

# INTEGRATING KNOWLEDGE ACROSS DISCIPLINES: A CASE STUDY FROM HEART TRANSPLANTATION

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## Session D-1

### Abstract

In this paper, we address the following research question: "How is coordination between multiple disciplines achieved in the heart transplant process?" Based on a case study conducted over a period of two years in a Norwegian hospital on the creation and use of the waiting list for heart transplantation, the paper contributes to the current discussion on knowledge sharing in cross-disciplinary collaborations. Drawing upon the concept of fluid object, the paper analyses the multiple identities of the waiting list and contributes to the understanding of object-centered processes of collaboration.

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**Suggested track:** D Knowledge sharing

## 1 Introduction

In recent years, there has been an emergent literature on interdisciplinary collaboration mainly based on the notion of communities of practice (Brown and Duguid, 1991). The notion of social learning systems has been developed by Wenger to understand how learning takes place among a number of related communities of practice (Wenger, 2000). Still, Wenger’s focus is on learning processes within each community and how they get transferred from one community to another. An alternative perspective on work within communities is proposed by the notion of epistemic cultures (Knorr-Cetina, 1999). Knorr-Cetina turns the focus from practice to machinery of knowledge production. However, she does not apply her perspective to cross-disciplinary collaboration. We think that a more thorough understanding of cross-disciplinary collaboration is needed. It is important to unfold modes of cross-disciplinary collaboration that sustain the integration and coordination of knowledge production and use, i.e. knowledge sharing.

Theoretically, the research builds on concepts elaborated to understand processes of collaboration across multiple heterogeneous contexts such as boundary object (Star, 1989), standardized packages (Fujimura, 1986, 1992, 1996), and a perspective on standards as gateways (Hanseth, 2001). Knowledge is here conceptualized as emerging from a historical, local and material context. Work of production and a network of heterogeneous elements allow knowledge to emerge and exist (Knorr-Cetina, 1999; Fujimura, 1987).

Empirically, the investigation focuses on the interactions between participants involved in the heart transplantation trajectory. In particular, the main research question addressed is the following:

*How is coordination between multiple disciplines achieved in the heart transplantation process?*

In particular, we approached the research question by studying the creation, handling and use of the Norwegian Waiting List (WL) for heart transplantation as standardized representation of the process itself. This leads us to focus on the micro-level dynamics of use of the WL, and on how the WL fits into the work ecology of the transplantation process. As it turned out, this detailed focus led us to uncover a multipurpose use of the WL and to unveil its fluid nature.

In this paper, we look at a disease trajectory, namely the one leading to heart transplantation. A trajectory is here conceptualized as proposed by Strauss who refers the term not only to the “physiological unfolding of a patient’s disease, but to the total *organization of work* done over that course, plus the *impact* on those involved with that work and its organization” (Strauss et al., 1985:8). The trajectory of a complex and chronic disease as a severe heart failure crosses various disciplines within the medical domain. Each discipline proposes its own lines of research and treatment, unit of analysis, representation of data, research materials, scales of time and space, agenda, concerns, responsibilities and conventions. Yet, the need to cooperate and collaborate is paramount.

Our case study points at complexities and challenges of interdisciplinary collaboration in the medical context. Over the past 20 years heart transplantation has developed from an experimental procedure to an accepted mode of therapy for treatment of patients with advanced heart failure. Long term survival once precluded by lack of immunosuppressive agents and the inability to diagnose rejection at an early stage is now fundamentally improved (Schofield and Corris, 1998). Intra-operative and post-operative patient management have been advanced by developments of new techniques and methodologies. As result, the heart transplantation process/problem is

distributed among different worlds of practice where work of medical professionals is intermingled: cardiologists, surgeons, transplant coordinators and others share management duties and responsibilities for this population of patients.

The paper is structured as follows. We will first provide a description of key concepts dealing with cross-disciplinary collaboration. Secondly, we will describe the methodological approach and provide a description of the research setting. Thirdly, we will provide an account of the case describing first the patient trajectory, then the waiting list as a shared artifact. Subsequently, the role of the list for the multiple actors will be analyzed and findings discussed. Finally, conclusions will be drawn and suggestion for further research will be given.

