

The right to privacy

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Section 1 – Why do care teams share everything within the team?

Despite its place in faith traditions, ancient law¹, the Universal Declaration of Human Rights², and the Constitutions of over 150 countries³, privacy lacks a clear, shared definition⁴. It has a low status in the United Kingdom⁵, partly due to the Government's lacklustre attempts to regulate news media following the Leveson Inquiry⁶, the vilification of whistle-blowers such as Edward Snowden and Julian Assange, and the approval, driven by abuse scandals and fears of terrorism, of 'the most extreme surveillance powers in the history of democracy'⁷. Meanwhile, the advance of digital technology and especially the emergence of the Internet of Things 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 under surveillance⁸. In the light of these things, privacy has become the focus of some campaigning organisations⁹ and deserves our attention.

Different kinds of project

Before addressing the topic of privacy directly, it is helpful to think about different kinds of teams and the tasks that they perform. The following illustration may help to distinguish different kinds of teamwork. Imagine a hiking trail in hilly country above the treeline in England. The first person to pass along the trail is a lone walker – a non-team. As he is in virgin territory, he balances a stone to help him recognise and return by the same path. This stone makes sense to him but is unrecognised by anyone else. Then he comes upon a simple pile of stones, known as a cairn, which has been

¹ The foundations of the concept of privacy are set out in the EPIC report from 2006 [here](#). For example, Aristotle distinguished the public sphere of political life from the private sphere of home and family life, while the legend of Peeping Tom originates from 1050 when Tom gawked at Lady Godiva and was punished for it. See Calvert C (2000) *Voyeur nation* 36-38. Privacy has also been criticised as a brake on the market, a cloak for oppression or an atheoretical bundle of loosely connected ideas.

² Article 12 says that 'No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.'

³ The relevant section of each constitution can be read at <https://www.constituteproject.org/search?lang=en&key=privacy>

⁴ Koops BJ, Newell BC, Timan T, Škorvánek I, Chokrevski T, & Galič M (2016) A Typology of Privacy *University of Pennsylvania Journal of International Law*, Vol. 38, 483-575. Available [here](#). Solove argues that the term privacy is rather like family resemblance, where each member shares some but not all of a suite of traits – hair and eye colour, height, build and so on. Privacy covers a set of similar topics but is not reducible to a single characteristic. See Solove DJ (2006) A Taxonomy of Privacy *University of Pennsylvania Law Review*, Vol. 154, No. 3, pp. 477-564. Available [here](#).

⁵ The UK was already towards the bottom of Privacy International's league table in 2007 – see [here](#). However, more attention may be paid in some of the devolved administrations – see <http://careaboutrights.scottishhumanrights.com/> for example.

⁶ See David Cameron's response at <https://www.theguardian.com/media/2012/nov/29/leveson-inquiry-david-cameron-statement>.

⁷ The Investigatory Powers Act passed into law in November 2016. See <https://www.theguardian.com/world/2016/nov/19/extreme-surveillance-becomes-uk-law-with-barely-a-whimper>

⁸ See <http://www.scottishcare.org/wp-content/uploads/2018/08/Tech-Rights-Booklet-PROOF.pdf>. As long ago as 1981, Rowles described the expansion of the 'surveillance zone' resulting from the introduction of technology in care settings. See Rowles, G.D. (1981) 'The surveillance zone as meaningful space for the aged', *The Gerontologist*, vol 21, no 3, pp 304-11.

⁹ See, for example, the [Electronic Frontier Foundation](#) or [Knowprivacy](#) or [Privacy Rights Clearinghouse](#).

formed through a tradition by which hikers pick up a stone as they approach and add it to the pile as they walk by to create a way-marker for all. Over a year, numerous individual walkers on a well-trodden path contribute to the cairn, despite having no other contact with one another. On rare occasions, a group of walkers travelling together might decide to heave a massive stone on to the cairn, thereby adding a rock that none of them could have shifted alone without the active help of the other members of the group.

This illustrates, albeit in a partial way, some of the different kinds of project that might be undertaken by a health or social care team. For example, a team of district nurses largely have their own caseload and one patient will routinely have a working relationship with just one of the nurses and be unknown to the others. In contrast, the multidisciplinary team working in an operating theatre are acting like the group of walkers heaving the massive rock – they must work together if they are to accomplish the task.

So how does the team work in a care home, and, in particular, how do they navigate the boundary between sharing information with one another about the person they support and upholding that person's right to privacy? In most situations, the staff act rather like the series of lone walkers who each add their own stone to the cairn. Only rarely do individual staff actually need to cooperate with one another to get the job done, like shifting the big rock, and when this happens, it is often in relation to practical tasks, such as where two staff are needed to help a person transfer from wheelchair to bath. When it comes to pooling personal information about the individual receiving care, there are very few occasions where one staff member really needs to know the personal details that the person disclosed to a staff member on the previous shift. Yesterday's personal disclosure rarely changes today's intervention.

Engaging other teams and services

There is a further matter to address before we step into the questions surrounding privacy within the team, and that relates to external teams. Some people using health or social care services are in touch with more than one team. There is a care team in the residential setting, another at the GP surgery and a third in the specialist learning disability service, for example. While there may be a case for merging separate services into one, or coordinating information-sharing across teams, the alternative argument also has merit.

For example, Supported Living principles aim for a separation of housing and support providers, so that the roles of landlord and personal carer are held by different organisations, preventing the undue concentration of power, and the risk of information or sanctions bleeding from one sector to another. In this scenario, becoming noncompliant or challenging of my carer should not be seen as a breach of tenancy responsibilities or lead to eviction. So the person gets to enjoy a life which is lived in separate compartments, free of tale-telling from one compartment into another, just like most citizens.

In a similar way, a community organisation prefers for the people who use one of its services to go elsewhere for other services, even if it provides them itself, rather than invest all these relationships and roles into the one organisation.

So the best way to uphold the right to privacy may be to ask questions about whether the same team should provide all the services it currently delivers and explore whether specialist provision can

be delivered by mainstream, universal services or by alternative providers with whom there is no conjoint relationship and personal information is not routinely disclosed. Of course, there will be occasions when routing all services through the same individual or team will be the best way to support and safeguard the person, but the default position should perhaps be to enable the person to live in several compartments (work, home, leisure, online) as most urban dwellers in the developed world do.

Team-held information

Services that are designed and run by user-led organisations might proclaim that privacy should come first. But most care organisations in England do not seem like this at all. They 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 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. For example, 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.'

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

It is important to note that the increasing nature of multi-agency care provision means that objecting to, or restricting sharing of records between carer 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.'

Where some or all staff are inexperienced, unqualified and overworked, maintaining a distinction between different kinds of confidence or even deciding when disclosure is 'suitable' and 'purposeful' can become too difficult. Rather than trusting the staff to exercise judgement, managers and regulators prefer to give guidance designed for the most risky 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.

Feeling left out

There is a second burden too, that is avoided by telling everyone everything. If one staff member knows that another has some secret knowledge about a resident, knowledge that is being

deliberately kept from him, then this is likely to frustrate his human curiosity¹⁰ and make him feel as if his colleague and the resident both distrust him. Again, if either the resident or their chosen confidante should overcome their reserve and ask the excluded worker to leave the room so that they can continue their private conversation, then this might be perceived as discourteous or hurtful. These uncomfortable feelings of being left out, deemed untrustworthy and sitting outside the circle of confidence may originate from prehistory, when sharing information, especially about predators, kept the tribe alive, and to be ostracised meant imminent, and perhaps violent, death¹¹.

