the proportion of their life that is potentially under surveillance [Scottish Care 2018]. In the light of these things, privacy has become the focus of some campaigning organisations [1]. The General Data Protection Regulation from the European Union, incorporated into United Kingdom law in 2018 [HM Government 2018], is in part a response to this.

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Privacy stands in law as a qualified or restricted right that may be outweighed by other concerns, such as the public interest [HM Government 2000] and so must be considered alongside other rights. The court has recognised a distinction between topics the public is interested in (such as the personal lives of celebrities) and what is actually in the public interest. When it comes to attitudes towards formal privacy protection, Westin [2003] has segmented the population into three – those who are suspicious of government and business and so wish to block any attempt to intrude on the public's private lives; those who are unconcerned and focus on the benefits in terms of targeted internet marketing, foiling of terrorist plots and so on, and the pragmatists, who judge each circumstance on its merits. Westin further observes that major events and worldwide trends shift the proportion of people occupying these segments, so for example, terrorist attacks lead to an upswing in popular support for Government intrusion into private lives. It is reasonable to assume that those using care services will also have a range of attitudes towards protection of their privacy.

Privacy provides relief from surveillance and interrogation with their attendant effects by which personal expression, interaction and contribution are inhibited. There is often a display of power near the heart of privacy violations, such as when the state collects personal information that the poor provide because they have no choice – although some choose to retain their privacy rather than disclose. Invasion of privacy can trigger harmful experiences such as feelings of violation, anxiety, aggression, powerlessness and shame, while witnesses to the violation are harmed by the sense of injustice and embarrassment. These emotions are particularly toxic to the therapeutic environment, since they stimulate defensiveness, secrecy and mistrust in relationships. To add yet more layers of complexity to the issue, health professionals sometimes gather detailed information about a patients' diagnosis and treatment and then refuse to share it with the person concerned [Volicer et al 1975]. Similar behaviour occurs when family and friends seek to "protect" the individual from information they may deem to be harmful.

Information sharing within health and care staff teams

Teams within the health and social care system meet their various needs for sharing information through a variety of structures. A care home has few occasions where one staff member needs to know all the personal details that the person disclosed to a colleague on the previous shift. Yesterday's personal disclosure may not be relevant to today's intervention.

In relation to health and social care records, the Caldicott principles insist that *only relevant information* can be shared [National Data Guardian 2016]. Indeed, the full suite of Caldicott principles might be applicable to interactions *within* a care team:

1. Justify the purpose(s)
2. Don't use personal confidential data unless it is necessary
3. Use the minimum necessary personal confidential data
4. Access to personal confidential data should be on a strict need-to-know basis
5. Everyone with access to personal confidential data should be aware of their responsibilities
6. Comply with the law
7. The duty to share information can be as important as the duty to protect patient confidentiality.

Some people using health or social care services are in touch with more than one team. There may be one care team in the residential setting, a second at the GP surgery and a third in the specialist learning disability service. While there is a case for coordinating information-sharing across teams, the alternative argument also has merit.

Supported Living principles [CIRCL, undated] aim for a separation of housing and support providers. Thus the roles of landlord and personal carer are held by different organisations, preventing the undue concentration of power, and reducing the risk that information bleeds from one sector to another. As a result, if the tenant chooses to challenge their care arrangements this will not be seen as a breach of tenancy responsibilities or lead to eviction. So, the person enjoys a life which is lived in separate compartments, free of unnecessary sharing from one compartment to another, just like most citizens. Promoting this separation may be an effective way to uphold the right to privacy.

The challenge for a care system is to create an environment where the individual's wellbeing is promoted, and potential risks managed. Safeguarding is how most systems manage risk. These processes are enshrined in the UK in the Care Act 2014 and require anyone who knows about abuse or neglect to act upon that knowledge rather than waiting to be asked for information about it. When working with vulnerable people this makes sense.