## **2 Theory: on liaison of ensembles**

In order to analyse cross-disciplinary collaborations, we need analytic concepts that help to disclose the nature of collaboration among several intersecting communities, and to identify object centred practices of collaboration. The concepts presented here are drawn from science and technology studies literature, and in particular from the work of Star and Fujimura (e.g. Bowker and Star, 1999; Fujimura, 1988; 1996). Moreover, the concept of gateway is described and the role of gateways for integration discussed (Hanseth, 2001).

One approach to the understanding of complex sets of arrangements between two or more communities proposes the concept of Boundary Object (BO). BOs are abstract or concrete objects which facilitate the coordination efforts of members of different social worlds. They are “plastic enough to adapt to local needs and the constraints of the several parties employing them, yet are robust enough to maintain a common identity across sites” (Star and Griesemer, 1989: 393). According to Star, BOs share two main qualities: ambiguity of meaning across communities and durability in time as a set of working arrangements.

The notion of BO has similarities to the role of standards, and in particular with the concept of gateways (Hanseth, 2001). According to Bowker and Star when objects are naturalised in more than one world they are not boundary objects, but rather they become standards within and across the multiple worlds in which they are naturalised. They also argue that BOs offer a much richer approach to the understanding of heterogeneity, and claim that “standards do not remain standards for very long, and that one person’s standard is another’s confusion and mess” (Bowker and Star, 1999: 293).

With reference to the development and evolution of large infrastructures, Hanseth argues that gateways are as important as standards in integrating separate different systems (Hanseth, 2001). Gateways work as translator devices which allow different elements to communicate. In general terms, gateways can be defined as a link between different elements: they may allow communication and connection, and as second effect the continued existence of parallel networks, where the one does not need to change and adapt to the other necessarily (David and Bunn, 1988). In this way, multiple local or internal standards can continue to co-exist.

A more comprehensive concept, that of standardized packages, is proposed by Fujimura in her study on how collective action is managed across social worlds in the context of cancer research (Fujimura, 1988). The problem of cancer research is distributed among different worlds of practice which cooperate by means of a combined package of new scientific theory and new specific standardized technologies. Thus, several boundary objects are combined with standardized methods. Fujimura emphasizes how in the standardized package the combination of theory and methods contributes to create both collective action and facts stabilization in a way that “such co-definition and co-restriction narrows the range of possible actions and practices but does not entirely define them” (Fujimura, 1992: 169)

The concepts presented have been applied to the understanding of cases characterized by communication among communities and across boundaries. These concepts will help us in our analysis to unfold the waiting list and the practices involved in its production and use. They will help us to point at the peculiarities of the waiting list, and at the same time to conceptualize the artefact as having multiple identities. The aim is to discuss issues related to the complexity of the heart transplantation process.

### **3 Research methods and research setting**

The empirical material comes from an interpretive case study on the heart transplantation process, and is set at the only hospital in Norway performing transplantations. The case is part of an ongoing research project which started in January 2002 and ended in September 2003 and includes 4 periods of ethnographic inspired fieldwork each lasting two months and including 10 semi-structured interviews each lasting about one hour. Furthermore, 18 hours of participative observation of daily work at the cardiology ward, and of specialized examinations have been conducted focusing on work practices, handling of documents, information flows. Finally, 6 hours have been spent reading and analyzing the paper and electronic record of a heart transplanted patient and retracing the temporal order of episodes, hospitalizations and

examinations. This patient has also been interviewed. The interviews have been taped and transcribed. In the interviews, different professions have been considered as senior physicians, physicians, nurses, and lab technicians that are not directly involved with the patients. Moreover, internal documentation on the heart transplantation procedure and guidelines for nurses has been read and analysed, together with articles from specialised journal publications.

The data have been collected with the aim of gathering information on how the actors involved in the process work with epistemic abstractions or practical problems; how they manage patients, blood samples, data or organs; how they read the same waiting list; how they relate to the waiting list; how the waiting list is part of their work.

