Informal **Care** **Scan** Aid

mapping out the composition, organisation
and risk factors of a care network

centre of expertise
for informal care

Colophon

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The Centre of expertise for Informal Care, the national knowledge centre for family care and family-care support, offers a wide range of services and products for all sectors of family-care support, where such caregiving is or should be a point of attention – from vision to practical solutions, from inspiration to knowledge and advice.

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1.1 Introduction

The Informal Care Scan, an instrument for professionals in care and welfare, is intended to help those in need of care and caregivers to map out a (informal care) network, which focuses attention on the strengths and weaknesses of that network. The scan provides visual aides that help in structuring all information across the network. Information about the network is important because caregiving often goes further than merely contact between a single client and a single caregiver. More people are often involved. Also, the impact of the care situation often extends beyond the care itself. The Dutch Social Support Act (SSA or Wmo in Dutch) places considerable importance on the self-reliability of citizens with their own dedicated social network. To utilise that network fully it is important to map out the possibilities and limitations of such a network. That is the purpose of the Informal Care Scan!

The Informal Care Scan came about as a result of a study of care networks carried out by the University of Amsterdam, 'Looking for Reflected Satisfaction' (*Op zoek naar weerkaatst plezier*' -Tonkens, van den Broeke and Hoijtink, 2008). The study focuses on discovering the ways in which care networks work and on points of departure to improve cooperation within these networks. In particular, the study offers a new perspective: do not simply place the emphasis on (over) burdened caregivers, but also have an eye for positive experiences. Professionals and policymakers for family-care support in the study indicate that, with the starting points of the aforementioned publication, they need an instrument to map out the network stresses.

Care and relief workers frequently lose sight of caregivers. Besides providing a complete picture for them, the creation of a structured chart of the care network could also offer unexpected benefits for caregivers:

> *'The findings were quite surprising. The filling in of the genogram, in particular, resulted in frankness that sometimes went well beyond what is needed for the Informal Care Scan: the caregiver seemed relieved to be able to express this at last.* [*Pilot*-project participant]

The Informal Care Scan derives its name from the Dutch word for family care, combined with the image of a *scanner*: each part of the care network is mapped out and investigated step by step. This 'helping hand' is available to any professional who has something to do with caregivers and care networks. It helps explain all parts of the Informal Care Scan step by step. Section 1 describes the background and conditions for using the scan. Section 2 treats the various parts of the Informal Care Scan and explains the use of the instrument. In section 3, attention is given to the underpinning of the instrument and section 4 discusses several examples from clinical practice.

Finally, we would like to express our thanks to all those professionals who contributed to the development of this instrument. Despite their already busy schedules, they still found time to participate in the pilot projects and share their findings. The final instrument reflects the results of their efforts. We would especially like to mention CMO Flevoland (the Centre for Societal Development) because of their efforts in organising a training afternoon.

1.2 Why use this instrument?

The strength of the Informal Care Scan is the way in which information received from an interview with a client and caregiver is structured. The questions asked are recognisable by and often familiar to professionals. The structure offered by the Informal Care Scan provides insight into a complex network. As a result, no information is lost. A pilot-project participant put it this way:

> *'In itself the Informal Care Scan is not unique; much of the information it provides can be found in other intake lists. The difference is more in the way in which the information is gathered. It took me some time to get used to it, but it is clear that you can get a clearer picture of the dynamic, along with leads for reinforcing the care team'.* [Pilot-project participant]

This structured approach also provides deeper insights in the situation. There is often a general view, but the use of the Informal Care Scan helps to clarify the situation:

> *'Using the Informal Care Scan gave me insight in the care situation and how caregivers feel about it. I was generally aware of their situation, but did not know the in's and out's'.* [Pilot-project participant]

The visual aspects of the Informal Care Scan, with the use of a genogram and an Ecomap, also contribute to better insights:

> *'The first page of the Informal Care Scan is conveniently arranged. You can see at a glance how the support system works'.* [Pilot-project participant]

In sum, the characteristics of the Informal Care Scan:
- content that dovetails with clinical practice;
- a structured approach;
- provides insight in the complexity of a care network;
- provides a clear visual image of the network.

1.3 Why was it developed?

The Informal Care Scan was developed in the Netherlands. This paragraph describes why it was developed to meet the specific situation in that country. Although there are differences among European countries with regard to the use of informal care, there is a common interest: how can family caregivers provide this care in the best possible way? The Informal Care Scan was developed to serve that common interest. As a result, professionals acquire a tool that enables them to work more closely with family caregivers and volunteers. It helps reduce the burdens that caregivers face.

Attention for the support for caregivers is extremely important. Increasingly, the nature of family care is becoming more obligatory (Sadiraj et al., 2009) and the care provided by caregivers, more intensive and protracted. The number of overburdened caregivers in the Netherlands has increased in recent years from 300,000 in 2001 to 450,000 in 2008 (Oudijk et al., 2010). However, besides negative experiences, the mentioning and support of positive experiences also deserves greater attention: looking for reflected satisfaction (Tonkens et al., 2008). In short, the importance of attention for the capacities and burdens of caregivers is increasing.

The Dutch Social Support Act imposes an obligation on people to make use of their own networks as much as possible before being entitled to professional help and care (Dutch ministry of Health, Welfare and Sport, 2007). It is therefore necessary to devote attention to how such a network works, along with the possibilities and limitations. In short: the importance of insight in the operation of care networks is increasing. The Informal Care Scan makes this possible.

There are 3.5 million caregivers in the Netherlands, of which 450,000 are significantly or seriously overburdened (Oudijk et al., 2010). There are numerous reasons for over burdening, including the nature, duration and intensity of care requirements, conflicting roles and shifting relations (de Boer et al, 2009); or, for example, that there is little discussion of experiences and expectations within the care field (Potting, 2001; Tonkens et al., 2011). Although this summary is not exhaustive, it reflects the complexity of care experiences.

A non- or poorly-functioning care network is a disadvantage for both clients and caregivers. Derailment of family care is lurking in the background (MOVISIE, 2010). The starting points for targeted support will be found by identifying opportunities and threats in the care network.