The counterpart of these negative feelings is the warm companionship that comes with sharing gossip, updating a friend with news of others in your community, and exchanging news of family and neighbours. As one independent advocacy organisation explained, *'We often have to ask health and care professionals to refrain from telling us information about a client they want to refer when they have not had their permission.'*¹² But when it comes to these informal exchanges with residents, the confidentiality principle can be used to excess, as in the following example. When a resident was suddenly moved to a more intensive care environment, the residents left behind wanted to express their love and support by sending cards and flowers or arranging a visit, but staff refused to assist, blanking any inquiries in the name of confidentiality. Residents described this vividly as like an alien abduction, with the person simply vanishing and staff conducting themselves as if the individual had never existed, as if any contact between current and past residents would be toxic¹³.

A linked matter is driven by concern about harm to staff. Paid carers are expected to follow the doctor's Hippocratic oath that demands they 'do no harm' to those under their care, while sometimes being subject to harm from the person they are paid to support. Such harm might be caused by challenging behaviour, when the person is rude, critical, demanding, aggressive or violent, and where the worker is subject to challenges to their confidence, identity and sense of self-worth.

In some teams, a staff member who admits to a difficulty in tolerating these events can be regarded as weak or incompetent, even when they are trying to process the traumatic experience of being verbally or physically abused by the person they are paid to support. The seriousness of the insult will affect how much harm it causes to the worker, and its impact will be moderated by their personal history of emotional development and access to loving support.

Few care environments are ideal settings for the creation of robust, resilient staff. Low pay and status, little opportunity for training or development, unpredictable or dogmatic management and fragmented teams combine to sabotage efforts to build a team where members help one another through the challenges of daily work. Some staff manage these challenges by withdrawing their emotional labour and just 'doing the job'.

Thus it is possible that attempts to create a team environment where staff afford people the right to privacy will inadvertently dismantle mechanisms for peer support and shared emotional loadbearing

¹⁰ Curiosity is a powerful driver for some people, as illustrated by the NHS staff who have pried into a patient's confidential notes without a valid reason and then been prosecuted for it – including Linda Reeves, Sally Anne Day, Steve Tennison and Brioney Woolfe – see [here](#).

¹¹ For an evolutionary perspective on the links between gossip and social bonding, see Dunbar [here](#).

¹² Personal communication May 2017

¹³ The practice of denying any further contact opportunities between current residents and people who have left the service is perhaps felt most strongly by care leavers. A Scottish initiative called [Relationships Matter](#) is challenging this practice.

within the team. Only in a sophisticated environment that balances these competing forces will all stakeholders be kept safe and the shameful procession of scandals and tragedies be slowed. It is no surprise that some teams abandon any attempt to uphold privacy and revert to a culture that shares everything.

The hive mind

Thirdly, anxiety about impending visits from inspection bodies and litigation presses staff to write everything down. Deciding what is relevant to write down again seems just too hard, and so it is easier to record everything¹⁴. The arguments for disclosure and recording are well rehearsed, while the right to privacy is neglected or framed solely in the context of data leakage to external audiences. The written record helps the staff team to coordinate their work so that it aligns with John's choices and preferences, deal with staff absences and support future investigations. The simplest solution is to have a single record for all team members to write in and where each staff member can read the notes made by their colleagues.

So the policy is adopted that says any disclosure made to anyone belongs to the whole multidisciplinary tribe and not to the individual worker. In the modern age, multidisciplinary care teams have adopted the 'hive mind' of Star Trek's Borg Collective, in which individual distinctiveness is assimilated. In English care services, this culture of 'share everything, record everything' is so pervasive that it is rare to find any reference to the right to privacy in policies on teamwork or record keeping. Nor does it seem that there is much academic or legal literature¹⁵ that discusses this issue, since most conversations about records and disclosure are concerned with personal information leaking into the public domain or with medical notes being shared with the patient concerned. In summary, most services frame the right to privacy as being about unwarranted information leakage and assume that anything a resident discloses to any staff member is automatically the property of the whole team. We might reasonably ask the resident if he feels that staff know too much about his life¹⁶.

¹⁴ For an example of a good practice that explicitly avoids writing things down except notes necessary to carry out the person's wishes, which are destroyed or returned to the person when no longer needed for that purpose, see <http://europe.ohchr.org/SiteCollectionImages/Events/Disabilities%20symposium%20October%202014/Maths%20Jesperson.pdf>

¹⁵ The following article discusses the balance between information sharing and privacy in the context of intensive care, where patients are often unable to communicate their wishes. It focuses on how clinicians share information with other family members, but this may help with thinking about the issues involved in coming to a decision about how the person's right to privacy is upheld. See Samuel M Brown, Hanan J Aboumatar, Leslie Francis, John Halamka, Ronen Rozenblum, Eileen Rubin, Barbara Sarnoff Lee, Jeremy Sugarman, Kathleen Turner, Micah Vorwaller, Dominick L Frosch (2016), Balancing digital information-sharing and patient privacy when engaging families in the intensive care unit *Journal of the American Medical Informatics Association*. Available at <http://jamia.oxfordjournals.org/content/early/2016/03/16/jamia.ocv182.article-info>

¹⁶ Louis Harris & Associates & Westin (1979) *The Dimensions of Privacy* surveyed US citizens and found that 11% felt that their neighbours knew too much about their personal lives.

Human diversity

A further challenge to the hive mind comes from the recognition of human diversity. Some team members will have a natural affinity with a particular resident, and will become the repository of many confidences, while others remain faceless functionaries. Indeed, it has been argued that privacy is an essential precondition for dignity, intimacy and meaningful personal relationships¹⁷, as the decision to confide in a carefully chosen human being is an act of trust and love which is a crucial part of developing an inner life and personality. The offer of hospitality that occurs when one person invites a chosen other into their home (whether that is the family home or their room in a residential care setting) not only connects the host and the guest to one another, but it also connects the host to their home. Living without privacy carries the fearful risk that it can degrade both body and spirit, as choice is eroded, the potential for friendship shrinks, confidences are twisted into interrogation and gossip¹⁸, and even lovemaking is observed and distorted into pornography.

In addition to these harmful consequences that may occur through the loss of privacy, the very action of intruding on another person's life can be humiliating or demeaning. This may occur when a person with dementia is required to wear a panic button or GPS location device, when a video camera is installed in the home or when staff talk and write things down about the person's speech or behaviour. Even though the watchers are well-meaning caregivers or loving relatives, these intrusions on privacy can be reminiscent of the treatment afforded to criminals, pets or wild animals. Moreover, the introduction of surveillance technology may have a perverse consequence if staff relax their vigilance, 'leave it to the machines' and neglect residents rather than spending the freed-up time on activities that enhance residents' quality of life¹⁹.

While some team members are recipients of a high level of trust, others will be forgetful, poor at recalling and recording, or reluctant to obey the instruction to write everything down. The effect will be that any team that tries to share everything will fail, and we know that any approach founded on an unachievable goal will be flawed²⁰. The alternative starts by celebrating the diversity of human relationships and the miracle that happens when we make a special connection with one of those rare individuals who help us recognise ourselves and feel understood, valued and sometimes even loved.