But some care organisations in England appear to be so focused on protecting staff and so attentive to allegations of abuse, that anyone who even suggested that a staff member should remain silent about anything they learn about a client, even if the disclosure has no safety implications whatsoever, would risk being accused of an abusive relationship. If a staff member wants to keep a secret, then it is assumed to be a guilty secret. As one safeguarding policy asserted,

> *'No individual staff member should hold information alone'* and '*information is confidential to the organisation and not to individuals working in the name of the organisation.'*

However, to balance this obligation to share information, official guidance on safeguarding has also included 'lack of respect for privacy' as one expression of institutional abuse [SCIE 2018). Some disclosures should trigger safeguarding actions, but not all.

In line with this, another organisation noted its general obligations to uphold the right to privacy, but then noted,

> *'It is considered good practice for anyone holding a position of trust regarding information about others, to be given support in terms of the work they undertake. Therefore, it is acceptable within these boundaries to share concerns /information, provided it is done in suitable circumstances and is purposeful.'*

The idea that information sharing within the team is the default and is almost considered an essential part of patient care also extends to information sharing between organisations. As one mental health trust's data protection policy asserted, without any direct reference to the importance of upholding the person's choice or right to privacy:

> *It is important to note that the increasing nature of multi-agency care provision means that objecting to, or restricting sharing of records between care providers may have a negative impact on an individual's care. Patients are advised that they should discuss any restrictions with the relevant care provider and understand any implications for their care if they wish to restrict or object to [data] processing.'*

This recognises the right of an individual to refuse permission for information to be shared, even if it undermines the provision of effective care, a right set out in Article 22 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), reinforced by Article 8 of the UK Human Rights Act 1998 and the Data Protection Act 1998. However, it puts onus onto the person using the service, who may be vulnerable or find it in other ways hard to raise such issues, or with staff, who may be inexperienced, unqualified and overworked.

Maintaining a distinction between different kinds of disclosure, or even deciding when disclosure is ‘suitable’ and ‘purposeful’ can become too difficult. To prevent poor care or abuse, rather than trusting the staff to exercise judgement, some managers and regulators prefer to issue guidance designed for the riskiest scenario and then apply it to each and every disclosure – even though these high-risk disclosures may be rare. This releases staff from the ‘burden’ of having to make a judgement, but also prevents them from recognising the uniqueness of individuals and situations and upholding the right to privacy.

Information sharing in other services

The UK Information Commissioner has recommended that organisations carry out a Privacy Impact Assessment [Information Commissioner’s Office 2019], and noted that this might cover both informational privacy and physical privacy, to which we might add other categories of privacy. The concept of a Privacy Impact Assessment has some potential for our discussion. However, many of the current examples found on the internet confine their interest to information governance rather than addressing broader aspects. This has been reflected in the European requirement to undertake a *Data Protection* Impact Assessment as specified in article 35 of the General Data Protection Regulations.

It is interesting to note here the approach taken by Independent Mental Capacity Advocates who have a statutory right to see their clients in private [HM Government 2005]. In some of these services, the default position is that information about an individual client remains confidential to the individual advocate and their line manager, with disclosure to work colleagues only permitted in exceptional and clearly defined circumstances. This means that staff do not pool their learning about an individual or a family, avoid case discussions where they might be able to identify the person being discussed, place a secure firewall around their case records to prevent colleagues from seeing them without authority, and quietly leave the office if a colleague is taking a phone call from someone they know.

The culture of the organisation supports the whole staff team in upholding privacy – both the worker who withholds information and the staff who do not know it. Information is only disclosed where there is an over-riding reason to do so.

While advocacy services are clearly different from care services, they show how staff teams can develop a way of working that accommodates the need to hold information back from one’s colleagues when there is a higher goal in mind. In their case that higher goal is the need for the advocate to maintain transparency with the person.

The financial world also offers a helpful approach to regulating the circumstances in which information is shared. Their transactions are sometimes mediated by a broker or escrow. In this model, the staff member writes their own record and lodges it with the escrow, who releases it only when there is an overriding reason and the case for this is clearly made and recorded. Managers, inspection agencies or safeguarding investigators could have independent access to the record via this mechanism.