1.4 Aim

The Informal Care Scan was developed to give family-care supporters in a back-office function an instrument with which they can obtain an overview of the care situation and estimate the risks of overburdening the (family) care network.

SMART aims

1. **S**pecific. The Informal Care Scan maps out the nature of the care requirement, the perceptions of the caregiver(s), the family and the care network. This is done with at least one caregiver. Clients could also be present. The Informal Care Scan can be done in people's homes or in the office. The scan can be used on first acquaintance -- for example, on intake – or (again) during a later stage to ascertain changes in the network.

2. **M**easurable. The Informal Care Scan utilises several proven instruments: the genogram, the Ecomap, the SRB scale and PPIC list (see section 3 for the underpinning of the Informal Care Scan).

3. **A**cceptable. The Informal Care Scan is a structuring instrument. Together with the caregiver and client, the professional must estimate the type of information about the care network that should be included in the Informal Care Scan.

4. **R**ealistic. It takes approximately one hour to do a Informal Care Scan. This is not feasible in all cases. A Informal Care Scan can therefore also be done partially at different times. In addition, a close watch must be kept on the limits of family care and clients. (Also see the contraindications in 1.5).

5. **T**ime-specific. The minimum period required to do a Informal Care Scan is approximately one hour; a more extensive scan takes between one-and-a-half and two hours.

1.5 Focus group

Indication

In principle, the Informal Care Scan can be used in any care situation that necessitates mapping out the capacities and burdens of the clients and caregivers concerned.

Contraindication

Contraindications can be grouped under time and nature of the care required.

Time

The time needed is not always available. The evaluation of the Informal Care Scan shows that sometimes only a half hour was available. In such a situation, the scan is therefore done in two different sessions. Sometimes mention is made of a two-hour requirement to perform the scan. In this regard, see sections 2 and 3 about delineating the use of the Informal Care Scan.

Nature of the care required

The questions are fairly general in nature, so that the Informal Care Scan can be used in the largest number of care situations possible. In specific situations, supplementary questions could reinforce the effectiveness of the instrument. However, this is in the hands of the professionals. The Informal Care Scan is primarily a structuring instrument.

Moreover, there could be situations in which the client and/or caregiver are unable to concentrate sufficiently long to perform the entire scan in one session. The scan can therefore be performed in two sessions.

1.6 Required professional competences

The Informal Care Scan was designed for family-care supporters in a back-office function. By this, we mean care and welfare staff:

- who have at least one hour at their disposal to conduct and compile a report of an interview;
- who are in a position to take action, if necessary, based on the results of the interview

The professional should have sufficient knowledge of:

- general themes within family care (support)
- the social map
- the limits of his/her own possibilities for support and when referral is necessary

The professional should possess the following skills:

- empathy
- interview techniques to enable the interviewer to stick to the core purpose and to provide ‘detours’ to return to this core message

2 The **Approach**

By simple means, the Informal Care Scan maps out the strengths and weaknesses of a (care) network. This section focuses on the use of the Informal Care Scan. The first page of the scan serves as a summary of the interview; the rest of the Informal Care Scan concerns the nature of the care requirement, caregiver-related stress and the main characteristics of the (care) network.

Please note! The data about the network comes from one or two members of the network, for example, the client and one caregiver. That means that the results could be biased. Other family members view the situation in their own, perhaps entirely different, way. Therefore, the Informal Care Scan includes a separate section for the caregiver who takes part in the interview. With the section, 'nature of the care requirement', this provides an impression of *who* talks about the network.

TIP

To save time, you can submit questions to the caregiver and client in advance of doing the scan. For example, this could entail questions about the nature of the care requirements (see step 2) or questions about how energy is expended and what it produces (see step 3 and appendix 1). This will ensure that there is more time for mapping out the network.

TIP

Keep the Informal Care Scan form at hand when reading this section.

2.1 Use of the Informal Care Scan

Running the Informal Care Scan is done in five steps. Each step is explained further in the following paragraphs. An overview:

Step 1: Meeting the family: producing the genogram
Step 2: The nature of the care requirement
Step 3: The caregiver
Step 4: The network and the Ecomap
Step 5: Advice

2.2 Step 1: Meeting the family: producing the genogram

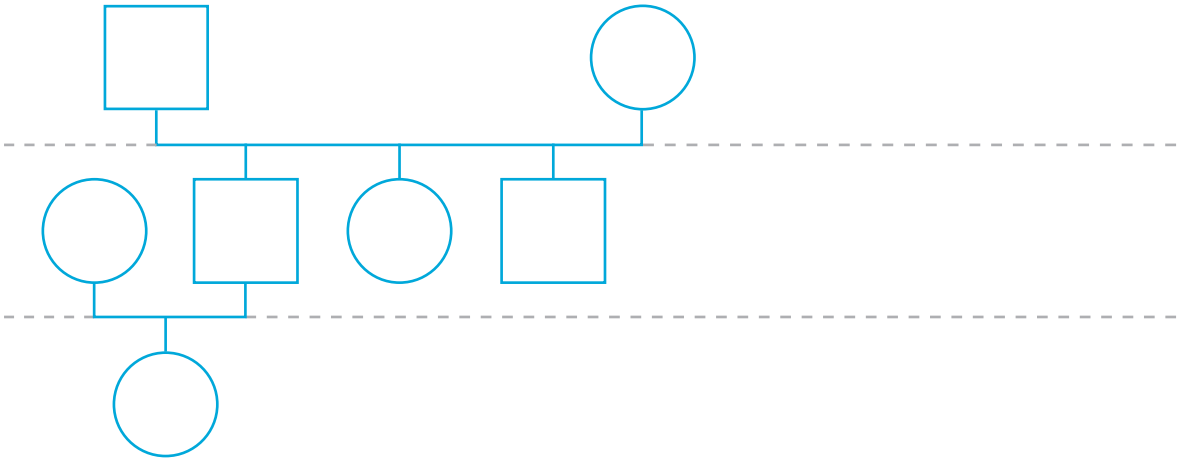
The only purpose for drawing the genogram is to get a clear picture of the family structure: number of persons, their names, ages and relationships. This should be kept as factual as possible. The nature of the relationships will be discussed with step 4.

