

The Ethics of Sharing

Practitioner concerns about recording in shared health records, and how they should be resolved

Executive summary

Health information is sensitive, and some information – such as details of abuse or trauma, alcohol or drug dependence, sexual or mental health problems – is particularly sensitive. Health practitioners are required to keep records and these records mean that information about clients is available to others. When it comes to particularly sensitive information, health practitioners make judgements about what to record and how. These judgements have implications for what exactly is recorded in the client record, and consequently, what information is shared with other health providers. In this project, questions about what should be recorded and why were explored in interviews with 11 health social workers. The aim was to gain a better understanding of the ethical principles that underpin decisions about what to record.

This report summarises the main findings from the interviews and draws out their implications for practice in a series of recommendations. In line with the theoretical framework of pragmatism, which acknowledges the status and value of practical knowledge as a source of ethical guidance, the interview findings were treated as evidence to inform recommendations. Philosophical literature on privacy and wider literature on recording were used as touchstones to understand and test the ethical implications of the findings. The recommendations therefore reflect an iterative process of reasoning between the findings and a broader body of knowledge and evidence.

A set of professional virtues that should govern recording were identified through this process: care, respect, justice and trustworthiness. These virtues are reflected in the following recommendations, which are followed by a more detailed explanation of the results.

Recommendations

Recommendations for practitioners

One

Relevance to health should be the dominant criteria for what is recorded. This preserves the client's expectations about their information in the context, and thus preserves their privacy. This entails that particularly sensitive or significant details can be left out of the record if they are not strictly relevant. Practitioners are trusted to record and share information for the purposes of client care, and to do so efficiently, yet empathy entails that clients should not be unduly exposed in the record. Recording what is relevant shows an acknowledgement for the value and significance of the client's personal details.

Implications for practice:

- Information can be excluded if it is not relevant, meaning that particularly sensitive details can be left out of the record.
- Information can be recorded in a way that generalises particular details. For example, recording 'disclosed history of abuse' summarises what is salient, but protects some of what is important to the client.

Two

Information should be recorded with attention to its accuracy. The record is used by other practitioners as a means of making judgements in their practice, and the status of information is important in those decisions. Practitioners are expected to maintain records in a way that can be trusted, both by their colleagues and by clients. This ensures quality health care for clients, who should be protected from the impacts of inaccurate information.

Implications for practice:

- The 'epistemic status' of information should be preserved in the record, for instance, whether information is fact or opinion.
- Unsubstantiated allegations or reports, for example information from third parties that is not known to the client, should be reflected as such.

Three

The record should be neutral and non-judgemental. The record forms a basis for future relationships between the client and care providers, and care should be taken to preserve the client's standing. Professionals are expected to maintain neutrality and nonjudgement towards clients. This acknowledges and preserves the client as a valuable individual and promotes the fair and appropriate allocation of healthcare.

Implications for practice:

 Language used should be neutral, and attention paid to the pejorative or judgemental aspects of certain words.

Four

When the record is used by other practitioners, it should be interpreted generously. Practitioners may be reluctant to record if they are concerned about how their colleagues might interpret the information, and they need to know that it will be read in a professional and trustworthy way. The record functions because of a system of trustworthy professionals, which includes those that read the records as well as the ones who write them.

Implications for practice:

- The record contains information that was relevant to care at the time. Thus, there is no guarantee that it will contain everything currently relevant to care, or that what is contained will still be relevant.
- What is contained in the record may have been disclosed in a context that is different to the current one; thus, practitioners should be sensitive about bringing up personal details that could offend clients, even if the information is recorded.
- Non-neutral or judgemental language should be interpreted with caution, and an effort made to meet the client without prior judgement.
- Attention should be paid to the 'epistemic status' of information in the record, for instance, whether it is an unsubstantiated report or an opinion.
- Some important information may be poorly communicated in written form.