¹⁷ For the relationship between privacy and dignity, see Bloustein E (1964) Privacy as an aspect of human dignity: An answer to Dean Rosser *New York University Law Review* 39; 962-1007. For the relationship with intimacy, see Innes J (1992) *Privacy, intimacy and isolation* Oxford: Oxford University Press. For the link with personal relationships, see Rachels J (1975) Why privacy is important *Philosophy and Public Affairs* 4: 323-333. The link between the right to a private life and its contribution to the development of human relationships and personality is endorsed by the European Court of Human Rights – see [here](#).

¹⁸ Studies of gossip show that it helps in conveying and upholding social norms and creates an emotional bond between the narrator and the audience, while it is harmful to know you have been talked about in your absence. 'Being talked about in your absence' might be a description of the behaviour of many care teams. See <http://www.rotarybalilovina.org/wp-content/uploads/2011/02/Dunbar%20gossip.pdf> and <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.948.434&rep=rep1&type=pdf>

¹⁹ Eltis K (2005) op cit.

²⁰ As an example, websites sometimes include a privacy statement. A decade ago, it was estimated that the average person would need 201 hours to read the privacy policies for the websites that they visited in a year. As a result, few people do so. See McDonald AM, Cranor LF. (2008) Cost of reading privacy policies. *ISJLP* 4:543.

Section 2 – what must individual staff report?

The foregoing broad discussion about privacy within teams comes to something of a head when we consider the circumstances under which it is vital to disclose information. This section is an extended discussion of this topic.

Imagine a house in England where six students live together as friends. One resident, John, could tell another resident - Andrew - some information and obtain Andrew's agreement that it was a confidence shared between the two of them that was not to be divulged to anyone else. By following John's instruction, Andrew keeps the matter a secret between the two of them, does not share it with other people who live in the house, and upholds John's right to privacy²¹. In this way, John builds a variety of distinctive relationships and social roles as an expression of his personality, individuality and social identity.

Now let's change the story a little. John lives in a staffed house run by the health or social care system. The other five people, including Andrew, are paid workers. Andrew and his colleagues work on a rota to support John to live as independently as possible and to participate in community life. He lives there long-term, by choice, and he is not detained under any kind of law. Staff generally do their best to listen carefully to John's wishes and ensure he lives the life he wants. He enjoys mental capacity and can understand and weigh information about his options, select between alternatives and communicate his decisions to others²². As such, he uses Alan Westin's classic definition of privacy – he 'determines what information about himself should be known to others'²³.

The workers have a tradition of keeping a record of their work, so that they can support John in the best possible way. They believe that thorough record keeping also helps to keep John, Andrew and his colleagues safe. They know that history is scarred by accounts of abusive staff who built a hidden, exploitative relationship with someone in the care system. They insist that writing everything down and sharing it with the whole staff team helps to protect everyone against abuse.

Some highly qualified, diverse teams of health professionals will not share everything, so that a psychotherapist, for example, might operate on a 'need to know' basis with the family doctor, and some records are segmented so that one person's entry cannot be routinely read by another; but in teams of care workers, where everyone is on broadly the same job description and payscale, the culture of 'record everything, share everything' predominates.

²¹ For a philosophical analysis of the concept of privacy, see <http://plato.stanford.edu/entries/privacy/>.

²² These last two points demand some further explanation. If services are poor or mental capacity is restricted, then this demands that additional safeguards be set in place to uphold the right to privacy, rather than providing an excuse for denying the right to privacy.

²³ Westin A (2003) Social and political dimensions of privacy *Journal of Social Issues* Vol 59, No 2, pp431-453.

This means that we might now follow two parallel tracks – what happens in the realm of speech and what happens to written records²⁴. There are, of course, important movements²⁵ dedicated to sharing health care records with the patient who has been written about, and much has been written about preventing the negligent or accidental breach of confidentiality that occurs when a worker leaves a file on the bus or an organisation throws out a photocopier without wiping its hard disk. In contrast, this paper focuses on how information is disclosed within the staff team, from one team member to another.

Back in 2009, the Knowprivacy report²⁶ into online privacy summarised evidence from a number of surveys that indicated the following consistent conclusions:

- 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, these demands for awareness, control and privacy may well form a foundation for a manifesto for people in receipt of care.

As we step into the privacy field, we also need to remember the differences between individuals²⁷, cultures and regions²⁸ in their perception of the importance of privacy and its implications. For example, a younger woman is more likely to perceive privacy violations when undressing for a medical examination²⁹, while a Muslim woman may expect only the relevant part of the body to be undressed, and then covered up again immediately³⁰, and, overall, people in the UK may be more sensitive to issues of privacy than their counterparts in Greece³¹. However, these matters may be

²⁴ Of course, many of the difficulties with sharing health records with the patient arise when the file contains more than a record of a conversation with the person and move into topics that have not been discussed with the person at all. Kim Nazi said, *'we encourage open communication with the patient so that the record is supplementary and not surprising.'* (personal communication 31/08/2016). The Professional Record Standards Body for health and social care (PRSB) aims to make sure that care records in the health and social care system follow a widely agreed set of quality standards. PRSB did not respond to an email inquiry sent 20/04/2017 to ask about the right to privacy within teams. See also Turvey C Personal Health Records, Patient Portals, and Mental Healthcare, in Maheu MM, Drude KP & Wright SD (2016) *Career Paths in Telemental Health*, Springer, pp.115-121.

²⁵ Over 10 million patients in the USA have access to their health records – see <http://www.opennotes.org/> or read the summary at <http://www.nejm.org/doi/full/10.1056/NEJMp1310132#t=article>. The Veteran's Administration has become the first US wide health provider organisation to adopt a fully open notes approach.

²⁶ http://knowprivacy.org/report/KnowPrivacy_Final_Report.pdf

²⁷ Harrison, Claire L, *The development of a Desire for Privacy Scale* (1993). Doctoral Dissertations. <http://opencommons.uconn.edu/dissertations/AAI9405263>.

²⁸ Pedersen DM & Frances S (1990) Regional Differences in Privacy Preferences *Psychological Reports* Vol 66, Issue 3, pp. 731 – 736. <https://doi.org/10.2466/pr0.1990.66.3.731>.

²⁹ We note that these differences may be due to differences in offensive behaviour, differences in perception or both. See Parrott, R., Burgoon, J., Burgoon, M., LePoire, B. (1989) Privacy between physicians and patients: More than a matter of confidentiality. *Social Science and Medicine* 29 (12), 1381–1385.

³⁰ Leino-Kilpi, H. et al (2001) Privacy: a review of the literature *International Journal of Nursing Studies*, Volume 38, Issue 6, 663–671.

³¹ Schopp A, Leino-Kilpi H, Valimaki M, et al. Perceptions of privacy in the care of elderly people in five European countries. *Nurs Ethics* 2003; 10(1): 39–48.

hard to be certain about. One study³² found that hospital patients were less concerned about privacy than the nurses who cared for them, but this may have been to do with the context – on admission to the hospital - or the changing room at the gym for that matter - one replaces everyday preferences with an ability to tolerate these congregate, public settings³³.

