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The Information

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Knowledge and knowing are very different forms of power. The former can involve a simple reading of certain facts: Lima is the capital of Peru. Knowing needs embodiment or personal experience. In this sense we might know that whatever mental health services are claimed to be for, they perform a myriad of functions. As for helping people in distress: some aspects of mental health services do, others patently do not. This paper examines one aspect of mental health services, information gathering, and considers what the process, effects and purpose of data collection might be.

The information

Some form of data collection has been going on in health services for centuries. Examining the records of nineteenth century asylums will reveal details on the sex, date of birth, income, occupation and diagnosis (including "child-birth out of wedlock") of countless patients. Then, as now, little of this information is verified (after all, we don't ask for a birth certificate when recording someone's date of birth) and the type of information required is subject to fashion, professional codes of conduct and legislation. Additional material is recorded at the discretion of the recording clinician. This can range from notes on "appearance at interview" to speculation about the person's psyche. Some of the most basic facts collected at assessment can highlight the difference between knowledge and knowing. With any luck

clinicians in their sixties will record a date of birth pre 1953 with a different mind set to a younger person. That clinician will have experienced rationing, something of the second world war, the years when young men were automatically recruited to the army and so on. A Jewish clinician is likely to take more note of a new patient with the surname Levy or Cohen. A parent is, hopefully, going to remark on a client's childcare arrangements through empathy in a way available to only the most sensitive non-parenting clinicians. All this information is available from the barest assessment data but may never be accessed due to the routine nature of recording so called client details. The second author has written elsewhere about the reasons why health professionals might keep detailed notes on patients (Newnes, 1995). Recording activity however is a relatively recent phenomenon, a process introduced by Körner in the 1980s and computerised and systematised ad nauseam up to the present day.

CNAT

Community Nursing and Therapy or `CNAT' for short is the name of the information system used until recently by Shropshire's Community & Mental Health NHS Trust to monitor the activity of community nurses, occupational therapists, psychologists and other professionals. It is one of several different information collection systems in the Trust, many incompatible with each other and with neighbouring Trusts' information systems. The previous Trust had used a system called FIP and had piloted FACE, a similar protocol now promoted by the BPS sponsored Centre for Outcome Research and Effectiveness. CNAT was by no means unusual; most of the management systems established in Trusts throughout Britain included similar electronic data collection systems from which Körner statistics could be extracted.

It is a symptom of a computer age that these systems have been developed and that there are rooms of obsolete computer equipment stored by the Department of Health, as there are also

rooms of busy information clerks and clinical staff inputting information into computers day after day after day …… Before this individuals filled in A4 sheets by hand and this was seen to suffice. This was an efficient information storage and collection system that also protected the confidentiality of people. Nowadays confidentiality comes a poor second to monitoring and centralisation of information.

The rationale given by Trust management for this kind of information system was that it was a contractual requirement of the purchasers. Another position taken was that some purchasers asked for specific information and it was the most effective way this could be provided. Yet another local argument has been that no other professionals apart from psychologists have objected to the system.

Eleven psychologists were asked about their experience of filling in CNAT forms (these bore a remarkable resemblance to lottery tickets, but did not carry the promise of millions). They were also asked about their ethical standpoint.

Experience of filling in CNAT forms

The CNAT forms had room for five contacts per day to be recorded. Once a patient was registered the forms were completed using a registration code and the first three letters of the patient's surname. Completing the forms was a weekly task for four psychologists, daily for another, fortnightly for another and monthly for three. At the time of the interviews two people were not completing CNAT forms. Comments on the process were generally negative:

"It's a complete doddle compared to other systems…………… and a complete waste of time."

"It's soothing and mildly pleasant, a bit like knitting."

"It's boring and frustrating. No sense of truthfulness."

Such comments point to a kind of numbing meaninglessness. As Holmes and Newnes (1999) remark "the only thing worse for someone's mental health than no job is a meaningless job or an oppressive job" (p278). How ironic that meaningless activity is one hallmark of a modern mental health system.

Ethical arguments against CNAT

The following comments illustrate the overall tone of responses:

"Totally reprehensible to make any recording of somebody that exposes them to stigma or becomes an obstacle to, for example, insurance cover. It's a sad state of affairs that we can't keep our own records and be trusted. There is no need for centralisation of data collection … but then we do loads of things that are against our morals."

"It's a way of keeping tabs on people, doesn't feel safe, the lists are for god know who … it's a part of the system I don't find very comforting."

"My client is a child. It is not in the best interests of that child to be registered as a psychiatric patient for the next 20 years – for a two-year-old who doesn't sleep! It is one of the reasons I left my last job."

"Registration is, I believe, morally wrong, but it would appear to the powers that be to be necessary."

Many of the comments jar with the DCP's professional guidelines on the subject. The most recent of these suggest that it is good professional conduct to record not only client details

such as date of birth, address and so on but that we should have readily accessible care plans, session notes, reports and letters to referrers about people. In general we are expected to follow our employers' instruction in the matter of registering and record keeping. Given the strength of feeling within the Department a compromise was reached wherein a leaflet (previously seldom used) concerning the information held about clients was redrafted and issued to all Trust clinicians to give to clients before registering them on the CNAT system. Redrafting the leaflet was an object lesson in understanding the difficulties of informed consent in the area of information and data protection.

Who knows what?