Producing a genogram with the caregiver and/or client is the first step in mapping out a care network. A genogram is a handy method for obtaining a picture of the family in a short time. It simplifies the interview because the names of the family members are known. It offers a quick view of the (potential) caregivers, who are often family members. In the beginning a genogram can look a bit complicated, but once you have produced one you will see that it is really quite easy.

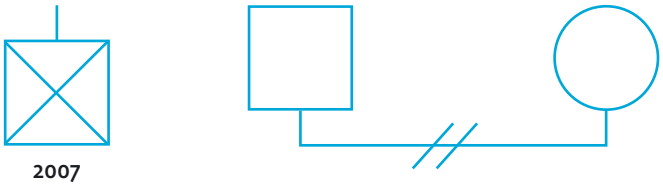
The basis is as follows: a square represents a man and a circle, a woman. Relationships are shown by connecting the figures by lines. As shown below, John and Mary are a married couple.

You can place names next to the symbols so that you can more easily talk with each other informally. You could also place the person's age – or, better yet, their dates of birth – in the symbols.

Children are drawn in below their parents, with grandchildren under the children. In this way, in the example below, you see a family with three children (son, daughter, son), the oldest of which is married and has one daughter. You can also see the dotted line with this illustration. You will also find this in the Informal Care Scan form – an aid in distinguishing separate generations.



In this basic drawing you can show much more about the family: for example, who the client is: you insert 'c' in his or her figure. You can also show who was present during the interview by shading in the figures. As it becomes clear (e.g. with step 4) who is in control, you can give that person a double edge. There are also symbols that could help reflect the family history. When someone in the family has died, you can show this in the genogram by placing a cross in the figure with the date of death underneath. You can indicate a divorce by placing two diagonal stripes through the connecting line.



You should start drawing the genogram with those who are present, followed step-by-step with questions about the other family members.

Be aware that producing a genogram could evoke many recollections. You should carefully weigh listening to family stories on the one hand and completely filling in the Informal Care Scan, on the other.

The main advantage of the genogram is that you get a clear picture of the entire family at once. You can then use this to see who *does* and who *does not* provide family care. Based on this, for example, you can see how flexible the network is.

In principle, the genogram is only used for the Informal Care Scan as a simple reflection of the family. The genogram, however, has other uses. Section 3 discusses this in greater detail.

In sum:

- a square represents a man; a circle represents a woman
- a line represents a relationship: for example, a marriage or parent-child relationship
- Place names above the symbols
- Add the dates of birth / ages
- Place "c" in the symbol for client
- Shade the symbols of those present at the interview
- Add a double edge to the persons who are in control

2.3 Step 2: the nature of the care requirement

After having mapped out the family, the next step is the nature of the care requirement. 'What is the problem?' is the leading question in this section of the Informal Care Scan. Using eight specially-chosen questions, you will get a sense of the intensity, duration and future prognosis of the care requirement. The answers to the questions usually increase in intensity. By repeatedly ticking the top answer, you indicate that the care required is less intensive than when you repeatedly tick the bottom answer.

Please note: The answers to the questions do not only concern what the caregivers do, but also the total help and care required for the client. This could include things that professionals or caregivers do. This is especially important with question 1c, which asks what kind of care is being provided.

Question 1H asks how the client is doing in terms of his/her illness or disorder. There are many possible answers to this. It is particularly important, with those present, to find the right words to describe this. Try to come up with one or two keywords. Several examples: accepting it, no insight in the illness, demanding and hard to please, manipulative, in denial, flexible.

TIP

By scrutinising the answers, you will get an initial impression of the objective burden of the caregiver, for example, about the duration and intensity of the care. With the next step the emphasis is on the subjective burden. You should take both into account in the advice section!

You can describe anything that suddenly springs to mind at 'Conclusions and Advice' on the last page.

TIP

2.4 Step 3: the caregiver

Once the family structure has been mapped out and there is insight in the nature of the care requirement, the caregiver is next. This section devotes attention to a single caregiver: the person present at the interview. It is therefore important that the caregiver who does the most and knows about the care is present at the interview. Clearly indicate this caregiver (if a family member) in the genogram (with shading) and assign this person a circle in the Ecomap.

An easy way to find out in a short time how this caregiver is doing is to ask whether he or she will express the perceived pressure on a scale of 0 to 100. This is called the *self-rated-burden* (Exel et al., 2005). You can then map out the perceived pressure by asking nine questions. This method is called Perceived Pressure through Informal Care – PPIC (*de Ervaren Druk door Informele Zorg*- EDIZ, A.M. Pot, 1995). To calculate the PPIC score, you then add up all the answers. 'No!' and 'No' are assigned a value of 0; 'more or less' and 'yes and yes!', a value of 1. The score could therefore be somewhere between 0 (no pressure) and 9 (heavy pressure). You could decide to ask the questions orally or give the caregiver a sheet of paper with the questions and ask him/her to answer them.

Remember that a high score could lead to questions about the perceived pressure and a low score, to questions about sources of energy!

TIP

Sometimes it is a good idea to give the caregiver the questionnaire, so that he or she can fill in the answers themselves. Appendix 4 contains a printable version of the PPIC.

TIP

Next, if necessary, there is room to ask questions about the financial situations of those present. You should do this as openly as possible. Following this, you should ask the caregiver about their sources of energy and how much energy they expend. In this regard, bear in mind the following types of stress:

1. Time pressures (the time pressure that care provision imposes on the caregivers);
2. Development pressures (the feeling that a caregiver has that he/she is lagging behind in personal development);
3. Physical stress (the negative effect on health – on the strength and energy of the caregiver);
4. Social stress (the feeling that the caregiver is confronted with conflicting roles);
5. Emotional stress (the negative feelings of caregivers about recipients, perhaps due to unpredictable behaviour by recipients of help). (Timmermans, 2005; 18. Originally Novak & Quest, 1989).

You will find these dimensions again when you look at the questions in the PPIC. It would be a good idea to bear these various dimensions in mind during the interview: certain things could spring to mind. You can note them under 'Remarks'. These dimensions could help to identify the (main) bottlenecks -- certainly when a caregiver indicates that he or she cannot (no longer) cope with the care.