In addition, privacy stands in law as a qualified or restricted right, in that it may be outweighed by other concerns, such as the public interest. 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 interest³⁴. When it comes to attitudes towards formal privacy protection, Westin³⁵ has segmented the population into three – those who are suspicious of government and business and so wish to block their attempts 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 over time shift the proportion of people occupying these market segments, so for example, terrorist attacks lead to an upswing in popular support for Government intrusion into private lives.

Safeguarding

On day 1, John tells staff member Andrew something. *'I have found a way to unlock the drugs cupboard. I am going to break in and take all the controlled medication at midnight tonight. I don't want anyone else to know.'* As the information relates to a potential crime and serious harm, is it reasonable to expect Andrew to override John's preference and breach confidence to prevent a crime being committed? In the face of a risk of harm, some people would choose 'safety first, care second.' However, it may be different for John himself. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) insists that disabled persons retain the right to equal treatment before the law, which means that the law recognises the decisions the person makes and others can support their decision-making, but not substitute their own decisions. Where John has mental capacity³⁶, on what authority might staff take control of the disclosure process and override John's choices? Would they be in jeopardy if they remained silent?

The Criminal Law Act 1967 makes it clear that a criminal offence has not usually been committed if someone fails to pass on knowledge of a crime, but there are qualifications to this general principle³⁷. These are set out in legislation which defines specific circumstances in which staff do

³² Back, E., Wikblad, K., 1998. Privacy in hospital. *Journal of Advanced Nursing* 27 (5), 940–945.

³³ Low LP1, Lee DT, Chan AW (2007) An exploratory study of Chinese older people's perceptions of privacy in residential care homes. *J Adv Nurs*. Mar;57(6):605-13.

³⁴ See <https://www.theguardian.com/uk-news/2017/sep/05/topless-photos-of-duchess-of-cambridge-were-invasion-of-privacy>.

³⁵ Westin A (2003) Social and political dimensions of privacy *Journal of Social Issues* Vol 59, No 2, pp431-453.

³⁶ See the provisions of the Mental Capacity Act 2005.

³⁷ The 1967 Act makes some exceptions to this general principle – it is a crime to: withhold information about criminal activity from the authorities in exchange for a reward; assist a criminal, or would-be criminal; share in the proceeds of a criminal act; or deliberately mislead the police. So withholding information might be seen as assisting in a criminal offence or perverting the course of justice.

bear responsibilities to proactively report information to avert the specific crimes of terrorism³⁸ and drug trafficking³⁹ - and the law also protects people who breach the right of confidentiality to so report⁴⁰. Some organisations write additional items into their policies, such as those who report any intent to break the security rules of a forensic or penal setting⁴¹.

In this situation, Andrew might find a way forward with John that may include staying on into the night with him or finding out why he dropped this information bomb in that way, why he chose Andrew as the recipient of this disclosure, and what John hopes will happen next.

This suggestion is shocking to many health and social care workers in the UK, where the ever-growing status of safeguarding has over-reached the traditional legal framework described above⁴² and swept away such nuances⁴³. Safeguarding processes, now enshrined in the Care Act 2014, require anyone who knows about abuse or neglect to act upon that knowledge rather than waiting to be asked for information about it. In response, some individual organisations have set out reporting requirements that go beyond those previously established by statute and some add a variety of other variables into the mix⁴⁴. However, to balance these obligations to report, official guidance on safeguarding has also included 'lack of respect for privacy' as one expression of institutional abuse⁴⁵. Some disclosures should trigger safeguarding actions, but not all.

³⁸ The Prevention of Terrorism Act 1984 places a legal duty on all citizens to divulge to official bodies any information relating to acts of terrorism. This is reinforced in the Terrorism Act 2000 and the Anti-Terrorism, Crime and Security Act 2001, which requires all citizens to divulge anything that would help the authorities prevent an act of terrorism.

³⁹ The Drug Trafficking Act 1994 makes it a criminal offence not to report a suspicion or knowledge of drug money laundering.

⁴⁰ Section 55 of the Data Protection Act 1998 allows for confidential information to be disclosed for the purpose of preventing or detecting crime – see <http://www.legislation.gov.uk/ukpga/1998/29/section/55> so someone who did so would escape prosecution for breach of confidentiality, but this is different from being required to disclose.

⁴¹ One organisation's policy I saw asserted that they will breach confidentiality if the matter is likely to have a detrimental effect upon the organisation's good name or reputation – in direct contravention of the Government's guidance on the Care Act 2014, paragraph 14.190 – see <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#safeguarding-1>. The same organisation has added radicalisation to their list of issues that must be dealt with under safeguarding procedures, thereby showing how new issues are being added to the safeguarding portmanteau.

⁴² For example, the *West Midlands Adult Safeguarding Policy and Procedures* paragraph 3.5.4 (available [here](#)) requires health and social care staff to report to the police any criminal offence that has occurred or is likely to occur.

⁴³ For example, while it is clear that drivers in the UK have an obligation to tell the Driver and Vehicle Licensing Authority about anything that seriously impairs their ability to drive, the General Medical Council has advised doctors that they have a duty to override the patient's wishes and notify the DVLA if in their professional judgement the patient's refusal to stop driving is a danger to others – see [here](#).

⁴⁴ One advocacy organisation includes the intent to break security rules in locked facilities, and information relating to an offence which there is reason to believe has not previously been disclosed as reasons to override the duty of confidentiality. Others adopt an informal approach in which risk of violence would be disclosed, while offences perceived to be of less importance (perhaps benefit fraud) might not. Yet another position is for the organisation to make a judgement on the likelihood that they would become the subject of prosecution or receive a Court Order requiring the disclosure of the information. The organisation would always answer inquiries from the Police or the Courts truthfully and freely.

⁴⁵ See [Safeguarding adults: Types and indicators of abuse \(SCIE At a glance 69\) last updated: April 2018](#).

As a result, some staff feel that they should record everything and disclose everything lest they find themselves subject to punishing challenges and investigations. To combat these pressures, the Privacy Commissioner in New Zealand has suggested five questions⁴⁶ to ask before information is collected or disclosed - and these might be adapted to relate to the broader privacy agenda, as follows:

- Can we get by without intruding on privacy, or by keeping information anonymous?
- Has the person given their consent?
- Has the person been told about the intrusion?
- Is there a serious threat⁴⁷ that will be reduced by intruding on the person's privacy?
- Is there another legal provision that can be used in this situation?

It is worth noting here that the above discussion has largely viewed privacy from a negative viewpoint, to do with stopping bad things happening in secret, where upholding privacy is about protection from unwarranted intrusion. Privacy provides relief from surveillance and interrogation with their attendant chilling effects by which personal expression, interaction and contribution are inhibited⁴⁸. The recent availability of surveillance technologies, ranging from GPS location finders, through movement sensors to video cameras has increased the capacity of staff and even distant relatives to observe care home residents⁴⁹. It is interesting to note in passing that Austrian law deems surveillance technologies to be a form of restraint⁵⁰, and, in contrast, if the person who watches is a lover rather than a critic, then being observed can elicit positive emotions⁵¹. The motive of the watcher is sometimes relevant, as in stalking, where there must be an element of malice and reasonable fear on the part of the victim, a situation that is quite different to that of caregivers.

