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# Chapter 7

## **Responsible and careful application of surveillance technology in residential care for people with dementia or intellectual disabilities: a guideline for residential care settings (English summary)**

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## **ABSTRACT**

The following text is the English summary of the guideline that was developed as a result of the research of this thesis and was published in Dutch. This summary will cover an introductory chapter on the development of the guideline, including a reading guide; an abridged version of all the normative themes as described in the guideline and a full translation of the key points for a responsible application of ST.

## INTRODUCTION

Residential care settings for people with dementia or intellectual disabilities (ID) are making increasing use of assistive living technologies (ALT). On the one hand ALT offers support to clients in their daily lives and on the other, there is a surveillance form of ALT which is primarily directed at restricting and safeguarding the client. This latter form of ALT can also serve as an alternative to fixation and other traditional forms of restraint. ALT is, therefore, a promising development, but at the same time the use of surveillance forms of ALT evokes ethical and legal questions.

This practice guideline deals with these ethical and legal questions in detail. The aim is for anyone who is considering making use of surveillance technology (ST) for long term care to get a better insight into its implications. What are the consequences for the care relation when the caregiver exercises his monitoring function at a greater physical distance? How does the client experience ST: as an extension to his freedom of movement or as an infringement of his privacy. In how far is the technique itself safe?

At the moment there is still no vision of care or policy development in residential care for vulnerable people as regards the daily application of ST. The conclusion of research done by the Dutch Health Inspectorate (IGZ) in 2009 was that the implementation of ST in long term care should be executed with more attention and that it lacked vision with regard to the significance of ST for clients.

This practice guideline wishes to provide a stepping stone towards outlining a guiding framework for residential care settings wishing to implement ST. It leaves enough room for care providers, professional organizations and professionals working in the field to specify and define the norms themselves in a more detailed way.

### *Development of the Guideline*

The basis for this practice guideline was the result of the research as presented in the other chapters of this thesis, which was started at the VU Medical Center in Amsterdam, The Netherlands in 2008. Members of the research project group included: A.R. (Alistair) Niemeijer, M.A. (PhD student), C.M.P.M. (Cees) Hertogh, M.D., PhD (project leader), B. J.M. (Brenda) Frederiks, LL.M., PhD (project supervisor), and M. F.I.A. (Marja) Depla, PhD (project supervisor), J.A. (Jan) Eefsting, M.D., PhD (external supervisor) and J. (Johan) Legemaate, LL.M., PhD (external supervisor).

As stated in the introduction of this thesis, this research entailed a multi-step approach whereby the following methods were used: a literature review, two concept mappings, an explorative survey and ethnographic field study. Next to the research findings, the input for this guideline consisted of several reports by the Dutch Health Inspectorate, legal documents on current (national and international) legislation with regard to ST and international guidelines on the use of technology for people with dementia or ID (Alzheimer Europe 2010, Bjørneby *et al.* 2001; Mahoney *et al.* 2007, Perry *et al.* 2010).

In addition, experts and key figures in the field of care were involved as an external supervisory committee, as well as the professional organizations (NVAVG and Verenso), the branch organizations, the Dutch Health Inspectorate and representatives of client organizations. This external advisory committee consisted of the following members: Tineke van Sprundel (Actiz); Alice Dallinga (VGN); Majorie de Been (V&VN); Jenneke van Veen, (IGZ); Yvonne van Gilse (LOC, Zeggenschap in zorg); Mieke van Leeuwen (Platform VG); Frans Ewals (Erasmus MC); and Robert Helle (KNMG).

The supervisory committee was closely involved with the selection of the expert panels for the concept mapping and also during the analysis of the ethnographic field study. With regard to the development of this guideline, several meetings were held with the supervisory committee to discuss the content of (earlier versions of) the guideline. Eventually all remarks were incorporated in a definitive version.

## Reading Guide

*For whom is this practice guideline intended?*

This practice guideline is intended for the policy officers of care settings who are considering making use of surveillance technology (ST). They can use this guide to apply ST in a careful and responsible way in their institutions.

*What kind of technology is involved?*

This guideline deals with the normative aspects of ST, such as monitoring devices, sensors, camera surveillance and GPS technology. The guideline, therefore, does not deal with supporting forms of ALT, such as automatic lighting and 'smart' household appliances and neither does it deal with medical technology such as a heart monitors.