You should also mention it if the caregiver perceives sources of energy. These could be good friends or good work support. In asking the questions, try to remain open to both negative and positive experiences that a caregiver could have. Describe briefly any unusual experiences at 2c. If there is insufficient space, use the space available at 'Conclusions and Advice'.

Describe the three most important findings in the green circles of the Ecomap. There, you can also mention the bottlenecks and sources of energy. The next paragraph provides a further explanation of the Ecomap.

To obtain good insight into the bottlenecks, as well as the positive experiences, it could be instructive for the caregiver to keep a log for a short time. See appendix 1 for an example. With a goal-orientated approach, the log could be provided for a period prior to taking the Informal Care Scan, so that it would be easier to fill in the answer to question 2d. A second option would be to pass out logs when the scan is taken, while the caregiver is still struggling with the questions. Keeping a log could give the caregiver greater insight about the situation.

TIP

2.5 Step 4: Ecomap – the care network

From the above three steps you have already gathered considerable information. You have mapped out the family, the nature of the care requirement is known and there is some understanding of both the subjective and objective pressures facing the caregiver. Following that, the Informal Care Scan focuses on the network. At the same time you fill in the answers, you should also fill in the Ecomap as completely as possible. Below is a brief instruction about the Ecomap.

Ecomap

Whereas family is the central focus of the genogram, the Ecomap concentrates on the social network. The Informal Care Scan itself is concerned with the care network. With the Ecomap, the client is the centre of attention. The other members of the care network are placed in the surrounding circles. These could be family members, caregivers, neighbours, friends (former) colleagues or professionals – anyone who contributes to the care can be added. If they do not appear in the Ecomap, this would present an opportunity for questions or advice!

The Informal Care Scan has two kinds of circles. The thin blue circles concern the client's care network and the green circles with the thick edges, the bottlenecks and sources of energy of the caregiver. When the Ecomap has been filled in completely, you will have information about the client's care network, together with supplementary information about the capacity and burdens of the caregiver.

See appendix 2. It contains a description of the various characteristics of care networks. These characteristics could provide support in asking the right questions.

TIP

Questions 3A and 3B: composition and type of network.

Based on the questions about the composition of the network (3A and 3B), you can determine how to fill in the Ecomap. If care is only being given by the family, all the blue circles can be used to represent the family. If there are also professionals involved or, for example, friends who regularly provide help, you can give each of them a separate circle. You will also now know what *kind* of network it is. Tick that off on the first page.

See appendix 3. It contains descriptions of the various kinds of networks, including related risk factors. These risk factors provide leads for asking the client and caregiver questions.

TIP

Question 3C: who does what?

Depending on the composition and size of the network, you should then explore each network member or group of networkers (family/professionals) to learn what they do. Write their name or names in the appropriate circles. To indicate what they do, you should use the list of abbreviations shown with the Ecomap. That list is also used with 'Step 2, the 'nature of the care requirement'. By comparing them, you can see whether your Ecomap is complete. Place the abbreviations in the appropriate circles on the Ecomap.

> It could be interesting here to see which persons in the genogram are included or not included in the Ecomap. If relevant, you can inquire about the reasons for this. This could provide clues about the flexibility of the network. If someone cannot provide care, for example, because of long travel times, care requirements at home or at work, the network could lose flexibility. After all, one can not easily call on them for care assistance!
>
> TIP

Questions 3D and 3E: coherence and competences

The first question concerns the team work of the network. The initial question is whether there are any difficult circumstances, frustrations or conflicts. Ask specific questions with regard to frustrations and the like, to find out which people it involves. You can indicate this in the Ecomap with a dotted line. Continue asking briefly about the nature of the frustration and record it concisely in the Ecomap. You should continually bear in mind the persons in the network and ask questions about different combinations of persons: 'Does that also apply to so and so...?' In this way, you can obtain a complete picture of the network.

You then have to investigate whether there are sufficient bureaucratic skills present in the network. Do members know the arrangements and support options? Do they know how to utilise these options and, if not, where the bottlenecks lie. If possible, you should indicate on the Ecomap which members have these competences.

Network flexibility

Based on all this data, you can estimate the flexibility of the network. With light demand, a large care network and sufficient bureaucratic competences present, flexibility will be high. But, with heavy demand for care and few family caregivers, flexibility could be low. This is not about an exact score but rather an indication, so that you can already get an impression on the first page. What is important here is that you collect all information from the previous steps: family size, nature of the care requirement, perceptions of the caregiver and the rest of the network.

Here you can note anything that stands out or is told to you in the meantime that deserves attention.

2.6 Step 5: conclusions and advice

After going through all these steps, you will have a lot of information about the care situation, the caregiver(s) and the network. Based on the bottlenecks discovered, you can offer specific advice. Record that advice in writing here.

Treat the starting points of the caregiver in terms of being able to, knowing and wanting. 'Being able to' refers to any bottlenecks of the caregiver in time, development, physical, emotional or social areas. 'Knowing' refers to acquiring expertise: knowledge and skills. Lastly, 'wanting' refers to the expectations and possible future needs of the caregiver.

3 Underpinning

This section offers a further explanation of the background of the Informal Care Scan. Besides providing a further explanation of the underpinning of the instrument and the instruments used therein, it offers a deeper perspective. Following an explanation of the vision behind the instrument, the text focuses on the various components of the Informal Care Scan, with special emphasis on the genogram and the Ecomap.

3.1 Vision

The study, *Looking for Reflected Satisfaction,* by Tonkens et al. (2008) formed the starting points for the development of this Informal Care Scan. This resulted in questions about the composition of the organisation and risk factors for a care network. Besides stress, attention is also given to the possibilities and positive experiences of caregivers. An important aspect here is the competences of the members of the network. They provide an indication of the capacity of the network.

As there are many different care situations and an equal number of different types of (care) networks, it was decided to take an open approach. The Informal Care Scan is designed to map out the components: the family, care situation, the nature of the care requirement, the experiences of the caregiver and the composition and organisation of the network. It is up to the professionals to delve deeper into some components and treat others more superficially. Although this requires considerable effort on the part of professionals, it dovetails smoothly with the reality of the complexities of care networks and clinical practice.