There is often a display of power near the heart of privacy violations, such as when the state insists on collecting personal information that the poor only provide because they have no choice. Indeed, in my own family, Elizabeth Barker (my 5 x great aunt) was refused poor relief in October 1837 because she refused to divulge the earnings of her teenage children. In our own generation, too, many people defiantly choose to retain their privacy rather than face the humiliation of disclosure.

⁴⁶ See the Escalation Ladder [here](#). In New Zealand, five responses of 'no' should mean that disclosure should be avoided, at least for now.

⁴⁷ These things are always about balancing competing priorities: it is important to uphold the right to privacy at the same time as ensuring protection from abuse, so that people are not left to 'rot with their rights on', as Appelbaum and Gutheil put it – see <https://www.ncbi.nlm.nih.gov/pubmed/549703>.

⁴⁸ Overt surveillance has this chilling effect, and so does the awareness of the possibility of surveillance – what some have called the 'panoptic effect' after Jeremy Bentham's 1791 Panopticon, where every prisoner was subject to the possibility of being watched at all times, and therefore felt obliged to conform to the rules. We might suspect that the panoptic effect is equally powerful whether or not there is film in the camera.

⁴⁹ Vermeer Y, Higgs P and Charlesworth G (2018) Marketing of surveillance technology in three ageing countries *Quality in Ageing and Older Adults*. The authors checked over 200 marketing websites advertising surveillance technology designed for use in care homes. The marketing portrayed people with dementia as animals and children and paid no attention to consent or privacy issues. See <https://www.emeraldinsight.com/doi/pdfplus/10.1108/QAOA-03-2018-0010>

⁵⁰ Heimaufg (2011), quoted in Niemeijer AR (2015) Exploring good care with surveillance technology in residential care for vulnerable people PhD thesis, VU, Amsterdam. Available at <https://research.vu.nl/en/publications/exploring-good-care-with-surveillance-technology-in-residential-c>.

⁵¹ See the discussion about the identity of 'Big Brother' in Robinson L, Hutchings D, Corner L, Finch T, Hughes J, Brittain K & Bond J (2007) Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia, *Health, Risk & Society*, 9:4, 389-406, DOI: 10.1080/13698570701612774

The UK law also protects the confidentiality of certain kinds of information, such as the National Health Service Act 2006, which defines ‘confidential patient information’ in section 251⁵². However, these are limited rights, and can be overturned if there is ‘substantial public interest’ in so doing⁵³.

The invasion of privacy can trigger harmful experiences such as feelings of violation, such as anxiety and aggression, powerlessness and shame. It is complex, as where someone who needs help to use the toilet willingly surrenders their privacy to the caregiver with whom they have a working relationship, but then feels violated when they believe that they are being watched by an unknown Big Brother through the use of surveillance technology. These emotions are particularly toxic to the therapeutic environment, since they stimulate defensiveness, secrecy and mistrust in relationships. Meanwhile, those who unwittingly observe a privacy violation are themselves harmed by the embarrassment this evokes. To add yet more layers of complexity to the issue, professionals sometimes invade the privacy of their patients, at the same time as refusing to disclose information to the patient about diagnosis and treatment in a perversion of the ethics of privacy⁵⁴.

As revealed by its etymology, the stem of the word privacy is ‘priv’, which is found in both a negative context, as in the word deprived, and in the positive sense of being privileged. This suggests that in addition to the negative aspects of privacy highlighted above, there is also a positive dimension to privacy, through which people have the opportunity to develop as unique individuals, exercise autonomy, unwind from emotionally stressful experiences, exercise creativity, engage in self-evaluation, and share confidences⁵⁵. However, for this positive consequence, privacy needs to be set in a rich environment, so the person can enjoy relaxation, select from a choice of activities, share an intimate moment with a friend or a lover, and capture the outputs of reflection for future use. Few of these things can be accomplished by the hostage kept against their will in solitary confinement in a bare cell.

Well informed therapy

On day 2, John tells staff member Susie something. ‘*When I was a child, my uncle attacked me and I often have bad dreams about it. I have never told anyone about it before and I don’t want anyone else to know.*’ The therapists on the team might regard this information about John’s childhood trauma to be vital to their work with him. Any future investment in treatment will be wasted if this information is not shared - and legislation in 2015 has placed a legal duty on health and adult social care staff to share information when it will facilitate care for an individual⁵⁶. Where the person is deemed to lack capacity, this decision should be made using a Best Interests framework, but it is worth noting that even this is a value-laden exercise and may favour safety and health gain above

⁵² See points 10 and 11 at <http://www.legislation.gov.uk/ukpga/2006/41/section/251>

⁵³ See the Data Protection (Processing of Sensitive Personal Data) Order 2000 here http://www.legislation.gov.uk/uksi/2000/417/pdfs/uksi_20000417_en.pdf

⁵⁴ Volicer, B., Wynne Bohannon, M., 1975. A hospital stress rating scale. *Nursing Research* 24 (5), 352–359.

⁵⁵ See Rawnsley, M. (1980) The concept of privacy. *Advances in Nursing Science* 2 (2), 25–31. Also Bronitt S (1995) ‘The Right to Sexual Privacy, Sado Masochism and the Human Rights (Sexual Conduct) Act 1994 (Cth) 2 (1) *Australian Journal of Human Rights* 59.

⁵⁶ The Health and Social Care (Safety and Quality) Act 2015 inserted sections 251A, B and C into the Health and Social Care Act 2012 – see <http://www.legislation.gov.uk/ukpga/2015/28/contents/enacted>. These sections make no reference to the right to privacy under the Human Rights Act, but they do indicate that information may be withheld if the person objects to it being disclosed.

more abstract concepts such as the right to privacy⁵⁷. Of course, one of the reasons for sharing information with other team members is that some explanations do not arise until observations from several perspectives are combined in an approach often called triangulation.

Susie knows this but is also aware that the 2015 Act allows for circumstances where the individual concerned objects to the information being shared with anyone else, and this law upholds their right to refuse permission for it to be shared, even if this undermines or prevents the provision of care. John's objection was unequivocal (*'I don't want anyone else to know'*) so she upholds his right to privacy under 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 1998⁵⁸ and the Data Protection Act 1998⁵⁹. As the events lie in the distant past, this reinforces the 'Right to be Forgotten' principle⁶⁰ and Susie knows that most human beings need a strong sense of trust, confidentiality and emotional safety if they are to disclose personal matters, whether sacred or profane, joyful or shameful. Deeply personal matters should not be bandied about like gossip, she feels, but will the other team members feel she has done the right thing, or does their perceived need for the 'facts' override John's right in practice to choose who knows his story?

On day 3, John tells staff member Angela, *'I feel self-conscious about my weight, but feel embarrassed when it is mentioned. I like it when people offer me fruit rather than cake.'* This time, John has not told Angela that he does not want anyone else to know but has hinted that he would feel embarrassed if he knew it was being talked about. Sharing the information would perhaps be a good thing, as it means that the team discreetly start to offer John fruit rather than cake, which is just what he wants. Effective communication would mean that his preferences are shared with the whole team and acted upon, even when different staff are on duty⁶¹.