*Which institutions are involved?*

This guideline is intended for residential care settings and small scale living accommodation for people with dementia or ID. This does not imply that there are no differences between both care sectors. That is why this guideline leaves room to the professionals working in the field to adjust the views presented here to their own situation. For the same reason the guideline could also be used for domestic care, although that is not its main focus.

*Section 2 and 3*

Section two is an abridged version of the original section and describes and explores very briefly the normative dilemmas which are linked to the application of ST. It offers the reader an insight into the backgrounds of section 3. Section 3 deals with points of consideration for a responsible and careful application of ST.

## **SECTION TWO: NORMATIVE ISSUES**

In this section the most important normative (ethical and legal) themes are briefly explored, related to the application of ST in the residential care of people with dementia or ID. We conclude with a paragraph in which a stepping stone is given for weighing up these different values. The contents of this section are based on literature studies and empirical research in care practice.

### **1. Safety**

One of the main reasons for care settings to decide to use ST is that it might ensure or increase safety (Nicolle 1998; Niemeijer et al. 2010). It is expected that the number of incidents is reduced through ST and the client's safety is increased.. Because the caregiver can see or hear what is going on (the client for example might be falling out of bed), he or she is able to intervene directly.

But does ST actually offer more security? As of yet there is no empirical data available which might confirm this. However, according to a study in the nursing home sector, the nursing staff here is not always sure whether this is the case (Depla et al., 2010). It is therefore important to have realistic expectations of ST. ST might provide security to clients, in the sense that they can signal that something bad such as a fall is about to happen, they however cannot avert this impending fall less conclusively than traditional means of freedom restriction. Thus, the security ST can offer is thus always a safety with risks. This fact should be recognized and requires, in many care settings- and society at large- a different kind of attitude when dealing with safety and risks.

### **2. Freedom restriction**

Electronic surveillance seems at first sight more desirable than the Swedish band, but are certain types of ST in itself not just as restrictive? An electronic barrier, albeit not physical, is still a barrier that is not to be broken. Some have therefore called ST a mild form of freedom restriction.

At the very least ST is often used instead of more (severe) traditional means of restricting freedom but nevertheless with the same goal. For instance, in an attempt to define norms for responsible care in the nursing home sector, several care organizations classified ST in 2005 as 'safety increasing' measure, instead of as a restricting measure (Het toetsingskader voor Verantwoorde Zorg, 2005). Of course this is only an arbitrary difference since classical physical restraints were and are also used with the intent of increasing the safety of the client (and in the past was called

a 'protective measure' as well). There are several countries where the use of certain types of ST are viewed as restrictive to the clients' freedom, for example, Austria (HeimAufG, 2011). Currently in The Netherlands, the law does not view ST as a form of freedom restriction, although the forthcoming law on the use of restraints 'Zorg en dwang' (Care and coercion) does, under certain circumstances view ST as 'involuntary care' (Kamerstukken 31996).

### **3. Autonomy**

In addition to offering more safety, a second important reason to apply ST, is that it might increase the client's autonomy. Think for instance of a GPS chip in a client's shoe, as a result of which they can move more freely and can (partly) decide for themselves where they want to go. Originally, respect for autonomy could be viewed as the person being able to decide him/herself what should happen to him/her, instead of others determining this for him/her (paternalism). Being able to lay down laws (nomos) oneself (auto) can then be viewed as the freedom to make personal choices or have personal control.

However, clients cannot always express their wishes adequately, due to their cognitive disabilities. Therefore it is important to analyse their behavior and interpret the meaning and significance of this as often as possible. For instance, wandering behaviour can be based on various motives and meanings, such as the need to relax, the wish to go for a walk or the desire to withdraw from the company of others for a while. This also applies to ST. For example, GPS might be seen as an 'improvement' as it offers the client more freedom than a closed door, but this might not necessarily be the client's perspective. The moment he is not allowed to go outside anymore without a GPS system could mean not a step forward (with respect to the closed door), but a step backward (when a client is used to going outside under personal accompaniment and values this greatly). This client too will not experience this as an increase of his possibilities, because he does not want to go outside alone (anymore). For this reason it is therefore important to reflect on each different application from the perspective of the client himself.