Finally here, the social inclusion agenda provides a further perspective by emphasising the importance of unpaid relationships and informal support from friends, relatives and acquaintances beyond the care system. From this viewpoint, care recipients are supported to retain or build meaningful connections with people beyond the care team, people with whom confidences may be shared, people who are unregulated by health and social care rules. This pressure valve creates opportunities for a different kind of relationship and makes the professional relationship of paid carers less smothering.

Privacy is, of course, also a response to fear. Where stigma, discrimination or derision exist, or are assumed to exist, people are much more likely to keep aspects of themselves private, as illustrated by the following two examples. In one situation, a man who had been ‘out’ as gay all his adult life moved into a care home, where he felt obliged to keep his sexuality secret for fear of a negative response from staff and residents. In contrast, another resident in a care setting loved opera but said nothing as they felt that others would, at best, have little in common with them and at worst, ridicule their interest. With staff support, they mentioned it to the person in the next room and, to their delight, found a kindred spirit.

In contemplating the impact of these practices, it may be worth separating out the legal from the ethical. Staff may frequently remind a resident that anything they tell a worker will be shared with the whole team and so satisfy the law. As the resident regulates their own boundary of privacy and exercises personal choice over what they share, they will tell *no one* what they don’t want *everyone* to know. For the person concerned, this may be a path to loneliness. Then there are some circumstances where sharing personal information around a team will be acceptable, especially where the intervention is high risk, brief and non-stigmatised.

In contrast, people who spend all their lives surrounded by care staff will have a different experience. Over years, they may be socialised into the ‘hive mind’ of the care system and lose any sense of privacy and trust with selected individuals, an essential skill in Western society [EMC 2019], vital for the development of personal identity and interpersonal skills. Sharing everything may protect the staff but will it be best for the person?

Having discussed the importance of privacy and its potential conflict with information sharing above, we will now consider how care homes and other organisations can seek to uphold the right to privacy, whilst enusuring that the care team share appropriate and necessary levels of information.

Designing privacy into the care home

Several countries have appointed a Privacy Commissioner to regulate data confidentiality, and two of their outputs help our discussion. First, New Zealand’s Commissioner has offered the following five questions [New Zealand Privacy Commissioner, undated]:

1. Can we get by without intruding on privacy?
2. Has the person given their consent?
3. Has the person been told about the intrusion?
4. Is there a serious threat that will be reduced by intruding on the person’s privacy?
5. Is there another legal provision that can be used in this situation?

Second, Commissioners have encouraged services to carry out a Privacy Impact Assessment to review the effect of their policies and procedures (Cavoukian 2012). Whilst useful, these assessments are generally confined to information privacy, and the foregoing discussion suggests that a larger definition of privacy would help care homes to meet their human rights obligations. This larger definition would go far beyond information governance by asking the five questions above, but also by grasping the positive aspects of privacy and celebrating the opportunities it affords. This larger definition would consider how care home residents enjoy their right to:

