

# ***Challenging the Hive Mind: privacy in team discussions***

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## **Contents**

Introduction .....	1
Different kinds of project.....	2
Whose team? .....	3
Engaging other teams and services .....	4
Feeling left out .....	4
The hive mind.....	5
Human diversity .....	6
What must individual staff report?.....	8
Safeguarding .....	10
Well informed therapy.....	13
Some alternative approaches .....	15
The example of advocacy.....	15
Learning from staff recruitment .....	16
Learning from information governance.....	17
Learning from participatory research .....	18
Learning from the financial world.....	19
Supporting community participation.....	19
Acknowledgements.....	19
What is the status of this paper? .....	20

## **Introduction**

This is a companion piece to Bates, P. and McLoughlin, B. (2019), “Respecting privacy in care services”, The Journal of Adult Protection, Vol. 21 No. 6, pp. 276-284. <https://doi.org/10.1108/JAP-06-2019-0020>. This paper reflects on the impact of taking a privacy approach to disclosures between team members in care services.

Privacy has a low status in the United Kingdom<sup>1</sup>, partly due to the Government's lacklustre attempts to regulate news media following the Leveson Inquiry<sup>2</sup>, the vilification of whistle-blowers such as Edward Snowden and Julian Assange, the intrusion of employers in the private lives of their staff<sup>3</sup> and patients<sup>4</sup>, and the approval, driven by abuse scandals and fears of terrorism, of 'the most extreme surveillance powers in the history of democracy'<sup>5</sup>. Ignatieff sums it up by linking risk management, surveillance and courage: 'A risk-averse horizon promises security at a price: not only more surveillance, but also a loss of confident daring.'<sup>6</sup> Meanwhile, the advance of digital technology and the adoption of the Internet of Things in care settings<sup>7</sup> means that privacy deserves our attention. The UK government's 2022 report on human rights in care settings makes no mention of the right to privacy in the ordinary sense of the term<sup>8</sup>.

## 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 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

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<sup>1</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>2</sup> See David Cameron's response at <https://www.theguardian.com/media/2012/nov/29/leveson-inquiry-david-cameron-statement>.

<sup>3</sup> Industrial tribunals in the UK have upheld employer's decision to dismiss staff for their behaviour outside work, even when the matter has not come into the public domain and the employee played no part in it coming to light. See Collins PM. Finding Fault in the Law of Unfair Dismissal: The Insubstantiality of Reasons for Dismissal. *Industrial Law Journal*. 2022 Sep;51(3):598-625.

<sup>4</sup> In what is to be hoped is an unusual example, NHS bosses made a list of patients and staff known to be critical of them and then engaged private investigators to track their online activities. <https://www.dailyrecord.co.uk/news/scottish-news/nhs-chiefs-used-private-investigators-30148530>.

<sup>5</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>6</sup> Ignatieff M (2017) *The ordinary virtues: moral order in a divided world* Cambridge, Mass: Harvard University Press. Page 144.

<sup>7</sup> 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. Newcastle has a project called the "Internet of Caring Things" – see [£5.6million "Internet of Caring Things" investment in North East Prolific North](#).

<sup>8</sup> See the report at House of Commons & House of Lords Joint Committee on Human Rights (13 July 2022) *Protecting human rights in care settings* Fourth Report of Session 2022–23. HC 216 HL Paper 51. There are numerous references to the human right to a 'private and family life' but this is then discussed in relation to deprivation of liberty rather than in relation to practices that mean people are rarely alone or supported to hold some parts of their life beyond the scrutiny of staff.

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<sup>9</sup> the personal details that the person disclosed to a staff member on the previous shift. Yesterday's personal disclosure rarely changes today's intervention.

## Whose team?

It is perhaps natural in this discussion of teamwork in health and social care to think about the staff team and their needs for private or pooled information. But before we get into the detail of this, it is worth stepping back for a moment to reflect on whose cairn is being built, whose information store is being augmented, and whose team are in view.