### **4. Privacy**

Ethics and law distinguish between two types of privacy which are relevant to ST. Firstly, privacy regarding sensitive information, such as personal data, and secondly, privacy in the sense of being alone undisturbed (also called spatial privacy). Although it is sometimes argued that GPS technology only invades privacy if the client in question tries to hide and does not want to be found (McShane, 1994), there is much



concern about the fact that the use of ST harms both forms of privacy (Niemeijer *et al.*, 2010).

The first concern is the question what happens to the collection of data and whether the material is really stored safely. In principle it is recommended that video-recordings are kept for a limited period (1 week). Yet there can be valid reason to diverge from such a storage-period, such as after an incident occurred, where a care setting must provide data in the form of a log book. Not only in order to ascertain what exactly happened, but also to check if ST was applied in the right manner.

The need for spatial privacy differs from person to person and from situation to situation. It is therefore important to observe well and get to know clients as well as is possible. That which one considers an infringement of his or her privacy, need not be a problem at all for somebody else. The point here is not only to respect their privacy, but also to protect their dignity. Clients who are used to 'surrendering' their privacy during their personal care (and do not experience this contact as an infringement of their privacy), can find it disturbing to be monitored (and do experience this as an infringement of their privacy). Their personal care is given by someone with whom they have a reciprocal bond, whereas the surveillance is done by a non-reciprocal, electronic application, where the question is whether the client knows who is behind the monitor and in how far this person is sympathetic towards him or her.

## **5. Informed consent**

The principle of informed consent is a corner stone of modern ethics and health law and also applies to people with dementia or ID. To obtain consent for care and treatment, the client must have the appropriate and detailed information. A client can only give valid informed consent if he/she is capable of understanding the information and making a meaningful choice. It is the task of the caregiver to provide the information and to adjust this to the (remaining) capabilities of the client. There is, however, a limit to this adjustment. If someone can only absorb the most basic of information about an impending decision, the question arises if one can still speak of informed consent.

The law requires that the information is adjusted to the (mental) capabilities of the client. Informing and asking consent or assent from clients about surveillance demands a lot of creativity and empathy of caregivers. In addition clients are sometimes prone to being easily swayed. Cooperative behavior can wrongly be interpreted as consent to surveillance, and forms of resistance in their turn need not mean that a client does not want to cooperate with the use of surveillance.

However, non-visible or barely visible technology (as discussed in the following paragraph) also has implications for giving consent or assent, because understanding invisible technology can become too abstract. The increasing invisibility of technology like ST has far reaching implications for the informed consent doctrine, because to what extent can informed consent be achieved with non-instrumental, non-visible, non-operated, automatic-in-the-background technology and how can one resist technology which cannot be observed? (cf. Mordini and De Hert, 2010).<sup>1</sup>

## **6. The visibility of technology**

In this paragraph we discuss the physical characteristics of ST. ST applications are sometimes spatial objects and therefore visible to the clients and other users of that space. This puts demands on the design of ST. One of those demands is that ST should not be too visible; it should not impose. Too large an obtrusiveness is seen as one of the negative aspects of ST (Zwijssen *et al.*, 2011). If it is evidently visible to everyone that the client needs care, then that is unnecessarily confrontational. Besides spatial visibility there is also the potential problem of visibility on the body, for instance wearing an electronic bracelet. That can symbolize vulnerability and dependence for some people and therefore lead to feelings of stigmatization. This is reinforced by the negative associations which these bracelets or wristbands evoke, because they are also applied to prisoners (Bail, 2003).

One way to compensate too great a visibility of ST is by using the principles of ‘universal design’. This means that the application is designed in such a way that it is attractive to use to anyone (whether you need it or not). Thereby it is made socially acceptable and devoid of its stigmatizing nature (Parette and Scherer, 2004; Perry *et al.*, 2008). Another way to make the application literally less visible. Although this can be viewed positively from a point of view of obtrusiveness or possible stigmatization, it could also have less positive consequences for the client, in particular to his ability to resist the application, as was discussed in the paragraph.