- **Private space** – to be alone and unobserved by live or electronic means, as well as the ability to withdraw from settings where there are things that one does not want to observe. Solitude offers the person an opportunity to focus on their inner dialogue [Westin 1967]. In contrast, some residential care staff enter resident's rooms before they are given permission to do so [Rahn et al 2016], thus trespassing on the person's solitude. This is also linked with ideas of personal space [Sommer 1969] and private territory [Hayter 1981].
- **Locational privacy** – to choose where to be and to be free of surveillance or the need to give account of where one has been [Blumberg and Eckersley 2009]. It is possible to enjoy locational privacy in a public place where one is casually noticed by others in the space, if there is no systematic tracking, recording, reporting to others or control of one's presence or participation [Peck v United Kingdom 2003].
- **Private property** – ownership of money and belongings that can be acquired, kept, used, amended and disposed of without permission or approval from someone else.
- **Private conversation** – opportunity to talk face to face, online or by telephone without being overheard.
- **Private relationship** – freedom to invite one or more other people into your space and spend time with them free from comment or evaluation by others.
- **Private association** – the right to join and participate in a social group without monitoring or censure from others [Allen 2011] which fosters democracy by enabling diversity and dissent in political views, worship and freedom of speech [Finn et al 2013]. The freedom to develop one's own expression of personal identity and reputation in social life while being appropriately inconspicuous [Goffman 1963] in social and public spaces.
- **Private activities** – specific activities where privacy, modesty and dignity are at a premium – intimate self-care, sleeping arrangements, access to the internet. Sometimes a carer needs to uphold the person's dignity and right to privacy when the person does not do so for themselves. This means that where a person with advanced dementia seems unaware that the door of the toilet cubicle has swung open, the carer will discretely close it on their behalf. The carer is upholding the person's dignity, whether the person themselves knows it or not, whether there is anyone else to see or not.
- **Private citizen** – to hold an identity that is represented through official documents such as a passport and voting papers, that is protected from identity theft, and yet is separate from the state, employer or identity documents. To occupy several distinct roles that do not overlap too much, so, for example, conduct at work is not reported to housemates.
- **Private body** – in its narrowest sense, this refers to regions of the body ('private parts') that it is impolite to mention in conversation, display or touch. More broadly, this term might refer to being able to manage one's own diet, hygiene, sexual activity, healthcare and exercise.

- **Private decision** – to be free to make decisions without intrusion from other people demanding information about the process, rationale or outcome [Allen 2011].
- **Private thoughts and feelings** – freedom to hold one's one ideas, emotions, conscience and beliefs, and to keep these things to oneself or not have to explain them. This ranges from the individual choosing to divert the conversation on to another topic, through to a suspect's right to remain silent in police examination or the courtroom.
- **Private information** – Personal information, whether spoken, written or photographed that is covered by a Data Privacy Impact Assessment.

Many care homes make public commitments on their websites in support of residents' rights, but it is unclear how this translates into practice (Green 2017).

Appendix 1 suggests how these wide-ranging aspects of privacy might be turned into a tool for care homes to review how they manage their residents' right to privacy. Once such an analysis had been coproduced with the stakeholders most closely impacted by these issues, then a broad Privacy Notice should be published, that explains to people using the service how their right to privacy will be upheld. Such a broad Privacy Notice will include but not be limited to questions of informational privacy.

Conclusion

If people who are being cared for are to have meaningful lives, those who do the caring need an understanding of what contributes to such a life so that they can contribute appropriately. This paper has sought to highlight the role of privacy in achieving a meaningful life and the challenges facing carers in supporting this right.

Privacy and confidentiality are different. Services tend to focus on confidentiality and then carry out their information governance responsibilities in accordance with a range of laws, regulations and policies. This is more straightforward for an organisation and its employees, but pays insufficient attention to the broader right to privacy and how this is enacted for those using care services.

Newly formed services could adopt a 'Privacy by Design' [European Union 2016] approach in which, from the outset, they build their values, procedures and culture to honour the right to privacy. The more challenging task is to help a traditional organisation where the system and culture has neglected the broader definition of privacy and shared all information within the team, to make the shift to a new culture, where privacy is broadly defined and honoured as a part of keeping residents safe.

Back in 2009, the Knowprivacy report into online behaviour (Gomez et al 2009) drew the following conclusions from a review of several surveys:

- users lack knowledge and understanding about data collection practices and policies.
- users desire control over the collection and use of information about them
- users are concerned about websites collecting information about them and using it for advertising.

While we offer no evidence to support the idea that online preferences are matched offline or that issues pertaining to information governance appear in the broader consideration of privacy, these demands for knowledge, control and restriction may well form a foundation for a manifesto for people in receipt of care.