The OpenNotes research in the USA explored what patients did if they gained access to their health records, and there are a series of research projects that report on their findings. One study explored two related questions – did patients want the option of sharing their notes with a friend or family member and did they do so during the study period. The answers were that 55% wanted the option and 22% actually did so, leading to better self-care and medication adherence<sup>10</sup>, although there can be unintended consequences<sup>11</sup>. This illustrates that, in a person-centred world, the team in question

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<sup>9</sup> Notice the qualifying condition in the following quotation 'in order to....' We must consider whether the information being shared is needed in order to deliver the health or social care or not. "While consent is good practice where possible, consent is not required. Under GDPR, personal information (including sensitive information) needed to carry out public tasks (such as the provision of health or social care) can be lawfully shared with professionals subject to professional confidentiality in order to provide health or social care. GDPR Article 6(1)(e) & s. 2 Sch.1 Data Protection Act 2018." Department of Health and Social Care (2019) *Core Capabilities Framework for Supporting Autistic People* page 67.

<sup>10</sup> Jackson SL, Mejilla R, Darer JD, Oster NV, Ralston JD, Leveille SG, Walker J, Delbanco T, Elmore JG (2014) Patients who share transparent visit notes with others: characteristics, risks, and benefits. *J Med Internet Res*. Nov 12;16(11):e247. doi: 10.2196/jmir.3363.

<sup>11</sup> See [Unintended consequences of patient online access to health records: a qualitative study in UK primary care | British Journal of General Practice \(bjgp.org\)](#). Also [Online-access-guidance-for-clinicians-and-practice-managers.pdf \(nihr.ac.uk\)](#)

is the informal team convened by the person themselves, in which professionals have at best a marginal role. In this world, half of the files kept by health and social care staff may actually be read, not just by the person themselves, but by their friend or relative.

Alongside the wish to disclose to family and friends is the wish to retain some privacy from the intrusions of professionals. Back in 1966, an early proposal for patient-written notes included the option for patients to tick the box labelled 'None of your damn business'<sup>12</sup>. With this in mind, let's return to the challenge of identifying teams within health and social care services.

## Engaging other teams and services

Some community organisations prefer for the people who use one of its services to go elsewhere for other services, even if it could provide them itself, rather than invest all these relationships and roles into the one organisation. Indeed, 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.

## Feeling left out

As well as the culture of team-held information that is common in care settings, a second burden 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 curiosity<sup>13</sup> 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, death<sup>14</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, 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*

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<sup>12</sup> Slack WV, et al (1966) A computer-based medical-history system. *N Engl J Med* 274(4): p. 194-8. DOI:10.1056/nejm196601272740406.

<sup>13</sup> 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](#).

<sup>14</sup> For an evolutionary perspective on the links between gossip and social bonding, see Dunbar [here](#).

*have not had their permission.*<sup>15</sup> 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 toxic<sup>16</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<sup>17</sup>. 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 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 litigation and impending visits from inspection bodies will press 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>18</sup>. The arguments for disclosure and recording are well rehearsed, while

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<sup>15</sup> Personal communication May 2017

<sup>16</sup> 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.

<sup>17</sup> This process is perhaps most vividly experienced by ambulance staff who are assaulted by the person they have come to help, but such experiences occur across a wide range of roles in the helping professions.

<sup>18</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

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 the person's choices and preferences, deals with staff absences and supports 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 all the notes made by all 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, record keeping or confidentiality. Nor does it seem that there is much academic or legal literature<sup>19</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 a resident discloses to any staff member is automatically the property of the whole team. We might reasonably ask the resident if she feels that staff know too much about her life<sup>20</sup>.

## 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 relationships<sup>21</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. 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

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<http://europe.ohchr.org/SiteCollectionImages/Events/Disabilities%20symposium%20October%202014/Maths%20Jespersion.pdf>

<sup>19</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 Brown SM, Aboumatar HJ, Francis L, Halamka J, Rozenblum R, Rubin E, Sarnoff Lee B, Sugarman J, Turner K, Vorwaller M & Frosch DL (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>20</sup> 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.