## **7. The care relation**

Because ST takes over (a part of) the surveillance task of the (primary) caregiver, the use of ST has implications for the care relation between caregiver and client. To begin with, one must be aware of an attenuation or of a reduction of the contact between caregiver and client. From our research it appears that checking clients (for

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<sup>1</sup> N.B. This observation on the invisibility of ST and the implications for informed consent, can originally be found under paragraph 6. ‘The visibility of technology’ of the Dutch version.

example if they are lying safely in bed) is not only a pretense of personal contact for many caregivers, but also that surveillance and control even coincides with offering personal attention. If these tasks were left out and the physical presence of a caregiver is no longer required, there would automatically be fewer primary contact moments. The tasks of the caregiver then change from caring and supporting into monitoring. One could wonder whether human contact is not indispensable with regard to this particular group vulnerable people. Without a carer nearby, especially during the night, clients might feel less safe and alone. What is more, for certain clients the contact with care staff is their only form of social interaction (Perry et al., 2008). Similar concerns have been expressed by professional caregivers, who understand the role of human contact and connection in providing optimal care and fear that technology could lead to “dehumanized” care (Sävenstedt et al., 2006). Caregivers are not guards who monitor, but people who care for other vulnerable people.

## **8. Responsibility**

This last normative issue concerns the question who is responsible for the application of ST. On the one hand this involves the responsibility for the (medical) indication, and on the other hand the final responsibility for the adequate functioning of the application. The present legal framework does not specify who is finally responsible for the indication of ST. In the forthcoming law on the use of restraints ‘Zorg en dwang’ (Care and coercion), ST is viewed for the first time as a risky and possibly involuntary treatment- the responsibility for the indication is relegated in principle to the responsible caregiver. But it could also –contrary to medication and freedom restriction- be an expert, to be determined later, who is appointed by ministerial decree (Frederiks *et al.*, 2009). It would, moreover, matter if electronic surveillance and or monitoring is needed for medical reasons (such as epilepsy or for a client in a terminal phase), in that case the medical authorities or physician is legally responsible for a correct application. Because the application of ST entails weighing up the various alternatives, it is recommended to prescribe a multidisciplinary approach in the decision-making process regarding ST, just as in the case of physical restraints, in which medical competences are represented as well as behavioral and caring competences.

By separating living and care the question of final responsibility for the adequate functioning of ST is more complex than with other interventions. It increasingly happens that care settings rent accommodation from housing corporations and that these have already installed (part of) the ST. The question is where the responsibility of the corporation ends and that of the care setting begins. With the purchase of

new ST from an external manufacturer the question also arises who is responsible for what. If a client for example is severely disadvantaged as a result of failing equipment, it is not clear who is responsible or liable for this: the manufacturer or the care setting. It should also be clear how maintenance is put in place. Therefore it is important that attention should be paid to this when performing a risk analysis.

## **9. Weighing-up values**

As a kind of normative checklist, for each client for whom ST applications are considered, the following should be answered:

### What added benefit is envisaged with the application?

In this chapter two reasons are mentioned to begin applying ST to a client: guaranteeing his security (§2.1.) and increasing his/her autonomy (positive freedom) (§ 2.3). It is recommended with the application of ST to first of all ascertain which added benefit one expects to gain in concrete terms with respect to one of these two values. In which way will this specific application enhance the safety and/ or autonomy of this specific client?

### What are the negative consequences for the client?

Consequently it is important to define the possible reverse effects of the application of ST for the specific client. This concerns the consequences for his/her freedom of movement (§2.2), his privacy (§2.4) and the care relation (§2.7). In what way does the application infringe on the client's freedom of movement? How far will the client experience the application as an invasion of his/her privacy? As stated before, the need for privacy can differ from person to person and from situation to situation. It is therefore important to specify this for the client concerned. The same goes mutatis mutandis for the consequences of the care relation between client and professional.

### How visible is the application?

In addition it must be clear how (in) visible the application itself is (§2.6). Is it not too invasive on the one hand and also stigmatizing? On the other hand is the application visible enough to the client?

### How well can this be explained to the client?

Finally, consent must be asked from the client and/or his/her proxy (§2.5). Even if a client has diminished capacity with regard to ST, he/she must be involved in the

decision-making process. Then his/her assent should be sought, in which in any case the client (understands) the implications of the application correctly.

By weighing up these questions of the various values involved, it becomes clear what is most important in every individual case. Then the multi-disciplinary view of the clients' behavior can be important to come to a better understanding of the experience of the client. The added value of the application for the individual client must be evident for all those involved at all times.