Should CRPD Article 22 on privacy be activated in these circumstances?⁶² Upholding the right to privacy should not be reduced to discussions about disclosure of information and the recording of facts, as is illuminated here. John feels self-conscious about his body image and seeks privacy where he can be away from the gaze of others, even if they are silent, non-judgemental and forgetful about what they have seen.

A second way in which the right to privacy is sometimes shrunk is to make too strong a connection between clinical or therapeutic intervention on the one hand and privacy on the other. This is seen

⁵⁷ We have no basis for assuming that as people age or cognitively decline, they begin to prioritise health above other goals. In fact, the increased suicide rates amongst the elderly may imply that a narrow focus on physical survival is not what people want.

⁵⁸ A request for comment on this issue was sent to British Institute of Human Rights and the Open Society Foundation in March 2017 yielded no response.

⁵⁹ 'Vital interest' is a term used in the Data Protection Act 1998 to permit sharing of information where it is critical to prevent serious harm or distress, or in life-threatening situations. If the only person that would suffer if the information is not shared is the subject of that information, and they have mental capacity to make a decision about it, then sharing it may not be justified.

⁶⁰ See <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/the-right-to-erasure/> and See the right to erasure set out as part of the General Data Protection Regulations [here](#) and comments about matters receding into the past becoming private [here](#).

⁶¹ This information also helps to humanise the staff, by keeping the focus on the uniqueness of the whole person – but it does so at the expense of the person's autonomy and control.

⁶² It has also been suggested that Article 19, the right to live in the community as an equal citizen, is relevant.

in Schopp et al's studies of attitudes to privacy in five European countries⁶³, where the authors are principally concerned with how privacy is upheld during nursing procedures. It is good to focus on how nurses behave when they need to assist a resident to use the commode or swallow a tablet, but the general way in which the nursing home is designed and organised will also affect its residents opportunities for privacy.

This part of John's story illustrates the importance of the personal, internal, psychological sense of privacy. John's own feelings are important, but this is not the only component of this complex topic. Take, for example, the rituals associated with death. The person has departed, and yet their rights to privacy and dignity remain as we deliberately cover their body or dress it in fine clothes for the final viewing. Society expects privacy to be upheld whether the person can feel it or not – a point of significance for people whose cognitive or communication faculties are compromised.

Finally we can move back in time to the moment before John disclosed these pieces of information to Susie and Angela. If John is constantly in the presence of others, where his every word is overheard and there is no opportunity for a private conversation, then he will be reluctant to disclose⁶⁴. Similarly, if he feels that what he tells Susie will be immediately written down and shared with people he has not chosen to confide in, then he will be reluctant to reveal personal matters, where it be physical pain, emotional trauma or moments of success and achievement. If pressed, he may be tempted to lie or gloss over the truth⁶⁵. Thus is diagnosis misinformed, formulation mistaken and intervention misdirected.

Section 3 – Some alternative approaches

The example of advocacy

An alternative approach may be found in the world of advocacy, where Independent Mental Capacity Advocates have a statutory right to see their clients in private⁶⁶. In one service, 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.

Advocates sometimes find themselves working with two people from the same family – perhaps a person using services and a carer. Some advocacy services manage this situation by recognising that

⁶³ Schopp A, Leino-Kilpi H, Valimaki M, et al. Perceptions of privacy in the care of elderly people in five European countries. *Nurs Ethics* 2003; 10(1): 39–48.

⁶⁴ Ama-Amadasun M (2016) Perceptions of caregivers towards patients' privacy rights in Swiss hospitals *International Journal of Management Research and Business Strategy* ISSN 2319-345X www.ijmrbs.com Vol. 5, No. 3, July 2016.

⁶⁵ Some might suggest that anyone using health or social care enters a contract in which their privacy is given up in exchange for help. This may be partly true (Olsen and Sabin found more than a third of patients surveyed in a hospital emergency room had overheard healthcare staff discussing the private details about other patients), but it is unacceptable. See Olsen JC, Sabin BR. (2003) Emergency department patient perceptions of privacy and confidentiality. *Journal of Emergency Medicine*;25: 329–33. Also Nahid DN and Aghajani M (2010) Patients' privacy and satisfaction in the emergency department: A descriptive analytical study *Nursing Ethics* March 2010,17(2):167-77. DOI: 10.1177/0969733009355377.

⁶⁶ Mental Capacity Act 2005, section 35(6)a.

the person and the carer may have differing priorities and addressing this by allocating a different advocate to each, rather like the way that each parent has their own legal representation in care proceedings. In this situation, the two advocates make a very deliberate decision not to speak to one another about the family, as they hold an underlying commitment to sharing everything they know with the person they are supporting, and so do not want to be in the position of knowing something that they cannot share. In this way their determination to be accountable and transparent with their client normally trumps their obligation to pool information with their colleague, unless, of course, a matter of substantial risk is involved. Further examples include:

- one advocate leaves the group supervision meeting if the other advocate wished to discuss their work with that family, as this is regarded as a conflict of interest - or the discussion is moved to another meeting where the first advocate will be absent.
- the manager, who has access to all files anyway, carries out some work on behalf of the absent advocate rather than passing the task to the second advocate who is involved with the family, thus upholding the second advocate's single perspective and accountability to the other family member.
- when one worker takes a sensitive phone call their colleague quietly leaves the office until the call is over, rather than remain within earshot.
- When an advocate attended a treatment review with the person they were supporting. Part-way through the meeting, the person decided to leave the room and asked the advocate to remain in the meeting on their behalf. As they left, the advocate announced to the people remaining in the room that they needed to go forward on the basis that the advocate would report everything that everyone said to the person, without filtering its content. Their responsibility towards the person eclipsed any tribal feelings towards the staff team, so the other team members should restrain themselves from saying things that they did not want the person to hear.
- the electronic case record is designed to show where advocates are working with the person, but staff in one department will not be able to see details recorded in another unless the person gives explicit consent. So, for example, a Care Act advocate will see that their colleague in Health Complaints Advocacy is working with the person, but they would not see any details of the subject or progress of the complaint.

In all these cases, the culture of the organisation supports staff in withholding such information unless there is an over-riding reason to disclose it to a colleague.

While these situations are somewhat different from our main focus, which is on a team of staff, they offer examples of 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, which in this case is the need for the advocate to maintain transparency with the person.

Learning from information governance

The UK Information Commissioner has recommended that organisations carry out a Privacy Impact Assessment⁶⁷, and noted that this might cover both informational privacy and physical privacy, to which we might other categories of privacy. The concept of a Privacy Impact Assessment has some potential for our discussion, although most of the current examples devote their energy to the issues surrounding compliance with regulations covering information governance rather than addressing broader aspects of privacy⁶⁸, and this has been reflected in the amended term Data Protection Impact Assessment required under article 35 of the General Data Protection Regulations.

Learning from the financial world

As well as drawing ideas from the world of information security, there may be some useful resources in the financial world, where 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 to do so. Managers, inspection agencies or safeguarding investigators could have independent access to the record. This approach would align with the Caldicott principles that insist that *only relevant information* can be shared⁶⁹. 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 absolutely 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.