<sup>21</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](#).



to their home. Living without a space of retreat 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>22</sup>, and even lovemaking is observed and distorted into pornography or perceived as abuse.

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 tracking device, when a video camera is installed in the home, care home or hospital<sup>23</sup> 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 life<sup>24</sup>. Meanwhile, there is some evidence<sup>25</sup> to indicate that citizens may find the use of body worn cameras provocative rather than reassuring, with the intrusion of surveillance acting as a trigger rather than a deterrent. Introducing these mechanisms into daily life of residential care settings, rather than as rare and brief moments, such as when police attend a road traffic accident, is likely to have a more nuanced but no less powerful effect<sup>26</sup>.

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

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<sup>22</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' 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>

<sup>23</sup> Several inpatient psychiatric units are installing Oxevision, which not only creates a video record of the patient, but also uses sensors to remotely track the patient's pulse and breathing rate 24 hours a day by measuring changes in skin tone and chest movements, even when they are under bedding. The sensor can alert staff if a patient gets out of bed, and so detect those who are at risk of falling or if they display activity or behaviour that may present a risk to their safety. This has been challenged by patients in at least one unit and installation has been paused. Clark H, Edwards A, Davies R, Bolade A, Leaton R, Rathouse R, Easterling M, Adeduro R, Green M, Kapfunde W, Olawoyin O, Vallianatou K, Bayley D, Gibson O, Wood C, Sethi F (2021) Non-contact physical health monitoring in mental health seclusion *Journal of Psychiatric Intensive Care*. 2 September. DOI: <https://doi.org/10.20299/jpi.2021.009>. Also [NHS trust to stop filming mental health patients in their bedrooms | NHS | The Guardian](#). A campaign continues to press hospitals to abandon the use of Oxevision - [Open letter on the use of Oxevision in inpatient settings - NSUN website](#).

<sup>24</sup> Eltis K (2005) op cit. It has been suggested that Oxevision has been installed as a response to inadequate staffing levels and the blanket surveillance of all counts as restrictive practice. See <https://committees.parliament.uk/writtenevidence/40801/pdf/>.

<sup>25</sup> Lum C, Koper CS, Wilson DB, Stoltz M, Goodier M, Eggins E, Higginson A, Mazerolle L. Body-worn cameras' effects on police officers and citizen behavior: A systematic review. *Campbell Systematic Reviews*. 2020 Sep;16(3).

<sup>26</sup> In 2023, Ruth Onafuye in the Department of Law & Criminology, University of Greenwich is researching the views of stakeholders on the use of video surveillance in care homes and intends to derive a good practice guide from her findings.

an unachievable goal will be flawed<sup>27</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.

## 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, Jim, 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 Jim'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 Jim's right to privacy<sup>28</sup>. In this way, Jim 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. Mike 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 Mike 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 Mike'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>29</sup>. As such, he uses Alan Westin's classic definition of privacy – he 'determines what information about himself should be known to others'<sup>30</sup>.

The workers have a tradition of keeping a record of their work, so that they can support Mike in the best possible way. They believe that thorough record keeping also helps to keep Mike, 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

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<sup>27</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>28</sup> For a philosophical analysis of the concept of privacy, see <http://plato.stanford.edu/entries/privacy/>.

<sup>29</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>30</sup> Westin A (2003) Social and political dimensions of privacy *Journal of Social Issues* Vol 59, No 2, pp431-453.



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>31</sup>. There are, of course, important movements<sup>32</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 its hard disk. In contrast, this paper focuses on how information is disclosed within the staff team, from one team member to another.

As we step into the privacy field, we also need to remember the differences between individuals<sup>33</sup>, cultures and regions<sup>34</sup> 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 examination<sup>35</sup>, while a Muslim woman may expect only the relevant part of the body to be undressed, and then covered up again immediately<sup>36</sup>, and, overall, people in the UK may be more sensitive to issues of privacy than their counterparts in Greece<sup>37</sup>. However, these matters may be hard to be certain about. One study<sup>38</sup> 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, as in hospital - or the changing room at the gym one replaces everyday preferences with an ability to tolerate these

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<sup>31</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. PSRB 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>32</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 Administration has become the first US wide health provider organisation to adopt a fully open notes approach.