The limits of confidentiality are notoriously difficult to define. The leaflet makes it clear that professionals have a legal duty to make sure that patient information is protected. In detailing who actually sees this information it is clear that a much wider range of people are involved than a patient might expect. These include the person themselves, health authorities, general practitioners and health service administrative staff, social services and "other agencies" and a catch-all "people involved in your care and treatment". Potentially, dozens of people can access a variety of information from simple numbers of face-to-face contacts through to detailed medical records. Curiously, the one group of professionals absolutely bound to confidentiality (solicitors) must have the written consent of the patient to access any information. The first author's experience as a service user has been that every effort was made by colleagues to keep professional contact strictly off the record.

To some the need to have this kind of information readily available to an indeterminate number of people is not a problem. It is even seen as one solution to the potential violence identified by the media as typical of people using mental health service; data of this kind,

easily recoverable and readily communicated, is supposed to prevent scandalous breakdowns in people's care. For others it is simply an accounting exercise, a harmless activity whereby the occasional lapse in confidentiality is to be ignored for the sake of a computerised contracting system.

For some patients however, distrustful of anyone in power, fearful of the assessment and recording process and acutely aware of the stigma that contact with psychiatry brings, even fairly simple procedures like registration of name and address are fraught with complexity. A clinician who cannot really say where any of this so-called information might end up is in danger of losing clients before they engage with the helping service at all.

What is it for?

The detail required in CNAT and similar systems is hard to square with the idea of contracting. Numbers of people seen would surely do; names and so on are neither here nor there to an accountant. Names, addresses and GP names might act as a double check in a system overburdened with Jones' and Smiths. A mere postcode and date of birth might suffice here however.

The information leaflet claims that date of birth, names, address, etc are needed to ensure that people receive "proper care and treatment". This is curious; if you didn't know someone's name or address would we treat them improperly? It might be true that accessing referral letters, session notes or reports from a file can be of use in treatment. It is much more difficult to understand why telling purchasers exactly how many times a particular person has been seen aids this process. It might be argued that such statistics can help identify need. If this is a necessary part of the planning process, then we would argue more strongly that data

sent to purchasers should always be anonymized. The condition of anonymity is incorporated into the DCP Guidelines but is not a constraint placed on other professionals in a mental health team.

Arguing the toss

We have not attempted in this paper to fully explore the pros and cons of information gathering. More to the point our experience has been that our employers have not fully considered the ethical issues involved. We agree that information is useful, after all knowledge is power. We have little difficulty in agreeing that passing some information about people to other people genuinely concerned about them, as individuals, can be helpful.

We are, however about to move on. The NHS Plan requires that all clinicians have a computer on their desks to enable easier information storage and retrieval, easier dissemination to, and from, centralised medical records, and easier transmission of information to other clinicians. There are obvious problems here: as noted above, information is not knowledge. Centralised record keeping poses considerable challenges in terms of confidentiality. The second author is currently chairing a Trust committee exploring these challenges: unhappily the issue was only deemed important enough for serious consideration after the introduction of a single mental health record for all service users. What to tell people whose records have been centralised and accessible to a very wide range of other people has suddenly become a burning issue, one that the BPS is exploring on behalf of the NHS Litigation Group, as there are major human rights concerns. Further, the type of information passed on through computerized systems is determined by those systems and may not be relevant to someone's care. The new system is also curiously dependent on the notion that storing a great deal of context specific data on individuals will be of help to those individuals. Some of this information may, of course, be

of some use, but is the time, effort and money involved in this kind of data collection worth the outcome? We suspect that something else is going on.

The reasons for developing particular kinds of information gathering systems occur within particular contexts. We live in an age obsessed with technology and technological solutions to human problems. Computers are the icons of our age. The idea of rapid communication is embedded in modern consciousness. Often computerised communication is invaluable, especially in health-care. This leads to an assumption that computerised systems are always the best and always necessary. We also live in an era of increased monitoring of our every activity. The information down-loaded to central records gives some indication of what clinicians are doing, although it cannot begin to approximate to a picture of what actually goes on between mental health professionals and their clients. It can however give the impression that certain things have occurred, for example, risk assessments, thus offering documentary protection for the organization should something go wrong. These are difficult issues to balance: the need for clinicians to develop trusting relationships with clients versus the need to monitor patient and clinical activity; the need to protect the organization versus the need to feel you are doing something of immediate value to clients. The documentation our Trust has developed to record the care co-ordination process makes CNAT look simple: 13 forms, some of which are repeated, the majority including the person's name, address, date of birth, "unit" number (for NHS purposes) and CRISSP number (for Social Services purposes). One CMHT nurse has estimated that she spends 80% of her time filling in forms. It is all too reminiscent of the work done in Canada in the 1980s showing that the number of bed sores found in elderly frail patients in hospital directly correlated with the amount of bureaucracy expected from nurses left with little time to perform nursing duties,

Psychologists, through their experience of psychometric testing are in a good position to understand the inadequacy and hidden ideologies of much data collection. We might question the types of information gathered, the reasons for data collection, and the ethical concerns involved. We might, as therapists, also question what message having a computer on your desk gives to clients in mental health services.

Data collection may make us look more professional and cautious sharing of information might help people. As David Boyle (2001) notes, however, counting can't make us happy. If information within mental health services is ultimately part of a process where we are trying to make people happier, then clinical psychologists need to promote discussion of the issues involved.

References

Boyle, D. (2001) *The Tyranny of Numbers: Why counting can't make us happy*. London: Harpercollins

Newnes C. and Holmes G. (1999). The future of mental health services. In: C. Newnes, G. Holmes and C. Dunn (eds) *This is Madness: A critical look at psychiatry and the future of mental health services.* Ross on Wye: PCCS Books.

Newnes, C. (1995) On note taking. **Clinical Psychology Forum,** 80, 31-36