

# The right to privacy

## Introduction<sup>1</sup>

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 privacy<sup>2</sup>. 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 others<sup>3</sup>.

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.

This means that we might now follow two parallel tracks – what happens in the realm of speech and what happens to written records<sup>4</sup>. There are, of course, important movements<sup>5</sup> 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 the hard disk. In contrast, this paper focuses on how information is disclosed within the staff team, from one team member to another.

Despite its place in faith traditions, ancient law<sup>6</sup> and the Universal Declaration of Human Rights<sup>7</sup>, privacy lacks a clear, shared definition<sup>8</sup> and has a low status in the United Kingdom<sup>9</sup>, partly due to the Government's lacklustre attempts to regulate news media following the Leveson Inquiry<sup>10</sup>, the vilification of whistleblowers 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'<sup>11</sup>. Against this backcloth, privacy deserves some attention.

## 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, then 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 capacity<sup>12</sup>, staff may not take control of the disclosure process, and are not in jeopardy if they remain silent, since 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<sup>13</sup>. In this situation, Andrew has to find a way forward with John that may include staying on into the night or finding out why John dropped this information bomb in that way, why John 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 legal framework described above and swept away such nuances<sup>14</sup>. Safeguarding processes have set expectations that are far in excess of legal obligations, and leave some staff feeling 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 questions<sup>15</sup> 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 threat that will be reduced by intruding on the person's privacy?
- Is there another legal provision that can be used in this situation?

Before moving on, it is worth noting that privacy has a negative dimension – protection from unwarranted intrusion – and also a positive dimension, through which people have the opportunity to develop as unique individuals, exercise autonomy, unwind from emotionally stressful experiences, exercise creativity and share confidences<sup>16</sup>. Privacy provides relief from surveillance and interrogation with their attendant chilling effects by which personal expression, interaction and contribution are inhibited<sup>17</sup>.

## 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

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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 individual<sup>18</sup>. 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 1998<sup>19</sup> and the Data Protection Act 1998<sup>20</sup>. As the events lie in the distant past, this reinforces the 'Right to be Forgotten' principle<sup>21</sup> and 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 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 discretely 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 duty<sup>22</sup>. Should CRPD Article 22 on privacy be activated in these circumstances?<sup>23</sup> Of course, 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 to be silent, non-judgemental and forgetful about what they have seen.

### **Team-held information**

Services that are designed and run by user-led organisations, advocates, personal ombudsmen or human rights lawyers might uphold John's right to privacy in some or all of these three situations. 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 any of John's confidences 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, that 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.'*

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*Therefore, it is acceptable within these boundaries to share concerns /information, provided it is done in suitable circumstances and is purposeful.'*

Where some or all staff are inexperienced, unqualified and overworked, maintaining a distinction between these 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 apply the guidance that is designed for the most risky scenario 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 Andrew knows that Susie has some secret knowledge about John, knowledge that is being deliberately kept from Andrew, then this is likely to frustrate Andrew's human curiosity<sup>24</sup> and make him feel as if both John and Susie distrust him. If either John or Susie overcome their reserve and ask Andrew 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, death<sup>25</sup>. 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, 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.*'<sup>26</sup>

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.

Many care environments are not ideal settings for the creation of robust, resilient staff. Low pay and status, few opportunities 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'.

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So 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 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 everything<sup>27</sup>. 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 CRPD Article 22 Right to Privacy in policies on teamwork or record keeping. Nor does it seem that there is much academic or legal literature<sup>28</sup> 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 John discloses to any staff member is automatically the property of the whole team.

### **The example of Advocacy**

An alternative approach may be found in the world of advocacy. In several services, advocates sometimes find themselves working with two people from the same family – perhaps a person using services and a carer. In this situation, they recognise that the person and the carer may have differing priorities and address 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:

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- one advocate leaves the group supervision meeting if the other advocate wished to discuss their work with that family.
- 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 the fields of information and finance**

The UK Information Commissioner has recommended that organisations carry out a Privacy Impact Assessment<sup>29</sup>, 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, 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 privacy<sup>30</sup>. The first step 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. A few of the items that might be included in a Privacy Impact Assessment that went beyond information governance<sup>31</sup> would be:

- **Private space** - to be alone<sup>32</sup> and unobserved by live or electronic means<sup>33</sup>, 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 dialogue<sup>34</sup>. In contrast, some residential care staff enter resident's rooms without knocking<sup>35</sup>, thus trespassing on the person's solitude.
- **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 – private relationship. Allen includes associational privacy – the right to join and participate in a social group without monitoring or censure from others<sup>36</sup>.
- **Private activities** - specific activities where privacy, modesty and dignity are at a premium – intimate self-care, sleeping arrangements, access to the internet
- **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 inconspicuous<sup>37</sup> in social and public spaces.
- **Private body** - 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 outcome<sup>38</sup>.
- **Private thought** – freedom to hold one's own ideas, conscience and beliefs, and to keep these things to oneself
- **Private information**.