<sup>33</sup> Harrison, Claire L, *The development of a Desire for Privacy Scale* (1993). Doctoral Dissertations. <http://opencommons.uconn.edu/dissertations/AAI9405263>.

<sup>34</sup> 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>.

<sup>35</sup> 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.

<sup>36</sup> Leino-Kilpi, H. et al (2001) Privacy: a review of the literature *International Journal of Nursing Studies*, Volume 38, Issue 6, 663–671.

<sup>37</sup> 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.

<sup>38</sup> Back, E., Wikblad, K., 1998. Privacy in hospital. *Journal of Advanced Nursing* 27 (5), 940–945.

congregate, public settings<sup>39</sup>. These comments do not render the practice of placing male staff in girl's bedrooms acceptable<sup>40</sup>.

## Safeguarding

**On day 1**, Mike 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 Mike'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 Mike 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 Mike has mental capacity<sup>41</sup>, on what authority might staff take control of the disclosure process and override Mike'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 principle<sup>42</sup>. These are set out in legislation which defines specific circumstances in which staff do bear responsibilities to proactively report information to avert the specific crimes of terrorism<sup>43</sup> and drug trafficking<sup>44</sup> - and the law also protects people who breach the right of confidentiality to so report<sup>45</sup>. Patient confidentiality can also be overridden when there is a threat to public health,

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<sup>39</sup> 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.

<sup>40</sup> Memmott et al (2020) describe the practices in an inpatient Child and Adolescent Mental Health unit where young women are judged to need 1:1 observation overnight for their own safety and the team has too few female staff available. It is unsurprising that the young woman concerned did not feel safe." Memmott A, Corbyn J, Williams G, Newton K (2020) *It's Not Rocket Science": Considering and meeting the sensory needs of autistic children and young people in CAMHS inpatient services*. Bath: NDTi. Page 107.

<sup>41</sup> See the provisions of the Mental Capacity Act 2005.

<sup>42</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.

<sup>43</sup> 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. Subsequent legislation (Prevention of Terrorism Act 2005, Terrorism Act 2006 and Counter Terrorism Act 2008) requires that any belief or suspicion of acts of terrorism are reported. It is a criminal offence if a person fails to disclose any information that may prevent a person carrying out an act of terrorism or bringing a terrorist to justice in the UK.

<sup>44</sup> The Drug Trafficking Act 1994 makes it a criminal offence not to report a suspicion or knowledge of drug money laundering. The Proceeds of Crime Act 2002 and subsequent Money Laundering Regulations requires that any suspicion of money-laundering activity must be reported to the Serious Organised Crime Agency. Failure to do so carries a maximum penalty of five years imprisonment or a fine.

<sup>45</sup> 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

particularly in respect of communicable diseases<sup>46</sup>. Some organisations go beyond the law's authority here and write additional items into their policies, such as those who require staff to report any intent to break the security rules of a forensic or penal setting<sup>47</sup>.

In this situation, Andrew might find a way forward with Mike 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 Mike 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 above<sup>48</sup> and swept away such nuances<sup>49</sup>. 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. Indeed, 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 mix<sup>50</sup>. However, to balance these obligations to report, official guidance on safeguarding has also included 'lack of respect for privacy' as one expression of institutional abuse<sup>51</sup>. Some disclosures should trigger safeguarding actions, but not all.

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 questions<sup>52</sup> to ask before information is

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someone who did so would escape prosecution for breach of confidentiality, but this is different from being required to disclose.

<sup>46</sup> The Health Service (Control of Patient Information) Regulations 2002 allow the processing of Confidential Patient Information (CPI) for specific purposes. This has been used in relation to Covid-19. See <https://www.nhs.uk/covid-19-response/data-and-information-governance/information-governance/copi-notice-frequently-asked-questions/>. Also <https://www.gov.uk/government/publications/coronavirus-covid-19-notification-of-data-controllers-to-share-information>.