## **SECTION THREE: RESPONSIBLE AND CAREFUL APPLICATION**

In this section points of attention are formulated which a responsible and careful application must comply with. These points are based on the normative framework that is described in chapter 2.

The following viewpoints are dealt with:

- 1) Before purchasing and implementing of ST**
- 2) Application of ST for clients**
- 3) Application of ST by caregivers**
- 4) The technology of ST**
- 5) Responsibility and evaluation**

### **1. BEFORE PURCHASING AND IMPLEMENTING ST**

Before purchasing and implementing ST, management should reflect – in consultation with staff- on what the organization aims to do with ST, which organizational terms must be met, and what risks (for the organization as a whole and individually per client) are attached to these. Any (self-respecting) organization draws up a risk analysis at organizational level annually. The theme of ST could be part of that. A responsible and careful application of ST implies that the care setting has reflected on the questions which were evoked in the normative framework and it that is aware of the consequences of ST for clients and staff.

#### **Vision on ST**

##### *Vision on surveillance*

Before developing a vision on ST it is fitting to develop a vision on how the care setting aims to regulate the surveillance in general. Under surveillance is meant in this respect: the way in which clients are protected, guarded and checked. With regard to this, questions should be answered such as: how much and how often is surveillance necessary? How do we see the relation between personal monitoring and electronic monitoring? At what price do we want to check the clients’

surroundings? Which accidents do we want to prevent at all times, or which risks are we willing to take in favor of the clients' freedom (of movement) and privacy.

#### *Vision on ST*

Different aims may be achieved by ST: enlarging or maintaining freedom and or the agency of clients; an increase of the safety of clients; as an alternative for physical restraints, reduction of staff during night (and/or day). It is recommended to indicate per different type of ST which aim the care setting tries to achieve and which disadvantages result in terms of freedom (of movement) and privacy for clients.

#### *Vision on general versus individually applied ST*

The starting point is that ST is applied on the basis of individual (medical) indication. This does not mean that general applications can also be needed. For example, camera surveillance at the entrance of the care setting and door codes. It is important to explain and motivate these applications in a correct manner.

### **Risk analysis**

#### *Risk analysis of ST*

The care setting should be aware of the possible failings and shortcomings of ST by means of a risk analysis. These should be analyzed per type of ST as much as possible.

#### *Failing technology*

Technology is fallible and can stop working. It is therefore important that an emergency protocol or scenario is prepared which can be used when something goes wrong (for example in the case of loss of electricity by fire of lighting, or the loss of a chip by client). Furthermore, it must be clear when the application is still on and when it is not on anymore. Moreover, there could also reports of situations, which on further inspection, need no intervention. The risk of this is that gradually a kind alarm fatigue can develop with staff, as a result of which they respond to signals less acutely. The management should be prepared for this and take measures to prevent alarm fatigue.

### **Consequences for staff**

#### *Making consequences transparent*

The introduction of ST always has consequences for staff. It is recommended to define these consequences as well as possible and to discuss them, so that neither

management nor staff are faced with surprises. One can think of more care at a distance, less personal contact with the clients and monitoring more clients at the same time (who are less well known as a result).

## **Consultation**

### *Staff consultation*

It is recommended to consult (representatives) of all disciplines who work in the care setting and to involve them with the purchase and implementation of ST. That does not only result in valuable input for the vision, risk analysis and taxation of the consequences for the staff; it also probably improves the chances of a successful implementation of ST.

### *Client and family consultation*

The client (representatives) council and clients and proxies should also be consulted about the possible advantages and disadvantages of ST.



## **2. APPLICATION OF ST FOR CLIENTS**

A responsible and careful application of ST implies that ST is not applied in a standard manner, but that the already formulated advantages and disadvantages of ST (as laid down in the vision statement of the care setting) will have to be examined again and again in each specific case and that the client should be involved in this.

### **ST made to measure**

#### *Individual application*

The fact that ST is available is no reason to apply ST in every individual case. The use should be considered with every individual client.

#### *Personal added benefit*

ST should have an added benefit for the clients to whom it is applied. This means that benefits are attached to the application of the measure which suit the wishes, needs and (functional) capabilities of the clients. This added benefit can be found in the support of somebody's need for agency, or the need of a client to move more freely, or in the need to offer him/her more safety.