⁶⁷ Information Commissioner's Office (version 1.0 undated) *Conducting privacy impact assessments code of practice* available at <https://ico.org.uk/media/for-organisations/documents/1595/pia-code-of-practice.pdf>. A similar approach will be imposed across the European Union through the General Data Protection Regulation 2016/679 (GDPR) which will take effect from May 25 2018. The Privacy Commissioner for New Zealand has a brief self-assessment checklist for a Privacy Impact Assessment that includes aspects of privacy beyond information governance. Emails sent in March 2017 to ask if anyone could contribute to this discussion - to the [Privacy Exchange](#), [Privacy Commissioner's Office of New Zealand](#), PORT, ICDPPC (unable to help), [Privacy Commissioner for Hong Kong](#), [Information Commissioner for Australia](#), [Privacy Commissioner for Alberta, Canada](#), [Privacy Commission for Belgium](#), [Privacy Commission for the Philippines](#), CATO, the [jiscmail data protection list](#), DPiLAB. Responses from the Office of the Australian Information Commissioner and the Belgian Information Commission both indicate that their work is entirely focused on information governance and has no recognition of the broader aspects of privacy (emails May 2017). The paper [here](#) acknowledges the differences in law between privacy and data protection. I could seek advice from members of the [IAPP](#).

⁶⁸ See, for example, the guidance on completing a PIA [here](#), that is entirely about information governance. See also [here](#).

⁶⁹ National Data Guardian for Health and Care (June 2016) *Review of Data Security, Consent and Opt-Outs* Paragraph 3.2.6. See [here](#).

Supporting community participation

The social inclusion agenda provides a further approach, by emphasising the importance of unpaid relationships and informal support from friends, relatives and acquaintances beyond the care system. In this scenario, 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 corporate ‘hug’ 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 that aspect of themselves private, as illustrated by the following two anecdotes. 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 return to the closet and keep his sexuality secret for fear of the response of 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 nothing in common with him and at worst, ridicule his interest. With staff support, he mentioned it to the person in the next room and, to his delight, found a kindred spirit.

Finally in this section, it may also be worth separating out the legal from the ethical. If staff frequently remind John that anything he tells a worker will be shared with the whole team, then the law might be satisfied, as John is viewed as regulating his own boundary of privacy and exercising personal choice over what he shares by telling no one what he doesn’t want everyone to know. In some circumstances, sharing personal information around a team will be acceptable, especially where the health intervention is brief and non-stigmatised. But people who spend all their lives surrounded by care staff will have a different experience. Over years, they will be socialised into the ‘hive mind’ of the care system and lose any sense of privacy and trust with selected individuals. Holding this sense of privacy and individuality is arguably an essential skill in Western society⁷⁰, and may be part of the philosophy that lies behind this aspect of human rights. In these circumstances, meeting the legal requirement by notifying the person that the whole team will know everything is ultimately harmful to the person’s interpersonal skillset and sense of identity.

Section 4 – An holistic Privacy Impact Assessment

The first step in a wide-ranging Privacy Impact Assessment would be to grasp the positive as well as the negative aspects of privacy in order to ensure that such an assessment tool upheld and celebrated the positive opportunities afforded by privacy, rather than simply focusing on privacy as an opportunity for harm. It is interesting to note that the General Data Protection Regulations, in force from May 2018, use the more precise title ‘Data Privacy Impact Assessment’, thereby clearing the ground for the broader Privacy Impact Assessment suggested below. A few of the items that might be included in such an assessment to take us beyond information governance⁷¹ would be:

⁷⁰ Cultures have different expectations around privacy and personal disclosure, as illustrated by the report on the Privacy Index – see <http://www.emc.com/collateral/brochure/privacy-index-executive-summary.pdf>.

⁷¹ See Finn, R. L., Wright, D., & Friedewald, M. (2013). [Seven types of privacy](#). In Gutwirth, S., Leenes, R., De Hert, P., & Poullet, Y. (Eds.), *European data protection: coming of age* (pp. 3-32). Netherlands: Springer. The list

- **Private space** - to be alone⁷² and unobserved by live or electronic means⁷³, as well as the ability to withdraw from settings where there are things that the person does not want to observe. Solitude offers the person an opportunity to focus on their inner dialogue⁷⁴. In contrast, some residential care staff enter resident's rooms without knocking⁷⁵, thus trespassing on the person's solitude. This is also linked with the ideas of personal space⁷⁶ (that overlaps with private body, below) and territory⁷⁷ (that overlaps with private association), which is where one feels at ease and empowered.
- **Locational privacy** – to choose where to be and to be free of surveillance or the need to give account of where one has been⁷⁸. It is possible to enjoy locational privacy in a public place where one is casually noticed by others in the space, as long as there is no systematic tracking, recording, reporting to others or control of one's presence or participation⁷⁹.
- **Private property** - ownership of money and belongings that can be acquired, kept, used, amended and disposed of without permission 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.

shown above an agglomeration of items from various sources and does not attempt to offer a taxonomy i.e. there is no explicit unifying concept, sequence, hierarchy or theoretical basis underpinning it.

⁷² One of the earliest attempts to define privacy refers to the 'right to be left alone'. See Warren S & Brandeis L (1890) *The Right to Privacy*, 4 *Harvard Law Review* 193-220 (1890). In England, the 1361 Justices of the Peace act outlawed peeping toms and eavesdroppers – see Justices of the Peace Act, 1361 (Eng.), 34 Edw. 3, c. 1. See also Louis Harris & Associates & Westin (1979) *The Dimensions of Privacy* which surveyed US citizens and found that 88% felt they were generally able to be by themselves when they needed to be.

⁷³ *Just Checking* technology uses small wireless sensors placed around an individual's home to build an objective picture of their daily living routine, without the use of cameras or microphones. Some care homes check on their residents each hour during the night, while the smart speaker *Amazon Echo* communicates with its server every couple of minutes - see <https://gizmodo.com/the-house-that-spied-on-me-1822429852>.

⁷⁴ See Westin AF (1967) *Privacy and freedom* New York: Atheneum. Available for purchase [here](#). Parental discipline sometimes includes sending children to their room for a time in an attempt to have them commune with their conscience.

⁷⁵ Rahn, A., Jones, T., Bennett, C., & Lykins, A. (in press). *Conflicting Agendas: The Politics of Sex in Aged Care*. *Elder Law Review*, 10. Available [here](#).

⁷⁶ The concept of personal space emerged from studies of the animal kingdom in the 1960s. See for example, Sommer, R. (1969) *Personal space. The behavioral basis of design*. Prentice-Hall, Englewood Cliffs, NJ.

⁷⁷ Hayter, J., 1981. Territoriality as a universal need. *Journal of Advanced Nursing* 6, 79–85.

⁷⁸ See <https://www.eff.org/wp/locational-privacy>. It is noteworthy that GPS surveillance technology can create electronic fencing, whereby an alarm sounds if the person moves beyond a designated perimeter – see <https://www.alzheimers.net/8-8-14-location-devices-dementia/>. Wandering may be both emotionally and financially costly for caregivers but may be highly beneficial to the wellbeing of the person, unless it leads to exposure, starvation or death. The Safely Home scheme (or Safe Return scheme) has been adopted in several countries, including the USA, Canada and Australia, by which the person wears an engraved bracelet and information is lodged with the Police Missing Person's Unit, so that they can be quickly identified and returned to their home if they get lost. Will people who refuse tagging be refused access to care, as they are more trouble than they are worth to finance-driven care providers?