<sup>47</sup> 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.

<sup>48</sup> 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.

<sup>49</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>50</sup> 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.

<sup>51</sup> See [Safeguarding adults: Types and indicators of abuse \(SCIE At a glance 69\) last updated: April 2018](#).

<sup>52</sup> See the Escalation Ladder [here](#). In New Zealand, five responses of 'no' should mean that disclosure should be avoided, at least for now.

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<sup>53</sup> 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 inhibited<sup>54</sup>. 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 residents<sup>55</sup>. It is interesting to note in passing that Austrian law deems surveillance technologies to be a form of restraint<sup>56</sup>, so Fisk<sup>57</sup> has recommended that cameras and other devices should be visible to prompt debate and informed consent should be sought prior to their use.

In contrast, if the person who watches is a lover rather than a critic, then being observed can elicit positive emotions<sup>58</sup>. 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.

Power lies near the heart of privacy violations, as evidenced in my own family. Elizabeth Barker (my 5 x great aunt) was denied poor relief in October 1837 because she refused to divulge the earnings

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<sup>53</sup> 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>.

<sup>54</sup> Overt surveillance has this chilling effect, and so does the awareness of the possibility of surveillance – what Michel Foucault in his 1975 work *Discipline and Punish* called the 'panoptic effect' after Jeremy Bentham's 1791 Panopticon, where every prisoner was subject to the possibility of being watched by unseen eyes at all times, and therefore felt obliged to conform to the rules. Foucault explains that the panoptic effect quickly becomes powerful whether or not there is anyone watching, as the conformity is achieved through the belief that there is one-way information harvesting about the person by an anonymous power in the central observation tower.

<sup>55</sup> 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>

<sup>56</sup> 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>.

<sup>57</sup> Fisk, M. (2015) Surveillance technologies in care homes: Seven principles for their use. *Working with Older People*, volume 19 (2): 51-59. DOI: 10.1108/WWOP-11-2014-0037

<sup>58</sup> 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

of her teenage children. In our own generation, too, many people defiantly choose to retain their privacy rather than face the humiliation of disclosure.

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 251<sup>59</sup>. However, these are limited rights, and can be overturned if there is ‘substantial public interest’ in so doing<sup>60</sup>.

The invasion of privacy is complex, as where someone who needs help to use the toilet<sup>61</sup> 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. Meanwhile, those who unwittingly observe a privacy violation are themselves harmed by the embarrassment this evokes.

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. However, for this positive consequence, privacy needs to be set in a rich environment, rather than the solitary confinement of a hostage cell.

## Well informed therapy

**On day 2**, Mike 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 Mike’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 individual<sup>62</sup>. 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 more abstract concepts such as the right to privacy<sup>63</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.

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<sup>59</sup> See points 10 and 11 at <http://www.legislation.gov.uk/ukpga/2006/41/section/251>

<sup>60</sup> 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](http://www.legislation.gov.uk/uksi/2000/417/pdfs/uksi_20000417_en.pdf)

<sup>61</sup> In July 2022, Camden and Islington NHS Trust removed toilet doors on mental health wards in an attempt to eliminate ligature points. Alternative solutions would have upheld patients’ right to privacy.

<sup>62</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>63</sup> 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.

Mike'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>64</sup> and the Data Protection Act 1998<sup>65</sup>. As the events lie in the distant past, this reinforces the 'Right to be Forgotten' principle<sup>66</sup> 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 Mike's right in practice to choose who knows his story?

**On day 3**, Mike 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, Mike 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 Mike 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>67</sup>.

Should CRPD Article 22 on privacy be activated in these circumstances?<sup>68</sup> Upholding the right to privacy should not be reduced to discussions about disclosure of information and the recording of facts, as is illuminated here. Mike 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 in Schopp et al's studies of attitudes to privacy in five European countries<sup>69</sup>, 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 Mike's story illustrates the importance of the personal, internal, psychological sense of privacy. Mike'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

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<sup>64</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>65</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 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>66</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>67</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.