By drawing on the culture and practices from other services such as advocacy, and adopting methods such as the Privacy Impact Assessment, users of care services can achieve control over the extent, timing, and circumstances under which they share themselves with others. At the same time, these things can support staff to keep people safe, share essential information, enable good quality care and uphold the right to privacy.

Note

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Appendix 1: Example Privacy Impact Assessment

Aspect of Privacy	Violations	Protections
Private space	I am required to share a bedroom. There is no lock on the door that I can use without explanation or apology. Peephole in the door. Cameras and tags that report my location. Night time checks. My belongings are tidied up and moved from my territory into my private space.	Individual bedroom and ability to spend time in it whenever I want to. People knock and wait to be invited in.
Locational privacy	Unwanted investigation of where I have been and why. Travel assistance rationed by staff who decide that some locations (e.g. medical appointments) are more important than leisure activities (e.g. going to the pub).	Mobility aids so I do not have to ask for help if I wish to move around. Freedom from unwanted location tracking.
Private property	Theft within care settings. Clothes going missing through the laundry system. Lack of lockable space. Restrictions on money and number or types of belongings allowed. Asking for unnecessary information about sources of income when negotiating a contract. Staff tampering with or looking at the person's belongings without permission.	Access to lockable space. Cupboard and door locks that can only be opened by the person.
Private conversation	Poor sound insulation so people who need to raise their voices to communicate can be overheard.	Rooms for 1:1 conversation. Provision of skype and phone. Disability friendly handsets.
Private relationship	Single beds. Splitting up long-term relationships when one member needs to access care and support. Treating adults like teenagers in need of constant supervision, cautionary advice and criticism. Discrimination towards LGBT persons.	Policy on supporting intimate and sexual relationships.
Private association	Staffing levels so low that people cannot leave the premises or engage in social activities in the community. Undue focus on attending community activities in a group or going to segregated provision rather than mainstream activities. Reporting from one part of my life to another (e.g. from work colleagues to housemates).	Support for voting and political affiliation. Active support for inclusive community activities. Help mainstream groups and community organisations to make reasonable adjustments.

Aspect of Privacy	Violations	Protections
Private activities	Missing door on toilet cubicle or failure to close it. Unnecessary people in bathroom or bedroom. Using the commode, being washed or meeting other personal care needs in view of roommates or others. Needing help with eating and being required to do this in public.	Adjusting clothing as necessary. Moving out of public view for private activities.
Private citizen	Holding official documents in the office rather than the person retaining these markers of citizenship themselves. Conspicuous outings into the community.	Retaining memorabilia such as armed forces identity, driving licence, National Insurance number and other identifiers that indicate citizenship.
Private body	Administering healthcare and personal care interventions without negotiating permission each time. Bath night. Taking control of routines that support eating and evacuating because it is quicker, when the person could do some aspects for themselves. Coercing people into exercise or medication compliance. Assuming that new staff or students can observe. Being able to hear others fart, snore or cry. Undressing too much of the body for too long or wearing poorly fitted clothes.	Self-management of medication. Self-directed exercise regime. Ensuring that medical interventions or caregiving that involve touching the body are carried out away from the view of others.
Private decision	Using past judgements about mental capacity in a blanket way to avoid involving the person in decision making now. Decisions to be alone or confidential with one or two others are overridden by interruptions or staff checks.	Supported decision making. Opportunities to make unwise decisions
Private thoughts and feelings	Interrogation of ideas and emotions. Unable to get away from TV or conversation. An imposed timetable lacking freedom of choice about when to rise, dress, socialise and eat.	Exercising preferences over personal presentation including grooming and clothing. Space to be alone, to pray, meditate or reflect.
Private information	Collecting information about the person's life that is not relevant to the treatment or care being provided. Records kept about the person without their knowledge or access. Discussing personal matters in the hearing of other people. Sharing information within and beyond the team without consent. CCTV.	Patient-held records. Care planning meetings have the person present, choosing who attends and what is discussed.