Five

The information that is recorded and shared should be predictable to clients, or its recording should be discussed with them explicitly. Clients have expectations about what information is collected about them in the context of healthcare, and respecting these expectations is an important element of virtuous professional practice.

Implications for practice:

- Practitioners should ensure at the start of the clinical relationship that clients understand what will be recorded, who their records will be shared with, and why.
- In instances where this is not clear, practitioners should make an effort to reiterate these expectations, to draw client's attention to their information, and to clarify their control with regard to their information. This might include therapeutic contexts and home visits.

Recommendations for record keeping systems

Recording systems should be designed in conjunction with practitioners. Recording client information requires professional ethical judgements, and practitioners' ability to record appropriately may be inadvertently obstructed by administrative factors.

Implications for practice:

- Practitioners should be expected to be consulted on the development of, or changes to, recording systems. Small differences could alter, for instance, practitioners' ability to keep some details separate.
- The record should not be the only way in which practitioners are able to communicate with their colleagues; face-to-face meetings and phone calls can be important for building trust.
- Fixed recording formats could backfire if they compromise practitioners' ability to record ethically.

Two

Explicit client consent should not be relied on as the only ethical safeguard in the system. Time to discuss records in detail was limited and not the priority for the clinical encounter, and practitioners are trusted by clients with their information.

Implications:

- The benefits of insisting that practitioners explicitly address records with clients should be weighed against the costs of diverting attention from the help the client is there for.
- Clients cannot necessarily be expected to be making fully formed and autonomous choices regarding their records, as they don't necessarily have access to full information, and obtaining and evaluating that information is not their priority.

Three

More research is needed on the separation of records for clinical settings that provide care that is more sensitive or stigmatising. Participants in this project raised concerns that separation of mental health records could be problematic for client care, yet it wasn't clear how this should best be addressed.

- Practitioners will include details that are relevant to the care of the client, and in more sensitive settings these details will be more sensitive.
- Their ability to leave details out of the record when they are not relevant is important for protecting the privacy of the client.
- Yet, participants were frustrated when information was not shared in a way that benefits the client. Such information could include that which could be 'sensitive', yet was relevant to the client's care.

Introduction/background

Health information is sensitive, and some information – such as details of abuse or trauma, alcohol or drug dependence, sexual or mental health problems – is particularly sensitive. Health practitioners are required to keep records and these records mean that information about clients is available to others. Access to health records is restricted because of the personal significance of the information held in them - but they are legitimately accessed, and utilised, by multiple health providers, the courts, and clients themselves. When it comes to particularly sensitive information, health practitioners make judgements about what to record and how. They may plausibly have ethical concerns about their recording.

Health social workers frequently come across information about patients that could be sensitive (financial issues, details of trauma or violence, or evidence of abuse of alcohol or drugs, for example), but share record keeping and information systems with the other health professionals they work with. Because of their role in the health care team, they could experience conflict when it comes to knowing what information to record and share, protecting the privacy of their clients while ensuring they receive the best possible healthcare. How they negotiate these conflicts provides important practical information about what ethical features of the situation health practitioners consider particularly salient.

Eleven health social workers were interviewed. They were based in various health settings in organisations across New Zealand's North Island. Four had roles associated with mental health care, two had a focus on older persons health, two on oncology, two had general roles, and one worked in primary care. One participant was male and the rest female; there was a range of ages from roughly late twenties to late fifties, and a variety of length of time engaged as a social worker. The interviews were semistructured, guided by a set of topics but allowing participants to discuss what they considered most relevant.

This report summarises the main findings from these interviews and draws out their implications for practice. These findings are illustrated with quotes from participants, which are italicised. The theoretical framework for the research is pragmatism. Pragmatism acknowledges the status and value of practical knowledge as a source of ethical guidance. Participants' views and experiences were treated as sources of evidence to inform recommendations. Philosophical literature on privacy and wider literature on recording were used as touchstones to understand and test the ethical implications of the findings. The recommendations therefore reflect an iterative process of reasoning between the findings and a broader body of knowledge and evidence.