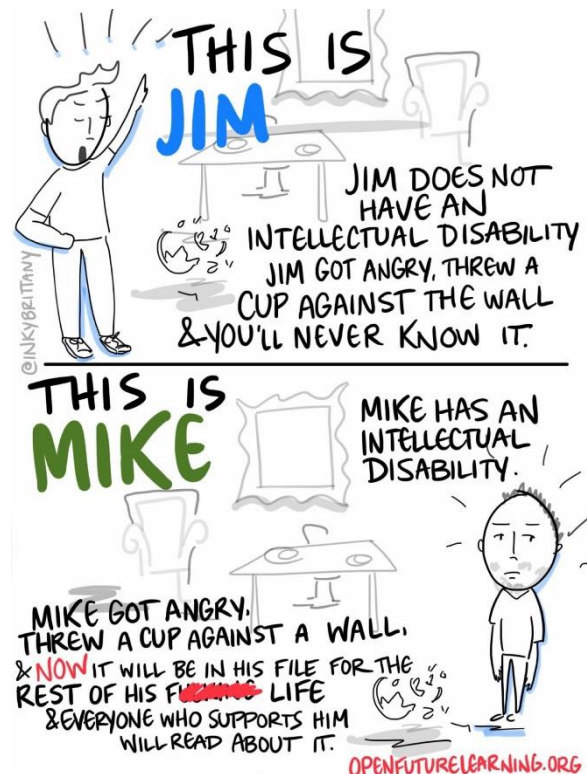
<sup>68</sup> It has also been suggested that Article 19, the right to live in the community as an equal citizen, is relevant.

<sup>69</sup> Schopp A, Leino-Kilpi H, Valimäki M, et al. Perceptions of privacy in the care of elderly people in five European countries. *Nurs Ethics* 2003; 10(1): 39–48.



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 Mike disclosed these pieces of information to Susie and Angela. If Mike 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 disclose<sup>70</sup>. 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<sup>71</sup>, 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 truth<sup>72</sup>. Thus is diagnosis misinformed, formulation mistaken and intervention misdirected.



## 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 private<sup>73</sup>. 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 the person and the carer may have differing priorities and so they allocate a different advocate to each, rather like the way that each parent has their own legal representation in care proceedings. In

<sup>70</sup> 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.

<sup>71</sup> Ben Drew, founder of Openfuture Learning, has given his permission for the image on this page to be used (personal correspondence, April 2021).

<sup>72</sup> 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.

<sup>73</sup> Mental Capacity Act 2005, section 35(6)a.

this situation, the two advocates may 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<sup>74</sup>. 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 are unable to view 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 staff recruitment

Decades ago, it was acceptable for a recruitment interviewer to ask all kinds of questions without restraint. Photos were sometimes required as part of the application<sup>75</sup>, people were asked their age

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<sup>74</sup> In another version of this approach, each advocate asks their client for an instruction on this matter and then discloses or maintains confidentiality as directed by the person they are working for.

<sup>75</sup> On 14/05/2023 [Barker Ross](#) were routinely inviting (but not obliging) job applicants to upload a photo of themselves, so perhaps the bias in favour of beauty is still affecting employment decisions.

and women were asked if they were pregnant. More recently, these questions have been outlawed by the Equalities Act 2010 because of their potential for driving discrimination, and interviews have been confined to topics that can be legitimately related to the competencies required to do the job. Significantly, even where the applicant volunteers such information, the selection panel will not record it, as such matters must not be seen to influence the outcome.

Employers have sometimes ask staff to share or withhold information – contracts of employment may require employees to notify the company of certain events<sup>76</sup>, while noncompete clauses are designed to prevent departing workers giving their new employer information that is commercial in confidence. Both of these restrictions have come under fire recently, weakening the notion that the employer is a hive where all information is corporately controlled.