3.2 Justification

Genogram

The genogram is an instrument that maps out the family. The Informal Care Scan only utilises the basic potential of the instrument: a simple, basic visual reflection of the family. The genogram, which is suitable for various purposes, is used in various sectors – primarily in relation and family therapy, but also in other health-care domains (Butler, 2008). Although the genogram is also used in scientific research (Neufeld & Kushner, 2009), the way in which the genogram is employed in this context is especially important in care and welfare. A simple genogram was chosen for the Informal Care Scan, intended only as an initial introduction to the family. In the professional literature, Wright & Leahey (1999) mention the use of this method, describing how hospital staff can make a sketch of the family in less than 15 minutes, so that they can estimate the extent to which the family can and will help support the client. At the same time, the genogram can be employed to describe the extensive life history of the client and of the caregivers (Royers, 2007).

The genogram can contain various data. The most important are the client's age, gender and recent changes in the family, course-of-life transitions, cultural and ethnic background and individual functioning (McGoldrick et al., 2008). The genogram is still going through a development stage – among others, because of criticism that it presents a too traditional view of the family (Rempel et al., 2007). As a result, several new variations have appeared over time in which the emphasis is on a specific theme. An example is the *gendergram* used as an instrument in therapy to distinguish gender roles (White & Tyson-Rawson, 1995). The cultural background, married couple or spirituality also became central features of specific genogram variations (Butler, 2008). Use of colours (Lewis, 1988) or a time frame (Friedman et al., 1988) was also developed to supplement the standard genogram. As a result of these developments, the number of symbols that can be used in the genogram has increased substantially. With the Informal Care Scan, therefore, a more extensive variant of the genogram could be used. Although not a requirement, professionals would benefit by learning more about this instrument.

Ecomap

An Ecomap maps out a person's social network. This instrument is also used in health care (Royers, 2007). While the genogram is limited to the family, the Ecomap devotes attention to the entire social network. It could contain friends, acquaintances, colleagues, caregivers and professionals. For the Informal Care Scan it was explicitly decided to use both instruments, because of the specific interaction between them. Since family care is mainly provided by the family (Beneken Genaamd Kolmer, 2007), the first expectation is that there will be huge overlap between the genogram and the Ecomap. The surplus value of the genogram is that it provides immediate insight in any bottlenecks for the care – e.g. when an elderly person is cared for by an adult child who has his or her own family with young children. The surplus value of an Ecomap is that it leaves room for other, close family members, who are also important for the social and care networks.

Rempel et al. (2007) therefore argue that the combination of the genogram and the Ecomap is preferable. This argument is based on their use of both instruments in the – then current – study of male caregivers in the family (Neufeld & Kushner, 2009). The argument has three underlying reasons. First, the interaction between the genogram and the Ecomap offered greater insight in social networks; second, it created opportunities for improving relations with the respondents; and finally, unused potential was discovered in the care network that would not have been found by one of the two instruments. It is interesting how the researchers have expanded the basis of the genogram and the Ecomap for their own research with relevant factors and remarks. This shows the flexibility of use of these instruments. Collaboration between researcher and respondent in composing the genogram and the Ecomap reinforces the power of both instruments. As a catalyst, the genogram and the Ecomap reinforce the interview and, with it, create detailed information about the context.

The most important thing mentioned by Rempel et al. (2007) about the use of both the genogram and the Ecomap are the results of comparing both diagrams. An example is given of a man who mainly received support for his care tasks from professionals. During the interview, he was asked how he felt about only seeing his children on special occasions and the fact that they offered him little support. It was also learned that his daughter, who lived around the corner, was excused from providing care because of her own family responsibilities and those of her job. Although this daughter did not appear on the Ecomap of the care network because of the little support that the respondent received from his daughter, the respondent was not disappointed and did not refer to a poor relationship with his daughter.

The researchers therefore used the comparison of the genogram and the Ecomap to see which members of the genogram did not appear on the Ecomap; and which information was then available on the genogram (e.g. travel time, health, death, family dynamic) that could explain this difference. In this way, one can get a more detailed picture of the family dynamic around care and shed light on potential sources of support.

The questions included

The Informal Care Scan contains several relevant questions designed to expose the nature of the care requirement. For this purpose use is made of current literature on family care (support) in which 'duration' and 'intensity' are major indicators of (over) burdening) (e.g. de Boer et al., 2009). To avoid viewing care as merely a snapshot but rather as a process (e.g. Potting, 2001; Mol, 2006), there were also questions about (near) future expectations.

To measure the subjective stress of the caregiver, use was made of two methods stemming from the research: the *self-rated burden scale* (see Exel et al., 2004) and the PPIC (Pot, 1995). The results of this scale provide leads for asking additional questions. The directions for this are in section 2.

Finally, there are questions about the composition, organisation cohesion and competences of the network from the publication by Tonkens et al. (2009).

4 Practical Experience

Reactions to the Informal Care Scan can be subdivided into three themes: the required competences of professionals, the delineation of the Informal Care Scan and the experiences of caregivers.

Professional Competences

The mapping out of a care situation can evoke many emotions. The use of a genogram and an Ecomap requires a distinct attitude on the part of the professional. On the one hand, professionals offer caregivers scope to talk about their experiences; on the other, one must not lose sight of the aim: the mapping out of the care network. The following examples show why this requires an alert attitude.

'The making of the genogram evokes many reactions. If you conduct an interview on the basis of the genogram, you can fill in most of the other items yourself. You should make sure this does not take too long: spent nearly two hours with a caregiver for the scan; she was so happy that she finally had an opportunity to get it all out in the open!'

'The other caregivers present think that they have to fill in too many forms. For this reason, I am separating it into visits.'

'Making the genogram is a nice way to get a picture of the origins of the caregiver. However, in practice, this family tree does not always end up in the care network. Discussing it – especially as a first question – could evoke many emotions or concealed distress /topics of conversation. It is important to allow sufficient time for this and to gain insight in the distillation of things related to the care situation of the moment. It requires interviewing skills to set priorities, where necessary, and to avoid straying from the confines of the interview.'