⁷⁹ In a landmark case, (see *Peck v United Kingdom* (2003) 36 EHRR 41; [2003] EMLR 287 summarised at <http://www.5rb.com/case/peck-v-united-kingdom/>) Peck's right to privacy in a public place was asserted by the European Court of Human Rights.

- **Private association.** Allen includes associational privacy – the right to join and participate in a social group without monitoring or censure from others⁸⁰, while Finn and colleagues⁸¹ note that this fosters democracy by enabling diversity and dissent in political views, worship and freedom of speech.
- **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 not⁸².
- **Private citizen** - To hold an identity that is represented through official documents such as a passport, is protected from identity theft, and yet is separate from the state, employer or identity documents. Alongside formal identity lies the freedom to develop one’s own expression of personal identity and reputation in social life while being appropriately inconspicuous⁸³ in social and public spaces. To occupy several distinct roles that do not overlap too much, so 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 – bodily privacy.
- **Private decision.** To be free to make decisions without intrusion from other people demanding information about the process, rationale or outcome⁸⁴.
- **Private thoughts and feelings** – freedom to hold one’s own 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.** The resultant Data Privacy Impact Assessment would belong here as a subset of the wide-ranging Privacy Impact Assessment.

Having defined these terms and recognised that they serve as viewpoints from which to study the broad notion of privacy, rather than mutually exclusive categories, one might then move on to

⁸⁰ Allen AL (2011) *Unpopular privacy: what must we hide?* New York: Oxford University Press.

⁸¹ Finn, R. L., Wright, D., & Friedewald, M. (2013). [Seven types of privacy](#). In Gutwirth, S., Leenes, R., De Hert, P., & Poullet, Y. (Eds.), *European data protection: coming of age* (pp. 3-32). Netherlands: Springer.

⁸² In Canadian law, the test of intrusion is not the response of the violated individual but rather whether the intrusion would be deemed to be highly offensive to a reasonable person. See Eltis K (2005) *Society’s Most Vulnerable Under Surveillance: The Ethics of Tagging and Tracking Dementia Patients With GPS Technology: A Comparative View* *Oxford University Comparative Law Forum* 3. Available at <https://ouclf.iuscomp.org/societys-most-vulnerable-under-surveillance-the-ethics-of-tagging-and-tracking-dementia-patients-with-gps-technology-a-comparative-view/>.

⁸³ Goffman referred to ‘civil inattention’ which is sometimes granted by potential observers in order to support this right of privacy in social settings. This is most obvious in settings like changing rooms, where users ignore one another rather than stare. See Goffman E (1963) *Behavior in public places: notes on the social organization of gatherings*. New York: Free Press; pp83-88. Available [here](#).

⁸⁴ Allen AL (2011) *Unpopular privacy: what must we hide?* New York: Oxford University Press.

reflect on examples of violation of these rights that occur in care settings and practical ways to uphold the right⁸⁵. Simple principles might be devised, such as the idea that intrusion should be minimised as far as possible by removing surveillance practices and technologies from as many spaces as possible, attenuating the data that is collected, such as by relying on audio rather than visual tracking, or relying on a person calling for help if they need it rather than listening to every word, and lengthening the interval between observations.

The table below may offer some starting places.

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 before entering. Freedom from unwanted location tracking.
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.
Private property	Theft within care settings. Clothes going missing through the laundry system. Lack of lockable space. Restrictions on money and number of 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.	Provide lockable space. Cupboard and door locks that cannot be used independently 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.

⁸⁵ The 2018 report by the World Health Organisation into institutional care across Europe for people with psychosocial or intellectual disabilities is a stark reminder that such violations are commonplace in some settings. See http://www.euro.who.int/_data/assets/pdf_file/0017/373202/mental-health-programme-eng.pdf?ua=1

Aspect of Privacy	Violations	Protections
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 activities to make reasonable adjustments.
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.
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.

Aspect of Privacy	Violations	Protections
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. 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.

Ozturk et al⁸⁶ have incorporated some of these factors into a validated 27-item scale for hospital nurses and further work is being undertaken by Rodriguez⁸⁷, [PIAF](#), [PRESCIENT](#), and [SAPIENT](#).

In passing, we might note that the purpose of scientific validation is to define a construct, such as privacy, using the minimum number of factors, to remove statistical redundancy and create the shortest possible definition. In contrast, stimulating awareness and discussion about the relevance and implications of a concept such as privacy sets off in the opposite direction by accumulating rather than shedding factors in order to show the potential application of the core concept in diverse and wide-ranging aspects of people's lives. Further, we might consider privacy to be a conditional rather than absolute right, so it exists in dynamic relationship with other rights, rather than as an isolated element. This presses us to conduct a Privacy Impact Assessment alongside other tasks in order to obtain a holistic view.

Once such an analysis had been coproduced with the stakeholders most closely impacted by these issues, then a broad Privacy Notice⁸⁸ 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 data privacy.

Conclusion

Some radical services may have adopted a 'Privacy by Design'⁸⁹ approach to disclosures within the staff team from the beginning, but the more challenging task is to help a traditional organisation where everything is shared to make the shift into a new culture where privacy is honoured. I'd be interested to know if others have designed an approach which *changes the culture* in staff teams and helps them to support John's right to privacy within the team, while meeting their other obligations.

⁸⁶ Özturk H, Bahçecik N, Özçelik KS (2014) The development of the patient privacy scale in nursing *Nursing Ethics* Volume: 21 issue: 7, pages: 812-828. <https://doi.org/10.1177/0969733013515489>. Emailed 3/2/18.

⁸⁷ See https://www.researchgate.net/profile/Antonio_Rodriguez60. Emailed 3/2/18.

⁸⁸ See [here](#) and [here](#).

⁸⁹ Privacy by Design is an approach developed by Ann Cavoukian, Information and Privacy Commissioner, Ontario, Canada to help with managing informational privacy (see [here](#)) but could be extended to include the 'privacy beyond information' dimensions. Privacy by Design has been adopted by the European Union General Data Protection Regulation [Regulation (EU) 2016/679].

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What is the status of this paper?

Most of the documents we read are finished pieces of work, carefully crafted and edited in private before being shared with anyone else. This is different – it was shared online from the first day, when the initial handful of ideas were incomplete, poorly phrased and tactless. The work has been edited many times and, on each occasion, a revised version has replaced the earlier material online. This process is still under way, and so this paper may still be lacking crucial concepts, evidence, structure and grammar. As readers continue to provide feedback and corrections, further insights will be used to update it, so please contact me with your contributions.

This way of writing is risky, as it opens opportunities to those who may misunderstand, mistake the stopping points on the journey for the destination, and misuse or distort the material. This way of writing requires courage, as an early version can damage the reputation of the author or any of its contributors. Or rather, it can harm those who insist on showing only their 'best side' to the public, who want others to believe that their insights appear fully formed, complete and beautiful in their simplicity. It can harm those who are gagged by their employer or the workplace culture, silenced lest they say something in a discussion that is not the agreed party line. It can harm those who want to profit from their writing, either financially or professionally through having their creations accepted by academic journals.

On the other hand, this way of writing can engage people who are not chosen to attend the meeting or asked for their view until the power holders have agreed on the 'right message'. It can allow for 'stop press' additions, draw in unexpected perspectives, stimulate debate and crowdsource wisdom. It can provide free, leading edge resources.