A set of professional virtues were identified through this process, and are reflected on here to guide the development of the recommendations for practitioners and for system design. These virtues are care, empathy and engagement with the client; respect, an effort to protect what it is independently valuable; justice, a need to ensure fair allocation; and trustworthiness, professional dependability and responsibility.

The ethics of the record

Most participants worked in hospital settings or in multidisciplinary teams. Their notes could be electronic or hard copy, but most often both. Their records were visible to at least their immediate colleagues but could also be accessed by others in the organisation if they were requested. However, these requests might happen infrequently, if at all. Participants did not display concern about their notes being open to other health professionals. Several participants described using email frequently, aware that this was an official part of the health record. The inclusion of emails within the health record was considered to be a good thing – emails contained useful information about what had taken place, including documented timely assessments, and they established accountability.

Participants showed they are aware that judgements regarding a client's care will be influenced by the records they keep. Sometimes records are used in a way that does not impact on the individual client specifically, for example, anonymised records used for research. But in so far as the record relates to the client, it used to transmit information about the client in order for that information to be used in some way that affects them. It will be used to make judgements regarding their healthcare, from the services they are considered eligible for, to a future practitioner's assumptions of them.

Time and resources in health care are limited, and making such judgements is both necessary and not inherently unethical – as long as these judgements are made appropriately. This research indicates that social workers are aware well of their responsibilities in this regard. They walk a fine line. They don't want to wish the client to receive inadequate or incomplete services or treatment in the future based on a judgement made from the record – for example, if the record prejudices a practitioner against the client in some way, or if the record downplays a significant risk. But they also don't want the client to receive inadequate services from not enough information being available, or risk a waste of time or resources on an issue that is not worth it.

This tension is compounded by the difficulties of communicating meaning through information that is written in one context and read in another context. For social workers, information may be released in a therapeutic setting, and it may not feel appropriate to make that information available to other contexts, even if those are health care ones. A social worker might not be sure what conclusions different clinicians might draw about particular kinds of information, such as that relating to mental health. Social workers might access information from a number of sources, and have to interpret its meaning for their practice, but also how other practitioners will interpret it.

Participants described following particular principles regarding what they recorded. The first was that details should be included if they are relevant to health, and excluded if they are not relevant. This reflects the practical purpose of the record – "no one wants to read an essay" (Interviewee 6). Judging what is relevant to be included is a clinical judgement about what the important factors of a client's situation are that other people need to know, and that the social worker could be called to account for in the future. This clinical judgement, like other clinical judgements, comes with experience and is developed and supported by supervision. It is also a judgement that is made in a particular context – judging what is relevant is related to the practice setting. It reflects the practitioner's judgement of whether a certain factor could impact on the outcome the team is working towards.

Social workers are often confronted with the necessity of recording information that is of dubious quality - that may or may not be true. "And we try and investigate, but often you're like following a maze, and you don't know where the truth is" (Interviewee 3). Including a reference for the epistemic quality of this information was important in order to make sure its meaning wasn't misinterpreted. This was significant, both because the social worker was accountable for the relevance of any information included, but also because including this information would have consequences for clients - it could send other clinicians down the wrong track, or risk that another agency "will jump on information and, you know, they'll put two and two together and make 75" (Interviewee 5). Another kind of information that would need to be included because it was helpful was social worker's impressions or opinions of a client's situation. When these were included, social workers would always distinguish them from the 'facts' of the case by marking them as 'opinion' - 'my impression was' or 'my opinion is'.

Care

Participants took their obligation to record and share information with other practitioners seriously. They expressed that it was important for them to share information with others, and they wanted information too to help with their practice. Clients didn't necessarily want to have to tell the same story over and over again, and information was particularly valuable when the client was sick and tired, and couldn't relate everything that was needed. Interviewee 9 described access to a client's history of hospital admissions as "putting more flesh around the person".