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 shared<sup>39</sup>. 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.
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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.

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 health and social care support 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 society<sup>40</sup>, 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.

## Human diversity

A final challenge to the hive mind comes from the recognition of human diversity. Some team members will have a natural affinity with John, 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 relationships<sup>41</sup>, 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. 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 gossip<sup>42</sup>, and even lovemaking is observed and distorted into pornography.

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 flawed<sup>43</sup>. 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.

## Conclusion

Some radical services<sup>44</sup> may have adopted a 'Privacy by Design'<sup>44</sup> 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

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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.

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<sup>1</sup> 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. In contrast, it 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, it can draw in unexpected perspectives, stimulate debate and crowdsource wisdom. It can provide free, leading edge resources.

<sup>2</sup> For a philosophical analysis of the concept of privacy, see <http://plato.stanford.edu/entries/privacy/>. Also Leino-Kilpi, H. et al (2001) Privacy: a review of the literature *International Journal of Nursing Studies*, Volume 38, Issue 6, 663 – 671.

<sup>3</sup> 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.

<sup>4</sup> 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.

<sup>5</sup> 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

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Administration has become the first US wide health provider organisation to adopt a fully open notes approach.

<sup>6</sup> The foundations of the right to privacy are set out in the EPIC report from 2006 [here](#). For example, 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.

<sup>7</sup> 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.'

<sup>8</sup> 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](#).

<sup>9</sup> 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.

<sup>10</sup> See David Cameron's response at <https://www.theguardian.com/media/2012/nov/29/leveson-inquiry-david-cameron-statement>.

<sup>11</sup> 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>

<sup>12</sup> See the provisions of the Mental Capacity Act 2005.

<sup>13</sup> 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. 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. In addition, 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. 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) would not.

<sup>14</sup> 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](#).

<sup>15</sup> See the Escalation Ladder [here](#). In New Zealand, five responses of 'no' should mean that disclosure should be avoided, at least for now.

<sup>16</sup> See 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.

<sup>17</sup> 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.

<sup>18</sup> 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.

<sup>19</sup> 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.

<sup>20</sup> '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

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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.

<sup>21</sup> 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](#).

<sup>22</sup> 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.

<sup>23</sup> It has also been suggested that Article 19, the right to live in the community as an equal citizen, is relevant.

<sup>24</sup> Curiosity is a powerful driver for some people, as illustrated by the prosecutions of NHS staff who have pruned into a patient’s confidential notes without a valid reason, such as Linda Reeves, Sally Anne Day, Steve Tennison and Brioney Woolfe – see [here](#).

<sup>25</sup> For an evolutionary perspective on the links between gossip and social bonding, see Dunbar [here](#).

<sup>26</sup> Personal communication May 2017

<sup>27</sup> 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%20Jespersion.pdf>

<sup>28</sup> 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 Vorwallier, 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>

<sup>29</sup> 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](#), DPiALAB. 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 of privacy and data protection. I could seek advice from members of the [IAPP](#).

<sup>30</sup> See, for example, the guidance on completing a PIA [here](#), that is entirely about information governance.

<sup>31</sup> 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 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.

<sup>32</sup> 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.

<sup>33</sup> 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.

<sup>34</sup> See Westin AF, *Privacy and freedom* New York: Atheneum, 1967. Parental discipline sometimes includes sending children to their room for a time in an attempt to have them commune with their conscience.

<sup>35</sup> 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](#).

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<sup>36</sup> Allen AL (2011) *Unpopular privacy: what must we hide?* New York: Oxford University Press.

<sup>37</sup> Goffman referred to 'civil inattention' which is sometimes granted by potential observers in order to support this right of privacy in social settings. See Goffman E (1963) *Behavior in public places: notes on the social organization of gatherings*. New York: Free Press; pp83-88. Available [here](#).

<sup>38</sup> Allen AL (2011) *Unpopular privacy: what must we hide?* New York: Oxford University Press.

<sup>39</sup> National Data Guardian for Health and Care (June 2016) *Review of Data Security, Consent and Opt-Outs* Paragraph 3.2.6. See

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/535024/data-security-review.PDF](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF)

<sup>40</sup> 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>.

<sup>41</sup> 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](#).

<sup>42</sup> 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' is a valid 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>

<sup>43</sup> 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.

<sup>44</sup> 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].