#### *Subsidiarity – proportionality – effectivity*

When the restriction of the freedom or capabilities of the client as a result of the application of ST is predominant as regards the personal added benefit of the application, the application should always meet the requirements of subsidiarity, proportionality and efficiency. This means that the application should be the least invasive option (subsidiarity), should be in relation to the aim to be achieved (proportionality), and be successful in realizing that aim (effectivity). It should be made clear that all possible alternatives (such as human support and behavioral interventions) have already been explored and that the client truly needs the measure in question.

### **Informed consent**

#### *Information prior to admittance*

Before a client moves to a care setting, the client and/or his/her proxy should be informed about all the ST applications that could possibly be used within the care setting. They must be informed both the added benefit and the risks of the applications.

#### *Informed consent client*

ST can only be applied with the informed consent of the client and/or proxy. It is expected from the caregiver that the latter adapts the information to the client's level of understanding. If the client in question has diminished capacity, the care setting or the caregiver should ask (informed) consent from his/her proxy.

#### *Assent client*

If the client cannot consent him/herself, his/her assent should be sought. Assent implies that the client has been able to form an idea/understanding of the application and that it can be deduced from his/her response that he/she does not object to it. Consent of the proxy does not free the care setting from the obligation to consult the client him/herself. That means that on the one hand, the care setting does everything to explain (the implications of) ST to client as well as possible (for example by the use of graphic symbols or a practical demonstration); and that on the other hand, one uses all the verbal, behavioral and emotional reactions of the clients to form a correct picture of his/her wishes as regards ST.

#### *Resistance to ST*

Possible ways of resistance of the client to the application of ST must always be taken seriously, no matter how strange or illogical they look. It should be investigated whether they are based on a wrong picture of reality or if there is really no consent/assent. In the first case it should be attempted to take away the worries of the client by explaining the application better. In the second case an alternative to the application should be sought.

#### *Repeated consent/assent*

Clients with memory problems will easily forget that they have consented/assented to a certain application. Therefore an affirmation should be sought in every care plan meeting or discussion of their consent/assent. The ways of communication as describe above (graphic symbols and or practical demonstrations) can be used for this. If there is no consent/assent of the client and if he/she resists the application, the staff member should report this in the file. In that case we speak of force.

## **Privacy**

### *Proportionality*

ST must not disproportionately harm the client's privacy.

### *Private rooms*

In bedrooms, toilet or bathroom, camera surveillance and audio surveillance are only permitted if it is strictly necessary to avoid serious harm to the client him/herself or other or to prevent that. If the use of video and audio surveillance is considered necessary, it should also be possible to switch of the device in an individual situation. For example, if there is care staff or family present and there is no need for electronic surveillance at that time.

### *Storage video and audio recordings*

Video and audio recordings should be destroyed within a short period (for example one week), unless there are legitimate reasons for not doing so, such as after an incident, when the care settings will have to provide log data to the Health Inspectorate or the client/proxy because of a complaints procedure. The care setting must have a clear policy on the storage of video and audio material.

## **Stigma**

### *Stigma*

To prevent stigmatization and feelings of shame or embarrassment among clients, the application of ST must be applied as discreetly as possible. This concerns both visibility of the application (e.g. electronic bracelets) as well the noise of the application (e.g. of the volume of alarm signals).

## **Consequences for other clients**

### *Weighing up the consequences for other clients*

The application of ST for a client can have negative consequences for the other clients with whom he/she shares a ward or communal living area. A good balance must be found weighing up the advantages of ST for the client in relation to the possible disadvantages of this application for his/her fellow- clients (in terms of reduced freedom of movement or privacy). These considerations must be noted in the care plan of the clients involved.

### **3. THE APPLICATION OF ST BY CARE STAFF**

A responsible and careful application of ST presupposes that the staff who are going with ST are aware of the advantages and disadvantages of ST and that they know how they must use the various applications.

#### **Training**

##### *Awareness*

To make staff members more aware of the advantages and disadvantages and risks of ST a schooling plan is needed in which they learn to make ethical decisions in cooperation with each other. It is recommended to involve staff members in the formulation of the vision and the risk analysis (see consultation staff) and to familiarize themes from the normative framework (what does ST mean for the privacy, safety, freedom of movement etc. of the client?). To prevent the vision from becoming a dead issue, the management must expound the vision on ST actively in the care setting and transpose it to the working area.