The field research has been conducted at the Norwegian National Hospital (NNH) which is the second largest in Norway, serving a population of about 1.5 million. NNH has mainly four highly specialized functions: organ transplantation, bone marrow transplantation, specialized heart surgery in children, and specialized neuro-surgery. NNH is amongst the hospitals performing the highest number of transplantation per citizen in the world: 26 patients had heart transplants in 2002, and 45 in 2003, that means almost one heart transplant a week (Vollebæk, 2004). Today, the survival rate is 90% after one year, and 70% after five years. Without the surgery, those patients would have not lived more than 6 months to one year (Dommerud, 2004). In 2003, the average waiting time has been of 0,7 months, with a minimum of 0 months and a maximum of 17 months. NNH does not have a unit or department dedicated to transplantation, but the process is geographically distributed. Heart transplantation involves personnel and facilities from different clinics, laboratories, and institutes.

#### **4 Patient trajectory**

The path toward a transplantation surgery is a long and diversified evaluative period and several processes run in parallel. Usually the following stages are involved:

1. Initial referral for a heart transplantation;
2. Evaluation;
3. Waiting period;
4. Transplant surgery;
5. Immediate post-operative recovery;
6. Long term follow up;

For the patient, it usually starts when a critical episode takes place e.g. a heart attack, and a heart failure is diagnosed. The first part of the evaluation is performed in district hospitals. If at the district hospital a severe heart failure is diagnosed and the patient is

considered a possible candidate for transplantation, a referral letter is submitted to the department of cardiology at NNH. The referral letter may also be sent together with exam results e.g. angiography. At NNH, the cardiologist evaluates the letter, and if necessary makes a priority for a formal pre-transplant evaluation. The pre-transplant evaluation includes a comprehensive history and physical examination. This process is organized by the transplant coordinators at the cardiology department, and it involves the work of several departments and laboratories. The examinations are very diversified and specifically consist of the hematological and chemical analysis of blood; urine-analysis for protein and creatinine; chest x-ray; pulmonary function tests; malignancy screening; cardiovascular evaluation, which consists of electrocardiogram ECG, echocardiogram, right heart catheterization evaluating pulmonary vascular resistance (PVR), left heart catheterization evaluating coronary artery and bypass patency, and cardiopulmonary stress testing; serologic screening, which consists of ABO/Rho, human immunodeficiency virus (HIV), hepatitis, cytomegalovirus (CMV) herpes simplex, tuberculosis; and immunologic evaluation. In order for the patient to be a possible candidate for a heart transplant, the responses from all examinations and tests should picture a health status that is defined as being "sick enough and healthy enough". In other words, if the patient is too healthy there may be alternative treatments as for instance drug treatments or implantation of a defibrillator or conventional heart surgeries, and transplantation may be postponed or even not necessary; in the other case, if the patient is too sick maybe other treatments are needed before transplantation or the transplantation will never take place. The timing for transplantation may be very difficult for some patients. In both cases, the patient is sent back to the district hospital.

The final decision to accept a patient for transplantation is taken during an interdisciplinary meeting, called heart meeting. The meeting is dedicated to discuss the status of every patient hospitalised in cardiology and a team of doctors both from cardiology and from surgery participate. They evaluate if the patient is a good candidate, a reasonable candidate or a marginal candidate for transplant. All information resulting from examinations are collected and discussed. At this point, the data are distributed in several sources: the electronic patient record (EPR) which is a text system storing notes from nurses and physicians; the radiology information system (RIS) which stores textual reports from radiological examinations, the picture archive system (PACS), as well as EchoPac and CardiacCat, which are two specialised systems for specific heart examinations with the ability to store images and video, the laboratory information system (EROS), plus information from Immunology and

Pathology. Beside the physiological status of the patient, reports from psychological evaluations are also provided. The team bases their decision on experience and on knowledge of prognostic indicators, and tries to accept cases that are not too critical. At the same time, they have the responsibility to try to include sicker patients and apply experience to new methods and new cases. In view of the limited availability of donor organs, other treatment options are always considered. The selection of appropriate patients for cardiac transplantation is a major factor in determining the long-term survival of those patients.