Delineation

There are various ways to use the Informal Care Scan. Some professionals might find it a useful guideline by means of which the steps described in section 2 are followed meticulously. With this kind of approach, the steps provide a certain structure. Other professionals do not necessarily stick to a strict sequence, but allow the situation to serve as a guide. The Informal Care Scan, which is then employed to assign a place to all the information obtained, could serve as a kind of 'checklist' to make sure that nothing is forgotten. With this approach, no information will be lost because the Informal Care Scan form provides structure.

'I notice that I am not following a strict sequence (the questions), but am getting more coherence. The instrument helps me not to forget anything.'

It would be a good idea to stop and think about how the Informal Care Scan will be used. The example below shows that following the steps in strict sequence proved to be too intensive:

'In my view, the Informal Care Scan is a less useful instrument for intake because it can be intensive and intimate in discussing everything so explicitly. People have to be able and willing to "look at themselves and the whole system". If (potential) overburdening or an acute problem is the reason for seeking contact, the Informal Care Scan demands considerable time and attention. The caregiver could get the impression that one is not listening to the real (initial) care requirement.'

In such cases, the Informal Care Scan form could be useful in preparing the report. The unanswered questions could be repeated at a later stage to gain full insight into the situation.

Experiences of caregivers

The experiences of the caregivers themselves are positive. Professionals who use the Informal Care Scan indicate that the instrument contributes to the creation of a basis for trust, helping caregivers to reflect on and make them more aware of the situation:

"All informal carers enjoyed the conversation, you establish a bond especially when talking about the genogram."

1 With several other organisations, the Univé-VGZ-IZA-Trias care offices have provided caregiver-aid passes and caregiver-aid maps to caregivers in the Tilburg (Netherlands) region. They can note their names and telephone numbers on the passes of their replacements, in case they should suddenly be indisposed. This initiative opens up the discussion about care and helps to organise an emergency backup. (Source: *De klant aan het roer 2012. Visie op langdurige zorg*)

'The caregiver was extremely positive, aware of her own key role in this family-care network: if she were to drop out, it would leave a huge gap in the care required. In the Dutch province of Brabant, they issued family-care passes[1]. She also had one, but not with her. She planned to keep it in her purse in future.'

'The caregivers on whom I performed the Informal Care Scan were very enthusiastic about the benefits you can obtain by using it. Because everything gets written down, the picture of the situation becomes increasingly clear. The Informal Care Scan contributes to an awareness and insight into the way in which care and family care work in practice and where attention or improvement is needed. By clarifying the care situation, it is easier to establish links. All caregivers found the interview very enjoyable, although occasionally intensive and emotional.'

Finally, a comment from a client:

In general, I think the Informal Care Scan is a good aid for mapping out the situation. 'My' caregivers enjoyed the experience.

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Appendix 1 - Log

What are my sources of energy?	Day 1	How do I use energy?

What are my sources of energy?	Day 2	How do I use energy?

What are my sources of energy?	Day 3	How do I use energy?

What are my sources of energy? **Day 4** How do I use energy?

What are my sources of energy? **Day 5** How do I use energy?

What are my sources of energy? **Day 6** How do I use energy?

What are my sources of energy? **Day 7** How do I use energy?

Appendix 2 - Network Characteristics

	SCALE AND TYPE	GUIDANCE	NATURE OF CARE REQUIREMENT	COHESION	COMPETENCES	FRAMING
Characteristic	**Who are the members of the network?**	**Who is the central caregiver?**	**What is the care requirement?**	**What are the relationships?**	**How competent is the caregiver?**	**What does the caregiver feel/ think?**
Explanation	Scale and composition, for example, affect the stability of the network. This is a crucial factor in arranging the typology. A family network, for example, is mainly comprised of close family members.	The function of the central caregiver is to coordinate network activities. The central caregiver looks after compilation of the rosters, applications for extra care and coordination among the various other caregivers. There are also pivotal caregivers who are the only caregiver. In the typology this should be referred to as an isolated or frustrated pivotal caregiver.	The nature of the care requirement is crucial for the burden of the network and, as a result, for the willingness to persevere, for example. • Intensive day and night care is easier to provide for a shorter period (for example, for a dying patient) than if it is needed for many years. • Family care for someone in an institution requires different activities than for a home patient.	Although existing relations could be strong and reliable, they could also have patterns that are complex and difficult to break through. A network of family members in a strong family culture has a different dynamic than a network of unrelated caregivers, friends and professionals. A network with loose relations is more flexible, but requires extra guidance from the pivotal caregiver. The cultural context of the network has a major impact on the perceptions (framing) of the family-care members.	A pivotal caregiver must possess a wide range of seemingly conflicting competences: • Business-like and firm towards professional care organisations • Appreciative and motivating towards caregivers and caregivers. • Flexibly defending his or her own limits and interests towards the patient and caregivers For migrant family care networks, linguistic skills are an extra point of attention. The bureaucratic language of decisions and forms often place too high demands on non-migrant caregivers.	The way in which the caregivers view their own efforts is crucial for the perception. • Is there a certain perceived degree of free choice? • How does one view alternative care solutions (calling in professionals or admittance to an institution)? In the Tonkens typology this is a decisive factor for *reflected satisfaction.* High expectations regarding (entitlement to) professional help could result in frustration and social resentment. A culture with strong family values (as is the case in many migrant families) makes it difficult to accept outside help.
Effect	Strength in numbers	The central caregiver has a greater risk of becoming overburdened.	The longer and more intensive a disorder, the more demanding the family care.	Lack of cohesion inhibits coordination. Very close ties makes it difficult to set limits and refuse requests.	The more competences, the more capable the network is in arranging the help.	The perception of the care is relevant for the burden-bearing capacity. See the Reflected Satisfaction Meter.