Similarly, in health and social care, assessment, monitoring and recording should be confined to those factors which are related to the matter in hand and anything else is beyond the scope of a reasonable inquiry. Knowing more than is needed can awaken stereotypical thinking and fuel inequalities while wholesome respect for the person's privacy will close down these lines of inquiry. This is sometimes forgotten by staff working in long term settings, such as residential or day services; by staff working in mental health or learning disability services, where a whole-life perspective is seen as crucial to understand the person; and by staff who intervene under the safeguarding banner. On this latter point, but applicable to all, privacy must never be used as a cloak to obscure abuse or tolerate shoddy assessment, but instead, bounded rigour must uphold both the requirements for relevant information and the person's right to conduct the rest of their life beyond the gaze of the professional.

## Learning from information governance

The UK Information Commissioner has recommended that organisations carry out a Privacy Impact Assessment<sup>77</sup>, 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

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<sup>76</sup> In April 2023, the US Securities and Exchange Commission fined Activision Blizzard \$35 million for having employees promise to contact HR if federal or state investigators contact them regarding allegations of wrongdoing by the company. The SEC concluded this violated the federal Whistleblower Protection Act. This shows that employees owe a duty to wider justice, not just to their employer and therefore information is not solely owned by the company.

<sup>77</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 was adopted by the European Union through the General Data Protection Regulation 2016/679 (GDPR) 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. It may be possible to seek advice from members of the [IAPP](#).

surrounding compliance with regulations covering information governance rather than addressing broader aspects of privacy<sup>78</sup>, 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 participatory research

Researchers who adopt participatory approaches undertake their investigations in ways that are designed to empower rather than subjugate informants and these very respondents may move from the role of data providers to data collectors as they partner with academics in a joint effort to generate knowledge. Such approaches narrow the gap between researcher and researched, creating the potential for social contact and disclosures beyond the bounds of the qualitative data collection interview. Lenette and colleagues<sup>79</sup> suggested several ways to manage this situation, of which one is to set “firm boundaries that exclude certain forms or sites of encounter (for example, communication outside of formal sessions)”, although they note that it might create uncertainty about what to do with “uncomfortable but important information” gleaned outside of the formal session.

We must be clear than Lenette and her colleagues are not suggesting that the researchers are forbidden from engaging in these encounters, since the whole foundation of participatory research is that such interactions will be inevitable, but simply that information gleaned in such an informal setting would be excluded from the record. To designate formal sessions as on record and informal sessions as off the record is certainly one way to handle the issue, although it is far from free of ethical and practical difficulties. It does have a simple attraction, however, which is to create an opportunity of removing items from the record. When professional relationships become informal, it is easy for a sense of intimacy to arise in which the person takes the opportunity to share something personal which they then regret saying. In the hive mind, there is no means of withdrawing such a disclosure, especially when everything is viewed from the standpoint of some safeguarding practices. Permitting some things to be removed from the record and placed beyond the scrutiny of colleagues who were absent from the moment of disclosure restores control to the person and honours their right to privacy.

An alternative way to divide disclosures into ‘on the record’ and ‘off the record’ categories is acknowledged by what is generally known as the Chatham House rule<sup>80</sup>, that allows anonymised information to be shared as long as it is not attributed to a particular source. Making such an agreement in advance supports those who withhold information from their peers.

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<sup>78</sup> See, for example, the guidance on completing a PIA [here](#), that is entirely about information governance. See also [here](#).

<sup>79</sup> Lenette, C., Stavropoulou, N., Nunn, C., Kong, S.T., Cook, T., Coddington, K. and Banks, S. (2019) ‘Brushed under the carpet: Examining the complexities of participatory research’. *Research for All*, 3 (2): 161–79. DOI <https://doi.org/10.18546/RFA.03.2.04>

<sup>80</sup> [Chatham House Rule | Chatham House – International Affairs Think Tank](#).

## 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.

## 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 Mike that anything he tells a worker will be shared with the whole team, then the law might be satisfied, as Mike 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 society<sup>81</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 may achieve legal compliance but could ultimately be harmful to the person’s interpersonal skillset and sense of identity.

## Acknowledgements

I’m grateful to the people listed below who have generously responded to my email inquiries. The remaining errors and omissions in this paper are, of course, no-one’s responsibility but mine. My

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<sup>81</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>.

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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.