DOAS SAP Concept Paper - Medicine and Care
TWO AMALGAMATED CONCEPTS
A SPECULATION IN THE LIGHT OF INFORMATION TECHNOLOGY
IN HEALTH AND SOCIAL SERVICES

Why speculate?

When examining both health and social care recording methods and systems, it becomes increasingly clear that there are two sets of language being talked and two major "themes" involved in the systems.

They appear to distinguish between medical concepts and care concepts.

This paper will look briefly at both themes from the point of view of the person (patient/service user) and from an IT point of view.

The differences need to be carefully handled when creating systems, so that we do not take the assumptions of one theme automatically into another.

Medicine

From a patient's point of view, the medical profession are the medical experts.

While they expect clinicians to explain treatments and their likely consequences, and to offer alternatives, they will largely be expert guided in what is done **to** them. They will probably accept a fair amount of jargon, especially if they can be pointed to places where they can get translation if they want.

Medicine is a scientific discipline of diagnosis and treatment. It becomes increasingly technical and specialized as people pass on from community to acute services.

It is largely evidence based – by working in research mode; it can discover what are the best **treatments (in care pathways) for conditions** (and also the reason for conditions). To do this having highly coded data for exploitation is really valuable. It also helps in describing things precisely for communication between professionals (but not necessarily with the patient).

As it becomes more technical, information technology can help understand information, and ensure that things like drug conflicts (decision support) can be analysed for the front line.

Systems tend to reflect the ideas above.

Not all medicine is concentrated on this scientific and precise description. In particular, Mental Health treats an individual holistically as a person with needs, and GPs amongst most doctors will be alert to other needs of a person as well as what they may be specifically treating. This may not all get into recording, which is where systems concentrate.

Care (in its support context)

From a person's point of view, they are personally competent in care and 98-99% of health and social care is done by people themselves every day of their life (resting when not feeling well etc.) – a situation which we need to encourage.

They will have their own views about their needs and what works for them. It is when self-support (and that of carers) no longer works that professions step in. Descriptions in highly formalized language which categorise people can end up being offensive and also insufficiently descriptive of their precise situations, which can cause people to think we do not understand them.

Care is about helping people handle the impacts of disease and other social ills (why health and social care need to work together), so that they can continue to live a ("normal") life, or sometimes (e.g. in hospital) sustain quite an abnormal life while dealing with medical problems).

However we are all individuals, and the way we care for ourselves, or, have others help us care is actually a matter of personal choice (smoking, diets, exercise, friendships, where we live etc.). What is recorded about care is about a person's way of living and then professional interactions with that when they need support.

While there is a lot of standardization of **support for needs,** what is actually delivered should fit with (or be negotiated around) a person's own view of their care and their life. Given that support will change according to a person's choices and priorities, it is much more difficult to define the same package of care (in medicine a care pathway) for lots of individuals, and outcomes will vary as well (and need defining from the person's point of view) – so that the simplistic research model loses some of its validity.

A key part of care will be engaging the person (and their relatives etc.) in that care, since we should only be supporting where they have needs that they cannot meet themselves. Communicating with them (including electronically and in our outputs from electronic systems) is probably a crucial part of that engagement, and can be expected to become more important as people develop information technology skills.

(In dealings with a social worker after the introduction of a computerized Electronic Social Care Record System, she affirmed very clearly that a major consequence of the system was that everybody, including the family had a copy of the care plan. This care plan was a negotiated document detailing what everybody did in terms of care. This had led to a clarity, which really helped the process of improving care.)

Example of system problems arising in a care/medical concept

As an example of the difference (which for a third reason causes problems in both camps), both medicine and care may use ethnic description codes.

In medical terms, diseases may be more relevant to populations with specific genetic inheritances – but the coding rarely goes far enough for that – and in any cases actual analysis of the genetic make-up is more important – ethnicity id used as a proxy for this..

In care cultural affinity is much more than just a code, and there are probably almost as many cultural affinities as there are people. And the result of these cultural affinities may be halal meals, the desire for a certain type of religious representative to comfort me when I am ill, abstention from alcohol or meat or transfusions or photographs

In both cases we have been reduced by a combination of monitoring policy and computer simplification to use a code of ethnic category, which helps neither of the potential uses above, although we do at least allow individuals to self categorise (choose their own label).

The solution to this would be a further two fields – one (coded?) around genuine genetic inheritance, and one (free text) about cultural affinity and its consequences for the individual.

The Care Records Services

From the descriptions above it is probably clear that CRS deals with both medicine and care. In comparison social services systems tends to deal just with care.

There has been a tendency for the CRS to be led by the acute sector – where medicine is at its most dominant in health care.

Coupled with the tradition of computer systems before the web dealing primarily in coded data (often money), this acute led approach has tended to create a CRS dominated by medicine, and less amenable to some of the different concepts of care.

This paper asks whether this is right, and whether some of the professionals involved in holistic care processes, like SAP and CPA in Mental Health, need to require a widening of the Care Records Service, so that the medical assumptions at its heart are broadened to admit care assumptions as well.

The key care assumption, when it comes to information is that its format should be compatible with the individual cared for (consultation with users over the information held and its format becomes crucial)

Conclusions

We need to code medicine but expect to use much more free-text around care (while still categorizing the text for research and management information purposes e.g. aggregating needs)

Medical systems may be more focused on communication between clinicians (care pathways, e-prescribing and decision support), and use technical terminology for precision and system processing. Care systems may need to balance inter professional communication, with the equally important communication with the person. Medical system may be able to move to communication with the person through translation of terminology.

Research assumptions around finding the best evidence based treatment for people may not be as valid in a care context where the person is making many more choices to handle their individual situation.

There needs to be more work on public communication, especially in the care area to see the best way of producing communication that helps engagement.

We noted the difference between the Electronic Social Care Record strategy with its emphasis on documents, and the medical emphasis on data.

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