SCALE AND TYPE	GUIDANCE	NATURE OF CARE REQUIREMENT	COHESION	COMPETENCES	FRAMING
Who are the members?	Who is the central caregiver?	What is the care requirement?	What are the relationships?	How competent is the caregiver?	What does the caregiver feel/think?
Partner / close family member	Patient	**Care location** • Extramural • Temporarily intramural • Permanently intramural	**Density** • Members already knew each other • Members know each other as part of the network • Members do not or hardly know each other • Sundry	**Bureaucratic skills** • Is familiar with the arrangements • Makes use of the arrangements • Assertive towards institutions	**About the obligation** • I think this is the right thing to do • My surroundings think this is the right thing to do • In this way, you do not bother others • I enjoy doing this • I enjoy doing this and get something in return
Extended family	Central figure	**Duration** • Weeks • Months • Years • Endless			
Neighbour-hood / friends	Isolated pivotal caregiver	**Degree of dependency** • Treatments • Day care • Night care		**Social skills** • Can handle the patient • Coordinates network members • Motivates network members	**About the options** • I do this voluntarily and can stop at any time • I cannot stop • I feel entrapped
Caregivers	Professional	**Progression** • Recuperating • Stable • Progressive • Terminal	**Relations** • Possible to discuss difficult subjects • Difficult subjects are avoided • Protracted conflicts and frustrations		**Appreciation** • It is bearable / unbearable • I am appreciated • I am not appreciated • C'est la vie • It's wrong
The attending caregiver				**Linguistic skills** • Linguistic network • Language of professional care • Bureaucratic jargon	
Attending care provider	Nobody	**Patient's attitude** • Passive • In control • Flexible • Demanding			**About paid care** • Professional care is an entitlement • You do as much as you can yourself • If you need professional care, you are not doing a good job

Appendix 3 - Types of Family care Networks

Research has revealed the existence of four frequently occurring types of networks with significant, similar characteristics ('Op zoek naar weerkaatst plezier' - Tonkens, van den Broeke and Hoijtink, 2008). This page contains descriptions of these four types of networks. Each network type has its own specific strengths and risk factors of which you as a provider of support should be aware.

Family network

Several, usually female caregivers care for and are supported by other family members. Although professionals are called in occasionally, their help is generally supplemental. In family networks the dominant starting point is, 'We look after each other'. In practice, 'we' are mainly women. One or more women provide much care and are therefore the central caregivers. They receive support from other women and, sometimes – to a limited extent – also from men in the family. Migrant clients, especially, have many family networks. Morever, many migrant networks perceive professional care as inferior to family care: family care is best. Only if this is no longer possible, it then becomes necessary to get assistance from professionals. Sometimes this cooperation goes well; sometimes, not. It goes well when professionals recognise the importance of -- and provide leeway for family care. Families are not always interested in cooperating.

Crucial characteristics
This network consists of multiple family members motivated by their social networks or their own values.

How does one view the care?
- We look after each other: intergenerational perception (I look after my mother; compared to my mother, the care I give is not a burden)
- You only ask for professional help in the last instance.

Strengths
Care is a joint activity. Family members provide care as long as possible; but such care is not limitless. When it is no longer feasible, professional help is called in.

Risks
Problems could arise when the client or caregiver does not want professional help, even though it is necessary. If the central caregiver continues to become more isolated from the outside world because of the work pressures, the family network changes into an isolated pivotal care network.

Mixed network

A diverse network in which family caregivers, professionals and non-family caregivers work together. Unexpected developments can be dealt with flexibly. The care is fairly evenly distributed between family caregivers, professioinals and any non-family caregivers. There is a single central person who is in charge, who oversees the care and coordinates everything. This is usually the central caregiver, but it could also be the client. Because of this balanced teamwork, the care for the client is properly arranged. Family caregivers, any non-family caregivers and professional care providers complement one another.

The pivotal caregiver in this network fulfills two different functions: flexible and friendly towards caregivers; firm towards authorities (Janus face).

Crucial characteristics
The people in this network have different relationships with the client (family, friends, caregivers, professionals). There is a central pivotal caregiver.

How does one view the care?
- You are entitled to care. Caregivers and clients are obviously the authority when it comes to the design and content of the care. When necessary, you call in professional help.
- As a member of the family, you do not have an obligation to provide care. Care from neighbours and friends is a favour, which could be repaid by offering a favour in return.

Strengths
Sound network in which unexpected occurrences can be dealt with flexibly. Low risk of stress.

Risks
Competition between caregivers. Higher staff turnover inhibits reflected satisfaction. Caregivers who do not defend their own interests could become overburdened. Organisational tasks could require too much of the central caregiver's time, resulting in less work or even stopping with work prematurely.

Professional network

There is a clear separation of tasks between caregivers and professionals. Professionals perform tasks that caregivers cannot or do not want to do, such as washing patients or other intimate actions. In this network considerable family care is given as part of a division of such tasks. Caregivers often see the providing of emotional support as one of their specific responsibilities, instead of spending time and energy on tasks at the expense of this, which professionals can do better. Professionals play an important role: they are in charge, not the caregivers or the clients. Caregivers expect professionals to arrange the cohesion, cooperation and coordination.

Crucial characteristics
This network depends heavily on professional care providers. They are in charge. Caregivers do supplementary work. One often sees this type of network when the client has been admitted to a care institution.

How does one view the care?
- **Non-migrant:** You are entitled to professional care. It is the responsibility of the government to provide this. Some care, such as washing, cleaning and nursing should be provided by professionals, not by caregivers.
- **Migrant:** Specialist (medical) help should be provided by professionals. When a family network becomes a professional network, there could be a sense of failure about having outsourced this work.

Strengths
Leeway for reflected satisfaction. Caregivers can focus well on emotional support of clients without any worries about arranging or coordinating things. A low risk of stress.

Risks
When no one is in charge, this could be at the expense of the care given to the client. Committed caregivers could feel an obligation to stay, even though it is too demanding.

When professionals do not provide leeway for migrant families, the result is mis-communication and frustration. The family can miss out on certain arrangements because of a lack of information, resulting in (an unnecessary) financial burden.

One-person (isolated) pivotal care network

A care network with one person who provides all the family care, possibly supplemented by a professional practictioner. Clients in isolated pivotal care networks often prefer it to be this way. It usually consists of one non-migrant man or a migrant woman. At an earlier stage, isolated pivotal care networks were often family networks.

When there are conflicts with professionals, a mixed network can change into a disappointing pivotal care network. Confidence in the government and care institutions is gone. Family networks can change into isolated pivotal care networks when the family places care responsibilities with a single caregiver and offers less and less support.