When clinicians decide to accept a patient as candidate they fill a paper-form, and send it via internal mail to the Institute for Immunology (IMMI). On the form, clinicians state the patient's identity, and part of the data that should appear on the waiting list e.g. weight, high, main diagnosis, and if there are special aspects which should be taken into consideration. The role of IMMI is to collect the data from this form, and enter it in an information system called HLA-Lab. In the next section, we will give a detailed description of the procedures at IMMI and of the information systems in use. The waiting list (hereafter denoted WL) is printed at IMMI and distributed to surgeons and transplant coordinators via internal mail. Once patients have completed the pre-transplant evaluation, and are accepted, they are placed onto the WL. The waiting period should not be regarded as a static period and patients need to be seen regularly, and appropriate adjustments need to be made to their medical treatments. A contact nurse is assigned to provide information and help during waiting time. Visits for control are requested every three months to closely monitor pre-existing contraindications to transplantation as worsening of these may deny the patient a new heart. Controls with the GP are also required.

When a donor is available, the harvesting procedure is performed by a team of doctors and surgical transplant coordinators, who go to the donor's hospital and come back to NNH with the organs. The maximum ischemic time for hearts is four hours: this is the time limit from when the heart is explanted from the donor until is placed in the recipient. The shortage of time makes it important for practical details related to patient's travelling are set in advance: the transplant coordinators in surgery are in charge of this task. Once an organ is accepted as a donor-organ, the surgeon on duty matches the data from the donor to the one appropriate recipient from the list. Subsequently, the recipient is notified and asked to come to the hospital as soon as possible, and the pre-operative procedure starts. Reasons for unacceptability of organs may be medical, or related to logistics, or to the fact that the donor is too sick and



unstable and organ preservation and harvesting is impossible, or that some disease is found during the exams or organ harvesting.

During the surgery, simply described, the diseased native heart is explanted. The initial hospitalization for the transplanted patient is approximately of 3-4 weeks. In the early post-operative period, the patient is in the Intensive Care Unit (ICU) of the surgical department. Here, priorities concern the delicate balance of preventing rejection and preventing the serious consequences of immunosuppression. The length of the time period spent in ICU depends on how the new heart is functioning and on possible complications that may arise, for instance viral infections. Then the patient is moved to cardiology.

Once discharged from the hospital, patients keep receiving an intensive physical therapy: careful and frequent follow-up is required to monitor their health and improve their quality of life. First, for two months, patients undergo weekly heart biopsies and screening for complications of immunosuppressive drug therapy. After this period, there are controls every six months, after this, every year if there are no particular problems. Controls take place more seldom over time, but they are regular for the rest of the patient's life. A number of conditions associated with heart transplantation may have a negative impact on recipients over time such as hypertension, renal dysfunction and diabetes. The patient then goes to local hospitals for routine controls more often so to limit the need for travelling. After the patient leaves the hospital, the contact with transplant coordinator is still constant over time.

## **5 The Heart Transplantation waiting list**

The waiting list for heart transplantation is a paper printout containing data on patients that are possible recipients for new hearts. It is used by clinicians when they need to decide whether a recipient is eligible for an available organ, and consequently if transplantation surgery can be performed. The list is structured in a way that can be consulted quickly so to support an effective decision making process. Data for each patient are displayed in four lines. The information contained for each patient in the waiting list (see table 1 for a schematized representation of single patient data on the WL) can be grouped five areas, specifically:

1. patient ID
2. cardiologic clinical information
3. immunology information
4. location of the patient
5. patient's contact data

**Table 1:** patient's data on the waiting list

(Name)	P.Nr:___	Adr:_____	Tlf-priv:___	arbeid:___	Sc.nr:___				
H:_	V:_	PVR:___	dato:___	TLC:___	Tidl.thoraxkir: ___	Txnr:___	mobil:___	søker:___	Påmeldt:___
ABO:___	HLA:_____	CMV:___	Transf:___	Sv.skap:___	Tidl.møtt:___				
ScrT:_____	ScrE:___	I:___	II:___	_____	Siste serum:_____	Mrk:_____			