##### *Knowledge of the guideline*

Staff must be informed about and have access to the relevant normative decisions and points of attention for them for a responsible and careful application of ST.

##### *Technical expertise*

A further requirement for a responsible application of ST is that the staff is trained in a technical sense in the use of the various applications. Staff members must feel adequately equipped to work with ST (how to operate, how to regulate, how to respond to signals etc.). Because of the risk attached to wrong use it is recommended to repeat this training periodically.

##### *Knowledge of the client*

When applying ST the risk can arise that there can be numerous incoming signals at the same time for a staff member. To know which signals should be given priority a thorough knowledge of the care needs and behavioral patterns of the clients who are linked to the ST system is required.

#### **Rights of staff members**

##### *Right of information*

With some kinds of ST not only the goings on of clients are registered but also the conduct of staff member who look after them or monitor them. Staff members have

a right to know in which situations they are being filmed or monitored in other ways and what are the implications of that.

*Right to privacy*

As cameras and audio surveillance are used on a larger scale, staff members are less able to withdraw from surveillance in their workplace. The management must be fully aware of this consequences of ST for their working staff. It is important that staff members can at least withdraw into a room without ST during their break.

#### **4. THE TECHNOLOGY OF ST**

A careful and responsible application of ST means the technology itself also needs to meet certain demands. It is thus important that ST is user-friendly and reliable.

##### **User friendly**

###### *User friendly*

ST must be easy to use. This is especially true for the staff member, but also – when applicable – to the client and his family. By this is meant that the use of ST does not require a high level of educational training and is easily transferable.

##### **Reliable**

###### *Emergency protocol*

Technology is fallible and can break down. It is therefore important that there is an emergency protocol that can be used if something goes wrong.

###### *Regulating the alarms*

When there is a high frequency of false-positive alarms, it should be investigated if the system is regulated to sensitively. It must be prevented that staff members do not take these signals serious anymore (see also fallible technology)

###### *Maintenance*

Periodical maintenance checks should be in place. For this a maintenance contract should be drawn up with an external party.

###### *Repairs and availability technical support*

There must be clear arrangements about the availability of the technical support staff in case something goes wrong or in case something does not function well anymore. If something needs to be repaired this should be done quickly, as part of the maintenance in which ‘quickly’ is defined in hours or days.

##### **Standard settings**

###### *Automatically off*

To do justice to the viewpoint that the use of ST is assessed per client (see individual application). The devices are only switched on and comply to the agreements as they have discussed and have been noted in the care plan (see multi-disciplinary ...). The standard setting is that the device is switched off.

## **5. RESPONSIBILITY AND EVALUATION**

Finally there is the issue of the responsibility and evaluation of ST which need to be addressed. It must be clear who is responsible and for what and how the use of ST is evaluated

### **Client level**

#### *Multidisciplinary decision making*

The decision to implement a certain type of ST for a specific client must be made in a multidisciplinary setting. This should entail staff with medical, behavioural and nursing background.

#### *Nightshift*

If the ST in question is meant for use during the nightshift it is necessary to include nightstaff in the decision making process

#### *Careplan*

If the decision to implement ST is made this should be noted in the careplan of the particular client in a standardized and straightforward way with the mentioning of the indication and the envisioned goal. The careplan should also mention the additive value of the specific ST as well as remarks on the aforementioned criteria of subsidiarity, proportionality and efficacy.

#### *Periodic evaluation*

The use of a specific type of ST for a particular client should be evaluated regularly (see decision on careplan AWBZ care). These evaluations should make clear whether or not the use of the ST for this client is still the most suitable option (is the ST still beneficial to the client?), especially in light of potentially changed needs, abilities and circumstances of the client. Especially if the ST in question potentially has far reaching consequences its use should be evaluated more frequently and the demands for implementation should be more stringent.

### **Administrative level**

#### *Responsibility*

It must be clear who is responsible and competent for which part of the (implemtenation of) ST. A difference must be made here between general use and individual use of ST as well as between the responsibility for the implementation process of ST and the actual use of ST (see page 50 multidisciplinary decision making).