Crucial characteristics
This network is not actually a network, but rather a solo taks performed by a close relative who provides all the family care. There is a greater risk of stress for caregivers in pivotal care networks than in other types of networks.

How does one view the care?
- Non-migrant: We can handle the care ourselves. You do not talk with others about care. You do not burden your neighbours or friends. Migrant: A good woman looks after her husband. You obey your parents / husband. Fear of gossip.
- Strengths
- If care in non-migrant pivotal care networks is not too intensive, it can give satisfaction and contribute to the intimacy of the relationship.

Risks
Isolation and overburdening of caregivers that go unnoticed by professionals, so that no solution is forthcoming.
Risks, non-migrant: Serious frustration and disappointment could occur if, according to the caregiver's conviction, the entitlements that people have to professional care by institutions and government are repeatedly not observed.
Risks, migrant: Family care is primary the woman's responsibility. As a result, this increases the unequal position of women.

	MIXED NETWORKS	FAMILY NETWORKS
Risks	• If they are not aware of their own limits, caregivers could become overburdened. • Central caregiver tasks could cost so much time that the caregiver works less or stops prematurely. • High staff turnover could impede reflected satisfaction. • Those concerned could experience competition.	• Overburdening is a threat when the client's health deteriorates, or when a crisis develops and the caregiver or the client refuses professional help. (If the client refuses assistance, the entire care network becomes isolated). • If one is not familiar with the available (financial) resources, this could result in an unnecessary burden.
Please note	• Is the caregiver aware of his or her own limits? • Is it possible to combine the central caregiver tasks with paid work? • Is there stability or are there always too many new faces? • Do they regularly discuss the division of tasks? Is everyone involved satisfied?	• Is professional help called in on time when a crisis threatens to develop? • Are the persons in the network sufficiently informed about the available (financial) and support arrangements and possibilities?
Support for overburdened networks	• A care organiser could help the network to get back on track. • A network meeting could add balance, foster appreciation and improve communication.	• Show appreciation and recognition; make contact by being a good listener. • Then discuss the possibilities of supplementary professional care. • Offer help in getting professional care. • Offer help in obtaining support or (financial) arrangements.
Support for non-overburdened networks	• Give recognition and show appreciation. • This network arranges everything by responding to the direct care requirement.	• Find out whether there is sufficient knowledge within the network of support possibilities and (financial) arrangements and indicate here how these could be applied for (perhaps in the future). Remember that, within the network, there could be a lack of fairly basic knowledge and information. • Give recognition and show appreciation.

	PROFESSIONAL NETWORKS	ISOLATED PIVOTAL CARE NETWORKS
Risks	• When no one is in charge, this could be at the expense of the client's care. • Poor communication with professionals could be frustrating. • High staff turnover impedes reflected satisfaction. • If one is not aware of which (financial) support possibilities there are, it could be an unnecessary burden. • Risk of the caregivers' trap	• High risk of being overburdened! • Isolation and overburdening of the pivotal caregiver that goes unnoticed by professionals, so that no solution is forthcoming. • Protracted overburdening could ultimately result in 'dropping out'.
Please note	• Is anyone in charge of this care network? • Is there good communication with the professionals? Is everyone satisfied? • Is everyone in the network sufficiently informed of any (financial) support arrangements and possibilities? • Do caregivers experience reflected satisfaction? • Is there good communication in the network?	• Offering support is a sensitive issue! • Has there ever been professional care in this network? How did it go and how did it end? • Is there good contact with the general practitioner? Does the relationship with the practitioner offer a means of getting help when the pivotal caregiver needs support? • Is there a care organiser in the network?
Support for overburdened networks	• Help the network by getting a care organiser (or personal counsellor). • Network meetings could help add balance, foster appreciation, improve communication and prevent the caregivers' trap. • Help prevent the repeated appearance of new faces.	• Recognition and appreciation: Many pivotal caregivers long for recognition and appreciation. They will not easily ask for help and support. Once there is contact, help in the household or relief care could be offered cautiously. Take care that it does not come across as insulting or threatening. • Offer help in getting professional care. • Offer help in obtaining support or (financial) arrangements. • Dinner, excursions, etc. • Offer help in joining a caregiver's support group: influencing policy could have a positive effect on the pivotal caregiver's peace of mind. • Offer to help the pivotal caregiver develop good contacts with the professionals concerned. • Limit the number of new faces. • Help the pivotal caregiver by finding a care organiser.
Support for non-overburdened networks	• Give recognition and show appreciation; respond to the initial care requirement.	• Keep an eye on things through periodic contacts. • If desired, offer help in finding a caregiver. • Point out the possibilities of support or (financial) arrangements.

Appendix 4 - Perceived Pressure through Informal Care (EDIZ)

Developed by Dr Anne Margriet Pot (1995). Always mention the correct sources when using this questionnaire.

Instruction

Below are several statements. With each statement, you should indicate to what extent it applies to you personally. You can choose any of the following answers.

○ No! ○ No ○ More or less ○ Yes ○ Yes!

If a statement applies perfectly to you, you should circle the word 'Yes!' If a statement does not apply to you at all, you should circle the word 'No!' Or something in between.

Statements

1. Because of my ...'s situation, I don't have much time for a social life	○ No! ○ No ○ More or less ○ Yes ○ Yes!
2. The responsibility for my ..., combined with my work and/or my family, is not easy	○ No! ○ No ○ More or less ○ Yes ○ Yes!
3. Because of my involvement with my ..., others suffer	○ No! ○ No ○ More or less ○ Yes ○ Yes!
4. I am always at the beck and call of my ...	○ No! ○ No ○ More or less ○ Yes ○ Yes!
5. My independence is compromised	○ No! ○ No ○ More or less ○ Yes ○ Yes!
6. The situation of my ... constantly demands my attention	○ No! ○ No ○ More or less ○ Yes ○ Yes!
7. Because of the involvement with my ..., there are conflicts at home and/or at my work	○ No! ○ No ○ More or less ○ Yes ○ Yes!
8. The situation of my ..., keeps haunting me	○ No! ○ No ○ More or less ○ Yes ○ Yes!
9. In general, I feel a lot of pressure as a result of the situation of my...	○ No! ○ No ○ More or less ○ Yes ○ Yes!

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