The first area contains the patient's name and social security number (*P. nr.*). The second concerns cardiac clinical information: the diagnosis (*Mrk*); the Pulmonary Vascular Resistance (*PVR*); information about anatomy that is if there have been previous thoracic surgeries (*Tidl.thoraxkir*), if this is the first transplantation (*Txnr*) and if there are congenital malformations; morph-metrical information as weight and height. The third area concerns information as ABO blood type (*ABO*), PRA antibodies (*HLA*), virology information (*CMV*), if there have been previous transfusions (*Transf*), pregnancies (*Sv.Skap*) or other remarks (*Tidl.møtt*). Further, results from screenings (*ScrT*; *ScrE*) and the date when the last serum was taken (*Siste Serum*). The fourth area concerns information on where the patient is located with addresses (*Adr*), and the fifth one provides information on how to find the patient, phone numbers private (*Tlf-priv*), mobile (*Mobil*), beeper (*søker*) and at work (*arbeid*). It also shows the date the patient has been accepted to the list (*Påmeldt*). The types of information provided in the list have been selected by experience over the years. The form as it is has been revised a few times, but with minor changes.

The waiting list has a first part for "active" patients, and a second for patients that are temporarily withdrawn. It is important that even if withdrawn their names are shown on the list to have a complete overview of the recipients status. Those who are permanently withdrawn are not displayed.

The waiting list is updated, printed out every week and distributed via internal mail to surgeons, cardiologists, pulmonologists (because it is a combined heart and lung waiting list) and to the transplant coordinators both in the surgical and cardiology department.

In the next sub-sections, actors directly and indirectly involved in the production and use of the waiting list are presented, and their work described. The aim is to describe practices related to the creation, management and use of the WL for heart

transplantation and the dimensions considered are direct versus indirect use, provision of data, direct versus indirect relation with the patient, participation in the heart meeting, and mode of updating information. Main actors considered are the Institute for Immunology and the Institute of Microbiology, the department of thoracic surgery and in particular the surgeon performing transplantation and the transplant coordinators, the department of cardiology and in particular the head physician and the transplant coordinators.

### **5.1 Collecting data: the role of the Institute of Immunology**

Several actors participate in the process of data production for the list. IMMI has the task to collect all data and create the list.

When at the heart meeting it is decided that a patient should be accepted on the list, a paper form is filled and sent to IMMI. The form is a combined schema for heart and lung and contains a large part of the data that are then to be shown on the list. The form shows name and social security number of the patient, address and phone numbers. This information is provided by the transplant coordinators at cardiology who are meeting the patient when he first comes to the hospital for the evaluation period. There are three transplant coordinators with different tasks: one is dedicated to meet the patients when they come to the department for their control and to inform candidate recipients about the implications of having transplantation. A second one administrate the cardiology unit setting everyday programs and planning controls and visits. A third one is dedicated to administrative tasks as for instance registering the patient registration paper form in PIMS, the patient information management system, or sending letters to patients when they are called in for visits and controls. The personal data are then retrieved and added to the form for the WL. Besides private phone numbers, the form also shows the patient beeper number: once a patient is accepted to the WL, he/she receives a beeper that allows the hospital to contact him everywhere at any time of day and night. Next, the form shows which organ is going to be transplanted: if it is heart or heart and lung combined, single or double lung.

Then, the diagnosis is provided in form of a code. The code system is explained at the bottom of the same paper form: there is a table in which the possible diagnoses are followed by their code in parenthesis: for instance a coronary disease is coded IHD. The table combines together two different coding systems. For each disease there is

the code in use in NNH, and also a numbering system that goes from 01 to 15 that is used in the Scanditransplant<sup>1</sup> WL.