### *Errors in equipment*

For responsible and optimal use of ST several disciplines are necessarily involved. The administration of the care institution must be aware of the responsible parties for each part of the process (i.e. supplier versus care institution, maintenance).

### *Periodic evaluation*

The use of ST must be evaluated periodically. It is recommended to include both staff, clients and proxies should partake in these evaluations. The staff should be asked to comment on reasons for changes in use of ST, difficulties in the use of ST, consequences of ST for both staff and clients; etc. The clients and/or their proxies should be included in the evaluation of the use of ST. Here also it must be the goal to stimulate clients as much as possible in their communication about their insights.



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## REFERENCES

- Alzheimer Europe** (2010). Alzheimer Europe Report: *The ethical issues linked to the use of assistive technology in dementia care*. Luxembourg: Alzheimer Europe.
- Bail, K. D.** (2003). Electronic tagging of people with dementia: devices may be preferable to locked doors. *British Medical Journal*, 326, 281.
- Bjørneby, S, Topo, P and Holthe, T.** (2001). Technology, ethics and dementia: A guidebook on how to apply technology in dementia care. Norway: Norwegian Centre for Dementia Research.
- Dutch Health Inspectorate** (2009). Toepassing van domotica moet zorgvuldiger. Den Haag: IGZ.
- Frederiks, B.J.M., Niemeijer, A.R. and Hertogh, C.M.P.M.** (2009). De juridische en ethische aspecten van domotica in de zorg voor mensen met dementie. *Tijdschrift voor Ouderengeneeskunde*: 34 (5): 181-185.
- Heimaufenthaltgesetz** (2011). § 3. Freiheitsbeschränkung. Gesetzestext (Berücksichtigter Stand der Gesetzgebung: 1. Juli 2011) Österreich.
- Kamerstukken II**, vergaderjaar 2008/2009, 31967, nr. 1 en 2.
- Mahoney, D.F., Purtilo, R.B., Webbe F.M., Alwa M., Bhaurcha A.J., Adlam T.D., Jimison H.B., Turner B., Becker S.A.** (2007). For the Working Group on Technology of the Alzheimer's Association. In-home monitoring of persons with dementia: Ethical guidelines for technology research and development. *Alzheimer's & Dementia* 3: 217-236.
- McShane, R. and Hope, T.** (1994). Tracking patients who wander: ethics and technology. *The Lancet*, 343, 1274, 1p.
- Mordini, E. & De Hert, P.** (Eds.) (2010). Ageing and Invisibility. Amsterdam: IOS Press.
- Nicolle, C.** (1998). Issues in the use of tagging for people who wander- a European perspective. *Personal Social Services in Northern Ireland*, 58, 10-22.
- Niemeijer, A.R., Frederiks, B.J.M., Riphagen, I.I., Legemaate, J., Eefsting, J.A. and Hertogh, C.M.P.M.** (2010). Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: an overview of the literature. *International Psychogeriatrics*, 4: 1-14.
- Parette, P. and Scherer, M.** (2004). Assistive technology use and stigma. *Education and Training*, 39, 217-26.

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**Perry, J., Beyer, S., Holm, S.** (2008). Assistive technology, telecare and people with intellectual disabilities: ethical considerations. *Journal of Medical Ethics*, 35, 81-86.

**Perry J., Beyer S., Francis J. & Holmes P.** (2010). *Ethical Issues in the Use of Telecare*. Social Care Institute for Excellence, London.

**Sävenstedt, S., Sandman, P. O. and Zingmark, K.** (2006). The duality using information and communication technology in elder care. *Journal of Advanced Nursing*, 56, 17–25.

**Toetsingskader voor verantwoorde zorg.** (2005). Utrecht: Arcares, NVVA, AVVV, Sting, LOC, Z-org, IGZ, VWS, ZN.

**Van den Ende, T.** (2011). *Waarden aan het werk. Over kantelmomenten en normatieve complexiteit in het werk van professionals*. Amsterdam: SWP/UvH Press

**Zwijzen, S.A., Niemeijer, A.R. & Hertogh, C.M.P.M.** (2011). Ethics of using assistive technology in the care for community-dwelling elderly people: An overview of the literature. *Aging & Mental Health* 15, Issue 4, 2011.