Social workers saw it as part of their role to contribute social or personal details that could help with a broader understanding of the situation. Interviewee 11 gave an example of how social workers illuminate the person and their situation for other clinicians. She described working with a client who spoke strangely because she had had a stroke:

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I'd put it in her notes, especially if they were electronic ones. And I have interpreted her personality to others that I'm working with around her. If they've met her, they've seen it anyway. But when I first encountered this person, I thought she was drunk over the phone, and if you were someone trying to arrange an appointment with her or whatever, you'd think, 'Oh heck, this is hopeless.' But then I sort of made a point of getting to know her, it was really hard work to understand her, but that's our job. That's what we needed to do.

The virtue of caring in the context of social work involves a degree of relational engagement, empathy and identification with the needs of the cared for person (Banks & Gallagher, 2009). It indicates that recording should take place with empathy and kindness towards the client, an attention to the caring relationship, and an engagement with their needs.

Because information could be excluded if it wasn't relevant, particularly sensitive information could be left out of the record when it wasn't directly related to the client's health. This provision could allow practitioners to refer in more general terms to topics that did not need to be recorded in detail, and where the details could be personal, revealing or exposing.

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I'm always very aware of whatever I write could be read by someone else. And you want to be respectful to the people that you work with, your client base. They don't want all the dirty linen aired, so ...

Making judgements about what was relevant to include was not always easy. Participants were aware of the significance of recording information in the health record - "I'm quite aware that that health record lasts forever" (Interviewee 1). Participants would have to be accountable for this information, and its relevance for inclusion, but they were also aware of the need to protect the client from possible future judgement.

So, often what I find happens, because I do mostly home visits, going into people's homes [...] It often can be a bit conflicting as to what exactly I then put down in our notes, as being, you know, relevant to health and my role, but then the other pieces of the story that I've been given which is still valid and relevant, but how much is that connected to health, and how much do people need to know. Because, for example, somebody, say, who is in a relationship with a spouse or a partner which is not emotionally very stable or supportive, that of course has an impact on health, but is that relevant enough or is that respectful to put that in the notes where all other types of healthcare professionals are accessing. [...] And, I guess the other concern could be that [a professional who has read the record could] bring it up with the patient, or... it changes their judgement of that patient. Which, in theory of course, should not impact anybody's professional care, but we're human as well. I quess it's about not wanting to, I don't know, impact on the overall picture too much.

Health social work was part of a wider practice setting in which information was often not straightforward. Clients who receive social work services tend to be in difficult situations, for a number of reasons. Information and recording is part of a context that can at times be fraught, and involves unknown and unknowable factors. For instance, in some settings, whether a client's statement was accurate or true could be doubted. Information might take on an extra significance in a mental health setting, if it was seen as shameful. For some participants, there was a lingering feeling that dissemination of the record could not be entirely controlled. The possibility that the notes could get into the 'wrong' hands - such as family members of the client - increased their unease with recording details that were sensitive but relevant and important for other clinicians to know.

One social worker, who worked with families and young people, found it worrisome that the organisation had stipulated she could only keep one file, under the name of the child. While she was aware of the provision for removing information about third parties, she was aware that if this was done to her notes it would look obvious and 'really dodgy'.

Right at the beginning of our work, we say, 'These things will be kept confidential, except for these particular people, which is our team, and if we had any need to share it with anybody else, we would always talk to you first.' And that does not include telling the child Mum and Dad's stuff. You wouldn't do it then, but you also wouldn't want it to be done later.

Thus, one of the client's needs is to feel protected and cared for; the practitioner can support this by leaving out details that aren't relevant. Showing care entails attention to how information will be interpreted and used in the future, and means that practitioners should pay attention to the accuracy of their records. It also means that practitioners should attend to protecting the rapport of clients with their future carers. Engagement with the client and responsiveness to their needs is a requirement of this virtue, and this includes a client's wishes regarding their information; attention should be paid to the client's expectations of what will be recorded and shared.