Next, in the form should be entered the PVR values with the date of the examination, the TLC value, and the CMV response. These are responses from different examinations to specific measurements. For instance, the CMV response tells if the patient has antibodies towards the cytomegalovirus, that is if he has had the infection. Consequences of a CMV infection can be devastating in a transplant patient. These tests are performed at the Microbiologic Institute (MIK), which then provides the information to IMMI via fax. At MIK data are entered in EROS, so to be accessible from the clinics and the transplant coordinators. Then, data on weight and height should be entered, and also if there have been previous thoracic surgeries, pregnancies or transfusions. Next in the form, the signature of the doctor is requested plus the department's name and date. At the bottom of the form, IMMI should mark when the information is registered in the HLA-Lab and in Århus database<sup>2</sup>. And a signature of the person who enters the data is requested.

The rest of the data for the list are related to haematological and chemical analyses of blood, serologic screening and immunologic evaluation. These tests are performed on blood and serum samples of potential recipients for heart transplant and of candidate donors.

When a blood sample arrives at IMMI it is sent over to the blood bank at NNH for the blood typing ABO. This test is performed in a dedicated lab called "delivery unit" that is part of the Clinical Chemistry Unit and is under the supervision of the central Blood Bank, which is situated at another hospital. This unit works as a separate section for the Blood Bank, and performs ABO typing and administrates the blood within NNH. Blood typing is necessary for transplantation because donor and recipient have to be ABO compatible. Every person has antibodies towards other blood groups: for instance if a person is blood group 0 then he has anti-A and anti-B. The presence of antibodies related to blood grouping can cause an early acute rejection. Since it shall be secure that when an organ is available, there is no mistake, the test is performed again at NNH even if other hospitals have already sent results.

Another important test is the HLA (human leukocyte antigens) typing and HLA antibodies screening. These are performed by bioengineers at a lab in IMMI on serum

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<sup>1</sup> Scandiatransplant is an organization on Scandinavian basis for the exchange of organs and Nordic patient waiting for an organ transplant are registered in one common waiting list for each organ. The purpose of this organization is fourfold: to guarantee the exchange of organs and tissues; to operate a database and communicate information from it; to promote the provision of human organs and tissues for transplantation; to support scientific activities.

samples. Generally, HLAs are molecules that have the main role in regulating the immune responses in the body. When two people share the same HLA, they are said to be a “match”, that is, their tissues are immunologically compatible with each other. Normally, there are no HLA antibodies in a body, but they may be produced by transfusions, pregnancy and transplantations. In case the patient has antibodies, this may create problems in finding an acceptable donor: if patient’s antibodies are directed towards the HLA antigens of the donor, an early and severe acute rejection is likely to occur and consequently there is high risk of causing total heart failure and death of the patient. When HLA test are performed serum samples are also stored. In case the patient is accepted on the list, it is checked that antibodies screening has been performed and that the stored serum is not too old. New serum samples are required approximately every three months and are needed to perform the cross match when there is a donor. Information about the HLA values is then entered in the HLA-Lab and will be shown on the WL.

At IMMI, the information is entered in a system called HLA-Lab implemented in 1999. HLA-Lab shares a database with another information system called Nyrebase. The two systems have different access rights, and user groups. IMMI can write the data for the WL in HLA-Lab, but this data are in read only mode for the users of Nyrebase. On the other hand, for instance medical diagnoses are entered in Nyrebase by clinicians and are read only mode for IMMI users. The database is only shared with the nephrology unit, but not with surgeons and cardiologists. This configuration has an historical reason: the database was originally made as a system for keeping track of renal transplantation, and for the administration of the nephrology unit. Since renal transplantation has the longest history and the highest number of transplantations, the HLA-Lab was added to the renal database. From HLA-Lab, the WL is printed and distributed internally in the hospital.

## **5.2 Decision making process: match by list**

Surgeons receive the waiting list on paper from IMMI. At NNH, Dr A is the head surgeon performing heart transplantations. He is the one that has performed the first heart transplantation in Norway twenty years ago. Copying the data from the paper list, he has made his own electronic version of the WL on his PC to keep track of data and produce statistical analysis. In his version, he is also able to add comments and details that are not shown in the official form. He has also a copy of the WL at home in case he receives a calling the night when he is on duty. Details could be information on

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<sup>2</sup> Scandiarttransplant runs a database which is located in Århus, Denmark.

electronic device implanted as a defibrillator or pacemaker, or on where the patient is hospitalised, for instance in the intensive care unit (ICU) at some other hospital. Anyway, he agrees that the information usually provided is sufficient.

The surgeon on duty is the one who takes the final decision for matching organ and recipient. This is a clinical decision that is based on the following values (in hierarchical order):

1. ABO blood type
2. Body size/ PVR
3. Urgency
4. Waiting time
5. CMV match
6. HLA match

It should fit first the blood type and have an acceptable size: this includes in heart transplantation PVC which is on the WL and recorded into CatLab. After this first selection, if there is more than one patient selected, urgency is considered, then the waiting time and the CMV value. HLA type is never considered even if in the long run might be important. This is because there are few donors compared to the number of patients on the waiting list, so it would be unrealistic to wait for a good match on the HLA type. Nevertheless, if all other values are equal for two patients, HLA is considered, and particularly the HLA DR match. The surgeon on call might also discuss his decision with the cardiologist in charge. Information provided on the list, in fact, might not be sufficient to understand which is the sickest patient, or if a patient is transportable or his conditions have changed due to infections preventing transplantation. This information is in the cardiologist's notes in the ordinary patient journal. The updated information on the status of the patient is collected by the transplant coordinator in cardiology and registered in their notes in the electronic patient record (EPR). If there are important variations they are communicated to the cardiologist in charge, who will then know the situation and register it in his notes in the EPR.

In Norway, the algorithm for the matching organ-recipient is a clinical one: geography, that is the location of the patient, is not considered. Since Norway is a small country of 4 million people and one transplant centre, the algorithm ensures a fair distribution of organs. It is possible in 95% of the cases to get a patient in time to NNH even from the northern part of the Norway. So wherever they live, patients have an equal chance to be selected for transplantations. In larger countries, as for instance in the US, there are a high number of patients on the waiting list and several institutions performing

transplantation therefore the United Network for Organs Sharing (UNOS) guarantees a fair share of organs between geographical areas.

## **6 Analysis: the central role of the list for multiple actors**

It is important to note that the WL is not to be taken as one well defined artefact. Its essence is revealed by considering the multiple identities that are created by being part of several social worlds. In our study, we find several identities can be unfolded.

First, the WL is a decision-making support tool for surgeons and cardiologists. As a tool, the WL by itself is a very simple paper: it considers some pertinent information of evaluated patients and presents an overview of the patient to the surgeon on call so to support his decision. By reading the list, the surgeon on call is able to select a single patient to be transplanted at that very day for a specific organ available at a precise time. Actually, the fact that information is presented in a standard form renders its meaning unambiguous and thus the understanding of the status of the patient. The diagnosis (Mrk) is shown on the list using a code system that is a diagnosis standard in use at NNH, thus the surgeon will understand that the code IHD means coronary disease and accordingly will put it in relation with the other values and make sense of the patient status.

Second, the WL is an artefact shared by several communities of practice. It bounds different practices and trajectories together, though its essence is not delimited to the concept of boundary object. As Fujimura points out, the concept of boundary object is not focused on fact stabilization across social worlds, rather on how such objects are easily reconstructed to fit local needs (Fujimura, 1992). Thus, the BO implies a more direct collaboration, and at the same time, a quite abstract, ill-structured and ambiguous conceptual and technical work space. The WL is originally created to specifically support the process of decision making of the surgeon on call when it is communicated that a heart is available. Therefore, it calls for well-defined actors and actions, while BOs usually emerge through the processes of work of multiple groups. Its characteristics as a boundary object are more related to its function as an interface among communities: the local, Scandinavian and international ones. From this perspective, the WL works as an interface to the outside at several levels: other hospitals, Scandiatransplant, Eurotransplant.