Respect and justice

This concern for recording what is relevant also reflects an effort to respect clients and the information they disclose.

But we're sitting in his kitchen, we're both having a cup of tea, and he's chatting away, and...

Interviewer

He feels comfortable enough to sort of ...

Tell me everything. And we hear, we often think, it's almost like we're somebody's auntie coming in. That's what it feels like. Because we actually come to their house, and we behave politely, and make sure that they have the control of the sessions. We direct it, but they get to say what they want. So, for this man, all this information came out. It's not anywhere, available, at the moment. When I was writing it up, I actually just wrote, instead of writing all the detail, I wrote 'Dad told me about his extensive history of trauma.' Because I didn't want to put all that stuff in there to expose him, to anybody else's view.

Respect is a concept central to social work. It indicates an appreciation for the humanity and perspective of another, an acknowledgement that they are independently valuable, and actions to preserve and enhance their dignity and autonomy (Banks & Gallagher, 2009). Preserving these valuable things can be difficult, as humans have the ability to subtly "enhance and diminish the dignity of others" (Banks & Gallagher, 2009, p. 124). The virtue of respect entails that practitioners should focus on recording what is relevant to the client's care, and excluding what is not relevant, which shows an acknowledgement for the value and significance of their personal details. These details may be ones over which they wish to exercise autonomy, even with regards to their health carers. Within the requirements of recording what is necessary to benefit the client's care, this autonomy should be respected.

An important aspect for social workers was concern for language. In the health sphere, certain words can take on a specific clinical meaning, which could need to be justified. But also, social workers made an effort to use language that was as neutral as possible both for clients accessing their notes and for the clinicians reading them. There were reports of coming across notes written by other professionals that were pejorative. Sometimes these negative judgements could be 'implied', but at other times they were

overt. This concerned participants, who saw it as poor recording, with negative consequences for clients.

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Like I once had a file and at the very front of the file, there was a page written by a care manager who said, 'This person is really manipulative, and be very careful when working with this person.' And I grew to really be quite fond of that client, and I think I might have even taken that note off the front of the file, because I just thought that really colours somebody's perception of the client, and it was pejorative, the way that it was written, so I just thought it was irrelevant.

The virtue of justice involves a commitment to the fair allocation of goods among people (Banks & Gallagher, 2009). Here, the virtue of justice includes a commitment to preserving this fair allocation in the future by not giving other professionals a reason to discriminate against the client based on irrelevant factors. Attention to the impact of particular details is indicated further by Interviewee 3, describing how sensitive details are kept separate if they are not yet substantiated.

3

Well, probably... it's not a grey area, but once every six weeks on Saturday we work in the emergency department, so if there's like a child protection issue, we notify... if we have a concern about a child being harmed, we notify [social service agency], but we don't keep it on the file, we keep it separate.

Interviewer

Right, OK.

3

Because it's not, it might not be proof.

Interviewer

[o-l] It's not corroborated.

3

But it covers us, we want to say that we did something, but we don't necessarily want it to be on the file and put a black mark against them, when it might just be an allegation.

Being respectful to the client entails that the record is accurate and non-judgemental. The opinion of a practitioner with regard to the client's situation shouldn't be misinterpreted as fact. This acknowledges and preserves the client as a valuable individual, apart from the practitioner's opinion of them. That clients could access their notes was considered to be a positive thing for recording.

I think it positively influences the way I write, because it forces me to think about, OK, how would I feel if this were me, and somebody were writing down this information about my conversation.

Trustworthiness

Participants reported that clients were rarely concerned about their records or what was in them, hardly ever making requests for things not to be recorded or making requests to see their records. They also, for the most part, did not think that clients held back information out of concern that it would be recorded. Exceptions were instances were clients were concerned about the consequences that sharing the information with a social worker would have on their interests – for example, being put into a rest home. But otherwise, clients were happy to disclose.