Third, the WL works as a gateway between information ecologies based on different units of analysis, methodological concerns and conventions. It translates languages and links different understandings. For instance, the list works as a translator device

when it displays HLA values. Blood samples, originally taken from the patient, and handled by lab bioengineers need the WL to communicate information to surgeons.

Fourth, the WL is not separable from the methodologies by which its data are produced. In this light, it is an object-centred package which facilitates the translation of different interests into one single direction, the one of the heart transplantation trajectory.

Fifth, observation in the cardiology ward shows how the WL is an instrument for daily work practices. It is used by transplant coordinators as a reliable source of biographical data and collected in files on their shelves. In this way the old WL becomes a repository of patient information and maintains its characteristic of being simple and ready for a quick look accruing to official information systems as the EPR.

Sixth, the WL is a critical passage point for the patient (Callon, 1986). By being accepted on the list, the patient becomes a candidate recipient: this implies a deep change in his life. His everyday personal life is invaded by the presence of the beeper which may ring at any time. Moreover, even a light flu may imply a temporary withdrawal and postpone the transplant.

Finally, the WL represents multiple and heterogeneous data collections. While the sharing of information is central to the use of the list for few key actors, its accomplishment is a fragmented procedure. So, for example, IMMI is responsible for analysing blood samples, but the task is performed by a laboratory in the chemical unit which in turn works under the supervision of the Blood Bank which is even situated in another hospital. In this case, a cascade of actors is involved in providing one single entry on the list, the ABO typing.

The formulation produced here are put forward to propose how the list does not represent collective work, but is a collective representation of fragmented and dispersed (in time and space) work. It helps to keep a reference point, and at the same time is a flexible instrument for coordination.

## **7 Discussion**

In our analysis, we have seen how the list embodies characteristics of the different views proposed by the concepts of boundary objects, gateways and standardised packages. First, it works as an interface between medical communities at different levels, second, it is a translator device between coding systems such as for instance the diagnosis coding used within NNH and across Scandinavia, and third, it is at the centre of a package of practices and understandings. Yet, our analysis shows that additional roles may be identified. In other words, the very nature of the WL cannot be



well described by or contained in concepts such as boundary objects, gateways, standardised packages since we have seen that they come short in handling all aspects of complexity inherent to the list.

To understand the nature of the WL, we introduce here the notion of fluid object. De Laet and Mol (2000) apply the metaphor of the fluid for the understanding of technology and its qualities. A fluid technology may be defined as having variable boundaries: it has many identities and each comes with its own different boundaries. Specifically, De Laet and Mol apply the metaphor to the analysis of a water pump in use in Zimbabwe and this shows a striking adaptability. They emphasise the fluidity of the pump as the reason for its success: it actually manages to work in many ways and in many sites. We suggest looking at the WL for heart transplantation as having aspects of fluidity.

The WL's fluid boundaries are tightly related to the fact that the WL ought to be a standardised representation of the patient to support decision making. A feature of this decision making is the difficulty in defining the status of the patient. Such status is always evolving and not stable, thus making it necessary to have a real time report rather than relying on the list alone. The apparent solidity and objectivity of the information on the WL is challenged by an ongoing flow of new data originated from the human body. Thus, the WL is not one isolated object but needs to be considered in relation with its work ecology. In other words, it is in relation to its multiple identities complemented by other actors involved in the routines for continuous updating of the patient's clinical status.

## **8 Conclusions**

Our study on the heart transplantation trajectory reveals several characteristics about the nature of the WL and of the interactions between key actors involved in the process. We have seen that in such process, coordination between multiple disciplines is achieved by means of an object-centred collaborative practice. The WL is at the centre of such collaboration.

We have discussed how concepts such as boundary objects, gateways, and standardized packages provide a limited understanding of the phenomenon considered. Its complexity and dynamicity ask for an alternative conceptualization.

Hence, we have suggested that the WL may be described by its multiple identities thus revealing a fluid nature. This argument stresses aspects of complexity in the everyday intermingling of practices and we believe it contributes to the understanding of the dynamics involved in cross-disciplinary collaboration in the heart transplantation context.

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