I feel if someone's meeting you for the first time, they just want to tell you what's been happening, so they're not, they're not really caught up in that detail of 'Do I want everyone to know or do I not.'

Establishing expectations about record keeping and who could see those records was something that social workers discussed at the start of their relationship with the client. These expectations were reinforced for many participants over their relationship with the client, as they took notes in front of them, read other colleagues' notes, and sometimes discussed notes with them. Yet, some settings such as home visits could make this trickier, as the change in context could mean more details could come out than in the clinic.

Interviewer

[...] you don't get the feeling like they'll telling you specifically and asking you not to spread it round, but just the environment in which it comes out means you feel like they probably haven't told everyone.

6

Correct. Most definitely, the environment and the time that we can give, and the type of questions that we ask. Yes, that's right.

The virtue of trustworthiness is central to that of the professional role (Banks & Gallagher, 2009). Health professionals are trusted by clients to perform their roles competently and well, and this trust has an extra ethical significance because clients are often in a position of vulnerability when they seek care (Banks & Gallagher, 2009). To be worthy of trust includes normative expectations – predictions that the trusted person will, and should, behave as relied upon, and that they accept responsibility for behaving in this reliable way; the person trusting imbues the trusted with a sense of general integrity, and the trusted person acknowledges the vulnerability of the trustee (Banks & Gallagher, 2009).

The expectations of clients regarding their records indicate that they do put such trust in social workers when it comes to recording, and that social workers anticipate this trust. The virtue of trustworthiness entails that practitioners must act in a way that it is predictable to clients. With regard to their information, clients expect that they will record and share what is relevant to their health, and not other details. Health practitioners are also trusted to be competent. Clients expect that recorded information will used to benefit their healthcare – thus, information should be recorded accurately and appropriately. Practitioners are trusted to be professionals in a way that displays

their integrity, and this means acting neutrally and in a way that is not biased. Recording should follow suit.

The findings elsewhere in this report indicate the significance that putting clients 'on the record' has for practitioners. Yet, they also had a need to trust the readers of the record - their fellow professionals - that they would treat sensitive information about clients appropriately and that they wouldn't make erroneous judgements.

It's that he has shared this information with me in a situation where he felt it was OK to do so, and he wouldn't necessarily feel that way if he was attending a different type of an appointment, and I would just hate for somebody who, maybe with best intentions, said something that didn't maintain his respect. [...] I think, ultimately, in regard to patient safety, then transparency is the best option. It's just, we are all human [laughter], and again, it's about trusting my colleagues to work in an ethical way, also.

Being a trustworthy professional means understanding the context that colleagues record in is similar in complexity to one's own practice environment. This entails an expectation that practitioners must act in a trustworthy way in relation to the record behaving sensitively with regard to personal details, interpreting the information generously and in a way that does not prejudice the client, and understanding that the situation may have changed or not be entirely reflected in the record.

Conclusion

This study focused upon the views and experiences of social workers employed in a health setting, but its findings are relevant beyond the social work profession. The judgements that social workers are called upon to make about what to record in client records are not the exclusive preserve of social work: all professionals engaged in the delivery of health services make similar judgements. The virtues of care, respect, justice and trustworthiness are applicable to all health care professions, and govern decisions about what to record in health records generally.

This study's contribution is to make explicit the virtues that apply to recording practices in health. Its conclusions, reached through a process of eliciting and critically analysing the judgements of participants, provide a foundation for ensuring the recording practices remain faithful to societal expectations at a time of great technological change. It is easy for practice to diverge, almost unconsciously, from client expectations that have formed through a process of societal-professional negotiation about the terms of engagement. A shared conception of the ethical standards governing a practice can guard against traumatic and destructive divergence, enabling technological change to improve practice without threatening trust in it.

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